

Protecting and improving the nation's health

# **Hepatitis C in the West Midlands**

# 2017 data

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#### About the Field Service

The Field Service (FS) supports Public Health England (PHE) Centres and partner organisations through the application of epidemiological methods to inform public health action. FS does this in 2 main ways, firstly by providing a flexible expert resource, available, as and when needed, to undertake epidemiological investigations for key health protection work and secondly through the expert analysis, interpretation and dissemination of surveillance information to PHE Centres, local health partners, service providers and commissioners of services. Within the FS network, excellence and innovation is encouraged, we foster academic collaborations and take active part and lead in research, development and training.

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### Executive summary and recommendations

Hepatitis C remains an important public health problem with the most recent national estimates suggesting that around 210,000 individuals are living with chronic hepatitis C infection in the UK<sup>1</sup>. Transmission of the virus is through contact with blood or blood products or bodily fluids from an infected person, with prevalence most common in marginalised and under-served groups, particularly people who inject drugs (PWID) and minority ethnic communities with links to high prevalence countries<sup>1</sup>.

Hepatitis C is a 'silent disease' with individuals often presenting with late-stage complications such as end-stage liver disease and hepatocellular carcinoma, which have poor survival rates. Measures aimed at preventing, managing, and controlling hepatitis C such as Needle and Syringe Exchange Programmes (NSP) and access to effective antiviral drugs continue to reduce the risk of individual infection and to limit the further spread of the virus. However, while progress continues to be made both nationally and within the West Midlands, further action is required in several key areas.

In 2016, the World Health Organisation adopted a Global Health Sector Strategy (GHSS) with the first global targets for reductions in hepatitis C virus (HCV) incidence, mortality and undiagnosed disease by 2020 and 2030<sup>1</sup>. Public Health England (PHE) is committed to supporting the WHO in eliminating HCV with the aim of increasing the number of people diagnosed, increasing the number of those diagnosed who access treatment and reducing the number of people becoming infected. Nationally, 2 main impact areas have been identified: the need to reduce the number of people becoming seriously ill or dying from the infection, and reducing the number of people who become newly or re-infected. Progress in both areas is achievable, particularly following the introduction of new direct acting drugs.

This report is part of a series of annual updates to summarise the progress made by the West Midlands in reducing the risk of infection, preventing further transmission of HCV, and improving the health outcomes of people affected. Furthermore, in light of the global hepatitis C targets, the data in this report can be used to monitor progress towards reaching the GHSS goals, and it can be used to identify gaps where further action is needed.

#### Burden

In 2017, laboratory reporting of HCV decreased by 10% in the West Midlands following a peak in 2016 (2016: n=1,152; 2017: n=1,036); however, the number of laboratory confirmed cases in 2017 was still the second highest reported in the last 10 years in the

West Midlands. Due to the limitations of laboratory data, it is not possible to determine the reasons for this decrease. A more modest 7% decrease was observed nationally.

Laboratory reports varied by local authority with Coventry and Birmingham having a rate of laboratory reporting higher than both the West Midlands and England. While the prevalence of HCV might be highest in these 2 local authorities, the higher rate of laboratory reporting in these areas could be due to increased testing and reporting rather than increased incidence, potentially due to targeted awareness and prevention campaigns.

The percentage of individuals testing positive for HCV in the West Midlands sentinel laboratory was the third lowest in England in the 5 years from 2013 to 2017 combined, which was significantly below the national average. Data from both laboratory reports and the sentinel laboratory showed that a HCV diagnosis was more common in males and those aged between 25 and 44 years.

#### Impact

In contrast to other years' reports, hospital admissions data for 2017 were not available. Data for 2016 show that admissions for individuals with HCV increased slightly compared to 2015 in the West Midlands; however, the number of individuals hospitalised with HCV End Stage Liver Disease (ESLD) remained stable during 2016 and the number hospitalised with hepatocellular carcinoma (HCC) decreased.

Death rates from ESLD or HCC in those with HCV mentioned on their death certificate are ranked nationally into 3 groups. The West Midlands was in the middle rank along with the South West, South East, East Midlands and Yorkshire and Humber (2008 to 2017 data).

#### Service coverage

Based on sentinel laboratory data, the number of individuals tested for HCV in the West Midlands increased in 2017 following 3 years of broadly stable numbers. The proportion of individuals tested who were positive was broadly similar in 2016 and 2017. The Unlinked Anonymous Monitoring (UAM) Survey found that anti-HCV prevalence among PWID fell from 39% in 2016 to 35% in 2017.

Hepatitis C remains high in the Asian ethnic group, although the proportion of individuals tested who were found to be positive in 2017 was lower than in the years from 2013 to 2015.

The number of PWID tested for HCV at sentinel laboratories increased in 2017 following a stable year in 2016 and a sharp fall in 2015. However, the number tested in

2017 was still much lower than the peak year of 2014; this is likely to reflect a change in testing method to Dried Blood Spot (DBS) testing, which is only partially recorded in the sentinel surveillance dataset. The proportion of PWID tested who were positive for HCV decreased slightly in 2017 compared to 2016. Among people responding to the Unlinked Anonymous Monitoring Survey of PWID, uptake of voluntary hepatitis C testing fell from 80% in 2016 to 77% in 2017, but is still much higher than the 64% reported in 2008.

There was little change in the proportion of people who inject drugs who reported sharing of injecting equipment in 2017 with 33% reporting direct and indirect sharing (compared to 35% in 2016) and 16% reporting direct sharing (compared to 16% in 2016).

#### Recommendations

Although the number of laboratory confirmed cases of hepatitis C in the West Midlands decreased in 2017, it was still higher than in the years from 2008 to 2015. The number and proportion of individuals testing positive from the south Asian and Eastern European ethnic groups was stable in 2017. There is a need for continued investment and awareness-raising campaigns to maintain the progress that has been made.

It was not possible to include data on prisons or young offender institutes in the West Midlands in this report due to the implementation of a new reporting system. However, there is a need to improve screening efforts in secure and detained settings in the region.

Hepatitis C prevalence remains high in PWID. The advent and increasing availability of the new direct acting antivirals (DAA) provides an opportunity to reduce morbidity and mortality from hepatitis C among those aware of their diagnosis, and decrease the risk of onward transmission. PWID are the main drivers of the hepatitis C epidemic and are thus a prime target group for the roll-out of DAAs. More work is needed to meet the 2030 targets set by the GHSS. Improving the offer and uptake of testing for hepatitis C is particularly important because many hepatitis C infections remain undiagnosed among PWID. Routine opt-out testing approaches should be considered where appropriate. Well-designed, supportive care pathways for those infected are needed, and those diagnosed with hepatitis C and who continue to inject should have access to effective treatment and care in line with current guidelines<sup>2</sup>.

One of the biggest obstacles to entering care pathways for HCV is the lack of treatment settings suitable for PWID. Multidisciplinary and peer-supported programmes have been shown to be successful, as well as offering blood-borne virus (BBV) testing, treatment and care in a variety of settings. In addition to community-based clinics, needle and syringe programmes (NSP), and drug treatment clinics, BBV testing is now being offered through the English and Welsh prison system on an 'opt-out' basis<sup>2</sup>.

Injecting risk behaviours have declined but remain a problem. The level of needle and syringe sharing among those currently injecting psychoactive drugs has fallen across the UK, but needle and syringe sharing remains a problem. People continue to be at risk of infection through injecting behaviours. A range of easily accessible NSP for all PWID, including those using drug treatment services, need to be provided in line with guidance, such as the provision of free services, including needle and syringe provision, as well as testing for BBV's. Low dead space injecting equipment\* should be offered and encouraged where appropriate. NSP should continue to also offer interventions that support entry into treatment and other interventions that encourage a reduction or cessation of injection as a route of consumption. They should aim to distribute sufficient appropriate injecting-related equipment to prevent sharing and reuse and support hygienic injecting practices<sup>2</sup>.

