

Protecting and improving the nation's health

# Hepatitis C in London: 2019 report

Field Service

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# Notes on the report

### Aim of report

This report describes the recent epidemiology of hepatitis C in London, providing an update on trends, identifying areas and populations of increased risk, with the aim to support focused action to eliminate hepatitis C as a major public health threat by 2030.

#### Intended audience

This report is aimed at healthcare professionals involved in the diagnosis and/or treatment of hepatitis C patients, commissioners involved in planning and financing of hepatitis C services, public health professionals, researchers, government and non-governmental organisations working in the field of hepatitis C.

#### Data sources

This report presents data from laboratory surveillance, sentinel surveillance, unlinked anonymous monitoring surveys of infections and risk among people who inject drugs, drug treatment services, hospital episode statistics, mortality data from the Office for National Statistics and transplant data from the UK transplant registry.

# **Abbreviations**

**BBV** Bloodborne virus

DAA Direct acting antivirals

ESLD End-Stage liver disease

HCC Hepatocellular carcinoma

HBV Hepatitis B virus
HCV Hepatitis C virus

JSNA Joint strategic needs assessments
NSP Needle and syringe programme

PHE Public Health England
PWID People who inject drugs

RNA Ribonucleic acid

**UAM** Unlinked anonymous monitoring

WHO World Health Organization

# **Executive summary**

Hepatitis C (HCV) is a virus which is an important cause of liver disease. The most common route of transmission is through exposure to the blood of an infected person. Contact with blood for example can be from sharing needles used to inject drugs, or through unprotected sex. Infection is usually asymptomatic in the early years but without successful treatment, the virus can persist for several decades and lead to end stage liver disease (ESLD) and hepatocellular carcinoma (HCC).

In May 2016, the UK signed up to the World Health Organization (WHO) Global Health Sector Strategy on Viral Hepatitis which commits participating countries to the elimination of hepatitis C as a major public health threat by 2030 (1). To meet this commitment, PHE works with our partners to improve prevention, raise awareness, increase testing and get more diagnosed individuals into treatment and care, whilst ensuring access to hepatitis C services is equitable.

In 2017, London accounted for nearly a third (31%) of new hepatitis C virus antibody positive laboratory reports in England and has the highest rate of new laboratory reports (36.1 per 100,000 residents) compared to other PHE Centre areas. The number of new hepatitis C virus antibody positive laboratory reports in London rose steadily from 1015 reports in 2007 to 4,075 reports in 2015. This rise was likely due to increased case ascertainment as laboratory reporting became a statutory requirement in 2010 (2). New laboratory reports in 2017 (3,140 reports) declined by 23% compared to 2015. It is important to note that new laboratory reports cannot be used to estimate new infections. Changes in the numbers may reflect trends in testing or reporting.

The estimated number of individuals who have been infected with hepatitis C varies considerably across local authorities in London. In 2017, Hammersmith and Fulham had the highest rate and numbers of new laboratory reports in London. Variations across local authorities most likely reflect differences in testing activity but also different underlying populations at risk, such as those using drugs or from minority ethnic and prison populations.

Injecting drug use remains the most important risk factor for hepatitis C infection. It was estimated that 63% of people who inject drugs (PWID) in London had ever been infected with hepatitis C in 2018. Among those ever infected, 41% had chronic hepatitis C infection. From the sentinel surveillance data, individuals originating from regions where the prevalence of hepatitis C is high, such as South Asia and Eastern Europe, are also at increased risk. The majority of reports of positive anti-HCV results were among males and those aged 35 to 54 years.

It is estimated that 18% of PWID were unaware of their infection. While better than the proportion unaware in England overall (35%), this still reflects the need for more frequent testing. In 2017/2018, 87% of eligible clients of drug treatment services received a hepatitis C test, a small increase from 86% in 2016/2017. Raising awareness, leading to increased testing, is important to identify undiagnosed cases.

A key prevention opportunity for PWID is reducing the sharing of drug paraphernalia through needle exchange schemes. While there has been an overall decline in the past 10 years, a significant proportion continue to share injecting equipment (33% indirect and direct sharing in 2018). Improvements in access to and uptake of harm reduction services will reduce the number of infections occurring in this population. The delivery of successful treatment and prevention programmes in this group requires the integrated input of healthcare and public health professionals, local government and other voluntary and professional organisations.

The number of first registrations for a liver transplant due to post-hepatitis C cirrhosis halved from 116 in 2010-2013 to 62 in 2014-2017. Hepatitis C was a primary, secondary or tertiary indication for 23% of transplants in 2010-2013 and decreased to 15% in the period 2014-2017. The number of deaths due to ESLD or HCC in those with hepatitis C mentioned on their death certificate has also decreased nationally by 16% since 2014. These trends suggest that the new class of direct acting antivirals (DAAs) have had an impact on hepatitis C-related ESLD/HCC.

In addition to reducing morbidity and mortality, modelling data has demonstrated that treatment as prevention can reduce the overall prevalence by treating people who are actively transmitting hepatitis C. People who inject drugs should therefore be considered a priority group for access to treatment. NHS England is responsible for commissioning and funding access to treatment via Operational Delivery Networks covering the whole of England. More information on treatment can be accessed through the Hepatitis C treatment monitoring in England report, published in November 2018.

PHE continues to work with partner organisations to improve collection of data on treatment outcomes. This will help in evaluating the impact of DAAs among those treated at different disease stages. It is widely accepted that DAAs should lead to a dramatic reduction in severe hepatitis C-related disease in comparison to previous interferon-based therapy. Furthermore, treatment of those with mild and moderate stage disease should reduce hepatitis C transmission and re-infection.

A national treatment monitoring dataset has been agreed that will help describe access to hepatitis C treatment and care in the ODNs across England. Data including ethnicity, country of birth, route of infection, disease stage, source of referrals and settings of treatment will describe which groups are accessing treatment and the impact of this treatment on the future burden of hepatitis C-related disease in England (3). Care pathways should be regularly reviewed to ensure that infected individuals are identified and can access treatment services. Hepatitis C is a particular concern in marginalised communities, and it is, therefore, important to monitor the equity of access to treatment and care services for all infected individuals in London.

The new treatments offer the opportunity to treat more people in community settings, outside of hospitals. The vast majority of London boroughs, in conjunction with the London ODNs, have developed the delivery of hepatitis C treatments in community drug treatment settings. In order to appropriately target people who inject drugs, all ODNs should offer treatment services in the few remaining boroughs without one in their drug treatment services. Further improvements in access to both treatment and harm reduction services will lead to substantial reductions in hepatitis C-related morbidity and mortality and put London on track to achieve the WHO goal to eliminate hepatitis C as a major public health threat by 2030.

# 1. Public Health recommendations

The following recommendations for London have been adapted from the Hepatitis C in England: 2019 report and Eliminating Hepatitis C in England: All-Party Parliamentary Group on Liver Health Inquiry Report. The recommendations are grouped by the relevant organisations and authorities focusing on:

- making improvements and monitoring metrics
- adequate harm reduction/prevention
- increasing the numbers and proportion diagnosed
- increasing the numbers accessing hepatitis C treatment

### Public Health England

Consider new ways of mapping and monitor needle and syringe programme activity, and advocate for these as cost-effective interventions that prevent hepatitis C transmission.

