Hepatitis C in England 2020

Working to eliminate hepatitis C as a major public health threat
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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

Prepared by: Claire Edmundson, Annastella Costella, Ross Harris, Sema Mandal and Helen Harris.

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Foreword

In England, an estimated 89,000 people are chronically infected with hepatitis C (HCV), with many drawn from marginalised and underserved groups in society.

Over the last year, substantial progress has been made towards the World Health Organization elimination target to reduce HCV mortality by 65% by 2030, but further work is needed. In this report, we present the latest data on HCV, review progress towards elimination targets and highlight the important actions needed to reach them.

The report includes new metrics for monitoring HCV mortality, late diagnosis, reflex testing, and chronic infection among the general population and high risk groups affected. For the first time, we include national data on people attending sexual health services and people who are homeless. Linkage of these data sources plays a vital role in national surveillance of the cascade of care, allowing us to identify where patients are falling through the net and improvements are needed.

Collaborative work between PHE, NHS England, local authorities, primary care, pharmaceutical companies and the third sector continue to drive innovations that raise awareness, increase testing and improve pathways into care for target populations, thereby helping to reduce health inequalities. The success of this work is evidenced by the 20% fall in HCV-related deaths in England between 2015 and 2018, exceeding the World Health Organization (WHO) target – to reduce HCV-related mortality by 10% by 2020 – 3 years early and twofold by 2018.

Nonetheless, there are worrying signals that prevention activity may be failing to keep pace with the gains made in other areas. The number of new infections has been static in recent years, and may have risen in 2018. Injecting drug use is the main driver of HCV transmission in England yet a significant minority of people who inject drugs remain unaware of their HCV infections, needle and syringe provision is suboptimal and sharing injecting equipment remains of concern.

In the coming year, the challenges of the COVID-19 pandemic will undoubtedly threaten the progress of our HCV elimination efforts. However, it is essential that we do not lose focus on the important actions needed to reduce incidence, increase testing and improve linkage into care if we are to eliminate HCV as a major public health threat by 2030.
Professor Gwenda Hughes
Deputy Director for Blood Safety, Hepatitis, Sexually Transmitted Infections and HIV Service
National Infection Service
## Glossary of abbreviations

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<td>Anti-HCV</td>
<td>Hepatitis C antibodies</td>
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<td>BBV</td>
<td>Bloodborne virus</td>
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<td>CI</td>
<td>Confidence Interval</td>
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<td>CQUIN</td>
<td>Commissioning for Quality and Innovation</td>
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<td>DAA</td>
<td>Direct-acting antiviral</td>
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<td>DBS</td>
<td>Dried blood spot</td>
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<td>ESLD</td>
<td>End-stage liver disease</td>
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<td>GHSS</td>
<td>Global Health Sector Strategy</td>
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<td>GP</td>
<td>General Practitioner</td>
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<td>GUMCAD</td>
<td>GUMCAD STI Surveillance System</td>
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<td>HARS</td>
<td>HIV and AIDS Reporting System</td>
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<tr>
<td>HCC</td>
<td>Hepatocellular carcinoma</td>
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<tr>
<td>HCV</td>
<td>Hepatitis C virus</td>
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<tr>
<td>HITT</td>
<td>High Intensity Test and Treat</td>
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<tr>
<td>HIV</td>
<td>Human Immunodeficiency Virus</td>
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<tr>
<td>HJIP</td>
<td>Health and Justice Indicators of Performance</td>
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<td>HMPPS</td>
<td>Her Majesty’s Prison and Probation Service</td>
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<td>IPED</td>
<td>Image and performance enhancing drugs</td>
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<td>LDSS</td>
<td>Low dead space syringe</td>
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<td>MSM</td>
<td>Gay, bisexual and other men who have sex with men</td>
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<tr>
<td>NDTMS</td>
<td>National Drug Treatment Monitoring System</td>
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<tr>
<td>NFA</td>
<td>No fixed abode</td>
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<tr>
<td>NHS</td>
<td>National Health Service</td>
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<td>NHSBT</td>
<td>NHS Blood and Transplant</td>
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<td>NICE</td>
<td>National Institute for Health and Care Excellence</td>
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<td>NSP</td>
<td>Needle and syringe programme</td>
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<td>ODN</td>
<td>Operational Delivery Networks</td>
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<td>OST</td>
<td>Opioid substitution treatment</td>
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<td>PHE</td>
<td>Public Health England</td>
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<td>PHPQIs</td>
<td>Prison Health Performance and Quality Indicators</td>
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<td>PWID</td>
<td>People who inject drugs</td>
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<tr>
<td>RCGP</td>
<td>Royal College of General Practitioners</td>
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<td>RNA</td>
<td>Ribonucleic acid</td>
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<tr>
<td>STI</td>
<td>Sexually Transmitted Infection</td>
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<tr>
<td>s-SHS</td>
<td>Specialist sexual health services</td>
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<tr>
<td>SVR</td>
<td>Sustained Virological Response</td>
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<td>UAM</td>
<td>Unlinked Anonymous Monitoring</td>
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<td>VCT</td>
<td>Voluntary Confidential Testing</td>
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<td>World Health Organization</td>
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Executive summary

In May 2016, the UK signed up to the 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 HCV infection in tax year 2018 to 2019 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 89,000 people in England were living with chronic HCV infection in 2019, a fall of around 30% on latest prevalence estimates for 2015. Injecting drug use continues to be the most important risk factor for HCV infection, being cited as the risk in over 90% of all laboratory reports where risk factors have been disclosed.\(^3\) Sentinel surveillance data suggests that, of all individuals testing positive for anti-HCV in 2018, 85% were tested for HCV RNA. Among persons who were HCV RNA tested after a positive anti-HCV test, 52% were RNA positive, of whom 42% had an HCV genotype recorded; 49% were genotype 1, with a further 43% genotype 3. In 2018, 55% of people who had ever 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), a proportion which has increased significantly since 2011 (45%). However, chronic prevalence has remained relatively stable over this period (28% in 2018); the prevalence of cleared infection (anti-HCV positive, RNA-negative) has increased from 19% in 2011 to 27% in 2018.\(^3\)

If we are to eliminate HCV as a major public health threat, there are 2 important areas where we need to make progress: we have to reduce the numbers becoming seriously ill or dying from this infection, whilst at the same time reduce the number of people becoming newly or re-infected with the virus. In England, our vision is that all people at risk of HCV infection should have easy access to testing and, once tested, that action should be taken to either reduce their risk of infection or to prevent further transmission of the virus, and – if viraemic – place the patient on a treatment pathway.

With a 20% fall in deaths between 2015 and 2018 in England, the WHO target to reduce HCV-related mortality by 10% by 2020 has been exceeded 3 years early, doubling the 2020 target by 2018. This is supported by a 37% decline in the crude mortality rates among those with an HCV diagnosis reported to PHE and a 34% decline in adjusted mortality rates over the same period (2015-18). This suggests that increased treatment provision (a 131% increase in tax year 2018 to 2019 compared to pre-2015 levels) with direct-acting antiviral (DAA) drugs is having an impact. Analyses using linked national mortality data suggest high levels of alcohol consumption, with
60% of deaths in those with HCV reported to PHE over the last 10 years also having an alcohol-related cause of death noted on the death certificate. Falling numbers of liver transplant registrations (44% fall by 2018, when compared to pre-2015 levels) and liver transplants undertaken (29% fall by 2018, when compared to pre-2015 levels) in those where post-HCV cirrhosis and hepatocellular carcinoma (HCC) is given as the indication for transplant, are also observed, although both show a rise over the last year (by 19% and 13% respectively). The proportion of all first liver transplants performed in England that were carried out in patients with HCV-related disease has halved over the last decade, from 18% in 2009 to 9% in 2018.

As treatment volumes rise further, the WHO GHSS target for a reduction in HCV-related mortality of 65% by 2030\(^1\) looks achievable in England. Despite this, only around one half (53% in 2018) of people who have ever injected psychoactive drugs sampled in the UAM Survey\(^4\) were aware of their chronic HCV infection (61% were aware of their anti-HCV positive status). Preliminary data from the 2019 UAM Survey suggest that 79% of its participants had received information regarding HCV, protective measures to take to avoid infection or information on how it is treated in the last year, just short of the 90% WHO target for 2020; this fell to 73% among PWID not currently injecting. Late diagnosis continues to be a problem with just under half (45%) of those with cirrhosis at treatment initiation in NHS England’s Hepatitis C Patient Registry and Treatment Outcome System, noted to have received their first HCV diagnosis within the previous 2 years (42% of those with decompensated cirrhosis or HCC). While the first WHO target of 50% being diagnosed by 2020 has been met in England, more needs to be done if we are to reach the 90% target by 2030.

Throughout England, a variety of initiatives are ongoing to increase both professional and public awareness of HCV to help find patients who are undiagnosed or untreated. The success of these initiatives is dependent on the significant contribution of numerous stakeholders working across a range of settings. Public Health England (PHE) have provided data to support the National Health Service (NHS) in identifying people who have been diagnosed with HCV in the past but who may not have cleared their infections (Hepatitis C re-engagement exercise),\(^5\) so they can be offered testing and treatment where appropriate. PHE is also working to synthesise HCV data, through the publication of an evidence review\(^6\) and the development of a data dashboard to support Operational Delivery Networks (ODNs) in case finding and resource allocation.

The Hepatitis C Trust continue their work raising awareness of HCV infection among the main risk groups, including those who are homeless, in prison and the South Asian population, by developing and implementing patient-centred HCV interventions like peer support, rapid testing, and a confidential helpline. Community drug and alcohol treatment services, funded by local authorities, continue to play a central role in testing for viral hepatitis in people accessing their services and recent NHS procurement agreements facilitate additional testing in poorly served communities who do not
access these services, including plans to introduce testing in community pharmacies in 2020, and via outreach services for people who are homeless.

PHE have worked with stakeholders to develop free resources to help people recognise any risk for HCV infection and to encourage those at risk to seek testing. This has included a campaign that has distributed more than 12,600 posters to GP surgeries throughout England, along with videos and banners for use via social media. Royal College of General Practitioners (RCGP) e-learning courses for primary care, and other professionals working with people at risk of HCV, were updated in 2018(7),(8) with more than 5,300 people having completed these by the end of February, 2020. A new initiative in participating primary care practices utilises installed software to identify patients with risk factors for HCV infection, highlighting the requirement for testing and helping to raise awareness among GP’s.

Over the last decade (2009 to 2018) the number of laboratory confirmed reports of HCV in England has increased by nearly 90% (89%), with 16,216 reports of individuals testing positive for anti-HCV and/or HCV ribonucleic acid (RNA) in 2018. In sentinel surveillance, a 28% increase in the number of individuals tested has been observed overall, with a 4.3% increase via GP surgeries, between 2014 and 2018. On average 2.7% of all people tested through sentinel laboratories between 2014 and 2018 were anti-HCV positive, with 1.8% testing positive for anti-HCV via GP surgeries in 2018. A subsequent RNA test was conducted for at least 85% of all those anti-HCV positive.

When looking at the principal risk groups, both UAM (85% in 2018) and National Drug Treatment Monitoring System (NDTMS) data (84% in tax year 2018 to 2019) suggest that more than four-fifths of people who have ever injected drugs report, or were recorded as having received, a HCV test respectively. Since dried blood spot (DBS) testing can increase and facilitate uptake of testing amongst PWID, it is encouraging that data from sentinel surveillance suggest that DBS testing now far outweighs testing of venous blood in the drug service setting. The number of individuals tested in drug services captured through sentinel surveillance more than doubled during the period 2014 to 2016 (108% increase), however, numbers have subsequently levelled off, with a fall of 14% between 2016 and 2018. Positivity was high among this group, with 1 in 5 people testing anti-HCV positive (2014 to 2018).

Across the prison estate, opt-out bloodborne virus (BBV) testing among new receptions to English prisons shows that testing has risen from 5% in tax year 2010 to 2011 to 32% in tax year 2018 to 2019. In tax year 2017 to 2018, Health and Justice Indicators of Performance (HJIP) testing data suggest that, after excluding previously confirmed cases, 79% of new receptions and transfers were offered HCV testing and of these 41% were tested. Of those tested, 8.1% were anti-HCV positive, 75% of these went on to be tested for HCV RNA and of these 81% were found to have chronic HCV infection. Preliminary data suggest that around 47% of those testing positive for HCV RNA
received specialist referrals for HCV treatment. An increase in testing from prison settings has also been seen in sentinel surveillance, with the number of individuals tested in prisons increasing by 242% between 2014 and 2018. Anti-HCV prevalence captured through this testing has declined over this period, from 11% to 6% as testing has moved from targeted to more generalised testing of people at relatively lower risk of infection. The NHS’s DAA procurement deal has resulted in a significant investment in testing and treatment services for those in secure and detained settings, with point of care testing aiding rapid diagnosis and immediate initiation of pan-genotypic treatment. Providers, like CARE UK, alongside other stakeholders, are successfully delivering high intensity test and treat (HITT) programmes across the prison estate. Overall, these data suggest an increasing awareness of HCV in prisons with significant increases in testing. Work is ongoing to move from the implementation of BBV testing for new receptions to improving the quality of the offer and uptake of testing; something that will be important if clearance of infection within individual prisons is to be attained and maintained.

HCV is also an important issue for people who are homeless. In 2018, data from the UAM survey suggest that chronic HCV prevalence is significantly higher among ever PWID reporting homelessness in the last year (35%) than in those never reporting homelessness (17%). Among those reporting homelessness in the last year, chronic HCV prevalence increased significantly from 29% in 2011 to 35% in 2018. When looking at all laboratory reports of HCV infection during the period 2014 to 2018, around 7% included an indicator for homelessness. Preliminary estimates suggest that the proportion of people rough sleeping with diagnosed and reported HCV infection increased from 22% in 2014 to 32% in 2017, after which a decrease is observed to 29% in 2018. It is therefore important that this high risk and vulnerable group are helped to access testing and treatment services.

Testing has been seen to rise in other groups at increased risk of infection. Between 2014 and 2018, the number of individuals tested rose by 17% in the South Asian population, and among individuals identified as being of Eastern European origin, the number tested increased by 45%, which may partially be the result of increased migration from Eastern Europe over the period. Prevalence of anti-HCV among these groups was noted to decline over the period 2014 to 2018, being on average 1.6% among South Asian and 4.4% among Eastern European population groups. When looking at screening data from low risk populations, NHS Blood and Transplant (NHSBT) testing data suggest that rates of HCV infection in new and repeat donors remained low (12/100,000 in new donors; zero in repeat donors) in 2018. However, the rate of HCV detected in new donors of ‘other white background’ and in new donors of South Asian ethnicity was higher at 67/100,000 donors, about 19-times higher than in White-British donors (3.6 per 100,000).
Testing has also increased in sexual health services, with the number of individuals tested in sentinel laboratories rising by 37% over the period 2014 to 2018, and the proportion testing anti-HCV positive remaining stable at around 1.3%. However, among attendees at all specialist sexual health services (s-SHSs) in England, there was a decrease in HCV diagnosis rates between 2014 and 2018 (61% from 62 to 24 per 100,000 attendees). Relative to all attendees (24 per 100,000), diagnosis rates of HCV were markedly higher among gay, bisexual and other men who have sex with men (MSM) in 2018 (81 per 100,000). Of those living with HIV and accessing HIV care in 2018, 1.5% tested positive for either an acute or chronic HCV infection, this too varied by exposure group with HCV coinfection being most common among those with an injecting risk factor alone (27%) or in combination with being MSM (6.5%). The British HIV Association have set ambitious targets for the micro-elimination of HCV in patients with HIV, with the aim of curing HCV in 80% of those co-infected by April 2019, in 90% by April 2020, and 100% by April 2021.\(^\text{(10)}\)

When looking at numbers of new infections, data from the UAM Survey suggest that incidence of HCV infection has not declined significantly in recent years (17/100 person-years in 2018, compared to 14/100 in 2011), although there is substantial uncertainty in the estimates and significant variability between years. In the same survey, transmission among recent initiates to psychoactive drug use, a proxy measure of incidence, remained relatively stable between 2011 to 2017, although anti-HCV prevalence is significantly higher in 2018 (33%) than in 2011 (20%). Laboratory reports show significant falls in the proportion of positive laboratory reports among young adults, another proxy measure of incidence, (14% average decline per year in 15 to 19 year olds and a 17% average decline per year in 20 to 24 year olds), however, this may not necessarily correspond to a fall in incidence as testing patterns may have changed over time with more individuals at relatively lower risk of infection being tested.

The proportion of PWID reporting adequate needle and syringe provision remains suboptimal with 64% of those who had injected psychoactive drugs reporting adequate provision for their needs in the 2018 survey. Just less than 60% of responding services (34/58) participating in the UAM survey reported providing low dead space syringes (LDSS), despite evidence of the lower HCV transmission risk associated with their use. In 2018, 18% of current PWID reported sharing of needles and syringes, which is comparable to that seen in 2009 (19%). When including the sharing of other equipment associated with injecting, such as filters or spoons, alongside the sharing of needles and syringes, sharing was reported by 39% of current PWID in 2018. While levels of opioid dependent PWID receiving OST in tax year 2011 to 2012 (56%) exceeded the WHO European region target of 40% by 2020, models are currently under development to provide robust updated estimates. Together these findings suggest that the WHO GHSS call to reduce new cases of chronic HCV by 30% by 2020 and 80% by 2030,\(^\text{(1)}\) represent a significant challenge for health services in England with sub-optimal levels.
of harm minimisation among PWID a potential threat to achieving and sustaining HCV elimination in England.

Data are available from the NHS England HCV Patient Registry and Treatment Outcome System. As at 18 October 2019, the Registry contained records for 40,938 people with at least 1 treatment episode. Treated patients were predominantly white (82%), with 9.0% classified as Asian/Asian British. When compared to the previous data download on 30 April 2018, information on injecting status showed an increased proportion (27%, compared to 16% in the earlier download) were currently injecting/had recently injected drugs and most of those treated reported acquiring their infection via injecting drug use (74%). Most patients were referred from primary care (40%), with increasing proportions coming from drug services (16% vs 10%) and prisons (8.8% vs 5.5%). Data on hepatic disease stage showed that 26% of patients had cirrhosis prior to treatment, 38% had no evidence of fibrosis and 26% had mild fibrosis. While patients with severe disease were initially prioritised for treatment, an increasing proportion of ODNs are now treating people with mild disease (64% vs 58%). The majority of patients (79%) were treated in secondary care, with increasing proportions receiving treatment in drugs services (11% vs 5.7%) and prisons (8.3% vs 5.1%). Amongst those for whom it was possible to determine the outcome of treatment (n= 28,079), 95% achieved a sustained viral response (SVR) 12 weeks after completing treatment.

