Public Health England

Protecting and improving the nation's health

# Hepatitis C in the North West

## 2017 data

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# Contents

# Abbreviations

| | |
|---|---|
| Anti-HCV | Antibodies to Hepatitis C virus |
| CDAS | Community Drug and Alcohol Services |
| DAA | Direct Acting Antivirals |
| DBS | Dried Blood Spot |
| ESLD | End Stage Liver Disease |
| GP | General Practitioner |
| HES | Hospital Episode Statistics |
| HCC | Hepatocellular Carcinoma |
| HCV | Hepatitis C Virus |
| HJIP | Health and Justice Indicators of Performance |
| NHS BT | National Health Service Blood and Transplant |
| NDTMS | National Drug Treatment Monitoring System |
| NHS E | National Health Service England |
| NW | North West |
| ODN | Operational Delivery Network |
| PCR | Polymerase Chain Reaction |
| PHE | Public Health England |
| PHPQI | Prison Health and Performance Indicator |
| PWID | People who inject drugs |
| RCGP | Royal College of General Practitioners |
| RNA | Ribonucleic Acid |
| SGSS | Second Generation Surveillance System |
| UAMS | Unlinked Anonymous Monitoring Survey of HIV and Viral Hepatitis among people who inject drugs |
| WHO | World Health Organisation |

# Executive summary

## Burden of hepatitis C infection in the North West 2017

An estimated 26,750 people are living with chronic hepatitis C virus infection (HCV) in the North West (NW). Around half of these are likely to be unaware of their infection.

The number of tests for HCV received by NW laboratories declined in 2017, however the proportion of tests that were positive remained stable.

Twice as many positive HCV tests were received for men than women. 68% of positive tests received were from people between the ages of 25 and 64.

2016 survey data suggest that the NW has a higher proportion of people who inject drugs (PWID) who have ever been infected with HCV compared to England (67% versus 54%).

Around 1 in 10 people in prison in the NW who are tested for HCV are found to have ever been infected.

A higher proportion of the South Asian population in the NW who are tested for HCV are found to have ever been infected compared to England.

## Monitoring impact: HCV-related morbidity and mortality

There was a 10% increase in all HCV-related hospital admissions in the NW in 2017 compared with 2015. However, admissions specifically for HCV-related end-stage liver disease (ESLD) or hepatocellular carcinoma (HCC) (liver cancer) remained stable.

In keeping with the national trend, new registrations and first transplants for HCV-related disease in the NW are declining.

Deaths from HCV-related ESLD or HCC were similar in 2017 to 2016 in the NW. Our region had the joint highest crude death rate from HCV-related liver disease in England across the period 2009 to 2017.

## Monitoring impact: Reducing the number of new infections

Indicators of the incidence of HCV infection are under development nationally. Available testing data in young people suggest that in the NW incidence is currently stable.

## Service coverage: Adequate harm reduction

Since 2007, a declining proportion of PWID in the NW have reported sharing needles and syringes, however the proportion who report sharing other injecting equipment appears to be increasing.

## Service coverage: Increasing awareness and the numbers diagnosed

Only half of PWID in the NW who have ever been infected with HCV are aware of their infection.

In 2016 and 2017 almost 90% of new entrants to NW prisons were offered a HCV test, with a quarter of these taking this up.

Nationally, new indicators are being developed to monitor dried blood spot testing (DBS) for HCV, as this is the principal way of testing the highest risk groups and is not currently captured in routine surveillance data.

## Service coverage: Increasing numbers accessing treatment

There was a rise of 36% in the numbers of people in the NW with HCV who were treated with direct acting antiviral drugs in 2017/18 compared to the previous financial year.

Three-quarters of people in prison found to be HCV positive were referred to a hepatologist in 2016 and 2017. This is a vast improvement on the previous year where less than 1 in 10 was reported to be referred.

# Progress on recommendations in the 2017 Annual Report

| Recommendation | Progress |
|---|---|
| 1. PHE North West should continue to work with local authorities across the region to improve understanding of the burden and distribution of HCV risk groups and disease in their populations | PHE North West proactively engages with LAs via representation at ODNs meetings and continues to support work to improve HCV detections rates. |
| 2. Increasing the numbers diagnosed and accessing treatment in secure and detained settings | PHE North West has worked with ODNs and providers to review treatment pathways of RNA positive hepatitis C cases and implementation of intensive test and treat campaigns in prisons. Work is ongoing in PHE at national level to more accurately capture testing done in secure and detained settings and to communicate this to ODNs |
| 3. PHE North West, NHS England and the 4 NW ODNs should continue to work collaboratively to build on recent increases in the numbers accessing treatment for HCV in the NW | PHE North West has continued to work closely with NW ODNs and NHS England. Specific examples from across the NW are in Section 4 of this report. |

# Recommendations: 2018 Annual Report

The following recommendations are directed towards commissioners, clinicians, providers and public health teams across the North West of England. These recommendations should be considered to be in addition to those outlined in the most recent national report produced by Public Health England.[1]

These recommendations are based upon the findings presented in this report and build upon progress towards the recommendations presented in the Hepatitis C in the North West Annual Report 2017. Progress against the 2018 recommendations should be measured when compiling the next hepatitis C annual report.

Making improvements and monitoring metrics: PHE North West should continue to work with local authorities across the region to improve understanding of the burden and distribution of HCV risk groups and disease in their populations. This work should include supporting local authorities to include HCV in Joint Strategic Needs Assessments, with the aim of improving service provision for those at risk of or experiencing HCV infection.

Increasing the numbers diagnosed and accessing treatment in secure and detained settings: PHE North West should continue to work with prisons and NHS England to ensure blood-borne virus opt-out testing is embedded into the prison culture through positive, whole-prison approaches to increasing both testing and onward referral for treatment. This should be facilitated by all prisons having representation at the relevant Operational Delivery Network (ODN), as well as ongoing monitoring by NHSE.

Increasing the numbers diagnosed and accessing treatment in community settings: PHE North West, NHS England and the 4 NW ODNs should continue to work collaboratively to build on recent increases in the numbers accessing treatment for HCV in the NW. This should include critical use of both this report and PHE's recently published 'Operational Delivery Network Profile Tool' to allow continuous quality improvement of the data supplied to ODNs. In addition, it should involve joint working on designing routes to HCV eradication, in particular taking account of the challenges for hard-to reach groups.

# 1. Introduction and background

## 1.1. Hepatitis C virus infection

HCV is a blood-borne virus that can cause both acute and chronic hepatitis (liver inflammation). Only a minority of people who contract the virus will clear it without treatment. Between 6 and 8 of every 10 people who contract HCV will go onto develop chronic infection.[2]

Over the 20-year period after developing chronic HCV infection, between 15% and 30% of people will develop cirrhosis (permanent liver scarring). Of these, a small number each year (somewhere between 1 in 20 and 1 in 50) will in turn develop liver cancer (hepatocellular carcinoma).[3] These conditions are associated with a significant burden of ill health, need for healthcare and premature death.

HCV principally affects marginalised and under-served groups in society. The greatest risk factor for acquiring HCV is injecting drug use. In the UK, HCV is concentrated in areas with high levels of current or past injecting drug use and those with high numbers of black and minority ethnic populations with close links to countries where HCV infection is common.[4]

## 1.2. Why is HCV a priority?

**HCV is a preventable cause of disease and death.** All or most deaths from this disease could be avoided through a combination of preventative measures and good quality curative healthcare.[5] Better prevention and treatment for HCV would also reduce the healthcare and ill health burden for those currently living with or at risk from the infection, many of whom face other health and socioeconomic inequalities.

