Hepatitis C in England 2017 report

Working to eliminate hepatitis C as a major public health threat
About Public Health England

Public Health England exists to protect and improve the nation’s health and wellbeing, and reduce health inequalities. We do this through world-class science, knowledge and intelligence, advocacy, partnerships and the delivery of specialist public health services. We are an executive agency of the Department of Health, and are a distinct delivery organisation with operational autonomy to advise and support government, local authorities and the NHS in a professionally independent manner.

Public Health England
Wellington House
133-155 Waterloo Road
London SE1 8UG
Tel: 020 7654 8000
www.gov.uk/phe
Twitter: @PHE_uk
Facebook: www.facebook.com/PublicHealthEngland

© Crown copyright 2017
You may re-use this information (excluding logos) free of charge in any format or medium, under the terms of the Open Government Licence v3.0. To view this licence, visit OGL or email psi@nationalarchives.gsi.gov.uk. Where we have identified any third party copyright information you will need to obtain permission from the copyright holders concerned.

Published: March 2017
PHE publications gateway number: 2016667
Acknowledgements

Editor
Dr Helen Harris, Public Health England

Authors and lead contributors
Annastella Costella (Report co-ordinator)
Helen Harris
Sema Mandal
Mary Ramsay

Other contributors
Elisa Allen
Koye Balogun
Łukasz Cieply
Maciej Czachorowski
Monica Desai
Robel Eyob
Rachel Glass
Charles Gore
Ross Harris
Vivian Hope
Georgina Ireland
Kate Martin
Rosanna O'Connor

Éamonn O'Moore
Celia Penman
Claire Reynolds
Ruth Simmons
Steve Taylor
Angeliqe Whitfield
Robert Wolstenholme
Ruth Zwizwai

We would like to thank the clinicians, microbiologists, public health practitioners and other colleagues who have contributed to the surveillance systems used in this report. We would like to thank drug service staff who support, and participants in, the Unlinked Anonymous Monitoring (UAM) survey of people who inject drugs; NHS Blood and Transplant; Hospital Episode Statistics (Copyright © 2017, re-used with the permission of NHS Digital, all rights reserved); NHS England for supplying treatment monitoring data for 2015; the Office for National Statistics (ONS carried out the original collection and collation of the data but bears no responsibility for their future analysis or interpretation), and the Royal College of General Practitioners (RCGP) for providing data in this report. In addition, we would like to acknowledge and thank the staff who work in the laboratories who contribute to the laboratory surveillance of hepatitis C and the Sentinel Surveillance of Hepatitis Testing Study.
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, such as people who inject drugs (PWID).

Our vision is 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 either reduce their risk of infection, prevent further transmission of the virus or place the patient on a treatment pathway.

In response to the Global Health Sector Strategy (GHSS) for viral hepatitis, we published our UK report to help support focused action to eliminate hepatitis C as a major public health threat in the UK by 2030.

This report concluded that the UK was well placed to meet WHO GHSS goals to reduce HCV-related morbidity and mortality, yet more needed to be done to reduce the persistently high numbers who remain undiagnosed and to reduce the number of new infections.

If we are to eliminate hepatitis C as a major public health threat in England by 2030, it is essential that we work cohesively with stakeholders to maximise our resource and effort.

To help with this, we plan to establish a cross-agency expert group on viral hepatitis to provide strategic direction and advice around hepatitis C (and other viral hepatitides). This group will be a forum to explore and develop operational and implementation issues that help us find the best ways to enact our commitments at local, regional and national level.

This Hepatitis C in England report follows the WHO GHSS on Viral Hepatitis 2016 to 2021. It has been structured to support monitoring of the recently agreed GHSS goals, which were updated to reflect the relatively more ambitious goals in the draft action plan for the health sector response to viral hepatitis in the WHO European region.

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.
By working together, we can do more to increase diagnoses, ensure easier access to testing and treatment, and prevent both new and re-infections.

Professor Derrick Crook
Director of National Infection Service
Executive summary

On 28 May 2016, the World Health Assembly adopted a Global Health Sector Strategy (GHSS) on viral hepatitis for the period 2016 to 2021. This strategy introduced the first-ever global targets for viral hepatitis control. Subsequently, the WHO European Region published its draft action plan for the health sector response to viral hepatitis, outlining their relatively more ambitious proposals for targets and milestones to tackle the estimated 15 million people living with chronic hepatitis C (HCV) infection in this region. The current report summarises the scale of the HCV problem in 2015 in England, as a baseline, to help support focused action to eliminate hepatitis C as a major public health threat by 2030.

In 2005, an estimated 160,000 people in England were thought to be living with chronic HCV infection, and injecting drug use continues to be the most important risk factor for HCV infection. In 2015, 52% 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.

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 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 place them on a treatment pathway.

Early estimates suggest that numbers of new cases of HCV-related end-stage liver disease (ESLD) and hepatocellular carcinoma (HCC) in England have remained relatively stable, averaging 1,700 new cases per year over the last five years. However, an 8% fall in the number of deaths from these indications over the last year, suggests that increased treatment (around a 40% increase in 2015) 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 registrations (42% fall in 2015) and liver transplants undertaken (32% fall in 2015) in those where post-hepatitis C cirrhosis is given as the indication for transplant, although it is too early to rule out a degree of deferred listing pending assessment of the impact of treatment. Either way, the World Health Organization (WHO) GHSS target for a reduction in HCV-related mortality of 10% by 2020 looks likely, and a reduction of 65% by 2030 seems achievable and could possibly be exceeded. Despite this, only around one half (53% in 2015) of people who had injected psychoactive drugs sampled in the UAM Survey were aware of their
Hepatitis C in England: 2017 report

HCV antibody positive status, and this figure has remained relatively stable at this level over the last decade.

Laboratory reports suggest a steady increase in the number of diagnosed infections over the past two decades, reaching a peak of 11,605 reports in 2015. An increase in testing is also observed in sentinel surveillance, which suggests a near 20% (18.6%) increase overall, and a 25.5% increase in testing via GP surgeries, between 2011 and 2015. The WHO European Region target of 50% of those with chronic HCV having been diagnosed and aware of their infection by 2020\(^3\) 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 (86% in 2015) and National Drug Treatment Monitoring System (NDTMS) data (81.5% in 2014/15) suggest that more than four-fifths of people who have ever injected drugs report or were recorded as having received a hepatitis C 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 11.5% in 2015/16.

