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# Progress on implementing the Dublin Declaration on Partnership to Fight HIV/AIDS in Europe and Central Asia



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## Abstract

The Dublin Declaration on Partnership to Fight HIV/AIDS in Europe and Central Asia, signed in February 2004, is a key European document on HIV/AIDS. It sets out 33 actions for governments to undertake as related to leadership, prevention, living with HIV (including treatment and care) and partnership in the 53 countries of the WHO European Region. This document, prepared under the auspices of UNAIDS, highlights the successes and shortcomings of the implementation of the Declaration, as called for in Action 33 of the Declaration itself. There are 15 thematic sections complemented by nine country reports. The report, written and reviewed by more than 50 experts in the field, is available online at [www.euro.who.int/aids](http://www.euro.who.int/aids).

## Keywords

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## ***Abbreviations***

ART	antiretroviral therapy
ARV	antiretroviral
CD4	cell cluster of differentiation antigen 4 cell (a subgroup of T lymphocytes)
CIS	Commonwealth of Independent States
ECDC	European Centre for Disease Prevention and Control
EMCDDA	European Monitoring Centre for Drugs and Drug Addiction
EU	European Union
GFATM	Global Fund to Fight AIDS, Tuberculosis and Malaria
HAART	highly active antiretroviral therapy
HBV	hepatitis B virus
HCV	hepatitis C virus
HIV	human immunodeficiency virus
IDU	injecting drug user
ILO	International Labour Organization
M&E	monitoring and evaluation
MSM	men who have sex with men
MTCT	mother-to-child transmission (of HIV)
NCPI	National Composite Policy Index
NEP	needle and syringe exchange programmes
NGO	nongovernmental organization
OI	opportunistic infection
OST	opioid substitution therapy
PDPs	Public–private product development partnerships
PITC	provider initiated testing and counselling
PLHIV	people living with HIV
PrEP	Pre-exposure prophylaxis
RCT	randomized control trial
SRH	sexual and reproductive health
STI	sexually transmitted infection
SW	sex worker
T&C	testing and counselling
TB	tuberculosis
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNICEF	United Nations Children's Fund
UNGASS	United Nations General Assembly Special Session
UNODC	United Nations Office on Drugs and Crime
WHO	World Health Organization

## ***Foreword***

When the Member States of the WHO European Region signed the Dublin Declaration on Partnership to Fight HIV/AIDS in Europe and Central Asia in February 2004, they could not have known what a historic document it would become. Fully two years before the rest of the international community, the European Region made a call in this Declaration for “universal access to effective, affordable and equitable prevention, treatment and care”. Now, four years after the Declaration signing, this initial progress report takes stock of the situation in the Region by discussing which indicators can best help us to understand current efforts to combat HIV, how to interpret the most recent data collected for these indicators and how to improve HIV efforts.

As the Acknowledgements attest, this report has been a massive undertaking that draws on all of the key national and international actors who were able to contribute. Such a united effort respects the principles of the Three Ones model established by UNAIDS, a model that also calls for increased multisectoral collaboration and coordination at the national level. Readers will note that while large amounts of data on HIV and related issues exist, there is still a need to streamline indicators, to ensure that such indicators are relevant for the European Region context and to harmonize data collection.

Further, this progress report on the Dublin Declaration dovetails with the monitoring processes for the 2001 Declaration of Commitment on HIV/AIDS and with current European Union (EU) HIV aims. The report is thus in line with global efforts to harmonize and streamline monitoring and evaluation activities. It assesses progress by using data from existing surveillance and monitoring efforts in the European Region. Major sources include routinely collected epidemiological data on HIV and STIs; data on access to HIV prevention, treatment and care services; and additional information collected through the UNGASS monitoring process, the publications of the European Monitoring Centre for Drugs and Drug Addiction and national HIV monitoring efforts. Using these data, the report qualitatively assesses the progress made on implementing the 33 actions of the Dublin Declaration.

Let this important work on the progress being made towards the Dublin Declaration’s lofty goals also be a call to:

- simplify data collection on HIV and other sexually transmitted infections, ensuring that the collected information is useful and relevant for individual countries while avoiding overlap and reducing the burden of reporting placed on the Member States;
- ensure that the information collected is accessible and available to other agencies and the general public;
- retain strong European political leadership and accountability for the Dublin Declaration, the Millennium Development Goals and the universal access goals; and
- continue this dynamic process of ongoing monitoring of the Declaration by arranging for key partners, including those from civil society, to meet periodically on HIV indicators and data collection issues in the European Region.

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## ***Executive summary: beyond the promises of Dublin***

The European Region is now experiencing the fastest rate of growth of HIV prevalence in any region of the world. Against the background of this worsening HIV epidemic and, in many countries, struggling health systems to address the emerging public health and societal challenges (1), the representatives of Governments from Europe and central Asia met in Dublin, Ireland, on 23–24 February 2004 for the conference “Breaking the Barriers – Partnership to fight HIV/AIDS in Europe and Central Asia” to explore these challenges and to develop a response to them. The conference culminated in a declaration to more effectively tackle in Europe and Central Asia the HIV epidemic and its consequences. The “Dublin Declaration on Partnership to Fight HIV/AIDS in Europe and Central Asia” recognised the principal factors contributing to the spread of HIV/AIDS, reaffirmed the Declaration of Commitment on HIV/AIDS adopted by the UN General Assembly Special Session (UNGASS) on HIV/AIDS on 27 June 2001 and subsequent international commitments and agreed 33 points of action to “...accelerate the implementation of the Declaration of Commitments on HIV/AIDS”.

Under the auspices of the Joint United Nations Programme on HIV/AIDS (UNAIDS), the WHO Regional Office for Europe and its partners have prepared this report on the progress made in implementing the Dublin Declaration since it was signed in early 2004. In accordance with Action 33 of the Declaration, this progress report seeks to help the Member States of the Region to “closely monitor and evaluate the implementation” of its actions.

The report draws on continuing monitoring efforts conducted by the United Nations, its agencies, the European Union (EU) and various national bodies in the Region, in accordance with global efforts to harmonize and streamline monitoring and evaluation activities. It comprises 15 thematic chapters followed by 9 country profiles. This effort is timely in that in 2005, the Group of Eight (G8) and the United Nations made similar commitments (2), in 2006, the United Nations member states agreed to work towards “universal access to comprehensive prevention programmes, treatment, care and support” by 2010 (3) and in 2007 the German EU Presidency held the conference “Responsibility and Partnership: Together Against HIV/AIDS,” again highlighting the gravity of the situation in Europe and calling for renewed action (4,5).

In reviewing the thematic chapters, several broad imperatives for HIV efforts in the European Region have emerged. They include the need to:

- establish greater accountability;
- amend legal and regulatory frameworks to enable them to better address HIV-related stigma, exclusion and discrimination;
- strengthen national and regional HIV and STI surveillance;
- improve and harmonize monitoring and evaluation efforts, including greater disaggregation of data for key indicators;
- intensify, scale up and improve the targeting of HIV efforts to reduce inequities;
- work for greater harmonization of the highest standards of prevention and treatment programmes and policies;
- expand the use of internationally recognized evidence-based interventions;
- strengthen cooperation between countries on such efforts; and
- increase civil society and private sector involvement.

The following section summarizes the report’s key findings and recommendations for each thematic area. It should be kept in mind that these summary statements are broad generalizations that will rarely apply to all 53 countries in the WHO European Region. More information can be

found in the particular chapters named, but even there the coverage is often representative rather than comprehensive. The particular Dublin actions listed for each chapter may be consulted in Appendix 1.

## **Key findings and recommendations: leadership and partnership**

### **Chapter 1. Political leadership (*Actions 1, 3, 5, 6, 22, 26 and 30*)**

Relevance. The largely unchecked growth of HIV in the first decades of the epidemic was due in great part to widespread denial among decision- and policy-makers. An effective HIV response requires political vision and leadership, especially since the groups at greatest risk for HIV tend to be disproportionately marginalized by society and their activities often criminalized by the state.

#### Key findings

- National and international political leadership on HIV has been significantly strengthened in the European Region.
- National leaders are increasingly speaking out on HIV.
- Financial resource constraints have eased in many countries.
- Regional institutions are now addressing HIV regularly and cross-border partnerships are stronger, though gaps persist.
- Civil society is being consulted more.
- Political leadership challenges now often lie in implementation rather than in making policy or allocating money. The worst implementation gaps lie in carrying out structural reforms to health systems, instituting harm-reduction programmes and confronting other injecting drug user (IDU) issues.

#### Key recommendations

- Progress and accountability on HIV commitments need to be consistently monitored and evaluated.
- The EU should strive for greater inclusion in its response to HIV of countries and subregions beyond its borders and neighbourhood programmes – as should the Commonwealth of Independent States (CIS) Coordination Council on HIV/AIDS.
- National and local leaders must redouble their efforts to implement every Dublin action and live up to each commitment. That means speaking out frequently about HIV, ensuring policy is evidence- and rights-based, and establishing coordination and management structures in accordance with the UNAIDS Three Ones principles (6).
- All countries should prepare timely, comprehensive UNGASS reports. A regional synthesis of reports from the Europe Region would be an invaluable supplement.
- Policy- and decision-makers should make concerted efforts to protect the rights of people living with HIV (PLHIV) or at high risk for it, to reach out to risk populations and to plan for future HIV resource increases to match the long-term growth of the epidemic (see specific recommendations below).

### **Chapter 2. Civil society and other nongovernment stakeholders (*Actions 2, 4, 27 and 32*)**

Relevance. Civil society (particularly community-based groups representing people living with or at risk for HIV) has long played a pioneering role in responding to HIV. Yet many governments have been slow to utilize their invaluable resources or recognize the right of affected communities to help shape the response.

The resources and outreach opportunities of the private sector are similarly underutilized.

#### Key findings

- Government commitments to greater involvement of civil society have yet to be translated to pervasive action. Government efforts to increase involvement have been patchy, incremental and uncoordinated.
- There *has* been a marked increase in civil society involvement in HIV policy- and decision-making in most countries – but it has been largely driven by civil society itself.
- Global, regional and subregional networks of PLHIV and risk group members have increased dramatically in number and size.
- There exist few systematic data on the participation of civil society, PLHIV or risk group members in the HIV response. Some of the best such data sources remain largely inaccessible to the public.
- While the Code of Good Practice for NGOs Responding to HIV/AIDS (7) has encouraged accountability and responsible action in civil society, no corresponding mechanism exists for private businesses engaged in HIV-related philanthropy and customer and community outreach.

#### *Key recommendations*

- Governmental bodies need to proactively involve civil society, PLHIV, risk group members and the private sector in shaping and implementing the national response to HIV.
- UNAIDS should post UNGASS shadow reports on its web site and make its country office data more widely available.
- The Code of Good Practice for NGOs Responding to HIV/AIDS should be more widely promoted and adopted.
- The Global Business Coalition should be urged to develop a version of the NGO Code for firms engaged in HIV-related philanthropy and outreach, including implementation and accountability mechanisms.

### **Chapter 3.** Resources in eastern Europe (*Actions 1, 7, 8, 9, 13, 17 and 29*)

Relevance. Roughly 2 million people in eastern Europe (the 15 former Soviet republics) live with HIV, while HIV incidence there has soared 20-fold in less than a decade. The area includes the fastest-growing HIV epidemics in the world, driven chiefly by injecting drug use. Meanwhile, some of its countries experienced severe economic downturns and turmoil after achieving independence, leading to increased income disparity.

European populations are increasingly mobile, and HIV recognizes no national boundaries. Accordingly, the Dublin Declaration commits all European Region nations to act collectively in addressing HIV – which means ensuring eastern Europe has adequate resources to fight HIV effectively.

#### Key findings

- Estimated HIV resource needs for eastern Europe have risen from US\$ 900 million in 2006 to US\$ 1.5 billion in 2008, with more than 70% for prevention.
- International donors have increased contributions to HIV efforts in the 12 CIS states from US\$ 12 million in 2003 to an estimated US\$ 60 million in 2006, including a sharp increase in 2005 from the Global Fund to Fight AIDS, Tuberculosis and Malaria.

- Domestic HIV funding has doubled in the same period, to US\$ 60 million in 2006 for CIS countries except for the Russian Federation.
- In the Russian Federation, domestic funding has risen even more dramatically, to US\$ 320 million in federal allocations in 2007, in addition to large commitments to reimburse the Global Fund and to develop an HIV vaccine. However, prevention efforts for risk populations remain seriously underfunded.
- Out-of-pocket expenditures, which affect the poor disproportionately, have also increased in the CIS, now averaging almost 50% of all HIV spending.

#### *Key recommendations*

- Despite large increases in international and domestic HIV funding, the gap between available resources and need continues to grow – as does the area’s epidemic.
- Domestic and international contributions to the HIV response in eastern Europe need to increase substantially.
- Allocations should be more closely matched to need. In particular, there is a desperate need for eastern European governments to expand evidence-based prevention efforts targeting IDUs dramatically.
- Governments and donors should seek for ways to reduce out-of-pocket expenditures for those least able to pay.
- Better measures to determine the national funding requirements for a comprehensive response to HIV need to be developed in the near future.
- Accurate, detailed HIV spending assessments need to be conducted nationally and subnationally to facilitate more efficient allocation of funds.
- Allocations also need to be aligned with current scientific findings and determination of best practice, following e.g. UNAIDS prevention guidelines (8), WHO clinical protocols (9) or nationally tested interventions.

## **Key findings and recommendations: prevention**

### **Chapter 4. Injecting drug use (*Actions 9, 10, 21 and 33*)**

Relevance. Injecting drug use is the primary driver of HIV epidemics in eastern European and central Asian countries. Injecting drug users continue to contribute to HIV epidemics in many western European countries. Despite overwhelming scientific evidence about the effectiveness of targeted “harm-reduction” efforts, including opioid substitution therapy and needle and syringe exchange programmes, in drastically reducing HIV transmission, some countries persist in persecuting IDUs and ignoring their prevention and care needs.

#### Key findings

- In western Europe and the EU, countries have demonstrated the political will to scale up access to opioid substitution therapy (OST) and needle and syringe programmes (NSPs). Progress in some of the new EU countries, notably the Baltic countries, is less than in the rest of the EU, but still substantial.
- The rest of eastern Europe shows far less progress, including five countries without OST and others where OST is only provided on a pilot basis. Even in Ukraine, where a concerted effort has been made to introduce OST, coverage remains poor.
- NSPs have adequate coverage in most of western Europe except in prisons, where it is rarely available.

- While access to highly active antiretroviral therapy (HAART) has improved across the European Region, discriminatory practices continue to prevent IDUs from accessing and adhering to it.
- United Nations agencies support harm reduction and have prepared a technical guide to facilitate national development of a framework, indicators and targets for monitoring progress on HIV interventions targeting IDUs (10,11).

#### *Key recommendations*

- Countries should make focused efforts to scale up IDU access to OST and other harm-reduction services and to HIV treatment.
- Where injecting drug use contributes significantly to HIV epidemics, or where IDUs are at risk of HIV, the government should use the United Nations technical guide (10) to determine the national mix and coverage levels of the nine interventions in the Comprehensive Package for prevention, treatment and care of HIV in injecting drug users
- Countries need to set national targets that ultimately aim at providing full access to indicated HIV prevention, treatment and care interventions for all IDUs. Suggested coverage targets are for NSPs to reach at least 60% of all IDUs, and for OST to reach at least 40% of opioid-dependent IDUs.
- Countries should utilize pharmacies in making NSPs and sterile injecting equipment widely available.
- Armenia, Kazakhstan, the Russian Federation, Tajikistan and Turkmenistan are urged to introduce OST promptly.
- Countries should massively scale up IDU access to HAART, using OST to improve access and adherence.
- Countries should use the United Nations technical guide to set ambitious but achievable national targets for scaling up IDU access to HIV prevention, treatment and care. They should also harmonize the ways they measure progress on scaling up with other countries in the Region.
- Countries should collect data on OST and HAART, and on current IDUs receiving HAART.

### **Chapter 5.** Prevention in vulnerable populations and risk groups (*Actions 9, 13, 25 and 27*)

**Relevance.** Risk groups are defined by behaviours that put members at risk for HIV. In western Europe, the HIV epidemic is especially concentrated among men who have sex with men (MSM), and in eastern Europe, among IDUs. Because risk groups tend to be marginalized and often driven underground, targeting them for prevention poses special challenges.

Vulnerable populations are defined by external circumstances that reduce members' ability to avoid HIV infection, such as poverty, incarceration and war, that often render them similarly invisible and likewise demand targeted interventions. Migrants and certain ethnic minorities are at high risk for HIV, as are prisoners throughout the Region.

#### Key findings

- Although sex workers are the risk group most likely to respond positively to prevention programmes, many national policies and laws aimed at sex workers continue to place them at heightened risk for HIV. Sex workers who are also MSM, migrants or IDUs are especially in need of targeted interventions.

- In central and eastern Europe, data on MSM continue to be minimal in comparison to other risk groups. Recent evidence suggests that in eastern European countries with a major HIV epidemic among IDUs, there is also a hidden epidemic among MSM.
- Same-sex relations have now been decriminalized in all nations of the Region except for Turkmenistan and Uzbekistan. Recent decriminalization has often been driven by intense external pressure, and in many countries MSM still face stigmatization, persecution and harassment, much of it sanctioned by the state.
- Following recent EU expansions, there has been a large-scale temporary influx of young sexually active migrants from central to western Europe. There is great concern that these migrants will bring HIV back to their home countries, where prevalence rates are now quite low. Migrants continue to face barriers in accessing medical and social services, while the monitoring of migration and HIV in the Region is lacking.

For key findings on IDU, gender, youth and prisoner issues, see the sections on chapters 4, 6, 8 and 15, respectively.

#### *Key recommendations*

National governments should:

- ensure that national HIV policies and strategies draw attention to those who are members of more than one vulnerable population or risk group;
- audit existing legislation and regulations for obstacles to the development and utilization of HIV prevention programmes for vulnerable populations and risk groups – and then remove the obstacles;
- implement a national policy to guarantee vulnerable populations and risk groups equitable access to HIV prevention and care;
- incorporate comprehensive surveillance systems into their national HIV policies and strategies to identify and support vulnerable populations and risk groups;
- ensure that national HIV prevention programmes satisfy the standards set out in the UNAIDS guidelines for intensifying prevention efforts (8);
- ensure that the national HIV strategy and related frameworks specifically mention the need to protect vulnerable populations and risk groups from violence;
- take steps to counter the stigma experienced by vulnerable populations and risk groups, including any stigma they may experience from health care providers;
- outline these targets and undertakings in programme guidance documents, and align national data collection surveys with them to monitor progress; and
- provide, in partnership with civil society organizations, a wide range of HIV prevention programmes targeting all major vulnerable populations and risk groups.

#### **Chapter 6.** Gender equity (*Actions 13, 14, 20 and 21*)

Relevance. Differing from each other physiologically, psychologically and socially, women and men have different needs and abilities. Moreover, they have been and continue to be treated very differently by government, society and health services in ways that do not address these natural differences and are thus patently inequitable. For maximum effectiveness – and justice – HIV efforts need to strive for equity while recognizing essential gender differences.

#### Key findings

- Statistics on HIV prevalence and access to HIV prevention, treatment and care are still very rarely disaggregated by sex, making it nearly impossible to monitor progress on gender equity – and thus to *make* progress on it.

- Men still comprise the overwhelming majority of new HIV infections in the European Region, but official rates of newly reported cases indicate a growing percentage of female PLHIV (36% in 2004 and 39% in 2006).
- While injecting drug use and sex between men continue to be the primary drivers of the European epidemic, many countries have observed an increase in reports of heterosexual transmission. Yet very few of these countries have developed or implemented prevention programmes aimed at women, specifically at the migrant women who are most in need of it.
- No data on HIV and transgender individuals are available.
- Sexual transmission of HIV from male IDUs to their female partners is helping drive the European epidemic, though partners of risk group members are very rarely targeted by prevention programmes.
- What has sometimes been termed “the feminization of HIV” does not apply to the European Region at this time.

#### *Key recommendations*

- HIV monitoring bodies should request – and countries should gather – surveillance statistics disaggregated by sex.
- Countries need to report the steps they are taking in combating HIV to target men and women respectively, and to measure the effectiveness of these efforts.
- Prevention programmes need to be developed to target the sexual partners of IDUs, migrants and prisoners, and the female partners of MSM.
- Countries need to identify obstacles to gender-equitable prevention and care – and dismantle them. Such barriers may include the location, hours, staffing and programming of services; unconsciously restrictive laws and policies; and gender-related violence.

### **Chapter 7.** Mother-to-child transmission of HIV (MTCT), and children living with HIV (*Actions 11, 12 and 14*)

Relevance. In the absence of preventive interventions, an infant born to and breastfed by an HIV-positive woman has a one-in-three chance of contracting HIV. Appropriate interventions – timely antiretroviral treatment, caesarean deliveries and safe alternatives to breastfeeding – can reduce MTCT to nearly zero.

Dublin Action 11 commits the Region to eliminating MTCT – defined as reducing transmission to less than 2% – by 2010. With a concerted effort, this goal is clearly achievable.

A comprehensive approach to paediatric HIV also requires addressing HIV incidence among women of childbearing age (especially in eastern Europe, where more new cases are being reported for this cohort), diagnosing HIV in children early and improving the treatment of paediatric HIV.

#### Key findings

- Significant progress has been made in eliminating MTCT in most countries.
- In 2005, the 23 countries of western Europe reported only 167 cases of MTCT.
- Many eastern European countries have rapidly scaled up their MTCT prevention programmes, though challenges remain, including improving service quality.
- Data quality is poor for several eastern European countries but indicates that in the countries most affected by HIV, MTCT has been reduced to about 10% or below.

- Though the European Region is home to only 1% of the world's children living with HIV, there is still cause for grave concern. In the most-affected countries of eastern Europe, the number of paediatric HIV deaths has risen steadily. Contributing factors include health system failures.
- Overall, however, access to treatment has increased substantially for children living with HIV.
- Children living with or affected by HIV require greater social support and legal protection in many countries.

#### *Key recommendations*

- Countries should seek to implement the “Four Ps”, the programmatic goals of the *Unite for Children, Unite against AIDS* initiative:
  - Prevent mother-to-child transmission of HIV
  - Provide paediatric treatment
  - Prevent infection among adolescents and young people
  - Protect and support children affected by HIV and AIDS (12).

#### Specifically:

- National policies and protocols for MTCT and paediatric HIV need to be updated to reflect the latest scientific evidence.
- Eastern European countries need to mobilize national and subnational resources for MTCT prevention programmes in order to reduce dependence on external funding. Such resources should be adequate to ensure uninterrupted supplies of HIV tests, antiretroviral drugs, drugs for prophylaxis and treatment of opportunistic infections, and supplies of modern contraceptive methods, including condoms.
- Countries need to strengthen their institutional capacity for addressing paediatric HIV, including upgrading the quality of medical and psychosocial support services (see Chapter 12 for further recommendations on this issue).
- Countries need to systematically monitor and evaluate the progress in their efforts related to PMTCT and paediatric HIV.
- Health systems should integrate PMTCT programmes with existing maternal and child health and reproductive health services, including family planning services.
- Special efforts need to be made to target MTCT in women who represent the most vulnerable populations and engage in risky behaviour. Several measures should be undertaken to provide a protective environment for children affected by HIV, including providing legal protection and monitoring of their rights, and ensuring that national policies favour adoption and foster care over institutionalization.
- Countries need to make sure that eliminating HIV among infants and young children is a priority in their national HIV strategies.

### **Chapter 8. Youth** (*Actions 3, 8, 13*)

Relevance. The youth of any nation – defined as being age 15 to 24 (and termed “young people” in the Dublin Declaration) – are its immediate future. It is morally incumbent upon society to give them the tools to avoid and, when necessary, learn to live with HIV. Moreover, educating youth about HIV is one of the best long-term strategies to combat the epidemic by helping them resist risk behaviours at a formative age, by reducing HIV-related stigma and discrimination and by improving health-seeking behaviour. Although antiretroviral therapy can make HIV a chronic rather than fatal disease, it is expensive, and the longer life expectancy of infected youth makes prevention efforts targeting them more cost-effective than ever.

### Key findings

- In 2005, the percentage of newly diagnosed cases found in youth was 31% in eastern Europe, 21% in central Europe and 10% in western Europe and declined to 27%, 17% and 10%, in 2006, respectively.
- In eastern Europe, which accounted for more than two thirds of the Region's new HIV infections in 2005, the rate of new cases reported among youth is falling.
- Females made up 27% of new HIV infections reported among eastern European youth in 1999–2002, and 53% in 2003–2005.
- In the worst affected areas, the drivers of HIV infection in youth are rooted in unemployment, social breakdown and the absence of a positive outlook.
- Data collection for major indicators on youth behaviour and the effectiveness of HIV education and prevention efforts targeting them remain weak globally and throughout the European Region, especially in eastern and central Europe.
- Early exposure to sexuality education is not associated with an earlier age of sexual debut; the promotion of safe sex is most effective if it begins in primary school, before debut.
- While sexuality education has been shown to be a cost-effective prevention strategy when of high quality, it continues to be marked by quality and consistency problems across the Region.
- While countries in the Region have all committed themselves to international declarations and action frameworks that support effective action on youth and HIV, these commitments have rarely been translated into a correspondingly supportive national legal environment.

### *Key recommendations*

- Policy-makers and service providers should approach youth development with a foundation of respect, understanding and openness.
- Youth–adult partnerships and youth participation should be key elements of HIV prevention programming.
- Efforts targeting youth at risk for HIV, including those who are MSM, IDUs or sex workers, should be prioritized, and the individuals treated with respect.
- Governments (through the ministries of health and education, or their equivalent) should support comprehensive sexuality and reproductive health education and take steps to ensure its quality.
- The health sector should prioritize the development of youth-friendly services, including sexual and reproductive health services.
- Governmental bodies need to prioritize long-term monitoring and the collection of age-disaggregated data, using the age brackets of 10–14, 15–19 and 20–24 years.
- International donors should ensure adequate attention to HIV youth programming, with an emphasis on harm reduction (condoms, opioid substitution therapy, etc.) and educational interventions.

## **Chapter 9.** HIV in the workplace (*Actions 2, 15 and 28*)

Relevance. Most PLHIV are in their economically productive prime, and HIV is responsible for a great deal of lost productivity in the European Region due to not only sickness, but also to the stigma and discrimination that its PLHIV suffer. Despite widespread social security coverage, employers must bear a large number of the direct and indirect costs of HIV. Small businesses and workers in the informal economy are hit particularly hard.

Conversely, because of its substantial resources and ubiquity, the “world of work” offers unique opportunities for combating HIV by providing a gateway for universal access to prevention, treatment and care; targeting everyday stigma and discrimination; and reintegrating PLHIV who are receiving antiretroviral treatment into the workplace.

#### Key findings

- Several European countries have revised laws to address HIV-related discrimination in the workplace.
- A variety of national and individual initiatives have been undertaken to institute workplace prevention and education programmes.
- In several countries, the government and civil society are jointly implementing programmes to (re)integrate PLHIV into the labour market.
- The International Labour Organization (ILO) has been using Decent Work Country Programmes to accelerate implementation of the *Code of Practice on HIV/AIDS and the World of Work (13)*, which addresses workplace issues including prevention, PLHIV support and care, and stigma and discrimination.
- The ILO is developing a new international labour standard on HIV to strengthen and speed up the workplace response for economic sectors ranging from forestry to tourism to public services.
- The UNAIDS Secretariat and several cosponsoring agencies have been working with 18 central and eastern European countries to develop and implement programmes addressing HIV in the armed forces.
- Migrant and mobile workers continue to be especially vulnerable to HIV infection – and consistently underserved by HIV services.

#### *Key recommendations*

- Employers and trade unions should work together to implement Article 27 of the Bremen Declaration on Responsibility and Partnership (4), including its call to establish non-discriminatory policies for PLHIV and risk groups in the workplace, provide information on HIV to employees and, in accordance with the ILO Code of Practice on HIV/AIDS (13), guarantee access to HIV prevention, testing, treatment and care.
- Governments should ensure that national laws prohibit HIV-related discrimination in hiring and in the workplace.
- Governments should include a world of work strategy in national HIV plans and promote HIV prevention programmes in all workplaces.
- Workers’ organizations should promote workplace HIV policies in line with the Code of Practice, including collective agreement provisions.
- Workers’ organizations should support the formation of associations for young people and for migrant workers.
- Civil society and trade unions should collaborate to monitor cases of stigma and discrimination suffered by PLHIV in the workplace.
- Civil society and trade unions should educate PLHIV about their workplace rights.

### **Chapter 10. Sexually transmitted infections (STIs) (Action 16)**

Relevance. Many acute STIs increase the risk of HIV infection and transmission. STI prevention is not only an important HIV prevention measure, but also a key health goal in itself. Conversely, PLHIV are at higher risk for STIs and can experience severer STI symptoms than HIV-negative people. With their shorter incubation periods and similar modes of transmission, certain STIs can serve as indicators of potential HIV infection, and a good reason for health care providers to offer a patient an HIV test.

### Key findings

- There is widespread variation in the composition and quality of national STI surveillance systems in the European Region. Relatively weak systems and a lack of consistency in case definitions greatly limit the recognition of regional trends and the comparability of data.
- Syphilis incidence increased from low levels to a peak in 2003–2004 in most western European countries, mirroring HIV trends; in central Europe the trends are mixed, but also mirrors the trends in new HIV cases reported. Gonorrhoea trends resemble HIV trends for both subregions, being concentrated among MSM and heterosexuals with many partners.
- In eastern Europe, the much higher syphilis rates have fallen but do not follow HIV trends, since HIV there is largely driven by injecting drug use. Gonorrhoea incidence there has also declined.

### *Key recommendations*

- As part of second-generation HIV surveillance, national STI surveillance systems need to be strengthened and harmonized throughout the Region (14).
- Governments should use high-quality STI surveillance and evidence-based approaches to integrate prevention and treatment services for HIV and STIs.
- A regional mechanism should be considered for systematically collating, assessing and monitoring the extent to which national health systems address STI and HIV control.
- STI efforts should be guided by both the public health approach (15) and the WHO global STI strategy (16).
- Safer sex behaviour needs to be encouraged throughout the Region with proven interventions – particularly condoms – and by addressing the factors underlying risky sexual behaviours, including socioeconomic factors and the use of alcohol and other recreational drugs.
- Proven methods should be used to encourage people to:
  - seek health care for sexual health problems;
  - integrate STI and HIV control into primary care and other health care services, where relevant;
  - provide specific STI services that target risk groups;
  - provide comprehensive case management; and
  - detect asymptomatic and symptomatic STIs earlier.

## **Chapter 11. Research and new technologies (Actions 19 and 24)**

Relevance. The last 15 years have seen remarkable advances in HIV therapy, but effective treatment remains expensive, adherence difficult and side-effects often debilitating. Diagnostic technology could be more accurate and easier to use. And, while generally efficacious, existing interventions do not meet all the prevention needs of PLHIV or members of risk groups. Such shortcomings can only be addressed by dedicated investment in research and development (R&D).

### Key findings

- Data on HIV-related R&D remain sparse, inconsistent and irregularly collected. What does exist focuses on funding commitments rather than actual expenditures.
- The EU has made a concerted and successful effort to improve coordination, cooperation and competitiveness among European researchers, e.g. by introducing the European Research Area, utilizing Framework Programmes for Research and Technological

Development (FPs) and setting up the European and Developing Countries Clinical Trials Partnership (EDCTP).

- While the European Commission increased funding for R&D on new HIV technologies in FP7 (2007–2013), its decision to hold the public health budget at the same level as the previous budget was a disappointing setback for HIV research, which is often linked to public health activities.
- More than 80% of HIV vaccine and microbicide R&D is funded by the public sector. Yet though the European Region is the wealthiest of the six WHO regions, it funds just 10% of the world's public sector investment in HIV vaccine R&D and 21% of global microbicide R&D.
- While support for vaccine R&D has been growing, the global investment of US\$ 760 million falls short of the estimated US\$ 1.2 billion needed to drive development forward at an optimal pace.
- The private sector, especially the pharmaceutical industry, continues to be very active in developing HIV treatments but reluctant to invest in other areas of HIV R&D, such as vaccines, microbicides and social science research, which have uncertain outcomes and poor commercial prospects.
- While many western European governments have abandoned certain types of HIV research as infeasible to undertake nationally, they have begun to provide substantial grants to international private–public product development partnerships (PDPs).
- Most central and eastern European countries, which struggle to fund HIV prevention and treatment programmes adequately, provide minimal or no funding for HIV research, though the Russian Federation is a recent exception.
- There is an EU funding gap for social and behavioural research and (due to inflexible participation rules) international PDPs.

#### *Key recommendations*

- Data needs to be collected at the European Region level about public, philanthropic and private funding of HIV-related research.

The European Commission should:

- increase resources for research efforts;
- include social science in its definition of HIV-related research eligible for funding;
- increase its public health budget and encourage HIV projects to incorporate a research component;
- increase the flexibility of contracting arrangements for FP7 grants to allow outsourcing approaches and responsive product-focused research;
- support global research efforts as outlined in *FP7 Cooperation Work Programme 2007–2008: health (17)*; and
- establish and maintain R&D capacity-building efforts in the countries that most need it.

National governments should:

- if EU members, satisfy all financial commitments to the EDCTP;
- increase the national budget for HIV-related research, as committed to in signing the Dublin Declaration, using as a possible guideline the Sydney Declaration, which calls for 10% of national HIV spending to be allocated to HIV research (18);
- explore partnerships whereby western European countries test HIV technologies in eastern Europe;
- increase support for international HIV research efforts, e.g. international PDPs and social science research; and
- improve national coordination of research funding.

## Key findings and recommendations: living with HIV

### Chapter 12. Treatment and care (*Actions 13, 21, 23 and 25*)

Relevance. The introduction of HAART in 1995–1996 to western Europe represented a major turning point in the response to HIV. It turned a mortal disease into a manageable chronic infection, so that a person infected with HIV at 25 can now expect to enjoy another 35 years of quality life. Where access to HAART has been made widely available, affordable and equitable – an admittedly difficult achievement – it has resulted in dramatic declines in HIV-related morbidity, mortality, infectivity and risk of onward transmission, with correspondingly substantial economic and demographic benefits.

#### Key findings

- HAART coverage for the European Region rose from 282 000 people in mid-2004 to 435 000 by December 2007, when it was estimated as “very good” (>75%) in 38 of the 53 Member States. For central and eastern Europe, where the need is greatest, coverage went from 16 000 to 55 000 in the same period – a substantial scale-up, but still far short of need.
- From mid-2004 to the end of 2006, reported HIV cases in the Region rose from 774 000 to 1 025 000, and reported AIDS cases from 285 000 to 328 000.
- HAART coverage for women and particularly children is high.
- In eastern Europe and Poland, IDUs represented about 80% of all reported HIV cases, but only 39% of HAART recipients at the end of 2006. While this percentage represents major progress in IDU access to HAART, such access remains greatly restricted and inequitable in the area. IDU coverage is poor because overall HAART coverage is low in countries where most PLHIV are IDUs, and because health care providers often discriminate against infected IDUs.
- Access to OST, which greatly increases IDUs’ treatment adherence, is minimal in much of central and eastern Europe.
- In most of central and western Europe, ARV drugs for the first-line regimen cost average about US\$ 10 000 annually. Significant price reductions have been achieved in eastern Europe, falling to as low as US\$ 300–400 in Ukraine.
- While the cost of ARV drugs remains prohibitive in many countries, they are offset by substantial reductions in treatment costs for opportunistic infections and other HIV-related conditions.
- The reported number of tuberculosis (TB)/HIV coinfections remains low in the Region – 6800 in 2005 – but that may be attributable to a lack of coordinated surveillance. Multidrug-resistant TB prevalence is especially high in eastern Europe.
- Liver disease is replacing AIDS as one of the most common cause of death among PLHIV in Europe, indicating an urgent need to address hepatitis B and C coinfection in the Region.
- The tracking and managing of pharmacovigilance and antiretroviral resistance in PLHIV, in order to ensure safety and efficacy, have emerged as major – and expensive – clinical challenges.
- In 2007, the WHO Regional Office for Europe, in collaboration with experts from around the world, developed a key set of 13 clinical protocols on HIV treatment and care (9).

### *Key recommendations*

- Countries should continue to strive towards the goal of providing universal access to HIV treatment by 2010 (19).
- Countries should ensure the same access and treatment standards for all, regardless of gender, age, sexual orientation, substance use, imprisonment or migratory status. A special effort should be made to remove obstacles to treatment of IDUs and other vulnerable populations such as migrants.
- Health care services for PLHIV should comprehensively address their needs, including prevention and treatment of comorbidities, age- and behaviour- related health issues.
- Universal HIV treatment access should be supplemented by the coordinated efforts of experienced care teams, including social workers, linked to sustainable, publicly funded community services providing nursing and home-based care.
- Accurate, detailed, regularly updated databases are needed to track antiretroviral treatment, HIV resistance, major HIV coinfections and risk behaviours.

### **Chapter 13.** Stigma, discrimination and human rights (*Actions 1, 20 and 31*)

Relevance. The Dublin Declaration observes that respecting, protecting and promoting human rights is “fundamental to preventing transmission of HIV, reducing vulnerability to infection and dealing with the impact of HIV/AIDS”. It also commits European nations to combating HIV-related stigma and discrimination.

Human rights are germane to nearly every aspect of the HIV response. The various Dublin actions reinforce national commitments to honour and protect numerous rights, including the right to life, the right to the highest attainable level of health, the right to an adequate standard of living, the right to social protection and the various rights of children.

The stigma and discrimination experienced by PLHIV and members of risk groups and vulnerable populations critically affect not only individual quality of life, but also access to prevention, treatment and care. Prevailing levels of stigma and discrimination also help determine how well a country will fulfil – or not fulfil – its Dublin commitments.

### Key findings

- Few of the 53 countries in the European Region have adopted an approach to stigma, discrimination and human rights that complies with their Dublin Declaration commitments.
- Only 4 of 28 European governments surveyed had conducted the “critical review ... of existing legislation, policies and legislation” promised in Action 20, to audit “existing legislation, policies and practices” for their promotion and protection of the rights of PLHIV and affected communities.
- While most European countries have laws in place to protect the rights of PLHIV, there is a broad lack of protection for the communities most affected by HIV, most notably prisoners, IDUs and sex workers, but also ethnic minorities, disabled people and MSM.
- Moreover, experience has shown that it is immensely difficult to take advantage of rights protections that do exist, and a massive gulf yawns between protection on the books and practices on the ground. The UNGASS shadow reports provide some of the clearest depictions of this gap between rhetoric and reality (20).
- In many countries, citizens are unable to seek redress for violations of their rights, particularly their economic, social and cultural rights.
- An April 2007 survey of 36 European Region countries found that 22 lacked legal aid; 20 did not provide confidentiality in legal proceedings; 19 did not have lawyers and judges

with appropriate training in HIV issues; and in the legal systems of about half, institutional discrimination against groups such as drug users, PLHIV, sex workers, MSM and migrants was present.

- At least 35 countries in the European Region have a national human rights commission or ombudsperson.
- The lack of HIV data that is disaggregated by e.g. gender, transmission route, age, nationality, etc. makes it nearly impossible to monitor progress on stigma and discrimination effectively, to identify the needs of particular groups or to assess the effectiveness of targeted interventions.

#### *Key recommendations*

- Future monitoring of progress on the Dublin Declaration should take an approach based on human rights and qualitatively assess country responses to indicators that directly address human rights issues.
- Outcome indicators for HIV services should be disaggregated wherever possible and appropriate by sex, age, ethnicity, socioeconomic status, urban/rural situation and risk group membership.

Countries need to:

- critically review their legislation, policies and practices for how well they promote the enjoyment of all rights by PLHIV and members of affected communities – and amend them where needed;
- establish a human rights commission or ombudsperson if they do not already have one;
- take steps to ensure that laws and policies providing human rights protections are honoured in practice, including by educating the public about them in and out of schools; and
- make sure that their residents can seek confidential redress for rights violations, and that the neediest can obtain free legal assistance to do so.

### **Chapter 14.** Testing and counselling (*Actions 10 and 13*)

Relevance. Scaling up the availability of and equal access to acceptable, affordable, safe, reliable testing and counselling (T&C) services for all in need is an essential prerequisite for moving towards achieving universal access to prevention, treatment, care and support services. PLHIV who do not know they are infected cannot take advantage of HIV treatment, care and support services, which can greatly improve their health and quality of life. Moreover, PLHIV who are aware of their status are likelier to avoid risky behaviour that can infect others. T&C services should be voluntary and informed consent and confidentiality should be clearly observed, recognizing the patient's right to refuse to be tested. Further, counselling is a crucial part of HIV testing and an essential preventive intervention.

#### Key findings

- All European countries offer HIV testing and counselling services, but there persist significant variations in their availability, accessibility, affordability and quality in the Region.
- Data on HIV testing coverage especially for major groups being at risk and vulnerable to HIV is spotty throughout the Region.
- While the number of HIV tests performed in some central and eastern European nations rose significantly from 2001 to 2005, it remained steady in western Europe during the same period. An increased number of tests performed does not necessarily lead to increased coverage.

- Access to T&C services for vulnerable populations and those at risk remains limited in many countries.
- Mandatory, imposed testing still takes place in a number of countries across the Region.
- The fear of stigma and discrimination experienced by PLHIV in many parts of the Region limits access and discourages testing.
- Access to quality counselling remains an issue of concern.
- CIS countries have made significant progress in accelerating access to HIV testing and counselling, but access remains far from universal.
- Positive experiences in a number of countries should be shared in order to improve testing programmes and policies.
- Other major unresolved issues include T&C services for minors, a supportive environment for scaling up T&C, capacity-building needs; sustainability and monitoring and evaluation.

#### *Key recommendations*

- The national response to meeting T&C needs should be further transformed from an episodic, one-time approach to a strategic long-term national commitment based on evidence and human rights approaches, national needs and opportunities.
- Further harmonization of policies and practices across the region is required, including reaching consensus on a set of T&C-related indicators for effective monitoring and evaluation is needed.
- There should be changes in national legislation, policies and strategies in order to promote evidence-based policies and practices and an enabling environment.
- Prevention from stigma, discrimination and violence has to be ensured, and disclosure issues should be addressed in the context of protecting human rights.
- There should be further promotion of the centrality of the “3 Cs” principle (confidentiality, counselling and informed consent).
- Ensure multisectoral collaboration, including civil society involvement, in policy, strategy development and service delivery.
- Promote T&C-related capacity-building and best practice and experience sharing across the Region.
- Create and promote national guidance on pre- and post-test counselling.
- Reach consensus in countries and develop guidance on home testing.
- Support operational research addressing current T&C needs in the Region

#### **Chapter 15.** HIV in prisons (*Actions 9 and 21; also 8, 10, 11, 13, 20 and 23*)

Relevance. People in prison have the same right to health as people in the outside community. When it comes to infectious diseases, the health of the two groups is intertwined, and safeguarding the health and lives of prisoners helps protect the health and lives of everyone outside. HIV rates are higher inside prisons than outside in much of the European Region, and ineffective prevention and treatment programmes can concentrate risk behaviours and effectively turn prisons into incubators for the virus.

Dublin Action 9 commits European governments to making comprehensive HIV prevention programmes accessible to 80% of all prisoners by 2010.

#### Key findings

- The coverage and quality of HIV prevention, treatment and care in European prisons is far lower than what is needed, than the coverage and quality levels found in the outside

community and than what countries have promised to provide by signing the Dublin Declaration.

- A 2004 review of available data suggests that prison populations in central Europe have a lower prevalence of HIV than the general population, while prisons in much of eastern Europe have much higher prevalence rates than outside, particularly in the countries hardest hit by HIV. The picture in western Europe is mixed.
- Many prisoners inject drugs in European prisons, often acquiring the habit in prison and often sharing needles. In 2002, drug use was more common among female prisoners in the EU than male prisoners.
- In 2006, the United Nations Office on Drugs and Crime (UNODC), WHO and UNAIDS jointly issued a national framework document laying out the actions needed to implement a comprehensive response to HIV in prisons (21). It prescribes the expansion of HAART in prison and endorses needle and syringe exchanges, substitution therapy and condom provision there, while opposing mandatory HIV testing for prisoners.
- While 24 of 25 EU member states had needle exchange programmes in the community in early 2007, only 3 had such programmes in prisons.
- The incarceration of people for non-violent drug offences – which in most cases is properly a health rather than a penal issue – unnecessarily crowds prisons and introduces a major risk behaviour, increasing the transmission rates for HIV and its two most significant coinfections, TB and hepatitis, and stretching resources.

#### *Key recommendations*

- European governments must act promptly to honour their commitments to providing prison populations with universal access to HIV services.
- National and regional progress on Action 9, which commits countries to achieving 80% coverage with comprehensive prevention programmes for prisoners by 2010, should be carefully monitored and widely publicized.
- Governments should significantly reduce the use of criminal penalties and incarceration as a response to non-violent drug offences.
- There should be greater involvement of NGOs in HIV surveillance and prevention with prison systems (22).
- The international community should provide financial, technical and professional assistance to states in economic transition to ensure their ability to meet their commitments to providing HIV programmes in prisons.
- Evidence-based HIV interventions should be introduced to prisons to provide them with the same levels of prevention and treatment coverage and quality as the outside community. Such interventions include voluntary counselling and testing, substitution therapy, needle exchange programmes, access to condoms and lubricants, and HAART.

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# 1. Political leadership

## Introduction

Despite a tragically slow start for much of the first two decades in the global response to AIDS, an impressive amount of resources have been marshalled for the cause in recent years. Yet the epidemic marches on as both the leading cause of death worldwide for adults aged 15–49 and arguably the largest obstacle to achieving the Millennium Development Goals (MDGs), globally. Western Europe is experiencing a resurgence in HIV infections and some areas of eastern Europe and central Asia are witnessing the world's most rapid growth in new infections (1). What accounts for this global paradox and why have some countries responded more successfully than others?

Then-United Nations Secretary General Kofi Annan pointed to insufficient and asymmetric political leadership as an important part of the answer in his 2006 World AIDS Day address. From the early days of the epidemic characterized by widespread denial among decision-makers, to the politically visible successes in HIV prevention in medium-income countries such as Brazil and Thailand, political leadership has been widely held as a necessary condition for effective national responses. The Secretary General urged that “Accountability... requires every president and prime minister, every parliamentarian and politician, to decide and declare that ‘AIDS stops with me.’” (2).

In February 2004, under the auspices of the Irish presidency of the European Union (EU), the governments of Europe and central Asia gathered in Dublin, **Ireland**, to express their grave concern about the state of the epidemic in the region and reaffirm their commitment to act collectively in the response to HIV and AIDS. This commitment is reflected in the Dublin Declaration, which sets out a range of actions to realize this commitment, putting special emphasis on leadership.

The HIV epidemic in Europe and central Asia has evolved in different ways across subregions and within a diverse range of epidemiological, socioeconomic and political contexts. Western Europe experienced the earliest epidemic, while central Europe has largely escaped the brunt of the disease, and eastern Europe and central Asia have experienced ‘late comer’ epidemics with rapid recent growth.

Yet throughout the region one constant remains; HIV is a burden disproportionately carried by populations, such as injecting drug users (IDUs), sex workers and men who have sex with men (MSM) that are often already marginalized by society and criminalized by the state. Multiple stigmas both exacerbate individual vulnerability and weaken political commitment against the powerful default forces of ignorance, intolerance and the harmful policies they breed, making strong leadership in this region as challenging and compelling, perhaps more so, than anywhere else. It is from this perspective that this chapter considers the commitments made in Dublin.<sup>1</sup>

## Measuring political leadership

Political leadership in the AIDS response is a multidimensional concept. The challenge in defining and analyzing political commitment begins with the task of identifying an objective measure. The current literature focuses on the observable indications of political commitment in terms of a range of proxy indicators, from the frequency that high-level politicians mention

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<sup>1</sup> Where civil society has the capacity, it usually leads the way in mobilizing social action and raising the visibility of HIV and AIDS at country level. Chapter 2 explores civil society contributions in detail.

AIDS in public, to the share of national spending and the existence of appropriate national response architecture.

Several indicators have also been constructed to reflect a synthesized measure of political support. An early example, the AIDS Programme Effort Index (API) developed in 1999 by the United Nations Joint Programme on HIV/AIDS (UNAIDS), the United States Agency for International Development (USAID), the World Health Organization (WHO) and the POLICY project, was a composite index designed to measure political commitment and national programme efforts. The National Composite Policy Index (NCPI) followed in 2003, integrated within the UNAIDS Core Indicators for the Implementation of the Declaration of Commitment on HIV/AIDS (3).

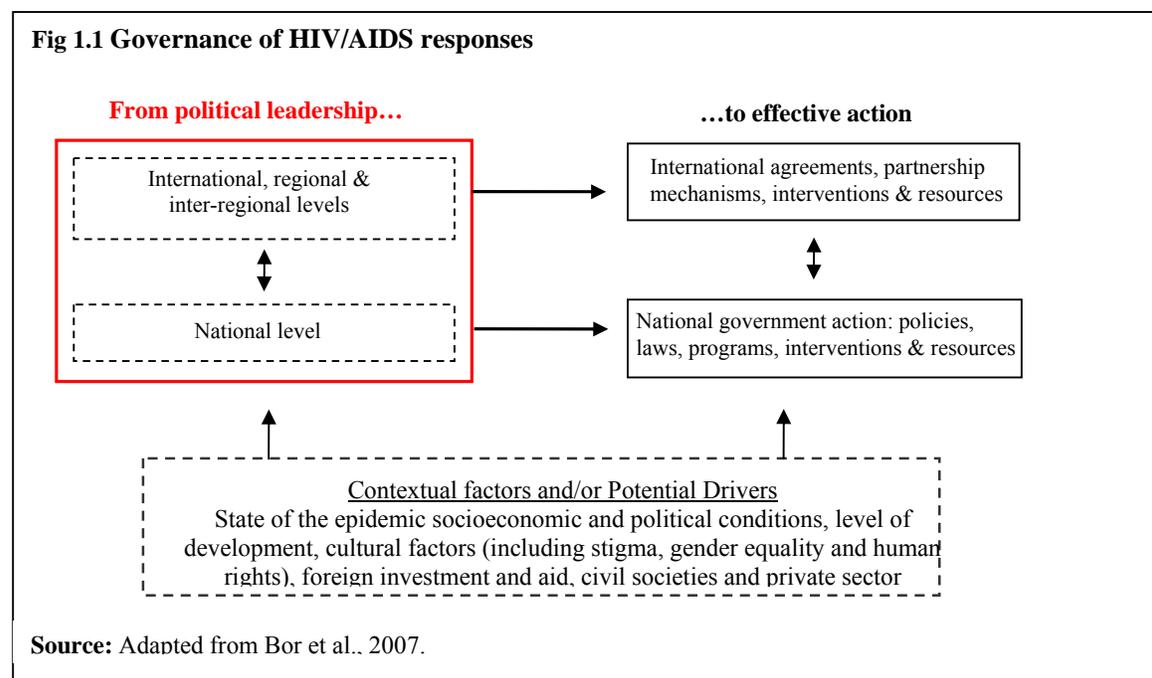
While these tools have demonstrated value in better understanding political commitment as a detailed 'snapshot', they are ultimately based on the subjective opinions of individuals, often of a 'yes/no' nature and as such, may be difficult to interpret in measuring trends over time or comparing performance across countries (4). Further, a number of indicators are self-reported, meaning government officials inform on national performance, which introduces potential conflict of interest. The fact that a number of countries choose not to report may also indicate either self-selection bias or other factors that serve to impede the usefulness for comparison between countries (for example, **Tajikistan** is the only one of five central Asian countries to have submitted the NCPI in the 2006 reporting round). In light of this, the World Bank is considering an index methodology to rank countries by performance across key governance and HIV/AIDS thematic areas, including political commitment.

However, the NCPI has been periodically refined and now includes both a section for self-reporting on political support and implementation (Part A) and a section in which nongovernmental, bilateral and United Nations organizations evaluate national responses across areas such as human rights and civil society involvement (Part B) to provide balance.

Together with the NCPI, the National Commitment and Action Indicator section of the United Nations General Assembly Special Session on HIV/AIDS (UNGASS) core indicators includes domestic and international AIDS spending as a key metric of national commitment as measured through National AIDS Spending Assessments (NASA) or National Health Accounts – AIDS subaccounts or resource flow surveys (3). This is undertaken with the caveat that governments may rationally choose to offset uneven donor flows by transferring national funds where resources are scarce and not all AIDS spending is captured in discrete AIDS budgets. It is further important to disaggregate, at least between spending on prevention and care, as a greater balance between the two likely reflects equally balanced 'political priorities' (4) and, perhaps most importantly, measuring the return on this investment either in terms of the *potential effectiveness* (i.e. the degree to which policy choices are evidence-based and fit the needs of the particular epidemic) or the *realized effectiveness* of how well those policies are implemented (e.g. results-based budgeting) is often lacking.

Of note, few investigations have sought to go further and explain the determinants of political commitment. The United Nations Development Programme (UNDP) has piloted a methodology that looks at the roles political interest groups and cultural factors play in influencing political priorities (5). A recent study by Bor (2007), which relied on the API as the benchmark measure, argues that specific democratic institutions, such as freedom of the press, rather than systems per se, display strong statistical correlation with political commitment (6). Though methodologically challenging, further research in this direction is merited.

Aligned with the Dublin Declaration and its associated collection of actions, the following conceptual framework (Fig.1.1) demonstrates the links between political leadership and the resulting institutional mechanisms necessary to manage the response, allowing for considerable channels of influence both within and across countries, underpinned by prevailing socioeconomic and cultural contextual issues.



## Monitoring progress

Following this conceptual framework, we consider progress on the Dublin Declaration actions. For analytical clarity, we present the assessment in two steps: a) international and regional political commitment and action; and b) national political commitment and action.

**Dublin Action 5:** In 2004–2005, promote the active involvement of the institutions of the European Union, and other relevant institutions and organisations such as the Commonwealth of Independent States, the Council of Europe, the Organisation for Security and Cooperation in Europe and the Regional Committee of the World Health Organisation, in partnership with UNAIDS through its co-sponsoring agencies and its Secretariat, in our common effort to strengthen coordination and cooperation;

**Dublin Action 6:** Make the fight against HIV/AIDS in Europe and Central Asia a regular item on the agendas of our regional institutions and organisations;

**Dublin Action 22:** Ensure early implementation of the WTO Decision of 30 August 2003 on the implementation of paragraph 6 of the Doha Declaration on the TRIPS Agreement and Public Health;

**Dublin Action 26:** Strengthen coordination, cooperation and partnership among the countries of Europe and Central Asia, as well as with their trans-Atlantic and other development partners, to scale up local capacity to fight the epidemic and mitigate its consequences in the most affected countries with the greatest needs, and in countries with a high risk of a major epidemic;

### (a) International and regional political commitment and action

Perhaps the most visible achievements in terms of political leadership have taken place on the international stage, from the establishment of the UNAIDS and the Millennium Declaration of 2000, which placed HIV/AIDS as one of eight global goals, to the signing of the UNGASS Declaration of Commitment in 2001 and the current consensus on the need for “universal access to treatment for those who need it by 2010” launched by the Group of Eight industrialized nations (G8). Equally dramatic is the recent increase in resources made available through public and private sources, from the launch of the Global Fund to Fight AIDS, Tuberculosis and Malaria (GFATM) to the recent groundbreaking US\$ 30 billion bilateral commitment from the United States, as well as significant contributions from other leading countries (7). The role of national leaders on the international stage presents an added dimension to political commitment. Countries that assign AIDS Ambassadors, such as **France** and **Sweden**, use their positions in the United Nations or G8 bodies, host international conferences, make large contributions to development assistance and achieve significant positive externalities across borders.

While global commitment and action indicators are incorporated in the monitoring of the Declaration of Commitment through the standardized UNGASS indicators, a quantitative measurement of regional action has not yet been proposed (8). There is, however, ample qualitative evidence of progress within the European Region that governments are responding to the need for making AIDS a priority in the face of a resurgent epidemic. Here a considerable degree of synergy can be observed between global and regional initiatives.

### ***The Group of Eight***

Though an institution with a global focus, the G8 and the region have a uniquely special relationship, with five of its eight members hailing from Europe (**France, Germany, Italy, the Russian Federation** and **the United Kingdom**) and representation also from the European Commission. For three years in a row, 2005–2007, European nations have presided over the G8 and made AIDS a key components of their platform. At the 2005 summit in Gleneagles, hosted by **the United Kingdom**, world leaders signed an unparalleled set of commitments on global poverty and AIDS. At the 2006 summit in St. Petersburg, the Russian hosts secured an agreed document pledging to strengthen efforts against infectious diseases, including AIDS, tuberculosis and malaria. The document called for increased cooperation in infectious disease surveillance and monitoring, intensified research and public awareness efforts, and increased access to prevention and treatment. As the G8 President during the first half of 2007, the German government pledged to keep the MDGs and AIDS at the centre of the G8 agenda. Specifically, **Germany** will commission the report on the efforts of G8 countries to respond to AIDS and will strive to achieve new decisions to ensure fulfilment of three key goals: universal access to prevention, treatment and care by 2010, halting and beginning to reverse the spread of HIV (MDG 6) (9). And on the summit’s final day, other G8 leaders agreed to match the US commitment for a total US\$ 60 billion for AIDS and other diseases (10). Yet despite this progress, civil society has pointed out that the G8 is still failing to live up to the promise of universal access, “at the current rate of scale-up, less than half of all people in urgent need of treatment by 2010 will be receiving it. Five million lives stand to be lost.” (11).

### ***The European Union***

The European Union (EU), unique among regional institutions in its breadth and depth, has played an instrumental role in mobilizing national and international responses to HIV and AIDS. In addition to political leadership, the EU – separate from its members – has contributed over €260 million annually to respond to HIV/AIDS, tuberculosis and malaria since 2003 globally (9). In June 2004 the European Council called for vigorous follow-up by the EU and relevant regional bodies on the outcome of the Dublin conference. In September 2004, the European Commission adopted the Working Paper: ‘Coordinated and Integrated Approach to Combat HIV/AIDS in the European Union and in its Neighbourhood’ and co-hosted with the government

of **Lithuania** a follow-up ministerial conference of health ministers, AIDS experts and civil society representatives from across the EU and its neighbours. The Vilnius conference endorsed a roadmap for tackling the HIV epidemic in Europe and its neighbourhood.

The Commission also established the HIV/AIDS Think Tank, a forum for information exchange between the Commission, the Member States, candidate and non-EU European Economic Area (EEA) countries (**Lichtenstein, Iceland and Norway**). And in 2005, the HIV/AIDS Civil Society Forum was established in line with the Commission's recommendation regarding the importance of civil society in addressing AIDS. Later that year, the Commission adopted a new document (12) outlining priorities regarding AIDS in Europe with the overall objective of raising public awareness, preventing the spread of HIV, ensuring access to affordable antiretroviral treatment and strengthening the epidemiological surveillance of HIV, all with deep civil society involvement (13).

In 2007, the German government made AIDS a core theme of its EU presidency and held a special conference in the German city of Bremen. EU Member State and neighbouring country governments, as well as the European Commission, pledged to provide political leadership in the response to AIDS at national, European and international levels. The resulting Bremen Declaration acknowledged that, despite great efforts at national and global levels, AIDS is "still outpacing our efforts". The Declaration also calls on the European Commission to include public health issues regarding HIV and AIDS prevention, treatment, care and support in the Seventh Framework Programme for Research (FP7) (14) and invites the private sector to partner with public research and development (R&D) efforts. German Chancellor Dr Angela Merkel encouraged European leadership not only on the global stage, but equally at home, "it is important that we do not push this issue aside during our Council presidency, that we don't pass the buck to our G8 presidency."

### ***The Commonwealth of Independent States***

Within the framework of the Programme of Urgent Response, launched in 2002, the Commonwealth of Independent States (CIS) Coordination Council on HIV/AIDS and Executive Council have promoted coordinated responses among the countries of the former Soviet Union. In 2006 the Council partnered with UNAIDS to organize two regional consultations on universal access target setting and monitoring and launched a new programme guiding the CIS regional response to AIDS for 2007–2011. Work continues on the development of model AIDS legislation in the CIS and on the possibility of creating a regional horizontal technical collaboration facility (15).

### ***United Nations action – UNAIDS, "Three Ones" and universal access***

The United Nations joined with donors and other stakeholders in 1996 to create UNAIDS. With a Geneva-based secretariat and regional and country-level staff, UNAIDS unites the efforts of 10 United Nations cosponsor agencies. The agency works through strategic alliances with national governments, media, religious and community-based groups, regional and country networks of people living with HIV, the private sector and other nongovernmental organizations (NGOs). In each country, **United Nations Theme Groups** and **Joint Teams** on AIDS provide a joint platform for UNAIDS and the cosponsors to support national efforts with the participation of the host government. United Nations Theme Groups have played an increasingly important role in the region and continue to be the primary instrument for United Nations coordination and leadership on AIDS at the country level. This includes promotion of the "**Three Ones**" **principles**, endorsed internationally in 2004 to strengthen national AIDS responses, calling for the establishment of one national action framework, one national AIDS coordination authority and one country level monitoring and evaluation system, as an increasingly recognized standard

among programme countries in Europe and central Asia – as discussed ahead under Dublin Action 30.

At the 2005 United Nations World Summit, leaders committed to a massive scaling-up of HIV prevention, treatment and care, with the aim of achieving the goal of **universal access** to the aforementioned by 2010 for all in need. Tasked by the General Assembly to facilitate inclusive and country-led processes to develop strategies to move towards universal access, UNAIDS has helped convene national consultations in 20 countries in the European Region, including additional subregional consultations for the CIS and south-eastern Europe.

### ***Global Fund to Fight AIDS, Tuberculosis and Malaria***

Since its inception in 2002, following the Declaration of Commitment on HIV/AIDS, the Global Fund has channelled more than US\$ 1 billion for AIDS into eastern Europe and central Asia and played a critical role in promoting evidenced-based policies (16). See Chapter 3 for a more detailed discussion on the role of the Global Fund in the region.

### ***Parliamentary working groups on AIDS***

Parliamentarians have a unique opportunity to influence the national response at multiple entry points, including enacting human rights legislation and oversight of budgetary allocations and government policy. **The United Kingdom** All-Party Parliamentary Group on HIV/AIDS has long been a leader in this area. Others, such as the European Parliament Working Group on Population and the Inter-European Parliamentary Forum on Population and Development have also been active. More recently, the Russian Parliamentary Working Group on AIDS and the Central Asia Inter-Parliamentary Working Group on AIDS have joined the cause, though greater cooperation among parliamentarians across the region should be a priority.

## **(b) National political commitment and action**

**Dublin Action 1:** Promote strong and accountable leadership at the level of our Heads of State and Government to protect our people from this threat to their future, and promote human rights and tackle stigma and ensure access to education, information and service for all those in need;

**Dublin Action 3:** Accelerate the implementation of the provisions of the Declaration of Commitment relating to orphans and girls and boys infected and affected by HIV/AIDS;

**Dublin Action 30:** Ensure effective coordination between donors, multilateral organisations, civil society and Governments in the effective delivery of assistance to the countries most in need of support in the implementation of their national HIV/AIDS strategies, based on ongoing processes on simplification and harmonization particularly the UNAIDS guiding principles

Political commitment is one component of a broader leadership response to AIDS. We examine national progress against Dublin actions using selected results from the 2003 and 2005 iterations of the National Composite Policy Index (NCPI) which, despite shortcomings, remains the best tool and source of data for systematic assessment of both political leadership per se and the channels by which it is translated into programmatic action. An important outcome of effective political leadership is the development of necessary mechanisms to deliver results within the “Three Ones” principles, including a national multisectoral strategy or action framework, the creation of one national coordinating body and a monitoring and evaluation system sufficiently strategic and accurate to reliably guide national responses.

Further, political leaders have an important role to play in educating the public, countering stigma and generating an environment conducive to civil society initiatives. One looks for evidence that the state has promoted human rights and that stigma and discrimination are addressed at the level of heads of state. The adoption and enforcement of laws and regulations securing the rights of people living with HIV is another important dimension of strong political commitment.

For consistency, we employ subregion classifications according to the WHO geographical grouping: western Europe, central Europe (including south-east Europe and all recent EU accession countries, except the Baltic states), eastern Europe (comprising all CIS countries, except central Asia and the Baltic states) and central Asia.

Any cross-country comparisons should be drawn with a caveat, however, as a number of countries failed to submit UNGASS reports at all, and of those reports submitted many do not include NCPI data. A cursory review indicates that in 2005 some 83% of countries in the western, 64% in the central and 73% in the eastern subregions submitted UNGASS reports, while only 47%, 33% and 64%, respectively, included NCPI data.

**Dublin Action 1:** Promote strong and accountable leadership at the level of our Heads of State and Government to protect our people from this threat to their future, and promote human rights and tackle stigma and ensure access to education, information and service for all those in need;

**Indicator Tracked:** UNGASS NCPI Part A, II.1: Do high officials speak publicly and favourably about AIDS efforts in major domestic fora at least twice a year?

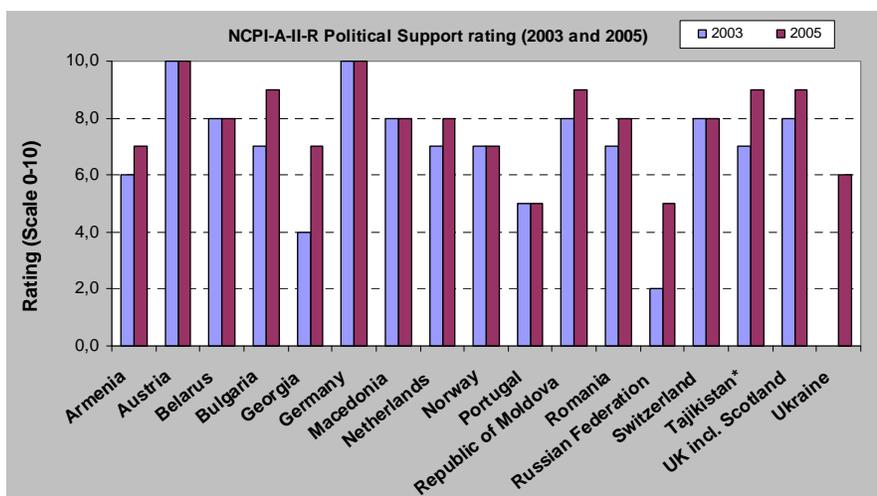
### *NCPI results*

Country reports reflect a favourable picture for eastern Europe, with 60% of countries reporting answering 'yes', while the same is true for only 31% of western and 27% of central European countries. **Tajikistan**, the only central Asian country to submit a UNGASS report, indicated 'yes'. This data may reflect relative apathy on the part of national leaders in western and central Europe and central Asia. Notably, all but one country (**Turkey**, which did not submit NCPI data) reporting a national multisectoral strategy also reported 'yes' to this question, suggesting a possible correlation between the two in support of the conceptual framework outlined above.

**Indicator Tracked:** UNGASS NCPI Part A, II.R: Overall Political Support Rating (scale 0/low – 10/high)

Reviewing the Fig. 1.2 below, it becomes clear that according to local government officials the countries of eastern Europe, especially **Georgia** and **the Russian Federation**, benefited from significant increases in political support from 2003 to 2005, though **the Russian Federation** still rates among the lowest in the sample. Self-reported civil society participation also improved during this time in nearly every eastern European and central Asian country reporting (see NCPI Part B, II.R). Central Asia and central Europe also demonstrated positive change, while western European countries have either reached maximum performance, such as **Germany**, or a ceiling beyond which AIDS has not achieved greater visibility.

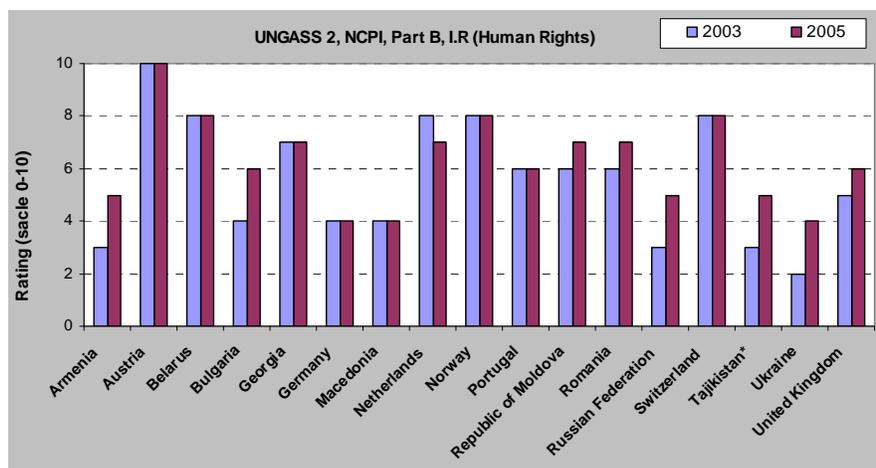
**Fig 1.2**



**Indicator Tracked:** UNGASS NCPI Part B, I.R: Overall score - Policies, laws and regulations in place to promote/protect human rights in relation to HIV and AIDS (scale 0/low – 10/high)

Here again, the countries of eastern Europe and central Asia demonstrate notable improvement over the reporting period, with some movement in central Europe and essentially no change in western Europe. Yet one must stay clear of the temptation to equate the existence of laws with their implementation. Comparing these scores with NCPI B1.R2, which measures efforts to enforce those policies, laws and regulations, one notes that indeed performance in a number of countries falls, given the tougher benchmark of implementation. Of countries reporting, this is especially the case for **Georgia, Norway, Portugal** and **Russian Federation**, whose scores on B1.R2 (implementation) are significantly less, meaning a drop of more than one point, than B1.R (Fig 1.3, policies, laws and regulations in place). In this respect, countries would do well to strengthen mechanisms for monitoring the implementation of human rights legislation on the books.

**Fig 1.3**



**Dublin Action 3:** Accelerate the implementation of the provisions of the Declaration of Commitment relating to orphans and girls and boys infected and affected by HIV/AIDS;

**Indicators Tracked:** UNGASS NCPI Part A, IV.3, and Part B, IV.2: Does your country have a policy or strategy to address the additional HIV and AIDS-related needs of orphans and other vulnerable children?

The data demonstrate that relatively few countries have policies or strategies in place addressing the needs of orphans and other vulnerable children (OVC), with only **Armenia, Belarus and Romania** reporting ‘yes’, though the number increases slightly when asked whether care and support is provided to OVC (NCPI B, IV.2). The countries of Europe and central Asia are clearly failing to meet their Dublin Declaration commitments in this area. This is especially concerning in countries such as **the Russian Federation and Ukraine** where the numbers of children affected are climbing rapidly.

**Dublin Action 30:** Ensure effective coordination between donors, multilateral organisations, civil society and Governments in the effective delivery of assistance to the countries most in need of support in the implementation of their national HIV/AIDS strategies, based on ongoing processes on simplification and harmonization particularly the UNAIDS guiding principles;

**Indicators Tracked:** UNGASS NCPI Part A, I.1: Has your country developed a national multisectoral strategy/action framework to combat HIV/AIDS?

UNGASS NCPI Part A, II.2: Does your country have a national multisectoral HIV and AIDS management/coordination body recognized in law?

Taking both indicators together, comprising two of the “Three Ones” principles, a picture emerges in which most countries reporting (except **Germany, the Netherlands, Norway and the United Kingdom**) and all countries outside of western Europe, reported having a national multisectoral HIV and AIDS coordination body. Most of the countries reporting outside of western Europe are also Global Fund grant recipients, with the usual requirement for a Country Coordination Mechanism to be in place likely playing a role. All countries with a coordination body also reported a national multisectoral strategy or action framework, with the exception of **the Russian Federation**, which did have a Federal Targeted Sub-Programme on HIV and AIDS at the time.

### *Review of national examples*

#### *Western Europe*

Western European countries responded to the epidemic relatively early and swiftly. When HIV first presented a threat in the mid-1980s, western Europe generated examples of effective leadership and partnership-led responses to the epidemic. Newly forged partnerships between governments, civil society and affected people and communities led to comprehensive policies and innovative care and education programmes. In **Scotland** in the late 1980s an emerging epidemic of HIV infection related to injecting drug use was halted because the government developed policy that permitted harm-reduction approaches, such as syringe exchange programmes, which were implemented by community-based organizations. HIV infection rates declined dramatically. Similar approaches were used successfully in **the Netherlands, Denmark, Italy**, and elsewhere. In **Germany**, funding from government to community-based organizations effectively led to the development of groundbreaking educational materials on safer sex practices targeting MSM, which at the time were considered too risqué for ministries to develop (17). As in other high-income regions, the majority of those in need of antiretroviral

therapy are able to receive it. As a result, the number of reported AIDS-related deaths has continued to slow in the region. People living with HIV are surviving longer than their counterparts in resource-poor settings (18). Yet, despite the introduction of highly effective antiretroviral treatments, HIV continues to pose a serious public health problem and there are reports of a resurgence in sexually transmitted HIV transmission.

In Bremen, Dr Merkel declared the response to AIDS a guiding theme of the German presidency of the EU and a central issue of the European Council, and has strongly advocated for the additional support of policy-makers. With over 100 nongovernmental organizations present at the conference, she led countries to commit to ensuring access throughout Europe to prevention, affordable treatment, and a life free from stigmatization and discrimination for PLHIV.

In addition to its international role, **Germany** has also demonstrated leadership at home by revising its strategy to respond to AIDS and implementing the commitments made in Dublin and Vilnius. The new strategy focuses on national resources and knowledge while emphasizing significant cooperation with United Nations agencies, the Global Fund, civil societies and the EU within the framework of the G8 negotiations.

In **the United Kingdom** strong high-level political support which emphasized responsible citizenship and public tolerance enabled wide access to voluntary counselling and testing and embraced education-based prevention strategies. Harm-reduction practices which encourage behavioural changes targeted at IDUs, MSM and sex workers were also adopted early. In 2005 the government began the implementation of a Department of Health plan that addresses HIV stigma and discrimination, based on UNAIDS good practice.

**The Netherlands**, which was first to introduce needle exchange programmes – leading to dramatic reductions in the spread of HIV among IDUs – and which also began universal screening of pregnant women, is among the countries that have adopted a national constitutional law technically prohibiting HIV-based discrimination.

Some countries, including **Italy** and **Spain**, had been initially slow to embrace harm-reduction approaches for IDUs due to socio-cultural and religious pressures on health system leadership, which resulted in poor funding of voluntary sector efforts. As a result, HIV infection spread rapidly among IDUs.

Overall, the 2006 UNGASS report noted some positive improvement in national human rights frameworks for western European countries between 2003 and 2005. More than two-thirds of countries reporting have regulations that protect people living with HIV against discrimination, while much of the region has adopted ethical guidelines for AIDS control such as voluntary counselling and testing (19). Yet leadership in the international arena is not always matched by equivalent action domestically, as Dr Merkel recently remarked, “one thing holds true for this issue...when the Europeans try to help throughout the world by giving good advice, all eyes are on them to see where they have to take action themselves.”<sup>2</sup>

### ***Central and south-eastern Europe***

In central Europe, the leadership commitment at the national level has been varied. About two-thirds of countries in the central region reported progress to UNAIDS. Based on these reports, we found that all of the countries reporting had developed a national multisectoral strategy on AIDS.<sup>3</sup> Of those reporting, 90% had a national HIV and AIDS coordinating committee or

<sup>2</sup> Speech by the Federal Chancellor Angela Merkel at the ‘Responsibility and Partnership – Together against HIV/AIDS’ conference, Bremen, 12 March 2007.

<sup>3</sup> 12 countries reporting in western Europe (UNGASS progress report).

commission recognized by law. About two-thirds reported having heads of government and/or other high-level officials speak publicly about AIDS efforts at least twice a year. Political leaders in **Hungary** have taken HIV prevention seriously with mass education campaigns and peer education programmes for sex workers. Harm-reduction approaches have also been implemented successfully in **Poland**.

In south-eastern Europe, the reported prevalence of HIV is generally low. In the Balkan states, including **Albania, Bosnia and Herzegovina, The former Yugoslav Republic of Macedonia, Montenegro, Serbia** and the **United Nations Administered Province of Kosovo**, this is due to low levels of infection among the population, but could also be partly due to inadequate coverage or inaccuracy of surveillance systems, creating a high-risk environment. Severe political instability, consequent economic crisis and high levels of migration over the last 10 years are major factors that contribute to vulnerability to HIV and present the countries in the region with overwhelming challenges to containment or to their ability to make an effective response.

All countries have now prepared and approved national AIDS strategies, prepared with the assistance of UNAIDS and other partner organizations. In some cases these strategies are not financed properly, though Global Fund resources have begun to help improve the situation. With the exception of **The former Yugoslav Republic of Macedonia** and **Serbia**, low political commitment and institutional capacity is hampering the use of available resources in the countries. **Croatia**, however, has recently agreed to continue Global Fund supported activities with domestic resources, as the country is no longer eligible for the grants given changes in its income classification (16).

In **Bosnia and Herzegovina**, the Parliament approved the AIDS strategy in 2004. A national AIDS board was established and submitted, with support from the United Nations Theme Group, a successful application to the Global Fund, for which UNDP serves as Principal Recipient. The United Nations Theme Group is also active in **The former Yugoslav Republic of Macedonia** and **Serbia**. In **The former Yugoslav Republic of Macedonia**, the existence of the Global Fund created incentives for the establishment of a national multisectoral AIDS commission and the development of the national strategy. Global Fund grants and the National Policy Framework for AIDS are key elements of **Serbia**'s strategy.

### *Eastern Europe*

Eastern Europe and the CIS have some of the highest rates of growth in HIV transmission in the world. The impact is compounded by insufficient public awareness, frequent stigmatization and lack of adequate policy instruments to cope with the infection. Yet national responses in the region, which have often previously been described as "in denial", are increasingly gaining political traction.

There have been some notable improvements in the leadership in eastern Europe. All of the countries reporting to UNAIDS have developed a national multisectoral strategy to combat HIV and AIDS.<sup>4</sup> All also report having a national AIDS coordinating committee or commission recognized by law. More importantly, 50% of the countries reporting to UNAIDS in 2005 saw increased political support for the national AIDS response.

Accounting for some 70% of all HIV infections in eastern Europe and 20% in central Asia respectively, **the Russian Federation** and **Ukraine** have also featured some of the most encouraging political commitment at different points. **Ukraine** was first to take visible action in

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<sup>4</sup> 8 out of 10 countries in the region have submitted UNGASS country progress reports.

many key policy areas, such as adopting proactive harm-reduction approaches with pilot programmes for opioid substitution therapy. The former President was one of the earliest leaders in the region to speak openly and often about the issue. However, it has not always been easy to translate these achievements into sustainable results and national budgetary commitment has been lacking.

**The Russian Federation** has lately made significant strides in prioritizing AIDS. In the wake of the first National Security Council discussion on AIDS in 2005, President Putin described the AIDS epidemic in **the Russian Federation** for the first time as “an acute problem which requires the attention of all sectors of society” and pledged that “all those in need of medication, however expensive, should have it.” (20). This increase in political commitment has been matched by an equivalent increase in financial resources. The annual federal AIDS budget from 2006 was raised some 20 times, albeit from a relatively low base, to well over US\$ 100 million per year. The government has also agreed to begin reimbursing the Global Fund for grant expenditures in country, estimated at around US \$250 million. In addition, federal funding for the first time includes a budget line to fund selected harm-reduction activities implemented by NGOs and the “acknowledgement of the rights of drug dependent people to [antiretroviral] treatment is a breakthrough.” (20). In May 2006, the Russian State Council, which is chaired by the President, held its first ever session devoted to AIDS, which was followed that month by the first eastern European and central Asian AIDS conference, held in Moscow. Finally, **the Russian Federation**’s presidency of the G8 Summit in St. Petersburg placed infectious diseases, including HIV, as one of the key substantive areas of discussion. A second eastern European AIDS conference will again be hosted by **the Russian Federation** in 2008.

Yet despite these achievements, serious challenges remain if **the Russian Federation** is to meet its own universal access targets. This is especially true in terms of access to antiretroviral treatment and other services for IDUs, who comprise the majority of people living with HIV in the country. Opioid substitution therapy, recommended by WHO, UNAIDS and the United Nations Office of Drugs and Crime (UNODC) as an effective means of promoting both HIV prevention and adherence to antiretroviral treatment among IDUs (21), still remains illegal.

Along with **the Russian Federation** and **Croatia**, **Estonia** has agreed to assume funding for the continuation of Global Fund activities with domestic resources (16). And in addition to outspoken leadership by the First Lady, who chairs the Country Coordination Mechanism, **Georgia** hosted the first region-wide Global Fund meeting for all countries of eastern Europe in 2007.

### *Central Asia*

The central Asian states have witnessed a proliferation in drug trafficking in recent years, followed by rapid spread of IDU-related HIV infection. Reaction in the region had been slow, hindered by governments’ limited capacity to coordinate the response. This is partly because the epidemic is concentrated among IDUs, while the absolute number of people living with HIV is relatively low, but rising rapidly.

More recently, there have been encouraging signs of increased government awareness aimed at increasing and galvanizing commitment to responding to AIDS. In four of the five countries, there is some evidence of high-level leadership and buy-in from the presidential administration and government. Though according to official statistics there are still only two AIDS cases in **Turkmenistan**, new opportunities may be appearing for a fresh look at the state of the epidemic and necessary responses. **Kazakhstan**, **Kyrgyzstan**, **Tajikistan** and **Uzbekistan** have developed multisectoral responses and secured support from Global Fund. **Kyrgyzstan** has been acknowledged for establishing a model multisectoral coordination committee, including a unit

for AIDS coordination and monitoring in the Prime Minister's Office, with support of the United Nations Theme Group and UNDP.

Relatively weak NGO presence, low technical capacities and inadequately trained human resources will make translating commitments to actions very challenging. Despite national coordination efforts, **Kazakhstan** and **Kyrgyzstan** have limited capacity and financial resources to scale up advocacy, education work and the overall quality of services. In **Tajikistan**, a national multisectoral plan is being developed with a multisectoral approach, and the United Nations Theme Group ensures a coordinated approach among its main donors. **Kyrgyzstan** has been a leader in adopting and demonstrating the effectiveness of harm-reduction approaches, including needle and syringe exchange programmes and substitution maintenance therapy. These measures have succeeded in keeping HIV transmission relatively stable among IDUs, unlike its neighbours (22).

A regional strategy prepared by UNAIDS in collaboration with the parties to the Central Asia Cooperation Organization<sup>5</sup> has provided the framework for country-specific multisectoral strategies to respond to HIV through a US\$ 27 million regional AIDS project launched in May 2005, funded by grants from the World Bank and **the United Kingdom** Department for International Development (DFID). This initiative is the first ever multi-country AIDS project in Europe and central Asia. Based in **Kazakhstan**, the Central Asia AIDS Project (CAAP) aims to minimize the human and economic impact of the HIV and AIDS epidemic and is overseen by a Regional Project Steering Committee (RPSC) comprising high-level representatives from all four participating governments.

All five central Asian countries have addressed forms of legal and political reform as they strive towards market economies, despite the considerable disparities regarding human rights conventions and legislative implementation to support them. They have passed laws that seek to eliminate discrimination against people living with HIV and other sexually transmitted infections, but these are unevenly interpreted. For example, in **Tajikistan**, **Turkmenistan** and **Uzbekistan** MSM are still criminalized and in the latter two countries homosexuality is officially illegal.

## Summary

In many respects, progress in strengthening political leadership and the establishment of mechanisms to implement Dublin Declaration commitments in Europe and central Asia has been significant. HIV is now regularly addressed by regional institutions and national leaders are speaking more openly on the issue. Cross-border partnerships in the region have been strengthened, civil society is increasingly consulted and financial resource constraints have been significantly relaxed in many countries.

Yet it is this very progress that brings the leadership challenge – making difficult, sometimes unpopular but necessary policy decisions – ever more sharply into focus. As the familiar excuse of resource gaps loses currency, political leaders are faced with a stark choice: promote often uncomfortable evidence-based policies and facilitate the development of systems to coordinate and deliver services in sometimes new and unfamiliar ways, or risk squandering an undeniable opportunity and obligation to make a great number of lives better and save even more. For example, the “refusal by some of our governments to provide appropriate and scientifically-proven treatment and harm reduction programmes – despite the fact that the majority of HIV

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<sup>5</sup> **Kazakhstan**, **Kyrgyzstan**, **Tajikistan** and **Uzbekistan** are members of the Central Asia Cooperation Organization (CACO).

infections in the region occur through injection drug use” as decried by civil society in Dublin, remains one of the most pressing political leadership challenges for the region.

## Recommendations

1. Regional collaboration has improved since the Dublin Declaration. Nonetheless, while HIV knows no boundaries, political or geographic, subregional “silos” remain a barrier to effective partnerships.
  - **Recommendation:** acknowledging advances to date, the EU should strive for greater inclusion of countries and subregions beyond its borders and neighbourhood programmes. The same holds true for the CIS Coordination Council on HIV/AIDS. These and other regional institutions can achieve far more together than individually.
2. National governments have made significant strides in implementing the Dublin Declaration actions and the broader UNGASS commitments from which they emerged. As this chapter has argued, however, there is a significant degree of inconsistency across the countries of Europe and central Asia.
  - **Recommendation:** national and local leaders of all signatory countries must redouble efforts to implement every action and live up to each commitment, from speaking out frequently about HIV and AIDS to ensuring an evidence-informed and rights-based policy environment and effective coordination and management structures based on the “Three Ones” principles.
3. The UNGASS reporting mechanism remains the most comprehensive platform available for capturing both national and international comparative progress against a range of agreed commitments. Yet the value of this tool in Europe and central Asia is lessened due to a lack of universal reporting and inconsistency in the quality of reports submitted.
  - **Recommendation:** with support from UNAIDS and other relevant organizations, all UNGASS and Dublin Declaration signatories, including western European states, should ensure timely and high-quality national UNGASS reports. This should include a full set of NCPI indicators encompassing political leadership. A regional-level synthesis of reports from Europe and central Asia could help further understanding of common challenges and appropriate responses.
4. There is an urgent need to protect the human rights of populations at higher risk, including IDUs, MSM and sex workers. To meet UNGASS, universal access and Dublin commitments, leaders must promote mechanisms to actively monitor and prosecute human rights violations.
  - **Recommended indicator:** a measure for the existence of active mechanisms (e.g. ombudsman) supported by the number of cases considered or violations prosecuted (over the past 12 months).
5. It is important to ensure that national response efforts are aligned with universal access targets. In Europe and central Asia this means significant focus must remain on populations at higher risk, including IDUs, MSM and sex workers, or targets will not be met.
  - **Recommended indicator:** a composite index of three existing key indicators targeting populations at risk, including IDU, MSM and sex workers, added to the NCPI: a) prevention services coverage, b) antiretroviral treatment coverage, and c) percentage of total AIDS spending targeted at populations at risk.
6. Leaders need to ensure that the resource envelope for HIV and AIDS responses matches the long-term growth of the epidemic. A “financial sustainability” indicator could be developed and added to the NCPI, as well as efforts to ensure that HIV is integrated into national planning processes.

- **Recommended indicator:** a forward-looking calculation of the number of months for which national response resource needs are costed, planned and secured.

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## 2. Strengthening the voices of civil society and other nongovernment stakeholders

**Dublin Action 2:** Encourage and facilitate strong leadership by civil society and the private sector in our countries in contributing to the achievement of the goals and targets of the Declaration of Commitment.”

With its tremendous variety, civil society is easiest to define by what it is not: the state or the private sector. Free from the responsibility of governing or earning money, civil society groups develop around particular passions, identities and values. The most important of the nongovernmental organizations (NGOs) fighting HIV/AIDS have arisen from shared situations (community-based organizations), religious convictions (faith-based organizations) or the protection and promotion of rights (e.g. trade unions). Chief among the community-based organizations working with HIV/AIDS are those that represent people living with HIV (PLHIV) and risk groups (e.g. gay men, drug users or sex workers).

NGOs have long led the way in developing effective interventions, providing care, spearheading prevention efforts, fighting discrimination and stigmatization, educating the public, collecting information and critiquing national and international responses. Governments now recognize the desirability of promoting civil society involvement in HIV/AIDS efforts, not only because the sector is effective, committed and responsive, but also because citizens have the right (if not the obligation) to act collectively for the public good. In consulting NGOs, governments also tap their considerable expertise while securing their support and cooperation.

Involving infected and at-risk people in the national response is especially prudent. PLHIV know firsthand about testing, transmission and treatment, not to mention the stigma of infection. The United Nations has acknowledged the value of increasing the PLHIV role in HIV/AIDS policy- and decision-making, known as the Greater Involvement of People Living with or Affected by HIV/AIDS (GIPA) Principle. As the Dublin Declaration preamble notes, the Principle “is critical to ethical and effective national responses to the epidemic”. Similarly, as the major transmission vectors for HIV, at-risk individuals are ideally situated to determine how to address the distinctive behaviours that put them at risk, how to collect data from their risk groups, etc.

Like civil society, the private sector has vast resources to bring to the fight, and it too consists of many heterogeneous, independent elements, each with its own goals, competences and methods. Since the private sector exists to create and leverage capital, it has financial reserves that the other sectors lack. Moreover, with its influence over the world’s workers and consumers, it is uniquely placed to implement prevention measures, combat discrimination and so on. Private sector philanthropy plays a key role too, albeit one closely resembling efforts of other sectors.

For these reasons, governments have pledged in the Dublin Declaration to increase the political effectiveness of nongovernment actors in the national and regional response. This chapter examines progress on commitments to promote three things: the strong leadership of civil society and the private sector in addressing HIV/AIDS (Action 2); the involvement of key civil society subsectors and the private sector in every stage of the national response (Actions 4 and 27); and networking and cooperation among European civil society groups and PLHIV (Action 32).

Since governments and multilateral agencies have only recently begun to embrace the critical role of nongovernment actors, there are few statistics on their participation in HIV/AIDS policy- and decision-making. Progress is thus difficult to gauge and thus largely anecdotal, and most of

it is in fact not due to any government actions. This chapter will therefore also propose indicators that should be collected to give a fuller depiction of civil society and private sector activity.

### *Spotlights and shadows: existing data sources*

There are two main sources for data on the involvement of civil society and the private sector in HIV/AIDS efforts. The first is the National Composite Policy Index (NCPI) in country progress reports for the United Nations General Assembly Special Session Declaration of Commitment on HIV/AIDS (UNGASS Declaration). Article 94 of the Declaration commits signatory countries to involve civil society in the preparation of these biennial reports.

However, after NGOs complained about inadequate involvement in the first reporting round in 2004, UNAIDS changed the reporting guidelines, as well as added a new section to the NCPI on “Civil society participation” (itself a noteworthy indication of progress). The guidelines now state that governments “should seek input from the full spectrum of civil society” and the private sector, have NGOs and international agencies fill out Part B of the NCPI, and hold a consultation workshop with all parties to discuss and endorse the final report (1). Yet civil society participation is not mandatory, and participation itself does not ensure a voice in the final report. After the 2006 reports, a CARE International study said (2):

In general, civil society interviewees concluded that they did not fully participate in the process of preparing inputs for the UNGASS reports. Though civil society has been allowed some input with regard to progress reports, respondents in almost all of the countries felt that their involvement was ad hoc and merely representational.

