



Public Health  
England

Protecting and improving the nation's health

# Hepatitis C in the South East

## 2015 data

Field Epidemiology Service South East and London

July 2017

# About Public Health England

Public Health England exists to protect and improve the nation's health and wellbeing, and reduce health inequalities. We do this through world-class science, knowledge and intelligence, advocacy, partnerships and the delivery of specialist public health services. We are an executive agency of the Department of Health, and are a distinct delivery organisation with operational autonomy to advise and support government, local authorities and the NHS in a professionally independent manner.

Public Health England  
Wellington House  
133-155 Waterloo Road  
London SE1 8UG  
Tel: 020 7654 8000  
[www.gov.uk/phe](http://www.gov.uk/phe)  
Twitter: @PHE\_uk  
Facebook: [www.facebook.com/PublicHealthEngland](http://www.facebook.com/PublicHealthEngland)

Prepared by Nastassya Chandra and Charlotte Anderson, PHE Field Epidemiology Services, National Infection Service. For queries relating to this document, please contact: [fes.seal@phe.gov.uk](mailto:fes.seal@phe.gov.uk)

© Crown copyright 2017

You may re-use this information (excluding logos) free of charge in any format or medium, under the terms of the Open Government Licence v3.0. To view this licence, visit [OGI](http://www.nationalarchives.gov.uk/ogl/) or email: [psi@nationalarchives.gsi.gov.uk](mailto:psi@nationalarchives.gsi.gov.uk). Where we have identified any third party copyright information you will need to obtain permission from the copyright holders concerned. Any enquiries regarding this publication should be sent to: [fes.seal@phe.gov.uk](mailto:fes.seal@phe.gov.uk)

Published: September 2017  
PHE publications  
gateway number: 2017332

PHE supports the UN  
Sustainable Development Goals



# Contents

About Public Health England	2
Notes on the report	4
Executive summary	5
Key points	7
Public Health recommendations for the South East	8
1. Epidemiology and risk factors	10
Background	10
Risk factors for hepatitis C	10
Estimates of the number of people infected with hepatitis C	15
2. Reducing morbidity and mortality	17
Hospital admissions for hepatitis C	17
Transplants	19
Deaths from hepatitis C	20
3. Reducing new infections	23
New reports of hepatitis C	23
Change in incidence of hepatitis C	24
4. Prevention and harm reduction	26
5. Raising awareness and increasing numbers tested	28
Trends in testing	29
Site of testing	30
People who inject drugs	31
Testing in prisons	32
6. Treatment of individuals with hepatitis C	35
Care pathways	37
People who inject drugs	37
Prisons	37
Discussion	39
Acknowledgements	40
Data sources	42
About Field Epidemiology Services	43
Appendix 1	44
Appendix 2	46
References	48

# Notes on the report

## Intended audience

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

## Aim of report

This report describes the recent epidemiology of hepatitis C in the South East, providing an update on trends, identifying areas of high burden of disease, at risk population groups, and opportunities for interventions and prevention of future cases. The aim is to support focused action to eliminate hepatitis C as a major public health threat by 2030.

## Data sources

This report presents laboratory data and sentinel surveillance data collated by PHE's immunisation, hepatitis and blood safety department; data from the unlinked anonymous monitoring survey of HIV and hepatitis in people who inject drugs managed by PHE's HIV and STI department; drug treatment service data provided by PHE's Alcohol and Drugs team; hospital admission data from hospital episode statistics dataset; mortality data from the Office for National statistics and transplant data from the NHS blood and transplant UK transplant registry.

## Other data displays

The national report presenting recent epidemiology of hepatitis C in England is available at:

[www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/599738/hepatitis\\_c\\_in\\_england\\_2017\\_report.pdf](http://www.gov.uk/government/uploads/system/uploads/attachment_data/file/599738/hepatitis_c_in_england_2017_report.pdf)

Additional infographics and slide sets are available at:

[www.gov.uk/government/publications/hepatitis-c-in-the-uk](http://www.gov.uk/government/publications/hepatitis-c-in-the-uk)

Data tables of the Unlinked Anonymous Monitoring Survey of HIV and Hepatitis in People Who Inject Drugs available at:

[www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/537598/UAM\\_Survey\\_of\\_PWID\\_2016\\_data\\_tables\\_with\\_2015\\_data\\_FINAL.pdf](http://www.gov.uk/government/uploads/system/uploads/attachment_data/file/537598/UAM_Survey_of_PWID_2016_data_tables_with_2015_data_FINAL.pdf)

Public Health England Liver Disease Profiles available at: [fingertips.phe.org.uk/profile/liver-disease/data#page/0/gid/8000063/pat/6/par/E12000008/ati/102/are/E06000036/iid/90879/age/163/sex/4](http://fingertips.phe.org.uk/profile/liver-disease/data#page/0/gid/8000063/pat/6/par/E12000008/ati/102/are/E06000036/iid/90879/age/163/sex/4)

## Executive summary

Hepatitis C is a bloodborne virus, transmitted when blood from an infected person gets into the blood of another person. Many people infected with Hepatitis C are asymptomatic and unaware they have been infected. The majority of infected individuals are unable to clear hepatitis C naturally, and without successful treatment, chronic infection can span several decades. Persistent infection can lead to end stage liver disease (ESLD) and hepatocellular carcinoma (HCC).

The four key areas of action in order to eliminate hepatitis C as a major public health threat are 1) To reduce the numbers becoming seriously ill or dying from this infection; 2) To reduce the number of people becoming newly or re-infected. Key to both of these are 3) Access to testing and good provision of needle exchange schemes which results in action to reduce the risk of infection and prevent further transmission and 4) Access to treatment of the infection.

An estimated 17,500 people in the South East have been infected with hepatitis C (they are hepatitis C antibody positive) of whom an estimated 69% have not cleared the infection.

There were 1,290 new laboratory reports of confirmed hepatitis C diagnoses in the South East in 2015, a 3-fold increase since 2008 but a decrease of 4% since 2014. This overall rise may reflect improvements in reporting (laboratory reporting became a statutory requirement in 2010) as opposed to an increase in underlying detection of infections.

In 2015, 1,162 people in the South East were admitted to hospital with a diagnosis of hepatitis C, an increase of 34% since 2008. If left unresolved, hepatitis C infection can 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 later complications of the infection. From 2008 to 2015, hospital admissions from hepatitis C related ESLD in the South East increased by 46% and admissions related to HCC increased by 61%. Hepatitis C was the primary indication for just under a fifth of liver transplants in the South East between 2008 and 2015.

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.

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%). Additionally, in the past 10 years, unprotected sexual contact between men who have sex with men (MSM) have also emerged as an important route of transmission, while individuals originating from South Asia, where the prevalence of hepatitis C is high, are also at increased 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). The greatest proportion of individuals testing positive for anti-HCV are males (75%) with the peak age group being 35 to 54 years.

Raising awareness, leading to increased – and where appropriate repeat – testing (e.g. for those with continued risk factors, such as the use of illicit drugs), is important to identify undiagnosed cases. 56% of PWID are reported as unaware of their infection. 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 has remained steady since 2013/2014 at 86%. Although there is marked variation by local authority.

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 be supported to apply harm reduction techniques. There is evidence that a significant proportion of PWID continue to share injecting equipment (34% indirect and direct sharing). Therefore, reducing the number of infections in this population is needed to prevent new infections occurring.

Globally, less than 1% of people with chronic hepatitis infection are receiving treatment. The Global Health Sector Strategy (GHSS) on viral hepatitis calls for three million people with chronic HCV to have been treated by 2020 and by 2030 treatment coverage to reach 80% of the eligible population. It is vital that those found to be chronically infected are referred appropriately. Treatment can be effective at clearing the virus and the increasing availability of new direct acting antiviral (DAA) drugs offers a fast and effective cure to the vast majority of patients. Without many of the complications associated with previous treatments.

NHS England is responsible for commissioning and funding access to these drugs, via Operational Delivery Networks. It will be important to monitor the equity of access to treatment and care services among individuals with hepatitis C infection in the South East. While reductions in hepatitis C-related morbidity and mortality should be possible, reducing the number of new infections among those most at risk is likely to prove more challenging. Tackling hepatitis C infection among PWID is key to achieving this.

## Key points

To eliminate hepatitis C as a major public health threat there are two key areas to focus on:

- 1) To reduce the numbers becoming seriously ill or dying from this infection
- 2) To reduce the number of people becoming newly or re-infected

Public Health recommendations for the South East include:

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

# Public Health recommendations for the South East<sup>5</sup>

## Making improvements and monitoring metrics:

- consideration should be given by local authorities to include HCV in health and wellbeing board joint strategic needs assessments and subsequent commissioning strategies
- steps should be taken to improve data quality. For example, ensure patient postcode or registered GP practice is recorded for all tests

## Adequate harm reduction/prevention:

- commissioners of bloodborne virus prevention services for people who inject drugs need to sustain or expand, as appropriate, the current broad range of provision (including opioid substitution treatment (OST), needle and syringe programmes (NSP), and patient information) to reduce transmission of hepatitis C. Including among people who inject new psychoactive substances or image and performance-enhancing drugs
- consideration should be given to mapping and monitoring NSP activity
- harm minimisation policies in secure and detained settings should be maintained, including the provision of disinfectant/decontamination equipment for sharps
- further testing of treatment as prevention, and its potential to reduce the number of new HCV infections in people who inject drugs, is required in order to guide policy and clinical practice

## Increasing the numbers and proportion diagnosed:

- initiatives should be considered to further raise awareness of HCV among professionals working in primary care and other settings, like drug services, to help reduce the number who remain undiagnosed. For example, by encouraging participation in e-learning (where appropriate) to improve the offer and uptake of HCV testing in risk groups. Guidelines are available to help raise awareness of, and testing for, hepatitis C infection to ensure that people at increased risk of hepatitis C are tested
- produce appropriate communications, like reporting and infographics, to help mark World Hepatitis Day
- testing needs to be sustained or enhanced, as appropriate, among those attending drug services. The use of newer technologies, like dried blood spot testing, that make testing easier in non-clinical settings, should be further expanded



- opportunities for bloodborne virus opt-out testing among high risk groups, such as new receptions to prisons, should be fully implemented and monitored to improve testing uptake, and consideration should be given to opt-out testing in drug services
- promote and offer testing to groups who are not in regular contact with health services who may have acquired hepatitis C many years previously, some of whom may have advanced asymptomatic disease (for example, those who acquired their infection via past injecting drug use, medical/dental treatment abroad in countries where poor blood screening/infection control practices exist, or via transfusion in the UK prior to September 1991)
- wherever possible, ribonucleic acid amplification (RNA) tests should be performed on the same sample as the original antibody assay as this decreases the turnaround time for referral, benefits patient care and increases cost effectiveness; consideration should also be given to including patient referral instructions on the laboratory report
- British HIV Association (BHIVA) guidelines 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, their partners, and all those with abnormal liver function tests

### Increasing the numbers accessing hepatitis C treatment:

- those responsible for commissioning hepatitis C treatment and care services should continue to work with public health agencies, clinicians and other stakeholders to simplify referral pathways; improve the availability, access and uptake of approved hepatitis C treatments in primary and secondary care, drug treatment services, prisons and other settings; and to drive innovative approaches to outreach and patient support. It will be important to consider those individuals who have been diagnosed but subsequently lost to follow-up, as well as those who are newly diagnosed or already engaged with treatment services
- those achieving a sustained viral response following treatment, should be provided with appropriate information and support to help prevent reinfection
- continued monitoring should take place to inform equity of access to HCV care and treatment pathways for all prisoners and immigration detainees

# 1. Epidemiology and risk factors

## Background

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).

Hepatitis C remains a major public health problem, with an estimated 214,000 adults living with chronic infection in the UK<sup>6</sup>. The Public Health England (PHE) reports Hepatitis C in the UK, 2015 and Hepatitis C in England 2017 provide a comprehensive review of the epidemiology of hepatitis C<sup>5,7</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>8</sup>.

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. Information from various sources can be used to build up a picture of hepatitis C epidemiology in the South East. These include laboratory reports, sentinel surveillance data, drug treatment services data, hospital episode statistics, mortality data, transplant data and data from the unlinked anonymous monitoring survey of HIV and hepatitis in people who inject drugs.

