

# Hepatitis C in the UK

2011 Report



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## Foreword

We hope that this report will be a valuable resource for those in the field and help to direct and focus future action in the area of hepatitis C prevention, management, and control. Since national hepatitis C action plans were published between one and seven years ago, there has been much progress in each of the UK countries. The final plan to be approved was in Wales, where a strong foundation for tackling all blood-borne virus infections is now in place. Across the UK, the extent of the problem has been more clearly defined and the specific interventions that are needed have been outlined. Despite this, the burden of HCV-related disease continues to accumulate, confirming the predictions and underlining the importance of sustained efforts.

Prevention continues to be vital if the pool of infected individuals is to be stopped from growing further. Evidence is emerging of the possible effectiveness of new approaches to prevention, such as the treatment of active injecting drug users. This will provide an opportunity to establish services in alternative settings, including primary care and drug services.

Monitoring the numbers of patients receiving treatment for hepatitis C is not straightforward and lack of local data prevents effective monitoring of performance in some parts of the UK. In Scotland, however, treatment rates have exceeded targets, demonstrating a successful model for the other countries. With the imminent availability of more effective, but expensive, anti-viral treatments, clear guidance on the appropriate indications for their use will be required to ensure the best use of scarce resources.

Future challenges remain significant, particularly in England and Northern Ireland, where recent and proposed changes to the NHS have introduced uncertainty. In England, the proposed changes to the NHS outlined in *Equity and Excellence: Liberating the NHS*<sup>1</sup> and the reorganisation of public health outlined in *Healthy Lives, Healthy People*<sup>2</sup> will change the accountability, commissioning and provision arrangements. When accompanied by the shift in public health responsibilities to local authorities, the potential for fragmentation of existing services, disruption of local networks and delays in implementation is real. Health and well-being boards in local authorities will need to promote better integration across health and social care; local Directors of Public Health will be well placed to advocate for this. Clinical networks and clinical senates will have an important role in providing specialist advice to clinical commissioning groups. The incorporation of the current functions of the Health Protection Agency (HPA) into Public Health England (PHE) should enable the continued monitoring of progress. PHE, as an Executive Agency of the Department of Health (DH), will retain the ability to give objective scientific advice on the surveillance and control of hepatitis C infection.

Dr Mary Ramsay  
Manager of the HPA Blood-borne Infections Programme and  
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## Summary

Updated estimates suggest that around 216,000 individuals are chronically infected with hepatitis C in the UK.<sup>3,4,5,6</sup> Much of the prevalent infection is concentrated in marginalised populations, with injecting drug users (IDUs) at greatest risk of acquiring infection.

Improvements in national surveillance have been made, and are ongoing, in all UK countries. Action plans and work programmes are in place across the UK to help tackle the infection. This report documents the progress of these plans and programmes.

In all UK countries, public health action is focused in four main areas:

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

### Prevention of new infections

Since 2001, England has further invested in effective and accessible community drug treatment. The number of people in contact with drug treatment services exceeded 206,000 in 2009/10; more than 114,500 of these were current or previous injectors who are at greatest risk of infection. A recent report concluded that prevention measures to reduce injecting drug use were having an impact with the prevalence of drug injecting in England falling.<sup>7</sup> A growing body of evidence exists to suggest that the combination of effective drug treatments, support for safe injecting, and treatment of hepatitis C virus (HCV) infection in IDUs can impact on the incidence and prevalence of HCV infection.<sup>8,9</sup>

Together with local drug partnerships, the National Treatment Agency for Substance Misuse (NTA) has continued to strengthen and review services for preventing hepatitis C transmission in England, including needle and syringe provision. In all UK countries, data suggest declining rates of risky injecting practices, with direct sharing of needles and syringes reported to be between 20% and 23% in 2010. The *Harm Reduction Works (HRW)* Campaign continues to be a key component of prevention activity and many other prevention initiatives from all sectors and countries complement and enhance activity in this area.

Despite these initiatives, data from the Unlinked Anonymous Monitoring survey (UAM) in 2010 suggest that 49% and 57% of IDUs in England and Scotland respectively are positive for HCV antibody (levels are lower in Northern Ireland and Wales). This underlies the importance of ongoing efforts to target this highest-risk group of the population.

In Scotland, the number of injection equipment provider outlets increased from 188 in 2004/05 to 240 in 2008/09. At least 4.4 million needles/syringes were distributed in 2008/09. In Wales, the *Harm Reduction Database (HRD)* was implemented in 2010 in all statutory and voluntary needle and syringe programme (NSP) services to enable national monitoring of: drug use, risk behaviours, blood-borne infection status and testing.

### Increasing awareness of infection

Hepatitis C is usually asymptomatic in the early years of infection, and consequently many individuals remain undiagnosed. Raising awareness is therefore an important component of reducing the burden of undiagnosed infection.

A variety of initiatives to increase public awareness of hepatitis C are ongoing, many specifically designed to target those at greatest risk of infection, including IDUs and individuals of South Asian origin. A number of initiatives, for example The Hepatitis C Trust's *Get Tested!* campaign, are well established. The World Health Organization (WHO) resolution on viral hepatitis that made World Hepatitis Day (28 July), one of only six official WHO days, was a significant milestone.

Education programmes for healthcare professionals are being developed across the UK. They include an e-learning package in Northern Ireland; a Royal College of General Practitioners (RCGP) Certificate in the Detection and Diagnosis of Hepatitis C in Primary Care in England, and a Train the Trainer course on blood-borne viruses (BBVs) in Wales aimed at individuals from across a range of social, health and other contexts working with individuals at risk of BBV infection.

## **Diagnosis and testing**

In 2010, the number of new hepatitis C diagnoses reported was 7,834; 106; 2,129; and 312 in England, Northern Ireland, Scotland and Wales respectively. In Scotland, new diagnoses in the past two years represent a considerable increase over previous years. In the rest of the UK laboratory reports, which are known to under-estimate true levels of diagnosis, suggest a fall in the numbers diagnosed over the past year. In Scotland, diagnosis by general practitioners (GPs) declined in 2010 despite the launch of professional and public awareness campaigns earlier that year. However, this was more than offset by the increase in diagnosis in drug treatment/harm reduction settings.

When data from the NTA and Health Protection Agency (HPA) enhanced surveillance systems are taken together, testing patterns and self-reports both suggest that HCV testing among IDUs in England is increasing. In 2010, 83% of IDUs participating in the UAM survey reported ever having had a voluntary confidential test for HCV (90% in Northern Ireland, 77% in Scotland, and 62% in Wales). National Drug Treatment Monitoring System (NDTMS) data suggest a 10% increase in testing in IDUs in England over the last year. The proportion of IDUs reporting that they were aware of their positive status has remained stable in recent years, and currently stands at 55% in England, 60% in Northern Ireland, 56% in Scotland, and 34% in Wales.

Enhanced surveillance in England shows increased testing via primary care and among individuals of South Asian origin, as well as in drug services, suggesting increased awareness of HCV across all these groups and settings. Even though integrated drug treatment has been further rolled out across the English prison estate, HPA data do not support an increase in testing in English prisons over the past year.

In England, Scotland and Wales, the roll out of dried blood spot (DBS) testing, has contributed to the increased levels of testing in IDUs. Following this success, a DBS testing pilot has taken place in Northern Ireland and DBS is being rolled out across the prison estate in Wales.

## **High quality, accessible treatment and care**

Antiviral treatments are available that will successfully clear the virus in the majority of patients. However, unless a significant increase in those receiving effective treatment occurs, the future burden of HCV-related disease will be substantial. All national data sources (hospital admissions for HCV-related end-stage liver disease, liver transplants and deaths) show that HCV-related liver disease is continuing to rise. In England alone it is predicted that in 2020, 15,840 individuals will be living with HCV-related cirrhosis or hepatocellular carcinoma (HCC).

In England the provision of high quality, accessible HCV-related care will be a key component of the forthcoming National Liver Disease Strategy (NLDS). As commissioning, accountability and provision arrangements in the new health economy become clear, opportunities will arise to improve and address the variation in hepatitis services that have been identified across the country.

In England, Northern Ireland and Scotland, the development of clinical networks and multi-disciplinary teams have been key to the successful delivery of services that ensure patient pathways are in place to address both individuals' medical and social needs. In Wales, similar networks are being developed. Surveys in England in 2010 suggest that around 70% of primary care trusts (PCTs) now have care pathways in place. In Scotland treatment rates continue to exceed targets; the number of initiates onto treatment increased by just over 100% during Phase 2 (April 2008 - March 2011) of Scotland's action plan. Databases to monitor national treatment levels exist in Scotland, are planned in Northern Ireland and Wales, but are proving difficult to establish in England. Alternative data sources for England suggest that 12,400 individuals were treated between 2006 and 2008, estimated to be less than 10% of those chronically infected. In Northern Ireland, since audit revealed that around half of those diagnosed with chronic infection failed to present to secondary care for assessment, rigorous follow-up protocols have been introduced to ensure that any new cases of chronic hepatitis C are picked-up.

Recommendations on the provision of antiviral services for patients with chronic viral hepatitis have been developed by the British Viral Hepatitis Group (BVHG) to help improve the quality of hepatitis C-related care across the UK (<http://bit.ly/ijXviH>).

## Public Health Recommendations

- 1. Commissioners and providers of services for injecting drug users need to sustain and improve the current broad range of prevention services (including needle and syringe programmes) to minimise on-going transmission of hepatitis C.**
- 2. Local NHS and other statutory bodies should work with the voluntary sector to support campaigns to sustain and further raise awareness of hepatitis C among the public and professionals.**
- 3. Further prevalence studies are required to better understand the amount of hepatitis C infection in migrants from areas other than the Indian sub-continent, to identify whether additional targeted awareness-raising campaigns are required.**
- 4. Continue to improve surveillance systems and data quality to better assess the impact of interventions.**
- 5. Testing in those attending specialist services for drug users needs to be sustained and enhanced, and the potential use of non-invasive specimens for testing in other settings should be considered.**
- 6. The imminent changes to the NHS in England provide an opportunity to ensure that reliable data on the number of patients treated for hepatitis C are available to inform commissioning and compare performance at national and local levels.**
- 7. Integrated pathways of care for patients with hepatitis C will need to be maintained during the transition from primary care trusts to clinical commissioning groups in England; care pathways should continue to be developed and updated in Wales, Scotland and Northern Ireland.**
- 8. All countries should develop plans to improve access to treatment services, for example by providing care in non-traditional settings.**
- 9. Hepatitis C awareness, testing and access to treatment should be strengthened in the prison setting.**

## 1. England

### 1.1 Surveillance and Research

#### **Action 1: Surveillance and Research:**<sup>10</sup>

*Key Issue: Improve surveillance and research so that trends in hepatitis C infection and the effectiveness of prevention measures can be monitored.*

A variety of national surveillance systems have been developed to monitor the prevalence, incidence and burden of hepatitis C virus (HCV) infection in England.

Health Protection Agency (HPA) systems, such as routine laboratory reporting,<sup>11</sup> sentinel surveillance of hepatitis C testing,<sup>12</sup> the Unlinked Anonymous Monitoring survey (UAM),<sup>13</sup> and the Enhanced Surveillance of Newly Acquired Hepatitis C infection in men who have sex with men (SNAHC)<sup>14</sup> allow monitoring of: HCV diagnostic testing, prevalence, and the generation of proxy measures of incidence within the general population and in specific risk groups. Data from other HPA systems, like the national surveillance of hepatitis-related end stage liver disease,<sup>15</sup> are used in combination with other national data sources (Hospital Episode Statistics (HES), Office for National Statistics (ONS) mortality data, and UK liver transplant data) to monitor the burden of HCV-related disease within the population.

Along with UAM data, stakeholder systems, including the National Drug Treatment Monitoring system (NDTMS),<sup>16</sup> the Integrated Drug Treatment System (IDTS),<sup>17</sup> and the Needle Exchange Monitoring System (NEXMS)<sup>18</sup> continue to provide key data for monitoring diagnostic testing and the impact of prevention and awareness raising initiatives amongst Injecting Drug User (IDU) and Offender populations. The NHS Blood and Transplant/HPA Blood Donor Infection Surveillance Scheme,<sup>15</sup> which detects infection in a population at low risk of blood-borne viruses, is useful because increases in numbers of infections provide a warning that transmission may have increased appreciably within the general population.

#### 1.1.1 National monitoring of diagnosis and testing

##### **National Outcome Indicator**

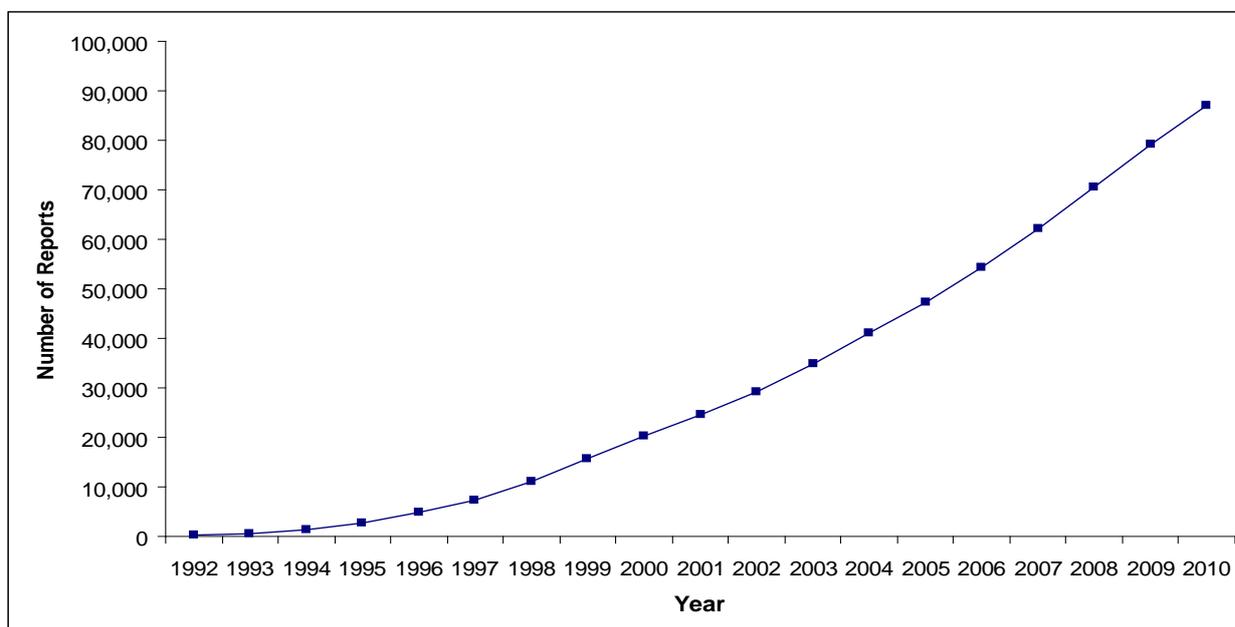
The total number of laboratory reports of confirmed hepatitis C infection has been set as a National Outcome Indicator.<sup>19</sup> An increase in the number of reports is expected as more testing of risk groups takes place. A total of 7,834 laboratory confirmed diagnoses of hepatitis C infection were reported to the Health Protection Agency, Colindale in 2010.

##### **The general population**

Overall, the number of reports of confirmed HCV infection has decreased by 9% from 2009 to 2010, suggesting that fewer people were diagnosed in 2010 (Figure 1). There is considerable regional variation, with numbers rising in some regions and falling in others (Table 1). As in previous years, the highest figures were reported by laboratories in the North West and the lowest figures were reported by laboratories in the North East (Table 1). Whilst routine laboratory reports are known to be incomplete,<sup>20;21</sup> new Health Protection regulations for England now make reporting of important public health infections (including hepatitis C) a

statutory obligation on laboratories and this may help to improve the completeness of routine surveillance.<sup>22</sup>

**Figure 1: Cumulative laboratory reports of hepatitis C infection from England: 1992–2010**



**Table 1: Laboratory reports of hepatitis C infection by English region: 1995-2010**

Region	1995	1996	1997	1998	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	Total
East Midlands	128	151	183	182	198	189	151	242	326	384	471	281	402	634	599	489	5,010
Eastern	125	224	374	546	565	553	432	353	414	523	589	623	624	683	606	541	7,775
London	203	263	257	335	300	265	319	332	397	749	811	1,197	1,023	975	862	901	9,189
North East	2	13	40	58	111	130	115	137	229	240	286	245	139	167	266	261	2,439
North West	206	135	110	631	1,057	898	1,068	1,383	2,001	1,851	1,504	1,367	1,742	1,671	2,185	2,001	19,810
South East	314	584	664	931	801	601	568	530	495	407	323	389	825	1,101	1,135	1,160	10,828
South West	312	411	483	449	715	855	726	855	709	940	689	871	1,044	1,120	1,001	713	11,893
West Midlands	36	145	229	558	642	618	559	671	523	563	593	516	633	707	876	788	8,657
Yorkshire and Humberside	66	77	157	142	237	393	236	306	477	588	1,032	1,475	1,380	1,324	1,094	980	9,964
<b>TOTAL</b>	<b>1,392</b>	<b>2,003</b>	<b>2,497</b>	<b>3,832</b>	<b>4,626</b>	<b>4,502</b>	<b>4,174</b>	<b>4,809</b>	<b>5,571</b>	<b>6,245</b>	<b>6,298</b>	<b>6,964</b>	<b>7,812</b>	<b>8,382</b>	<b>8,624</b>	<b>7,834</b>	<b>85,565</b>

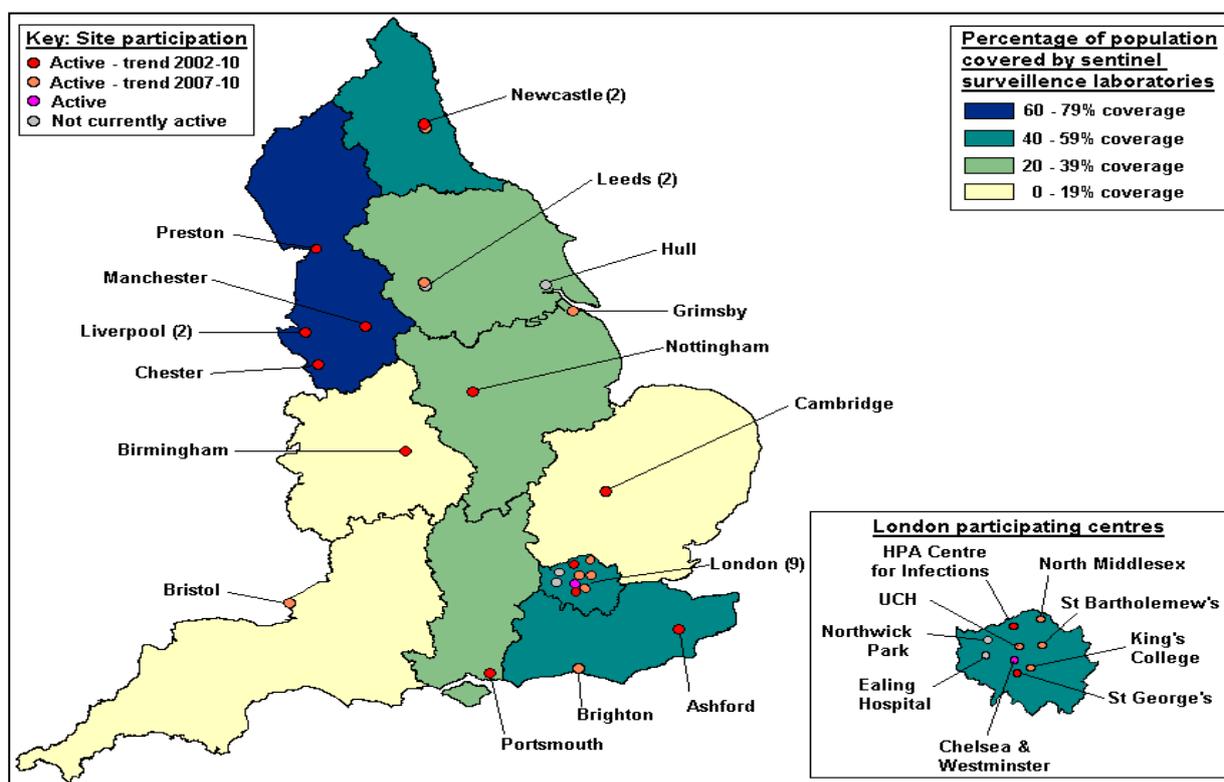
More than two thirds (69%) of hepatitis C laboratory reports were in men, and half of all reports received (49%) were in individuals aged between 25 and 39 years. This age/sex distribution is likely to be a reflection of the pattern of injecting drug use, which continues to be the predominant risk factor for acquisition of infection (Table 2).

**Table 2: Risk factor information in laboratory reports of hepatitis C infection from England: 1996-2010**

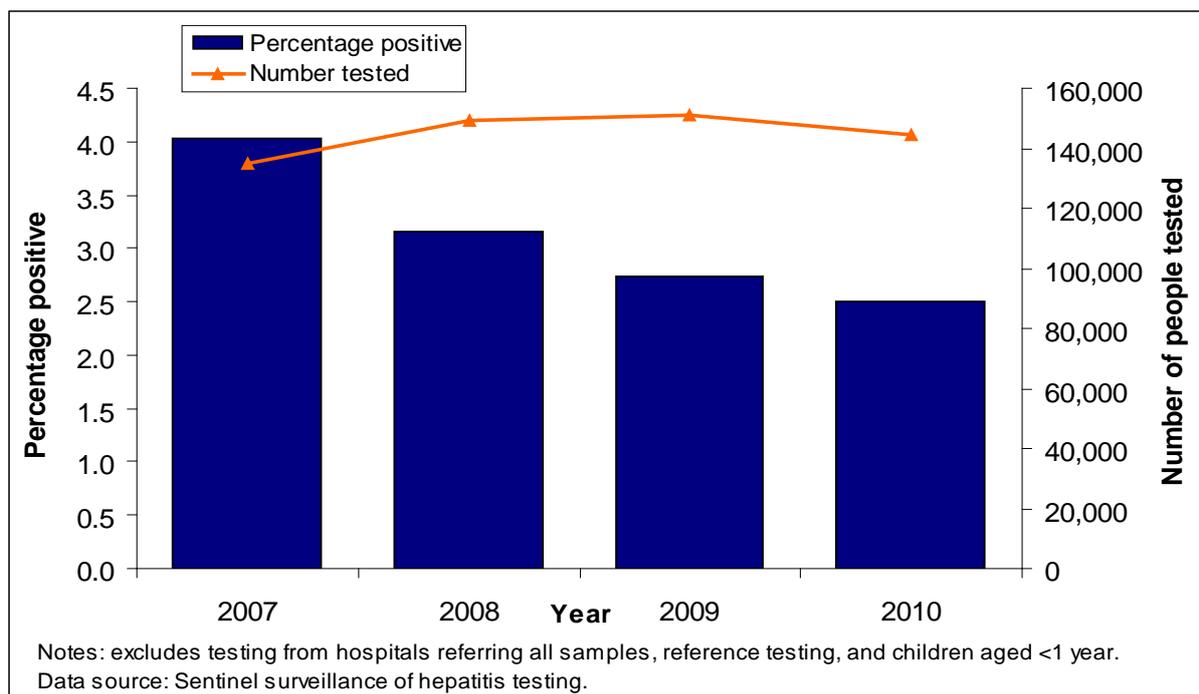
Risk factor (where reported)	Number of reports	Percentage
Injecting drug use	14296	87.9
Transfusion	221	1.4
Blood product recipient	120	0.7
Sexual exposure	334	2.1
Renal failure	80	0.5
Vertical (mother to baby) or household	65	0.4
Occupational	17	0.1
Other	1130	6.9
<b>TOTAL</b>	<b>16263</b>	<b>100</b>

Trends in testing were analysed using data from the 21 sentinel laboratories (Figure 2) where complete data from January 2007 to the end of December 2010 were available (Figure 3). These data suggest that more testing is being done but that the rate of testing may be levelling off.<sup>23</sup> This may partly be the result of testing saturation, since groups of patients tested in earlier years are those relatively easy to access, whereas the remaining individuals at risk are harder to identify. In 2010, 144,430 individuals were tested for anti-HCV, 2.5% of whom tested positive (n=3,622). Of these anti-HCV positive individuals 2,591 (71.5%) were tested by PCR, 68.9% of whom tested positive (n=1,786). As in previous years, the proportion of people testing anti-HCV positive has declined, which is consistent with the decline in laboratory reports. This suggests that more testing is being extended to people at relatively lower risk of infection.

**Figure 2: Geographic distribution of centres who have participated in the Sentinel Surveillance of Hepatitis Testing**

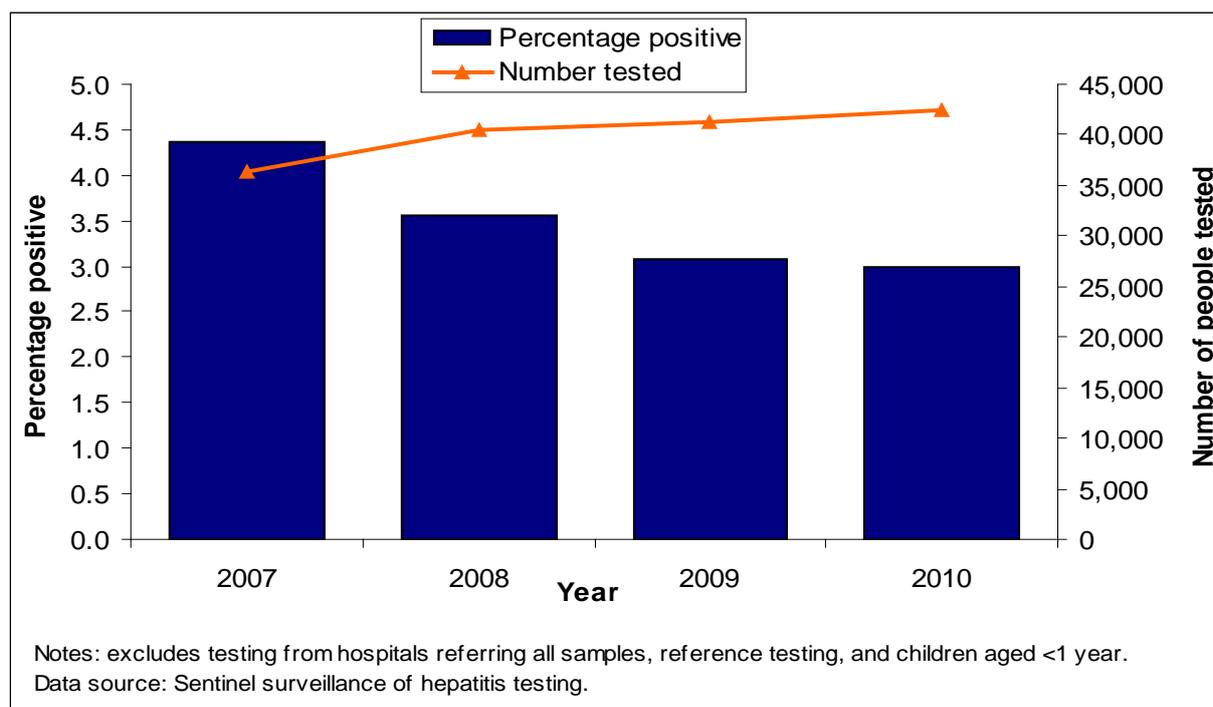


**Figure 3: Number of people tested for anti-HCV by year, and proportion positive, in 21 sentinel laboratories: 2007- 2010**



In primary care, testing has continued to increase gradually each year between 2007 and 2010 suggesting that awareness of hepatitis C in this setting may be rising. The proportion of individuals testing positive has decreased over the period (Figure 4).

**Figure 4: Number of people tested for anti-HCV by year, and proportion positive, via GP surgeries in 21 sentinel laboratories: 2007-2010**

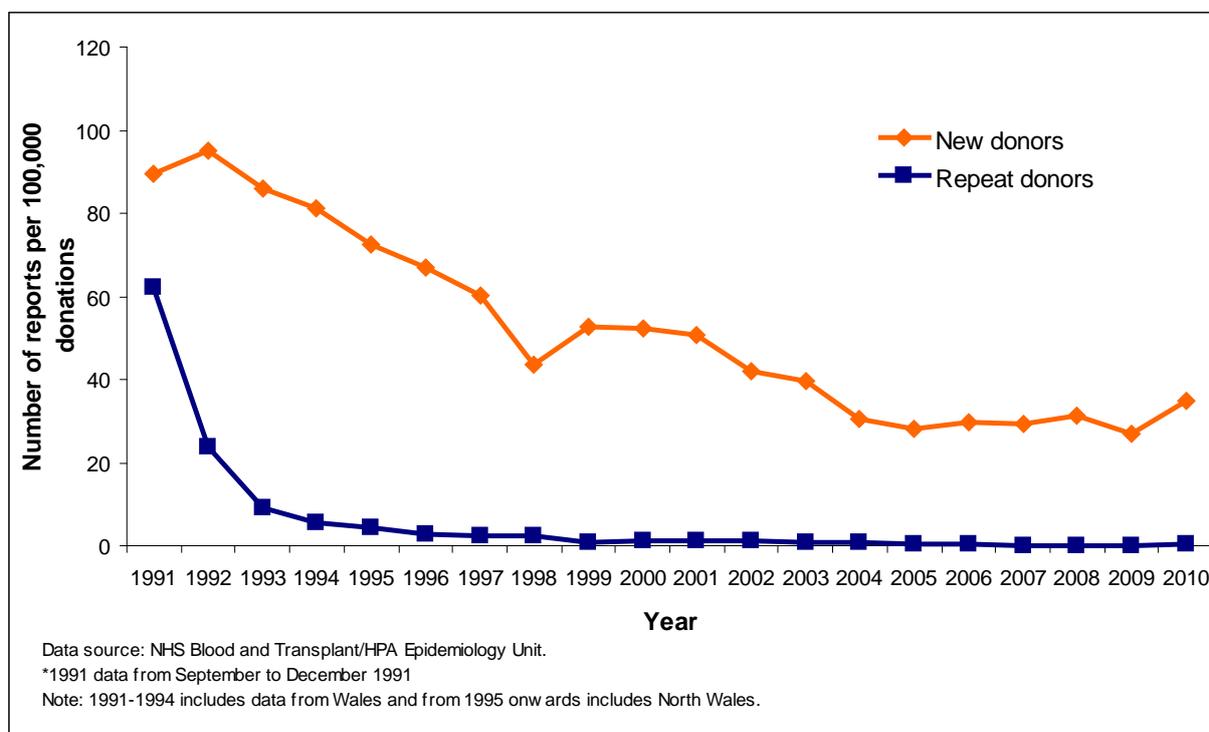


**Blood donors (low-risk population)**

The English blood services collect blood from voluntary donors who are selected to be at low risk from blood-borne infections (BBI). In 2010, 59 new donors tested positive for HCV; this approximates to around 34.9 per 100,000 donations tested and is similar to levels in previous years (Figure 5). Thirty seven HCV-infected new donors were male (63%), with a mean age of 39 years (range 17-60 years), similar to females. Ethnic origin was known for 58/59 infections (98%). Of these, 46 (79%) were white and seven (12%) were of South Asian (Indian/Pakistani/Bangladeshi) origin. Denominator data for 2010, supplied by NHS Blood and Transplant Donor Insight, suggests that, where known, the proportion of new donors in England with a white background was 91.8% compared to 3.2% of South Asian origin; this extrapolates to a frequency of 30.6 infections per 100,000 donations from white new donors (0.03%) and 131.5 infections per 100,000 donations from South Asian new donors (0.13%) in 2010.

Country of birth was stated for 47/59 (80%). Of these, 28 (60%) were born outside the UK: 16 in Europe (12 Eastern European), nine in Asia and three elsewhere.

**Figure 5: Frequency of hepatitis C in blood donors in England: 1991\*-2010 New and repeat donors**



Risk factor information was known for 45/59 (76%) new donors, 24 (53%) of whom were thought to have been infected outside the UK. Injecting drug use was reported in nine (20%), seven of these were of white ethnicity, six of whom were probably infected in the UK; two others were Asian, one of whom was probably infected in the UK. The mean age of those infected by injecting drug use was 45 years (range 31-59 years) and eight were male. These donors reported ceasing injecting on average 24 years prior to donating (range 7-40 years). Non-injecting drug use (i.e. snorting cocaine) was reported in five of the 45 (11%) and heterosexual contact was implicated in three cases (7%), two of whom had partners who had injected drugs. Transfusion before 1991 was a possible source of infection in three cases (7%), two had received their transfusions abroad. 'Other possible blood contact' was reported by 17 (38%) of the infected donors, 15 of these occurred abroad. Body piercing was cited as a

possible reason in another five cases (11%), 2 were undertaken in Eastern Europe. For the remaining three cases (7%), their only reported risk was being born in a country with mid to high HCV prevalence.