<sup>\*</sup> The term 'dead space' refers to the volume of fluid retained in a needle/syringe once the plunger has been fully depressed, this residual fluid provides an opportunity for BBVs to be transmitted if the needle is reused by another individual. The amount of dead space varies by syringe type; with standard high dead space syringes containing up to 10 times the volume of dead space than low dead space syringes. In 2012, the World Health Organization recommended the provision of LDSS in all NSPs<sup>2</sup>.

### Introduction

Hepatitis C remains an important public health problem with the most recent national estimates suggesting that around 210,000 individuals are chronically infected in the UK<sup>1</sup>. Transmission of the virus is through contact with blood or blood products, or bodily fluids from an infected person, with injecting drug use (IDU) an important risk factor for infection<sup>3</sup>. Of the diagnosed hepatitis C infections in England where exposure data was known, around 90% are thought to have been acquired through injecting drug use<sup>2</sup>.

Hepatitis C is a 'silent disease' with the majority of infections asymptomatic, making it difficult to estimate true incidence and prevalence. As a result, presentation with the infection is often at later stages with complications such as hepatitis C-related endstage liver disease (ESLD) and hepatocellular carcinoma (HCC), which have poor survival rates. Estimates suggest that numbers of new cases of hepatitis C virus (HCV)related ESLD and HCC in the UK remained relatively stable, at an average of 1,974 new cases per year between 2011 and 2015. However, mortality data suggest a fall in death registrations from these indications of 3% by 2016, with data suggesting a further fall of 11% in 2017. It seems likely that the fall observed since 2015 is the result of the increased treatment with new direct acting antiviral (DAA) drugs that has taken place over recent years. Although data suggest that while DAA drugs may lead to a reduction in deaths from ESLD, the risk of HCC may persist after successful clearance of the virus<sup>1</sup>. NHS England Operational Delivery Networks (ODNs) are in place to deliver treatment equitably across the country. The Birmingham hepatitis C ODN has a very similar geographical footprint to the West Midlands PHE centre, therefore ODN-level data is not presented in this report; all figures, tables and commentary refer to the geographical area served by the West Midlands PHE centre unless otherwise specified.

Worldwide, the burden of hepatitis has been increasing since 1990, with viral hepatitis a leading cause of death globally. As a result, from May 2016, the World Health Organization (WHO) adopted a Global Health Sector Strategy (GHSS) with the first global targets for viral hepatitis, including a 30% reduction in new cases of HCV and a 10% reduction is HCV-related mortality by 2020, and the diagnoses of 90% of HCV positive individuals and the elimination of hepatitis C as a major public health threat by 2030<sup>1</sup>. Reports suggest that the UK should meet the GHSS mortality targets, in part due to the availability of new DAA drugs<sup>1</sup>. However, improvements need to be made in order reduce the number of new cases, particularly among people who inject drugs. Furthermore, although there has been a steady increase in testing over the past 2 decades, evident by laboratory reports and sentinel surveillance, more needs to be done if the UK is to meet the target of 90% of HCV-positive people diagnosed by 2030.

The focus of Public Health England's approach to support the WHO in eliminating Hepatitis C as a major public health threat by 2030 can be captured in the PHE vision statement below, while a comprehensive summary of national hepatitis C epidemiology can be found in the Hepatitis C in England 2018 report<sup>4</sup>.

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

This report is part of a series of annual updates that summarise the progress made by the West Midlands in reducing the risk of infection, preventing further transmission of HCV, and improving the health outcomes of people with hepatitis C. It is produced to support local and regional action towards hepatitis C prevention, testing, treatment and care. Furthermore, as this report summarises the 2017 picture of HCV in the West Midlands, it can be used to monitor progress towards reaching the GHSS goals and it can be used to identify gaps where further action is needed.

#### Data sources

This report is based on data from a variety of surveillance sources up to and including 2017 (unless otherwise specified). Data on hepatitis C morbidity and mortality (and related data) were obtained from routine and sentinel laboratory surveillance, anonymised prevalence monitoring surveys of people who inject drugs (PWID), Hospital Episode Statistics (HES), NHS Blood and Transplant (NHSBT), and the Office for National Statistics (ONS).

Laboratories in the UK routinely report blood samples positive for the antibody to hepatitis C (anti-HCV) and this has been a statutory requirement since October 2010. A positive test to anti-HCV indicates that a person has been exposed to hepatitis C; it cannot distinguish between a current and past infection. For this reason, these laboratory reports are only reflective of patterns of testing rather than trends in incidence or prevalence.

The sentinel surveillance of blood-borne virus testing was set up in 2002 to enhance routine laboratory surveillance of hepatitis C. It collects data on laboratory test results and demographic and risk factor data for all individuals tested for the hepatitis C antibody in 21 sentinel laboratories in England, covering approximately 40% the population<sup>5</sup>. Limitations of the data include some duplication of individual patients and exclusion of dried blood spot, oral fluid, reference testing, and testing from hospitals referring all samples which do not have the original location identified. Individuals aged less than one year, in whom positive tests may reflect the presence of passively acquired maternal antibody rather than true infection, are excluded.

As infection is often highest in marginalised groups such as PWID, anonymous testing and surveys are used to gather data on prevalence and risk factors for infection. The PHE Unlinked Anonymous Monitoring (UAM) Survey measures the prevalence of hepatitis C in current and former PWID who are in contact with over 60 specialist drug agencies (e.g. needle and syringe exchange services and treatment centres) in England, Wales and Northern Ireland<sup>6</sup>. The programme also monitors levels of risk and protective behaviours among PWID.

# Burden of hepatitis C in the West Midlands

#### Laboratory reports of hepatitis C in the West Midlands

It is difficult to accurately determine the burden of hepatitis C as infections are usually asymptomatic in the initial stages with many people unaware that they have the virus. Furthermore, as laboratory tests are unable to distinguish between new and chronic infections, laboratory reporting generally reflects trends in testing and reporting rather than trends in incidence.

In 2017, laboratory reporting of hepatitis C in the West Midlands decreased by 10% from 2016, with 1,036 individuals testing positive (Figure 2.1). This decrease followed increases in reporting in 2015 and 2016, a decrease in 2014 and a period of stability between 2010 and 2013. Despite a decrease in laboratory reporting in both in the West Midlands and nationally from 2016 to 2017, there has been a general upward trend in laboratory reporting over the last decade (Figure 2.2). In both 2016 and 2017, the crude rate of laboratory confirmed HCV infection in the West Midlands was similar to the national rate; in 2017, the West Midlands rate was 17.9 per 100,000 population, compared to 18.5 per 100,000 population for England (Figure 2.2).





Data source: Second Generation Surveillance System (SGSS).

<sup>\*</sup> 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 hepatitis C antibody and/or detection of hepatitis C RNA. Due to the variability in the quality of laboratory reports and the inability of current serological assays to differentiate acute from persistent infections we are unable to estimate the actual proportion of cases with evidence of past infection or persistent infection. Mothers who are anti-HCV positive usually pass this maternal antibody to their baby. However most of these babies are not actually infected with the hepatitis C virus. The antibodies showing up in the baby's blood are most often the mother's antibodies that were passed to the baby before birth. A baby born to a mother with hepatitis C will probably have maternal antibodies to the virus for the first 12 to 18 months of life, therefore the baby will have a positive anti-HCV test irrespective of whether the baby is infected. For this reason tests in those aged under one are excluded from the dataset for 2016 and 2017.





Data source: Second Generation Surveillance System (SGSS).

#### Key findings

In 2017, laboratory reporting of HCV decreased by 10% in the West Midlands, reversing the recent trend of increased reporting. Due to the limitations of laboratory data it is not possible to determine the reasons for this decrease, however, the number of cases reported in 2017 was still higher than the numbers reported in the years from 2008 to 2015.

In the West Midlands, the number (Table 2.1) and rate (Figure 2.3) of laboratory confirmed diagnoses of hepatitis C infection varied across upper-tier local authorities in 2017. This variation was also observed when directly standardised rates (DSR) were applied. DSRs are used to compare populations which differ in in one or more underlying characteristic, for example population size and age structure. The directly

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standardised rate (DSR) per 100,000 population showed that although Coventry, Walsall and Solihull experienced an increase in reporting in 2017, these increases were not statistically significant; the only upper tier local authority to see a statistically significant decrease in the DSR was Stoke-on-Trent. In 2017, Coventry and Birmingham had the highest DSRs per 100,000 population; the DSR for both of these local authorities was significantly higher than the West Midlands and England DSRs in 2016 and 2017 (Figure 2.3).