Because we have the means to act on HCV, the WHO has produced a Global Health Sector Strategy on Viral Hepatitis with ambitious targets. These include an 80% reduction in new cases and a 65% reduction in HCV-related deaths by 2030. The UK is a signatory to this strategy, and PHE is responsible for monitoring progress against it in England. In the light of the WHO strategy, PHE has developed the following vision statement:

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

# 2. Burden of hepatitis C infection

## Overview

Accurately estimating the numbers of people living in the NW who are infected with HCV is complex. PHE's national team is continuing to develop up-to-date and robust modelling for this purpose.[6] The best current estimate is that around 26,750 people in the NW are living with chronic HCV. Approximately 8,500 of these are estimated to be living across Cumbria and Lancashire, with around 8,800 in Greater Manchester and East Cheshire and 9400 in the rest of Cheshire and Merseyside.

It is likely that only about half of those with chronic HCV are aware of their infection.[6] The WHO target is to diagnose 90% of chronic HCV by 2030.[7] Thus there is much to do to increase both professional and public recognition of the risks for HCV infection and of the need to test when these risks are identified.

## 2.1. HCV testing

Information on testing for HCV comes from 2 main sources – sentinel surveillance and routine laboratory notifications (see Appendix 1 for data information). In many cases of chronic hepatitis C there are initially either no symptoms, or only mild and non-specific ones. People therefore often do not get tested until complications of the disease develop. As a result, the numbers tested do not give a good indication of the prevalence (number of existing cases) or incidence (number of new cases) of chronic HCV in the general population. In addition, the initial HCV antibody test (anti-HCV) only indicates whether someone has ever been exposed to HCV. A further test for HCV ribonucleic acid (RNA) is needed to determine whether or not someone has developed chronic HCV infection. Furthermore, the majority of those in the highest risk groups (people who inject drugs (PWID)) and those entering prison) are now tested using dried blood spot (DBS) samples which are not currently included in sentinel surveillance. Testing patterns can however give useful insight into trends in testing, the burden of laboratory confirmed disease and the positivity rates in different risk groups.

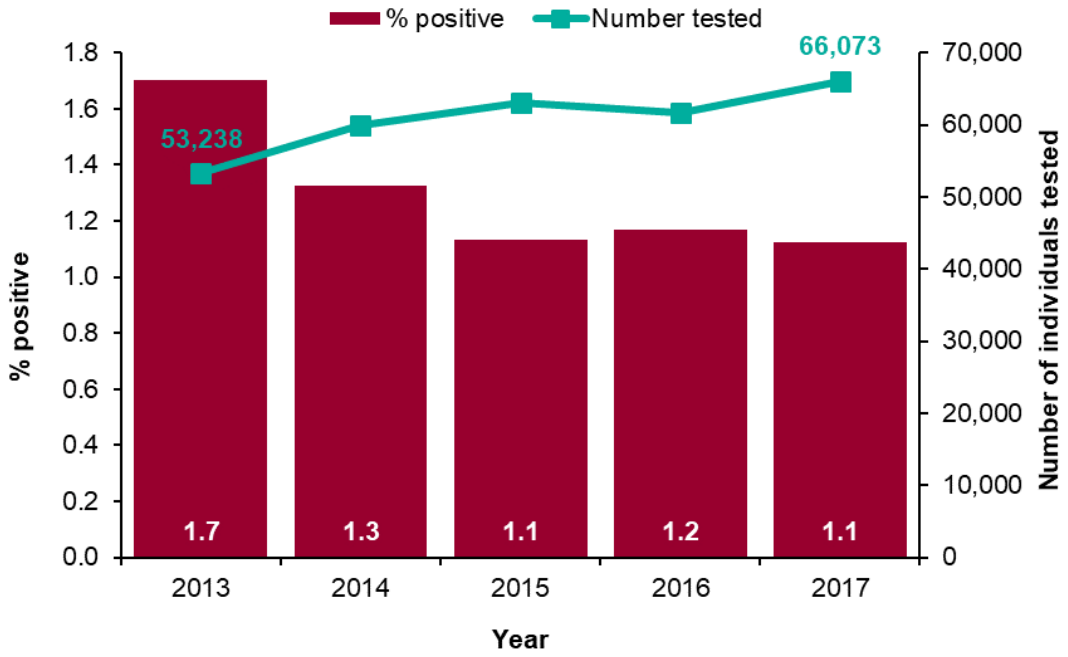
### 2.1.1. Trends in testing

Figure 1 shows that there has been a slight increase in the number of HCV tests received at NW sentinel laboratories over the last year, (7% increase from 2016 to 2017). However, the number of tests is still 8% higher than in 2012.

In keeping with this, both the number and crude rate of NW routine laboratory reports positive for hepatitis C slightly increased in 2017 compared with 2016, (916 and 12.8

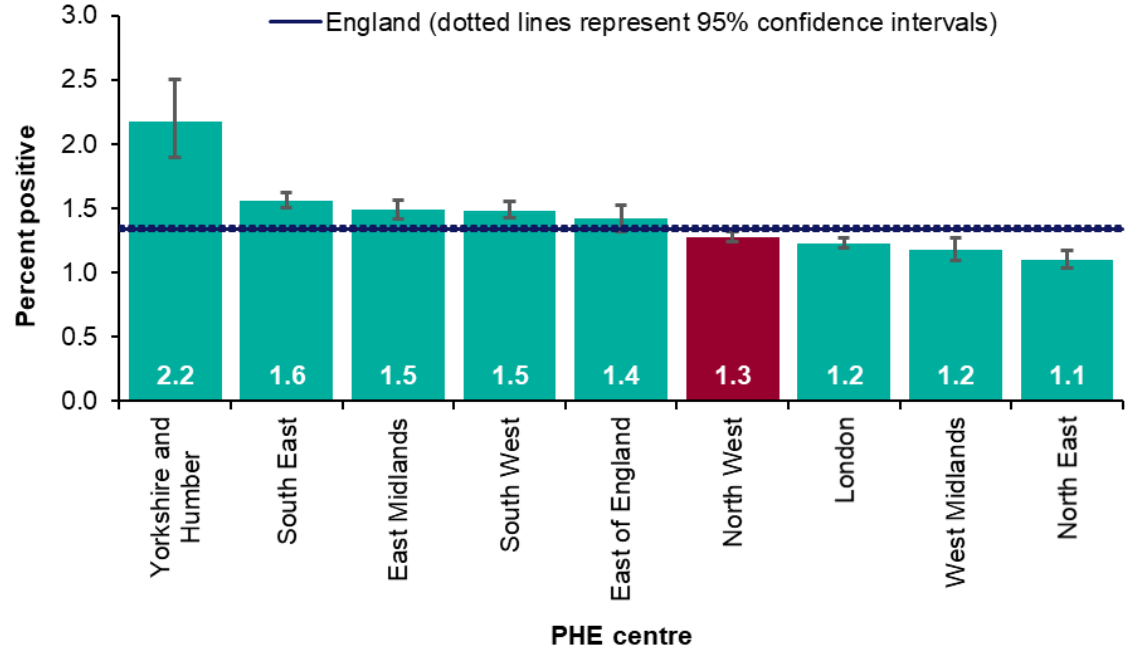
per 100,000 in 2016, 935 and 13.0 per 100,000 in 2017). In England, the rate of positive routine laboratory reports declined by 7.9% over the same period.

