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England

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# **Hepatitis C in the South East Public Health England Centre**

## 2015 report

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Published November 2015  
PHE publications gateway number: 2015488

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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 the South East Public Health England Centre area, 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).

An estimated 17,500 people in the South East have been infected with hepatitis C (ie they are hepatitis C antibody positive), of whom an estimated 40% remain undiagnosed.

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 in England appears to be stable or declining.

There were 1,317 new laboratory reports of confirmed hepatitis C diagnoses in the South East in 2014. However, 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.

Injecting drug use remains the major risk factor. It is estimated that over half of people who inject drugs (PWID) in the South East have hepatitis C (58%). It is estimated that 41% of people who have been infected with hepatitis C in the South East are those who

currently inject drugs, however, nearly a third are people who used to inject drugs many years ago and no longer inject (29%).

Individuals originating from south Asia, where the prevalence of hepatitis C is high, are also particularly at risk. It is estimated that nearly a third of people in the South East who have been infected with hepatitis C have never injected drugs (30%), just over one third of whom are Indian, Pakistani or Bangladeshi (11% of total).

In the past 10 years, sex between men has also emerged as an important route of transmission.

The overall 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. In 2014, over 1,100 people in the South East were admitted to hospital with a diagnosis of hepatitis C and there has been an increase in hospital admissions from hepatitis C related ESLD and HCC in the past 5 years. The number of hepatitis C related transplants has also increased since 2000 in the South East, with hepatitis C being the primary indication for 17% of first liver transplants between 2010 and 2014. Deaths from hepatitis C in the UK have more than doubled in the past decade.

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 86% in 2013/14, although there is marked variation by local authority. Despite this, half of PWID remain unaware of their infection. Reported testing in prisons is poor, with 7.3% of new receptions reported as having been tested in the South East, compared with 7.9% 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 (37% indirect and direct sharing).

It is vital that those testing positive and shown to be chronically infected are referred appropriately. Only 65% of prisons in the South East 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 Operational Delivery Networks.

## 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 (even if the risk was many years ago)
- explore ways to improve their knowledge of hepatitis C, including undertaking e-learning or other training, for example, the 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 among men who have sex with men (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 and continuity of care for people moving between prison and community settings (in both directions). 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
- the use of newer technologies, like dried blood spot testing, that make testing easier in non-clinical settings should be further expanded
- provide in-house treatment of hepatitis C



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

- ensure all PWID (which includes people who previously injected) 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
- ensure that services 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](http://www.harmreductionworks.org.uk/hep_c.html)
- 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
- delivery of hepatitis treatment to PWID in a community drug treatment setting

**PHE South East** 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

**People who inject drugs** 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](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.<sup>1</sup> The Public Health England (PHE) *Hepatitis C in the UK, 2015 report* 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 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).<sup>3</sup>

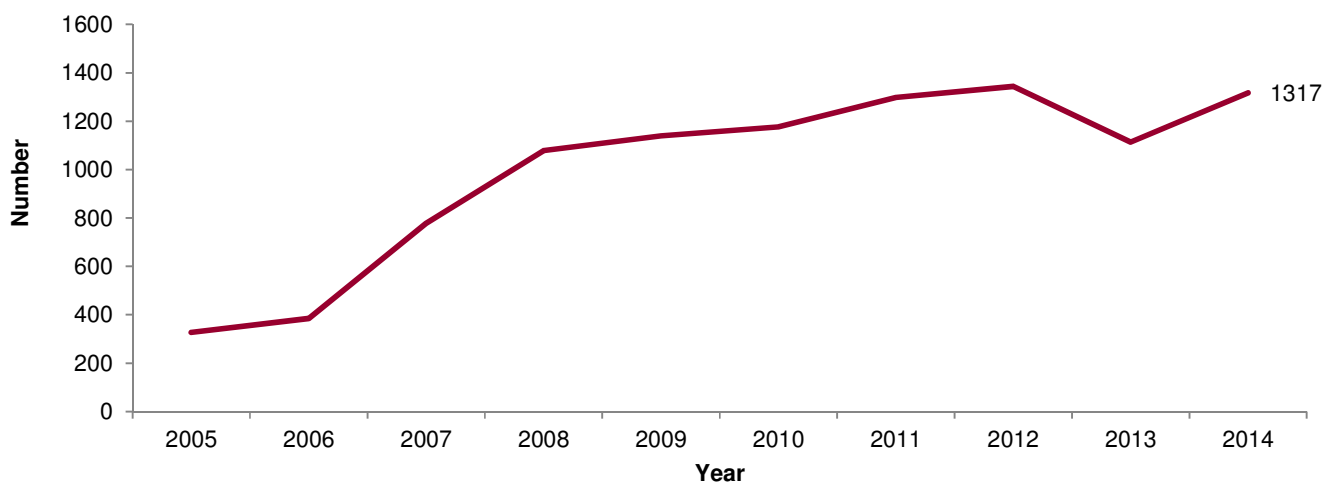
Information from various sources can be used to build up a picture of hepatitis C epidemiology in the South East. We do not have complete information about hepatitis C because we are not able to accurately determine the number of new infections each year and there is no prevalence survey of the local 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 in the South East has continued to rise steadily since 2008, with 1,317 confirmed diagnoses in 2014. Although there was a drop in the number of laboratory confirmed diagnosis of hepatitis C in 2013, the number of diagnosis reached the same level as in 2012 (Figure 1). Recent rises 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> The number and rate of laboratory reports in 2014 by local authority is presented in Appendix 1.

**Figure 1: Laboratory confirmed diagnoses of hepatitis C from laboratories in the South East, 2005–2014<sup>5</sup>** (increases are likely to reflect improved testing and reporting)



The South East account for 11% of all hepatitis C diagnoses reported in England in 2014<sup>2</sup> (Figure 2). 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<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 in England appears to be stable or declining.

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<sup>6</sup> 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 suggest 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.<sup>2</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 data from the South East 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 drug

People who received a blood transfusion before 1991 or blood products before 1986, when screening of blood donors for hepatitis S 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, 1996–2014<sup>4</sup>**

Risk factor (where reported)	Number of reports	Percentage (%)
PWID	16,883	90.6
Transfusion	240	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	1,060	5.7
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>6</sup> In the South East, this survey estimated the prevalence of hepatitis in PWID to be 58% in 2014, which is higher than the estimated prevalence recorded in 2005 (46%).

### 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, 16% of those tested from 2010 to 2014 were antibody positive.<sup>8</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 2014, 470 recently acquired cases of hepatitis C were reported, the majority (94%) of whom were HIV positive.<sup>9</sup>

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.

