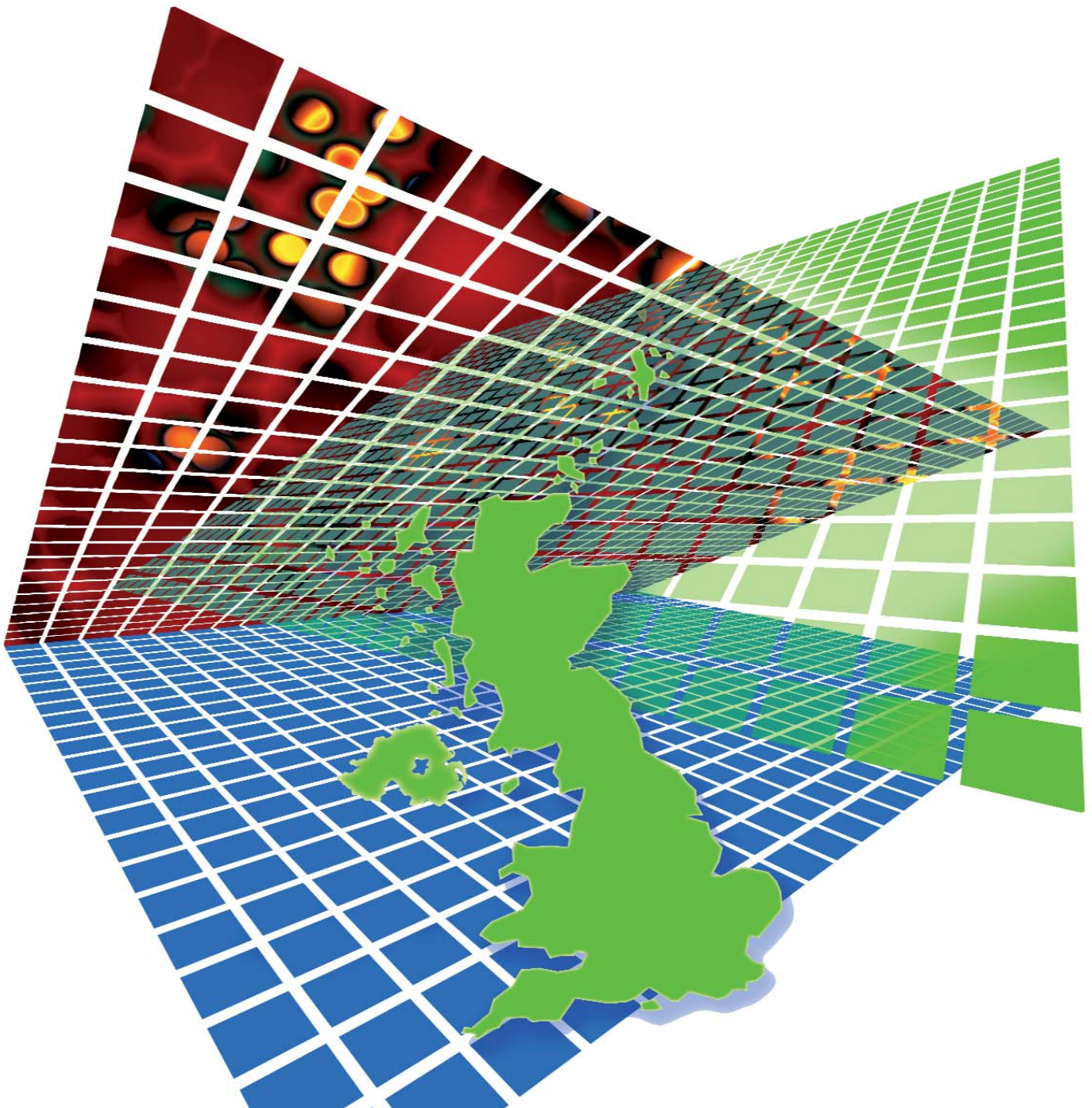


Hepatitis C in the UK

2009 Report



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Acknowledgements

We would like to thank:

The clinicians, microbiologists, public health practitioners, and other colleagues who have contributed to the surveillance systems used in this report.

In particular, in England, we would like to thank the National Treatment Agency for Substance Misuse; the staff who coordinate and work in the laboratories, as well as those who contribute to the Sentinel Surveillance of Hepatitis Testing Study. Also, NHS Blood and Transplant; Altrix Healthcare Ltd (a wholly owned subsidiary of Concateno plc); the Information Centre for Health and Social Care who supplied Hospital Episode Statistics data and the Office for National Statistics who carried out the original collection and collation of death data but who bear no responsibility for their future analysis or interpretation.

From Northern Ireland, we would like to thank the Regional Virus Laboratory, Belfast Health and Social Care Trust; the Health and Social Care Board; the Department of Health and Social Services and Public Safety Northern Ireland; the Northern Ireland Blood Transfusion Service and the Northern Ireland Hepatitis C Managed Clinical Network Steering Group. From Scotland, particular thanks go to the Scottish Hepatitis C Clinical Database Monitoring Committee; the Information Services Division, Scotland; the University of West of Scotland; the West of Scotland Specialist Virology Centre and the Scottish National Blood Transfusion Service. We would also like to thank the Welsh Blood Service and Public Health Solutions who supplied Patient Episode Database for Wales.

We are grateful to the British Liver Trust, the Hepatitis C Trust and Mainliners for their contributions to the report. Thanks also go to Munro & Forster for providing images from the Department of Health's hepatitis C awareness campaigns and to Shirley Cole and Jade Griffiths for their administrative support.

Citation

Hepatitis C in the UK 2009. London: Health Protection Agency Centre for Infections, December 2009.

Foreword	2
Executive Summary	4
Public Health Recommendations	5
1.0 England	6
1.1 Surveillance and research	7
1.2 Increasing awareness and reducing undiagnosed infections	22
1.3 High-quality health and social care services	27
1.4 Prevention	31
1.5 Summary	37
2.0 Northern Ireland	38
2.1 Prevention	39
2.2 Clinical services	41
2.3 Information and research	41
2.4 Making it happen	45
2.5 Summary	45
3.0 Scotland	46
3.1 Introduction	47
3.2 Testing, treatment, care and support	47
3.3 Prevention	52
3.4 Disease trends	57
3.5 Summary	60
4.0 Wales	61
4.1 Introduction	62
4.2 Ongoing work in areas identified as a priority	62
4.3 Summary	68
5.0 The UK picture	69
5.1 Prevalence	70
5.2 Awareness-raising	71
5.3 Diagnosis and testing	72
5.4 Treatment and care	72
5.5 Overall coordination and monitoring	74
5.6 Summary	75
6.0 Awareness raising in the UK	76
6.1 Raising public awareness at a national level	77
6.2 Special projects	79
6.3 Healthcare professional awareness	82
6.4 The voluntary sector	83
6.5 Summary	85
7.0 News items	86
7.1 A National Liver Strategy for England	87
7.2 Reports	87
7.3 Frameworks and guidelines	88
7.4 Surveillance and testing	88
7.5 Research and evaluation	89
7.6 Other news	91
7.7 Summary	91
Appendix	92
Glossary of Abbreviations	94
References	95

Foreword



Tackling hepatitis C virus (HCV) infection, and the burden of chronic liver illness that it causes in our society, requires interruption of the transmission pathway and action at all stages in the natural history of the disease (see figure overleaf). This report shows clearly that rates of new infection remain high in segments of the population. Injecting drug users are a major identifiable risk group. Primary prevention of hepatitis C infection involves a variety of practical measures, some aimed particularly at risk groups, and other more general measures to ensure that the national blood supply is safe through donor selection and screening.

Rates of HCV-related serious liver disease are increasing. Unfortunately, many people living with hepatitis C are unaware of their infection status, resulting in a silent reservoir of infection in society. An important part of the overall strategy to control hepatitis C is to improve awareness of the infection and encourage testing in risk groups.

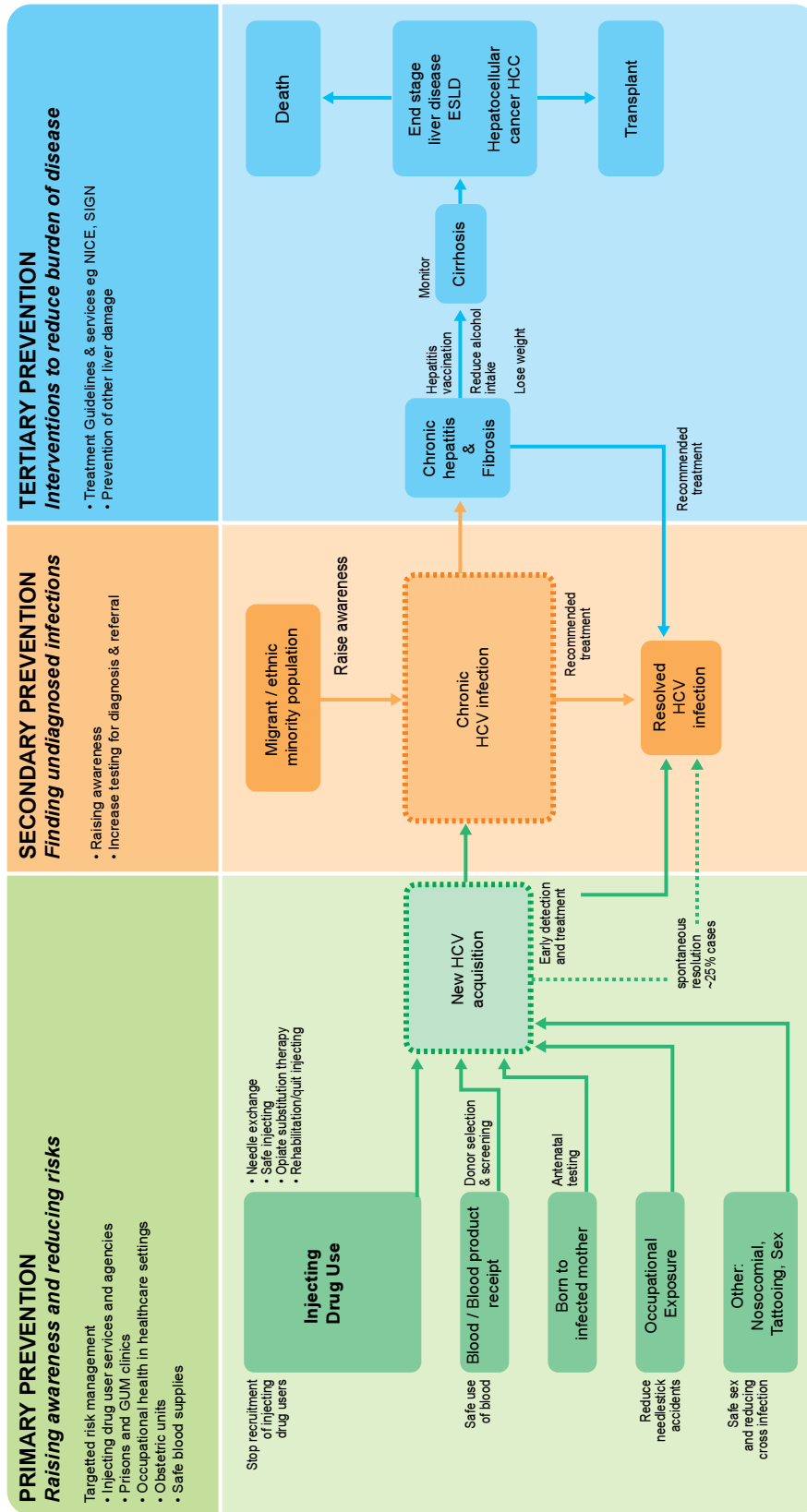
Once diagnosed, effective treatment can help eliminate a persistent infection, in at least some patients, and so reduce the number of infected individuals. Treatment before the onset of recognisable disease reduces the progression to late complications of infection. Patients who respond to therapy

by clearing the virus can avoid the risk of serious liver damage. Among patients who do not respond to therapy, the risk of developing long-term liver damage can be reduced by modifying other risk factors, such as alcohol consumption and avoiding infection with other hepatitis-causing viruses.

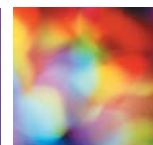
Having a clear strategy is only the first step in achieving a real impact. Equally important is the delivery of interventions and review of their efficiency.

Progress made to date in the UK varies from country to country, reflecting the different stages of implementation of hepatitis C control programmes and the different approaches taken in the different administrations. A four nations approach will encourage the sharing of good practice and help to identify best practice. However, this report also highlights several gaps and challenges for each of the UK countries, and indicates areas where further effort is needed to deliver actions necessary to prevent and reduce the burden of undiagnosed chronic liver disease.

Professor Maria Zambon



Executive Summary



Overall, it is estimated that around 185,000 individuals in the UK are chronically infected with hepatitis C (HCV). Much of the prevalent infection is concentrated in marginalised populations – with injecting drug users (IDUs) at greatest risk of acquiring infection. More recent evidence suggests that some minority ethnic populations are also at high risk of infection.

National Action Plans are in place in all UK countries to help tackle HCV infection. This annual report documents the progress of these UK hepatitis C action plans. In all of the plans, public health action is focussed on:

- **preventing new infections**
- **increasing awareness** of the infection among the public and healthcare professionals
- **increasing diagnosis**
- getting diagnosed individuals into **treatment and care**

Preventing new infections

In each plan the specific actions chosen to improve hepatitis C prevention across the UK have differed. Since 2001, England has invested in effective and accessible community drug treatment as well as improved needle exchange provision. Despite this, the prevalence of anti-HCV in drug users attending specialist services has remained high at 41%. In Scotland, recognising that opiate substitution therapy services are well developed, the focus of the action plan has been on expanding needle and syringe programmes. In 2008, the prevalence of hepatitis C among IDUs in Scotland was 53%, ranging from 17% to 70% across mainland NHS Boards. In Wales, prevalence in current IDUs is lower, at around 26%, but rises to around 40% in the major cities. Expansion of needle exchange has been agreed in Northern Ireland and will form a major plank of the Welsh plan.

Awareness-raising

Hepatitis C infection is usually asymptomatic in the early years, and therefore many individuals remain undiagnosed. Awareness-raising is therefore an important component of reducing the burden of undiagnosed infection. The English awareness campaigns are now well established. In 2009, the Department of Health launched new campaigns targeting former IDUs (*Get Tested, Get Treated*) and the UK population of South Asian origin (*Hepatitis C. The more you*

know, the better). In Scotland a campaign focusing on former IDUs within the five large NHS Boards, will start next year. A programme of education and training for general practice has just started in Northern Ireland and will continue in 2010.

Increasing diagnosis

In England, Northern Ireland and Scotland, rates of diagnostic testing and the number of newly diagnosed individuals have increased. In 2008, the number of new hepatitis C diagnoses reported was 8,196, 132, 1,720 and 260 in England, Northern Ireland, Scotland and Wales respectively. Diagnostic testing has also increased in injectors attending specialist services, reaching 77% in both England and Scotland.

Treatment and care

Antiviral treatments are available that will successfully clear the virus in more than half of those treated (up to 80% success rate if the genotype is favourable). Unless a major increase in those receiving effective treatment occurs, however, the future burden of hepatitis C-related disease is likely to be substantial. All national data sources (hospital admissions from end-stage liver disease (ESLD); liver transplants and deaths) show that HCV-related liver disease is continuing to increase year-on-year. In England, deaths registered from HCV-related end-stage liver disease rose from 81 in 1996 to 230 in 2008. In Scotland liver-related deaths among people diagnosed with hepatitis C have continued to rise from 45 in 1996 to 113 in 2008. In Wales and Northern Ireland numbers of hepatitis C-related deaths remain low.

In England the degree to which strategic health authorities (SHAs) are monitoring the provision of care has been shown to be variable, and no national data on treatment is available. In Northern Ireland a managed care network (MCN) for hepatitis C has been running since October 2007 and will be reviewed in 2009/10 following re-organisation of health services. In Scotland, MCN leads and coordinators have been appointed in 12 out of the 14 NHS Boards. This infrastructure has resulted in the plan reaching its target, with 560 individuals commencing antiviral therapy in Scotland in 2008.

Public Health Recommendations

- All primary care organisations in England and Wales should ensure that integrated pathways of care are available for patients with hepatitis C (ideally coordinated through a clinical network).
- Strategic health authorities in England should take the lead in supporting local commissioners to ensure complete implementation of the hepatitis C Action Plan across all PCTs in their regions.
- Commissioners and providers of services for injecting drug users in Wales and Northern Ireland need to review their programmes to ensure that a broad range of prevention services (in addition to needle and syringe exchange) is available.
- Primary care organisations in England should develop mechanisms for obtaining reliable data on the number of patients referred, seen and treated for hepatitis C.
- Lead agencies in Northern Ireland, Scotland and Wales need to urgently initiate expanded public information campaigns to raise awareness of hepatitis C.
- Lead agencies in Wales and Northern Ireland should investigate the need for targeted public information campaigns to raise awareness of hepatitis C in individuals from the Indian sub-continent.
- Commissioners and providers need to ensure that a high rate of testing in those attending specialist services for drug users is maintained. Lead agencies in all UK countries should ensure widespread access to testing for hepatitis C using alternative specimens (for example, oral fluid and dried blood spot).
- Providers of prison health services should develop testing strategies and care pathways that allow equitable access to treatment services for offenders.
- Lead agencies in all countries should assess the impact of awareness campaigns, by monitoring testing outside of high risk group settings.
- National and local agencies should make efforts to understand and improve the completeness of routine surveillance systems for hepatitis C.
- All commissioners of HCV services should evaluate the coverage of HCV testing services in their area and ensure that laboratories have appropriate pathways for referring samples for confirmatory testing.
- National surveillance centres should develop systems for assessing and monitoring the incidence of hepatitis C in key risk groups. This includes injecting drug users, and if appropriate, HIV positive MSMs.

1.0

England



1.0 England

1.1 Surveillance and research

Action 1: Surveillance and Research¹

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

In England, surveillance has been strengthened to provide better estimates of the incidence and prevalence of hepatitis C (HCV) infection, as well as the burden of HCV-related disease, both in the general population and among specific risk groups.

The Health Protection Agency (HPA) collects data via a number of national surveillance systems (see Table 1) and results of analyses can be combined with information from other national stakeholder systems (see Table 1b) to help monitor and inform HCV prevention and control in England.

Table 1: HPA surveillance system for monitoring the incidence, prevalence and burden of HCV infection in England

Surveillance system	Groups monitored	Focus of monitoring
Routine Laboratory Reporting ³	Total population	<ul style="list-style-type: none"> Monitoring diagnostic testing Risk factors for infection Monitor the impact and yield of awareness-raising Proxy measures of incidence
Sentinel Surveillance of Hepatitis Testing Study ⁴	Catchment population for sentinel laboratories	<ul style="list-style-type: none"> Prevalence of infection Genotype distribution Monitoring diagnostic testing Impact of awareness-raising Incidence in tested population⁵
NHSBT/HPA Blood Donor Infection Surveillance Scheme ³	Blood donor population	<ul style="list-style-type: none"> Prevalence of infection Incidence in low risk populations Risk factors for infection
The Unlinked Anonymous Prevalence Monitoring Programme (UAPMP) agency survey ⁶	IDU population attending a reflective sample of around 60 specialist services for drug users	<ul style="list-style-type: none"> Prevalence of infection Proxy measures of incidence Monitoring testing/Impact of awareness-raising Impact of prevention measures
Hospital Episode Statistics (HES) monitoring	Total population	<ul style="list-style-type: none"> Burden of HCV-related disease Impact of treatment
Office of National Statistics mortality data monitoring	Total population	<ul style="list-style-type: none"> Burden of HCV-related disease Impact of treatment
UK Liver Transplant monitoring	Total population	<ul style="list-style-type: none"> Burden of HCV-related disease Impact of treatment
National surveillance of hepatitis-related end-stage liver disease ³	Catchment population for sentinel centres	<ul style="list-style-type: none"> Burden of HCV-related disease Impact of treatment Risk factors for infection
Enhanced Surveillance of Newly Acquired Hepatitis C infection in men who have sex with men (SNAHC) ⁷	MSM population attending GUM clinics in London, Manchester and the South-East	<ul style="list-style-type: none"> Incidence in high risk MSM population



Table 1b: Stakeholder systems and data used to help inform national HCV prevention and control strategies

System/Data	Groups monitored	Strategies that data can be used to inform
The National Drug Treatment Monitoring System (NDTMS) ⁸	Individuals in drug treatment	<ul style="list-style-type: none"> • Monitoring diagnostic testing • Impact of awareness-raising • Prevention
The Needle Exchange Monitoring System (NEXMS) ⁹	IDU populations	<ul style="list-style-type: none"> • Prevention
The Integrated Drug Treatment System (IDTS) ¹⁰	Offenders	<ul style="list-style-type: none"> • Prevention
Commercial oral fluid testing*	Populations attending services for drug users	<ul style="list-style-type: none"> • Monitoring diagnostic testing • Impact of awareness-raising

*Data supplied by Altrix Healthcare Limited, a wholly owned subsidiary of Concateno plc.

One-off studies of the prevalence of antibody to HCV were first conducted in the mid-1990s^{11, 12, 13} and used to inform the current estimate of the overall prevalence of HCV infection in England. A study conducted using residual sera collected as part of the HPA Sero-epidemiology programme suggested that around 106,000 individuals became infected with hepatitis C between 1986 and 2001¹⁴.

Further studies at the HPA have recently been completed in samples collected as part of the HIV-1 Unlinked Anonymous Prevalence Monitoring Programme (UAPMP). Provisional results for individuals attending genitourinary medicine (GUM) clinics across England in 2005 showed a similar overall prevalence (0.63%) to the 1995 study where prevalence was 0.65%¹². Similarly, the 2005 prevalence in antenatal clinics in London and Yorkshire (0.31% and 0.32% respectively) was around the same level as observed in 1995/6, when prevalence was found to be 0.43% and 0.21% respectively¹⁵. Work to update the overall prevalence estimates is currently under way. The new antenatal prevalence and updated blood donor data will be used to update the model, as well as more detailed information from the Home Office to better estimate prevalence of injecting drug use. More recent data from the British Crime Survey will be used to inform estimates of the ratio of current-to ex-injectors, a key variable in the model. Data is also available on differences in HCV prevalence by ethnicity, which may be incorporated into the evidence synthesis model.

A variety of other research studies have been undertaken to obtain information on the incidence of HCV infection^{16, 17, 18, 5} and other issues like the prevalence of cosmetic body piercing and associated risks of infection¹⁹. Data from a variety of sources, including the Hepatitis C National Register^{20, 21} provide information for ongoing modelling studies to help predict the future numbers of patients needing specialist treatment and care²². Molecular studies have also been undertaken to detect changes in the circulating genotypes of the virus³.

1.1.1 Routine laboratory reporting of hepatitis C infections

Public health and NHS laboratories in England report laboratory confirmed cases of HCV infection, under a voluntary surveillance scheme, to the HPA Centre for Infections (Cfi)³. By the end of 2008, a cumulative total of 69,865 laboratory-confirmed diagnoses of HCV infection from England had been reported to Cfi (Figure 1).

Between 1996 and 2008, more than two-thirds (68%) of the hepatitis C reports were in men, and half of all reports received (50%) were among individuals aged between 25 and 39 years (Figure 2).

Figure 1: Cumulative laboratory reports of hepatitis C infection from England: 1992 - 2008

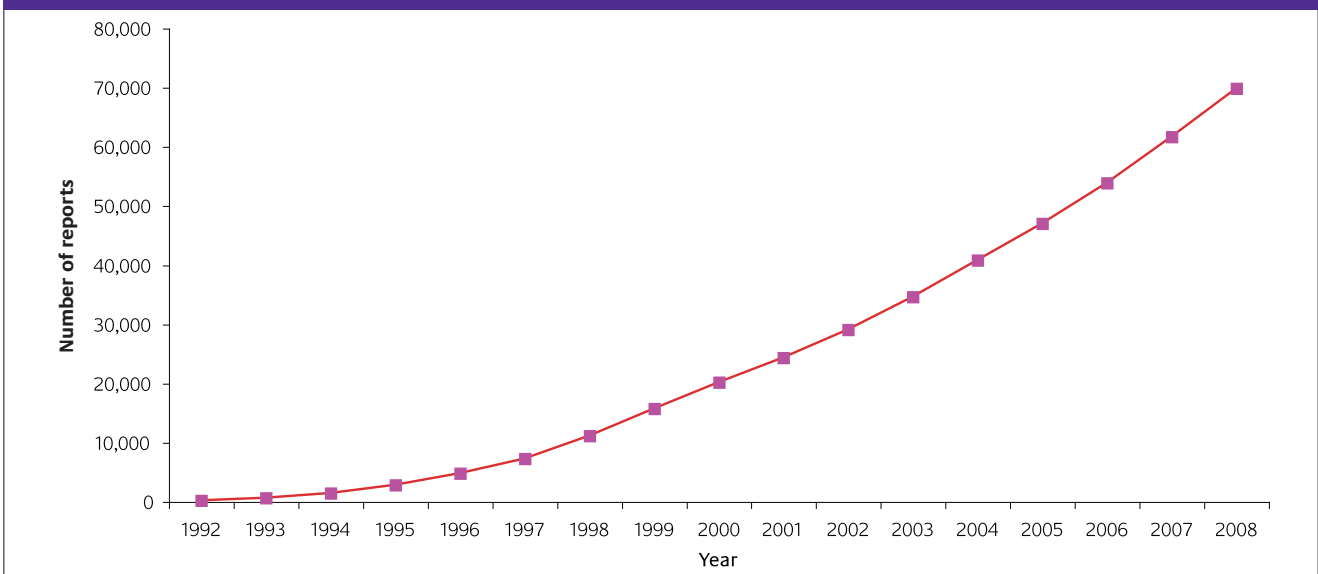


Figure 2: Age and sex distribution of laboratory reports of hepatitis C infection from England: 1996 - 2008

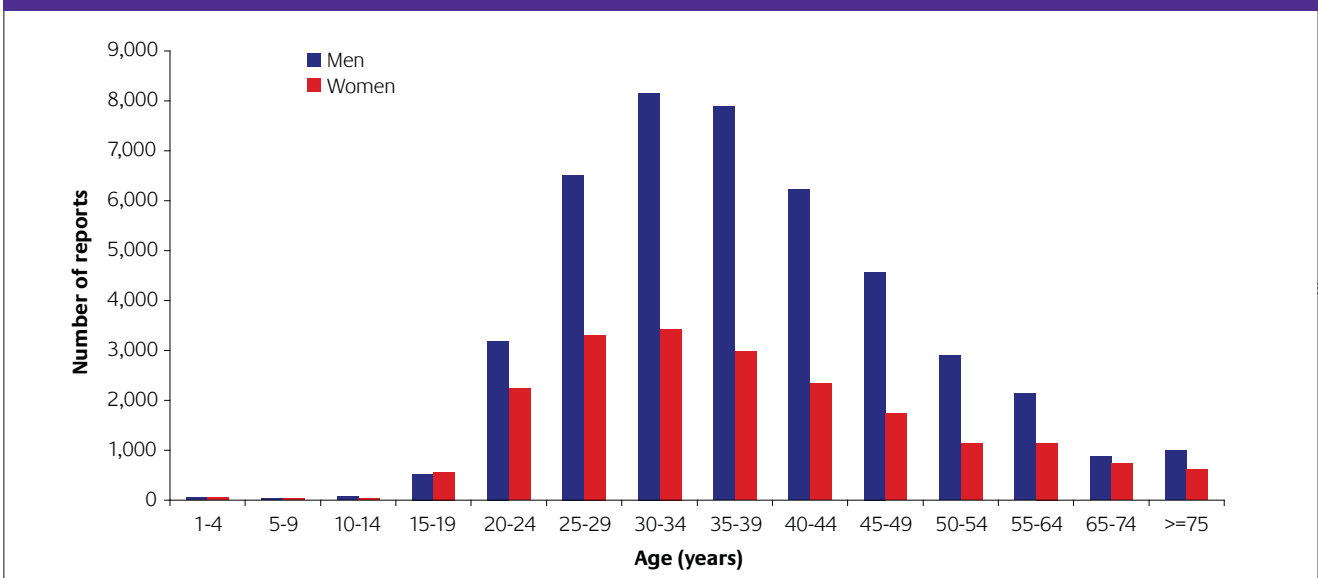


Table 2: Laboratory reports of hepatitis C infection by English region: 1995 - 2008

Region	1995	1996	1997	1998	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008	Total
East Midlands	128	151	182	181	196	189	151	241	322	380	466	278	398	636	3,899
Eastern	125	224	374	541	565	552	430	351	408	522	584	620	617	680	6,593
London	203	263	257	334	299	263	316	331	388	744	811	1,189	1,016	972	7,386
North East	2	13	40	58	110	130	113	136	228	238	281	243	138	163	1,893
North West	206	135	110	626	1,054	896	1,061	1,367	1,998	1,839	1,487	1,359	1,743	1,679	15,560
South East	314	584	662	928	800	601	569	531	492	404	322	387	816	947	8,357
South West	312	411	477	443	713	851	722	831	697	929	684	858	1,038	1,103	10,069
West Midlands	36	145	225	559	638	612	551	666	514	554	582	511	625	698	6,916
Yorkshire and Humberside	66	77	156	141	236	392	236	305	473	584	976	1,428	1,370	1,318	7,758
Total	1,392	2,003	2,483	3,811	4,611	4,486	4,149	4,759	5,520	6,194	6,193	6,873	7,761	8,196	68,431

Since 1995 there has been a steady increase in the number of reports received from most regions in England. The number of laboratory-confirmed diagnoses of HCV infection has increased by 6% from 2007 to 2008.

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 2).

Information on risk factors for acquisition of infection were reported in 17% of laboratory confirmed HCV infections between 1996 and 2008. Of these, more than 90% reported injecting drug use as a risk factor (Table 3). Other risk factors were less common. Fifty three per cent of Injecting Drug Users (IDUs) were males aged between 25 and 44 years of age.

Routine laboratory reports are known to be incomplete²³, and routine reports may be the only data available to inform local commissioning. New Health Protection regulations for England propose to 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 surveillance²⁴.

Table 3: Risk factor information in laboratory reports of hepatitis C infection from England: 1996 - 2008

Risk factor (where reported)	Number of reports	Percentage
Injecting drug use	10,785	92.5
Transfusion	204	1.8
Blood product recipient	118	1.0
Sexual exposure	164	1.4
Renal failure	80	0.7
Vertical (mother to baby) or Household	63	0.5
Occupational	13	0.1
Other	230	2.0
Total	11,657	100

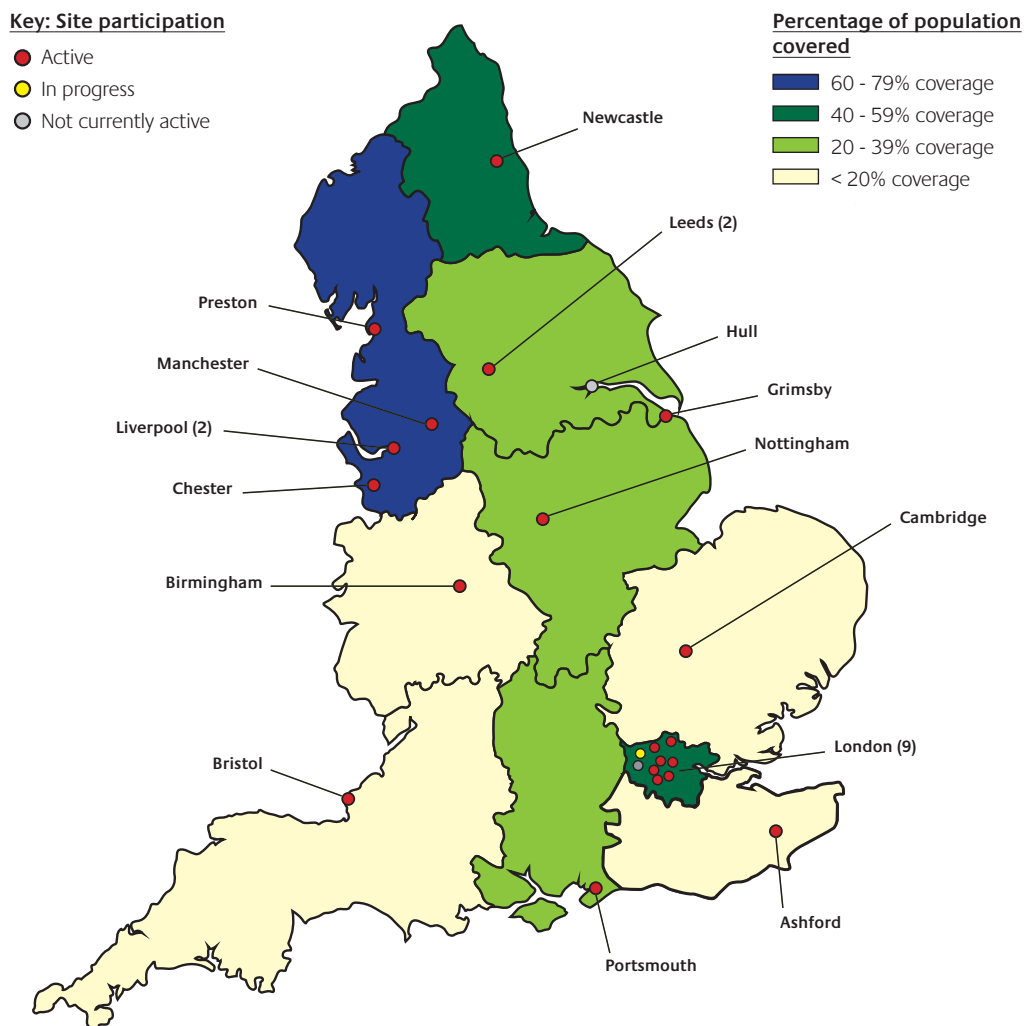
1.1.2 Sentinel Surveillance of Hepatitis Testing Study

In 2002, the Sentinel Surveillance of Hepatitis Testing Study was set up to enhance routine surveillance of hepatitis C; data is currently available from 24 sentinel laboratories across England (see Map 1). An estimate of the coverage of routine anti-HCV testing in England showed approximately one third of the population was covered by these sentinel laboratories in 2008.

As part of this study, laboratory test results and demographic data for all individuals tested for anti-HCV in the sentinel centres are collected electronically.