Upper tier local authority	Number of laboratory reports										
of residence	2008	2009	2010	2011	2012	2013	2014	2015	2016	2017	Trend
Birmingham	231	239	241	208	231	237	130	229	425	392	~~~~
Coventry	74	133	146	121	96	121	106	128	121	138	$\sim$
Dudley	62	38	29	29	39	23	10	57	56	52	$\sim$
Herefordshire	14	7	31	27	28	33	37	27	19	14	$\sim$
Sandwell	57	7	15	2	11	18	12	27	57	56	~
Shropshire	37	53	28	34	36	31	42	40	32	26	$\sim$
Solihull	6	8	4	12	4	6	6	8	12	13	~~~
Staffordshire	38	93	34	41	40	61	78	73	82	80	$\sim$
Stoke-on-Trent	3	112	92	119	76	65	75	70	73	40	$\sim$
Telford and Wrekin	9	14	11	9	10	13	8	13	25	16	$\sim\sim$
Walsall	23	40	25	32	21	29	11	46	44	52	$\sim\sim$
Warwickshire	48	30	44	52	58	47	55	58	77	60	
Wolverhampton	5	8	13	35	42	35	11	16	47	45	$\sim$
Worcestershire	70	84	71	52	51	58	71	85	82	52	$\sim$
Total	677	866	784	773	743	777	652	877	1,152	1,036	~~~~~

### Table 2.1: Number of laboratory reports of hepatitis C by upper tier local authority of residence, West Midlands, 2008 to 2017\*

Data source: Second Generation Surveillance System (SGSS)

<sup>\*</sup> 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 hepatitis C antibody and/or detection of hepatitis C RNA. Due to the variability in the quality of laboratory reports and the inability of current serological assays to differentiate acute from persistent infections we are unable to estimate the actual proportion of cases with evidence of past infection or persistent infection. Mothers who are anti-HCV positive usually pass this maternal antibody to their baby. However most of these babies are not actually infected with the hepatitis C virus. The antibodies showing up in the baby's blood are most often the mother's antibodies that were passed to the baby before birth. A baby born to a mother with hepatitis C will probably have maternal antibodies to the virus for the first 12 to 18 months of life, therefore the baby will have a positive anti-HCV test irrespective of whether the baby is infected. For this reason tests in those aged under one are excluded from the dataset for 2016 and 2017.





Upper tier local authority of residence

Data source: Second Generation Surveillance System (SGSS)

<sup>\*</sup> 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 hepatitis C antibody and/or detection of hepatitis C RNA. Due to the variability in the quality of laboratory reports and the inability of current serological assays to differentiate acute from persistent infections we are unable to estimate the actual proportion of cases with evidence of past infection or persistent infection. Mothers who are anti-HCV positive usually pass this maternal antibody to their baby. However most of these babies are not actually infected with the hepatitis C virus. The antibodies showing up in the baby's blood are most often the mother's antibodies that were passed to the baby before birth. A baby born to a mother with hepatitis C will probably have maternal antibodies to the virus for the first 12 to 18 months of life, therefore the baby will have a positive anti-HCV test irrespective of whether the baby is infected. For this reason tests in those aged under one are excluded from the dataset for 2016 and 2017.

The number of laboratory reported cases varied across the 12 laboratories in the West Midlands in 2017 (Figure 2.4). Almost a quarter of laboratory reports in the West Midlands came from Sandwell and West Birmingham Hospitals NHS Trust (24%), followed by University Hospital Coventry (21%) and the PHE West Midlands Birmingham Laboratory (20%). The variation in laboratory testing across the West Midlands is likely to reflect the size and throughput of each laboratory, rather than differences in local disease incidence.





<sup>\*</sup> 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 hepatitis C antibody and/or detection of hepatitis C RNA. Due to the variability in the quality of laboratory reports and the inability of current serological assays to differentiate acute from persistent infections we are unable to estimate the actual proportion of cases with evidence of past infection or persistent infection. Mothers who are anti-HCV positive usually pass this maternal antibody to their baby. However most of these babies are not actually infected with the hepatitis C virus. The antibodies showing up in the baby's blood are most often the mother's antibodies that were passed to the baby before birth. A baby born to a mother with hepatitis C will probably have maternal antibodies to the virus for the first 12 to 18 months of life, therefore the baby will have a positive anti-HCV test irrespective of whether the baby is infected. For this reason tests in those aged under one are excluded from the dataset for 2016 and 2017.

Nationally and in the West Midlands there continues to be regional and local variation in the number of laboratory reports of hepatitis C. As previously stated, increases in laboratory reporting do not necessarily indicate an increase in incidence. Rather, the trend in laboratory reporting may suggest changes in testing and reporting and may be influenced by local initiatives to identify and screen those at risk. However, due to the limitations of the data it is not possible to say for certain why reporting varied across laboratories.

In the West Midlands, 70% of laboratory reports were in men, a proportion comparable to that seen in England overall (67%) (Figure 2.5). Reports of HCV were most common in persons aged between 25 to 44 years in the West Midlands (62%), with the highest number of reports in the 35 to 44 years' age group for both genders. This was higher than national figures, where just over half (51%) of laboratory reports were in adults aged 25 to 44 years.





Data source: Second Generation Surveillance System (SGSS)

#### Key findings

Laboratory reports varied by local authority, with Coventry and Birmingham having a rate of laboratory reporting that was significantly higher than both the West Midlands and England rates. The higher rate of laboratory reporting could potentially be due to increased testing and reporting because of targeted awareness and prevention campaigns due to the higher incidence in these areas.

<sup>&</sup>lt;sup>\*</sup> 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 hepatitis C antibody and/or detection of hepatitis C RNA. Due to the variability in the quality of laboratory reports and the inability of current serological assays to differentiate acute from persistent infections we are unable to estimate the actual proportion of cases with evidence of past infection or persistent infection. Mothers who are anti-HCV positive usually pass this maternal antibody to their newborns. However most of these newborns are not actually infected with the hepatitis C virus. The antibodies showing up in the newborn's blood are most often the mother's antibodies that were passed to the baby before birth. A baby born to a mother with hepatitis C will probably have maternal antibodies to the virus for the first 12 to 18 months of life. Therefore, the baby will have a positive anti-HCV test irrespective of whether the baby is infected. For this reason, tests in those aged under one are excluded from the dataset for 2016 and 2017.

<sup>\*\*</sup> Chart excludes cases where gender and/or age are unknown.

#### Sentinel surveillance of hepatitis C testing

Sentinel surveillance of hepatitis testing aims to supplement routine laboratory surveillance of hepatitis viruses in England by monitoring trends in testing<sup>5</sup>. Trends in HCV testing are useful for monitoring the impact of awareness-raising and prevention activities. The West Midlands has only one sentinel laboratory (Birmingham Heartlands). As a result, caution should be exercised when interpreting sentinel surveillance data as the dataset may not be representative of trends in the West Midlands overall.

Between 2013 and 2017, a total of 48,049 individuals were tested for antibodies against HCV (anti-HCV) in the West Midlands by sentinel laboratories. Of these tests, 716 were positive (1.5%). Positivity in the West Midlands was significantly lower than the England average of 1.6% (Figure 2.6). Although it is not possible to establish the reason for the lower proportion of positive tests in the West Midlands, it is possible that in the West Midlands a larger number of low-risk people are being tested than in other regions.





Data source: Sentinel surveillance of hepatitis C testing.

