Public Health England

Hepatitis C in the UK
2013 report

Health Protection Scotland

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About Public Health England

We work with national and local government, industry and the NHS to protect and improve the nation's health and support healthier choices. We address inequalities by focusing on removing barriers to good health.

We were established on 1 April 2013 to bring together public health specialists from more than 70 organisations into a single public health service.

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Foreword

The overarching vision guiding current government public health policy is to improve and protect the nation's health and wellbeing, and to improve the health of the poorest fastest. In this way, healthy life expectancy can be increased and differences in life expectancy between communities can be reduced.

Hepatitis C predominantly affects marginalised groups of society, including people who inject drugs and minority ethnic populations, and so the government policy gives us a clear mandate to tackle hepatitis C. National Institute for Health and Care Excellence (NICE) recommended treatments exist that can clear the virus in the majority of patients, and new treatments are on the horizon that have the potential to be more easily accessed in community settings. As such, it becomes increasingly important to raise awareness of the infection so that individuals who are at risk can be diagnosed and treated. There are many examples of good practice, where hepatitis C treatment has been delivered safely and effectively in appropriate settings and it is important that these are rolled out more widely across the UK. People will not remain 'hard to reach' if the services become easier to access.

Beyond the obvious benefits for the individual, there is also a growing body of evidence to suggest that successful treatment has a contribution to make in reducing transmission of the virus within the population. As such, effective treatment – when coupled with other effective prevention measures – is an important weapon to reduce the incidence of this infection. By tackling hepatitis C, we will be able to reduce preventable mortality from liver disease and cancer – both outcomes for which we are required to demonstrate improvements.

Over the past decade since the hepatitis C action plans and work programmes have been in place, much has been achieved in each of the UK countries. This is now the fifth report of progress across the UK and the eighth report for England.

Reorganisation in England provides opportunities for better co-ordination and integration of services. It is vital that local commissioners in the NHS and in local authorities continue to work together to ensure that individuals are able to access a comprehensive range of high quality health care and prevention services. We hope that this report will be a valuable resource towards achieving this for those working in hepatitis C prevention, management and control throughout the UK.

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Executive summary

The scale of the problem

The most recent national estimates suggest that around 215,000 individuals are chronically infected with hepatitis C (HCV) in the UK;[1,2,3,4] most of this infection (~90%) is genotype 1 and genotype 3.

Injecting drug use continues to be the most important risk factor for HCV infection in the UK. Data from the Unlinked Anonymous Monitoring (UAM) survey of people who inject drugs (PWID) suggest that levels of infection in this group remain high in 2012 (49% in England, 34% in Northern Ireland and 33% in Wales); in 2011/12, 53% of PWID surveyed in Scotland tested positive for antibodies to hepatitis C.

While it is acknowledged that both hospital episode statistics and death certification underestimate true numbers of admissions and deaths from HCV-related end stage liver disease (ESLD) and hepatocellular carcinoma (HCC),[5,6] national data shows that levels of both are continuing to rise in the UK. Hospital admissions have risen from 612 in 1998 to 2268 in 2011, while deaths have risen from 98 in 1996 to 381 in 2011. An overall increase in registrations for liver transplants with a primary code of post-hepatitis C cirrhosis has been observed from 45 in 1996 to 124 in 2012, although figures have been relatively stable over the last five years.

To help tackle HCV infection, public health programmes need to make progress in the following four action areas:

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

Prevention of new infections

Since 2001 England has continued to invest in effective and accessible community drug treatment with the number of adult injectors receiving drug treatment increasing from 84,216 in 2005/06 to 111,939 in 2011/12.

Among those who continue to inject drugs, sharing of injecting equipment and associated paraphernalia is the main route of transmission of infection. National surveys of PWID across the UK suggest that levels of sharing are falling. In 2012 the UAM Survey found that among those who injected during the preceding four weeks, the levels of reported needle/syringe sharing were: 14% in England; 19% in Northern Ireland; and 10% in Wales. In Scotland in 2011/12, 17% of PWID attending drug treatment services who had injected in the previous month reported needle/syringe sharing in that month.

To help reduce levels of sharing, Needle and Syringe Programmes (NSP) are provided and continue to be developed throughout the UK. In Scotland, the number of injection equipment provider outlets has increased to 292 in 2011/12 with approximately four million needles/syringes distributed to PWID during that year. In Northern Ireland, the number of packs dispensed by NSP has increased year-on-year since 2007/08, reaching 25,530 in 2011/12. In England, indirect measures of NSP coverage in 2012 suggest that the vast majority of PWID are accessing NSP (in 2012, the UAM Survey found 83% of people who had injected drugs in the previous year reported that they had used an NSP during that time). The Welsh Harm Reduction Database (HRD) is now active in 46 statutory and voluntary sector NSP sites across Wales, and data from these sites from October 2010 to March 2013 show that just over 10,000 individuals attended these services on two or more occasions.

In the prison estate, a recent audit of hepatitis C services published by PHE showed that disinfection tablets for sterilising injecting equipment were available in over 80% of English prisons[7].

While data suggests that NSP are being accessed by increasing numbers of PWID across the UK, there remains a need to increase the amount of equipment distributed, with better targeting of this provision and education on appropriate needle and syringe cleaning techniques.

Across the UK, a number of methods have been used to gain insight into the number of new hepatitis C virus (HCV) infections and likely trends in incidence over time. Preliminary data suggests that incidence of HCV infection among PWID in England, Wales and Northern Ireland during 2011- 2012 was between 7 and 20 infections per 100 person years of exposure; in Scotland, incidence of infection among PWID in 2011/12 is estimated at 6.1 infections per 100 person years. In England, infections in young adults and recent initiates to drug use suggest that incidence has remained relatively stable over recent years. Enhanced surveillance of newly acquired HCV infection in men who have sex with men (MSM) provides evidence of ongoing, but declining sexual transmission of HCV among HIV-positive MSM in England. In this population,

the estimated incidence of infection has declined significantly over the last four years to 2.2 per 1,000 person years in 2012.

Raising awareness of infection

Raising both professional and public awareness remains a priority and an important component of reducing the burden of undiagnosed infection.

Throughout the UK a variety of initiatives are ongoing to increase public awareness of hepatitis C. These are specifically designed to target those at greatest risk of infection, including past or current PWID, offenders and individuals of South Asian origin. The success of these initiatives has been dependent on the significant contribution of numerous key stakeholders working across a range of settings. The non-governmental organisation (NGO) sector has been particularly influential and their work continues to complement that of government and public sector initiatives in this area.

In 2012 the UAM Survey suggests that 54% of participating PWID in England were aware of their HCV positive status (an increase from 42% seen in 2002); levels of awareness of infection have been relatively stable in Wales and Northern Ireland in recent years (2012 levels are 42% and 53% respectively). In similar surveys of PWID in Scotland in 2011/12, among those who tested hepatitis C antibody positive, 45% reported that they had been diagnosed with hepatitis C and a further 13% reported having cleared the virus.

Education programmes are being developed to raise professional awareness both in primary care and among other individuals working with at risk populations. By May 2013, more than 900 individuals had completed the e-module from the Royal College of General Practitioners (RCGP) Certificate in the Detection, Diagnosis and Management of Hepatitis B and C in Primary Care; around 450 had attended face-to-face training days and 360 individuals had completed Level 1 of the certificate.

In England, audit suggests that four out of five prisons had received training on blood borne viruses (BBVs) for healthcare staff, although the content and frequency of this varied considerably[7]. In Wales, an e-learning package has been developed to improve the knowledge of prison staff in relation to BBVs and over 500 staff have completed this training.

Increasing testing and diagnosis

By monitoring testing and diagnosis, we are able to assess the impact of awareness raising initiatives and prevention activity at a population level, as well as in sub-groups who are at increased risk of infection.

In England, sentinel surveillance suggests that levels of testing have stabilised since 2008, which may be the result of testing saturation among the pool of easy to access individuals and/or a reduction in awareness raising activity. In Northern Ireland a marked increase in testing occurred in 2012, which is partly attributable to increased testing in sexually transmitted infection (STI) clinics. The increase in laboratory reports observed in England and Wales in 2011/2012, particularly in London, is consistent with improved laboratory reporting, probably as a result of recent legislative changes in the notification of infectious diseases.[8] Sentinel surveillance shows that testing via primary care in England has continued to increase year-on-year between 2008 and 2012, suggesting that awareness of hepatitis C may be increasing in this setting. In the four largest NHS Boards in Scotland, levels of testing increased from approximately 18,000 in 1999 to 41,200 in 2012. Of the estimated 37,600 people living in Scotland with chronic HCV infection, approximately half (52%) were thought to have been diagnosed by 2012.

Among PWID, data from the National Drug Treatment Monitoring Systems (NDTMS) suggests that levels of hepatitis C testing are continuing to rise in England. Also in 2012, more than 80% of PWID participating in the UAM Survey reported ever having had a voluntary confidential test (VCT) for hepatitis C (83% in England, 87% in Northern Ireland and 84% in Wales). In similar surveys in Scotland in 2011/12, 83% of PWID reported having been tested for hepatitis C in the past. Across the UK, alternative testing technologies, in particular dried blood spot testing (DBS), are continuing to contribute to the increased uptake of testing among PWID.

Sentinel surveillance data in England suggest that testing via prison services varies by gender with the number of males tested increasing year-on-year from 2008, while the number of females tested has varied over the same period. Between 2008 and 2012, significantly more females (25%) tested positive than males (11%), which may be due to a difference in the relative risk of female offenders having acquired hepatitis C compared to males, and/or differences in the offer and acceptance of BBV testing. A recent survey[9] and audit[7] suggest that HCV testing is offered in more than 95% of English prisons; in Welsh prisons a liver health programme, which includes the promotion of diagnostic testing, is in place and an automated system to capture monthly testing and referral data has been developed and was introduced in 2012.

In the UK, hepatitis C in both new and repeat blood donors has continued to fall to a rate of 32.7 and 0.3 infections per 100,000 donations in new and repeat donors, respectively (2012). In England and North Wales, a disproportionately large number of infections were seen in those of South Asian origin and in those of 'other white' backgrounds, the majority of whom were born outside the UK (particularly in Asia and Eastern Europe). In England, sentinel surveillance data indicates that the number of people tested who were identified as being of Asian or Asian British origin increased by 11% from 2008 to 2012. The overall increase in testing may be a reflection of targeted awareness-raising campaigns that have taken place among Asian or Asian British communities over recent years. Sentinel surveillance also indicates that the number of people tested who were identified as being of Eastern European origin increased by 31% between 2008 and 2012. Over this period 5.4% of people of Eastern European origin tested HCV positive, suggesting that these individuals may be at increased risk of HCV infection and/or are subject to more targeted testing.

The public health guidance recently published by the National Institute for Health and Care Excellence (NICE) should help to focus activity to ensure that more people at increased risk of hepatitis C (and B) infection are offered testing.[10]

Treatment and care

NICE recommended antiviral treatments that will successfully clear hepatitis C virus in most patients should be available, including the recently recommended direct acting antiviral agents for the treatment of genotype 1 infection.[11,12, 13, 14,15]

In England, an estimated 27,500 patients were treated between 2006 and 2011 with pegylated interferon as part of NICE recommended combination therapy; treating approximately 3% of those chronically infected per year. New methods are being developed to estimate the numbers of individuals undergoing treatment from 2012 and to monitor response to antiviral therapy. Preliminary results from statistical models suggest that numbers of HCV-related ESLD/HCC cases can be substantially reduced each year by increasing treatment, with an estimated total of 5880 (95% CrI 5,020-7,520) additional cases averted over the next 30 years if the numbers treated are doubled over the next 10 years.

In Scotland, of the estimated 19,500 diagnosed individuals living with chronic hepatitis C in 2012, an estimated 26% attended a specialist centre that year. Between 2007/08 and 2012/13 more than 5,000 individuals had been initiated on antiviral therapy. Among patients (with either genotype 1, 2 or 3) initiated on pegylated interferon and ribavirin across 17 clinics in Scotland during 2000-2010, 56% achieved a sustained viral response (SVR); this ranged from 42% in

those with genotype 1 infection to 67% among those with genotype 2 or 3 infection.

In the prison estate, a survey in 2011 suggests that the majority of English prisons (74%) have written pathways in place to describe what happens following a positive result.[9] Audit in December 2012 shows the most common model of service delivery in English prisons to be hospital outpatient care (52% of prisons), followed by hospital in-reach (43%) and GP led care (5%).[7] When prisoners are released into the community, 95% of prisons used a variety of methods to ensure that they were referred to appropriate services, and all prisons took some action to ensure continuity of care when prisoners were transferred from one prison to another.[7] In Scotland, between 2007/08 and 2012/13, more than 528 chronically infected offenders were initiated on antiviral therapy within the prison estate.

In Northern Ireland referral rates of 90% have been achieved in recent years by following-up new laboratory confirmed diagnosis of HCV infection three months after the initial confirmation; this practice is now embedded as part of routine clinical care.
Among PWID, data from the 2012 UAM Survey in England show that 62% of the PWID who were aware of their hepatitis C status reported having seen a specialist nurse or doctor about their infection. Of the PWID participating in the UAM Survey in Wales during 2011-12 who were aware of their hepatitis C status, 50% (27/54) had reported ever seeing a specialist nurse or doctor about their infection.

In England a template to help drug action teams (DATs) and health and wellbeing boards to estimate the prevalence of HCV in their local population is available.[16] Local prevalence estimates can be obtained by entering the DAT name, and the template also generates local predictions of the future burden of disease as well as estimates of the costs to treat infected individuals.

Conclusion

Action plans and work programmes have driven improvements in the prevention, diagnosis and treatment of HCV across the UK. Despite this, the morbidity and mortality from HCV-related liver disease continues to rise. However, there is still much work to be done if we are to reduce the future burden of HCV-related disease in the UK.

UK public health recommendations

Prevention

Commissioners of prevention services for people who inject drugs, need to sustain and expand as appropriate, the current broad range of provision (including oral substitution therapy and needle and syringe programmes) to minimise ongoing transmission of hepatitis C.

Diagnosis, testing and awareness of infection

Awareness-raising activity needs to be sustained and enhanced to ensure that more people at increased risk of hepatitis C infection are tested, and levels of undiagnosed infection are reduced.

Testing needs to be sustained among those attending specialist services for people who use drugs, and enhanced across the prison estate; the use of newer technologies for testing in non-traditional settings should be further expanded throughout the UK.

Further efforts are required to raise awareness of hepatitis in primary care by encouraging clinicians to undertake e-learning or other training, for example, the RCGP Certificate in the Detection, Diagnosis and Treatment of Hepatitis C (and B) in primary care.

Treatment and care

Commissioners should consider expanding provision of treatment in non-traditional settings, including primary care, drug treatment settings and prisons, to make treatment more accessible for individuals and thereby reduce the potential for transmission.

UK countries will need to review and establish systems for monitoring resistance to new direct acting antiviral drugs, and develop appropriate assays for future monitoring.

Surveillance

Reliable data on the number of patients treated for hepatitis C, including the use of recently recommended drugs, should be collected by providers and be available for performance monitoring by commissioners.

Proposals for more up-to-date prevalence studies, both overall and in migrants, should be considered to improve national prevalence estimates and to identify whether additional targeted awareness-raising campaigns are required.

The scale of the problem

Hepatitis C infection in the UK

The most recent national estimates suggest that around 215,000 individuals are chronically infected with HCV in the UK.[1,2,3,4]
In England, latest estimates from evidence synthesis models, which date to 2005,[1] indicate that 160,000 adults are chronically infected with hepatitis C, equating to 0.4% of the adult population.

In Scotland approximately 38,000 people were estimated to be chronically infected with HCV during 2012 (equating to 0.7% of the Scottish population). This number is lower than that estimated for previous years (reaching 39,000 people in 2008-2009),[17] based on available data which now indicate that the annual number of people leaving the chronically infected population (through a combination of treatment, mortality and migration) exceeds the annual number of people joining the chronically infected population (as a result of infection acquisition through injecting drug use and migration).

In England, sentinel surveillance data from 2008-2012 show genotypes 1 (46%) and 3 (43%) predominating, with other genotypes comprising just over 10% of infections. In Northern Ireland, of the 842 cases where the genotype was known, 370 (44%) were genotype 1 and 373 (44%) were genotype 3 (Table 1). In Scotland, 34% of the 33,595 people who had ever been diagnosed with hepatitis C antibodies by the end of 2012 were known to have had a genotype test; of these, 49% were genotype 1, 46% genotype 3, and the remainder genotypes 2, 4 or 5.

Throughout the UK, injecting drug use continues to be the most important risk factor for HCV infection (Table 2, Table 3)[17,18,19] therefore, monitoring infection among this important risk group remains a UK priority.

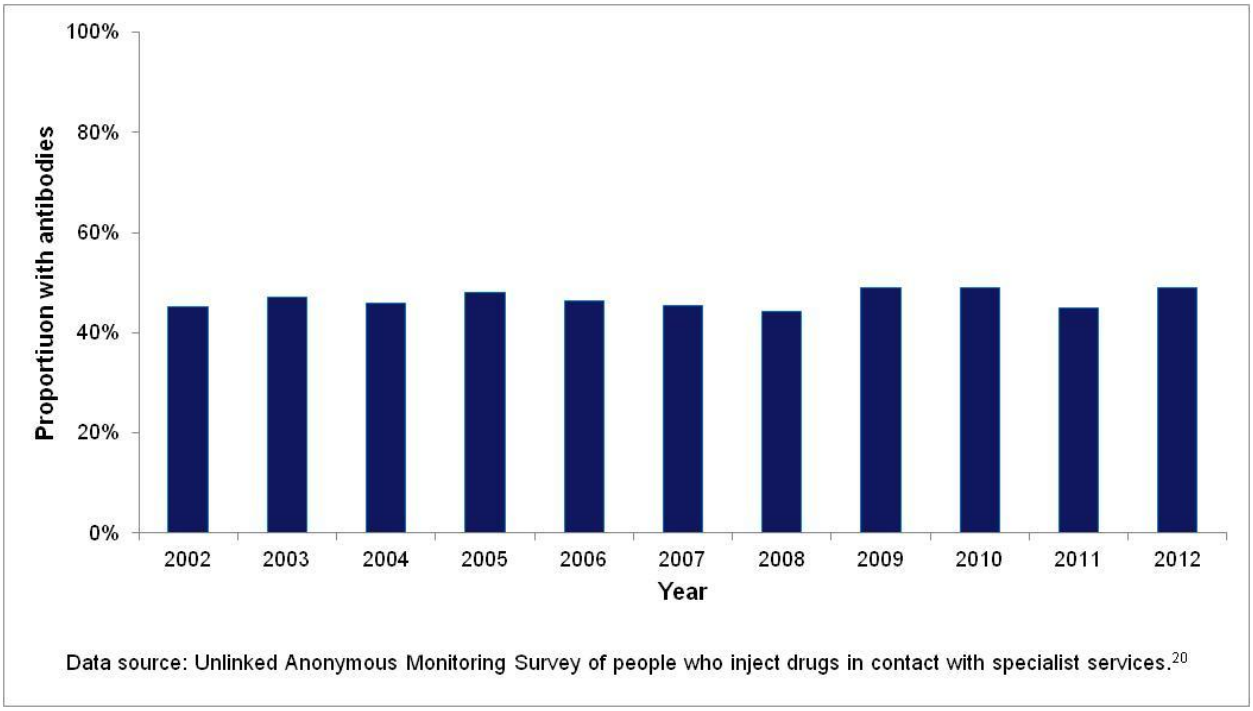
Prevalence of infection in people who inject drugs

In England, 49% of PWID tested positive for antibodies to HCV (anti-HCV) in the 2012 UAM Survey of PWID in contact with drug services. This proportion has remained relatively stable over recent years (Figure 1)[20]

Hepatitis C prevalence among PWID participating in the UAM Survey in 2012 varied across England, with prevalence ranging from 33% in the North East region to 64% in the North West.[20] This finding is supported by statistical

modelling, which shows that the prevalence of infection among individuals in England who have ever injected drugs is markedly higher in London and the North West (Table 4).[1]

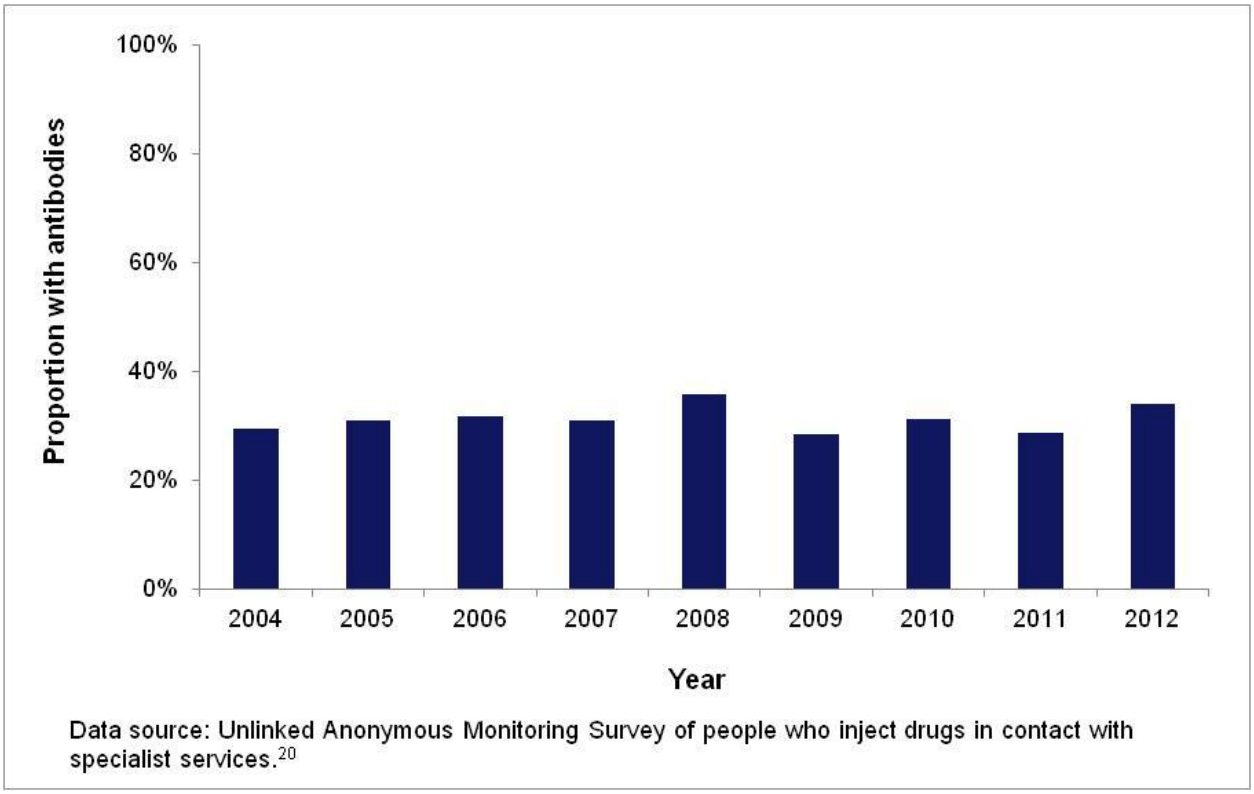
Figure 1: Trend in HCV prevalence* among people who inject drugs in England: 2002-2012



* During 2009 to 2011 there was a phased change in the sample collected in the survey from an oral fluid to dried blood spot (DBS). The sensitivity of the anti-HCV tests on these two sample types is different. The sensitivity of the oral fluid test for anti-HCV is approximately 92%[21] that on DBS samples is close to 100%. Data presented here has been adjusted for the sensitivity of the oral fluid test.

In Northern Ireland, levels of infection are lower overall with 34% of PWID participating in the UAM Survey testing positive for antibodies in 2012; levels have varied little since 2004 (Figure 2).[20]

Figure 2: Trend in HCV prevalence* among people who inject drugs in Northern Ireland: 2004-2012



Data source: Unlinked Anonymous Monitoring Survey of people who inject drugs in contact with specialist services.[20]

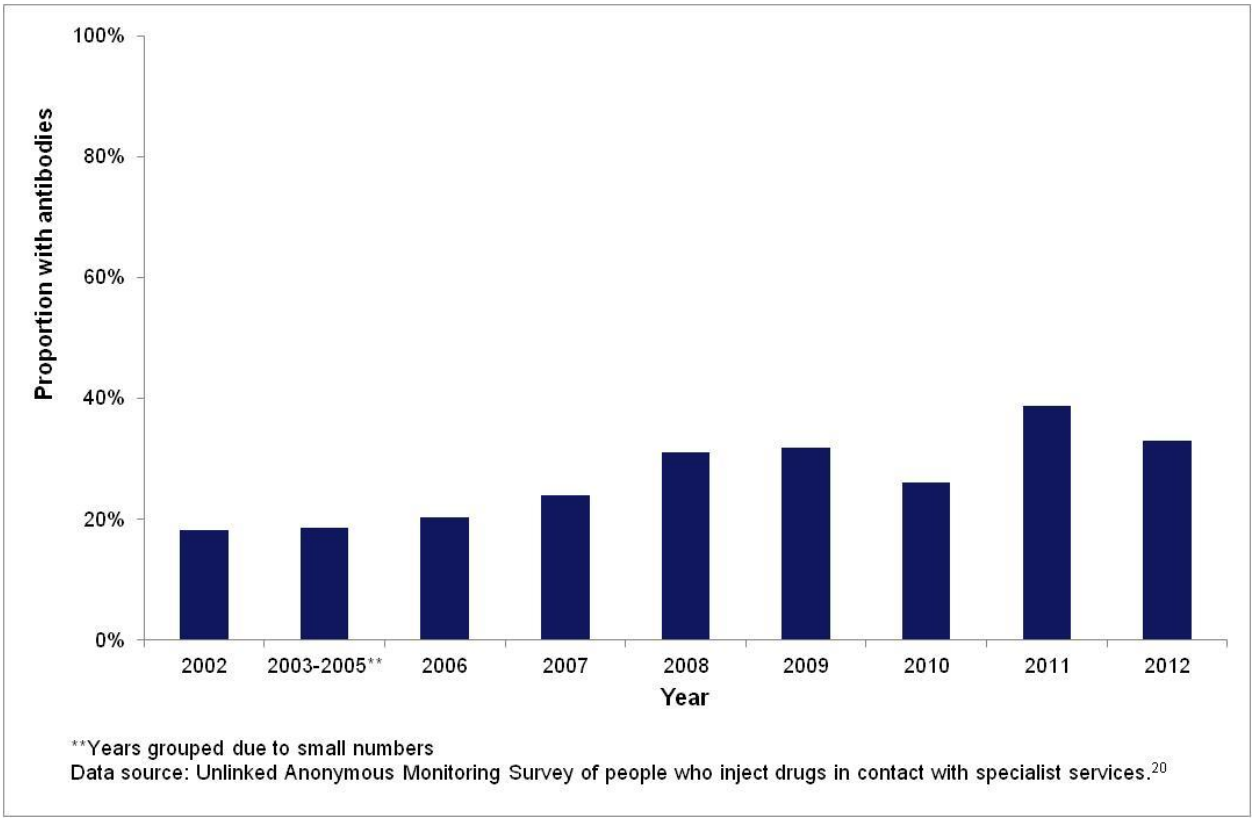
* During 2009 to 2011 there was a phased change in the sample collected in the survey from an oral fluid to dried blood spot (DBS). The sensitivity of the anti-HCV tests on these two sample types is different. The sensitivity of the oral fluid test for anti-HCV is approximately 92%,[21] that on DBS samples is close to 100%. Data presented here has been adjusted for the sensitivity of the oral fluid test.

In Wales, UAM Survey data suggest that whilst the level of infection among PWID in 2012 (33%) was higher than a decade ago (18% in 2002), it has changed little in recent years (Figure 3).[20] However, given the relatively small sample size, these results should be interpreted with caution. Enhanced surveillance of clients of specialist drug services undergoing routine diagnostic testing indicates a lower prevalence in 2012; of the 491 individuals with HCV test results who reported injecting drug use, 95 (19%) were found to have a reactive test for HCV antibody.[22] The difference in estimates may reflect the different methods used and populations captured by these two systems. For example, those whose HCV infection has already been diagnosed will be captured in the UAM Survey but may not be included in the enhanced surveillance system.

Enhanced surveillance of PWID accessing BBV testing in drug services in Wales suggests that in those tested in 2011, antibody prevalence ranged from 9% among those injecting for two years or less, to 35% among those injecting

for five years or more. For those tested in 2012, the prevalence in the same respective groups was 9% and 23%[22] (Table 5).

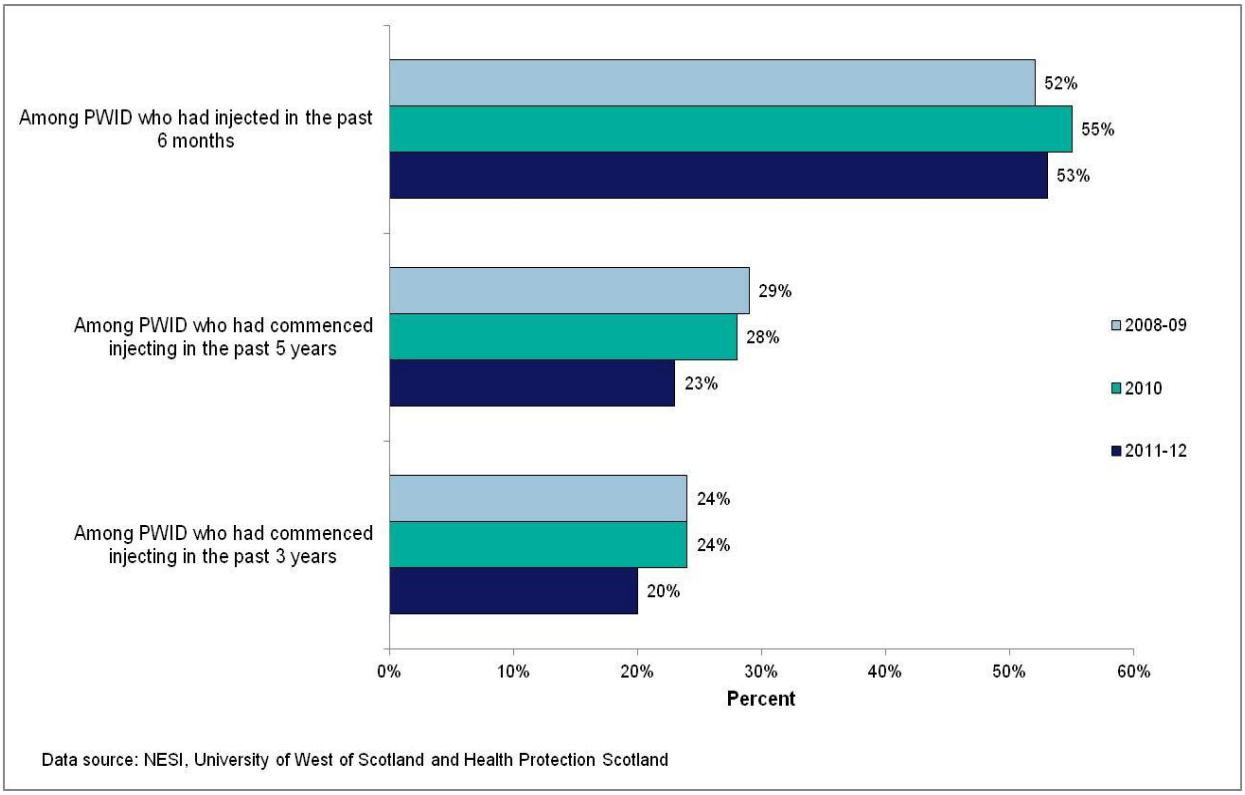
Figure 3: Trend in HCV prevalence* among people who inject drugs in Wales: 2002-2012



* During 2009 to 2011 there was a phased change in the sample collected in the survey from an oral fluid to dried blood spot (DBS). The sensitivity of the anti-HCV tests on these two sample types is different. The sensitivity of the oral fluid test for anti-HCV is approximately 92%[21] that on DBS samples is close to 100%. Data presented here has been adjusted for the sensitivity of the oral fluid test.

In Scotland, among 1,791 PWID surveyed at services providing injection equipment during 2011-12, 954 (53%) tested positive for hepatitis C antibodies (in anonymous testing of their DBS samples; Figure 4); similar proportions tested positive in 2008-09 (52%) and 2010 (55%).

