About Public Health England

Public Health England exists to protect and improve the nation’s health and wellbeing, and reduce health inequalities. It does this through world-class science, knowledge and intelligence, advocacy, partnerships and the delivery of specialist public health services. PHE is an operationally autonomous executive agency of the Department of Health.

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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 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).

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

Compared to other areas, London has a high rate of laboratory confirmed hepatitis C diagnoses. There were 3,858 new laboratory reports of confirmed hepatitis C diagnosis in London in 2014, a rise of 25% since 2013. 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 newly acquired infections (as opposed to new reports) of hepatitis C per year appears to be stable or declining.

In 2014, over 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 (60%). 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 overall 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 from hepatitis C related ESLD and HCC in the UK have nearly tripled in the past decade (2004–2013) and deaths more than doubled.

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 addiction treatment services continues to steadily rise, to 80% in 2013/14, although there is marked variation by local authority across London. Reported testing in prisons is poor, with 6.4% of new receptions in London reported as having been tested, compared with 7.8% in England.

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 (32% 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 is likely to revolutionise the outlook for infected patients. NHS England is responsible for commissioning and funding access to the newer drugs, which will be available for patients with cirrhosis who are in the most need, via four operational delivery networks in London.
Hepatitis C in London

Recommendations

GPs are advised to:

- ensure that those people at increased risk of infection are identified and tested, and the chronically infected are referred to a specialist for follow-up (even if the risk was many years ago)

- explore ways to improve their knowledge of hepatitis C, including undertaking e-learning or other training such as the Royal College of General Practitioners (RCGP) certificates in the Detection, Diagnosis and Treatment of Hepatitis C (and B) in Primary care, and Hepatitis C: Enhancing Prevention, Testing and Care

- 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

- ensuring continued investment in testing for hepatitis C in local drug and alcohol services, and in needle and syringe programmes, via the public health grant
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 those among men who have sex with mem (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 and consider how they may capture the more detailed blood-borne virus data items that the National Drug Treatment Monitoring System (NDTMS) can record

- working closely with clinical commissioning groups (CCGs) to ensure that CCG and local authority (LA) commissioning is aligned, and with local hospitals to ensure 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 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

- continue the roll out of the new operational delivery networks for the provision of the new drugs and support the development of pathways to access treatment from drug treatment services

- provide clear advice to all parties about access to and eligibility for the new drugs

- collect data on the number of people referred to hepatology for hepatitis C treatment, the number that start treatment, and the outcome achieved for these patients

- 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

- further expand the use of newer technologies, like dried blood spot testing, that make testing easier in non-clinical settings

- 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
Hepatitis C in London

- raise awareness of local pathways to hepatology services and refer those who test positive
- ensure that service users are offered continued harm reduction advice to reduce the spread of infection, including those who have already tested positive, as well as those who are currently negative, but report continued risk factors
- 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
- further expand the use of newer technologies, like dried blood spot testing, that make testing easier in non-clinical settings

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
- providing delivery of hepatitis treatment to PWID in a community drug treatment setting

PHE London 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 robust 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
People who inject drugs (PWID) are advised to:

- use a full set of clean equipment for each injecting episode
- 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
- make use of resources available from the Hepatitis C Trust for those who test positive
1. Epidemiology and burden of hepatitis C

Background

Hepatitis C remains a major public health problem, with an estimated 214,000 adults living with chronic infection in the UK.\(^1\) The Public Health England (PHE) *Hepatitis C in the UK, 2015 report* provides a comprehensive review of the epidemiology of hepatitis C nationally.\(^2\)

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 hepatitis C, about 40% recover; but the remainder, whether they have symptoms or not, become chronic carriers, and may develop cirrhosis, with up to 20% developing hepatocellular carcinoma (HCC).\(^3\)

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 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 2010. There were 3,858 diagnoses confirmed in London in 2014, a rise of 25% compared to 3,079 in 2013 (Figure 1). Recent rises are likely be due to increased reporting as opposed to an increase in infection detection since laboratory reporting became a statutory requirement in 2010.\(^4\)
Hepatitis C in London

Figure 1: Laboratory confirmed diagnoses of hepatitis C from laboratories in London, 2005–14\(^5\) (increases are likely to reflect improved testing and reporting)

London alone accounts for a third (34%) of all hepatitis C diagnoses reported in England in 2014\(^2\) and has the highest rate of laboratory confirmed diagnoses when compared to other PHE Centre areas (Figure 2). However, caution should be applied when comparing London to other Centres as you are not specifically comparing London with other large cities. The number and rate of laboratory reports in 2014 by local authority is presented in Appendix 1.