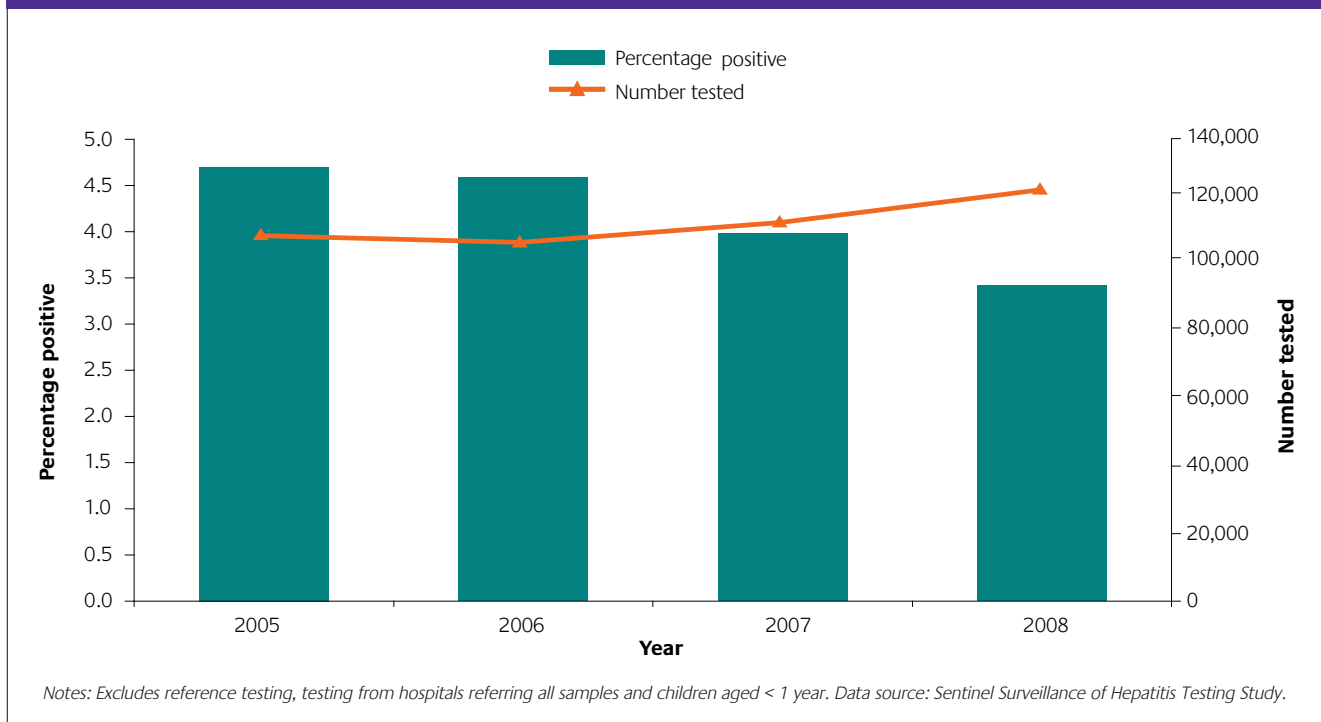
Trends in testing were analysed using data from the 18 sentinel laboratories where complete data from January 2005 to the end of December 2008 were available. The number of people tested for anti-HCV and the proportion testing positive by year in these sentinel laboratories is shown in Figure 3.

Map 1: Geographic distribution of centres who have participated in the Sentinel Surveillance of Hepatitis Testing Study



Data from Chester, Liverpool and Preston are gathered through the Manchester site.

Figure 3: Number of people tested for anti-HCV by year, and proportion positive, in eighteen sentinel laboratories: 2005 - 2008



Overall, testing increased between 2005 and 2008. Over the same period, the proportion of people tested who were anti-HCV positive declined from 4.7% to 3.4%.

After adjusting for sex and age group, individuals tested in 2008 were 27% less likely to be positive for anti-HCV compared with those tested in 2005 (OR=0.73, 95% CI=0.70-0.76, $P<0.001$).

1.1.3 Surveillance in adolescents and young adults

As most new infections are acquired via injecting drug use, which often begins in late adolescence and early adulthood, it is likely that individuals in this age group acquired their infections within the past few years. Therefore the number of hepatitis C cases in individuals aged between 15 and 24²⁵ years can be used as a proxy indicator of incidence (more recent infection). Despite the overall increase in reports of newly diagnosed infections, the number of reports in 15-24 year olds fell from 628 in 2005 to 538 in 2008. 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 continued to fall (from around 10.1% (628/6,234) in 2005 to 7.1% (538/7,541) in 2008).

Data from the 18 sentinel laboratories with complete data participating in the Sentinel Surveillance of Hepatitis Testing Study also shows a decline in the number of positive individuals in this age group, despite an increase in the number of tests (Figure 4). This may reflect more testing in young adults at low risk of infection, and is consistent with a declining incidence of HCV infection in the tested population.

1.1.4 NHSBT/HPA Blood Donor Infection Surveillance Scheme

National Health Service Blood and Transplant (NHSBT) collects blood from voluntary donors who are selected to be at low risk of blood-borne infections such as hepatitis C. Prevalence and incidence of hepatitis C in a population at very low risk of blood-borne virus (BBV) infections can be estimated using data about blood donations tested and donors found positive for hepatitis C. Monitoring trends in HCV infection among populations at low risk of BBVs, such as blood donors, is useful because rises in numbers of infections provide a warning that levels of infection have increased appreciably within the general population.

Hepatitis C in new donors

The frequency of positive donations detected among people wishing to donate blood for the first time (new donors) in England has declined overall since 1991, when testing for antibodies to HCV was introduced, and has remained at a low level since 2004. In 2008, 61 new donors tested positive for hepatitis C. This approximates to around 31 per 100,000 donations tested (Figure 5).

Ethnic origin and country of birth were known for 56/61 infections (92%). Of these, 43 (77%) were white and eight (14%) were of South Asian (Indian/Pakistani/Bangladeshi) origin. Thirty three (55%) were born in the UK and 12 (20%) were born in Europe.

Based on data supplied for one month in 2008, the proportion of white new donors in England was 83.3% compared to only 2.2% of South Asian origin. This extrapolates to a frequency of 26.5 per 100,000 donations from white new donors (0.03%) and 185.3 per 100,000 donations from South Asian new donors (0.19%) in 2008.

Risk factor information was known for 47 (77%) new donors. The two main risk factors reported were injecting drug use (12/47, 26%) and piercing (12/47, 26%). Seven (15%) were

Figure 4: Number of anti-HCV tests performed in young adults and number positive by year: Sentinel Surveillance in eighteen laboratories 2005 - 2008

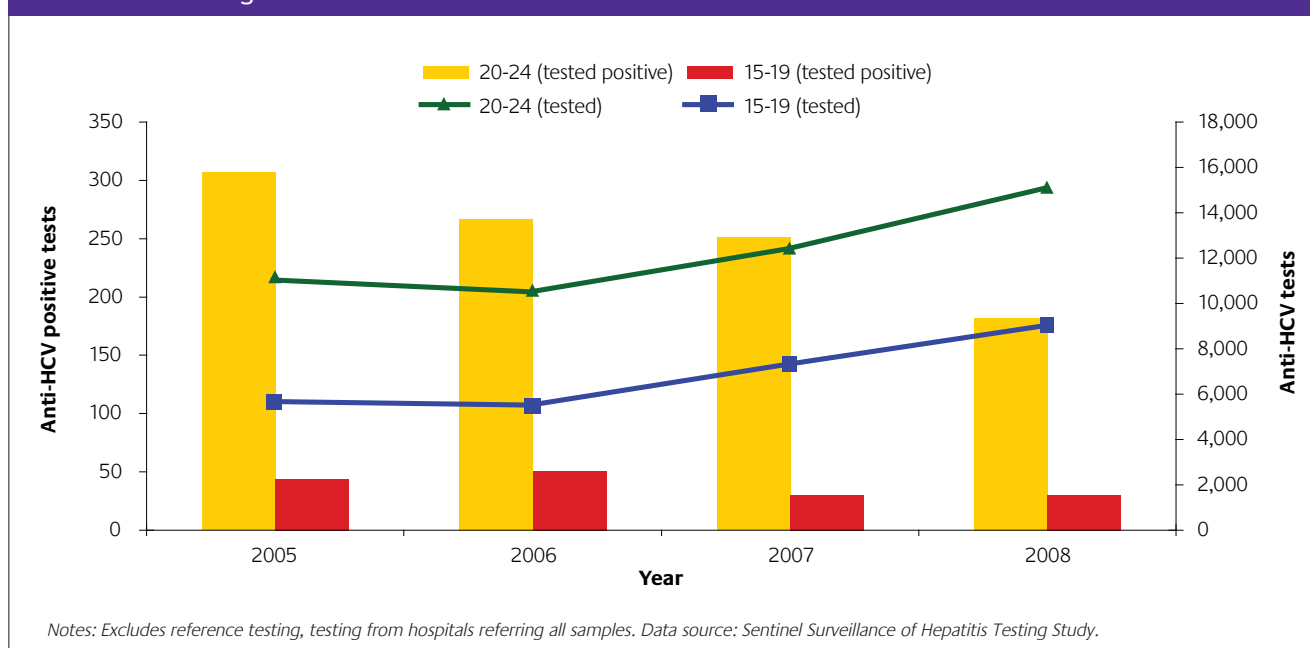
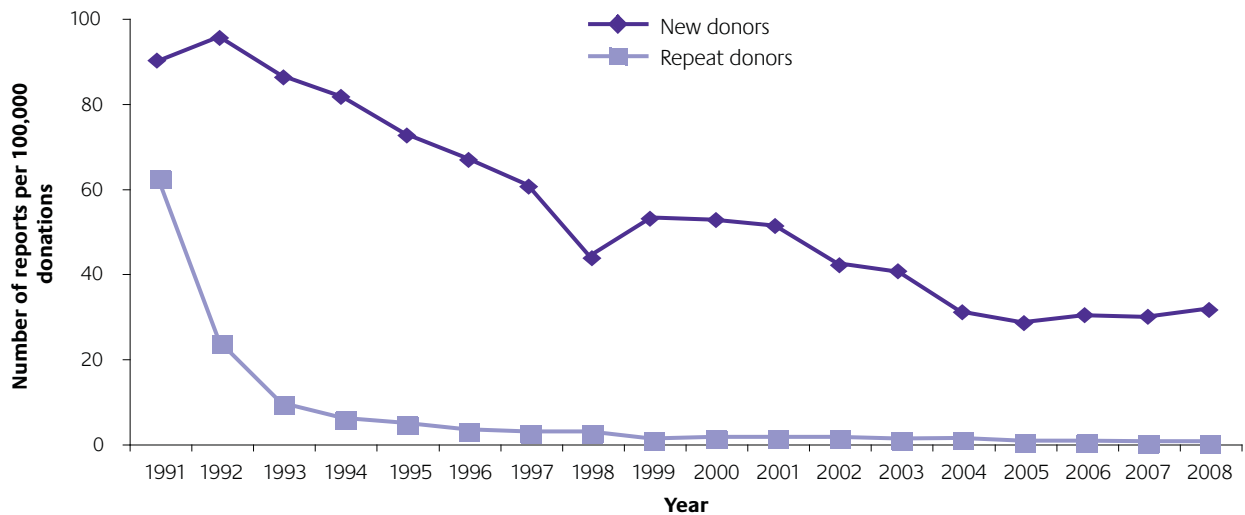


Figure 5: Frequency of hepatitis C in blood donors in England: 1991* - 2008. New and repeat donors



Data source: NHSBT/HPA Epidemiology Unit.

*1991 data from September to December 1991.

Note: 1991 to 1994 includes data from Wales and from 1995 onwards includes North Wales.

either born in, or had parents from, an HCV endemic country with no other specific risk identified. Four (9%) had received blood or tissue products, three (6%) had non-injecting drug exposure, three (6%) had heterosexual contact and three (6%) had possible blood contact, two (4%) were probably infected via sex between men and one (2%) could have been infected via a household contact.

Of the 12 donors who reported injecting drug use, all were probably infected in the UK. Of these, 11 were of white ethnicity, the ethnicity of the other was unknown. Males (5/12) tended to be older than the females (7/12) with a mean age of 42 and 37 years respectively. One donor was probably still injecting at the time of donating, but, where reported, the remaining donors reported ceasing injecting on average 20 years before donating (range 4-32 years).

Hepatitis C in repeat donors

Since blood donation testing began, fewer HCV infections have been detected in donations from repeat donors compared with first time donors, and frequencies of infection have declined from 62.3 to 0.16 per 100,000 donations (Figure 5). In 2008, only three repeat donors seroconverted for antibodies to hepatitis C since their previous donation, giving an estimated incidence in blood donors of 0.09 per 100,000 person years. All three were male, white and born in the UK with an average age of 38 years. All disclosed links to drug use, one injecting, one non-injecting and one with a heterosexual partner who injected.

1.1.5 Unlinked Anonymous Prevalence Monitoring Programme survey of anti-HCV prevalence among IDUs

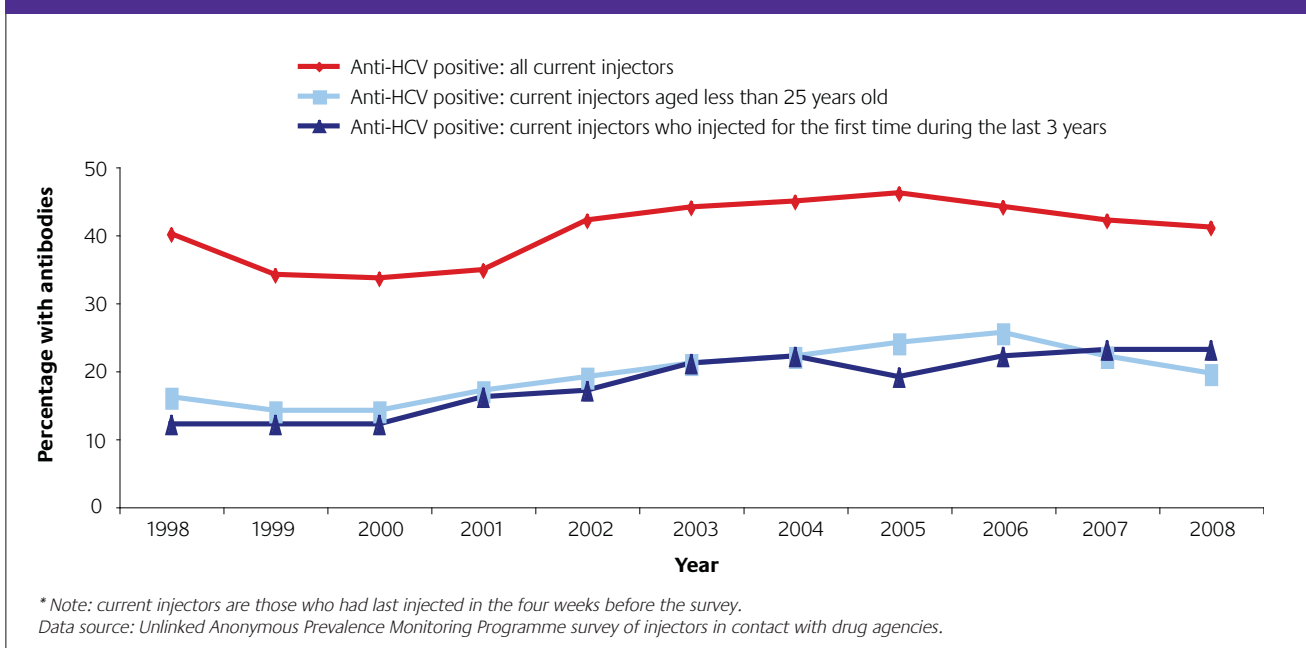
National Outcome Indicator

The prevalence of hepatitis C in current and past injectors who began injecting in the last three years, a marker of recent transmission, has been chosen as an outcome measure in the Hepatitis C Strategy for England². In 2008, among those who recently began injecting, the prevalence of anti-HCV was 23% (81/423). This is similar to last year's figure of 22% (94/423) and has remained relatively stable at this level over the last 5 years.

In 2008, of the current and former IDUs from England who participated in the UAPMP agency survey, 41% (1,177 of 2,893) had antibodies to hepatitis C in oral fluid²⁶. Overall, anti-HCV levels in current IDUs (those who had injected in the four weeks before taking part in the survey) in contact with specialist drug services in England have remained relatively stable in recent years (Figure 6).

Recent analysis of all 24,311 records collected as part of unlinked anonymous surveillance of injecting drug users in England and Wales between 1992 and 2006 suggested that adjusted HCV prevalence decreased from 70% (95% credible interval: 62, 78) in 1992 to 47% (95% credible interval: 43, 51) in 1998²⁷. The fall in anti-HCV prevalence was consistent with a recent study in individuals with a history of injecting drug use²⁸ attending genitourinary medicine clinics across England between 1995 and 2001. This study suggested that prevalence of infection in injectors fell from 36.9% to 28.7% over this period. The UAPMP analysis suggested that prevalence has started to rise again, reaching 53% (95% credible interval: 48, 58) in 2006²⁷. More recent data are therefore consistent with a stabilisation of this upward trend.

Figure 6: Trends in HCV prevalence among current* injecting drug users in England: 1998 - 2008



Regional variations were seen in the prevalence of hepatitis C in IDUs (data from 2006 and 2007 combined) from 21% (117 of 553) in the North East to 56% (641 of 1,140) in London and 58% (534 of 916) in the North West²⁶ (Figure 7). As study numbers are small in some regions, data is presented for the last two years.

1.1.6 Enhanced Surveillance of Newly Acquired Hepatitis C infection in men who have sex with men (SNAHC)

In response to an increasing number of reports of newly acquired HCV among HIV-infected men who have sex with men (MSM), commonly without a history of injecting drug use, the HPA established an enhanced surveillance system in collaboration with the British HIV Association (BHIVA) and the British Association for Sexual Health and HIV (BASHH). *The Enhanced Surveillance of Newly Acquired Hepatitis C infection in men who have sex with men (SNAHC)* was established in January 2008, and collected data prospectively between January 2008 and May 2009 from 22 centres in London, Manchester and the South East. A diagnosed newly acquired HCV infection was defined as either a 'Confirmed case' (HCV antibody positive and had a documented negative HCV antibody within the previous 36 months), or a 'Probable case' (HCV RNA positive and HCV antibody negative or equivocal).

During the first 17 months, 105 newly acquired HCV cases were reported; 56 confirmed and 49 probable cases. The median age at diagnosis was 38 years (range 19-62) and the majority of MSM were UK born (63%), and of white ethnic origin (89%). The majority of MSM (96%) had already been diagnosed with HIV, with a median of four years between HIV and HCV diagnoses. The main reason for testing was raised liver function tests (LFTs) reported in 62% of cases.

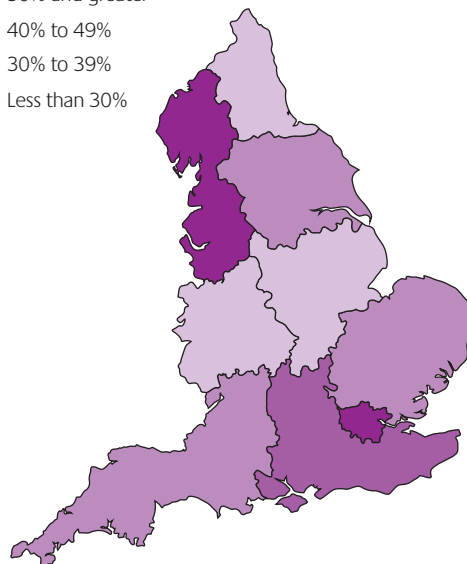
A history of intravenous drug use was reported for only 17 (16%) cases, seven of whom injected within the last six months. Recreational drug use (non-injecting) during the last 12 months, however, was reported in 60% of cases, with a high proportion engaging in sex while under their influence. The majority of cases were among HIV positive MSM with high numbers of recent partners, a high rate of unprotected anal intercourse and a high rate of other recently diagnosed STIs.

These high risk activities along with the higher HCV viral load²⁹, the higher rate of HCV RNA in semen³⁰, and the prolonged viral half-life³¹ in individuals with HIV infection, compared to HIV negative individuals, may account for the enhanced transmission observed among HIV positive MSM. Formal incidence estimates have not yet been undertaken, but the overall number of reports in 2008 was lower than the number expected from a pilot scheme conducted in 2006 and 2007⁷, and provisional numbers suggest a further decline in 2009. This suggests that transmission may have stabilised in London and the South East. The inclusion of other geographical areas in SNAHC is being actively pursued.

Figure 7: Geographic variations in the prevalence of antibodies to hepatitis C among current and former injecting drug users in England (2007 and 2008 data combined)

Proportion with antibodies to hepatitis C

- 50% and greater
- 40% to 49%
- 30% to 39%
- Less than 30%



Data source: Unlinked Anonymous survey of injectors in contact with drug agencies.

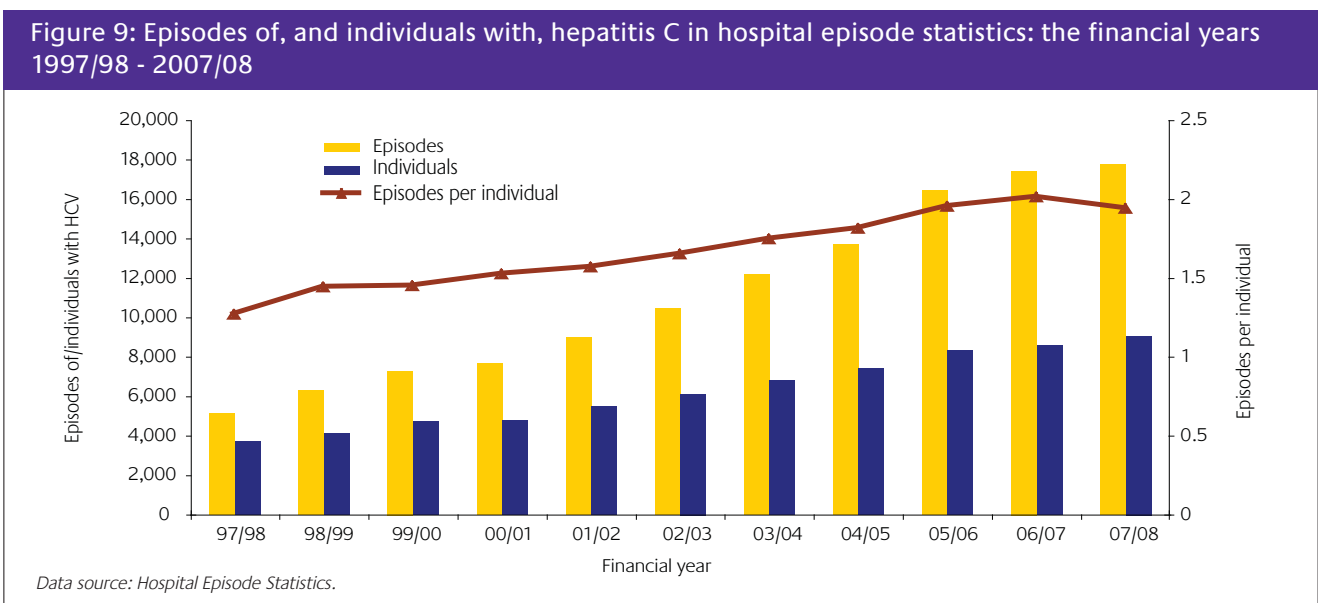
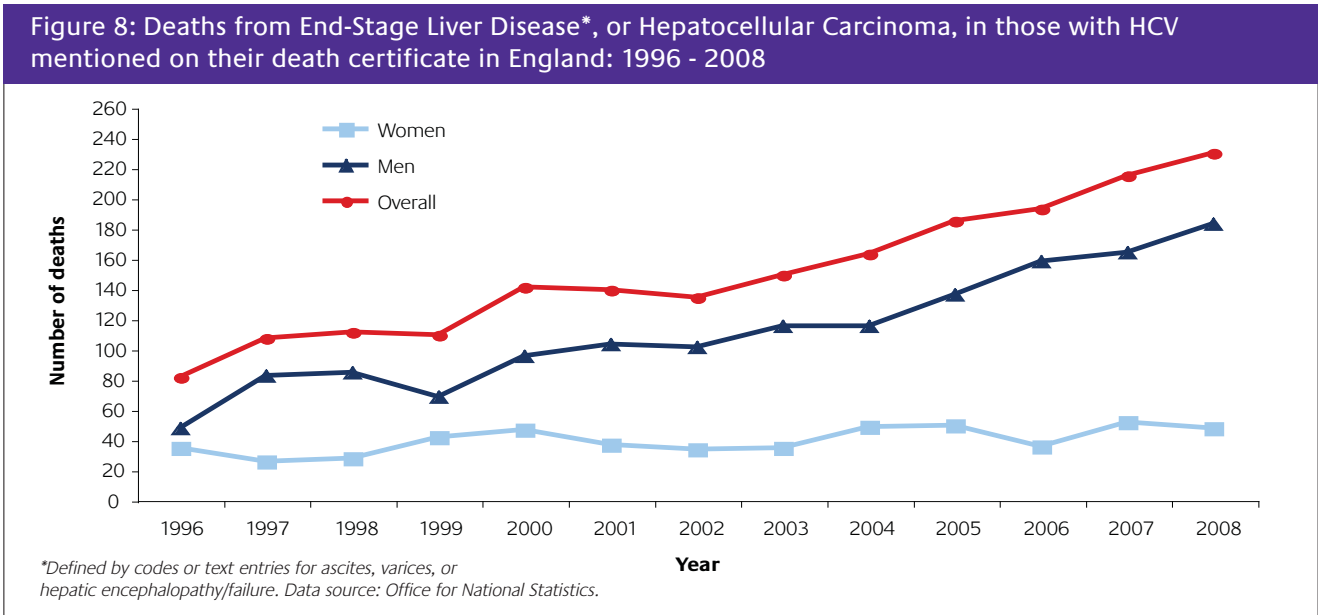
Further regional data from this survey is available at:
http://www.hpa.org.uk/web/HPAwebFile/HPAweb_C/1254510660636.

1.1.7 Office for National Statistics mortality data - deaths from hepatitis C-related end-stage liver disease

The number of deaths in England due to end-stage liver disease (ESLD) or hepatocellular carcinoma (HCC) with any mention of hepatitis C on the death certificate continues to increase. The number of deaths registered has increased from 81 in 1996 to 230 in 2008 (Figure 8). The majority of deaths are in men. The number of deaths in women has remained relatively stable over the last decade.

1.1.8 Hospital Episode Statistics – Admissions with hepatitis C and hepatitis C-related end-stage liver disease

In line with the existing trends, the number of episodes and individuals with one or more hospital episodes coded to hepatitis C increased in 2007/08 (Figure 9). As other data suggests that diagnosis of HCV infection is increasing in England, it is perhaps not surprising that more admissions have occurred in individuals with diagnosed infection.



Admissions coded to end-stage liver disease or hepatocellular carcinoma in individuals with a hepatitis C diagnosis, however, should be a better indicator of trends in the burden of disease in England. The numbers of such admissions have continued to increase each financial year, as have the number of deaths in hospital among individuals with these diagnoses (Table 4).

1.1.9 UK Transplant Data – Liver transplants in individuals with hepatitis C

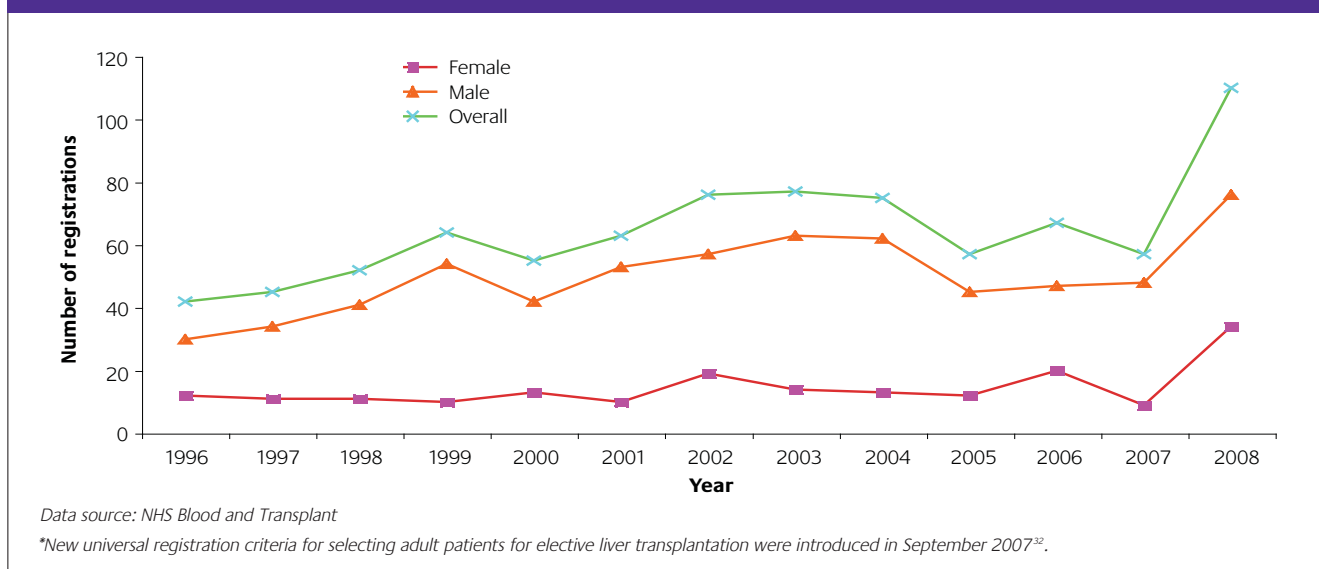
The number of English residents with post-hepatitis C cirrhosis registering at NHSBT for a liver transplant has increased overall since 1996, with the largest number seen in 2008 (42 registrations in 1996 and 110 registrations in 2008). Although the number of men registering continues to be higher, the number of women registering in 2008 has increased (Figure 10) more than three-fold compared with 2007 (9 registrations in 2007 and 34 registrations in 2008).

Table 4: Number of individuals with hepatitis C (HCV) who have end-stage liver disease (ESLD) and/or hepatocellular carcinoma (HCC) and deaths from these conditions, in England: the financial years 1997/98 - 2007/08

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	3,751	473	76 (16)	75	28 (37)
1998/1999	4,148	558	127 (23)	127	28 (22)
1999/2000	4,764	567	128 (23)	126	30 (24)
2000/2001	4,807	626	144 (23)	123	33 (27)
2001/2002	5,490	672	162 (24)	135	32 (24)
2002/2003	6,138	703	170 (24)	187	48 (26)
2003/2004	6,813	741	186 (25)	166	50 (30)
2004/2005	7,419	849	216 (25)	211	50 (24)
2005/2006	8,349	1,016	256 (25)	244	60 (25)
2006/2007	8,625	1,030	251 (24)	257	65 (25)
2007/2008	9,078	1,199	287 (24)	287	70 (24)

Data source: Hospital Episode Statistics.

Figure 10: Transplant list first registrations with a code of post-hepatitis C cirrhosis in England: 1996 - 2008*



Since 1996, an overall increase has been seen in the number of first liver transplants performed for each patient with hepatitis C-related disease. There was a marked increase from 2007 to 2008 (65 and 112 first liver transplants respectively). 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 (10% in 1996 to 21% in 2008).

The number of first liver transplants in patients with post-hepatitis C cirrhosis has increased from 2007 to 2008 (31 and 62 respectively). The number of patients with HCV-related hepatocellular carcinoma has also increased by 66% from 2007 to 2008 (27 and 45 respectively; Table 5).

These data suggest a substantial increase in hepatitis C-related disease requiring transplantation over the last year. However, it is important to note that new universal registration criteria for selecting adult patients for elective liver transplantation were introduced in September 2007³², and these have the potential to create changes in the data. While the levels of disease are real, the recent rise in registrations may partially be a reflection of changes in registration practice.

1.1.10 Enhanced surveillance of hepatitis-related end-stage liver disease

By July 2008, 379 first diagnoses of ESLD in people with hepatitis C were reported from centres participating in the End-Stage Liver Disease Study (see Table 6). The case definition used for reporting is: *a patient with hepatitis C or B who is suffering from decompensated cirrhosis, as demonstrated by the presence of ascites, bleeding varices or hepatic encephalopathy, or hepatocellular carcinoma*. Of these, 75% were of white ethnicity; 5% were of Bangladeshi origin and 5% were Pakistani (Table 6). Of those with a known risk exposure, 63% reported IDU as the risk for acquisition of infection. A description of these patients is given in Table 6.

In the majority of cases, the date of acquisition of HCV infection is unknown; the age distribution for individuals with HCC is higher than for ESLD (Figure 11), and this reflects the longer period between acquisition and development of HCC compared with other complications.

Table 5: Indications for transplant in hepatitis C (HCV) infected individuals in England: 1996 - 2008

First liver transplants with post hepatitis C cirrhosis at registration and HCV positive at registration or transplant (per cent of all liver transplants)					
Year	All liver transplants	Total (percent)	Post-hepatitis C cirrhosis (percentage)	Hepatocellular carcinoma (percentage)	Other indication (percentage)
1996	447	43 (10)	31 (7)	7 (2)	5 (1)
1997	486	58 (12)	44 (9)	10 (2)	4 (1)
1998	456	49 (11)	31 (7)	9 (2)	9 (2)
1999	497	76 (15)	51 (10)	19 (4)	6 (1)
2000	479	66 (14)	36 (8)	20 (4)	10 (2)
2001	484	68 (14)	45 (9)	19 (4)	4 (1)
2002	520	83 (16)	50 (10)	27 (5)	6 (1)
2003	479	75 (16)	46 (10)	21 (4)	8 (2)
2004	546	82 (15)	56 (10)	21 (4)	5 (1)
2005	469	56 (12)	30 (6)	20 (4)	6 (1)
2006	494	60 (12)	31 (6)	25 (5)	4 (1)
2007	498	65 (13)	31 (6)	27 (5)	7 (1)
2008	540	112 (21)	62 (11)	45 (8)	5 (1)

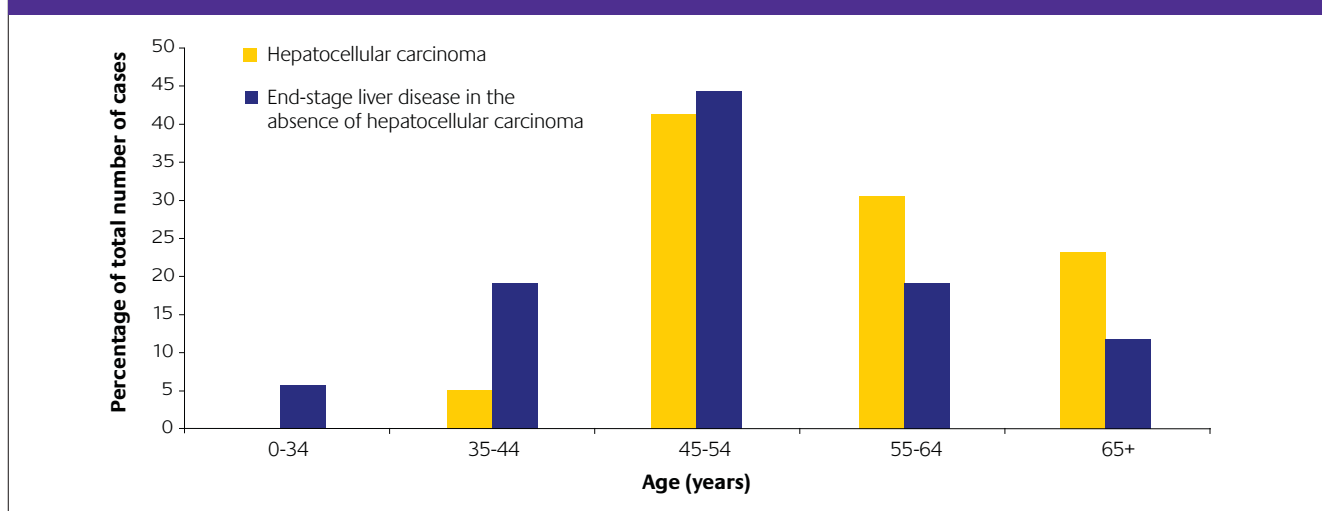
Data source: NHS Blood and Transplant.

Table 6: Enhanced surveillance of severe liver disease in hepatitis C-infected people in England: 1999 - 2008 (n= 379)

Characteristic	N	(%)	Characteristic	N	(%)
Sex			Sexual contact	7/252	(2.7)
Male	295	(77.8)	Occupational exposure	4/252	(1.6)
Female	77	(20.3)	Tattoo	7/252	(2.7)
Not known	7	(1.8)	Other risk factor	7/252	(2.7)
Ethnic group			Hep B co-infection	28/379	(7.4)
White	283	(74.6)	HCV RNA positive	236/379	(62.2)
Bangladeshi	20	(5.2)	Liver transplanted**	27/379	(7.1)
Pakistani	19	(5.0)	Ascites	211	(55.6)
Black African	8	(2.1)	Bleeding varices	75	(19.7)
Black Caribbean	4	(1.0)	Encephalopathy	92	(24.2)
Indian	7	(1.8)	Hepatocellular carcinoma	144	(37.9)
Unknown or Other country	38	(10.0)	Dead**	46	(12.1)
Risk factor*			Mean		(SD)
Risk factor known	252	(66.5)	Age in years** (n=372)	53.6	(10.6)
IDU	159/252	(63.1)	Time from start of exposure to first diagnosis of ESLD in years (n=90)	25.0	(11.4)
Transfusion recipient	39/252	(15.5)			
Blood product recipient	42/252	(16.6)			
Medical procedures abroad	17/252	(6.7)			

* Certain individuals reported more than one risk; for others risks were not known. ** Noted at diagnosis or on follow-up.