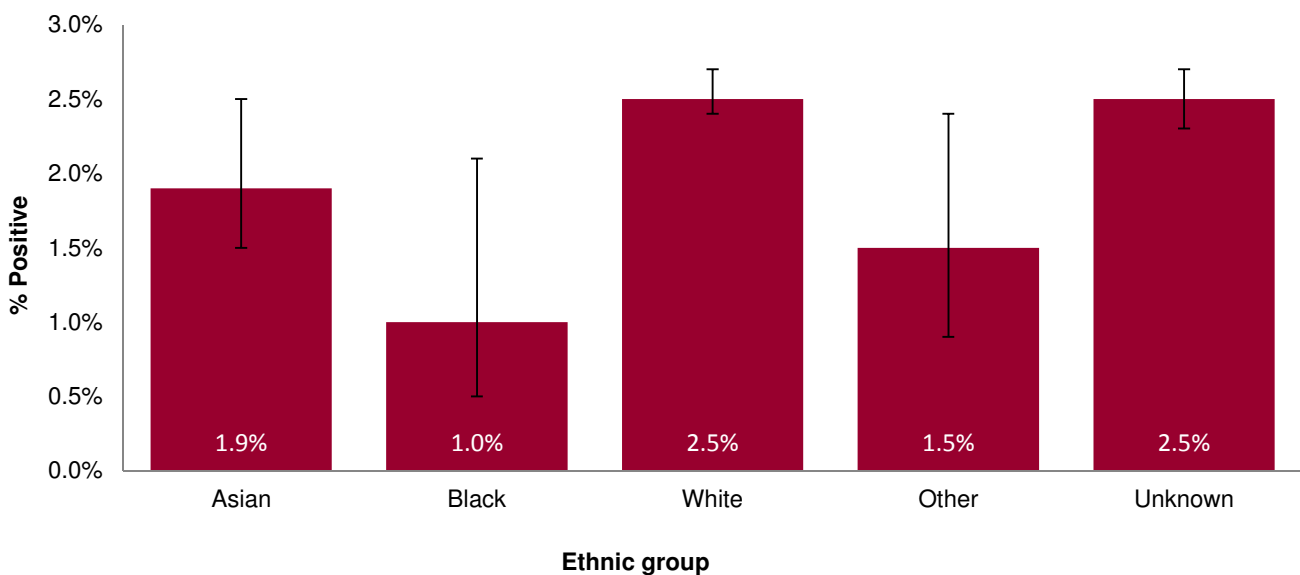
Almost a half of men reported a recent history of unprotected insertive (47%) and receptive (52%) anal intercourse, non-injecting recreational drug use (54%) and sex under the influence of drugs (47%). A recent STI diagnosis was reported among 44% of men alongside high rates of partner change in the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

In total, 24 laboratories in England participate in the Sentinel Surveillance of Hepatitis Testing Study, including three laboratories in the South East. These laboratories collect more detailed information about hepatitis C testing (more information in data sources).<sup>8</sup> Data from the Sentinel Surveillance of Hepatitis Testing Study suggest that the proportion of those tested who are positive for hepatitis C varies by ethnicity (Figure 3).

**Figure 3: Proportion testing positive for anti-HCV by ethnicity in sentinel laboratories in the South East, 2010–2014<sup>8</sup>**

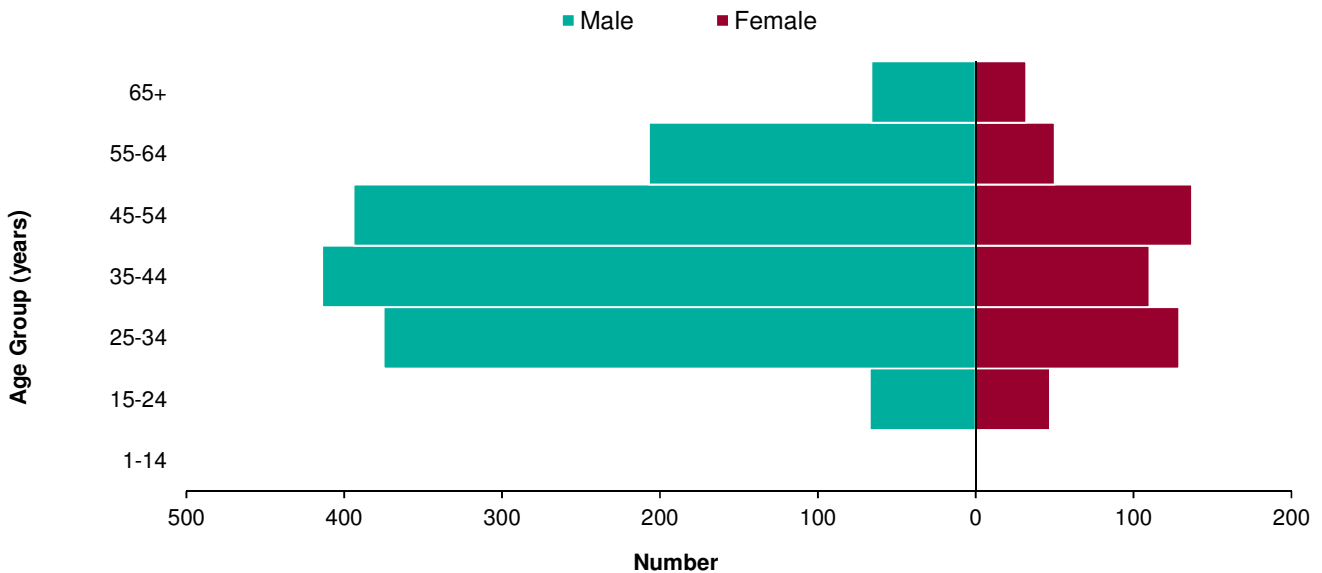


Different positivity levels may partly reflect different levels of injecting drugs in different ethnic groups. The prevalence of hepatitis C in individuals originating from South Asia is higher than the general non-injecting population.<sup>1</sup> National data suggests that Eastern Europeans may also be at increased risk of hepatitis C. Over the period 2010-2014 in England, 5.0% of people of Eastern European origin tested positive.<sup>2, 8</sup>

### Age and sex

Figure 4 shows that males account for 75% of those testing positive for hepatitis C, with the peak age group being those aged between 35–54 years.

**Figure 4: Age-group and gender of individuals testing positive for anti-HCV in sentinel laboratories in the South East, 2014<sup>8</sup>**

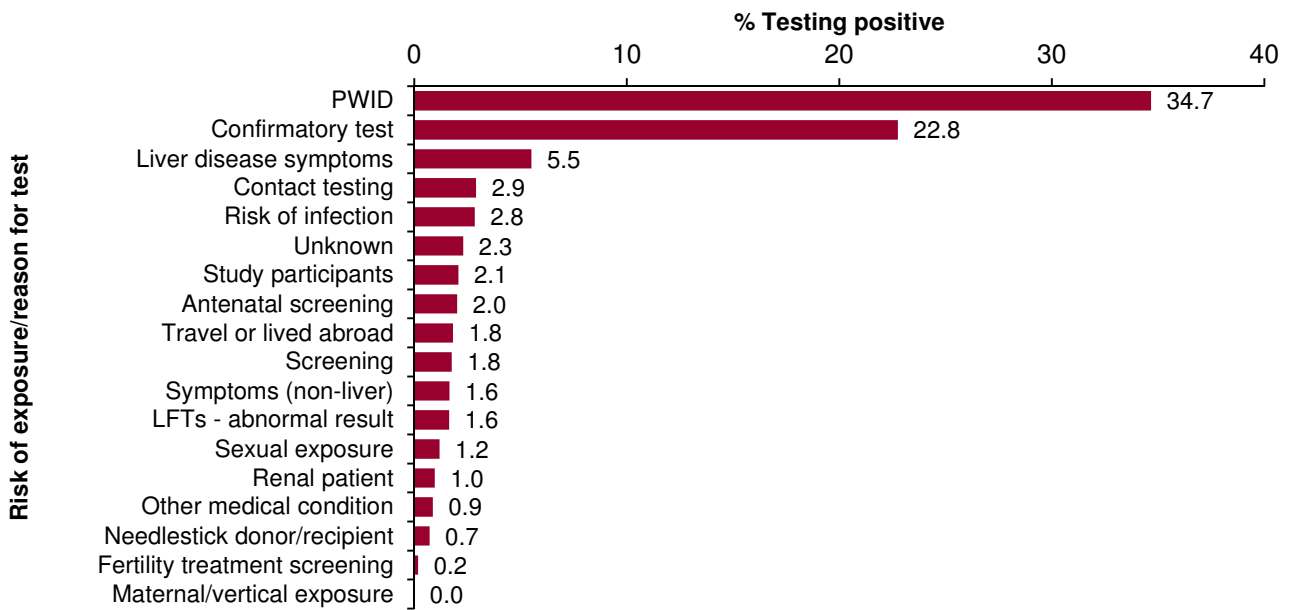


### Other risk factors

We have information on what proportion of individuals who are tested for hepatitis C are positive according to the reason for the test, although for 27% of cases, this information is missing. Where a reason was given, a third of those were tested because they were PWID were positive (Figure 5). Other relatively high positivity rates were found in those tested due to antenatal care (2.0%), because they travelled or lived abroad (1.8%), or due to sexual exposure (1.2%)