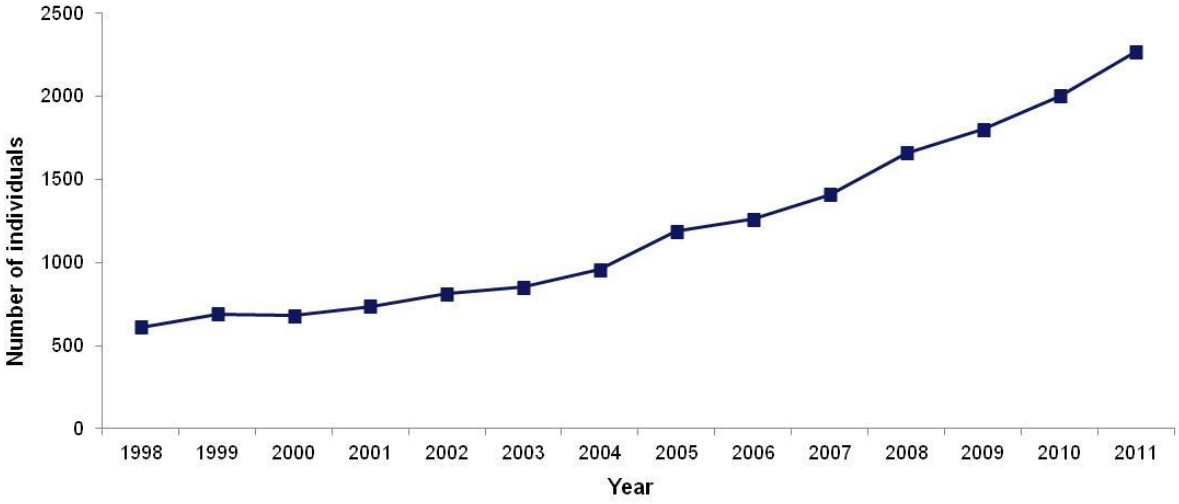
Figure 4: Proportion of PWID, surveyed at services providing injection equipment across mainland Scotland in 2008-09, 2010, and 2011-12 who were found to be hepatitis C antibody positive



Deaths from, and hospital admissions for, HCV-related end stage liver disease

Both hospital admissions (Figure 5) and deaths (Figure 6) from HCV-related ESLD and HCC are continuing to rise in the UK; hospital admissions rose from 612 in 1998 to 2,268 in 2011 (Figure 5), while deaths rose from 98 in 1996 to 381 in 2011 (Figure 6).

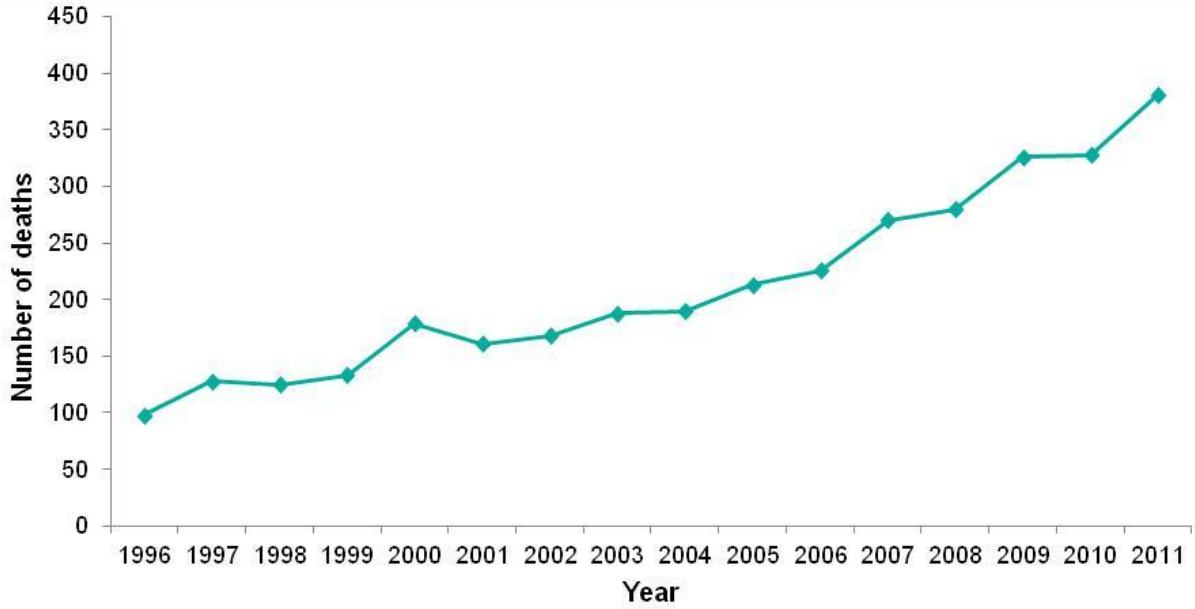
Figure 5: Annual number of individuals in England[1], Scotland[2], Wales[1] and Northern Ireland[3] hospitalised with HCV-related ESLD* or HCV-related HCC: 1998-2011



* Defined by codes or text entries for ascites, bleeding oesophageal varices, hepato-renal syndrome , hepatic encephalopathy or hepatic failure.
[1]Refers to individuals in England and Wales hospitalised with HCV-related ESLD or HCV-related HCC
[2]Refers to individuals in Scotland diagnosed with hepatitis C and admitted to hospital for the first-time with either ESLD or HCC.
3Refers to individuals in Northern Ireland hospitalised with HCV-related ESLD or HCV-related HCC. Data available from 2009 only.

Data source:Hospital Episode Statistics (HES), The NHS Information Centre for Health and Social Care, England;
Patient Episode Database for Wales (PEDW). NHS Wales Informatics Service,
Health Protection Scotland, in association with the Information Services Division.
Patient administration system via Health Intelligence Public Health Agency, Northern Ireland

Figure 6: Deaths from ESLD* or HCC in those with hepatitis C mentioned on the death certificate in the UK: 1996-2011

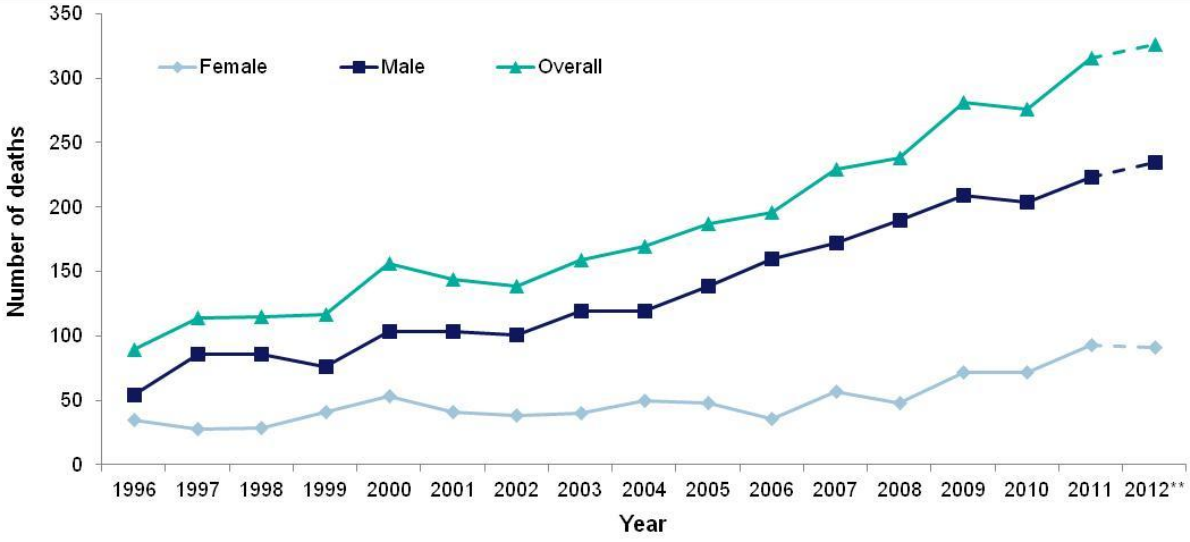


* Defined by codes or text entries for ascites, bleeding oesophageal varices, hepato-renal syndrome , hepatic encephalopathy or hepatic failure.

Data source: Office for National Statistics (England & Wales); Health Protection Scotland, in association with the Information Services Division; Northern Ireland Statistics and Research Agency

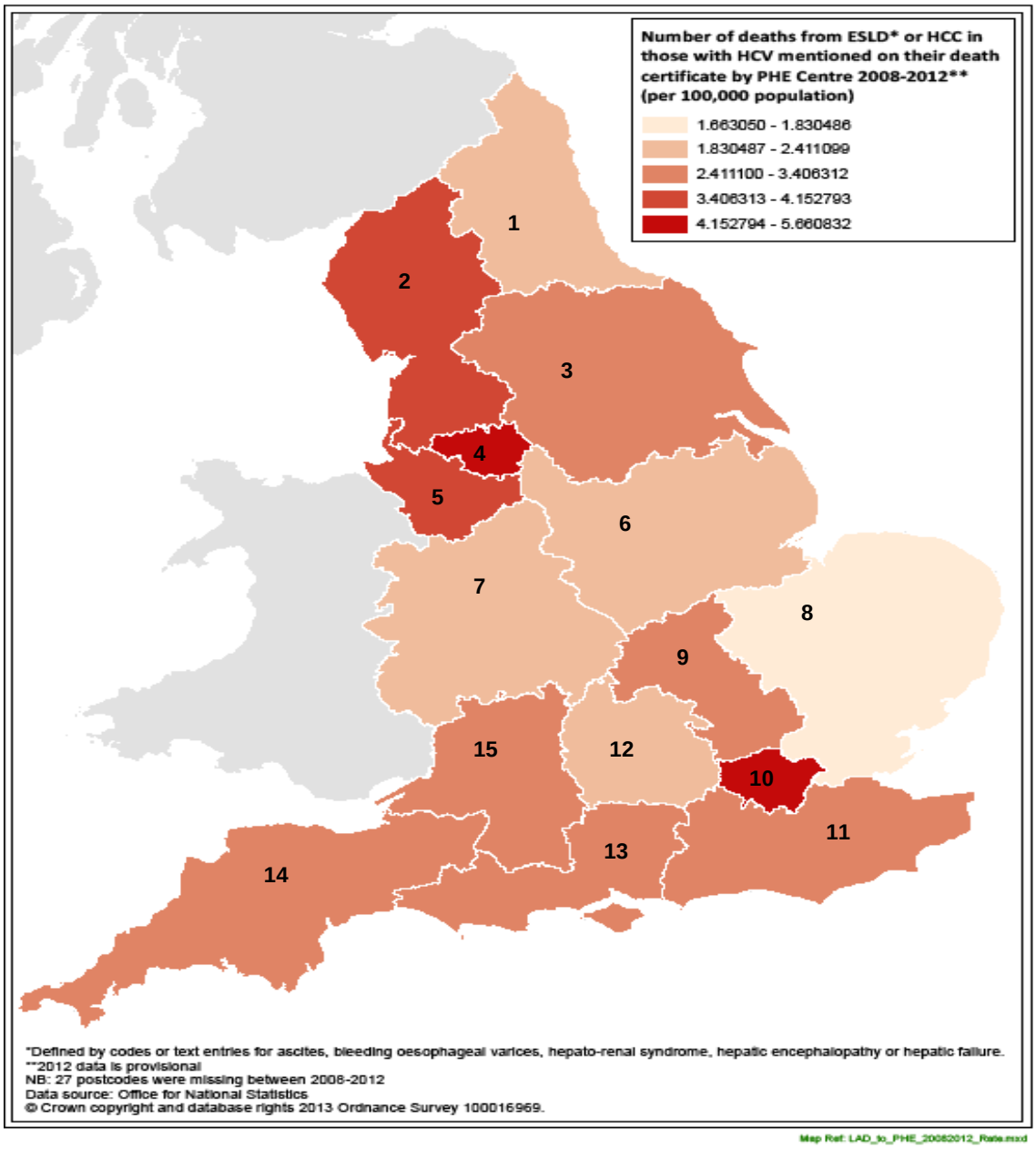
In England, a similar pattern is observed, with both hospital admissions (Table 6) and deaths (Figure 7) from HCV-related ESLD and HCC rising year-on-year. Deaths have risen from 89 in 1996 to 326 in 2012 (Figure 7), while hospital admissions have risen from 574 in 1998 to 2,266 in 2012 (Table 6). Deaths per 100,000 population vary across England, with highest rates observed in London and the North West (Map).

Figure 7: Deaths from ESLD* or HCC in those with HCV mentioned on their death certificate in England: 1996-2012**



* Defined by codes or text entries for ascites, bleeding oesophageal varices, hepato-renal syndrome, hepatic encephalopathy or hepatic failure.
**2012 data is provisional
Data source: Office for National Statistics

Map: Number of deaths from ESLD* or HCC in those with HCV mentioned on their death certificate by PHE Centre 2008-2012** (per 100,000 population)



1 North East; 2 Cumbria and Lancashire; 3 Yorkshire and Humber; 4 Greater Manchester;

5 Cheshire and Merseyside; 6 East Midlands; 7 West Midlands; 8 Anglia and Essex;

9 South Midlands and Hertfordshire; 10 London integrated region and centre;

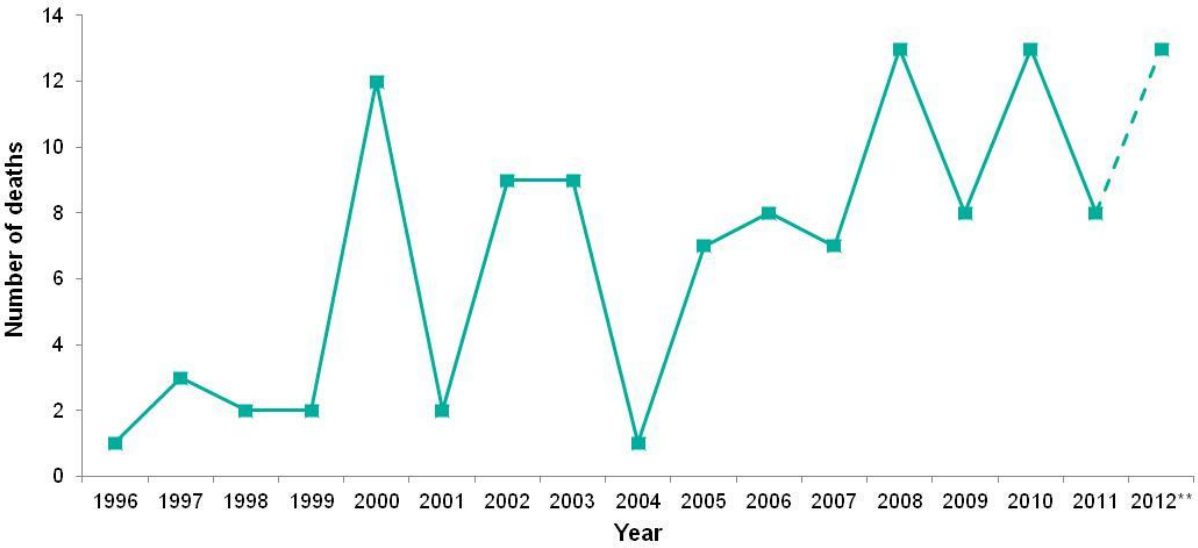
11 Kent, Surrey and Sussex; 12 Thames Valley; 13 Wessex; 14 Devon, Cornwall and Somerset;

15 Avon, Gloucestershire and Wiltshire

In Northern Ireland, seven deaths from HCV-related ESLD or HCC were registered in 2012. In the past decade, deaths with HCV-related ESLD or HCC in Northern Ireland have numbered less than 10 each year, except in 2011 when 11 were recorded.

In Wales, deaths recorded as HCV-related ESLD or HCC have fluctuated over recent years (Figure 8), but have averaged 11 deaths per year over the last five years. The majority of deaths were seen in males. Hospital admissions, counting each individual only once in any calendar year, for these indications have risen from 45 in 1997-2000 to 221 in 2008-2012 (Table 7).

Figure 8: Deaths from ESLD*, or HCC, in those with HCV mentioned on their death certificate in Wales: 1996-2012**



* Defined by codes or text entries for ascites, bleeding oesophageal varices, hepato-renal syndrome , hepatic encephalopathy or hepatic failure.
**2012 data is provisional
Data source: Office for National Statistics

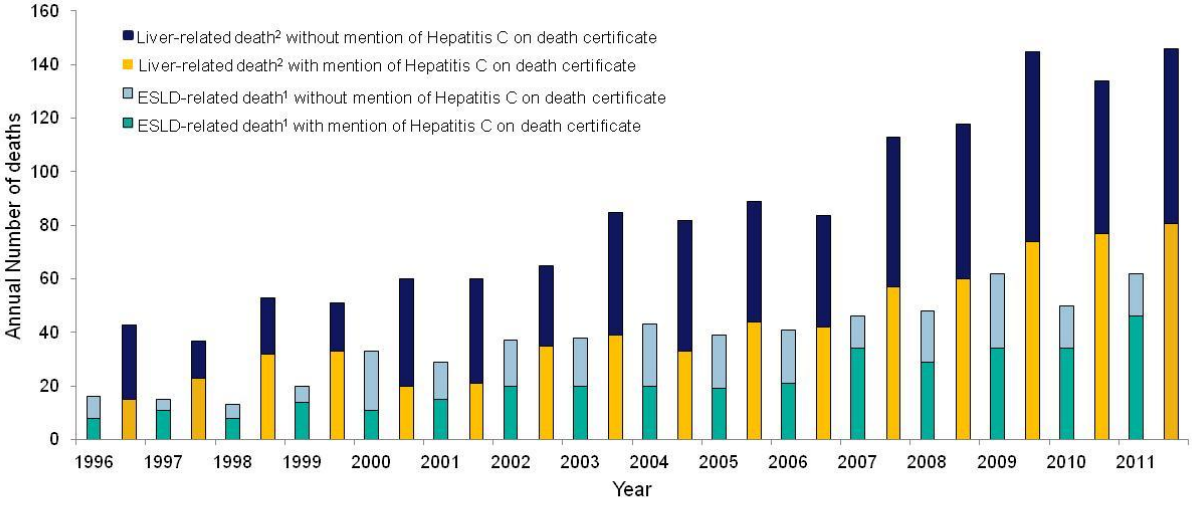
In Scotland, liver-related deaths among people diagnosed with hepatitis C increased from 43 in 1996 to 146 in 2011 (Figure 9), at an average annual increase of 9.3%. However, in the last three years (2009-2011), the average annual rate of increase was only 0.4%.

By linking records in Scotland's National Hepatitis C Diagnoses Database to the national register of deaths, it is possible to determine that only 686 (50%) of the total 1,365 liver-related deaths during 1996-2011 among people diagnosed with hepatitis C, had any mention of hepatitis C on their death certificate. Among the 146 liver-related deaths in 2011, 108 (74%) had liver disease recorded as the underlying cause of death (alcoholic liver disease was the most prevalent underlying cause in 43), and 38 (26%) had liver disease only as a contributing cause of death; 105 (72%) were male, and 79 (54%) were aged less than 50 years.

ESLD-related disease among people diagnosed with hepatitis C in Scotland increased from 16 in 1996 to 62 in 2011 (Figure 9) at an average annual increase of 9%. Of the total 592 ESLD-related deaths during 1996-2011 among

people diagnosed with hepatitis C, only 344 (58%) had hepatitis C mentioned on the death certificate.

Figure 9: Annual number of deaths related to liver disease and end-stage liver disease (ESLD) among persons diagnosed with hepatitis C (antibody positive or RNA positive) in Scotland, during 1996-2011.



[1] Deaths were defined as related to ESLD if the underlying/contributing cause of death was either ascites, hepatic encephalopathy, hepatic failure, hepato-renal syndrome, HCC or bleeding oesophageal varices.
[2] Deaths were defined as related to liver disease if the underlying cause of death was either (a) viral hepatitis, (b) liver cancer, (c) alcoholic liver disease or (d) non-alcoholic liver disease, and the contributing cause of death was either (b), (c) or (d).

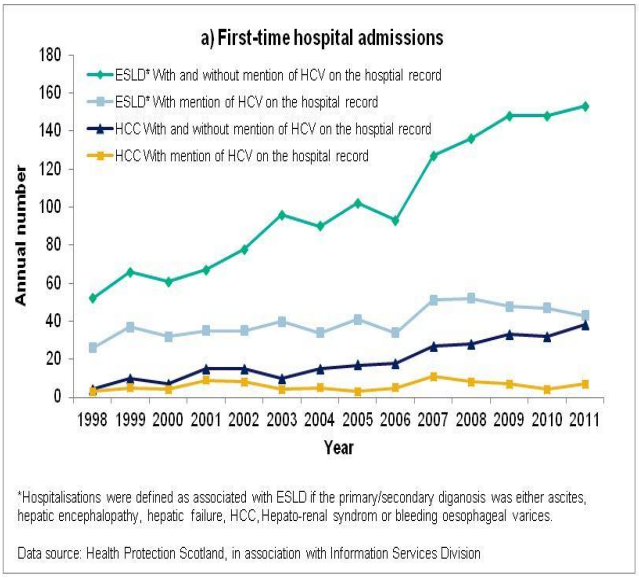
Data Source: Health Protection Scotland

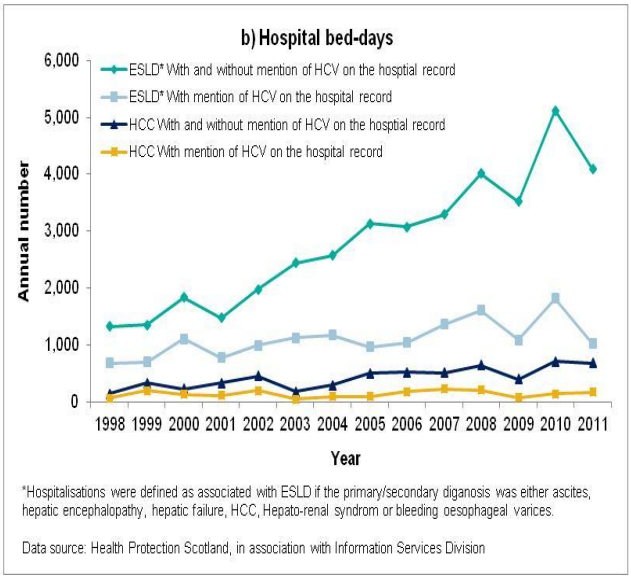
Data on hospitalisations were obtained via record-linkage of Scotland's National Hepatitis C Diagnoses Database to the national database on hospital admissions. These showed that first-time hospital admissions with ESLD in Scotland among people diagnosed with hepatitis C increased from 52 in 1998 to 153 in 2011 (Figure 10), at an average annual increase of 8.6%. However, in the last three years (2009-2011), the average annual rate of increase was only 1.7%. Of the total 1,417 first-time hospital admissions for ESLD during 1998-2011 among people diagnosed with hepatitis C, only 555 (39%) had hepatitis C mentioned on the hospital record. Among the 153 first-time hospital admissions for ESLD in 2011, 113 (74%) were male, and 91 (59%) were aged less than 50 years. Hospital bed-days with ESLD among people diagnosed with hepatitis C increased from 1,320 in 1998 to 4,085 in 2011 (Figure 10), at an average annual increase of 10.1%.

First-time hospital admissions with HCC in Scotland among people diagnosed with hepatitis C increased from four in 1998 to 38 in 2011 (Figure 10), at an average annual increase of 14.1%. Of the total 269 first-time hospital admissions during 1998-2011 for HCC among people diagnosed with hepatitis C, only 83 (31%) had hepatitis C mentioned on the hospital record. Among the 38 first-time hospital admissions for HCC in 2011, 35 (92%) were male, and five

(13%) were aged less than 50 years. Hospital bed-days with HCC among people diagnosed with hepatitis C increased from 144 in 1998 to 679 in 2011 (Figure 10), at an average annual rate of 9.1%.

Figure 10: Annual number of: (a) first-time hospital admissions and (b) hospital bed-days associated with ESLD and HCC among persons diagnosed with hepatitis C (antibody positive or RNA positive) in Scotland, during 1998-2011.

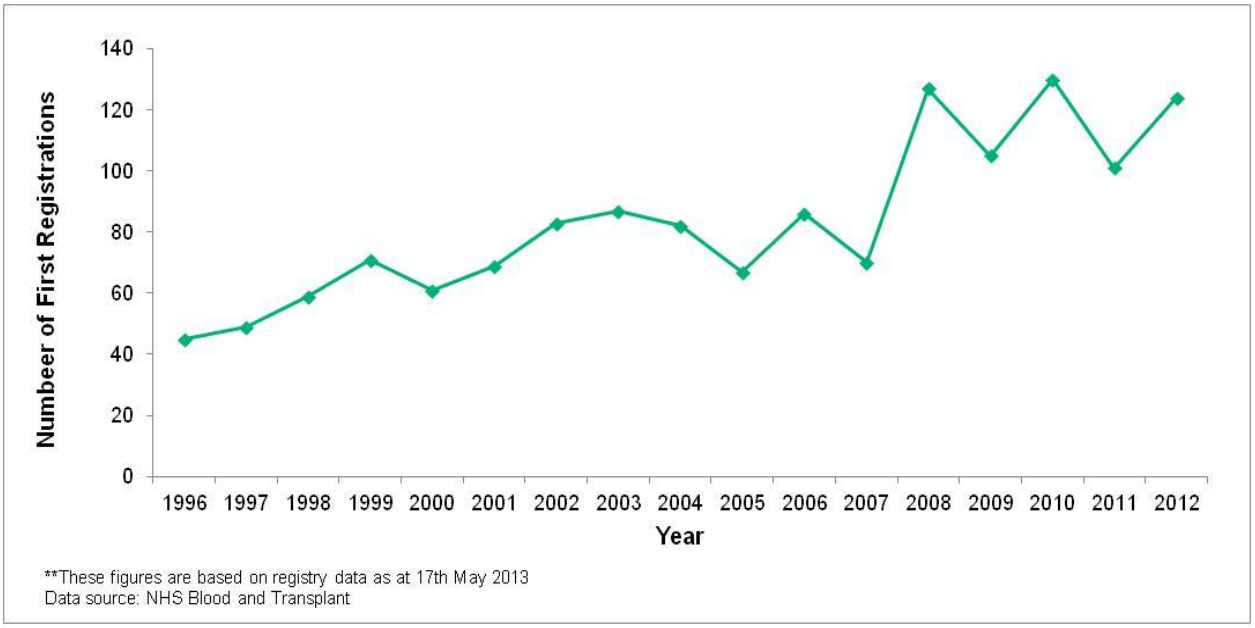




Liver registrations and transplants for hepatitis C-related disease

In the UK, an overall increase in registrations for liver transplants with a code of post-hepatitis C cirrhosis from 45 in 1996 to 124 in 2012 is observed, although figures have been relatively stable over the last five years (Figure 11).

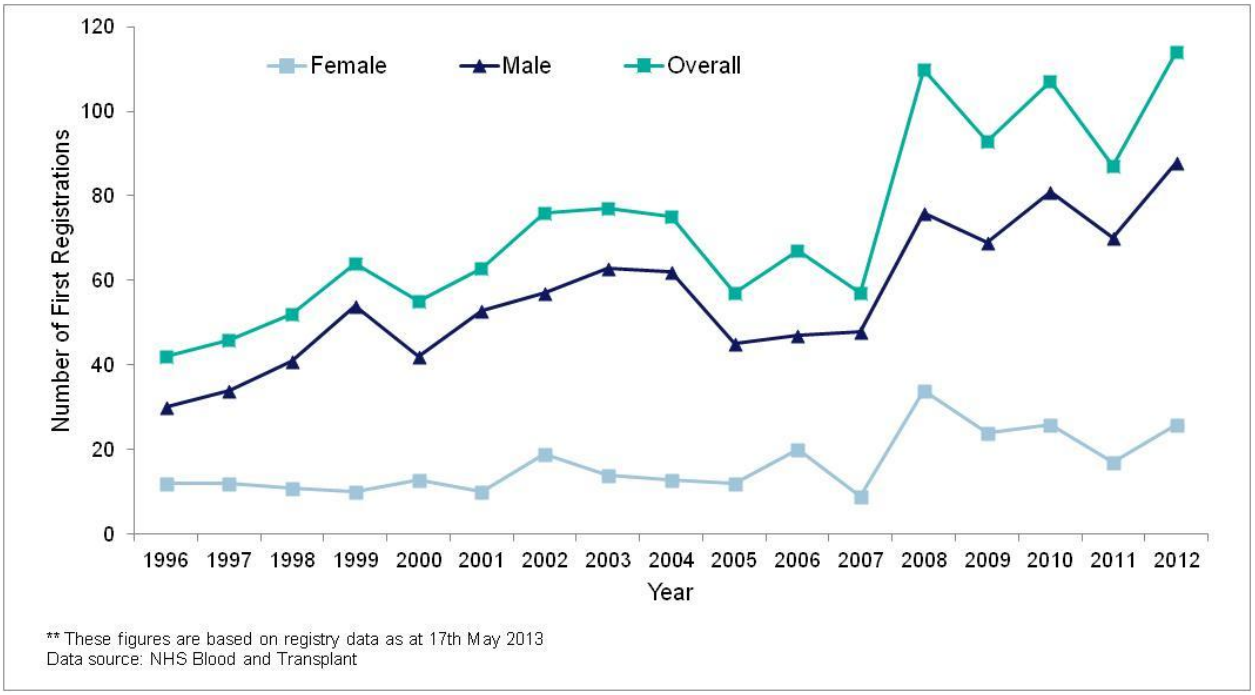
Figure 11: Number of first registrations* for a liver transplant in the UK where post-hepatitis C cirrhosis was the primary indication for transplant: 1996-2012**



*New universal registration criteria for selecting adult patients for elective liver transplantation were introduced in September 2007[23]

The number of English residents with post-hepatitis C cirrhosis registering at NHS Blood and Transplant for a liver transplant increased from 42 registrations in 1996 to 114 in 2012, with no overall increase in the last five years (Figure 12). A rise in liver transplants undertaken for this indication, from 44 in 1996 to 101 in 2012, was also observed (Table 8). Of all liver transplants performed in England, the percentage carried out in patients with hepatitis C-related disease increased from 10% in 1996 to 16% in 2012, but has not increased over the last five years (Table 8).

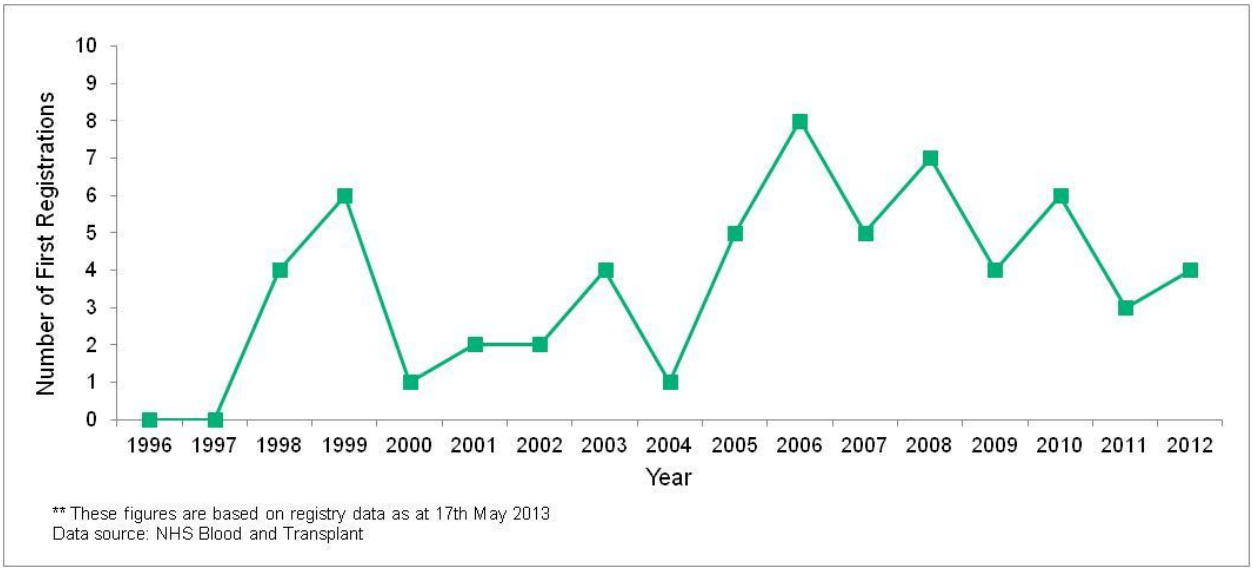
Figure 12: Number of first registrations* for a liver transplant in England where post-hepatitis C cirrhosis was the primary indication for transplant: 1996-2012**



*New universal registration criteria for selecting adult patients for elective liver transplantation were introduced in September 2007[23]

When taken together, only four residents from Northern Ireland and Wales with post-hepatitis C cirrhosis registered at NHS Blood and Transplant for a liver transplant in 2012 (Figure 13), and three patients underwent a transplant (Table 9). Neither the number of registrations, nor the number of transplants undertaken, for this indication has exceeded eight or ten in any one year since 1996 in Northern Ireland and Wales together respectively (Figure 13, Table 9).

