

Addressing hepatitis C in prisons and other places of detention:

Recommendations to NHS England

by a prison health expert group convened by The Hepatitis C Trust

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1. Introduction

On April 1st 2013, NHS England (NHSE) gained responsibility for commissioning healthcare in all detention settings. Public Health England (PHE) has dedicated resources to support work on public health issues in prisons and other places of detention in partnership with NHSE and partners within the Criminal Justice System (CJS).

This provides a unique opportunity to make progress in addressing an important public health issue: hepatitis C virus (HCV) infection, which is highly prevalent in the prison and other detained populations.

The benefits achieved through better prevention, diagnosis and treatment of HCV in prison and detention populations extend beyond institutional walls and represent a potential health gain for the whole community as well as savings to the NHS.

In February, The Hepatitis C Trust convened an expert group of doctors, nurses, consultants, commissioners and public health specialists to develop recommendations for how hepatitis C healthcare in prisons could be improved through the new commissioning arrangements.

This paper summarises the recommendations from this meeting in order to:

- advise NHSE on providing a nationally commissioned, locally implemented, clinically
 effective, and high quality hepatitis C healthcare service appropriate for, and adapted to
 the specific needs of prisons and other places of detention in England.
- ensure appropriate levels of testing and treatment in prisons and other places of detention necessary to reduce the mortality from hepatitis C, and therefore liver disease generally.

2. Background

2.1 Roles and responsibilities of NHS England

Following the re-organisation of the NHS and the abolition of Primary Care Trusts and Strategic Health Authorities, from April 1st 2013, most clinical services in primary and secondary care will be commissioned at local level by Clinical Commissioning Groups (CCGs). However, Section 15 of the Health and Social Care Act 2012 gives the Secretary of State for Health (SoS) the power to require NHSE to commission certain services instead of CCGs. These include 'services or facilities for persons who are detained in a prison or other accommodation of a prescribed description'ii.

NHSE will be responsible for ensuring that services are commissioned to consistently high standards of quality across the country, promote the NHS Constitution and deliver the requirements of the Secretary of State's Mandate and the Section 7a agreement with NHSE.

The scope of 'places of detention' includes prisons (public and 'contracted out' estate), Immigration Removal Centres (IRCs), the Young People's Secure Estate (including Secure Training Centres & Secure Children's Homes), Police Custody Suites and Courts.

2.2 NHS and PHE resources for offender health

NHSE is structured with 4 regions and 27 Area Teams (ATs). Nine ATs and a regional team for London have been designated to build the expert capacity necessary to undertake NHSE's commissioning role, including commissioning of preventive and public health services as set out in the Section 7a agreement with SoS, in respect of persons detained in prison, or in other secure accommodationⁱⁱⁱ. The ATs and London regional team will work with the NHSE national team.

Public Health England also has a dedicated resource to support work on understanding and managing the health needs of people in contact with the criminal justice system. The national team, the Health and Justice Team, sits within the Health and Wellbeing Directorate of PHE. Ten Health and Justice Public Health Specialists are to be based in Public Health England Centres (PHECs), working in the Operations Directorate, and covering the same geographical area as the ten NHSE AT Offender Health 'leads'.

These resources within both NHSE and PHE at national and local level allow for effective horizontal and vertical integration within organisations and between organisations.

2.3 Hepatitis C

Liver disease is the only major cause of mortality and morbidity which is rising in England, whilst decreasing in Europe^{iv}. There was a 25% increase in liver disease deaths between 2001 and 2009^v.

The most recent national estimates suggest that around 216,000 individuals are chronically infected with the hepatitis C virus (HCV) in the UK, but only approximately 3% are treated each year^{vi}. By the year 2020, over 15,000 people in England are expected to be living with cirrhosis or liver cancer caused by hepatitis C, unless they are diagnosed and treated. The most seriously affected will require liver transplants^{vii}. Direct healthcare costs of hepatitis C are currently in excess of £0.5bn per annum and rising by 10% per year. Both hospital admissions and deaths from HCV-related end stage liver disease (ESLD) and hepatocellular carcinoma (HCC) are continuing to rise in the UK. Hepatitis C is the only cause of liver disease amendable to intervention^{viii}. It is also preventable^{ix}.