Support commissioners of hepatitis C treatment and care services, primary and secondary care clinicians, and other stakeholders with data analysis and monitoring the availability, access and uptake of approved hepatitis C treatments in primary and secondary care, drug treatment services, prisons and other settings in London.

Work with commissioners, providers of laboratory services, hepatitis C treatment and care services to improve the quality and availability of testing and treatment data on hepatitis C.

## NHS England

Health and Justice to ensure that bloodborne virus opt-out testing for new receptions to prisons in London continues to be monitored to inform strategies to improve the offer and uptake of testing.

Health and Justice leads to monitor harm minimisation policies in detention settings, including provision of disinfectant/decontamination equipment for sharps.

Continue to work with public health agencies, clinicians and other stakeholders to monitor and support the equity of access to treatment and care services among individuals with hepatitis C infection in London.

### Local authority

Public health professionals working in London local authorities to include hepatitis C in Joint Strategic Needs Assessments (JSNA) and subsequent health and wellbeing strategies.

Commissioners of services for people who inject drugs to sustain or expand, as appropriate, the current range of provision, including opioid substitution treatment and needle and syringe programmes according to NICE guidance. Other provisions may include:

- initiatives such as capillary blood sampling and point of care testing, and opt-out testing approaches
- testing to be introduced in as many community settings as possible, including pharmacies, homeless hostels, daycentres, and through street outreach teams, in addition to sexual health clinics and substance misuse services
- ensure the legal requirement to report hepatitis C positive laboratory results with patient identifiers to PHE, including those from dried blood spot testing
- PCR/RNA testing should be carried out, or reflex testing on antibody positive Dry Blood Spot (DBS)

Drug treatment and BBV prevention services should ensure that appropriate information, repeat testing and support are provided to prevent re-infection.

## Clinical commissioning groups (CCG)

Public health professionals working in London local authorities and CCGs to include hepatitis C in Joint Strategic Needs Assessments (JSNA) and subsequent health and wellbeing strategies.

Commissioners and providers of laboratory services to ensure that RNA amplification tests are performed on the same sample as the original antibody assay (reflex testing) to reduce referral delays and increase cost effectiveness.

Diagnostic laboratories should include patient referral instructions on the laboratory report, and implement direct reporting of new diagnoses to their ODN, as well as to the individual requesting the test.

Ensure that integrated and robust pathways of care are available for patients with hepatitis C, ideally co-ordinated through a clinical network. This includes pathways for patients who test positive for hepatitis C in primary care.

### **Operational Delivery Networks**

Testing and treatment in the community to be prioritised, the patient pathway to be reviewed and flexible services located where patients are most likely to access them to be designed

Treatment must be made available in community settings, and be flexible and accessible to all patients

Treatment should also be made available to those who are re-infected in line with a 'treatment as prevention' approach.

ODN managers and clinicians should make targeted efforts to engage with currently injecting individuals infected with hepatitis C and offer treatment in accessible community settings

#### All stakeholders

All stakeholders to support improved awareness among professionals, for example by encouraging participation in e-learning (Appendix 3)

All stakeholders to continue to produce and disseminate appropriate communications, like reporting and infographics, to help mark World Hepatitis Day using resources (Appendix 3)

# 2. Background

Hepatitis is a term meaning 'inflammation of the liver'. Hepatitis C virus (HCV) is an important cause of hepatitis. Symptoms can include anorexia, abdominal discomfort, nausea and vomiting, fever and fatigue, progressing to jaundice in approximately a quarter of patients. However, infection is usually asymptomatic in the early years.

Of those exposed to hepatitis C without successful treatment, about 40% recover; but the remainder, whether they have symptoms or not, develop chronic infection, which can lead to cirrhosis, end stage liver disease (ESLD) and liver cancer (hepatocellular carcinoma, HCC) (4).

Previous modelling studies suggested that around 113,000 people in England are living with chronic hepatitis C infection (5). Modelling work is ongoing to update this estimate. PHE publishes comprehensive annual reviews of the epidemiology of hepatitis C in the UK and England (3, 6).

The new class of direct acting antivirals (DAA) offers a fast and effective cure to the vast majority of people with hepatitis C, without many of the complications associated with previous treatments. The WHO Global Health Sector Strategy on viral hepatitis calls for three million people with chronic hepatitis C to have been treated by 2020 and by 2030 treatment coverage to reach 80% of the global eligible population.

Specialised hepatitis C Operational Delivery Networks (ODNs) are responsible for delivering hepatitis C treatment in England. The Networks involve regional centres that manage treatment decisions and prescribing, but have a dispersed treatment model to support partnership working and local treatment access. There are 22 NHS Operational Delivery Networks (ODNs) across England, of which 4 ODNs serve primarily London residents: West London, North Central London Viral Hepatitis Network, Barts and South Thames Hepatitis Network.

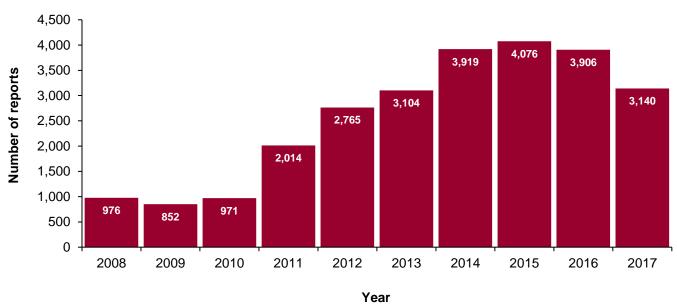
# 3. Trends in testing

### 3.1 New laboratory reports of hepatitis C

The number of laboratory confirmed reports of hepatitis C in London rose steadily between 2010 and 2015 (Figure 1). These rises were likely due to increased reporting as opposed to an increase in infection rates, since laboratory reporting became a statutory requirement in 2010 (2). In 2017 there was a decline in the number of lab reports to 3140, a decline of 23% since 2015 (4076 reports).

New laboratory reports cannot be used to estimate new infections. Hepatitis C is usually asymptomatic and there are no routinely available laboratory markers to identify recent infection. Changes in the numbers diagnosed in laboratories often reflect trends in testing or reporting, rather than incidence.

Figure 1\*: Number of laboratory confirmed reports of hepatitis C from laboratories in London, 2008–2017

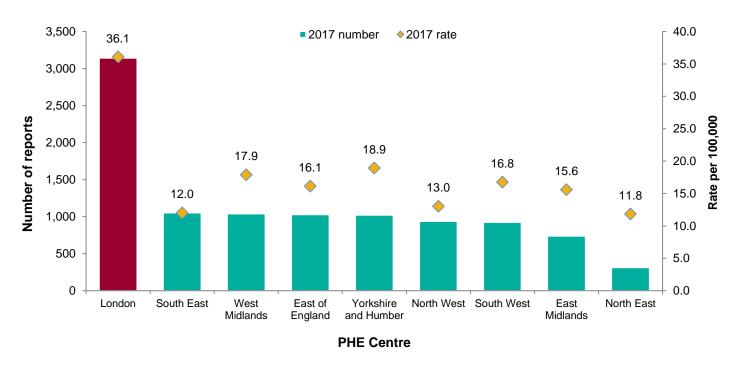


<sup>\*</sup> Includes individuals with a positive test for hepatitis C antibody and/or detection of hepatitis C RNA. Due to the variability in the quality of laboratory reports and the inability of current serological assays to differentiate acute from persistent infections we are unable to estimate the actual proportion of cases with evidence of past infection or persistent infection. Tests in those aged under one are excluded from the dataset for 2016 and 2017.