When looking at screening data from low risk populations, NHS Blood and Transplant testing suggests that rates of infection in new (26.9/100,000) and repeat (0.06/100,000) donors remain low. 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; 93/100,000) or ‘other-white’ (most cases born in Europe; 141/100,000) backgrounds. Sentinel surveillance suggests that testing in people of Asian or Asian British origin and in those of Eastern European origin has continued to rise by 16.5% and 46.9%, respectively, between 2011 and 2015, with 2.0% and 5.1% 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 in recent initiates to psychoactive drug use were similar in 2015 (7.4/100 person years) to those observed in 2011 (8.1/100 person years), and prevalence of infection in recent initiates to psychoactive drug use were similar in 2014/15 (23%) to those observed in 2006/07 (22%). Neither laboratory reports nor sentinel surveillance suggest any increase in levels of infection in young adults. However, the proportion of PWID reporting adequate needle/syringe provision was found to be suboptimal, with just less than one half (between 45% and 48% in 2011-2015) 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 17% in 2015, 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 direct acting antiviral (DAA) drugs, England is well placed to meet WHO GHSS goals to reduce HCV-related morbidity and mortality. Yet, we need to do more to reduce the persistently high proportion who remain undiagnosed if levels of avoidable premature mortality are to be reduced. It will also be important to monitor equity of access to treatment and care services. At the other end of the spectrum, there is 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.
Public health recommendations

Making improvements and monitoring metrics

- Further develop national indicators, and tools at both national and lower level, to help monitor progress towards the WHO GHSS goal to eliminate hepatitis C as a serious public health threat by 2030.\(^1\)
- Establish a cross-agency expert group on viral hepatitis to provide strategic direction and advice around hepatitis C (and other viral hepatitides) to serve as a forum for the exploration of operational and implementation issues and development of commitments to be enacted at local, regional and national level. This group will oversee and monitor national progress against the WHO elimination strategies.\(^{1,3}\)
- Consideration should be given by local authorities to include HCV in health and wellbeing board joint strategic needs assessments and subsequent commissioning strategies.

Adequate harm reduction/prevention

- Commissioners of bloodborne virus prevention 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 hepatitis C, including among people who inject new psychoactive substances or image and performance-enhancing drugs; NICE guidance is available on NSP\(^8\) and OST.\(^9\)
- Consideration should be given to mapping and monitoring NSP activity
- Harm minimisation policies in secure and detained settings should be maintained, including the provision of disinfectant/decontamination equipment for sharps.
- Further testing of treatment as prevention, and its potential to reduce the number of new HCV infections in people who inject drugs, is required in order to guide future public health policy and clinical practice.

Increasing the numbers and proportion diagnosed

- Initiatives should be considered to further raise awareness of HCV among professionals working in primary care and other settings, like drug services, to help reduce the number who remain undiagnosed, for example by encouraging participation in e-learning\(^{10,11}\) to improve the offer and uptake of HCV testing in
Hepatitis C in England: 2017 report

risk groups. Guidelines are available to help raise awareness of, and testing for, hepatitis C infection to ensure that people at increased risk of hepatitis C are tested.\(^{(12)}\)

- Produce appropriate communications, like national reporting and infographics, to help mark World Hepatitis Day.
- Testing needs to be sustained or enhanced, as appropriate,\(^{(13)}\) among those attending drug services; the use of newer technologies, like dried blood spot testing, that make testing easier in non-clinical settings, should be further expanded throughout England.
- Bloodborne virus opt-out testing for new receptions to prisons in England should continue to be monitored to inform strategies to further improve the offer and uptake of testing. Consideration should also be given to the commissioning of bloodborne virus opt-out testing in drug services.
- Local provision should be in place to promote and offer testing to those groups who are not in regular contact with health services who may have acquired hepatitis C many years previously, some of whom may have advanced asymptomatic disease (for example, those who acquired their infection via past injecting drug use, medical/dental treatment abroad in countries where poor blood screening/infection control practices exist, or via transfusion in the UK prior to September 1991).
- Wherever possible, ribonucleic acid amplification (RNA) tests should be performed on the same sample as the original antibody assay as this decreases the turnaround time for referral, benefits patient care and increases cost effectiveness;\(^{(14)}\) consideration should also be given to including patient referral instructions on the laboratory report.

**Increasing the numbers accessing hepatitis C treatment**

- Those responsible for commissioning 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 hepatitis C treatments in primary and secondary care, drug treatment services, prisons and other settings; and to drive innovative approaches to outreach and patient support. It will be important to consider those individuals who have been diagnosed but subsequently lost to follow-up, as well as those who are newly diagnosed or already engaged with treatment services.
- Those achieving a sustained viral response following treatment, should be provided with appropriate information and support to help them guard against re-infection.
- Regular analysis by PHE of the agreed national treatment monitoring dataset should take place 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.

- Continued monitoring, via Health and Justice Indicators of Performance (HJIP), should take place to inform equity of access to HCV care and treatment pathways for all prisoners and immigration detainees.
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.