2.4 Hepatitis C and the prison population

The last comprehensive survey of hepatitis C prevalence in prisoners in England was undertaken in 1997. The then Public Health Laboratory Service (PHLS) undertook an unlinked, anonymous survey of the prevalence of blood borne viruses among prisoners in England in 1997–98. This indicated that 9% of adult men, 11% of women and 0.6% of male young offenders had evidence of previous exposure to hepatitis C^x. A study last year in Scotland showed the overall prevalence of hepatitis C antibodies among prisoners to be 19%^{xi}.

Injecting drug use is the primary risk factor for infection in the UK (over 90% of new infections are acquired through intravenous drug use, where risk factors are known)^{xii}. Research from the Ministry of Justice on a sample of newly sentenced adult prisoners from 49 prisons in England and Wales found that 68% had used an illicit drug in the past year and 40% had injected a drug during the four-week period prior to custody^{xiii}. Close to 50% of people who inject drugs and 30% of former injecting drug users in England are believed to have hepatitis C^{xiv, xv}. Hepatitis C is therefore a significant issue within English prisons. Potential transmission routes for hepatitis C include sharing needles, sharing tattooing equipment, sharing toothbrushes and sharing hair clippers, all of which may occur more frequently in the prison setting.

Prison provides an ideal opportunity to identify, test and treat high-risk 'hard-to-reach' groups and reduce the prevalence of hepatitis C both in prisons and in the wider community. For a critical percentage of inmates, prison provides the *only* opportunity to safely treat the patient because of close supervision and other optimal factors such as nutrition and reduced exposed to alcohol or other non-prescribed drugs. This strategy will avoid downstream costs to the NHS from untreated hepatitis C, including the management of cirrhosis and liver cancer.

To date, efforts to diagnose and treat hepatitis C patients within prisons have varied widely. In July 2012^{xvi}, a survey of hepatitis C services in prisons in England was published by the Health Protection Agency's Prison Infection Prevention team^{xvii} (HPA PIP team) in partnership with the Offender Health Division^{xviii} and the Liver Disease Strategy team in the Department of Health (DH). This revealed variation in the structure, accessibility and quality of hepatitis C services delivered in prisons across England.

2.5 Seizing the Opportunity

To make the most of the upcoming opportunity of the National Commissioning Board commissioning healthcare in detention settings, in February 2013 The Hepatitis C Trust convened a meeting of expert healthcare professionals who work in prisons and on prison health policy to develop the key components of a service specification for hepatitis C in prisons, to inform NHSE (See **Annex 1: List of participants**). This builds on the NICE guidance, 'Hepatitis B and C: ways to promote and offer testing to people at risk of infection' (2012)xix and other relevant guidance and advice.

Box 1 - National Evidence, guidance and outcomes frameworks

- NICE TA106 Peginterferon alfa and ribavirin for the treatment of mild chronic hepatitis C
- NICE TA200 Peginterferon alfa and ribavirin for the treatment of chronic hepatitis C
- NICE TA252 Hepatitis C (genotype 1) telaprevir (2012)
- NICE TA253 Hepatitis C (genotype 1) boceprevir (2012)
- NICE PH43 Hepatitis B and C: ways to promote and offer testing to people at increased risk of infection (2012)
- NHS Outcomes Framework 2012-13:
 - o Domain one Preventing People from Dying Prematurely xx
 - •1a Potential Years of Life Lost (PYLL) from causes considered amenable to health care
 - •1b.i and 1b.ii Life Expectancy at 75, males and females
 - •1.3 Under 75 mortality rate from liver disease
 - +1.4.i-vi Cancer survival
 - ◆1.5 Excess under 75 mortality rate in adults with serious mental illness
- Public Health Outcomes Framework 2012-2013
 - o Domain 4 Healthcare, public health, and preventing people from dying prematurely xxi
 - o 4.6 Mortality from liver disease
- Hepatitis C Strategy for England, Department of Health, August 2002
- Hepatitis C Action Plan for England, Department of Health, 2004
- Guidance for the prevention, testing, treatment & management of hepatitis C in primary care, RCGP, 2007
- National survey of hepatitis C services in prisons in England, HPA, July 2012
- Prison Health Performance and Quality Indicators: Guidance Notes, Department of Health, 2012
- An audit of hepatitis C services in a representative sample of English prisons, PHE, to be published May 2013

3. Recommendations: prisons

Participants in the roundtable concluded that a cultural shift is required in prisons to destigmatise the condition and normalise testing. Training and education for all prison staff at every level, including healthcare and discipline, will be central to achieving this culture shift. The recommendations in this document will help to translate this culture shift into tangible outcomes of increased numbers of patients, diagnosed, educated about, treated and cured of the virus and help reduce the national burden of liver disease as required by the NHS Outcomes Framework.