Source: SGSS

London accounted for nearly a third (31%) of all hepatitis C laboratory reports in England in 2017 and had the highest rate of reporting compared to other PHE Centre areas (Figure 2). The number and rate of laboratory reports in 2017 by local authority is presented in Appendix 2. The rate of laboratory reports in London has also declined in recent years, however remains double the national rate (Figure 3).

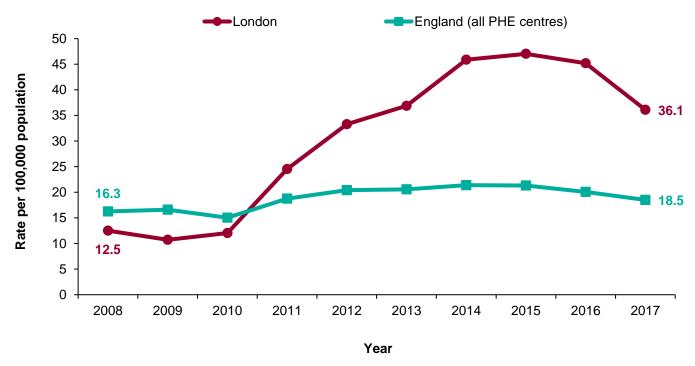
Figure 2: Number and rate of laboratory confirmed reports of hepatitis C per 100,000 residents, by PHE Centre, 2017



Includes individuals with a positive test for hepatitis C antibody and/or detection of hepatitis C RNA. Tests in those aged under one are excluded from the dataset for 2016 and 2017.

Source: SGSS

Figure 3: Rate of laboratory reports of hepatitis C per 100,000 population, residents of London and England, 2008-2017



Source: SGSS

While one less laboratory was reporting data in 2017 compared to 2016, the 3 laboratories with the highest number of reports in 2016 showed large declines. In 2017 Charing Cross Hospital, St Bartholomew's Hospital, and St Thomas' Hospital reported 23%, 16%, and 15% fewer laboratory reports compared to 2016 (Figure 4). Further investigation demonstrated that the decline in laboratory reports in 2017 compared to 2016 was due to changes in reporting by high throughput laboratories. Therefore, changes in laboratory reports over time should be interpreted with caution.

Charing Cross Hospital St Bartholomew's Hospital St Thomas' Hospital, London St George's Hospital, Tooting University College Hospital, London Hillingdon Hospital Kings College Hospital Royal Free Hospital, Hampstead London North West Healthcare Trust (Ealing and... **2016** North Middlesex Hospital, London 2017 Queens Hospital, Romford -aboratory Queen Elizabeth Hospital, Woolwich Whittington Hospital Barnet Hospital St Helier Hospital, Carshalton Homerton Hospital Princess Royal University Hospital, Orpington Lewisham Hospital Royal Marsden Hospital Royal Brompton Hospital, Chelsea Great Ormond Street Hospital for Sick Children 0 200 400 600 800 1000 1200 **Number of laboratory reports** 

Figure 4: Number of reports of hepatitis C by reporting laboratory, London, 2016-2017

### 3.2 Positivity in sentinel surveillance

Sentinel surveillance collects data on testing for hepatitis C-specific antibodies (anti-HCV), a marker of ever having a hepatitis C infection. Participating laboratories cover approximately 32% of the population registered with GPs. As part of the sentinel laboratory surveillance programme, 8 laboratories in London (Chelsea and Westminster hospital, Dulwich laboratory, Ealing Hospital, North Middlesex Hospital, PHE Centre for Infectious Disease Surveillance and Control, St Bartholomew's Hospital, St George's Hospital and University College Hospital) are participating and collect more detailed information about people being tested for hepatitis C (more information in data sources) (7). While numbers tested have increased, the proportion testing positive for hepatitis C in London decreased from 1.6% in 2013 to 1.3% in 2017 (Figure 5). This decline in positivity may be the result of extending testing to individuals at relatively lower risk of infection.

0.0

2013

Number tested % positive 60,000 2.2 Number of individuals tested 51,527 2.0 50,000 1.8 Percentage positive 1.6 40,000 1.4 1.2 30,000 1.0 8.0 20,000 0.6 0.4 10,000 0.2 1.5 1.3 1.2 1.8 1.3

Figure 5: Number of individuals tested and the percentage testing positive for anti-HCV in sentinel laboratories, London, 2013-2017

2016

2017

Trend data only includes locations that have been consistently reported in each of the 5 years. Source: sentinel laboratory surveillance

2015

Year

2014

Sentinel surveillance data is presented for Barts, North Central London and South Thames ODNs (Figure 6-8: 5-year trend data was not available for West London). Testing in sentinel laboratories has increased since 2013 in Barts and South Thames ODNs, and from 2013 to 2016 in North Central London ODN. In 2017 there was a sharp decline in testing in North Central London, however, this may be due to one laboratory stopping participation in the sentinel surveillance programme. Positivity decreased the most from 2013 to 2014 and has remained relatively stable to 2017 in all ODN areas.

Figure 6: Number of individuals tested and percentage testing positive for anti-HCV in sentinel laboratories, Barts ODN, 2013-2017

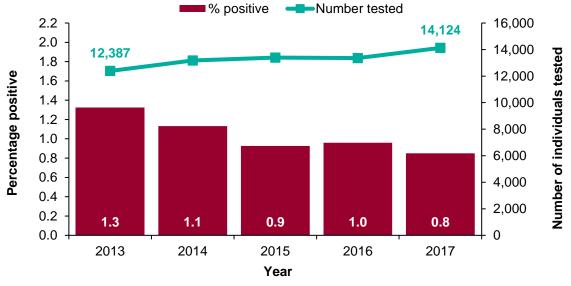


Figure 7: Number of individuals tested and percentage testing positive for anti-HCV in sentinel laboratories, North Central London ODN, 2013-2017

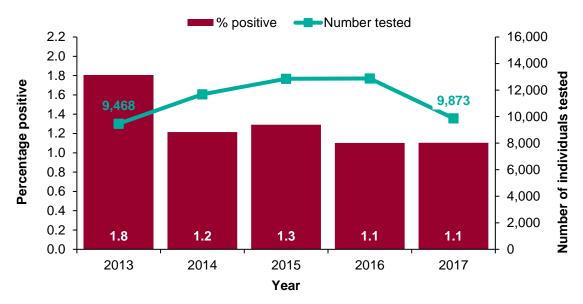
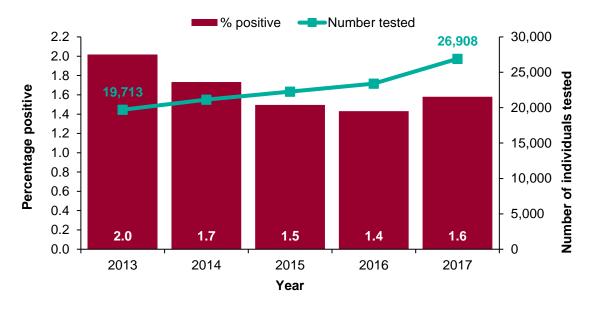


