



Public Health  
England

Protecting and improving the nation's health

# Hepatitis C in London

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# Key findings

In response to the Hepatitis C Action Plan for England, published in 2004, public health action is focused on four main areas:

- prevention of new infections
- increasing awareness of infection
- increasing testing and diagnosis
- getting diagnosed individuals into treatment and care

This report focuses on the epidemiology of hepatitis C in London, using in the main routinely available surveillance data, and provides recommendations for stakeholders on measures to prevent further infections and to reduce the morbidity and mortality of those already infected.

## Summary

Hepatitis C is a blood borne virus. Infection is usually asymptomatic in the early years. The majority of infected individuals are unable to clear hepatitis C naturally, and without successful treatment chronic infection can span several decades and can be lifelong. Persistent infection can lead to end stage liver disease (ESLD) and hepatocellular carcinoma (HCC).

Compared to other regions, London has a high rate of laboratory confirmed hepatitis C diagnoses. There were 3,079 new laboratory reports of confirmed hepatitis C diagnoses in London in 2013, a rise of 12% since 2012. This rise may reflect improvements in reporting (laboratory reporting became a statutory requirement in 2010) as opposed to an increase in underlying detection of infections. The number of new infections of hepatitis C per year appears to be stable or declining.

An estimated 60,000 people in London have been infected with hepatitis C (ie they are hepatitis C antibody positive), of whom an estimated 40% remain undiagnosed.

In 2013, nearly 2,000 people in London were admitted to hospital with a diagnosis of hepatitis C. Hepatitis C was the primary indication for just under a quarter of first liver transplants in London.

Injecting drug use remains the major risk factor. It is estimated that over half of people who inject drugs (PWID) in London have hepatitis C (59%). In the past 10 years, sex between men has also emerged as an important route of transmission. Individuals originating from south Asia, where the prevalence of hepatitis C is high, are also

particularly at risk. The number of diagnoses is highest in males, the peak age group being 35 to 54 years.

If left untackled, hepatitis C infection will result in great costs, not only in terms of morbidity and mortality due to chronic disease, but also in financial costs due to treatment of the late complications of the infection. Hospital admissions and deaths from hepatitis C related ESLD and HCC have risen four-fold in the UK since 1998. In London, the overall estimated cost of treating those already diagnosed is over £99 million. In addition, the annual cost of treating those who are newly diagnosed is estimated to be nearly £20 million.

Raising awareness, leading to increased testing, is important to identify previously unrecognised cases. However, for those with continued risk factors, repeat testing is also important. It is encouraging to see evidence that testing for hepatitis C has increased in recent years, especially in primary care. Furthermore, testing of clients in drug treatment continues to steadily rise, to 80% in 2013/4, although there is marked variation by local authority across London. Reported testing in prisons is poor, with 6.4% of new receptions reported as having been tested in London, compared with 7.8% in England (2013).

Prevention is primarily focused on PWID and there has been marked success in reducing the sharing of drug paraphernalia through needle exchange schemes. However, more needs to be done to ensure that service users can access the right equipment and hear the right harm reduction messages. There is evidence that a significant proportion of PWID continue to share injecting equipment (36% indirect and direct sharing).

It is vital that those testing positive and shown to be chronically infected are referred appropriately. Only a quarter of London prisons and a minority of providers of services for PWID reported having written care pathways in place.

Treatment can be effective at clearing the virus and a new generation of anti-hepatitis C treatments may revolutionise the outlook for infected patients. The latest information on treatment is for 2011, when it was estimated that 1,492 people in London received treatment for hepatitis C.

## Recommendations

**GPs** are advised to:

- ensure that those people at increased risk of infection are identified, tested and the chronically infected are referred to a specialist for follow-up

- explore ways to improve their knowledge of hepatitis C, including considering completing the Royal College of General Practitioners (RCGP) online module on the detection, diagnosis and management of hepatitis B and C
- ensure appropriate harm reduction messages are given to patients to help them manage the condition and reduce health harms

**Directors of Public Health** are advised to consider:

- raising the profile of hepatitis C in their area, highlighting the costs associated with the sequelae, the benefits of early diagnosis and treatment and the need for quality prevention services for PWID
- encouraging co-ordinated work to raise awareness among the general population, and those at increased risk of hepatitis C
- liaising with the clinical commissioning group (CCG) to ensure that there are robust local care pathways in place—from primary care and drug treatment services to hepatology services
- ensuring that there is an on-going education programme for professionals providing health and social care services for people at increased risk of hepatitis C, utilising free resources such as those available from the RCGP
- ensuring the inclusion of hepatitis C in the health and wellbeing board's joint strategic needs assessment
- reviewing current local provision against the 2014 NICE Public Health Guidelines 52 for needle and syringe programmes

**Local authorities and commissioners of drug treatment services** are advised to consider:

- ensuring that a broad range of prevention services (including harm reduction advice, needle exchange and opioid substitution treatment) is available for PWID, including among MSM and those who inject new psychoactive substances or image and performance-enhancing drugs
- ensuring a high rate of hepatitis C testing in those attending specialist services for drug users, including monitoring repeat testing for PWID who have continued risk factors

- providing harm reduction advice to reduce the spread of infection in PWID, including advice regarding lifestyle factors for those who test positive, such as reducing alcohol intake
- ensuring that specialist services for drug users collect robust information on hepatitis C testing
- working closely with clinical commissioning groups (CCGs) to ensure that CCG and local authority (LA) commissioning is aligned and that clear pathways are developed from testing into treatment services
- ensuring that sexual health services are offering hepatitis C testing to those at increased risk, for example men who have sex with men (MSM)
- ensuring that homeless services are offering hepatitis C testing to those at increased risk

**Clinical commissioning groups** are advised to:

- 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
- consider delivery of hepatitis treatment to PWID in a community drug treatment setting
- commission to ensure that acute providers provide robust information on the numbers of patients with hepatitis C who are referred, seen and treated for hepatitis C and their clinical outcomes

**NHS England** is advised to:

- take measures to increase testing in primary care, especially in those areas with large populations at increased risk
- improve the uptake of hepatitis C testing in prisons
- ensure that Prison Health Services have testing strategies and written care pathways that allow equitable access to treatment services for offenders

- ensure that there is an ongoing education programme for professionals providing services for people at increased risk of hepatitis C infection

**Providers of Prison Health Services** are advised to:

- develop testing strategies and written care pathways that allow equitable access to treatment services for offenders. These should be designed to meet the challenges of both the prison environment and continuity of care in the community. All prison health services should increase reported testing of hepatitis C
- provide in-house treatment of hepatitis C

**Providers of drug treatment services** are advised to:

- ensure all PWID entering services are tested for hepatitis c and are supported to take up the test, and that those with continued risk factors are offered regular repeat testing
- ensure all relevant staff have appropriate training on hepatitis C detection, diagnosis and management, utilising free resources such as those available via the RCGP
- raise awareness of local pathways to hepatology services and refer those who test positive
- make use of the free resources available via the Harm Reduction Works website to raise awareness among PWID: [http://www.harmreductionworks.org.uk/hep\\_c.html](http://www.harmreductionworks.org.uk/hep_c.html)

**Providers of hepatitis C treatment services** are advised to consider:

- providing robust information on the numbers of patients with hepatitis C who are referred, seen and treated for hepatitis C and their clinical outcomes
- delivery of hepatitis treatment to PWID in a community drug treatment setting

**PHE London Centre and Region** is advised to:

- work with commissioners and providers to encourage increased testing rates of those at increased risk, especially those in drug treatment, including repeat testing for those with continued risk factors (ie those currently injecting)



- support and encourage the development of pathways from place of testing, especially drug treatment services, into hepatitis treatment services, where these are not in place

**Laboratories** are advised to consider:

- automatically testing samples that are positive for hepatitis C antibody for the presence of hepatitis C virus (for example, using a polymerase chain reaction assay), or refer the sample to a laboratory that can perform this test
- ensuring that Public Health England health protection teams are notified of cases of hepatitis C infection, in line with national public health legislation

**PWID** are advised to:

- request testing if they have not been offered it
- request referral to hepatology services if they test positive
- make use of resources on the Harm Reduction Works website to keep themselves safe and reduce health harms: [http://www.harmreductionworks.org.uk/hep\\_c.html](http://www.harmreductionworks.org.uk/hep_c.html)
- make use of resources available from the Hepatitis C Trust for those who test positive
- use a full set of clean works for each injecting episode

# 1. Epidemiology and burden of hepatitis C

## Background

Hepatitis C remains a major public health problem, with an estimated 215,000 adults living with chronic infection in the UK.<sup>1</sup> The Public Health England (PHE) report, *Hepatitis C in the UK, 2014* provides a comprehensive review of the epidemiology of hepatitis C nationally.<sup>2</sup>

Hepatitis is a general term meaning 'inflammation of the liver'. Hepatitis C is caused by infection with the hepatitis C virus (HCV). Symptoms can include anorexia, abdominal discomfort, nausea and vomiting, fever and fatigue, progressing to jaundice in approximately a quarter of patients. However, it can often be asymptomatic. Of those exposed to HCV, about 40% recover; but the remainder, whether they have symptoms or not, become chronic carriers, develop cirrhosis, with up to 20% developing hepatocellular carcinoma (HCC).<sup>3</sup>

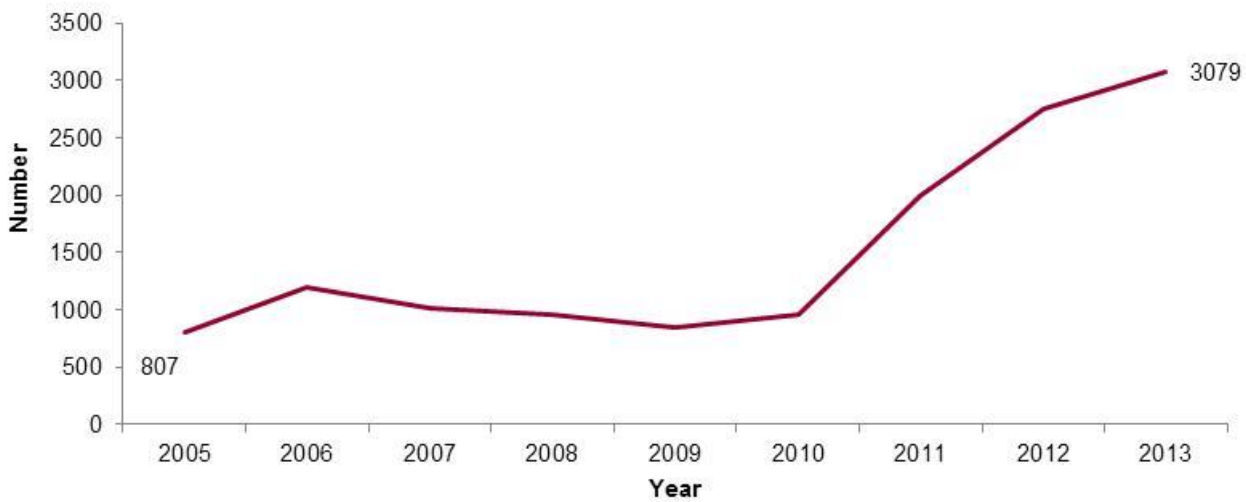
Information from various sources can be used to build up a picture of hepatitis C epidemiology in London. We do not have complete information about hepatitis C across the region because we are not able to accurately determine the number of new infections each year and there is no prevalence survey of the local general population.