**Figure 1: Number of individuals tested and % testing positive for anti-HCV in sentinel laboratories in North West PHE centre, 2013 to 2017**




Excludes dried blood spot, oral fluid, reference testing and testing from hospitals referring all samples. Data are de-duplicated subject to availability of date of birth, soundex and first initial. Excludes individuals aged less than 1 year, in whom positive tests may reflect the presence of passively-acquired maternal antibody rather than true infection. All data are provisional.

**Figure 2: Percentage of individuals testing positive for anti-HCV in sentinel laboratories by PHE centre of laboratory, 2013 to 2017**



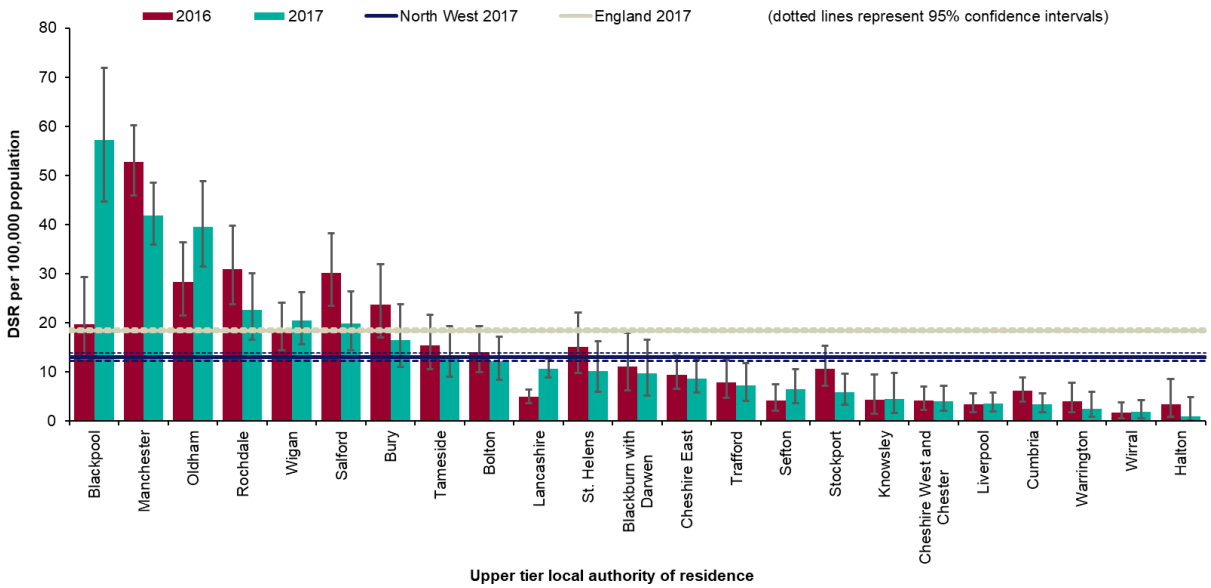

Excludes dried blood spot, oral fluid, reference testing and testing from hospitals referring all samples. Data are de-duplicated subject to availability of date of birth, soundex and first initial. Excludes individuals aged less than 1 year, in whom positive tests may reflect the presence of passively-acquired maternal antibody rather than true infection. All data are provisional.

Despite the modest increase in the number of tests, the percentage of individuals testing positive for anti-HCV in the NW changed little between 2016 and 2017 (from 1.2% to 1.1%). Notably, when looking at pooled data for 2013 to 2017, the NW is the region of the country with the sixth highest proportion of positive anti-HCV test results (Figure 2).

### 2.1.2. Burden of laboratory confirmed disease

The burden of HCV in a given local authority (LA) is affected by the age, sex and ethnicity of those in its population, as well as by the number in specific risk groups such as PWID. Laboratory confirmed disease represents the number of individuals in contact with health services in a LA who have been both exposed to HCV and tested. It is not a measure of all cases of HCV in the LA population. Neither does it reflect total testing activity, as only positive results are reported. However, examining the differences in the rates of laboratory confirmed disease, after allowing for the differences in age structure between LAs (by direct standardisation), may point towards variations in HCV awareness and approaches to testing. Figure 3 shows that in 2017, Blackpool, Manchester and Oldham all had significantly higher directly standardised rates of laboratory confirmed disease than both England and the NW. Conversely, 9 NW LAs had significantly lower rates than England and the NW.

**Figure 3: Laboratory reports of hepatitis C, directly standardised rate (DSR) per 100,000 population by upper tier local authority of residence, North West PHE centre, 2016 and 2017**




Data are summarised by upper tier local authority of residence, not upper tier local authority of laboratory. Data are assigned to upper tier local authority by patient postcode where present; if patient postcode is unknown, data are assigned to upper tier local authority of registered GP practice; where both patient postcode and registered GP practice are unknown data are assigned to upper tier local authority of laboratory.

Includes individuals with a positive test for hepatitis C antibody and/or detection of hepatitis C RNA. Due to the variability in the quality of laboratory reports and the inability of current serological assays to differentiate acute from persistent infections we are unable to estimate the actual proportion of cases with evidence of past infection or persistent infection.

DSRs per 100,000 population have been calculated using mid-year population estimates supplied by the Office for National Statistics (ONS).

Excludes cases where age and/or gender are unknown.

### 2.1.3. Age group and gender distribution of positive tests

In keeping with what is known about the sex distribution of HCV in Europe, about twice as many positive anti-HCV tests were received for men than for women by NW laboratories in 2016. A majority of male samples (58.5%) was also seen in sentinel surveillance of HCV testing between 2013 and 2017.

68% of those testing positive for HCV in sentinel surveillance from 2013 to 2017 were aged between 25 and 64. The 35 to 44 age group contributed the highest proportion of all positive tests (32%).

## 2.2. Burden in high risk groups

Recognised high risk groups for HCV in England are:

- people who inject drugs (the most important risk factor for HCV infection)
- people in prescribed places of detention
- people originating from countries with higher HCV prevalence than the UK (largely due to the risk of transmission during unsterile medical or dental treatment)

### 2.2.1. People who inject drugs

Currently the best estimates of the prevalence of HCV in PWID come from the Unlinked Anonymous Monitoring Survey of HIV and Viral Hepatitis among People Who Inject Drugs (UAMS) (see Appendix 1 for details of this data). Table 1 shows that the proportion of survey participants testing positive for HCV in 2017 was higher in the NW than in England.[9] The proportion of samples testing positive in the NW has remained similar since 2012.

Regional level data should be interpreted cautiously as the survey recruits participants through a nationally reflective sample of the services provided to people who inject drugs. In addition, there is no analysis of the statistical significance of the differences seen.

**Table 1: Proportion of dried blood spot samples tested in the Unlinked Anonymous Monitoring Survey of HIV and Viral Hepatitis among People Who Inject Drugs that were positive for anti-HCV in 2017**

| PHE Area | North West | England |
|---|---|---|
| Proportion of samples anti- HCV positive 2017 | 60% | 51% |

### 2.2.2. People originating from countries with higher HCV prevalence than the UK

The percentage of the local authority population that is identified as being from an ethnic minority varies across the NW from 1.1% to 28.6%.[10] The relative priority given to targeted HCV screening according to country of origin is thus also likely to vary. Regional testing

patterns do not accurately reflect individual local authority or ODN level testing activity but are worthy of consideration by local areas in order to respond appropriately to the challenge to increase awareness and testing in their own high-risk groups.

Sentinel surveillance systems assign ethnicity to individuals using a combination of self-reported ethnicity and name analyses software. This methodology has limitations as an indicator of country of origin. Between 2012 and 2016 NW sentinel surveillance data show a reduction in the proportion of tests received for which an ethnicity was able to be assigned. It is therefore difficult to draw meaningful conclusions from it.