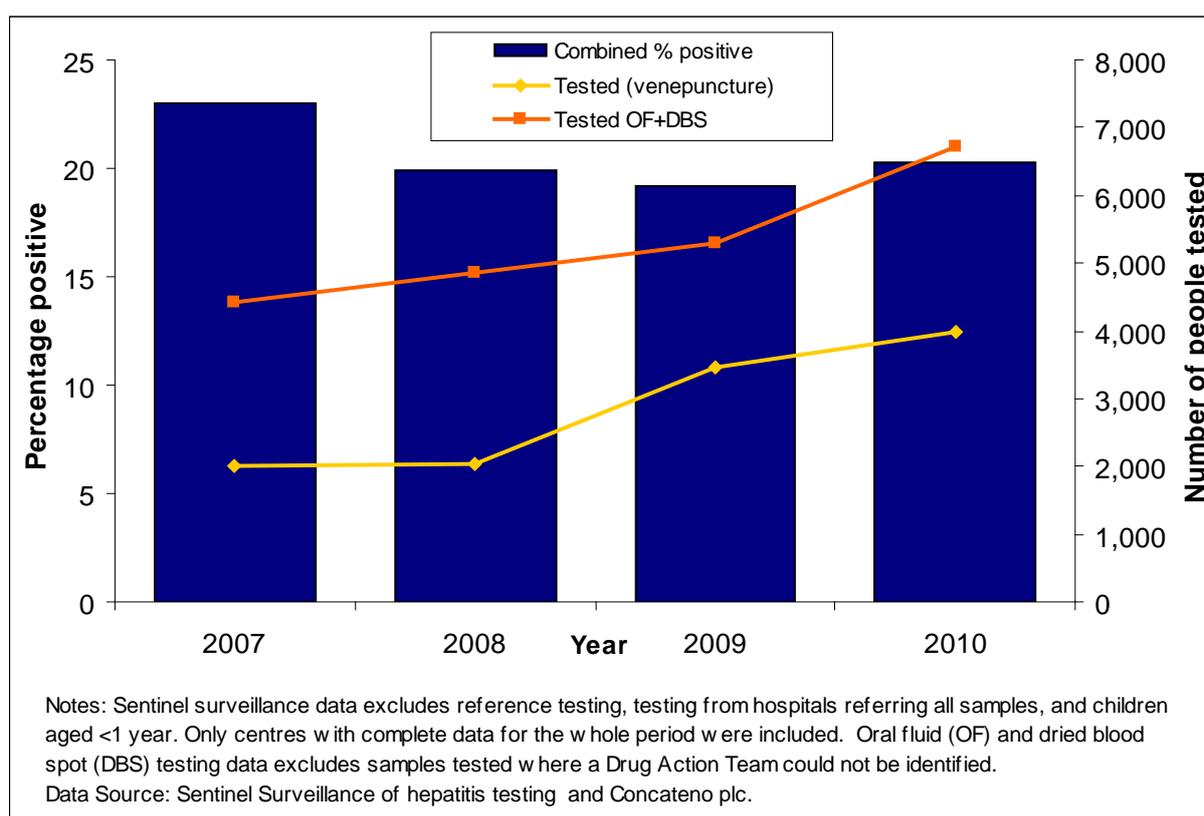
Since blood donation testing began, fewer hepatitis C infections have been detected in donations from repeat donors compared with first time donors, and frequencies of infection have declined from 62.3 to 0.43 per 100,000 donations (Figure 5).

### ***Injecting Drug Users***

IDUs remain one of the most important groups in which to monitor HCV infection because the majority of new infections occur within this population (Table 2).

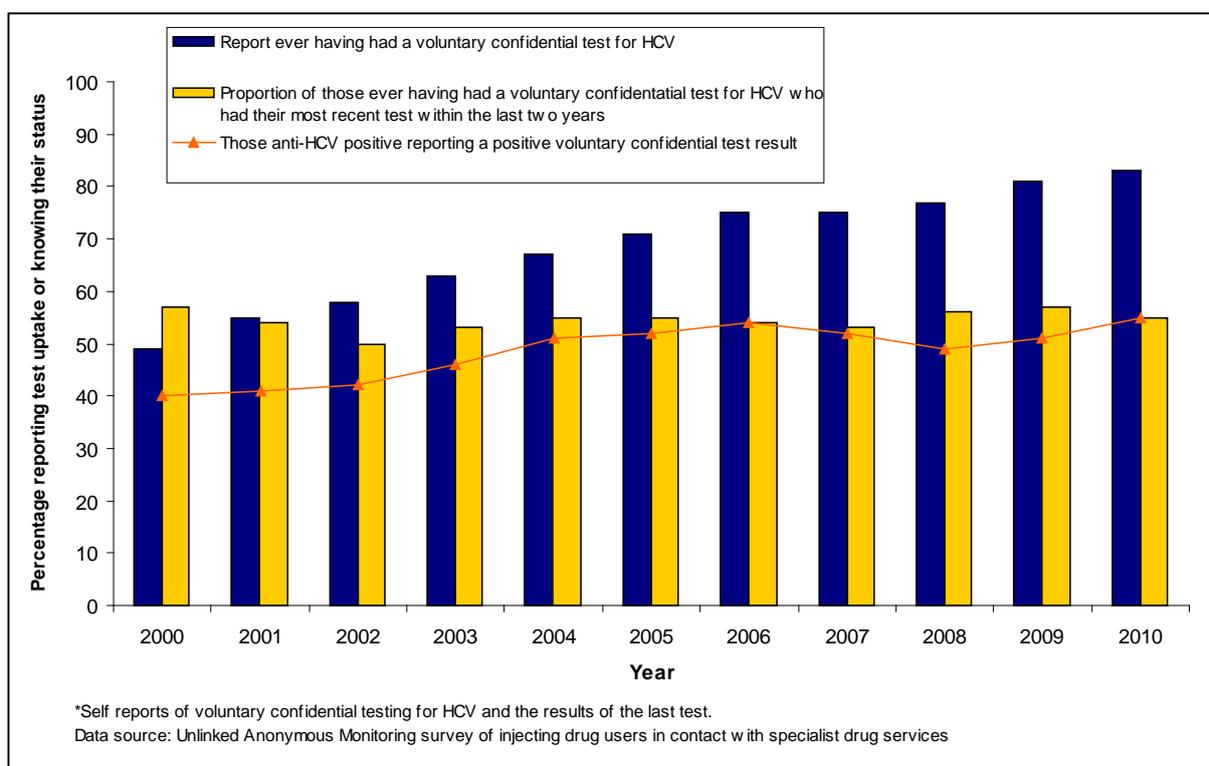
Sentinel surveillance suggests that alternative testing technologies are continuing to contribute to the increased uptake of testing in IDUs (Figure 6). Rates of testing are continuing to rise in this risk group, particularly rates of dried blood spot (DBS) and oral fluid testing (Figure 6). The percentage found to be HCV positive remains high, having risen from 19.2% in 2009 to 20.3% in 2010.

**Figure 6: Number of injecting drug users tested for anti-HCV in specialist services for drug users, by year, in 21 sentinel laboratories: 2007- 2010**



Data continues to suggest that increasing numbers of IDUs have been tested for hepatitis C. Among those taking part in the UAM survey of IDUs in contact with specialist drug services, four-fifths (83%) reported ever having had a voluntary confidential test for HCV in 2010, an increase from the 49% seen in 2000<sup>24</sup> (Figure 7). The proportion of those ever tested who had their last test during the preceding two years was around 55% in 2010 (n=1,918, figure 7), similar to the proportion reported in the 2009 (57%, n=1,942).

**Figure 7: 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: 2000–2010**



### National Outcome Indicator

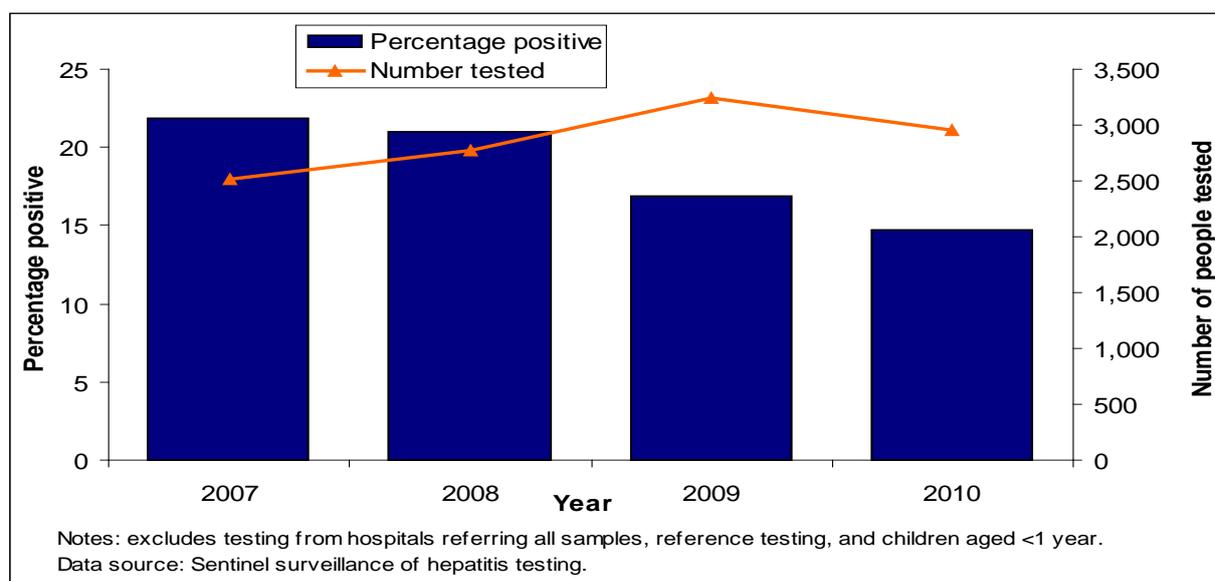
Of the IDUs who took part in the UAM survey who were infected with hepatitis C, the proportion aware of their positive status in the 2010 survey was 55% compared with 40% in 2000.

Of the IDUs who were infected with hepatitis C taking part in the UAM survey during 2010, the proportion aware of their status was 55% (Figure 7), which is similar to the level reported in 2009 (51%) but has improved since 2000 when only 40% were aware of their infection.

### Offenders

Sentinel surveillance data suggest that testing via prison services has fallen slightly over the past year (Figure 8). This fall does not appear to be the result of prisons transferring testing away from sentinel laboratories, but rather the result of a true decline in numbers tested in these settings. This apparent fall may not be representative of the prison estate overall, as sentinel surveillance covers less than one third of English prisons. The proportion testing positive has undergone a steady decline each year, but like those tested in IDU services, the overall yield of positives remains high at 18% (Figure 8).

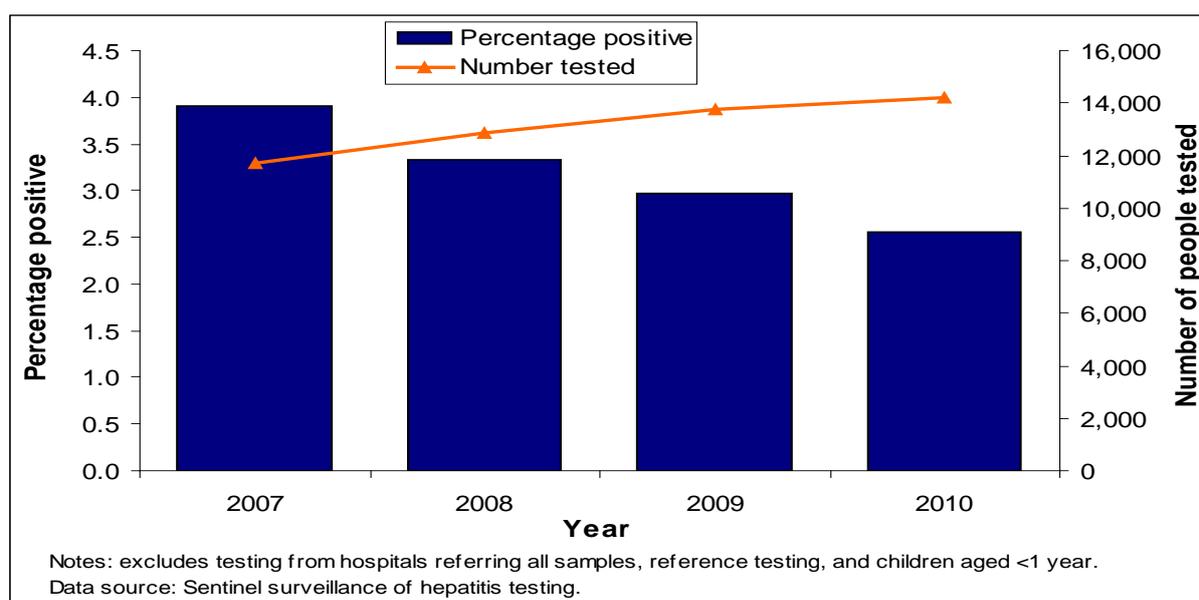
**Figure 8: Number of people tested for anti-HCV by year, and proportion positive, via prison services in 21 sentinel laboratories: 2007- 2010**



**Individuals of South Asian origin**

Previous studies<sup>25</sup> have identified individuals of South Asian origin, living in England, to be at particular risk of hepatitis C infection. For this reason targeted awareness raising campaigns have been introduced to help diagnose infection. Sentinel surveillance data suggest that the number of people tested who were identified as being of South Asian origin increased overall between 2007 and 2010 (Figure 9). This suggests that an increasing number of South Asian individuals are accessing anti-HCV testing. This may be a reflection of targeted awareness-raising campaigns that have taken place among South Asian communities in recent years. The proportion of people testing anti-HCV positive has continued to decline, which is consistent with extending testing to individuals at relatively lower risk of infection.

**Figure 9: Number of South Asian people tested, and proportion positive, in 21 sentinel laboratories: 2007-2010**



### ***Individuals of West African origin***

To help quantify the risk of infection in other ethnic groups with an increased risk of infection in their countries of origin, a pilot study to investigate the prevalence of hepatitis C among Africans living in London is currently underway. This study involves testing a number of individuals from the African community to help inform the need for further larger studies or targeted screening programmes. This is a collaborative study between the South East London health protection unit (HPU) and HPA Colindale. Preliminary findings should be available for the next report.

## **1.1.2 Prevalence of hepatitis C virus infection**

### ***In England***

The statistical model used previously to estimate prevalence of HCV antibodies in England in 2003<sup>26</sup> has been updated for 2005.<sup>3</sup> This includes two key developments: firstly, data on ethnicity have been used to estimate prevalence in non-injectors in South Asians and other ethnic groups separately; and secondly, new estimates of the number of current injectors have been used which cover the whole of England rather than London only.

The current model suggests that in 2005, the number of individuals aged 15-59 years with antibodies to hepatitis C virus in England was around 203,000 with a 95% credible interval (CrI: the Bayesian equivalent of confidence intervals) of 153,000 to 286,000).<sup>3</sup> This equates to around 150,000 (95% CrI:113,000, 226,000) individuals with chronic hepatitis C infection, of which 44% were attributable to current IDU, 43% to ex-IDU, 5.6% to South Asian never-injectors and 7.3% to white/other ethnicity never-injectors. In this 15-59 year age group, this equates to a prevalence of 0.67% for antibodies to hepatitis C infection (95% CrI: 0.50, 0.94) and a 0.50% prevalence (95% CrI 0.37, 0.75) for chronic HCV infection.<sup>3</sup>

When an estimate for prevalence in over 60s is included, the overall prevalence of HCV antibody in the adult population (aged 15 and over) in England is thought to be 0.54% (95% CrI 0.40, 0.75) or 218,000 individuals (95% CrI:163,000, 305,000).<sup>3</sup> Assuming a chronicity rate of 74%,<sup>27</sup> 161,320 adults would be living in England with chronic HCV infection (0.40%) of the adult population.

### **Prevalence of HCV infection in England**

The prevalence of HCV antibody in the adult (over 15 years of age) population in England in 2005 is estimated to be 0.54%, equating to 218,000 individuals.<sup>3</sup>

Assuming a chronicity rate of 74%,<sup>27</sup> 161,320 adults would be living in England with chronic HCV infection (0.40% of the adult population)

Overall, the model produces a 10 times higher prevalence in South Asian never-injectors compared with other ethnicities, with the highest prevalence in Pakistanis and recent migrants from South Asia.<sup>3</sup> Despite accounting for the increased risk in these groups, overall estimates of HCV prevalence in never-injectors are similar to those for 2003. This is because the high HCV prevalence in South Asians has been balanced by lower HCV prevalence in other never-injectors. The latter factor is a result of new data that shows HCV prevalence to have decreased over time in blood donors and genitourinary medicine (GUM) clinics attendees, and to a lesser extent in those screened antenatally.

New estimates of the numbers of current and ex-injectors predict a somewhat older injecting population than estimated in 2003, and this has the effect of increasing the average length of

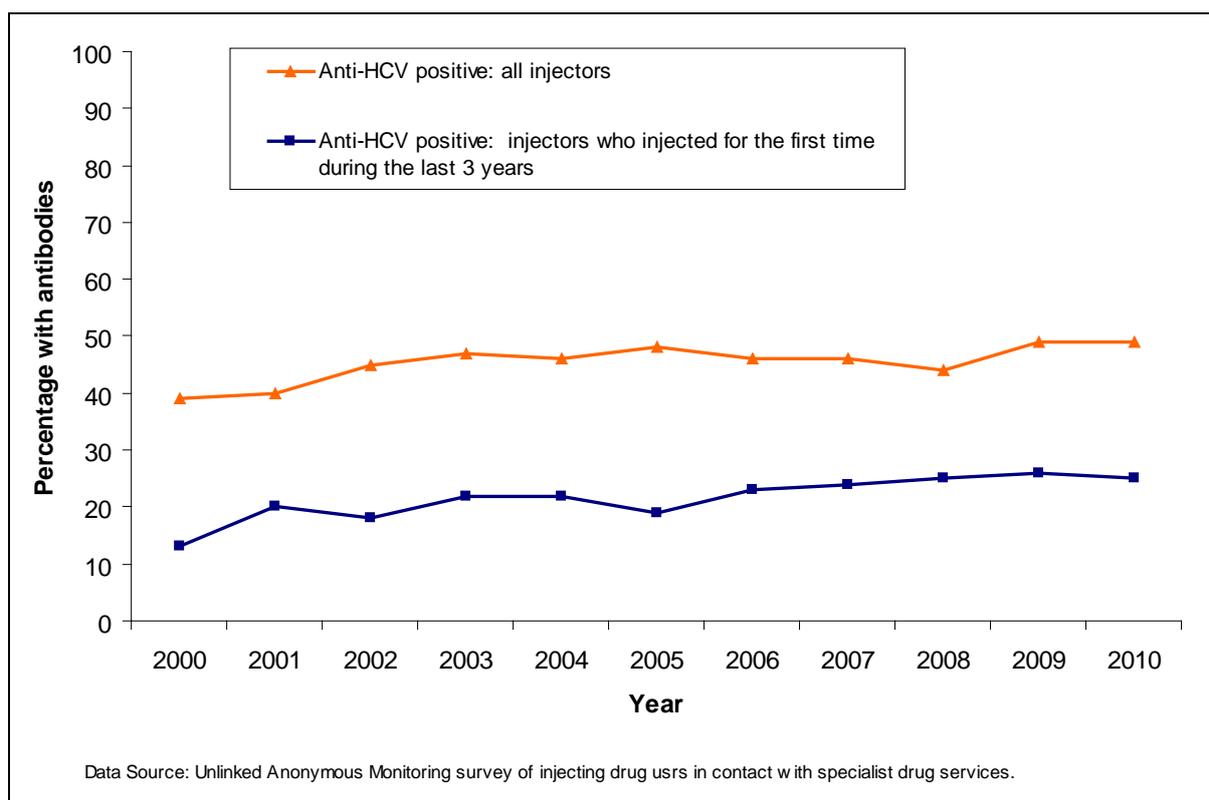
injecting career, and hence decreasing the size of the ex-injector population. However, HCV prevalence has increased recently in current injectors, even after accounting for changes in age,<sup>28</sup> therefore, despite a smaller estimated population of ever-injectors, the number of HCV-infected injectors has remained similar.

Although the updated model is more robust and gives a better understanding of those at risk, it still has limitations. Improved information on the natural history of injecting is still required, as the uncertainty in numbers of ex-injectors affects the overall estimate of HCV prevalence. Estimates of the number of current injectors were undertaken independently from a capture-recapture analysis using methods similar to those employed to estimate the size of the current injector population in Scotland.<sup>29</sup> When raw data become available, it will be possible to incorporate the capture-recapture estimation step within the HCV prevalence model. Finally, only two studies contribute to estimates of prevalence in South Asians and there is some conflict between them; community screening gave a higher estimate of HCV prevalence than data from blood donors. More information is therefore required in order to test the consistency of these data.

### ***Injecting Drug Users***

In 2010, of the current and former IDUs from England who participated in the UAM survey, 49% had antibodies to hepatitis C.<sup>24</sup> This compares to 39% in 2000,<sup>24</sup> (Figure 10) but is lower than the 61% found in 1992.

**Figure 10: Trends in HCV prevalence among IDUs in England: 2000-2010**



Regional variations were seen in the prevalence of hepatitis C among the current and former IDUs participating in the UAM survey in 2010. Prevalence ranged from 28% in the West Midlands and 29% in the North East regions to 64% in London and 65% in the North West.<sup>24</sup>

### ***Circulating hepatitis C genotypes***

In England, sentinel surveillance suggests that 90% of all infections are of genotype 1 (45%) or 3 (45%). Other genotypes continue to be relatively rare.

### **1.1.3 Incidence of hepatitis C virus infection**

Estimates of hepatitis C incidence are difficult to obtain. One approach suggested that the overall incidence of hepatitis C peaked at around 15,000 new infections annually in the late-1980s, coinciding with a major increase in injecting drug use.<sup>11</sup> Several studies have attempted to estimate the incidence among IDUs, but the range of estimates obtained is wide. The lowest estimate suggests that only three per cent of susceptible injectors become infected each year; the highest suggests that almost 42 per cent become infected.<sup>11</sup>

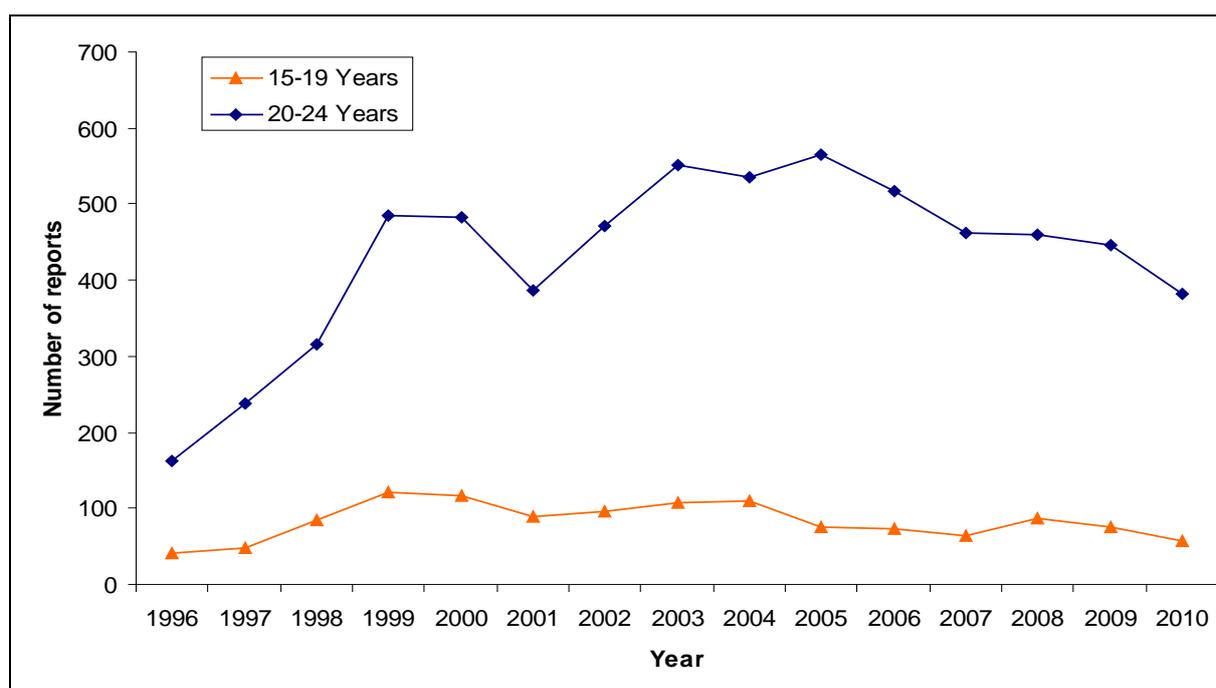
Robust overall estimates of incidence from the period since 1990 are not yet available, but work is ongoing to derive them using different approaches.

### ***Proxy measures of incidence***

Because most new infections are acquired via injecting drug use, which often begins in late adolescence and early adulthood, it is likely that individuals aged between 15 and 24 years acquired their infections within the past few years. Therefore the number of hepatitis C cases in individuals in this age group can be used as a proxy indicator of incidence, or more recent infection.<sup>30</sup>

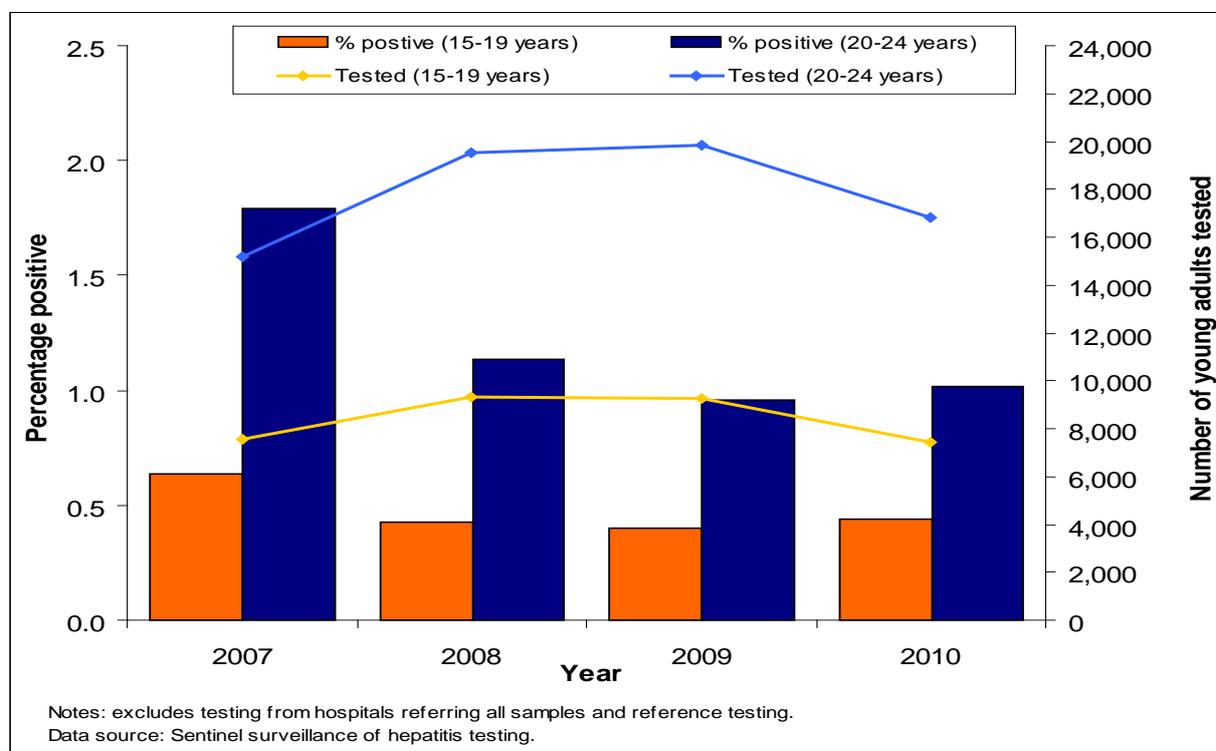
The number of laboratory reports of infections in 15-19 year olds has remained fairly constant over the past few years, while the number of infections in individuals aged 20-24 has continued to fall since 2005 (Figure 11). Taken together, the number of reports in 15-24 year olds fell from 640 in 2005 to 439 in 2010. The number of reports in young adults continues to form a small proportion of the total number of reports received and the proportion of infections in these age groups has fallen from 10.2% (640/6,298) in 2005 to 5.6% (439/7,834) in 2010.

**Figure 11: Number of laboratory reports of hepatitis C reported in young adults in England: 1996-2010**



Data from sentinel surveillance suggests that testing, and the percentage found positive, in these age groups has remained relatively stable over the past three years (Figure 12).

**Figure 12: Number of anti-HCV tests performed in young adults and number positive by year in 21 sentinel laboratories: 2007-2010**



Likewise, data from the UAM survey show stable anti-HCV prevalence among those who injected for the first time during the preceding three years (Figure 10)<sup>24</sup> suggesting that transmission levels may be relatively constant.

**National Outcome Indicator**

The prevalence of hepatitis C in current and past injectors who began injecting in the last three years, is a marker of recent transmission, and has been chosen as an outcome measure in the Hepatitis C Strategy for England.<sup>19</sup> In 2010, among those who recently began injecting, the prevalence of anti-HCV was 25%. This is similar to the 2009 figure of 26% and prevalence in this group has remained relatively stable at this level over the last five years (Figure 10).

The UAM survey of IDUs is in the process of changing the sample collected from an oral fluid specimen to a DBS; this change will be completed in 2011. DBS allows testing for other markers, including those techniques that distinguish recent infections. Such testing will be undertaken in 2011 and will permit a fuller ascertainment and monitoring of HCV incidence within the IDU population.

**Incidence in men who have sex with men**

Enhanced Surveillance of Newly Acquired Hepatitis C infection in men who have sex with men (SNAHC) collected data prospectively from 22 centres in London, Manchester and the South East. Between January 2008 and March 2010, 218 newly acquired HCV cases were reported, of which 84.4% (184/218) were from London centres. The number of reports received each

quarter has declined over time, from 29 in the first quarter of 2008, to 11 reports for the last quarter of 2010. Overall, 144 cases were classified as confirmed, and 74 as probable cases. The median age at diagnosis was 38 years (range 19-62), the majority were UK born (63.3%; 138) and of white ethnic origin (90.8%; 198). The majority of men who have sex with men (MSM) (94.4%) had already been diagnosed with HIV, with a median of 4.4 years between HIV diagnosis and HCV diagnosis. The main reason for testing was elevated liver function tests (LFTs).

Reported behaviours among cases included: IDU, having a high number of sexual partners in the three months prior to diagnosis, anal intercourse within the six months preceding their diagnosis, having sex whilst under the influence of drugs and having unprotected sex.<sup>31</sup>

These findings suggest that sexual transmission of HCV is ongoing but may be declining in HIV positive MSM, many of whom engage in high-risk sexual practices and frequently use recreational drugs during sex. As HIV positive individuals have a higher HCV viral load,<sup>32</sup> more HCV RNA in the semen<sup>33</sup> and a prolonged viral half-life<sup>34</sup> when compared to HIV uninfected individuals, it is not surprising that enhanced transmission has been observed. This highlights the need for targeted public health initiatives and continued enhanced surveillance of HCV in this group. Furthermore, these data emphasize the need for HCV evaluation for all MSM with abnormal LFTs as well as routine screening for HIV positive MSM.

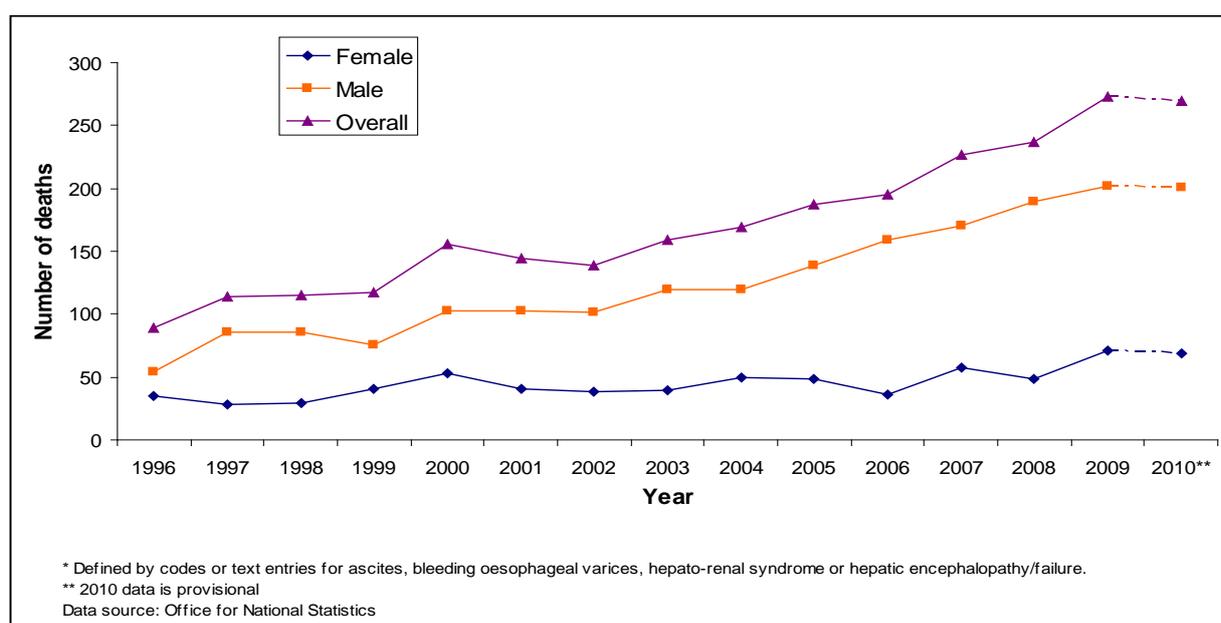
#### 1.1.4 Current burden of hepatitis C virus infection

National data sources show that HCV-related end-stage liver disease and death is continuing to rise.

##### ***Deaths from hepatitis C virus-related end stage liver disease***

Data from the ONS show the number of deaths from end-stage liver disease (ESLD) or hepatocellular carcinoma (HCC), in those with HCV mentioned on their death certificate, to have increased from 89 in 1996 to 270 in 2010 (Figure 13). As in previous years, the rise is occurring predominantly in men, with deaths in women continuing to remain relatively stable (Figure 13)

**Figure 13: Deaths from ESLD\* or HCC in those with HCV mentioned on their death certificate in England: 1996-2010**



***Hospital admissions for end-stage liver disease or hepatocellular carcinoma in individuals with hepatitis C***

Similarly, hospital admissions coded to ESLD or HCC in individuals with a hepatitis C diagnosis, have risen from 474 in 1997/98 to 1,743 in 2009/2010 (Table 3). A similar trend is observed in deaths in hospital among individuals with these diagnoses (Table 3).

