

Protecting and improving the nation's health

### Hepatitis C in the North West Annual report 2016

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Published: March 2018 PHE publications gateway number: 2017790

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### Abbreviations

Anti-HBc	Antibodies to Hepatitis B virus
Anti-HCV	Antibodies to Hepatitis C virus
Anti-HIV	Antibodies to Human Immunodeficiency Virus
BBV	Blood Borne Viruses
DAA	Direct Acting Antivirals
DAT	Drug Action Team
DBS	Dried Blood Spot
DSR	Directly Standardised Rate
ESLD	End Stage Liver Disease
GP	General Practitioner
HES	Hospital Episode Statistics
HBc	Hepatitis B virus
HCC	Hepatocellular Carcinoma
HCV	Hepatitis C Virus
HIV	Human Immunodeficiency Virus
HJIP	Health and Justice Indicators of Performance
ICD	International Classification of Diseases
IVF	In Vitro Fertilisation
NHS BT	National Health Service Blood and Transplant
MSM	Men who have Sex with Men
NDTMS	National Drug Treatment Monitoring System
NHS E	National Health Service England
NICE	National Institute for Health and Care Excellence
ODN	Operational Delivery Network
ONS	Office for National Statistics
OST	Opiate Substitution Therapy
PCR	Polymerase Chain Reaction
PHE	Public Health England
PHPQI	Prison Health and Performance Indicator
PWID	Persons who inject drugs
RCGP	Royal College of General Practitioners
RNA	Ribonucleic Acid
SGSS	Second Generation Surveillance System
STP	Sustainability and Transformation Partnership
UAMS	Unlinked Anonymous Monitoring Survey of infections and risk among people who inject drugs

### Executive summary

This report concerns the epidemiology of hepatitis C virus (HCV) infection in the North West of England using surveillance data that are routinely available up to the end of 2015.

#### Epidemiology and burden

- approximately 40,000 have acquired HCV infection in the North West of England, with an estimated 27,000 having developed chronic HCV infection; remaining unchanged since 2014. It is estimated that 40% (16,000) of these infections remain undiagnosed. More than one-quarter of individuals with HCV infection are thought to reside in Lancashire and Manchester local authority areas
- an estimated 68% of people who inject drugs in the North West are infected with HCV, higher than any other region
- using positivity rates in young people who inject drugs as a proxy for incidence, the incidence of HCV infection has remained relatively stable since 2011
- there were 1,373 laboratory reports for HCV infection in 2015 in the North West, fewer than any of the preceding 10 years

#### Morbidity and mortality

- crude rates of hospital admissions for HCV-related end stage liver disease (ESLD) and hepatocellular carcinoma (HCC) were significantly higher in the North West than in England overall between 2012 and 2015, with 3.9 and 2.4 per 100,000, respectively. These crude rates are significantly higher in 11 out of the 23 local authorities compared to the rate in England overall. However, there is considerable variation between North West authorities, with crude rates ranging from 1.5 per 100,000 in Cumbria to 7.8 per 100,000 in Liverpool
- the rate of premature mortality resulting from HCV-related ESLD or HCC between 2013 and 2015 was significantly higher in the North West than in England overall, with 1.02 and 0.67 deaths per 100,000, respectively. Mortality rates in six North West local authorities were significantly higher than England overall
- the modelled projections for the burden of disease in the North West of England estimate that 1,669 individuals will have cirrhotic or end stage liver disease by 2023

#### Increasing awareness and reducing undiagnosed infections

 sentinel surveillance data indicates that testing activity has increased whilst positivity rates have decreased in the North West during recent years. Overall, the number of individuals tested each year increased by 14% between 2011 (27,705) and 2015 (31,669) whilst the positivity rate halved during this period, with 1.6% antibody positive in 2015

- dried blood spot (DBS) testing is playing an increasingly important role in specialist drug services and is now available in this setting across 21/23 local authorities in the North West. For individuals with injecting drug use recorded as the reason for testing, DBS accounted for 82% of individuals tested in drug services in 2011, which had increased to 99.4% by 2015. However, whilst DBS testing data is captured through sentinel surveillance it is not included in routine reporting and analyses of sentinel surveillance data. This resulted in 881 individuals tested using DBS in 2015 not being included in sentinel reporting; therefore reports show only 7 individuals tested in this setting (those tested using standard venepuncture). Furthermore, laboratory reports of HCV infection from DBS are not captured in surveillance of routine laboratory reports
- in North West prisons during 2015/16, more than three-quarters (77.9%) of prisoners were offered a test for HCV infection within 72 hours of reception. This equates to over 24,000 individuals being offered a test; representing excellent opportunistic testing of a population at increased risk of infection. Despite the majority of individuals being offered a test, uptake was low with only 12.1% tested. Therefore, 20,773 individuals declined the offer of a test for HCV infection, which is a missed opportunity to diagnose and treat individuals with asymptomatic infection
- sentinel surveillance data shows an upward trend in the number of South Asian individuals tested, with 2,387 in 2011 compared to 2,687 in 2015. During this period, there was a slight downward trend in positivity rates, which decreased from 3.7% in 2011 to 2% in 2015. Testing individuals of South Asian origin accounted for 10% of total testing activity each year between 2011 and 2015 (where ethnicity was known)

#### Preventing new infections

- 78.6% of people who inject drugs (PWID) in drug treatment in the North West were tested for HCV infection between 2014 and 2015. There was considerable variation between local authority areas, where the proportion ranged from only 59.4% in Oldham to 93.6% in Warrington. 7 authority areas in the North West had rates significantly better than the overall rate in England whilst rates were significantly worse in 10 authorities
- there was a general downward trend in levels of direct sharing of injecting equipment among PWID in the North West of England between 2005 and 2015, with rates decreasing from 24% to 15%. Indirect sharing also became less commonplace during the same period with 34% in 2015 compared to 45% in 2005. Whilst these downward trends should be acknowledged as progress and demonstrate improvements, the findings indicate the one-third of PWID are still indirectly sharing injecting equipment

### Progress on recommendations: 2015 Annual Report

Table 1. Summary of progress against recommendations outlined in the Hepatitis C in the North West 2015 Annual Report

Recommendation (abridged)	Progress
1. Services should be commissioned and provided	HCV was included in recent needs assessments for PWID in 13/23 local
based on a clear understanding of local needs and	authorities in the North West of England
risk groups. Blood borne viruses should be	<ul> <li>HCV/liver disease not yet included as a priority area in North West Sustainability</li> </ul>
included in needs assessments.	and Transformation Partnerships – so more progress to be made
2. Service commissioners and providers should	PHE North West Centre supported the development of multi-stakeholder groups by:
commit to developing whole system perspectives.	<ul> <li>organising and hosting events to develop viral hepatitis in each of the 3 PHE</li> </ul>
PHE centres should support the development of	North West areas
multi-stakeholder groups that can lead on the	There is potential for further improvement:
development and implementation of local strategy	<ul> <li>multi-agency strategy groups to address HCV have been established in 2/3 PHE</li> </ul>
and improved care pathways.	North West areas
<b>3.</b> Providers and commissioners of specialist and	Using testing activity as a proxy for awareness:
non-specialist services should support and enable continuing professional training to increase	<ul> <li>there were 1,373 laboratory reports for HCV infection in 2015, fewer than any of the preceding 10 years</li> </ul>
awareness of HCV infection, groups at greater risk	<ul> <li>there has been a gradual upward trend in testing activity, with a 14% increase</li> </ul>
(including specific ethnic groups), and best practice	between 2011 and 2015. The positivity rate halved during this period, with 1.6% of
regarding, testing, treatment and preventative	individuals tested antibody positive in 2015
advice.	PHE North West supported HCV-related professional development by:
	<ul> <li>organising and hosting 4 HCV training events for healthcare professionals reaching</li> </ul>
	an audience of approximately 300 people
4. Work to increase systematic testing in prisons	BBV opt out testing has been rolled out across all North West prisons. It is
needs to continue and should be integrated into	commissioned by NHS England and is monitored as part of HJIPS
local strategies. It is essential that opportunities to	

test, diagnose and treat are not missed.	<ul> <li>NHS England is evaluating delivery of BBV opt out screening: currently awaiting final report and recommendations</li> <li>The PHE North West Centre is are working in partnership with NHS England and all NW prisons to develop the pathway.</li> </ul>
<b>5.</b> Service providers and commissioners should consider outreach and peer champion models to extend the reach of their prevention, testing and awareness raising activities in line with need.	<ul> <li>NW prisons to develop the pathway</li> <li>Specific examples of progress in this area include outreach initiatives:</li> <li>South Asian community: Engagement with 1,182 individuals and 445 individuals tested at a mosque and the Mega Mela Festival in Manchester over 6 days between 2015 and 2016</li> <li>prisons: outreach projects in Cheshire and Merseyside prisons are underway.</li> <li>migrant population: Awareness raising events in Lancashire</li> </ul>
6. Implementation of dry blood spot testing as a more acceptable form of testing should be encouraged.	<ul> <li>DBS testing is available in specialist drug services in 21/23 local authorities (based upon 2015 PHE North West Centre survey)</li> <li>it is unclear to what extent this method of specimen collection is available in other settings across the North West of England</li> </ul>
7. Commissioners of services for people who inject drugs should consider the needs of people who inject performance and image enhancing drugs and promote regular testing.	<ul> <li>There is limited evidence to measure progress against this recommendation.</li> <li>people who inject performance and image enhancing drugs were included in needs assessments for substance misuse in many local authorities</li> <li>however, this was not always explicitly linked with HCV and other blood borne viruses</li> </ul>
<b>8.</b> Providers of sexual health services should assess risks from 'chemsex' and offer HCV testing accordingly.	<ul> <li>PHE Greater Manchester Health Protection Team has been undertaking a health needs assessment for chemsex</li> </ul>
<b>9.</b> Commissioners and providers of treatment services, and operational delivery networks should contribute to the development of improved datasets to describe patterns and levels of treatment uptake, completion and outcome. Data should be used to conduct equity audits and improve services.	<ul> <li>4/4 ODNs have been collecting data systematically on treatment completion and outcome</li> <li>each ODN has taken their own approach to collecting and analysing treatment data. A consistent approach, which will align with plans for a national treatment dataset has recently been requested by NHS England</li> </ul>

<b>10.</b> Care pathway/patient journey mapping should	<ul> <li>3/4 ODNs have participated in events to review and develop the viral hepatitis</li> </ul>
be regularly reviewed at a local level in order to	clinical pathway
recognise and address barriers to successful	
treatment outcomes and reduce loss to follow-up.	
This should also include prison pathways and	
opportunities for providing treatment in non-	
hospital settings.	

### Recommendations: 2016 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 (Appendix 0).

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 2015 (Table 1). Progress against these recommendations should be measured when compiling the next hepatitis C annual report.

#### **Recommendation 1**

PHE North West should ensure that future reports on the epidemiology of hepatitis C virus (HCV) are structured to support national monitoring of the recently signed World Health Organization (WHO) elimination strategy, whilst also ensuring the reports meet the needs of the Operational Delivery Networks. Nationally, PHE has committed to the WHO goal with the data and metrics in Appendix **Error! Reference source not found.** roposed to measure progress.

Audience: PHE North West.

#### **Recommendation 2**

PHE North West should work with local authorities, who did not include HCV in recent needs assessments for groups at risk of HCV infection, to improve understanding of the burden of disease in their populations and to ensure services meet the needs of groups at increased risk (Table 1). This follows on from progress made towards 2015 recommendations 1-3, 5 and 7-8.

Audience: PHE North West and North West local authorities.

#### **Recommendation 3**

PHE North West and NHS England should work with Operational Delivery Networks to strengthen collection of HCV treatment data, ensuring that public health principles are followed and appropriate analyses are completed to assess equity of access and to identify unmet needs. This builds upon progress made towards 2015 recommendations 9-10.

Audience: PHE North West, NHS England and Operational Delivery Networks.

#### **Recommendation 4**

PHE North West should continue to work with local authorities to ensure that dried blood spot testing for HCV infection is available in all community drug and alcohol services across the North West. This recommendation relates to the work completed on 2015 recommendation 6.

Audience: PHE North West and North West local authorities.

#### **Recommendation 5**

PHE North West should continue to work with NHS England, North West prisons and Operational Delivery Networks to increase uptake of testing and reduce attrition across the clinical pathway. This should be monitored via Health and Justice Indicators of Performance. This leads on progress towards 2015 recommendation 4. **Audience:** PHE North West, North West prisons, NHS England and Operational Delivery Networks.

