



Public Health
England

Protecting and improving the nation's health

Hepatitis C in England **2018 report**

Working to eliminate hepatitis C as a major public health threat

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Foreword

In England, around 160,000 people are chronically infected with hepatitis C, the majority of whom are from marginalised and underserved groups in society.

Last year we shared our vision that all people at risk of hepatitis C virus (HCV) infection in England should have access to testing and, once tested, that action should be taken to reduce their risk of infection and to prevent further transmission of the virus, or – if they are infected – to place the patient on a treatment pathway.

This important work has now started. Public Health England (PHE) has established a National Strategic Group on Viral Hepatitis (NSGVH), and its members are already working together to define the key strands of work where we can have most impact. This cross-agency expert group will provide strategic direction and good practice guidance around hepatitis C (and other viral hepatitis) and will serve as a forum to explore operational and implementation issues to help us find the best ways to enact our commitments at local, regional and national level. This group will oversee and monitor national progress against WHO elimination strategies.

There has been renewed focus to evaluate interventions and review existing evidence on testing and engagement in care to support commissioning of case finding activities. Modelling has indicated that treatment of the individual may contribute to prevention benefits at a population level but empirical evidence has so far been lacking. This is being addressed by a National Institute for Health Research (NIHR) funded multi-agency 5 year study led by the University of Bristol and Glasgow Caledonian University that has just started.

Over the last year, we have been working with our partners in the third sector to produce a **range of resources** in different languages to help raise awareness of hepatitis C. Amongst these was a **hepatitis C testing quiz**, hosted by The Hepatitis C Trust, to encourage people to find out whether they might have been exposed to the virus and would benefit from a hep C test. A linking **poster campaign**, fronted by TV's Dr Christian Jessen, involved the distribution of posters to GP surgeries throughout England, encouraging people to take the quiz to see whether they might be at risk of infection.

As well as working hard to find those who remain undiagnosed, it is also important to re-engage those who have been diagnosed in the past but have not cleared their infections. To ensure that as many eligible people as possible are treated with the new more effective treatments, PHE are providing data to the NHS to help identify those people, registered with a GP, who have been diagnosed with hepatitis C in the

past and who have not yet cleared their infections. These patients should be offered testing to confirm whether they have active infection and then be assessed for the newer more effective treatments.

The NHS England direct acting antiviral (DAA) treatment programme continues to be rolled out, with year on year increases in treatments, and the importance of case finding initiatives to support this cannot be over-emphasised.

In this report, we summarise the impact of action plans in England to drive down mortality from HCV, reduce the number of new infections, and outline the actions required to make further progress.

The findings of this report, suggest that much work has been done, but there is still much to do. If we are to eliminate hepatitis C as a major public health threat by 2030, it is essential that we continue to work cohesively with stakeholders to pool our resource and thus to maximise our impact.



A handwritten signature in grey ink that reads 'Mary Ramsay'.

Dr Mary Ramsay
Head of Immunisation, hepatitis and blood safety department
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Executive summary

In May 2016, the UK signed up to the World Health Organization (WHO) Global Health Sector Strategy (GHSS) on Viral Hepatitis^[1] which commits participating countries to the elimination of hepatitis C (HCV) as a major public health threat by 2030. The current report summarises the scale of the HCV problem in 2016 in England, to help support focused action to meet our commitment to reduce the incidence of chronic HCV infection by 80% and HCV mortality by 65% by 2030 at the latest.

In 2015, there were an estimated 71 million people with chronic HCV infection worldwide.^[2] Most recent estimates suggest that around 160,000 people in England are living with chronic HCV infection,^[3] and modelling work is ongoing to update this estimate. Injecting drug use continues to be the most important risk factor for HCV infection, being cited as the risk in around 90% of all laboratory reports where risk factors have been disclosed.^[4] In 2016, 54% of people who had injected psychoactive drugs, participating in the Unlinked Anonymous Monitoring (UAM) Survey of people who inject drugs (PWID), tested positive for antibodies to HCV (anti-HCV), and this proportion has remained relatively stable over the past decade, although there is some evidence of an increase since 2011.^[4]

If we are to eliminate hepatitis C as a major public health threat, there are two main impact areas where we need to make progress: we need to reduce the numbers becoming seriously ill or dying from this infection, whilst at the same time reducing the number of people who become newly or re-infected. In England, our vision is that all people at risk of HCV infection should have access to testing and, once tested, that action should be taken to reduce their risk of infection and to prevent further transmission of the virus, or – if they are infected – to place the patient on a treatment pathway.

Against a background of rising HCV-related mortality that was predicted to increase in the future, the first fall in deaths in more than a decade, has been sustained for another year, with a 3% fall in deaths from HCV-related end stage liver disease (ESLD) and hepatocellular carcinoma (HCC) between 2014 and 2016. This suggests that increased treatment (a 19% increase in 2015/16 compared to earlier years, and 56% more in 2016/17 than in 2015/16) with new direct acting antiviral (DAA) drugs, particularly in those with more advanced disease, may be starting to have an impact. Falls have also been observed in liver transplant registrations (43% fall by 2016, when compared to pre-2014 levels) and liver transplants undertaken (25% fall by 2016, when compared to pre-2014 levels) in those where post-hepatitis C cirrhosis is given as the indication for transplant. These falls are encouraging although it is too early to rule out a degree of deferred listing pending assessment of the impact of treatment. Either way, as treatment is rolled out further, the WHO GHSS target for a reduction in HCV-related

mortality of 10% by 2020^[1] looks within our reach. Despite this, only around one half (52% in 2016) of people who had injected psychoactive drugs sampled in the UAM Survey^[4] were aware of their HCV antibody positive status, and this figure has remained relatively stable at this level over the last decade.

Throughout England, a variety of initiatives are ongoing to increase both professional and public awareness of HCV. The success of these initiatives has been dependent on the significant contribution of numerous stakeholders working across a range of settings. **Resources** have been developed to help people recognise any risk for HCV infection and to encourage those at risk to seek testing. Public Health England will also provide the NHS with a list of people, currently registered with a GP, who have been diagnosed with hepatitis C in the past but who may not have cleared their infections, so the NHS can offer assessment for treatment with new direct acting antiviral (DAA) drugs.

Over the last two decades (1996-2016), there has been a more than fivefold increase in the number of laboratory confirmed reports of HCV in England, with 10,731 reports of individuals testing positive for antibodies to HCV and/or HCV RNA in 2016. An increase in testing is also observed in sentinel surveillance, which suggests a 24% increase overall, and a 21% increase in testing via GP surgeries, between 2012 and 2016. The WHO European Region target of 50% of those with chronic HCV having been diagnosed and aware of their infection by 2020^[5] may have already been met in England, but more work is needed if we are to meet the target of 90% diagnosed by 2030.^[1]

When looking at key risk groups, both UAM (84% in 2016) and National Drug Treatment Monitoring System (NDTMS) data (83% in 2015/16) suggest that more than four-fifths of people who have ever injected drugs report or were recorded as having received a HCV test, respectively. Among new receptions to English prisons, levels of testing have been seen to rise from 5.3% in 2010/11 to a provisional 10.5% in 2016/17.

When looking at screening data from low risk populations, NHS Blood and Transplant testing suggests that rates of infection in new and repeat donors remain low (<18.5/100,000 donations). Acknowledging that donors who disclose a history of injecting drugs are permanently deferred from donating in the UK, disproportionately high numbers of HCV infections are observed in new donors from South Asia (Pakistan, Bangladesh or India; 128 /100,000) or 'other-white' (74 /100,000) backgrounds. Sentinel surveillance suggests that testing in people of South Asian origin and in those of Eastern European origin has increased by 27% and 52%, respectively, between 2012 and 2016, with 1.3% and 3.2% testing positive over this period.

Data from the UAM survey suggest that numbers of new HCV infections have remained relatively stable over recent years: estimated rates of infection were not significantly different in 2016 (16.4/100 person years) to those observed in 2011 (8.0/100 person years). Although there was some evidence to suggest that transmission among recent initiates to psychoactive drug use may have increased marginally since 2011-2012 (23%) to 26% in 2015-2016, neither laboratory reports nor sentinel surveillance suggest any increase in levels of infection in young adults. Regrettably, the proportion of PWID reporting adequate needle and syringe provision remains suboptimal, with just less than one half (45% in 2016) of those who had injected psychoactive drugs surveyed reporting adequate provision for their needs. Although levels of sharing of needles and syringes have declined from 28% in 2005 to 18% in 2016, there is no evidence of any fall over the last five years. Together these findings suggest that the WHO GHSS call to reduce new cases of chronic HCV by 30% by 2020 and 80% by 2030,^[1] represents a significant challenge for health services in England.

Overall, with the increasing availability of new DAA drugs, the WHO GHSS goals to reduce HCV-related morbidity and mortality should be within our reach, provided current improvements in numbers accessing treatment can be sustained in future years. Our ability to sustain the current increase in numbers accessing treatment will ultimately be limited by our capacity to find and treat those who remain undiagnosed, and to help those who are diagnosed but untreated to engage with local services; only then will we be able to build on the current fall in avoidable HCV-related deaths. It will also be important to make preliminary assessments of the equity, access, uptake and impact of treatment on the future burden of HCV-related disease in England using new data from the national treatment monitoring dataset. At the other end of the spectrum, there is currently little evidence to support a fall in the number of new HCV infections; if GHSS goals to reduce these levels are to be reached, then a radical change in our response to HCV among PWID is required.

We are interested in receiving your feedback on this report and would be grateful if you could take two minutes to complete this [short survey](#).

Thank you.

Public health recommendations

Making improvements and monitoring metrics

- The National Strategic Group for Viral Hepatitis (NSGVH) to consider determining what 'elimination as a major public health threat' means for England and whether England specific milestones should be defined.
- Public Health England (PHE) to further develop national indicators and tools at both national and lower levels, to help monitor progress towards the WHO Global Health Sector Strategy (GHSS) goal to eliminate hepatitis C as a serious public health threat by 2030.^[1]
- Public health professionals working in local authorities and CCGs to consider including HCV in Joint Strategic Needs Assessments (JSNA) and subsequent health and wellbeing strategies.

Adequate harm reduction/prevention

- Commissioners of services for people who inject drugs need to sustain or expand, as appropriate, the current broad range of provision (including opioid substitution treatment (OST), needle and syringe programmes (NSP), and patient information) to reduce transmission of HCV, including among people who inject new psychoactive substances or image and performance-enhancing drugs (IPED); National Institute for Health and Care Excellence (NICE) guidance is available on NSP^[6] and OST.^[7]
- PHE to consider mapping and monitoring NSP activity
- Health and Justice Leads to help ensure that harm minimisation policies in secure and detained settings are maintained, including the provision of disinfectant/decontamination equipment for sharps.
- Commissioners of services for people who inject drugs to ensure the legal requirement to report HCV positive laboratory results, including Dry Blood Spot (DBS) Testing, to PHE is met.

Increasing the numbers and proportion diagnosed

- All stakeholders to help improve awareness among professionals, for example by encouraging participation in e-learning^{[8],[9]}
- All stakeholders to improve the offer and uptake of HCV testing to those at risk of HCV infection by implementing NICE guidelines.^[10]
- All stakeholders to continue to produce and disseminate appropriate communications, including **resources**, national reporting and infographics, to help mark World Hepatitis Day.
- Drug prevention services should ensure that testing is sustained or enhanced, as appropriate,^[11] among those attending drug services; the use of newer technologies,

like DBS testing, that make testing easier in non-clinical settings, should be further expanded throughout England.

- Health and Justice to ensure that bloodborne virus opt-out testing for new receptions to prisons in England continues to be monitored to inform strategies to further improve the uptake of testing.
- Commissioners and providers of drug services to consider bloodborne virus opt-out testing.
- Commissioners and providers of laboratory services to ensure, wherever possible, that ribonucleic acid (RNA) amplification tests are performed on the same sample as the original antibody assay (reflex testing) to decrease the turnaround time for referral, benefit patient care and increase cost effectiveness;^[12] consideration should also be given to including patient referral instructions on the laboratory report.

Increasing the numbers accessing hepatitis C treatment

- Commissioners of hepatitis C treatment and care services should continue to work with public health agencies, clinicians and other stakeholders to simplify referral pathways; improve the availability, access and uptake of approved HCV treatments in primary and secondary care, drug treatment services, prisons and other settings; and to drive innovative approaches to outreach and patient support.
- Public Health England to provide the NHS with a list of people, currently registered with a GP, who have been diagnosed with hepatitis C in the past but who may not have cleared their infections, so the NHS can offer assessment for treatment with new direct acting antiviral (DAA) drugs.
- Treatment and prevention services should ensure that appropriate information and support are provided to help guard against re-infection among those achieving a sustained virological response (SVR) following treatment.
- NHS England to provide treatment data to PHE to enable preliminary assessments of the equity, access, uptake and impact of treatment on the future burden of HCV-related disease in England to inform future healthcare planning and to monitor progress against WHO goals to eliminate HCV as a serious public health threat by 2030

Introduction

Hepatitis C (HCV) is a bloodborne virus that is often asymptomatic, and symptoms may not appear until the liver is severely damaged. As a consequence, many individuals with chronic HCV infection remain undiagnosed and fail to access treatment. These individuals can then present late with complications of HCV-related end-stage liver disease (ESLD) and cancer, which have poor survival rates.

Globally, viral hepatitis caused 1.34 million deaths in 2015, a number comparable to deaths caused by tuberculosis and higher than those caused by HIV.^[2] However, the number of deaths due to viral hepatitis is increasing over time, while mortality caused by tuberculosis and HIV is declining.^[2] In 2015, there were an estimated 71 million people with chronic HCV infection worldwide.^[2]

In May 2016, the UK signed up to the World Health Organization (WHO) Global Health Sector Strategy (GHSS) on Viral Hepatitis^[1] which commits participating countries to the elimination of hepatitis C as a major public health threat by 2030. As part of this, the UK has committed to meeting targets of a 80% reduction in incidence of HCV infection and a 65% reduction in mortality from HCV by 2030. For HCV, the global vision is that by implementing the GHSS for viral hepatitis, preventative efforts leading to fewer infections and deaths, as well as treatment efforts resulting in longer survival, together have the potential to prevent 2.1 million HCV-associated deaths worldwide by 2030.^[13]

If we are to tackle HCV infection in England, it is critical that we continue to work with our partners to improve prevention, raise awareness, increase testing and get more diagnosed individuals into treatment and care, whilst ensuring access to HCV services is equitable.

This England report summarises the scale of the HCV problem in 2016, and presents metrics that allow us to monitor our progress (see appendix 2) and identify where focused action is needed if we are to honour our commitment to eliminate hepatitis C as a major public health threat by 2030.

Vision and monitoring metrics

Hepatitis C is a curable infection, and it is our aspiration to support the WHO in their goal to eliminate hepatitis C as a major public health threat by 2030 at the latest. This can be achieved via the collective action of all partner organisations involved in the prevention, diagnosis, treatment and care of those living with, or at risk of acquiring, HCV infection. The focus of our vision can be captured in the following statement:

Vision statement

All people at risk of hepatitis C virus infection should have access to testing and, once tested, action should be taken to either reduce their risk of infection, prevent further transmission of the virus, or – if they are infected – to place the patient on a treatment pathway.

To track our progress, it is important to **monitor the impact** of interventions in the following two impact areas:

- reducing transmission, and hence the number of new (incident) HCV infections
- reducing morbidity and mortality due to HCV and its complications

To support this, it is also important to **monitor the coverage of services** that are critical in driving down the levels of HCV infection and HCV-related mortality in England, namely the:

- adequacy of harm reduction
- numbers and proportion of infected people who are diagnosed
- numbers, and ultimately the proportion, of infected people accessing treatment

The preliminary indicators (see appendix 2), reported in the sections that follow and summarised in the headline data table,^[4] describe our progress so far and set out the scale of the challenge ahead so that meaningful goals can be developed and progress towards achieving them can be monitored in the years ahead. Where indicators are missing or in development, placeholders have been included (see appendix 2). With more focused monitoring, we hope to continue to work with stakeholders to identify barriers and drive forward improvements across the system to help eliminate hepatitis C as a major public health threat by 2030 at the latest.

