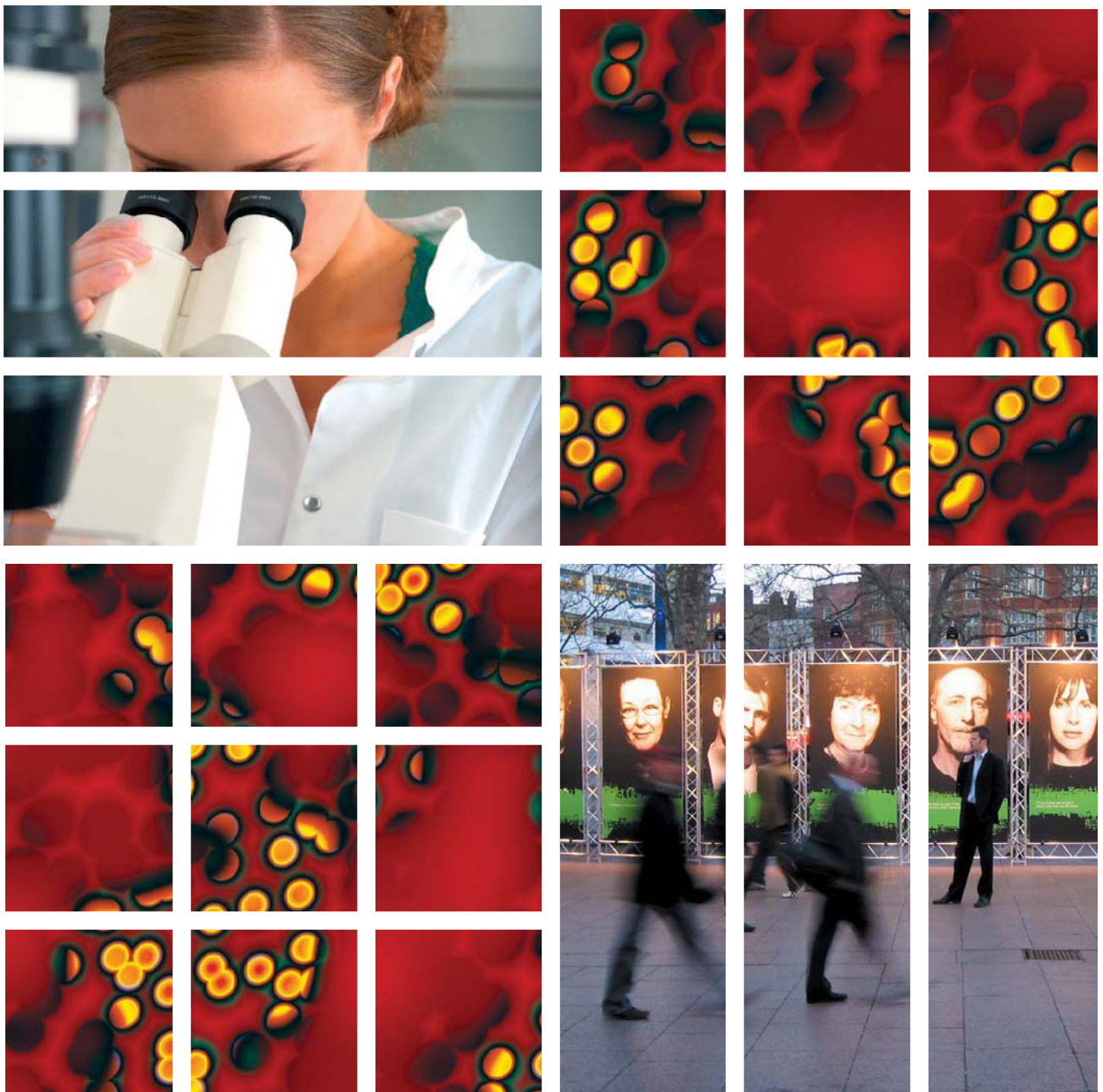


# Hepatitis C in England

The Health Protection Agency Annual Report 2007



## Glossary of Abbreviations

ACMD	Advisory Council on Misuse of Drugs
AGH	Advisory Group on Hepatitis
ALT	Alanine Aminotransferase
APPHG	All Party Parliamentary Hepatology Group
Anti-HCV	Antibodies to Hepatitis C virus
BASHH	British Association of Sexual Health and HIV
BASL	British Association for the Study of the Liver
BBV	Blood Borne Virus
BHIVA	British HIV Association
BLT	British Liver Trust
Cfi	Centre for Infections
CI	Credibility Interval
CIIP	Criminal Justice Interventions Programme
CLDF	Children's Liver Disease Foundation
DAT	Drug Action Team
DBS	Dried Blood Spot
DH	Department of Health
EHO	Environmental Health Officer
EPHN	European Paediatric HCV Network
ESLD	End Stage Liver Disease
EU	European Union
GP	General Practitioner
GUM	Genitourinary Medicine
HBV	Hepatitis B Virus
HCC	Hepatocellular Carcinoma
HCV	Hepatitis C Virus
HCW	Health Care Worker
HES	Hospital Episode Statistics
HIV	Human Immunodeficiency Virus
HMPS	Her Majesty's Prison Service
HPA	Health Protection Agency
HPA NE	Health Protection Agency North East
HSE	Health and Safety Executive
HTA	Health Technology Assessment
HPU	Health Protection Unit
IDTS	Integrated Drug Treatment System
IDU	Injecting Drug User
LA	Local Authority
LaRS	Local and Regional Services
LSHTM	London School of Hygiene & Tropical Medicine
MEP	Member of the European Parliament
MRC	Medical Research Council
MSM	Men who have Sex with Men
NDTMS	National Drug Treatment Monitoring System
NEX	Needle Exchange
NICE	National Institute for Health and Clinical Excellence
NHS	National Health Service
NRI	No Risk Identified
NTA	National Treatment Agency
ONS	Office for National Statistics
PCR	Polymerase Chain Reaction
PCT	Primary Care Trust
PSA	Public Service Agreement
PR	Public Relations
RNA	Ribonucleic Acid
SSDPB	Surveillance Strategy Development Programme Board
SHA	Strategic Health Authority
STI	Sexually Transmitted Infection
UAPMP	Unlinked Anonymous Prevalence Monitoring Programme
UK	United Kingdom

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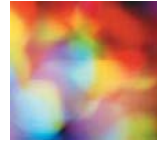
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## Major Facts at a Glance



- In 2006, the number of confirmed hepatitis C infections reported from laboratories in England rose to 8,346; 10 per cent higher than in 2005.
- Injecting drug use remains the single most important reported risk factor for acquiring hepatitis C infection.
- In 2006, the prevalence of hepatitis C infection amongst those who have recently started injecting drugs within the last 3 years remained high at 22 per cent.
- Deaths, transplants and hospital admissions for hepatitis-related end stage liver disease continue to rise, and the number of people with such severe disease is predicted to increase to 2,670 by 2015.
- Hepatitis C testing in specialist drug services has increased nearly ten-fold between 2002 and 2006; testing via GP surgeries also remains high.
- An estimated 194,211 people were in contact with specialist, structured drug treatment in England during 2006/07, 7 per cent higher than 2005/06, and 128 per cent higher than in 1998/99.
- In 2006, around 94 per cent of current injectors reported recent use of a needle exchange service, but the harm reduction advice received was variable.
- A DVD - *Hepatitis C: Inside and Out* - has been developed to deliver messages on prevention, transmission, management and treatment within the prison setting.
- During 2006/07 there was more than a 60 per cent increase in media coverage about hepatitis C from the previous year.

## Executive Summary

The current best estimates of the prevalence of chronic hepatitis C infection in England and Wales derive from a statistical model developed at the Health Protection Agency (HPA), in collaboration with the Medical Research Council's (MRC) Biostatistics Unit in Cambridge. This model suggested that in 2003 around 231,000 individuals in England and Wales aged 15-59 years had antibodies to hepatitis C virus. This equates to a chronic prevalence in this age group of 0.53 per cent. Over the coming year estimates of the prevalence of hepatitis C will be updated as new data sources become available.

Over the past year efforts have been made to improve surveillance and research so that trends in hepatitis C infection and the effectiveness of prevention measures can be monitored. The continued rise in laboratory confirmed diagnoses of HCV infection - 10 per cent over the last year, support the view that more HCV diagnosis is taking place in England. Given the likely degree of under-reporting, it seems plausible that around half of the total estimated prevalent HCV infections have been diagnosed, which represents an improvement on the high proportion of undiagnosed infections suggested in 2004<sup>1</sup>. How many of these individuals who have tested positive for anti-HCV are aware of their diagnosis and have been appropriately referred and managed is less clear.

Laboratory reports of diagnosed HCV infections continue to show that a history of injecting drug use is the principal route of transmission for HCV infection in England. Another increasingly recognised risk group for infection are individuals who originate from the Indian sub-continent. Preliminary results from a study investigating the prevalence of hepatitis in people originating from these areas, suggest that people coming from Pakistan are at increased risk of HCV infection. The disproportionate number of HCV infections seen amongst individuals originating from the Indian sub-continent, detected during routine screening of blood donors, also provides evidence to support a higher HCV risk in these groups.

Data from the Unlinked Anonymous Prevalence Monitoring Programme (UAPMP) shows that anti-HCV prevalence in current injectors remains high at 43 per cent.

In addition, the prevalence of anti-HCV amongst IDUs who have begun injecting within the last three years remains high, and in 2006 stood at 22 per cent. Transmission of hepatitis C in HIV positive men who have sex with men continues to be a cause for concern and a recent survey identified almost 400 cases of newly acquired infection in the South East of England. This survey emphasises the importance of adherence to British HIV Association (BHIVA) guidelines for routine and repeat HCV screening in HIV positive individuals.

Sentinel surveillance suggests that genotype 3a is the most common genotype in England. From a treatment perspective, this is probably good news for patients, as this genotype is known to be particularly sensitive to current therapies<sup>2</sup>. However, data show that genotype 1 infections still make up more than 40 per cent of all prevalent infections in England, and these are known to be the hardest to treat<sup>2</sup>.

There has been a considerable increase in media coverage about hepatitis C from a variety of sources over the last year. The NHS awareness campaign has achieved a more than 60 per cent increase in media coverage of hepatitis C, with a potential audience reach of more than 40 million people in England. The surge in visits to the NHS website (<http://www.hepc.nhs.uk>) and Hepatitis C Information Line provide evidence that increased awareness has been achieved. National advertising campaigns involving radio, newspapers and consumer magazines continue to be the mainstay of this campaign and there are plans to extend this coverage over the coming year. The media campaign has been specifically developed to address concerns that individuals from the Indian sub-continent may be at increased risk of HCV infection.

Awareness raising in the voluntary sector remains high and its role in tackling the infection is crucial. Charities, including The British Liver Trust, The Hepatitis C Trust, and The Children's Liver Disease Foundation have continued a range of activities to raise the profile of hepatitis C. The late Dame Anita Roddick's commitment to raising the awareness of hepatitis C infection has undoubtedly made a significant contribution in this area.



All indicators suggest that HCV testing in the injecting drug user population is increasing, with 75 per cent of the individuals in the UAPMP agency survey reporting ever having had a voluntary confidential hepatitis C test; data from sentinel surveillance and commercial oral fluid screening also show a substantial increase in HCV testing in this key risk group. The numbers accessing testing via their GP surgeries remains high and testing via this route will be key in reaching those individuals who may have been at risk of HCV infection in the past, but who are not currently in contact with services.

Sentinel surveillance, oral fluid screening and reports of laboratory confirmed diagnoses of hepatitis C infections all indicate that more testing is taking place and that more infected individuals are being diagnosed. Oral fluid screening in specialist drug services has increased uptake, and the potential role of HCV antibody and RNA testing of dried blood spots for diagnostic and confirmation, particularly in low threshold settings where it is difficult to take blood, could be significant.

Research undertaken by the HPA (alone and in collaboration with others) and by external groups, continue to inform the natural history of HCV infection in England. Recent studies have helped to define the morbidity and mortality from HCV-related disease and have identified risk factors for progressive disease in both adults and children. It is also encouraging to see that the therapeutic combination of interferon and ribavirin is associated with improved rates of survival in the HCV-infected population.

Routine sources of national data - deaths, transplants and hospital admissions - all show that HCV-related end stage liver disease in England is continuing to rise. Similarly, statistical models developed in collaboration with the MRC predict that the number of people living with end stage liver disease due to hepatitis C in England will increase to 2,670 by 2015. This is a real cause for concern, particularly when the true number of people in England suffering from severe HCV-related liver disease is known to be under-estimated in routinely recorded hospital and death data.

Continuing increases in the burden of HCV-related disease show that there is no room for complacency in tackling this infection; despite increases in the awareness and diagnosis of HCV infection, there is still some considerable way to go if the burden of HCV-infection is to be reduced in the future. National data on referral, uptake and outcome of treatment will be key (and are urgently required) if local hepatitis C services are to be planned effectively.

Continued increases in the funding allocation of national drug treatment services should help to get more people into treatment and away from a life of drugs and crime. Provisional data from the National Drug Treatment Monitoring System (NDTMS) reveal that 194,211 people were in contact with specialist, structured drug treatment in England during 2006/07, an increase of 7 per cent on 2005/06 (181,390) and 128 per cent on the 1998/99 baseline of 85,000. This is significant as injecting drug use (IDU) remains the principal driver of HCV infection in England.

Prevention strategies continue to target those groups at greatest risk of infection, and new initiatives include: improving drugs education, reducing initiation of injecting drug use, helping IDUs to quit injecting, and harm minimisation strategies for those who continue to inject. The core work in this area has necessarily centered on injecting drug users themselves as well as around settings, like prisons, where injecting drug use is concentrated. Tools like the national health promotion DVD - *Hepatitis C: Inside and Out* - have been developed to deliver messages on the prevention, transmission, management and treatment of Hepatitis C within the prison setting and existing resources have been updated. Other recently introduced strategies around harm minimisation include: a new programme rolling out disinfectant tablets across the prison estate; harm reduction being highlighted as one of two key themes of the joint NTA/Healthcare Commission improvement review of 2006/07 and the publication of a joint Department of Health/NTA action plan on reducing drug-related harm, produced in response to the increase in blood borne virus infections, including HCV, amongst IDUs.

Recent surveys report that approximately 94 per cent of current injectors used drug services, specialist needle exchange or pharmacy needle exchanges to obtain sterile injecting equipment and paraphernalia. However, the harm reduction advice these individuals receive is variable. Because HCV prevalence among IDUs remains high and the current coverage (the amount of injecting equipment distributed) seems insufficient to reduce HCV transmission among IDUs, Hepatitis C prevention has been made the subject of the current Advisory Council on Misuse of Drugs (ACMD) Prevention Working Group.

The HPA has increased its activity on hepatitis C over the last year, expanding its initiatives and networks on a local and national level. The HPA has developed a practical tool to provide local estimates of HCV prevalence, and predictions of the likely number of individuals requiring treatment at a Primary Care Trust (PCT) level. It is hoped that this initiative will help PCTs to better approach the commissioning of services for hepatitis C for their local populations.

The HPA Local and Regional Services Prison Network are currently undertaking an exercise to map Health Protection Unit-Prison activity on screening, referral and commissioning of hepatitis C services. The HPA have also set up a network of designated HPA hepatitis leads for each region (and local Health Protection Units) to provide a local point of contact for viral hepatitis, for disseminating information and coordinating work. Work is in progress to assess the feasibility and acceptability of self-testing for HCV and, as part of a generic process, the HPA systems for surveillance of hepatitis C are also being evaluated.

The HPA hopes to develop existing programmes and initiate new ones over the coming year.



# Introduction



In the annual reports of the Chief Medical Officer in 2001 and 2002, liver disease was identified as an area of rising concern, {[http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/AnnualReports/DH\\_4005607](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/AnnualReports/DH_4005607)}, {[http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/AnnualReports/DH\\_4006432](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/AnnualReports/DH_4006432)}. Since 2002, the importance of hepatitis C infection as a major infectious disease priority for the UK has been reflected in a series of documents<sup>3,4,5</sup> culminating in Action Plans in each of the UK countries<sup>1</sup> (<http://www.scotland.gov.uk/Publications/2006/09/15093626/13>; <http://www2.nphs.wales.nhs.uk/icds/docopen.cfm?ID=403>; [http://www.dhsspsni.gov.uk/hepatitisc\\_strategic\\_framework.pdf](http://www.dhsspsni.gov.uk/hepatitisc_strategic_framework.pdf)). It has now been three years since the *Hepatitis C Action Plan for England*<sup>1</sup> was launched. As reported last year, some actions have occurred quickly, whereas progress towards other actions has been less evident. National Health Service campaigns to raise professional and public awareness have been sustained and developed an increasingly high public profile in 2006. This work has been enhanced by the work of the voluntary sector culminating in the announcement, in February 2007, by Dame Anita Roddick that she herself was infected with the hepatitis C virus.

This is the third annual report on HCV from the HPA, working with other stakeholders, summarising current knowledge about HCV, the action being taken in England to tackle the infection, and the progress against the National Outcome Indicators as of 2006. We hope that agencies working with hepatitis C infection, in particular the newly configured Primary Care Trusts, can use this document to revisit the challenges in the Action Plan and to review their own progress.