**Figure 5: Percentage of individuals testing positive for anti-HCV by risk/reason for test in sentinel laboratories in the South East, 2010-2014<sup>8</sup> (LFT-liver function test)**



## Burden

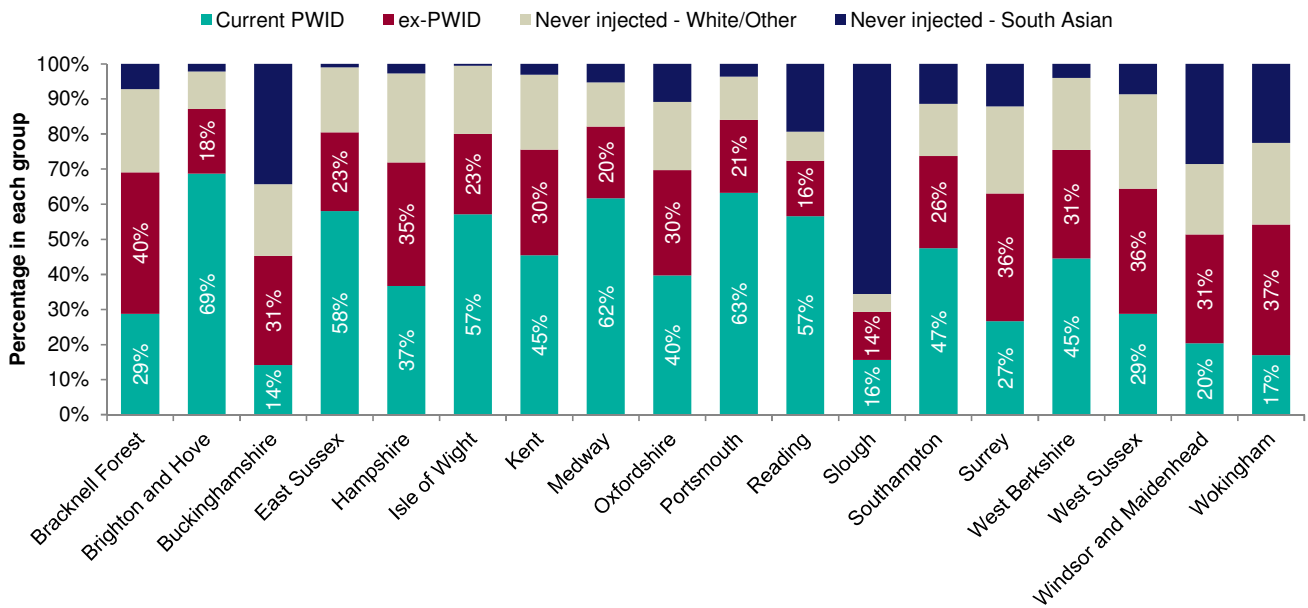
### Estimates of the number of people infected with hepatitis C

It is estimated that over 17,500 people have been infected with hepatitis C in the South East ie they are hepatitis C antibody positive (Appendix 2). Of these, an estimated 12,000 (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 the local authorities (LAs) in the South East, with the highest number in the Kent area (~2,843). 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 41.

While it is estimated that 41% of people infected with hepatitis C in the South East are those who are current injecting drug users, nearly a third are those who used to inject drugs many years ago and no longer inject (29%).

It is estimated that a smaller proportion of people in the South East who have been infected with hepatitis C have never injected drugs (30%), just over one third of whom are Indian, Pakistani or Bangladeshi (11% of total). The corresponding figures for each LA are displayed in Figure 6.

**Figure 6: Estimates of the proportion of all people who have been infected with hepatitis C in each South East LA in each risk group<sup>10</sup>**



### 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.<sup>5, 10, 11</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 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.

### Hospital admissions for hepatitis C

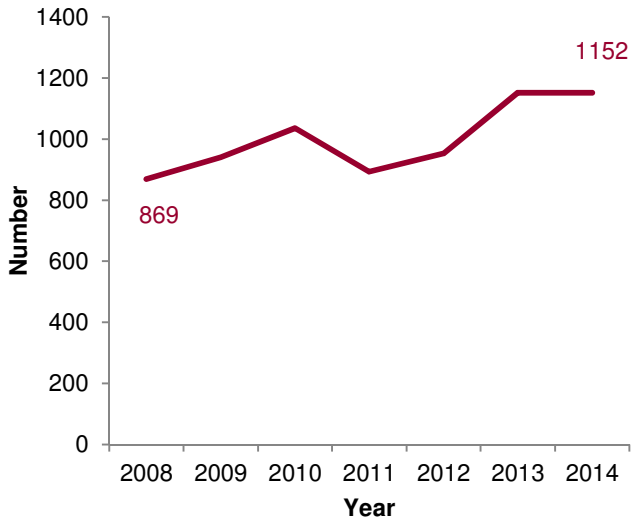
Hospital admissions from hepatitis C related ESLD and HCC in the UK have nearly tripled in the past decade (2004-2014) and deaths more than doubled.

The number of admissions due to hepatitis C in the South East is increasing. In 2014, 1,152 residents from the South East were admitted to hospital with hepatitis C (Figure 7), a 33% increase since 2008.<sup>12</sup> However, it is likely that hospital episode statistics underestimate the true numbers of admissions from hepatitis C.

Since 2008 increases have been seen in the number of people admitted due to hepatitis C related ESLD (197 in 2014, 54% increase since 2008) and HCC (83 in 2014, 63% increase since 2008) (Figures 8 & 9).<sup>12</sup>

**Figure 7: Individuals resident in the South East admitted to hospital with a diagnosis of hepatitis C (2008–2014)<sup>12</sup> \*, \*\*\*, see footnotes**

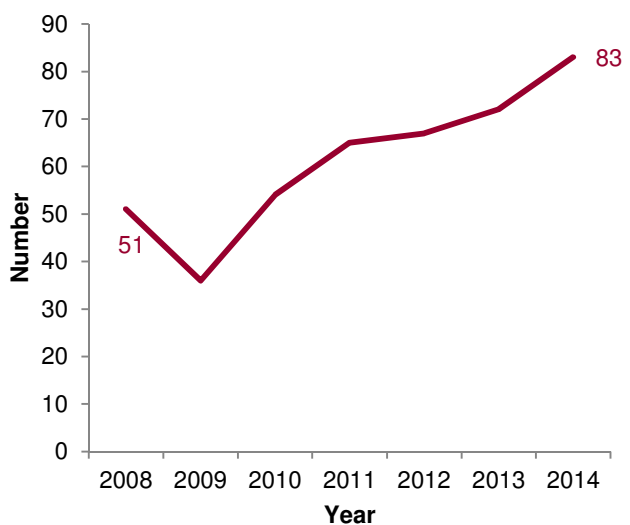
on next page for figures 7 & 9



**Figure 8: Individuals resident in the South East admitted to hospital with a diagnosis of HCV related ESLD, 2008–2014<sup>12</sup> \*, \*\*, \*\*\***



**Figure 9: Individuals resident in the South East admitted to hospital with a diagnosis of HCV related HCC, 2008–2014<sup>12</sup> \*, \*\*\*, see footnotes**



Data source: Health and Social Care Information Centre, Hospital Episode Statistics; Copyright © 2015, re-used with the permission of the Health and Social Care Information Centre, all rights reserved

Data relate to the number of individuals who were admitted to hospital and the episode in hospital ended in each calendar year. If an individual had more than one episode in the calendar year - we have only counted them once for this particular analysis ie all patients with HCV/ESLD/HCC admissions were de-duplicated to give one individual with HCV/ESLD/HCC per calendar year.