UNAIDS also allows NGOs to submit their own “shadow reports”. Though the 2006 guidelines call them “a parallel process” (3), the 2008 guidelines backtrack, saying that “shadow reports are not intended as a parallel reporting process” (1) or a substitute for multisectoral engagement. The few extant have proven valuable advocacy tools for NGOs, Unfortunately, civil society is often weakest where its critique of the national response would be most useful. For 2006, shadow reports were prepared for just 9 of the 52 countries then in the WHO European Region: **Germany, Greece, Ireland, Latvia, the Netherlands, Romania, Serbia, Ukraine** (preliminary) and **the United Kingdom**. Moreover, while the official reports are readily available on the UNAIDS website, the shadow reports are not.<sup>6</sup>

The second invaluable source for tracking civil society involvement in political processes is the annual reports and surveys compiled by UNAIDS country offices, which in the European Region are chiefly located in central and eastern Europe. While preparation of these materials does not require consultation with civil society, the results provide a detailed perspective. However, they are not publicly available, though they may be accessed by any UNAIDS cosponsor. As the only United Nations agency which includes civil society in its structure and decision-making processes, the International Labour Organization is also a source of useful information on actions by employers’ and workers’ organizations. A 2008 report issued in preparation for a new international labour standard on HIV/AIDS provides extensive information.<sup>7</sup>

### *Civil society leadership*

In the Dublin Declaration, Action 2 is the core action for both civil society and the private sector. The key word is “leadership”, which describes three ways to effect social change: through authority, advocacy and example. *Authoritative leadership* means using a position of power to act through established structures. Though often considered the primary type, advocacy and

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<sup>6</sup> See [www.ua2010.com/index.php/en/ua2010/universal\\_access/civil\\_society\\_papers/shadow\\_reports\\_2006](http://www.ua2010.com/index.php/en/ua2010/universal_access/civil_society_papers/shadow_reports_2006) for access.

<sup>7</sup> See [www.ilo.org/public/english/protection/trav/aids/index.htm](http://www.ilo.org/public/english/protection/trav/aids/index.htm)

example have proven more significant in the history of HIV/AIDS, particularly for civil society.

*Advocative leadership* can be external or internal. Advocacy from without uses the tools of ordinary people, such as letter-writing and boycotts. Because states have been slow to advocate the interests of PLHIV and HIV risk groups, NGOs have usually done so instead, becoming the driving force behind the greatest changes in governmental response to HIV/AIDS. For advocacy from within (e.g. service on a national HIV council), see the section on Actions 4 and 27 below.

Finally, leadership can also be manifested through action, or leading by example. Again, civil society has exhibited such *exemplary leadership* in most of the European Region, particularly western Europe, for a quarter century now, responding to the unmet needs of not just the infected and the affected but everyone else as well, initiating prevention programmes, patient-centred care and much more.

Where civil society has not led actively, it is typically because the political system has deterred it. Communist states have been particularly notorious for outlawing NGOs, violating the right of association that forms the basis for a healthy civil society (see Article 20 of the Universal Declaration of Human Rights (4)). Although the fall of Communism in central and eastern Europe gave civil society a foothold there, it remains weak and underdeveloped in most of the area. NGOs there still depend largely on foreign funding, while government actions can profoundly affect their ability to operate, both positively and negatively.

**The Russian Federation**, for instance, funnelled part of its huge 2006 increase in HIV/AIDS funding to NGO needle exchanges, sex worker and prisoner prevention programmes, anti-stigmatization and – discrimination campaigns, treatment adherence, counselling and training projects. The national HIV/AIDS civil society networks also gained a voice in policy- and decision-making. Yet at the same time, a federal law tightened NGO registration requirements, giving the state broad powers to limit NGO activities and contributing to the closing of several human rights groups. Nor are NGOs permitted to provide opioid substitution therapy, which remains illegal, and the new system does not fund regional NGOs (5).

In **Ukraine**, poor government stewardship prompted the Global Fund to withdraw a Round 1 grant. National NGOs later assumed a major role in drafting the application for a larger grant in Round 6, which was then awarded to two civil society networks as principal recipients.

Most recent attention has focused on giving civil society an official role in HIV policy- and decision-making. However, politicians and activists both portray the ideal role as being “full participation”, rather than “strong leadership”. While it may be appropriate to, say, reserve the chairmanship of the national AIDS authority for PLHIV, it seems clear that the strong leadership that Action 2 calls for is *not* authoritative but exemplary and advocative.

#### *European progress on civil society leadership and involvement*

Civil society leadership on HIV/AIDS is as varied as the European Region itself. The following snapshots of recent milestones in all three types of leadership, representing national progress on Actions 2, 4 and 27, are drawn from UNGASS country and shadow reports, UNAIDS country office annual reports and consultation with the advisory group for this chapter.

*Eastern Europe.* In **Armenia**, a new strategic framework was developed in 2006 drawing on extensive consultation with civil society. In **Azerbaijan**, 2006 saw civil society participating in a national consultation on universal access, while UNAIDS and the United Nations Development Programme (UNDP) helped establish a PLHIV association that now has representatives on the National Commission on Prevention of HIV. The number of NGOs implementing the Global

Fund grant in **Belarus** increased to 68 by the end of 2006, being most notably responsible for risk-group prevention and PLHIV care. NGO activity in **Estonia** has also increased due to Global Fund money targeting risk groups. In **Kazakhstan**, a 2006 revision of the national strategic plan was carried out after consultation with organizations representing the major risk groups and young people as well as the three national AIDS service organizations. New funding sources there and in **Tajikistan** have encouraged the development of quasi-nongovernmental organizations (QUANGOs) that meet the letter of donor requirements while evading the spirit. The national coordinating committee in **Kyrgyzstan** now includes NGOs and PLHIV associations that are charged with ensuring implementation of the national HIV strategy among major risk groups.

In **Latvia**, EU accession has meant withdrawal of most international funding, leaving one active NGO working in HIV/AIDS, and many unfunded requests for information and participation. Direct PLHIV representation is impractical; the country has no multisectoral coordinating body, and the National AIDS Commission (NAC) has effectively no interaction with civil society. The two NGO representatives who joined a 2008–2012 strategy development group felt their presence fulfilled a formal requirement but carried very little influence. UNAIDS and its cosponsors provided training to PLHIV groups in **Moldova** leading to the legalization of the National League of PLHIV and greater participation of PLHIV in national strategic planning. For **the Russian Federation**, see the previous subsection. In **Tajikistan**, representatives from seven NGOs participated in national strategic planning in 2006 and helped establish universal access targets. Also in 2006, **Ukraine** reinvigorated its National Coordination Council for HIV/AIDS with participation of civil society, PLHIV and donors. Broad stakeholder consultation resulted in a large Round 6 Global Fund grant (see previous subsection) and a detailed roadmap for achieving ambitious universal access targets in 2010. **Uzbekistan** has few NGOs, and the few that work with HIV/AIDS have limited technical capacity. Led by an Uzbek NGO (Hope and Life), a national PLHIV network was established in 2006 with local branches in 9 of 13 regions.

*Central Europe.* During the last three years, PLHIV in **Albania** have played a larger role in the national partnership forum, which itself became more effective. A new Global Fund grant (starting April 2007) has greatly strengthened NGOs' role. In **Romania**, a 2005 NAC reorganization reduced civil society representation to less than a third of what it was before, undermining an already weak voice in planning, decision-making and budgeting. EU accession caused most donors to withdraw funding. Global Fund grants have given the NAC more influence, but the government officials serving on it are not decision-makers. NGOs in **Serbia** have led the fight to protect the rights of risk group members. While early Global Fund grant processes encouraged collaboration between NGOs and the government, denial of Round 5 funds left the national strategy unimplemented. There was still a dearth of PLHIV groups at the end of 2005. In **Turkey**, Global Fund grants in 2005 and 2006 spurred the founding of PLHIV, MSM and transgender groups, which in January 2007 were represented in the Global Fund's country coordinating mechanism (CCM) but not the NAC.

*Western Europe.* In **Greece**, NGOs working with HIV/AIDS are not supported by the Ministry of Health. Tellingly, the lone NGO on its epidemiological monitoring body was (as of January 2006) the Greek Orthodox Church. In **Ireland**, some of the NGO respondents surveyed for a March 2006 report praised strong government financial and technical support for civil society activities in both service provision and strategy. Others felt that NGO and PLHIV representation on decision-making bodies amounted to tokenism, and that medical professionals had too much say. **The Netherlands** has an HIV/STI/sexual health forum in which civil society and PLHIV exercise strong leadership. The forum has become more effective in influencing policy and planning in the last three years but still has no voice on budgets. In **Portugal**, thematic task

forces with civil society representatives and PLHIV have been advising the National AIDS Commission since 2005, but criteria for their selection and involvement are not public. Previously, government officials developed and implemented all plans and programmes alone. In **Ireland, the Nordic countries, the Netherlands, Portugal, and the United Kingdom** trade unions combine information and education programmes for their national members with solidarity actions to support the HIV programmes of trade unions in the South.

#### *Indicators for civil society leadership*

Gauging civil society leadership on HIV/AIDS requires first assessing its activity level. Since so much NGO work is pro bono, the best measure would be simply workforce size.

**Indicator 2.1** (proposed)      How many civil society volunteers/employees work at least half-time on HIV/AIDS efforts?

A description of the legal, financial and practical knowledge climate for civil society efforts would not only indicate government support, but also help clarify key issues for reform.

**Indicator 2.2** (proposed)      How conducive are national laws to the development of a free civil society that can engage the challenges in the Declaration of Commitment? What drives or hinders such development?

**Indicator 2.3** (existing)      To what extent is civil society able to access adequate financial support to implement its HIV activities? adequate technical support to implement its HIV activities? (*new in the 2008 NCPI, B.II.6*)

The mark of effective leadership is change, and Indicator 2.4 uses it to measure the overall effectiveness of civil society advocacy, both from within (see the next section on Actions 4 and 27) and without. It would be helpful to divide it in two parts and add the follow-up “How?”

**Indicator 2.4** (existing)      To what extent has civil society contributed to strengthening the political commitment of top leaders and national policy formulation? (*2008 NCPI, B.II.1*)

For 2005, European responses (as formulated chiefly by NGOs and international agencies) averaged 7.0 on a 0–10 scale, ranging from 4 (**Russian Federation**) to 10 (**Austria**).

By signing the UNGASS and Dublin declarations, European Region countries have committed to the GIPA Principle. Officials and advocates both need to know about these commitments in order to make sure they are honoured.

**Indicator 2.5** (proposed)      How aware of national GIPA commitments are government officials working with HIV/AIDS?

**Indicator 2.6** (proposed)      How aware are HIV/AIDS NGOs of national GIPA commitments?

One way to encourage civil society to be responsible and effective in turn would be to encourage adoption the Code of Good Practice for NGOs Responding to HIV/AIDS. (For more information on the Code, see [www.ifrc.org/what/health/hiv/aids/code](http://www.ifrc.org/what/health/hiv/aids/code).)

**Indicator 2.7** (proposed)      What per cent of NGOs working with HIV/AIDS have signed the NGO Code?

**Indicator 2.8** (proposed)      What per cent of NGOs represented on the National AIDS Council have signed the NGO Code?

### *Private sector leadership*

Unlike NGOs, private sector actors are driven chiefly by market forces and the profit motive, which tend to trump social concerns. Businesses have been justly criticized for AIDS profiteering (elevated drug prices), gross discrimination (refusing life insurance to PLHIV) and inappropriate lobbying (sponsoring European Parliament lunches in connection with HIV meetings). Private sector involvement in HIV/AIDS efforts must thus not only be encouraged but managed. For firms wanting to address the epidemic, something akin to the NGO Code is strongly needed.

Again, in distinguishing between leadership based on authority, advocacy and example, it is clear that Action 2 refers to the latter two. As mentioned above, there are many ways for businesses to lead by example: customer and community outreach, HIV-related philanthropy and a wide range of workplace initiatives (see Chapter 9 for detailed coverage of workplace efforts).

As an advocate, the private sector will inevitably promote the interests of industry. Traditionally adept at lobbying governments through informal means, the private sector is increasingly being included in the defined membership of national HIV bodies. For such advocacy from within, see the next section on Actions 4 and 27. (Though these actions do not name the private sector explicitly, Action 2 and the mention of national partnership forums in Actions 4 and 27 imply a commitment to private sector participation in HIV policy- and decision-making.)

For business to advocate its interests, however, it first needs to clarify them. Yet there is a widespread lack of private sector dialogue on HIV/AIDS. A few invaluable international discussions have begun, most notably through the Global Business Coalition, which as of June 2007 had 75 members based in 16 countries of the European Region. It should be borne in mind that the private sector includes workers and their representatives as well as employers. In **Sweden**, for example, the confederations of Swedish enterprises and of trade unions have established the Labour Market Dialogue, which has included HIV/AIDS in its dialogues since 2005.

To be fruitful, however, such dialogue requires acknowledgement of HIV's pervasive – and growing – effect on business. Insofar as corporations resemble small nation-states, it similarly behoves them to “mainstream” HIV efforts in every department. Action on HIV/AIDS goes beyond corporate social responsibility, important as that is; it is also a strategic matter, with profound ramifications both internally (a firm's workforce, benefit outlay, management, operations, morale) and externally (its customer base, labour pool, community relations, need for economic stability, tax burden) – all affecting the bottom line.

National governments can help urge private sector engagement of HIV/AIDS issues, e.g. via:

- granting tax relief for HIV philanthropy, both domestic and foreign, monetary and in kind
- sponsoring forums and workshops with prominent business leaders
- helping establish a national private sector coalition to coordinate the sector response.

### *Indicators for private sector leadership*

For private sector engagement, the best marker is expenditure, just as for civil society it is human capital. Private HIV/AIDS investment is already tracked in several ways; see the 2008 UNGASS guidelines for a discussion of the National Funding Matrix and major alternatives (1). Some disaggregation (domestic vs. foreign, prevention vs treatment, etc.) would help clarify the picture.

**Indicator 2.9** (proposed)      What is the overall private sector budget for HIV/AIDS efforts as a

percentage of the gross national product (GNP)?

A telling complement to Indicator 2.9 would be the size of direct profits on HIV.

**Indicator 2.10** (proposed)      What is the overall profit on HIV/AIDS as a percentage of the GNP?

While state support of the private sector may not appear much of an issue in comparison to support for civil society, oversight of – and interference with – the private sector is both complex and universal. And where free enterprise is impeded, business responses to HIV often are too.

**Indicator 2.11** (proposed)      How conducive are national laws to the development of a vibrant private sector that can engage the challenges of the Declaration of Commitment? What drives or hinders such development?

**Indicator 2.12** (proposed)      To what extent is the private sector able to access adequate technical support to implement its HIV activities?

Corresponding to Indicator 2.4, Indicator 2.13 tracks the overall political effectiveness of private sector advocacy. See the next section on Actions 4 and 27 for more on advocacy from within.

**Indicator 2.13** (proposed)      To what extent has the private sector helped strengthen the political commitment of top leaders and national policy formulation? How?

**Dublin Action 4:** Establish and reinforce national HIV/AIDS partnership forums including meaningful participation of civil society, and particularly of people living with HIV/AIDS and their advocates, to design [initiatives], [to] review, monitor and report progress in the fight against the disease, and to take timely and determined action to identify and address barriers to implementation.”

**Dublin Action 27:** Involve civil society and faith-based organizations, as well as people living with HIV/AIDS and persons at the highest risk of and most vulnerable to HIV/AIDS infection in the development and implementation of national HIV/AIDS prevention and care strategies and financing plans, including through participation in national partnership forums.

Actions 4 and 27 describe how European Region countries can honour their pledge in Action 2 to promote HIV/AIDS leadership by civil society (and implicitly the private sector) through advocacy from within the system. The two actions complement and overlap each other somewhat confusingly, but a careful reading suggests replacing them with one simple action addressing the involvement of all major HIV/AIDS stakeholders in every aspect of the national response.

First it is necessary to define “national partnership forum”. Though in 2002 UNAIDS committed to supporting the development of these forums (6), the term rarely appears in UNAIDS literature. A 2004 leadership statement (7) defines the mechanism most succinctly:

[We p]ledge to promote the development and maintenance of national partnership forums that provide all major stakeholders, including people living with HIV, a role in ... prioritizing, planning, implementing and monitoring the national AIDS response.

“Major stakeholders” include the government, multilaterals, the civil society subsectors listed in

Action 27<sup>8</sup> and the private sector. A partnership forum can be convened by a government, a National AIDS Council or a United Nations agency (e.g. evolving from an expanded HIV/AIDS theme group). It may also overlap with the Global Fund CCM.

With the widespread adoption of the Three Ones model in the three years since the Dublin Declaration, the trend has been to give a single body (known as the national AIDS coordinating authority) broad say in every aspect of the national response, from planning to evaluation. One role often omitted from the remit of such bodies is budgeting. However, as many civil society representatives observed when consulted for this chapter, denying nongovernment actors a say in HIV financing severely limits their contributions to the national strategy.

#### *Proposed indicators for Actions 4 and 27*

Taken together, these two actions express a pledge by European Region governments to promote a national body that involves major stakeholders – including key subsectors of civil society and, implicitly, the private sector – in the full cycle of the national HIV/AIDS response. To monitor this commitment properly, an indicator is needed to describe the composition and functioning of the most important national multi-stakeholder bodies contributing to this cycle.

- Indicator 4/27.1** (proposed) Which national HIV/AIDS bodies provide major nongovernment stakeholders a substantive role in determining the national HIV/AIDS response?
- How often does each body meet? Whom does it report to?
  - How are members chosen? Does the body have a defined membership that includes representatives from civil society? PLHIV? major risk populations (and if so, which ones)? faith-based organizations? the private sector?
  - What kind of financial and technical support does the government provide for civil society participation?
  - With respect to the national HIV/AIDS response, does this body participate in strategy development? priority-setting? coordination? budgeting? implementation? monitoring and evaluation?
  - Is this body primarily an advisory body, or do its decisions have the force of official policy? Explain.
  - How could this body become more effective in improving the national HIV/AIDS response?

The third follow-up is included because governments often do not realize that support for civil society participation in national policy- and decision-making has financial and technical as well as political dimensions. Government and private sector representatives to national HIV bodies continue to draw salaries while participating; civil society representatives should also be compensated for their efforts on the public behalf, especially as these responsibilities increase.

While Indicator 4/27.1 can provide a good portrait of civil society participation in the national HIV/AIDS response, measuring effectiveness calls for a more easily quantifiable indicator.

- Indicator 4/27.2** (proposed) How significant is the role of civil society in:
- developing the national HIV/AIDS strategy?
  - drawing up the national HIV/AIDS financing plan and budget?
  - implementing the national strategy?

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<sup>8</sup> The mention of vulnerability in Action 27 perpetuates a widespread conflation of *risk groups*, which are defined by shared behaviours that increase members' risk of contracting HIV (e.g. needle-sharing), with *vulnerable populations*, which are defined by conditions in the physical or socioeconomic environment that increase vulnerability to HIV infection but lie out of an individual's control (e.g. poverty and illiteracy).

- monitoring and evaluating national strategy implementation?

*Existing indicators*

Perhaps the best measure of government progress on Actions 4 and 27 is the summary question for “Civil society participation” in the NCPI, to be filled out by nongovernment stakeholders.

**Indicator 4/27.3** (existing) Overall, how would you rate the efforts to increase *civil society participation* in 2007 and in 2005? (2008 NCPI, B.II end)

In 2006, respondents’ ratings of such efforts averaged 4.8 on a 0-to-10 scale for 2003 and 6.3 for 2005 – substantial improvement. (See the Statistical Annex.) Change ranged from –2 for **Israel** (due to controversies triggered by a new NGO leader) to + 5 for **Armenia** (due to NGO/PLHIV roles in drafting a Global Fund application and the HIV work plan and budget; NGO implementation of Global Fund money; an NGO as CCM chair; and NGO capacity-building aid).

The NCPI also tracks several elements of Indicator 4/27.1, and in the absence of such a unified, comprehensive indicator, they provide useful information on the situation to date. (A follow-up to the next question makes clear that “multisectoral” here includes nongovernment actors.)

**Indicator 4/27.4** (existing) Has the country ensured “full involvement and participation” of civil society in the development of the multisectoral strategy/action framework [to combat AIDS]? Explain. (2008 NCPI, A.I.1.8)

**Indicator 4/27.5** (existing) Does the country have an officially recognized national multisectoral AIDS management/coordination body? (2008 NCPI, A.II.2)

**Indicator 4/27.6** (existing) Does the country have a national AIDS body or other mechanism that promotes interaction between government, people living with HIV, civil society and the private sector for implementing HIV and AIDS strategies/programmes? (2008 NCPI, A.II.3)

**Indicator 4/27.7** (existing) Has the Government, through political and financial support, involved most-at-risk populations in governmental HIV-policy design and programme implementation? (2008 NCPI, B.I.6)

**Indicator 4/27.8** (existing) What percentage of the national HIV and AIDS budget was spent on activities implemented by civil society in the past year? (2008 NCPI, A.II.4)

**Indicator 4/27.9** (existing) What kind of support does the NAC (or equivalent) provide to implementing partners of the national programme, particularly to civil society organizations? (2008 NCPI, A.II.5)

**Indicator 4/27.10** (existing) To what extent are the services provided by civil society in areas of HIV prevention, treatment, care and support included in both the National Strategic plans and national reports? in the national budget (2008 NCPI, B.II.3)

**Indicator 4/27.11** (existing) To what extent have civil society representatives been involved in the planning and budgeting process for the National Strategic Plan on AIDS or for the current activity plan (e.g. attending planning meetings and reviewing drafts)? (2008 NCPI, B.II.2)

Since civil society often is more involved in developing the national strategy than in budgeting

it, the question should be split into two. Moreover, the standard for civil society involvement implied here – attending meetings and reviewing documents – falls short of specifying that civil society have a voice that is heard, much less that it exhibit the “strong leadership” of Action 2.

### **Action 32: strengthening European collaboration of civil society groups and PLHIV**

**Dublin Action 32:** Support stronger regional cooperation and networking among people living with HIV/AIDS and civil society organisations in Europe and Central Asia, and call upon the Joint United Nations Programme on HIV/AIDS in partnership with the European Union, existing civil society networks and other regional partner institutions to assist, facilitate and coordinate such collaboration.

In the first part of Action 32, European Region countries pledge to support regional cooperation and networking of PLHIV and civil society groups. Such support has been chiefly indirect, through contributions to WHO, the European Union, the Global Fund and UNAIDS. The rare instances of direct national support include British Department for International Development (DFID) grants to the International Community of Women Living with HIV/AIDS (ICW), Dutch Ministry for Foreign Affairs grants to the Global Network of People Living with HIV/AIDS (GNP+) and German sponsorship of the Bremen Partnership Forum in March 2007.

The second part of the Action is self-fulfilling: it is itself a public call for global and regional institutions to support PLHIV and civil society collaboration. It serves as a regional as well as a national commitment, implicating a secondary audience of nongovernment actors.

Despite the lack of concrete government support, the last three years has seen substantial progress in this area. Many new networks have sprung up, most notably AIDS Action Europe (AAE) and HIV Europe, while most existing ones have expanded. Numerous conferences have provided NGOs and PLHIV opportunities to learn from each other and coordinate efforts.

**Table 1. Major European networks of NGOs and PLHIV**

- AIDS & Mobility Europe ([www.aidsmobility.org](http://www.aidsmobility.org))
- AIDS Action Europe (AAE) ([www.aidsactioneurope.org](http://www.aidsactioneurope.org))
- AIDSPortal ([aidsportal.org](http://aidsportal.org))
- Eurasian European Harm Reduction Network (EHRN) ([www.ceehrn.org](http://www.ceehrn.org))
- Civil Society Forum on HIV/AIDS (European Commission)
- CONNECTIONS - “Integrated responses to drugs and infections across European criminal justice systems” (<http://www.connectionsproject.eu/>)
- Correlation Network ([www.correlation-net.org](http://www.correlation-net.org))
- East European & Central Asian Union of PLHIV Organisations (ECUO) ([www.ecuo.org](http://www.ecuo.org))
- European AIDS Treatment Group (EATG) ([www.eatg.org](http://www.eatg.org))
- European Liver Patients Association (ELPA) ([www.elpa-info.org](http://www.elpa-info.org))
- European Network for HIV/STI Prevention and Health Promotion Among Migrant Sex Workers (TAMPEP) ([tampep.com](http://tampep.com))
- GNP+ Europe ([www.gnpplus.net](http://www.gnpplus.net))
- HIV & AIDS Services Worldwide ([www.aidsmap.com/cms1038779.asp](http://www.aidsmap.com/cms1038779.asp))
- HIV Europe ([www.hiveurope.org](http://www.hiveurope.org))
- HIV/AIDS Think Tank ([ec.europa.eu/health/ph\\_threats/com/aids/aids\\_think\\_en.htm](http://ec.europa.eu/health/ph_threats/com/aids/aids_think_en.htm))
- The Integration Projects ([www.integration-projects.org](http://www.integration-projects.org))
- International Community of Women Living with HIV/AIDS (ICW) ([icw.org](http://icw.org))
- International Harm Reduction Association (IHRA) ([www.ihra.net](http://www.ihra.net))
- International Treatment Preparedness Coalition – East Europe and Central Asia (ITPCru) ([itpcru.org/en/home](http://itpcru.org/en/home))

Especially noteworthy was the Planning and Technical Consultation on Working with Civil Society to Scale up Access to HIV Prevention, Treatment and Care, held in Berlin in October 2005. The strongest external support for regional collaboration of civil society groups and PLHIV comes from international organizations that are already major supporters. For the past three years, the *WHO Regional Office for Europe* has employed a community advocate on the staff of its HIV/AIDS programme, whose many responsibilities have included organizing the Berlin technical consultation in conjunction with the European AIDS Treatment Group. The *European Commission* (EC) has instituted two important linked organizations, the Civil Society Forum on HIV/AIDS and the HIV/AIDS Think Tank (which includes observers from the Civil Society Forum), while funding key initiatives including the Integration Projects and European Partners in Action on AIDS. Finally, the *Global Fund* and *UNAIDS* incorporate such collaboration into their governing structures, in which NGO members are charged with consulting and representing European NGOs and PLHIV networks (8,9). Further, the Global Fund has a community advocate on their staff. Table 1 presents a list of European networks of NGOs and PLHIV.

### *Suggested indicators for Action 32*

The best way to evaluate the state of regional collaboration among NGOs and among PLHIV would be a regional assessment conducted with appropriate survey techniques. Measuring national support for such activities is more difficult, but several country-based indicators are possible. The best approach would concentrate on results rather than membership lists.

**Indicator 32.1** (proposed)      How well do civil society organizations addressing HIV/AIDS in your country communicate and coordinate efforts with other such organizations in the European Region?

**Indicator 32.2** (proposed)      How well do PLHIV groups in the country communicate and coordinate efforts with other PLHIV groups in the European Region?

### **Conclusion**

In the Dublin Declaration, the countries of the European Region made several strong, principled commitments to expanding the role of civil society and the private sector in the fight against HIV/AIDS, including greater say in policy- and decision-making and enhanced regional networking. Since then, the activity of both sectors has increased markedly in most countries.

However, this progress has been largely independent of any government initiative, inevitably originating where most change in the response to the HIV/AIDS epidemic originates: civil society. Its efforts to be heard and included have finally percolated up to the major international HIV/AIDS agencies and donors, which are, in fact, funded primarily by national governments. Yet the most that can be said about these governments is that they have merely acquiesced in civil society's incremental assumption of its proper role in HIV/AIDS efforts.

### **Recommendations**

1. Post UNGASS shadow reports on the UNAIDS website
2. Make UNAIDS country office data more widely available.
3. Modify Indicator 2.4 in the NCPI as stated above, and add Indicators 2.1, 2.2 and 2.5–2.8 to it.
4. Encourage governments and employers to further support the ILO *Code of Practice on HIV/AIDS and the world of work* (see Chapter 9 below).
5. Add Indicators 2.9–2.13 (see above) to the NCPI.

6. Replace Indicators 4/27.4–11 in the NCPI with Indicators 4/27.1 and 4/27.2.
7. Add Indicators 32.1 and 32.1 to Part B.II of the NCPI.

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### 3. Resource generation: eastern Europe's response to HIV

**Dublin Action 1:** Promote strong and accountable leadership at the level of our Heads of State and Government to protect our people from this threat to their future, and promote human rights and tackle stigma and ensure access to education, information and services for all those in need;

**Dublin Action 7:** Provide increased and results-based financial and technical resources to scale up access to prevention, care and sustained treatment, including effective low cost treatment such as generics, in the most affected countries with the greatest needs through national and regional allocations as well as from the Global Fund to Fight AIDS, TB and Malaria, the European Union, new public and private partnerships, multilateral and bilateral financing mechanisms;

**Dublin Action 8:** Reinvigorate our efforts to ensure the target of the Declaration of Commitment that, by 2005, at least 90 percent of young men and women aged 15 to 24 have access to the information, education, including peer education and youth-specific HIV education, and services necessary to develop the life skills required to reduce their vulnerability to HIV infection, in dialogue with young persons, parents, families, educators and health-care providers;

**Dublin Action 9:** By 2010, ensure through the scaling up of programmes that 80% of the persons at the highest risk of and most vulnerable to HIV/AIDS are covered by a wide range of prevention programmes providing access to information, services and prevention commodities and identifying and addressing factors that make these groups and communities particularly vulnerable to HIV infection and promote and protect their health, and intensify cross border, sub-regional and regional technical collaboration and sharing of best practices through the EU and regional organisations in the prevention of HIV transmission among vulnerable groups;

**Dublin Action 13:** Ensure men, women and adolescents to have universal and equitable access to and promote the use of a comprehensive range of high quality, safe, accessible, affordable and reliable reproductive and sexual health care services, supplies and information including access to preventive methods such as male and female condoms, voluntary testing, counseling and follow-up;

**Dublin Action 17:** Fund, improve, and harmonise surveillance systems, in line with international standards, to track and monitor the epidemic, risk behaviours and vulnerability to HIV/AIDS;

**Dublin Action 29:** Involve the national and international pharmaceutical industry in a public-private partnership including with relevant international organisations such as the World Health Organisation in helping to tackle the epidemic along all points of the drug supply chain – from manufacturing to pricing to distribution;

#### Introduction

According to UNAIDS, an estimated 1.5 [1.0–2.3] million people were living with HIV in the 12 members of the Commonwealth of Independent States (CIS) and the three Baltic countries<sup>9</sup> at the end of 2005, and new infections have increased twenty-fold in less than a decade (1) It is estimated that 220 000 people became infected with HIV in 2005. Eastern Europe and central Asia were estimated to have the fastest-growing HIV epidemics in the world, driven in large part by injecting drug use.

The Dublin Declaration (2) reaffirms the commitment to act collectively to tackle the HIV/AIDS epidemic, and this chapter focuses on the financial resources dedicated to HIV and AIDS-related activities in eastern Europe to achieve the goals of the Declaration. While there has been a steep increase in the financial resources available for HIV/AIDS-related activities in the region, both

<sup>9</sup> Namely: Armenia, Azerbaijan, Belarus, Estonia, Georgia, Kazakhstan, Kyrgyzstan, Latvia, Lithuania, the Republic of Moldova, the Russian Federation, Tajikistan, Turkmenistan, Ukraine and Uzbekistan.

from domestic and international sources, a funding gap remains between the resources available and those needed.

### **Global flows from donor countries and assistance agencies including bilateral and multilateral funding channels**

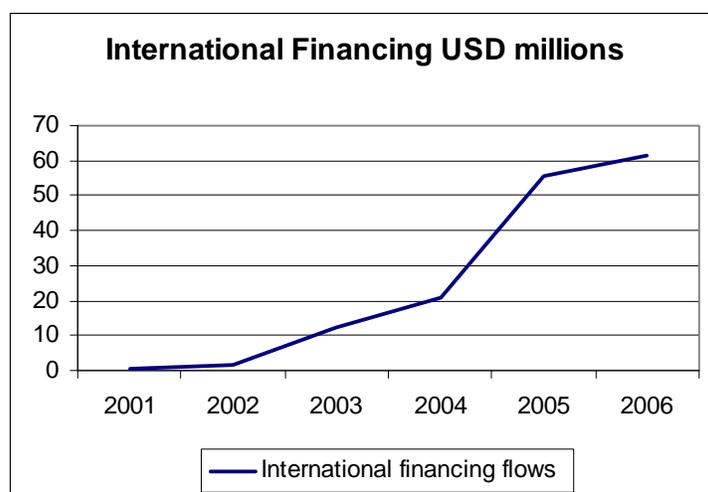
International financing flows from donors to 11 eastern European countries (**Armenia, Azerbaijan, Belarus, Georgia, Kazakhstan, Kyrgyzstan, Moldova, Tajikistan, Turkmenistan, Ukraine and Uzbekistan**) have been calculated using the Official Development Assistance statistics of the Organization for Economic Cooperation and Development (OECD) and the Development Assistance Committee (DAC) Creditor Reporting System (CRS). They include disbursements from donors using either bilateral or multilateral channels.

The three Baltic states (**Estonia, Latvia and Lithuania**) are excluded, because the level of their Gross National Input (GNI) means they are not eligible for Official Development Assistance and they are not included in the OECD/DAC/CRS database. Likewise, **the Russian Federation** does not qualify for Official Development Assistance, so the amount of international aid it received in 2004 is reported as estimated in the 2004 national AIDS spending assessment. A separate section below will describe the recent trends in the financing of AIDS activities in **the Russian Federation** using direct reports.

In 2001, less than US\$ 0.5 million were disbursed from international donors to CIS countries. The region received and spent more than US\$ 55 million in 2005, so, if trends continued, the estimated disbursement in 2006 would be US\$ 60 million.

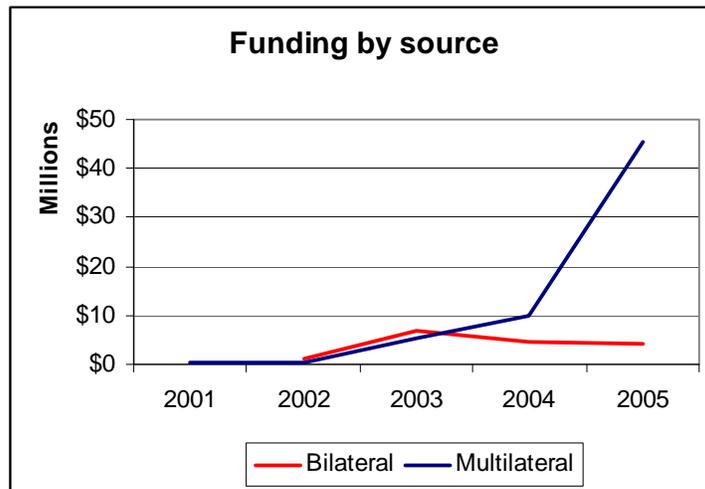
Funding to the region from donor countries increased slowly up to 2003 then nearly doubled from 2003 to 2004, from about US\$ 12 million to around US\$ 21 million. Figure 3.1 shows a sharp increase in growth since the middle of 2004. This coincides with the Dublin Declaration, signed in February 2004, which aimed at putting more focus on the HIV epidemic in the region.

**Fig 3.1. International financing flows for HIV/AIDS-related activities in 12 countries of the Commonwealth of Independent States, 2001–2006**



The greatest share of funding comes from multilateral sources, and this trend seems to be increasing (see Fig. 3.2). According to the OECD online database (3), the Global Fund to Fight Aids, Tuberculosis and Malaria (GFATM) is the largest channel of foreign aid to the region, followed by **the United States** and **the United Kingdom**.

Fig 3.2. International financing to 10 countries of the Commonwealth of Independent States for HIV/AIDS-related activities, by source



### Domestic public expenditures

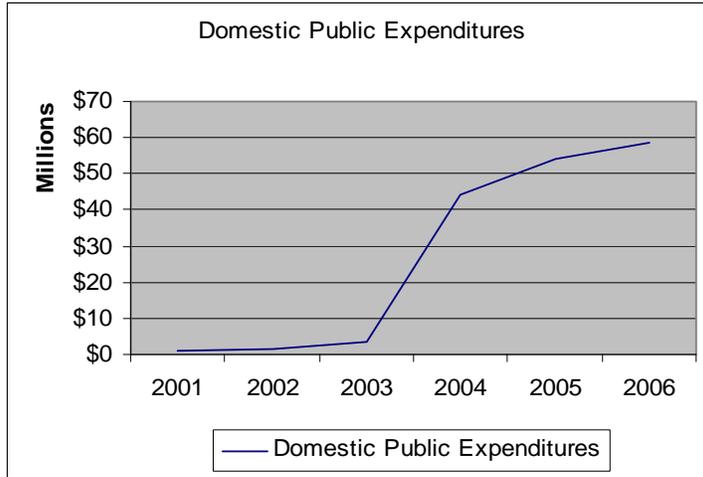
The Dublin Declaration also aimed to increase countries' own funds to respond to the HIV/AIDS epidemic. Government expenditures from domestic public funds were estimated in 11 countries (**Armenia, Belarus, Georgia, Kazakhstan, Kyrgyzstan, Latvia, Moldova, the Russian Federation, Tajikistan, Ukraine and Uzbekistan**),<sup>10</sup> using the reports to monitor the Declaration of Commitment submitted to the United Nations General Assembly Special Session (UNGASS), national AIDS spending assessments and statistical projections based on global resource flows. These countries' HIV/AIDS-related expenditures were approximately US\$ 30 million in 2003 and doubled to almost US\$ 60 million in 2006 (Figure 3.3).

**The Russian Federation** accounts for over 60% of the domestic public expenditures related to HIV and AIDS in the region (Figure 3.4). This might be a direct cause of **the Russian Federation** being the richest and most populated country. When adjusting for population size, **Belarus** spends the most – about 80 cents – per inhabitant (Figure 3.5).

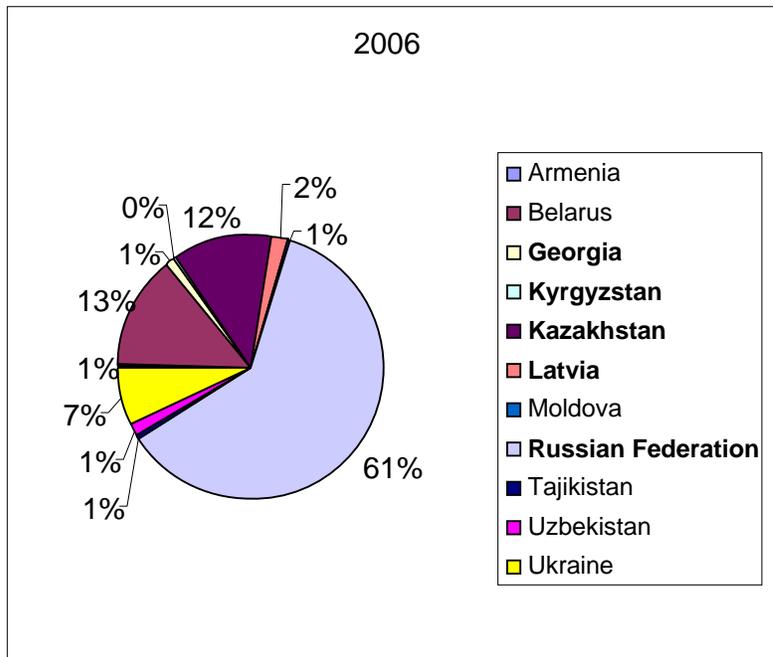
There are significant spending variations in the region. Some countries, such as **Kyrgyzstan** and **Tajikistan**, spend only half a cent per capita on HIV and AIDS, and none of the countries have reached US\$ 1 per capita in HIV/AIDS expenditures using domestic public funds.

<sup>10</sup> Information on domestic public expenditure was not available for **Azerbaijan, Estonia, Lithuania** or **Turkmenistan**. When three or more data points were available and it was necessary to extrapolate for one year ahead, linear extrapolation (least squares) was used (n=3). In two instances the most recent available figure was used.

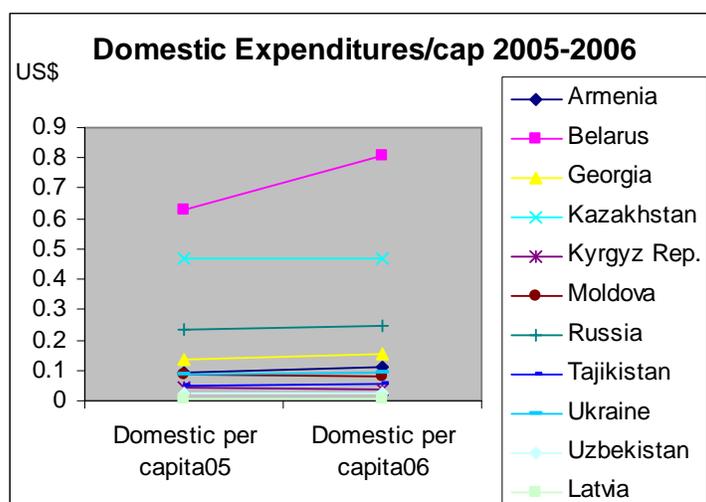
**Fig 3.3. Domestic public expenditures related to HIV and AIDS in the Commonwealth of Independent States and Latvia**



**Fig 3.4. Domestic public expenditures for HIV and AIDS as a proportion of the total in 10 countries of the Commonwealth of Independent States and Latvia, 2006**



**Fig 3.5. Per capita domestic public expenditures for HIV and AIDS in 10 countries of the Commonwealth of Independent States and Latvia, 2005–2006**



### **Boost in public funding for HIV and AIDS in the Russian Federation**

Expenditures for the response to HIV and AIDS have increased dramatically in **the Russian Federation**. On the eve of the St Petersburg G8 summit in July 2006, President Vladimir Putin announced pledges of Rub 3.1 billion (approx. US\$ 121 million) in domestic resources to combat the epidemic(4). A substantial portion of these funds were allocated for the implementation of the AIDS component of the Health National Priority Project. In addition, there were plans to mobilize almost Rub 400 million through regional budgets, increasing public expenditures for HIV and AIDS in 2006 to a total of US\$ 136 million (5). Domestic funding has increased even further in 2007. At the federal level, Rub 8.15 billion (approx. US\$ 318 million) have been allocated to HIV prevention, treatment and care programmes (5).

In addition to this dramatic increase in domestic spending on HIV and AIDS, **the Russian Federation** doubled its pledge to the GFATM to US\$ 40 million. It also announced that it will reimburse US\$ 270 million in aid received from the GFATM for HIV prevention and treatment programmes between now and 2010 (6). Furthermore, in July 2007, **the Russian Federation's** chief doctor announced the government's plans to allocate Rub 1.4 billion (approx. US\$ 54 million) to develop a vaccine for HIV (7).

While these funding increases have allowed scaling up access to antiretroviral treatment for people living with HIV and have improved the quality of medical and laboratory services, there is a strong need to ensure efficient planning, procurement and funds management at the regional and federal levels. In addition, substantial inefficiencies have been observed in the allocation of funds; programmes related to HIV testing and treatment have benefited most (Rub 2.9 billion in 2006), while prevention programmes and interventions targeting the country's considerable most-at-risk populations have been seriously underfunded (only Rub 200 million in 2006) (8). Numerous experts have expressed concern about these imbalances, but so far no funds have been reallocated.

Federal-level funding is expected to increase further until 2009, the final year of the National Priority Project. As this funding source dries out, the 'Anti HIV/AIDS' Federal Sub-programme is expected to receive a boost in funding in 2010 and 2011 to partly bridge the funding gap. However, if current planning holds, public expenditures to combat the epidemic will drop sharply after 2009, and it is unlikely that international funding will be made available to **the**

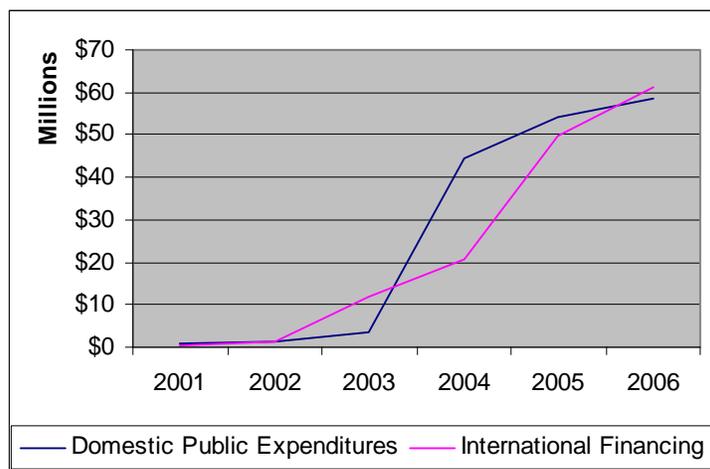
**Russian Federation** to cover the shortage. **The Russian Federation's** recent classification as an upper-middle-income country by the World Bank means that the nation is no longer eligible for multilateral assistance for HIV/AIDS, including new grants from the GFATM (9).

#### **Total financing flows: domestic public and international sources**

Ten countries had information available on both sources, so total financing flows were estimated by adding the international financing to the domestic public expenditure for **Armenia, Belarus, Georgia, Kazakhstan, Kyrgyzstan, Moldova, the Russian Federation, Tajikistan, Ukraine and Uzbekistan** (Figure 3.6).

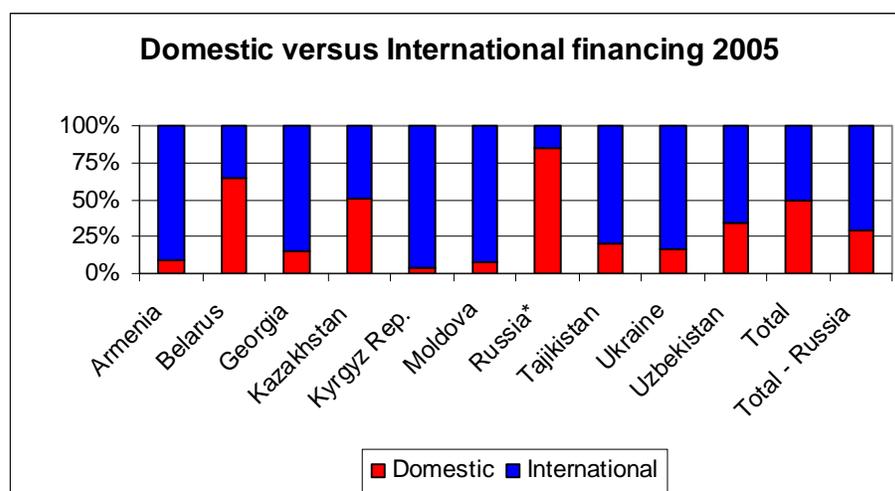
The findings suggest that there has been a trend of growth in both domestic public expenditures and international financing for HIV and AIDS-related activities. However, the rate of growth seems to have slowed down (Figure 3.7). The findings suggest that there has been a stronger commitment from the national governments since 2003, followed by an increase in donor financing soon after the Dublin Declaration was signed.

**Fig 3.6. Trends in public and international financing among 10 countries of the Commonwealth of Independent States**



In 2004, the countries in the region invested more of their own resources (domestic public sources) than they received from international sources; in 2006, there was an even split between domestic and international sources. However, the main driver for this regional average is the composition of **the Russian Federation's** financial resources for HIV/AIDS: taking **the Russian Federation** out of the regional figures for 2006 reduces the domestic public expenditures to around 28% of the total.

Fig 3.7. **Composition of the financing of HIV/AIDS-related activities, domestic public compared to international flows, 2005**



### Estimates of out-of-pocket expenditure for HIV and AIDS

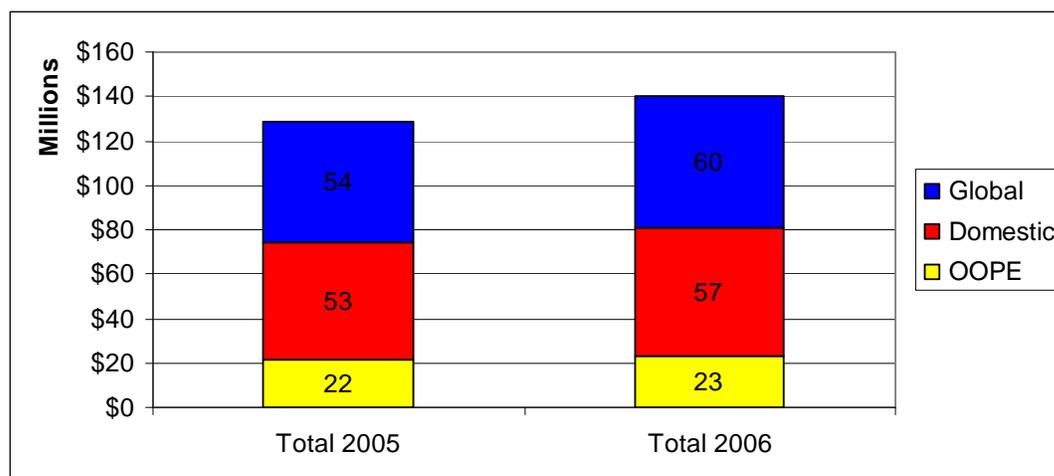
Any assessment of the total resources spent on HIV/AIDS-related activities in the region should include out-of-pocket expenditures (OOPE). Since OOPE data are scarce, we need to rely on estimates. To compute OOPE it is assumed that health spending on HIV/AIDS-related activities is in line with health spending in general. Using the proportion of OOPE reported by the National Health Accounts estimated by the World Health Organization (WHO), the OOPE ratios in relation to government expenditures were estimated (Figure 3.8).

Fig 3.8. **Estimated ratios for out-of-pocket expenditures to government expenditures on HIV and AIDS in 10 countries of the Commonwealth of Independent States**

<i>Region</i>	<i>Ratio OOPE/government expenditures</i>
Western Asia and central Asia (6 countries)	0.614
Eastern and southern Europe (4 countries)	0.362

The United Nations ‘Composition of macro geographical sub-regions’ was used to define which ratios to use (10), hence the selection of four eastern European countries, two western Asian countries, and four central Asian countries. The estimate for OOPE for the region as a whole thus reached more than 40% of government expenditure. Should this estimate hold true, the total estimate for the region in 2005 could be about US\$ 130 million – and up to US\$ 140 million in 2006, if the same growth rate for government and donor expenditure is assumed for OOPE (Figure 3.9). Given that OOPE is regressive, i.e. the poor pay more of their income than wealthy, the high level in the region is of great concern.

**Fig 3.9. Total resources available for HIV and AIDS from all sources: government, households and international sources, in 10 countries of the Commonwealth of Independent States**



### Resource needs estimates

According to UNAIDS, estimates developed in 2005 on global resource requirements amounted to approximately US\$ 55 billion from 2006 to 2008, based on country estimations using globally set targets and coverage of services, and using a regional average of unit service costs. This sum included funds for prevention, treatment and care, support for orphans and vulnerable children,<sup>11</sup> as well as programme and human resource costs (11). The estimated needs of the 12 CIS and three Baltic countries were part of this analysis.

The figures for total HIV/AIDS resource needs from 2006 to 2008 indicated that resource requirements for the 12 CIS and three Baltic countries amounted to nearly US\$ 1 billion in 2006 (Figure 3.10), US\$ 1.2 billion in 2007 and US\$ 1.5 billion in 2008 for prevention, treatment and care, social mitigation for orphans and other vulnerable children, and programme support costs.

**Fig 3.10. Total HIV/AIDS resource needs in 15 countries in 2006 using globally set targets**

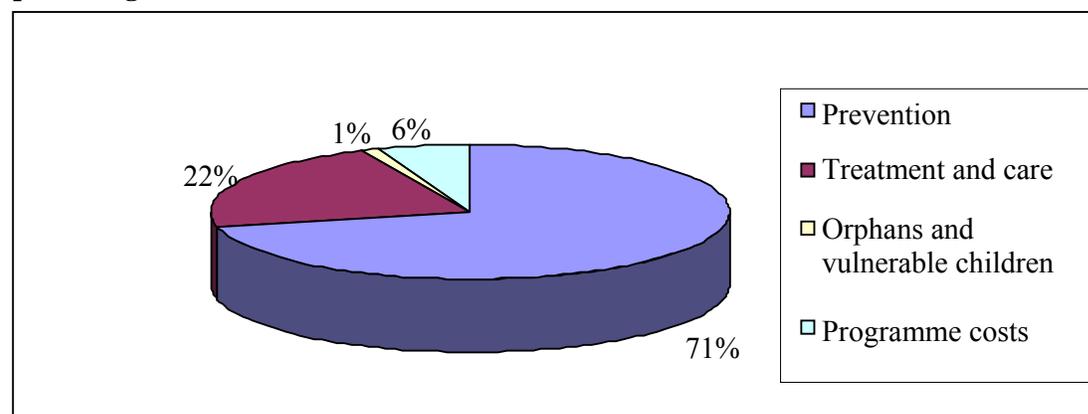
US\$ (in millions)	2006
<b>Prevention</b>	755
<b>Treatment and care</b>	150
<b>Orphans and vulnerable children</b>	8
<b>Programme costs</b>	78
<b>Total</b>	<b>991</b>

Fig 3.11. (below) shows that more than 71% of the resource needs estimates are allocated to prevention methods, 22% to treatment and care, whereas support for orphans and vulnerable children and programme costs are less significant. Globally only 54% of resource needs are allocated to prevention methods but around 12% to orphans and vulnerable children, which leads

<sup>11</sup> Support for orphans and vulnerable children includes education, health care support, family/home support, community support and administrative costs.

to the conclusion that orphans and vulnerable children are regarded as less significant within the region than they are globally.

**Fig 3.11. HIV/AIDS resource needs in 15 countries from 2006 to 2008 by type, as a percentage of the total**



As stated in the UNAIDS report, there appears to be a funding gap between resources available and those needed of at least US\$ 18 billion globally from 2005 to 2007. This is likely to be a significant underestimate and seems to be equally true for the 12 CIS and three Baltic states. A gap between the resource needs estimates and available funding seems to be unavoidable in this region.

### **Conclusion and recommendations**

There has been a steep increase in the financial resources available for HIV/AIDS-related activities in the region, both from domestic and international sources. However, there are significant differences between countries in the level of these financial resources and their origin.

While the needs in the region have been estimated using globally set targets to determine the potential need for a comprehensive response to HIV, these estimates need to be further aligned with country targets using strategic and operational plans owned and developed in-country. When compared to the available resources for HIV, the estimates show an increasing gap between needs and availability. Unfortunately, with the information currently available, it is impossible to compare in-country use of resources, by activity, with estimated needs.

There is, therefore, a need to further develop measures to determine the financial requirements in the immediate future and to compare these with actual expenditures in each country. Such a comparison will only be possible by conducting national and sub-national AIDS spending assessments. Spending assessments permit the analysis of past expenditure by defining the financial agents involved (e.g. financial sources and financing agents) and a detailed description of the use of resources (provision of services according to the function or activities developed and the beneficiaries reached).

If every country is able to develop, in a comparable fashion, estimates of financial needs and methods of fulfilling those needs, policy-makers will be able to use this kind of strategic information in the planning cycle. They will be able to establish a credible and costed operational plan (e.g. using the resource needs model available for global, regional and country estimation of financial needs) and to use a monitoring tool to track implementation, such as national AIDS spending assessments.

Each country will thus need to analyse its response to its own epidemic and apply the best available guidelines to determine the most appropriate set of actions. For example, to provide comprehensive, yet adequate, preventive services, the use of UNAIDS prevention guidelines (12) might be recommended. For the provision of treatment, care and support, WHO guidelines to start antiretroviral treatment and related care may be most appropriate (13). Alternatively, countries may have or be in the process of developing their own respective normative guidelines.

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## 4. Injecting drug use and HIV

**Dublin Action 9:** By 2010, ensure through the scaling up of programmes that 80% of the persons at the highest risk of and most vulnerable to HIV/AIDS are covered by a wide range of prevention programmes providing access to information, services and prevention commodities and identifying and addressing factors that make these groups and communities particularly vulnerable to HIV infection and promote and protect their health, and intensify cross border, sub-regional and regional technical collaboration and sharing of best practices through the EU and regional organisations in the prevention of HIV transmission among vulnerable groups.

**Dublin Action 10:** Scale up access for injecting drug users to prevention, drug dependence treatment and harm reduction services through promoting, enabling and strengthening the widespread introduction of prevention, drug dependence treatment and harm reduction programmes (e.g. needle and syringe programmes, bleach and condom distribution, voluntary HIV counselling and testing, substitution drug therapy, STI diagnosis and treatment) in line with national policies.

**Dublin Action 21:** By 2005, provide universal access to effective, affordable and equitable prevention, treatment and care including safe anti-retroviral treatment to people living with HIV/AIDS in the countries in our region where access to such treatment is currently less than universal, including through the technical support of the UN through the global initiative led by the World Health Organization and UNAIDS to ensure 3 million people globally are on anti-retroviral treatment by 2005 (“3 by 5”). The goal of providing effective anti-retroviral treatment must be conducted in a poverty-focused manner, equitable, and to those people who are at the highest risk of and most vulnerable to HIV/AIDS.

**Dublin Action 33:** We commit ourselves to closely monitor and evaluate the implementation of the actions outlined in this Declaration, along with those of the Declaration of Commitment of the United Nations General Assembly Session on HIV/AIDS, and call upon the European Union and other relevant regional institutions and organisations, in partnership with the Joint United Nations Programme on HIV/AIDS, to establish adequate forums and mechanisms including the involvement of civil society and people living with HIV/AIDS to assess progress at regional level every second year, beginning in 2006.

### Background

Declarations on HIV/AIDS are sometimes overly cautious, particularly with regard to injecting drug use. This caution is, in part, because of reluctance in some countries to embrace evidence-based interventions targeting drug users that have been proven to reduce sexual and injecting risk behaviours. This reluctance results, not from a public health perspective and a careful consideration of the evidence, but from a conservative position that believes such approaches will undermine drug control and abstinence-based approaches to treating and preventing drug dependence (1,2); it remains rooted in an outdated paradigm based on opinions, instinct and prejudice (3).

This reluctance to adopt a public health approach to HIV/AIDS, drug use and drug users is far more apparent in the eastern part of the WHO European Region than in the other parts. In many countries in eastern Europe and central Asia, outdated, unresponsive and centralized systems have been slow to cope with HIV/AIDS, and population-based approaches, such as mass screening, have been favoured over targeted interventions for the most vulnerable, namely injecting drug users (IDUs). In these countries, vertical programming continues to dominate, with little or no integration of HIV/AIDS and drug-dependence services. Old attitudes and views prevail, with a rigid demarcation of responsibilities (3) that are at best unsupportive of evidence-based interventions for IDUs.

Many countries in western Europe have made important progress towards preventing and reducing the health-related harms associated with drug use. On 18 June 2003, predating the Dublin Declaration, the Council of Europe adopted a Recommendation on the “prevention and

reduction of health-related harm associated with drug dependence”. The aim of the Recommendation is to reduce the number of drug-related deaths and drug-related health damage, such as HIV, hepatitis B and C and tuberculosis, by encouraging Member States to set up and develop responses and strategies to prevent and reduce drug-related harm through harm-reduction services and facilities. This was reiterated in the European Union (EU) Drugs Strategy 2005–2012, the EU Drugs Action Plan 2005–2008 and a 2007 report from the European Commission to the European Parliament and the Council of Europe on the implementation of the 2003 Council Recommendation, which concluded that work on drug demand reduction (including harm reduction) should be linked to HIV/AIDS prevention in the EU and neighbouring countries.

This political commitment is reflected in most countries of the EU, where all Member States have public health policies in place to prevent drug-related harm; most have needle and syringe programmes, drug-dependence treatment (including access to methadone, increasingly buprenorphine and a range of drug-free treatment options), a variety of information, education and communication programmes and screening, treatment and vaccination for drug-related infectious diseases (4,5,6). In addition to the shared objective of preventing and reducing the individual and collective harms resulting from drug use, EU Member States have commonly adopted a “comprehensive approach” that links reducing drug supply with reducing drug demand and harms (4).

Transmission of HIV among IDUs in *most* EU countries is relatively low. Evidence suggests that while a reduction in levels of injecting drug use in some countries has played an important role, low transmission is almost certainly related to the increased availability of prevention, treatment and harm-reduction measures, including opioid substitution therapy (OST) and needle and syringe exchange programmes (NSPs), which are discussed below. Many older EU Member States, including those with large IDU populations such as **the United Kingdom** (7), never experienced serious HIV epidemics among IDUs. Other western European countries that were slower to embrace harm-reduction approaches, such as **France, Italy and Spain**, experienced severe IDU-related HIV epidemics that were later brought under control by harm-reduction measures (1). However, in several EU countries and regions, HIV transmission among IDUs still continues at relatively high rates, and in some, local and national HIV prevalence among IDUs continues to increase, emphasizing the need for continued efforts to increase access and improve the coverage and quality of interventions. **Portugal** is the western European country with the highest incidence of IDU-related AIDS and, unlike other countries in the region, AIDS did not decline between 1997 and 2002, suggesting poor access to highly active antiretroviral therapy (HAART) (4).

While political commitment to HIV/AIDS is increasingly apparent at the international level (see Chapter 1), and civil society has made progress in mobilizing social action to raise the visibility of the HIV/AIDS epidemic, IDUs are often invisible in HIV/AIDS declarations or obscured among such euphemisms as “especially vulnerable” or “most-at-risk” populations. “Most-at-risk” populations can include IDUs as just one population among many. Sometimes young people and women are included in this definition, hiding the fact that in many parts of Europe IDUs represent the overwhelming majority of reported HIV cases and are by far the most “at-risk” population. This is particularly true of countries in **eastern Europe and central Asia**, where injecting drug use is driving HIV epidemics. Relegating IDUs to just another most-at-risk population has serious consequences for how HIV epidemics are perceived and tackled. UNAIDS, in its 2006 report on the global AIDS epidemic, stated that IDUs are one of four key populations that are especially at risk of HIV/AIDS and, paradoxically, the most neglected in terms of prevention and treatment.

In most countries [IDUs] have a higher prevalence of HIV infection than that of the general population because: (i) they engage in behaviours that put them at higher risk of becoming infected and (ii) they are among the most marginalised and discriminated against populations in society. At the same time, the resources devoted to HIV prevention treatment and care for these populations are not proportional to the HIV prevalence – a serious mismanagement of resources and a failure to respect fundamental human rights. (8)

There has been some progress in the United Nations at recognizing the centrality of drug injectors, harm reduction and drug-dependence treatment in relation to HIV/AIDS prevention. Predating Dublin, in 2001, its General Assembly set targets for countries to make available “harm reduction efforts related to drug use” by 2005 (9). In 2003, the 192 WHO Member States endorsed the Global Health Sector Strategy for HIV/AIDS, which includes harm reduction as a core component of a health sector response to HIV (10). In 2005, following Dublin, UNAIDS included harm reduction as one of 11 essential programmatic actions for HIV prevention (11). Most recently in 2008, the Executive Director of the United Nations Office on Drugs and Crime (UNODC) commented in the preface to a landmark discussion paper:

Harm reduction is often made an unnecessarily controversial issue as if there was a contradiction between prevention and treatment on one hand and reducing the adverse health and social consequences of drug use on the other. This is a false dichotomy. They are complementary.” (12)

The 2004 Dublin Declaration on Partnership to Fight HIV/AIDS in Europe and Central Asia was notable in that it explicitly called for action with regard to IDUs and, unusually for an international declaration, specifically mentioned drug-dependence treatment and harm-reduction programmes. Bold reference to scaling up access to needle and syringe programmes and substitution drug therapy was made (see Action 10). In addition to this daring call for specific action related to IDUs, the Dublin Declaration also agreed an ambitious, albeit generic and poorly defined, target for prevention programmes to cover 80% of “persons at the highest risk of and most vulnerable to HIV/AIDS” by 2010 (see Action 9). Vitaly, the Declaration commits governments to specific and time-bound deliverables.

The Dublin Declaration also indirectly supported increased access to ART for IDUs, by calling for “universal access to effective, affordable and equitable prevention, treatment and care including safe anti-retroviral treatment” to those people “who are at the highest risk of and most vulnerable to HIV/AIDS” (see Action 21). The Declaration thus set the scene and provided legitimization for scaling up drug-dependence treatment and harm-reduction programmes, for increasing access to HIV/AIDS treatment and for measuring progress on both these (and other) actions (see Action 33).

### **Monitoring and Evaluating Progress**

In the four years since the Dublin Declaration, measuring progress on its implementation has been frustrated by the lack of a framework, indicators and agreed targets for interventions specifically targeting drug users<sup>12</sup>. Major progress in this regard has recently been achieved with the development of a WHO/UNODC/UNAIDS *Technical Guide for Countries to Set Targets for Universal Access to HIV Prevention, Treatment and Care for Injecting Drug Users* (13,14) and

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<sup>12</sup> Generic targets, for example the Millennium Development Goal to halt and begin to reverse the spread of HIV/AIDS, with typical indicators used to assess progress – including HIV prevalence among pregnant women aged 15–24, condom use rates, and the number of children orphaned by HIV/AIDS – are of limited relevance in Europe, due to the low number of AIDS orphans, the fact that most people living with HIV are over the age of 24 and that prevalence among pregnant women is an insensitive indicator in epidemics mainly concentrated among male IDUs.

related technical consultations.<sup>13</sup> This document provides technical guidance to countries on setting ambitious but achievable national targets<sup>14</sup> for scaling up towards universal access to HIV/AIDS prevention, treatment and care for IDUs. Although primarily a tool for measuring access to HIV/AIDS prevention, treatment and care for IDUs, it may also be useful for setting targets for HIV interventions for problematic drug users who do not inject yet but who are at risk of doing so.

The Technical Guide was developed as a collaboration between UNAIDS, UNODC, WHO and national and international experts. It builds on previous UNAIDS guidelines and adheres to the principles therein<sup>15</sup>. It serves to provide more consistent methods of measuring and comparing countries' progress towards universal access and includes:

- a framework and process to set national targets for two specific time points: 2008 and 2010 (but can be applied to other time points);
- a comprehensive package of core interventions for IDUs;
- a set of indicators and indicative targets to be used to set programmatic objectives and monitor and evaluate HIV interventions for IDUs;
- examples of data sources; and
- examples of indicators and indicative targets.

The Technical Guide describes a comprehensive package for prevention, treatment and care of HIV in IDUs and includes the following nine interventions targeted specifically at them:

- needle and syringe programmes;
- opioid substitution therapy;
- voluntary HIV counselling and testing;
- antiretroviral therapy;
- prevention of sexually transmitted infections;
- condom programming for IDUs and partners;
- targeted information, education and communication for IDUs and their sexual partners;
- HBV/HAV vaccination, and diagnosis and treatment of Hepatitis B and C; and
- diagnosis and treatment of tuberculosis.

It also provides a set of indicators and indicative targets, for each of the nine interventions, suitable for measuring progress in implementing the Dublin Declaration with regard to IDUs. An important criticism of efforts to set targets for universal access has been the narrow focus solely on coverage, which neglects other important aspects of access, namely the availability and quality of interventions. The improved technical guidance proposes three access indicators, derived from country experiences, to measure access for each intervention by its availability, coverage and quality.

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<sup>13</sup> In **Lithuania (Estonia, Latvia and Lithuania (15))** (Vilnius, February 2007) and **Uzbekistan (Azerbaijan, Kazakhstan, Kyrgyzstan, Tajikistan, Turkmenistan and Uzbekistan)** (Tashkent, May 2007). A third consultation will take place in Barcelona, **Spain**, in May 2008.

<sup>14</sup> Although primarily for national target setting this Guide will also be useful for setting targets for regions in large countries (for example oblasts in the **Russian Federation**) and for smaller geographical areas such as cities.

<sup>15</sup> United Nations. *Towards universal access: assessment by the Joint United Nations Programme on HIV/AIDS on scaling up HIV prevention, treatment, care and support*. United Nations General Assembly document A/60/37, March 2006. New York, United Nations, 2006.

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**Availability** – Indicators of availability measure whether an intervention is available and accessible to the IDU population. Simple measures of the presence/absence of an intervention are combined with indicators of accessibility for the target population (e.g. are there waiting lists, are services based on low-threshold and outreach principles? etc). These simple measures can be supplemented by a measure of the extent of that availability (e.g. number of NSP sites per 1000 IDUs).

**Coverage** – Although the term has been used to describe different aspects of the reach and effectiveness of interventions, and there are many challenges to be considered when attempting to define coverage indicators (16,17,18), in this case “coverage” describes the proportion of the target population (IDUs) in need of an intervention that is reached by that intervention. Indicators of coverage measure the extent to which an intervention is delivered to an IDU population. Simple coverage indicators are used, including the estimated proportion of all IDUs regularly reached by NSPs and the estimated proportion of opioid-using IDUs on OST.

**Quality** – This describes the scope, completeness, effectiveness, efficiency and safety of interventions. A full quality assessment may be complex; however, here we propose relatively simple measures of whether quality standards are achieved (i.e. whether an intervention meets a defined standard). For example, it can be relatively simple to check whether a needle exchange programme provides only one-for-one exchange or distributes syringes according to need, whether information is provided on safe injecting practices, if referral is given to other services, etc. The quality standard can be set by UNODC/WHO/UNAIDS or national guidelines, and a simple measure of whether these guidelines are adhered to may suffice. Examples of guidelines include: WHO Regional Office for Europe (2008) *Clinical Protocol on HIV/AIDS Treatment and Care for Injecting Drug Users* (19) and WHO (2008) *Guidelines for the Psychosocially Assisted Pharmacological Treatment of Opioid Dependence* (20).

Quality standards for drug-dependence treatment (including OST) have recently been reviewed in a number of European countries, including **Denmark, Germany and the United Kingdom**. National clinical guidelines and protocols are being prepared or revised in **Denmark, Hungary, Ireland, Norway, Portugal and the United Kingdom** (4). An OST client-monitoring system is in place in 17 EU Member States. In central and eastern Europe, OST programmes have been evaluated by WHO and partners in a number of countries, including **Albania, Estonia, Kyrgyzstan, Moldova and Ukraine**. In Ukraine, WHO is working with the Chief Narcologist to revise the methodological guidelines for methadone substitution therapy. Drug-dependence services in some eastern European and central Asian countries are typically overly restrictive, with unnecessary regulations that prevent access and scale-up. In-patient treatment in residential facilities is common in eastern Europe and central Asia but much less so in western European countries, where the majority of opioid users are treated as out-patients. In western Europe the co-location of treatment and medical care, including psychiatric treatment, HAART and other HIV/AIDS treatment and the treatment of liver disease, has become more common, as has the use of OST to stabilize clients.

**Impact** – The best impact data are HIV incidence data (i.e. the desired impact being a reduction in new infections), but they are generally difficult (often impossible) to collect. Prevalence data take time to reveal changes, but model projections suggest that interventions that reduce injecting frequency and sharing will also reduce HIV transmission. Some simple, readily obtainable “proxy” measures of true impact (e.g. reductions in number of reported HIV cases in the injecting drug use transmission category, and reductions in self-reported frequency of syringe sharing) are used. Simple measures of potential impact are proposed (e.g. for NSP and OST: reduction in frequency of injecting and/or syringe sharing, measured as the percentage of IDUs who report not having used non-sterile injecting equipment in the last month).

**Progress** – Preliminary data from programmes applying the technical guidance, mainly from two UNODC/WHO technical consultations held in **Lithuania** (15) (for **Estonia, Latvia, Lithuania** and **Poland**) and central Asia (for **Azerbaijan, Kazakhstan, Kyrgyzstan, Tajikistan, Turkmenistan** and **Uzbekistan**) are presented to illustrate what progress has been made on scaling up access to prevention and treatment for IDUs. We have also applied some of the indicators to other country data to provide indicative results for three key interventions: needle and syringe programmes, opioid substitution therapy and antiretroviral therapy for IDUs. Data collection for the other interventions is ongoing.

The WHO European Region includes countries that have fully embraced a public health response to HIV and injecting drug use, mostly in the west,<sup>16</sup> and those that remain the staunchest opponents of such approaches are mostly in the east, (most notably **the Russian Federation**). In most western European countries, there is remarkable consensus on an effective public health response for the prevention and reduction of health-related harms associated with drug dependence. In all EU Member States, including those in the central and eastern parts of the WHO European Region<sup>17</sup>, the prevention and reduction of drug-related harm is a defined public health objective at the national level. All EU Member States have established harm-reduction services and facilities to varying degrees (21), and, importantly, they all have policies to promote integration between health services and specialized harm-reduction services. Such integration is far less common in eastern Europe.

### **Needle and syringe programmes**

Needle and syringe programmes (NSPs) have been identified as a priority measure for addressing the spread of infectious disease among IDUs in three-quarters of EU countries (4) and are available in all EU Member States including, since 2007, **Cyprus**. The Swedish Parliament passed a new law in April 2006 enabling regional health authorities to provide needle exchange facilities. However, **Sweden** still only has two “pilot” syringe exchange programmes. It is notable that NSPs are no longer controversial in most EU countries. However, in prisons, NSPs are only available in a few countries, including **Germany, Luxembourg** and **Spain**. It should be noted that where prisoners are unable to access NSPs (in the majority of EU countries) access cannot be described as “universal”.

A simple measure of the availability of NSPs in western European countries – the number of programmes per 1000 estimated IDUs – is summarized in Table 1. With the exception of **Cyprus** (where NSPs have not been established), **Greece** (where NSPs are uncommon and only established in four sites), **Norway** (with only six sites) and **Sweden** (with only two pilot sites), there is more than one NSP site per 1000 drug injectors in all western European countries. In Austria, with relatively few fixed-site needle and syringe exchange programmes, needle and

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<sup>16</sup> Pre-dating Dublin, in June 2003, the Council of the European Union adopted a Recommendation on the “prevention and reduction of health-related harm associated with drug dependence”. The aim of the Recommendation is to reduce the number of drug-related deaths and drug-related health damage by encouraging Member States to set up and develop responses and strategies to prevent and reduce drug-related harm, through harm reduction services and facilities. This was reiterated in the EU Drugs Strategy 2005-2012, the EU Drugs Action plan 2005-2008 and a 2007 report from the Commission to the European Parliament and the Council on the implementation of the 2003 Council Recommendation, which concluded that work on drug demand reduction (including harm reduction) should be linked to HIV/AIDS prevention in the European Union and neighbouring countries.

<sup>17</sup> **Austria, Belgium, Cyprus, Czech Republic, Denmark, Estonia, Finland, France, Germany, Greece, Hungary, Ireland, Italy, Latvia, Lithuania, Luxembourg, Malta, the Netherlands, Poland, Portugal, Slovakia, Slovenia, Spain, Sweden, United Kingdom; Bulgaria** and **Romania** joined the EU in 2007 (EU Members in central and eastern parts of the WHO European Region).

syringe provision is supplemented by the wide availability of injecting equipment through vending machines.

**Table 4.1. Availability of needle and syringe programmes in Western Europe 2003–2005 (number of NSP sites per 1000 injectors)**

Countries	Number of NSP Sites		Estimated number IDUs		Number of NSP sites per 1000 IDUs	
	2003	2005	2003 (or latest)	2005 (or latest)	2003	2005
Austria	17	23	17 500 <sup>a</sup>		0.97	1.31
Belgium	39	-	25 800 <sup>c</sup>		1.51	-
	88 <sup>b</sup>				3.41	
Cyprus	0	0	512	327	0	
Denmark	135	-	15 416 <sup>e</sup>		8.76	-
	243 <sup>d</sup>				15.76	
Finland	36	41	15 650 <sup>f</sup>		2.3	2.62
France	490	-	122 000 <sup>h</sup>		4.02	-
	18 490 <sup>g</sup>				151.56	
Germany	>100	-	124 000	94 250 <sup>i</sup>	>0.81	-
Greece	4	4	9 626	9416	0.42	0.42
Iceland	-	-	-	-	-	-
Ireland	20	23	6289 <sup>j</sup>		3.18	3.66
Italy	-	-	326 000 <sup>k</sup>		-	-
Luxembourg	10	12	1715 <sup>l</sup>		5.83	7.00
Malta	7	7	3000 (24)		2.33	2.33
Netherlands	>120	127	3115 <sup>m</sup>		>38.52	40.77
Norway	21	-	16 215	14 406	1.3	-
Portugal	80	37	45 197 <sup>p</sup>		1.77	0.82
	1312 <sup>n</sup>	1364 <sup>o</sup>			29.03	30.18
Spain	297	408	83 972 <sup>t</sup>		3.54	4.86
	1243 <sup>q</sup>	2678 <sup>r,s</sup>			14.7	31.89
Sweden	2	2	20 000 (24)		0.1	0.1
Switzerland	-	-	-	-	-	-
United Kingdom	400	-	123 498 <sup>v</sup>	164 036	3.24	-
	>2000 <sup>u</sup>				>16.19	-

*Source:* EMCDDA (4, 22 23)

**Notes:**

- a Austria 2000 estimate
- b Belgium - includes 49 pharmacy sites
- c Belgium 1997 estimate
- d Denmark - includes 108 pharmacy sites
- e Denmark 1996 estimate
- f Finland 2002 estimate
- g France - includes 18 000 pharmacy sites
- h France 1999 estimate
- i Germany 2000 estimate
- j Ireland 1996 estimate
- k Italy 1996 estimate
- l Luxembourg 2000 estimate
- m Netherlands 2001 estimate
- n Portugal - includes 1232 pharmacy sites in 2003
- o Portugal - includes 1327 pharmacy sites in 2005
- p Portugal 2000 estimate
- q Spain - includes 946 pharmacy sites in 2003
- r Spain - includes 2 310 pharmacy sites in 2005

s Spain - 2003 data has been reported by 17 Autonomous Communities and 2 Autonomous Cities while 2005 data has been reported by 19 Autonomous Communities and 2 Autonomous Cities. Probably explains difference.

t Spain 1998 estimate

u UK - includes >1600 pharmacy sites

v UK 2001 estimate

Pharmacy-based needle and syringe exchange programmes are common in some western European countries. Where such schemes do exist, for example in **Belgium, Denmark, France, Portugal, Spain** and **the United Kingdom**, the availability of NSPs is greatly increased. For example in France, inclusion of the 18 000 pharmacy-based programmes increases availability to almost 152 sites per 1000 IDUs. With the exception of **Sweden** there are no restrictions on pharmacy sales of needles and syringes in European Union countries.

In central and eastern European countries, Table 2 shows that rates of NSP availability in excess of one NSP site per 1000 IDUs have been achieved in **Czech Republic, Estonia, Hungary, Latvia, Lithuania** and **Poland** (all EU Member States). NSP availability also exceeds one site per 1000 IDUs in **Croatia, Tajikistan, Ukraine** and **Uzbekistan**. Elsewhere, availability of NSPs is low, most notably in **the Russian Federation**. In some central and eastern European countries, pharmacy sales are an important, and often the most significant source of clean injecting equipment for IDUs. In the Russian cities of Moscow, Volgograd and Barnaul, for example, over 90% of injectors used pharmacies as their main source of equipment, and less than 10% reported ever having contact with NSPs (25). Pharmacy-based syringe distribution should be included in estimates of both availability and coverage; however, it should be noted that NSPs have many advantages over pharmacies, including additional health and social services that pharmacies are unable to provide.

**Table 4.2. Availability of needle and syringe exchange programmes in central and eastern Europe 2004–2007**

Countries	Number of NSP Sites			Estimated number of IDUs mid-point			Number of NSP Sites per 1000 IDUs		
	2003 (26)	2005 (15)	2007	2003 (22)	2005 (or latest)	2007 (or latest)	2003	2005	2007
Albania	1	2	-	20 000			0.05	0.10	-
Armenia	-	1	4 <sup>a</sup>	9000		10 000 <sup>a</sup>	-	0.11	0.40
Azerbaijan	2	2	14 <sup>b</sup>	19 000		14 451 <sup>b</sup>	0.11	0.11	0.97
Belarus	6	4	58 <sup>c</sup>	46 000	60 000 <sup>c</sup>		0.13	0.07	0.97
Bosnia & Herzegovina	1	1	-	11 000			0.09	0.09	-
Bulgaria	6	6	-	8000			0.75	0.75	-
Croatia	6	17 <sup>d</sup>	-	3 318(4) <sup>e</sup> 21 000			1.81 0.29	5.12 0.81	- -
Czech Republic	166 (22)	165(23)	-	27 000(4)	29 800 (4) <sup>f</sup>	29 013 (4)	6.15	5.54	-
Estonia	19 (22)	23 (23)	-	20 000	13 886 (4) <sup>g</sup>	13 800 <sup>h</sup>	0.95	1.67	-
Georgia	4	5	6 <sup>i</sup>	12 000		80 000 <sup>i</sup>	0.33	0.42	0.08
Hungary	10(22)	13 (23)	-	3941 (4)			2.54	3.30	-
Kazakhstan	10	15	-	174 000			0.06	0.09	-

Kyrgyzstan	5	17	>20 <sup>j</sup>	21 000	25 000 <sup>b</sup>	0.24	0.68	>0.8
Latvia	22 (22)	22 (23)	13 <sup>h</sup>	11 000	12 000 <sup>h</sup>	2.00	1.83	1.08
Lithuania	8 (22)	7 (23)	8 <sup>h</sup>	8000 <sup>h</sup>		1.0	0.88	1.0
The former Yugoslav Republic of Macedonia	4	3	-	5000		0.8	0.6	-
Moldova	7	17 <sup>k</sup>	16 <sup>l</sup>	97 000	47 500	0.07	0.36	0.34
Poland	29(22)	48 (31)	-	43 000		0.67	1.12	-
Romania	4	3 (23)	-	40,000 <sup>m</sup>		0.01	0.08	-
Russian Federation	53	56	63 <sup>o</sup>	1 977 000	500 000 <sup>p</sup> 3,500,000	0.03	0.11 0.02	0.13 0.02
Serbia and Montenegro	-	3 <sup>q</sup>	-	27 000		-	0.11	-
Slovakia	11(22)	12 (23)	-	13 000	18 000 (4)	0.31	0.67	-
Slovenia	1	3	-	7 320 <sup>r</sup>		0.14	0.41	-
Tajikistan	4	6	40 <sup>s</sup>	53 000	35 000 <sup>s</sup> 15 000 <sup>b</sup>	0.08	0.17	2.67
Turkmenistan	2	1	-	11 000	4600 <sup>b</sup>	0.18	0.22	-
Ukraine	44	45	637 <sup>t</sup>	397 000	375 000	0.11	0.12	1.70
Uzbekistan	4	5	230 <sup>u</sup>	87 000	87 000 <sup>b</sup>	0.05	0.06	2.64

**Notes:**

- a WHO (Armenia) Country Office estimate  
b UNODC/WHO Technical Consultation Tashkent May 2007  
c WHO (Belarus) Country Office estimate  
d Croatia GFATM Grant Performance Review July 2005  
[http://www.theglobalfund.org/search/docs/2HRVH\\_83\\_171\\_gpr.pdf](http://www.theglobalfund.org/search/docs/2HRVH_83_171_gpr.pdf)  
e Croatia 2006 estimate (EMCDDA)  
f Czech Republic 2004 estimate (EMCDDA)  
g Estonia 2004 estimate (EMCDDA)  
h UNODC/WHO Technical Consultation Vilnius February 2007  
i WHO (Georgia) Country Office estimate  
j WHO (Kyrgyzstan) Country Office estimate  
k Moldova GFATM Grant Performance Review July 2005  
[http://www.theglobalfund.org/search/docs/1MOLHT\\_411\\_66\\_gpr.pdf](http://www.theglobalfund.org/search/docs/1MOLHT_411_66_gpr.pdf)  
l WHO (Moldova) Country Office estimate  
m Romania GFATM Grant Proposal 2006  
<http://www.theglobalfund.org/programs/countrysite.aspx?countryid=ROM&lang=en>  
o WHO (Russia) Country Office estimate  
p 500,000 officially registered  
q GFATM Grant Performance Review July 2005  
[http://www.theglobalfund.org/search/docs/1SERH\\_430\\_64\\_gpr.pdf](http://www.theglobalfund.org/search/docs/1SERH_430_64_gpr.pdf)  
r Slovenia 2001 estimate (EMCDDA)  
s WHO (Tajikistan) Country Office estimate  
t WHO (Ukraine) Country Office estimate  
u WHO (Uzbekistan) Country Office estimate

A simple measure of coverage of NSPs in central and eastern Europe is summarized in Table 3. None of the countries achieve coverage of over 60% of IDUs regularly reached by NSPs, and NSPs in the majority of the countries reach fewer than 10% of IDUs. In the two countries with the largest IDU-related HIV/AIDS epidemics, **the Russian Federation** and **Ukraine**, less than 5% and 35% of IDUs are covered, respectively. In the case of Ukraine, this figure represents IDU *ever* reached with NSP programmes, while regular reach is significant lower. However, recent estimates for regular reach are only available for a limited number of countries, and the

historical data in this table do not necessarily reflect “regular reach”, defined as the percentage of IDUs regularly reached (i.e. at least once a month) (13,14).

**Table 4.3. Coverage of needle and syringe exchange programmes in central and eastern Europe**

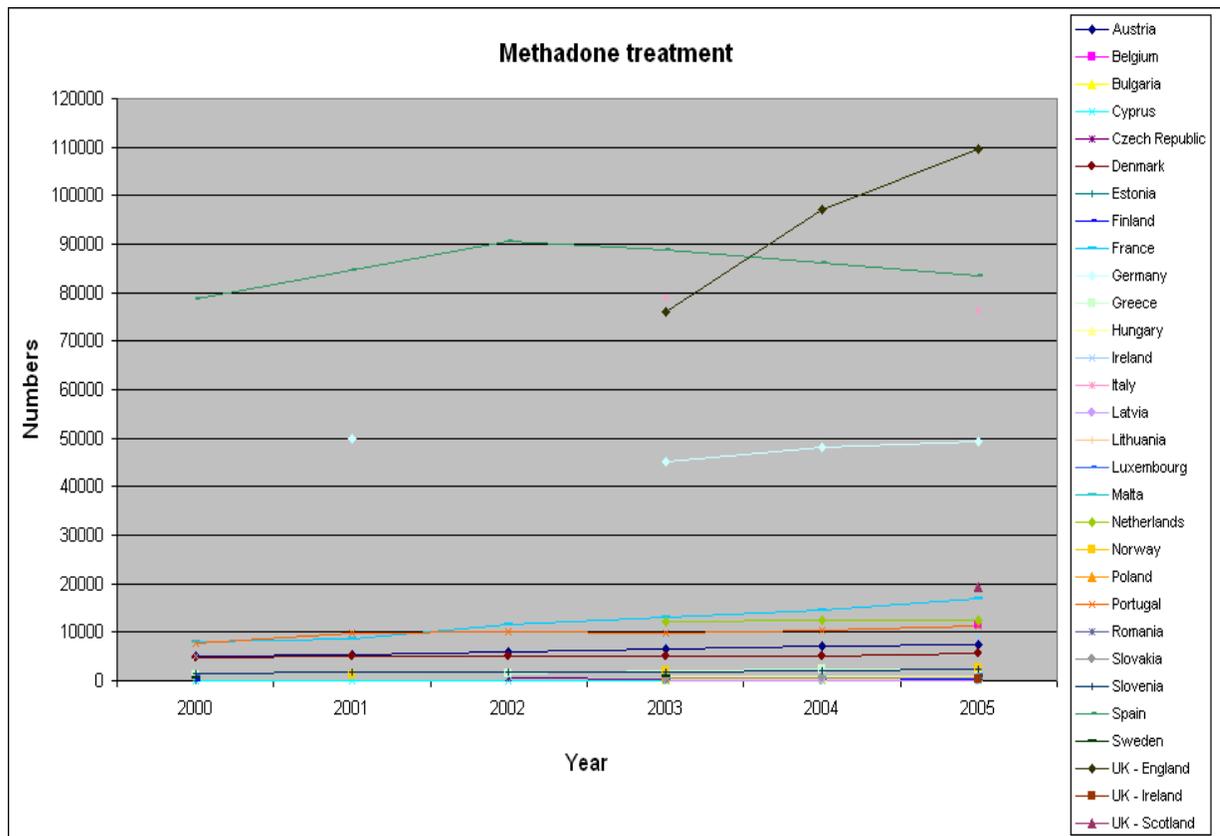
Countries	Coverage Estimate		
	% IDUs reached	Year of estimate	Source of estimate
Albania	1.8 <10	2001/2 2005	Aceijas et. al 2007 GFATM application
Armenia	-	-	
Azerbaijan	3.8 10 15	2001/2 2004 2007	Aceijas et. al 2007 GFATM proposal UNODC/WHO Technical Consultation (Tashkent)
Belarus	10 5.1 5	2001 2001/2 2007	GFATM application Aceijas et. al 2007 WHO Country Office (Belarus)
Bosnia and Herzegovina	8.7 <5	2001/2 2004	Aceijas et. al 2007 GFATM application
Bulgaria	11.4	2001/2	Aceijas et. al 2007
Croatia	6.9 35	2001/2 2005	Aceijas et. al 2007 GFATM Grant Performance Review
Czech Republic	66.7 50	2001/2 2003	Aceijas et. al 2007 EMCDDA 2004
Estonia	22.7 10-30 >36	2001/2 2005 2007	Aceijas et. al 2007 GFATM Grant Performance Review UNODC/WHO Technical Consultation (Vilnius)
Georgia	24 5 10	2001/2 2003 2007	Aceijas et. al 2007 GFATM application WHO Country Office (Georgia)
Hungary	12.7	2001/2	Aceijas et. al 2007
Kazakhstan	8.7 <15 16	2001/2 2005 2007	Aceijas et. al 2007 GFATM Grant Performance Review UNODC/WHO Technical Consultation (Tashkent)
Kyrgyzstan	8.3 <5 40	2001/2 2002 2007	Aceijas et. al 2007 GFATM proposal UNODC/WHO Technical Consultation (Tashkent)
Latvia	5-10	2007	UNODC/WHO Technical Consultation (Vilnius)
Lithuania	47.3 10-19	2001/2 2007	Aceijas et. al 2007 UNODC/WHO Technical Consultation (Vilnius)
The former Yugoslav Republic of Macedonia	12.5 20-25	2001/3 2003	Aceijas et. al 2007 GFATM proposal
Moldova	4.2 5-10	2001/2 2005	Aceijas et. al 2007 GFATM Grant Performance Review
Poland	6	2001/2	Aceijas et. al 2007
Romania	3.3 10	2001/2 2002	Aceijas et. al 2007 GFATM proposal
The Russian	4.1	2001/2	Aceijas et. al 2007

Federation	<5	2003	GFATM proposal
Serbia and Montenegro	<5	2005	GFATM Grant Performance Review
Slovakia	93.2	2001/2	Aceijas et. al 2007
Slovenia	12.8	2001/2	Aceijas et. al 2007
Tajikistan	3 <10 21-30	2001/2 2005 2007	Aceijas et. al 2007 GFATM Grant Performance Review UNODC/WHO Technical Consultation (Tashkent)
Turkmenistan	2.2	2001/2	Aceijas et. al 2007
Ukraine	8.1 35	2001/2 2007	Aceijas et. al 2007 UNGASS report 2006/07 (programmatic coverage)
Uzbekistan	1.6 1	2001/2 2003	Aceijas et. al 2007 GFATM proposal

### Opioid substitution therapy

OST, with methadone and/or buprenorphine supported by psychosocial care, exists in all EU Member States with the exception of **Cyprus**, where OST programmes are being planned (4,6). In some western European countries, for example **Germany, Norway, Italy and the United Kingdom**, over 40% of those engaged in problem opioid use are in OST programmes (4). Some cities achieve even better coverage, between 67% and 77% in Amsterdam, for example (27). Since the Dublin Declaration, there is good evidence that OST has been strongly scaled up in the EU at the aggregate level (4). In several new EU Member States there has also been a significant increase. In the EU countries, OST data quality is better than before, most coming from registries established to control double-prescribing and thus measure individual clients. For many EU countries, there are now trend data over several years (see Fig. 1) that demonstrate these increases.