# 1.0

Background: Estimated prevalence of Hepatitis C in England

# 1.0

## Background: Estimated prevalence of Hepatitis C in England



# 1.0 Background: Estimated prevalence of Hepatitis C in England

## KEY POINTS

- A statistical model estimated that the number of individuals aged 15-59 years with antibodies to hepatitis C virus in England and Wales in 2003 was 231,000.
- For the total 15-59 years population of England and Wales, anti-HCV prevalence was estimated to be 0.72 per cent in 2003, approximating to a chronic prevalence of 0.53 per cent.
- Models to estimate the prevalence of hepatitis C in England and Wales are currently being updated as new data sources become available.

If services for people with hepatitis C are to be commissioned effectively, then it is essential to have an accurate estimate of the numbers of individuals in England who are chronically infected.

Attempts to estimate HCV prevalence in the past have been complicated by the fact that many infections occur in injecting drug users, a population group that is notoriously difficult to study. This remains true today, and methods to estimate prevalence should always take account of the fact that IDUs are often under-represented in many national data sources, like household surveys, because they move around frequently and a proportion of them will be homeless at any given point in time.

When estimating the prevalence of hepatitis C in any populations sampled, the final prevalence figure will ultimately depend on the overlap between the populations studied and those groups at high risk of infection.

### 1.1 A statistical model to estimate the prevalence of hepatitis C

In collaboration with the Medical Research Council's (MRC) Biostatistics Unit in Cambridge, the Health Protection Agency (HPA) has developed a statistical model aimed at estimating the prevalence of HCV antibodies in England and Wales by combining a variety of data sources<sup>6</sup>.

Data on HCV prevalence from a number of sub-populations is combined through knowledge about the composition of each sub-population in terms of the high-risk injecting drug user (IDU) group. Further data on the prevalence of current and ex-IDUs allows estimation of HCV prevalence in the population.

This model estimated that the number of individuals aged 15-59 years with antibodies to hepatitis C virus living in England and Wales in 2003 was 231,000 (95 per cent credibility interval: 144,000-381,000)<sup>6</sup>. These figures correspond to an estimated anti-HCV prevalence of 0.72 per cent (95 per cent CI: 0.45 - 1.19) for the total 15-59 years population of England and Wales. Assuming that 74 per cent of the antibody positive population become chronically infected<sup>7</sup>, this equates to a chronic prevalence of 0.53 per cent (95 per cent CI: 0.33 - 0.88). Based on this model, the



HPA has also developed a tool to help PCTs estimate the number of individuals likely to be needing treatment to help with commissioning services locally (see Chapter 6 and [http://www.hpa.org.uk/infections/topics\\_az/hepatitis\\_c/hcvtemp.xls](http://www.hpa.org.uk/infections/topics_az/hepatitis_c/hcvtemp.xls)).

The national model uses data from the Unlinked Anonymous Prevalence Monitoring Programme (UAPMP) on HCV prevalence in antenatal women<sup>8</sup> and genitourinary medicine (GUM) clinic attendees<sup>9</sup>. Originally, antenatal samples were only tested for the presence of HCV antibodies in 1996, whilst non-IDU GUM attendees were only tested in 1995. However, the Department of Health has awarded funding to test antenatal and GUM samples from the UAPMP survey in 2005. Once available, the statistical model will be developed to incorporate these new data and prevalence results will be updated.

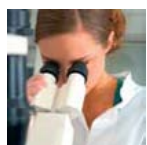
Other data sources that informed the original research are also due to be updated; work is ongoing to test UAPMP IDU samples back to the early 1990's for the presence of HCV antibodies. This will allow greater precision in the estimation of HCV prevalence in the IDU sub-group, and in particular will allow better understanding of how HCV prevalence may have changed according to different time periods during which users were injecting. In addition to this, more information is being sought regarding past IDU incidence and the length of injecting careers. These new data will help to characterise the IDU population in terms of current and ex-users and hence improve the precision of the overall estimate of HCV prevalence.

## Summary

A statistical model developed at the HPA in collaboration with the MRC, suggested that in 2003, the number of individuals aged 15-59 years with antibodies to hepatitis C virus in England and Wales was around 231,000. This equates to a chronic prevalence in this age group of 0.53 per cent.

Over the coming year estimates of the prevalence of hepatitis C in England and Wales will be updated as new data sources become available.





## 2.0 Surveillance and research

# 2.0

## Surveillance and research



# 2.0 Surveillance and research

## KEY POINTS

- A cumulative total of 62,726 laboratory-confirmed diagnoses of hepatitis C infection from England were reported to the HPA between 1992 and 2006.
- The number of laboratory-confirmed diagnoses of hepatitis C infection from England reported to the HPA in 2006 was 8,346; a rise of 10 per cent on 2005.
- Data suggest that routine laboratory reporting may underestimate the numbers of diagnosed hepatitis C infections by up to 60 per cent.
- Injecting drug use remains the single most important risk factor for acquisition of hepatitis C infection, estimated to be responsible for more than 90 per cent of all newly acquired infections.
- The prevalence of anti-HCV amongst IDUs who have commenced injecting in the last three years (a marker of recent transmission) remains high, at 22 per cent in 2006.
- A recent survey estimated the incidence of diagnosed newly acquired HCV infections in HIV positive MSM to be 9 per 1000 patient years, and the average annual rise in incidence was 20 per cent. This supports the importance of adherence to BHIVA guidelines for repeat HCV screening in people with HIV.
- Sentinel surveillance suggests that almost 90 per cent of individuals in England have genotype 1 or 3 infections, with genotype 3a being the single most common genotype.
- Preliminary results from a study investigating the prevalence of hepatitis in people originating from the Indian sub-continent, suggests that people who originate from Pakistan are at increased risk of HCV infection.
- Reports of direct sharing of needles and syringes amongst IDUs who participated in the UAPMP survey have remained high, with direct sharing reported by around one in four IDUs in 2006.

### Action 1

as set out in the *Hepatitis C Action Plan*<sup>1</sup>, aims to:

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

## 2.1 Routine surveillance

### Laboratory Reports

Under a voluntary surveillance scheme, public health and NHS laboratories in England and Wales have been reporting laboratory confirmed hepatitis C infections to the HPA Centre for Infections since 1990. The definition of a laboratory confirmed case is an individual with a positive test for antibodies to the hepatitis C virus (anti-HCV) or for detection of hepatitis C viral RNA in the serum. For infants aged less than one year, who may test anti-HCV positive because of maternally acquired antibodies, only those confirmed by hepatitis C RNA testing or by a subsequent positive anti-HCV test are included.

Usually acute hepatitis C is asymptomatic and there are no laboratory methods to distinguish between acute (recent) and chronic (long-standing) hepatitis C virus infections. In recent years most tests performed are undertaken as part of the investigation of liver disease, or as part of screening, particularly amongst known risk groups. Therefore, trends in the number of hepatitis C reports reflect the number of individuals being tested rather than the incidence of infection.

A cumulative total of 62,726 laboratory-confirmed diagnoses of hepatitis C infection from England were reported to CfI between 1992 and 2006 (Figure 1). Males accounted for 69 per cent, and half (52 per cent) of all reports were in people aged 25-39 (Figure 2).



Figure 1: Cumulative laboratory reports of hepatitis C infection from England: 1992 to 2006

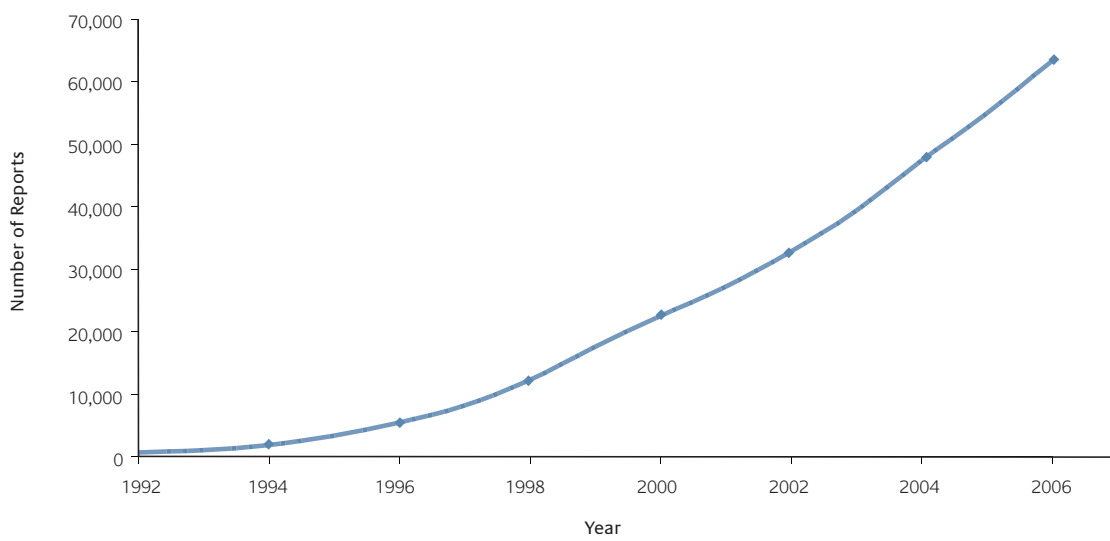
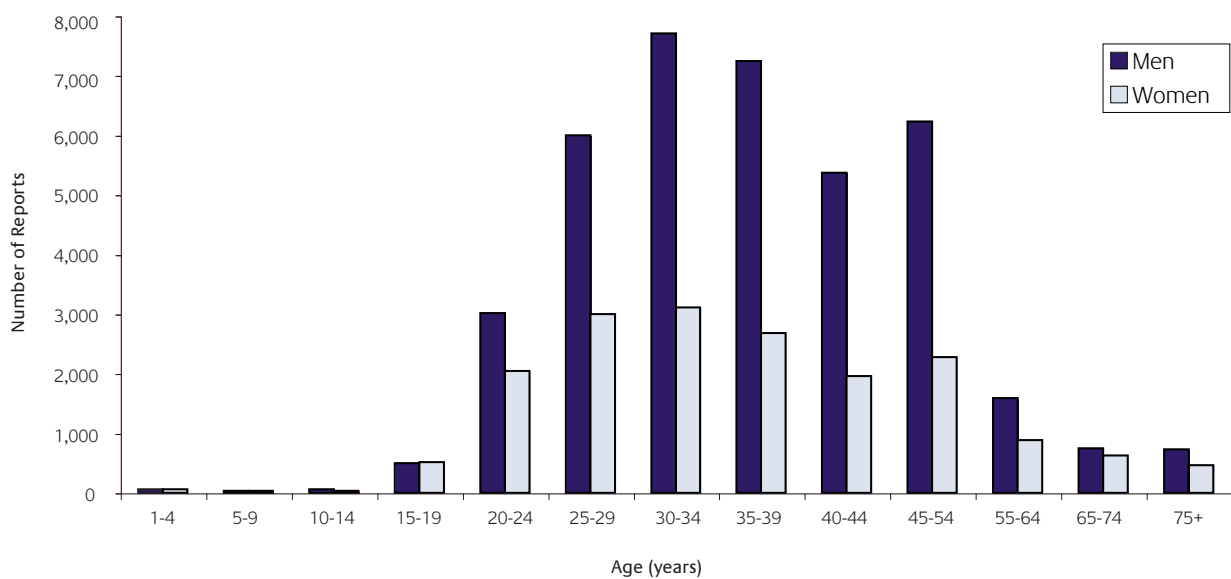


Figure 2: Age and sex distribution of laboratory reports of hepatitis C infection from England: 1996 to 2006



**Table 1: Laboratory reports of hepatitis C infection by English region: 1992 to 2006**

Region	1992	1993	1994	1995	1996	1997	1998	1999	2000	2001	2002	2003	2004	2005	2006	Total
Eastern	12	38	60	129	229	398	590	673	637	488	419	481	649	726	743	6,272
London	75	100	153	215	276	271	354	338	283	399	366	460	895	898	1,367	6,450
South East	76	136	226	325	621	711	1003	937	673	642	630	592	465	294	459	7,790
South West	23	55	138	334	448	521	476	815	929	811	1,023	887	1,302	882	1,149	9,793
West Midlands	7	17	36	37	151	240	595	743	667	640	786	597	704	734	651	6,605
North West	27	46	87	221	137	116	684	1,173	972	1,158	1,611	2,387	2,516	2,019	1,629	14,783
Yorkshire and Humberside	4	11	20	67	80	162	148	258	416	246	334	529	695	1,161	1,741	5,872
East Midlands	3	6	74	135	161	192	186	224	205	160	264	370	472	524	320	3,296
North East	1	1	2	2	13	41	62	133	135	131	157	263	295	342	287	1,865
<b>Total</b>	<b>228</b>	<b>410</b>	<b>796</b>	<b>1,465</b>	<b>2,116</b>	<b>2,652</b>	<b>4,098</b>	<b>5,294</b>	<b>4,917</b>	<b>4,675</b>	<b>5,590</b>	<b>6,566</b>	<b>7,993</b>	<b>7,580</b>	<b>8,346</b>	<b>62,726</b>

There has been a steady increase in the number of reports from 1992 to 2006, with a 10 per cent rise in the number of laboratory-confirmed diagnoses of HCV infection from 2005 to 2006. Reports were received from all regions in England. Overall, the highest figures were reported by laboratories in the North West and the lowest figures were reported by laboratories in the North East (Table 1).

It is recognised that laboratory reporting is incomplete<sup>6</sup>. Data from the Sentinel Surveillance of Hepatitis C testing can be used to investigate the extent of under-reporting in national surveillance, since test results on all individuals tested for hepatitis in participating sentinel centres are extracted electronically from laboratory records, providing a complete data set for comparison. To calculate the proportion of confirmed positive hepatitis C tests from laboratories participating in the sentinel surveillance study that were also reported to the national surveillance scheme, a process of matching between the two data sets was undertaken. Individuals were matched on laboratory number, hospital number, date of birth, soundex, sex, region, date of test, and a combination of these variables.

When interpreting this data, it should be remembered that laboratories are only responsible for reporting cases identified as part of primary screening within their laboratory to the national surveillance scheme. Laboratories testing samples for reference/confirmatory purposes are not responsible for reporting these cases to national surveillance; this is the responsibility of the original testing laboratory.

In total, 5,989 (42.8 per cent) of 13,999 anti-HCV and/or HCV PCR positive individuals identified through the sentinel surveillance during 2006 could be matched to reports from routine surveillance of hepatitis C, suggesting that these individuals had been reported to this scheme. There is considerable variation in reporting by region (Table 2).

Overall, these data suggest that routine laboratory reporting of individuals testing positive in these centres underestimates the numbers of diagnosed HCV infections by around 60 per cent. This figure appears to vary dramatically and therefore the extent to which this is generalisable to the whole of England will depend upon the coverage of primary testing and the volume of reference work undertaken and performed in these sentinel laboratories. As the participating laboratories include several large centres providing confirmatory virological testing, this estimate is likely to be a reasonable estimate of the overall completeness of routine surveillance.

**Table 2: Number of individuals reported as hepatitis C positive in the Sentinel Surveillance of Hepatitis C Testing study during 2006 that could be matched to a report from the routine national surveillance, by region**

Region (number of participating centres)	Number of positive individuals matched	Total number of positive individuals	% matched
East Midlands (1)	83	667	12.4
Eastern (1)	351	830	42.3
London (6)	1388	4972	27.9
North East (1)	101	235	43.0
North West (5)	1781	3336	53.4
South East (2)	170	350	48.6
West Midlands (1)	719	1540	46.7
Yorkshire & Humberside (2)	1396	2069	67.5
<b>Total (19)*</b>	<b>5989</b>	<b>13999</b>	<b>42.8</b>

\* Data was not available for the full 2006 period from 4 of the 23 sentinel centres hence results from these centres are not shown here



A total of 20 per cent of laboratory confirmed hepatitis C infections that were reported included risk factor information. Of these, approximately 93 per cent reported injecting drug use as a risk factor (Table 3). Fifty three per cent of IDUs were males aged between 25 to 44 years. Other risk factors were less common.

A similar age distribution was seen in laboratory confirmed hepatitis C cases between cases where there was no risk identified (NRI) and where injecting drug use was identified as a risk factor. However, slightly more cases of NRI were seen in older individuals compared to individuals who reported IDU as a risk factor (Figure 3) and 68 per cent of those with NRI were male compared to 74 per cent in IDU reports. This suggests that a large proportion of the NRI infections are likely to be caused by injecting drug use that is not reported or disclosed.

One potential indicator of more recent infection, and therefore of incidence, is the number of infections in young adults (aged between 15 and 24 years)<sup>6</sup>. As most new infections are acquired by injecting drug use, and because this behaviour usually begins in late adolescence and early adulthood, it is likely that infections in these age groups will have been acquired within the past few years. Since 2001, the number of infections in individuals aged 15-19 years has remained fairly constant, whereas the number of infections in those aged 20-24 years rose

sharply between 2001 and 2004 (Figure 4), after which date the numbers have been falling. The number of reports in young adults was lower in 2006 than in 2005 and forms a small proportion of the total reports received. This suggests that laboratory reports in adolescents and young adults do not provide evidence of an increase in incidence. In contrast, the pattern of reports is actually consistent with an increase in testing, particularly in older individuals.