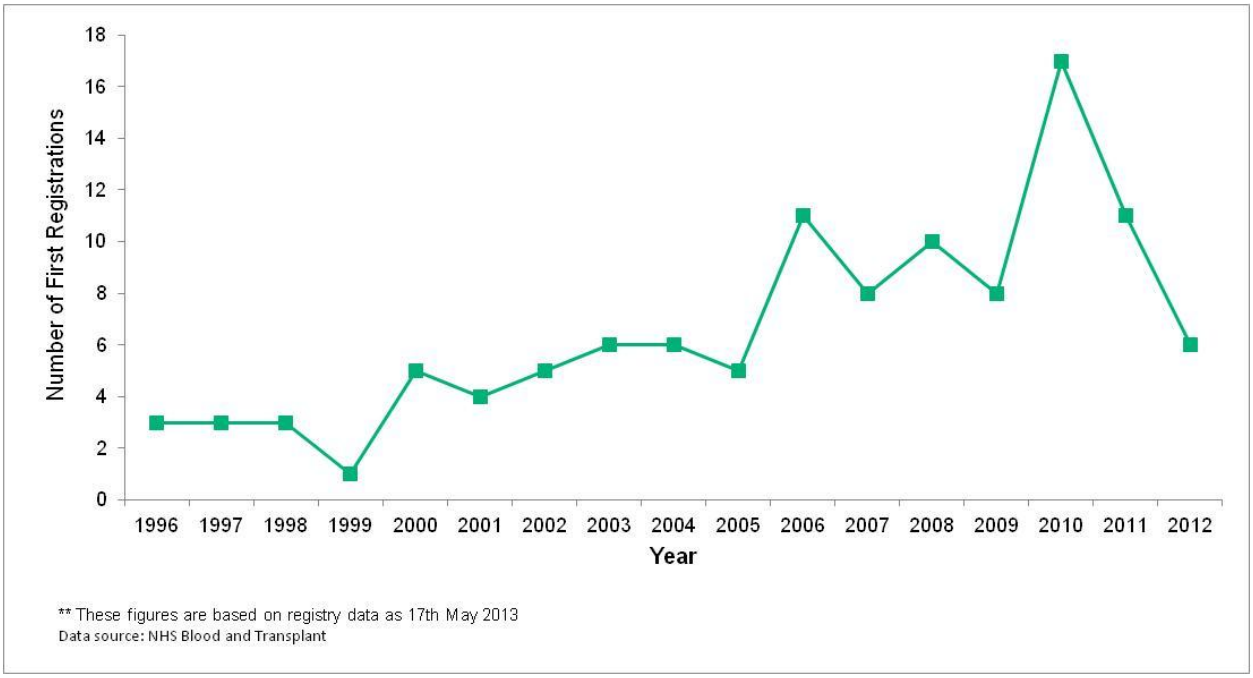
Figure 13: Number of first registrations* for a liver transplant in Northern Ireland and Wales where post-hepatitis C cirrhosis was the primary indication for transplant: 1996-2012**



*New universal registration criteria for selecting adult patients for elective liver transplantation were introduced in September 2007[23]

In Scotland, the overall number of liver transplant first registrations with a code of post-hepatitis C cirrhosis has varied over the last 16 years, from one in 1999 to a peak of 17 in 2010 (Figure 14). The number of first liver transplants in patients with post-hepatitis C cirrhosis and HCV-related HCC fluctuated between 1996 and 2012 (Table 10).

Figure 14: Number of first registrations* for a liver transplant in Scotland where post-hepatitis C cirrhosis was the primary indication for transplant: 1996-2012**

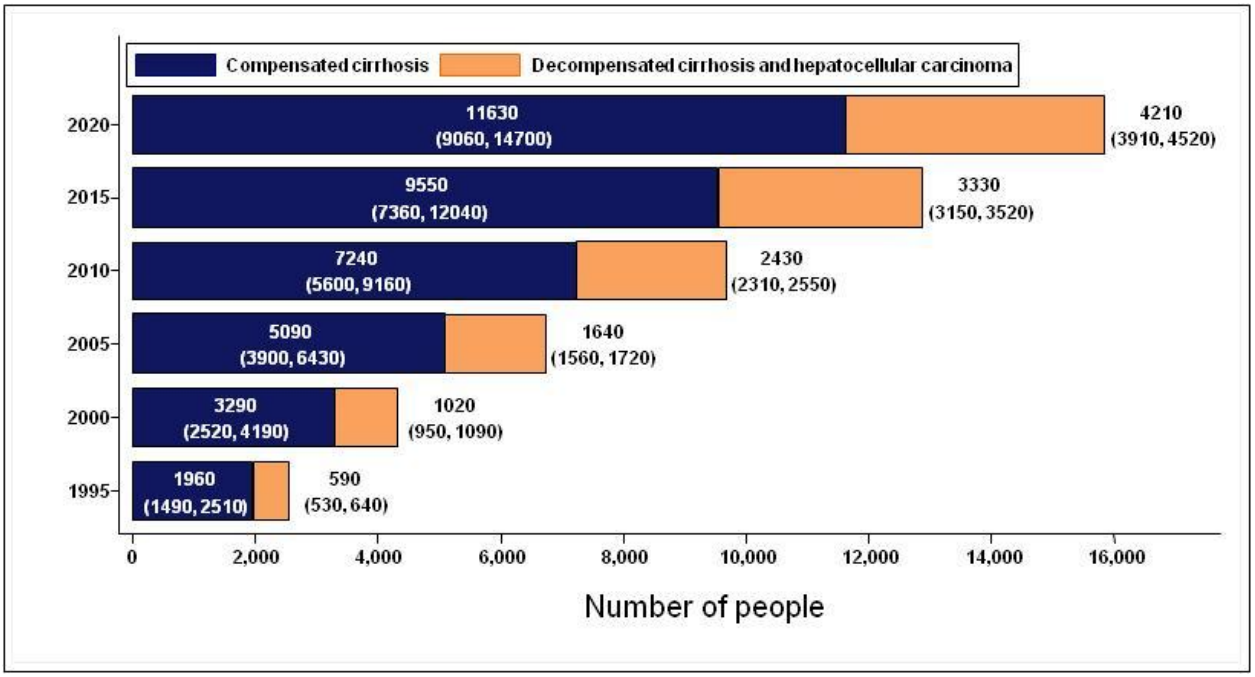


*New universal registration criteria for selecting adult patients for elective liver transplantation were introduced in September 2007[23]

Future burden of HCV-related disease and action areas

In England, statistical modelling predicts that 15,840 individuals will be living with HCV-related cirrhosis or HCC in England in 2020 if left untreated (Figure 15).[17,24]

Figure 15: Estimated number of people living with HCV-related cirrhosis or decompensated cirrhosis/HCC in England: 1995-2020 (95% credible intervals are given in parentheses)



To help tackle HCV infection in the UK, public health programmes need to make progress in the following four action areas:

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

The outcome data presented in this report allow us to monitor the impact of prevention initiatives and awareness-raising activities that are taking place across the UK. National monitoring of numbers diagnosed and treated helps us to track our progress in controlling the infection, both in the general population as well as in those groups at particular risk of infection.

Prevention of infection in people who inject drugs

Good evidence now exists to suggest that the combination of effective drug treatments, such as opiate substitution therapy; support for safe injecting, for example through NSPs; and treatment of HCV infection in PWID, can impact on the incidence and prevalence of HCV infection.[25, 26, 27, 28, 29]

England

England has continued to invest in effective and accessible community based drug treatment. As a result, the number of adults that had ever injected receiving drug treatment has increased by a third (33%) from 84,216 in 2005/06 to 111,939 in 2011/12 (Table 11). This represents around half of all persons in drug treatment in 2011/12;[30] 46% (50,972/111,939) of those that had ever injected were currently injecting when they entered treatment (Table 11). Of the 69,434 people newly presenting to treatment in 2011/12,[30] 30,196 (44%) were either currently or had previously injected drugs, the same proportion as in 2010/11.

In England, prevention measures to reduce injecting drug use are thought to be having an impact with evidence indicating that the prevalence of opiate and crack-cocaine injecting is falling.[31]

NSPs are provided throughout England principally through pharmacies and specialist services. NSP coverage in England is estimated using data collected through the UAM Survey of PWID. Participants in the UAM Survey are asked about their use of NSPs, and in 2012 the vast majority (83%, 1,514/1,835) of the participants who had injected during the preceding year, reported that they had used an NSP during that time; only 5% (95/1,835) of these participants had never used an NSP.

Those who had injected in the preceding four weeks were also asked about both the number of times they had injected, and the number of needles they had received during that time. In 2012, just less than half (47%, 545/1,160) indicated that the number of needles they had received during the preceding four weeks was greater than the number of times that they had injected (this compares to 50% in 2011 (435/878). These data should to be interpreted very cautiously. First, some people get more needles than they need from NSPs, and pass them on to partners or friends (secondary distribution). Second, on average, more than one needle is likely to be needed per injection, as needles may also be

used during drug preparation and an injection may require several attempts (and therefore needles) to access a vein.

One-third (33%, 416/1,254) of UAM Survey participants in 2012 who had injected during the preceding four weeks had injected with a needle that had been previously used and which they had attempted to clean.

Together these findings indicate that, in England the majority of PWID are accessing NSPs. However, they also suggest that the amount of equipment provided needs to be increased, and that provision needs to be better targeted. They also suggest a need for education on appropriate cleaning techniques for needles and syringes, such as using cold water and bleach to kill any virus on the equipment.

Offender Health at the Department of Health commissioned a DVD resource entitled “Bleach Works”,[32] which was disseminated across the English prison estate during 2012. The DVD, developed by Exchange Supplies, shows prisoners how to use bleach disinfectant tablets to protect themselves from BBVs and other infections. A recent audit of hepatitis C services in a representative sample of English prisons suggested that disinfection tablets for sterilising injecting equipment were available in 81% of English prisons.[7] These tablets were accessed in a variety of ways: 53% of prisons made them available via dispensers, 41% of prisons distributed them directly via prison officers, and 12% of prisons distributed them via healthcare staff.[7] A variety of staff were responsible for monitoring and replenishing disinfectant tablets.[7]

Wales

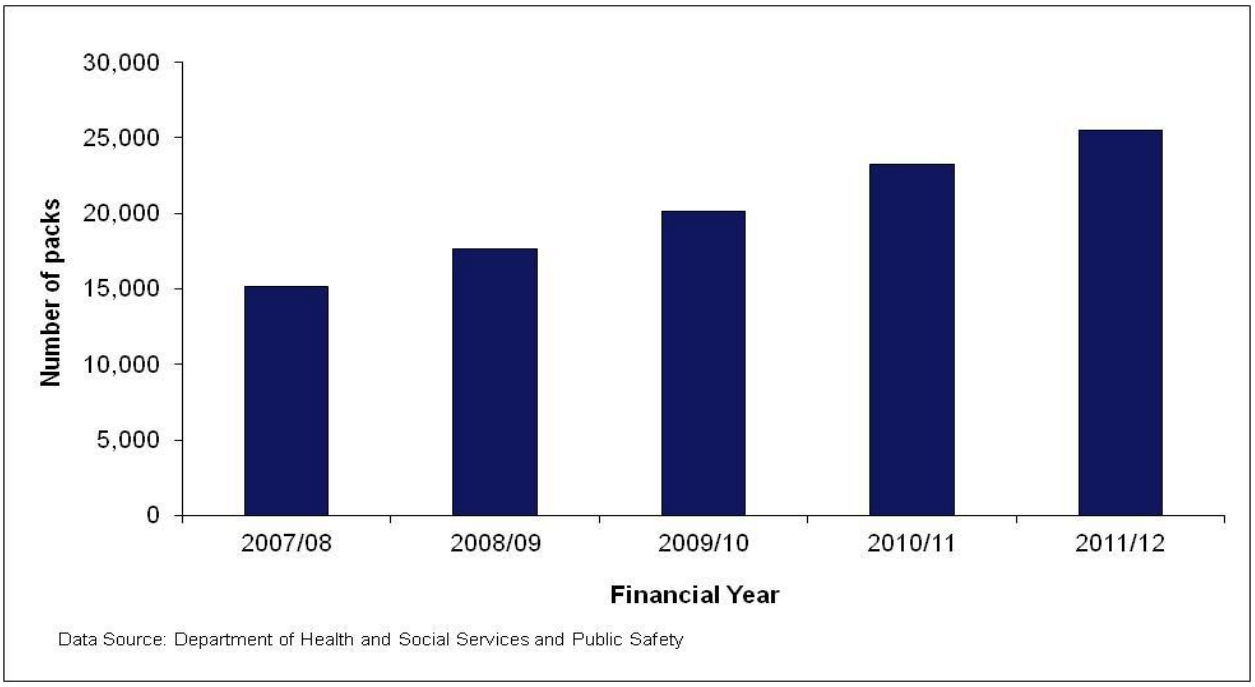
In 2012 the Welsh HRD was active in 46 statutory and voluntary sector NSP sites across Wales, including five mobile services and three hostels. There remain 207 community pharmacies providing NSP services not yet linked to the HRD and it is planned that these will be incorporated in 2013. As such, data reported here do not represent activity among all PWID accessing NSP services across Wales.[33] Data were available from October 2010 to March 2013, and during this period just over 10,000 individuals attended these NSP services at least twice.

Northern Ireland

In Northern Ireland, NSPs have been developed, and by the end of 2012 were available in 17 locations, with continued planned expansion in 2013. A Forum meets twice a year with membership from pharmacies, community addiction

teams, service users, voluntary organisations and outreach workers. The number of packs dispensed by needle exchange schemes has increased year-on-year since 2007/08, reaching 25,530 in 2011/12 (Figure 16).

Figure 16: Number of packs dispensed by NSPs in Northern Ireland: 2007/08-2011/12

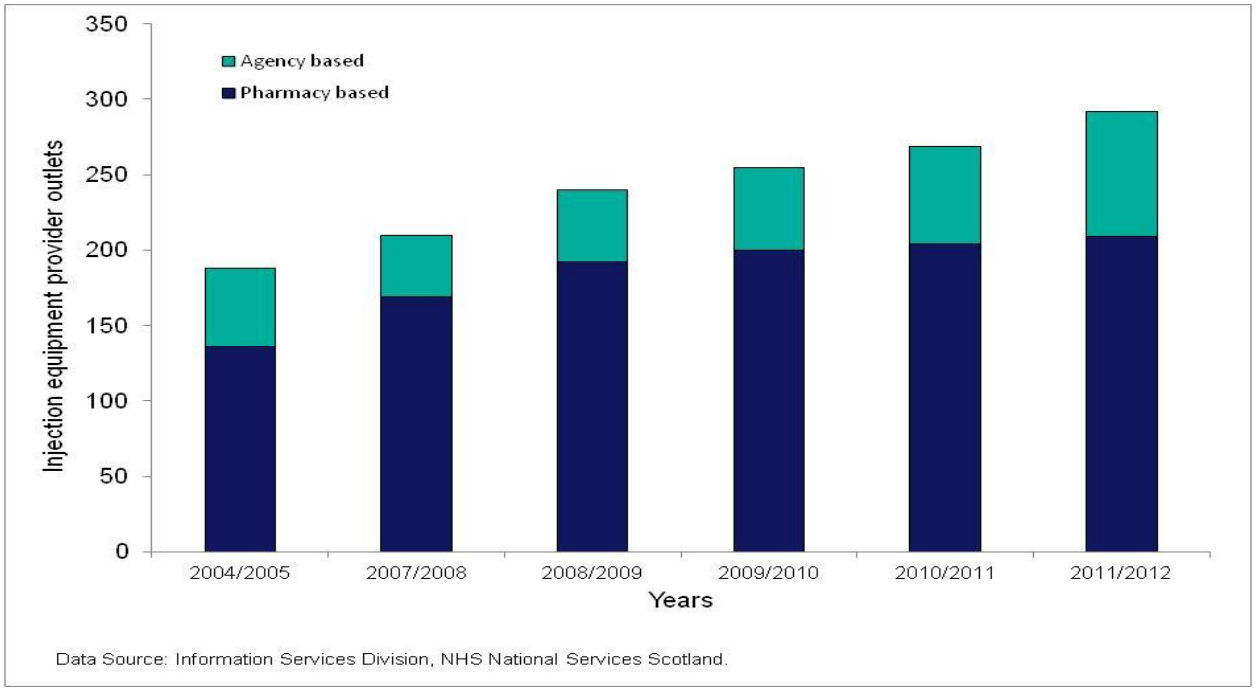


Scotland

The number of PWID (current) in mainland Scotland during 2009 has been estimated to be in the range 11,500-18,600, representing 0.3-0.6% of the Scottish population aged 15-64 years**;** this represents a decrease in the number of PWID (current) in mainland Scotland from 2006, which was estimated in the range of 16,300-27,000 (Personal Communication: Overstall A, University of St Andrews).

In 2011/12, 292 injection equipment provider outlets, of which 209 (72%) were pharmacy based, were reported to be operating in Scotland.[34,35] These figures represent an increase from 188 in 2004/05 (Fig 17).[36, 37,38]

Figure 17: Injection equipment provider outlets operating in Scotland between 2004/2005 and 2011/2012.



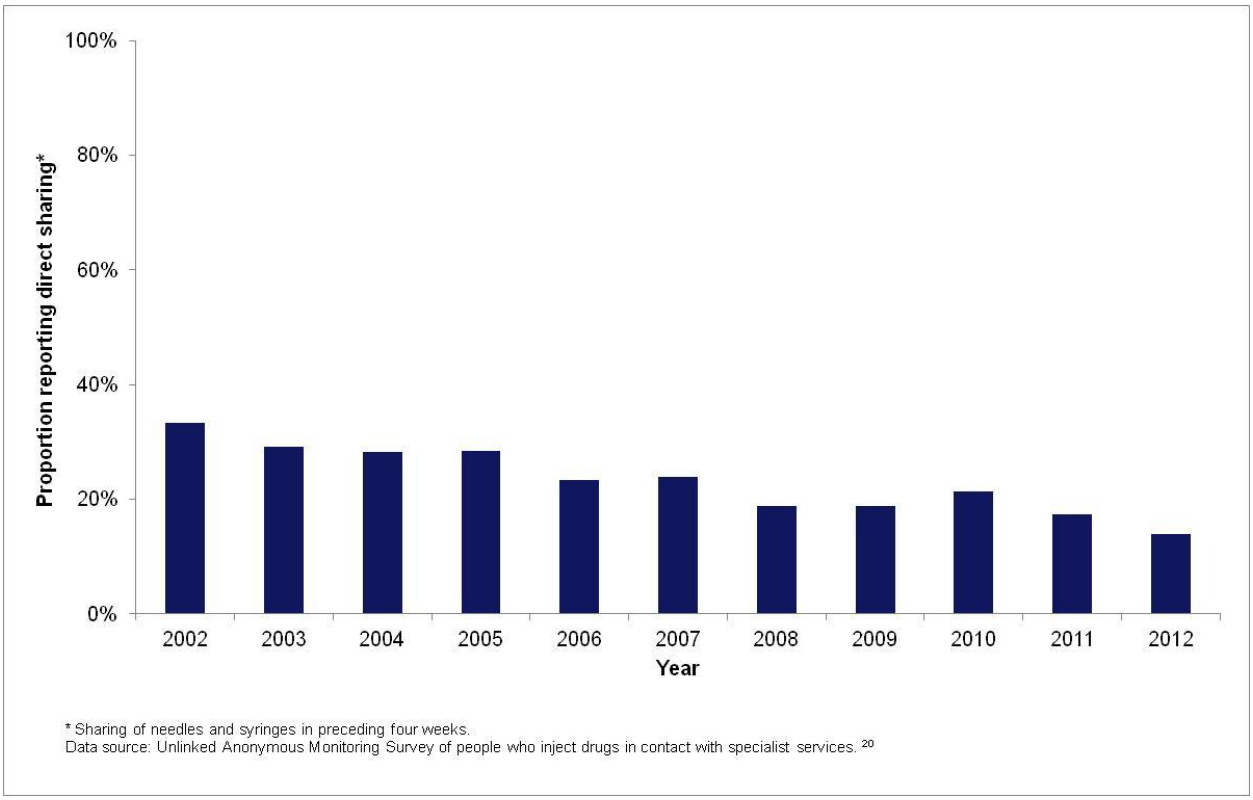
Approximately four million needles/syringes were distributed to PWID in Scotland during 2011/12, based on data reported by only 84% (249/298) of the injection equipment provider outlets. Accounting for the under-reporting in 2011/12, this is higher than the 3.6 million needles/syringes reported to have been distributed to PWID in Scotland during 2004/05, and similar to the number of needles/syringes – in the range 4.4 to 4.7 million per year - reported to have been distributed in recent years (2007/08 to 2010/11) (Table 12). The number of injecting paraphernalia items distributed to PWID has remained stable in recent years, since the several-fold rise in the provision of filters and spoons/cookers between 2008/09 and 2009/10 (Table 12).

UK data on the sharing of needles and syringes by PWID

As the sharing of injecting equipment and associated paraphernalia is the main route of transmission of infection among PWID, it is important to monitor levels of sharing within this population.

In England, 14% of current injectors participating in the UAM Survey, reported direct sharing of needles and syringes in 2012 (Figure 18); this level has declined from 33% in 2002.[20] The reported level of needle and syringe sharing among PWID participating in the UAM Survey in 2012 varied across England; with the level ranging from 5.5% in the East of England region to 20% in the South West.[8;20]

Figure 18: Trends in sharing of needles and syringes in the preceding four weeks among people who inject drugs in England 2002-2012

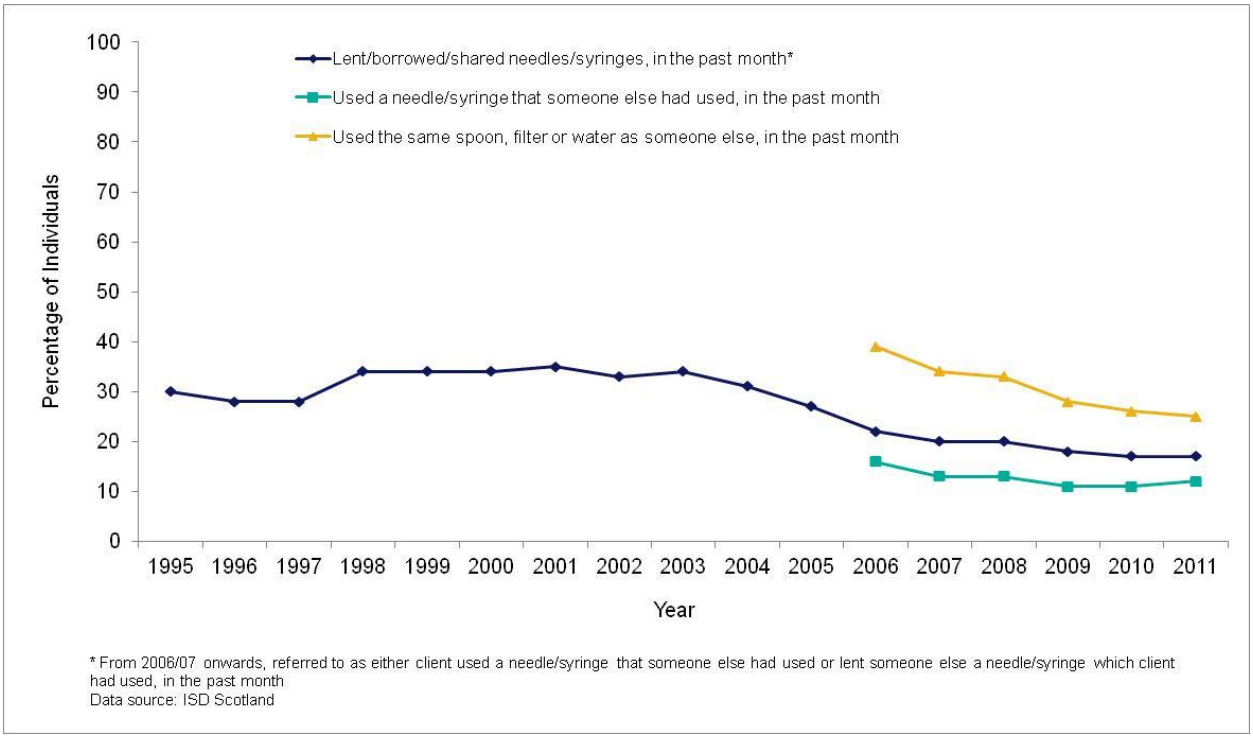


In Northern Ireland, 19% of current injectors reported direct sharing of needles and syringes in 2012; this level has declined from 44% in 2002/03. In Wales, 10% reported direct sharing in 2012; this level has declined from 38% in 2002.[20,8]

In Scotland, among individuals attending drug treatment services and who had injected in the previous month, a decline in needle/syringe sharing (either borrowing or lending a used needle/syringe) in the previous month was observed from 27-35% during 1995/96-2005/06 to 18-22% during 2006/07-2009/10, and 17% during both 2010/11 and 2011/12 (Figure 19). Furthermore, a decline in only borrowing used needles/syringes in the past month was observed from 16% in 2006/07 to 11-12% in years 2009/10, 2010/11 and 2011/12.

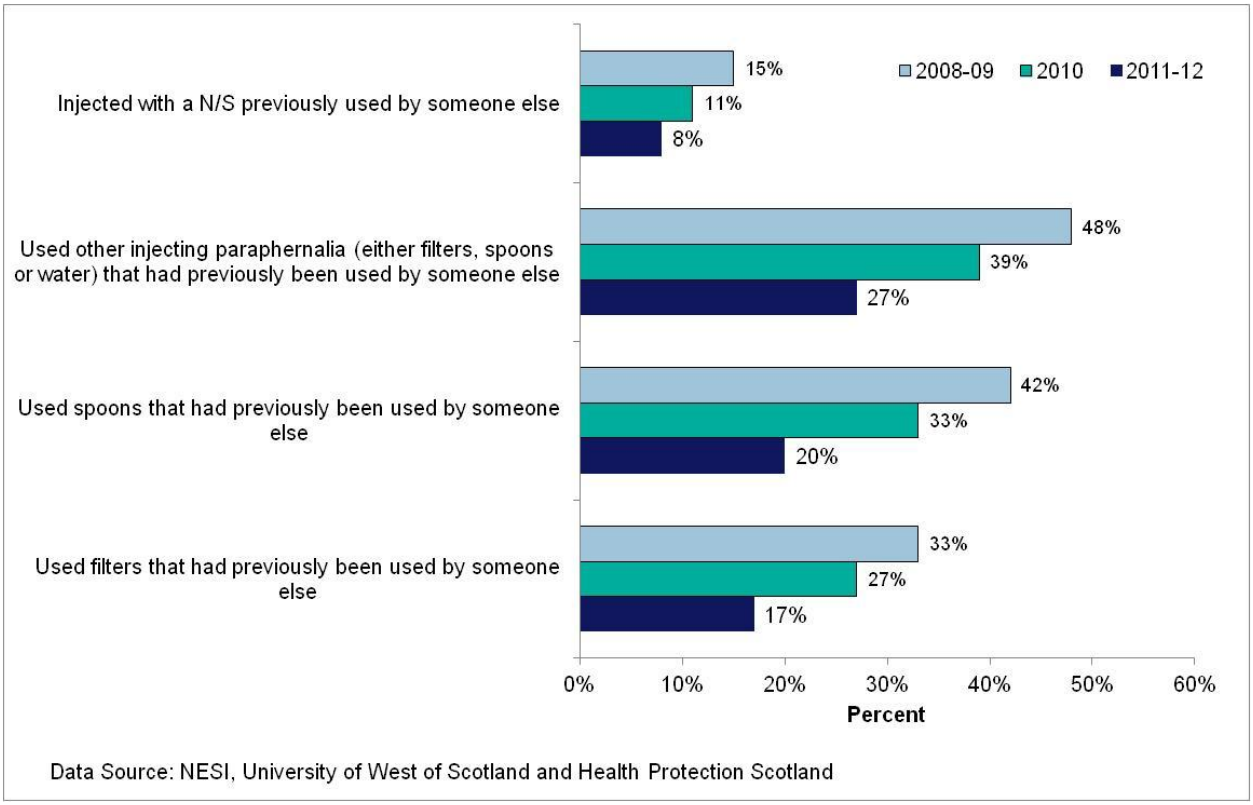
Among individuals attending drug treatment services in Scotland who had injected in the previous month, a decline in the proportion who had used the same injecting equipment (either a spoon, filter or water) as someone else in the past month was observed from 39% in 2006/07 to 25% in 2011/12 (Figure 19).

Figure 19: Percentage of individuals who reported that they had shared injecting equipment in the past month, among clients attending drug treatment services in Scotland who had injected drugs in the past month



In Scotland, among 1,800 PWID interviewed at services providing injection equipment during 2011-12 and who had injected in the past six months, 8% reported having recently (last six months) injected with a needle/syringe previously used by someone else; this compares to 15% and 11% among PWID (current) similarly surveyed during 2008-09 and 2010, respectively (Figure 20). In this 2011-12 survey, 27% reported having recently (last six months) used other injecting paraphernalia (either filters, spoons or water) that had previously been used by someone else (with 20% having indicated spoons, 17% indicated filters, and 20% indicated water). These figures are lower than that reported among PWID (current) surveyed in 2010, where 39% had recently (last six months) used other injecting paraphernalia that had previously been used by someone else (with 33% having indicated spoons, 27% indicated filters, and 29% indicated water) (Figure 20).

Figure 20: Proportion of PWID, surveyed at services providing injection equipment across mainland Scotland in 2008-09, 2010, and 2011-12, who reported sharing injection equipment.



Incidence of infection

Monitoring the impact of prevention measures on the incidence of infection remains a challenge as incident infection is difficult to measure directly. As a result, a number of methods have been used to generate information to provide insight into the likely trends in incidence over time.

In England, Wales and Northern Ireland, recent transmission of hepatitis C has been explored among the participants in the UAM Survey of PWID by looking for those who have recently developed antibodies to hepatitis C. This has been undertaken by testing the HCV antibody positive DBS samples collected in the survey for antibody avidity. Samples from HCV-infected individuals (demonstrated by the detection of HCV RNA), with HCV antibodies whose overall avidity is weak are likely to be from individuals who have recently been infected with hepatitis C. The length of time that samples from recently infected individuals will have antibodies with weak avidity is uncertain, but this state may last from two to six months.[39,40,41] Avidity testing was used to explore recent transmission in 2011-12 among those survey participants who had injected during the preceding year. Those anti-HIV positive or who had participated in 2012 but reported previously participating in 2011 were excluded. Preliminary

data indicate that in this group there were 67 HCV antibody positive samples where the avidity of the antibody was weak and hepatitis C viral RNA was also present and 2,056 participants who were HCV antibody negative. Therefore, of the survey participants who were potentially at risk of acquiring hepatitis C, 3.3% (95% CI, 2.6%-4.1%) had been infected. These preliminary data are consistent with an incidence of hepatitis C infection among PWID in England, Wales and Northern Ireland of between 7 and 20 infections per 100 person years of exposure.

In the very early stages of HCV infection, individuals have high levels of viraemia prior to developing antibodies – often referred to as the viraemic pre-seroconversion window. During this relatively short period, individuals will test hepatitis C antibody negative but RNA positive. In Scotland, among 996 PWID who tested hepatitis C antibody negative at services providing injecting equipment during 2011-12, 0.9% were found to be RNA positive on DBS testing; lower than the level among PWID surveyed in 2008-2009 (2.1%) and 2010 (1.5%). Assuming a viraemic pre-seroconversion window period of 51 days,[42] the incidence of HCV infection among PWID across Scotland is estimated at 6.1 per 100 person years during 2011-12; this compares with estimated incidence rates of 13.3 and 9.9 per 100 person years during 2008-2009 and 2010, respectively.

In Scotland the incidence of HCV infection has been found to be very low among prisoners in a nation-wide study conducted during 2010-2011; the low incidence of infection is due most probably to the low occurrence of in-prison injecting and high coverage of opiate substitute therapy.[43]

Because most new infections are acquired via injecting drug use at a relatively young age[44] the prevalence of infection in young adults or in recent initiates to injecting drug use, can be used as proxy measures. In England, these proxy measures suggest that incidence has remained relatively stable over recent years (Figure 21; Figure 22; Figure 23).