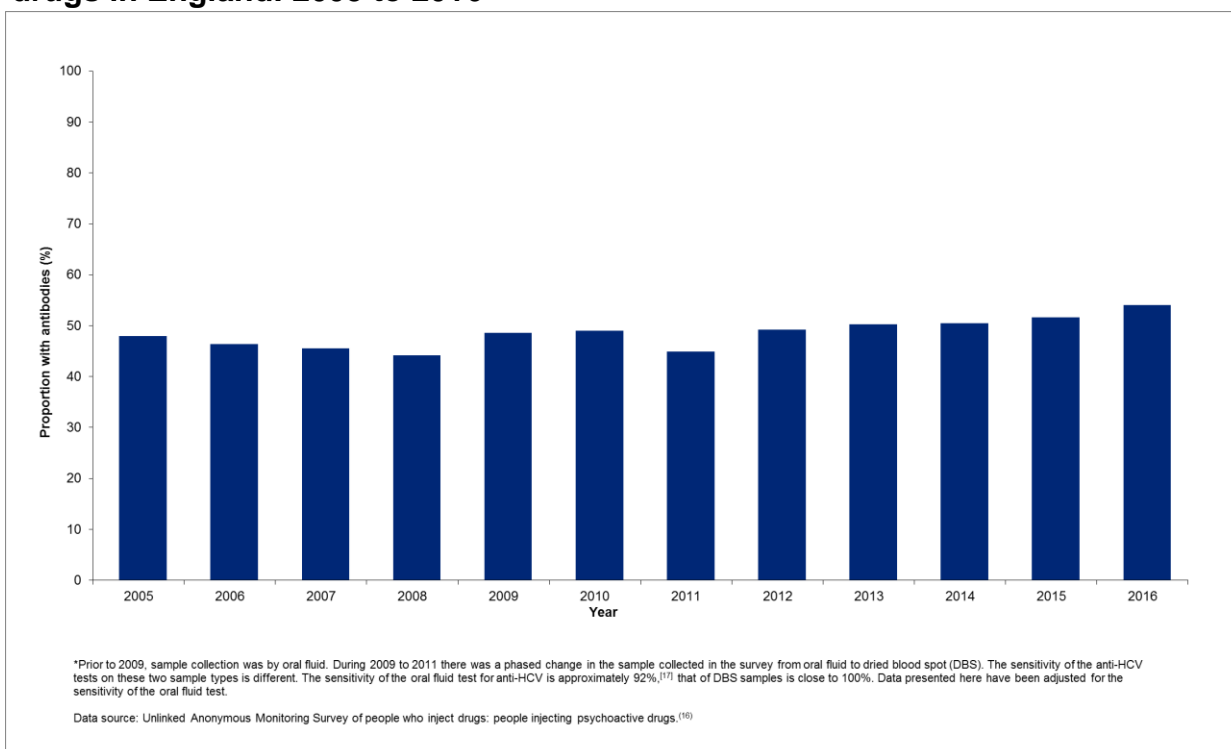
Burden of HCV infection

Most recent estimates suggest that around 160,000 people in England are living with chronic HCV infection,^[3] and modelling is underway to update this figure. Our current provisional modelling estimates a similar 2015 prevalence to the 160,000 chronic infections estimated for 2005, suggesting that prevalence may have been somewhat higher than that estimated previously for 2005, although well within the 95% credible interval (120,000-225,000). Sentinel Surveillance of Bloodborne Virus Testing suggests that, in 2016, the majority of infections were either genotype 1 (50.1%) or genotype 3 (38.4%).^[14]

Injecting drug use continues to be the most important risk factor for HCV infection, being cited as the risk in 90.5% of all laboratory reports where risk factors have been disclosed.^[4]

In 2016, of the people injecting psychoactive drugs, such as heroin, in the Unlinked Anonymous Monitoring (UAM) Survey of people who inject drugs (PWID), 54% tested positive for antibodies to HCV (anti-HCV); this proportion has remained relatively stable over the past 12 years, although there is some evidence of an increase since 2011^[4] (Figure 1). In England and Wales, levels of infection are also elevated among survey participants who inject image or performance enhancing drugs (IPEDs), such as anabolic steroids, 5.1% of whom tested positive for antibodies to HCV during 2014-15.^[15]

Figure 1. Trend in anti-HCV prevalence* among people injecting psychoactive drugs in England: 2005 to 2016



Hepatitis C prevalence among people injecting psychoactive drugs and participating in the UAM Survey in 2016 varied across England.^[18] Prevalence of infection is not only concentrated in areas with high levels of current/past injecting drug use, but also in areas where there are high numbers of black and minority ethnic (BAME) populations who have close links to countries with a high prevalence of HCV infection.^[19] HCV disproportionately affects populations who are marginalised and under-served with poorer access to healthcare and poorer health outcomes.

Monitoring impact

If we are to eliminate hepatitis C as a major public health threat, there are two key impact areas where we need to make progress: we need to reduce the numbers becoming seriously ill or dying from this infection, whilst at the same time reducing the number of people who become newly or re-infected. Everything we do should have an impact in these two areas.

Reducing HCV-related morbidity and mortality

Up until 2014, mortality from HCV-related liver disease has been on the increase in England as people who acquired their infections decades earlier progress to advanced liver disease and access to previous treatment has been inadequate.^{[20],[21]} However, the new DAA drugs that have recently become available,^{[22],[23],[24],[25],[26],[27],[28, 29],[30]} and the development of Operational Delivery Networks (ODNs) through which to deliver them, offer the potential to significantly reduce the number of individuals progressing to serious HCV-related ESLD/hepatocellular carcinoma (HCC) and reduce the premature mortality that results.^[31] As new treatments are rolled-out to those with more advanced disease, it should be possible to achieve a rapid reduction in the severe morbidity and mortality that has been observed ^{[31],[32]} and has been predicted to continue in the future.^[21]

Metrics to monitor trends in HCV related morbidity and mortality

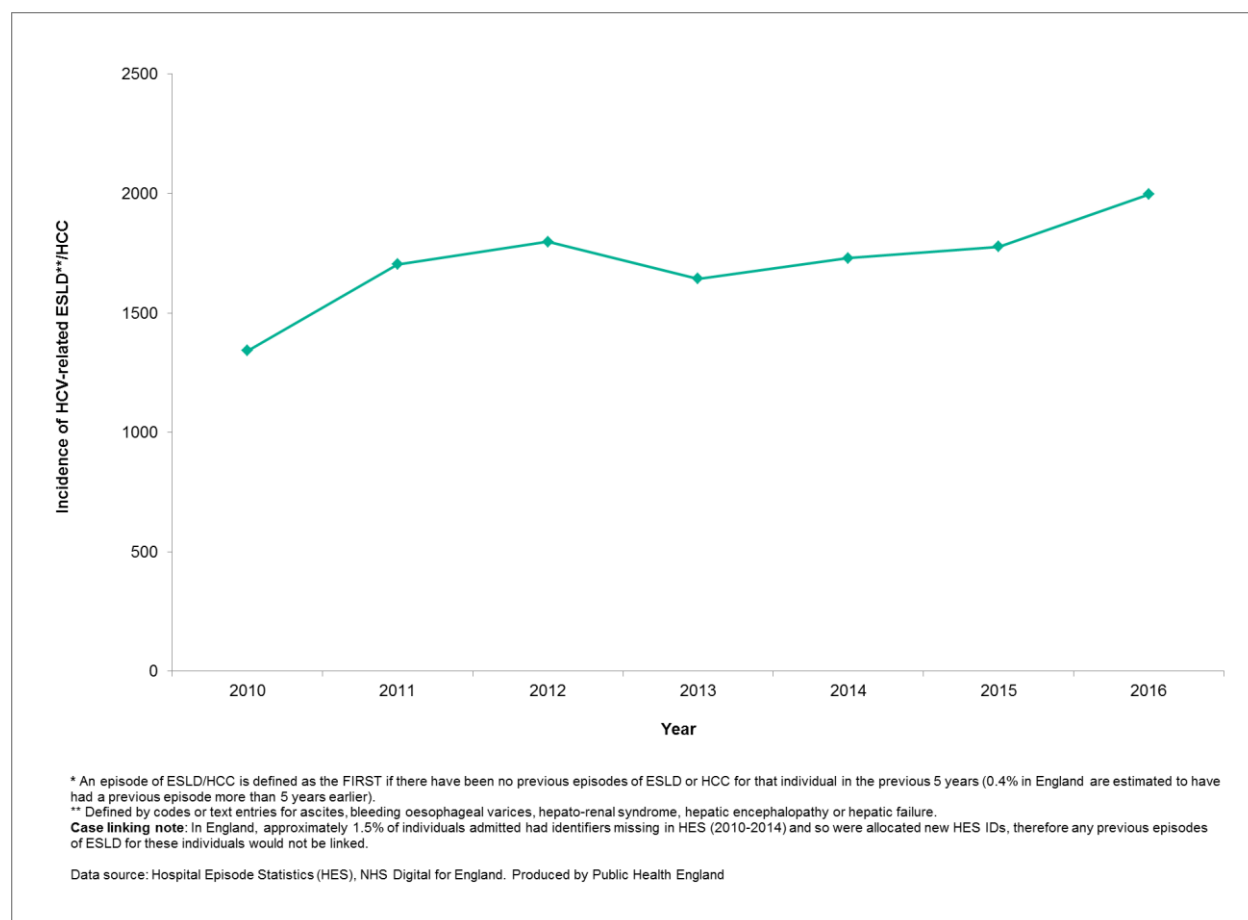
- Estimated incidence of HCV related ESLD/HCC
- Registrations for liver transplant and transplants undertaken, where post hepatitis C cirrhosis is given as the indication for transplant
- Death registrations for HCV related ESLD/HCC

Incidence (new cases) of HCV-related ESLD/HCC

Novel methodologies are being developed to monitor the incidence of HCV-related ESLD/HCC using Hospital Episode Statistics (HES).^[33] While the limitations of these preliminary estimates are acknowledged,^[33] early data suggest that new cases of HCV-related ESLD/HCC remained relatively stable at around 1730 (Mean: 1731) incident cases per year between 2011 and 2015 (Mean: 1731; Range: 1644, 1798; Figure 2), but rose to around 2000 incident cases in 2016, an increase of 15% ($265/1731 \times 100$) on earlier years. Investigations into these increases are ongoing, but reveal that the increase is focussed in certain geographic areas in England, and was proportionally greater for HCV-related HCC than ESLD. Certain patterns in the data point strongly toward changes in identification or management practices, due to abrupt changes in observed cases in HES in particular areas. As there is a long incubation time between infection and severe liver disease, genuine changes in ESLD/HCC

incidence will tend to occur over the course of several years. Further investigation of this apparent recent increase is therefore warranted. In much of England, new cases of ESLD/HCC have remained stable (or fallen) in the past few years. In the absence of treatment interventions, modelling predicted a continued increase in ESLD and HCC.[21] Further work is required to understand these new data, whether the rising burden in HCV-related disease will be less severe than anticipated, and the estimated impact of new treatment.

Figure 2. Preliminary estimates of incidence* of HCV-related ESLD/HCC in England: 2010-2016**

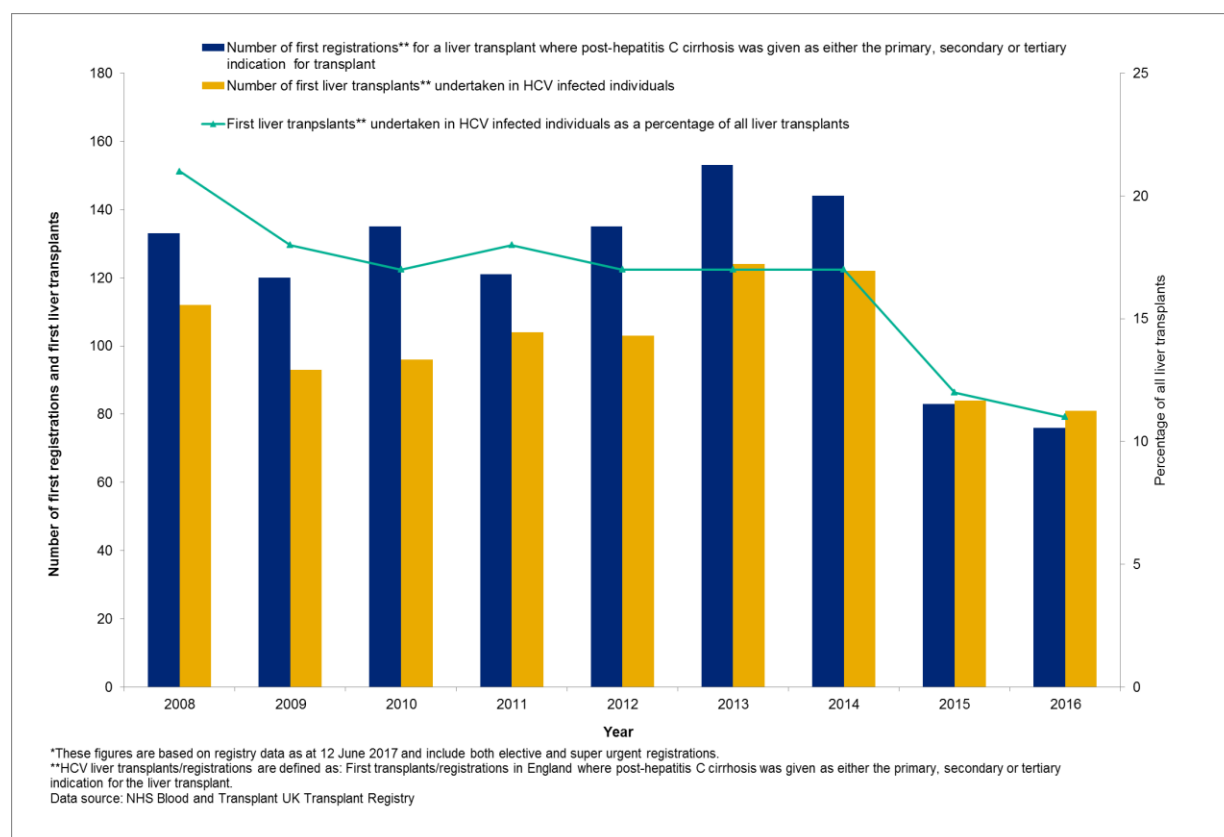


Registrations and liver transplants undertaken, where post-hepatitis C cirrhosis is given as the indication for transplant

Another marker of HCV-related morbidity is the number of English residents with post-hepatitis C cirrhosis (recorded as either the primary, secondary or tertiary indication for transplant) **registering** at NHS Blood and Transplant for a liver transplant. Between 2008 and 2014 registrations have remained relatively stable averaging 134 per year (Range: 120, 153; [4] Figure 3), with highest numbers of registrations occurring in London (21.5% between 2008-2016). However, over the last two years registrations have fallen dramatically by over 40% (43%) compared to earlier years, to a nine year low of 76 in 2016[4] (Figure 3). Likewise, liver transplants **undertaken** for this indication,

have remained relatively stable between 2008 and 2014, averaging 108 transplants per year (Range 93, 124). However, over the last two years, numbers of transplants exceeded registrations, with the former decreasing by one quarter (25%) compared to earlier years.^[4] Of all liver transplants performed in England, the percentage carried out in patients with hepatitis C-related disease decreased from 21% in 2008 to 11% in 2016 (16% overall throughout the period).^[4] This might suggest that new treatments are having an impact with the annual number of livers transplanted for this indication being down by 24 (in 2015) and 27 (in 2016) compared to earlier years. Whilst the fall in numbers does not seem to be the result of increased removals from the list because of improved condition (personal communication), it is possible that fewer patients are being put onto the transplant list because of clinical intervention, perhaps following a potential positive influence on severe disease progression resulting in patients failing to meet the threshold for registration. However, it is not possible to rule out a degree of deferring listing pending assessment of the impact of treatment on clinical condition. It will therefore take longer to assess whether this is the start of an established trend rather than simply an adjustment phenomenon.

Figure 3. Number of first patient registrations in England where post-hepatitis C cirrhosis was given as either primary, secondary or tertiary indication for transplant and number of liver transplants undertaken in patients who were HCV positive (RNA or antibody) at transplant: 2008 to 2016



Deaths from HCV-related ESLD/HCC

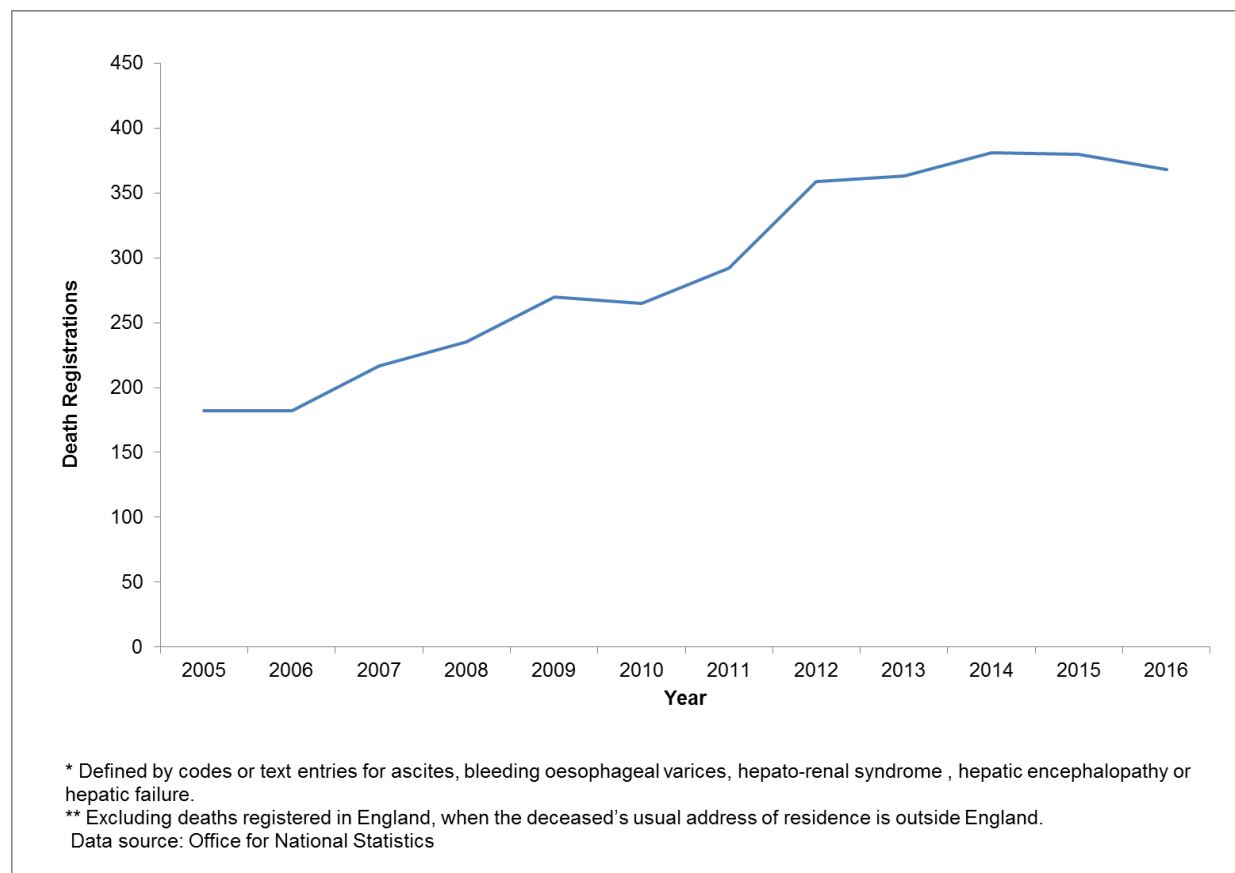
Between 2005 and 2014, death registrations for HCV-related ESLD and HCC in England more than doubled, rising from 182 in 2005 to 381 in 2014 ^[4] (Figure 4). Since 2014, however, deaths have been falling, with a fall of 3% between 2014 and 2016. Confirmation that the first fall in deaths in more than a decade has been sustained for another year is extremely encouraging against the background of rising mortality that was predicted to increase in the future.^[21]

Changes have been made to the way deaths are counted this year, moving away from monitoring deaths (registered in England) in the year they occurred to monitoring deaths according to the year they were registered where postcodes matched to England. This makes the latest available data more accurate as it avoids the late classification of deaths that occur in one year but are not registered until the next. Also, in previous years deaths were allocated to England based on their reported region; from 2018 changes in the data available to PHE mean that deaths are now allocated to England using the postcode of individuals' usual place of residence. This means that individuals whose deaths are registered in England but whose usual place of residence is outside England are excluded from the dataset. Others excluded by the new method are the small number of individuals for whom no postcode is available; when comparing the two methods between 2005-2015, only 55 cases had no postcode, and further enquires revealed that all these cases had usual places of residence outside the UK, with most cases coming from Kuwait (n=10) or Pakistan (n=9).