**Table 3: Risk factor information in laboratory reports of hepatitis C infection from England: 1996 to 2006**

Risk factor (where reported)	Number of reports	Percentage
Injecting drug use	11,484	92.5
Transfusion	193	1.6
Blood product recipient	116	0.9
Sexual exposure	169	1.4
Renal failure	78	0.6
Vertical (mother to baby) or household	59	0.5
Occupational	15	0.1
Other known	299	2.4
<b>Total</b>	<b>12,413</b>	<b>100</b>

**Figure 3: Age distribution of laboratory reports of hepatitis C infection in England where injecting drug use (IDU) was reported and those with no risk identified (NRI): 1996 to 2006**

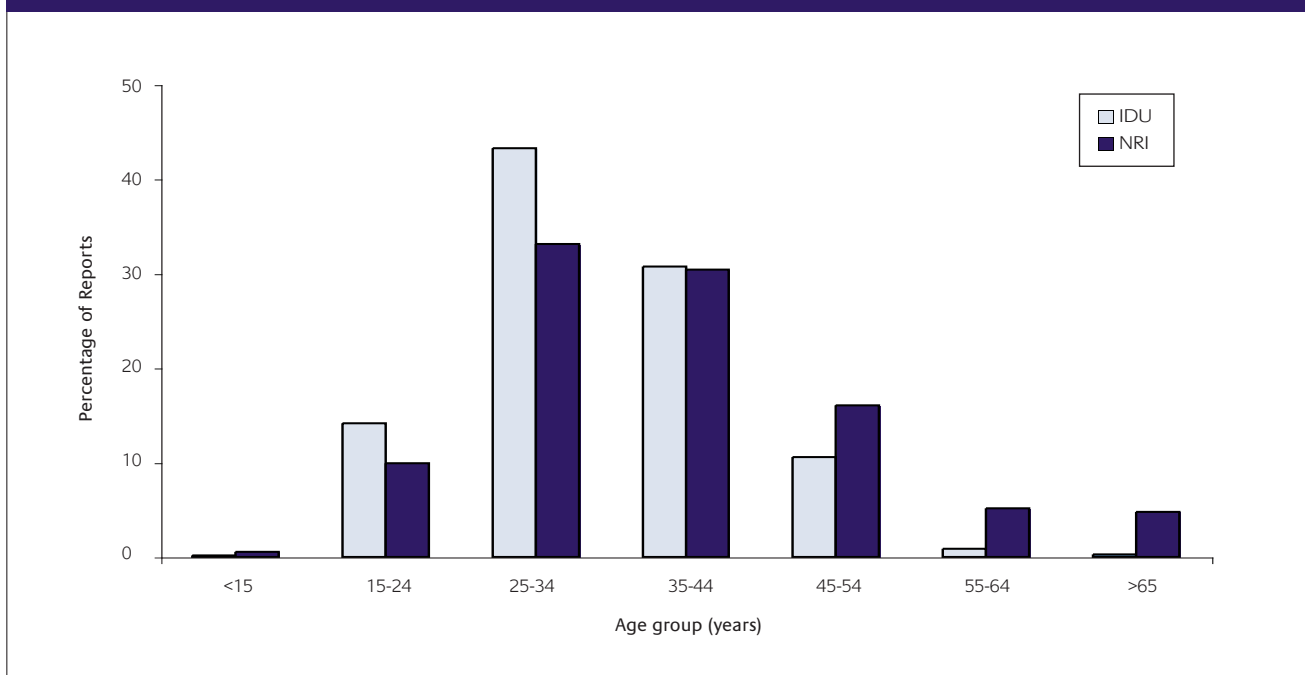
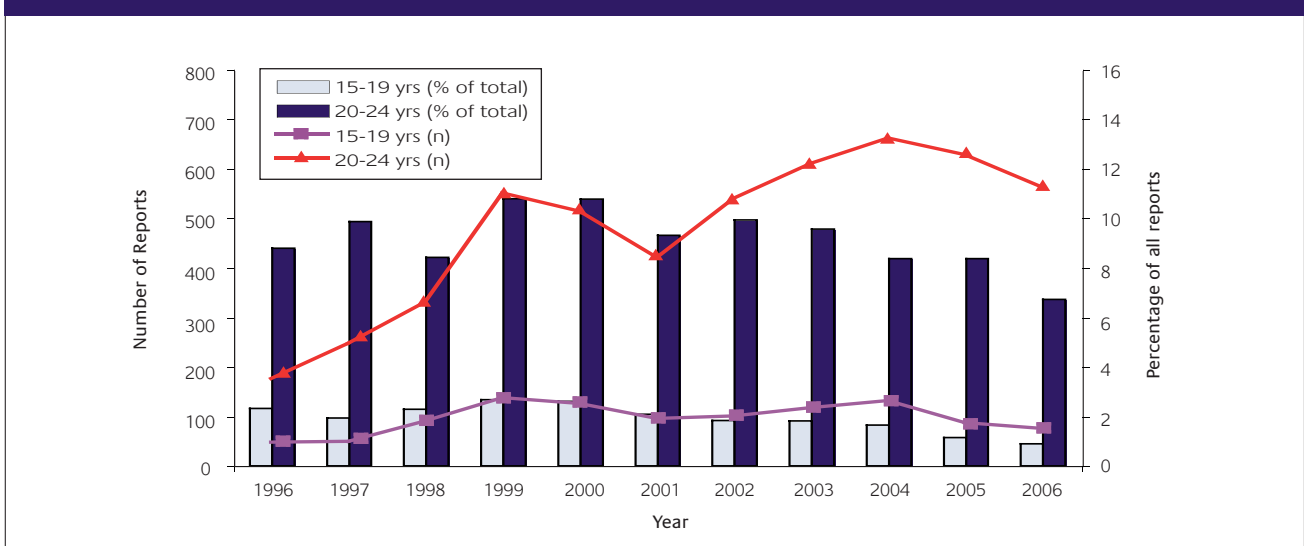


Figure 4: Number of laboratory reports of hepatitis C infection reported in young adults in England: 1996 to 2006



## Blood donor testing

The English National Blood Service (NBS) collects blood from voluntary donors who are selected to be at low risk of blood borne infections such as hepatitis C. Data about blood donations tested, and donors found positive for hepatitis C give an indication of prevalence and incidence in a population at very low risk of blood borne virus infection.

### *Hepatitis C in new donors*

The rate of positive donations detected amongst 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 2006, 64 new donors tested positive for hepatitis C - this approximates to around 30 per 100,000 donations tested (Figure 5). Of the 64 new donors who tested positive for hepatitis C in 2006, ethnic origin was known for 61/64 (95 per cent). Of these, 52 (85 per cent) were white and five (8 per cent) were of South Asian origin. This ethnic distribution does not mirror the ethnic make-up of the English National Blood Service donor population, 98 per cent of whom are of white ethnicity and approximately 1 per cent are of Asian ethnicity<sup>10</sup>. This suggests that blood donors of South Asian origin are at higher risk of hepatitis C infection than white donors.

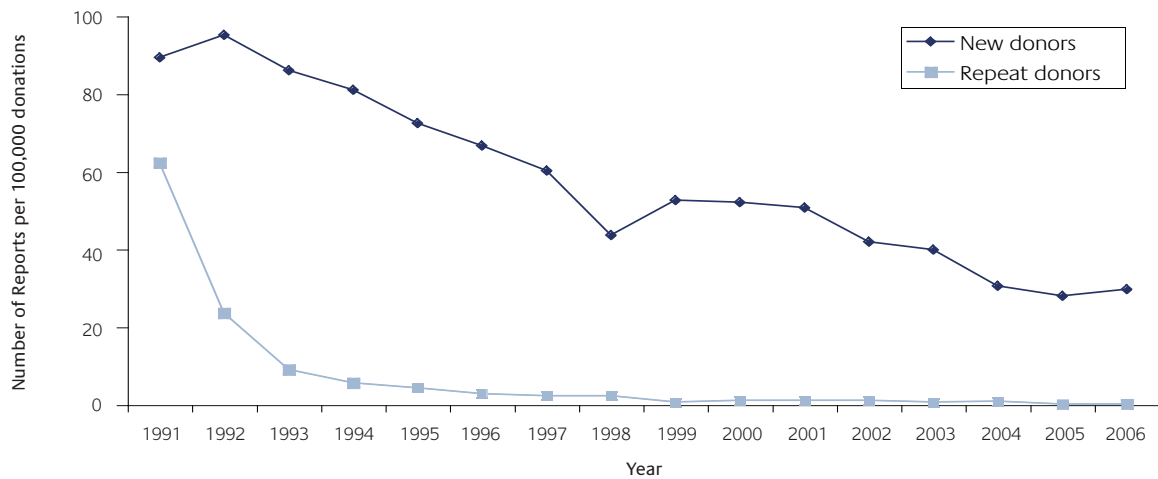
Risk factor information was not obtained for a third of new donors. Where risk information was identified, heterosexual sex was reported as the risk in nine cases (21 per cent), four of whom reported sex with an injecting drug user (IDU).

Despite those who have ever injected drugs being asked not to donate, IDU was reported in eight donors (19 per cent): one current user and seven ex-users reporting exposure between 1971 to 1999. Twelve (28 per cent) new donors identified a range of other blood contact e.g. tattoo, acupuncture or other piercing as possible sources of infection. Blood or tissue products were attributed as the source for only six (14 per cent) donors. Four of the six had received blood in the UK between 1972 and 1986 before screening for hepatitis C antibodies was introduced in 1991<sup>11</sup>; the remaining two had received blood products abroad.

### *Hepatitis C in repeat donors*

Since blood donation testing began, fewer hepatitis C infections have been detected in donations from repeat donors than first time donors and rates of infection have been consistently lower each year (Figure 5). In 2006, only four donors (three male and one female) who had made previous donations, tested positive and were confirmed to have seroconverted since the previous donation. This gives an estimated incidence in blood donors of 2.4 per 100,000 person years, and confirms the low risk of hepatitis C transmission outside of the known risk groups. Sex was reported to be the principal risk factor - two identified heterosexual sex as their only risk factor with one reporting that their partner was found to be an injecting drug user. Another male was thought to have had sex with men, whilst another male proposed blood contact from an injury as their risk.

Figure 5: Hepatitis C positive blood donations in England: 1991\* to 2006. New and repeat donors



Note: 1991-1994 includes Wales

\*1991 data from September to December 1991 only.

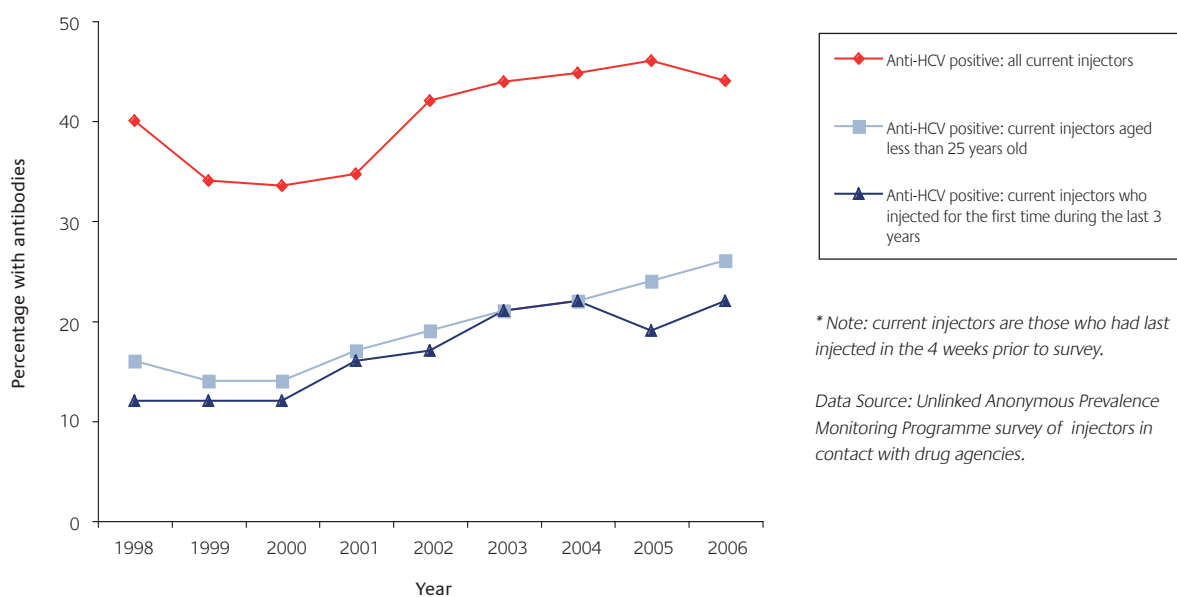
Data source: National Blood Service/HPA Infection Surveillance

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

In 2006, of the current and former IDUs from England who

participated in the Unlinked Anonymous Prevalence Monitoring Programme agency survey, 43 per cent (1,233 of 2,893) had antibodies to hepatitis C in oral fluid<sup>12</sup>. Overall, anti-HCV levels in current IDUs (those who had injected in the four weeks prior to taking part in the survey) in England have remained relatively stable in recent years (Figure 6).

Figure 6: Trends in HCV prevalence among current\* injecting drug users in England: 1998 to 2006.

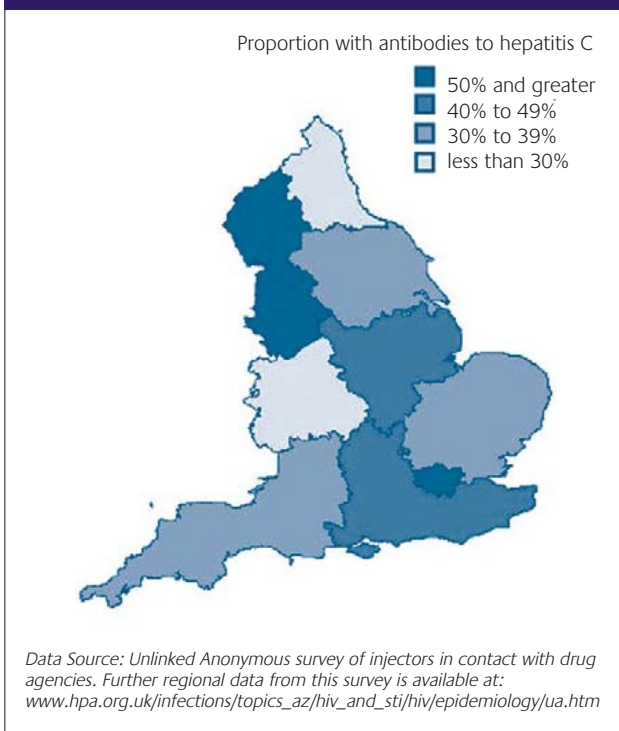


\* Note: current injectors are those who had last injected in the 4 weeks prior to survey.

Data Source: Unlinked Anonymous Prevalence Monitoring Programme survey of injectors in contact with drug agencies.

Regional variations were seen in the prevalence of hepatitis C in IDUs (data from 2005 and 2006 combined) with 22 per cent (122 of 566) in the North East to 57 per cent (690 of 1,221) in London and 60 per cent (628 of 1,042) in the North West (Figure 7)<sup>12</sup>. As study numbers are small in some regions, data are presented for the last two years.

**Figure 7: Geographic variations in the prevalence of antibodies to hepatitis C among current and former injecting drug users in England (2005 and 2006 data combined).**



## 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 Action Plan*<sup>1</sup>. In 2006, among those who recently began injecting, the prevalence of anti-HCV was 21.5 per cent (77/358). This is higher than last years figure of 17 per cent (60/351) and continues the increasing trend since 2000's figure of 12 per cent (89/767).

## 2.2 Enhanced surveillance

### HCV-HIV co-infection

In London and Brighton there have been clinic based reports of emerging HCV co-infection in HIV positive men who have sex with men (MSM)<sup>13 14</sup>. To investigate this further, the HPA carried out a collaborative survey in GUM and HIV clinics in London jointly with the British Association for Sexual Health and HIV (BASHH) and the British HIV Association (BHIVA), to ascertain the burden of newly acquired HCV in MSM across London and the South East region from January 2002 to June 2006<sup>15</sup>.

This survey identified 389 newly diagnosed, recently acquired, HCV infections in HIV positive MSM over the preceding four and a half years. Only six cases of recently acquired HCV infection were reported in MSM with negative or unknown HIV status. However, this may reflect ascertainment bias in this group due to the specificity of the case definition<sup>15</sup>. The study estimated the overall incidence of diagnosed, newly acquired, HCV infections in HIV positive MSM to be 9 per 1000 patient years, and the average annual rise in incidence was 20 per cent.

This HPA collaborative study<sup>15</sup> provides additional evidence to suggest that HIV-HCV co-infection is a growing problem and that it extends beyond local clinic settings. This underlines the importance of the 2004 BHIVA HCV/HIV co-infection guidelines for routine and repeat HCV screening in HIV positive patients (<http://www.bhiva.org/files/file1001579.pdf>), and highlights the need for consistent harm minimisation messages for MSM.

There are limitations in our understanding of the burden of disease and incidence in MSM with negative or unknown HIV status. Whilst the survey<sup>15</sup> did not gather information on risk factors for acquisition of infection, it confirmed the need for better information about newly acquired HCV infection among MSM to refine public health responses. The HPA London Regional Epidemiology Unit and the CfI, in close collaboration with clinical and public health stakeholders, is currently developing a proposal for a pilot of enhanced surveillance of newly acquired and acute HCV infection in MSM to provide timely information on the burden of disease and spatial and temporal trends across London and Brighton.

