Hepatitis C in the UK 2019

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

Public Health England exists to protect and improve the nation’s health and wellbeing, and reduce health inequalities. We do this through world-leading science, research, knowledge and intelligence, advocacy, partnerships and the delivery of specialist public health services. We are an executive agency of the Department of Health and Social Care, and a distinct delivery organisation with operational autonomy. We provide government, local government, the NHS, Parliament, industry and the public with evidence-based professional, scientific and delivery expertise and support.

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: Helen Harris, Annastella Costella, Ross Harris and Sema Mandal.

© Crown copyright 2019
You may re-use this information (excluding logos) free of charge in any format or medium, under the terms of the Open Government Licence v3.0. To view this licence, visit OGL. Where we have identified any third party copyright information you will need to obtain permission from the copyright holders concerned.

Published September 2019
PHE publications
gateway number: GW-704

PHE supports the UN
Sustainable Development Goals

Corporate member of the Plain English Campaign
Commited to clearer communication

339

2
Foreword

Duncan Selbie
Chief Executive

Hepatitis C infection (HCV) is a bloodborne virus that can cause life-threatening liver disease, but thanks to new treatments it can be cured.

HCV largely affects people from marginalised and under-served groups, such as people who inject drugs.

New estimates suggest that around 143,000 people in the UK are living with chronic HCV infection; a figure which is down more than 20% on 2015.

There has also been a 19% fall in deaths reported between 2015 and 2018, and the World Health Organization target of reducing HCV-related mortality by 10% by the year 2020\(^{(1)}\) has been exceeded 3 years early in the UK.

Of those people living with HCV, around 95,600 are thought to be undiagnosed, and this underlines the importance of continued efforts to find and treat those people. It is also equally important to help those who are diagnosed but untreated to engage with treatment services. To achieve this there has been a rise in partnerships across the system, new resources and re-engagement exercises to help vulnerable people navigate the system.

The findings of this report tell us that much good work has been done, but there remains lots to do if we are to eliminate hepatitis C as a major public health threat by 2030. It is therefore essential that we continue to work cohesively together to pool our resources and maximise our impact.
## Contents

About Public Health England .................................................. 2  
Foreword ................................................................................. 3  
Glossary of abbreviations ...................................................... 5  
Acknowledgements ................................................................. 6  
Executive summary ................................................................. 8  
Background .............................................................................. 11  
Introduction ........................................................................... 12  
Burden of HCV infection ........................................................ 14  
Monitoring service coverage ................................................. 15  
  Adequate harm reduction ...................................................... 16  
  Increasing the proportion diagnosed .................................... 18  
  Increasing the numbers accessing hepatitis C treatment ...... 21  
Monitoring impact ................................................................... 23  
  Reducing HCV-related morbidity and mortality ..................... 23  
  Reducing the number of new (incident) infections ............... 26  
Data sources ............................................................................ 29  
Appendices .............................................................................. 31  
  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.\(^{(11)}\) .................................................. 31  
  Appendix 2. Preliminary UK indicators to monitor the impact of key interventions to tackle hepatitis C virus ................................................................. 32  
References ............................................................................... 33
# Glossary of abbreviations

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>DAA</td>
<td>Direct acting antiviral</td>
</tr>
<tr>
<td>ESLD</td>
<td>End-stage liver disease</td>
</tr>
<tr>
<td>GHSS</td>
<td>Global Health Sector Strategy</td>
</tr>
<tr>
<td>HCC</td>
<td>Hepatocellular carcinoma</td>
</tr>
<tr>
<td>HCV</td>
<td>Hepatitis C virus</td>
</tr>
<tr>
<td>HES</td>
<td>Hospital Episode Statistics</td>
</tr>
<tr>
<td>HIS</td>
<td>Hospital Inpatient System</td>
</tr>
<tr>
<td>NSP</td>
<td>Needle and syringe programme</td>
</tr>
<tr>
<td>NESI</td>
<td>Needle Exchange Surveillance Initiative</td>
</tr>
<tr>
<td>NSGVH</td>
<td>National Strategic Group on Viral Hepatitis</td>
</tr>
<tr>
<td>OST</td>
<td>Opioid substitution treatment</td>
</tr>
<tr>
<td>PHE</td>
<td>Public Health England</td>
</tr>
<tr>
<td>PWID</td>
<td>People who inject drugs</td>
</tr>
<tr>
<td>RNA</td>
<td>Ribonucleic acid</td>
</tr>
<tr>
<td>SHPN</td>
<td>Scottish Health Protection Network</td>
</tr>
<tr>
<td>SVR</td>
<td>Sustained virological response</td>
</tr>
<tr>
<td>UAM</td>
<td>Unlinked Anonymous Monitoring Survey</td>
</tr>
<tr>
<td>WHO</td>
<td>World Health Organization</td>
</tr>
</tbody>
</table>
Acknowledgements

Contributors

Noel Craine, Claire Edmundson, David Goldberg, Ellen Heinsbroek, Sharon Hutchinson, Neil Irvine, Andrew McAuley and Jane Salmon.

Our thanks also go to Helen Bennett, Ruth Campbell, Geoff Dusheiko, Graham Foster, Mike Gent, Rachel Giffen, Megan Glancy, Adele Graham, Rachel Halford, Jake Hall, Brendan Healy, Samreen Ijaz, William Irving, Conall McCaughey, Annelies McCurley, Neil McDougall, Allan McLeod, Gareth Morgan, Siew Lin Ngui, Eamonn O’Moore, Norah Palmateer, Amy Plimmer, John Poh, Berry Puyk, Giri Shankar, Justin Shute, Josie Smith, Shanley Smith, Steve Taylor, Amanda Weir, April Went, and Alan Yeung for their contributions to the report.