Codes for HCV/ESLD/HCC were extracted from all diagnosis codes (information about a patient's illness or condition - this includes primary/secondary/subsidiary diagnoses) - The following ICD10 codes were used: B171 (Acute hepatitis C), B182 (Chronic viral hepatitis C), C220 (Liver cell carcinoma), and the following codes for ESLD (our definition of ESLD is defined by codes or text entries for ascites (R18), bleeding oesophageal varices (I850), hepato-renal syndrome (K767), hepatic encephalopathy or hepatic failure (K704) (K720) (K721) (K729).

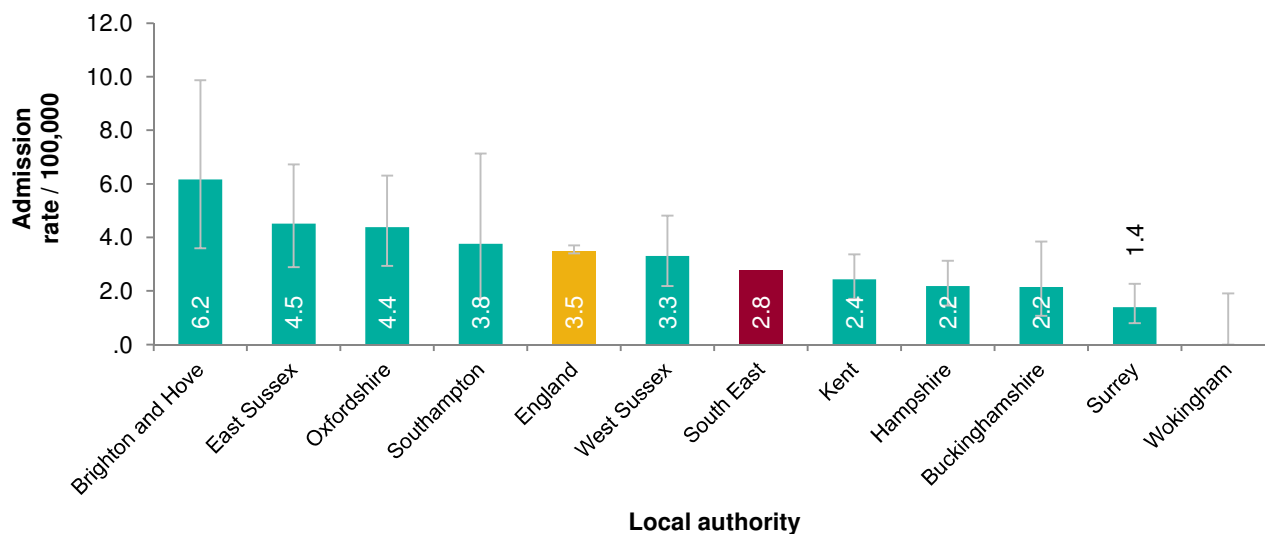
\*Patient counts are based on the unique patient identifier, HESID. This identifier is derived from a patient's date of birth, postcode, sex, local patient identifier and NHS number, using a standard algorithm. Where data are incomplete, HESID might wrongly link episodes or fail to recognise episodes for the same patient. Care is therefore needed, especially where the data includes duplicate records. Patient counts must not be summed across a table where patients may have episodes in more than one cell.

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

\*\*\* Hospital Episode Statistics (HES) data for 2013 and 2014 were analysed using the HES Data Interrogation System (HDIS). 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.

The crude hospital admission rate for hepatitis C related ESLD or HCC in the South East (2.8 per 100,000) is lower than the rate in England (3.5 per 100,000, 2012/3).<sup>13</sup> Only Brighton and Hove local authority had a rate significantly above the England rate (Figure 10).

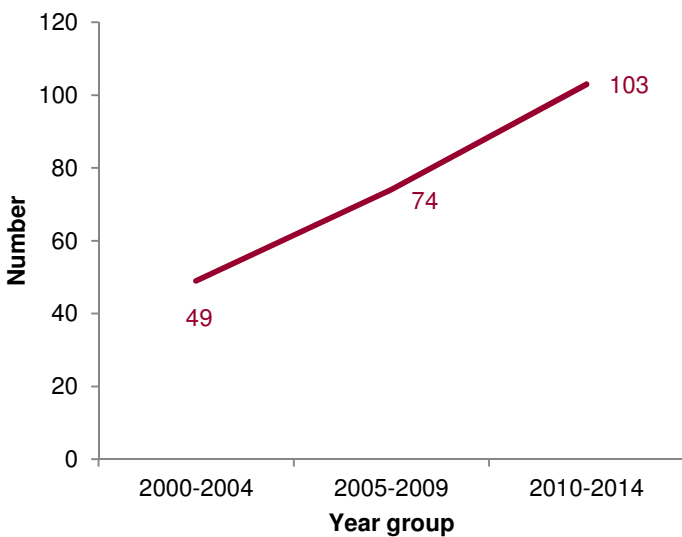
**Figure 10: Crude hospital admission rate for hepatitis C related end-stage liver disease and hepatocellular carcinoma, persons per 100,000 population by South East local authority, 2012/3.** <sup>13</sup> (Medway, Bracknell Forest, West Berkshire, Reading, Slough, Windsor & Maidenhead, Portsmouth and Isle of Wight values suppressed for disclosure control due to small count)



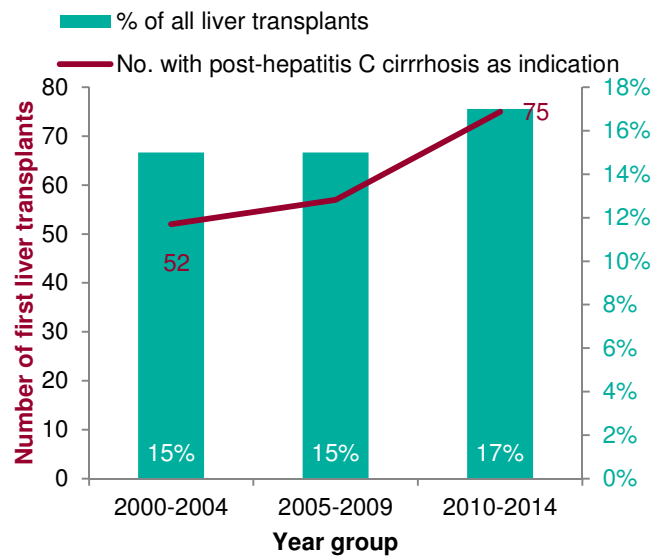
## Transplants

The number of first registrations in residents from the South East for liver transplants in patients with post-hepatitis C cirrhosis as a primary, secondary or tertiary indication observed during 2010 - 2014 (n=103) 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 17% of all liver transplants in residents in the South East during 2010–2014.