## Molecular Epidemiology

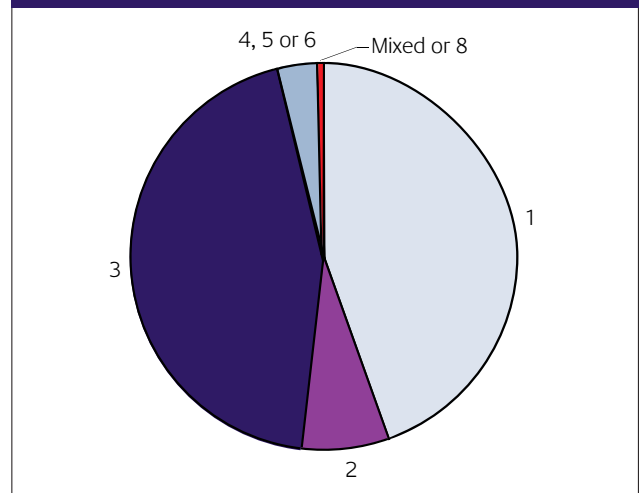
The Sentinel Surveillance of Hepatitis C testing collects data on routine HCV genotyping being performed in the participating sentinel centres. Additionally, samples from HCV RNA positive individuals identified through the study were requested for genotyping during the pilot phase (2002/03) to monitor the genetic diversity of hepatitis C infections in a representative sample of individuals.

Genotypes were reported for a total of 13,703 individuals between 2002 and 2006. The majority of these genotypes were reported through routine testing (474 were requested for genotyping during the pilot phase).

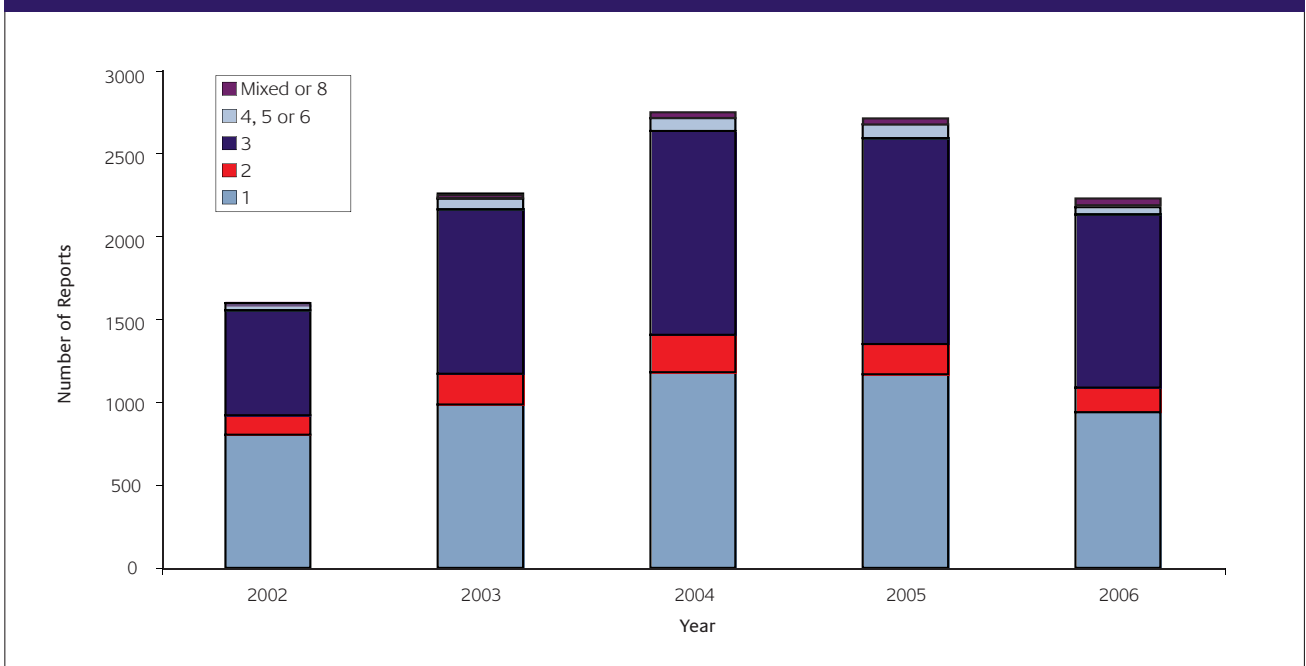
Overall, almost 90 per cent of people had genotype 1 or 3 infections (Figure 8). Genotype 3a was the single most commonly identified genotype, found in 40 per cent of people tested, then 1a (21 per cent). To examine whether the genotypes being detected had changed over time, data from centres reporting in each year between 2002 and 2006 were examined. A total of 11,462 individuals from 11 centres were included. These data suggested that the number of people being genotyped increased between 2002 and 2004, levelled out in 2005 and declined in 2006 (Figure 9). This pattern may be due to changes in laboratory referral amongst the sentinel laboratories or may reflect a real change in amount of

genotyping being done. Preliminary analyses suggest the proportion of genotype 3 infections has increased from 40 per cent of all genotypes reported in 2002 to 47 per cent of all genotypes in 2006. Further analyses are currently underway to see if this effect is due to changes in the prevalence of various types or due to changes in the demographics of those individuals having genotyping performed.

**Figure 8: Genotype distribution among hepatitis C positive individuals reported to the Sentinel Surveillance of Hepatitis C testing between 2002 and 2006 (n=13,703)**



**Figure 9: HCV genotypes reported in individuals identified through the Sentinel Surveillance of Hepatitis C testing, by year and grouped by genotype**





### Minority ethnic populations

The Department of Health is currently supporting a study in conjunction with the Hepatitis C Trust supported by The National Lottery, to examine the prevalence of viral hepatitis in minority ethnic populations. The study, led by Professor Foster at the Royal London Hospital, involves testing people born in the Indian sub-continent and living in the UK for the presence of hepatitis B and C antibodies.

To-date over 2,000 volunteers have been screened and it is becoming clear that different regions of the Indian sub-continent have markedly different rates of infection. People originating from Pakistan appear to be at increased risk, whilst those born in Bangladesh have lower rates of infection. The study will determine risk factors for infection and allow evidence based, targeted awareness campaigns to inform those who are at risk of disease.

Currently a working group of the Advisory Group on Hepatitis (AGH) is looking at the issue of hepatitis B and C case-finding in minority ethnic populations. The working group will make recommendations to the AGH in 2008.

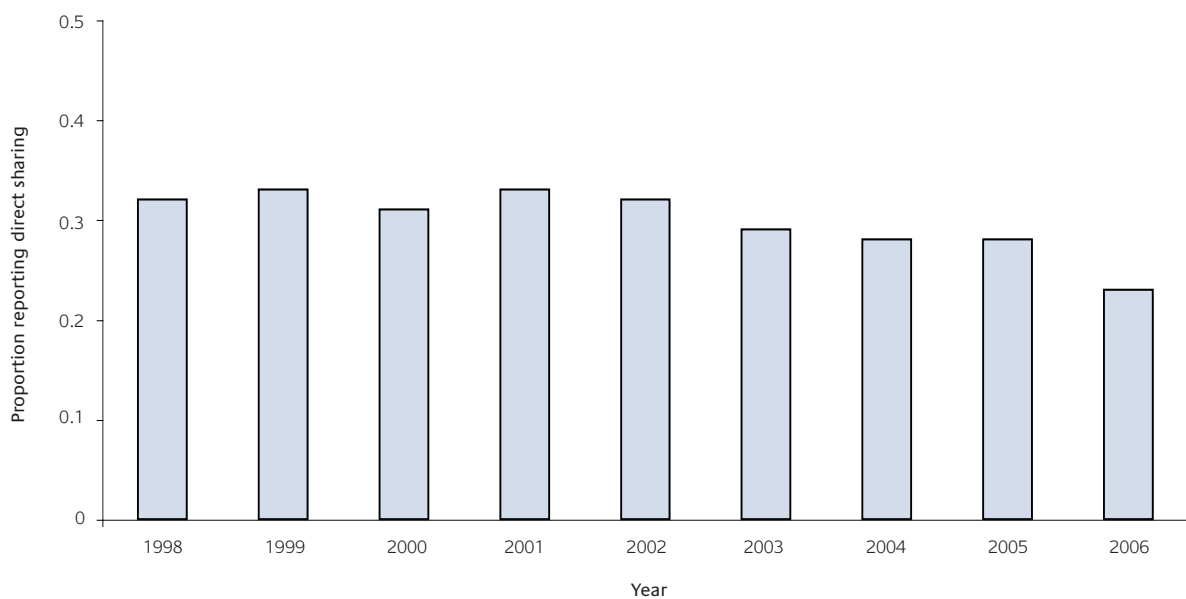
### 2.3 Behavioural surveillance and research

#### UAPMP data on behaviours and environmental factors affecting IDUs

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 2006, 23 per cent of current injectors (those who reported injecting within four weeks before participating in the survey) reported direct sharing in England. Although lower than in the previous year, when 28 per cent of current IDUs reported direct sharing (Figure 10), this remains higher than the level seen in the mid 1990's. In addition, 45 per cent of current injectors in England also reported sharing of filters, mixing containers and flushing water<sup>12</sup>.

As for hepatitis C antibody prevalence, variation in the proportion of those injecting drug users who share needles and syringes is observed between regions.

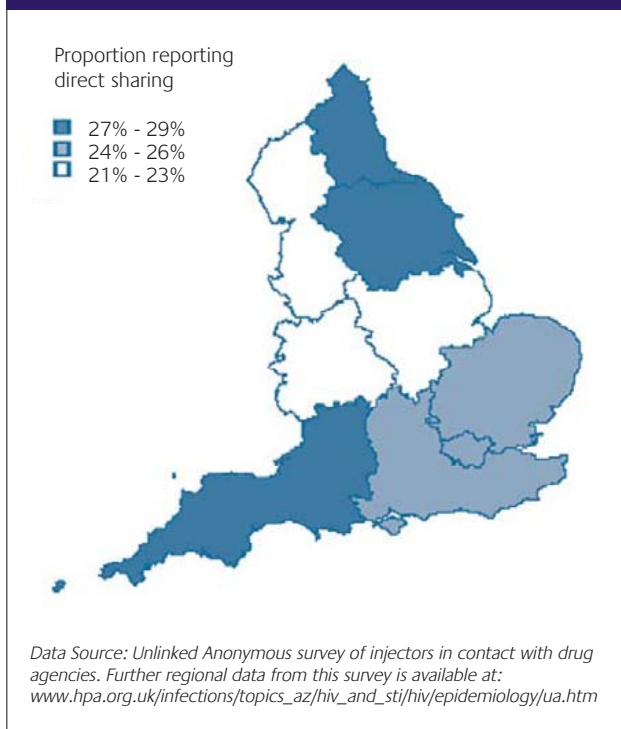
Figure 10: Trends in sharing of needles and syringes in the past four weeks among injecting drug users in England: 1998 to 2006.



Data Source: Unlinked Anonymous Prevalence Monitoring Programme survey of injectors in contact with drug agencies.

Paradoxically, the highest levels of direct sharing are observed in those regions with relatively lower anti-HCV prevalence (South West, Yorkshire and Humberside and North East regions; see Figure 11). The lowest level of direct sharing was seen in the West Midlands. This is likely to reflect different historical patterns of drug use and service provision in different regions.

**Figure 11: Geographic variation in the prevalence of needle and syringe sharing in the previous four weeks among current and former injecting drug users by English Region: 2005/06 combined.**



## Summary

Recent efforts to improve surveillance and research are beginning to allow trends in hepatitis C infection and the effectiveness of prevention and control measures to be better monitored. The continued rise in laboratory confirmed diagnoses of HCV - 10 per cent over the last year, support the view that more HCV diagnosis is taking place in England. Given the likely degree of under-reporting, it seems plausible that around half of the estimated prevalent HCV infections may have been diagnosed, which represents an improvement on the high proportion of undiagnosed infections suggested in 2004<sup>1</sup>. How many of these individuals who have tested positive for anti-HCV are aware

of their diagnosis and have been appropriately referred and managed is less clear.

Laboratory reports of diagnosed HCV infections continue to show that a history of injecting drug use was the major route of transmission for individuals with diagnosed HCV infection in England. Another increasingly recognised risk group for infection are individuals who originate from the Indian sub-continent. Preliminary results from a study investigating the prevalence of hepatitis in people originating from these areas, suggest that people coming from Pakistan are at increased risk of HCV infection. The disproportionate number of HCV infections seen amongst individuals originating from the Indian sub-continent, detected during routine testing of blood donors, also provides evidence to support a higher HCV risk in these groups.

Data from the UAPMP shows that anti-HCV prevalence in current injectors remains high at 43 per cent. In addition, the prevalence of anti-HCV amongst IDUs who have recently begun injecting within the last three years also remains high.

Transmission of hepatitis C in HIV positive men who have sex with men continues to be a cause for concern and a recent survey identified almost 400 cases of newly acquired infection in the South East of England. This survey emphasises the importance of adherence to BHIVA guidelines for routine and repeat HCV screening in HIV positive individuals.

Sentinel surveillance suggests that genotype 3a is the most common genotype in England. From a treatment perspective this is probably good news for patients, as this genotype is known to be more sensitive to current treatment than other genotypes<sup>2</sup>. However, data show that genotype 1 infections still make up more than 40 per cent of all prevalent infections in England, and these are known to be the hardest to treat<sup>2</sup>.



### 3.0 Increasing awareness and reducing undiagnosed infections

# 3.0

Increasing awareness and reducing undiagnosed infections



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## KEY POINTS

- In 2006/07 there has been over a 60 per cent increase in media coverage about hepatitis C, with a potential audience of more than 40 million people reached via the NHS awareness campaign. Visits to the NHS website (<http://www.hepc.nhs.uk>) and Hepatitis C Information Line more than doubled compared to the previous year.
- A national advertising campaign was rolled out across regional and local radio stations and in national newspapers and consumer magazines.
- A campaign to raise awareness among the South Asian community was launched, accompanied by a new audio CD resource tailored to this community.
- Awareness raising in the voluntary sector remains high; the late Dame Anita Roddick's contribution in this area has been considerable.
- The proportion of injecting drug users who have been tested for hepatitis C continued to increase, with 75 per cent of the individuals in the 2006 UAPMP agency survey reporting ever having a voluntary confidential hepatitis C test.
- Of the IDUs who took part in the UAPMP agency survey who were infected with hepatitis C, the proportion who were aware of their status in the 2006 survey was 54 per cent compared with 52 per cent in 2005 and 51 per cent in 2004.
- Sentinel surveillance shows that there has been an increase in the number of people being diagnosed with hepatitis C. The number tested in 2006 was 6.4 per cent lower than in 2005, but the percentage testing positive has risen.
- HCV testing in specialist drug services has increased nearly ten-fold between 2002 and 2006, largely as a result of the availability of oral fluid testing; testing via GP surgeries also remains high.
- A total of 8,346 laboratory confirmed diagnoses of hepatitis C infection were reported to the HPA in 2006 suggesting that more diagnosis is taking place and more infected individuals are being identified.
- HCV antibody testing from dried blood spots is highly sensitive and specific and has great potential to be used diagnostically, particularly in low threshold settings where it is difficult to take blood.

Action 2 in the *Hepatitis C Action Plan*<sup>1</sup> states:

*An estimated five out of every six people with chronic hepatitis C are unaware of their infection. This requires action to increase awareness of hepatitis C amongst health professionals, the public and high-risk groups and the promotion of testing in a range of accessible clinical and community settings.*

### 3.1 Public awareness

#### Advertising

In February and March 2007, a national advertising campaign was rolled out across radio networks, national newspapers and consumer magazines.

Adverts in newspapers and magazines (e.g. *Daily Express*, *Daily Mail*, *the Sunday Telegraph*, *the Radio Times*, *Readers Digest*, *Today's Golfer*, *Classic Cars*, *Motorcycle News*, *Eastern Eye*, *Asian Leader*, *The Nation*, *The Voice* and *African Voice*) used a simple flow chart as a way for members of the public to self-assess whether they may have been at risk of contracting hepatitis C in the past. Radio adverts on stations from all regions in England and Wales (e.g. *Heart 106.2 FM*, *Capital Gold Manchester*, *GWR FM*, *Kestrel FM*, *96 Trent FM*, *Sun FM*, *96.9 Chiltern FM*) describing hepatitis C as 'a devious little virus', referred listeners to the NHS hepatitis C website.

The advertising campaign resulted in more than 8,000 calls to the Hepatitis C Information Line and a surge in visits to the NHS hepatitis C website - there were around





195,000 visits to the website in 2006/07, compared to the 68,000 visits that were recorded in 2005/06. Numbers of visits to the NHS hepatitis C website in January, February and March 2007 were 9588, 30,356 and 96,904 respectively.

## Events

The *FaCe It* exhibition continued touring throughout 2006/07 (see <http://www.hepc.nhs.uk>). The photography exhibition of giant portraits of people living with hepatitis C was staged in 15 town and city centres across the country (bringing the total to 30 events since 2004), resulting in media coverage on six regional TV stations, 45 radio stations and in 40 regional newspapers, with a total audience reach of more than 11 million people.

New elements were added to the regional tour in order to heighten and sustain the impact of each event. *FaCe It* patient leaflets were distributed to members of the public via shops, restaurants, leisure centres and public buildings, as well as inserted in local newspapers, and at each event representatives from the local NHS and related agencies met to discuss raising awareness of hepatitis C and local service provision.