### 1. Introduction and background

#### 1.1. Hepatitis C virus infection

Hepatitis C virus (HCV) is a blood borne virus that is often asymptomatic, and symptoms may not appear until the liver is severely damaged. Therefore, many individuals with chronic HCV infection remain undiagnosed and fail to access treatment. These individuals can then present late with complications of HCV-related end-stage liver disease (ESLD) and cancer, which have poor survival rates.

HCV is a major public health problem affecting an estimated 200 million worldwide.<sup>1</sup> HCV infection disproportionately affects marginalised populations in the UK.<sup>2</sup> Approximately 90% of cases are attributable to injecting drug use with the remaining proportion largely occurring in populations who have close links to countries with a high prevalence of HCV infection.<sup>3</sup>

HCV infection in the UK general population is uncommon, with an estimated 214,000 adults or 0.67% of the population infected (95% CI 0.5-0.94%). By contrast, half of people who inject drugs (PWID) in the UK have HCV infection (49%; 95% CI 47-51%).<sup>4</sup> In the non-injecting drug user UK population HCV infection is 15 times more prevalent in South Asians than other ethnicities, with rates of 0.76 and 0.05%, respectively.<sup>3</sup> Ethnicity, however, is not in itself a risk factor for HCV but reflects the increased risk of iatrogenic transmission in countries of high prevalence.<sup>3,5</sup>

HCV is the third most common cause of liver disease in the UK where associated morbidity and mortality have increased for 14 consecutive years.<sup>6</sup> More than half of the estimated 214,000 individuals infected remain undiagnosed.<sup>6</sup> HCV-related disease now accounts for 18% of liver transplants and HCV-related cirrhosis is predicted to increase from 10,850 to 13,590 individuals during the next decade.<sup>6,7</sup>

New and more effective treatments are available for people with HCV infection including those with advanced forms of HCV-related liver disease.<sup>7,8</sup> However, systematic data collection concerning treatment uptake, completion and outcome remains under development.<sup>9,10</sup>

#### 1.2. Elimination of hepatitis C virus infection

On 28 May 2016, the World Health Assembly adopted a Global Health Sector Strategy (GHSS) on viral hepatitis for the period 2016 to 2021.<sup>11</sup> This strategy introduced the first ever global targets for viral hepatitis control.<sup>11</sup> Subsequently, the WHO European Region published its draft action plan for the health sector response to viral hepatitis, outlining their relatively more ambitious proposals for targets and milestones to tackle the estimated 15 million people living with chronic HCV infection in this region.<sup>12</sup>

PHE has committed to support WHO in their goal to eliminate HCV as a major public health threat by 2030.<sup>10</sup> This can be achieved via the collective action of all partner organisations involved in the prevention, diagnosis, treatment and care of those living with, or at risk of acquiring, HCV infection. PHE has released the following vision statement for HCV infection:

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

To eliminate HCV as a major public health threat, there are 2 main impact areas where we need to make progress: we need to reduce the numbers becoming seriously ill or dying from this infection, whilst at the same time reducing the number of people who become newly or re-infected.<sup>10</sup>

To track our progress, it is important to monitor the impact of interventions in the following 2 impact areas (see Table 2, Appendix 9.2):

- reducing transmission, and hence the number of new (incident) HCV infections
- reducing morbidity and mortality due to HCV and its complications

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

- adequacy of harm reduction
- numbers and proportion of infected people who are diagnosed
- numbers, and ultimately the proportion, of infected people accessing treatment

#### 1.3. Data sources

This report describes HCV statistics for the North West of England, encompassing the areas of Cheshire and Merseyside, Cumbria and Lancashire and Greater Manchester. It 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 highlighted in the text and also 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 - describes trends in testing, positivity rates and distribution of risk factors/exposures. 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. Coverage is 60-79% in Cheshire and Merseyside and 40-59% elsewhere in the North West.

**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 one 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 of people who inject drugs Survey (UAMS) estimates 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.

Office of National Statistics mortality data – can be used as a measure of clinical activity to address an important outcome of HCV infection.

**Limitations:** may not provide sufficient information to correctly attribute a death from HCV-related related causes

Other data sources include:

- Health Episode Statistics quantifies the burden of disease and complications at the more severe end of the spectrum
- National Drug Treatment Monitoring System (NDTMS) provides an indication of offer and uptake of testing in a high risk population at local authority area level
- UK Transplant Registry provides a measure of clinical activity to address important complications of HCV infection
- the PHE HCV commissioning template for estimating disease prevalence and burden of disease in England - provides estimates to support health service commissioning, projections and prioritisation of resources

### 2. Epidemiology and burden of hepatitis C

#### 2.1. The scale of the problem in the North West: burden of disease and trends

Understanding the scale of the problem that HCV infection presents the North West of England is complex and challenging. Estimating the number of individuals infected using statistical modelling requires 2 parameters: the size of each at-risk population and the prevalence of infection with of these groups. The complexity arises due to the considerable uncertainty around each of these parameters.<sup>13</sup> At regional and local level, estimated numbers of infected do not account for the statistical uncertainty of the estimates and it currently not possible to produce confidence intervals that would give an indication of upper and lower bounds for these estimates.<sup>14</sup> Future modelling work will aim to incorporate data at a more local level, and estimate local prevalence within a formal statistical model, which will allow this uncertainty to be reported.<sup>10</sup>

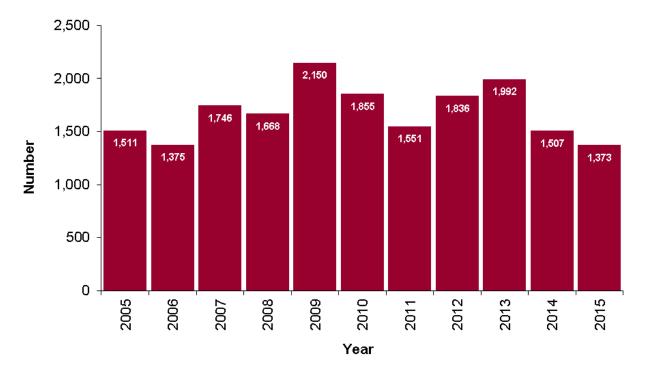
Notwithstanding these limitations, it is estimated that approximately 40,000 have acquired HCV infection in the North West of England, with an estimated 27,000 having developed chronic HCV infection. These individuals are distributed across the region, with an estimated 10,959 people living in Cheshire and Merseyside, 11,250 residing in Cumbria and Lancashire and the remaining 17,452 in Greater Manchester. Based upon statistical modelling, an estimated 40% of these individuals have not yet been diagnosed. Diagnosing these 16,000 individuals is a public health priority. Ensuring that those already diagnosed receive treatment is an equally important public health goal.

#### 2.1.1. Laboratory reports in the North West

The number of antibody positive HCV laboratory reports between 2009 and 2015 in residents of the North West of England by year are presented in Figure 1. Here were fewer reports during 2015 than any of the preceding 10 years. The 1,373 reports in 2015 equates to a crude rate of 19.1 per 100,000 of population. Whilst the number of reports has varied considerably during this period, including peaks in 2009 and 2013, there is no evidence of a directional trend. Conversely, there has been an upward trend in laboratory reports for England overall, with an 82.6% increase between 2005 and 2015. By 2015, this upward trend resulted in the crude rate for England exceeding the rate observed in the North West for the first time, with 21.1 per 100,000 of population.

Trends in laboratory reports help to quantify the number of individuals that have been exposed to HCV who are in contact with healthcare services and have been tested. It is important to recognise that antibody positive HCV laboratory reports describe neither the incidence nor the prevalence of HCV infection. Firstly, antibody testing, the routine frontline testing method, cannot differentiate between acute, chronic or past infection. Secondly, due to the asymptomatic nature of the infection a large proportion of

individuals infected will not seek medical assessment until many years after acquiring the infection when symptoms have developed.



### Figure 1. Number of laboratory reports of hepatitis C, residents of North West PHE Centre, 2005-2015.

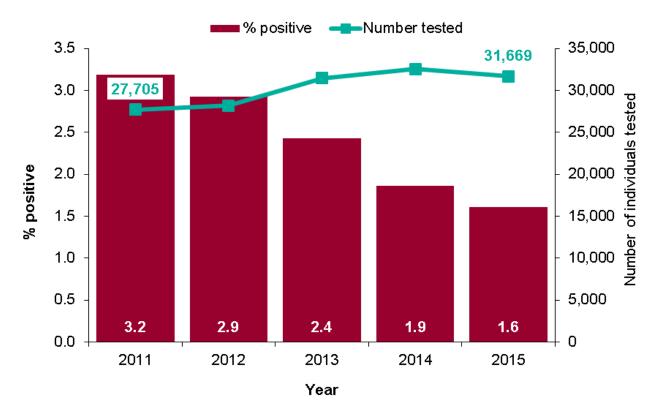
Data are summarised by PHE centre of residence, not PHE centre of laboratory. Data are assigned to PHE centre by patient postcode where present; if patient postcode is unknown, data are assigned to PHE centre of registered GP practice; where both patient postcode and registered GP practice are unknown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

Includes individuals with a positive test for HCV antibody and/or detection of HCV 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.

Furthermore, surveillance of laboratory reports cannot be used to describe testing activity, as negative test results are not included. Therefore, there is no denominator available for the number of individuals tested. Data collected through the Sentinel Surveillance Study of Blood Borne Virus Testing includes all tests, not just positives, and can therefore provide a denominator for overall testing activity as well as positivity rates (for areas with a participating laboratory). Sentinel data shows that there has been a gradual upward trend in the number of individuals tested each year in the North West of England in recent years, with 31,669 individuals tested in 2015 compared to 27,705 in 2011 (Figure 2).

The positivity rate halved during this period, with 1.6% of individuals tested antibody positive in 2015. A decrease in positivity rate might be expected following in increase in testing activity, but not necessarily of this magnitude. It is also important to acknowledge

that these data do not include results from dried blood spot or oral fluid testing methods. This is significant, as the use of these methods (DBS in particular) became increasingly commonplace in specialist drug services during this period. Further possible explanations for this decrease will be explored by analyses of Sentinel data stratified by setting of test and demographic characteristics of individuals tested.



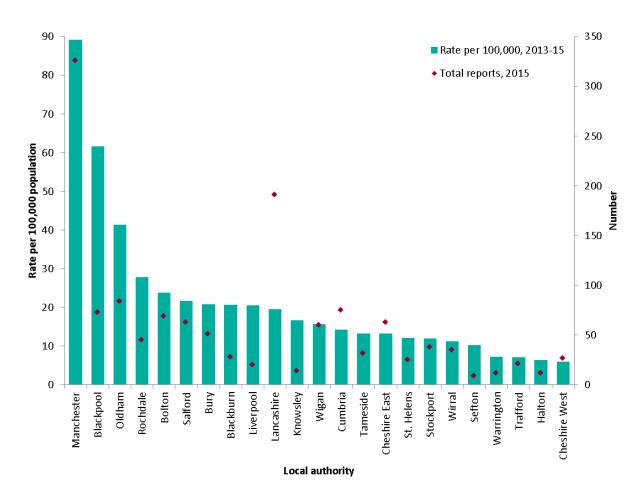
### Figure 2. Number of individuals tested and % testing positive for anti-HCV in sentinel laboratories in North West PHE centre, 2011-2015.

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 one year, in whom positive tests may reflect the presence of passively acquired maternal antibody rather than true infection. All data are provisional.

#### 2.1.2. Laboratory reports: Local authority areas

The number and crude rate of antibody positive HCV laboratory reports varies between local authorities in the North West of England. Figure 3 shows that in absolute terms, there were more HCV laboratory reports in Manchester than any other area in 2015 with 326 reports compared to 191 in the next highest area, Lancashire. The numbers of reports in these areas are orders of magnitude higher than in the authorities with the lowest numbers, which include Sefton with 9 and Halton with 12. The number of reports relative to population size was also highest in Manchester, with a crude rate of 89.2 reports per 100,000 of population between 2013 and 2015, 4 times greater than the overall rate for the North West in 2015. Crude rates in Blackpool and Oldham are also outliers, with 61.6 and 41.4 per 100,000, respectively.

The estimated prevalence rate of HCV infection varies between local authorities in the North West of England. This can, in part, explain some of the variation in rates of laboratory reports between areas. However, testing policies and awareness among healthcare professionals are also likely to account for some of the variation.