**Figure 11\*: First registrations with post-hepatitis C cirrhosis as primary, secondary or tertiary indication for transplant, South East residents, 2000–2014<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 hepatitis C positive at registration or transplant, South East residents, plus percentage of all liver transplants, 2000–2014<sup>14</sup>**

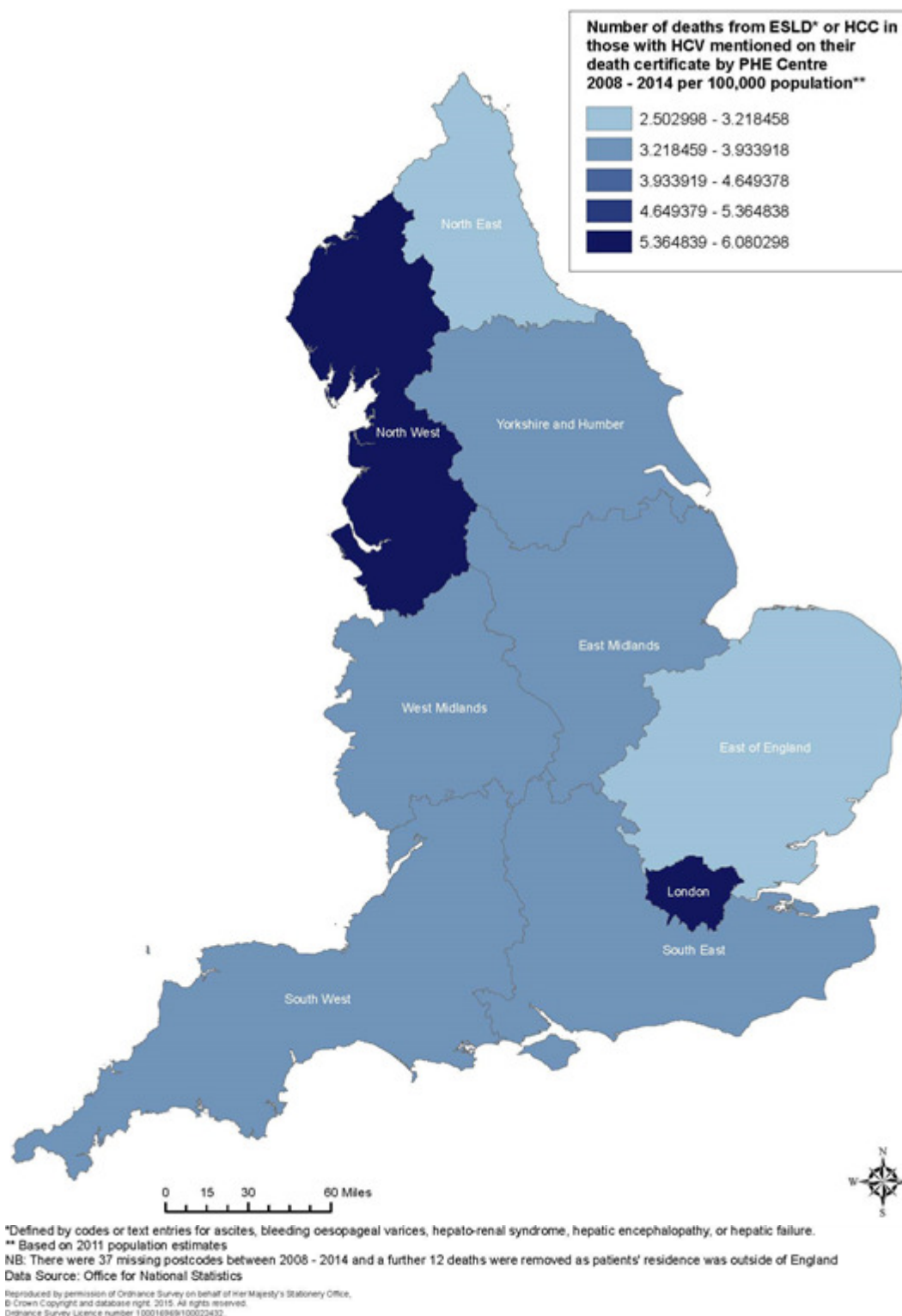


\* These figures are based on registry data as at 09 April 2015. New national registration criteria for selecting adult patients for elective liver transplantation were introduced in September 2007: NHSTB. Liver Transplantation: Selection Criteria and Recipient Registration (June 2015). Available at: <http://www.odt.nhs.uk/transplantation/guidance-policies/> (Accessed 19/06/2015).

## Deaths from hepatitis C

London and the North West PHE Centres have the highest rates in England of deaths from ESLD or HCC in individuals with hepatitis C mentioned on their death certificate (Figure 13).<sup>15</sup>

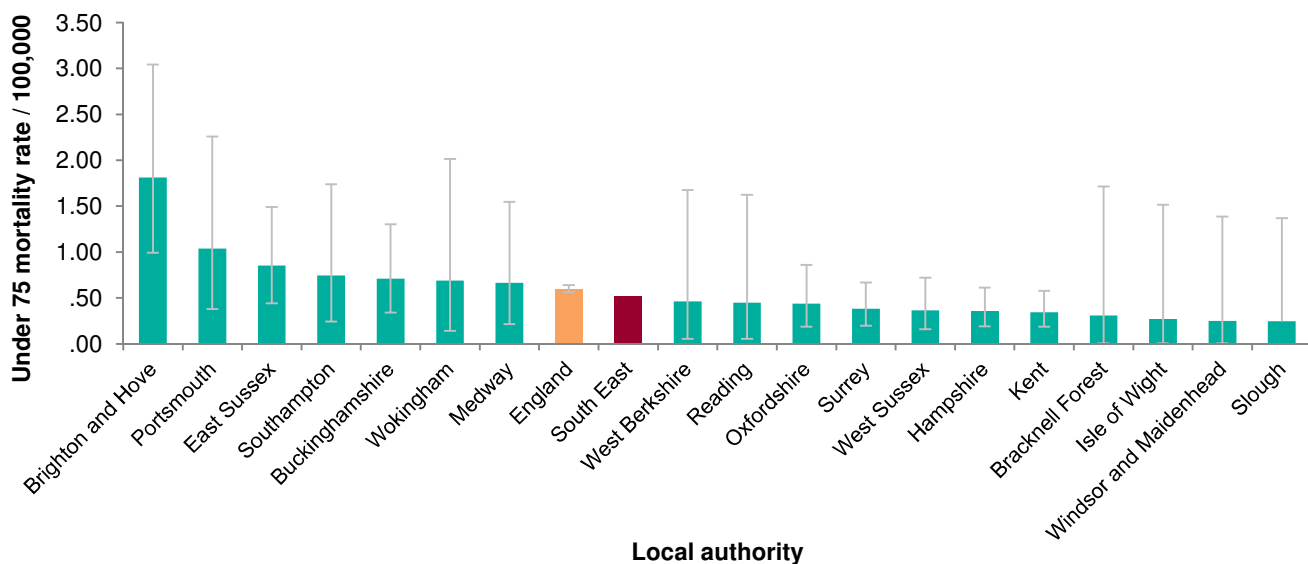
**Figure 13: Map showing the rate of deaths from ESLD or HCC in individuals with hepatitis C mentioned on their death certificate by PHE Centre, 2008–14<sup>15</sup>**



The under 75 crude mortality rate from hepatitis C related ESLD or HCC varies seven-fold across the South East, from 1.81 per 100,000 in Brighton and Hove to 0.25 per

100,000 in Slough from 2011-13 (Figure 14).<sup>13</sup> However, only Brighton and Hove had a rate significantly above the England rate.<sup>13</sup>

**Figure 14: Crude mortality rate from hepatitis C related end-stage liver disease/hepatocellular carcinoma in persons less than 75 years per 100,000 population by South East local authority, 2011-13<sup>13</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 among both the public and professionals 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 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 Royal College of GPs (RCGP), HCV Action and The Hepatitis C Trust, have launched an educational film to support primary care to increase their knowledge about hepatitis C and help them to 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 the South East by December 2014, 182 individuals had completed the e-learning module and 65 had attended face-to-face training days.<sup>2</sup> 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.<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. However, there has been a decrease in testing in the South East since 2010.<sup>8</sup> The data in Figure 15 from sentinel surveillance shows the numbers tested and proportions positive in the South East.<sup>8</sup>

In 2014, 2% of those tested for hepatitis C tested positive. There is no clear trend in the proportion testing positive for hepatitis C over recent years.