Insight into the cascade of care can be achieved through linkage of testing data from sentinel laboratories to the NHS England HCV Patient Registry and Treatment Outcome System. For the period 2014 to 2018, 41% of HCV RNA positive patients successfully linked to the treatment registry dataset and 86% of these had commenced treatment. A treatment outcome was available for 87% of those who commenced treatment, of whom 77% were reported to have achieved SVR 12, however, 15% were reported as lost to follow up, 4.0% were reported as either having a breakthrough, relapse, or non-response to treatment and 1.9% were reported to have died. When those who did not commence treatment, were lost to follow-up or who were known to have died prior to starting treatment were excluded, 92% achieved a SVR.

Given the numbers treated so far and current trends, statistical modelling predicts that around 5,400 people will be living with HCV-related compensated cirrhosis in England by 2020 and around 1,300 by 2030, representing a fall of 57% by 2020 and of 90% by 2030 compared with a 2015 baseline. Incidence of HCV-related ESLD/HCC is also expected to fall, with reductions of nearly 80% by 2030 compared with 2015.

The COVID-19 pandemic poses a serious threat to our ability to meet WHO HCV elimination goals. Delivering WHO goals depends on effective primary prevention, case ascertainment, treatment, linkage to and retention in care; monitoring progress in meeting these objectives also requires high-quality surveillance data. While COVID-19 may drive innovative modes of service delivery, any reduction in service capacity for
prevention, testing, diagnosis and treatment will delay progress towards delivery of these goals. Likewise, any reduction in the quality and timeliness of surveillance data will hamper our ability to monitor progress towards delivery of WHO goals, and to monitor the impact of changes in service capacity and effectiveness.

Overall, data suggest significant reductions in the prevalence of chronic HCV infection in England but chronic infection remains stable in those who are injecting drugs. Increasing numbers of PWID have evidence of exposure and clearance of HCV infection, suggesting that increased access to treatment, rather than improved harm reduction, is holding levels of chronic infection stable in this important group who are at risk of transmitting the virus. With improved access to new DAA drugs, the WHO GHSS 2020 goal to reduce HCV-related mortality has been achieved 3 years early in England and the 2030 goal should be within our reach provided current improvements in numbers accessing treatment can be sustained in future years. Much progress has been made raising awareness and increasing diagnosis over the last year and this should help support the continued reduction in avoidable HCV-related deaths. At the other end of the spectrum, there is currently little evidence of any fall in the number of new HCV infections, with some evidence of an increase in 2018. Sub-optimal harm reduction among PWID represents a threat to achieving and sustaining HCV elimination goals as elimination not only relies upon scaling up of testing and treatment, but also upon adequate harm reduction provision to prevent infection and reinfection following treatment. Currently available data suggest that the WHO target to reduce the number of new infections by 30% by 2020 is unlikely to be met in England, and a radical change in our approach to HCV prevention and harm minimisation among PWID is urgently required.

We are interested in receiving your feedback on this report and would be grateful if you could take 2 minutes to complete this short survey.

Thank you.
Important Findings

Burden of HCV infection

In England, chronic hepatitis C (HCV) prevalence is estimated to have fallen by around 30% since 2015, with 89,000 predicted to have chronic HCV infection in 2019.

In 2018, sentinel surveillance suggests that among persons who were HCV RNA tested after a positive anti-HCV test, 52% were RNA positive, of whom 42% had an HCV genotype recorded; 49% were genotype 1, with a further 43% genotype 3.

Drug injection continues to be the most important documented risk factor for HCV infection in 2018, being cited as the risk in 93% of all laboratory reports where risk factors were disclosed.

Of those participating in the Unlinked Anonymous Monitoring (UAM) Survey, the proportion of people who inject drugs (PWID) who test HCV antibody (anti-HCV) positive has increased in recent years, from 45% in 2011 to 55% in 2018, however, chronic prevalence has remained relatively stable over this period (28% in 2018); the prevalence of cleared infection (anti-HCV positive, RNA-negative) has increased from 19% in 2011 to 27% in 2018.

Available data suggest significant reductions in the prevalence of chronic HCV infection in England but chronic infection remains stable among those who inject drugs. Increasing numbers of PWID have evidence of exposure and clearance of HCV infection, suggesting that increased access to treatment, rather than improved harm reduction, is holding levels of chronic infection stable in this important group who are at risk of transmitting the virus.

Monitoring impact

Reducing HCV-related morbidity and mortality

The proportion of all first liver transplants carried out in patients with HCV-related disease in England has halved over the last decade, from 18% in 2009 to 9% in 2018.

By 2018, the number of liver transplant registrations and transplants undertaken in those where post-HCV cirrhosis and hepatocellular carcinoma (HCC) is given as the indication for transplant, fell by 44% and 29% respectively when compared to pre-2015 levels, although both show a rise over the last year (by 19% and 13% respectively).
Deaths from HCV-related end stage liver disease (ESLD) and hepatocellular cancer (HCC) have been falling since 2014, with a decline of 20% by 2018 from the 2015 World Health Organization (WHO) baseline.

Over the period 2015 to 2018, a 37% decline in crude mortality rates, and a 34% decline in adjusted mortality rates, is observed among those with an HCV diagnosis reported to PHE. This linkage study suggests high levels of alcohol consumption, with 60% of deaths in those with HCV reported to Public Health England (PHE) over the last 10 years also having an alcohol-related cause of death noted on the death certificate.

The WHO target to reduce mortality by 10% by 2020 has been met 3 years early and was exceeded at least twofold by 2018.

Reducing the number of new infections

UAM survey data provide no evidence for a fall in HCV incidence between 2011 and 2018.

Anti-HCV prevalence among recent initiates to injecting drug use, a proxy marker of incidence, has been relatively stable between 2011 and 2017, however, anti-HCV prevalence in 2018 (33%) is significantly higher than in 2011 (20%).

The WHO target to reduce the number of new infections by 30% by 2020 is unlikely to be met in England.

Monitoring the coverage of important services

Adequacy of harm reduction

In the tax year 2011 to 2012, 56% of opioid dependent PWID were receiving OST, exceeding the WHO European region target of 40% to receive OST by 2020.

In 2018, 64% of PWID participating in the UAM Survey reported adequate NSP for their needs, as the number of needles they collected met or exceeded the number of times they injected in the last month.

Low dead space syringes (LDSS) which, if shared, have a lower risk of BBV transmission when compared to traditional syringes with a high dead space, were provided by 59% of responding UAM Survey sites.

The 2018 UAM Survey shows no evidence of any decline in sharing of injecting equipment since 2012, with 18% of people currently injecting psychoactive drugs reporting sharing needles and syringes; when other injecting equipment, like mixing containers or filters, are included this figure rises to 39%.
Sub-optimal NSP and the absence of any fall in direct or indirect sharing of injecting drug equipment over the last 5 years is concerning as adequate harm reduction provision is needed to prevent infection and reinfection following HCV treatment.

**Awareness of infection**

The 2018 UAM survey data suggests that 61% of PWID were aware of their anti-HCV positive status; 53% reported that they were aware of their chronic (HCV RNA positive) infection status, a reduction from the 58% reported in the previous year.

As a marker of late diagnosis of HCV infection, just under half (45%) of those with cirrhosis at initiation of treatment in the NHS England Hepatitis C Patient Registry and Treatment Outcome System, were noted to have received their first HCV diagnosis within the previous 2 years (42% of those with decompensated cirrhosis and/or HCC).

Free resources for the public and educational courses for professionals (for example, RCGP e-learning courses for primary care and other professionals) are available to help people recognise any risk for HCV infection and to encourage those at risk to seek testing.

Royal College of General Practitioners (RCGP) e-learning courses are available for primary care and other professionals working with people at risk of HCV.

Preliminary data from the 2019 UAM Survey suggest that 79% of its participants had received information regarding HCV, protective measures to take to avoid infection or information on how it is treated in the last year, short of the 90% WHO target for 2020; this fell to 73% among PWID not currently injecting.

While the first WHO target of 50% being diagnosed by 2020 has been met in England, more needs to be done if we are to reach the 90% target by 2030.

**Increasing testing and diagnosis**

The number of laboratory confirmed reports of HCV in England between 2009 to 2018 has increased by nearly 90%, with 16,216 reports of individuals testing positive for anti-HCV and/or HCV ribonucleic acid (RNA) in 2018.

Overall sentinel surveillance suggests that the number of individuals tested increased by 28% between 2014 to 2018, with an average of 2.7% testing anti-HCV positive; a subsequent RNA test was conducted for at least 85% of all those anti-HCV positive.
The number of individuals tested through GP surgeries captured via sentinel surveillance increased by 4.3% between 2014 and 2018, with a slight decline in the proportion testing anti-HCV positive over this period (1.8% testing positive in 2018).

The number of individuals tested through sexual health services captured via sentinel surveillance increased by 37% between 2014 and 2018, with the proportion testing anti-testing positive remaining stable at around 1.3%.

Diagnosis rates of HCV in s-SHS were markedly higher among gay, bisexual and other men who have sex with men (MSM) in 2018 (81 per 100,000) compared to all attendees (24 per 100,000).

Of those living with HIV and accessing HIV care in 2018, 1.5% tested positive for either an acute or chronic HCV infection, this too varied by exposure group with HCV coinfection being most common among those with an injecting risk factor alone (27%) or in combination with being MSM (6.5%).

In both UAM (85% in 2018) and National Drug Treatment Monitoring System (NDTMS) data (84% in tax year 2018 to 2019) more than four-fifths of people who have ever injected drugs report, or were recorded as having received, a HCV test respectively. UAM Survey data also show an increase in the proportion of PWID tested in the current or previous year, from 40% in 2009 to 47% in 2019.

In Sentinel Surveillance, the number of individuals tested in drug services more than doubled during the period 2014 to 2016 (108% increase), however numbers have subsequently levelled off, with a fall of 14% between 2016 and 2018. Positivity was high among this group, with 1 in 5 people testing anti-HCV positive (2014 to 2018).

Preliminary estimates suggest that the proportion of people rough sleeping with diagnosed and reported HCV infection increased from 22% in 2014 to 32% in 2017, after which a decrease is observed to 29% in 2018.

The 2018 UAM survey suggests that chronic HCV prevalence is significantly higher among PWID reporting homelessness in the last year (35%) compared to those never reporting homelessness (17%). Since 2011, chronic prevalence among those reporting homelessness in the last year has increased significantly from 29% to 35% in 2018.

Across the prison estate, opt-out bloodborne virus (BBV) testing among new receptions to English prisons, shows levels of testing to have increased from 5.3% in tax year 2010 to 2011 to 32% in tax year 2018 to 2019.

In tax year 2017 to 2018, Health and Justice Indicators of Performance (HJIP) testing data suggest that, after excluding previously confirmed cases, 79% of new receptions
and transfers were offered HCV testing, of these 41% were tested and, of these tests, 8% were anti-HCV positive. Of those anti-HCV positive, three-quarters were tested for HCV RNA and 81% tested positive.

The number of individuals tested through prison services captured via sentinel surveillance increased by 242% between 2014 and 2018, with a decline in the proportion testing anti-HCV positive over this period from 11% to 6% as testing moved from targeted to more generalised testing.

The number of individuals tested via sentinel surveillance has increased by 17% among the South Asian population and by 45% among those of Eastern European origin over the period 2014 to 2018. During this period, anti-HCV prevalence has declined to 1.5% among South Asian and to 3.6% among Eastern European populations in 2018.

NHS Blood and Transplant (NHSBT) testing data suggest that rates of HCV infection in blood donors remained low (12/100,000 in new donors; no infections in repeat donors) in 2018.

**Improving access to treatment**


NHS England commissioning data suggest that treatment provision increased by 131% by tax year 2018 to 2019 when compared to pre-2015 levels.

For the period 2014 to 2018, linkage of testing data from sentinel laboratories to the NHS England HCV Patient Registry and Treatment Outcome System, suggests that (amongst those HCV RNA positive patients that could be successfully linked to the registry dataset; 41%), 86% had commenced treatment. A treatment outcome was available for 87% of these patients, of whom 77% were reported to have achieved SVR-12, 15% were reported as lost to follow up, 4.0% were reported as either having a breakthrough, relapse, or non-response to treatment and 1.9% were reported to have died. When those who did not commence treatment, were lost to follow-up or who were known to have died prior to starting treatment were excluded, 92% achieved a SVR.

Among PWID participating in the UAM survey in 2018, 75% of those anti-HCV positive and aware of their infection reported seeing a specialist regarding their HCV infection. Of these, 52% reported being offered and accepting treatment, up from 36% reported in 2011.
Data from first treatments recorded in the NHS England Hepatitis C Patient Registry and Treatment Outcome System, as at 18 October 2019, have been compared to data downloaded on 30 April 2018, and indicate:

- an increasing proportion (27%, compared to 16% in the earlier download) currently or recently injected drugs; most of those treated reported having acquired their infection via injecting drug use (74%)

- most patients were referred from primary care (40%), with an increasing proportion being referred by drug services (16% vs 10%) and prisons (8.8% vs 5.5%)

- prior to treatment, 38% of patients had no evidence of fibrosis and 26% had mild fibrosis; an increasing proportion of ODNs are treating people with mild disease (64% vs 58%)

- most patients (79%) were treated in secondary care, with an increasing proportion receiving treatment within drug services (11% vs 5.7%) and prisons (8.3% vs 5.1%)

- amongst those for whom it was possible to determine the outcome of treatment (n=28,079), 95% achieved a sustained viral response (SVR) 12 weeks after completing treatment

Statistical modelling predicts that during 2020 around 5,400 people would be living with HCV-related compensated cirrhosis in England and this would reduce to around 1,300 by 2030, representing a fall of 57% by 2020 and of 90% by 2030 compared with a 2015 baseline. Incidence of HCV-related ESLD/HCC is also expected to fall, with reductions of nearly 80% by 2030 compared with 2015.

The impact of COVID-19 on HCV elimination

The COVID-19 pandemic poses a serious threat to our ability to meet WHO HCV elimination goals.
Public health recommendations

Making improvements and monitoring metrics

PHE to further develop national indicators and tools at both national and local levels, to help monitor progress towards the WHO GHSS goal to eliminate HCV as a serious public health threat by 2030 at the latest.\(^1\)

All stakeholders to support national and local initiatives to improve quality of data used to inform monitoring metrics.

Public health professionals working in local authorities and Clinical Commissioning Groups to consider including HCV in Joint Strategic Needs Assessments and subsequent health and wellbeing strategies.

As soon as is reasonably practicable, the National Strategic Group for Viral Hepatitis should take stock of HCV elimination progress in the context of the COVID-19 pandemic, and work with stakeholders to plan how best to proceed with the HCV elimination agenda and to identify research to support this.

Adequate harm reduction/prevention

Commissioners of services for people who inject drugs need to expand access to the full range of provision (including opioid substitution treatment (OST), needle and syringe programmes (NSP), including the provision of LDSS, and patient information) to reduce HCV transmission, 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\(^12\) and OST.\(^13\)

PHE to consider how access to and uptake of NSP and their activity can be mapped and monitored.

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 use drugs and alcohol to specify the legal requirement to report HCV positive laboratory results with patient identifiers to PHE, including those from DBS testing.

The National Strategic Group on Viral Hepatitis to work with stakeholders to identify how to improve harm reduction and prevention activity among those who are homeless.
Increasing the numbers and proportion diagnosed

All stakeholders to help improve awareness among health care professionals, for example by encouraging participation in e-learning.\(^{(8),(7)}\)

All stakeholders to improve the offer and uptake of HCV testing to those at risk of HCV infection by implementing NICE guidelines.\(^{(14)}\)

All stakeholders to continue to produce and disseminate appropriate communications, including resources, national reporting and infographics, with enhanced efforts to mark World Hepatitis Day (28 July).

BBV prevention services should ensure that testing is sustained or enhanced, as appropriate, among those attending drug, and other, services;\(^{(15)}\) the use of alternative approaches to testing, including capillary blood sampling and point of care testing, that facilitate testing in non-clinical settings or alleviate delays in onset of treatment, should be considered.

Health and Justice to ensure that BBV opt-out testing for new receptions to prisons in England continues to be monitored to inform strategies to improve the offer and uptake of testing.

Commissioners and providers of drug services to consider implementing BBV opt-out testing upon initial assessment, and repeat testing for those at continued risk, including after successful antiviral treatment.

Commissioners and providers of laboratory services to ensure, wherever possible, that 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.\(^{(16)}\)

Diagnostic laboratories should include patient referral instructions on the laboratory report and implement direct reporting of new diagnoses to their ODN, as well as to the individual requesting the test.

Increasing the numbers accessing hepatitis C treatment

Commissioners of HCV treatment and care services should continue to work with public health agencies, primary and secondary care 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, homeless services and other settings; and to drive innovative approaches to outreach and patient support under the supervision of ODNs.
PHE to continue to evaluate the impact of the Hepatitis C re-engagement exercise,\(^{(5)}\) and consider whether this exercise should be extended.

Treatment and BBV prevention services should ensure that appropriate information and support are provided to help guard against re-infection among those achieving a SVR following treatment.

The Department of Health and Social Care to consider funding a national media campaign to encourage those with past risk factors but silent disease to come forward for testing, and to evaluate the impact of the campaign.
Introduction

Hepatitis C is a bloodborne virus that infects and damages the liver; persistent infection over time can lead to cirrhosis, liver failure or cancer and extrahepatic manifestations of the disease. As many infections are asymptomatic for several years, or may result in non-specific symptoms, people are often unaware of their infection until the symptoms of severe liver damage are experienced. As a result, many individuals with chronic HCV infection remain undiagnosed and fail to access treatment. These individuals can present later with complications of HCV-related end-stage liver disease (ESLD) and primary liver cancer, which have poor survival rates.

HCV disproportionately affects populations who are marginalised and under-served, with reduced engagement in healthcare and poor health outcomes. HCV is most prevalent in individuals with a current or past history of injecting drug use, those incarcerated, the homeless, and also in populations who have close links to countries where HCV is endemic.\(^{(17)}\) Other groups at increased risk of HCV include: recipients of blood or blood products prior to the introduction of routine blood screening in the UK, healthcare workers, infants born to HCV positive mothers and individuals engaging in high-risk sexual behaviours.\(^{(18)}\)

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.\(^{(2)}\)

The development of DAA drugs revolutionised the HCV treatment landscape, providing a finite well-tolerated and effective orally administered cure with fewer side effects than previously experienced with interferon-based treatment regimens.\(^{(19)}\) As a result, despite the absence of a vaccine, there has been international interest in striving for global elimination of HCV as a major public health threat, with the WHO setting elimination targets for 2030.\(^{(1),(20)}\) 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 and reduced transmission, together have the potential to prevent 2.1 million HCV-associated deaths worldwide by 2030.\(^{(1)}\)

In May 2016, the UK signed up to the WHO GHSS on Viral Hepatitis,\(^{(1)}\) committing to meet targets of an 80% reduction in incidence of HCV infection and a 65% reduction in mortality from HCV by 2030 (see Appendix 1).