The age and sex distribution of anti-HCV positive individuals reported by the sentinel laboratory between 2013 and 2017 differed from the age group and gender of HCV in West Midlands residents as determined by laboratory reporting in 2017, with a higher proportion of females reported in the sentinel dataset (Figure 2.5). These differences

<sup>\*</sup> 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. Cumulative data will not necessarily balance back to trend data because only locations that have been consistently reported in each of the 5 years can be included in trend data.

may be due to testing methods as the sentinel dataset excludes DBS and oral fluid testing. In the sentinel dataset half of individuals tested were men (50%), 47% were women and 3% were of unreported gender – however, the percentage of positive cases was higher for males in every age group, with the exception of 1-14 years and 65 years and over, with males showing a higher overall positivity (2.1% vs. 1.5%) (Figure 2.7). Most confirmed cases of hepatitis C occurred in persons aged between 25 to 44 years (55%), with the highest number of female cases observed in those aged 25 to 34 years and the highest number of male cases observed in those aged 35 to 44 years.

### Figure 2.7: Age-group and gender of individuals testing positive for anti-HCV in sentinel laboratories, West Midlands, 2013 to 2017\*



(Please note that the numbers relate to those tested in the sentinel laboratory, and do not represent all tests across West Midlands)

Data source: Sentinel surveillance of hepatitis C testing.

#### **Key Findings**

The percentage of individuals testing positive for anti-HCV in the West Midlands sentinel laboratory was the third lowest in England in the 5 years from 2013 to 2017 combined and was significantly lower than the England average. As in the laboratory reporting dataset and national figures, HCV was more commonly reported in males in the sentinel laboratory – although this was to a lesser extent – and in 25 to 44 year olds. Caution should be exercised when interpreting sentinel surveillance data as the dataset may not be representative of the West Midlands overall.

<sup>\*</sup> 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. Chart excludes cases of unknown gender and/or age. Cumulative data will not necessarily balance back to trend data because only locations that have been consistently reported in each of the 5 years can be included in trend data.

# Impact of Hepatitis C

Progress needs to be made both locally and nationally to reduce the numbers of people becoming infected and to reduce the numbers of infected people who become seriously ill or die from hepatitis. Monitoring hospital admissions for HCV-related conditions gives an indication of morbidity and mortality associated with HCV, allowing the impact of infection to be monitored. Unfortunately, hospital admissions data for 2017 are not available due to technical difficulties with the incorrect classification of HCV codes, which has affected data across England and is not unique to the West Midlands. This means that it was not possible to de-duplicate individuals and identify multiple patient admissions in 2017, therefore only hospital admissions data to 2016 are presented in this report<sup>1</sup>.

#### Hospital admissions for hepatitis C and related diseases

In the West Midlands, hospital admissions for HCV increased slightly in 2016, when compared to previous years (Figure 3.1). Conversely, the number of individuals hospitalised with HCV-related ESLD (Figure 3.2) remained stable in 2016 when compared to 2015. Admissions for individuals with HCV-related HCC (Figure 3.3) decreased in 2016 when compared to 2015. This difference between the increase in hospital admissions, the stable number of people with a diagnosis of ESLD and decrease in HCC diagnoses may be due to improved detection and treatment before individuals develop advanced disease. However, the numbers are small and it is, therefore, difficult to draw conclusions.





Figure 3.2: Hospital admissions for individuals\* with a diagnosis code for HCV-related ESLD§ admitted to hospital, West Midlands residents, 2013-2016^



Data source: Hospital Episode Statistics (HES), NHS Digital (NHS Digital is the trading name of the Health and Social Care Information Centre. Copyright © 2019, Re-used with the permission of NHS Digital. All rights reserved). Produced by Public Health England. Data based on Hospital Episode Statistics as at July 2018.

<sup>\*</sup> 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.

<sup>§</sup> Defined by codes for ascites, bleeding oesophageal varices; hepato-renal syndrome, hepatic encephalopathy or hepatic failure.

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





Data source: Hospital Episode Statistics (HES), NHS Digital (NHS Digital is the trading name of the Health and Social Care Information Centre. Copyright © 2019, Re-used with the permission of NHS Digital. All rights reserved). Produced by Public Health England.

Data based on Hospital Episode Statistics as at July 2018.

<sup>\*</sup> 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.

<sup>#</sup> For 2016 HCV-related HCC data, cells with values from 1 to 7 have been suppressed to prevent possible identification of individuals. All other counts and totals have been rounded to the nearest 5.

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

#### Liver transplants

A further marker of HCV-related morbidity is the number of individuals with posthepatitis C cirrhosis as the primary, secondary or tertiary indication for transplant at registration registering at NHS Blood and Transplant for a liver transplant. Between 2014 and 2017, the number of people first registering for a transplant in the West Midlands was similar to the number in 2010 to 2013 (2010 to 2013, n=38; 2014 to 2017 n=39) (Figure 3.4). The number of transplants undertaken decreased in 2014 to 2017 when compared to 2010 to 2013 (2010 to 2013 n=38; 2014 to 2017 n=34) (Figure 3.5). The number of transplants carried out in individuals with post-HCV cirrhosis decreased as a percentage of all liver transplants performed (2010 to 2013: 13%; 2014 to 2017: 9%). While this decrease was small and may be due to chance (especially with the small numbers involved), it was also observed at the national level, suggesting that new DAA treatments may be resulting in fewer patients being put onto the transplant list.

Figure 3.4: Number\* of first registrations for a liver transplant in England where post-hepatitis C cirrhosis was the primary, secondary or tertiary indication for transplant, residents of West Midlands PHE centre, 2010 to 2013 and 2014 to 2017 Figure 3.5: Number\* of first liver transplants with post-hepatitis C cirrhosis as primary, secondary or tertiary indication for transplant at registration or patient who were HCV positive at registration or transplant and % of all liver transplants, residents of West Midlands PHE centre, 2010 to 2013 and 2014 to 2017





Data source: UK Transplant Registry held by NHS Blood and Transplant.

<sup>\*</sup> These figures are based on registry data as at 5 August 2018 and include both elective and super urgent registrations.

#### Deaths from hepatitis C

Figure 3.6 shows the death rate per 100,000 population from ESLD or HCC in individuals with HCV mentioned on their death certificate for the 10-year period from 2008 to 2017. Death rates are ranked nationally into 3 groups. The West Midlands was in the middle rank along with the South West, South East, East Midlands and Yorkshire and Humber.

#### Key findings

Hospital admissions for HCV increased slightly in 2016. However, the number of individuals hospitalised with HCV-ESLD remained stable and the number individuals hospitalised with HCV-HCC decreased in the West Midlands in 2016. While this could be due to normal variation, the reflection of this trend at the national level possibly suggests that improved detection has resulted in more patients being diagnosed with HCV, but that earlier detection and improved treatments have reduced the number of individuals going on to develop serious disease. Deaths from ESLD or HCC in individuals with HCV mentioned on their death certificate remain low with the death rate in the West Midlands in the middle rank of 3 national ranks.

### Figure 3.6: Map\* showing rate of deaths from ESLD or HCC in those with HCV mentioned on their death certificate by PHE Centre, 2008 to 2017\*\*



Data source: Office for National Statistics (ONS). ONS carried out the original collection and collation of the data but bear no responsibility for their future analysis or interpretation.

\* Methodology used to create this map is in line with that used in the "2nd Atlas of variation in risk factors and healthcare for liver disease in England" (numerator = aggregate numbers of deaths by PHEC, denominator = mid-year population estimates by PHEC for 2010 - 2017).

\*\* Changes have been made to the way deaths are counted this year, moving away from monitoring deaths (registered in England) in the year they occurred to monitoring deaths according to the year they were registered where postcodes of individuals' usual place of residence were in England.

# Increasing awareness and reducing undiagnosed infections

Early diagnosis of hepatitis C is important in both enabling the provision of adequate treatment and care and to limit the onward transmission of the virus. It is necessary to increase awareness of hepatitis C to increase testing and reduce the pool of undiagnosed individuals<sup>4</sup>. Effective public health messages and awareness campaigns aimed at high risk groups are vital in helping to curb the ongoing transmission of hepatitis C. For PWID, needle exchange programmes and interventions from drug action teams can have a significant impact; however, prevalence remains high within this risk group. With improved drug treatments available, increasing the diagnosis and treatment of HCV through coordinated and sustained awareness-raising activities will contribute to improved clinical and public health outcomes.