The global burden of viral hepatitis has been increasing since 1990, reaching 1.46 million deaths in 2013.\(^\text{(15)}\) Viral hepatitis is a leading cause of death globally with a toll exceeding that of HIV (1.3 million deaths), tuberculosis (1.2 million deaths) and malaria (0.5 million deaths).\(^\text{(15)}\) Despite the significant burden it places on communities across all global regions, hepatitis has largely been ignored as a health and development priority. However, in 2010 and 2014, two World Health Assembly resolutions (WHA63.18\(^\text{(16)}\) and WHA67.6\(^\text{(17)}\)) focused on viral hepatitis, and a specific action to, ‘combat viral hepatitis’ was included within the resolution on the 2030 Agenda for Sustainable Development.\(^\text{(18)}\)

Following on from these, on the 28 May 2016, the World Health Assembly adopted a Global Health Sector Strategy (GHSS) on viral hepatitis for the period 2016 to 2021,\(^\text{(1)}\) with its targets aligned with the 2030 Agenda for Sustainable Development and the relevant World Health Assembly resolutions. This strategy introduced the first-ever global targets for viral hepatitis, including a 30% reduction in new cases of hepatitis C (HCV) and B (HBV) by 2020 and a 10% reduction in mortality.\(^\text{(1)}\) For HCV, the 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.\(^\text{(15)}\)

In response to the GHSS,\(^\text{(1)}\) a report was published to help support focused action to eliminate hepatitis C as a major public health threat in the UK by 2030.\(^\text{(2)}\) This report concluded that, with the increasing availability of new direct acting antiviral (DAA) drugs, the UK was well-placed to meet World Health Organization (WHO) GHSS goals to reduce HCV-related morbidity and mortality. However, more needed to be done to reduce the persistently high proportion who remain undiagnosed. At the other end of the spectrum, the report provided little evidence to support any fall in numbers of new HCV infections, suggesting that a radical change in our response to HCV among people who inject drugs (PWID) is required if the GHSS goal to reduce the number of new infections is to be reached.

Since publication of the *Hepatitis C in the UK* 2016 report\(^\text{(2)}\), the WHO European Region has published its draft action plan for the health sector response to viral hepatitis, outlining their relatively more ambitious proposals for targets and milestones to tackle
the estimated 15 million people living with chronic HCV infection\(^4\) in this region (see appendix 1).\(^3\) 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 2015, as a baseline, and sets out our vision for tackling the infection. Within this report we have presented metrics that allow us to monitor our progress (see appendix 2), and identify where focused action is needed if we are 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. 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 in England 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 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,\(^6\) 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.
Burden of HCV infection

Most recent estimates suggest that around 160,000 people in England are living with chronic HCV infection.\(^{(5)}\)

Injecting drug use continues to be the most important risk factor for HCV infection, being cited as the risk in approximately 90% of all laboratory reports where risk factors have been disclosed.\(^{(6)}\)

In 2015, of the people injecting psychoactive drugs, such as heroin, in the Unlinked Anonymous Monitoring (UAM) Survey of PWID, 52% tested positive for antibodies to HCV (anti-HCV) and this proportion has remained relatively stable over the past decade\(^{(6)}\) (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.\(^{(19)}\)

**Figure 1. Trend in anti-HCV prevalence* among people injecting psychoactive drugs in England: 2005 to 2015**

* During 2009 to 2011 there was a phased change in the sample collected in the survey from an oral fluid to dried blood spot (DBS). The sensitivity of the anti-HCV tests on these two sample types is different. The sensitivity of the oral fluid test for anti-HCV is approximately 92%,\(^{(20)}\) that on DBS samples is close to 100%. Data presented here have been adjusted for the sensitivity of the oral fluid test.
Hepatitis C prevalence among people injecting psychoactive drugs and participating in the UAM Survey in 2015 varied across England, with prevalence ranging from 26% in the West Midlands region to 68% in the North West.\(^7\)

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 (BME) populations who have close links to countries with a high prevalence of HCV infection.\(^{21}\) HCV disproportionately affects populations who are marginalised and underserved and have poorer access to healthcare and 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

Over the past decade, morbidity and mortality from HCV have been on the increase in England as people who acquired their infections decades earlier progress to advanced liver disease and access to suboptimal treatment has been inadequate.\(^{(22),(23)}\) However, the new DAA drugs that have recently come online,\(^{(24),(25),(26),(27),(28),(29),(30)}\) and the creation 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 is currently observed\(^{(31),(32)}\) and has been predicted to continue in the future.\(^{(22)}\)

<table>
<thead>
<tr>
<th>METRICS TO MONITOR TRENDS IN HCV-RELATED MORBIDITY AND MORTALITY</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Estimated incidence of HCV-related ESLD/HCC</td>
</tr>
<tr>
<td>• Registrations for liver transplant, and transplants undertaken, where post-hepatitis C cirrhosis is given as the indication for transplant</td>
</tr>
<tr>
<td>• Deaths from HCV-related ESLD/HCC</td>
</tr>
</tbody>
</table>

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).\(^{(2)}\) While the limitations of these first preliminary estimates are acknowledged,\(^{(2)}\) early data suggest that new cases of HCV-related ESLD/HCC have remained relatively stable over the last five years, averaging around 1,700 per year between 2011 and 2015 (Range: 1,627, 1,790; Figure 2).
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;\(^6\) Figure 3), with highest numbers of registrations occurring in London (22% between 2008-2015). However, over the last year registrations have fallen dramatically by over 40% (42%), to an eight year low of 83 in 2015\(^\text{6}\) (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, numbers decreased by 32% from 122 in 2014 to 83 in 2015.\(^\text{6}\) Of all liver transplants performed in England, the percentage carried out in patients with hepatitis C-related disease decreased from 21% in 2008 to 12% in 2015 (17% overall throughout the period).\(^\text{6}\) This might suggest that new treatments are having an impact with the annual number of livers transplanted for this indication being down by around 25 compared to previous 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 less patients are being put onto the transplant list because of clinical intervention. 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 registrations and liver transplants undertaken in England where post-hepatitis C cirrhosis was given as either the primary, secondary or tertiary indication for transplant: 2008 to 2015**

Deaths from HCV-related ESLD/HCC

Between 2005 and 2014, deaths from HCV-related ESLD and HCC in England more than doubled, rising from 187 in 2005 to 387 in 2014\(^6\) (Figure 4). However, a fall of 8% was observed in 2015. It is possible that this fall is the result of increased access to new DAA drugs that were introduced from 2014/2015\(^{33,34}\) (Figure 22), particularly for those individuals with more advanced disease\(^{33,34}\). This suggests that new drugs may already 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 seems likely in England, and a reduction of 65% by 2030\(^1\) (see appendix 1) within our reach.
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 whole. As a result, a number of methods are used to generate information to provide insight into likely trends in incidence over time.\(^{22}\)

**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\(^{(7),(8)}\) by looking for those who have recently developed antibodies to HCV. This has been undertaken by testing the HCV antibody positive dried blood spot (DBS) samples collected in the survey for antibody avidity. Samples from HCV-infected individuals (demonstrated by the detection of HCV RNA), with HCV antibodies whose overall avidity is weak are likely to be from individuals who have recently been infected with the virus. Avidity testing has been used to explore recent transmission among those survey participants who had injected during the preceding year, and data suggest that incidence of infection has remained relatively stable over recent years, rates observed in 2015 (7.4/100 person years; CI 4.1–12) being similar to those observed in 2011 (8.1/100 person years; CI 4.5–14;\(^{(6)}\) Figure 5).