In order to achieve or exceed these elimination goals in England, it is critical that we continue to work with our partners to improve prevention, raise awareness, increase
testing and ensure that those diagnosed have equitable access to antiviral treatment and care. This report summarises the scale of HCV infection and related disease in England during tax year 2018 to 2019 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 HCV as a major public health threat by 2030 at the latest.
Vision and monitoring metrics

HCV is a curable infection, and we aim to support the WHO in achieving their goal to eliminate HCV as a major public health threat by 2030 at the latest. Through 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, we will strive to achieve these goals.

The focus of our vision is captured in the following vision statement:

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

In order to track our progress towards these goals, it is important to monitor the impact of interventions in the following 2 important 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 to reducing 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 proportion of infected people accessing treatment

The indicators (see Appendix 2) reported in the sections that follow and summarised in the headline data table describe our progress and set out the scale of the challenge ahead so that meaningful goals can be developed and progress towards achieving them can be monitored.

New monitoring metrics

Substantial progress has been made improving monitoring metrics over the last year. New indicators include death registration data linked to HCV diagnosis data, and a new indicator to monitor late diagnosis of HCV infection. In addition to reporting numbers ever infected, sentinel surveillance testing data has been expanded to show the time interval between an anti-HCV positive test and subsequent RNA testing (an indicator of reflex testing) and the proportion who are chronically infected among all those tested. HCV RNA prevalence data are now included for the UAM survey of PWID and additional DBS testing data from private laboratories have been incorporated into
laboratory reporting and sentinel surveillance. GUMCAD data (2014 to 2018) for diagnosis rates of HCV and HIV co-infection among attendees to sexual health services have been included (among all attendees and among MSM), as have data from the HIV and AIDS Reporting System (HARS) for the proportion of people accessing HIV care for their HIV/HCV co-infection by exposure category for years 2017 to 2018. Information on HCV prevalence among the homeless has been included from laboratory reports and the UAM Survey, and data from the Hepatitis C Patient Registry and Treatment Outcome System and sentinel surveillance have been linked to show the cascade of care for those accessing HCV testing.

As in previous years, where indicators are missing or in development, placeholders have been included (see Appendix 2). With focused monitoring, we hope to continue to work with stakeholders to identify barriers and drive forward improvements across the system to help eliminate HCV as a major public health threat by 2030 at the latest.
Burden of HCV infection

The burden of HCV infection can be assessed by monitoring the prevalence of chronic HCV infection. Testing for antibodies for HCV allows us to determine whether individuals have ever been infected with HCV, whereas testing for HCV RNA indicates current infection. If an individual is anti-HCV positive but RNA negative, they have been exposed to HCV in the past, but have since cleared the virus either naturally or through treatment. However, if HCV RNA positive, they have a current HCV infection, whether acute (RNA positive, anti-HCV negative) or chronic (RNA positive, anti-HCV positive).

Latest modelled estimates suggest that around 129,000 people (95% credible interval 117,000 to 142,000) in England were living with chronic HCV infection in 2015. Prevalence is estimated to have fallen by around 30% since 2015, the year that elimination targets were agreed, and is predicted to have declined to 89,000 in 2019 (95% credible interval: 77,000 to 102,000) with the advent of new DAA treatments (Figure 1).[3, 21] The modelling approach makes use of multiple sources of routine surveillance data to track progress over time and is under a process of continued review and development.

Figure 1: Estimates of chronic prevalence of HCV in England, 2010 to 2019 (bars represent 95% credible intervals).[21]

Data source: Modelled estimates of chronic HCV prevalence, based on HCV prevalence data from the Unlinked Anonymous Monitoring Survey of People Who Inject Drugs; estimates of the number of people who inject drugs[4]; Hospital Episode Statistics (HES), NHS Digital for England. Produced by Public Health England (data on severe HCV-related liver disease); Trent cohort data (estimates of disease progression probabilities) and data on HCV treatment (IMS sales data, Sentinel Surveillance of Blood Borne Virus Testing and the NHS England Hepatitis C Patient Registry and Treatment Outcome System).
Data for HCV testing conducted through sentinel laboratories in England is collated through the Sentinel Surveillance of BBV Testing (SSBBV)\(^{(22)}\), and includes those testing positive and negative for hepatitis C. Location of test is also collected, allowing for stratification by testing venue in order to review positivity among the main risk groups, such as those tested through drug services, sexual health clinics and prison settings. SSBBV data suggests that, of all individuals testing positive for anti-HCV in 2018, 84.7% were tested for HCV RNA. Among persons who were HCV RNA tested after a positive anti-HCV test, 52.1% were RNA positive, of whom 41.7% had an HCV genotype recorded; 49.1% were genotype 1, with a further 42.8% genotype 3\(^{(22)}\).

Injecting drug use continues to be the most important documented risk factor for HCV infection, being cited as the risk in 92.5% of all laboratory reports in 2018 where risk factors were disclosed\(^{(3)}\).

In 2018, of the people who have ever injected psychoactive drugs participating in the UAM survey\(^{(4)}\), the proportion testing anti-HCV positive has increased in recent years, from 44.6% in 2011 to 55.2% in 2018 (p<0.001; Figure 2). Routine HCV RNA testing to determine chronic infection was introduced in 2016 and retrospective testing of stored samples from previous years completed; HCV RNA prevalence data are now available for the period 2011 to 2018 (Figure 2). A small proportion of anti-HCV positive samples were insufficient for RNA testing; estimates for the proportion of chronic and cleared HCV infection have been adjusted to take these samples into account. The adjustment was completed by applying the ratio of chronic versus cleared infection to the anti-HCV positive samples with missing RNA status by year and region. Over the period 2011 to 2018, chronic prevalence has remained relatively stable among survey participants (26.1% in 2011; 27.8% in 2018; Figure 2). The prevalence of cleared infection (anti-HCV positive, RNA-negative) has increased significantly in recent years, from 18.5% in 2011 to 27.4% in 2018 (p<0.001).

Chronic HCV prevalence among PWID participating in the UAM survey during 2018 varied across England, being higher in the North West (33.5%), South East (31.4%), South West (32.3%), North East (29.5%) and lower in London (24.3%), East of England (23.8%), Yorkshire and Humber (23.4%) East Midlands (22.6%), and the West Midlands (22.5%).

Data on HCV testing among PWID arising from NHS England elimination initiatives will also be available over the coming years to help inform prevalence in this high risk group.
Figure 2: Trend in HCV prevalence* among people injecting psychoactive drugs in England: 2011 to 2018

See footnotes in Appendix 3.

Data source: Unlinked Anonymous Monitoring Survey of people who inject drugs in contact with specialist services.\(^{(4)}\)

In England and Wales, when compared to the general population, levels of HCV infection are also elevated among survey participants who inject IPEDs, such as anabolic steroids, 5.1% of whom tested positive for antibodies to HCV during 2014 to 2015.\(^{(23)}\) We aim for updated prevalence data from the 2016 to 2018 IPED survey to be available next year and published in the HCV in England 2021 report.

Overall, available data suggest significant reductions in the prevalence of chronic HCV infection in England but chronic infection remains stable among those who have ever injected drugs. Increasing numbers of PWID have evidence of exposure and clearance of HCV infection, suggesting that increased access to treatment, rather than improved harm reduction, is holding levels of chronic infection stable in this important group who are at risk of transmitting the virus.
Monitoring impact

To eliminate HCV as a major public health threat, progress has to be made in 2 important impact areas: we need to reduce the numbers becoming seriously ill or dying from complications of HCV infection, whilst at the same time reducing the number of people who become newly or re-infected.

Reducing HCV-related morbidity and mortality

In England, mortality from HCV-related liver disease increased up until 2014, as people who acquired their infections decades earlier progressed to advanced liver disease and access to sub-optimal interferon-based treatments had been inadequate.\(^{(24)}\) Since new DAA drugs\(^{(25-33)}\) have been available and delivered through the ODNs that were established in 2013, a fall in the number of HCV-related liver transplants and deaths has been observed.\(^{(24)}\) As treatment uptake increases, trends in severe HCV-related morbidity and mortality are monitored to ensure that treatment is having an impact and that WHO elimination goals (see Appendix 1) are being met.

Metrics to monitor trends in HCV-related morbidity and mortality:

- registrations for liver transplant and transplants undertaken, where post-HCV cirrhosis is given as the indication for transplant
- death registrations for HCV and HCV-related ESLD/HCC
- mortality rates from HCV and HCV-related ESLD/HCC in persons aged ≥15 years whose HCV diagnoses have been reported to PHE

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

HCV-related morbidity can be monitored by reviewing the number of English residents with post-HCV cirrhosis (recorded as either the primary, secondary or tertiary indication for transplant) registering at NHSBT for a liver transplant, as well as the number and proportion of transplants undertaken in those with an HCV infection. During the period 2009 to 2014, first liver transplant registrations remained relatively stable averaging 135 per year (range: 120 to 152; Figure 3), with highest numbers of registrations occurring in London (21.8% between 2009 and 2014). However nationally, post 2014, registrations fell dramatically to a 10-year low of 63 in 2017, with a slight increase to 75 in 2018 (Figure 3).\(^{(3)}\)

Likewise, first liver transplants undertaken for this indication, remained relatively stable between 2009 and 2014, averaging 107 transplants per year (range: 93 to 123, Figure 3). Yet, between 2015 and 2017 the numbers of transplants declined year on year and
exceeded the number of registrations over this period. In 2018, the number of first liver transplants was similar to the number of registrations, increasing slightly to 76 from a low of 67 in 2017. Further work is required to identify whether the observed rise in transplants and transplant registrations in 2018 is the result of improved surveillance for HCC in those patients with cirrhosis who achieve SVR following HCV treatment.

Figure 3: Number of first patient registrations in England where post-HCV cirrhosis was given as either the primary, secondary or tertiary indication for transplant and the number of first liver transplants undertaken in patients who were HCV positive (RNA or antibody) at registration and transplant: 2009 to 2018*

See footnotes in Appendix 3.

Data source: NHS Blood and Transplant UK Transplant Registry

The proportion of all first liver transplants performed in England which were carried out in patients with HCV-related disease has halved over the last decade, from 18% in 2009 to 9% in 2018 suggesting that new HCV treatments are having an impact.

Whilst the overall falls in numbers registering and undergoing liver transplants for HCV-related liver disease are encouraging, it will be important to continue to monitor these trends over the coming years to ensure that the rises observed in 2018 are not sustained, which could suggest that earlier falls might have, in part, been the result of deferring registration pending assessment of the impact of treatment on clinical condition, or whether they are the result of delayed HCC occurring post SVR as patients survive longer with decompensated cirrhosis. 

\[34, 35\]
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 (Figure 4). Since 2014, however, deaths have been falling, with a decline of 19.9% between 2014 and 2018, a reduction of 19.7% from the 2015 WHO baseline (Figure 4).

Figure 4: Death registrations for ESLD* or HCC in those with HCV mentioned on their death certificate in England: 2005 to 2018**

See footnotes in Appendix 3.

Data source: Office for National Statistics.(36)

HCV-related ESLD/HCC, rather than just deaths associated with HCV infection, is monitored since ESLD/HCC presents clinically so the full spectrum of deaths from this indication should be captured. When monitoring deaths from ESLD/HCC as well as deaths where HCV is coded as the underlying cause of death, without any mention of ESLD/HCC, overall numbers are higher and trends similar, with a slightly greater fall in deaths of 24.9% since 2015 (Figure 4).

Since HCV is known to be under-reported on death certificates,(37, 38) mortality has also been explored amongst persons known to have been diagnosed with HCV. To achieve this, death registrations were linked to data for persons aged 15 years or over who were
Hepatitis C in England 2020

reported to PHE via routine HCV laboratory reporting between 1998 and 2018 in England. In this way deaths are ascertained when ESLD or HCC are reported, regardless of whether HCV is recorded on the death certificate. This method also has the advantage of minimising the impact of changes in HCV reporting on death certificates over time, although it will inevitably capture deaths that may have causes other than HCV infection as the principal reason for death (for example, alcohol related deaths in people who were HCV infected but cleared the virus in the early stages of infection).

Crude mortality rates for persons diagnosed with HCV are presented in Figure 5. Changes in mortality rates in this cohort following the introduction of the WHO elimination strategy in 2015 were assessed using Poisson regression, adjusting for age at HCV diagnosis, sex, year, and follow up time. When compared to 2015, mortality rates for all HCV-associated mortality in 2016, 2017 and 2018 reduced by 13.2%, 21.4% and 37.4% respectively (all p<0.03). When assessing mortality from HCC and ESLD specifically, mortality rates from HCC were similar in 2016 and 2017 when compared to 2015 (both p>0.8) however rates in 2018 were 18.1% lower (p=0.03). For ESLD, mortality rates reduced by 18.5%, 36.2% and 53.9% in 2016, 2017 and 2018 respectively (all p<0.03) when compared to 2015. As observed elsewhere, current evidence suggests that while de novo HCC risk is reduced after a SVR, the risk of HCC may persist even after successful clearance of the virus, particularly amongst those with added risk factors for HCC including cirrhosis, diabetes mellitus, hepatitis B co-infection, hepatic steatosis, genotype 3 infection, high alcohol consumption, advanced age, lower platelet counts, male gender and possibly genetic factors.\(^{(39-42)}\) Although the greatest falls are in more recent years, reductions in crude deaths precede the introduction of DAAs, declining steadily from 2013 onwards. This could be the result of interferon alpha and interferon and ribavirin treatments and/or changes in the cohort in terms of morbidity risks. The latter could occur if increases in testing over time result in individuals being diagnosed at earlier disease stages, thus the average risk of developing severe liver disease declines in the cohort of diagnosed individuals. The alternative is that HCV-related mortality started to reach a plateau prior to the introduction of DAAs. Nevertheless, these results corroborate the findings of death certificate analysis, showing significant decreases in HCV-associated mortality in persons diagnosed with HCV following the introduction of DAAs in England.

These new analyses using linked data show that, over the last 10 years, 60.0% of all HCV-associated deaths also had an alcohol-related cause of death noted on the death certificate, with no change in the likelihood of alcohol being reported with a HCV-associated death over the last 5 years (logistic regression: p=0.4). In contrast, only 4.0% also had a drug-related cause of death noted on the death certificate. Death certificate information will under-estimate the proportion of people with HCV-associated mortality who also have problematic alcohol and drug use but still suggests a very high prevalence of alcohol misuse in this population.
With a fall in deaths from HCV-related ESLD/HCC of 19.7% by 2018, from a 2015 baseline (which reached 24.9% when deaths from HCV with no mention of ESLD/HCC were included), the WHO target to reduce HCV-related mortality by 10% by 2020 (see Appendix 1) has been exceeded 3 years early in England and was exceeded at least twofold by 2018. These findings are corroborated by both crude and adjusted mortality rates. Crude mortality rates capturing deaths with a reported diagnosis of HCV fell by 37.1%, and adjusted mortality rates capturing all HCV-associated mortality, fell by 34.0% over the same period (2015 to 2018).

Figure 5: Crude mortality rates for HCC, ESLD and HCV in persons aged ≥15 years reported to PHE as HCV antibody positive between 1998 and 2018, for the period 2005 to 2018.

See footnotes in Appendix 3

Data source: Office of National Statistics\(^{(36)}\) and Sentinel Surveillance\(^{(43)}\)

Reducing the number of new (incident) infections

Monitoring the impact of prevention measures on the incidence of infection remains a challenge as incident HCV infection is difficult to measure directly. Ideally, we would monitor the actual or estimated number of new HCV infections that arise annually in PWID, as well as any that result from net migration and other sources, and monitor this
over time. However, the former is difficult to estimate because a significant proportion of acute infections are asymptomatic, and hence undiagnosed, and there is considerable uncertainty around the number of PWID in England.\textsuperscript{(44-47)} In addition to this, it is difficult to select a sentinel population of PWID for monitoring that is representative of PWID as a whole as not all PWID are engaged with services or healthcare. As a result, a number of methods are used to generate information to provide insight into likely trends in incidence over time.\textsuperscript{(48)}

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

- estimated incidence of HCV among PWID
- prevalence of anti-HCV among recent initiates to injecting drug use (proxy measure)
- prevalence of anti-HCV among young adults (proxy measure)

**Estimated incidence of infection among people who inject drugs**

Recent transmission of HCV has been explored among participants in the UAM survey\textsuperscript{(4)} who reported injecting psychoactive drugs in the previous year, the methods for which are described elsewhere.\textsuperscript{(49)} In previous years HCV antibody avidity data were used as a possible proxy to calculate de novo infection and hence incidence for the years 2011 to 2016. However, as retrospective RNA testing is now complete, HCV RNA in serum prior to seroconversion to anti-HCV antibody can be used to calculate the proportion RNA positive among anti-HCV negative individuals for the years 2011 to 2013. Incidence estimates are therefore calculated using this method for the years 2011 to 2013 and 2017 to 2018; incidence estimates for 2014 and 2015 are not available as RNA testing was conducted on anti-HCV positive samples only. Estimates for 2016 were calculated using a combination of RNA and avidity data as RNA testing was conducted for half of the year. When reviewing these estimates, there is no indication of any fall in incidence between 2011 to 2013 and 2016 to 2018 (Figure 6; p=0.9).
Figure 6: Estimated incidence of HCV among HIV negative* people injecting psychoactive drugs in England who reported injecting in the previous year, 2011 to 2018** (95% CI)

See footnotes in Appendix 3

Data source: Unlinked Anonymous Monitoring Survey of people who inject drugs in contact with specialist services. (4)

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, the prevalence of infection in young adults can be used as a proxy measure of incidence. Another proxy measure for incidence is monitoring HCV antibody prevalence in recent initiates to injecting drug use, as these individuals are unlikely to have been infected prior to engaging in this risk behaviour.