In addition, a number of pilot events were undertaken at cultural festivals and exhibitions across the country as a means of targeting niche audience groups.



Photo Tour  
Oxford



Pilot Tour  
Bromley



Pilot Tour  
Guildford



Pilot Tour  
Southampton



Photo Tour  
Middlesbrough

## Editorial features

There was a noticeable increase in editorial features about the virus, including consumer magazines such as *Take a Break* and *Pick Me Up*, as well as niche media such as the travel and expatriate press. The *FaCe It* campaign generated editorial media coverage with a combined potential audience reach of 40.5 million (an increase of 63 per cent on 2005/06). In addition, paid-for advertorials about hepatitis C ran in 15 consumer magazines including *Mojo*, *TV Choice*, *FHM* and *Nuts*, with a combined readership of 4.5 million people.



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## Engaging South Asian communities

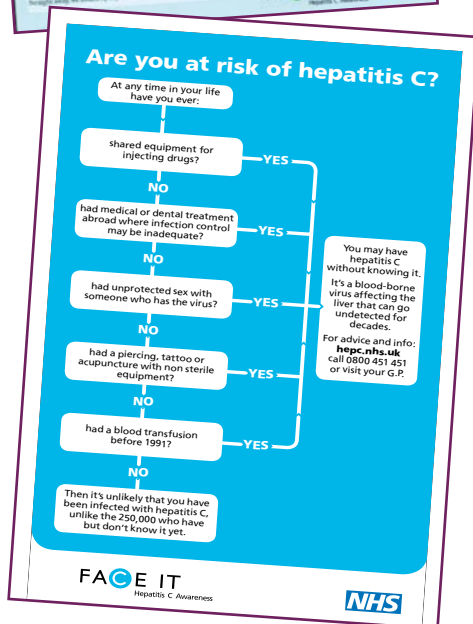
*FaCe It* ambassadors of Pakistani origin have been raising awareness of hepatitis C among the South Asian community. The ambassadors, all of whom have been personally affected by hepatitis C, have been equipped with a new audio CD resource developed specifically for a South Asian audience.

The CD is in the format of a radio show and recorded in both English and Urdu. Popular Asian music is interwoven with an interview with one of the ambassadors who talks openly about her own experiences of hepatitis C, as well as a health professional. The CD was distributed through community organisations, retailers and at Asian mela festivals throughout the summer of 2007 and was supported by a public relations campaign.



## DVD Educational Resource for Prisons

A short, high-impact film about hepatitis C has been produced by Offender Health in collaboration with Munro & Forster Media Company (who have also worked on the national Hepatitis C awareness campaign - *FaCe It*), as a new resource to support health workers raise awareness in prisons. Real-life testimonials from former prisoners are interwoven with dramatised sequences using actors. The 18 minute DVD is structured modularly so that it can be viewed either start to finish, or in short sections as a visual aid for health promotion classes. The film is currently being tested among prison audiences. This DVD for Prisoners *Hepatitis C: Inside and Out*, is intended for adult prisoners and is in addition to the *Music4Messages* urban music CD for young offenders' institutes that was launched in 2005/06.



## Website and Hepatitis C Information Line

Visits to the website in 2006/07 rose by 187 per cent over the previous year as interest in hepatitis C increased. In response to this interest, the website was revamped to simplify the information available on hepatitis C. An email enquiry service was also launched. New features were added to engage with healthcare professionals, such as the inclusion of a monthly online report, written by a hepatitis C specialist nurse, outlining the challenges faced in hepatitis C management and treatment. There was a significant rise in calls to the Hepatitis C Information Line of more than 270 per cent, compared to the previous year.

## 3.2 Healthcare professional awareness

### NHS Quick Reference Guide for Primary Care

In addition to existing leaflets, posters and briefing notes, in January 2007 a new NHS Quick Reference Guide was produced and distributed to GP practices in England (see Appendix). Designed to be retained by GPs and practice nurses and used as a day-to-day source of information, the Quick Reference Guide conveyed in concise terms how patients with hepatitis C should be managed through testing, diagnosis and referral to a specialist.

### Professional Media

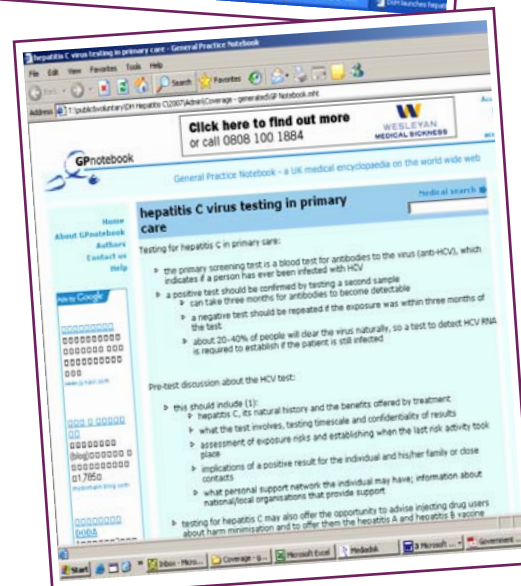
The *FaCe It* campaign targeted health professionals' journals and other titles, resulting in news items and clinical feature articles on hepatitis C diagnosis and treatment. The Quick Reference Guide in particular was well profiled in titles such as *Independent Nurse*, *GP Notebook*, and *Healthcarerepublic.com*.



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Originally published 5 March 2007 on www.healthcarerepublic.com. Copyright: Haymarket Medical Media.



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## Professional Events

Over the period 2006/07, the campaign exhibited at a series of professional events including conferences organised by the Royal College of Nursing, Royal College of General Practitioners, Nursing in Practice, and the Community Practitioners and Health Visitors Association. More than 7,000 hepatitis C information resources were handed out to professionals at these events.

## 3.3 Future awareness raising

As well as targeting the general public through mainstream media with prevention and diagnosis messages, the campaign will continue to focus on individual audience groups at an increased risk of being or becoming infected with hepatitis C virus, such as prisoners and people of South Asian origin.

The healthcare professional awareness campaign will be focused on getting existing information resources into

the hands of primary care professionals, as well as developing new resources. In addition, a further national advertising campaign is planned to take place in 2007/08.

## 3.4 Awareness raising by the voluntary sector

### Grants from the Department of Health to the voluntary sector

In line with Section 64 of the Health Services and Public Health Act 1968, the Secretary of State is able to make grants to voluntary organisations whose activities support the Department of Health's policy priorities. In line with this, funding has been awarded by the Department of Health to support hepatitis C work in the voluntary sector in 2006/07, and these grants are summarised in Table 4. The total grants supporting this work in 2006/07 total just over £270,000.

**Table 4: An update to Department of Health funding for hepatitis C work in the voluntary sector: the financial year 2006/07**

Name of organisation	Type of grant	Purpose of grant	Amount awarded in the financial year 2006/07
British Liver Trust	Core	To support the core running costs of the organisation.	£40,000
British Liver Trust	Project	To fund a hepatitis C and liver disease telephone helpline.	£50,000
Hepatitis C Trust	Core	To support the core running costs of the organisation.	£35,000
Hepatitis C Trust	Project	To fund a website manager.	£32,500
Hepatitis C Trust	Project	To fund the hepatitis C wellness day programme for people with hepatitis C.	£14,000
Hepatitis C Trust	Project	To raise awareness of hepatitis C in the South Asian community.	£16,500
Hepatitis C Trust	Project	To help prevent HIV and hepatitis C co-infection in HIV positive men who have sex with men.	£1,000
Mainliners	Project	To support the UK Hepatitis C Resource Centre, which provides information and advice about hepatitis C.	£40,000
Mainliners	Project	To fund a programme of activities connected with raising hepatitis C awareness.	£42,500
		<b>Total</b>	<b>£271,500</b>

## Dame Anita Roddick and her work with The Hepatitis C Trust



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Dame Anita Roddick's decision in February 2007 to make public that she was living with the hepatitis C virus became the focal point for awareness-raising by The Hepatitis C Trust, of which she became a patron.

Her story - being infected from a blood transfusion in 1971 following the birth of her daughter and then remaining undiagnosed until 2004 by

which time she had developed cirrhosis - highlighted the need for increased proactive testing as well as significantly helping to change the perception of hepatitis C as just a drug users' disease. Her story generated extensive coverage in the UK and globally. She was totally committed to this cause, continuing to raise the subject in a steady stream of media articles and interviews. Her foundation funded a conference in April for The Hepatitis C Trust to provide PCTs with practical tools, including the HPA's local prevalence model, to help them implement the *Hepatitis C Action Plan for England*<sup>1</sup>.

In March 2007, Anita Roddick wrote to all 785 Members of the European Parliament (MEPs) urging them to sign up to an EU Parliament Written Declaration calling for EU-wide action on hepatitis C. This was followed by intense lobbying in Strasbourg by The Hepatitis C Trust and other members of the European Liver Patients Association. Four hundred and seventy MEPs signed the Declaration as a result, the strongest level of support for a Declaration since 1999, and it was formally adopted by the Parliament on March 29.

Extensive plans for future awareness-raising by The Hepatitis C Trust were brought to a sudden halt by her unexpected death in September. It is a tribute to how much she achieved in just 6 months that the global coverage of her death always mentioned hepatitis C even though the cause of death was a brain haemorrhage.

## What not to share

The Hepatitis C Trust has been running a prevention/awareness campaign aimed at 15-30 year olds called: *What not to share*. It has involved celebrities from the music industry and has used a website (<http://www.whatnottoshare.com>), club nights in the UK and Ibiza, concerts, stalls at festivals, T-shirts and badges, a photographic exhibition and the distribution of more than a million cards to universities, clubs and cinemas to engage its target audience.

## Blood borne virus information in prisons

The British Liver Trust is undertaking preliminary research and consultation to develop a range of educational resources for use in UK prisons. Funding for this project comes from a successful Section 64 application.

The materials are aimed at explaining transmission risks of HCV, along with other blood-borne virus's (BBVs), and promoting appropriate harm minimisation practices. The theme of the campaign is to highlight the presence of BBVs in the prison setting.

Materials that are developed will be for use by both prisoners and prison staff (both custodial and medical) to promote wide-ranging understanding of BBVs, and facilitate better dissemination of them in the absence of any formal distribution arrangements. Materials aimed at inmates will be attuned to the literacy needs of this population and will also encompass specific resources to meet the needs of women prisoners and young offenders. The materials will comprise graphic-led information leaflets in both conventional and card-sized formats. Posters dealing with BBVs individually and collectively are also in development.

## Information on hepatitis C for young people

Using a Section 64 grant from the Department of Health, the Children's Liver Disease Foundation (CLDF) has delivered a project entitled: *Empowering young people with Hepatitis C*. This project delivers information in a range of formats for young people with hepatitis C infection, in an age appropriate way, to allow young people and their families to take control of their lives and take responsibility for the management of their disease.

Young people reported that they wanted ‘short, snappy’ information. In response, the CLDF has developed a series of fact cards, which are a handy, small size and can be slipped easily into a pocket. Each card has the key facts about a particular topic. The topics covered are: *Why should I think about hepatitis C?; How can I find out if I have hepatitis C?; I’m hepatitis C positive – what is the next step?; Treatment for hepatitis C in young people; How can I find out if my baby has hepatitis C?*



Young people also reported that, whilst finding the information on the cards helpful, they wanted more information on a topic. Thus, each card has a leaflet which accompanies the topic. Three further leaflets are within the series; two address living with hepatitis C from the viewpoint of a parent/carer and the other from the viewpoint of a young person. The final leaflet addresses the testing of babies for hepatitis C.

Since launching the series, parents (biological, adoptive and prospective adoptive), and children, as well as adoption teams, have all reported finding the leaflet series very useful. Full details of the fact cards and the leaflet series are available on the web (<http://www.hepcfacts.org.uk/>) and on MySpace (<http://www.myspace.com/hepcfacts>). Copies can also be obtained directly from the Children’s Liver Disease Foundation (36 Great Charles Street, Birmingham. B3 3JY; Tel: 0121 212 3839; Email: [info@childliverdisease.org](mailto:info@childliverdisease.org); <http://www.childliverdisease.org>).

Further work over the coming year will continue to promote the leaflets. The CLDF is also partnering with other voluntary sector bodies to make the information more widely available.

## 3.5 Testing

### UAPMP data on self-reported testing in IDUs

Increasing the proportion of IDUs who are aware of their hepatitis C infection through increased uptake of voluntary confidential testing is one of the aims of the Hepatitis C Strategy for England<sup>4</sup>. As the national standard of good practice, the Hepatitis C Strategy<sup>4</sup> states that all those attending specialist drug treatment services should be offered hepatitis C testing routinely. In 2006, 75 per cent of those IDUs who took part in the UAPMP agency survey reported ever having a voluntary confidential test for HCV. This represents an increase of 26 per cent from 2000, and an increase of 4 per cent on the previous year (Figure 12). Figures for 2006 continue to follow the upward trend towards increased testing of IDUs who are in contact with specialist treatment services.

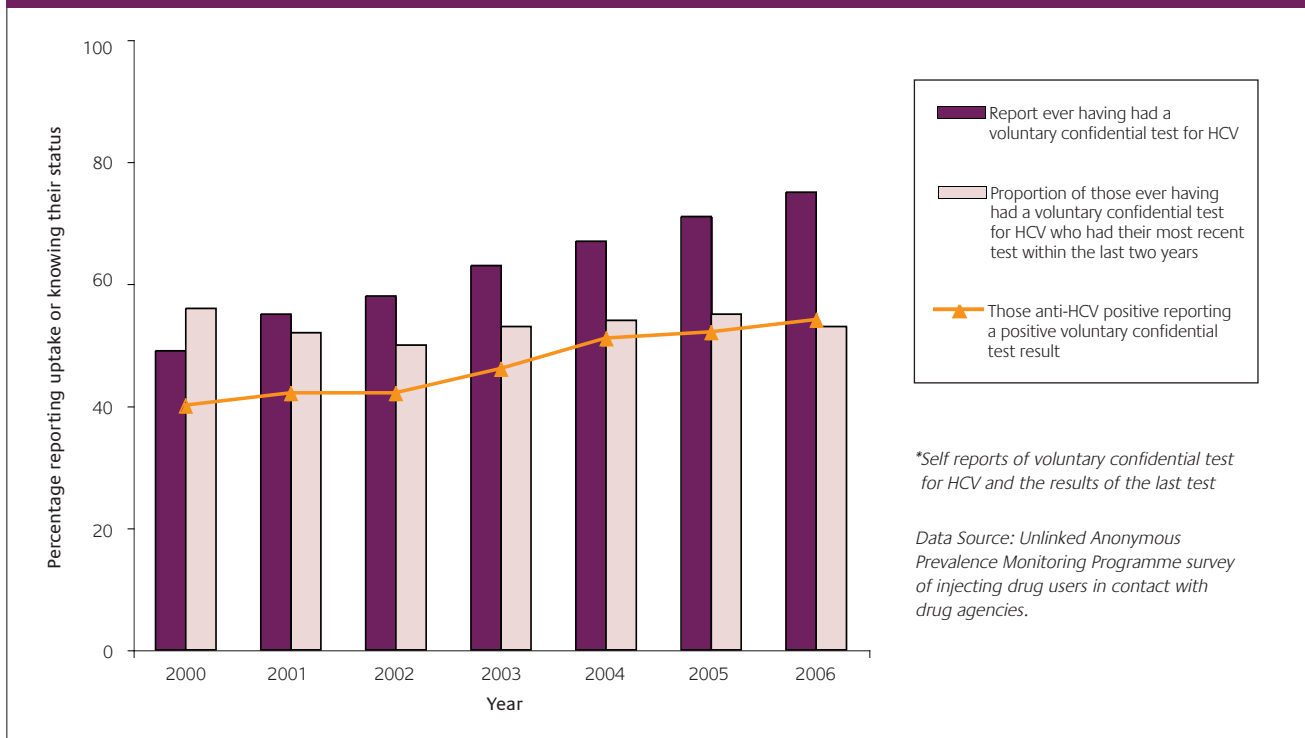
The proportion of those attending specialist drug treatment and support services for injecting drug users who are aware of their hepatitis C infection has been set as a National Outcome Indicator in the *Hepatitis C Action Plan for England*<sup>1</sup>. Of the IDUs who were infected with hepatitis C, the proportion who were aware of their status in the 2006 survey was 54 per cent compared with 52 per cent in 2005 and 51 per cent in 2004. The proportion of those tested who had been tested in the past two years was around 53 per cent in 2006, similar to the proportion reported in each survey since 2000.

### National Outcome Indicator

Of the IDUs who took part in the UAPMP agency survey who were infected with hepatitis C, the proportion who were aware of their positive status in the 2006 survey was 54 per cent compared with 52 per cent in 2005 and 51 per cent in 2004.



Figure 12: 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 to 2006.



## Monitoring the offer and uptake of hepatitis C testing of those attending specialist drug treatment

In 2006/07 there were 183,485 episodes of specialist drug treatment attendance for people with evidence of current or former injecting drug use (50 per cent of all episodes) (Table 5). Hepatitis C testing was recorded in the treatment notes for 23 per cent of these episodes, a doubling of the provisional figure reported for the first quarter of 2006/07<sup>6</sup>. Testing was seen to vary by region, with the highest percentages seen in the East Midlands and the South West and the lowest percentages in the South East and North East of England. This figure is markedly lower than the percentage of HCV tests reported in the UAPMP survey (75 per cent) for 2006, and this is likely to be due to low recording of test status in the drug treatment notes rather than low rates of testing.