3.1 Staffing and service structure

- There should be a multi-disciplinary prison steering group to oversee the delivery of hepatitis C services and a suitably qualified clinical lead for HCV (or BBVs).
- The clinical lead for HCV (or BBVs) should provide clinical leadership around hepatitis C and other BBV testing and treatment, primary prevention including hepatitis B vaccination, and develop a care pathway for hepatitis B and C patients, including those co-infected with HIVxxii. Leadership is crucial and the steering group needs to meet regularly to also examine the quality of services provided, particularly training of healthcare staff.
- All prisons must have access to a suitably qualified viral hepatitis nurse working as part of a wider multi-disciplinary team (MDT). This nurse may be prison, community or hospital based. NHSE could consider options for joint commissioning with local CCGs of community viral hepatitis nurse-led services to include primary care BBV services, GUM, drug/rehab services, prisons and other places of detention, secondary care and community based services.
- All prisoners with hepatitis C should have their care and treatment discussed by a MDT familiar with aspects of healthcare provision specific to the prison environment.

3.2 Pathway

- All prisons should have a hepatitis C policy in place which covers the areas detailed in the PHPQI 2012 guidance (See Annex 2)*x*iii.
- PHE should work closely with NHSE and other key stakeholders to co-produce a high level service specification in relation to hepatitis C testing, treatment, care and health promotion in prison.
- Every prison must have a written hepatitis C pathway in place which describes the service from awareness raising and prevention through to testing, treatment and general management of the disease**xiv*. Access to the HCV service by the inmate must be straightforward and discrete.
- Closer co-ordination and partnership between the multiple agencies carrying out BBV testing (healthcare staff, GUM services, IDTS, and others involved such as CARAT teams) may improve effectiveness and generate efficiencies.
- Assuming such care pathways are in place, hepatitis C testing should be offered in all prisons and should be available at any stage during the prisoner's stay, not just at reception or immediately afterwards.
- Laboratories should automatically undertake PCR testing of all positive hepatitis C antibody tests.
- The hepatitis C pathway must include links to community services and must specify how prisoners with a positive hepatitis C diagnosis or who are on hepatitis C treatment will be linked up with community services on releasexxv.

3.3 Training

- In depth training on hepatitis B and C should be mandatory for prison GPs, nursing and other healthcare staff and IDTS staff, including staff who offer and carry out hepatitis C tests and deliver results, for example the RCGP Certificate, Hepatitis B&C Detection Diagnosis and Management (the first part of which is free, online and takes around 2 hours).
- PHE should work in partnership with NHSE to address the training needs of prison staff with regards to hepatitis C.
- All prison staff, including discipline staff, should be given training on hepatitis C, such as the RCGP e-module.

3.4 Awareness

- Appropriate hepatitis C awareness and information materials in all relevant languages must be made available in all prisons.
- Use of multi-media information resources should be encouraged to allow complex information to be provided in a way which is accessible and comprehensible even to people who do not speak or read English as a first language. For example, the animated DVD resource developed by the Department of Health on use of disinfectant tablets.