Targeted testing of migrant groups in the UK has primarily focussed on individuals of South Asian origin, on account of the size of the migrant population and the prevalence of HCV in the countries of origin.[11] However over recent years an increase in testing in those of Eastern European origin (as identified by the surveillance system) has been seen in England. This suggests that these individuals may be at relatively increased risk of having acquired HCV and/or that testing of this ethnic group is more targeted at higher risk individuals than in the general population.[1]

Table 2 below highlights the proportion of anti-HCV positive laboratory tests in those identified as being of South Asian ethnicity and of Eastern European origin. There is also a small increase in the number of tests in South Asians in the NW, increasing from 5,479 in 2016 to 5,655 in 2017. Similarly, there is an increase in testing in Eastern Europeans in the NW, from 821 in 2016 to 897 in 2017. There is no information on the statistical significance of these observed differences.

**Table 2: Patterns of anti-HCV testing and positive results in PHE North West 2016 to 2017**

| | South Asian origin | | Eastern European origin | |
|---|---|---|---|---|
| | 2016 | 2017 | 2016 | 2017 |
| Proportion of anti-HCV tests that are positive | 1.5% | 1.7% | 2.8% | 2.7% |

NamPehchan was used to identify individuals of South Asian origin as ethnicity is not routinely available from the participating laboratory information systems.

Excludes dried blood spot, oral fluid, reference testing and testing from hospitals referring all samples. Data are de-duplicated subject to availability of date of birth, soundex and first initial. Excludes individuals aged less than 1 year, in whom positive tests may reflect the presence of passively-acquired maternal antibody rather than true infection. All data are provisional.

# 3. Monitoring impact

This section of the report focuses on the priority public health impacts for HCV in England:

1. Reducing the numbers becoming seriously ill or dying from HCV.
2. Reducing the number of new infections and reinfections with HCV.

## 3.1. Reducing HCV-related morbidity and mortality

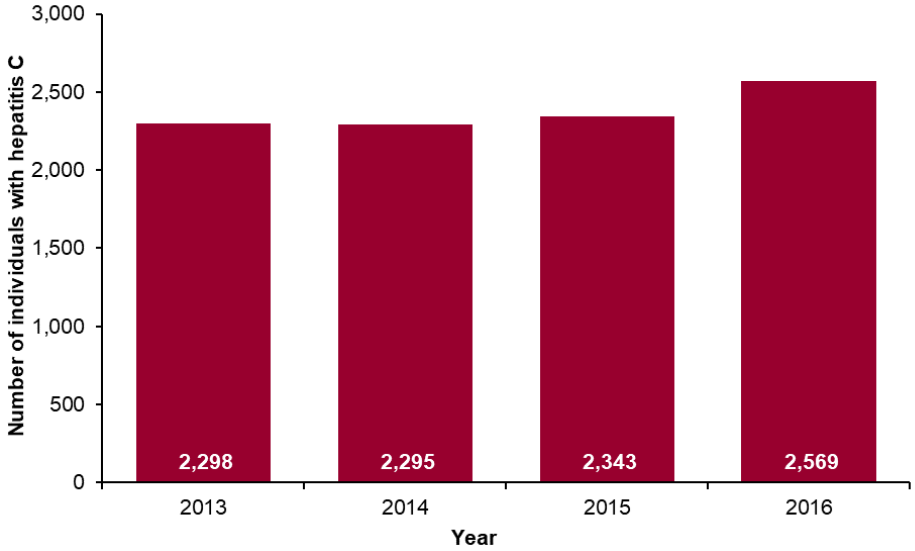
The preferred indicator to examine HCV-related end stage liver disease (ESLD) and hepatocellular carcinoma (HCC) is estimated incidence. This is under development nationally and will be based on hospital episode statistics (HES).[1]

However, at present only other proxy measures of acute and chronic HCV-related morbidity are available for the NW. These are detailed below.

### 3.1.1. Hospital admissions

There was a 10% increase in absolute numbers of hospital admissions in the NW for individuals with a diagnosis code for HCV in 2016 compared with the previous year. This was a larger increase than in either of the 2 previous years (Figure 4).

**Figure 4: Hospital admissions for individuals with a diagnosis code for HCV, residents of North West PHE centre, 2013 to 2016**




Codes for HCV/ESLD/HCC were extracted from all diagnosis codes (information about a patient's illness or condition – this includes primary/secondary/subsidiary diagnoses) – The following ICD10 codes were used: B171 (Acute hepatitis C), B182 (Chronic viral hepatitis C), C220 (Liver cell carcinoma), and the following codes for ESLD** (our definition of ESLD** is defined by codes for ascites (R18), bleeding oesophageal varices (I850, 198.3), hepato-renal syndrome (K767), hepatic encephalopathy or hepatic failure (K704) (K720) (K721) (K729).

**For full details of data in this figure see Appendix 1**

In comparison, admissions for individuals with a diagnosis code for HCV-related ESLD and HCV-related HCC remained fairly stable from 2015 to 2016.

Crude 3-year pooled rates of hospital admission for HCV-related ESLD and HCC combined are available at LA level for the NW as seen in Figure 5 (data from PHE Fingertips website (see Appendix 1)). These demonstrate the variation in admission rates both between and within different ODNs. For example, the Cheshire and Merseyside ODN has several LAs with admission rates that are similar to England (yellow) but several with significantly higher rates (red).

**Figure 5: Hospital admission rate for hepatitis C related end-stage liver disease/ hepatocellular carcinoma (crude rate per 100,000) 2012 to 2013 and 2014 to 2015, by local authority.**

| Area | Count | Value | 95% Lower CI | 95% Upper CI |
|---|---|---|---|---|
| **England** | 3,950 | 2.4 | 2.4 | 2.5 |
| North West region | 823 | 3.9 | 3.6 | 4.1 |
| Liverpool | 110 | 7.8 | 6.4 | 9.4 |
| Manchester | 107 | 6.9 | 5.7 | 8.4 |
| Bury | 33 | 5.9 | 4.1 | 8.3 |
| Rochdale | 37 | 5.8 | 4.1 | 8.0 |
| Wirral | 54 | 5.6 | 4.2 | 7.3 |
| Sefton | 46 | 5.6 | 4.1 | 7.5 |
| Blackburn with Darwen | 23 | 5.2 | 3.3 | 7.8 |
| Salford | 34 | 4.7 | 3.3 | 6.6 |
| St. Helens | 25 | 4.7 | 3.1 | 7.0 |
| Bolton | 34 | 4.1 | 2.8 | 5.7 |
| Wigan | 37 | 3.9 | 2.7 | 5.3 |
| Blackpool | 15 | 3.5 | 2.0 | 5.8 |
| Halton | 12 | 3.2 | 1.6 | 5.5 |
| Oldham | 20 | 2.9 | 1.8 | 4.5 |
| Lancashire | 102 | 2.9 | 2.3 | 3.5 |
| Warrington | 17 | 2.8 | 1.6 | 4.4 |
| Stockport | 19 | 2.2 | 1.3 | 3.5 |
| Cheshire East | 24 | 2.1 | 1.4 | 3.2 |
| Tameside | 13 | 2.0 | 1.0 | 3.4 |
| Trafford | 13 | 1.9 | 1.0 | 3.2 |
| Knowsley | 8 | 1.8 | 0.8 | 3.6 |
| Cheshire West and Chester | 18 | 1.8 | 1.1 | 2.9 |
| Cumbria | 22 | 1.5 | 0.9 | 2.2 |

*Source: Calculated by Public Health England: Clinical Epidemiology Knowledge and Intelligence from data from NHS Digital, formally the Health and Social Care Information Centre (HSCIC) - Hospital Episode Statistics (HES) and Office for National Statistics (ONS) - Mid Year Population Estimates*

## 3.1.2. Liver transplants

Nationally, between 2008 and 2014, there was a stable number both of registrations for liver transplant for post-HCV cirrhosis and of transplants being carried out for this indication.[1] Over the subsequent 3 years (2015 to 2017) the number of national registrations has fallen by 53% and the number of transplants by 39%. This may represent the positive impact of new treatments for HCV on the progression of the disease, although it is too early to draw firm conclusions on this.