Figure 11: Clinical diagnoses by age in people with severe liver disease due to hepatitis C, enhanced surveillance of severe liver disease: 1999 - 2008 (n=368)



1.1.11 Circulating hepatitis C genotypes

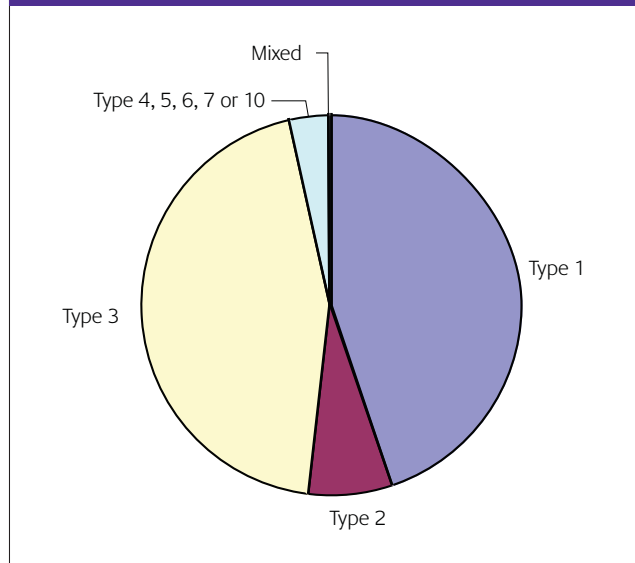
The Sentinel Surveillance of Hepatitis Testing Study collects data on routine HCV genotyping undertaken at 24 participating sentinel centres. Between 2002 and 2008 a total of 24,284 samples were genotyped. Almost 90% of tested individuals had genotype 1 or 3 infection (Figure 12). The most common genotype continues to be 3a, identified in 38.6% of all patients tested, followed by 1a identified in 23.2% of patients tested.

1.1.12 Cosmetic body piercing and the associated risks of infection

The HPA undertook an investigation into the prevalence of cosmetic body piercing in adults in England and its associated risks of infection¹⁹. In 2005, a cross-sectional household survey was carried out in all regions of England. A two-stage selection process was undertaken resulting in 10,503 adults aged over 16 being surveyed. In order to reflect the national demographic profile of adults aged 16 and over, the results were weighted.

Results showed that the prevalence of body piercing, at sites other than the earlobe, was 10% (1,049/10,503). Of the 1,934 piercings reported; the navel, nose, tongue, nipple and eyebrow were the most common. A higher number of women (n=788) had one or more body piercings compared with men (n=261); body piercing was also more common in the 16-24 age group (n=754) with 46% of women (305/659) in this age group reporting having had a piercing. Most piercings were performed in specialist piercing or tattooing shops although around 20% were performed outside of these settings. No data were collected

Figure 12: Genotype distribution among hepatitis C-positive individuals reported to the Sentinel Surveillance of Hepatitis Testing Study, 2002 - 2008 (n=24,284)

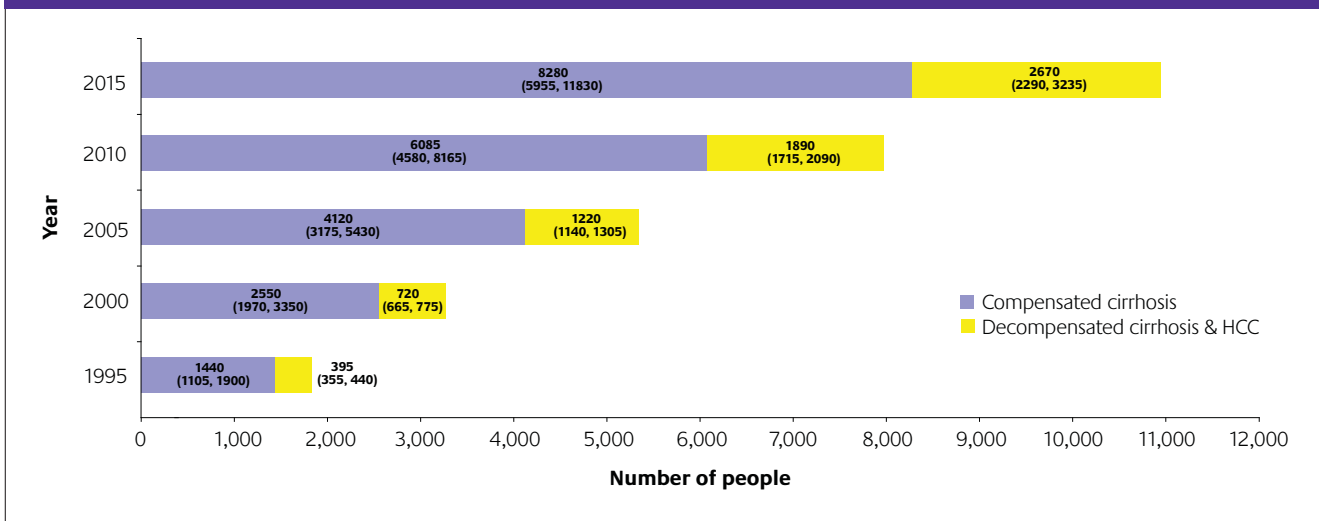


on blood-borne infections associated with piercing but swelling, local infection and bleeding complications were commonly reported, often requiring the assistance of health services.

1.1.13 Predicting the future burden of infection in England

Using a back-calculation approach, the future burden of hepatitis C-related deaths in England has been estimated (Figure 13)³³.

Figure 13: Estimated number of people living with HCV-related cirrhosis or decompensated cirrhosis / hepatocellular carcinoma (HCC) in England, 1995-2015 (95% credibility intervals are given in parentheses)



Updated information on deaths from hepatitis C-related HCC and ESLD, as well as data on hospital admissions for these indications, are now available and can be used to update burden estimates. The HPA treatment pilot study should also provide information on the numbers of individuals on treatment. This new data can be used to look at the contribution of current treatment levels to the future burden of disease in England. Further, data from the HCV National Register will also be used to investigate updating estimates of progression rates that are used within the model.

1.2 Increasing awareness and reducing undiagnosed infections

Action 2: Increasing awareness and reducing undiagnosed infections¹

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.

A number of national government, NHS and non-government organisations have continued to work in partnership on initiatives to help raise awareness of hepatitis C among healthcare professionals and the public. Over the last year, a variety of approaches have been used, ranging from the production of targeted information and advertising to specific testing campaigns. Full details of these initiatives are reported in Chapter 6.

Hepatitis C testing facilities are provided by NHS organisations in a range of clinical and community settings including genitourinary medicine clinics, general practice, prisons and

drug treatment centres. The HPA uses data from its national and sentinel surveillance systems to monitor trends in testing and diagnosis that may result from awareness-raising campaigns. Uptake and access to HCV testing is monitored within the general population and in specific settings, including drug services, GP practices and prisons. Testing in other groups with increased risk of infection is also monitored.

1.2.1 Increasing awareness

Professional awareness

Raising professional awareness of hepatitis C is important so that healthcare professionals are fully up-to-date with knowledge of which groups are at particular risk of infection and the current testing algorithms and treatment options. The Department of Health (DH) has continued its ongoing campaign to raise awareness of hepatitis C among healthcare professionals by advertising in specialist journals such as the *British Medical Journal*, *GP* and the *Nursing Standard*. Further information on these initiatives can be found in Chapter 6.

Publications and information materials for healthcare professionals working with risk groups such as injecting drug users and prisoners have also been developed. The British Liver Trust recently published: *A Professional's Guide to Hepatitis C and Injecting Drug Use* and *A Professional's Guide to Hepatitis B*. Reviewed by the HPA, both publications give up-to-date information about viral hepatitis for professionals who work with IDUs or in a primary care setting⁸⁸. The British Liver Trust has also worked closely with Offender Health, the HPA, drug and alcohol teams, HIV charities and prison clinics to produce a range of educational materials on blood-borne viruses aimed specifically at prison staff and prisoners (see Chapter 6).

In October 2009, the Department of Health confirmed funding for the HPA to commission the Royal College of General Practitioners (RCGP) to produce an accredited Certificate in the Detection, Diagnosis and Management of Hepatitis B and C in Primary Care. The project group will develop and deliver the certificate programme in two parts: Part 1, the introductory course, will cover the detection and diagnosis of hepatitis B and C, their aetiologies, transmission, symptoms, management and prevention, and Part 2, the advanced certificate, will cover the above topics in more depth, to include investigations and the assessment of

liver disease as well as treatment options and research. The programme will be tailored to the needs of general practitioners, practice nurses and other healthcare professionals, including drug, sexual health and outreach workers.

The Department of Health has also updated guidance for healthcare professionals on who should be offered HCV testing, the nature of discussions before and after tests, and referral for specialist assessment. The quick reference guide for primary care, which was updated in January 2009, is included in the appendix to this report³⁴.

Public awareness

Raising awareness of hepatitis C in the general population, particularly among risk groups, is crucial for reducing the numbers of undiagnosed infections. As more individuals become aware of their infections they can take steps to reduce transmission of the virus, reduce their risk of developing progressive disease (for example, by moderating their consumption of alcohol), and seek treatment. The Department of Health and other stakeholders, including the NHS and the voluntary sector, have all been actively involved in developing public awareness-raising campaigns for the general public and those groups at particular risk of infection.

To coincide with World Hepatitis Day on 19 May 2009, the Hepatitis C Trust launched a Pharmacy Testing Pilot in 20 pharmacies across England offering free anonymous hepatitis B and C tests to customers at risk of infection (see Chapter 7). It also organised a *Get Tested* bus tour event on 18 May 2009, where a double-decker bus toured key sites in London offering testing.

The UK Hepatitis C Resource Centre, set up by the charity Mainliners, continues to promote awareness and education of hepatitis C. Over the last year it has continued to organise conferences and other projects, including the *Be Blood Aware* campaign, as well as running an information line for public and professionals who require information and advice about hepatitis C (see Chapter 6).

Raising awareness in risk groups

It is estimated that more than 90% of all newly diagnosed HCV infections in England are acquired via injecting drug use. In 2009, the National Treatment Agency (NTA) continued to roll out a *Hep C* campaign as part of its national *Harm Reduction Works* campaign, which informs those working

with injecting drug users about the disease, and drug users about the risks of infection and how to avoid them (further information on this campaign can be found in section 6.2.2). Other groups have also been shown to be at increased risk of infection, including individuals originating from South Asia where the prevalence of hepatitis C is high, and therefore exposure through other routes is more common. It is therefore critically important to raise awareness of hepatitis C in these populations.

In 2009, the Department of Health's hepatitis C awareness campaign *FaCe It* was re-launched as the *Get Tested, Get treated* campaign which targeted former injecting drug users. The campaign advertised in national newspapers, over 70 regional newspapers, on 10 regional radio stations and on bar and pub washroom panels. A further campaign *Hepatitis C. The More you Know, the Better* was launched in 2009 targeting the South Asian population. This campaign included television, press and radio adverts, professional events and community outreach. Further information on both these campaigns is given in Chapter 6.

1.2.2 Trends in testing - Monitoring the impact of awareness-raising campaigns

In England hepatitis C testing facilities are being provided by NHS organisations in a range of clinical and community settings which have enabled marginalised groups such as injecting drug users to be tested. Testing and diagnosis data collected by the HPA via its national and sentinel surveillance systems can then be used to monitor the impact of awareness-raising campaigns in the general population and in key risk groups.

National Outcome Indicator

The total number of laboratory reports of confirmed hepatitis C infection has been set as a National Outcome Indicator². An increase in the number of reports is expected as more testing of risk groups takes place. A total of 8,196 laboratory confirmed diagnoses of hepatitis C infection were reported to CfI in 2008. This is an increase of 6% on the previous year. This continued rise in reports suggests that more infected individuals are being identified.

National monitoring of diagnosis and testing

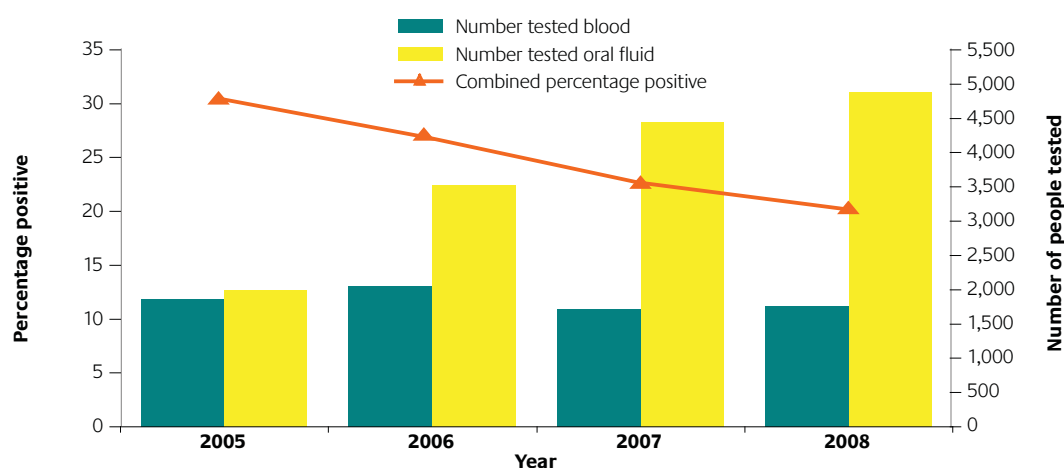
In England, the cumulative total of laboratory reports has continued to increase (see Figure 1), with numbers of reported diagnoses rising year-on-year (see Table 2). Similar trends are observed in data from the Sentinel Surveillance of Hepatitis Testing Study, suggesting that the increase in diagnoses reflects increasing testing activity (see Figure 3). It is likely that the public and professional awareness-raising campaigns have contributed to the higher numbers of HCV diagnoses in England. The falling proportion of tested individuals who are found to be anti-HCV positive over recent years (see Figure 3) is in line with testing being offered to individuals at relatively lower risk of infection – further evidence that these awareness campaigns are having an effect.

Testing and diagnosis in key risk groups

Data from the UAPMP, the Sentinel Surveillance of Hepatitis Testing Study, and from commercial oral fluid testing can all be used to look at trends in testing among key risk groups that have been targeted by recent awareness-raising campaigns.

When sentinel surveillance data from individuals who have accessed testing in specialist services for drug users are combined with data from oral fluid testing, the combined data suggests that numbers of individuals tested for anti-HCV in these service settings have increased year on year between 2005 and 2008 (Figure 14). This increase is largely explained by wider access to oral fluid testing, which has increased each year and may account for the slight decrease in the number of individuals tested by venepuncture between 2006 and 2008. The proportion of people tested who were anti-HCV positive fell from 30.3% in 2005 to 20.0% in 2008 suggesting that testing is being offered widely in these settings, and is not limited to those at highest risk (Figure 14).

Figure 14: Number of injecting drug users tested for anti-HCV in specialist services for drug users, by year, in eighteen sentinel laboratories: 2005 - 2008

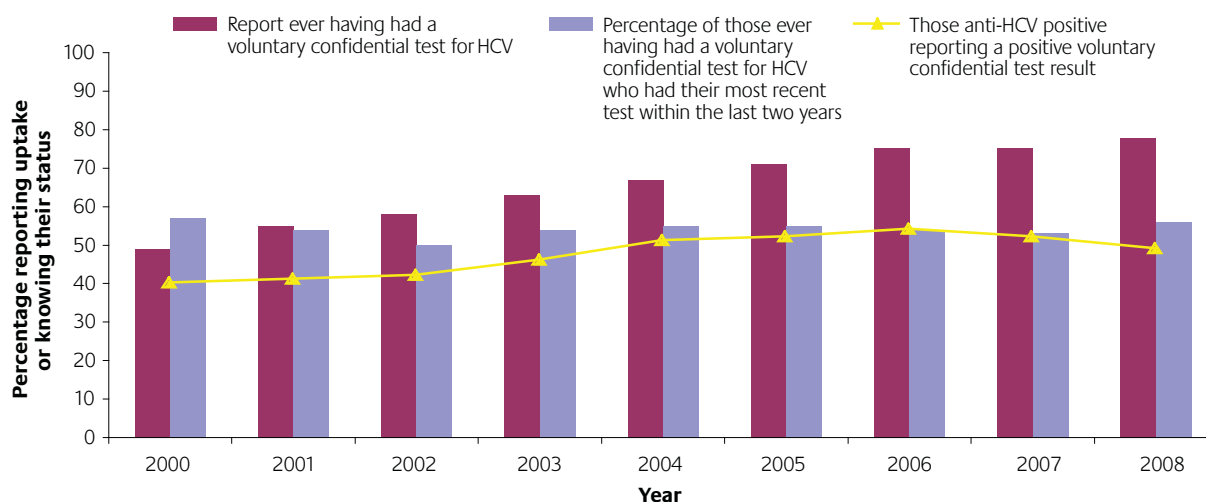


Notes: Sentinel surveillance data excludes reference testing, testing from hospitals referring all samples and children aged <1 year. Only centres with complete data for the whole period were included.

Oral fluid testing data excludes samples tested where a DAT could not be identified.

Data source: Sentinel Surveillance of Hepatitis Testing Study and Altrix Healthcare Ltd (a wholly owned subsidiary of Concateno plc).

Figure 15: 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 - 2008



*Self reports of voluntary confidential test for HCV and the results of the last test.

Data source: Unlinked Anonymous Prevalence Monitoring Programme survey of injecting drug users in contact with drug agencies.

Data from the UAPMP continues to suggest that increasing numbers of IDUs taking part in the UAPMP agency survey report ever having had a voluntary confidential test for HCV, rising to 77% in 2008 (2,114/2,757). This represents an increase from 49% (1,466/2,998) in 2000 (Figure 15).

The proportion of individuals attending specialist drug treatment and support services for IDUs who are aware of their HCV infection has been set as a National Outcome Indicator in the *Hepatitis C Strategy for England*². Of the IDUs who were infected with hepatitis C, the proportion aware of their status in the 2008 survey was 49%, similar to the level reported in the previous year (52%). The proportion of those tested who had a previous test during the past two years was around 56% in 2008, similar to the proportion reported in the previous year (53% in 2007).

National Outcome Indicator

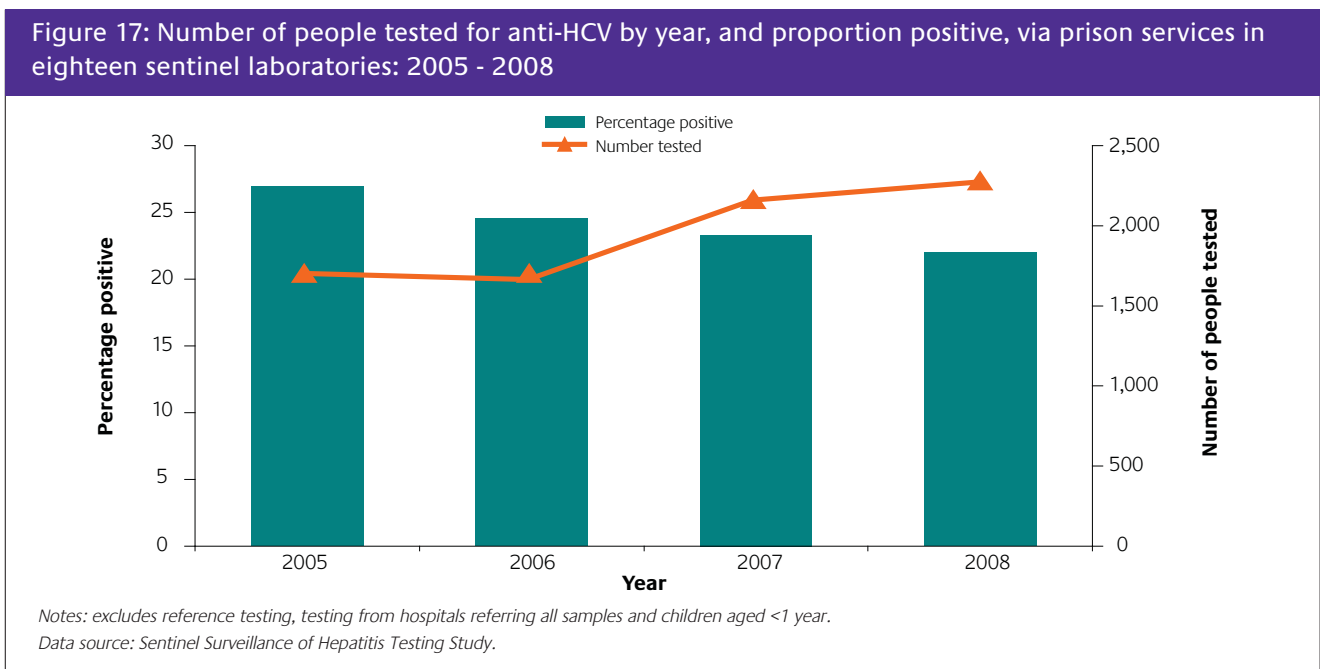
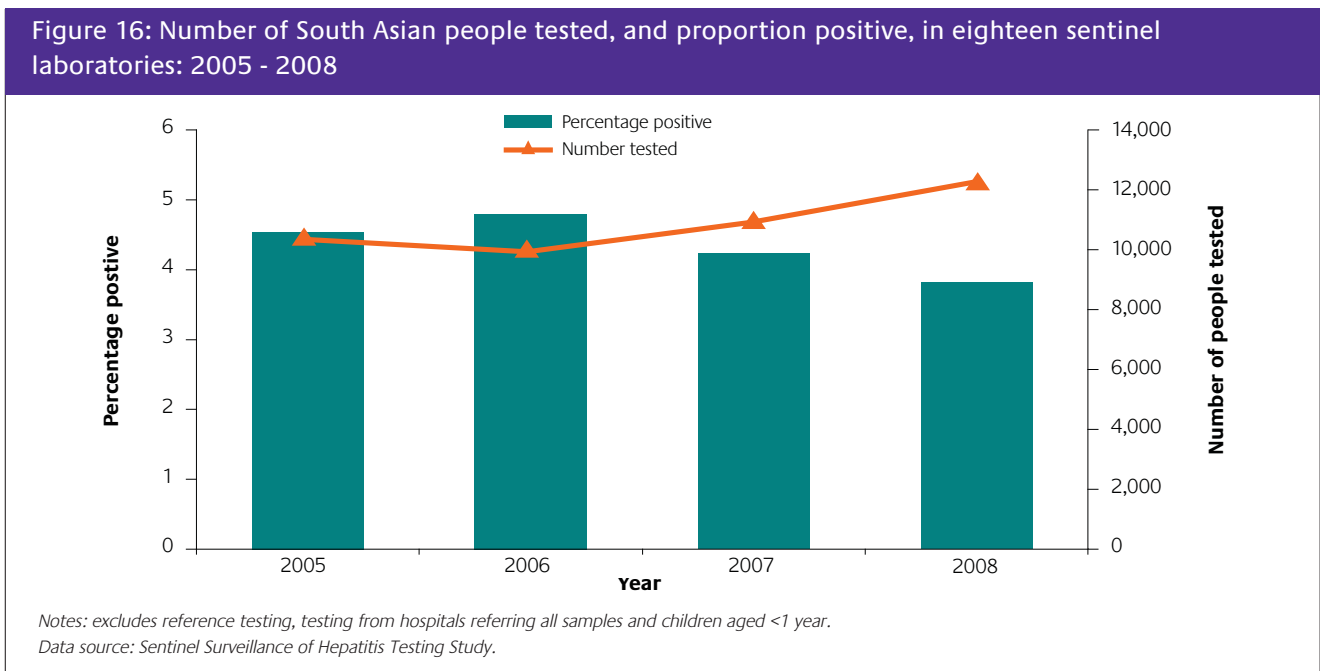
Of the IDUs who took part in the UAPMP agency survey who were infected with hepatitis C, the proportion aware of their positive status in the 2008 survey was 49% compared with 52% in 2007.

When taken together, testing patterns and self-reports suggest that HCV testing among IDUs is increasing, particularly in recent years. However, the proportion of IDUs reporting that they were aware of their positive status has remained fairly stable, or may even be down slightly on previous years. This suggests some impact of awareness-raising campaigns in IDUs, but underlies the importance of ongoing efforts to target this highest risk sub-group of the population.

When Nam Pehchan software is used to identify names of South Asian (Indian subcontinent) origin³, sentinel surveillance data suggest that the number of people tested who were identified as being of South Asian origin increased overall between 2005 and 2008 (Figure 16). The proportion of South Asian people tested has also increased each year between 2005 and 2008. This suggests that an increasing number of South Asian people 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 number of individuals accessing testing in prison health services, and the proportion testing positive for anti-HCV, between 2005 and 2008, in eighteen sentinel laboratories is shown in Figure 17. Overall, surveillance data showed that 7,760 people had been tested in 35 prisons, and that the number of people tested within the prison services increased between 2005 and 2008 (Figure 17). The proportion testing positive has undergone a steady decline each year. Individuals

tested in prison in 2008 were 54.9% less likely to be positive than in 2005 after adjusting for age group and sex (OR=0.55, 95% CI=0.45-0.68, p<0.001). This suggests that more people are accessing anti-HCV testing through prison services, and that testing is being extended to individuals at relatively lower risk of infection than were previously being tested. However, like those who are tested in IDU services, the overall yield of positives remains high (Figure 17).



Testing via primary care

Sentinel surveillance suggests that the number of people tested via GP surgeries has increased each year between 2005 and 2008 and that the proportion of individuals testing positive has also decreased year on year over the same period (Figure 18). Individuals tested in general practice in 2008 were 27% less likely to be positive than in 2005 after adjusting for age group and sex (OR=0.73, 95% CI=0.67-0.80, $p<0.001$). This suggests that people at lower risk of infection are accessing testing in general practice. The rates of increase of testing in primary care (7.0% increase in testing from 2005 to 2006; 12.6% increase from 2006 to 2007, and 13.4% increase from 2007 to 2008), suggest that awareness of hepatitis C in primary care and among the general public is rising.

Reducing the number of undiagnosed infections and getting infected individuals into care is important, both for the individuals themselves and for the wider population. By getting diagnosed individuals into care, they are able to learn about their infections, how to modify their behaviour to reduce their risk of developing more serious disease (for example, by limiting their intake of alcohol) and how to limit transmission of the virus. Eligible patients can also access treatments that can clear the virus in more than half of those treated³⁵. For the wider population, reducing the pool of infected individuals (through treatment) and limiting transmission among those who remain infected will reduce transmission of the virus in the wider population and contribute to reducing HCV-related morbidity and mortality.

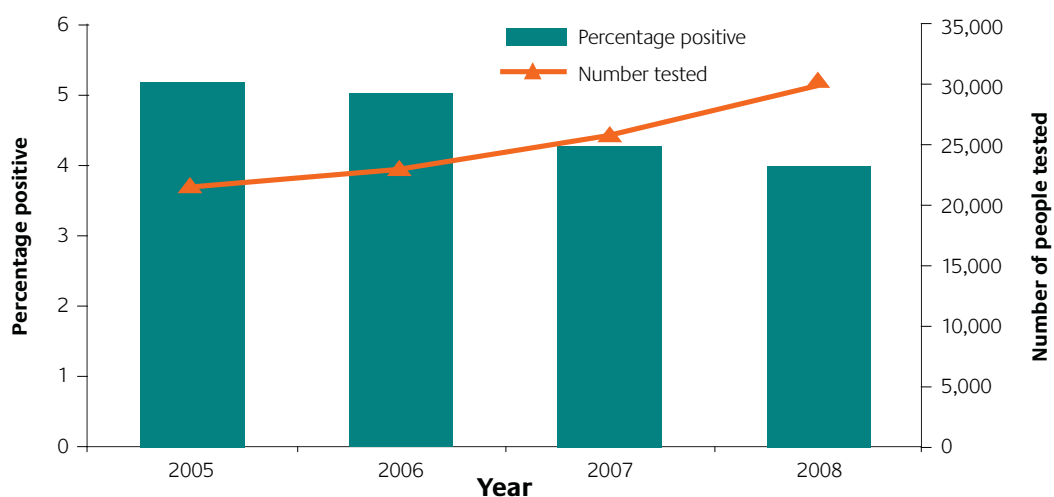
1.3 High-quality health and social care services

Action 3: High-quality health and social care services¹

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.

Data from the Office for National Statistics (ONS), Hospital Episodes Statistics (HES) and UK Transplant all suggest that HCV-related morbidity and mortality is continuing to rise (see Figures 8, 9, 10 and Tables 4 and 5). This underlines the importance of early diagnosis and treatment of HCV-infected individuals. Primary and secondary care services need to be adequate with multidisciplinary networks in place to enable models of best clinical practice to be effective. The Action Plan for England highlights five key areas within this Action and has tasked SHAs with ensuring that local NHS arrangements are in place within their region to achieve them.

Figure 18: Number of people tested for anti-HCV by year, and proportion positive, via GP surgeries in eighteen sentinel laboratories: 2005 - 2008



Notes: excludes reference testing, testing from hospitals referring all samples and children aged <1 year.
Data source: Sentinel Surveillance of Hepatitis Testing Study.

1.3.1 Commissioning specialised services for local hepatitis C populations

Commissioning is the main mechanism for shaping service delivery for local populations³⁶, and commissioning of liver services is currently variable and sub-optimal. To support the commissioning of services for hepatitis C, in 2007 the HPA developed a template to estimate the local prevalence of HCV and the likely numbers eligible for treatment in each PCT. This template automatically provides an estimate of the number of individuals with hepatitis C when a PCT code is entered into the spreadsheet. The template takes into account the prevalence of injecting drug use which varies across regions. Local data on the number of current IDUs has been derived from estimates produced by the Home Office. Data on the prevalence of ex-injectors has been obtained from household surveys, which have been corrected for under-reporting and assigned to broad areas. It also allows for adjustment to be made for local prison populations and the ethnic makeup of the PCT area. Data from local drug action team (DAT) needs assessment can also be used to refine final figures. The template is available on the HPA website³⁷. An audit of PCTs conducted in September 2007 suggested that, although nearly 60% of PCTs had used the template, around four-fifths had not used it to estimate the number (and cost) of patients requiring treatment^{38,37}.

Information on the prevalence of HCV virus among IDUs is an important tool for agencies involved with the commissioning and delivery of services for drug users. The HPA currently collects data on the HCV prevalence among IDUs from around 60 sites across the UK through the national UAPMP survey of IDUs. The UAPMP survey monitors blood borne viral infection levels among IDUs in contact with a broadly representative sample of specialist drug services. As part of this programme, the NTA commissioned the HPA to provide local drug commissioning partnerships with reports placing each area into an HCV prevalence band (low, medium or high). These bandings are based on the HPA's UAPMP data and other local level data, such as the numbers in drug treatment, estimates of the number of problem drug users and crime levels.

High band areas have an estimated HCV prevalence among local injectors of more than 50%. As the majority of those injecting for more than five years will have HCV, those starting to inject are likely to be exposed to HCV fairly quickly.

Medium band areas have a HCV prevalence of between 25% and 50%. In these areas it is estimated that, after around 13 years of injecting, half of IDUs will have been exposed to HCV. Low band areas have a HCV prevalence of less than 25%. In these areas it is estimated that only after around 18 years of injecting will half of IDUs have been exposed to HCV.

While commissioners in all HCV prevalence band areas should ensure that core services intended to prevent infection (needle exchanges, substitution therapy and safer injection advice) are widely accessible, alongside voluntary confidential diagnostic testing for HCV, these bandings are intended to inform more targeted commissioning work. So, for example, as there are likely to be many undiagnosed HCV infections in high band areas, commissioners in these areas should consider investing in preventive interventions such as outreach and safer injection advice. Also, while accessible voluntary confidential diagnostic testing for HCV should be available to all IDUs in low prevalence areas, commissioners in these areas should consider ensuring that testing is targeted at local longer term injectors.

While the estimates presented for each local drug treatment commissioning area should be used cautiously (the methods being used in this process still require further development), they can be viewed as being broadly indicative of the likely prevalence of HCV among IDUs in each area and help to inform future commissioning decisions.

1.3.2 Development of clinical networks for the assessment and treatment of patients with hepatitis C

The development of clinical networks for the assessment and treatment of patients with hepatitis C is a core part of best clinical practice. A paper³⁹ discussing the formation of clinical networks in the UK was published in 2006. At that time 97 comprehensive service providers were identified, including one in virtually all English health authorities, that could provide the focus for a managed clinical network.

The report called for clinical networks to be developed with a critical mass of staff, clear referral guidelines, outreach arrangements and a unified information system to support these networks and to monitor service performance.

Following on from this, the All Party Parliamentary Hepatology Group (APPHG) has undertaken two audits of PCTs in 2006 and 2008^{40,38} addressing the role of hepatitis C clinical networks. By 2008 roughly 54% of PCTs had put such networks in place, up from 31% in 2006, and 68% of PCTs had appointed a hepatitis lead. The report also highlighted the South East Coast region where there is a well established clinical network, but called for more work to be completed to ensure clinical networks were present in all regions.

1.3.3 Access to accredited laboratory services with appropriate diagnostic tests and services

The adequacy of access to microbiology, pathology and radiology services for hepatitis C has not been assessed nationally. National algorithms for microbiology laboratories exist and a recent update to the HCV antibody testing algorithm is currently under consultation⁴¹. The UK National External Quality Assessment Service for Microbiology offers a comprehensive service for external quality assurance for most areas of clinical microbiology. Recent distributions for hepatitis C serology suggest that the quality of performance by participating UK microbiology laboratories is high with 99.8% of participants reporting correct results.

In February 2008, a survey of 46 laboratories across London, Kent, Surrey, Sussex, Essex, Bedfordshire and Hertfordshire was reported³. The survey concluded that there was good coverage of HCV antibody testing across these counties, with 45 out of the 46 participating laboratories performing HCV antibody testing. Sixty three per cent reported following the national algorithms published by the HPA's Evaluation and Standards Laboratory⁴². Roughly 90% performed, or referred samples for a second assay if the first test was positive and 67% of participating laboratories also requested a second sample to confirm a positive result. After the confirmation of a positive HCV antibody test, further tests to establish if the virus was still present were routinely conducted or referred for by 83% of the laboratories surveyed. The numbers of tests performed were high, but the numbers of positive samples remained low in some laboratories, suggesting that it may be more efficient for laboratories to refer samples for confirmatory testing.

As laboratory reports provide an opportunity to encourage better clinical practice, it was reassuring that 72% of participating laboratories recommended referral to a hepatologist for all newly diagnosed cases. Although this large survey suggests that laboratory services are good, there is room for improvement - data from other areas are required to evaluate whether access is equitable across England. In the report *Hepatitis C - out of control*⁴³, The Hepatitis C Trust report that six out of ten of the SHAs have not made any attempt to ensure local NHS arrangements are in place for delivering access to accredited laboratory services.

1.3.4 Development of local protocols between primary and secondary care centres to ensure patient pathways for both medical and social care

The adequacy of clinical provision was assessed in an audit conducted through local Health Protection Units in 2008. This audit suggested that only 48% of PCTs had an established HCV treatment care pathway. Currently there are no national surveillance systems in place to monitor access to, or uptake of, hepatitis C care and treatment in England. However, there is general agreement that the number of individuals currently accessing hepatitis C treatment is sub-optimal for a range of reasons, despite the availability of NICE recommended therapy^{44,45}.