Fig. 4.1. **Methadone treatment in Europe**



In central and eastern Europe and central Asia, particularly outside of the new EU Member States, there is little evidence of a significant scale-up of access to OST. Although it is increasingly available in central and eastern Europe, five countries (**Armenia, Kazakhstan, Russian Federation, Tajikistan and Turkmenistan**) still do not provide OST. Elsewhere, coverage of OST in central and eastern Europe – see Table 4 – is extremely poor. Only **Bulgaria, Croatia, Hungary and Slovenia** reach 10% or more of IDUs with OST, and most countries reach less than 1%. Efforts to introduce OST in **the Russian Federation** continue to face fierce opposition. Since 1995, there has been a rapid growth of HIV/AIDS in **the Russian Federation**, principally driven by injecting drug use. In spite of the overwhelming evidence for the efficacy of OST (28) and its promotion as an evidence-based intervention by the Joint United Nations Programme on HIV/AIDS (UNAIDS), the United Nations Office on Drugs and Crime (UNODC) and WHO, Russian legislation does not permit the use of OST. **The Russian Federation** is one of the few countries in the world where the use of methadone in the treatment of opioid dependence is illegal and where regulations prevent the use of buprenorphine in drug treatment. There continue to be misconceptions about OST in **the Russian Federation**; its introduction is highly controversial, and opposition remains strong. However, data (29) suggest that, between 2004 and 2006, attitudes changed towards OST among health and law enforcement professionals, drug users, their families and the general public. While opposition to OST in **the Russian Federation** remains strong, advocacy work among professionals (including medical staff and law enforcement officials) is having an effect. Acceleration of advocacy efforts among communities of IDUs and their families is needed, and dissemination of the scientific evidence should be further expanded to address low levels of understanding and unawareness (29).

Table 4.4a. Coverage of opioid substitution therapy, central and eastern Europe 2003-2007

Countries	Year OST first available	Estimated no. of persons receiving OST
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	Methadone	Buprenorphine	2003	2005	2007
Albania	2005	-	0	-	110 <sup>a</sup>
Armenia	Never	Never	0	-	0
Azerbaijan	2004	-	15	-	158 <sup>c</sup>
Belarus	2007 <sup>e</sup>	Never	0	0	18 <sup>c</sup>
Bosnia and Herzegovina	1990	-	75	-	-
Bulgaria	1996	2000	380	920	-
Croatia	1990	-	2000	-	-
Czech Republic	1998	2000	2306	2592	-
Estonia	2001	2003	60	500	555 <sup>f</sup>
Georgia	2005	-	0	-	200 <sup>g</sup>
Hungary	1995	-	750	766	-
Kazakhstan	Never	Never	0	-	0 <sup>h</sup>
Kyrgyzstan	2002	-	114	-	200 <sup>c</sup>
Latvia	1996	2003	67	169	124 <sup>f</sup>
Lithuania	1996	2002	444	629	402 <sup>f</sup>
FYR Macedonia	1989	-	316	-	-
Moldova	2004	-	22	-	28 <sup>i</sup>
Poland	1993	-	865	969	-
Romania	1998	-	400	570	-
Russian Federation	Never	Never	0	0	0
Serbia and Montenegro	1987	-	105	-	-
Slovakia	1997	1999	457	525	-
Slovenia	1990	2004	1841	2401	-
Tajikistan	Never	Never	0	-	0
Turkmenistan	Never	Never	0	-	0 <sup>c</sup>
Ukraine	2008	2004	801	-	530 <sup>m</sup>
Uzbekistan	-	-	0	-	137 <sup>c</sup>

Table 4.4b. Coverage of opioid substitution therapy, central and eastern Europe 2003–2007

Countries	Estimated number of IDUs mid-point			Coverage % of estimated IDUs OST		
	2003	2005 (or latest)	2007 (or latest)	2003	2005	2007
Albania	20 000		11 500 <sup>a</sup>	0	-	0.96
Armenia	9 000		10 000 <sup>a</sup>	0	-	0
Azerbaijan	19 000	14 451 <sup>b</sup>	14 451 <sup>c</sup>	0.1	-	1.1
Belarus	46 000	60 000 <sup>c</sup>		0	0	0.03
Bosnia and Herzegovina	11 000			0.7	-	-
Bulgaria	8000			4.8	11.5	-
Croatia	3 318 21000			60.3 9.5	-	-
Czech Republic	27 000	29 800 (4)	29 013 (4)	8.9	8.7	-
Estonia	20 000	13 88	13 80	0.3	3.6	4

		6 (4)	0 <sup>c</sup>			
Georgia	12 000		80 000 <sup>f</sup>	0	-	0.3
Hungary	3941 (4)			19.0	19.4	-
Kazakhstan	174 000			0	-	0
Kyrgyzstan	21 000	25 000 <sup>b</sup>		0.5	-	0.8
Latvia	11 000	12 000 <sup>h</sup>		0.6	1.4	1
Lithuania	8000 <sup>h</sup>	8000 <sup>f</sup>		5.6	7.9	5
FYR Macedonia	5000			6.3	-	-
Moldova	97 000	47 500		<0.01	-	0.1
Poland	43 000			2.0	2.3	-
Romania	40,000			1.0	1.4	-
Russian Federation	1 977 000	500 000 <sup>l</sup>		0	0	0
	0	3, 500,000		0	0	0
Serbia and Montenegro	27 000			0.4	-	-
Slovakia	13 000	18 000 (4)		3.5	2.9	-
Slovenia	7 320			25.2	32.8	-
Tajikistan	53 000	35 000 <sup>n</sup>	15 000 <sup>b</sup>	0	0	0
Turkmenistan	11 000	4600 <sup>b</sup>		0	0	0
Ukraine	397 000	375 000		<0.01		0.1
Uzbekistan	87 000	87 000 <sup>b</sup>		0		0.2

**Notes for tables 41 and 4b:** Source for EU countries: EMCDDA (4, 22, 23).

a Aksion Plus (2007) Evaluation Report on the community-based methadone programme in Tirana (unpublished)

bWHO (**Armenia**) Country Office estimate

c UNODC/WHO Technical Consultation Tashkent May 2007

d WHO (Azerbaijan) Country Office estimate

e WHO (Belarus) Country Office

f UNODC/WHO Technical Consultation Vilnius March 2007

g WHO (Georgia) Country Office estimate

h WHO (Kazakhstan) Country Office

i WHO (Moldova) Country Office

j 500,000 officially registered

k WHO (Tajikistan) Country Office estimate

l 2004

m WHO (Ukraine) Country Office

In some European countries, notably but not exclusively **the Czech Republic, Estonia, Hungary and Slovakia**, many injectors are amphetamine-type stimulant (ATS) injectors, so denominator populations might be overestimated and therefore OST coverage rates are likely to be under-estimates. However, in the majority of countries the majority of injectors are users of heroin and other opioids. Recent WHO/UNODC and UNAIDS guidance on target setting (13,14) notes that not all injectors use opioids and that where non-opioid use and injection are common separate estimates of opioid users and injectors and non-opioid injectors are needed.

In 2005, **Ukraine** had the fastest growing HIV epidemic in Europe and one of the most explosive in the world. Injecting drug use accounts for over 54.4% of all HIV cases in **Ukraine**. The need to treat opioid dependence and increase access to highly active antiretroviral therapy (HAART) for IDUs led to the establishment of pilot buprenorphine substitution/maintenance programmes in 2004 and, utilizing Global Fund resources, its further expansion in 2005. The pilot

demonstrated that scale up of OST and co-administration of HAART are possible, however, the programmes have yet to be taken to full scale, and only just more than 500 of the estimated 60 000 opioid dependent IDUs in need of OST were enrolled as of December 2007 (30). Many restrictions remain, including: low dosages; intensive resistance of police and some politicians that prevent the use of methadone; restrictive involvement of GPs and HIV/AIDS specialists; and high costs (31). In **Ukraine**, there have been great efforts to introduce and scale up access to OST, which to date has been only of limited success. Buprenorphine was introduced on a pilot basis in 2003 – 2004 and continued with a grant from the GFATM<sup>18</sup>. At the time of writing in early 2008, methadone was also about to be introduced. In spite of the recently increased political support, leadership and coordination to scale up OST services, there remain serious shortcomings and weaknesses in access, coverage and quality.

The quality of OST services across eastern Europe and central Asia is at best sub-optimal and often poor, with low average dosages, overly restrictive entry criteria and over-regulation of patients, resulting in high numbers of patients not continuing in treatment. OST programmes are typically isolated from mainstream drug-dependence (narcological) services and not integrated with other services, particularly HIV/AIDS and TB services. In western Europe, OST is usually delivered in out-patient settings at specialized drug treatment units but also increasingly by doctors in private practice (4). In **Croatia, France, Germany** and **the United Kingdom**, general practitioners are involved in drug-dependence treatment.

### Highly active antiretroviral therapy

Access to HAART in Europe is increasing, from 242 000 people in 2002, to 326 000 in 2005 and 435 0000 in 2007 (See Chapter 12). AIDS incidence among IDUs in some western European countries has dramatically declined since the introduction of HAART in 1996. This is particularly apparent in **Spain, Italy** and, to a lesser extent, **France** (4). In Europe, IDUs continue to have poor and inequitable access to HAART, with only a relatively small improvement in access between 2002 and 2005 (32,33). Inequities in IDU access to HAART are worst in eastern European countries (32,33). A simple measure of relative equity in access to HAART is summarized in Table 5. It shows that in 2002 in the WHO European Region as a whole, 46% of reported HIV cases in 27 reporting countries were in the IDU transmission category, yet in those same countries only 10% of people receiving HAART were IDUs. By 2006 in 38 reporting countries, IDUs represented 59% of reported HIV cases and 30% of people on HAART.

Table 4.5. **Injecting drug users on HAART in the WHO European Region 2002–2006**

Region	End 2002			End 2006		
	Number of reporting countries	Reported HIV cases, IDUs (% among total reported HIV cases with known transmission route) <sup>♦</sup>	Reported IDUs on HAART (% among total reported people on HAART with known transmission route)	Number of reporting countries	Reported HIV cases, IDUs (% among total reported HIV cases with known transmission route) <sup>♦</sup>	Reported IDUs on HAART (% among total reported people on HAART with known transmission route)
West	(8) <sup>a</sup>	37 179 (31%)	3 984 (10%)	(12) <sup>b</sup>	56 551 (29%)	45 757 (30%)
Centre	(8) <sup>c</sup>	538 (29%)	121 (19%)	(13) <sup>d</sup>	5875 (39%)	1493 (14%)

<sup>18</sup> It is notable that GFATM has been a significant player in scaling up access to OST in central and Eastern Europe, providing funds to implement such services in many countries.

East	(11) <sup>c</sup>	47 922 (73%)	15 (14%)	(13) <sup>f</sup>	246 559 (79%)	4102 (39%)
Europe	(27)	85 639 (46%)	4 120 (10%)	(38)	308 985 (59%)	51 352 (30%)

#### Notes:

<sup>d</sup> Data source: European Centre for the Epidemiological Monitoring of AIDS (EuroHIV). Due to incomplete national HIV reporting reported AIDS cases were used for Spain.

<sup>a</sup> **Andorra, Finland, Germany, Luxembourg, Malta, Netherlands, Norway, the United Kingdom.**

<sup>b</sup> **Andorra, Belgium, Finland, Germany, Greece, Israel, Luxembourg, Malta, Netherlands, Spain, Sweden (2005 HAART data), the United Kingdom (2005 HAART data, excludes Scotland).**

<sup>c</sup> **Albania, Bosnia and Herzegovina, Bulgaria, Croatia, The former Yugoslav Republic of Macedonia, Serbia and Montenegro, Slovakia, Slovenia.**

<sup>d</sup> **Bosnia and Herzegovina, Bulgaria (2005 HAART data), Croatia, Czech Republic, Hungary (2005 HAART data), The former Yugoslav Republic of Macedonia, Montenegro, Poland, Romania, Serbia, Slovakia, Slovenia, Turkey.**

<sup>e</sup> **Armenia, Belarus, Estonia, Kazakhstan, Kyrgyzstan, Lithuania, Moldova, Tajikistan, Turkmenistan, Ukraine, Uzbekistan.**

<sup>f</sup> **Armenia, Azerbaijan, Belarus (2005 HAART data), Estonia, Georgia, Kazakhstan (2005 HAART data), Kyrgyzstan, Latvia, Lithuania, Moldova, Russian Federation, Tajikistan, Ukraine.**

IDUs represented 31% of reported HIV cases in eight western European countries in 2002 and 29% in 12 countries in 2006. The proportion of HAART recipients in the IDU transmission category increased from 10% in 2002 to 30% in 2006. In eastern European countries, more than 70% of reported HIV cases were in the IDU transmission category at both time points, while the proportion of HAART recipients that were IDUs increased from 14% to 39%.

There is evidence that HAART has improved survival among western European IDUs. In Barcelona, Spain, among IDUs admitted to drug treatment since 1997, when HAART became widely available, mortality rates for people with and without HIV are similar, demonstrating the beneficial impact of HAART (34). However in Portugal, annual AIDS mortality (most likely due to injecting drug use) has not declined since the introduction of HAART in 1997 and until 2002, suggesting low coverage (4).

#### Opioid substitution therapy and highly active antiretroviral therapy

OST has been demonstrated to improve IDU access and adherence to HAART and to reduce mortality (35). Only a small number of European countries collect data on the number of people on HAART who also receive OST, and these data are summarized in Table 6. In **Spain**, over 30% of IDUs on HAART also receive OST, available since 1992. In the **Netherlands**, 90% of IDUs on HAART also receive OST. In comparison with **Spain**, the **Netherlands** has a relatively small IDU population in need of HAART. Data for other western European countries on OST and HAART recipients are scarce. In central European countries, only **Bulgaria, Croatia, Czech Republic, Serbia and Slovenia** report on HAART patients also receiving OST. Here the numbers are relatively small. In the east, OST is not available in five countries: **Armenia, Kazakhstan, Russian Federation, Tajikistan and Turkmenistan**. There has been an increase in the reported number of IDUs receiving HAART and OST, from just eight in 2004 to 293 in 2006; however, the overall number is still low. The majority of these are in **Ukraine**, where buprenorphine was introduced to improve HAART access and adherence.

Table 4.6. **Number of people on HAART who receive OST in reporting countries in WHO European Region (2004, 2005 and 2006)**

Number of IDU HAART recipients receiving OST, n (% of total number of IDUs on HAART)		
End 2004 (19 reporting)	End 2005 (20 reporting)	End 2006 (19 reporting)

	countries)	countries)	countries)
<b>West</b>			
Finland	35 (35)	-	-
Greece	-	-	11 (10)
Malta	1 (100)	0 (-)*	0 (0)
Netherlands	-	254 (95)	266 (90)
Portugal	-	-	368 (-)
Spain	-	15 209 (39)	13 438 (34)
<i>Total (average)</i>	<i>36 (36)</i>	<i>15 463 (39)</i>	<i>14 083 (35)</i>
<b>Centre</b>			
Bosnia and Herzegovina	1 (25)	2 (50)	0 (0)
Bulgaria	-	2 (67)	4 (80)
Croatia	8 (42)	13 (62)	10 (43)
Cyprus	0 (-)†	-	-
Czech Republic	0 (0)	2 (13)	4 (33)
Hungary	0 (0)	0 (0)	-
Macedonia FYR	-	-	0 (-)*
Poland	-	75 (98)	-
Romania	0 (0)	-	-
Serbia and Montenegro	100 (67)	50 (25)	100 (50)**
Slovakia	0 (0)	0 (0)	0 (0)
Slovenia	5 (83)	3 (60)	3 (38)
<i>Total (average)</i>	<i>114 (57)</i>	<i>147 (11)</i>	<i>121 (49)</i>
<b>East</b>			
Armenia	HAART not available	0 (0)	0 (0)
Belarus	0 (0)	0 (0)	-
Georgia	0 (0)	0 (0)	18 (12)
Kazakhstan	0 (0)	-	-
Kyrgyzstan	HAART not available	10 (23)	12 (32)
Latvia	5 (6)	15 (19)	20 (11)
Lithuania	3 (50)	4 (31)	6 (32)
Moldova	0 (0)	2 (2)	2 (2)
The Russian Federation	0 (0)	0 (0)	-
Ukraine	0 (0)	38 (2)	93 (5)
Uzbekistan	-	-	46 (-)
<i>Total (average)</i>	<i>8 (0.8)</i>	<i>69 (4)</i>	<i>293 (13)</i>
<b>Total European Region (average)</b>	<b>158 (12)</b>	<b>15 679 (37)</b>	<b>14 497 (34)</b>

\* No IDUs on HAART in the country

\*\* Includes Serbia only

### Current injectors and highly active antiretroviral therapy

Current injectors are rarely accepted as good candidates for HAART, and data on the injecting status of HAART recipients are rarely collected. Data on current drug injectors receiving HAART are summarized in Table 7. In **Spain**, just over 3500 people were current injectors at the time of entry into treatment, representing 9% of the total number of injectors on HAART. In central European countries, relatively small numbers of current injectors were receiving HAART, the exceptions being in **Bosnia and Herzegovina**, **Czech Republic** and **Slovenia**. In eastern Europe, where it was previously reported that current injectors rarely, if ever, receive

HAART, a small number of countries (**Armenia, Azerbaijan, Estonia, Kyrgyzstan and Moldova**) report current drug injectors among HAART recipients.

**Table 4.7. Current drug injectors\* among IDUs on HAART in reporting countries in WHO European Region (2004, 2005 and 2006)**

	Number of IDUs on HAART who were <i>current</i> injecting drug users, n (% of total number of IDUs on HAART)		
	End 2004 (17 reporting countries)	End 2005 (17 reporting countries)	End 2006 (17 reporting countries)
<b>West</b>			
Finland	35 (35)	-	-
Greece	-	-	16 (15)
Malta	0 (0)	0 (-)†	0 (0)
Spain	-	2 908 (7)	3 557 (9)
<i>Total (average)</i>	<i>35 (35)</i>	<i>2 908 (7)</i>	<i>3 573(9)</i>
<b>Centre</b>			
Bosnia and Herzegovina	0 (0)	0 (0)	2 (67)
Bulgaria	-	2 (67)	0 (0)
Croatia	3 (16)	-	-
Cyprus	0 (-)†	-	-
Czech Republic	10 (91)	10 (67)	7 (58)
Hungary	0 (0)	0 (0)	-
Macedonia FYR	-	-	0 (-)†
Poland	-	175 (16)	-
Serbia and Montenegro	10 (7)	10 (5)	25 (13)**
Slovakia	0 (0)	1 (25)	0 (0)
Slovenia	2 (33)	2 (40)	8 (100)
Turkey	-	-	1 (10)
<i>Total (average)</i>	<i>25 (13)</i>	<i>200 (15)</i>	<i>43 (18)</i>
<b>East</b>			
Armenia	No HAART	3 (19)	8 (29)
Azerbaijan	-	-	1 (25)
Belarus	4 (11)	5 (10)	-
Estonia	-	13 (8)	75 (25)
Georgia	7 (19)	11 (15)	-
Kazakhstan	0 (0)	-	-
Kyrgyzstan	-	-	37 (100)
Latvia	-	15 (19)	-
Lithuania	0 (0)	1 (8)	0 (0)
Moldova	27 (44)	29 (24)	42 (39)
The Russian Federation	0 (0)	-	-
<i>Total (average)</i>	<i>38 (11)</i>	<i>77 (15)</i>	<i>163 (33)</i>
<b>Total European Region (average)</b>	<b>98 (15)</b>	<b>3 185 (8)</b>	<b>3 779 (9)</b>

\* Current injecting drug users *at the time of entry into treatment* (had injected within the previous four weeks)

† No IDUs on HAART in the country

\*\* Includes Serbia only

## Summary

Progress on implementing the Dublin Declaration with regard to IDUs is mixed. In western Europe and the EU Member States there is a political will and a consensus that has allowed for a scale-up of access to interventions, particularly to opioid substitution therapy, but also needle and syringe programmes and HIV/AIDS treatment and care. This is less true of some of the new EU members such as **Estonia, Latvia and Lithuania**, but even here some limited progress is being made.

In eastern Europe and central Asia, far less progress is being made. Of the six countries that do not provide OST, five are in the eastern part of the European Region (**Armenia, Kazakhstan, the Russian Federation, Tajikistan and Turkmenistan**). Elsewhere, OST programmes are little more than pilots that fail to reach anywhere near enough clients to have an impact on the epidemic. Services are often of a poor quality and lack integration. Needle and syringe programmes have higher coverage in most western European countries but are rarely available in prisons. Elsewhere, poor coverage is certainly contributing to the continued transmission of HIV and other infectious diseases among drug injectors.

Access to HAART is improving throughout Europe, but IDUs, particularly in the east, continue to have poor access, and discriminatory practices prevent them from accessing and adhering to this treatment.

In the four years since the Dublin Declaration, measuring progress on implementing the Declaration has been frustrated by the lack of a framework, indicators and targets. Major progress in this regard has been achieved with the development of WHO/UNODC/UNAIDS technical guidance. Countries should consider this technical guidance and set ambitious but achievable national targets, with more consistent methods of measuring and comparing progress towards universal access. They should also collect data on OST and HAART and current injectors on HAART. Additionally, they should endeavour to achieve the recommendations listed below.

## **Recommendations**

### *Progress on commitments*

It is apparent that limited progress has been made in central and eastern Europe with regard to commitments to scaling-up access to drug dependence treatment, harm reduction services and HIV/AIDS treatment for injecting drug users. Concrete recommendations include:

1. Countries should make far more serious efforts to scale up access to drug-dependence treatment in general and OST in particular, harm-reduction services and HIV/AIDS treatment for IDUs.
2. Countries with IDU-related epidemics should consider the nine components of the comprehensive package (13) and determine the mix and coverage levels appropriate for their country.
3. The concepts of universal access and coverage need to be quantifiable at the national level. National targets need to be set that ultimately aim at full access to prevention, treatment and care for all IDUs for whom the intervention is intended.
4. Indicative coverage targets of *at least* 60% of IDUs regularly reached by NSPs and *at least* 40% of opioid-dependent IDUs in OST are suggested. Ideally, 100% of those in need of the services should be able to access them.
5. Pharmacies play an important role in increasing access both through NSP provision and sales of sterile injecting equipment. Both should be widely available.

6. The five countries which currently do not provide OST (**Armenia, Kazakhstan, the Russian Federation, Tajikistan and Turkmenistan**) should introduce it urgently.
7. Countries should massively scale up access to HAART for IDUs and use OST to improve their access and adherence.

### *Monitoring*

In the four years since the Dublin Declaration, measuring progress on implementing the Declaration has been frustrated by the lack of a framework, indicators and targets. Major progress in this regard has been achieved with the development of a WHO/UNODC/UNAIDS Technical Guide for Countries to Set Targets for Universal Access to HIV Prevention, Treatment and Care for Injecting Drug Users (12, 13).

8. Countries should consider the Technical Guidance and set ambitious, but achievable national targets for scaling-up towards universal access to HIV/AIDS prevention, treatment and care for injecting drug users.
9. Countries should apply more consistent methods of measuring and comparing progress towards universal access.
10. Countries should collect data on OST and HAART and current injectors in receipt of HAART.

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## 5. Vulnerable populations and risk groups

**Dublin Action 9:** “By 2010, ensure through the scaling up of programmes that 80% of the persons at the highest risk of and most vulnerable to HIV/AIDS are covered by a wide range of prevention programmes providing access to information, services and prevention commodities and identifying and addressing factors that make these groups and communities particularly vulnerable to HIV infection and promote and protect their health, and intensify cross border, sub-regional and regional technical collaboration and sharing of best practices through the EU and regional organisations in the prevention of HIV transmission among vulnerable groups.”

The Dublin Declaration commits the governments of the WHO European Region to tackle the spread of HIV/AIDS among vulnerable populations and risk groups and to find mechanisms to monitor that progress. The challenge is set out in specific terms by Action 9 above (For definitions of vulnerability and risk, see Box 5.1 below).

### Box 5.1. UNAIDS definitions of vulnerability and risk (1)

“Vulnerability. Vulnerability results from a range of factors that reduce the ability of individuals and communities to avoid HIV infection. These may include: (i) personal factors such as the lack of knowledge and skills required to protect oneself and others; (ii) factors pertaining to the quality and coverage of services, such as inaccessibility of services due to distance, cost and other factors[; and] (iii) societal factors such as social and cultural norms, practices, beliefs and laws that stigmatize and disempower certain populations, and act as barriers to essential HIV prevention messages. These factors, alone or in combination, may create or exacerbate individual vulnerability and, as a result, collective vulnerability to HIV.

“Risk. Risk is defined as the probability that a person may acquire HIV infection. Certain behaviours create, enhance and perpetuate risk. Examples include unprotected sex with a partner whose HIV status is unknown[,] multiple unprotected sexual partnerships and injecting drug use with non-sterile injecting equipment.

This chapter addresses the adequacy of prevention programmes and policies in place for men who have sex with men (MSM), injecting drug users (IDUs), sex workers, ethnic and national minorities, migrant/mobile workers and prisoners. Reference to IDU, gender, youth and prisoner issues will be brief, as they are covered at length in Chapters 4, 6, 8 and 15, respectively.

Throughout Europe and central Asia, there exists considerable epidemiological variation in HIV. Currently, the HIV epidemic in the European Region is concentrated within the vulnerable populations and risk groups mentioned and, though evidence suggests an increasing number of affected women, people living with HIV (PLHIV) are predominantly male. By preventing the spread of HIV in these populations, not only can governments save individual lives, but they can also significantly diminish the potential for this concentrated epidemic to evolve into a generalized one.

The focus of Action 9 and other relevant actions is on prevention, but it should also be stressed that improvements in treatment and care for vulnerable populations and risk groups are crucial in tackling the spread of HIV in the Region. The inclusion of PLHIV in the formulation of prevention strategies and programmes is also vital (see Chapter 2).

Action 9 is essentially divided into four actions to be achieved by 2010:

- scaling up HIV prevention programmes so that they cover 80% of the members of vulnerable populations and risk groups;
- identifying and addressing factors that make these groups vulnerable to or at risk for HIV;
- promoting and protecting the health of vulnerable populations and risk groups; and
- utilizing the EU and other regional organizations to intensify international collaboration and sharing of best practice on HIV prevention in vulnerable populations and risk groups.

Other Dublin actions also address vulnerable populations and risk groups. Action 13 calls for equality of access for individuals of different sexes and ages, while Action 9 and Action 25 both call for collaboration and sharing of best practices.

This chapter will briefly review current progress, outline how progress towards meeting Action 9 can be measured and comment on areas of concern. Recommendations will then be made concerning prevention, which remains the cornerstone of any comprehensive approach to HIV/AIDS.

A variety of existing data were used in assessing progress. We also circulated a questionnaire to civil society organizations to identify issues of concern and promote engagement with the monitoring process. The questionnaire solicited suggestions for how to measure progress and asked respondents to assess whether they believed progress had been made. We promoted this online tool via civil society email lists. It comprised 17 questions in English and Russian, mainly multiple choice; it could be answered anonymously, though multiple responses from the same Internet address were not permitted. We received almost 200 responses in six weeks. The survey was designed not to provide robust statistical data, but rather to generate ideas and highlight specific concerns that we could then explore in greater detail. We also assessed current literature on vulnerable populations and risk groups, including reports and statistical information from both government and nongovernment sources.

### **Snapshot of current situation**

In western Europe, the greatest risks for HIV transmission are within certain ethnic minorities and MSM. In eastern Europe, the predominant means of transmission is needle sharing among IDUs (see Chapter 4). There is also evidence of a hidden epidemic among MSM (2). Evidence from studies into the behaviour of MSM in eastern Europe suggests high levels of risk-taking (3). In central Europe, HIV prevalence remains low, while the epidemic is heterogeneous and varies from country to country (4). Across the European Region, prisoners remain at serious risk of contracting HIV; their lack of political and social agency is compounded by high levels of high-risk behaviour; with regards to MSM, this is often coerced (5–7).

#### *Sex workers*

Whether male, female or transgender, sex workers engage in behaviours and live in environments that can place them at increased risk for HIV, a situation compounded by their marginalized and stigmatized position in society. Many sex workers have multiple sexual partners every day. They often face difficulties negotiating condom use because of various vulnerabilities, including lack of knowledge, skills and gender-related issues, not to mention the lack of access to places where relevant information can be usually be obtained. Sex workers are more likely to face stigma and discrimination in accessing health care services that relate to their sexual health needs than other individuals and, where sex work has not been decriminalized, are likely to be targeted by law enforcement officers. The World Bank has documented that sex workers are the risk group that is most likely to respond positively to prevention programmes

(8), yet many European policies targeting sex workers have negative implications for their health and place them at heightened risk for HIV. They include harsh policies on soliciting sex, which pushes sex workers into less safe areas, and restrictions on their working together, which makes them more vulnerable to exploitation by clients (9).

Sex workers are especially vulnerable to HIV when they are also migrants, MSM or IDUs (9). Evidence from **Uzbekistan** suggests that sex workers who are also IDUs have much higher prevalence rates of HIV (10). This tendency confounds attempts to ascertain the relationship between sex work and HIV and highlights the increased risks that injecting drug-using sex workers face (10). The European Network for HIV/STI Prevention and Health Promotion Among Sex Workers (TAMPEP) has drawn attention to the fact that for sex workers, especially those who are also migrants, merely knowing about the risks of HIV infection does not necessarily enable them to avoid these risks. The social isolation and marginalization of sex workers is further exacerbated for the more marginal subgroups of the sex worker population. It is these more marginal groups that are most in need of HIV prevention, health promotion and protection, and the addressing of factors that increase vulnerability and risk (9).

#### *Men who have sex with men*

The International Lesbian and Gay Association (ILGA) has reported that in central and eastern Europe, data on MSM are minimal in comparison to data for other groups (11), while UNAIDS reports that globally, only 10% of MSM have access to the health services they require (12). Recent evidence suggests that in eastern European countries where the HIV epidemic is largely driven by injecting drug use, there exists a hidden epidemic among the MSM subpopulation (13). Consequently, greater emphasis needs to be placed on surveillance and prevention in these areas if prevention programmes, both primary and secondary, are to remain well targeted and pertinent (14); the civil rights of lesbian, gay, bisexual and transgender (LGBT) people also need to be made a reality. In western Europe, it is the efforts of LGBT communities, working in partnership with others, that have provided (and continue to provide) the most effective responses to the spread of HIV in the subregion.

Same-sex relations are now decriminalized throughout the European Region, with the exception of **Turkmenistan** and **Uzbekistan** (15). However, this development is a recent one in many states, often occurring only as the result of intense external pressure and factors such as a desire for membership in the Council of Europe (16). An ILGA global survey of laws (15) details the history of stigmatization, persecution and harassment that individuals and groups from LGBT communities face in much of the Region, much of it sanctioned or instigated by the state. The survey also documents the existence and implementation of discriminatory sexual offence laws throughout the Region (17).<sup>19</sup>

The right to “freedom of assembly and association” is a basic human right. However, attacks against members of the LGBT community for exercising that right abound. Marches in 2007 in Moscow (**The Russian Federation**), Riga (**Latvia**) and Tallinn (**Estonia**) in 2007 all made world headlines because of the controversies they engendered. The reluctance of civil authorities to uphold the right of association in these cases was widely condemned by human rights organizations and members of the European Parliament. These examples are the tip of the iceberg; the registration or indeed existence of LGBT organizations and events is still often problematic and sometimes dangerous for the people involved. In many cases, discrimination is state sanctioned. Fear of disclosing one’s sexual orientation remains an issue in many countries across Europe and central Asia (11). Until states promote the full equality of LGBT communities

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<sup>19</sup> For instance, while the practice of homosexuality is not illegal in Turkey, articles of the highly flexible police regulations there are used to ban meetings and demonstrations on so-called public morality grounds (17).

(not merely decriminalizing consenting sexual acts) and protect the rights of LGBT individuals and groups, their ability to respond effectively to HIV/AIDS is greatly compromised. Difficulties in scaling up interventions targeted at MSM are compounded by the negative impact of associating HIV with MSM. In countries where MSM remain highly stigmatized, scaling up interventions can raise the visibility of MSM and lead to heightened levels of discrimination (12).

For more discussion on efforts to address stigma and discrimination, see Chapter 13.

### *Prisoners*

Chapter 15 deals with prisons and prisoners in detail, so the comments here will be confined to prevention issues. Worldwide, HIV prevalence rates are higher in prisons than outside (6). Eastern Europe has the highest incarceration rates in the European Region, while in western Europe, the highest rates are found in **Israel, Luxembourg and the United Kingdom** (19). Prisoners have almost no choice of services and are marginalized economically and socially. Risk behaviours such as sharing of injecting and tattooing equipment are more common in prison than outside. Homosexual activity (often coerced) in prisons is also commonplace, often among men with no previous exposure to HIV prevention information. Prisons can be areas where HIV spreads rapidly, as demonstrated by the Glenochil Prison Study in Scotland and evidenced by the explosion of HIV in Lithuanian prisons (5).

Across the Region, greater HIV surveillance is needed in prisons, especially in low and middle-income countries, where pilot studies have situated the most rapid increases in infection rates for bloodborne diseases and other public health threats (7). The release from prisons of large numbers of PLHIV has been likened to “the state manufacturing a ticking time bomb” (20). Although the HIV epidemic began more than two decades ago, there is an almost total failure to provide effective evidence-based prevention programmes in prisons (21). The disastrous consequences for public health are compounded by the higher rates of imprisonment that individuals from vulnerable populations and risk groups face (6).

The United Nations Office on Drugs and Crime (UNODC) has noted that, in most countries, prison health standards and prison conditions suffer because of a lack of political and public interest in the well-being of prisoners. This is often a result of the poor regard in which prisoners are held and can lead to policies based more on public opinion and political expediency than evidence-based policies driven by a concern for health (6).

### *Migrant and mobile populations*

One third of the world’s foreign-born migrants live in Europe, with many of them being marginalized and socially excluded (22). In western Europe, migrants from Africa and from central and eastern Europe often face barriers in accessing information and medical and social services, particularly those who are undocumented. These barriers may be in the form of increasingly restrictive legislation or frontline staff restricting access to commodities (23). HIV surveillance among migrants appears lower than among other populations in many European and central Asian countries, as evidenced by the lack of HIV prevalence figures for migrants in national reports on progress in implementing the United Nations Declaration of Commitment on HIV/AIDS (UNGASS country reports) (24).

Of particular concern is the potential risk of HIV spreading from western to central Europe. Large-scale temporary migration of young sexually active individuals has taken place following expansion of the European Union. In many cases people are going from countries with low HIV prevalence, such as **the Czech Republic and Poland**, to countries where prevalence rates are much higher, such as **the United Kingdom** (25). There is the risk that these individuals,

especially those who are MSM, may contract HIV in western Europe and increase the risk of contributing to the development of epidemics in their home countries when they return. Current monitoring of the impact of migration patterns on HIV epidemics in the Region is insufficient and needs to be expanded. It should include temporary and seasonal migration, as well as other forms of mobility such as employment in the transport and fishing industries.

#### *Ethnic and national minorities*

Certain ethnic minorities in Europe and central Asia are especially vulnerable to HIV. Many of these populations engage in high-risk behaviours and often face stigma and discrimination from the authorities and other members of society. Furthermore, ethnic and national minorities are more likely to be economically and socially marginalized. A study of Roma in **Bulgaria** (26) uncovered disturbing levels of high-risk behaviours, including high levels of unprotected heterosexual anal and vaginal intercourse, compounded by economic and social exclusion and poor access to services. Prevalence rates among African communities in western Europe are very high. In **the United Kingdom**, prevalence of HIV among black Africans is 46 times higher than among non-African heterosexuals. However, levels of onward transmission among black Africans in **the United Kingdom** remain much lower than among MSM (27). To avoid further spread of HIV among ethnic and national minorities, surveillance and prevention programmes need to be further developed to target these populations.

#### **Indicators for the four calls to action**

##### *1. Scale up HIV prevention programmes so that they cover 80% of the members of vulnerable populations and risk groups*

Adequate surveillance systems must be in place to identify vulnerable populations and risk groups, their sizes and HIV prevalence rates. Existing indicators should be expanded to cover the vulnerable populations and risk groups mentioned above, along with other groups as appropriate. Where possible, surveillance should include data on risk behaviours.

Examples of good surveillance practice exist already and they are becoming more common. They include work carried out by **the United Kingdom** Health Protection Agency and the initiation of HIV surveillance in **Tajikistan** that began in 2005 (28). A desire to implement such systems is cited in several applications to the Global Fund to Fight AIDS, Tuberculosis and Malaria, e.g. the Round 6 applications from **Georgia, Moldova** and **Serbia** and the Round 5 application from **Montenegro** (29–32).

Surveillance still needs further attention throughout the European Region. In recent years, the number of countries reporting HIV cases has improved, with 48 of the 52 countries then in the Region reporting them for 2005 (2). Though high-income countries have no excuse for not having comprehensive countrywide surveillance, **Italy** and **Spain** have failed to establish such systems, and reporting remains problematic in other high-income countries in the Region. Reporting of HIV prevalence in vulnerable populations and risk groups also continues to be inadequate. According to the European Centre for the Epidemiological Monitoring of AIDS (EuroHIV) (33), sex worker prevalence studies for 1997–2002 had to be based on data from only 11 countries in the Region, data that reflected moreover a large variety of methodologies. EuroHIV data for IDUs have been more comprehensive; prevalence studies for 1998–2003 were based on 90 studies in 36 countries. Worldwide, surveillance systems for HIV in prisons are inadequate for many low- and middle-income countries (7). Finally, because of the retrospective nature of surveillance, most of the compilations of prevalence studies produced by EuroHIV are based on studies carried out before the signing of Dublin in 2004, making subsequent progress impossible to monitor yet.

A range of prevention programmes targeting vulnerable populations should be provided either by Government or through civil society organizations. Several of the 2005 UNGASS reports highlight the existence of such programmes (24). However, only 33 of the 52 countries then in the European Region submitted an UNGASS report to UNAIDS and they were highly variable in terms of their usefulness in monitoring progress on Action 9. Some only highlighted the state of the epidemic, without providing details of government action, while others gave detailed accounts of policies and programmes targeting vulnerable populations and risk groups.

Those reports that were submitted in the UNAIDS Country Response Information System (CRIS) format typically proved the most useful (34). CRIS includes the National Composite Policy Index (NCPI), which directly asks whether prevention programmes exist for sex workers, MSM, IDUs and other risk groups.

While the responses to these questions do not reveal the percentage coverage of these programmes nor their quality, affirmative answers at least indicate the existence of targeted prevention efforts. The Ministry of Health in **Ukraine**, for example, reported that at the end of 2005, policies or strategies were in place for prison inmates and IDUs but not for other vulnerable populations and risk groups (13).

Less than one third of the countries submitted a fully completed CRIS to UNAIDS for the 2005 reports. Convincing more countries to submit complete reports may help prompt improved targeting of vulnerable populations and risk groups for prevalence studies and prevention programmes.

The key to assessing whether countries are making progress towards Action 9's 80% target lies in assessing the reach of prevention programmes. UNGASS Knowledge Indicator Questions provide information on the percentage of vulnerable populations and risk groups reached by prevention programmes.

Data have primarily been provided on IDUs, MSM and sex workers and occasionally on prisoners and certain ethnic groups such as Roma (24). Monitoring should be expanded to other vulnerable populations and risk groups. It should be noted that Action 9 calls for a "wide range" of prevention programmes. To enable progress on Action 9 to be monitored, each country in the Region should define in its National AIDS Strategy exactly what constitutes a wide range of preventive programmes, with clear qualitative and quantitative indicators.

Several Knowledge Indicator Questions have the potential to provide proxy information on the reach of prevention programmes by providing evidence of risk-avoidance behaviours.

**Indicator 8.** Percentage of most-at-risk populations that have received an HIV test in the last 12 months and who know their results

**Indicator 18.** Percentage of female and male sex workers reporting the use of a condom with their most recent

**Indicator 19.** Percentage of men reporting the use of a condom the last time they had anal sex with a male partner.

**Indicator 20.** Percentage of injecting drug users reporting the use of a condom the last time they had sexual intercourse.

**Indicator 21.** Percentage of injecting drug users reporting the use of sterile injecting equipment the last time they injected.

The above indicators, while useful, are not enough in themselves to show the existence of appropriate and effective programmes that reach all individuals in vulnerable populations and risk groups.

Applications to the Global Fund highlight disparities between the coverage countries committed to in signing the Dublin Declaration and the coverage they aim for in their national strategies. The Round 6 Global Fund applications of **Romania, Tajikistan and Ukraine** (28, 35, 36) all list coverage targets for prevention programmes that differ from the 80% Dublin target. The targets set out in the Global Fund applications tend to be more pragmatic than the aspirational targets of the UNGASS and Dublin declarations. While such divergences may be justifiable, an effort to relate the two types of targets, or at least a reference in Global Fund applications to the Dublin target, would facilitate the process of monitoring progress on Action 9.

For the survey conducted for this chapter, most civil society respondents who gave a figure estimated coverage as currently being between 0% and 39%. These numbers lie well below the 2010 target of 80% set out in Action 9. Yet these respondents also reported progress, with many feeling that coverage by a wide range of prevention programmes has increased since the signing of the Dublin Declaration.

All prevention programmes should be evidence based and scientifically sound. Access to certain commodities, information and services is essential for a prevention programme to reach this minimum standard. WHO and UNAIDS guidelines on prevention among sex workers, MSM and IDUs (37) provide a good audit tool for assessing a government's progress in this area, as well its capacity for delivering appropriate programmes.

Prevention programmes should also make appropriate literature available in easily accessible media, offer prevention commodities such as condoms, clean needles and disinfectant and also provide services that are not discriminatory but accessible, without fear of harassment or arrest by authorities. It is reasonable to expect that more elaborate prevention commodities and more refined programmes will be in place in the more affluent countries of the Region. Efforts should be made to ensure that markets that enable individuals to access prevention commodities can develop without hindrance. Furthermore, the utilization of prevention commodities should be promoted through assistance in their social marketing.

Good examples of why and how to implement HIV prevention programmes among vulnerable populations and risk groups can be found in Annex 1 of *Practical guidelines for intensifying HIV prevention* (38). While not fully comprehensive, these guidelines do outline the “essential components of the recommended prevention measures”. We suggest these measures be adopted as a minimum standard for national prevention programmes.

#### *Identify and address factors that make people particularly vulnerable to or at risk for HIV*

An individual's likelihood of becoming infected with HIV is the result of a complex interplay among risk factors, risk behaviours and geographic and socioeconomic vulnerability – elements that originate in both the macro and micro environments (39). The government and other stakeholders should seek to understand how this interplay increases the spread of HIV.

Individuals who are members of multiple vulnerable populations and risk groups are at increased risk for HIV, as shown by prevalence and surveillance studies (9). The overlapping of such populations confounds attempts to identify and address factors that increase vulnerability and risk; these overlaps need to be observed and studied in more depth (38). For instance, migrant sex workers face the cultural and linguistic obstacles and reduced access to health care and social

services that other migrant workers face, alongside the vulnerabilities and risk factors that all sex workers experience (9). HIV prevalence is also likely to be higher among sex workers who are IDUs than among those who are not (9).

Progress on identifying and addressing vulnerability and risk factors should not be evaluated on the basis of government-published data alone. Such data may emphasize areas where factors are being identified and addressed rather than those areas that require attention and action. Information from other sources, such as civil society organizations, may highlight areas where progress is currently lacking.

For example, the Romanian Association Against AIDS assessment of national progress on the UNGASS Declaration (40) drew attention to several areas where the Romanian government was not addressing factors making population groups vulnerable to HIV. According to the Association, cultural, legal and institutional barriers were still restricting access to health care among vulnerable populations and risk groups. Furthermore, they noted that the continued punishment of sex workers through the penal code was marginalizing these individuals and making them more vulnerable to HIV. Harsh policies towards sex workers and IDUs, which push sex work and drug-injecting underground and promote risk behaviours, should be avoided.

Protecting the health of vulnerable populations and risk groups involves ensuring that legislation and laws do not assist in the marginalization these individuals. Apart from repealing discriminatory, unhelpful legislation that compounds the spread of HIV, governments need to uphold the rights of the members of vulnerable populations and risk groups and guarantee their equality before the law.

In responding to the survey for this chapter, civil society representatives expressed a considerable variety of opinions on whether their governments had identified and addressed the factors that make vulnerable populations and risk groups more prone to HIV infection.

*Promote and protect the health of vulnerable populations and risk groups*

**Indicator 9.5** (existing)      Does your country have a policy to ensure equal access to prevention and care for most at-risk populations?

Human rights law should guarantee the protection and promotion of everyone's health. The following NCPI indicator examines whether this is true in the responding country.

**Indicator 9.6** (existing)      Is the promotion and protection of human rights explicitly mentioned in any HIV/AIDS policy/strategy?

To promote and protect the health of vulnerable populations and risk groups, adequate laws and regulations need to be in place, human rights need to be upheld, and health promotion campaigns targeting these groups need to be initiated and continued. It is critical that governments weigh which legislative steps and policies are needed to vouchsafe individual rights and promote individual health. Rights that affect health include the right to know one's serostatus (or not), the right to privacy, the right to health care, the right to equality before the law, and equal treatment regardless of incarceration status or lack of agency. Any legislation that curtails or restricts these rights should be amended or repealed.

As when addressing HIV vulnerability and risk factors, in implementing policies and laws designed to limit the spread of HIV among vulnerable populations and risk groups, it is important to ensure that they are observed by all relevant state and non-state actors. Such observance may necessitate special training.

When vulnerable populations and risk groups are subjected to discrimination or stigma, it contravenes their human rights. Laws and regulations need to be adopted to protect these groups from stigma and discrimination, which can lead to greater risk-taking. Two other NCPI indicators are relevant here.

**Indicator 9.7** (existing) Does your country have laws or regulations that protect people living with HIV/AIDS against discrimination?

**Indicator 9.8** (existing) Does your country have non-discrimination laws or regulations which specify protections for certain groups of people identified as being especially vulnerable to HIV/AIDS discrimination?

MSM in **Ukraine** continue to face discrimination due to high levels of stigma and a lack of basic legislation protecting their property rights, medical rights and other rights. According to a report by the All Ukraine Network of PLWHA (3), existing antidiscrimination legislation does not really address discrimination on the basis of sexual orientation. Moreover, the report states that there remains a perception that PLHIV services primarily target IDUs, which likely contributes to the fact that 60% of MSM in **Ukraine** have never been tested for HIV.

In **the Netherlands**, AIDS & Mobility Europe reports that the political and social environment is becoming increasingly hostile towards migrants (41). This environment is leading to the adoption of discriminatory legislation that pushes migrants into already marginalized occupations such as sex work. Although in theory, migrants continue to have access to treatment if in dire need, many health care services are provided only according to the judgement of “gatekeepers”, who are often influenced by negative media and political attention directed at migrants. The raising of work and health care barriers compounds their vulnerability to HIV. Similar situations are found in other western European countries, including **Austria**, **Sweden** and **the United Kingdom** (42). Accordingly, national HIV strategies and related frameworks should specifically mention the need to protect vulnerable populations and risk groups from violence.

Members of vulnerable populations and risk groups are often increasingly subject to physical, emotional and sexual violence, whether perpetrated by state or non-state actors. Non-state actors include the clients of sex workers, overseers of migrant workers, drug dealers and fellow prisoners.

Violence perpetrated by state actors is that perpetrated by law enforcement officers and other government agents. The social and economic marginalization of vulnerable populations and risk groups often places them at high risk for such violence. Since membership in vulnerable populations and risk groups frequently involves a status or activity that is illegal or legally dubious, members often find themselves in highly unequal power relationships with state actors, which can lead to exploitation (43).

Violence of all kinds, especially sexual violence, increases the likelihood of individuals becoming infected with HIV, and policies should be in place to reduce the risk of vulnerable and at-risk individuals being the targets of violence. Currently there are no indicators for monitoring how much violence is directed against vulnerable populations and risk groups or what measures are being taken to address this problem. (See also Chapter 6.)

It is especially important to promote and protect the health of those individuals whose agency is restricted. Prisoners, for instance, are almost entirely dependent on the state for access to health and social services. As noted above, risk behaviours are commonplace in prisons, populations

disproportionately affected by HIV are more likely to be imprisoned, and HIV prevalence is higher in prisons than outside. Five countries in the Region have recorded prevalence of over 10% in prisons: **Estonia, Lithuania, Romania, Slovakia** and **Ukraine** (7), all many times greater than the prevalence rate for the general population.

*Use the EU and other regional organizations to intensify international collaboration and sharing of best practice on HIV prevention in vulnerable populations and risk groups*

To a great degree, this call for action in Action 9 is the same as Action 25:

**Dublin Action 25:** Monitor best practices on and take concrete steps to exchange information on service delivery for prevention, treatment and care, particularly for persons at the highest risk of and most vulnerable to HIV/AIDS infection

Collaboration and sharing of best practice should take place at all levels: nationally between the government and civil society organizations, bilaterally between individual governments and internationally on a broad regional scale. Many of the issues relating to vulnerable populations and risk groups pertain to the entire European Region, and with the Region's internal migration on the rise, the policies of one country often have a direct impact on conditions in another.

Our survey highlighted concern regarding the promotion and protection of the health of vulnerable populations and risk groups. While many respondents suggested there had been improvements in these areas, the number of respondents attributing progress to the work of civil society was three times the number attributing it to government action. While the survey sample was not representative, this widely held perception among credible civil society actors suggests that governments need to devote more energy to health promotion in these groups and coordinate their efforts with civil society.

Members of vulnerable populations and risk groups should be included in the design and implementation of health promotion campaigns that target them. Such inclusion is clearly implied in Action 27 (see Chapter 2), the UNAIDS Three Ones model and funding applications to the Global Fund. Involving vulnerable and at-risk individuals along with PLHIV, leads to programmes being more effectively focused, as well as building trust in the targeted groups.

There is considerable room for better sharing of best practice on health promotion among migrant populations, especially when the migration is within the Region. One of the best examples of collaborative efforts can be found in the close work between agencies in **Austria** and **Slovakia** relating to migrants from Bratislava to **Austria** (44).

## **Recommendations**

The following recommendations arise either from experience (including the experience of civil society representatives surveyed across the Region) or from comparing current conditions with existing guidelines and standards. Except for Recommendations 1 and 3, they are addressed primarily to national governments. They should be incorporated as appropriate into national HIV programme guidance documents, as well as into national data collection surveys in order to facilitate future monitoring of progress on Action 9. Further, the targets and undertakings should be outlined in programme guidance documents and national data collection surveys should be aligned with them to monitor progress.

1. Adopt the UNAIDS definitions of risk and vulnerability in assessing progress on Action 9.

2. Incorporate into the national HIV policy/strategy comprehensive surveillance systems to identify and support vulnerable populations and risk groups.
3. Provide a wide range of HIV prevention programmes, through the government and/or civil society organizations, targeting relevant vulnerable populations and risk groups.
4. Ensure that national HIV prevention programmes meet the standards set out in *Practical guidelines for intensifying HIV prevention (35)*.
5. Draw attention in the national HIV policy/strategy to individuals who are members of more than one vulnerable population or risk group.
6. Audit existing legislation and regulations for obstacles to the development and utilization of HIV prevention programmes for vulnerable populations and risk groups – and remove them.
7. Implement a national policy to ensure vulnerable populations and risk groups equitable access to HIV prevention and care.
8. Take steps to counter the stigma experienced by vulnerable populations and risk groups, including that which they experience from health care providers.
9. Ensure that the national HIV strategy and related frameworks specifically mention the need to protect vulnerable populations and risk groups from violence.

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## 6. Gender equity

**Dublin Action 13:** “Ensure [that] men, women and adolescents ... have universal and equitable access to and promote the use of a comprehensive range of high quality, safe, accessible, affordable and reliable reproductive and sexual health care services, supplies and information including condoms, voluntary testing, counselling and follow-up.”

**Dublin Action 14:** “By 2005 ... develop national and regional strategies and programmes to increase the capacity of women and adolescent girls to protect themselves from the risk of HIV infection, and reduce their vulnerability to HIV/AIDS.”

**Dublin Action 20:** “Combat stigma and discrimination [suffered by] people living with HIV/AIDS in Europe and Central Asia, including through a critical review and monitoring of existing legislation, policies and practices[,] with the objective of promoting the effective enjoyment of all human rights for people living with HIV/AIDS and members of affected communities.”

**Dublin Action 21:** “By 2005, provide universal access to effective, affordable and equitable prevention, treatment and care including safe anti-retroviral treatment to people living with HIV/AIDS in the countries in our region where access to such treatment is currently less than universal, including through the technical support of the UN through the global initiative led by the World Health Organization and UNAIDS to ensure 3 million people globally are on anti-retroviral treatment by 2005 (“3 by 5”). The goal of providing effective anti-retroviral treatment [should be pursued] in a poverty-focused manner [that is also] equitable [and targets] those people who are at the highest risk of and most vulnerable to HIV/AIDS.”

**GENDER EQUITY** refers to fairness and justice in the distribution of benefits and responsibilities between women and men. The concept recognizes that women and men have different needs and powers and that these differences should be identified and addressed to rectify the imbalance between the sexes (1).

This definition moves beyond the popular notion of gender<sup>20</sup> equality by recognizing that fairness requires not equal treatment, but attention to the needs of each sex to allow them to achieve equity in society. While there are obvious gaps in this evolving notion – most notably, the absence of any reference to transgendered people – it is the definition that will guide the focus of this chapter.

There is scant information about gender in reports about the HIV/AIDS epidemic, making it difficult to measure the progress that the WHO European Region has made on issues of gender equity. Data provided in response to most indicators are rarely disaggregated by sex, and where data on gender are available, it is unclear how reliable they are. This lack of reliability is due in part to small sample sizes. Little if any information is provided about how women and men access programmes and services, much less about what societal and other barriers exist for those who do not. Gender is mentioned infrequently in describing the steps countries are taking to institute effective prevention programmes, expand testing availability and improve treatment access.<sup>21</sup>

Injecting drug use and unsafe sex between men have been the primary routes of transmission for HIV in the Region. However, an increasing proportion of new HIV cases are being attributed to

<sup>20</sup> A distinction is often drawn between “sex” – for the biologically determined state of being female or male – and “gender” – for the socially and psychologically constructed state of being female or male. For the purposes of this chapter, however, both terms are used to indicate biological identity.

<sup>21</sup> For example, the Austrian government noted in its 2005 UNGASS report (2) that women and girls were a target population and that the government had a strategy/action framework for women (p. 83), yet the report contained no qualitative or quantitative information referring to gender.

heterosexual transmission.<sup>22</sup> In western Europe, this trend has been observed in **France, Italy, Portugal** and **Spain**, while in the Caucasian republics, at least one quarter of new infections are due to heterosexual sex in **Azerbaijan** and **Georgia** and nearly one half in **Armenia** (5).

Many western European countries have indicated that the rise in heterosexual transmission rates is due to the increasing number of migrants, both legal and illegal, who test positive, including many who have contracted the virus in their countries of origin, notably countries in sub-Saharan Africa. For example, in **the United Kingdom**, where nearly 60% of all new HIV infections are due to heterosexual transmission, the government estimates that nearly three quarters were acquired outside the country (6).

It is also increasingly clear that sexual transmission from male injecting drug users (IDUs) to their female partners, whether injecting or not, is helping drive the epidemic (7, 8). Nevertheless, what some have called the “feminization of HIV” is not the case in the European Region.

Of the countries where heterosexual transmission is on the rise, very few have identified the steps that need to be taken to provide women with the tools, knowledge and ability to protect themselves. This is particularly true in eastern Europe, but even in western Europe, gender receives scant attention.<sup>23</sup>

To assess progress that the countries of the European Region have made on honouring the commitments they made to gender equity in the Dublin Declaration, we reviewed the 31 national reports they submitted in English on progress they made through the end of 2005 in implementing the United Nations General Assembly Special Session Declaration of Commitment on HIV/AIDS (UNGASS Declaration). As information on gender was limited, we also consulted publications from a wide variety of nongovernmental organizations (NGOs) in the Region and several international bodies. Reports from eastern Europe were far more detailed than those from western Europe, a fact that the text of this chapter reflects. But even with the supplemental sources, there is little information on gender and HIV in Europe.

Accordingly, while this chapter will examine what is known about gender and HIV in the Region, it will raise more questions than it answers. It will review incidence rates, prevention efforts (including access to HIV education and harm-reduction services), access to sexual and reproductive health services, and utilization of testing schemes. It will also critique the quality of information available for assessing progress on gender equity, and provide recommendations to countries and international monitoring bodies about how to better gauge progress on this issue in the future, including a list of suggested indicators that should be collected to determine whether countries are effectively meeting the complex challenges it presents.

### **HIV incidence and gender in the European Region**

While men still comprise the majority of new HIV infections, officially reported rates of newly diagnosed cases in the Region indicate that the percentage of women being infected continues to

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<sup>22</sup> In some countries of eastern Europe, government officials have acknowledged that the percentage of injecting drug users among new infections has decreased due to changed testing procedures, and that the reported statistics do not represent the actual prevalence among IDUs. For example, after mandatory testing of drug users stopped in **Ukraine**, the percentage of drug users among all people with HIV dropped, but government officials have stated publicly that this drop is largely due to changes in testing procedures and not changes in real prevalence (3). Some have also surmised that the rise in the number of newly diagnosed women may be the result of larger numbers of women taking up injecting drug use (4). It is likely a combination of these factors. Other experts question the accuracy of reporting, noting that the Caucasian republics, for example, report almost no cases of MSM transmission.

<sup>23</sup> **Ireland**'s 2005 UNGASS report (9) is not atypical. In it, the word “women” appears only once, in the context of antenatal care, and no statistics cited by the government are disaggregated by sex.

grow. In 2004, approximately 36% of all newly diagnosed infections reported in Europe were women (8). It appears that this increase is occurring primarily in eastern Europe.

In some western European countries, there has been a reported increase in the proportion of new seroconversions among men who have sex with men (MSM). The Swiss government noted that, like **Germany**, the country has experienced an increase in the number of gay men seroconverting, which it attributes to the relaxation of preventive behaviour some two-and-a-half decades into the epidemic.

Official statistics indicate that close to 90% of newly infected women in the Region are infected through heterosexual contact. The highest proportions of infected women contracting HIV through heterosexual transmission occur in **Estonia, Latvia, the Russian Federation and Ukraine** (10), countries where the primary mode of HIV transmission is through injecting drug users. In a recent study, researchers have concluded that determining the true mode of transmission is difficult because many infected women have more than one risk factor. Most notably, many of the pregnant women testing positive in **the Russian Federation** – who reported heterosexual transmission of HIV – were also found to be injecting drug users (11).

### **Government response**

Response to the changing epidemic in terms of gender varies across the Region, but it is fair to say that little attention to gender was evident in any of the 2005 UNGASS reports from the Region, or in the work that they are doing. When asked to identify groups of interest or target populations for education and prevention efforts, most countries rightly focused on traditional male risk groups or groups that encompass both men and women (or boys and girls) (12). In **Montenegro**, for example, the “groups of interest” identified by the government in its report were youth, IDUs, (male and female) sex workers, MSM, sailors, people working in tourism and hotel management, Roma and prisoners (13). Further, gender was not explicitly mentioned in the national plans for either **Estonia** or **Latvia** (7). Some countries state that women and girls are not target populations (14). On the other hand, the UNGASS reports from **Ukraine** and **the United Kingdom** (6, 3) paid relatively significant attention to women and girls.<sup>24</sup>

**Switzerland** is another country that appears to pay attention to gender in planning. Concerning the country’s work with migrant communities, for example, the Swiss government specifically stated that they work with men and women, and the listing the government provided of the places where outreach is done included religious communities, hairdressing salons and bars demonstrated that they are attempting to reach out to both sexes. The government’s report also mentioned “mediators” being both male and female. The Swiss government was the only one of all the reporting European countries to note that both men and women were employed as HIV/AIDS prevention workers. In addition, the government reported that African women are a specific target in its prevention work among migrant communities.

### **Education**

Strong cultural barriers to increasing the level of knowledge about HIV among women exist in countries throughout the Region where it is taboo for women to know about any matters relating to sex. “Women who share knowledge or interest in sexual activities with their partner are at risk of being considered ‘dirty, bad women’” (7). Not surprisingly, levels of knowledge about HIV and transmission routes in particular have been disturbingly low throughout the Region, even for

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<sup>24</sup> The Ukrainian Ministry of Health devoted particular attention to “youth and women, people with risky sexual behavior, people living with HIV, [people] suffering from AIDS and their relatives” (3). In the **United Kingdom**, the Department of Health works closely with the Department for Education and Skills, which oversees implementation of the “Teenage Pregnancy Strategy aimed at reducing the number of unplanned teenage pregnancies and reducing unsafe sex” (6).

those groups prevention efforts seem to have reached, suggesting either that prevention messages were ineffective, or that the questions posed to measure HIV knowledge were poorly designed. For example, the Government of **Kyrgyzstan** reported in its 2005 UNGASS report that no IDUs or prisoners (and only a handful of female sex workers) responded accurately to questions about HIV transmission, despite the fact that the government reports reaching large numbers of IDUs, prisoners and female sex workers through its prevention programmes (15). (As in most UNGASS reporting, there was no breakdown of how many men and how many women in these populations were reached.)

In the 2006 UNAIDS global report on the epidemic (16), young men had higher levels of HIV-related knowledge than young women in all but three countries in which the data were broken down by sex. Nevertheless, more men are living with HIV than women in every single Member State of the European Region. There is a clear need to move beyond interventions that focus on knowledge and address the underlying causes of gender inequity.

For example, all but two countries in the Region aimed public education campaigns at the general population. **Poland** noted its implementation of a social marketing campaign to encourage women to get tested, targeting pregnant women and those who were planning to become pregnant (17). The Swiss campaign, “Love Life—Stop AIDS”, features a DVD in male and female versions, presumably taking into account the importance of providing sex-specific information (18). The government also reported that one doctor in the film is male, the other female. The DVD is used in schools as well.

### **Harm reduction**

It is evident from the UNGASS country reports that harm-reduction efforts have been scaled up throughout the Region, but it is difficult to assess the different impact these services may have had on men and on women because the data are infrequently disaggregated by sex, and because the overwhelming majority of countries provide no indication that the design of their harm-reduction programmes takes gender differences into account.

It is important to pay attention to harm-reduction programme design because of the ways in which gender differences affect the way that men and women obtain and use drugs, and the way that they engage in prevention activities. For example, while men are often “in charge” of obtaining drugs, women are often the ones who obtain the money to buy the drugs by engaging in low-wage or illicit work such as sex work or shoplifting.

Studies across the Region have shown that men are more likely than women to utilize syringe exchange programmes. In areas where syringes are scarce, the partner in a couple who controls the syringe holds the power to control the way in which it is used, and hence, who injects first and who may be forced to use a contaminated syringe. In eastern Europe, where injecting drug use is common, women may be the last to use the needle. On the other hand, men may experience heightened risk because of gender expectations, a concept that is explained more fully below (19). Gender differences thus translate into power imbalances that affect harm-reduction efforts.

Unfortunately, nearly every 2005 UNGASS report from the European Region was marked by something close to gender-blindness when it came to discussing prevalence, prevention and treatment for IDUs – probably because most IDUs are men. Yet estimates of the proportion of

IDUs who are women, range from 20% in some countries in the Region to 40% and higher in others (19). Official figures of female IDUs are more often than not vast underestimates.<sup>25</sup>

In one of the most exhaustive 2005 reports from the Region, the Swiss government devotes more than a page to discussing prevalence and behaviour change among IDUs, but none of the statistics provided are disaggregated by sex. Nor was **Latvia's** report (20) atypical. The government cites the introduction of harm-reduction programmes in the republic as a “notable success.” However, the government provides information on the kinds of harm reduction services accessed by IDUs disaggregated by age but not by sex.

Even if statistics reflecting who is accessing harm-reduction services were disaggregated by sex, major obstacles to monitoring progress on gender equity remain because so little is known throughout the Region about the prevalence of substance use and the characteristics of users by sex (19).

Recent United Nations statistics (19) show that in eastern Europe, young men and young women are beginning to use illicit substances at the same rates. Disaggregating data on substance use and prevalence is important to determine whether men and women are accessing harm-reduction programmes in comparable proportions, but simple disaggregation does not provide enough information to discern whether harm-reduction interventions adequately reflect the needs of both men and women, since the nature of HIV risk among IDUs differs by gender and therefore requires targeted interventions.

Ill-informed and punitive policies, ferocious stigma and lack of access to accurate information jeopardize the health of women drug users and their children. In some countries, including **the Russian Federation** and **Ukraine**, drug-using or HIV-positive women are pressured or coerced to abort or to give up their children to the care of the state, and are denied accurate information about PMTCT or drug use and treatment during pregnancy (21).

### **Sexual and reproductive health**

The 2005 UNGASS reports contained virtually no information on sexual and reproductive health. The Albanian Government, for example, only reported that referrals to family planning services are not offered through the country's voluntary counselling and testing programme (22). And while the reports indicate no European progress on sexual and reproductive health services, the government of **the Netherlands** at least stated a goal of “better linking the promotion of safe sex with the promotion of sexual and reproductive health” (23).

Wherever data on condom use were disaggregated by sex, the percentages of men who reported having used a condom during sex with their last non-regular partner differed starkly from the percentages of women who did. For example, in **the Czech Republic**, only 31% of young women reported using a condom with their last non-regular sexual partners, as opposed to 55% of young men who did; in **Serbia**, the figures were 19% for young women and 46% for young men; and in **Ukraine**, they were 17% for young women and 44% for young men (3, 24, 25).<sup>26</sup>

Aside from the incidence of sexually transmitted infections (STIs) (see Chapter 10), other indicators that could signify progress in the area of sexual and reproductive health are abortion rates among women with HIV, access to modern contraception methods, access to and use of

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<sup>25</sup> In **Estonia**, for instance, the Ministry of Social Affairs has estimated that 14% of the country's IDUs are female, while NGOs believe that the true proportion is closer to one third (7).

<sup>26</sup> These figures may reveal something other than just gender disparities; they may also indicate the reliability of self-reported data. A more reliable indicator would be the number of condoms distributed, disaggregated where possible by gender and type of distribution venue.

condoms disaggregated by gender, and access to post-exposure prophylaxis (PEP) in cases of sexual assault. Only the latter two are included in the UNGASS reporting mechanism, and, consistent with the pattern of reporting discussed thus far, countries provided very little information on them in their 2005 reports. For example, most countries did not respond to the query about access to PEP at all. **Spain** specifically reported that PEP was available for non-occupational exposure (26); on the other hand, **Albania**, where PEP is available for occupational exposure to HIV, reported that it is not available in cases of sexual assault (22).

Detailed information about progress in the Region in the area of sexual and reproductive health, however, is available in two reports from European NGOs. The first, *Sexual and reproductive health rights in Europe* (8), published in 2006, observes that:

In its recent Statement on HIV Prevention for an AIDS-Free Generation, the EU has acknowledged that growing epidemics in eastern Europe highlight the needs for evidence-based HIV prevention and notes that access to sexual and reproductive health information and services, including sexuality education, is key to fighting the spread of HIV/AIDS within the Union.

The report cited inadequate sex education and low rates of modern contraceptive use throughout the European Union and raised significant questions about HIV prevention and transmission. The information it provided about individual central and eastern European countries painted a mixed, but fairly grim, picture.

- **Ukraine** has one of the highest birth rates in Europe among adolescents and, not surprisingly, a lack of comprehensive sex-education programmes in schools.
- Public education on HIV/AIDS, sex education and condoms are all rarities in **the Russian Federation**. Russian adolescents are contracting the virus faster than any other group in the country, indicating, in combination with the high rates of teenage pregnancies and STIs, that girls are extremely vulnerable to infection. The lack of condoms, comprehensive sex education and family planning centres exacerbates the situation.
- In **Bulgaria**, sex education is not required in schools, and when health education classes do include information on sexuality, they are taught by teachers with insufficient training. Progress is being made, however, as the government has begun rolling out a new comprehensive sex education package in cooperation with NGOs.
- While young people in **Latvia** currently hold many misconceptions about various sexual and reproductive health issues, the government does appear to be moving to implement sex education in the general school curriculum.
- **Romania** seems to have made progress on expanding access to family planning, sex education and gynaecological services to women by establishing a unit within the Ministry of Health, opening specialized health care centres in rural areas and adopting a strategic plan on sexual and reproductive health issues in 2003, although it is unclear what progress the country has made since 2004.
- **Croatia** appears to be moving backwards, reducing the number of family planning counselling centres it has throughout the country. As one measure of the impact of this development, the percentage of women under 19 who “undergo abortion ... increased from 6% in 2000 to 8.3[%] in 2003 and there is a growing incidence of STIs, primarily infections caused by *Chlamydia* and HPV [(human papillomavirus)]”.

The second report (27), on sexuality education in Europe by the Sexual Awareness for Europe (SAFE) Project, documents that throughout the Region, comprehensive sex education faces political, ideological and religious opposition. Sex education is not mandatory for most of the Region, the exceptions being **Estonia, Finland, Hungary, the Netherlands** and **Norway**. Most countries' sex education programmes are, moreover, insufficient. Even in countries where there are few barriers to effective sex education programmes, there is little evidence that gender is a

priority – either in initiating discussions of gender that go beyond physical differences or in targeting programmes specifically to boys and to girls.<sup>27</sup> While research from the SAFE Project found no clear linkage between sex education and condom use, comprehensive sex education was found to be essential for reducing HIV-related stigma (28).

### **Access to testing**

HIV testing rates are generally low in eastern Europe, though they are declining even further among certain high-risk populations due to confidentiality and law-enforcement concerns. In general, however, in many countries there appear to be comparable numbers of women and men being both tested and informed about the results, e.g. in **Germany, Ukraine and the United Kingdom** (6, 3, 29). While access to testing is discussed more broadly in Chapter 14, it is important to point out some gender concerns about testing here.

In some countries, the surveillance systems have been designed to identify particular groups of people who are HIV positive, for example by focusing on IDUs and prisoners. As a result, “not all potentially affected groups of people are being tested. Therefore, the data reflect the situation among those people and groups (chiefly injecting drug users) who come into contact with HIV-testing programmes” (30). Targeted surveillance systems throughout the Region are thought to obscure HIV epidemics among MSM. A more accurate picture of HIV might be obtained if confidentiality is ensured and, particularly, law enforcement access to testing sites is curbed.

### **Moving forward on gender equity**

There is clearly much work to be done both in achieving gender equity in HIV education, prevention and testing, and treatment and care, and in measuring the progress of the countries in the Region in doing so. To better understand how gender affects HIV and how HIV affects men and women differently, countries should take the following actions – and international monitoring bodies should encourage them to do so.

#### ***Disaggregate data by sex and subject it to qualitative analysis***

At a minimum, monitoring bodies must request, and countries must begin to track and report, access to prevention and care and disaggregate the statistics by sex. But knowing the number of men and women who access services is not nearly enough. In order to understand better why certain interventions may be failing to stem the spread of HIV among Group X or Y, countries must engage in some level of qualitative inquiry, asking “why” instead of just “who” and “what”.<sup>28</sup> If individual countries are unable to bear the cost of such inquiries, the task should be undertaken by international donors or monitoring bodies.

#### ***Identify and prioritize risk groups***

Scarce resources require that certain populations be prioritized, but for high-risk groups that encompass both men and women, for instance Roma, information should be more nuanced to better determine the identity of the target population more precisely and the existence of any special programming needs. Identifying other risk groups and designing interventions to reach them can be challenging because they often do not take advantage of HIV services – one of the

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<sup>27</sup> For example, according to the SAFE Project, although some countries specifically have sex education programmes that deal with respect for the opposite sex and gender equality, only **Sweden** and **Poland** pay any attention to the different ways that boys and girls receive sex education information. In **Sweden**, sex education is offered in single-sex groups; while **Poland** acknowledges that boys receive a different form of sex education because they are more likely than girls to attend schools that employ an ideologically driven lecture method of education.

<sup>28</sup> For example, **Kyrgyzstan** was the only country in the Region during the last UNGASS round to report asking sex workers why they had not used condoms during their last sexual encounter with a non-regular partner. A total of 38.6% of the respondents said their partner was unwilling to do so (15).

key characteristics of a risk group is its invisibility. The cost of not attempting to do so, however, is steep.

The commonly overlooked risk groups where gender plays a role include both the sexual partners of members of traditional risk groups, and anyone who suffers economic or ethnic oppression. These are:

- *Partners of risk group members.* In reviewing the UNGASS reports from the Region and looking at how countries plan to address the epidemic, and how they report on it to international monitoring bodies, it is overwhelmingly evident that countries focus on risk groups and vulnerable populations as vectors of disease transmission, rather on their risk and vulnerability and their resulting suffering. For many women, what places them at the most risk for HIV is their relationship to men.
- *Partners of IDUs.* IDUs present a risk to each other through shared injection equipment, but they also have a high number of non-injecting sexual partners.<sup>29</sup> There is high recognition throughout the Region that an increasing number of men and women are placed at risk because they are the sexual partners of IDUs, but beyond mention of this possibility, there is little indication that any country has made any effort to design programming or create services that will address this risk.
- *Partners of prisoners.* Being in prison is a major risk factor for HIV, but it is becoming increasingly clear that incarceration increases the risk of infection not only for those incarcerated, but also for the communities they come from. The sexual partners of prisoners are vulnerable to infection for two reasons. First, when a primary sexual partner is absent, there is a strong tendency to engage with new, and often concurrent, sexual partners. Second, prisoners often return home with infections that they contracted in prison.<sup>30</sup> The risk is exacerbated when there are particularly high concentrations of incarceration in communities, which is the case in many central and eastern European countries. For example, the median incarceration rate for central and eastern Europe is 185 per 100 000 population compared with 90 for southern Europe, and in the five central Asian republics the rate is 292 compared with 57 for the south central Asian sub-continent (35).
- *Female partners of MSM.* Some men who have sex with men also have sex with women.<sup>31</sup> In eastern Europe and particularly in central Asia, the intense stigma that homosexual behaviour carries puts pressure on many MSM to marry, often placing their sexual partners, female and male, at risk. There is scarcely any mention in reports from the Region about the risk to the female partners of MSM or about how MSM cope with homosexual identities, desires and

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<sup>29</sup> Some countries acknowledged this risk in their 2005 reports. For example, **the Russian Federation** devoted a section to the risk that IDUs pose to non-injecting sexual partners, noting that “65.3% of men who use intravenous drugs had sex with women who do not use” (31). Significant numbers of non-injecting sexual partners are at risk throughout eastern Europe. “In Kharkiv, **Ukraine**, 40% of community-recruited IDUs reported non-injecting regular sexual partners. In Warsaw, **Poland**, 26% of IDUs had regular partners who did not inject. In Tver, **the Russian Federation**, 63% of IDUs had non-injecting sexual partners.” (10)

<sup>30</sup> In **the United States**, the fastest-growing group of new heterosexually acquired HIV cases is among African-American women. A recent study in *Infectious diseases corrections report* draws the connection between the high incarceration levels of black men and new cases of HIV among black women. The authors identify two factors related to incarceration affect the risk of HIV transmission to the partners of those incarcerated: the return of newly infected people from prison, where high-risk behaviours are widespread, and the disruption of social networks that result from incarceration (32). “As black men cycle in and out of jail and prison, black women are torn from relationships and go on to have more ‘concurrent relationships,’ or more than one partner in communities where more people are infected” (33).

<sup>31</sup> A survey among MSM in Moscow and Saint Petersburg (34) points out that, 16.5% of MSM in Moscow also had sex with female partners and 35% in Saint Petersburg identified themselves as bisexual.

activities. The additional risk that MSM expose women to makes services to MSM and policies to reduce the stigma associated with them even more important.

- *Partners of migrants.* Spouses and other sexual partners of male migrants are highly vulnerable to HIV, and at least one country (**Moldova**) points this out specifically in its last UNGASS report (36). Migrants themselves are at risk due to poor access to health services and the fact that they may turn to sex workers to satisfy their sexual needs while working abroad, which in turn may place their partners at greater risk when they return home.

Expectations for men's role in society and in relationships can make them particularly vulnerable to HIV. Most cultures in the European Region expect men to be more sexually active and knowledgeable than women. "Such expectations encourage young men to deny risks and prevent them from admitting their lack of knowledge." (7) Whether they have sex with other men or only with women, and whether they are married or single, men statistically have more sexual partners than women do. Having a large number of partners increases one's risk for HIV and other STIs, as well as increasing the risk for one's sexual partners (7).<sup>32</sup> Men from countries that are economically devastated or in transition, as most of the former Soviet republics are, have a tendency to express a "hyper-masculine identity, which includes taking risks sexually and with their drug use" (7). Injection itself is often seen as "masculine behaviour", and more "macho" than taking pills (7).

#### ***Identify and dismantle barriers to prevention and care***

A number of factors coloured by gender affect the ability of both men and women to access HIV education, prevention, care and treatment. Few indicators exist that permit assessment of a country's progress in adapting HIV services to meet the needs of men and women respectively. Yet while barriers to access are difficult to address, progress in doing so is less difficult to measure.

*Location and hours of operation.* In their 2005 UNGASS reports, many countries in the Region noted that harm reduction, testing and HIV care facilities were centrally located in urban areas, and that this presents a barrier for those people, most of them women, who do not have means of transportation to reach these facilities on their own. But location, as well as hours of operation, is important for other reasons as well. Several questions are useful to ask. For instance, are HIV services available through specialized centres where entering the building might subject users to the effects of stigma? Are there separate hours reserved for women only? Are there hours that allow children's caregivers and people who are employed outside their homes to attend?

*Staffing.* Nowhere in any European country report was there a mention of the percentages of male and female staff in HIV prevention, testing and treatment services. The sex of staff members often has a profound impact on who accesses such services. For example, in **Estonia**, the staffs of the Family Planning Association's Youth Counselling Centres (YCCs) are primarily female. The centres' client base reflects its staff composition – only 4% of the clients are young men (7).

*Programming.* Perhaps more important than the gender composition of staff is programming: are the available services designed to draw both men and women in? With regard to the example

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<sup>32</sup> In **Kyrgyzstan**, for example, "polygamy is often approved of and if a man has an extra-marital child this may be regarded with hidden respect"<sup>(7)</sup>. Similarly, after having "their self-esteem undermined by ethnic discrimination, low economic or social status", men often try to regain their masculinity by taking risks, e.g. in **Estonia**, where "Drug use becomes an escape as well as a protest" (7). "For socially disadvantaged young men, performing illegal and dangerous activities such as injecting drugs may be the most accessible means to affirm their masculine identities."<sup>(7)</sup>

from **Estonia** above, one region in the country saw an increase in the number of young men who visited a local YCC that set aside one afternoon a week for services geared toward young men. Services geared to a target population draw it in. Offering women such services as income support and child care are reliable ways to attract more women, but successful efforts need not be that expensive; offering feminine hygiene supplies, grooming supplies and women's clothing can also be effective, as has been shown by Odysseus in **Slovakia** (37).

*Economic dependence.* Regarding the question of whether women and men have equal opportunities for access to prevention and care, the Government of **Kyrgyzstan** stated frankly: "Commercial clinics and healthrooms are more affordable for men, because women are more economically dependent" (16). Certainly, convenience and affordability play a large role in whether people can access services; even when the services are free, clients must still pay for transportation to services, and perhaps child care or lost income as well.

*Laws and policies.* The question "Does your country have laws and regulations that present obstacles to effective HIV prevention and care for most at-risk populations?" – from the 2005 National Composite Policy Index that formed the basis for the latest UNGASS country reports – was ineffective.<sup>33</sup> Most countries answered "No", despite the fact that they did have statutes and policies in place that created such barriers.<sup>34</sup> One such policy in effect in many eastern European countries – but one not a single country reported as a barrier – is a requirement to register in order to receive health care – a policy that affects women disproportionately because of their heightened need for reproductive health care. In much of eastern Europe, many sex workers, IDUs and poor people move around without proper housing or addresses, and are therefore not registered. This policy also discourages migrant workers from utilizing health services, thus making them more vulnerable to HIV (7). National policies that require sex workers to register pose similar problems.

*The role of violence and power.* "Inattention to the reality of gender-based violence in the promotion of healthy sexuality and safer sex makes messages of abstinence, partner communication and condom negotiation seem irrelevant and naive, if not ludicrous ..." (38). The clearest example of the way that violence and power affect prevention is their impact on the ability to negotiate condom use, but there are other manifestations as well. Violence affects every aspect of a country's HIV/AIDS plan: from access to prevention tools and the ability to use them, to access to care. Violence, notably violence against women, is a serious problem in the Region,<sup>35</sup> but the only European country to mention violence as a risk factor for HIV

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<sup>33</sup> In 2007 the question was changed to "Does the country have laws, regulations or policies that present obstacles to effective HIV prevention, treatment, care and support for vulnerable sub-populations?" See [http://data.unaids.org/pub/Report/2007/jc1318\\_core\\_indicators\\_manual\\_en.pdf](http://data.unaids.org/pub/Report/2007/jc1318_core_indicators_manual_en.pdf).

<sup>34</sup> Some countries were more forthright. Consider **Ukraine**'s response:

Current laws do not contain direct norms or regulations that would present obstacles to effective HIV prevention and care. However, a number of by-laws (resolutions, orders of various government bodies) there are some regulations, which do not facilitate prevention and care. A special issue is criminalization of certain most-at-risk populations (injecting drug users, female sex workers). In other words, there are no direct obstacles for the implementation of prevention and care programmes, but the abovementioned groups have limited access to such services (15).

**The Russian Federation** replied with a similar insight: "... repressive strategies are harmful to the legislative environment that is indispensable for the implementation of modern prevention and support programs" (31). And the **United Kingdom** was perhaps the most exhaustive in listing barriers it was responsible for, identifying seven of its policies that posed obstacles to effective prevention and care (6).

<sup>35</sup> For statistics on the prevalence of violence in the European Region, see "Violence against women and trafficking" in *HIV/AIDS in Europe* (38). The 2005 UNGASS report from **the Russian Federation** notes, "31% of premarital sexual encounters for schoolgirls are reported to be the result of rape." A study of sex and drugs among Moldovan youth states, "More than 50% of youth from rural areas report that they know people who have been sexually

transmission in its 2005 report was **the Russian Federation**, and that was only for female sex workers (32). There are no statistics available on violence as a risk factor for male and transgender sex workers – though for HIV-related vulnerability and stigma, the greatest source associated with gender identity is in fact violence against gay, lesbian, bisexual and transgender people.

### Suggested indicators

<b>Indicator 1</b> (proposed)	Does your country monitor violence against men and women, respectively? Does it monitor violence against sexual minorities?
<b>Indicator 2</b> (proposed)	Does your country evaluate the messages contained in public and school-based HIV education efforts? If yes, how? Are they gender-specific?
<b>Indicator 3</b> (proposed)	Are sexual education programmes in school addressing gender differences in sexual behaviour?
<b>Indicator 4</b> (proposed)	Is sex work criminalized?
<b>Indicator 5</b> (proposed)	Is the transmission of HIV criminalized?
<b>Indicator 6</b> (proposed)	Are modern methods of contraception (e.g. oral or injectable contraception, implants and intra-uterine devices) available? Are they provided free of charge? Are data on access to contraception differentiated by sex?
<b>Indicator 7</b> (proposed)	Does your country require that a person register his or her residency in order to access health care?
<b>Indicator 8</b> (proposed)	Is homosexuality criminalized in your country?
<b>Indicator 9</b> (proposed)	Can male or female IDUs retain custody of their children while being treated for drug use?
<b>Indicator 10</b> (proposed)	Do injecting-drug prevention programmes address the different behaviours of men and women? If yes, how?
<b>Indicator 11</b> (proposed)	Do harm-reduction programmes address the different needs of men and women? If yes, how?
<b>Indicator 12</b> (proposed)	Do harm reduction programmes address the needs of IDUs and pregnant women?
<b>Indicator 13</b> (proposed)	Do gender-based violence policies address the links with HIV risk?

### Conclusion

Monitoring progress on gender equity in responding to HIV/AIDS in the European Region is nearly impossible because so few statistics on HIV prevalence and access to HIV prevention, education and treatment are disaggregated by sex. Progress itself is difficult without information that would indicate the extent of gender disparities. The overarching message that should emerge

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abused” (39). Rates of violence are high everywhere, but rates of violence against the groups that are most vulnerable to or at risk for HIV – women, IDUs, sex workers and MSM – are even higher (7).

from this chapter is that European countries must begin to examine the complicated issues that pose barriers to gender equity. Doing so will require them to report the steps they are taking to combat HIV/AIDS that respectively target men and women, and to measure the impact that these efforts are having.

## Recommendations

1. HIV monitoring bodies should disaggregate all possible HIV data by sex and subject it to qualitative analysis.
2. International experts should develop a clear, operational definition of gender for use in surveillance, drawing on the suggested indicators listed above.
3. Identify and prioritize risk groups from both sexes.
4. Prevention programmes need to be developed to target the sexual partners of IDUs, migrants and prisoners, and the female partners of MSM.
5. Countries need to identify obstacles to gender-equitable prevention and care – and dismantle them. Such barriers may include the location, hours, staffing and programming of services; unconsciously restrictive laws and policies; and gender-related violence.

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## 7. Prevention of mother-to-child transmission and paediatric AIDS

**Dublin Action 11:** Ensure that HIV-positive women and expectant mothers have access to high quality maternal and reproductive health care services in order to prevent mother to child transmission

**Dublin Action 12:** By 2010, eliminate HIV infection among infants in Europe and central Asia (with elimination defined as less than 2% of all new infections being acquired by an infant from its infected mother)

**Dublin Action 14:** By 2005, to develop national and regional strategies and programmes to increase the capacity of women and adolescent girls to protect themselves from the risk of HIV infection, and reduce their vulnerability to HIV/AIDS

### 1. Introduction

The World Health Organization European Region contributes to less than 1% of the global burden of HIV among children. Given the available interventions and resources in the Region, reaching the Dublin Declaration goal of the virtual elimination of HIV among children by 2010 is a real possibility.

Western Europe is close to achieving the goals of virtual elimination of mother-to-child transmission of HIV and HIV infection among infants. The challenge is to extend this success throughout eastern Europe and central Asia, where increasing HIV infection among young women is reported in a context of weakened health and social systems as a result of the socio-economic and political transition.

The implementation of PMTCT programmes has been rapidly scaled up in many countries in eastern Europe and central Asia, but such programmes still face a number of challenges, particularly in moving from increased access towards increased quality of services and ensuring better access to routine services for most-at-risk populations.

Facilitating inter- and intra-regional cooperation in sharing experiences, knowledge and technology related to the prevention of mother-to-child transmission and paediatric AIDS is a good investment for accelerating effective programming and achieving the goals of elimination of HIV in children.

### 2. Prevention of mother-to-child transmission of HIV: status and progress

In the absence of any preventive interventions, infants born and breastfed by HIV-positive mothers have roughly a one-in-three chance of acquiring HIV infection (1). This can happen during in utero, during labour and delivery or through breastfeeding. The risk of mother-to-child transmission can be significantly reduced through the complementary approaches of providing antiretroviral treatment for the mother with or without prophylaxis to the infant, implementation of safe delivery practices (for example, Caesarean section) and safe alternatives to breastfeeding.

In Europe, significant progress has been made in preventing mother-to-child transmission of HIV. Many countries have been able to report substantial reductions in transmission rates and some have achieved the virtual elimination of infections through this route. Western Europe is well on the way to totally eliminating HIV infection among infants. In 2005, only 167 cases of HIV-infected children were recorded among 23 western European countries (2).

While important progress has taken place in eastern Europe and central Asia, there is still a need to accelerate PMTCT programmes in order to achieve the full elimination of HIV infection among infants by 2010. In the most affected countries, transmission from mothers to infants has

been reduced to around or fewer than 10% through preventive interventions. However, in order to achieve further reductions it will be critical to intensify national PMTCT efforts and ensure that they reach all HIV-positive pregnant women.

The true elimination of HIV among infants will require all countries to adopt a comprehensive approach to PMTCT as recommended by the European Strategic Framework for the Prevention of HIV Infection in Infants, developed by UNAIDS cosponsors under the leadership of WHO in 2004. The Framework focuses on four interrelated elements: 1) preventing HIV infection among women of child-bearing age and their partners; 2) preventing unintended pregnancies among HIV-infected women; 3) preventing HIV transmission from infected women to their babies and 4) providing care and support to HIV-infected women, their infants and families.

## **2.1 Analysis of PMTCT intervention coverage**

Progress in the implementation of national PMTCT programmes varies from country to country, reflecting both the varying characteristics of the epidemic as well as the capacity of the health system and related sectors to respond to HIV. There has been important progress in several key areas of PMTCT programmes, as presented below.

### *2.1.1 HIV Testing and Counselling*

Ensuring access to voluntary HIV counselling and testing (VCT) for all pregnant women is a critical component of any PMTCT programme. Given the availability of effective interventions that can eliminate the risk of HIV transmission from mothers to infants, there is growing consensus among public health professionals worldwide that increasing access to routine HIV testing during pregnancy is a cost-effective and efficient way to prevent HIV infections among infants.

A positive trend of increasing percentages of women tested for HIV during pregnancy has been observed in a number of European countries. In 2005, of the 2.6 million women giving birth in seven countries of eastern Europe and central Asia, an estimated 75% were counselled on PMTCT and received an HIV test, up from 66% in 2004. These seven countries together account for 90% of the estimated HIV-positive pregnant women in the sub-region (3).

National governments in eastern Europe and central Asia are increasingly adopting policies and providing services facilitating access to VCT for pregnant women, but important differences remain among and within countries. In some of the hardest-hit countries, such as **the Russian Federation** and **Ukraine**, more than 80% of women receive state-funded HIV testing during pregnancy. Access to VCT services is highest in the areas that also have the highest HIV prevalence. In some of the lower-prevalence countries in eastern Europe and central Asia, VCT is still not routinely offered to all pregnant women.

Early diagnosis of HIV infection in women is important in order to increase their chances to fully benefit from available services. Investments in increasing access to VCT for women of child-bearing age are therefore essential, particularly for those most vulnerable to HIV infection. In western Europe most women access VCT services and many know their HIV status well before they become pregnant. Anonymous and confidential VCT services are within easy reach of the majority of women, including those most marginalized and vulnerable to HIV. In contrast, in eastern Europe and central Asia, most women find about their HIV status only during pregnancy or delivery. For example, women in western Europe are five times more likely to get their first HIV diagnosis before pregnancy than women in **Ukraine** (4). The situation is particularly difficult for the most vulnerable women such as sex workers and injecting drug users (IDUs) – often overlapping groups – who are the least likely to access VCT prior to pregnancy.