## New reports of hepatitis C

New laboratory reports do not provide a good guide to new infections, as hepatitis C is usually asymptomatic and there is no laboratory marker of recent infection. Therefore, changes in the numbers diagnosed in laboratories often reflect trends in testing or reporting, rather than incidence.

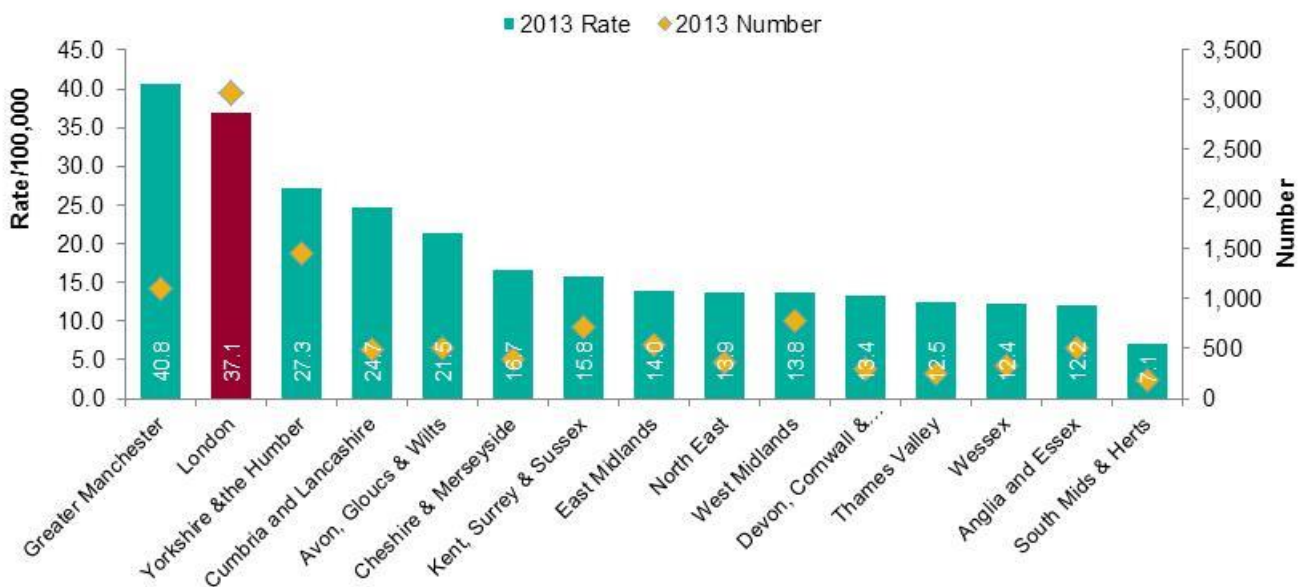
The number of laboratory confirmed diagnoses of hepatitis C from laboratories has continued to rise steadily since 2009, and sharply over the past three years. There were 3,079 diagnoses confirmed in London in 2013, compared to 2,754 in 2012 (Figure 1). Recent rises (12%) may be due to increased reporting as opposed to an increase in infection detection since laboratory reporting became a statutory requirement in 2010.<sup>4</sup>

**Figure 1: Laboratory confirmed diagnoses of hepatitis C from laboratories in London, 2005–2013<sup>5</sup>** (increases are likely to reflect improved reporting)



London alone accounts for 28% of all hepatitis C diagnoses reported in England in 2013<sup>2</sup>) and has the second highest rate of laboratory confirmed diagnoses when compared to other PHE Centre areas (Figure 2).

**Figure 2: Rate of laboratory confirmed diagnoses of hepatitis C per 100,000 residents, by Region, 2013<sup>5</sup>**

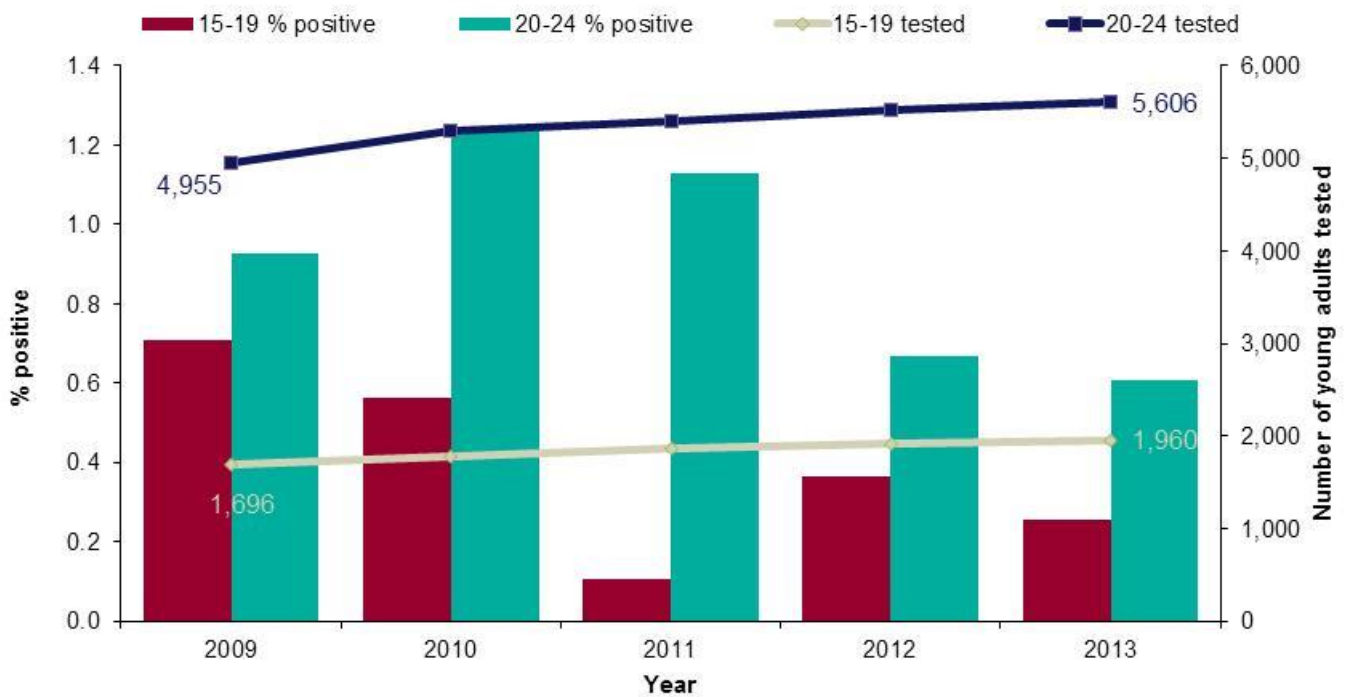


## Change in incidence of hepatitis C

As most new infections are acquired via injecting drug use, which often begins in late adolescence and early adulthood, the number of positive tests in individuals aged 15 to 24 years has been used as a proxy indicator of incidence.

Using this proxy, the incidence of hepatitis C appears to be stable or declining. Although the number of 15 to 19-year-olds tested for anti-HCV has remained steady over recent years, the trend is for a decline in the proportion testing positive. In the 20 to 24 year age group, there is also a trend for a decrease in the proportion testing positive over the past five years, in the context of an increase in testing (Figure 3).

**Figure 3: Number of young adults tested and testing positive for anti-HCV in sentinel laboratories in London, 2009–2013<sup>6</sup>**



### Risk factors for hepatitis C

A number of groups are at increased risk of hepatitis C (Table 1). The principal risk factor for hepatitis C is injecting drug use. Robust London data is unavailable but national data highlights that people who inject drugs (PWID) account for nine out of every 10 diagnoses of hepatitis C in England (Table 2).<sup>2</sup> However, for the vast majority of people this information is not available and therefore this figure may not be representative of all those testing positive.

### Table 1: Risk groups for hepatitis C<sup>7</sup>

People who have ever injected drugs

People who received a blood transfusion before 1991 or blood products before 1986, when screening of blood donors for hepatitis C infection or heat treatment for inactivation of viruses were introduced.

People born or brought up in a country with an intermediate or high prevalence (2% or greater) of chronic hepatitis C. Although data are not available for all countries, for practical purposes this includes all countries in Africa, Asia, the Caribbean, Central and South America, Eastern and Southern Europe, the Middle East and the Pacific islands.

Babies born to mothers infected with hepatitis C

Prisoners, including young offenders

Looked-after children and young people, including those living in care homes

People living in hostels for the homeless or sleeping on the streets

HIV-positive men who have sex with men

Close contacts of someone known to be chronically infected with hepatitis C

### Table 2: Risk factor information in laboratory reports of hepatitis C infection from England, 1996–2013<sup>4</sup>

Risk factor (where reported)	Number of reports	Percentage (%)
PWID	16,540	90.9
Transfusion	239	1.3
Blood product recipient	132	0.7
Sexual exposure	188	1.0
Renal failure	74	0.4
Vertical (mother to baby) or Household	42	0.2
Occupational	17	0.1
Other	966	5.3
Total	18,198	100

## People who inject drugs (PWID)

The prevalence of hepatitis C among PWID is known to be high. The PHE's Unlinked Anonymised Monitoring Survey of PWID (more information in data sources) measures changing prevalence of hepatitis C in current and former PWID.<sup>8</sup> In London, this survey estimated the prevalence of hepatitis in PWID to be 59% in 2013, which is similar to levels recorded in 2009.

## Prisoners

A relatively high proportion of prisoners have hepatitis C, most likely due to injecting drug use. Of the prisons that were included in sentinel surveillance, 9% of those tested were antibody positive.<sup>6</sup>

## Men who have sex with men

Men who have sex with men (MSM) are a risk group for hepatitis C transmission. Enhanced surveillance of Newly Acquired Hepatitis C infection in MSM collected data prospectively from 22 centres in London, Manchester and the south east. Between January 2008 and December 2012, 403 recently acquired cases of HCV were reported, the majority (94.5%) of whom were HIV positive.<sup>9</sup>

Among HIV positive men, the estimated incidence of HCV declined over time from 7.28 (5.94-8.83) per 1,000 person years in 2008 to 2.37 (1.72 – 3.19) in 2012.