Recent initiates to injecting are defined as individuals who began injecting up to 3 years prior to their participation in the UAM Survey. Data from the UAM survey of PWID (4) suggest that anti-HCV prevalence among recent initiates to injecting drug use has been
relatively stable between 2011 and 2017, at around 24% (range 20% to 27%), although prevalence of anti-HCV infection is significantly higher in 2018 (33%; CI 26 to 40) when compared to that seen in 2011 (20%; CI 15 to 26; p=0.03; Figure 7).\(^3\)

**Figure 7: Prevalence of anti-HCV among recent initiates to injecting* in England 2011 to 2018**

![Figure 7: Prevalence of anti-HCV among recent initiates to injecting* in England 2011 to 2018](image)

See footnotes in Appendix 3

**Data source:** Unlinked Anonymous Monitoring Survey of people who inject drugs in contact with specialist services.\(^4\)

In the UAM survey of PWID, only 8.3% (205/2,478) of participants recruited in England during 2018 were recent initiates and therefore the statistical power to detect changes in incidence is low; data for serological markers of recent infection are even sparser. As such, markers of incidence from the UAM survey of PWID are unlikely to be able to determine small reductions in incidence at this stage of DAA treatment delivery, although a statistically significant increase in prevalence among recent initiates is observed in the most recent year. Further work is needed to determine the expected impact of treatment in PWID on incidence, perhaps to include targeted re-testing of individuals who have already cleared the virus following treatment.

Laboratory reports of positive HCV tests (HCV RNA and/or anti-HCV; Figure 8) captured through PHE’s Second Generation Surveillance System (SGSS)\(^5\) show a steady decline in the proportion of positive tests from those aged 15 to 19 years (14.1% per year) and aged 20 to 24 years (17.3% per year) between 2014 and 2018, although overall numbers of positive tests in those aged 15 to 19 and 20 to 24 years have
remained comparatively stable. However, interpretation is difficult as overall numbers tested have increased substantially over time, with potential expansions into different settings and risk groups.

**Figure 8: Laboratory reports of HCV in young adults in England: 2009 to 2018***

See footnotes in Appendix 3

**Data source:** CoSurv/SGSS.\(^{(50)}\)

In summary, data from the UAM survey provide no convincing evidence of any fall in HCV incidence over the last 5 years and, in fact, provide some evidence of a rise in incidence over the last year. Data from laboratory reports show falls in the proportion of positive laboratory reports (either anti-HCV or RNA) among young adults, however, these do not necessarily correspond to a fall in numbers of infections in young adults, because testing has increased over time with potential expansions into different settings and risk groups. It is therefore difficult to assess progress towards the targets to reduce new cases of chronic HCV infection, although currently available data suggest that the GHSS target to reduce new cases by 30% by 2020\(^{(1)}\) (see Appendix 1) looks unlikely to be met in England.
Monitoring the coverage of important services

In England, it is feasible to drive down HCV-related mortality and prevent new infections from occurring/re-occurring in order to eliminate HCV as a major public health threat.\(^{(51,\ 52)}\)

This is achieved with investment in 3 core intervention areas:

1. Ensuring adequate harm reduction for PWID.
2. Increasing the proportion of viraemic individuals who are diagnosed.
3. Increasing the proportion of viraemic individuals who access and complete treatment, achieving SVR.

Adequate harm reduction

Harm reduction interventions for PWID, including access to sterile injecting equipment via NSP and effective drug dependence treatment, can prevent and control HCV transmission among PWID.\(^{(51,\ 53-58)}\) Specifically, OST is associated with a reduction in the risk of HCV acquisition, which is strengthened in studies that assess the combination of OST and NSP.\(^{(58)}\) Therefore, optimal access to clean injecting equipment and OST is important 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
- provision of LDSS through drug services
- sharing of injecting equipment and associated paraphernalia among PWID
- number of current and past PWID in drug treatment
- proportion of opioid dependent PWID receiving OST

NSP coverage

In Europe, high NSP coverage has been shown to be associated with a reduction in the risk of HCV acquisition,\(^{(58)}\) with NSP being a highly effective, low-cost, intervention that can be cost saving in certain settings.\(^{(59)}\)

The draft action plan for the health sector response to viral hepatitis in the WHO European region\(^{(20)}\) and the GHSS on viral hepatitis\(^{(1)}\) call for comprehensive harm reduction services to be in place for all PWID, including a major global increase in provision and availability 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. Ideally, provision should be sufficient to
allow PWIDs to use a new sterile needle/syringe for each drug preparation and injection attempt; individual need therefore varies widely depending on venous access, dependency, and drug preference. In order to better reflect the adequacy of needle and syringe provision, data from the UAM survey of PWID\(^{(4)}\) are presented here on self-reported adequacy of needle and syringe provision (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 in the past month.

**Figure 9: Estimated proportion of people injecting psychoactive drugs reporting adequate* needle and syringe provision in England, 2011 to 2018**

In 2016, the UAM survey questionnaire was reviewed, resulting in a number of changes to data items from 2017 onwards. Questions around NSP access were updated to reflect changes in NSP provision that have been observed nationally and to incorporate information on secondary distribution of injecting equipment occurring among this population. Prior to 2017, participants in the UAM survey were asked how many needles they collected per month, and from 2017 onwards they were asked to report the frequency of NSP visits per month and the number of needles collected per visit for themselves and for others. As a result, the 2017 indicator is not directly comparable to previous years.
Among people injecting psychoactive drugs participating in the UAM survey during 2018, 64% (95%CI 61% to 67%) reported adequate NSP for their needs; the reported number of needles received met or exceeded the number of times the individual reported injecting in the past month (Figure 9). These data should be interpreted cautiously as more than 1 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. In 2018, 60.4% of those who injected in the last month reported having to make multiple attempts before successfully accessing a vein the last time they injected.

Another factor to consider when reviewing NSP provision is the availability of LDSS. LDSS provision through drug services is an acceptable strategy for reducing HCV transmission among PWID as, after use, LDSS retain less blood than traditional syringes with a higher dead space.\(^6^0\) Recent evidence suggests the provision of LDSS as an alternative to traditional needles is likely to be a cost-saving strategy for reducing the transmission of HCV in the UK.\(^6^1\) To assess the provision of LDSS, the UAM survey collected data on the provision of these syringes directly from participating drug and alcohol services across England during 2019. Of the 58 (of 89) sites providing NSP who completed this information, 34 (58.6%) stated that they provided LDSS. Although over half of responding sites provide LDSS, scaling up of provision of LDSS is required in line with current guidance\(^6^2\) in order to ensure availability for all those who wish to use them.

Altogether, these findings indicate that, while evidence suggests that the majority of PWID may be able to access NSP to some degree\(^2^4\),\(^6^3\) more needs to be done to ensure universal adequate provision. The amount and type of equipment provided needs to be scaled up, with an emphasis on increasing the availability of LDSS; provision needs to be more accessible and targeted, and transmission risks should be emphasised among PWID in order to enable them to take steps to mitigate these risks.

Sharing of injecting equipment and associated paraphernalia by PWID

As 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. Injection equipment sharing includes the sharing of needles and syringes (direct sharing) and sharing of other injecting paraphernalia such as filters and spoons (indirect sharing). In England, 18.4% of people currently injecting psychoactive drugs and participating in the UAM survey reported direct sharing of needles and syringes in 2018 (Figure 10); this is comparable with levels seen in 2009 (19%), but an increase from 14% in 2012 when direct sharing was at its lowest. When including the sharing of mixing containers or filters as well as needles and syringes, the proportion of those reporting direct and indirect sharing in 2018 is 39% (Figure 10).\(^3\),\(^4\) Among those
surveyed who have ever injected IPED’s in England and Wales, 13% reported that they had ever shared a needle, syringe or vial in 2014 to 2015.\(^{(23)}\)

Reported level of sharing of needles, syringes and other injecting paraphernalia among people injecting psychoactive drugs participating in the UAM survey in 2018 varied across England; with the level ranging from 33% in both London and the East of England to 51% in the East Midlands region.

The absence of any fall in direct or indirect sharing over the last 5 years is concerning if elimination targets are to be met. Achieving and sustaining HCV elimination not only relies upon scaling up testing and treatment, but also upon adequate harm reduction provision. In order to achieve this, these data suggest that the scale of equipment provided needs to be increased, access improved, and innovative action taken to raise awareness regarding transmission risks and protective behaviours.

**Figure 10: Trends in the sharing of injecting equipment and associated paraphernalia in the preceding 4 weeks among people injecting psychoactive drugs in England, 2009 to 2018**
Drug treatment

The draft action plan for the health sector response to viral hepatitis in the WHO European region\(^{(20)}\) 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 to 2012.\(^{(3)}\) Analysis of injecting drug use prevalence has now moved within PHE and models are under development to provide updated, robust estimates of the number of PWID and the proportion on OST.

Raising awareness and increasing the numbers and proportion diagnosed

Early diagnosis of HCV infection is important for the most effective treatment and care and prevention of progression to more advanced liver disease, 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,\(^{(64)}\) but are still suboptimal. In addition positive HCV test results do not always rapidly link individuals into treatment and care services.\(^{(65)}\)

Metrics to monitor trends in awareness, numbers and proportions diagnosed:

- proportion of PWID testing positive for HCV who are aware of their positive status
- proportion of patients in the NHS England Hepatitis C Patient Registry and Treatment Outcome System with late stage disease at their first recorded treatment initiation who were first diagnosed with HCV less than 2 years previously (late diagnosis marker)
- proportion of PWID receiving targeted HCV information
- numbers of GPs, and others working with groups at risk of HCV infection, completing RCGP HCV e-learning courses
- laboratory reports of hepatitis C in England
- trend in numbers tested and proportion anti-HCV and HCV RNA positive in the general population
- time interval to HCV RNA testing after testing anti-HCV positive in the general population
- trend in numbers tested and proportion anti-HCV positive in primary care
- trend in numbers tested and proportion anti-HCV positive in the main risk groups including PWID, those in secure and detained settings, those attending sexual health services, and individuals of South Asian and Eastern European origin
- trend in rates of HCV by HIV status in sexual health services, among all attendees and in MSM
- proportion of those diagnosed with HIV and coinfectcd with HCV among people accessing HIV care, by demographic/exposure group
- reported uptake of 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
• self-reported HCV status among PWID in drug treatment
• HCV prevalence among PWID reporting homelessness in the last year
• number and proportion of laboratory reports of HCV with an indicator for homelessness
• proportion of people rough sleeping with reported diagnosed HCV infection
• proportion of new receptions to prisons tested for HCV
• HCV testing cascade in the English prison estate
• rates of infection in the blood donor population, along with risk factors for acquisition of infection and rates of infection among individuals of South Asian and other white background ethnicities

Estimated proportion aware of their HCV status, and late diagnosis

Estimates of the proportions of PWID ever diagnosed and chronically infected with HCV infection can be obtained from the UAM survey.\(^4\) Throughout the period 2010 to 2016, survey data suggests that only around one half of PWID sampled in England were aware of their positive anti-HCV status (Figure 11). However, more recent UAM survey data suggest slightly higher levels of awareness, with 60.8% of PWID sampled aware of their anti-HCV positive status in 2018 (Figure 11). This figure should be interpreted with caution as changes in the 2017 UAM survey, introduced to differentiate between past and chronic HCV infection, have resulted in increased levels of non-response to this question which is likely to account for some of the increase observed in this metric. In 2018, 52.8% of PWID sampled were aware of their chronic (HCV RNA positive) infection, a reduction from that seen in the previous year (58.2%; p=0.027; Figure 11).
Figure 11: Estimated proportion of people injecting psychoactive drugs testing positive for HCV who are aware of their infection, England, 2010 to 2018

See footnotes in Appendix 3

**Data source:** Unlinked Anonymous Monitoring Survey of people who inject drugs: people injecting psychoactive drugs. (4)

The draft action plan for the health sector response to viral hepatitis in the WHO European region calls for at least 90% of PWID to be receiving targeted HCV information, education and communications (20). Progress against this goal has yet to be fully quantified in England, although during 2019, the UAM survey asked its participants if they had received any information in the last year that explained what hepatitis C is, how they could avoid catching it, or how it is treated. Preliminary data suggest that, of those who had injected drugs in the last year, 78.7% reported receiving any element of the aforementioned information with regards to HCV; this proportion is lower (73.3%) among UAM survey participants who reported that they had not injected in the last year.

Data from NHS England’s Hepatitis C Patient Registry and Treatment Outcome System can be analysed to provide insight into the numbers diagnosed at a late stage of disease. Although data on disease stage at first diagnosis of hepatitis C are not available from the Registry, it is possible to calculate the time since first diagnosis for those identified as being at a late stage of disease (defined as the presence of cirrhosis) when commencing their first HCV treatment in the Registry.
When looking at the first treatment recorded in the Register for those people with complete data on disease stage (98%), 26.1% (10,488/40,209) of patients had cirrhosis recorded at treatment initiation. Data were available in the Registry for 69.8% of these patients (7,323/10,488) to determine the interval between year of first diagnosis and year of treatment. (Figure 12). Of these patients with cirrhosis just under half (45.1%) received their first HCV diagnosis within the previous 2 years. When reviewing those with late stage liver disease as defined by Mauss et al (cirrhosis with past or current decompensation and/or HCC), 6.5% of patients had late stage liver disease at their first treatment recorded in the Registry. Data to determine the interval between year of first diagnosis and year of treatment were available for 75.8% of these patients (Figure 12). Of these patients with late stage disease at first treatment (n=2,029), 41.9% received their first HCV diagnosis within the previous 2 years.

Figure 12: Time from first diagnosis to treatment* among patients with late stage liver disease at their first recorded treatment initiation in the NHS England Hepatitis C Patient Registry and Treatment Outcome System

See footnotes in Appendix 3

Data Source: NHS England Hepatitis C Patient Registry and Treatment Outcome System, as of 18 October 2019

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. 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 (20) (see Appendix 1). While the first target of 50% being diagnosed by 2020 has already been reached in England, more needs to be done if we are to reach the 90% target by 2030. Sustained and enhanced efforts are required to find those who remain undiagnosed since infected individuals become harder to find as those who are relatively easier to engage are diagnosed. A re-doubling of effort is required so diagnosis does not become a limiting factor for ODNs as they successfully treat their diagnosed population.

To further reduce levels of undiagnosed infection, it is necessary to continue to raise awareness of HCV and roll out (and monitor) testing (14) to more individuals at risk of infection, including priority populations like PWID, the homeless, those in secure and detained settings, and to populations with close links to countries with a high prevalence of HCV infection. As time goes by, those who are no longer in contact with services because they acquired their infections many years earlier (for example, through historic injecting drug use or via blood transfusion before the introduction of routine screening of the blood supply), will represent an increasing proportion of those who remain undiagnosed.

Initiatives to raise awareness and increase numbers diagnosed

Because HCV is usually asymptomatic in the early years of infection, many individuals are unaware of their positive status. There are also other individuals who may have been tested in the past but have not accessed treatment or who have been tested for anti-HCV but not further tested for HCV RNA. Therefore, raising both professional and public awareness remains a priority, and an important component of reducing the burden of undiagnosed and untreated HCV infection.

Initiatives to support health care providers and commissioners

To support commissioners and health care providers in making decisions on prioritisation of resources and the commissioning of services, PHE has published an evidence review highlighting interventions that are effective in increasing case-finding and linkage to care for hepatitis C-infected patients. (6) HCV Action has updated their Hepatitis C Commissioning Toolkit which outlines the importance of effective commissioning in eliminating hepatitis C by setting out important commissioning responsibilities. (68) PHE is also working alongside NHS England to develop a data dashboard to provide accurate epidemiological data at ODN level. This dashboard will aid ODNs in case finding and resource allocation, highlighting deficient areas, and thus enabling better targeting of testing initiatives and monitoring of progression towards elimination goals.
A PHE drugs commissioning support pack for adults\(^{(69)}\) is also available and outlines principles that local areas might consider when developing plans for integrated alcohol and drugs prevention, treatment and recovery systems. The pack includes data and prompts relating to HCV testing and pathways to treatment and support for HCV.

**Initiatives and resources to support case finding and increase testing among the general population and the main risk groups**

To ensure that as many eligible people as possible are treated with the new more effective treatments, PHE provided data to support the NHS to identify people, registered with a GP, who have been diagnosed with HCV in the past but who may not have cleared their infections (**Hepatitis C re-engagement exercise**)\(^{(70)}\). The NHS is in the process of contacting these patients to offer testing, so those with chronic infection can be referred for assessment for treatment. Data from the NHS England Hepatitis C Patient Registry and Treatment Outcome System suggest that at least 65 individuals had already been identified and accessed treatment via this exercise by 18 October 2019.

A variety of initiatives are ongoing throughout England to increase public awareness of HCV. Many of these are specifically designed to target those at highest risk of infection, including past or current PWID, the homeless, those in secure and detained settings, and individuals of South Asian origin. 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 at Melas, Mosques and other community centres, in partnership with community leaders and local health authorities, to help raise awareness of HCV and encourage testing within the South Asian community. In addition, The Hepatitis C Trust has an outreach and testing van supported by Kings College Hospital, London, which is used to visit the most at-risk populations in areas where testing is not yet easily accessible, offering clear information and advice from trained staff with on-the-spot rapid point of care antibody testing. Before deployment, The Trust work with local services to publicise the visit, to ensure maximum engagement and that the right facilities and onward referral steps are in place. Peer-to-peer support has been shown to be particularly important, with people who have lived experience of hepatitis C delivering workshops and one-to-one support to help increase awareness of hepatitis C, encourage people to access testing, and support engagement with treatment.\(^{(71)}\) Other services include the development and implementation of patient centred HCV interventions in collaboration with drug providers, including staff training, buddying, and the provision of a confidential helpline: (+44 (0) 20 7089 6221), which received a record number of contacts (n= 4,150) in 2019.

Local authorities continue to play a central role in testing for viral hepatitis in people accessing community drug treatment services, and recent NHS procurement agreements\(^{(9)}\) facilitate additional testing in poorly served communities, including among
people who are homeless and those who do not currently access addiction services. This increased testing and treatment activity is supported by peer workers and helps vulnerable people to access testing and care. To improve access to testing for PWID, hepatitis C testing in community pharmacies for people using needle and syringe programmes who are not otherwise in contact with services, is also planned to start later this year.