Overall, it is likely that the 3% fall in registered deaths is the result of increased access to new DAA drugs that were introduced from 2014/2015 (Figure 22), particularly for those individuals with more advanced disease.^[34] This suggests that new drugs may be having an impact on mortality from HCV-related ESLD/HCC.

As more infected individuals access new therapies, the GHSS on viral hepatitis' call for a 10% reduction in HCV deaths by 2020 should be within our reach^[1] (see appendix 1).

Figure 4. Death registrations for ESLD* or HCC in those with HCV mentioned on their death certificate in England: 2005 to 2016**



Reducing the number of new (incident) infections

Monitoring the impact of prevention measures on the incidence of infection remains a challenge as incident infection is difficult to measure directly. Ideally we would monitor the actual or estimated number of new chronic HCV infections that arise annually in PWID as well as any that result from net migration, and monitor this over time. However, the former is difficult to estimate because much of the acute infection is asymptomatic and undiagnosed and there is considerable uncertainty around the number of people in the UK who are injecting drugs.^[35-38] Added to this, it is also difficult to select a sentinel population of PWID for monitoring that is representative of PWID as a whole. As a result, a number of methods are used to generate information to provide insight into likely trends in incidence over time.^[20]

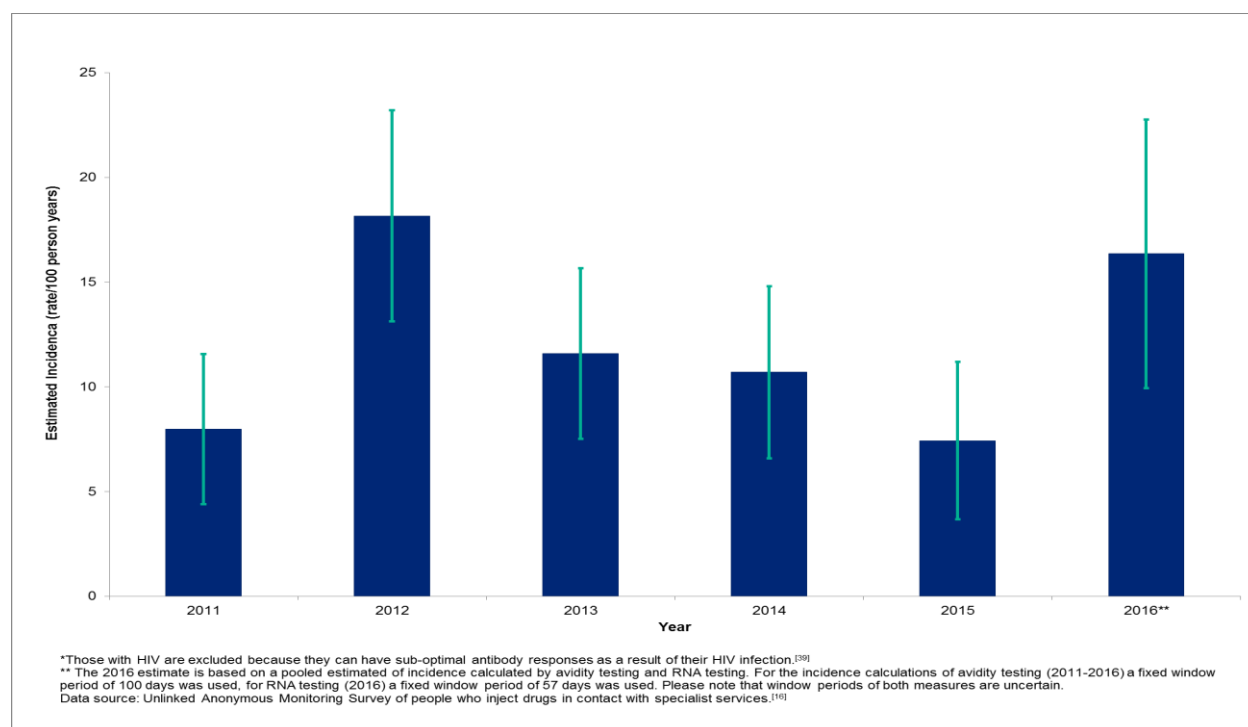
Metrics to monitor trends in numbers of new (incident) infections

- Estimated incidence of HCV among PWID
- Estimated prevalence of antibodies to HCV among recent initiates to injecting drug use (proxy measure)
- Prevalence of antibodies to HCV among young adults (proxy measure)

Estimated incidence of infection among people who inject drugs

Recent transmission of HCV among those who had injected psychoactive drugs has been explored among the participants in the UAM Survey of PWID^{[18],[33]} by looking for those who have recently developed antibodies to HCV. This has been undertaken in two ways. Prior to September 2016, antibody positive DBS were tested for avidity where DBS with overall weak avidity are likely to be from individuals who have recently been infected with the virus. From September 2016, instead of avidity all DBS have been tested for the presence of viral RNA. Samples from recently-infected individuals will be positive for RNA but will not yet have developed antibodies against HCV. Avidity and RNA testing have been used to explore recent transmission among those survey participants who had injected during the preceding year. After adjusting for the two different methods used to measure incidence, data suggest that incidence of infection has remained relatively stable over recent years with rates observed in 2016 (16.4/100 person years; CI 9.9-22.8) not being significantly different from those observed in 2011 (8.0/100 person years; CI 4.4-11.6; Figure 5)

Figure 5. Estimated incidence of HCV among people injecting psychoactive drugs in England who reported injecting in the previous year: 2011- 2016* (95% CI)



Estimated prevalence of anti-HCV among recent initiates to drug use and in young adults

As most new infections are acquired via injecting drug use at a relatively young age,^[40] the prevalence of infection in young adults or in recent initiates to injecting drug use, can be used as proxy measures of incidence.

Data from the UAM Survey of people who inject psychoactive drugs^[18] suggest that transmission among recent initiates may have increased in recent years. Due to a change in sample collection (oral fluid to DBS) between 2009 to 2011, data collected prior to 2011 cannot be directly compared to more recent data. However in the years since 2011 the data suggest a small but significant increase in transmission in recent initiates (Figure 6).^[4] In contrast, neither laboratory reports nor sentinel surveillance show any evidence of increased levels of infection in young adults over recent years^[4] (Figures 7-8).

Figure 6. Prevalence of antibodies to hepatitis C* among people who began injecting psychoactive drugs in the previous three years in England: 2005-2006 to 2015-2016

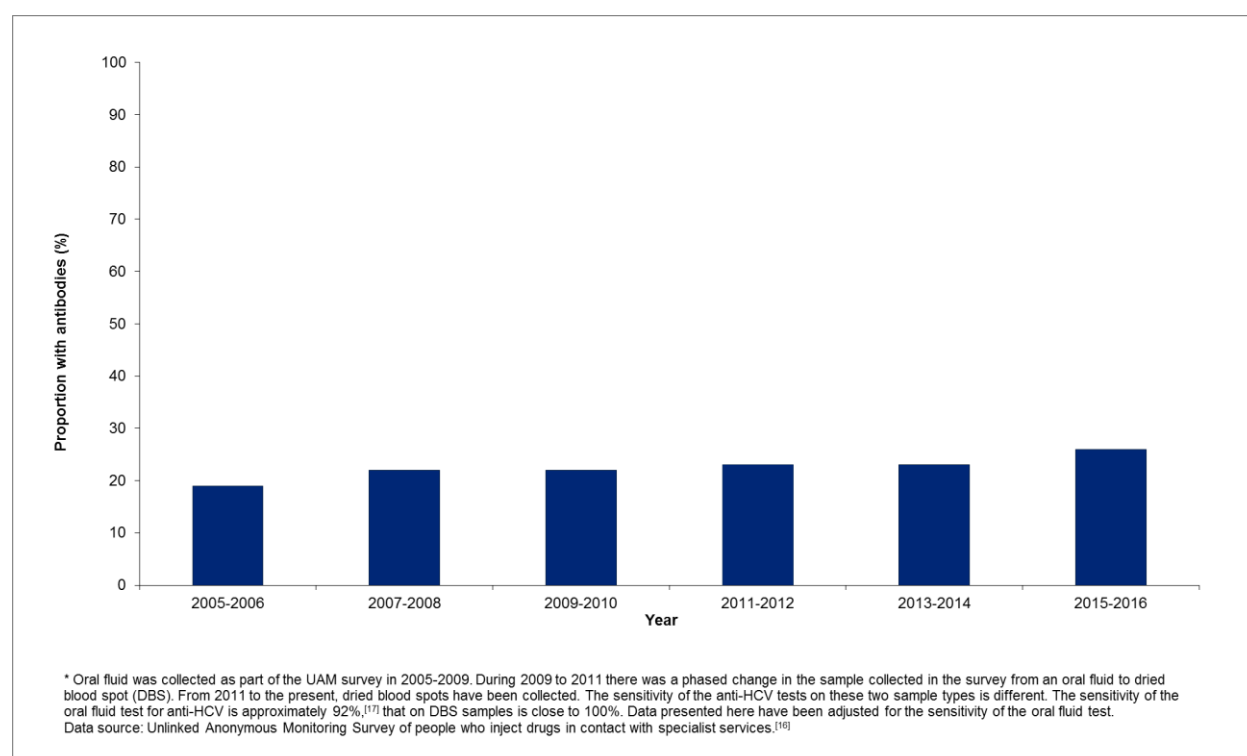


Figure 7. Number of young adults first tested for anti-HCV and proportion positive by year in 15 sentinel laboratories: 2012 to 2016*

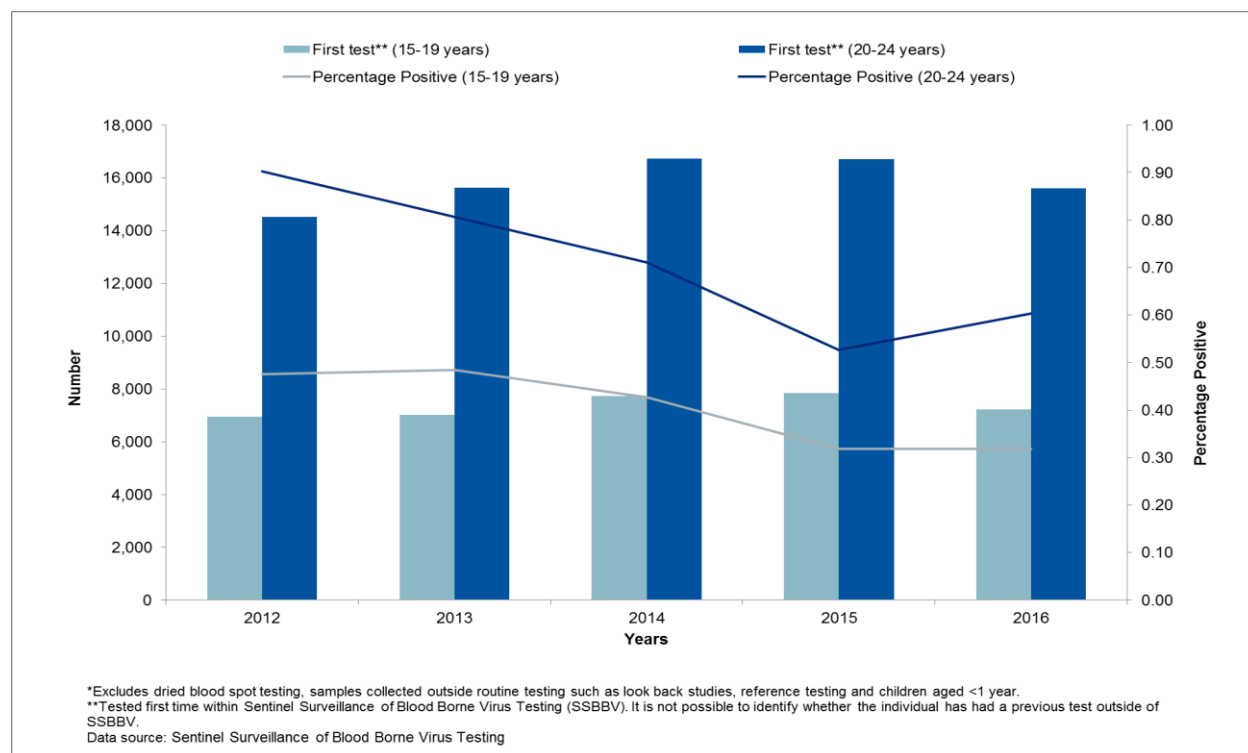
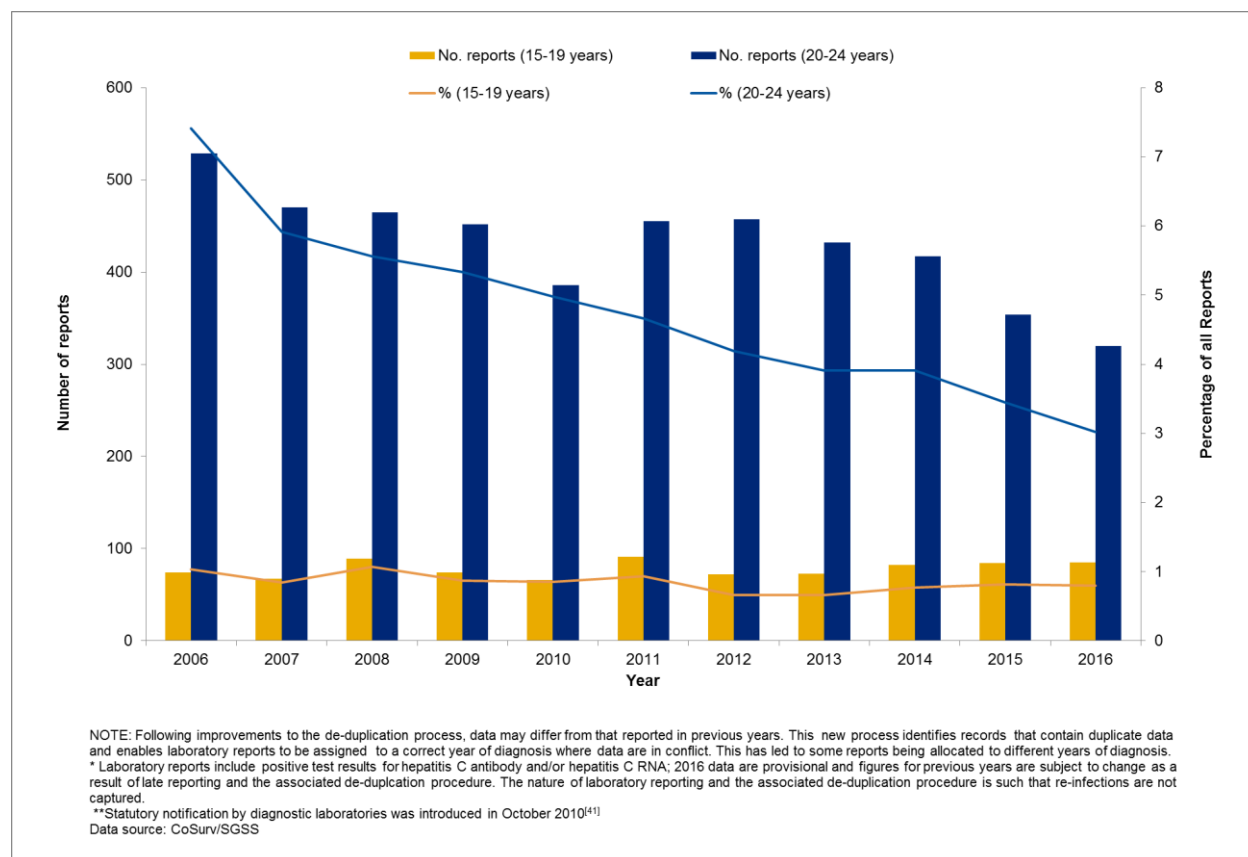


Figure 8. Laboratory reports of hepatitis C in young adults in England: 2006-2016/****



Overall estimates and proxy indicators of HCV incidence suggest that the call to reduce new cases of chronic HCV by 30% by 2020, and 80% by 2030^[1] (see appendix 1), represents a significant challenge for health services. If these goals are to be achieved, a radical change in the response to HCV among PWID is required.