Estimates of the number of patients undergoing treatment with pegylated interferons alpha-2a or 2b and ribavirin can be calculated from hospital pharmacy audit data provided by Intercontinental Medical Statistics (IMS), which are based on information from 97% of acute English hospitals. These calculations indicate that, in 2007, the number of weeks treatment of Peginterferon (Pegasys (2a) and Viraferon-Peg (2b)) purchased would be sufficient to treat about 4,000 patients with hepatitis C as part of combination therapy, and the number of weeks treatment of ribavirin (Copegus and Rebetol) purchased would be sufficient to treat between 3,000 and 4,500 patients as part of combination therapy. The comparable figures for 2008 show an increase of about 20% in the amount of peginterferon purchased which would be sufficient to treat 4,800 patients and a 28% increase in the amount of ribavirin purchased, which would be sufficient to treat between 3,800 and 5,800 patients. However, the accuracy of these figures is compromised for a variety of reasons, including the fact that peginterferon

alfa-2a is also licensed for the treatment of chronic hepatitis B, the treatment of hepatitis C with non-pegylated interferons is not included in the calculations, and data from 3% of hospitals are not available. An additional consideration is that pharmacy figures show only the amount of medication that is purchased, but not necessarily prescribed or taken. As such these figures provide a crude measure of overall uptake of drugs used for combination therapy of hepatitis C, but data is not sufficiently accurate to provide enough to provide valid trends or relate them to the number of patients diagnosed or referred.

In 2009, the HPA received a year's funding from the Department of Health to undertake a pilot project to investigate monitoring hepatitis C-related care in the NHS.

Researchers are using this year to pilot mechanisms for collating national data on the numbers of patients referred and treated for HVC infection and, where possible, on the outcome of their treatment. The project is focusing on collecting data for the year 2007, the last year for which there should be complete information, by distribution of questionnaires.

In many centres this information has not been readily available, so the secondary aim of the project is to investigate and describe any barriers to data provision, and to identify mechanisms to overcome them. Particular emphasis will be placed on the large treatment centres, in order to facilitate and improve data collection in areas where the majority of patients with hepatitis are seen and treated. In many centres, this will involve visits by HPA staff to look at methods of data collection, storage and retrieval and where possible offer help in retrieving data from databases, spreadsheets and, in some cases, from paper records.

In addition to collecting clinic data, the HPA project will explore novel ways of estimating the numbers of individuals undergoing treatment for hepatitis C. These include using currently available data sources, such as hospital prescribing and hospital episode statistics (HES) and also pharmaceutical company data.

By the middle of next year, the HPA hopes to have more complete information on hepatitis C service provision. This will be reported to DH along with a description of the barriers to the effective storage and retrieval of the data that could, in the future, provide this information on a regular basis.

1.3.5 Develop arrangements to ensure that the NHS has enough appropriately skilled staff to deliver service improvements to patients with hepatitis C infection

The APPHG report *Location, Location, Location*³⁸ also surveyed NHS Hospital Trusts to review the number of staff in place. The APPHG was disappointed by the number of responses to the survey, but the number of consultants and specialist nurses in the 141 NHS Hospital Trusts that responded had risen steadily between 2006 and 2008 (from 99 to 124 and from 51 to 68 respectively). It is not clear, however, to what extent this increase has kept pace with the increasing demand from increasing diagnosis. This may have contributed to the finding that 59% of responding NHS trusts reported that some of their patients had their treatment delayed for more than three months from their first hospital consultation. The most recent survey by The Hepatitis C Trust *Hepatitis C - out of control*⁴³, reports that the workforce directorates in six of the ten SHAs had not worked with Care Group Workforce Teams to ensure that there were sufficient numbers of appropriately skilled hepatitis C staff in their regions.

1.3.6 Strategic health authorities will ensure that local NHS arrangements are in place to achieve the objectives of this action area

The degree to which strategic health authorities are monitoring the provision of high quality health and social care services for individuals with hepatitis C has been questioned^{43,46}, and it is critically important that hepatitis C provision is monitored at national level.

Strategic health authorities have been tasked with ensuring that primary care trusts and hospital trusts undertake the actions assigned to them to deliver high-quality hepatitis C health services. To audit their performance in this area, the Hepatitis C Trust used Freedom of Information requests to ask SHAs 17 questions relating to their oversight role; their findings suggest wide variation in SHA performance in this area⁴³. In particular, only three SHAs had any direct oversight of commissioning in their areas.

Improved service provision may result from collaborative approaches across more than one PCT. For example, in Greater Manchester a multi-agency group developed a strategy based on the results of a comprehensive health needs assessment and a consensus model funded by all PCTs in the Greater Manchester area. It is not clear how much support is offered by SHAs to local commissioners, for example by encouraging such collaborative approaches. NHS North West has also recently commissioned a rapid review to produce some clear recommendations to improve the way the NHS prevents and treats hepatitis C in the region. This model may provide a way forward that other strategic health authorities could adopt.

1.4 Prevention

Action 4: Prevention¹

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.

Prevention strategies focus primarily around injecting drug use, as this is the most important risk factor for acquisition of the virus in England today (see Table 3). Reducing the number of individuals who begin injecting drugs; encouraging injectors to quit injecting; reducing risky behaviour (like sharing needles and syringes) in those who continue to inject, and the early diagnosis and treatment of those who become infected with HCV are all components of the prevention programme. The delivery of successful prevention programmes in this challenging risk group requires the integrated input of government, professional organisations and public health and healthcare professionals from a variety of clinical, social and drug service backgrounds.

The 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 injecting drug users

The NTA, local drug partnerships and prison service have all been reviewing and strengthening harm reduction services for the prevention of hepatitis C transmission associated with injecting drug use. In line with best clinical practice, as set out in the *Hepatitis C Strategy for England*², recent efforts have been focused in the following areas.

Provision of needle, syringe and other injecting equipment exchange services in the community

The National Institute for Health and Clinical Excellence's (NICE) public health guidance 18, *Needle and Syringe Programmes: Providing People who Inject Drugs with Injecting Equipment*⁴⁷, issued in February 2009, promotes the optimal provision of needle and syringe programmes (NSPs) for people over 18 who inject illicit substances. It endorses the supply of sterile needles and syringes and other injecting equipment used to prepare and take illicit drugs, in order to reduce the transmission of blood-borne viruses and other infections caused by sharing injecting equipment. It recommends that Local Strategic Partnerships, local drug partnerships (including DATs), drug joint commissioning managers and PCT commissioners commission a mix of generic and targeted needle and syringe programme services to meet local needs, and that services should aim to increase the proportion of injecting drug users in contact with NSPs and increase the proportion of people who have 100% 'coverage' (defined as the number who have more than one sterile needle and syringe available for every injection). Because NSPs may be the only contact that some people have with health services, they have an important role in providing information and advice as well as in acting as an effective 'gateway' to other services, including drug treatment.

In July 2009, the NTA and NICE jointly hosted *Delivering Effective Needle and Syringe Programmes – Implementing NICE Guidance*, a national event to promote the NICE NSP guidance. The NTA has posted all the presentations from the implementation event on its website⁴⁸.

NICE have also produced extensive supporting information on implementing the recommendations contained in the guidance. The NICE commissioning guide, published on 18 September 2009, includes further advice on how to assess need and improve needle and syringe coverage⁴⁷; this and other supporting materials, along with the full guidance, are available on the NICE website⁴⁷.

The NTA commissioned *Exchange Supplies* to produce a web resource as part of the *Harm Reduction Works* campaign. The 'coverage calculator' is an online tool designed to help estimate the extent to which the number of syringes being distributed to illicit drug users within an area compares to an estimate of the potential need for sterile injecting equipment. It is available through the *Harm Reduction Works* website at www.harmreductionworks.org.uk (for more information on the *Harm Reduction Works* campaign, see section 6.2.2).

The Needle Exchange Monitoring System (NEXMS) has been developed to provide local, regional and national figures for the amount of injecting equipment distributed, and estimated numbers of needle/syringes returned and needle exchange clients. The first reports estimating local needle exchange activity were distributed to local drug commissioning partnerships in September 2009 and will be used to inform the 2010/11 local drug treatment planning round. This information will complement the routine auditing of harm reduction 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 regional teams work with partners to identify where shortfalls exist and plan appropriate remedial action.

Safe disposal of used needles and syringes

The recent NICE guidance gives recommendations for the safe disposal of used needles and syringes. This includes the provision of sharps bins, advice on how to dispose of needles and syringes safely and recommendations for the provision of services for the safe disposal of used equipment in a variety of settings, including community pharmacies and specialist needle and syringe programmes⁴⁷.

Provision of outreach and peer education services

As part of *Reducing Drug-related Harm: An Action Plan*⁴⁹, the NTA funded eight innovative user and carer led projects to increase awareness of drug-related harms among users, carers and their families and friends, and how to develop ways to reduce those harms. These initiatives, which started in July 2008, included:

- improving awareness of, and access to, harm reduction services among rough sleepers in Rotherham.
- work in Nottinghamshire to help service users and carers better understand hepatitis and support their loved ones to complete hepatitis treatment.
- a DVD produced by service users in Wolverhampton that aimed to increase knowledge about drug related harm among local drug users.

The lessons learnt from these projects should help other service user groups, their carers and families and friends to develop similar initiatives in their areas.

Provision of specialist drug treatment services

Good quality drug treatment services play a vital role in helping to reduce the spread of hepatitis C among IDUs by helping people reduce and/or stop injecting and sharing injecting equipment. England has an ambitious community drug treatment programme, which currently caters for around half the country's estimated number of problem drug users and has the highest rate of new entrants of any similar programme globally⁵⁰. The overall number of individuals in contact with treatment services has more than doubled since 1998. Figures provided by the National Drug Treatment Monitoring System show a 3% increase in the numbers of individuals aged over 18 years in treatment, from 200,805 in 2007/08 to 207,580 in 2008/09. Drug treatment services can also help to ensure that injectors are offered a test for HCV and, if appropriate, refer them for treatment and support.

Provision of specialist drug treatment services for offenders

The Integrated Drug Treatment System (IDTS) was launched in 2006 to improve the quality of, and increase the numbers receiving, drug treatment in prisons. The NTA project managed the roll-out of IDTS from April 2008, working alongside the National Offender Management Service (NOMS), the Department of Health and a range of regional stakeholders. By the end of 2008/09, 76 prisons had the programme as their primary drug treatment regime, and it is expected that this number will rise to 130 prisons by the end of 2009/10. There were some 25,076 admissions to drug treatment in the first 53 IDTS prisons in 2008/09, and the project is due to be completed in 2011⁵¹.

Until now there has been no single source of data on drug treatment for offenders; NOMS, national drug treatment monitoring system (NDTMS) and the drug intervention programme (DIP) have all collected data separately. The situation will become clearer, as from April 2009 existing data collection systems were updated to ensure that all data about prison-based drug treatment could be reported to NDTMS. The first count of the total numbers of prisoners in structured drug treatment should be available once data is sufficiently robust to report as national statistics.

Provision of disinfecting tablets throughout the prison estate

In October 2007 disinfecting tablets and specially designed dispensers were distributed to adult prisons across England and Wales.

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)

In addition to the Department of Health's hepatitis C awareness-raising campaigns (see Section 1.2 and Chapter 6), the NTA has developed a number of initiatives to raise awareness of HCV and its transmission routes, both for injecting drug users and those working with these risk groups. In 2008, the NTA initiated its *Harm Reduction Works* campaign which comprised a website and a wide range of free print and film resources giving information on harm reduction.

Raising awareness schemes have also been set up by the charity Mainliners. Its UK Hepatitis C Resource Centre (see Section 1.2) promotes education and awareness of hepatitis C, provides educational materials, organises conferences and runs an information line for the public and professionals. *Be Blood Aware* is a campaign (see Section 1.2) developed by Mainliners which has been used at a number of venues across the country; the campaign focuses on the main risk factors for HCV transmission.

1.4.2 Prevention in other risk groups

All NHS organisations are required to minimise the risk of HCV transmission within healthcare settings by adopting rigorous standard universal infection control precautions, occupational health checks for staff and effective management of occupational blood exposure incidents. *The Health Act 2006 Code of Practice for the Prevention and Control of Health Care Associated Infections*⁵² is in place to help NHS bodies plan and implement ways in which they can prevent and control healthcare-associated infections (HCAIs), including hepatitis C.

Within the Code are clinical care protocols for infection prevention and control that NHS bodies should have in place, including appropriate core policies on Standard (universal) infection control precautions, safe handling and disposal of sharps, management of occupational exposure to BBVs, post exposure prophylaxis and the requirement to report all HCAIs to the HPA. The Codes of Practice also lay down the duties of management to ensure compliance with these protocols.

Local authorities are continuing to work with NHS organisations to promote and audit good infection control practice in cosmetic skin piercing businesses, to provide information to the public about the potential health risks and how to choose a reputable business. The Health and Safety Executive's Local Authority Circular on Health and Safety issues relating to body piercing, tattooing and scarification (LAC No.76/2)⁵³ is scheduled for review in April 2010. The guidance is intended for health and safety inspectors but is also available to manufacturers, importers, suppliers, purchasers, practitioners and anyone considering these treatments. Local Authority enforcement officers ensure that certain levels of hygiene and training exist, that operators are correctly licensed, there is effective infection control, a suitable working environment is maintained, and that no aspect of the business on the registered premises adversely affects the health of the public or those employed.

The NHS Choices website also hosts pages on body piercing, including concise information on the importance of safe piercing, risks (including transmission of BBVs) and information on how to prevent and treat infections⁵⁴.

The Department of Health produced the *Travel Safe* leaflet in 2008. This leaflet provides information for travellers on how to avoid becoming infected with HCV and other blood-borne viruses abroad⁵⁵.

1.4.3 Monitoring the impact of prevention messages

Levels of injecting among the drug-using population

The NTA analysed NDTMS data for the 2008/09 treatment population to look at injecting status (current and previous injectors). These figures show that over half of the current treatment population (n=207,581) are injectors, of whom 30.2% are current injectors and 25.1% have had a history of injecting. Of the 83,080 clients newly presenting to treatment in 2008/09, 38,750 (22.8%) are current injectors (see Table 7).

Levels of sharing needles/syringes and injecting paraphernalia

The UAPMP survey of current and former IDUs in contact with drug agencies monitors self-reported sharing of needles and syringes (direct sharing) in the survey population. In 2008, 19% (316 of 1,683) of current injectors (those who reported injecting within four weeks before participating in the survey) reported direct sharing in England. This level has declined in recent years from 28% in 2005 (Figure 19). Among current injectors, 37% (613/1,668) also reported sharing of filters, mixing containers and flushing water²⁶ in 2008. As with direct sharing, the proportion reporting sharing of such equipment has declined in recent years.

Table 7: Injecting status of clients in drug treatment 2008 - 2009

Injecting status	In treatment 2008/09	Newly presenting in 2008/09
Current injector	62,770	18,956
Previous	52,209	19,794
All injectors	114,979	38,750

Data source: National Drug Treatment Monitoring System.

Note: 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 which is wholly or partially within 2008/09.

If a person has been classified as 'currently injecting' and 'previously injecting' they are assumed to be 'currently injecting'.

'Newly presenting' refers to a person starting a new treatment journey in the financial year 2008/09.

Like HCV antibody prevalence, the proportion of injecting drug users who share needles and syringes varies between regions. In 2008, the highest levels of direct sharing were observed in the South East (25%, 92/401), and the lowest levels of direct sharing were seen in the West Midlands (16%, 52/325). This is likely to reflect different historical patterns of drug use and service provision in different regions.

Figure 19: Trends in sharing of needles and syringes in the past four weeks among injecting drug users in England: 1998 - 2008

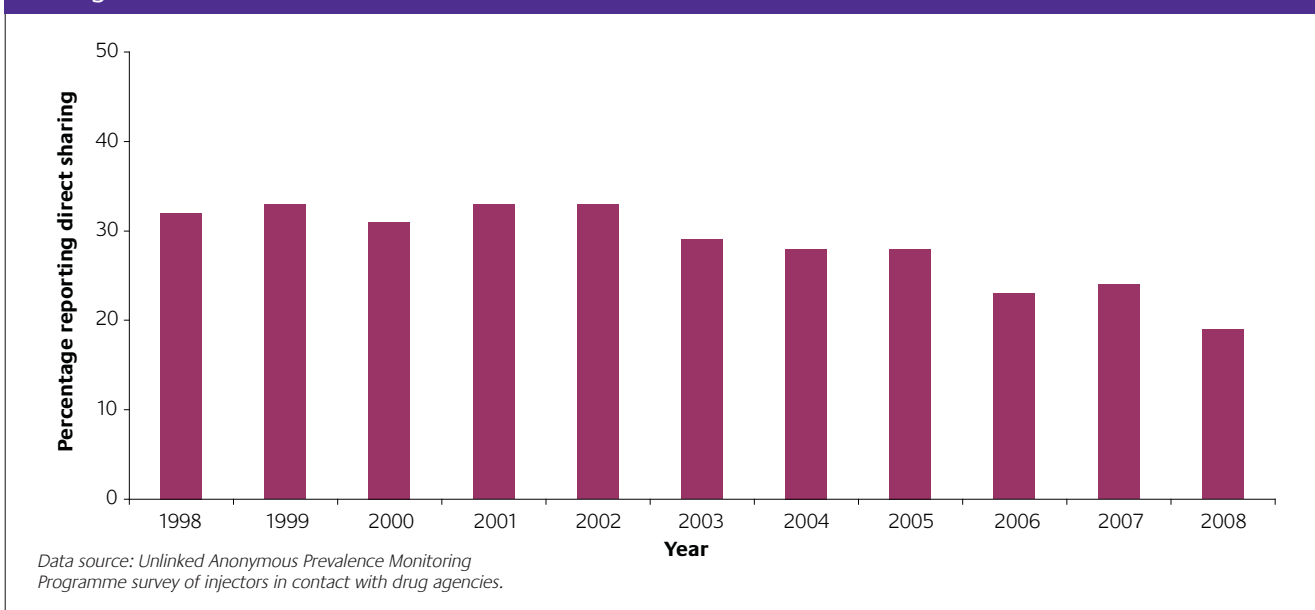


Table 8: Hepatitis C test status of clients in drug treatment 2008 - 2009

	In treatment 2008/09		Newly presenting in 2008/09	
	All persons (percentage of total treatment population)	Injectors (percentage of total treatment population)	All persons (percentage of total treatment population)	Injectors (percentage of total treatment population)
Has a hepatitis C test recorded	74,040 (35.7)	53,969 (46.9)	26,906 (32.4)	17,578 (45.4)
Does not have a hepatitis C test recorded	133,541 (64.3)	61,010 (53.1)	56,174 (67.6)	21,172 (54.6)
Total	207,581	114,979	83,080	38,750

Data source: National Drug Treatment Monitoring System.

Note: A person is classed as having a hepatitis C test recorded by the presence of a test date in any episode of treatment which is wholly or partially within 2008/09. Not having a hepatitis C test date does not automatically mean they have not had a test.

'Newly presenting' refers to a person starting a new treatment journey in the financial year 2008/09.

Levels of hepatitis C testing in the drug-using population

The NTA analysed the NDTMS data for the 2008/09 treatment population to look at hepatitis C test status and intervention status (whether the client was offered a test for hepatitis C, and if that offer was accepted by the client). Just under half of all injectors (current and previous injectors) currently in treatment were recorded as having had a hepatitis C test (46.9%, n= 53,969). A slightly smaller proportion of all injectors newly presenting to treatment (45.4%, n=17,578) were recorded as having had a hepatitis C test (see Table 8).

Figures show that nearly 60% of injectors currently in treatment have been offered a test for hepatitis C while in contact with drug treatment (56.7%, n = 65,217), and 38.5% accepted that offer. The figure rises for injectors newly presenting to treatment, where around 70% have been offered a test for hepatitis C (n = 27,087), and nearly half accepted that offer (see Table 9).

Proxy measures of incidence in the IDU population

The number of laboratory reports of infections in 15-19 year olds has remained fairly constant over the last few years, while the number of infections in individuals aged 20-24 has continued to fall since 2005 (see Figure 4). This decline in the number of laboratory reports in young adults (an indicator of incidence) has occurred despite evidence of an increase in testing.

Data from the UAPMP agency survey shows a slight fall in anti-HCV prevalence among current injectors in contact with drug services (see Figure 6), and a similar fall in anti-HCV prevalence is observed among current injectors aged less than 25 years over the last couple of years. However, this fall is not observed among current injectors who injected for the first time during the last three years (see Figure 6).

Current developments to the UAPMP include a pilot to replace oral fluid with dried blood spot (DBS) testing. The expansion of this pilot over the next two years will enable the generation of incidence estimates using techniques to distinguish window period infections (by detecting HCV RNA positive, anti-HCV negative individuals).

Table 9: Hepatitis C intervention status for clients in drug treatment 2008 - 2009

Recorded hepatitis C status	In treatment 2008/09		Newly presenting in 2008/09	
	All persons (percentage of total treatment population)	Injectors (percentage of total treatment population)	All persons (percentage of total treatment population)	Injectors (percentage of total treatment population)
Offered and accepted	67,936 (32.7)	44,292 (38.5)	31,983 (38.5)	18,193 (46.9)
Offered and refused	42,319 (20.4)	20,925 (18.2)	21,872 (26.3)	8,894 (23.0)
Not offered	27,507 (13.3)	13,506 (11.7)	13,595 (16.4)	5,504 (14.2)
No recorded status	69,819 (33.6)	36,256 (31.5)	15,630 (18.8)	6,159 (15.9)
Total	207,581	114,979	83,080	38,750

Data source: National Drug Treatment Monitoring System.

Note: Hepatitis C status is taken according to the 'best' status recorded in any episode of treatment which is wholly or partially within 2008/09, i.e. 'offered and accepted' is selected over 'offered and refused' and so on.

'Newly presenting' refers to a person starting a new treatment journey in the financial year 2008/09.

1.5 Summary

A variety of national surveillance systems are in place to monitor HCV infection in England. Both laboratory reporting and sentinel surveillance suggest that more individuals are being tested and diagnosed year on year. Surveillance systems continue to show that most new infections are acquired via injecting drug use. More direct methods for estimating incidence in injectors are being implemented. Laboratory reports and infections in blood donors suggest that other risks are important too, like body piercing and originating from a country where HCV is endemic. Infections in young adults have continued to fall despite increases in reports of newly diagnosed infections. Since the rate of testing in this age group is increasing this suggests a fall in incidence within the tested population. The number of hospital admissions, liver transplants and deaths due to hepatitis C-related end-stage liver disease or hepatocellular carcinoma has continued to increase.

Data from SNAHC provide evidence of ongoing sexual transmission of HCV among HIV positive MSM, many of whom engage in high risk sexual practices. Although falling over recent years, the UAPMP data suggests that the prevalence of anti-HCV in drug users remains high, varies hugely around the country, and is increasing in recent initiates to injecting.

Genotype 1 and 3 infections still predominate in England and national mortality, hospital admission and transplant data all show that HCV-related end-stage liver disease is continuing to rise. Continued efforts to diagnose and treat HCV infected individuals are required if the future burden of HCV-related end-stage liver disease is to be minimised.

Overall, trends in national testing suggest that awareness of hepatitis C may be increasing in the general population as well as in key risk groups, like IDUs and individuals of South Asian origin. Increased levels of testing and the falling proportion testing positive both support the fact that awareness campaigns may be having an effect. Increasing

numbers of individuals accessing testing via primary care and the highest ever levels of IDUs reporting voluntary confidential HCV testing suggest that awareness is increasing among professionals, the public and in key risk groups. However, campaigns will need to be sustained and enhanced if the burden of disease from undiagnosed infection is to be reduced.

The HPA and the NTA have worked with stakeholders on initiatives to support the commissioning of services for hepatitis C. However, there is still further work to be completed to ensure clinical networks are present in all regions and that access to microbiology, pathology and radiology services for hepatitis C is equitable across England. Over the coming year it is hoped that the HPA pilot study looking at the monitoring of hepatitis C-related care in the NHS and at novel ways of estimating the numbers of individuals undergoing treatment, will help to provide more complete information on hepatitis C service provision in England. It is critically important that hepatitis C provision is monitored at national level, and the degree to which strategic health authorities are monitoring the provision of care has been questioned.

From the prevention perspective, data from the NDTMS is supported by that from the Sentinel Surveillance of Hepatitis Testing Study and the UAPMP suggesting that hepatitis C testing in IDU populations has increased in recent years. Likewise, NDTMS and UAPMP data supports the case that levels of risk behaviours (injecting and sharing) may have fallen. Laboratory reports and UAPMP data suggests that infections in young adults, which serve as a proxy measure for incident infections, may be falling, making up an increasingly smaller proportion of HCV infections overall. This data suggests that harm minimisation strategies and awareness-raising programmes may be beginning to have an effect.

For those IDUs diagnosed with HCV, it is critically important that services are configured in such a way that pathways into treatment are accessible for this population group.

2.0

Northern Ireland



2.0 Northern Ireland

In January 2007, the Department of Health, Social Services and Public Safety (DHSSPS) issued its Action Plan for the Prevention, Management and Control of Hepatitis C in Northern Ireland⁵⁶. The plan detailed fourteen recommended actions. A summary of the progress against these actions is given below.

2.1 Prevention

2.1.1 Increasing awareness and understanding

Action 1

The Health Protection Agency (HPANI) in conjunction with hepatologists and other key stakeholders has developed public information materials on hepatitis C infection, including *Hepatitis C – Could I be at risk?*⁵⁷

Action 2

An information leaflet for primary care professionals⁵⁸ has also been developed to enable them to:

- recognise the risk factors for, and symptoms of, hepatitis C infection.
- have an informed discussion with patients about hepatitis C.
- offer testing for hepatitis C to those at risk.
- appropriately refer those with hepatitis C infection for specialist assessment and management.

A programme of education and training for general practice has begun and will continue in 2009 and 2010. The regional hepatology service has developed training for GPs on liver disease which includes a section on hepatitis C risk factors, prevention, testing and treatment. Delivery of this training is facilitated by the Family Practitioner Units across Northern Ireland. An update on the work of the managed clinical network has also been distributed.

During 2010, the needs of further groups of professionals will be considered and targeted training materials developed.

Action 3

The Regional Virus Laboratory now provides an information sheet when communicating all hepatitis C positive test results to clinicians. This covers implications of the positive result, and advice on further testing, referral and infection control measures⁵⁹.

2.1.2 Injecting drug users (IDUs)

Action 4

Injecting drug use is the leading risk behaviour for transmission of hepatitis C. Progress has been made in a number of areas highlighted in the Action Plan, as outlined below. Further development of information materials for IDUs is planned for 2009/10.

- In 2008, responsibility for healthcare services within prisons in Northern Ireland was transferred to the South Eastern Health and Social Care Trust. Liaison meetings have taken place with the Trust and NI Prison Service (NIPS) to promote actions to reduce hepatitis C transmission and harm reduction services in the prison environment. These built on the work already undertaken by the Prison Service with Drug and Addiction services and voluntary groups. This liaison will continue.
- Annual updates for addiction services from the specialist hepatology nurses based at the Liver unit have commenced. These are interactive sessions where updates on testing, referral and treatment are given by the hepatology nurses and issues such as low attendance at hepatology clinics can be discussed. These sessions will increase communication and develop relationships between addictions staff and the specialist nursing staff. Additional training for other groups, for example the voluntary sector, will be considered in 2010.



- The Health Protection Agency presented findings from the UAPMP agency survey⁶⁰ to Addiction Service representatives from the four Health Trusts in Northern Ireland and members of the prison service in May 2008. The findings of this survey were that 21% of current injectors who participated shared needles and syringes, and 26% shared other equipment in 2006 and 2007. The prevalence of hepatitis C antibodies in participants in Northern Ireland in 2006 and 2007 was 29%. One quarter were unaware of their hepatitis C status, but only 8.8% had not been tested for hepatitis C at some stage. These findings are of tremendous importance in indicating the importance of harm reduction measures and encouraging testing and treatment if indicated. It is hoped that sharing these results will encourage increased participation in the survey by addiction professionals and prison health care staff.
- The Health Development Policy Branch, the Department of Health and Social Services and Public Safety (DHSSPS), has agreed to fund a pilot of blood spot testing as an alternative to venous blood testing. This pilot targets intravenous drug users in the Northern Trust area and began this year. The future role of this technique will be considered following the pilot.
- A regional multi-agency addiction subgroup has been established.
- Expansion of the needle exchange programme has been agreed in the Northern Trust area for four additional fixed pharmacy sites and out-reach provision to be provided by drug out-reach workers and Northern Trust Addiction staff.

2.1.3 Health care settings

Action 5

DHSSPS has issued further guidance on health clearance for health care workers regarding tuberculosis, hepatitis B, hepatitis C and HIV⁶¹ and is also developing guidance on the management of hepatitis C-infected healthcare workers.

Action 6

Trusts regularly review local guidelines on the prevention of blood-borne viruses and policies on the management of blood exposure incidents. Training for all staff is under review in the light of the guidance recently issued by DHSSPS.

2.1.4 Cosmetic piercing

Action 7

DHSSPS has published guidance⁶² on the regulation of cosmetic piercing and skin colouring businesses, enforceable through by-laws.

2.1.5 Prisons

Action 8

The Northern Ireland Prison Service (NIPS) has updated its policy on the prevention and control of blood-borne viruses. NIPS is also part of the managed clinical network (MCN). Very useful liaison has been established between NIPS, the South-Eastern Health and Social Care Trust, who have responsibility for prison healthcare services, and the regional hepatology service. An education day was held in 2009 for the Northern Ireland Prison Service and further visits are planned. Preparation has been made for the delivery of HCV treatment to prison inmates should the need arise.

2.2 Clinical services

Action 9

DHSSPS-endorsed NICE guidance on the treatment of people with chronic hepatitis C is being followed.

A care pathway, including referral and treatment guidelines, has been developed and agreed. Links have been established with the Peninsula Hepatology Group, South West England to undertake quality assurance of HCV diagnosis and management in Northern Ireland. The care pathway has been peer reviewed by the Peninsula Hepatology Group clinical lead. Feedback has been obtained through a questionnaire from patients who have received treatment and this is being used to enhance diagnostic and treatment services.

Action 10

A second hepatology nurse specialist was appointed in spring 2008, significantly enhancing the team and increasing capacity. This additional resource has also facilitated the development of enhanced links with drug addiction services and prison services.

Action 11

Eastern Health and Social Services Board facilitated the development of the MCN for hepatitis C. Launched in October 2007, the network is drawn from a range of groups including hepatologists, gastroenterologists with an interest in hepatology, specialist nurses, virologists, public health specialists, commissioners of services, drug treatment services and health promotion specialists.

Responsible for coordinating the overall management of people with chronic hepatitis C infection, key aims are to ensure equity of access to treatment and care, and that models of best practice are followed and audited. The network has also been charged with working in partnership with others to provide high quality surveillance arrangements to profile the epidemiology of hepatitis C and to inform prevention and control activities as well as service provision. Workstreams have been established in education and awareness, surveillance, drug and addiction services, and diagnostic and treatment services.

The structure and membership of the MCN will be reviewed in 2009/10 following the re-organisation of the health services in Northern Ireland.

2.3 Information and research

Action 12

The MCN has reviewed surveillance arrangements for hepatitis C and future arrangements have been agreed. Objectives of surveillance are as follows:

- Determine prevalence of HCV and trends in transmission.
- Recognise new modes of transmission including nosocomial routes.
- Determine the size of the gap between individuals detected as HCV positive and patients presenting for treatment.
- Inform decisions about service provision.
- Fulfil director of public health (DPH)/consultant in communicable disease control (CCDC) responsibilities.

Risk factor information will be collected proactively, as will information on referral and treatment. An annual report will be prepared. When appointed, the MCN manager will take forward these actions. Development of further policy on follow-up of individuals who have not been referred is a key issue for 2010.

2.3.1 Laboratory reports of HCV infection

Laboratory confirmed HCV infections have remained static at around 135-140 cases annually for the years 2005-2008 (Figure 20), and the majority of cases continue to be in the 25-54 year old age group (Figure 21).

Risk factor information remains difficult to obtain, but where this is available injecting drug use remains the most commonly reported risk. Improving the availability of this information is a priority in the workplan for the MCN in the next 12 months.

Figure 20: Hepatitis C laboratory reports in Northern Ireland: 1990 - 2008

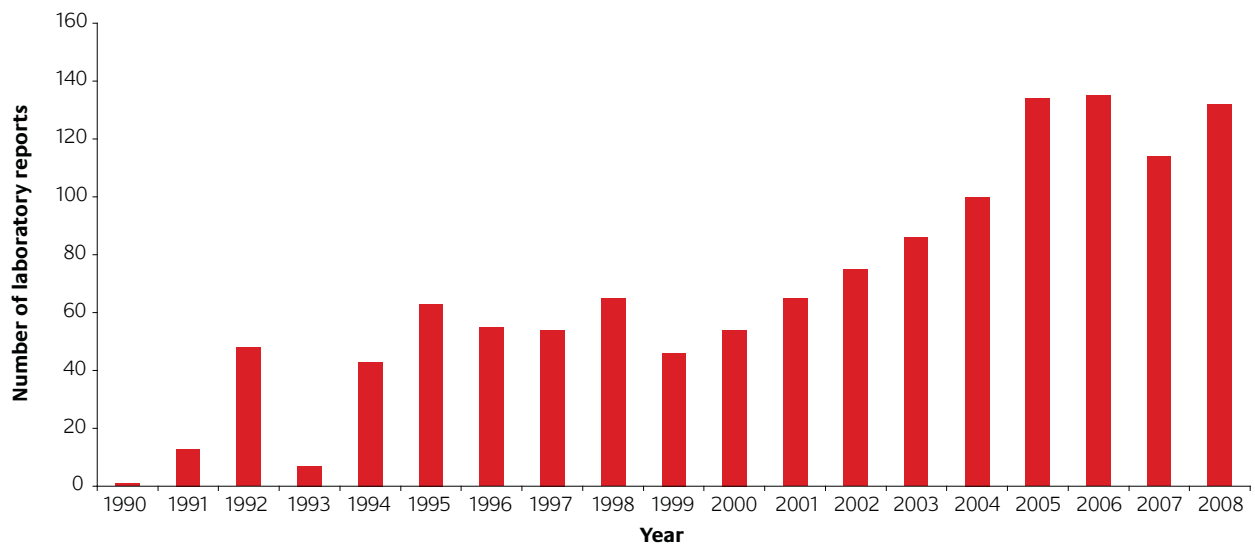


Figure 21: Hepatitis C laboratory reports by age in Northern Ireland: 1999 - 2009

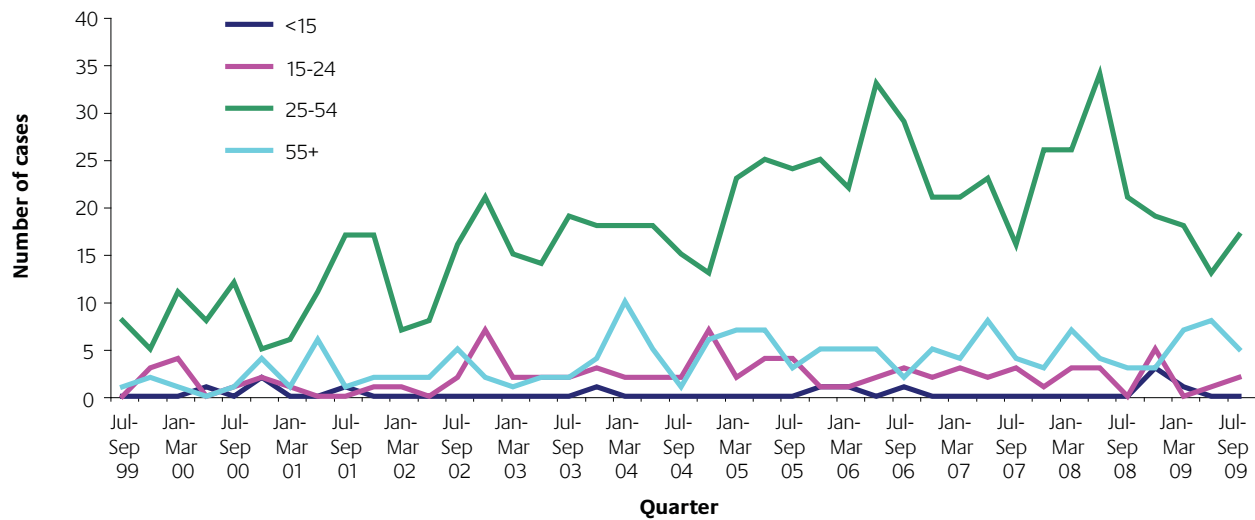
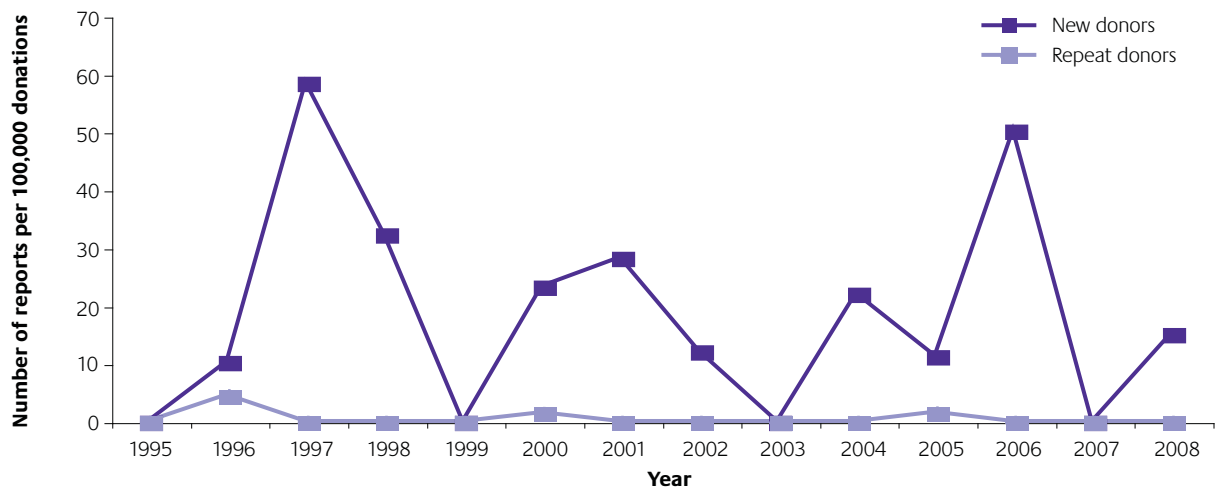


Figure 22: Frequency of hepatitis C in blood donors in Northern Ireland: 1995 - 2008. New and repeat donors



Data source: NHSBT/HPA Epidemiology Unit using data supplied by NIBTS from 1995 onwards.