## 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 ten diagnoses of hepatitis C in England<sup>7</sup> (Table 2). However, for the vast majority of people this information is not available. Therefore, this figure may not be representative of all those testing positive.

**Table 1: Risk groups for hepatitis C<sup>9</sup>**

People who have ever injected drugs.

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

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

Babies born to mothers infected with hepatitis C.

Prisoners, including young offenders.

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

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

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>10</sup>** Total number of reports may differ due to cases having more than one risk factor.

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. PHE's Unlinked Anonymous Monitoring Survey of PWID (more information in data sources) measures changing prevalence of hepatitis C in current and former PWID<sup>11</sup>. In the South East, this survey estimated the prevalence of hepatitis in PWID to be 58% in 2015, 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, but may be due to other reasons such as sexual practice. Of the prisons that were included in sentinel surveillance, 15.6% of those tested from 2011 to 2015 were antibody positive<sup>1</sup>.

## Men who have sex with men (MSM)

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>12</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 MSM 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, their partners and all those with abnormal liver function tests.

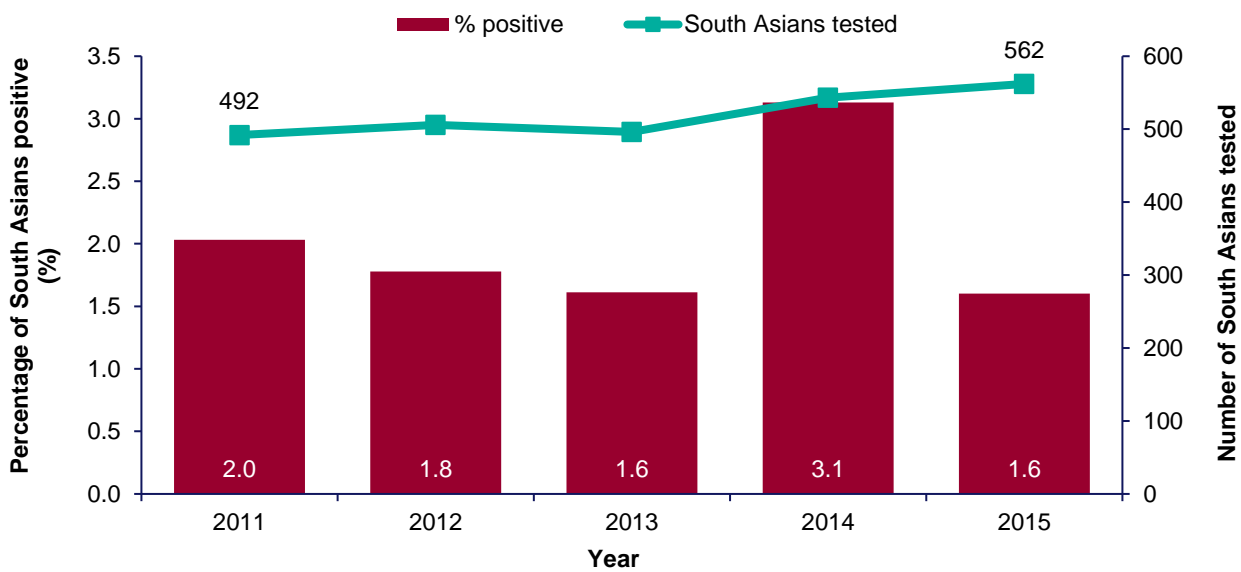
## Ethnicity

In total, 24 laboratories in England participate in the Sentinel Surveillance of Hepatitis Testing Study, including three laboratories in the South East (Ashford, Brighton and Portsmouth). These laboratories collect more detailed information about hepatitis C testing (more information in data sources)<sup>1</sup>.

This data suggests that the proportion of those tested that are positive for hepatitis C varies by ethnicity. Overall in the South East in 2015, White and Asian ethnic groups were equally more likely to test positive (1.5%) than Black ethnic groups (0.7%) and

Other/mixed ethnic groups (1.0%). Different positivity levels may partly reflect different levels of injecting drug use in different ethnic groups<sup>1</sup>. The prevalence of hepatitis C in individuals originating from South Asia is higher than the general non-injecting population<sup>6</sup> (Figure 1). Specific research into raising awareness of hepatitis C infection in the South Asian community is ongoing in the South East. For example, Royal Surrey County and Frimley Park Hospitals in Surrey have developed community specific focus groups<sup>13</sup>.

**Figure 1: Number of South Asian individuals tested and proportion testing positive for anti-HCV in sentinel laboratories in the South East, 2011–2015<sup>1</sup>** NamPehchan software was used to identify individuals of South Asian origin because ethnicity is not routinely available from the participating laboratory information systems.

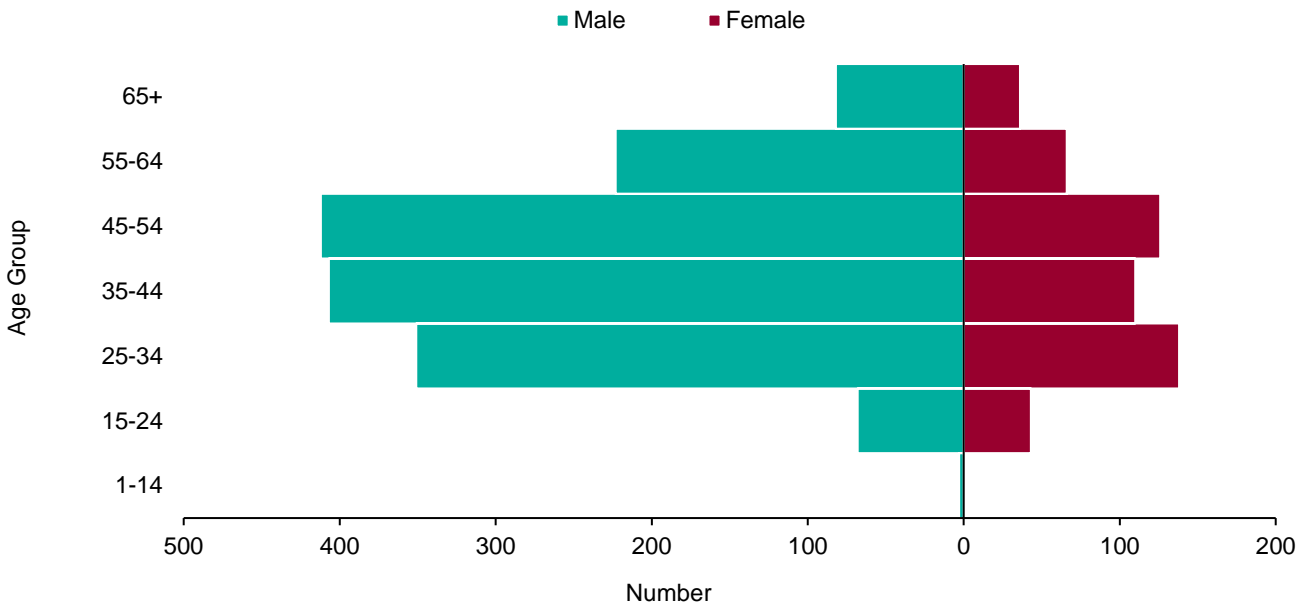


National data suggests that Eastern Europeans may also be at increased risk of hepatitis C. Over the period 2011-2015 in England, 5.0% of people of Eastern European origin tested positive<sup>1,5</sup>.

### Age and sex

Figure 2 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<sup>1</sup>.

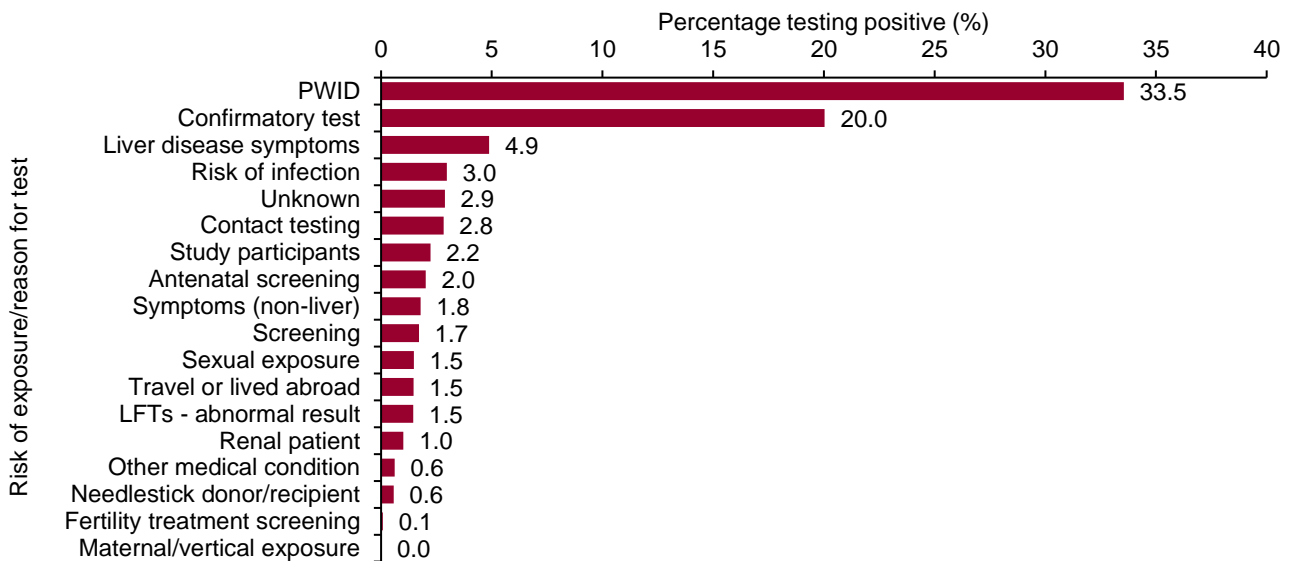
**Figure 2: Age-group and gender of individuals testing positive for anti-HCV in sentinel laboratories in the South East, 2015<sup>1</sup>**



**Other risk factors**

There is limited information for the reason for testing/risk of exposure among individuals who have tested and are positive for hepatitis C, because for 28% of all positive cases this information is missing. Where a reason was given, a third of those were tested because they were PWID. Other relatively high positivity rates were found in those tested because they had liver disease symptoms (4.9%) for antenatal care purposes (2.0%), because they travelled or lived abroad (1.5%), or due to sexual exposure (1.5%)<sup>1</sup> (Figure 3).

**Figure 3: Percentage of individuals testing positive for anti-HCV by risk/reason for test in sentinel laboratories in the South East, 2011-2015<sup>1</sup>** (LFT-liver function test)



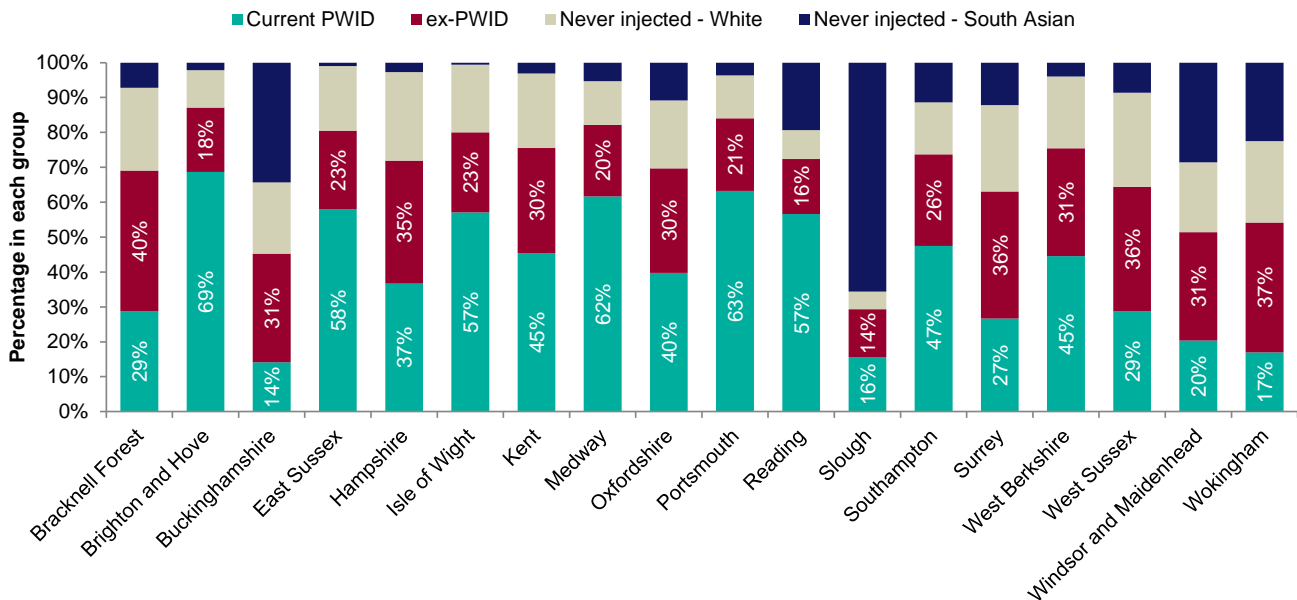
## Estimates of the number of people infected with hepatitis C

It is estimated that over 17,500 people have been infected with hepatitis C in the South East i.e. they are hepatitis C antibody positive (Appendix 1). Of these, an estimated 12,000 (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 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 the limitations with this modelling approach, outlined on page 45.