Figure 21: Number of anti-HCV tests performed in young adults and proportion positive by year in 24 sentinel laboratories 2008-2012

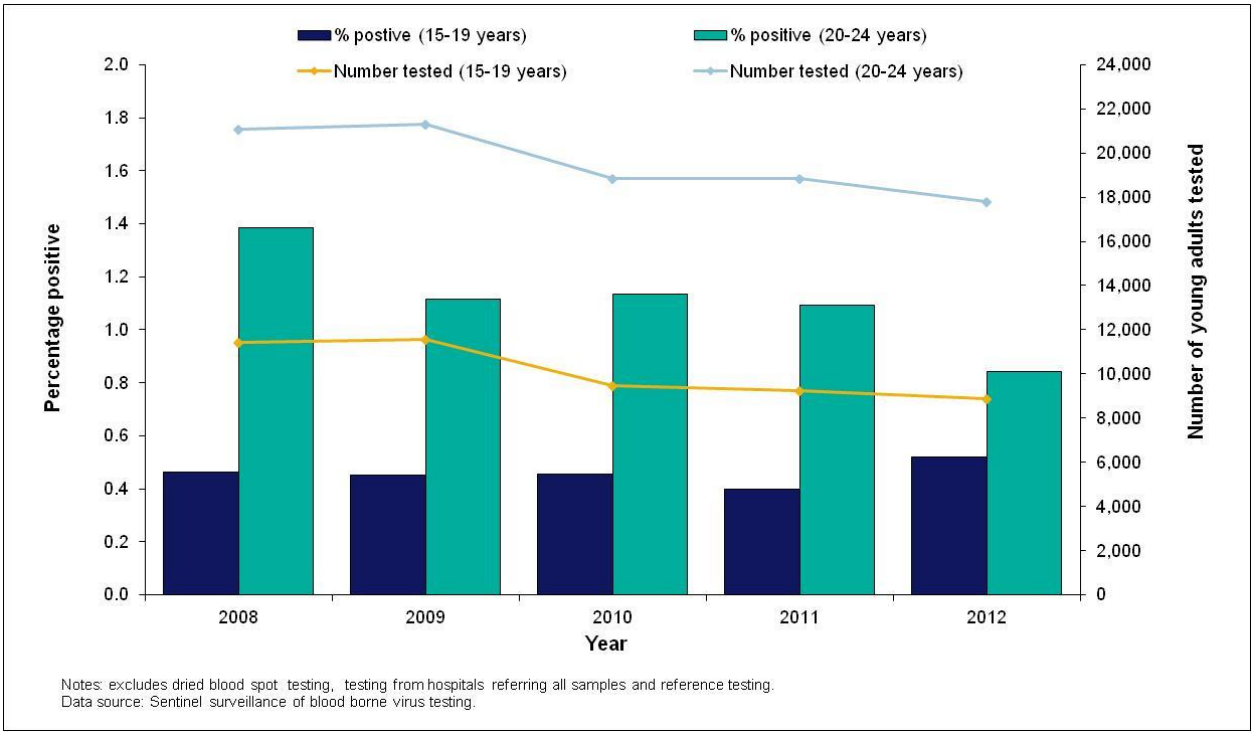
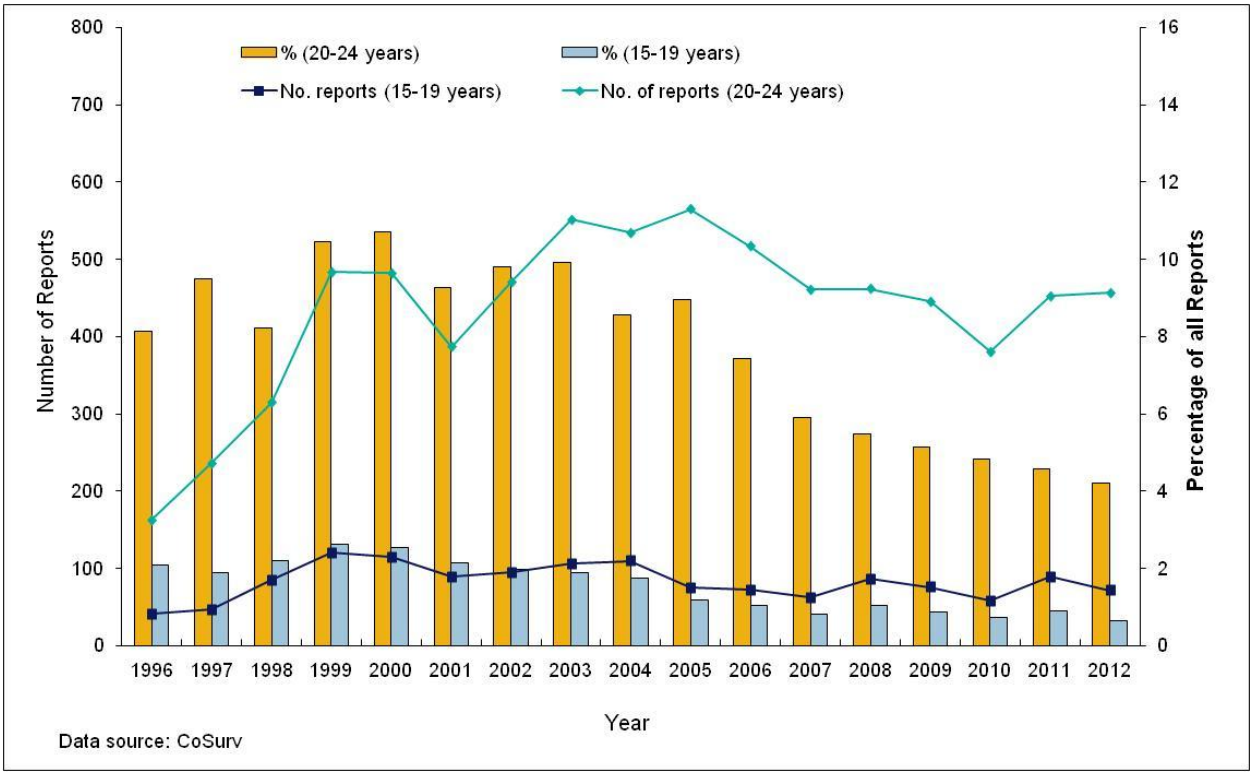
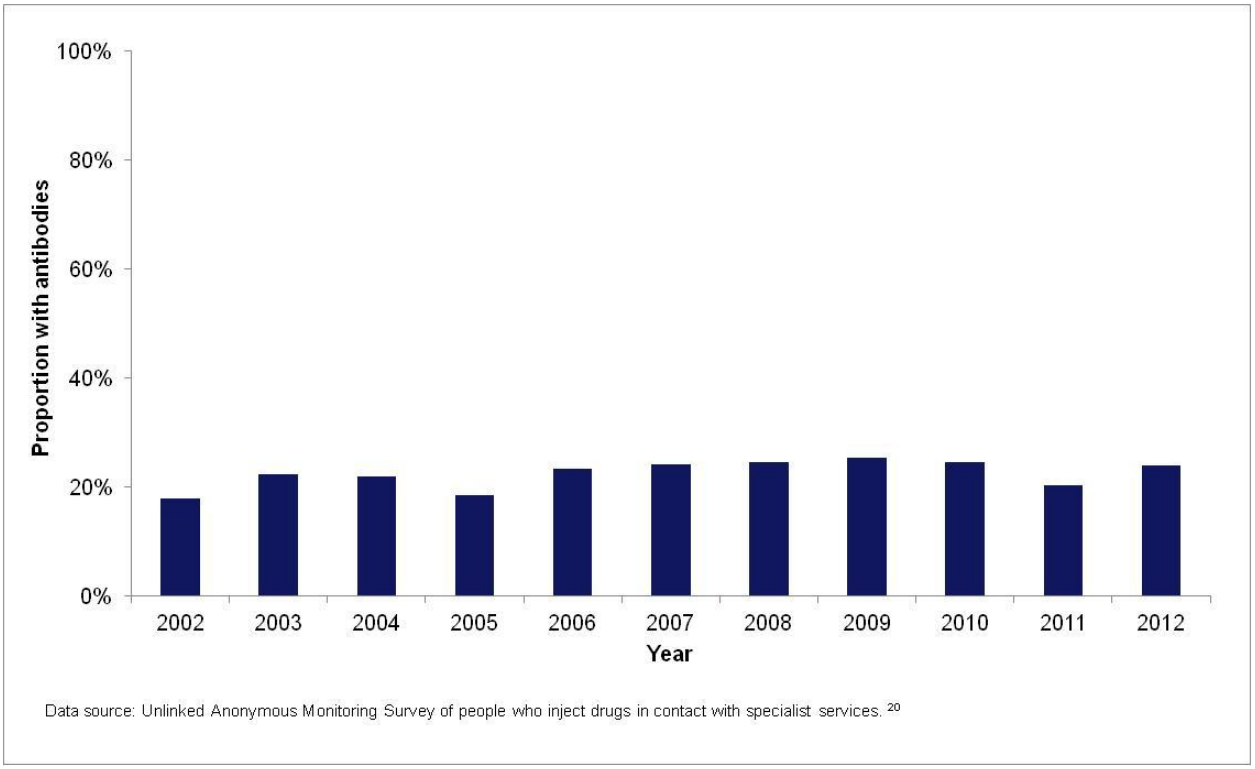


Figure 22: Number of laboratory reports* of hepatitis C reported in young adults in England: 1998-2012



*Statutory notification by diagnostic laboratories was introduced in October 2010[8]

Figure 23: Hepatitis C prevalence* in those who began injecting in the last three years: England 2002-2012



* During 2009 to 2011 there was a phased change in the sample collected in the survey from an oral fluid to dried blood spot (DBS). The sensitivity of the anti-HCV tests on these two sample types is different. The sensitivity of the oral fluid test for anti-HCV is approximately 92%,[21] that on DBS samples is close to 100%. Data presented here has been adjusted for the sensitivity of the oral fluid test.

In England, enhanced surveillance of newly acquired HCV infection in MSM provides evidence of ongoing, but declining sexual transmission of HCV among HIV positive MSM. In this population, the estimated incidence of infection declined significantly over time from 7.0 per 1,000 person years in 2008 to 2.2 in 2012 ($p<0.001$).

In Scotland, among 454 PWID surveyed at services providing injection equipment during 2011-12 and who had commenced injecting in the past five years, 23% tested positive for hepatitis C antibodies (in anonymous testing of their DBS samples); lower than the proportions who had tested positive in 2008-09 (29%) and 2010 (28%) (see Figure 4).

Diagnosis, testing and awareness of infection

Raising awareness of infection

Because hepatitis C is usually asymptomatic in the early years of infection, many individuals remain undiagnosed. Raising both professional and public awareness therefore remains a priority and an important component of reducing the burden of undiagnosed infection.

As in previous years, a variety of initiatives are ongoing throughout the UK to increase public awareness of hepatitis C. Many of these are specifically designed to target those at highest risk of infection, including past or current PWID, offenders, and individuals of South Asian origin. The success of these initiatives has been dependent on the significant contribution of numerous stakeholders working across a range of settings. The NGO sector has been particularly influential and organisations such as The Hepatitis C Trust, the British Liver Trust, Addaction and the Scottish Drugs Forum (Hepatitis Scotland) deserve a special mention. Such work is essential and complements government and public sector initiatives in this key area.

In England, 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.[45] By May 2013, 936 individuals had completed the e-learning module (76% in England; ~1% in Northern Ireland; 9% in Wales; 14% in Scotland); 447 had attended face-to-face training days and 360 individuals had completed Level 1 of the certificate (comprising both the e-module *and* face-to-face training) (Table 13). Thirty-one candidates had completed Level 2 of the certificate, which is aimed at the more advanced practitioner (Table 13). Level 2 training includes the preparation of a portfolio of evidence and a course completion interview following completion of specialist clinical placements, self-directed study and work-based reflection and learning.

RCGP Certificate in the Detection, Diagnosis and Management of Hepatitis B and C in Primary Care

The e-module can be accessed free of charge at: www.elearning.rcgp.org.uk/course/info.php?id=76 and Level 1 face-to-face training days are currently being organised by the RCGP; interested individuals can find out more information and book onto these courses at: www.rcgp.org.uk/smah. Due to an organisational restructure, RCGP is taking expressions of interest for Level 2 of the certificate, which will be rolled out again as soon as possible. Anyone wishing to be contacted when the course is accepting applications can send their expressions of interest to hepbandc@rcgp.org.uk.

In England, a recent audit of hepatitis C services in a representative sample of English prisons suggested that 81% of prisons had training on BBVs for healthcare staff; 48% had training for prison officers and 57% had training for drug workers.[7] In Wales, within the prison setting, an e-learning package has been developed to improve the knowledge of prison staff in relation to BBVs and over 500 staff have completed this training; an evaluation will be published shortly.

Dedicated hepatitis C websites for healthcare professionals, the general public and South Asian communities are available on the NHS Choices website:

- www.nhs.uk/hepc includes a self-assessment tool on risk of having HCV infection.
- www.nhs.uk/hepatitisc/southasian
- www.nhs.uk/hepatitisc/hcp

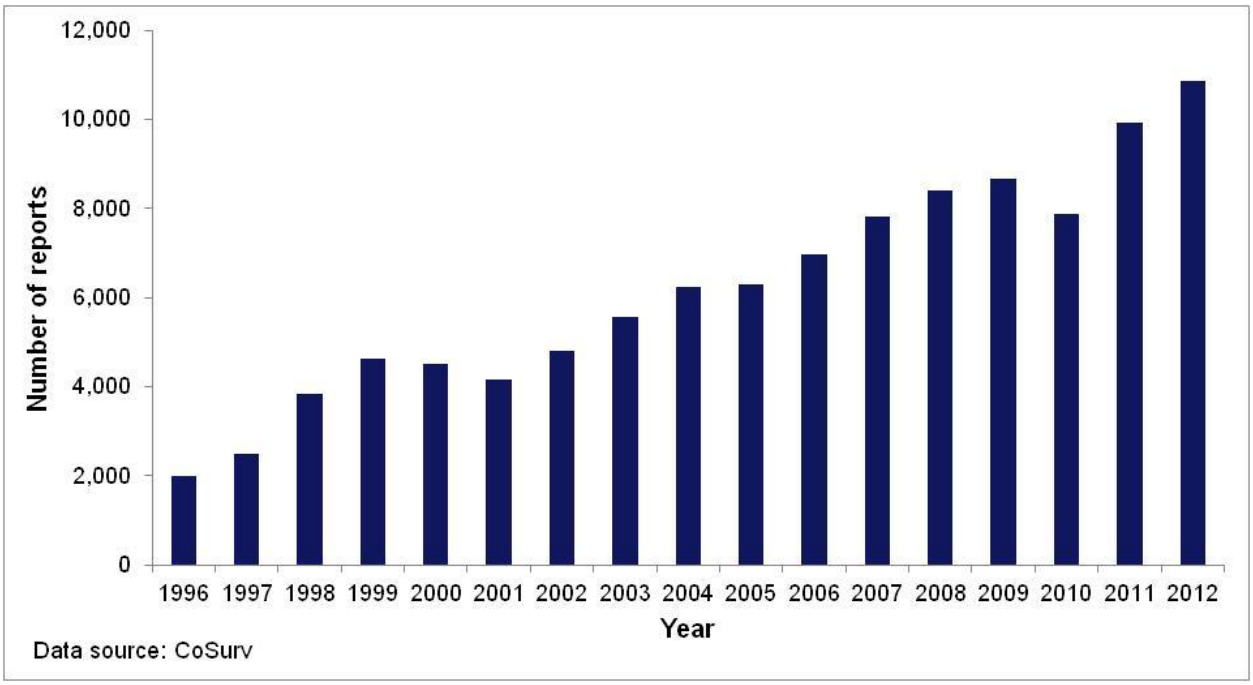
Testing and diagnosis in the general population

Trends in HCV diagnosis and testing are useful for monitoring the impact of awareness-raising initiatives and prevention activity; this in turn helps to track national progress in controlling the infection. Monitoring testing and diagnosis is useful at a population level, as well as in sub-groups that are at increased risk of infection. Monitoring infection in blood donors, who are at low risk of BBV infection, is also very useful for identifying new groups of individuals who may be at increased risk of infection. The NICE public health guidance should help to focus activity to ensure that more people at increased risk of hepatitis C (and B) infection are offered testing.[10]

England

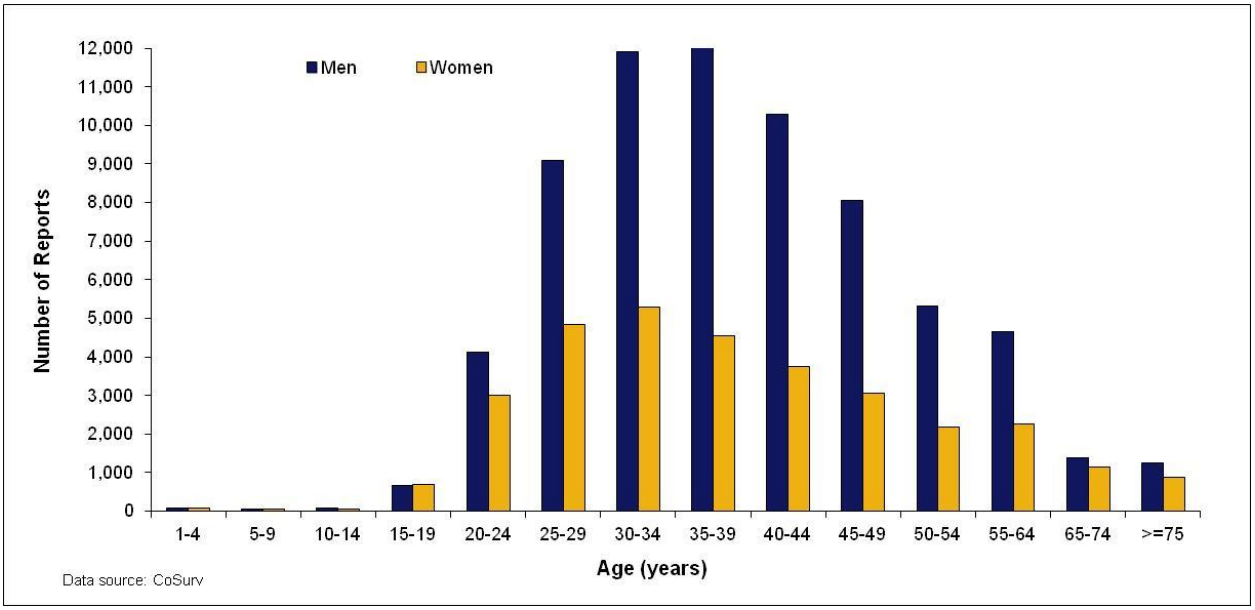
Over nearly two decades, there has been a steady increase in the number of laboratory confirmed reports of HCV in England with a more than five-fold increase between 1996 and 2012. The number of laboratory reports of individuals testing positive for antibodies to HCV increased by 9.6% from 2011 to 2012 (Figure 24). More than two-thirds of laboratory reports (68%) were in men; almost half (47%) of all reports received were in individuals aged between 25 and 39 years (Figure 25).

Figure 24: Number of laboratory reports* of hepatitis C infection from England: 1996-2012



*Statutory notification by diagnostic laboratories was introduced in October 2010[8]

Figure 25: Age and sex distribution of laboratory reports* of hepatitis C from England: 1996-2012

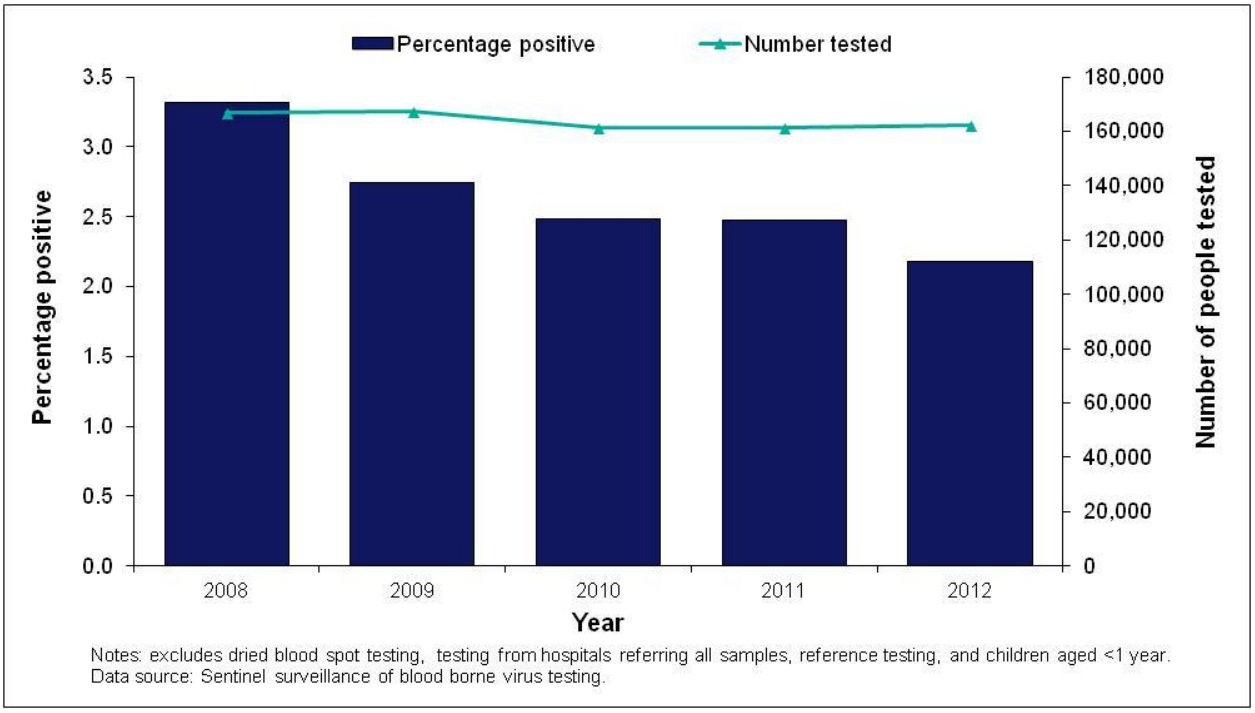


*Statutory notifications by diagnostic laboratories was introduced in October 2010[8]

There continues to be regional variation in the number of laboratory reports of hepatitis C in England with the highest figures being reported by laboratories in London and the lowest figures being reported by laboratories in the North East (Table 14). Major increases were seen in London and the North West (Table 14). A proportion of the increase observed is likely to have resulted from the introduction of statutory reporting in 2010[8], leading to reports from laboratories that had not reported previously.

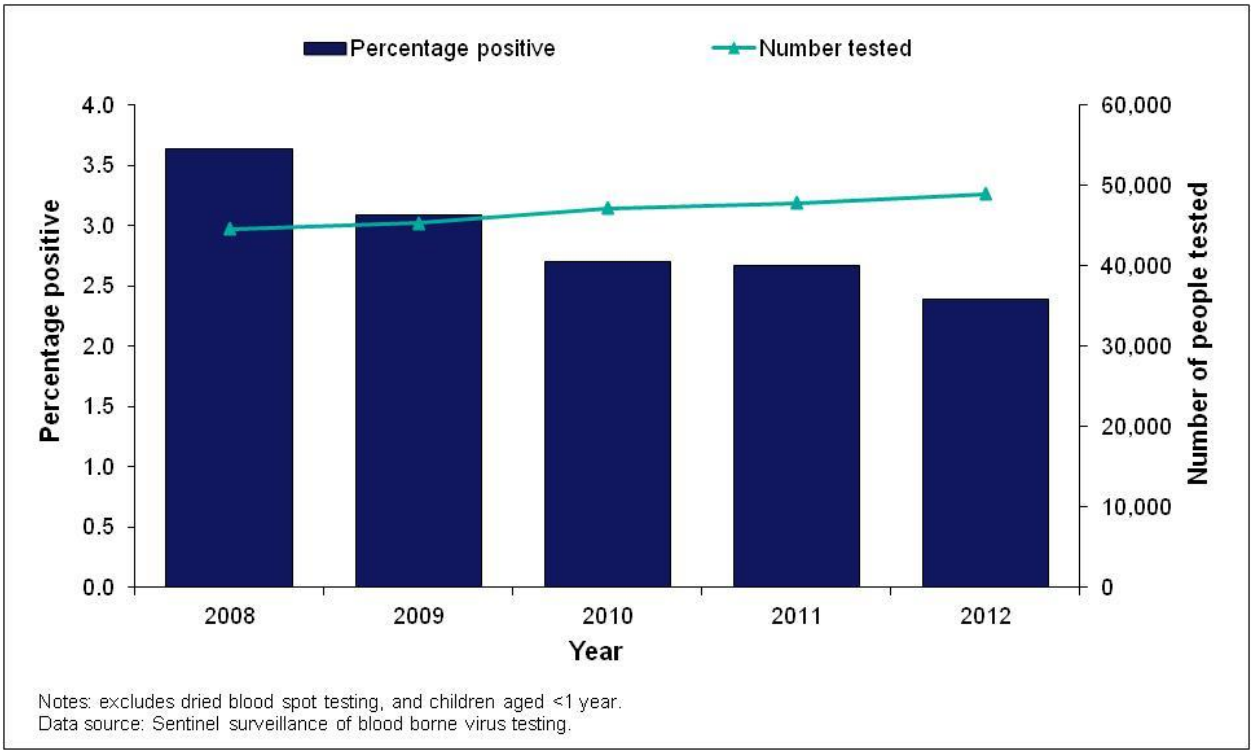
Trends in testing were analysed using data from the 24 sentinel laboratories where complete and consistent data have been available from January 2008 to December 2012 (Figure 26). Numbers of tests undertaken have levelled off since 2008. This may be partly due to testing saturation among the pool of 'easy-to-access' individuals. Overall, the proportion of people testing positive for anti-HCV has declined in recent years from 3.3% in 2008 to 2.2% in 2012, which is consistent with a higher proportion of individuals at relatively lower risk of infection being tested.

Figure 26: Number of people tested for anti-HCV by year, and proportion positive, in 24 sentinel laboratories: 2008-2012



In general practice, testing continued to increase year-on-year between 2008 and 2012, suggesting that awareness of hepatitis C in this setting may be increasing. The proportion of individuals testing positive for hepatitis C decreased over this period from 3.6% in 2008 to 2.4% in 2012 (Figure 27).

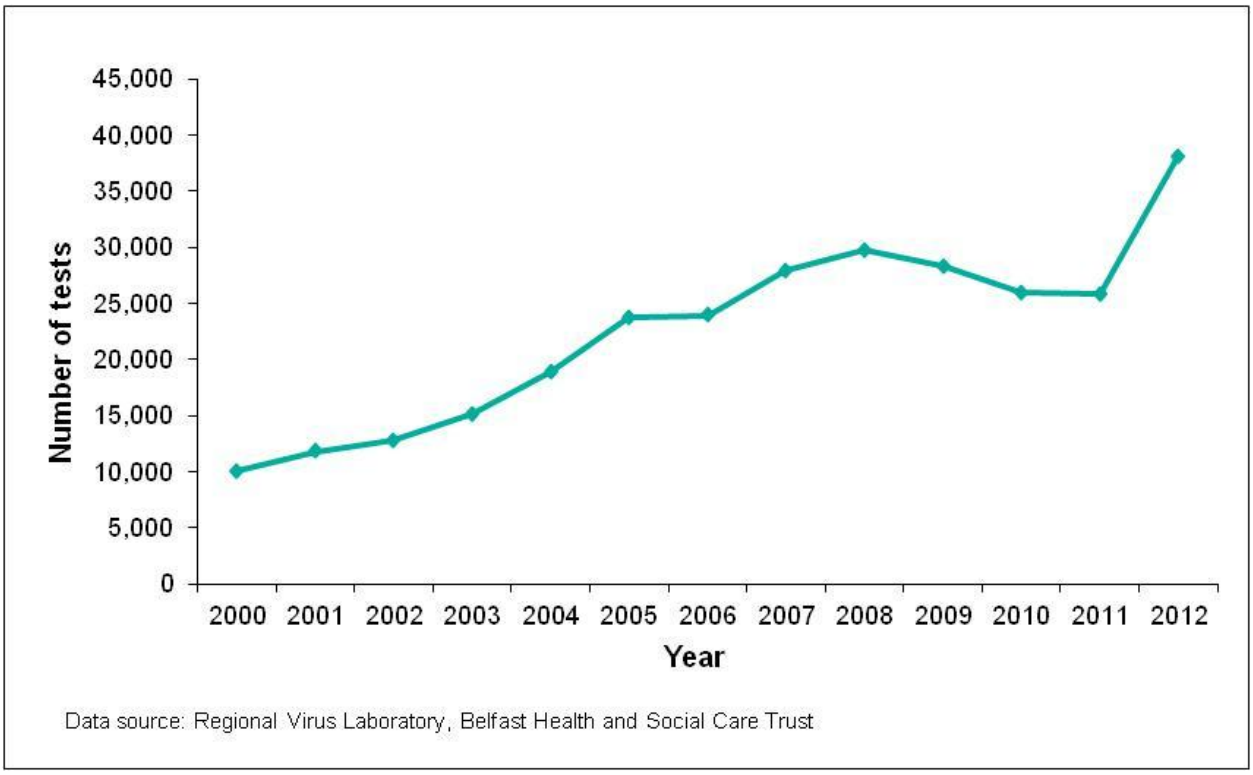
Figure 27: Number of people tested for anti-HCV by year, and proportion positive, through GP surgeries in 24 sentinel laboratories: 2008-2012



Northern Ireland

In Northern Ireland there has been an increasing trend in testing since 2000 (Figure 28). In 2012 there was a marked increase in testing, which is partly attributable to an increase in testing in STI clinics. (Figure 31)

Figure 28: Number of HCV antibody tests requested in Northern Ireland: 2000-2012



The number of new laboratory confirmed antibody positive reports of hepatitis C has increased in 2012 to 134, (Figure 29). In 2012, 93 (69%) of the 134 new laboratory confirmed cases were HCV RNA positive on the initial sample (Table 15).

The majority of confirmed cases of hepatitis C occurred in persons aged from 15 to 44 years old, with little change in proportions of different age groups over the past five years (Figure 30); 71% of newly-diagnosed cases in 2012 were male.