2.3.2 Blood donor testing

The Northern Ireland Blood Transfusion Service (NIBTS) collects blood from voluntary donors who are selected to be at low risk of blood-borne infections, such as hepatitis C, in the same way as other UK blood services. The frequency of positive donations detected among people wishing to donate blood for the first time (new donors) in Northern Ireland has been variable since 1995, when surveillance data became available, and was zero in a number of years. In 2008, only one new donor tested positive for hepatitis C. This approximates to around 15.2 per 100,000 donations tested (Figure 22). In 2008 there were no hepatitis positive repeat donors. Hepatitis C-positive repeat donors were only found in 1996, 2000 and 2005.

2.3.3 Deaths and transplants

Between 2001 and 2008, there was only one death with an underlying cause of chronic hepatitis C registered in Northern Ireland. This death occurred in 2006 with the primary cause of death registered as hepatocellular carcinoma. This and additional surveillance data, such as blood donor testing (Figure 22) and hepatitis C diagnosis in registrations for liver transplants (Figure 23), continue to indicate that Northern Ireland has a low prevalence of hepatitis C infection and hepatitis C-related end-stage liver disease.

2.3.4 Hepatitis C testing

A key priority for the MCN is to further increase the identification of undiagnosed hepatitis C infections. A programme of public and health professional education continues, which emphasises testing of appropriate individuals. The effectiveness of this programme can be assessed by monitoring levels of HCV antibody testing.

A total of 125 individuals were newly diagnosed with hepatitis C in 2008, an increase from 105 diagnosed in 2007. The number of HCV antibody tests performed on specimens from Northern Ireland in the Regional Virus Laboratory, Royal Hospitals, Belfast, rose from 12,700 in 2002 to 29,161 in 2008 (Figure 24). This laboratory performs all HCV testing in Northern Ireland. Of the 29,161 tests carried out in 2008, 14,115 had unique dates of birth so it can be assumed that at least 14,115 individuals were tested in 2008. Of the specimens, 15% were sent from general practice and 27.4% were identified as coming from genitourinary medicine (GUM). This information will be used as the baseline, and comparable data in future years will be collected to monitor if actions to raise awareness among public and professionals have resulted in increased testing, particularly in primary care.

Figure 23: Transplant list first registrations with a code of post-hepatitis C cirrhosis in Northern Ireland: 1996 - 2008*.

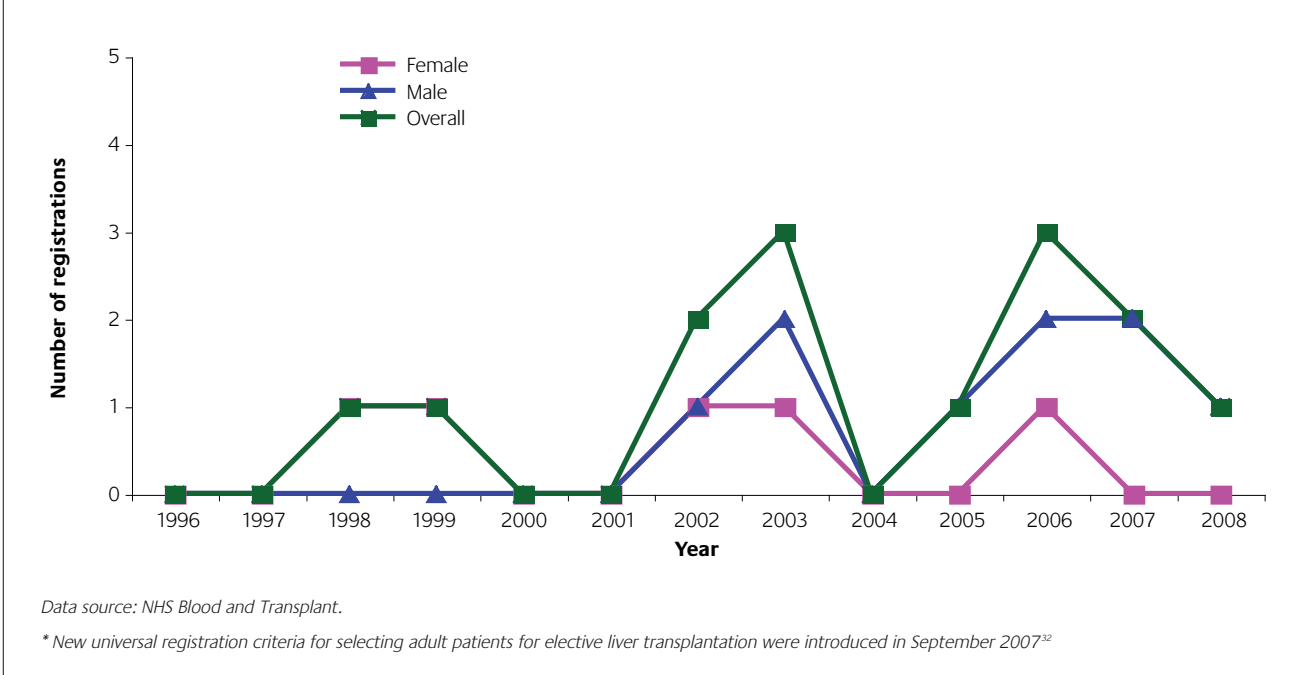
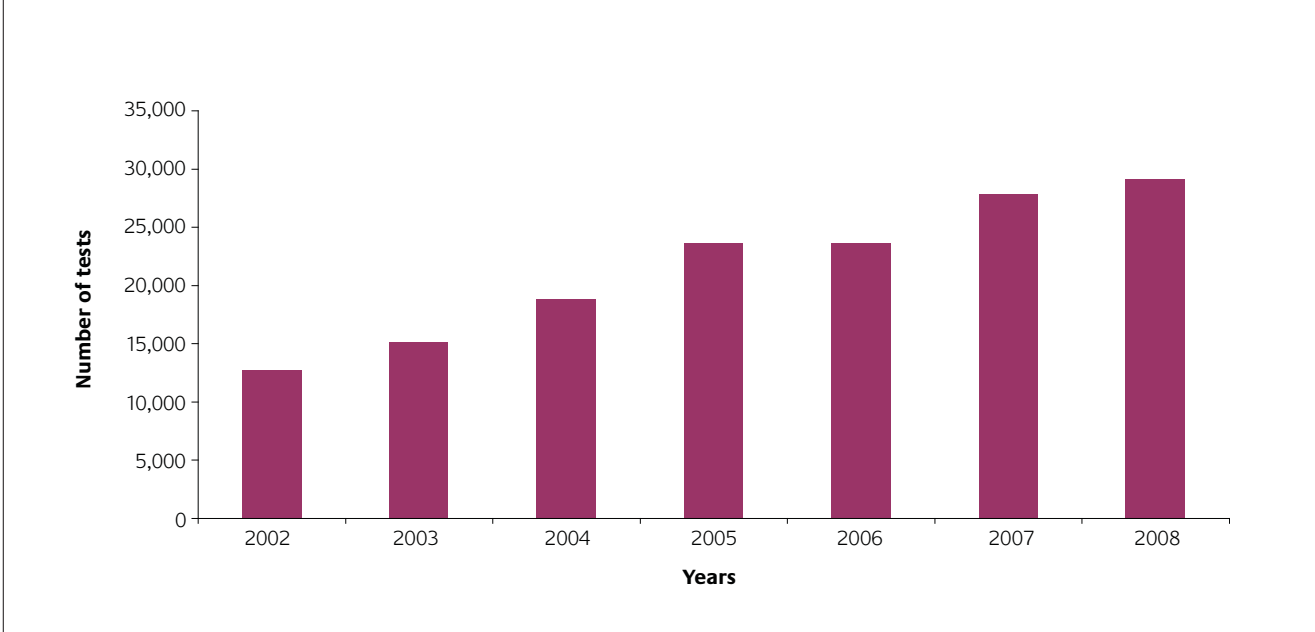


Figure 24: HCV Antibody tests 2002 - 2008 (Regional Virus Laboratory, Belfast)



2.4 Making it happen

Action 13

To support the work of the MCN, each Health and Social Services Board designated a senior board officer as a blood-borne virus coordinator in 2007.

Action 14

DHSSPS has monitored progress on the implementation of the action plan at six-monthly intervals.

2.5 Summary

Considerable progress has been made since the Department of Health, Social Services and Public Safety (DHSSPS) issued its *Action Plan for the Prevention, Management and Control of Hepatitis C* in Northern Ireland in January 2007. This progress has been made by a wide range of agencies in key areas such as prevention, raising awareness and providing treatment services. Importantly for the future, most of these agencies are actively engaged in the Northern Ireland Hepatitis C Managed Clinical Network. However none of these actions can be considered complete.

Key priorities for 2010 include:

- Reviewing the MCN structure and membership following health and social care re-structuring in Northern Ireland.
- Establishing the post MCN project manager.
- Developing the work programme for 2010-2013.
- Implementing the agreed surveillance arrangements.
- Reviewing existing information and training materials and extending the target audience.
- Strengthening links with voluntary organisations.

3.0

Scotland



3.0 Scotland

3.1 Introduction

Following an extensive consultation in 2005, the Scottish government launched Scotland's Action Plan for hepatitis C in September 2006⁶³. Its aims are:

- To prevent the spread of hepatitis C, particularly among Injecting Drug Users (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)⁶³ comprised 41 actions spread across the areas of coordination, 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 2008⁶⁴, saw serious commitment from the Scottish government, to tackle the hepatitis C challenge facing Scotland, with an investment of approximately £43m, 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 first annual report of Phase II⁶⁵, published in May 2009, provided an update on progress made on the implementation of the 34 Phase II actions. 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 one (2008/09), 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 (HCV), and (d) reducing the number of infected people who develop severe hepatitis C-related liver disease.

3.2 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. Table 10 provides a summary of progress made on the implementation of the twelve actions on testing, treatment, care and support during year one (2008/09)⁶⁵.

The following sub-sections present data on: (i) diagnosis of hepatitis C infection, (ii) blood donor testing and (iii) treatment of hepatitis C infection. These data were obtained through a survey of Scotland's hepatitis C testing laboratories; analysis of existing data on Scotland's National Hepatitis C Diagnoses Database⁶⁶ 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 Scotland⁶⁷.

3.2.1 Diagnosis of hepatitis C infection

- In 2008, an estimated 39,000 people living in Scotland were chronically infected with HCV (Figure 25); of these, 15,500 (40% of those chronically infected) were estimated to have been diagnosed with HCV by the end of 2008.
- A total of 70,600 HCV antibody tests were undertaken in Scotland during 2008, which compares to 61,700 in 2006. Of the 70,600 HCV antibody tests in 2008, 2.4% (1,720) related to a new hepatitis C diagnosis.
- 1,720 new hepatitis C diagnoses were made in Scotland during 2008, which compares to an average of 1,600 new diagnoses made per year during 2003-2007 (Figure 26)⁶⁶. Of these 1,720 new hepatitis C diagnoses:
 - 28% were aged 20-29 years, 34% aged 30-39 years, 23% aged 40-49 years and 12% were aged 50 years and above, at the time of diagnosis.
 - 64% were male.
 - 45% reported injecting drug use, representing 88% of those with a known risk factor.



- A total of 25,355 people had been diagnosed with hepatitis C in Scotland by the end of 2008 (Figure 26)⁶⁶. Of these, 13% were known to have died by 31 December 2008.
- Among 2,460 IDUs interviewed at services providing injection equipment in Scotland during June 2008 to June 2009, 77% reported having been tested for hepatitis C in the past, while 36% reported a test in the last year. When those who were diagnosed positive from a past test (that is, before 12 months ago) were excluded, the percentage of respondents who had been tested for hepatitis C in the last year increased to 43%.
- Among 1,373 IDUs who were hepatitis C antibody positive, and were interviewed at services providing injection equipment in Scotland during June 2008 to June 2009, only 46% reported that they had been diagnosed with hepatitis C.

Figure 25: Estimated number of living persons in Scotland, in 2008, who were (i) chronically infected with hepatitis C, (ii) chronically infected with hepatitis C and ever diagnosed, (iii) chronically infected with hepatitis C and had attended a specialist centre in 2008, and (iv) initiated on hepatitis C antiviral therapy in 2008.

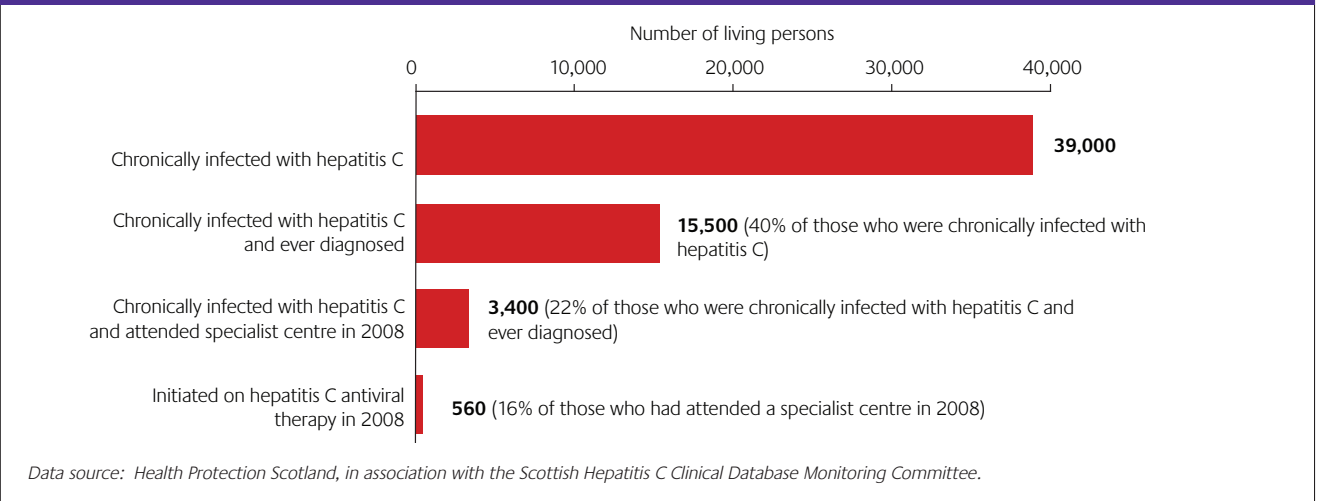


Figure 26: Annual and cumulative numbers of persons reported to be diagnosed hepatitis C antibody positive in Scotland during 1991-2008.

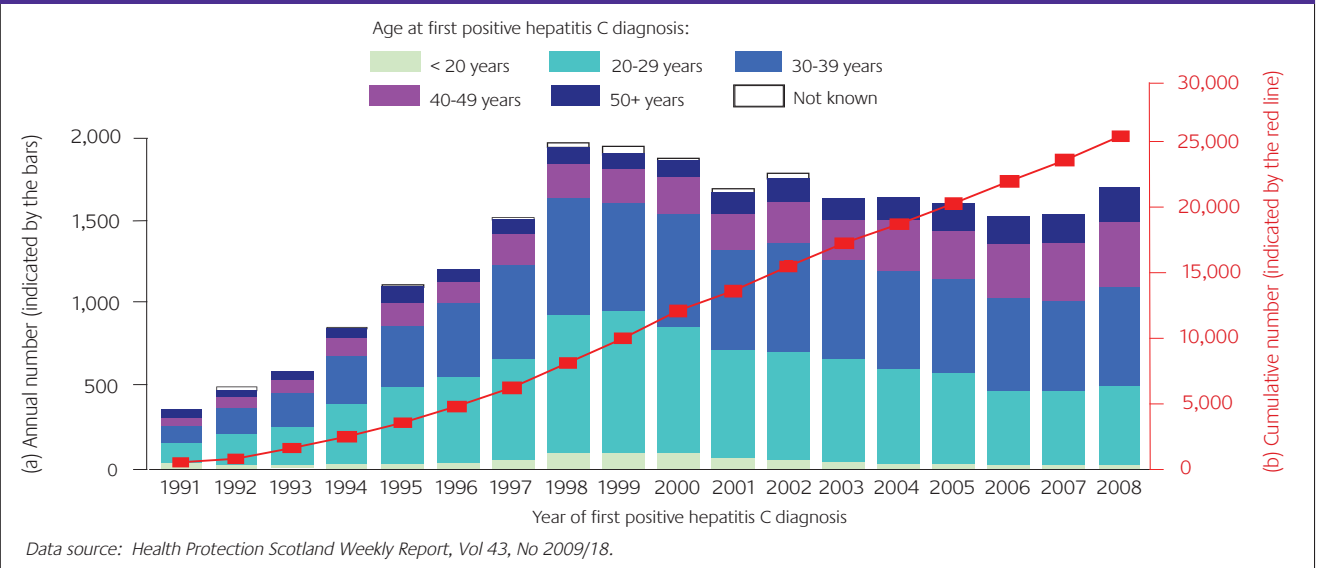
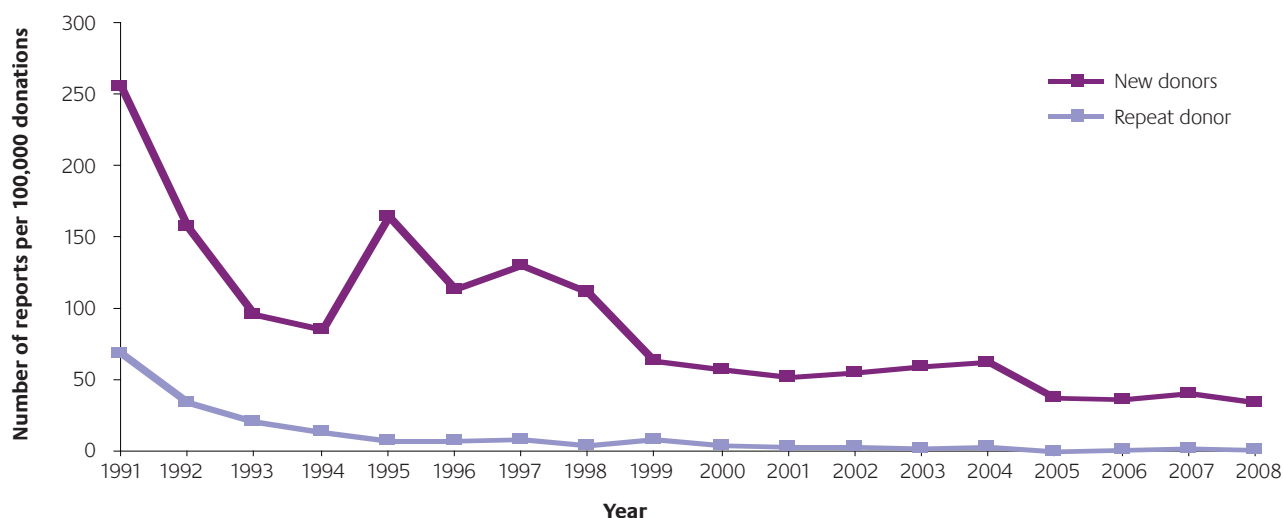


Figure 27: Frequency of hepatitis C in blood donors in Scotland: 1991* - 2008. New and repeat donors



Data source: NHSBT/HPA Epidemiology Unit using data supplied by SNBTS.
*1991 data from September to December 1991.

3.2.2 Treatment of hepatitis C infection

- By 2008, an estimated 15,500 people living in Scotland with chronic hepatitis C had been diagnosed with their infection; of these 15,500, an estimated 3,400 (22%) had attended a specialist centre in 2008 (Figure 25).
- In 2008, approximately 560 hepatitis C-infected people began antiviral therapy in Scotland; this is in excess of the Action Plan 2008/09 target of 500 treatment initiations.
- Among patients (with either genotype 1, 2 or 3) initiated on pegylated interferon and ribavirin across ten clinics in Scotland during 2000-2007, 57% were known to have achieved a sustained viral response.

3.2.3 Blood donor testing

The SNBTS collects blood from voluntary donors who are selected to be at low risk of blood-borne infections, 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, although higher than in other UK countries, has declined since 1991 (Figure 27). In 2008, ten new donors tested positive for HCV, which approximates to 34.5 per 100,000 donations tested.

Hepatitis C in repeat donors

Since 1991, when blood donation testing for HCV was first introduced, fewer HCV infections have been detected in donations from repeat donors than in those from first time donors. The detection of HCV infection among repeat donors has reduced from 68.3 to 1.4 per 100,000 donations between 1991 and 2008 (Figure 27). In 2008, three repeat donors were positive for hepatitis C.

Table 10: Hepatitis C Action Plan for Scotland Phase II actions on testing, treatment, care and support: Summary of progress in 2008/09⁶⁵

Action	Summary of progress
<p>1 Each NHS Board will have, or be affiliated to, a MCN for hepatitis C; this Network will comprise representatives of relevant specialists in healthcare and other stakeholder groups including those for the prison service, local authority, social work, the voluntary sector, mental health / addictions, and people living with and affected by hepatitis C. The Network will be guided in its practice through the use of 'Care' Guidelines, prepared by the hepatitis C Action Plan's Testing, Treatment, Care and Support Networking Group and Scottish Intercollegiate Guidelines Network (SIGN) guidelines on the management of hepatitis C.</p>	<p>MCN leads and coordinators, or their equivalent, have been appointed in 12 out of the 14 NHS Boards.</p> <p>Full establishment of a MCN has been completed at a local level in 10 out of the 14 NHS Boards. Network establishment was defined as the network membership and terms of reference being signed off.</p>
<p>2 NHS Quality Improvement Scotland (QIS) will develop standards for hepatitis C testing and the treatment, care and social support of persons with hepatitis C infection.</p>	<p>The development of standards for the treatment and care of persons with hepatitis C infection is ongoing. Standards are due to be published for consultation in December 2010.</p>
<p>3 A National Hepatitis C Learning and Workforce Development Framework will be developed.</p>	<p>A national framework for workforce development and education has been finalised and a national workforce development coordinator appointed to support its implementation nationally across Scotland.</p>
<p>4 NHS Boards, working with their partners, will identify a hepatitis C workforce development lead, review the learning and development needs of the hepatitis C workforce, and implement a coordinated approach to Hepatitis C Workforce Development consistent with the National Hepatitis C Learning and Workforce Development Framework.</p>	<p>A hepatitis C workforce development and education lead has been appointed/nominated in 12 out of the 14 NHS Boards.</p> <p>An assessment of the learning and development needs of the workforce has been completed in 13 out of the 14 NHS Boards. Local plans to address the needs identified are currently being developed.</p>
<p>5 Awareness-raising campaigns and communications initiatives will continue to be developed, implemented and evaluated to meet the information and education needs of a range of professional audiences (including those responsible for the delivery of prevention services).</p>	<p>Activities begun in Phase I are continuing, with agreement to target future activities to all relevant healthcare professionals. The Year 2 campaign has been re-scheduled to launch in February 2010 to avoid coinciding with pandemic (H1N1) 2009 influenza (also known as swine flu) activities with the same professional group. Insight gathering, production of the branding creative and communication routes for the campaign are currently being revised in preparation.</p>

Action	Summary of progress
<p>6 Testing, Treatment, Care and Support services within each NHS Board will be developed to increase the numbers of persons undergoing therapy in Scotland from 450/year to 500 in 2008/09, 1,000 in 2009/10, 1,500 in 2010/11 and at least 2,000/year thereafter.</p>	<p>During 2008, approximately 560 hepatitis C-infected persons were initiated onto treatment in Scotland, exceeding the Year 1 target. Appointments and the development of services to further increase the number of persons undergoing therapy are continuing. MCN Work Plans are currently being developed by NHS Boards.</p> <p>A national contract for the procurement of anti-viral drugs for the treatment of hepatitis C was signed off in October 2009 following a successful national procurement process.</p>
<p>7 Service Level Agreements / Memoranda of Understanding, between NHS Boards and the Scottish Prison Service (SPS), to promote the treatment of hepatitis C-infected inmates in prisons, will be developed in the context of the SPS Blood Borne Virus (BBV) strategy.</p>	<p>A national Memorandum of Understanding between SPS and NHS Boards has been developed. Service Level Agreements between local prison establishments and NHS Boards are currently in development and have been completed for three out of the nine applicable NHS Boards.</p>
<p>8 For each NHS Board a formal plan, indicating how it has integrated or will integrate appropriate elements of hepatitis C specialist treatment services into those for social care, mental health and addiction in local authority, voluntary sector, primary care and secondary care settings, will be developed and implemented.</p>	<p>The MCN Work Plan (see Action 6) for each NHS Board will address the integration of hepatitis C treatment services with those for social care, mental health and addiction.</p>
<p>9 Each local authority will identify a strategic and operational lead for HCV infection.</p>	<p>While NHS Boards have identified a local authority lead, some have encountered difficulties engaging with their local authorities. Work is ongoing to assess barriers to local authority involvement in the Action Plan. A Local Authority Network for Hepatitis C is due to be initiated in December 2009 to support this activity.</p>
<p>10 NHS Boards will work with Community Health Partnerships (CHPs) to develop and implement a plan, incorporating innovative approaches to improve hepatitis C testing and referral activities by general practitioners (GPs) and other community setting practitioners.</p>	<p>The MCN Work Plan (see Action 6) for each NHS Board will address approaches to improve HCV testing and referral activities in the community setting.</p>

Action	Summary of progress
<p>11 An awareness-raising campaign, to promote HCV testing among those at risk of being infected, will be implemented and evaluated.</p>	<p>The awareness-raising campaign will target all those at risk of having been infected. Initially, the campaign will focus on former IDUs within the five large NHS Boards and thereafter all those at risk of being infected throughout Scotland. The campaign has been re-scheduled to launch in March 2010 to avoid coinciding with pandemic flu activities. Insight gathering to inform and develop campaign activities is ongoing.</p>
<p>12 A programme of work to evaluate different approaches to hepatitis C testing/body fluid sampling (for example, near patient testing/use of saliva and dried blood spots (DBS)) will be undertaken.</p>	<p>Work to determine the ability to detect or predict the presence or absence of infection using finger prick blood with a DBS specimen and commercially available near patient testing is ongoing.</p>

3.3 Prevention

One of the aims of the Action Plan is to reduce the number of people becoming infected with hepatitis C. Recognising that opiate substitution therapy services are well developed, the Phase II actions are 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 HCV 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 blood-borne viruses among IDUs. Table 11 provides a summary of progress made on the implementation of the six actions on prevention during year one (2008/09)⁶⁵.

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 of hepatitis C among IDUs. This data was obtained through capture-recapture analysis of IDU-relevant health and criminal justice data in Scotland^{68,69}; a questionnaire survey of injecting equipment providers across Scotland^{70,71}; an unlinked anonymous hepatitis C testing survey of IDUs in Glasgow⁷²; and a serological and questionnaire survey of IDUs attending services providing injecting equipment in Scotland⁶⁷.

Table 11: Hepatitis C Action Plan for Scotland Phase II actions on prevention: Summary of progress in 2008/09

Action	Summary of progress
<p>13 Each NHS Board will have, or be affiliated to, a Network covering the prevention of hepatitis C and comprising representatives of all stakeholder sectors. Guidance regarding Network membership and terms of reference for the hepatitis C component will be established. Each NHS Board will identify a hepatitis C prevention lead.</p>	<p>Prevention leads have been identified in 13 out of the 14 NHS Boards.</p> <p>Full establishment of a Prevention Network or equivalent has been completed at a local level in 12 out of the 14 NHS Boards. Network establishment was defined as the network membership and terms of reference being signed off.</p>
<p>14 National guidelines for services providing injection equipment to IDUs will be developed. A Guideline Development Group will be established.</p>	<p>National Guidelines for Services Providing Injecting Equipment have been finalised. Publication is expected by early next year following approval by the Lord Advocate/Crown Office in Scotland.</p>
<p>15 Services providing injection equipment (needles/syringes and other injection paraphernalia) will be improved in accordance with guidelines (see Action 14). Improvements will be made in terms of the: (i) quantity (increasing access and uptake of equipment through innovative, including outreach, approaches), (ii) quality (for example, the colour coding of equipment to avoid sharing) and (iii) nature (for example, provision of equipment other than needles/syringes), of provision.</p>	<p>NHS Boards are continuing to expand injecting equipment provision in the context of the National Guidelines (see Action 14). Local Prevention Plans are currently being developed in line with the Guidelines.</p>

Action	Summary of progress
<p>16 Educational interventions aimed at vulnerable individuals, IDUs and those at risk of starting to inject will be designed and implemented to highlight how hepatitis C transmission can be prevented. Particular attention should be given to initiatives aimed at identifying existing and newly diagnosed IDUs with hepatitis C to prevent the onward transmission of infection.</p>	<p>A literature search has been completed to identify educational interventions with potential application to hepatitis C that have previously been evaluated. A national coordinator has been appointed to coordinate the implementation of selected interventions in Years 2 and 3. A mapping exercise is ongoing to baseline current provision of educational interventions by NHS Boards.</p>
<p>17 An in-prison needle/syringe exchange initiative will be piloted as one of a range of harm reduction measures to reduce the transmission of hepatitis C.</p>	<p>SPS have faced significant challenges obtaining support from prison unions for this intervention. Discussions with government ministers and prison unions are ongoing.</p>
<p>18 Hepatitis C guidance and educational support materials (within the context of BBVs/drug misuse) will be developed, disseminated and evaluated to raise awareness among young people in school, and further education and community settings, and other settings which support vulnerable young people. Staff/peer group training initiatives will facilitate the implementation of this action.</p>	<p>The development of guidelines and/or national initiatives to provide education on hepatitis C in primary and secondary schools in Scotland within the context of Curriculum for Excellence is ongoing. Materials developed for mainstream primary and secondary schools and staff are currently being piloted and thereafter will be revised for use in other settings.</p>

3.3.1 Injecting drug user population

- The estimated number of current IDUs in mainland Scotland during 2006 was 23,900 (with 95% confidence interval: 21,600 – 27,200)⁶⁸, 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 2003⁶⁹.

3.3.2 Provision of injection equipment to IDUs

- In 2007/08, 210 injection equipment provider outlets, of which 169 were pharmacy based and 15 offered mobile/outreach services, were reported to be operating in Scotland⁷⁰. This compares to 188 injection equipment provider outlets, of which 136 were pharmacy based and 22 offered mobile/outreach services, which were operating in Scotland during 2004/05⁷¹.
- At least 4.3 million needles/syringes were distributed to IDUs in Scotland during 2007/08. This is higher than the 3.5 million needles/syringes reported to have been distributed to IDUs in Scotland during 2004/05, although a higher response to the 2007/08 survey may in part account for the increase.
- The estimated number of needles/syringes distributed to each IDU in Scotland during 2007/08 was approximately 180, and ranged from 120 to 400 across NHS Boards (Table 12).
- 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 510 per year), is estimated to be approximately eight million per year.

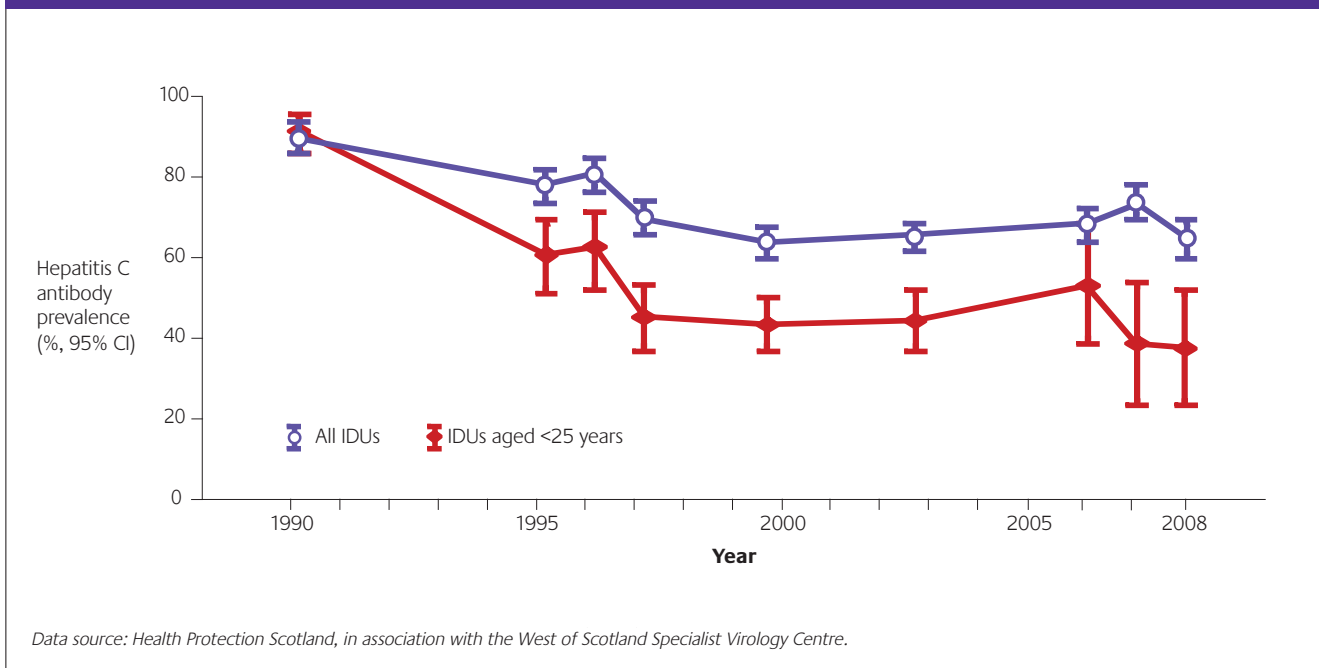
Table 12: Distribution of sterile needles/syringes (N/S) compared to the prevalence of current injecting drug users (IDUs), by NHS Board in Scotland

NHS Board	Estimated number of current IDUs 2006	Number of N/S distributed, 2007/08*	Number of N/S per IDU per year
Dumfries & Galloway	486	197,000	405
Fife	1,270	483,493	381
Forth Valley	786	285,590	363
Lanarkshire	1,649	394,927	239
Grampian	3,056	653,560	214
Lothian	3,262	653,448	200
Tayside	1,254	197,791*	158
Borders	201	26,600	132
Highland	734	90,332	123
Greater Glasgow & Clyde	8,862	1,076,244	121
Ayrshire & Arran	2,373	285,658	120
Mainland Scotland	23,933	4,344,643	182

Data source: (i) Hay G, Gannon M, Casey J, McKeganey N. Estimating the National and Local Prevalence of Problem Drug Misuse in Scotland. Edinburgh: ISD Scotland, October 2009; and (ii) Provision of injecting equipment in Scotland, 2007/08. ISD Scotland, June 2009 (revised data presented).