# Figure 3. Number of laboratory reports of hepatitis C (2015) and rate of laboratory reports per 100,000 population (2013-2015), residents of PHE North West Centre, by upper tier local authority.

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 HCV antibody and/or detection of HCV 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.

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

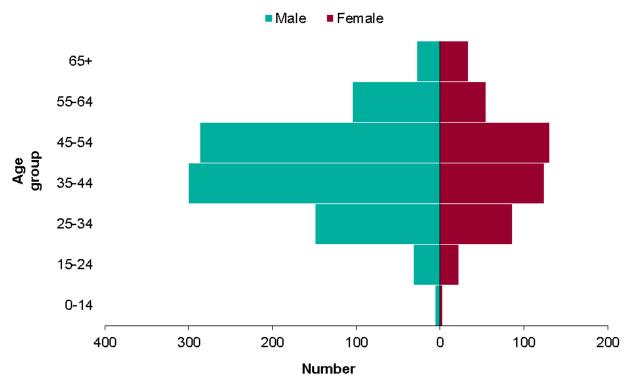
Calculating directly standardised rates goes some way towards addressing the different prevalence rates between areas, by taking into account the underlying population structure, which in part reflects the size of the population at increased risk of HCV

infection. Figure 22 (Appendix 0) shows that once age differences are accounted for, the areas with the greatest burden of laboratory confirmed HCV infection in 2015 were Manchester, followed by Blackpool and Oldham; with rates in standardised rates in these areas all significantly higher than England overall. These findings demonstrate that many areas in the North West are experiencing a greater demand on services and face a greater challenge to address HCV infection than would be expected from their age profiles and associated behavioural risks.

#### 2.2. Population characteristics and risk exposures

#### 2.2.1. Age and sex

The age and sex distribution of positive HCV laboratory reports for the PHE North West Centre in 2015 is presented in Figure 4. With 907 reports, males accounted for two thirds of all reports. 61% reports were for individuals aged between 35 and 54 years of age, with 31% in 35-44 year olds.



### Figure 4. Age group and gender of reported cases of hepatitis C, residents of PHE North West centre, 2015.

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

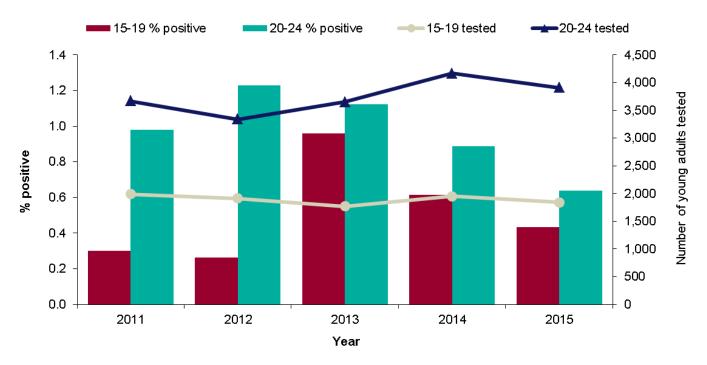
Includes individuals with a positive test for HCV antibody and/or detection of HCV RNA. Due to the variability in the quality of laboratory reports and the inability of current serological assays to differentiate acute from persistent infections we are unable to estimate the actual proportion of cases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

The majority of new infections acquired through injecting drug use occur at a relatively young age, the prevalence of infection in young adults or in recent initiates to injecting drug use, can be used as proxy measures of incidence.<sup>10</sup> Data collected through Sentinel Surveillance on number of young people tested and the proportion testing positive for HCV in the North West of England are presented in Figure 5.

These data demonstrate that the number of individuals aged 15-19 years tested has remained relatively stable over the past 5 years, with 1,842 tested in 2015. The positivity rate also remained relatively stable ranging from 0.3% to 1%, which equates to very few individuals (only 5 and 17, respectively). Testing of 20-24 year olds increased during the same period, with a general upward trend, with 3,911 individuals tested in 2015, a small decrease from the number tested in 2014.

Positivity rates in this age group were also low throughout this period, with a gradual downward trend between 2012 and 2015, following a small increase between 2011 and 2012. The proportion of individuals that were antibody positive was consistently higher in this age group than in the 15-19 year olds, ranging from 1.2% in 2012 to 0.6% in 2015.

As a proxy for incidence, these rates suggest that acquisition of HCV infection has remained relatively stable during this period, with a possible small reduction in 20-24 year olds. Both of these trends broadly correspond to observations in other PHE Centres. It is important to highlight the potential impact of DBS and oral testing data being excluded from these analyses, given the increasing use of these methods (DBS in particular) in specialist drug services, a setting in which people who inject drugs are more likely to be tested. It is also important to note that given the small numerator in these rates, small changes can result in exaggerated variations.



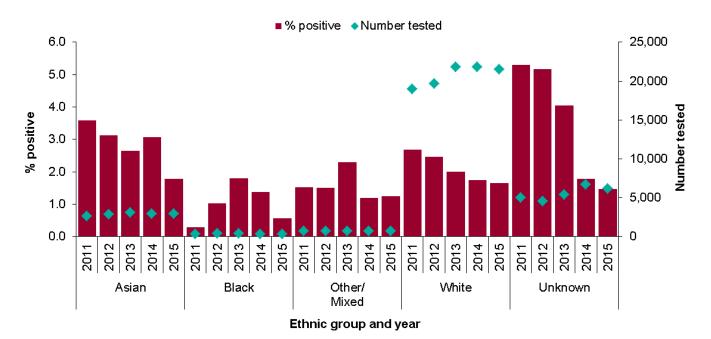
### Figure 5. Number of young adults tested and % testing positive for anti-HCV in sentinel laboratories in PHE North West centre, 2011-2015.

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.

#### 2.2.2. Ethnicity

In many countries, HCV infection is more common in the general never injected drugs population than it is in the UK general population. As a result, migrant groups from specific countries are targeted for testing. 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 in the countries of origin. Country of birth is not recorded in laboratory information systems, therefore ethnicity is used as a proxy. For data collected through Sentinel Surveillance, ethnicity of individuals tested in the North West of England were categorised using self-reported ethnicity where available and OnoMap or NamPehchan name analytical software (Figure 6).

As expected, white ethnicity accounted for the largest proportion (at least two thirds) of testing activity in each of the 5 years. However, it is important to acknowledge that this group included a large number of people who injected drugs, which is reflected in the positivity rates of between 1.7% and 2.7%, considerably higher than the general population in England. Testing in 'black' and 'other or mixed' ethnic groups remained low but stable, with positive results less than 20 per year between 2011 and 2015. With ethnicity unknown in approximately one-fifth of individuals tested each year and annual positivity rates of between 5.3% and 1.5%, it is important to acknowledge the limitation in our understanding of ethnicity and HCV infection in the North West of England.

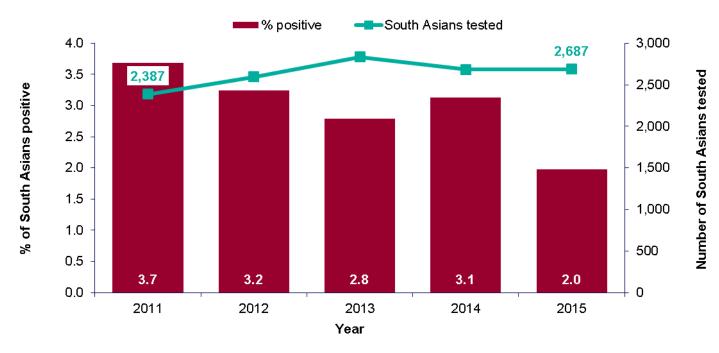


### Figure 6. Number of individuals tested and % positive for anti-HCV by ethnic group, sentinel laboratories in PHE North West centre, 2011-2015.

These sentinel surveillance data exclude 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 one year, in whom positive tests may reflect the presence of passively acquired maternal antibody rather than true infection. All data are provisional.

A combination of self-reported ethnicity, and OnoMap and NamPehchan name analyses software were used to classify individuals according to broad ethnic group.

Figure 7 presents more detailed data of testing of individuals of South Asian origin. This shows a small upward trend in the number of individuals tested, with 2,387 in 2011 compared to 2,687 in 2015. During this period, there was a slight downward trend in positivity rates, which decreased from 3.7% in 2011 to 2% in 2015. Testing individuals of South Asian origin accounted for 10% of total testing activity each year (where ethnicity was known).



### Figure 7. Number of individuals of South Asian origin tested and testing positive for anti-HCV by ethnicity in sentinel laboratories in PHE North West centre, 2011-2015.

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

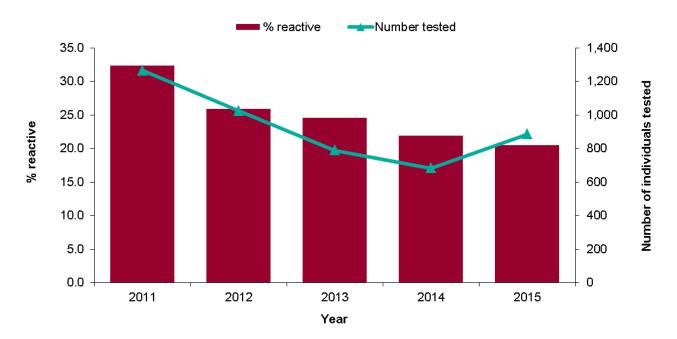
#### 2.2.3. People who inject drugs

Testing for HCV infection in people who inject drugs is a key component to the public health goal of identifying and treating all infected individuals. Data collected through Sentinel Surveillance between 2011 and 2014 shows a downward trend in the number of individuals tested in specialist drug services in the North West of England, with injecting drug use recorded as the reason for test, followed by an increase in 2015. There was a year on year reduction in the positivity rates during this period, with 32.4% in 2011 compared to 20.5% in 2015. Possible explanations for this reduction in positivity rates include reduced transmission from safer injecting practices and, or improvements in treatment uptake and completion.

Further analysis of these data demonstrate how much DBS contributes to total testing activity of people who inject drugs, in drug services; with DBS accounting for 82% individuals tested in 2011 which had increased to 99.4% by 2015. It is important to note that the reason for test field is often not completed by the clinician requesting the test and, therefore, the data only include individuals where injecting drug use was explicitly recorded on the test request form.

Further information from the Unlinked Anonymous Monitoring Survey of people who inject illicit drugs or are in contact with specialist drug agencies is provided in the 'prevention and harm reduction' section of this report. The discrepancy between

positivity from sentinel surveillance of specialist drug services and UAMS data may be due to a variety of factors. For example, self-selection in voluntary testing surveys and incomplete coverage of the drug-using population through sentinel surveillance, as well as differing characteristics in relation to engagement, testing and treatment between the 2 population samples.



### Figure 8. Number of persons who inject drugs tested and testing positive for anti-HCV at specialist drug services in sentinel laboratories in PHE North West centre, 2011-2015.

These sentinel surveillance data exclude reference testing. These sentinel surveillance data and testing from hospitals referring all samples. Data are de-duplicated subject to availability of date of birth, soundex and first initial. All data are provisional.

3 participating laboratories have rolled out dried blood spot testing of anti-HCV. These data are presented from 2010 and are shown by PHE Centre of the requesting clinician.

### 3. Morbidity and mortality

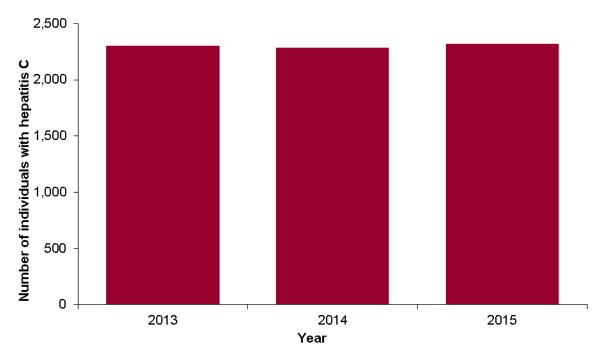
When measuring and describing HCV-related morbidity and mortality it is important to consider the natural history of chronic HCV virus infection. The extended asymptomatic period which typically occurs following acquisition of HCV infection can result in a lead time of 15-30 years before infected individuals present at healthcare services with HCV-related illnesses.<sup>15</sup> Therefore, current rates of the sequelae of chronic HCV infection, ascertained by healthcare usage or mortality registration, do not reflect the incidence of new HCV infections.