Figure 2: Rate of laboratory confirmed diagnoses of hepatitis C per 100,000 residents, by PHE Centre, 2014\(^5\)

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 24-year-olds tested for hepatitis C has increased over recent years, the proportion testing positive is stable in 15 to 19-year-olds and the proportion testing positive has declined in the 20 to 24 year age group (Figure 3).

**Figure 3: Number of young adults tested and testing positive for anti-HCV in sentinel laboratories in London, 2010–14**

In England, Wales and Northern Ireland, recent transmission of hepatitis C has been explored among the participants in the PHE’s Unlinked Anonymous Monitoring Survey of PWID by looking for those who have recently developed antibodies to hepatitis C. Across the UK, a number of methods have been used to gain insight into the number of new HCV infections and likely trends in incidence over time. Preliminary data suggests that incidence of hepatitis C infection among PWID in England, Wales and Northern Ireland during 2014 was between 5 and 16 infections per 100 person years of exposure.2

**Risk factors for hepatitis C**

A number of groups are at increased risk of hepatitis C (Table 1). The principal risk factor 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).2 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

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 and 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 is 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, 1996–2014

<table>
<thead>
<tr>
<th>Risk factor (where reported)</th>
<th>Number of reports</th>
<th>Percentage (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>PWID</td>
<td>16,883</td>
<td>90.6</td>
</tr>
<tr>
<td>Transfusion</td>
<td>240</td>
<td>1.3</td>
</tr>
<tr>
<td>Blood product recipient</td>
<td>132</td>
<td>0.7</td>
</tr>
<tr>
<td>Sexual exposure</td>
<td>188</td>
<td>1.0</td>
</tr>
<tr>
<td>Renal failure</td>
<td>74</td>
<td>0.4</td>
</tr>
<tr>
<td>Vertical (mother to baby) or household</td>
<td>42</td>
<td>0.2</td>
</tr>
<tr>
<td>Occupational</td>
<td>17</td>
<td>0.1</td>
</tr>
<tr>
<td>Other</td>
<td>1,060</td>
<td>5.7</td>
</tr>
<tr>
<td>Total</td>
<td>18,198</td>
<td>100</td>
</tr>
</tbody>
</table>
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. In London, this survey estimated the prevalence of hepatitis C in PWID to be 60% in 2014, which is similar to levels recorded in 2005.

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 from 2010 to 2014 were antibody positive.

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 2014, 470 recently acquired cases of hepatitis C were reported, the majority (94%) of whom were HIV positive.

Among HIV positive men, the estimated incidence of hepatitis C declined over time from 7.3 per 1,000 person years in 2008 to 2.3 in 2013.

Almost a half of men with hepatitis C reported a recent history of unprotected insertive (47%) and receptive (52%) anal intercourse, non-injecting recreational drug use (54%) and sex under the influence of drugs (47%). A recent STI diagnosis was reported among 44% of men alongside high rates of partner change in the previous three months. In addition, a third (27%) 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 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

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). This data suggests that the proportion of those tested that are positive for hepatitis C varies by ethnicity. Overall in London, White ethnic groups were more likely to test positive (1.9%) than Asians (1.5%) and Black ethnic groups (0.7%) in 2014. This is likely to reflect different levels of injecting drugs in these groups.

The prevalence of hepatitis C in individuals originating from South Asia is higher than that in the general non-injecting population. 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 in sentinel laboratories in London, 2010–14. NamPehchan software was used to identify individuals of South Asian origin because ethnicity is not routinely available from the participating laboratory information systems.

Eastern Europeans may be at increased risk of hepatitis C. Over the period 2010–2014 in England, 5% of people of Eastern European origin tested positive.