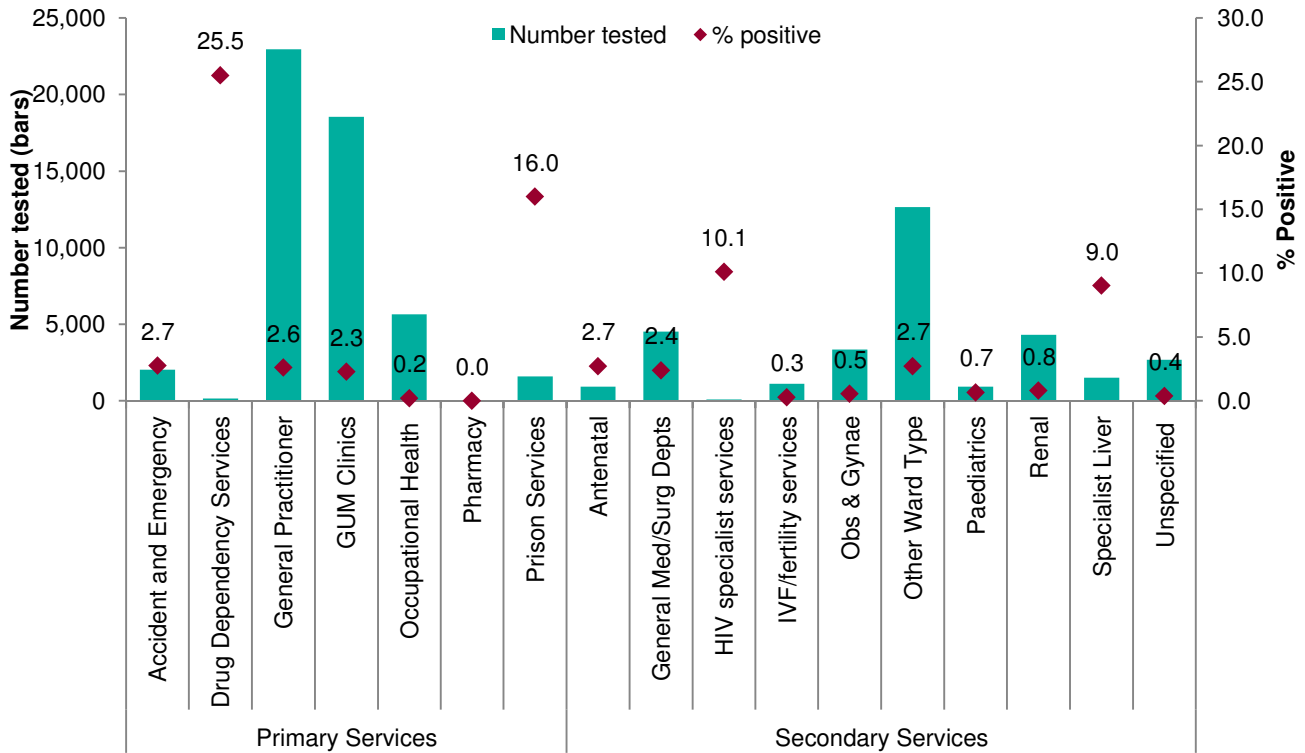
**Figure 15: Number of individuals tested and the proportion testing positive for anti-HCV in sentinel laboratories in the South East, 2010 to 2014.**<sup>8</sup> Please note that the numbers relate to those tested in the sentinel laboratories, and do not represent all tests across the South East.



### Site of testing

Information from sentinel surveillance indicates that testing was most often conducted by general practitioners (Figure 16).<sup>8</sup> However, this data does not include dried blood spot testing and oral fluid testing (commonly used in drug services).

**Figure 16: Number of individuals tested for anti-HCV and the proportion testing positive by service type in sentinel laboratories in the South East, 2010 to 2014.<sup>8</sup> Please note that the numbers relate to those tested in the sentinel laboratories and do not represent all tests across the South East.**

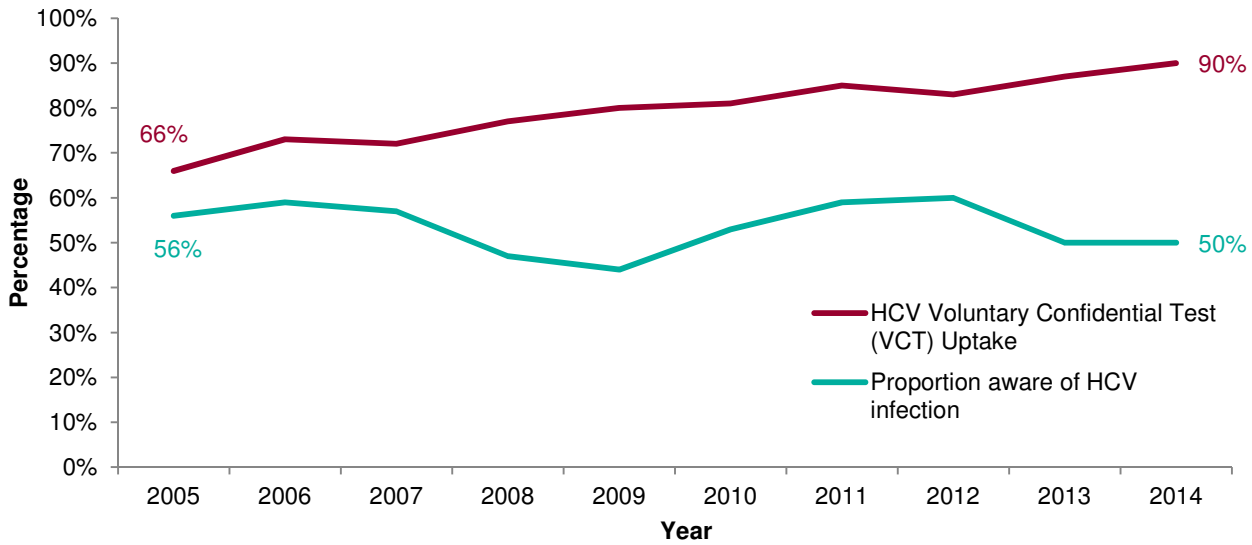


Encouragingly, there is evidence from sentinel surveillance to suggest increased testing by GPs (increase by 7% from 2010 to 2014) and A&E (19% increase).