**Table 3: Number of individuals with HCV who have ESLD\* and/or HCC and deaths from these conditions, in English Hospital Episodes: the financial years 1997/98-2009/10**

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)
1997/1998	3,677	401	78 (20)	73	26 (36)
1998/1999	4,086	476	123 (26)	125	27 (22)
1999/2000	4,723	473	122 (26)	126	32 (25)
2000/2001	4,775	553	145 (26)	121	28 (23)
2001/2002	5,441	542	158 (29)	135	29 (22)
2002/2003	6,093	593	170 (29)	185	47 (25)
2003/2004	6,770	619	177 (29)	165	44 (27)
2004/2005	7,369	734	211 (29)	210	49 (23)
2005/2006	8,289	918	255 (28)	243	57 (24)
2006/2007	8,582	923	258 (28)	256	63 (25)
2007/2008	9,077	1,069	283 (26)	287	65 (23)
2008/2009	10,220	1,077	244 (23)	305	65 (21)
2009/2010	10,505	1,357	361 (27)	386	74 (19)

**Data source: Hospital Episode Statistics, The NHS Information Centre for Health and Social Care**

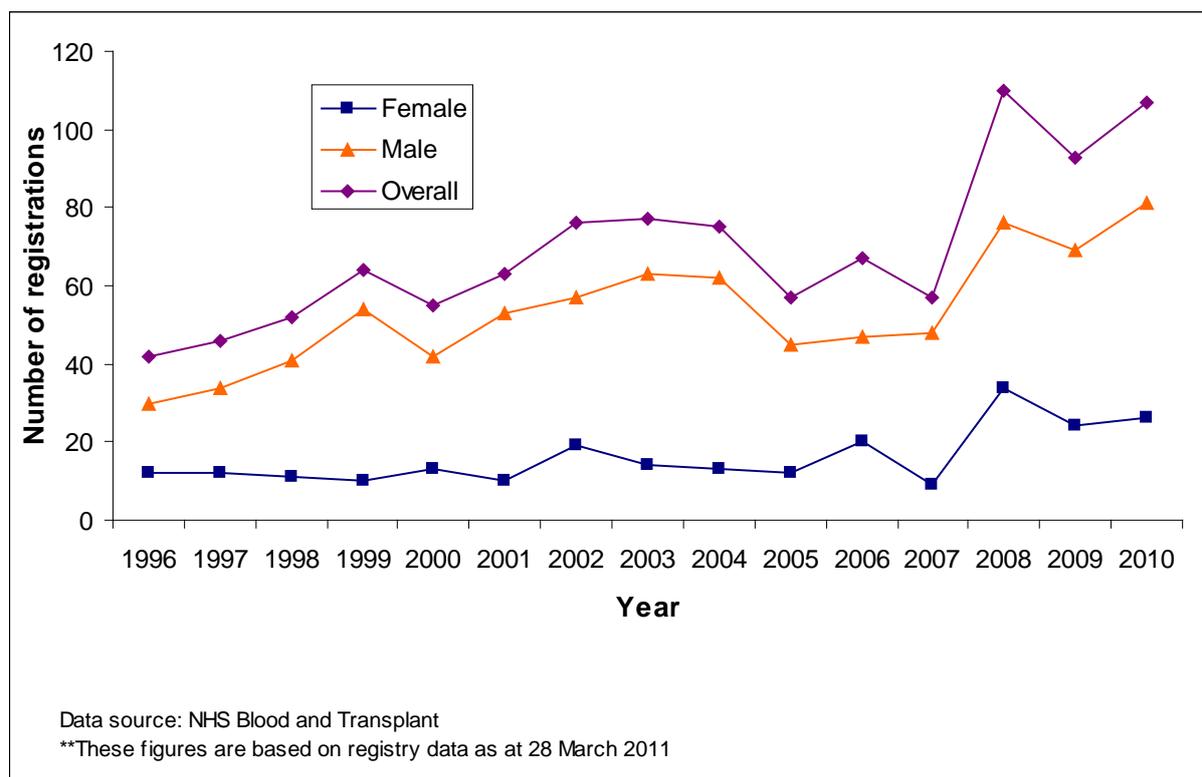
\* Defined by codes or text entries for ascites, bleeding oesophageal varices, hepato-renal syndrome or hepatic encephalopathy/failure.

***Liver transplants, and registrations, in those with post-hepatitis C cirrhosis or hepatocellular carcinoma***

The number of English residents with post-hepatitis C cirrhosis registering at NHS Blood and Transplant for a liver transplant has increased overall from 42 registrations in 1996 to 107 registrations in 2010 (Figure 14). Although the numbers of individuals registering have fluctuated from year to year, the overall trend is upward with an increase of 95% over the past decade.

Since 1996, there has been an increase in the number of first liver transplants performed in patients with hepatitis C-related disease, from 43 in 1996 to 96 in 2010 (Table 4). Of the total number of liver transplants, there has also been an increase in the percentage of first liver transplants carried out on patients with hepatitis C-related disease from 10% in 1996 to 18% in 2010.

**Figure 14: First registrations\* for a liver transplant with a code of post-hepatitis C cirrhosis in England: 1996-2010\*\***



\*New universal registration criteria for selecting adult patients for elective liver transplantation were introduced in September 2007<sup>35</sup>

**Table 4: Indications for liver transplants undertaken in HCV infected individuals in England: 1996-2010\***

Year	All Liver Transplants	First liver transplants with post hepatitis C cirrhosis at registration and HCV positive at registration or transplant (per cent of all liver transplants)			
		Total	Post-hep C Cirrhosis	Hepatocellular carcinoma	Other Indication
1996	444	43 (10%)	31 (7%)	7 (2%)	5 (1%)
1997	484	57 (12%)	44 (9%)	10 (2%)	3 (1%)
1998	455	48 (11%)	31 (7%)	9 (2%)	8 (2%)
1999	494	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	519	83 (16%)	49 (9%)	28 (5%)	6 (1%)
2003	476	76 (16%)	46 (10%)	21 (4%)	9 (2%)
2004	545	82 (15%)	55 (10%)	22 (4%)	5 (1%)
2005	467	55 (12%)	28 (6%)	21 (4%)	6 (1%)
2006	493	60 (12%)	31 (6%)	25 (5%)	4 (1%)
2007	497	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	96 (18%)	44 (8%)	50 (9%)	2 (0.4%)
<b>TOTAL</b>	<b>7441</b>	<b>1079 (15%)</b>	<b>615 (8%)</b>	<b>382 (8%)</b>	<b>82 (1%)</b>

\*These figures are based on registry data as at 28 March 2011

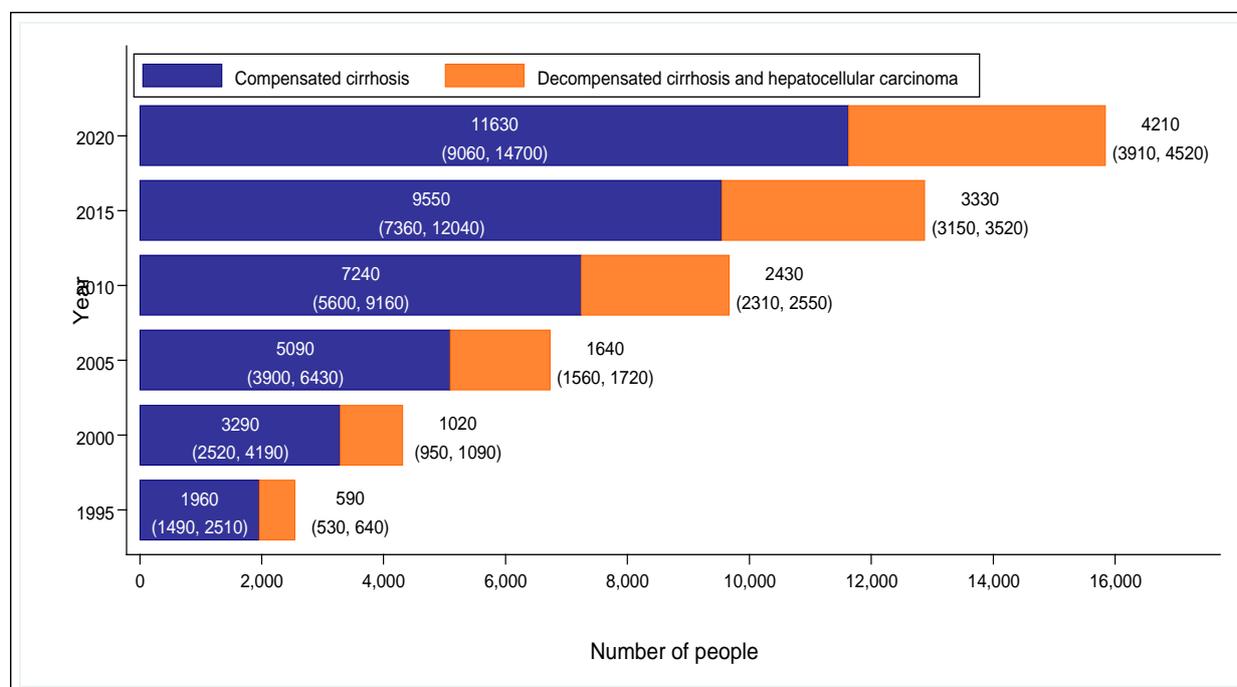
Data Source: NHS Blood and Transplant

### 1.1.5 Future burden of hepatitis C virus infection

Updated national prevalence estimates<sup>3</sup> allow predictions of the future burden of HCV infection in England to be revised.

Sweeting et al. used a back-calculation model to estimate the current and future burden of HCV.<sup>36</sup> This model uses data from HES and the ONS on HCV-related morbidity, combined with estimates of disease progression probabilities taken from the literature. HES and ONS data up to 2009 were used and new results have been obtained by applying the model to these new data. By 2020 it is predicted that 15,840 individuals will be living with HCV-related cirrhosis or HCC in England; more than 4,200 of these are predicted to be living with severe decompensated disease or HCC (Figure 15). For the latter, liver transplantation may be the only therapeutic option. These predictions have not taken into account current and/or future levels of diagnosis and treatment.

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



## 1.2 Increasing awareness and reducing undiagnosed infections

### Action 2: Increasing awareness and reducing undiagnosed infections<sup>10</sup>

*Key issue: In 2004, an estimated five out of every six people with chronic hepatitis C were unaware of their infection. This requires action to increase awareness of hepatitis C among health professionals, the public and high-risk groups and the promotion of testing in a range of accessible clinical and community settings.*

Efforts to increase the awareness of hepatitis C among the public and healthcare professionals are essential if the burden of undiagnosed infection is to be reduced. Awareness-raising campaigns can be valuable in providing important information to the public

on risk behaviour, methods of diagnosis and treatment options. However, a more tailored approach is required for *at risk* individuals such as IDUs and individuals born in high prevalence countries. In addition, healthcare professionals should be regularly updated on hepatitis C to ensure patient care is optimised.

### 1.2.1 Public awareness and promotion of testing

**Get Tested!** - The Hepatitis C Trust testing awareness campaign is continuing to support government awareness initiatives throughout the UK. The campaign has been designed to increase the involvement of celebrities, especially those in the music business. Throughout 2010/11, events have been held at clubs, at the premiere of *A Little Bit of Tom Jones* and at the International Music Summit in Ibiza. Boy George took a series of photos of current celebrities like Sadie Frost, Paloma Faith, Matt Horne and Jimi Mistry dressed up as 1980s icons to encourage people to consider whether they could have put themselves at risk during that period. The photographs were exhibited at the HMV store in Oxford Street and many of those featured, including Boy George and Adam Ant, took part in a concert at London's Jazz Cafe attracting widespread media coverage.

**Mobile testing and awareness raising** - The Department of Health (DH) has provided a 3-year grant from April 2011 to The Hepatitis C Trust to equip and run a testing and awareness van that offers testing to *hard-to-reach* communities including homeless people, current drug users, and the South Asian community who may not be accessing testing in more traditional settings but are at high risk of infection. The van will also be used as a focal point for awareness-raising in conjunction with local NHS staff who also distribute materials produced by the DH as part of its *Get Tested. Get Treated* campaign.



Sadie Frost as Madonna



Paloma Faith as Boy George



Matt Horne as Adam Ant



Jimi Mistry as Freddie Mercury

*Reproduced with permission of The Hepatitis C Trust*

**Pharmacy testing** - In 2010, funding from the DH supported the roll-out of a community pharmacy testing scheme developed by The Hepatitis C Trust in collaboration with local NHS organisations. To date, more than 90 pharmacists and pharmacy staff, operating in more than 70 pharmacies, have been trained to deliver dry blood spot testing for hepatitis C and B. This initiative endeavours to ensure that those identified as positive are appropriately referred for treatment and care. Pharmacy testing is proving to be a popular choice because of its ease of access and because some clients prefer not to discuss their reasons for seeking a test.

As Blackpool has been identified as having some of the worst liver-related health inequalities, the British Liver Trust ran a week-long viral hepatitis testing event in one of the busiest pharmacies in the Blackpool area. The pharmacy screening aimed to serve as a platform for

building up relationships with local healthcare staff. Members of the project worked with the local blood-borne virus team to provide out-reach services to target ex- and current injecting drug users using the needle exchange and methadone provision. The initiative was a success. Out of 110 people tested, 16 have already been confirmed HCV RNA positive.

**Liver Let Live** - is an online game developed by the British Liver Trust ([www.britishlivertrust.org.uk/LiverLetLive](http://www.britishlivertrust.org.uk/LiverLetLive)) to educate players about how alcohol, fatty foods and hepatitis B and C can lead to liver damage. The game helps people to identify whether they could have been exposed to these risks and encourages diagnosis and treatment. The game has been well received, with 75% of players indicating that after playing the game, they had learnt more about protecting their liver from these risks.

**Liver Let Live**

**Liver cancer is silent and deadly**

Make healthy choices to score points and avoid the risks to help protect your liver.

Get protected, get tested, get treated.

PLAY

HIGH SCORES

Help us to support people affected by liver disease

DONATE

BRITISH LIVER TRUST

Developed by Mediakitchen Limited

©2009 British Liver Trust

*Reproduced with permission of the British Liver Trust*

**Awareness-raising in the South Asian community** - The Hepatitis C Trust has employed a South Asian community project worker to increase awareness and testing. A testing event was held in May 2010 at the Bradford Mela festival. Out of 113 people who were tested using oral swabs four were reported to be antibody positive.



The Hepatitis C Trust held an event in Parliament in July 2011, just ahead of World Hepatitis Day, to highlight to MPs, peers and community leaders, the need for increased awareness in the South Asian community, where 10% of all deaths from hepatitis C between 1996 and 2009 have occurred. Anne Milton, the Public Health Minister was the keynote speaker.

**World Hepatitis Day 2010** - In the week of 19 May 2010, The Hepatitis C Trust held testing and information events in 13 cities across the UK. On the day itself Sadie Frost, together with a doctor and a patient, did non-stop radio interviews that reached an audience of 40 million. The Public Health Minister spoke at an evening reception at the House of Commons. Clear Channel provided almost 1,000 poster sites throughout the UK, many of them for extended periods either side of the day itself.



In the same week, the 193 member countries of the World Health Organization (WHO) adopted the first ever resolution on viral hepatitis calling for a comprehensive approach, including a global strategy, to tackle these diseases. The resolution made World Hepatitis Day one of only six official WHO days, changing the date from 19 May to 28 July.

**World Hepatitis Day 2011 (28 July)** – To coincide with World Hepatitis Day, The Hepatitis C Trust launched a major awareness event called **The Great British C Party**. Promoted by celebrity chefs like Gizzi Erskine, it aims to highlight that hepatitis C is a liver disease and to promote a liver-friendly diet. Participants will be invited to hold their own lunches and dinners using celebrity recipes specially created for the occasion, or to invent their own and share them via social media networks.

**NHS Choices website** - the DH continues to provide information and downloadable resources about hepatitis C on a dedicated website for the general public, South Asian communities and healthcare professionals at [www.nhs.uk/hepc](http://www.nhs.uk/hepc)

### 1.2.2 Professional awareness

**Royal College of General Practitioners Certificate in the Detection, Diagnosis and Management of Hepatitis B and C in Primary Care** - To help raise awareness of hepatitis C (and B), the Department of Health has funded the HPA to produce a Certificate in the

Detection, Diagnosis and Management of Hepatitis B and C in Primary Care (see section 1.3.2).

**The Hepatitis C Trust awareness raising campaign in primary care** - The Hepatitis C Trust has recently begun a pharmaceutical industry supported two-year campaign to increase awareness amongst GPs using around 200 volunteers throughout the country to visit GP surgeries, talk to practice managers and distribute leaflets.

The Hepatitis C Trust has also been working with two pharmaceutical companies to pilot programmes that search GP databases for disease codes that identify individuals who may be at risk of HCV infection but who have not been tested. These pilots will evaluate the practicality and (cost-) effectiveness of this approach in reducing levels of undiagnosed infection.

### 1.3 High-quality health and social care services

#### **Action 3: High-quality health and social care services<sup>10</sup>**

*Key issue: High-quality services for the assessment and treatment of all patients with hepatitis C need to be coordinated and accessible across the country.*

#### 1.3.1 National audit, recommendations and policy

##### ***National Liver Disease Strategy and Hepatitis C***

Chronic hepatitis C is one of the major contributors to the escalating burden of liver disease that presents to the NHS, and is beginning to impact on the rising mortality from liver disease in this country. For this and other reasons, a national liver disease strategy (NLDS) is being developed.

Undiagnosed chronic hepatitis C infection, access to testing, advice, and onward clinical pathways for groups at risk of infection are major issues.

Surveillance by the HPA has demonstrated that in recent years, as awareness amongst health care professionals and the public has improved, hepatitis C testing has increased. But there is still much more that can be done to reduce the level of undiagnosed infection and to get diagnosed individuals into care pathways. The NLDS will build on progress to date by highlighting the key role that primary care can play in assessing and testing patients, and where necessary working with them to bring individuals into contact with treatment services. In this respect, the forthcoming Royal College of General Practitioners (RCGP) Certificate in Detection, Diagnosis and Management of Hepatitis B and C in Primary Care will be a valuable resource.

A co-ordinated approach is needed to increase testing in risk groups where hepatitis C often remains undetected, including in prison and drug services. The DH's National Clinical Director for Liver Disease and relevant agencies are identifying successful approaches.

Improved access to testing and information also needs to be accompanied by expertise on treatment. Hepatitis C is a curable condition for many people, but it is important that opportunities for treatment are optimised and audited.

Hepatitis C and its outcome in relation to liver disease are greatly influenced by co-morbid factors including alcohol consumption and obesity. The NLDS will highlight how these are

major contributors to liver disease in their own right, to improve awareness of all the factors that need to be addressed in order to optimise treatment.

The HPA has worked closely with the DH's National Clinical Director for Liver Disease, Professor Martin Lombard in the preparation of the strategy with representation on the various committees and technical sub-groups.

### ***HPA response to the Public Health White Paper***

The HPA blood-borne infection programme board (BBIPB) submitted a response to the Public Health White paper *Healthy Lives, Healthy People*<sup>2</sup> in March 2011, which included recommendations for the future control of viral hepatitis and BBIs in England. The response underlined the importance of maintaining hepatitis as a priority for health services, continued improvement of treatment services, public health management, surveillance and commissioning of appropriate services e.g. services for drug users, gastrointestinal medicine, infectious diseases, hepatology and microbiology services. It also discussed the role of PHE and the HPA in the future management of viral hepatitis and BBIs.

### ***Review of the support available to individuals infected with hepatitis C***

Following the Ministerial Written Statement by Anne Milton MP on 14 October 2010 the HPA supported the expert review of clinical evidence on the impact of living with hepatitis C infection on patients who acquired the virus via transfusion or treatment with blood, blood products or tissues. This included comparison with the impact of living with HIV, and any specific issues for patients who were co-infected or living with underlying haemophilia.

The full review report from the DH was published on the 10th January,<sup>37</sup> with an oral statement made by the Secretary of State for Health and a Department of Health press release issued.<sup>38</sup> The report's main recommendations increase parity with HIV payments so that those with *Skipton Fund stage 2 hepatitis C* should now receive recurrent yearly payments rather than a single lump sum; the initial payment received will also be increased.

### ***In The Dark – An audit of hospital hepatitis C services across England by the All-Party Parliamentary Hepatology Group***

This third audit report from the ***All-Party Parliamentary Hepatology Group*** (APPHG) was published in August 2010 and highlights the urgent need for both national and local information on hepatitis services, in particular information on referrals, treatment and treatment outcomes.<sup>39</sup> The report concludes that a lack of data inevitably hampers local and national planning and efficient commissioning of services. Although response rates to the survey were low, there was evidence of considerable variation in hepatitis services available to patients across the country.

### ***British Viral Hepatitis Group - Recommendations on the provision of antiviral services for patients with chronic viral hepatitis (2010)***

In February 2010, members of the British Viral Hepatitis Group (BVHG), and other invited stakeholders met at the King's Fund to discuss the provision of services for patients with chronic viral hepatitis. The meeting led to the production of a set of draft guidelines that were sent out for further consultation in March-June 2010. Following this period of consultation, final guidelines were developed; key recommendations are summarised in the box below. Full details are available to British Association for the Study of the Liver (BASL) and BVHG members at the following link: <http://bit.ly/ijXvjH>, or by contacting BASL directly (email: [info@basl.org.uk](mailto:info@basl.org.uk); telephone: 0845 521 0272).

**British Viral Hepatitis Group – Summary of key recommendations for the provision of antiviral services for patients with chronic viral hepatitis (2010)**

- All patients with viral hepatitis should have access to high quality care provided by an experienced team led by a specialist with appropriate training and experience.
- Robust policies to ensure that all those diagnosed with viral hepatitis have multiple opportunities to access services must be put in place.
- All the required investigations needed to confirm the diagnosis should be performed prior to specialist review and therapy should be initiated within 18 weeks of referral.
- A variety of different monitoring schemes should be in place to meet the differing needs of different patient groups.
- Support services including radiology, histopathology, virology and psychiatry should be readily available, appropriately funded and must conform to national standards. All imaging procedures (including ultrasounds) must be performed by appropriately trained, registered, monitored personnel. There is no role for ultrasound examinations by untrained clinicians.
- All those treating patients with viral hepatitis must have ready access to liver transplantation and services for the management of liver cancer. Clear referral pathways must be in operation.
- Service provision in the community is a welcome innovation that may increase access to care. Provision of anti-viral therapy in the community should be safe, clinically and cost effective and must provide care of equal quality to that delivered in tertiary centres. Out-reach services must be managed by an appropriate specialist and patients treated in the community must have equal access to support services. Since it is not possible to predict in advance of therapy which patients will require additional support it is not appropriate to stratify patients and provide reduced support for patients being managed in the community.
- Local networks play a key role in developing local services and ensuring that high quality care is available to all. Networks should be multidisciplinary and should inform commissioning and monitor outcomes.
- All those involved in managing patients with viral hepatitis must commit to a program of regular audit and should actively contribute to on-going research programs

### **1.3.2 National HPA initiatives**

#### ***National monitoring of hepatitis C treatment***

In 2009, the DH gave the HPA a year's funding to undertake a pilot project to investigate monitoring hepatitis C-related care in the NHS. Researchers used this year to pilot mechanisms for collecting and collating national data on the numbers of patients referred and treated for HCV infection and, where possible, on the outcome of their treatment. The project focused on collecting data for the year 2007, the last year for which complete information was available.

Using three main questionnaires and a rigorous follow-up protocol, the HPA identified 131 hospitals in England where anti-HCV treatment is administered and 64 where patients with HCV are seen, but referred elsewhere for treatment. Mapping has shown the geographical distribution of this service provision.

One hundred and nineteen (91%) centres completed a questionnaire on referral of new HCV patients and numbers treated. Only 51% could report or estimate how many new patients were seen in the year 2007 (n=6,395), 65% could report how many had started treatment (n=2,829) and 63% how many had completed treatment (n=1,476). Twenty-nine centres (24%) could provide no data at all and visits by HPA staff to a number of these helped with data retrieval from spreadsheets or paper records. Data on treatment outcome for 2007 were received from only 24 (54%) of the 44 centres that were approached. The major barriers to data provision were reported to be the lack of an appropriate database to store information and a lack of manpower to retrieve it manually.

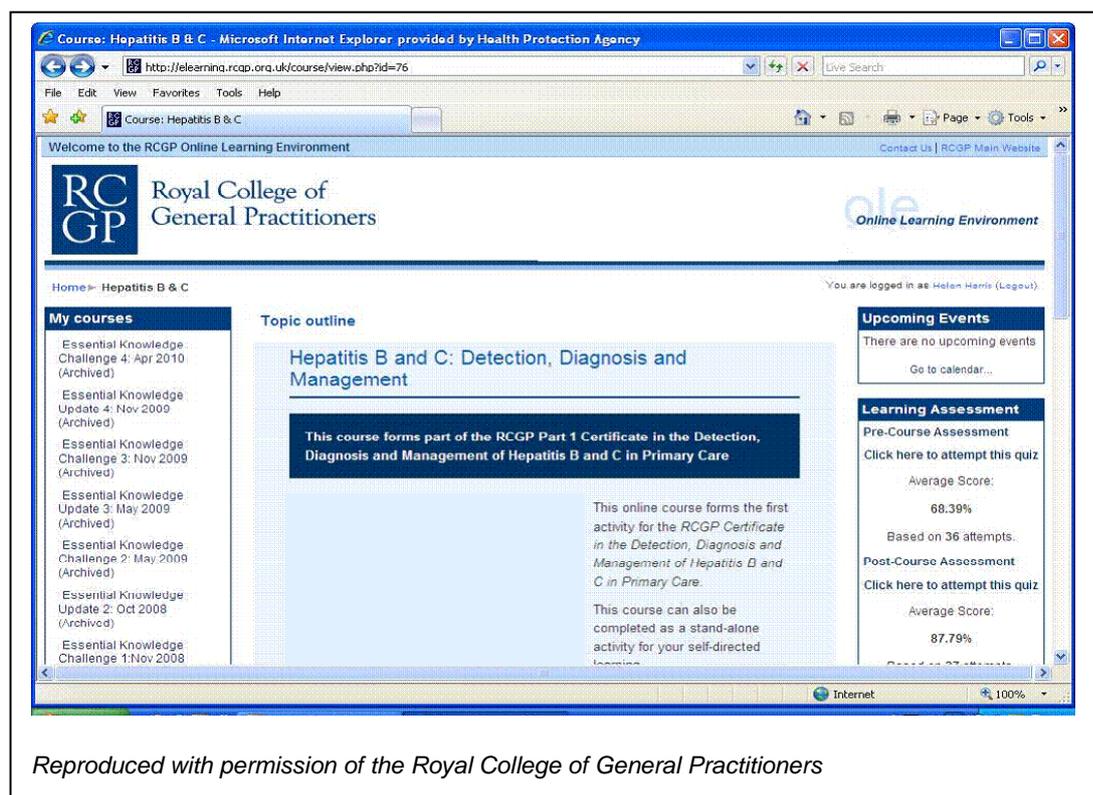
Funding was renewed for a further year, and similar data for the year 2008 are currently being collected. More detailed information on genotype distribution and treatment outcome have been requested, and should be available for the next report.

Alternative methods of estimating the number of patients receiving treatment, including pharmacy prescribing data and pharmaceutical companies' sales data have provided a direct comparison with treatment estimates given by clinical centres, and will continue to do so for 2008. All data sources suggest that between 2006 and 2008 a maximum of 12,400 patients with hepatitis C were treated in England; a figure likely to represent fewer than 10% of the total chronically infected population.

***Royal College of General Practitioners Certificate in the Detection, Diagnosis and Management of Hepatitis B and C in Primary Care*** – The DH has funded the HPA to produce a Certificate in the Detection, Diagnosis and Management of Hepatitis B and C in Primary Care. The HPA has commissioned the RCGP to develop the certificate in conjunction with the Substance Misuse Management in General Practice (SMMGP) team. The certificate is an educational package primarily aimed at GPs, practice nurses and other primary healthcare workers, such as midwives and health visitors, as well as sexual health and drug workers.

The certificate consists of a free online e-module (<http://elearning.rcgp.org.uk/course/category.php?id=8>) and an RCGP accredited training day. In part two, the course will consist of a training day for more advanced practitioners and will have a greater focus on the treatment of hepatitis B and C in primary care. The programme will help primary care practitioners in the detection, diagnosis and management of hepatitis B and C and enable commissioners to confidently commission hepatitis services across all levels of healthcare.

An advisory group with representatives from the DH, the HPA, the NHS, the SMMGP, the RCGP, the NTA, the British Liver Trust and The Hepatitis C Trust is overseeing the development of the certificate.



### **Local and regional epidemiological information on hepatitis C**

Following work within the HPA on hepatitis C reports requested of Strategic Health Authorities (SHAs) by the Department of Health in 2009, data from various national hepatitis C datasets together with the format of region wide reports were reviewed by HPA hepatitis regional leads. In late 2010, each hepatitis lead was provided with an updated standard report template together with a workbook containing their region-wide data (including laboratory reports, sentinel surveillance data, data estimating the burden of disease, data from the UAM survey of drug users, and pilot study treatment data).

This will facilitate local/regional annual reports, and efficient analysis of routine data, while allowing for the inclusion of information on local/regional initiatives.

### **Audit of hepatitis C care pathways – a survey of Health Protection Units in October/November 2010.**

One of the objectives in the HPA Local and Regional Services (LaRS) business plan was to work with commissioners to plan, implement and evaluate prevention and control measures for hepatitis C. The proportion of primary care trusts (PCTs) that have treatment care pathways in place was one measure of progress.

A survey of HPUs was undertaken in September 2010 using a proforma that was sent to hepatitis leads. Completed proformas were returned to the Regional Epidemiology Unit, HPA North West. The proforma was the same as one used for a similar survey in early 2009 so that comparative information was available. Information was sought on:

- the proportion of PCTs that had a treatment care pathway in place;
- the proportion of care pathways that had specific provision for prisoners;
- the proportion of Drug Action Teams (DATs) that had a joint prevention plan with their PCTs;
- the extent to which HPUs were involved in care pathways and prevention plans.

Proformas were returned from all 26 HPUs, and showed that 71% of PCTs (107/150) were reported as having care pathways in place and 21 (81%) HPUs were involved in development of all or more than half of these pathways. Seventeen (65%) HPUs reported that all or more than half of the care pathways had specific provision for prisoners, and 13 (50%) HPUs reported that all or more than half of DATS had joint prevention plans with their PCTs; 11 (42%) HPUs reported that they were involved in all or more than half of the development plans. These results represent an improvement from 2009 for nearly all domains (Table 5).

**Table 5: Audit of hepatitis C care pathways: 2010 survey of Health Protection Units**

		Number of PCTs in 2010	150		
		Number of prisons in 2010	129		
			Number in 2010	% in 2010	% in 2009
<b>Treatment care pathways</b>	PCTs with treatment care pathway		107	71.3	47.8
	HPU involved in all		13	50	41.7
	HPU involved in more than half		8	30.8	20.8
	HPU involved in less than half		5	19.2	20.8
	Don't know		0	0	8.3
	Involved in none		0	0	4.2
<b>HPUs reporting proportion of care pathways with specific provision for prisoners</b>	All care pathways		9	34.6	26.1
	More than half		8	30.8	8.7
	Less than half		3	11.5	30.4
	Don't know		4	15.4	21.7
	None		2	7.7	8.7
<b>HPUs reporting proportion of DATs that have joint prevention plans with PCTs</b>	All DATs		6	23.1	20.8
	More than half		7	26.9	16.7
	Less than half		4	15.4	20.8
	Don't know		6	23.1	29.2
	None		3	11.5	12.5
<b>Extent to which HPU involved in development of DAT prevention plan</b>	HPU involved in all		6	23.1	29.2
	HPU involved in more than half		5	19.2	16.7
	HPU involved in less than half		7	26.9	29.2
	Don't know		2	7.7	12.5
	Involved in none		6	23.1	12.5

***Identifying diagnosed individuals with no laboratory evidence of treatment or clearance – a health impact assessment***

A national multi-disciplinary group was set up by the HPA to assess the impact on health, and healthcare services, of a proposal to conduct 'lookbacks' to identify individuals who were diagnosed and reported as HCV infected in the past, but for whom there is no subsequent laboratory evidence to suggest access to treatment or clearance of infection. The group had their first meeting in April 2011 and terms of reference were agreed.

### ***HPA laboratory training day***

In December 2010, the HPA's BBIPB organised a hepatitis laboratory training day at HPA Colindale. HPA and external experts gave talks relating to the role of the laboratory in surveillance and outbreak monitoring, new testing methods, as well as quality and reporting issues.

### **1.3.3 Local and regional initiatives – all sectors**

In order that individuals receive the best possible care, it is essential that specialised services are commissioned for local hepatitis C populations. The development of clinical networks is key to the assessment and treatment of patients with hepatitis C, including access to accredited laboratory and other services. This requires the development of local protocols between primary and secondary care to ensure patient pathways for both medical and social needs are in place as well as arrangements to ensure that NHS staff are appropriately skilled to deliver service improvements to patients with hepatitis C infection. Some examples of local initiatives are given below:

#### ***Isle of Wight Integrated Sexual Health Service diagnoses hepatitis C virus via its prison healthcare in-reach sexual health service***

In October 2006 a weekly in-reach sexual health service commenced for adult male inmates of HMP Camp Hill. Staffed by a consultant nurse and healthcare support worker from the Isle of Wight GUM clinic, the service was held in a clinic room within the prison primary healthcare unit. Inmates were offered a wide range of sexual health services including BBV screening. All inmates agreeing to BBV screening were tested for HIV, syphilis, hepatitis B core antibody and hepatitis C antibody, regardless of disclosed risk factors. Patients testing positive for hepatitis C antibody were tested for hepatitis C RNA by PCR and liver function with results available the following week; negative BBV screening results were given via letter within two weeks. With informed consent, hepatitis C diagnoses and treatment plans were recorded in the inmate's medical records and the prison healthcare team was informed. Patients who were hepatitis C PCR positive were referred to the prison substance misuse specialist nurse on the wing for ongoing support, health promotion advice and to arrange for the Southampton Hepatology Clinical Nurse Specialist (CNS) to review them at their monthly in-reach hepatology clinic.