Age and sex

Figure 5 shows that males account for 72% of those testing positive for hepatitis C, with the peak age group being those aged 35–54 years.
Other risk factors

We have limited information on what proportion of individuals who are tested for hepatitis C are positive according to the reason why they were tested as, for 95% of cases, this information is missing (Figure 6). Where a reason was given, nearly a fifth of those tested because they were PWID were positive. Other relatively high positivity rates were found in those tested due to contact testing (8.8%), because they travelled or lived abroad (6.5%), or due to sexual exposure (5.7%).

Figure 6: Percentage of individuals testing positive for anti-HCV by risk/reason for test in sentinel laboratories in London, 2010-14 (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, i.e., they are hepatitis C antibody positive (Appendix 2). Of these, an estimated 41,500 (69%) are RNA positive (i.e., 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 the 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 modeling approach, outlined on page 43.

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

- Current PWID
- ex-PWID
- Never injected - White
- Never injected - South Asian
Modelling the 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 hepatitis C infection by drug action team (DAT) area, the burden of disease and treatment needs. This model can be found in Appendix 2.5,10,11

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. The number of those people already infected who are newly diagnosed each year with ‘steady state’ testing activity is also calculated.

Hospital admissions for hepatitis C

Hospital admissions from hepatitis C related ESLD and HCC in the UK have nearly tripled in the past decade (2004–2013) and deaths more than doubled.

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 2014, 2,072 London residents were admitted to hospital with hepatitis C (Figure 8) which is similar to the number admitted in 2008.12

Since 2008 increases have been seen in the number of people admitted due to hepatitis C related ESLD (355 in 2014, 28% increase since 2008) and HCC (151 in 2014, 51% increase since 2008) (Figures 9 & 10).12
The crude hospital admission rate for hepatitis C related ESLD or HCC in London (5.5 per 100,000) is significantly higher than the rate in England (3.5 per 100,000, 2012/3). There is four-fold variation across local authorities, from 13.3 per 100,000 in Camden to 3.3 per 100,000 in Havering (Figure 11). Ten local authorities have rates significantly above the England rate: Camden, Hammersmith and Fulham, Westminster, Lewisham, Hackney, Islington, Enfield, Waltham Forest, Brent and Wandsworth.
Figure 11: Crude hospital admission rate for hepatitis C related end-stage liver disease and hepatocellular carcinoma, persons per 100,000 population by London local authority, 2012/3. (City of London not displayed due to wide confidence intervals, Bexley, Harrow, Kingston upon Thames, Richmond upon Thames values suppressed for disclosure control due to small count)

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 2010–14 (n=143) was higher than levels reported in the previous five-year periods (Figure 12). 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 13). These indications accounted for 22% of all liver transplants in Londoners during 2010–2014.
Deaths from hepatitis C

London and the North West PHE Centres have the highest rates of death in England from ESLD or HCC in individuals with hepatitis C mentioned on their death certificate (Figure 14).\textsuperscript{15}
Figure 14: Map showing the rate of death from end-stage liver disease (ESLD) or hepatocellular carcinoma (HCC) in individuals with hepatitis C mentioned on their death certificate by PHE Centre, 2008–14

The under 75 crude mortality rate from hepatitis C related ESLD or HCC varies 10-fold across London, from 1.67 per 100,000 in Lambeth to 0.15 per 100,000 in Bexley from...
2011–13 (Figure 15). However, only Lambeth, Hammersmith and Fulham, Westminster and Barnet local authorities have rates significantly above the England rate.

**Figure 15: Crude mortality rate from hepatitis C related end-stage liver disease/hepatocellular carcinoma in persons less than 75 years per 100,000 population by London local authority, 2011–13** (City of London is not included due to very wide confidence intervals)
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\(^6\) identified that raising awareness among both the public and professionals was an important component of reducing the burden of undiagnosed infection. With many new and improved treatments becoming available, 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 campaigns targeting former PWID (Get Tested, Get Treated)\(^7\) and the UK population of South Asian origin (Hepatitis C. The more you know, the better).\(^8\)

The Royal College of General Practitioners (RCGP), HCV Action and The Hepatitis C Trust, have launched an educational film to support primary care in increasing their knowledge about hepatitis C and help them build confidence in diagnosing and supporting people through treatment (http://hcvaction.org.uk/resource/film-detecting-managing-hepatitis-c-primary-care).