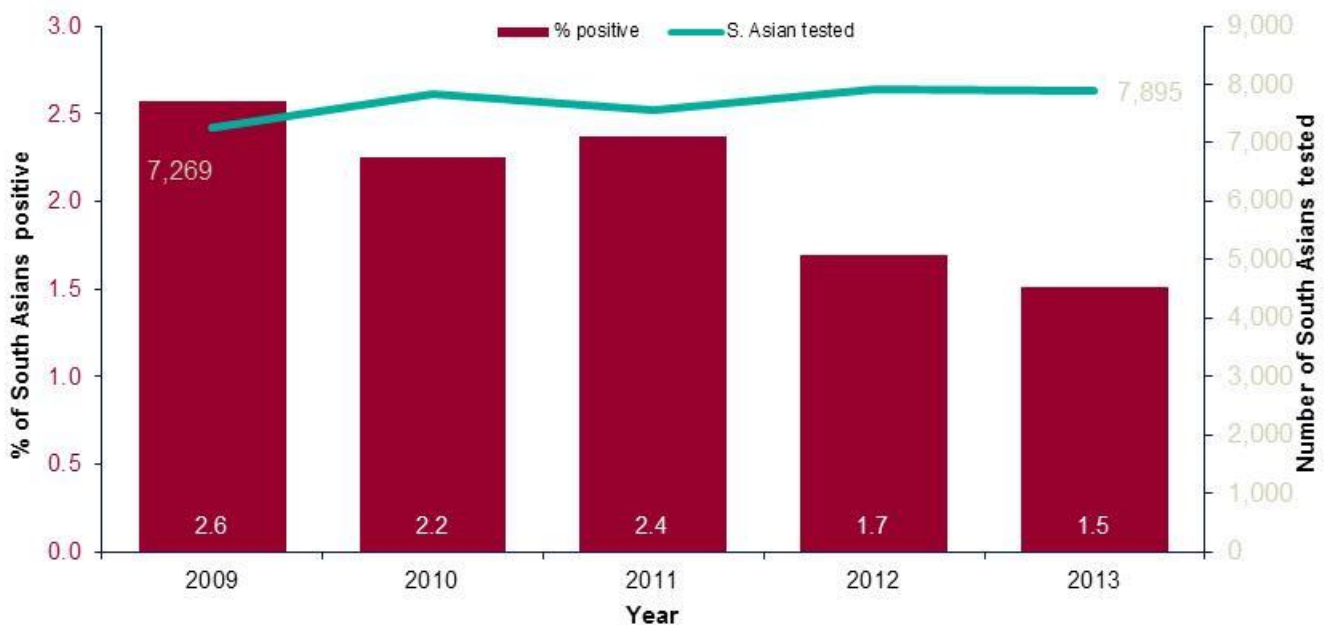
The majority of men reported a recent history of unprotected insertive (64%) and receptive (71%) anal intercourse, non-injecting recreational drug use (75%) and sex under the influence of drugs (86%). A recent STI diagnosis was reported among 62% of men alongside high rates of partner change in the previous three months. In addition, a third (33%) of men reported a history of injecting drug use.

These findings provide evidence of ongoing, but declining, sexual transmission of hepatitis C among HIV-positive MSM, which may have been driven by an increase in awareness as a result of timely hepatitis C campaigns. Therefore, accurate and appropriately tailored information on the risk factors for hepatitis C transmission must continue to be made available. Furthermore, these findings underscore the British HIV Association (BHIVA) guidelines<sup>10</sup> that recommend that all patients with HIV should be screened for hepatitis C at the time of their diagnosis—annually among known positive patients, more frequently for those at higher risk of infection, and among all those with abnormal liver function tests.

## Ethnicity

The prevalence of HCV in individuals originating from South Asia is higher than the general population. However, the proportion of those testing positive has declined over the last five years, partially as a result of increased testing reducing the pool of undiagnosed infection (Figure 4).

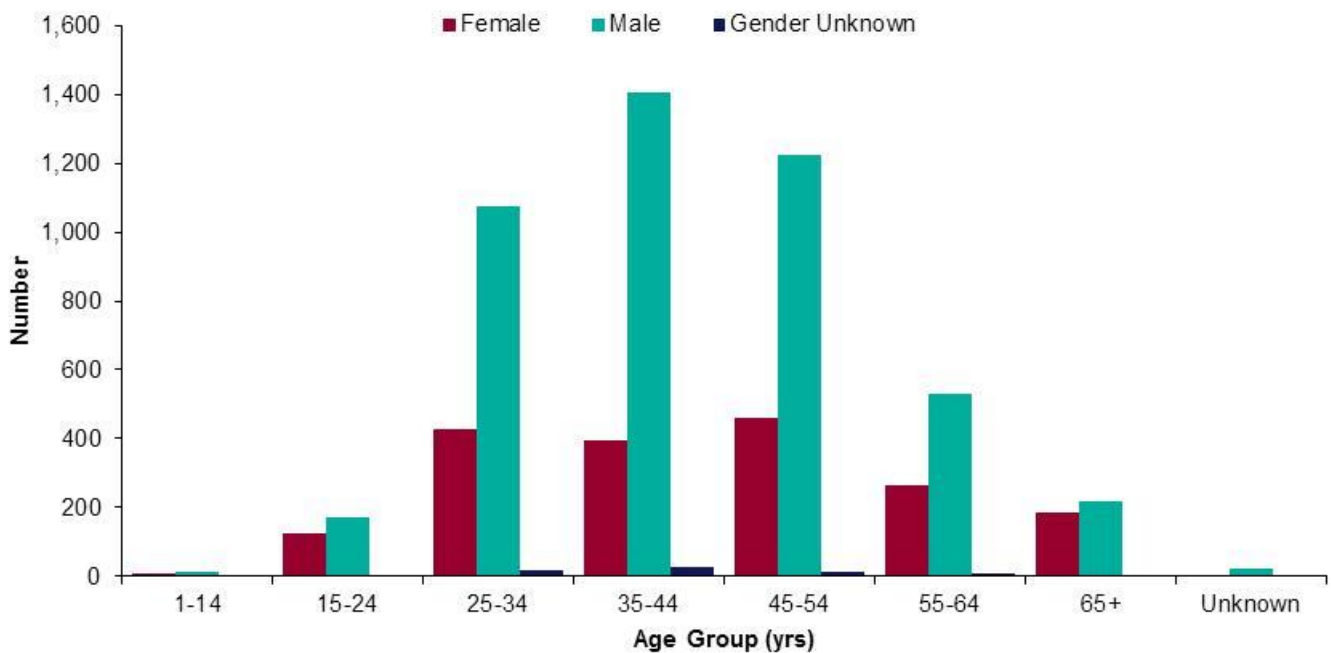
**Figure 4: Number of South Asian individuals tested and testing positive for anti-HCV by ethnicity in sentinel laboratories in London, 2009–2013<sup>6</sup>.** NamPehchan software was used to identify individuals of South Asian origin because ethnicity is not routinely available from the participating laboratory information systems.



## Age and sex

Eight laboratories in London participate in the Sentinel Surveillance of Hepatitis Testing Study, which means they collect more detailed information about hepatitis C testing (more information in data sources).<sup>6</sup> Figure 5 shows that males account for 71% of those testing positive for hepatitis C, with the peak age group being those aged between 35–54 years.

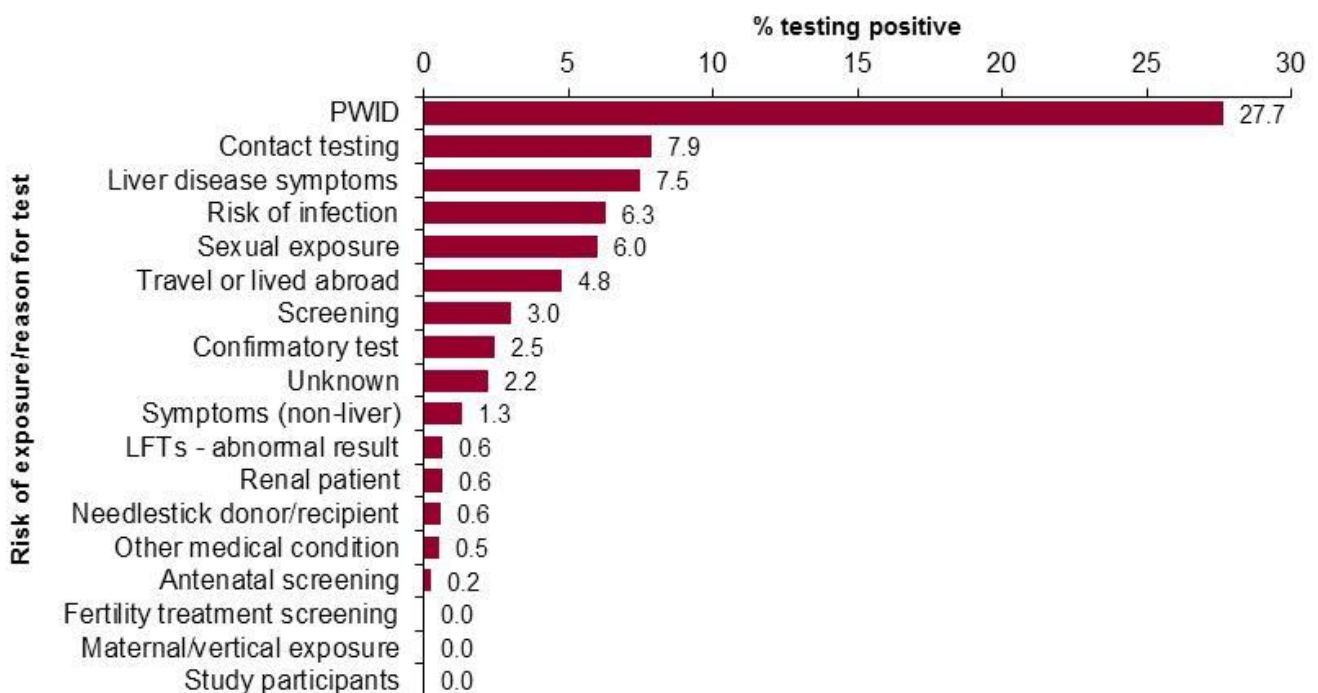
**Figure 5: Age-group and gender of individuals testing positive for anti-HCV in sentinel laboratories in London, 2013<sup>6</sup>**



### Other risk factors

We have limited information on what proportion of individuals who are tested for hepatitis C are positive according to the reason for the test (Figure 6). Nearly a quarter of those tested because they were PWID were positive. Other relatively high positivity rates were found in those tested due to contact testing (7.9%), sexual exposure (6.0%), or because they travelled or lived abroad (4.8%).