* Data reported for Tayside excluded pharmacy distribution.

Figure 28: Prevalence of hepatitis C antibodies (% , 95% CI) among IDUs in Greater Glasgow & Clyde NHS Board, by age and year during 1990-2008: Data from unlinked anonymous testing of specimens taken for named HIV testing.



- Variations in access to injection paraphernalia other than needles/syringes (particularly with respect to filters, stericups/cookers and sterile water) across NHS Boards in Scotland remained during 2007/08⁷⁰.
- In 2007/08, 123 injection equipment provider outlets in Scotland provided a service at weekends, albeit mainly on Saturday mornings (involving all of the 113 pharmacy-based and 10/36 non-pharmacy based outlets who had replied, across ten of the eleven mainland NHS Board areas); only one injection equipment provider outlet (in Greater Glasgow and Clyde NHS Board) provided a 24/7 service.

3.3.3 The sharing of injection equipment by IDUs

- Of approximately 2,050 current IDUs interviewed at services providing injection equipment in Scotland during June 2008 to June 2009, 15% reported having recently (last six months) injected with a needle/syringe previously used by someone else; 48% reported having recently (last six months) used other injecting paraphernalia (filters, spoons and water) that had previously been used by someone else.

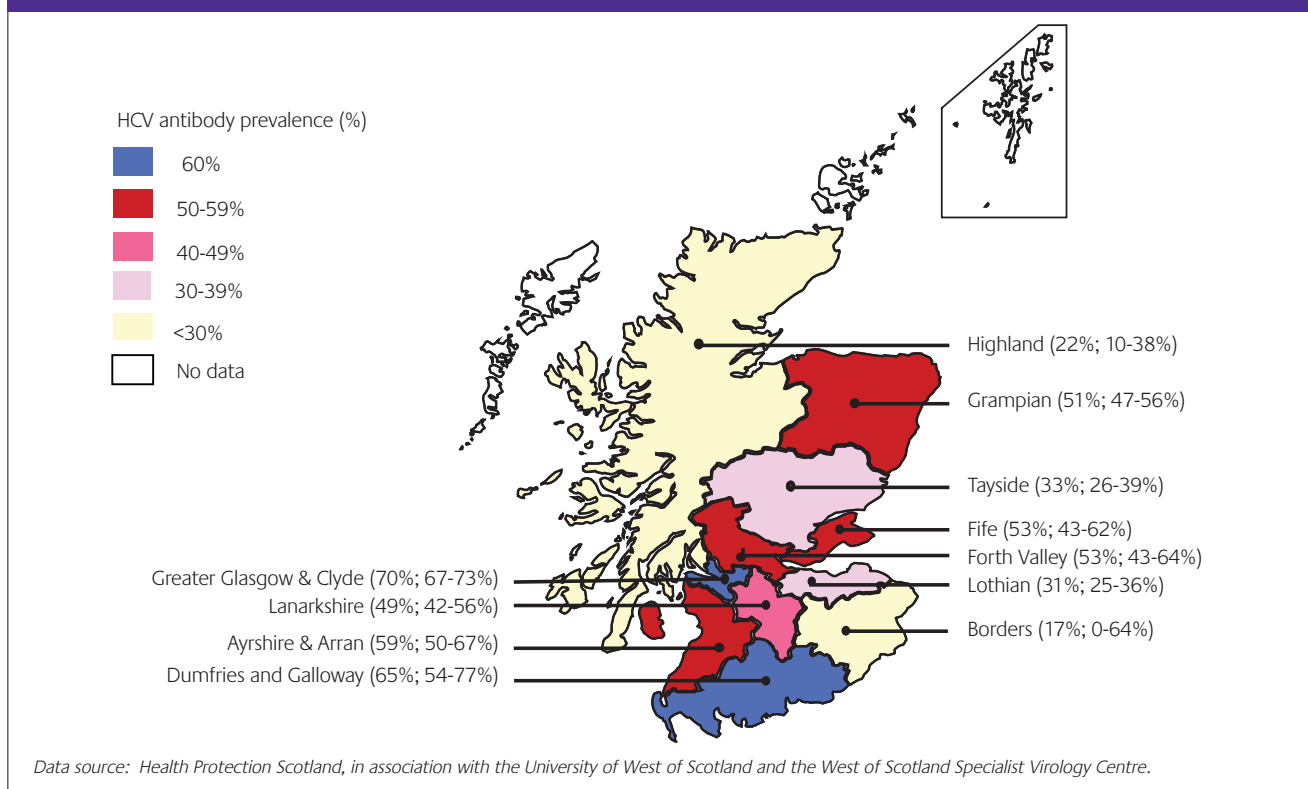
3.3.4 Prevalence of hepatitis C among IDUs

Information on the prevalence of hepatitis C among IDUs comes from unlinked anonymous testing of residual sera from specimens provided by IDUs for a named HIV test and from surveys of current and former IDUs at services providing injection equipment.

3.3.4.1 Unlinked anonymous testing survey

- To monitor trends in hepatitis C prevalence among IDUs over time, residual sera from specimens provided by IDUs for a named HIV test during 1990-2008 were anonymously tested for hepatitis C antibodies⁷². This survey revealed significant reductions in hepatitis C prevalence among IDUs from Glasgow between 1990 (all IDUs: 89%; IDUs aged under 25 years: 91%) and 1999/2000 (all IDUs: 62%; IDUs aged under 25 years: 41%), suggesting that there had been a decrease in hepatitis C incidence during the 1990s. Since then, no further reductions in the prevalence of hepatitis C were observed among IDUs in Glasgow during 2006-2008 (all IDUs: 68%; IDUs aged under 25 years: 41%) (Figure 28).

Figure 29: Prevalence of hepatitis C antibodies (%; 95% CI) among 2,516 IDUs surveyed at needle exchange settings, by NHS Board in Scotland during 2008-2009.



3.3.4.2 Needle exchange surveillance initiative

- Among 2,516 current and former IDUs surveyed at services providing injection equipment during June 2008 to June 2009:
 - 1,373 (55%) tested positive for hepatitis C antibodies in DBS.
 - The prevalence of hepatitis C among IDUs ranged from 17% to 70% across mainland NHS Boards in Scotland (Figure 29).
 - The adjusted overall prevalence of hepatitis C among IDUs in Scotland was 53%, adjusting survey data for the estimated regional and age distribution of current IDUs across mainland Scotland^{68,73}.
 - The prevalence of hepatitis C was 32% among 660 current and former IDUs across Scotland who had started injecting in the previous five years, and 24% among 401 current and former IDUs across Scotland who had started injecting in the previous three years.

3.4 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 to the end of 2008 on: (i) deaths from hepatitis C-related liver disease, (ii) hospitalisations from hepatitis C-related liver disease and (iii) liver transplants related to hepatitis C. 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^{74,75}.

3.4.1 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 45 in 1996 to 113 in 2008 (Figure 30), at an average annual rate of 8.7% (95% CI 6.8–10.6%).
- Of the total 949 liver-related deaths during 1996–2008 among people diagnosed with hepatitis C, only 460 (48%) had hepatitis C mentioned on the death certificate.
- Among the 113 liver-related deaths in 2008:
 - 90 (80%) had liver disease as the underlying cause of death (alcoholic liver disease was the most prevalent underlying cause in 47) and 23 (20%) had liver disease only as a contributing cause of death.
 - 86 (76%) were male, and 66 (58%) were aged less than 50 years.
- End-stage liver disease-related deaths (defined as either ascites, hepatic encephalopathy/failure, hepatocellular carcinoma (HCC) or varices) among people diagnosed with hepatitis C increased from 14 in 1996 to 47 in 2008 (Figure 30), at an average annual rate of 10.3% (95% CI 7.3–13.4%).
- Of the total 394 end-stage liver disease-related deaths during 1996–2008 among people diagnosed with hepatitis C, only 221 (56%) had hepatitis C mentioned on the death certificate.

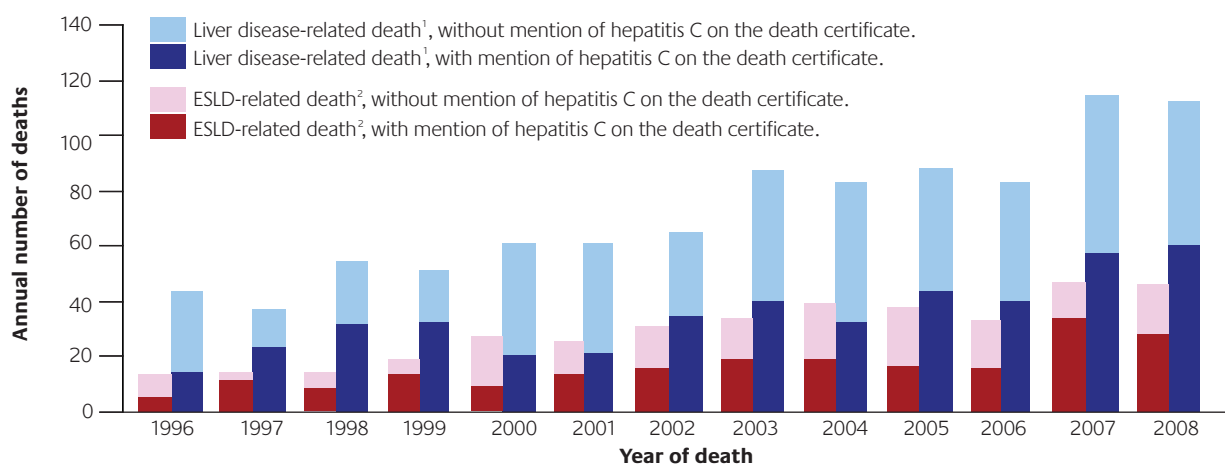
3.4.2 Hospitalisations from hepatitis C-related liver disease

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

3.4.2.1 End-stage liver disease (ESLD)

- First-time hospital admissions with ESLD (as defined in 3.4.1) among people diagnosed with hepatitis C increased from 47 in 1996 to 159 in 2008 (Figure 31a), at an average annual rate of 8.8% (95% CI 7.2–10.5%).
- Of the total 1304 first-time hospital admissions for ESLD during 1996–2008 among people diagnosed with hepatitis C, only 484 (37%) had hepatitis C mentioned on the hospital record.
- Among the 159 first-time hospital admissions for ESLD in 2008, 111 (70%) were male, and 98 (62%) were aged less than 50 years.
- Hospital bed-days with ESLD among people diagnosed with hepatitis C increased from 1144 in 1996 to 4691 in 2008 (Figure 31b), at an average annual rate of 11.8% (95% CI 11.4–12.1%).

Figure 30: Annual number of deaths related to (i) liver disease¹ and (ii) end-stage liver disease (ESLD)² among persons diagnosed with hepatitis C in Scotland, during 1996–2008.

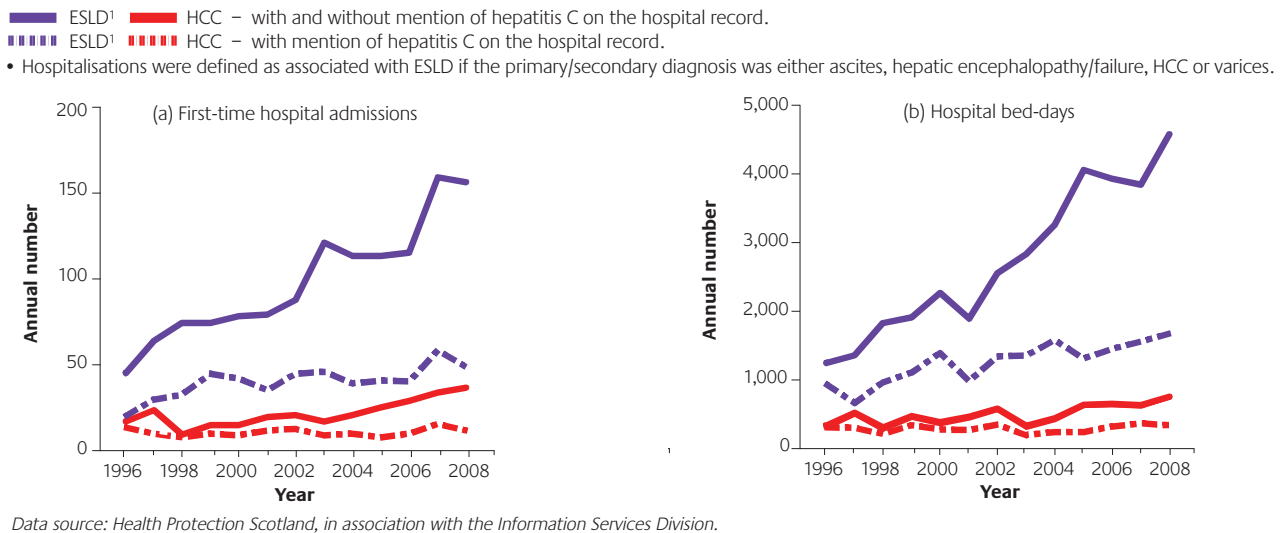


1. Deaths were defined as related to liver disease if the underlying cause of death was either (a) viral hepatitis, (b) liver cancer, (c) alcoholic liver disease or (d) non-alcoholic liver disease, and the contributing cause of death was either (b), (c) or (d).

2. Deaths were defined as related to ESLD if the underlying/contributing cause of death was either ascites, hepatic encephalopathy/failure, hepatocellular carcinoma or varices.

Data source: Health Protection Scotland, in association with the Information Services Division.

Figure 31: Annual number of (a) first-time hospital admissions and (b) hospital bed-days associated with end-stage liver disease (ESLD)¹ and hepatocellular carcinoma (HCC) among persons diagnosed with hepatitis C in Scotland, during 1996-2008.



3.4.2.2 Hepatocellular carcinoma (HCC)

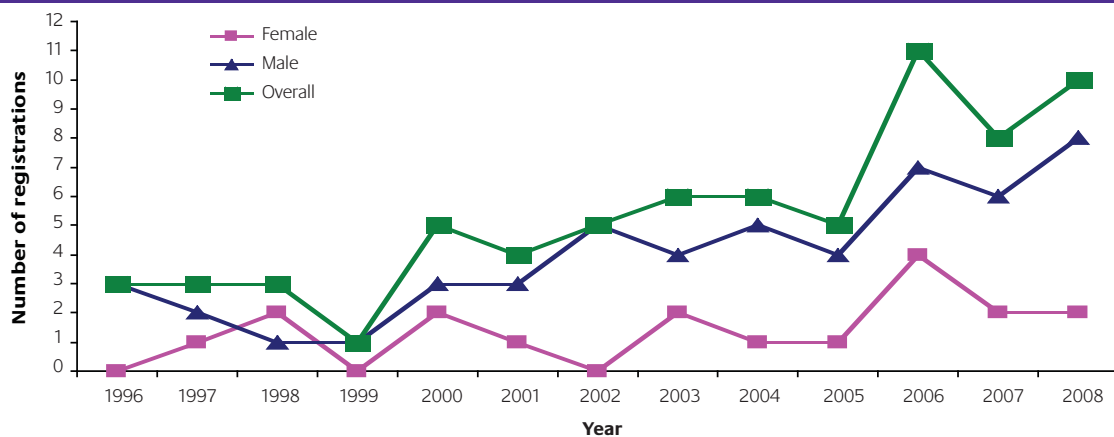
- First-time hospital admissions with HCC among people diagnosed with hepatitis C increased from 10 in 1996 to 29 in 2008 (Figure 31a), at an average annual rate of 10.4% (95% CI 6.1–14.8).
- Of the total 195 first-time hospital admissions during 1996-2008 for HCC among people diagnosed with hepatitis C, only 77 (39%) had hepatitis C mentioned on the hospital record.
- Among the 29 first-time hospital admissions for HCC in 2008, 26 (90%) were male, and 5 (17%) were aged less than 50 years.

- Hospital bed-days with HCC among people diagnosed with hepatitis C increased from 176 in 1996 to 639 in 2008 (Figure 31b), at an average annual rate of 8.8% (95% CI 8.0–9.7%).

3.4.3 Liver transplants

The overall number of liver transplant first registrations with a code of post-hepatitis C cirrhosis has increased from 3 in 1996 to 10 in 2008 (Figure 32).

Figure 32: Transplant list first registrations with a code of post-hepatitis C cirrhosis in Scotland: 1996 - 2008*.



The number of first liver transplants in patients with post-hepatitis C cirrhosis and HCV-related hepatocellular

carcinoma has fluctuated between 1996 and 2008 (Table 13).

Table 13: Indications for transplant in hepatitis C (HCV) infected individuals in Scotland: 1996 - 2008.

Year	All liver transplants	First liver transplants with post-hepatitis C cirrhosis at registration and HCV positive at registration or transplant (percentage of all liver transplants)			
		Total (percentage)	Post-hepatitis C cirrhosis (percentage)	Hepatocellular carcinoma (percentage)	Other indication (percentage)
1996	43	4 (9)	4 (9)	0 (0)	0 (0)
1997	41	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)	4 (7)	2 (4)	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)	5 (8)	0 (0)	1 (2)
2007	55	8 (15)	5 (9)	3 (5)	0 (0)
2008	78	12 (15)	5 (6)	7 (9)	0 (0)

Data source: NHS Blood and Transplant.

3.5 Summary

One-and-a-half years following the launch of Scotland's Hepatitis C Action Plan, much has been achieved. Year 1 allowed Health Boards and national agencies, responsible for 34 Actions, to establish organisational and coordination infrastructure and to plan the development/improvement of services designed to prevent HCV transmission, detect persons infected with HCV and to ensure that those infected receive optimal care and treatment. In this respect, nearly all Health Boards have functioning hepatitis C Managed Care Networks and Networks which incorporate the specific hepatitis C prevention function. A Programme Management approach, with both national and local elements, has been successfully implemented and Health Board plans for the enhancement of services, in the main, have been completed. On the treatment and care front, for example, the number of infected persons initiated on therapy has increased by almost 50% over a two year period (since 2006) and it is anticipated that by the end of Year 2 (March 2010)

that the increase will be nearer 100%. On the prevention front, national guidelines on injection equipment provision are now available and Health Boards are developing services to comply with these; for example, all Boards will be expected to make injecting paraphernalia (for example, spoons, filters) available to injecting drug users. Awareness campaigns for both professionals and the public will be launched in early 2010 to avoid a clash with intense pandemic flu activity. Surveillance systems, specifically those designed to monitor the treatment of infected persons, the uptake of testing and the incidence of HCV infection, are well on their way to becoming fully established and have already provided sound baseline data against which the performance of the Action Plan, in terms of its aims as above, can be gauged.

Much has already been achieved and the response of all stakeholders has been impressive. Nevertheless, there is still much to do and many challenges lie ahead as death, transplant and hospital admission data all show that HCV-related ESLD is continuing to rise in Scotland.

4.0
Wales



4.0 Wales

4.1 Introduction

In April 2009, the Minister released the Blood Borne Virus Action Plan for Wales 2010-2015 for wider public consultation. The consultation period ended in July 2009 and funding to implement the Action Plan has been approved by Welsh Assembly Government (WAG) to begin in 2010.

This Action Plan has been informed by research, commissioned by the WAG, and carried out by the National Public Health Service (NPHS) Wales between 2004 and 2007. The research clearly identifies areas which must be addressed if BBV, including hepatitis C transmission is to be halted.

A comprehensive review of primary, secondary and tertiary health care and substance misuse treatment services was completed in 2005/06 and provided a baseline of current hepatitis service provision along with a description of patient experience over time.

The Welsh Action Plan sets out the hepatitis B and C programme for Wales for the period April 2010 until April 2015. It is proposed that during this period, services in Wales will be continually re-evaluated and markers of success (reduction in transmission rates and significant increases in numbers diagnosed and treated) as well as barriers to progress will be identified. Further actions to tackle chronic hepatitis B and hepatitis C infection in Wales will be identified from 2014.

This Action Plan aims to provide a clear, costed and time defined framework for the planning and provision 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.

The response to these challenges, and responsibilities for implementation, will cut across the remit of different partners in health, social care and criminal justice.

4.2 Ongoing work in areas identified as a priority

While the Action Plan was being considered by the WAG, work has continued in those areas that have been identified as a priority.

4.2.1 Prevention

The All Wales Needle Exchange Forum and NPHS, in conjunction with Welsh Assembly Government, are looking to establish a national data collection system for needle exchange in Wales. This will provide a rolling estimate of the number of injecting drug users to assist in quantifying the current at risk population for hepatitis C.

4.2.2 Diagnosing infection

A cumulative total of 4,063 laboratory-confirmed diagnoses of hepatitis C (HCV) infection from Wales were reported to Cfl between 1992 and 2008 (Figure 33). In 2008, 266 individuals were newly diagnosed with hepatitis C, similar to the number in 2007.

4.2.3 Management, treatment and care pathways

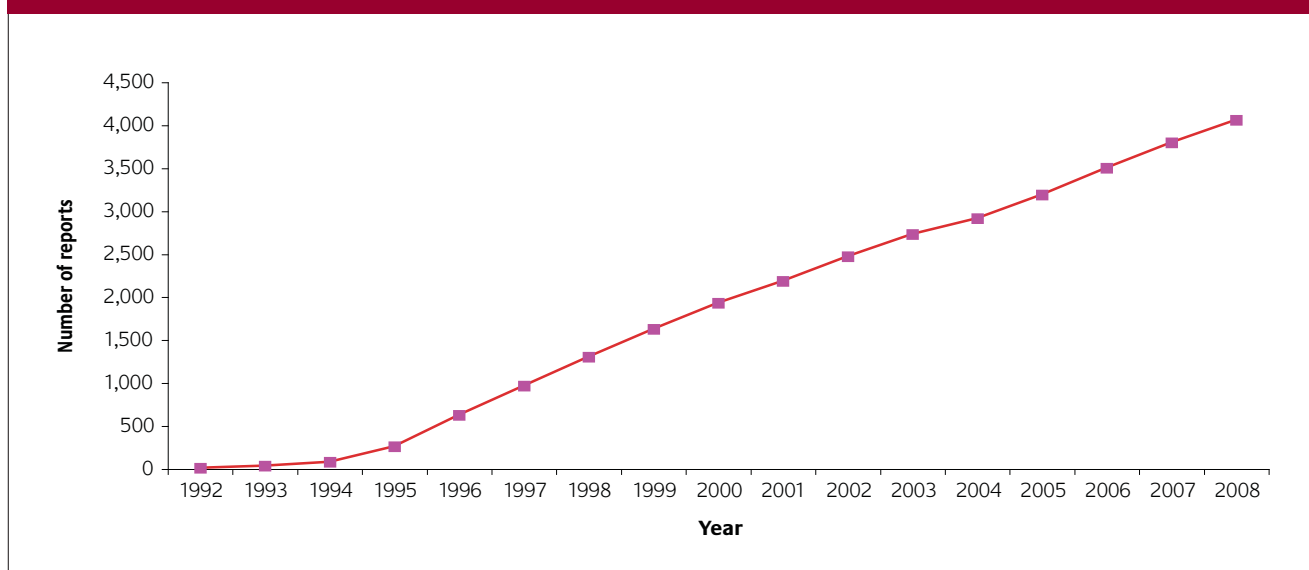
Clinicians have identified individuals in need of treatment and care, however, services have been unable to expand to meet any increase in demand while the Action Plan is awaiting implementation.

4.2.4 Surveillance and follow-up

Welsh seroprevalence studies suggest around 0.5% (14,700) of individuals have been infected with HCV in Wales; based on this, it is estimated that 12,000 people are chronically infected with the virus as outlined in the Action Plan⁷⁶.



Figure 33: Cumulative laboratory reports of hepatitis C infection from Wales: 1992 - 2008



Laboratory reports

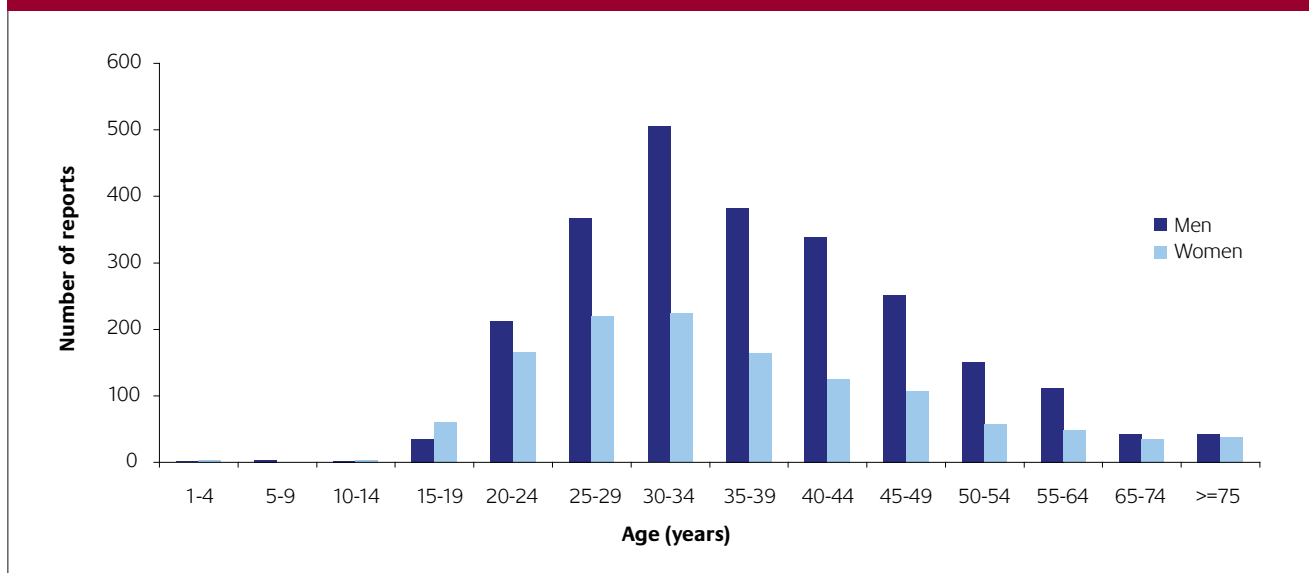
A total of 27% of laboratory confirmed HCV infections that were reported between 1996 and 2008

(Figure 33), included information on risk factors for acquisition of infection. Of these, 94% reported injecting drug use as a risk factor (Table 14).

Table 14: Risk factor information in laboratory reports of hepatitis C infection from Wales: 1996 - 2008

Risk factor (where reported)	Number of reports	Percentage
Injecting drug use	949	94.1
Transfusion	14	1.4
Blood product recipient	19	1.9
Sexual exposure	10	1.0
Renal failure	2	0.2
Vertical (mother to baby) or Household	6	0.6
Occupational	0	0.0
Other	8	0.8
Total	1,008	100

Figure 34: Age and sex distribution of laboratory reports of hepatitis C infection from Wales: 1996 - 2008



Between 1996 and 2008, 66% (2,447/3,701) of hepatitis C reports were in men, and 50% of all reports received were among individuals aged between 25 and 39 years (20% of which were in the 30-34 age group) (Figure 34).

Injecting drug user (IDU) populations

NPHS have undertaken a prevalence estimate of problematic drug use (heroin, other opiates and cocaine/crack) in Wales for 2006/07 using capture-recapture methods providing a provisional prevalence rate of 10.1 per 1,000 population aged 15 to 64⁷⁷. However, it is not currently possible to provide a prevalence estimate of injecting drug use in Wales at this time. Other research undertaken by NPHS indicates that among current IDUs across Wales, around 26% are already infected with HCV, rising to around 40% in the major cities, with an estimated annual incidence rate of 6 per 100 person years. Full details of the NPHS research and findings are available online⁷⁸.

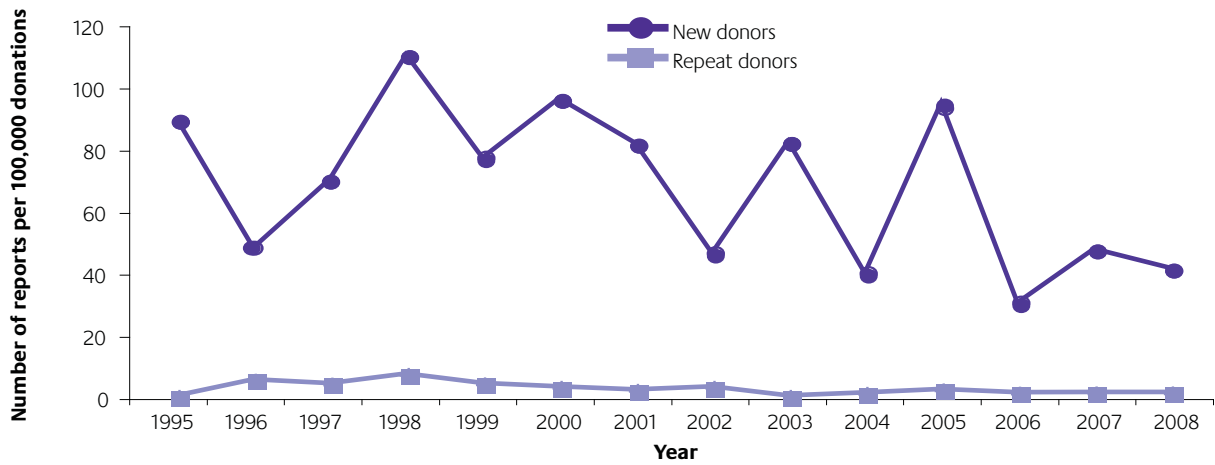
Blood donors

The Welsh Blood Service (WBS) collects blood from voluntary donors who are selected to be at low risk of blood-borne infections, such as HCV, in the same way as other UK blood services. Donations made in North Wales are included in the English blood donor data. Excluding donations from North Wales, the frequency of positive donations detected among all other Welsh people 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 2008, five new donors tested positive for hepatitis C. This approximates to around 41 per 100,000 donations tested (Figure 35). All five donors were white with four born in the UK and one born in Europe. There were three males and two females with a mean age of 37 years. Risk factor information was available for all five of the new donors; two reported IDU, two tattooing and the other donor originated from a country where HCV was endemic.

Since blood donation testing began, fewer HCV infections have been detected in donations from repeat donors than first time donors (Figure 35). In 2008, only one repeat donor seroconverted for antibodies to HCV giving an estimated incidence of infection in blood donors of 0.59 per 100,000 person years. The risk factor was assigned to household contact with a known positive case.

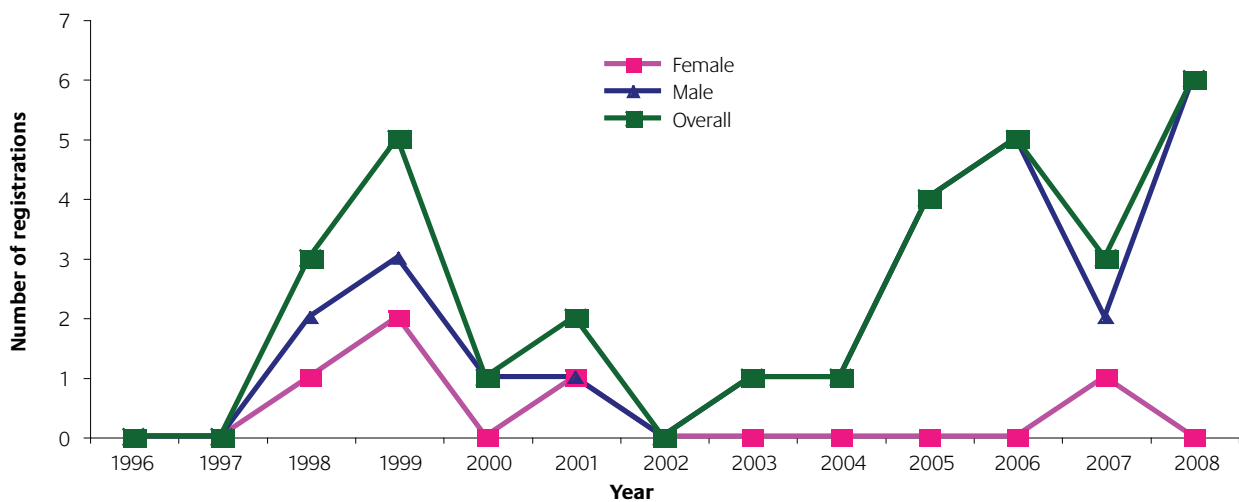
Figure 35: Frequency of hepatitis C in blood donors in Wales*: 1995 - 2008. New and repeat donors



Data source: NHSBT/HPA Epidemiology Unit using data supplied by WBS.

*Excluding North Wales.

Figure 36: Transplant list first registrations with a code of post-hepatitis C cirrhosis in Wales: 1996-2008*



Data source: NHS Blood and Transplant.

* New universal registration criteria for selecting adult patients for elective liver transplantation were introduced in September 2007³²

Hospital episode data

Patient Episode Data for Wales (PEDW) shows that the number of HCV positive Welsh residents diagnosed with end-stage liver disease (ESLD) and hepatocellular carcinoma (HCC) has steadily increased over the past ten years; a similar trend is observed in deaths from these indications (see Table 15).

Transplant data

Since 1996 the number of Welsh residents with post-hepatitis C cirrhosis who registered with NHSBT for a liver transplant has fluctuated. Overall transplant list first registrations are higher in men than in women (Figure 36).

The first liver transplants performed for each patient with hepatitis C-related disease have shown an increase from one in 1996 to five in 2008 (5% and 16% of the total number of liver transplants respectively). Within this, the number of patients receiving first liver transplants with HCV-related HCC have been low in number with the highest number (four cases) being recorded in 2006 (Table 16).

Deaths

The number of deaths from HCV-related ESLD or HCC has fluctuated since 1996. The majority of deaths are seen in men (Figure 37).