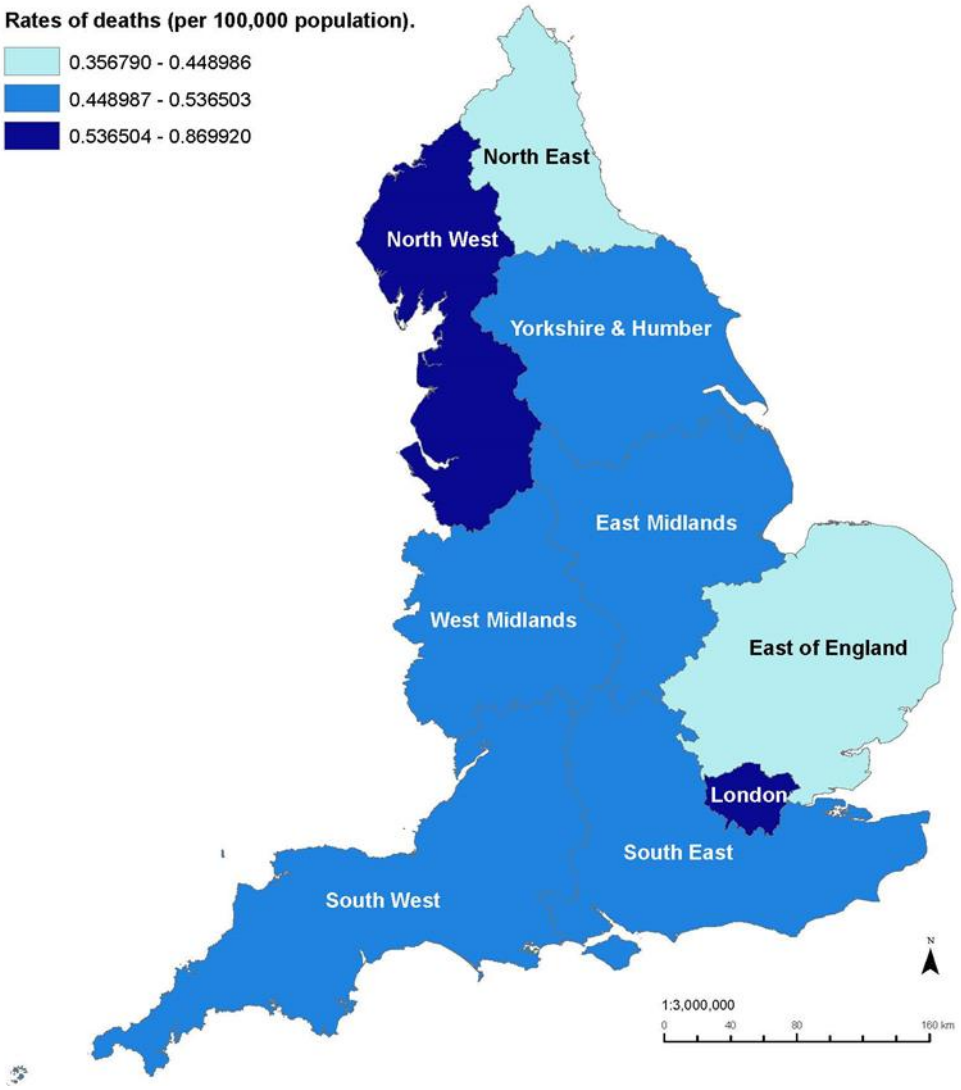
Transplant data for the NW has been pooled from 2010 to 2013 and 2014 to 2017. In keeping with the national picture, both the numbers of both new registrations and of first transplants related to HCV have declined (by 50% and 34%, respectively).

### 3.1.3. HCV deaths

A decrease in death registrations for HCV-related ESLD and HCC has been seen in England since 2014, with a fall of 16.3% between 2014 and 2017.[1] This follows a long period of rising HCV deaths, which more than doubled between 2005 and 2014. The reversal in the mortality trend may be associated with increasing access to new direct acting antiviral (DAA) drugs which were introduced in 2014 to 2015.

In the NW a similar trend has been seen. The crude rate of registered HCV-related ESLD and HCC deaths rose from 0.6 per 100,000 in 2007 to 2009 to a peak of 1.02 per 100,000 in 2013 to 2016. The crude rate has subsequently declined to 0.91 per 100,000 in 2015 to 2017. However, looking across the 10-year period of 2008-2017, the NW is, with London, 1 of 2 PHE regions with the highest crude HCV-related death rate in England (Figure 6).

**Figure 6: Rate of deaths from ESLD* or HCC in those with HCV mentioned on their death certificate by PHE Centre 2008 to 2017** per 100,000 population*****




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

** Based on 2008 to 2017 mid-year estimate population data.
Data source: Office for National Statistics

As with HCV-related hospital admissions, data on premature mortality from HCV-related ESLD and HCC is available at LA level on Fingertips.[12]

## 3.2. Reducing the number of new infections

The WHO has set challenging targets for reductions in the number of new cases of chronic HCV (30% by 2020 and 80% by 2030). As most new infections are acquired via injecting drug use at a relatively young age, the prevalence of infection in young adults or in recent initiates to injecting drug use (that is those who have started injecting within the previous 3 years) can be used as proxy measures of incidence.[1]

National UAMS data suggests that the level of HCV infection amongst recent initiates to injecting has probably changed little in recent years.[13] At present this data is not available for the NW.

The proportion of all laboratory confirmed disease reports that are from young people (15 to 24) in the NW has remained stable between 2013 and 201 (range 3.5% to 4.2%). The majority of these are done for people aged 20 to 24, with a much smaller proportion being for those in the 15 to 19 age group.

NW sentinel surveillance data shows that, in keeping with data for all ages, the number of anti-HCV tests reported for both 15 to 19 and 20 to 24-year olds has increased from 2016 to 2017. The total number of positive tests in both these age groups is only 188 for the period 2013 to 2017. Bearing this in mind, the proportion of positive tests, and therefore the number of new infections in the NW, has declined consistently over this period and was 23 positive (0.3% positive) in 2017.