**Figure 6: Percentage of individuals testing positive for anti-HCV by risk/reason for test in sentinel laboratories in the London region, 2009-2013<sup>6</sup> (LFT-liver function test)**





## Burden

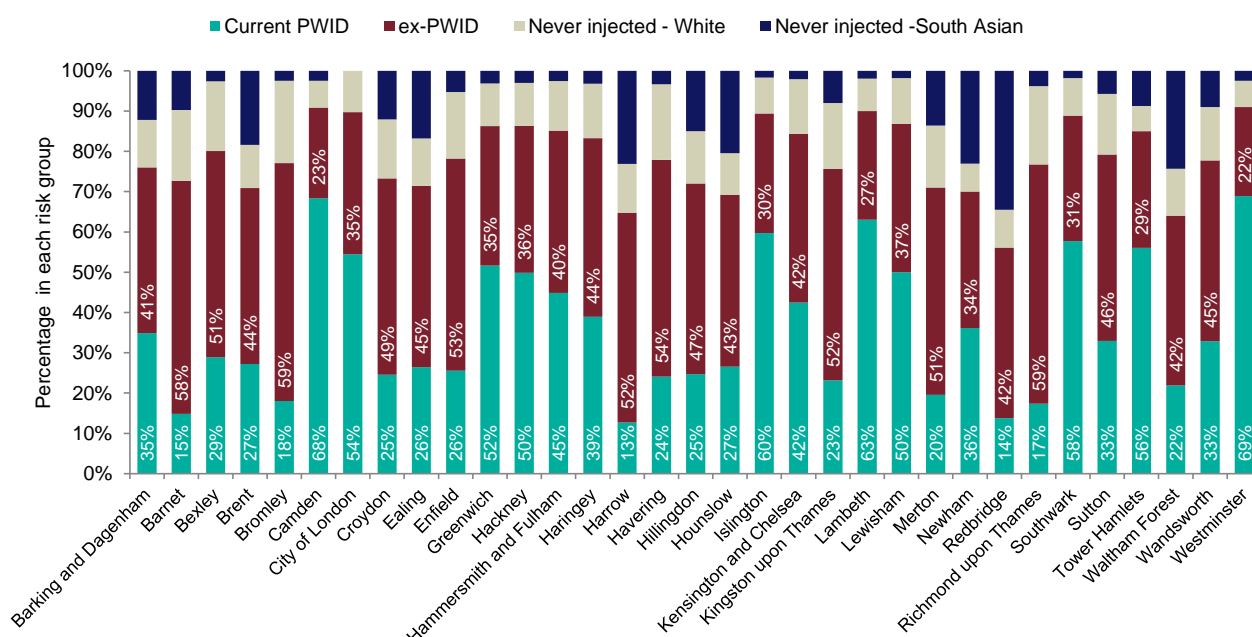
### Estimates of the number of people infected with hepatitis C

It is estimated that over 60,000 people have been infected with hepatitis C in London ie they are HCV antibody positive (Appendix 1). Of these, an estimated 41,500 (69%) are RNA positive (ie they have not cleared their infection). The estimated number of individuals who have been infected with hepatitis C varies considerably across London local authorities (LAs), with the highest number in Lambeth Drug Action Team (DAT) area (~3,605). Variations reflect differences in underlying populations, for example in drug use, ethnicity and prison populations. Please note some of the limitations with this modelling approach, outlined on page 37.

It should be noted that a large proportion of people who have been infected with hepatitis C in London are those who used to inject drugs many years ago and no longer inject (40%).

It is estimated that a smaller proportion of people in London who have been infected with hepatitis C have never injected drugs (20%), just under one half of whom are Indian, Pakistani or Bangladeshi (9% of total). The corresponding figures for each LA are displayed in Figure 7.

**Figure 7: Estimates of the proportion of all people who have been infected with hepatitis C in each London LA in each risk group<sup>11</sup>**



## Modelling costs and burden

In order to plan services effectively, it is important to estimate the number of people likely to need treatment. To support commissioners, PHE has developed a model that estimates the prevalence of HCV infection by drug action team (DAT) area, the burden of disease and treatment needs. This model can be found in Appendix 1.<sup>5, 11, 12</sup>

The model uses estimates of the proportion of those already infected with hepatitis C who have already been diagnosed (~60%). Of these, a certain proportion are assumed to have already been successfully treated, based on regional sales/dispensing data and reported sustained virological response (SVR) rates. Of those remaining, 10% are assumed to be permanently ineligible for treatment, and of the rest 37% will ultimately go on to be treated. The number of those people already infected who are newly diagnosed each year with 'steady state' testing activity is also calculated, with estimates for the cost of treating these new diagnoses.

The overall estimated cost of treating people who are already diagnosed with hepatitis C stands at £99 million for London overall, with the highest cost in Lambeth (£6 million). The additional estimated annual cost of treating people in London who are newly diagnosed with hepatitis C is nearly £20 million (assuming that 7% of people infected with hepatitis C are diagnosed each year).

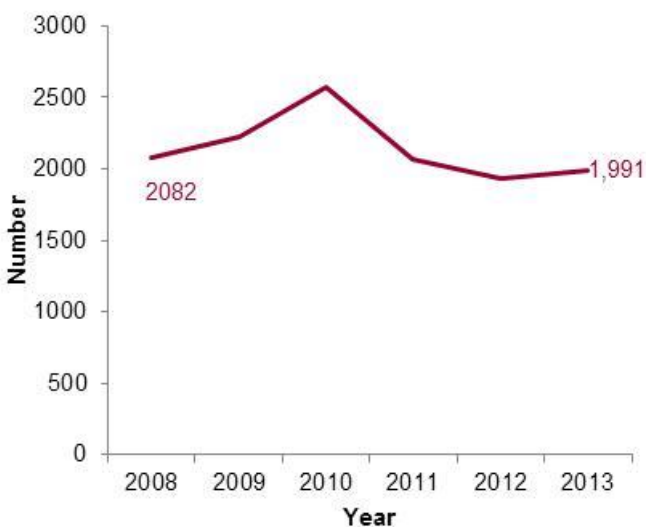
The model also includes estimates of the future burden of disease by DAT.<sup>5</sup> The burden of hepatitis C hospital admissions and deaths from hepatitis C related end stage liver disease (ESLD) and HCC has risen four-fold in the UK since 1998.

### Trends in hospital admissions for hepatitis C

The number of admissions due to hepatitis C in London remains high. Although it is likely that hospital episode statistics underestimate the true numbers of admissions from hepatitis C, in 2013, 1,991 London residents were admitted to hospital with HCV (Figure 8).<sup>13</sup> There is no clear trend since 2008.

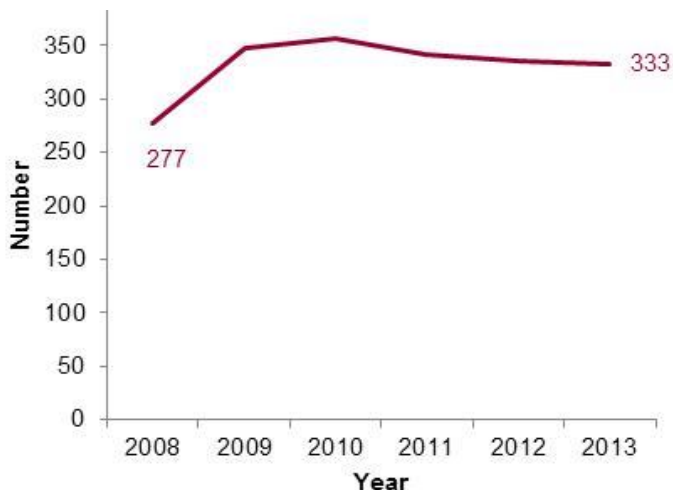
More people were admitted due to hepatitis C related ESLD (333 in 2013) than HCC (141 in 2012) (Figures 9 & 10).<sup>13</sup> While the trend for admissions for hepatitis C related ESLD is not clear, there does appear to have been an increase in admissions for hepatitis C related HCC over the past five years.

**Figure 8: Individuals resident in the London region admitted to hospital with a diagnosis of hepatitis C (2008–2013)<sup>13</sup>**



Data source: Hospital Episode Statistics (HES), Health and Social Care Information Centre

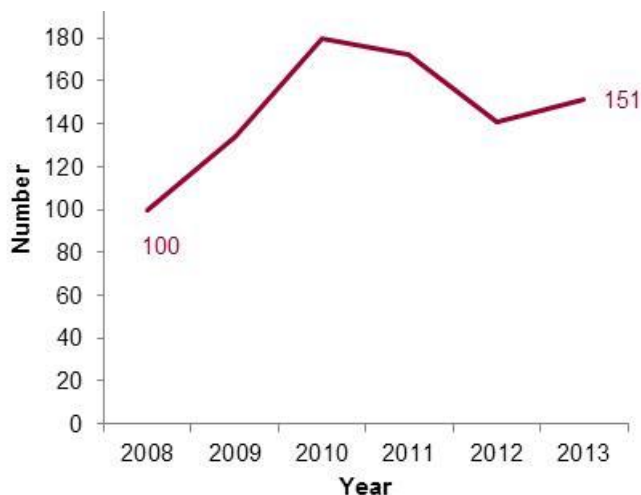
**Figure 9: Individuals resident in the London region admitted to hospital with a diagnosis of HCV related ESLD\*, 2008–2013<sup>13</sup>**



Data source: Hospital Episode Statistics (HES), Health and Social Care Information Centre

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

**Figure 10: Individuals resident in the London region admitted to hospital with a diagnosis of HCV related HCC, 2008–2013<sup>13</sup>**



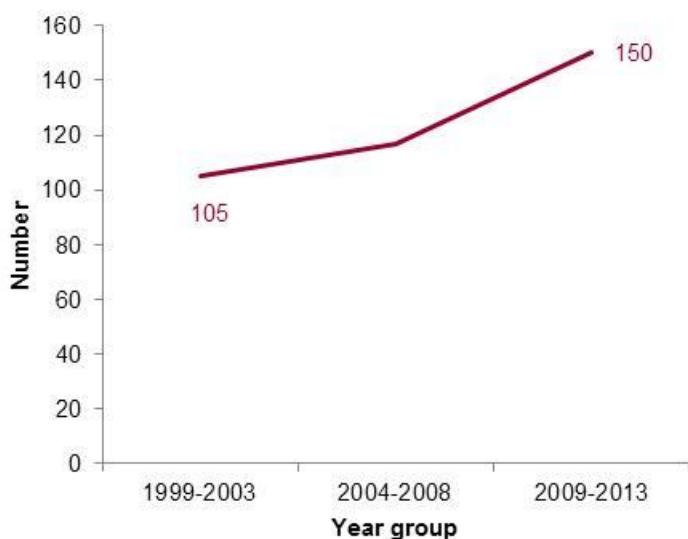
Data source: Hospital Episode Statistics (HES), Health and Social Care Information Centre

The information above (Figures 8-10) is sourced from Hospital Episode Statistics (HES). HES data for 2013 were analysed for the first time using the HES Data Interrogation System (HDIS) this year. HDIS is a remotely accessed secure data portal provided and hosted by the Health and Social Care Information Centre (HSCIC) for the purposes of analysing HES data in a secure environment. 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.