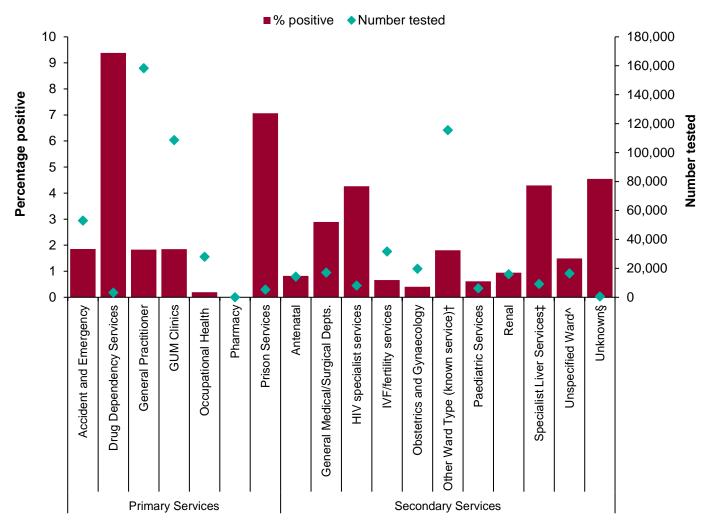
Figure 8: Number of individuals tested and percentage testing positive for anti-HCV in sentinel laboratories, South Thames Hepatitis ODN, 2013-2017



### 3.3 Site of testing

Information from sentinel surveillance indicates that hepatitis C testing was most often requested by general practitioners (Figure 9) (7). However, this data does not include dried blood spot testing and oral fluid testing (commonly used in drug services), reference testing and testing from hospitals referring all samples. The highest percentage of positives were among people tested in Drug Dependency Services, and Prison Services.

Figure 9: Number of individuals tested and percentage testing positive for anti-HCV by service type in sentinel laboratories, London, 2013-2017



The numbers relate to those tested in the sentinel laboratories and do not represent all tests across London.

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

Source: sentinel laboratory surveillance

# 4. Groups at increased risk

Among the various group recommended for hepatitis C screening by NICE (Table 1), the principal risk group are people who inject drugs.

Table 1: Risk groups recommended for hepatitis C screening by NICE (8)

### Offer screening

- People who have ever injected drugs, at any point in the past, even if it was only once
- People who have received medical, cosmetic, or dental treatment (or any other invasive treatment) in countries where hepatitis C is
- People who received a blood transfusion or organs/tissue prior to 1992 or blood products before 1986
- Babies and children whose mothers have hepatitis C
- Anyone accidentally exposed to hepatitis C (for example, healthcare workers with needlestick injuries)
- People who have had tattoos, body piercing, acupuncture, or electrolysis where unsterilized equipment may have been used
- People who have tested positive for hepatitis B or HIV

Consider screening, particularly in the presence of non-specific or unexplained symptoms

- People who have, or are currently, snorting or smoking drugs (such as cocaine), particularly if they have shared straws or pipes.
- Regular sexual partners of people who are known to have chronic hepatitis C
- Household contacts of people who are known to have chronic hepatitis C
- People who are at risk through sharing of contaminated items such as razors or toothbrushes
- People who were born in countries where hepatitis C is endemic, such as Egypt, Pakistan, and China; and migrants from mediumor high-prevalence areas, such as north Africa and central and east Asia

# Routine screening by specialist services

- All pregnant women, as part of routine antenatal care
- People who intend to donate blood or organs/tissue
- People with end-stage chronic kidney disease requiring renal replacement therapy
- Healthcare workers who perform invasive or exposure-prone procedures (for example surgeons)

### 4.1 People who inject drugs

PWID are the group most affected by hepatitis C in the UK (6). 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 (9).

PHE's Unlinked Anonymous Monitoring (UAM) Survey of PWID measures prevalence of hepatitis C antibodies in current and former PWID in England, Wales and Northern Ireland (10). In London, this survey estimated the prevalence of antibodies to the hepatitis C virus in PWID as 63% in 2018, above the England prevalence (55%) (10).

Number of samples % anti-HCV prevalence 700 80% 70% 600 Number of samples 60% 500 50% Percentage 400 40% 300 30% 200 20% 100 10% 418 280 386 352 276 446 546 591 573 377 332 0 0% 2008 2009 2010 2011 2012 2013 2014 2015 2016 2017 2018 Year

Figure 10: Number of samples tested and anti-HCV prevalence, London, 2008-2017

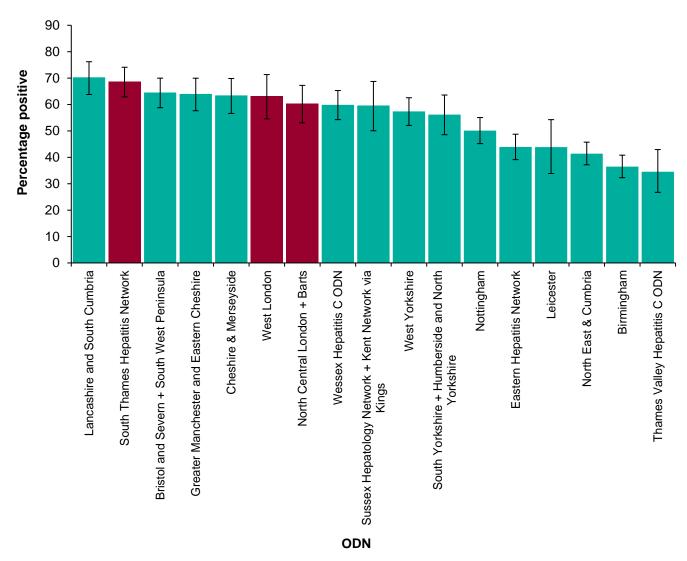
Source: Unlinked Anonymous Monitoring Survey of HIV and Hepatitis in People Who Inject

The prevalence of hepatitis C RNA, an indicator for chronic hepatitis C infection, was tested for 2017 and 2018 surveys, and retrospectively for 2011 and 2014-2016 surveys (10). Among those ever infected (anti-HCV positive), the prevalence of chronic hepatitis C infection (HCV RNA positive) in 2018 in London was 41%. This was a large decrease compared to 63% in 2014; consistent with the scale-up of DAAs in 2015 (10).

Anti-HCV prevalence data from the UAM survey by ODN was available for 2016 and 2017 (Figure 11). Anti-HCV prevalence was estimated to be 69% (95% CI 63%-74%) for South Thames ODN, 63% (95% CI 55%-71%) for West London ODN and 60% (95% CI 53%-67%) for North Central London and Barts ODN. Please note that differences in anti-HCV prevalence may be reflective of differences in recruitment for

the UAM survey and that only 137 samples were available for West London ODN. Data from North Central London ODN and Barts ODN were combined due to small numbers.

Figure 11: Percent anti-HCV prevalence in people who inject drugs by ODN, 2016 and 2017



Data is combined to account for low numbers for individuals ODNs for South Yorkshire + Humberside and North Yorkshire; North Central London + Barts; Bristol and Severn + South West Peninsula; Sussex Hepatology Network + Kent Network via Kings. Data are not available for Surrey Hepatitis Services ODN.