In many circumstances, even the VCT services offered through antenatal clinics are not accessed by these women.

### *2.1.2 Antiretroviral drugs and safe delivery practices*

The use of antiretroviral (ARV) drugs during pregnancy has resulted in remarkable reductions in new cases of HIV transmission to infants. The effectiveness of ARVs in preventing mother-to-child-transmission varies depending on the type and combination of ARV drugs used and the duration treatment. Combination ARV drugs are considered more effective in preventing transmission than single drugs. Starting ARV treatment earlier in pregnancy achieves better results than starting just prior to labour or during delivery.

European countries reported that more than 90% of women who tested HIV-positive during pregnancy or delivery received ARV drugs for PMTCT in 2005. The predominant ARV prophylaxis regimen used in the most affected countries of eastern Europe and central Asia was a single-drug regimen (zidovudine or nevirapine), resulting in an overall HIV transmission rate of 10% to infants. Most clinical centres in western Europe that use three-drug combinations have been able to minimize the risk of HIV transmission to under 2%.

A further reduction in mother-to-child transmission of HIV can be achieved through elective Caesarean section, the main method of delivery among HIV-infected women in western Europe, where it has reduced mother-to-child transmission, which mainly takes place around the time of delivery in non-breastfeeding populations. In eastern Europe and central Asia, the majority of HIV-positive women deliver vaginally. Many countries still lack clear and feasible guidelines on appropriate methods of delivery for HIV-infected women. Moreover, even when guidelines are available, there is reluctance among some health care providers to follow them, due to unfounded fears of exposure while performing Caesarean section. Nevertheless the leadership and enthusiasm of health care workers in some of the clinical centres in eastern Europe and central Asia have achieved elective C-section rates similar to those observed in western European centres and, as a result, lower mother-to-child transmission rates than other centres.

### *2.1.3 Family planning and contraception*

Strengthening family planning services for all women is important for their own health and for reducing the risk of HIV transmission to their children. Access to family planning and reproductive health services by HIV-infected women is a key component that will empower them to make informed decisions about their reproductive choices.

The availability and quality of family planning services for HIV-infected women varies across the Region. The need for contraception remains high in most eastern European and central Asian countries. Use of modern contraception methods among the general population is estimated as three times lower than in western Europe. The number of HIV-infected women delivering at a very young age is two times higher in **Ukraine** than in western Europe (5). A 2005 study among HIV-positive women in **the Russian Federation** reported that 54% of the women who delivered a child and 94% of those who terminated their pregnancy had not planned to become pregnant (ibid.). This reflects low access to family planning and reproductive health services, as well as inadequate HIV counselling.

Access to reproductive health and family planning services is even worse among IDUs, who are difficult to reach through the usual services and may mistakenly consider themselves infertile because of drug-related amenorrhoea. Special efforts are required to ensure that services reach out to this often neglected and marginalized population.

While in the past there were many reports of coerced termination of pregnancies among HIV-infected women, most countries in eastern Europe and central Asia have now developed policies prohibiting any form of coercion of HIV-infected women to terminate.

#### *2.1.4 Services for HIV-infected mothers, their children and other family members*

The HIV epidemic disproportionately affects socially and materially disadvantaged families, and is often just one of many social, economic, health and psychological problems they face. Families affected with HIV therefore have a variety of needs that should be addressed, including complex protection needs that change over time as the disease progresses.

At the end of 2006, most eastern European and central Asian countries reported universal availability of HAART for pregnant women and children who meet the clinical criteria for the initiation of treatment. However, the uptake of HAART during pregnancy is still not as high as it could be due to a variety of factors, including the insufficient availability of quality counselling and psychosocial support services. In western Europe, use of HIV treatment has been practically universal. A variety of social, legal, peer support and other services have been widely available through governmental and non-governmental agencies.

Peer counselling approaches and the engagement of people living with HIV as peer counsellors and group leaders have been insufficient in eastern Europe and central Asia. In many places there is not enough demand for such services because of the degree of stigma and discrimination associated with HIV infection. Particularly difficult is the double stigma often faced by HIV-positive IDUs and their sexual partners. Access to services for drug users, including methadone substitution treatment, remains extremely low in the region despite a high demand and evidence of its effectiveness. The situation is even more complex for pregnant HIV-positive IDUs, since health and social services often lack even the most basic capacities for their effective servicing and that of newborns suffering from drug-withdrawal syndrome.

The provision of care, treatment and support services for HIV-exposed and affected infants has always been a challenge. Different models for addressing the needs of HIV-infected and affected infants have been developed. A family-focused approach – where the mother receives services together with the child during routine follow-up visits – has been the predominant successful model in many western European countries. In eastern Europe and central Asia, most services are still provided through HIV-specialized clinical centres that cater to mothers and children separately. This generates barriers to the effective management of the mother-child pair. However, there have been some successful experiences in several eastern European countries. The Sunflower day clinics for HIV-infected children in **Romania** and day care centres (DCC) for families affected by HIV in **Ukraine** have demonstrated that an investment in child and family- friendly services, often in close collaboration with local NGOs, can generate positive results by avoiding prolonged hospitalization and reducing the costs of care. In both these examples, the centres provided timely and comprehensive services to families with HIV-infected and exposed children, including support to ensure adherence to treatment, help with transportation to medical institutions, respite care (child care while the mother seeks medical care), liaison with social services and paediatricians, nutritional support, mediation between clinicians and families, special trips and camps for the children.

## **2.2 Analysis of paediatric HIV care and AIDS treatment**

The European region carries an estimated 1% of the global HIV burden among children. While this represents a low burden on the global scale, it hides important variations across the Region. While in several Nordic countries, no paediatric AIDS deaths have been recorded during the last decade, in the most affected countries of eastern Europe and central Asia, which are seeing an increase in HIV-infected women, there has been a steady increase in HIV-infected children who

die. In addition, in some countries, paediatric AIDS is not only linked to vertical transmission from mother to child, but is sometimes a direct result of failures in the health system as well as risky behaviours starting at an early age. The outbreak of paediatric HIV infection that occurred in early 2006 in southern **Kazakhstan**, as well as similar outbreaks that have occurred earlier in other countries, including **the Russian Federation** and **Romania**, indicate the vulnerability of children to HIV as a result of medical malpractice, blood-bank system failure and/or corruption in the system. In other contexts, paediatric AIDS cases have been observed as a result of increasing levels of risk-taking among children at ever younger ages. Reports from various countries indicate an early debut in risk behaviours such as injecting drug use and sexual intercourse among some children, in particular children living on the streets and other children without parental supervision.

Access to treatment for children has been substantially improved over the last three years, but there are still important challenges. Access to paediatric ARV formulations and the capacity of the health care systems in dealing with paediatric AIDS need further strengthening in the eastern part of the continent. In 2003 few clinical sites in eastern Europe had the capacity and experience to treat children with AIDS. With the leadership and commitment of many national governments, technical collaboration with international organizations and funding partners, the number of sites with the capacity to deliver paediatric treatment has been substantially increased within a relatively short time period. A report from the Ministry of Health of **the Russian Federation** indicates that up to 90% of children in need of HAART received it in 2006.<sup>36</sup> Similarly, 55% of HIV-infected children in **Ukraine** – about 90% of those needing ART – were reported to have received HAART in 2006 (6). As access to treatment increases, however, countries need to address the quality of the services, including registered paediatric drug formulations and treatment combinations, inadequate case management, inappropriate counselling and adherence support. These problems are relevant both for countries with only few HIV-infected children (such as **Bosnia and Herzegovina** which has reported significant impediments to paediatric treatment access) as well as countries with many HIV-infected children (**the Russian Federation, Ukraine**). Even in eastern European countries with adequate financing of national AIDS programmes, ensuring the uninterrupted and timely supply of drugs and commodities remains a challenge.

A critical component of successful treatment of children exposed to HIV is the early diagnosis. Polymerase chain reaction (PCR) testing detects HIV infection in infants born to HIV-infected mothers much earlier than the standard HIV antibody tests more widely used for adults. PCR is particularly useful for testing infants because only some of the infants who have a positive HIV antibody test are really infected; the others (the majority) are only carrying their mother's antibodies temporarily. These maternal antibodies disappear from infants at around 18 months of age; thus antibody tests before this age cannot tell whether an infant is truly infected. However, waiting until the age of 18 months is a psychological burden for families, a challenge for health professionals (to maintain contact with these infants and their families while the infant is of indeterminate HIV status) and can affect the quality of care for the HIV-infected infant. In addition, in some countries, children have been abandoned or left in hospital care until their HIV status is known.

Despite rising laboratory capacities for PCR testing in many eastern European countries, still only a very small proportion of infants receive an early diagnosis of HIV infection, which has a negative impact on child morbidity and mortality. Some countries that have the resources and emphasize early detection of HIV in infants, such as **Sweden**, have not registered a single case of AIDS related child deaths among HIV-infected children during the last decade. In **Ukraine**,

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<sup>36</sup> Unpublished report from the UNICEF country office in **the Russian Federation**.

early PCR diagnosis, introduced at the end of 2005, has led to increasing access to timely ART administration. In contrast, there were 65 registered deaths of HIV-infected children under one year old in **Ukraine** in 2005, before PCR diagnosis was available. **Ukraine** has made important progress in the prevention of paediatric AIDS through cotrimoxazole prophylaxis, which prevents opportunistic infections and is a valuable method of preventing early onset paediatric AIDS. Without cotrimoxazole prophylaxis or other treatments an estimated 20% of HIV-infected children will progress to AIDS in their first year of life. In 2006, 88% of HIV-exposed infants in **Ukraine** received cotrimoxazole syrup from the first months of life, to the credit of the health care system.

### **2.3 Protection of orphans and children affected by HIV**

Children affected by HIV are particularly vulnerable to violation of their rights because HIV is usually linked to a number of other problems in their lives. Risks and lack of protection for children increase when their families are poor and lack access to basic services, when parents are absent due to illness, death or abandonment. Reaching this group of children with support and services may be difficult because they may be hidden from view due to the stigma of HIV and AIDS. Protection of orphans and children affected by HIV is problematic in many countries in eastern Europe and central Asia. Social and legal protections, care and support services and family-oriented care are inadequate for HIV-affected children. Approaches taken by national authorities often lead to further stigmatization, social exclusion and marginalization.

In some western European centres in the earlier years of the HIV epidemic, abandoned infants remained in hospitals for long periods of time because there were no alternative care settings (7). However, respite care and longer-term foster care, adoption and supported extended family care were developed relatively quickly as alternative responses to the needs of HIV-exposed and abandoned children.

Recent studies in **the Russian Federation** and **Ukraine** showed that about 10% of children born to HIV-infected mothers are abandoned. Almost all are left in institutions, including orphanages and hospitals. The problem of abandonment and institutionalization of infants born to HIV-infected mothers must be considered in a broader context, however. In general, with economic transition and the socioeconomic pressures on families, the abandonment of children to institutional care has been rising. In **Ukraine** an estimated 103 000 children (481 born to HIV-positive mothers) were living in state-run residential institutions in 2003, a doubling from the previous decade. Children born to HIV-infected parents are more likely to be abandoned than other children. Factors that increase the likelihood of abandonment include poverty, insecure or inadequate housing, drug addiction, sexual abuse, teenage pregnancy, mental illness, unwanted pregnancy, and lack of antenatal care and social and economic services.

An analysis of experiences in **the Russian Federation** and other countries indicates that close contact between the mother and infant immediately after birth and throughout the stay in the maternity hospital is an important factor in preventing abandonment. A friendly and supportive environment in maternal-and-child health services where medical/nursing staff do not stigmatize HIV-infected women can help lessen fears thus prevent abandonment.

Most children with HIV who are placed in institutions remain there for a long time, sometimes in special areas separated from other children. This may have damaging consequences, promotes stigmatization and may result in serious developmental deprivation. There are only sporadic reports of alternative forms of care, including adoption or foster care, for HIV-infected children. **Romania**, for example, has had more than 10 years of increasingly positive de-institutionalization of children with HIV in favour of establishing family homes and foster care for them.

HIV-infected and affected children and families face discrimination in many countries. There are continuing reports of children being excluded from schools and kindergartens, denied access to medical care or being isolated, often along with rampant violations of their privacy. Strong advocacy efforts in close collaboration with associations of people living with HIV are critical for ensuring a reversal of this situation.

### **3. The role of UNICEF and United Nations country teams on AIDS**

UNICEF supports realization of the Convention on the Rights of the Child as it relates to HIV and within the framework of the global Unite for Children – Unite Against AIDS campaign promoted by the United Nations. Critical for children and young people are the rights to non-discrimination, health, information, education, support to families in need, support to orphans and freedom from sexual violence and exploitation, including trafficking. The Unite for Children – Unite against AIDS campaign emphasizes four principal areas (the ‘4 Ps’):

- protection of orphans and vulnerable children
- provision of paediatric treatment
- prevention of mother to child transmission of HIV
- prevention of infection among adolescents and young people (8).

Working in collaboration with national governments, civil society partners, and the UNAIDS Secretariat and Cosponsors, UNICEF contributes towards ensuring universal access to HIV prevention, treatment, care and support for children. Particular emphasis is put on ensuring inclusion of children and adolescents who are marginalized and overlooked by health and social services. Facilitating the full participation of children and young people in national and community responses to AIDS is a priority for UNICEF.

### **4. Recommendations**

Accomplishing the Dublin goals of eliminating HIV infection in infants by 2010 will require intensified and accelerated action. The timely achievement of this fully reachable target will require extension of effective HIV prevention and care services to every woman of childbearing age. Coordinated partnerships among community, national and international partners across Europe and additional financial and human resources will be needed. The recommendations below outline some of the priority actions for governments, civil society and international partners in making progress towards eliminating mother-to-child-transmission of HIV in the European Region.

#### **1. Prioritize eliminating HIV in children in national AIDS responses**

National strategic plans for AIDS in Europe need to be updated to ensure that the goal of eliminating HIV infection among infants and young children is included as a national priority.

#### **2. Mobilize resources to scale up PMTCT programmes**

In a number of countries in eastern Europe and central Asia more efforts are needed to ensure that PMTCT programmes are adequately funded from national or sub-national budgets so as to reduce dependence on external funding sources. This will require continuous advocacy and stronger political commitment of national governments. Particular efforts have to be made to ensure that health care systems have uninterrupted supplies of HIV tests, combination ARV treatments and cotrimoxazole prophylaxis and reliable supplies of condoms.

#### **3. Strengthen institutional capacity to address HIV in children**

Building the institutional capacity and improving the quality of medical and psychosocial support services are critical. Training and information for health care professionals, educators

and social service providers working with HIV-infected women and children need to be increased.

#### **4. Build partnerships between governments, civil society and the international community**

Facilitating East-West and East-East cooperation in sharing experiences, knowledge and technologies for PMTCT and paediatric AIDS is a good investment for accelerating effective programmes. Technical support and strategic partnerships among governments, civil society and the international community should also be strengthened.

#### **5. Increase the involvement of people living with HIV as advocates for children**

National and community associations of people living with HIV should be supported in their advocacy for children. Mechanisms to strengthen the involvement and participation of children and adolescents living with HIV in such associations should also be encouraged. This is a critical to ensuring that the policies and programmes developed for children effectively address their real needs, keeping in mind their full rights and responsibilities.

#### **6. Monitor progress towards the virtual elimination of HIV in infants**

National monitoring and evaluation should ensure that reliable information is systematically collected on issues related to PMTCT and paediatric AIDS. Indicators of the effectiveness of PMTCT programmes should reflect progress made towards the virtual elimination of HIV infection in infants and monitor the development of HIV-infected and affected children. More research needs to be conducted to evaluate the quality of PMTCT interventions. Patterns of HIV transmission from mother-to-child and of paediatric AIDS should be closely monitored throughout the different areas of Europe in order to support informed decision-making about programming.

Further steps after the priority measures include the following:

#### **Increase the extent of PMTCT programmes**

A key component of strong PMTCT programmes is ensuring effective delivery of services through better integration within existing maternal and child health (MCH) and reproductive health settings. Routine MCH services need to address the needs of pregnant HIV-positive women, and HIV services need to be better able to address the management of HIV during pregnancy and prevention of mother-to-child transmission.

#### **Reach marginalized women**

The goal will not be achieved without reaching the vulnerable populations who are usually missed by standard antenatal care services or present for services too late. Special efforts are needed to extend services to IDUs and other marginalized women such as sex workers, trafficked women, ethnic minorities and legal and illegal immigrants. Harm reduction programmes and outreach programmes need to provide women with the information, skills and tools required to deal with HIV and pregnancy. This can only be achieved through better links with reproductive health services. The full involvement of the vulnerable populations and of people living with HIV/AIDS in the design and implementation of interventions is critical for their success.

#### **Improve the quality and accessibility of HIV testing and counselling**

Achieving the goal will require ensuring that every woman of childbearing age has access to voluntary HIV testing and counselling services. Approaches to testing (routine testing, opt-in, opt-out) may vary, but emphasis should be placed on ensuring that services are widely available in the highest prevalence contexts. The quality of voluntary counselling and confidential HIV testing services needs to be improved to ensure that appropriate information and advice is provided to HIV-infected women prior to and during pregnancy. More efforts are needed to link

PMTCT and VCT services to those dealing with drug dependence and harm reduction, including substitution treatment services.

### **Prevent unintended pregnancies among HIV-infected women**

PMTCT programmes need to integrate information and education for preventing unintended pregnancies among HIV-infected women and ensure availability of services and uninterrupted contraceptive supplies. This is critical to ensuring the well-being of HIV-infected women and their capacity to make fully informed decisions about reproduction. The promotion of planned parenthood among HIV-positive women will facilitate the birth of wanted and HIV-free babies, and help prevent abandonment.

### **Revise national policies and guidelines on PMTCT and paediatric AIDS**

National policies, guidelines and protocols for PMTCT and the clinical management of HIV-positive children and pregnant women need to be updated according to the evidence base and new recommendations concerning ARV regimens, safe delivery practices and multi-disciplinary management of paediatric AIDS, among others.

### **Ensure a protective environment for children affected by HIV or at risk of HIV**

A number of measures need to be put in place in order to ensure the well-being of children infected and affected by HIV as well as those at increased risk of HIV infection as a result of their own behaviour or social vulnerability. Access to key services for those children based on the respect of their rights needs to be ensured. Priority actions include:

- developing national policies that favour family-based alternatives (foster care, adoption) to institutionalising;
- countering stigma and discrimination, for example through legal protection and improved monitoring of violations of the rights of children and families affected by HIV;
- protecting confidentiality and the right of equal access to educational opportunities; and
- ensuring access to quality care and treatment for infected and affected children and their parents; efforts should be made to ensure greater treatment literacy and the involvement of parents in the care of the child.

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## 8. Young people and the Dublin Declaration

**Dublin Action 8:** reinvigorate our efforts to ensure the target of the Declaration of Commitment that, by 2005, at least 90 percent of young men and women aged 15 to 24 have access to the information, education, including peer education and youth-specific HIV education, and services necessary to develop the life skills required to reduce their vulnerability to HIV infection, in dialogue with young persons, parents, families, educators and health-care providers.

### 1. Introduction

Young people are vital to the continued development and prosperity of any country: their productivity supports older generations, and their desire and ability to raise children affects future demographic trends. Yet the lack of a sense of purpose and hope stemming from the absence of decent work opportunities in many settings often amplifies HIV risk-taking behaviour linked to unsafe sex and/or drug and alcohol abuse.

Thus the relationship between young people and HIV/AIDS involves both potential and vulnerability. Improved knowledge and understanding about HIV, and increased access to necessary services, will contribute to long-term management of the epidemic; and promoting comprehensive, evidence-informed approaches to HIV/AIDS among young people will contribute to reducing stigma and discrimination. At the same time, factors including young people's stage of life, behaviours and lack of knowledge make them vulnerable to HIV infection. This potential and vulnerability applies to young people across the European region, although in some countries, notably in eastern Europe,<sup>37</sup> the need for a focus on young people is particularly urgent.

Certain themes cut across the comments made in this chapter:

- the need to understand the national situation (both the epidemic and population knowledge and behaviour characteristics) to be effective in programming (*1*);
- the benefit of involving young people in the creation and implementation of youth-related HIV/AIDS policies and interventions; and
- the importance of focusing on young people at risk: as young people are often highly represented among high-risk groups, the emphasis on education and development of life skills also applies to outreach aimed at these young people.

This chapter will focus on Action 8 of the Dublin Declaration, but will also touch on Action 3 regarding the United Nations General Assembly Special Session on HIV/AIDS (UNGASS) commitments relating to orphans and children, and Action 13 on access to services, supplies and information. Actions regarding girls and young women from a gender perspective are covered in Chapter 6 of this volume.

Data collection and monitoring of HIV/AIDS indicators for young people are inconsistent and generally inadequate. Examples of progress are based on a number of sources, including: national UNGASS reports, proposals to and grant performance reports from the Global Fund to Fight AIDS, Tuberculosis and Malaria (GFATM), regular and ad hoc reports from the United Nations Joint Programme on HIV/AIDS (UNAIDS), the World Health Organization (WHO)

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<sup>37</sup> For the sake of brevity, 'eastern Europe' covers the countries of the former Soviet Union, including the central Asian, Caucasian and Baltic republics, unless otherwise stated. 'Central Europe' includes **Turkey** and the countries of south-eastern Europe (excluding **Greece**), while 'western Europe' includes **Israel**.

Regional Office for Europe, the UN Population Fund (UNFPA), the United Nations Children's Fund (UNICEF) Innocenti Research Centre and other sources (including Reproductive Health Surveys, Eurobarometer and civil society organizations). This is not intended as a systematic review, and the list of sources consulted is not exhaustive.

## 2. HIV and young people

For many years, the international community has highlighted the importance of preventing HIV infections among young people – as noted by UNFPA in 2001 regarding the International Conference on Population and Development (ICPD) +5 review and the UNGASS Declaration, and reaffirmed more recently by the Dublin Declaration, the United Nations General Assembly's Political Declaration on HIV/AIDS and the Bremen Declaration on Responsibility and Partnership (2). Further, the European Centre for Epidemiological Monitoring of AIDS (EuroHIV) 2005 end-of-year report states that “prevention amongst young people is essential”(3).

### 2.1 Defining 'young people'

Dublin Declaration Action 8 refers to young people as 15–24 years old, in line with the standard definition of 'youth'.<sup>38</sup> While in-depth knowledge and behavioural data collection tends to run from 15, sexual activity often starts before that age (4), and educational initiatives ought to include younger adolescents (5). Sexual activity before the age of 15 is important to record, even if less common, due to increased social and physical vulnerability to infection at younger ages.

National reports often use different age ranges. This need not be a problem, as “youth” is primarily a sociological rather than statistical concept (and youth risk behaviours continue much later than age 24 in parts of Europe); a problem may arise where national reporting allows prejudices about what young people *ought* to be doing at a given age to override evidence-informed approaches to what they *are* doing; for this reason, and for comparability over time, the 15–24 definition is desirable. While WHO and UNAIDS now reliably use the 15–24 age range, reports from EuroHIV still tend to use a 20–29 range and, therefore, some figures below will use the under-30 age group.

### 2.2 Infection rates

In the last decade, central and eastern Europe has had the fastest growing HIV epidemic of any region in the world (6), with reported incidence peaking in 2001 in **the Russian Federation** and **Estonia**, but continuing to rise in **Ukraine** and central Asia (3). Over two-thirds of new HIV infections in 2005 occurred in **the Russian Federation** and **Ukraine** (7).

In central and eastern Europe, more than 80% of those infected with HIV are aged under 30, compared with 30% of reported cases in western Europe (8). Many of these are aged 25–29 – a key group for targeted interventions – and many contracted HIV aged under 25. Between 2001 and 2005, almost 75% of reported infections in eastern Europe were among people under 30; this age group accounted for 34% of reported new infections in western Europe and 54% in central Europe (3). The number of newly diagnosed cases among young people fell overall in the period 2001–2005 (particularly for young men aged 15–19 in eastern Europe: from 12 588 new diagnoses to 945), although the number of new cases in those under 30 in western Europe increased, particularly among women. In 2005, the number of newly diagnosed cases among young people aged 15–24 was 31% in eastern Europe, 21% in central Europe and 10% in western Europe (3). Estimates of the scale of the epidemic by WHO and UNAIDS are much

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<sup>38</sup> In the United Nations system, 'adolescents' are aged 10 to 19, 'youth' 15 to 24, and 'young people' are all those from 10 to 24.

higher than reporting indicates, particularly in central and eastern Europe where surveillance systems are poorest (9). The range of estimated cases in eastern Europe is from 1.2 million to 2.6 million (10).

The majority of those infected through drug use are younger men, but as increasing numbers of sexual transmissions occur, the proportion of infections among women is rising (11). The proportion of reported females among new HIV infections in young people aged 15–24 in **the Russian Federation** was 27% in the period 1999–2002 and 53% in 2003–2005; most of eastern Europe recorded increases in the female-to-male ratio, while there is no trend in western or central Europe (12). Adolescent girls are at even greater physical risk of infection (13), as are adolescent males who have sex with men. See Table 8.1 for an overview of newly diagnosed HIV cases by age.

Table 8.1. Newly diagnosed HIV cases in 2006 and cumulative total by age

Age at diagnosis (yrs)		2006	%	Cumulative total reported*	%
<b>Western Europe</b>					
<b>Male</b>	<15	85	1%	2 409	1%
	15-24	1 190	7%	16 769	9%
	25-49	12 462	77%	135 472	76%
	50+	2 308	14%	20 046	11%
	Unknown age	122	1%	4 439	2%
<b>Total West – male **</b>		<b>16 167</b>	<b>19%</b>	<b>179 135</b>	<b>22%</b>
<b>Female</b>	<15	121	1%	2 095	3%
	15-24	1 165	14%	12 966	17%
	25-49	6 469	75%	54 038	71%
	50+	795	9%	5 075	7%
	Unknown age	41	0%	1 868	2%
<b>Total West – female **</b>		<b>8 591</b>	<b>10%</b>	<b>76 042</b>	<b>9%</b>
<b>Central Europe</b>					
<b>Male</b>	<15	18	1%	2 343	13%
	15-24	177	13%	3 252	18%
	25-49	872	66%	9 361	51%
	50+	115	9%	1 071	6%
	Unknown age	133	10%	2 226	12%
<b>Total Centre – male **</b>		<b>1 315</b>	<b>2%</b>	<b>18 253</b>	<b>2%</b>
<b>Female</b>	<15	17	4%	1 721	23%
	15-24	96	21%	1 923	25%
	25-49	275	60%	2 563	34%
	50+	36	8%	294	4%
	Unknown age	36	8%	1 120	15%
<b>Total Centre – female **</b>		<b>460</b>	<b>1%</b>	<b>7 621</b>	<b>1%</b>
<b>Eastern Europe</b>					
<b>Male</b>	<15	252	1%	1 472	0%
	15-24	6 207	18%	138 353	40%
	25-49	27 597	78%	175 365	51%
	50+	1 126	3%	5 352	2%
	Unknown age	43	0%	22 505	7%
<b>Total East – male **</b>		<b>35 225</b>	<b>41%</b>	<b>343 047</b>	<b>43%</b>
<b>Female</b>	<15	173	1%	941	1%
	15-24	9 834	40%	79 879	50%
	25-49	13 985	57%	65 228	41%
	50+	637	3%	2 680	2%

Unknown age	8	0%	10 586	7%
<b>Total East – female **</b>	<b>24 637</b>	<b>28%</b>	<b>159 314</b>	<b>20%</b>
<b>Total WHO European Region ***</b>	<b>86 912</b>		<b>806 258</b>	

\* Cumulative totals since the beginning of reporting and until 31 December 2006

\*\* % refers to the proportion among the total number of cases in the WHO European Region

\*\*\* Includes cases with unknown sex

*Source:* European Centre for the Epidemiological Monitoring of AIDS (EuroHIV). Unpublished data 2007.

### 2.3 Routes of transmission

The primary route of HIV transmission in the European Region as a whole is through injecting drug use, due largely to the high levels in **the Russian Federation** and **Ukraine**, and the general trend in the former Soviet Union. Prevention efforts for injecting drug users (IDUs), men who have sex with men (MSM), and sex workers have reached small proportions of those affected in eastern Europe (less than 10% of IDUs, 4% of MSM, and 8% of sex workers) (14). In eastern Europe, up to a quarter of IDUs are estimated to be under 20 years of age (15). Heterosexual transmission is increasingly reported among the sexual partners of IDUs. In several western European countries, sex between men is the primary route of transmission.

In some countries, a large proportion of infections do not have a known route of transmission; almost half (48%) of new HIV infections in women in eastern Europe in 2004 gave “other/undetermined” as the route of transmission (16), and several countries have serious gaps in their reported data (17). Within its recommendation to improve the quality of reported data, EuroHIV stresses the importance of identifying probable routes of transmission, (3) though this can be difficult as stigma of drug users or fear of prosecution may influence the decision to report. Further, a recent study from **the Russian Federation** shows that many women who report heterosexual transmission had a history of injecting drug use (18).

### 2.4 The life stage factor: experimentation, risk and the attitudes of adults

Young people are at increased risk of HIV infection for several reasons. Experimentation is an integral part of being young, in many areas of life, across cultures and regardless of demographic profiles; this includes sexual experimentation (19), as well as substance use. Combined with peer pressure and unemployment, new behaviours become attractive, but young people often do not yet have the knowledge to make informed choices or the skills to negotiate against pressure from peers or sexual partners. According to WHO, higher-risk sex is unsafe sex with a non-marital, non-cohabiting partner (even if considered a long-term partner), which in many countries covers a large proportion of sexual activity among young people (20). (This risk in Europe contrasts with some generalized epidemics, where the risk within marriage is higher than outside (21).) Excluding certain groups, such as urban MSM under 30, heterosexual young people tend to have a higher number of sexual partners than the general population (5). In addition to individuals’ sex lives, there is a serious problem of youth sex work (both male and female) which, in the case of eastern European women often working in central and western Europe, is often coerced (22)

Injecting drug use is generally deemed unacceptable and harshly punished in society, and often begins during adolescence or youth. Zero-tolerance and abstinence-only approaches to substance use are ineffective and may be counter-productive (23). Although the attraction inherent in prohibition plays a role (in both sex and drug use), social problems such as unemployment and a lack of leisure activities contribute greatly to risk behaviours. This is compounded in many former socialist countries by generally high unemployment rates and the lack of positive long-

term outlooks. Poverty and desperation drive the high numbers of young women in sex work. In such contexts, the deterioration of public health systems further increases risks for young people (22). In some societies with ready availability of antiretroviral therapy, HIV infection is perceived as less severe now than in the past. This has affected sexual behaviours toward increasing the risk of the spread of infection (24).

#### *2.4.1 The attitudes of adults: condemnation, denial, stigma, acceptance*

To date, HIV prevention efforts regarding young people have failed to keep pace with the epidemic (1). Among the cultural drivers of HIV infection is the reluctance of governments and societies to recognize and address the issues of young people's sexuality. Expressions of sexuality by young people are often discouraged or condemned by their parents, teachers and other elders (even though sexual behaviour per se is neither illegal nor uncommon). Restrictive public and private approaches to sexuality reinforce gender stereotypes and skewed images of sexual life, and further limit the ability of young people to be informed in exploring their sexuality.

Decision-makers are often reluctant to give messages about sex to young people, believing the myth that sex education leads to promiscuity and early sexual intercourse. At the same time, sexualized images are widespread and tolerated in the media, particularly in advertising (not to mention pornography). Such images form part of young people's sexual education (5), and double-standards on the part of policy-makers undermine balanced education on sexuality (25). Intergenerational relations which recognize the life stage of young people have potential to limit the spread and burden of HIV. Harm reduction is a somewhat similar approach – seeking to understand and accept aspects of behaviour which were previously condemned outright – and has had great positive effects, now forming a crucial component in HIV-related activities, particularly regarding IDUs.

#### *2.4.2 Cultural sensitivity*

To be effectively delivered, it is useful to deliver HIV interventions targeting young people alongside those adults who are involved in the process of growing up (2). The 2004 UNFPA report *Culture Matters* gives examples of conducting HIV/AIDS activities in culturally sensitive ways (albeit from outside Europe) (26). Factors shaping sexual behaviour are similar between societies (27). Even in supposedly more traditional societies, risks remain, including through mobility, urban–rural migration and proximity to countries with much higher levels of infection. The HIV/AIDS epidemic motivates governments to engage with sexual health issues, especially among young people. As an illustration, governments in central Asia, **Turkey** (as well as the Islamic countries of the Economic Cooperation Organization) have publicly recognized that increasing numbers of people aged under 15 are sexually active; their statement that education prior to sexual onset can delay sexual intercourse is a progressive step (28).

**Box 8.1.** There are always those opposed to sexuality education, to information regarding harm reduction or contraception, and even to youth-friendly services. In recent years in **Lithuania**,<sup>a</sup> for example, small groups of fanatic conservatives have damaged broadly supported efforts to promote sex education and youth-friendly services. Using lies and scare-stories, these groups appealed to fear and ignorance in their attempts to deny young people the education and information needed to protect themselves from risk and live fulfilling lives. Cultural sensitivity requires understanding of the society in question, but does not imply the need to satisfy all actors.

<sup>a</sup> Family Planning and Sexual Health Association of Lithuania. *Strong Families and a Strong Country*. Vilnius, Family Planning and Sexual Health Association of Lithuania, 2005.

Cultural sensitivity does not exclude asking questions which may be difficult: desiring an evidence-informed approach means that assertions of national or cultural characteristics should not be allowed to undermine important indicators. The Reproductive Health Surveys do well in managing to survey unmarried women even where their sexual behaviour is stigmatized, as in **Georgia**. Sometimes there is less national compliance, as in the exclusion of unmarried Turkish women from a 2005 survey of trends in contraception and abortion (29).

### 3. Indicators and progress

The basic indicators to determine progress towards Action 8 of the Dublin Declaration ask:

Have 90% of young people had access to information, education, peer education and youth-specific HIV education (four indicators); and have 90% of young people had access to services to develop life skills to reduce their vulnerability?

These recall the goals of the 2001 UN General Assembly Special Session on HIV/AIDS, and of the ICPD+5 progress review in 1999<sup>39</sup>. Participation – of young people, parents, families, educators and health providers – is a cross-cutting feature. Other similar indicators include whether countries have a policy or strategy promoting HIV/AIDS-related sexual and reproductive health education for young people, and whether HIV-related education is part of the curriculum in primary and secondary schools.

Dublin Declaration and UNGASS monitoring also include behaviour and knowledge indicators:

- What proportion of youth has comprehensive correct knowledge of HIV/AIDS?
- What proportion of 15-year-olds have ever had sex?
- What proportion of young people aged 15–24 used a condom during their last high-risk sex?

Regular data collection on all indicators is weak, particularly in central and eastern Europe and central Asia. Ad hoc surveys (such as the Eurobarometer referred to below) provide some information on whether populations have received information, but their irregularity means they are of limited usefulness for comparisons over time. The ‘90%’ indicators themselves raise additional questions: what does it mean to have had access to services to develop life skills? Do the services merely need to *exist*, or must they be *seen as accessible* and youth-friendly by young people? And who should be asked to find out? Not only is national data collection unreliable, but given the almost complete lack of data for youth indicators for European countries in the UNAIDS country profiles, what data do exist appear not to be routinely reported to monitoring bodies<sup>40</sup>.

One example of good practice comes from **Finland**: three regular national surveys of school-aged children take place (every year, two years and four years), covering health-related behaviours including sexual activity and substance use (including the WHO Health Behaviour in School-aged Children surveys, which ask sexual health questions of 15-year-olds). While there are good data on school-aged children, there is no separation of ‘youth’ from the monitoring of adults generally.

The UNICEF Innocenti survey provides data on sexually transmitted infections (STIs) in young people aged 15–19 in central and eastern Europe and central Asia, which suggests good progress

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<sup>39</sup> To ensure that by 2005 at least 90% of young people have access to information, education, services and life skills that enable them to reduce their vulnerability to HIV infection; and at least 90% of young people have comprehensive correct knowledge of HIV/AIDS (UNGASS 2001). This in turn reflects the key HIV/AIDS action of the 1999 UNGASS five-year review of the International Conference on Population and Development.

<sup>40</sup> See Annex 1 of the global report, [http://www.unaids.org/en/HIV\\_data/2006GlobalReport/default.asp](http://www.unaids.org/en/HIV_data/2006GlobalReport/default.asp).

in most of central Europe, the Baltic states and the former Soviet Union (apart from the Caucasus), while several Balkan countries and **Turkmenistan** provide no data. However, the Innocenti survey does not contribute to any of the youth HIV indicators covered under the Dublin Declaration; and even as reported rates of STIs among adolescent have fallen, new HIV cases in the wider population have broadly increased (30)

Several thorough and high-quality population-based surveys exist but have limited coverage (as suggested by the paucity of data in the statistical sections on the UNICEF national websites regarding youth sexual knowledge and behaviour related to HIV/AIDS, which draw their data from these surveys<sup>41</sup><sup>42</sup>); along with other, ad hoc surveys, such as the Eurobarometer on AIDS, these surveys are not currently frequent enough to guide national responses.

There is also a focus on young people in specific thematic areas: reports on the vulnerability of young migrants have recently been completed for **Belgium, the Czech Republic, Denmark and Spain** (with the now defunct network AIDS & Mobility Europe) (31).

### 3.1 Education

Despite common concerns among those responsible for education policy, early exposure to sexuality education is not associated with earlier sexual activity, and in many cases leads to a delay of first sexual intercourse (32). Safe sexual behaviour can be learned, and education promoting safer sexual behaviour is most effective if initiated prior to sexual debut. As early puberty is associated with early sexual activity (33), the most effective preventive education begins in primary school.

The UNAIDS Programme Coordinating Board recorded “demonstrated progress” in 2007 in integrating HIV into national education strategies in central Asia, **Belarus** and **the Russian Federation** (34), and several countries report providing HIV-related education in their UNGASS reports:

- The HIV/AIDS and Education toolkit was adapted for use in **Kyrgyzstan** and **Tajikistan** in 2006 (35). The 2005 UNGASS report states that, between 2003 and 2005, school-based AIDS education was introduced in **Tajikistan**, though implementation of this is slow (36).
- Over 75 000 young adults in **Kyrgyzstan** have been reached by HIV/AIDS prevention messages in schools supported by the GFATM (37) (although the total population aged 15–24 is over 1 million (38)).
- There is a positive increasing trend in the number of children reached by HIV/AIDS education in school in **Azerbaijan** (39).
- The proportion of young people in schools in **Belarus** reached by HIV/AIDS educational programmes rose from 60% in 2000 to over 90% in 2006 (40).
- Although not an HIV-specific intervention, a campaign in **Turkey** run by the ministry of education and UNICEF – Let’s Go To School, Girls! – has to date enrolled 223 000 girls and 100 000 boys in primary education, who would otherwise have been out of school (although school-based sexual and reproductive health and HIV/AIDS education is often of poor quality).

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<sup>41</sup> See HIV/AIDS statistics for countries through UNICEF, <http://www.unicef.org/infobycountry/ceecis.html>;  
<http://www.unicef.org/infobycountry/industrialized.html>.

<sup>42</sup> Demographic and Health Surveys (DHS) have been conducted in **Armenia** (2000, 2005), **Azerbaijan** (2006 ongoing), **Kazakhstan** (1995, 1999), **Kyrgyzstan** (1997), **Turkey** (1993, 1998), **Turkmenistan** (2000), **Ukraine** (2007 ongoing) and **Uzbekistan** (1996). Reproductive Health Surveys (RHS) have been conducted in **Albania** (2002), **Azerbaijan** (2001), **Georgia** (1999, 2005), **Moldova** (1997), **Romania** (1993, 1996, 1999), **Russian Federation** (1996) and **Ukraine** (1999). Multiple Indicator Cluster Surveys (MICS) from 2000 exist for more countries, but often do not disaggregate data by age.

However, the implications of progress towards school-based education are not clear: **Slovakia** reports covering sexual health matters including HIV/AIDS in its human biology classes (41), while the 2006 International Planned Parenthood Federation (IPPF) Reference Guide on sexuality education in Europe, records that these classes are ‘inconsistent and inadequate’, and that modern contraception – a basic ingredient in any sexual and reproductive health curriculum – is largely absent (42).

**Slovakia** is not unique: in the vast majority of countries assessed in the IPPF guide, there were problems with the quality and consistency of sexuality education – this was often worse in rural areas or those with a particularly strong religious tradition, but was lacking in urban areas too; moreover, sex education being mandatory did not necessarily affect its quality. In several countries, nongovernmental organizations (NGOs) are invited to give school lessons about sex and sexuality, ensuring the message is conveyed while making the school staff one step removed. In **Norway**, for example, teenagers prefer to receive messages about contraception from health care personnel (43). When the National AIDS Trust, an NGO in **the United Kingdom**, produced a Schools Pack in 2006 to enable teachers to integrate HIV/AIDS into the national curriculum, several thousand copies were ordered or downloaded. Other examples include:

- **Moldova** reports great improvements in comprehensive knowledge of HIV transmission among young people aged 15–24, from 12% in 2003 to 28% in 2005 (with an increase from 3.7% to 25% among rural females) (44).
- Knowledge of HIV/AIDS among young people in **Armenia** improved between the 2000 and 2005 Demographic and Health Survey: substantially higher numbers of both sexes identified ways to avoid HIV infection, and higher numbers also rejected misconceptions; nonetheless, only 22.6% of women and 15.1% of men aged 15–24 had comprehensive knowledge about AIDS (45).
- A survey of young people aged 12–25 in **the Netherlands** found that half of 17-year-olds have sexual experience, the same as 10 years ago, while condom use has increased in that period (46).
- Between 1999 and 2004, the number of newly reported HIV cases more than doubled in **Ukraine**. At the same time, condom use among young people aged 15–20 increased by only 3% (from 66% to 69%) (47); as most HIV infections in **Ukraine** are related to injecting drug use, non-drug users may not view themselves as at risk from HIV, but this does have consequences for other STIs and unwanted pregnancy.

The 2006 European Commission Eurobarometer survey on AIDS prevention surveyed aspects of knowledge and behaviour among citizens of EU Member States and acceding and candidate countries (48). Over 90% of young people in all current Member States except **Bulgaria** and **Cyprus** (and markedly lower in **Turkey**) knew the ways HIV can be transmitted – but misconceptions about transmission remain significant in many places. Youth are more likely than people aged 25–39 to indicate that the emergence and spread of AIDS has led them to take precautions in sexual intercourse (71% against 61%); however, asked whether AIDS led them to seek more stability in sexual partners, 39% said ‘no’ while 42% said ‘yes’. This poll suggests that efforts to improve knowledge around HIV and AIDS have had some success in western and central Europe, in that the vast majority of young people know the major transmission risks (injecting drug use and unprotected sex). It was not measured whether young people feel they also have the skills to reduce their vulnerability.

Life skills, particularly psychosocial skills around communication and the development of self-confidence are important to enable young people to resist peer pressure and make decisions for themselves, including negotiating condom use and delaying intercourse with sexual partners.

Although life skills are valuable for HIV prevention and sexual health – as recognised by the Dublin Declaration indicator – they need not be taught in relation to sexuality.

- Irish aid funded a two-year, 10-country programme run by UNICEF which included the introduction of youth-friendly health services and strengthening life skills education.
- A **United Kingdom** Department for International Development – United Nations Fund for International Partnerships (UNFIP) project entitled “Comprehensive Partnership Strategies for HIV/STI Prevention among Young People in the Russian Federation” involved a number of United Nations agencies, in partnership with government authorities and academic institutions, to develop prevention strategies for young people, including an HIV/STI information system to ensure access to information and medical services for vocational students and unemployed young people.
- ‘Basic training in self-assertiveness’ is reportedly valuable for young girls in **Norway** (43).
- In **Moldova**, UNFPA supports life skills-based programmes of reproductive health education for young people aged 14–19 and of HIV/AIDS prevention for vulnerable young people.
- In **Bulgaria**, the number of young people reached by life skills-based health education in schools focused on HIV prevention rose from 3500 in 2003 to over 12 000 in 2005, and the number of schools supporting HIV prevention policies rose from 27 to 131 (49).

#### **Box 8.2. Peer education**

Peer education is often celebrated as a highly effective way of communicating safe sex and healthy lifestyle messages to young people (behaviour-change communication). The Y-PEER network of peer educators, run by young people and supported by UNFPA, operates in 27 countries in eastern Europe and central Asia. Coverage of Y-PEER-initiated activities with peer education at its core increased from 2.1 million young people in 2005 to 2.7 million in 2007. However, this and other peer education efforts are still far short of reaching over 90% of young people. Further, behaviour-change communication is one of many types of intervention targeting young people. Peer education schemes must also strive to reach out to those less likely to access peer education services, particularly if the services are based online.

- Linking peer education with big communication campaigns and events, such as the initiative run by Y-PEER **Serbia** at the EXIT music festival in 2007, can help popularize intervention and increase demand.
- GFATM, UNFPA and UNICEF have supported consolidation of all peer education initiatives and development of national standards within the framework of Y-PEER **Tajikistan**.
- From 2006 to 2008, through the Y-PEER Russia network, UNFPA expanded its BCC programmes led by peer educators to the far east of **the Russian Federation**.
- In other places, such as **France**, peer education is virtually non-existent.<sup>d</sup>

<sup>a</sup> GFATM Grant Performance Report for Round 3 project in Macedonia, March 2007.

<sup>b</sup> Tajikistan UNGASS report for the period 2003–2005.

<sup>c</sup> Serbian proposal to the sixth call for proposals by GFATM, May 2006.

<sup>d</sup> IPPF European Network. *Sexuality Education in Europe: a reference guide to policies and practices*. Brussels, IPPF European Network, 2006.

### *3.2 Information*

The indicator on access to information is again troublesome, as is measuring the impact of informational campaigns. Better impressions of the effectiveness of particular campaigns can be gained through building evaluation into the campaign design (for example, the success of media campaigns in eastern Europe run by the Dutch-based AIDS Foundation East-West is assessed using baseline knowledge, attitudes, behaviour and practices (KABP) surveys (50)).

Collaboration with media partners has been effectively used in a number of countries to increase exposure:

- MTV has partnered with Y-PEER in an effort to reinforce prevention messages created by their Staying Alive Campaign. In 2007 it resulted in the highly visible and successful ‘Me’ campaign ([www.staying-alive.org/me](http://www.staying-alive.org/me)).
- Almost 30% of young people in targeted areas of **the Russian Federation** have been regularly exposed to mass media safer sex campaigns (51).
- Among young people aged 16–29 in **Germany**, 93% reported having seen the ‘mach’s mit’ posters (<http://www.machsmitt.de/>), and half had seen cinema ads; far fewer (19%) had actively attended information events (52).

Involving celebrities in HIV/AIDS awareness promotion is also popular among young people:

- In **Georgia**, the Reproductive Health Initiative for Youth in the South Caucasus organizes a large-scale youth festival with the theme Stop AIDS, involving music stars and broadcast on television.
- In **Bulgaria**, UNFPA and Y-PEER national network involved top Bulgarian celebrities in development of their national campaign promoting safe behaviour of girls aged 15–17. The campaign combines media events, training workshops and youth festivals.

### 3.3 Services

In addition to the goals regarding young people in Action 8 of the Dublin Declaration, Action 13 calls for all adults and adolescents to be ensured:

... universal and equitable access to and promote the use of a comprehensive range of high quality, safe, accessible, affordable and reliable reproductive and sexual health care services, supplies and information including access to preventive methods such as male and female condoms, voluntary testing, counselling and follow-up.

Sexual and reproductive health services include voluntary counselling and testing for HIV, prevention and treatment of STIs, contraceptive provision and services and counselling related to unwanted pregnancy. According to a UNFPA assessment, coverage of sexual health services for young people varies hugely, from under 1% in **the Russian Federation** to 50% in **Belarus** and 75% in **Kazakhstan** (53). For these services to be youth-friendly, they should be openly accessible, non-discriminatory, convenient, and provided with respect for privacy and dignity (54). There are guidelines on the implementation of youth-friendly services (55) and a range of resources for providers and programmers, (56) but little evidence of the effectiveness of models is available, as many initiatives have not been appropriately assessed (57). Youth-friendliness is

particularly important, as bad experiences can make young people less inclined to seek medical help in the future (52).

**Box 8.3.** Since 1994 the Estonian Sexual Health Association has run a series of youth clinics across **Estonia**, providing reproductive and sexual health services – including counselling and testing – to young people, primarily aged 15–24. For several years these clinics suffered from uncertainty over funding, but since 2002 they have developed positive relationships with the (state) Estonian Health Insurance Fund (which now funds the pioneering online counselling service), as well as with UNFPA and GFATM. The number of service users has risen year-on-year, although young males still make up under 10% of visitors (partly due to a lack of male sexual health specialists).

*Source:* Estonian Sexual Health Association (ESHA). A decade of youth clinics in Estonia. *Entre Nous*, 2004; and information from ESHA.

There are widespread commitments to youth-friendly services (58). New efforts have been and are being made to increase national capacity, supported by the WHO Regional Office for Europe in **Turkey** (59), and by UNFPA in central Asia (2005–2009 projects in **Kyrgyzstan**, **Turkmenistan** and **Uzbekistan**), the Caucasus (through the Reproductive Health Initiative for Youth in the South Caucasus) and eastern Europe (in **Belarus** 2003–2007 and in **Ukraine** 2003–2006). In **The former Yugoslavian Republic of Macedonia**, 643 teachers, military staff and other professionals were trained in youth-friendly services under a GFATM project, exceeding the target by 135 (60).

### 3.4 Treatment

Indicators regarding treatment of young people living with HIV/AIDS are:

- Percent of people aged under 15 and aged 15–24 among registered HIV cases; and
- Percent of people living with HIV/AIDS on HAART aged under 15 and aged 15–24.

The *Towards Universal Access* progress report from April 2007 states that those aged 0–14 comprise 3% of the need for treatment in the European Region, and 4% of those on treatment (61). Figures in that report are not disaggregated by age group for the population aged 15 and over. Data suggests that those aged 15–24 are often under-represented among those on HAART (although in younger epidemics, a smaller proportion of HIV-positive people need to start treatment (61)). The situation varies: in **Moldova**, for example, only 5% of those on treatment at the end of 2006 were youth, although youth represent 20% of all people living with HIV/AIDS (including those with an unknown age); in **Ukraine**, the figures were 4% and 15% of all reported cases (including those with an unknown age); by contrast, in **Estonia** the figures were 63% on HAART while 46% of the total reported cases were among youth.

Due to similarities in their treatment schedules, young people and adults tend to be aggregated in data and guidelines on treatment (62); this masks the reality that young people infected with HIV have a distinct experience of treatment. Challenges for youth-friendly treatment and care include the difficulties of confidentiality and responsibility in the patient–parent–clinician relationship, which is common in chronic disease management (63). In addition, management of HIV in particular is complicated by the stigma attached to sexual transmission and injecting drug use, and many of those affected face social exclusion and may have less supportive family backgrounds.

What research exists suggests that young people often show poor adherence to antiretroviral therapy. Most research in the area of adherence to therapy comes from the United States – there is not much research from the European region (and in some parts, an absence of therapy to not adhere to), while little has been done anywhere to study effective ways of tackling youth non-adherence to treatment (64); life skills development may contribute to the ability to ‘self-manage’ (65). Efforts to improve the quality of care for people living with HIV/AIDS also improve the overall credibility and impact of programmes (66).

### 3.5 Out-of-school young people, orphans and abandoned children

Civil society organizations are crucial to education and prevention among out-of-school adolescents. Many such young people face marginalization and become involved in risk behaviours including sex work and criminal activity. Data on interventions aimed at this group are difficult to obtain: the population of those not attending school are difficult to quantify; and the civil society organizations providing non-formal education and outreach activities may not be integrated into reporting systems, especially if operating at a local level.

In certain countries and settings – most commonly in rural areas of **Turkey**, Roma populations and among migrant groups – young girls (and occasionally boys) are kept out of school (67). Early marriage and the lack of importance attached to girls’ education play a role, as does the prohibitive cost of education. Encouraging their attendance is challenging – most often such girls live in rural areas (although rural–urban migration is common, and may lead to exposure to HIV). Again, a culturally sensitive approach is needed when aiming to decrease the vulnerability of such young people to HIV/AIDS. Under the sixth (most recent) round of GFATM grants, **Ukraine** has proposed a project to increase access for vulnerable populations, including homeless children aged 10–18 who had not previously been covered at all (68).

**Dublin Action 3:** “Accelerate the implementation of the provisions of the Declaration of Commitment relating to orphans and girls and boys infected and affected by HIV/AIDS.” The one place in Europe – **Romania** – where there has been a large cohort of HIV-positive children has not dealt with the problems faced by this group (including orphans and other children abandoned to institutional care). Access to antiretroviral treatment has improved since 2001, but the system of provision is still inadequate, particularly regarding interruptions of treatment. Young HIV-positive Romanians continue to suffer discrimination and poor treatment in education and health services; stigma is widespread in society, and official bodies are rarely youth-friendly. A three-year GFATM project with a special focus on HIV-positive young people began in July 2007.<sup>b</sup>

<sup>a</sup> Human Rights Watch. “*Life Doesn’t Wait*”: Romania’s Failure to Protect and Support Children and Youth Living with HIV. New York, NY, Human Rights Watch, August 2006, <http://hrw.org/reports/2006/romania0806/>.

<sup>b</sup> Approved proposal from Romania to GFATM, July 2007, [www.theglobalfund.org/search/docs/6ROMH\\_1406\\_563\\_gpr.pdf](http://www.theglobalfund.org/search/docs/6ROMH_1406_563_gpr.pdf).

#### 4. Other matters: a supportive environment, and research and reporting

##### 4.1 A supportive policy environment

Following years of focus on young people in HIV policies, particularly with regard to sexual transmission, effective interventions have been identified in the response to HIV/AIDS among young people<sup>43</sup>. Principles developed for more general programming with regard to young people – such as the WHO European Strategy for Child and Adolescent Health and Development – offer guidance in HIV/AIDS programming (69).

The supportive policy environment encouraged in the UNFPA Framework for Action has been strengthened by the 2006 Political Declaration on HIV/AIDS, as well as regional commitments such as those made in **Kyrgyzstan** in 2003<sup>44</sup>. The European Commission White Paper on Youth (2001) recognizes that providing sexual health education is essential (70), while the Dakar Framework for Action on Education for All (2000) foresaw commitments to urgently implement education programmes to combat HIV/AIDS, using formal and non-formal approaches and life skills development (71).

The translation of such a seemingly supportive environment at international level into a supportive legal framework at national level remains to be seen (explicit legal requirements for youth-friendliness of sexual health services, for example, are rare). These statements highlight the huge gap between the words and deeds of governments, a gap which can only partly be closed through technical support from international agencies.

<sup>43</sup> See the WHO information brief, *Steady ...Ready ...Go!* on the Talloires consultation to review the evidence for policies and programmes to achieve global goals on young people and HIV/AIDS, [http://www.who.int/child-adolescent-health/New\\_Publications/ADH/IB\\_SRG.pdf](http://www.who.int/child-adolescent-health/New_Publications/ADH/IB_SRG.pdf). A youth-friendly version of this document is currently being prepared by the Global Youth Coalition on HIV/AIDS.

<sup>44</sup> By politicians and technical staff of the Economic Cooperation Organization, at the Roundtable Meeting on HIV/AIDS and Young People (Kyrgyz Republic, 5–7 June 2003).

Donor decisions play a role and affect attempts to make evidence-informed responses: for example, funding for the WHO Task Force on the health of young people was stopped when donor priorities switched to the provision of treatment (72).

#### 4.2 Research and reporting

Incredibly, there is still a lack of default disaggregation of data by age in UNGASS reporting (although such data seem to exist, as it is input into the WHO database) (12). Many reports (such as those for **France, Ireland, Israel and Spain**) do not refer to any youth age range (or to 'youth' in reporting figures), even where they indicate youth-specific strategies or actions.

**Box 8.4.** The Health Behaviour in School-Aged Children (HBSC) survey seeks information on the sexual behaviour of 15-year-olds, and often has trouble asking basic questions: in **Denmark, Ireland and Norway**, no questions on sexual behaviour were asked, while some questions were modified or excluded in **the Czech Republic, Germany, Israel, Italy, Malta and the Russian Federation**.

The development of knowledge and best practices has been driven by high-quality research, including national research efforts for formulation of educational programmes (5,27,57). Turning such knowledge into successful, sustainable interventions has been driven by the consolidation and cohesion of the response to HIV/AIDS, on the global and national levels, through UNAIDS, the WHO and EuroHIV, and initiatives such as the "Three Ones" principle (73).

The AIDS Indicator Survey has good coverage of key indicators, including sexual behaviour, HIV testing and STI experience, but has never been used in Europe (74). The Health Behaviour in School-aged Children survey asks several questions about the sexual behaviour of 15-year-olds, comparable across many countries of the European Region, though not focused on HIV/AIDS (75). The results of the 2006 survey will be available in late 2007, including data on

**Box 8.5.** Data collection to support programming for young people should cover some basic variables:

- |   |                           |
|---|---------------------------|
| - age (including 10–14, 15–19, 20–24)                           | - sex (male/female)       |
| - age at first sexual intercourse                               | - location (rural/urban)  |
| - involvement in risk activities (injecting drug use, sex work) | - in school/out of school |
| - marital status (married or cohabiting/unmarried)              | - sexual orientation      |

As well as helping to monitor national progress, such variables are useful for providing baselines against which to assess the impact of specific interventions, including those made by NGOs (whose data collection is often inadequate). A rapid assessment and response tool would allow for cost-effective and useful measurement of the impact of interventions on youth knowledge or behaviour, and would allow such data to be collected by NGOs, where governments are unwilling or unable to do so. Bearing in mind that the usefulness of rapid assessment and response "may be judged by its adequacy for decision making, rather than increasing scientific knowledge for academic purposes",<sup>b</sup> it might be best used with actions designated 'Go' in the Talloires review on achieving youth HIV/AIDS goals.<sup>c</sup>

<sup>a</sup> UNFPA. *2006 Mid-term Report*. New York, NY, UNFPA, 2006, p. 2.

<sup>b</sup> WHO. *Rapid Assessment and Response Technical Guide*. Geneva, WHO, 2003, ch. 3, section 2.3. <http://www.who.int/docstore/hiv/Core/Contents.html>.

<sup>c</sup> WHO information brief, *Steady ...Ready ...Go!*, on the Talloires consultation to review the evidence for policies and programmes to achieve global goals on young people and HIV/AIDS.

the sexual behaviour and experience of 15-year-olds comparable with those from 2001.

Data availability is better for indicators of what is being done to meet goals (so-called determinant indicators (76)) than for outcome indicators (reliable measures of behaviour, knowledge, attitudes and other outcomes), which are needed for ongoing understanding of the

situation regarding HIV/AIDS and young people and for evaluating and planning responses. The diversity of data collection efforts<sup>45</sup> makes it difficult to find data comparable over time or internationally, and does not encourage government compliance, although the “Three Ones” initiative aims to have an agreed monitoring and evaluation framework in each country. There is no accepted best practice model yet, but there is a comprehensive ‘guide to indicators for monitoring and evaluating national HIV/AIDS prevention programmes for young people’, which recommends a number of standard indicators and tools for their measurement (76).

## 5. Conclusion

The number of new infections in Europe in 2006 was the third highest ever, including in **the Russian Federation**, the worst-affected country. Annual numbers of diagnoses continue to rise in central Asia and **Ukraine**. Newly reported cases also continue to rise in western Europe, particularly in **the United Kingdom**, while **Spain’s** lack of data hides the reality there. The extent of many epidemics (including among young people) is unknown, while estimates are daunting.

Efforts in all areas of prevention must be increased. Education, information and services for all can greatly improve people’s abilities to protect themselves. The education of young people, in school and outside of school, can be viewed as a ‘long-term’ preventive measure, preparing people to live in a world with HIV. Working with young people on the basis of understanding, respect and non-discrimination may often require adults to tackle difficult subjects, but is the only effective way to proceed. Official negligence and policies of criminalization have harmed eastern European efforts to reduce incidence and prevalence (77), and policy-makers need to take a human rights-based approach to achieve effective results.

In the worst affected areas, the drivers of HIV infection among young people are rooted in wider social issues of unemployment, social breakdown and lack of a positive outlook. While these are complex problems largely outside the field of public health, measures can be taken to reduce the vulnerability of young people to infection. Targeted interventions for those young people at highest risk are needed to reduce the threat of concentrated epidemics.

The lack of high-quality sexuality education remains a problem across the region, despite all evidence suggesting its cost-effectiveness. Moreover, sexuality education has further positive effects on wider sexual and reproductive health (including STIs and abortion trends), which particularly impact young people. Quality nongovernmental service provision exists, but this should be part of a full national system, rather than an alternative to state provision. It is undoubtedly positive that youth-friendly services have gained greater prominence and use in recent years. The challenge now is to ensure that youth-friendliness becomes ingrained in health service provision and that services are adequate to meet the needs of all young people, including those in rural areas and those most vulnerable.

## 6. Recommendations for improving the response to HIV/AIDS with regard to young people:

### *General recommendations*

1. Policy-makers and service providers, including teachers and health care workers, should approach young people’s development on the basis of respect, understanding and openness.

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<sup>45</sup> EuroHIV, UNGASS/UNAIDS, WHO Regional Office for Europe; RHS, DHS, MICS; ad hoc work by groups such as IPPF EN; and sharing of data between these groups.

2. Countries should draw on the technical and capacity-building resources of United Nations agencies and relevant bilateral and non-governmental organizations to help adults to engage with youth sexuality and experiences.
3. Youth–adult partnership and youth participation should be over-arching principles in comprehensive HIV prevention programming.
4. Young people should be integrally involved in planning, implementing and evaluating actions to combat HIV.
5. Civil society actors including representatives of young people should be fully involved in HIV/AIDS reporting, monitoring and evaluation processes, including by using UNGASS National Composite Policy Index Part B.
6. Young people at risk, including MSM, IDUs and sex workers, should be specially targeted for help (including non-formal education interventions and harm reduction) and treated with respect.

*Education and services (78):*

7. Governments should actively support comprehensive sexuality education.
8. Governments should include comprehensive sexuality education or reproductive health education in educational curricula, provide high-quality training for teachers and undertake a thorough assessment of the quality of sexuality education.
9. Links should be encouraged between school sex education programmes and local service providers and community activities (5).
10. Youth-friendly health services including reproductive and sexual health services should be a priority for development.

*Research, reporting and monitoring*

11. Research into young people at risk, including MSM, IDUs and sex workers, should be prioritized and supported by a non-discriminatory approach to these groups.
12. Research into youth sexuality, including access to information and services, should be strengthened, particularly in central Asia, the Caucasus and south-eastern Europe.
13. Alongside efforts on education, information and service provision, governments need to prioritize age-disaggregated data collection (including the brackets 10–14, 15–19 and 20–24) and monitoring of progress over time.
14. All actors should support the expansion and regularization of population-based surveys.
15. Technical agencies should develop an indicator on adherence to treatment for use where adherence among young people is a problem.

*Donor governments*

16. Donor governments in Europe should ensure that adequate attention is given to the region, particularly to prevention in eastern Europe, the Balkans and central Asia, emphasizing harm reduction (both condom use and for drug users), support for formal and non-formal educational interventions, and the other recommendations outlined above.

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## 9. HIV in the workplace

**Dublin Action 2:** Encourage and facilitate strong leadership by civil society and the private sector in our countries in contributing to the achievement of the goals and targets of the Declaration of Commitment;

**Dublin Action 15:** By 2005, to develop national and regional strategies ensuring that all men and women in uniformed services, including armed forces and civil defence forces, have access to information, services and prevention commodities to reduce risk-taking behaviour and encourage safe behaviour, and urge the European Union, NATO and other regional and international security institutions in partnership with UNAIDS to lead such efforts;

**Dublin Action 28:** Work with leaders from the private sector in fighting HIV/AIDS through workplace education programmes, employee non-discrimination policies, provision of treatment, counseling, care, and support services, and through engagement with policy makers on the local, national and regional levels;

### **Introduction: the impact of HIV/AIDS in the world of work in Europe**

Most people living with HIV in Europe are adults in their productive prime, so obviously there will be an impact on the workforce of the region. However, workers are not just being lost as the result of sickness but also due to stigma and discrimination. Such cases have been reported across the region, especially in more severely affected parts of eastern Europe. Furthermore, despite widespread social security coverage, a number of costs – direct and indirect – are being borne by employers with an inevitable impact on productivity, profitability, tax revenues and investment. The effects of HIV on workers and their families include a loss of rights and income. Issues for the state include pressure on public services and the consequences – often hard to calculate – for social insurance, pensions and human resources.

The impact on employment and labour is particularly harsh for small businesses and the informal economy – sources of work and income for many women and men in eastern European countries. Almost invariably, workers in the informal economy have no health insurance or access to medical facilities at their place of work and often their livelihoods are heavily reliant on their physical labour and skills.

The International Labour Organization (ILO) is the United Nations agency for the world of work. Its main aims are to promote rights at work, encourage decent employment opportunities, enhance social protection and strengthen dialogue in handling work-related issues. Within UNAIDS it has responsibility for the promotion of workplace HIV policies and programmes and private sector mobilization. It recognizes the global implications of the HIV epidemic and the need to integrate HIV responses in its work in all regions. It produces reports on the labour and employment impact of HIV and AIDS, as well as providing policy analysis and guidance for its constituents and other workplace actors. It pays special attention to some of the more vulnerable groups of workers, such as migrant workers, and economic sectors, such as transport.

In Europe the most important HIV-related workplace issue is the increase in the numbers of newly reported diagnoses in a number of countries. This has implications for rights at work, occupational safety and health, and impacts on work-related migration and mobility. Priorities in Europe with regard to HIV/AIDS, therefore, include:

- using the workplace as a gateway for universal access to prevention, treatment and care;
- targeting stigma and discrimination at the workplace and protecting the rights of people living with HIV, including ensuring confidentiality; and

- assisting the reintegration in the labour market of HIV-positive workers on antiretroviral treatment.

### **How the world of work can contribute to universal access**

Through direct provision of programmes and services, as well as information and referral, the workplace contributes significantly to achieving universal access to prevention, treatment, care and support – the target agreed by the United Nations General Assembly on 23 December 2005.<sup>46</sup> In this context, the ILO has a vital role to play in promoting the development of workplace policies and programmes (see Box 9.1, below). Its tripartite structure makes it possible to mobilize the commitment and resources of its three constituencies (ministries of labour and employers’ and workers’ organizations) to play an active part in national HIV/AIDS programmes. The focus is on reaching workers through enterprises and linking workplace services to community-based programmes. Stigma and discrimination are addressed through policy formulation and education and prevention through occupational safety mechanisms and behaviour change communication.

#### **Box 9.1. HIV responses in the world of work: the ILO approach**

- integrating HIV/AIDS in existing workplace structures and programmes, such as apprenticeship training or occupational safety and health, and mainstreaming the issue in Decent Work Country Programmes – the ILO’s mechanism for delivering comprehensive programmes to promote labour standards, create employment, provide social protection and ensure social dialogue and participation;
- mobilizing the commitment, networks and resources of its constituents, and supporting their capacity to take effective and sustainable action;
- helping put in place comprehensive workplace programmes as well as an enabling legal policy environment, with an emphasis on the defence of rights and prohibition of discrimination; and
- outreach into the informal economy and initiatives to promote employment opportunities for those infected with and affected by HIV.

### **Workplace partners**

In Europe, the ILO helps its constituents develop policies and action plans for their own organizations, set up networks of HIV focal points, trainers and peer educators, and mobilize and support workplaces to take action. Government officials and key members of employers’ and workers’ organizations have received in-depth training on the development of HIV/AIDS workplace policies and programmes. Guidance for the social partners has been strengthened by new tools, based on examples of good practice and lessons learned, like the CD-ROM for employers’ organizations and a report on trade union responses to HIV and AIDS, published jointly with the Global Unions and UNAIDS in the Best Practice Collection. Other sector-focused guidelines are available (covering the transport, construction, mining, education and health sectors), as are research and training tools in a number of languages.

### **An enabling legal policy framework**

#### *The role of international instruments*

The ILO developed its *Code of Practice on HIV/AIDS and the world of work (1)* (see Box 9.2) in response to many requests for guidance, on the basis of a widespread consultation with its

<sup>46</sup> This requested UNAIDS and its co-sponsors to assist in “facilitating inclusive, country-driven processes ... for scaling up HIV prevention, treatment, care and support with the aim of coming as close as possible to the goal of universal access to treatment by 2010 for all those who need it.”

constituents in all regions and a range of other stakeholders. The Code of Practice has been translated into 14 European languages<sup>47</sup> and has been widely disseminated, complemented by other training and resource materials, and supported by advisory services and capacity-building activities.<sup>48</sup> Implementation of the Code of Practice has been accelerated by integrating HIV in its Decent Work Country Programmes – the mechanism developed to coordinate and strengthen the ILO’s technical and policy support at country level– also now supported by UNDP.

**Box 9.2. The ILO Code of Practice on HIV/AIDS and the world of work**

The Code of Practice provides the framework for action related to the workplace. It contains key principles for policy development and practical guidelines for programmes at enterprise, community and national levels. It covers the following main areas:

- prevention of HIV
- management and mitigation of the impact of HIV and AIDS on the world of work
- care and support of workers infected with and affected by HIV/AIDS
- elimination of stigma and discrimination on the basis of real or perceived HIV status.

In order to accelerate and strengthen the workplace response, in March 2007 the ILO’s Governing Body decided to develop a new international labour standard on HIV/AIDS in the form of an autonomous Recommendation. Preparatory work is underway as is the first report, a law and practice report called *HIV/AIDS and the world of work*. It provides an overview on measures taken at both the national and international level. This is the most comprehensive compilation to date of the collective efforts of work done at the national level. The report and its accompanying questionnaire were sent to ILO member states in January 2008 and they are to reply, in consultation with employers’ and workers’ organizations, before 31 August 2008 (2). Due to the broad scope of the subject, the report itself advises the ministries of labour to consult other national ministries and institutions dealing with HIV/AIDS. These include ministries of health, social affairs, education, justice, gender, youth, finance and planning, and the national AIDS commissions, for the preparation of the replies to the questionnaire. The report also states that it might be desirable to consult other relevant organizations, including organizations of people living with HIV and others working with them, and to reflect their advice in the responses.

A summary of the replies and conclusions will be presented in a second report to be sent out to member states in February 2009. These two reports will be discussed at the first tripartite committee discussions that will take place at the International Labour Conference in June 2009. Based on these discussions, a third report will be prepared that will contain the first draft text of the recommendation to be sent out in August 2009 and the member states have until November 2009 to provide their comments. The two last reports: one a summary of comments provided and another with a bilingual text of the draft recommendation will be sent to member states in February 2010. The recommendation will be discussed a second time at the International Labour Conference in June 2010, where the final recommendation is expected to be adopted.

*National and sectoral policies*

Significant progress has been made in improving the policy environment for HIV/AIDS in the world of work. The ILO regularly responds to requests from numerous governments seeking assistance in revising labour laws or other legislation and developing national and workplace

<sup>47</sup> It is available in Armenian, Azerbaijani, English, Estonian, French, German, Georgian, Hungarian, Polish, Portuguese, Romanian, Russian, Spanish and Ukrainian.

<sup>48</sup> The education and training manual on the implementation of the ILO Code of Practice has also been translated into Romanian, Russian and Ukrainian for training and seminars.

policy. Laws on HIV/AIDS and the world of work have been or are being developed or revised in **Albania, Bosnia Herzegovina, Moldova, the Russian Federation and Ukraine**. Policies and programmes have been developed for a range of economic sectors, including hotels and tourism, mining, transport, forestry, construction, and public services.

Since the signing of the Dublin Declaration, a number of western European countries have amended their laws – mainly those concerning discrimination – to include HIV/AIDS (see Box 9.3).

#### **Box 9.3. Protecting people at the workplace in the United Kingdom**

In the **United Kingdom** the Disability Discrimination Act (DDA) now provides protection in the workplace for people living with HIV. In December 2005 it was amended to include HIV, as previously it referred only to AIDS. The amendment to the DDA means that in the **United Kingdom** it is illegal to discriminate against people with HIV in “employment, education and the provision of services”. People living with HIV are now offered the same legal protection as people with other long-term health conditions such as cancers and multiple sclerosis.

### **Workplace policies and programmes**

#### *Information, education and practical measures for prevention*

Prevention is the first stage of a comprehensive workplace programme. One example includes a programme now in place for the staff of Ukrainian International Airlines. In the Altay territory and the Volgograd region of **the Russian Federation**, HIV/AIDS workplace components have been built into vocational training: 65 directors of employment centres were trained on issues related to HIV and sexually transmitted infections (STIs), and 24 experts of the Head Office of the State Employment Service in the same regions improved their knowledge of health and HIV/STI prevention issues. More capacity building was provided through two-stage training on HIV and STIs to educate 69 psychologists and occupational guidance experts from the employment centres of the Altay territory to be master instructors, and workshops were held to discuss the report *Evaluating the process of promoting pilot educational materials on healthy lifestyles, prevention and HIV/STI-related issues in the vocational training system*. The participants included 30 experts in Barnaul and 29 in Volgograd who had tested the *Your Health* educational kit and other prevention materials for vocational training schools. Moreover, 75 heads of municipal labour committees and 100 trainers in the Altay krai region received training on HIV/AIDS and the workplace. To provide sustainability in HIV/AIDS prevention efforts by employment services in **the Russian Federation**, a widely circulated policy document was developed, providing recommendations on the introduction of HIV/AIDS components in the work of employment services.

Other examples of successful workplace education programmes can be found in the regions of Moscow and Murmansk. The ILO has also established programmes for women migrant workers in **Albania, Moldova and Ukraine**, and a network of peer educators in the education sector in **Ukraine**.

The *Joint ILO/WHO guidelines on health services and HIV/AIDS* are also being implemented in several countries across the region, having so far been translated from English into French, Latvian, Portuguese, Russian and Spanish. There are plans to translate it into Romanian and to implement it in **Moldova**.

In 2005 and 2006 the international trade union federation, Public Services International, organized seminars on HIV/AIDS in conjunction with its two Estonian affiliates, the Trade

Union of State and Self-government Institution Workers and the Federation of Health Care Professions. Representatives of Lithuanian and Latvian health care workers also attended. The main aim of the seminars was to create greater awareness of HIV as a workplace issue and to develop a trade union response. There was a focus on the occupational safety and health of health care workers and the application of the *Joint ILO/WHO guidelines on health services and HIV/AIDS*. The needs of other public service workers, such as fire fighters, the police, prison officers and social workers, were also taken into consideration. An important outcome was the development of printed materials in Estonian and Russian for use in different workplaces. During the seminars, visits were made to hospitals and clinics in the higher-prevalence areas of eastern **Estonia**, for attendees to gain firsthand experience of government needle exchange and drug substitution programmes.

### *Care, support and impact mitigation*

To reduce vulnerability to the impact of HIV/AIDS, the ILO promotes skills development and income generation among affected populations in Europe, especially women and young people. Work opportunities are complemented by social protection, including access to social security, medical benefits and health insurance, as well as decentralized insurance and income support schemes. The ILO works with employers' and workers' organizations to provide social protection through industry-wide collective agreements, and helps governments adapt benefit mechanisms to the needs of workers with HIV, including applying modelling of the social policy costs of HIV/AIDS for **the Russian Federation** and similar health systems (3), and for pension funds in **Ukraine** (4). It is also exploring innovative approaches such as social transfers to poor households to support income and ensure adherence to antiretroviral regimes.<sup>49</sup> The ILO approach to HIV/AIDS also extends to small businesses, the informal sector and trafficking.

In a number of European countries, governments and civil society are jointly implementing programmes of (re)integration of people living with HIV into the labour market, for example in **Poland** by the National AIDS Centre and Polish nongovernmental organizations (NGOs). 'Back-to-work' projects have been running in **Germany** since 1997, implemented by regional HIV/AIDS organizations and Deutsche AIDS-Hilfe, a nationwide German HIV/AIDS NGO. It created a development partnership named LINK-UP (see Box 9.4) in collaboration with seven regional HIV/AIDS organizations in 2005, funded by the European Social Fund.

#### **Box 9.4. LINK-UP**

LINK-UP aims to increase the participation of people living with HIV/AIDS in the labour market by improving the adaptability of businesses to integrate people living with HIV/AIDS and increasing the employability of this target group. The main objective is improve measures of qualification of people living with HIV/AIDS, such as resource-bound training, testing of atypical employment conditions (working schedules) and psychological and social support to integration. The network of local and regional cooperation structures providing reintegration and rehabilitation has also been strengthened.

An evaluation of the Swiss HIV and Employment project (5), which has provided an online job search engine ([www.workpositive.ch](http://www.workpositive.ch)) since 2003, has analysed employers' reasons for posting their jobs on the website. It reports that they are mainly due to a personal link to the subject of HIV/AIDS, good experiences with HIV-positive employees, marketing reasons, or a component of their corporate social responsibility. Reasons for not posting their jobs were given as a

<sup>49</sup> Regarding HIV/AIDS, the ILO is active in the following European countries: Albania, Armenia, Austria, Azerbaijan, Bulgaria, Estonia, **Georgia**, Germany, Moldova, **Poland**, **Portugal**, **Romania**, Russia, Ukraine, as well as the following Central Asian countries: **Kazakhstan**, **Kyrgyzstan**, Tajikistan.

shortage of vacant jobs, unwillingness to accept applications by people not disclosing their HIV status, a fear of negative reactions by their customers and additional administrative expenditure.

#### **Box 9.5. The Transatlantic Business and Labor Task Force on HIV/AIDS**

The ILO was a founding member of the Transatlantic Business and Labor Task Force on HIV/AIDS, which helped organize the first US–Russia Business and Labor Summit on AIDS in September 2003, leading to the establishment of Transatlantic Partners Against AIDS (TPAA). This body works directly with businesses to provide a range of programmes and services in the **Russian Federation** and **Ukraine**, and in 2006 it merged with the Global Business Coalition on HIV/AIDS, Tuberculosis and Malaria (GBC). Since May 2007, the TPAA has supported the National Association of Business Against AIDS (BAA) in the **Russian Federation**, a local network of leading Russian and international companies, business associations and trade unions, aiming to mobilize the Russian business community in the fight against HIV/AIDS and to foster open and constructive dialogue on HIV/AIDS prevention.

The TPAA has set up and runs the HEALTH@WORK programme which helps companies raise awareness among employees, safeguard their health, and reduce the economic losses caused by HIV/AIDS and other preventable diseases. The programme includes specialized seminars for workers, medical staff and human resource managers, as well as targeted consulting services for company executives. Successful awareness-raising activities have resulted in an expansion from the capital cities to other regions. Participants have included representatives from local companies, trade unions, local government, medical institutions and NGOs. From HEALTH@WORK's inception in August 2004 to June 2007 the programme has:

- organized events in seven regions of the **Russian Federation** and two regions of **Ukraine** involving over 150 companies;
- delivered 72 training sessions in the **Russian Federation** and seven in **Ukraine**; and
- trained more than 1400 executives, managers, human resources and other office professionals and occupational health service providers.

#### **Public–private partnerships**

The ILO organized a consultation with the private sector in September 2006 at its Berlin office. German multinational corporations, such as Daimler-Chrysler, Volkswagen and Deutsche Post World Net,<sup>50</sup> the German Technical Cooperation Agency (GTZ) and NGOs discussed how the lessons learned from workplace programmes in Africa could be adapted and transferred to regions with lower HIV prevalence, especially western and eastern Europe and China. There was consensus that companies' workplace policies and programmes should be valid globally, not only in high-prevalence countries. The implementation of such programmes is a feature of corporate social responsibility, according to Daimler-Chrysler, which has a programme for their apprentices in **Germany** assisted by Deutsche AIDS-Hilfe. Volkswagen sees it as a social and human rights issue and an economic necessity to implement HIV/AIDS workplace programmes in all branches of the enterprise. The consultation also saw the launch of the German translation of the ILO Code of Practice and other related guidelines.

The Interpipe Corporation in **Ukraine**, with 100 000 employees, requested assistance from the ILO for the provision of training programmes and materials for its workforce in the television and scrap metal industries. In 2004 HIV/AIDS workplace programmes were developed for four enterprises in the Zakarpatska region, including a dentist's clinic, a clothing factory, a hotel and a sanatorium. In Moldova the ILO has offered training programmes to Union Fenosa Group – a

<sup>50</sup> These are all member companies of the Global Business Coalition on HIV/AIDS, Tuberculosis and Malaria (see [www.businessfightsaids.com](http://www.businessfightsaids.com)).

member of the Global Compact network and one of the largest employers in the country with over 1500 employees – to establish workplace programmes and involve other enterprises from the private and public sectors to replicate this experience. HIV/AIDS workplace programmes in **the Russian Federation** were implemented at 14 enterprises in the Murmansk and Moscow regions, covering 10 000 employees, including enterprises in the metallurgical industry, services and transportation sectors, food industry and mass media. At the pilot enterprises, 170 peer educators were trained to provide sustainability of HIV/AIDS workplace prevention efforts.

### **National security – working with uniformed services and prisons**

The UNAIDS Secretariat, in collaboration with several of the cosponsoring agencies, is working with 18 countries in eastern Europe and central Asia to address the issue of HIV among uniformed services. Of these, 15 countries have implemented or are implementing programmes, and three have submitted proposals for funding. The objectives of support to the region include:

- advocacy for high-level commitment to address HIV and AIDS from the relevant ministries governing national armed and civil defence forces;
- prevention of HIV transmission among uniformed services by raising awareness through the promotion of peer education, condom provision and distribution, and care and support services; and
- involvement of uniformed services as advocates in the national response to HIV and AIDS, by ensuring that they are provided with the relevant tools.

At the political level, the UNAIDS Secretariat has signed Declarations of Partnership with ministries of Defence, the Interior and Health of **Albania, Kazakhstan, Kyrgyzstan and The former Yugoslav Republic of Macedonia**. At the technical level, HIV prevention among uniformed services has been or is being implemented in: **Albania, Armenia, Bosnia and Herzegovina, Croatia, Estonia, Kazakhstan, Kyrgyzstan, Latvia, Lithuania, Moldova, the Russian Federation, Tajikistan, Ukraine and Uzbekistan**, while proposals for similar activities have been submitted for funding from countries such as **Armenia, Romania, Tajikistan and Turkey** (second phase).

To date, approximately US\$ 1.1 million has been transferred to UNAIDS cosponsors for funding of country projects for the region, and US\$ 300 000 has been used for the production of 300 000 uniformed services awareness cards, which have been translated into a number of languages and distributed to countries as part of the HIV/AIDS awareness strategy. Details of three programmes for the uniformed services in the region are provided in Box 9.6, below.

#### **Box 9.6. Working with the uniformed services**

##### **Kazakhstan (US\$ 50 000, executing agency: UNDP)**

The main outcomes of the joint project between UNAIDS and the **Kazakhstan** armed forces were the formulation and governmental adaptation of a strategy for HIV prevention among armed forces in the country and the integration of HIV-related modules in the programmes of the Military Academy.

##### **The former Yugoslav Republic of Macedonia (US\$ 68 000, executing agency: UNDP)**

A project developed by the newly established Police Academy aims at introducing HIV, AIDS and STI topics in the training curriculum of police and military officers and training police force staff and their family members on HIV awareness and prevention.

##### **Moldova (US\$ 25 000, executing agency: UNDP)**

UNAIDS and national authorities in **Moldova** have been collaborating since 2002 to establish an HIV and STI prevention education programme in the armed forces. Under this programme approximately 120 teachers in military schools and 12 000 servicemen and -women have been trained.

In prisons, reported HIV prevalence among inmates has risen steeply over the last decade. For example, in **the Russian Federation** it rose from 0.4% in 1999 to 3.4% in 2001 and 4.5% in 2006 (6) (see Chapter 15 on prisons). In **Estonia** police, rescue workers and prison staff are regularly trained in HIV-related occupational safety issues, and in **Bulgaria** HIV/AIDS programmes for inmates of 12 prisons and a correctional establishment for minors are also accessible for prison workers (7).

### **Migrant and mobile workers**

Most migration is for economic reasons, mainly the need to work, and many factors have an impact on HIV risk and the rights of migrants living with HIV – social, cultural and political factors, as well as government processes and the conditions in destination countries. Movement across borders in search of work may introduce HIV risk due to detachment from traditions and the norms of one's home community, the loss of family and cultural networks, poverty, substandard living and/or working conditions, the abuse of rights, language barriers and inadequate access to HIV prevention information and services. Temporary workers are often not allowed to migrate with their families. Migrant workers, particularly those of irregular status, often lack access to health, social and legal services in destination countries, as they rarely have the same entitlements as citizens or permanent residents to the social security and health insurance schemes which make medical care affordable. The stigma and discrimination migrant workers often experience is an additional barrier to accessing voluntary testing, counselling, treatment and support.

Female migrant workers may be employed in relatively unskilled roles within the manufacturing, domestic service or entertainment sectors, with few alternative employment opportunities. This can make them more vulnerable to exploitation or violence, including by their employers.

People living with HIV, and groups at risk such as labour migrants, are entitled to the same basic rights as everyone else. These rights are enshrined in international legal instruments and include the right to social security, the right to non-discrimination and equality before the law, the right to work, the right to the highest standard of physical and mental health and the right to freedom of movement. HIV status in itself is not an indication of fitness to work. Moreover, migrants, irrespective of their HIV status, can and do make important economic contributions. To maintain this, they need access to culturally and linguistically appropriate HIV programmes. Such programmes need to be available in both origin and destination countries at all stages of the migration process – prior to departure, on arrival and during the stay in the destination country, and upon return and reintegration into their country of origin. More about this issue is available in *HIV/AIDS and work in a globalizing world* (8).

### **Recommendations**

#### *Actions for all*

Implement Article 27 of the Bremen Declaration on Responsibility and Partnership – Together Against HIV/AIDS (2007), referring to the world of work:

1. the private sector to contribute to raising the awareness of the risks of HIV/AIDS and to show solidarity with people living with HIV/AIDS;
2. the media to include information and education about effective HIV/AIDS responses;
3. employers and trade unions to ensure non-discriminatory policies for people living with HIV/AIDS and vulnerable groups in the workplace, and to reduce fears among staff by providing information, and access to prevention, testing, treatment and care, according to the ILO's *Code of Practice on HIV/AIDS in the world of work*;

4. the pharmaceutical industry:
  - to facilitate access to affordable treatment;
  - to enter into partnerships with the public and private sectors to support research and development and technology transfer; and
  - to cooperate in securing distribution channels for drugs to treat HIV/AIDS in cooperation with governmental institutions and NGOs.

*Actions for governments*

5. ensure national laws and regulations prohibit HIV-related discrimination in hiring, employment and at the workplace;
6. ensure laws, policies and programmes respect the rights of workers living with HIV in line with the ILO Code of Practice;
7. ensure any HIV testing related to entering or staying in a country is voluntary and adheres to the principles of informed consent, confidentiality and counselling;
8. include a strategy for the world of work in national AIDS plans, and promote HIV prevention programmes at every private and public workplace;
9. ensure access for workers and their families, including migrant workers, to HIV prevention, treatment, care and support programmes which are affordable and sensitive to culture and gender;
10. review the broader security issues for the region, including links between HIV/AIDS and human trafficking, uncontrolled movement of people across borders and the long-term impact on state functioning; and
11. solidify and ensure sustainability of initiatives by including HIV programmes and services in national strategies and budgets, and by supporting or conducting relevant research, monitoring and evaluation.

*Actions for workers' organizations*

12. promote the development and adoption of workplace policies on HIV in line with the ILO Code of Practice, and include relevant provisions in collective agreements;
13. support efforts to eliminate stigma and discrimination against people living with HIV, and against migrants, in the workplace;
14. support the formation of associations of young and migrant workers, and promote incorporation of HIV-related work into their programmes; and
15. advocate for stronger political commitment and increased budgetary allocation for HIV/AIDS within Europe and globally

*Actions for civil society*

16. in collaboration with trade unions, monitor and document breaches of law and cases of stigma and discrimination against people living with HIV in the workplace;
17. in collaboration with trade unions, advise people living with HIV on their rights and responsibilities in the workplace;
18. advocate for the implementation of workplace policies, procedures and programmes in line with the principles outlined in the ILO Code of Practice;
19. lobby governments to adopt and revise laws and policies to conform to international labour standards and the ILO Code of Practice; and
20. advocate for stronger political commitment, reduced drug prices and increased budgetary allocation for HIV/AIDS within Europe and globally.

### *Actions for employers' organizations*

21. implement workplace policies, procedures and programmes in line with the principles outlined in the ILO Code of Practice;
22. advocate for governments to adopt and revise laws and policies to conform to international labour standards and the ILO Code of Practice; and
23. advocate for stronger political commitment and increased budgetary allocation for HIV/AIDS within Europe and globally.

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## 10. Sexually transmitted infections

**Dublin Action 16:** Control the incidence and prevalence of sexually-transmitted infections, particularly amongst those at the highest risk of and most vulnerable to HIV/AIDS, through increased public awareness of their role in HIV transmission, improved and more accessible services for prompt diagnosis and efficient treatment;

In the WHO European Region, sexually transmitted infections (STIs)<sup>51</sup> are responsible for a large disease burden from stigmatization, acute illness, infertility, disability and mortality. This burden is amplified because many acute STIs increase the risk of HIV infection and transmission. In tandem with the Dublin Declaration, WHO's 10-year Global Strategy for the Prevention and Control of Sexually Transmitted Infections (1) emphasizes the importance of STI prevention as both a health goal in itself and as an important measure to prevent HIV.

### Sexually transmitted infections and HIV

In the Netherlands, for example, 15% of STI diagnoses in the surveillance system derive from HIV-positive individuals, who constitute only 1% of the visitors to the systems' sentinel centres (JE van Bergen, personal communication, 2007). Since STIs and HIV are transmitted by some of the same sexual behaviours, they share some of the same risk factors. It is therefore important to control and prevent STIs as a means of controlling and preventing HIV; to identify HIV-positive individuals, without coercion and compulsion, in order to prevent, detect and treat STIs; and to offer voluntary tracing of sexual contacts as part of an approach to prevent the wider spread of both HIV and STIs.

STIs not only increase the risk of infection by HIV from similar sexual behaviours, they also greatly increase the risk of acquiring or transmitting HIV, especially in their early phase, e.g. STI-induced ulcers from syphilis or genital herpes increase the risk nine-fold (2). Syphilis can also progress more rapidly and be more difficult to treat in people already infected with HIV. Both types of infections tend to affect similar population groups, such as men who have sex with men (MSM), injecting drug users (IDUs) and their sexual partners, and heterosexuals with frequently changing sexual partners. *Chlamydia* also increases the risk of HIV infection by a factor of 3 to 5. It is the most common STI in the European Region, especially among young people, and it is often asymptomatic, particularly in women. Lymphogranuloma venereum, caused by *Chlamydia trachomatis*, is increasingly frequent among MSM (3).

The hepatitis C virus (HCV) is mainly transmitted via injecting drug use, but it can also be transmitted sexually. Coinfection with HIV is around 40% in the Region, although there is wide variation (3). The hepatitis B virus (HBV) can be transmitted by either sexual contact or injecting drug use. Risk factors for its transmission and infection are hence similar to those for HIV, although HBV is more infectious. HBV infection tends, therefore, to exhibit the same trends as HIV infection.