As well as targeting those people who are currently injecting drugs, it is critical to find and engage those exposed to hepatitis C during past episodes of injecting drug use (who are no longer in contact with services for people with addiction) and those who may have been exposed via other routes in the past, for example those receiving blood transfusions in the UK before 1991. It is therefore important to raise awareness among GPs so they can recognise and ask about the risks for infection and offer testing to these important groups. To help with this, the NHS elimination programme is planning a new testing initiative in primary care which uses a software tool installed in participating general practice electronic patient management systems to identify and provide testing to those who have risk factors for infection.\(^{(72)}\)

It is difficult to know precisely how many people were infected with HCV via transfusion of blood, blood products or clotting factor concentrates in England before the introduction of routine HCV screening of the blood supply in September 1991. However, it is estimated that approximately 13,500 transfusion recipients were infected with HCV during the decade prior to the start of donation testing, with around 5,250 thought to be alive at the end of 1995.\(^{(73)}\) Transfusion-related transmission of hepatitis C has infected a large group of individuals, and while this group constitutes a small and declining proportion of all HCV infections in the English population today, it is believed that the national HCV lookback programme in the 1990s identified only around 13% of the total number of people living in 1995 who were thought to have been infected with HCV by transfusion between 1 January 1980 and 1 September 1991.\(^{(73)}\) It is therefore important that recipients of blood and blood products living with undiagnosed HCV infection are identified and offered testing and treatment, and the GP practice search tool, along with other resources, will help to identify these individuals.

In addition, 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. By the end of February 2017, 2,827 individuals had completed the e-learning module.\(^{(3)}\) In November 2018, the course was updated\(^{(74)}\) and by the end of February 2020, 322 individual’s had completed the updated course.\(^{(3)}\) A further free RCGP course for non-clinical workers, ‘Hepatitis C: Enhancing Prevention, Testing and Care’ is also available.\(^{(8)}\) This course was updated in September 2019, and by the end of February 2020, 2,166 individuals had completed this e-learning module.\(^{(3)}\) Other downloadable resources are also available, like those accessible via the International Network on Hepatitis in Substance Users.
On 28 July each year, World Hepatitis Day continues to provide a focus for raising awareness of HCV, and a range of resources, developed by PHE in collaboration with stakeholders, are available to help support local initiatives. Available resources include posters in English and 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. By the end of 2019, 12,657 posters featuring TV’s Dr Christian Jessen had been issued to GP surgeries throughout England via the Health and Social Care Publications Order line: (+44 (0) 300 123 1003; Product code: HEPCQUIZ001/HEPCQUIZ002). This poster campaign encourages people to take a HCV testing quiz, hosted by The Hepatitis C Trust to see whether they might be at risk of infection and should seek a test; from its 2019 launch on World Hepatitis Day (28 July) to 22 January 2020, over 1,400 people had completed the quiz (n=1,433). During this period, 34.8% (n=498) of people taking the quiz identified at least 1 risk factor for HCV infection. The most commonly reported risk factor was ever engaging in unprotected sex with someone who has or might have had hepatitis C, particularly if there were opportunities for blood-to-blood contact during sex (13.2% n=189). Potential exposure via receipt of a blood product was the second most common, with 11.9% (n=171) reporting having received a blood transfusion before September 1991 or a blood product (such as clotting factor) before 1986 in the UK. Less frequently reported risk factors included; ever having had a tattoo, piercing, acupuncture, electrolysis or semi-permanent make-up using equipment that may have been unsterilized (10.6% n=152); sharing a razor or toothbrush with a person who is HCV positive or status unknown (5.2% n=74) and ever receiving medical or dental treatment in unsterile conditions (4.5% n=65). Ever sharing a needle or other equipment for injecting drugs was the least commonly reported risk factor despite being the main route of transmission for HCV in England, with 4.4% (n=63) reporting ever sharing injecting equipment and 1.6% (n=23) stating they did not know whether they had ever shared injecting equipment.

Initiatives to raise awareness and improve testing in secure and detained settings

To improve awareness and identification of people with HCV infection within the prison estate, PHE in partnership with NHS England and HM Prison and Probation Service (HMPPS) have overseen the rollout of BBV testing, primarily at reception, in adult prisons on an ‘opt-out’ basis. A significant milestone was reached in April 2018, when after more than 4 years of phased introduction, the programme was successfully rolled out across the entire adult prison estate. The challenge moving forward will be increasing and sustaining BBV testing levels to within the upper NHS England performance standard (see section ‘Testing and diagnosis in secure and detained settings; pages 69 to 72). To this end, focus will move from programme implementation to improving the quality and uptake of testing within prisons. This aligns with NHS England’s wider ambition of eliminating HCV in England by 2025 and entails a ‘whole system approach’ that will see collaboration between public, private and third sector
agencies to improve peer support networks, identify BBV lead nurses, standardise testing offer and organise various stakeholder engagement events with a focus on improving testing and treatment rates in prisons.

The NHS’s DAA procurement deal\(^9\) includes significant investment in localised testing and treatment services for those in secure and detained settings, which is providing a welcome boost to gains already achieved following the introduction of opt-out reception testing, by extending testing to the entire prison population.\(^75\) Point of care testing approaches help to provide a rapid diagnosis of infection, which when combined with early access to pan-genotypic treatments, allows immediate initiation of treatment and the possibility of clearing hepatitis C from the prison estate. For example, a partnership with CARE UK, Gilead and The Hepatitis C Trust is already delivering a High Intensity Test and Treat (HITT) programme within all CARE UK prisons and has achieved testing uptake rates of 99% in 2 women’s prisons (HMP Low Newton and HMP Foston Hall) and an average of 90% uptake in male prisons (HMP Leeds, HMP Warren Hill and HMP Stafford); intensive test and treat programmes at all other prison sites will be delivered through NHS England elimination initiatives. When micro-elimination has been achieved across the prison estate, opt-out testing of new receptions will be important in maintaining elimination status within individual prisons.

Overall, significant progress has been made raising awareness, increasing diagnosis and improving access to treatment and care, and this has been the result of partnership working across non-government organisations, public bodies and the private sector who have come together to work on multiple initiatives to make improvements in this vitally important area.

**Testing, diagnosis and trends in infection**

In England, testing and diagnosis monitoring data are available from a variety of surveillance systems: the UAM survey of PWID,\(^4\) SSBBV Testing,\(^43\) Laboratory Reporting,\(^60\) the NDTMS, the NHSBT/PHE Epidemiology Unit Blood Donor Surveillance Scheme, GUMCAD, HARS and via HJIPs. 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 less likely to have bloodborne virus infection, is also 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 HCV (and HBV) infection are offered testing.\(^14\)
Testing and diagnosis in the general population and primary care

Over the last decade (2009 to 2018), there has been a near 90% (89.2%) increase in the number of laboratory confirmed reports\(^{(50)}\) of HCV infection in England (Figure 13). Data for DBS testing completed through private laboratories are now available and have been added from 2011 onwards. This has increased the overall number of HCV reports and improved the coverage and completeness of laboratory reporting as the majority of DBS testing through drug services is now captured through these private laboratories. In 2018, 16,216 laboratory reports of individuals testing positive for anti-HCV and/or HCV RNA were reported (Figure 13).\(^{(3)}\) Although de-duplication procedures have been undertaken to prevent double counting of individuals, the quality of reports is such that linking is unlikely to be complete. Between 2009 to 2018 of all laboratory reports, 95.6% reported gender and 98.9% reported age, of these around two-thirds (69.6%) were in men and just under half (46.4%) were in individuals aged between 30 and 44 years (Figures 13 to 15).

**Figure 13: Number of laboratory reports\(^*\) of HCV from England: 2009 to 2018.**

![Graph showing the number of laboratory reports of HCV from England: 2009 to 2018.](image)

See footnotes in Appendix 3

**Data source:** CoSurv/SGSS.\(^{(50)}\)
Figure 14: Age and sex distribution of laboratory reports of HCV from England: 2009 to 2018*,**,^.

See footnotes in Appendix 3

Data source: CoSurv/SGSS.\(^{(50)}\)
Figure 15: Age distribution of laboratory reports of HCV in England by ODN: 2018, \( ^* \), \( ^** \), \( ^* \)

See footnotes in Appendix 3

Data source: CoSurv/SGSS.\(^{(50)}\)

Trends in testing were analysed using data from 17 of the 22 sentinel laboratories where complete and consistent data have been available from January 2014 to December 2018 (Figure 16).\(^{(3)}\) Number of individuals tested rose by 27.9% between 2014 and 2018, with anti-HCV test positivity among those tested remaining relatively stable over this 5-year period (mean 2.7%; range 2.5% to 2.8%; Figure 16).
Figure 16: Number of individuals tested for anti-HCV by year, and proportion positive, in 17 sentinel laboratories: 2014 to 2018* †. ††

![Graph showing number of individuals tested and anti-HCV positivity by year from 2014 to 2018](image)

See footnotes in Appendix 3

**Data source:** Sentinel Surveillance of Blood Borne Virus Testing.[43]

Overall, 84.5% of the people testing positive for anti-HCV had a subsequent RNA test during 2014 to 2018, ranging from 80.7% to 87.0% over the 5 years. During the period 2014 to 2018, 84.4% of the RNA tests were conducted within a week of the anti-HCV positive test result, with little difference over time as 2018 data are likely to change as further RNA tests are received (Figure 17). This short interval between anti-HCV and RNA testing is indicative of reflex testing, where the RNA test is conducted on the same sample as the anti-HCV test. It is reassuring to see that a higher proportion of samples are being reflex tested, as testing the same sample reduces the possibility of an individual being lost to follow up, minimises the number of appointments required and, for those testing positive, encourages a prompter diagnosis and start to treatment.
Figure 17: Time to an RNA or antigen test among people testing positive for anti-HCV by year of anti-HCV test, in 17 sentinel laboratories: 2014 to 2018

Between 2014 and 2018, the proportion of individuals where their last reported RNA or antigen test within that year was positive decreased from 30.9% in 2014 to 10.0% in 2018 (Figure 18). This decrease presumably mirrors the persistence of anti-HCV in those who have cleared HCV RNA, and is a measure of the impact of direct acting antiviral drugs and the ongoing efforts to find and treat people with chronic HCV.
In sentinel laboratories, the number of individuals tested via GP surgeries remained relatively stable, with a small increase in number tested (4.3%) between 2014 and 2018. The proportion of tests conducted in GP surgeries identified as anti-HCV positive declined from 2.2% in 2014 to 1.8% in 2018 (Figure 19).
Figure 19: Number of individuals tested for anti-HCV by year, and proportion positive, through GP surgeries in 17 sentinel laboratories: 2014 to 2018* † ††

![Graph showing number of individuals tested and proportion positive](image)

See footnotes in Appendix 3

**Data source:** Sentinel Surveillance of Blood Borne Virus Testing.(43)

**Testing and diagnosis in sexual health services**

Data from sentinel surveillance(43) on the number of individuals tested for HCV in sexual health services shows an increase between 2014 and 2018 (37.4%; Figure 20). The proportion of individuals testing anti-HCV positive shows little change over the same time period, remaining at around 1.3% (range: 1.2 to 1.4%; Figure 20).
In people living with HIV, HCV co-infection can lead to faster progression to liver disease. In response to increased levels of HCV infection among patients with HIV, the British HIV Association announced ambitious targets for the micro-elimination of HCV in patients with HIV, with the aim of curing HCV in 80% of those co-infected by April 2019, 90% by April 2020, and 100% by April 2021.

Data collected through GUMCAD show that between 2014 and 2018, there was a decrease in rates of HCV diagnoses in all individuals attending s-SHSSs in England (Figure 20). Among attendees of negative or unknown HIV status, rates decreased by 56.3% from 48 in 2014 to 21 per 100,000 attendees in 2018, while among HIV-positive attendees, rates decreased by 78.6% from 14 to 3 per 100,000 over the same period. The relatively lower HCV diagnosis rates among HIV-positive individuals is likely due to surveillance artefact as people living with diagnosed HIV may be more likely to be tested for, and diagnosed with, HCV at their HIV care services rather than in s-SHSSs; HCV diagnoses in these individuals may therefore be under-reported in GUMCAD. As MSM are at greater risk of HCV compared to heterosexuals, rates of HCV diagnoses in

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**Figure 20: Number of individuals tested** for anti-HCV by year, and proportion positive, through sexual health services in 17 sentinel laboratories: 2014 to 2018**† ††

See footnotes in Appendix 3

**Data source:** Sentinel Surveillance of Blood Borne Virus Testing. [43]
this group are presented separately. Compared to the overall rate in all attendees, MSM showed elevated rates of HCV diagnoses regardless of HIV status. This could be driven by a greater prevalence of high-risk behaviours among MSM (that is, higher number of condomless anal intercourse partners or, for some MSM, injecting recreational drugs prior to or during sex (‘slamming’)). The higher diagnosis rates of HCV in MSM may be also attributed to more intensive hepatitis testing at s-SHSs among this group compared to heterosexuals. In 2017, there was a shift in rates among MSM by HIV status, with a steeper decline in HCV diagnoses seen in those HIV-positive than those HIV-negative or of unknown HIV status. The overall decline may be a reflection of the successful rollout of highly effective treatment (DAAs), while the relatively higher diagnosis rates in HIV-negative/unknown (vs. HIV-positive) MSM since 2017 may be a result of a recently increased risk of HCV in HIV-negative MSM, some of whom may be using HIV pre-exposure prophylaxis. The change in the relative magnitude of HCV diagnosis rates between HIV-positive and HIV-negative/unknown MSM may also be due to surveillance artefact as not all HCV diagnoses in MSM attending services for HIV care are captured in GUMCAD. Ongoing surveillance developments will help improve data quality for future years and will enable PHE to monitor the number of HCV tests in this setting.

Figure 21: Rates of HCV diagnoses by HIV status in specialist sexual health clinics per 100,000 attendees, shown for all attendees (MSM inclusive) and MSM alone, England, 2014 to 2018*

See footnotes in Appendix 3

Data Source: GUMCAD STI Surveillance system.
Data from HARS suggest that, of the people living with HIV and accessing care in England, 0.69% (598/86,997) tested positive for either an acute or chronic HCV infection in 2017 and 1.47% (1,298/88,002) in 2018, and HCV prevalence varied by exposure group (Figure 22). In 2018, HCV prevalence was highest in people living with HIV with an injecting drug use risk factor alone (27.0% in 2018) and in combination with being MSM (6.5%). HCV co-infection was least common among people living with HIV who were heterosexual men (0.8%) or women (0.5%). A new field for hepatitis C was introduced to HARS in 2016 and preliminary data are available from 2017, although completion is low; ongoing surveillance developments will help improve data quality for future years.

**Figure 22: Proportion of people accessing HIV care who have HCV by demographic group, England, 2018**

See footnotes in Appendix 3

**Data Source:** HARS.(80)

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

In the UAM survey of PWID,(4) 85.3% of the survey participants reported ever having had a voluntary confidential test (VCT) for HCV in 2018. Although UAM survey data for reported uptake of an HCV VCT increased up until 2009, the proportion of PWID reporting ever testing for HCV has showed little improvement in the last decade (Figure 23).(83) However, an increase can be seen in the proportion tested in the current or
previous year where, the proportion reporting a recent diagnostic HCV test rose from 40.4% in 2009 to 47.1% in 2018, the highest it has been in the past decade (Figure 23).\(^\text{(63)}\) Despite the plateau in the proportion ever tested, higher levels of awareness can be seen for 2017 and 2018 for ever infection (60.7% in 2017 vs 60.8% in 2018), however these data should be interpreted with caution due to a change in the UAM questionnaire at this time (see Figure 11). Although these data indicate higher levels of awareness in this group, much still needs to be done as just under half (47.2%) remain unaware of their chronic HCV infection in 2018. 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, a diagnostic HCV test, and of those that do, some will not have a repeat test at regular intervals. This suggests that more needs to be done in order to promote the offer and uptake of testing (and repeat testing) among this group and to ensure the availability of testing across a number of services so as to increase opportunities for testing.

Among UAM survey participants who reported ever being tested for hepatitis C in 2018, 64.6% reported that their most recent diagnostic HCV test was provided by a drug service, 14.4% through prison healthcare and 11.4% at their GP. Homeless services (1.9%), pharmacy (1.1%), s-SHS clinics (3.0%) and A&E (6.7%) were less commonly reported as the service providing the survey participant’s most recent HCV test.
Figure 23: Trends in self-reported uptake of VCT for HCV infection among PWID in England: 2009 to 2018

Data source: Unlinked Anonymous Monitoring Survey of People Who Inject Drugs: people injecting psychoactive drugs.\(^4\)

Among those injecting IPEDs in England and Wales, 41% reported a voluntary and confidential test for HCV in 2014 to 2015.\(^{23}\)

NDTMS data\(^{81}\) suggest that levels of HCV testing among people in treatment for drug and alcohol use are continuing to rise in England.\(^3\) Among all adults in drug and alcohol treatment who are eligible to receive a test, the proportion who have an HCV test recorded has increased from 43.2% (tax year 2009 to 2010) to 68.7% (tax year 2018 to 2019). A similar rise has been recorded in adults newly presenting to drug treatment (37.1% in tax year 2009 to 2010 compared with 54.1% in tax year 2018 to 2019). During tax year 2018 to 2019, 56.0% of all adults in drug treatment who were eligible to receive a HCV test reported ever injecting a drug; this reduced to 41.0% among those newly presenting to drug treatment. When considering the number of those in treatment who have ever injected drugs, in tax year 2018 to 2019 more than four-fifths (85.4%) were recorded as having received a HCV test, a 13.0% increase from the number seen in tax year 2009 to 2010 (56.9%). Levels of HCV testing among those who have ever injected drugs who are newly presenting to treatment have remained stable at around 74.3% (range: 72.7 to 76.2) over the last 5 years.
In tax year 2018 to 2019, more than four-fifths (84.3\%) of all adults receiving drug and alcohol treatment were recorded as having been offered a HCV test, but only just over one half of these (56.1\%) accepted this offer. Of those newly presenting to treatment, four-fifths (80.0\%) were offered testing, with only just under one half of those offered (47.2\%) accepting this offer. When considering those in treatment who have ever injected drugs, the majority were offered a test (88.9\%), and almost two-thirds of those offered (64.2\%) accepted a test in tax year 2018 to 2019. A similar proportion of those newly presenting to treatment were offered testing (84.7\%) in tax year 2018 to 2019, with just over half of those offered (53.7\%) accepting a test.

Among people who have ever injected drugs newly presenting to drug or alcohol treatment in England in tax year 2018 to 2019 who had received a HCV test, 61\% reported knowing their HCV antibody status, of whom 33\% reported they were antibody positive, and 48\% reported knowing their HCV RNA status, of whom 25\% reported they were chronically infected with HCV (RNA positive). This is comparable to that seen in PWID participating in the UAM survey during 2018 where 61\% of participants were aware of their antibody positive status and 53\% of those with a chronic infection knew their HCV RNA positive status. NDTMS data suggest that the proportion reporting to be chronically infected is similar (25\%) to that reported in the UAM survey (28\%).