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%)<sup>14</sup>.

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)<sup>14</sup>. The corresponding figures for each LA are displayed in Figure 4.

**Figure 4: Estimates of the proportion of all people who have been infected with hepatitis C in each South East LA in each risk group<sup>14</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 upper tier local authority, the burden of disease and treatment needs. This model can be found in Appendix 1<sup>14-16</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.



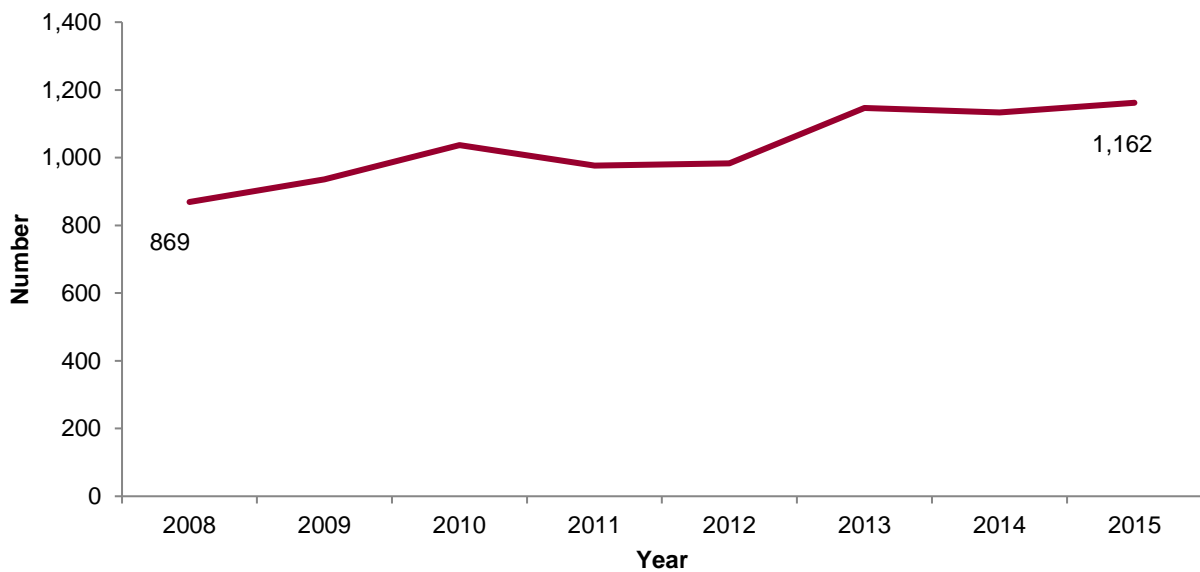
## 2. Reducing morbidity and mortality

### Hospital admissions for hepatitis C

Early data suggest that new cases of HCV related ESLD/HCC have remained relatively stable over the last five years, averaging around 1,700 per year between 2011 and 2015 in England.

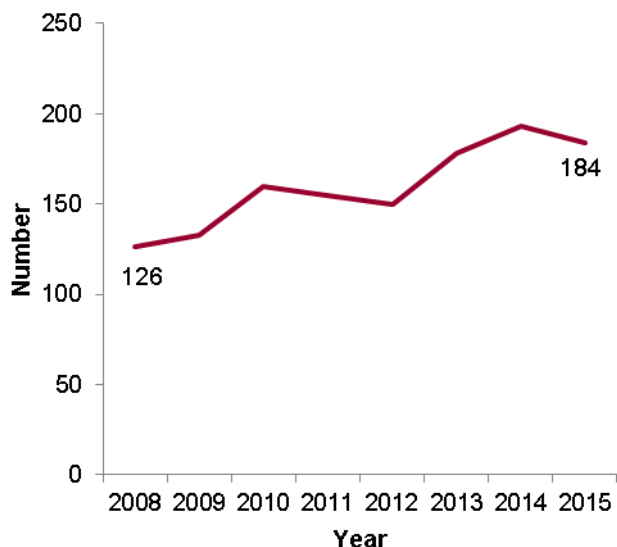
The number of admissions due to hepatitis C in the South East is increasing. Although it is likely that hospital episode statistics underestimate the true numbers of admissions from hepatitis C, in 2015, 1,162 residents from the South East were admitted to hospital with hepatitis C (Figure 5), a 34% increase since 2008<sup>2</sup>.

**Figure 5: Individuals resident in the South East admitted to hospital with a diagnosis of hepatitis C (2008–2015)<sup>2</sup> , \*\*\* see footnotes on next page for figures 6 and 7.**



Since 2008, increases have been seen in the number of people admitted due to hepatitis C related ESLD (184 in 2015, 46% increase since 2008) and HCC (82 in 2015, 61% increase since 2008). However, since 2014, there has been a slight decline in the admission rates (Figures 6 and 7)<sup>2</sup>.

**Figure 6: Individuals resident in the South East admitted to hospital with a diagnosis of HCV related ESLD, 2008–2015<sup>2</sup> \*, \*\*, \*\*\***



**Figure 7: Individuals resident in the South East admitted to hospital with a diagnosis of HCV related HCC, 2008–2015<sup>2</sup> \*, \*\*, \*\*\***



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 i.e. 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)).

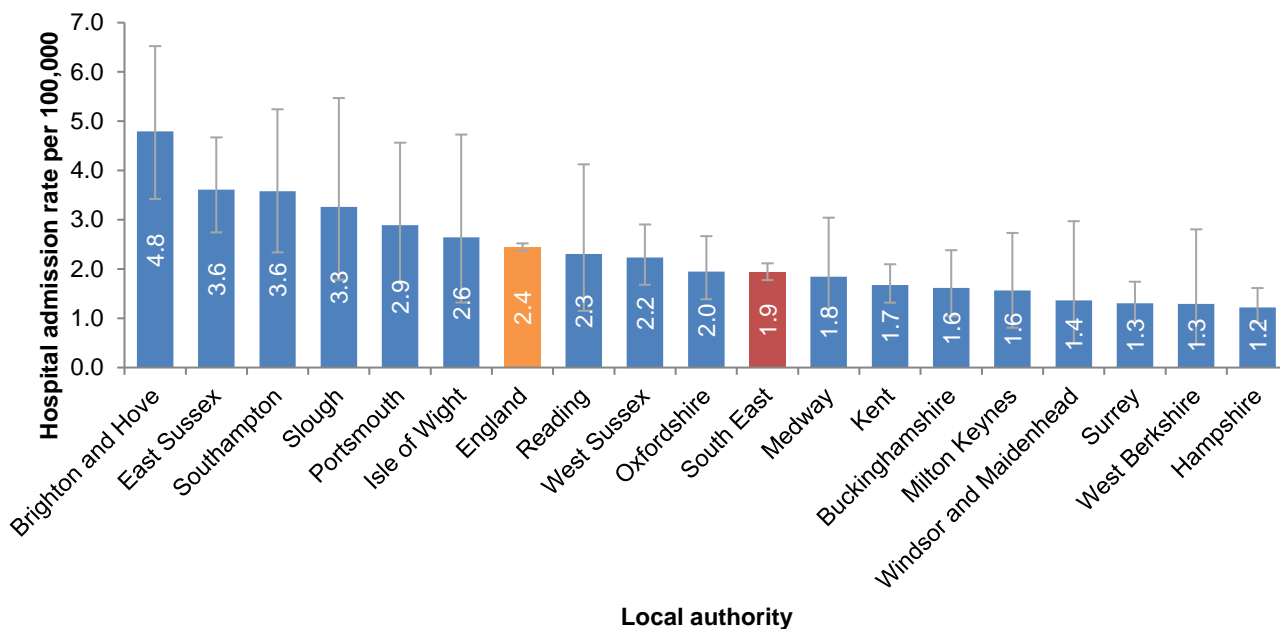
\*Patient counts are based on the unique patient identifier, HESID. This identifier is derived from a patient's date of birth, postcode, sex, local patient identifier and NHS number, using a standard algorithm. Where data are incomplete, HESID might wrongly link episodes or fail to recognise episodes 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). Only Brighton and Hove local authority had a rate significantly above the England rate<sup>3</sup> (Figure 8).

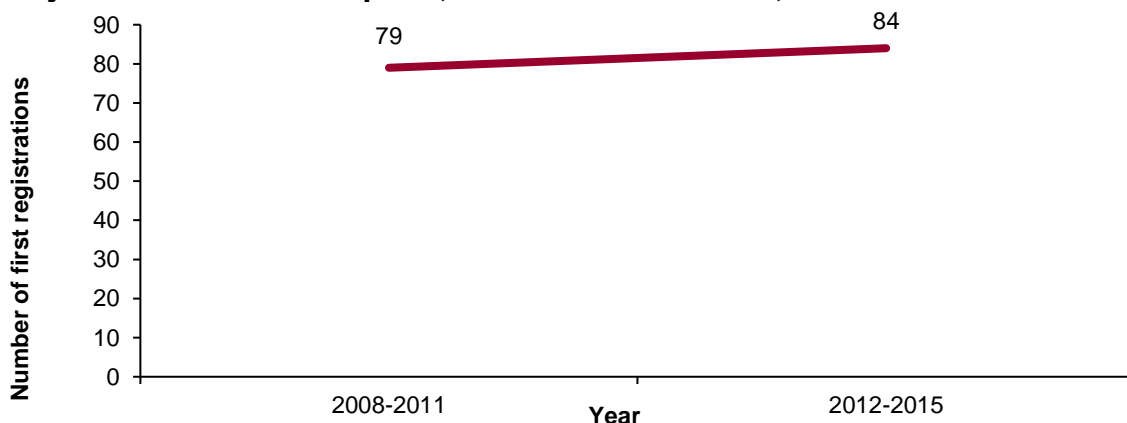
**Figure 8: Crude hospital admission rate for hepatitis C related end-stage liver disease and hepatocellular carcinoma, persons per 100,000 population by South East local authority, 2012/2013-2014/2015<sup>3</sup>.** Values for Bracknell Forest and Wokingham have been suppressed for disclosure control due to small count.