The RCGP Certificate in the Detection, Diagnosis and Management of Hepatitis B and C in Primary Care was developed to help raise awareness in primary care and among other professionals working with groups at high risk of chronic viral hepatitis infection. In London, 238 individuals had completed the e-learning module and 97 had attended face-to-face training days by December 2014.\(^2\) To supplement this, a new RCGP course was launched in April this year, ‘Hepatitis C: Enhancing Prevention, Testing and Care’ which comprises four lessons: understanding hepatitis C; preventing transmission; testing and diagnosis; and treatment and care.

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.\(^8\) 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 2010. The data in Figure 16 from sentinel surveillance shows the numbers tested and proportions positive in London.

The proportion testing positive for hepatitis has decreased year-on-year from 2.6% in 2009 to 1.7% in 2014. 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 16: Number of individuals tested and the proportion testing positive for anti-HCV in sentinel laboratories in London, 2010–14.** 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 17). However, this data does not include dried blood spot testing or oral fluid testing (commonly used in drug services).
Figure 17: Number of individuals tested for anti-HCV and the proportion testing positive by service type in sentinel laboratories in London, 2010–14. 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, genito-urinary medicine (GUM) clinics and A&E has increased since 2010 (Figure 18).

Figure 18: Number of hepatitis C tests by service type in sentinel laboratories by year in London, 2010–2014. 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 (UAM) 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 2014 (Figure 19).\(^7\)

**Figure 19: Hepatitis C test uptake among PWID and their awareness of infection in London, 2005–14.\(^7\)**

However, 41% of PWID remain unaware of their infection. 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.\(^19\) 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 20).
According to a survey of London commissioners and providers in 2012, dried blood spot testing was reported by commissioners to be available in 63% (15/24) of drug treatment services, whereas providers only reported it being available in 37% (14/38). 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%).
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). 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 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

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

New national indicators, Health and Justice Indicators of Performance (HJIPs), have been developed in England for use by commissioners and partners to monitor the quality and performance of healthcare in all prescribed places of detention. HJIPs will support the introduction of HCV opt-out testing in England including the offer and uptake of HCV testing.
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 32% reporting both direct and indirect sharing in 2014 (Figure 21). 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 21: Level of direct and indirect sharing among PWID in London, 2005–2014**

![Graph showing percentage of direct and indirect sharing from 2005 to 2014](image-url)
In England, indirect measures of needle and syringe programme (NSP) coverage suggest that the vast majority of PWID are accessing NSP; in 2014, the UAM Survey found that 85% of people who had injected drugs in the previous year reported that they had used an NSP during that time. While data suggests that NSP are being accessed by many PWID, there remains a need to increase the amount of equipment distributed in many areas, with better targeting of this provision and education on appropriate needle and syringe cleaning techniques.

**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. Neither HMP Wormwood nor Brixton, the two London prisons that participated in the audit, had any form of written document. This level of documentation was lower than that published by the survey in July 2012, when the proportion was 74% (82/110). 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 that will successfully clear the virus in the majority of patients are available and approved for use in the UK.\textsuperscript{24-32} Newer treatments have improved effectiveness, reduced treatment durations and fewer side-effects. However, the cost of the new treatments, when coupled with the numbers potentially requiring them, raises real issues of affordability for UK health services.

NHS England is responsible for commissioning and funding access to the newer drugs for hepatitis C and has recently announced national investment to deliver the drugs to those patients with cirrhosis who are in the most need. The new drugs will be delivered via operational delivery networks (ODN) under a ‘hub and spoke’ model\textsuperscript{33}. There will be four ‘hub’ hospitals in London, with local hospitals acting as ‘spokes’. Local ‘spoke’ hospitals will be able to refer patients into the hub for approval of treatment with the new drugs.

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-term 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.\textsuperscript{34} 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 \textit{Hepatitis C Action Plan for England}.

Statistical modelling suggests that increased uptake and new therapies are both needed to avert rises in hepatitis C-related ESLD in England. Preliminary results from further modelling suggest that extending new treatments, with their markedly improved rates of sustained virological response, to just 2,000 people in England with cirrhosis per year from 2015 would have a significant impact on the incidence of hepatitis C-related ESLD/HCC, with 5,220 people predicted to consequently be living with hepatitis C-related cirrhosis or HCC in 2020 compared to 11,710 if the new treatments were only given to people with ESLD/HC. However, without increasing new treatments in those
with moderate disease, reductions in numbers of people with hepatitis C-related ESLD/HCC would not continue beyond five years.