We have limited information on risk exposure(s)/reason for testing in the West Midlands sentinel laboratory dataset, with information available for a relatively small number of individuals. From 2013 to 2017, risk exposure(s)/reason for testing was recorded as unknown for 99% of individuals tested and 91% of individuals testing positive. For this reason, these data are not presented in this report.

#### Trends in testing as an indicator of increased awareness

Trends in testing are one indicator of the impact of increasing awareness. Using sentinel surveillance data<sup>5</sup> it is possible to examine trends in testing over time. From 2014 to 2016, the number of individuals in the general population that underwent testing for HCV remained relatively stable in the West Midlands, but in 2017 a 7% increase was observed in the number tested, although the number testing positive remained stable (Figure 4.1). The proportion of those tested that had a positive result was highest in 2014 at 1.9%; the percentage of positive tests decreased slightly in 2017 compared to 2016 (1.3% vs. 1.4%).

### Figure 4.1: Number of individuals tested and % testing positive for anti-HCV in sentinel laboratories, West Midlands, 2013 to 2017\*



(Please note that the numbers relate to those tested in the sentinel laboratory, and do not represent all tests across West Midlands)

Data source: Sentinel surveillance of hepatitis C testing.

#### Site of testing for the general population

From 2013 to 2017, over a quarter of individuals tested at sentinel laboratories had their samples taken at general practice (28%), 16% of samples were from specialist liver services, 15% were from other ward types and 15% were from genitourinary medicine clinics (Figure 4.2). Testing appeared to be low in drug dependency services – however, the data presented in Figure 4.2 does not capture all dried blood spot testing, which is more commonly used by drug services. Where tests were performed in drug services, 8.3% of those tested were positive for HCV, the third highest proportion reported by any service. IVF/fertility services accounted for just 0.1% of tests but had the highest proportion of positive tests (11.9%), followed by specialist HIV services (9.2%) and drug dependency services (8.3%), possibly as a result of targeted testing within these populations. It is important to note that the numbers relate to anti-HCV reactivity testing at sentinel laboratories and do not represent all laboratories and test sites across the West Midlands.

<sup>\*</sup> 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. Trend data will not necessarily balance back to cumulative data because only locations that have been consistently reported in each of the 5 years can be included in trend data.

### Figure 4.2: Number of individuals tested and % testing positive for anti-HCV by service type in sentinel laboratories, West Midlands, 2013 to 2017\*

(Please note that the numbers relate to those tested in the sentinel laboratory, and do not represent all tests across West Midlands)



Data source: Sentinel surveillance of hepatitis C testing.

<sup>\*</sup> Excludes dried blood spot, oral fluid, reference testing, and testing from hospitals referring all samples. Data are deduplicated 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. Cumulative data will not necessarily balance back to trend data because only locations that have been consistently reported in each of the 5 years can be included in trend data.

<sup>†</sup> Other ward types include cardiology, dermatology, haematology, ultrasound, x-ray

<sup>‡</sup> Specialist liver services refer to infectious disease services, hepatology departments and gastroenterology departments.

<sup>^</sup> 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.

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

#### **Key Findings**

The number of people tested for HCV in the West Midlands increased in 2017, although the number testing positive was broadly stable. Between 2013 and 2017 more individuals were tested at GP practices and specialist liver services than at other locations. The highest proportion of positive tests were from IVF/fertility services (11.9%), although this was probably due to the targeting of certain risk groups and accounted for just 0.1% of individuals tested for HCV in the region. The proportion of people testing positive was also high at specialist HIV services and drug dependency services (9.2% and 8.3% respectively), although the number of samples from these services being tested at the West Midlands sentinel laboratory was low. There is likely to be an underestimation in testing at drug services as the sentinel laboratory data does not capture all dried blood spot testing, which is more commonly used in individuals who are dependent on drugs.

#### Testing and diagnosis in minority ethnic populations

The number of people tested and the proportion of those that tested positive is also available by broad ethnic group in the West Midlands for the period of 2013 to 2017. Due to a lack of self-reported ethnicity on laboratory forms, ethnicity was predominantly determined using computer software tools (Onomap<sup>7</sup> and Nam Pehchan<sup>8</sup>). The number of individuals tested was highest in those of white ethnicity, reflecting the relative size of this population in the West Midlands (Figure 4.3). Testing was also high in the Asian ethnic group, potentially due to targeted testing due to the high risk of hepatitis C in this population. Testing was low in black and the other/mixed ethnic groups.

Where ethnicity was known, the proportion of individuals tested who were anti-HCV positive was highest in those of Asian ethnicity, with 1.8% (2013 to 2017) of those tested having a positive result. The proportion of positive tests were lowest in those of Black and mixed/other ethnicity (0.6% and 0.7% respectively from 2013 to 2017). Hepatitis C is more prevalent in Asian and British Asian populations when compared to the general population – therefore trends in HCV testing are of interest in this high-risk group. Since 2009 national and regional awareness-raising campaigns have aimed to encourage testing within South Asian communities.

### Figure 4.3: Number of individuals tested and % positive for anti-HCV by ethnic group in sentinel laboratories, West Midlands, 2013 to 2017\*



(Please note that the numbers relate to those tested in the sentinel laboratory, and do not represent all tests across West Midlands)

Data source: Sentinel surveillance of hepatitis C testing.

Sentinel surveillance data indicates the number of people tested who were identified as being of Asian or British Asian ethnicity. Between 2013 and 2016 the number of people tested who were of Asian or British Asian origin remained fairly stable in the West Midlands, but numbers increased in 2017 (Figure 4.4). The proportion of those testing positive for anti-HCV decreased from 2014 to 2015 (2.4% to 1.8%), and again from 2015 to 2016 (1.8% to 1.5%), but remained stable in 2017. The general decrease in the proportion of people testing positive between 2014 and 2017 may be due to reduced transmission within the South Asian community as a result of more targeted testing and greater adherence to treatment.

<sup>\*</sup> 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. Trend data will not necessarily balance back to cumulative data because only locations that have been consistently reported in each of the 5 years can be included in trend data.

A combination of self-reported ethnicity, and Onomap<sup>7</sup> and Nam Pehchan<sup>8</sup> name analyses software were used to classify individuals according to broad ethnic group. Trend data will not necessarily balance back to cumulative data because only locations that have been consistently reported in each of the 5 years can be included in trend data.

### Figure 4.4: Number of South Asian<sup>†</sup> individuals tested and % testing positive for anti-HCV in sentinel laboratories, West Midlands, 2013 to 2017<sup>\*</sup>



(Please note that the numbers relate to those tested in the sentinel laboratory, and do not represent all tests across West Midlands)

Data source: Sentinel surveillance of hepatitis C testing.

#### Key findings

Hepatitis C incidence remains high in the South Asian ethnic group, although the proportion of those that tested positive decreased to 1.5% in 2016 and 2017 from a peak of 2.4% in 2014.

<sup>†</sup> NamPehchan was used to identify individuals of South Asian origin as ethnicity is not routinely available from the participating laboratory information systems. Nam Pehchan<sup>8</sup> is a computer software programme, which enables users to identify names of South Asian origin, in the absence of ethnicity data. Although the gold standard for ethnicity classification is to be self-assigned by an individual, the system offers a way of identifying ethnicity where this data is not readily available. \* 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. Trend data will not necessarily balance back to cumulative data because only locations that have been consistently reported in each of the 5 years can be included in trend data.

Between 2013 and 2017 the number of individuals tested who were of Eastern Europeans origin more than doubled from 92 to 202. The proportion of those testing positive for anti-HCV also increased from 3.3% to 4.5%, in the same time period (Figure 4.5). Coding problems in 2014 may have led to a reduced proportion of those tested being reported as positive. This increase in positivity could be due to an actual increase in incidence or could be due to increasing awareness in GP practices and other health settings where these individuals are tested.