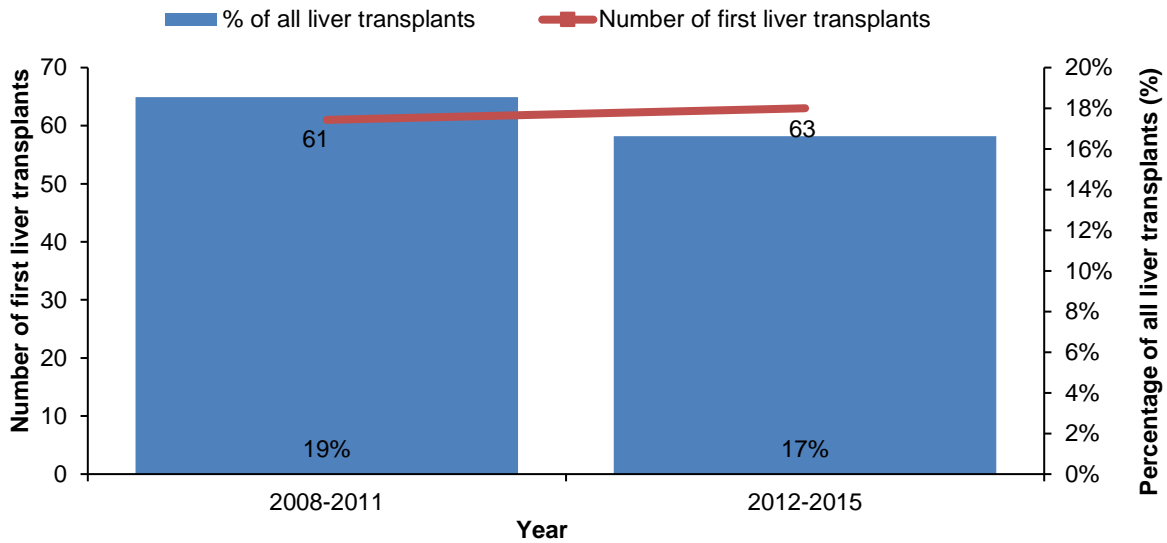
## Transplants

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 2012-2015 (n=84) was higher than levels reported in the previous four-year period<sup>4</sup> (Figure 9). A similar trend was seen for the number of first liver transplants with post-hepatitis C cirrhosis as a primary, secondary, or tertiary indication (Figure 10). These indications accounted for 18% of all liver transplants in residents in the South East during 2008–2015<sup>4</sup>.

**Figure 9\*:** First registrations with post-hepatitis C cirrhosis as primary, secondary or tertiary indication for transplant, South East residents, 2008-2015<sup>4</sup>



**Figure 10\*: 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,**



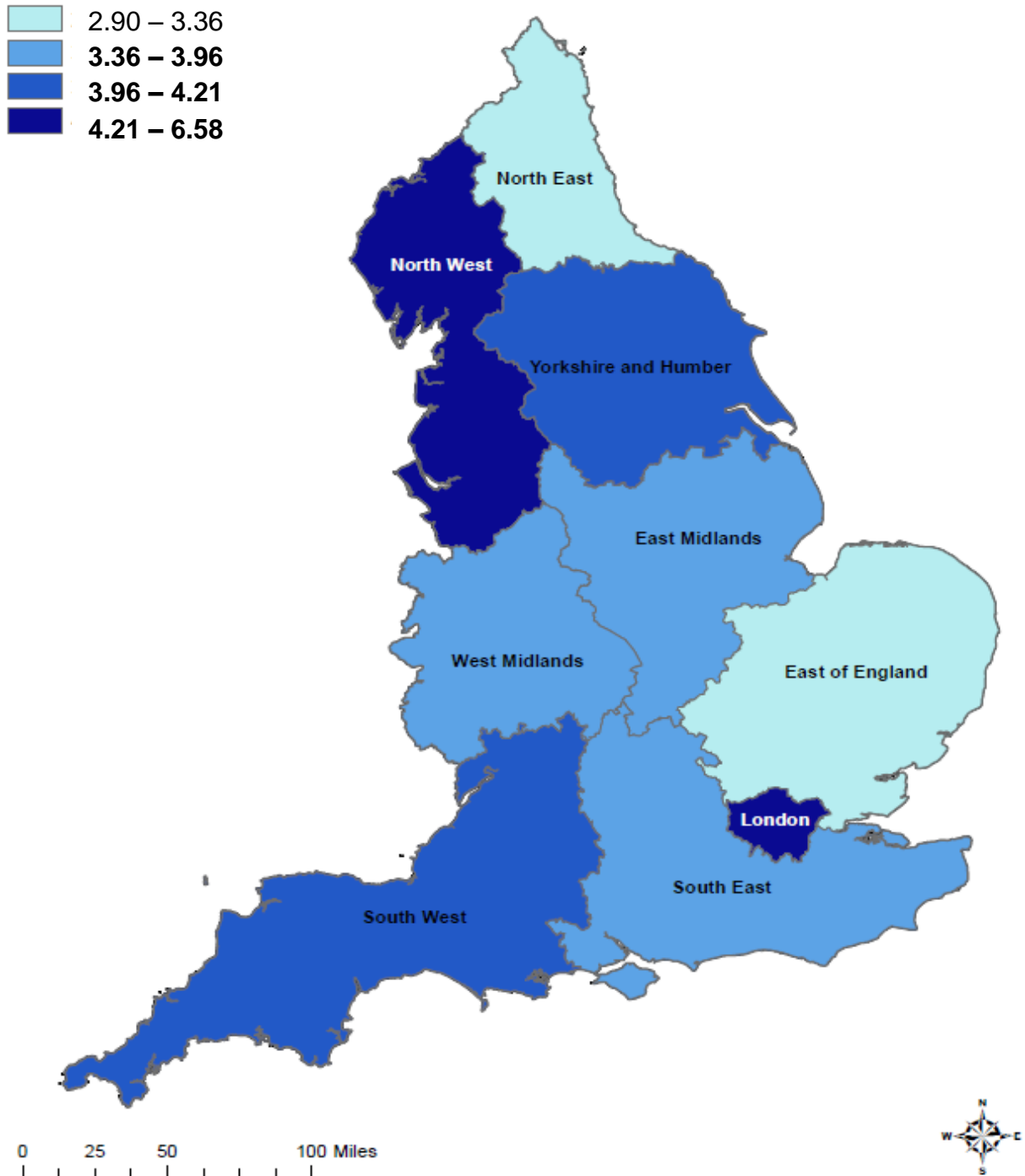
\* Figures 9 and 10 are based on registry data as at 23 June 2016 and include both elective and super urgent registrations. New national registration criteria for selecting adult patients for elective liver transplantation were introduced in September 2007: NHSTB. Liver Transplantation: Selection Criteria and Recipient Registration (June 2015). Available at: [www.odt.nhs.uk/transplantation/guidance-policies](http://www.odt.nhs.uk/transplantation/guidance-policies) (Accessed 19/06/2015).

## Deaths from hepatitis C

Between 2005 and 2014, deaths from HCV-related ESLD and HCC in England more than doubled. However, a fall of 8% was observed in 2015. It is possible that this fall was the result of increased access to new direct acting antiviral (DAA) drugs that were introduced from 2014/2015<sup>5</sup>.

In the South East, the death rate from ESLD or HCC in individuals with hepatitis C mentioned on their death certificate<sup>17</sup> is ranked in the middle to lower end compared to the rest of the PHE centres with a death rate between 3.36 and 3.96 per 100,000 (Figure 11).

**Figure 11: Map showing the rate of deaths from end-stage liver disease (ESLD) or hepatocellular carcinoma (HCC) in individuals with hepatitis C mentioned on their death certificate by PHE Centre, 2008-2015 per 100,000 population<sup>17</sup>**

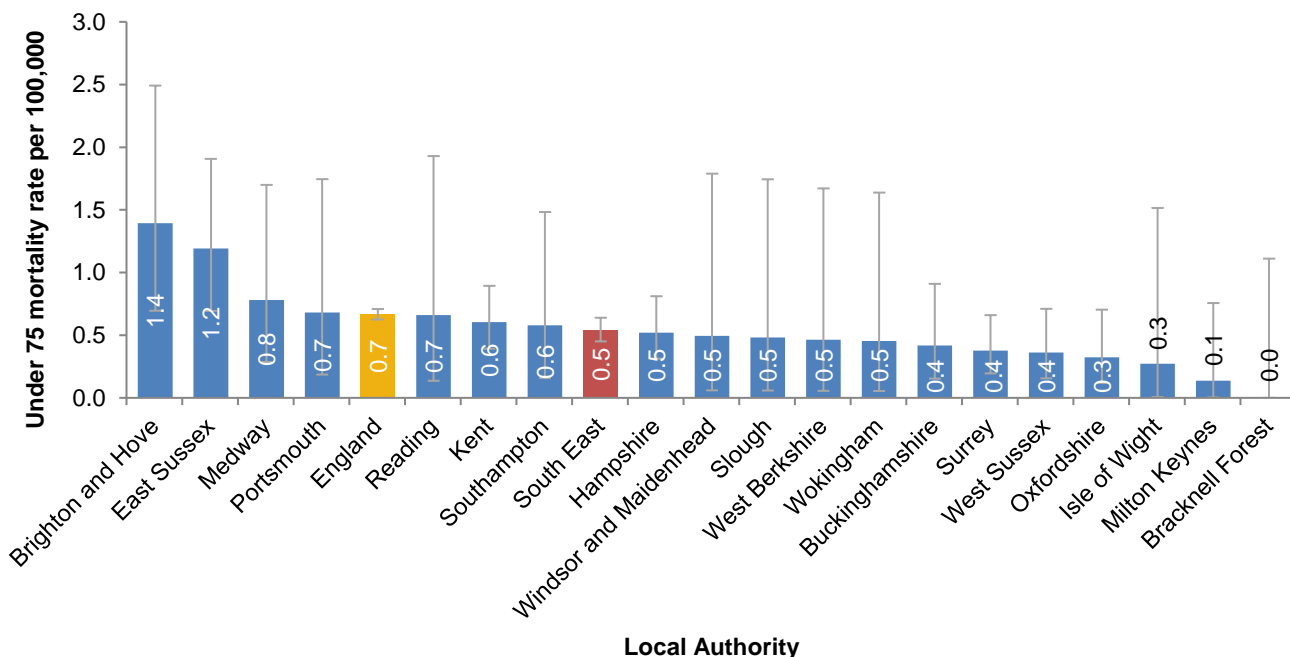


\* Defined by codes or text entries for ascites, bleeding oesophageal varices, hepato-renal encephalopathy or hepatic failure  
\*\* Based on 2015 mid year estimate population data.  
NB: There were 35 missing postcodes between 2008-2015 and a further 12 deaths were removed as patients' residence was outside of England.  
Data source: Office for National Statistics

Reproduced by permission of Ordnance Survey on behalf of Her Majesty's Stationery Office,  
© Crown Copyright and database right, 2017. All rights reserved.  
Ordnance Survey Licence number 100016969/10002432.

The under 75 crude mortality rate from hepatitis C related ESLD or HCC varies considerably across the South East, from 1.4 per 100,000 in Brighton and Hove to 0.0 per 100,000 in Bracknell Forest from 2013 to 2015<sup>3</sup> (Figure 12). Brighton and Hove, East Sussex and Medway had the highest rates, and were above the England rate<sup>3</sup>.