This service has been successful in terms of the number of inmates seen, the acceptability of the clinic to inmates, prison healthcare and security staff and the pathology diagnosed. Hepatitis C is commonly diagnosed through this service: on average one new diagnosis is made each month. Inmates with a hepatitis C PCR diagnosis can be seen by a member of the hepatology team within four weeks of obtaining their test result. Two monthly in-reach clinics are also offered at two other sites within the local prison estate.

#### ***British Liver Trust work on health inequalities***

As part of a three-year initiative focusing on health inequalities in liver disease, the DH funded the British Liver Trust to develop a number of initiatives that include hepatitis C. The Trust is currently focusing the next health inequalities project on prisons and has conducted initial research on issues relating to the treatment of hepatitis C within this setting and also the low uptake of screening for HCV by prison staff.

In addition, the Trust will be carrying out further work among minority ethnic groups that have an increased risk of viral hepatitis.

***Survey of arrangements in local health economies for planning and delivering specialist assessment and treatment services for hepatitis C within the West Midlands region***

The West Midlands Regional HCV Project Group commissioned a survey of NHS Acute Trusts, PCTs and local DATs to review and describe existing arrangements in local health economies for planning and delivering specialist assessment and treatment services for Hepatitis C.

The survey was undertaken in October 2010 and had an overall response rate of 73%. The survey findings showed that although some progress had been made in implementing certain aspects of the hepatitis C action plan, the West Midlands region was still some way from implementing all necessary structures and processes needed to support progressive and sustainable improvements in hepatitis C-related health outcomes.

Key findings from the survey included:

- Individuals with lead responsibility for ensuring or facilitating the implementation of the HCV action plan exist in all responding NHS organisations in the region. These individuals were either public health or commissioning leads, other senior personnel in PCTs, or lead clinicians and hepatitis C specialist nurses.
- Responding PCTs did not have a formal hepatitis C strategy although some reported that they were in the process of developing one. However, most PCTs and acute trusts in the region had prioritized the development of a formal care pathway for assessment, testing and treatment and, where absent, had been working to informally agreed pathways.
- DAT teams in the region had a formal blood-borne virus strategy in place and most also had joint hepatitis C prevention/treatment policies with their PCTs. The majority of responding PCTs commission services for the prevention and early diagnosis of HCV, particularly in high-risk groups such as intravenous drug users - mainly through local DATs.
- There was a lack of multi-disciplinary clinical networks in the region to support collaborative work aimed at HCV prevention and control. HPU appeared to have limited engagement with PCTs, acute trusts and DATs in developing policies and plans.

***Hepatitis C virus diagnosis and uptake of specialist treatment services in the West Midlands Region***

A project was undertaken in 2010/11 to determine the trends in HCV testing in the West Midlands region and to derive an estimate of uptake of HCV drug treatment using laboratory data as a proxy indicator.

The findings provided an estimate of the number and proportion of HCV positive individuals in the region who accessed specialist treatment services in NHS acute trusts over a four-year period. This gave some indication of the level of clinical activity in specialist treatment units in the region and an estimate of likely unmet need. The findings will be shared with local commissioners to support HCV-related health service planning and commissioning within local health economies.

***Hepatitis C Look back Exercise and Risk Assessment in West Midlands North***

This HPU-led project (in collaboration with two PCTs and an NHS acute trust) involved a retrospective review of laboratory records to identify individuals who had been diagnosed with

hepatitis C since 1995, but who did not appear to have accessed specialist treatment services in the area.

The findings from this work included an estimate of the size of this cohort of potentially untreated HCV infected individuals who were likely to benefit from antiviral treatment, as well as modelled estimates of HCV-related complications that might arise in this untreated cohort. The study also provided an estimate of the financial cost to the NHS; potential health benefits; and potential harm that could arise should these individuals be invited to take up antiviral treatment.

A risk assessment framework has been developed to help local commissioners and providers make decisions on access to specialist treatment for identified cohorts of untreated HCV infected individuals.

### ***Hepatitis Strategy for Birmingham***

The PCT cluster and City Council in Birmingham have chosen hepatitis as a priority area and included it within their health protection strategy. The strategy is undergoing consultation after which implementation plans will be produced.

Heart of Birmingham teaching PCT is also developing a dedicated general practice for new migrants where hepatitis screening will be offered routinely on registration.

A pilot project was conducted to test the use of community pharmacies to provide screening of the drug-using population for hepatitis B virus (HBV) and HCV (via DBS testing) together with a hepatitis B vaccination service. This tailored approach was tested because these patients often struggled to keep vaccination/screening appointments but did attend their pharmacy each day to collect their methadone or buprenorphine. Pharmacists were also seeing individuals who were not known to drug treatment services (via their needle exchange service).

Dried blood sampling is being successfully used in Birmingham to test for HBV, HCV and HIV in GP surgeries, with drug workers taking the samples.

### ***Hepatitis Network in Coventry and Warwickshire***

A hepatitis network has been established by West Midlands East HPU and Coventry and Warwickshire PCTs in collaboration with clinicians, virologists, GUM, drug and alcohol action teams (DAATs) and the voluntary sector. The network is focussing action on understanding surveillance systems, epidemiology and care pathways for hepatitis B and C as well as developing a hepatitis strategy for the cluster. A hepatitis strategy has also been developed for Solihull.

### ***Hepatitis Coventry***

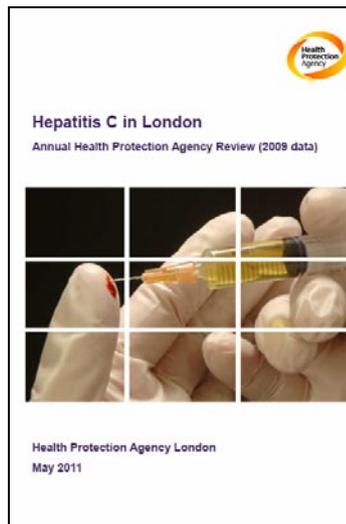
Since 2010, The Hepatitis C Trust has run a holistic hepatitis C support service for adult drug users in the Coventry area which engages with people who may be, or have previously been, at risk of contracting the virus. Hepatitis Coventry provides outreach at rough sleeper and sex worker projects and runs drop-in clinics for clients at various other services across the city. A major part of the project is to offer peer support for people who want to access testing and/or treatment for hepatitis C.

Hepatitis Coventry offers a specific peer support service for those undergoing treatment with the aim of increasing adherence. The project also facilitates access to complementary therapies to help people deal with some of the side effects of treatment.

### ***Hepatitis C in London - Annual Health Protection Agency Review 2009***

In May 2011, the HPA published a report on hepatitis C in London. This report focuses on the epidemiology of hepatitis C in London and makes recommendations for commissioners and providers of services for individuals with hepatitis C.

The report is available at:  
[http://www.hpa.org.uk/web/HPAwebFile/HPAweb\\_C/1296687771656](http://www.hpa.org.uk/web/HPAwebFile/HPAweb_C/1296687771656)



### ***The London Joint Working Group for Substance Misuse and Hepatitis C***

The London Joint Working Group (LJWG) ([www.ljwg.org.uk](http://www.ljwg.org.uk)) for Substance Misuse and Hepatitis C was formed in October 2009 by expert clinicians, alongside patient advocacy and voluntary sector leads with a wide knowledge and experience of the subject. Their aim is to develop an integrated plan for London to drive improvements in the prevention, diagnosis, treatment and outcomes of hepatitis C in people who use drugs, and to reduce the spread of the virus. The membership of the LJWG includes senior figures from Imperial College London, King's College Hospital, Addaction, Central and North West London NHS Foundation Trust, St. Mary's and Hammersmith Hospitals, the Royal Free, Lewisham PCT and The Hepatitis C Trust.

LJWG held their first conference at King's College London in October 2010, and a consensus document was produced. Proposed guidelines were subsequently developed in consultation with experts from a wide range of disciplines including clinical practice, policy development, community liaison, treatment R&D, and service user experience from across the UK. The guidelines represent a statement of current best practice from opinion leaders and practitioners and it is hoped that they will form a blueprint to enable government, NHS London (and any successor agency), national and local commissioners, GP consortia, clinicians and providers, to deliver effective, integrated services for the treatment of hepatitis C in London for people who use drugs. It is also hoped that it might serve as a template for service development in other areas.

The LJWG are also working to improve education and awareness among drug service workers, service users, prison services and others in London. The group's aim is to support the development of integrated care pathways for larger numbers of people with hepatitis C and a history of injecting drug use, and to help individuals access treatment, address health inequalities and help reduce the future burden of HCV-related disease in London.

## 1.4 Prevention

### **Action 4: Prevention<sup>10</sup>**

*Key issue: There is evidence of ongoing transmission of hepatitis C, particularly among injecting drug users. Prevention efforts need to be intensified to reduce the spread of hepatitis C in at-risk populations.*

Acknowledging that the vast majority of infections in England now occur in people who inject drugs, many of the primary and secondary prevention activities continue to centre on this high-risk population. These encompass a wide range of programmes and require an integrated approach from government agencies, professional organisations, health and social care, and public health.

Primary prevention strategies focus on avoiding or removing the cause of the disease before it occurs. These include reducing the number of individuals who begin injecting drugs, raising awareness among people who are currently injecting drugs about the risks of infection and encouraging them to quit or reduce injecting or drug use (including through opioid substitute treatment) and minimising the risk in those who continue to inject (including through needle and syringe programmes (NSPs)). Secondary prevention aims to identify those with early disease before they become symptomatic through increasing awareness of the importance of testing to identify cases early and promptly refer for treatment. These are discussed in section 1.2 of the report. Tertiary prevention strategies aim to reduce the consequences of the disease in those who are already known to be infected. This involves improving access to treatment and specialist services to reduce the morbidity and mortality associated with infection. These are discussed in section 1.3 of the report.

The National Treatment Agency for Substance Misuse (NTA) continues to work with local drug partnerships to develop local multi-agency arrangements for hepatitis C prevention which link into other related areas, including sexual health and drug misuse.

### **1.4.1 Harm reduction services for people who inject drugs**

The NTA together with local drug partnerships have continued to strengthen and review services for preventing hepatitis C transmission including a range of activities in the following areas:

- ***Provision of needle, syringes and other injecting equipment in the community***  
The National Institute for Health and Clinical Excellence's (NICE) 2009 public health guidance: *'Needles and Syringe Programme: Providing People who Inject Drugs with Injecting Equipment'*,<sup>40</sup> promoted the provision of NSPs for adults over 18 years injecting illicit substances. The guidance made specific recommendations on the local commissioning of generic and targeted NSPs to increase the proportion of injecting drug users in contact with them, to increase coverage (i.e. the availability of a clean needle and syringe for every injection), to ensure needles and syringes are available in a range of sizes and at a range of locations, and to offer advice and referrals to other services. Throughout 2009/10, the NTA continued to support local areas in reviewing their needle and syringe provision against these recommendations.

The Needle Exchange Monitoring System (NEXMS) has been developed by the NTA to provide local, regional and national figures for the amount of injecting equipment

distributed, and estimated numbers of needle/syringes returned and clients accessing the services.

Using reports from the NEXMS, NTA local teams continued to work throughout 2009/10 with drug commissioning partnerships on their levels of needle and syringe provision. This information complements the routine auditing of services that takes place in each partnership area as part of the annual treatment planning and performance monitoring round – a process in which the NTA local teams work with partners to identify where shortfalls exist and plan appropriate remedial action.

- ***Training and education***

The NTA has supported the development of the new RCGP Certificate in Harm Reduction, Health and Wellbeing for substance users. It comprises an e-module and face-to-face training day.

The certificate trains front line practitioners working in primary care, open access drug and alcohol services, Accident and Emergency and other health and social care services. The training aims to improve awareness and understanding of practitioners in knowing how and when to offer a hepatitis C test to their patients or clients. It also aims to increase their confidence in advising people who use drugs and/or alcohol about all elements of harm reduction.

In addition, The Hepatitis C Trust has been active in developing peer education services. Peer educators, who themselves have a history of injecting drug use and hepatitis C, visit drug and alcohol treatment centres on a rolling basis. The aim is to instil three key messages: the importance of testing, the availability of effective treatment and how to avoid contracting the virus or prevent transmission to others.

- ***Provision of specialist drug treatment services***

The delivery of good quality drug treatment plays an important role in reducing the incidence of hepatitis C infection among people who inject drugs by helping them to reduce and/or stop injecting and sharing injecting equipment. Figures published by the National Drug Treatment Monitoring System (NDTMS) show that the number of individuals in contact with treatment services have increased from 200,805 in 2007/08 to 206,889 in 2009/10. These services are important in encouraging individuals to get tested and ensuring that infected individuals are promptly referred into treatment.

- ***Provision of specialist drug treatment services for offenders***

In 2006, the IDTS was launched to improve drug treatment services in prisons and to increase the number of offenders that benefit. IDTS is now fully implemented in all prisons in England and responsibility for prison substance misuse services has now transferred from the Ministry of Justice to the DH in order to develop a more recovery-oriented prison-based substance misuse service.

The National Centre for Social Research (NatCen) has been commissioned by the DH to evaluate the IDTS in prison. This is the first formal evaluation of the programme since 2006. The findings are due to be published in 2012.

- ***Provision of information and advice about hepatitis C and other blood-borne viruses and the risks of injecting drugs (including stopping injecting, the risks of sharing injecting equipment and avoiding initiating others)***

The *Harm Reduction Works* (HRW) campaign, a key element of *Reducing Drug-related Harm: An Action Plan*<sup>41</sup> aims to inform and change the conversations that occur between drug workers and people who use drugs, and between people who use drugs

themselves to reduce the risks they take. The campaign includes a range of posters, booklets, and films which can be viewed and ordered on the HRW website. To complement the HRW film *Cleaning Works*, the NTA, in conjunction with the DH, has commissioned a new film that will show prisoners how to clean injecting and other equipment using disinfectant tablets which have been available in adult prisons across England and Wales since October 2007. The film is expected to be available later this year.

#### 1.4.2 Monitoring the impact of prevention messages

A recent report, *Injecting Drug Use in England: A Declining Trend*<sup>7</sup> has reviewed the various prevention measures that have been taken to reduce injecting drug use activity, including opioid substitution treatment, NSPs, talking therapies, education and outreach projects. It reviewed data from the NDTMS, the Treatment Outcomes Profile (TOP), and the HPA's UAM survey of injecting drug users. Findings included a fall in the estimated prevalence of drug injecting in England; some evidence of stabilised and even declining rates of risky injecting practices and encouraging evidence of increased testing and vaccination. The report concludes that continued investment in these prevention initiatives, has improved their availability and effectiveness; had a positive impact on reducing the injecting-related risks and is an investment worth continuing in the future.

Analysis of successive years of Glasgow prevalence estimates indicates a continuing downward trend in the number of people injecting drugs in England. This is testament to the success of sustained measures to prevent and reduce injecting drug use in England.

#### **Levels of injecting among people receiving treatment for drug use**

The number of adult injectors receiving drug treatment has increased from 84,216 (2005/06) to 114,580 (2009/10) (Table 6). This represents around half of all persons in drug treatment in 2009-10; 49% (56,419) of injectors are currently injecting. Of the 79,255 people newly presenting to treatment in 2009/10, 35,340 (44.6%) were currently or previously injecting drugs.

**Table 6: Injecting status of adults in drug treatment: 2005/06-2009/10\***

Injecting status of adults in drug treatment										
	2005-2006		2006-2007		2007-2008		2008-2009**		2009-2010	
Injecting status	All in treatment	Newly presenting								
Current injector	47,897	18,724	54,570	18,589	57,500	18,524	59,923	18,421	56,419	14,892
Previously injected	36,319	16,180	42,510	16,976	48,124	18,413	54,371	20,415	58,161	20,448
All current/previous injectors	84,216	34,904	97,080	35,565	105,624	36,937	114,294	38,836	114,580	35,340

Data source: National Drug Treatment Monitoring System

\*Table 6 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 in any episode of treatment that is wholly or partially within the year. 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.

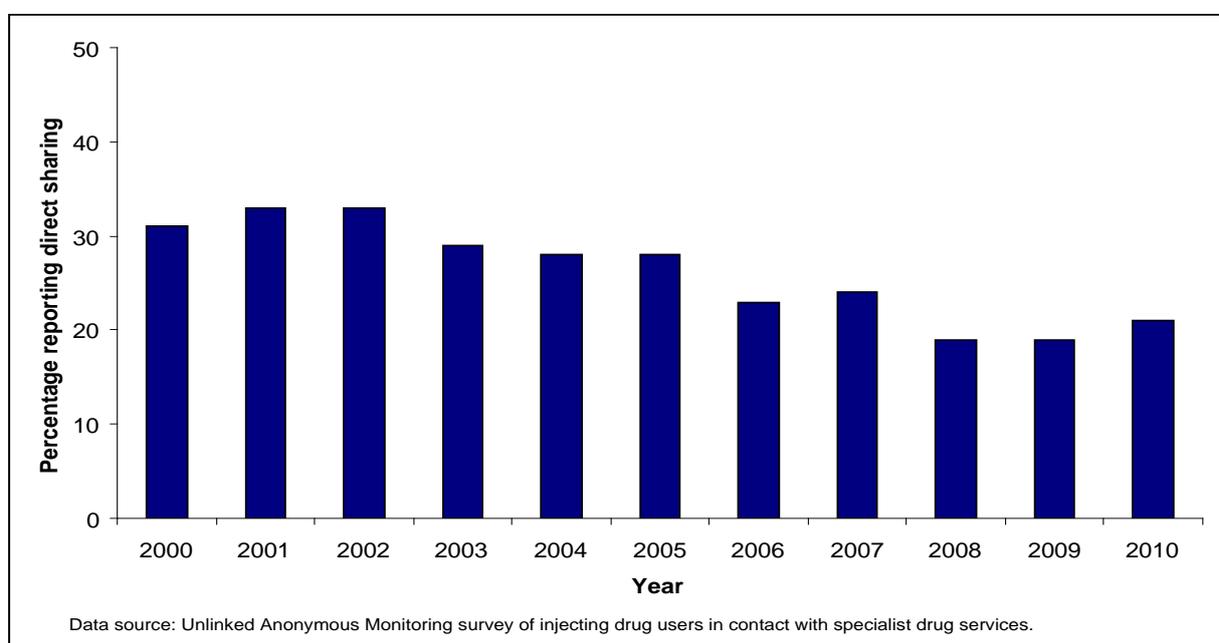
\*\*The numbers for 2008/2009 are slightly higher than those submitted for the 2009 HCV in the UK report<sup>15</sup> because the figures were revised to include data from Bristol which were not available at the time of the 2009 publication.

**Levels of sharing needles/syringes and injecting paraphernalia**

The UAM survey of IDUs monitors self-reported sharing of needles and syringes (direct sharing) and the sharing of paraphernalia (indirect sharing) in the population surveyed. In 2010, 21% of current injectors (those who reported injecting within four weeks before participating in the survey) reported direct sharing in England.<sup>24</sup> This level has declined from 31% in 2000<sup>24</sup> (Figure 16). Amongst these current injectors, 40% reported direct or indirect sharing in 2010. As with direct sharing, the overall proportion reporting direct or indirect sharing has declined from 60% in 2000.<sup>24</sup>

Like hepatitis C antibody prevalence, the proportion of IDUs who share needles and syringes varies between regions. In 2010, the highest levels of direct sharing in the UAM survey of IDUs were observed in the South West (31%) and the lowest levels in the West Midlands (12%).<sup>24</sup> This is likely to reflect different historical patterns of drug use and service provision in different regions.

**Figure 16: Trends in sharing of needles and syringes in the past four weeks among injecting drug users in England: 2000-2010**



**Levels of hepatitis C testing in the drug using population**

Like HPA sentinel surveillance and UAM data (see Figures 6 & 7), NDTMS data show that levels of hepatitis C testing among people who use drugs are continuing to rise. This demonstrates the importance and success of preventative strategies; NICE states that early identification and treatment of hepatitis C is both clinically and cost effective.<sup>42</sup> Data from NDTMS on the hepatitis C test status of adults in drug treatment is available from 2005-2010 (Table 7). The proportion of adults in drug treatment who have a hepatitis C test recorded has increased from 11.8% (2005-06) to 45.0% (2009-10). A similar rise has been recorded in those adults newly presenting for treatment (11.6% in 2005/06 compared with 39.9% in 2009-10).

**Table 7: Hepatitis C test status of adults in drug treatment - all persons: 2005/06-2009/10\***

Hepatitis C test status of adults in drug treatment - all persons											
		2005-2006		2006-2007		2007-2008		2008-2009**		2009-2010	
		All in treatment	Newly presenting								
Has a hepatitis C test recorded	No.	20,773	9,608	35,096	15,143	57,929	22,378	75,668	27,690	93,162	31,629
	%	11.8%	11.6%	18.1%	18.9%	28.8%	27.2%	35.9%	32.8%	45.0%	39.9%
Does not have a hepatitis C test recorded	No.	155,096	73,327	159,077	65,079	142,876	59,957	135,147	56,830	113,727	47,626
	%	88.2%	88.4%	81.9%	81.1%	71.2%	72.8%	64.1%	67.2%	55.0%	60.1%
<b>Total</b>		<b>175,869</b>	<b>82,935</b>	<b>194,173</b>	<b>80,222</b>	<b>200,805</b>	<b>82,335</b>	<b>210,815</b>	<b>84,520</b>	<b>206,889</b>	<b>79,255</b>

Data source: National Drug Treatment Monitoring System

\*A person is classed as having a hepatitis C test recorded by the presence of a test date within their latest treatment journey. Not having a hepatitis C test date does not automatically mean they have not had a test.

\*\*The numbers for 2008/2009 are slightly higher than those submitted for the 2009 HCV in the UK report<sup>15</sup> as the figures were revised to include data from Bristol which were not available at the time of the 2009 publication.

There continues to be a rise in testing among injectors (including those newly presenting for treatment) with a 21% increase in testing reported between 2008/09 and 2009/10. For the first time, over half of all injectors in treatment have had a recorded test for hepatitis C in 2009/10 (57.7%, Table 8). This compares with less than 20% in 2005-06. A slightly lower proportion of new injectors newly presenting to treatment (55.4%) were recorded as having had a hepatitis C test in 2009/10.

**Table 8: Hepatitis C test status of adults in drug treatment - injectors only: 2005/06-2009/10\***

Hepatitis C test status of adults in drug treatment - injectors only											
		2005-2006		2006-2007		2007-2008		2008-2009**		2009-2010	
		All in treatment	Newly presenting								
Has a hepatitis C test recorded	No.	15,562	6,976	26,611	10,903	41,743	14,414	54,507	17,917	66,130	19,575
	%	18.5%	20.0%	27.4%	30.7%	39.5%	39.0%	47.7%	46.1%	57.7%	55.4%
Does not have a hepatitis C test recorded	No.	68,654	27,928	70,469	24,662	63,881	22,523	59,787	20,919	48,450	15,765
	%	81.5%	80.0%	72.6%	69.3%	60.5%	61.0%	52.3%	53.9%	42.3%	44.6%
<b>Total</b>		<b>84,216</b>	<b>34,904</b>	<b>97,080</b>	<b>35,565</b>	<b>105,624</b>	<b>36,937</b>	<b>114,294</b>	<b>38,836</b>	<b>114,580</b>	<b>35,340</b>

Data source: National Drug Treatment Monitoring System

\*A person is classed as having a hepatitis C test recorded by the presence of a test date within their latest treatment journey. Not having a hepatitis C test date does not automatically mean they have not had a test.

\*\*The numbers for 2008/2009 are slightly higher than those submitted for the 2009 HCV in the UK report<sup>15</sup> as the figures were revised to include data from Bristol which were not available at the time of the 2009 publication.

## Hepatitis C in the UK

Figures show that in 2009/10, over 70% of all adults currently receiving drug treatment (71.5%; n=206,889) were recorded as being offered a hepatitis C test and 44.2% accepted the offer, an increase of 33% compared with 2008/09 (Table 9).

**Table 9: Hepatitis C intervention status for adults in drug treatment – all persons: 2005/06-2009/10\***

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	
		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
	%	0.3%	0.2%	1.4%	1.8%	18.8%	28.3%	32.6%	38.4%	44.2%	42.7%
Offered and refused	No.	452	180	1,878	962	23,531	15,345	42,711	22,080	56,488	25,450
	%	0.3%	0.2%	1.0%	1.2%	11.7%	18.6%	20.3%	26.1%	27.3%	32.1%
Assessed as not appropriate to offer	No.	n/a	n/a	n/a	n/a	n/a	n/a	1,253	614	8,603	6,176
	%	-	-	-	-	-	-	0.6%	0.7%	4.2%	7.8%
Not offered	No.	685	300	3,193	1,797	22,294	14,014	27,421	13,561	17,843	6,193
	%	0.4%	0.4%	1.6%	2.2%	11.1%	17.0%	13.0%	16.0%	8.6%	7.8%
No recorded status	No.	174,169	82,252	186,350	76,058	117,299	29,635	70,626	15,841	32,609	7,564
	%	99.0%	99.2%	96.0%	94.8%	58.4%	36.0%	33.5%	18.7%	15.8%	9.5%
<b>Total</b>		<b>175,869</b>	<b>82,935</b>	<b>194,173</b>	<b>80,222</b>	<b>200,805</b>	<b>82,335</b>	<b>210,815</b>	<b>84,520</b>	<b>206,889</b>	<b>79,255</b>

Data source: National Drug Treatment Monitoring System

\*The intervention status is the status within their latest treatment journey that reports the most positive clinical intervention, i.e. 'offered and accepted' is selected over 'offered and refused'. The code 'assessed as not appropriate to offer' (for example, the individual had already received a test recently and did not need a further test offer) in the hepatitis C status field was available from 2008-09 onwards, only.

\*\*The numbers for 2008/2009 are slightly higher than those submitted for the 2009 HCV in the UK report<sup>15</sup> as the figures were revised to include data from Bristol which were not available at the time of the 2009 publication.

Three quarters of adults who were injecting drugs had been offered a test (75.6%; n=86,641), and over half accepted the offer (51.7%; Table 10). An even higher proportion (79.2%; n=27,956) newly presenting to treatment were offered testing with a similar proportion accepting (51.6%).

**Table 10: Hepatitis C intervention status for adults in drug treatment – injectors only: 2005/06-2009/10\***

Hepatitis C intervention status for adults in drug treatment - injectors only											
		2005-2006		2006-2007		2007-2008		2008-2009**		2009-2010	
Recorded hepatitis C status		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
	%	0.5%	0.4%	2.1%	2.7%	23.1%	36.4%	38.8%	47.0%	51.7%	51.6%
Offered and refused	No.	297	100	1,224	533	11,809	6,409	20,918	8,913	27,431	9,738
	%	0.4%	0.3%	1.3%	1.5%	11.2%	17.4%	18.3%	23.0%	23.9%	27.6%
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
	%	-	-	-	-	-	-	0.6%	0.8%	3.5%	7.2%
Not offered	No.	424	171	2,076	1,019	11,340	5,832	13,230	5,384	8,471	2,249
	%	0.5%	0.5%	2.1%	2.9%	10.7%	15.8%	11.6%	13.9%	7.4%	6.4%
No recorded status	No.	83,053	34,489	91,720	33,056	58,089	11,247	35,032	5,958	15,403	2,596
	%	98.6%	98.8%	94.5%	92.9%	55.0%	30.4%	30.7%	15.3%	13.4%	7.3%
<b>Total</b>		<b>84,216</b>	<b>34,904</b>	<b>97,080</b>	<b>35,565</b>	<b>105,624</b>	<b>36,937</b>	<b>114,294</b>	<b>38,836</b>	<b>114,580</b>	<b>35,340</b>

Data source: National Drug Treatment Monitoring System

\*The intervention status is the status within their latest treatment journey that reports the most positive clinical intervention, i.e. 'offered and accepted' is selected over 'offered and refused'. The code 'assessed as not appropriate to offer' (for example, the individual had already received a test recently and did not need a further test offer) in the hepatitis C status field was available from 2008-09 onwards, only.

\*\*The numbers for 2008-2009 are slightly higher than those submitted for the 2009 HCV in the UK report<sup>15</sup> as the figures were revised to include data from Bristol which were not available at the time of the 2009 publication.

## 1.5 Summary

Updated figures for prevalence of HCV antibody in the adult population in 2005, suggest an overall prevalence of 0.54% in England, equating to 218,000 individuals; 161,320 of these, or 0.40% of the adult population, would have chronic infection. As in previous years, genotypes 1 and 3 predominate (90% of all infections).

Models are currently under development to estimate HCV incidence, however, reports in young adults and IDUs who have recently begun injecting, suggest that transmission levels may be relatively stable.

HPA surveillance data suggest that more individuals with HCV have been diagnosed, but that numbers diagnosed may be levelling off. Other than in drug services, the proportion testing positive is declining, suggesting that tests are being extended to those at lower risk of infection. Increased testing via primary care, drug services and among individuals of South Asian origin suggests increased awareness of HCV in these groups and settings.

Infections in new blood donors have occurred mostly in those of white ethnicity, but disproportionately large numbers occur in those of South Asian origin. Data suggest that the majority of infections in new donors were acquired outside of the UK, particularly in Eastern Europe and Asia. A pilot study to investigate the prevalence of HCV among Africans living in London is also underway; similar studies may be required in other migrant groups, for example in Eastern Europeans.

There is some early evidence to suggest a decline in the sexual transmission of HCV among HIV positive MSM. This suggests that more HCV screening in HIV positive MSM and in MSM with abnormal LFTs may have taken place.

The NTA works with local drug partnerships to develop multi-agency arrangements for hepatitis C prevention. Together with local drug partnerships, the NTA reviews services for preventing hepatitis C transmission, including needle and syringe provision. The NTA has supported RCGP in the development of the 'Certificate in Harm Reduction, Health and Wellbeing for Substance Users'. Others, including The Hepatitis C Trust, have been active in developing peer education services. The HRW campaign continues to be a key component of prevention activity by providing a range of information and education materials, including posters, booklets and films.

Overall, the number of individuals in contact with drug treatment services has increased from 200,805 in 2007-08 to 206,889 in 2009-10. NDTMS data suggest that the number of people currently or previously injecting drugs in drug treatment has increased from 84,216 in 2005-06 to 114,580 in 2009-10, and increasing numbers of adults in drug treatment have a hepatitis C test recorded. There continues to be a rise in testing amongst people who have a history of injecting drugs, with a 21% increase reported between 2008-09 and 2009-10. NDTMS figures show that in 2009-10, over 70% of all adults currently in drug treatment were offered a hepatitis C test and 44% accepted the offer; numbers were even higher amongst those who injected, with more than half accepting a test.

Integrated drug treatment has been rolled out further across the prison estate. However, HPA data do not support an increase in testing in this setting.

A recent report, *Injecting Drug Use in England: A Declining Trend*<sup>7</sup> concluded that prevention measures to reduce injecting drug use activity are having an impact, resulting in a fall in the prevalence of drug injecting in England. Like UAM data, this report also suggests stabilisation and even declining rates of risky injecting practices and an increased uptake of HCV testing.

When data from HPA surveillance systems are taken together, testing patterns and self-reports also suggest that HCV testing among IDUs is increasing. Alternative testing technologies are continuing to contribute to the increased uptake of testing in IDUs and yields remain high at around 20%. The proportion of IDUs reporting that they were aware of their positive status has however remained fairly stable in recent years, and currently stands at 55%. Despite increases in testing, UAM data suggest that around half of all IDUs are positive for HCV antibody, and this figure is closer to 65% in London and the North West. This underlies the importance of ongoing efforts to target this highest risk sub-group of the population.

National data sources show that HCV-related ESLD and death are continuing to rise. By 2020 it is predicted that 15,840 individuals will be living with HCV-related cirrhosis or HCC in England. To help stem this, a number of initiatives to increase the awareness of hepatitis C among the public and healthcare professionals are continuing, many led by non-governmental organisations (NGOs). Awareness-raising campaigns targeting the general public and particular risk groups continue to be valuable by providing information on risk behaviour, methods of diagnosis and treatment options. It is hoped that the RCGP Certificate in the Detection and Diagnosis of Hepatitis B and C in Primary Care, along with other initiatives, will help improve levels of diagnosis and ensure that patient care is optimised.

The WHO resolution on viral hepatitis that made World Hepatitis Day (28 July) one of only six official WHO days was a significant milestone. This will provide a focus for future awareness raising events.

Increased diagnosis and provision of high quality, accessible HCV-related care remain priorities and will be key components of the NLDS. The NLDS has been developed in partnership with stakeholders and will aim to address these key issues within the new health economy.

The HPA BBIPB and hepatitis C teams have been active in areas of policy over the past year. A response to the Public Health White Paper, '*Healthy Lives, Healthy People. Update and way forward*'.<sup>2</sup> has been submitted offering recommendations for the future control of viral hepatitis and BBIs in England.

An audit of hospital hepatitis C services across England by the APPHG highlights the need for data on referral, treatment and treatment outcome. Although response rates to the survey were low, there was evidence of considerable variation in hepatitis services available to patients across the country.

The HPA are undertaking a pilot study of national hepatitis C treatment monitoring and this has already allowed mapping of hepatitis C service provision across England. Alternative methods of estimating the number of patients receiving treatment, have provided a direct comparison with treatment estimates given by clinical centres, and suggest that, between 2006 and 2008, a maximum of 12,400 patients with hepatitis C were treated in England; a figure likely to represent fewer than 10% of the total chronically infected population. Hepatitis leads have been provided with an updated standard report template together with a workbook containing their region-wide data, to help inform planning of local hepatitis C services.

A survey of HPUs in 2010 showed that around 70% of PCTs reported having care pathways in place, and around 80% of HPUs were involved in the development of all or more than half of these pathways. Results of this care pathway audit represented an improvement from 2009 across nearly all domains. Work to assess the impact on health, and healthcare services, of identifying individuals diagnosed and reported as HCV infected in the past but who have no laboratory evidence to suggest access to treatment or clearance of infection is also underway.