# 4. Service coverage

The elimination of HCV in England is feasible and depends on 3 core intervention areas:

- ensuring adequate harm reduction for people who inject drugs (PWID)
- increasing the proportion of infected individuals who are diagnosed
- increasing the proportion of infected individuals who access and complete treatment, achieving a sustained viral response (SVR)

## 4.1. Adequate harm reduction

Sharing of injecting equipment is thought to be the principle cause of the epidemic of HCV in the UK.[11] The provision of adequate supplies of sterile injecting equipment, effective behaviour change interventions leading to safe injecting practice and optimal access to opioid substitute treatment are thus all critical to prevent both new and reinfections with HCV. The metrics proposed to monitor these nationally are:

- estimated adequacy of needle and syringe provision coverage among PWID
- sharing of injecting equipment by PWID
- proportion of opioid dependent PWID receiving opioid substitution therapy
- numbers of current/past PWID in drug treatment

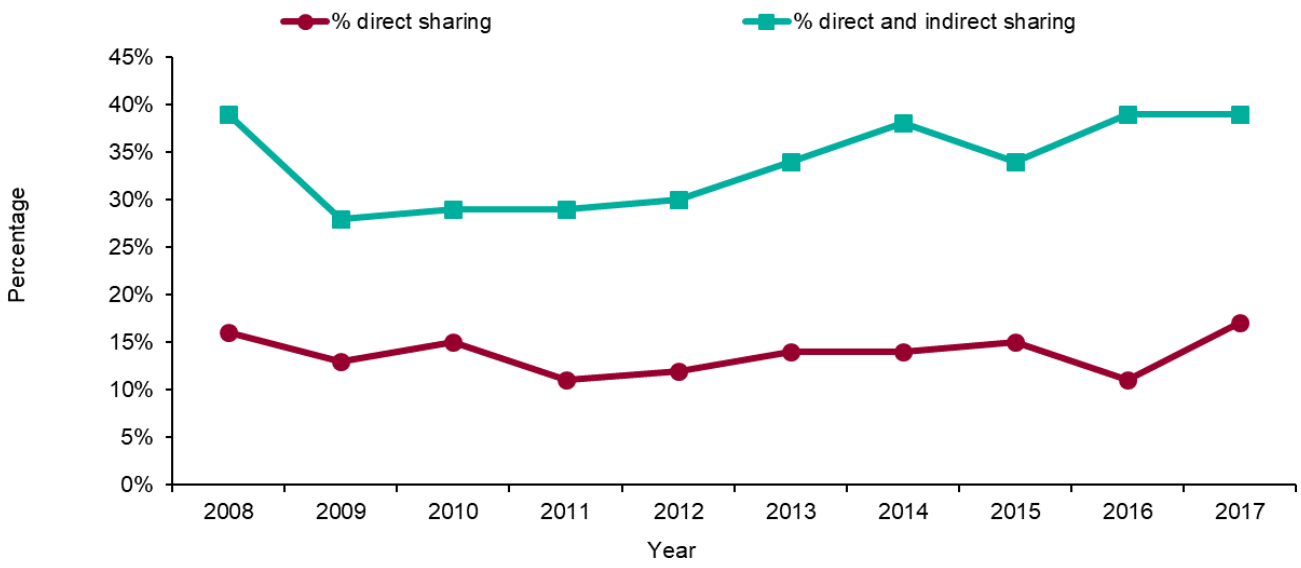
At present NW data is only available regarding sharing of injecting equipment, but the others should be forthcoming in future years.

Figure 7 shows that the level of direct sharing of injecting equipment in the NW has been consistent since 2008. The proportion reporting this behaviour in the 2017 UAMS data is 17% in the NW, an increase over the 11% observed in 2016.

However combined direct and indirect sharing has been rising since 2009. The proportion reporting this behaviour in the 2017 UAMS data is 39% in the NW, in comparison to 40% nationally.

It is important to remember that these data only come from PWID who are in contact with specialist services, and that PWID who are not in treatment may well exhibit different risk behaviours.

**Figure 7: Level of direct‡ and indirect‡‡ sharing of injecting equipment amongst people who inject drugs, North West region, 2008 to 2017**




‡ Sharing of needles and syringes in preceding 4 weeks.

‡‡ Sharing of needles and syringes, mixing containers, or filters among those who had last injected during the 4 weeks preceding participation in the survey.

## 4.2. Increasing awareness and the numbers and proportion diagnosed

Both public and professional awareness are key to increasing the detection of HCV in England. Nationally there are a number of initiatives that PHE is involved in to increase awareness, and the full details of these are available in the 2018 national HCV report.[1]

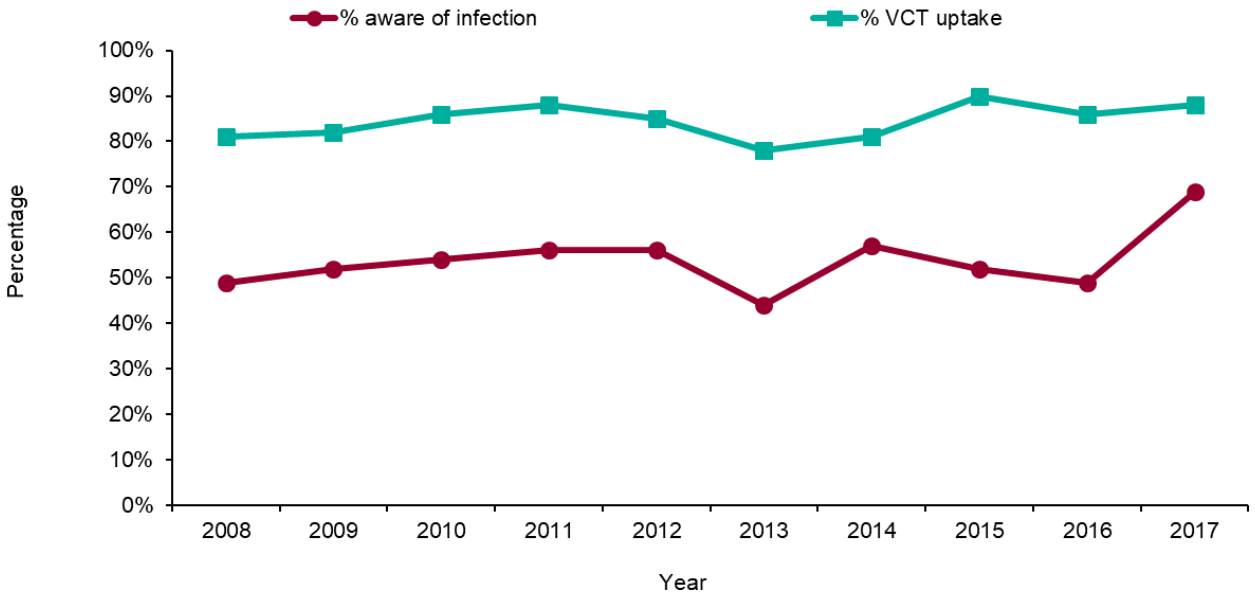
### 4.2.1. Testing in primary care

Sentinel surveillance data shows that between 2013 and 2017 24.4% of anti-HCV samples received in the NW came from GP surgeries (excluding dried blood spot (DBS) and oral fluid testing and only counting the earliest test for any individual). The proportion of positive samples from this source was 2.0%.

### 4.2.2. Testing in PWID

Sentinel surveillance data on testing in specialist services for drug users has not been presented in the most recent national PHE report on HCV. This is due to the fact that so much testing in this setting is now via DBS, and much of this testing activity is not currently captured in sentinel surveillance. This issue is being addressed currently and surveillance including DBS should be available in future years.

**Figure 8: Hepatitis C test voluntary confidential test (VCT) uptake amongst people who inject drugs and their awareness of infection, North West region, 2008 to 2017**




Notes: Data from the Unlinked Anonymous Monitoring Survey of people who inject drugs in contact with specialist services. The Unlinked Anonymous survey of PWID is an annual cross-sectional survey of individuals who currently or previously inject psychoactive drugs who are in contact with specialist services. Those who agree to take part provide a biological specimen that is tested anonymously for HIV, hepatitis C and hepatitis B. Behavioural and limited demographic information is collected through a brief anonymous subject-completed questionnaire linked to the specimen but unlinked from any client identifying information. The biological sample collected in the survey was changed from an oral fluid to a dried blood spot (DBS) during 2009 and 2010. From 2011 onwards, only DBS samples have been collected. The sensitivities of the tests on a DBS sample for antibodies to hepatitis C and hepatitis B core antigen are close to 100%. The sensitivity of the oral fluid sample test for antibodies to hepatitis C is about 92% and that for antibodies to the hepatitis B core antigen is about 75%. Regional level data should be interpreted cautiously as the survey recruits participants through a nationally reflective sample of the services provided to people who inject drugs.