Measuring the incidence of HIV infection can be difficult because it can have a lengthy asymptomatic period and lasts for life. In contrast, some bacterial STIs are highly infectious and have a short incubation period, with larger proportions of infected people becoming symptomatic earlier on (although many cases remain asymptomatic); many of these STIs are also curable. In many middle- and high-income countries, increases in laboratory-confirmed gonorrhoea and syphilis among MSM have been linked to an increase in unprotected sex and frequent new sex partners. Incidences of certain STIs may therefore indicate recent changes in sexual behaviour

<sup>51</sup> In this chapter, the term STI refers to any sexually transmitted infection *except* HIV.

and thus serve as proxy indicators for HIV transmission rates. For instance, a decline in STI incidence could herald the success of an HIV prevention programme before a reduction in HIV prevalence is detectable.

### Surveillance systems

Historically, there has been considerable variation in the surveillance of STIs across Europe (4). The European Surveillance of Sexually Transmitted Infections (ESSTI) network, a collaborative effort of 25 countries, chiefly from the Europe Union (EU), recently conducted a survey of its member countries (5). The responses confirmed widespread variation in the composition and quality of current STI surveillance systems in Europe. For example, while clinician or laboratory case reporting was the mainstay of surveillance systems for bacterial STIs, coverage of case reporting varied from less than 10% to more than 75%. There was also a lack of consistency in the case definitions used, which affects the relative specificity and sensitivity of the individual surveillance systems. Other variations were found in STI services and their accessibility to various subpopulations, as well as in partner notification methods, screening practices and the laboratory diagnostic tests employed. The high degree of heterogeneity results in poor comparability of surveillance data and limits the interpretability of STI trends in the European Region. In addition, surveillance data on sexual and drug-related risk behaviours are particularly poor throughout the Region. The ability to plan and monitor national and subnational STI/HIV prevention programmes is thus constrained by weak and heterogeneous surveillance systems.

WHO and UNAIDS both recommend that strong STI surveillance systems be used as part of second-generation HIV surveillance (6). Effective surveillance involves more than collecting data and describing epidemiological patterns; other key components include providing feedback to data collectors and providers, seeking to improve the quality of surveillance processes and using the surveillance data to improve the quality and effectiveness of STI/HIV prevention programmes. The UNAIDS/WHO Working Group on Global HIV/AIDS/STI Surveillance has also issued guidance on STI surveillance (6). The Declaration of Commitment reporting guidelines (7) and other global recommendations by WHO on STI surveillance (8) advocate population-based prevalence studies, but in relatively low prevalence/incidence countries, sentinel studies are preferable. Whereas anonymous HIV seroprevalence sentinel studies have been used to estimate overall population prevalence in some European countries, more specific HIV and STI seroprevalence studies are advised instead, focusing on vulnerable populations and risk groups such as MSM, IDUs and sex workers.

A good example of continuing improvement in a national STI surveillance system has been observed recently in **the United Kingdom** in **England** and **Wales**. Previously, STI surveillance relied on aggregated statistical data from clinical cases, data legally required from all genitourinary medicine clinics and supplemented by laboratory reporting. Although this approach provided relatively robust data, information on risk factors to guide STI control and prevention measures proved insufficient. The recent rise in STIs in **England** and **Wales**, along with numerous outbreaks there, have required a more sophisticated system (9). In addition to the original aggregated case and laboratory reporting demanded by law, the system now includes:

- enhanced STI surveillance in some local areas;
- surveillance of the prevalence of, and risk factors associated with, antimicrobial-resistant gonococcal strains;
- enhanced surveillance of genital chlamydial infection;
- surveillance of infectious and congenital syphilis (*Treponema pallidum*) through enhanced laboratory reporting by selected laboratories with reference facilities; and
- enhanced surveillance of STI outbreaks through implementation of an STI outbreak control plan.

The new system in **England** and **Wales** now collects the following data on each case:

- clinic
- patient number
- sex
- date of birth
- postal code of residence
- health authority of residence
- ethnic origin
- date of first attendance at genitourinary medicine clinic
- diagnosis code
- mode of infection
- date of diagnosis
- date(s) of attendance
- attendance category.

By contrast, problems persist in **Lithuania**, where a recent study identified difficulties with laboratory diagnosis in the STI surveillance system (10). Only 6% of the respondents were able to provide a confirmatory diagnosis, in accordance with international recommendations, for the minimum range of relevant bacterial STIs. Access to STI diagnostic services also varied from county to county, and several laboratories analysed very few samples in a given year.

Relatively weak surveillance systems are, however, the norm in the EU and the European Region. The European Commission has charged the European Centre for Disease Prevention and Control (ECDC) with ensuring the integrated operation of dedicated surveillance networks, partly through the harmonization and rationalization of surveillance systems. It can only do this through the cooperation of EU member states, calling on the expertise of some while supporting the improvement of others.

### **STI and HIV trends**

Although there are problems with some European surveillance systems, some good data is available. The best information on STI trends in the European Region is collated by the WHO Regional Office for Europe in the Centralized Information System for Infectious Diseases (CISID) (11). Some important trends are summarized below, but because of limitations in the surveillance data and reporting delays, it forms a baseline for the Dublin Declaration rather than a full progress report since the Declaration was signed in February 2004. As of June 2007, the 2006 data have still not been received from many countries.

#### *Syphilis*

In western Europe, the incidence of syphilis fell significantly in most countries during the 1980s, stabilized in the 1990s, and started increasing slightly again around 1999 or 2000. Syphilis and HIV showed similar patterns during this period. More specifically, since the late 1990s, reported syphilis incidence increased to a small peak in 2003–2004 in **Austria, Belgium and Germany**. Meanwhile, **Spain and the United Kingdom** showed smaller increases but started from higher baselines in the late 1990s. By 2004, both still had a low incidence compared to the European Region as a whole, but relatively high by western European standards. By 2004, most western European countries were showing the beginnings of a decline again, although by 2006, trends appeared to be increasing slightly again in, for example, **the United Kingdom**.

It is likely that, at least in part, recently observed increases resulted from some changes in surveillance systems and improved case detection. That was the case in the large artefactual rise

in syphilis incidence observed in **Ireland**. Changes in the surveillance systems therefore need to be taken into account when reporting. In western Europe, the recent small increase in the overall syphilis incidence rate is thought to be mainly due to localized urban outbreaks among high-risk groups exhibiting high-risk behaviour – mainly MSM, for example, in Manchester, **the United Kingdom** (12), and in Paris, **France**.

In central Europe, the picture has been mixed, but on the whole, HIV trends have again been similar to syphilis trends. HIV in this subregion has been mainly sexually transmitted, while syphilis outbreaks have occurred primarily among MSM. By 2004, the range of annual syphilis incidences for central European countries resembled those of western Europe. Of particular note is the sustained rise in syphilis incidence of **the Czech Republic** to a much higher peak than any other country in the subregion in 2001–2002, with a subsequent sharp decline that dropped to below 6 per 100 000 population in 2005 and 2006. **Slovakia** showed a similar pattern, though slightly less pronounced. Although syphilis incidence in **Cyprus** and **Slovenia** began to decline in 1999 and 2000, respectively, it started to rise again sharply in 2004–2005. **Poland** shows a different pattern than other countries, with an almost continuous decrease from a very high incidence rate in the 1980s to levels similar to western European countries by the late 1990s and continuing through 2005, the last year for which data are reported.

In eastern Europe, peak national incidence rates – averaging 201/100 000 – were about 200–1000 times higher than the corresponding western European rates. The most serious epidemics occurred (in order of declining incidence) in **the Russian Federation, Kazakhstan, Belarus, Moldova, Kyrgyzstan, Ukraine, Latvia, Lithuania** and **Estonia**. The eastern European syphilis epidemic appeared to have retreated – at least for the time being – by 2004, when average incidence decreased to around a still very high 50/100 000. By 2005, the rate in **the Russian Federation** had declined to less than 70/100 000, and by 2006, the Baltic states had levelled off at less than 20/100 000. Unlike in western and central Europe, the syphilis and HIV epidemics in eastern Europe are unrelated – the syphilis epidemic began in the early-to-middle part of the 1990s, whereas HIV incidence increased significantly starting around 2000–2001. The reason is that injecting drug use remains the main mode of HIV transmission, responsible for about 70–90% of infections for most countries in the subregion. However, there is increasing heterosexual transmission of HIV as young male IDUs pass HIV on to female partners. The eastern European STI epidemic that began in the 1990s is attributed to unprecedented rapid socioeconomic changes following the collapse of the Soviet Union, in combination with an equally rapid contraction of health services. During this time there also was an increase in sex work. It is not entirely clear why the epidemics of syphilis and gonorrhoea (see below) eventually declined, since socioeconomic problems persisted and improvement in the health care systems was slow to materialize.

### *Gonorrhoea*

In most of western Europe, the reported incidence rates of gonorrhoea fell 40–70% between 1991 and 1995, to less than 10 per 100 000 population. However, from the late 1990s onwards, some western European countries also saw large increases over low baselines. For example, in **Austria**, the number of gonococcal notifications increased from 2.9 to 5.2 per 100 000 between 2000 and 2002. Meanwhile, the trend in **the United Kingdom** stands out from the pattern in other western European countries. Beginning in 1989, the country persistently had the highest incidence of gonorrhoea in the subregion, and unlike other countries, the rate gradually rose after 1993, and more sharply around 1996. By the signing of the Dublin Declaration in 2004, **the United Kingdom** still had by far the highest incidence of gonorrhoea in western Europe, with 40 per 100 000. By 2006 it decreased to 32 per 100 000. Most other countries in western Europe were still below 10 per 100 000 in 2005–2006.

Because HIV is transmitted in this subregion mainly through sexual contact, gonorrhoea has followed the same pattern as HIV for the last decade. In many western European countries, gonorrhoea incidence is now concentrated among young MSM, heterosexuals who frequently change sexual partners and relatively socioeconomically deprived groups.

In central Europe, there was also a sustained reduction in gonorrhoea incidence in the 1980s. The rate of decline was less rapid, however, becoming even less so in the late 1980s. The incidence rate of most countries reached low levels by 2000. Gonorrhoea risk groups resemble those for HIV in this subregion, as do the trend patterns.

In contrast, eastern Europe experienced a gonorrhoea epidemic that started with a brief gradual rise in incidence at the very beginning of the 1990s. A sharp increase in incidence followed, peaking in 1994 with an annual average of 137 new cases per 100 000 population. The highest incidence was observed in the Baltic states and **the Russian Federation**. The gonorrhoea epidemic paralleled the subregion's syphilis epidemic. After slowly declining again, by 2004, gonorrhoea incidence in eastern Europe was still higher than in the rest of the European Region. It fell to 71 per 100 000 in **the Russian Federation** by 2005. **Estonia's** incidence had plateaued at 21 per 100 000 by 2006 and **Lithuania's** at 13 per 100 000. However, the trend in **Latvia** appears to be a rising one again, reaching 32.5 per 100 000 in the same year. As with syphilis, the observed trends in gonorrhoea incidence in eastern Europe are largely independent of HIV trends.

### **Prevention, treatment and care**

Preventing and controlling STIs are important aspects of Action 16 of the Dublin Declaration. However, the STI epidemic is, just like the HIV epidemic, a complex problem, affected by the social, economic, political and legal environment, as well as the immediate personal environment, all of which influence individual behaviour (13). While a coordinated health system response is essential in addressing both STIs and HIV simultaneously, integrating services for both, an overarching public health approach is also required to tackle the epidemics' complex underlying factors. WHO's Global Strategy for the Prevention and Control of Sexually Transmitted Infections provides the international framework and the public health approach needed for the prevention and control of STIs (1). The key targets of the Global Strategy, which are also relevant for the European Region, are:

- the availability of STI diagnosis and treatment at 90% of the relevant primary point-of-care sites;
- targeted interventions for high-frequency transmission groups;
- implementation of second-generation HIV surveillance (including STI surveillance);
- eradication of congenital syphilis; and
- age-appropriate sex education and reproductive health services.

The published strategy complements the earlier *Public health approach to STD control* (14), published by UNAIDS. The latter document advocates specific public health measures, including:

- promoting safer sex behaviour
- strengthening condom programming
- promoting health-care-seeking behaviour
- integrating STI control into primary health care and other health care services
- providing specific services for populations at increased risk for STIs
- comprehensive case management
- monitoring resistant pathogens as they emerge
- early detection of asymptomatic and symptomatic infections.

At present, there is no systematic overview of the entire European Region that assesses the extent to which national health systems address STI prevention, treatment and care with respect to either the Global Strategy or the UNAIDS public health approach. For successful STI surveillance, certain key health system elements are necessary. The variations in these elements seen throughout the Region suggest that there is likely a correspondingly large variation in the success of the Region's national health systems in preventing and treating STIs. The lack of such an overview makes it difficult to obtain a baseline assessment for the Dublin Declaration on the performance of European health systems in tackling STIs, let alone a systematic assessment of progress since 2004.

In western Europe, reductions in STI incidence initially occurred in many countries partly as a result of early efforts to prevent the first emergence of the HIV epidemic. This success emphasizes the need to tackle both HIV and STIs together. For example, in **Sweden**, mass media campaigns addressing issues around HIV testing also promoted safer sex (15, 16). In **the United Kingdom**, early HIV/AIDS efforts – including mass media campaigns, targeted educational outreach and harm-reduction initiatives – had the added benefit of initially reducing STI incidence (15, 17). When the promotion of sexual health there became less of a health system priority, one consequence was a resurgence of STIs in the younger population, especially among some risk groups such as MSM.

Particular features of the situation in **the United Kingdom** include an increasing use of alcohol and other recreational drugs and a young average age of first sexual experience, two factors associated with risky sex behaviour (18, 19) that the country still needs to address fully. More recently within **the United Kingdom**, problems have been reported in **England** and **Wales** with access to their unique network of specialist genitourinary clinics, problems which have led to delays in the diagnosis and treatment of STIs (20). Integration of services with primary care has also been variable. By contrast, in **the Netherlands**, 70% of STI care already takes place in primary care (21). Due to these problems, the Welsh government recently reviewed sexual health services and developed a new strategy. A mass media sexual health promotion campaign targeting young people ensued, genitourinary services are being combined with family planning services, and a training toolkit for sexual health services in primary care has been launched (22). However, resources to establish new standards for sexual health in **Wales** remain limited, and problems persist in addressing sexual health and vaccinating high-risk groups such as prisoners and IDUs for hepatitis B. Among IDUs in the community in south **Wales**, 71% reported having been in prison, 39% reported being homeless in the previous year and only 54% had received at least one hepatitis B vaccine dose (23). The emergence of resistant pathogens, such as gonococci resistant to quinolones or herpes simplex viruses resistant to azidovir, has to be monitored and clinical guidelines adjusted accordingly. The ESSTI network has started to address this issue in EU member states, **Iceland**, **Norway** and **Turkey** (see [www.essti.org](http://www.essti.org)).

At the beginning of this decade in eastern Europe, there were few state-sponsored STI/HIV prevention and control programmes that were integrated, comprehensive and based on human rights and civil society involvement. In **the Russian Federation**, for example, the approach is fragmented, with only a few scattered, often externally funded, projects (24). More recently, nongovernmental organizations (NGOs) have developed and implemented programmes for sex workers and their clients in low-resource settings, with little or no support from local and national governments (25). To take another example from **the Russian Federation**, in Penza, the Anti-AIDS Foundation implemented a programme with sex workers that included:

- HIV and STI prevention education for female sex workers and their clients
- outreach
- psychosocial counselling and administrative support

- development and distribution of information, educational materials and condoms
- referrals to free STI and other medical services
- harm-reduction interventions for sex workers who were also IDUs
- involvement of pimps in HIV and STI prevention interventions.

The health system response to STIs and HIV in **the Russian Federation** and elsewhere in eastern Europe tends to lack leadership and governmental coordination. It relies too much on specialist care, is fragmented among various private specialists, does not take an overall public health approach to tackle prevention in the general population and does not reach out to risk groups (26). The criminalization of HIV and STI risk behaviours further hampers prevention and control efforts (27, 28). Although contact tracing of the sexual partners of those diagnosed with HIV or STI is desirable, it needs to be voluntary and confidential, not obligatory or punitive. It is also important to encourage civil society engagement with the health system in order to facilitate and improve the public health response (see chapter 2). However, such engagement remains very limited in eastern Europe. Harm reduction efforts are an essential part of effective HIV and STI prevention and control, but programmes targeting risk groups – especially IDUs, MSM and prisoners – remain inadequate in the subregion. The proportion of HIV budgets in eastern Europe allocated to prevention and harm reduction is small compared to equipment and testing budgets, with obvious implications for STI prevention (29).

One example of an attempt to better integrate STI/HIV prevention and treatment into primary care is occurring in **Kyrgyzstan** as part of the government's general health system development plan through support by the United Nations Population Fund (UNFPA). The training there of primary care providers will be evaluated in 2008. Furthermore, since 2005, several countries – **Kyrgyzstan, Moldova, Tajikistan and Uzbekistan** – have been developing (and in some cases approving) reproductive health strategies in which STIs are a priority. In addition, as part of the UNFPA/WHO Strategic Partnership Programme to improve support for national efforts, the two agencies have provided assistance to many central Asian countries and **Armenia** to adapt or adopt WHO STI guidelines (G Lazdane, personal communication, 2007).

### Summary

STIs can increase the risk of HIV infection and transmission. Controlling STIs is one means of controlling HIV, just as identifying HIV-positive individuals, without coercion, can help control STIs. Although WHO and UNAIDS recommend strong STI surveillance systems as part of second-generation HIV surveillance, there is widespread variation in the quality of STI surveillance systems throughout the European Region, leading to poor comparability and interpretability of data.

Despite the difficulties with surveillance, it is possible to establish a baseline for progress on Action 16. In western Europe, syphilis incidence increased in most countries from a low level, peaking in 2003–2004 and mirroring HIV trends. The highest rates for this subregion remain in **the United Kingdom and Spain**, mainly due to localized urban outbreaks among high-risk groups, primarily MSM. In central European countries the picture is mixed, but syphilis trends are similar to HIV trends, with outbreaks occurring primarily among MSM. The range of syphilis incidence rates now resembles that of western Europe. In eastern Europe, unlike the rest of the Region, the syphilis and HIV epidemics are unrelated. There, injecting drug use remains the main mode of HIV transmission, while the current STI epidemic arose due to a combination of rapid socioeconomic changes, a rapid contraction of health services and an increase in commercial sex work. STI rates have fallen again, though they remain much higher than in western Europe. Since the signing of the Dublin Declaration in 2004, gonorrhoea incidence in eastern Europe has continued to fall. Incidence is still higher than in western and central Europe, with the exception of **the United Kingdom**, where it is higher than in the Baltic states.

Complementing the UNAIDS public health approach, the WHO Global Strategy for the Prevention and Control of Sexually Transmitted Infections provides a needed international framework for the prevention and control of STIs. However, since there is no mechanism for systematically assessing the health systems of the Region with respect to either approach, it is impossible to establish a Dublin Declaration baseline for health system responses to STIs, much less report on progress. Weak surveillance systems also limit many countries' ability to plan and to monitor the success or failure of their STI/HIV prevention programmes.

### **Recommendations**

As part of second-generation HIV surveillance, weak and heterogenous national STI surveillance systems need to be strengthened and harmonized throughout the European Region, especially in eastern Europe, with adequate resourcing, the expansion and support of relevant networks and the sharing of expertise and best practice. These steps will enable not only the monitoring of progress on Action 16, but also improved monitoring of STI trends and outbreaks in the Region and better planning, targeting and outcome assessment for STI/HIV prevention and treatment programmes and services. Surveillance systems should also collect information on risk factors for STIs and HIV infection, and they should focus on vulnerable populations and risk groups.

As part of efforts to control HIV, there is an urgent need for national and regional governments, particularly in eastern Europe and certain countries of western and central Europe, to use high quality STI surveillance and evidence-based approaches to integrate prevention and treatment services for HIV and STIs. Such efforts should be guided by both the UNAIDS public health approach and the WHO global STI strategy and rely on existing networks, available expertise and adequate resources. In particular, safer sex behaviour needs to be encouraged, using proven interventions and addressing the factors underlying risky sexual behaviour, including socioeconomic factors and the use of alcohol and other recreational drugs. There is also a strong need to strengthen condom programming, encourage people to seek health care, integrate STI (and HIV) control into primary health care and other health care services, provide specific services targeting risk groups, provide comprehensive case management and detect asymptomatic and symptomatic STIs earlier.

The development of a regional mechanism for systematically collating, assessing and monitoring the extent to which national health systems address STI/HIV control should also be considered, again in accordance with the UNAIDS and WHO strategies mentioned. Other concrete recommendations include:

1. As part of second-generation HIV surveillance, weak and heterogenous national STI surveillance systems need to be strengthened and harmonized throughout the European Region
2. Surveillance systems should collect information on risk factors for STIs and HIV infection, and they should focus on vulnerable populations and risk groups
3. Governments should use high quality STI surveillance and evidence-based approaches to integrate prevention and treatment services for HIV and STIs
4. The development of a regional mechanism for systematically collating, assessing and monitoring the extent to which national health systems address STI/HIV control should be considered
5. All efforts should be guided by both the UNAIDS public health approach and the WHO global STI strategy
6. Safer sex behaviour needs to be encouraged – particularly by strengthening condom programming - using proven interventions and addressing the factors underlying risky sexual behaviours, including socioeconomic factors and the use of alcohol and other recreational drugs

7. Proven methods should be used
  - to encourage people to seek health care
  - to integrate STI and HIV control into primary health care and other health care services
  - to provide specific services targeting risk groups
  - to provide comprehensive case management
  - to detect asymptomatic and symptomatic STIs earlier.

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## 11. Research and new technologies

**Dublin Action 19:** “Increase commitment to research and development for new technologies that better meet the prevention needs of people living with or most vulnerable to HIV transmission including increasing public sector investment in vaccines and microbicides to prevent HIV infection.”

**Dublin Action 24:** “Invest in public research and development for the development of affordable and easier to use therapeutics and diagnostics to support expanded treatment access and improve the quality of life of people living with HIV.”

This chapter differs thematically from some of the others in this progress report as it does not address immediate issues, such as preventing HIV transmission or treating people living with HIV (PLHIV), but rather long-term investment into research. While the results of such investment may seem far off, today we actually hear about research advances in HIV knowledge, treatment and prevention all the time.

Existing prevention measures, such as condom distribution, behavioural modifications and HIV education, can reduce transmission significantly, but even when scaled up, the current options do not address all prevention needs. Therefore, there is a need to develop better preventive technologies as well as better treatment for those who are living with HIV; furthermore, HIV research and development (R&D) should be an integral part of the comprehensive response to HIV/AIDS. However, funding for HIV-related research is insufficient and many countries still struggle with the implementation of existing prevention measures, pushing R&D of new technologies into the background.

The Dublin Declaration recognizes research as an integral part of a comprehensive response to HIV/AIDS. The two relevant actions, 19 and 24, call for increased commitment to the development of new technologies for prevention, treatment and diagnostics to improve the quality of life for PLHIV. Action 19 calls for increased commitment to new preventative technologies and Action 24 calls for investment in “affordable and easier to use therapeutics and diagnostics”.

This chapter will assess the levels of commitment to HIV-related R&D in the WHO European Region. The aim is on the one hand to provide an overview of current trends in public sector investment by the European Commission and national governments, and on the other to outline the scope of future monitoring efforts by looking at the shortcomings in available data.

### Sources of information

In preparing this chapter, we found relevant, available data to be sparse. They are not currently being collected regularly or with a consistent methodological approach. We obtained data on European Commission funding by contacting European commissioners directly, particularly members of the Health and Consumer Protection Directorate-General (DG Sanco) and its Public Health Executive Agency (PHEA), the Research Directorate-General (DG Research) and the Development Directorate-General (DG Development), as well as the European and Developing Countries Clinical Trials Partnership (EDCTP).

For national information, we approached the national research institutes for budget data for 2003–2008. Members of the European Commission Think Tank on HIV/AIDS<sup>52</sup> provided information on whether research is addressed in each national HIV/AIDS plan, whether there is an HIV research budget and whether the national research institute is publicly funded. They also provided information about other government funding for HIV-related research.

For information on funding for international HIV-research we contacted the International Partnership for Microbicides (IPM), the Global Campaign for Microbicides (GCM) (including its fact sheet on European spending on microbicides), the International AIDS Vaccine Initiative (IAVI) and the AIDS Vaccine Advocacy Coalition (AVAC). We also used reports on European funding allocations for HIV-related research, including from the HIV Vaccines and Microbicides Resource Tracking Working Group (Resource Tracking Working Group).

### **Research activities in the biomedical and social sciences**

#### *Definition of research and development (R&D)*

R&D couples scientific research with technological development. It applies knowledge developed in basic research to the development of products, such as new drugs or vaccines. Basic research activities are usually, although not exclusively, publicly funded and undertaken by academic research institutions. Development activities (e.g. lead identification and optimization, clinical trials and product development) are primarily carried out by the private sector and driven by commercial priorities.

R&D can be divided into different stages of research, namely *basic research*, which is essential to developing leads for potential product development, *translational research*, which takes potential candidates through Phase II and III trials, *capacity-building* in developing countries and *product development*.

A brief description of some of the most critical HIV-related research areas follows.

#### *HIV vaccine R&D*

The mainstay of any prevention approach to a communicable disease is a vaccine. The development of an effective HIV vaccine is crucial for future prevention efforts and scientists are increasingly confident that a vaccine against HIV can be found.

While first-generation vaccines may not completely protect against HIV infection, they should still be effective in lowering the likelihood of becoming infected or slowing down the progression of AIDS (1). However, the development of vaccine candidates is a lengthy and costly process that may take up to 15 years apiece, with no certainty of success (1). There are currently more than 30 vaccine candidates being tested in clinical trials around the world (for a full review of AIDS vaccine clinical trial activity in 2006 and a comprehensive listing of all ongoing trials as of January 2007, see that month's issue of *VAX* (2)). Two are in an advanced stage of testing (testing for efficacy), and results are expected towards the end of the decade. IAVI and its partners have developed six vaccines for testing in human trials during the past 10 years.

In 2003, vaccine development efforts suffered a serious setback when a Phase III trial of a leading vaccine candidate did not prove effective (3).

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<sup>52</sup> The Think Tank was set up by the European Commission as a response to the Dublin Declaration and is represented by governmental HIV/AIDS focal points from every EU member state.

### *Microbicide R&D*

Microbicides are a range of substances being developed for HIV prevention initiated by receptive partners in sexual intercourse. Applied topically vaginally or rectally, they will substantially reduce or prevent the sexual transmission of HIV. Microbicides could be delivered in a variety of ways, including gels, rings, films and tablets.

Several microbicide candidates are currently being tested for vaginal use. One, Carraguard, has completed a Phase III clinical trial, with results expected in late 2007. Two others, Pro-2000 and Buffer Gel, are currently in efficacy trials in sub-Saharan Africa (4). All three products are gel-based and must be used each time a person has sex. The next generation of microbicides, based on the topical use of antiretroviral drugs (ARVs) is now in safety trials, with one product (PMPA Gel) recently starting a Phase IIb proof-of-concept efficacy trial in South Africa. ARV-based products provide longer protection and may not require reapplication before each sex act. A number of products are also in early-stage development for use as potential rectal microbicides.

There are significant short-term benefits in conducting research into AIDS vaccines and microbicides with and in developing countries. For the developing countries, advantages include permanent research facilities, strengthening the health infrastructure, increased HIV awareness, access to HIV education, access to voluntary counselling and testing (VCT), access to existing prevention methods and engagement of local professionals. Together, these benefits can help the country achieve the short-term goals of its HIV/AIDS response and Millennium Development Goals (MDGs).

Although the news from vaccine and microbicide trials has been disappointing in recent years, expanding scientific knowledge and greater understanding of the role these technologies may play in controlling the epidemic underpins confidence in future development efforts. This confidence is to an extent reflected in growing, if still insufficient, funding for these research areas (5). Microbicides and vaccine candidates are primarily being developed by international public-private product development partnerships (PDPs) (see Box 11.1).

#### **Box 11.1. Public-private product development partnerships (PDPs)**

PDPs are not-profit organizations that receive funding from the public, philanthropic and private sectors and use these funds to partner with academic researchers, government institutions and private industry in product R&D efforts (6). PDPs arose in response to the need for appropriate tools to treat and prevent poverty-related diseases, including HIV/AIDS, which have not been priorities for commercially driven product development.

PDPs support the development of and future access to public health products for use in developing countries. They primarily focus on translational research, taking promising candidate from preclinical trials to clinical trials, with a parallel focus on product development (e.g. developing manufacturing processes). However, the exact focus of PDP activities varies according to the current state of research in the relevant disease and technology fields.

PDPs utilize approaches to product development like those of private industry, including active portfolio management, outsourcing and milestone-driven research funding. PDPs enjoy strong support and funding from several European Union (EU) member states, **Norway, Switzerland**, the Group of Eight (G8) and DG Development. Research has shown that PDPs are more efficient in developing drugs than efforts driven solely by public institutions (7).

### *Diagnostic technologies*

New technologies that have been developed for diagnosing HIV/AIDS have proven to have benefits far beyond this disease. They have often resulted in major changes in perception by medical scientists and the general population when they are implemented widely.

An example of this is polymerase chain reaction (PCR) technology for detecting viral load. Since its development, PCR has been implemented throughout the health care sector for detecting other infections. Such developments are largely funded by the private sector and therefore do not need to be addressed here at length.

### *Therapeutics*

The improvement of antiretroviral drugs has changed our perception of the illness from a death sentence to a chronic disease. The introduction of highly active antiretroviral therapy (HAART) in the mid-1990s significantly improved the quality of life for PLHIV. As drug development is usually conducted by pharmaceutical companies, there exists very limited public-private sector collaboration in this field.

Drug coverage and affordability still needs to be improved, especially in eastern Europe, where access to medicine and health care services is far from universal. (See Chapter 12 for information on access to HIV treatment.)

### *Male circumcision and HIV prevention*

The results of three clinical trials in Africa have shown that male circumcision reduces the risk of HIV transmission from women to men by up to 60% (8–10). These results are promising, though serious questions about safety, cultural practices and a possible tendency towards less consistent condom use should be addressed before this intervention is implemented widely (see the WHO/UNAIDS policy recommendations of March 2007 for more information (11)).

### *Sperm-washing*

There is sufficient evidence showing that washing the semen of HIV-positive men for insemination purposes has not resulted in any seroconversion of the inseminated women or the resulting children (12,13). Sperm-washing was introduced in **Italy** in 1989, but many countries do not allow it or call for further research. If sperm-washing is to fulfil its potential as a public health measure reducing the risk of HIV transmission to seronegative female partners of seropositive men who wish to have children together, it should be allowed and even encouraged. Operational research efforts should focus on identifying national centres that can provide this service and reach those who could benefit from it.

### *Pre-exposure prophylaxis*

Pre-exposure prophylaxis (PrEP) – not to be confused with post-exposure prophylaxis (PEP) – involves taking antiretroviral drugs before likely exposure to HIV in order to reduce the risk of infection. PrEP could be of use for members of various risk groups, including men who have sex with men (MSM), injecting drug users (IDUs) and their partners, prisoners, sex workers, hospital staff and seronegative partners of PLHIV. Effectiveness research on PrEP should be complemented by behavioural research to evaluate possible encouragement of risky behaviour.

### *Social science research, including behavioural studies*

While social science research is not named directly in Actions 19 and 24, it is worth mentioning because it can help predict a new technology's social impact and probable utilization, and because it informs all clinical, operational and behavioural research. More specifically, social science research can be critical in:

- designing and implementing robust, ethically sound clinical trials
- interpreting clinical trial results
- understanding the likely use of technologies in the field and their impact on behaviour
- understanding how to deliver products and services more effectively.

In order to expand treatment access and improve the quality of life for PLHIV, as called for in Action 19 and 24, public investment in HIV clinical research should be complemented by investment in HIV social science research – including behavioural, policy and operational research – to ensure that as new technologies are developed, they can be licensed, introduced, delivered and used as effectively as possible.

### **The case for increasing research commitment**

Action 19 in the Dublin Declaration emphasizes vaccine and microbicide development. Public sector funding for R&D of these two preventive technologies is being tracked by the HIV Resource Tracking Working Group (5). The Working Group reports that the public sector dominated funding for HIV prevention-related R&D in 2005, accounting for 88% of the global investment in HIV vaccine R&D and 85% of global investment in microbicide R&D (83% and 86% respectively in 2006) (14). Yet European national governments and the European Commission account for just 10% of global public sector investment in HIV vaccine R&D and 21% of funding for microbicide R&D (5).

How much funding is needed for HIV-related research? According to IAVI, it takes between €150 million and €400 million to develop and fully test each vaccine candidate (1). While investment has steadily increased in recent years, budget allocations for HIV research fall short of the “estimated resources required to optimally accelerate the development of and assured access to these technologies” (5).

- In 2005, significant investments were made in AIDS vaccine R&D, amounting to approximately US\$ 760 million (€560 million) globally (5). The funding available has doubled between 2000 and 2005, demonstrating increased commitment to AIDS vaccine R&D, mainly by government donors. Despite the commitment and growth in financial support for AIDS vaccine R&D in recent years, existing funding is insufficient to drive the field forward as rapidly as the scientific challenges involved and the potential impact of a vaccine would argue for. The Global HIV Vaccine Enterprise estimates that about US\$ 1.2 billion (€890 million) is needed annually to advance AIDS vaccine development (15). The Global HIV Vaccine Enterprise estimates that about US\$ 1.2 billion (€890 million) is needed annually to advance AIDS vaccine development (15), indicating a yearly shortfall of about US\$ 440 million (€325 million).
- For microbicides, the Alliance for Microbicide Development and the International Partnership for Microbicides estimate that US\$ 280 million ( (about €205 million) per year will be required over the next five years to accelerate development of a safe and effective microbicide (5,16). Future investment needs are now being assessed again by experts in the field.

To these figures should be added the funds needed for other biomedical and social science research, for an overall total need that the actual funding levels for HIV research can be compared to. As we shall see, actual contributions to R&D do not meet these estimates.

The increasing confidence of scientists in their ability to develop new preventive technologies, coupled with the growing body of knowledge about the potential of these untried tools to effectively curtail the HIV epidemic (17), is undermined by the decreasing focus on HIV/AIDS in general. HIV research must compete with other pressing research priorities, such as

bioterrorism and pandemic influenza, to stay on the political agenda and obtain the necessary funding.

### **HIV research in EU policy and documentation**

In signing the Dublin Declaration, the governments of the European Region also committed themselves to intensifying their political leadership on HIV issues (see Chapter 1). One essential element in this commitment was to support action and coordination by regional bodies, most notably the European Commission. Commission documents do demonstrate a fundamental commitment to research as an integral part of the fight against HIV/AIDS.

The main documents that we shall discuss here are two programmes for action (PfA1 and PfA2, dated 2001 and 2005 respectively) (18, 19). These two documents outline the basis for inter-directorate action on HIV, tuberculosis (TB) and malaria, including increasing R&D support through the Commission’s framework programmes for basic and strategic research. In calling for a “European clinical trials platform”, PfA1 became a driving force behind the establishment of the EDCTP. It also underlined the need for increased capacity-building in developing countries and for incentives to develop specific global public goods.

In reviewing relevant European Commission documents, it becomes evident that they are becoming more specific about HIV research needs. The most recent Parliamentary Report on HIV, for example, supports R&D of innovative ARVs, vaccines and microbicides, as well as research into vaginal and rectal physiology and ecology and into the transmission of viruses (20). It also urges the Commission to ensure that HIV research is gender balanced.

The European Council conclusions of 23 April 2007 emphasize the feminization of the HIV epidemic worldwide and the need to improve affordable prevention options and choices for women, including the female condom and microbicides. They furthermore underline the need to intensify R&D of better and more affordable tools for HIV prevention, treatment and early diagnosis, including vaccines, paediatric drugs and again, microbicides (21). These conclusions furthermore state that the EU will continue addressing HIV/AIDS through a wide array of existing financing instruments globally and nationally, including the Global Fund to Fight HIV/AIDS, Tuberculosis and Malaria.

The Council conclusion of 31 May 2007 additionally calls for research into PrEP and the most effective ways to achieve behavioural change, thereby acknowledging the importance of the social sciences to HIV research (22).

This increasing level of detail is a welcome development in EU policy documents, making it easier to fund specific projects and enabling documents to be used as advocacy tools in funding requests for specific research areas.

See Table 11.1 for an overview of major European Commission funding for HIV-related research since 2004.

**Table 11.1. Types of research funded by EU directorates and instruments**

	Therapeutics	Microbicides	Vaccine	HIV total
FP5	0 projects	0 projects	13 projects	26 projects

AIDCO: EuropeAid Co-operation Office, DG Development: Development Directorate-General, DG Research: Research Directorate-General, DG Sanco: Health and Consumer Protection Directorate-General, EDCTP: European and Developing Countries Clinical Trials Partnership, FP: Framework Programme for Research and Technological

Development, PDP: public-private product development partnership, PHP: Public Health Programme, R&D: research and development

<sup>a</sup> Talks on funding for PDPs through FP7 are currently underway, but the EU funding gap for this type of research has not yet been bridged.

### *DG Research*

The objectives of DG Research funding are to improve innovation in the EU and to strengthen its competitive edge. In health research, the primary aim is improve the health of EU residents, although there is some recognition of the importance of tackling global health challenges.

Through the primary funding mechanism of DG Research, the 6<sup>th</sup> Framework Programme for Research and Technological Development (FP6, 2002–2006), HIV-related research was positioned as a top priority for the European Commission. FP6 financed preventive and therapeutic research efforts with approximately €50 million per year (23). Forty-five per cent of this funding went to HIV/AIDS-related research activities, amounting to almost €126 million for 2002–2006 (see Table 2 below).

FP6 featured several different funding instruments, the biggest of which was the Network of Excellence (NoE) (24). This initiative funded research collaborations and efforts to harmonize and bring together research activities and knowledge, involving as well new member states and neighbouring eastern European countries (25). Other instruments, such as Specific Targeted Research Projects (STREPs) and Integrated Projects (IPs) have also funded HIV-related research, for example in microbicide development.

FP5 and FP6 focused on investigator-led research, which is suitable for basic research but not well suited to translational research. Moreover, the inflexible grant regulations were unattractive for some research groups engaged in product development, particularly international PDPs (see Box 11.1), and they have consequently fallen into a European Commission funding gap (26). Product development and translational projects must adapt considerably as candidates are prioritized, and PDPs often use outsourcing to keep core costs low and provide flexible access to expertise and other resources. However, these work methods were not funded by FP5 and FP6.

Table 11.2 shows the number of projects and level of funding under FP5 and FP6. Funding for HIV projects more than doubled between FP5 and FP6.

**Table 11.2.** HIV R&D projects in FP5 and FP6

	Therapeutics	Microbicides	Vaccine	HIV total
FP5	0 projects	0 projects	13 projects	26 projects
Total cost	€0	€0	€49 387 305	€67 313 490
European Commission contribution (post-negotiation)	€0	€0	€32 318 976	€47 465 661
FP6	18 projects	6 projects	21 projects	45 projects
Total cost	€68 581 916	€39 567 250	€78 755 181	€186 904 347
European Commission contribution (post negotiation)	€48 715 412	€27 966 160	€49 310 058	€125 991 630

HIV/AIDS research will continue to be a priority under FP7, which runs from 2007 to 2013 and has a total budget of over €50 billion, of which €6.1 billion is for health (27). Like previous FPs, FP7 aims to influence the structure of European research by setting up research networks and increasing the mobility of individual researchers “in order to counter the fragmented nature of the European research landscape” (28).

The FP7 Cooperation Work Programme on Health for 2007–2008 aims to link European action on global public health issues to international efforts, including via public–private partnerships (29). It will emphasize preclinical and early clinical research activities and where relevant, such as for HIV/AIDS vaccines, collaboration with European and global initiatives. Such collaboration is called for in the second round of proposals under Specific International Cooperation Actions (SICA) with a deadline of 18 September 2007. Unlike FP6, which had a unit for “poverty-related diseases” that included HIV, TB and malaria, FP7 has a new structure that brings together all infectious and emerging diseases in one place. Within FP7, HIV research therefore has to compete with diseases such as severe acute respiratory syndrome (SARS) and avian influenza in addition to TB and malaria. Funding for HIV research will thus not increase substantially unless the overall allocation for “emerging and infectious diseases” is enlarged.

As under FP5 and FP6, the challenge remains to make the funding more flexible. While the current language is promising, the test of FP7 will be how flexible the actual contracting agreements are. A group of international PDPs (including IPM and IAVI in the field of HIV research) have been exploring opportunities with the European Commission to support their activities through the use of more flexible, milestone-driven contracting arrangements in FP7 (26). The first FP7 grants are yet to be awarded, and the application and implementation process should be reviewed as decisions are made and projects initiated.

#### *European and Developing Countries Clinical Trials Partnership (EDCTP)*

EDCTP was established in 2002 by 14 EU member states, plus **Norway** and **Switzerland** and African countries to share and improve R&D efforts to combat poverty-related diseases (HIV/AIDS, malaria and tuberculosis) with a focus on phase II and III clinical trials in sub-Saharan Africa. The EDCTP is an integral part of FP6 and FP7 and a vehicle for taking promising product candidates to Phase II and III clinical trials.

The initial funding for EDCTP over a five-year period was €200 million from DG Research, €200 million from EU member states and €200 million from the private sector. However, there has been a persistent lack of clarity about the nature of member state commitments and progress in implementing projects has been slow. Consequently, project-related contributions from the private sector have also been limited to date.

In view of the adamant need to strengthen research capacity, especially in countries that currently do not have the voice, negotiation capacity and/or voting rights to design and implement research priorities and regulatory frameworks to their advantage (as outlined in the Coherent European Policy Framework for External Action to Confront HIV/AIDS, Malaria and Tuberculosis (30)), it is hard to comprehend that only €8.3 million of the committed funds have been translated into actual expenditure, 18% of which were directed to HIV-related clinical trials (6). The EDCTP has directed an additional €6.8 million to capacity-building and site preparation for trials. The first EDCTP call for microbicide proposals was issued in December 2007 and was for a minimum €6.1 million, matched by an equivalent amount from Member States and other donors ([http://www.edctp.org/HIV\\_Microbicides.305.0.html](http://www.edctp.org/HIV_Microbicides.305.0.html)).

### *DG Development*

The new overarching framework for the EU development policy, entitled *European Consensus on Development Policy*, was agreed upon by all member states, and includes PfA2 as a critical component (<http://europa.eu/scadplus/leg/en/lvb/r12544.htm>).

Support for microbicide- and vaccine-related projects has been channelled through “Aid for poverty-related diseases (HIV/AIDS, tuberculosis and malaria) in developing countries”, a budget line established in 2002 to fund PfA1 activities. Annual expenditures for 2002–2006 were approximately €42.8 million, with an additional €108.9 million per annum allocated to the Global Fund. HIV research funding from the recently launched Investing in People programme has not yet materialized.

Under the previous “Aid for poverty-related diseases” budget line, DG Development and the EuropeAid Co-operation Office (AIDCO) provided three grants for HIV-related research (6): €6 million to IAVI (€3 million for 2004–2006 and €3 million for 2006–2008); €0.87 million to IPM for 2005–2008, with an additional €4.2 million for 2007–2010; and €1.45 million to International Family Health/Program for Appropriate Technology in Health (PATH) for 2002–2006 for microbicide advocacy efforts. The total commitment of DG Development to HIV research in 2002–2009 is thus €12.52 million.

DG Development also supports specific PDPs through country-level funding. However, no data are available on the amount of such support (6).

### *DG Sanco*

While EU member states retain most public health responsibilities, the Commission assumes responsibility for cross-border health threats, patient mobility and reducing health inequalities. DG Sanco is in charge of implementing the Public Health Programme (PHP) through health projects, which are currently approved and monitored by the Public Health Executive Agency (PHEA). PHEA supports actions to improve and protect human health in the EU (31).

The maximum budget for the PHP for 2003–2008 is €353.77 million. According to the annual work plan, the budget available for 2007 is €40 million, €38.8 million of which is the “operational budget” used to award grants for selected projects (32). For the new European Commission public health programme (33), the budget is €365.6 million, a disappointing third of the originally proposed €969 million for health and consumer protection.

The PHP has three main research areas: health information, health threats and health determinants. Both the 2006 and 2007 work plans prioritize efforts for HIV prevention (including harm reduction for drug users), treatment and VCT (34, 35). Research activities are not directly financed through DG Sanco, as such projects overlap with the FP, but its impact assessment and social programme evaluation efforts incorporate an important component of social science and behavioural research, although they may often not be recognized as research, per se, and there exists a funding gap in European Commission support for such research.

While social science research is not explicitly mentioned in the Dublin Declaration, behavioural research is mentioned in the most recent *Council conclusion on combating HIV/AIDS* from 31 May 2007 (22), and the Commission grants support to social-behavioural, epidemiological, operational, health systems and applied research, as well as cost-projection studies (19).

A more precise definition and awareness of what health research involves is needed to close the perceived gap between health action and health research activities in DG Research and DG Sanco funding. It is worth considering how social science research can be integrated into the

formulation and understanding of health action and prevention programmes in order to make sure that all promising areas of HIV research receive funding.

*Summing up: the EU commitment to HIV-related research*

The EU has made a major effort to improve coordination, cooperation and competitiveness among European researchers, for example by introducing the European Research Area and utilizing the FPs, which have affected the configuration of HIV research. The EDCTP was specifically set up to improve coordination of HIV/AIDS, TB and malaria research.

The European Commission has also made clear progress in funding allocations for R&D of new HIV technologies since the publication of the Dublin Declaration by increasing funding in FP7. However, the fact that the public health budget for the period 2007–2013 was not increased is a disappointing setback for health efforts, including HIV research.

European Commission research funding constituted only 5–6% of all national governmental research investment in the EU throughout the period of FP5 (36). Given that the total European public contributions (EC and Member States) to R&D in microbicide and HIV vaccine research in 2005 comprised of 21% and 10% respectively of all such global investments (5) and 29% and 11% respectively in 2006 (16), there was considerable room for increased investment via EC funding instruments. See the end of the chapter for European Commission recommendations.

**Monitoring and coordination of funding at the national level**

The overview below of national government allocations for HIV-related research is based on national HIV/AIDS plans, input from government representatives (members of the Think Tank on HIV/AIDS) and information from the main national research institutes (e.g. the National Agency for Research on AIDS and Viral Hepatitis (ANRS) in **France**, the Medical Research Council (MRC) in **the United Kingdom**, the Competence Network and the Robert Koch Institute in **Germany**, International Antiviral Therapy Evaluation Center (IATEC) in **the Netherlands** and the Copenhagen HIV Programme in **Denmark**). The focus of this review is mainly on western European governments, as they are the highest-income countries and leading donors.

The first issue to be raised is that most countries have very poor mechanisms for monitoring public funding of HIV-related research, which made it difficult for them to provide data for this chapter. Secondly, the HIV research activities of many countries are not centrally organized, nor do their national HIV/AIDS plans allocate any funds for research. For most of the region, national plans accordingly play little or no role in budgeting for HIV-related research. HIV research is usually coordinated at a lower level, where it must compete with other health areas on the initiative of individual institutions, rather than growing out of central policy.

Thirdly, HIV R&D usually falls under either a domestic or an international policy umbrella, and objectives differ significantly for international development-oriented R&D projects and domestic research efforts. Finally, HIV research funds are inevitably managed by different ministries – a fragmentation that also was a major hurdle in collecting data for this chapter.

*Western Europe*

The countries that do have centrally organized research activities are mainly western European (**France, Germany, the Netherlands and the United Kingdom**). Research budgeting structures and funding sources vary widely in the subregion, but the ministries that most commonly direct research funding are the education and research, health and foreign affairs ministries (the last through development funds). One main issue that becomes evident in collating data from across

western Europe is that it is no longer feasible for national governments to conduct certain types of HIV-related research at the national level. One example is the Dutch government's decision to shut down the National AIDS Therapy Evaluation Center (NATEC). Many western European countries have provided substantial grants to international PDPs, which should be clear in the brief country examples below.

**Belgium.** The main problem with collating data on HIV research in **Belgium** comes from the fact that there is no national AIDS plan and that competencies lie with both the federal and the regional authorities. Many institutions receive funding for HIV research, mostly on prevention activities, but some universities also conduct basic research. The Belgian government provided the first grant to IPM in 2007 (€1 million per year for three years). The Institute for Tropical Medicine is actively researching microbicides.

**Denmark** has increased its commitment to IPM from DKK 5 million (€0.67 million) per year in 2003 to DKK 10 million (€1.34 million) in 2006 and 2007. Cumulative Danish support through 2007 amounts to DKK 37.5 million, equivalent to €5.03 million. The Ministry of Foreign Affairs has supported IAVI since 2001, and last year made its first multiyear commitment (2006–2008), for DKK 30 million (€4.02 million), bringing the total support to DKK 65 million (€8.74 million).

**France.** While the ANRS budget has increased slightly since 2003, it continues to vary considerably, dropping to a low of €29.2 million in 2006 before rising again to €39.2 million annually in 2007–2009. The institute is funded by the Ministry of Research, the Ministry of Health and the Ministry of Foreign Affairs, as well as receiving €120 000 from the European Commission through FP6 in 2007 for a European AIDS Treatment Network (NEAT) project in clinical research. The French government provided €170,000 to IPM in 2007.

**Finland.** The Finnish national AIDS plan addresses HIV research, but since the plan is merely a guidance document, there is no set budget.

**Germany.** The German Action Plan for Implementing the Strategy of the Federal Government to Fight HIV/AIDS outlines current budgeting for HIV-related research. The Federal Ministry of Health has roughly €1.6 million per year for HIV-related R&D projects. The Federal Ministry of Education and Research (BMBF) supports projects in HIV/AIDS research with approximately €25 million. Additionally, institutional funding is provided. The Competence Network for HIV/AIDS is a national research system providing a platform for cooperation and scientific exchange between relevant stakeholders including clinical and basic researchers, practitioners and patients. Based on a patient cohort of more than 8000 well documented patients from over 25 clinical sites and private practitioners, the network provides a basis for biomedical, clinical and socio-scientific research in Germany and on international level. The network has been funded by the Ministry of Education and Research since 2002 and will receive a total of €18.5 million until 2010.

Germany supports the European Art. 169 initiative EDCTP (European and Developing Countries Clinical Trials Partnership) and provides national cofunding. The Federal Ministry of Development Cooperation has budgeted 1 million € for the International Partnership on Microbicides (IPM)

**Ireland** has funded IPM with a spectacular €19 million from 2002 to 2007, placing it among the top investors in microbicide R&D as a proportion of gross domestic product (GDP) (5). The republic's staunch commitment to HIV research is also witnessed by its IAVI support, which totals almost €23 million to date.

**Luxembourg.** Research is part of the national AIDS plan, but no budget is outlined for it. Funded institutes include Centre de Recherche Public – Santé and Centre Hospitalier de **Luxembourg**. Both the Ministry of Research and the Ministry of Health fund research, but it is included in quite a number of budget lines.

In **Malta**, the government allocates no money for HIV-related research.

**The Netherlands.** The Dutch Ministry of Health does not directly support HIV research, except surveillance studies. However, it does fund research institutes, which award support to research proposals competitively. The Ministry of Foreign Affairs supports the Science for Global Development division (WOTRO) of the Netherlands Organisation for Scientific Research (NWO), which funds HIV research that focuses on developing countries, again awarded competitively. Research is also conducted privately (e.g. through AIDS Fund and academic centres). **The Netherlands** also has set up the Netherlands-African Partnership for Capacity Development and Clinical Interventions Against Poverty-Related Diseases (NACCAP), which is their contribution to EDCTP, and will have provided IPM with €22 million between 2002 and 2009. The Ministry of Foreign Affairs was one of IAVI's first European donors, and it remains one of the most important European contributors to AIDS vaccine R&D, with cumulative IAVI support of more than €59 million.

From 2001 to 2005, NATEC received funding to conduct research on therapy adherence, side-effects such as lipodystrophy, treatment interruption and coinfections. NATEC collaborated with partners from Thailand, Australia and **the Netherlands**. However, in 2006 the government discontinued funding for NATEC, as it was no longer cost-effective to conduct these types of research in a small country like **the Netherlands**. Instead, the funds were directed towards international efforts (NATEC, unpublished report).

**Norway.** The Research Council of **Norway** has newly established the Programme for Global Health and Vaccination Research (GLOBVAC), focusing on research of relevance to health problems in low- and middle-income countries, a focus that naturally includes HIV/AIDS research. The annual budget for this programme is currently about €2 million for global health research and €6 million for vaccination research. In addition, **Norway** has given IPM €11.3 million between 2002 and 2007, and the Ministry of Foreign Affairs has given IAVI €12.2 million since 2001.

**Spain.** The Basque Autonomous government has given IAVI a grant of €328 800. The Ministry of Foreign Affairs in June 2007 announced a €1 million grant, making **Spain** the most recent European government to support IAVI.

**Sweden** provided €3.32 million to IPM in 2004–2006. The Ministry of Foreign Affairs has supported IAVI since 2002, with funding totalling €3.86 million.

**The United Kingdom.** The MRC is the leading institute conducting HIV research in **the United Kingdom**, allocating a total of £44.8 million (€58.9 million) to HIV research in 2003–2007.

The Department for International Development (DfID) is strongly committed to HIV prevention research. It has supported microbicide and vaccine R&D with £86.7 million (€116 million) to date (37). This figure includes £40 million (€53.5 million) for the Microbicide Development Programme (MDP), £8.7 million (€116 million) to IPM and, as IAVI's oldest and most unwavering European supporter, more than £38 million (€50.9 million) since 1998, including

£20 million (€26.8 million) for 2005–2008. Total British funding for HIV-related research has increased considerably in recent years, totalling £158.9 million (€234.4 million) for 1998–2008.

The most recent DfID white paper includes a statement about doubling the research budget to £220 million (€294 million) per year by 2010/2011, including continued support for the development of new HIV drugs, vaccines and microbicides (DfID, unpublished report).

#### *Government support for private sector engagement in HIV research*

While the private sector (especially pharmaceutical companies) has been very active in the development of treatments for HIV, it has been reluctant to invest in other R&D areas, such as vaccines, microbicides and social science projects. This hesitancy is largely due to HIV research being a complex and demanding undertaking with uncertain outcomes and poor commercial prospects, with the possibility of forced low-cost distribution in developing countries for some products.

However, the role of biotechnology and pharmaceutical companies in supporting R&D and international PDPs is crucial. National governments and the European Commission can do much to support these investments by implementing “push-and-pull” mechanisms to decrease the risks faced by the private sector in these fields of research. Push mechanisms reduce the cost of R&D through such instruments as direct funding, tax credits and liability protection. Pull mechanisms increase future potential revenues from product sales through e.g. market guarantees, tax credits on sales and intellectual property incentives (1).

Very little information is available on government support for private sector investment in HIV research. However, **the United Kingdom** provides tax credits to companies undertaking AIDS vaccine and microbicide R&D. The Revenue & Customs Agency estimated that the cost of these credits over the two-year tax period 2003–2005 was around €1.2 million (5).

#### *Central and eastern Europe: funding from international organizations*

When it comes to funding HIV research, most central and eastern European countries allocate either no money (**Albania, the Czech Republic, Lithuania, Poland, Moldova, Romania and the Russian Federation**) or very little (**Croatia and Ukraine**). In **Poland**, the only HIV research funded by the government is the obligatory surveillance carried out by the ministries responsible. The Croatian HIV/AIDS plan allocates 2–3% of its HIV prevention and treatment budget to research. In 2005, it amounted to €175 000. In **Romania**, research is not covered by the national HIV plan, but some research has been undertaken in HIV. In addition, the Romanian Ministry of Education and Research has a special budget for improving national coordination of research activities.

The absence of European Region-wide coordination that includes the EU’s neighbouring countries exacerbates the regional fragmentation of HIV research. Global health partnerships, especially the Global Fund, play an important role in funding HIV programmes in eastern Europe, including behavioural and operational research. These programmes concentrate particularly on harm reduction for drug users, for example in **Ukraine**.

As a key donor for HIV efforts in many eastern European countries, the Global Fund has drawn increased attention to the importance of research, with guidance tools and a checklist for applicants who wish to apply for operational research funds (38). The Round 7 Guidelines furthermore mention the possibility to include both behaviour change interventions and operational research (39).

### *Summing up: funding at the national level*

Many European Region countries allocate no money for HIV research at all, and European commitment in general to HIV research falls well short of the resources needed to speed up the development of new prevention technologies. Especially in eastern Europe, limited resources leave no funds for investing in HIV research. It is crucial, however, that even in the face of pressing prevention and treatment needs, research into future HIV prevention technologies should not be forgotten.

The fact that national governments are increasingly supporting international research initiatives, such as PDPs, is a positive development. The reluctance of some countries to contribute fully to funding European research may have many reasons, including vested interests, nationalism, mistrust and worries about how money will be spent. However, most of the researchers who advised on the writing of this chapter articulated the immediate need for better international coordination. Recommendations for national governments appear at the end of this chapter.

### **Conclusions**

This study of HIV research funding in the European Region has painted an uneven picture. In the EU, European Commission investment through the FPs has increased steadily over the past five years, consistent with the Commission's commitment to increase investment in the R&D of new technologies. However, it remains unclear exactly how much of the allocated money has actually been expended. The DG Sanco budget for the PHP has not increased for 2007–2013. The interface between social science research and health interventions is, moreover, still insufficiently defined, resulting in a funding gap between DG Sanco and DG Research for social and behavioural research. There is also a funding gap for international PDPs, since FP rules for participation are inflexible and often unattractive to such applicants.

Nationally, monitoring of HIV research funding is poor and data are difficult to obtain. Only the countries with the best HIV research networks – such as **France, the United Kingdom** and especially **Germany** – have provided a thorough overview of their research budgets. While the western European countries are the main donors for research, all countries are urged to increase funding for HIV-related research (for example operations research), even in the face of serious prevention and treatment needs.

One problem posed by the available data is that it only provides an insight into part of the resource flow, namely financial commitments. To date, no major study has looked into how much of, and how the committed funds are actually spent. In order to understand the specific resources for research activities, it is important to gain an overview of expenditures relative to the commitments made with a breakdown by research area (basic research, translational research, product development, capacity-building research and clinical trials) (5). Both the European Commission and the Region's national governments are urged to improve their tracking of research funding.

Considering the Region's limited contribution to global investment in HIV-related R&D to date, there is considerable room for increasing its contributions across the board, not only through European Commission funding tools such as FP7 and EDCTP, but also through funding by national governments, who tend to play down or “forget” the need for more investment in research when confronted with urgent prevention and treatment needs.

If we are to keep up with future developments of the epidemic, it is crucial that European governments start prioritizing research funding. It should be remembered that research itself is a cost-effective long-term investment in treatment and prevention.

## **Recommendations**

### *Recommendations for future monitoring*

1. Collect data at the European Region level about public sector, philanthropic sector and private/commercial sector funding for HIV-related research, including a breakdown in expenditure routes
2. For monitoring Regional commitment to HIV-related research, consider adapting the methodology of the Resource Tracking Working Group's global study on funding levels for microbicide and vaccine research (5).
3. Translate all national HIV/AIDS plans into English to facilitate future monitoring and coordination of all HIV/AIDS efforts, including but not limited to research activities, in the European Region.

### *Recommendations for the European Commission*

4. Increase funding and resources for research efforts.
5. Include social science in the definition of HIV-related research that is eligible for funding.
6. Increase the public health budget and allow it to include a research component.
7. Increase the flexibility of contracting arrangements for FP7 grants to allow outsourcing approaches and responsive product-focused research.
8. Support global research efforts, as outlined in the *FP7 Cooperation Work Programme 2007–2008: health* (24).
9. Establish and maintain capacity-building efforts in the countries that most need it.
10. European Region-wide coordination should include the EU's neighbouring countries in order to avoid the regional fragmentation of HIV research

### *Recommendations for national governments*

11. (For EU member states.) Satisfy all financial commitments to the EDCTP.
12. Increase the national budget for HIV-related research, as committed to in signing the Dublin Declaration. Given the success of partnering with African countries in HIV R&D, a similar approach should be initiated to test products in eastern Europe and central Asia, where HIV now infects more than 1% of the population in many places.
13. While Action 19 does not set any specific targets for HIV-related research, countries implementing Recommendation XI.11 should consider using as a guideline the Sydney Declaration, which calls for 10% of all HIV spending to be allocated to research (40).
14. Increase support for international HIV research efforts, for example by increasing funding for international PDPs and social science research.
15. Improve the coordination of research funding and, if there is no National AIDS Commission (i.e. a coordination authority functioning as the central body for the entire HIV/AIDS response), work to establish one.

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## 12. HIV treatment and care

**Dublin Action 13:** Ensure men, women and adolescents to have universal and equitable access to and promote the use of a comprehensive range of high quality, safe, accessible, affordable and reliable reproductive and sexual health care services, supplies and information including access to preventive methods such as male and female condoms, voluntary testing, counseling and follow-up;

**Dublin Action 21:** By 2005, provide universal access to effective, affordable and equitable prevention, treatment and care including safe anti-retroviral treatment to people living with HIV/AIDS in the countries in our region where access to such treatment is currently less than universal, including through the technical support of the UN through of the UN through the global initiative led by the World Health Organization and UNAIDS to ensure 3 million people globally are on antiretroviral treatment by 2005 (“3 by5”). The goal of providing effective anti-retroviral treatment must be conducted in a poverty-focused manner, equitable, and to those people who are at the highest risk of and most vulnerable to HIV/AIDS;

**Dublin Action 23:** Increase access to non-discriminatory palliative care, counselling, psychological support, housing assistance, and other relevant social services for people living with HIV/AIDS;

**Dublin Action 25:** Monitor best practices on and take concrete steps to exchange information on service delivery for prevention, treatment and care, particularly for persons at the highest risk and most vulnerable to HIV/AIDS infection;

### Introduction

The introduction of highly active antiretroviral therapy (HAART) in 1995–1996 in western Europe and other industrialized countries represented the major turning point in the response to the HIV/AIDS epidemic.

Now, more than ten years since its initiation, the unprecedented impact of HIV treatment has been documented; an infectious disease with an almost universally fatal outcome has been turned into a manageable chronic infectious disease. At the population level, universal access to HAART (where it has occurred) has resulted in dramatic declines in HIV-related morbidity, mortality and a reduction in both infectivity and the risk of onward transmission, with significant economic and demographic benefits.

It is currently estimated that, due to the availability of HAART, a person living with HIV at the age of 25 now has a realistic chance of living an average of another 35 years of quality life. That represents a comparable (though shorter) life expectancy and life quality to that of a person not infected with HIV.

Long-term monitoring of the HIV epidemic and treatment in **the Netherlands**, for example, demonstrated that the risk of HIV infection halved between 1995 and 2005, due to universal access to HAART in that country. This is only one example of how universal access has also had a profound impact on HIV prevention, but it reinforces the importance of simultaneous scale-up of both prevention and treatment and care.

Universal access to effective, affordable and equitable treatment and care is a very ambitious challenge for the international community and requires the commitment and involvement of all stakeholders, including governments, donors, international agencies, researchers and affected communities. The WHO/UNAIDS “3 by 5” initiative helped to promote a steady increase in access to ART in European countries and globally. As a continuation of this initiative, in 2005, leaders of the G8 countries agreed to “work with WHO, UNAIDS and other international bodies

to develop and implement a package for HIV prevention, treatment and care, with the aim of as close as possible to universal access to treatment for all those who need it by 2010”.

The WHO Regional Office for Europe has been monitoring access to treatment and care in Europe since early 2003. Five surveys of all its Member States were conducted between 2003 and 2007, evaluating indicators related to HIV/AIDS treatment and care. The results of these surveys, as well as the most up-to-date data received from the countries during 2006–2007, are used here to present the scale-up efforts.

The purpose of the WHO Regional Office for Europe surveys on HIV/AIDS and ART was to provide a region-wide overview of the situation in the 53 Member States in the WHO European Region. The surveys provided point-in-time estimates of the progress of HAART scale-up and its associated clinical outcomes. They attempted to document the access to and the coverage and impact of HAART, as well as specific aspects of provision, such as equity in access, treatment guidelines, HIV testing and counselling policies and practices, prevention of mother-to-child transmission of HIV, the capacity of health systems to provide HIV/AIDS treatment and care, and the pricing of antiretroviral medicines. The surveys also provided an indication of the data available in different countries and identified needs for further follow-up.

Not all countries reported data on HAART in all of the WHO surveys. Several countries do not have a national reporting system or registry for patients receiving treatment. For these countries, “best estimates” provided by in-country experts are used. Several of the countries that have provided HAART data have included data based on large HIV/AIDS cohorts in the country and not on national patient registries. In some countries, different sources have been used for the surveys. This is important to consider when comparing the data over time.

Data from the four cross-sectional surveys presented in this chapter clearly identify areas which are very important for monitoring treatment and care programmes and practices, and countries which do not have the necessary or appropriate monitoring and evaluation (M&E) tools.

Experience gained over the two years of the “3 by 5” initiative clearly demonstrates the need for good-quality, standardized and comparable M&E systems for HIV treatment and care. These systems should not only enable countries to monitor the size of scale-up, but also to monitor treatment and care outcomes, and provide the basis for review and improvement of treatment and care programmes.

Strategically, those national systems will be compatible with practices and norms in western European countries and will provide an entry point into Europe-wide surveillance, monitoring and evaluation agencies, such as the European Centre for Disease Prevention and Control (ECDC), the Copenhagen HIV Programme (e.g. the EuroSIDA study), the European Monitoring Centre for Drugs and Drug Addiction (EMCDDA) and others.

### **Antiretroviral treatment access, coverage and rate of scale-up**

At the beginning of the monitoring period, around 242 000 patients were receiving HAART in the European Region, of which around 7000 were in central and eastern Europe (see Table 12.1 below).

By mid-2004, this number grew to around 282 000, including around 16 000 in central and eastern Europe. In December 2005, an estimated 343 000 patients were on HAART in 52 WHO European Region Member States, including 23 000 in central and eastern Europe. Therefore, by December 2005, the countries in the European Region had reached the target set in the Dublin Declaration to provide HAART to an additional 100 000 patients by the end of 2005.

At the end of 2006, 385 000 were on HAART in Europe and an estimated 435 000 by December 2007.

The number of patients receiving HAART in central and eastern Europe has grown six-fold since the end of 2002 and continues to increase steadily. It reached 35 000 by the end of 2006 and is estimated at around 55 000 at the end of December 2007.

While the overall number of new patients in central and eastern Europe lags behind the actual treatment need, tremendous progress has been achieved in scaling up provision and in expanding the number of countries providing HAART for the first time and the number of countries providing universal and equitable access to care and treatment.

In early 2003, only seven countries in central and eastern Europe were providing very good coverage of HAART (to over 75% of people in need of treatment), and another eight countries were providing partial coverage of treatment and care. Thirteen countries were providing minimal (to less than 1% of those in need) or no HAART at all at that time. By December 2005, 15 countries in central and eastern Europe were providing very good HAART coverage, and only four countries were providing no treatment.

So, by the end of the “3 by 5” initiative in the WHO European Region, the number of countries providing very good HAART coverage had grown from 30 to 38. By the end of 2006, HAART had become available in every country of the region with the exception of **Turkmenistan**. Two countries in eastern Europe with the highest estimated treatment needs, **Ukraine** and **the Russian Federation**, have made the most impressive progress of all, even though they remain the countries with the lowest coverage rates in the region. By mid-2007, coverage was estimated as very good in at least 38 of the 53 Member States.

Table 12.1. **Number of reported HIV and AIDS cases and number of people on HAART in the WHO European Region, 2002–2006**

	<b>Total reported HIV cases</b>			
Sub-region <sup>1</sup>	End 2002	Mid 2004	End 2005	End 2006
Central Europe (5)	9 898	11 160	12 363	13 348
South-east Europe (10)	17 447	19 492	23 158	23 980
Baltic States (3)	5 901	7 993	9 495	10 562
Caucasus (3)	1 066	1 493	2 011	2 595
Central Asia (5)	5 458	8 936	14 801	19 199
Western newly independent states (4)	287 759	341 123	432 577	497 199
<b>Central and Eastern Europe (30)</b>	<b>327 529</b>	<b>390 197</b>	<b>494 405</b>	<b>566 883</b>
Western Europe (23)	353 084	384 212	430 434	458 092
<b>Total Europe (53)</b>	<b>680 613</b>	<b>774 409</b>	<b>924 839</b>	<b>1 024 975</b>
	<b>Total reported AIDS cases</b>			
Sub-region <sup>1</sup>	End 2002	Mid 2004	End 2005	End 2006
Central Europe (5)	1 957	2 248	2 618	2 755
South-east Europe (10)	9 970	10 876	13 902	13 158
Baltic States (3)	256	380	595	705
Caucasus (3)	203	321	654	860
Central Asia (5)	55	252	461	601

Western newly independent states (4)	6 876	7 393	8 666	22 021
<b>Central and Eastern Europe (30)</b>	19 317	21 470	26 896	40 100
Western Europe (23)	251 338	263 886	279 524	287 988
<b>Total Europe (53)</b>	270 655	285 356	305 087	328 088
<b>Total reported number of people on HAART</b>				
Sub-region <sup>1</sup>	End 2002	Mid 2004	End 2005	End 2006
Central Europe (5)	2 283	3 079	3 786	4 245
South-east Europe (10)	4 114	6 930	8 101	8 791
Baltic States (3)	153	300	545	835
Caucasus (3)	8	15	167	322
Central Asia (5)	0	7	255	706
Western newly independent states (4)	742	3 581	10 375	20 266
<b>Central and Eastern Europe (30)</b>	7 000*	16 000*	23 000*	35 000*
Western Europe (23)	235 000*	266 000*	320 000*	350 000*
<b>Total Europe (53)</b>	242 000	282 000	343 000	385 000

In this table the 53 Member States of the WHO European Region are divided into the following subregions: Central Europe (5): the Czech Republic, Hungary, Poland, Slovakia, Slovenia. South-east Europe (10): Albania, Bosnia and Herzegovina, Bulgaria, Croatia, Cyprus, Montenegro, Romania, Serbia, The former Yugoslav Republic of Macedonia, Turkey. The Baltic States (3): Estonia, Latvia, Lithuania. The Caucasus (3): Armenia, Azerbaijan, Georgia. Central Asia (5): Kazakhstan, Kyrgyzstan, Tajikistan, Turkmenistan, Uzbekistan. Western newly independent states (4): Belarus, Moldova, Russian Federation, Ukraine. Central and Eastern Europe includes all 30 countries in the above six subregions.

Western Europe (23): Andorra, Austria, Belgium, Denmark, Finland, France, Germany, Greece, Iceland, Ireland, Israel, Italy, Luxembourg, Malta, Monaco, Netherlands, Norway, Portugal, San Marino, Spain, Sweden, Switzerland, United Kingdom.

\* Rounded numbers

### Equity in access to treatment and care

Three main parameters are used to measure equity in access to treatment: age, sex and HIV transmission route. In the WHO European Region as a whole, injecting drug users (IDUs) represent the majority of all reported HIV cases and a large percentage of all reported AIDS cases. By the end of 2006, women represented around 29% and children (persons under the age of 15) 1% of the total number of reported HIV cases in the total European Region since the beginning of the epidemic; at the same time, women represented 27% and children 2% of all people on HAART.

Overall, the collected survey data indicate an equitable access to HAART across Europe in terms of sex and age, even though the percentage of women and children on HAART was somewhat higher than their relative share of reported HIV cases in eastern Europe: 42% and 8% compared to 34% and 0.5%, respectively.

In eastern Europe and in **Poland**, IDUs represented between 60% and 90% (79% on average) of all reported HIV cases, but they represented only around 39% of all recipients of HAART at the end of 2006. Moreover, the majority of countries were unable to report the number of active drug injectors among HAART patients in the WHO Regional Office for Europe surveys, as opposed to the number who were infected with HIV through injecting drug use in the past. While the fact that IDUs represent 30% of all HAART recipients across Europe represents significant progress since 2002, access to HAART for IDUs is still greatly restricted and inequitable. This also partly

explains the inequitable access to HAART for males in some central and eastern European countries, as the majority of people living with HIV and in need of treatment are male IDUs.

The inequitable access to HAART for IDUs in central and eastern Europe is due to two main reasons: firstly, there is generally low HAART coverage in countries where IDUs are the largest part of the HIV-infected population; secondly, they are also often discriminated against by health care providers. This is most significant in two countries – **Ukraine** and **the Russian Federation** – while other central and eastern European countries have made significant progress over the past two years.

While formal exclusion criteria for IDUs do not exist in any of the countries, the formal requirement in almost one-quarter of central and eastern European countries for the patients to be assessed as “adherent” to therapy is often used as the justification for denying HAART to drug users (based on the false presumption that persons using illicit drugs are *a priori* non-adherent to treatment regimens and, therefore, poor candidates for HIV treatment). In many countries there is either no, or only symbolic, access to opioid substitution treatment which, according to all available data from the western countries, greatly enhances the ability of IDUs to adhere to HAART (1). Also, the involvement of patient groups in treatment support activities, and the knowledge and skills of health professionals on how to provide adequate support to adherence to their patients are limited and inadequate.

Experience in western countries shows that IDUs have generally poorer treatment outcomes than the non-drug-using population. This is because IDUs have greater difficulty accessing treatment in general – meaning that IDUs start treatment in a more advanced stage of HIV infection than other patient groups, which in turn represents a higher risk of poorer outcomes. Furthermore, IDUs are significantly more often coinfecting with tuberculosis (TB) and hepatitis B or C, which represents a difficult challenge for case management and follow-up. They also suffer from an overall significantly higher mortality than the non-IDU population, caused mainly by end-stage liver disease, overdose or bacterial infections which are not related to their HIV status.

However, none of these factors should be a reason for denying treatment to users of illicit drugs, as HAART still greatly improves their chances of survival and quality of life. On the contrary, poor HIV treatment outcomes among IDUs are a clear indicator of inflexible and inadequate health services, since numerous examples from around the world provide evidence that IDUs can achieve adherence levels comparable to non-IDUs, if appropriate strategies for treatment support are implemented (2).

### **Quality of HIV treatment and care and treatment outcomes**

Since 2003, population-level data demonstrate that treatment outcomes differ throughout the WHO European Region. AIDS mortality has been significantly reduced in western Europe (from 3 196 cases in 2003 to 1 621 case in 2006), while in eastern Europe it still increasing (from 1 154 cases in 2003 to 2501 cases in 2006) (3). This can be explained by the fact that, while countries start or expand access to ART, the most severely ill patients, who have developed AIDS, are prioritized over all those who need treatment; inevitably, this does not have an immediate impact on mortality rates.

A closer analysis of treatment outcomes at the country level is needed to monitor and evaluate the discrete problems that are known to occur in some parts of Europe. Pharmacovigilance has not yet been addressed at the population level in many countries, nor have the quality of service delivery or client satisfaction with such services.

Poor procurement management systems have caused numerous shortages of antiretroviral medicines in the past couple of years, and patients were either switched between a variety of combinations of medicines, depending on their availability, or the patients interrupted their treatment for shorter or longer periods of time. Occasional disruptions in the supply of diagnostics have resulted in clinical management decisions being based on incomplete or insufficient patient monitoring.

### **Stigmatization and discrimination of PLHIV and of populations at risk of HIV**

Stigmatization and discrimination, in the general public and in particular within the health care sector, remain a serious concern for scaling up treatment and care, and for providing universal access and coverage throughout Europe. In some countries, it particularly affects specific populations, such as migrants, but the lack of access to treatment and care and of appropriate services for IDUs remains the crucial obstacle in most central and eastern European countries.

IDUs represent the largest number of those in need of ART, and yet they are the group whose access to services is most severely restricted. Prejudice and lack of experience in dealing with their complex health problems (coinfection with hepatitis or TB, and mental health issues) are the key challenges that need to be overcome to reach universal access targets in Europe. For example, the current repressive and punitive approaches to injecting drug use need to be replaced by public health approaches.

The lack of harm-reduction services, of opioid substitution treatment beyond isolated pilot projects, and of linkage with community-based organizations in providing treatment adherence support, severely harm and limit efforts to achieve universal access to ART in central and eastern Europe.

### **Adequacy of health care services**

Responding to the dramatic increase in need for ART puts tremendous pressure on health services in central and eastern Europe. Developing the capacity of treatment-providing facilities and services, diversification of service providers, scale-up of laboratories, significant scale-up of HIV counselling and testing services, and substantial and operational links with other parts of the health and non-health sectors (TB, infectious diseases, hepatitis treatment, harm reduction, psycho-social support services, etc.) are all urgently needed. The production and procurement of antiretroviral drugs, ensuring both their quality and the necessary quantity, is of particular concern. To make this possible, health systems need to be strengthened and reformed, at least on a limited scale.

### **Cost of antiretroviral treatment and care**

The cost of ART remains relatively high in most of western and central Europe. In most of the countries from these parts of Europe that reported expenditure on ART to the WHO Regional Office for Europe in the 2006 annual survey, the average annual price of first-line regimens is between US \$8000 and \$12 000 per patient per year, and the price of second-line regimens costs at least a further 50% or more.

However, significant price reductions have been achieved in eastern Europe. The procurement of generic medicines, direct negotiations with manufacturers of antiretroviral drugs, and applying differential pricing schemes based on the country's income, have resulted in a significantly lower cost of medicaments, in some cases as low as \$300–400 per patient per year in **Ukraine** (down from \$10 000 in 2002) and \$600 in **Kyrgyzstan**.

The WHO Regional Office for Europe surveys of antiretroviral prices do not, however, include the full economic costs of providing HIV/AIDS care and treatment. The basic package of out-patient care, including laboratory monitoring, that is essential in addition to the antiretroviral medicines is probably in the range of \$4000–6000 per patient per year in western Europe. No systematic efforts to estimate the economic cost of HIV/AIDS treatment and care in eastern Europe have been noted.

In 2007, data were published from studies in **Germany** and **Austria** on the cost of HIV/AIDS treatment and care. The German study (4) estimated the direct cost of antiretroviral drugs between 1995 and 2005 at €38.85 per patient per day, which amounts to €14 410 per patient per year. The average daily cost increased from €19 in 1996 to €50 in 2006. This increase was attributed to the use of intensified regimens, a slight decrease in prescribing non-nucleoside reverse transcriptase inhibitors (NNRTIs), the licensing of more expensive drugs, and increases in prices of licensed drugs.

The study in **Austria**, on the other hand, attempted to estimate the lifetime cost of an HIV or AIDS case (5). Depending on sex, age and adherence, life-long cost is estimated at €446 960 to €563 582 for HIV cases, and €557 760 to €633 284 for each AIDS case. This estimate included medication, in- and out-patient visits and care, and eventual pension payments (for AIDS cases). In cases of poor adherence, lifetime cost can increase by €63 000.

If the findings from this study could be extrapolated to Europe as a whole, the full cost of treatment and care for the estimated 2.3 million people living with HIV in 2006, at an average lifetime cost of €0.5 million, would be far in excess of €1 trillion, without counting any future infections.

At the same time, a number of studies have demonstrated the cost-effectiveness of ART. In **the United Kingdom**, it has been estimated that the cost of HAART per life-year gained is between US \$8500 and \$20 000, depending on the regimen prescribed, which compares with studies done in the USA and Canada. Studies from other countries, including **the Russian Federation** and South Africa, have clearly demonstrated its cost-effectiveness, even in poorer settings.

Overall, various analyses of the cost of HAART have demonstrated its cost-effectiveness. While the actual annual expenditure may not have decreased significantly per patient since 1995, it has been demonstrated, for example in **the Netherlands**, that the increase in the cost of antiretroviral drugs has been offset by significant reductions in the cost of treatment for opportunistic infections and other HIV-related conditions in the pre-HAART era.

Therefore, despite the staggering economic cost of the HIV epidemic and the related treatment and care needed for universal access, there is every reason to pursue this political objective.

### **Capacity to scale up**

In the 2005 survey, countries were asked to provide the number of people “seen for care” (defined as having made at least one visit to the service provider during 2005) and the number of facilities at which HIV/AIDS treatment and care were provided, including the type of health care facility providing services. A total of 34 out of 52 countries were able to respond to this question. In the countries that responded, more than 400 000 people living with HIV, close to half of them on HAART, were “seen for care” in 1361 facilities. About 230 000 patients, including 21 000 on HAART, were cared for in 277 facilities in central and eastern Europe.

Throughout central and eastern Europe, care and treatment services are provided through secondary and tertiary health care facilities – specialized hospitals, such as AIDS centres and

infectious diseases departments – which were providing in- and out-patient care and treatment. Unlike for other diseases, this model actually concentrated expertise and was supposed to facilitate procurement and management of antiretroviral drugs and other commodities. It also created a critical mass of patients, so that investment in laboratory equipment for monitoring treatment would be used efficiently. While provision of primary care services in secondary or tertiary facilities may have enhanced the quality of ART, it also may have developed barriers to an integrated management of coinfections, such as TB or hepatitis, or other prevalent conditions, such as substance abuse or mental health problems. In countries with few patients, this concentration of services in one or two places limited physical access to HIV treatment and care, as many patients from areas outside the capital cities had to travel far to attend their regular medical appointments or to receive treatment and care.

On average, a significantly lower number of HAART patients were managed by each facility in central and eastern Europe than in western Europe, which indicates that there is some spare capacity for further scale-up of treatment and care, even without further physical expansion of facilities and services. In the near future, and particularly in the long term, achieving universal access to HIV treatment and care will require not only a quantitative scale-up, but also systemic changes in models of health care delivery, especially in localities where there are, or will be, tens of thousands of patients. For example, even now, there are cities in **Ukraine** and **the Russian Federation** with more than 20 000 people living with HIV, and appropriate scale-up of treatment and care will not only be an issue of adding more specialized service providers or facilities. However, in the majority of countries starting HAART between 2003 and 2005, there has been no capacity to deliver these services until recently.

WHO has provided crucial technical assistance for training inter-disciplinary teams (physicians, nurses and social workers or volunteers) throughout central and eastern Europe. The main mechanism for technical assistance was the GTZ-funded Knowledge Hub on HIV/AIDS treatment and care in **Ukraine**, developed by WHO and supported by UNAIDS. The majority of training was funded from Global Fund grants received by individual countries. By February 2007, 109 training courses on ART were conducted, and 2650 service providers from eastern European countries were trained through the Knowledge Hub and were supported by on-site mentoring.

## **Key medical issues in the treatment and care of people living with HIV in Europe**

### ***TB/HIV coinfection***

TB is the most frequent opportunistic infection associated with HIV/AIDS and one of the leading killers of people living with HIV. In 2005, it was estimated that 525 000 people were infected with TB across the WHO European Region and that 6 786 of them were coinfecting with HIV (6).

The highest prevalence of TB is found in eastern Europe, with coinfections distributed unevenly across the region (7). In 2005, TB was reported as the indicative disease of AIDS in 22% of all cases in western Europe, 24% of cases in central Europe and 52% of cases in eastern Europe. The total percentage of TB reported as the indicative disease of AIDS fell from 28% in 2004 to 14% in 2005, mainly due to fewer countries in eastern Europe reporting in 2005 (2,8). However, countries with the highest HIV prevalence among TB cases are found in western Europe. With an estimated 16% HIV prevalence in adult TB cases, **Spain** has the highest prevalence in the entire region, with both TB and HIV strongly associated with injecting drug use (9).

However, the number of reported cases of TB/HIV coinfection remains low throughout the region. This could be due to a lack of coordinated surveillance efforts, since the surveillance data available are insufficient to monitor overlap between the two diseases (10).

The WHO European Region has the lowest coverage of directly observed treatment short course (DOTS) of all WHO regions (60%), and it has the lowest treatment success rate among people who have previously been treated (52%) (1). The countries of eastern Europe are experiencing one of the world's highest prevalence rates of multi-drug resistant TB (MDR-TB) (11). Evidence suggests that HIV is associated with higher prevalence of MDR-TB because HIV generates a higher number of MDR-TB cases. TB drug resistance arises mainly because of inadequate TB control, poor patient or clinician adherence to standard TB treatment regimens, poor-quality drugs or inadequate drug supplies. People living with HIV are particularly vulnerable to developing MDR-TB because of their increased susceptibility to infection and progression to active TB. This underscores the need to rapidly ensure prompt TB diagnosis and effective TB treatment for people living with HIV to prevent drug resistance developing and spreading (12).

### ***Coinfection of HIV with hepatitis B and C viruses***

The effect of viral coinfection is complex and results in changes to the natural history of other diseases. HIV coinfection reduces the chance of recovery from acute hepatitis C virus (HCV); increases the degree of HCV viremia; diminishes the antiviral response to IFN-based anti-HCV regimens; and accelerates the progression of HCV infection to cirrhosis (13), hepatocellular carcinoma and liver failure (14). HCV coinfection increases the degree of hepatotoxicity from ART and decreases immune reconstitution in HIV-infected patients who are undergoing ART. Due to increasing numbers of HIV-infected people receiving ART, and their increased life expectancy, liver disease has increasingly replaced AIDS as the most common cause of death in people living with HIV in western Europe; therefore, special attention should be paid to coinfection with HCV – as well as with hepatitis B (HBV) – when assessing the burden of liver disease in people living with HIV and AIDS (15).

In contrast to the rest of the world, the prevalence of HCV infection in HIV-infected patients in Europe is particularly high and still rising, with about 80–90% of cases occurring among IDUs (16). In a large cohort of around 5 000 patients who took part in a EuroSIDA study, viral markers for HBV were present in 9% and for HCV in 34% of people living with HIV (17). The highest prevalence of HCV coinfection was found in eastern Europe (47.7%).

Comparing coinfection rates in the new European Union member states and neighbouring countries to the east, available data from samples of IDUs show a wide range, from 0% in samples tested for HIV and HCV in **Hungary, Romania and Slovenia**, to 3% in **Lithuania**, 72% in samples in Tallinn, **Estonia**, and 93% in Togliatti, **the Russian Federation**.

According to information from the annual WHO Regional Office for Europe surveys, the prevalence of HCV and HBV in HIV-infected patients seen for care varies substantially from country to country (see Table 12.2 below). Some countries, however, do not have a policy on routine HCV and HBV testing for HIV-infected individuals, which limits these data. In addition, the lack of national surveillance systems for hepatitis in several countries limits the availability of data in those countries, making the presented data incomplete. In response to the lack of data derived from tested HIV patients, some countries have provided estimates of HIV/hepatitis coinfection rates developed by national experts instead.

**Table 12.2. Rates of HBV/HIV and HCV/HIV coinfection in the countries of the WHO European Region, as of end 2006 or latest available**

<b>Country</b>	<b>Number of people living with HIV co-infected with</b>	<b>% HIV/HBV coinfected</b>	<b>Number of people living with HIV co-infected with</b>	<b>% HIV/HCV coinfected</b>
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	HBV		HCV	
<b>Western Europe</b>				
Austria	106	4%	440	18%
Germany <sup>a</sup>	11 000–13 000*	53%	6000–7000*	37%
Greece <sup>b</sup>	1 344	66%	52	3%
Luxembourg	34	8%	89	22%
Malta	5	5%	4	4%
Netherlands	853	9%	964	11%
Spain	7 000*	<10%	38 000*	35–40%
Sweden	300*	8%	600*	17%
<b>Central Europe</b>				
Bosnia and Herzegovina	0	0%	0	0%
Bulgaria	9	3%	27	10%
Croatia	6		35	
Cyprus	14		8	
Czech Republic	205	27%	210	28%
Hungary	5	1%	16	2%
Poland	1 000*	20%	1 000*	20%
Romania	1 716	29%	185	5%
Serbia	80*	10%	280*	35%
Slovakia	3	4%	4	5%
Slovenia	11	6%	15	8%
The former Yugoslav Republic of Macedonia	2	6%	1	3%
Turkey	21	7%	16	7%
<b>Eastern Europe</b>				
Armenia	8	7%	54	53%
Azerbaijan	92	15%	412	66%
Belarus	8	4%	394	27%
Estonia	1 250*	71%	1 250*	71%
Georgia	132	13%	343	35%
Kazakhstan	158	4%	1 808	46%
Latvia		70%	1 460	60%
Lithuania	56	8%	592	80%
Moldova <sup>d</sup>	80	8%	308	30%
Russian Federation	6 777	7%	71 000*	52%
Tajikistan <sup>c</sup>			6	27%
Ukraine	5 660–32 700*	9–52%	49 000*	77–80%
<b>Western (8)</b>	21 642	4–66%	46 649	3–40%
<b>Central (13)</b>	3 072	0–29%	1 797	0–35%
<b>Eastern (12)</b>	29 450	4–71%	126 627	27–80%
<b>TOTAL (23)</b>	54 164	0–71%	175 073	0–80%

\* Estimated numbers provided by national experts.

<sup>a</sup> Calculated based on risk distribution among diagnosed HIV patients, with an estimated 95% of IDUs and haemophiliacs coinfecting and tested for HBV and HCV, 70% of men who have sex with men coinfecting with HBV and 5% with HCV, but only half of them tested, and lower proportions coinfecting among heterosexuals and persons from high-prevalence regions.

<sup>b</sup> Data are based on three out of 23 clinics.

<sup>c</sup> Data reflect 204 people living with HIV identified in 2006.

<sup>d</sup> Testing for HBV and HCV virus is done in selected population groups only and is not a routine procedure.

Among HIV-positive people, there were reports of HCV prevalence of 20–40% in **Belarus, the Czech Republic, Georgia, Germany, Luxembourg, Moldova, Poland, Serbia, Spain and Tajikistan**; more than 40% in **Armenia, Azerbaijan, Latvia, Kazakhstan and the Russian Federation**; and more than 70% in **Estonia, Lithuania and Ukraine**. In most central European countries (except those mentioned above), HCV coinfection rates were usually less than 10%. Also, HBV prevalence varied greatly across Europe, but, in general, HBV/HIV coinfection rates were usually lower than those for HCV/HIV. High rates of HBV/HIV coinfection were found in **Estonia, Germany, Greece, Latvia and Ukraine**.

### **Prospects for people living with HIV and epidemic development in the era of HAART**

At the beginning of the 21st century, people living with HIV have an opportunity to commence ART regimens which are very efficacious in suppressing HIV and that have few side-effects. Survival rates of newly infected HIV-infected individuals have significantly improved: the estimated median remaining lifetime has increased from eight years in 1995–1996 to 23 years in 1997–1999 and to 33 years in 2000–2005 (18). Among persons not coinfecting with HCV, the median remaining lifetime in 2000–2005 was 39 years, which is similar to that of a young person with diabetes (19). In comparison, the median remaining lifetime for a 25-year-old not infected with HIV was 51 years. People living with HIV may now plan their professional career, join a pension plan or start a family – things that just a few years ago were all but impossible. They may expect to be treated equally with other members of society and to have easy access to health and life insurance. They also expect to receive high-quality health care for non-HIV-related conditions, including fertility treatment.

### ***Changing morbidity and mortality***

The HIV-infected population is getting older and, therefore, becomes increasingly affected by the diseases common in the general population. They will contract age-related diseases, and the disease burden on some individuals may even come to be dominated by non-HIV-related conditions. Some of these diseases may have a worse prognosis and, therefore, become more important than HIV for some patients.