In England and Wales, we would like to thank the clinicians, microbiologists, public health practitioners and other colleagues who have contributed to the surveillance systems used in this report. We would like to thank drug service staff who support, and participants in, the Unlinked Anonymous Monitoring (UAM) survey of people who inject drugs; Hospital Episode Statistics (HES), NHS Digital (NHS Digital is the trading name of the Health and Social Care Information Centre. Copyright © 2019, re-used with the permission of NHS Digital. All rights reserved); NHS England for supplying treatment monitoring data for 2015/16, 2016/17, 2017/18 and 2018/19 in England; the Office for National Statistics (ONS carried out the original collection and collation of the data but bears no responsibility for their future analysis or interpretation); and the NHS Wales Informatics Service (NWIS). Retrospective testing of UAM survey data (2011-2016) for HCV RNA was performed as part of the EPIToPe study, funded by the National Institute for Health Research (NIHR) Programme Grants for Applied Research programme (Grant Reference Number RP-PG-0616-20008). The views expressed are those of the author(s) and not necessarily those of the NIHR or the Department of Health and Social Care.

In Scotland, we would like to thank the blood bourne virus (BBV) co-ordinators in each NHS Board, the Hepatitis C Clinical Database Monitoring Committee, hepatitis C testing laboratories and treatment centres, services providing injecting equipment, Glasgow Caledonian University, the West of Scotland Specialist Virology Centre and Scottish Government for their support and contributions to the surveillance systems used in this report.

In Northern Ireland, we would like to thank the Northern Ireland Hepatitis B and C Managed Clinical Network, the Regional Virus Laboratory and Hepatology Service, the Northern Ireland Statistics and Research Agency, the information staff of the Health
Protection Service, and Health Intelligence Staff, Public Health Agency for providing the data used in this report.
Executive summary

On 28 May 2016, the World Health Assembly adopted a Global Health Sector Strategy (GHSS) on viral hepatitis for the period 2016-2021. This strategy introduced the first-ever global targets for viral hepatitis control, including a 30% reduction in new cases of hepatitis B and C by 2020 and a 10% reduction in mortality. This report summarises UK progress towards meeting these targets, to help support focused action to eliminate hepatitis C as a major public health threat by 2030 at the latest.

Latest estimates suggest that in 2015 around 182,400 people (95% credible interval 162,300-203,500) in the UK were living with chronic hepatitis C virus (HCV) infection, and that this figure has fallen by around 20% to 143,000 in 2018 (95% CI: 122,400, 164,500). Of these remaining 143,000 chronic infections, two-thirds (95,600; 95% CI 78,300, 113,800) are thought to be undiagnosed.

Injecting drug use continues to be the most important risk factor for HCV infection in the UK, with data from UK surveys of people who inject drugs (PWID) suggesting that in 2018, just over half of PWID (54% in England, Wales and Northern Ireland; 57% in Scotland in 2017-18) tested positive for HCV antibody, and just over one quarter had evidence of current infection (27% in the England, Wales and Northern Ireland; 31% in Scotland).

Latest data from surveys of PWID suggest that around two thirds of participating PWID in the UK were aware of their HCV antibody positive status (72% among those who had injected in the past 6 months in the Needle Exchange Surveillance Initiative (NESI) survey in Scotland in 2017-18; 63% among those who had injected in the past year in the Unlinked Anonymous Monitoring (UAM) survey in 2018 in the rest of the UK). In 2018, 48% of PWID sampled in the UAM survey and 60% of those sampled in the NESI survey (2017-18) were aware of their current persistent viraemic (HCV RNA positive) infection. These figures are higher than, but consistent with, modelled estimates of the proportion of prevalent chronic infection diagnosed in England, Northern Ireland and Wales in 2018 (33%) since the modelled estimates are based on those infections that are reported, and levels of awareness of infection are expected to be higher amongst those PWID who are in contact with services.

Although the WHO target of 50% of those ever infected in the WHO European region knowing their status by 2020 looks to have already been met in the UK, more needs to be done if we are to reach the 90% target by 2030.

Mortality data suggest a fall in death registrations from HCV-related end-stage liver disease (ESLD) and hepatocellular carcinoma (HCC) of 13% between 2015 and 2017, with provisional data suggesting a further fall of 6% in 2018. Thus with a fall in deaths of...
around 19% by 2018, from the 2015 baseline, the WHO target of reducing HCV-related mortality by 10% by the year 2020\(^{(1)}\) will have been exceeded 3 years early in the UK and hence a reduction of at least 65% by 2030\(^{(1)}\) seems achievable.

The fall in mortality from HCV-related ESLD and HCC observed since 2015 is consistent with increased treatment and sustained virological response rates (SVR) achieved with new direct acting antiviral (DAA) drugs that have taken place over the past five years (an increase in treatment of 6% in 2018/19, and of 138% when compared to pre-2015 levels). Importantly the fall is largely the result of a reduction in HCV-related ESLD rather than HCV-related HCC. As observed elsewhere,\(^{(4),(5),(6),(7)}\) this suggests that while DAA drugs may lead to a reduction in deaths from ESLD, and a reduction in the incidence of de novo HCC, the risk of HCC is not altogether obviated after successful clearance of HCV in those with cirrhosis before treatment.