### 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 90% in the South East in 2014 (Figure 17).<sup>6</sup>

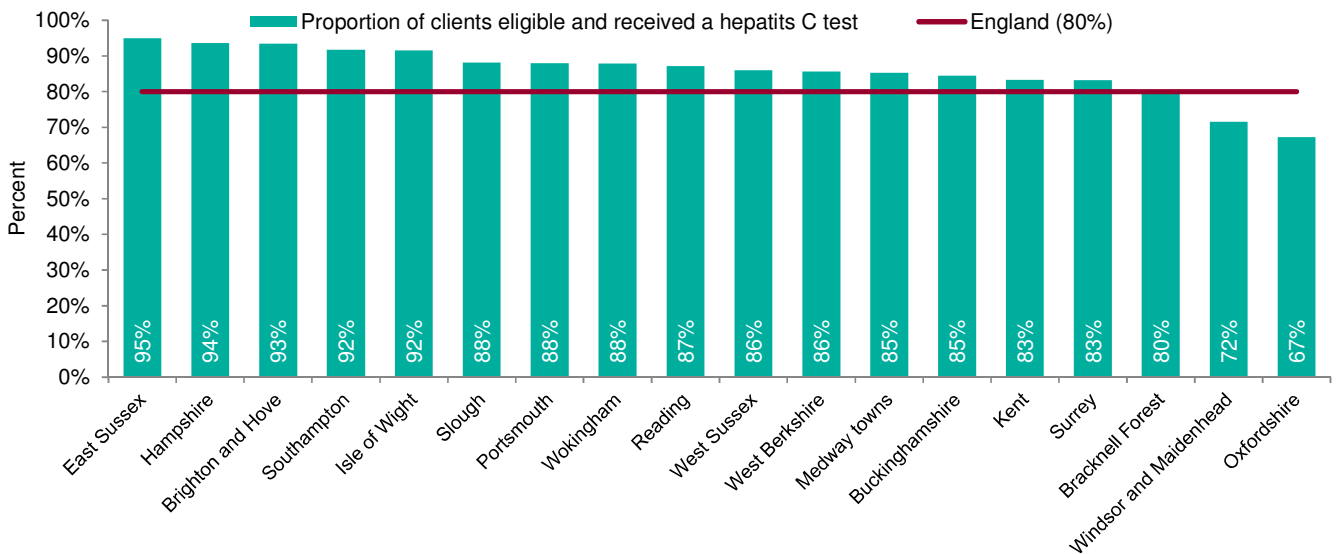
**Figure 17: Hepatitis C test uptake among PWID and their awareness of infection in the South East, 2005–2014.<sup>6</sup>**



However, 50% 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 addiction treatment services in the South East has also increased. In 2013/14, 86% of eligible clients received a hepatitis C test (10,055 tests), a rise from 64% in 2010/11.<sup>19</sup> This was higher than the level of testing in England (80%), but varied considerably by LA, with two LAs testing less than 80% of eligible clients (Figure 18)

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



## Testing in prisons

Only a small proportion of prisoners are reported as being tested for hepatitis C in the South East in 2013 (7.3%) (Table 3), compared to 7.9% in England.<sup>20</sup> Only HMP Downview, HMP Coldingley, HMP/YOI East Sutton Park, HMP/YOI Rochester HMP reported testing more than 20% 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>21</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.

New national indicators, Health and Justice Indicators of Performance (HJIPs), have recently 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.

Opt-out testing for blood-borne viruses in prisons was published as a joint developmental priority in the National Partnership Agreement between Public Health England, NHS England and National Offender Management Service (NOMS) in October 2013. The lessons learned from the experience of 11 pathfinder prisons has been reported in a preliminary evaluation.<sup>22</sup> Preliminary data suggests a near doubling of BBV testing following the introduction of the opt-out testing policy.

**Table 3: Hepatitis C testing in prisons in the South East, NHS Trust Development Authority, Prison Health Reporting System, 2013<sup>20</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
Buckinghamshire	Aylesbury (HM/YOI)	387	1	0%
Kent	Blantyre House (HMP)	87	0	0%
Surrey	Bronzefield (HMP)	1,883	306	16%
Oxfordshire	Bullingdon (HMP)	3,596	188	5%
Surrey	Coldingley (HMP)	286	104	36%
Kent	Cookham Wood (HMP)	339	0	0%
Surrey	Downview (HMP)	162	56	35%
Kent	East Sutton Park (HMP/YOI)	111	73	66%
Kent	Elmley (HMP/YOI)	3,666	176	5%
West Sussex	Ford (HMP)	767	54	7%
Buckinghamshire	Grendon (HMP)	89	8	9%
Surrey	High Down (HMP)	3,679	64	2%
Oxfordshire	Huntercombe (HMYOI)	645	59	9%
Isle of Wight	Isle of Wight (HMP)	1,473	44	3%
East Sussex	Lewes (HMP/YOI)	2,585	211	8%
Kent	Maidstone (HMP)	493	91	18%
Reading	Reading (HMP/YOI)	626	73	12%
Kent	Rochester (HMP/YOI)	1,014	263	26%
Surrey	Send (HMP)	230	52	23%
Buckinghamshire	Spring Hill (HMP)	438	5	1%
Kent	Standford Hill (HMP)	560	29	5%
Kent	Swaleside (HMP)	444	50	11%
Hampshire	Winchester (HMP)	3,466	64	2%
<b>South East</b>		<b>27,026</b>	<b>1,971</b>	<b>7.3%</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.

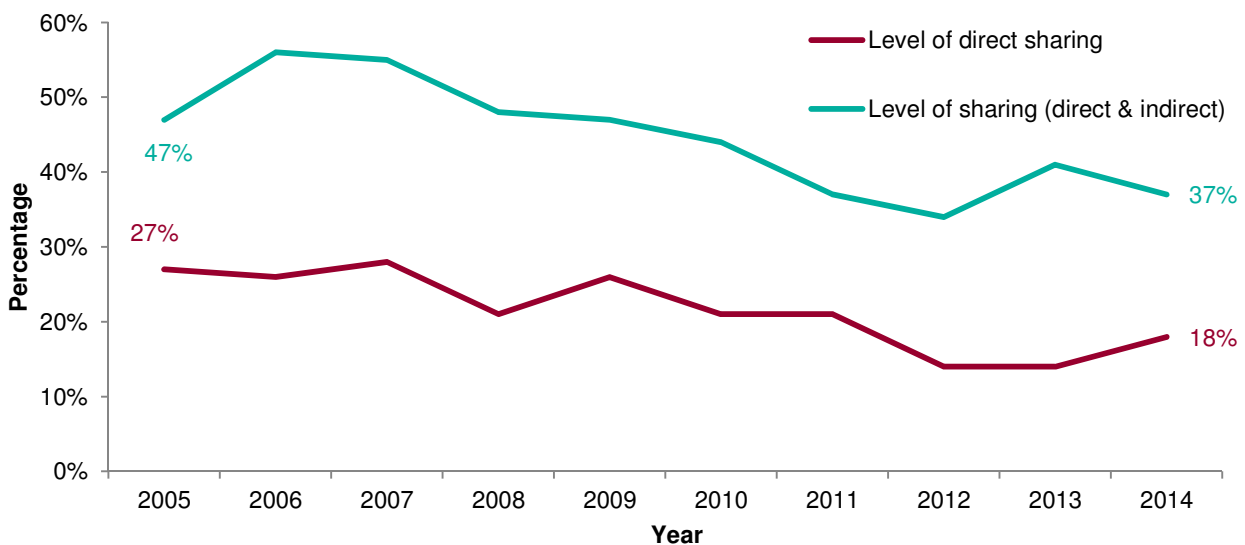
Reducing the number of individuals who begin injecting drugs; encouraging injectors to quit injecting; reducing risky behaviour (eg sharing needles and syringes) in those who continue to inject; and the early diagnosis and treatment of those who become infected with hepatitis C are all components of 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 18% reporting direct sharing and 37% reporting both direct and indirect sharing in 2014 (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 the South East, 2005–2014<sup>6</sup>**



In England, indirect measures of need and syringe programmes (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<sup>2</sup>. 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.<sup>21</sup> In addition, the majority (81%, 17/21) of the prisons reported having disinfectant tablets available. 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>23-31</sup> 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 (NHSE) 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<sup>32</sup>. 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.<sup>33</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*.

Statistical modelling suggests that increased uptake and new therapies are both needed to avert rising hepatitis C-related end stage liver disease in England (ESLD). Preliminary results from further modelling suggest that extending new treatments, with their markedly improved rates of sustained virological response (SVR), to just 2,000 people in England per year with cirrhosis 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/HCC. However, without an increase in new treatments in those with moderate disease, reductions in



numbers of people with hepatitis C-related ESLD/HCC would not continue beyond 5 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.