#### 3.1. Hospital admissions

New cases of HCV-related illness, including ESLD and HCC, can be monitored using Hospital Episode Statistics (HES) and International Statistical Classification of Diseases and Health Related Problems (ICD 10) diagnostic codes. The numbers of individuals admitted to hospitals in the North West of England between 2013 and 2015, with HCV diagnostic codes recorded, are presented in Figure 9.

The overall annual total remained relatively stable over the 3 years, with only a small decrease from 2,749 to 2,707. However, there were larger differences in the individual classification groups of which the total is comprised. ESDL represented 13.9% (n=382) of admissions in 2013, compared to 11.7% (n=316) in 2015.

Direct comparisons with years prior to 2013 are not possible due to changes in the geographical boundaries used for surveillance purposes (PHE North West Centre [2013 onwards] and Government Office North West [pre-2013]). However, it is possible to determine that annual hospital admissions have remained relatively stable since 2008.



### Figure 9. Hospital admissions for individuals\* with a diagnosis code for hepatitis C, residents of PHE North West centre, 2013-2015.

Data source: Hospital Episode Statistics (HES), NHS Digital.

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 one episode in the calendar year - they have been counted once for this particular analysis, for example, all patients with HCV/ESLD/HCC admissions were de-duplicated to give one individual with HCV/ESLD/HCC per calendar year.

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 or text entries for ascites (R18), bleeding oesophageal varices (I850), hepato-renal syndrome (K767), hepatic encephalopathy or hepatic failure (K704) (K720) (K721) (K729).

\*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 one cell.

Crude rates of hospital admissions for HCV-related ESLD and HCC were significantly higher in the North West than in England overall between 2012 and 2015, with 3.9 and 2.4 per 100,000, respectively (Figure 10). These crude rates are significantly higher in 11 out of the 23 local authorities compared to the rate in England overall (denoted by red bars in Figure 10). However, there is considerable variation between North West authorities, with crude rates ranging from 1.5 per 100,000 in Cumbria to 7.8 per 100,000 in Liverpool.

These data not only demonstrate the burden of disease experienced by North West population, but also serve as a reminder of the scale of the demand placed on healthcare system and resources.

Area	Value		Lower Cl	Upper Cl
England	2.4	Н	2.4	2.5
North West region	3.9	H	3.6	4.1
Liverpool	7.8		- 6.4	9.4
Manchester	6.9		5.7	8.4
Bury	5.9		4.1	8.3
Rochdale	5.8		4.1	8.0
Wirral	5.6	<b>⊢−−−−</b>	4.2	7.3
Sefton	5.6	<b>⊢</b>	4.1	7.5
Blackburn with Darwen	5.2		3.3	7.8
Salford	4.7	<b>⊢</b> −−−−−	3.3	6.6
St. Helens	4.7	<b>⊢−−−−</b>	3.1	7.0
Bolton	4.1	H	2.8	5.7
Wigan	3.9		2.7	5.3
Blackpool	3.5	<b>┝────</b> ┥	2.0	5.8
Halton	3.2		1.6	5.5
Oldham	2.9	<b>⊢−−−</b>	1.8	4.5
Lancashire	2.9	⊢- <mark> </mark>	2.3	3.5
Warrington	2.8		1.6	4.4
Stockport	2.2	<mark>┝━━</mark> ━━━┥	1.3	3.5
Cheshire East	2.1		1.4	3.2
Tameside	2.0	<mark>⊢</mark>	1.0	3.4
Trafford	1.9	<mark>┝━━</mark> ━━━━┥	1.0	3.2
Knowsley	1.8	<del></del>	0.8	3.6
Cheshire West and Chest	1.8	<mark>⊢</mark>	1.1	2.9
Cumbria	1.5		0.9	2.2

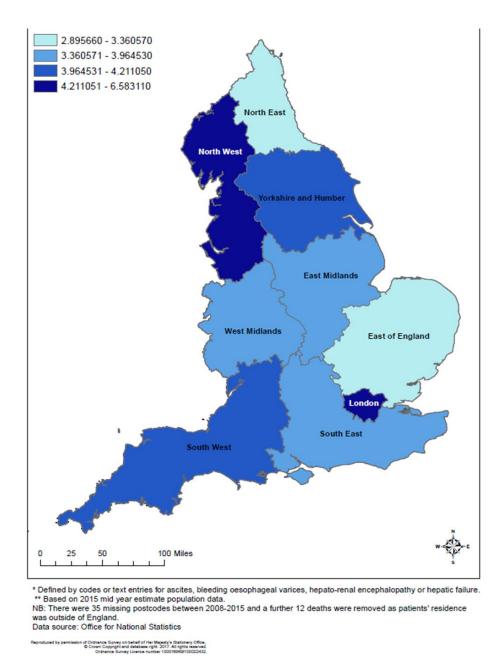
Source: Calculated by Public Health England: Clinical Epidemiology Knowledge and Intelligence from data from NHS Digital, formally the Health and Social Care Information Centre (HSCIC) - Hospital Episode Statistics (HES) and Office for National Statistics (ONS) - Mid Year Population Estimates

### Figure 10. Hospital admission rate for hepatitis C related end-stage liver disease/hepatocellular carcinoma (crude rate per 100,000) 2012/13-2014/15, by local authority.

#### 3.2. Mortality from hepatitis C-related conditions

Estimating mortality resulting from HCV-related ESLD or HCC in England is completed using two sources of data. First, the Office of National Statistics (ONS) collates numbers of deaths based upon information recorded during death certification. This method may result in underestimating the number of deaths due to inaccurate recording or hierarchical coding for cause of death. Second, estimates can be derived from HES where the main treatment diagnosis for a care episode ending in death was recorded as ESLD or HCC. Estimates calculated using this method might also be subject to misclassification where deaths were actually due to another cause.

Between 2008 and 2015, rates of HCV-related ESLD or HCC were highest in PHE North West and PHE London Centres (Figure 11).



# Figure 11. Mortality rate from end stage liver disease\* or hepatocellular carcinoma in those with hepatitis C mentioned on their death certificate (per 100,000 population), by PHE Centre 2008-2015.

We would like to thank the Office for National Statistics (ONS) for providing the data used in this report. The ONS carried out the original collection and collation of the data but bear no responsibility for their future analysis or interpretation.

The rate of premature mortality resulting from HCV-related ESLD or HCC between 2013 and 2015 was significantly higher in the North West than in England overall, with 1.02 and 0.67 deaths per 100,000, respectively (Figure 12). Mortality rates in 6 North West local authorities were significantly higher than England overall. As was observed with morbidity, there was also wide variation in mortality rates between areas in the North

West, with rates ranging from 0 per 100,000 in Halton to 2.62 deaths per 100,000 in Blackpool.

Although the highest rate was observed in Blackpool, it is important to note that hospital admissions for the same classifications were not significantly different from England (Figure 12).

Area	Value	Lower Cl	Upper Cl
England	0.67 H	0.63	3 0.71
North West region	1.02 H	0.88	3 1.17
Blackpool	2.62	1.25	5 4.81
Salford	1.62	<b>-</b> 0.81	1 2.90
Bury	1.54	- 0.67	7 3.04
Sefton	1.51	0.75	5 2.69
Manchester	1.47	0.92	2 2.23
Liverpool	1.43	0.86	6 2.24
Lancashire	1.29	0.93	3 1.75
Trafford	1.25	0.54	4 2.47
Oldham	1.25	0.54	4 2.46
Wirral	1.15	0.55	5 2.11
Rochdale	1.01	0.37	7 2.20
Blackburn with Darwen	0.97	0.26	6 2.47
Wigan	0.90	0.39	9 1.77
Stockport	0.77	0.28	3 1.67
Bolton	0.64 +	0.21	1 1.49
Warrington	0.52	0.11	1 1.53
Tameside	0.49	0.10	0 1.43
Cheshire West and Chest	0.44 🛏 🛏	0.12	2 1.13
St. Helens	0.41	0.05	5 1.49
Cheshire East	0.40	0.11	1 1.01
Cumbria	0.37 🛏 🚽	0.12	2 0.87
Knowsley	0.25	0.01	1 1.38
Halton	0.00	0.00	1.05

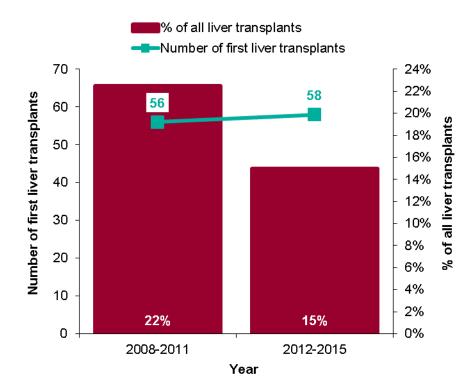
Source: Public Health England (based on ONS source data)

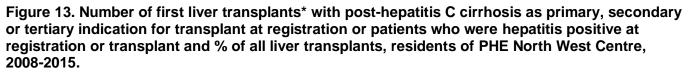
### Figure 12. Under 75-mortality rate from hepatitis C related end-stage liver disease/hepatocellular carcinoma (crude rate per 100,000 population) 2013-15, by local authority.

When considering the mortality data presented above, it should be remembered that HCV infection is curable. Therapies which are both clinically and cost-effective are available across the country and HCV is considered the cause most amenable to healthcare.

#### 3.3. Transplants

Another important marker of HCV-related morbidity is the number of residents with post-HCV cirrhosis (recorded as either the primary, secondary or tertiary indication for transplant) registering at NHS Blood and Transplant for a liver transplant. In the North West of England, the number of liver transplants remained stable for the three-year periods of 2008-2011 and 2012-2015, with 56 and 58 transplants, respectively (Figure 13). However, as the number of transplants during these periods increased from 249 between 2008 and 2011 to 387 between 2012 and 2015, HCV-related transplants accounted for only 15% compared to 22% during the same periods.





Data source: NHS Blood and Transplant UK Transplant Registry. \*These figures are based on registry data as at 23 June 2016 and include both elective and super urgent registrations.

#### 3.4. Estimating the future burden

Proportions in each disease state are obtained from the PHE burden model. This is based on the back-calculation model of Sweeting et al, and uses data on observed endpoints (HCV-related morbidity and mortality) from Hospital Episode Statistics (HES) and ONS deaths.<sup>15</sup> The observed endpoint data are combined with probabilities of progression between disease states, taken from the literature, within a statistical model. The resulting outputs from this model are total numbers in each disease state over time; and future projections of numbers in each state if the currently infected population

continues to progress through disease states at the same rate. The most recent PHE model also includes a certain proportion of those infected being treated (approximately 3% each year).

The modelled projections for the burden of disease in the North West of England, by Drug Action Team area, are presented in Table 3 (Appendix). These projections estimate that 1,669 individuals will have cirrhotic or end stage liver disease in the North West by 2023.<sup>14</sup> It is important to note that the proportions in each disease state are based on a national model and may not apply to local populations, which may have varying levels of alcohol usage, co-morbidities and age of infection, which are known to affect progression rates. In the absence of better information at this time, these assumptions must be borne in mind.

These projections, assume that 3% are treated each year, with genotype 1 infected individuals receiving standard treatment (pegylated interferon and ribavirin) plus directing acting antivirals (DAA, boceprevir or teleprevir) and non-1 genotypes receiving standard treatment. These estimates also assume the proportion of those treated annually will remain the same over time, and further, that the probability of successfully clearing the virus will not change.

Based upon the estimated total number of individuals with HCV infection in the North West of England, the total drug cost to treat infected individuals, will amount to approximately £84million.<sup>14</sup> This estimated cost excludes individuals that have already received treatment. It is important to note that the estimated treatment costs have not taken into account new therapeutics, which have become available since 2014 and are based upon the NICE guidance TA252 and TA253 costing templates.