Our ability to sustain the current increase in numbers accessing treatment will be limited by our capacity to find and treat the undiagnosed, and to help those who are diagnosed but untreated to engage with local treatment services. Throughout the UK, a variety of enterprising partnerships support this. In England, resources have been developed to help people recognise their risk for infection, and innovative procurement agreements with substantial investment from NHS England and the pharmaceutical industry have been secured to help improve the numbers diagnosed and accessing treatment. This increased testing and treatment activity will be supported by peer workers who will help vulnerable people to navigate the system to achieve cure. Re-engagement exercises have been launched in England, Northern Ireland and Wales to identify people who have been diagnosed with HCV in the past but who may not have accessed new HCV treatments. Point of care testing is also being piloted and rolled out in various settings throughout England and Wales, including the prison estate. In Wales, testing of clients of substance misuse services has become a key performance indicator for these services. In Scotland, new recommendations on HCV case-finding and access to care have been published\(^{(8)}\) offering practical guidance to improve HCV testing, diagnosis, and treatment uptake. In Northern Ireland, there has been a focus on screening and harm reduction education amongst PWID; actions include raising awareness of the risks of blood-borne virus transmission among PWID and those working with these populations. There has been increased testing of PWID for blood-borne viruses including the introduction of dried blood spot testing, and work is underway to increase the ready availability of clean injecting equipment.

In contrast to the improvements in liver related mortality, data from UK surveys of PWID\(^{(2),(3)}\) do not suggest any reduction in numbers of new HCV infections over recent years; prevalence of infection in recent initiates to drug use in the UK were similar in 2017 (22%) to those observed in 2008 (24%), and incidence of infection was higher in 2018 (17.6 per 100 person years) than in previous years (6.9% per 100 person years in 2011), although there is substantial uncertainty in the estimates and significant
variability between years. In 2017 and 2018, only an estimated 3 out of every 5 (63%) PWID in the UK reported having adequate needle/syringe provision for their needs. Taken together, these data suggest that the WHO GHSS call to reduce new cases of chronic HCV by 30% by 2020 and 80% by 2030,\(^{(1)}\) represents a significant challenge for UK HCV prevention and treatment services.

Overall, with unrestricted availability of new DAA drugs, and the expansion of initiatives to increase diagnosis and referral into care, the UK is well-placed to meet WHO GHSS goals to reduce HCV-related morbidity and mortality, provided case-finding and diagnosis can keep pace with planned treatment scale-up. At the other end of the spectrum, there is little evidence to support a fall in the number of new HCV infections; if GHSS goals to reduce these levels are to be reached, then a radical change in our response to tackling HCV acquisition in PWID is required.

We are interested in receiving your feedback on this report and would be grateful if you could take two minutes to complete a short survey (closing date: 31 March 2019):


Thank you.
Background

The World Health Organization (WHO) estimates that viral hepatitis B and C affect 325 million people worldwide, leading to about 1.4 million deaths a year.\(^9\) Viral hepatitis has the second highest mortality of any infectious disease after tuberculosis, and 9 times more people are infected with hepatitis than HIV.\(^9\)

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

In 2015, an estimated 71 million people were living with chronic HCV infection (1% of the global population) and an estimated 1.75 million new infections occurred worldwide.\(^10\) Closer to home in the WHO European Region, it was estimated that more than 14 million people were living with chronic HCV infection in 2015, with an estimated 565,000 new infections in 2015.\(^10\) Recognising the differences in viral hepatitis epidemiology between regions, a draft action plan for the health sector response to viral hepatitis in the WHO European region was published, outlining the relatively more ambitious proposals for targets and milestones to tackle infection in this region (see Appendix 1).\(^11\)

In the UK, injecting drug use continues to be the most important risk factor for HCV infection, with just over half of PWID in England and Wales thought to have been infected, with levels being lower in Northern Ireland (22%)\(^12\) but higher in Scotland (57%).\(^3\) Prevalence of infection in the wider population varies regionally, being concentrated in areas with high levels of current/past injecting drug use and high numbers of black and minority ethnic populations who have close links to countries with a high prevalence of HCV infection. HCV disproportionately affects populations who are marginalised and underserved and those who have poorer access to healthcare and have poorer health outcomes.

In the UK, we are working towards elimination of HCV as a major public health threat, by 2030 at the latest, working with our partners to improve prevention, raise awareness, increase testing and get more individuals diagnosed and into treatment and care.
Introduction

HCV is a bloodborne virus that frequently results in chronic infection. The disease may be asymptomatic, and symptoms may not appear until the liver is severely damaged. As a consequence, many individuals with chronic HCV infection remain undiagnosed and fail to access treatment. These individuals can then present late with complications of HCV-related ESLD and primary liver cancer, which have poor survival rates.

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

National action to tackle HCV is already underway, and being further developed across the UK. In Wales, a circular from the Chief Medical Officer for Wales has been issued outlining measures to support elimination of viral hepatitis, including improved access to DAAs, and the NHS and its partners are working to a Liver Disease Delivery Plan to 2020. In Scotland, action is guided by the updated Sexual Health and Blood Borne Virus Framework, 2015-2020 and their newly released Hepatitis C Elimination Strategy. In England, the NHS have concluded a procurement deal for antiviral treatments that involves a partnership approach to elimination, with the pharmaceutical industry contributing their expertise and support in a series of new initiatives. These elimination initiatives involve substantial new investment from both the manufacturers of antiviral agents and NHS England, and are aimed at accelerating elimination progress. PHE captures wider public health activities in their annual HCV report for England and their cross-agency National Strategic Group on Viral Hepatitis (NSGVH) continues to provide strategic direction and advice around viral hepatitis in England. In Northern Ireland, the Hepatitis B and C Managed Clinical Network publishes its annual report containing information on the epidemiology of hepatitis C, as well as public health and clinical activities related to hepatitis C disease prevention and control.