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

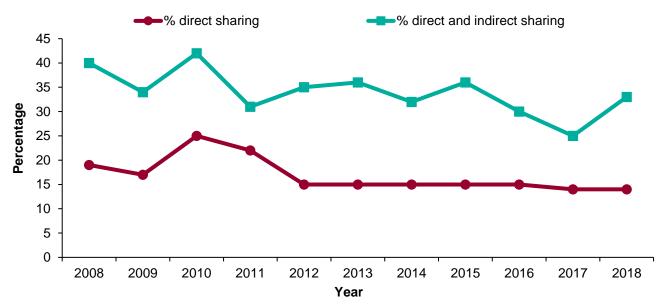
### Needle and syringe sharing and use of needle and syringe programmes among PWID

Overall, the level of needle and syringe sharing (either receiving or passing on a used needle or syringe) reported by those currently injecting psychoactive drugs has fallen across the UK in the past decade. In England, Wales and Northern Ireland, sharing of needles and syringes ("direct sharing") in the past month fell from 23% of current injectors in 2007 to 18% in 2018 (10). When including the sharing of mixing containers

or filters ("indirect sharing") as well as needles and syringes, the proportion of current injectors reporting sharing in the past month was 39% in 2017 in England, Wales and Northern Ireland, a decrease from 45% in 2007 (10).

In London, the proportion of current injectors reporting direct sharing in the past month was 14% in 2018 and the proportion of current injectors reporting direct and indirect sharing in the past month was 33%, lower than the prevalence in England overall (18% direct, 39% direct and indirect) (Figure 11)(10).

Figure 12: Level of direct\* and indirect\*\* sharing of injecting equipment amongst people who inject drugs, London, 2008–2017



<sup>\*</sup>Sharing of needles and syringes among those who had last injected during the 4 weeks preceding participation in the survey

Source: Unlinked Anonymous Monitoring Survey of HIV and Hepatitis in People Who Inject Drugs

In 2018, in England, Wales and Northern Ireland 91% of people who have ever injected drugs reported using needle and syringe programmes (NSP) (10). Adequate provision of injecting equipment is important, to reduce sharing and re-use of injecting equipment (11). 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 (9).

<sup>\*\*</sup>Sharing of needles and syringes, mixing containers, or filters among those who had last injected during the 4 weeks preceding participation in the survey

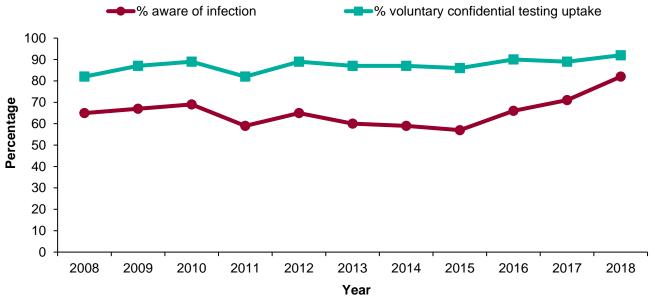
### Hepatitis C testing uptake among people who inject drugs

Recently updated UK clinical guidelines recommend that all PWID accessing treatment services are tested for hepatitis C and HIV at first assessment, and that repeat testing should be considered when the risk of exposure continues (12).

The proportion of PWID who report uptake of voluntary confidential testing for hepatitis C has increased across the UK in the last decade (9). Whilst Scotland has seen a sustained increase, England, Wales and Northern Ireland have seen a more gradual increase in testing which has plateaued over the last 7 years (9).

The proportion of the UAM participants in London with anti-HCV, who reported that they were aware of their hepatitis C infection was 82% in 2018 (Figure 12). Awareness has increased since 2015 and is at its highest since 2008. However, 18% of those ever infected with hepatitis C, were unaware that they ever contracted the virus. Results for 2018 should be interpreted with caution as changes in the 2017 UAM survey, introduced to differentiate between past and current hepatitis C infection, have resulted in increased levels of non-response to this question (49% did not respond to this question). This is likely to account for some of the changes observed in these figures compared to previous years.

Figure 13: Hepatitis C test uptake amongst people who inject drugs and their awareness of infection, London, 2008–2018



Due to changes in survey questions regarding awareness of hepatitis C infection status, data from 2017 are not directly comparable to previously collected data

Source: Unlinked Anonymous Monitoring Survey of HIV and Hepatitis in People Who Inject Drugs

Reported testing among clients of drug treatment services in the London has also remained the same. In 2017-2018 financial year, 87% of eligible clients received a

hepatitis C test, similar to 2016/2017 (86%) (13). Eligible clients are people in drug misuse treatment who currently inject, or have previously injected, drugs. This was higher than seen in England (83%), but varied considerably by local authority in London, with 12 boroughs testing fewer eligible clients than the England average (13). Of note, these figures may capture people who were tested when first entering treatment but may not have been retested more recently.

Percentage 25 Islington Ealing Redbridge Brent Hammersmith and Fulham Waltham Forest Wandsworth Barking and Dagenham Enfield Kensington and Chelsea Croydon London PHE centre Haringey Bromley England Bexley Kingston upon Thames Havering Hillingdon Sutton Nestminster Lewisham ower Hamlets Barnet Southwark Richmond upon Thames Harrow Newham Greenwich Merton of London Camden ambeth Hackney Hounslow Local authority

Figure 14: Percentage of clients of drug treatment services eligible and who received a hepatitis C test by local authority, London, 2017-2018 financial year

Eligible clients are people in drug misuse treatment who currently inject, or have previously injected, drugs. Source: PHE Fingertips Liver Profiles (based on National Drug Treatment Monitoring System data)

### 4.2 Ethnicity

Among sentinel laboratory surveillance data, the proportion of those tested that are positive for hepatitis C varies by ethnicity (Figure 15). Since 2013, positivity decreased among most ethnic groups, while testing remained stable or increased. There was an exception in those of white ethnicity, where positivity increased in 2017. The

prevalence of hepatitis C in individuals originating from South Asia has continued to decrease from 1.3% in 2013 to 0.8% in 2017 (Figure 16). In those originating from Eastern Europe, hepatitis C prevalence has increased from 2.2% to 3.5% (Figure 17).

Figure 15: Number of individuals tested and percentage positive for anti-HCV by ethnic group in sentinel laboratories, London, 2013-2017

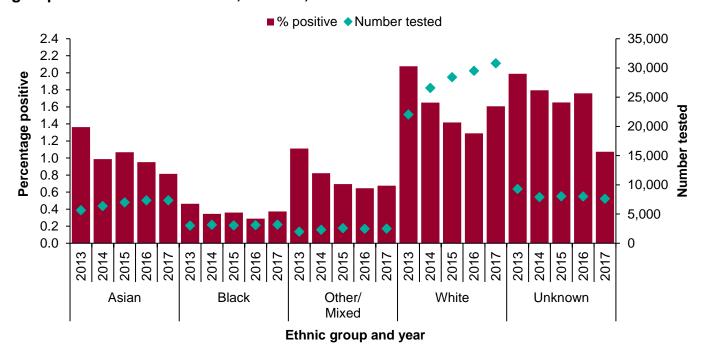
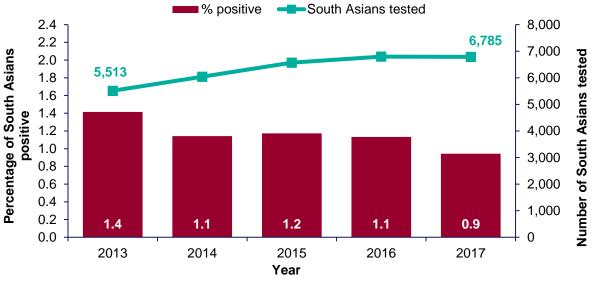
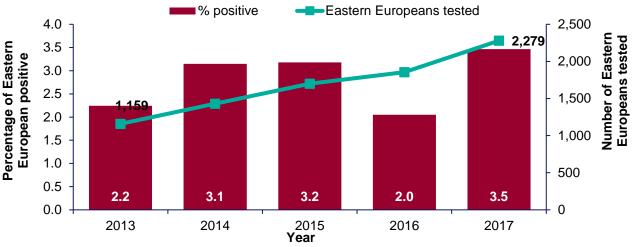