3.5 Testing

- In line with NICE guidance to increase the number of people at increased risk of hepatitis C infection being tested^{xxvi}, active case finding for hepatitis C should be encouraged in prisons.
- Opt-out hepatitis C testing should be offered to all prisoners at second reception by appropriately trained staff. However, this should not be the only time or place an offer of testing is made. Inmates must be reassured that testing is available "without prejudice".
- Testing should be a 'continuous offer' and should be re-offered at all available opportunities, for example at hepatitis B vaccination appointments, treatment review and CARAT courses by all appropriate staff (for instance IDTS staff).
- Staff offering testing must be given specific training in how to offer tests appropriately and how to deliver results, both positive and negative and on pre- and post-test discussions.
- Venous blood testing should be offered and, following NICE guidance, prison services should have access to dried blood spot HCV testing for people for whom venous access is difficultxxxii.
- Samples should be of sufficient quantity that they can be immediately PCR tested following
 a positive antibody test. No prisoner should receive a positive antibody result without having
 a PCR result at the same time.
- Ideally, the same person who gave the hepatitis C test should deliver the result. However, there should be no undue delay in providing results to patients. For example, if a clinician is on annual leave then their workload should be covered by a locum or other colleagues, including providing results.
- Prisoners who are tested for hepatitis C should receive their results when they are available, regardless of whether they have been released or transferred.
- Results from the test should be shared with the patient's community GP where consent has been given including enabling patient's to do so themselves by providing them with written information resources if they so request.
- The use of the same READ code for hepatitis C should be promoted across the prison health system to ensure all cases of hepatitis C can be collated together for reporting purposes.

3.6 Treatment

- Treatment options should be considered and discussed with patients and all patients should be given the option of any treatment recommended by NICE. Careful consideration should be given to the length of sentence before initiating treatment to ensure the best chance of adherence and completion.
- Prisons should ensure that, where possible, prisoners are put on medical hold whilst receiving treatment for hepatitis C.
- In-reach or GP-led treatment should be the model of prison treatment delivered in prison, in accordance with NICE guidance^{xxix}.
- Access to The Hepatitis C Trust helpline or an analogous level of support (for example, from appropriately trained healthcare staff) must be made available to all prisoners undergoing hepatitis C treatment.
- Appropriate clinical governance must be in place for prisoners on treatment including consultant-led MDT.
- The care pathway must include access to mental health services, dermatology services and other relevant support services where necessary, as occurs in non-prison based HCV services.

3.7 Peer-to-peer support

• Support for the development of hepatitis C or wider healthcare peer-to-peer mentoring schemes should be provided in all prisons.

3.8 Continuity of care

- Once a prisoner has begun hepatitis C treatment, medical hold should be considered, to ensure continuity of care, in line with NICE guidance**x.
- Hepatitis C should be specifically flagged clearly on patients' notes on SystemOne or other electronic patient record systems, or written notes, when they move or leave to ensure it is picked up by future medical staff.
- Prisoners should always be offered paper copies of their notes. The option of storing notes electronically for patients to access should be explored by the NHS Commissioning Board.
- The hepatitis C lead in the prison is responsible for ensuring that every effort is made to enable the hepatitis C patient to be successfully referred for continuous care in the community and between prisons.

3.9 Measuring outcomes and improvement

- The Prison Health Performance and Quality Indicators should be updated to include specific measures to monitor the quality of hepatitis C healthcare, in particular by recording data on the indicators below and reporting them to the PHE:
 - o Number of people offered testing
 - o Number of people tested
 - o Number of people testing positive for PCR
 - o Number of people initiated on treatment
 - o Number of people completing treatment (in prison or in the community)
 - o Number of people achieving a SVR (in prison or in the community)
 - o Prevalence of hepatitis C in prisons (measured every 5 years)

4. Recommendations: other detention settings

- Every immigration removal centre should have a hepatitis C lead and clear policies and pathways in place for testing and treatment.
- Healthcare and other staff at YOIs and immigration detention centres must undertake training on hepatitis C such as the RCGP Hepatitis B&C detection, diagnosis and management e-module.
- Hepatitis C awareness materials must be available in all detention settings, and in all relevant languages.

Annex 1

List of participants:

Chair: Charles Gore, Chief Executive, The Hepatitis C Trust

Hazel Allen, Senior Clinical Nurse Specialist, Royal Bournemouth Hospital

Dr Iain Brew, GP, HMP Leeds

Dr Ashley Brown, Consultant Hepatologist, Imperial College Healthcare NHS Trust and Chairman, British Viral Hepatitis Group

Jane Cox, Policy and Public Affairs Advisor, The Hepatitis C Trust

Dr Mark Hallam, Service Clinical Director, Leeds Community Drug Partnership

Gary Hemphill, Peer-to-Peer Educator, The Hepatitis C Trust

Becky Hug, Policy and Public Affairs Advisor, The Hepatitis C Trust

Dr Charlie Millson, Consultant Hepatologist, NHS York

Dr Éamonn O'Moore, Director, Health and Justice Team, PHE

Dr Autilia Newton, Chair, PHE Health Protection Prison Network and Local Director Health Protection, PHE