Informed by GHSS goals and targets (see Appendix 1), countries have been called upon to develop, as soon as practicable, ambitious national goals and targets for 2020 and beyond. These are intended to take into consideration the country context, including the country-specific nature and dynamics of viral hepatitis, the populations affected, the structure and capacity of the health care and community systems, as well as the resources that can be mobilised. Targets also need to be feasible and developed based on country realities, the best possible data, trends and responses, and should be monitored through a set of standard, measurable indicators.
This report summarises the progress tackling HCV in 2018 and the scale of the challenge ahead, to help support focused action in the UK countries to eliminate hepatitis C as a major public health threat by 2030 at the latest. To track our progress, the impact of key interventions in the following two impact areas are monitored:

- reducing transmission of HCV
- reducing morbidity and mortality due to HCV and its complications

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

- the adequacy of harm reduction in PWID
- the proportion of infected people who are diagnosed/aware of their infections
- the numbers, and ultimately the proportion, of infected people accessing treatment

The UK indicators (see Appendix 2), reported in the sections that follow, describe our progress so far and set out the scale of the challenge ahead.
Burden of HCV infection

Latest estimates suggest that in 2015 around 182,400 people (95% credible interval 162,300-203,500) in the UK were living with chronic HCV infection (Figure 1). The prevalence is estimated to have fallen in recent years, and was predicted to have declined to around 143,000 in 2018 (95% CI: 122,400, 164,500). Of these 143,000 chronic infections, two-thirds (95,600; 95% CI 78,300, 113,800) are thought to be undiagnosed (Figure 1). The modelling approach used to estimate prevalence in England, Northern Ireland and Wales is under continued development and makes use of multiple sources of routine surveillance data to track progress over time. (21)

Figure 1. Estimated chronic prevalence of HCV infection in the UK, 2008-2018

Injecting drug use continues to be the most important risk factor for HCV infection in the UK, being cited as the risk in more than 90% of all laboratory reports where risk factors have been disclosed. (19), (24) While injection of drugs in the UK, largely driven by heroin use, is thought to be declining generally, there have been increases in the injection of...
specific drugs in some parts of the country, especially stimulants and primarily cocaine/crack.\(^{(12),(3)}\) These are associated with more frequent injection, more damage at the injection site and with the spread of viral and bacterial infection.

Data from UK surveys of PWID (UAM Survey\(^{(2)}\) in England, Northern Ireland and Wales, and the NESI Survey\(^{(3)}\) in Scotland) show that in 2018, just over half of PWID (54% in the England, Wales and Northern Ireland; 57% in 2017-2018 in Scotland) had evidence of ever being infected with HCV, and just over a quarter had evidence of current viraemic (HCV RNA positive) infection (27% in England, Wales and Northern Ireland; 31% in Scotland; Figure 2).

**Figure 2. Trend in HCV prevalence among people injecting psychoactive drugs in the UK: 2011 to 2018**

A comprehensive response to hepatitis C requires the implementation of effective, high-impact interventions along the full continuum of hepatitis services, including interventions for prevention, testing, treatment and care. Mathematical modelling\(^{(25)}\) suggests that HCV could be eliminated as a major public health threat by 2030 if the response reaches the service coverage targets set out in the GHSS on viral hepatitis\(^{(1)}\) (see Appendix 1).

In the UK, eliminating hepatitis C as a major public health threat by driving down HCV-related mortality and preventing new infections from occurring is potentially feasible with the tools currently available. Investment is expanding in many parts of the three core
intervention areas: (i) ensuring adequate harm reduction for PWID, (ii) increasing the proportion of infected individuals who are diagnosed/aware of their infections, and (iii) increasing the proportion of infected individuals who access and complete treatment, achieving a SVR.

Adequate harm reduction

Harm reduction interventions for PWID, including access to sterile injecting equipment and effective drug dependence treatment, can prevent and control HCV among PWID. Optimal access to clean injecting equipment and opioid substitution treatment (OST) is crucial in curbing the spread of HCV, particularly given that they also have the potential to reduce the risk of reinfection after treatment.

Globally, harm reduction for PWID falls far short of the 2030 GHSS target of 300 sterile needles and syringes provided per PWID per year with, on average, only 27 syringe and needle sets distributed per PWID each year. However, these inevitably somewhat arbitrary figures do not make any allowance for individual differences in need or secondary distribution. Therefore, in order to better reflect the adequacy of needle/syringe provision, data from UK surveys of PWID (UAM Survey and NESI Survey) are presented here on self-reported adequacy of needle/syringe provision (Figure 3). In this metric, needle/syringe provision is considered ‘adequate’ when the reported number of needles received, met or exceeded the number of times the individual injected.

Figure 3 shows that in 2017 and 2018, around three out of every five PWID in the UK (63% in 2018) reported having adequate needle/syringe provision for their needs.
In the 2018 UAM survey, 18% of people currently injecting psychoactive drugs reported direct sharing of needles and syringes; this level has plateaued in the last decade from 19% in 2008. When including the sharing of spoons mixing containers or filters as well as needles and syringes, the proportion of those reporting sharing is higher at 39% which is also similar to that reported in 2008 (40%). In NESI, levels of reported needle and syringe sharing in the past six months remained low in 2017-18 (10%), and reported sharing of injecting equipment (spoons/cookers, filters, water) in the past six months in 2017-18 (26%) was almost half the proportion reported in 2008-09 (48%).