Even though survival has increased markedly, people living with HIV still die at rates that are three to 15 times higher than the general population (20). Decreased risk of AIDS has led to a change in patterns of co-morbidity and cause of death, and most deaths in the countries with universal access to treatment and care (50–70% of all death) are now non-HIV-related (21,22,23). Common causes of non-HIV-related deaths are non-AIDS-defining cancers (~10% of all deaths), cardiovascular diseases (~7%), substance-abuse-related deaths (~7%), liver-related deaths (up to 15% reported) and bacterial infections (~6%) (19,20,24). Some non-AIDS-defining cancers relate to coinfections with HBV, HCV and human papilloma virus (HPV), whereas others may be associated with smoking (21). Behavioural risk factors for disease and death, such as cigarette smoking and excessive alcohol consumption, are common in many HIV-infected populations (25,26) and potentially play a pronounced role in morbidity and mortality.

### ***Drug resistance***

The efficacy of ART can be impaired by several factors, including drug-related toxicities, poor adherence, suboptimal antiviral potency and drug concentrations, and selection of antiretroviral drug-resistant HIV-1 variants. The development of drug resistance in HIV-infected individuals is generally progressive, beginning with resistance to one or a few drugs, and can result in multi-drug-resistant variants that can seriously compromise the efficacy of alternate drug regimens.

Prevalence of HIV drug resistance varies between countries and at population level is linked to the duration of ART availability in the countries and the history of treatment (mono- and dual

therapy). Triple-class drug resistance is more prevalent among patients who started HIV treatment prior to the advent of potent combination HAART than among those who started treatment later, when HAART became available. In western Europe, the transmission of drug-resistant HIV occurs with a frequency of between 5% and 25% of all primary infections (27,28,29). A nationwide study in **France** (30) suggests that 19% of all treated patients contributed to the spread of resistance and 4% had complete resistance to two classes of antiretroviral drugs. In the countries of eastern Europe where ART has become available just recently, circulation of drug-resistant HIV strains is unlikely at the moment. A 2006 WHO sentinel survey of drug resistance in **the Russian Federation**, the country in eastern Europe with the longest history of ART, revealed no circulation of drug-resistant HIV strains.

Managing antiretroviral resistance in patients infected with HIV is one of the greatest challenges clinicians are confronted with in the West. It requires the use of new antiretroviral drugs which often are very expensive, are available only for clinical trials and with which doctors have limited experience. The transmission of drug-resistant viruses can contribute to the expansion of resistance across the region. This may lead to a continuous challenge in the clinical management of patients with drug-resistant HIV, especially in countries with limited availability of antiretroviral drugs, as well as to a challenge in response to the epidemic in general.

### **WHO Regional Office for Europe response**

One of the most important tasks and a huge responsibility for WHO, is the development of normative guidance and setting the standards of service delivery. The WHO Regional Office for Europe has developed a set of 13 clinical protocols on HIV/AIDS treatment and care which respond to different medical and health needs of people living with HIV and provide a comprehensive approach to their clinical management. The protocols include updated recommendations in line with current scientific evidence and also address new areas related directly to the quality of long-term treatment and care outcomes, such as coinfection with hepatitis and TB, HIV treatment in IDUs, sexual and reproductive health for people living with HIV/AIDS, and recommendations for the immunization of people living with HIV (31).

### **Recommendations**

1. The ultimate goal of treatment programmes in European countries should be the further increase of survival and improving the quality of life of people living with HIV, through addressing both HIV-related and unrelated morbidities.
2. Closing the treatment gap in the WHO European Region remains an important objective. Universal access to HIV/AIDS treatment and care can and should be achieved by 2010 in every country.
3. In countries where coverage with treatment and care services is high, and where access to them is relatively good, particular efforts should be made towards ensuring the same standards of treatment and care for all people, regardless of their gender, age, sexual orientation, substance use, imprisonment or migratory status. Special efforts should be undertaken to reduce barriers in access to treatment for IDUs and for documented and undocumented immigrants.
4. Comparable standards and quality of treatment and care services should be ensured across Europe, as well as equal opportunities to access second-line treatment, salvage regimens for treatment-experienced patients, and treatment and care for the leading co-morbidities such as TB and hepatitis.
5. Addressing health issues related to age and behaviour should become an integral part of a comprehensive package of health care services for people living with HIV (i.e. prophylactic

treatments, such as cholesterol-lowering and antihypertensive therapy, and addressing smoking and alcohol consumption as risk factors for disease and death).

6. Universal access to ART and health care, which should be supplemented by a coordinated effort of experienced care teams – physicians, nurses and social workers – to adequately address each individual's need, but also linked to sustainable and publicly-funded community interventions and services, providing nursing and home-based care, including palliative and end-of-life care.
7. Countries should regularly monitor and evaluate HIV treatment and care programmes and their outcomes. This is important for improving clinical management and achieving health outcomes, while at the same time designing rational health system policies concerning health care financing, models of delivery, human resources development, institutional capacity, procurement systems, research and development and the like.
8. To establish more accurate, specific and sustained databases to track incidence, prevalence and trends in coinfection of HIV with TB, HCV and HBV, as well as risk behaviours.

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### 13. Stigma discrimination and human rights

**Dublin Action 1:** Promote strong and accountable leadership at the level of our Heads of State and Government to protect our people from this threat to their future, and promote human rights and tackle stigma and ensure access to education, information and services for all those in need;

**Dublin Action 20:** Combat stigma and discrimination of people living with HIV/AIDS in Europe and Central Asia, including through a critical review and monitoring of existing legislation, policies and practices with the objective of promoting the effective enjoyment of all human rights for people living with HIV/AIDS and members of affected communities;

**Dublin Action 31:** Establish sustainable partnerships with the media, recognising the critical role that it plays in influencing attitudes and behaviour and in providing HIV/AIDS related information;

The Preamble of the Dublin Declaration notes the fundamental importance of respect for human rights to the fight against HIV/AIDS, as well as the impact of human rights violations and related intolerance. It asserts that respecting, protecting and promoting human rights is “fundamental to preventing transmission of HIV, reducing vulnerability to infection and dealing with the impact of HIV/AIDS”; recognizes the need to focus on the most vulnerable and at-risk communities; and acknowledges that the greater involvement of people living with HIV (PLHIV) is critical to ethical and effective responses to the epidemic.

The Dublin Declaration therefore clearly points to the need for systemic protection of human rights that recognizes and addresses the root causes of social exclusion and vulnerability to infection, empowers PLHIV and vulnerable communities and creates a conducive environment for effectively implementing (and establishing accountability for implementing) the Declaration commitments. To the human rights framework identified in the Preamble, Action 20 adds both a general commitment – to combat stigma<sup>53</sup> and discrimination – and a specific one – to “critically review” national policy and practice – in order to promote the enjoyment of all human rights by not only PLHIV but also members of affected communities. In order for a state to demonstrate its compliance with these commitments, it must show that it has incorporated them into its overall response to HIV/AIDS.

Stigma and discrimination affect many areas of policy-making and government decision-making having to do with HIV/AIDS, and therefore affect the implementation of many actions in the Declaration. To truly measure progress on Action 20, it is necessary to make a much broader and more holistic analysis of national compliance with Dublin Declaration commitments as a whole.

Clearly, if all the actions in the Dublin Declaration were implemented, countries would be making progress in reducing stigma and discrimination and promoting human rights. For example, resource commitments (see Chapter 3) are closely connected to the obligation to devote the maximum of available resources to securing economic, social and cultural rights (*1:Article 4, 2:Article 2.1*). Commitments to address young people and HIV (Chapter 8) address many rights

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<sup>53</sup> Stigma, in this context, refers to negative attitudes and beliefs about people living with HIV (PLHIV) based on their actual or perceived HIV status and about members of vulnerable populations (sex workers, injecting drug users, men who have sex with men, prisoners etc) based on their or perceived membership of that group. The stigma that attaches to PLHIV and vulnerable populations reinforces the social inequalities that increase vulnerability to HIV infection and serves to justify discriminatory policies and practices that fail to target interventions at those most in need.

contained in the Convention on the Rights of the Child (1). Treatment and care concerns (Chapter 12) involve the rights to life (3:Article 3, 4:Article 6, 1:Article 6), the highest attainable standard of health (1:Article 24, 2:Article 12), an adequate standard of living (1:Article 27, 2:Article 11), social security (1:Article 26, 2:Article 9), the recognition of the dignity inherent in every human being (3:Article 1), etc. The challenge for external stakeholders is to adequately assess state progress across a wide spectrum of government activities, both in the specific context of Action 20 and the broader terms of the Declaration as a whole. Though this task is beyond the scope of a single chapter, it should govern the approach of subsequent progress reports on the Dublin Declaration.

This challenge of monitoring is one that has been explored in detail by Paul Hunt, the United Nations Special Rapporteur on the Right to Health, in his 2006 Annual Report to the United Nations Commission on Human Rights.<sup>54</sup>

[T]he Special Rapporteur wishes to emphasize that there is no alternative but to use indicators to measure and monitor the progressive realization of the right to the highest attainable standard of health. While a key question used to be “*Is there a role for indicators in relation to the right to the highest attainable standard of health?*”, today the crucial question is “*How can indicators be most appropriately used to measure and monitor this fundamental human right?*” (5)

This chapter will explore the corresponding question for human rights and HIV/AIDS, with the objective of suggesting ways in which health indicators used to measure progress towards other Dublin Declaration commitments can also be used as measurements of progress on reducing stigma and discrimination and promoting human rights. It will explore some of the available data relating to the obligations in Action 20, as well as analysing the limitations of many indicators in providing adequate benchmarks for measuring progress over time. Finally, it will suggest possible ways forward for future monitoring consistent with the Special Rapporteur’s question in order to establish an adequate baseline for assessing national progress, and it will illustrate the approach by using selected indicators specific to stigma.

### **Reality vs. rhetoric**

A review of available data related to Action 20 indicates that few of the 53 countries in the WHO European Region have adopted an approach to stigma, discrimination and human rights that complies with the Dublin Declaration commitments.

For example, a survey of voluntary sector representatives from 28 European countries conducted by the National AIDS Trust (NAT) of **the United Kingdom** in preparation for this chapter revealed that only 4 of 28 national governments had conducted the promised “critical review” since 2004. Nothing could more starkly underline the failure of governments across the Region to live up to the Dublin Declaration commitments in this regard. It is all the more disappointing given the significant levels of stigma and discrimination experienced by PLHIV, and the human rights breaches and abuses endured by those communities most affected by the epidemic, in particular men who have sex with men (MSM), migrants and ethnic minorities, injecting drug users (IDUs), prisoners and sex workers.

Further evidence of these gaps was identified in connection with an expert seminar on legislation and judicial systems in relation to HIV and AIDS, organized in April 2007 by NAT and AIDS Action Europe (AAE). A survey of all European countries conducted in advance of the seminar (6) showed that most have legislation in place that, at least in theory, provided legal protection

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<sup>54</sup> The UN Commission on Human Rights was abolished in 2006 and replaced by the Human Rights Council, a more senior “standing body” reporting directly to the General Assembly.

for PLHIV. However, it was also clear that there is a lack of legal protection for the communities most affected by HIV, in particular for prisoners, IDUs and sex workers. Furthermore, one of the most striking messages from both the survey and seminar was that it is immensely difficult in practice to take advantage of legal protections that do exist, and that a massive gulf exists between protections in the law and practices on the ground.

This gap in protections also affects other communities particularly vulnerable to, or affected by, HIV/AIDS, including ethnic minorities, disabled persons and MSM. While most European countries now have some form of legislative protection against it, a recent Eurobarometer survey on discrimination found that “discrimination on the basis of ethnic origin, disability and sexual orientation is considered by [European Union] citizens to be widespread” (7). Recent events in some central and eastern European countries (as well as **Israel**) in relation to gay pride marches demonstrate an acutely homophobic public climate actively supported by elected and state officials (8–10). Similarly, the denial of migrants’ rights in many western European countries results in many people suffering effective destitution with minimal or non-existent access to health and social care in some countries (11, 12).

This “reality gap” between legal protections on paper and in practice has been documented by national nongovernmental organizations (NGOs) in the Region, notably in their “shadow” reports that monitor national progress on the United Nations General Assembly Special Session Declaration of Commitment on HIV/AIDS (UNGASS Declaration). For example, the shadow report on **Latvia** states, “Although **Latvia**’s legal environment for the response to HIV/AIDS is satisfactory, there is a gap between the rhetoric and the way that laws are implemented, due largely to a negative public perception of PLHIV [PLHIV] and members of vulnerable populations” (13). The **Romanian** shadow report painted a picture of a similar gap between law and practice, as evidenced by the denial of rights to HIV-positive children and teenagers and the “routine harassment” of sex workers, IDUs, prisoners and MSM by public officials (14).

Human Rights Watch has documented situations in **Ukraine** where the provision of needle exchange services is effectively negated by police harassment of those using them (15). This example illustrates the limitations of the “checklist” approach to human rights monitoring, and how such a minimalist approach can fail to capture the impact of stigma and discrimination on the ground. While officials in **Ukraine** can answer “Yes” to questions about whether they provide needle exchange, this might not fully reflect restrictions that might exist in practice in certain settings. Better questions include whether such access is safe and confidential, how many use the service regularly and for how long. This case illustrates not only how undesirable, but how extremely difficult it is to monitor human rights and the impact of stigma and discrimination in isolation from the other commitments in the Dublin Declaration. It also provides a vivid example of the shortcomings in current indicators that make assessing progress on Action 20 difficult, and why effective monitoring of progress is only possible through the development of indicators that are well formulated and properly used.

### **Key elements of human rights protection and accountability**

There are a number of essential mechanisms and structures that must be in place in order to effectively protect human rights and hold those in power accountable for their commitments. These things must form a part of any “critical review” a government carries out, and their absence highlights systemic weaknesses in human rights protection.

#### *Access to justice*

A number of significant improvements have been made in this area in the 2008 National Composite Policy Index (NCPI), the policy questionnaire that countries fill in as part of their UNGASS. For example, rather than simply asking whether anti-discrimination legislation is in

place, as in the 2006 NCPI, a follow-up question now asks which “mechanisms are in place to ensure these laws are implemented”. The new NCPI further asks for a description of the “systems of redress put in place to ensure the laws are having their desired effect”, an essential requirement.

However, some gaps remain, for example, information regarding the existence of a legal aid system that allows for HIV/AIDS case work. In 2006, civil society respondents from a number of countries, including **Austria** (16) and **the Russian Federation** (17), noted that such a system was not in place<sup>55</sup>. For countries that did have legal aid systems, such as **Armenia** (18) and **the United Kingdom** (19), the UNGASS monitoring questionnaire did not request details of PLHIV accessing that system, nor any other qualitative data (20). In **the United Kingdom**, for example, recent amendments to the legal aid system which came into force on 1 April 2007 will mean that taking on civil legal aid cases may no longer be financially viable for law firms. As legal aid is usually only available to those with low incomes or on welfare, it is the most vulnerable whom these changes will affect. Nonetheless, it would still be acceptable to answer “Yes” to the same question in its 2008 report. As a result, current data collected for UNGASS monitoring does nothing to illuminate whether existing legal aid systems help address the specific needs of PLHIV.

The failure of many states to promote human rights protections consistent with Action 20 commitments is evident in other areas of their judicial systems. For example, to effectively combat stigma and discrimination, it is necessary that individuals have the ability to seek redress for violations of their rights, especially their economic, social and cultural rights, in the courts. Yet there exist significant gaps in such protection in many European countries (6).

Although most European countries have ratified the International Covenant on Economic, Social and Cultural Rights<sup>56</sup>, which includes the right to health, rarely are individuals able to challenge the denial of rights enumerated there in national courts. In some countries, such as **Slovenia** (21), the constitution allows for the direct applicability of the Covenant in the national courts. In other countries, separate national legislation is required, but in most, for example **Malta** (22) and **the United Kingdom** (23), no legislation has in fact been introduced. In **Hungary**, where the Covenant has been incorporated into national law, most of its enumerated rights are not directly

#### Box 13.1. Stigma, discrimination and access to justice

Access to justice is greatly affected by HIV/AIDS stigma and discrimination. The 2007 NAT/AAE survey revealed serious obstacles to accessing legal protections from discrimination (6).

Respondents described conditions in 36 countries of the European Region, including a lack of legal aid/funding in 22, the lack of confidentiality in legal proceedings in 20, a lack of lawyers and judges appropriately trained in HIV issues in 19 and institutional discrimination within the legal system of about half, against drug users, PLHIV, sex workers, MSM and immigrants. In **Poland**, for example, this discrimination was particularly acute against MSM, while in **Slovakia**, the Roma population is especially discriminated against. The illegality in many countries of activities such as drug use and sex work further hampers access to legal services

applicable in the national courts (24). In both **Lithuania** and **The former Yugoslav Republic of Macedonia**, where the Covenant is part of national law, there is little evidence that its provisions have been invoked in the courts (25, 26). The lack of legal decisions on economic, social and cultural rights in national courts throughout Europe indicates that these rights – including the

<sup>55</sup> Yet remarkably, Austria rated itself 10 out of 10 on the same questionnaire when asked how it would assess its policies, laws and regulations to promote and protect human rights relating to HIV/AIDS.

<sup>56</sup> For a full list, <http://www2.ohchr.org/english/bodies/ratification/3.htm>.

right to health – remain highly controversial in judicial settings. The primary argument against their applicability in the courts is one of cost<sup>57</sup>.

### *Budget allocation*

Adequate budgetary allocation and monitoring are essential to ensuring that human rights are respected, protected and, most importantly, fulfilled. Scaling up Dublin commitments in many areas requires that national governments make the necessary funding available, and for PLHIV to enjoy their rights fully, each state must allocate the “maximum of its available resources”<sup>58</sup> to meeting human rights commitments.

There is evidence of increasing expenditure on HIV/AIDS in some countries. In **Ireland**, for example, expenditure on HIV treatment increased by €6 million between 1997 and 2005 (28). In **Poland**, spending on antiretroviral drugs doubled from 2001 to 2005. However, simply increasing expenditure is insufficient; monitoring expenditure is also essential. The 2006 NCPI, did ask whether certain groups are targeted, but did not ask whether expenditures matched the identified needs (19). It would be unacceptable, for example, for 50% of a national HIV prevention budget to be devoted to abstinence projects for middle-class teenagers in a country where the epidemic is primarily driven by injecting drug use among ethnic minorities. The 2008 NCPI has made some improvements in this area. Countries are now asked whether budgets have been earmarked for specific sectors (e.g. health, education, women, children) and whether target populations were identified through a needs assessments. Unfortunately, however, there is still no question on budgets linked to those target populations, based on identified needs.

### *Participation of PLHIV*

Political and social participation is a basic tenet of human rights-based systems (3:Article 21, 4:Article 25,17:Article 12) and is essential in ensuring the government’s full accountability. Therefore, meeting Action 20 commitments would require the implementation of a human rights-based system that empowers PLHIV and affected communities and enables them to advocate for their own interests and promote their own rights. Such a system would require first of all that PLHIV and affected communities be consulted and their views taken into account in all policy decisions affecting them.

The participation of civil society and PLHIV is addressed at various points in the NCPI, primarily in the form of yes-or-no questions such as the involvement of PLHIV in the national action plan and a general scale measuring civil society involvement (see Chapter 2 for a fuller discussion) (19). However, the questionnaire requests no further information to measure quality of participation and impact. As a result, it offers no evidence that the views of PLHIV are *in fact* being represented in national policy. These questions and the answers they invite are therefore at best meaningless, often hiding mere tokenism behind a “yes”. At worst, they do not make it possible to uncover and learn from examples of good practice, where the real impact of the participation of PLHIV has been felt. Despite a significant improvement between the 2006 and 2008 NCPI in requiring an explanation of why there may have been “no” or merely “moderate” involvement of PLHIV, the available indicators remain insufficient to assess the current state of affairs, let alone measure progress in the future.

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<sup>57</sup> “The UK supports the view that all human rights are universal, indivisible, interdependent and interrelated. Economic, social and cultural rights therefore have equal status with civil and political rights. But whereas respect for civil and political rights does not depend on significant resources, respect for economic, social and cultural rights can only be realised progressively, within the limitations imposed by the availability of public resources.” (27)

<sup>58</sup> “Each State Party to the present Covenant undertakes to take steps, individually and through international assistance and co-operation, especially economic and technical, to the maximum of its available resources, with a view to achieving progressively the full realization of the rights recognized in the present Covenant by all appropriate means, including particularly the adoption of legislative measures” (2: Article 2.1)

### *National action plans*

Another indicator of progress in meeting Action 20 commitments is the presence or absence of national action plans on human rights and HIV/AIDS. While the NCPI addresses this issue in some detail, the quality of the data is again ultimately insufficient for assessing impact (19). A national plan of action should indicate whether and how human rights are being respected in the national HIV/AIDS strategy, yet current indicators merely ask whether respect for human rights are included in the plan. This has not changed between the 2006 and 2008 NCPIs and without investigating the individual plan, its actual human rights content is largely unknowable.

### *National independent human rights institutions*

The existence of a national independent institution for human rights, such as an ombudsperson or human rights commission, is another key element in a system that promotes access to justice for all, and it is an important national mechanism to combat stigma and discrimination. Although an exact figure is difficult to ascertain, more than 35 European countries have human rights commissions or ombudspersons.<sup>59</sup> Some offices are human rights-specific, while others are broader but have human rights sections. With regard to **Spain**, for example, the country's 2006 UNGASS report states that there is no independent human rights institution, though in fact it has an office, El Defensor del Pueblo (the Defender of the People), that is charged in part with protecting basic rights ( 29, 30). Some jurisdictions, such as **Sweden** and, in **the United Kingdom, Northern Ireland** and **England**, have more than one such entity, each focusing on specialized areas. Others still lack such an institution, such as **the Czech Republic**, where the human rights element of the national HIV/AIDS strategy is coordinated by an NGO representative<sup>60</sup> (31, 32).

However, the mere existence of such mechanisms is not enough to satisfy the commitments in Action 20. The scope and effectiveness of the office is of fundamental importance, as is whether it is in fact addressing issues relating to HIV/AIDS. Human rights institutions should fully comply with the Paris Principles (33) and many of the current human institutions fall far short of these requirements. In **the United Kingdom**, for example, the commissioner responsible for children's rights in **Northern Ireland** may take individual complaints (34), but his or her English counterpart cannot. In **The former Yugoslav Republic of Macedonia**, the Ombudsman is charged with investigating individual complaints, yet the government does not always act upon its recommendations and requests for information (35). On the other hand, some countries have recently revisited their human rights institutions and enacted laws to strengthen their powers, such as **Albania**, which strengthened the authority of the People's Advocate in May 2005 (36, 37), and **Latvia**, which created the office of the Rights Defender in January 2007 to replace the previous human rights office (38).

### **Developing a human rights-based approach to monitoring progress**

There are two clear conclusions that can be drawn from the information above. The first is that many countries are failing to take even the most basic concrete steps needed to meet their Dublin commitments to combat stigma and discrimination and to promote the human rights of PLHIV and affected communities. The second is that the indicators currently being collected are insufficient to truly measure progress on Action 20 over time.

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<sup>59</sup> For a list of many, though not all, of the human rights institutions in the European Region, see [www.nhri.net/NationalDataList.asp?MODE=1&ID=1](http://www.nhri.net/NationalDataList.asp?MODE=1&ID=1).

<sup>60</sup> The **Czech Republic** does have an Ombudsman, but the powers of this office are related primarily to administrative matters, including police actions and detention. It is not human rights-specific.

Rectifying the quality gap in currently available data requires that a new approach to monitoring progress be developed, one described by the United Nations Special Rapporteur on Health as a “human-rights based approach”. The Special Rapporteur has identified several elements as necessary for a comprehensive rights-based approach to monitoring state progress on supporting the population’s right to health. These same elements should be considered similarly essential for monitoring progress on the commitments made in the Dublin Declaration, including those in Action 20, and adapted accordingly.

Some of the key features necessary for a human rights-based approach are outlined below. They should be integrated into not only the specific indicators required to assess a human rights system (see above), but also into the monitoring for all Dublin actions.

*Disaggregation.* According to the United Nations High Commissioner for Human Rights, “Data must be disaggregated to capture disparities and patterns of discrimination” (39). The Special Rapporteur on the Right to Health also identifies disaggregation of indicators as a key element in effectively monitoring progress on the right to health, where possible and appropriate by gender, ethnicity, age, rural/urban situation, socioeconomic status and risk group membership (5). Without adequate disaggregation, it is difficult if not impossible to identify the needs of the populations most at risk for HIV/AIDS or to assess the impact of efforts to reduce stigma and discrimination.

Chapter 4 of this report illustrates the importance of data disaggregation in focusing services and resources on those most in need. It clearly shows that IDUs are falling far behind in access to highly active antiretroviral therapy (HAART), especially in eastern Europe<sup>61</sup> (40).

The significance of this approach can be illustrated by looking at Action 9, which requires, by 2010, 80% coverage “of the persons at highest risk of and most vulnerable to HIV/AIDS” by prevention and care services (see Chapters 5 and 15 for further details). From a human rights perspective, it is insufficient to simply monitor whether a country has achieved 80% coverage of services. If the 20% not covered by services are predominantly from certain identifiable populations – e.g. people who use drugs (as in the above study), women, young people or ethnic and linguistic minorities – focussing on the 80% receiving services is to effectively participate in concealing the impact of stigma and discrimination on the remainder.

An added benefit of disaggregation in identifying the effects of stigma and discrimination is illustrated in a 2005 report from the Global Network of People Living with HIV/AIDS Europe (GNP+ Europe) and the Terence Higgins Trust on the criminalization of HIV transmission in Europe (41). The fact that criminal prosecutions of HIV transmission are apparently increasing across Europe may itself be an indicator of the increasing stigmatization of PLHIV. However, the disaggregated data provided in this report enables the identification of other levels of discrimination. For example, while homosexual HIV transmission has been more common in **Norway** and **the United Kingdom**, all the convictions in those countries related to heterosexual transmission. Data from western European countries such as **Sweden** and **Finland** showed that convictions were concentrated among non-nationals, primarily African and Asian men. The breakdown of data provides opportunities to assess the impact of other forms of stigma and discrimination within the context of HIV/AIDS and the basis for a more incisive assessment of country conditions.

Another example of the value of disaggregated data in highlighting the impact of stigma and discrimination is found in research in **the United Kingdom** on the employment experiences of

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<sup>61</sup> The problem occurs throughout the European Region, however. For instance, of the 33 329 IDUs accessing HAART in western Europe, 31 500 are from Spain (39).

PLHIV. When the figures are disaggregated for race, sex, continent of origin and sexual orientation, the impact of multiple levels of stigma and discrimination is striking. Among white gay men, 31% indicated that they had disclosed their HIV status to their employers, while only 16% of non-white gay men had. The figures drop to 11% for African women and 9% for African men (42).

*Measurable over time.* All commitments in the Dublin Declaration require positive actions aimed at progressive change over time for PLHIV and affected communities. This mirrors state obligations under international human rights law for the “progressive implementation” of rights (1:Article 4, 2:Article 2.1). If “progress” on human rights, discrimination and stigma is to be measured, all data must be collected in a way that is measurable over time. This objective can be achieved through baseline surveys, benchmark- or target-setting and the use of indicators to assess whether targets have been met (43).

*Sufficient content for policy analysis.* According to the Special Rapporteur, a human rights-based approach should not only monitor key outcomes, but also some of the processes by which they are achieved (5). Quarantining people who test HIV-positive, for example, is clearly a violation of human rights and is unacceptable, even if it were effective in reducing transmission. Indicators should accordingly be able to delve into the policies and practices employed. (See next subsection for a discussion of structure, process and outcome indicators.)

For example, the 2006 NCPI asked, “Is HIV education part of the curriculum in: Primary schools? Secondary schools?” (A.III.2.1) (19) Governments that answered only “yes” provided a rather meaningless piece of data. Are their students being taught just an abstinence approach? Are they taught accurate information on methods of HIV transmission? It is important not only that HIV education be part of the curriculum, but that it be accurate and comprehensive. This has not improved in the 2008 form. Similarly, the NCPI question about legal aid systems, criticized above, fails to delve into the services provided under those systems. The same principle of ensuring the quality of both content and process needs to extend across all data, so that measures undertaken to achieve Dublin commitments protect and support human rights.

*Qualitative data.* Stigma and discrimination are almost entirely experiential phenomena for everyone involved. Qualitative data reflecting the experiences of PLHIV and the wider community are therefore essential to any study of progress on Dublin commitments. For example, in the 2007 survey conducted by the NAT and AAE (6), the fear of disclosure of HIV status emerged as a significant barrier to challenging discriminatory practices and accessing justice. A comment from **Ireland** stated that antidiscrimination legislation is non-specific – and

#### **Box 13. 2. Stigma as a barrier to political action**

In 2003, AIDS-Fondet (The AIDS Foundation) in **Denmark** surveyed Danes’ sympathy for different groups of people living with HIV (44). When asked which groups of HIV-positive people the respondents would *not* have sympathy for, only 2% said children. Infected heterosexual men and women were seen as unworthy of sympathy by respectively 19% and 18% of those surveyed, while 37% had no sympathy for infected homosexuals, a substantial disparity, and 38% of respondents had no sympathy for infected prostitutes. In the **United Kingdom**, a 2006 study carried out in Great Britain by the National AIDS Trust (45) found that 44% of respondents agreed with the statement, “People who have sex without a condom have only themselves to blame”.

These examples are extremely useful in highlighting the multiple levels of discrimination faced by PLHIV and the need for qualitative and disaggregated data to get to the heart of stigma and discrimination. Who a person is or how they live their lives affects how their HIV status is perceived. HIV is more than a virus. For many, it is also a moral indictment.

that it stays the same because “people with HIV fear stigma and discrimination”. Respondents from **Portugal** noted that “[antidiscrimination] regulations, when they exist, are hard to [use] because citizens don’t want to go to court because they fear disclosure and public exposure”.

The views and experiences, over time, of both HIV-positive and HIV-negative people need to form an integral part of the Dublin Declaration indicators. Otherwise, progress will be limited to actions such as legislation and training, without any measurement of impact or change.

### Box 13.3. **Public attitudes and political action**

The studies also raise another important issue: the relationship between public attitudes and political action. The study on IDU access to HAART referenced earlier serves as an excellent example (40). In that study, no information was available in either 2002 or 2004 on how many known HIV-positive IDUs were accessing treatment in **Denmark**, a serious barrier to addressing access to services for IDUs. Is the government likely to address this gap, however, when 49% of the Danes surveyed by AIDS-Fondet said they had no sympathy for them? Similarly, in **the United Kingdom** in 2004, just 623 out of 4202 HIV-positive IDUs were accessing HAART. Is it likely that resources would be made available for this group when, in 2006, NAT found that 48% of respondents in **the United Kingdom** thought that HIV-positive IDUs had “only themselves to blame” for their HIV status?

Stigma and discrimination cut to the very core of policy making and access to services. The importance of changing public attitudes cannot be overstated. This recognized in the UNGASS NCPI but only partly addressed. Respondents are asked whether programmes are in place to address public attitudes but the yes-or-no answers required do very little to measure the content or impact of those programmes (2008 NCPI B.I.15).

### *Arranging the indicators*

While any single indicator cannot, of course, possess all of the above characteristics, a *collection* of indicators can. Accordingly, indicators need to be arranged so that they illustrate a systemic approach, rather than presenting a disparate collection of facts. Again, the work of the Special Rapporteur provides guidance (5), suggesting that indicators be separated into those that provide information about structures, processes and outcomes.

*Structural* indicators measure whether recommended systems and mechanisms are in place, including legislation, legal aid, national plans of action, etc. While they are often yes-or-no questions, they may require elaboration based upon the framework above, e.g. to provide information about the content and quality of legislation.

*Process* indicators add more detail in measuring programmes, activities and interventions. They include, for example, budget and staffing data. In other words, they describe “state effort” – what the government is doing to achieve desired outcomes. The processes themselves must also be consonant with human rights requirements.

Finally, *outcome* indicators measure the impact of these efforts. Outcome indicators must incorporate appropriate disaggregation.

To illustrate, the following (non-exhaustive) list of indicators related to stigma has been arranged in this manner.<sup>62</sup>

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<sup>62</sup> For a more detailed example, see §§21–34 of the Special Rapporteur’s 2006 report (1), where he applies this approach to reproductive and sexual health.

### *Structural indicators*

**Indicator 20.1** (existing) Does your country have laws and regulations that protect people living with HIV and AIDS against discrimination? (2008 NCPI, B.I.1)

This indicator needs to be supplemented with qualitative content. For example, the legislation should contain several substantive features, each of which merits a sub-indicator:

- coverage of HIV status as a specific ground for discrimination
- coverage of indirect and direct discrimination
- coverage of those presumed to be infected
- coverage of vilification<sup>63</sup>
- narrow exemptions (i.e. strict limitations on when the legislation might not apply)
- wide jurisdiction in both public and private sectors (including employment, education, health care, etc.)<sup>64</sup>

### *Process indicators*

**Indicator 20.2** (existing) Are there programmes designed to change societal attitudes ... ? (2008 NCPI, B.I.15)

Again, this indicator should be supplemented with qualitative follow-ups, e.g.:

- Please provide details of the relevant programmes.
- How much have budgets for these programmes increased or decreased each year over the last five years?
- How much were PLHIV and civil society organizations involved in programme design?

**Indicator 20.3** (existing) Have members of the judiciary been trained/sensitized to HIV/AIDS and human rights issues that may come up in the context of their work? (2008 NCPI, B.I.13)

**Indicator 20.4** (proposed) Have the police been similarly trained/sensitized? Do they record motives for violent assault?

**Indicator 20.5** (proposed) Have the media been similarly trained/sensitized?

### *Outcome indicators*

- What percentage of PLHIV feel that antidiscrimination law is effective/ineffective (disaggregated by age, gender, ethnicity, membership of vulnerable groups such as MSM, IDUs and sex workers)?
- What percentage of PLHIV feel that attitudes have changed for the better over time (disaggregated)?
- How many judicial decisions on HIV/AIDS-based discrimination have there been each year in the last five years, and what percentage of cases resulted in a positive outcome for the plaintiff?
- How many cases of police brutality against IDUs, sex workers, homosexuals and PLHIV have been recorded annually for the last 5 years?

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<sup>63</sup> “Vilification is any public act that could incite others to hate, have serious contempt for, or severely ridicule an individual because they belong to a particular group or have a particular characteristic” (46)

<sup>64</sup> For further sub-indicators required for anti-discrimination see UNAIDS *Handbook for legislators on HIV/AIDS, law and human rights* (47)

- What percentage of PLHIV and members of risk groups feel that police behaviour and attitudes towards them have changed over time (disaggregated, also by nature of the change);
- How many violent assaults based on HIV status or membership of a risk group have been recorded each year over the last five years? How many arrests have been made based on those assaults and how many convictions have been achieved based on those arrests?
- What percentage of PLHIV feel that media reporting has improved or become more positive over time (disaggregated)?

## **Conclusions and recommendations**

In assessing progress towards meeting the commitments of Action 20, it is clear from the available data that many countries are failing to take the basic actions necessary to combat stigma and discrimination and to promote the human rights of PLHIV and affected communities. However, it is also clear that the data being currently collected are for the most part insufficient in quality and scope to adequately assess national progress over time, or to create a reasonable baseline by which to gauge progress.

Human rights are germane to nearly every aspect of national HIV/AIDS efforts and accordingly inform the entire Dublin Declaration. The prevailing levels of stigma and discrimination in a country help determine how well it will fulfil – or not fulfil – its Dublin commitments. Therefore, the impact of stigma and discrimination should not, and cannot, be properly measured in isolation from other Dublin actions. Indeed, it may even be misleading and suboptimal to devote a separate chapter of this progress report to stigma, discrimination and human rights, as these issues inform every chapter in some way and affect the fulfilment of most Dublin commitments.

Drawing upon the work of the United Nations Special Rapporteur on the Right to Health, this chapter has attempted to present a human rights-based approach to monitoring progress on not only Action 20 but all the Dublin commitments. Future monitoring of the Dublin Declaration should be carefully thought out within this framework.

## **Recommendations**

1. Mainstream human rights throughout the Dublin monitoring process.
2. Develop new indicators to fill existing gaps on access to justice, addressing: legal aid, justiciability of human rights in the courts; and national independent human rights institutions.
3. Disaggregate outcome indicators, wherever possible and appropriate, by gender, age, ethnicity, socioeconomic status, urban/rural situation and risk group membership.
4. Expand structural indicators with qualitative/content elements and supplement with process indicators, to measure government efforts and ensure that the processes used to achieve the desired outcomes are themselves in keeping with human rights obligations.
5. Develop new indicators to measure the impact of the participation of PLHIV in policy formation and planning.
6. Include qualitative data in the form of the experiences of PLHIV and vulnerable populations in data collection

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## 14. Testing and counselling

**Dublin Action 10:** Scale up access for injecting drug users to prevention, drug dependence treatment and harm reduction services through promoting, enabling and strengthening the widespread introduction of prevention, drug dependence treatment and harm reduction programmes (e.g. needle and syringe programmes, bleach and condom distribution, voluntary HIV counselling and testing, substitution drug therapy, STI diagnosis and treatment) in line with national policies;

**Dublin Action 13:** Ensure men, women and adolescents to have universal and equitable access to and promote the use of a comprehensive range of high quality, safe, accessible, affordable and reliable reproductive and sexual health care services, supplies and information including access to preventive methods such as male and female condoms, voluntary testing, counseling and follow-up;

When discussing the size of the HIV/AIDS epidemic and related trends in the European Region, it is important to consider the number of undiagnosed cases of HIV infection. In the European Union (EU) the overall level of undiagnosed cases is estimated to be approximately 30% (1), up to 40% in some countries (2), or even higher (for example, up to 58% of injecting drug users (IDUs) in Rotterdam were unaware of their serostatus) (3). Data on non-EU countries in the region show that in some countries half of all IDUs who tested positive in prevalence studies were unaware of their status (4) a similar trend to that reported in London in the early 1990s (5).

The implications of not knowing one's serostatus – missed benefits of prevention, treatment, care and support, as well as possible transmission to others– will create serious obstacles in the movement towards achieving universal access to HIV/AIDS prevention, treatment, care and support to all in need.

### Availability of testing and counselling services in the European Region

Data suggest that the availability of testing and counselling (T&C) services, and their accessibility, affordability and acceptability for the people most in need of them, varies significantly across the European Region.

#### *Current policies and practices*

The most recent data on current HIV testing policies and practices in countries in the European Region are available from the EuroHIV 2006 survey (6), to which 44 countries have responded, and from the WHO Regional Office for Europe survey of 2006 (7). Data indicate that all countries routinely offer voluntary and mandatory HIV testing, but the range of each type of testing differs from country to country (6). Furthermore, the populations to whom these tests are systematically being offered vary considerably, as can be seen in Table 14.1.

Table 14.1. **Percentage of countries routinely offering testing to high-risk groups**

<b>Risk groups</b>	<b>Countries routinely offering testing</b>
Immigrants	25 %
Injecting drug users (IDU)	73 %
Men who have sex with men (MSM)	36 %
Pregnant Women	84 %
Prisoners	45 %
Sex workers	39 %
Sexually transmitted infection (STI) clinic clients	59 %
Young people	14 %

Some countries report 100% or almost 100% (either 80–90% or >90%) testing on a routine basis for pregnant women, IDUs, STI clinic and TB hospital patients, prisoners, immigrants, MSM and sex workers. This begs the question: is it possible to reach 100% testing for any population group with the routine offer of T&C services on a truly voluntary basis while maintaining the clients' right to decline testing?

Data also show that in some countries only a relatively small percentage of population groups at most risk of and most vulnerable to HIV are tested. Does this mean that those groups do not access or do not have access to T&C services? Data regarding testing sites is usually limited (although the recent WHO Regional Office for Europe survey will provide information), as is data on selection criteria for testing, sex and age distribution and, most importantly, data concerning the major reasons individuals choose to decline testing.

The available data on the number of HIV tests performed in countries in the European Region (excluding unlinked anonymous testing and testing for blood donations) suggest significant country to country variations (8), with the rate of HIV tests per 1000 population being highest in **San Marino and the Russian Federation**. While the number of tests performed in western Europe remained steady between 2001 and 2005, it has significantly increased in some countries of central and eastern Europe, reflecting in some of those countries improved coverage of populations at risk and vulnerable to HIV/AIDS and thus contributing to the early detection of infection. The HIV testing algorithms used in the WHO European Region are shown in Fig 14.1.

Fig 14.1. **HIV testing algorithms in the WHO European Region, 2006**

<i>First screening test</i>	<i>Confirmation test</i>	<i>Number of countries</i>
ELISA +	No Test	2
	2 <sup>nd</sup> ELISA	17
	Western Blot	34
	Immunoblot	13
	2 <sup>nd</sup> +3 <sup>rd</sup> ELISA or other test	5
PCR P24 antigen Viral Culture	→	10

*Source:* (EuroHIV. Report on the EuroHIV 2006 survey on HIV and AIDS surveillance in the WHO European Region, Saint-Maurice: Institut de veille sanitaire, 2007.

#### *Mandatory testing*

Data show that mandatory testing in situations other than blood donations still exists in a number of European countries: HIV testing is mandatory for immigrants and the armed forces in three countries, for sex workers in four countries, for pregnant women in two countries and for surgical patients in one country (6).

#### *Home testing*

In the majority of countries (86%), policies on home testing and home sampling are not approved or not available, despite HIV testing kits available from the internet (6). Home testing is, therefore, an area that should be addressed to reach consensus across the region and develop guidance. Discussions held at a WHO Regional Office for Europe technical consultation for nongovernmental and community-based organizations in the European Region (Lisbon, June 2007) suggest that the idea of promoting home testing would be useful but well-balanced guidance is needed.

#### *Partner notification*

Partner notification is voluntary in the majority of countries (82%) that responded to the EuroHIV 2006 survey (6). 35% carry it out through patients only and 51% through the combined efforts of patients and service providers. In 46% of the countries that responded, the proportion of people living with HIV revealed via partner notification was less than 10%, and was thought to be between 10% and 50% in 36% of the countries. Data from the majority of countries that responded (72%) are estimates based on personal assessments. In five countries they are from published or unpublished surveys, and in one country from an ongoing multi-centre assessment.

The main issue is whether partner notification is performed on a truly voluntary basis and confidentiality and anonymity are always maintained. The issues surrounding partner notification, data confidentiality and anonymity need to be clearly articulated in national legislation and human rights-based approaches and, importantly, followed in practice, which is still not the case across the region.

#### *Pre- and post-test counselling*

Pre- and post-test counselling, as suggested by data from the EuroHIV 2006 survey, were most frequently offered within provider-initiated testing and counselling (PITC) in 70% of respondent countries, and voluntary/self-initiated testing (VCT) in 64% of the respondent countries. The low rate of provision of counselling is associated with home testing (in 98% of respondent countries).

#### *Quality of counselling*

Quality of counselling remains an issue in the majority of countries across the European Region. Experience gained from workshops supported by the WHO Regional Office for Europe on pre- and post-test counselling and implemented in a number of central, south-eastern and eastern European countries highlights areas requiring attention with the main concerns and challenges expressed being:

- counselling service providers usually have varying degrees of experience and, generally speaking, little experience, especially in the post-test counselling of individuals diagnosed with HIV. Their shortcomings in conducting sexual risk assessment are particularly related to MSM;
- the lack of post-test counselling for people who are HIV-positive;
- insufficient capacity to adequately address the emotional concerns within the counselling context:
  - about being too emotional and involved;
  - feelings of powerlessness, hopelessness and uncertainty when notifying a client of an HIV-positive test result;
  - worries about how to handle the emotional reactions (e.g. depression, suicidal ideas and aggressive behaviours) from clients who have just been notified of an HIV-positive test result;
- fear of burn-out;
- lack of follow-up for people diagnosed HIV-positive; and

- long-term counselling for people living with HIV.

Discussions with leading experts across the region suggest that the quality of counselling service provision remains an important challenge to be addressed. Some experts emphasized the importance of maintaining pre-test counselling. Pre-test information is preferentially absorbed by both positive and negative test result clients as neither emotional response (feeling shocked or relieved) renders the client able to fully understand, absorb and follow the recommendations given within the post-test counselling sessions. The discussions identified measures to assure the quality of counselling services, including promoting best practices, sharing training programmes and curricula for undergraduates and postgraduates, and establishing and sharing guidelines, protocols, norms and standards, including tools for quality monitoring.

### Achievements, challenges, opportunities

The reports that countries submit to monitor their progress against commitments made in the United Nations General Assembly Special Session on HIV/AIDS (UNGASS) could be a valuable data source for monitoring Dublin Declaration commitments related to T&C, as the reporting format for UNGASS Declaration monitoring envisages a number of issues concerning T&C. However, the structure and content of available UNGASS reports, and consequently the completeness of T&C-related data therein, vary significantly from country to country. For example, there are Policy Index Questionnaires (PIQs), which are meant to be part of UNGASS reports and include T&C-related questions; however, not all UNGASS reports contain PIQs. Data obtained from available PIQs show that very few countries address T&C issues in their policies, strategies and programmes. Some data are available from UNGASS reports themselves, but are often limited. T&C-related data available in PIQs suggest is show in Table 14.2.

Table 14.2 **Testing and counselling data from Policy Index Questionnaires**

	Austria	Armenia	Belarus	Germany	Israel	Russian Federation	Spain	Ukraine	United Kingdom
National strategy or action framework addressing VCT	x	x	x	x	x	x	x	x	x
Have a policy or strategy to expand access to VCT, including among most-at-risk populations		x	x	x		x	x		x
Implemented prevention activities, including VCT, in 2003 and 2005, in support of an HIV prevention strategy		x	x		x	x	x	x	x
Have a policy or strategy to promote comprehensive HIV/AIDS care and support, including VCT, with sufficient attention to barriers for women, children and most-at-risk populations		x	x	x	x		x		x
Have a policy to ensure equal access for men and women to prevention and care		x	x	x	x	x	x	x <sup>65</sup>	x <sup>66</sup>

<sup>65</sup> Limited access in penitentiary institutions.

<sup>66</sup> Some of the government's recent immigration and entitlement policies have a disproportionate impact on women living with HIV, since there are nearly twice as many African-born women as African-born men living with HIV in the United Kingdom.

Have a policy to ensure equal access to prevention and care for most-at-risk populations		x	x		x		x		x <sup>67</sup>
Have a policy prohibiting HIV screening for general employment purposes (such as appointment, promotion, training or benefits)			x	x			x		

Data on the UNGASS core indicator – percentage of most-at-risk populations who received HIV testing in the last 12 months and know their test results – obtained from the available UNGASS country reports are shown in Table 14.3 below. Not all UNGASS reports provide data on this indicator, and available data typically cover one particular year, which is often different in different country reports and thus complicates both in-country and inter-country analysis.

**Table 14.3. Percentage of most-at-risk populations who received HIV testing in the last 12 months and know their test results**

Countries	Injecting drug users	Men who have sex with men	Female sex workers	Prisoners	Young people
Armenia	21% (year unknown)	42% (year unknown)	33% (year unknown)		
Belarus	39% (in 2005)	55% (in 2005)	49% (in 2005)		
Bulgaria	17% (in 2004)		35% (in 2004)		
Georgia	6% (in 2002) 6% (in 2004)	27.14% (in 2005)	34% (in 2002); 24% (in 2004)		
Romania			36% (in 2005)		
Serbia		52% (in 2004) 41% (in 2002)			
Spain	70% (in 2002)	70% (in 2003)		80–91%	
Turkey			26% (in 2005); 32% (in 2003)		
Ukraine	27% (year unknown)	25% (year unknown)	32% (year unknown)	18% (year unknown)	5% (year unknown)

The above table shows **Spain** as the country with the highest rates among MSM (70%) and IDUs – the active opiate users newly admitted to drug treatment – (70%). Available data also suggest that all prison inmates are offered VCT services when entering prison; in 2004 between 8% and 20% of them did not know their HIV (9) status.

In **Turkey**, due to policy changes initiated by police dealing with sex work, the proportion of female sex workers knowing their HIV status declined to 26% in 2005 from 32% in 2003 (10).

In **Serbia**, data show an increase in the rate among MSM from 41% in 2002 to 52% in 2004. Positive experience gained in the involvement of nongovernmental organizations (NGOs), especially serving the student population, and collaboration with professional settings could further positively contribute to addressing current challenges (11).

<sup>67</sup> Despite the government's national policy commitment to targeted prevention work among MSM and African men and women, there are no incentives, monitoring or sanctions in place to ensure it takes place at the local level.

In **Georgia**, data suggest that, despite the expansion of HIV prevention programmes targeting IDUs, access and coverage are rather inadequate and hardly have any impact on the epidemic. Available data also show a decline in the percentage of sex workers tested in 2004 who know their test results (24%) from 2002 (34%) (12).

In **Belarus**, 73 anonymous counselling centres for drug users were established and are funded by grants from the state and the Global Fund to Fight AIDS, Tuberculosis and Malaria (GFATM). In 2005, those centres' capacities were further strengthened, their outreach work intensified and counselling services expanded. The same year, 16% of the estimated number of IDUs were covered by services in those centres. According to 2005 behavioural survey data, 73% of IDUs, 81% of MSM and 77% of female sex workers indicated having access to HIV testing services. All health care institutions in both urban and rural areas offer access to anonymous and free HIV T&C services, and access to these services has also been ensured in penitentiary institutions (13).

Some countries, like **Ukraine**, provide more detailed data in their UNGASS report. Ukrainian data show that the percentage of those tested and who know the results is highest among female sex workers (30%) and lowest in young people aged 15–24 (5%). For IDUs the percentage was highest in those over 25 years of age (30%). While figures were similar in female and male IDUs under the age of 25, the percentage in those over 25 was a little higher for males than females. There are also data showing differences in the number of people tested and those who know the results. Those differences were highest in IDUs. The fact that among MSM the number of respondents who know their test results is higher than the number of respondents who received an HIV test in the last 12 months shows the importance of creating robust data collection and analysis procedures (14).

#### *Access to T&C services for IDUs*

Improving access to T&C services for IDUs is one of the most important issues, especially for countries in this region with IDU-driven epidemics. Recent experience from **Portugal** suggests that outreach-based and peer-led HIV interventions for IDUs make significant contributions to reducing their prevalence of HIV infection, and that the launch of new T&C programmes for IDUs has had a major positive impact. The Portuguese experience suggests that routine testing should be offered wherever basic HIV care and prevention are available. Such an approach would improve efforts on prevention, allow infected people to receive care (such as cotrimoxazole prophylaxis) and normalize HIV testing. Prophylaxis against opportunistic infections is within the reach of even the countries with the most limited resources, and detection of those who need it benefits the entire public health system. The Portuguese experience also implies that programmes require the capacity to determine what is effective and what is not within their country, to estimate resources required at the country level and scale up access to HIV prevention services to ensure its availability for those in need. Programmes for IDUs in **Portugal** also include needle and syringe exchange, opioid substitution therapy and medically-assisted injection facilities.

The introduction and promotion of a simple, rapid test is one option for increasing IDUs' access to T&C services. Such a test could be particularly beneficial in areas with a poor or underdeveloped laboratory infrastructure and a lack of qualified staff.

#### *Community-based HIV T&C services*

Community-based HIV T&C services are growing in importance. **The United Kingdom** has already gained experience in this regard, with country-wide community clinics for HIV and sexually transmitted infections (STIs) with the aim to reduce the spread of HIV and promote good health. The availability of mobile drop-in clinics enables greater access to testing for people who otherwise will not attend local health facilities because of fear of discrimination and

marginalization. These community-based facilities offer nurse-led clinics, with nurses undertaking pre- and post-test discussions and performing HIV tests. They use new technologies which allow easy detection of HIV – without the use of traditional laboratory equipment – and produce rapid results. Community clinics can also test for hepatitis and STIs, treat non-complex STIs, and provide contraception and hepatitis B vaccination services.

The challenge of reducing the proportion of people with undiagnosed HIV is addressed in **the United Kingdom** through the national Strategy and the Choosing Health White Paper by offering all genitourinary medicine (GUM) attendees an HIV test on their first screening for STIs, improving the capacity of GUM clinics and also by working with national NGOs promoting HIV testing in non-clinical community settings for MSM and African communities. The Unlinked Anonymous Prevalence Monitoring Programme enables the measuring of the prevalence of undiagnosed HIV infection in different population sub-groups. An uptake of voluntary confidential testing for HIV in GUM clinics increased among MSM from 64% in 2003 to 79% in 2004, and among heterosexuals from 54% in 2003 to 75% in 2004. The proportion of HIV infected people attending GUM clinics that attended and left with their infection diagnosed also increased. The change is not significant among MSM: from 45% in 2003 to 44% in 2004, but is great in heterosexuals –from 41% in 2003 to 35% in 2004 (15).

#### *Ethnic minorities*

Access to T&C for ethnic minorities differs from country to country and closely correlates with their access to services in general. The lifestyle of these groups, including high mobility, is an important factor to consider when implementing T&C services targeting ethnic minorities as different challenges exist. For example, some may not even have civil registration in the country in which they are living and thus remain outside the reach of the health care system. Roma people are particularly marginalized and vulnerable in many countries. Lack of social skills, low motivation for socialization and the resulting social isolation, high unemployment rate, low educational level, increasing injecting drug use and engagement in street sex work are not unusual for this group, and they do not perceive health as a priority, despite having significant health problems.

The WHO Regional Office for Europe, with financial support from the French government, initiated the establishment of a network of VCT centres in **Bulgaria** that offer free T&C services and targets the Roma community by setting up the service near their communities and offering culturally sensitive, friendly services. The network recently expanded to 15 VCT sites as part of a GFATM project. The Bulgarian government actively supported the network and the integration of the VCT centres into the national health service to ensure their sustainability without donor support. At present 10 of the 15 VCT centres are coordinated by regional inspectorates that are part of the national public health system; one site is run by the national centre for infectious and parasitic diseases (hosting the national reference laboratory); and – of particular note – four centres are run by NGOs (16).

In **Montenegro**, stigma related to HIV and concerns regarding the confidentiality of the testing process hinder people from taking an HIV test, and they are reluctant to be tested until symptoms develop. There is limited pre- and post-test counselling available and weak “social marketing” of the benefits of testing. A consequence of confidentiality concerns is that those who can afford it often go abroad to get tested. The first VCT service was established in **Montenegro** in mid-2005 (17).

Few T&C facilities are operational in **Albania**. Testing is provided in two locations in Tirana. VCT centres operate in the public health institute and in one NGO, supported by Project HOPE/SIDA. Counselling services are also offered by another NGO. VCT services for young

people are available outside of the capital, in Vlora, as part of youth-friendly services supported by UNICEF (18).

### *Migrants*

Migrants, especially from high-prevalence countries, play a significant role in the epidemiological picture of HIV/AIDS. Many immigrants and migrants living with HIV are unaware of their serostatus, particularly women (19). According to available data, the proportion of recently diagnosed infections among heterosexual immigrants from high-prevalence countries was lower than among citizens, which could be a reflection of the limited access to T&C services for this group, both in their country of residence and in their country of origin (20). People from black minority ethnic groups are being diagnosed later in the course of HIV infection than white patients. Some available data from **the United Kingdom** suggest that in the Midlands and southern **England** stigma and fear of discrimination discourage Africans living in **the United Kingdom** from testing for HIV (21). Existing government policies support the fact that immigrants are dispersed outside of the capital and mostly in areas where HIV-related services are not widely available, which thus contributes to limited access to services. Data suggest that the work of ethnic communities, including faith-based organizations, is highly important in motivating and empowering people to seek those services (22).

Data from a survey conducted in 2004 in five European countries (23) assessed the help-seeking behaviours of immigrants and their knowledge about HIV/AIDS and STIs. Data for **Germany** suggest that knowledge about HIV testing services is very low – just 24% of immigrants knew that an HIV test was free and anonymous in **Germany**. Of the people that underwent HIV testing, just 52% remembered receiving pre-test counselling, despite it being required, and the proportion of those who did not receive or could not remember receiving post-test counselling was equally high – 57%. Results of that survey suggest that preventive messages are not reaching immigrants as effectively as German citizens, despite 48% of the immigrant population being well educated (having a university or college qualification). Thus these populations would appear to remain outside the reach of T&C services, and the extent of their needs is unknown. This example suggests that availability should be accompanied by a number of other issues, such as acceptability and affordability to achieve the maximal accessibility. Services for immigrants need to be tailored to their T&C needs. While immigration contributes to an increase in the number of HIV-positive cases, international mobility within Europe – including among MSM communities – also heavily influences the epidemiological picture and has to be taken into account when developing preventive measures regarding access to T&C services (24).

### *Male and transgender sex workers*

Male and transgender sex workers sell sex, predominantly to men and HIV prevalence in these populations is frequently high. For example, an HIV infection rate of over 12% was found within a recent study conducted among male sex workers visiting HIV testing clinics in 19 Spanish cities (25).

Some public health experts believe that fear of stigma and discrimination prevent these population groups from actively seeking T&C services as discovery of a high HIV prevalence rate could result in negative consequences for them. Some countries have established dedicated centres for transgender people with mediators to facilitate access to and improve the acceptability of services offered to them. The transgender sex workers' self-organized group in Paris, being one of active places of the transgender sex workers' circuit, has set up an HIV/AIDS/STI prevention programme. A minibus, led by a prevention team and cultural mediators, all of them transgender, criss-crosses the main sex work locations of Paris. Anonymous and free testing is part of the services offered along with brochures with prevention

information printed in several languages (including Albanian, Arabic, French, Portuguese, Russian and Spanish) (26).

### *Cost implications*

Cost implications remain an important issue in facilitating access to T&C services. People without insurance or a civil registration remain outside the health care system and do not have access to T&C services. Usually, they are too poor to seek private health services or services in settings for which they have to pay.

### *Urban and rural areas*

Access to T&C services varies considerably between urban and rural areas. Several factors potentially contribute to lower coverage of T&C services for rural populations, such as a lower awareness and less active health-seeking behaviour; a lack of T&C services in rural areas; and fear of stigma and discrimination, which often leads rural populations to seek T&C services away from where they live, preferably in cities. But if they cannot afford to get there they may choose not to be tested at all.

### *Sustainability*

The sustainability of successful T&C projects is of concern, especially in countries where these projects are being supported by international organizations, donor funds or GFATM grants. The project in **The former Yugoslav Republic of Macedonia**, initiated by the WHO Regional Office for Europe and supported by the Norwegian government and a GFATM grant, is an example of a project running successfully. It is developing T&C networks and a pool of well-trained counsellors, and positive experience is being gained. Currently, there is an urgent need to ensure the future sustainability of the work and further scale up to universal access for all in need.

### *Access*

Extending the types of settings in which T&C services are offered could play a significant role in improving access. Experience suggests that the promotion of integration and collaboration, especially in settings traditionally providing dedicated, separate vertical services, could become and often is a sensitive issue that meets opposition from professional groups. However, there are positive examples from across the region of successful models of integration and collaboration, as follows.

For example, against a background of increasing rates of HIV, gonorrhoea and syphilis among MSM, the Norwegian public health institution – in cooperation with Gay and Lesbian Health **Norway** and the largest dedicated STI clinic in **Norway** – has produced recommendations for annual testing for HIV and other STIs among MSM. More frequent testing might also be recommended (every three to six months), depending on the individual context (27). Because many MSM have no access to dedicated STI clinics outside the capital city, new national guidelines were issued to general practitioners (GPs) to actively involve them in providing services. The consultations provided by GPs include a physical examination, laboratory tests and counselling, and also vaccination for hepatitis A and B if needed.

This initiative may be of particular interest to public health officials in some central and eastern European countries who are concerned about ongoing health care reforms in their countries. Some individuals believe that giving GPs or family doctors the responsibility to also provide HIV testing and counselling might jeopardize the quality of T&C service provision unless the additional responsibilities are accompanied by capacity-building efforts, which often is not the case. Others fear the loss of income.

Polish experience provides a good example of the importance of close collaboration between STI and HIV services in countries with separate vertical settings (28). It was found that about 36% of AIDS cases are diagnosed at the time of HIV diagnosis, which could be a reflection of poor access to T&C services or a low perception of risk in the population. Authorities believe that the approval of self-testing practices could be an important contribution to wider access to T&C services.

In **the Netherlands**, recognition of the fact that relatively few people were aware of their HIV status led to changes in testing policy, namely:

- integrating an active testing policy into the STI/HIV protocol for GPs;
- establishing additional facilities offering anonymous, voluntary and free T&C services for HIV and other STIs. More testing facilities were put in place in January 2006 and resources have increased from €6.4 million to more than €12 million in 2006. The financing system is set up in such a way that as STI numbers rise, so do the resources for VCT.
- Awareness, through mass media campaigns and internet interventions promoting HIV testing among MSM, helped to increase the testing rate 42% in 1999 to 54% in 2003 and to 60% in 2006 (and in Amsterdam 70–80%) (28).

The network of STI clinics has been expanded and strengthened to improve prevention efforts in response to rising rates of STIs, particularly among MSM (suggesting an increase in risky sexual behaviour), and to data they show an increase in the number of consultations at STI clinics and a significant increase in the number of HIV diagnoses (30). Despite available data also suggesting a high rate of STI/HIV co-infection among MSM, public health officials emphasize that it may even be underestimated due to underreporting of HIV status, including cases when patients are unaware of their serostatus.

Experience from **the Czech Republic** shows that offering T&C services in specialized centres – such as those for drug users and sex workers (including street workers) – as well as a wide availability in general health care settings offers a good balance of provision. The majority of HIV-positive diagnoses in 2006 were detected in asymptomatic patients, which suggests good access to T&C services and health-seeking behaviour (31).

### *T&C in eastern Europe*

Progress made by countries of the Commonwealth of Independent States (CIS) in accelerating access to T&C services, and the remaining challenges and existing opportunities, were discussed at the technical consultation on T&C for the CIS organized by the WHO Regional Office for Europe (Yerevan, **Armenia**, April 2007). In general, presentations and discussions showed that significant progress has been achieved: T&C services exist in all participant countries, with related infrastructure including trained staff and referral systems. At the same time, all participants emphasized that, despite progress achieved, there is still a long way to go to attain universal access to quality T&C services for all in need. Participants undertook a highly professional and critical overview of the remaining challenges and opportunities, and discussed issues that included policies (particularly legal aspects); strategies; issues related to programme planning and implementation; financial aspects and the possible implications related to further scale-up of T&C services; T&C as it is viewed from the perspective of treatment data monitoring; surveillance-related aspects; and others. Within the framework of the recently developed WHO/UNAIDS ‘Guidance on Provider-initiated HIV Testing and Counselling in Health Facilities’, the consultation provided a forum for participants to comment on the draft document and share their experience of providing T&C services.

The following were identified as major obstacles and challenges for scaling up availability of and access to quality T&C services:

- stigma and discrimination of people living with HIV are still prevalent in many of CIS countries, which negatively affects the access to and utilization of T&C and other HIV/AIDS services;
- a lack of:
  - coverage and quality T&C services provided to groups most at risk and vulnerable to HIV
  - sustainable financing of T&C services
  - integrated and standardized M&E system
  - quality counselling
  - T&C related infrastructure
  - civil society involvement in T&C service provision
  - counselling services
  - counselors in general and especially qualified ones
  - coordination between the governmental and non-governmental sector
  - informed decision-making by the government officials responsible for health services;
- poorly developed legal and normative framework addressing groups at most risk of and vulnerable to HIV;
- challenges related to laboratory diagnosis including a lack of laboratory networks and access to simple, rapid tests;
- poorly developed VCT network.

The participants drafted action plans on scaling up access to quality T&C services to move towards universal access, identifying major obstacles that need to be addressed and indicating possible solutions for further scaling up of T&C in their respective countries. The conclusions and main recommendations of the consultation are as follows:

- The WHO/UNAIDS PITC guidance may be an important tool in further scaling up T&C services in combination with other approaches and when appropriate. However, clearer language should be used to explain that within PITC the provider offers an HIV test and patient is given the right to refuse.
- It was stressed that T&C is an important component of the comprehensive strategy to achieve universal access to HIV/AIDS prevention, treatment, care and support.
- A variety of settings should be taken into account when planning to scale up T&C services as T&C takes place in multiple settings and is delivered by different providers, including penitentiary institutions. Access to T&C services will be significantly improved by the active involvement of civil society organizations.
- T&C has multiple purposes. The key principle here is that, regardless of the risk-taking behaviour-, there should be easy access to T&C for all in need. In addition to being the significant and necessary first step towards prevention, treatment, care and support, T&C can also be the entry point for other health care interventions.
- T&C should reflect and respond to the needs of diverse populations. T&C services should be scaled up to reach population groups most at risk of and vulnerable to HIV. Tailoring services to the needs of clients is essential, so efforts should be made to promote client-centered health services, and a client- and human rights-based approach should be the cornerstone of T&C policies and practices. In the CIS, the HIV epidemic is at low-level or concentrated stage, and the T&C services should reflect the scope and scale recommended for this stage of the epidemic.

- Quality of T&C services should be of paramount importance. The need for both in-service training and post-graduate education of health care personnel was identified as among the essential actions to be undertaken to contribute to capacity building needed to provide quality T&C services.
- Health system aspects of T&C should be especially taken into consideration, by promoting the full incorporation of T&C services within the existing health systems to ensure sustainability and effective functioning. Health systems need to be flexible to address individual patient needs. A supportive health system environment should also include broad, equal access to client-friendly services.
- Legal aspects play a significant role in scaling up access to quality T&C services.
- Evidence and human rights-based approaches are essential when developing HIV T&C related national legislation, policies and practices.
- Financial and economic aspects of T&C should be given serious consideration.
- A year-by-year increase in state allocations to deliver T&C services is essential. Rational use of the limited resources, by targeting them at the most effective interventions, is critical. Effective M&E systems are of vital importance to identify effective interventions and to allocate resources to them.
- The development of a European T&C policy brief was recognized as an important step in assisting CIS countries in further scaling up access to quality T&C services. Implementation of regular T&C related consultations by WHO /UNAIDS was recognized as being of high importance in contributing to T&C scale up (32).

#### *T&C: The community perspective*

The recent technical consultation on T&C run by the WHO Regional Office for Europe for nongovernmental and community-based organizations in the European Region (Lisbon, June 2007) provided valuable insights into users' perspectives. Despite progress made, challenges still remain, primarily in widening the availability of and equal access to T&C services across the Region and especially for population groups most at risk of and vulnerable to HIV. While T&C is reported as being voluntary, anonymous and confidential in almost all countries in the European Region, this is not always the case and often is staff dependant. In some places, clients are forced to provide identification, so further promotion of the "3 Cs" principle – confidentiality, counselling and informed consent – is of great importance.

The two major issues addressed at the consultation were the legal aspects of T&C (which should be further promoted and play an important role in forming human rights-based policies and approaches to ensure they are followed by service providers) and counselling-related issues, both in terms of policy and quality of service provision. At the consultation, participants identified the vital role of the active involvement of civil society organizations and the importance of cross-regional collaboration in support of sharing best practice and mutual capacity-building.

#### *Provider-initiated HIV testing and counselling*

In response to the growing needs at the country level for basic operational guidance in T&C, WHO and UNAIDS has developed *Guidance on Provider-initiated HIV Testing and Counselling in Health Facilities* (33). The document is intended for a wide audience including policy-makers, HIV/AIDS programme planners and coordinators, health care providers, NGOs providing HIV/AIDS services, and civil society groups. The drafting process began with a consultation convened by WHO and UNAIDS in July 2006, followed by online consultation and public comments from more than 150 organizations and individuals between November 2006 and February 2007, and additional consultations with a wide range of individuals and

organizations. It does not address client-initiated HIV counselling and testing in detail, for which guidance already exists (34,35) and which WHO and UNAIDS strongly support but at the same time recognize the need for additional, innovative and varied approaches. The guidance aims for synergy between medical ethics and clinical, public health and human rights objectives. These include:

- enabling people with HIV to know their HIV status in an informed and voluntary manner; to seek and receive HIV prevention, treatment, care and support services; to prevent the transmission of HIV and to be protected from HIV-related stigma, discrimination and violence;
- improving treatment and prevention outcomes;
- promoting the right to autonomy, privacy and confidentiality;
- promoting evidence-based policies and practices and an enabling environment for implementation; and
- expanding the roles and responsibilities of health care providers to ensure access to HIV-related testing, counselling and related interventions.

PITC is neither mandatory nor compulsory, and WHO and UNAIDS do not support mandatory or compulsory testing of individuals on public health grounds. During the development of the new document, there was substantial discussion pertaining to whether PITC should employ so-called “opt-out” or “opt-in” approaches. Guidance in the document is formulated in terms of whether a health care provider should recommend HIV testing and counselling to the patient, and in what circumstances. The terms “opt-in” and “opt-out” are generally avoided in the final version of the document in favour of “provider-initiated HIV testing and counselling” which incorporates the informed right of the patient to decline the recommendation of an HIV test. Terminology such as “HIV screening”, “routine offer” and “routine recommendation”<sup>68</sup> is also avoided in favour of “provider-initiated HIV testing and counselling”.

PITC refers to HIV T&C which is recommended by health care providers to people attending health care facilities. In the case of those attending health facilities with symptoms or signs of illness that could be attributable to HIV, it is a basic responsibility of health care providers to recommend HIV T&C as part of the patient's routine clinical management. PITC also aims to identify unrecognized or unsuspected HIV infection in people attending health facilities. Health care providers may, therefore, recommend HIV T&C to patients in some settings even if they do not have obvious HIV-related symptoms or signs. Such patients may nevertheless be HIV-infected and may benefit from knowing their HIV status in order to receive prevention, treatment, care and support services.

As in the case of client-initiated HIV T&C, PITC is voluntary and the “3 Cs” must be observed. In recommending HIV T&C, service providers should always aim to do what is in the best interests of the individual patient. This requires giving individuals sufficient information to make an informed and voluntary decision to be tested, maintaining patient confidentiality, performing post-test counselling and making referrals to appropriate services.

Concerns about the potential coercion of patients and adverse outcomes of disclosure underscore the importance of adequate training and supervision for health care providers and the need for close monitoring and evaluation of PITC programmes.

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<sup>68</sup> Some of these terms were proposed in earlier drafts of this document, and the term “routine offer” was used in the WHO/UNAIDS Policy Statement on HIV Testing and Counselling. The Policy Statement will be updated to reflect the terminology used in this document.

Guidance on PITC is categorized according to the epidemic types: low-level, concentrated, and generalized HIV epidemics. It is emphasized that PITC should be accompanied by a set of HIV-related prevention, treatment, care and support services (which are described in the guidance document) and implemented within the framework of a national plan to achieve universal access to antiretroviral therapy for all who need it. At the same time as implementation of PITC, efforts must be made to ensure that a supportive social, policy and legal framework is in place to maximize positive outcomes and minimize potential harms to patients. This includes:

- community preparedness and social mobilization to support implementation;
- adequate resources and infrastructure;
- training for health care providers;
- codes of conduct for health care providers, and methods of redress for patients; and
- a strong monitoring and evaluation system.

Optimal delivery of PITC in the long term requires the implementation, monitoring and enforcement of laws and policies against discrimination on the basis of HIV status, risk behaviour and gender. Because WHO and UNAIDS encourage voluntary disclosure of HIV status, ethical partner notification and counselling, national policies and ethical codes should be developed to authorize partner notification in clearly defined circumstances. Governments may also need to develop and implement clear legal and policy frameworks that stipulate the specific age and/or circumstances in which minors may consent to HIV testing for themselves or for others, and how the assent of and consent for adolescents should best be assessed and obtained.

Adaptation of PITC guidance at the country level will require an assessment of the local epidemiology as well as risks and benefits, including an appraisal of available resources, prevailing standards of HIV prevention, treatment, care and support, and the adequacy of existing social and legal protections. Implementation of PITC should be undertaken in consultation with key stakeholders, including civil society groups. It is believed that implementation will contribute to widening the availability of and access to T&C services.

At the same time, it should be emphasized that, while PITC is important, it is just one approach in the comprehensive efforts to be undertaken at the country level to scale up access to T&C services.

## **Recommendations**

1. The national response to meeting T&C needs should be further transformed from an episodic, one-time approach to a strategic long-term national commitment based on evidence and human rights approaches, national needs and opportunities.
2. Further harmonization of policies and practices across the region is required, including standardized monitoring and evaluation, to avoid fragmentation and quality fluctuations of T&C services. The creation of a pan-European T&C policy, with a variety of options for countries, would be beneficial.
3. There should be changes in national legislation, policies and strategies which promote evidence-based policies and practices and an enabling environment for implementation, including adequate and sustainable funding for scaling up equal access to safe, acceptable, affordable, reliable T&C and follow-up services as required.
4. Prevention from stigma, discrimination and violence has to be ensured, and disclosure issues should be addressed in the context of human rights.
5. There should be further promotion of the centrality of the “3 Cs” principle (confidentiality, counselling and informed consent).

6. Ensure multisectoral involvement should, including community preparedness and social mobilization, is essential for accelerating and widening availability of and access to T&C services. Services run by nongovernmental and community-based organizations, civil society involvement in policy, strategy development and service delivery, and active support in related capacity-building to ensure close collaboration with national HIV/AIDS programmes and other major stakeholders should be promoted.
7. Promote T&C-related best practice and experience across the region as well as regional, subregional and inter-country collaboration.
8. Create and promote national guidance on pre- and post-test counselling, defining its role and setting standards including quality monitoring and building national capacities.
9. Support national T&C-related capacity-building, including human resources, infrastructure and other capacities needed locally to ensure long-term sustainability.
10. Reach consensus in countries and develop guidance on home testing.
11. Support operational research addressing current T&C needs in the region.
12. Develop and reach consensus on the set of T&C-related indicators for effective monitoring and evaluation.
13. Improve the completeness of T&C-related data in UNGASS reports to facilitate the monitoring of Dublin Declaration commitments by contributing to data collection needs and preventing the duplication of data collection efforts. The recent additions and refinement to the UNGASS indicators and Country Progress Report format for reporting in 2008 will contribute in this respect (34).

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## 15. HIV/AIDS and prisoners

People in prison have the same right to health as people outside, and the lives and health of people in prison are connected to those of people outside prison in many ways. If we protect them, we also protect our broader communities...As the representatives of 55 governments from Europe and Central Asia gather in Dublin this week to discuss “Breaking the Barriers” in the fight against HIV/AIDS, we call upon them to begin by breaking down the barriers over which they have total control – the barriers that have thus far prevented comprehensive HIV/AIDS services from being implemented in prisons.

– *Dublin Declaration on HIV/AIDS in Prisons in Europe and Central Asia*  
24 February 2004

The *Dublin Declaration on Partnership to Fight HIV/AIDS in Europe and Central Asia* was not the first “Dublin Declaration” to be released on 24 February 2004. Preceding it by several hours was the release of the *Dublin Declaration on HIV/AIDS in Prisons in Europe and Central Asia* (available at <http://www.iprt.ie/iprt/1204>), launched on the sidelines of the inter-ministerial conference by representatives from groups including AIDS Action Europe, the Central and Eastern European Harm Reduction Network, AIDS Foundation East-West, the Canadian HIV/AIDS Legal Network, the Global Network of People Living with HIV/AIDS and the Irish Penal Reform Trust.

An advocacy document prompted by nongovernmental organizations (NGOs) and endorsed by 100 organizations and experts from 25 countries across the region, the *Dublin Declaration on HIV/AIDS in Prisons in Europe and Central Asia* was driven by the urgent need to place the health care needs and rights of incarcerated populations onto the agenda of the government officials meeting in Dublin that week. In particular, the groups called upon officials attending the inter-ministerial conference to take action to address the issue of HIV/AIDS in prisons by implementing comprehensive prevention, care, treatment and support programmes.

When the official Dublin Declaration was released later that same day, it contained no actions specifically directed at incarcerated populations. However, this does not mean that the Declaration does not contain commitments to HIV/AIDS prevention, care, treatment and support for this group. In fact, by identifying prisoners as a vulnerable population, it sets time-bound targets for national governments to provide comprehensive HIV/AIDS services for them. Ironically, despite the lack of specific attention paid to prisons in the Declaration, providing comprehensive HIV/AIDS services in prisons is not only a central commitment made by governments in Dublin, but represents perhaps the *only* quantitatively measurable commitment contained in the Declaration as a whole.

### **Background on HIV/AIDS in prisons in Europe and central Asia**

In many of the countries in the European Region, rates of HIV infection in prison populations are much higher than those found in the general population outside of prisons, a fact primarily related to unsafe drug injection practices, both in and outside of prisons, and also to unprotected sexual contacts in prisons. Furthermore, criminal justice approaches that result in the mass incarceration of people who use drugs also play a significant role in increasing the likelihood of high-risk injecting practices in prisons and the concomitant risk of transmission of blood-borne viruses.

Detailed data on HIV infection in prisons are available in many European (especially western European) countries, and numerous examples of high rates of infection have been reported. For example, in **Spain**, it is estimated that the overall rate of HIV infection among prisoners is 10% (all prisons), with a figure as high as 31% in some regions (1). In **Italy**, a rate of 17% has been reported (2). High HIV infection rates among prisoners have also been reported in **France** (13%; testing of 500 consecutive new admissions to prison), **Switzerland** (11%; cross-sectional study in five prisons in the Canton of Berne), and **the Netherlands** (11%; screening of a sample of prisoners in Amsterdam (3)). In contrast, some European countries, including **Belgium, Finland, Iceland, Ireland, the United Kingdom**, and some states in **Germany**, report lower levels of HIV prevalence (4).

High rates of HIV infection among people who inject drugs and among prisoners have also been found in the countries of central and eastern Europe and the former Soviet Union. Various sources have reported high rates of HIV infection among prisoners in **Belarus** (4), **Estonia** (5), **Kazakhstan** (5), **Latvia** (6), **Lithuania** (7), **Moldova** (7), **the Russian Federation** and **Ukraine** (5). According to official figures, from 1996 to 2003, HIV prevalence in Russian prisons increased more than thirty-fold from under one per 1000 inmates to 42.1 per 1000 prisoners (8).

According to an August 2004 review of HIV infection in prisons in developing and transitional countries (5), prevalence studies have been carried out in most countries in the region. Only for four countries (**Bosnia and Herzegovina, Croatia, Turkmenistan** and **Uzbekistan**) could no prevalence data be located. The most extensive information was found for **Estonia, Kazakhstan, Latvia, Lithuania, the Russian Federation** and **Ukraine**. The available data tends to suggest lower HIV prevalence in prisons in central Europe (e.g. **Bulgaria, the Czech Republic, Hungary** and **Poland**), and a much higher prevalence in some of the states of the former Soviet Union – in particular, **the Russian Federation** and **Ukraine**, but also **Estonia, Latvia** and **Lithuania**.

Risk behaviours for the transmission of HIV in prisons are also well documented in the region. Research has consistently shown that a significant number of prisoners in Europe and central Asia continue to use drugs and to inject drugs on a regular or occasional basis while incarcerated, often sharing syringes. In the countries of the pre-2004 and 2007 expansions of the European Union (EU), for example, the number of prisoners actively using drugs during incarceration is between 16% and 54% (9). These EU studies indicate that figures for drug use are even higher among incarcerated women (9). A 2002 report prepared for the EU showed that 0.3% to 34% of the prison population in the pre-expansion EU and **Norway** injected while incarcerated. The report also found that 0.4% to 21% of people who inject drugs started injecting in prison, and that a high proportion of prisoners who inject drugs share injection equipment. Studies in **France** and **Germany** found the prevalence of sharing injection equipment among incarcerated women to be even higher than among incarcerated men (9).

This evidence, particularly that of initiation of injecting in prisons by previous non-injectors, has led the United Nations Office on Drugs and Crime (UNODC), the World Health Organization (WHO) and the United Nations Joint Programme on HIV/AIDS (UNAIDS) to call for a reduction in the criminalization of non-violent drug offences as a way to significantly reduce the use of incarceration as a response to drug offenders as a key element of an HIV prevention strategy (10). According to their joint policy framework on HIV in prisons, “The incarceration of significant numbers of drug users increases the likelihood of drug use inside prisons, and therefore an increase in unsafe injecting practices and the risk of HIV transmission.”(10).

Similar data have also been collected in eastern Europe and the former Soviet Union. In **the Russian Federation**, a study of 1087 prisoners found that 43% had injected a drug in their lives,

and that 20% had injected while incarcerated. Of this second group, 64% used injection equipment that had already been used by somebody else, and 13.5% started injecting in prison (11). In the oblast of Nizhni-Novgorod, which has a prisoner population of 28 000, the authorities found that all of the 220 HIV-positive prisoners had contracted HIV through injecting drug use (11).

In addition to the extensive evidence of risk behaviours among prisoners in many European countries, there is also documented evidence of the transmission of blood-borne infections within prisons. Over 10 years ago, a 1993 study in Glenochil Prison in Scotland provided definitive evidence that outbreaks of HIV infection can occur among incarcerated populations via syringe sharing (12). More recently, in **Lithuania**, HIV testing undertaken in 2002 found that 263 prisoners at Alytus prison were infected with HIV. Tests at **Lithuania**'s other 14 prisons found only 18 cases. It has been stated that the outbreak at Alytus was due to sharing drug injection equipment (12). Evidence of hepatitis transmission in a European prison was also found in a 1996 German study conducted in the women's prison in Vechta, Lower Saxon(13).

While sharing injecting equipment is the single greatest factor driving HIV infection in European prisons, unsafe sexual contacts are also a concern. The European Network on HIV/AIDS and Hepatitis Prevention in Prison found rates for sexual intercourse among men in prison of between 0.4% (**Sweden**), 1.4% (**Austria**) and 5% (**Spain**) (14). The rates of condom use for the last intercourse were between 0% (**Belgium**) and 30% for **Spain** (14). In **Austria**, 2.8% of men stated that they had been raped in prison, 1.4% stated that they had sexual intercourse with another man in prison, no one stated they had accepted payment for sexual intercourse, and no one stated they had used a condom (15).

These data clearly demonstrate the need for the implementation of comprehensive HIV prevention, testing, care and treatment in prisons across the region.

#### **Policy developments since 2004**

Since the publication of the Dublin Declaration in 2004, there have been a number of important policy developments related to HIV in prisons. The most significant of these was the publication in August 2006 of *HIV/AIDS Prevention, Care, Treatment and Support in Prison Settings: A Framework for an Effective National Response*. This document, published jointly by UNODC, WHO and UNAIDS, articulates the most up-to-date set of actions necessary to implement a comprehensive and human rights-based approach to HIV/AIDS at the national level. The framework is significant in that it not only clearly supports the expansion of antiretroviral therapy in prisons as part of national scale-up plans, but also endorses sometimes controversial programmes such as syringe exchange, substitution treatment and safer sex measures such as condom provision. The framework also explicitly opposes mandatory HIV testing of people in prison.

Since the publication of the framework, WHO, UNAIDS and UNODC have jointly published a series of four comprehensive *Evidence for Action Technical Papers* on prisons (16). The topics covered include HIV care, treatment and support, needle and syringe programmes, opioid substitution therapies, and the provision of condoms and safer sex measures. Again, these technical papers clearly spell out the evidence in support of these interventions.

In the European Region, new data gathering on prisons has been initiated by both the European Monitoring Centre on Drugs and Drug Addiction (EMCDDA) and the WHO Health in Prisons Project. The WHO Regional Office for Europe has published two important documents, the *Status Paper on Prisons, Drugs and Harm Reduction* (2005) and *Health in prisons: A WHO guide to the essentials in prison health* (2007). Numerous international and regional meetings

and conferences have been held, providing opportunities for sharing new research and best practice models. Also the *International Journal of Prisoner Health* has been launched as another important vehicle to share peer-reviewed research on prisons.

On the legal front, another potentially significant development is the acceptance by the European Court of Human Rights of the case of *Shelley v. The United Kingdom*. This case will examine whether the failure of **the United Kingdom** government to provide sterile syringes to prisoners who inject drugs constitutes a violation of the European Convention of Human Rights. If successful, this case has the potential to provide a legal framework to expand needle/syringe programmes in prisons across the 47 Member States of the Council of Europe.

### **Dublin Declaration commitments on prison populations**

The Dublin Declaration's Preamble recognizes prisoners among those "persons at the highest risk of and most vulnerable to HIV/AIDS infection". This recognition is significant, as it commits governments to very specific and time-bound deliverables for prison populations. These commitments are found in Actions 9 and 21.

**Dublin Action 9:** By 2010, ensure through the scaling up of programmes that 80% of the persons at the highest risk of and most vulnerable to HIV/AIDS are covered by a wide range of prevention programmes providing access to information, services and prevention commodities and identifying and addressing factors that make these groups and communities particularly vulnerable to HIV infection and promote and protect their health, and intensify cross border, sub-regional and regional technical collaboration and sharing of best practices through the EU and regional organisations in the prevention of HIV transmission among vulnerable groups.

**Dublin Action 21:** By 2005, provide universal access to effective, affordable and equitable prevention, treatment and care including safe anti-retroviral treatment to people living with HIV/AIDS in the countries in our region where access to such treatment is currently less than universal, including through the technical support of the UN through the global initiative led by the World Health Organization and UNAIDS to ensure 3 million people globally are on anti-retroviral treatment by 2005 ("3 by 5"). The goal of providing effective anti-retroviral treatment must be conducted in a poverty-focused manner, equitable, and to those people who are at the highest risk of and most vulnerable to HIV/AIDS;

Action 9 commits governments to achieving 80% coverage of "prevention programmes providing access to information, services and prevention commodities" among "the persons at the highest risk of and most vulnerable to HIV/AIDS" by the year 2010. As the Preamble defines prisoners as one of these most vulnerable populations, governments are, therefore, committed to achieving an 80% scale-up of HIV prevention measures in prisons by 2010.

Similarly, Action 21 commits states to "provide universal access to effective, affordable and equitable prevention, treatment and care including safe anti-retroviral treatment to people living with HIV/AIDS in the countries in our region where access to such treatment is currently less than universal...The goal of providing effective anti-retroviral treatment must be conducted in a poverty-focused manner, equitable, and to those people who are at the highest risk of and most vulnerable to HIV/AIDS". Again, this action suggests the need for concerted effort to scale-up prevention and treatment, including antiretrovirals, to the most vulnerable populations, among which prisoners are included. Action 21 identified the target for achieving this objective as 2005 – two years ago.

This raises the related issue of defining which HIV/AIDS services are included in these commitments. The answer to this question is found in the other actions in the Declaration that are universal, or near universal, in scope. People in prison clearly fall within the populations covered by such universal commitments, and for a government to suggest otherwise would constitute

discrimination against prisoners as a group, therefore breaching the commitment in Action 20 to combat discrimination.

Actions falling into this universal category are:

Action 8: "... to ensure ... that, by 2005, at least 90 percent of young men and women aged 15 to 24 have access to the information, education, including peer education and youth-specific HIV education, and services necessary to develop the life skills required to reduce their vulnerability to HIV infection..."

Action 10: "Scale up access for injecting drug users to prevention, drug dependence treatment and harm reduction services through promoting, enabling and strengthening the widespread introduction of prevention, drug dependence treatment and harm reduction programmes (e.g. needle and syringe programmes, bleach and condom distribution, voluntary HIV counselling and testing, substitution drug therapy, STI diagnosis and treatment) in line with national policies."

Action 11: "Ensure that HIV positive women and expectant mothers should have access to high quality maternal and reproductive health care services in order to prevent mother to child-transmission."

Action 13: "Ensure men, women and adolescents to have universal and equitable access to and promote the use of a comprehensive range of high quality, safe, accessible, affordable and reliable reproductive and sexual health care services, supplies and information including access to preventive methods such as male and female condoms, voluntary testing, counseling and follow-up."

Action 20: "Combat stigma and discrimination of people living with HIV/AIDS in Europe and Central Asia, including through a critical review and monitoring of existing legislation, policies and practices with the objective of promoting the effective enjoyment of all human rights for people living with HIV/AIDS and members of affected communities."

Action 23: "Increase access to non-discriminatory palliative care, counseling, psychosocial support, housing assistance, and other relevant social services for people living with HIV/AIDS."

Based on these actions, the "services and prevention commodities" that must be provided in prisons include at minimum:

- Condoms
- Syringe exchange
- Substitution treatment
- Bleach programmes
- Voluntary HIV testing and counselling
- Prevention of mother-to-child transmission
- Sexual health services
- Antiretroviral treatment
- Palliative care
- Action to combat stigma and discrimination.

### **Progress on Dublin Declaration actions on prison populations**

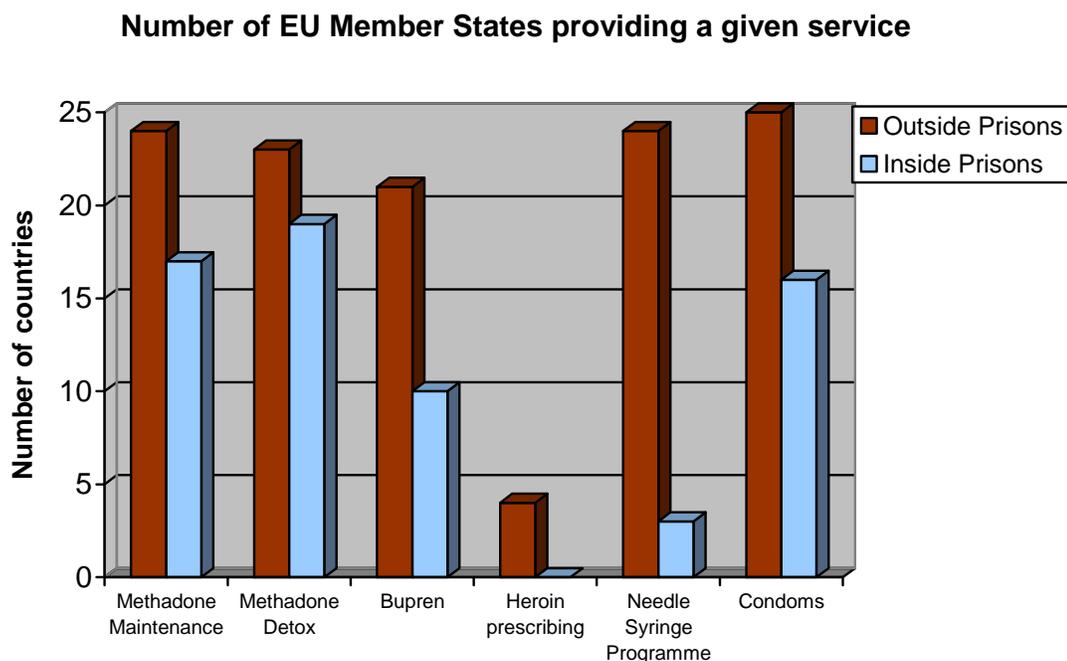
As is evident from the attached statistical annex, the commitment identified in Action 21 to "provide universal access to effective, affordable and equitable prevention, treatment and care including safe anti-retroviral treatment" remains far from being achieved in the vast majority of

countries in 2007, a full two years after the 2005 target date. In fact, no state met its Action 21 commitment by the agreed target date.