Jo Noble, Hepatitis C Liaison Nurse, HMP Manchester

Cathie Railton, Prison Infection Prevention Team Scientist, Health and Justice Team, PHE

Dr Steve Ryder, Consultant Hepatologist, Nottingham University Hospitals NHS Trust and Biomedical Research Unit and Chair, HCVAction

Dr Ray Walsh, Clinical Member, Lambeth CCG

Annex 2

Prison Health Performance Quality Indicator 2012 – Hepatitis C

1.29 Hepatitis C Green Indicator

The following are all evidenced:

- Hepatitis C policy agreed by the PCT/Prison Partnership Board, including as a minimum, health promotion, criteria for offering testing and a care pathway with clear criteria for referral to specialist treatment where this is indicated.
- Access to information on harm minimisation, provided through both healthcare and education programmes.
- All those at risk are offered confidential screening for hepatitis C: the numbers of tests performed should be recorded.

Suggested Supporting Evidence

- A written hepatitis C policy which includes health promotion, criteria for offering testing, and a care pathway with clear criteria for referral to specialist treatment where this is indicated.
- Data on the numbers of tests offered and tests performed should be recorded on a monthly basis and submitted as part of quarterly hepatitis B/C returns to the SHA.

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- viii Office for National Statistics, Avoidable Mortality in England and Wales, 2010 Reference Table 3, May 2012: http://www.ons.gov.uk/ons/publications/re-reference-tables.html?edition=tcm%3A77-262418
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- ^{xvi} Department of Health, National survey of hepatitis C services in prisons in England, July 2012: https://www.gov.uk/government/publications/national-survey-of-hepatitis-c-services-in-prisons-in-england
- xvii The Health Protection Agency's PIP team is commissioned by Offender Health to co-ordinate the surveillance of infectious diseases affecting the prison population.
- xviii The Offender Health Division is responsible for leading on development and delivery of a cross government Health and Criminal Justice Programme. The programme's common aim is improving health and social care outcomes for adults and children in contact with the criminal justice system, focusing on early intervention, liaison and diversion.
- xix National Institute for Health and Care Excellence, Hepatitis B and C: ways to promote and offer testing to people at increased risk of infection, March 2013: http://publications.nice.org.uk/hepatitis-b-and-c-ways-to-promote-and-offer-testing-to-people-at-increased-risk-of-infection-ph43
- ^{xx} Under Domain One of the NHS Outcomes Framework, hepatitis C is listed as a numerator for key outcomes: 1a Potential Years of Life Lost (PYLL) from causes considered amenable to health care (hepatitis C listed under Public Health and Social Care contribution); 1b.i and 1b.ii Life Expectancy at 75, males and females (hepatitis C listed under Public Health and Social Care contribution); 1.3 Under 75 mortality rate from liver disease (chronic viral hepatitis listed under numerator description and hepatitis C listed under Public Health and Social care contribution); 1.4.i-vi Cancer survival (hepatitis C listed under Public Health and Social care contribution); 1.5 Excess under 75 mortality rate in adults with serious mental illness (hepatitis C listed under Public Health and Social care contribution). See Department of Health, The NHS Outcomes Framework 2012/13: Technical Appendix, December 2011: http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_131721.pdf
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xxix Prisoners and immigration detainees with hepatitis B and C should be treated in the prison or immigration removal centre, using in-reach services involving local specialist secondary care providers or the prison or immigration removal centre healthcare team. The prison or immigration removal centre should support this, for example, by giving security clearance to healthcare staff. See National Institute for Health and Care Excellence, Hepatitis B and C: ways to promote and offer testing to people at increased risk of infection, March 2013: http://publications.nice.org.uk/hepatitis-b-and-c-ways-to-promote-and-offer-testing-to-people-at-increased-risk-of-infection-ph43

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For more details please contact the report author, Becky Hug, at becky.hug@hepctrust.org.uk



The Hepatitis C Trust 27 Crosby Row, London SE1 3YD T 020 7089 6220 W www.hepctrust.org.uk