

Hepatitis C in the UK 2023

Working to eliminate hepatitis C as a public health threat

Data to end of 2021

Produced in collaboration with:

Public Health Agency Northern Ireland **Public Health Scotland Public Health Wales**







lechyd Cyhoeddus Public Health

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Foreword by Professor Susan Hopkins

The Hepatitis C in the UK report comes at a pivotal point in the elimination of hepatitis C. In May 2022 the UK government adopted the World Health Assembly's updated global strategies that support the World Health Organization's (WHO) ambition to eliminate viral hepatitis by 2030. UKHSA has prioritised work to reduce the harmful impact to health of hepatitis C, hepatitis B and HIV. In this report we review the progress that has been made in the UK towards the WHO elimination targets for hepatitis C with data to the end of 2021.

The number of people living with chronic hepatitis C (HCV) infection in the UK has fallen dramatically by over 47% from 2015 to 92,900 in 2021. If the rate of current reduction in HCV prevalence continues, the UK should be on track to achieve an 80% reduction in chronic HCV prevalence, compared to 2015, by 2030. The decline in numbers of people living with chronic HCV infection in the UK is largely due to improved testing and access to treatment with substantial progress made to increase the numbers of individuals accessing direct-acting antivirals (DAAs). Across UK nations, almost 90% of those who were diagnosed with HCV infection and linked to a treatment database (and so linked to care) over the past 5 years have commenced treatment for HCV. However, only three-quarters of patients who were diagnosed with chronic HCV in the UK between 2015 and 2020 were linked to specialist HCV treatment services and less than three-quarters of those who started their treatment were recorded as having successfully cleared their infection. UKHSA is working with partners to support people living with chronic HCV to engage with specialist care through a series of engagement and reengagement exercises with primary care and Operational Delivery Networks to ensure that those not linked to care are supported to do so.

We should also be encouraged by the considerable progress that has been made in reducing HCV-related mortality. The UK has surpassed the WHO absolute target of mortality \leq 2 per 100,000 and exceeded the 2020 WHO target of a 10% reduction in mortality compared to 2015; with the target met in each country. Further declines in mortality will require redoubling of effort to ensure that there is early diagnosis and linkage to care and treatment of those who remain undiagnosed.

We cannot be complacent, however. Almost three-quarters of those still living with chronic HCV remain unaware of their infection; testing for HCV and access to treatment was significantly impacted by the coronavirus (COVID-19) pandemic and has yet to fully recover. Reaching those who remain undiagnosed will require novel approaches recognising the syndemic nature of HCV, such as opt-out blood-borne virus testing in Emergency Departments which is being rolled out by the NHS and evaluated by UKHSA and academic partners. Early data suggests that this programme is identifying individuals living with blood-borne virus infection and through this programme successfully engaging into care.

The data suggests that prevention has failed to keep pace with gains made in other areas; the number of new infections and re-infections poses a threat to England meeting the WHO

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incidence targets. Injecting drug use remains the main driver of HCV transmission in England and needle and syringe provision has remained suboptimal across all UK nations; it remains vitally important to ensure that there is adequate harm reduction available and the government's Drug Strategy and investment of £780 million to rebuild drug treatment and recovery services, including for young people and offenders, with effective partnerships aims to prevent 1,000 deaths.

The achievements to date are testament to excellent collaborative work across multiple sectors and fields in the UK. But now, more than ever, it is essential that all system partners sustain and strengthen the actions that we need to achieve and maintain elimination of HCV and reduce inequalities.

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Professor Susan Hopkins Chief Medical Advisor at the UK Health Security Agency (UKHSA)



Introduction

Hepatitis C virus (HCV) is a bloodborne virus that damages the liver. Over time, persistent infection can lead to cirrhosis, liver failure or cancer. Globally, HCV causes around 290,000 deaths and 1.5 million new infections each year ($\underline{1}$). Injecting drug use (previous or current) continues to be the most important risk factor for HCV infection in the UK.

In May 2022, the World Health Assembly updated its global strategy for viral hepatitis for the period 2022 to 2030, renewing the ambitions of the 2016 to 2021 strategy with a focus on absolute targets and system integration and promoting the WHO ambition to eliminate viral hepatitis as a public health threat by 2030. In 2021, WHO introduced absolute impact targets for incidence (\leq 5 per 100,000 persons and \leq 2 per 100 for people who inject drugs (PWID)) and mortality (\leq 2 per 100,000 persons) from hepatitis C.

This report summarises the UK's progress towards the WHO elimination targets for HCV infection with data to end of 2021. Updates on data for England are also included where possible.

Summary

The main messages outlined in this report are as follows:

- Latest modelled estimates suggest that around 92,900 (95% credible interval 76,000 to 116,800) people in the UK were living with chronic HCV infection at the end of 2021, equivalent to a prevalence estimate of 0.17% (95% Crl 0.14% to 0.21%) among adults aged 16 and over. Whilst incidence is challenging to measure directly, the decline in HCV prevalence by 47.2% from 2015 suggests that significant progress has been made. The UK should be on track to achieve an 80% reduction in chronic HCV prevalence, compared to 2015, by 2030 at the rate of current reduction in HCV prevalence.
- 2. The estimated proportion of PWID ever infected with HCV remains relatively stable, and combined with recent decreases in chronic HCV infection among PWID between 2017 and 2021 (2) this suggests that increased access to treatment, rather than improved prevention of infection due to improved harm reduction, may be the main driver of the reduction in prevalence of chronic HCV infection among PWID.
- 3. Just under half of PWID ever infected with HCV (who injected in the past year) were aware of ever having HCV infection in 2021, and 28.3% of people currently living with chronic HCV were aware of their infection.
- 4. Across UK nations, almost 90% of people who were diagnosed with HCV infection and linked to care initiated treatment for HCV; however, this figure is lower (67.2%) where all people diagnosed with HCV and who have a recorded NHS or CHI (Community Health Index) number, regardless of whether they have been linked to care or not, are considered.
- All countries in the UK have surpassed the WHO absolute target of mortality ≤2 per 100,000; the consistent reduction in HCV-related morbidity and mortality in the UK since 2015 may be a reflection of the improved and earlier access to direct-acting antivirals (DAAs).
- 6. More needs to be done to prevent new infections and reinfections; provision of adequate harm reduction remains a challenge and poses a threat to the UK's ability to achieve and maintain elimination; the UK Government's 10-year Drug Strategy released in April 2022 outlines significant investment for harm reduction to be used by local authorities.
- Whilst much has been done to improve HCV testing and access to HCV treatment, levels have not yet recovered to pre coronavirus (COVID-19) pandemic levels (<u>3</u>). More needs to be done to engage individuals with care.

1. Reducing the incidence of HCV infection

Table 1a. WHO impact targets for reducing incidence of HCV infection

Impact target area	WHO GHSS 2020 target relative to 2015 baseline (<u>4</u>)	WHO GHSS 2030 target relative to 2015 baseline (<u>4</u>)	WHO interim guidance elimination validation target: annual absolute HCV incidence rates (5)
Incidence: New cases of chronic viral hepatitis C infection	30% reduction	80% reduction	Less than or equal to 5 per 100,000 persons (less than or equal to 2 per 100 for PWID)
Alternative (proxy) measurement indicators			Reduction in HCV viraemia prevalence by 80% from 2015 baseline (in general population and PWID)

Table 1b. Progress in the UK

Measure	Progress in the UK	Progress in England	Progress in Northern Ireland	Progress in Scotland	Progress in Wales
Proxy measure: reduction in HCV viraemia prevalence from 2015 baseline (in general population)	47.2% to 2021	43.3% to 2021* (36.8% to 2020)	Not available	Not available	Not available
Proxy measure: reduction in HCV viraemia prevalence from 2015 baseline (in PWID)	Not available	55.1% to 2021** (34.8% to 2020)	Not available	51.3% to 2019 to 2020***	Not available

Notes for Table 1

* Provisional and subject to change as further work on the modelling is carried out.

** During 2020 and 2021, recruitment to the UAM Survey was impacted by coronavirus (COVID-19) pandemic. As a result, there were changes in the geographic and demographic profile of people taking part. This should be taken into account when interpreting data for these years. For more information see the <u>UAM annual data tables report</u>.

*** NESI 2019 to 2020 was suspended before completion due to the COVID-19 pandemic. As a result, the sample includes data from 8 out of 11 mainland NHS Boards originally included in the sampling framework. The 3 missing NHS Boards in 2019 to 2020 account for just 10% of the total NESI sampling framework.