### Figure 4.5: Number of Eastern Europeans individuals tested and testing positive for anti-HCV in sentinel laboratories, West Midlands, 2013 to 2017\*

(Please note that the numbers relate to those tested in the sentinel laboratory, and do not represent all tests across West Midlands)



Data source: Sentinel surveillance of hepatitis C testing.

<sup>\*</sup> Excludes 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. Trend data will not necessarily balance back to cumulative data because only locations that have been consistently reported in each of the 5 years can be included in trend data. Only one laboratory offers dried blood spot testing of anti-HCV. Please note: Sentinel surveillance captures a small proportion of all dried blood spot testing in England, therefore these data should be interpreted with caution.

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

The number of PWID who were tested for HCV decreased sharply in 2015 and remained similar in 2016 (number tested in 2015: n=308; in 2016: n=311), but increased to 485 in 2017, although this is still less than half the number tested in the peak year of 2014 (n=1,012) (Figure 4.6). The percentage testing positive peaked at 29.9% in 2015 before falling to 24.4% in 2016 and 23.5% in 2017. From the data available it is not possible to determine the reason for the higher proportion of individuals testing positive in 2015, however it is possible that given the reduction in the number tested in that year, that testing was more targeted or that laboratory tests were confirmatory. It must also be noted that sentinel surveillance excludes oral fluid testing and captures only a small proportion of all dried blood spot testing, therefore the reduction in testing in the West Midlands in 2015 may reflect a change in testing methods in PWID. Nationally the number tested decreased from 2016 to 2017 but the proportion positive increased from 16.8% to 18.5%.

# Figure 4.6: Number of people who inject drugs tested and testing positive for anti-HCV at specialist drug services in sentinel laboratories, West Midlands, 2013 to 2017\*

(Please note that the numbers relate to those tested in the sentinel laboratory, and do not represent all tests across West Midlands)



Data source: Sentinel surveillance of hepatitis C testing.

<sup>\*</sup> Excludes 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. Trend data will not necessarily balance back to cumulative data because only locations that have been consistently reported in each of the 5 years can be included in trend data. Only one laboratory offers dried blood spot testing of anti-HCV. Please note: Sentinel surveillance captures a small proportion of all dried blood spot testing in England, therefore these data should be interpreted with caution.

The Unlinked Anonymous Monitoring (UAM) Survey<sup>6</sup> of PWID carried out annually by PHE measures prevalence, risk and protective behaviours among PWID.

This anonymous cross-sectional survey is comprised of a subject-completed questionnaire linked to a biological specimen and is carried out on a sample of drug treatment service users. Survey respondents are individuals who currently or previously inject psychoactive drugs who are in contact with specialist services. Those who agree to take part provide a biological specimen that is tested anonymously for HIV, hepatitis C and hepatitis B.

Behavioural and limited demographic information is collected through a brief anonymous subject-completed questionnaire linked to the specimen but unlinked from any client identifying information. The biological sample collected in the survey was changed from an oral fluid to a dried blood spot (DBS) during 2009 and 2010. From 2011 onwards, only DBS samples have been collected. The sensitivities of the tests on a DBS sample for antibodies to hepatitis C and hepatitis B core antigen are close to 100%. The sensitivity of the oral fluid sample test for antibodies to hepatitis C is about 92% and that for antibodies to the hepatitis B core antigen is about 75%. Regional level data from the UAM survey should be interpreted with caution as the survey recruits participants through a nationally reflective sample of the services provided to PWID.



Figure 4.7: Number of samples and % anti-HCV prevalence<sup>\*</sup>, PWID, West Midlands, 2008 to 2017

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

<sup>\*</sup> Anti-HCV Prevalence = [(number of oral fluids anti-HCV positive/0.92) + number of DBS anti-HCV positive] / (number of oral fluids + number of DBS) x 100.

The number of samples obtained in the West Midlands peaked at 412 in 2013 before falling in 2014 and 2015; numbers increased to 254 in 2016 and to 280 in 2017. This may reflect a change in the number of people agreeing to take part in the survey, rather than a change in the number of service users. The overall prevalence of HCV infection in PWID who took part in the UAM survey has been variable over the past decade, with a peak in 2013 of 42% (Figure 4.7). In 2017, the prevalence was 35%, down from 39% in 2016 and lower than the prevalence in England overall (52%)6. The reason for the variability in anti-HCV prevalence is not clear. However, from 2008 to 2017, the West Midlands consistently had a prevalence lower than that for England, Wales and Northern Ireland overall, and in 2017 had the lowest prevalence of all English regions.

Recently updated UK clinical guidelines recommend that all PWID accessing treatment services are tested for HCV and HIV at first assessment, and that repeat testing should be considered when the risk of exposure continues9. When risk is assessed as high, testing may need to be carried out up to once or twice a year<sup>9</sup>. The proportion of PWID who report uptake of voluntary confidential testing for hepatitis C has increased across the UK in the last decade<sup>2</sup>. Whilst Scotland has seen a sustained increase, England, Wales and Northern Ireland have seen a more gradual increase in testing which has possibly plateaued over the last 7 years<sup>2</sup>. Overall, there has been an increasing trend in voluntary hepatitis C testing in the West Midlands from 64% of all PWID who responded to the survey in 2008 to 77% of PWID who responded to the survey in 2017, although the proportion overserved in 2017 was lower than that of the preceding 3 years. The proportion of individuals who were aware of their HCV infection stood at 52% in 2017 (Figure 4.8); due to changes in survey questions regarding awareness of HCV infection status, introduced to differentiate between past and current infection, data from 2017 are not directly comparable to previously collected data.

### Figure 4.8: Hepatitis C voluntary confidential test (VCT) uptake among PWID and their awareness of infection, West Midlands, 2008 to 2017



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

Data on hepatitis C testing among clients of drug treatment services in the West Midlands are also available from the National Drug Treatment Monitoring System (NDTMS). In 2016 and 2017 NDTMS data show that 77% of eligible clients of drug treatment services in the West Midlands received a hepatitis C test, compared to 83% in England overall. Within the West Midlands this varied considerably by upper tier local authority from 64% in Coventry to 91% in Stoke-on-Trent (Figure 4.9). These figures may capture people who were tested when first entering treatment but may not have been re-tested more recently.



# Figure 4.9: Proportion of clients of drug treatment services eligible and who received a hepatitis C test by upper tier local authority local authority, West Midlands, 2016 to 2017

Data source: Public Health England, National Drug Treatment Monitoring System.

In the UK, most new infections are acquired via injecting drug use at a relatively young age, for this reason, the burden of infections in young adults (15 to 24 years) or in recent initiates to injecting drug use can be used as a proxy measure of incidence. From 2016 to 2017 the number of 15 to 19 year olds tested remained stable but lower than in the years of 2014 and 2015. The number of 20 to 24 year olds tested has been decreasing every year since 2013 and fell to 672 in 2017. However, in the same time period the percent positive has varied year-on-year. In the 15 to 19 years' age group positivity varied from 0.5% in 2015 to 1.4% in 2014 and in the 20 to 24 years' age group it varied from 0.2% in 2013 to 1.0% in 2014 (Figure 4.9). The overall positivity for the 5 years from 2013 to 2017 was 0.9% in 15 to 19 year olds and 0.6% in 20 to 24 year olds. Using this proxy indicator, the incidence of HCV has fluctuated over the period with no clear trend emerging.

### Figure 4.9: Number of young adults tested and % testing positive for anti-HCV in sentinel laboratories, West Midlands, 2013 to 2017\*



(Please note that the numbers relate to those tested in the sentinel laboratory, and do not represent all tests across West Midlands)

#### **Key Findings**

The number of people who inject drugs (PWID) who were tested for HCV decreased sharply in 2015 and although it increased in 2017 it is still less than half of the number tested in 2014. However, this may reflect a change in testing method to DBS, as this is only partially captured in the sentinel surveillance dataset, rather than a decrease in testing uptake. The proportion of PWID tested who were positive for HCV decreased in 2016 and was broadly stable in 2017; the reason for this is unclear, although it could be due to more targeted testing, for example confirmatory testing of those who tested positive by DBS testing. In 2017, uptake of a VCT among PWID was 77%, lower than that of the preceding 3 years but higher than the 64% reported in 2008. The proportion of individuals aware of their HCV status was 52% in 2017.