To help improve the quality of hepatitis C-related care, the BVHG have worked with their members and other stakeholders to produce recommendations on the provision of antiviral services for patients with chronic viral hepatitis.

A variety of local and regional initiatives have been reported across all sectors for delivering high quality accessible, diagnosis and treatment services. The development of clinical networks and multi-disciplinary teams have been key to the successful delivery of services that ensure patient pathways are in place that address individuals' medical and social needs.

## 2. Northern Ireland

In January 2007, the DH, Social Services and Public Safety issued its action plan for the Prevention, Management and Control of Hepatitis C in Northern Ireland<sup>4</sup>

The Health and Social Care Boards that were then in place in Northern Ireland were charged with developing a managed clinical network (MCN) for hepatitis C<sup>43</sup> The network, comprising a wide range of stakeholders, was formally launched in October 2007.

Since then Boards have been replaced by a single Health and Social Care Board and the Public Health Agency<sup>44</sup> These changes have been reflected in the network.

Four main work streams were established:

- Surveillance
- Education and Awareness
- Drugs and Addiction Services
- Diagnostic and Treatment Services

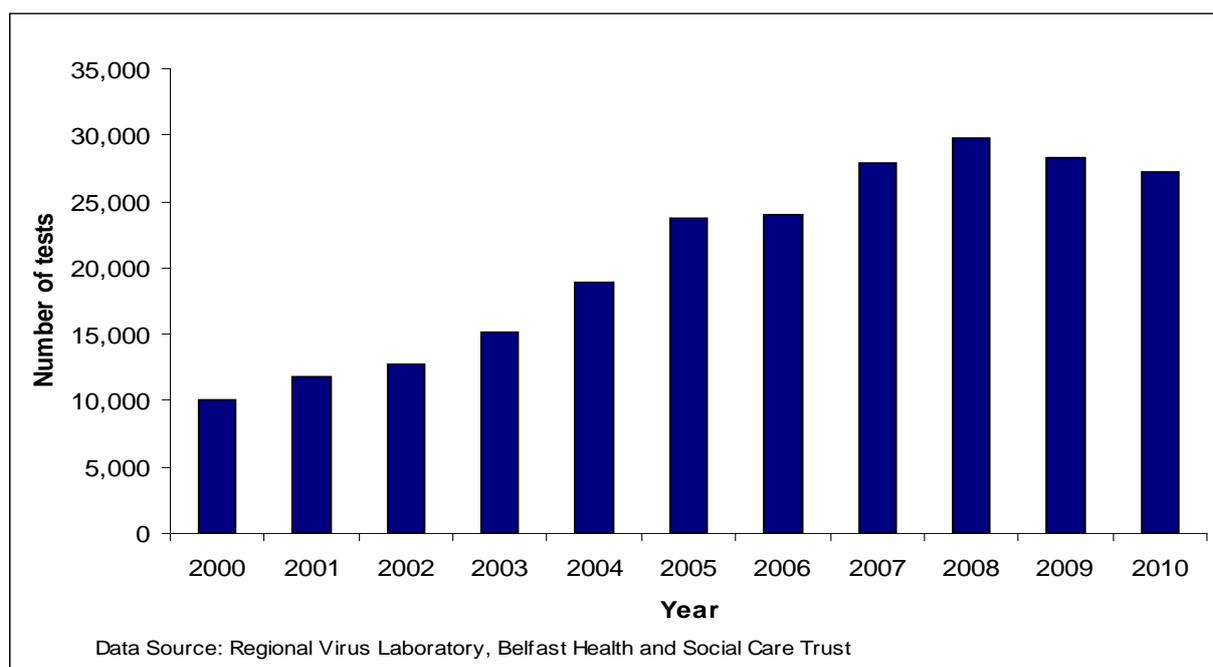
The MCN completed the relevant actions in the 2007 Action plan and subsequently, in 2010, compiled a new work programme. Progress is summarised below.

### 2.1 Surveillance

#### ***Laboratory reports and hepatitis C virus testing***

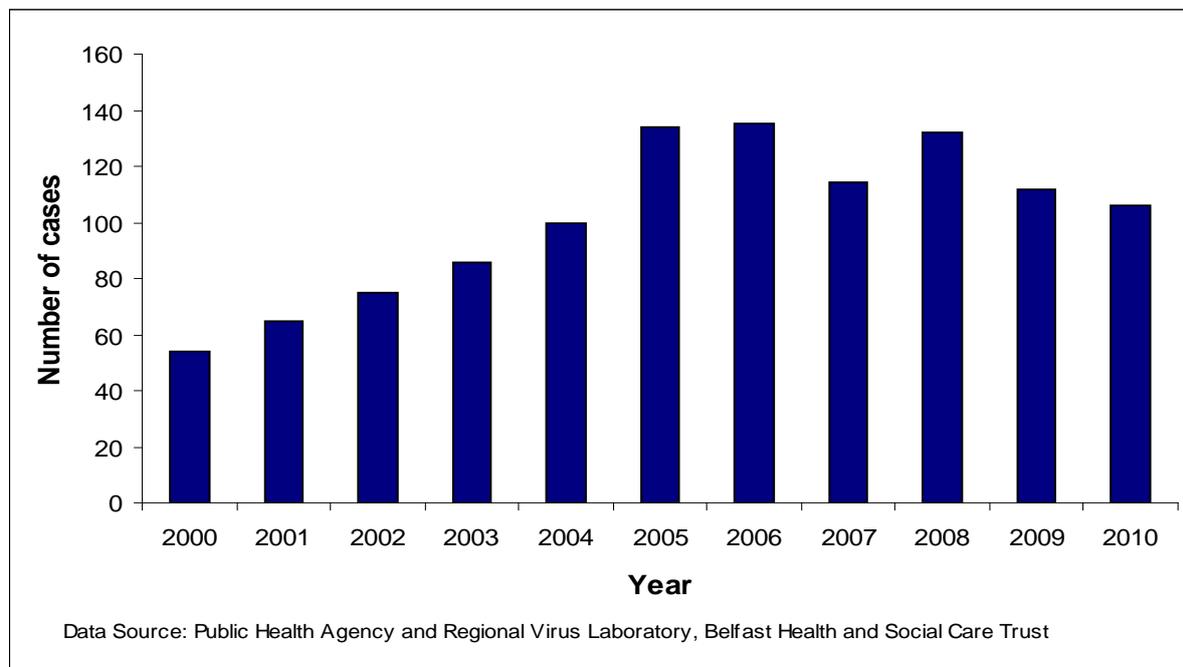
The number of HCV antibody tests rose from 12,700 in 2002 to 29,161 in 2008 with a slight drop to 27,247 requests in 2010 (Figure 17).

**Figure 17: Number of HCV antibody tests requested in Northern Ireland: 2000-2010**

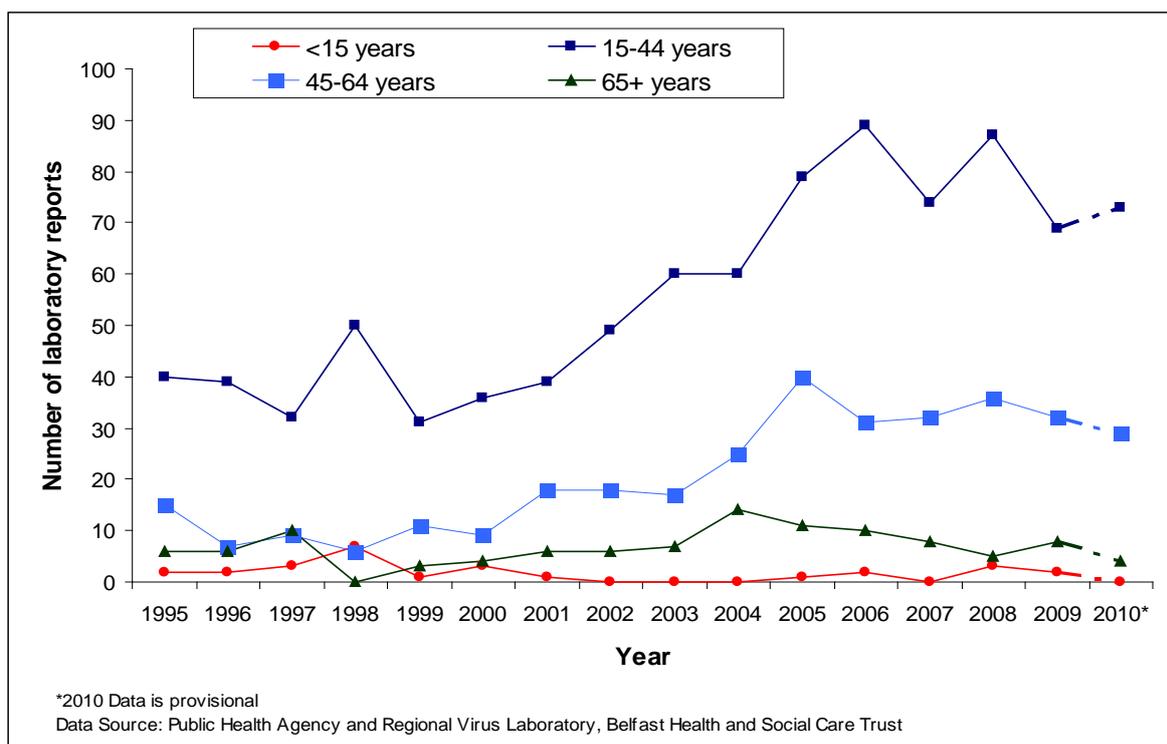


The annual number of new antibody-positive reports of hepatitis C in Northern Ireland fluctuated between 40 and 65 from 1992 to 2001, and then rose progressively to a peak of 135 in 2006; 106 cases were confirmed in 2010 (Figure 18). Of the 106 newly diagnosed antibody-positive cases in 2010, 73 were PCR-positive on the initial sample.

**Figure 18: Laboratory-confirmed HCV antibody positive cases in Northern Ireland: 2000-2010**



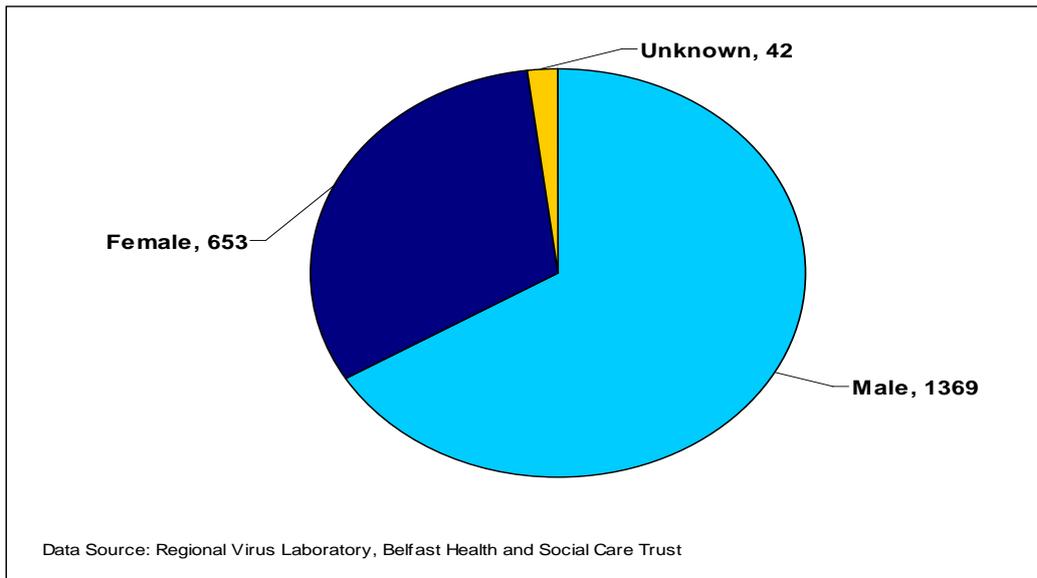
**Figure 19: Laboratory-confirmed HCV antibody positive cases in Northern Ireland, by age: 1995-2010**



The majority of confirmed cases of Hepatitis C in Northern Ireland occur in persons aged between 15-44 years of age (Figure 19).

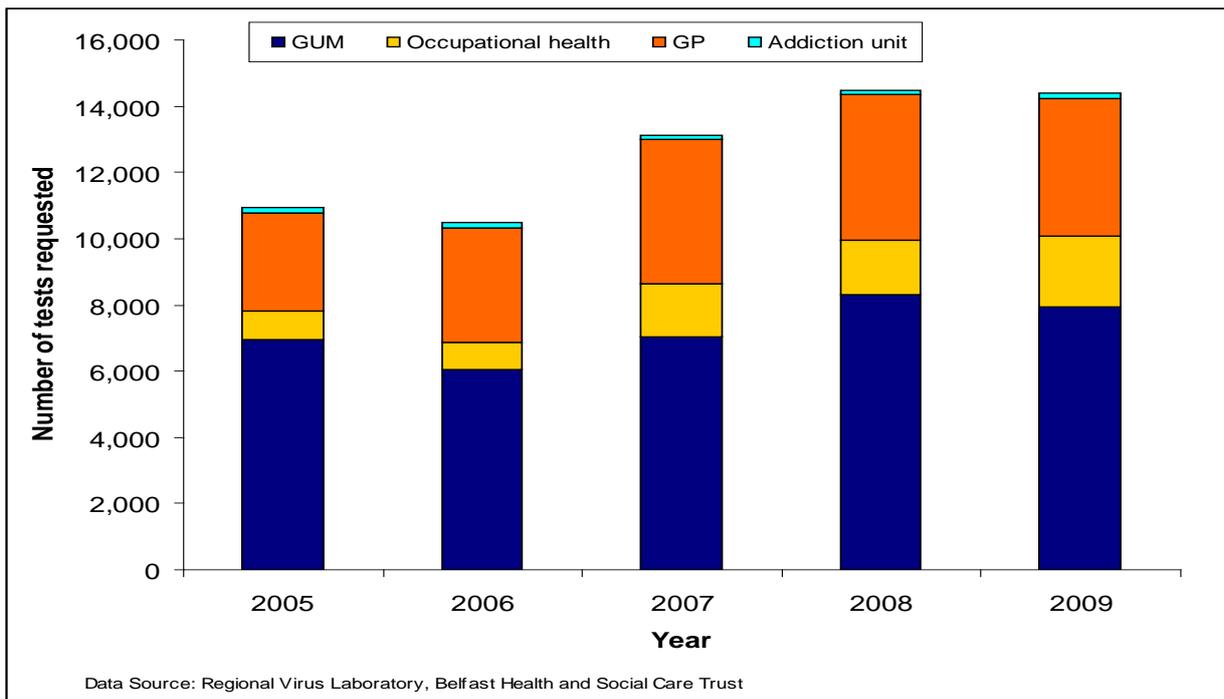
Information supplied by the Regional Virus Laboratory show that gender was recorded for 2,022/2,064 HCV antibody positive cases from 1990–2010. Of this group 67% (1369) were male compared to 32% (653) female (Figure 20).

**Figure 20: Gender of Laboratory confirmed cases of HCV antibody positive cases: 1990-2010**



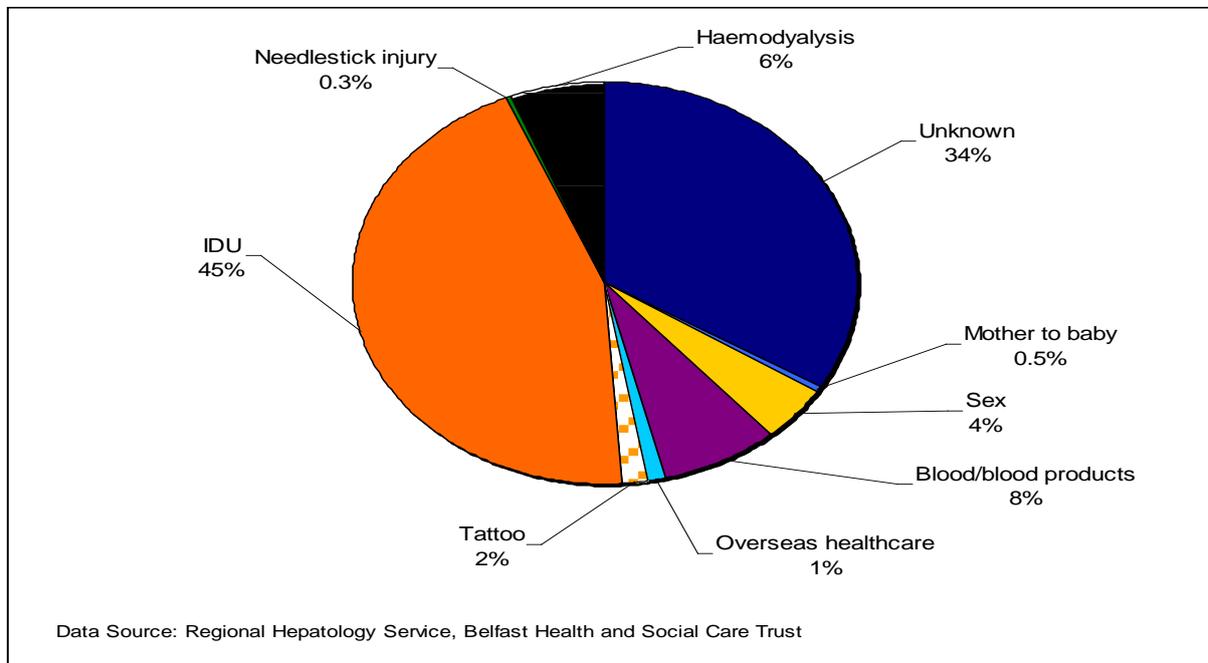
The majority of Hepatitis C testing requests were received from GUM, followed by GPs, occupational health departments and addiction services (Figure 21).

**Figure 21: Source of Hepatitis C test requests in Northern Ireland: 2005-2009**



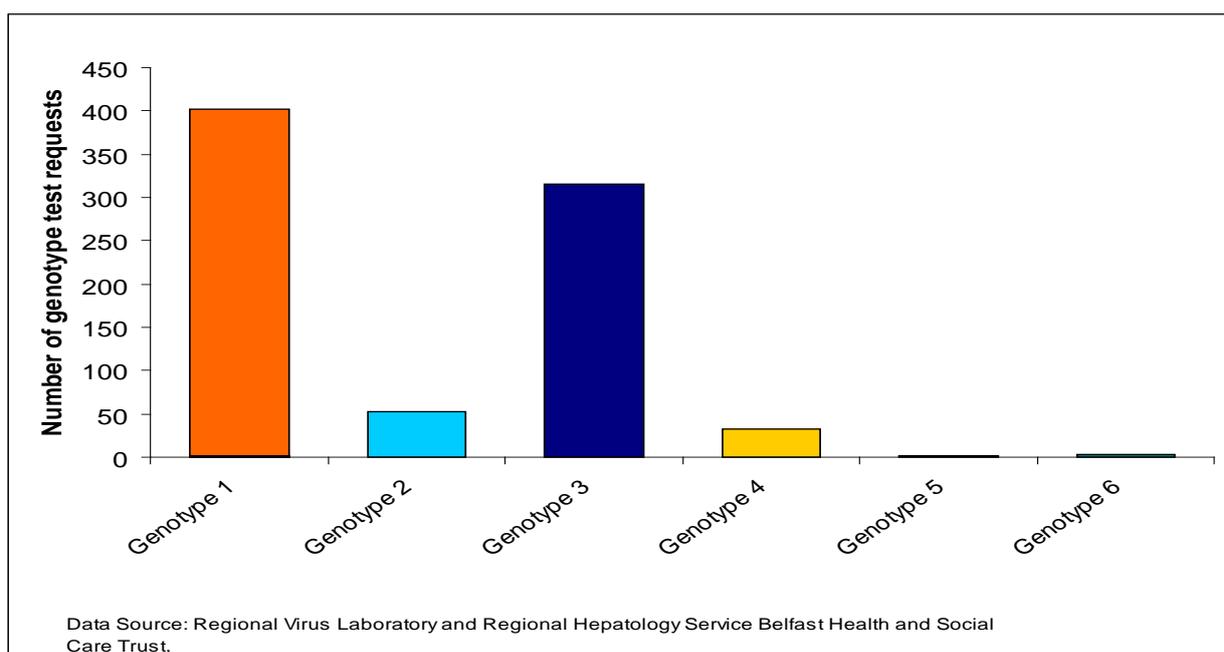
Risk factor information is available for 66% of the 728 cases who have presented for treatment at the Hepatology Clinic in the Royal Victoria Hospital Belfast. A large proportion of HCV infection can be attributed to injecting drug use (Figure 22).

**Figure 22: Risk factors for acquisition of HCV recorded by patients living in Northern Ireland who have presented for treatment**



In Northern Ireland, of the 1,508 laboratory confirmed cases of chronic hepatitis C, genotype testing has been completed for 806; the majority (89%) have genotype 1 or genotype 3 infection (Figure 23).

**Figure 23: Genotyping in laboratory confirmed cases of chronic hepatitis C (n= 806): 1990-2010.**



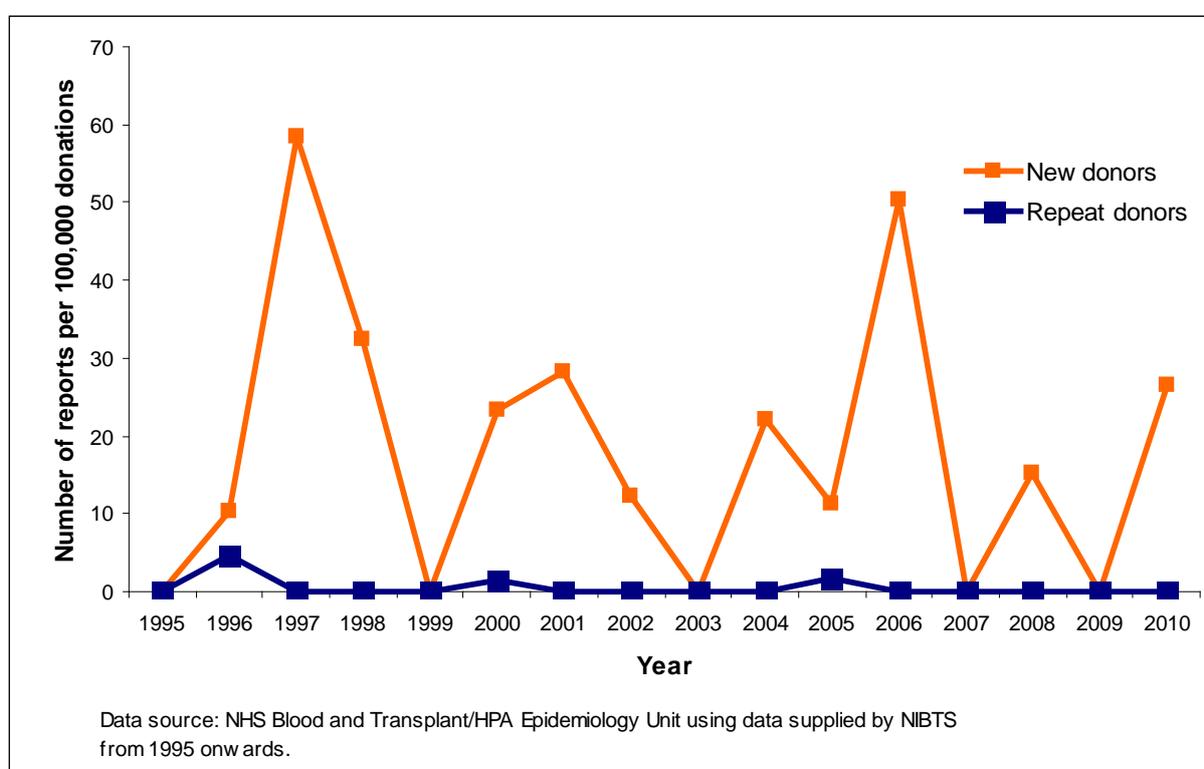
**Unlinked Anonymous Monitoring survey of injecting drug users**

Findings from the UAM survey of IDUs attending specialist addiction services in Northern Ireland indicate that 23% of current injectors who participated, reported direct sharing of needles and syringes, and 39% reported direct sharing of needles and syringes or paraphernalia (direct or indirect sharing) in 2010.<sup>24</sup> The prevalence of hepatitis C antibodies in participants in Northern Ireland in 2010 was 31%.<sup>24</sup> Two fifths (40%) were unaware of their hepatitis C status, but only 10% had never been tested for hepatitis C.<sup>24</sup>

**Infections in blood donors**

The Northern Ireland Blood Transfusion Service (NIBTS) collects blood from voluntary donors who are selected to be at low risk of BBIs. Frequency of hepatitis C positive new donors remains variable with no detections in repeat donors in most years. (Figure 24)

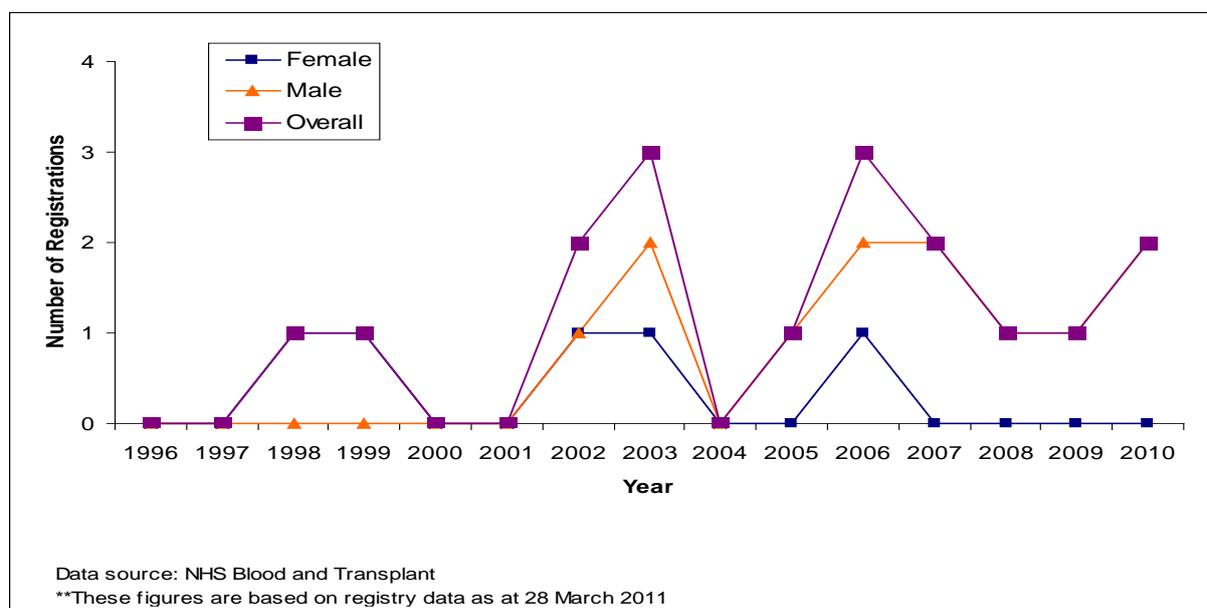
**Figure 24: Frequency of hepatitis C in blood donors in Northern Ireland: 1995-2010 New and repeat donors**



**Hepatitis C virus-related liver transplants and mortality**

Prevalence of hepatitis C has historically been low in Northern Ireland, and this is reflected in the low numbers of patients requiring transplants due to cirrhosis caused by hepatitis C (Figure 25), although there is some indication of a rise in the past five years. Between 2001 and 2008, there had been only one death due to ESLD or HCC in those with HCV mentioned on their death certificate. In 2009 and 2010 however, a total of eight such deaths were recorded, three in 2009 and five in 2010.

**Figure 25: First registrations\* for a liver transplant with a code of post-hepatitis C cirrhosis in Northern Ireland: 1996 - 2010\*\***



\*New universal registration criteria for selecting adult patients for elective liver transplantation were introduced in September 2007<sup>35</sup>

## 2.2 Education and Awareness

Good progress has been made in this area, with the development and distribution of information about hepatitis C itself and how to manage positive results. This information has been developed for healthcare professionals and the public and is supplemented by a programme of educational updates for GPs, drugs and addictions teams and prison staff. The MCN Website<sup>43</sup> continues to be a source of information and support.

### Key progress

- Public information leaflet 'Hepatitis C – could I be at risk,<sup>45</sup> now distributed and available in translation on the website.
- An updated clinician result factsheet 'Hepatitis C positive and PCR positive,<sup>46</sup> information sheet has been developed and is sent out with every PCR positive result.
- A patient fact sheet has been developed, for those that test positive – 'Hepatitis C–what now?,'<sup>47</sup> This leaflet accompanies the virology result sent to the referrer.
- Programme of educational updates for GPs, drugs and addictions staff and prison staff continues.
- The Hepatitis C Managed Clinical Network Website is updated regularly [www.hepcni.net](http://www.hepcni.net). A linked email address, [info@hepcni.net](mailto:info@hepcni.net) allows the public and professionals to request more information or to ask questions. These emails are sent to the Regional Hepatitis C Clinical Network Manager who then forwards the questions to the appropriate team member to be answered.

## 2.3 Drugs and addictions

A multi-agency addiction group and a forum with strong links to the MCN are now in place, and joint working is being strengthened as a priority. Services are being developed for the IDU population; agreement has been obtained to expand needle exchange and a pilot study of DBS testing has been undertaken. Annual updates for addiction services from the specialist hepatitis nurses based at the Liver Unit have commenced, and it is hoped that this will increase communication and help develop relationships between addictions staff and the specialist nursing team.

### Key Progress:

- A regional multi-agency addiction group has been re-established with strong links to the network.
- The Northern Ireland Community Addiction Teams Forum has also been re-invigorated following health and social care reorganisation, again with strong network links.
- Expansion of the needle exchange programme has been agreed with four additional fixed pharmacy sites and out-reach provision to be provided.
- A pilot of DBS testing has been completed.
- Joint working between prison addiction services and community addiction teams is under development. This will include exchange of information on HCV infection. It is expected that as the joint work develops the resource of the prison addiction teams can provide an opportunity to feedback treatment, prevention and surveillance issues into the network.
- Annual updates for addiction services from the specialist hepatitis nurses based at the Liver Unit have commenced.

## 2.4 Diagnostic and treatment services

A care pathway is in place to ensure appropriate referral and to increase access to currently available treatments; clinical databases are also being updated and adopted to support service delivery. Specialist nurse provision has been expanded, and this has allowed joint protocols for the delivery of HCV treatment to prison inmates.

Feedback from patients is helping to improve diagnostic and treatment services and audits have allowed referral rates to be investigated. As a result, all newly diagnosed chronic cases are now followed-up after six months and their clinicians are contacted if they have not been referred to the Regional Hepatology Unit for assessment.

**Key progress:**

- Current Royal Victoria Hospital, Belfast Health and Social Care Trust hepatitis C clinical database is being updated. The national hepatitis C clinical database 'C-Thru' has been adopted and all new referrals are put on this system.
- New hepatitis C referrals are added to both clinical databases currently in use.
- A care pathway, including referral and treatment guidelines, has been developed and agreed.
- A second hepatology nurse specialist was appointed in spring 2008 significantly enhancing the team and increasing capacity.
- A joint protocol for the delivery of HCV treatment to prison inmates has been agreed.
- Feedback has been obtained through a questionnaire from patients who have received treatment and this is being used to enhance diagnostic and treatment services.
- An audit of referral of chronic hepatitis C cases diagnosed in Northern Ireland has been undertaken. Of the 1,508 PCR-positive cases diagnosed from 1990–2010, 728 or 48% of HCV positive individuals have presented for assessment at the Regional Hepatology Unit. The referral rate has improved somewhat after the network was established.

## **2.5 Summary**

The network continues to develop following the re-organisation of health and social care in Northern Ireland, and the appointment of a project manager in 2010 has been a welcome dedicated resource for the network.

Reducing inequalities continues to be a key priority in the Public Health Agency. As part of work in this area a number of groups have been established in recent months such as a multi-organisational group on migrant health and a sexual health network. Strong collaborative links between the network and these groups should maximise further progress in relevant areas of the work programme. This co-ordinated approach, with an emphasis on prevention, is especially important in current times of resource constraint.

A new work programme has been drawn-up and progress has been made against this. Improved surveillance arrangements are in place; in particular, a process for identifying and following-up new cases of chronic hepatitis C who have not been referred to hepatology services.

New leaflets for the public have been developed and distributed. Further work is required to increase awareness, particularly among migrant groups at greater risk of hepatitis C infection. Evaluation of this work is also under consideration.

An education programme with a range of professionals continues, and work has commenced on an e-learning package. Progress has also been made in the area of harm reduction, with the network maintaining strong links with relevant regional groups.

### 3. Scotland

Following an extensive consultation in 2005, the Scottish Government launched its action plan for hepatitis C in September 2006.<sup>48</sup> The aims are:

- To prevent the spread of hepatitis C, particularly among IDUs.
- To diagnose hepatitis C infected persons, particularly those who would most benefit from treatment.
- To ensure that those infected receive optimal treatment, care and support.

Taking a two-phased approach, phase I (undertaken during September 2006 to March 2008)<sup>48</sup> comprised 41 actions spread across the areas of co-ordination, prevention, testing/treatment/care/support and education/training/awareness-raising, and involved increasing awareness about hepatitis C among professionals and undertaking extensive research and consultation to inform proposals for the development of hepatitis C services during Phase II.

Phase II, launched in May 2008,<sup>49</sup> saw serious commitment from the Scottish Government to tackle the hepatitis C challenge facing Scotland, with an investment of approximately £43 million, subject to Scottish Government budget revisions. The bulk of this funding is being allocated to NHS Boards, over the three years of the plan, to deliver 34 actions designed to dramatically improve prevention, diagnosis, treatment, care, and support services for hepatitis C throughout the country. Implementation of the plan has involved representatives from all relevant disciplines and organisations, and has taken a graduated approach, focusing on establishing the necessary infrastructures in year one (2008/09), in preparation for services being delivered and developed in years two (2009/10) and three (2010/11).