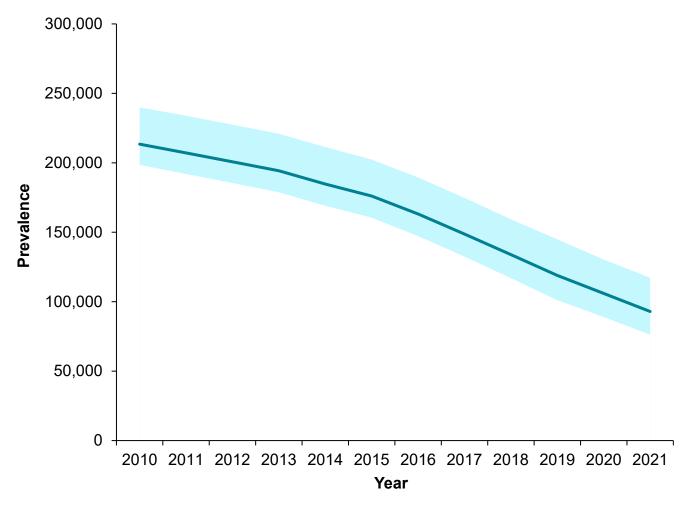
Further information in <u>Technical notes</u>.

1.1 Estimated HCV prevalence in the UK in the general population

In the UK latest estimates suggest that by the end of 2021 around 92,900 people (95% Crl 76,000 to 116,800) were living with chronic HCV infection, equivalent to a prevalence estimate of 0.17% (95% Crl 0.14% to 0.21%) among adults aged 16 and over. Less than 1% of infections are estimated to be in those aged less than 16. Estimated chronic prevalence in the UK has declined by 47.2% since 2015 and the estimated fall between 2019 and 2021 is around 26,000 (21.9%). At the rate of current reduction in chronic HCV prevalence the UK should be on track to achieve an 80% reduction, compared to 2015, by 2030.

Modelled estimates of prevalence in Scotland, Wales and Northern Ireland are included to produce the UK total. Due to challenges measuring incident infections directly, the UK uses the reduction in HCV viraemia prevalence as a proxy measure.

In England latest modelled estimates suggest that in 2021, around 74,600 people (95%Crl: 59,100 to 97,500) were living with chronic HCV infection, equivalent to a prevalence estimate of 0.16% (95% Crl 0.13%-0.21%). The proportion of people aged 16 and over who have ever been infected with HCV and who continue to live with chronic HCV infection has declined to 37.4% in 2021 (95% Crl 33.2% to 42.7%) from 59.9% in 2015 95% Crl 57.4% to 62.6%).





Data source: Estimates are based on available data in each nation on: the size of at-risk populations (such as PWID), HCV prevalence and incidence data among risk groups, HCV diagnoses, treatment data and incidence of severe liver disease (from hospital data). See references <u>6 to 11</u> for approaches used to generate estimates.

Note for Figure 1

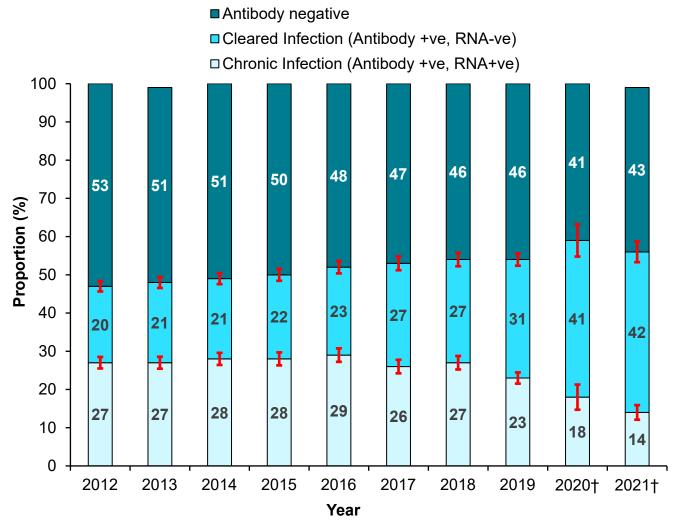
* Provisional and subject to change as further work on the modelling is carried out.

1.2 Estimated HCV prevalence among PWID in England, Northern Ireland, and Wales

Injecting drug use (previous or current) continues to be the most important risk factor for HCV infection in the UK (12 to 15). Data from the Unlinked Anonymous Monitoring (UAM) Survey of PWID suggests that the prevalence of chronic HCV infection among PWID in England, Northern Ireland and Wales has significantly declined since 2017, which corresponds with the increased availability of DAAs (direct-acting antivirals) (2).

In 2021, just over half of PWID surveyed in the UAM (56.8%) had evidence of ever being infected with HCV; this proportion has remained relatively stable. However, the proportion that had evidence of current (HCV Ribonucleic acid (RNA) positive) infection dropped to 14.4% in 2021 compared to 17.9% in 2020 and 28.1% in 2015. More than twice the proportion of people surveyed in 2021 had cleared a previous infection than in 2012, suggesting better treatment outcomes and/or improvement in access/engagement with services. It should be noted that recruitment to the UAM survey in 2020 and 2021 was significantly impacted by COVID-19. Therefore, figures should be interpreted with caution for this period given changes in the geographic, demographic and risk factor profile of participants during this period.

Figure 2a. Trend in HCV prevalence among people injecting psychoactive drugs (with 95% Confidence Intervals): 2012 to 2021 (England, Northern Ireland, and Wales*, **, ***, †)



Data sources: Unlinked Anonymous Monitoring survey of people who inject psychoactive drugs (<u>16</u>) conducted by UKHSA with assistance from Public Health Wales and the Public Health Agency Northern Ireland

Notes for Figure 2a

* Retrospective analysis of HCV RNA (2011 to 2016) was performed as part of the EPIToPE study, funded by the National Institute for Health Research Programme Grants for Applied

Research programme (Grant Reference Number RP-PG-0616-20008). The views expressed are those of the authors and not necessarily those of the NIHR or the Department of Health and Social Care.

** Estimates for chronic and cleared HCV infection have been adjusted to take into account antibody-HCV positive samples with missing RNA status. The ratio of chronic/cleared infection was applied to the antibody-HCV positive samples with missing RNA status by year and region.

*** Figures may not sum due to rounding.

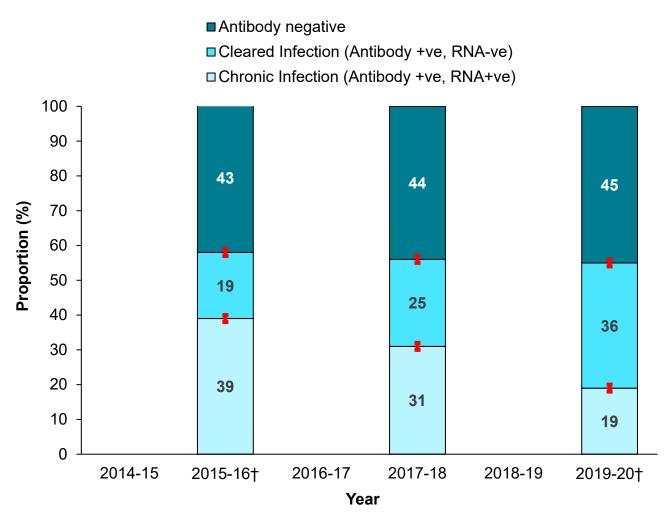
† During 2020 and 2021, recruitment to the UAM Survey was impacted by coronavirus (COVID-19) pandemic. As a result, there were changes in the geographic and demographic profile of people taking part. This should be taken into account when interpreting data for these years.

For more information see the UAM annual data tables report.

1.3 Estimated HCV prevalence among PWID in Scotland

Latest data from the Scottish Needle Exchange Surveillance Initiative (NESI) survey (2019 to 2020) indicates similar trends to the UAM survey (<u>16</u>) with a decline in the prevalence of chronic HCV among PWID surveyed in Scotland to 19.3% in 2019 to 2020 compared to 38.8% in 2015 to 2016 and an increase in the proportion of individuals who have cleared a HCV infection. The proportion of people surveyed who have ever been infected with HCV has remained stable. Due to the COVID-19 pandemic the NESI survey was not conducted in 2021 but the latest survey for 2022 to 2023 is now underway.

Figure 2b. Trend in HCV prevalence among people injecting psychoactive drugs (with 95% Confidence Intervals): 2015 to 2016 to 2019 to 2020 (Scotland *, **, ***, †)



Data sources: Needle Exchange Surveillance Initiative, Glasgow Caledonian University, University of West of Scotland, and Public Health Scotland (42).

Notes for Figure 2b

* Figures may not sum due to rounding.

** Data is shown for those years where HCV RNA testing data is available.

*** Estimates for chronic and cleared HCV infection have been adjusted to take into account antibody-positive samples with missing RNA status. The ratio of chronic to cleared infection was applied to the antibody positive samples with missing RNA status by year and health board (GGC, Tayside or rest of Scotland).

† NESI 2019 to 2020 was suspended before completion due to the COVID-19 pandemic. As a result, the sample includes data from 8 out of 11 mainland NHS Boards originally included in the sampling framework. The 3 missing NHS boards in 2019 to 2020 account for just 10% of the total NESI sampling framework.