Data from sentinel surveillance suggests that DBS testing far outweighs testing of venous blood in the drug service setting, and data from private laboratories are now included within laboratory reports. As a result, SSBBV now captures the majority of DBS testing conducted through drug services. While the numbers of individuals tested through drug services increased by 107.9\% between 2014 and 2016, numbers have subsequently levelled off, with a fall of 13.7\% between 2016 and 2018 (Figure 24). Anti-HCV positivity is high among individuals tested within drug services with around 1 in 5 individuals anti-HCV positive (mean:18.7\%, range 16.4 to 20.6\%), with little change over the last 4 years.
Testing and diagnoses among those homeless

In the 2018 UAM\(^4\) survey, chronic HCV prevalence was significantly higher among PWID who report being homeless in the last year (35%) than in both those who had ever been homeless, but not in the last year (24%; \(p=0.01\)) and those who had never been homeless (17%; \(p<0.001\)). Chronic prevalence among PWID reporting homelessness in the last year has increased from 29% in 2011 to 35% in 2018 (\(p<0.001\); Figure 25).
Hepatitis C in England 2020

Figure 25: Trend in HCV prevalence* among PWID reporting homelessness in the last year in England: 2011 to 2018

![Figure 25: Trend in HCV prevalence* among PWID reporting homelessness in the last year in England: 2011 to 2018](image)

See footnotes in Appendix 3

Data source: Unlinked Anonymous Monitoring Survey of people who inject drugs in contact with specialist services.(4)

When reviewing data for HCV from laboratory reports, homelessness can be identified through the allocation of a no fixed abode (NFA) code to an individual’s postal address at the time of first diagnosis. Although this can be used as an indicator of homelessness, it is important to note that NFA codes may be subject to underreporting or misclassification, as well as changes in reporting practice over time. Notwithstanding these limitations, during the period 2014 to 2018, around 7.0% of laboratory reports of HCV were among individuals with homelessness indicated (Figure 26). It is possible to obtain a crude trend in prevalence of HCV among those who are homeless, using laboratory reports of HCV among individuals with homelessness indicated and estimates of the number of people sleeping rough in England.(82) Like laboratory reports, it is important to recognise that rough sleeping figures are also subject to some uncertainty as they are based on the number of people sleeping rough on a single night, but should give an indication of trends over time. Recognising the limitations of these data sources, preliminary estimates suggest that the proportion of people rough sleeping with reported, diagnosed HCV infection increased from 21.5% in 2014 to 31.9 % in 2017, after which a decrease is observed to 28.8% in 2018 (p<0.001) (blue line; Figure 26).
Hepatitis C in England 2020

Figure 26: Laboratory reports* of HCV among those homeless/rough sleeping in England: 2014 to 2018

See footnotes in Appendix 3

Data source: CoSurv/SGSS\(^{(50)}\); Ministry of Housing, Communities & Local Government (annual Rough Sleeping Snapshot)

Testing and diagnosis among people in secure and detained settings

HCV affects a larger proportion of people in prison and other detention settings than in the wider population, principally as a result of the relatively higher levels of injecting drug use that are observed among this population.\(^{(83),(84)}\)

Prison Health Performance and Quality Indicators (PHPQIs) and HJIPs have shown a rise in HCV tests performed among new receptions to prisons from 5.3% in tax year 2010 to 2011 to 32.3% in tax year 2018 to 2019\(^{(3)}\) (2018 to 2019 data are provisional; Figure 27). It is likely that this increase in testing is due to the introduction of BBV opt-out reception testing which was agreed in October 2013 by PHE, NHS England and HMPPS.\(^{(85)}\) While this increase in testing is welcomed, current levels are still below the minimum BBV testing threshold proposed by NHS England (50% to 74%), and well below the target threshold of at least 75% uptake, which may be partly because of high prisoner turnover across the estate.
Performance in relation to the BBV opt-out testing programme is measured at the prison level by NHS England through the collection of data via HJIPs. These metrics include specific reports on the number of BBV tests offered within 72 hours of reception, the number of tests undertaken, the number of people newly diagnosed, the number of patients referred for specialist treatment following diagnosis, and the number who received treatment. These data are used by NHS England commissioners to performance manage healthcare providers in prisons and are important for identifying potential attrition points in the testing and treatment pathway. In the tax year 2018 to 2019, provisional HJIP testing data suggest that, after excluding previously confirmed cases, 78.5% of new receptions and transfers were offered HCV testing and of these 41.2% were tested (Figure 28). Of those tested, 8.1% were anti-HCV positive, 75.0% of these went on to be tested for HCV RNA and 80.6% of those tested for HCV RNA were found to be viraemic. Preliminary data suggest that only around 46.8% of those testing positive for HCV RNA received specialist referrals for HCV treatment.
Figure 28: Hepatitis C testing cascade in the English prison estate, tax year 2018 to 2019* (n= 112 prisons).

In sentinel laboratories,\(^{(43)}\) the number of individuals tested via prison services rose by 242.4% between 2014 and 2018 (Figure 29). This increase in the number of individuals tested for anti-HCV predominately occurred in 2017 and 2018 (Figure 29). Improved uptake of opt-out testing may be associated with the increase in testing, alongside elimination initiatives in prisons. The proportion of individuals tested via prison services identified as anti-HCV positive declined from 11.0% in 2014 to 6.2% in 2018 (Figure 29). This decrease is not surprising with the change to opt-out testing leading to more generalised testing rather than targeted testing of the highest risk groups.
Figure 29: Number of individuals tested for anti-HCV by year, and proportion positive, through prisons in 17 sentinel laboratories: 2014 to 2018* † ††

See footnotes in Appendix 3

Data source: Sentinel Surveillance of Blood Borne Virus Testing.(43)

Overall, these data suggest an increasing awareness of HCV across the prison estate with significant increases in testing. While levels of testing of new receptions remain sub-optimal, as does the level of treatment of RNA positive persons in prisons, work is ongoing to move from the implementation of BBV testing to improving the quality and uptake of testing along with the onward referral of those found positive within prisons. These data suggest that the prevalence of chronic HCV among those tested in prison settings is much higher than that seen in other settings, which further supports the requirement to improve testing uptake and entry into treatment among prison populations. This work will see the continued development of a number of commissioned interventions and important pieces of work by NHS England, PHE, HMPPS and other private and third sector partners in the coming years.
Testing and diagnosis in South Asian and minority ethnic populations

In sentinel surveillance,\(^{(43)}\) ethnicity is assigned using information from laboratory reports, and supplemented using name analysis software (Nam Pehcham\(^{(86)}\) and ONOMAP\(^{(87)}\)) when ethnicity is not reported. The number of individuals among the South Asian population tested for anti-HCV rose by 16.5\% between 2014 and 2018 (Figure 30). Over this period (2014 to 2018), 1.6\% tested anti-HCV positive, declining from 2.0\% in 2014 to 1.5\% in 2018 (Figure 30).

**Figure 30: Number of individuals tested for anti-HCV by year, and proportion positive, in people of South Asian\(^{\wedge}\) origin in 17 sentinel laboratories: 2014 to 2018\(^{\ast \dagger \dagger}\)**

See footnotes in Appendix 3

**Data source:** Sentinel Surveillance of Blood Borne Virus Testing.\(^{(43)}\)

Sentinel surveillance data indicates that the number of individuals tested who were identified as being of Eastern European origin (using laboratory reported ethnicity and ONOMAP\(^{(87)}\) name analysis software), increased by 44.6\% between 2014 and 2018 (Figure 31), which may partially be a reflection of increased migration from Eastern Europe to the UK over this period. Between 2014 and 2018, 4.4\% (range 3.6\% to 5.4\%) of individuals of Eastern European origin tested anti-HCV positive (Figure 31). These
figures suggest that these individuals may be at relatively increased risk of having acquired HCV and/or that testing of Eastern Europeans resident in the UK is more targeted at higher risk individuals than in the general population.

Figure 31: Number of individuals tested for anti-HCV by year, and proportion positive, in people of Eastern European origin\(^*\) in 17 sentinel laboratories: 2014 to 2018\(^*\) \(^{†} \) \(^{††}\)

![Graph showing number of individuals tested and proportion positive for anti-HCV by year from 2014 to 2018.]

See footnotes in Appendix 3

Data source: Sentinel Surveillance of Blood Borne Virus Testing.\(^{[43]}\)

Testing of the blood donor (low-risk) population

Blood donors are a cohort with a lower risk of BBV infection; monitoring infections is important as observations in this group can signal issues in the wider population. NHS Blood and Transplant currently collects blood donations from donors in England; all donations are screened for anti-HCV and RNA while repeat reactive donations/donors undergo confirmatory testing (Figure 32).\(^{[88]}\)

In 2018, 21 blood donors were confirmed positive for HCV, all of whom were new donors identified by HCV antibody screening; 81.0% (17/21) were also positive for HCV RNA (annual range for period 1999 to 2018: 61.9% to 89.3%; average 75.0%).
The rate of confirmed anti-HCV positivity in new donors during 2018 decreased to 12.4 per 100,000 donations from 18.0 per 100,000 donations in 2017 (Figure 32); this is a continuation of the decreasing trend seen in the rate of anti-HCV positivity among new donors since 1992.

**Figure 32: Rate of HCV among donations from new and repeat blood donors in England: September 1991 to 2018.**

In 2018, 13 of the 21 blood donors testing positive for anti-HCV in England were of White ethnicity, 4 were born in the UK, and 7 were born in other parts of Europe. Seventeen of the 21 were male, and 17 were aged 35 years and over. Similar to previous years, new donors of South Asian and ‘other white background’ ethnicities were disproportionately affected. Four HCV positive donors of South Asian origin were identified in 2018 (67.3 per 100,000 new donors; Figure 33), and though rates show variation year on year, rates in new donations in 2018 are lower than that seen in new donations in 2010 (138.6 per 100,000 new donors).
Figure 33: Donations from new donors of South Asian ethnicity and proportion anti-HCV positive: England, 2010 to 2018*

See footnotes in Appendix 3

Data source: NHSBT/PHE Epidemiology Unit, denominator supplied by NHSBT Donor Insight

Of the new donors of ‘other white background’ ethnicities during 2018, 7 were confirmed as anti-HCV positive in 2018, and although variation in rates can be seen in the intervening years (Figure 34), this is a decrease from 17 new donors in 2010.

When compared to new donors of White British ethnicity (3.6 per 100,000), rates of confirmed anti-HCV were 19-times higher among those of South Asian (67.3 per 100,000 new donors) or other white background ethnicities (66.6 per 100,000 new donors; Figure 34) in 2018.
When investigating the probable exposure risk among new donors during 2018 who were confirmed anti-HCV, 6 of the 21 new donors had no assignable risk factor. People with a history of injecting use are permanently deferred from donating in the UK, although donors do not always disclose this behaviour. The number of HCV positive donors reporting injecting drug use varies each year but is currently at a very low level, with only 1 donor reporting this risk behaviour in 2018 and 1 donor reporting drug use by modes other than injecting (6.7% of those with risk factors known). Possible blood contact, which covers a wide range of not necessarily causal exposures, accounted for 4 of 15 HCV cases where risk factors were known, with 2 of these exposures occurring outside of the UK. In a further 9, originating from a country with a higher prevalence of HCV than the UK without any other possible reported exposure (India (n=2), Pakistan (n=2), Afghanistan (n=1), Turkey (n=1), Lithuania (n=1), Russia (n=1) and Brazil (n=1)), was the only risk factor. Further data on donors with HCV are available from the NHSBT/PHE Epidemiology Unit Annual Review: https://www.gov.uk/government/publications/safe-supplies-annual-review.
Increasing the numbers accessing hepatitis C treatment

The GHSS on viral hepatitis 2016-2021 calls for 3 million people with chronic HCV to have been treated by 2020, and by 2030 for 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\(^{(20)}\) (see Appendix 1). Worldwide, it is estimated that 7 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 sub-optimal, with around 20% of those testing positive for HCV RNA thought to have accessed treatment.\(^{(90)}\)

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 morbidity and the number of deaths in the short and medium term.\(^{(91)}\)

From a public health perspective, DAA drugs offer a considerable advantage over previous HCV treatments as they are potent and safe orally administered drugs, and have shorter treatment durations. Together these factors allow them to be easily rolled out in community/outreach settings, improving ease of access and reducing many of the barriers to engaging those infected. While the high price of these drugs represents a major barrier to access in many countries worldwide, these medicines are now available without restriction in England.\(^{(9)}\)

Metrics to monitor numbers/access to hepatitis C treatment:

- numbers initiating HCV treatment
- annual predictions of the number of people living with HCV-related compensated cirrhosis in 2020 and 2030
- cascade of care among individuals with a positive RNA or antigen test
- proportion of people originating from, or born in, South Asia and Eastern Europe accessing treatment services
- proportion of treatments in those reporting current/recent drug injection
- proportion of referrals from services for the main risk groups; drug services and prisons
- proportion with no/mild disease stage accessing treatment
- proportion of people treated outside traditional secondary and tertiary care settings via prison and drug services
Treatment in England

NHS England commissioning data suggest significant increases in the number of people accessing treatment since 2014 (Figure 35). 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 to 5,484;[3] Figure 35). However, between tax years 2015 to 2016 and 2018 to 2019, NHS England data suggest that significantly more people (38,784 in total) accessed treatment than in earlier years. When compared with the average annual number treated during 2008 to 2014, the number treated in tax year 2015 to 2016 increased by almost one-fifth (18.3%) to 6,031. This 2015 to 2016 figure increased by 56.5% the following year to 9,440 in tax year 2016 to 2017. Since tax year 2016 to 2017 the number tested continues its upward trend, increasing by 24.5% to 11,756 people tested in tax year 2018 to 2019. This increase is the result of improved access to DAA drugs that have become available since tax year 2014 to 2015 and their ease of administration.[25-33]

In 2017, NHS England commissioned Arden and Greater East Midlands Commissioning Support Unit to produce a HCV patient registry and treatment outcome system in order to capture more detailed information for patients.[92] Since its rollout in May and June 2017, NHS HCV ODNs across England have been inputting data into the system, supported by the Commissioning for Quality and Innovation (CQUIN) framework, which supports improvements in the quality of services and the creation of new, improved patterns of care.[93] These registry data (yellow and red bars, Figure 35) suggest that over 36,000 people (n= 36,260) were treated between tax years 2015 to 2016 and 2018 to 2019, less than estimated via commissioning data (2,524 less when subsequent treatments are excluded or 1,938 less when subsequent treatments are included). Of the 586 subsequent treatments episodes, the majority (92.7%) were individuals commencing a new treatment (323 relapsed following previous treatment, 86 were non-responders, 41 had viral break-through, 29 were lost to follow-up and 64 had other/unknown reasons), with the remainder (7.3%) starting a new treatment following reinfection.
Figure 35: Provisional estimates of numbers initiating HCV treatment in England, 2007 to tax year 2018 to 2019

See footnotes in Appendix 3

Data Source: (i) NHS England for data from the hepatitis C patient registry and treatment outcome system as of 18 October 2019 (yellow bars) and for DAA drug commissioning data (blue bars) for tax years 2015 to 2016 and 2018 to 2019 (commissioning data is based on clinician intention to treat and invoicing and is subject to data quality issues and contract adjustments); (ii) Sentinel surveillance of hepatitis bloodborne virus testing for scaled estimates for the period 2012 to 2014; (iii) Estimates from Roche sales, IMS supply chain manager, and Pharmex data for 2007 to 2011

Data from sentinel laboratories can be linked to NHS England’s Hepatitis C Patient Registry and Treatment Outcome System to follow individuals through the care pathway, from testing to treatment initiation and outcome. Data linkage however is reliant on laboratories providing sufficient patient identifiable information for their test to be linked to the treatment dataset. For the period 2014 to 2018, 43,911 individuals tested positive in sentinel surveillance, of these 40.8% were successfully linked to the national treatment registry database (Figure 36). Of those linked to the registry, 86.3% commenced treatment for their HCV infection. A treatment outcome was available for 87.2% of those who commenced treatment, of whom 77.1% were reported to have achieved SVR-12 (Figure 36). Although the majority of those who started treatment were known to have successfully cleared the virus, 15.0% of patients were lost to follow up, 4.0% were reported as either having breakthrough (HCV RNA negative during treatment but became HCV RNA positive again during treatment), relapse, or non-response to treatment and 1.9% had died. When those who did not commence treatment, were lost to follow-up or who were known to have died prior to starting treatment were excluded, 91.6% achieved a SVR.
Figure 36: Treatment pathway for individuals with a positive RNA or antigen test in SSBBV between 2014 and 2018*

Impact of HCV treatment on HCV-related end stage liver disease.

NHS England figures suggest that 9,440 patients in tax year 2016 to 2017; 11,557 in 2017 to 2018; and 11,756 in 2018 to 2019 were treated for their HCV, with targets to have treated around 11,204 in tax year 2019 to 2020 and 12,435 in 2020 to 2021.

Given the numbers treated so far and current trends, statistical modelling\(^{(21)}\) predicts that during 2020 around 5,400 people would be living with HCV-related compensated cirrhosis in England and this would reduce to around 1,300 by 2030 (Figure 37), representing a fall of 57.3% by 2020 and 89.5% by 2030 compared with a 2015 baseline. Incidence of HCV-related ESLD/HCC is predicted to fall from 851 in 2020 to 321 in 2030, representing a fall of 46.3% by 2020 and 79.7% by 2030 compared with a 2015 baseline. These estimates are lower than those obtained from previous modelling, which made the conservative assumption that the same proportions would be treated across disease stages. More detailed data on treatment are now available, which indicate higher proportions of those with cirrhosis being treated, and therefore the predicted fall in HCV-related cirrhosis is greater.
Figure 37: Estimated prevalence of HCV-related compensated cirrhosis and first occurrences of HCV-related ESLD/HCC; estimates from modelling the HCV epidemic and disease burden, 2015 to 2030.(21)


These figures are based on a number of modelling assumptions.(21) Information is now available for age, disease stage and risk group of those treated, and conditional on the information on natural history of HCV and other aspects of the modelling being correct, the model will now better predict the impact of treatment on the development of HCV-related cirrhosis. However, although rates of post-SVR disease progression to ESLD in those with cirrhosis are assumed to be low, long-term outcomes are not yet well-quantified; achieving SVR may not necessarily prevent progression to ESLD. There is also evidence that achievement of an SVR after cirrhosis has developed reduces, but does not obviate the risk of, HCC.(34, 35) Longer survival because rates of ESLD are reduced may increase the relative risk of development of HCC and the influence of non-alcoholic fatty liver disease, diabetes mellitus and alcohol abuse on residual HCC risk post SVR requires further data. It is also assumed that the proportion of infected individuals who are treated does not fall over time. To maintain this will require increasing efforts in case-finding and linkage to care as the numbers who are easier to treat fall, leaving those who are relatively harder to engage. If this cannot be achieved, the impact will be correspondingly less.
Despite the uncertainties and potential limitations of modelling, a substantial reduction in severe HCV-related disease is likely; and it is inevitable that DAA drugs will have a dramatic impact in comparison to previous interferon-based therapy.\textsuperscript{(95)} When DAAs were first introduced individuals with more advanced disease were prioritised; treatment has been recommended for all those with a chronic HCV infection since 2017, regardless of disease stage, and should reduce the risk of developing severe disease in the long term. It is important to treat to prevent cirrhosis.