Figure 29: Laboratory-confirmed HCV antibody positive cases in Northern Ireland: 2000-2012

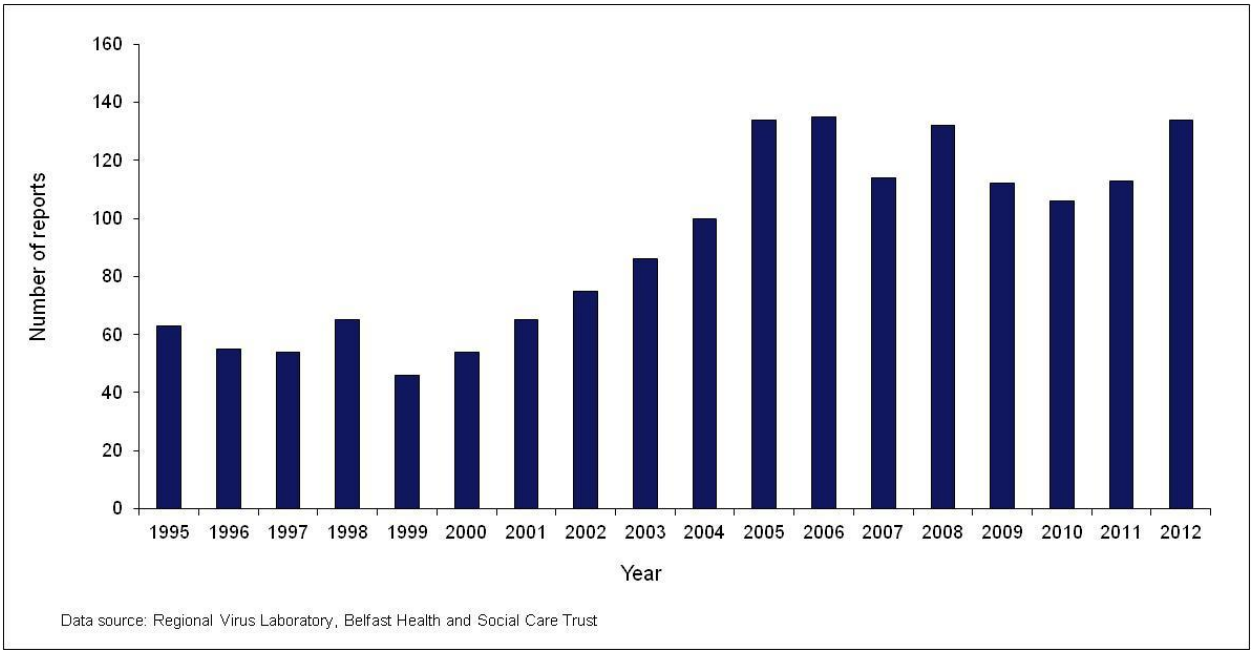
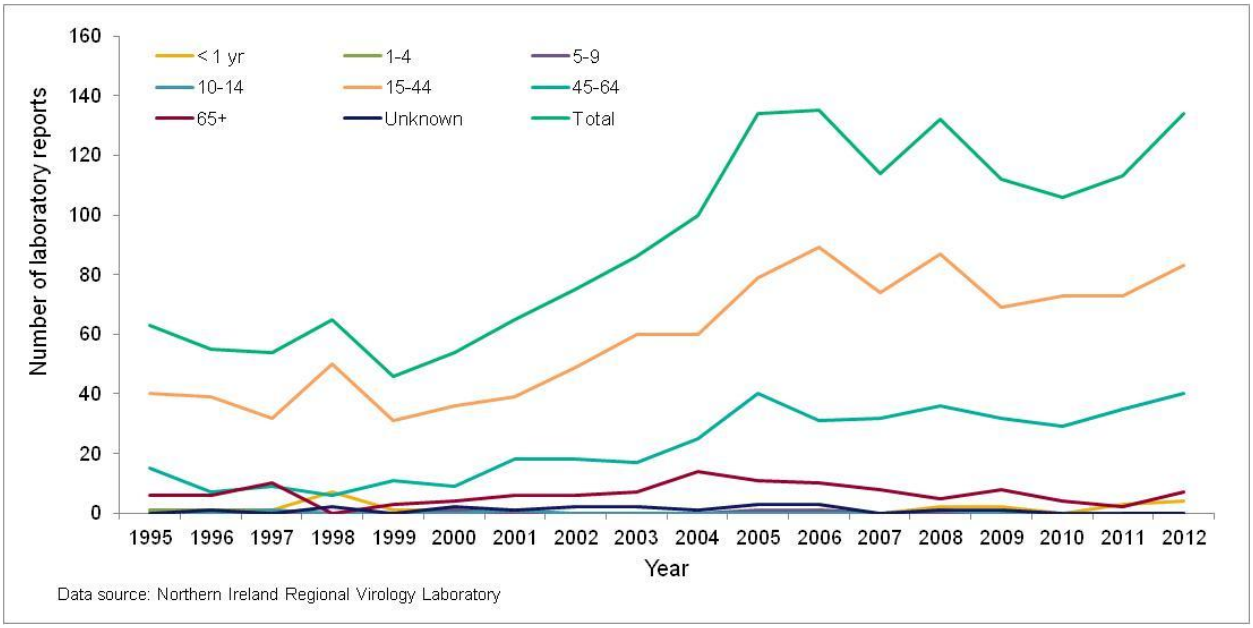


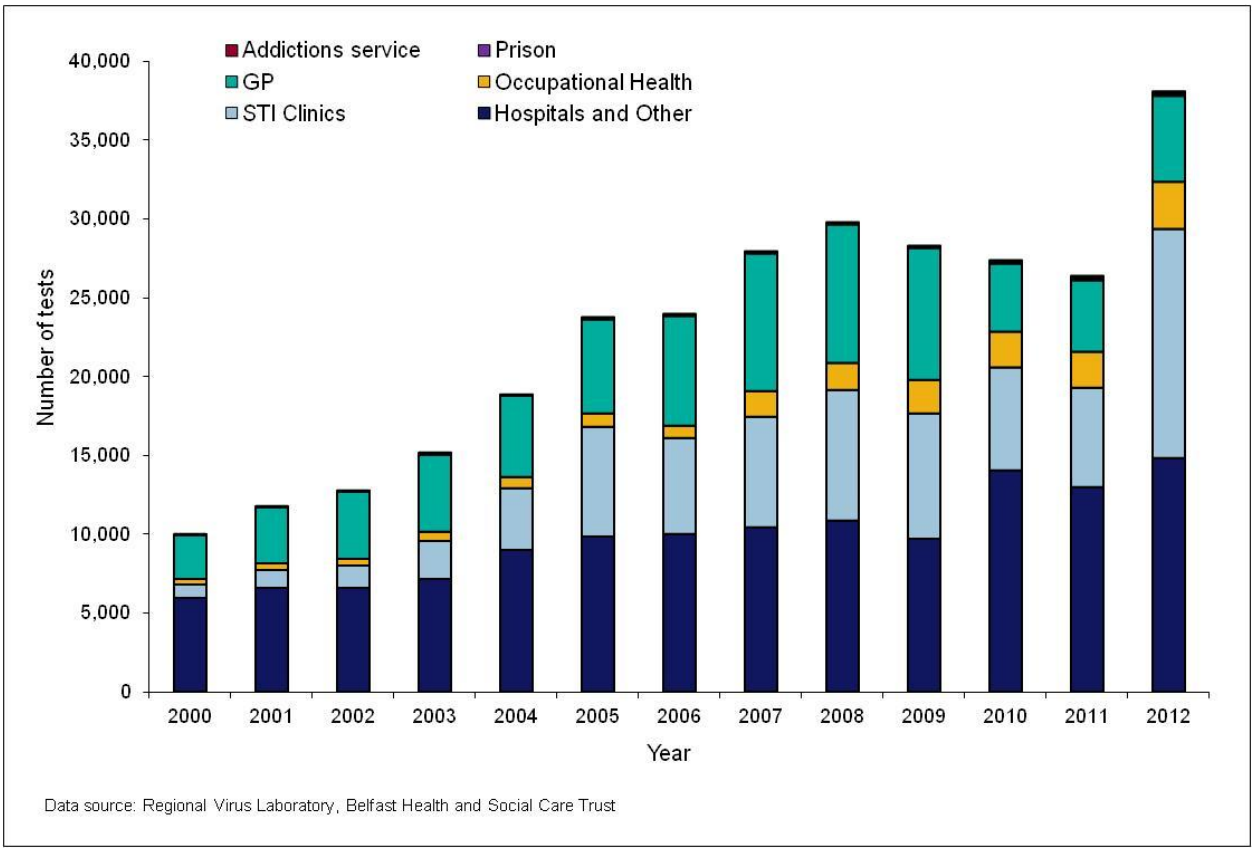
Figure 30: Laboratory confirmed HCV antibody positive cases in Northern Ireland, by age: 1995-2012



In Northern Ireland, the number of HCV testing requests received from hospitals (excluding STI clinics and occupational health) and STI clinics were almost equal in 2012. This represents a large rise in testing in STI clinics. Most other requests were received from primary care and occupational health (Figure 31);

the proportion of requests from primary care has increased since 2011, but remains below the level of 2008.

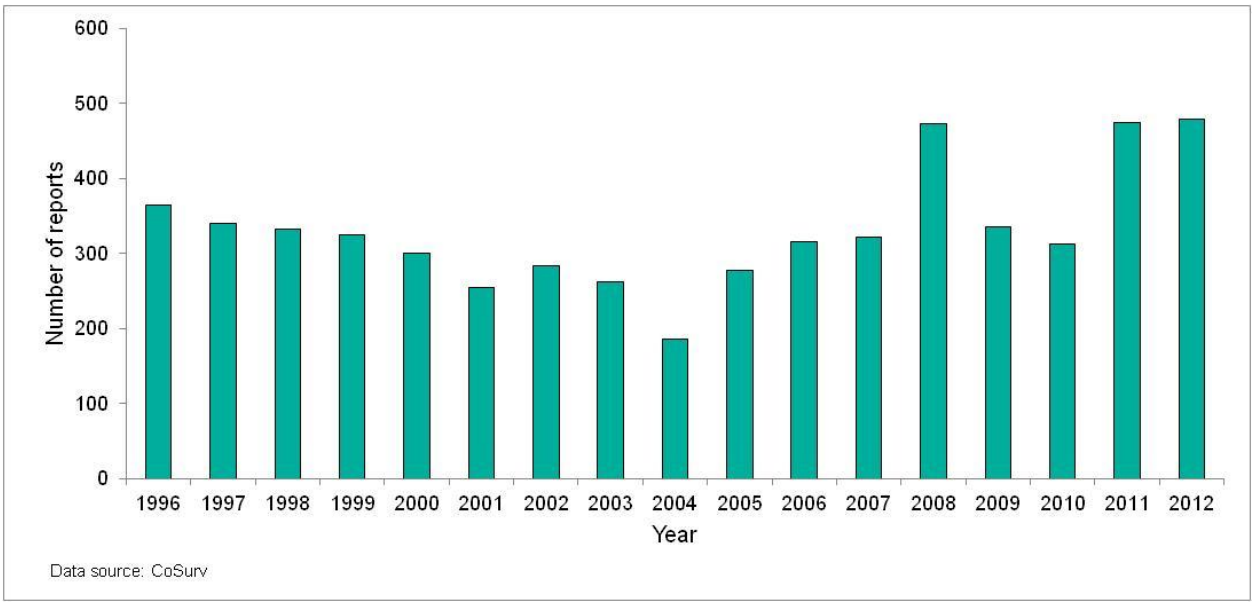
Figure 31: Source of hepatitis C antibody requests in Northern Ireland: 2000-2012



Wales

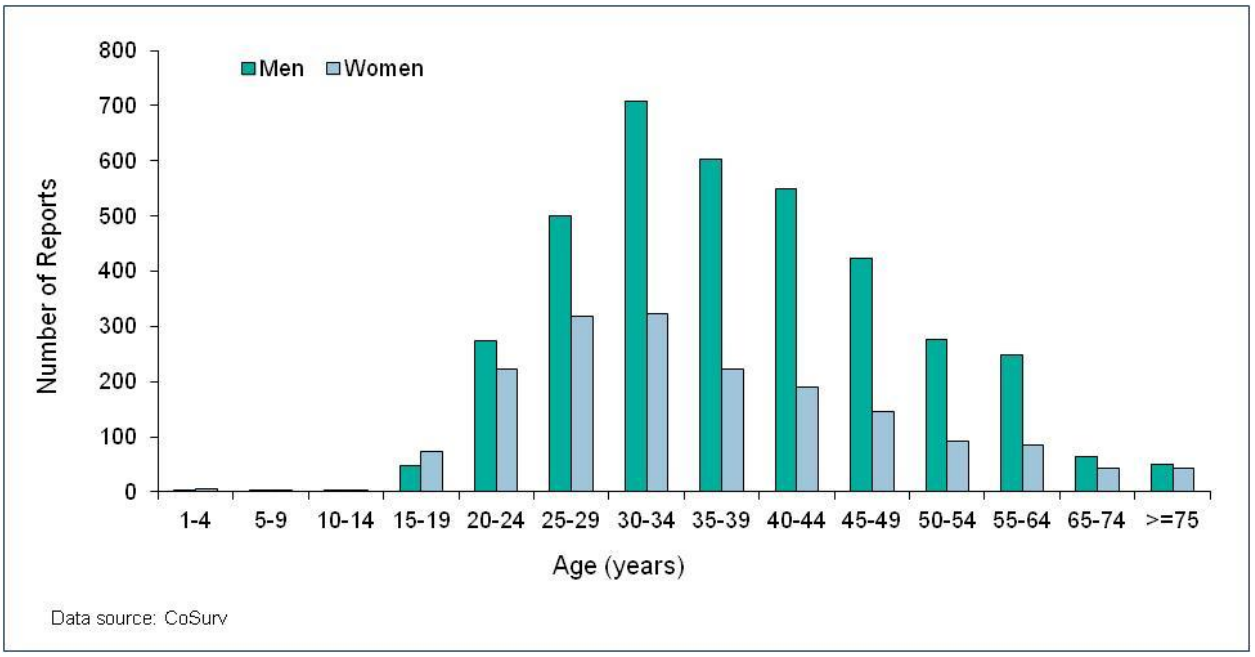
In Wales the number of laboratory reports of HCV infection has shown some variation since 1996, reaching 480 reports in 2012 (the highest number reported in any one year since 1996; Figure 32). Most infections are occurring in males between the ages of 25 and 49 years, with a peak in those aged 30 to 39 years (Figure 33).

Figure 32: Number of laboratory reports* of hepatitis C from Wales: 1992-2012



*Statutory notification by diagnostic laboratories was introduced in October 2010[8]

Figure 33: Age and sex distribution of laboratory reports* of hepatitis C in Wales: 1996-2012



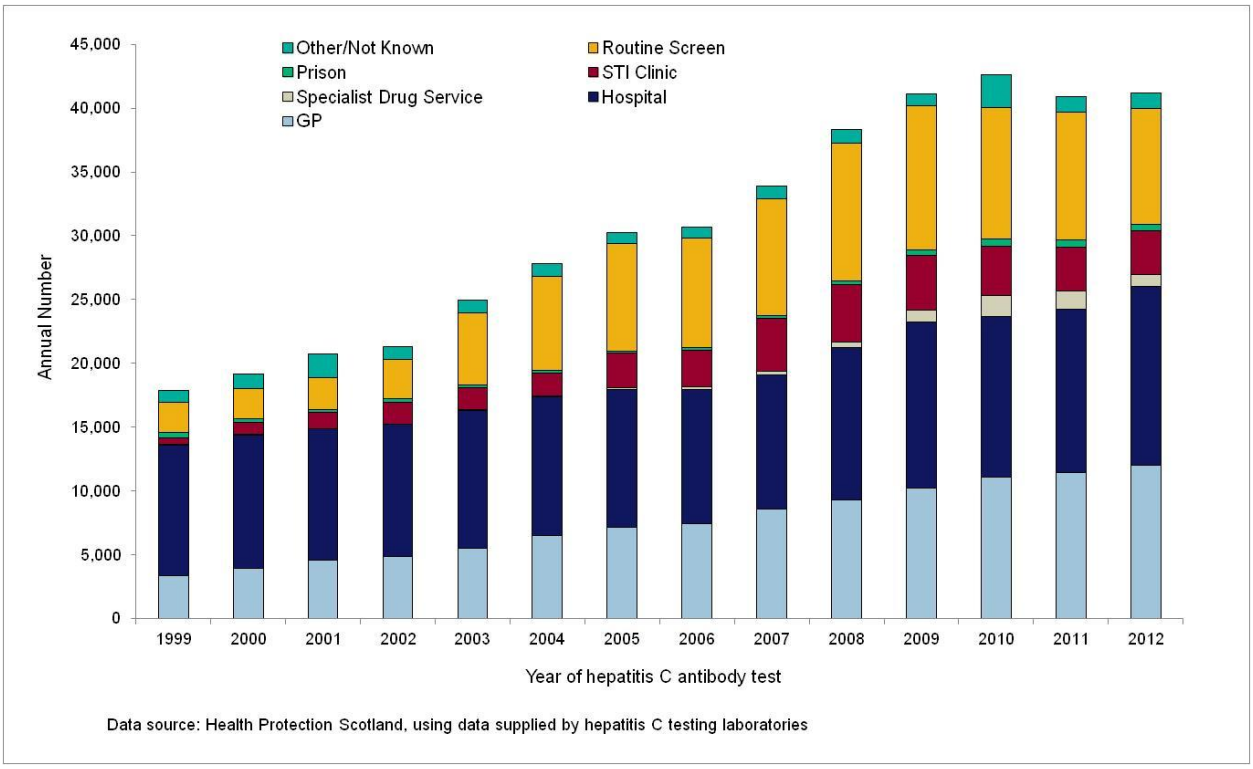
*Statutory notification by diagnostic laboratories was introduced in October 2010[8]

Scotland

The number of people tested for hepatitis C antibody in Scotland's four largest NHS Board areas (ie Lothian, Grampian, Greater Glasgow & Clyde, and

Tayside) each year has increased from approximately 18,000 in 1999 to 41,200 in 2012 (Figure 34), at an average annual increase of 8.7%. Of the 41,200 people tested for hepatitis C antibody in 2012, 33.8% were undertaken in the hospital setting (including infectious disease and gastroenterology units), 29.3% by general practitioners, 22.0% as part of a routine screen (at either a renal, fertility or occupational health clinic), 8.2% in STI clinics, 2.3% in specialist drug services, 1.3% in prisons, and 2.9% in other/not known settings. From 1999 to 2012, the number of people tested for hepatitis C antibody increased the most in STI clinics (11.5%), in settings undertaking routine screens (11.0%), and in general practice (9.9%). While in more recent years (from 2006 to 2012), the number of people tested for hepatitis C antibody increased the most in specialist drug services (by an average annual increase of 30.1%) and prisons (19.6%).

Figure 34: Annual number of people tested for hepatitis C antibody in Scotland's four largest NHS Board areas during 1999-2012, according to referral source

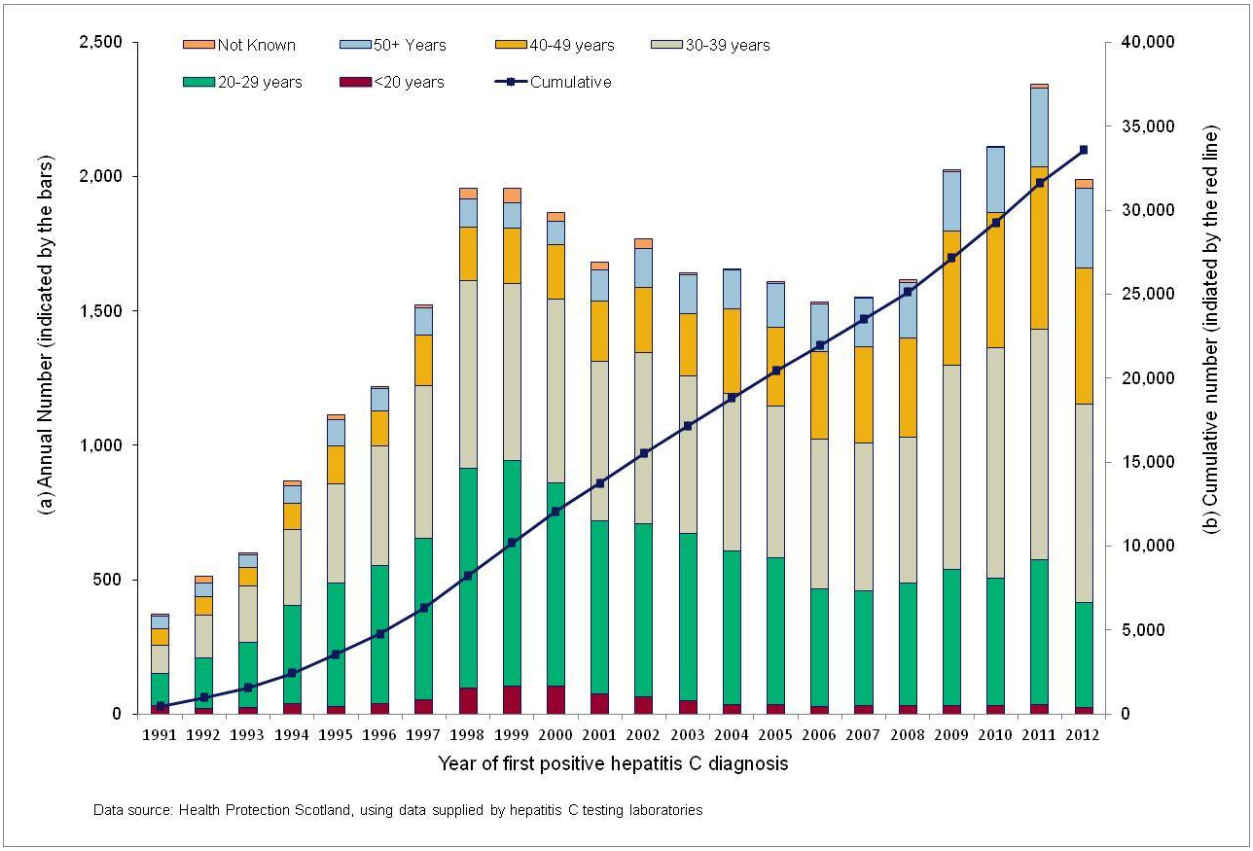


An average of 2,118 (range 1,991 to 2,343) new hepatitis C diagnoses were made each year in Scotland from 2009 to 2012, which compares to an average of 1,601 (range 1,532 to 1,656) new diagnoses made per year from 2003 to 2008 (Figure 35).[46] Of 1,991 new hepatitis C diagnoses made during 2012,[46] 20% were aged 20-29 years, 37% aged 30-39 years, 26% aged 40-49 years and 15% were aged 50 years and above, at the time of diagnosis; 63% were male; 35% reported injecting drug use, representing 95% of those with a known risk factor; and 21% were known to have been diagnosed by general practitioners, 21% in the hospital setting, 14% in specialist drug services, 6% in

STI clinics, and 5% in prisons (source of referral was not known in 31% of cases).

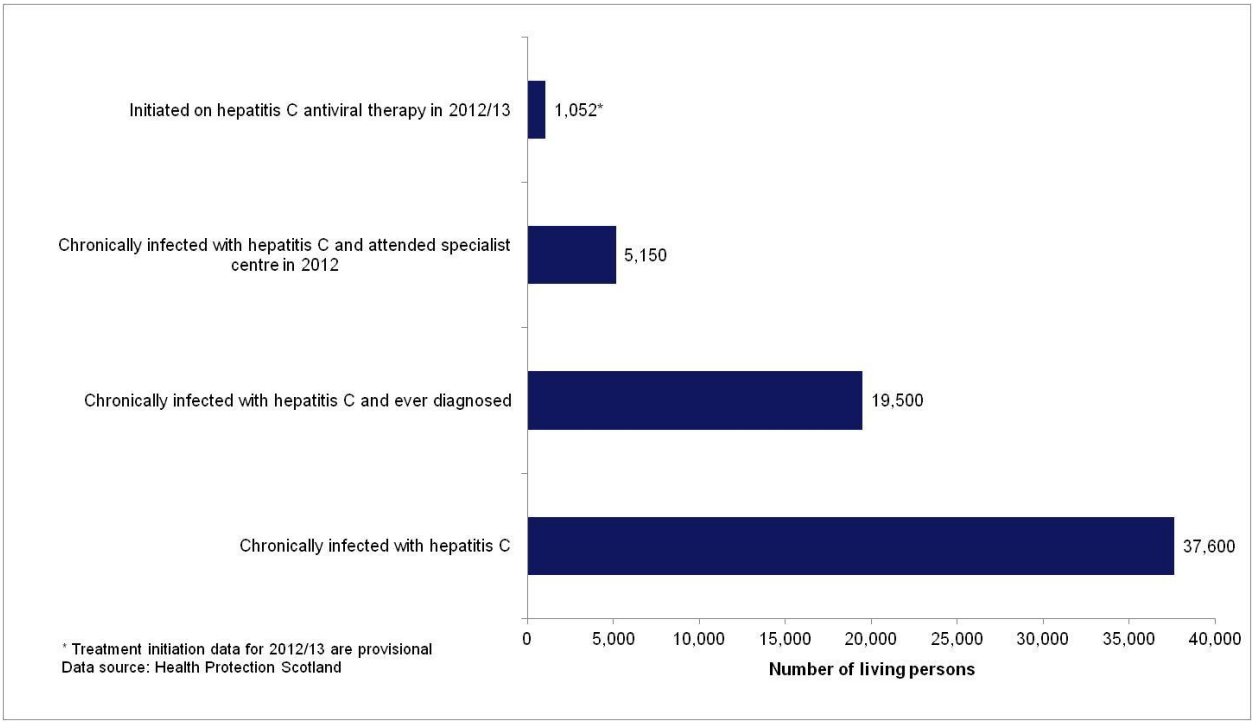
A total of 33,595 people had been diagnosed with hepatitis C in Scotland by the end of 2012 (Figure 35).[46] Of these, 14% were known to have died by 31 December 2011. Thus, approximately 0.8% of Scotland's population aged 15-59 years had been diagnosed hepatitis C antibody positive by the end of 2012.

Figure 35: Annual and cumulative numbers of people reported to be diagnosed hepatitis C antibody positive in Scotland, 1991-2012



Of an estimated 37,600 people living in Scotland with chronic HCV infection during 2012, approximately 19,500 (52%) were estimated to have been diagnosed with hepatitis C by the end of 2012 (Figure 36), leaving an estimated 18,100 (48%) undiagnosed.

Figure 36: Estimated number of living people in Scotland in 2012, who were (i) chronically infected with hepatitis C, (ii) chronically infected with hepatitis C and ever diagnosed, (iii) chronically infected with hepatitis C and had attended a specialist centre in 2012, and (iv) initiated on hepatitis C antiviral therapy in 2012/13

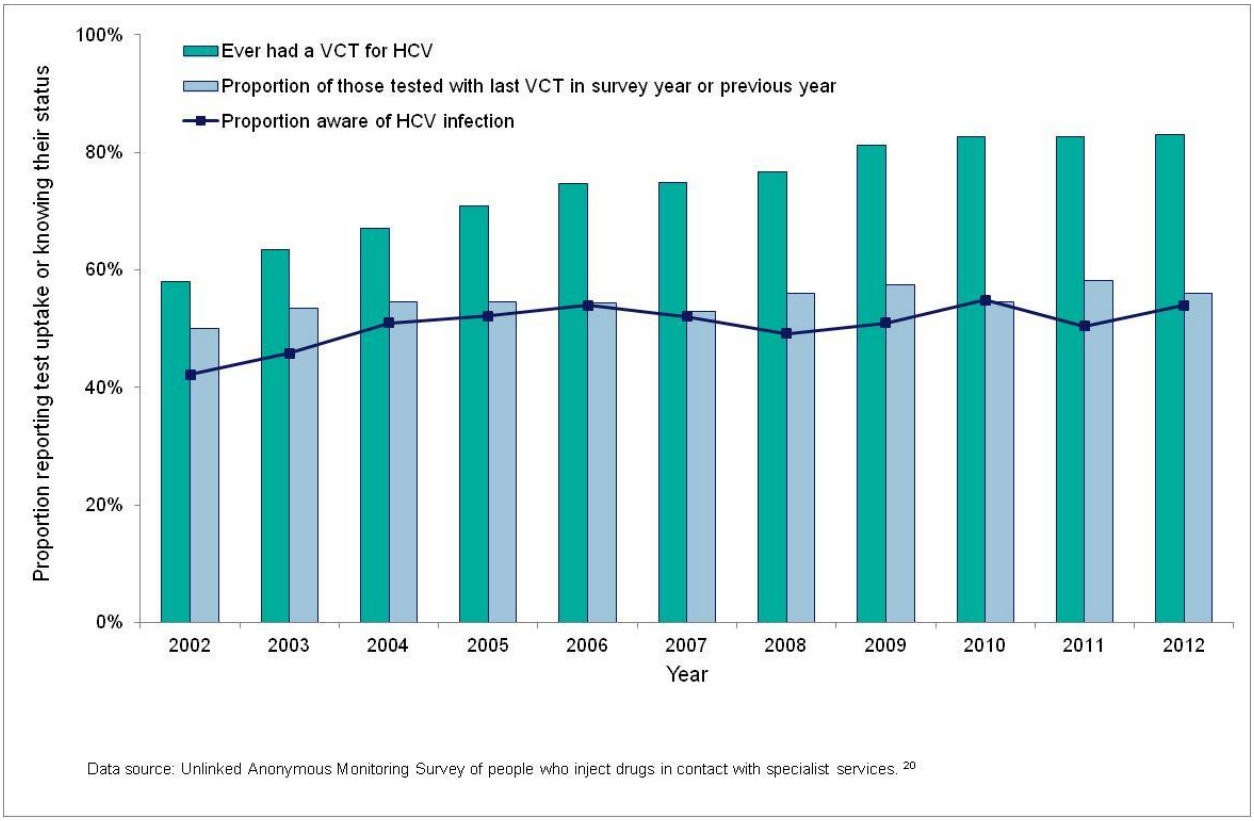


Testing and diagnosis in people who inject drugs

England

In 2012, 54% of HCV infected PWID in England participating in the UAM Survey reported being aware of their HCV positive status, an increase from 42% in 2002 (Figure 37).[20] In the same survey, 83% of PWID reported ever having had a VCT for HCV in 2012, an increase from 58% in 2002 (Figure 37).[20] The proportion of those ever tested who had their last test during the preceding two years was around 56% in 2012 (n=975), which was similar to the proportion found in previous years (Figure 37).

Figure 37: Trends in reported uptake of voluntary confidential testing for HCV infection and the proportion of those with HCV reporting being aware of their infection in England: 2002-2012



NDTMS data shows that levels of hepatitis C testing among people who use drugs are continuing to rise in England. The hepatitis C test status of adults in drug treatment is available from 2005-2012 (Table 16). The proportion of adults in drug treatment who have a hepatitis C test recorded has increased from 11.8% (2005/06) to 57.4% (2011/12). A similar rise has been recorded in those adults newly presenting for drug treatment (11.6% in 2005/06 compared with 49.3% in 2011/12).

There continues to be a rise in testing among those who have ever injected drugs (including those newly presenting for treatment), and in 2011/12, over two-thirds (70.6%) of all adults who have ever injected, in treatment were recorded as having received a test. Similarly, among those who have ever injected and newly presenting to treatment, the number tested continues to rise, with 67.5% recorded as having had a hepatitis C test in 2011/12 (Table 17).

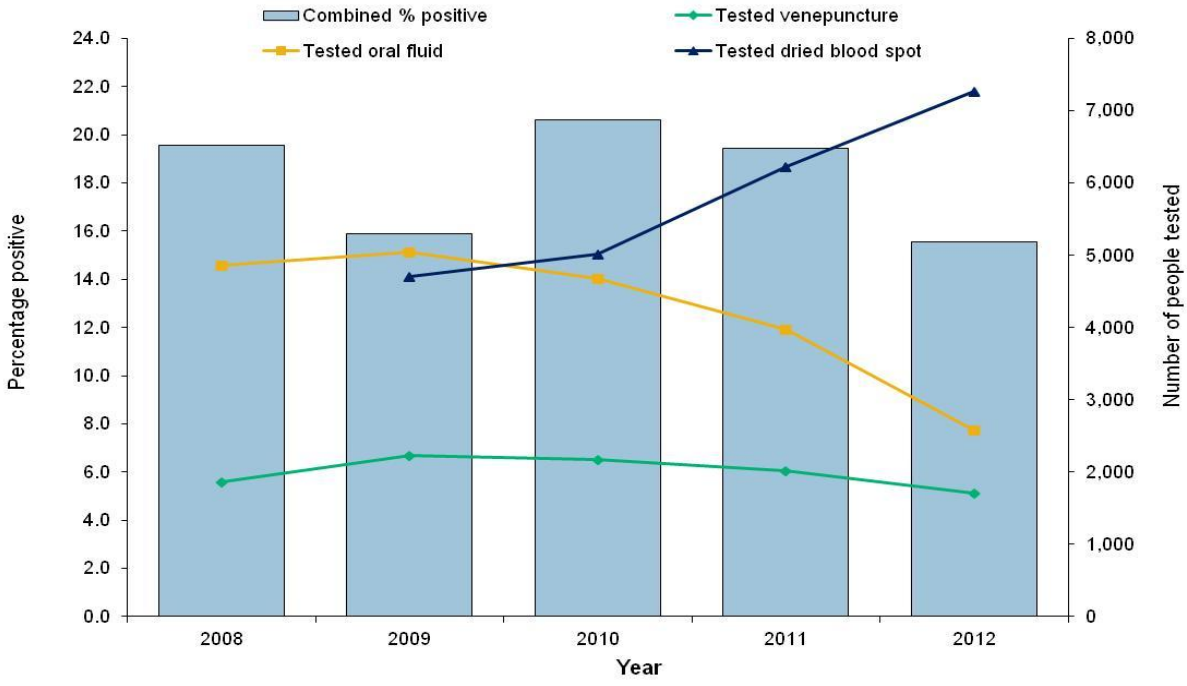
In 2011/12 more than three-quarters (82.2%; n= 161,968) of all adults receiving drug treatment were recorded as having been offered a hepatitis C test (information about whether people have been offered a hepatitis C test is recorded at the beginning of their latest period of treatment) and about one

half (50.5%, n= 99,458) accepted the offer. The number of those accepting the offer of testing has increased each year since 2005/06, and has increased by 45% since 2008/09 (Table 18).

In 2011/12 over four-fifths of those who have ever injected drugs (those who report injecting at the beginning of their latest period of treatment; it also includes those who were not injecting when they began treatment, but who report previous injecting) being treated by drug services in England were offered a test (85.2%, n= 95,342), and nearly 60% accepted the offer (58.4%, n= 65,402). About the same proportion of those newly presenting to treatment were offered testing (82.7%, n= 24,975), with over half accepting the offer (Table 19).

Sentinel surveillance data suggests that alternative testing technologies are continuing to contribute to the uptake of testing in PWID, with DBS being the predominant method of testing in this population group (Figure 38). The number of people tested by venepuncture has remained relatively consistent, whereas the rate of DBS has increased, replacing oral fluid testing in many centres (Figure 38). The percentage testing HCV positive remains high in this population group at 18% overall.