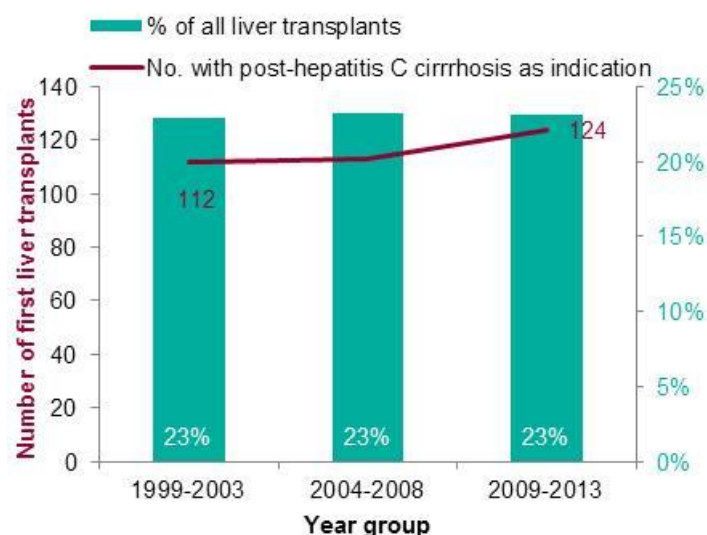
## Transplants

The number of first registrations in Londoners for liver transplants with post-hepatitis C cirrhosis as a primary, secondary or tertiary indication observed during 2009–13 (n=150) was higher than levels reported in the previous five-year periods (Figure 11).<sup>14</sup> 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 12). These indications accounted for 23% of all liver transplants in Londoners during 2009–2013.

**Figure 11\*: First registrations with post-hepatitis C cirrhosis as primary, secondary or tertiary indication for transplant, London residents, 1999–2013<sup>14</sup>**



**Figure 12\*: First liver transplants with post-hepatitis C cirrhosis as primary, secondary or tertiary indication for transplant at registration who were HCV positive at registration or transplant, London residents, plus percentage of all liver transplants, 1999–2013<sup>14</sup>**

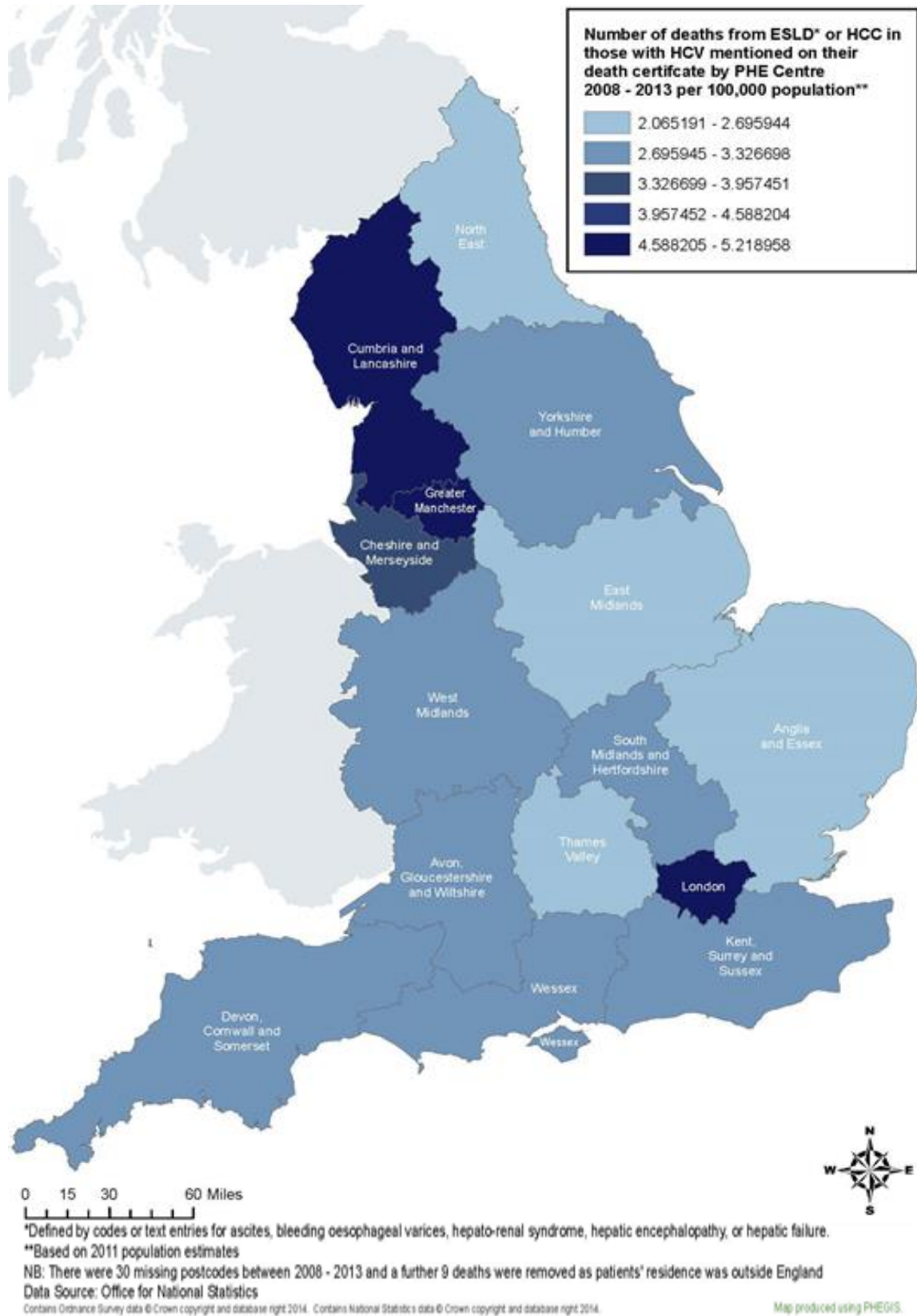


\* These figures are based on registry data as at 2nd July 2014. New national registration criteria for selecting adult patients for elective liver transplantation were introduced in September 2007 ([http://odt.nhs.uk/pdf/liver\\_selection\\_policy.pdf](http://odt.nhs.uk/pdf/liver_selection_policy.pdf)) Data source: NHS Blood and Transplant UK Transplant Registry

## Death from hepatitis C

Figure 13 shows London, Cumbria and Lancashire, and Greater Manchester PHE Centres as having the highest rates in England of deaths from ESLD or HCC in individuals with HCV mentioned on their death certificate.<sup>15</sup>

Figure 13: Map showing the rate of deaths from ESLD or HCC in individuals with HCV mentioned on their death certificate by PHE Centre (2008–13)<sup>15</sup>



## 2. Increasing awareness and reducing undiagnosed infections

Hepatitis C is usually asymptomatic in the early years, therefore many individuals remain undiagnosed. The *Hepatitis C Action Plan for England*<sup>16</sup> identified that awareness raising was an important component of reducing the burden of undiagnosed infection. With many new and improved treatments on the horizon, it is increasingly important to raise awareness of the infection so that more individuals can be diagnosed and treated.

Awareness campaigns in England are now well established. In 2009, the Department of Health launched new campaigns targeting former PWID (Get Tested, Get Treated)<sup>17</sup> and the UK population of South Asian origin (Hepatitis C. The more you know, the better).<sup>18</sup>

The National Institute for Health and Care Excellence (NICE) published its public health guidance *Hepatitis B and C: ways to promote and offer testing to people at increased risk of infection* in 2012.<sup>7</sup> This included a summary of available evidence and recommendations to a range of stakeholder organisations, which covered the following areas:

- awareness raising among the general population and people at increased risk of hepatitis C
- developing the knowledge and skills of healthcare professionals and others providing services for people at increased risk of hepatitis C
- testing in primary care, prisons, immigration removal centres, drugs services and sexual health services.
- commissioning of hepatitis C testing and treatment services
- laboratory services for hepatitis C testing

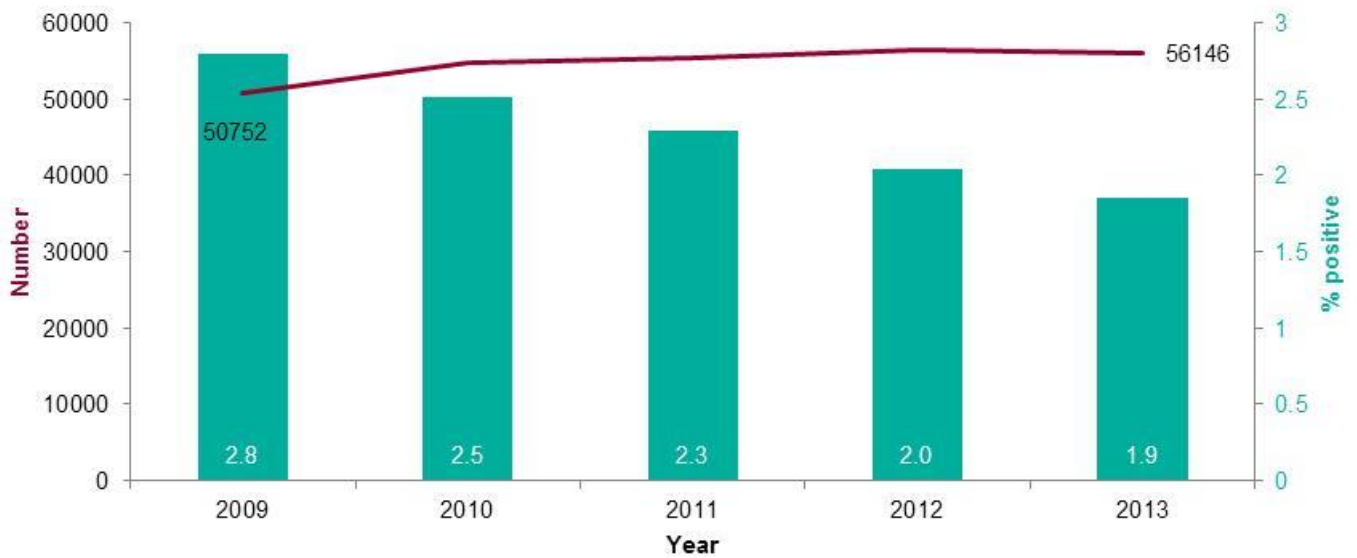
### Trends in testing

Trends in testing are one indicator of increased awareness and, encouragingly, there has been an increase in testing in London since 2008.<sup>6</sup> The data in Figure 14 from sentinel surveillance shows the numbers tested and proportions positive in London.<sup>6</sup>

The proportion testing positive for hepatitis has decreased year-on-year from 2.9% in 2009 to 1.9% in 2013. This decline in positivity may be the result of extending testing to individuals at relatively lower risk of infection or the beneficial effect that an increase in

testing has had on decreasing the proportion of the long-term infected who remain undiagnosed.