Modelling studies have also shown that while strategies prioritising persons with advanced liver fibrosis have the most advantageous impact on severe liver morbidity, they are suboptimal in terms of curtailing incident transmission.

### Estimates of numbers receiving therapy for hepatitis C

Currently, there are no national surveillance systems to monitor referral, uptake or response to treatment. PHE has previously used national data from pharmaceutical companies, pharmacy purchasing data and pharmacy prescribing data to estimate how many individuals have been treated for hepatitis C in England (Figure 22).

**Figure 22: Estimated numbers of hepatitis C positive patients receiving combined therapy based on national supply of pegylated interferon by region, 2006–2011**

In addition to the usual contractual reporting that providers are required to provide to commissioners, work is underway to agree arrangements for the collection of further epidemiological, treatment and outcome data to add to the understanding of hepatitis C in England and the effectiveness of the new treatments. A dataset has been agreed with the involvement of clinicians, patient representatives and PHE; and work is underway to validate that it meets clinical requirements and to confirm how these data will be collected, stored and analysed.

There is a lack of recent information for London. Up until 2011, the trend was for an increase in the numbers of hepatitis C positive patients receiving treatment in London. In 2011, 1,492 individuals were treated (Figure 22).
treated than any other PHE Centre, which likely reflects the large population and a higher burden of infection.

Sentinel surveillance data in England suggest that the number of individuals experiencing treatment for the first time increased between 2002 and 2009 but has declined since; when most recent treatment events are examined, the numbers undergoing treatment have increased year on year between 2002 and 2014\textsuperscript{2}.

**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**

Overall across the UK, data suggests that referrals for hepatitis C treatment and care are rising. Among UAM survey participants in England and Wales with antibodies to hepatitis C who were aware of their infection, increasing numbers of PWID report having seen a specialist nurse or doctor about their infection, with around 70\% reporting having done so in the 2013 and 2014 surveys\textsuperscript{2, 7}.

Previous evidence suggests that only a minority of areas in London had 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 (11/38, 29\%) and a third of providers (12/38, 32\%) reported having a documented patient pathway for PWID with hepatitis C. 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 hepatitis C 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.
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 by 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 had a written pathway in place to describe what happens following a positive result (HMP Holloway and HMP Brixton). All the prisons that responded indicated that they use venous blood, as opposed to dried blood spot, to test for hepatitis C and just half indicated that their laboratory automatically tests using PCR.

The majority of London prisons (6/8) referred to hospital outpatients for treatment, with the others using an ‘in reach’ service provided by the hospital (HMP Belmarsh and HMP Wandsworth). HMP Belmarsh conducted appointments via video link, which cuts down on costs such as escorts and health specialist time. All the prisons indicated that they provided referral for those leaving prison who are hepatitis C positive if these prisoners were 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. 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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NHS Trust Development Authority

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Hepatitis C in London

The Office for National Statistics

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

The Health and Social Care Information Centre (HSCIC)

- 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 eight participating centres in London—PHE CIDSC, North Middlesex Hospital, St Bartholomew’s Hospital, King’s College Hospital, Ealing Hospital, St George’s Hospital, Chelsea and Westminster Hospital, Dulwich Laboratory 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.
About Field Epidemiology Services

The Field Epidemiology Service (FES) supports Public Health England Centres and partner organisations through the application of epidemiological methods to inform public health action.

FES does this in two main ways, firstly by providing a flexible expert resource, available, as and when needed, to undertake epidemiological investigations for key health protection work and secondly through the expert analysis, interpretation and dissemination of surveillance information to PHE Centres, local health partners, service providers and commissioners of services.

Within the FES network, excellence and innovation is encouraged, we foster academic collaborations and take active part and lead in research, development and training.

You can contact your local FES team at fes.seal@phe.gov.uk

If you have any comments or feedback regarding this report or the FES service, please contact fes.seal@phe.gov.uk
Appendix 1

Local authority data on laboratory reports of hepatitis C is presented in Table A1. Due to incomplete reporting extreme caution should be applied when using this data as it is unlikely to robustly represent the true rate of laboratory reports in each local authority.