Table 15: Number of individuals (Welsh residents) with hepatitis C who have end-stage liver disease (ESLD) and / or hepatocellular carcinoma (HCC) and deaths for these conditions, in Wales: the financial years 1997/1998 - 2008/2009

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	188	17	2 (12)	0	0 (0)
1998/1999	190	15	3 (20)	1	1 (100)
1999/2000	223	14	3 (21)	3	0 (0)
2000/2001	219	17	7(41)	5	3 (60)
2001/2002	226	9	2 (22)	4	1 (25)
2002/2003	282	20	9 (45)	2	1(50)
2003/2004	296	26	7 (27)	6	3 (50)
2004/2005	272	29	3 (10)	1	1 (100)
2005/2006	337	35	9 (26)	2	1 (50)
2006/2007	343	37	7 (19)	8	3 (37.5)
2007/2008	318	41	9 (22)	6	0 (0)
2008/2009	354	36	8 (22)	10	0 (0)

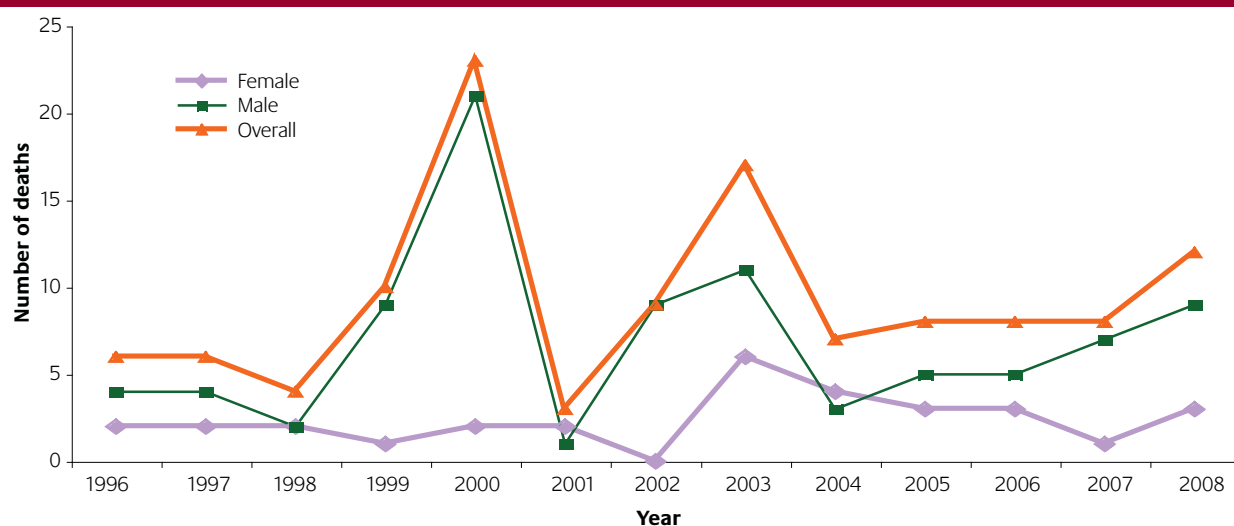
Data source: Patient Episode Database for Wales, 2009.

Table 16: Indications for transplant in hepatitis C-infected individuals in Wales: 1996 - 2008

Year	All liver transplants	First liver transplants with post hepatitis C cirrhosis at registration and HCV-positive at registration or transplant (percentage of all liver transplants)			
		Total (percentage)	Post-hepatitis-C cirrhosis (percentage)	Hepatocellular carcinoma (percentage)	Other indication (percentage)
1996	21	1 (5)	1 (5)	0 (0)	0 (0)
1997	24	0 (0)	0 (0)	0 (0)	0 (0)
1998	26	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	32	3 (9)	3 (9)	0 (0)	0 (0)
2008	32	5 (16)	3 (9)	2 (6)	0 (0)

Data source: NHS Blood and Transplant

Figure 37: Deaths from ESLD*, or HCC, in those with HCV mentioned on their death certificate in Wales: 1996 - 2008



*Defined by codes or text entries for ascites, varices, or hepatic encephalopathy/failure.

Data source: Office for National Statistics.

4.3 Summary

In Wales it is estimated that 12,000 people are chronically infected with hepatitis C, and surveillance shows that more individuals are getting tested and diagnosed each year. However, treatment services have been unable to expand to meet the increase in demand while awaiting implementation of the Action Plan.

It is hoped that with implementation of the Action Plan, and the subsequent development of hepatitis surveillance systems, that future reports will be better able to describe hepatitis C in Wales and evaluate the efficacy of current and future prevention, diagnosis and treatment services.

5.0

The UK picture



5.0 The UK picture

Hepatitis C remains a major public health problem in the UK. Action Plans have now been developed in all UK countries to tackle the infection, and each of the plans reflects the different priorities and concerns of that country, taking into consideration the differing systems for service delivery and the level of local accountability versus national coordination within each country.

The UK countries are at different stages of implementation, with their Action Plans having been launched at different times: England in 2004, Northern Ireland in 2007 and Scotland launching their plan in two phases in 2006 and 2008. The Action Plan for Wales is still awaiting implementation. Despite this, all plans share common goals: improving prevention, increasing diagnosis, and providing high quality services for individuals with hepatitis C. By comparing the approach in the four nations, countries can improve programmes at home by learning from each other's successes, reflecting on failures and by sharing experience.

5.1 Prevalence

Estimates suggest that around 142,000 individuals aged 15-59 years were living with chronic hepatitis C (HCV) infection in England and Wales in 2003. In Scotland, around 39,000 are thought to have chronic infection. Estimates from Northern Ireland suggest that around 4,000 individuals are likely to be chronically infected. In all countries the major risk factor for infection is injecting drug use.

The prevalence of infection in injecting drug users (IDUs) continues to be high in all countries, although there is some evidence of a stabilisation in England and Scotland in recent years. Efforts to improve services for drug users must be sustained. The recent Advisory Council on Misuse of Drugs (ACMD) review suggests that needle and syringe programmes need to be combined with other measures, such as opiate substitution therapy to maximise effectiveness⁷⁹. Scotland's Hepatitis C Action Plan prevention strategy focuses on the provision of injecting equipment and education, recognising that opiate substitution therapy services are already well developed, organised and funded through separate

arrangements. Expansion of injection equipment provision is also the main focus of the Northern Irish and Welsh plans. In England a broad strategy to reduce harm in IDUs has been implemented, which includes needle and syringe programmes, and improving the penetration of specialist drug treatment services. This has resulted in a major increase in the number of IDUs accessing such services since 2004.

Recommendation: Commissioners and providers of services for injecting drug users in Wales and Northern Ireland need to review their programmes to ensure that a broad range of prevention services (in addition to needle and syringe exchange) is available.

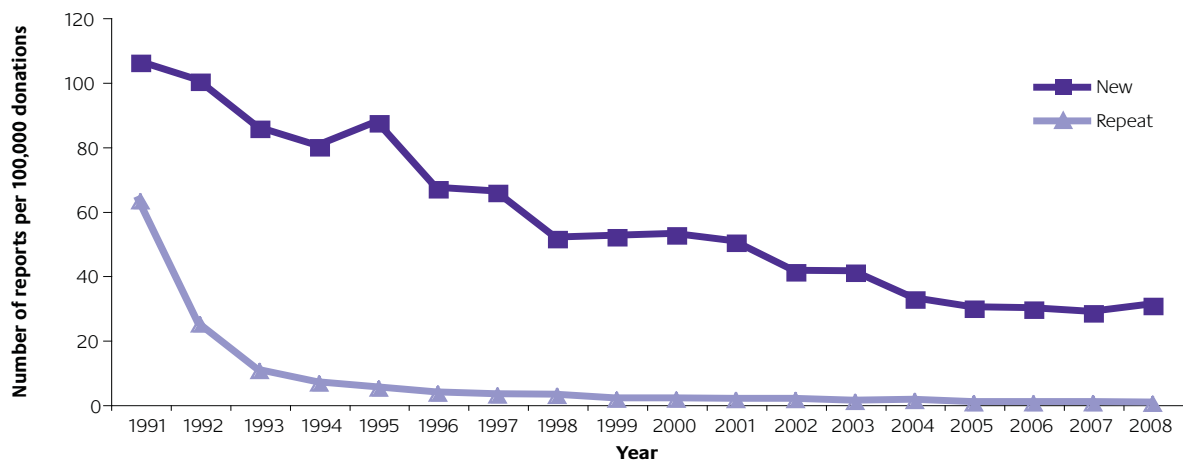
Direct measurements of the incidence of hepatitis C would help to evaluate the impact of prevention services. Limited information is available on the incidence of hepatitis C in IDUs across the UK. The introduction of novel methods – such as detecting HCV RNA positive, anti-HCV negative window period infections in cross sectional studies - offers the opportunity to undertake routine monitoring in the IDU population.

Data from London, Manchester and south-east England provides further evidence of ongoing sexual transmission of HCV among HIV positive men who have sex with men (MSM), many of whom engage in high risk sexual practices. This highlights the need for targeted public health initiatives in this group and the need for HCV evaluation for all MSM with abnormal liver function tests (LFTs) as well as routine HCV screening in HIV positive MSM.

Recommendation: National surveillance centres should develop systems for assessing and monitoring the incidence of hepatitis C in key risk groups. This includes IDUs and, if appropriate, HIV positive MSMs.



Figure 38: Frequency of hepatitis C in blood donors in the UK: 1991* - 2008. New and repeat donors



Data source: NHSBT/HPA Epidemiology Unit using data supplied by WBS, NIBTS and SNBTS. *1991 data from September to December 1991.
Note: 1991-1995 does not include Northern Ireland.

Frequency of HCV infection in blood donors remains low in all countries (Figure 38). This suggests that the respective blood services are highly effective in excluding high risk donors, helping to ensure that the risk of acquiring hepatitis C through a UK blood transfusion is the lowest it has ever been⁸⁰. The declining prevalence in donors also provides reassurance that hepatitis C transmission outside of the known risk groups is small, but that infections in low risk populations can still occur.

In England, prevalence studies suggest that the South Asian population are at increased risk of having hepatitis C infection. Enhanced surveillance data also suggests that they are over-represented among cases of hepatitis C-related serious liver disease. Targeted awareness-raising, including the *Hepatitis C. The more you know, the better* campaign, has recently been undertaken among the South Asian population. Of the four countries, only England has information on testing in ethnic minority groups, and this suggests that an increasing number of South Asians are accessing testing and being diagnosed with infection. In Scotland, a study to determine the prevalence of hepatitis C among South Asians is underway.

Recommendation: Lead agencies in Wales and Northern Ireland should investigate the need for targeted public information campaigns to raise awareness of hepatitis C in individuals from the Indian sub-continent.

5.2 Awareness-raising

In England several awareness campaigns, aimed at both health professionals and the public, have been undertaken since 2004. In 2009, the Department of Health launched its *Get Tested, Get Treated* campaign, which targeted former IDUs. In Scotland the public awareness-raising campaign has been delayed because of the pandemic (H1N1) 2009 influenza (also known as swine flu); it will now be launched in March 2010. Public information leaflets have been developed in Northern Ireland, but no major campaign has been launched. It is particularly important to raise awareness among groups who may have had past exposure, but who are no longer in regular contact with services. These groups will include ex-injectors, even individuals who have injected only once or twice in the past.

Recommendation: Lead agencies in Northern Ireland, Scotland and Wales need to urgently initiate expanded public information campaigns to raise awareness of hepatitis C.

5.3 Diagnosis and testing

The proportion of IDUs who report having ever been tested for hepatitis C in England has risen to 77% in 2008; the same level was reported in Scotland in 2008-2009. Data from the NDTMS in England suggests that almost 70% of IDUs newly presenting to treatment in England have been offered a test for hepatitis C. The sentinel surveillance scheme in England suggests that the increase in testing in specialist services for IDUs in England has been largely due to the use of oral fluid testing. Access to dried blood spot testing is being rolled out in England, Northern Ireland and Wales. In Scotland a project to evaluate different approaches to hepatitis C testing/body fluid sampling is underway.

Recommendation: Commissioners and providers need to ensure that a high rate of testing in those attending specialist services for drug users is maintained. Lead agencies in all UK countries should ensure widespread access to testing for hepatitis C using alternative specimens (for example, oral fluid and dried blood spot).

In England, testing in prisons is increasing; data is not available from other countries. Access to testing and to appropriate care pathways for those found to be positive for hepatitis C is likely to be variable.

Recommendation: Providers of prison health services should develop testing strategies and care pathways that allow equitable access to treatment services for offenders.

The overall number of tests performed for hepatitis C has risen considerably in England, Scotland and Northern Ireland. Data from England and Northern Ireland suggests that testing is being undertaken in a broad range of settings, including general practice and genitourinary medicine clinics.

Recommendation: Lead agencies in all countries should assess the impact of awareness campaigns, by monitoring testing outside of high risk group settings.

Recommendation: All commissioners of HCV services should evaluate the coverage of HCV testing services in their area and ensure that laboratories have appropriate pathways for referring samples for confirmatory testing.

Laboratory reports of newly diagnosed individuals with confirmed hepatitis C show an increase in 2008 – probably reflecting increased testing. A total of 10,307 new diagnoses of hepatitis C were reported across the UK in 2008. The completeness of laboratory data varies across the four countries, reflecting the different methods used to enhance reporting.

In England, where a larger number of laboratories undertake anti-HCV testing, reporting has been enhanced in a sentinel group of laboratories, and this suggests major under-reporting in routine reports. As routine reports may be the only data available at a local level, data for local commissioning may not be available. Consultation on the new Health Protection regulations for England closed on 30 September 2009; these propose to make reporting of important public health infections (including hepatitis C) a statutory obligation on laboratories, and this may help to improve the completeness of laboratory surveillance²⁴.

Recommendation: National and local agencies should make efforts to understand and improve the completeness of routine surveillance systems for hepatitis C.

5.4 Treatment and care

Routine national data sources in all UK countries show that hepatitis C-related deaths, transplants and hospital admissions are continuing to rise (see Figures 39, 40, 41), emphasising the scale of the problem and the urgent need to increase the number of people being treated for their infection.

In Scotland, the number of patients treated for hepatitis C is monitored using a national database. Scotland is also the only country to have reliable data on the number of patients referred to specialist care. Targets for increasing the number

of patients being treated have been exceeded in year one – this success probably reflects the clear central resource allocation to the Health Boards. The staff required to treat the target number of patients was estimated, and resources for increasing the specialist capacity identified.

Figure 39: UK deaths from end-stage liver disease (ESLD) or hepatocellular carcinoma (HCC), in those with hepatitis C mentioned on the death certificate: 1996 - 2008

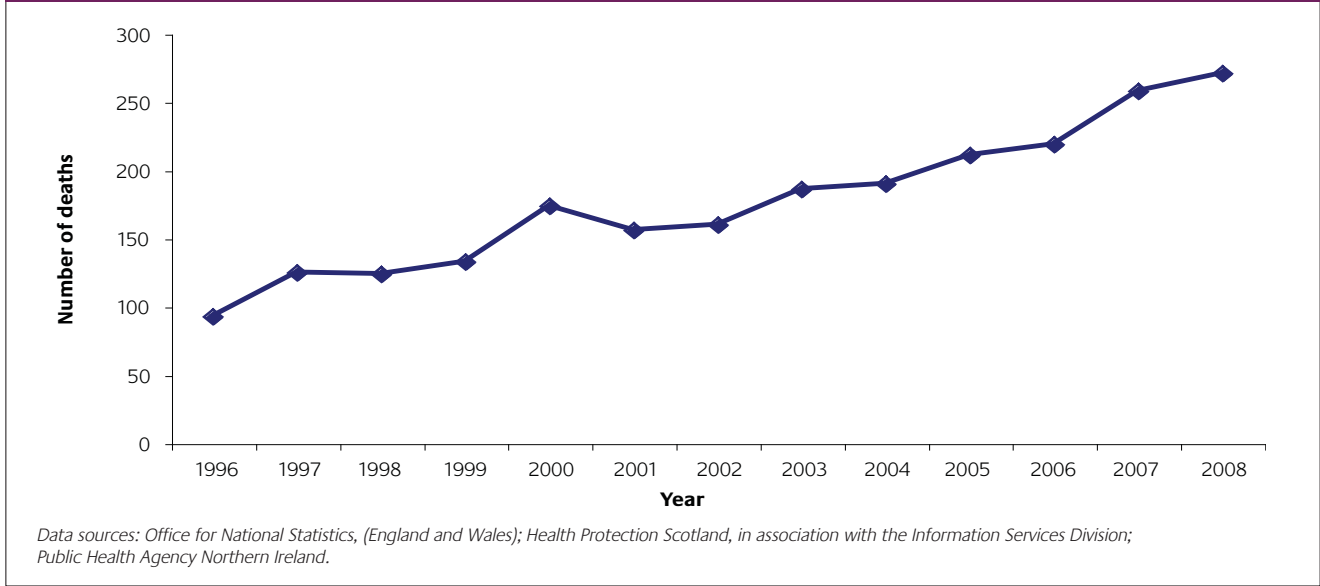


Figure 40: Annual number of individuals in England, Scotland and Wales hospitalised with hepatitis C (HCV)-related end-stage liver disease (ESLD) and HCV-related hepatocellular carcinoma (HCC)

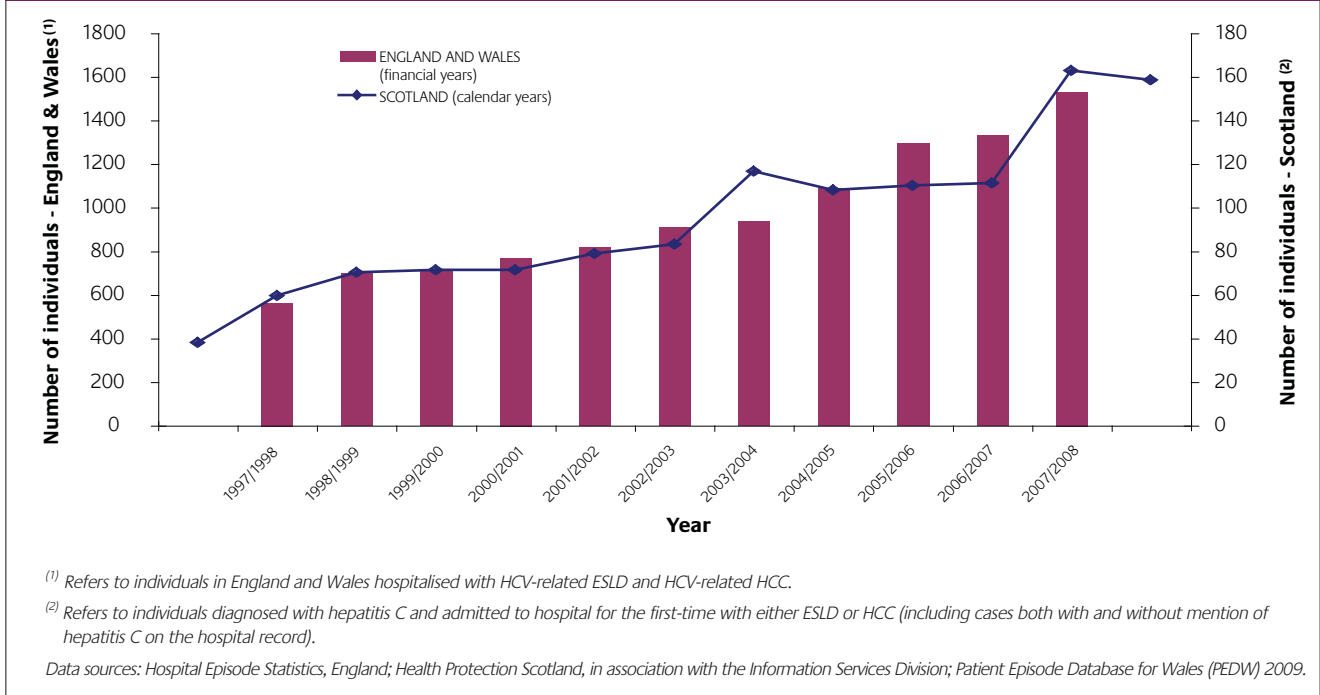
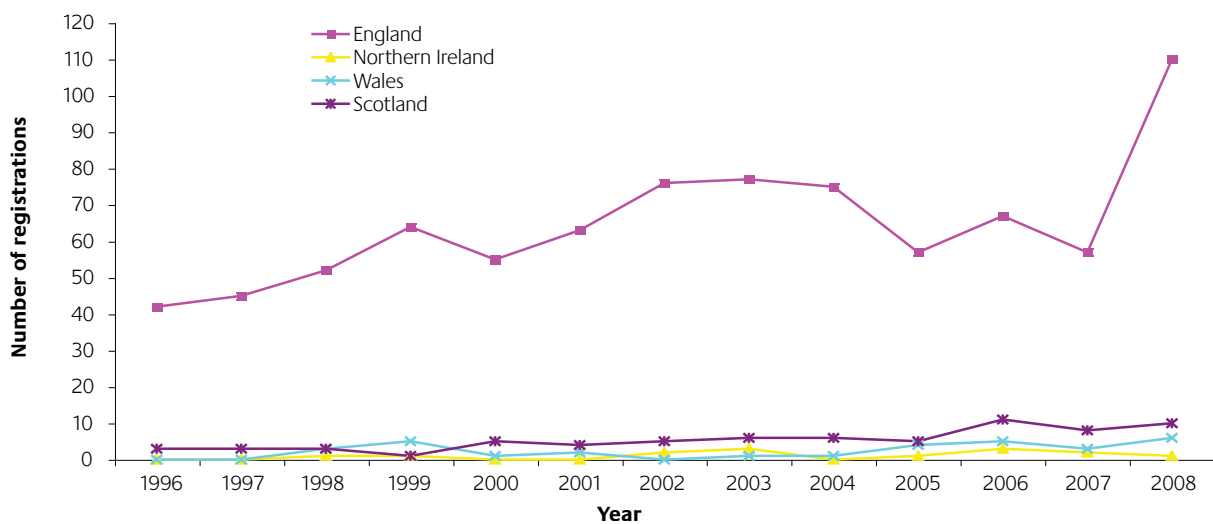


Figure 41: Overall numbers of transplants list first registrations with a code of post-hepatitis C cirrhosis in the UK: 1996 - 2008*



Data source: NHS Blood and Transplant.

*New universal registration criteria for selecting adult patients for elective liver transplantation were introduced in September 2007³².

In Scotland, clinical networks have been fully established in 10 of the 14 Health Boards. In contrast, in England, where responsibility for planning service provision is based at primary care trust (PCT) level, there is no accurate data to monitor the number of patients treated. Provisional estimates suggest that around 4,000 individuals may have been treated in England in 2007 and 4,800 in 2008, but figures provide only a crude measure, and are not available at PCT level. The All Party Parliamentary Hepatology Group (APPHG) audit suggests that treatment capacity has expanded since 2004, but coordination and monitoring of implementation is patchy⁴³.

In Northern Ireland, new staff were appointed in 2008, and the Eastern Health Board has taken the lead in bringing a managed clinical network together. In Wales, no expansion of service provision has yet occurred whilst awaiting implementation of their Action Plan.

Recommendation: Primary care organisations in England should develop mechanisms for obtaining reliable data on the number of patients referred, seen and treated for hepatitis C.

Recommendation: All primary care organisations in England and Wales should ensure that integrated pathways of care are available for patients with hepatitis C (ideally coordinated through a clinical network).

5.5 Overall coordination and monitoring

In Scotland a programme management approach has ensured strong national coordination and governance of their Action Plan. Leads have been appointed in each Health Board and specific allocation of resources in line with estimated need has occurred. In contrast, in England local implementation has been left to PCTs with limited national or regional oversight. The role of the strategic health authorities (SHAs) in monitoring the implementation of the plan is variable. The recent initiation of a rapid review of hepatitis C in NHS North West may provide a model for other regions to follow. In Northern Ireland a single Health Board has taken the lead on implementation for the whole country. The Welsh plan has not yet been ratified by the Welsh Assembly Government.

Recommendation: Strategic health authorities in England should take the lead in supporting local commissioners to ensure complete implementation of the hepatitis C Action Plan across all PCTs in their region.

5.6 Summary

In all countries of the UK, the highest risk of hepatitis C infection is in IDUs. In England a broad strategy to reduce harm in IDUs has been implemented, which includes an expansion in needle and syringe programmes, improving access to, and effectiveness of specialist drug treatment services and successive hepatitis C awareness campaigns. This has resulted in a major increase in the number of IDUs accessing needle and syringe and specialist services since 2004. The approach to prevention in the rest of the UK has focused on needle and syringe exchange, although broader interventions such as opiate substitution should also be improved to increase the effectiveness of harm reduction in those countries where these services are not already well developed.

Awareness-raising is an important component of reducing the burden of undiagnosed infection, and the English campaigns are well established. In England, Northern Ireland and Scotland rates of diagnostic testing and the number of newly diagnosed individuals have increased, but better data to ensure equity of access to testing would help. Most worryingly, the burden from HCV-related severe liver disease is increasing and is likely to increase further before treatment can have any significant impact. The costs of treating ESLD are substantial and if the number of individuals diagnosed and treated does not increase, then the future burden of disease on healthcare services will be substantial.

6.0

Awareness-raising in the UK

NHS

Have you ever...

- a** Pranged your mate's car?
- b** Pulled a sickie after a night out on the lash?
- c** Injected drugs at a party?

There are loads of things you might have done in your life. If 'c' is one of them, you might have hepatitis C. Most people have no symptoms for many years, but it can be fatal. Effective treatment is now available. So, if you've ever injected drugs, got a tattoo or piercing with unsterile equipment, or had a blood transfusion (before September 1991), ask your GP for a test. It's as simple as the one you've just taken.

For more information on other ways that you can contract hepatitis C, visit nhs.uk/hepc or call 0800 181 4013

Hepatitis **C Get tested. Get treated.**

6.0 Awareness-raising in the UK

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 injecting drug users (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.

Governments, the NHS and the voluntary sector have all developed initiatives to raise the awareness of hepatitis C among the public, at risk groups and healthcare professionals.

6.1 Raising public awareness at a national level

Over the past year in England, the Department of Health's hepatitis C public awareness campaign has targeted former IDUs, alerting individuals to the fact that they may have put themselves at risk of infection and encouraging them to get tested and treated. Advertisements ran in the tabloid national press, regional newspapers and on regional radio during February and October 2009 as well as appearing in washroom panels in bars and pubs in key city conurbations.

In Scotland, the Education Training and Awareness-raising Network has agreed with the Scottish government that their awareness campaign to be launched in March 2010, will target all those at risk of being infected. The objective of the campaign is to increase the number of at risk individuals coming forward for testing, using a two pronged approach; the first targeting former IDUs in five NHS Board areas and the second aiming to reach all at risk individuals across Scotland.

The Media

Ongoing media activity occurring both during and after the launch of the new Department of Health's advertising campaign has resulted in a series of high profile national and regional news and feature articles in 89 publications (such as *The Daily Express*, *The Sun* and *BBC News Online*). Their use of patient case studies has assisted in conveying complex information to a potential audience of almost 38 million people, representing 39% of the target audience.

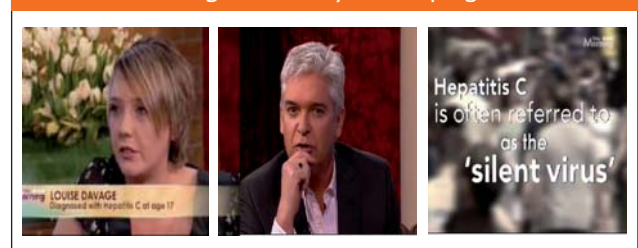
The public and healthcare professional print advertisements



Reproduced with kind permission from the Department of Health

During the launch of the advertising campaign, the Department of Health partnered with ITV.com to create a new 'hepatitis C' section on their health pages where four patient story videos were screened alongside health information and signposts to the campaign website on NHS Choices. As part of this same partnership, the *This Morning* programme featured an 'on the sofa' interview with a patient case study and liver specialist.

A hepatitis C patient case study interviewed on ITV's *This Morning* on the day of campaign launch



Reproduced with kind permission from ITV This Morning



There was also a lot of media interest in this year's World Hepatitis Day, including 20 articles in the national and regional print and broadcast media (including the *Daily Mirror* and *ITV East Anglia*) reaching over 2.6 million people.

National and regional news articles surrounding World Hepatitis Day 2009



Reproduced with kind permission from *The Daily Mirror*



Reproduced with kind permission from *ITV Local News: Anglia*

Raising awareness in Greater Manchester

A social marketing campaign aimed at past and current IDUs was launched in May 2009 in Greater Manchester to coincide with World Hepatitis Day as part of their Hepatitis C Strategy⁸¹. Although designed for the general public, it incorporated messages that would appeal to the ex-IDU community. This involved a month-long local radio promotion entitled *Back in the Day* and a series of three radio adverts informing people about how they could contract the hepatitis C virus and where they could go to get help. An 0800 number and text messaging service were set up. This campaign was run alongside various awareness-raising events targeting professionals from a range of services across the Greater Manchester area.

Initial results from the campaign show a 200% increase in people visiting the Strategy's website and the radio campaign was estimated to have reached an audience of up to 2 million people.

Further information about this campaign can be obtained from Jeanette Livings, Communications Manager - GM Hep C Strategy Alcohol and Drugs Directorate, Greater Manchester West Mental Health NHS Foundation Trust, Bury New Road, Prestwich, Manchester. Email: Jeanette.Livings@gmw.nhs.uk

Safer Herefordshire – Be Safe, Be Tested

In November 2008, Herefordshire Acute Hospitals NHS Trust appointed its own dedicated hepatitis C Specialist Nurse, based at Hereford County Hospital. An extension to her role is to provide hepatitis awareness sessions for those ‘at risk’ groups in the county, which are supported by Safer Herefordshire (Herefordshire’s Community Safety Partnership).

The sessions are held at locations across Herefordshire, which house ex-offenders and dependant substance users as well as those who are homeless. The friendly and informal sessions are designed to educate ‘at risk’ groups, as well as healthcare professionals working in the field. The long-term objective of these sessions is to raise the profile of blood-borne (BBVs), increase the numbers of those being offered testing and vaccination against hepatitis A and B, as well as diagnosing and referring those who are chronically infected into acute services for assessment for treatment.

Safer Herefordshire has designed a hepatitis leaflet⁹¹ which complements the awareness sessions with facts, information and advice, and hepatitis organisations’ contact details and clinic times.

For further information on the hepatitis awareness sessions, please contact either Joanne Spicer (Hepatitis C Clinical Nurse Specialist) on 01432 364167 or Sharon Amery (Safer Herefordshire) on 01432 260324.

6.2 Special projects

6.2.1 Targeting the South Asian community

The Department of Health has developed a specialist campaign designed to target South Asians aged between 25-55 years and community and faith leaders. The campaign is known as *Hepatitis C. The more you know, the better.* It was expanded to cover advertising, public relations, attendance at healthcare professional events and community outreach. Targeting was weighted towards Pakistani communities as emerging evidence suggested that this audience could be at higher risk of infection.

Advertising

The South Asian advertising campaign ran in March, April and June 2009 with advertisements appearing on nine specialist television channels, seven print publications, four radio stations and nine websites. The advertising creative targeted young and older South Asian audiences, primarily encouraging those who might have been at risk to come forward to get tested, but also included key prevention messages.

South Asian print advertisement



Reproduced with kind permission from the Department of Health

Screen grabs from the South Asian Television adverts



Reproduced with kind permission from the Department of Health

Media

Media outreach involved key South Asian stakeholder groups and celebrities such as Ameet Chana, Faryal Khan, H Dhami and Sakina Samo to endorse the campaign at launch. This resulted in 10 pieces of broadcast and print coverage in South Asian media, reaching approximately 772,000 people.

Celebrities H Dhami and Ameet Chana endorse the launch of the South Asian hepatitis C campaign



Health stakeholder conferences and mail-out

Three pilot health conferences were held during February 2009 in locations with a high population of South Asians (Manchester, Redbridge and Sandwell), with 211 local healthcare professionals including GPs, pharmacists and nurses in attendance. Additional information on the campaign together with bilingual information leaflets were provided to all GP practices and pharmacies in the 10 areas with the highest proportion of South Asians.

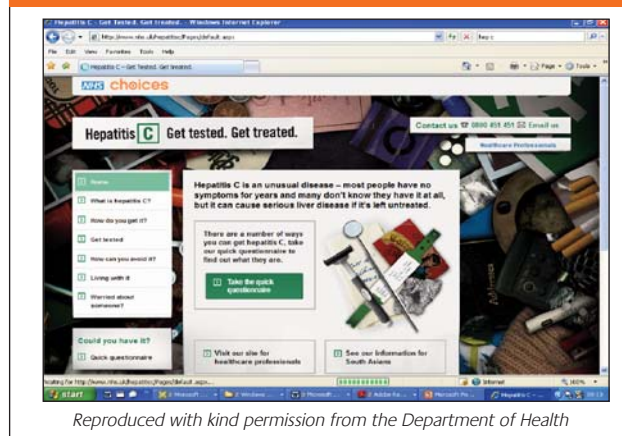
Community outreach

This project involved a bilingual team (Urdu and English) visiting 87 mosques and 55 community centres in the 10 areas across England with the largest South Asian populations. During this activity a total of 21,635 hepatitis C leaflets, 536 posters and 3,600 CDs were distributed.

Websites and the Hepatitis C Information Line

A revised campaign website hosted on the NHS Choices website was launched in March 2009. The website was revised to improve the hepatitis C self-assessment questionnaire – improving the average user's journey through the site by making information more accessible. Three separate sites were developed: one for the wider general public, one for South Asian audiences and one for healthcare professionals.

The revised hepatitis C 'Get Tested, Get Treated' website⁸²



The Department of Health also worked with key internet search providers to help increase the number of web users visiting the website – targeting specifically those searching for key search terms/words relating to hepatitis C and associated risk factors. The NHS Choices website received over 115,000 visits between January and August 2009.

The Hepatitis C Information Line (0800 451 451), which provides confidential information and advice about hepatitis C, received over 2,800 calls reflecting the more targeted nature of the campaign and the large number of visitors who chose to visit the campaign website for information.

Information for the Scottish public is available on the hepatitis C Scotland website⁸³ which is due for redevelopment following web-usability analyses completed successfully with members of the public.

In Northern Ireland a website⁸⁴ has been launched to support awareness-raising, provide a point of contact for information on all aspects of services and facilitate the other work of the managed clinical network for Northern Ireland.

6.2.2 The National Treatment Agency (NTA): *Harm Reduction Works* campaign

Risky injecting practices drive the spread of hepatitis C among IDUs. Although getting IDUs into drug treatment is the key strategy in the prevention of hepatitis C, harm reduction initiatives aimed at raising awareness of hepatitis C and offering strategies to prevent sharing of injecting equipment are also very important.

In 2009, the NTA continued to roll out the national *Harm Reduction Works* campaign, a key element of *Reducing Drug-related Harm: An Action Plan*⁸⁵. The *Harm Reduction Works* campaign comprises a dedicated website⁸⁶ and a wide range of free materials that aim to inform and change the conversations that occur between drug workers and drug users, and between drug users themselves, to reduce the risks they take.

One of the major strands of *Harm Reduction Works* is its *Hep C* campaign, which aims to inform those working with IDUs about the disease, and drug users about the risks of infection and how to avoid them.

A short, powerful animation, *How small is the hep C virus?* is designed to get across the message to injectors that just because a syringe looks clean, it doesn't mean that it is, and that infection can be avoided by not sharing needles, syringes, spoons, filters or mixing water.

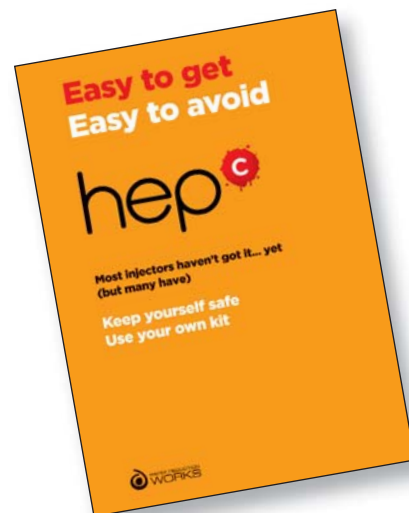
How small is the hepatitis C virus?