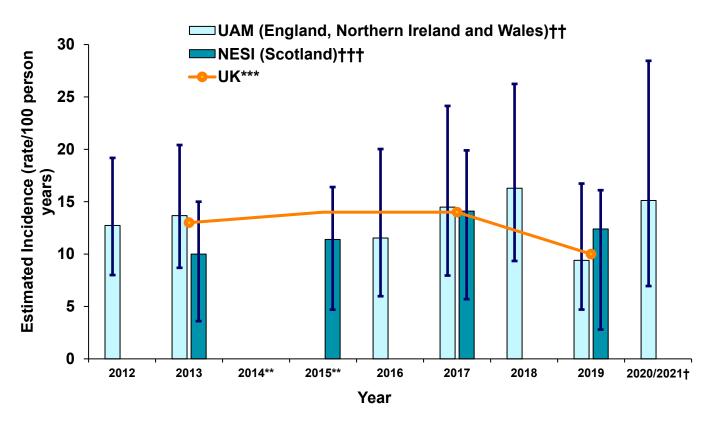
1.4 Estimated HCV incidence in PWID

Monitoring incidence of HCV infection remains a challenge as this is difficult to measure directly. Incidence can be estimated using data from people who have evidence of HCV viraemia but are HCV antibody-negative. This does not take into account people who have an incident re-infection.

The UAM survey reported HCV incidence among PWID was 15.1 per 100 person-years (95% CI 6.9, 28.5) in 2020 to 2021. This is broadly similar to levels seen in 2019; 9.4 per 100 personyears (95% CI 4.7, 16.7), though numbers are small and should be interpreted with caution. In the NESI Survey, incidence of infection among previously uninfected (that is, antibody negative) PWID remains relatively stable at 12.4 per 100 person-years (95% CI 8.7, 22.0) in 2019. Data is not available for Scotland for 2021.

Future improvements in harm reduction interventions and the scaling up of DAA treatment among PWID is likely to be associated with further reductions in HCV prevalence and circulating viraemia and is expected to lead to a reduction in incident infections over time ($\underline{17}$).

Figure 3. Estimated UK-wide incidence *, **, *** of HCV among PWID, 2012 to tax year 2020 to 2021 $\ensuremath{\dagger}$



Data sources: (i) Needle Exchange Surveillance Initiative, Glasgow Caledonian University, University of West of Scotland and Public Health Scotland (<u>42</u>), and (ii) Unlinked Anonymous Monitoring survey of people who inject psychoactive drugs (<u>16</u>), conducted by UKHSA with assistance from Public Health Wales and the Public Health Agency Northern Ireland.

Notes for Figure 3

* In the UAM survey, incidence is calculated among those antibody-HCV negative who reported injecting in the past year. People with HIV are excluded because they can have sub-optimal antibody responses as a result of their HIV infection.

** For the incidence calculations using RNA testing a fixed window period of 51 days was used and there is some uncertainty regarding the use of this measure. Estimates for 2014 and 2015 are not available as RNA testing was not conducted on antibody-HCV negative samples.

*** For years where incidence estimates are available from both surveys, data is combined to produce a UK estimate after weighting them by the sizes of the adult (16 to 64 years) populations for the countries they cover (orange line). UK data is only presented for those years where both surveys are conducted. Confidence Intervals (95%) have been shown for both UAM (England, Northern Ireland, and Wales) and NESI (Scotland) data.

† During 2020 and 2021, recruitment to the UAM Survey was impacted by coronavirus (COVID-19) pandemic. As a result, there were changes in the geographic and demographic profile of people taking part. This should be taken into account when interpreting data for these years. Due to small numbers data for 2020 and 2021 is combined. For more information see the <u>UAM</u> <u>annual data tables report</u>.

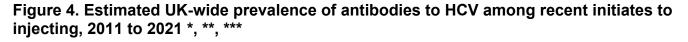
†† Laboratory testing data for 2016 to 2018 in the UAM survey may differ from those provided previously as information on DBS sample quality has been used to exclude insufficient DBS samples collected between 2016 and 2019 from analyses.

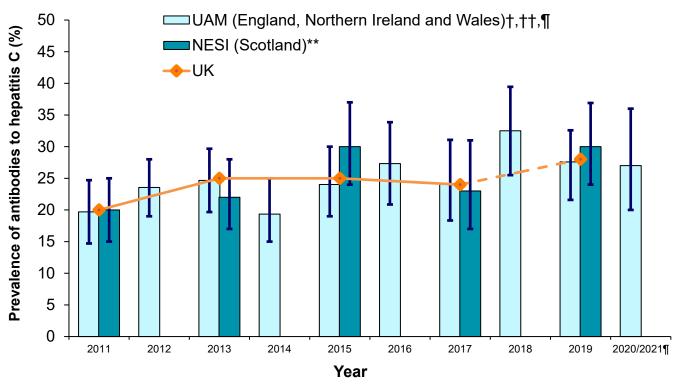
††† The NESI (Scotland) data is available by survey year so 2013 refers to 2013 to 2014, 2015 refers to 2015 to 2016, 2017 refers to 2017 to 2018 and 2019 refers to 2019 to 2020. NESI 2019 to 2020 was suspended before completion due to the COVID-19 pandemic. As a result, the sample includes data from 8 out of 11 mainland NHS boards originally included in the sampling framework. The 3 missing NHS boards in 2019 to 2020 account for just 10% of the total NESI sampling framework.

1.5 Estimated HCV antibody prevalence among recent initiates to injecting

Prevalence of antibodies to HCV infection among people who have recently initiated injecting drug use can be used as a proxy measure of incidence for the whole population as most new infections are acquired via this route. Data from the UAM survey and NESI suggests that the prevalence of antibodies to HCV among recent initiates in the UK has remained relatively stable over recent years.

For 2020 and 2021 combined, the prevalence of HCV antibody among recent initiates to injecting across the 3 countries was estimated at 27.3%. Confidence intervals are wide however, due to the small (and declining) numbers of recent initiates in the sample. This data suggests that there is ongoing primary infection and a need for renewed focus on provision of adequate harm reduction.





Data sources: (i) Needle Exchange Surveillance Initiative, Glasgow Caledonian University, University of West of Scotland and Public Health Scotland (<u>42</u>), and (ii) Unlinked Anonymous Monitoring survey of people who inject psychoactive drugs, (<u>16</u>) conducted by UKHSA with assistance from Public Health Wales and the Public Health Agency Northern Ireland.

Notes for Figure 4

* This figure uses data from 2 ongoing survey programmes, which together cover the whole of the UK. Data from these 2 surveys has been weighted by the size of the adult (16 to 64) population (2011, 2013, 2015, 2017, 2019 and tax year 2020 to 2021) UK figures weighted on mid-year population estimates for each respective year and then combined (represented by the orange line). UK data is only presented for those years where both surveys are conducted. Confidence Intervals (95%) have been shown and are fairly wide due to the relatively small (and declining) numbers of recent initiates in the sample. Therefore, the power to detect a reduction is low (if prevalence decreased by 50% then this would be detected with 80% power in the UAM study, comparing samples of 152 recent initiates from one year to another (within that currently sampled). However, to detect a 25% reduction would require a sample size of over 600 in each group (over 1,200 in total).

** The NESI (Scotland) data is available by survey year so 2011 refers to 2011 to 2012, 2013 refers to 2013 to 2014, 2015 refers to 2015 to 2016, 2017 refers to 2017 to 2018 and 2019 refers to 2019 to 2020. NESI 2019 to 2020 was suspended before completion due to the COVID-19 pandemic. As a result, the sample includes data from 8 out of 11 mainland NHS Boards originally included in the sampling framework. The 3 missing NHS boards in 2019 to 2020 account for just 10% of the total NESI sampling framework.

*** Recent initiates are defined as PWID who commenced injecting drugs within the 3 years prior to their participation in UAM and NESI Surveys.

† In the UAM Survey, laboratory testing data for 2016 to 2018 may differ from that provided previously as information on DBS sample quality has been used to exclude insufficient DBS samples collected between 2016 and 2021 from analyses. Behavioural data for 2010 to 2018 may differ from those provided previously as questionnaires completed between 2010 and 2021 with no accompanying biological specimen have been now included in analyses.

++ UAM antibody-HCV prevalence data for 2010 was calculated using the following equation to ensure comparability of the oral fluid and DBS samples received during this year = [(number of oral fluids antibody-HCV positive/0.92) + number of DBS antibody-HCV positive]/(number of oral fluids + number of DBS)x100.

¶ During 2020 and 2021, recruitment to the UAM Survey was impacted by coronavirus (COVID-19) pandemic. As a result, there were changes in the geographic and demographic profile of people taking part. This should be taken into account when interpreting data for these years. Due to small numbers data for 2020 and 2021 is combined. For more information please see the <u>UAM annual data tables report</u>.

1.6 Reinfections

People who have been previously treated for HCV infection, and who remain at risk, are at risk of becoming re-infected with HCV.

In England, a reinfection is identified as a positive RNA and/or subsequent treatment following an SVR or negative RNA result in a person who has previously been treated for HCV infection (at least 196 days after first treatment initiation). A control group who had a post-treatment RNA test at least 196 days after first treatment initiation is used to calculate the reinfection rate. Among people who initiated treatment between 2015 and 2021 in England, the reinfection rate was 7.4 per 100 person years. This data is reliant upon linkage between the treatment database and SSBBV and thus are subject to change dependent upon the patient information becoming available to successfully link between the 2 databases.