These findings indicate that, while the majority of PWID may be accessing needle and syringe programmes (NSPs), the amount of apparatus and equipment provided needs to be increased and provision better targeted. NSPs can also be an important setting for delivering testing and prevention information to PWID and an important route into drug treatment and recovery.
Increasing the proportion diagnosed

Early diagnosis of HCV infection is important for the most effective treatment and care, yet globally only 20% (14 million) of those infected have been tested and know their status. In the UK, levels of awareness of infection are well above the 20% global average, but are still suboptimal, and positive test results do not always successfully link individuals into treatment and care services.

Up until 2016, surveys have suggested that only around one half of PWID sampled in the UK were aware of their anti-HCV positive status (Figure 4). However, data from the latest surveys suggest higher levels of awareness in 2017 and 2018, with around two thirds of PWID sampled in the UK aware of their HCV antibody positive status (Figure 4). In 2018, 48% of UAM participants who had injected in the last year were aware of their current (HCV RNA positive) infection, a slight fall compared to the previous year (55%; Figure 4). In NESI, 60% were aware of their current (HCV RNA positive) infection in 2017/18 (Figure 4).

Figure 4. Estimated UK-wide proportion of PWID testing positive for HCV* who are aware of their infection, 2011-2018**

---

* Figures for England, Northern Ireland and Wales are for PWID who had injected during last year. Figures for Scotland are for PWID who injected in the past 6 months.
** The figure uses data from two ongoing survey programmes, which together cover the whole of the UK. Data from these two studies have been weighted by the size of the adult (16-64) population (2011, 2013, 2015 and 2017 UK figures weighted on mid-year population estimates for each respective year and then combined). Data from the NESI is not annual. UK data are only presented for those years where both surveys are conducted.
---

Data sources: (i) needle Exchange Surveillance Initiative (NESI), Glasgow Caledonian University, University of Edinburgh and Public Health Protection Scotland, and (ii) Unlinked Anonymous Monitoring (UAM) survey of people who inject psychoactive drugs — conducted by Public Health England with assistance from Public Health Wales and the Public Health Agency Northern Ireland.
Modelling used to obtain estimates of chronic HCV prevalence in 2015\textsuperscript{(21)} can also be used to derive a lower bound estimate of the number of diagnosed individuals in England, Wales and Northern Ireland. The model tracks the infected population over time, with the proportion diagnosed in each year being informed by laboratory reports of first diagnoses of HCV. After accounting for spontaneous clearance, mortality and viral clearance following treatment, and including equivalent data for Scotland, the proportion of remaining chronic infections that were undiagnosed in 2018 in the UK is estimated to be two thirds (67\%; Figure 1). Of those ever chronically infected (i.e. including those that have been diagnosed, treated and achieved SVR) the proportion undiagnosed in 2018 was estimated to be 47\% in the UK. These are upper bound estimates as not all HCV positive tests are reported; they also relate to estimated prevalence. The modelled estimate of 33\% diagnosed is lower, but consistent with, the UAM survey estimate of around 50\% aware of their current HCV infection status, since modelled estimates are based on those infections that are reported, and levels of awareness of infection are expected to be higher amongst those PWID in contact with services. Although 67\% of current untreated chronic infection being undiagnosed represents the upper bound, this figure may flag a warning that testing and diagnosis might not be keeping up with the necessary planned treatment targets.

The GHSS on viral hepatitis\textsuperscript{(1)} and the draft action plan for the health sector response to viral hepatitis in the WHO European region\textsuperscript{(11)} call for a major increase in the diagnosis of chronic HCV infection, with 50\% of ever infected people in the WHO European region knowing their status by 2020 and 90\% by 2030 (see Appendix 1). While the first target may have already been reached in the UK, it is recognised that more needs to be done if we are to reach the 90\% target by 2030.

In England, resources have been developed by PHE including a HCV testing quiz, posters, 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. In England, local authorities continue to play a central role in testing for viral hepatitis in people accessing community drug treatment services, and the new NHS procurement agreements will allow additional testing in poorly served communities, including people who are homeless and those who do not currently access addiction services. This increased testing and treatment activity will be supported by peer workers and will help vulnerable people to access testing and care. The new procurement deal in England also includes very significant investment in testing and treatment services for those in secure and detained settings, which will provide a welcome boost to gains already achieved following the introduction of opt-out testing across the prison estate;\textsuperscript{(19)} point of care testing approaches will be used to provide a rapid diagnosis of infection, which will be combined with early access to pan-genotypic treatments allowing immediate initiation of treatment within the prison setting. Support for prisoners will be provided by The Hepatitis C Trust, who have developed information leaflets and poster campaigns to inform prisoners of the options available to them. To improve access to testing for PWID,
there are also plans to fund the introduction of hepatitis C testing in community pharmacies for people using needle and syringe programmes in 2019/20.\(^{(33)}\) As well as targeting those people who are currently injecting drugs, it is also 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 addictive disorders). Thus, it is key to raise awareness among GPs so they can recognise and ask about the risks for infection and offer testing. To help with this, the elimination programme includes a new testing initiative in primary care which uses a software algorithm installed in participating general practice systems to identify and provide testing to those who may be at risk of infection.