# 4. Increasing awareness and reducing undiagnosed infections

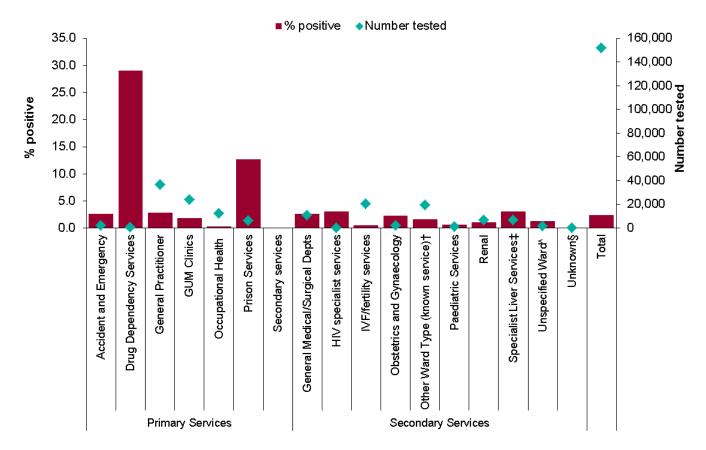
Early diagnosis of HCV infection is important to achieve the best outcome for patients and to prevent further transmission. To fulfil this goal it is important to increase awareness of groups at increased risk of HCV infection among healthcare professionals, including familiarity with and implementation of public health guidance on testing produced by NICE. Accessing testing and subsequent diagnosis are important stages on the clinical pathway. Globally, less than 5% of people with chronic viral hepatitis are aware of their status.<sup>9</sup> In the UK, levels of awareness of infection are well above the 5% global average, but are still suboptimal with positive results often failing to successfully link individuals into treatment and care services.<sup>10</sup>

#### 4.1. Testing activity by setting

Data collected through the Sentinel Surveillance Study of Blood Borne Virus Testing in participating laboratories in the North West of England between 2011 and 2015 are presented in Figure 14. More individuals were tested in general practice than any other setting, accounting for 24% of all testing activity with over 36,000 individuals tested and a positivity rate of 2.8%. Positivity rates varied between settings, with the highest rate (29.1%) observed in specialist drug treatment services, as expected. Importantly, specimens collected in specialist drug treatment services in this setting, using oral fluid and dried blood spot methods, are not included in these data.

During the period of observation, these methods (DBS in particular) became standard practice for testing in this setting (used in 21 out of 23 local authorities). This may explain why the positivity rate is considerably lower than the estimated prevalence of HCV infection in people who inject drugs in the region and may also lead to an underestimate of the volume of testing activity taking place in this setting.<sup>16</sup>

Testing in prisons resulted in the next highest yield, with antibody positive results for 12.6% of individuals tested, and accounted for 4.2% of testing activity. The lowest positivity rates were observed in occupation health (0.3%) and fertility services (0.5%), where testing was likely completed as part of pre-employment screening and routine clinical assessment prior to IVF, respectively. Consequently, over one-fifth of testing activity was likely completed as part of routine practice rather than based upon the identification of a risk factor, which is likely to have reduced the overall positivity rate of 2.4%.



### Figure 14. Number of individuals tested for anti-HCV and % positive by service type in Sentinel laboratories in PHE North West centre, 2011-2015.

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 one year, in whom positive tests may reflect the presence of passively-acquired maternal antibody rather than true infection. All data are provisional.

† Other ward types includes cardiology, dermatology haematology, ultrasound, x-ray.

<sup>‡</sup> This refers to infectious disease services, hepatology departments and gastroenterology departments.

^ These are hospital services, which are currently being investigated to identify specific service type, and may include any of the secondary care services mentioned above.

§ These services are currently being investigated to identify specific service type, where possible.

When using data collected through the Sentinel Surveillance Study of Blood Borne Virus Testing it is important to acknowledge the possibility of bias towards earliest location/setting of test. Individuals are often tested on more than one occasion for HCV infection.<sup>17</sup> To ensure the data included in analyses reflect individuals, rather than number of tests, only one test result is included per unique individual (the earliest test). All subsequent tests are excluded from the data for analyses. Therefore, these data provide an accurate representation of the number of individuals at risk being tested but may underestimate the volume of testing activity completed in a defined period of time and/or setting.

#### 4.2. Testing people who inject drugs

Testing for HCV infection in people who inject drugs is a priority to ensure timely diagnosis and access to treatment services, and prevention of onward transmission of infection. A systematic approach to testing in drug treatment services presents a great opportunity to reduce the proportion of undiagnosed infections. In the North West of England, only 78.6% of PWID in drug treatment were tested for HCV infection in the 2014-2015 period (Figure 15). There was considerable variation between local authority areas, where the proportion ranged from only 59.4% in Oldham to 93.6% in Warrington. 7 authority areas in the North West had rates significantly higher (better) than the overall rate in England (light blue bars) whilst rates were significantly lower (worse) in 10 authorities (dark blue bars). Whilst all services drug treatment should aspire to achieving 100% it should be noted that these data represent an improvement on earlier periods, where during 2012-2013 the overall North West rate was 66.2%, including authorities with rates ranging from only 41.1% to 90.2%.<sup>18</sup>

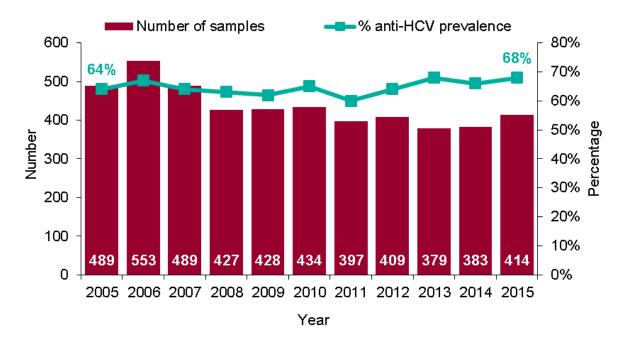
Area	Value		Lower Cl	Upper Cl
England	81.5		81.2	81.7
North West region	78.6	Η	78.0	79.2
Warrington	93.6	н	90.6	95.7
Salford	92.6	н	89.7	94.7
Halton	89.0	⊢–⊣	83.4	92.8
Blackpool	87.8	Н	85.5	89.8
Manchester	86.5	Н	84.8	88.1
Sefton	86.2	н	83.3	88.6
Bolton	85.3	н	83.0	87.3
Blackburn with Darwen	83.5	⊢ <mark>⊣</mark>	80.3	86.2
St. Helens	82.5	H	78.6	85.9
Bury	81.1	⊢ <mark>-</mark> -	76.7	84.8
Rochdale	79.7	F-4	76.4	82.6
Stockport	78.5	⊢ <mark>-</mark> -	74.3	82.2
Cumbria	78.0	н	75.5	80.3
Wigan	77.9	FH	74.9	80.6
Trafford	76.9	⊦ <mark></mark>	71.0	81.8
Cheshire East	76.6	<b>⊢</b> ⊣	72.9	79.8
Liverpool	75.8	H	73.7	77.8
Wirral	74.8	F-1	72.1	77.3
Lancashire	71.6	Н	69.9	73.3
Knowsley	70.3	<b>⊢</b>	63.1	76.7
Cheshire West and Chest	69.2	<b>⊢</b> ⊣	65.5	72.7
Tameside	63.0	⊢I	58.6	67.2
Oldham	59.4	<b>⊢</b>	54.4	64.1

Source: Public Health England, (based on National Drug Treatment Monitoring System data)

### Figure 15. Percentage of current and previous injectors in substance misuse treatment who have received a hepatitis C test, by local authority areas in PHE North West centre 2014/15.

Please note that there may be a delay in a client getting a HCV test. Clients with a missing HCV intervention status are assumed to be eligible and clients with no information about receipt of a hep C test are assumed not to have had a test. Completion for these fields is very high nationally but this may differ at a Local Authority level. Care should, therefore, be taken when comparing Local Authorities to the national figure.

Data collected through the Unlinked Anonymous Monitoring Survey of PWID indicates that the prevalence of HCV infection in the PWID population of the North West of England has been relatively stable over the 10 year period, with approximately two-thirds of PWID infected (based upon presence of antibodies to HCV, not HCV RNA). There was some variation in rates between years (Figure 16), ranging from 62% in 2009 to 68% in 2015; but prevalence in the North West was consistently higher than England overall which ranged from 46% to 50% during the same period. It is important to note that these data are an estimate of prevalence in the population based upon a sample recruited via drug treatment services. It is, therefore, not clear to what extent this estimate can be generalised to the population of PWID not in contact with services.



#### Figure 16. Number of samples and anti-HCV prevalence in North West region, by year 2005-2015.

Notes: Data from the Unlinked Anonymous Monitoring Survey of people who inject drugs in contact with specialist services. Behavioural data have not been collected in all years. In 2009, a phased change in the sample type from oral fluid to dried blood spot (DBS) started. The sensitivity of the anti-HCV and anti-HBc tests on these two samples types is different.

The annual uptake of HCV testing and awareness of HCV infection status in the same samples of PWID are presented in Figure 17. Uptake increased from 69% in 2005 to 90% in 2015. This increase represents considerable progress with possible explanations for this increase including the availability of DBS testing and the development of less toxic and more effective therapies alongside and changes in policy regarding the eligibility of PWID for treatment of HCV infection.<sup>7</sup> Despite the increase in testing uptake, awareness of HCV infection status remained relatively stable, with a modest increase from 47% in 2005 to 52% in 2015. This finding is an important reminder that whilst increasing testing uptake is a priority area for the elimination of HCV infection, it should not be seen as an endpoint. Robust clinical pathways are vital to ensure that all individuals tested are informed of their test result and that those infected should be assessed for referral into treatment services promptly.

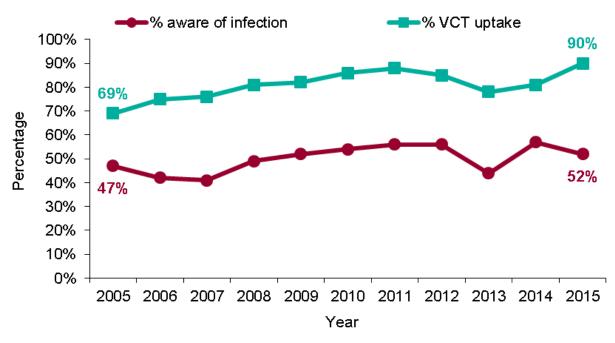


Figure 17. Hepatitis C test uptake amongst people who inject drugs and their awareness of infection status, North West region, 2005-2015.

Data source: Unlinked Anonymous Monitoring Survey of HIV and Hepatitis in People Who Inject Drugs.

#### 4.3. Testing people in prisons

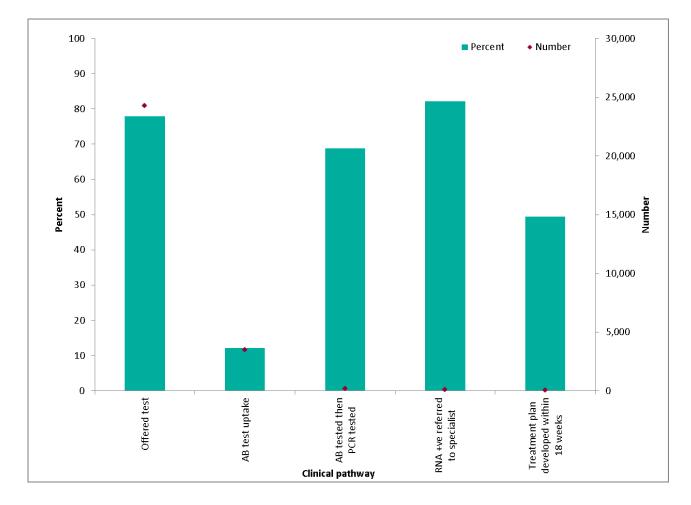
Prisoners have complex health needs and can experience poorer access to healthcare.<sup>19</sup> An estimated 65% of prisoners have a history of injecting drug use (compared to <1% in the general population) and chronic HCV infection prevalence is estimated to be 7-11% in prisoners.<sup>20,21</sup> As such, prisons are a setting in which there are a large number of individuals with risk factors for HCV infection and are, therefore, important settings for diagnosis and treatment as well as primary prevention.<sup>22</sup>

Prisons have been identified as a priority setting for addressing the public health challenge of HCV, through targeted testing and subsequent treatment.<sup>23,24</sup> However, a national audit indicated a lack of progress towards these priorities with only 6.2% of the prison population tested for CHC and inadequate referral processes leading to limited treatment.<sup>20,25</sup>

To address these uptake issues, an opt-out HCV testing policy was piloted in English prisons. Preliminary findings indicate that anti-HCV testing at reception increased from 11% (2,387/20,605) to 21% (2,164/10,302) during the first 6 months.<sup>26</sup> However, the pilot scheme was not able to demonstrate what proportion of anti-HCV positive test results were confirmed via PCR testing and only 5/11 prisons automatically tested for HCV RNA.