In Scotland reinfection rates have risen contemporaneous with initial scale-up of DAAs among PWID reflecting widening access from treatment in community settings, but are expected to eventually lead to a reduction in incident infection as prevalence of viraemia falls in the community (<u>18</u>). Among PWID who achieved SVR following treatment in the DAA era (2015 to 2018), 68% were tested for RNA within the first year post-SVR but only 30% in the second year. Among people re-tested post SVR, 169 reinfections were diagnosed to the end of 2019, translating to a reinfection rate of 6.4 per 100 person years. However, an estimated 200 reinfections (54% of the estimated total) may have gone undetected during follow-up (<u>17</u>).

2. Reducing HCV-related mortality

Table 2. WHO impact targets for reducing HCV-related mortality and UK progress

Impact target area	WHO GHSS 2020 target relative to 2015 baseline (<u>4</u>)	WHO GHSS 2030 targets relative to 2015 baseline (<u>4</u>)	WHO interim guidance elimination validation target: annual absolute HCV-related mortality rate (<u>5</u>)
Mortality: Viral hepatitis C deaths (target)	10% reduction	65% reduction	Equal to or less than 2 per 100,000 persons
Progress in the UK Mortality: HCV-related end stage liver disease (ESLD)/hepatocellular carcinoma (HCC) deaths	31.3% reduction		0.48 per 100,000 population* (2020)**
Progress in England Mortality: HCV-related ESLD/HCC deaths	30.8% reduction		0.47per 100,000 population* (2020)**
Progress in Northern Ireland Mortality: HCV-related ESLD/HCC deaths	25.0% reduction		0.19 per 100,000 population* (2020)
Progress in Scotland *** Mortality: HCV-related ESLD/HCC deaths †	36.7% reduction		0.70 per 100,000** population * (2020)
Progress in Wales Mortality: HCV-related ESLD/HCC deaths	25.0% reduction		0.63 per 100,000 population * (2020)

Notes for Table 2

* Based on ONS mid-year population estimates: <u>Estimates of the population for the UK,</u> England and Wales, Scotland and Northern Ireland (ONS)

** Even if reporting of HCV on death certification has not improved beyond levels historically reported (<u>19</u>, <u>20</u>) these preliminary figures show the 2030 WHO interim elimination metric has already been met.

*** HCV-related ESLD/HCC deaths in people who were ever chronic with HCV and with a mention of HCV on the death certificate.

† Between 2015 and 2020, Scotland also saw a 69% reduction in the number of people who died with decompensated cirrhosis and/or HCC who had chronic HCV infection at the time of their death and a 19% reduction in the number of people who died of decompensated cirrhosis and/or HCC who had ever been diagnosed with chronic HCV infection (<u>13</u>).

Further information can be found in <u>Technical notes</u>.

2.1 Mortality in the UK

In the UK death registrations from HCV-related ESLD and HCC peaked at 464 in 2015. Between 2015 and 2020 these numbers fell by 31.3% which appears to be predominantly driven by the decrease in HCV-related ESLD which fell by 50.5% during this period.

The decline in deaths from a 2015 baseline, indicates that the WHO target to reduce HCVrelated mortality by 10% by 2020 has been exceeded more than threefold in the UK, further work will be required to meet the 65% target (<u>12</u>). The WHO elimination metric to achieve an HCV-related annual mortality rate of less than or equal to 2 per 100,000 has also been surpassed for the UK, at 0.48 per 100,000 population in 2020.

The decrease in registered deaths is likely to be the result of increased access to DAA drugs that were introduced in 2015, particularly for individuals with more advanced disease (21).

England data demonstrates a fall in HCV-related ESLD and HCC mortality rate from 0.69 in 2015 to 0.47 per 100,000 in 2020 (12). Between 2015 and 2020, Scotland also saw a 68.7% reduction in the number of people who died with decompensated cirrhosis and/or HCC who were last known to have chronic HCV infection at the time of their death, while only a 19.2% reduction in the number of people who died of decompensated cirrhosis and/or HCC who had ever been diagnosed with chronic HCV infection (that is, including people with and without chronic HCV at the time of death) (13).

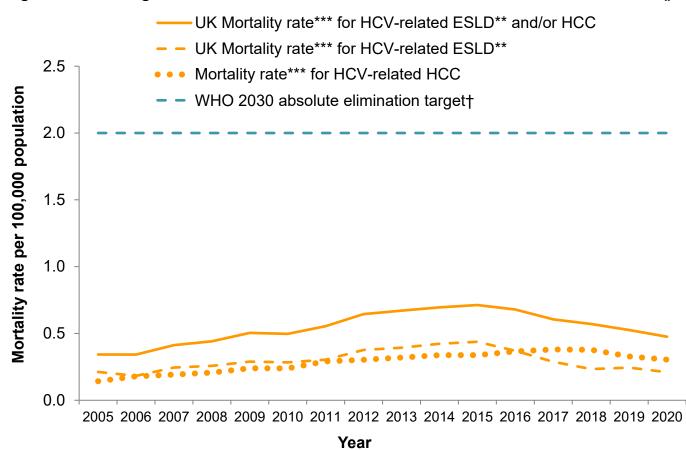


Figure 5. Death registrations* for HCV-related ESLD** and HCC in the UK: 2005 to 2020¶

Data source: Office for National Statistics for England and Wales; Deaths registration data as supplied by Hospital Information Branch in the Department of Health, Public Health Agency (Health Intelligence) and NI Statistics and Research Agency; Public Health Scotland in association with the Information Services Division.

Notes for Figure 5

* Death registrations for England, Northern Ireland and Wales are those where HCV is mentioned on the death certificate. Data for Scotland is based on year of death and are obtained via record-linkage of Scotland's National Hepatitis C Diagnoses Database to the national deaths register; thus, all individuals who were ever chronic with HCV infection in Scotland and with hepatitis C recorded on their death certificate are reported. These individuals were diagnosed with HCV antibodies and either (i) PCR/Ag positive at diagnosis or (ii) PCR/Ag status not known at time of diagnosis and either PCR/Ag positive >6 months post diagnosis or evidenced to have been treated for HCV.

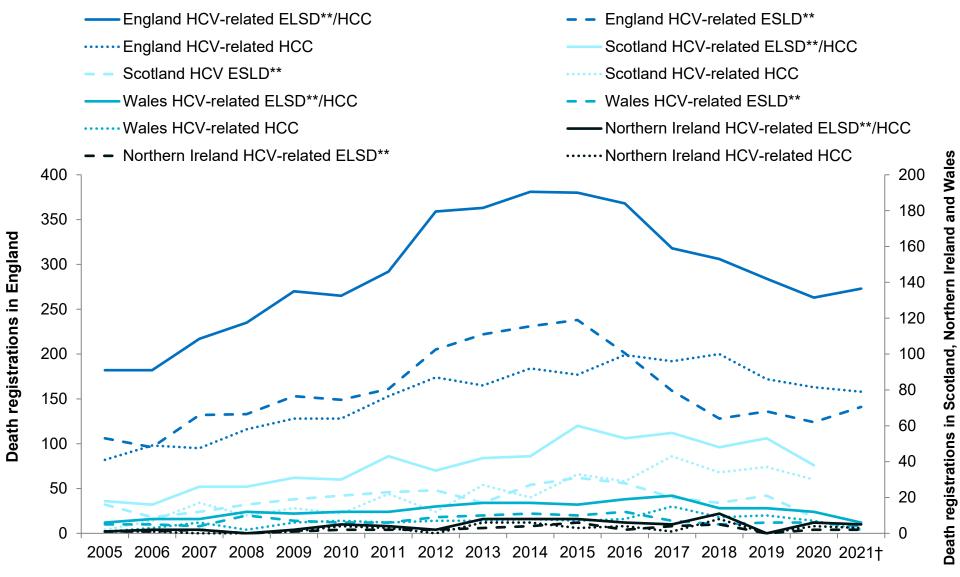
** Defined by codes or text entries for ascites, bleeding oesophageal varices, hepato-renal syndrome, hepatic encephalopathy, or hepatic failure.

*** Based on ONS mid-year population estimates: Estimates of the population for the UK, England and Wales, Scotland and Northern Ireland (ONS)

 \P 2021 data not currently available for Scotland.

† Less than or equal to 2 per 100,000 persons.

Figure 6. Death registrations* for HCV-related ESLD** and HCC in UK countries: 2005 to 2021***



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Data source: Office for National Statistics for England and Wales; Deaths registration data as supplied by Hospital Information Branch in the Department of Health, Public Health Agency (Health Intelligence) and NI Statistics and Research Agency; Public Health Scotland.