Figure 16: Number of South Asian individuals\* tested and percentage testing positive for anti-HCV in sentinel laboratories, London, 2013–2017



\*NamPehchan software was used to identify individuals of South Asian origin because ethnicity is not routinely available from the participating laboratory information systems. Source: sentinel laboratory surveillance

Figure 17: Number of Eastern Europeans individuals tested and percentage testing positive for anti-HCV in sentinel laboratories, London, 2013-2017



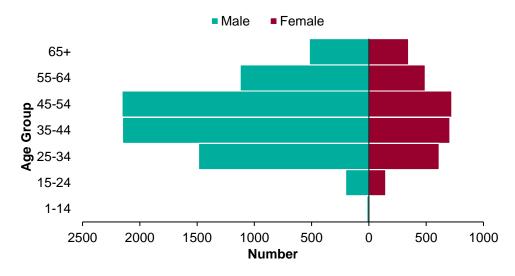
Source: sentinel laboratory surveillance

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

### 4.3 Age and sex

Among sentinel surveillance data, males accounted for 71% of those testing positive for hepatitis C between 2013 and 2017, most frequently those aged between 35 and 54 years (Figure 18).

Figure 18: Age-group and gender of individuals testing positive for anti-HCV in sentinel laboratories, London, 2013-2017

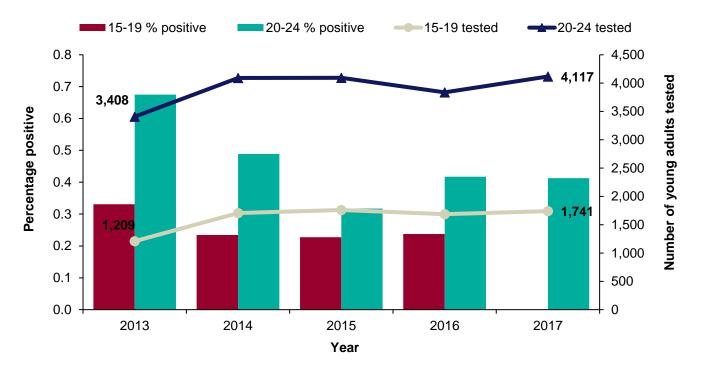


Source: sentinel laboratory surveillance

As most new infections are acquired via injecting drug use at a relatively young age, the prevalence of infection in young adults can be used as proxy measures of incidence. In the 2017, no hepatitis C positive samples from 15-19 year olds were

reported via the sentinel surveillance scheme, although numbers tested were similar to previous years (Figure 19). Numbers tested and positivity (0.4%) among 20-24 year olds was similar to previous years.

Figure 19: Number of young adults tested and testing positive for anti-HCV in sentinel laboratories, London, 2013-2017\*



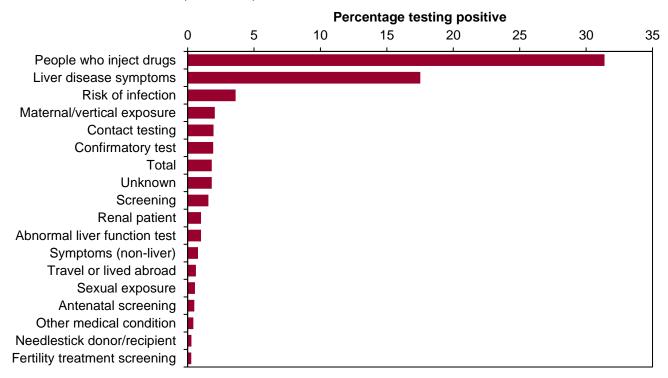
<sup>\*</sup>Excludes dried blood spot, oral fluid, reference testing and testing from hospitals referring all samples. Data are de-duplicated subject to availability of date of birth, soundex and first initial

Source: sentinel laboratory surveillance

#### 4.4 Other risk factors

Data on reason for hepatitis C testing was available for 11% of individuals reported by sentinel laboratories in 2017 (Figure 20). Among these, people who inject drugs (24%) and those with liver disease symptoms (14%) had the highest positivity rates.

Figure 20: Percentage of individuals testing positive for anti-HCV by risk/reason for test in sentinel laboratories, London, 2013-2017



Source: sentinel laboratory surveillance

# 5. Morbidity and mortality

### 5.1 Hospital admissions for hepatitis C

Updated hospital admissions data for individuals with a diagnosis code for hepatitis C was not available for 2017 at the time of report writing. Hospital admissions data for 2016 is available in the Liver Disease Profiles (13).

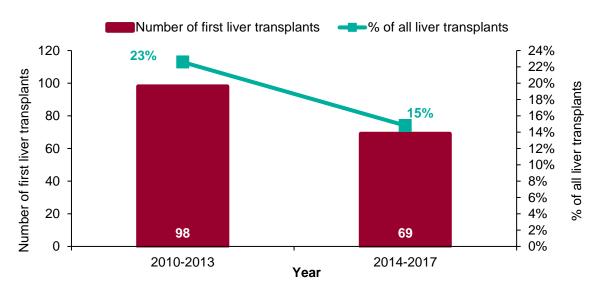
### 5.2 Transplants

In London, the number of first registrations for liver transplants with post-hepatitis C cirrhosis as a primary, secondary or tertiary indication during 2014–2017 (62) was nearly half the number (116) in the previous 4-year period (2010-2013) (14).

A similar but less marked trend was seen for the number of first liver transplants with post-hepatitis C cirrhosis as a primary, secondary, or tertiary indication (Figure 21). In 2010-2013, these indications accounted for 23% of all liver transplants in London, and decreased to 15% of liver transplants in the period 2014-2017 (14).

This data may suggest that new treatments may be having an effect on longer term, with a year-on-year decrease in longer term sequalae since 2014 (3). However, this decline may be due to alternative explanations and continued monitoring is necessary to determine whether this is an established trend.