Where possible, data is summarised by upper tier local authority of residence. However, where data on patient postcode or registered GP practice is not available, data is assigned to the local authority of the laboratory.

In 22% of reports, the data was assigned to the local authority of the laboratory. This means that there will be a bias to observing increased reports in those local authorities where laboratories are located.
### Table A1: Laboratory reports of hepatitis C by local authority in London, 2014

<table>
<thead>
<tr>
<th>Local authority</th>
<th>No. of laboratory reports</th>
<th>Directly standardised rate (DSR) per 100,000 population*</th>
<th>95% lower confidence interval</th>
<th>95% upper confidence interval</th>
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<tbody>
<tr>
<td></td>
<td></td>
<td>DSR</td>
<td></td>
<td></td>
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<tr>
<td>Barking and Dagenham</td>
<td>42</td>
<td>23.3</td>
<td>16.3</td>
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<td>Barnet</td>
<td>114</td>
<td>33.3</td>
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<td>40.2</td>
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<td>17</td>
<td>7.5</td>
<td>4.3</td>
<td>12.0</td>
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<td>130</td>
<td>47.3</td>
<td>39.1</td>
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<td>11.3</td>
<td>7.9</td>
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<td>332</td>
<td>152.1</td>
<td>135.1</td>
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<td>106.0</td>
<td>43.5</td>
<td>209.4</td>
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<td>39.7</td>
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<td>186</td>
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<td>76.2</td>
<td>103.9</td>
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<tr>
<td>Total</td>
<td>3,858</td>
<td>47.0</td>
<td>45.5</td>
<td>48.6</td>
</tr>
</tbody>
</table>

*DSRs per 100,000 population have been calculated using mid-year population estimates supplied by the Office for National Statistics.
### Table A2: Estimates of hepatitis C prevalence, burden, and treatment by DAT in London

(please see notes on the next page for interpretation and the notes on the original models available on the PHE website http://www.hpa.org.uk/Topics-InfectiousDiseases/InfectionsAZ/HepatitisC/EpidemiologicalData/)

<table>
<thead>
<tr>
<th>DAT</th>
<th>Estimated total infected population</th>
<th>Estimated Burden in 2023</th>
<th>Estimated no. of backlog of current diagnosed infections requiring treatment</th>
<th>Estimated additional number of annual new diagnoses requiring treatment</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mild/moderate</td>
<td>Cirrhotic/ESLD/HCC</td>
<td>Died</td>
<td>SVR*</td>
</tr>
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<td>573</td>
<td>51</td>
<td>139</td>
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<td>192</td>
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<td>1047</td>
<td>94</td>
<td>254</td>
</tr>
<tr>
<td>DAT</td>
<td>Estimated total infected population</td>
<td>Estimated Burden in 2023</td>
<td>Estimated no. of backlog of current diagnosed infections requiring treatment</td>
<td>Estimated additional number of annual new diagnoses requiring treatment</td>
</tr>
<tr>
<td>----------------------------</td>
<td>------------------------------------</td>
<td>--------------------------</td>
<td>-------------------------------------------------------------------------------</td>
<td>-----------------------------------------------------------------------</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Mild/moderate</td>
<td>Cirrhotic/ESLD/HCC</td>
<td>Died</td>
</tr>
<tr>
<td>Kensington and Chelsea</td>
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<td>534</td>
<td>48</td>
<td>129</td>
</tr>
<tr>
<td>Kingston upon Thames</td>
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<td>406</td>
<td>36</td>
<td>98</td>
</tr>
<tr>
<td>Lambeth</td>
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<td>1691</td>
<td>152</td>
<td>410</td>
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<tr>
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<tr>
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</tr>
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<td><strong>London</strong></td>
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<td><strong>28,228</strong></td>
<td><strong>2,531</strong></td>
<td><strong>6,848</strong></td>
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</table>

*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. 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.
References


8. National Institute for Health and Clinical Excellence. Hepatitis B and C: ways to promote and offer testing to people at increased risk of infection. NICE public health guidance 43. 2012.


18. Department of Health. Hepatitis C. The more you know, the better.


35. Roche Sales IMS Supply Chain Manager data Pharmex. Estimated numbers of HCV positive patients receiving combined therapy based on national supply of pegylated interferon by region. 2006-2011.