Notes for Figure 6

* Death registrations for England, Northern Ireland and Wales are those where HCV is mentioned on the death certificate. Data for Scotland is based on year of death and are obtained via record-linkage of Scotland's National Hepatitis C Diagnoses Database to the national deaths register; thus, all individuals who were ever chronic with HCV infection in Scotland and with hepatitis C recorded on their death certificate are reported. These individuals were diagnosed with HCV antibodies and either (i) PCR/Ag positive at diagnosis or (ii) PCR/Ag status not known at time of diagnosis and either PCR/Ag positive >6 months post diagnosis or evidenced to have been treated for HCV.

** Defined by codes or text entries for ascites, bleeding oesophageal varices, hepato-renal syndrome, hepatic encephalopathy, or hepatic failure.

*** 2021 data not currently available for Scotland.

† Provisional data for Northern Ireland.

3. Proportion of people with chronic HCV diagnosed and aware of their infection

Table 3a. WHO programme targets for HCV diagnosis and awareness of infection

Service coverage or programme target area	WHO GHSS 2030 target (<u>4</u>)	WHO interim guidance elimination validation target ($\underline{5}$)
Proportion of people with chronic HCV diagnosed*	Greater than or equal to 90%	Greater than or equal to 90%

Table 3b. Progress in the UK

Measure	Progress in the UK	Progress in England	Progress in Northern Ireland	Progress in Scotland	Progress in Wales
Proxy measure: For UAM Survey, proportion of PWID (who injected in the past year) testing positive for HCV RNA who are aware of their current HCV infection (HCV RNA positive). For NESI, proportion of PWID (who had injected in the past 6 months) with chronic HCV reporting being aware of their infection.	Not available	34.4% in 2021**,*** (39.0% in 2020)	Not available	48.4% in 2019 to 2020 (59.9% in 2017 to 2018)	Not available

Notes for Table 3

* The numerator for this indicator in terms of HCV diagnosis is the number of persons with chronic HCV infection who have been diagnosed, and the denominator is the estimated number of persons with chronic HCV infection.

** UAM data regarding awareness of HCV RNA result, and therefore chronic infection status, is available for 2017 onwards due to changes in the UAM survey questionnaire. 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.

*** During 2020 and 2021, recruitment to the UAM Survey was impacted by coronavirus (COVID-19) pandemic. As a result, there were changes in the geographic and demographic profile of people taking part. This should be taken into account when interpreting data for these years. For more information see the <u>UAM annual data tables report</u>.

Further information can be found in <u>Technical notes</u>.

3.1 HCV Diagnosis and awareness of infection

The latest UAM survey suggests that 28.3% of PWID (England, Northern Ireland and Wales) with chronic hepatitis (antibody-HCV and HCV RNA positive) were aware of their infection in 2021, significantly fewer than in 2017 (50.6%). The proportion aware of ever having HCV infection (antibody-HCV positive) has declined from 61.1% in 2017 to 47.2% in 2021. The causes of these declines are likely to be multifactorial; the impact of the COVID-19 pandemic on diagnosis and treatment, sampling methods during this period and a change in the geographical spread and demographics of participants in 2020 and 2021. Data from NESI suggests a similar decline in Scotland, falling from 59.9% in the survey year 2017 to 2018 to 48.4% in survey year 2019 to 2020.

Early diagnosis of HCV infection is important for the most effective treatment and care. As treatment with DAAs is more widely available, people aware of their status are more likely to have been treated, and those remaining are less likely to be aware of their primary or re-infection, suggesting that more still needs to be done to achieve the 2030 target (Figure 7).

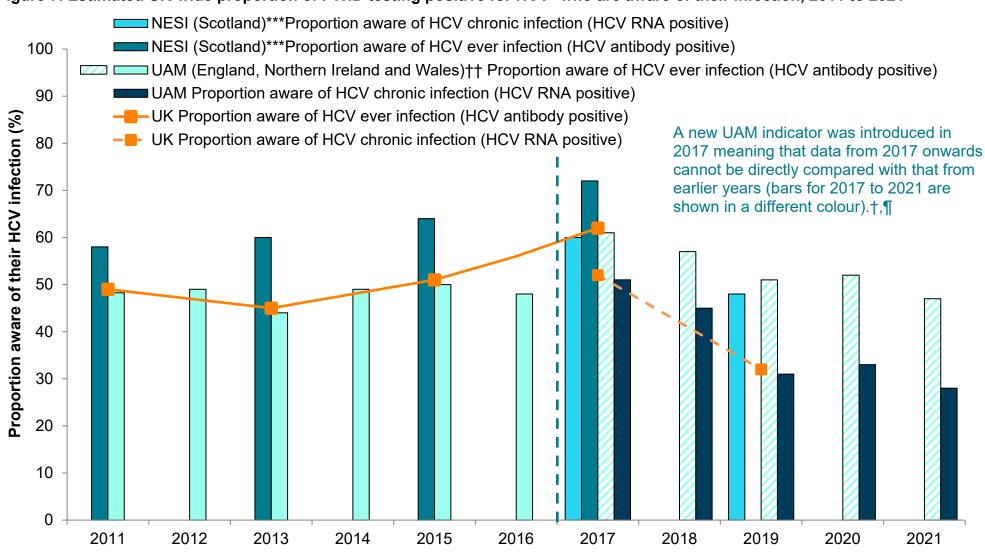


Figure 7. Estimated UK-wide proportion of PWID testing positive for HCV* who are aware of their infection, 2011 to 2021**

Year

Data sources: (i) Needle Exchange Surveillance Initiative , Glasgow Caledonian University, University of West of Scotland and Public Health Scotland ($\underline{42}$), and (ii) Unlinked Anonymous Monitoring survey of people who inject psychoactive drugs ($\underline{16}$) conducted by UKHSA with assistance from Public Health Wales and the Public Health Agency Northern Ireland.

Notes for Figure 7

* Figures for England, Northern Ireland and Wales are for PWID who had injected drugs in the last year and differ from those in UAM data tables which refer to all people who injected drugs; figures for Scotland are for PWID who injected in the past 6 months.

** This figure uses data from 2 ongoing survey programmes, which together cover the whole of the UK. Data from these 2 surveys has been weighted by the size of the adult (16 to 64) population (2011, 2013, 2015, 2017, 2019, 2020 and 2021). UK figures weighted on mid-year population estimates for each respective year) and then combined (represented by the blue lines). The survey covering Scotland is not annual, so full UK data is only presented for those years where both surveys are conducted.

*** Data for Scotland is available by survey year so 2011 refers to 2011 to 2012, 2013 refers to 2013 to 2014, 2015 refers to 2015 to 2016, 2017 refers to 2017 to 2018 and 2019 refers to 2019 to 2020. NESI 2019 to 2020 was suspended before completion due to the COVID-19 pandemic. As a result, the sample includes data from 8 out of 11 mainland NHS boards originally included in the sampling framework. The 3 missing NHS boards in 2019 to 2020 account for just 10% of the total NESI sampling framework.

† UAM data regarding awareness of HCV RNA result, and therefore chronic infection status, is available for 2017 onwards due to changes in the UAM survey questionnaire. 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.

†† For UAM survey, 2016 to 2018 laboratory testing data may differ from those provided previously as information on DBS sample quality has been used to exclude insufficient DBS samples collected between 2016 and 2019 from analyses. Behavioural data for 2011 to 2018 may differ from those provided previously as questionnaires completed between 2011 and 2021 with no accompanying biological specimen have been now included in analyses.

¶ During 2020 and 2021, recruitment to the UAM Survey was impacted by coronavirus (COVID-19) pandemic. As a result, there were changes in the geographic and demographic profile of those taking part. This should be taken into account when interpreting data for these years. For more information, please see the <u>UAM annual data tables report</u>.

4. Prevention of infection by ensuring adequate harm reduction in PWID

Table 4a. WHO programme targets for harm reduction

Service coverage or programme target area	WHO GHSS 2030 target (<u>4</u>)	WHO interim guidance elimination validation target $(\underline{5})$
Harm reduction: A comprehensive package of harm reduction services to all PWID (<u>22</u>) including:	At least 300 sterile needles and syringes provided per person who injects drugs per year.	At least 300 sterile needles and syringes provided per person who injects drugs per year. >40% of opioid-dependent people on OST

Table 4b. Progress in the UK

Country	Harm reduction: A comprehensive package of harm reduction services to all PWID (22) including:
Progress in UK	In 2019, 66.0% reported having adequate needle or syringe provision for their needs.
Progress in England	 among people injecting psychoactive drugs participating in the UAM Survey during 2021, 65.6%† reported adequate needle and syringe provision (NSP**) for their needs (62.7% in 2020) 55.5% of opioid dependent PWID receive OAT (tax year 2011 to 2012*) 77%† of UAM Survey participants in 2021 (76% in 2020), who had injected drugs in the last year, reported receiving some form of information that explained what HCV is, how they could avoid catching it, or how it is treated, in the last year
Progress in Northern Ireland	Not currently available

Country	Harm reduction: A comprehensive package of harm reduction services to all PWID (22) including:
Progress in Scotland	 Among people who inject drugs participating in NESI, 65.6% reported adequate NSP for their needs in 2019 to 2020 and 80.2% in 2017 to 2018.†† 66% of people who inject drugs attending NSP for services other than OAT received prescribed methadone in 2019 to 2020 and 69% in 2017 to 2018.
Progress in Wales	 82 sterile needles and syringes (median number of syringes to PWID injecting psychoactive drugs) provided per person who injects drugs per year – 22% coverage 13% of opioid dependent PWID receive OAT (this has been calculated using the number of PWID in regular contact with NSP services and the number of individuals receiving OST in treatment services indicating current or recent injecting of opioids). 63% of PWID receiving targeted HCV information, education, and communication

Notes for Table 4

* Analysis of injecting drug use prevalence is under development to provide updated, robust estimates of the number of PWID and the proportion on OAT.