Without a corresponding improvement in HCV PCR testing, opt-out testing will fail to address access to treatment services. Furthermore, it is not clear why anti-HCV testing was refused by 79% prisoners at reception.

Routine HCV testing and treatment activity in prisons is captured and reported via the Health and Justice Indicators or Performance (HJIPs). HJIPs are reported on a quarterly basis, with annual data relating the 12-month financial calendar (April to March). The data presented below relate to the 2015/16 financial period and are, therefore, not aligned with the other testing data presented in this report. These data are presented at aggregate level for the 16 prisons in the North West of England. It should also be noted that these data are provisional and there are some data quality issues due to the newness of the HJIP monitoring system, in relation to the 2015/16 period.



## Figure 18. Number and percentage of prisoners reaching each stage of the hepatitis C clinical pathway in North West prisons, 2015/16. A) offered test B) accepted test C) antibody and PCR tested D) referred to specialist, if RNA positive and E) treatment plan developed within 18 weeks.

More than three-quarters (77.9%) of prisoners were offered a test for HCV infection within 72 hours of reception, in North West prisons during 2015/16 period (Figure 18). This equates to over 24,000 individuals being offered a test; representing excellent opportunistic testing of a population at increased risk of infection. This was prior to the

opt-out BBV testing policy having been fully implemented. It would now be expected that this percentage should be 100%; which would have resulted in the remaining 6,901 prisoners having been offered a test.

Whilst the vast majority of individuals were offered a test, uptake was low and only 12.1% were tested (Figure 18). Therefore, 20,773 individuals declined the offer of a test for HCV infection, which is a missed opportunity to diagnose and treat individuals with asymptomatic infection.

Of the 3,940 individuals that were tested, a total of 282 individuals (8.1%) were found to be HCV antibody positive (Figure 18). Confirmatory PCR testing was completed for 194 (68.8%) of these individuals. Failing to complete confirmatory testing for almost one-third of individuals demonstrates a significant issue in the clinical pathway, which should be addressed by ensuring the appropriate laboratory service has been commissioned, and that test request documentation is completed correctly.

The latter stage of the clinical pathway appeared to be more robust with 82.1% of HCV RNA positive individuals being referred to a specialist service (Figure 18). Whilst this rate is high, the 20 individuals that missed out on referrals equates to missed clinical and public health opportunities. Of the 91 individuals referred to a specialist service, 49.5% had a treatment plan developed with 18 weeks of their test, leaving 46 individuals without a treatment plan within the target period.

Further work is required to understand the barriers, which lead to the attrition, which is present across the continuum of care and to maximise the opportunity prison presents for the diagnosis and treatment of HCV infection. It is also important to acknowledge the variation between prisons in the rates presented above. Prison-level analyses may help identify specific issues to be addressed.

# 5. Preventing new infections and harm reduction

Prevention strategies primarily focus on injecting drug use, as this is the most important risk factor for acquisition of the virus in England. Reducing the number of individuals who begin injecting drugs; encouraging PWID to stop injecting; reducing risky behaviour (for example, sharing needles and syringes) in those who continue to inject; and the early diagnosis and treatment of those who become infected with HCV are all components of an effective primary, secondary and tertiary prevention programme. The delivery of successful prevention programmes in people who inject drugs requires an integrated cross-sector approach.

The responsibility for commissioning harm reduction services in England sits with local authorities. Reductions in the Public Health Grant over recent years have resulted in considerable budgetary pressures on local public health teams. Drug treatment and harm reductions services are one of many competing demands for resources, which Directors of Public Health must balance to ensure the continued delivery of prescribed and non-prescribed public health services. Whilst the financial benefits of preventing incident cases of HCV infection may not be immediate or likely to be recovered directly by the local authority, where possible these benefits should be seen as system-wide and ultimately cost saving to public finances.

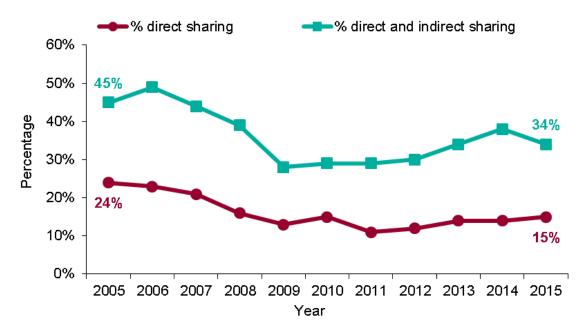
Updates on secondary and tertiary prevention efforts are reported in sections 4 and 6, respectively.

#### 5.1. Primary prevention

Sharing of injecting equipment is major risk factor for transmission of HCV infection and is understood to be the principal cause of the epidemic in the UK. Harm reduction interventions for PWID, including access to sterile injecting equipment and effective drug dependence treatment, can prevent and control HCV among PWID. Optimal access to clean injecting equipment and opioid substitution treatment (OST) is crucial in curbing the spread of HCV, particularly given that it also has the potential to prevent re-infection after treatment.

The UAMS collects information on injecting practices, including sharing of injecting equipment. There was a general downward trend in levels of direct sharing of injecting equipment among PWID in the North West of England between 2005 and 2015, with rates decreasing from 24% to 15% (Figure 19). Indirect sharing also became less commonplace during the same period with 34% in 2015 compared to 45% in 2005. Whilst these downward trends should be acknowledged as progress and demonstrate improvements, the findings indicate the one-third of PWID are still indirectly sharing

injecting equipment. The rates in the North West were similar to those seen in England overall during the same period. Again, when interpreting these findings it is important to note that the sample was recruited from PWID currently using specialist drug services, where injecting equipment is available. It is unclear how injecting practices may differ in PWID not in contact with services.



### Figure 19. Level of direct and indirect sharing of injecting equipment amongst people who inject drugs, North West region, 2005-2015.

Direct sharing: sharing of needles and syringes in preceding 4 weeks. Indirect sharing: sharing of needles and syringes, mixing containers, or filters among those who had last injected during the four weeks preceding participation in the survey.

#### 5.2. Chemsex and preventing sexual transmission

Enhanced surveillance suggests there is a downward trend in HCV transmission amongst HIV positive men who have sex with men. However, recent research carried out in a North West sexual health clinic in 2014 reported that 2.1% of participants (10/471) were infected with HCV infection and behaviours that pose high-risk of transmission were common regardless of HIV status. These included 24.4% who reported having sex under the influence of recreational drugs, 32.1% who had unprotected sex in the last 3 months, 12.3% engaging in group sex and 18.5% who reported indirect sharing of equipment.

The use of drugs in relation to sexual activity, particularly in men who have sex with men (MSM), has been on the increase. Chemsex is the term coined for this distinct type of drug use. Public Health England's Greater Manchester Health Protection Team has been undertaking a health needs assessment for chemsex for Greater Manchester.

An online survey of MSM who engage in chemsex has been conducted by PHE North West, to gain intelligence on their demographic characteristics, their HIV and HCV status, involvement in risky sexual practice and barriers to accessing specialist support services. The survey has been promoted via 2 voluntary sector organisations and a sexual health clinic. 52 MSM have completed the survey so far.

Preliminary findings from the survey suggest that:

- 76% are HIV positive and 21% are HCV positive, all of which were HIV/HCV coinfected – 10% did not know their HIV status and 38% did not know their HCV status
- 77% heard about chemsex parties via geospatial networking applications
- routes of drugs administered: 37% inject/slam, smoke 13%, inhale 50%, rectal administration 6%
- 52% had used chemsex related drugs once in the last 3 months, with 8% using once per week
- high-risk sexual practices include: group sex (79%), fisting (17%), unprotected active anal intercourse (63%) and passive intercourse (60%)

### 6. Treatment and care

The new direct acting antiviral (DAA) drugs have the potential to transform the treatment landscape, offering a fast and effective cure to the vast majority who receive them, without many of the complications associated with previous treatments.<sup>27,28</sup> Whilst primary prevention activity must remain paramount in reducing the rate of new infections, numbers already infected would remain high for many years without effective HCV treatment, which has the potential to dramatically reduce the number of deaths in the short and medium term.<sup>27,28</sup>

From the public health perspective, the new generation of DAA drugs offer a considerable advantage over previous HCV treatments because their all-oral, shorter treatment durations, and improved side-effect profiles make them easier to roll out in community/outreach settings where it is easiest to reach many of those infected. These medicines are now being rolled out, in accordance with national recommendations, in England, Northern Ireland, Scotland and Wales.<sup>10</sup>

Several models exist to assess and treat patients in prison, including escorted hospital out-patient appointments, hospital in-reach and GP in-reach. Prisons can be an ideal opportunity to treat PWID, who may not be able to complete treatment outside prison due to chaotic lifestyles. However, limited uptake/availability of diagnostic testing, waiting times and the highly mobile nature of the prison population combined present significant challenges to treating HCV infection in prisons.

There is an opportunity to dramatically improve HCV testing and treatment in prison presented by recent reorganisation. These changes include the recent transfer of responsibility for commissioning of healthcare in prisons to NHS England (from local commissioners); the replacement of Prison Health Performance Quality Indicators (PHPQIs) with Health and Justice Indicators of Performance (HJIPs) and the possible roll out of an opt-out testing policy across the prison estate.

#### 6.1. Operational Delivery Networks

Operational Delivery Networks (ODNs) were established to facilitate specialist oversight of all HCV treatment delivered in England and provide patients with the safest treatment possible. Their overall aim is to maximise appropriate uptake and completion of HCV treatment to cure more people of infection. Treatment of HCV infection in the North West of England is overseen by 4 ODNs:

- Cheshire and Merseyside
- Greater Manchester and Eastern Cheshire
- Lancashire and South Cumbria

#### North East and Cumbria

#### 6.2. Numbers receiving treatment

Historically, there has been no surveillance programme of HCV treatment activity at national (England) or regional level.<sup>9</sup> To address the gaps in English data availability, a novel approach to estimate hepatitis treatment activity was developed using SSSBBVT data.<sup>9</sup> This method used the frequency of HCV RNA tests in a given period to identify individuals that received treatment. This method estimated that one-fifth (20.8%) of HCV RNA positive patients commenced treatment during the 10-year period.

Overall, initiation of treatment was prompt with 65.6% treated within one year of diagnosis. Treated patients were older than those who were not, with median ages of 41 and 38 years, respectively (p<0.001). In the absence of a coordinated surveillance programme, this approach remains the only method available to measure HCV treatment activity in England beyond individual hospital/trust boundaries.

The creation of ODNs provides an opportunity for the systematic collection and collation of HCV treatment in England. NHS England has recently requested that ODNs collect and report the following metrics:

- number of MDT referrals (total and by Trust)
- number accepted by MDT for discussion
- number approved for treatment
- number confirmed as completed treatment
- run rate set and achievement by month, quarter and by year
- outcome data following treatment with definitions
- follow up data following completion of treatment with definitions
- treatment centres by ODN and confirmation of treatment referral pathways

The ODNs were launched late in 2015. Therefore, data for the period covered by this report are not available. Data were collected by ODNs for 2016. However, this was not completed in the standardised format described above.

### 7. Good practice

#### 7.1. Greater Manchester Viral Hepatitis Strategy

In August 2017, the Greater Manchester Viral Hepatitis Strategy was presented to the Directors of Public Health in Greater Manchester and signed off by the group.

The strategy group continues meet quarterly, and now has established leadership and a programme of work under all of the identified subgroups working to support the strategy. The strategy group continues to recognise the ongoing work and outputs from the subgroups, including:

- a Greater Manchester Hepatitis Pathways event was held in September. This brought together key stakeholders with drug treatment services and clinicians to consider current pathways for hepatitis screening, diagnosis, treatment and support in each local authority area, agree best practice and put together joint action plans to move towards an ideal pathway for each area and increased consistency across Greater Manchester
- continued awareness raising and engagement work with migrant groups at increased risk of infection
- continued work within the clinical care group to improve accessibility to clinical service, continued development of care pathways and consideration of how to work in new and innovative ways

#### 7.2. North West prisons

Over the last 12 months, PHE North West has collaborated with NHSE Prison Healthcare providers to introduce OPT out in all prisons and increase the rates of testing. Prisons have been asked to review their BBV pathways to optimise and increase BBV screening in prisons, ideally working towards testing at second reception for all prisoners.