Monitoring the coverage of key services

Eliminating hepatitis C as a major public health threat by driving down HCV-related mortality and preventing new infections from occurring/re-occurring is potentially feasible with the tools and approaches currently available in England. Investment in three core intervention areas is needed: (i) ensuring adequate harm reduction for people who inject drugs (PWID), (ii) increasing the proportion of infected individuals who are diagnosed, and (iii) increasing the proportion of infected individuals who access and complete treatment, achieving a sustained viral response (SVR).

Adequate harm reduction

Harm reduction interventions for PWID, including access to sterile injecting equipment and effective drug dependence treatment, can prevent and control HCV among PWID.^{[42],[43],[44],[45],[46],[47]} Optimal access to clean injecting equipment and opioid substitution treatment (OST) is crucial in curbing the spread of HCV, particularly given that it also has the potential to prevent re-infection after treatment.

Metrics to monitor trends in the adequacy of harm reduction

- Estimated adequacy of NSP coverage among PWID
- Sharing of injecting equipment by PWID
- Proportion of opioid dependent PWID receiving OST
- Numbers of current/past PWID in drug treatment

NSP coverage

The GHSS on viral hepatitis^[1] and the draft action plan for the health sector response to viral hepatitis in the WHO European region^[5] call for a comprehensive package of harm reduction services to be in place for all PWID, including a major global increase in provision of sterile needles and syringes, from an estimated baseline of 20 needles and syringes per PWID per year to 200 by 2020 and 300 by 2030^[1] (see appendix 1). However, these inevitably somewhat arbitrary figures, do not make any allowance for individual differences in need. In order to better reflect the adequacy of needle and syringe provision, data from the UAM Survey of PWID^[18] are presented here on self-reported adequacy of needle and syringe provision^[4](Figure 9). In this metric, needle and syringe provision is considered 'adequate' when the reported number of needles received, met or exceeded the number of times the individual injected.

Figure 9. Estimated proportion of people injecting psychoactive drugs reporting adequate* needle and syringe provision in England, 2011-2016

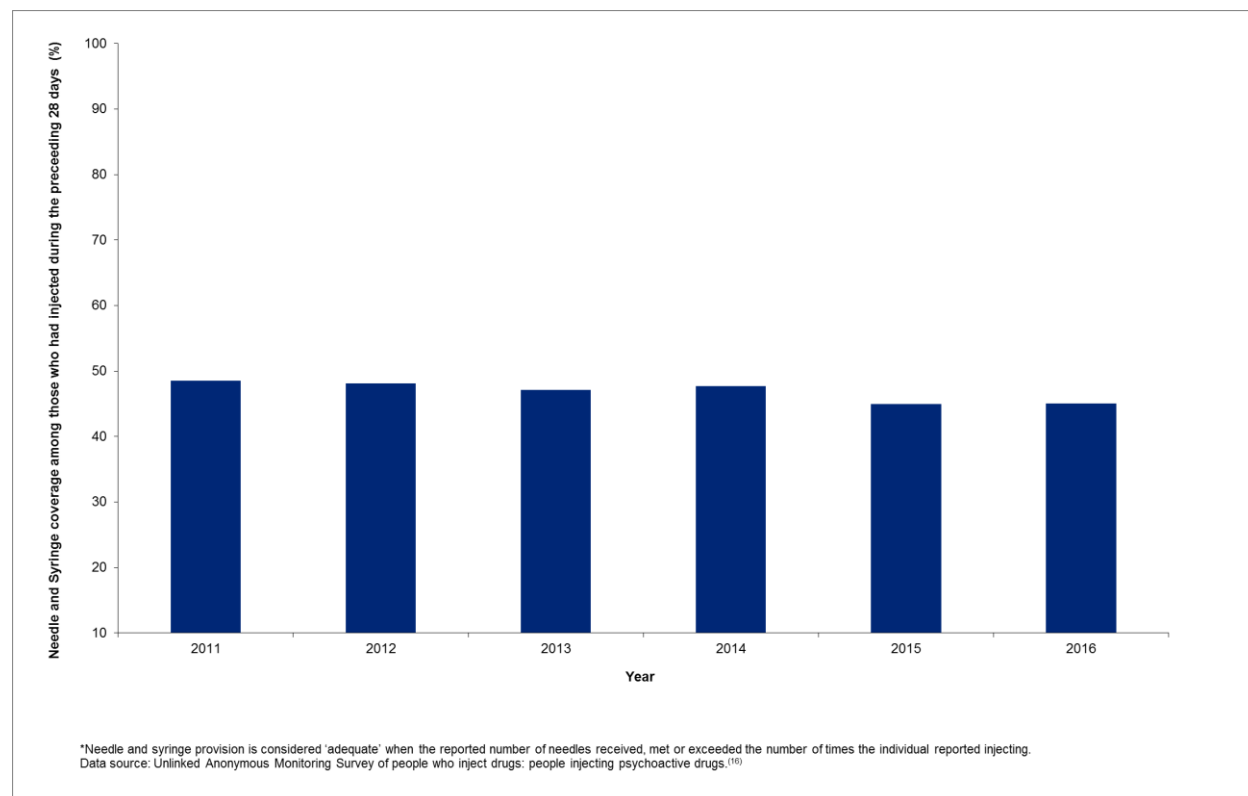
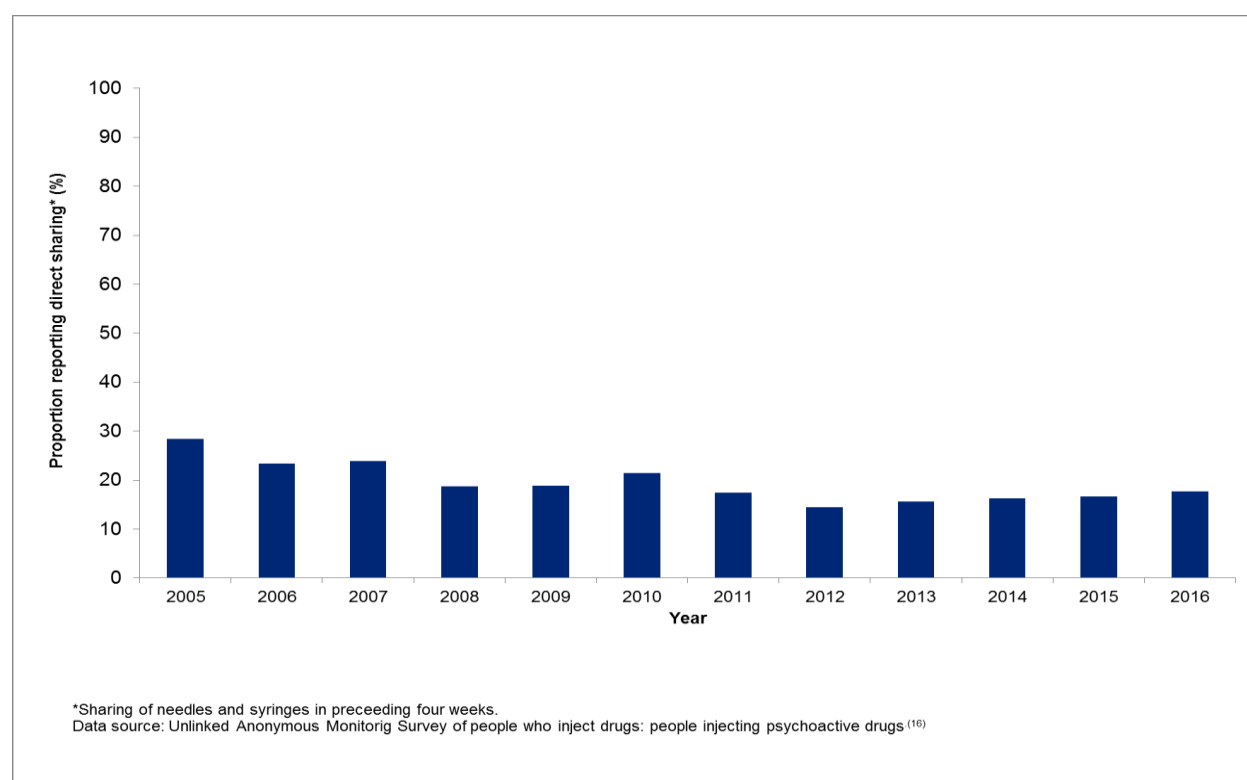


Figure 9 shows that among people injecting psychoactive drugs, the proportion reporting adequate needle and syringe provision is suboptimal, with less than one half of those surveyed indicating adequate provision for their needs (45% in 2016). These data should be interpreted cautiously as some people receive more needles than they need from NSPs because they pass them on to partners or friends, known as 'secondary distribution'. Also, more than one needle is often required per injection, as needles may also be used during drug preparation and an injection may require several attempts (and therefore needles) to access a vein. Nevertheless, these findings indicate that, while evidence suggests that the majority of PWID may be accessing needle and syringe programmes (NSP),^[20] the amount of equipment provided needs to be increased and provision better targeted. NSP have been in the forefront of public health programmes to reduce transmission of infectious diseases since the beginning of the HIV epidemic. NSP are also a vital point of contact for PWID unable or not yet willing to enter a treatment programme. As the majority of HCV infections in England are acquired via injecting drug use, it is important to build on their presence and experience.

Sharing of needles and syringes by PWID

As the sharing of injecting equipment and associated paraphernalia is the main route of transmission of infection among PWID, it is important to monitor levels of sharing within this population. In England, 18% of people currently injecting psychoactive drugs and participating in the UAM Survey, reported direct sharing of needles and syringes in 2016^[4] (Figure 10); this level has declined from 28% in 2005. When including the sharing of mixing containers or filters as well as needles and syringes, the proportion of those reporting sharing is higher still.^[16] The reported level of needle and syringe sharing among people injecting psychoactive drugs participating in the UAM Survey in 2016 varied across England; with the level ranging from 11% in the North West and East Midlands regions to 24% in the South East.^[18] Although levels of sharing have declined over the past decade, there is no evidence of any fall over the last five years. This suggests that the amount of equipment provided needs to be increased and provision better targeted.

Figure 10. Trends in the sharing of needles and syringes in the preceding four weeks among people injecting psychoactive drugs in England 2005 to 2016



Among those injecting image and performance enhancing drugs (IPED) in England and Wales, the reported sharing of injecting equipment has remained relatively low with 13% reporting that they had ever shared a needle, syringe or vial in 2014-2015.^[18]

Drug treatment

The draft action plan for the health sector response to viral hepatitis in the WHO European region^[5] calls for at least 40% of opioid dependent PWID to be receiving OST by 2020, a figure already estimated to have been exceeded in England with 55.5% receiving OST in 2011/12.^[4] Their call for at least 90% of PWID to be receiving targeted HCV information, education and communications^[5] has yet to be quantified in England, although there are a variety of targeted information and education communications available (see section on raising awareness, pages 31-33).

In England, based on the most recent estimates available, there is evidence that the prevalence of opiate and crack-cocaine injecting fell at the beginning of the decade.^[38] However, less is known about the extent of the injection of other psychoactive drugs or about the extent of the use of IPEDs. In England, the number of adults who had ever injected drugs and who were receiving drug and alcohol treatment fell by nearly 12% (11.6%) from 119,140 in 2009/10 to 105,346 in 2015/16;^[4] less than one-fifth of all people in drug and alcohol treatment in 2015/16^[48] (16%, 46,727/288,843) were currently injecting when they entered treatment.^[4] Of the 138,081 people newly presenting to treatment in 2015/16,^[48] 29,958 (22%)^[4] were either currently or had previously injected drugs.

Raising awareness and increasing the numbers and proportion diagnosed

Early diagnosis of HCV infection is important for the most effective treatment and care, yet in 2015, of the 71 million persons estimated to be living with HCV infection globally, only 20% knew their diagnosis.^[2] In the UK, levels of awareness of infection are well above the 20% global average, but are still suboptimal with positive results often failing to successfully link individuals into treatment and care services.^[20]

Metrics to monitor trends in awareness, numbers and proportion diagnosed

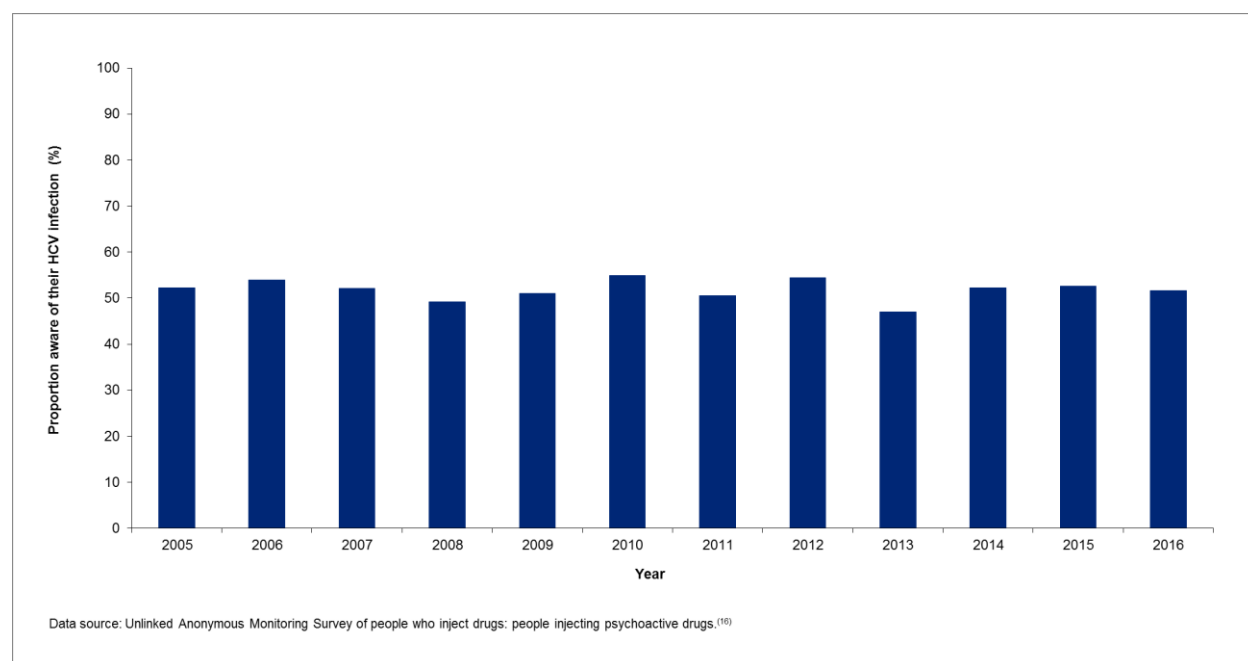
- Proportion of PWID testing positive for antibodies to HCV who are aware of their positive status
- Numbers of GPs, and others working with groups at risk of HCV infection, completing RCGP hepatitis C e-learning courses
- Trend in numbers tested and proportion positive in the general population and primary care
- Trend in numbers tested and proportion positive in key risk groups including PWID, those in secure and detained settings, and individuals of South Asian origin
- Offer and uptake of HCV testing among PWID
- Uptake of HCV testing in English prisons
- Rates of infection in the blood donor population, along with risk factors for acquisition of infection

Estimated proportion of PWID aware of their HCV antibody positive status

While we work towards developing national estimates of the proportion of individuals with chronic HCV infection who remain undiagnosed, an estimate of the proportion of PWID diagnosed can be obtained from the UAM Survey.^[15, 18] In this survey, only around one half of people injecting psychoactive drugs sampled are aware of their HCV antibody positive status (52% in 2016), and this figure has remained relatively stable at this level (averaging 52%) over the past decade^[4] (Figure 11).

The GHSS on viral hepatitis calls for a major global increase in the diagnosis of chronic HCV infection, with 30% of people infected knowing their status by 2020 and 90% by 2030.^[1] However, the WHO action plan for the European region sets relatively more ambitious targets of 50% diagnosed and aware of their infection by 2020 and 75% of those with late-stage HCV-related liver disease diagnosed by 2020^[5] (see appendix 1). While the first target of 50% being diagnosed by 2020 may have already been reached in England, more needs to be done if we are to reach the 90% target by 2030. It will be important to act promptly to increase the numbers diagnosed in England, as this will very quickly become a limiting factor for Operation Delivery Networks as they successfully treat their known diagnosed population.

Figure 11. Estimated proportion of people injecting psychoactive drugs testing positive for HCV antibodies in England, who are aware of their infection, 2005-2016



To reduce the levels of undiagnosed infection, it is necessary to raise awareness of HCV and to roll out (and monitor) testing to more individuals at risk of infection, including priority populations like PWID, those in secure and detained settings, and to populations with close links to countries with a high prevalence of HCV infection.^[10] There are also those who may no longer be in contact with services because they

acquired their infections many years earlier, for example following a past period of injecting drug use or via blood transfusion before the introduction of screening of the blood supply in 1991.

Raising awareness

Because HCV is usually asymptomatic in the early years of infection, many individuals remain unaware of their positive status. There are also other individuals who may have been tested in the past but have not accessed treatment. Raising both professional and public awareness remains a priority therefore, and an important component of reducing the burden of HCV infection.

To ensure that as many eligible people as possible are treated with the new more effective treatments, Public Health England are providing data to support the NHS in identifying people, registered with a GP, who have been diagnosed with HCV in the past but who may not have cleared their infections. The NHS can then contact these patients to offer testing to confirm whether they have active infection, and those that do can be referred for assessment for treatment.