<sup>\*</sup> 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. Trend data will not necessarily balance back to cumulative data because only locations that have been consistently reported in each of the 5 years can be included in trend data.

# Monitoring the coverage of key services

#### Prevention and harm reduction

Prevention of hepatitis C focuses primarily on people who inject drugs as this is the most important risk factor in England. Strategies include reducing injecting and the sharing of injecting equipment, reducing harm from other blood borne infections (for example by hepatitis B vaccination) and early diagnosis. A good indication of the impact of local drug services in increasing the uptake of testing in this community is the proportion of PWID taking part in PHE's Unlinked Anonymous Prevalence Monitoring Survey who report having had a voluntary confidential test; these data are shown in Figure 4.8 and stood at 77% in 2017.

In 2017, in England, Wales and Northern Ireland 91% of people who have ever injected drugs reported using needle and syringe programmes (NSP)<sup>6</sup>. Adequate provision of injecting equipment is important, to reduce sharing and re-use of injecting equipment<sup>10</sup>. Needle and syringe provision is considered 'adequate' when the reported number of needles and syringes received met or exceeded the number of times the individual injected. In 2017, the proportion of PWID in the UK reporting adequate needle needle/syringe provision was sub-optimal; around two-thirds (61%) of PWID who had injected during the preceding month reported adequate needle/syringe provision in England, Wales and Northern Ireland<sup>2</sup>.

The reported level of direct sharing<sup>‡</sup> of injecting equipment and direct and indirect sharing<sup>‡‡</sup> of injecting equipment remained relatively stable between 2016 and 2017 (direct sharing: 2016=16%, 2017=16%; direct and indirect sharing: 2016=35%, 2017=33%) and were lower than the levels reported in England overall in 2017 (direct sharing: 18%; direct and indirect sharing: 36%)<sup>6</sup>. The levels reported in the West Midlands in 2017 are reasonably consistent with all years since 2008 except for 2015 where both levels of sharing were low (direct: 4% and direct and indirect sharing: 25%) (Figure 5.1). It is uncertain why this decrease occurred in 2015.

<sup>‡</sup> Direct sharing: sharing of needles and syringes in preceding 4 weeks.

<sup>‡‡</sup> Direct and indirect sharing: sharing of needles and syringes, mixing containers, or filters among those who had last injected during the 4 weeks preceding participation in the survey.





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

#### Key findings

There was little change in the proportion of people who inject drugs who reported direct or indirect sharing of injecting equipment from 2016 to 2017. Apart from 2015, proportions have varied little over the past 10 years.

The rate of confirmed HCV positive cases among new blood donors has varied yearon-year from 2010 to 2017 in the West Midlands from a high of 29.5 per 100,000 donations in 2011 to a low of 8.0 per 100,000 donations in 2017. The rate of confirmed HCV positive cases among repeat blood donors has been either zero or very low throughout this period (Figure 5.2).

<sup>‡</sup> Direct sharing: sharing of needles and syringes in preceding 4 weeks.

<sup>&</sup>lt;sup>‡‡</sup> Direct and indirect sharing: sharing of needles and syringes, mixing containers, or filters among those who had last injected during the 4 weeks preceding participation in the survey.





Data source: NHSBT/PHE Epidemiology Unit.

<sup>\*</sup> Blood donors are volunteers over 17 years old, selected to be at low risk of HCV. Rates should be interpreted with caution: the number of confirmed HCV cases are small and include resolved infections. All HCV confirmed positive donors are notified to the local Health Protection Team and a letter is sent to their GP. For those whose donation was HCV PCR negative the GP is advised to retest in 6 months and for those with a HCV PCR positive donation the GP is advised to refer to specialist services.

Further data on HCV in blood donors can be found in the NHSBT/PHE Epidemiology Unit Annual Review Supplementary tables: https://www.gov.uk/government/publications/safe-supplies-annual-review

# Local initiatives

Currently, there are several local initiatives taking place to combat hepatitis in the West Midlands. This section describes some of these initiatives, which aim to improve testing, diagnostic and treatment services amongst at-risk groups.

Gilead Sciences, a research-based biopharmaceutical company, has commenced a strategic collaboration with Change, Grow, Live (CGL) West Midlands, a drug and alcohol treatment service, across Birmingham, Coventry, Warwickshire, Walsall and Dudley. The aim of the initiative is to ensure service users can be tested, diagnosed and treated within the service by improving and expanding on CGL's capability, ensuring effective relationships between CGL, the local NHS trust providing hepatitis treatment and the West Midlands Hepatitis C Operational Delivery Network (ODN) and to engage all stakeholders to support optimum pathway development. To enhance capability and enable more of the diagnostic pathway to be undertaken by onsite nurses and key workers, an extensive workforce development and train the trainer programme has been undertaken including phlebotomy and the provision of training materials on blood borne viruses. This aims to embed the necessary skills within the workforce and ensure regular refresher training.

The Gilead Fellowship Programme has funded 2 projects, that are now underway, in the West Midlands, which are:

- University Hospitals Birmingham NHS Foundation Trust is delivering a peer-to-peer viral hepatitis testing strategy among the Asian population in Birmingham.
- the Royal Wolverhampton NHS Trust is undertaking a cost-effectiveness analysis for developing a nurse led in-reach service to drug services and prisons

Stoke-on-Trent Drug and Alcohol Services have continued to improve access to screening and treatment of hepatitis B and hepatitis C for people with drug and alcohol problems. A nurse led service is overseen by a consultant gastroenterologist and has a test to treat time of 4 weeks. Outreach clinics have significantly increased the number of patients receiving treatment for hepatitis B and hepatitis C, staff and service users have been educated and testing has been encouraged among new entrants to the Stoke-on-Trent community drug service, particularly stimulant users who were previously unaware of the risk prior to entering the service. A flexible community-based approach encourages attendance at clinic appointments and ensures continued engagement with healthcare professionals.

Since June 2010, the service has undertaken 2,060 DBS tests, 373 individuals have tested positive for hepatitis C, 234 have commenced treatment and 230 have completed treatment. The service has also administered 2,089 hepatitis A/B vaccinations.

Abbvie is one of the 3 pharmaceutical companies with the licence to manufacture the hepatitis C direct-acting antiviral (DAA) treatments for hepatitis C. They have undertaken a comprehensive mapping exercise across the West Midlands community and prisons, to ascertain the effectiveness and efficiency of pathways between drug and alcohol services and treatment for hepatitis C. As part of this exercise they were also able to influence and guide those services receptive to, and able to instigate change. A report will be compiled in collaboration with PHE – this report will provide local authorities and NHS partners with key local intelligence and examples of useful practice that can be adopted by others

# Conclusions

Despite progress in decreasing the burden and impact of Hepatitis C infections, HCV remains an important public health issue both within the West Midlands and nationally. Although laboratory reporting is high compared to much of the last decade, this is potentially due to increased testing and reporting rather than increased incidence overall. Two local authorities – Birmingham and Coventry – had higher rates of laboratory reporting than the West Midlands overall, which likely reflects the higher prevalence of at risk populations in these areas. Positively, in these local authorities there is a high proportion of testing in at risk populations such as PWID, suggesting that targeting testing programmes are having an effect.

Progress has also been made in improving the outcomes of people diagnosed with HCV in the West Midlands. In 2016, the number of hospital admissions for HCV increased slightly, however the number of admissions for individuals with HCV-related ESLD remained stable while the number for those with HCV-related HCC decreased. The suggests that earlier detection and improved treatments have reduced the number of individuals going on to develop serious disease.

Hepatitis C continues to disproportionally affect vulnerable and marginalised groups such as prisoners and PWID. In the West Midlands, there has been some success in improving service coverage in such groups over the last 10 years but there is no room for complacency. Percentage uptake of voluntary confidential testing for HCV decreased among PWID in 2017 for the second year running, although it is still higher than in the period from 2008 to 2012. The proportion of PWID sharing injecting equipment appears to have plateaued at a level slightly higher than that reported in 2008. This demonstrates that there is still a clear need for continued investment in awareness raising campaigns, particularly aimed at those at greatest risk.