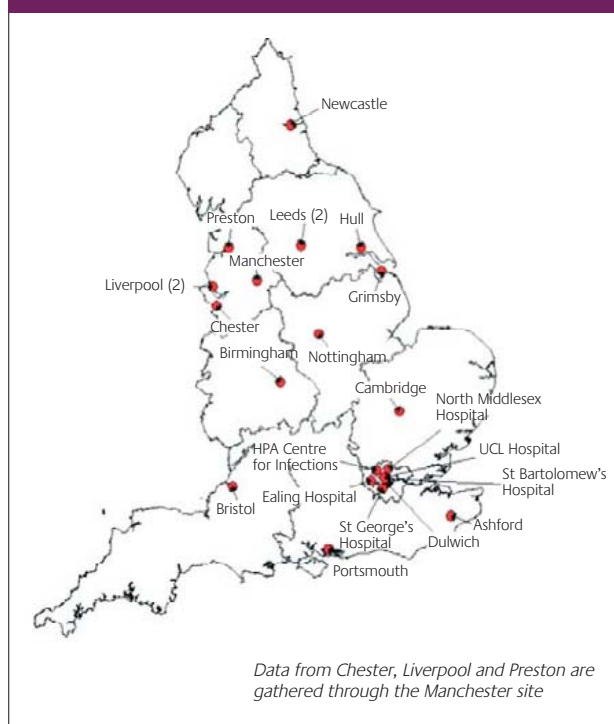
## Sentinel Surveillance Study of Hepatitis C testing

In 2002 the Sentinel Surveillance Study of Hepatitis C testing was set up in order to enhance routine surveillance of hepatitis C<sup>6</sup>. Data are now available from 23 sentinel laboratories across England, increasing the geographic coverage of the study (see Map A) and providing a more detailed picture of hepatitis C testing across England. 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. Additional data for some individuals tested are obtained via questionnaires sent to the clinician or GP who requested the hepatitis C test.

Trends in testing were analysed using retrospective data from the ten sentinel laboratories with complete data from January 2002 to the end of December 2006. The number of people tested for anti-HCV and the proportion testing positive by year in the ten sentinel laboratories is shown in Figure 13.

Figure 13 suggests that the number of individuals being tested in the sentinel laboratory surveillance in 2006 is slightly lower than in the previous year (6.4 per cent decrease), but that the proportion of those testing positive has risen slightly over the same period (from 5.3 to 5.5 per cent). This is consistent with more targeted testing of individuals at higher risk of HCV infection, but overall the volume of testing and percentage testing positive have remained relatively stable.

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

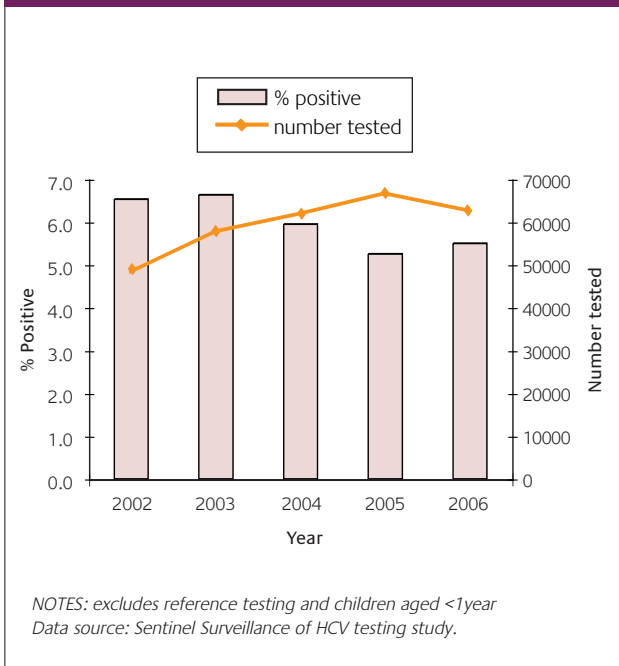


**Table 5: Monitoring the offer and uptake of hepatitis C testing of those attending specialist drug treatment: 2006/07.**

Region	Total number of episodes	Number (per cent) of episodes indicating current or former IDU	Number (per cent) episodes for current/former IDUs with record of hepatitis C test
London	64,545	22,959 (36)	5,163 (22)
North East	19,340	10,818 (56)	1,564 (14)
South East	33,915	14,702 (43)	1,800 (12)
Eastern	23,810	9,664 (41)	1,536 (16)
West Midlands	40,908	19,211 (47)	3,963 (21)
South West	45,505	29,253 (64)	9,743 (33)
East Midlands	26,116	15,896 (61)	5,332 (34)
Yorkshire and Humberside	54,356	31,276 (58)	7,824 (25)
North West	60,751	29,706 (49)	4,404 (15)
<b>Total</b>	<b>369,246</b>	<b>183,485 (50)</b>	<b>41,329 (23)</b>

Data source: National Drug Treatment Monitoring System (NDTMS)

**Figure 13: Number of people tested for anti-HCV by year, and per cent positive, in ten sentinel laboratories: 2002 to 2006**



### Sentinel surveillance of anti-HCV testing in injecting drug users

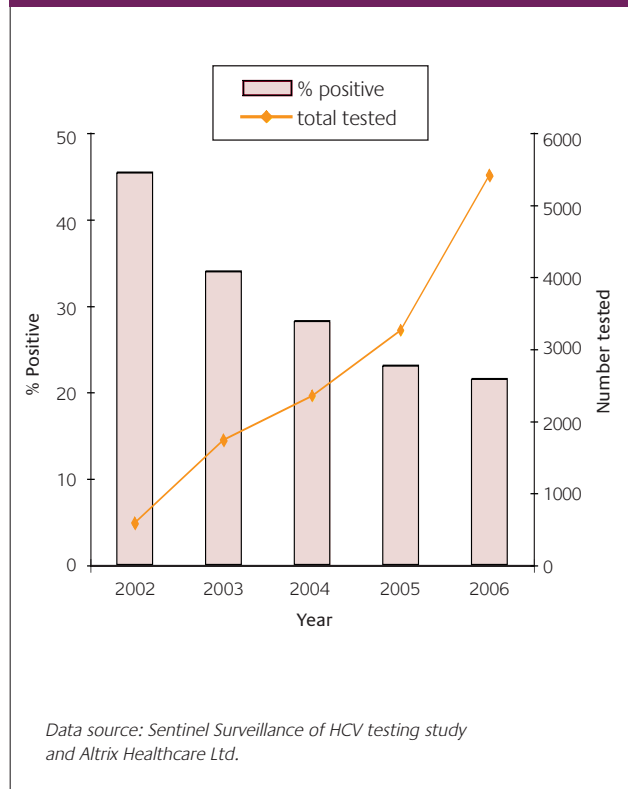
Individuals accessing testing in specialist services for drug users can be identified through the Sentinel Surveillance of Hepatitis C testing scheme. Additionally data on oral fluid testing (OraSure®, Altrix Healthcare Ltd, Warrington, UK) in these services have been supplied to the HPA by Altrix Healthcare Ltd, to help improve the national picture. The number of attendees tested in specialist drug services, and the proportion testing positive for anti-HCV, between 2002 and 2006 in ten sentinel laboratories and via commercial oral fluid testing, is shown in Figure 14.

By adding data on oral fluid testing to data available from the sentinel surveillance study, there is evidence that the number of HCV tests undertaken each year in specialist services for drug users has increased greatly each year since 2002. The proportion of those testing positive has halved over the same period (from 45 to 22 per cent), although it is recognised that oral fluid testing is likely to include repeat testing of the same person.

When data from the sentinel surveillance study *only* are

examined, results suggested that there was an initial steep increase in testing between 2002 and 2003, and then the number of HCV tests remained stable, with a slight increase in 2006. Oral fluid HCV testing in specialist drug services seems to have led to an increase in testing uptake. As oral fluid testing is at present used as an initial screening tool, it is important that all individuals who test positive have their status confirmed by a blood test. At present it is not clear how often this confirmation takes place. Both data sources suggest that the recent increase in testing in drug services has included individuals at relatively lower risk of HCV infection.

**Figure 14: Number of people tested for anti-HCV by year, and per cent positive, among attendees of specialist services for drug users in ten sentinel laboratories: 2002 to 2006**



### Sentinel surveillance of anti-HCV testing in GP surgeries

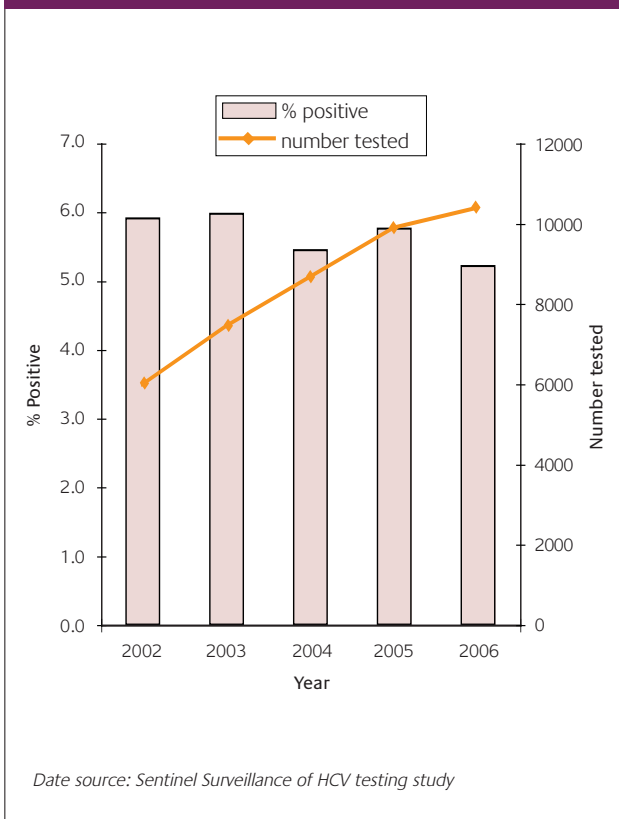
Individuals accessing testing via their GP surgeries can also be identified in the Sentinel Surveillance scheme. The

number of individuals tested via this route, and the proportion testing positive for anti-HCV, between 2002 and 2006, in ten sentinel laboratories is shown in Figure 15.

The amount of HCV testing undertaken via GP surgeries has continued to rise, although the rate of increase has fallen slightly over the last year. The proportion testing positive has also fallen over the last year from 5.8 per cent in 2005 to 5.2 per cent in 2006. It seems therefore that more people are being tested via this setting, but that these individuals are less likely to be positive. This suggests that, in this setting, more people at lower risk of infection are being tested.

of confirmed HCV infections to the HPA CfI. Laboratory reports of hepatitis C have increased year on year since reporting began in the early 1990s (see Section 2.1), and the Department of Health’s hepatitis C awareness campaign *FaCe It* is likely to have contributed to sustaining this increase over recent years. The total number of laboratory confirmed diagnoses of hepatitis C in England exceeded 8,300 in 2006, a rise of 10 per cent on the previous year. Monthly numbers of reports show a sustained and on-going rise with fluctuations across the year (Figure 16). Laboratory reports reflect testing in a wide range of settings, and although it is acknowledged that they underestimate the true numbers of infections in England, they should give a reliable estimate of rises and falls in national testing.

Figure 15: Number of people tested for anti-HCV by year, and per cent positive, via GP surgeries in ten sentinel laboratories: 2002 to 2006



### Laboratory reports to the Health Protection Agency Centre for Infections (CfI)

An increasing number of individuals being tested should be reflected by an increase in the number of laboratory reports

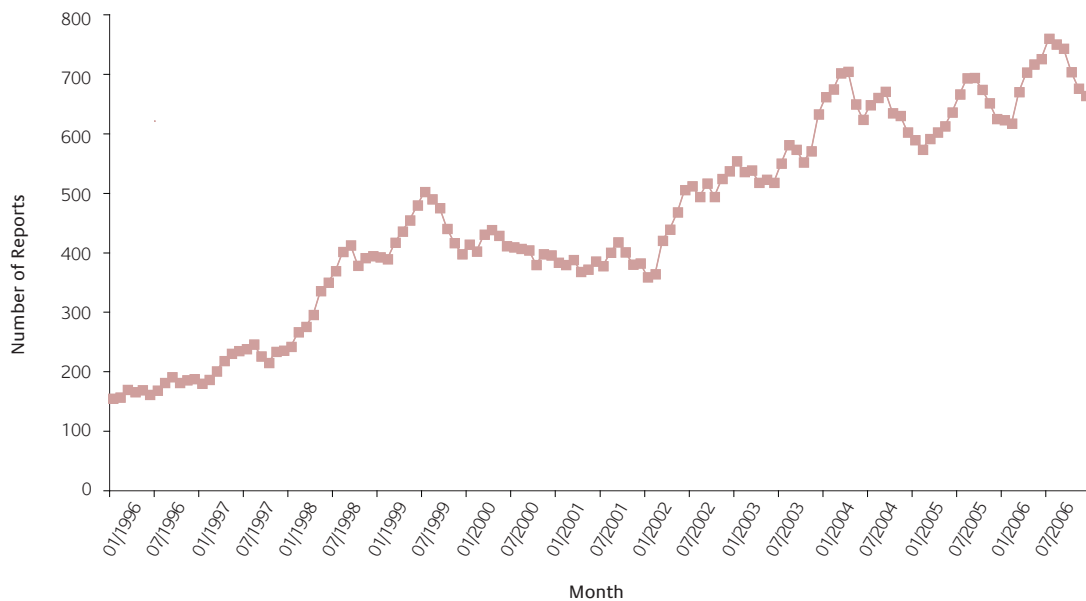
### National Outcome Indicator

The total number of laboratory reports of confirmed hepatitis C infection has been set as a National Outcome Indicator. An increase in the number of reports is expected as more testing of risk groups takes place. A total of 8,346 laboratory confirmed diagnoses of hepatitis C infection were reported to CfI in 2006. This is an increase of 10 per cent on the previous year. This continued rise in reports suggests that more infected individuals are being identified.

### Pilot dried blood spot screening

The use of oral fluids (saliva) and finger-stick capillary blood specimens dried onto filter papers (DBS) as more convenient specimens to facilitate both surveillance and diagnostic testing for HCV and other blood borne infections has been pioneered at the HPA Centre for Infections. DBS tests have been shown to have several advantages over oral fluid specimens, including the potential to provide greater sensitivity<sup>16</sup> and to permit a wider range of tests to be performed. Optimised assay methods for anti-HCV antibody detection in DBS provide over 99 per cent sensitivity and 100 per cent specificity, and therefore could be used diagnostically to encourage hepatitis C testing in low threshold settings in which it is difficult to take blood because of poor vein access or lack of trained phlebotomists. A randomized controlled trial funded by the Department of Health found that rates of testing varied considerably between centres and that DBS tests can increase uptake of HCV testing.

Figure 16: Five month moving average of laboratory reports of hepatitis C infection from England: January 1996 to December 2006



To be more effective such interventions may need to be introduced alongside health education and staff training that raises the importance of hepatitis C testing and the investigation and control of infectious diseases. In collaboration with the Hepatitis C Trust, Nottingham University NHS Trust and Boots the chemist, the offer of free HCV testing based on DBS was piloted in Nottingham city centre at Boots the chemist on World Hepatitis Awareness Day - 1 October 2007.

A follow-on study is examining the use of DBS tests to assess the incidence of hepatitis C, HIV and HBV in selected high throughput clinics, and a wider range of tests that can be conducted from DBS are being developed - including a range of HBV tests and hepatitis C PCR. To facilitate this work, significant advances have been made in the use of DBS for HCV RNA detection and characterisation, including the ability to reliably subtype the infecting HCV strain and undertake sophisticated molecular epidemiology. These developments promise exciting new insights in low threshold field settings into the incidence and transmission patterns of HCV in IDUs and other vulnerable populations at both a local and national level and provide a tool with the potential to better understand the natural history of HCV infection.

## Summary

There has been a considerable increase in media coverage about hepatitis C over the last year from a variety of sources.

The NHS awareness campaign has achieved more than a 60 per cent increase in media coverage about hepatitis C, reaching a potential audience of more than 40 million people in England. The surge in visits to the NHS website (<http://www.hepc.nhs.uk>) and Hepatitis C Information Line indicate that the national advertising campaign involving radio, national newspapers and consumer magazines caught the public's attention and there are plans to do further advertising in 2007/08. It is noteworthy that their media campaign has been developed to address current concern that individuals from the Indian sub-continent may be at increased risk of HCV infection.

Awareness raising in the voluntary sector remains high and its role in tackling the infection is crucial. Charities, including The British Liver Trust, The Hepatitis C Trust, and The Children's Liver Disease Foundation have continued a range of activities to raise the profile of hepatitis C. The late Dame Anita Roddick's commitment to raising the awareness of hepatitis C infection has undoubtedly made a significant contribution in this area.

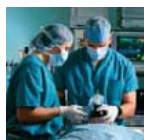
All indicators suggest that HCV testing in the injecting drug user population is increasing, with 75 per cent of the individuals in the UAPMP agency survey reporting ever having had a voluntary confidential test; data from sentinel surveillance and commercial oral fluid testing also show a substantial increase in HCV testing in this key risk group. The numbers accessing testing via their GP surgeries remains high and testing via this route will be key in reaching those individuals who may have been at risk of HCV infection in the past, but who are not currently in any risk group for infection.