As in previous years, a variety of initiatives are ongoing to increase public awareness of hepatitis C. Many of these are specifically designed to target those at highest risk of infection, including past or current PWID, those in secure and detained settings, and individuals of South Asian origin. Working with HCV Action, PHE have co-hosted a series of roadshows throughout England which have focused on HCV generally but also served to raise awareness of the opt-out bloodborne virus (BBV) testing in prisons. Recent roadshows have taken place in London, Cardiff and Leeds. More information about these and other events is available on their website. The success of all these initiatives has been dependent on the significant contribution of numerous stakeholders working across a range of settings. For example, The Hepatitis C Trust's South Asian outreach officer leads awareness and testing events within the South Asian community in partnership with community leaders and local health authorities to help raise awareness of HCV in the South Asian community. Other initiatives include the Trust's outreach and testing van, which in the three years since its launch, has accompanied more than 225 testing and awareness events engaging over 4,000 people of whom 2,000 were tested. Other services include the development and implementation of patient centred HCV interventions in collaboration with drug providers, including staff training, peer-to-peer education, buddying, and the provision of a confidential helpline (+44 (0) 20 7089 6221).

World Hepatitis Day, observed on 28 July each year, continues to provide a focus for raising awareness of HCV. Last year (2017), PHE launched a hepatitis C testing quiz, hosted by The Hepatitis C Trust, to encourage people to find out whether they might have been exposed to the virus and would benefit from a hep C test. A linking poster campaign, fronted by TV's Dr Christian Jessen, involved the distribution of posters to

GP surgeries throughout England, encouraging people to take the quiz to see whether they might be at risk of infection. Posters are available from the Health and Social Care Publications Orderline along with a guidance factsheet (+44 (0) 300 123 1003; Product code: HEPCQUIZ001).

Later in 2017 further **resources** were developed by PHE, in collaboration with stakeholders, and launched during European HIV/hepatitis testing week (17 - 24 Nov). These included posters in Urdu, along with risk videos and banners for social media in different languages co-branded by the World Hepatitis Alliance, The British Liver Trust and The Hepatitis C Trust. These free **resources** help people to recognise any risk for infection and encourage those at risk to seek testing.

The RCGP Certificate in the Detection, Diagnosis and Management of Hepatitis B and C in Primary Care was developed to help raise awareness in primary care and among other professionals working with groups at high risk of viral hepatitis infection.^[8] By the end of February, 2017, over 2,800 (n= 2,827) individuals had completed the e-learning module.^[4] This course is currently being updated and should be available later this year. A further RCGP course, 'Hepatitis C: Enhancing Prevention, Testing and Care' is also available and comprises four lessons: understanding hepatitis C; preventing transmission; testing and diagnosis; and treatment and care.^[9] By the end of February, 2018, over 1,600 (n= 1653) individuals had completed this e-learning module.^[4]

A PHE drugs commissioning support pack for adults^[49] is available and outlines principles that local areas might consider when developing plans for integrated alcohol and drugs prevention, treatment and recovery system. The pack includes data and prompts relating to HCV testing and pathways to treatment and support for hepatitis C. A PHE 'Turning Evidence Into Practice' briefing gives an overview of the main issues relating to HCV that local providers and commissioners of drug and hepatitis treatment should be aware of, with advice on improving access to, and completion of, HCV treatment.^[50]

To support the final implementation phase of the national prison blood-borne virus (BBV) opt-out testing programme for eligible adults, an engagement event was organised by PHE, NHS England and Her Majesty's Prison and Probation Service (HMPPS) on November 30 in London. The event aimed to share lessons learnt from the early stages of BBV opt-out testing implementation in prisons in England and promote good practice in the final stages of the programme. The event was held within a few months of the planned programme end date (March 2018) so as to provide a final 'push' towards timely programme completion and identify any obstacles to implementation. Participants heard from leading experts in prison healthcare, public health and virology as well as from patients themselves, and were encouraged to take part in discussions and table-top exercises. Invited speakers shared their knowledge and experience of the current challenges and opportunities that exist to providing BBV treatment and care in prisons. More information, including the event programme, can be found on the **official**

[event website](#). An event evaluation report will also be available on the PHE [Health and Justice website](#) in March 2018.

Overall, the NGO sector has been particularly influential and their work is essential and complements government and public sector initiatives in this important area.

Testing and diagnosis

In England, testing and diagnosis monitoring data are available from a variety of surveillance systems: the UAM Survey of PWID,^[18] Sentinel Surveillance of Blood Borne Virus Testing, laboratory reporting, the National Drug Treatment Monitoring System (NDTMS), the NHS BT/PHE Epidemiology Unit Blood Donor Surveillance Scheme and via Health and Justice Indicators of Performance (HJIP). Trends in HCV diagnosis and testing are useful for monitoring the impact of awareness-raising initiatives and prevention activity; this in turn helps to track national progress in controlling the infection. Monitoring testing and diagnosis is useful at both a population level, as well as in sub-groups that are at increased risk of infection. Monitoring HCV in blood donors, who are at low risk of bloodborne virus infection, is also very useful for identifying new groups of individuals who may be at risk of infection.

NICE public health guidance exists to help focus activity to ensure that more people at increased risk of hepatitis C (and B) infection are offered testing.^[10]

Laboratory reports of hepatitis C

Over the last two decades (1996-2016), there has been a more than fivefold increase in the number of laboratory confirmed reports of HCV in England (Figure 12). In 2016, 10,731 laboratory reports of individuals testing positive for antibodies to HCV and/or HCV RNA were reported^[4] (Figure 12). Where reported, around two-thirds of laboratory reports (68.8%) were in men; almost one half (45.2%) of all reports received were in individuals aged between 25 and 39 years (Figure 13).

Figure 12. Number of laboratory reports* of hepatitis C from England: 1996 to 2016**

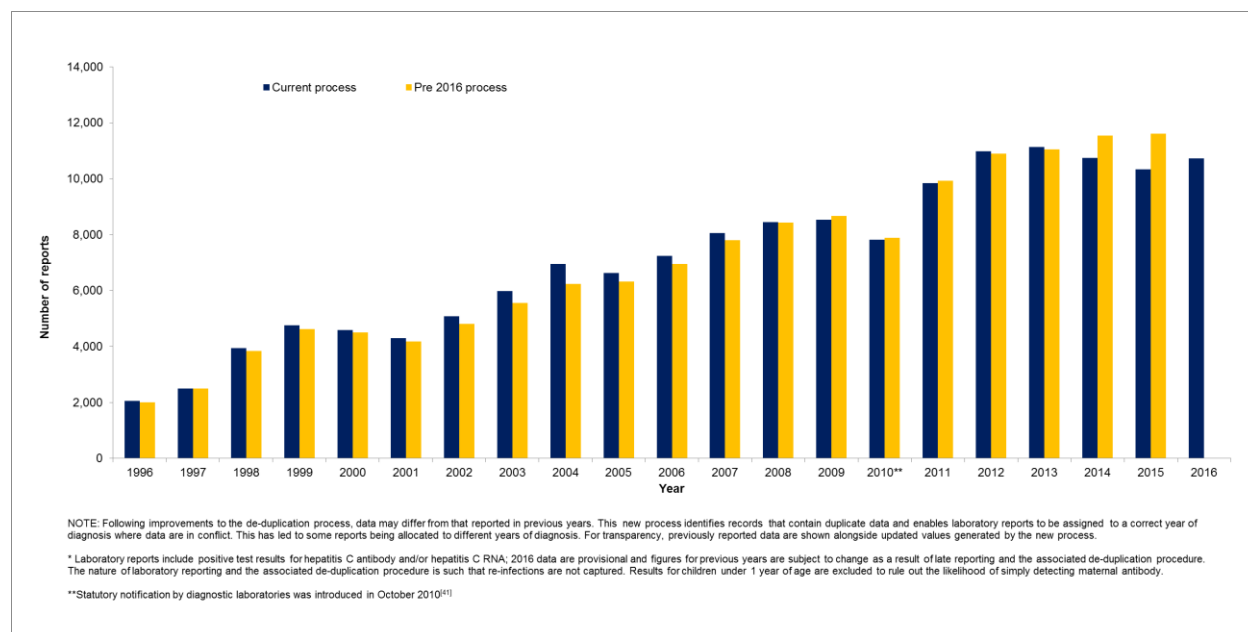
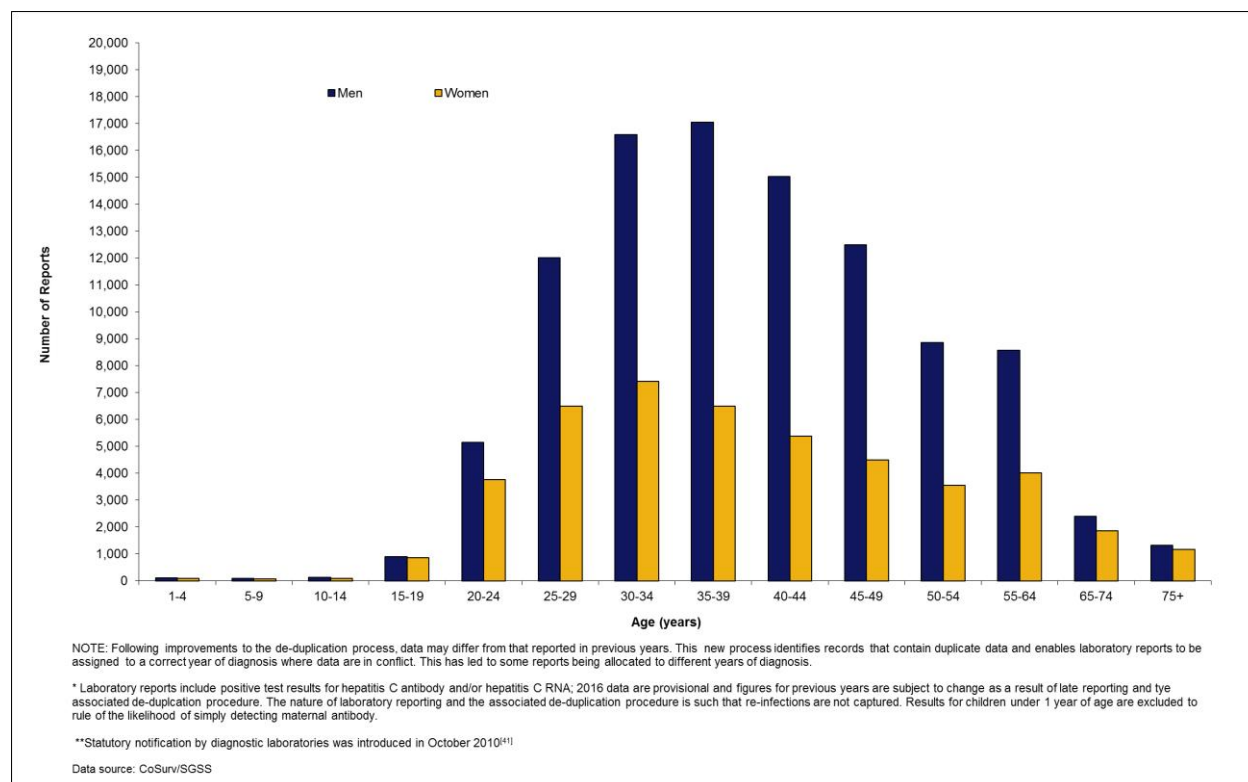


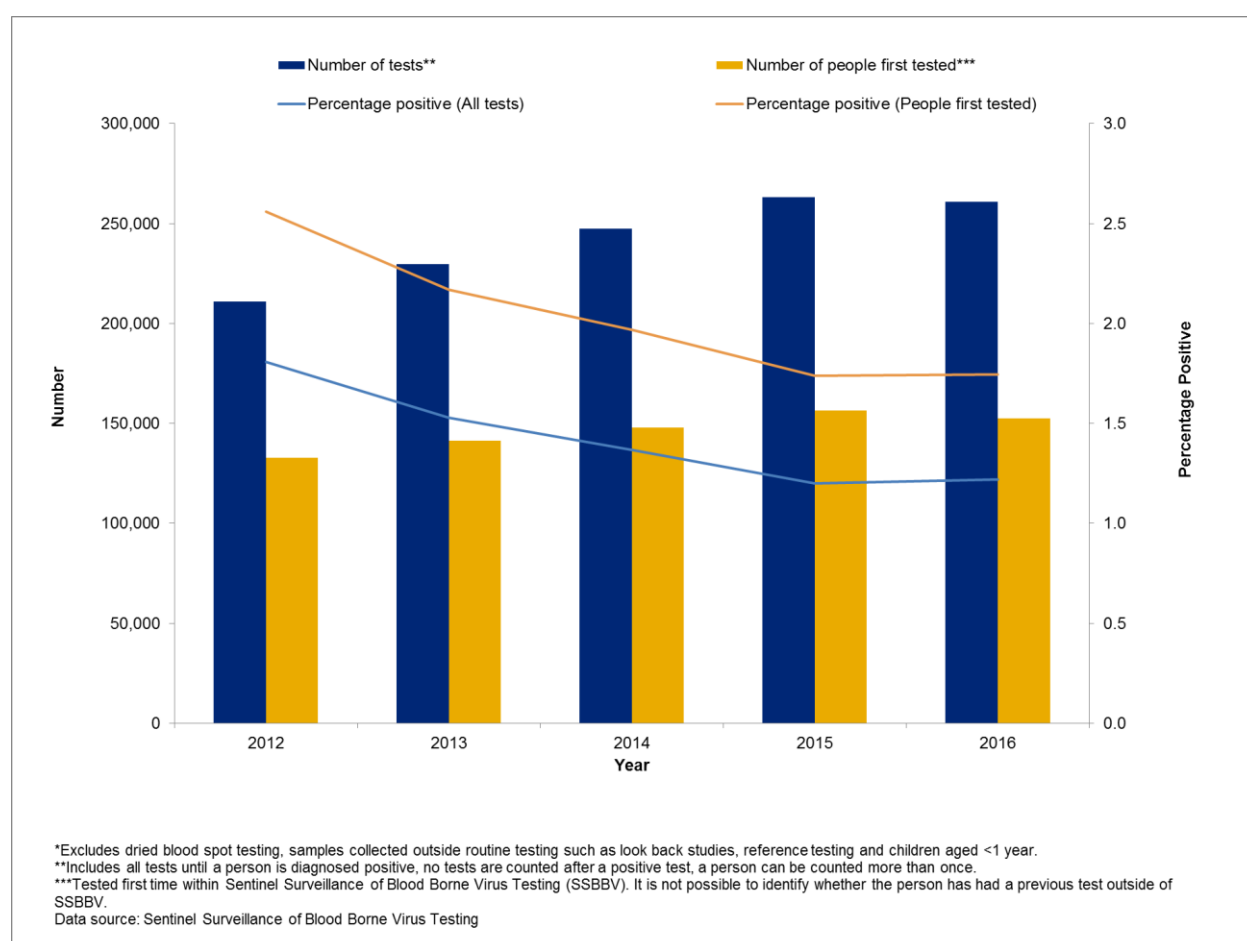
Figure 13. Age and sex distribution, where reported, of laboratory reports of hepatitis C from England: 1996 to 2016**



Testing and diagnosis in the general population and primary care

Trends in testing were analysed using data from 15 of the 22 sentinel laboratories where complete and consistent data have been available from January 2012 to December 2016^[4] (Figure 14). Numbers of tests undertaken rose by 23.7% between 2012 and 2016, with a 14.8% increase in the number of tests conducted among people who have never had a previous test reported by the sentinel laboratories. It is important to note that these figures do not include dried blood spot (DBS) testing due to the continued failure to capture testing data from private laboratories and therefore numbers are likely to be higher; investigations are ongoing to obtain a fuller picture. The proportion of tests identified as anti-HCV positive declined from 1.8% in 2012 to 1.2% in 2016, and among people who had no previous test reported by the sentinel laboratories from 2.6% to 1.7% respectively. These figures are consistent with a higher proportion of people at relatively lower risk of infection being tested.