**Access to treatment and outcomes**

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

Data are available from the NHS England National HCV Patient Registry and Treatment Outcome System, and preliminary findings from analyses of these data, downloaded in April 2018\textsuperscript{(92)} and December 2018\textsuperscript{(24)} have previously been reported, alongside an overview of the Registry’s content and completeness.\textsuperscript{(92)} Following the addition of data downloaded from the Registry on 18 October 2019, updated information is now available and reported here. As records within the Registry are continually added, modified and updated, data will differ from that reported previously. The analysis of these updated data allows us to determine whether treatment is reaching high risk groups and helps us to understand the extent to which treatment is being delivered outside traditional secondary and tertiary care settings via outreach services.

As at 18 October 2019, the register contained 50,751 patient records from across the 3 Registry downloads from tax year 2012 to 2013 up to tax year 2019 to 2020. Of these, 1,878 were excluded as duplicate records (1,053 were patient registry entries with no treatment recorded, 35 were records of patients restarting their first treatment, 790 were duplicate treatment episodes in the registry (that is, the patient was registered by 2 providers or entered into the registry by the same provider more than once)). Where the registry data were not sufficient to clearly determine whether the record was a duplicate, first or subsequent treatment, the record was excluded (n=234). The remaining 48,639 records were for 6,999 people who had no treatment, 40,938 people with a first treatment episode in the register (Figure 38) and 702 subsequent treatments.
Focusing on the ‘first’ treatments for individuals with a treatment episode in the Register (40,938 people in total; yellow bars, Figure 38), where data were available, 71.7% of patients were male and patients’ average age was 47.7 (SD: 11.7) years. Patients were predominantly white (82.3%), with 9.0% Asian/Asian British and 3.9% classified as Black/African/Caribbean/Black British. Twenty-seven percent were born outside the UK, with 6.9% of patients with a South Asian country of birth and 5.7% with an Eastern European country of birth. The mean date of HCV diagnosis was 2011, with 43.9% of infections first diagnosed in 2013 or earlier, and 39.6% first diagnosed after 2015. Most infections were genotype 1 (51.1%) with a further 38.8% genotype 3. Data for injecting status was provided for 73.7% of the sample and showed 27.0% of patients had currently/recently injected drugs (injected in the last 3 years; an increase on the 16% reported by April 2018\(^3\)), 31.9% had never injected drugs, while most patients (41.2%) had a history of injecting drugs but were no longer injecting. The distribution of injecting status amongst those accessing treatment varied considerably by ODN (Figure 39), and it is encouraging to see a significant proportion of people who currently/recently injected drugs accessing treatment in a number of ODNs. Where route of transmission was known (66.5%), the majority acquired their infection via injecting drug use (74.4%) or via non-occupational contact with blood in a healthcare setting (9.8%), although other routes were reported.
Most patients were referred from primary care (39.6%), with 24.0% coming from General Medicine, Gastroenterology, or Infectious Diseases; increasing numbers were referred from drug services (16.4%, an increase on the 10% reported by April 2018\(^3\)) and prisons (8.8%, an increase on the 6% reported by April 2018\(^3\)) and 3.8% came via sexual health services. Referrals from other sources were relatively rare, making up less than 10% of the overall total. The distribution of referral sources amongst those accessing treatment, varied by ODN (Figure 40), and it is encouraging to see a significant proportion of people from drug services and prisons accessing treatment in a number of ODNs (for example, Nottingham, North East and Cumbria, South Yorkshire, Humberside and North Yorkshire, Kent Network via Kings, Lancashire and South Cumbria, West Yorkshire and Greater Manchester; Figure 40).

Previous treatment was reported in 19.4% of patients; 16.4% reported previous treatment with interferon/pegylated interferon (with or without ribavirin), 2.3% reported pegylated interferon (with or without ribavirin) plus a protease inhibitor, and 2.4% reported previous treatment with an all-oral interferon-free regimen. In 16.7% of patients, alcohol was reported to be a contributor to the individual’s liver disease, 6.0% were reported to be co-infected with HIV and 1.1% were reported to have renal failure.
Disease stage was well reported (98.2% complete) and showed that 26.1% of patients had either biopsy proven or a non-invasive estimate of cirrhosis prior to treatment, some of which was decompensated (9.7% of those with cirrhosis) or had past decompensation (3.8% of those with cirrhosis). Over 60% of all patients treated with disease stage recorded (63.8%, an increase on the 58% reported by April 2018(3)) had either no evidence of fibrosis prior to treatment (38.2%) or had only mild fibrosis (26.2%). The distribution of disease stage at treatment varied by ODN (Figure 41). Given that patients with severe disease were initially prioritised, it is clear that ODNs are now treating an increasing proportion of people with no, or only mild, fibrosis (Figure 41). Fibroscan results were recorded for only 83.0% of the sample, and 20.5% of these people had scores indicative of cirrhosis.(66) Of the 40,938 patients, 1.1% were reported to be post-transplant and 3.4% diagnosed with HCC.

Data Source: NHS England data from the Hepatitis C Patient Registry and Treatment Outcome System as of 18 October 2019
The majority of patients (78.5%) were treated in secondary care, with the remainder receiving treatment in either drug services (10.7%, an increase on the 5.7% reported by April 2018\(^{(3)}\)), prisons (8.3%, an increase on the 5.1% reported by April 2018\(^{(3)}\)) or elsewhere (2.5%). Again, this varied by ODN, with some notable examples, like Nottingham and Sussex, treating around a fifth of patients in drug services (Figure 42).

Amongst those in whom it was possible to determine the outcome of treatment (n= 28,079), 95.2% achieved a SVR 12 weeks after completion of treatment (0.4% breakthrough, 3.3% relapse and 1.1% non-response). A variety of DAA drugs were used, with 36.3% receiving them in combination with ribavirin.
Information on access to HCV treatment services by PWID is also available via the UAM survey. In 2018, among the UAM survey participants testing anti-HCV positive who were aware of their infection, 74.6% (409/548) reported they had ever seen a specialist nurse or doctor about their infection. Of these 31.5% (129/409) reported being offered treatment but declined; 16.9% (69/409) reported that treatment was not offered; and 51.6% (211/409) reported being offered and accepting treatment. This latter proportion (those reporting being offered and accepting treatment) increased significantly from 2011 (35.9%, 85/237, p<0.001), when the question was first asked in the UAM survey.

In prisons and other places of detention, referrals are monitored via a HJIP metric that were 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. Preliminary HJIP data from 110 prisons suggest that around 47% of those testing HCV RNA positive received specialist referrals for their HCV in tax year 2018 to 2019 (see Figure 28).
The impact of COVID-19 on HCV elimination

The COVID-19 pandemic poses a serious threat to our ability to meet WHO HCV elimination goals. Delivering WHO goals depends on effective primary prevention, case ascertainment, treatment, linkage to and retention in care; monitoring progress in meeting these objectives also requires high-quality surveillance data. Any reduction in service capacity for prevention, testing, diagnosis and treatment will delay progress towards delivery of these goals. Likewise, any reduction in the quality and timeliness of surveillance data will hamper our ability to monitor progress towards delivery of WHO goals, and to monitor the impact of changes in service capacity and effectiveness.

Changes to service provision and access.

For PWID, NSP may be reduced, both in terms of availability and accessibility and, at the time of writing, models of delivering OST are under review at a national level. The availability of BBV testing varies by provider but has largely reduced. COVID-19 guidance for commissioners and providers of services involved in assisting people who use drugs or alcohol is available.\(^{96}\)

Prison hepatitis C elimination initiatives have been paused unless clinical need is identified. Consequently, high-intensity testing initiatives are 'on hold' and all prisons are closed to external visitors, including The Hepatitis C Trust peers and hepatology specialist nurses; commencing new treatment is at the discretion of ODNs. Over the coming few weeks, some low risk people will be released from prison and discussions are currently underway about how to continue providing hepatitis C treatment in the community.

The changes to service provision described above will lead to a considerable reduction in BBV specimens submitted to primary diagnostic laboratories for testing and, consequently, referred to PHE reference laboratories for characterisation, resistance profiling and surveillance; as PHE reference laboratories are providing critical support to the COVID-19 response, turnaround times for reference services may also be affected.

Impact on PHE’s data collection, surveillance, monitoring and evaluation

It is anticipated that service providers and laboratories will experience a loss of capacity to code, enter, validate and report data submissions for routine surveillance, thereby leading to reporting delay; this will cause a delay in the analysis of surveillance data to monitor trends, evaluate interventions, and produce surveillance reports. There has also been a loss of capacity in PHE as staff are diverted to the COVID response that will further compound the delay in the production and publication of surveillance reports. Conversely, the COVID-19 response has also accelerated development of laboratory
reporting systems to PHE, such as unified reporting of negative and positive laboratory tests through PHEs Second Generation Surveillance System, which may leave a lasting positive legacy for reporting of other notifiable organisms, including hepatitis.

A reduction in HCV testing will lead to a reduction in diagnoses and a potential skewing of the case mix towards symptomatic and away from more vulnerable populations who are less able to access services that are being delivered remotely; this will further challenge the interpretation of trends that must also account for anticipated changes in incidence related to the adoption of social distancing measures and the continuation, either partial or comprehensive, of selected interventions like HCV testing and hepatitis B immunisation.

Impact on drug use behaviours, public health outcomes and longer-term service provision

The effect of social distancing on the need for drug and alcohol services is not yet known, and when social distancing measures are relaxed, any ‘rebound’ in higher risk drug use behaviour risks may lead to a rapid increase in infection transmission and outbreaks.

For PWIDs, including homeless people, changing social mixing patterns and development of new networks in temporary accommodation during this period of social distancing may influence drug use and practice, other risk behaviours and BBV transmission. Any reduction in street drug supply and purity will also lead to adverse health outcomes in PWIDs due to cutting with dangerous substances, wide variation in potency, or forcing people to switch to riskier alternatives (in the drug itself or administration route). Alongside increases in the street sale of OST, these changes would increase overdoses and drug-related hospital admissions. Any reduction in BBV testing will lead to delays in diagnosis and linkage to care, increasing the risk of poor health outcomes and onward transmission of HCV.

As the response to COVID-19 settles, there is a risk that comprehensive BBV testing is not fully restored as ‘business as usual’, leading to a permanent reduction in service provision, or changes to standard delivery models, for example from predominantly face-to-face to online or telemedicine models, which have not been evaluated for impact on clinical and public health outcomes and inequalities. Overall, while COVID-19 may drive innovative models of service delivery, if services are not adequately re-instated, systematic under-diagnosis could lead to increased inequalities. People who are already disproportionately affected by HCV are often those who may find it more challenging to access healthcare; if models of access to services change, there is a risk of widening health inequalities.
Data sources

Genitourinary Medicine Clinic Activity Dataset (GUMCAD):
https://www.gov.uk/guidance/gumcad-sti-surveillance-system

Hepatitis C Patient Registry and Treatment Outcome System:
https://www.ardengemcsu.nhs.uk/showcase/case-studies/case-studies/developing-a-clinical-registry-and-outcomes-system-for-hepatitis-c/

The HIV and AIDS Reporting System (HARS):
https://www.gov.uk/guidance/hiv-surveillance-systems#the-hiv-and-aids-reporting-system-hars

Homelessness and rough sleeping.
https://www.gov.uk/housing-local-and-community/homelessness-rough-sleeping

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

Office for National Statistics mortality data:
https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths

People who inject drugs: HIV and viral hepatitis monitoring.

PHE Sentinel Surveillance of Hepatitis C Testing:

Prison Health:
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\(^{(20)}\)

<table>
<thead>
<tr>
<th>Target area</th>
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<th>2030 targets(^{(1)})</th>
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<td><strong>Impact targets</strong></td>
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<td>Incidence: New cases of chronic viral hepatitis C infection</td>
<td>30% reduction</td>
<td>80% reduction</td>
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<td>Mortality: Viral hepatitis C deaths</td>
<td>10% reduction</td>
<td>65% reduction</td>
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<td><strong>Service coverage targets</strong></td>
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<tr>
<td>Blood safety:**Proportion of donations screened in a quality-assured manner</td>
<td>100%</td>
<td>100%</td>
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<td>Safe injections:** Percentage of injections administered with safety engineered devices in and out of health facilities</td>
<td>50%</td>
<td>90%</td>
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<td>Harm reduction: A comprehensive package of harm reduction services to all PWID(^{(97)}) 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>
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<td></td>
<td>At least 40% of opioid dependent PWID receive OST</td>
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<td></td>
<td>90% of PWID receiving targeted HCV information, education and communication</td>
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<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>
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<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>
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</tbody>
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* 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\(^{(20)}\)

** In England, 2020 and 2030 targets are already met.\(^{(98)}\)

*** 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.\(^{(99)}\) by using safety engineered devices.
Appendix 2. Preliminary indicators to monitor the impact of important interventions to tackle hepatitis C virus in England

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<th>Data source</th>
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<td>Modelled estimate(^{(21)})</td>
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<td>• Trend in HCV prevalence among PWID</td>
<td>UAM survey</td>
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<td>• Death registrations for HCV and HCV-related ESLD/HCC</td>
<td>ONS</td>
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<tr>
<td>• Mortality rates from HCV and HCV-related ESLD/HCC in persons aged ≥15 years whose HCV diagnoses have been reported to PHE</td>
<td>ONS and Sentinel Surveillance</td>
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<td>2. Reducing the number of new (incident) infections</td>
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<tr>
<td>• Estimated incidence of HCV among PWID</td>
<td>UAM survey</td>
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<td>• Prevalence of anti-HCV among recent initiates to injecting drug use (proxy measure)</td>
<td>UAM survey</td>
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<td>• Prevalence of anti-HCV among young adults (proxy measure)</td>
<td>CoSurv/SGSS</td>
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<td>• Placeholder: Prevalence of anti-HCV and HCV RNA among young adults (proxy measure)</td>
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<td>• Placeholder: Estimated number of new infections originating from injecting drug use and net migration</td>
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<td>• Proportion of opioid dependent PWID receiving OST</td>
<td>NDTMS; Hay et al.(^{(47)})</td>
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<td>• Number of people in drug treatment currently injecting drugs</td>
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<td>• Number of people in drug treatment who previously injected drugs</td>
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### 2. Increasing awareness and the numbers and proportion diagnosed

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<td>Proportion of patients in the NHS E Hepatitis C Patient Registry and Treatment Outcome System with late stage disease at their first recorded treatment initiation who were first diagnosed with HCV less than 2 years previously (late diagnosis marker)</td>
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<td>Proportion of PWID receiving targeted HCV information</td>
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<td><strong>Placeholder: Proportion of chronic HCV infection diagnosed (lower bound estimate)</strong></td>
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<td>Laboratory reports of HCV in England</td>
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<td>Trend in numbers tested and proportion anti-HCV and HCV RNA positive in the general population</td>
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<td>Trend in numbers tested and proportion anti-HCV positive in primary care</td>
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<td>Time interval to HCV RNA testing after testing anti-HCV positive in sentinel laboratories</td>
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<td>Trend in numbers tested and proportion anti-HCV positive in key risk groups including PWID, those in secure and detained settings, people attending sexual health services and individuals of South Asian and Eastern European origin</td>
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<td>Offer and uptake of HCV testing in adults – both newly presenting to, and all in, drug treatment</td>
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<td>Offer and uptake of HCV testing in adults currently or previously injecting – both newly presenting to, and all in, drug treatment</td>
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<td>CoSurv/SGSS; Ministry of Housing, Communities &amp; Local Government (annual Rough Sleeping Snapshot)</td>
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### 3. Increasing numbers accessing treatment

- **Numbers initiating HCV treatment**
- **Annual predictions of the number of people living with HCV-related compensated cirrhosis in 2020 and 2030**
- **Placeholder: Proportion of population with late stage HCV-related liver disease (cirrhosis/HCC) diagnosed**
- **Cascade of care among individuals with a positive RNA or antigen test**
- **Proportion of people originating from, or born in, South Asia and Eastern Europe accessing treatment Services**
- **Proportion of treatments in those reporting current/recent drug injection**
- **Proportion of referrals from services for key risk groups; drugs services and prisons.**
- **Proportion with no/mild disease stage accessing treatment**
- **Proportion of people treated outside traditional secondary/tertiary care settings via prison and drugs services**

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

** HCPRTOS: The NHS England Hepatitis C Patient Registry & Treatment Outcome System
Appendix 3: Footnotes for figures.

Figure 2: Trend in HCV prevalence* among people injecting psychoactive drugs in England: 2011 to 2018
* Estimates for chronic and cleared HCV infection have been adjusted to take into account anti-HCV positive samples with missing RNA status. The ratio of chronic/cleared infection was applied to the anti-HCV positive samples with missing RNA status by year and region. Note: chronic prevalence in 2017 and 2018 without adjustment for insufficients was near identical at 26% and 28% respectively.

Figure 3: Number of first patient registrations in England where post-HCV cirrhosis was given as either the primary, secondary or tertiary indication for transplant and the number of first liver transplants undertaken in patients who were HCV positive (RNA or antibody) at registration and transplant: 2009 to 2018*
* These figures are based on registry data as at 13 August 2019 and include both elective and urgent registrations.
** HCV liver registrations are defined as first transplant registrations in England where post-hepatitis C cirrhosis was given as either the primary, secondary or tertiary indication for the liver transplant.
*** First liver transplants for patients with post-hepatitis C cirrhosis as either primary, secondary or tertiary indication for transplant at registration or transplant and/or patients who were HCV positive at registration or transplant.

Figure 4: Death registrations for ESLD* or HCC in those with HCV mentioned on their death certificate in England: 2005 to 2018**
* Defined by codes or text entries for ascites, bleeding oesophageal varices, hepato-renal syndrome, hepatic encephalopathy or hepatic failure.
** Excluding deaths registered in England when the deceased’s usual residence is outside England.