Figure 21: Number and percentage of first liver transplants\* for patients with post-hepatitis C cirrhosis as either primary, secondary or tertiary indication for transplant at registration or patients who were hepatitis C positive at registration or transplant, London, 2010-2017

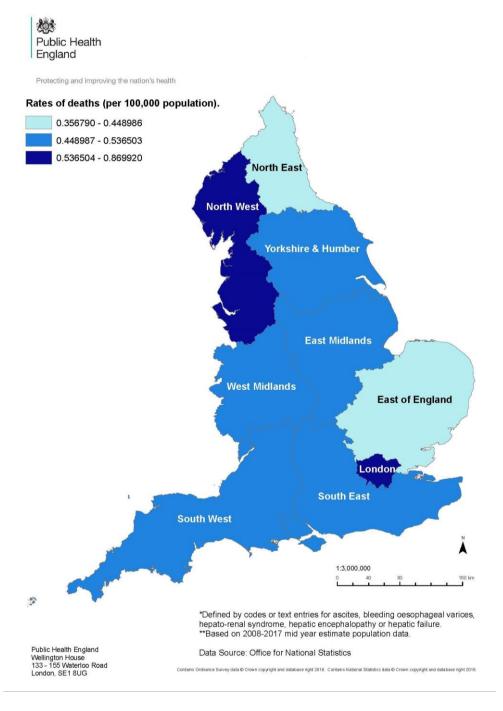


Source: NHS Blood and Transplant UK Transplant Registry

### 5.3 Deaths from hepatitis C

London and the North West PHE Centres had the highest rates of deaths in England from ESLD or HCC in individuals with hepatitis C mentioned on their death certificate (Figure 22) (15). This likely reflects the increased burden of disease in these areas. The number of deaths nationally decreased by 16% from 2014 to 2017. This is thought be due to the availability of DAAs since 2014/2015 (3).

Figure 22: Map showing the rate of deaths (per 100,00 population)\*\* from end-stage liver disease (ESLD)\* or hepatocellular carcinoma (HCC) in individuals with hepatitis C mentioned on their death certificate by PHE Centre, 2008–2017(15)



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).

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.

In London, the under 75 crude mortality rate from hepatitis C related ESLD or HCC varies greatly. In the period of 2014-2016, the mortality rate due to hepatitis C related ESLD or HCC was 0.85 per 100,000. This declined to 0.75 per 100,000 in the period of 2015-2017. Only in Kensington & Chelsea and Kingston upon Thames, has the mortality rate increased in recent years (13).

<sup>\*\*</sup>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.

# 6. Treatment

Information on treatment of hepatitis C is currently available through the Hepatitis C treatment monitoring in England report. The report covers the first data download from the NHS England Hepatitis C patient registry and treatment outcome system. The report summarises data from 24,592 patients with at least one treatment episode and treated in the financial years 2015/2016-2017/2018 (16). The report includes information on socio-demographic characteristics, infection details, clinical details, treatment, and outcome of patients on the registry. Some data are summarised by reporting ODN, providing more detailed information for the London ODNs.

In addition, ODN-tailored hepatitis C testing and treatment dashboards are now available for each of the 22 ODNs. The dashboard summarises testing, diagnosis and treatment data at ODN level down to the level of individual service providers, to support resource allocation and monitoring of local case finding and linkage to care activities. The dashboard collates data from laboratory surveillance systems, the NHS England Hepatitis C patient treatment monitoring and outcome system, and the national drug treatment monitoring system (NDTMS). These data are not currently available publicly but are provided to ODN leads or data managers. For more information please contact your local Health Protection Team, Field Service, or the national Hepatitis Division of the National Infection Service.

# 7. Infected Blood Inquiry

The Infected Blood Inquiry (IBI) is a public inquiry which will examine the circumstances in which patients treated by the NHS in the 1970s and 1980s received infected blood and/or blood products; the impact on their families; how the authorities (including government) responded; and the care and support provided to those infected and affected (such as their families, loved ones and carers). Information about the inquiry to GPs and patients are available at www.gov.uk/government/publications/infected-blood-inquiry-information-for-gps-and-patients. More information can be found at the IBI website: www.infectedbloodinquiry.org.uk.

Local meetings with the inquiry team are scheduled to take place in London early 2020 for people infected and/or affected. The team will be in London on the 30 January 2020 and 24 March 2020. More information is available at

www.infectedbloodinquiry.org.uk/news/local-meetings-inquiry-team-1

# Appendix 1. Data sources

### Laboratory notifications

www.gov.uk/government/collections/notifications-of-infectious-diseases-noids

People who inject drugs: HIV and viral hepatitis monitoring www.gov.uk/government/publications/people-who-inject-drugs-hiv-and-viral-hepatitis-monitoring

PHE Sentinel Surveillance of Hepatitis C Testing

www.gov.uk/government/publications/sentinel-surveillance-of-blood-borne-virus-testing-in-england-2017

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

PHE Liver Disease Profiles https://fingertips.phe.org.uk/profile/liver-disease

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

NHS England Specialised Commissioning www.england.nhs.uk/commissioning/spec-services/

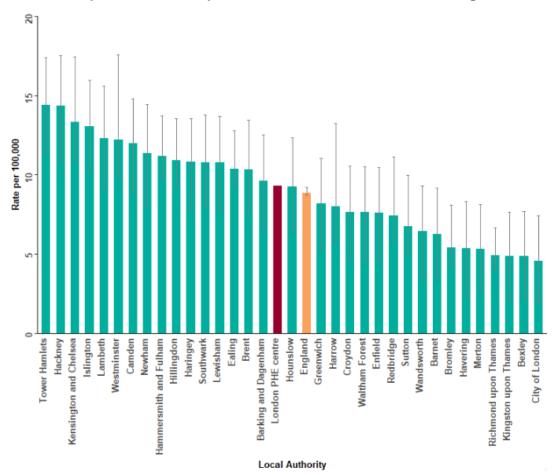
#### Prison Health

www.gov.uk/government/collections/public-health-in-prisons

Mortality data from the Office for National statistics www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths

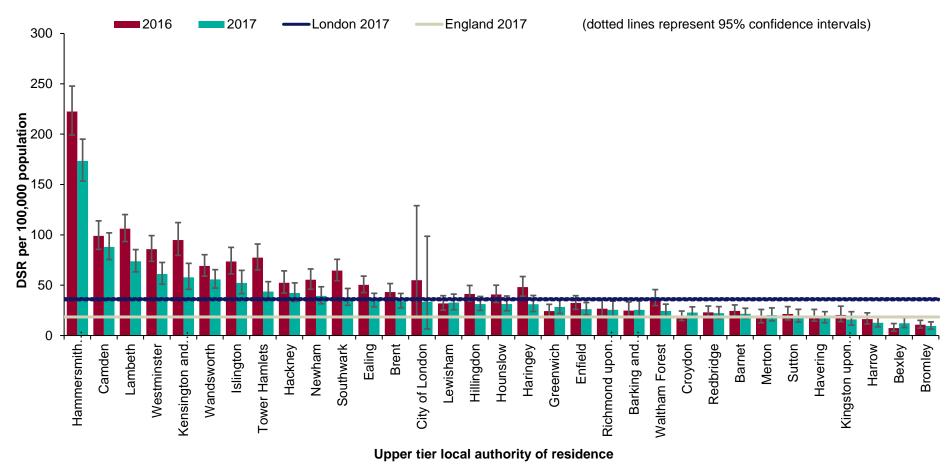
# Appendix 2. Additional data on groups at risk by local authorities in London

Estimated prevalence of opiate and/or crack cocaine users aged between 15-64 years, London PHE centre, 2016/2017