2 workshops have been carried out to address good practice in pathway development and peer support for BBV screening. Dry blood spot testing will be introduced into all 15 North West prisons once electronic reporting in place and training. This should increase uptake rates and give more opportunity for screening opportunistically.

#### 7.3. Pathway development in Lancashire

Lancashire Country Council ran 2 consecutive HCV workshops with community drug and alcohol service (CDAS) commissioners and providers in 2017. The outputs from

these workshops were presented to the ODN and a training programme is being developed through the ODN network

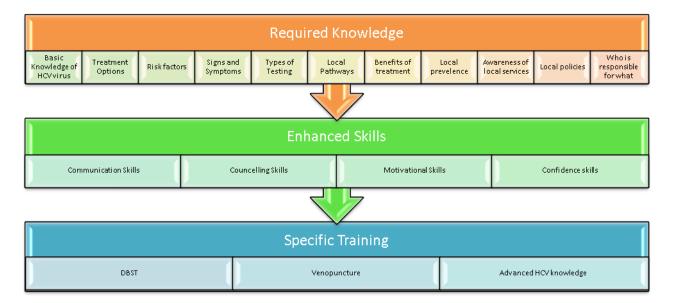
#### 7.3.1. Day one: CDAS HCV training needs assessment workshop

4 key staff groups were identified:

- GPs/Nurses
- Substance Misuse Workers
- Healthcare Assistants
- Volunteers

A tiered education program consisting of baseline training for all staff with options to build with additional skill sets would provide a consistent level of knowledge. The tiers could be tailored to each staff type and be compulsory or optional.

The following items were agreed to be relevant aspects of training. Educational items were grouped into the 3 tiered categories: required knowledge; enhanced skills; and specific training (Figure 20).



#### Figure 20. Educational items identified in HCV training needs assessment workshop.

#### 7.3.2. Day two: HCV pathway mapping and improvement proposals CDAS clients

Key improvement proposals developed during day 2 of the workshop included:

- an electronical referral and communication process for CDAS patients referred into HCV treatment services
- CDAS support for support baseline blood tests and wrap around support for appointment attendance

The pathway improvement proposal was presented to the Lancashire and South Cumbria HCV ODN in September 2017. The improvement pathway is being trialled by the East Lancashire CDAS and treatment providers and will be evaluated in 2018.

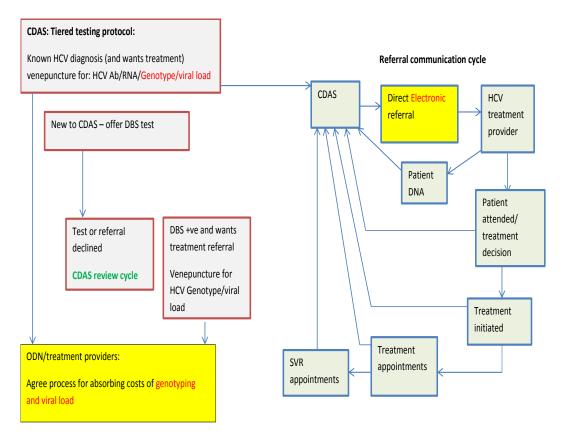


Figure 21. Lancashire and South Cumbria HCV Improvement Pathway for CDAS patients.

#### 7.4. Viral hepatitis events: Cheshire and Merseyside and Greater Manchester

PHE North West coordinated viral hepatitis events in July and September 2017, supported by Gilead Sciences and in collaboration in with Cheshire and Merseyside and Greater Manchester and East Cheshire Operational Delivery Networks. These events brought together over 120 key stakeholders (drug treatment commissioners, drug treatment provider leads, hepatitis treatment providers, leads for homelessness provision and community criminal justice contacts) to consider current pathways for hepatitis testing, diagnosis, treatment and support across Cheshire and Merseyside and Greater Manchester.

At each event, delegates saw presentations on local hepatitis epidemiology, the role of operational delivery networks, the hepatitis C treatment pathways, barriers to successful treatment and current pathways outcomes. The main focus of the events were for delegates to work in groups based on local authority area to consider current hepatitis pathways, barriers and good practice within current pathways and commitments to action to overcome barriers and improve patient experience. Mapping was recorded on

provided sheets and actions were recorded including timescales and personal responsibilities. Maps and action sheets were circulated to attendees.

System barriers identified in Greater Manchester included:

- low staff awareness regarding pathways and new treatments
- low attendance at hepatitis treatment appointments in drug and alcohol service
- too many steps in the process
- not all staff trained to do DBS
- not all clients are tested for Hep C and after relapse may not be re-tested
- lack of support for people as they complete hepatitis treatment
- clients not returning for result of tests
- financial barriers to expanding screening to other agencies

Action and solutions in Greater Manchester included:

- training for all case managers on DBS
- basic awareness raising sessions for all staff
- increased one stop shop' clinics in community substance use treatment services and tie in with routine clinic appointments
- introduce opt out testing for all clients or ensuring testing always happens at assessment and medical reviews
- introduce peer support/buddy system and train health and well-being mentors
- improve links with GPs to ensure diagnosis is communicated or at least is held on records

System barriers identified in Cheshire and Merseyside included:

- staff awareness
- accessibility (location) of Hepatitis treatment services
- clients fear of the treatment process
- poor communication links between substance use treatment and secondary care
- inconsistency in NDTMS recording
- not all clients being screened or more than one stage in screening process
- funding issues affecting staff time and fibro scanner availability

Actions and solutions in Cheshire and Merseyside included:

- increased one stop shop' clinics in community substance use treatment services and tie in with routine clinic appointments
- education sessions for non-specialist staff
- Peer educators and peer led groups focused on Hepatitis. 'Buddy' system
- development of agreement re: treatment updates
- identify staff Hepatitis champions in all services working with high numbers of PWID

- quality assurance work to improve consistency in NDTMS data
- purchasing more fibro scanners and training more staff to use
- using blood testing, for example, APRI to streamline diagnosis of cirrhosis and reduce requirement for fibro scanning
- streamlining screening (at assessment, using Dry Blood Spot, including PCR as standard to avoid second appointment)

### 8. References

- 1. Razavi H, Waked I, Sarrazin C, Myers RP, Idilman R, Calinas F et al. The present and future disease burden of hepatitis C virus (HCV) infection with today's treatment paradigm. *J Viral Hepat* 2014; 21:34-59.
- Public Health England. Hepatitis C in the UK: 2016 report. Public Health England [accessed 2017 Jul 1]; Available from: www.gov.uk/government/publications/hepatitis-c-in-the-uk.
- 3. Harris RJ, Ramsay M, Hope VD, Brant L, Hickman M, Foster GR et al. Hepatitis C prevalence in England remains low and varies by ethnicity: an updated evidence synthesis. *Eur J Public Health* 2012; 22(2):187-192.
- 4. Hope VD, Hickman M, Ngui SL, Jones S, Telfer M, Bizzarri M et al. Measuring the incidence, prevalence and genetic relatedness of hepatitis C infections among a community recruited sample of injecting drug users, using dried blood spots. *J Viral Hepat* 2010.
- 5. Uddin G, Shoeb D, Solaiman S, Marley R, Gore C, Ramsay M et al. Prevalence of chronic viral hepatitis in people of south Asian ethnicity living in England: the prevalence cannot necessarily be predicted from the prevalence in the country of origin. *J Viral Hepat* 2009.
- Public Health England. Hepatitis C in the UK: 2014 report. Public Health England [accessed 2017 Jul. 1]; Available from: www.gov.uk/government/publications/hepatitis-c-in-the-uk.
- 7. Harris RJ, Thomas B, Griffiths J, Costella A, Chapman R, Ramsay M et al. Increased uptake and new therapies are needed to avert rising hepatitis C-related end stage liver disease in England: Modelling the predicted impact of treatment under different scenarios. *Journal of Hepatology* 2014; 61(3):530-537.
- National Institute for Health and Care Excellence. Technology Appraisal Guidance (TA413): Elbsavir - Grazoprevir for treating chronic hepatitis C. National Institute for Health and Care Excellence. 2016 [accessed 2017 Jul. 1]; Available from: https://www.nice.org.uk/guidance/ta413.
- 9. Lattimore S, Irving W, Collins S, Penman C, Ramsay M, on Behalf of the Collaboration for the Sentinel Surveillance of Blood-Borne Virus Testing. Using surveillance data to determine treatment rates and outcomes for patients with chronic hepatitis C virus infection. Hepatology 2014; 59(4):1343-1350.
- 10. Public Health England. Hepatitis C in the UK 2017. London: PHE, 2017. Available from: www.gov.uk/government/uploads/system/uploads/attachment\_data/file/632465/HCV\_in\_the\_uk\_report\_2017.pdf. [Accessed 01/08/2017].
- 11. World Health Organization. Global health sector strategy on viral hepatitis, 2016-2021. Towards Ending Viral hepatitis. 2016. Available from:

apps.who.int/iris/bitstream/10665/246177/1/WHO-HIV-2016.06-eng.pdf?ua=1. [Accessed 19/01/2017].

- 12. Hope VD, Eramova I, Capurro D, Donoghoe MC. Prevalence and estimation of hepatitis B and C infections in the WHO European Region: a review of data focusing on the countries outside the European Union and the European Free Trade Association. Epidemiol Infect. 2014;142(2):270-86.
- 13. De Angelis D, Sweeting M, Ades AE, Hickman M, Hope V, Ramsay M. An evidence synthesis approach to estimating Hepatitis C prevalence in England and Wales. Statistical Methods in Medical Research 2009; 18(4):361-379.
- 14. Public Health England. Hepatitis C: Commissioning template for prevalence and treatment. Public Health England 2014. [accessed 2017 Jul. 1]; Available from: www.gov.uk/government/publications/hepatitis-c-commissioning-template-for-estimating-disease-prevalence.
- 15. Sweeting MJ, De AD, Neal KR, Ramsay ME, Irving WL, Wright M et al. Estimated progression rates in three United Kingdom hepatitis C cohorts differed according to method of recruitment. *J Clin Epidemiol* 2006; 59(2):144-152.
- 16. Brant LJ, Hurelle M, Balogun MA, Klapper P, Ahmad F, Boxalle E et al. Sentinel laboratory surveillance of hepatitis C antibody testing in England: understanding the epidemiology of HCV infection. Epidemiol Infect 2007; 135(3):417-426.
- 17. Tweed E, Brant L, Hurrelle M, Klapper P, Ramsay M. Hepatitis C testing in sexual health services in England, 2002-7: results from sentinel surveillance. Sex Transm Infect 2010; 86(2):126-130.
- 18. Public Health England. Hepatitis C in the North West. 2015.
- 19. Public Health England. Health and Justice report 2014. Public Health England 2015 [cited 2017 July 1]; Available from: www.gov.uk/government/publications/prison-health-health-and-justice-annual-report.
- 20. Humphreys C, Railton C, O'Moore E, Lombard M, Newton A. An audit of hepatitis C service provision in a representative sample of prisons in England. J Public Health 2014.
- 21. Weild AR, Gill ON, Bennett D, Livingstone SJ, Parry JV, Curran L. Prevalence of HIV, hepatitis B, and hepatitis C antibodies in prisoners in England and Wales: a national survey. Commun Dis Public Health 2000; 3(2):121-126.
- 22. National Institute for Health and Care Excellence. Hepatitis B and C: ways to promote and offer testing to people at increased risk of infection. National Institute for Health and Clinical Excellence website 2012 [accessed 2017 Jul. 7]; Available from www.nice.org.uk/guidance/ph43.
- 23. Department of Health. Hepatitis C Strategy for England. Department of Health 2002 [accessed 2017 Jul. 1]; Available from: www.nhs.uk/hepatitisc/SiteCollectionDocuments/pdf/hepatitis-c-strategy-for-england.pdf.