Figure 5: Crude mortality rates for HCC, ESLD and HCV in persons aged ≥15 years reported to PHE as HCV antibody positive between 1998 and 2018, for the period 2005 to 2018.
* Where HCC is not also reported on the death certificate
^ Where HCV is reported as the underlying cause of death and HCC and ESLD are not reported on the death certificate

Figure 6: Estimated incidence of HCV among HIV negative* people injecting psychoactive drugs in England who reported injecting in the previous year, 2011 to 2018** (95% CI)
* Incidence is calculated among those anti-HCV negative. Those with HIV are excluded because they can have sub-optimal antibody responses as a result of their HIV infection.
** The 2016 estimate is based on a pooled estimated of incidence calculated by antibody avidity testing and HCV RNA testing. For the incidence calculations of avidity testing (2016) a fixed window period of 100 days was used, for RNA testing (2011 to 2018) a fixed window period of 51 days was used. Please note that the window periods of both measures are uncertain. Estimates for 2014 and 2015 are not available as RNA testing was not conducted on anti-HCV negative samples.

Figure 7: Prevalence of anti-HCV among recent initiates to injecting* in England 2011 to 2018
* Recent initiates are defined as PWID who commenced injecting drugs within the 3 years prior to their participation in the UAM Survey.
**Figure 8: Laboratory reports of HCV in young adults in England: 2009 to 2018***  
* Laboratory reports include positive test results for hepatitis C antibody and/or hepatitis C RNA; 2018 data are provisional and figures for previous years are subject to change as a result of late reporting and the associated de-duplication procedure. The nature of laboratory reporting and the associated de-duplication procedure is such that re-infections are not captured. In addition, patient identifiable data submitted by NHS laboratories is variable, particularly from sexual health and drug and alcohol services, which limits the ability to deduplicate. Results for children <1 year of age are excluded to rule out the likelihood of simply detecting maternal antibody.  
** Statutory notification by diagnostic laboratories was introduced in October 2010.  
^ HCV DBS testing data from 2011 onwards has now been obtained and included from additional laboratories, resulting in an increase in the overall number of HCV reports.

**Figure 9: Estimated proportion of people injecting psychoactive drugs reporting adequate* needle and syringe provision in England, 2011 to 2018**  
* Needle and syringe provision is considered ‘adequate’ when the reported number of needles received, met or exceeded the number of times the individual reported injecting in the past month.

**Figure 10: Trends in the sharing of injecting equipment and associated paraphernalia in the preceding 4 weeks among people injecting psychoactive drugs in England, 2009 to 2018**  
‡ Self-reported sharing of needles and syringes in preceding 4 weeks.  
§ Self-reported sharing of needles, syringes and other injecting paraphernalia (that is, spoons or filters) in the preceding 4 weeks.

**Figure 11: Estimated proportion of people injecting psychoactive drugs testing positive for HCV who are aware of their infection, England, 2010 to 2018**  
* Due to a change in the questionnaire for 2017, completion of the self-reported status question was lower, resulting in a higher proportion of missing data than seen in previous years for 2017 and 2018.  
** Data regarding awareness of HCV RNA result, and therefore chronic infection status, are available for 2017 onwards due to changes in the UAM survey questionnaire.

**Figure 12: Time from first diagnosis to treatment* among patients with late stage liver disease at their first recorded treatment initiation in the NHS England Hepatitis C Patient Registry and Treatment Outcome System**  
* The diagnosis to treatment interval is the number of years between the year of first diagnosis and year of first recorded treatment in the Hepatitis C Patient Registry and Treatment Outcome System, displayed as the proportion of people with cirrhosis within each diagnosis to treatment interval.  
** Late stage disease as defined by Maus et al. (67)

**Figure 13: Number of laboratory reports* of HCV from England: 2009 to 2018.**  
* Laboratory reports include positive test results for hepatitis C antibody and/or hepatitis C RNA; 2018 data are provisional and figures for previous years are subject to change as a result of late reporting and the associated de-duplication procedure. The nature of laboratory reporting and the associated de-duplication procedure is such that re-infections are not captured. In addition, patient identifiable data submitted by NHS laboratories is variable, particularly from sexual health and drug and alcohol services, which limits the ability to deduplicate. Results for children <1 year of age are excluded to rule out the likelihood of simply detecting maternal antibody.  
** Statutory notification by diagnostic laboratories was introduced in October 2010.  
^ HCV DBS testing data from 2011 onwards has now been obtained and included from additional laboratories, resulting in an increase in the overall number of HCV reports.
Figure 14: Age and sex distribution of laboratory reports of HCV from England: 2009 to 2018**,**,^  
* Laboratory reports include positive test results for hepatitis C antibody and/or hepatitis C RNA; 2018 data are provisional and figures for previous years are subject to change as a result of late reporting and the associated de-duplication procedure. The nature of laboratory reporting and the associated de-duplication procedure is such that re-infections are not captured. In addition, patient identifiable data submitted by NHS laboratories is variable, particularly from sexual health and drug and alcohol services, which limits the ability to deduplicate. Results for children <1 year of age are excluded to rule out the likelihood of simply detecting maternal antibody.  
** Statutory notification by diagnostic laboratories was introduced in October 2010(100)  
^ HCV DBS testing data from 2011 onwards has now been obtained and included from additional laboratories, resulting in an increase in the overall number of HCV reports.

Figure 15: Age distribution of laboratory reports of HCV in England by ODN: 2018**,**,^  
* Laboratory reports include positive test results for hepatitis C antibody and/or hepatitis C RNA; 2018 data are provisional and figures for previous years are subject to change as a result of late reporting and the associated de-duplication procedure. The nature of laboratory reporting and the associated de-duplication procedure is such that re-infections are not captured. In addition, patient identifiable data submitted by NHS laboratories is variable, particularly from sexual health and drug and alcohol services, which limits the ability to deduplicate. Results for children <1 year of age are excluded to rule out the likelihood of simply detecting passively transferred maternal antibody.  
** Statutory notification by diagnostic laboratories was introduced in October 2010(100)  
^ HCV DBS testing data from 2011 onwards has now been obtained and included from additional laboratories, resulting in an increase in the overall number of HCV reports.

Figure 16: Number of individuals tested for anti-HCV by year, and proportion positive, in 17 sentinel laboratories: 2014 to 2018* † ††  
* Excludes samples collected outside routine testing such as look back studies, reference testing, renal patients, children aged <1 year, and testing through oral fluid. Patient identifiable data submitted by laboratories is variable, particularly from sexual health and drug and alcohol services, which limits the ability to de-duplicate. Data are de-duplicated subject to availability of date of birth, soundex, NHS number and first initial. All data are provisional. The proportion positive is calculated using number of individuals tested. Numbers include venous and DBS testing, with retrospective DBS data added from 2014.  
** Includes all tests until a person is diagnosed positive, no tests are counted after a positive test, a person can be counted more than once.  
† Trend data does not reflect cumulative data as only locations that have consistently reported during the 5 years presented are included in trend data to remove any artificial changes in testing.  
†† The positive result is the first reported by participating laboratories and may not reflect an individual’s first diagnosis.

Figure 17: Time to an RNA or antigen test among people testing positive for anti-HCV by year of anti-HCV test, in 17 sentinel laboratories: 2014 to 2018  
* No RNA recorded could reflect where an RNA test was not conducted or the RNA test was conducted in a laboratory not included within sentinel surveillance  
** Reporting and processing time means that not all RNA tests conducted within 2019 have been processed, so the distribution is likely to change.  
† Excludes samples collected outside routine testing such as look back studies, reference testing, renal patients, children aged <1 year, and testing through oral fluid. The distribution of time to an RNA or antigen test is dependent on the laboratories reporting to SSBBV and may not reflect the distribution of RNA and antigen testing in laboratories who are not reporting to SSBBV.
Figure 18: Proportional distribution of the last reported RNA or antigen test within a year: 2014 to 2018*

*Reporting and processing time means that not all RNA tests conducted within 2019 have been processed, so the distribution is likely to change. An individual can only be counted once in a year, however can be reported within multiple years. Excludes samples collected outside routine testing such as look back studies, reference testing, renal testing, and children aged <1 year. Patient identifiable data submitted by laboratories is variable. Particularly from sexual health and drug and alcohol services, which limits the ability to de-duplicate. Data are de-duplicated subject to availability of date of birth, soundex, NHS number and first initial. All data are provisional. The proportion positive is calculated using number of individuals with an RNA or antigen test. Numbers include venous and DBS testing, with retrospective DBS data added from 2014. Service information from private laboratories testing for DBS can be limited and therefore difficult to map to geographies. Manchester Royal infirmary and Abbott (formerly Alere Toxicology PLC) conduct the majority of DBS testing, both report to SSBBV.

‘Below detection’ means that the quantitative result indicates that the result is below the lower level of quantification; it is not possible to determine whether this indicates an individual has tested negative.

Figure 19: Number of individuals tested for anti-HCV by year, and proportion positive, through GP surgeries in 17 sentinel laboratories: 2014 to 2018† ††

* Excludes samples collected outside routine testing such as look back studies, reference testing and children aged <1 year. Patient identifiable data submitted by NHS laboratories is variable, particularly from sexual health and drug and alcohol services, which limits the ability to deduplicate.
** Includes all tests until a person is diagnosed positive, no tests are counted after a positive test, a person can be counted more than once.
† Trend data does not reflect cumulative data as only locations that have consistently reported during the 5 years presented are included in trend data to remove any artificial changes in testing.
†† The positive result is the first reported by participating laboratories and may not reflect an individual’s first diagnosis.

Figure 20: Number of individuals tested** for anti-HCV by year, and proportion positive, through sexual health services in 17 sentinel laboratories: 2014 to 2018* † ††

* Excludes samples collected outside routine testing such as look back studies, reference testing and children aged <1 year. Patient identifiable data submitted by NHS laboratories is variable, particularly from sexual health and drug and alcohol services, which limits the ability to deduplicate.
** Includes all tests until a person is diagnosed positive, no tests are counted after a positive test, a person can be counted more than once.
† Trend data does not reflect cumulative data as only locations that have consistently reported during the 5 years presented are included in trend data to remove any artificial changes in testing.
†† The positive result is the first reported by participating laboratories and may not reflect an individual’s first diagnosis.

Figure 21: Rates of HCV diagnoses by HIV status in specialist sexual health clinics per 100,000 attendees, shown for all attendees (MSM inclusive) and MSM alone, England, 2014 to 2018*

* GUMCAD database retains only first known HCV diagnosis per patient. HCV test results reported to GUMCAD do not specify anti-HCV and HCV RNA tests and therefore it does not distinguish between acute and chronic infections.
** Rates of diagnoses are calculated using the number of s-SHS clinic attendees per year as the denominator and not the number tested as testing reported to GUMCAD does not distinguish between hepatitis A, B or C, and the uptake of a test could only be recorded in GUMCAD from 2015.
Figure 22: Proportion of people accessing HIV care who have HCV by demographic group, England, 2018*
* Demographic group refers to probable route of HIV acquisition. This may not reflect how a person identifies sexually.
** Proportion co-infected is calculated of all individuals attending for HIV care, including those not tested or where their testing status is unknown.

Figure 24: Number of individuals tested for anti-HCV by year, and proportion positive, through drug services in 17 sentinel laboratories: 2014 to 2018* † ††
* Excludes samples collected outside routine testing such as look back studies, reference testing and children aged <1 year. Patient identifiable data submitted by NHS laboratories is variable, particularly from sexual health and drug and alcohol services, which limits the ability to deduplicate.
** Includes all tests until a person is diagnosed positive, no tests are counted after a positive test, a person can be counted more than once.
† Trend data does not reflect cumulative data as only locations that have consistently reported during the 5 years presented are included in trend data to remove any artificial changes in testing.
†† The positive result is the first reported by participating laboratories and may not reflect an individual’s first diagnosis.

Figure 25: Trend in HCV prevalence* among PWID reporting homelessness in the last year in England: 2011 to 2018
* Estimates for chronic and cleared HCV infection have been adjusted to take into account anti-HCV positive samples with missing RNA status. The ratio of chronic/cleared infection was applied to the anti-HCV positive samples with missing RNA status by year and region.

Figure 26: Laboratory reports* of HCV among those homeless** in England: 2014 to 2018
* Laboratory reports include positive test results for hepatitis C antibody and/or hepatitis C RNA; 2018 data are provisional and figures for previous years are subject to change as a result of late reporting and the associated de-duplication procedure. The nature of laboratory reporting and the associated de-duplication procedure is such that re-infections are not captured. In addition, patient identifiable data submitted by NHS laboratories is variable, particularly from sexual health and drug and alcohol services, which limits the ability to deduplicate. Results for children <1 year of age are excluded to rule out the likelihood of simply detecting maternal antibody.

** Indicators for homelessness are based on the NFA code in the NHS spine allocated to individuals at time of first diagnosis; this indicator could be subject to underreporting, misclassification and/or changes in reporting practice over time

*** People sleeping rough are defined as “People sleeping, about to bed down (sitting on/in or standing next to their bedding) or actually bedded down in the open air (such as on the streets, in tents, doorways, parks, bus shelters or encampments). People in buildings or other places not designed for habitation (such as stairwells, barns, sheds, car parks, cars, derelict boats, stations, or ‘bashes’ which are makeshift shelters, often comprised of cardboard boxes)” The definition does not include people in hostels or shelters, people in campsites or other sites used for recreational purposes or organised protest, squatters or travellers. Bedded down is taken to mean either lying down or sleeping. About to bed down includes those who are sitting in/on or near a sleeping bag or other bedding. These figures are subject to some uncertainty and should be treated as estimates of the number of people sleeping rough on a single night and an indication of trends over time. There are a range of factors that can impact on the number of people seen or thought to be sleeping rough on any given night such as the weather, where people choose to sleep, the date and time chosen, and the availability of alternatives such as night shelters.
Figure 27: Proportion of new receptions to English prisons tested for hepatitis C: from tax year 2010 to 2011 up to tax year 2018 to 2019*

* Figures above bars are the number of prisons providing data / total number of prisons (numbers change due to closures). HJIP data are provisional.

** Robust data currently not available for the first year following introduction of HJIPs.

Figure 28: Hepatitis C testing cascade in the English prison estate, tax year 2018 to 2019* (n= 112 prisons).

* Provisional published data.** Figures above bars represent the proportion of those eligible.

** Excluding previously confirmed cases.

Figure 29: Number of individuals tested for anti-HCV by year, and proportion positive, through prisons in 17 sentinel laboratories: 2014 to 2018* † ††

* Excludes samples collected outside routine testing such as look back studies, reference testing and children aged <1 year. Patient identifiable data submitted by NHS laboratories is variable, particularly from sexual health and drug and alcohol services, which limits the ability to deduplicate.

** Includes all tests until a person is diagnosed positive, no tests are counted after a positive test, a person can be counted more than once.

† Trend data does not reflect cumulative data as only locations that have consistently reported during the 5 years presented are included in trend data to remove any artificial changes in testing.

†† The positive result is the first reported by participating laboratories and may not reflect an individual’s first diagnosis.

Figure 30: Number of individuals tested for anti-HCV by year, and proportion positive, in people of South Asian^ origin in 17 sentinel laboratories: 2014 to 2018* † ††

^ Ethnicity is assigned using information from laboratory reports, and supplemented using name analysis software (Nam Pehcham(86) and ONOMAP(87)) when ethnicity is not reported.

* Excludes samples collected outside routine testing such as look back studies, reference testing, renal patients and children aged <1 year. Patient identifiable data submitted by NHS laboratories is variable, particularly from sexual health and drug and alcohol services, which limits the ability to deduplicate.

** Includes all tests until a person is diagnosed positive, no tests are counted after a positive test, a person can be counted more than once.

† Trend data does not reflect cumulative data as only locations that have consistently reported during the 5 years presented are included in trend data to remove any artificial changes in testing.

†† The positive result is the first reported by participating laboratories and may not reflect an individual’s first diagnosis.

Figure 31: Number of individuals tested for anti-HCV by year, and proportion positive, in people of Eastern European origin^ in 17 sentinel laboratories: 2014 to 2018* † ††

^ Ethnicity is assigned using information from laboratory reports, and supplemented using name analysis software (Nam Pehcham(86) and ONOMAP(87)) when ethnicity is not reported.

* Excludes samples collected outside routine testing such as look back studies, reference testing, renal patients and children aged <1 year. Patient identifiable data submitted by NHS laboratories is variable, particularly from sexual health and drug and alcohol services, which limits the ability to deduplicate.

** Includes all tests until a person is diagnosed positive, no tests are counted after a positive test, a person can be counted more than once.

† Trend data does not reflect cumulative data as only locations that have consistently reported during the 5 years presented are included in trend data to remove any artificial changes in testing.

†† The positive result is the first reported by participating laboratories and may not reflect an individual’s first diagnosis.
Figure 32: Rate of HCV among donations from new and repeat blood donors in England: September 1991 to 2018.*  
* 1991-1995 includes Wales, from 1995-2016 North Wales is included.

Figure 33: Donations from new donors of South Asian ethnicity and proportion anti-HCV positive: England, 2010 to 2018*  
* Includes North Wales to 1 April 2016.

Figure 34: Donations from new donors of other white background ethnicities and proportion anti-HCV positive: England, 2010 to 2018*  
* Includes North Wales to 1 April 2016.

Figure 35: Provisional estimates of numbers initiating HCV treatment in England, 2007 to tax year 2018 to 2019  
*Treatment initiations include first treatments episodes (n=36,260) and subsequent treatment episodes (n=586). For treatment episodes with missing start dates (n=797) or start dates in the future (n=16), their distribution across the years was assumed to mirror that of those patients with treatment start dates and they were allocated to treatment years accordingly. Within the register there were 35 records where individuals with a first treatment recorded restarted this treatment (3 in tax year 2015 to 2016; 10 in 2016 to 2017; 19 in 2017 to 2018; and 3 in 2018 to 2019) and there were 234 records where it was not possible to determine whether the record was a treatment restart, the same or a subsequent treatment (2 in tax year 2015 to 2016; 18 in 2016 to 2017; 34 in 2017 to 2018; and 180 in 2018 to 2019).

Figure 36: Treatment pathway for individuals with a positive RNA or antigen test in SSBBV between 2014 and 2018*  
* RNA and antigen tests were linked to the NHS England’s Hepatitis C Patient Registry and Treatment Outcome System using NHS Number, Name, DOB, hospital number and excludes samples collected outside routine testing such as look back studies, reference testing, renal testing, and children aged <1 year. Patient identifiable data submitted by sentinel laboratories is variable, particularly from sexual health and drug and alcohol services, which limits the ability to link datasets or de-duplicate. Data are de-duplicated subject to availability of date of birth, soundex, NHS number and first initial. All data are provisional.
References