Figure 38: Number of people who inject drugs tested for anti-HCV in specialist services for drug users, by year, from multiple data sources: 2008-2012

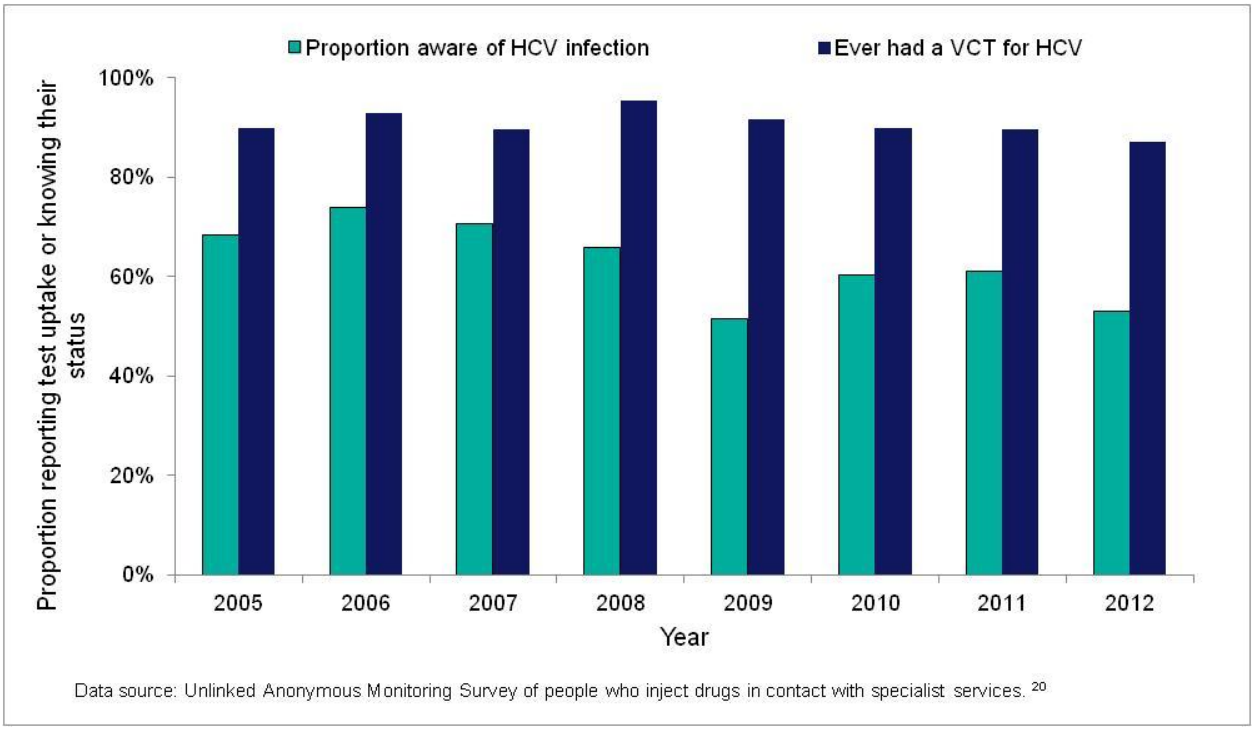


Notes: Sentinel surveillance data excludes reference testing, testing from hospitals referring all samples, and children aged <1 year. Only centres with complete data for the whole period were included.
Oral fluid and dried blood spot testing data excludes samples tested where a drug action team could not be identified.
Data Source: Sentinel Surveillance of blood borne virus testing and Concateno plc.

Northern Ireland

In the UAM Survey, 53% of HCV infected PWID in 2012 reported being aware of their HCV positive status, similar to levels reported in recent years; 87% reported ever having had a VCT for HCV in 2012 (Figure 39).[20]

Figure 39: Trends in reported uptake of voluntary confidential testing for HCV infection, and the proportion of those with HCV reporting being aware of their infection in Northern Ireland: 2005 -2012*

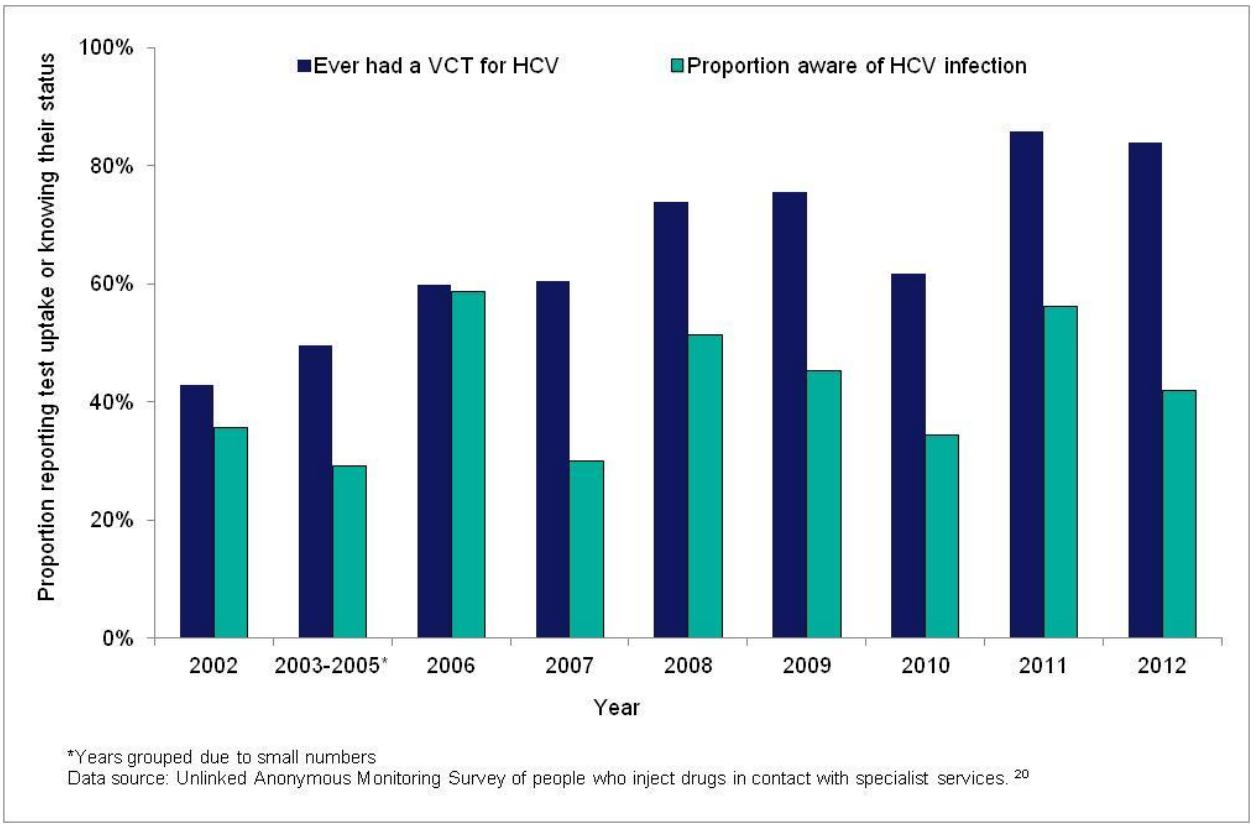


*HCV VCT uptake in 2002-2003 and 2004 was 79% and 80% respectively; the proportion aware of their HCV infection in 2002-2004 was 74%; data is grouped due to small numbers

Wales

In Wales, 42% of HCV infected PWID participating in the UAM Survey in 2012 reported being aware of their HCV positive status, similar to levels reported in previous years (Figure 40); 84% reported ever having had a VCT for HCV in 2012, an increase from 43% in 2002 (Figure 40).[20]

Figure 40: Trends in reported uptake of voluntary confidential testing for HCV infection, and the proportion of those with HCV reporting being aware of their infection in Wales: 2000-2012



DBS testing, primarily within drug services and potentially including non-injectors, in Wales showed that 18% (339/1847) of the specimens tested in 2011 and 11% (214/1937) of those tested in 2012 were HCV antibody reactive (Table 20); of those with follow-up samples, 77% were confirmed as having chronic infection in both years (Table 20). Work is ongoing to improve follow-up testing and during this period the number of follow up samples linked to HCV antibody reactive results was 21% in 2011 and 29% in 2012.

Data from the Welsh HRD from October 2010 to March 2013 were examined over two time periods: October 2010 to March 2012 (18 month period) and April 2012 to March 2013 (12 month period). In relation to image and performance enhancing drug injectors (including steroids, growth hormone and melanotan), self-reported HCV status was recorded for 25-28% of these individuals in both time periods (Table 21). Of these, less than 1% were recorded as known positive (Table 21). Amongst psychoactive drug injectors (including heroin, cocaine, amphetamine and new psychoactive substances), data on self-reported HCV status was recorded for approximately 40% of those accessing these services in both time periods (Table 21). Of these, 10% self-reported as having known positive HCV status during the initial time period and 12% self reported

as known HCV positive in the second time period (Table 21). Self reported HCV status data quality remains an issue and work is ongoing to improve the completeness of these data. Further information on the findings of the HRD is available at: www.publichealthwales.org/substancemisuse-hrd2013

Scotland

In Scotland, among 2,154 PWID interviewed at services providing injection equipment during 2011-12, 83% reported having been tested for hepatitis C in the past, while 42% reported a test in the last year. When those who reported they had been diagnosed with infection from a past test (that is, prior to 12 months ago) were excluded, the percentage of respondents who had been tested for hepatitis C in the last year increased to 49%; this figure compares to 40% and 45% reported by PWID surveyed in 2008-09 and 2010, respectively.

Among 1,141 PWID interviewed at services providing injection equipment in Scotland during 2011-12 and who were hepatitis C antibody positive (in anonymous testing of their DBS samples), 45% reported that they “have hepatitis C” (ie were aware of their infection) and a further 13% reported having “cleared hepatitis C”. These figures are comparable to the 44% and 12% of hepatitis C antibody positive PWID who reported having the virus and having cleared the virus, respectively, in the 2010 survey.

In Scotland, the introduction of DBS in specialist drug service settings has had a significant impact on levels of diagnosis. Of 1,991 new hepatitis C diagnoses made during 2012,[46] 274 (14%) were known to have been diagnosed in specialist drug services where DBS testing for hepatitis C was first introduced in 2009 (this figure compares with 12, 189, 442, and 441 for years 2008, 2009, 2010 and 2011, respectively).

Testing and diagnosis among people in prisons

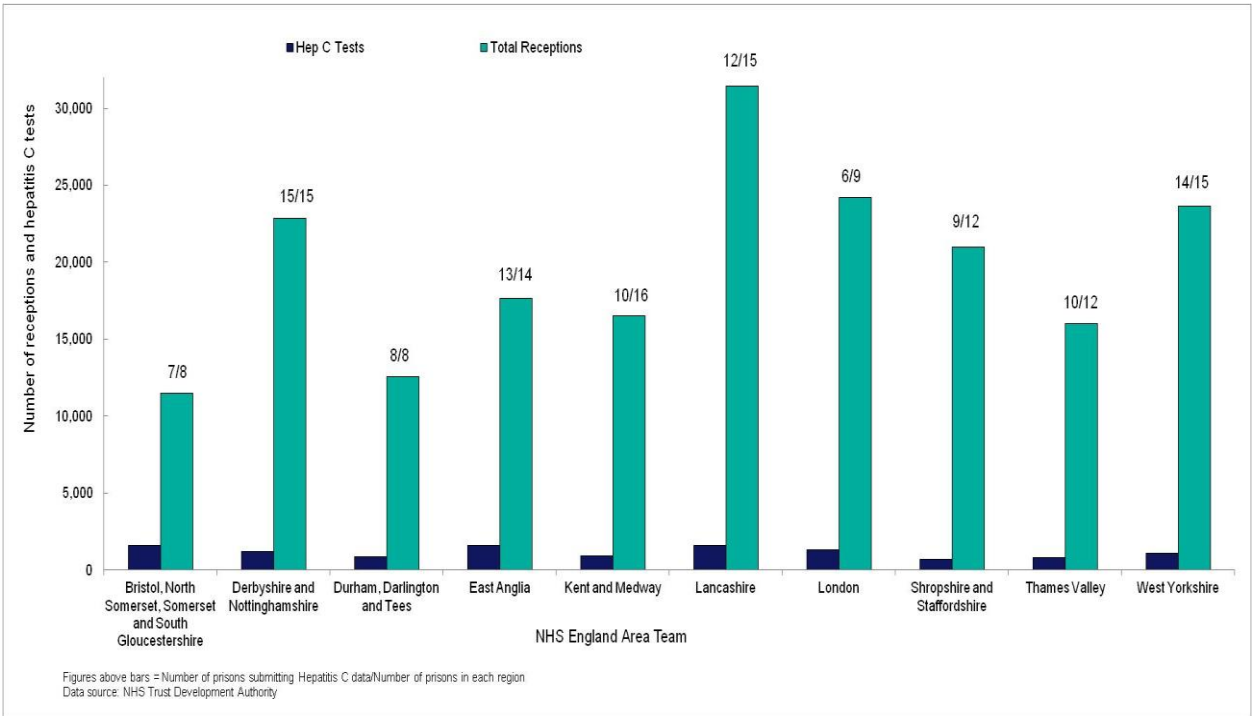
Hepatitis C affects a larger proportion of people in prison and other detention centres than the wider population, principally as a result of the relative higher levels of injecting drug use that are observed among this population.[47]

In England the Public Health in Prisons (PHiPs) Team (part of the Health and Justice Team, PHE) is responsible for the national surveillance of infectious diseases in prisons and other places of detention. This team works closely with other national surveillance teams to monitor infectious diseases in this important population group.

In December 2012 an audit of hepatitis C services in a representative sample of English prisons was undertaken.[7] This audit showed that HCV testing was offered in 95% of prisons, and in all these prisons testing was carried out by healthcare staff.[7] All prisons surveyed used venous blood testing, with 95% of prisons using this method as their predominant mode of testing. Sixty-two percent of prisons stated that blood samples were automatically tested for HCV RNA by PCR; 76% of prisons had a documented pre-test discussion and 71% a documented post-test discussion.[7] This audit, along with the results of previous surveys[9], provide a useful insight into hepatitis C services that are available to prisoners and detainees.

In England, prison health performance and quality indicators (PHPQIs) exist to help monitor the delivery and quality of healthcare services within the prison estate.[48] In 2012 these data show that, overall, 5.9% (11,690/197,389) of new receptions to English prisons received a hepatitis C test (Figure 41); similar to the number in 2011 (6.2%; 9970/161,125).[49] This figure varies from region to region, as does the proportion of prisons submitting data in each region (Figure 41); hepatitis C test results are also known to be greatly under-reported.

Figure 41: Receptions to English prisons in 2012 who received a hepatitis C test

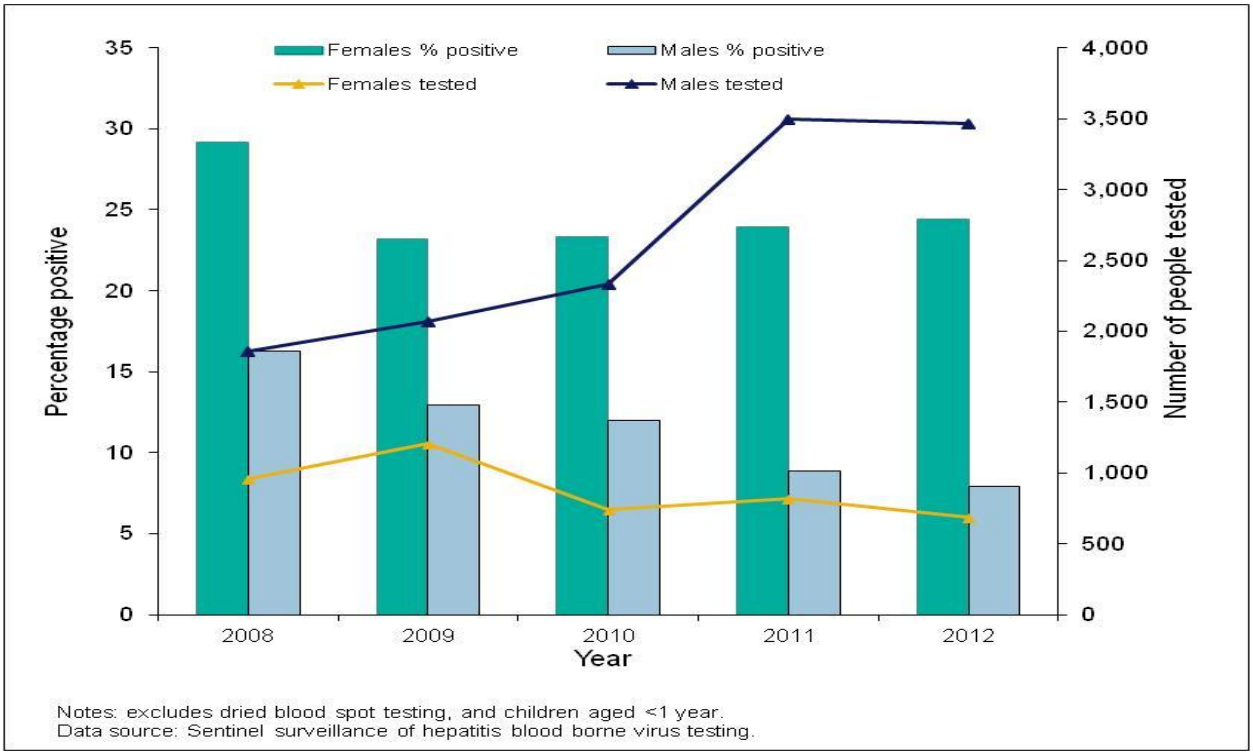


The PHPQI data are useful for measuring the amount of testing taking place, but do not provide information regarding test results; these data are obtained via reporting to the PHiPs Team. Table 22 shows the number of cases reported to the PHiPs Team during 2010, 2011 and 2012. Reported cases have increased

substantially over these three years, with 417 antibody positive cases and 205 cases of chronic infection being reported in 2012 (Table 22), however this increase is most likely the result of improved reporting over the period. It is likely that these reports still substantially under-estimate the actual number of individuals with hepatitis C in prisons and other places of detention as a result of the quality of information laboratories provide to the local health protection teams, and the variable amount of processing this information undergoes at the local unit level. The Health and Justice Team is working with other partners, including NHS England and the National Offender Management Service to look at improving the uptake of hepatitis C testing and treatment across the estate, as well as addressing how data collection can be improved throughout England.

Sentinel surveillance data in England suggests that testing via prison services varies by gender with the number of males tested increasing year-on-year, while the number of females tested has varied over the same period (Figure 42). The proportion of males testing positive has undergone a steady decline each year, however, the proportion of females testing positive has plateaued since 2009. Between 2008-2012, 25% of females tested positive compared to 11% of males ($p<0.001$). This may be due to a difference in the relative risk of female offenders having acquired hepatitis C compared to males, and/or differences in the offer and acceptance of BBV testing.

Figure 42: Number of people* tested for anti-HCV, and proportion positive, through prison services by year in 24 sentinel laboratories: 2008-2012



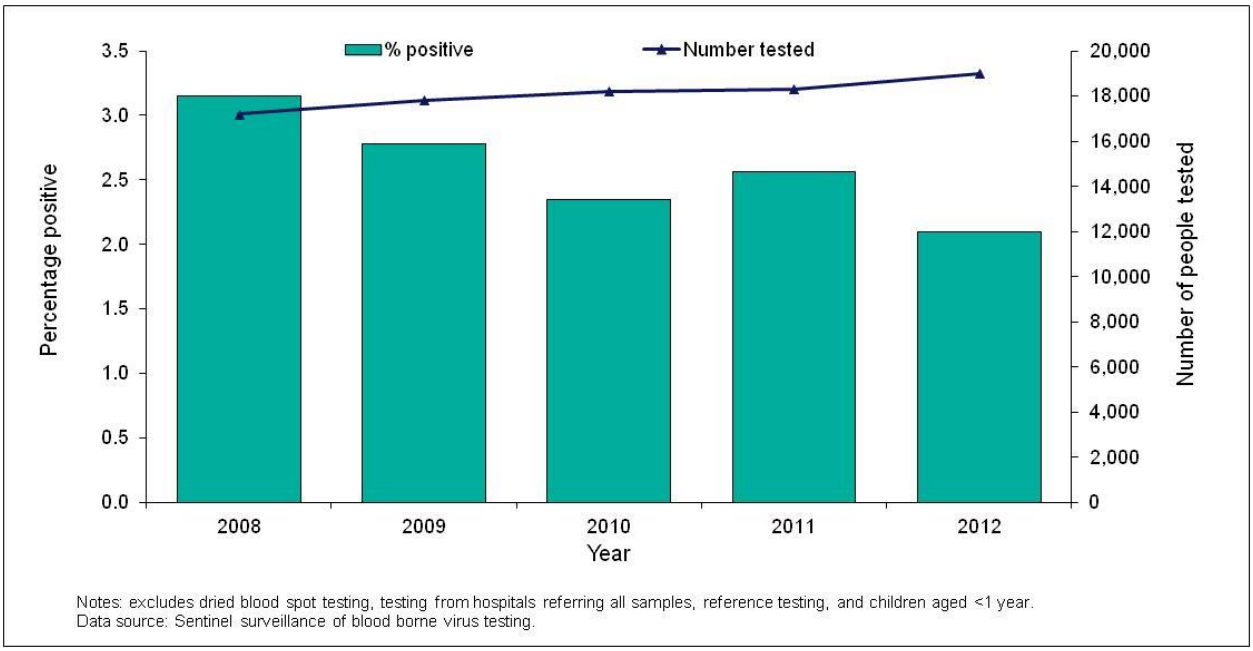
*510 individuals of unknown gender are not included in these figures.

In Wales in 2012, a liver health promotion programme was launched across Welsh prisons. Literature, to be given to every prisoner during their reception health screen, was produced to promote awareness of BBVs and to encourage people to come forward for testing. DBS testing was also made available in every prison. By September 2012 each prison began reporting monthly testing data from automated reports run from the clinical record system. Monthly data now being reported includes: number of DBSs taken, number of venepuncture samples taken, number of hepatitis C antibody positive samples, number of hepatitis C PCR detected and number referred to hepatology services.

Testing and diagnosis in black and minority ethnic populations

In England, sentinel surveillance data indicates that the number of people tested who were identified as being of Asian or Asian British origin has increased year-on-year from 2008 (Figure 43). The overall increase in testing may be a reflection of targeted awareness-raising campaigns that have taken place among South Asian communities over recent years. Overall, the proportion of people of Asian or Asian British origin testing anti-HCV positive declined from 3.2% in 2008 to 2.1% in 2012.

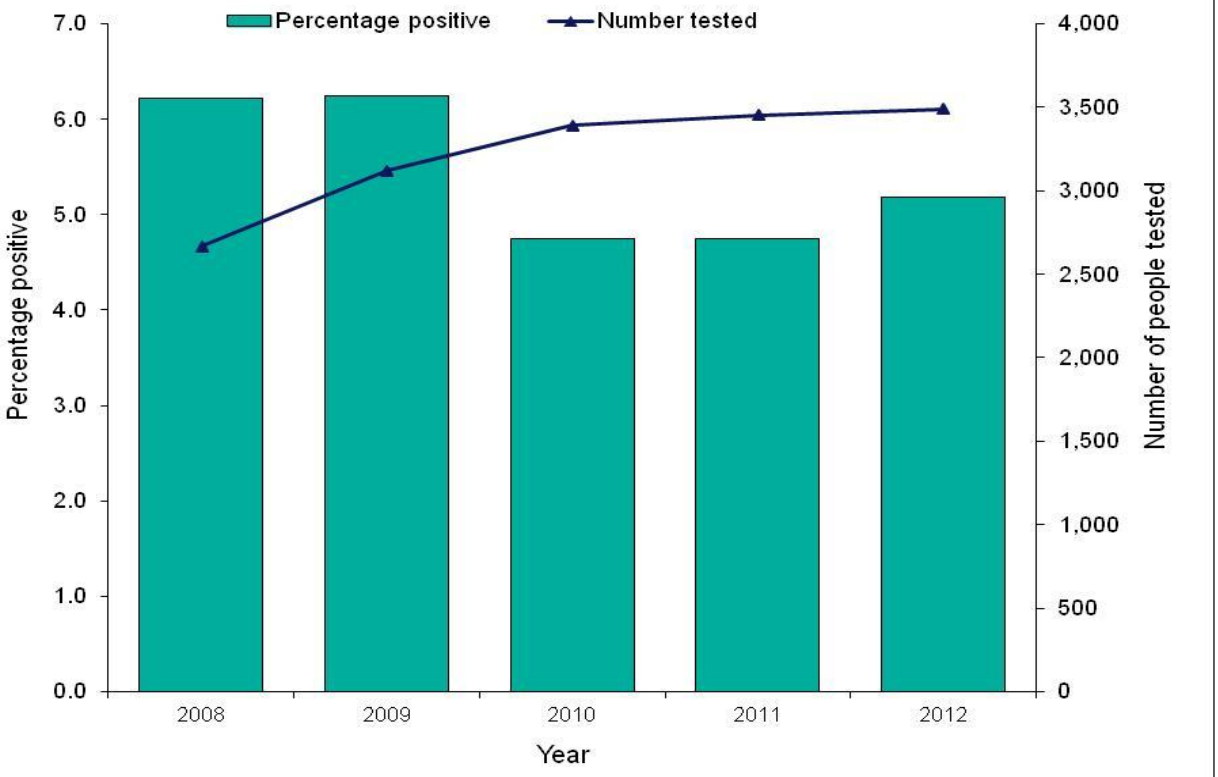
Figure 43: Number of Asian or Asian British people tested, and proportion positive, in 24 sentinel laboratories: 2008-2012



Sentinel surveillance data indicates that the number of people tested who were identified as being of Eastern European origin (using self-reports or ONOMAP[50] name analysis software), increased from 2,670 in 2008 to 3,490 to 2012 (Figure

44). Over this period (2008-2012), 5.4% of people of Eastern European origin tested positive. This data suggests that these individuals may be at relatively increased risk of having acquired hepatitis C and/or that testing of these ethnic groups is more targeted at higher risk individuals that in the general population.

Figure 44: Number of Eastern European people tested, and proportion positive, in 24 sentinel laboratories: 2008-2012



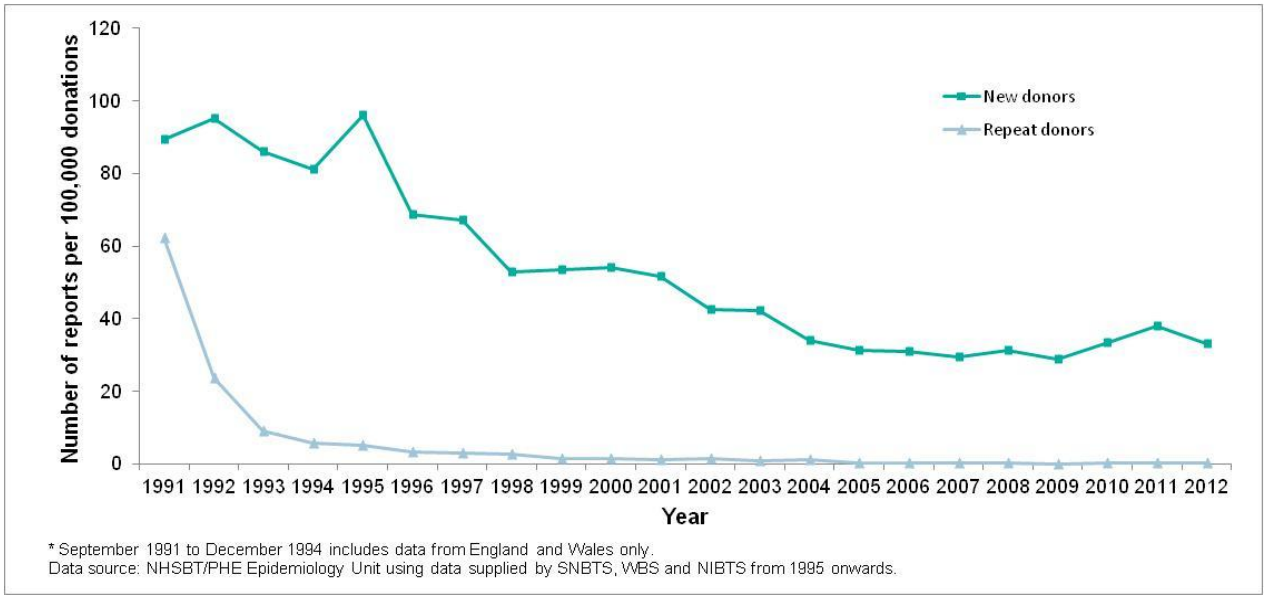
Notes: excludes dried blood spot testing, testing from hospitals referring all samples, reference testing, and children aged <1 year.
Data source: Sentinel surveillance of blood borne virus testing.

Testing and diagnosis in UK blood donors (low-risk population)

Monitoring infections in blood donors is important, as infections in populations at low risk of BBVs can be a marker of more significant problems in the wider population.

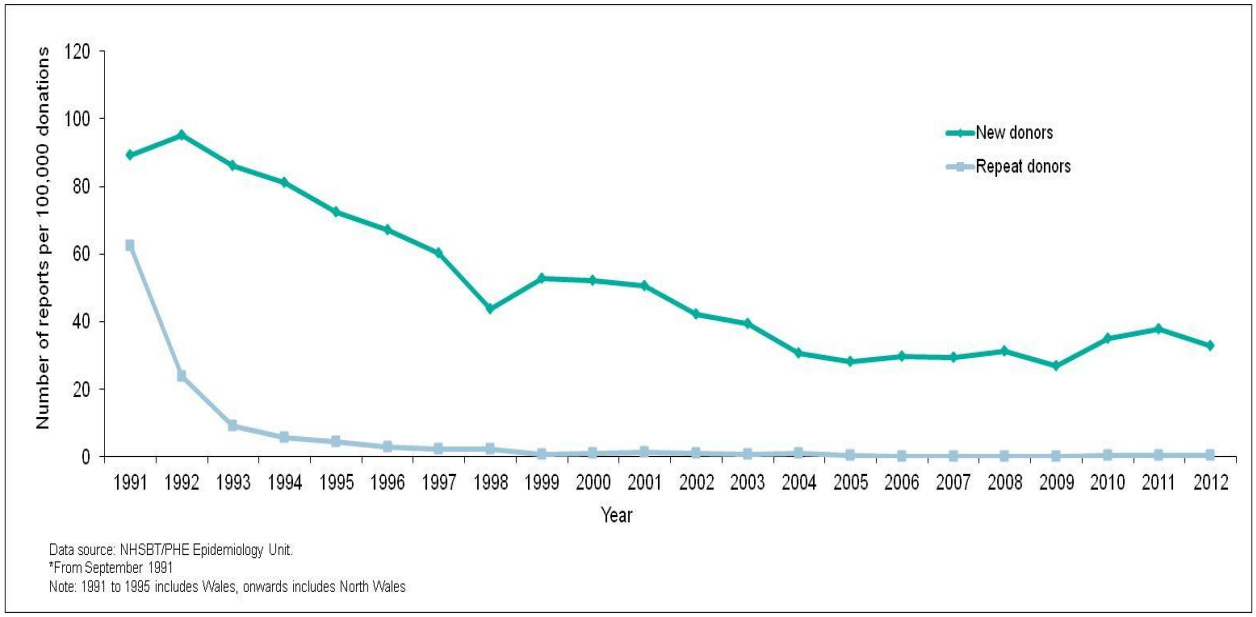
Overall in the UK, hepatitis C in both new and repeat donors has fallen. Since1995 (Figure 45), infections in new donors have fallen from a rate of 96.2 per 100,000 donations in 1995 to 33.2 in 2012, and the rate in repeat donors fell from 5.2 per 100,000 donations to 0.2 over the same period.