**Figure 12: 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, 2013-15<sup>3</sup>**



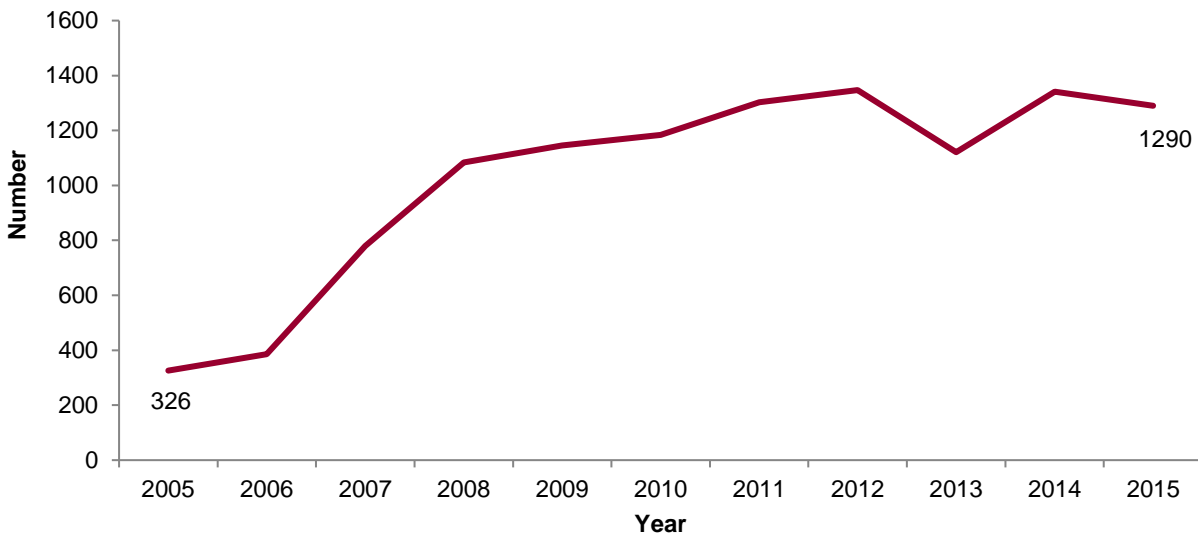
### 3. Reducing new infections

#### 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.

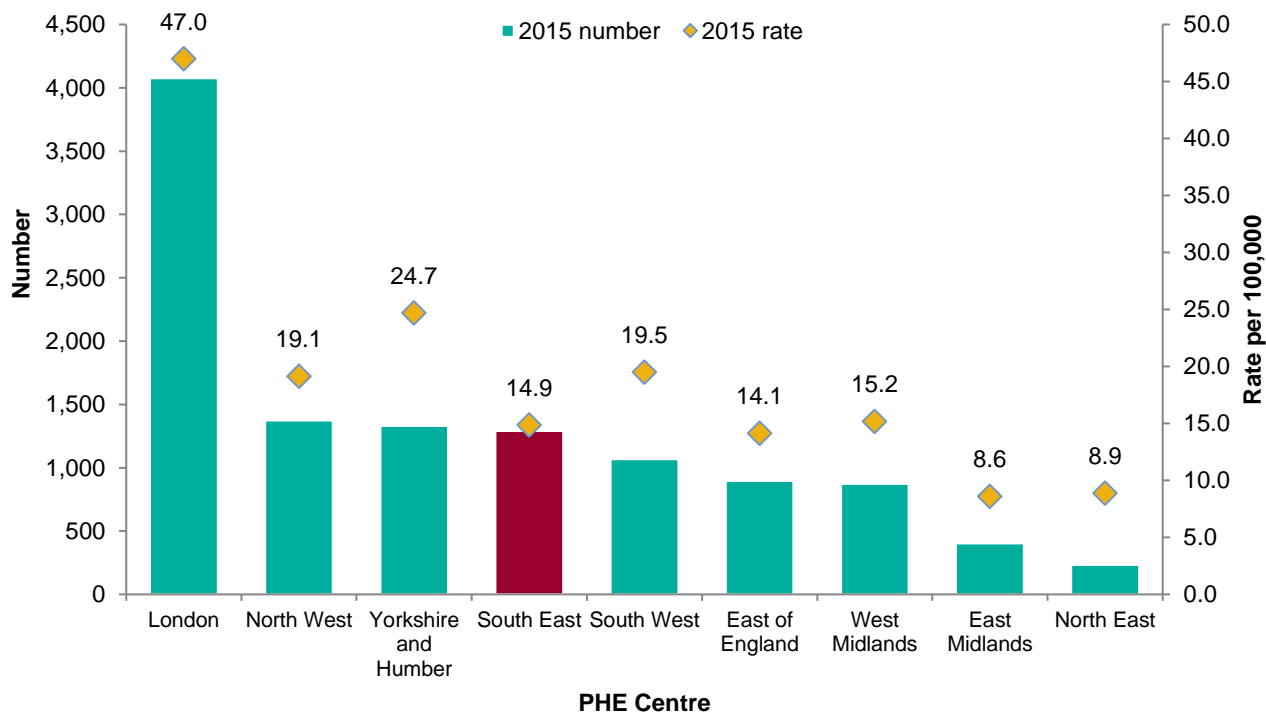
The number of laboratory confirmed diagnoses of hepatitis C in the South East has continued to rise steadily since 2008, with 1,290 confirmed diagnoses in 2015. Although there was a drop in the number of laboratory confirmed diagnosis of hepatitis C in 2013, the number of diagnoses in 2014 reached the same level as in 2012 (Figure 13). 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>10</sup>. The number and rate of laboratory reports in 2015 by local authority is presented in Appendix 2.

**Figure 13: Laboratory confirmed diagnoses of hepatitis C from laboratories in the South East, 2005–2015<sup>16</sup>** (increases are likely to reflect improved testing and reporting)



The South East accounts for over 11% of all hepatitis C diagnoses reported in England in 2015<sup>5</sup> (Figure 14). The number and rate of laboratory reports in 2015 by local authority is presented in Appendix 2<sup>16</sup>.

**Figure 14: Rate of laboratory confirmed diagnoses of hepatitis C per 100,000 residents, by PHE Centre, 2015<sup>16</sup>** Includes individuals with a positive test for hepatitis C antibody and/or detection of hepatitis C RNA



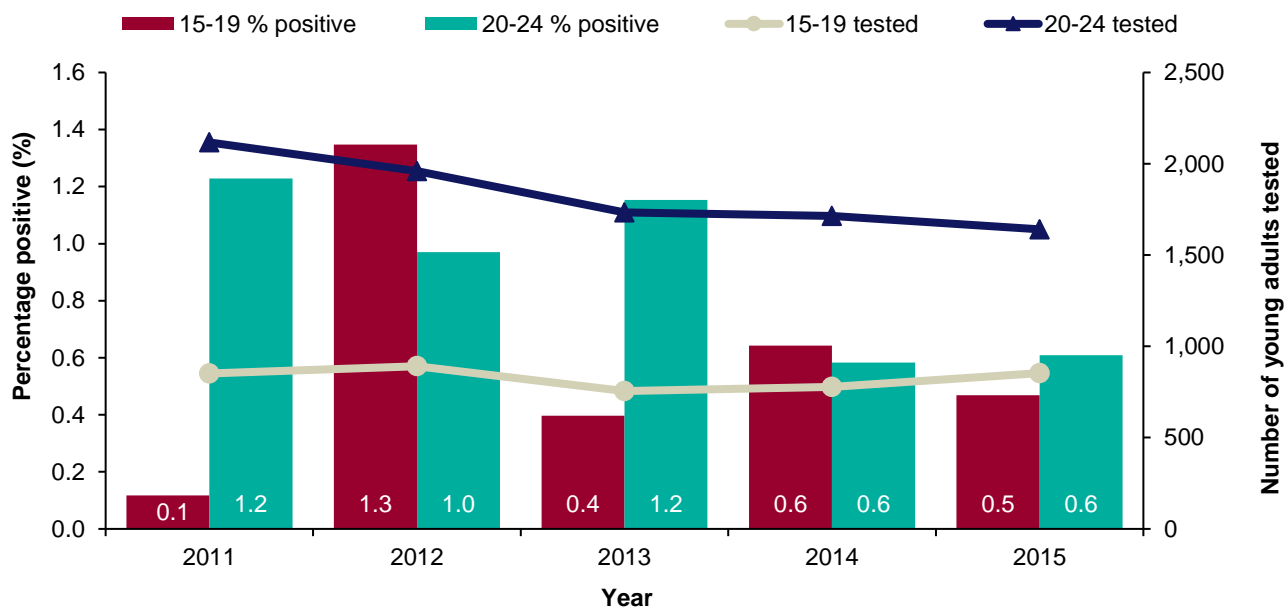
## Change in incidence of hepatitis C

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 the South East, the number of 15 to 19-year-olds tested for hepatitis C has remained relatively stable between 2011 and 2015, whereas there has been a slight decline in the number of 20 to 24 year-olds tested from 2,117 to 1,641. The proportion positive of 15 to 19 year olds has seen an overall decrease since a peak in 2012, from 1.3% to 0.5%. The proportion positive of 20 to 24 year olds has fluctuated between 2011 and 2015, but overall there has been a decline from 1.2% in 2011 to 0.6% in 2015<sup>1</sup> (Figure 15).



**Figure 15: Number of young adults tested and testing positive for anti-HCV in sentinel laboratories in the South East, 2011-2015<sup>1</sup>**



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>11</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 hepatitis C infections and likely trends in incidence over time. The estimated incidence of hepatitis C infection among PWIDs during 2015 was between 4 and 12 infections per 100 person years of exposure<sup>5</sup>.

## 4. 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.

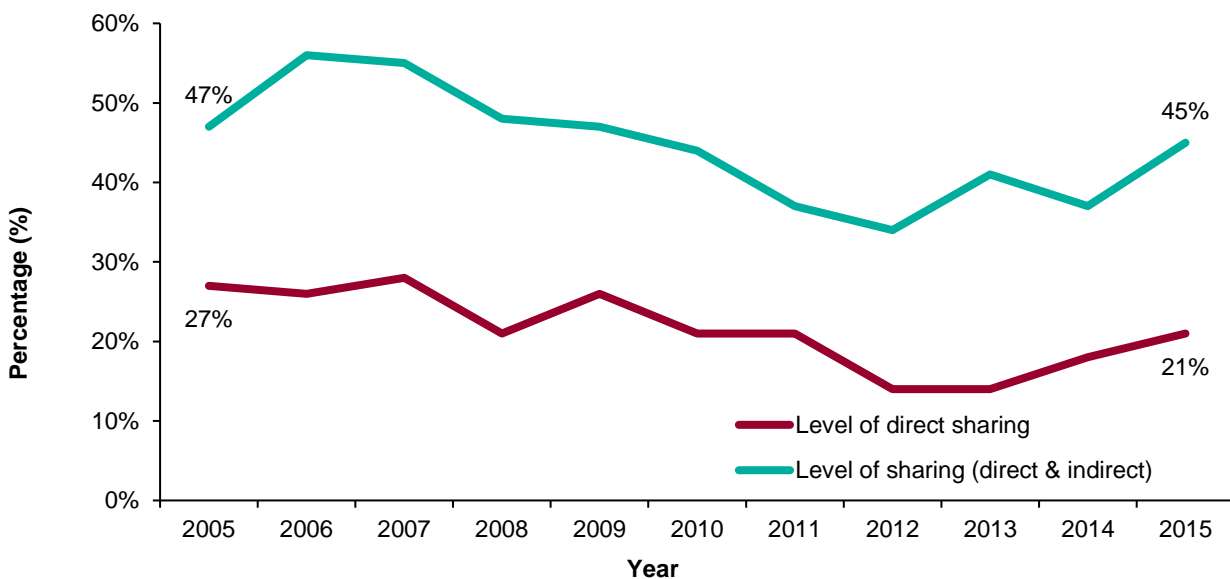
Reducing the number of individuals who begin injecting drugs; encouraging injectors to quit injecting; reducing risky behaviour (eg sharing needles and syringes) in those who continue to inject; and the early diagnosis and treatment of those who become infected with hepatitis C are all components of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

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

### People who inject drugs

Between 2005 and 2012 there was an overall decline in the proportions of PWID in the South East that reported sharing equipment, with 14% reporting direct sharing and 34% reporting both direct and indirect sharing in 2012. Since 2012, there has been an increase in this proportion, with 21% reporting direct sharing and 45% reporting both direct and indirect sharing<sup>11</sup> (Figure 16). 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 16: Level of direct and indirect sharing amongst PWID in the South East, 2005-2015<sup>11</sup>**



In 2015, in England, Wales and Northern Ireland 90% people who have ever injected drugs reported using needle and syringe programmes (NSP)<sup>18</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. The proportion of PWID reporting adequate needle/syringe provision was found to be suboptimal, with just less than one half (between 45% and 48% in 2011-2015) of those who had injected psychoactive drugs surveyed reporting adequate provision for their needs. Although levels of sharing of needles and syringes have declined from 28% in 2005 to 17% in 2015, there is no evidence of any fall over the last five years<sup>5</sup>.

## Prisoners

The audit of selected English prisons in 2013 revealed that almost two-thirds of those audited (62%, 13/21 prisons) had written hepatitis C documentation in place<sup>19</sup>. In addition, the majority (81%, 17/21) of the prisons reported having disinfectant tablets available. Disinfectant tablets are used to sterilise injecting equipment.

## 5. Raising awareness and increasing numbers tested

Hepatitis C is usually asymptomatic in the early years. Therefore, many individuals remain undiagnosed. The Hepatitis C Action Plan for England<sup>20</sup> 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 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>21</sup> and the UK population of South Asian origin (Hepatitis C. The more you know, the better)<sup>22</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: [hcvaction.org.uk/resource/film-detecting-managing-hepatitis-c-primary-care](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>7</sup>. To supplement this, a new RCGP course was launched in April 2015, 'Hepatitis C: Enhancing Prevention, Testing and Care' which comprises four lessons: understanding hepatitis C; preventing transmission; testing and diagnosis; and treatment and care<sup>a</sup>.