- 24. Department of Health. Hepatitis C Action Plan for England. Department of Health 2004 [accessed 2017 Jul. 1]; Available from: www.nhs.uk/hepatitisc/SiteCollectionDocuments/pdf/hepatitis-c-action-plan-forengland.pdf.
- 25. Department of Health. National survey of hepatitis C services in prisons in England. Department of Health 2012 [accessed 2017 Jul. 20]; Available from: www.gov.uk/government/uploads/system/uploads/attachment\_data/file/212817/Hep-C-Prison-Survey.pdf.
- 26. Public Health England. Blood-borne Virus Opt-Out Testing in Prisons: Preliminary Evaluation of Pathfinder Programme. Public Health England 2015 [accessed 2017 Jul 15]; Available from: www.gov.uk/government/publications/blood-borne-virus-opt-out-testing-in-prisons-evaluation-of-pathfinder-programme.
- 27. Harris RJ, Martin NK, Rand E, Mandal S, Mutimer D, Vickerman P, et al. New treatments for hepatitis C virus (HCV): scope for preventing liver disease and HCV transmission in England. J Viral Hepat.2016 Mar 29. doi: 10.1111/jvh.12529.
- 28. Innes H, Goldberg D, Dillon J, Hutchinson SJ. Strategies for the treatment of Hepatitis C in an era of Interferon-free therapies: what public health outcomes do we value most? Gut. 2014; doi:10.1136/gutjnl-2014-308166 1-1029.

### 9. Appendices

9.1 Appendix 1: Public health recommendations (extract taken from Hepatitis C in England: 2017 report).

#### Making improvements and monitoring metrics:

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

#### Adequate harm reduction/prevention:

- commissioners of bloodborne virus prevention services for people who inject drugs need to sustain or expand, as appropriate, the current broad range of provision (including opioid substitution treatment (OST), needle and syringe programmes (NSP), and patient information) to reduce transmission of hepatitis C, including among people who inject new psychoactive substances or image and performanceenhancing drugs; NICE guidance is available on NSP and OST
- consideration should be given to mapping and monitoring NSP activity
- harm minimisation policies in secure and detained settings should be maintained, including the provision of disinfectant/decontamination equipment for sharps
- further testing of treatment as prevention, and its potential to reduce the number of new HCV infections in people who inject drugs, is required in order to guide future public health policy and clinical practice

#### Increasing the numbers and proportion diagnosed:

 initiatives should be considered to further raise awareness of HCV among professionals working in primary care and other settings, like drug services, to help reduce the number who remain undiagnosed, for example, by encouraging participation in e-learning, to improve the offer and uptake of HCV testing in risk groups. Guidelines are available to help raise awareness of, and testing for, hepatitis C infection to ensure that people at increased risk of hepatitis C are tested

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

#### Increasing the numbers accessing hepatitis C treatment:

- those responsible for commissioning hepatitis C treatment and care services should continue to work with public health agencies, clinicians and other stakeholders to simplify referral pathways; improve the availability, access and uptake of approved hepatitis C treatments in primary and secondary care, drug treatment services, prisons and other settings; and to drive innovative approaches to outreach and patient support. It will be important to consider those individuals who have been diagnosed but subsequently lost to follow-up, as well as those who are newly diagnosed or already engaged with treatment services
- those achieving a sustained viral response following treatment, should be provided with appropriate information and support to help them guard against re-infection
- regular analysis by PHE of the agreed national treatment monitoring dataset should take place to enable preliminary assessments of the equity, access, uptake and impact of treatment on the future burden of HCV-related disease in England to inform future healthcare planning and to monitor progress against WHO goals to eliminate HCV as a serious public health threat by 2030
- continued monitoring, via Health and Justice Indicators of Performance (HJIP), should take place to inform equity of access to HCV care and treatment pathways for all prisoners and immigration detainees

#### 9.2 Appendix 2: Indicators to monitor impact

Table 2. Preliminary indicators to monitor the impact of key interventions to tackle hepatitis C virus in England.

	Monitoring areas: burden, impact and service coverage	Data source		
Burden	<ul> <li>Reducing the burden of infection in England</li> <li>Placeholder: Estimated prevalence of HCV infection in England</li> <li>Risk factors for infection from laboratory reports</li> <li>Trend in anti-HCV prevalence among PWID</li> </ul>	TBC SGSS UAM survey		
act	<ul> <li>1. Reducing HCV-related morbidity and mortality</li> <li>Estimated incidence of HCV-related ESLD/HCC</li> <li>Registrations for liver transplants in patients with HCV</li> <li>First liver transplants undertaken in patients with HCV (% of all liver transplants)</li> <li>First liver transplants undertaken in patients with HCV HCC (% of all liver transplants in patients with HCV)</li> <li>Deaths from HCV-related ESLD/HCC</li> </ul>	HES NHS BT NHS BT NHS BT ONS		
Impact	<ul> <li>2. Reducing the number of new (incident) infections</li> <li>Estimated incidence of HCV among people injecting psychoactive drugs</li> <li>Estimated prevalence of anti-HCV among recent initiates to drug use</li> <li>Number of HCV tests performed in young adults (and proportion testing positive) in sentinel laboratories</li> <li>Number of HCV laboratory reports in young adults (and proportion of all reports they represent)</li> <li>Placeholder: Estimated number of new infections originating injecting drug use and net migration</li> </ul>			

1. Ad	equate harm reduction	
• Sha • Nun • Prop	mated proportion of PWID reporting adequate needle/syringe provision ring of needles and syringes among PWID nber of current and past PWID in drug treatment portion of opioid dependent PWID receiving OST ceholder: Proportion of PWID receiving targeted HCV information	UAM survey UAM survey NDTMS NDTMS; Hay <sup>1</sup> TBC
2. Inc	reasing awareness and the numbers and proportion diagnosed	UAM survey
<ul> <li>Place</li> <li>Place</li> <li>Place</li> <li>Place</li> <li>Num</li> <li>Labo</li> <li>Num</li> <li>Rep</li> <li>Offee</li> <li>Offe</li></ul>	mated proportion of PWID testing positive for anti-HCV, aware of their infection ceholder: Proportion of chronic HCV infections in England diagnosed ceholder: Proportion of population with late stage HCV-related liver disease (cirrhosis/HCC) diagnosed nebers completing RCGP HCV e-learning oratory reports of HCV infection neber of HCV tests (and proportion testing positive) in sentinel laboratories neber of HCV tests via GP surgeries (and proportion testing positive) in sentinel laboratories noted uptake in voluntary confidential HCV testing among PWID er and uptake of HCV testing in adults - both newly presenting to, and all in, drug treatment er and uptake of HCV testing in adults currently or previously injecting - both newly presenting to, and all ug treatment ceholder (awaiting DBS data): Number of HCV tests via drug services (and proportion testing positive) in nel laboratories portion of new receptions to prisons tested for HCV ceholder (awaiting DBS data): Number of HCV tests via prisons (and proportion testing positive) in sentinel atories net laboratories portion of HCV tests in Asian or Asian British people (and proportion testing positive) in sentinel atories neber of HCV tests in Eastern European people (and proportion testing positive) in sentinel laboratories e of hepatitis C infection among new and repeat blood donors ereasing numbers accessing treatment mated number initiating HCV treatment ceholder: Proportion of diagnosed population linked into care and monitored ceholder: Proportion of diagnosed population linked into care and monitored ceholder: Future additional metrics on treatment access	TBC TBC RCGP SGSS Sentinel surv Sentinel surv NDTMS NDTMS Sentinel surv PHPQI/HJIP Sentinel surv Sentinel surv Sentinel surv NHS BT NHS E TBC: National Rx Monitoring

#### Table 2 acronyms:

Hay:	Hay G, Gannon M, MacDougall J, Millar T, Eastwood C, McKeganey N. National and regional estimates of the prevalence of opiate use and/or crack cocaine use 2005/06: a summary of key findings. Research Development and Statistics Directorate, Home Office, 2007.
HES:	Hospital Episode Statistics
NDTMS:	National Drug Treatment Monitoring System
NHS BT:	National Health Service Blood and Transplant
NHS E:	NHS England
PHPQI/HJIP:	Prison Health and Performance Indicator/Health and Justice Indicators of Performance
Sentinel Surv:	Sentinel Surveillance of blood borne virus testing
SGSS:	Second Generation Surveillance System
UAM survey:	Unlinked Anonymous Monitoring survey of infections and risk among people who inject drugs

#### 9.3 Appendix 3: Hepatitis C laboratory reports, directly standardised rates, by local authority, 2014-15

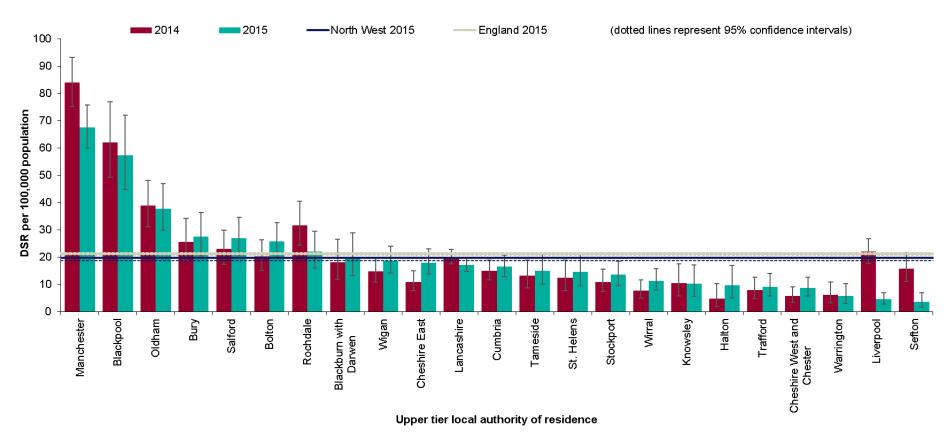


Figure 22. Laboratory reports of hepatitis C, directly standardised rate (DSR) per 100,000 population by upper tier local authority of residence, PHE North West Centre, 2014 and 2015.

#### 9.4 Appendix 4: Estimated burden of hepatitis C, by Drug Action Team in North West PHE centre

	Estimated total	Predicted numbers in disease state at 2023			Current number	Annual new	
Drug Action Team	infected population	Mild/ Moderate	Cirrhotic or end stage	Died (all causes)	Sustained virologic response	remaining diagnosed and untreated	diagnoses
Blackburn with Darwen	1,207	566	51	137	78	313	58
Blackpool	1,397	656	59	159	91	363	67
Bolton	2,063	968	87	235	134	536	100
Bury	960	450	40	109	62	249	46
Cheshire	2,946	1,382	124	335	191	765	142
Cumbria	2,992	1,404	126	341	194	777	145
Halton	518	243	22	59	34	134	25
Knowsley	580	272	24	66	38	151	28
Lancashire	5,653	2,652	238	644	367	1,468	273
Liverpool	2,613	1,226	110	298	169	678	126
Manchester	5,124	2,404	216	583	332	1,330	247
Oldham	1,481	695	62	169	96	384	72
Rochdale	1,591	747	67	181	103	413	77
Salford	1,137	533	48	129	74	295	55
Sefton	1,161	545	49	132	75	301	56
St. Helens	827	388	35	94	54	215	40
Stockport	1,262	592	53	144	82	328	61
Tameside	1,244	584	52	142	81	323	60
Trafford	885	415	37	101	57	230	43
Warrington	716	336	30	82	46	186	35
Wigan	1,706	800	72	194	111	443	82
Wirral	1,598	750	67	182	104	415	77
Total	39,661	18,609	1,669	4,515	2,572	10,297	1,916

Table 3. Estimates of hepatitis C prevalence, burden, treatment and cost of treatment by Drug Action Team in North West PHE centre.

### Acknowledgements

#### **Public Health England North West Centre**

Paul Duffy, Elizabeth Farrington, Diane Fiefield and Dr Su Sethi (good practice in the North West of England)

Public Health England, Field Epidemiology Service

Kathy Chandler (hospital admissions, North West)

Public Health England, Centre for Infections, Disease Surveillance and Control:

Dr Koye Balogun (Laboratory reports of hepatitis C)

Georgina Ireland, Celia Penman and Ruth Simmons (Sentinel Surveillance of Hepatitis Testing)

Dr Obaghe Edeghere, Field Epidemiology Service (West Midlands) - facilitating supply of data from colleagues at Colindale

Dr Vivian Hope and Rachel Glass (data from Unlinked Anonymous Monitoring Survey of HIV and Hepatitis in People Who Inject Drugs)

Annastella Costella, Dr Helen Harris, Ross Harris, Dr Vivian Hope, Dr Sema Mandal and Dr Mary Ramsay (Commissioning Template)

Annastella Costella (Mortality Maps)

Annastella Costella (Hospital Admissions)

Annastella Costella, National Infection Service and Elisa Allen and Agne Zarankaite, NHS Blood and Transplant (Transplants)

#### **External bodies:**

Elisa Allen and Agne Zarankaite, NHS Blood and Transplant (Transplants)