Figure 45: Rate of hepatitis C among donations from new and repeat blood donors in UK during 1991*-2012



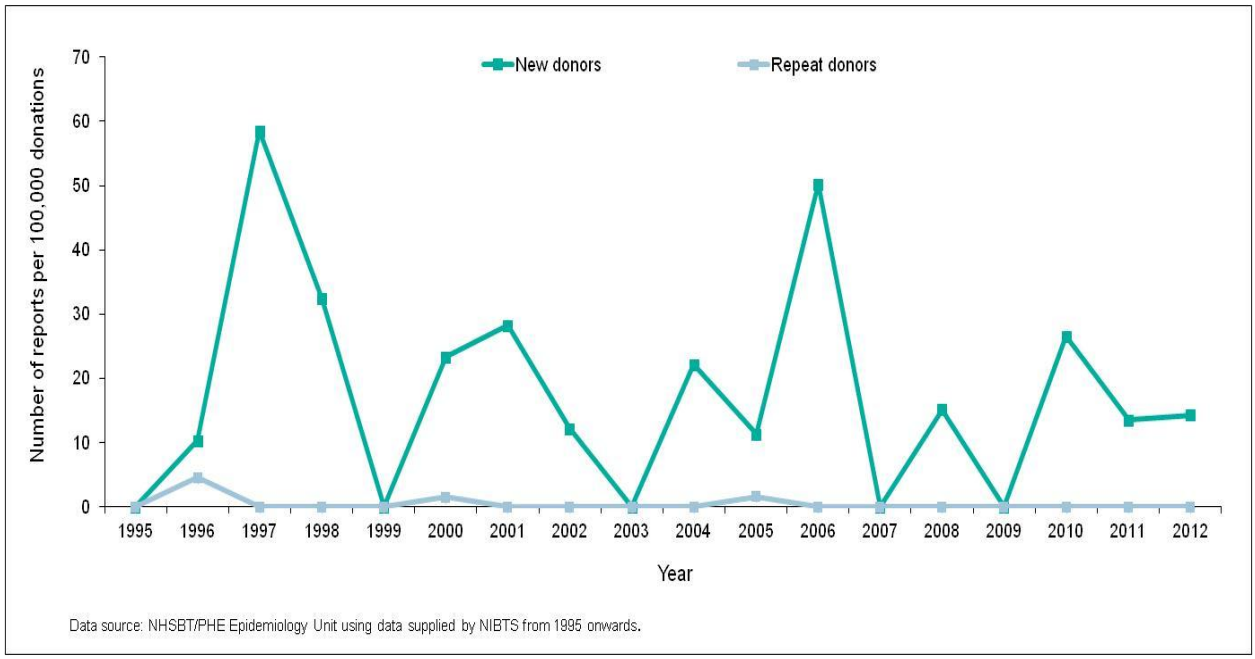
In 2012, 57 blood donors tested positive for HCV in England and North Wales; just over half of all infections detected were in new male blood donors (56%) and of white British ethnicity (58%) (Table 23); a disproportionately large number of infections were seen in those of South Asian origin (India, Pakistan or Bangladesh) and in those of “other white” backgrounds, the majority of whom were born outside the UK, particularly in Asia and Eastern Europe. Since blood donation testing began in1991, fewer HCV infections have been detected in donations from repeat donors compared with first time donors, and rates of infection have declined from 62.3 (1991) to 0.3 per 100,000 donations (in 2012) (Figure 46).

Figure 46: Rate of hepatitis C among donations from new and repeat blood donors in England: 1991*-2012



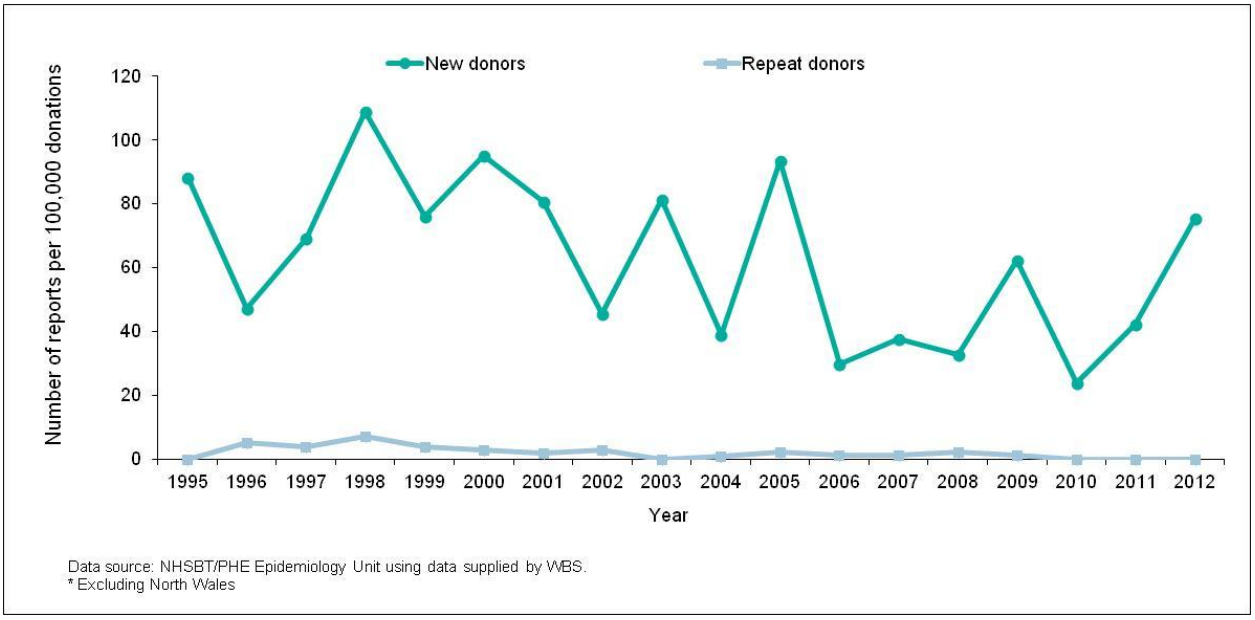
In Northern Ireland in 2012, 14.3 per 100,000 donations from new donors tested HCV positive (Figure 47). Hepatitis C has not been detected in repeat donor since 2005. The rate of infection in new donors remains low and variable with between zero and four HCV positive new donors identified each year. (Figure 47)

Figure 47: Rate of hepatitis C among donations from new and repeat blood donors in Northern Ireland: 1995-2012.



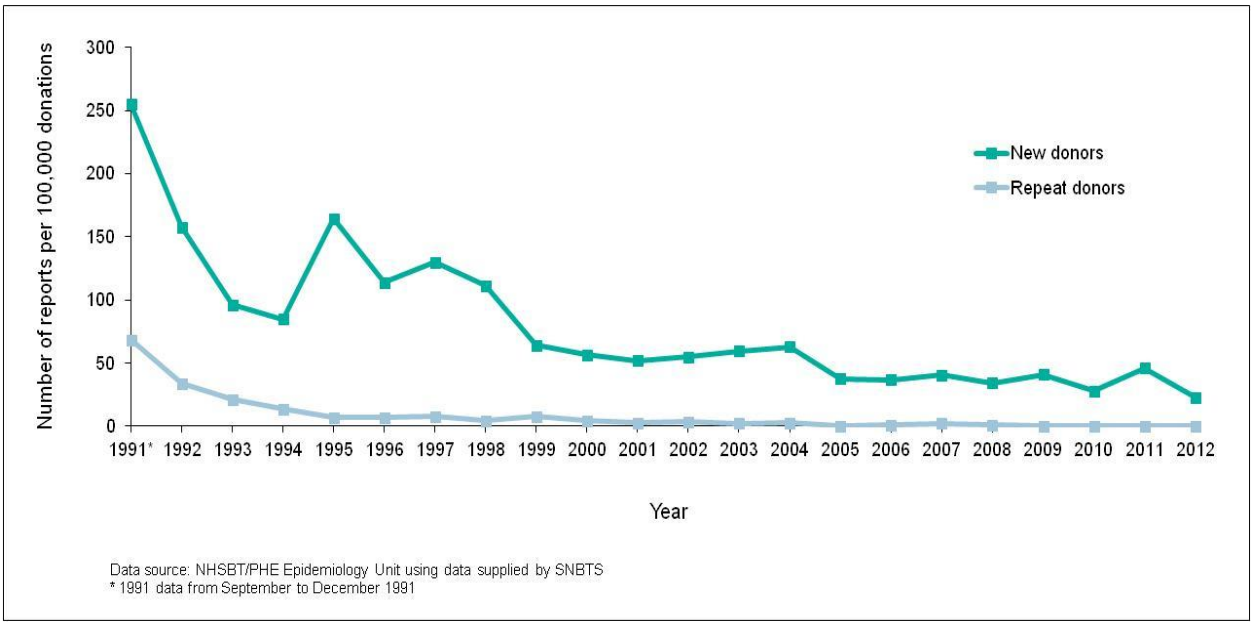
Excluding donations from North Wales, which are included in the English blood donor data, the rate of hepatitis C positive donations detected among all other new blood donors resident in Wales has declined overall (Figure 48) despite year on year fluctuations. In 2012, a rate of 75.4 per 100,000 donations tested was observed among new donors. However, caution is required in the interpretation of these figures as the numbers are very small. Hepatitis C is rarely detected in repeat donors (Figure 48).

Figure 48: Rate of hepatitis C among donations from new and repeat blood donors in Wales*: 1995-2012



In Scotland, the rate of detection of hepatitis C among blood donors has declined in both new and repeat donors since 1991 (Figure 49). In 2012, a rate of 22.72 per 100,000 donations tested was the lowest rate ever observed among newly tested blood donors in Scotland; no repeat donor was found to be positive for hepatitis C.

Figure 49: Rate of hepatitis C among donations from new and repeat blood donors in Scotland, during 1991*-2012.



Treatment and care

Many HCV infections occur in marginalised communities, in particular 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 the treatment and care they need.

Access to treatment and care

In England, information on access to HCV treatment services by PWID has been obtained from those participating in the UAM Survey in 2012. The survey asked participating PWID who reported having had a positive result to a diagnostic test for hepatitis C: 'Have you ever seen a specialist nurse or doctor (eg a hepatologist) about your hepatitis C?' Among the survey participants in England with antibodies to hepatitis C who were are aware of their infection, 62% (357/574) reported that they had seen a specialist nurse or doctor about their infection, and 39% (229/574) reported being given any medication related to their HCV infection.

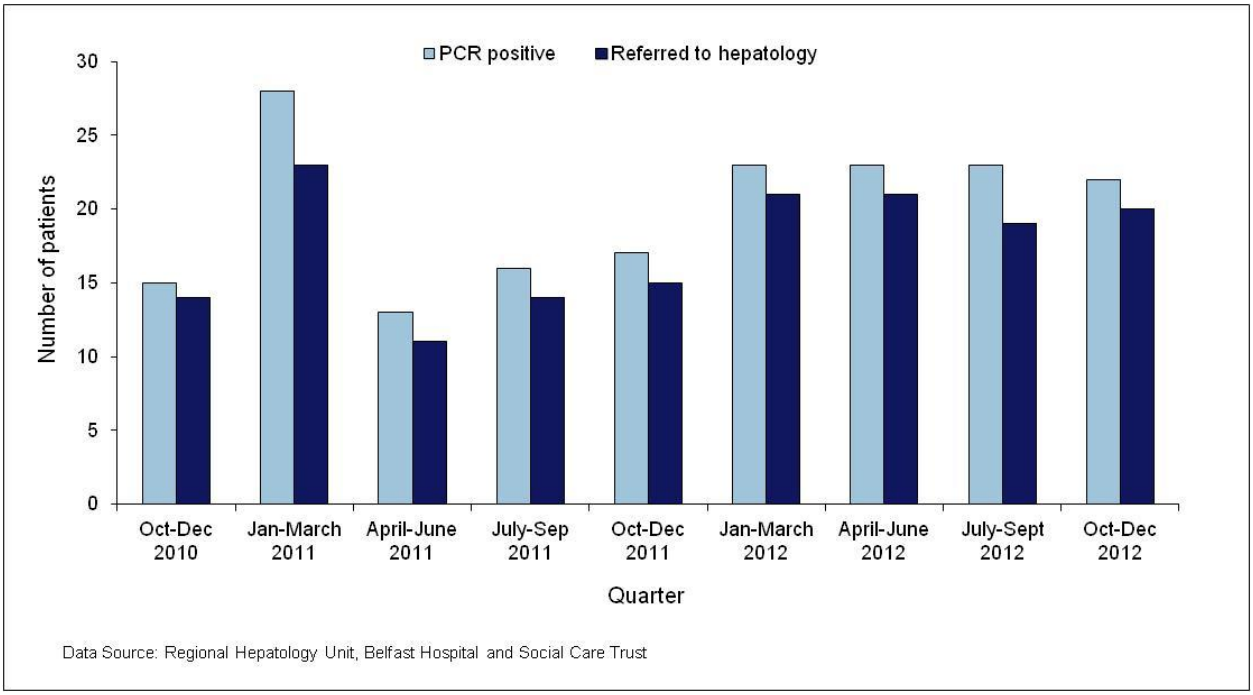
In the 2011 survey[51] of hepatitis C services in English prisons, 82/110 responding prisons (74%) had a written pathway in place to describe what happens following a positive hepatitis C result. More recent national audit suggests that the most common model of service delivery in English prisons is hospital outpatient care (52% of prisons), followed by hospital in-reach (43%) and GP led care (5%).[7] Eighty-six per cent of prisons in the audit reported that they either always or sometimes placed prisoners on medical hold if they had started treatment.[7] When prisoners on treatment were released into the community, prisons used a variety of methods to ensure that they were referred to appropriate services: 52% contacted local providers, 24% contacted local service providers *and* primary care, 5% contacted either one or the other, and 14% gave the prisoner a summary from the prison *SystmOne* clinical management system to give to their GP (5% did not provide this information).[7] When prisoners with hepatitis C were transferred from one prison to another, all prisons took action to ensure continuity of care, either by sharing clinical information via their *SystmOne* management systems and/or contacting the receiving prison healthcare and/or hospital consultant by phone or fax.[7]

Since 1 April 2013 NHS England have been responsible for commissioning public health services for people in prisons and other places of detention, including testing and treatment for hepatitis C and other BBVs. The advantage of the new system is that there is now a single national commissioner for the whole prison estate. Previously, when prison health services were

commissioned by local primary care trusts, there was often great variability in the nature and quality of commissioned services. PHE is working closely with NHS England and with the National Offender Management Service to improve the quality of care provided in prisons. Intelligence and data gathered through surveys and audits conducted by PHE and its predecessor, the Health Protection Agency (HPA), are very helpful for commissioners in designing specifications for hepatitis C services for people in prison.

In Northern Ireland, from the third quarter of 2009, new laboratory-confirmed cases of hepatitis C have been followed-up three months after initial confirmation to check whether a referral to the regional hepatology unit has been made. Contact is made with originating clinicians of HCV RNA positive cases where possible. The improvement in referral rates seen following the introduction of this initiative continues, with 89% of newly diagnosed HCV RNA positive patients in the period January 2012 to December 2012 referred to hepatology services; this work is now routine (Figure 50).

Figure 50: Referral of newly-diagnosed HCV RNA positive patients to hepatology



In Scotland, an estimated 19,500 people living in Scotland with chronic hepatitis C had been diagnosed with their infection by 2012; of these an estimated 5,150 (26%) had attended a specialist centre in 2012 (Figure 36).

Antiviral treatment for HCV infection

NICE recommended that antiviral treatments that will successfully clear hepatitis C virus in the majority of patients are made available.[11, 12, 13, 14,15] In some UK countries, the number of individuals receiving anti-viral treatment is being monitored at a national level. It is important to monitor levels of antiviral treatment at both national and local level to assess whether sufficient numbers of infected individuals are accessing treatment, and to identify and address any geographical variation in hepatitis services that may exist.

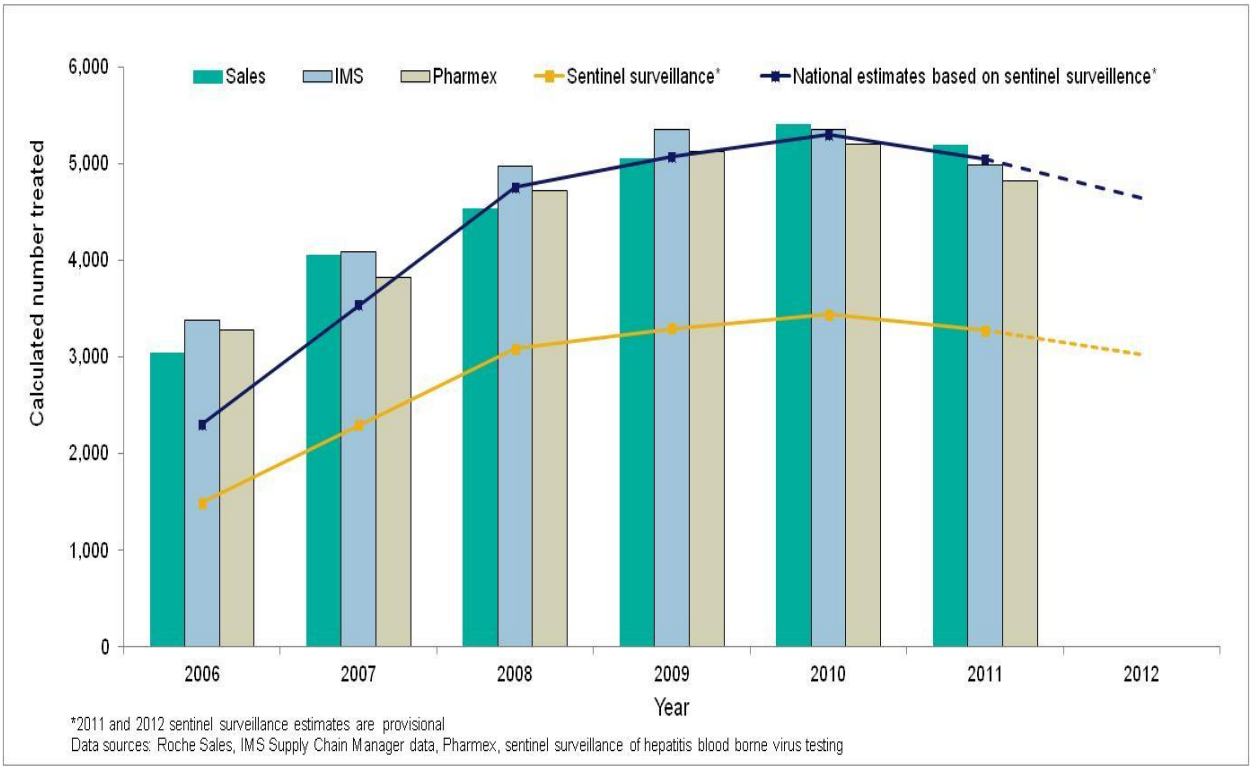
Data from England

In 2012 the HPA used national data from pharmaceutical companies, pharmacy purchasing data and pharmacy prescribing data to estimate how many individuals had been treated in England (Figure 51).[49] These calculations suggested that around 27,500 patients with HCV could have been treated with pegylated interferon as part of the NICE recommended combination therapy between 2006 and 2011. This was sufficient to have treated around 20% of the estimated total chronically infected population.

As new drugs for the treatment of hepatitis C are approved and come on line, new methods are required to estimate the numbers of individuals undergoing treatment. In England, new methods are being developed to detect patterns of serial testing within sentinel surveillance laboratory data that indicate participation in treatment. Demographic and testing data for all individuals tested for anti-HCV and HCV RNA between January 2002 and June 2013 have been extracted from the sentinel surveillance database, and individuals identified using a unique reference number to link all their related test results. Quality control samples, children aged less than one year (as a positive test for anti-HCV in this group may be due to passively-acquired maternal antibodies), those without a positive PCR test result, and individuals tested through renal units are excluded. Information on each individual and all their associated tests are then run through a suite of algorithms. Individuals with chronic infection and three or more sequential PCR test results within a 390-day period, suggestive of monitoring during treatment, are then identified. The year of the first PCR test result in this series is assumed to approximate the year treatment was initiated. Results of qualitative and quantitative PCR test results are combined to identify PCR positive individuals, and those treatment experienced individuals with a final negative PCR test result within the 390-day window, who remain negative throughout subsequent PCR testing, are considered to have responded to therapy.

Participating sentinel laboratories are estimated to cover approximately 65% of the English population for primary and reference HCV testing, and be broadly representative of most laboratories providing routine and reference HCV testing; estimates can therefore be scaled-up to provide national treatment figures (see Figure 51).

Figure 51: Estimated numbers of HCV-positive patients receiving combined therapy based on national supply of pegylated interferon (2006-2011), and provisional estimates[1] from national sentinel surveillance testing data (2006-2012*)



[1]Estimates rely upon repeat PCR testing within a 390-day window period. Those tested later in the study period may have a reduced opportunity of being detected as being treated. This is particularly the case for those with a first PCR test result in 2012, who are therefore are plotted with a dashed line. All data is provisional and will change as further data is received. Quality control samples, children aged less than one, those without a positive PCR test result and individuals tested through renal units were excluded from this analysis.

When 2013 data are available to confirm treatment in those who initiated treatment in 2012 but did not complete it within that year, provisional treatment figures for 2012 (Figure 51) will rise and can be confirmed as an estimate of HCV treatment in England for 2012; it will also be possible to report treatment response using this method. Comparison of treatment levels derived from sentinel surveillance data with those derived from national drug sales, prescription and dispensing data, suggest that this method to estimate levels of

HCV treatment in England is reliable, particularly over recent years when sentinel surveillance coverage has been at its highest level (Figure 51).

Overall, the magnitude of annual increases in treatment declined between 2006 and 2010; in 2011 6% fewer patients were treated than in 2010. The decline in 2011 could be the result of a number of factors including: clinicians and/or patients waiting for new drugs, reaching clinical capacity, or reaching treatment saturation of those individuals who are easy-to-access, leaving mostly those who are harder to reach.

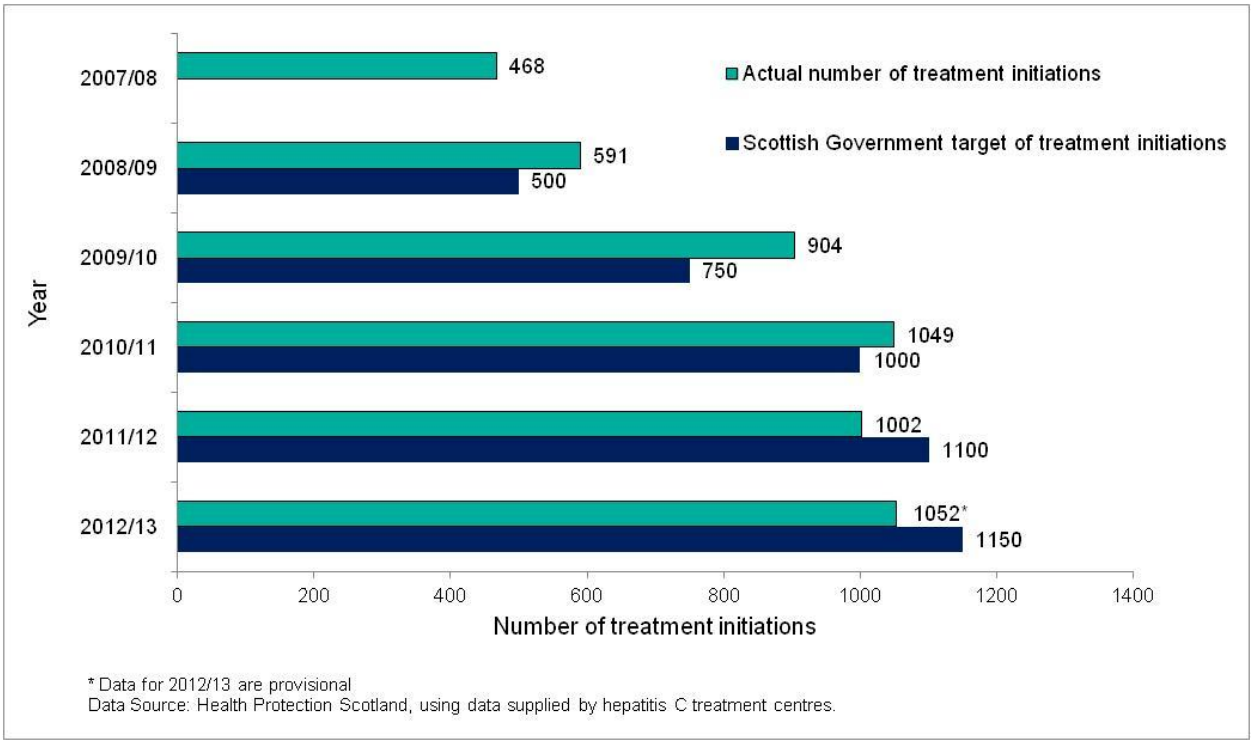
In England, estimates of future disease burden that have previously been published[1,49,] are based on the back-calculation approach of Sweeting et al. [24] This model has now been extended to incorporate a certain proportion treated each year, with rates of SVR based on a cohort of HCV-infected individuals.[52] Under current treatment levels (approximately 3% per year), new cases of ESLD and HCC in England are predicted to rise over the next 20 years, from 1,170 (95% credible interval (CrI) 1,060-1,300) in 2014 to a peak of 1,680 (95% CrI 1,460-2,000) in 2033. In the absence of treatment, the predicted peak would be 2,290 (95% CrI 2,000-2,520), but there is still substantial room for improvement on current treatment levels.

Various scenarios for increasing treatment have been explored, including 50% and 100% increases in treatment levels over the next 10 years, and gradual/rapid moves to complete coverage. The estimated peak of new ESLD/HCC cases, and when the peak occurs under the various treatment scenarios, are shown in Table 24. These analyses show that numbers of HCV-related ESLD/HCC cases can be substantially reduced each year by increasing treatment, with 190 (95% CrI 170-240) additional cases averted per year if the numbers treated are increased by 100% over the next 10 years, and 430 (95% CrI 370-550) additional cases averted per year if treatment levels move towards complete coverage over the next 15 years. More modest increases still result in substantial gains, although some increases in incidence are likely over the next 10-15 years. These scenarios assume that standard treatment will continue to be used over the next 30 years, whereas in reality new treatments with higher rates of SVR are starting to be used,[14,15] with further improvements likely in the near future.[53] These would reduce the number of new ESLD/HCC cases beyond the predictions; and if new regimes are easier to tolerate, increasing treatment rates to high levels would become more feasible. Standard treatment with pegylated interferon and ribavirin has low rates of SVR in those with advanced disease, therefore even high levels of standard treatment will have little effect on short-term rises in those progressing to ESLD/HCC. In particular, if new treatments can improve outcomes for these groups, then short-term rises in disease burden are more likely to be prevented.

Data from Scotland

The number of chronically infected people who began hepatitis C antiviral therapy in Scotland increased from 468 in 2007/08 to 1,049 in 2010/11 (Figure 52). The numbers initiated on antiviral therapy exceed the Scottish Government targets of 500 in 2008/09, 750 in 2009/10 and 1,000 in 2010/11. In recent years, a total of 1,002 people were initiated on hepatitis C antiviral therapy in 2011/12 and 1,052 in 2012/13; 91% of the Scottish Government targets of 1,100 and 1,150 for those respective financial years.

Figure 52: The actual number, and the Scottish Government's target, of chronically infected people initiated on hepatitis C antiviral therapy in Scotland for the financial years, 2007/08-2012/13



Among patients (with either genotype 1, 2 or 3) initiated on pegylated interferon and ribavirin across 17 clinics in Scotland during 2000-2010, 56% were known to have achieved an SVR; this rate ranged from 42% among those with genotype 1 to 67% among those with genotypes 2 or 3. SVR rates were comparable between patients who reported having ever injected drugs and those who reported other risk factors.[54]

Among people initiated on hepatitis C antiviral therapy in 17 hepatitis C treatment centres across Scotland, and who had reported a risk factor for infection, the number (and proportion) who had reported having ever injected

drugs increased from 144 (58%) among those initiated in years 2000-2001 to 1,203 (82%) in years 2011-2012.

In Scotland the number of chronically infected people initiated on hepatitis C antiviral therapy within the prison setting increased from 17 in 2007/08 (representing 4% of treatment initiations in that year) to 37 in 2008/09 (representing 6%), 112 in 2009/10 (representing 12%), 143 in 2010/11 (representing 14%), 102 in 2011/12 (representing 10%), and 117 in 2012/13 (representing 11%).

Support to help commission hepatitis C treatment and care

A template to help DATs and health and wellbeing boards estimate the prevalence of HCV in their local population is available.[16] Local prevalence estimates can be obtained by entering the DAT name; the template will also generate local predictions of the future burden of disease as well as estimates of the costs to treat infected individuals. This information is still available by primary care trust by following the same link.[16]

Data tables

Table 1: Laboratory confirmed cases of chronic hepatitis C in Northern Ireland (n=842) by genotype: 1990-2012

Genotype	Number of reports (%)
1	370 (44)
2	60 (7)
3	373 (44)
4	35 (4)
5	1 (0.1)
6	3 (0.4)
Total	842 (100%)
Source: NI Regional Virus Laboratory	

Table 2: Risk factor information in laboratory reports* of hepatitis C infection from England: 1996-2012

Risk factor (where reported)	Number of reports	Percentage
Injecting drug use	15153	90.3
Transfusion	221	1.3
Blood product recipient	120	0.7
Sexual exposure	334	2.0
Renal failure	73	0.4
Vertical (mother to baby) or Household	39	0.2
Occupational	17	0.1
Other	815	4.9
TOTAL	**16772**	**100**
Data source: CoSurv		

***Statutory notification by diagnostic laboratories was introduced in October 2010[8]

Table 3: Route of HCV transmission recorded for patients presenting for treatment to Regional Hepatology Unit, Belfast. 1990-2012

Route (where recorded)	Number (%)
PWID	460 (68)
Blood/blood products	118 (17)
Sex	40 (6)
Needlestick injury	13 (2)
Tattoo	22 (3)
Overseas healthcare	14 (2)
Mother to baby and household	7 (1)
Other	6 (1)
TOTAL	680 (100%)
Data Source: Regional Hepatology Unit, Belfast Hospital and Social Care Trust	

Table 4: Estimated HCV Prevalence by region and risk group in England (95% credible intervals) (2005)[1]

	Currently injecting drugs	Previously injected drugs	White/other never injectors	South Asian never injectors
HCV prevalence (%) by region and risk group				
London	56 (51, 62)	39 (33, 46)	0.13 (0.08, 0.23)	0.76 (0.47, 1.35)
North West	61 (56, 66)	40 (34, 47)	0.05 (0.03, 0.09)	1.10 (0.35, 2.93)
Rest of England	37 (33, 41)	24 (19, 29)	0.04 (0.02, 0.07)	0.66 (0.40, 1.10)
HCV prevalence (in thousands) by region and risk group				
London	23 (19, 28)	26 (11, 51)	5.4 (3.4, 9.8)	4.1 (2.5, 7.3)
North West	20 (18, 23)	18 (8, 35)	1.8 (1.1, 3.5)	1.7 (0.5, 4.6)
Rest of England	45 (37, 54)	43 (19, 85)	7.5 (4.8, 14.4)	5.4 (3.2, 9.0)

Table 5: Enhanced Surveillance of BBV in people who inject drugs in Wales 2011-2012[22]

Number of years injecting drugs	Number of Individuals		Number of Individuals HCV +ve		Prevalence (%)	
	2011	2012	2011	2012	2011	2012
0-2y	112	88	10	8	9	9
3-4y	68	58	9	8	13	14
>5y	551	345	195	79	35	23
Total	731	491	214	95	29	19
Data source: Enhanced Surveillance of BBV in Wales database held by Public Health Wales, CDSC						

Table 6: Hospital admissions for end-stage liver disease* or hepatocellular carcinoma in individuals with hepatitis C in England 1998-2012

Year	Individuals with HCV	Individuals with HCV-related ESLD	Deaths** from HCV-related ESLD (percentage of individuals with HCV-related ESLD)	Individuals with HCV-related HCC	Deaths** from HCV-related HCC (percentage of individuals with HCV-related HCC)
1998	4,072	469	110 (23)	105	26 (25)
1999	4,708	489	124 (25)	145	36 (25)
2000	4,635	521	138 (26)	107	23 (21)
2001	5,304	543	149 (27)	137	33 (24)
2002	6,007	574	162 (28)	177	36 (20)
2003	6,563	607	175 (29)	173	46 (27)
2004	7,293	692	199 (29)	201	46 (23)
2005	8,025	868	252 (29)	243	56 (23)
2006	8,460	928	254 (27)	256	62 (24)
2007	8,962	1,029	287 (28)	275	63 (23)
2008	10,091	1,224	290 (24)	339	70 (21)
2009	10,447	1,317	349 (26)	361	71 (20)
2010	11,195	1,413	363 (26)	463	83 (18)
2011	11,616	1,608	349 (22)	519	81 (16)
2012	12,473	1,759	396 (23)	507	86 (17)
Data source: Health and Social Care Information Centre					

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

**Hospital Episode Statistics data cannot be used to determine the cause of death of a patient while in hospital. Deaths recorded on the Hospital Episode Statistics database may be analysed by the main diagnosis for which the patient was being treated during their stay in hospital, which may not necessarily be the underlying cause of death. For example, a patient admitted for a hernia operation (with a primary diagnosis of hernia) may die from an unrelated a heart attack. The Office for National Statistics collects information on the cause of death, wherever it occurs, based on the death certificate and should be the source of data for analyses on cause of death.