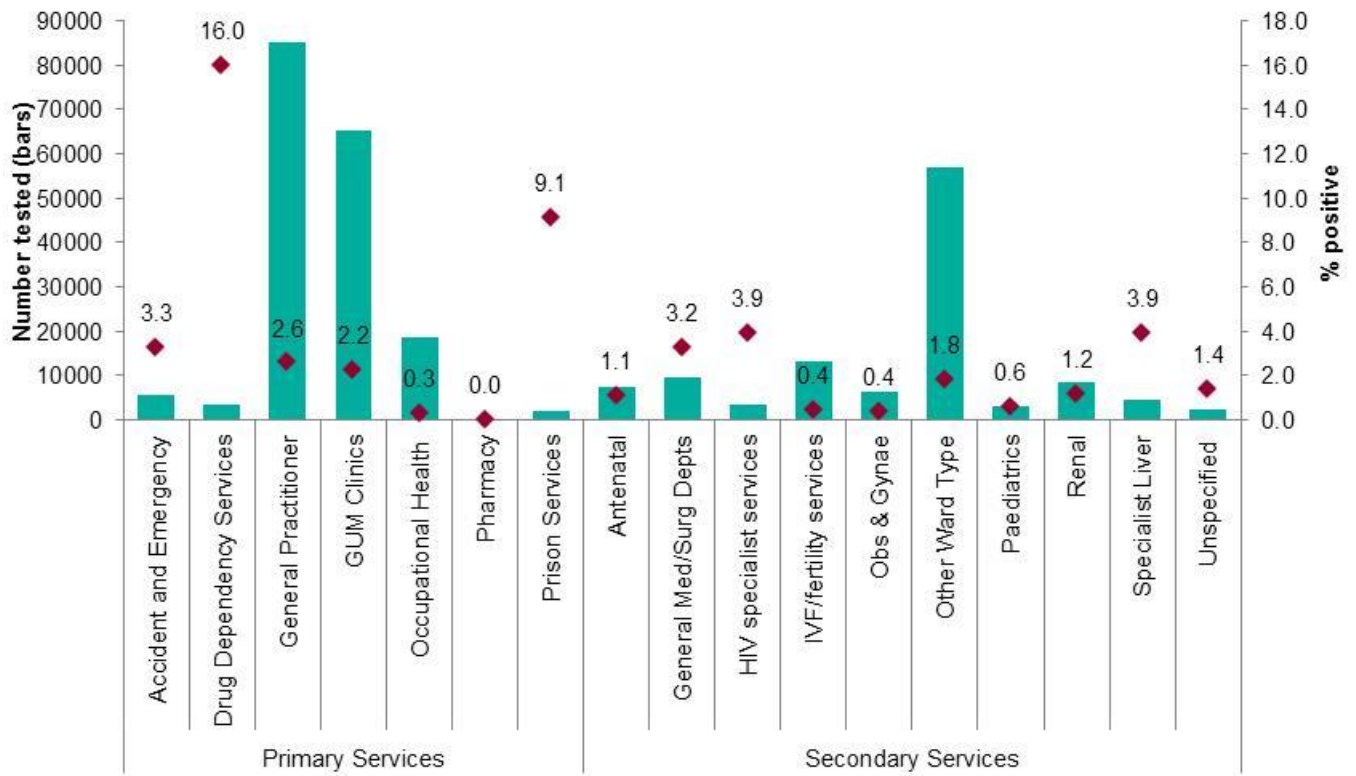
**Figure 14: Number of individuals tested and the proportion testing positive for anti-HCV in sentinel laboratories in London, 2009 to 2013.**<sup>6</sup> Please note that the numbers relate to those tested in the sentinel laboratories, and do not represent all tests across London.



### Site of testing

Information from sentinel surveillance indicates that testing was most often conducted by general practitioners (Figure 15).<sup>6</sup> However, this data does not include dried blood spot testing and oral fluid testing (commonly used in drug services).

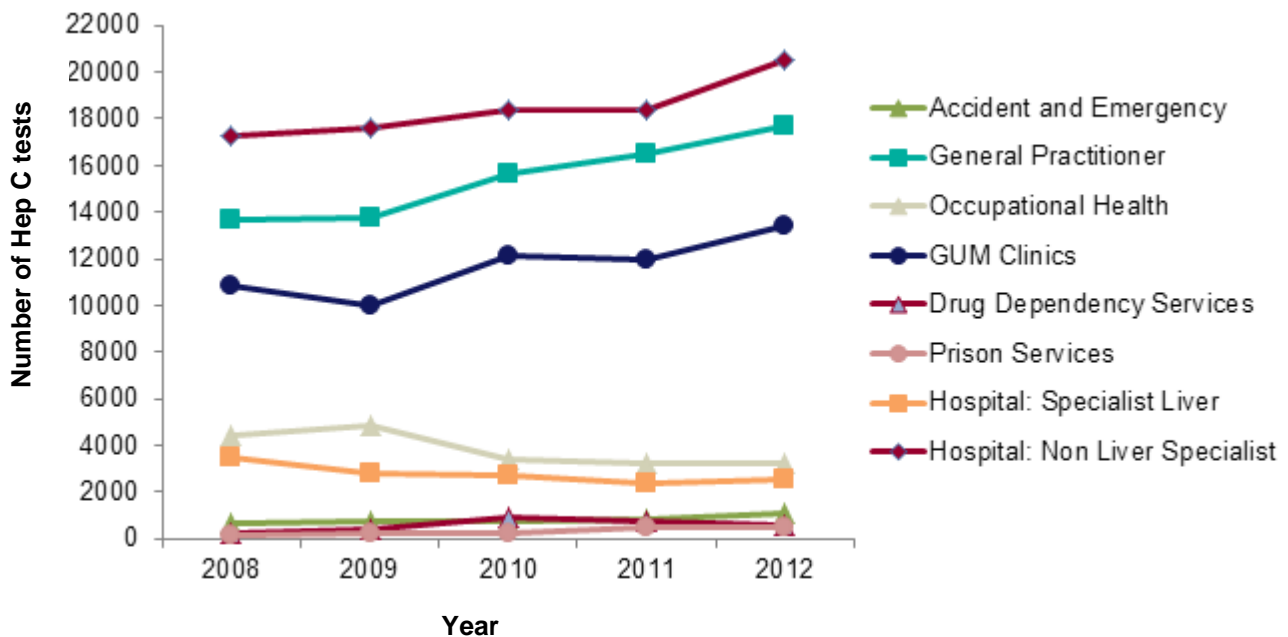
**Figure 15: Number of individuals tested for anti-HCV and the proportion testing positive by service type in sentinel laboratories in London, 2009 to 2013.<sup>6</sup> Please note that the numbers relate to those tested in the sentinel laboratories and do not represent all tests across London.**



Encouragingly, there is evidence to suggest that testing by GPs, GUM clinics and A&E has continued to increase since 2008 (Figure 16).



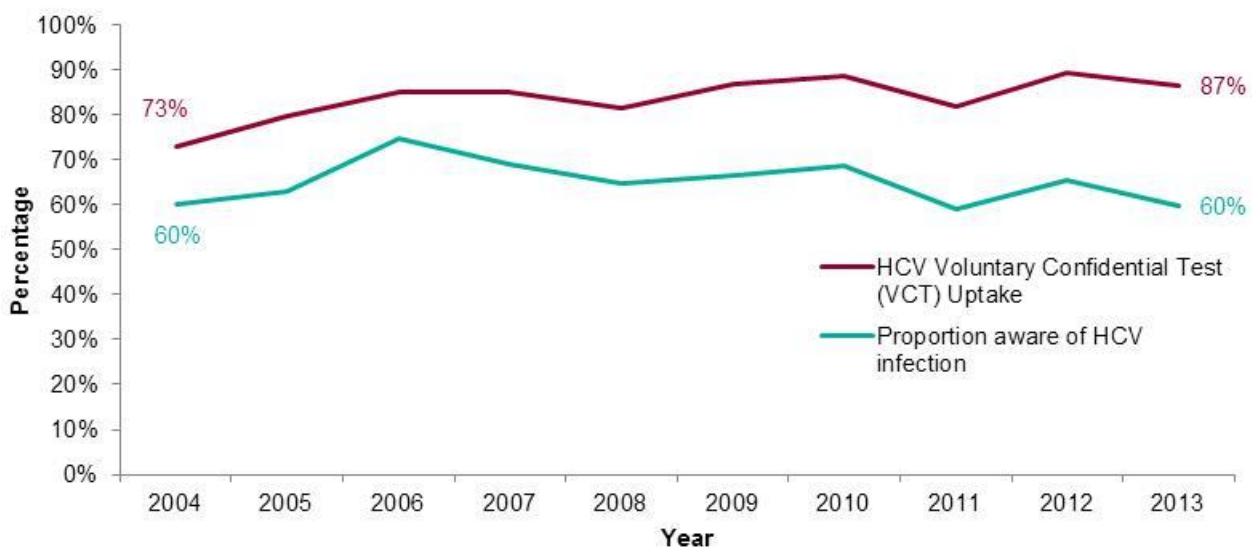
**Figure 16: Number of hepatitis C tests by service type in sentinel laboratories by year in London, 2008–2012.**<sup>6</sup> Please note that the numbers relate to those tested in the sentinel laboratories, and do not represent all tests across London.



### People who inject drugs

There is a long-term, gradual trend for increased testing of PWID. The PHE’s Unlinked Anonymous Monitoring Survey of PWID monitors levels of risk and protective behaviours among PWID. It is encouraging to see that the proportion of PWID taking up the offer of a hepatitis C test has increased in the past 10 years to 87% in London in 2013 (Figure 17).<sup>8</sup>

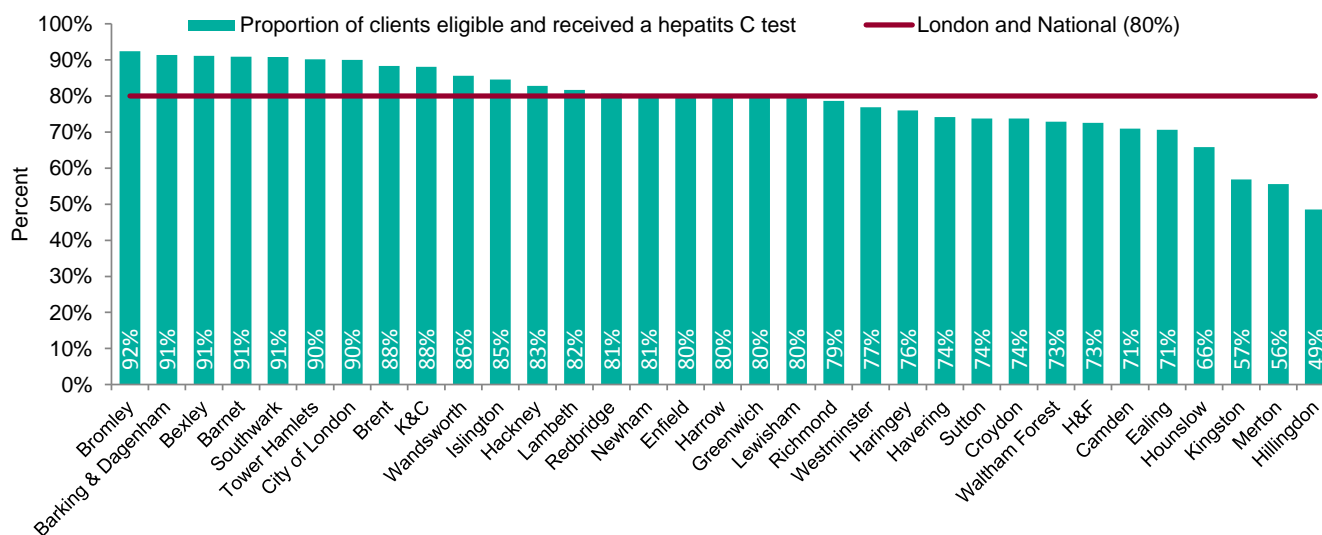
**Figure 17: Hepatitis C test uptake among PWID and their awareness of infection in London, 2004–2013.**<sup>8</sup>



However, 40% of PWID remain unaware of their infection (40%). While hepatitis C testing has been shown to be acceptable, this reflects the need for more frequent testing.