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.\(^{(34)}\) Free online training resources and an e-learning module on hepatitis C (and hepatitis B) are available for GPs, from the Royal College of General Practitioners (RCGP), to help with this, and other downloadable resources, like those accessible via the International Network on Hepatitis in Substance Users,\(^{(35)}\) have also been developed.

In Scotland, a Short-Life Working Group on behalf of the Scottish Health Protection Network (SHPN), has published new recommendations on HCV case-finding and access to care.\(^{(8)}\) The purpose of the recommendations is to support ambitious new HCV treatment targets set by Scottish Government, with the aim of eliminating HCV as a major public health concern in Scotland by 2024.\(^{(18)}\) The recommendations offer practical guidance for Health Boards in Scotland to improve HCV testing, diagnosis, and treatment uptake in a variety of settings, including drug use services, community pharmacies, injecting equipment providers, and prisons.

In Wales, work is being co-ordinated via the Liver Disease Delivery Plan to increase diagnosis in a range of settings. Work has been undertaken in some health boards to pilot HCV case finding using electronic GP patient records, and point of care testing is being piloted in various settings, including prisons. In addition, the national microbiology service are now undertaking reflex PCR testing on antibody positive dried blood spot samples and diagnostic testing is being developed in pharmacies. A key performance indicator related to diagnostic HCV testing, reportable to Welsh Government, has also been introduced in substance misuse services.

In Northern Ireland, there has been a focus on screening and harm reduction education amongst PWID; actions include raising awareness of the risks of blood-borne virus transmission among PWID and those working with these populations, including staff working in hostels for the homeless. There has also been increased testing of PWID for blood-borne viruses, including the introduction of dried blood spot testing, and work is underway to increase the availability of clean injecting equipment.
Increasing the numbers accessing hepatitis C treatment

Among people diagnosed with chronic HCV infection globally, an estimated 7% started treatment in 2015 (1.1 million people).\(^\text{(10)}\) As of 2015, a cumulative total of 5.5 million people with chronic HCV had ever received treatment, although the majority of these treatments were older, less effective interferon-based regimens.\(^\text{(10)}\) The GHSS on viral hepatitis\(^\text{(1)}\) and the draft action plan for the health sector response to viral hepatitis in the WHO European region\(^\text{(11)}\) call for treatment coverage of people diagnosed with chronic HCV in the European region to reach 75% in 2020 and 80% by 2030. (see Appendix 1)

In the UK, new DAA drugs have transformed the treatment landscape, offering a fast and effective cure to the vast majority who receive them.\(^\text{(36)}\) While prevention activities are key in reducing the rate of new infections, numbers already infected would remain high for many years without effective HCV treatment, which has already begun to reduce the number of HCV-related deaths and transplants in the UK.\(^\text{(37),(19)}\)

While the high price of new drugs remains a major barrier to access in many countries worldwide, negotiations in the UK are leading to reduced prices and these medicines are being rolled out, without restriction, in accordance with national recommendations.\(^\text{(38-43),(44),(45),(46)}\) in all UK countries. In England, the NHS concluded a procurement deal for antiviral treatments involving a partnership approach to elimination with the pharmaceutical industry. These elimination initiatives involve substantial new investment from both the manufacturers of antiviral agents and NHS England to accelerate elimination. PHE have also provided data to support the NHS in England to identify people, registered with a GP, who have been diagnosed with HCV in the past but who may not have cleared their infections, to ensure that as many eligible people as possible are re-engaged and treated with the new more effective treatments.\(^\text{(47)}\) The NHS is in the process of contacting these patients to offer testing, so those with current infection can be referred for assessment for treatment. Public Health Wales are undertaking a similar HCV re-engagement exercise in Wales.

In Scotland, National Procurement has also secured substantial reductions in drug prices. In line with these price reductions, Scottish Government has set new targets for treatment, increasing the number of people treated to 3,000 per year from 2020/21 onwards, to help achieve elimination by the end of 2024.\(^\text{(18)}\)

In Northern Ireland, a call-back exercise is ongoing to trace and treat patients who were previously diagnosed with chronic active infection and referred, but who never attended clinic. Patients are contacted and offered testing to confirm their infection status before referral for assessment for treatment.

Figure 5 summarises estimates of the numbers initiating HCV treatment in the UK since 2007. Between 2009 and 2014, estimates suggest that numbers initiating HCV...
treatment in the UK remained relatively stable at around 6,400 initiations per year (6,390; Range: 6,130, 6,808). Since 2014 however, numbers accessing treatment have increased dramatically, more than doubling pre-2015 levels to reach an all-time high of 15,200 treatment initiations by 2018/19, with a rise of 6% (5.9%) between 2017/18 and 2018/19 (Figure 5). This is the result of improved access to the new DAA drugs that have been coming online since 2014/15, and by 2018 around one-third of individuals who had been infected with HCV are estimated to have been successfully treated.

Figure 5. UK-wide estimates of numbers initiating HCV treatment, calendar years 2007-2014 and financial years 2015/16-2018/19* **

In the 2018 UAM survey (England, Northern Ireland and Wales), among those participants testing positive for HCV antibodies who were aware of their infection, 39% had seen a specialist nurse or hepatologist for their HCV infection and been offered and accepted treatment; this is an increase from 20% in 2011. In the 2017-18 NESI survey (Scotland), 50% of those who self-reported as eligible for treatment (those that answered they have HCV or had cleared HCV through treatment) reported ever having received therapy for their HCV infection, which is a marked increase from 28% in 2015-16. Of those who had ever received therapy, 44% had received it in the last year; this compares to 36% in 2015-16.