**Figure 5. Estimated incidence of HCV among people injecting psychoactive drugs in England who reported injecting in the previous year: 2011-2015* (95% CI)**
Estimated prevalence of anti-HCV among recent initiates to drug use and in young adults

Because most new infections are acquired via injecting drug use at a relatively young age, 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 drugs⁷ suggest that transmission among recent initiates to drug use has remained relatively stable over recent years, with levels of infection in 2014-2015 (23%) being similar to those observed in 2006-2007⁶ (22%; Figure 6).

Figure 6. Prevalence of antibodies to hepatitis C* among people who began injecting psychoactive drugs in the previous three years in England: 2006-2007 to 2014-2015

* During 2009 to 2011 there was a phased change in the sample collected in the survey from an oral fluid to dried blood spot (DBS). The sensitivity of the anti-HCV tests on these two sample types is different. The sensitivity of the oral fluid test for anti-HCV is approximately 92%,⁸ that on DBS samples is close to 100%. Data presented here have been adjusted for the sensitivity of the oral fluid test.

Likewise, no evidence of any increase in levels of infection in young adults has been observed over recent years⁶ (Figures 7-8).

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 2030¹¹ (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.
Figure 7. Number of anti-HCV tests performed in young adults and proportion positive by year in 23 sentinel laboratories: 2011 to 2015

Figure 8. Laboratory reports* of hepatitis C in young adults in England: 2006-2015

*Statutory notification by diagnostic laboratories was introduced in October 2010(40)
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.\(^{(41),(42),(43),(44),(45),(46)}\) 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\(^{(3)}\) 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/syringe provision, data from the UAM Survey of PWID\(^{(7)}\) are presented here on self-reported adequacy of needle/syringe provision\(^{(6)}\) (Figure 9). In this metric, needle/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, 2011-2015

Figure 9 shows that among people injecting psychoactive drugs, the proportion reporting adequate needle/syringe provision is suboptimal, with only around one half of those surveyed indicating adequate provision for their needs. 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), 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. They are also a vital point of contact with those not yet ready for treatment. 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, 17% of people currently injecting psychoactive drugs and participating in the UAM Survey, reported direct sharing of needles and syringes in
2015\(^{(6)}\) (Figure 10); this level has declined from 28% in 2005. The reported level of needle and syringe sharing among people injecting psychoactive drugs participating in the UAM Survey in 2015 varied across England; with the level ranging from 4% in the West Midlands region to 22% in the South West.\(^{(7)}\) Although levels of sharing have declined over the past decade, there is no evidence of any fall over the last five years, again suggesting 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 2015**

Among those injecting image and performance enhancing drugs, the reported sharing of injecting equipment has remained low with only 13% reporting that they had ever shared a needle, syringe or vial in 2014-2015.\(^{(7)}\)

**Drug treatment**

The draft action plan for the health sector response to viral hepatitis in the WHO European region\(^{(3)}\) 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.\(^{(6)}\) Their call for at least 90% of PWID to be receiving targeted HCV information, education and communications\(^{(3)}\) has yet to be quantified, although there are a variety of targeted information and education communications available (see section on raising awareness, pages 27-29).
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 image and performance enhancing drugs. In England, the number of adults who had ever injected drugs and who were receiving drug and alcohol treatment fell by nearly 10% (9.4%) from 119,140 in 2009/10 to 107,992 in 2014/15;\(^{(6)}\) under one-fifth of all people in drug and alcohol treatment in 2014/15\(^{(47)}\) (16%, 48,507/295,224) were currently injecting when they entered treatment.\(^{(6)}\) Of the 141,646 people newly presenting to treatment in 2014/15,\(^{(47)}\) 30,420 (21%)\(^{(6)}\) 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 globally less than 5% of people with chronic viral hepatitis are aware of their status.\(^{(1)}\) In the UK, levels of awareness of infection are well above the 5% global average, but are still suboptimal with positive results often failing to successfully link individuals into treatment and care services.\(^{(22)}\)

### 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 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.\(^{(7},\,\,19)}\) In this survey, only around one half of people injecting psychoactive drugs sampled are aware of their HCV
antibody positive status (53% in 2015), and this figure has remained relatively stable at this level (averaging 52%) over the past decade\(^6\) (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\(^3\) (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 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, 2005-2015**

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.\(^12\) 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 hepatitis C is usually asymptomatic in the early years of infection, many individuals remain unaware of their infection. Raising both professional and public awareness remains a priority, therefore, and an important component of reducing the burden of undiagnosed infection.

As in previous years, a variety of initiatives are ongoing throughout the UK 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. The success of these initiatives has been dependent on the significant contribution of numerous stakeholders working across a range of settings. For example, the RCGP, HCV Action and The Hepatitis C Trust, have produced an educational film to increase knowledge about HCV in primary care and to build confidence in diagnosing and supporting people through treatment (www.hcvaction.org.uk/resource/film-detecting-managing-hepatitis-c-primary-care).

Other films have been developed with a focus on minority ethnic communities at increased risk of infection, like the health resource produced by Maslaha in both English and Urdu, to help tackle the high rates of hepatitis C (and B) among British Pakistani communities (www.understandhepbandc.org). Such films can be particularly useful as they combine medical and cultural guidance to help learn about infection and how best to get tested.