** NSP Coverage is now calculated differently to previous years as data was previously split in 2 categories 'less than or equal to 100% NSP coverage' and 'Greater than 100% NSP coverage', and are now categorised as 'Less than 100% coverage' and 'equal to or greater than 100% coverage', corresponding to 'inadequate' and 'adequate' coverage, respectively.

† During 2020 and 2021, recruitment to the UAM Survey was impacted by coronavirus (COVID-19) pandemic. As a result, there were changes in the geographic and demographic profile of those taking part. This should be taken into account when interpreting data for these years. For more information see the <u>UAM annual data tables report</u>.

†† NESI 2019-20 was suspended before completion due to the COVID-19 pandemic. As a result, the sample includes data from 8 out of 11 mainland NHS boards originally included in the sampling framework. The 3 missing NHS boards in 2019 to 2020 account for just 10% of the total NESI sampling framework.

Further information is available in <u>Technical notes</u>.

4.1 Harm reduction

Access to sterile injecting equipment and opioid agonist therapy (OAT) are important harm reduction interventions for PWID that can prevent and reduce the risk of transmission of HCV ($\underline{23 \text{ to } 28}$) and reduce the risk of reinfection after treatment. The use of low dead space injecting equipment instead of traditional needles ($\underline{29}$, $\underline{30}$) has been shown to reduce HCV transmission.

In 2019, around 3 out of every 5 PWID in the UK (66.0%) reported having adequate needle or syringe provision for their needs, similar in both the UAM and NESI surveys. In 2020 the UAM reported a decline to 62.7%. NESI was suspended in April 2020 due to the COVID-19 pandemic. The decline in NSP provision in 2020 may be due to changes in service provision due to the impact of the COVID-19 pandemic (<u>31</u>). In 2021, this figure rose again to 65.6% of participants in England, Northern Ireland and Wales reporting having adequate needle and syringe provision.

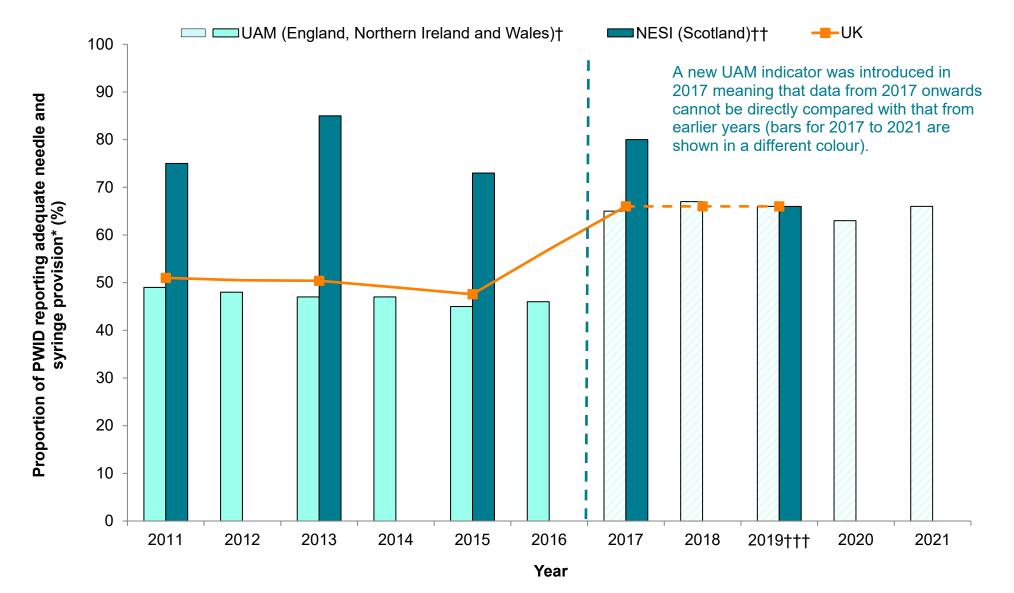


Figure 8. Estimated UK-wide proportion of PWID reporting adequate* needle and syringe provision, 2011 to 2021**,***

29

Data sources: (i) Needle Exchange Surveillance Initiative, Glasgow Caledonian University, University of West of Scotland and Public Health Scotland ($\underline{42}$), and (ii) Unlinked Anonymous Monitoring survey of people who inject psychoactive drugs ($\underline{16}$), conducted by UKHSA with assistance from Public Health Wales and the Public Health Agency Northern Ireland.

Notes for Figure 8

* 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.

** This figure uses data from 2 ongoing survey programmes, which together cover the whole of the UK. Data from these 2 surveys has been weighted by the size of the adult (16 to 64) population (2011, 2013, 2015, 2017, 2019, 2020 and 2021 UK figures weighted on mid-year population estimates for each respective year) and then combined (represented by the blue line). The survey covering Scotland is not annual so full UK data is only presented for those years where both surveys are conducted.

*** During 2020 and 2021, recruitment to the UAM Survey was impacted by coronavirus (COVID-19) pandemic. As a result, there were changes in the geographic and demographic profile of those taking part. This should be taken into account when interpreting data for these years. For more information, please see the <u>UAM annual data tables report</u>.

† UAM data for 2011 to 2021 may differ from those provided previously as questionnaires completed between 2011 and 2021 with no accompanying biological specimen have now been included in analyses.

†† Data for Scotland is available by survey year so 2011 refers to 2011 to 2012, 2013 refers to 2013 to 14, 2015 refers to 2015 to 2016, 2017 refers to 2017 to 2018 and 2019 refers to 2019 to 2020.

††† NESI 2019 to 2020 was suspended before completion due to the COVID-19 pandemic. As a result, the sample includes data from 8 out of 11 mainland NHS boards originally included in the sampling framework. The 3 missing NHS boards in 2019 to 2020 account for just 10% of the total NESI sampling framework.

5. Monitoring access to HCV treatment

Table 5a. WHO programme targets for monitoring access to HCV treatment

Service coverage or programme target area	- (-)	WHO interim guidance elimination validation target (5)
Treatment coverage of people diagnosed with chronic HCV	Equal to or greater than 80%	Equal to or greater than 80%

Table 5b. Progress in the UK

Country	Progress update	Percentage of diagnosed patients with chronic HCV initiated treatment
Progress in UK (2015 to 2020)	 74.9%* of diagnosed patients with chronic HCV were linked to specialist HCV treatment services 67.2%** of diagnosed patients with chronic HCV initiated treatment Where treatment information is available, 89.7% initiated treatment for their HCV infection 72.2%*** of those who initiated treatment achieved SVR 	67.2%**
Progress in England	2015 to 2020	65.3%** (2015 to 2020)
(Between 2015 and 2020 and 2016 to 2021)	73.5%* of diagnosed patients with chronic HCV were linked to specialist HCV treatment services	73.0%** (2016 to 2021)
	65.3%** of diagnosed patients with chronic HCV initiated treatment Where treatment information is available, 88.8% initiated treatment for their HCV infection.	

	 70.2%*** of those who initiated treatment achieved SVR 2016 to 2021 81.8%* of diagnosed patients with chronic HCV were linked to specialist HCV treatment services 73.0%** of diagnosed patients with chronic HCV initiated treatment Where treatment information is available, 89.3% initiated treatment for their HCV infection. 71.6%*** of those who initiated treatment achieved SVR 	
Progress in Northern Ireland † (between 2015 and 2020)	100%* of diagnosed patients with chronic HCV were linked to specialist HCV treatment services 96.3%** of diagnosed patients with chronic HCV initiated treatment Where treatment information is available, 96.3% initiated treatment for their HCV infection 91.3%*** of those who initiated treatment achieved SVR	96.3%**
Progress in Scotland (between 2015 and 2020)	 86.9%* of diagnosed patients with chronic HCV were linked to specialist HCV treatment services 81.8%** of diagnosed patients with chronic HCV initiated treatment Of those linked to specialist HCV treatment services, 94.2% initiated treatment for their HCV infection. 91.6%*** of those who initiated treatment reported achieved SVR 	81.8%**
Progress in Wales †† (between 2015 and 2020)	81.7%** of diagnosed patients with chronic HCV initiated treatment 68.2%*** of those who initiated treatment reported achieved SVR	81.7%**

Notes for Table 5

* Numerator: Number of individuals linked to HCV treatment services. Denominator: Number of individuals who tested positive for HCV RNA with NHS or CHI number or name and date of birth.

** Numerator: Number starting treatment; Denominator: Number of individuals who tested positive for HCV RNA with NHS or CHI number or name and date of birth.