---

* Data for Scotland are only available by financial year between 2007 and 2014 so these have been grouped with calendar years. For example, data for calendar year 2011 are grouped with data for the financial year 2011/12
** Data for Wales not available for 2007-2010. One Health Board is missing in 2014 and data, where available, are subject to data quality issues.
†† Data for 2018/19 are provisional.

Monitoring impact

Reducing HCV-related morbidity and mortality

Up until 2014, mortality from HCV has been on the increase in the UK (37) as people who acquired their infections decades earlier progressed to advanced liver disease and access to less effective and poorly tolerated treatments had been inadequate. (9),(8),(48) New DAA drugs however, can be administered to patients with cirrhosis and even decompensated cirrhosis and it is apparent from the data that the new DAA drugs are already having an impact across the UK, with premature HCV-related liver mortality declining. (19),(37)

Morbidity – Reducing the incidence of HCV-related ESLD/HCC

In England, new cases of HCV-related ESLD/HCC are monitored using Hospital Episode Statistics (HES), the Patient Episode Database in Wales (PEDW) and the Hospital Inpatient System (HIS) in Northern Ireland. New cases are identified by first linking all episodes of ESLD or HCC for an individual using their unique patient identifier and then linking these to hospital records with a diagnosis of HCV since 2004 (since 2000 for Northern Ireland). Once these are linked, a case of HCV-related ESLD or HCC is classified as ‘new’ if no previous episodes of ESLD or HCC for that individual are found in at least the previous five years (In England, less than 1% of ESLD/HCC episodes are estimated to have had a previous episode more than five years earlier). In Scotland, data on new ESLD/HCC hospitalisations are obtained via record-linkage of Scotland’s National Hepatitis C Diagnoses Database to the national database on hospital admissions, as well as laboratory HCV PCR test data; thus, first-time ESLD/HCC hospitalisations for all individuals diagnosed with HCV infection in Scotland, and last known to be HCV RNA positive at time of admission, are reported (including those with, but also those without, hepatitis C recorded on their hospital admission/discharge record). (49), (50), (51) Together these analyses have enabled us to produce UK-wide preliminary estimates of new cases (incidence) of HCV-related ESLD/HCC. (37) However, it is important to recognise the limitations of these estimates since different datasets were utilised in different UK countries, HCV may be unreported in HES, and patient episodes can only successfully be linked when identifiers exist in HES/PEDW/HIS to allow this.

This year updated estimates of new cases of HCV-related ESLD/HCC are available for Wales, Scotland and Northern Ireland (Figure 6), but not for England/the UK due to problems with HES data that have prevented cases in England being linked across years. (37) NHS Digital are taking steps to mitigate this error so data are available to PHE in future years. In the interim, Figure 6 shows the incidence of HCV-related ESLD/HCC to have fallen by 67% in Scotland between 2013 and 2018, and to have decreased since 2013 in Wales.
Figure 6. Preliminary estimates of incidence* of HCV-related ESLD**/HCC in UK countries: 2010-2018*

Mortality – Reducing deaths from HCV-related ESLD/HCC

Between 2005 and 2015, deaths registrations from HCV-related ESLD and HCC more than doubled in the UK, rising from 209 in 2005 to a peak of 468 in 2015 (Figure 7). After 2015, deaths from HCV-related ESLD and HCC have begun to decrease, falling by 13% (13.2%) between 2015 and 2017 (Figure 7). Over the last year, provisional data suggest a further fall of 6% (6.4%), although as these data are provisional, they should be interpreted cautiously.

The fall in deaths of 19% (18.8%) by 2018, from a 2015 baseline, indicates that the WHO target to reduce HCV-related mortality by 10% by 2020 (see appendix 1) will have been exceeded 3 years early in the UK. The fall in registered deaths is likely to be the result of increased access to DAA drugs that were introduced from 2014/15 (Figure 5), particularly for those individuals with more advanced disease.\(^{(52)}\) Because HCV is not always reported on the death certificates of those who die with ESLD/HCC and are HCV infected,\(^{(53)}\) actual numbers of deaths may be higher and reporting of HCV infection may vary over time.\(^{(53)}\)
While death registrations for HCV-related ESLD/HCC in the UK have fallen overall in recent years, this is largely accounted for by a fall in HCV-related ESLD (Figures 7 and 8). 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.\(^{(4),(5),(6),(7)}\) It is important to note that whilst HCC risk may persist post SVR, recent evidence does not support any increase in risk of HCC associated with interferon-free regimens when compared with interferon-based regimens.\(^{(54)}\) The data presented here support the view that treatment outcomes are best when HCV infection is treated at an earlier stage, and underlines the importance of ongoing surveillance for HCC in those who clear the virus at more advanced stages of disease or who have co-factors for HCC.\(^{(55)}\)

As more infected individuals access new therapies in the UK (Figure 5), the GHSS on viral hepatitis’ call for a 65% reduction in HCV deaths by 2030\(^{(1)}\) (see Appendix 1) seems within our reach, provided current improvements in numbers accessing treatment can be sustained.
Reducing the number of new (incident) infections

Monitoring the impact of prevention measures on the incidence of infection remains a challenge as incident infection is difficult to measure directly. Ideally we would monitor the actual or estimated number of new chronic HCV infections that arise annually in PWID as well as any that result from net migration and other sources, over time. However, the former is difficult to estimate because most acute infection is asymptomatic and undiagnosed and there is considerable uncertainty around the number of people in the UK who are injecting drugs.\cite{22,56-58} Added to this, it is also difficult to select a sentinel population of PWID for monitoring that is representative of PWID as a whole. As a result, a number of methods are used in the UK to generate information to provide insight into likely trends in incidence over time.\cite{59}

In England, Wales and Northern Ireland, recent transmission of HCV among those who had injected psychoactive drugs has been explored among participants in the UAM
survey of PWID,\(^{(12)}\) the methods for which have been described elsewhere.\(^{(37)}\) In Scotland, recent transmission of HCV is also explored among participants in the NESI Survey of PWID.\(^{(3)}\) For those years where incidence estimates are available from both surveys, data are combined after weighting them by the sizes of the adult (16 to 64 years) populations for the countries they cover (blue line, Figure 9).