Action 9 also commits states to provide comprehensive HIV programmes and services in prisons, and mandates governments to have them accessible to 80% of prisoners by 2010. This commitment is strictly measurable on both a national and regional scale, and governments must be held to their commitments in this regard. Unlike other vulnerable populations identified in the Declaration's Preamble (the true size of which may only be estimated) the number of people in prison in any country is an identifiable figure. As a result, the commitment to 80% coverage in prisons is not one open to interpretation, but is measurable. For example, as **Ireland** has an average prisoner population of just over 3000 (see statistical annex), by 2010 comprehensive HIV services as defined above must be in place for at least 2400 of those prisoners. The success or failure of states in meeting this commitment should be strictly monitored, and publicly highlighted.

One example of the current failure to meet Dublin Declaration commitments is found in a recently released report from the European Commission on the progress of EU Member States in implementing Council Recommendation of 18 June 2003 on the prevention and reduction of health-related harm associated with drug dependence (17). As is clear from Fig.15.1 (below), the provision of harm-reduction and HIV-prevention measures in prisons lags far behind the availability of these interventions in the community outside of prisons in these countries, most strikingly in the area of syringe exchange. While 24 of the 25 EU Member States have syringe exchange programmes in the community, only 3 of those 24 have initiated them in prisons.

Fig 15.1. **HIV prevention measures in prisons in the European Union, number of countries (N=?) providing a given service**



Source: European Commission, April 2007.

This disparity led the Commission to conclude that, “harm reduction interventions in prisons within the European Union are still not in accordance with the principle of equivalence adopted by UN General Assembly, UNAIDS/WHO and UNODC, which calls for equivalence between health services and care (including harm reduction) inside prison and those available to society outside prison. Therefore, it is important for the countries to adapt prison-based harm reduction activities to meet the needs of drug users and staff in prisons and improve access to services.”(17). Although it represents only approximately half of those countries covered by Dublin Declaration commitments, this survey clearly demonstrates the current gap in prison-based services, even among high-income countries in the region.

From the information gathered for this document, the number of countries in the region providing the prevention and treatment standards identified above in prisons are as follows:

- Condoms = 18
- Syringe exchange = 6
- Substitution treatment = 17
- Bleach programmes = 9
- Voluntary HIV testing and counselling = 9
- Sexual health services = no data
- Antiretroviral treatment = 14

Indeed, it is fair to suggest that these figures *over-represent* the extent of coverage of these services to prisoners in the region. In many of these countries, the measures and services listed above are only provided in a limited number of prisons in the system; in some only as pilots. It is also important to understand that in the prison context *availability* and *accessibility* are two different issues. Many prisoners will choose not to access HIV prevention services even where such services are provided, due to stigma, lack of confidentiality and concerns about identifying themselves as either sexually active or using drugs within the institution. This means that *how* these programmes are implemented and supported by prison management and staff can be as important as *whether* they are implemented, and highlights the need for proper monitoring and evaluation of health interventions in prisons.

## Conclusions

Based upon an analysis of the Dublin Declaration commitments on prisons, and a review of the current status of states in meeting those targets, the following conclusions can be drawn.

1. Despite having no specific actions directed at prisoners, by identifying prisoners as a vulnerable population, the Dublin Declaration in fact sets clear, measurable and time-bound obligations on governments to implement comprehensive HIV/AIDS services in prisons.
2. In committing to the Dublin Declaration, governments have committed to providing universal access to HIV/AIDS services in prisons. These obligations are found in Actions 9 and 21.
3. Despite these commitments, the scale-up of HIV/AIDS prevention and treatment programmes and services in prisons lags far behind what is needed, what is available outside of prisons, and what is mandated within the Declaration itself.
4. No state succeeded in meeting its Action 21 commitments to have in place universal access to HIV/AIDS prevention and treatment programmes in prisons by the agreed target date of 2005.
5. Action 9 commits states to achieve 80% coverage of comprehensive HIV programmes and services in prisons by 2010. As the total number of prisoners in every country is identifiable, the success or failure of states in meeting this target is strictly measurable.

6. The vast majority of states are lagging far behind the pace of implementation required to meet their Action 9 commitments within the next 2.5 years. That said, international experience has shown that scale-up of HIV interventions need not be a prolonged process where the political will exists.

## Recommendations

1. Governments must meet their obligations under the Dublin Declaration, including the obligation to provide universal access to HIV/AIDS prevention and treatment in prisons.
2. Governments must be made aware that their commitments under the Declaration include measurable and time-bound obligations regarding prison health programmes.
3. The failure of all governments to meet their Action 21 commitments in regards to prisons should be publicly highlighted.
4. Governments must be made aware of their Action 9 commitments to achieve 80% coverage of comprehensive HIV programmes and services in prisons by 2010.
5. As this 80% commitment is strictly measurable, national and regional progress towards this target should be assessed annually and the results published.
6. Reducing the incarceration of non-violent drug offenders must be an integral component of an effective HIV-prevention strategy in prisons. Therefore, governments should decrease the use of criminal penalties and incarceration as a response to non-violent drug charges.
7. The international community must provide financial, technical, and professional assistance to low-income states and states in economic transition to ensure their ability to meet these targets, in keeping with the partnership approach to combating HIV articulated in the Declaration.
8. Evidence-based actions, well described and acknowledged, should be introduced at the same level in prisons as in the community. Voluntary counselling and testing, target group-specific information, education and communication, substitution treatment, needle exchange projects, and access to condoms and lubricants are all part of a core strategy to combat HIV/AIDS in prisons on a preventive level. Antiretroviral treatment but also antiviral treatment (against hepatitis C for co-infected persons) must be provided as a regular treatment option.

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## Country report – France

Pop. 60 496 000

### **Epidemiological summary and surveillance (1)**

In absolute terms, France has the most people living with HIV and the second highest estimated prevalence of HIV in the European Union (EU), after Spain. France only began mandatory HIV case reporting in March 2003, so analysis of its HIV epidemic over a longer period of time is not possible. From March 2003 to December 2006, the authorities reported a total of 20 677 new HIV cases. From the beginning of the epidemic through December 2006, they reported 62 059 AIDS cases and 34 875 AIDS deaths (2). Under-reporting is estimated to be 35% for HIV cases, 15% for AIDS cases and 20% for AIDS deaths.

Since the advent of HIV reporting in March 2003, 59% of cases have been male, and 90% of all reported cases were over 25 years old at the time of diagnosis. Of the cases with a known mode of transmission, 28% concerned men having sex with men (MSM), 66% heterosexual contacts and 5% injecting drug users (IDUs). Of the 4142 new HIV cases in 2005 (reported up to June 2006), 61% were among non-nationals, with the majority being women originating from sub-Saharan Africa infected through heterosexual transmission.

Of the cumulative reported AIDS cases since the beginning of the epidemic, 24% have been among IDUs, 45% have been MSM and 27% due to heterosexual contact.

The decrease in the prevalence of AIDS cases in IDUs to 4% in 2006 (2), confirms the reduction of HIV transmission in this population. The success of screening IDUs can be seen by the fact that a large proportion of HIV-positive IDUs were identified before acquiring AIDS. The number of AIDS cases among French nationals decreased by approximately 40% between 1999 and 2005, while simultaneously increasing by about 20% among immigrants, most notably those from sub-Saharan Africa or Haiti.

In conjunction with the institution of a mandatory reporting system for HIV, virological surveillance of recent infections (defined as within the previous six months) was set up to contribute to measuring HIV incidence. Determination of recent infection was possible for 4353 patients (70% of the new diagnoses) in the 2003–2004 period. The proportion of recent infections among the new diagnoses in 2003 was 31%. Of the recently infected cases, more than half (51%) of new diagnoses were MSM, while nearly a quarter were infected through heterosexual contact. This higher prevalence in MSM is consistent with the increase in incidence of sexually transmitted infections (STIs) observed among French MSM in recent years. However, given that MSM test for HIV more frequently than other risk groups, the probability of their being screened shortly after infection is correspondingly higher and, therefore, the data may be a reflection of screening practices rather than of reality.

According to a standardized national self-reporting study of gay men's sexual behaviour, the number of reported acts of unprotected anal intercourse in the previous year doubled between 1997 and 2004 among both seropositive and seronegative men. Thirteen per cent of respondents reported being HIV-positive, and 17% were of unknown HIV status, although 86% reported having been tested for HIV at least once in their lifetime. In addition, 10% of the respondents reported contracting an STI other than HIV in the past 12 months: 30% reported gonorrhoea and 20% syphilis, an increase of 100% and 300%, respectively, since 1997. Consistent with this self-reported syphilis prevalence of 2.0%, a syphilis prevalence survey in 2002 recorded prevalence of 2.6% among MSM, approximately 10 times higher than among heterosexuals. The same study

found a prevalence of 8.9% among all people living with HIV, regardless of sexual orientation. Out of an estimated 85 000 patients seen for HIV/AIDS care in 2005, 58 000 were on highly active antiretroviral therapy (HAART).

The Institute for Public Health Surveillance (Institut de Veille Sanitaire) coordinates the following HIV/AIDS surveillance systems:

- reports of HIV cases;
- reports of AIDS cases;
- LaboVIH (HIV screening in 4300 community and hospital laboratories); and
- virological surveillance of people living with HIV (determination of time since infection and surveillance of subtypes) (3).

The total number of HIV reports in 2005 was 4142; with a delay-adjusted estimate of 4400. Assuming an under-reporting proportion of 34%, 6700 new HIV diagnoses were estimated to have occurred in 2005. After adjustment for reporting delays, the number of reports was stable from the second semester of 2003 to the second semester of 2005 (approximately 2200 reports per semester) (2).

## **A. Leadership**

### **1. Political leadership (national framework)**

HIV/AIDS was included in health policy legislation in August 2004, and in 2005 the response to HIV/AIDS was recognized as a “major national cause 2005” by the Prime Minister. In France, the response to HIV/AIDS is one of the sections of the health and society sub-directorate, itself under the department of prevention, health programmes and risk management, which is in turn included in the general health directorate. Hierarchically, the response to HIV is placed at the same level as addictive behaviours, mental health, and population health, precariousness and exclusion (4).

A national programme for the response to HIV/AIDS and STIs for the period 2005–2008 (5) has been established, focusing on:

- prevention, by reducing the incidence of HIV and STIs, particularly among priority regions, migrants, MSM, people living with HIV, and other most-at-risk populations (sex workers, IDUs, prison inmates and transgender people), maintaining a low incidence of HIV in the general population and fighting Chlamydia, herpes, and HPV infections;
- diagnosis, by decreasing the delay in diagnosis and promoting STI screening;
- treatment and support; and
- care and treatment of people living with HIV, by increasing their quality of life and fighting stigma and discrimination.

The programme promotes the decentralization of care, by establishing centres for the regional coordination of the response to HIV (COREVIH).

### **2. Community involvement and the private sector**

In February 1989, the National Council on AIDS was created as an independent advisory body on society’s perspective on AIDS in France. The council produces periodical reports and press releases on relevant topics related to HIV/AIDS. The sixth and last Ethics, AIDS and Society activity report was published in October 2006 and referred to the period 2004–2005.

The law of 4 March 2002, followed by the public health law of 9 August 2004, introduced the concept of “health democracy”, according to which citizens should be involved in major health decisions. The definition of public health priorities was decentralized to respond to regional needs (6).

France has several nongovernmental organizations (NGOs) dedicated to HIV/AIDS. The national programme for HIV/AIDS and STIs recognizes that NGOs have been an essential component of governmental policies on the response to HIV/AIDS since the early days of the epidemic, and they have undertaken numerous prevention, care and support activities. The 2005–2008 programme involves the cooperation and financial support of 33 NGOs (6).

### **3. Resource generation**

National investment in the response to HIV/AIDS increased between 2001 and 2004, with funds decentralized towards the provision of health insurance (6).

France devoted US \$140 million to the global response to AIDS in 2004, ranking fifth among donor nations, behind the United States (US \$1.6 billion), the United Kingdom (US \$600 million), Canada (US \$190 million) and Japan (US \$145 million). Its contribution in 2005 was US \$145 million (7). France is a donor country for the Global Fund to Fight AIDS, Tuberculosis and Malaria, donating over US \$287 million in 2006 and pledging over US \$403 million in 2007 (8).

## **B. Prevention**

### **4. Injecting drug use and HIV**

Harm reduction for drug users in France officially became a national policy in July 1994 (thanks to the Simone Veil initiative); prior to that, efforts were limited to the legalization of the sale of syringes in pharmacies (in 1987), a few small-scale quasi-illegal needle exchange projects managed by NGOs, and a few attempts by medical practitioners to prescribe substitution. As of 1993, only 52 people in France benefited from methadone treatment (9).

The vast increase in both needle exchange and substitution programmes since 1994 has resulted in a considerable drop in the proportion of IDUs among new cases of HIV infection and AIDS, as well as in overdose-related deaths. Also, most studies indicate that the frequency of injecting among drug users seeking treatment in France has decreased substantially since 1996.

However, the strict French legislation on drugs impedes harm-reduction approaches: the Drug Law of 1970 widely restricts discourse on drugs, hindering education and health-related prevention messages from reaching the general public and IDUs. The law also prohibits public debate on drugs in France, as well as education and harm-reduction initiatives. Even certain initiatives by the Interministerial Mission for the Fight against Drugs and Drug Addiction (MILDT) could be seen as illegal under this law. Furthermore, there remains a refusal to establish supervised facilities for drug use in safe-injection rooms, which forces the most marginalized IDUs to inject in very unhygienic conditions, further subjecting them to high levels of stress. This leads to greater injection-related risks, while simultaneously depriving them of medical supervision (7).

According to the 2005 French report for the European Monitoring Centre for Drugs and Drug Addiction (10), since the beginning of the 1970s, the responsibility for addictions to illicit drugs has rested with specialist facilities. These facilities were developed after the adoption of the 1970 law, which included provisions guaranteeing anonymous treatment, free of charge, to all users of

illicit drugs wanting treatment. Almost all French departments today have a specialized centre for drug addicts (CSST). These facilities were originally financed by the State and, since 1 January 2003, have been funded by national insurance as medical and welfare establishments. Their mission is to provide medical, social and educational treatment that includes assistance with social re-integration. Three types of CSST exist:

- outpatient treatment centres (201 in 2003);
- inpatient treatment centres providing group accommodation (42 in 2003); and
- treatment centres in prisons (16 in 2003).

The outpatient CSSTs provide patients with the opportunity to enter into a rehabilitation programme without institutionalization. They can also organize drug withdrawal in a hospital environment and assist patients who wish to use this method. CSSTs remain the primary facilities in which a patient can begin methadone treatment. General practitioners have been able to prescribe methadone treatment since 1995. Patients can also be prescribed buprenorphine directly by general practitioners or by a CSST.

The new five-year plan for 2004–2008 recommends the development of non-substitution programmes and therapeutic communities. Treatment based on opiate substitution on a wide scale is relatively recent in France, only starting in 1996.

Thanks to the development of substitution treatments, drug withdrawal programmes have become less frequent since the mid-1980s. In 2003, it was estimated that between 63 000 and 69 000 individuals were following a treatment programme, which represents less than half the predicted number of opiate users in France. Since then, between 11 200 and 16 900 individuals have accessed methadone treatments through an urban practitioner. To further increase accessibility to substitution treatment, a parallel treatment based on high-dose buprenorphine was instigated. Between 1996 and 2002, around 82 500 individuals were prescribed buprenorphine. Among them, 52 000 at most were undergoing a six-month treatment process, 22 000 at least were beginning a treatment or “in-between substitution”, and 6% (5000 individuals) were carrying out an important “subutex dealing” activity (11).

Harm-reduction activities are predominantly developed by organizations outside the CSST system, with support from the State, local communities or private foundations. The system is based on the following complementary actions:

- wide availability of syringes in pharmacies (sold without prescription since 1987);
- dispensing machines delivering Stéribox® injection kits (225 in total in 2002) or collecting used syringes (153 in 2002);
- other community needle and syringe programmes (118 in 2001); and
- drop-in centres or contact centres for drug users (40 in 2001).

Overall, harm-reduction systems cover the greater part of the country, but access to some essential services (notably methadone prescription) remains difficult in some rural areas. However, much work remains to be done on many fronts, including the introduction of harm-reduction initiatives into French prisons, improvements in prescription practices to ensure substitution treatments match as much as possible the personal needs of each patient, far more emphasis on the hepatitis C epidemic among drugs users (both in terms of medical care and prevention), and the introduction of safe injection rooms (7).

## **5. Most vulnerable and high-risk populations**

In France there are several active NGOs that work with the MSM community. These NGOs and the Institute for Public Health Surveillance produce a periodical bulletin communicating the

results of a behavioural survey of the MSM community, the *Baromètre Gay* (12). From 2003 to the first semester of 2006, homosexual transmission was the second most frequent mode of transmission reported in HIV and AIDS reports and AIDS deaths in France. In 2005, among 3423 MSM in the Ile de France region (Paris and its suburbs), 15% were self-reported HIV-positive and 22% were not aware of their HIV status, suggesting that there is a need to improve service delivery and develop innovative prevention strategies for this high-risk group.

Recent tightening of French laws surrounding sex workers has strengthened discriminatory measures and has made their working conditions considerably worse (7), which ultimately increases their risk of HIV infection. Fear and the arbitrary nature of arrests have pushed sex work to the outskirts of cities, far from the public eye. The consequences of this have been disastrous. In addition to increased physical and verbal abuse by clients and ever more frequent harassment and abuse by police, clandestine practices have increased, negotiation over condom use has become more difficult, and sex workers are paid less, stigmatized more and pushed further away from public health care and social services. Consequently, their social and health situation has become significantly worse. The increasingly clandestine nature of the profession has made the work of community-based health care and prevention organizations even more difficult. The National AIDS Council confirmed that the loss of contact between these organizations and sex workers leads to reduced education and relaxed vigilance regarding the risk of HIV and STIs. By virtue of their legal status, foreign sex workers are particular targets of discriminatory measures. When arrested, they are often deported, despite at times holding a valid residence permit. HIV-positive sex workers are also subject to discriminatory treatment, particularly regarding access to health care in custody (7).

The French national programme established the maintenance and adaptation to the current context of the existing programmes for HIV/AIDS prevention for sex workers, which are mostly community-initiated. Specific actions included the improvement of access to prevention and care, the integration of a health component in programmes targeting sex workers, and the development of monitoring of the health status of sex workers (6).

In 2006, Act Up-Paris, AIDES and Solidarité SIDA produced a report on the assessment of France's 2001 commitments regarding the United Nations General Assembly Special Session on HIV/AIDS (UNGASS), which stated that "the 2003 law encourages discriminatory practices against sex workers, a group especially vulnerable to HIV/AIDS. This legally sanctioned and heightened discrimination reduces their access to prevention and care. The law's measures also lead to repeated violations of their human rights and fundamental freedoms, and they keep vulnerable people away from education and prevention programs, thus increasing the risk of exposure to the disease" (7).

In France, more than 20% of HIV cases are among non-nationals. The VESPA survey and reporting data (13) indicate that non-nationals are more frequently affected by diagnostic delay, mainly among men, that there are cultural constraints which prevent condom use, and, in addition to therapeutic measures, social care should also be improved. In July 2004, an HIV programme for migrants was set in motion, aiming to improve access to testing, decrease the diagnostic delay, decrease rates of transmission within the migrant population, and to assure and improve the quality of care within these groups (14).

However, in the 2006 UNGASS shadow report, NGOs commented that "Contrary to its commitment, not only has France not taken any measures since 2001 to protect the health of foreign/migrant populations on its soil, but it has adopted a series of measures that are directly harmful to their health, particularly with respect to health care access and residence rights. As several studies have shown, ill foreigners/migrants come up against arbitrary, dysfunctional

prefectures and medical officers who put them in inextricable situations harmful to their health.” (7) A new and somewhat stricter immigration policy was communicated by the Council of Ministers in June 2007, according to which migration will be even more controlled; co-development policies with the countries of origin will be promoted; integration of the immigrants in the national community will be encouraged; and national identity will be promoted (15). It is unclear what impact this will have on HIV/AIDS.

## **6. Gender equity**

In 2005, women represented 42% of new HIV cases but 58% of new cases with heterosexual transmission. In 2001, France made a commitment to ensuring programmes providing wider access to female condoms; however, access remains limited, largely due to the high cost of female condoms (6).

## **7. Prevention of mother-to-child transmission and paediatric AIDS**

Between 2003 and 2005, 116 cases of mother-to-child transmission of HIV were reported in France. In 2005, these made up 0.6% of all reported HIV cases (16). Policies now propose that all pregnant women undergo voluntary testing for HIV.

## **8. Young people**

A proposal to install condom machines in French high schools was initially made in June 1992 by the Education Minister, but today condom machines have been set up in only about half of high schools and vocational schools (17). A 2003 decree on sexual education in schools defines the obligation to provide clear information (tailored to each age group) on sexuality, contraception and STIs, including HIV.

## **9. HIV in the workplace**

In France, labour law addresses the right to equity for ill and handicapped people, and, although no specific mention to HIV/AIDS is made in the labour code, it is considered under the same principles as other diseases. Despite these laws, the VESPA-ANRS survey showed that the risk of being unemployed was five times higher among people living with HIV than the general population. Additionally, more than two-thirds of the respondents who had lost their jobs after announcing their HIV status wished to start working again. The national programme recognizes the necessity of preventing discrimination against people living with HIV at the moment of hiring, as well as at all other stages in the working contract (6). The Haute Autorité de Lutte contre les Discriminations et pour l'Égalité has recently produced a guide on the prevention of discrimination on hiring (18). Les Chroniques Associés, the French coalition of people affected by chronic long-term illnesses (including HIV/AIDS, multiple sclerosis, cystic fibrosis and cancer), advocates for specific improvements in French laws and practices on the integration of people with disabilities in the workplace (19).

## **10. Sexually transmitted infections**

The legal recognition of the necessity to coordinate efforts between the responses to both STIs and HIV/AIDS has resulted in the inclusion of STIs in the 2005–2008 French programme for the response to HIV/AIDS (6).

From 2001 to 2005, there was a resurgence of gonorrhoea infections, particularly in men. Syphilis cases peaked in 2003, mainly among MSM (83% of cases from 2000 to 2005), and decreased thereafter. Reported Chlamydia cases have also increased in France, primarily among young people. Moreover, an estimated 0.7% of the general population was chronically infected by hepatitis B, with sexual transmission accounting for 40% of new cases since the implementation of mandatory reporting in 2003 (20).

In 2003, 79.63 million male condoms were sold and 3.79 million distributed for free (6).

### **11. Research and new technologies**

In 2006, the budget for the National Agency for Research on AIDS and Viral Hepatitis (ANRS) was €44 million, of which 20% was devoted to fundamental research, 9% to vaccine research, 31% for clinical and therapeutic research, and 3.5% for research on public health and human and social sciences (6).

The ANRS has made finding a preventive vaccine against HIV one of its priorities, devoting one-fifth of its budget to the project. In ten years, the ANRS has launched an impressive 16 vaccine trials in France. Research into the adverse effects of antiretroviral drugs – particularly once they are on the market – and into ways of remedying these effects, is insufficient, despite the ANRS' commitment and some change in attitude on the part of drug regulatory agencies for the better (AFSSAPS for France and EMEA for Europe). The main problem remains the pharmaceutical companies' inadequate commitment in this area.

Operational research facilitating the set-up and/or assessment of interventions and programmes aimed at prevention or support for people living with HIV is not sufficiently developed. The small number of studies of this type at ANRS is evidence of this.

There are currently 60 microbicides compounds under development in France, with four of these in phase III trials (large-scale efficacy trials on an at-risk population).

## **C. Living with HIV and AIDS**

### **12. Treatment and care**

Between 1992 and 2002, 88 908 people living with HIV were seen for care, of which 40 000 were seen in 2002, highlighting a growth in treatment. Eighty per cent of patients received ART (70% under HAART), 60% had a viral load under 500 copies/ml, and 5% had a CD4 count under 200/ml or a viral load over 30 000/ml (6). National guidelines for the medical care of people living with HIV have been produced since 1990 and updated every two years by an interdisciplinary group of experts that systematically includes several NGO delegates.

### **13. Stigma, discrimination and human rights**

The current national HIV/AIDS programme sets the specific target of reinforcing the role of people living with HIV as actors and partners of the health care system as an initiative to combat stigma (6). The Haute Autorité de Lutte contre les Discriminations et pour l'Égalité has produced a number of deliberations and documents addressing discrimination against people living with HIV and establishing good practice recommendations for the general population and for employers (18).

### **14. Testing and counselling**

Voluntary counselling and testing is available for the general population at centres for anonymous and free screening (CDAGs). In the event of a positive test result, the centres have the capacity to offer counselling and provide referrals for specialized health care. The 273 CDAGs conducted 313 325 HIV tests in 2005, showing an increasing trend since 2002 (251 857 tests). In 2005, CDAG tests accounted for 8% of all HIV tests conducted in the country. The estimated number of HIV tests in laboratories increased from 4.3 million in 2001 to 5.3 million in 2005, and the proportion of positive tests has stabilized, both in CDAGs and laboratories (21).

People seeking HIV testing at CDAGs are more frequently young, male, and consider themselves to be at higher risk than the general population (22).

In 2004, 7.9% of the population were tested for HIV in France (16), a comparatively high level for Europe. The support expressed in November 2007 by the French Ministry of Health for the introduction of rapid HIV tests should enable the development of more user-friendly testing services, better able to reach most-at-risk populations such as MSM and people originating from sub-Saharan Africa (23).

## 15. HIV in prisons

There are no needle exchange programmes in French prisons, where the prevalence rate of HIV is four to six times higher than the general population and 30% of inmates are IDUs. Harm-reduction strategies that have been in wide use since the mid-1980s must be introduced into prisons imminently to control this highly localized HIV epidemic. Currently, drugs are more easily found in prison than clean injection equipment (5). In 2004, the national methodological guide for prisoners' health care recommended the distribution of condoms and bleach, accompanied by information on risk reduction (24). However, the guide neglects to refer specifically to syringe exchange programmes. The 2006 UNGASS NGO shadow report stated that France continues to support a repressive and archaic approach towards inmate health. These policies are directly perpetuating health issues among prisoners, who are at extremely high risk from HIV/AIDS (7).

## D. Overall progress and challenges for the future

With the mandatory reporting of HIV in place since 2003, it should now be easier to monitor this aspect of the HIV/AIDS epidemic. Immediate key issues include prevention among MSM and migrants, including improved access to treatment for the latter group. France has a tradition of taking a leading role on HIV/AIDS issues, both through its ambassadors and international funding. Maintaining this during the French Presidency of the EU during the second half of 2008 and in future is another challenge.

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## Country report – Germany

Population: 82 689 000

### **Epidemiological summary and surveillance (1–3)**

By the end of 2006 there were an estimated 56 000 people living with HIV (PLHIV) in Germany, and approximately 82 000 are estimated to have become infected since the beginning of the epidemic. A total of 32 500 cases of AIDS have been diagnosed, with approximately 26 000 fatalities. It is estimated that in 2006 about 1200 new AIDS cases occurred and the number of deaths among AIDS cases in 2006 was about 600.

In 2006 alone, the country reported 2638 new HIV cases, the highest reported annual incidence since reporting began in 1993. Each year there are about 10–20 HIV infections in children (17 in 2005), substantially less than 1% of all new infections. In Berlin, one of the five German cities with the highest AIDS prevalence, pregnant women have an HIV prevalence of less than 0.1%.

The increase in new HIV diagnoses is mainly among men who have sex with men (MSM), who comprise 70% of all reported domestic infections, excluding those (7500) diagnosed in migrants from high prevalence regions, who are assumed to have become infected in the region of origin. The HIV diagnosis incidence rate among MSM has been on the rise since 2001. STI rates have also increased in this risk group in recent years. An additional 20% of cases are heterosexually transmitted.

The number of infected injecting drug users (IDUs) decreased in the 1990s, but has since stabilized, and in 2006 they accounted for about 7% of all new infections with known means of transmission. Since the early 1990s, HIV prevalence has decreased among IDUs entering drug treatment centres. As in other western European countries, prevalence among non-IDU sex workers (SW) is similar to that found in the general population.

HIV prevalence is low in the general population, particularly outside metropolitan areas. Blood transfusion testing is mandatory by law. HIV testing is systematic among blood donors and recommended for pregnant women, who have an estimated coverage rate of 50–80%. Laboratories (since 1987) anonymously report newly diagnosed HIV cases to a national database. Since 1993, HIV laboratory reports have differentiated between newly diagnosed and previously diagnosed patients. Since 1998, the laboratory reports were complemented by clinician reports (a copy of the laboratory report is sent to the clinician, who completes data which are unavailable to the laboratory) which are available for more than 90% of the new cases and contain a name-based code to allow detection of duplicate reports.

Highly active antiretroviral treatment (HAART) is universally available in Germany. In June 2006 there were an estimated 26 600 people receiving HAART, equivalent to 66% of all PLHIV (40 000) who are estimated to be aware of their diagnosis, or equivalent to 75% of all PLHIV (35 000) who are estimated to be under regular medical follow-up.

At the national level, the Robert Koch Institute is responsible for surveillance in Germany, while, at the regional level, Germany cooperates with the European Centre for the Epidemiological Monitoring of AIDS (EuroHIV) and the European Centre for Disease Control (ECDC) “in continuing and further developing the Europe-wide HIV-surveillance system and will support other countries in building national surveillance systems with the emphasis on the monitoring of especially vulnerable groups” (4).

## **A. Leadership and Partnership**

### **1. Political leadership (national framework)**

Germany has formalized and adopted the National Strategy to Combat HIV/AIDS in July 2005. The strategy includes internationally recommended instruments and follows on the obligations taken over by signing the Dulin and the Vilnius declarations.<sup>69</sup> Germany's HIV strategy has a global, regional and national focus and involves all government sectors, also immigration. The strategy recognizes that all levels of society must take responsibility for implementing HIV programmes. The strategy, which was endorsed by civil society, promotes interaction among the government, PLHIV and the private sector and outlines the current activities, challenges and goals of the government related to seven key elements in the fight against HIV:

- education and prevention for the general public
- universal access to testing and therapy
- solidarity and the prevention of discrimination
- coordination and cooperation in national and international activities
- surveillance of the epidemic
- strengthening research
- continuing evaluation of achievements.

The strategy addresses the most important areas of prevention, including voluntary counselling and testing (VCT) and condom promotion and distribution. It protects the main target populations, encourages and supports the involvement of PLHIV and recognizes the strong connection between poverty reduction and the fight against HIV (5). In the country progress report (4) from December 2005, Germany's National Strategy was rated 10 on a scale of 10, up from 6 in 2003. A recent increase in HIV incidence has led to new approaches toward the epidemic. All measures are being taken in close cooperation with civil society (4).

Since the 1980s, the main advisory body for the German government on HIV has been the National AIDS Council (der nationale AIDS-Beirat). Since 2005, an interministerial committee coordinates the response to HIV and AIDS of the Federal Government. The Federal Government has the responsibility for the statutory social security system including health care for the general population. The Federal Centre for Health Education (Bundeszentrale für gesundheitliche Aufklärung, BzGA) is responsible for prevention and information campaigns among the general population, The States have the responsibility for health issues such as health education in schools, local health authorities, prison health care and health care for asylum seekers. The Federal government and the States meet regularly in the Federal Centre for Health Education to exchange experiences. In spite of the clear distinction of responsibilities and some divergence in the approach e.g. to prison health there is consensus between the States and the Federal Government on the continued importance of the response to HIV/AIDS (4).

Germany co-operates closely with relevant UN agencies, such as the UNAIDS and WHO, with the Global Fund to Fight AIDS, Tuberculosis and Malaria (GFATM) and the EU, within the framework of the G8 negotiations, as well as with the civil society.

## **2. Community involvement and the private sector**

German civil society is actively involved in the prevention of HIV in vulnerable groups, the care and support of PLHIV and in advocacy. For example, the Association of AIDS Self Help Groups (*Deutsche AIDS-Hilfe*) is responsible for the coordination of HIV-related service delivery by civil society organizations (6).

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<sup>69</sup> The *Vilnius declaration on measures to strengthen responses to HIV/AIDS in the European Union and in neighbouring countries* was signed by health ministers in support of the Dublin Declaration, with the aim to coordinate activities among member states to avoid duplication of work.

### 3. Resource generation

Germany is a donor country and is committed to the UN Millennium Goal to halt and begin to reverse the spread of HIV by the year 2015. Public resources for the fiscal year 2005 are outlined in Table 1 (4).

**Table 1. Public resources for the fiscal year 2005**

Federal Ministry for Development and Cooperation	Bilateral and multilateral development cooperation	About €300 million
Ministry of Health	Awareness, research and development, surveillance	€12.6 million
Ministry of Education and Research	HIV research in the Competence Network for HIV/AIDS and HIV/AIDS-related projects in different funding programmes)	€9.2 million

Bilateral and multilateral activities of the Federal Ministry for Development Cooperation include contributions to the GFATM, support for the European Union's AIDS response, World Bank programmes and extra budgetary contributions to WHO, UNAIDS other international agencies. At the state level there is around €11.5 million available per year. Support from private industry (mainly insurance and advertising companies) amounts to around €15 million (4).

### B. Prevention

Germany has implemented a comprehensive strategy based on prevention and non-discrimination since 1987, and PLHIV and vulnerable populations (MSM, SW and IDUs) have been included in the governmental HIV-policy design and programme implementation. The Federal Centre for Health Education is responsible for providing information on the modes of transmission, prevention, education and communication (IEC) on HIV to the general public. The Centre develops radio and TV ads for public and private broadcasting and has implemented the largest national HIV prevention campaign "Don't give AIDS a chance" (*Gib AIDS keine Chance*). Seventy-five per cent of the over 16-year-old population have been reached by the colourful posters and condom slogans of the "*mach's mit*" campaign, while 69% have seen one or more TV spots (4). The media are permanent partners in national, regional and local HIV-prevention efforts. Knowledge of the most important modes of HIV transmission and how to protect against infection is practically universal.

### 4. Injecting drug use and HIV

IDU transmission makes up about 7% of new domestic infections. Sterile needles and syringes are freely available from pharmacies and substitution therapy is an important part of prevention activities for IDUs. The number of new HIV infections through injecting drug use has remained stable with about 150–200 new cases per year, but HIV infections have increased among IDUs from eastern Europe, who are not well reached by prevention and assistance services (4). IDUs have the least favourable clinical ART outcomes in Germany. Targeted treatment and support programmes for this patient group need to be improved (4).

According to the 1981 provision on "therapy instead of punishment" for IDUs (sections 35 to 38), the public prosecutor may postpone the completion of a prison sentence, provided that the convict undergoes treatment. A treatment period of a maximum two years can be deducted from

the prison sentence upon completion (7). Imprisoned drug users do not have access to clean needles and syringes, except for one prison in Berlin.

## **5. Most vulnerable and high-risk populations**

Germany has a strategy to provide IEC among IDUs and other vulnerable populations, such as MSM, SW, prisoners, immigrants and refugees (4). MSM account for 70% of new infections, and prevalence in this group is increasing due to reduced mortality and higher incidence. Knowledge and behaviour indicators in MSM are monitored by repeated behavioural surveillance questionnaire studies (8). The latest was conducted in 2003 and included questionnaires distributed in community settings and GP clinics. An internet survey by the Robert Koch Institute with 6569 responses via several gay portals revealed that knowledge of HIV transmission is practically universal, but the findings highlight changes in sexual behaviour and motives among MSM since 1996, including increasing numbers of sexual partners, revival of unprotected anal intercourse, HIV sero-sorting and HIV sero-positioning (8). This is confirmed by another internet-based survey, *SexCheck 2006*, conducted by the largest gay dating portal Gay Romeo with over 45 000 responses. Fifty-three per cent of respondents reported having had between two and five HIV tests (9). There has thus been a shift from risk-avoidance, which was the main motive in sexual behaviour in the 1980s and 1990s, to a strategy of risk-reduction. However, prevention strategies must take these changes into consideration, through the introduction of a system of second-generation surveillance, for example (9). The government is aware of the rising HIV incidence among MSM. A new prevention campaign for MSM to address these new behavioural patterns is currently in the pre-testing phase.

Immigrants from high-prevalence countries have much less general knowledge about HIV than native Germans. HIV is more stigmatized in this group and they are more difficult to reach for prevention efforts because of cultural and language barriers. Asylum seekers are entitled to HIV therapy, if this is necessary for their health according to the asylum law (4).

Heterosexual transmission of HIV plays a limited role in Germany. Most heterosexual infections occur in relationships in which one of the partners is from a high-risk group, such as bisexual men, IDUs or persons from high-prevalence areas.

## **6. Gender equity**

The German health care system guarantees equal access to prevention and care for men and women. The non-governmental AIDS service organizations particularly aim at ensuring equal access to prevention and care (4).

## **7. PMTCT and paediatric AIDS**

Mother-to-child transmission of HIV makes up less than 1% of total infections. However, the number of infections found in children born to HIV-infected mothers is about 7%, which is much higher than the WHO/UNAIDS goal of eradicating MTCT. This is mainly because HIV testing is not routinely offered to all pregnant women during antenatal care. Therefore, a new guideline was included in the maternity guidelines in 2008 which obliges doctors to offer an HIV test to every pregnant woman. The offer must be noted in the maternity “passport” which every pregnant woman receives in antenatal care. The number of HIV-infected women receiving prophylaxis treatment during pregnancy is estimated to be about 80% (200 out of 250) (4). In 2005, the number of children under 15 years old infected with HIV was 23, of which 17 cases were MTCT, 5 were unknown and 1 was infected through heterosexual intercourse (4).

## **8. Young people**

HIV is part of the curriculum in secondary schools. About 90% of all pupils are made aware of HIV through awareness campaigns in schools. Information is distributed for both boys and girls, differing as necessary. The material aims “to encourage self confidence, consideration, communication and respect for the partner” (4).

### **9. HIV at the workplace**

Germany has a strategy/action framework for addressing HIV issues among its uniformed services, military, peacekeepers and police, including HIV prevention, care and support, voluntary counselling and testing and of equal treatment for soldiers living with HIV and AIDS.

### **10. Sexually transmitted infections**

The number of STIs among MSM has increased substantially since 2001. Syphilis cases among men, for example, increased from 1378 to 3016 between 2001 and 2004, while the number of cases among women has remained stable around 300 per year (4). However, STI rates in the general population remain low compared to international figures.

### **11. Research and new technologies**

The German Action Plan for Implementing the Strategy of the Federal Government to Fight HIV/AIDS outlines the current budgeting for HIV-related research in Germany. According to this the Federal Ministry of Health has roughly €1.6 million per year available for HIV-related research and development projects. The Federal Ministry of Education and Research currently supports projects in HIV/AIDS research with approximately €25 million. Additionally, institutional funding is provided.

The Competence Network for HIV/AIDS is a national research system providing a platform for cooperation and scientific exchange between relevant stakeholders including clinical and basic researchers, practitioners and patients. Based on a patient cohort of more than 8000 well documented patients from over 25 clinical sites and private practitioners, the network provides a basis for biomedical, clinical and socio-scientific research in Germany and at the international level. The network has been funded by the Ministry of Education and Research since 2002 and will receive a total of €18.5 million by 2010.

Germany supports the European Art. 169 initiative European and Developing Countries Clinical Trials Partnership (EDCTP) and provides national co-funding.

Germany has budgeted €1 million for the International Partnership on Microbicides in 2007–2008.

## **C. Living with HIV and AIDS**

### **12. Treatment and care**

All treatment and care activities have been implemented for many years and about 90% of the German population (about 72 million people) are covered by statutory health insurance schemes (4). PLHIV receive HAART through their health insurance and have access to counselling and care by qualified medical doctors. The publicly-funded Association of AIDS Self Help Groups and its regional sub-divisions offer psychosocial care for PLHIV, including centres for drug users and opioid substitution therapy programmes.

The estimated number of people on HAART in June 2006 was 26 600, or 48% of PLHIV in Germany. Difficulties of access to HIV prevention and care are mainly found among, IDUs, immigrants and asylum seekers.

### **13. Stigma, discrimination and human rights**

Article 3 of the German constitution guarantees non-discrimination. The promotion and protection of human rights is a cornerstone of the German response to the epidemic and is one of the central aims of the national HIV prevention strategy. Germany has laws and regulations that protect PLHIV from discrimination, though without mentioning HIV risk groups specifically.

HIV generally carries low stigma in Germany and 71% of the general population over the age of 16 reported that they were willing to help people living with HIV and AIDS in 2004. The information and prevention campaigns in the 1980s and 1990s focusing on creating a climate of non-discrimination have likely contributed to the development of solidarity with PLHIV.

### **14. Testing and counselling**

Every person living in Germany has the right to voluntary counselling and testing (VCT). VCT is usually free of charge at the local health office and from GPs when there is an indication of infection. At GP medical practices a fee of €25 for HIV testing may be charged, and testing procedures may vary slightly from state to state. Every test involves both pre- and post-test counselling.

### **15. HIV in prisons**

Needle and syringe exchange depends on the jurisdiction of the States. In most States it is not accepted. Needle exchange trials were conducted in two prisons in Berlin in 2005 (10), reducing the level of needle sharing from 71% to 11% during the first four months of follow-up and to virtually zero after that. Further trials of needle and syringe exchange programmes were also conducted in Lower Saxony (Vechta) and Hamburg. The experiences did not proceed to an institutional programme.

## **D. Overall progress and main challenges for the future**

Germany has for many years responded comprehensively to the HIV epidemic, with strong cooperation between the government and civil society organizations. HIV carries low stigma, the general population shows practically universal knowledge about HIV and the media provide independent and broad coverage. The main challenges in the German HIV response concern:

- gaps in research and detailed knowledge of HIV infection
- increasing risky sexual practices, especially among MSM
- increasing STI rates among MSM
- poor response to clinical treatment programmes on the part of IDUs
- lack of needle exchange programmes in prisons
- cultural and language barriers with respect to non-German immigrants.

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## Country report – Moldova

Pop. 3 595 187 (4.2 million including Transnistria)

### **Epidemiological summary and surveillance (1–3)**

By the end of 2006, a cumulative total of 3400 HIV cases – including 873 cases in Transnistria – had been reported in Moldova. Of these, 314 had developed AIDS, including 127 who died. For 2006, 618 new HIV cases were reported, including 260 cases in Transnistria. A total of 94 AIDS cases and 21 AIDS deaths were also reported for the year. The majority of HIV cases are concentrated in the districts of Balti and Chisinau (the capital), followed by Transnistria.

After initial rapid growth in HIV incidence in 1997–1998, the reported annual rates of new cases in the country stabilized at around 40–50 per million population, but then increased sharply to 85 and 127 new cases per million in 2004 and 2005, respectively. Despite the recent increase in new HIV cases, the UNAIDS estimate of the HIV prevalence of 1.1% (0.6%–2.6%) in 2005 is likely to be an overestimate. 2007 UNAIDS estimates indicate that 8814 adults and 51 children are living with HIV in Moldova (0.21%) (4).

In 2000, 82% of the cases with documented transmission routes were associated with injecting drug use and 17% with heterosexual sex. In 2007, however, heterosexual transmission was reported to comprise 63.2% of new cases versus 36.2% due to injecting drug use. The HIV prevalence rate in pregnant women was 0.21% in 2006 and 0.23% in 2007 (4).

There are some 19 harm reduction programmes across the country, chiefly needle exchange and condom distribution services. Opioid substitution therapy (OST) with methadone started in September 2004, when 14 people (including 2 HIV-positive individuals) enrolled in treatment for half a year to tally up to 99 injecting drug users (IDU) as of 30 June 2007, including 44 from the prisons, 54 in Chisinau and 1 at the recently opened OST site in Balti. There is no consistent monitoring of how many IDUs living with HIV are still injecting drugs. Excluding Transnistria, there were 36 live births in HIV-positive pregnant women in 2007, and one child was diagnosed with HIV (MTCT rate 2.77%) (5).

During 2006, 121 new people started receiving HAART in the country's three treatment facilities. During 2007, 73 pregnant women were provided with antiretroviral prophylaxis. By 1 January 2008, 527 adults and 20 children had received HAART in Moldova (464 still adhering to the treatment), to which can be added another 80 patients at the outpatient clinic in Tiraspol, which opened in August 2007.

The network of the centres for preventive medicine located in all administrative territories is responsible for surveillance of HIV, and the National Centre for AIDS Prevention and Control is the main HIV surveillance agency.

## **A. Leadership and partnership**

### **1. Political leadership (national framework)**

The first legal framework for controlling the HIV epidemic in Moldova was provided by the “Law on the prevention of AIDS,” adopted in March 1993. The legislation and the resulting system of epidemic control had firm roots in the former Soviet Union, where infectious disease control was part of a wider scheme of population control that often included draconian measures.

A 2003 assessment of the law found it to be coercive in nature, as it included involuntary mandatory testing and the treatment of high-risk population groups (6).

The Ministry of Health and Social Protection initiated drafting of new legislation, consulting with civil society in order to ensure ownership, adequate response and efficiency. The “Law of the Republic of Moldova on prevention and control of HIV/AIDS” was implemented in October 2005. In the summer of 2006, the new AIDS law was passed in its first reading by the Parliament subject to further amendments and debates.

The country’s National Strategic Programme on Prevention and Control of HIV/AIDS and STIs 2006–2010 (the National Programme) includes the following elements:

- a national interdepartmental, multisectoral system to coordinate activities of state and non-governmental institutions in the control and prevention of HIV-related disease and STIs;
- information, education and communication (IEC) activities for the general public, youth and vulnerable groups;
- an epidemiological surveillance system with second generation elements (behavioural surveillance);
- expansion of prevention activities among vulnerable groups to consolidate NGO and state efforts;
- medical assistance capacities, social and palliative care of people living with HIV, their families and children affected by HIV;
- voluntary counselling and testing services in state medical institutions and youth-friendly health services;
- prevention of HIV and STI transmission from mother to child;
- integrated provision of blood transfusions, medical interventions and other kinds and prevention of nosocomial spread of HIV infection and syphilis and
- prevention, diagnosis, treatment and care for people coinfecting with HIV and TB, including in penitentiaries (5).

The National Coordination Council (NCC), at the vice-ministerial level, is the highest authority for dealing with HIV. NGOs, people living with HIV (PLHIV) and international development agencies are part of the NCC as well. The NCC’s activity is regulated through a government order, and its secretariat is headed by the Government Counsellor on Social Issues and is responsible for organizing, advocating and documenting the decision-making process (8). As many as seven technical working groups on HIV operate under the NCC.

## **2. Community involvement**

Civil society participation in the response to HIV/AIDS has been institutionalized through the establishment of several coordination mechanisms such as a harm reduction network and a network of NGOs working in HIV-related fields, including the League of PLHIV organizations established in the summer of 2007 (9). The law on HIV requires promoting greater involvement of PLHIV in the relevant information, education and communication activities.

A range of NGOs (including the Open Society Institute, American International Health Alliance and local NGOs), United Nations agencies and programmes (WHO, UNICEF, UNAIDS, UNFPA, UNDP etc.) as well as the Global Fund for AIDS, Tuberculosis and Malaria (GFATM) work alongside the government in mobilizing communities and supporting people living with HIV. For example, ‘Credinta’ [*Belief*], a nongovernmental organization of people living with HIV, is an active partner for treatment advocacy and facilitating access of people living with HIV/AIDS to care and support services (3).

## **3. Resource generation**

In addition to just over 52 million lei (US \$4.1 million) in government funds for the National AIDS Program (NAP) 2006–2010 (accounting for 26.8% of the overall budget), the HIV programme is supported by international donors. The country submitted a successful Round 1 proposal for US \$11.7 million to the GFATM to respond to the HIV/TB epidemic. Among the main objectives of the programme are strengthening treatment, care and support for PLHIV and scaling up programmes, including those to prevent STIs, targeting vulnerable groups. As of March 2007, US \$10.4 million had been disbursed for implementation of activities. Moldova was granted category I for its HIV/AIDS component of GFATM Round 6 application, worth slightly over US \$15.9 million, including US \$6.4 million for phase 1, to cover the country's HIV-related needs beyond 2008.

Some funds are also committed by United Nations agencies and bilateral partners such as the Swedish International Development Cooperation Agency (3). The World Bank AIDS Control Project for Moldova 2003–2008 finances the AIDS component of the TB/AIDS programme, which aims at assisting the country in achieving its health-related Millennium Development Goals by reducing mortality, morbidity and transmission of HIV and other STIs and TB. This programme is one of the key pieces of the government's poverty-reduction strategy in the health sector. The total budget is US \$5.7 million (8).

## **B. Prevention**

### **4. Injecting drug use and HIV**

Results from behavioural sentinel surveillance among IDUs showed an HIV prevalence of 22.6% in 2004 and 21% in 2007 (4). The previously mentioned 2003 analysis of Moldovan legislation noted that a large emphasis on coercive strategies in HIV testing and treatment for IDUs and close ties with law enforcement were undesirable and counter-productive from the perspective of public health, particularly regarding the control of HIV infection. Most IDUs are well aware of the close connections between treatment, mandatory HIV testing and the police, and for that reason, most tried to avoid contacts with testing facilities or drug treatment (6). The 2005 HIV law emphasizes that testing and counselling of IDUs should be done on a voluntary and confidential basis. As a result of new legalization providing for needle exchange and opiate substitution treatment both inside and outside prisons, there has been an increase in the number of people covered (9). In 2004 an estimated 14.5% of IDUs were reached by prevention programmes and 22% in 2005 (10). As of 30 June 2007, authorities reported that 99 IDUs had received substitution treatment with methadone and more than 11000 had benefited from needle exchange programmes by the end of 2006 (11).

### **5. Most vulnerable and high-risk populations**

Behavioural sentinel surveillance studies estimated an 8.5% HIV prevalence among sex workers (SWs) and 2.5% among men who have sex with men (MSM) in 2004, to reach 11% and 4.8% respectively, by 2007 (1). Many prevention activities have taken place among these high-risk groups in recent years and studies show that 14% of SWs and 638 MSM (denominator unknown) were reached by prevention programmes in 2005 (10).

Official data suggest that less than 1% of registered HIV cases are associated with MSM, but this is due to structural underreporting of homosexuality, which is highly stigmatized. In contrast, information from the Moldovan NGO GenderDoc-M suggests that many gay men have multiple partners, while few use condoms. Like other former Soviet states, Moldova inherited repressive legislation pertaining to sexual minorities. In 1995, the country repealed Article 106 of its penal code, which punished consensual, adult homosexual behaviour with 2–5 years of imprisonment.

Though the situation seems to be improving, most sexual minorities are still “in the closet” and fear of beatings, police abuse or simply being recognized results in hurried anonymous sexual encounters with little room for negotiating safer sex (4).

Authorities reported that 25 out of 1000 PLHIV seen for care in 2005 were non-nationals, but there is no available data on the HIV prevalence among immigrants in the country, yet IOM findings show 1.7% HIV prevalence in trafficked people from Moldova (12). However, the law on HIV includes an article on prevention activities mandating prevention programmes for immigrants, asylum seekers and seasonal workers. The institution of prevention programmes for refugees is to be organized by the Refugee Division.

## **6. Gender equity**

The Moldovan law on HIV stipulates that the Government and specialized ministries shall design and implement policies and strategies promoting gender equality in all social spheres, including education, employment, economic opportunities and social assistance, rehabilitation and assistance programmes for victims of domestic and sexual violence. For the purpose of public health, HIV-positive women shall be entitled to contraception free of charge, including voluntary sterilization based on informed consent subsequent to thorough counselling.

## **7. PMTCT and paediatric AIDS**

The law on HIV includes an article on the prevention of mother-to-child transmission (PMTCT), stipulating that all pregnant women shall have access to free voluntary counselling and testing, HIV-positive women and their children shall have full access to free-of-charge ARV treatment, and all children born to HIV-positive mothers shall be provided with artificial milk formula. In 2004, 31 pregnant women benefited from ARV treatment to prevent MTCT and in 2005, 62 pregnant women from all over the country were treated, with the same trends being reported again in 2006: 62 women and 63 children born to them, and 2007: 73 more women, totalling 245 by January 2008 (4,10).

## **8. Young people**

A 2005 study among 1205 people aged 15–50 showed that 28.8% reported to have had sex before the age of 15. Another study the same year showed a low level of knowledge of the modes of HIV transmission and an underestimation of the risk: only 28.3% of 15–24 years old respondents could both correctly identify ways of preventing the sexual transmission of HIV and reject major misconceptions about it. The level of knowledge of HIV prevention is especially low within the rural population and women (10).

The National Programme stipulates that by 2010 a mandatory life-skills course should train over 560 000 children and adolescents and youth annually, and include a component on HIV prevention, but the sexual education component was reduced to optional status. The Strategic Framework for Communication on HIV/AIDS/STI for 2005–2010 should contribute to coordinated communication, education and information campaigns among the general population, youth and vulnerable groups to encourage behavioural change (7). In 2007, Moldovan authorities reported that 465 000 school children had received at least some HIV/AIDS/STI education (10, 11).

## **9. HIV in the workplace**

The 1993 Law on AIDS Prevention prohibits employment discrimination based on HIV status. The Labour Code, adopted in 2003, prohibits discrimination based on any grounds not connected to the qualifications of the worker. This provision could be interpreted as prohibiting discrimination based on HIV status. The Labour Code is also intended to protect the

confidentiality of medical data by prohibiting employers from requesting information on the state of health of employees that does not concern their capacity to execute their labour responsibilities. According to the International Labour Organization (ILO), HIV in the workplace is a new issue in Moldova, and understanding of its implications is limited. Therefore, the ILO works to achieve the following, for example: greater awareness of HIV as a workplace issue on the part of political leaders and leaders of employers' and workers' organizations and a reform of labour laws to address HIV-related discrimination (13).

The National Programme includes an article stating that the Ministry of Defence, Ministry of Interior and Border Guard Troops Department should develop efficient HIV prevention programmes by promoting safe behaviours, developing minimal knowledge standards and incorporating such awareness and prevention programmes in the regular training of military personnel at all levels in armed forces, and other police or protection forces.

### **10. Sexually transmitted infections**

The official statistical data noted a decrease in the incidence of syphilis (mandatory reporting) since 1996 but an increase in gonorrhoea since 2002. The government does recognize the linkage between STIs and the increased risk of HIV infection subsequent to an unprotected sexual contact (10).

### **11. Research and new technologies**

In 2004, UNICEF conducted a National Baseline Evaluation of Knowledge, Attitudes and Practices of Young People in Relation to their Health and Development study); in 2006 the World Bank and Global Fund to Fight AIDS, Tuberculosis and Malaria conducted a follow-up survey primarily focusing on HIV/AIDS mostly. Moreover, UNICEF has further studies on most-at-risk adolescents and HIV/AIDS in the works.

Considering that almost one-third of the country's population of working age is travelling in and out of the country, the International Organization of Migration conducted the study "The Health Risks of Migration: The Link Between Health and Migration with particular consideration of Knowledge and Attitudes towards HIV/AIDS/STIs and Sexual Practices of Moldovan Migrants".

Moldova's first Demographic and Health Survey (2005) indicate that the total fertility rate in Moldova is 1.7, and most men and women want small families; that knowledge of contraception is nearly universal, with 99% of all women ages 15 to 49 aware of at least one modern method of family planning; 68% of currently married women use a family planning method to delay or prevent pregnancy; and public or government facilities provide contraceptives to more than two-thirds of contraceptive users.

A second generation sentinel surveillance and behavioural study in vulnerable groups (men who have sex with men, injecting drug users and sex workers) was started by the Ministry of Health's monitoring and evaluation unit in 2007.

The country just concluded the next UNGASS Progress Report for 2006–2007, outlining the latest trends in the HIV epidemic in Moldova in the general population and the most vulnerable groups (4).

## **C. Living with HIV and AIDS**

### **12. Treatment and care**

The law on HIV stipulates that the state shall ensure universal access of all PLHIV to ART and treatment of opportunistic infections, based on clinical and immunological indications, free of charge. The National Centre for AIDS Prevention and Control estimates that 250 people living with HIV needed ART by the end of 2005. The government declared a target of 150 people living with HIV on ART for the GFATM (3). In 2006, 121 people living with HIV received ART (14), making a total of 390 patients who had received HAART by March 2007, including in prisons and 15 children. There were 464 people in HAART in Moldova as of 1 January 2008 (4).

Access to ART is greatly reduced for patients coming from outside of metropolitan Chisinau because of the long distances, relatively poor knowledge about the availability of free treatment and provisions concerning financial incapacity to pay for additional care (or bed-days, in the case of Transnistria). As of the end of April 2005, there were only 16 patients from Transnistria on ART in Chisinau. Therefore, ART was nearly inaccessible to patients from Transnistria despite a huge need (15). Thanks to donor efforts, eight Transnistrian patients on Combivir were switched to HAART in February 2007. Moreover, a project was initiated for the treatment of another 15 patients in the outpatient department in Tiraspol, Transnistria, in August 2007, tallying up around 80 patients by 2008, with view to expand to the prisons as well.

According to WHO/UNAIDS, the proportion of PLHIV in need of HAART was about 48% in 2006 and 54% in 2007. Men have better access to HAART than women do – 56% vs. 41% in 2006, and 64% vs. 45% in 2007. The access to HAART improved from 45% to 49% for children, and from 48% to 54% for adults, during 2006–2007 (4).

### **13. Stigma, discrimination and human rights**

The former HIV legislation involved mandatory testing of certain sub-populations, including sex workers, IDUs and men who have sex with men. The 2003 analysis pointed to numerous human rights arguments against the involuntary approaches and emphasized that these were in violation of the non-discrimination principle under international human rights law (6). Mandatory testing of high-risk groups became prohibited with the new law on HIV/AIDS in 2005. The current law states that it will regulate the legal situation of people affected by the HIV/AIDS epidemic and guarantee respect for their human rights. However, people living with HIV and those in high-risk groups continue to be subject to extensive stigma and discrimination, which is a major barrier to HIV prevention (3).

### **14. Testing and counselling**

Approximately 227 000 people were tested in 2005, an increase since 2003 that is mainly due to GFATM and World Bank assistance. The locations of HIV laboratories ensure good accessibility to the HIV testing (10). Of 35,761 women carrying their pregnancy to delivery, 34839 (97.42%) were tested for HIV in 2006 (16).

The current law stipulates that all HIV tests shall be carried out with voluntary and informed consent from the individual, expressed in writing. Policies calling for mandatory testing as precondition for employment, travel, access to medical services, and admission to educational institutions were prohibited in 2005. However, exceptions exist in relation to foreigners entering the country, blood donors and those charged with the intentional transmission of HIV.

HIV transmission is criminalized in Moldova and people diagnosed as HIV-positive are informed in writing by the medical institutions of the need to follow the rules for the prevention of HIV transmission, as well as the criminal charges for intentionally infecting others.

The HIV law requires that HIV test results be confidential. However, medical personnel should release test results to the following people when relevant: parents and legal guardians of minors,

the legal guardian of a person with mental disabilities, the head of the public medical institution or judges who have issued court orders. Furthermore, partner notification is mandatory and health care professionals may notify the sexual partners of their HIV patient's status. A new AIDS law was ratified by the Parliament in 2007, amending many of the shortcomings.

Moldova is considered a high priority country for both HIV and TB (17). In 2006, 2.4% of TB patients were co-infected with HIV (11). HIV testing is mandatory for all people with TB when first diagnosed. Opt-out testing and counselling is offered to pregnant women, IDUs and people with STIs. Voluntary counselling and testing is offered to blood recipients six months after a transfusion and to Moldavians returning from abroad. Vulnerable population groups are screened periodically as a part of sentinel surveys (3). Roughly, 23 patients were receiving both ARV and TB treatment in 2007, accounting for about 10% of the needs, according to WHO estimates (4).

A new USAID-funded project started to scale up voluntary testing and counselling facilities all over the country, one in each district, and several in the two largest municipalities, Chisinau and Balti, with the first six pilot sites already selected on epidemiological, resources and geographic grounds and will further be contracted by the National Health Insurance Company starting in 2008, to total 54 voluntary testing and counselling sites by 2009. Negotiations have started to open similar sites in Transnistria.

### **15. HIV in prisons**

The law on HIV prevention stipulates that the Ministry of Justice be responsible for the following prevention interventions and activities in penal institutions: education and information activities for staff and inmates with the purpose of creating competencies and knowledge on HIV/AIDS prevention, safe behaviours, informed consent for HIV testing, harm reduction programmes including bleach and needle exchange and free condom distribution in all prisons and access to free ARV treatment and treatment for opportunistic infections. HAART is available to inmates through the Chisinau HAART Unit.

UNAIDS is considering the NGO prison projects a global best practice. In Moldova these include needle exchange projects, OST with methadone (44 IDUs) and the implementation of the DOTS strategy to control TB (17).

## **D. Overall progress and main challenges for the future**

The technical working groups of the National Coordination Council have developed an analysis of gaps facing stakeholders in 2007 (9), identifying four areas of systemic weakness:

- lack of sustainable funding for the HIV/AIDS response
- lack of human resource and health and social system capacity, and high HR turnover rates;
- low availability of affordable commodities and low-cost technologies; and
- high stigmatization of and discrimination against PLHIV.

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## Country report – Poland

Pop. 38 530 000

### Epidemiological summary and surveillance

By the end of May 2007, Polish authorities had reported a cumulative total of 10 853 HIV cases, of which 1930 of the infected individuals had developed AIDS, including 862 who had died (1). In the cumulative data, 50% of the HIV infections were through injecting drug use (80% of the HIV cases with a known route of transmission) (2,3). About 76% of all HIV cases were male, and 59% older than 25 years of age. In 2006, the authorities reported 754 new HIV cases, among which there were 166 new AIDS cases (3) and 38 AIDS deaths.

The number of new HIV cases peaked in 1990 with 809 registered cases, declined to 384 in 1993, and has increased slowly since. Currently, the most affected regions are Dolnoslaskie in the south-west (bordering the Czech Republic and Germany), with an average annual incidence in 1999–2005 of 35 new HIV infections per million population, and Warminsko-Mazurskie in the north-east (bordering the Kaliningrad district of the Russian Federation), with an annual rate of 22 per million. This compares with an average national HIV incidence rate of 15 per million in 1999–2005 (4).

The first HIV case in Poland was officially diagnosed in 1985 and, at present, the leading known cause of infection is through injecting drug use (IDU). In 2005, 21% of new infections were attributed to IDU, 8% to heterosexual contact and 5% to men who have sex with men (MSM). However, it should be stressed that the transmission route was unknown for 65% of reported cases, thus masking the true face of Poland's HIV epidemic. This figures reaches 85% for some years (4).

Despite the state-guaranteed universal availability of HAART, AIDS incidence continues to rise due to a rapidly increasing number of late-presenting cases (5). Reported AIDS mortality has tended to decrease after 1996, when HAART was introduced, but a comparison with official death statistics indicates extensive under-reporting of AIDS-related deaths (4).

An estimated 5000–5400 people were seen for care in Poland during 2005; of these, 2652 were on HAART by the end of the year (including 1000–1200 IDUs and 133 prisoners). By the end of April 2007, 3109 people were on HAART<sup>70</sup>.

Surveillance of HIV/AIDS in Poland is undertaken by the National Institute of Hygiene. HIV testing is mandatory for blood donors, and all other groups are tested on a voluntary basis<sup>71</sup>. The laboratories confirming an HIV diagnosis report all cases to the national HIV database using personal identifiers. The laboratory-based HIV case surveillance used to be run centrally and still not all cases are reported to the regional public health authorities. However, a new electronic reporting system will be introduced in 2008 to improve the quality of HIV surveillance. In 2005, the mode of transmission was not known for 65% of infections, which hinders accurate estimates of the relative burden of each individual transmission route in the epidemic.

### A. Leadership and partnership

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<sup>70</sup> Grey literature or governments reports: files of the Ministry of Health and the National AIDS Center.

<sup>71</sup> There is a VCT system implemented by the National AIDS Centre; it currently includes 22 sites with 13 000–15 000 clients annually.

## **1. Political leadership (national framework)**

Poland has developed a National Programme for Combating AIDS and Preventing HIV Infections for 2007–2011 (national HIV programme)<sup>72</sup>, which is the main document defining the government’s HIV policy. It includes objectives in the following five areas:

- prevention
- assistance and support for people living with HIV, and their families
- access to diagnostic methods in line with current medical knowledge
- antiretroviral treatment (ART) in line with current medical knowledge
- research, with special consideration of analysis, enabling quick and precise evaluation of the epidemiological situation (6).

The implementation process for the national HIV programme is administered by the Minister of Health and coordinated by the National AIDS Center (6), an agency of the Ministry of Health that acts as a multisectoral country coordination mechanism.

The Polish HIV policy includes the implementation of the “Three Ones” strategy proposed by UNAIDS with support from the European Commission. Following this strategy, a coordination institution has been established, a country-level HIV action plan has been prepared, and epidemiological, medical and prevention monitoring is increasingly being implemented (7).

All actors in the response to HIV/AIDS in Poland are extremely aware of the gravity of the situation in eastern Europe as a whole. There are currently around 50 NGOs working with HIV/AIDS in Poland. Some nongovernmental organizations (NGOs) and governmental bodies are also implementing projects in Belarus, Ukraine or the Russian Federation. (9).

## **2. Community involvement**

The national HIV programme includes community involvement by encouraging the promotion and support of NGOs working in the field of HIV prevention and providing assistance to people living with HIV, providing support for volunteer work, and promoting and supporting the implementation of activities leading to social integration (6).

Over recent years, 59 regional, national and international NGOs have collaborated with the National AIDS Center in providing HIV prevention programmes, including training for outreach workers, an HIV call centre, web counselling and various events (7).

Most NGOs providing direct prevention and support services remain financially dependent on funding from short-term projects. This source of funding is usually provided by the national government (US \$800 000 in 2006), at local authority level and other European or international sources. A noticeable exception is MONAR – an NGO managing both harm-reduction and abstinence-based centres for drug users – which has been able to secure several relatively stable sources of funding (9).

The Catholic Church does not play a significant role in addressing the HIV/AIDS issue in Poland. It does not openly address HIV/AIDS, except for a few clerics who occasionally speak on the subject (6). However, the Church does have a significant role in influencing public opinion and, with its negative stance towards premarital sex and condom use, makes open discussion within the community difficult (6).

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<sup>72</sup> The Strategy is available online; [http://www.aids.gov.pl/index\\_en.php?page=krajowy\\_program&act=aktualny](http://www.aids.gov.pl/index_en.php?page=krajowy_program&act=aktualny).

### 3. Resource generation

The National AIDS Center coordinates governmental programmes sponsored by the Ministry of Health and its partners: the Ministries of Education, Economy, Social Policy, Transport and Infrastructure, National Defence, Justice, Sport, Internal Affairs and Administration. These partners are obliged to provide financial contributions to the programmes (10).

The response to HIV/AIDS is funded through the Ministry of Health. The budget for prevention activities has been US \$2 million per year since 2002 and, despite the need for new activities and the continuation of those already set up, the budget has not increased. The National AIDS Center applied for a PLN 3.7 million funding for prevention programmes during 2007. Financial resources for ART, which is funded through the National Health Fund, have tripled from US \$13 million in 2002 to more than US \$42 million in 2006 (7). The funding request for drug treatment from the National AIDS Center for 2008 was PLN 125 million (US \$55 million).

## B. Prevention

### 4. Injecting drug use and HIV

Injecting drug use contributes significantly to HIV/AIDS infection rates in Poland. Between 1985 and May 2007, 50% of HIV infections were contracted through injecting drug use. Despite these high infection rates, there is still not enough attention being paid to IDUs. Drug users are, therefore, strongly encouraged to become clean before they can access treatment, and those that have not joined a substitution programme do not have access to antiretroviral drugs. This remains a problem, as only 20% of HIV-positive drug users are on ART (7,8)<sup>73</sup>.

Three factors help to explain the rapid transmission of HIV among drug users in Poland:

- the easy availability and wide use of cheap, home-produced heroin known as kompot
- a strong tradition of syringe sharing
- a general shortage of disposable needles and syringes (10).

Most addicts in Poland are homeless, unemployed and unskilled. They are widely perceived as irresponsible and dangerous, an image compounded by reports of drug users stealing to pay for drugs. The surge in HIV infection among drug users has intensified pre-existing fears and prejudices while at the same time contributing to a more general intolerance towards all people affected by HIV.

In 2005, Poland had an estimated 34 000 to 71 000 drug users, including IDUs. The estimated prevalence of IDUs is only available for Warsaw, where it is between 0.87% and 1.15% of the population (11). IDU was reported as a transmission route for 149 new HIV cases in 2005 (12). By the end of 2005, of 175 active IDUs receiving HAART and 75 of them received methadone as an opioid substitution treatment (12).

According to surveillance data, approximately four to 10 new HIV infections are detected for every 100 tests administered to IDUs. Harm-reduction programmes in Poland have been operating since 1989 and are subsidized by the state. However, opioid substitution programmes are high-threshold programmes and eligibility criteria thus prevent many drug users from

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<sup>73</sup> Grey and unpublished literature shows a significant new issue for stigma and discrimination concerning IDUs, which are refused access to substitution therapy. Substitution therapy is perceived as “immoral” by part of the medical profession. There is a large lobby in favour of abstinence-only programmes for IDUs. This makes ART difficult to access for this population.

accessing them (6). At present, 1221 clients take part in 12 existing programmes offering substitution therapy. One of the tasks within the National Anti-Drug Strategy 2006–2010 is to set up new methadone programmes to cover 20% of IDUs.

## **5. Most vulnerable and high-risk populations**

Reported HIV infection in Poland has previously been more a result of injecting drug use than male-to male sex. After the year 2000, that pattern started to change and sexual contacts became the predominant reported mode of transmission. However, as noted above, in some years as many as 85% of the reported cases are reported with no known mode of transmission. A 2004 study (13) reported an HIV prevalence of 4.7 % among MSM in Poland. The MSM population has become more visible in recent years, with 70% of people from Lesbian Gay Bisexual Transgender populations disclosing themselves as homosexual to their relatives/friends etc. After 2004, homosexuality became an important political issue with an extreme polarisation of attitudes within Polish society. In a recent study (14), 84% of non heterosexuals declared that they had suffered stigma and discrimination, 20.2% of MSM had suffered physical violence and 54.6% of MSM had suffered psychological violence. Finally, 23% of homosexuals stated that they suffered discrimination in accessing health care services (15).

Data collected by HIV diagnostic services show that there has been a considerable increase in the number of infections among the heterosexual population and MSM. Reports say that the use of condoms in the latter population group has fallen (6), and male-to-male sex was reported as the transmission route for 5% of new HIV cases in 2005 (12). It is important to remember, however, that 65% of HIV cases are of unknown origin for this reporting year.

The HIV prevalence among non-injecting sex workers has been rather low to date: 0.8% (16). There has been an unprecedented increase in the number of sex workers in Poland, and especially Warsaw; however, there are no reliable estimates on the actual number. The Warsaw police estimates Poland to have about 900 sex work agencies, but other sources put the figure at 3000, with at least 14 000 call girls and sex workers. Due to the illegal nature of the sex trade, most women do not qualify for social security benefits or free health care. This implies that sex workers need private health insurance to access the public health care system. However, many do not have any insurance (17).

Poland has a number of harm-reduction programmes targeted at high-risk populations (7). In 2005, of the 5200 people living with HIV who received care, there were seven non-nationals, 260 prisoners, approximately 2800 people infected through injecting drug use and 360 who were practising drug users (7).

In 2002, Poland was inhabited by representatives of 13 national and ethnic minorities, whose population was estimated at approximately 1 million people, around 2–3% of all inhabitants. Immigrants are mainly from Germany and eastern European countries, such as Belarus and Ukraine (18). The National Minorities Division was established as a part of the Ministry of the Interior and Administration in January 2000, and its main purpose is to deal with national minority issues. The Team on National Minorities was established on 6 February 2002 as an advisory body to the Prime Minister (19). The team is composed of representatives of ministries responsible for interior affairs and administration, finance, education, labour and social support, justice, foreign affairs, the Central Statistical Office, the Council for the Protection of Memory of Struggle and Martyrdom, the European Integration Committee and Chairman of the Foreigners and Repatriates Office. Its main responsibilities are:

- to develop government measures to create adequate conditions for national minorities;
- to coordinate activities pursued by the government bodies dealing with national minority issues;

- to assess and propose solutions aimed at ensuring the rights and satisfying the needs of national minorities;
- to prevent any infringement of national minority rights;
- to prepare studies on the situation of national minorities in Poland; and
- to publish and promote national minority issues and problems among the general public.

## **6. Gender equity**

Currently, there are about three times more men than women registered as HIV-positive in Poland. However, the percentage of women among newly diagnosed HIV cases increased in the 1990s from 20% to 29% in 2003 and then decreased again to 23% in 2006. In 2005, there were an estimated 7500 (3800–13 000) women living with HIV in Poland (20). Poland is one of the few EU countries without any gender equity law regulation. See below on reproductive health services for people living with HIV.

## **7. Prevention of mother-to-child transmission and paediatric AIDS**

The National AIDS Center continues its efforts to promote testing of women, especially among those who are pregnant or plan to be. Although testing of pregnant women is encouraged, it is still not practised routinely<sup>74</sup>, and the incidence of vertically transmitted AIDS in Poland continues to rise (21). Transmission occurs primarily in women who do not know their HIV status (21). Based on a study of 25 000 newborns tested in 2001–2002 in the Mazowieckie region, between 100 and 200 HIV-positive women give birth each year in Poland (21).

In 2005, eight cases of mother-to-child HIV transmission were reported to the national surveillance system (22). In 2006, 62 pregnant women received ART (7).

## **8. Young people**

As in most countries, HIV in Poland is mainly a problem concerning young adults. By 2005, 58% of the cumulative total of infected individuals were younger than 29, and nearly 8% of them were younger than 20 when they were infected (6).

Intervention by the Catholic Church has previously prevented young people from accessing information about sexual and reproductive health through the education system. In 1990, Catholic instruction was incorporated in the school curriculum, and a series of laws were introduced to ensure that television and radio broadcasters respected conservative Christian values in their transmissions. Lately, numerous HIV prevention programmes have been dedicated to young people in Poland. Educational forums have reached young people through schools, social support offices, socio-therapy and drug treatment centres. Several multimedia campaigns have targeted young people, including a campaign in 2005 based on the ABC methodology (Abstinence, Being faithful, Condom use). In 2004, 4370 youth educators received training (7) and the 2006 national awareness raising campaign had a strong impact on the Polish youth (23)<sup>75</sup>.

## **9. HIV in the workplace**

The national HIV programme identifies the uniformed services as an indirect target group for primary, secondary and tertiary HIV prevention (6). The Polish health policy programme on HIV treatment includes post-exposure treatment for occupational accidents. In most cases it concerns

<sup>74</sup> In reality, it is hard for HIV positive pregnant women to access a proper care; services related to reproductive health are not free of charge. Grey literature with regards to this is available from: The Little Prince [www.dziedzicazids.pl](http://www.dziedzicazids.pl) and Polish Network of PLHIV SIEC PLUS at <http://www.integration-projects.org/publications/QualityOfLifeWithHIV-ENG-RU-POL.pdf>.

<sup>75</sup> The results of the campaign were encouraging. See <http://www.aids.gov.pl/?page=badania&act=res&id=19>.

jobs such as firemen, policemen and health care workers. In 2006, 1274 post-exposure prophylaxes were administered. All post-exposure treatment has been successful, and by the end of 2006 there had been no accidental workplace-related HIV infections (7). Some companies implemented internal workplace HIV strategies. In 2006, 9.6% of employed adults reported having any HIV prevention program in workplace (24).

### **10. Sexually transmitted infections**

Reported data on sexually transmitted infections in Poland show a steady decrease in Chlamydia (from 1811 cases in 2000 to 1122 cases in 2006) and gonorrhoea (from 779 in 2000 to 395 in 2006) (25). However, the decrease is very likely to be due to an inadequate surveillance system, with very limited reporting from the private sector and a decreasing number of laboratory tests performed (26). Reported cases of syphilis have remained relatively stable in comparison over the past six years, at around the mid-900s (25).

### **11. Research and new technologies**

One of the main objectives defined in the national HIV programme is research, with special consideration of analysis to enable a quick and precise evaluation of the epidemiological situation (6). In Poland, it is very difficult to obtain information from companies and research institutes on biomedical research efforts.

## **C. Living with HIV and AIDS**

### **12. Treatment and care**

Since 2001, the National AIDS Center has prepared and coordinated the implementation of the health policy programme “Antiretroviral treatment for people living with HIV/AIDS in Poland”. The goal of the programme is to ensure that people living with HIV, and who need it, have access to ART, to monitor its effectiveness and, as a consequence, to reduce morbidity and mortality and limit the spread of HIV in Poland. The programme stipulates that all people who meet clinical criteria receive ART (7,27).

The national HIV programme includes the following objectives that relate to ART:

- ensure access to diagnostics, ART and its continuity
- ensure professional care for women living with HIV during pregnancy and childbirth
- ensure professional care for children living with HIV
- ensure constant updating of health care standards for people living with HIV with regard to the introduction of new antiretroviral drugs to the treatment, in line with current medical knowledge and
- ensure access to ART post-exposure prevention (6).

ART is available at 14 reference clinics and penitentiary centres in Poland (7). By the end of April 2007, 3109 patients were receiving ART – 2195 men and 914 women (11).

### **13. Stigma, discrimination and human rights**

Fears among medical personnel about the risk of HIV infection have been expressed in many ways. Drug users are frequently refused admission to hospital because of fears that they may be infected with HIV and thus pose a risk to staff. For many months only one doctor worked in the drug rehabilitation unit in Warsaw's psychiatric hospital, because the other members of staff were worried about the presumed risk of HIV transmission. There have been reports of individuals in life-threatening situations being denied medical care out of staffs' fear of transmission.

There has been recognition of the need to decrease such stigma and stereotyping. The national HIV programme builds on the belief that promotion and protection of human rights, including rights concerning reproductive health, are a crucial component of HIV prevention that can reduce negative stereotypes and stigmas (6).

#### **14. Testing and counselling**

The national HIV programme includes opening new voluntary testing and counselling centres which offer free HIV testing and professional pre- and post-test counselling. Furthermore, the programme includes objectives to ensure expert diagnostics to monitor HIV infection and treatment, and to introduce voluntary HIV testing for large numbers of individuals, with special consideration for pregnant women (6).

HIV testing is mandatory for Polish blood donors and all other groups are tested on a voluntary basis. The laboratories confirming an HIV diagnosis report all cases to the national HIV database using personal identifiers (6). Voluntary screening of IDUs is recommended in treatment centres, but the implementation of this recommendation is not routine and depends on available resources.

The majority of HIV tests (over 80%) are done in blood donation; however, the majority of positive test results (over 70%) are obtained from people who report to the diagnostic services because of health issues or after risky behaviour, and 20% of all HIV infections are detected in voluntary counselling and testing centres (6). The National AIDS Center runs 18 testing centres and HIV tests are offered anonymously and free of charge, along with pre- and post-test counselling. A total of 12 871 tests were taken at these centres in 2004 and 13 267 in 2006. According to the monitoring system for the centres, approximately 1% of the clients are HIV-positive.

#### **15. HIV in prisons**

According to the data obtained from the Central Board of Prison Service of The Ministry of Justice, about 20% of HIV infections are detected at penitentiaries (6). HIV specialists from the ART reference clinics manage the treatment of prisoners in Poland (7), and by the end of 2005, 133 prisoners received HAART in Poland (11).

### **D. Overall progress and challenges for the future**

- Good progress has been made to improve the availability of HAART.
- A new, comprehensive Strategy for AIDS Control and Prevention of HIV Infection in 2007–2011 has been adopted by the Polish government (Ordinance of the Council of Ministers).
- A more diversified offer of prophylactic programmes has been developed (for example, the new HIV/AIDS programme in the world of work).
- Major challenges include:
  - increasing resources for prevention;
  - increasing availability of maintenance therapy for opioid users (currently below 20% coverage);
  - increasing accessibility to palliative care for AIDS patients;
  - improving information and reporting systems including the mode of HIV transmission; and

- increasing human resources involved in all fields of HIV/AIDS prevention and control.

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## Country report – Portugal

Pop. 10 549 424

### Epidemiological summary and surveillance

The first AIDS case in Portugal was reported in October 1983 and 30 366 cases of HIV had been reported to the National Centre for the Epidemiological Surveillance of Communicable Diseases (CVEDT) by December 2006. The cumulative number of reported AIDS cases as of early 2007 was 13 515, of which 17.7% were women; 84.7% were between the ages of 20 and 49; 3.3% were HIV 2 infected and 1.4% were HIV 1/2 coinfecting (1).

In 2005, there were 2635 newly diagnosed cases of HIV, corresponding to a rate of 251.1 cases per million population, which places Portugal with the second highest estimate in the European Region. AIDS-related deaths increased until 1996 but stabilized thereafter and currently there are about 1000 AIDS-related deaths annually in Portugal. When compared to the decreasing trends found in other European countries, the absence of a substantial decrease in mortality in Portugal represents a major failure of the health care and related systems, particularly since the state provides free universal access to combination therapy (2).

UNAIDS estimates indicate that within the 15–49 age range there were about 32 000 people living with HIV in Portugal in 2006, assuming an estimated 30% sub-notification (under-reporting) rate (2).

The mode of transmission has been known in 97% of all reported HIV cases since the year 2000, and because of this fact, it has become increasingly possible to observe patterns of transmission. The Portuguese epidemic reflects a typical pattern for a concentrated epidemic, with HIV prevalence below 1% in the general population, and above 5% in at least two of the most-at-risk populations: injecting drug users (IDUs) and prison inmates. However, the numbers of different types of modes of transmission have changed substantially over the last decade. In 1999, injecting drug use and heterosexual transmission accounted for 57.4% and 33.1%, respectively, of all reports with a known mode of transmission. In 2006, heterosexual contact had become the most frequently reported mode of transmission, representing 58.0% of HIV cases, while injecting drug use accounting for 26.8% (1). The success of harm-reduction strategies among IDUs and the changes in drug consumption patterns may account for the observed shift in the transmission pattern. In 2006, 14.6% of reported HIV cases with a known mode of transmission were reported among men who have sex with men (MSM).

The HIV epidemic in Portugal has one of the highest HIV/tuberculosis (TB) coinfection rates in the European Union (2): 15% of TB patients are also HIV infected, and TB is the AIDS-defining illness in more than 40% of cases. Since October 2007, health services are required to offer HIV testing to all TB patients, in an opt-out strategy (3). PLHIV are not systematically screened for TB, though as of March 2008 a national policy regarding this issue is under discussion.

Before 2000, the national surveillance system collected information only on AIDS cases. Since 2000, surveillance has included all HIV cases, regardless of their stage. Since January 2005, HIV/AIDS reporting has been mandatory and in March 2005, a standardized surveillance form was published. The CVEDT centralizes reporting forms and produces annual reports on the HIV/AIDS situation in Portugal. Under-reporting has been notorious, and reporting delays have also been an issue of concern. Recent efforts at various levels to increase the proportion of cases that are reported and to decrease reporting delays have been made by the coordinating body.

## **A. Leadership and partnership**

### **1. Political leadership**

Since the 2004 Dublin Declaration was signed, the Portuguese government and the national coordinating bodies have shown an increasing commitment to HIV/AIDS. A new government took office in March 2005, and it recognized HIV/AIDS as a “dramatic problem in Portugal, which has rates of new infections above the rest of the European countries”. The XVII Constitutional Governmental Programme (4) also stated that “The loss of the sense of urgency and priority is particularly serious. The government aims at re-launching policies directed at the prevention of HIV/AIDS, by reactivating the National Plan for the Fight against AIDS. Special attention will be given to the promotion of actions and campaigns directed at information, aiming for an effective change of behaviours.”

In August 2005, the Ministry of Health created the High Commissariat for Health to coordinate public policies for the preparation and implementation of the 2004–2010 National Health Plan. Aiming at better implementation of the plan, along with better coordination of the institutions involved, and a more effective horizontal link with other agencies and sectors (with the ultimate goal of achieving better results), the National Commission for the Fight against AIDS was replaced by the National Coordination for HIV/AIDS Infection (CNIVS). CNIVS sits within the High Commissariat for Health and is thus dependent on the Ministry of Health and fully integrated into national health policies.

In September 2005, the Ministry of Health recognized the need to analyse the epidemic in Portugal in view of the clear failure of previous approaches. The subsequently released document (5) referred to the Dublin Declaration, particularly to strong leadership, involving national and international institutions, with a commitment to prevention and a response to the needs of people living with HIV that is capable of fighting stigma and discrimination, and of organizing treatment and social support. The same document stated that future policies should promote partnerships between professionals, people living with HIV and other civil society representatives (5).

The 2004–2006 National Plan for the Fight against AIDS was followed by the CNIVS 2007–2010 National Programme for the Prevention and Control of HIV/AIDS, issued in December 2006. The programme was subject to public discussion and received input from national and international experts. Its main goals are:

- to reduce by at least 25% the number of new HIV cases and AIDS deaths
- to contribute internationally to a reduction in HIV transmission
- to improve the care and support to people living with HIV.

The main intervention areas identified were: knowledge of the dynamics and determinants of infection; prevention, with a particular focus on most-at-risk populations; access to early detection and adequate referral; access to state-of-the-art treatment; continued care and social support to people infected with and affected by HIV; reducing stigma and discrimination; sharing responsibilities among governmental bodies, the private sector and civil society; continuing education; research; international cooperation; and monitoring and evaluation (2).

### **2. Community involvement and the private sector**

Since the early days of the HIV epidemic, several nongovernmental organizations (NGOs) have been involved in advocacy for a response to the epidemic, the empowerment of people living with HIV and the availability and quality of care and support, at both national and international levels.

CNIVS provides technical and financial support to civil society organizations through an HIV/AIDS programme (AIDS Support Development Intervention) which was created in 2002 to support projects in three major areas: prevention, social support, and education. The number of applications to the programme has been increasing each year and in 2006, there were 96 applications for funding, of which 40 were approved: 21 for prevention, 16 for social support and 3 for education. Prevention projects, approved in 2006, covered 39 094 people (migrants and ethnic minorities, sex workers, IDUs, prison inmates, young people and the general population), social support projects covered 1878 people and education projects covered 401 people (young people, health, education and social service workers, and prison inmates). Table 1 shows the breakdown of funding between the three major project areas.

**Table 1. AIDS programme funding in 2005 and 2006**

	2005	2006*
Prevention	€653 014.83	€918 483.93
Social support	€1 662 043.19	€1 689 673,32
Education	€20 616.65	€27 185.10

\* numbers for 2006 refer to approved funding (no exact data are currently available)

During its public discussion period, the 2007–2010 National Programme for the Prevention and Control of HIV/AIDS received several individual and collective external contributions from NGOs and civil society representatives. The programme also includes a set of strategies aimed at ensuring the commitment of the private sector and civil society, including the formation of a multisector group of consultants, from which continuous input on strategies and monitoring may be expected (2).

### **3. Resource generation**

Public funding for HIV in Portugal is directed via the High Commissariat for Health to CNIVS which then further allocates resources in each area. The governmental budget allocated to CNIVS for 2006 was €11 780 500. Portugal has also contributed to the Global Fund to Fight AIDS, Tuberculosis and Malaria: US\$ 2.5 million were pledged between 2001 and 2005, US\$ 2 million in 2006, and US\$ 3 million in 2007 (6).

## **B. Prevention**

### **4. Injecting drug use and HIV**

The most recent assessment of the burden of injecting drug use in Portugal was conducted in 2002 by the National Institute for Drugs and Drug Addiction (IDT), according to which 4.3 to 6.4 per thousand population aged between 15 and 64 were IDUs. According to a national survey, 1% of the Portuguese general population had at some time used heroin. IDT reported that HIV prevalence among IDUs seeking treatment for the first time decreased from 19% in 1999 to 12% in 2004. Despite this, 2004 data collected at IDUs' first visits to drug treatment centres showed that only 23% (1154 out of 5023) of IDUs had ever been tested for HIV. Among IDUs who were in contact with street teams in the same year, 51% had had an HIV test and among these, 51% had tested positive.

There are 45 drug treatment centres in the country that provide free needle exchange and opioid substitution programmes (methadone and buprenorphine). IDUs in substitution programmes may obtain free methadone at drug treatment centres, primary care centres, centres for TB diagnosis,

and community pharmacies. The number of IDUs in opioid substitution therapy has had an approximately linear growth, from 6040 in 1998 to 21 054 in 2005 (7). The needle exchange programme was implemented in 1993, and since then several institutions have been involved, including community pharmacies and governmental and nongovernmental organizations. By 2006, 2 591 150 needles had been exchanged in this programme, with community pharmacies playing a major role. The programme promotes the exchange of used needles for free AIDS prevention kits and in 2006, the contents of the kit were altered according to WHO recommendations to include citric acid and a recipient for preparation, in addition to needles, filters, antiseptic towels, condoms and distilled water (8).

To improve the awareness and detection of HIV infection among IDUs, CNIVS and IDT set up a programme for prevention, early detection and adequate referral of HIV/AIDS in IDUs in June 2006. The programme's goals for 2007 were:

- to cover 100% of public drug treatment centres
- to ensure that 80% of IDUs in these units know their HIV status
- to ensure that 90% of IDUs in these units know their HIV status at their first visit
- to include 10 harm-reduction units and 2 mobile units in the programme (9).

## **5. Most vulnerable and high-risk populations**

Although there are no official estimates of the number of MSM in the country, trends in the modes of HIV transmission in Portugal show that MSM contact accounts for 10% to 15% of reported HIV infections since 2000 and that this proportion is relatively stable (10). These trends indicate that there has been a population-level response to the epidemic, reflecting increasing awareness and prevention by the Portuguese MSM community. It also suggests that interventions by civil society, namely several NGOs and activist groups, have been highly effective. In June 2007, CNIVS, in collaboration with NGOs, started distributing an MSM safe-sex kit, composed of lubricant gel and condoms. Currently, there is no additional national strategy specifically targeting the prevention of HIV in MSM. Future approaches are planned as part of a wider goal of preventing HIV transmission among vulnerable populations (11).

Heterosexual transmission of HIV in Portugal has increased substantially since 2000, making up 58% of reported HIV cases in 2006. Although the impact of sex work on homo- or heterosexual transmission in Portugal is not clear, sex workers are a target population for national strategies and primary and secondary prevention programmes have been conducted in the largest cities. These programmes are frequently funded by CNIVS, namely the Lisbon Drop-in Counselling Centre (since 1994), and the Porto outreach VAMP programme (since 1998). The Lisbon Red Light programme is promoted by a national NGO (Associação Positivo). Programmes typically provide sex workers with counselling on prevention and health promotion, hygiene facilities, condoms and needle exchange. For secondary prevention, the programmes direct sex workers to treatment, care and support institutions. Outside Lisbon and Porto there have been no major primary or secondary prevention programmes among sex workers (12).

At present, migrants are estimated to represent 9% of the working population and 4.5% of the country's population. Since 2001, there has been specific legislation on immigrants' access to health care. However, equity was only assured to immigrants with a legal status in the country or who had been in Portugal for the previous 90 days. In May 2007, the government published a national plan for the integration of immigrants, together with the revised law of Portuguese citizenship. The integration plan provides 120 detailed strategies to assure equity in several sectors of society. Overall, the document offers a positive vision on immigration, the acceptance of cultural and social specificities, the importance of participation and co-responsibility in all sectors of society and equal opportunities for all. Major roles in the integration process are

attributed to the state and civil society (13). Specific strategies include the scaling up of intervention and support measures, both at the National Centres for the Support of Immigrants (CNAI) in Lisbon and Porto, and at the Local Centres for the Support of Immigrants (CLAII). Furthermore, in May 2007, the structure and functions of the recently created High Commissariat for Immigration and Intercultural Dialogue (ACIDI) were legislated (14).