*** Numerator: Number achieving SVR. Denominator: Number starting treatment.

† In Northern Ireland all HCV positive cases (with NHS number or name and date of birth) have been linked to a treatment database until June 2020.

†† Linkage to a treatment database is not currently available in Wales.

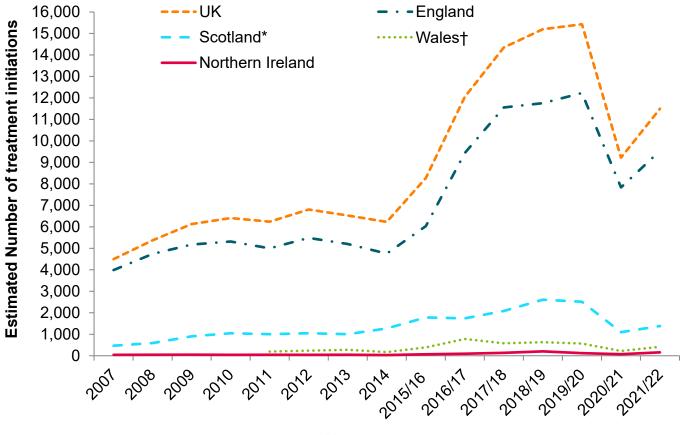
Further information is available in <u>Technical notes</u>.

5.1 Access to HCV treatment

The number of individuals initiating HCV treatment in the UK between 2009 and 2014 remained stable at around 6,400 treatment initiations per year (6,390; Range: 6,130 to 6,808). However, from 2015 the number increased to 15,428 in the tax year 2019 to 2020, which may be a reflection of improved access to DAA drugs since tax year 2014 to 2015 (32 to 40).

Between tax years 2019 to 2020 and 2020 to 2021 the number of individuals accessing HCV treatment in the UK decreased by 40.2%, linked to the impact of the COVID-19 pandemic on service provision, and challenges in finding and engaging under-reached HCV positive individuals during this period of restrictions and data completeness. Nevertheless, the lifting of pandemic restrictions, re-engagement with services, and a renewed focus on DAA roll-out is likely to be the reason for the 24.6% increase in treatment initiations between tax years 2020 to 2021 and 2021 to 2022.





Year

Data sources: (i) Regional Hepatology Unit for Northern Ireland; (ii) Public Health Scotland, using data supplied by NHS Boards/hepatitis C treatment centres; (iii) Public Health Wales using data from treatment services in the Health Boards; (iv) NHS England from tax years 2015 to 2016 and tax years 2019 to 2020; provisional estimates for England based on new DAA drug treatments only, and on commissioning data which includes clinician intention to treat and invoicing, rather than patient level treatment registry data: this data is subject to data guality issues and contract adjustments; (v) Sentinel surveillance of hepatitis bloodborne virus testing for scaled estimates for 2012 to 2014 for England; (vi) Estimates from Roche sales, IMS supply chain manager, and Pharmex data for England for 2007 to 2011 (Harris and others. Journal of Hepatology 2014: volume 61, pages j 530 to 553).

Notes for Figure 9

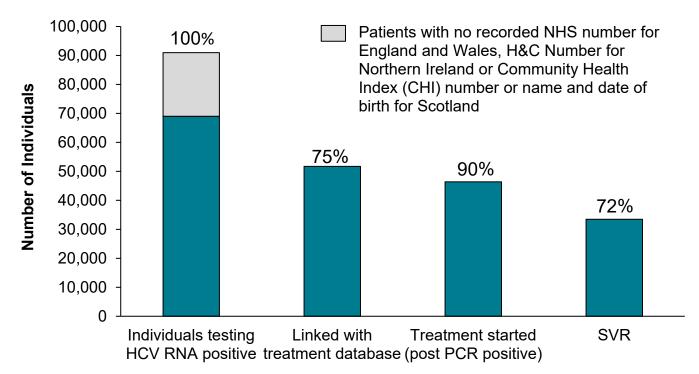
* Data for Scotland is only available by tax year between 2007 and 2014 so this has been grouped with calendar years. For example, data for calendar year 2011 is grouped with data for the tax year from 2011 to 2012.

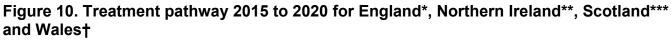
† Data for Wales is not available for 2007 to 2010: one health board is missing in 2014 and data, where available, is subject to data quality issues.

5.2 HCV treatment pathway

UK data has been used to follow individuals through the care pathway, from testing to treatment initiation and outcome. For the period 2015 to 2020, 90,983 individuals in the UK tested positive for HCV RNA. Of these, 56.8% were successfully linked to a record on a treatment database (see <u>Technical notes</u>) or linked to a specialist service in Scotland.

This figure rose to 74.9% when those with no NHS number or CHI number or name and date of birth were excluded; 89.7% of people engaged with care commenced treatment for their HCV infection, of whom 72.2% were reported to have cleared their infection (figure 10). However, when all individuals who tested positive for HCV RNA (and have a recorded NHS or CHI number) are considered, only 67.2% were recorded as having initiated treatment. This proportion is even lower (50.9%) where all people who tested positive for HCV RNA are considered. This may be due to a combination of incomplete data, not requiring treatment, not yet referred to care, awaiting treatment, not yet engaged with, or lost to care.





Data source: For England, Sentinel Surveillance of Bloodborne Virus Testing (<u>41</u>) and NHS England data from the Hepatitis C Patient Registry and Treatment Outcome System as of 19 October 2021. For Scotland ECOSS, testing and diagnosis data up to June 2022; clinical data up to March 2021; RIDU data (Lothian) up to June 2022; CHI data (deaths, migrated and HB of residence) up to November 2021. For Northern Ireland, Public Health Agency with data supplied by NI Hepatitis B and C. Managed Clinical Network. For Wales, HCV e-form, Welsh Clinical Portal as at 8 November 2022 and LIMS, Public Health Wales 2022.

Notes for Figure 10

* 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 children aged under one. Patient identifiable data submitted by sentinel laboratories is variable, particularly from sexual health and drug and alcohol services, which limits the ability to link data sets or de-duplicate. Data is de-duplicated subject to availability of date of birth, Soundex, NHS number and first initial. All data is provisional. Individuals who died are exclude from the total of those who tested HCV RNA positive.

** For Northern Ireland, includes individuals with positive RNA or Antigen test in SSBBV. Individuals who died are included in the total of those who tested HCV RNA positive.

*** For Scotland, the number of individuals who tested positive for HCV RNA with a CHI number include those that were ever chronic, or RNA status was not known since diagnosis. Individuals who died or migrated are excluded from the total of those who tested HCV RNA positive.

† For Wales, the total number of individuals who tested positive for HCV RNA includes those that died.

Technical notes

These technical notes outline or describe the methodology used to produce the figures and tables used within this report.

Reducing the incidence of HCV infection

Due to challenges measuring incident infections directly, the UK uses the reduction in HCV viraemia prevalence as a proxy measure (supported by WHO guidance). A modelling approach is used to estimate prevalence, including both diagnosed and undiagnosed infections for the UK nations. Multiple sources of routine surveillance data are included to track progress over time, including seroprevalence data, HCV-related liver disease, and information on the number of PWID and other risk groups ($\underline{7}$).

The <u>HCV burden model used to estimate chronic prevalence</u> is described online. The following data sources to inform the model are used:

- incidence of HCV infection in PWID over time, estimated via a force of infection model using 20 years of cross-sectional UAM data
- rates of disease progression from the Trent cohort (annual, age-specific probabilities of progression through mild, moderate, cirrhosis and HCC/ESLD states)
- disease endpoint data (age-specific HCV-related ESLD and HCC from HES, 2011 onwards)
- rates of injecting cessation
- mortality (drug-related mortality for people currently injecting, plus background mortality)
- recent estimates of the size of the PWID population
- background rates of infection in never-injecting populations
- treatment data to model, and predict, the impact of treatment scale up and those clearing chronic infection through SVR

The model reconstructs the epidemic of injecting drug use and associated HCV infections that would be consistent with several key sources of surveillance data: the UAM, estimated numbers of PWID and the numbers of infected individuals who progress to HCV-related HCC/ESLD over time.

The advantage of a combined approach is that surveillance data alone provides information only on infections in people who are currently injecting. Data on disease progression and endpoints (using 'back-calculation' methods) provides information on longer-term infections, but prevalence in people infected more recently (that is, currently injecting) is highly uncertain. Model outputs thus include the total number of chronic infections over time, and the current and future burden in terms of HCV-related cirrhosis, ESLD and HCC. The model also estimates underlying rates of incident chronic infection (new and reinfections). However, these estimates are not at a fine temporal granularity and ongoing work is being carried out to generate incidence estimates in PWID for monitoring purposes.