UAMS data (Figure 8) demonstrates that both the percentage uptake of voluntary confidential testing for HCV and the proportion of those who were aware of being anti-HCV positive in the NW have remained fairly stable over the past decade. In 2017 just over half (69%) of PWID in contact with specialist services were aware of their infection. The equivalent figure for England is similar (66%) and has also been stable for the last 10 years.[9] There is much work to be done to achieve the 2030 WHO target of 90% awareness of chronic HCV infection.

Data on the proportion of people in drug misuse treatment and eligible for HCV testing who have received a test is available at LA level on Fingertips for the 2016/17 financial year.[14]

### 4.2.3. Testing in prescribed places of detention

HCV testing in prescribed places of detention is being monitored by NHSE through the Health and Justice Indicators of Performance metrics (HJIPs). Preliminary data suggests that across England, 10.5% of all new receptions and transfers to adult prisons in England received an anti-HCV test in the 2016/17 financial year. The majority (81.7%) of those testing positive also received a test for active disease (HCV PCR).[1]

The opt-out HCV testing policy has now been rolled out across all 15 NW prisons. The latest HJIPs data only covers the period up to the end of March 2017, and will not capture the impact of this roll-out. Table 3 shows that overall, around 9 out of 10 prisoners in the NW were being offered testing for HCV on entry to prison between April 2015 and March 2017. Just over a quarter of these accepted the test in 2016/17, an increase on the previous year and a noticeably higher proportion than the national figure of 10.5%.

However, only around half of those found to be anti-HCV positive went on to be tested for HCV PCR in 2016/17 (active disease), a decline on the previous year and well below the national figure. The summary figures presented mask some wide variation in performance within the prison estate and are also likely to reflect some of the limitations of this relatively new dataset (see Appendix 1).

**Table 3: North West Health and Justice Indicators of Performance on HCV testing, financial years 2015/16 and 2016/17**

| Health and Justice Indicator of Performance | Attainment in NW prisons financial year 2015/16 | Attainment in NW prisons financial year 2016/17 |
|---|---|---|
| Proportion of new receptions/transfers offered HCV testing | 95% | 87% |
| Proportion of new receptions/transfers undergoing HCV testing | 13% | 27% |
| Proportion of anti-HCV positive prisoners undergoing an HCV PCR test | 69% | 49% |

See Appendix 1 for limitations of this data

ODNs across the North West region are working towards improving diagnostic and treatment pathways in prison sites. For example, in Lancashire and South Cumbria treatment pathways fir RNA positive HCV cases has been reviewed to inform changes in referral and treatment access, with planned intensive test and treat intervention to commence un the new year. In the Greater Manchester area work is ongoing with targeted testing events, including at weekends, and introduction of point-of-care testing (POCT).

### 4.2.4. Testing in people originating from countries with high HCV prevalence

Testing patterns for non-White-British ethnic groups are discussed in chapter 2, section 2.3.3.

### 4.2.5. Testing of the blood donor (low risk) population

There has been a declining trend in the rate of confirmed HCV positive cases among new blood donors in the NW over the last 5 years. This mirrors the national trend.[1]

## 4.3. Increasing numbers accessing treatment

Increasing treatment uptake and completion for those with chronic HCV is a key target area for action in England. The WHO action plan for the European region sets ambitious targets of 75% of diagnosed patients with chronic HCV having accessed treatment by 2020, with more than 90% of these cured. 90% of all diagnosed patients should be linked into care and adequately monitored by 2020.

### 4.3.1. Operational Delivery Networks

ODNs are formal networks through which treatment with the direct acting antivirals (DAAs) for HCV is promoted and organised at a local level. There are 4 ODNs in the PHE NW region:

| ODN | Laboratory reports of hepatitis C (2017) |
|---|---|
| Cheshire and Merseyside | 97 |
| Greater Manchester and Eastern Cheshire | 624 |
| Lancashire and South Cumbria | 213 |
| North East and Cumbria | 318* |

Metrics to monitor progress in this area will come from the NHS England ODN National Treatment Monitoring Dataset. This will look at both equity and access to HCV treatment and care, as well as at the impact of treatment.

Provisional national NHS data suggests that in the financial years 2015/16 and 2016/17, significantly more people accessed treatment than in earlier years. This is due to the new DAA drugs that have become available, and which are being delivered through ODNs.[1]

All NW ODNs saw increases in the numbers receiving DAA drugs over the last 2 financial years (table 3), with a total 36% increase in the numbers treated across the region.

**Table 4: Numbers receiving direct acting antiviral treatment in PHE North West region Operational Delivery Networks for the financial years 2016/17 and 2017/18[6]**

| ODN | Numbers receiving direct acting antiviral treatment in the financial year | |
|---|---|---|
| | 2016/2017 | 2017/2018 |
| North East and Cumbria | 395 | 620 |
| Greater Manchester and Eastern Cheshire | 687 | 845 |
| Cheshire and Merseyside | 347 | 585 |
| Lancashire and South Cumbria | 330 | 343 |
| **TOTAL** | 1759 | 2393 |

Treatment numbers based on DAA drug treatments are given based on commissioning data which includes clinician intention to treat and invoicing rather than patient level treatment registry data. These data are subject to data quality issues and contract adjustments.

While further metrics are under development, some examples of the progress made by NW ODNs for the financial year 2017/18 are provided below:

| Cheshire and Merseyside HCV ODN |
| --- |
| **Treatment access:** Treatment is shifting from Liverpool's hospitals to the community. In the first 2 quarters of 2017, 123 of Liverpool's patients were treated in the hospital whilst only 24 were treated within the community. For the first 2 quarters of 2018 to date, 55 patients were treated in the hospital and 101 patients were treated in the community. The majority of treatments will now be administered in community clinic settings going forward, as we believe this is the best way to treat hard to reach patients. The hope is to get our Spoke sites to do what we are doing in Liverpool. |
| **Equity of access:** Work on active case finding for those lost to follow up or in hard-to-reach groups has begun in partnership with the Hepatitis C Trust and the charity Change Grow Live. A peer co-ordinator has been employed to help patients across the ODN engage with the treatment teams. There has recently been outreach testing and treatment in a local YMCA. |
| **Treatment outcomes:** known SVR12 rates for 2017 to 2018 are approaching the WHO 2020 target. At the ODN Hub we regularly update the HCV national registry, sending out lists of patients who do not have an outcome recorded to their treating centre, and then updating records once we get information back. The outreach work mentioned above is another way of re-engaging patients lost to follow up. |

| North East and Cumbria ODN |
| --- |
| **Treatment access**: The ODN now operates 17 outreach clinics across a range of sites. This includes 5 prisons, drug treatment services, needle exchanges and GP practices. Approximately 70% of HCV treatment is now delivered in outreach clinics. During the remainder of 2018 the ODN aims to increase this further with minimal HCV service delivery coming from secondary care. |
| **Equity of access**: The ODN places great importance on equity of access to HCV treatment for all patients. Treatment delivery is offered to patients in the clinic most suitable for them, with facilities that allow the patient to address other health and social needs at the same time. Excellent links have been built with substance misuse services and there are clear and well-defined test and treatment pathways in place. Moving forward the ODN has secured a Gilead fellowship to fund dry blood spot testing in community pharmacies that dispense methadone and link these patients into HCV treatment. |