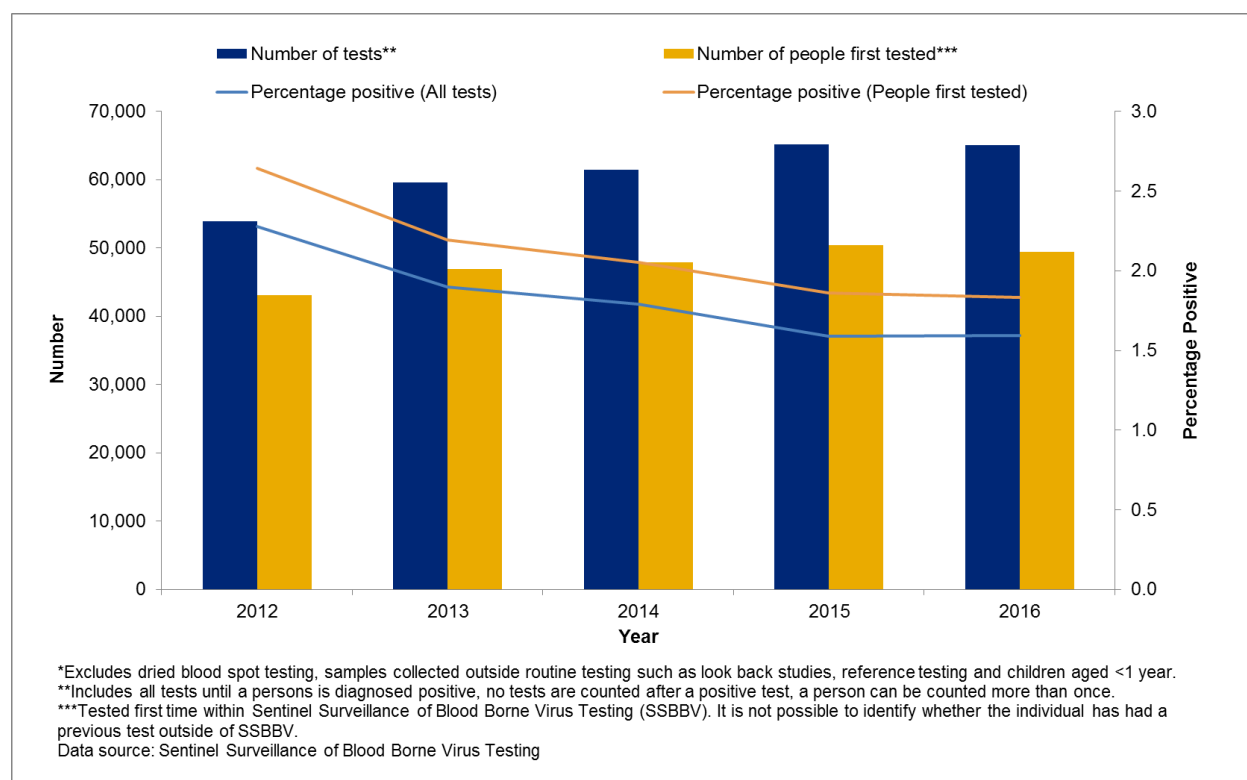
Figure 14. Number of tests and number of people first tested for anti-HCV by year, and proportion positive, in 15 sentinel laboratories: 2012 to 2016*



In sentinel laboratories, the number of tests undertaken via GP surgeries rose by 20.8% between 2012 and 2016, with a 14.6% increase in the number of tests conducted among people who have never had a previous test reported by the sentinel laboratories,

suggesting that awareness of HCV in this setting may be increasing,^[4] (Figure 15). Again, it is important to note that these figures do not include DBS testing due to the continued failure to capture testing data from private laboratories; investigations are ongoing to obtain a fuller picture. The proportion of tests conducted in GP surgeries identified as anti-HCV positive declined from 2.3% in 2012 to 1.6% in 2016, and from 2.6% to 1.8% among people who had not had a previous test reported by the sentinel laboratories (Figure 15). These figures again suggest that a higher proportion of individuals at relatively lower risk of infection are being tested.

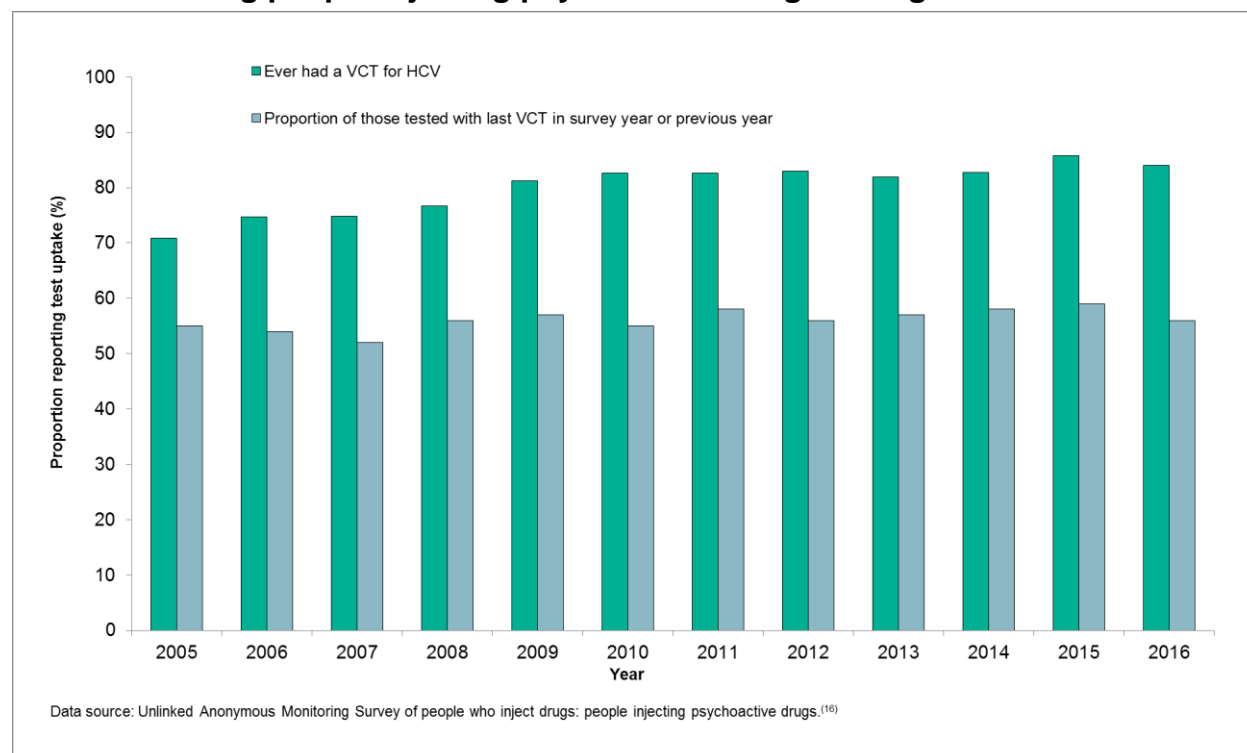
Figure 15. Number of tests and number of people first tested for anti-HCV by year, and proportion positive, through GP surgeries in 15 sentinel laboratories: 2012 to 2016*



Testing and diagnosis in people who inject drugs

In the UAM Survey of PWID,^[15, 18] 84% of those injecting psychoactive drugs reported ever having had a voluntary confidential test (VCT) for HCV in 2016, an increase from 71% in 2005^[4] (Figure 16). The proportion of those ever tested who had their last test during the preceding two years was 56% in 2016 (n= 808), which was similar to the proportion found in previous years ^[4] (Figure 16). These findings suggest that increasing the uptake of testing does not necessarily translate directly into improved levels of awareness of infection in this population group (see Figure 11). In part at least, this will be because those who are at continuing risk of infection may not always be offered, or take up the offer of, further HCV tests at regular intervals.

Figure 16. Trends in reported uptake of voluntary confidential testing (VCT) for HCV infection among people injecting psychoactive drugs in England: 2005 to 2016



Among those injecting IPEDs in England and Wales, 41% reported a voluntary and confidential test for HCV in 2014-2015.^[18]

Similarly, NDTMS data suggest that levels of HCV testing among people in treatment for drug and alcohol use, are continuing to rise in England.^[4] Among adults in drug and alcohol treatment who are eligible to receive a test, the proportion who have a HCV test recorded has increased from 43.2% (2009/10) to 66.4% (2015/16).^[4] A similar rise has been recorded in adults newly presenting for drug treatment (37.1% in 2009/10 compared with 51.3% in 2015/16; ^[4]). When considering just those who have ever injected drugs, in 2015/16 more than four-fifths (82.5%) were recorded as having received a test,^[4] an increase from just over one half (56.9%) in 2009/10. Levels of testing among those who have ever injected drugs who are newly presenting to treatment have remained stable at around 72% (Range: 70.2, 73.5) over the last five years.^[4]

In 2015/16, more than four-fifths (83%; n= 170,009) of all adults receiving drug and alcohol treatment were recorded as having been offered a HCV test and around one half of those offered (48.5%, n= 98,848) accepted the offer. ^[4] Of those newly presenting to treatment, around three-quarters (77%, n=61,814) were offered testing, with just over one third of those offered (36.4%, n=29,249) accepting the offer.^[4] Considering just those who have ever injected drugs, over four-fifths were offered a test (88.1%, n= 92,805), and nearly three-fifths of those offered (59.1%, n= 62,304) accepted the offer in 2015/16 ^[4]. A similar proportion of those newly presenting to

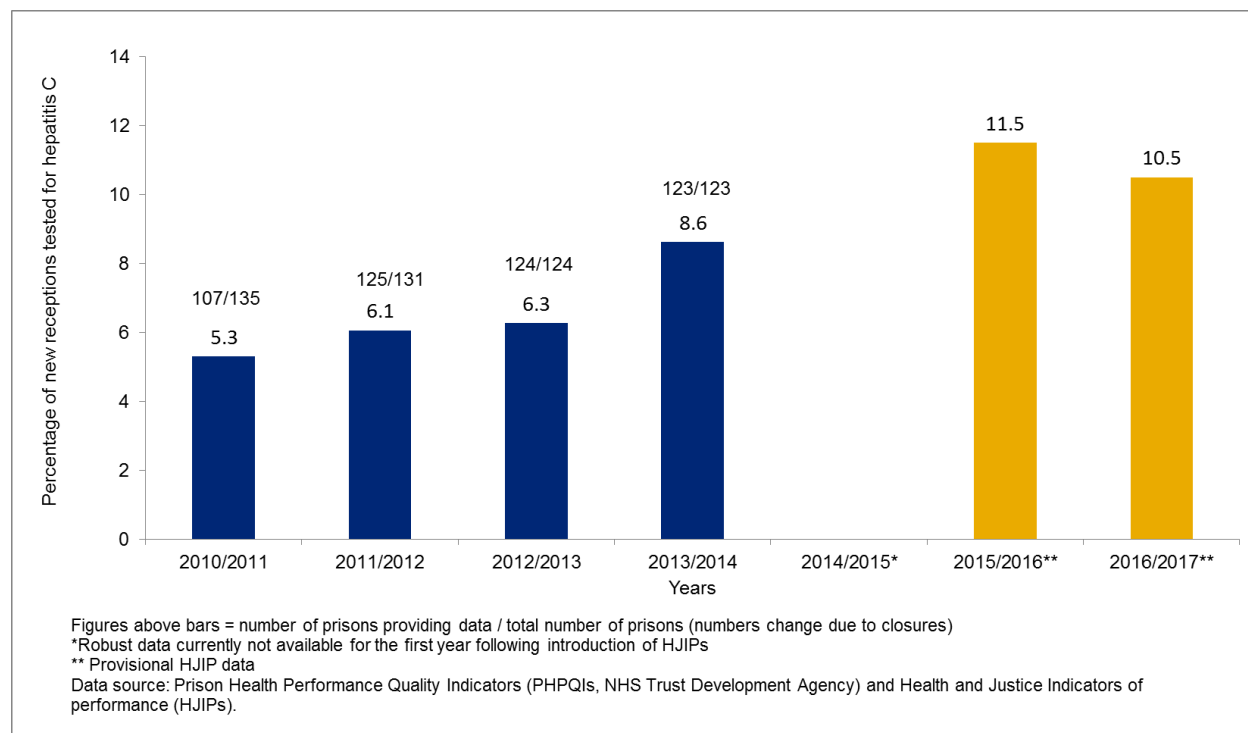
treatment were offered testing (82%, n= 24,564), with nearly half of those offered (46.2%, n=13,844) accepting the offer.^[4]

Sentinel surveillance data on testing in specialist services for drug users are not presented this year as it is recognised that additional DBS testing data from private laboratories are required to obtain a full picture of testing in sentinel laboratory areas, particularly since expansion of DBS testing has been actively encouraged over recent years in this setting. Until 2015, these data were collected at an aggregate level by region, however, work is currently underway to determine whether additional information on testing facility can be collated and used to help understand recent changes in testing.

Testing and diagnosis among people in secure and detained settings

Hepatitis C affects a larger proportion of people in prison and other detention centres than the wider population, principally as a result of the relatively higher levels of injecting drug use that are observed among this population.^{[51],[52]} Prison Health Performance Quality Indicators (PHPQI) have shown a steady rise in HCV tests performed, from 5.3% in 2010/11 to 8.6% in 2013/14^[4] (Figure 17). The HJIP dataset that replaced the PHPQIs in April 2014, includes a new set of improved indicators for monitoring HCV testing (Figure 18). These will help to inform commissioners, healthcare providers and public health specialists about the uptake and impact of testing among people in prisons following the full implementation and validation of the system. Data quality improvement has been ongoing on the HJIPs dataset since its inception and HCV testing information for English prisons using revised testing metrics will be available for the 2017/18 financial year. However, preliminary testing data received from HJIPs for the 2016/17 financial year indicates that 10.5% of all new receptions and transfers to adult prisons in England received an HCV antibody test (Figure 17), and of those testing positive, 81.7% were tested for active disease by HCV PCR testing.

Some of the increase in testing for people in prisons may be due to the introduction of bloodborne virus (BBV) opt-out testing programme, which was agreed in October 2013 by PHE, NHS England and HMPPS.^[53] While this increase in testing is welcomed, current levels are still below the lower BBV testing threshold proposed by NHS England (50-74%), and well below the target threshold of at least 75% uptake. The programme will be fully implemented across the English prison estate by the end of March 2018; as of November 2017, 75% of adult prisons in England were implementing BBV opt-out testing.

Figure 17. Proportion of new receptions to English prisons tested for hepatitis C: financial years 2010/11 to 2016/17**Figure 18. Health and Justice Indicators of performance relating to hepatitis C testing**

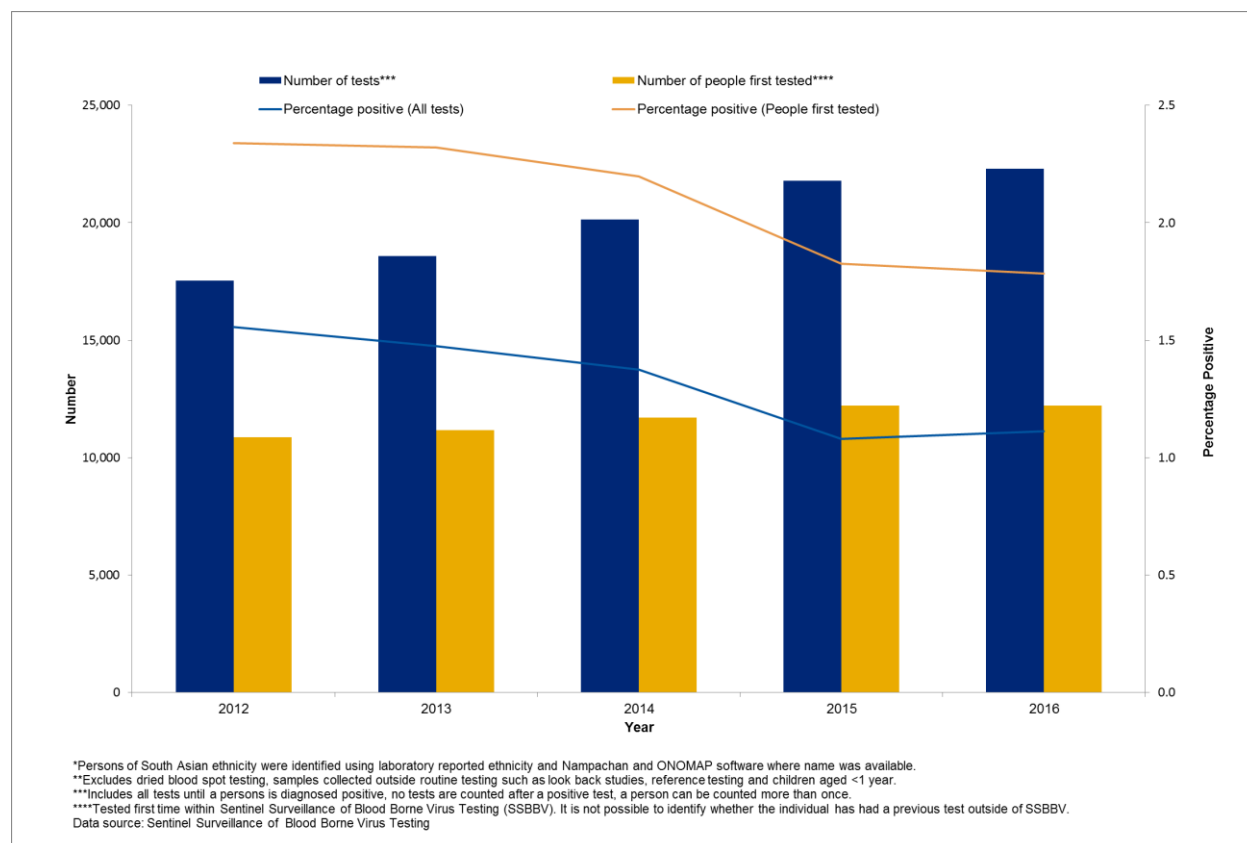
Hepatitis C testing	Percentage of patients offered hepatitis C testing, within 72hrs of reception
Hepatitis C antibody testing	Percentage of eligible patients who have undertaken a HCV antibody test
Hepatitis C PCR testing	Percentage of HCV antibody positive patients who underwent HCV PCR testing

Acute HCV infection among people in prison are reported directly to the National Health and Justice Team for public health action. Over the period spanning calendar years 2014 to 2016, just one confirmed case of acute HCV was reported to the Public Health Intelligence for Prisons and Secure Settings Service (PHIPS) in 2014. Overall, these data suggest an increasing awareness of HCV across the prison estate. As with testing data from specialist services for drug users, sentinel surveillance testing data from prison services are not presented this year while additional DBS testing data from private laboratories are being sought to better understand trends in testing within this setting. While levels of testing remain suboptimal in this setting, further improvements are anticipated as the opt-out BBV testing policy gains ground.^[54]

Testing and diagnosis in black and minority ethnic populations

In sentinel surveillance, ethnicity is assigned using information from laboratory reports, and supplemented using name analysis software (NAMPACHAN and ONOMAP^[55]) when ethnicity is not reported. The number of anti-HCV tests undertaken among the South Asian population rose by 27.2% between 2012 and 2016, with a 12.5% increase in the number of tests conducted among people who had no previous test reported by the sentinel laboratories (Figure 19). It is important to note that these figures do not include dried blood spot testing due to the continued failure to capture testing data from private laboratories; investigations are ongoing to obtain a fuller picture. The overall increase in testing may be a reflection of targeted awareness-raising campaigns that have taken place among South Asian communities over recent years. Over this period (2012 to 2016), 1.3% of tests among people of South Asian origin were anti-HCV positive, declining from 1.6% in 2012 to 1.1% in 2016; the corresponding figures for people of South Asian origin who had no previous test reported by the sentinel laboratories were 2.1%, 2.3%, and 1.8%, respectively (Figure 19).