Reported testing among clients of drug treatment services in London has also increased. In 2013/14, 80% of eligible clients received a hepatitis C test, a rise from 66% in 2010/11.<sup>19</sup> This was the same as seen in England (80%), but varied considerably by LA in London, with four LAs testing less than 70% of eligible clients (Figure 18).

**Figure 18: Proportion of clients of drug treatment services eligible and received a hepatitis C test by local authority in London 2013/4<sup>19</sup>**



According to a survey of London commissioners and providers in 2012, dried blood spot testing was reported to be available in 63% (15/24) of drug treatment services by commissioners, but providers only reported it being available in 37% (14/38).<sup>20</sup> The same survey identified that the hepatitis C testing services were commissioned from drug treatment services by a block contract (11/24, 46%) or as one part of a larger block contract (5/24, 21%).<sup>20</sup>

### Testing in prisons

Only a small proportion of prisoners are reported as being tested for hepatitis C in London in 2013 (6.4%), which is a slight increase on 2012/13 (5.7%) but less than the English average (7.9%) (Table 3).<sup>21</sup> Only HMP Pentonville and HMP Isis reported

testing more than 10% of new receptions; however it should be noted that reporting is often incomplete.

The audit of hepatitis C services in a sample of English prisons<sup>22</sup> recommended that prisons should ensure that in-house treatment of hepatitis C is available and that laboratories should automatically undertake PCR testing of all positive hepatitis C antibody tests.

**Table 3: Hepatitis C testing in prisons in London, NHS Trust Development Authority, Prison Health Reporting System, 2013<sup>21</sup>**

LA	Prison	Number of receptions	Number of hepatitis C tests performed within 31 days of reception	% of receptions with a hepatitis C test performed within 31 days of reception
Greenwich	Belmarsh (HMP)	3,830	39	1.0%
Lambeth	Brixton (HMP)	1,785	0	0.0%
Hounslow	Feltham (HMYOI/RC)	2,744	0	0.0%
Islington	Holloway (HMP/YOI)	2,006	162	8.1%
Greenwich	Isis (HMP)	922	100	10.8%
Islington	Pentonville (HMP)	6,264	1,663	26.5%
Greenwich	Thameside (HMP)	5,650	13	0.2%
Wandsworth	Wandsworth (HMP)	6,311	208	3.3%
Hammersmith & Fulham	Wormwood Scrubs (HMP)	5,958	82	1.4%
<b>London</b>		<b>35,470</b>	<b>2,267</b>	<b>6.4%</b>
<b>England</b>		<b>210,197</b>	<b>16,512</b>	<b>7.9%</b>

### 3. Prevention and harm reduction

Prevention strategies primarily focus on injecting drug use because this is the most important risk factor for acquisition of the virus in England today.

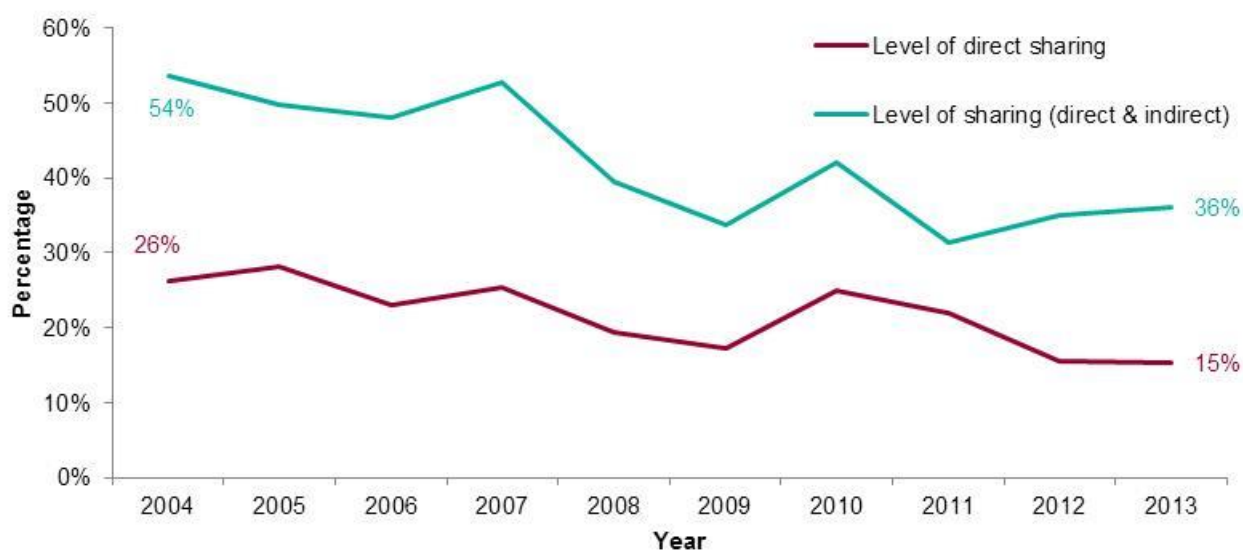
Reducing the number of individuals who begin injecting drugs; encouraging injectors to quit injecting; reducing risky behaviour (eg sharing needles and syringes) in those who continue to inject; and the early diagnosis and treatment of those who become infected with hepatitis C are all components of the prevention programme.

The delivery of successful prevention programmes in this challenging risk group requires the integrated input of government, professional organisations and public health and healthcare professionals from a variety of clinical, social and drug service backgrounds.

#### People who inject drugs

There has been a 10-year downward trend in the proportions of PWID that report sharing equipment, with 15% reporting direct sharing and 36% reporting both direct and indirect sharing in 2013 (Figure 19). Direct sharing is the sharing of needles and syringes among those who injected in the previous four weeks. Indirect sharing is the sharing of mixing containers, filters or the water used to prepare drugs.

**Figure 19: Level of direct and indirect sharing amongst PWID in London, 2004–2013<sup>8</sup>**



## Prisoners

The audit of selected English prisons in 2013 revealed that almost two-thirds of those audited (62%, 13/21 prisons) had written hepatitis C documentation in place.<sup>22</sup> Neither HMP Wormwood nor Brixton, the two London prisons that participated in the audit, had any form of written document. This was lower than the survey published in July 2012, when the proportion was 74% (82/110).<sup>23</sup> The majority (81%, 17/21) of the prisons reported having disinfectant tablets available, including HMP Brixton, although HMP Wormwood did not. Disinfectant tablets are used to sterilise injecting equipment.

## 4. Treatment of individuals with hepatitis C

Antiviral treatments are available and approved for use in the UK that will successfully clear the virus in the majority of patients.<sup>24-29</sup> Newer treatments have improved effectiveness, reduced treatment durations and fewer side-effects.

Only a small proportion of those tested for hepatitis C have typically received treatment. This may have been due to issues around referral, for example patients were not appropriately referred to a specialist or did not attend appointments. Some people found it difficult to adhere to long treatment. Furthermore, many individuals affected by hepatitis C are from marginalised populations such as PWID or the prison population, who often find it difficult to access treatment in specialist hospital settings.

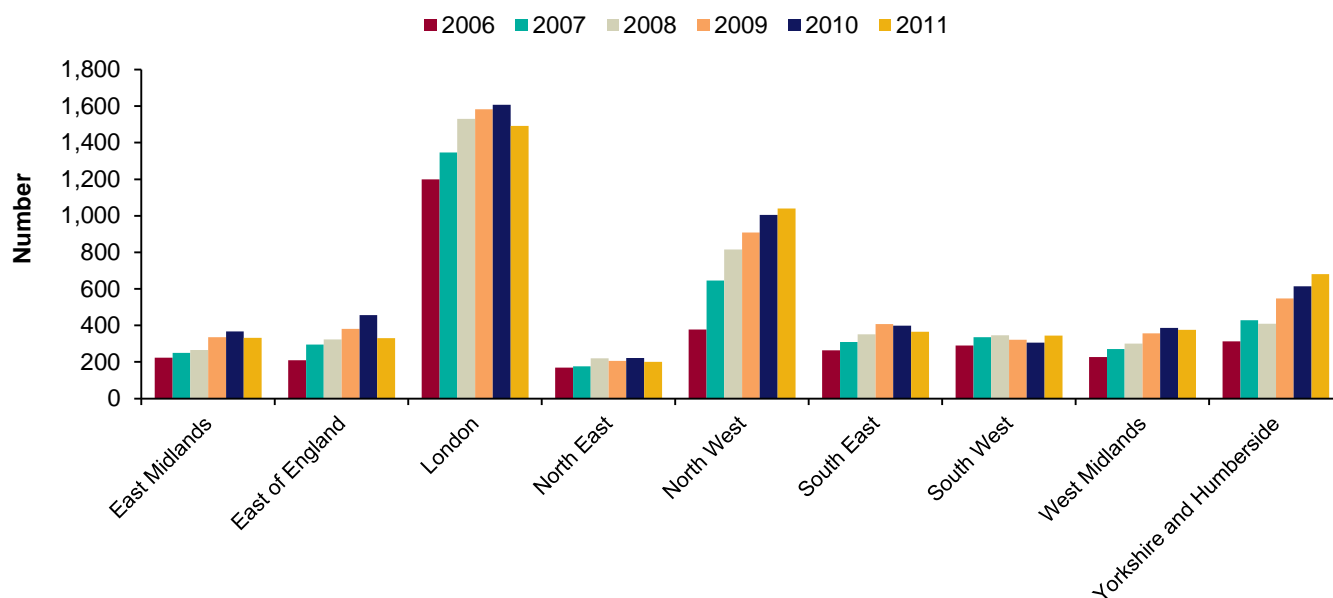
If the infected population is left untreated, the number of patients with severe hepatitis C related diseases will continue to increase and represent a substantial future burden on healthcare resources. This can be mitigated by increasing treatment uptake, which will have the greatest impact if implemented quickly.<sup>30</sup> Introduction of new treatment regimens would be expected to improve treatment uptake, compliance and outcomes. Co-ordination of high quality services for assessment and treatment was one of the key issues identified in the *Hepatitis C Action Plan for England*.