| Greater Manchester and Eastern Cheshire ODN |
|---|
| **Treatment access:** 75% of referrals are seen out of hospital. The number of clinics provided in drug services, GP practices and hospitals without a local service has increased over the last year, and clinics also continue in prisons and community clinics. 23 outreach clinics run in total and further expansion is planned. A diagnostic pilot project has started in 8 pharmacies |
| **Equity of access:** There is ongoing work to promote better access to the homeless population. Currently this is provided through a joint clinic with the GP commissioned to provide primary care to this group. There are ongoing challenges with following up those in marginalised groups to the point of test of cure, particularly due to the high mobility of these individuals |

| Lancashire and South Cumbria ODN |
|---|
| **Treatment access:** A number of outreach clinics within SMS have been developed across the network, working closely with the local service providers. The majority of the patients started on treatment over the last year (>75%), have been seen in these clinics. 20% of the patients treated over the last year were cirrhotic. The ODN ensures that these patients are identified, prioritized for access to treatment and long term follow up is offered. Success rates for those completing treatment are more than 90%. |
| **Equity of access:** Home delivery service of medication or direct dispensing of treatment by the Liver team has been the standard process across the L&SC ODN, to ensure access to treatment for patients not engaging with Hospital based services. A joint care model with active involvement of the substance misuse clinical team in the delivery of the treatment is currently running as a pilot in 2 areas of the ODN, aiming to increase access to treatment by simplifying the traditional treatment pathways. The ODN is currently exploring different options to ensure access to treatment for the most difficult to engage patients. One of the first priorities of the ODN is to deliver testing and treatment in the most vulnerable patients, in the homeless and asylum seekers shelters or via community pharmacies. |
| **ODN infrastructure:** In October 2018 the ODN appointed a full time Project Manager, relaunched the quarterly Operational Group and established an ODN Board structure |

### 4.3.2. Care and treatment in Prescribed Places of Detection

Regarding monitoring access to care and treatment for the prison population with chronic HCV, new HJIP metrics were introduced in April 2014. These measure the proportion of those with chronic HCV who are referred to specialist services, and who have a treatment plan developed within 18 weeks. NW data is available on the former at present. Encouragingly, it shows that across the NW in 2016 and 2017 73% of those found to be HCV PCR positive were referred to a liver specialist. This is a large improvement on the 9% referral rate for the previous financial year. Again, this summary figure masks wide variation within the prison estate and the data has limitations (see Appendix 1).

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# 6. Appendices

## 6.1 Appendix 1: Information on data sources

This report is based on epidemiological data, which is collated annually by PHE and comes from variety of routine data collection and other sources. Important limitations of these data are discussed briefly below.

### Laboratory notifications:

Quantifies the burden of laboratory confirmed disease overall and in specific groups and locations. Laboratory reports are sent to PHE centres for individuals with a positive test for HCV antibody (a marker of past infection) or detection of HCV Ribonucleic acid (a marker of active infection).

### Limitations:

Currently laboratory reports cannot differentiate between past and current infection and so do not provide information about incidence or prevalence. Instead, they reflect patterns of testing and provide some insight into the impact of awareness-raising interventions with healthcare workers and at-risk individuals. Positive laboratory reports underestimate the true burden of infection because lack of symptoms means people are less likely to test and some symptomatic individuals may not present to health services until complications are present.

### Sentinel surveillance laboratory testing data:

The Sentinel Surveillance of Blood Borne Virus Testing Study collects data on laboratory test results and demographic data for all individuals tested for HCV antibodies in 24 sentinel laboratories in England. Information collected by the sentinel laboratory includes test result, demographic details of patient, location of test and reason for test.

This additional information gives an insight into the effectiveness of awareness campaigns aimed at, in particular, at-risk groups. Sentinel laboratory reports also provide counts of all individuals tested as well as positive results, which conveys information about trends in testing, numbers and rate of positive tests. Participating sentinel laboratories in the North West are Manchester PHE Laboratory (incorporating previous Health Protection Agency laboratories in Chester, Liverpool, Manchester and Preston) and Royal Liverpool University Hospital.

### Limitations**:**

There is some potential duplication of individual patients and distortion resulting from exclusion of dried blood spot, oral fluid and reference testing. Individuals aged less than 1 year, in whom positive tests may reflect the presence of passively acquired maternal antibody rather than true infection, are also excluded.

## The Unlinked Anonymous Monitoring Survey of HIV and Hepatitis in People Who Inject Drugs Survey

This annual cross-sectional survey is co-ordinated by Public Health England, with support from Public Health Wales and Public Health Agency Northern Ireland. It is targeted at those who inject psychoactive drugs. It estimates the current burden of disease in a key at-risk population and describes secular trends and levels of protective and risky behaviour.

### Limitations:

Participants consent to take part, so there is potential for selection bias. Additionally, the sample is drawn from individuals in contact with drug services and therefore may not be representative of all PWID. Regional level data should be interpreted cautiously as the survey recruits participants through a nationally reflective sample of the services provided to people who inject drugs.

### Health and Justice Indicators of Performance

An indicator set co-developed by NHSE, PHE and the National Offender Management Service. It replaced the Prison Health Performance Quality Indicators in April 2014. Data is returned quarterly from providers via a template.

### Limitations:

Some inconsistency and incompleteness in coding and the use of templates is recognised as an ongoing issue. This is likely to explain some of the variation in indicator values seen across the NW and is the reason that prison level data has not been presented in the report. Data from one of the 15 NW prisons has been excluded from the summary NW HJIP values due to these issues.

### Fingertips

This PHE website (fingertips.phe.org.uk) hosts a broad range of public health outcome indicators at various geographical levels. Each specific indicator has a definitions tab which details how the indicator is calculated, and the limitations of the data. A wide variety of routine data sources are used to build the indicators.

## Figure 4 (see 3.1.1) hospital admissions data – further details

*Patient counts are based on the unique patient identifier, HESID. This identifier is derived from a patient's date of birth, postcode, sex, local patient identifier and NHS number, using a standard algorithm. Where data are incomplete, HESID might wrongly link episodes or fail to recognise episodes for the same patient. Care is therefore

needed, especially where the data includes duplicate records. Patient counts must not be summed across a table where patients may have episodes in more than 1 cell.

***2016 data are provisional; HES provisional data may be incomplete or contain errors for which no adjustments have yet been made. Counts produced from provisional data are likely to be lower than those generated for the same period in the final dataset. It is also probable that clinical data are not complete. There may also be errors due to coding inconsistencies that have not yet been investigated and corrected. Patients who have had more than 1 hospital episode with a diagnosis of ESLD** in any one year and who have moved residence within that year have been grouped into the PHEC of their latest hospital episode in that year.
Data based on Hospital Episode Statistics as at July 2017.

Data relate to the number of individuals who were admitted to hospital and the episode in hospital ended in each calendar year. If an individual had more than 1 episode in the calendar year – we have only counted them once for this particular analysis, that is all patients with HCV/ESLD/HCC admissions were de-duplicated to give 1 individual with HCV/ESLD/HCC per calendar year.

Patients who have had more than 1 hospital episode with a diagnosis of HCV, HCV-related ESLD or HCV-related HCC in any one year and who have moved residence within that year have been grouped into the PHEC of their latest hospital episode in that year.

Data source: Hospital Episode Statistics (HES), NHS Digital. Produced by Public Health England. 