Reproduced with kind permission from The National Treatment Agency for Substance Misuse. Hosted on YouTube.

Raising awareness of hepatitis C risk has to be done within the context of optimism about the ability of injectors to protect themselves from this infection. Otherwise, there is a real risk that injectors will give up and consider infection to be inevitable. The *Easy to get, easy to avoid* and *Time for a test?* posters (posters 1 and 2) are based on this concept and aim to build on awareness of hepatitis C risk to promote positive behaviour change.

Poster 1: *Harm Reduction Works* 'Hep C' campaign poster *Easy to get, easy to avoid*



Reproduced with kind permission from The National Treatment Agency for Substance Misuse

Poster 2: *Harm Reduction Works* 'Hep C' campaign poster *Time for a test?*



Reproduced with kind permission from The National Treatment Agency for Substance Misuse

The campaign DVDs intended for injectors (*Safer injecting and Keep walking*) include short films designed to inform injectors about hepatitis C, and how to protect themselves from it. They also include advice on how to clean syringes. A hepatitis C handbook giving drug users clear information on transmission, disease progression, testing and treatment is expected to be published before the end of 2009.

The *Harm Reduction Works* film, '*HIV, hepatitis C and injecting drug use*' is aimed at drug workers, peer trainers, policy makers and commissioners, and anyone interested in injecting drug use. It features leading experts in the field discussing the survival time of different viruses inside syringes. The film also covers issues such as hepatitis C treatment, the role of needle exchange and substitute prescribing in the prevention of blood-borne virus epidemics, as well as describing the HIV epidemic that occurred in Edinburgh in the late 1980s.

Since the *Harm Reduction Works* campaign was launched by the Minister of State for Public Health in October 2008, there has been a two-phase roll out of new resources. By the end of 2009, it is expected that there will be more than 20 resources available on the website. A selection of films produced for the campaign is also available on the *Harm Reduction Works* channel on YouTube⁸⁷ as well as on DVD.

The reaction to the *Harm Reduction Works* campaign has been overwhelmingly positive. Between 71% and 93% of delegates at the NTA's regional *Harm Reduction Works* campaign launches were either very or totally satisfied with the campaign and its materials. Since the website launch in January 2009, there have been on average 600 unique visitors a month ordering an average total of 6,000 items per month. In late 2009, the NTA commissioned an independent evaluation of the campaign. The results are expected early next year.

6.3 Healthcare professional awareness

In order to raise awareness among healthcare professionals, the Department of Health in England undertook a number of activities including:

- Advertisements in the *British Medical Journal*, *GP*, *Nursing Standard*, *Nursing Times*, *Practice Nurse* and *Pulse*.
- A media campaign focusing on peer-to-peer communication reaching more than 625,000 healthcare professionals.
- Advertorials which appeared in the specialist healthcare titles *GP*, *Healthcare Republic* and *Independent Nurse* ahead of the advertising for the public in order to flag a potential influx of patient information requests to healthcare professionals and to help them prepare.

The advertorial that appeared in GP specialist press

Reproduced with kind permission from the Department of Health

In Scotland, the government has agreed to expand the target audience for the Phase II campaign to include any professional who may come into contact with someone infected with, or at risk of acquiring, hepatitis C. The campaign will specifically attempt to raise professional awareness around identifying those who need to be tested, supporting those who come forward for testing, and accessing treatment for diagnosed patients. A Usability Analysis has been completed to examine how professionals (and the public), across a range of groups and disciplines, utilise the internet as an information resource for hepatitis C.

Activities undertaken by the Scottish government to raise professional awareness have included:

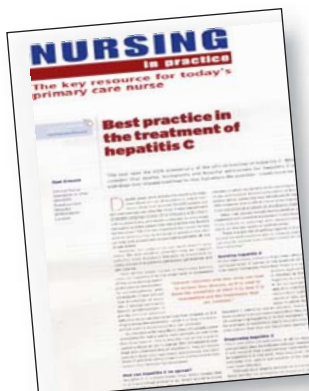
- Media campaign targeted at health professionals and social care, addiction services and criminal justice staff.
- Editorial coverage secured in publications including *Scottish Drugs Forum Bulletin*, *Holyrood* magazine, *BMA News* and *COSLA Connections*, along with online news pieces on sites including the *Nursing Standard*, *Royal College of Nursing* and *Healthcare Republic*.
- Copy supplied for advertorial features in publication including *Care Appointments Scotland*, *Scottish Primary Care* and *Skills 4 Nurses*.

Total opportunities to see print and online coverage were estimated to be 1,350,000.

Specialist health trade articles that appeared before main advertising burst



This article originally appeared on Healthcare Republic on 14 January 2009 – www.healthcarepublic.com
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Courtesy of Nursing in Practice – www.nursinginpractice.com
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6.4 The voluntary sector

The British Liver Trust

The British Liver Trust received funding from the Department of Health to produce a range of educational materials specifically for prisoners and prison staff on blood-borne viruses (hepatitis B, hepatitis C and HIV) to explain modes of transmission, prevention strategies and harm minimisation practices. To date, over 23,000 leaflets have been sent out by the Trust.

The initial leaflet, *Get out of jail BBV free*, was completed in 2008 and has subsequently been followed by two more leaflets and posters. All the materials use highly visual cartoon graphics and straightforward language to give clear messages: *keep it clean, protect yourself, get tested, get treated*.

BBVs are Bad Company is aimed particularly at women, whose perspective can be neglected in traditional materials, and *Wise up to BBVs*, a pocket sized leaflet, includes a vaccination schedule and space for inmates to record the dates on which they have received immunisations. The images, language used and the addition of a vaccination record is intended to create a sense of ownership and promote the idea that vaccination is something inmates can take control of and is to their benefit, rather than something which is being forced upon them.

The materials have been well received by prison staff and have received a number of awards including the winner of 2009 *European Liver Patients Association | Roche Innovation Award* and 'Highly Commended' in the *British Medical Association 2009 Patient Information Awards* and the *AMRC 2009 Science Communication Awards*.



Reproduced with kind permission from the British Liver Trust

The British Liver Trust has also recently published *A Professional's Guide to Hepatitis C and Injecting Drug Use*. It provides up-to-date information and has been designed specifically for professionals working with IDUs and includes information about the virus, hepatitis, cirrhosis, transmission, prevention, testing and treatment. A copy of the guide can be found on the British Liver Trust website⁸⁸.



Reproduced with kind permission from the British Liver Trust

Mainliners

Mainliners received funding from the Scottish government through the Hepatitis C Action Plan Phase II for its core Hepatitis C Resource Centre activities in Scotland. The UK Hepatitis C Resource Centre based in Glasgow, promotes information and good practice around the complex social and medical issues presented by hepatitis C. Centred on strong partnership working between public, private and voluntary sector bodies, the resource centre has aided almost 150 UK organisations providing them with patient information materials and has assisted in the development of the Scottish Hepatitis C Patients Forum providing a platform for people living with the infection to express their concerns and views. In addition, the centre runs a confidential *Information Line* which is open to anyone and offers information, advice and a friendly ear to anyone who calls. The service receives a very broad range of calls including members of the public and professionals. Individuals can contact *Information Line* by telephone (0870 242 2467) or email (info@hepccentre.org.uk). The *Information Line* is open from Monday to Friday from 10.00am to 4.00pm.

In addition to the core activities of the Hepatitis C Resource Centre above, Mainliners also runs a number of other hepatitis C projects:

- **The Peer Involvement Project (PIP)**, a project funded by the Scottish government and run by the resource centre seeks to ensure wider voluntary sector involvement in hepatitis C issues and will roll out across 20 areas of high risk/prevalence of hepatitis C over the next two years.
- **C Plus** is the information, advice and support service funded jointly by NHS Lothian and City of Edinburgh Council Drug and Alcohol Team for people in the Lothian region of Scotland, living with or affected by hepatitis C. It is currently working with approximately 100 people across Lothian. A similar service will be launched in Fife in early 2010 and it is hoped that the model will be replicated in other UK areas.
- **Be Blood Aware** is an intervention tool for individuals and organisations, designed to highlight the main risk factors for hepatitis C transmission. The tool is flexible enough to work in a wide variety of environments and concentrates on areas of an individual's life where they might come into contact with blood (for example, through sharing drug works, sharing personal items like tooth brushes and razors, transfusions, tattooing and piercing). In the last year, it has successfully been used by approximately 1,000 people across the UK, at several venues including music festivals, and university freshers' fairs.

Further Links

www.mainliners.org.uk

www.hepccentre.org.uk

www.cplus-lothians.org.uk

The Hepatitis C Trust

The second World Hepatitis Day was held on May 19 2009, providing a focus for awareness-raising activities.

Clear Channel and *Redbus*, two of the major outdoor media companies, between them gave over 1,000 large outdoor advertising sites in city centres and on university campuses to feature posters from the combined voluntary sector. Events were held throughout the UK and organised by both patient groups and NHS trusts, notably in Bournemouth and Manchester. There were also red double-decker buses in London, Cardiff and Glasgow offering hop-on testing. The Department of Health in England and the Scottish government supported the day with Health Protection Scotland hosting a National Stakeholder Conference in Glasgow to review the progress of the Scottish Hepatitis C Action Plan.

Worldwide, events were held in over 60 countries generating almost 3,000 pieces of media coverage reaching more than 1 billion people. In the run up to the day, intense advocacy by the World Hepatitis Alliance, the patient organisation responsible for World Hepatitis Day, succeeded in getting viral hepatitis added to the agenda of the World Health Assembly, the annual meeting of the 193 member countries of the World Health Organization. The agenda included a resolution calling for concerted global efforts to combat hepatitis C and hepatitis B. In the event, the Assembly, which had been scheduled to run from May 18-27 2009 was significantly shortened because of pandemic flu and discussion of viral hepatitis was postponed until 2010.

6.5 Summary

Over the last year a number of awareness-raising initiatives have been conducted by the government, agencies, the NHS and voluntary sector with messages aimed at the general public, risk groups and healthcare professionals. It is hoped that these initiatives will help reduce the levels of undiagnosed infection, and help individuals to access treatment and care.

7.0

News items



7.0 News items

7.1 A National Liver Strategy for England

In recognition that liver disease is now the fifth most common cause of death in England, the Department of Health are in the process of recruiting a national clinical director to provide clinical leadership to develop a National Strategy for Liver Disease. The strategy will include actions to improve prevention, identification, treatment, care and support for people with liver disease. The aim of the strategy is to improve the quality of liver disease services for patients from diagnosis to end of life.

7.2 Reports

7.2.1 Primary prevention of hepatitis C among injecting drug users

In February 2009, the UK Advisory Council on the Misuse of Drugs (ACMD) published its report: *The Primary Prevention of Hepatitis C Among Injecting Drug Users*⁷⁹. This report focuses on hepatitis C (HCV) prevention in injecting drug users (IDUs). Following a review of evidence, the ACMD concluded that no single intervention was sufficient to prevent the spread of the hepatitis C virus. The report concludes that the most effective way of reducing HCV incidence among active IDUs is through a combination of opiate substitution therapy and the provision of needle and syringe programmes. Further recommendations around gathering data on HCV, regarding epidemiology, testing and treatment referrals were made to improve the evidence base upon which decisions underpinning policy can be made. The Home Office website has more information on the report⁷⁹.

7.2.2 Hepatitis C: Out of Control⁴³

In the Hepatitis C Action Plan for England¹, strategic health authorities (SHAs) were tasked with ensuring that primary care trusts and NHS hospital trusts carried out the actions assigned to them to deliver high-quality hepatitis C health services and to prevent new infections. Using Freedom of Information requests, the Hepatitis C Trust asked SHAs 17 questions in order to audit their performance in this area and marked them (on a scale of 0-100) on the basis of their replies.

The report *Hepatitis C: Out of Control* released in July 2009⁴³ describes wide variation in SHA performance in this area, with the best SHA scoring 92 out of 100, and the worst scoring nil. Overall, seven out of the ten SHAs scored 33 or less. The report concluded that this indicated a failure of SHAs to oversee primary care trusts and NHS hospital trusts in implementing the Hepatitis C Action Plan. The authors suggest that this was a cause of the slow implementation of the Action Plan by the local NHS.

7.2.3 Divided Nations: Tackling the hepatitis C challenge across the UK⁴⁶

In January 2009, the All Party Parliamentary Hepatology Group (APPHG) released their report: *Divided Nations: Tackling the Hepatitis C Challenge Across the UK*⁴⁶. The report focused on the different approaches that England, Scotland and Wales have taken in tackling hepatitis C. Recommendations were made following a comparative analysis of the Action Plans for England and Scotland and the draft Action Plan for Wales⁴⁶.



7.3 Frameworks and guidelines

7.3.1 Hepatitis C workforce education development: an outline of requirements for Scotland

This national framework for hepatitis C workforce development and education was published by NHS Education for Scotland in August 2009. The framework has been developed in partnership with key stakeholders including the Education, Training and Awareness-raising (ETA) Network, NHS Education for Scotland, Hepatitis C Education Advisory Group and local workforce development and education leads that have been established in each NHS Board across Scotland specifically for hepatitis C.

7.3.2 Development of national guidelines for services providing injection equipment to IDUs in Scotland

A Guideline Development Group has been established to develop National Guidelines for Services Providing Injection Equipment in Scotland. The guidelines are intended for people who have responsibility for planning, commissioning and delivering injection equipment provision (IEP) services, and contain recommendations addressing: (i) the process of developing and reviewing local injection equipment provision to meet client needs, (ii) increasing the quantity of injection equipment (both sterile needles *and* other injecting paraphernalia) that IEP services give out, (iii) improving the quality of IEP services (iv) the integration of care for IDUs, particularly those infected with hepatitis C within the IEP setting and (v) protecting the health and safety of staff and the promotion of the safe disposal of used injection equipment.

The guidelines were drafted by January 2009 and stakeholder consultation was undertaken during February-March 2009. The guidelines were submitted to the Scottish government for approval in June 2009, and publication is anticipated in late 2009.

7.4 Surveillance and testing

7.4.1 Improving reporting of acute hepatitis from genitourinary medicine clinics to HPUs in England

Following a request from the British Association of Sexual Health (BASHH) for guidance on reporting hepatitis to the HPA, representatives from the HPA Local and Regional Hepatitis Leads' Group, the HPA Regional Microbiology network and the HPA hepatitis programme manager met with representatives from BASHH and the following was agreed:

- Genitourinary medicine (GUM) clinics would be asked to report all cases of acute hepatitis A, acute hepatitis B and acute hepatitis C to their local health protection unit.
- A pro-forma was developed for reporting cases that includes demographic details, laboratory markers, information on transmission route and contact tracing⁸⁹.

7.4.2 Pharmacy testing pilot

To coincide with World Hepatitis Day, The Hepatitis C Trust launched a three-month pilot hepatitis C testing programme in 20 pharmacies in Hackney, Sandwell, Tameside, the Isle of Wight and Nottingham. Supported by the local primary care trusts, this scheme was designed to discover whether hepatitis C diagnosis could be increased by making testing more accessible. This is in line with a movement to offer testing in pharmacies for an increasing range of diseases and conditions such as chlamydia, cholesterol and hypertension. Dried blood spot tests, involving just a finger prick, were used to ensure the procedure was as simple and quick as possible.

The results are currently being collated and analysed and should be available early next year. Preliminary results suggest that the offer of pharmacy testing can help diagnose more hepatitis C patients.

7.5 Research and evaluation

7.5.1 Educational interventions to prevent hepatitis C: A review of the literature and expert opinion

A review of literature on educational interventions which may be effective in preventing the transmission of hepatitis C among IDUs or those who are at risk of injecting has been completed by NHS Health Scotland, supplemented by interviews conducted to derive expert opinion in the field.

Educational interventions to prevent hepatitis C: A Review of the Literature and Expert Opinion has since been published by NHS Health Scotland in August 2009. A rapid mapping of educational interventions currently employed by NHS Boards across Scotland has also been undertaken and presented to the National Prevention Leads Network in October 2009.

7.5.2 Hepatitis C infection among children in Scotland

Ethical approval for a survey of hepatitis C prevalence among children attending the general anaesthetic assessment clinic of the Glasgow Dental Hospital and School has been sought and obtained. The study aims to determine (i) the prevalence of hepatitis C among children in Glasgow, (ii) the proportion of hepatitis C-positive mothers who also have a child who is hepatitis C-positive and (iii) risk factors for hepatitis C infection in children.

7.5.3 Hepatitis C infection in Africans living in London

Ethical approval was granted in August of this year for a pilot study to investigate the prevalence of hepatitis C among Africans living in London. This study will involve 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 HPU and the HPA Centre for Infections. It is anticipated that the study will begin in winter 2009/10.

7.5.4 Hepatitis C infection among people in Scotland who have lived in Pakistan and other South Asian countries

Ethical approval for a survey on the prevalence of viral hepatitis among South Asians living in Greater Glasgow and Clyde NHS Board has been sought and obtained. The study aims to: (i) estimate the prevalence of hepatitis C among immigrants to Glasgow who were born in South Asia, in particular in Pakistan, (ii) compare the prevalence of hepatitis C infection between those of Pakistani origin born in the UK and those born in Pakistan, and (iii) identify risk factors for hepatitis C infection in first and second generation migrants of Pakistani origin residing in Glasgow.

Hepatitis C in the African community in London

A new study to estimate the prevalence of infection

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What is Hepatitis C?

- Hepatitis C (or HCV) is a blood-borne virus, causing damage to the liver
- Current estimates suggest that 142,000 individuals in England and Wales, aged 15-59, are chronically infected with the virus
- This equates to a prevalence of 0.44% in the above population

Are African communities at greater risk of hepatitis C infection?

- The World Health Organisation (WHO) estimates the prevalence of HCV in Africa to be around 5.3%, although this is known to vary considerably within and between African countries.
- However, we do not know whether this higher prevalence also exists amongst Africans living in London. It is therefore important to obtain an estimate of HCV prevalence in this community.
- It is in Africa, Africans living in London also have a high prevalence of HCV infection, then increased awareness raising and targeted testing would be important in these communities.

Project Aims

- a) To undertake a pilot study to obtain a first estimate of HCV prevalence in Africans living in London
- b) To test the methodology for a larger study, if results suggest that this community has a high prevalence of hepatitis C infection.

What happens to those who are found to have HCV?

- Local hospital consultants would see any individuals who screen HCV positive
- Repeat blood tests would be undertaken to confirm the infection, and to find out the HCV viral type
- Treatment options would be discussed with the hospital consultant, and arrangements made for the appropriate treatment and/or management
- Several months of anti-viral treatment may be indicated; the duration of therapy would depend on individual factors, including the viral type identified, and would be discussed with the consultant responsible for each patient's care.

What does the literature tell us about HCV prevalence in Africa?

- Estimates of HCV prevalence in different risk groups have been reported, for example:
 - In one study of 167 blood donors in Lagos, 8.4% were found to be hepatitis C positive (Ayolabi, 2006)
 - In another Ghanaian study, 808 blood donors were tested, and 8.4% were found to be positive, yet only 0.9% were confirmed after supplementary testing with another assay (Jumofin, 2002)
 - In a Nigerian study, 1.4% of 150 ABE attendees were found to be positive (Ishim, 2000)
 - Of 1456 prison inmates tested in Ghana, 18.7% were found to be positive for hepatitis C (Adeji, 2006)
- There is very little reliable information on the prevalence of HCV in Africans living in Europe

Risk factors for HCV infection in England

- National surveillance suggests that more than 90% of all newly diagnosed hepatitis C infections in England are acquired via injecting drug use
- Other routes of acquisition include:
 - Blood/blood products received in England before the introduction of routine screening for hepatitis C, or in countries where blood is not routinely screened for hepatitis C infection
 - Transmission from an HCV-infected mother to her child
 - Exposures where blood from an infected individual can pass to another e.g. by sharing razors or tattooing in unsterile conditions etc.

Who gets tested for hepatitis C infection in England?

- Currently most individuals tested for hepatitis C are those who have developed signs and/or symptoms of liver disease or who have been picked-up because they have risk factors for acquiring the infection, in particular injecting drug use.
- Individuals with no signs or symptoms of liver disease, who are not in contact with services that undertake routine HCV screening (e.g. drug services), are far less likely to be tested for the virus.
- If many Africans have acquired HCV infection via routes other than injecting drug use (e.g. following receipt of unscreened blood in Africa), then they may be less likely to be tested.

What would we do with the results?

- Data will be used to help inform local and national hepatitis C service provision
- Findings will help to ensure that those communities at greatest risk of developing HCV-related disease are identified and referred for treatment.

Sample size and method

- If we assume a prevalence of 4%, then about 500 people would need to be tested
- Testing would be by finger prick blood and saliva sampling
- A pre-test discussion with a clinical nurse specialist would take place before the tests are taken
- A short questionnaire to obtain demographic and risk factor information would also be administered at the time of the test.
- Ethical approval for the study will be obtained from the National Research Ethics Service.

Interested in participating?

For further information on this study, please contact either:-

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7.5.5 Evaluating disease prevention and health promotion policies and programme initiatives for tackling blood-borne viruses in prisons in England and Wales

The University of Stirling, in collaboration with the University of Central Lancashire, has been commissioned by Offender Health⁹⁰ to evaluate the Department of Health's disease prevention and health promotion policies and programme initiatives for tackling blood-borne viruses (BBVs) in prisons in England and Wales. The evaluation is designed to:

- Assess the impact of the disinfectant tablets programme.
- Assess the hepatitis B Key Performance Indicators (KPIs) and BBV programmes on voluntary uptake of tests among prisoners.
- Assess response to and impact of disease prevention and health promotion materials (including those produced by the British Liver Trust).
- Identify enabling factors and barriers which have an effect on implementation of policies and programme initiatives.
- Examine interactive effects between varying interventions and initiatives.
- Identify good practice and provide practical recommendations for service and policy development.

The study combines quantitative and qualitative data collection, in two main stages:

- Mapping BBV related activity across all relevant prisons.

A single questionnaire designed to collect overview information covering key activities will be circulated to all prisons for completion by the most appropriate staff member(s) as designated by the governing governor.

- Prison Case Studies.

In-depth examination of key implementation activities and impact issues will be undertaken with a small number of individual prisons. This will incorporate interviews with prison staff and prisoners, and analysis of relevant documentation.

A detailed evaluation report will include results and recommendations to inform future practice and policy developments in relation to Offender Health and National Offender Management Service (NOMS). Findings will be widely disseminated. The research will be completed by March 2010.

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Michelle Baybutt, Healthy Settings Development Unit, School of Public Health and Clinical Sciences, University of Central Lancashire. Email: mbaybutt@ucan.ac.uk Tel: 01772 893764.

Offender Health Contact: Rachael Hunter, Public Health and Substance Misuse Team, Offender Health.

Email: Rachael.hunter@dh.gsi.gov.uk Tel: 020797 24860.

7.5.6 New antiviral therapies - evaluating their impact

New selective inhibitors targeted at the viral protease and the viral polymerase of HCV have been developed and are currently being evaluated in clinical trials. However, these inhibitors are likely to prompt the emergence of drug-resistant viruses when used widely, and trials have already demonstrated that viral resistance and breakthrough can occur in a very short time. The two classes of protease and polymerase inhibitors each will have their own routes to viral drug resistance.

Virtually all studies of these drugs so far have been conducted on patients infected with genotype 1 virus, whereas genotype 3 is responsible for most hepatitis C infections in England. The HPA has submitted a proposal to develop a web-enabled, sequence and clinical/epidemiology-linked database as a platform for investigating HCV in the UK. This will aim to inform the expected natural genetic variation within each genotype in the UK, and determine the prevalence of naturally existing resistance mutations and correlating this with genotype. In addition, funds are being sought to establish cell culture based methods for investigating the characteristics of such viruses. Such data will inform the impact of the genetic diversity observed in HCV genotypes on the success of these new treatments.

7.6 Other news

7.6.1 The Hepatitis C Trust opens an office in Scotland

The Scottish government has provided two-years' funding for the Hepatitis C Trust to open an office in Edinburgh to take a strategic role in the concerted action to tackle hepatitis C in Scotland.

7.6.2 Scottish Drugs Forum young person's project

The Scottish government has also provided two-years' funding to the Scottish Drugs Forum to support a young person's project, recognising that this is an important client group that has not been previously well serviced. The project will contribute to the education and prevention activities of the Hepatitis C Action Plan in Scotland.

7.6.3 A hepatitis C specialist for Herefordshire

In November 2008, Herefordshire Acute Hospitals NHS Trust acquired its own hepatitis C specialist nurse, based at Hereford County Hospital. Joanne Spicer, who has worked in hepatology, substance misuse and blood-borne virus services for 15 years, is now providing specialist treatment and support to those diagnosed with hepatitis C in Herefordshire. Before this, those residing in the county were required to travel to Birmingham to access treatment services. As well as providing treatment services, there is also a weekly drop-in 'hepatitis clinic' at DASH (Drug Advisory Service Herefordshire), a local drug service provider. Awareness sessions have also been offered throughout 2009, with support from Safer Herefordshire (Herefordshire's Community Safety Partnership), in order to reach other potential at-risk groups. These have been held in different supported housing premises, where the residents mostly consist of ex-offenders, substance users and the homeless. Joanne also acts as a valuable educational resource for other healthcare professionals, seeking hepatitis advice and information.

For further information on hepatitis C treatment in Herefordshire, please contact Joanne Spicer on 01432 364167.

7.7 Summary

A number of reports, strategies, frameworks and guidelines have been published over the last year in relation to hepatitis C service and care provision across the UK. In recognition that liver disease is now the fifth most common cause of death in England, the Department of Health is in the process of recruiting a national clinical director to provide clinical leadership to develop a National Strategy for Liver Disease. These, and other reported initiatives, will help to guide the development of services in the future, extend the evidence base, and evaluate the effectiveness of existing service provision. Reports from the Hepatitis C Trust and the All Party Parliamentary Hepatology Group underline the scale of the work ahead.

As new selective inhibitors targeted at HCV protease and polymerase are being evaluated in clinical trials, the HPA plans to develop a web-enabled, sequence and clinical/epidemiology-linked database as a platform for investigating HCV in the UK as careful monitoring of predicted drug-resistant viruses will be required when these inhibitors are widely used.

Appendix



Hepatitis C

Quick reference guide for primary care

What is hepatitis C (HCV)?

- A blood-borne virus, spread mainly through blood-to-blood contact
- Can damage the liver, potentially causing cirrhosis and primary liver cancer
- Symptoms can take years or decades to occur
- An estimated 200,000 people are chronically infected in England
- HCV has been associated with injecting drug use, but there are a variety of ways in which it can be transmitted (see below)

Why should I be proactive in diagnosing HCV?

- About half of those infected in England are probably unaware of it
- Treatment can successfully clear the virus in more than half of patients treated overall

Who is at risk of HCV?

Hepatitis C testing should also be offered to anyone who:

- Has unexplained abnormal liver function tests (e.g. elevated ALT), or unexplained jaundice
- Has ever injected drugs in the past (including anabolic steroids) using shared equipment, however long ago, even if this was only once or twice
- Has had a blood transfusion in the UK before September 1991 or received any blood products before 1986
- Has received medical or dental treatment in countries where infection control may be poor
- Is the child of a mother with HCV
- Is a regular sexual partner of someone with HCV
- Has been accidentally exposed to blood where there is a risk of transmission of HCV
- Has had tattoos, piercings, acupuncture or electrolysis where infection control procedures are poor

How do I test for HCV?

The primary screening test is a blood test for antibodies to the virus (anti-HCV), which indicates if a person has ever been infected with HCV. A positive test should be confirmed by testing a second sample. It can take three months for antibodies to become detectable. A negative test should be repeated if the exposure was within three months of the test.

About 20–40% of people will clear the virus naturally, so a test to detect HCV RNA is required to establish if the patient is still infected.

Pre-test discussion

Pre-test discussion should include:

- Hepatitis C, its natural history and the benefits offered by treatment
- What the test involves, testing timescale and confidentiality of results
- Assessment of exposure risks and establishing when the last risk activity took place
- Implications of a positive result for the individual and his/her family or close contacts
- What personal support network the individual may have; information about national/local organisations that provide support

It may also offer the opportunity to advise injecting drug users about harm minimisation and to offer them the hepatitis A and hepatitis B vaccine.

Post-test discussion

Post-test discussion should also include:

Negative antibody result

- Further testing will be required if the last exposure risk occurred in the preceding three month 'window period'
- Ways of avoiding infection in the future

Positive antibody result

- Positive antibody results should be followed by tests for HCV RNA. A second blood sample should be taken for confirmation
- Advise not to donate blood or carry an organ donor card

Positive HCV RNA result

- Patients should be referred to a specialist for further assessment
- Stop or reduce alcohol consumption (associated with more rapid progression of liver disease)
- Ways of avoiding infecting others
- Consider the need to test other family members or close contacts

Negative HCV RNA result

- A positive antibody and negative HCV RNA test indicates a previously resolved infection, but not immunity to further infection
- Patients who are antibody positive but HCV RNA negative should have a second HCV RNA test after 4–6 weeks to confirm their negative status

Hepatitis C Get tested. Get treated.

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NHS

Appendix



Hepatitis C

What you need to know

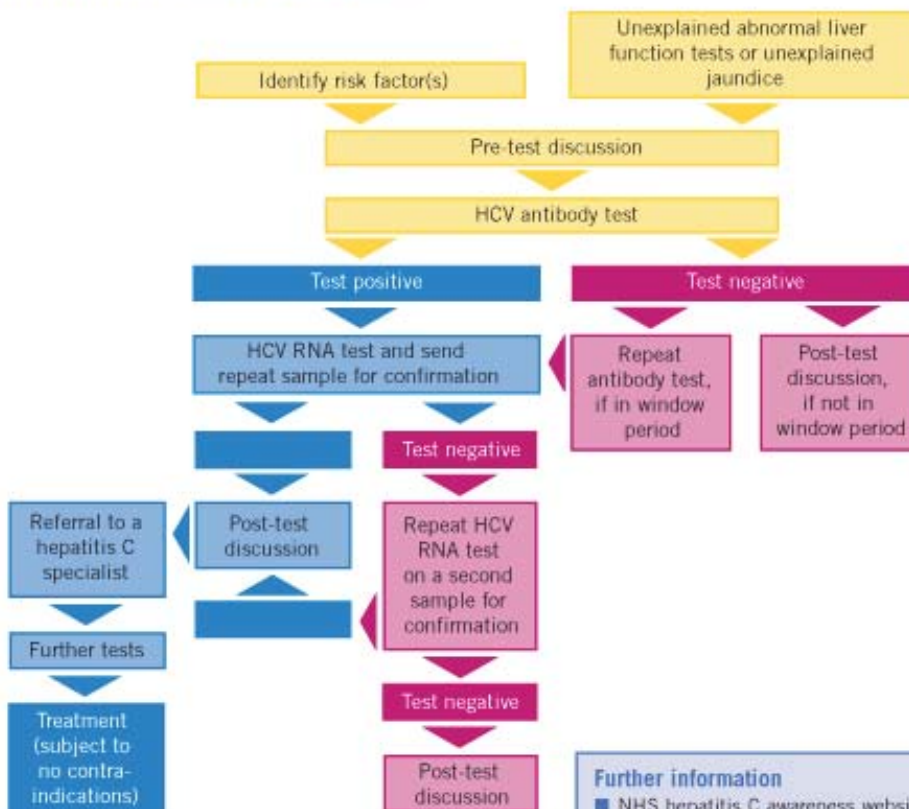
Treatment for HCV

The National Institute for Health and Clinical Excellence (NICE) recommends treatment of chronic hepatitis C with combined pegylated interferon and ribavirin, which can successfully clear the virus in up to 55% of patients overall. Current injecting drug users and people who drink excess alcohol are **not** precluded from treatment.

Since the recent NICE recommendations, liver biopsy need no longer be routine in assessing patients for treatment, though it may be advised for some patients.

Treatment may have side effects but these can be satisfactorily managed in most cases. Treatment may be contraindicated for some medical and psychiatric conditions.

From diagnosis to treatment – flow chart



Further information

- NHS hepatitis C awareness website: www.nhs.uk/hepc
- Hepatitis C Information Line: 0800 451 451

If you require further copies of this title call 0300 123 1002 or visit www.orderline.dh.gov.uk and quote: 292688/Hepatitis C: Quick reference guide for primary care.

Hepatitis C Get tested. Get treated.

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Glossary of Abbreviations



ACMD	Advisory Council on Misuse of Drugs	MCN	Managed Clinical Network
Anti-HCV	Antibodies to Hepatitis C Virus	MSM	Men who have Sex with Men
APPHG	All Party Parliamentary Hepatology Group	NDTMS	National Drug Treatment Monitoring System
AMRC	Association of Medical Research Charities	NEXMS	Needle Exchange Monitoring System
BASHH	British Association of Sexual Health and HIV	NI	Northern Ireland
BBV	Blood-Borne Virus	NIBTS	Northern Ireland Blood Transfusion Service
BHIVA	British HIV Association	NDTMS	National Drug Treatment Monitoring System
CCDC	Consultant in Communicable Disease Control	NICE	National Institute for Health and Clinical Excellence
Cfi	Centre for Infections	NIPS	Northern Ireland Prison Service
CHP	Community Health Partnerships	NHS	National Health Service
CI	Confidence Interval	NHSBT	National Health Service Blood and Transplant
	Drug Advisory Service Herefordshire	NHS IC	National Health Service Information Centre
DAT	Drug Action Team	NOMS	National Offender Management Service
DBS	Dried Blood Spot	NPHS	National Public Health Service
DH	Department of Health	NSP	Needle and Syringe Programme
DHSSPS	Department of Health and Social Services and Public Safety	NTA	National Treatment Agency for Substance Misuse
DIP	Drug Intervention Programme	ONS	Office for National Statistics
DPH	Director of Public Health	OR	Odds Ratio
ESLD	End-Stage Liver Disease	PCR	Polymerase Chain Reaction
ETA	Education, Training and Awareness-raising	PCT	Primary Care Trust
GP	General Practitioner	PEDW	Patient Episode Data for Wales
GUM	Genitourinary Medicine	PIP	Peer Involvement Project
HCAIs	Healthcare Associated Infections	QIS	Quality Improvement Scotland
HCC	Hepatocellular Carcinoma	RCCGP	Royal College of General Practitioners
HCV	Hepatitis C Virus	RNA	Ribonucleic Acid
HES	Hospital Episode Statistics	SD	Standard Deviation
HIV	Human Immunodeficiency Virus	SHA	Strategic Health Authority
HPA	Health Protection Agency	SIGN	Scottish Intercollegiate Guidelines Network
HPANI	Health Protection Agency Northern Ireland	SNAHC	Surveillance of Newly Acquired Hepatitis C
HPU	Health Protection Unit	SNBTS	Scottish National Blood and Transfusion Service
IDTS	Integrated Drug Treatment System	SPS	Scottish Prison Service
IDU	Injecting Drug User	STI	Sexually Transmitted Infection
IEP	Injection Equipment Provision	SVR	Sustained Viral Response
IMS	Intercontinental Medical Statistics	UAPMP	Unlinked Anonymous Prevalence Monitoring Programme
ISD	Information Services Division	UK	United Kingdom
KPI	Key Performance Indicator	WAG	Welsh Assembly Government
LAC	Local Authority Circular	WBS	Welsh Blood Service
LFT	Liver Function Test	WHO	World Health Organisation
		WNDSM	Welsh National Database for Substance Misuse

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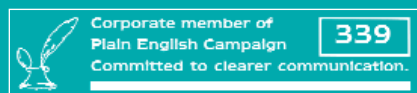
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December 2009
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