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 chronic viral hepatitis infection. Over the last four years, nearly 1,500 (n=1,489) individuals had completed the e-learning module. A further RCGP course, ‘Hepatitis C: Enhancing Prevention, Testing and Care’ is available and comprises four lessons: understanding hepatitis C; preventing transmission; testing and diagnosis; and treatment and care. By the end of November 2016, 1,944 attempts to complete the pre-course assessment resulted in an average score of 61% and 1,449 attempts to complete the post-course assessment resulted in an average score of 84%.

PHE’s drugs joint strategic needs assessment support pack 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 hepatitis C 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 hepatitis C that local providers and commissioners of drug and hepatitis treatment should be aware of, with advice on improving access to, and completion of, hepatitis C treatment. ‘Harm Reduction Works’ materials on hepatitis C aim to build
awarness\(^{50}\) while trying to avoid creating or reinforcing a perception that hepatitis C risk is ubiquitous among injecting drug users, and that attempts to avoid it are futile.

Working with HCV Action, PHE co-hosted a series of roadshows in England during 2015 which focused on hepatitis C generally but also served to raise awareness of the opt-out bloodborne virus (BBV) testing in prisons. During 2015, roadshows were held in Liverpool, London, Birmingham and Brighton. More information about these events is available on their website at: http://www.hcvaction.org.uk/search/node/roadshows.

Within the prison setting, an audit of hepatitis C services in a representative sample of English prisons suggested that 81% of prisons had training on BBVs for healthcare staff; 48% had training for prison officers and 57% had training for drug workers.\(^{51}\)

Overall, the NGO sector has been particularly influential and organisations such as The Hepatitis C Trust, the British Liver Trust, HCV Action and Addaction deserve a special mention. Such work is essential and complements government and public sector initiatives in this important area. Dedicated hepatitis C websites for healthcare professionals, the public and South Asian communities are available on the NHS Choices website:

- www.nhs.uk/hepc includes a self-assessment tool on risk of having HCV infection.
- www.nhs.uk/hepatitisc/southasian
- www.nhs.uk/hepatitisc/hcp

Testing and diagnosis

In England, testing and diagnosis monitoring data are available from a variety of surveillance systems: the UAM Survey of PWID,\(^{7}\) Sentinel Surveillance of Bloodborne 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.\(^{12}\)
Laboratory reports of hepatitis C infection

Over nearly two decades, there has been a steady increase in the number of laboratory confirmed reports of HCV in England with a more than fivefold increase between 1996 and 2015 (Figure 12). In 2015, 11,605 laboratory reports of individuals testing positive for antibodies to HCV were reported\(^\text{(6)}\) (Figure 12). Around two-thirds of laboratory reports (67%) were in men; almost half (45%) of all reports received were in individuals aged between 25 and 39 years (Figure 13).

There continues to be regional variation in the number of laboratory reports of hepatitis C in England with the highest figures for 2015 being reported in London and the lowest in the North East.

**Figure 12. Number of laboratory reports\(^*\) of hepatitis C from England: 1996 to 2015**

*Statutory notification by diagnostic laboratories was introduced in October 2010\(^\text{(40)}\)*
Figure 13. Age and sex distribution of laboratory reports* of hepatitis C from England: 1996 to 2015

*Statutory notifications by diagnostic laboratories was introduced in October 2010\(^{(40)}\)

**Testing and diagnosis in the general population and primary care**

Trends in testing were analysed using data from the 23 sentinel laboratories where complete and consistent data have been available from January 2011 to December 2015\(^{(6)}\) (Map 1; Figure 14). Numbers of tests undertaken rose by 18.6% between 2011 and 2015, and the proportion of people testing positive for anti-HCV declined from 2.6% in 2011 to 1.5% in 2015, which is consistent with a higher proportion of individuals at relatively lower risk of infection being tested.
Map 1. Geographic distribution of centres who have participated in the Sentinel Surveillance of Hepatitis Testing Study by Public Health England Centre.

Figure 14. Number of people tested for anti-HCV by year, and proportion positive, in 23 sentinel laboratories: 2011 to 2015

Note: Excludes dried blood spot testing; samples collected outside routine testing, such as look backs and studies; reference testing; and children aged <1 year.

Data source: Sentinel surveillance of blood borne virus testing.
In sentinel laboratories (Map 1), the number of tests undertaken via GP surgeries rose by 25.5% between 2011 and 2015, suggesting that awareness of hepatitis C in this setting may be increasing\(^6\) (Figure 15). The proportion of individuals testing positive for anti-HCV declined from 2.7% in 2011 to 1.6% in 2015 (Figure 15), again suggesting that a higher proportion of individuals at relatively lower risk of infection are being tested.

**Figure 15. Number of people tested for anti-HCV by year, and proportion positive, through GP surgeries in 23 sentinel laboratories: 2011 to 2015**

![Graph showing the number of people tested for anti-HCV by year and proportion positive through GP surgeries in 23 sentinel laboratories from 2011 to 2015.](image)

*Note: Excludes dried blood spot testing, and children aged <1 year. Data source: Sentinel surveillance of blood borne virus testing.*

**Testing and diagnosis in people who inject drugs**

In the UAM Survey of PWID,\(^7\)\(^,\)\(^19\) 86% of those injecting psychoactive drugs reported ever having had a voluntary confidential test (VCT) for HCV in 2015, an increase from 71% in 2005\(^6\) (Figure 16). The proportion of those ever tested who had their last test during the preceding two years was 59% in 2015 (n=840), which was similar to the proportion found in previous years\(^6\) (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 hepatitis C tests at regular intervals.
Among those injecting IPEDs, 41% reported a voluntary and confidential test for hepatitis C in 2014-2015.\(^7\)

Similarly, NDTMS data suggest that levels of hepatitis C testing among people in treatment for drug and alcohol use, are continuing to rise in England.\(^6\) Among adults in drug and alcohol treatment who are eligible to receive a test, the proportion who have a hepatitis C test recorded has increased from 43.2% (2009/10) to 65.7% (2014/15)\(^6\). A similar rise has been recorded in adults newly presenting for drug treatment (37.1% in 2009/10 compared with 52.2% in 2014/15;\(^6\)). When considering just those who have ever injected drugs, in 2014/15 more than four-fifths (81.5%) were recorded as having received a test,\(^6\) 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 four years.\(^6\)