The National Institute for Health and Care Excellence (NICE) published its public health guidance Hepatitis B and C: ways to promote and offer testing to people at increased risk of infection in 2012<sup>9</sup>. This included a summary of available evidence and recommendations to a range of stakeholder organisations, which covered the following areas:

---

<sup>a</sup> This course was specifically developed in order to meet the learning needs of those working in drug services who may not have a clinical background, such as keyworkers and peer mentors. This course is freely accessible online at: [elearning.rcgp.org.uk/hepc](http://elearning.rcgp.org.uk/hepc)

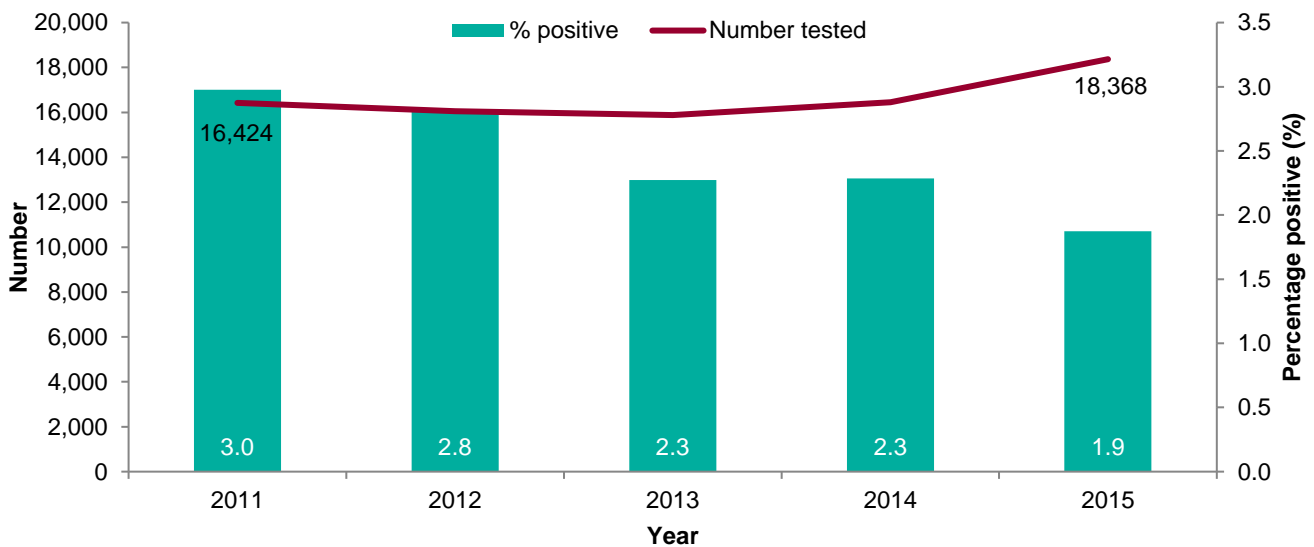
- awareness raising among the general population and people at increased risk of hepatitis C
- developing the knowledge and skills of healthcare professionals and others providing services for people at increased risk of hepatitis C
- testing in primary care, prisons, immigration removal centres, drugs 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 the South East in 2015 with 18,368 individuals tested. This followed a stable period of testing between 2011 and 2014 (16,424 and 16,458 individuals tested, respectively). The data in Figure 17 from sentinel surveillance shows the numbers tested and proportions positive in the South East<sup>1</sup>.

The proportions testing positive for hepatitis has appeared to decrease year-on year from 3.0% in 2011 to 1.9% in 2015. 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 17: Number of individuals tested and the proportion testing positive for anti-HCV in sentinel laboratories in the South East, 2011 to 2015<sup>1</sup>.** Please note that the numbers relate to those tested in the sentinel laboratories, and do not represent all tests across the South East. Excludes dried blood spot, oral fluid, reference testing and testing from hospitals referring all samples. Data are de-duplicated subject to availability of date of birth, soundex and first initial. Excludes individuals aged less than one year, in whom positive tests may reflect the presence of passively-acquired maternal antibody rather than true infection. All data are provisional.



## Site of testing

Information from sentinel surveillance indicates that testing was most often conducted by general practitioners<sup>1</sup> (Figure 18). However, this data does not include dried blood spot testing and oral fluid testing (commonly used in drug services).

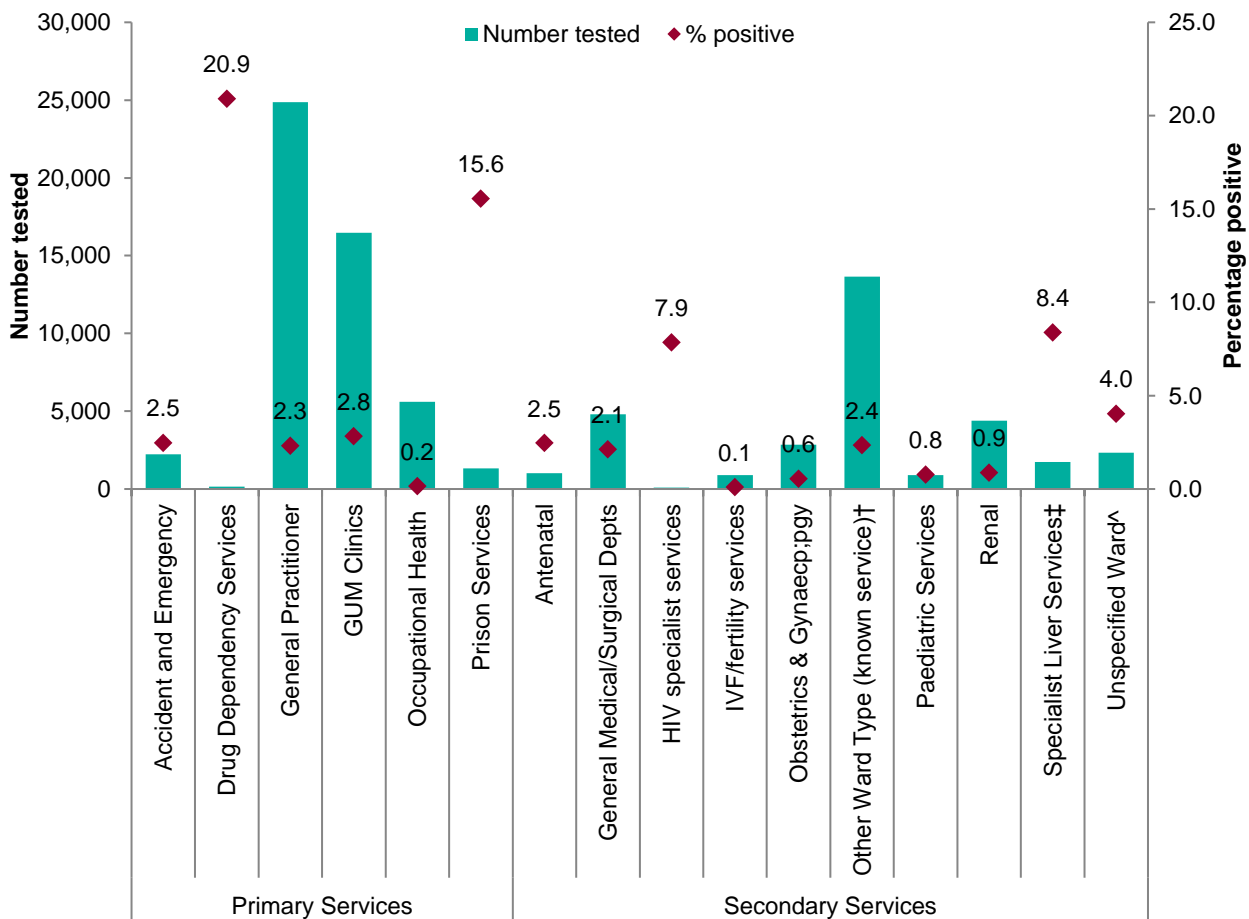
**Figure 18: Number of individuals tested for anti-HCV and the proportion testing positive by service type in sentinel laboratories in the South East, 2011 to 2015<sup>1</sup>.** Please note that the

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

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

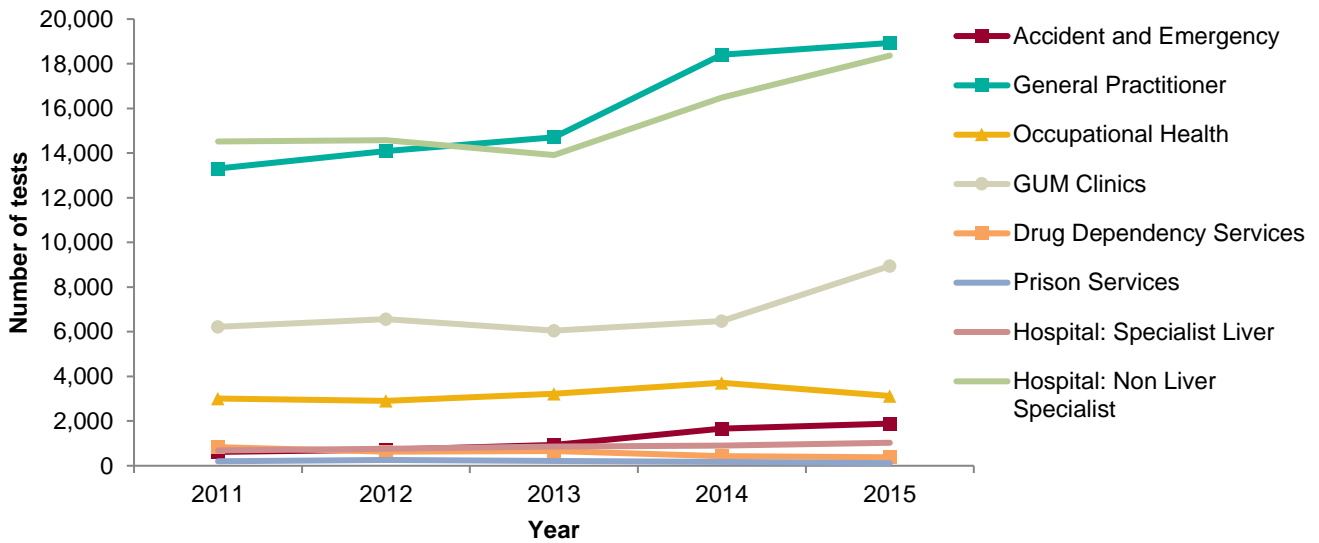
‡ This refers to infectious disease services, hepatology departments and gastroenterology departments.

^ These are hospital services which are currently being investigated to identify specific service type, and may include any of the secondary care services mentioned above.



Encouragingly, there is evidence from sentinel surveillance to suggest increased testing by GPs, GUM clinics and A&E (Figure 19).

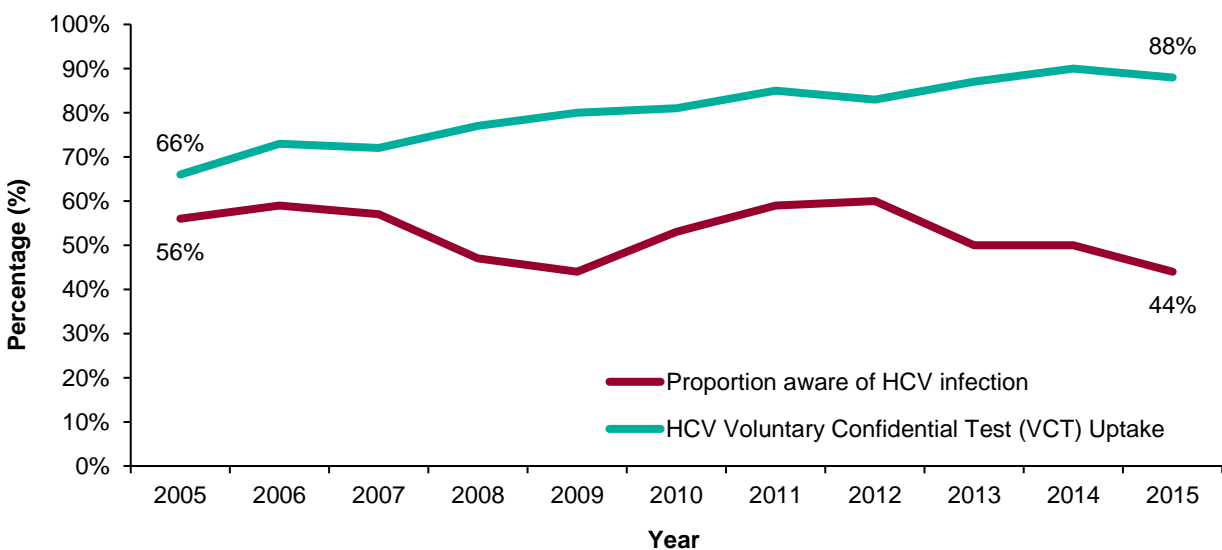
**Figure 19: Number of hepatitis C tests by service type in sentinel laboratories by year in the South East, 2011–2015<sup>1</sup>.** Please note that the numbers relate to those tested in the sentinel laboratories, and do not represent all tests across the South East.