Table 7: Number of Welsh residents[1] with hepatitis C who have ESLD[4] and/or HCC and have died from these conditions, in Wales 1997-2012*

	Number of patients[2] with HCV	Number of patients[2] with HCV related ESLD[4]	Deaths from HCV[3] related ESLD[4]	Number of patients[2] with HCV related HCC	Deaths from HCV[3] related HCC
Year	Total	Total	Total (%)	Total	Total (%)
1997-2000	794	38	12 (32%)	7	4 (57%)
2001-2004	1069	71	18 (25%)	14	6 (43%)
2005-2008	1333	124	31 (25%)	23	4 (17%)
2009-2012	1382	167	52 (31%)	54	14 (26%)
Data source: Patient Episode Database for Wales (PEDW). NHS Wales Informatics Service.					

1. Data based on patients resident in Wales, admitted to providers in Wales or England. Admissions to non-NHS providers are not included.
2. Count of distinct patients per year. If a patient is admitted twice within the same year, they are counted once only. Patients admitted in two years are counted once in each relevant year.
3. Deaths based on deaths in hospital. Deaths that occur elsewhere are not included in the analysis.
4. Defined by codes for ascites, bleeding oesophageal varices; hepato-renal syndrome or hepatic failure.

*Data may be subject to change, as further data submissions may be received.

Table 8: Indications for liver transplants undertaken in HCV infected individuals in England: 1996-2012*

		First liver transplants with post hepatitis C cirrhosis at registration and HCV positive at registration or transplant (per cent of all liver transplants)			
Year	All Liver Transplants	Total	Post-hep C Cirrhosis	Hepatocellular carcinoma	Other Indication
1996	445	44 (10%)	32 (7%)	7 (2%)	5 (1%)
1997	484	58 (12%)	44 (9%)	10 (2%)	4 (1%)
1998	455	49 (11%)	31 (7%)	9 (2%)	9 (2%)
1999	493	76 (15%)	51 (10%)	19 (4%)	6 (1%)
2000	477	66 (14%)	34 (7%)	22 (5%)	10 (2%)
2001	482	68 (14%)	44 (9%)	20 (4%)	4 (1%)
2002	518	83 (16%)	49 (9%)	28 (5%)	6 (1%)
2003	475	74 (16%)	46 (10%)	21 (4%)	7 (1%)
2004	545	80 (15%)	55 (10%)	22 (4%)	3 (1%)
2005	468	55 (12%)	28 (6%)	21 (4%)	6 (1%)
2006	493	60 (12%)	31 (6%)	25 (5%)	4 (1%)
2007	496	65 (13%)	30 (6%)	28 (6%)	7 (1%)
2008	537	112 (21%)	57 (11%)	51 (9%)	4 (1%)
2009	523	92 (18%)	40 (8%)	49 (9%)	3 (1%)
2010	548	95 (17%)	44 (8%)	50 (9%)	1 (0%)
2011	572	103 (18%)	49 (9%)	53 (9%)	1 (0%)
2012	621	101 (16%)	51 (8%)	49 (8%)	1 (0%)
TOTAL	8632	1281 (15%)	716 (8%)	484 (6%)	81 (1%)
*These figures are based on registry data as at 17th May 2013					
Data Source: NHS Blood and Transplant					

Table 9: Indications for liver transplants undertaken in HCV infected individuals in Northern Ireland and Wales: 1996-2012*

		First liver transplants with post hepatitis C cirrhosis at registration and HCV positive at registration or transplant (per cent of all liver transplants)			
Year	All Liver Transplants	Total	Post-hep C Cirrhosis	Hepatocellular carcinoma	Other Indication
1996	31	1 (3%)	1 (3%)	0 (0%)	0 (0%)
1997	42	1 (2%)	1 (2%)	0 (0%)	0 (0%)
1998	45	3 (7%)	3 (7%)	0 (0%)	0 (0%)
1999	45	6 (13%)	5 (11%)	1 (2%)	0 (0%)
2000	35	4 (11%)	2 (6%)	1 (3%)	1 (3%)
2001	43	1 (2%)	0 (0%)	1 (2%)	0 (0%)
2002	46	4 (9%)	3 (7%)	1 (2%)	0 (0%)
2003	31	3 (10%)	1 (3%)	0 (0%)	2 (6%)
2004	48	4 (8%)	2 (4%)	1 (2%)	1 (2%)
2005	24	1 (4%)	1 (4%)	0 (0%)	0 (0%)
2006	39	8 (21%)	4 (10%)	4 (10%)	0 (0%)
2007	50	6 (12%)	5 (10%)	1 (2%)	0 (0%)
2008	52	8 (15%)	4 (8%)	3 (6%)	1 (2%)
2009	39	10 (26%)	7 (18%)	3 (8%)	0 (0%)
2010	40	5 (13%)	2 (5%)	3 (8%)	0 (0%)
2011	51	4 (8%)	1 (2%)	2 (4%)	1 (2%)
2012	56	3 (5%)	2 (4%)	1 (2%)	0 (0%)
TOTAL	717	72 (10%)	44 (6%)	22 (3%)	6 (1%)
*These figures are based on registry data as at 17th May 2013					
Data Source: NHS Blood and Transplant					

Table 10: Indications for liver transplant undertaken in HCV infected individuals in Scotland: 1996-2012*

		First liver transplants with post hepatitis C cirrhosis at registration and HCV positive at registration or transplant (per cent of all liver transplants)			
Year	All Liver Transplants	Total	Post-hep C Cirrhosis	Hepatocellular carcinoma	Other Indication
1996	44	5 (11%)	4 (9%)	0 (0%)	1 (2%)
1997	40	4 (10%)	2 (5%)	0 (0%)	2 (5%)
1998	54	7 (13%)	3 (6%)	2 (4%)	2 (4%)
1999	54	4 (7%)	1 (2%)	2 (4%)	1 (2%)
2000	58	7 (12%)	4 (7%)	1 (2%)	2 (3%)
2001	56	7 (13%)	3 (5%)	3 (5%)	1 (2%)
2002	59	5 (8%)	4 (7%)	1 (2%)	0 (0%)
2003	52	4 (8%	1 (2%)	2 (4%)	1 (2%)
2004	55	6 (11%)	3 (5%)	3 (5%)	0 (0%)
2005	60	10 (17%)	9 (15%)	1 (2%)	0 (0%)
2006	64	6 (9%)	4 (6%)	1 (2%)	1 (2%)
2007	55	8 (15%)	5 (9%)	3 (5%)	0 (0%)
2008	78	12 (15%)	5 (6%)	7 (9%)	0 (0%)
2009	76	6 (8%)	3 (4%)	3 (4%)	0 (0%)
2010	85	19 (22%)	10 (12%)	9 (11%)	0 (0%)
2011	95	11 (12%)	5 (5%)	5 (5%)	1 (1%)
2012	96	11 (11%)	5 (5%)	5 (5%)	1 (1%)
TOTAL	1081	132 (12%)	71 (7%)	48 (4%)	13 (1%)
*These figures are based on registry data as at 17th May 2013					
Data Source: NHS Blood and Transplant					

Table 11: Injecting* status of adults in drug treatment 2005/06-2011/12 in England

Injecting status of adults in drug treatment														
	2005-2006		2006-2007		2007-2008		2008-2009**		2009-2010		2010-2011		2011-2012	
Injecting status	All in treatment	Newly presenting	All in treatment	Newly presenting	All in treatment	Newly presenting	All in treatment	Newly presenting	All in treatment	Newly presenting	All in treatment	Newly presenting	All in treatment	Newly presenting
Currently injecting	47,897	18,724	54,570	18,589	57,500	18,524	59,923	18,421	56,419	14,892	53,853	12,850	50,972	11,928
Previously injected	36,319	16,180	42,510	16,976	48,124	18,413	54,371	20,415	58,161	20,448	61,002	19,719	60,967	18,268
Total ever injected	84,216	34,904	97,080	35,565	105,624	36,937	114,294	38,836	114,580	35,340	114,855	32,569	111,939	30,196
Data source: National Drug Treatment Monitoring System														

*This table shows the number of people who have injected drugs where a person is classed as ever having injected if they are currently injecting or have previously injected. If a person has been classified as 'currently injecting' and 'previously injecting' they are assumed to be 'currently injecting'. For all in treatment, clients who reported as 'currently injecting' when they entered treatment over the years may have ceased to inject during the reporting period. 'Newly presenting' refers to a person starting a new treatment journey in the financial year.

**The numbers for 2008/2009 vary slightly from those submitted for the 2009 HCV in the UK report for two main reasons – (i) because the 2008-09 drug treatment statistics were revised to include data from Bristol which were not available at the time of the 2009 publication, and (ii) a small change in the methodology used to calculate the numbers of people injecting drugs in order to correspond with methodology used in other reports by the NTA.

Table 12: Number of injecting paraphernalia items (rounded to nearest 1,000) reported to have been distributed by injection equipment provider outlets in Scotland.

	2004/05	2007/08	2008/09	2009/10	2010/11	2011/12
Needles/syringes	3,554,000	4,438,000	4,381,000	4,681,000	4,506,000	4,723,000*
Filters	NA	NA	356,000	2,224,000	2,500,000	2,534,000
Spoons/Cookers	NA	NA	509,000	2,143,000	2,438,000	2,527,000
Water	NA	NA	62,000	77,000	72,000	69,000
***Estimated, accounting for under-reporting**						

Table 13: Numbers participating in the RCGP Certificate in the detection and diagnosis of hepatitis B & C in primary care (up until end May 2013)

Region	Level 1 components				Level 1		Level 2	
	E-module		Face-to-Face training		Both components completed			
	By Dec 2012	Jan to May 2013	By Dec 2012	Jan to May 2013	By Dec 2012	Jan to May 2013	By Dec 2012	Jan to May 2013
EAST OF ENGLAND	41	8	0	0	0	0	0	0
EAST MIDLANDS	38	14	23	2	17	2	2	0
LONDON	104	11	21	5	20	4	2	0
NORTH EAST	33	5	28	2	13	2	0	0
NORTH WEST	113	12	88	1	75	1	6	0
SOUTH EAST	65	13	45	7	29	7	2	0
SOUTH WEST	56	9	42	1	23	1	2	0
WEST MIDLANDS	70	15	40	7	31	7	7	0
YORKSHIRE AND THE HUMBER	82	19	44	0	39	0	6	0
NORTHERN IRELAND	4	0	0	0	0	0	0	0
SCOTLAND	45	82	3	0	3		2	0
WALES	66	21	68	20	66	20	2	0
UNKNOWN	10	0	0	0	0	0	0	0
Total	727	209	402	45	316	44	31	Not Applicable

Data source: Royal College of General Practitioners

Table 14: Laboratory reports* of hepatitis C infection by English region: 1996-2012

Region	1996	1997	1998	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012	Total
East Midlands	151	183	182	198	189	151	242	326	384	471	281	402	633	599	489	650	636	6,167
Eastern	224	374	546	564	553	432	353	414	522	589	623	623	683	606	541	794	688	9,129
London	264	257	335	300	265	319	332	397	749	811	1,197	1,023	976	864	954	2,024	2,844	13,911
North East	13	40	58	111	130	115	137	229	240	286	245	139	168	266	261	270	255	2,963
North West	135	110	631	1,056	898	1,068	1,383	2,000	1,849	1,503	1,364	1,738	1,662	2,179	1,990	1,685	2,043	23,294
South East	585	663	931	801	601	569	531	495	407	322	389	825	1,131	1,170	1,165	1,261	1,244	13,090
South West	410	483	449	714	855	726	855	709	938	688	871	1,045	1,121	1,005	714	906	1,052	13,541
West Midlands	145	229	558	642	616	558	670	523	563	593	516	633	708	876	788	768	729	10,115
Yorkshire and Humbersi	77	157	142	236	393	236	306	477	588	1,032	1,475	1,380	1,325	1,097	980	1,559	1,382	12,842
TOTAL	2,004	2,496	3,832	4,622	4,500	4,174	4,809	5,570	6,240	6,295	6,961	7,808	8,407	8,662	7,882	9,917	10,873	105,052

Data source: CoSurv

*Statutory notification by diagnostic laboratories was introduced in October 2010[8]

Table 15: HCV RNA status (from testing initial sample) of new cases of hepatitis C reported in Northern Ireland

	PCR POS	PCR NEG	INSUFFICIENT	TOTAL
2010	73	28	5	**106**
2011	76	37	0	**113**
2012	93	40	1	**134**

Data source: Regional Virus Laboratory, Belfast and Social Care Trust

Table 16: Hepatitis C test status of adults in drug treatment in England - all persons

Hepatitis C test status of adults in drug treatment - all persons															
Hepatitis C test recorded		2005-2006		2006-2007		2007-2008		2008-2009*		2009-2010		2010-2011		2011-2012	
		All in treatment	Newly presenting	All in treatment	Newly presenting	All in treatment	Newly presenting	All in treatment	Newly presenting	All in treatment	Newly presenting	All in treatment	Newly presenting	All in treatment	Newly presenting
Yes	No.	20,773	9,608	35,096	15,143	57,929	22,378	75,668	27,690	93,162	31,629	105,380	32,397	113,131	34,211
	%	11.8%	11.6%	18.1%	18.9%	28.8%	27.2%	35.9%	32.8%	45.0%	39.9%	51.5%	43.8%	57.4%	49.3%
No	No.	155,096	73,327	159,077	65,079	142,876	59,957	135,147	56,830	113,727	47,626	99,093	41,631	83,979	35,223
	%	88.2%	88.4%	81.9%	81.1%	71.2%	72.8%	64.1%	67.2%	55.0%	60.1%	48.5%	56.2%	42.6%	50.7%
Total		**175,869**	**82,935**	**194,173**	**80,222**	**200,805**	**82,335**	**210,815**	**84,520**	**206,889**	**79,255**	**204,473**	**74,028**	**197,110**	**69,434**
Data source: National Drug Treatment Monitoring System															

*The numbers for 2008/2009 vary slightly from those submitted for the 2009 HCV in the UK report for two main reasons – (i) because the 2008-09 drug treatment statistics were revised to include data from Bristol which were not available at the time of the 2009 publication, and (ii) a small change in the methodology used to calculate the numbers of people injecting drugs in order to correspond with methodology used in other reports by the NTA.

Table 17: Hepatitis C test status of adults in drug treatment in England - those who have ever injected*

Hepatitis C test status of adults in drug treatment - currently injecting* or previously injected* only															
Hepatitis C test recorded		2005-2006		2006-2007		2007-2008		2008-2009**		2009-2010		2010-2011		2010-2011	
		All in treatment	Newly presenting	All in treatment	Newly presenting	All in treatment	Newly presenting	All in treatment	Newly presenting	All in treatment	Newly presenting	All in treatment	Newly presenting	All in treatment	Newly presenting
Yes	No.	15,562	6,976	26,611	10,903	41,743	14,414	54,507	17,917	66,130	19,575	73,942	19,532	79,052	20,390
	%	18.5%	20.0%	27.4%	30.7%	39.5%	39.0%	47.7%	46.1%	57.7%	55.4%	64.4%	60.0%	70.6%	67.5%
No	No.	68,654	27,928	70,469	24,662	63,881	22,523	59,787	20,919	48,450	15,765	40,913	13,037	32,887	9,806
	%	81.5%	80.0%	72.6%	69.3%	60.5%	61.0%	52.3%	53.9%	42.3%	44.6%	35.6%	40.0%	29.4%	32.5%
Total		**84,216**	**34,904**	**97,080**	**35,565**	**105,624**	**36,937**	**114,294**	**38,836**	**114,580**	**35,340**	**114,855**	**32,569**	**111,939**	**30,196**
Data source: National Drug Treatment Monitoring System															

*This table shows the number of injectors where a person is classed as an injector if they have 'currently injecting' or 'previously injecting' listed as their injecting status within their latest treatment journey. If a person has been classified as 'currently injecting' and 'previously injecting' they are assumed to be 'currently injecting'. For all in treatment, clients who reported as 'currently injecting' when they entered treatment over the years may have ceased to inject during the reporting period. 'Newly presenting' refers to a person starting a new treatment journey in the financial year.

**The numbers for 2008/2009 vary slightly from those submitted for the 2009 HCV in the UK report for two main reasons – (i) because the 2008-09 drug treatment statistics were revised to include data from Bristol which were not available at the time of the 2009 publication, and (ii) a small change in the methodology used to calculate the numbers of people injecting drugs in order to correspond with methodology used in other reports by the NTA.

Table 18: Hepatitis C intervention status for adults in drug treatment in England- all persons

Hepatitis C intervention status for adults in drug treatment - all persons															
Recorded hepatitis C status*		2005-2006		2006-2007		2007-2008		2008-2009**		2009-2010		2010-2011		2011-2012	
		All in treatment	Newly presenting	All in treatment	Newly presenting	All in treatment	Newly presenting	All in treatment	Newly presenting	All in treatment	Newly presenting	All in treatment	Newly presenting	All in treatment	Newly presenting
Offered and accepted	No.	563	203	2,752	1,405	37,681	23,341	68,804	32,424	91,346	33,872	98,231	31,702	99,458	29,215
	%	0.3%	0.2%	1.4%	1.8%	18.8%	28.3%	32.6%	38.4%	44.2%	42.7%	48.0%	42.8%	50.5%	42.1%
Offered and refused	No.	452	180	1,878	962	23,531	15,345	42,711	22,080	56,488	25,450	62,199	26,291	62,510	25,853
	%	0.3%	0.2%	1.0%	1.2%	11.7%	18.6%	20.3%	26.1%	27.3%	32.1%	30.4%	35.5%	31.7%	37.2%
Assessed as not appropriate to	No.	n/a	n/a	n/a	n/a	n/a	n/a	1,253	614	8,603	6,176	13,287	7,858	15,167	7,923
	%	-	-	-	-	-	-	0.6%	0.7%	4.2%	7.8%	6.5%	10.6%	7.7%	11.4%
Not offered	No.	685	300	3,193	1,797	22,294	14,014	27,421	13,561	17,843	6,193	10,949	3,447	7,532	2,802
	%	0.4%	0.4%	1.6%	2.2%	11.1%	17.0%	13.0%	16.0%	8.6%	7.8%	5.4%	4.7%	3.8%	4.0%
Status recorded	No.	1,700	683	7,823	4,164	83,506	52,700	140,189	68,679	174,280	71,691	184,666	69,298	184,667	65,793
No recorded status	No.	174,169	82,252	186,350	76,058	117,299	29,635	70,626	15,841	32,609	7,564	19,807	4,730	12,443	3,641
	%	99.0%	99.2%	96.0%	94.8%	58.4%	36.0%	33.5%	18.7%	15.8%	9.5%	9.7%	6.4%	6.3%	5.2%
Total		**175,869**	**82,935**	**194,173**	**80,222**	**200,805**	**82,335**	**210,815**	**84,520**	**206,889**	**79,255**	**204,473**	**74,028**	**197,110**	**69,434**
Data source: National Drug Treatment Monitoring System															

*Information about whether people have been offered a hepatitis C test is recorded at the beginning of their latest period of treatment.

**The numbers for 2008/2009 vary slightly from those submitted for the 2009 HCV in the UK report for two main reasons – (i) because the 2008-09 drug treatment statistics were revised to include data from Bristol which were not available at the time of the 2009 publication, and (ii) a small change in the methodology used to calculate the numbers of people injecting drugs in order to correspond with methodology used in other reports by the NTA.

Table 19: Hepatitis C test status of adults in drug treatment in England - those who have ever injected*

Hepatitis C intervention status for adults in drug treatment - currently injecting* or previously injected* only															
Recorded hepatitis C status***		2005-2006		2006-2007		2007-2008		2008-2009**		2009-2010		2010-2011		2011-2012	
		All in treatment	Newly presenting	All in treatment	Newly presenting	All in treatment	Newly presenting	All in treatment	Newly presenting	All in treatment	Newly presenting	All in treatment	Newly presenting	All in treatment	Newly presenting
Offered and accepted	No.	442	144	2,060	957	24,386	13,449	44,376	18,258	59,210	18,218	63,603	16,589	65,402	15,449
	%	0.5%	0.4%	2.1%	2.7%	23.1%	36.4%	38.8%	47.0%	51.7%	51.6%	55.4%	50.9%	58.4%	51.1%
Offered and refused	No.	297	100	1,224	533	11,809	6,409	20,918	8,913	27,431	9,738	29,949	9,915	29,940	9,526
	%	0.4%	0.3%	1.3%	1.5%	11.2%	17.4%	18.3%	23.0%	23.9%	27.6%	26.1%	30.4%	26.7%	31.5%
Assessed as not appropriate to offer	No.	n/a	n/a	n/a	n/a	n/a	n/a	738	323	4,065	2,539	6,190	3,197	7,437	3,242
	%	-	-	-	-	-	-	0.6%	0.8%	3.5%	7.2%	5.4%	9.8%	6.6%	10.7%
Not offered	No.	424	171	2,076	1,019	11,340	5,832	13,230	5,384	8,471	2,249	5,599	1,306	3,695	976
	%	0.5%	0.5%	2.1%	2.9%	10.7%	15.8%	11.6%	13.9%	7.4%	6.4%	4.9%	4.0%	3.3%	3.2%
Status recorded	No.	1,163	415	5,360	2,509	47,535	25,690	79,262	32,878	99,177	32,744	105,341	31,007	106,474	29,193
No recorded status	No.	83,053	34,489	91,720	33,056	58,089	11,247	35,032	5,958	15,403	2,596	9,514	1,562	5,465	1,003
	%	98.6%	98.8%	94.5%	92.9%	55.0%	30.4%	30.7%	15.3%	13.4%	7.3%	8.3%	4.8%	4.9%	3.3%
Total		**84,216**	**34,904**	**97,080**	**35,565**	**105,624**	**36,937**	**114,294**	**38,836**	**114,580**	**35,340**	**114,855**	**32,569**	**111,939**	**30,196**
Data source: National Drug Treatment Monitoring System															

*This table shows the number of injectors where a person is classed as an injector if they have 'currently injecting' or 'previously injecting' listed as their injecting status within their latest treatment journey. If a person has been classified as 'currently injecting' and 'previously injecting' they are assumed to be 'currently injecting'. For all in treatment, clients who reported as 'currently injecting' when they entered treatment over the years may have ceased to inject during the reporting period. 'Newly presenting' refers to a person starting a new treatment journey in the financial year.

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***Information about whether people have been offered a hepatitis C test is recorded at the beginning of their latest period of treatment.

Table 20: Hepatitis C results from Dried Blood Spot Testing Wales in 2011/2012

Year	Number of DBS tested	Number Of HCV Ab reactive	Number of follow up bloods received*	Number of HCV PCR positive from FU
2011	1847	339	70	54
2012	1937	214	61	47
Data source: Virology Specialist Centre, Public Health Wales, University Hospital of Wales, Cardiff				
* within the calendar year				

Table 21: Number of active PWIDs who have self-reported HCV status in Wales from the Harm Reduction Database: October 2010-March 2013

Self-reported HCV status recorded	Drug type – reported primary substance used number and percentage of total within 'substance type'			
	Image and performance enhancing drugs*		Psychoactive drugs**	
	Oct 2010-March 2012 (18 months)	April 2012- March 2013	Oct 2010-March 2012 (18 months)	April 2012- March 2013
	Number (%)	Number (%)	Number (%)	Number (%)
Positive	≤5 (≤1)	≤5(≤1)	116 (10)	125 (12)
Negative	271 (43)	189 (35)	735 (63)	639 (61)
Status Not Known	352 (56)	342 (64)	323 (27)	278 (27)
Not recorded	1905	1365	1657	1635
Data from Harm Reduction Database, Public Health Wales				

* steroids, growth hormone, melanotan,

** including heroin, cocaine, amphetamine, new psychoactive substances

Table 22: Hepatitis C reports made to the Public Health in Prisons (PHiPs) Team in England, 2010-2012

	2010	2011	2012
Hepatitis C acute	**0**	**1**	**0**
Hepatitis C antibody	**106**	**289**	**417**
Hepatitis C HCV RNA	**9**	**89**	**205**
Source: PHE Public Health in Prisons (PHiPs) Team, Health and Justice			

Table 23: Characteristics and probable exposure history of HCV infected blood donors by gender England and North Wales, 2012

Characteristics of infected donors	New donors[1]				Repeat donors[1]				Total	
	Male	Female	Total	%	Male	Female	Total	%		%
Number	32	19	51	*100*	4	2	6	*100*	57	*100*
Prevalence per 100 000 donors	47.8	21.4	32.8		0.5	0.2	0.318		3.0	
Ethnic group										
White-British	19	9	28	*55*	3	2	5	*83*	33	*58*
Mixed-white/black African	0	0	0	*0*	0	0	0	*0*	0	*0*
Mixed-white/black Caribbean	0	0	0	*0*	0	0	0	*0*	0	*0*
Any other white background	5	8	13	*25*	1	0	1	*17*	14	*25*
Indian/Pakistani/Bangladeshi	8	2	10	*20*	0	0	0	*0*	10	*18*
Any other mixed background	0	0	0	*0*	0	0	0	*0*	0	*0*
Ethnicity information not disclosed	0	0	0	*0*	0	0	0	*0*	0	*0*
Area of birth										
UK	14	10	24	*47*	3	2	5	*83*	29	*51*
Europe excl UK	3	6	9	*18*	0	0	0	*0*	9	*16*
Asia	6	1	7	*14*	0	0	0	*0*	7	*12*
Other	0	0	0	*0*	0	0	0	*0*	0	*0*
Not known	9	2	11	*22*	1	0	1	*17*	12	*21*
Probable exposure category										
People who inject drug	9	2	11	*22*	0	1	1	*17*	12	*21*
Intranasal drug use	1	1	2	*4*	0	1	1	*17*	3	*5*
Sex between men	0	0	0	*0*	1	0	1	*17*	1	*2*
Sex between men and women	3	1	4	*8*	1	0	1	*17*	5	*9*
Blood/tissue transfer, blood product treatment	1	3	4	*8*	0	0	0	*0*	4	*7*
Tattooing/body piercing/acupuncture/Blood contact	4	6	10	*20*	0	0	0	*0*	10	*18*
Family/household contact	0	0	0	*0*	0	0	0	*0*	0	*0*
Born in an endemic country[2]	2	1	3	*6*	0	0	0	*0*	3	*5*
Incomplete follow up	11	3	14	*27*	1	0	1	*17*	15	*26*
No indentified exposure	1	2	3	*6*	1	0	1	*17*	4	*7*

[1] As classified according to evidence supplied to the NHSBT/PHE Epidemiology Unit

[2] Probable risk in the absence of any other information

Table 24: Model predictions for peak incidence of end stage liver disease (ESLD)* and hepatocellular carcinoma (HCC) under different scenarios for treatment levels

Scenario	Cases of HCV-related ESLD/yr at peak	Year of peak incidence	Cases averted per year (avg)
1. **No treatment**	2290 (2000, 2520)	2035	
2. **Past** but no future treatment	2080 (1820, 2500)	2035	
3. Maintain **current treatment levels** (3% per year)	1680 (1460, 2000)	2033	480
4. Treatment numbers **increase by 50%** over next 10 years	1530 (1330, 1820)	2031	600
5. Treatment numbers **increase by 100%** over next 10 years	1440 (1270, 1670)	2028	670
6. **Gradual complete coverage**. As in (5) above, then treatment continues to rise from 2023 until 100% coverage is achieved in 2043	1400 (1250, 1600)	2024	740
7. **Rapid complete coverage**. Treatment rates rise rapidly from 2013, with up to 30,000 per year treated and 100% coverage achieved in 15 years	1180 (1060, 1310)	2015	910

*The presence of ascites, bleeding oesophageal varices; hepato-renal syndrome, hepatic encephalopathy or hepatic failure.

Data sources

- Public Health in Prisons (PHiPs) reports: www.hpa.org.uk/Topics/InfectiousDiseases/InfectionsAZ/PrisonInfectionPreventionTeam
- Laboratory Reporting via COSURV: www.hpa.org.uk/ProductsServices/InfectiousDiseases/ServicesActivities/surveillance/SourcesOfSurveillanceData/survLaboratoryReporting www.hpa.org.uk/Topics/InfectiousDiseases/InfectionsAZ/HepatitisC/EpidemiologicalData/hepcLabAge www.hpa.org.uk/webc/HPAwebFile/HPAweb_C/1194947381307
- HPA Sentinel Surveillance of Hepatitis C Testing: www.hpa.org.uk/ssbbv
- Unlinked Anonymous Monitoring survey of PWID in contact with specialist drug services. http://www.hpa.org.uk/web/HPAweb&HPAwebStandard/HPAweb_C/1202115519183
- NHS Blood and Transplant/HPA Blood Donor Infection Surveillance Scheme: www.organdonation.nhs.uk
- Enhanced Surveillance off Newly Acquired Hepatitis C infection in men who have sex with men: www.hpa.org.uk/Topics/InfectiousDiseases/InfectionsAZ/HIVAndSTIs/SurveillanceSystemsHIVAndSTIs/hivsti_SNAHC
- Office for National Statistics mortality data: www.statistics.gov.uk/default.asp
- Hospital Episode Statistics, The NHS Information Centre for Health and Social Care: www.hesonline.nhs.uk/Ease/servlet/ContentServer?siteID=1937&categoryID=53
- Oral fluid testing data, Concateno plc: www.concateno.com
- Transplant data, NHS Blood and Transplant: www.organdonation.nhs.uk/ukt/default.jsp
- National Drug Treatment Monitoring System: www.ndtms.net/Default.aspx

- Northern Ireland Blood Transfusion Service: www.nibts.org
- NHS National Services Scotland (Health Protection Scotland and Information Services Division): www.nhsnss.org/index.php
- Hepatitis C Testing Laboratories in Scotland: www.documents.hps.scot.nhs.uk/ewr/pdf2012/1218.pdf
- Needle Exchange Surveillance Initiative in Scotland (University of West of Scotland, Health Protection Scotland, and West of Scotland Specialist Virology Centre): http://www.hepatitisscotlandc.org.uk/media/50084/nesi-report-08-09.pdf
- Scottish National Blood Transfusion Service: www.scotblood.co.uk
- Welsh Blood Service: www.welsh-blood.org.uk
- Patient Episode Database for Wales, NHS Wales Informatics Service 2011: http://www.wales.nhs.uk/nwis/page/52490
- Enhanced Surveillance of BBV in People who inject drugs in Wales: http://howis.wales.nhs.uk/sites3/page.cfm?orgid=457&pid=47693
- Pharmex: http://cmu.dh.gov.uk/pharmex-upload
- Roche: www.roche.co.uk/portal/uk
- Merck, Sharp & Dohme Ltd: www.msd-uk.com
- Public Health Agency: www.publichealth.hscni.net
- Royal College of General Practitioners: www.rcgp.org.uk
- Belfast Trust: www.belfasttrust.hscni.net
- Northern Ireland Hepatitis B and C Managed Clinical Network: www.hepbandcni.net
- Department of Health, Social Services and Public Safety: www.dhsspsni.gov.uk
- Northern Ireland Statistics and Research Agency: www.nisra.gov.uk

Glossary of abbreviations

Anti-HCV	Antibodies to hepatitis C virus
BBV	Bloodborne virus
CrI	Credible interval, the Bayesian equivalent to a confidence interval (CI). Both capture the uncertainty associated with an estimate, and in a Bayesian framework the interpretation is that there is a 95% probability that the estimate lies within the interval.
DAT	Drug action team
DBS	Dried blood spot
ESLD	End-stage liver disease
GP	General Practitioner
HCC	Hepatocellular carcinoma
HCV	Hepatitis C virus
HIV	Human immunodeficiency virus
HPA	Health Protection Agency
HRD	Harm reduction database
MSM	Men who have sex with men
NDTMS	National Drug Treatment Monitoring System
NESI	Needle Exchange Surveillance Initiative
NGO	Non-governmental organisation
NICE	National Institute for Health and Care Excellence
NHS	National Health Service
NSP	Needle and syringe programme
NTA	National Treatment Agency for Substance Misuse
PCR	Polymerase chain reaction
PHE	Public Health England
PHiPs Team	Public Health in Prisons Team
PHPQI	Prison health performance and quality indicators
PWID	People who inject drugs
RCGP	Royal College of General Practitioners
RNA	Ribonucleic acid
STI	Sexually Transmitted Infections
SVR	Sustained viral response
UAM	Unlinked Anonymous Monitoring survey
UK	United Kingdom
VCT	Voluntary confidential test/testing
WHO	World Health Organization

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