In 2014/15, more than four-fifths (83%; n= 170,712) of all adults receiving drug and alcohol treatment were recorded as having been offered a hepatitis C test and around one half of those offered (47.7%, n= 98,324) accepted the offer.\(^6\) Of those newly presenting to treatment, around three-quarters (76.4%, n=61,361) were offered testing, with just over one third of those offered (36.0%, n=28,290) accepting the offer.\(^6\)

Considering just those who have ever injected drugs, over four-fifths were offered a test (87.2%, n= 94,140), and nearly three-fifths of those offered (58.1%, n= 62,693)
accepted the offer in 2014/15\(^{(6)}\). A similar proportion of those newly presenting to treatment were offered testing (80.8%, \(n=24,571\)), with nearly half of those offered (45.7%, \(n=13,891\)) accepting the offer.\(^{(6)}\)

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.\(^{(52),(53)}\) Prison Health Performance Quality Indicator (PHPQI) data have shown a steady rise in hepatitis C tests performed, from 5.3% in 2010/11 to 8.6% in 2013/14\(^{(6)}\) (Figure 17), rising to 10% in quarter 4 of 2013/14 (personal communication). 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 during 2015/16. Preliminary testing data received from HJIPs for the financial year 2015/16 suggest that 11.5% of new receptions to adult prisons in England received a HCV antibody test (Figure 17), and of those testing positive, 79.5% were tested for active disease by HCV PCR testing. Some of the increase in testing may be due to the introduction of bloodborne virus (BBV) opt-out testing, which was agreed in October 2013.\(^{(54)}\)

Evaluation of the first phase of BBV opt-out testing\(^{(55)}\) suggested a near doubling of testing following the introduction of the opt-out policy. Between April and September 2014, 21% of new receptions were tested for hepatitis C in nine of the 11 pathfinder prisons that provided data, compared to only 11% of new receptions tested for hepatitis C prior to introduction of the programme. Further evaluation of BBV opt-out testing implementation in ten different prisons as part of the second phase of the evaluation is also available,\(^{(56)}\) and a revised questionnaire focusing on patient ‘linkage into care’ has been finalised and will be sent to prison healthcare teams as part of a phase three evaluation later this year. Unlike in the first two phases of implementation where prison testing levels were collected directly via questionnaire, phase three will also rely on the HJIPs dataset to collect this information.
Figure 17. Proportion of new receptions to English prisons tested for hepatitis C: financial years 2010/11 to 2015/16

Figure 18. Health and Justice Indicators of performance relating to hepatitis C testing

<table>
<thead>
<tr>
<th>Hepatitis C testing</th>
<th>Percentage of patients offered hepatitis C testing, within 72hrs of reception</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hepatitis C antibody testing</td>
<td>Percentage of eligible patients who have undertaken an HCV antibody test</td>
</tr>
<tr>
<td>Hepatitis C PCR testing</td>
<td>Percentage of HCV antibody positive patients who underwent HCV PCR testing</td>
</tr>
</tbody>
</table>

Up until March 2016, the National Health and Justice Team received reports of infectious diseases directly from health protection teams within PHE Centres, including reports of acute and chronic HCV diagnosed among people in prison. In March 2016, with increasing availability of data from the HJIPs dataset, this function ceased and only reports of acute HCV are now reported directly to the national team for public health action. Over the period spanning calendar years 2014 and 2015, 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 with increased offers and uptake of testing. 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.\(^{(57)}\)

**Testing and diagnosis in black and minority ethnic populations**

Sentinel surveillance data indicates that the number of people tested who were identified as being of Asian or Asian British origin (using self-reports, NAMPACHAN or ONOMAP\(^{(58)}\) name analysis software) has increased by 16.5% between 2011 and 2015\(^{(6)}\) (Figure 19). 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 (2011 to 2015), 2.0% of people of Asian or Asian British origin tested positive, declining from 2.7% in 2011 to 1.5% in 2015 (Figure 19).

**Figure 19. Number of Asian or Asian British people tested, and proportion positive, in 23 sentinel laboratories: 2011 to 2015**

![Figure 19](image)

Sentinel surveillance data indicates that the number of people tested who were identified as being of Eastern European origin (using self-reports or ONOMAP\(^{(58)}\) name analysis software), increased by 46.9% between 2011 and 2015\(^{(6)}\) (Figure 20). Over this period, 5.1% of people of Eastern European origin tested positive\(^{(6)}\) (Figure 20), suggesting that these individuals may be at relatively increased risk of having acquired
hepatitis C and/or that testing of this ethnic group is more targeted at higher risk individuals than in the general population.

**Figure 20. Number of Eastern European people tested, and proportion positive, in 23 sentinel laboratories: 2011 to 2015**

![Graph showing the number of Eastern European people tested and proportion positive from 2011 to 2015.](image)

*Note: Excludes dried blood spot testing; samples collected outside routine testing, such as look backs and studies; reference testing; and children aged <1 year.*