### Estimates of numbers receiving therapy for hepatitis C

Currently, there are no national surveillance systems to monitor referral, uptake or response to treatment. PHE uses national data from pharmaceutical companies, pharmacy purchasing data and pharmacy prescribing data to estimate how many individuals have been treated for HCV in England (Figure 20).<sup>31</sup>

The general trend is for an increase in the numbers of hepatitis C positive patients receiving treatment in London. In 2011, 1,492 individuals were treated. London has much higher numbers treated than any other region, which likely reflects the large population and a higher burden of infection.

**Figure 20: Estimated numbers of HCV-positive patients receiving combined therapy based on national supply of pegylated interferon by region, 2006–2011<sup>31</sup>**



## Care pathways

It is essential that robust treatment care pathways are in place in order for patients to be referred and treated appropriately.

## People who inject drugs

Only a minority of areas in London have treatment care pathways for PWID. The London Joint Working Group on Substance Misuse and Hepatitis C (LJWG) undertook a survey of substance misuse commissioners and providers in 2012, with responses from 73% (24/33) of commissioners and 38 providers. Only a third of commissioners reported having a documented patient pathway for PWID with hepatitis C (11/38, 29%) and a third of providers (12/38, 32%).

Over half of the commissioners who responded to the survey (14/24, 58%) were able to provide an account of the mechanism employed to follow up referrals into specialist services. Of the boroughs with a mechanism in place, half included follow up and monitoring as the remit of the blood borne virus specialist nurse, and six relied on the service user's key worker to monitor outcomes of referral. One borough employed assertive outreach to increase attendance in specialist services.

Where information was available (11 providers), providers reported that a quarter (26%) of clients with chronic hepatitis C infection had initiated treatment in the preceding 12

months. Two providers reported that HCV treatment was offered as an integrated part of the drug treatment service. The other nine providers reported that 28% of all referrals resulted in clients initiating treatment.

## Prisons

It is important that prisons have a clear and accessible pathway in place for hepatitis C testing, treatment and care. The pathway should be designed to meet the challenges of both the prison environment and continuity of care in the community. As a matter of good practice, prisons should offer proactive and targeted diagnostic testing for hepatitis C. Laboratories should ensure that all blood samples that test positive for hepatitis C antibody (a marker of whether someone has ever been infected) should be routinely tested for PCR as the first step in accessing a care pathway in prison. The PCR test is needed to identify those who remain infected, as opposed to those who have cleared the infection.

The results of a survey published in July 2012 indicate that only 25% (2/8) of prisons in London have a written pathway in place to describe what happens following a positive result (HMP Holloway and HMP Brixton).<sup>23</sup> All the prisons that responded indicated that they use venous blood to test for hepatitis C, as opposed to dried blood spot, and the laboratory automatically tests using PCR for only half of prisons.

The majority of London prisons (6/8) refer to hospital outpatients for treatment, with the others using an 'in reach' service provided by the hospital (HMP Belmarsh and HMP Wandsworth). HMP Belmarsh conducts appointments via video link, which cuts down on costs such as escorts and health specialist time. All the prisons indicated that they provide referral for those leaving prison who are hepatitis C positive if these prisoners are released into the community.

The 2013 prison audit, in which 21 prisons participated, covered key areas of best practice including health promotion, testing, treatment, and care for hepatitis C in prison.<sup>22</sup> Recommendations from the audit included:

- prisons should ensure in-house treatment of hepatitis C is available
- laboratories should automatically undertake PCR testing of all positive hepatitis C antibody tests



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## Public Health England, Centre for Infectious Disease Surveillance and Control

- Koye Balogun & Sarah Collins, PHE (Laboratory reports)
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- Anastella Costella, Helen Harris, Ross Harris, Vivian Hope, Sema Mandel, Mary Ramsay (Commissioning Template for Estimating Hepatitis C Prevalence by PCT and Numbers Eligible for Treatment)
- Sam Lattimore (The Enhanced Surveillance of Newly Acquired Hepatitis C infection in men who have sex with men)
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- We would like to thank HSCIC for providing the Hospital Episode Statistics data used in this report; (Copyright © 2015, re-used with the permission of The Health and Social Care Information Centre, all rights reserved)

## Data sources

### Sentinel Surveillance of Hepatitis Testing Study

This was set up in 2002 to enhance routine surveillance of hepatitis C. The study collects data on laboratory test results and demographic data for all individuals tested for hepatitis C antibody in 24 sentinel laboratories in England, covering approximately one-third of the population.

There are seven participating centres in London—PHE Colindale, North Middlesex Hospital, St Barts and the London Hospital, King's College Hospital, St George's Hospital, Chelsea and Westminster Hospital (only since 2008 and information not included in five-year trend data in this report) and University College Hospital.

Limitations of the data include: some duplication of individual patients; exclusion of dried blood spot, oral fluid, reference testing; and exclusion of testing from hospitals referring all samples that do not have the original location identified. Individuals aged less than one year are excluded because positive tests in this group may reflect the presence of passively-acquired maternal antibody rather than true infection.

### Unlinked Anonymised Monitoring Survey of People Who Inject Drugs

This survey measures the changing prevalence of hepatitis C in current and former PWID who are in contact with 60 specialist drug agencies (eg needle exchange services and treatment centres) in England, Wales and Northern Ireland. The programme also monitors levels of risk and protective behaviours among PWID.

# Appendix 1

**Table 1: Estimates of hepatitis C prevalence, burden, treatment and cost of treatment by DAT in London <sup>11</sup> (please see notes on p37 for interpretation and the notes on the original models available on the PHE website <http://www.hpa.org.uk/Topics/InfectiousDiseases/InfectionsAZ/HepatitisC/EpidemiologicalData/>)**

DAT	Estimated total infected population	Estimated Burden in 2023				Estimated no. of backlog of current diagnosed infections requiring treatment	Estimated drug cost to treat backlog of current diagnosed infections	Estimated additional number of annual new diagnoses requiring treatment	Estimated annual drug cost of treating newly diagnosed cases
		Mild/moderate	Cirrhotic / ESLD/ HCC	Died	SVR*				
Barking and Dagenham	1,221	573	51	139	79	108	£2,015,948	22	£404,857
Barnet	1,686	791	71	192	109	149	£2,783,566	30	£559,016
Bexley	1,178	553	50	134	76	104	£1,945,092	21	£390,628
Brent	2,089	980	88	238	136	184	£3,449,051	37	£692,664
Bromley	1,356	636	57	154	88	120	£2,239,061	24	£449,665
Camden	3,002	1408	126	342	195	265	£4,955,640	53	£995,228
City of London	69	33	3	8	4	6	£114,421	1	£22,979
Croydon	2,049	962	86	233	133	181	£3,383,136	36	£679,426
Ealing	2,183	1024	92	249	142	193	£3,603,312	39	£723,644
Enfield	1,620	760	68	184	105	143	£2,673,932	29	£536,999
Greenwich	2,111	991	89	240	137	186	£3,485,566	37	£699,997
Hackney	2,100	985	88	239	136	185	£3,466,111	37	£696,090
Hammersmith and Fulham	1,441	676	61	164	93	127	£2,378,604	26	£477,689
Haringey	1,729	811	73	197	112	153	£2,853,811	31	£573,123
Harrow	1,260	591	53	143	82	111	£2,079,882	22	£417,697

DAT	Estimated total infected population	Estimated Burden in 2023				Estimated no. of backlog of current diagnosed infections requiring treatment	Estimated drug cost to treat backlog of current diagnosed infections	Estimated additional number of annual new diagnoses requiring treatment	Estimated annual drug cost of treating newly diagnosed cases
		Mild/moderate	Cirrhotic / ESLD/ HCC	Died	SVR*				
Havering	1,133	531	48	129	73	100	£1,869,974	20	£375,542
Hillingdon	1,609	755	68	183	104	142	£2,655,459	29	£533,289
Hounslow	1,728	811	73	197	112	153	£2,852,206	31	£572,801
Islington	2,231	1047	94	254	145	197	£3,682,416	40	£739,530
Kensington and Chelsea	1,137	534	48	129	74	100	£1,877,457	20	£377,045
Kingston upon Thames	865	406	36	98	56	76	£1,428,201	15	£286,822
Lambeth	3,605	1691	152	410	234	318	£5,951,220	64	£1,195,167
Lewisham	2,229	1046	94	254	145	197	£3,679,939	40	£739,032
Merton	1,125	528	47	128	73	99	£1,856,747	20	£372,885
Newham	2,785	1307	117	317	181	246	£4,597,258	49	£923,255
Redbridge	1,815	851	76	207	118	160	£2,995,901	32	£601,659
Richmond upon Thames	866	406	36	99	56	76	£1,429,360	15	£287,054
Southwark	2,921	1371	123	333	189	258	£4,822,454	52	£968,480
Sutton	1,110	521	47	126	72	98	£1,832,946	20	£368,106
Tower Hamlets	2,839	1332	119	323	184	251	£4,686,368	50	£941,151
Waltham Forest	1,791	840	75	204	116	158	£2,956,167	32	£593,679
Wandsworth	2,179	1023	92	248	141	192	£3,597,848	39	£722,546
Westminster	3,100	1454	130	353	201	274	£5,116,778	55	£1,027,589
<b>London</b>	<b>60,162</b>	<b>28,228</b>	<b>2,531</b>	<b>6,848</b>	<b>3,901</b>	<b>5310</b>	<b>£99,315,832</b>	<b>1,068</b>	<b>£19,945,334</b>

\*SVR=sustained virological response  
Please see notes overleaf

This template has been produced to help local authorities (LA) and health and wellbeing boards estimate the prevalence of hepatitis C virus (HCV) infection in their local population, and the likely disease burden and associated treatment costs. Estimates are produced for drug action team (DAT) areas, which in many cases are equivalent to LAs. The template draws heavily on methods produced for estimating HCV prevalence at a national level, with limited data available at a local level. The estimates produced by this template are therefore naturally less accurate than national estimates, as assumptions must be made about the distribution of HCV prevalence at the local level that do not fully reflect local variation and differences in populations. These assumptions must be borne in mind when interpreting the output from this template. Similarly, projections of current and future morbidity, and rates of diagnosis and treatment are based on national or regional estimates.

This template is an update of the 2011 template. Where possible, data sources have been updated based on recent modelling work, and some improvements to the methodology have been made. In a minority of cases, this has resulted in substantial changes in estimates of local prevalence. Again, it must be stressed that any observed differences should not necessarily be interpreted as genuine changes in prevalence over time, and are at least in part due to changes in the data and methods used. For example, estimates at drug action team (DAT) level for the prevalence of opiate and crack-cocaine injecting, published by the National Treatment Agency (NTA, now part of Public Health England) have changed substantially over time, local HCV prevalence estimates have shifted due to some previously sampled DATs no longer being sampled (and vice versa), and the methodology for estimating the prevalence of ex-injectors has been refined. In some cases, these factors work in conjunction, resulting in a significant difference compared to previous estimates.

Crucially, the local level estimates do not account for the statistical uncertainty of the estimates, ie it is not possible to produce confidence intervals that would give an indication of upper and lower bounds for these estimates. Future modelling work will aim to incorporate data at a more local level, and estimate local prevalence within a formal statistical model, which will allow this uncertainty to be reported.

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