Sentinel surveillance, oral fluid testing data and reports of laboratory confirmed diagnoses of hepatitis C infections all indicate that more testing is taking place and that more infected individuals are being diagnosed.

Oral fluid testing in specialist drug services has increased uptake of testing, and the potential role of HCV antibody testing of dried blood spots as a diagnostic tool, particularly in low threshold settings where it is difficult to take blood, could be significant. Further development suggests that this format will also be useful for epidemiological work including studies of incidence and molecular diversity.



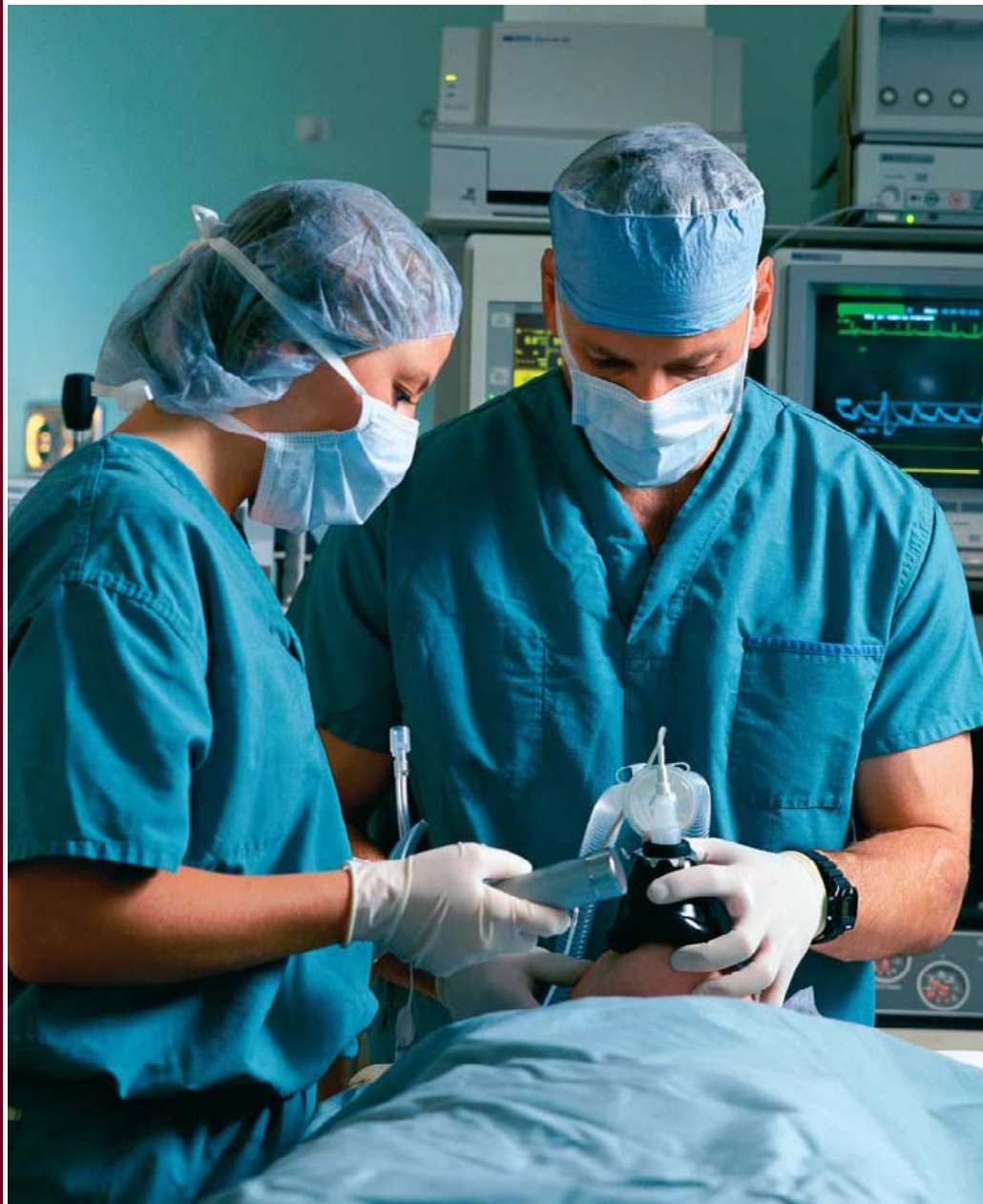




## 4.0 Burden of disease and health care services

# 4.0

## Burden of disease and health care services



# 4.0 Burden of disease and health care services

## KEY POINTS

- Analysis of cases in the National Register of HCV infections with a known date of acquisition, suggests that genotype 1 infections are associated with more advanced stages of histological fibrosis but are also more often associated with spontaneous viral clearance.
- In the first two decades of infection the presence of co-morbidities appears to be the most influential factor associated with progressive HCV-related disease in those who acquire their infections in childhood or adolescence.
- Analysis by the Trent HCV Study Group suggests that the probability of survival of patients with severe hepatic fibrosis secondary to hepatitis C virus infection was 97 per cent at 1 year, 88 per cent at 3 years and 78 per cent at 5 years; combination therapy was associated with improved survival.
- Deaths, transplants and hospital admissions for HCV-related end stage liver disease continue to rise.
- The true number of people in England suffering from severe HCV-related liver disease is underestimated in routinely collected hospital and death data.
- The number of people with HCV-related decompensated cirrhosis and/or hepatocellular carcinoma in England is predicted to increase to 2,670 by 2015.
- National data on referral, uptake and outcome of treatment are urgently required to plan for local hepatitis C services, and to monitor progress of the *Hepatitis C Action Plan*<sup>1</sup>. The HPA is investigating how this might be taken forward.

Action 3 of the *Hepatitis C Action Plan*<sup>1</sup> states that:

*High-quality services for the assessment and treatment of all patients with hepatitis C need to be co-ordinated and accessible across the country.*

### 4.1 Informing the natural history of hepatitis C infection

The role of HCV viral type in the outcome of infection

Data from the HCV National Register was used to investigate whether there was any association between HCV viral type and the clinical outcome of both acute and chronic infection<sup>17</sup>. Although no evidence of an association was found between the viral type and mortality, clinical signs and symptoms of liver disease or histological grade of liver disease, an association was found between HCV type and the histological stage of liver disease. In this study, genotype 1 was associated with more advanced stages of histological fibrosis<sup>17</sup>. Type 1 infections were also found to be more often associated with spontaneous clearance of HCV infection than were other viral types<sup>17</sup>.

Further research is currently being undertaken at Addenbrooke's Hospital, Cambridge to investigate the effect of HCV genotype on viral clearance. HCV typing of specimens from all patients who have attended the Hepatology Clinic at Addenbrooke's since 2004, and have been confirmed HCV antibody positive, is underway. All specimens from un-treated patients who are chronically infected with HCV, are being genotyped; those who test positive for HCV antibodies but negative for viral RNA are undergoing serotyping. The results of this research, which is being undertaken in collaboration with the HCV National



Register, should help to inform whether the initial observation that genotype 1 infections are more likely to clear spontaneously is correct.

## HCV infection in childhood and adolescence

The long-term consequences of hepatitis C in patients who acquire their infections in childhood are not yet clear. Data from the HCV National Register have been used to look at the outcome of infection in individuals who acquired their HCV infections before 16 years of age<sup>18</sup>. In particular, researchers have investigated risk factors for progressive disease as well as response to antiviral treatment. This study examined demographic, laboratory and clinical outcome data from 246 individuals who acquired their infections in childhood or adolescence.

Overall, HCV-related liver disease in the first two decades of infection was mild for most, with the presence of co-morbidities being the most influential independent factor associated with progressive HCV-related disease<sup>18</sup>. This suggests that the natural history of HCV infection in children will vary according to any underlying disease that may be present; this will be particularly pertinent for those who acquired their infections through the receipt of blood or blood products. Relatively benign HCV-related disease in children, when compared to adults, has been reported by others<sup>19, 20, 21</sup>, and it is likely that this is partly the result of the relatively shorter time period that children have been infected. However, because HCV infection that is acquired in childhood persists for many years, it may well be responsible for significant morbidity and mortality later in life. Systematic follow-up of these individuals is planned to establish the long-term outcome of their infections.

Nearly half of the individuals in this study had undergone some form of antiviral treatment, and early observations suggest that around half have successfully cleared the virus<sup>18</sup>. Response rates were reported to vary according to the therapy type undertaken (interferon monotherapy vs. interferon in combination with ribavirin therapy), with those receiving combination therapy achieving higher response rates<sup>18</sup>. Likewise, response rates among those with non-1 type infections were reported to be more than four fold higher than the response rates achieved in those with genotype 1 infections<sup>18</sup>.

## Mode of, and age at, acquisition of HCV infection

Researchers at the Institute of Child Health are currently working in collaboration with the National HCV Register looking at clinical and biological HCV disease progression according to the mode of infection and the age that infection was acquired. To undertake this, two large databases are being interrogated and data analysed - the UK National HCV Register<sup>22</sup> and the European Paediatric HCV Network (EPHN) database<sup>23</sup>.

Data from the National HCV Register will be used to look at the natural history of parenterally-acquired HCV infection which will then be compared to disease progression in patients who were vertically infected from the EPHN. Analyses will be carried out to examine the effect that age at infection, as well as mode and duration of infection have on clinical, virological and immunological outcomes.

One variable used to demonstrate disease progression is the level of Alanine aminotransferase (ALT). However ALT levels vary with age and cut-off levels vary between laboratories. Consequently, age-related ALT levels and variation with age will be analysed and can then be compared with immunological markers and HCV RNA levels in correlation analysis. Variation between vertically and parenterally infected groups will be analysed by looking at markers of disease progression or age-related ALT values. In this case, adjustments will need to take account of factors such as age at infection and HIV co-infection. Combining data from the UK National HCV Register and the EPHN is a unique opportunity to clarify the impact of mode of acquisition and age at infection on paediatric HCV infection in a larger group than has previously been available.

## The natural history of hepatitis C with severe hepatic fibrosis

A study was carried out by the Trent HCV Study Group investigating morbidity and mortality of patients with severe hepatic fibrosis secondary to hepatitis C virus infection<sup>24</sup>.

One hundred and fifty patients with severe fibrosis (Ishak stage  $\geq 4$ ) seen in biopsies taken before 2002, participated in the study. At enrolment, none of these patients had evidence

of hepatocellular carcinoma (HCC) or a co-existing liver disease that may have been the cause of fibrosis. Follow-up of patients was carried out at the date of death or liver transplant or the last visit to the clinic before the data was collected. If patients developed HCC within the first 6 months of the study they were excluded from the cohort. Patients were included in the study if they consumed excess alcohol. Of the 150 patients, 131 had no prior history of decompensation and were used in the main analysis of the study. The source of infection for 47 per cent of these patients was injecting drug use.

Results showed that the probability of survival to either death or transplantation in patients with no prior history of decompensation, was 97 per cent at 1 year, 88 per cent at 3 years and 78 per cent at 5 years. The median interval from either biopsy to death or biopsy to transplantation was 42 months (range 1-109). This was almost twice as long as the median interval seen in patients with previous evidence of decompensation. In patients with no prior evidence of decompensation, the median interval between the first episode of decompensation and either death or transplant was 10.2 months (range 0-91). Within the same group of patients, 25 per cent were diagnosed with HCC and/or decompensation after a median of 41 months (range 1-106). Seventy eight per cent of patients in the main analysis received treatment (Interferon monotherapy or interferon and ribavirin or pegylated interferon and ribavirin), and combination therapy was associated with improved survival.

## Mortality rates in patients infected with the hepatitis C virus

The Trent Hepatitis C Study Group have also been involved in looking at mortality rates in patients infected with hepatitis C as well as identifying the all-cause and liver-related mortality within the Trent Hepatitis C cohort<sup>25</sup>.

Survival length was calculated using the first known positive HCV test and either date of death or date of last hospital consultation. Patients who died within the first year of the follow-up were excluded from analysis. The average follow-up period was 6.7 years.

The death rate within this cohort was found to be three times higher than that of the general population in England<sup>25</sup>. Increased numbers of deaths were the result of liver-related causes as well as causes associated with a drug-using lifestyle. The average age of death was only 51.6 years, but this may well be the result of the lifestyle of these individuals.

Multivariate analysis showed that predictors for all-cause mortality were sex, age, liver biopsy fibrosis scores and treatment. Age, liver biopsy fibrosis scores, alcohol consumption and treatment were predictors for liver-related mortality however sex was not. Completion of a course of therapy was associated with survival from all-cause and liver-related mortality.

The study also found that only 23 per cent of the deaths in this cohort had HCV mentioned on their death certificate<sup>25</sup>.

## 4.2 Estimating the current burden of disease

### Mortality data

Deaths in England from end stage liver disease\* (ESLD) or hepatocellular carcinoma with any mention of hepatitis C on the death certificate are continuing to rise. The number of deaths registered has increased from 81 in 1996 to 193 in 2006 - the latter showing a rise of 24 deaths on the total from 2005 (Figure 17). The majority of these deaths continue to be seen in men.

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

### Transplant data

The number of English residents who join the UK Transplant List with cirrhosis of the liver resulting from hepatitis C, has risen over the last year (see Figure 18). The total number of men registering remains higher than the number of women. However, the rise in registrations observed over the last year is the result of increased first registrations in women; the number of men being registered has remained stable between 2005 and 2006.

First liver transplants performed for patients with hepatitis C-related disease increased from 34 in 1996 to 59 in 2006 (10 per cent and 12 per cent of the total number of transplants respectively). In addition, the number of first liver transplants carried out for patients with HCV-related HCC has also increased from 6 in 1996 to 24 in 2006 (see Table 6). Nevertheless, the majority of liver transplants performed in England are not due to hepatitis C infection.



Figure 17: Deaths from End-Stage Liver Disease\*, or Hepatocellular carcinoma, in those with HCV mentioned on their death certificate in England: 1996 to 2006

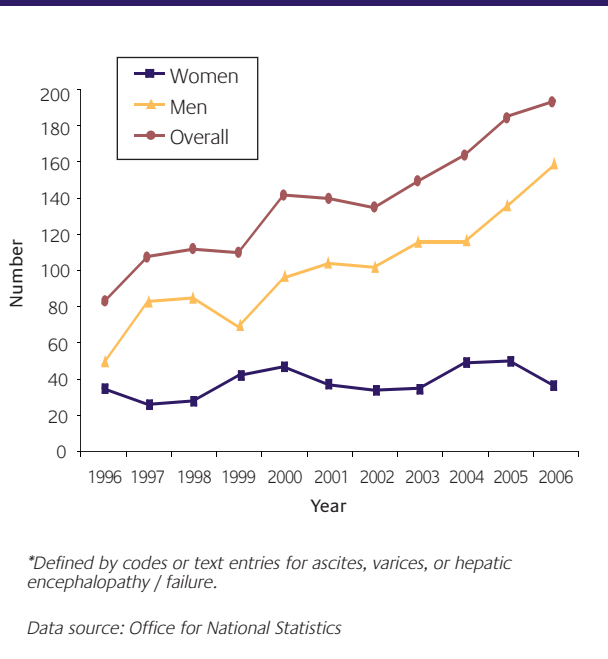


Figure 18: Transplant list first registrations with a code of post-hepatitis C cirrhosis in England: 1996 to 2006

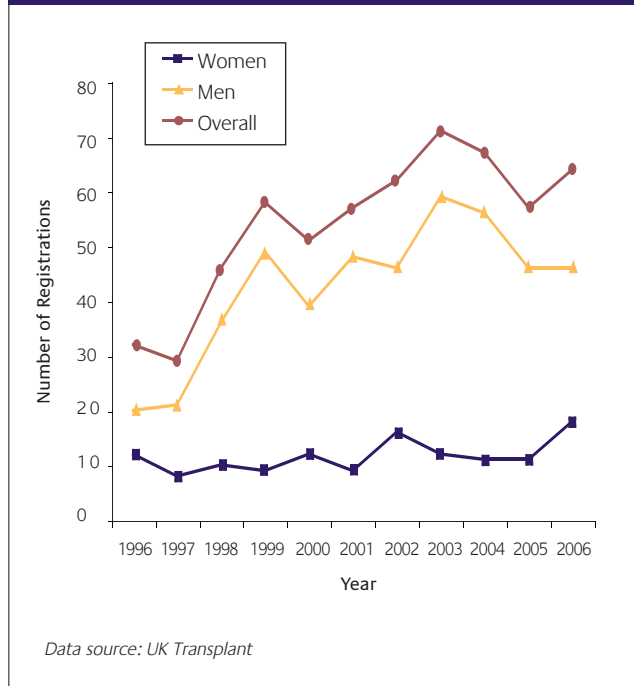


Table 6: Indications for transplant in hepatitis C (HCV) infected individuals in England: 1996 to 2006.