These data suggest that incidence of infection has not declined in recent years being higher in 2018 (17.6, 95% CI 11.0, 26.8) than in 2011 (6.9, 95% CI 4.2, 10.6; \(P<0.001\), Figure 9), although there is substantial uncertainty in the estimates, and significant variability between years \((P=0.034\) for the UAM data).

**Figure 9. Estimated UK-wide incidence of HCV among PWID, 2011-2018**

Because most new infections are acquired via injecting drug use, the prevalence of infection among recent initiates to injecting drug use can be used as a proxy measure of incidence. When taken together, data from UK surveys of PWID in contact with services (UAM\(^{(2)}\) & NESI\(^{(3)}\)) provide no evidence of any fall in incidence over recent years, with levels of infection in 2017 in the UK (22%, 95% CI 16, 28) being similar to those observed in 2008 (24%, 95% CI 20, 28), and levels of infection in the UAM survey in 2018 being higher still (31%, 95% CI 25,31) (Figure 10). Confidence intervals are fairly wide however, due to the relatively small (and declining) numbers of recent initiates in the sample; the power to detect a reduction is therefore low.
UK estimates of HCV incidence suggest that the call to reduce new cases of chronic HCV by 30% by 2020, and 80% by 2030\(^{(1)}\) (see Appendix 1), represent a significant challenge for UK HCV prevention and treatment services. If these goals are to be achieved, a comprehensive and effective range of interventions to prevent and treat HCV infections among PWID is required.
Data sources

- Health Protection Scotland: www.hps.scot.nhs.uk/


- MSD: www.msd-uk.com

- Needle Exchange Surveillance Initiative in Scotland (Health Protection Scotland, University of West of Scotland, Glasgow Caledonian University and West of Scotland Specialist Virology Centre): https://www.hps.scot.nhs.uk/a-to-z-of-topics/needle-exchange-surveillance-initiative-nesi/

- NHS National Services Scotland (Health Protection Scotland and Information Services Division): https://nhsnss.org/


- Northern Ireland Hepatitis B and C Managed Clinical Network: http://www.hepbandcni.net/

- Northern Ireland Statistics and Research Agency: www.nisra.gov.uk

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

- Patient Episode Database for Wales, NHS Wales Informatics Service: http://www.wales.nhs.uk/nwis/page/52490

- Pharmex: https://www.gov.uk/government/collections/commercial-medicines-unit-cmu
• PHE Operational Delivery Network profile tool: 
  https://www.gov.uk/government/publications/hepatitis-c-commissioning-template-for-
estimating-disease-prevalence

• PHE Sentinel Surveillance of Hepatitis C Testing: 
  https://www.gov.uk/government/publications/sentinel-surveillance-of-blood-borne-
virus-testing-in-england-2015

• Public Health Agency: www.publichealth.hscni.net

• Public Health Wales: www.publichealthwales.wales.nhs.uk/

• Roche: www.roche.co.uk/

• Unlinked Anonymous Monitoring survey of PWID in contact with specialist drug 
viral-hepatitis-monitoring
### 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.\(^{(11)}\)

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

* Abstracted from the WHO Global Health Sector Strategy for Viral Hepatitis\(^{(1)}\) and modified to reflect the draft action plan for the health sector response to viral hepatitis in the WHO European Region\(^{(11)}\)

** In England, 2020 and 2030 targets are already met \(^{(62)}\)

***In England, 2020 and 2030 targets are already met in the health care setting as the UK follows the EU Directive for the prevention of sharps injuries in the health care setting \(^{(63)}\) by using safety engineered devices.
### Appendix 2. Preliminary UK indicators to monitor the impact of key interventions to tackle hepatitis C virus

<table>
<thead>
<tr>
<th>Impact and Service Coverage Monitoring Areas</th>
<th>Preliminary UK Indicator</th>
</tr>
</thead>
</table>
| **Burden**                                  | • Prevalence of chronic HCV infection (modelled estimates)  
• Estimated prevalence of chronic HCV among PWID |
| **Impact**                                  | 1. Reducing HCV-related morbidity and mortality  
• Estimated incidence of HCV-related ESLD/HCC  
• Deaths from HCV-related ESLD/HCC |
|                                             | 2. Reducing the number of new (incident) infections  
• Estimated incidence of HCV among PWID  
• Estimated prevalence of anti-HCV among recent initiates to drug use |
| **Service coverage**                        | 1. Adequate harm reduction  
• Estimated proportion of PWID reporting adequate needle/syringe provision |
|                                             | 2. Increasing the proportion diagnosed  
• Estimated proportion of PWID testing positive for HCV, who are aware of their infection  
• Modelled estimates of the proportion diagnosed |
|                                             | 3. Increasing numbers accessing treatment  
• Number initiating HCV treatment |
References