The second annual report of phase II provided an overview of progress made on the implementation of actions during 2009/10.<sup>50</sup> The following sections on: (i) testing, treatment, care and support, (ii) prevention, and (iii) disease trends, provide data to monitor progress made with the action plan during year two (2009/10) and, where possible, year three (2010/11), in terms of: (a) reducing the proportion of infected people who are undiagnosed, (b) increasing the number of infected people who clear their virus as a consequence of antiviral treatment, (c) reducing the number of people becoming infected with hepatitis C, and (d) reducing the number of infected people who develop severe hepatitis C-related liver disease.

#### 3.1 Testing, treatment, care and support

Two of the main aims of the action plan are to: (a) reduce the proportion of infected people who are undiagnosed, and (b) increase the number of infected people who clear their virus as a consequence of antiviral treatment.

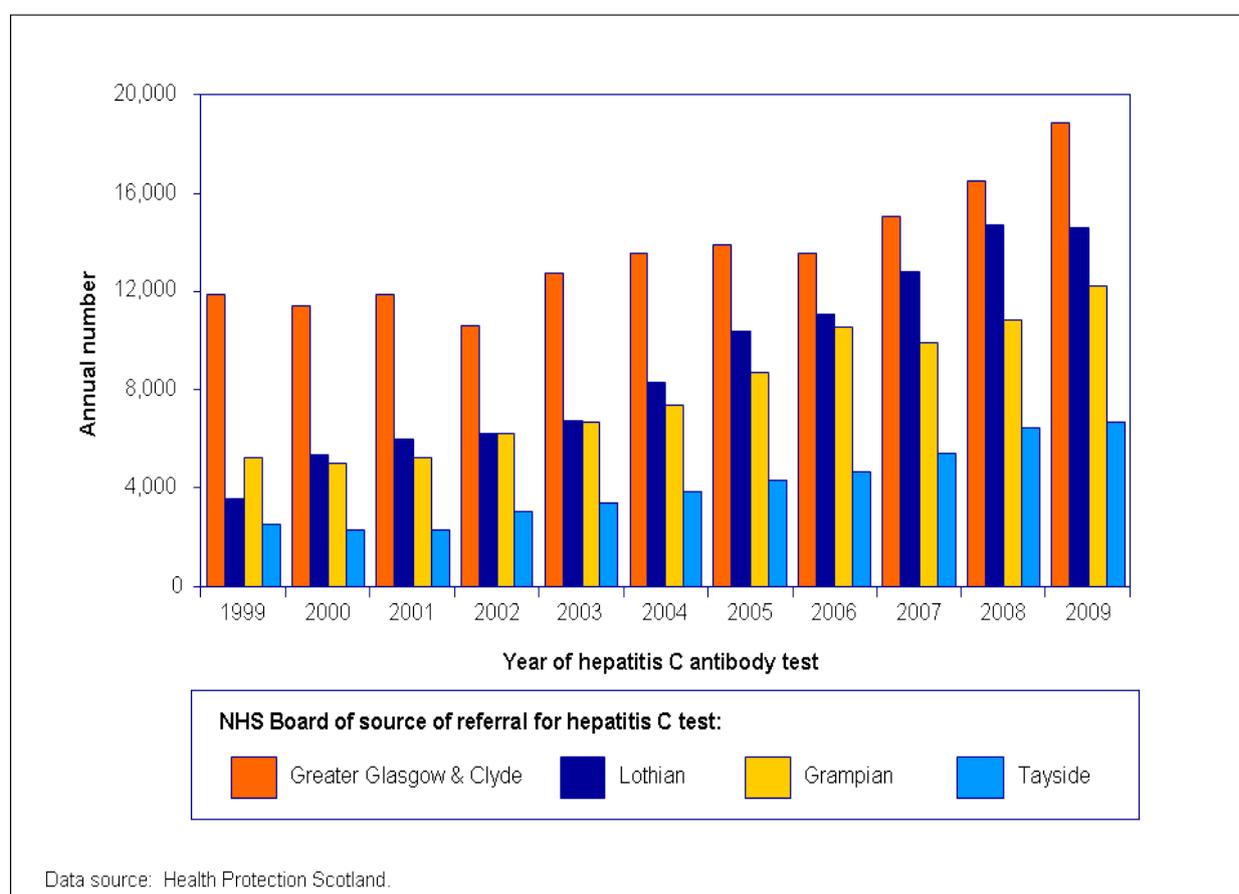
The following sub-sections present data on: (i) testing for and diagnosis of hepatitis C infection, (ii) blood donor testing and (iii) treatment of hepatitis C infection. These data were obtained through analysis of existing data on Scotland's National Hepatitis C Diagnoses Database,<sup>51</sup> Hepatitis C Test Database, and Hepatitis C Clinical Database; surveillance data from the Scottish National Blood Transfusion Service (SNBTS); and a questionnaire survey of IDUs attending services providing injecting equipment in Scotland.<sup>52</sup>

### 3.2.1 Testing and diagnosis of hepatitis C infection

A total of 73,000 hepatitis C antibody tests were undertaken throughout Scotland during 2009, which compares to 61,700 in 2006 and 70,600 in 2008. Of the 73,000 hepatitis C antibody tests performed in 2009, 6.6% were antibody positive. This antibody positive rate compares to 5.2% in 2006 and 5.4% in 2008.

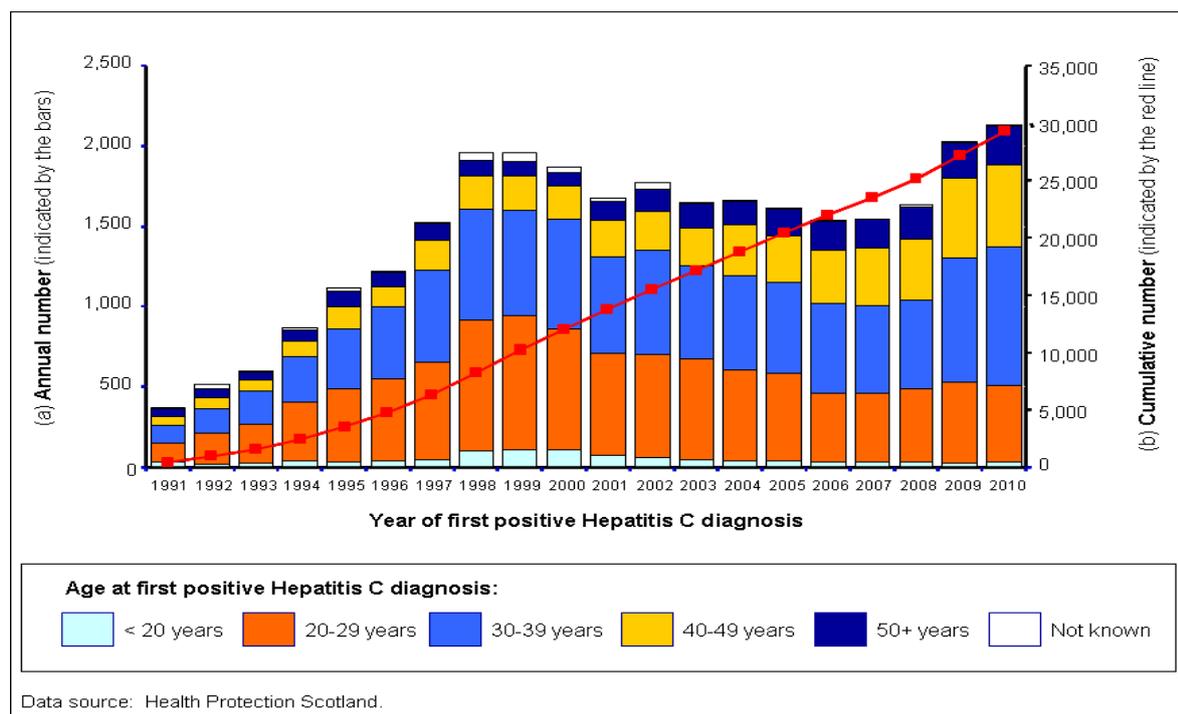
Figure 26 illustrates the rise in the annual number of hepatitis C antibody tests performed in four large NHS Boards (relating to Scotland's four largest cities), from a total of approximately 23,171 in 1999 to 52,369 in 2009. Of the 52,369 hepatitis C antibody tests performed in 2009, 32.6% were undertaken in the hospital setting (including infectious disease and gastroenterology units), 28.2% as part of a routine screen (at either a renal, fertility or occupational health clinic), 25.3% by GPs, 9.1% in GUM clinics, 2.5% in specialist drug services, 1.2% in prisons, and 1.2% in other settings.

**Figure 26: Annual number of hepatitis C antibody tests performed in four large NHS Boards in Scotland, during: 1999-2009**



There were 2,030 and 2,129 new hepatitis C diagnoses made in Scotland during 2009 and 2010, respectively, which compares to an average of 1,605 (range 1,533 to 1,657) new diagnoses made per year during 2003-2008 (Figure 27).<sup>51</sup>

**Figure 27: Annual and cumulative numbers of people reported to be diagnosed hepatitis C antibody positive in Scotland: 1991-2010**



Of the 2,129 new hepatitis C diagnoses made during 2010:<sup>51</sup>

- 23% were aged 20-29 years, 41% aged 30-39 years, 24% aged 40-49 years and 11% were aged 50 years and above, at the time of diagnosis.
- 69% were male.
- 48% reported injecting drug use, representing 92% of those with a known risk factor.
- 440 (21%) were known to have been diagnosed in specialist drug services, where DBS testing for hepatitis C was introduced in 2009. This figure compares with 12 and 191 for 2008 and 2009, respectively.
- 362 (17%) were known to have been diagnosed by GPs in 2010. This figure compares with 421 and 415 for 2008 and 2009, respectively. Thus, no increase in the number of new diagnoses by GPs was observed in 2010, despite the launch of professional and public awareness raising campaigns during early 2010 (see [www.hepcscotland.co.uk](http://www.hepcscotland.co.uk) for further details on these campaigns).

A total of 29,312 people had been diagnosed with hepatitis C in Scotland by the end of 2010 (Figure 27).<sup>51</sup> Of these, 14% were known to have died by 30 June 2010. Thus, approximately 0.7% of Scotland's population aged 15-59 years had been diagnosed hepatitis C antibody positive by the end of 2010.

Among 3,099 IDUs interviewed at services providing injection equipment in Scotland during 2010, 77% reported having been tested for hepatitis C in the past, while 38% reported a test in the last year. When those who were diagnosed positive 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 48%; this figure compares to 43% reported by IDUs similarly surveyed during June 2008 to June 2009.

Among 1,723 IDUs who were hepatitis C antibody positive, and were interviewed at services providing injection equipment in Scotland during 2010, 44% reported that they had been diagnosed hepatitis C positive and a further 12% reported having cleared the virus.

In 2009, an estimated 39,000 people living in Scotland were chronically infected with hepatitis C; of these, 16,500 (42%) were estimated to have been diagnosed with hepatitis C by the end of 2009, and 22,500 (58%) were estimated to remain undiagnosed. Data for 2010 (for example, on the number of IDUs with newly acquired hepatitis C infection) are being collated to update our estimate of the number of people living in Scotland with chronic infection; however, if it is assumed that this number has remained stable at 39,000, then the proportion estimated to have been diagnosed with hepatitis C by the end of 2010 will have increased to 45%.

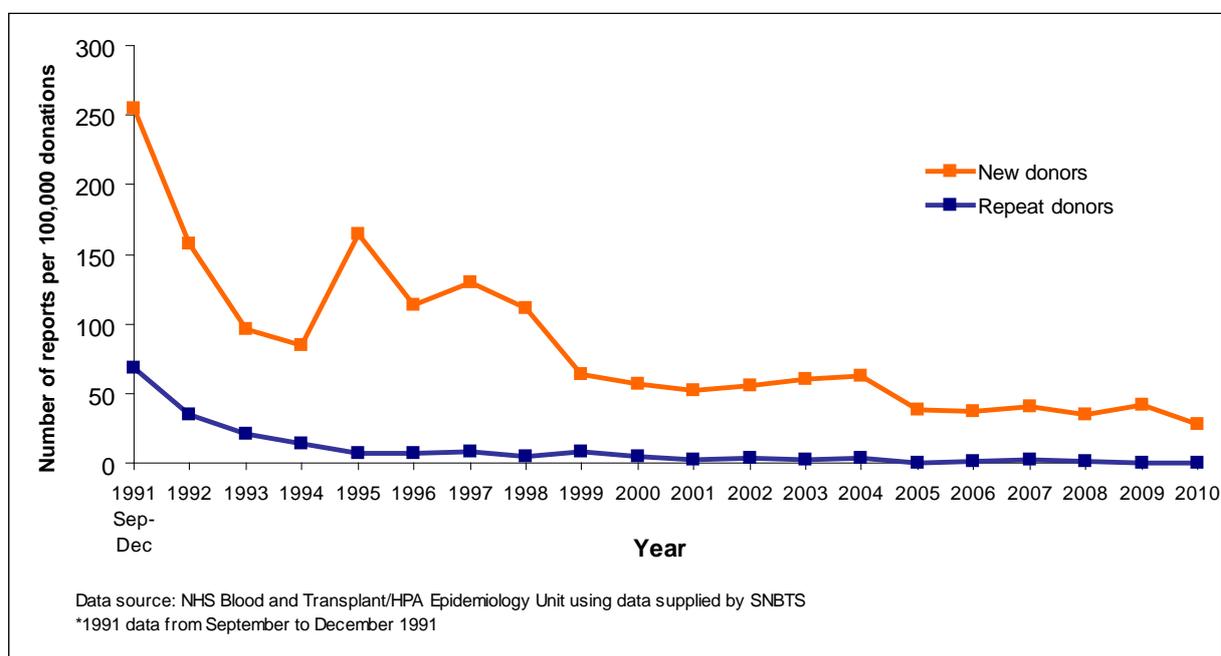
### 3.1.2 Blood donor testing

The SNBTS collects blood from voluntary donors who are selected to be at low risk of BBV infection, such as hepatitis C, in the same way as other UK blood services.

#### *Hepatitis C in new donors*

The detection of hepatitis C among people wishing to donate blood for the first time (new donors) in Scotland has declined since 1991 (Figure 28), although the frequency was higher than in other UK countries in all years except 2010. In 2010, seven new donors tested positive for hepatitis C, which approximates to 28.1 per 100,000 donations tested.

**Figure 28: Detection of hepatitis C among new and repeat blood donors in Scotland: 1991\*-2010**



#### *Hepatitis C in repeat donors*

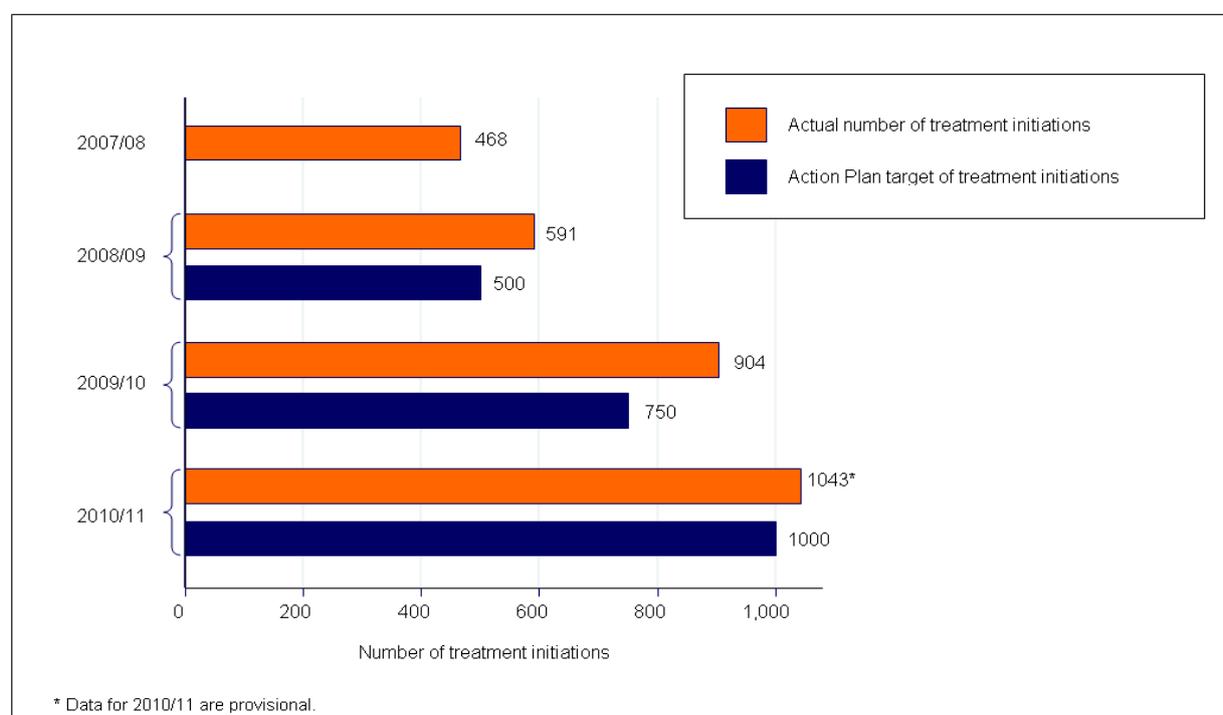
Since 1991, when blood donation testing for hepatitis C was first introduced, fewer hepatitis C infections have been detected in donations from repeat donors than in those from first time donors. The detection of hepatitis C infection among repeat donors has reduced from 68.3 to 0.4 per 100,000 donations between 1991 and 2010 (Figure 28). In 2010, one repeat donor was found to be positive for hepatitis C.

### 3.1.3 Treatment of hepatitis C infection

The number of chronically infected people initiated on hepatitis C antiviral therapy in Scotland increased from 468 in the financial year 2007/08 to 591 in 2008/09, 904 in 2009/10 and a provisional total of 1,043 in 2010/11 (Figure 29). The numbers initiated on antiviral therapy are in excess of the Hepatitis C Action Plan targets of 500 in 2008/09, 750 in 2009/10 and 1,000 in 2010/11.

The number of chronically infected people initiated on hepatitis C antiviral therapy within the prison setting in Scotland increased from 17 in 2007/08 (representing 4% of treatment initiations in that year) to 37 in 2008/09 (representing 6%) and 112 in 2009/10 (representing 12%).

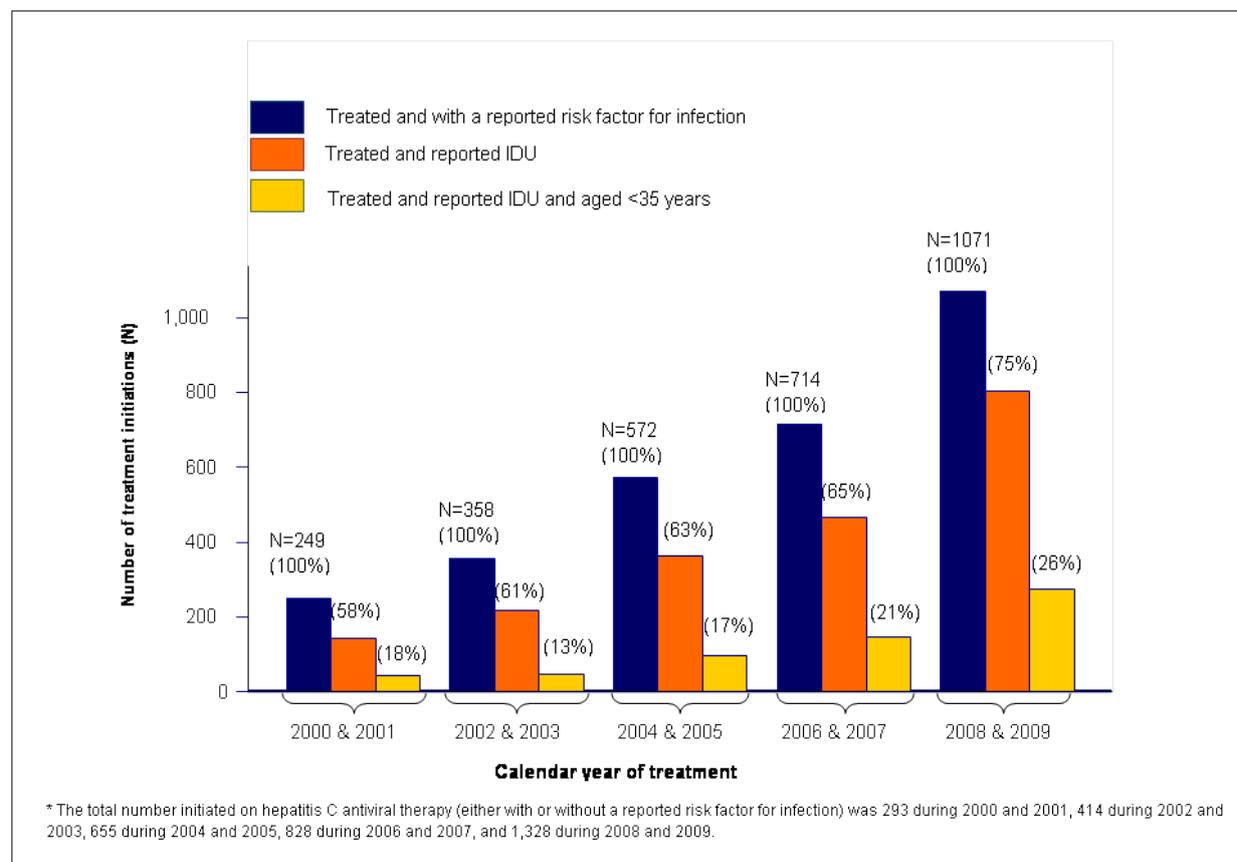
**Figure 29: The actual number, and the Scottish Government's Hepatitis C Action Plan target, of chronically infected people initiated on hepatitis C antiviral therapy in Scotland for each financial year: 2007/08-2010/11\* (data from hepatitis C treatment centres in Scotland)**



Among patients (with either genotype 1, 2 or 3) initiated on pegylated interferon and ribavirin across nine clinics in Scotland during 2000-2007, 58% were known to have achieved a sustained viral response (SVR); this rate ranged from 39% among those with genotype 1 to 70% among those with genotypes 2 or 3.

Among people initiated on hepatitis C antiviral therapy in sixteen 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 2000 and 2001 to 803 (75%) in 2008 and 2009 (Figure 30).

**Figure 30: The number of chronically infected people initiated on hepatitis C antiviral therapy (i.e. interferon) in Scotland with a reported risk factor for hepatitis C infection, by calendar year of treatment initiation and according to whether ever having injected drugs and whether aged less than 35 years at time of treatment initiation (Data from 16/18 hepatitis C treatment centres)\***



Modelling work has highlighted that modest rates of hepatitis C treatment among active IDUs could effectively reduce transmission in this population, despite the possibility of re-infection.<sup>8</sup>

### 3.2 Prevention

One of the aims of the action plan was to reduce the number of people becoming infected with hepatitis C. Recognising that opiate substitution therapy services are well developed in Scotland, the phase II actions were confined to the prevention of hepatitis C among IDUs through, in the main, the provision of injection equipment. This is because: (i) the great majority of hepatitis C infections occur as a consequence of drug injecting practices and, (ii) this intervention type, unlike, for example, methadone maintenance, was and is designed principally to prevent the transmission of BBVs among IDUs.

National guidelines for the provision of injection equipment in Scotland have been developed and approved by the Lord Advocate.<sup>53</sup> In accordance with these guidelines, services throughout Scotland are being expanded to reduce the inequality of provision and to create a new culture whereby, if someone is going to inject drugs, he or she does so using sterile equipment (needle/syringe and other paraphernalia – spoon, filter and water) on each occasion.

The following sub-sections present data on: (i) the IDU population, (ii) the provision of injection equipment to IDUs, (iii) the sharing of injection equipment by IDUs, and (iv), the prevalence

and incidence of hepatitis C among IDUs. These data were obtained through capture-recapture analysis of IDU-relevant health and criminal justice data in Scotland;<sup>54, 55</sup> a questionnaire survey of injecting equipment providers across Scotland;<sup>56, 57, 58</sup> data from IDUs attending drug treatment services in Scotland; an unlinked anonymous hepatitis C testing survey of IDUs across four large NHS Boards in Scotland;<sup>59</sup> and a serological and questionnaire survey of IDUs attending services providing injecting equipment in Scotland.<sup>52</sup>

### 3.2.1 Injecting drug user population

The estimated number of current IDUs in mainland Scotland during 2006 was 23,900 (95% CI: 21,600 – 27,200),<sup>54</sup> representing 0.7% of the Scottish population aged 15-64 years. This compares to an estimated 18,700 current IDUs (95% CI: 17,700 – 20,300) in mainland Scotland during 2003.<sup>55</sup> Data for 2009/10 are currently being collated and analysed by the Information Services Division (ISD) to generate an updated estimate of the number of current IDUs in Scotland by NHS Board area.

### 3.2.2 Provision of injection equipment to injecting drug users

In 2008/09, 240 injection equipment provider outlets, of which 192 (80%) were pharmacy based, were reported to be operating in Scotland.<sup>58</sup> These figures compare to 188 (including 136 pharmacy based) and 210 (including 169 pharmacy based) injection equipment provider outlets reported to be operating in Scotland during 2004/05 and 2007/08, respectively.<sup>56, 57</sup>

At least 4.4 million needles/syringes were distributed to IDUs in Scotland during 2008/09, based on data reported by 93% (222/240) of injection equipment provider outlets. This is higher than the 3.6 million needles/syringes reported to have been distributed to IDUs in Scotland during 2004/05, but comparable to the 4.4 million needles/syringes reported to have been distributed in 2007/08 (Table 11). Data reported for the first six months (April to September) of 2009/10 indicate that the number of needles/syringes distributed to IDUs in Scotland per year remains stable.

**Table 11: 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*	N-fold increase from 2008/09 to 2009/10
Needles/syringes	3,554,000	4,438,000	4,381,000	4,320,000	1.0
Filters	NA	NA	356,000	1,447,000	4.1
Spoons/Cookers	NA	NA	509,000	1,435,000	2.8
Water	NA	NA	62,000	74,000	1.2
*Data for the six-month period of April to September 2009 have been multiplied by two to generate an estimate for the year 2009/10.					
NA - Data not available					

The estimated number of needles/syringes distributed to each IDU in Scotland during 2008/09 was approximately 180, and ranged from 130 to 360 across NHS Boards.<sup>58</sup> The shortfall in sets of needles/syringes that need to be distributed to IDUs in Scotland, if the number of such sets is to correspond with the number of injecting events (estimated at on average 500 per year), is estimated to be approximately seven to eight million per year.

Provisional data (based on the first six months of 2009/10) indicate that a several fold increase in the number of injecting paraphernalia items distributed to IDUs occurred between 2008/09 and 2009/10, with an estimated four-fold increase in filters and three-fold increase in spoons/cookers (Table 11).

Data on injecting equipment provision for the full financial year 2009/10 are currently being collated and analysed by ISD.

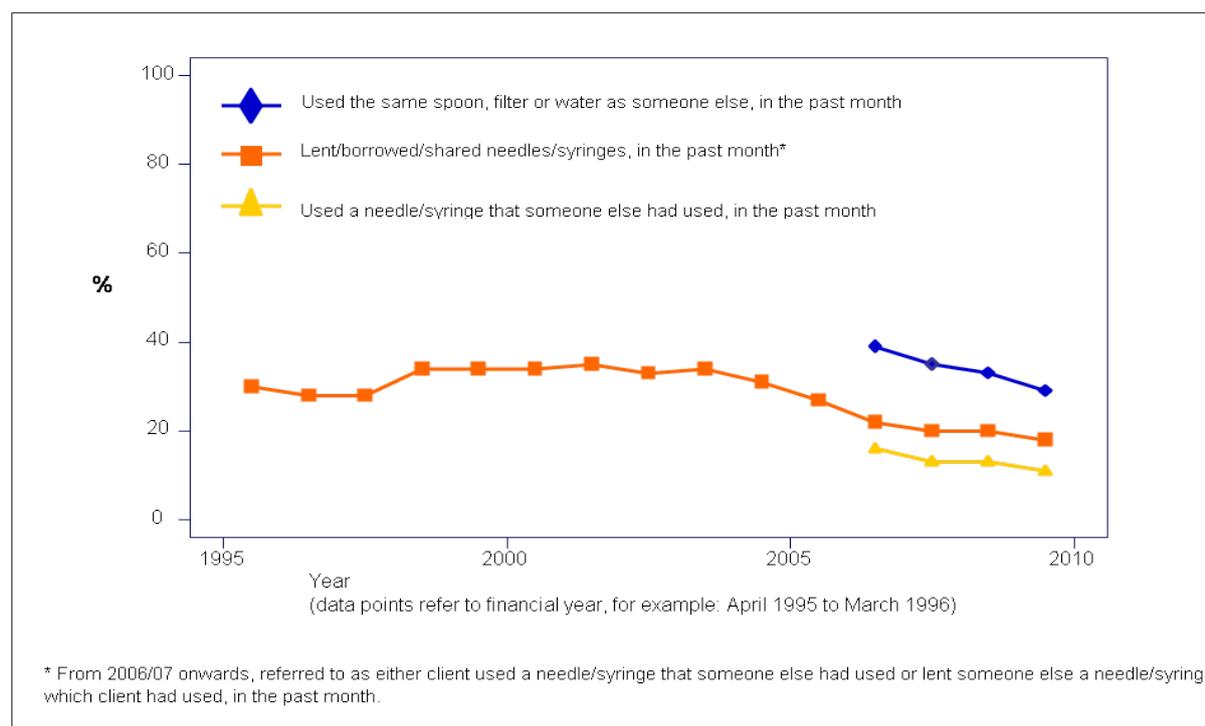
### 3.2.3 The sharing of injection equipment by injecting drug users

Information on the sharing of injection equipment was available from two national data sources on IDUs attending services providing: (i) drug treatment, from the Scottish Drugs Misuse Database; and (ii) injection equipment, from the Needle Exchange Surveillance Initiative.

#### ***Injecting drug users attending services providing drug treatment***

Among individuals attending drug treatment services in Scotland 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 (Figure 31); further, a decline in only borrowing used needles/syringes in the past month was observed from 16% in 2006/07 to 11% in 2009/10.

**Figure 31: 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. (Data source: ISD Scotland)**



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 29% in 2009/10 (Figure 31).

***Injecting drug users attending services providing injection equipment***

Of 2,407 current IDUs interviewed at services providing injection equipment in Scotland during 2010, 11% reported having recently (last six months) injected with a needle/syringe previously used by someone else; this compares to 15% among current IDUs similarly surveyed during June 2008 to June 2009.

Of 2,407 current IDUs interviewed at services providing injection equipment in Scotland during 2010, 39% reported having recently (last six months) used other injecting paraphernalia (either filters, spoons or water) that had previously been used by someone else (with 33% having indicated spoons, 27% indicated filters, and 29% indicated water). These figures are lower than that reported among current IDUs surveyed during June 2008 to June 2009, where 48% had recently (last six months) used other injecting paraphernalia that had previously been used by someone else (with 42% having indicated spoons, 33% indicated filters, and 31% indicated water).

**3.2.4 Prevalence and incidence of hepatitis C among injecting drug users**

Information on the prevalence of hepatitis C infection was available from two data sources, on IDUs who have: (i) had a named HIV test, from an unlinked anonymous testing survey; and (ii) attended services providing injection equipment, from the Needle Exchange Surveillance Initiative.

***Injecting drug users who have had a named HIV test***

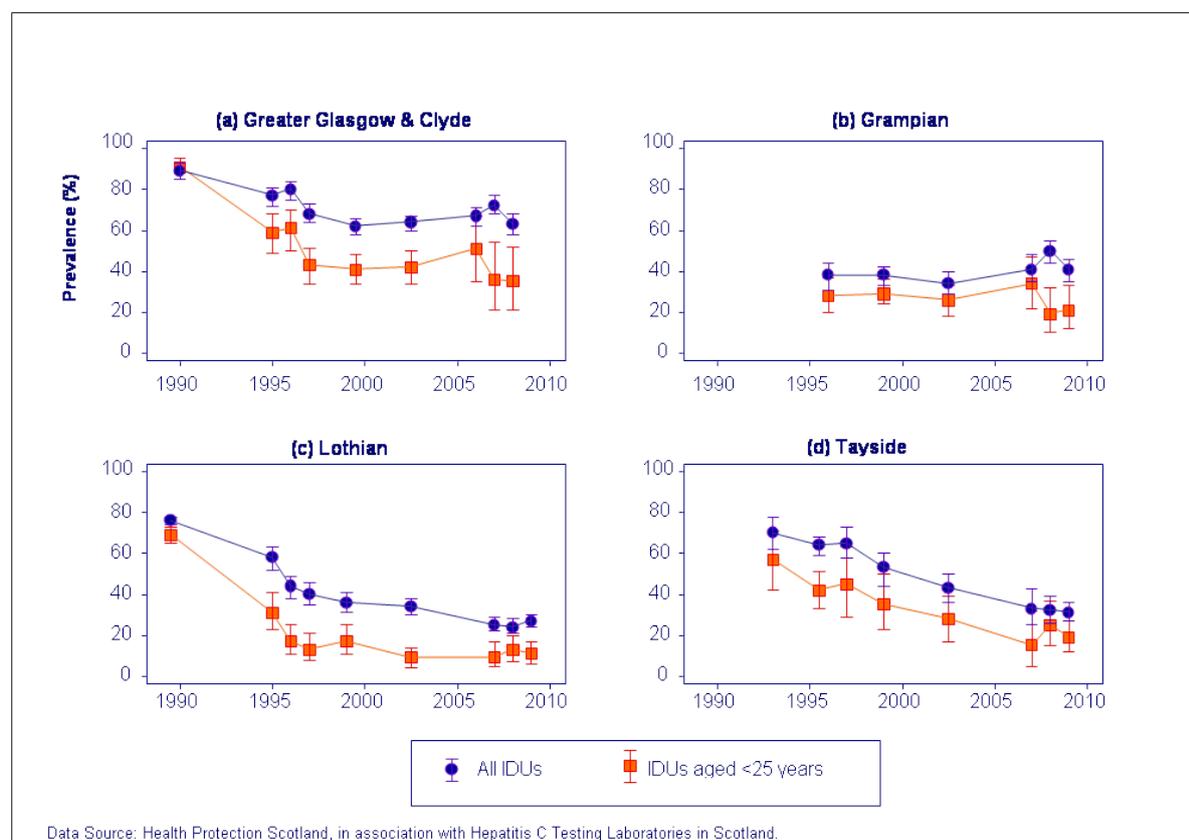
To monitor trends in hepatitis C prevalence among IDUs over time, residual sera from specimens provided by IDUs for a named HIV test were anonymously tested for hepatitis C antibodies.<sup>59</sup>

This survey revealed significant reductions in hepatitis C prevalence among IDUs from three large NHS Boards (Greater Glasgow and Clyde, Lothian and Tayside) between the early and late 1990s, suggesting that there had been a decrease in hepatitis C incidence during this time (Figure 32).<sup>59</sup>

Since then, further significant reductions in the prevalence of hepatitis C were observed among IDUs in Lothian (from 36% in 1999 to 27% in 2009;  $p < 0.0001$ ) and Tayside (from 53% in 1999 to 31% in 2009;  $p < 0.0001$ ), but no further reductions were observed among IDUs in Greater Glasgow and Clyde (from 62% in 1999/2000 to 63% in 2008) and Grampian (from 38% in 1999 to 41% in 2009).