This model has been applied to England data up to 2021. The resulting estimates for England are combined with prevalence estimates for other UK nations to produce UK totals. For Wales and Northern Ireland, estimates are available up to 2019 and prevalence within each risk group is assumed to have followed the same trend in England over the subsequent 2 years. Estimates for Scotland were produced by Public Health Scotland in previous years (up to 2018), and a 2021 estimate obtained by assuming a continued downward trend as that in the 2013-2018 period. Work is ongoing to update estimates for each country and adapt the burden model to data available for Scotland.

Reducing HCV-related mortality

The number of HCV-related deaths are used to measure mortality for all UK countries.

For England, Northern Ireland and Wales, deaths are based on the year they were registered and where HCV is mentioned on the death certificate along with codes for ESLD and/or HCC.

For Scotland, deaths are based on the year of death and obtained via record linkage of Scotland's National Hepatitis C Diagnosis database to the national deaths register. Thus ESLD/HCC deaths for all individuals who ever had chronic HCV infection in Scotland are reported (including people with, but also without, hepatitis C on their death record). In this report, Scottish death data includes individuals who were ever chronic with HCV and where HCV is mentioned on the death certificate. Ever chronic can be defined as people diagnosed with HCV antibodies and either (i) PCR/Ag positive at diagnosis or (ii) PCR/Ag status not known at the time of diagnosis and either PCR/Ag positive >6 months post diagnosis or evidenced to have been treated for HCV.

These were estimated using slightly different ICD-10 codes from those used by WHO. A <u>comparison of the codes used</u> can be found online.

Table 6. Comparison of ICD10 codes used by UKHSA and WHO and European Centre for Disease Prevention and Control (ECDC) for monitoring annual HCV-related mortality rates and death registrations for HCV and HCV-related HCC/ESLD

Codes	UKHSA	WHO/ECDC
B171– Acute hepatitis C		
B182 – Chronic viral hepatitis C		
C220 – HCC		
R18 – ASCITES (ESLD)		
1850 – Oesophageal varices with bleeding (ESLD)		
I98.3 – Oesophageal varices with bleeding in diseases classified elsewhere (ESLD)		
K704 – Alcoholic hepatic failure (ESLD)		
K720 – Acute and subacute hepatic failure (ESLD)		
K721 – Chronic hepatic failure (ESLD)		
K729 – Hepatic failure, unspecified (ESLD)		
K73* – Chronic hepatitis, not elsewhere classified (CLD)		
K74.0 – Hepatic fibrosis (CLD)		
K74.1 – Hepatic sclerosis (CLD)		
K74.2 – Hepatic fibrosis with hepatic sclerosis (CLD)		
K74.3 – Primary biliary cirrhosis (CIRRHOSIS) (CLD)		
K74.4 – Secondary biliary cirrhosis (CIRRHOSIS) (CLD)		
K74.5 – Biliary cirrhosis, unspecified (CIRRHOSIS) (CLD)		
K74.6 – Other and unspecified cirrhosis of liver (CIRRHOSIS) (CLD)		
K75* – Other inflammatory liver diseases (CLD)		
K767 – Hepatorenal syndrome (ESLD)		

Proportion of people with chronic HCV diagnosed and aware of their infection

The UAM survey (<u>16</u>) is a cross-sectional bio-behavioural survey that recruits PWID in England, Wales and Northern Ireland through specialist agencies. Collection of data is through a brief anonymous self-completed questionnaire. The aim of the survey is to monitor the prevalence and incidence of HIV, hepatitis B and hepatitis C, and associated risk behaviours in this population. A similar survey is carried out in Scotland, the Needle Exchange Surveillance Initiative (NESI) (<u>13</u>) which collects anonymous bio-behavioural data from PWID through a questionnaire. Both surveys provide a proxy measure of several HCV indicators, given that HCV prevalence is highest in PWID. This includes the proportion of people with chronic HCV diagnosed who are aware of their infection.

Prevention of infection by ensuring adequate harm reduction in PWID

Data on the adequacy of harm reduction including OAT and NSP is derived from the UAM and NESI surveys. The UAM survey (<u>16</u>) is a cross-sectional bio-behavioural survey that recruits PWID in England, Wales, and Northern Ireland through specialist agencies. Collection of data is through a brief anonymous self-completed questionnaire (<u>12</u>). In addition, Wales uses the Harm Reduction Database to record data from a range of interventions such as NSP (<u>15</u>).

Monitoring access to HCV treatment

HCV treatment initiation data from all countries is used to monitor access to HCV treatment; records from individuals with a diagnosis of HCV are linked to individuals in treatment databases. Treatment coverage is defined as the proportion of individuals diagnosed with chronic HCV infection (HCV RNA or HCV core antigen positive) and initiated treatment during a specified time frame over the number of individuals diagnosed with chronic HCV infection for the specified time period ($\underline{5}$).

The NHS England Registry that was commissioned by NHS England in 2017 from the Arden and Greater East Midlands Commissioning Support Unit to capture more detailed information for patients. <u>The Hepatitis C treatment monitoring in England report</u> summarises the data held within the registry and treatment outcome system up to the end of April 2018.

Glossary

Acronym	Meaning
СНІ	Community Health Index
Crl	Credible interval
DAA	Direct-acting antiviral
DBS	Dried blood spot (test)
ESLD	End-stage liver disease
GHSS	Global Health Sector
HCC	Hepatocellular carcinoma
HCV	Hepatitis C virus
HES	Hospital Episode Statistics
HIS	Hospital Inpatient System
ICD-10	International Classification of Diseases Tenth Revision
NSP	Needle and syringe programme
NESI	Needle Exchange Surveillance Initiative
NHS	National Health Service
NSGVH	National Strategic Group on Viral Hepatitis
ODN	(NHS) Operational Delivery Network
ΟΑΤ	Opioid agonist therapy
OST	Opioid substitution treatment
PCR	Polymerase chain reaction
PWID	People who inject drugs
RNA	Ribonucleic acid
SHPN	Scottish Health Protection Network
SSBBV	Sentinel Surveillance of Blood Borne Virus (testing)
SVR	Sustained virological response
UAM	Unlinked Anonymous Monitoring Survey
UKHSA	UK Health Security Agency
WHA	World Health Assembly
WHO	World Health Organization

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Acknowledgments

Monica Desai (editor), Annastella Costella, Hannah Moore, Helen Dwyer, Claire Edmundson, Ross Harris, Sema Mandal, Holly Mitchell and Ruth Simmons at UKHSA.

Gillian Armstrong, Sarah Arnold, Ruth Campbell, Annelies McCurley, Claire Neill, Eimhear Rainey, Gerry Waldron at the Public Health Agency Northern Ireland, and Siobhan Morgan and Stewart Dunbar at the Hospital Information Branch in the Department of Health Northern Ireland.

Sharon Hutchinson, Andrew McAuley, Victoria Hamill, Norah Palmateer, Shanley Smith, Eleftheria Vasileiou, Amanda Weir, and Alan Yeung at Public Health Scotland and Glasgow Caledonian University.

Noel Craine, Jane Salmon and Josie Smith at Public Health Wales.

Our thanks also go to, Chris Biggam, Iain Brew, Beatrice Emmanouil, Graham Foster, Rachel Giffen, Mark Gillyon-Powell, Rachel Halford, Brendan Healy, Matthew Hibbert, Craig Hogg, Susan Hopkins, William Irving, Zoe James, Philip Jordan, Anne Mackie, Allan McLeod, Berry Puyk, Steve Taylor, Kate Travers, 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. In particular: the drug service staff and Hepatitis C Trust peer workers who support, and participants in, the Unlinked Anonymous Monitoring (UAM) survey of people who inject drugs; Hospital Episode Statistics (HES) (copyright © 2023, re-used with the permission of NHS Digital, all rights reserved); NHS England and Arden and Greater East Midlands Commissioning Support Unit; 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) ; the North of England Commissioning Support (NECS) team; the Practice Plus Group (PPG) who contributed prison data; NHS England for supplying treatment monitoring data for tax year 2015 to 2016 up to tax year 2021 to 2022 in England; and the NHS Wales Informatics Service (NWIS).

Retrospective testing of UAM survey data (2011 to 2016) and NESI survey (2011 to 2012, 2013 to 2014) for HCV ribonucleic acid (RNA) and NESI 2019 to 2020 survey was funded as part of the 'Evaluating the population impact of hepatitis C direct acting antiviral treatment as prevention for people who inject drugs' (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 authors and not necessarily those of the NIHR or the Department of Health and Social Care.

PHS thanks collaborators and contributors to national HCV surveillance initiatives throughout Scotland for their assistance in the compilation and production of these data, in particular the blood borne virus research team at Glasgow Caledonian University for supporting the delivery of hepatitis C surveillance, and associated evaluation, initiatives. We would also like to thank NESI participants and staff who facilitated fieldwork at their sites.

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 Health Protection Surveillance team, and Health Intelligence staff in the Public Health Agency (PHA), and staff of the Hospital Information Branch of the Department of Health. We would also like to thank drug service staff in Northern Ireland who support, and participants in, the UAM survey of PWID.

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<u>UKHSA</u> is an executive agency, sponsored by the <u>Department of Health and Social Care</u>.

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Published: February 2023 Publishing reference: GOV-13605

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