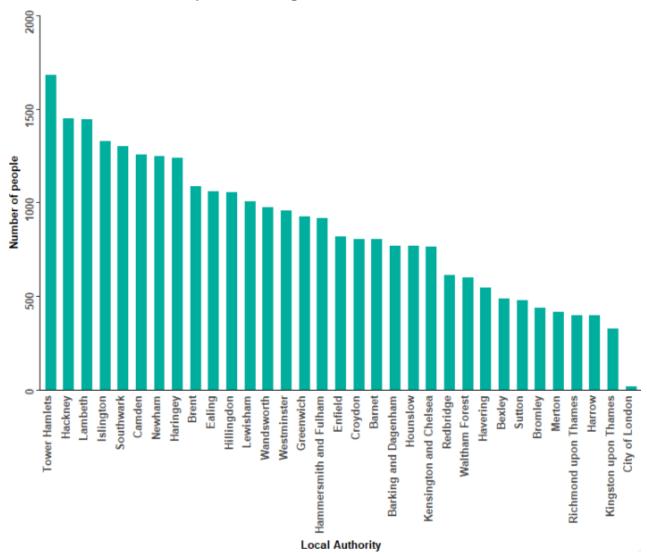
Estimate includes exclusively non-opiate clients in treatment who are not injecting drugs and therefore are not required hepatitis C testing. Source: PHE Fingertips, Public Health Profiles

# Laboratory reports of hepatitis C, directly standardised rate (DSR) per 100,000 population by upper tier local authority of residence, London, 2016 and 2017



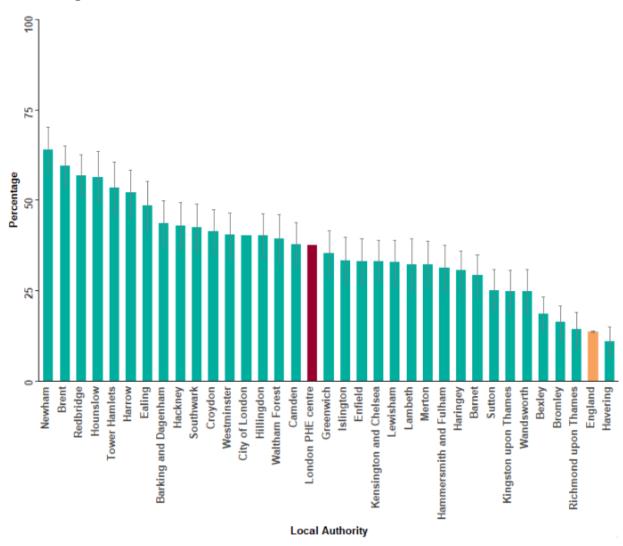
Data are summarised by upper tier local authority of residence, not upper tier local authority of laboratory. Data are assigned to upper tier local authority by patient postcode where present; if patient postcode is unknown, data are assigned to upper tier local authority of registered GP practice; where both patient postcode and registered GP practice are unknown data are assigned to upper tier local authority of laboratory. DSRs per 100,000 population have been calculated using mid-year population estimates supplied by the Office for National Statistics (ONS).

### Number in treatment at specialist drug misuse services, London, 2017/2018



Source: PHE Fingertips, Public Health Profiles

### Percentage ethnic minorities, London, 2016



Source: PHE Fingertips, Public Health Profiles

# Appendix 3. Hepatitis C resources

### Hepatitis C in the UK and England

Latest PHE hepatitis C virus (HCV) reports, slide sets and infographics for England and the UK

www.gov.uk/government/publications/hepatitis-c-in-the-uk

#### **Hepatitis C treatment monitoring in England**

Summary of the content and completeness of data contained within the Hepatitis C patient registry and treatment outcome system www.gov.uk/government/publications/hepatitis-c-treatment-monitoring-in-england

#### Hepatitis C: Operational Delivery Network (ODN) profile tool

This tool provides local level estimates of hepatitis C disease burden by ODN areas. www.gov.uk/government/publications/hepatitis-c-commissioning-template-for-estimating-disease-prevalence

#### **Liver Disease Profiles**

The liver disease profiles produced annually contain data for Upper Tier Local Authorities, former Government Office regions, England and Lower Tier Local Authorities and provide key facts, prevention strategies and links to further resources. https://fingertips.phe.org.uk/profile/liver-disease

#### People who inject drugs: HIV and viral hepatitis monitoring

Data tables and commentary for the unlinked anonymous monitoring surveys of infections and risk among people who inject drugs (PWID) www.gov.uk/government/publications/people-who-inject-drugs-hiv-and-viral-hepatitis-monitoring

#### PHE resource summary on hepatitis C, HBV and HIV

The document includes links to videos, posters and banners for raising public and professional awareness.

https://publichealthengland-immunisati.app.box.com/s/iptxtlziu57evyejw8zgvhimh0pjwa05

#### Hepatitis C testing quiz, hosted by The Hepatitis C Trust

This quiz encourages people to find out whether they might have been exposed to the virus and would benefit from a hep C test.

www.hepctrust.org.uk/quiz

#### Eliminate Hep C Poster

A poster for the 'Eliminate Hep C' campaign can be ordered by all GP surgeries and practices for display in waiting rooms.

www.orderline.dh.gov.uk/ecom\_dh/public/saleproduct.jsf?catalogueCode=HEPCQUIZ001

#### **RCGP** liver disease toolkit

The aims of the British Liver Trust/RCGP Liver Clinical Priority Project are to raise awareness of liver disease as an increasingly important cause of morbidity and mortality in the UK and to provide resources to support its optimal management in primary care. www.rcgp.org.uk/clinical-and-research/resources/toolkits/liver-disease-toolkit.aspx

#### RCGP Learning - Hepatitis C: Enhancing Prevention, Testing and Care

This course is aimed at improving knowledge of everyone who works in drug treatment, or with drug users, and is specifically aimed at those who have a non-clinical or non-medical background. It provides an understanding of hepatitis C and its prevalence. It also gives an overview of the liver and its function, and the stages and natural history of untreated hepatitis C liver disease.

http://elearning.rcgp.org.uk/course/info.php?popup=0&id=175

# NICE Public Health Guideline - Hepatitis B and C testing: Needle and syringe programmes

This guideline, intended for commissioners and providers, directors of public health, professional with a remit for infectious disease prevention, and members of the public, covers needle and syringe programmes for people (including those under 16) who inject drugs, to reduce transmission of hepatitis B and C.

www.nice.org.uk/guidance/PH52

# NICE Public Health Guideline - Hepatitis B and C testing: people at risk of infection

This guideline, intended for commissioners and providers, people at increased risk of viral hepatitis and members of the public, provides recommendations on raising awareness of and testing for those who are at increased risk of hepatitis B and C infection.

www.nice.org.uk/guidance/ph43

# The International Network on Hepatitis in Substance Users (INHSU) education programme

Resources, including an online training module, on hepatitis C in primary care and drug and alcohol settings, aimed at clinical staff working with people who inject drugs. http://inhsueducation.org/

#### National Drug Treatment Monitoring System (NDTMS) Data Recording

Information about current levels of testing in local drug services is available to local authority commissioners and providers on the restricted section of the NDTMS wesbite www.ndtms.net/

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#### **External bodies**

Office for National Statistics (ONS) and Annastella Costella (mortality maps). ONS carried out the original collection and collation of the data but bear no responsibility for their future analysis or interpretation.

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). Analysis undertaken by Annastella Costella, National Infection Service. Produced by Public Health England.

Callum Pearson, Bhavita Vishram and Claire Reynolds, NHS Blood and Transplant / PHE Epidemiology Unit (Blood donor data).

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