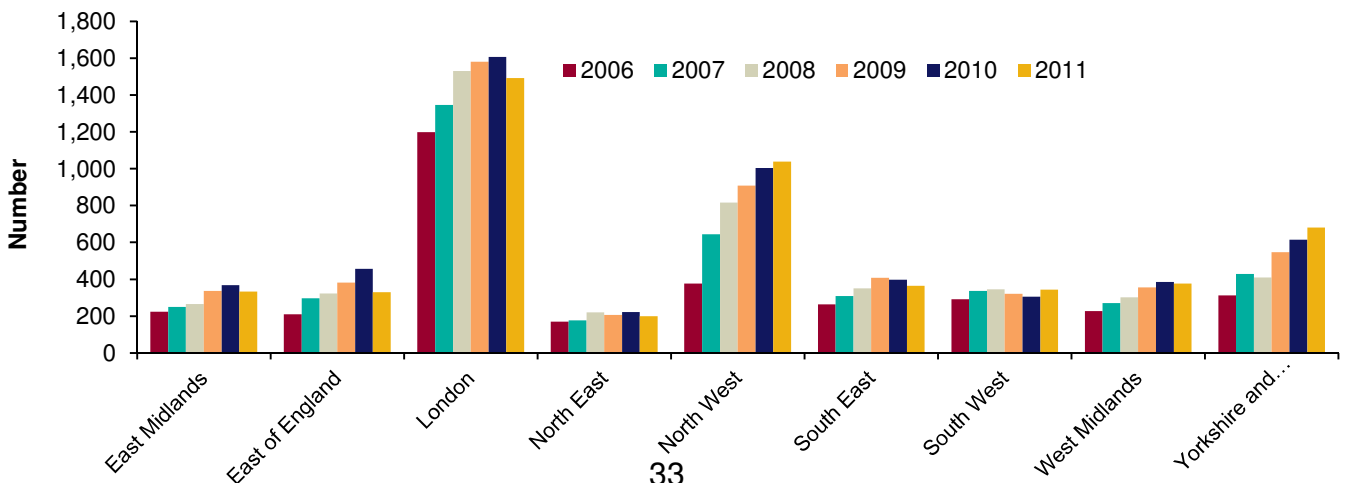
### Estimates of numbers receiving therapy for hepatitis C

Currently, there are no national surveillance systems to monitor referral, uptake or response to treatment. PHE has 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 20).<sup>34</sup> 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 the South East. Up until 2009, the trend was for an increase in the numbers of hepatitis C positive patients receiving treatment in the South East. In 2011, 365 individuals were treated (Figure 20).

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

**Figure 20: Estimated numbers of HCV-positive patients receiving combined therapy based on national supply of pegylated interferon by region, 2006–2011<sup>34</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

Overall across the UK, data suggest 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.<sup>2, 6</sup>

## 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 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 65% (15/23) of prisons in the South East have a written pathway in place to describe what happens following a positive result.<sup>35</sup> All the prisons that responded indicated that they use venous blood to test for hepatitis C, and three prisons indicated dried blood spot to test for hepatitis C. In only 26% (6/23) of the prisons does the laboratory automatically test by PCR.

Over half of the prisons in the South East (14/23, 61%) refer to hospital outpatients for treatment, with others using an 'in reach' service provided by the hospital (11/23, 48%) or in prison by a prison doctor (4/23, 17%). All the prisons indicated that they provide referral for those leaving prison who are hepatitis C positive if these prisoners are moving to another prison.

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>21</sup> Recommendations from the audit included that prisons should ensure in-house treatment of hepatitis C is available and laboratories should automatically undertake PCR testing of all positive hepatitis C antibody tests

# Acknowledgements

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

- Lukasz Cieply & Koye Balogum, PHE (Laboratory reports)
- Lukasz Cieply & Sam Lattimore, PHE (Sentinel Surveillance of Blood-borne Virus Testing & oral fluid testing data provided by Concateno Plc.)
- Vivian Hope and Katelyn Cullen, PHE (Data from Unlinked Anonymous Monitoring Survey of HIV and Hepatitis in PWID)
- 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)
- Anastella Costella, Philip Keel (Admissions, Deaths, Transplants)
- Kevin Shelton, Jonathan Alderson (Drug services hepatitis C testing data)

## Public Health England South East

- Rachel Cloke

## Public Health England Field Epidemiology Services (FES)

- Rehman Teagle, Sophie Newitt, Obaghe Edeghere (compilation of the PHE Centre template report & collated each PHE Centre's data)
- Piers Mook

## NHS Trust Development Authority

- John Hastings (Prison hepatitis C testing data)

## The Office for National Statistics

- We would like to thank 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)

- 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 three participating centres in the South East — Portsmouth, Brighton, and Ashford.

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 1 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](mailto: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](mailto: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 they are unlikely to robustly represent the true rate of laboratory reports in each local authority.

Where possible, data are 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 laboratory.

In 28% of reports, the data were 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 the South East, 2014<sup>5</sup>**

Local authority	No. of laboratory reports	Directly standardised rate (DSR) per 100,000 population*		
		DSR	95% lower confidence interval	95% upper confidence interval
Bracknell Forest	7	5.9	2.4	12.2
Brighton and Hove	228	78.3	68.1	89.5
Buckinghamshire	77	15.0	11.8	18.8
East Sussex	98	20.6	16.6	25.2
Hampshire	100	7.9	6.4	9.6
Isle of Wight	9	6.5	2.9	12.5
Kent	160	11.2	9.5	13.1
Medway	30	11.1	7.5	15.9
Oxfordshire	137	20.4	17.1	24.2
Portsmouth	55	27.9	20.8	36.5
Reading	21	11.9	7.2	18.4
Slough	39	26.7	18.6	36.9
Southampton	34	14.5	9.9	20.3
Surrey	193	16.2	13.9	18.8
West Berkshire	15	10.0	5.5	16.5
West Sussex	94	11.8	9.5	14.5
Windsor and Maidenhead	12	8.7	4.5	15.2
Wokingham	8	5.0	2.1	9.8
<b>Total</b>	<b>1,317</b>	<b>15.6</b>	<b>14.8</b>	<b>16.5</b>

\*DSRs per 100,000 population have been calculated using mid-year population estimates supplied by the Office for National Statistics

## Appendix 2

**Table A2: Estimates of hepatitis C prevalence, burden, treatment and cost of treatment by drug action team (DAT) in the South East <sup>10</sup> (please see notes on p41 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 additional number of annual new diagnoses requiring treatment
		Mild/moderate	Cirrhotic/ESLD/HCC	Died	SVR*		
Bracknell Forest	181	85	8	21	12	48	9
Brighton and Hove	1,014	476	43	115	66	271	49
Buckinghamshire	966	453	41	110	63	258	47
East Sussex	1,275	598	54	145	83	340	62
Hampshire	2,192	1,029	92	250	142	585	106
Isle of Wight	326	153	14	37	21	87	16
Kent	2,843	1,334	120	324	184	759	137
Medway	808	379	34	92	52	216	39
Oxfordshire	1,352	634	57	154	88	361	65
Portsmouth	653	306	27	74	42	174	32
Reading	665	312	28	76	43	178	32
Slough	672	315	28	77	44	179	32
Southampton	606	285	26	69	39	162	29
Surrey	1,859	872	78	212	121	496	90
West Berkshire	300	141	13	34	19	80	15
West Sussex	1,288	604	54	147	84	344	62
Windsor & Maidenhead	280	131	12	32	18	75	14
Wokingham	254	119	11	29	16	68	12
<b>South East</b>	<b>17,537</b>	<b>8,228</b>	<b>738</b>	<b>1,997</b>	<b>1,137</b>	<b>4,679</b>	<b>847</b>



*\*SVR=sustained virological response*

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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