A further significant reduction in the prevalence of hepatitis C was also observed among IDUs aged under 25 years in Tayside (from 35% in 1999 to 19% in 2009;  $p = 0.01$ ), and reductions in prevalence were also observed (although not statistically significant at the 5% level) among IDUs aged under 25 years in Greater Glasgow and Clyde (from 41% in 1999/2000 to 35% in 2008), Grampian (from 29% in 1999 to 21% in 2009), and Lothian (from 17% in 1999 to 11% in 2009).

**Figure 32: Prevalence of hepatitis C antibodies (% and 95% confidence intervals indicated by vertical bars) among IDUs in four large NHS Board areas in Scotland, by age and year. (Data from unlinked anonymous testing of specimens taken for named HIV testing)**



### ***Injecting drug users attending services providing injection equipment***

Among current and former IDUs interviewed at services providing injection equipment across mainland Scotland during 2008-2009 and 2010, similar proportions tested positive for hepatitis C antibodies (in anonymous testing of their DBS samples) between the two surveys:

- 55% among all 2,516 IDUs surveyed in 2008-2009 and 57% among all 3,029 IDUs surveyed in 2010;
- 32% among 660 IDUs surveyed in 2008-2009 and 33% among 901 IDUs surveyed in 2010, and who had both commenced injecting in the previous five years; and
- 24% among 401 IDUs surveyed in 2008-2009 and 25% among 471 IDUs surveyed in 2010, and who had both commenced injecting in the previous three years.

In the very early stages of hepatitis C infection, individuals have high levels of viraemia prior to developing antibodies (seroconverting); this is often referred to as the viraemic pre-seroconversion window. During this relatively short period, individuals will test hepatitis C antibody negative and RNA positive. Among 1,115 hepatitis C antibody negative IDUs surveyed during 2008-2009, 21 were found to be RNA positive on DBS testing. Assuming a viraemic pre-seroconversion window period of 51 days, the incidence of hepatitis C infection among IDUs across Scotland was estimated at 12 per 100 person years during 2008-2009. Further laboratory testing of DBS samples from IDUs surveyed during 2010 is underway to generate an estimate of the incidence of hepatitis C infection in this most recent survey.

Analysis of pooled data from across the UK, involving almost 1,000 IDUs surveyed in Greater Glasgow and Clyde NHS Board during 2008-2009, demonstrated that both the uptake of

opiate substitution therapy and high levels of needle/syringe provision (i.e. a sterile needle/syringe for each injection) can achieve substantial reductions in the risk of hepatitis C transmission among IDUs.<sup>60</sup>

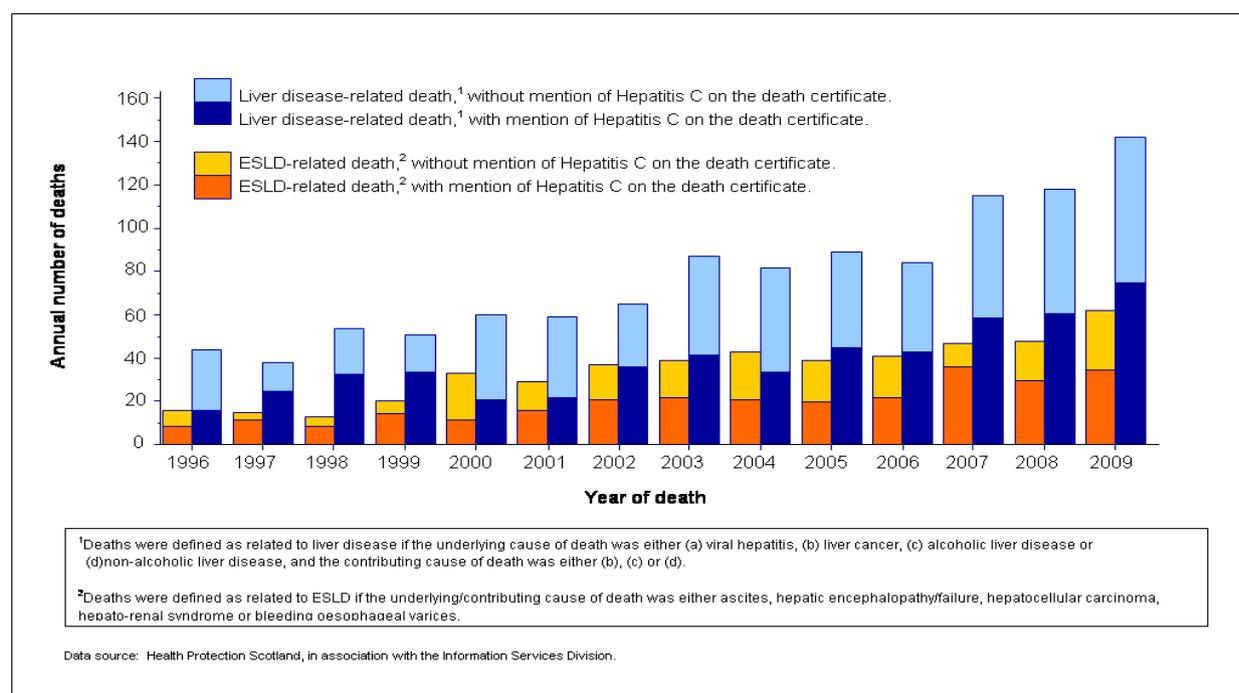
### 3.3 Disease trends

The ultimate aim of the action plan is to reduce the numbers of people who develop severe hepatitis C-related liver disease through improving prevention, diagnosis, treatment, care and support services. The following sub-sections present data on: (i) deaths from hepatitis C-related liver disease to the end of 2009, (ii) hospitalisations from hepatitis C-related liver disease to the end of 2009, and (iii) liver transplants related to hepatitis C to the end of 2010. The data on deaths and hospitalisations were obtained through record-linkage of Scotland's National Hepatitis C Diagnoses Database (on all people who have been diagnosed hepatitis C antibody and/or PCR positive in Scotland) to other national databases on deaths and hospital admissions, as described elsewhere.<sup>61, 62</sup>

#### 3.3.1 Deaths from hepatitis C-related liver disease

Liver-related deaths (defined as either: viral hepatitis, liver cancer, alcoholic liver disease or non-alcoholic liver disease) among people diagnosed with hepatitis C increased from 44 in 1996 to 142 in 2009 (Figure 33), at an average annual rate of 9.6% (95% CI: 8.0–11.4%).

**Figure 33: Annual number of deaths related to: (i) liver disease<sup>1</sup> and (ii) ESLD<sup>2</sup> among persons diagnosed with Hepatitis C in Scotland: 1996-2009**



Of the total 1,088 liver-related deaths during 1996-2009 among people diagnosed with hepatitis C, only 532 (49%) had hepatitis C mentioned on the death certificate.

Among the 142 liver-related deaths in 2009:

- 111 (78%) had liver disease as the underlying cause of death (alcoholic liver disease was the most prevalent underlying cause in 50) and 31 (22%) had liver disease only as a contributing cause of death.

- 114 (80%) were male, and 85 (60%) were aged less than 50 years.

ESLD-related deaths (defined as either ascites, hepatic encephalopathy/failure, hepato-renal syndrome, HCC or bleeding oesophageal varices) among people diagnosed with hepatitis C increased from 16 in 1996 to 62 in 2009 (Figure 33), at an average annual rate of 10.3% (95% CI: 7.8–12.9%).

Of the total 482 ESLD-related deaths during 1996-2009 among people diagnosed with hepatitis C, only 266 (55%) had hepatitis C mentioned on the death certificate.

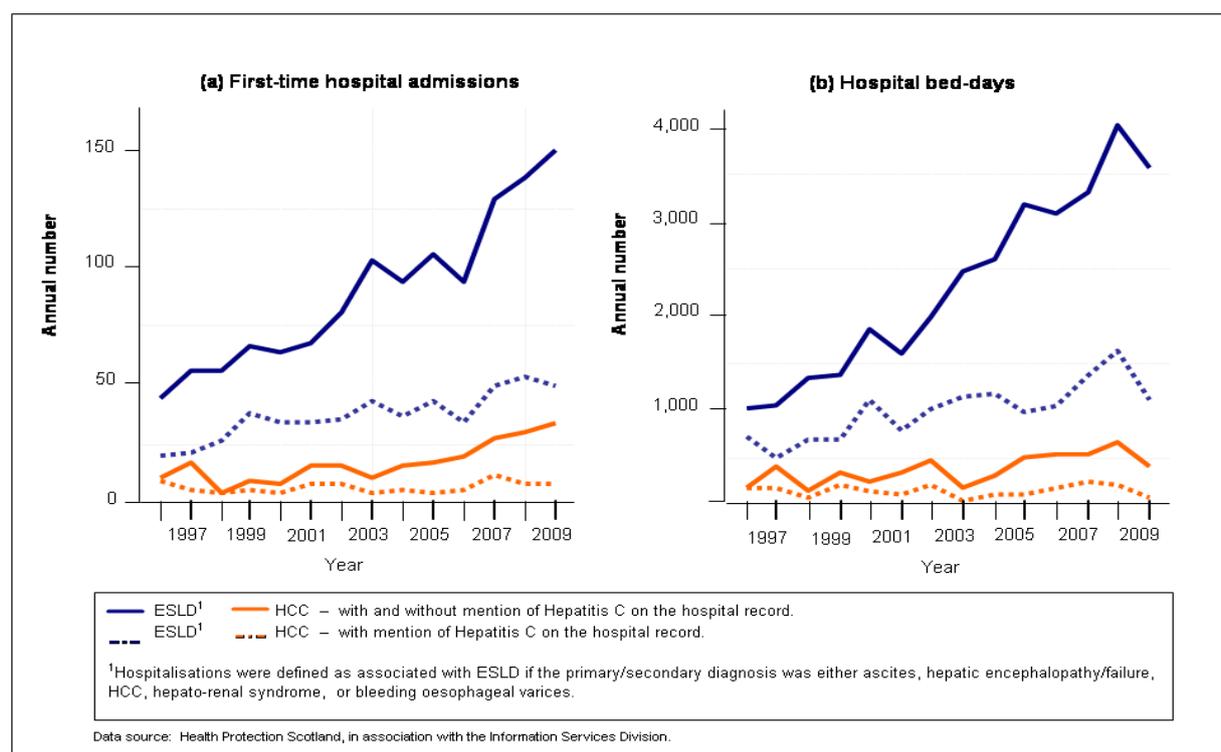
### 3.3.2 Hospitalisations from hepatitis C-related liver disease

Data on hospitalisations were obtained via record-linkage of Scotland's National Hepatitis C Diagnoses Database to national databases on hospital admissions.

#### **End-stage liver disease**

First-time hospital admissions with ESLD (as defined in 3.3.1) among people diagnosed with hepatitis C increased from 44 in 1996 to 150 in 2009 (Figure 34a), at an average annual rate of 9.2% (95% CI: 7.6–10.8%).

**Figure 34: Annual number of: (a) first-time hospital admissions and (b) hospital bed-days associated with ESLD<sup>1</sup> and HCC among persons diagnosed with hepatitis C in Scotland: 1996-2009**



Of the total 1,242 first-time hospital admissions for ESLD during 1996-2009 among people diagnosed with hepatitis C, only 509 (41%) had hepatitis C mentioned on the hospital record. Among the 150 first-time hospital admissions for ESLD in 2009, 106 (71%) were male, and 92 (61%) were aged less than 50 years.

Hospital bed-days with ESLD among people diagnosed with hepatitis C increased from 995 in 1996 to 3,581 in 2009 (Figure 34b), at an average annual rate of 11% (95% CI: 10.7–11.4%).

### ***Hepatocellular carcinoma***

First-time hospital admissions with HCC among people diagnosed with hepatitis C increased from 10 in 1996 to 33 in 2009 (Figure 34a), at an average annual rate of 11.2% (95% CI: 7.5–15.1).

Of the total 227 first-time hospital admissions during 1996-2009 for HCC among people diagnosed with hepatitis C, only 85 (37%) had hepatitis C mentioned on the hospital record.

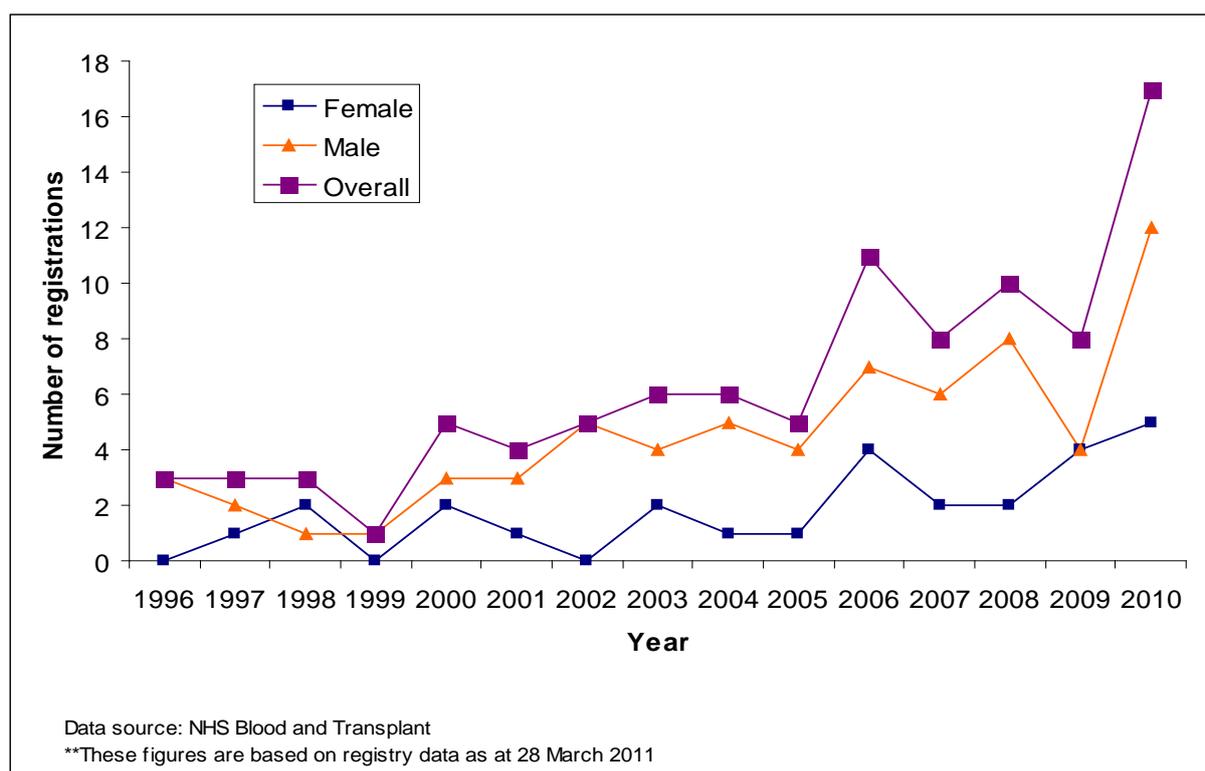
Among the 33 first-time hospital admissions for HCC in 2009, 22 (67%) were male, and five (15%) were aged less than 50 years.

Hospital bed-days with HCC among people diagnosed with hepatitis C increased from 176 in 1996 to 398 in 2009 (Figure 34b), at an average annual rate of 7.3% (95% CI: 6.5–8.0%).

### **3.3.3 Liver transplants**

In Scotland, the overall number of liver transplant first registrations with a code of post-hepatitis C cirrhosis has increased from three in 1996 to 17 in 2010 (Figure 35).

**Figure 35: First registrations\* for a liver transplant with a code of post-hepatitis C cirrhosis in Scotland: 1996 - 2010\*\***



\*New universal registration criteria for selecting adult patients for elective liver transplantation were introduced in September 2007<sup>35</sup>

The number of first liver transplants in patients with post-hepatitis C cirrhosis and HCV-related HCC has fluctuated between 1996 and 2010 (Table 12).

**Table 12: Indications for liver transplants undertaken in HCV infected individuals in Scotland: 1996 – 2010\***

Year	All Liver Transplants	First liver transplants with post hepatitis C cirrhosis at registration and HCV positive at registration or transplant (per cent of all liver transplants)			
		Total	Post-hep C Cirrhosis	Hepatocellular carcinoma	Other Indication
1996	44	4 (9%)	4 (9%)	0 (0%)	0 (0%)
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%)
<b>TOTALS</b>	<b>890</b>	<b>109 (12%)</b>	<b>61 (7%)</b>	<b>38 (4%)</b>	<b>10 (1%)</b>
<b>*These figures are based on registry data as at 28 March 2011</b>					
<b>Data Source: NHS Blood and Transplant</b>					

### 3.4 Summary

Three years have elapsed since the launch of Scotland's Hepatitis C Action Plan Phase II and a considerable amount of data, permitting the early evaluation of the plan's impact, are now available. From a diagnostic perspective, 2010 saw the highest number of annual diagnoses ever made and provisional estimates indicate that just under half of all persons in Scotland living with chronic HCV have now been diagnosed. There is no question that awareness of hepatitis C among professionals as a consequence of a wide range of action plan initiatives, including the establishment of numerous local and national networks, is likely to have played a major role in the promotion of HCV testing and thus diagnosis. However, the introduction of DBS testing in the specialist drug service setting, arguably, has had the greatest impact on the diagnosis effort. A dramatic increase from 12 diagnoses in 2008 to 440 in 2010 is highly indicative of the acceptability of this approach which has been limited to a few Health Boards in Scotland to date. Accordingly, there is strong evidence that a real breakthrough has been made in getting people who have injected drugs to be tested for hepatitis C.

From a treatment perspective, much has been achieved in developing clinical services throughout the country. It is highly satisfying that over the three years of Phase II, the annual number of initiates onto antiviral therapy has increased by over 100% to 1,043 in 2010/11. Of critical importance is the observation that, for the great majority of this

group, injecting drug use was the principal risk factor for HCV transmission. While work is being undertaken to further understand the characteristics of such individuals in terms of current/past injecting drug use, it is evident that having a history of injecting drug use, per se, is no barrier to receiving, and indeed fully benefitting from, combination therapy.

It will be some time before the full impact of increasing numbers of individuals being treated will be reflected by HCV disease progression rates but data linkage work involving Scotland's Hepatitis C Diagnosis Database and Morbidity and Mortality Registers clearly indicate the extent of the challenge; between 1996 and 2009, an average annual increase of around 10% has been observed for nearly all HCV disease progression, including ESLD and mortality, indicators.

A considerable investment has been made to improve access to, and uptake of, injection equipment among people who inject drugs and, in many respects, a natural experiment is taking place. One of the principal recommendations of the Guidelines for the Provision of Injection Equipment, published in 2010,<sup>53</sup> is that injection equipment paraphernalia (spoons, filters etc) should be made available to all individuals who inject drugs. Between 2008/09 and 2009/10, a several-fold increase in the number of sets of such paraphernalia given to people who inject drugs was observed. During this period, other indicators of harm reduction activity, including the provision of needles and syringes and opiate substitution therapy uptake, remained relatively static. With surveys of HCV among people who inject drugs being undertaken pre and post introduction of the paraphernalia intervention - in the context of other factors being stable - it will be possible to evaluate the impact of this specific intervention in terms of HCV incidence (the baseline estimate for 2008/2009 was 12 infections per 100 person years), measured through PCR RNA testing of antibody negative DBS. It is anticipated that an additional approach involving avidity testing of HCV antibody positive specimens will further enhance our understanding of the incidence of HCV among IDUs.

Although it is too early to say what impact the prevention investment will make, it is encouraging that behavioural data are indicating a downward trend in the sharing of injection equipment. Nevertheless, we need to be cautious when interpreting these data as behavioural trends have not always been consistent with HCV incidence/prevalence ones.

It is evident that a considerable amount of progress has been made in improving prevention, diagnosis and treatment services for people at risk of acquiring, and those affected by, hepatitis C in Scotland. Much of the infrastructure, including networks and governance arrangements, to ensure that hepatitis C is managed as a mainstream condition both within and outwith NHS settings, has been embedded. The Scottish Government has maintained funding for hepatitis C during 2011/12 within the context of a national BBV and Sexual Health Framework. The framework recognises the strategic links that exist across sexual health and BBV service sectors in Scotland and the benefits that further integration can afford where appropriate. Such an approach will provide resilience at a time of increasing financial pressure as a consequence of, for example, the likely availability of protease inhibitors for the treatment of HCV infected individuals with genotype 1 virus infection.

While the Scottish Government should be applauded for its investment in the hepatitis C cause, the role of hundreds of key stakeholders working in a wide range of spheres, in making things happen, should be acknowledged. The NGO sector has been particularly influential in the establishment and implementation of the plan and, in this respect, organisations such as The Hepatitis C Trust (which established an office in Scotland in 2010), Scottish Drugs Forum (which established a new initiative – Hepatitis Scotland – in 2011) and Addaction deserve a special mention.

## 4. Wales

The Blood Borne Viral Hepatitis Action Plan for Wales 2010 – 2015<sup>63</sup> was approved by the Welsh Assembly Government and implementation began in April 2010. The action plan sets out the programme for hepatitis B and hepatitis C in Wales. This action plan provides a clear, costed and time-defined framework for the planning and delivery of key services in Wales that:

- Reduce the transmission of blood-borne viral hepatitis infection in Wales
- Reduce the pool of undiagnosed infection
- Improve the provision of treatment and support to infected individuals
- Monitor and evaluate treatment and prevention programmes

To support the implementation of the action plan a series of specialist subgroups have been established:

- Prevention, education and awareness raising
- Diagnostics and surveillance
- Treatment and care pathways

These multidisciplinary subgroups report to the Welsh Government (formerly the Welsh Assembly Government) Blood Borne Viral Hepatitis Programme Board.

In this first year of implementation a number of actions have already been achieved and the building blocks for many more have been put in place.

### 4.1 Prevention, education and awareness raising – achievements and next steps

#### 4.1.1 The Harm Reduction Database

The Harm Reduction Database (HRD) database was established to provide a national data collection system for NSP, supervised consumption of opiate substitution treatment and naloxone provision. The system was implemented in all statutory and voluntary NSP services across Wales from 1 September 2010. The system enables analysis of demographic data along with data on the type of substances used, risk behaviour, BBV status and testing.

As of the end of March 2011 just over 8,000 individual IDUs were registered on this database. Data quality and reporting completeness remain key areas for improvement over the next year. However, initial analysis suggests that self-knowledge of HCV antibody status is poor (36% of 1,786 respondents reported no knowledge of their status) and only 7% of respondents self-reported as anti-HCV positive. HBV vaccine coverage is incomplete; of the total number of individuals registered, data for hepatitis B vaccination is available for 40% (n=3,202), of these 71% of respondents reported having completed a course.

#### 4.1.2 Train the trainer course on blood-borne viruses

Public Health Wales, in conjunction with the Prevention, Education and Awareness Raising subgroup, has developed and implemented a Level 1 'Training the Trainer' course on BBVs. To date 87 trainers have been trained to deliver this course across a range of organisations, including health care, criminal justice, local authority, education, social services, prisons and

housing/homelessness. Level 2 training, including more detailed information on patient management, is under development and is planned for roll out later in 2011. The Level 2 training will utilise the NHS e-learning portal. Both training packages will be assessed annually to ensure their content remains up to date.

#### **4.1.3 Education and awareness raising in prisons**

Education and awareness raising in the prisons in Wales is also moving forward. Each prison has nominated key nurses to take the lead on BBV clinical care for their prison to provide a clear link and support for the community nurse specialists treating patients within the prisons. A training package covering all aspects of BBV care has been developed for these staff and these key nurses have been prioritised to undergo this training. Subsequently this training will be provided to other healthcare staff in the prisons.

A general BBV education programme for all prison staff is planned. A 'task and finish' group chaired by a prison governor has been established to take this forward. In addition, an online BBV training package is planned for roll out in April 2012.

Prison 'listeners' (inmates trained by the Samaritans to listen to other inmates)<sup>64</sup> are undergoing BBV awareness sessions to prepare them for supporting those who may be concerned about BBVs and, where necessary, to direct prisoners to clinical staff for testing or further support.

An awareness raising campaign is being developed to promote '*liver health*' within prisons. The main component of this will target BBVs. Once launched, every prisoner entering the Welsh estate will be given information on liver health and offered BBV testing. Work is ongoing to bring together appropriate materials tailored to the needs of differing target groups.

#### **4.1.4 Research into effective health messages for those at high risk of blood-borne viruses**

Public Health Wales, working collaboratively with academic units in Wales, is progressing research to identify effective health messages for a range of groups at high risk of BBVs. The findings of this work will help inform the development of effective targeted awareness campaigns planned for roll out in 2012.

## **4.2 Diagnosis and surveillance – achievements and next steps**

### **4.2.1 Dried blood spot testing**

In October 2010, Public Health Wales introduced dried blood spot (DBS) testing for anti-HCV, anti-HBV core, HBV surface antigen and HIV, primarily in NHS substance misuse services. An education programme to support the use of this testing was introduced at the same time.

To date, the uptake of DBS testing has varied across the country. In the first six months of rollout, 348 DBS samples were received from 341 individuals. HCV antibody was detected in 26% (90/341) of the individuals tested. PCR testing of follow-up plasma samples on 26% (23/90) of those with anti-HCV detected revealed that 78% (18/23) were RNA positive and therefore had ongoing infection.

DBS testing, along with an education and training package, is currently being rolled out to the prisons on a month-by-month basis as part of a research trial to evaluate this intervention. This trial commenced in April 2011 and it is anticipated that all prisons in Wales will have enrolled by August 2011.

Key areas for future work include improving follow-up sampling and validation work to determine the sensitivity and specificity of PCR from DBS compared to venepuncture.

#### **4.2.2 A voluntary unlinked enhanced surveillance form**

A voluntary unlinked enhanced surveillance form was introduced as part of the DBS testing scheme in substance misuse services in Wales. This collects results of DBS testing along with a limited set of behavioural data. During the first six months, 223 forms were returned from these services. Initial analysis indicates an anti-HCV prevalence of 31% (66/214). Eleven per cent of respondents (22/207) reported injecting for two years or less; of these 18% (4/22) were anti-HCV positive.

As this dataset increases it should help us to better understand the epidemiology of HCV infection in Wales and allow an exploration of factors associated with infection within this cohort. Data quality and reporting are key areas for improvement in the next year.

#### **4.2.3 Development of information systems to monitor hepatitis C virus and other infections**

Work to better understand previous and current testing and diagnosis of active HCV infection from existing laboratory systems is nearing completion. In addition, a scoping exercise is underway to determine the feasibility of using data held in all the current laboratory systems to establish a dataset of all HCV testing and results.

An all-Wales laboratory information management system is planned for implementation over the next few years and a new infectious disease surveillance system is currently being developed. Work is ongoing to ensure that these new systems meet the needs of blood-borne viral hepatitis surveillance.

A blood-borne viral hepatitis database for Wales is planned for development to collate information on diagnosis, genotype, care pathway, effectiveness of treatment and risk factors for people with blood-borne viral hepatitis. This database is intended to complement existing surveillance schemes, improve our knowledge of the epidemiology of infection in Wales, support health service planners in the design of future services and also support the evaluation of the impact of the action plan. Its main objectives will be:

- To determine the total number of persons diagnosed with blood-borne viral hepatitis infection in Wales.
- To monitor trends in diagnosed blood-borne viral hepatitis infection in Wales (by year, NHS board, age, gender, risk group and referral source).
- To estimate the proportion of people with diagnosed blood-borne viral hepatitis infection who are in receipt of specialist blood-borne viral services (referrals, attendances, anti-viral treatment).
- To provide data on the outcome of treatment for blood-borne viral hepatitis infection.
- To estimate the number of people with blood-borne viral hepatitis infection who will progress to severe disease including liver failure and cancer.

A 'task and finish' group has been established to examine the current systems in place for collection of clinical information and to consider the options, make recommendations for improvements to these systems, and facilitate clinical data collection for input into the proposed blood-borne viral hepatitis database.

Detailed indicators to support the evaluation of the action plan have been agreed. It is anticipated that, in time, the planned blood-borne viral hepatitis database will provide the information required to facilitate this.

### **4.3 Treatment and Care – achievements and next steps**

All the Health Boards with treatment centres have submitted their local delivery plans to the Welsh Government. These outline how the Health Boards intend to implement the action plan locally and utilise their additional funding.

All the Health Boards with treatment centres have designated a clinical lead to provide the critical local clinical leadership.

The Welsh Government has released funding to the Health Boards and several new appointments have already been made to take this work forward at the frontline. However, not all Health Boards have completed their recruitment process; progress in recruitment will be critical to the success of the action plan.

Health Boards have been requested to provide progress reports on activity data around blood-borne viral hepatitis and how resources have been allocated. This information will help in monitoring and evaluating the action plan and inform future planning. While some of the Health Boards initially experienced some difficulties returning the required data, it is anticipated that returns will improve with the increased resources available for blood-borne viral hepatitis work within the Health Boards.

#### **4.3.1 Hepatitis C consensus workshop**

A hepatitis C consensus workshop was held in November 2010 to discuss eligibility criteria for treatment. Clinicians working with BBV diagnosis and care participated, and a consensus statement was agreed. This has been circulated for sign-off to the designated clinical leads for the Health Boards.

#### **4.3.2 Appointment of a blood-borne virus hepatitis prison nurse**

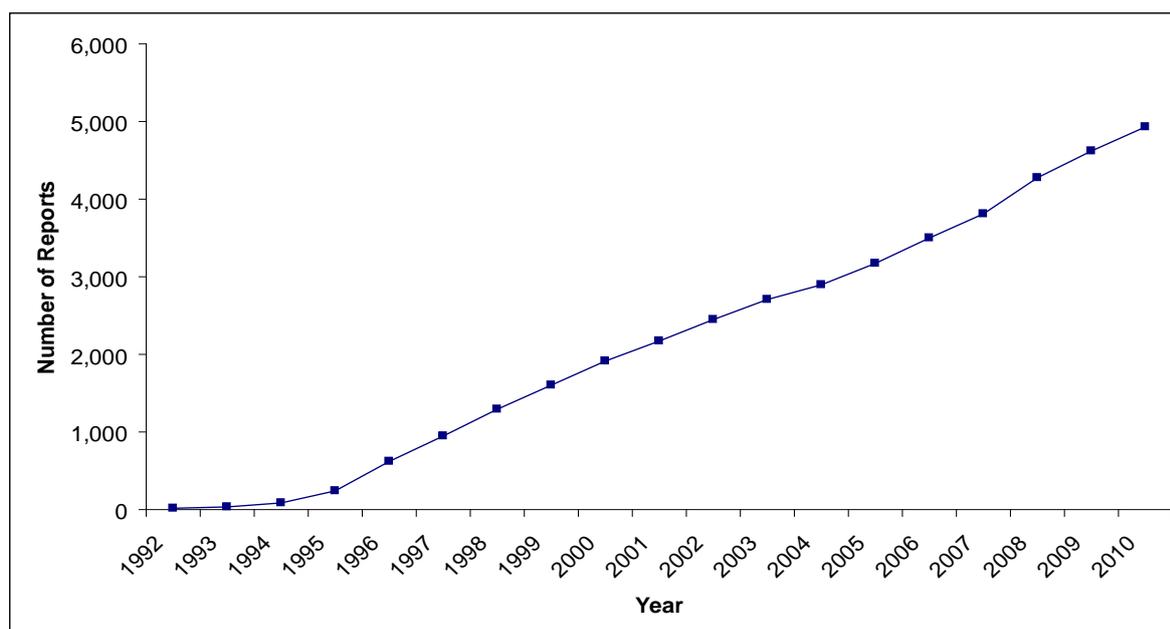
Public Health Wales has appointed a blood-borne viral hepatitis prison nurse. The role of this individual includes supporting the links that have been established between the prison nurses and the CNS serving their prison. Referral pathways are in place for each prison to ensure that all those diagnosed with BBVs are able to access referral for treatment either whilst in prison or are linked into community services on release.

### **4.4 Surveillance of hepatitis C in Wales**

#### **4.4.1 Laboratory reports of hepatitis C virus infection**

A total of 312 laboratory reports of hepatitis C infection were received by the Health Protection Agency, Colindale in 2010. This suggests that infected individuals are continuing to be identified in Wales (Figure 36).