### 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 88% in the South East in 2015, with a peak of 90% in 2014<sup>11</sup> (Figure 20).

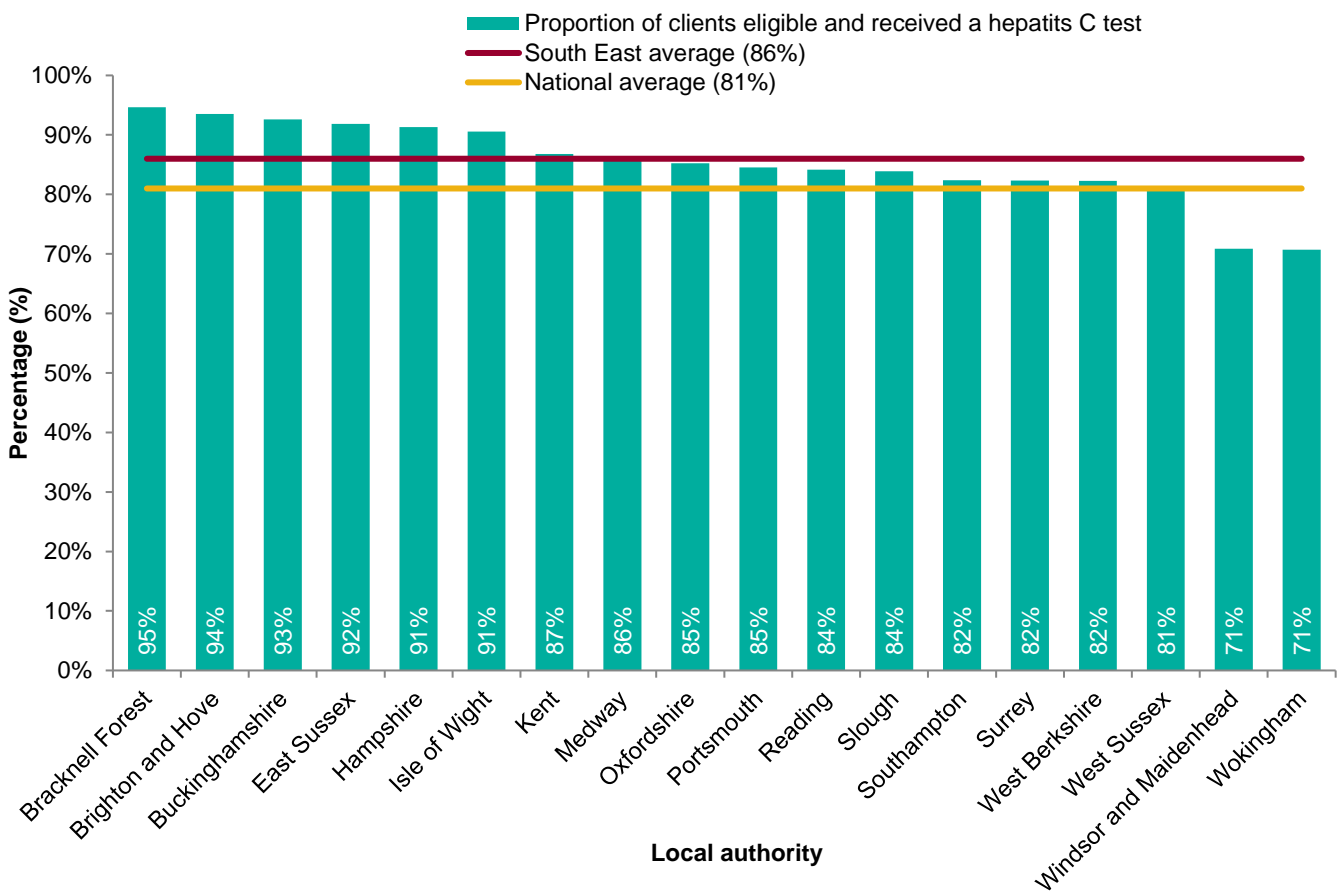
**Figure 20: Hepatitis C test uptake among PWID and their awareness of infection in the South East, 2005–2015<sup>11</sup>**



However, 56% 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 remained stable since 2013/14. In 2014/15, 86% of eligible clients in the South East received a hepatitis C test (10,152 tests), a rise from 64% in 2010/11. This is higher than the level of testing in England (81%), but varied considerably by LA, with two LAs testing fewer than 80% of eligible clients<sup>23</sup> (Figure 21).

**Figure 21: Proportion of clients of drug addiction treatment services eligible and received a hepatitis C test by local authority in the South East, 2014/15<sup>23</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>24</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<sup>24</sup>.

The audit of hepatitis C services in a sample of English prisons<sup>19</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 and 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 bloodborne 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>25</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>24</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>

## 6. Treatment of individuals with hepatitis C<sup>5</sup>

Over the past decade, morbidity and mortality from HCV have been on the increase in England as treatment has been sub-optimal and people who acquired their infections decades earlier progress to advanced liver disease. However, the new DAA drugs that have recently come online, and the creation of operational delivery networks (ODNs) through which to deliver them, offer the potential to significantly reduce the number of individuals progressing to serious HCV-related ESLD/hepatocellular carcinoma (HCC) and reduce the premature mortality that results. As new treatments are rolled out to those with more advanced disease, it should be possible to achieve a rapid reduction in the severe morbidity and mortality that is currently observed and has been predicted to continue in the future<sup>5</sup>.

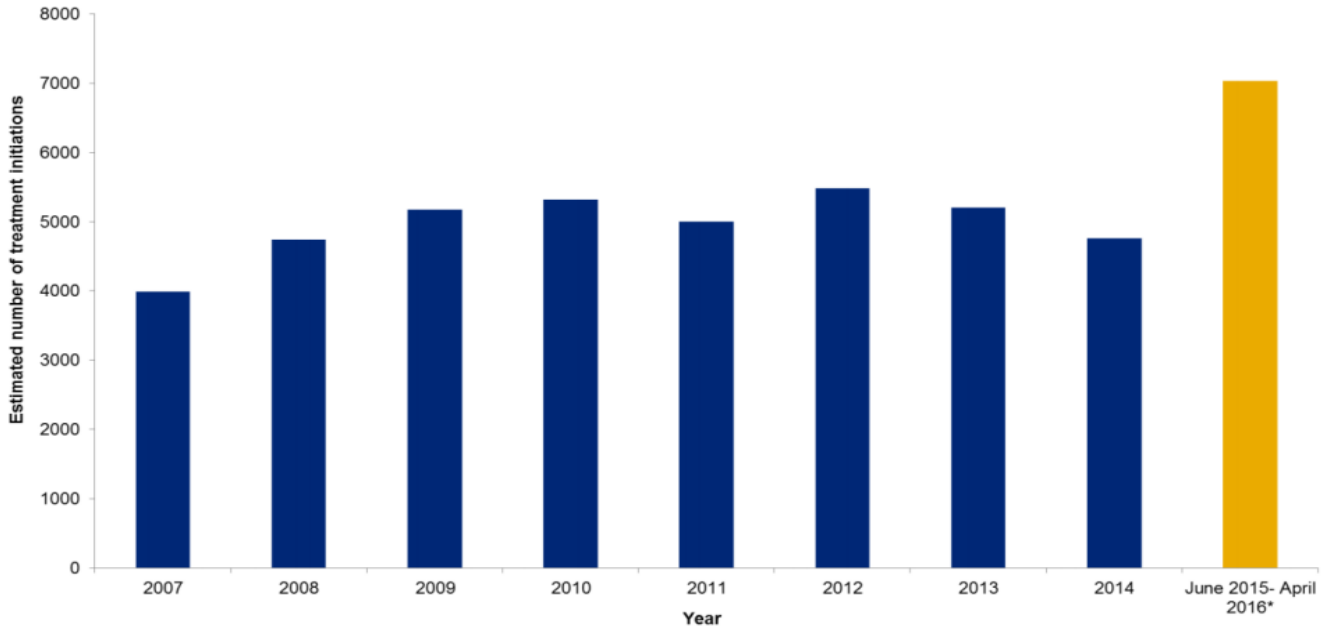
Globally, fewer than 1% of people with chronic hepatitis infection are receiving treatment. The Global Health Sector Strategy (GHSS) on viral hepatitis calls for three million people with chronic HCV to have been treated by 2020 and, by 2030, treatment coverage to reach 80% of the eligible population. However, the WHO action plan for the European region sets relatively more ambitious targets of 75% of diagnosed patients with chronic HCV having accessed treatment by 2020, with more than 90% of these cured, and 90% of all diagnosed patients being linked into care and adequately monitored by 2020<sup>5</sup>.

New DAA drugs have the potential to transform the treatment landscape, offering a fast and effective cure to the vast majority who receive them, without many of the complications associated with previous treatments. While prevention activity is crucial in reducing the rate of new infections, numbers already infected would remain high for many years without effective HCV treatment, which has the potential to dramatically reduce the number of deaths in the short and medium term. From the public health perspective, the new generation of DAA drugs offer a considerable advantage over previous HCV treatments because their all-oral, shorter treatment durations, and improved safety profiles make them easier to roll out in community/outreach settings where it is easiest to reach many of those infected. While the high price of these new drugs represents a major barrier to access in most countries worldwide, these medicines are now being rolled out in England in accordance with national recommendations<sup>5</sup>.

Provisional UK data suggest significant increases in the number of people accessing treatment in 2015. Between 2008 and 2014, provisional estimates suggest that numbers initiating HCV treatment in England remained relatively stable at around 5,100 initiations per year<sup>5</sup> (Figure 22). However, in the 11-month period from June 2015 to April 2016, provisional NHS England data suggest that significantly more people (7,036 in total)

accessed treatment than in earlier years, 38% more than mean 2008-2014 levels, and 48% more than in 2014. This is likely to be the result of access to new DAA drugs that have been coming online since 2014/2015<sup>5</sup>.

**Figure 22: Provisional estimates of numbers initiating HCV treatment in England, 2007-2015<sup>5</sup>**



\*Data for England for June 2015-April 2016 are provisional and based on clinician reported intention to treat where there is some robustness about the intention to treat (e.g. incomplete or other records excluded).

Data sources: (i) NHS England for 2015 provisional estimate for England; (ii) Sentinel surveillance of hepatitis bloodborne virus testing for scaled estimates for 2012-2014 for England; (iii) Estimates from Roche sales, IMS supply chain manager, and Pharmex data for England for 2007-2011 (Harris et al. Journal of Hepatology 2014 vol. 61 j 530-53)

NHS targets are to have treated around 12,500 patients in 2017/18 and to increase the number treated to 15,000 per year in 2020. Assuming this can be achieved and a rate of 15,000 per year continues, statistical modelling predicts that around 5,480 people would be living with HCV-related cirrhosis or HCC in England by 2020 and around 2,620 by 2030, representing a fall in HCV-related cirrhosis/HCC of 56% by 2020 and 81% by 2030. These figures are based on a number of modelling assumptions, which are described in detail elsewhere<sup>5</sup>.