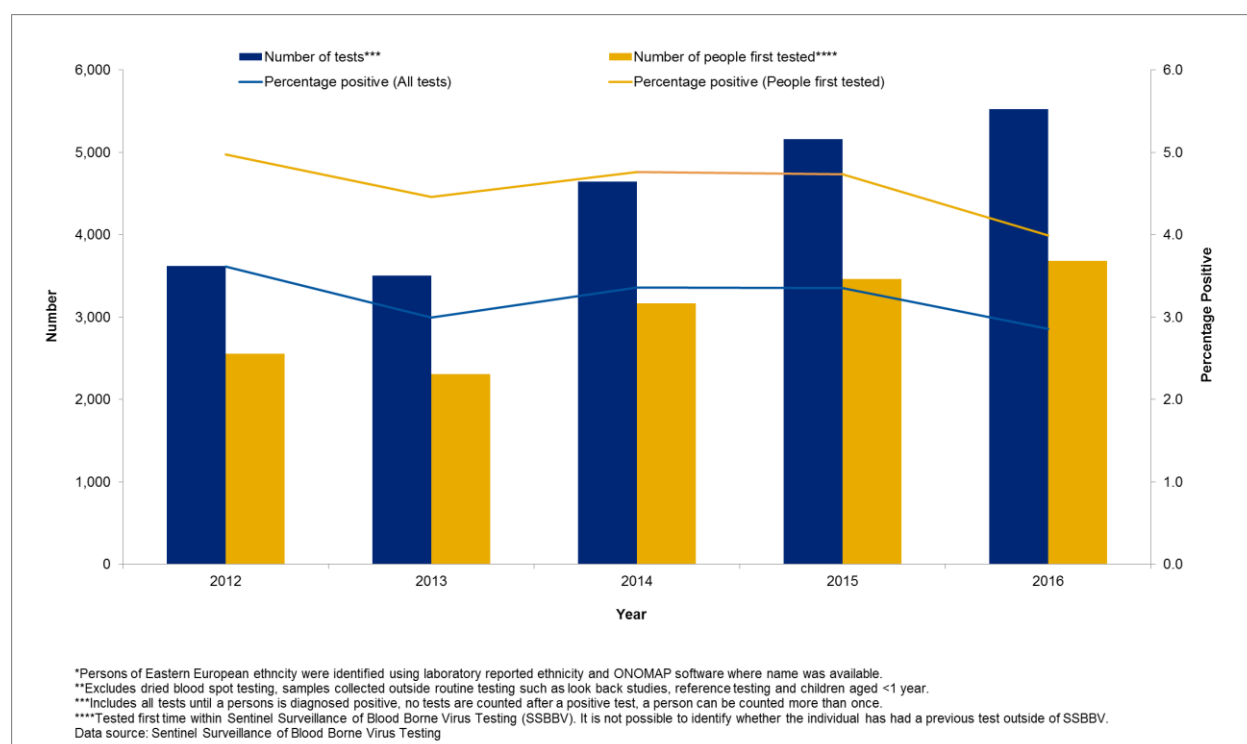
Figure 19. Number of tests and number of people of South Asian* origin first tested for anti-HCV, and proportion positive, in 15 sentinel laboratories: 2012 to 2016**



Sentinel surveillance data indicates that the number of tests among people who were identified as being of Eastern European origin (using laboratory reported ethnicity and

ONOMAP^[55] name analysis software), increased by 52.5% between 2012 and 2016, with a 44.3% increase over the same period in the number of tests conducted among people who have never had a previous test reported by the sentinel laboratories ^[4] (Figure 20). Over this period, 3.2% of tests among people of Eastern European origin were anti-HCV positive, and 4.6% among people of Eastern European origin who had no previous test reported by the sentinel laboratories ^[4](Figure 20). These figures suggest that these individuals may be at relatively increased risk of having acquired HCV and/or that testing of this ethnic group is more targeted at higher risk individuals than in the general population.

Figure 20. Number of tests and number of people of Eastern European origin* first tested, and proportion positive, in 15 sentinel laboratories: 2012 to 2016**



Testing to establish levels of co-infection with HIV

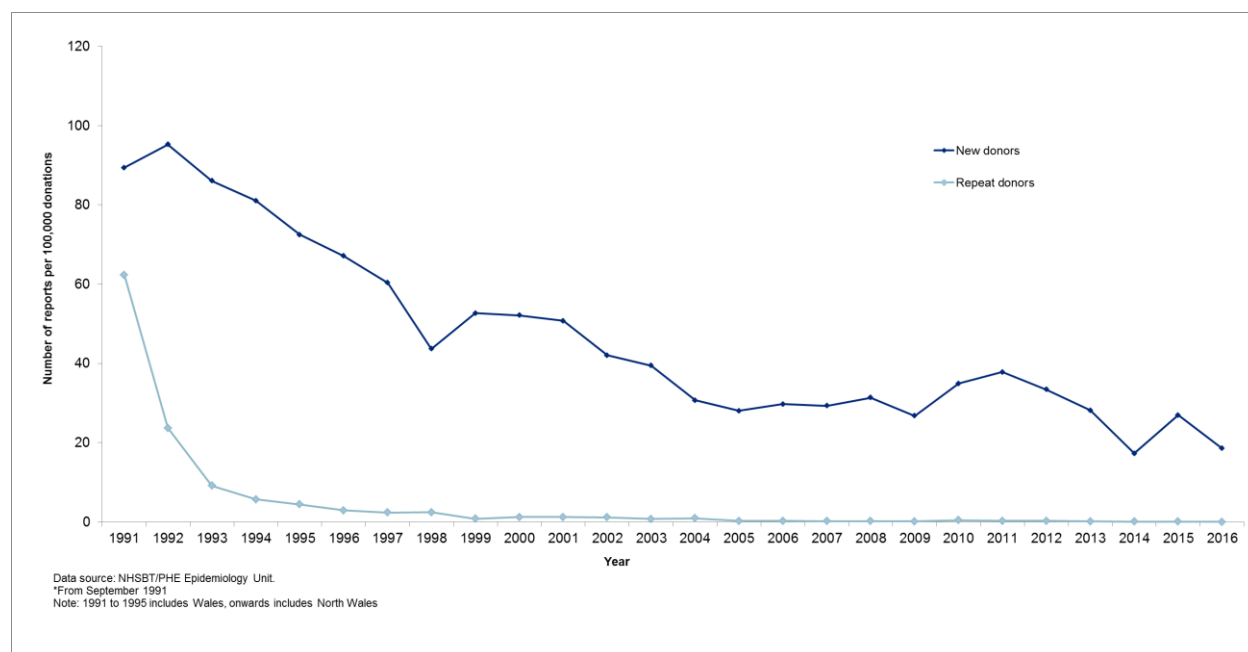
In people with HCV, HIV co-infection can lead to faster progression to liver disease.^[56]
^[57] In order to estimate levels of co-infection among the HCV population in England, adults with current HCV infection reported to sentinel surveillance were linked to the PHE national HIV database. Preliminary results suggest that between 2008 and 2014, 5.0% of adults with a current HCV infection were diagnosed with HIV infection; around two thirds reported their probable route of HIV transmission as sex between men, and nearly one quarter reported injecting drug use.

Testing of the blood donor (low-risk) population

Blood donors are generally at low risk of bloodborne viruses; monitoring infections among them is important as observations in this group may suggest issues in the wider population. NHS Blood and Transplant currently collects blood donations from donors in England (and North Wales to 1 April 2016); all donations are screened for HCV antibody and nucleic acid while repeat reactive donations undergo confirmatory testing. Numbers and rates shown are for confirmed positive donations/donors ^[4] (Figure 21).

In 2016, 28 blood donors tested positive for hepatitis C, with all infections detected in new donors. The rate in new donors decreased to 18.5 per 100,000 donations from 26.9 per 100,000 new donations in 2015, and is similar to the rate in 2014 ^[4] (Figure 21). This continues the declining trend in HCV in new donors in England (and North Wales).^[58]

Figure 21. Rate of hepatitis C among donations from new and repeat blood donors in England (and North Wales): 1991* to 2016



In 2016, 39% of all the blood donors testing positive for HCV in England (and North Wales) were of white British ethnicity followed by 32% of 'other-white' ethnicity; 61% were male and 50% were aged 45 years and over. Rates in new donors were higher in males at 28.8 per 100,000 donations compared to 11.9 per 100,000 donations for females. In 2016, by ethnic group, new donors of South Asian ethnicity and 'other white background' had the highest rates of HCV infection with 127.7 and 74.4 per 100,000 new donors respectively, although the numbers are small; in 2015 the rate was highest in other-white new donors, followed by South Asian new donors. Of the HCV positive

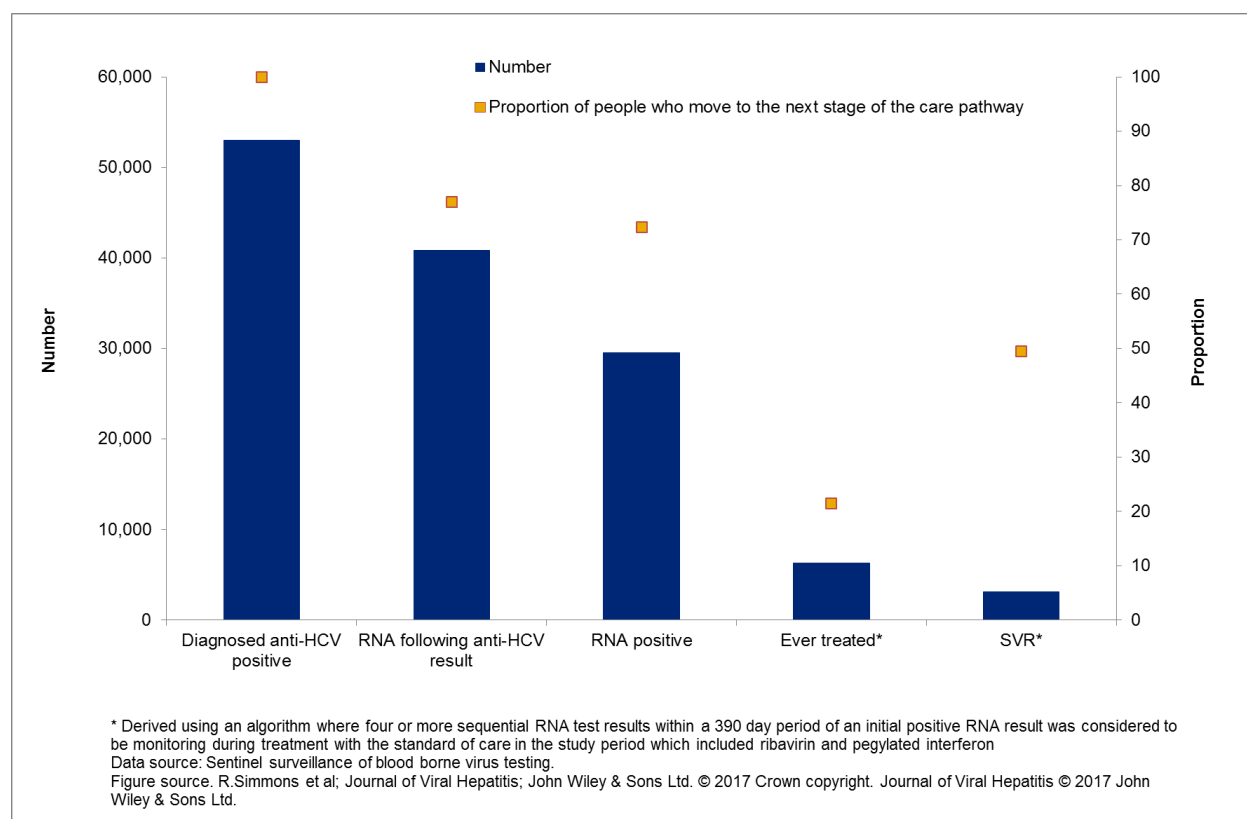
donors of South Asian ethnicity, 86% (6/7) were born in Pakistan, although country of birth is not available for all donors.

Fourteen percent of HCV positive new donors (4/28) had no risk factor assigned. Persons with a history of injecting drugs are permanently deferred from donating in the UK although donors do not always disclose this behaviour. The number and proportion of HCV positive donors reporting injecting drug use varies each year but is currently at a very low level. In 2016, three reported a history of injecting while one reported intranasal drug use. Three donors had sex between men and women assigned as their exposure; two had partners with a history of injecting drugs. Where known, possible blood contact covering a wide range of not necessarily causal exposures, accounted for 46% of HCV cases (11/24), mostly abroad (9/11). A further 25% (6/24) were assigned as originating from a country with higher prevalence of HCV than the UK without any other possible exposure reported (four from Pakistan, one from India and one from Latvia).

Increasing the numbers accessing hepatitis C treatment

The GHSS on viral hepatitis calls for three million people with chronic HCV to have been treated by 2020, and by 2030 treatment coverage to reach 80% of the eligible population.⁽¹⁾ However, the WHO action plan for the European region sets relatively more ambitious targets of 75% of diagnosed patients with chronic HCV having accessed treatment by 2020, with more than 90% of these cured, and 90% of all diagnosed patients being linked into care and adequately monitored by 2020^[5] (see appendix 1). Worldwide, it is estimated that seven per cent of those diagnosed with HCV were started on treatment in 2015.^[2] In the era of pegylated interferon and ribavirin treatment in England, this figure was estimated to be higher, but still suboptimal, with around 20% of those testing positive for HCV RNA thought to have accessed treatment (Figure 22).^[59]

Figure 22. The cascade of care for persons with chronic HCV in England in the era of ribavirin and pegylated interferon treatment, 2005-2014



New DAA drugs have the potential to transform the treatment landscape, swiftly clearing the virus in the vast majority who receive them, without many of the complications associated with previous treatments. While prevention activity is crucial in reducing the rate of new infections, numbers already infected would remain high for many years without effective HCV treatment, which has the potential to dramatically reduce the number of deaths in the short and medium term.^[21]

From the public health perspective, the new generation of DAA drugs offer a considerable advantage over previous HCV treatments because their all-oral, shorter treatment durations, and improved safety profiles make them easier to roll out in community/outreach settings where it is easiest to reach many of those infected. While the high price of these new drugs represents a major barrier to access in most countries worldwide, these medicines are now being rolled out in England in accordance with national recommendations.^{[22],[23],[24],[25],[26],[27],[28],[31],[34],[60]}

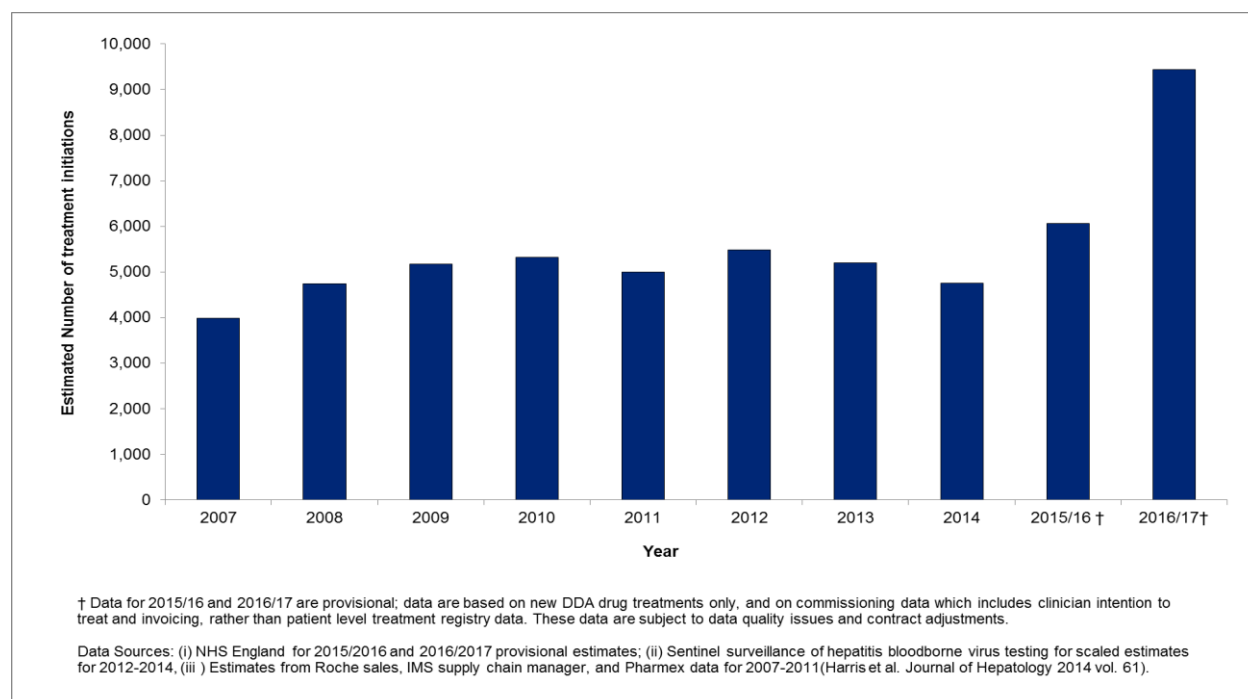
Metrics to monitor numbers/access to hepatitis C treatment*