*Data source: Sentinel surveillance of blood borne virus testing.*

**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\(^6\) (Figure 21).

In 2015, the decline in HCV in donors overall in England (and North Wales) continued despite the rate in new donors increasing to 26.9 per 100,000 donations from the low rate of 17.3 observed in 2014\(^6\) (Figure 21). The rate in repeat donors was unchanged from 2014 at 0.06 per 100,000 donations\(^6\) (Figure 21). Overall, 43 blood donors tested positive for hepatitis C, with the majority (42, 98%) of infections detected in new donors.
Similar to 2014, around one third of all the blood donors testing positive for hepatitis C in 2015 in England (and North Wales) were of white British ethnicity and one third of ‘other-white’ ethnicity, 56% were male and 56% were aged between 25-39 years. As in recent years, a disproportionately high number of HCV infections in new donors were observed in those of South Asian (Pakistan, Bangladesh or India), or ‘other-white’ background with rates of 93 and 141 per 100,000 new donors, respectively, most cases being born in Asia or Europe. Twenty-one per cent of HCV positive new donors (9/42) 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 2015, only one reported a history of injecting while three others reported injecting drug use in contacts: two in heterosexual partners and one whose mother had injected and was assigned as possible vertical transmission. One reported intranasal drug use only. Where known, possible blood contact accounted for 58% (19/33), mostly abroad (17/19). A further 18% (6/33) were assigned as originating from a country with higher prevalence of HCV than the UK, five with no specific risk factor reported and one whose mother had been diagnosed with HCV. Three had heterosexual contact with someone from a country with higher prevalence than the UK. In 2015, one repeat donor tested positive for HCV, seroconverting at some time in the 18 months since the previous negative donation. The only possible risk factor reported in this timeframe was multiple piercings in the UK.
For the most part, HCV disproportionately affects populations who are marginalised and underserved and have poorer access to healthcare, so testing in alternative/community settings, using alternative technologies like dried blood spot (DBS) testing, will be important in reducing the levels of undiagnosed infection. If gains in testing are to be translated into cures, it is also important to ensure that we continue to work together to improve key linkages between testing and treatment services so that diagnosed individuals can access treatment and care.

Increasing the numbers accessing hepatitis C treatment

Globally, less than 1% of people with chronic hepatitis infection are receiving 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. 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 (see appendix 1).

New DAA drugs have the potential to transform the treatment landscape, offering a fast and effective cure to 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.

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.

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 when it is available
As we work towards producing UK estimates of the proportion of the chronically infected population who achieve a SVR following treatment, provisional UK data suggest significant increases in the number of people accessing treatment in 2015.\(^2\) 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;\(^6\) Figure 22). However in the 11-month period from June 2015 to April 2016, provisional NHS England data suggest that significantly more people (7,036 in total) accessed treatment than in earlier years, 38% more than mean 2008-2014 levels (1940/5096*100), and 48% more than in 2014 (2281/4755*100). This is likely to be the result of access to new DAA drugs that have been coming online since 2014/15.\(^{25,27,28,26,24}\)

**Figure 22. Provisional estimates of numbers initiating HCV treatment in England, 2007-2015**

NHS targets are to have treated around 10,000 patients in 2016 and to increase the number treated to 15,000 per year in 2020. Assuming this 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 23), 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.\(^{(47)}\) Firstly, the SVR rates assumed here for those with compensated cirrhosis are conservative, as nearly 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.\(^{(60)}\) Secondly, no re-treatment is incorporated in the model as there is minimal evidence on re-treatment following failure with new antivirals at present; 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 23.** 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 23). 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\(^{22}\) that will help describe access to HCV treatment and care in England. Data including ethnicity, country of birth, route of infection, disease stage, source of referrals and settings 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.\(^{7}\) The survey asked participating people injecting 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 (eg a hepatologist) about your hepatitis C?’ Among the survey participants in England with antibodies to hepatitis C who were aware of their infection, 64% (316/493) reported that they had seen a specialist nurse or doctor about their infection, and 25% (121/493) 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; these data will be available in future years. Evaluation of prison pathfinders implementing the opt-out BBV testing programme, suggests that the numbers being referred for hepatitis C treatment increased significantly following the introduction of the opt-out testing policy, with 226 individuals being referred during the 12-month period between January and December 2013 compared to 185 during the 6-month period between April and September 2014 (based on data from eight of the 11 participating prisons).\(^{55}\) Linkage into care is the focus of the Phase 3 pathfinder prison evaluation, and a report on their performance will be published in the third quarter of 2016-17.
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.

- 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:

- Pharmex: https://www.gov.uk/government/collections/commercial-medicines-unit-cmu

- Prison Health

- Roche: www.roche.co.uk/

- MSD: www.msd-uk.com
## Glossary of abbreviations

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>BBV</td>
<td>Bloodborne virus</td>
</tr>
<tr>
<td>DAA</td>
<td>Direct acting antiviral</td>
</tr>
<tr>
<td>DBS</td>
<td>Dried blood spot</td>
</tr>
<tr>
<td>ESLD</td>
<td>End-Stage liver disease</td>
</tr>
<tr>
<td>GHSS</td>
<td>Global Health Sector Strategy</td>
</tr>
<tr>
<td>HCC</td>
<td>Hepatocellular carcinoma</td>
</tr>
<tr>
<td>HBV</td>
<td>Hepatitis B virus</td>
</tr>
<tr>
<td>HCV</td>
<td>Hepatitis C virus</td>
</tr>
<tr>
<td>HES</td>
<td>Hospital Episode Statistics</td>
</tr>
<tr>
<td>HJIP</td>
<td>Health and Justice Indicators of Performance</td>
</tr>
<tr>
<td>IPED</td>
<td>Image and performance enhancing drugs</td>
</tr>
<tr>
<td>NDTMS</td>
<td>National Drug Treatment Monitoring System</td>
</tr>
<tr>
<td>NSP</td>
<td>Needle and syringe programme</td>
</tr>
<tr>
<td>OST</td>
<td>Opioid substitution treatment</td>
</tr>
<tr>
<td>PHE</td>
<td>Public Health England</td>
</tr>
<tr>
<td>PHIPS</td>
<td>Public Health Intelligence for Prisons and Secure Settings Service</td>
</tr>
<tr>
<td>PHPQI</td>
<td>Prison Health Performance Quality Indicator</td>
</tr>
<tr>
<td>PWID</td>
<td>People who inject drugs</td>
</tr>
<tr>
<td>RNA</td>
<td>Ribonucleic acid</td>
</tr>
<tr>
<td>SVR</td>
<td>Sustained viral response</td>
</tr>
<tr>
<td>UAM</td>
<td>Unlinked Anonymous Monitoring</td>
</tr>
<tr>
<td>WHO</td>
<td>World Health Organization</td>
</tr>
</tbody>
</table>
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.\(^{(3)}\)