In subsequent years, it will be possible to directly estimate the impact of DAAs (rather than modelling their predicted impact) as known numbers of those treated at different disease stages, in particular those with cirrhosis, should translate to a reduction in observed HCV morbidity and mortality. Despite the potential limitations of modelling, a substantial reduction in severe HCV-related disease is likely; and it is inevitable that DAAs will have a dramatic impact in comparison to previous interferon-based therapy. Although treating those with cirrhosis is imperative, a rising number of those infected are progressing to cirrhosis. Therefore, treatment of mild and moderate stage disease is

also required to maintain reductions in HCV-related disease and reduce transmission and re-infection<sup>5</sup>.

## Care pathways

Many HCV infections occur in marginalised communities, including PWID, and black and minority ethnic populations. It is, therefore, important to ensure that care pathways exist that allow these individuals, as well as others, to access treatment and care<sup>5</sup>.

A national treatment monitoring dataset has been agreed that will help describe access to HCV treatment and care in England. Data including ethnicity, country of birth, route of infection, disease stage, source of referrals and settings of treatment will all help to describe which groups are accessing treatment and the impact of this treatment on the future burden of HCV-related disease in England<sup>5</sup>.

## People who inject drugs

Information on access to HCV treatment services by PWID is available via the UAM Survey. The survey asked participating people injecting psychoactive drugs who reported having had a positive result to a diagnostic test for hepatitis C: 'Have you ever seen a specialist nurse or doctor (e.g. a hepatologist) about your hepatitis C?' Among the survey participants in England with antibodies to hepatitis C who were aware of their infection, 64% (316/493) reported that they had seen a specialist nurse or doctor about their infection, and 25% (121/493) reported being given any medication related to their HCV infection<sup>5,11</sup>.

## Prisons

In prisons and other places of detention, referrals will be monitored via an HJIP metric that was introduced in April 2014 to monitor the percentage of those with chronic HCV infection who are referred to specialist services, and who have a treatment plan developed within 18 weeks. This data will be available in future years. Evaluation of prison pathfinders implementing the opt-out BBV testing programme, suggests that the numbers being referred for hepatitis C treatment increased significantly following the introduction of the opt-out testing policy, with 226 individuals being referred during the 12-month period between January and December 2013 compared to 185 during the 6-month period between April and September 2014 (based on data from eight of the 11 participating prisons)<sup>5</sup>.

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<sup>5</sup>.

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>5,26</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%). Prison healthcare indicated that they provide referral for those leaving prison who are hepatitis C positive if these prisoners are moving to another prison or come to the end of their sentence<sup>5,19</sup>.

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>5,19</sup>. Recommendations from the audit included:

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

## Discussion

An estimated 17,500 people in the South East have been infected with hepatitis C (i.e. they are hepatitis C antibody positive), of whom a high proportion have not cleared their infection.

Hepatitis C infection can result in great costs if left unresolved due to treatment of the late complications such as ESLD and HCC. Hospital admissions with a diagnosis of hepatitis C has increased since 2008 and hospital admissions from hepatitis C related ESLD and HCC has increased considerably since 2008 in the South East and England.

Injecting drug use remains the most important risk factor for hepatitis C infection, but sex between men is an important route of infection, and individuals originating from South Asia, where the prevalence of hepatitis C is high are also at increased risk. The greatest proportion of individuals testing positive for anti-HCV are males (75%) with the peak age group being 35 to 54 years.

Raising awareness, leading to increased testing, is important to identify undiagnosed cases. A high proportion of PWID are unaware of their infection, which highlights the need for more frequent testing. Testing for hepatitis C has increased in recent years, especially in primary care, and testing in drug addiction treatment services in the South East remains steady.

Prevention is primarily focused on PWID because reducing the number of infections in this population is needed to prevent new infections occurring. There has been marked success in reducing the sharing of drug paraphernalia through needle exchange schemes. However, more needs to be done as there is evidence that a significant proportion of PWID continue to share injecting equipment.

NHS England specialised commissioning team are responsible for commissioning and funding access to direct acting antiviral (DAA) drugs which offer a fast and effective cure to the vast majority of patients, via Operational Delivery Networks. CCGs are responsible for commissioning pathways and access to treatment. It will be important to monitor the equity of access to treatment and care services among individuals with hepatitis C infection in the South East.

# Acknowledgements

The authors would like to thank the following.

## **Public Health England, South East Hepatitis Leads**

- Rachel Cloke, Jason Mahoney, Max Courtney, Margot Nicholls, PHE (advice on report)

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

- Koye Balogun, PHE (Laboratory reports)
- Georgina Ireland, Celia Penman and Ruth Simmons, PHE (Sentinel Surveillance of Bloodborne Virus Testing and oral fluid testing data provided by Concateno Plc)
- Vivian Hope and Rachel Glass, PHE (Data from Unlinked Anonymous Monitoring Survey of HIV and Hepatitis in PWID)
- Helen Harris, Ross Harris, Vivian Hope, Sema Mandal, 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)

## **Public Health England, Health and Wellbeing**

- Brian Eastwood and Kevin Shelton (Drug services hepatitis C testing data)

## **Public Health England Field Epidemiology Services (FES)**

- Sarah Foulkes and Rehman Teagle (compilation of the regional template report and collated each PHE Centre's data) FES, West Midlands

## **NHS Trust Development Authority**

- John Hastings (Prison hepatitis C testing data)



### **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

### **NHS digital formerly known as the Health and Social Care Information Centre (HSCIC)**

- NHS digital (formerly HSCIC) for providing the Hospital Episode Statistics data used in this report (Copyright © 2016, Re-used with the permission of the Health and Social Care Information Centre, also known as NHS Digital. 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 (Kent).

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 Anonymous 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 (e.g. 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. 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

**Table A1 Estimates of hepatitis C prevalence, burden, treatment and cost of treatment by upper tier local authority in the South East** <sup>14</sup>. Please see notes on the next page for interpretation and the notes on the original models available on the PHE website: [www.hpa.org.uk/Topics/InfectiousDiseases/InfectionsAZ/HepatitisC/EpidemiologicalData/](http://www.hpa.org.uk/Topics/InfectiousDiseases/InfectionsAZ/HepatitisC/EpidemiologicalData/)

Upper tier local authority	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 upper tier local authority. 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 upper tier local authority 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 upper tier local authorities 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, i.e. 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.

## Appendix 2

Local authority data on laboratory reports of hepatitis C is presented in Table A2. 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 A2: Laboratory reports of hepatitis C by local authority in the South East, 2015<sup>16</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	14	11.8	6.3	19.9
Brighton and Hove	228	79.6	69.4	90.8
Buckinghamshire	69	13.2	10.2	16.7
East Sussex	92	18.9	15.2	23.2
Hampshire	80	6.2	4.9	7.8
Isle of Wight	15	11.3	6.1	19.2
Kent	152	10.7	9.1	12.6
Medway	53	19.5	14.6	25.6
Oxfordshire	97	13.4	10.7	16.5
Portsmouth	44	22.6	16.2	30.5
Reading	27	17.7	11.4	25.9
Slough	43	31.7	22.3	43.5
Southampton	39	16.1	11.3	22.2
Surrey	209	18.0	15.6	20.6
West Berkshire	20	13.6	8.3	21.1
West Sussex	93	11.7	9.4	14.3
Windsor and Maidenhead	8	6.1	2.6	12.1
Wokingham	7	4.3	1.7	8.9
<b>Total</b>	<b>1,290</b>	<b>15.2</b>	<b>14.4</b>	<b>16.1</b>

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

## References

1. Public Health England. Sentinel Surveillance of Bloodborne Virus Testing.
2. Health and Social Care Information Centre. Hospital Episode Statistics (HES).
3. Public Health England. Liver Disease Profiles. [10 May 2017]; Available from: [fingertips.phe.org.uk/profile/liver-disease](http://fingertips.phe.org.uk/profile/liver-disease)
4. NHS Blood and Transplant. UK Transplant Registry.
5. Public Health England. Hepatitis C in England - 2017 report: Working to eliminate hepatitis C as a major public health threat. 2017. [www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/599738/hepatitis\\_c\\_in\\_england\\_2017\\_report.pdf](http://www.gov.uk/government/uploads/system/uploads/attachment_data/file/599738/hepatitis_c_in_england_2017_report.pdf)
6. Harris RJ, Ramsay M, Hope VD, Brant L, Hickman M, Foster GR, et al. Hepatitis C prevalence in England remains low and varies by ethnicity: an updated evidence synthesis. *The European Journal of Public Health* 2012;22(2):187-92.
7. Public Health England. Hepatitis C in the UK: 2015 Report. 2015. [www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/448710/NEW\\_FINAL\\_HCV\\_2015\\_IN\\_THE\\_UK\\_REPORT\\_28072015\\_v2.pdf](http://www.gov.uk/government/uploads/system/uploads/attachment_data/file/448710/NEW_FINAL_HCV_2015_IN_THE_UK_REPORT_28072015_v2.pdf)
8. World Health Organization. EASL International Consensus Conference on Hepatitis C. Consensus statement. 1999.
9. 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.
10. Health Protection Agency. Laboratory Reporting to the Health Protection Agency, Guide for Diagnostic Laboratories. 2010.
11. Public Health England. Unlinked Anonymous Survey of People Who Inject Drugs.
12. Public Health England. The Enhanced Surveillance of Newly Acquired Hepatitis C infection in men who have sex with men (SNAHC).
13. Bristol-Myers Squibb Pharmaceuticals Ltd. Hepatitis C in the South Asian Community: A best practice casebook. 2015; Available from: [hcvaction.org.uk/sites/default/files/resources/CASE%20BOOK%20FINAL%20%283%29.pdf](http://hcvaction.org.uk/sites/default/files/resources/CASE%20BOOK%20FINAL%20%283%29.pdf)
14. Public Health England. PHE Commissioning Template for Estimating HCV Prevalence by PCT and Numbers Eligible for Treatment. 2014.
15. Public Health England. Shooting Up: Infections among people who inject drugs in the UK 2012. An update: November 2013. 2013. [www.hpa.org.uk/Publications/InfectiousDiseases/BloodBorneInfections/ShootingUp/1311ShootingupInfectionsamongIDUS/](http://www.hpa.org.uk/Publications/InfectiousDiseases/BloodBorneInfections/ShootingUp/1311ShootingupInfectionsamongIDUS/)
16. Public Health England. Laboratory Surveillance Data.
17. Office of National Statistics. Death certification.
18. Public Health England. Data tables of the Unlinked Anonymous Monitoring Survey of HIV and Hepatitis in People Who Inject Drugs. 2016. [www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/537598/UAM\\_Survey\\_of\\_PWID\\_2016\\_data\\_tables\\_with\\_2015\\_data\\_FINAL.pdf](http://www.gov.uk/government/uploads/system/uploads/attachment_data/file/537598/UAM_Survey_of_PWID_2016_data_tables_with_2015_data_FINAL.pdf)
19. Public Health England and Department of Health. An audit of hepatitis C services in a representative sample of English prisons. 2013. [www.hpa.org.uk/webc/HPAwebFile/HPAweb\\_C/1317139084753](http://www.hpa.org.uk/webc/HPAwebFile/HPAweb_C/1317139084753)



20. Department of Health. Hepatitis C Action Plan for England 2004.; 2004.  
[www.dh.gov.uk/prod\\_consum\\_dh/groups/dh\\_digitalassets/@dh/@en/documents/digitalasset/dh\\_4084713.pdf](http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_4084713.pdf)
21. Department of Health. Hepatitis C. Get Tested. Get Treated.; 2007.  
[www.nhs.uk/hepatitisc/Pages/default.aspx](http://www.nhs.uk/hepatitisc/Pages/default.aspx)
22. Department of Health. Hepatitis C. The more you know, the better.
23. National Drug Evidence Centre University of Manchester on behalf of Public Health England. National Drug Treatment Monitoring System.
24. NHS Quality Observatory. Prison Health Performance and Quality Indicators (PHPQIs).
25. BBV Opt-Out Task and Finish Group. Blood-borne Virus Opt-Out Testing in Prisons: Preliminary Evaluation of Pathfinder Programme. Phase 1, April to September 2014. 2015.  
[www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/428942/BBV\\_pathfinder\\_evaluation\\_Phase\\_1\\_FINAL.PDF](http://www.gov.uk/government/uploads/system/uploads/attachment_data/file/428942/BBV_pathfinder_evaluation_Phase_1_FINAL.PDF)
26. Department of Health. National Survey of hepatitis C services in prisons in England. 2012.