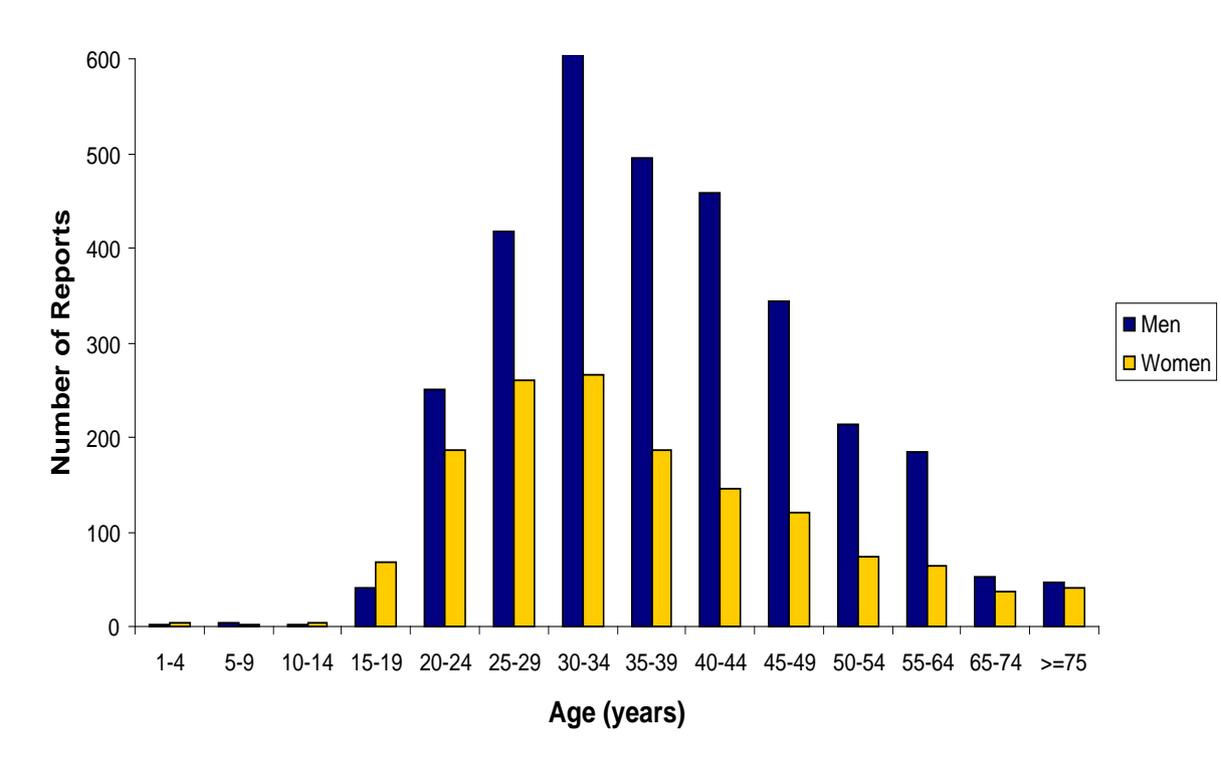
**Figure 36: Cumulative laboratory reports of hepatitis C from Wales: 1992-2010**



Laboratory reports of HCV infection suggest that injecting drug use is responsible for more than 90% of newly acquired infections where the risk is known (Table 13). However, the extent to which risk factor information can be generalised is limited as the information was only available for 21% of the laboratory reports of HCV infection. The age/sex distribution of laboratory reports of hepatitis C infection in Wales from 1996 to 2010 is shown in Figure 37.

**Table 13: Risk factor information in laboratory reports of hepatitis C from Wales: 1996-2010**

Risk factor (where reported)	Number of reports	Percentage
Injecting drug use	969	93.6
Transfusion	14	1.4
Blood product recipient	19	1.8
Sexual exposure	10	1.0
Renal failure	2	0.2
Vertical (mother to baby) or Household	6	0.6
Occupational	0	0.0
Other	15	1.4
<b>TOTAL</b>	<b>1035</b>	<b>100</b>

**Figure 37: Age and sex distribution of laboratory reports of hepatitis C from Wales: 1996-2010**

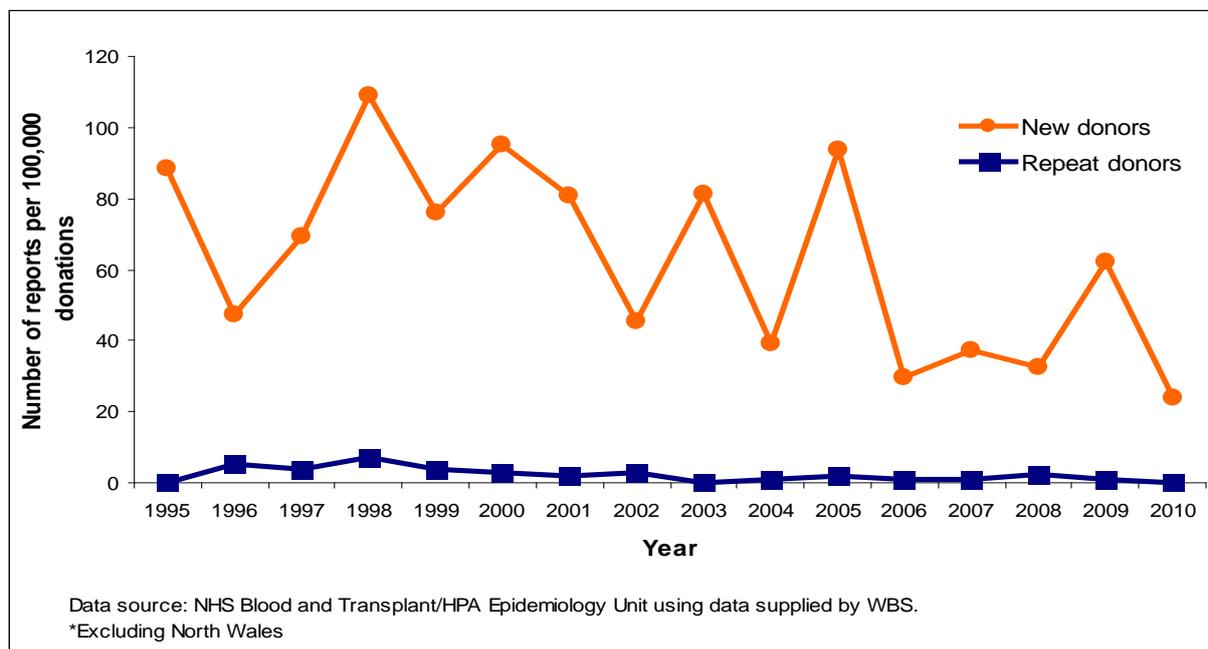
#### 4.4.2 Unlinked Anonymous Monitoring survey of Injecting Drug Users

Findings from the UAM survey of IDUs attending specialist services for drug users in Wales indicates that 20% of current injectors who participated in the survey reported direct sharing of needles and syringes, and 41% reported direct sharing of needles and syringes or paraphernalia (direct or indirect sharing) in 2010.<sup>24</sup> The prevalence of hepatitis C antibodies in participants in Wales in 2010 was 26%.<sup>24</sup> About two thirds (66%) were unaware of their hepatitis C status, with 38% having never been tested for hepatitis C.<sup>24</sup>

#### 4.4.3 Infections in blood donors

The Welsh Blood Service (WBS) collects blood from voluntary donors who are selected to be at low risk of BBIs, such as hepatitis C, in the same way as other UK blood services. Donations made in North Wales are included in the England blood donor data. Excluding donations from North Wales, the frequency of hepatitis C positive donations detected among all other residents in Wales wishing to donate blood for the first-time (new donors) has declined overall since 1995, when separate surveillance data became available, but varied widely each year. In 2010, two new donors tested positive for hepatitis C. This approximates to around 23.8 per 100,000 donations tested (Figure 38).

**Figure 38: Frequency of hepatitis C in blood donors in Wales:\* 1995-2010 new and repeat donors**



Since blood donation testing began, fewer HCV infections have been detected in donations from repeat donors than first time donors (Figure 38). In 2010, there were no hepatitis positive repeat donors.

#### 4.4.4 Hepatitis C virus-related patient episodes

Patient Episode data for Wales (PEDW) indicates that the number of individuals with HCV-related ESLD and HCC continues to increase gradually (Table 14).

**Table 14: Number of Welsh residents with hepatitis C who have ESLD\* and/or HCC and deaths from these conditions, in Wales: the financial years 1997/1998-2009/10**

Welsh Residents						
	Number of patients with HCV	Number of patients with HCV related ESLD	Deaths from HCV related ESLD	Number of patients with HCV related HCC	Deaths from HCV related HCC	
Year	Total	Total	Total (%)	Total	Total (%)	
1997/1998	188	11	2 (18)	0	0 (0)	
1998/1999	190	9	2 (22)	1	1 (100)	
1999/2000	223	10	2 (20)	3	0 (0)	
2000/2001	219	15	8 (53)	5	3 (60)	
2001/2002	226	7	2 (29)	4	1 (25)	
2002/2003	282	18	9 (50)	2	1 (50)	
2003/2004	296	22	5 (23)	6	3 (50)	
2004/2005	272	25	2 (8)	1	1 (100)	
2005/2006	337	28	8 (29)	2	1 (50)	
2006/2007	343	29	6 (21)	8	3 (38)	
2007/2008	318	34	9 (26)	6	0 (0)	
2008/2009	358	31	7 (23)	10	0 (0)	
2009/2010	318	40	13 (33)	10	3 (30)	

Data source: Patient Episode Database for Wales (PEDW). NHS Wales Informatics Service, 2011

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

#### 4.4.5 Hepatitis C virus -related transplants

The number of Welsh residents registering for liver transplants associated with HCV infection has fluctuated over the past 10 years (Table 15).

**Table 15: Indications for liver transplant undertaken in HCV infected individuals in Wales: 1996-2010\***

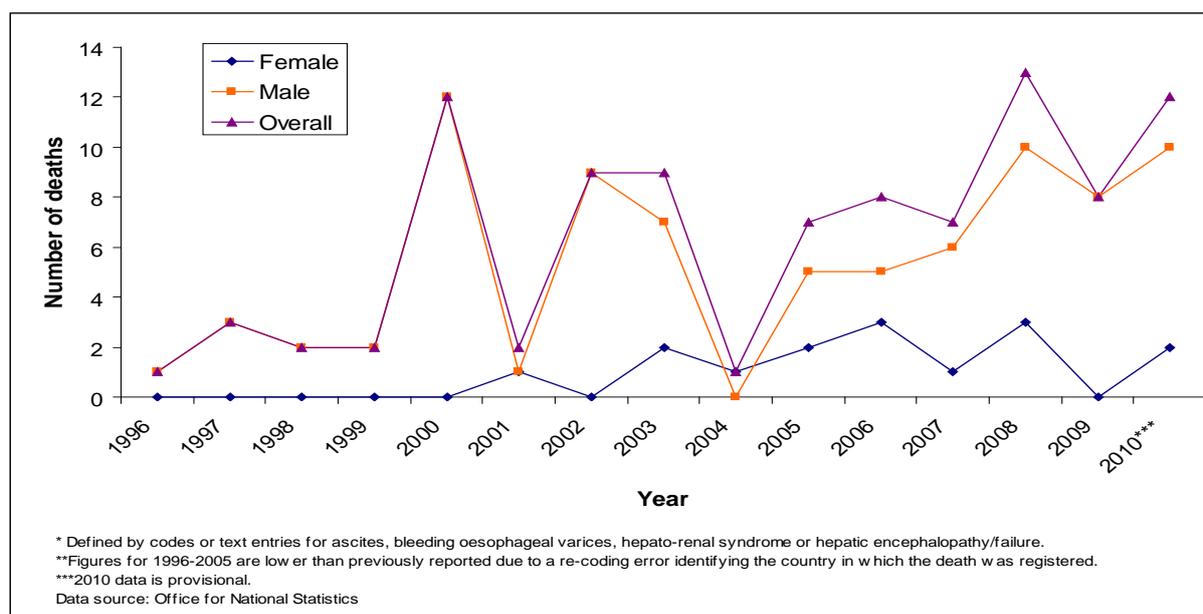
Year	All Liver Transplants	First liver transplants with post hepatitis C cirrhosis at registration and HCV positive at registration or transplant (per cent of all liver transplants)			
		Total	Post-hep C Cirrhosis	Hepatocellular carcinoma	Other Indication
1996	21	1 (5%)	1 (5%)	0 (0%)	0 (0%)
1997	24	0 (0%)	0 (0%)	0 (0%)	0 (0%)
1998	25	2 (8%)	2 (8%)	0 (0%)	0 (0%)
1999	31	5 (16%)	4 (13%)	1 (3%)	0 (0%)
2000	18	3 (17%)	2 (11%)	1 (6%)	0 (0%)
2001	24	1 (4%)	0 (0%)	1 (4%)	0 (0%)
2002	24	2 (8%)	2 (8%)	0 (0%)	0 (0%)
2003	18	3 (17%)	1 (6%)	0 (0%)	2 (11%)
2004	21	2 (10%)	1 (5%)	0 (0%)	1 (5%)
2005	12	1 (8%)	1 (8%)	0 (0%)	0 (0%)
2006	21	6 (29%)	2 (10%)	4 (19%)	0 (0%)
2007	31	3 (10%)	3 (10%)	0 (0%)	0 (0%)
2008	32	5 (16%)	2 (6%)	3 (9%)	0 (0%)
2009	26	8 (31%)	5 (19%)	3 (12%)	0 (0%)
2010	22	4 (18%)	2 (9%)	2 (9%)	0 (0%)
<b>TOTAL</b>	<b>350</b>	<b>46 (13%)</b>	<b>28 (8%)</b>	<b>15 (4%)</b>	<b>3 (1%)</b>

\*These figures are based on registry data as at 28 March 2011  
Data Source: NHS Blood and Transplant

#### 4.4.6 Hepatitis C virus-related mortality

In Wales, deaths from HCV-related ESLD and HCC have fluctuated over the past decade. Since 1996, deaths from these indications have not exceeded 15 in any year (Figure 39).

**Figure 39: Deaths from ESLD\*, or HCC, in those with HCV mentioned on their death certificate in Wales:\*\* 1996-2010\*\*\***



## 4.5 Summary

The Blood Borne Viral Hepatitis Action Plan for Wales 2010-2015 was approved by the Welsh Government and implementation began in April 2010.

In this first year of implementation a number of actions have already been achieved and the building blocks for many more have been put in place.

Achievements include the introduction of the Harm Reduction Database in all statutory and voluntary NSP services across Wales and the roll out of a Level 1 *'Training the Trainer'* course on BBVs to more than 100 individuals across a range of organisations. DBS testing has been introduced in selected substance misuse services and an enhanced surveillance system designed to capture the results alongside a limited set of behavioural data has been established. DBS testing has also been introduced in the prisons in Wales and a BBV prison nurse specialist has been appointed to work across the five prisons. A further achievement has been the establishment of local delivery/action plans for the Health Boards with treatment centres and clinical leads also identified.

Next steps include improving the provision of education and awareness raising in a variety of settings including the prison environment; taking forward the DBS testing by increasing the follow-up sampling of DBS positive individuals and undertaking validation work to determine the sensitivity and specificity of PCR from DBS compared to venepuncture. In addition, the development of a database to improve our knowledge of the epidemiology of blood-borne viral hepatitis infection in Wales is planned. This database is also intended to support health service planners in the design of future services and to support evaluating the impact of the action plan. The completion of the implementation of the Health Board local delivery/action plans and associated recruitment along with improving data returns will also be next steps in moving forward.

## 5. UK Data and Research

### 5.1 UK data on the burden of HCV-related disease

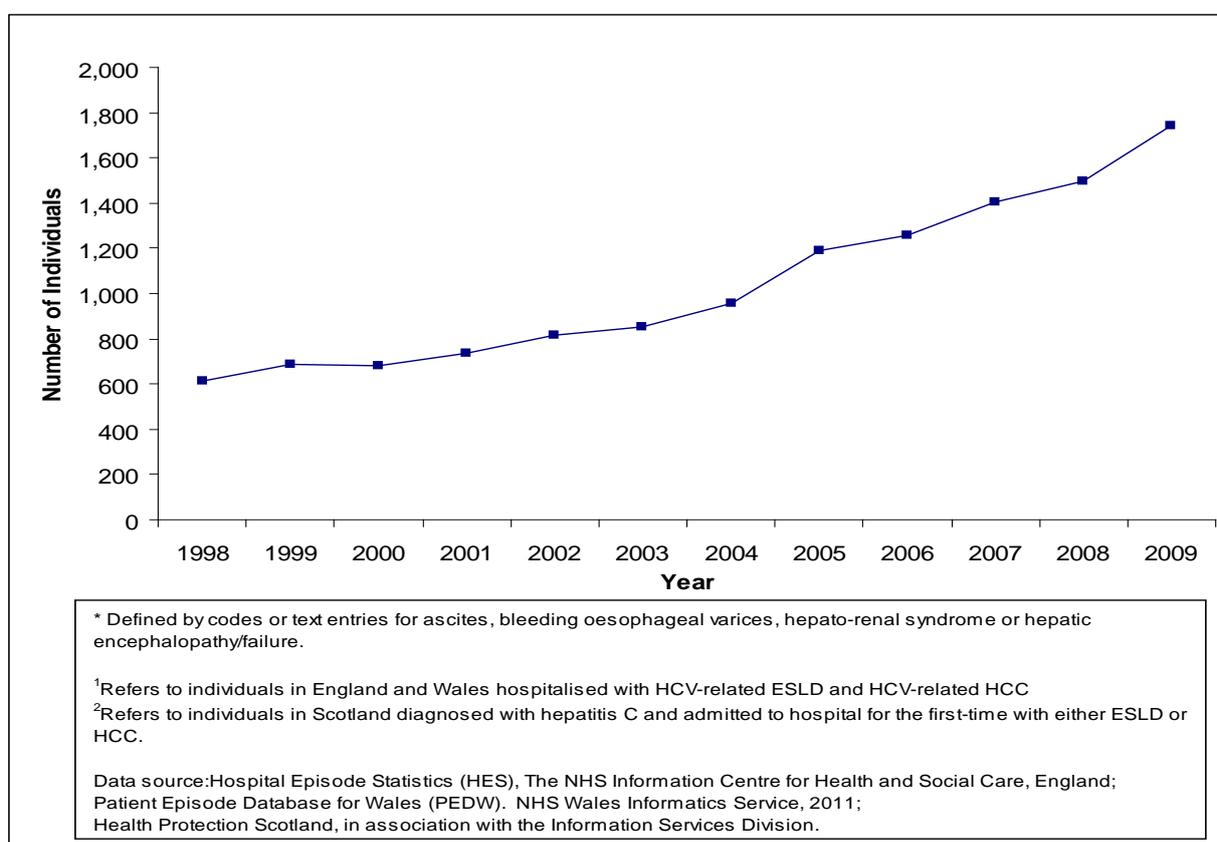
Hepatitis C remains a major public health problem, with an estimated 216,000 individuals chronically infected in the UK (England 161,000;<sup>3</sup> Northern Ireland 4,000;<sup>4</sup> Scotland 39,000,<sup>5</sup> and Wales 12,000.<sup>6</sup> The progress of action plans and programmes to tackle the infection in UK countries are presented in the earlier chapters.

It has been possible to produce data on the burden of HCV infection for the UK, and these are presented below. Whether it is HCV-related hospital admissions (Fig 40), transplants (Fig 41) or deaths (Fig 42), the message is the same: HCV-related ESLD and mortality are continuing to increase. It is therefore necessary to sustain and enhance efforts to raise awareness, prevent new infections, increase diagnosis, and treat more individuals with infection. This will be challenging in the current times of financial constraint and will require efficient and innovative approaches and collaborative working.

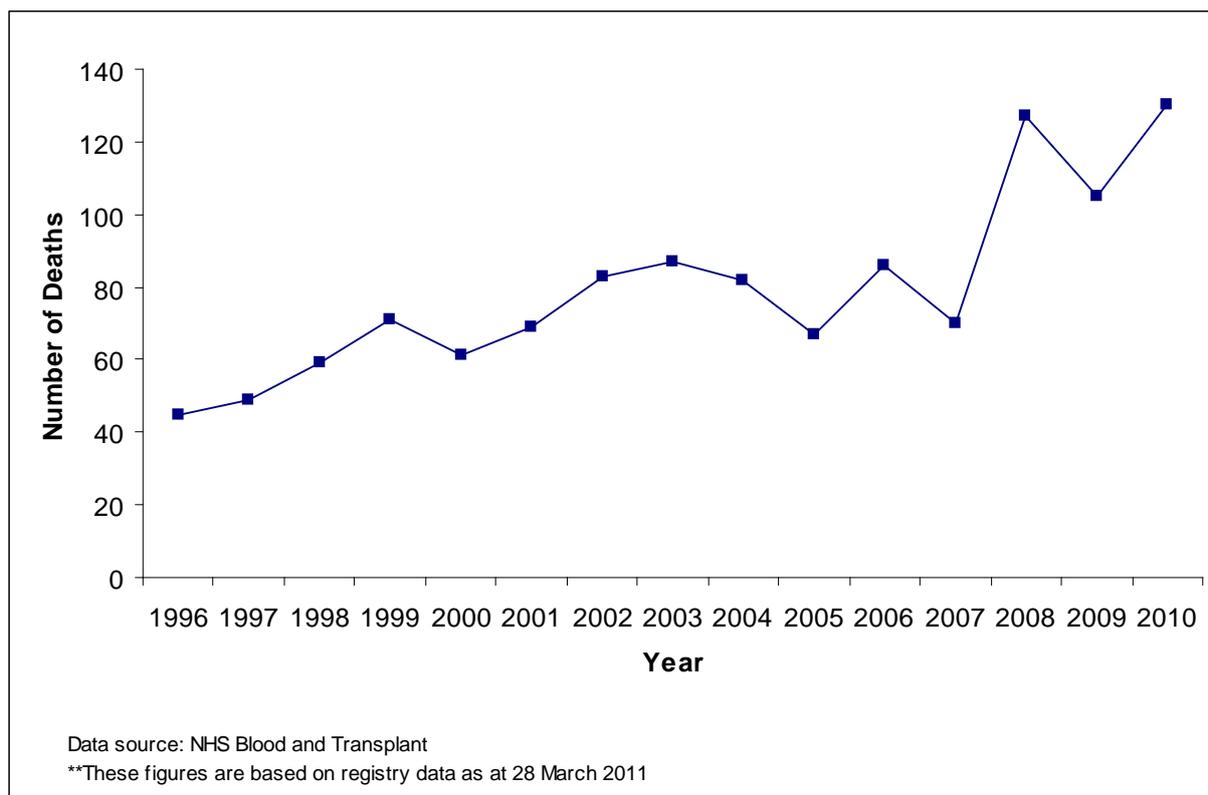
It is recognised that research is an essential component in driving innovation that will help inform and direct improvements in hepatitis C prevention, awareness, diagnosis and care.

With this in mind, a conglomerate of 30 co-applicants have applied for, and been awarded, a research grant from the Medical Research Foundation to set up a national study of patients with HCV infection.

**Figure 40: Annual number of individuals in England<sup>1</sup>, Scotland<sup>2</sup> and Wales<sup>1</sup> hospitalised with HCV-related ESLD\* and HCV-related HCC: 1998-2009**

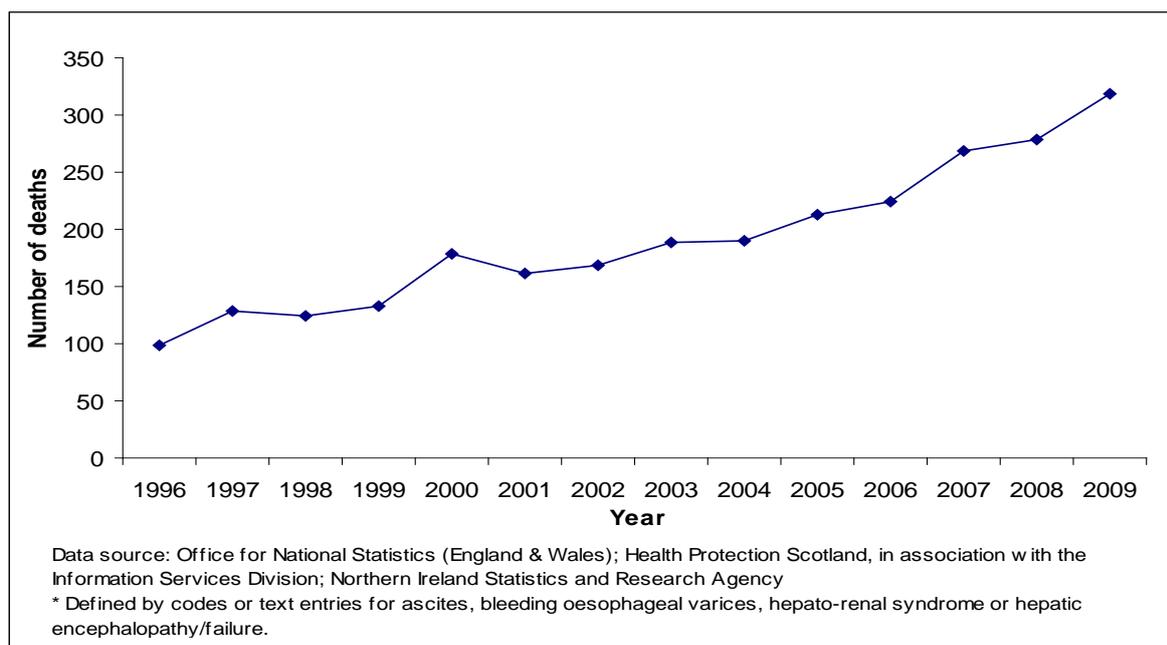


**Figure 41: Overall numbers of first registrations\* for a liver transplant with a code of post-hepatitis C cirrhosis in the UK: 1996-2010\*\***



\*New universal registration criteria for selecting adult patients for elective liver transplantation were introduced in September 2007<sup>35</sup>

**Figure 42: UK Deaths from ESLD\* or HCC in those with hepatitis C mentioned on the death certificate: 1996 - 2009**



## 5.2 HCV Research UK

The project, referred to as HCV Research UK, is being co-ordinated within the MRC and University of Glasgow Centre for Virus Research and the National Institute for Health Research Biomedical Research Unit in Gastroenterology and the Liver at the Queen's Medical Centre Trust/University of Nottingham. The project Steering Committee is multidisciplinary, including clinicians, laboratory specialists, geneticists, and representatives from both Health Protection Scotland and the HPA.

The project seeks to:

- Establish a national cohort of around 10,000 HCV-infected patients, supported by an integrated clinical database with demographic, clinical and core laboratory parameters.
- Create a biobank of biological samples from the cohort for studies of host, viral, and environmental factors associated with disease outcome and treatment response.
- Establish a robust and efficient structure to allow appropriate access to the clinical database and biomaterials to underpin a diverse range of future research programmes.

The strength of the proposal lies in the added value of collecting real-time clinical data and biological samples which, in due course, will be linked to long-term disease outcomes. It is hoped that the existence of a national resource will stimulate a wide set of proposals for detailed studies on HCV infection for many years hence. HCV Research UK will create a unique and valuable national resource to underpin future basic science, translational and clinical research related to HCV infection.

Patients will be recruited over a two-year period from 18 centres from Plymouth to Aberdeen. It is hoped recruitment will begin in late 2011, once the ethics and research governance issues have been dealt with. The biobank will include serum and plasma samples, and stored DNA, from all patients, plus access to diagnostic liver biopsy tissue, and peripheral blood mononuclear cells from a subset of patients. There will be a tissue access committee to handle requests for access to the data and biological samples.

HCV Research UK resource should support future research across a wide range of disciplines, and thereby enable current and future research questions to be addressed, including:

- Identification of host and viral genetic factors associated with different disease outcomes.
- Analysis of the effectiveness and cost-effectiveness of directly acting antiviral drugs once these are introduced into clinical practice in the UK.
- Phylodynamic studies on the HCV variants that are circulating in the various population groups and geographical regions across the UK.
- Studies of the immunological response to HCV infection over time, and its relationship to disease outcome.
- Long-term disease outcome data from a large cohort of infected individuals to enable longitudinal, natural history studies on the roles of factors such as age, obesity, insulin resistance, and alcohol consumption on disease progression to be investigated.

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- Health services research to define patient and environmental factors associated with compliance to management and treatment pathways.
- Collected serum samples from patients with defined fibrosis stage, and with disease outcome recorded in real-time as progression occurs, as an essential resource to allow definition of biomarkers of fibrosis progression and carcinogenesis.

## Data Sources

1. Laboratory Reporting to the HPS HPA Colindale  
<http://www.hpa.org.uk/ProductsServices/InfectiousDiseases/ServicesActivities/Surveillance/SourcesOfSurveillanceData/survLaboratoryReporting/>  
<http://www.hpa.org.uk/Topics/InfectiousDiseases/InfectionsAZ/HepatitisC/EpidemiologicalData/hepcLabAge/>
2. HPA Sentinel Surveillance of Hepatitis C Testing  
<http://www.hpa-bioinformatics.org.uk/hepc/home.php>
3. Unlinked Anonymous Monitoring survey of IDUs in contact with specialist drug services.  
<http://www.hpa.org.uk/Topics/InfectiousDiseases/InfectionsAZ/InjectingDrugUsers/>
4. NHS Blood and Transplant/HPA Blood Donor Infection Surveillance Scheme:  
<http://www.blood.co.uk/>
5. Enhanced Surveillance of Newly Acquired Hepatitis C infection in men who have sex with men.  
[http://www.hpa.org.uk/Topics/InfectiousDiseases/InfectionsAZ/HIVAndSTIs/SurveillanceSystemsHIVAndSTIs/hivsti\\_SNAHC/](http://www.hpa.org.uk/Topics/InfectiousDiseases/InfectionsAZ/HIVAndSTIs/SurveillanceSystemsHIVAndSTIs/hivsti_SNAHC/)
6. Office for National Statistics mortality data: <http://www.statistics.gov.uk/default.asp>
7. Hospital Episode Statistics, The NHS Information Centre for Health and Social Care:  
<http://www.hesonline.nhs.uk/Ease/servlet/ContentServer?siteID=1937&categoryID=537>
8. Oral fluid testing data, Concateno plc: <http://www.concateno.com/>
9. Transplant data, NHS Blood and Transplant:  
<http://www.organdonation.nhs.uk/ukt/default.jsp>
10. National Drug Treatment Monitoring System: <https://www.ndtms.net/Default.aspx>
11. Integrated Drug Treatment System: <http://www.nta.nhs.uk/prison-based.aspx>
12. Needle Exchange Monitoring System: <http://www.nta.nhs.uk/healthcare-nems.aspx>
13. Northern Ireland Blood Transfusion Service: <http://www.nibts.org/>
14. NHS National Services Scotland (Health Protection Scotland and Information Services Division): <http://www.nhsnss.org/index.php>
15. Hepatitis C Testing Laboratories in Scotland:  
<http://www.documents.hps.scot.nhs.uk/ewr/pdf2011/1118.pdf>
16. Needle Exchange Surveillance Initiative in Scotland (University of West of Scotland, Health Protection Scotland, and West of Scotland Specialist Virology Centre):  
<http://www.hepcscotland.co.uk/media/50084/nesi-report-08-09.pdf>

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17. Scottish National Blood Transfusion Service: <http://www.scotblood.co.uk/>

18. Welsh Blood Service: <http://www.welsh-blood.org.uk/>

19. Patient Episode Database for Wales (PEDW), NHS Wales Informatics Service 2011:  
<http://www.wales.nhs.uk/nwis/page/52490>

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## Glossary of Abbreviations

Anti-HCV	Antibodies to hepatitis C virus
APPHG	All Party Parliamentary Hepatology Group
BBI	Blood-borne Infection
BBIPB	Blood-borne Infection Programme Board
BBV	Blood-borne Virus
BVHG	British Viral Hepatitis Group
CI	Confidence Interval
Crl	Credible interval (Crl) is 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.
CNS	Clinical Nurse Specialist
DAT	Drug Action Team
DAAT	Drug and Alcohol Action Team
DBS	Dried Blood Spot
DH	Department of Health
ESLD	End-Stage Liver Disease
GP	General Practitioner
GUM	Genitourinary Medicine
HBV	Hepatitis B Virus
HCC	Hepatocellular carcinoma
HCV	Hepatitis C virus
HES	Hospital Episode Statistics
HIV	Human Immunodeficiency Virus
HPA	Health Protection Agency
HPU	Health Protection Unit
HRD	Harm Reduction Database
HRW	Harm Reduction Works campaign
IDTS	Integrated Drug Treatment System
IDU	Injecting Drug User
ISD	Information Services Division
LARS	Local and Regional Services (HPA)
LFT	Liver Function Test
LJWG	London Joint Working Group
MCN	Managed Clinical Network
NatCen	National Centre for Social Research
MSM	Men who have sex with men
NDTMS	National Drug Treatment Monitoring System
NEXMS	Needle Exchange Monitoring System
NGO	Non-Governmental Organisation
NIBTS	Northern Ireland Blood Transfusion Service
NICE	National Institute for Health and Clinical Excellence
NHS	National Health Service
NHSBT	National Health Service Blood and Transplant
NLDS	National Liver Disease Strategy
NSP	Needle and Syringe Programme
NTA	National Treatment Agency for Substance Misuse
ONS	Office for National Statistics
PCR	Polymerase Chain Reaction
PCT	Primary Care Trust

## Hepatitis C in the UK

PEDW	Patient Episode Data for Wales
PHE	Public Health England
RCGP	Royal College of General Practitioners
RNA	Ribonucleic Acid
SMMGP	Substance Misuse Management in General Practice
SNAHC	Surveillance of Newly Acquired Hepatitis C infection
SNBTS	Scottish National Blood Transfusion Service
STI	Sexually Transmitted Infection
SVR	Sustained Viral Response
TOP	Treatment Outcomes Profile
UAM	Unlinked Anonymous Monitoring survey
UK	United Kingdom
WBS	Welsh Blood Service
WHO	World Health Organisation

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