- Numbers initiating HCV treatment
- Based on the above, annual predictions of the number of people expected to be living with hepatitis C related end-stage liver disease/hepatocellular carcinoma in 2020 and 2030

*Future additional metrics on uptake and access to treatment will be available via the National Treatment Monitoring Dataset, including ethnicity, country of birth, source of referral, route of infection, and setting of treatment

As we work towards producing estimates of the proportion of the chronically infected population who achieve a SVR following treatment, provisional data suggest significant increases in the number of people accessing treatment in 2015/16 and 2016/17 (Figure 23). Between 2008 and 2014, provisional estimates suggest that numbers initiating HCV treatment in England remained relatively stable at around 5,100 initiations per year (Mean: 5,096; Range: 4,738-5,484; ^[4] Figure 23). However in the financial years 2015/16 and 2016/17, provisional NHS England data suggest that significantly more people (15,506 in total) accessed treatment than in earlier years, 19% more in 2015/16 than mean 2008-2014 levels ($970/5096 \times 100$), and 56% more in 2016/17 than in 2015/16 ($3374/6066 \times 100$). This is the result of access to new DAA drugs that have been coming online since 2014/15.^{[23],[27],[28],[26],[24][29],[30]}

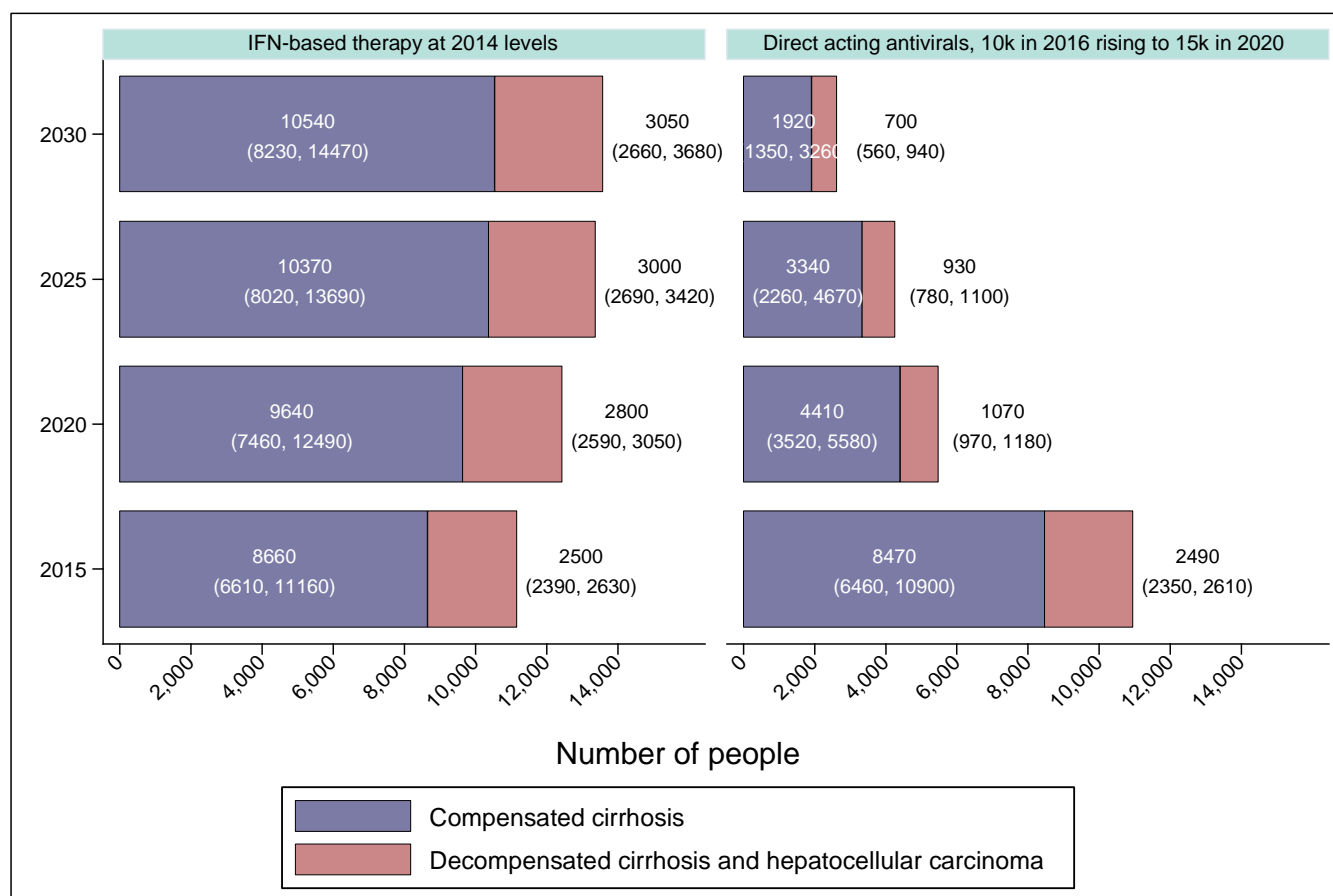
Figure 23. Provisional estimates of numbers initiating HCV treatment in England, 2007-2016/2017



The NHS England treatment run-rate figures were developed based on information from NICE on clinical and cost effectiveness and clinical advice regarding predicted uptake rates. NICE guidance supports access to DAAs but requires the prioritisation of patients based on highest unmet clinical need. NHS England has established 22 ODNs across the country to ensure national access to antiviral therapy. ODNs are given a share of the national annual treatment run-rates based on estimated local need. Current NHS targets are to have treated around 10,000 patients in 2016/17, 12,500 in 2017/18, 13,000 in 2018/19, 14,000 in 2019/20 and 15,000 in 2020/21. Given the numbers treated in 2016/17, and assuming the planned scale-up can be achieved and a rate of 15,000 per year continues, statistical modelling^[31] predicts that around 5,480 people would be living with HCV-related cirrhosis or HCC in England by 2020 and around 2,620 by 2030 (Figure 24), representing a fall in HCV-related cirrhosis/HCC of 56% by 2020 and 81% by 2030.

These figures are based on a number of modelling assumptions.^[48] Firstly, the SVR rates assumed here for those with compensated cirrhosis are conservative, as near-100% rates have been observed in many trials, including in those with cirrhosis. Conversely, rates of post-SVR disease progression in those with cirrhosis are assumed to be low, but long-term outcomes are not yet well-quantified.^[61] Secondly, no re-treatment is incorporated in the model, but conversely, re-infection is also assumed to be zero. Thirdly, treatment rates of up to 70% per year have been assumed for cirrhosis and ESLD/HCC, which may be somewhat optimistic, as not all those with cirrhosis will be diagnosed and achieving this rate in practice may be difficult. Crucially, numbers of people living with compensated cirrhosis, and all preceding disease stages, are estimated quantities; if a greater or smaller number of people are at, or approaching, cirrhotic disease stage this will of course affect the short-term impact of DAAs on severe HCV-related disease. The dramatic impact of DAAs predicted here rests largely on the assumption of being able to treat a large proportion of those with cirrhosis before reaching ESLD/HCC.

Figure 24. Predicted number of people living with HCV-related cirrhosis or decompensated cirrhosis/HCC in England under new DAAs compared to previous IFN-based therapy (95% credible intervals are given in parentheses)^[31]



In subsequent years, it will be possible to directly estimate the impact of DAAs (rather than modelling their predicted impact) as known numbers of those treated at different disease stages, in particular those with cirrhosis, should translate to a reduction in observed HCV morbidity and mortality. Despite the potential limitations of modelling, a substantial reduction in severe HCV-related disease is likely; and it is inevitable that DAAs will have a dramatic impact in comparison to previous interferon-based therapy (Figure 24). Although treating those with cirrhosis is imperative, a rising number of those infected are progressing to cirrhosis. Therefore, treatment of mild and moderate stage disease is also required to maintain reductions in HCV-related disease and reduce the numbers becoming newly or re-infected.^[31]

Access to treatment and care

Many HCV infections occur in marginalised communities, including PWID and black and minority ethnic populations. It is therefore important to ensure that care pathways exist that allow these individuals, as well as others, to access treatment and care.

A national treatment monitoring dataset has been agreed^[20] that will help describe equity and access to HCV treatment and care in the ODNs across England. Data including ethnicity, country of birth, route of infection, disease stage, source of referrals and setting of treatment will all help to describe which groups are accessing treatment and the impact of this treatment on the future burden of HCV-related disease in England.

Information on access to HCV treatment services by PWID is available via the UAM Survey.^[18] The survey asked participating people who had ever injected psychoactive drugs who reported having had a positive result to a diagnostic test for hepatitis C: 'Have you ever seen a specialist nurse or doctor (e.g. a hepatologist) about your hepatitis C?' Among the 2016 survey participants in England with antibodies to HCV who were aware of their infection, 68% (352/518) reported that they had seen a specialist nurse or doctor about their infection, and 21% (108/518) reported being given any medication related to their HCV infection.

In prisons and other places of detention, referrals will be monitored via an HJIP metric that was introduced in April 2014 to monitor the percentage of those with chronic HCV infection who are referred to specialist services, and who have a treatment plan developed within 18 weeks. Due to data quality issues these data will only be available for the 2017/18 financial year, with quarter 1 data published in the phase three pathfinder report of the BBV opt-out testing programme in prisons.^[62] This more robust information indicates that 52% (226 people) of people in prison who tested positive for HCV following PCR testing were referred to specialist care.^[62]

Data sources

- Office for National Statistics mortality data:
<https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths>
- People who inject drugs: HIV and viral hepatitis monitoring.
<https://www.gov.uk/government/statistics/people-who-inject-drugs-hiv-and-viral-hepatitis-monitoring>
- Hospital Episode Statistics, NHS Digital: <http://content.digital.nhs.uk/hes>
- NHS England Specialised Commissioning:
www.england.nhs.uk/commissioning/spec-services/
- NHS Blood and Transplant/PHE Epidemiology Unit
www.gov.uk/guidance/blood-tissue-and-organ-donors-surveillance-schemes
- PHE Sentinel Surveillance of Hepatitis C Testing:
www.gov.uk/government/publications/sentinel-surveillance-of-blood-borne-virus-testing-in-england-2016
- Pharmex:
<https://www.gov.uk/government/collections/commercial-medicines-unit-cmu>
- Prison Health
<https://www.gov.uk/government/collections/public-health-in-prisons>
- Roche: www.roche.co.uk/
- MSD: www.msd-uk.com

Glossary of abbreviations

BAME	Black and minority ethnic
BBV	Bloodborne virus
DAA	Direct acting antiviral
DBS	Dried blood spot
ESLD	End-Stage liver disease
GHSS	Global Health Sector Strategy
HCC	Hepatocellular carcinoma
HBV	Hepatitis B virus
HCV	Hepatitis C virus
HES	Hospital Episode Statistics
HJIP	Health and Justice Indicators of Performance
IPED	Image and performance enhancing drugs
JSNA	Joint Strategic Needs Assessments
NDTMS	National Drug Treatment Monitoring System
NSP	Needle and syringe programme
OST	Opioid substitution treatment
PHE	Public Health England
PHIPS	Public Health Intelligence for Prisons and Secure Settings Service
PHPQI	Prison Health Performance Quality Indicator
PWID	People who inject drugs
RNA	Ribonucleic acid
SVR	Sustained Virological Response
UAM	Unlinked Anonymous Monitoring
WHO	World Health Organization

Appendices

Appendix 1.* WHO GHSS targets^[1] for viral hepatitis, relevant to HCV in the UK context, with 2020 targets updated to reflect the draft action plan for the health sector response to viral hepatitis in the WHO European Region.^[5]

TARGET AREA	2020 TARGETS ^[5]	2030 TARGETS ^[1]
Impact targets		
Incidence: New cases of chronic viral hepatitis C infection	30% reduction	80% reduction
Mortality: Viral hepatitis C deaths	10% reduction	65% reduction
Service coverage targets		
Blood safety:**Proportion of donations screened in a quality-assured manner	100%	100%
Safe injections:*** Percentage of injections administered with safety engineered devices in and out of health facilities	50%	90%
Harm reduction: A comprehensive package of harm reduction services to all PWID ^[63] including:	At least 200 sterile needles and syringes provided per person who injects drugs per year At least 40% of opioid dependent PWID receive OST 90% of PWID receiving targeted HCV information, education and communication	At least 300 sterile needles and syringes provided per person who injects drugs per year
Proportion of people with chronic HCV diagnosed and aware of their infection	50% [75% of estimated number of patients at late stage of viral hepatitis-related liver disease (cirrhosis or HCC) diagnosed]	90%
Treatment coverage of people diagnosed with chronic HCV who are eligible for treatment	75% (>90% cured) [90% of diagnosed patients with chronic HCV are linked to care and adequately monitored]	80%

* Abstracted from the WHO Global Health Sector Strategy for Viral Hepatitis^[1] and modified to reflect the draft action plan for the health sector response to viral hepatitis in the WHO European Region^[5]

** In England, 2020 and 2030 targets are already met.^[64]

***In England, 2020 and 2030 targets are already met in the health care setting as the UK follows the EU Directive for the prevention of sharps injuries in the health care setting.^[65] by using safety engineered devices.

Appendix 2. Preliminary indicators to monitor the impact of key interventions to tackle hepatitis C virus in England

	Burden, Impact and Service Coverage Monitoring Areas • Preliminary Indicator (UK indicators in red; <i>Placeholders* in italics</i>)	Data source
Burden	Reducing the burden of infection in England <ul style="list-style-type: none"> • <i>Placeholder: Estimated prevalence of HCV infection in England</i> • Risk factors for infection from laboratory reports • Trend in anti-HCV prevalence among PWID 	<i>TBC</i> CoSurv/SGSS UAM survey
Impact	1. Reducing HCV-related morbidity and mortality <ul style="list-style-type: none"> • Estimated incidence of HCV-related ESLD/HCC • Registrations for liver transplants in patients with HCV • First liver transplants undertaken in patients with HCV (% of all liver transplants) • First liver transplants undertaken in patients with HCV HCC (% of all liver transplants in patients with HCV) • Death (registrations) from HCV-related ESLD/HCC 	HES NHS BT NHS BT NHS BT ONS
	2. Reducing the number of new (incident) infections <ul style="list-style-type: none"> • Estimated incidence of HCV among people injecting psychoactive drugs • Estimated prevalence of anti-HCV among recent initiates to drug use • Number of HCV tests performed in young adults (and proportion testing positive) in sentinel laboratories • Number of HCV laboratory reports in young adults (and proportion of all reports they represent) • <i>Placeholder: Estimated number of new infections originating injecting drug use and net migration</i> 	UAM survey UAM survey Sentinel surveillance CoSurv/SGSS <i>TBC</i>
Service coverage	1. Adequate harm reduction <ul style="list-style-type: none"> • Estimated proportion of PWID reporting adequate Needle and syringe provision • Sharing of needles and syringes among PWID • Number of current and past PWID in drug treatment • Proportion of opioid dependent PWID receiving OST • <i>Placeholder: Proportion of PWID receiving targeted HCV information</i> 	UAM survey UAM survey NDTMS NDTMS; Hay et al. ^[38] <i>TBC</i>
	2. Increasing awareness and the numbers and proportion diagnosed	

	<ul style="list-style-type: none"> • Estimated proportion of PWID testing positive for anti-HCV, aware of their infection • <i>Placeholder: Proportion of chronic HCV infections in England diagnosed</i> • <i>Placeholder: Proportion of population with late stage HCV-related liver disease (cirrhosis/HCC) diagnosed</i> • Numbers completing RCGP HCV e-learning • Laboratory reports of HCV infection • Number of HCV tests (and proportion testing positive) in sentinel laboratories • Number of HCV tests via GP surgeries (and proportion testing positive) in sentinel laboratories • Reported uptake in voluntary confidential HCV testing among PWID • Offer and uptake of HCV testing in adults - both newly presenting to, and all in, drug treatment • Offer and uptake of HCV testing in adults currently or previously injecting - both newly presenting to, and all in, drug treatment • <i>Placeholder (awaiting DBS data): Number of HCV tests via drug services (and proportion testing positive) in sentinel laboratories</i> • Proportion of new receptions to prisons tested for HCV • <i>Placeholder (awaiting DBS data): Number of HCV tests via prisons (and proportion testing positive) in sentinel laboratories</i> • Number of HCV tests in Asian or Asian British people (and proportion testing positive) in sentinel laboratories • Number of HCV tests in Eastern European people (and proportion testing positive) in sentinel laboratories • Rate of hepatitis C infection among new and repeat blood donors 	<p>UAM survey</p> <p>TBC</p> <p>TBC</p> <p>RCGP CoSurv/SGSS Sentinel surveillance Sentinel surveillance NDTMS</p> <p>NDTMS</p> <p>NDTMS</p> <p>Sentinel surveillance</p> <p>PHPQI/HJIP Sentinel surveillance</p> <p>Sentinel surveillance</p> <p>Sentinel surveillance</p> <p>NHS BT</p>
	<p>3. Increasing numbers accessing treatment</p> <ul style="list-style-type: none"> • Estimated number initiating HCV treatment • <i>Placeholder: Proportion of diagnosed population linked into care and monitored</i> • <i>Placeholder: Proportion of diagnosed population eligible for HCV treatment who have accessed treatment, and proportion cured</i> • <i>Placeholder: Future additional metrics on treatment access including ethnicity, country of birth, source of referral, route of infection, and setting of treatment</i> 	<p>NHS E TBC</p> <p>TBC</p> <p>TBC; via agreed National Treatment Monitoring Dataset</p>

*Placeholders are for indicators that are not currently available/in development or are absent because key data were not available at the time of publication.

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