National guidance has been developed to assist PHE, commissioners, service providers and local authority Directors of Public Health to promote and to offer testing to people at increased risk of infection. In the following section evidence-based recommendations are provided to continue the progress currently being made in the West Midlands and to address any gaps in service provision with the aim of further reducing the burden and impact of HCV in order to meet the 2020 and 2030 hepatitis targets.

# Recommendations

Although the number of laboratory confirmed cases of hepatitis C in the West Midlands decreased in 2017, it was still higher than in the years from 2008 to 2015. The number of individuals testing positive from the south Asian and Eastern European ethnic groups was stable in 2017. There remains a need for continued investment and awareness-raising campaigns to maintain the progress that has been made.

It was not possible to include data on prisons or young offender institutes in the West Midlands in this report due to the implementation of a new reporting system. However, there is a need to improve screening efforts in secure and detained settings in the region.

Hepatitis C prevalence remains high in PWID. The advent and increasing availability of the new direct acting antivirals (DAA) provides an opportunity to reduce morbidity and mortality from hepatitis C among those aware of their diagnosis, decrease the risk of onward transmission and address health inequalities. PWID are the main drivers of the hepatitis C epidemic and are thus a prime target group for the roll-out of DAAs. More work is needed to meet the 2030 targets set by the GHSS. Improving the offer and uptake of testing for hepatitis C is particularly important because many hepatitis C infections remain undiagnosed among PWID. Routine opt-out testing approaches should be considered where appropriate. Well-designed, supportive care pathways for those infected are needed, and those diagnosed with hepatitis C and who continue to inject should have access to effective treatment and care in line with current guidelines<sup>2</sup>.

One of the biggest obstacles to entering care pathways for HCV is the lack of treatment settings suitable for PWID. Multidisciplinary and peer-supported programmes have been shown to be successful, as well as offering blood-borne virus (BBV) testing, treatment and care in a variety of settings. In addition to community-based clinics, needle and syringe programmes, and drug treatment clinics, BBV testing is now being offered through the English and Welsh prison system on an 'opt-out' basis<sup>2</sup>.

Injecting risk behaviours have declined but remain a problem. The level of needle and syringe sharing among those currently injecting psychoactive drugs has fallen across the UK, but needle and syringe sharing remains a problem. People continue to be at risk of infection through injecting behaviours.

A range of easily accessible NSP for all PWID, including those using drug treatment services, need to be provided in line with guidance, such as the provision of free services, including needle and syringe provision, as well as testing for BBV's. Low dead

space injecting equipment\* should be offered and encouraged where appropriate. NSP should continue to also offer interventions that support entry into treatment and other interventions that encourage a reduction or cessation of injection as a route of consumption. They should aim to distribute sufficient appropriate injecting-related equipment to prevent sharing and re-use and support hygienic injecting practices<sup>2</sup>.

<sup>&</sup>lt;sup>\*</sup> The term 'dead space' refers to the volume of fluid retained in a needle/syringe once the plunger has been fully depressed, this residual fluid provides an opportunity for BBVs to be transmitted if the needle is reused by another individual. The amount of dead space varies by syringe type; with standard high dead space syringes containing up to 10 times the volume of dead space than low dead space syringes. In 2012, the World Health Organization recommended the provision of LDSS in all NSPs<sup>2</sup>.

### Data sources

Office for National Statistics mortality data:

https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deat hs

Unlinked Anonymous Monitoring Survey of HIV and Viral Hepatitis among People Who Inject Drugs:

https://www.gov.uk/government/statistics/people-who-inject-drugs-hiv-and-viral-hepatitis-monitoring

Hospital Episode Statistics, NHS Digital: http://content.digital.nhs.uk/hes

NHS Blood and Transplant/PHE Epidemiology Unit: http://www.gov.uk/guidance/blood-tissue-and-organ-donors-surveillance-schemes

PHE Sentinel Surveillance of Hepatitis C Testing: http://www.gov.uk/government/publications/sentinel-surveillance-of-blood-borne-virustesting-in-england-2016

Laboratory reporting, Second Generation Surveillance System (SGSS): https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachme nt\_data/file/739854/PHE\_Laboratory\_Reporting\_Guidelines.pdf

# **Glossary of Abbreviations**

Anti-	Antibodies to Hepatitis C Virus
BBV	Blood Borne Virus
CGL	Change, Grow, Live
DAA	Direct-acting Antiviral Agent
DAT	Drug Action Team
DBS	Dried Blood Spot
DSR	Directly Standardised Rate
ESLD	End Stage Liver Disease
GHSS	Global Health Sector Strategy
HCC	Hepatocellular Carcinoma
HCV	Hepatitis C Virus
HES	Hospital Episode Statistics
HIV	Human Immunodeficiency Virus
IDU	Injecting Drug Use
IVF	In vitro fertilisation
NDTMS	National Drug Treatment Monitoring System
NHSBT	NHS Blood and Transplant
NICE	National Institute for Health and Care
NSP	Needle and Syringe Programme
ODN	Operational Delivery Networks
ONS	Office for National Statistics
PHE	Public Health England
PWID	People Who Inject Drugs
RNA	Ribonucleic Acid
UAM	Unlinked Anonymous Monitoring
WHO	World Health Organization

# Appendix

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

Linner for least sutherity		2016		2017			
of residence	DSR	95% LCI	95% UCI	DSR	95% LCI	95% UCI	
Coventry	33.8	27.7	40.7	40.6	33.9	48.2	
Birmingham	39.8	35.9	43.9	35.2	31.6	39.0	
Walsall	16.8	12.2	22.6	19.7	14.6	25.9	
Wolverhampton	18.2	13.3	24.4	18.1	13.1	24.2	
Dudley	18.8	14.2	24.5	18.0	13.4	23.7	
Sandwell	18.3	13.8	23.8	17.5	13.2	22.8	
Stoke-on-Trent	30.0	23.5	37.8	16.9	12.1	23.1	
Warwickshire	14.4	11.3	18.0	11.2	8.5	14.4	
Worcestershire	14.8	11.7	18.5	9.8	7.3	12.9	
Staffordshire	10.0	7.9	12.4	9.7	7.7	12.1	
Telford and Wrekin	15.3	9.9	22.7	9.7	5.5	15.7	
Shropshire	11.2	7.6	15.9	9.1	5.9	13.4	
Herefordshire	11.3	6.7	17.7	7.4	4.0	12.4	
Solihull	6.4	3.3	11.1	6.5	3.4	11.1	
West Midlands PHEC	20.6	19.4	21.9	18.5	17.4	19.7	
England	20.2	19.9	20.6	18.4	18.1	18.8	

<sup>\*</sup> Data are summarised by upper tier local authority of residence, not upper tier local authority of laboratory. Data are assigned to upper tier local authority by patient postcode where present; if patient postcode is unknown, data are assigned to upper tier local authority of registered GP practice; where both patient postcode and registered GP practice are unknown data are assigned to upper tier local authority of laboratory. Includes individuals with a positive test for hepatitis C antibody and/or detection of hepatitis C RNA. Due to the variability in the quality of laboratory reports and the inability of current serological assays to differentiate acute from persistent infections we are unable to estimate the actual proportion of cases with evidence of past infection or persistent infection. Mothers who are anti-HCV positive usually pass this maternal antibody to their babies. However most of these babies are not actually infected with the hepatitis C virus. The antibodies showing up in the baby's blood are most often the mother's antibodies that were passed to the baby before birth. A baby born to a mother with hepatitis C will probably have maternal antibodies to the virus for the first 12 to 18 months of life. Therefore, the baby will have a positive anti-HCV test irrespective of whether the baby is infected. For this reason, tests in those aged under one are excluded from the dataset for 2016 and 2017.DSRs per 100,000 population have been calculated using mid-year population estimates supplied by the Office for National Statistics (ONS). Excludes cases where age and/or gender are unknown.

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