<table>
<thead>
<tr>
<th>TARGET AREA</th>
<th>2020 TARGETS(^{(3)})</th>
<th>2030 TARGETS(^{(1)})</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Impact targets</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Incidence: New cases of chronic viral hepatitis C infection</td>
<td>30% reduction</td>
<td>80% reduction</td>
</tr>
<tr>
<td>Mortality: Viral hepatitis C deaths</td>
<td>10% reduction</td>
<td>65% reduction</td>
</tr>
<tr>
<td><strong>Service coverage targets</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Blood safety: Proportion of donations screened in a quality-assured manner</td>
<td>100%</td>
<td>100%</td>
</tr>
<tr>
<td>Safe injections: Percentage of injections administered with safety engineered devices in and out of health facilities</td>
<td>50%</td>
<td>90%</td>
</tr>
<tr>
<td>Harm reduction: A comprehensive package of harm reduction services to all PWID(^{(61)}) including:</td>
<td>At least 200 sterile needles and syringes provided per person who injects drugs per year</td>
<td>At least 300 sterile needles and syringes provided per person who injects drugs per year</td>
</tr>
<tr>
<td></td>
<td>At least 40% of opioid dependent PWID receive OST</td>
<td></td>
</tr>
<tr>
<td></td>
<td>90% of PWID receiving targeted HCV information, education and communication</td>
<td></td>
</tr>
<tr>
<td>Proportion of people with chronic HCV diagnosed and aware of their infection</td>
<td>50% [75% of estimated number of patients at late stage of viral hepatitis-related liver disease (cirrhosis or HCC) diagnosed]</td>
<td>90%</td>
</tr>
<tr>
<td>Treatment coverage of people diagnosed with chronic HCV who are eligible for treatment</td>
<td>75% (&gt;90% cured) [90% of diagnosed patients with chronic HCV are linked to care and adequately monitored]</td>
<td>80%</td>
</tr>
</tbody>
</table>

* 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\(^{(3)}\)
** In England, 2020 and 2030 targets are already met\(^{(62)}\)
*** 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,\(^{(63)}\) by using safety engineered devices.
Appendix 2. Preliminary indicators to monitor the impact of key interventions to tackle hepatitis C virus in England

<table>
<thead>
<tr>
<th>Burden, Impact and Service Coverage Monitoring Areas</th>
<th>Data source</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Burden</strong></td>
<td></td>
</tr>
<tr>
<td>Reducing the burden of infection in England</td>
<td></td>
</tr>
<tr>
<td>• Placeholder: Estimated prevalence of HCV infection in England</td>
<td>TBC</td>
</tr>
<tr>
<td>• Risk factors for infection from laboratory reports</td>
<td>CoSurv/SGSS</td>
</tr>
<tr>
<td>• Trend in anti-HCV prevalence among PWID</td>
<td>UAM survey</td>
</tr>
<tr>
<td><strong>Impact</strong></td>
<td></td>
</tr>
<tr>
<td>1. Reducing HCV-related morbidity and mortality</td>
<td></td>
</tr>
<tr>
<td>• Estimated incidence of HCV-related ESLD/HCC</td>
<td>HES</td>
</tr>
<tr>
<td>• Registrations for liver transplants in patients with HCV</td>
<td>NHS BT</td>
</tr>
<tr>
<td>• First liver transplants undertaken in patients with HCV (% of all liver transplants)</td>
<td>NHS BT</td>
</tr>
<tr>
<td>• First liver transplants undertaken in patients with HCV HCC (% of all liver transplants in patients with HCV)</td>
<td>ONS</td>
</tr>
<tr>
<td>• Deaths from HCV-related ESLD/HCC</td>
<td></td>
</tr>
<tr>
<td>2. Reducing the number of new (incident) infections</td>
<td></td>
</tr>
<tr>
<td>• Estimated incidence of HCV among people injecting psychoactive drugs</td>
<td>UAM survey</td>
</tr>
<tr>
<td>• Estimated prevalence of anti-HCV among recent initiates to drug use</td>
<td>UAM survey</td>
</tr>
<tr>
<td>• Number of HCV tests performed in young adults (and proportion testing positive) in sentinel laboratories</td>
<td>Sentinel surveillance</td>
</tr>
<tr>
<td>• Number of HCV laboratory reports in young adults (and proportion of all reports they represent)</td>
<td>CoSurv/SGSS</td>
</tr>
<tr>
<td>• Placeholder: Estimated number of new infections originating injecting drug use and net migration</td>
<td>TBC</td>
</tr>
<tr>
<td><strong>Service coverage</strong></td>
<td></td>
</tr>
<tr>
<td>1. Adequate harm reduction</td>
<td></td>
</tr>
<tr>
<td>• Estimated proportion of PWID reporting adequate needle/syringe provision</td>
<td>UAM survey</td>
</tr>
<tr>
<td>• Sharing of needles and syringes among PWID</td>
<td></td>
</tr>
<tr>
<td>• Number of current and past PWID in drug treatment</td>
<td></td>
</tr>
<tr>
<td>• Proportion of opioid dependent PWID receiving OST</td>
<td></td>
</tr>
<tr>
<td>• Placeholder: Proportion of PWID receiving targeted HCV information</td>
<td></td>
</tr>
</tbody>
</table>
### 2. Increasing awareness and the numbers and proportion diagnosed

- Estimated proportion of PWID testing positive for anti-HCV, aware of their infection
- **Placeholder: Proportion of chronic HCV infections in England diagnosed**
- **Placeholder: Proportion of population with late stage HCV-related liver disease (cirrhosis/HCC) diagnosed**
- 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
- **Placeholder (awaiting DBS data): Number of HCV tests via drug services (and proportion testing positive) in sentinel laboratories**
- Proportion of new receptions to prisons tested for HCV
- **Placeholder (awaiting DBS data): Number of HCV tests via prisons (and proportion testing positive) in sentinel laboratories**
- 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

### 3. Increasing numbers accessing treatment

- **Estimated number initiating HCV treatment**
- **Placeholder: Proportion of diagnosed population linked into care and monitored**
- **Placeholder: Proportion of diagnosed population eligible for HCV treatment who have accessed treatment, and proportion cured**
- **Placeholder: Future additional metrics on treatment access**

* 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.*
References


prevalence cannot necessarily be predicted from the prevalence in the country of origin. Journal of Viral Hepatitis. 2010;17:327-35.