## 6. Gender equity

The proportion of women among reported HIV infections increased from 24% in 2000 to 31% in 2004 and has stabilized at that level (30% in 2006). In 2006, among 32 000 PLHIV in the country 1300 were women, which gives an HIV prevalence in the general population of 0.03% in women and 0.72% in men. However, the proportion of women among incident AIDS cases rose from 19% to 24% between 2004 and 2006 (1). Gender equity has been a subject of governmental concern in recent decades and the third National Plan for Equity – Citizenship and Gender – was produced by the government for 2007 to 2010. Regarding health, the plan aims to promote gender equity in access, treatment and care in the national health system, to assure equal sexual and reproductive rights to men and women, and to promote women's health, specifically by ensuring that women and girls are targeted in all public health interventions, namely those addressing HIV/AIDS, endemic diseases and sexual and reproductive health (15).

## 7. Prevention of mother-to-child transmission and paediatric AIDS

Mother-to-child transmission has decreased substantially to below 2%, owing to the universal implementation of early detection and prevention measures. In 2004, a normative document from the General Health Directorate established that all pregnant women should be screened for HIV after providing informed consent, as part of their standard prenatal care (in addition to preconceptional HIV testing, according to the 1998 normative document) (16). Prenatal testing is now conducted twice during the course of pregnancy, while rapid tests are used for women in labour who have no documentation on their HIV status and agree to be screened. Women with a confirmed positive diagnosis are immediately referred to the corresponding hospital for high-risk pregnancy. HIV-positive pregnant women are advised to undergo scheduled elective caesarean section in the 38<sup>th</sup> or 39<sup>th</sup> week of gestation. Health care workers were also instructed to engage fathers in the process of counselling and testing.

From between 2000 to 2006, there were 761 reports of pregnant women living with HIV, of which 8.5% were AIDS cases. Heterosexual transmission was reported in 89% of women and injecting drug use in 10%. Systematic preconceptional testing has contributed to the observed decrease in the number of infected pregnant women, from over 100 up to 2004 to below 75 in 2005 and below 60 in 2006. In 2005 and 2006, mother-to-child transmission accounted for less than 0.5% of all reported HIV/AIDS cases with a known mode of transmission (1). Health care for pregnant women living with HIV is improving and can be seen by the comparison of statistics from 2004 and 2005 shown in Table 2.

Table 2. Comparison of health care for pregnant women living with HIV from 2004 to 2005

	2004	2005
HIV-positive deliveries in 27 public hospitals	241	174
HIV-positive percentage of total deliveries in 27 public hospitals	0.4%	0.3%
Antiretroviral therapy coverage during pregnancy	87.6%	90.2%
Antiretroviral prophylaxis during labour	90.3%	94.8%

Up to December 2006, 302 HIV infections had been reported in children 0 to 14 years of age (0.99% of all reported PLHIV). Among these, 111 (36.7%) were AIDS cases. The fraction of paediatric AIDS among reported AIDS cases has stayed below 0.5% since 1996 (1).

## **8. Young people**

In February 2006, the ministries of health and education established a joint protocol, which specified that all schools should include health education in their curriculum, specifically focusing on sexuality and sexually transmitted infections (STIs), in particular HIV/AIDS (17). During that year, CNIVS and the National Working Group on Sexual Education initiated a school contest at primary school level involving 2227 students all over the country (18).

## **9. HIV at the workplace**

The national Labour Platform against AIDS was created in 2004, through a manifesto signed by a partnership of 12 workers' associations and the National Commission for the Fight against HIV/AIDS, in collaboration with the International Labour Organization (19). The Platform aims to reduce discrimination, promote equity between men and women, promote a healthy workplace, respect confidentiality, promote the maintenance of positions of employment regardless of HIV status, and improve prevention and solidarity. In 2006, it made progress on the production of a White Paper on HIV/AIDS infection and labour and defined strategies to implement and hold employers accountable for occupational health measures covering HIV/AIDS (18).

## **10. Sexually transmitted infections**

The 2004–2010 National Health Plan recognizes the absence of epidemiological data on STIs in Portugal, the lack of a reliable surveillance system – mainly due to significant under-reporting – and the absence of education on STIs among health care providers and the general population (20). Reporting is mandatory for syphilis and gonorrhoea, and there were 116 reported syphilis (congenital and early syphilis) cases in 2004, 125 in 2005 and 119 in 2006; and 28 cases of gonorrhoea in 2004, 52 in 2005 and 39 in 2005 (21). Chlamydia infections are comparatively rare in Portugal.

During 2006, three national surveys were set in motion that aimed to assess the knowledge of and attitudes towards HIV and other STIs in the general population, IDUs and teenagers. The results of these surveys are still being collated. Additionally, a brief questionnaire on the availability of condoms and educational material was conducted among HIV/AIDS centres in hospitals. According to this survey, more than half of all hospitals did not provide condoms or educational material.

In 2005, the national health service and the needle exchange programme distributed 22 972 686 free condoms. In the same year, 16.1 million condoms were sold in the country, a 2.48% increase from the previous year. However, the annual per capita consumption of condoms in Portugal is still only 1.6, probably due to their high price compared to the country's GDP (18).

## **11. Research and new technologies**

During 2004 and 2005, CNIVS provided funding of €689 260 for 14 projects on basic and applied research and social sciences (22). In 2006, €625 000 was allocated to research and development, namely to a collaborative project with the National Foundation for Science and Technology (€500 000), a set of prizes for teams of researchers (basic research, applied research and technology, and social sciences) and eight grants for individual researchers (18).

There are currently two major scientific associations devoted to research on HIV/AIDS: the National Association for the Clinical Study of AIDS (APECS) and the Association for the Development of Teaching and Research in Microbiology (ADEIM). The current HIV/AIDS strategies for the period 2007–2010 include: to promote high-quality research on HIV/AIDS in Portugal; to promote Portuguese participation in the international effort for the development and experimentation of vaccines; to encourage basic laboratory research on virology and immunology; and to endorse research on new HIV therapies (2).

## **C. Living with HIV/AIDS**

### **12. Treatment and care**

HIV/AIDS treatment is hospital-based and has been free in Portugal since 1987, and highly active antiretroviral treatment has been available since 1996. In the 32 hospitals that treat the vast majority of HIV/AIDS cases in the country, 12 435 people living with HIV were seen for care at the end of 2005. Among these, 10 479 were receiving antiretroviral treatment (18). Since 2005, CNIVS has been responsible for recommendations on the prescription and evaluation of antiretroviral treatment. The main objectives of these recommendations are to promote a uniform level of care in all the centres that monitor HIV/AIDS, to establish a useful antiretroviral treatment reference source, both in therapeutic decisions and in the interaction between health care providers and hospital administrations or other public funding sources, and to establish a reference source for the infected patient. These recommendations were under public discussion until 15 June 2007 (23).

The national strategy for the delivery of continued care and social support has relied mainly on projects by NGOs. Since 1998, an increasing number of organizations have been funded by the national HIV/AIDS budget. CNIVS funded 18 social support projects in 2005 and 17 in 2006. Focal areas have included psychosocial support and temporary and permanent housing and domiciliary support for people living with HIV. Continued care and social support is provided in cooperation with the National Institute for Social Security and the National Network for Continued Care (18).

### **13. Stigma, discrimination and human rights**

Article 13 of the Portuguese Constitution explicitly establishes the right to equity regarding gender and sexual orientation, ethnicity and language, religious, political or ideological beliefs, education, and socio-economic status, as a contribution to the promotion of the right to diversity and to non-discrimination (24). Further legislation on the prohibition and punishment of discrimination on matters of disability or health was published in August 2006 (25).

In the context of the European Year of Equal Opportunities for All, the Portuguese government published a national action plan for 2007, which focused on the right to equity and non-discrimination, the representation of minorities in society and the acknowledgement of and respect for diversity. The main strategic focus of the plan was to ensure an approach of equal opportunity and social inclusion centred on multiple discrimination and gender mainstreaming, and collaboration with civil society – and its many components – in defining and putting into action the specific objectives and actions (26).

### **14. Testing and counselling**

Specialized national network centres for counselling and early detection provide free anonymous testing and pre- and post-test counselling to the general population. There are currently 21 centres that cover 17 out of 18 regions. The number of people who use this network for HIV

testing increased from 2337 in 2000 to 14 258 in 2006. The capacity to detect HIV infection also improved in this period, with the introduction of rapid testing and more flexible schedules (18). To better access groups with the most need for testing, free rapid HIV testing and counselling have also been made available at drug treatment centres and were introduced at TB diagnosis centres during 2007. Rapid tests will be free and applied in a provider-initiated strategy, together with qualified pre- and post-test counselling.

### **15. HIV in prisons**

At the end of 2005, the General Directorate for Prison Services reported that the 57 Portuguese prisons held 12 889 inmates (an occupation rate of 103%). Among the inmates, 93% were male, mean age was 34 years, and 17% were non-nationals (27). Although access to prevention and harm-reduction programmes was legislated in 1999 (28), countrywide measures have not yet been implemented. Harm-reduction measures in prisons have been rare and rely on the policies of individual prisons. Data on the prevalence of HIV or AIDS is scarce, as is information on drug consumption patterns and sexual behaviour in prisons. Aggregated data provided by each correctional facility indicated that, at the end of 2005, 10.4% of male and 7.2% of female inmates were HIV-positive. Of these, 56.9% were receiving antiretroviral treatment (27). HIV/HCV coinfection was present in 6.2% of men and 2.6% of women. In a 2005 survey conducted in two Portuguese prisons, about a quarter of all inmates who reported injecting drugs (without sharing injecting materials) were HIV-positive and half of all inmates who reported having ever shared injecting materials were HIV-positive.

To ensure a concerted effort to effectively improve health in Portuguese prisons, the ministries of health and justice created a multisectoral working group to define a national plan to reduce the transmission of infectious diseases in prisons. A number of recommendations for future legislation included: access to prevention and treatment; continuous education, prevention and health promotion; access to drug-dependence treatment; and awareness and treatment of STIs, HIV/AIDS, TB, HCV and HBV infections. This list of recommendations initiated the implementation of a pilot risk- and harm-reduction programme to take place in two prison settings during 2007 and to be extended to all prisons if successful. Specific legislation on needle exchange programmes in prisons was published in January 2007 to regulate these interventions (29).

## **D. Overall progress and main challenges for the future**

In the last three years, Portugal has shown increasing political commitment to respond to the HIV epidemic. Important legislation has been produced or updated and official bodies dealing with HIV have been restructured. The involvement of civil society has improved and NGOs contribute significantly. Additionally, resource generation, both for national and international initiatives, has been enhanced. Mandatory case reporting has contributed to the surveillance of the epidemic. Prevention strategies directed at the general population have been frequent, and prevention of mother-to-child transmission has been successful overall. Voluntary counselling and testing have been scaled up, for both the general population and for specific risk groups, and treatment and care are free and universal.

However, future strategies should address the following problems:

- Under-reporting of HIV cases and the lack of a centralized information system
- Lack of accurate estimates of the size of the most-at-risk populations, namely sex workers, IDUs and migrants, their HIV status and clinical and behavioural characteristics
- Insufficient prevention targeted at most at-risk populations

- Failure to implement countrywide, comprehensive harm-reduction strategies in strategic settings, such as prisons
- Barriers to treatment access.

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## Country report – Ukraine

Pop. 46 481 000

### **Epidemiological summary and surveillance (1)**

In 2007, the Ukrainian National AIDS Centre reported 17 687 new HIV cases, bringing the cumulative total of HIV cases since 1987 to 122 674 (2). In 2006, there were 16 116 new HIV cases in Ukraine, which is the highest reported annual incidence to date. According to the National Consensus Estimates, the actual number of HIV cases in Ukraine is estimated to be much higher, at 395 000 (range 230 000–573 000), equivalent to a national adult HIV prevalence of 1.63% in 2007 (4). Of the reported number of people living with HIV, a total of 22 456 had developed AIDS and 12 511 had died by December 2007. With 4 575 new AIDS cases and 2 508 AIDS deaths in 2007, Ukraine reports the highest number of annual AIDS deaths in the European Region. Of the estimated almost 22 000 people living with HIV that need antiretroviral therapy, only 7 657, or 35%, received treatment at the end of December 2007.

Unsafe injecting drug use remains the most common mode of HIV transmission in Ukraine. The number of individuals infected through unsafe drug injection continues to grow, from 3881 in 2000 to 7 084 in 2007. However, the percentage of injecting drug users (IDUs) among newly reported HIV cases has been decreasing significantly, from 60% in 2001 to 40% in 2007 (2). Since 1999, sentinel surveillance studies have been conducted among IDUs, female sex workers and patients treated for sexually transmitted infection (STIs) in several regions. The sentinel surveillance data from 12 sites in 2006 have suggested the range of HIV prevalence among IDUs to be between 18.0% and 62.8%. The cities with the highest burden include Odessa, Poltava and Kyiv, while Sumy reported the lowest prevalence of HIV infection among IDUs (5).

The number of newly reported HIV cases acquired through unsafe heterosexual contacts is on the increase. Females aged 15–30 are more likely to be infected through heterosexual contact than males of the same age, and almost half (47%) of the reported HIV cases are among females of the most active reproductive age, 20–29. Currently, more than half of all sexual transmissions can be directly associated with unprotected sex with an injecting drug user partner (3). By the end of 2007, heterosexual transmissions made up 38% of the cumulative total number of new HIV cases and thus constitute the second most prevalent mode of HIV transmission in Ukraine.

Although Ukraine has achieved a significant reduction in mother-to-child transmission (MTCT) rates from 28% in 2001 to 7.1% in 2006, MTCT remains a big problem in the country (3). HIV prevalence among pregnant women reached 0.34% in 2007, which is among the highest in Europe. In 2006, 91% of all pregnant women received voluntary HIV counselling and testing, and 90% of the HIV-positive pregnant women obtained antiretroviral prophylaxis. C-section is now accepted as part of the routine package of prevention of MTCT but is not yet fully implemented. The number of children born to HIV-positive mothers continues to rise, and had reached a record 3 430 by the end of 2007 (2).

Along with unsafe injection of drugs, sex work among women is thought to play an important role in the further spread of the epidemic. Recent studies from nine different sentinel sites show high but varying prevalence in this group of women, ranging from 4% in the city of Kyiv to 31% in the city of Poltava (5). To date, only 158 cases of HIV have been reported among men who have sex with men (MSM), and only very limited data on this risk group are available. Studies reveal that prevalence among MSM ranges between 4% in Kiev and 23% in Odessa (5). In 2006, there were 2579 newly reported HIV cases among prisoners, bringing the estimated total to 4300

HIV-infected prisoners. The HIV prevalence in this population is estimated to have increased from 9% in 2003 to 14% by mid-2006 (3).

The surveillance system in Ukraine is reminiscent of the Soviet tradition that was based on official case reporting in a highly centralized health system. Since the dissolution of the Soviet Union, Ukraine has struggled to reform the health system, which remains very unequal and inefficient (6). The amended version of the 1998 Law of Ukraine on AIDS Prevention and Social Protection of Population abolished all mandatory HIV testing except among blood donors. In parallel with a routine surveillance system, in 1999 Ukraine implemented HIV sentinel surveillance methodology as part of the second generation of HIV surveillance approach recommended by WHO and UNAIDS. For the last three years, within the framework of the Global Fund to Fight AIDS, Tuberculosis and Malaria (GFATM) grant-supported programme, the sentinel surveys have been conducted annually among IDUs, female sex workers and STI patients.

## **A. Leadership and Partnership**

### **1. Political leadership (national framework)**

The Ukrainian government has shown a high level of political commitment and is one of the leading countries in the region with regard to the scale of the national response to the HIV epidemic, including involvement of civil society.

The legislative framework for the response to HIV is the Law of Ukraine on AIDS Prevention and Social Protection of Population, which was adopted in 1991 and most recently amended in 2001. The law complies with UNAIDS international guidelines and recommendations. The Ukrainian government is thus bound to a number of commitments, including epidemiological surveillance of the epidemic; free access to antiretroviral treatment; voluntary and confidential counselling and testing; public education on HIV, including through the mass media, schools and universities; and HIV prevention efforts targeting the general public and most-at-risk populations, such as needle and syringe exchange programmes for IDUs (7).

In 2004, Ukraine's Cabinet of Ministers approved both the National Programme to Prevent HIV Infection, to Support and Treat People Living with HIV/AIDS for 2004–2008 and the Multisectoral Strategy on Approval of the Concept of Government Actions Strategy to Prevent the Spread of HIV/AIDS for the period to 2011. The National Programme identifies two key strategic areas in the response to the HIV epidemic, namely the prevention of the further spread of HIV infection, and the expansion of access to treatment, support and care for people living with HIV (5). It also provides a framework for attracting additional financial and technical resources. However, a central problem with the National Programme is that the document was put together by various agencies, without a central coordinating authority, which can lead to uncontrolled and inefficient use of funds. Furthermore, it lists goals with neither the inclusion of an implementation action plan, nor the contribution of international donors in response to the AIDS epidemic in Ukraine (8).

In May 2007, the Cabinet of Ministries of Ukraine re-organized National Coordination Council on HIV/AIDS (NCC), headed by the Vice Prime Minister of Ukraine into the National Council on Tuberculosis and HIV/AIDS. In December 2007, the President of Ukraine Victor Yushchenko issued a Decree which envisaged the establishment of an additional Council on HIV/AIDS, Tuberculosis and Drug Abuse as an advisory body to the President of Ukraine. In late 2007, the Government of Ukraine commenced work on the development of a new National Programme for the period 2009-2013. A multisectoral working group was created by

the Ministry of Health, which includes the Governmental key stakeholders of the existing National Program, as well as international and civil society organizations. This effort is coordinated by the Committee on HIV/AIDS and Other Socially Dangerous Diseases at the Ministry of Health of Ukraine.

## **2. Community involvement and the private sector**

Ukraine is leading the field in terms of community involvement in the response to HIV. In 2004, the Coalition of HIV Service NGOs, uniting 66 nongovernmental organizations (NGOs) from 21 regions of Ukraine, was founded and registered at the Ministry of Justice. The aim of the Coalition is to strengthen and expand the participation and licensing of NGOs in the provision of prevention and reproductive health services to most-at-risk groups and people living with HIV and to involve NGOs in the planning, management, implementation and monitoring of HIV programmes, including those supported by the GFATM grant and a World Bank loan (9).

Representatives of the Coalition participated in the creation of the NCC and the development of documents regulating its activity. The Coalition's members take part in the work of all the NCC committees, and 29 HIV NGOs are members of the 17 coordination councils for combating HIV at oblast level. The Coalition took part in the revision of the National Programme, contributed to the formulation of the United Nations General Assembly Special Session on HIV/AIDS (UNGASS) progress report (9), and participated in the legislative process to implement the Law on Social Services.

The All-Ukrainian Network of People Living with HIV/AIDS is an active member of the NCC through its two members, one of whom co-chairs the NCC. The Network was established in 1999 and has been very successful in empowering communities of people living with HIV. It lobbies for universal access to HIV treatment, care and support, draws attention to the issues of stigma and discrimination, and organizes day-care centres, self-support groups and community centres for those affected by the epidemic. In 2006, the Network was nominated and at the International AIDS Conference in Toronto, received the Red Ribbon Award presented for leadership on "addressing stigma and discrimination related to HIV/AIDS".<sup>76</sup> In 2007, the Network was identified as one of the two GFATM Round 6 grant principal recipients in Ukraine.

## **3. Resource generation**

Since Ukraine is addressing the HIV epidemic in the middle of an economic transition, the country is facing a severe lack of resources. Although the national budget allocations for HIV have increased in recent years, from US\$ 7 million in 2006 to approximately US\$ 20 million in 2007, the lack of adequate funding still remains a major obstacle to implementing effective measures to respond to the epidemic. According to the recently conducted costing of the comprehensive national AIDS strategy, a minimum of over US\$ 100 million is needed each year to optimally tackle the HIV epidemic in the country (10). In addition, the annual national budgets allocated for HIV have been inconsistent since 1997 and actual spending per year does not match the amounts allocated (8). The current governmental budgeting system is based on top-down planning rather than on bottom-up budget planning based on resource needs and programmatic target indicators.

A US\$ 92 million GFATM grant agreement was signed in 2003 and aims at increasing access to antiretroviral treatment and HIV prevention, care and support services through the programme Overcoming HIV/AIDS Epidemic in Ukraine. The grant went through in April 2004, with the

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<sup>76</sup> For information on the Red Ribbon Award, see: <http://www.redribbonaward.org/content.php?pg=community&event=dinner> (accessed 21 February 2007).

International HIV/AIDS Alliance serving as the principal recipient and being tasked with coordinating the implementation of the programme. Improvements in the national response, in particular with regard to strategy planning efforts and political support, are largely thought to be due to the GFATM programme (5). In 2006, Ukraine applied for additional support from the GFATM through the Round 6 call for grant proposals for 2007–2011, requesting a total amount of US\$ 151 million. The proposal was approved by GFATM and grant implementation commenced in the autumn 2007.

A World Bank loan of US\$ 60 million, including approximately US\$ 30 million for HIV activities, was provided in January 2004 in the framework of the project Control of Tuberculosis and HIV/AIDS in Ukraine. According to national priorities, the project is focusing on the prevention of the further spread of the HIV epidemic in Ukraine and on strengthening national capacities to control tuberculosis. After two years of implementation, the project had carried out very limited activities and disbursed only 2% of the US\$ 60 million loan. Consequently, the World Bank suspended the disbursement of the loan and asked the government to take three time-bound actions: (1) adoption of the new national tuberculosis control strategy based on Directly Observed Treatment, Short-course (DOTS); (2) acceptance of using United Nations agencies to accelerate project procurement; and (3) improvement of project management and integration of the functions of the Project Implementation Unit (PIU) into the Ministry of Health. After lifting the suspension in November 2006, some improvement in project implementation was observed, and the World Bank, with technical assistance from WHO and UNAIDS, is now in the process of negotiating the possible extension of the financing with the Government of Ukraine.

Other contributors directing significant funds to respond to the HIV epidemic in Ukraine include the United States Agency for International Development (USAID), the European Union, the Canadian International Development Agency (CIDA), the Swedish International Development Cooperation Agency (SIDA), the United Kingdom Department for International Development (DFID), and many bilateral donors. The total budget allocated in 2006 to HIV in Ukraine amounted to US\$ 58.5 million (11).

## **B. Prevention**

### **4. Injecting drug use and HIV**

IDUs remain the group worst affected by the epidemic in Ukraine. The drug scene in Ukraine is characterized by drugs being “obtained in exchange for preparing, reselling or transporting them or for sexual services” (12). Furthermore, “most substance drug users consume in groups and, due to high levels of stigmatization in Ukraine, the drug scene is hidden and difficult to reach” (12).

Ukraine’s drug legislation criminalizes the possession of very small amounts of illicit drugs. The National Programme on HIV recognizes opioid substitution therapy (OST) for IDUs as an important element of the HIV response, and the Government of Ukraine is finalizing the strategy for its wide-scale implementation. However, due to the out-of-date and complicated legislation regulating legal drug turnover (13), as well as opposition among the general population (14), such programmes have only recently begun to be implemented. At the end of 2006, in the state budget for 2007, funds were allocated to provide OST with buprenorphine for 300 patients in six regions of the country. To ensure coordination of efforts to implement OST on a wide scale, a draft National Operational Scale-up Plan for Opioid Substitution Treatment in Ukraine, 2007–2011 has been developed. The scale-up of OST is planned through national (state budget) and international funding to cover more than 11 000 individuals in 2011, in particular within the

framework of the already approved GFATM Round 6 country proposal. A multisectoral working group comprising governmental and nongovernmental representatives was created in December 2006 to oversee the implementation of the national scale-up strategy.

By March 2007, only 519 clients were receiving OST provided by multidisciplinary staff at 11 sites in Ukraine, of which 328 were HIV-positive, 326 were infected with hepatitis B and C, and 106 were receiving antiretroviral treatment (15). WHO, UNAIDS and UNODC estimate that up to 60 000 IDUs need OST for the intervention to have an impact on the epidemic (11).

According to the International HIV/AIDS Alliance, by 2006, approximately 110 400 IDUs were reported to be accessing prevention and care services.<sup>77</sup> These services are considered of high quality for the region. In 2004, 38% of IDUs surveyed for the UNGASS review reported to have been reached by prevention programmes. Only 31% of IDUs under the age of 25 are reached by prevention programmes, compared to 44% of IDUs in the age group of 25 years and older.

The International HIV/AIDS Alliance coordinates the activities of more than 48 harm reduction sites across Ukraine, with the aim of promoting effective and humane responses to injecting drug use and HIV (16). However, there are currently only 11 sites providing OST.

In 2007, the law on drugs, psychoactive drugs and precursors was revised and approved. It directs state policy in this field, including reduction of harm related to illegal use of narcotic drugs and psychoactive substances.

## **5. Most-at-risk populations**

Female sex workers in Ukraine are at high risk of HIV infection, and there is a significant overlap between sex work and drug use. The HIV prevalence rates among female sex workers who also inject drugs are very high, ranging between 25% and 86%, while the prevalence remains between 0% and 21% among female sex workers that do not use drugs (5). Paradoxically, reported condom use among female sex workers is fairly high (80% with the most recent commercial partner) (5).

HIV prevalence rates have increased more consistently among female sex workers than IDUs since 2000, when sentinel surveillance in this population began, which indicates the need for improved and intensified prevention programmes in this at-risk group (5).

According to the International HIV/AIDS Alliance, by 2006, approximately 15 500 female sex workers were reported to be accessing prevention and care services.<sup>ii</sup> However, existing prevention programmes reach only 34% of female sex workers. Those under 25 years are reached noticeably less often by HIV prevention programmes than older sex workers. Only 24% of female sex workers were reached by STI screening and/or treatment services, while only 7% received HIV counselling and testing (5). Furthermore, there are no policies promoting information, education and communication on HIV and preventive health interventions among sex workers.

Ukraine rescinded the act on homosexual activities in 1991, but to this day homosexuality carries intense stigma and discrimination in society. Since 1987, only 110 cases of HIV have been officially reported among MSM in Ukraine. The low number of reported HIV cases is likely to be due to underreporting, which indicates that MSM are either not seeking voluntary counselling

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<sup>77</sup> International HIV/AIDS Alliance, Presentation at the stakeholders meeting 2007. Brighton, International HIV/AIDS Alliance, 2007.

and testing services or do not disclose their sexual orientation. MSM in Ukraine are thus still hard to reach for research and prevention purposes (5).

Prevalence studies among MSM are very rare. However, two small studies conducted in 2004 in Odessa and Nikolayev revealed that 19% and 8.7%, respectively, of MSM tested positive for HIV. The International HIV/AIDS Alliance's behavioural surveillance study among 886 MSM revealed relatively high awareness about HIV transmission (49% of the participants correctly answered five questions on HIV transmission) and a high level of condom use (72%) (5). More behavioural and sentinel studies are obviously needed among MSM to strengthen prevention measures in this risk group.

## **6. Gender equity**

The proportion of women among newly reported cases of HIV in Ukraine was 38.2% in 2001 and increased to 41.6% in 2005. Ukraine has a policy in place to ensure equal access for men and women to prevention and care. However, HIV programming does not take a gender-sensitive or gender-specific approach, especially for the most vulnerable subgroups (e.g. female drug users, female sex workers who are also injecting drugs, etc). Double stigma associated with HIV and drug abuse and related to the social role of females affects their health-seeking behaviour and access to preventive services. The level of stigma and discrimination towards female IDUs and women living with HIV is higher from various sectors of society, including health care providers, than towards male IDUs and men living with HIV. Both women and men are provided with access to antiretroviral treatment on the basis of clinical progression. At the end of 2005, 29.1 % of men and 41.0% of women with advanced HIV infection had access to antiretroviral therapy.

## **7. Prevention of mother-to-child transmission and paediatric AIDS**

The increasing number of HIV-positive women has led to an increasing number of infants born to HIV-positive mothers, accounting for 17% of all reported new cases in 2006. Since 1987, 570 HIV-positive children developed AIDS, including 123 new cases in 2006, and 218 children died of AIDS, including 32 cases in 2006. As of January 2007, 650 children were provided with highly active antiretroviral treatment, representing 13.6% of all PLHIV who are currently on antiretroviral therapy.

In 2004, 97% of all pregnant women were tested for HIV, and 86% of HIV-positive pregnant women received a complete course of antiretroviral prophylaxis through state-owned clinics (5), increasing to more than 90% by the end of 2006. The high uptake is due to a combination of factors: the integration of government programmes for preventing HIV infection in infants into existing maternal and child health care services and HIV-specific services supervised by the Ministry of Health; a universal opt-out strategy for voluntary counselling and testing during pregnancy; and the provision of antiretroviral prophylaxis.

The reproductive health rights of women in Ukraine are of concern, according to a report by Human Rights Watch. A 2004 study reveals grave discrimination against HIV-positive women in delivery settings (13). Nearly half of the participants reported that they had been strongly encouraged to have an abortion by a health care provider, while several women "reported that they were not given a choice but told they must have an abortion" (13).

## **8. Young people**

Young people are one of the age groups most affected by the epidemic, yet they demonstrate extremely low awareness of HIV transmission. Findings from the International HIV/AIDS Alliance's behavioural study among 2501 young people aged 15–24 in 2004 showed that only

14% of the young respondents correctly identified ways of preventing the sexual transmission of HIV and rejected major misconceptions about HIV transmission. While 83% of the respondents reported having been in contact with prevention programmes of some sort, only 20 young people, or 0.9% of the participants, had received HIV counselling and testing; and 69% of the respondents had reported using a condom last time they had intercourse with a non-regular sexual partner (5).

Ukraine does not have a specific policy or strategy that promotes information, education and communication on HIV to the general population, nor is one in place to ensure accurate HIV reporting by the media. This is of serious concern, since ignorance about HIV is widespread in the country, in particular among young people. Findings from a 2005 study by the International HIV/AIDS Alliance show that 52% of young people indicated that HIV can be transmitted through mosquitoes and animal bites; 26% of the respondents believed that it was possible to get infected with HIV through common use of a swimming pool or toilet, and 28% were unable to answer the question (17).

HIV education is included in the curriculum in primary and secondary schools, and the same reproductive and sexual health education is provided for young men and women. According to a UNICEF/UNAIDS/WHO report, 99% of young women have heard about AIDS (17). However, considering the extremely low knowledge of and widely held misconceptions about HIV, the sexual and reproductive health education provided to young people needs to be drastically improved and intensified.

## **9. HIV in the workplace**

In 2005, Business Against AIDS, a national association of leading Ukrainian and international companies, business associations and labour unions, was established by Transatlantic Partners Against AIDS (TPAA), with the aim of bringing business forces together to respond to the HIV epidemic in Ukraine. The association supports the implementation of international guidelines on HIV practices in the workplace which include awareness-raising and commitment at senior management level; networking with partners of the government, mass media and civil society, including international organizations; implementation of non-discrimination policies in the workplace; initiating workplace HIV education and training programmes for employees; and helping companies support their local communities (18).

A survey funded by the International HIV/AIDS Alliance found that, while the majority of the companies have implemented parts of the recommended policies and programmes to respond to HIV in the workplace, none of them had implemented the full programme (5). Some forms of HIV education activities are in place in most companies, as 21 of the 30 participating enterprises distributed posters, leaflets and booklets and organized workshops and lectures on HIV/AIDS, STIs and drug use for employees and senior management. However, condom distribution remains the largest gap in HIV prevention programmes in the workplace (5). It is obvious that the promotion of awareness and anti-discrimination of HIV in the workplace needs to be intensified. In addition, large enterprises should be motivated to engage more closely with their local community.

The Ukrainian action framework for addressing HIV and AIDS issues among national uniformed services, the military, peacekeepers and police is entitled *Comprehensive plan of response to HIV epidemic spread in the Armed Forces of Ukraine for 2004–2008*. It was approved by the Minister of Defence in 2004 and includes HIV prevention, voluntary counselling and testing, and a study of risk behaviour among military servicemen in Ukraine. The plan does not mention care and support. A behavioural study among military staff reveals that military servicemen are highly sexually active. The level of condom use among military personnel is relatively high, with

80% of participants reporting the use of condoms during sexual intercourse with non-regular partners in 2004 (5).

## **10. Sexually transmitted infections**

The STI epidemic in Ukraine is still rampant, with an incidence rate for syphilis of 42 cases per 100 000 population in 2005 (19). While the number and rates of newly reported STIs have fallen in recent years (mainly due to underreporting), the rates are still extremely high in comparison with western Europe. The HIV and STI co-infection rates in 2004 varied from 0.7% in Kharkiv to 25% in Nikolayev (20).

The Ukrainian system for STI control is supported by the Ministry of Health's regulations and includes the performance of diagnosis, treatment and prevention of STIs (5). The national standards for diagnosis are generally consistent with European standards, while treatment guidelines need further update and revisions. According to a survey published in the UNGASS report, 41% of patients who were treated for STIs received counselling on HIV.

## **11. Research and new technologies**

By 2008, Ukraine plans to have domestically produced medications for OST that are consistent with and cheaper than imported drugs (15).

The current National HIV/AIDS Programme envisages carrying out scientific research in the area of pathogenesis, diagnosis and treatment of HIV/AIDS and AIDS-related diseases and some further research into the socio-economic impact of HIV in Ukraine. Some special studies have been funded and conducted under the supervision of the International HIV/AIDS Alliance in Ukraine, mainly focusing on behaviour changes and HIV prevalence in the most-at-risk groups. Evaluation of the socio-economic impact of the HIV epidemic in Ukraine was completed in 2006 with assistance from the World Bank and the International HIV/AIDS Alliance and in partnership with the Ministry of Health of Ukraine. The special research into HIV drug resistance in naïve patients is commencing in Ukraine in the framework of the all-European project funded by the European Commission. Currently, the Ukrainian pharmaceutical company, Darnitsa, and the State Pharmaceutical Centre are carrying out clinical trials on the effectiveness of domestic antiretrovirals – FDC(AZT+3TC). However, there are still examples of the use and promotion of non-evidence-based technologies (e.g. Armonicum for treatment of HIV patients or clinical trials of Proteflazid in patients with HIV and hepatitis B and C coinfections).

A two-year research project on the prevention of initiation of injecting drug use among vulnerable youth (2005–2006) assessed the reasons for occasional drug use, vulnerability factors, social circumstances and motives that lead young people to start injecting drugs. The project was implemented by the Ukrainian Institute of Social Research with the support of the DV8-RTD Institute in Rotterdam, supported by UNICEF and UNAIDS in Ukraine. Based on the research, strategies to decrease the incidence and prevalence of injecting drug use among youth were developed.

## **C. Living with HIV and AIDS**

### **12. Treatment and care**

The Law of Ukraine on AIDS Prevention and Social Protection of the Population stipulates free access to antiretroviral treatment for people living with HIV. Expanding access to antiretroviral treatment has been highly prioritized in recent years and has been implemented with support from the GFATM grant based on a step-by-step policy of setting up sites providing antiretroviral

treatment. At present, highly active antiretroviral treatment is available in all 27 administrative regions of Ukraine (21), with about 4777 individuals receiving it in January 2007 (22). However, according to the Ukrainian Road Map towards Universal Access, the estimated number of people in need of antiretroviral treatment was 11 990 in 2006 (22), so coverage was only an estimated 39.8% at the end of 2006, and access to treatment is still considered highly insufficient (23). In 2004, Ukraine joined the Clinton HIV/AIDS Initiative Procurement Consortium, which helps the country purchase antiretroviral drugs at a lower price (11). Treatment and care are provided based on the National HIV/AIDS Treatment Guidelines adapted in 2006 in line with WHO Regional Office for Europe protocols and recommendations.

There has been an increase in the number of people receiving highly active antiretroviral treatment from only 37 in 2003 to 4777 in January 2007, including 1776 infected through injecting drug use and 55 prisoners, treated at 41 facilities. The scaling up of highly active antiretroviral treatment has been achieved to a great extent through international loans and funding, in particular the GFATM grant of US\$ 92 million, which aims to increase access to antiretroviral treatment to 6000 people by September 2008 (11).

### **13. Stigma, discrimination and human rights**

Despite the efforts of the Ukrainian government in the fight against HIV, not enough is being done to protect the rights of the people directly affected by the epidemic. A recent survey by the International HIV/AIDS Alliance in Ukraine reveals that 69% of people living with HIV have been denied health care at some point, and 70% believe that their right to confidentiality has been violated outside specialized clinics. Furthermore, only about 18% of respondents “feel comfortable informing health care workers of their HIV-positive status, even if it seems vital to do so” (8) Human Rights Watch confirms this situation with data from its 2004 survey of 692 people living with HIV from 16 cities in Ukraine: 42% of respondents reported violations of their rights to employment, education, health care or privacy due to their HIV status, 10% had lost a job because of their HIV status, and 9% had had to change jobs. Furthermore, one-third had been tested for HIV without their consent and 60% did not know of their legal right to receive free antiretroviral treatment, or that it was even available (13).

The lack of awareness of HIV contributes to widespread stigma and discrimination faced by people living with HIV, and people show alarmingly low awareness of how HIV is transmitted. None of the young people aged 15–24 and only 2% of the adults interviewed had tolerant attitudes towards people living with HIV (5). In October 2005, the Coalition of HIV Service NGOs organized a workshop entitled ‘Discrimination in the times of HIV’ to strengthen anti-discrimination legislation. The workshop resulted in the formation of a wide-scale anti-discrimination movement and the development of an anti-discrimination law (9). However, the implementation of these measures still needs to be ensured.

### **14. Testing and counselling**

Since 1987, within the framework of the government-supported surveillance system, wide-scale mandatory HIV testing of several subpopulations has been in place, often with no provisions for informed consent from the individuals (6). From 1987 to 1993, Ukraine conducted mass population screening for HIV, performing more than 33.5 million HIV tests. This very costly surveillance method proved highly inefficient, detecting only 356 cases of HIV (24).

In 1998 mandatory testing of high-risk groups was abolished, and only testing of donors’ blood for HIV remains mandatory. The National Protocol on Voluntary HIV Counselling and Testing was developed by a Ministry of Health working group, the USAID Policy Project and the International HIV/AIDS Alliance in Ukraine. A national voluntary counselling and testing

protocol was approved by a decree of the Ministry of Health in August 2005 and was registered at the Ministry of Justice in November 2005. The protocol is currently being field-tested in three regions of Ukraine, and results will be available by the end of 2007.

To this end, the Ministry of Health created a working group on counselling and testing that consists of representatives from governmental, nongovernmental and international organizations. In November 2006, a national consultation meeting on scaling up HIV rapid testing was held with the involvement of national and international stakeholders. Following the recommendations of the consultation, the working group on counselling and testing developed the National Comprehensive Working Plan of Rapid Testing Scale-Up in Ukraine that the Ministry of Health recently approved for implementation.

Despite all these efforts, HIV testing remains patchy among most-at-risk groups. According to the sentinel behavioural studies, 27% of IDUs, 32% of female sex workers and 25% of MSM received an HIV test during the past 12 months and know the test results (5).

### **15. HIV in prisons**

According to information presented by the State Department of Corrections, 1848 new cases of HIV were registered in 2006, bringing the cumulative total number of HIV cases registered since 1987 to 19 700. The highest number of new cases was reported in 2004, when 2588 cases were registered. In 2006, 1188.3 cases per 100 000 inmates were newly diagnosed, which was less than in previous years (1526.1 in 2004 and 1234.4 in 2005). Of the people living with HIV in the prison system, a total of 1172 had developed AIDS since 1987, with 357 new cases of AIDS and 130 deaths in 2006. As of 1 January 2007, 55 patients were receiving antiretroviral treatment in penitentiary institutions (International HIV/AIDS Alliance presentation at the stakeholders meeting on 15 March 2007).

## **D. Overall progress and future challenges**

Ukraine has made some progress over the past years in an effort to reduce the spread of HIV in the country. These include the increased participation of civil society organizations in HIV prevention efforts; the integration of government HIV prevention programmes into existing maternal and child health programmes; and an increase in the number of people having access to antiretroviral treatment, with highly active antiretroviral treatment now available in all 27 regions in the country.

Despite strong political commitment to the national HIV/AIDS response, the HIV epidemic in Ukraine continues to spread (3). The main challenges for the Ukrainian government in its response to HIV will be to deal with societal taboos regarding the most-at-risk groups, to make effective use of all existing resources, and to mobilize additional resources to implement large-scale interventions, in particular among the most vulnerable and 'bridge' populations (5).

Although the government has developed a secure legal basis for the response to HIV which is consistent with international guidelines, this legislation is often not implemented, so its efforts are not sufficient to have a measurable impact on the epidemic. The following challenges are partly adapted from a TPA Policy Brief on strengthening Ukraine's response to HIV (8):

- Policymaking and budgeting processes need to be improved – inconsistent and unrealistic budgeting results in a gap between planned and actual spending.

- Policymakers, government officials and the general population need more information about HIV, particularly about effective prevention methods, such as harm reduction and OST.
- Stigma and discrimination of vulnerable populations remain widespread, and knowledge and awareness about HIV need to be increased among health care workers, the police and prison staff. The general population, in particular young people, show low knowledge of HIV and foster intolerant attitudes towards people living with HIV.
- Currently, fewer than 40% of people living with HIV in need of antiretroviral treatment are receiving it. This needs to be scaled up to 100% in accordance with the national law on HIV and the government should work to reduce the cost of antiretroviral drugs.
- The coverage and intensity of prevention and harm-reduction programmes need to be urgently increased among most-at-risk groups. Laws, policies and standards of prevention and care need to be developed to enable the country to put in place effective services for IDUs.
- Maternal health programmes need to be further intensified and sustained to progress towards the virtual elimination of mother-to-child transmission. This will include the expanded use of combination antiretroviral treatment for pregnant women and wider coverage of programmes to prevent mother-to-child transmission among vulnerable groups (IDUs, sex workers) who are at the centre of the epidemic and yet currently left out of these services.
- While educational programmes to prevent sexual transmission among the general public are important, prevention efforts still need to be focused on most-at-risk populations in Ukraine (25).
- The general population, but especially young people, need more information on sexual transmission and prevention of HIV.
- The involvement of civil society organizations, including the network of people living with HIV, needs to increase and be made more meaningful.
- More behavioural and sentinel studies are needed among MSM to strengthen prevention measures in this risk group.

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## Country report – United Kingdom

Pop. 59 668 000

### **Epidemiological summary and surveillance**<sup>78</sup>

This country profile covers the United Kingdom, which in turn encompasses diverse sub-profiles. To the extent possible, separate information is given for England, Scotland, Wales and Northern Ireland. However, whenever the overall situation and progress are overlapping, the country is profiled as a whole.

By the end of June 2007, British authorities had reported a cumulative total of 88 627 HIV cases in the United Kingdom, of which 22 755 had developed AIDS and 17 338 had died (*1*). The same report also stated that at the end of 2006, there were an estimated 69 400 (64 800–75 500) people living with HIV in the United Kingdom, approximately 21 600 of whom were still unaware of their infection. By June 2007, 7093 new HIV infections emerged in the United Kingdom, the highest increment in reported new cases in western and central Europe. This represents a 157% increase in HIV infection diagnoses from 1997 (*1*).

Of all the newly reported HIV cases within the UK 2006–June 2007, 92% had been reported in England (of which 58% were in London), 2.2% in Wales, 0.8% in Northern Ireland and 4.0% in Scotland. Although London continues to be the most affected area, HIV diagnoses have increased substantially in other English Strategic Health Authorities (SHAs), such as North West and East of England SHAs (*1*).

Nearly three quarters of newly diagnosed persons in 2006 were aged between 25 and 44, with only 5.9% (420) of persons under the age of five or over 55. This pattern was observed in all ethnic groups and exposure categories. AIDS-related deaths have declined in the era of highly active antiretroviral treatment and many of the 497 deaths that occurred in 2006 were associated with a late diagnosis of HIV.

In 2006, 59% of infections with a known exposure category were transmitted heterosexually, while 36% were attributable to MSM and 2.5% to injecting drug use. Mother-to-child transmission accounted for 2% of the cases, and blood or tissue reception for 1%. In 17% of the 2006 diagnoses, the transmission mode was other or undetermined.

Current primary prevention efforts directed towards interrupting HIV and STI transmission among men who have sex with men (MSM) are not succeeding adequately. After adjustment for reporting delay, there were an estimated 2700 new HIV diagnoses in MSM in 2006, a total similar to the highest previous annual number of 2650 diagnoses in 2005. The proportion of heterosexually transmitted HIV infections has increased from 232 in 2000 to an estimated 750 in 2006.

Evidence indicates that the introduction of high-quality harm-reduction services at the early stages of the epidemic accounts for the sustained low HIV prevalence among injecting drug users (IDUs) during that time (*2*). The incidence among IDUs in recent years has been relatively stable, at an annual average of 131 reports from 1998 to 2005. By June 2007, however, that figure had increased to 156. In 2006, 23% of IDUs reported sharing equipment with other IDUs in the previous month. Overall, around 1 in 50 IDUs is now infected, which is still low compared

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<sup>78</sup> The summary is based on WHO epidemiological country report and data from Health Protection Agency as referenced.

to many other countries. By the end of 2006, there had been a cumulative total of 4 662 HIV diagnoses reported in the UK where infection was thought to have been acquired through injecting drug use – 4.2% in England, 26% in Scotland, 3.8% in Wales and 2.1% in Northern Ireland. The prevalence remains highest in London, with around one in 25 IDUs being HIV infected. The recent increase in HIV prevalence among IDUs has been greatest in England and Wales, where the prevalence has risen from around one in 400 in 2003 to about one in 65 in 2005 (3).

HIV/AIDS surveillance is coordinated by the Health Protection Agency. Additionally Health Protection Scotland, the National Public Health Service for Wales, and the Department of Health, Social Services and Public Safety in Northern Ireland are involved. The Health Protection Agency produces quarterly reports using the following data sources:

- Laboratory and clinician reports of newly identified HIV antibody positive individuals and AIDS cases (clinician only) reported to the HIV and sexually transmitted infection (STI) department of the Health Protection Agency Centre for Infections and to Health Protection Scotland;
- Returns to the Oxford Haemophilia Centre for the United Kingdom Haemophilia Centre Directors' Organisation;
- Paediatric data compiled at the Institute of Child Health in collaboration with the Health Protection Agency Centre for Infections and Health Protection Scotland and from follow-up of monthly notifications to the British Paediatric Surveillance Unit of the Royal College of Paediatrics and Child Health, and the National Study of HIV in Pregnancy at the Royal College of Obstetricians and Gynaecologists.

Cumulative data from all these sources are amalgamated at the end of each quarter to produce the current United Kingdom dataset of reported HIV-positive individuals. However, these data are not in the public domain until officially released in report form, typically every 18 months, though laboratory data are available on a quarterly basis.

## **A. Leadership and Partnership**

### **1. Political leadership (national framework)**

The British government has prioritized the response to the HIV epidemic since the first cases were reported in 1982. While sexual health is prioritized at the national level, civil society and frontline staff continue to report issues of lack of investment and problems regarding access to services in local settings. HIV prevention and treatment have been further integrated into general health care services. The United Kingdom has always had different health policy processes because of the separate administrative structures in the four nations. However, since devolution in 1999 and the creation of national assemblies for Wales, Northern Ireland and Scotland, differences between them are becoming more apparent.

National political support was revived in 2004 with the government's public health White Paper, *Choosing Health*, which focused on improving sexual health services and campaigns to increase awareness of sexual health. Issues include contraception, abortion, psychosexual services and the detection and treatment of STIs and HIV. Later, in 2006, the White Paper *Our Health, Our Care, Our Say* was launched with the aim to improve community health and social services for everyone. The Department of Health invited the public to contribute suggestions of where they thought improvement was needed. The main goals the paper identified were improving prevention of and access to treatment for STIs, HIV and reproductive health, and meeting the goal of everyone having access to genitourinary medicine (GUM) clinics within 48 hours. The

paper recommends the development of locally managed networks for sexual health, specifically with regards to young people.

The United Kingdom has no national HIV/AIDS coordinating body devoted to promoting interaction between government, people living with HIV, the private sector and civil society for implementing HIV/AIDS strategies and programmes. Each of the four United Kingdom administrations has a programme comprising specific goals and strategies for HIV and STIs.

The Scottish strategy and action plan for addressing HIV/AIDS and improving sexual health is outlined in *Respect and Responsibility*, published by the Scottish Executive in 2005 (4). This document describes Scotland's desire to further integrate sexual and reproductive health into the education sector, and all schools are expected to provide sex and relationships education, specifically "abstinence plus" education to delay the onset of sexual activity. In *Respect and Responsibility*, a national sexual health strategy, now in its third year of implementation, has focused on reducing unintended pregnancies and STIs, enhancing the provision of sexual health services and promoting a broad understanding of sexual health and relationships. The independent agencies, Health Protection Agency and Health Protection Scotland, are responsible for epidemiological surveillance and, as part of this function, report on performance against relevant sexual health indicators defined by the National Sexual Health Advisory Committee for Scotland. Their annual reports include data collection, analysis, reporting and information feedback in a framework of well-defined standardized indicators and a budget plan (5).

In Wales, the Strategic Framework for promoting Sexual Health was launched in 2000. The National Public Health Service (NPHS), established in 2003 along with the 22 Local Health Boards in each of the local authorities in Wales, established the Sexual Health Programme which collects and collates data on the levels of STIs, including HIV, in the Welsh population. Such data allow significant trends and any particular groups of the population affected to be identified, and will facilitate the effective delivery of high-quality, accessible and appropriate specialist public health services, both in partnership and in support of other national and local bodies (6).

The Department of Health in Northern Ireland addresses HIV through its Sexual Health Promotion Strategy and Action Plan, issued in the spring of 2006. The consultative document, *A Five Year Sexual Health Promotion Strategy and Action Plan*, was issued by the Department of Health, Social Services and Public Safety. The aim of the document is to improve, protect and promote the sexual health and well-being of the population in Northern Ireland. The key objectives are to reduce the incidence of STIs, including HIV, and the number of unplanned births to teenage mothers, provide accessible information on sexual health and personal relationships and facilitate equitable access to high-quality sexual health services (7).

In England, the government drafted the first national strategy for sexual health and HIV in 2001, entitled *Better prevention, Better services, Better sexual health*, which is still currently in use (8). The national strategy aims to reduce the transmission of HIV and STIs, the prevalence of undiagnosed HIV and STIs, and rates of unintended pregnancy, improve health and social care for people living with HIV and reduce the stigma associated with HIV and STIs (8). One of the main successes associated with the strategy has been the increased access to GUM clinics.

In addition, in connection with the implementation of the national strategy, the Department of Health set up the multisectoral Independent Advisory Group on Sexual Health and HIV (IAG) in 2003. The IAG advises the Department of Health and monitors the implementation of the national strategy through its annual report (5).

## **2. Community involvement and the private sector**

Civil society has been widely involved, particularly in England, and from the beginning of the epidemic, the voluntary sector has performed a key role in developing prevention, treatment and care initiatives, in cooperation with local and national statutory health organizations (8). Both the Department of Health and the IAG welcome the input of the voluntary sector “in providing expert advice and consultation to Government and, increasingly, services for sexual health” (9). For example, nongovernmental organizations (NGOs) run programmes to educate and raise awareness among people living with HIV concerning their rights. It is noted that financial cutbacks have led to increasing difficulties in meeting the needs of the growing number of people living with HIV (5). The IAG believes that the voluntary sector can increase its scope of service provision, providing standards can be met and monitored, and the government should consider this as a valuable pool of expertise (9).

Four NGOs – Terrence Higgins Trust, the National AIDS Trust, the UK Coalition of People Living with HIV and the African HIV Policy Network – were involved in the completion of the UNGASS report in 2006 (5). In particular, people living with HIV and others representing affected communities were part of the working group overseeing development and implementation of a national strategy for HIV/AIDS for England and took part in consultations with the IAG and the Expert Advisory Group on AIDS. However, the aforementioned NGOs considered that more could be done to include people living with HIV and affected groups in policy consultation across government (5).

Civil society organizations have been involved with advocating for accurate HIV/AIDS reporting by the media. According to the IAG, good sexual health is not widely promoted in society. The media often present an “aggressive” or negative image of sexuality, and this presents a challenge to those trying to create an understanding of what good sexual health is and the behaviours to achieve it (9). Therefore, the IAG emphasizes the role of the government-funded sexual health media campaign, which targets younger men and women, focusing on the prevention of HIV/AIDS and other STIs by improving basic awareness of sexual health issues.

## **3. Resource generation**

Since 2003, the Department of Health has allocated £16.5 million annually to local authorities for social care services in England. It also funds NGOs for health promotion related to HIV for MSM and African communities at the national level, in line with the epidemiological situation in the United Kingdom, and current contracts for England total £1.7 million a year. However, for the current and previous financial year, it gave an additional £1 million each year for targeted prevention work. The government provides core funds to the UK Coalition of People Living with HIV/AIDS.

In accordance with the *Choosing Health* White Paper, the government allocated £300 million to improve sexual health services, namely GUM and contraceptive services (£40 million pledged for 2006), implementing the accelerated roll-out of the Chlamydia Screening Programme, and the sexual health media campaign. An extra £15 million was announced in July 2005, specifically for the improvement of infrastructure for genitourinary units. The annual £1 million allocated by the Department of Health to the Medical Research Council (MRC) for research received a boost from the MRC of a further £700 000. This helped to support eight new research proposals in the 2005 funding round (9).

However, financial pressure and the marginalization of HIV/AIDS in the national policy of devolution of health planning to the local level have resulted in cutbacks in local HIV prevention in the face of growing numbers of people in need of treatment and care. Funds for HIV prevention are currently derived from National Health Service mainstream funding (as there are

no longer ring-fenced funds available). This means that in England, Wales and Northern Ireland, HIV programmes must compete directly with other health programmes for funding and it is up to the newly formed local Primary Care Trusts to determine their spending priorities. There are clear signs that the 2005–6 and 2006–7 funds are declining at the local level despite central government commitment to HIV/AIDS services (5). This paradox needs to be addressed, since funds are not generally earmarked for HIV/AIDS or any other illness when they are delivered to local health authorities or local health organizations in England, Wales and Northern Ireland. In Scotland, however, the NHS Trusts do ring-fence funds with regards to bloodborne viruses, which include HIV, as they are entirely funded via the Scottish budget.

## **B. Prevention**

The United Kingdom has had preventive programmes in place for years (most were implemented before 2003) concerning blood supply, sex education in schools, behaviour change communication, voluntary counselling and testing, prevention of mother-to-child transmission and programmes to ensure universal precautions in health care settings (5). However, there is worrying evidence of a decline in recent years in public awareness of routes of HIV transmission (10).

In all parts of the United Kingdom, HIV prevention and treatment are part of local mainstream health care services through the National Health Service (NHS). In England, an information, education and communication strategy is in place to address health risks in most-at-risk populations, including harm reduction for IDUs, MSM, sex workers, prisoners, refugees and black communities at risk of HIV, but not specifically migrants and other mobile populations. A social marketing programme for condoms, Condom Essential Wear, has been recently implemented, although HIV is not mentioned explicitly in this programme, and the levels of funding invested thus far have been less than promised. Condoms are available free of charge to this initiative from the NHS.

### **4. Injecting drug use and HIV**

In 1998 the 10-year national drug strategy was launched: *Tackling Drugs to Build a Better Britain*. An update of the United Kingdom strategy was published in 2002. Since devolution in 1999, where appropriate, Scotland, Wales and Northern Ireland formulate policies that complement the overall aims of the United Kingdom strategy. Anti-drug strategies in Scotland (*Tackling Drugs in Scotland – Action in Partnership*), Wales (*Tackling Substance Misuse in Wales – A Partnership Approach*) and Northern Ireland (*Drug Strategy for Northern Ireland*) deal with drug-related problems specific to them. All three strategies reflect the same four aims as the United Kingdom strategy, relating to young people, reducing supply, communities and treatment, but with specific objectives and action priorities tailored to the particular problems and circumstances in each place (11). There have also been a number of initiatives, such as the establishment of the National Treatment Agency for Substance Misuse and Models of Care, in England, to support the development of services to meet the strategies' aims (3).

The United Kingdom introduced harm-reduction services for the injecting drug use community early in the epidemic to prevent the spread of HIV and other infectious diseases, and it stands as a best practice example in Europe (2). As with the other main strategies, the current harm-reduction strategies are outlined in the national drug strategy and further specified in each of the decentralized strategies (11).

Primary care bodies (Primary Care Trust in England, Local Health Care Cooperatives and NHS Boards in Scotland, Local Health Boards in Wales, and Health and Social Services Boards

supported by Local Health and Social Care Groups in Northern Ireland) and Drug Action Teams or local partnerships “should give priority to preventing the spread of infections among IDUs and reducing the harm that these infections cause” as outlined by national drug strategies (3) and *Models of Care for Treatment of Adult Drug Misusers* by the National Treatment Agency for Substance Misuse (12). This should be done by continuing the development of high-quality needle exchange programmes (NEPs) for those unable to stop injecting, ensuring sufficient distribution of injecting equipment to prevent the sharing of needles and syringes, and providing information and practical advice on safer injecting practices and easy access to health care services (3).

In England, 80% of NEP sites are pharmacies (72% in Scotland). The remainder are specialist services, including mobile or outreach sites. Pharmacies and specialist services distribute approximately equal numbers of syringes, but specialist services offer a wider range of injecting equipment (3). A national survey on NEP facilities in the United Kingdom identified 1326 sites in England, but, due to a lack of response, there are likely to be more. Only 31% of NEP facilities in England offered HIV testing, while 43% offered testing for hepatitis C. On average, specialist NEP services and pharmacies were given the equivalent of about one syringe per user for every two days (3). In Scotland, there were a total of 188 NEP sites, 40% of which offered hepatitis C testing and only 29% HIV testing. They reportedly distributed approximately 3.5 million needles and syringes from April 2004 to March 2005, although the actual total is likely to be higher (3).

In 2005, 53% of IDUs seen for HIV-related care were on a combination of three antiretroviral drugs, and 15% (151 people) were receiving four or more drugs, while only 23 individuals were receiving mono or dual drug combinations. Thirty per cent of them were not receiving antiretroviral therapy in 2005.

## **5. Most vulnerable and high-risk populations**

Early in the epidemic, the government coordinated a multisectoral response that included broad-based awareness-raising programmes aimed at the general population and prevention programmes aggressively targeting IDUs, MSM and sex workers, thereby containing potentially serious HIV epidemics to low levels in the late 1980s.

The government is targeting local prevention and treatment programmes to black and minority ethnic populations, including non-clinical HIV testing sites. In 2005, 22 000 black and minority ethnic individuals accessed HIV-related care, which constitutes a sevenfold increase since 1996. Furthermore, the proportion of HIV-diagnosed black and minority ethnic individuals living outside of London has increased from 14% to 47% between 1996 and 2005. Before 2005, there had been a greater uptake of voluntary counselling and testing among both heterosexuals and MSM born abroad and attending 16 sentinel GUM clinics in England, Wales and Northern Ireland compared with United Kingdom-born heterosexuals. However, in 2005 these proportions have converged to 82% in United Kingdom-born MSM and 80% in MSM born abroad and to 82% and 81%, respectively, in heterosexuals. Although, once HIV is diagnosed, Africans are equally as likely as MSM to receive HIV treatment, HIV persists in causing serious illness and death due to late diagnosis in black and minority ethnic populations. Therefore, the promotion of HIV testing among these groups and the reduction of HIV-related stigma are required to reduce the delay in diagnosis, and the expansion of appropriate opportunistic screening in cooperation with health care professionals and patients is necessary (13).

The current legislation in the United Kingdom poses obstacles to HIV/AIDS prevention and care among migrants and mobile populations. Namely, the Nationality, Immigration and Asylum Act 2002 and the Asylum and Immigration Act 2004 allow for the withdrawal of support from and

detention, dispersal and deportation of failed asylum seekers and do not permit asylum seekers to work while their claim is being processed. The consequent dispersal and deportation, in particular, present obstacles for HIV prevention and continuity of care. Additionally, the 1989 NHS Charges to Overseas Visitors Regulation stipulates that those ineligible for free NHS care must pay for HIV treatment. This affects all categories of undocumented migrants, most of whom may have no recourse to funds and are, therefore, effectively denied access to HIV treatment. Asylum seekers receiving treatment at the time their application fails are able to continue receiving treatment without charge up to the time they leave the country or are deported (5).

Although MSM accounted for 37% of HIV reports in 2006, this remains the group most at risk of acquiring the infection within the UK (13). Prevalence has increased among MSM due to both an increasing number of infections and prolonged life expectancy after the introduction of highly active antiretroviral therapy. One of the main challenges in response to the epidemic is to deal with increased risk-taking, such as higher frequency of unprotected anal intercourse and a general switch from risk-avoidance strategies to risk-reduction. This is particularly of concern among those unaware of their infection and in those that have never been tested for HIV (13). STIs in this risk group are also increasing, which indicates high levels of unprotected sex and may facilitate the further spread of HIV. In 2004, reports emerged of new and increasing rates of the bacterial infection Lymphogranuloma Venereum (LGV), which before 2004 was rarely seen in the UK. Among those MSM who had LGV, 80% were coinfecting with HIV. Among syphilis cases, 34% were co-infected with HIV and among individuals who had acquired gonorrhoea, 49% were co-infected with HIV. Dual infection with HIV and hepatitis C in this risk group is also of concern (13). The governments of England and Wales have made a policy commitment to target prevention work among the two most-at-risk communities, which are MSM and African men and women, but there are no incentives, monitoring or sanctions in place to ensure the implementation of these commitments at a local level (5).

The Department of Health and the UK AIDS and Human Rights Project agree that there is a lack of strategies directed at sex workers in the United Kingdom. Although prevention activities have been implemented among this population, there are no specific anti-discrimination laws or regulations regarding HIV/AIDS discrimination among sex workers (5). Sex workers are briefly mentioned in England's national sexual health and HIV strategy as a group needing targeted sexual health information and HIV/STI prevention measures, but they are not mentioned in the implementation action plan. Moreover, sex workers are not mentioned in the Scottish sexual health strategy and are only briefly mentioned twice in the Welsh strategy action plan.

In 2006, a new policy on sex work in England and Wales was published, entitled *A Co-ordinated Strategy on Prostitution*, which focuses on the development of ways out of sex work, rather than on the health needs of this population. The Scottish Executive has shown a different perspective by announcing changes in relation to street-based sex work, including a focus on harm reduction and actions to improve access to mainstream health care services, and the establishment of an effective dedicated health service (14).

## **6. Gender equity**

The United Kingdom has a clear policy and statutory basis to protect people from discrimination on grounds of their biological sex in health care. However, the recent immigration and entitlement policies disproportionately affect women, since women make up two-thirds of African-born people living with HIV in the United Kingdom. Although women are included in the 2001–2011 National Strategy for Sexual Health and HIV as a risk group for STIs, no specific strategies to promote gender equality regarding HIV diagnosis, care and support are outlined. However, the English Department of Health makes available dedicated funding to local

authorities for social care linked to HIV, prioritizing women and children with HIV. From 2002 to 2004 the proportion of women leaving sentinel GUM clinics in London unaware of HIV infection decreased, while the prevalence of previously undiagnosed HIV infection among women attending sentinel GUM clinic attendees in London remained constant (5).

## **7. Prevention of mother-to-child transmission and paediatric AIDS**

Between 2000 and 2003, policies were implemented in England, Wales, Scotland and Northern Ireland to offer and recommend HIV testing as a routine part of antenatal care. By the end of 2001, 97% of maternity units across England had implemented the policy and, although the target of 90% uptake was only met by 30% of clinics, the estimated detection rate of HIV infection in pregnant women exceeded the 80% target (13).

Between 2000 and 2004, most pregnant women were unaware of their infection, but in 2005 this had changed and most women were already diagnosed when they entered antenatal care. This means that many previously diagnosed women are receiving HAART, while newly diagnosed women start treatment during the second trimester of pregnancy (13). HIV prevalence among women giving birth in the United Kingdom in 2005 varied according to where they were born: 2.4% (503/21 315) of women born in sub-Saharan Africa, 0.8% in Central America and the Caribbean, and 0.04% (14/31 185) born in Asia were HIV infected (13). In England and Scotland in 2005, an estimated 0.09% of all pregnant women had an undiagnosed HIV infection prior to antenatal testing. Most of these women will have been diagnosed as a result of antenatal testing.

By the end of 2005, a total of 1765 cases of HIV were reported in the United Kingdom among children under the age of 16 at the time of diagnosis; 82% (1397/1706) of them acquired their infection from their mother, and the majority (89%; 1054/1182) of these mothers were likely to have become infected in Africa (13). The remaining cases were transmitted through blood or blood products, before the introduction of blood screening procedures in 1985 (13).

Of a total of 7010 children born to HIV-positive women reported by the end of 2005, 89% (6173/6949) were born in the United Kingdom. Of these, 12% (761) were known to be HIV positive, 69% (4276) uninfected and 18% (1136) were still of indeterminate, i.e. either unresolved or unreported, HIV status (13). Around 95% of HIV-positive pregnant women in England and Scotland were diagnosed prior to delivery in 2005, compared with about 83% in 2001. Due to improvements in detection rates in HIV-positive pregnant women and the introduction of HAART, the proportion of infants exposed to vertical transmission who become infected with HIV has fallen from almost 7% in 2002 to an estimated 3% in 2005 (13).

## **8. Young people**

Young people aged 16 to 24 account for about 11% of HIV diagnoses each year and the uptake of voluntary confidential testing is higher among young people than those aged 25 and over. Young people are a crucial population for targeted sexual health promotion, as rates of HIV, chlamydia, syphilis, genital warts and genital herpes have continued to rise in this group. For example, the English National Chlamydia Screening Programme found that 1 in 10 young people are testing positive for Chlamydia (15).

The government-funded Sexual Health Media Campaign targets younger men and women and focuses on the risks of unprotected sex and the benefits of using condoms to avoid contracting STIs. However, the IAG underlines the necessity for school-based sexuality education, since “the more targeted and personal the information is at an early age, the more effective it is” (9). Currently, school-based education covers basic biological aspects of sexuality education and

HIV, whereas sexuality and relationships education is neither compulsory nor of uniform quality between schools (5).

The United Kingdom has the highest birth rate among 15–19-year-olds in western Europe (16). In England, the Department of Health works closely with the Department for Children, Schools and Families (formerly the Department for Education and Skills) which oversee the implementation of the Teenage Pregnancy Strategy, which is aimed at reducing the number of unplanned teenage pregnancies and reducing unsafe sex.

### **9. HIV in the workplace**

In 2003, the Health and Safety Executive published a report entitled *The extent of use of health and safety requirements as a false excuse for not employing sick or disabled persons* (17). The aim was to establish the nature and extent of the problem of health and safety requirements being used as a “false excuse” for not employing or continuing to employ disabled people or people with an injury or health condition. The report stated that health and safety was frequently being used as the rationale for non-recruitment or dismissal of a disabled person. Moreover, organizations varied considerably in their recruitment procedures towards people with a disability or health condition, and there was no consensus regarding the stage at which applicants should be asked to disclose a disability or health condition, and impairments were not viewed or treated the same by all employers. Additionally, there was a lack of understanding among some employers over what constituted a health and safety risk, probably due to the lack of knowledge about the impact of particular conditions or disabilities.

When employers were surveyed, HIV/AIDS was one of the least frequently mentioned conditions cited as grounds for not employing or dismissing employees. Only a minority of people interviewed had any experience of a potential employer raising health and safety concerns relating to their disability when they applied for a job. However, most suspected that on at least one occasion an employer had rejected their application because they were considered to be a safety risk.

According to the report, further guidance may be required to ensure that employers are clearer about the range of options and adjustments to consider when faced with an applicant or employee with a disability or health condition.

### **10. Sexually transmitted infections**

In 2005, there were 790 443 STI diagnoses and 1 841 886 attendances recorded at sexual health clinics. Between 1996 and 2005 the total number of diagnoses of STIs made at GUM clinics increased by 60%, and the total workload increased by 268%. Chlamydia remains the most commonly diagnosed STI in GUM clinics, with 109 958 diagnoses in 2005. Diagnoses of gonorrhoea declined by 13% in GUM clinics, from 22 321 in 2004 to 19 392 in 2005, whereas diagnoses of syphilis have continued to rise, by 23% from 2282 in 2004 to 2814 in 2005, and levels of ciprofloxacin resistance in *Neisseria gonorrhoeae* isolates increased from 14% in 2004 to 22% in 2005 in England and Wales, and from 19% to 24% in Scotland. While the numbers of gonorrhoea diagnoses declined in the population overall, the numbers of new diagnoses among MSM rose by 10% between 2004 and 2005 (18).

The United Kingdom has some of the world’s most comprehensive HIV and STI surveillance systems. These are predominantly based on data from GUM and HIV clinics and laboratory reports. In *Choosing Health*, the government allocated £300 million to GUM services, including £50 million for a national sexual health campaign. This funding was to help reduce waiting times and meet the 48-hour access target (19). However, these funds were not earmarked and many are thought to have been lost to cover the budget deficits of health trusts (20). The national

government has, thus far, spent less than £10 million of the £50 million earmarked for the national sexual health campaign.

### **11. Research and new technologies**

The MRC is the leading institute conducting HIV research in the United Kingdom, with a £500 million budget, of which a total of £44.78 million has been allocated to HIV research in the period 2003–2007.

The Department for International Development (DfID) is strongly committed to HIV prevention research. It has, so far, supported research and development into microbicides and vaccines with £86.7 million. This includes £40 million support for the Microbicide Development Programme (MDP) and £8.7 million for the International Partnership for Microbicides (IPM). In addition, DfID is the oldest and most unwavering European supporter of the International AIDS Vaccine Initiative, with funding totalling over £38 million since 1998, the latest £20 million of which was for the period 2005–2008.<sup>79</sup>

The most recent DfID White Paper includes a statement about doubling the research budget to £220 million per year by 2010/11, to include the continued support of the development of new drugs, vaccines and microbicides.

## **C. Living with HIV and AIDS**

### **12. Treatment and care**

A total of 47 517 individuals accessed HIV-related care in the United Kingdom during 2005, which represents an increase of 13% on 2004 (42 177) and a three-fold increase since 1996 (14 908). In 2005, over 47 000 people living with HIV were seen for care in the United Kingdom and 30 123 received HAART as of December 2005 (13). The treatment has been widely available throughout the United Kingdom since its introduction in the mid-1990s, and it is prescribed in line with British HIV Association guidelines (5, 21). People living with HIV are offered a comprehensive treatment and care package, including treatment of opportunistic infections, combination antiretroviral therapy, treatment of STIs, psychosocial support, home-based care, palliative care, treatment of common HIV-related infections and post-exposure prophylaxis (5).

In 2005, the most common AIDS-defining illnesses at the time of HIV diagnosis were pneumocystis pneumonia, pulmonary tuberculosis and extrapulmonary tuberculosis. Most of the tuberculosis cases occurred among black African heterosexuals (101 cases of pulmonary tuberculosis and 57 of extrapulmonary tuberculosis), whereas among MSM the most common AIDS-defining illness was pneumocystis pneumonia, with Kaposi's Sarcoma the second most common (13).

Equal access to treatment is undermined by charging people without legal residency status for HIV treatment although they are settled in the United Kingdom (5).

### **13. Stigma, discrimination and human rights**

The anti-discrimination law protects people living with HIV in employment with regard to the provision of goods and services, education and housing. The passing of the Disability Discrimination Act in 2005 recognizes HIV infection as a disability, and people living with HIV

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<sup>79</sup> For information on DfID funding of product development public-private partnerships, see: [http://www.research4development.info/PPP\\_VaccinesMicrobicides.asp#MDP](http://www.research4development.info/PPP_VaccinesMicrobicides.asp#MDP).

are thus protected under the act from the point of diagnosis. Although the government is generally committed to the principles of human rights, “an explicit commitment to the promotion and protection of human rights as the foundation of the Government’s HIV Strategy would provide an important corrective to an approach which is too often individually focused, ignoring or underestimating structural inequalities and injustices which help spread HIV” and harm the health of people living with HIV (5). The European Convention for Human Rights is embedded in British law through the Human Rights Act, which provides protection for people belonging to marginalized groups living with HIV (5). There are protective anti-discrimination regulations for MSM, and racial discrimination is prohibited.

However, several laws present obstacles for effective HIV prevention and care. Laws continuously marginalize sex workers and asylum seekers, in particular. Moreover, the criminalization of sexual transmission of HIV poses a problem as it may drive people living with HIV further underground and make them reluctant to be tested and seek information and counselling. The IAG is concerned about the use of criminal law to regulate public health, especially in areas of personal and sexual behaviour. At the moment, cases before the courts have concerned reckless transmission of HIV in male–female and male–male sexual partnerships in England, Scotland and Wales. The prosecutions in England and Wales have been based on the Offences against the Person Act 1861, Section 20, which relates to recklessly causing grievous bodily harm. These prosecutions for transmission of HIV have very serious consequences for key public health interventions, such as testing for HIV status, patient confidentiality and partner notification.

The IAG believes that an inappropriate use of the law could well discourage people from testing for HIV; in addition, it could undermine trust in the confidentiality of discussions with health professionals – the result being people living with HIV will be far less likely to ask for support to practise safer sex and less likely to provide details of sexual partners who may have been exposed to the risk of infection (9). In September 2006, the Crown Prosecution Service held an open consultation on a public document to explain the way in which it deals with cases involving the intentional or reckless sexual transmission of infections which cause grievous bodily harm. To that date, there had been eight convictions in England and Wales under Section 20 of the Offences against the Person Act 1861, and a further two in Scotland, based on the reckless transmission of HIV (22).

#### **14. Testing and counselling**

One of the main challenges in the United Kingdom is to reduce the number of late diagnoses and the number of people unaware of their infection by improving access to early testing and counselling. In 2005, in the United Kingdom an estimated 34% of adults (aged 16 or over) living with HIV were diagnosed late, and 11% had AIDS at the time of HIV diagnosis. The proportion of adults diagnosed late was lowest among MSM (22% with a low CD4 cell count and 7% with AIDS) and increased among IDUs (28% and 11%, respectively), heterosexual women (37% and 10%) and heterosexual men (47% and 19%). Late diagnosis has been more frequent among black and minority ethnic populations, among whom 40% of diagnoses in 2005 were made when the CD4 cell count was below 200 cells/ml. Late diagnosis also increases with age (13).

The high number of late diagnoses is being addressed through offering all GUM attendees an HIV test on their first screening for STIs, improving capacity in GUM clinics, including increased funding, and more recently by working with a national NGO to pilot HIV testing in non-clinical community settings for MSM and African communities (5).

The uptake of voluntary HIV counselling and testing at GUM clinics has increased year after year since 2001. In 2005, 80% of MSM and 82% of heterosexuals being screened for STIs

accepted voluntary HIV counselling and testing at GUM clinics (13) and the United Kingdom has one of the best STI screening programmes in the European Region.

### **15. HIV in prisons**

In September 2002, it was announced that funding responsibility for prisoners' health care would transfer from the Prison Service to the Department of Health from April 2003, and responsibility would devolve fully to NHS Primary Care Trusts over the following three to five years. In 2005, the vast majority of prisons in England had transferred the responsibility for commissioning health services (23). Prisoners' health in Scotland, however, is still the responsibility of the Scottish Prison Service.

Although the government explicitly commits to the principle of equivalent health care for prisoners, implementation has yet to be seen. However, since more than one in five IDUs have been infected with hepatitis B and new infections continue to occur, a prison vaccine programme for hepatitis B has been established. The vaccination programme's coverage is good, and the majority of IDUs have now taken up the offer of vaccination (3).

A large percentage of prisoners are drug users. Annually about 130 000 offenders go through the prison system and of these an average of 84 500 use drugs (12). Almost half (47%) of drug-using prisoners were imprisoned before beginning to inject. Seventeen per cent of those who had been in prison reported injecting while in prison (310 out of 1937). Drug treatment is a core element of the prison drug strategy and consists of clinical services and drug treatment programmes, including rehabilitation programmes and therapeutic communities. The drug interventions are designed to meet the needs of prisoners with, respectively, low, moderate and severe drug use problems (12). In Scotland, a current pilot needle exchange programme in Aberdeen's Craiginches Prison will be expanded further in 2008 to a full in-prison needle exchange programme (24).

Access to condoms in British prisons varies significantly, and existing guidance is sometimes disregarded by prison governors. In England and Wales, the policy guidance on condom provision is set out in the form of a letter to prison medical officers ("the 'Dear Doctor' letter") which recommends that condoms and lubricants should be prescribed when, in the doctor's opinion, there is a genuine risk of HIV transmission. There is evidence that this policy is not in force in some prison establishments. In the prisons of Northern Ireland condoms are not available. Condoms are not currently readily available in Scottish prisons, although a requirement since 2005 as set out in "Respect and Responsibility" (4).

## **D. Overall progress and main challenges for the future**

The United Kingdom has been successful in maintaining relatively low HIV infection rates among IDUs by a strong initial response to the epidemic. There has been increasing financial support towards creating more comprehensive sexual education and services, and new policies have provided increased access to GUM clinics. However, there are still many challenges, such as:

- sustaining local HIV prevention in the face of increasing treatment costs;
- empowering people infected with or affected by HIV to challenge HIV-related stigma and discrimination, within both communities and the broader social environment; addressing HIV-related stigma and discrimination was prioritized in the 2001 national strategy for sexual health and HIV;

- for health promoters, the challenges include responding to increasing risk-taking behaviour and safer-sex “fatigue” among MSM in an era of effective treatments;
- reducing the proportion of people with undiagnosed HIV and STIs; and
- addressing the needs of HIV among migrant populations to access treatment and care.

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## Appendix 1. **Dublin Declaration on Partnership to Fight HIV/AIDS in Europe and Central Asia**

*Against the background of the global emergency of the HIV/AIDS epidemic with 40 million people worldwide living with HIV/AIDS, 90 per cent in developing countries and 75 per cent in Sub-Saharan Africa, representatives of States and Governments from Europe and Central Asia, together with invited observers, met in Dublin, Ireland, from 23 to 24 February 2004, for the Conference "Breaking the Barriers – Partnership to fight HIV/AIDS in Europe and Central Asia" and made the following declaration:*

Recognising that poverty, underdevelopment and illiteracy are among the principal contributing factors to the spread of HIV/AIDS, and noting with grave concern that HIV/AIDS is compounding poverty and is now reversing or impeding development in many countries;

Emphasising the importance of sustained, pro-poor economic growth through poverty-reduction policies, programmes and strategies for the success of the fight against HIV/AIDS;

Recognising that the promotion of equality between women and men, girls and boys and respecting the right to reproductive and sexual health, and access to sexuality education, information and health services as well as openness about sexuality, are fundamental factors in the fight against the pandemic;

Reaffirming the Declaration of Commitment on HIV/AIDS adopted by the UN General Assembly Special Session on HIV/AIDS on 27 June 2001;

Reaffirming the development goals as contained in the Millennium Declaration adopted by the United Nations General Assembly at its fifty-fifth session in September 2000, and in the Road Map towards the implementation of the United Nations Millennium Declaration, and other international development goals and targets;

Reaffirming the Programme of Action of the International Conference on Population and Development (Cairo, 1994) and key actions for the further implementation of the Programme of Action of the International Conference on Population and Development adopted by the twenty-first special session of the United Nations General Assembly in July 1999;

Reaffirming the Beijing Platform for Action (Beijing, 1995) and the further actions and initiatives to implement the Beijing Declaration and the Platform for Action adopted at the twenty-third special session of the United Nations General Assembly in June 2000;

Expressing profound concern that in the European and Central Asian region at least 2.1 million of our people are now living with HIV/AIDS;

Noting with serious concern the particularly rapid escalation of the epidemic among young people in Eastern Europe, where HIV prevalence in the adult population is reaching critical levels in a number of countries and also the significant potential for the rapid spread of HIV in South-Eastern Europe and Central Asia;

Also noting with serious concern the resurgence of HIV/AIDS prevalence in Western Europe, including HIV resistant to anti-retroviral therapy, where the disease remains a potent threat to our young people;

Emphasising that the most seriously affected countries, mainly in southern Africa, are facing collapse in one or more sectors of society, and agreeing that the HIV/AIDS epidemic threatens to become a crisis of unprecedented proportions in our region, undermining public health, development, social cohesion, national security and political stability in many of our countries;

Agreeing that we must act collectively to tackle this crisis through a deepening of coordination, cooperation and partnership within and between our countries and are encouraged by proposals made at the Conference to strengthen the capacity of the European Union to fight effectively against the spread of HIV/AIDS;

Confirming that the respect, protection and promotion of human rights is fundamental to preventing transmission of HIV, reducing vulnerability to infection and dealing with the impact of HIV/AIDS;

Acknowledging that the prevention of HIV infection, through the promotion of safer and responsible sexual behaviour and practices, including through condom use, must be the mainstay of the sub-national, national, regional and international response to the epidemic and that prevention, care, support and treatment for those infected and affected by HIV/AIDS are mutually reinforcing elements of an effective response and must be integrated in a comprehensive approach to combat the epidemic;

Recognising that in our region persons at the highest risk of and most vulnerable to HIV/AIDS infection include drug injectors and their sexual partners, men who have sex with men, sexworkers, trafficked women, prisoners and ethnic minorities and migrant populations which have close links to high prevalence countries;

Stressing that without urgent action, HIV/AIDS will continue to move into the general population;

Recognising that women and girls are particularly vulnerable to HIV infection;

Recognising that a focus on the role of men and boys in combating HIV/AIDS and in the promotion of gender equality will benefit everyone and society as a whole, and that engaging men and boys as partners will encourage them to take responsibility for their sexual behaviour and to respect the rights of women and girls;

Recognising that in order to be able to tackle the HIV/AIDS crisis, we need strong basic health care systems and services to ensure universal and equitable access to HIV/AIDS prevention, treatment and care;

Recognising that success in the fight against HIV/AIDS is linked to the fight against other sexually transmittable infections and the fight against tuberculosis;

Emphasising that while young people are vulnerable, they themselves are key actors and agents of change in the fight against HIV/AIDS and are a major resource for the response at national and regional levels;

Acknowledging that the principle of greater involvement of people living with or affected by HIV/AIDS is critical to ethical and effective national responses to the epidemic;

Recognising that investment in research and development for more effective therapeutic and preventive tools, such as microbicides and vaccines, will be essential to securing the long-term success of HIV and AIDS responses;

We have agreed on the following actions to accelerate the implementation of the Declaration of Commitment on HIV/AIDS;

### **Leadership**

1. Promote strong and accountable leadership at the level of our Heads of State and Government to protect our people from this threat to their future, and promote human rights and tackle stigma and ensure access to education, information and services for all those in need;

2. Encourage and facilitate strong leadership by civil society and the private sector in our countries in contributing to the achievement of the goals and targets of the Declaration of Commitment;
3. Accelerate the implementation of the provisions of the Declaration of Commitment relating to orphans and girls and boys infected and affected by HIV/AIDS<sup>80</sup>;
4. Establish and reinforce national HIV/AIDS partnership forums including meaningful participation of civil society, and particularly of people living with HIV/AIDS and their advocates, to design, review, monitor and report progress in the fight against the disease, and to take timely and determined action to identify and address barriers to implementation;
5. In 2004-2005, promote the active involvement of the institutions of the European Union, and other relevant institutions and organisations such as the Commonwealth of Independent States, the Council of Europe, the Organisation for Security and Cooperation in Europe and the Regional Committee of the World Health Organisation, in partnership with UNAIDS through its co-sponsoring agencies and its Secretariat, in our common effort to strengthen coordination and cooperation;
6. Make the fight against HIV/AIDS in Europe and Central Asia a regular item on the agendas of our regional institutions and organisations;
7. Provide increased and results-based financial and technical resources to scale up access to prevention, care and sustained treatment, including effective low cost treatment such as generics, in the most affected countries with the greatest needs through national and regional allocations as well as from the Global Fund to Fight AIDS, TB and Malaria, the European Union, new public and private partnerships, multilateral and bilateral financing mechanisms;

### **Prevention**

8. Reinvigorate our efforts to ensure the target of the Declaration of Commitment<sup>81</sup> that, by 2005, at least 90 percent of young men and women aged 15 to 24 have access to the information, education, including peer education and youth-specific HIV education, and services necessary to develop the life skills required to reduce their vulnerability to HIV infection, in dialogue with young persons, parents, families, educators and health-care providers;
9. By 2010, ensure through the scaling up of programmes that 80% of the persons at the highest risk of and most vulnerable to HIV/AIDS are covered by a wide range of prevention programmes providing access to information, services and prevention commodities and identifying and addressing factors that make these groups and communities particularly vulnerable to HIV infection and promote and protect their health, and intensify cross border, sub-regional and regional technical collaboration and sharing of best practices through the EU and regional organisations in the prevention of HIV transmission among vulnerable groups;
10. Scale up access for injecting drug users to prevention, drug dependence treatment and harm reduction services through promoting, enabling and strengthening the widespread introduction of prevention, drug dependence treatment and harm reduction programmes<sup>82</sup> (e.g. needle and syringe programmes, bleach and condom distribution, voluntary HIV counselling and testing, substitution drug therapy, STI diagnosis and treatment) in line with national policies;

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<sup>80</sup> Declaration of Commitment of the UN General Assembly Special Session on HIV/AIDS, paragraphs 65-67

<sup>81</sup> Declaration of Commitment of the UN General Assembly Special Session on HIV/AIDS, target 53, page 21.

<sup>82</sup> The WHO recommends that at least 60% of injecting drug users have access to drug dependence treatment and harm reduction programmes in order to have an impact on the epidemic among this group.

11. Ensure that HIV positive women and expectant mothers should have access to high quality maternal and reproductive health care services in order to prevent mother to child-transmission;
12. By 2010, eliminate<sup>83</sup> HIV infection among infants in Europe and Central Asia;
13. Ensure men, women and adolescents to have universal and equitable access to and promote the use of a comprehensive range of high quality, safe, accessible, affordable and reliable reproductive and sexual health care services, supplies and information including access to preventive methods such as male and female condoms, voluntary testing, counseling and follow-up;
14. By 2005, to develop national and regional strategies and programmes to increase the capacity of women and adolescent girls to protect themselves from the risk of HIV infection, and reduce their vulnerability to HIV/AIDS;
15. By 2005, to develop national and regional strategies ensuring that all men and women in uniformed services, including armed forces and civil defence forces, have access to information, services and prevention commodities to reduce risk-taking behaviour and encourage safe behaviour, and urge the European Union, NATO and other regional and international security institutions in partnership with UNAIDS to lead such efforts;
16. Control the incidence and prevalence of sexually-transmitted infections, particularly amongst those at the highest risk of and most vulnerable to HIV/AIDS, through increased public awareness of their role in HIV transmission, improved and more accessible services for prompt diagnosis and efficient treatment;
17. Fund, improve, and harmonise surveillance systems, in line with international standards, to track and monitor the epidemic, risk behaviours and vulnerability to HIV/AIDS;
18. Request the Global Commission on International Migration to take into account in its work the threat of exposure to HIV/AIDS particularly to migrant women and unaccompanied and orphaned children;
19. Increase commitment to research and development for new technologies that better meet the prevention needs of people living with or most vulnerable to HIV transmission including increasing public sector investment in vaccines and microbicides to prevent HIV infection;

### **Living with HIV/AIDS**

20. Combat stigma and discrimination of people living with HIV/AIDS in Europe and Central Asia, including through a critical review and monitoring of existing legislation, policies and practices with the objective of promoting the effective enjoyment of all human rights for people living with HIV/AIDS and members of affected communities;
21. By 2005, provide universal access to effective, affordable and equitable prevention, treatment and care including safe anti-retroviral treatment to people living with HIV/AIDS in the countries in our region<sup>84</sup> where access to such treatment is currently less than universal, including through the technical support of the UN through the global initiative led by the World Health Organisation and UNAIDS to ensure 3 million people globally are on anti-retroviral treatment by 2005 ("3 by 5"). The goal of providing effective anti-retroviral treatment must be conducted in a poverty-focused manner, equitable, and to those people who are at the highest risk of and most vulnerable to HIV/AIDS;

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<sup>83</sup> Elimination is defined as less than 2% of all new infections are acquired by an infant from his or her infected mother

<sup>84</sup> The treatment gap in the region is estimated by the WHO to be at least 100,000 people in 2003.

22. Ensure early implementation of the WTO Decision of 30 August 2003 on the implementation of paragraph 6 of the Doha Declaration on the TRIPS Agreement and Public Health;
23. Increase access to non-discriminatory palliative care, counseling, psychosocial support, housing assistance, and other relevant social services for people living with HIV/AIDS;
24. Invest in public research and development for the development of affordable and easier to use therapeutics and diagnostics to support expanded treatment access and improve the quality of life of people living with HIV;
25. Monitor best practices on and take concrete steps to exchange information on service delivery for prevention, treatment and care, particularly for persons at the highest risk of and most vulnerable to HIV/AIDS infection;

### **Partnership**

26. Strengthen coordination, cooperation and partnership among the countries of Europe and Central Asia, as well as with their trans-Atlantic and other development partners, to scale up local capacity to fight the epidemic and mitigate its consequences in the most affected countries with the greatest needs, and in countries with a high risk of a major epidemic;
27. Involve civil society and faith-based organizations, as well as people living with HIV/AIDS and persons at the highest risk of and most vulnerable to HIV/AIDS infection in the development and implementation of national HIV/AIDS prevention and care strategies and financing plans, including through participation in national partnership forums;
28. Work with leaders from the private sector in fighting HIV/AIDS through workplace education programmes, employee non-discrimination policies, provision of treatment, counseling, care, and support services, and through engagement with policy makers on the local, national and regional levels;
29. Involve the national and international pharmaceutical industry in a public-private partnership including with relevant international organisations such as the World Health Organisation in helping to tackle the epidemic along all points of the drug supply chain – from manufacturing to pricing to distribution;
30. Ensure effective coordination between donors, multilateral organisations, civil society and Governments in the effective delivery of assistance to the countries most in need of support in the implementation of their national HIV/AIDS strategies, based on ongoing processes on simplification and harmonization particularly the UNAIDS guiding principles;<sup>85</sup>
31. Establish sustainable partnerships with the media, recognising the critical role that it plays in influencing attitudes and behaviour and in providing HIV/AIDS related information;
32. Support stronger regional cooperation and networking among people living with HIV/AIDS and civil society organisations in Europe and Central Asia, and call upon the Joint United Nations Programme on HIV/AIDS in partnership with the European Union, existing civil society networks and other regional partner institutions to assist, facilitate and coordinate such collaboration;

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<sup>85</sup> These are: that there should be one agreed national HIV/AIDS Action Framework that drives alignment of all partners., one national AIDS authority with a broad-based multisectoral mandate, and one agreed country-level monitoring and evaluation system.

### **Follow-up**

33. We commit ourselves to closely monitor and evaluate the implementation of the actions outlined in this Declaration, along with those of the Declaration of Commitment of the United Nations General Assembly Session on HIV/AIDS, and call upon the European Union and other relevant regional institutions and organisations, in partnership with the Joint United Nations Programme on HIV/AIDS, to establish adequate forums and mechanisms including the involvement of civil society and people living with HIV/AIDS to assess progress at regional level every second year, beginning in 2006.

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