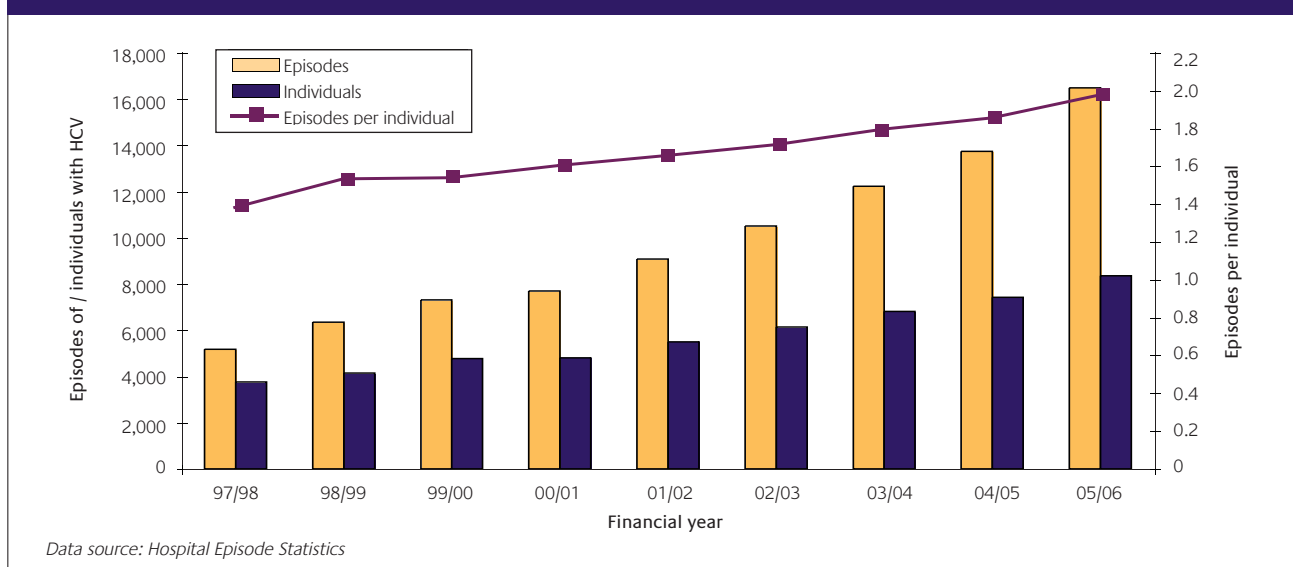
Year	All liver transplants	First liver transplants for HCV related disease (per cent of all liver transplants)			
		Total	Post-hep C cirrhosis	Hepatocellular carcinoma	Other indication
1996	350	34 (10%)	25 (7%)	6 (2%)	3 (1%)
1997	392	43 (11%)	34 (9%)	6 (2%)	3 (1%)
1998	384	41 (11%)	25 (7%)	9 (2%)	7 (2%)
1999	423	67 (16%)	49 (12%)	14 (3%)	4 (1%)
2000	436	61 (14%)	32 (7%)	20 (5%)	9 (2%)
2001	450	61 (14%)	39 (9%)	18 (4%)	4 (1%)
2002	474	68 (14%)	44 (9%)	18 (4%)	6 (1%)
2003	447	71 (16%)	44 (10%)	18 (4%)	9 (2%)
2004	505	74 (15%)	51 (10%)	18 (4%)	5 (1%)
2005	442	52 (12%)	27 (6%)	19 (4%)	6 (1%)
2006	478	59 (12%)	30 (6%)	24 (5%)	5 (1%)

Data source: UK Transplant.

## Hospital Episode Statistics\*

\*A HES record is generated for each episode of admitted patient care under a particular consultant within a single hospital provider

Figure 19: Episodes of, and individuals with, hepatitis C in hospital episode statistics: the financial years 1997/98 to 2005/06



Increases in the number of episodes and number of individuals with one or more hospital in-patient episodes coded to hepatitis C were seen between 1997/98 and 2005/06 (Figure 19). Because this increase is most likely the result of increases in HCV testing of patients admitted for any reason, trends in the numbers of HCV-infected individuals presenting with ESLD in each year serve as a more

reliable indicator for monitoring hepatitis C-related morbidity over time. There is a continued increase in the number of HCV-infected individuals with one or more episode of ESLD or hepatocellular carcinoma (HCC) in each year. In 2005/06 the number rose by 19 per cent from the previous year to 1,260 (Table 7).

Table 7: Number of individuals with hepatitis C who have end-stage liver disease (ESLD) and/or hepatocellular carcinoma (HCC) and deaths for these conditions, in England: the financial years 1997/98 to 2005/06.

Year	Individuals with HCV	Individuals with HCV-related ESLD	Deaths from HCV-related ESLD (percentage)	Individuals with HCV-related HCC	Deaths from HCV-related HCC (percentage)
1997/1998	3751	473	76 (16)	75	28 (37)
1998/1999	4148	558	127 (23)	127	28 (22)
1999/2000	4764	567	128 (23)	126	30 (24)
2000/2001	4807	626	144 (23)	123	33 (27)
2001/2002	5490	672	162 (24)	135	32 (24)
2002/2003	6138	703	170 (24)	187	48 (26)
2003/2004	6813	741	186 (25)	166	50 (30)
2004/2005	7419	849	216 (25)	211	50 (24)
2005/2006	8349	1016	256 (25)	244	60 (25)

Data source: Hospital Episode Statistics

Although individuals may be counted in successive years, it is likely that the proportion of cases counted in previous and subsequent years is consistent over the period. This suggests that hepatitis C-related morbidity is continuing to increase over recent years.

## Enhanced surveillance of severe liver disease due to hepatitis C

As part of CfI's enhanced surveillance of severe liver disease there are currently seven sentinel English centres reporting first diagnoses of hepatitis C/B-related severe liver disease (defined as presence of ascites, bleeding varices, hepatic encephalopathy/failure or hepatocellular carcinoma) each month. By August 2006, 298 first diagnoses of end-stage liver disease in people with hepatitis C had been reported for the years 1999 to 2006 (some centres had outstanding reports for 2005 and 2006). Seventy-four per cent of people were white and 67 per cent reported an exposure of injecting drug use. A description of these patients is shown in Table 8. Although for the majority of cases, the date of acquisition is unknown, the age distribution for individuals with hepatocellular carcinoma is higher than for end stage liver disease. This reflects the longer period between acquisition and development of HCC compared to other complications (Figure 20).

## Estimated diagnoses of, and deaths attributable to, severe liver disease due to hepatitis C in England

It is not known precisely how many people in England are suffering from severe liver disease associated with long-standing hepatitis C infection. Statistical models that are being built at the HPA have recently improved our understanding of how many people are suffering hepatitis C-related liver disease in England<sup>26</sup>. To complement this work, routinely collected data on diagnoses of hepatitis C, hospital admissions due to hepatitis C, and on deaths related to hepatitis C, have been analysed. Specifically, analyses were undertaken to estimate the number of people diagnosed with hepatitis C-related liver disease in England as well as the numbers dying from it. In addition, investigations were carried out to ascertain how closely one of the datasets - Hospital Episode Statistics - reflects the true picture of hepatitis C-related liver disease in England.

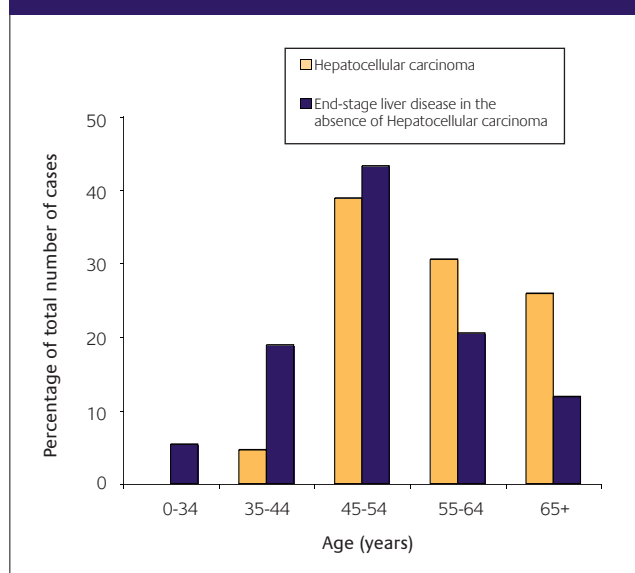
In order to estimate the numbers of people with hepatitis C-related liver disease who are not recorded as having hepatitis C-

**Table 8: Enhanced surveillance of severe liver disease in hepatitis C-infected people in England: 1996 to 2006 (n=298).**

Variable (number of observations)	
Age (n=294)	Mean years (standard deviation) 53.6 years (10.9)
Sex (n=291)	Male 78%
Hep B co-infection (n=237)	5%
HCV viraemia	61%
Time since start of exposure (n=61)	Median years (inter-quartile range) 25 years (18.5-30.5)
Liver transplanted*	10%
Ascites	56%
Bleeding Varices	22%
Encephalopathy	25%
Hepatocellular carcinoma	37%
Dead*	17%

\*Noted at diagnosis or on follow-up.

**Figure 20: Clinical diagnoses by age in people with severe liver disease due to hepatitis C, enhanced surveillance of severe liver disease: 1999 to 2006**



related liver disease, people on two lists were compared: one list contained individuals who had been diagnosed with HCV-related liver disease by a small number of clinicians who were participating in the HPA’s ESLD sentinel surveillance scheme, and the second list contained individuals who were recorded as having hepatitis C-related liver disease in Hospital Episode Statistics. Likewise, to ascertain the numbers of people who die from HCV-related complications who are not recorded as having died from HCV-related complications, a list of the people who died as a result of hepatitis C disease in Hospital Episode Statistics was compared to a list of people recorded as having died from HCV-related disease in death certificates provided by the Office for National Statistics.

A simple capture-recapture technique was used to estimate the number of people missed off the two pairs of lists. Using this technique, the numbers of people on both lists were compared to the numbers of people on only one of the two lists to estimate the number of people on neither list. People were matched between lists using date or month and year of birth, sex and either the name of the hospital where they received their care (in the case of diagnoses of liver disease due to hepatitis C) or the date of death (in the case of deaths due to hepatitis C).

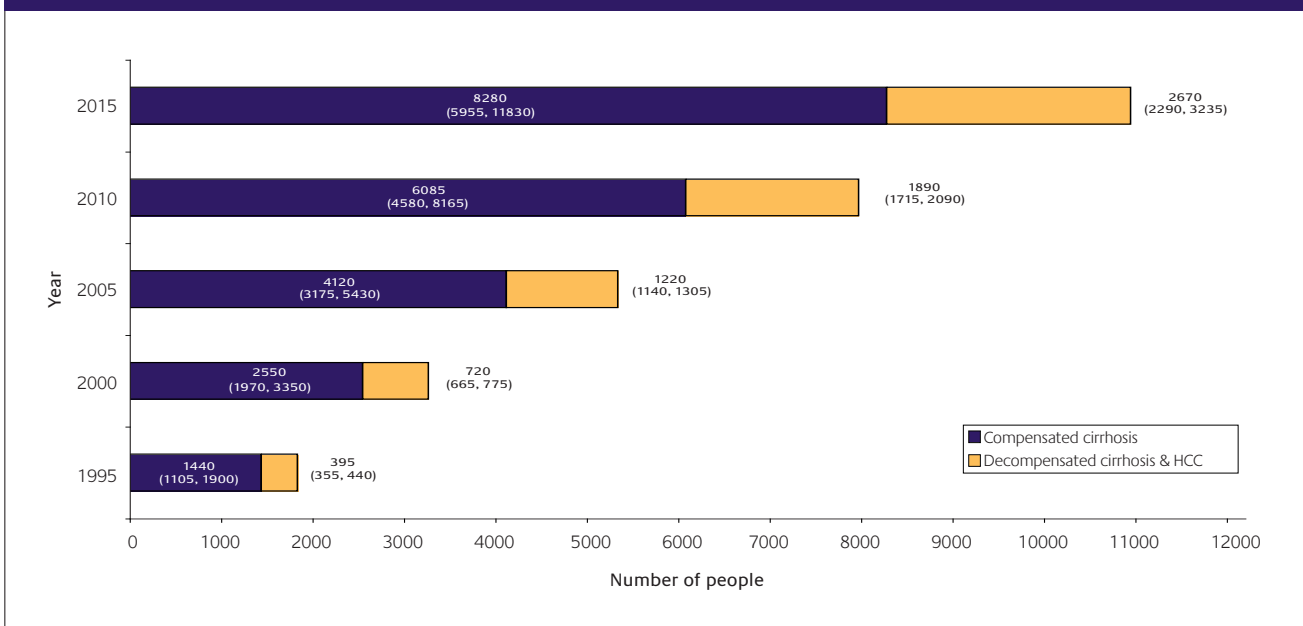
Between 2001 and 2004, it was estimated that the total number of individuals diagnosed with liver disease due to hepatitis C infection each year, was somewhere between 1,181 and 1,272 individuals. The number of people who died

due to hepatitis C-related end-stage liver disease was estimated to be between 432 and 530 deaths per year from 2001 to 2004. Overall, it appears clear that the true number of people in England suffering from severe HCV-related liver disease is substantially under-estimated in routinely collected hospital and death data. This under-estimation is likely to be due to incomplete recording of both hepatitis C infection and of end-stage liver disease.

### 4.3 Predicting the future burden of disease

Using a back-calculation approach, the future burden of hepatitis C-related deaths in England can be estimated<sup>27</sup>. This method uses ONS data on deaths from hepatocellular carcinoma and information on age-specific HCV progression to infer the underlying incidence of HCV infection and predict the future burden of HCV-related disease. The model is continually being updated as new data become available, and Figure 21 shows the predicted number of people living with hepatitis related cirrhosis or ESLD for 1995 to 2015 in England. Overall, this model predicts a substantial increase in the prevalence of HCV-related severe liver disease in England. The model does not, as yet, take into account any potential impact of increasing diagnosis and treatment for infected individuals.

Figure 21: Estimated number of people living with HCV-related cirrhosis or decompensated cirrhosis/hepatocellular carcinoma in England, 1995-2015. (95 per cent credibility intervals are given in parentheses).



## 4.4 Monitoring hepatitis C-related care in the NHS and new initiatives to improve care

### Improving Hepatitis C Healthcare Conference

In 2006, the All-Party Parliamentary Hepatology Group (APPHG) published a report following their audit of hepatology services in England<sup>28</sup>. This report showed that many Primary Care Trusts (PCTs) and acute hospital trusts were taking some steps to implement the *Hepatitis C Action Plan for England*<sup>1,6</sup>, but that more needed to be done. In April 2007, The Hepatitis C Trust organised a conference with sponsorship from the Roddick Foundation – *Improving Hepatitis C Healthcare*. The theme of this conference was to help find practical solutions to the challenges of implementing the Department of Health's *Hepatitis C Action Plan for England*<sup>1</sup>. Senior public health officials, clinicians, commissioners and managers from PCTs, Strategic Health Authorities and Hospital Trusts in England were encouraged to attend to share examples of best practice in implementing the Department of Health's *Hepatitis C Action Plan*<sup>1</sup>. Initiatives included: practical approaches to reach socially excluded patients; developing local awareness campaigns; building clinical networks; enhancing the knowledge base of primary care practitioners and information and tools to help with the commissioning of services for hepatitis C.

### National treatment data and estimating the local need for hepatitis C services

National data on treatment outcome are urgently needed to help inform specialist commissioners of the resources required locally for treatment of hepatitis C; these data are also needed by the Department of Health to help monitor the progress of the *Hepatitis C Action Plan*<sup>1</sup>.

A pilot questionnaire developed by the HPA in association with the British Association for the Study of the Liver (BASL) has been sent to centres, identified by BASL, to collect information about clinical databases currently in use and asking them to provide treatment data for one year. Although some clinicians were able to provide excellent data, there was overall a disappointing response to the survey which means that there is still no national picture of how many people who test positive for chronic hepatitis C virus are referred, take up, and complete treatment in different areas.

The HPA is encouraging London Specialist Commissioners in their decision to request treatment information from local clinicians via the Audit, Information and Analysis Unit. The Agency and its local health protection units are complementing the London treatment figures by providing an estimate of the local hepatitis C population along with information on number of individuals tested and the number who test positive for hepatitis C antibody to allow commissioners to allocate resources more effectively. The HPA has also developed a tool to help PCTs estimate the number of individuals likely to be needing treatment to help with commissioning services locally (see Chapter 6 and [http://www.hpa.org.uk/infections/topics\\_az/hepatitis\\_c/hcvtemp.xls](http://www.hpa.org.uk/infections/topics_az/hepatitis_c/hcvtemp.xls)).

It is now three years since the *Hepatitis C Action Plan*<sup>1</sup> was launched, and the necessary re-configuration of service provision has been challenging<sup>28</sup>. In addition, existing guidance for the treatment of individuals with moderate or severe hepatitis C disease (<http://www.nice.org.uk/TA075> guidance) was updated in 2006 to extend to those with mild chronic hepatitis C (<http://www.nice.org.uk/TA106> guidance). These new guidelines offer the possibility of commencing treatment without a liver biopsy and therefore new opportunities to consider providing care outside the acute trust setting.

The needs of those at risk of, and living with, hepatitis C are varied and complex and a multidisciplinary approach is required if these needs are to be met. Models of care that have been developed in some areas illustrate how services can be brought together in innovative ways to improve quality and access to specialist services<sup>6</sup>. However, if service provision is to be equitable across the country, then national surveillance systems are required to monitor referral, uptake and response to treatment across the country. Currently, it is difficult to monitor treatment for hepatitis C in England because there are no such national surveillance systems in existence, and their development should be a priority. To address this, the HPA is investigating opportunities to pilot mechanisms for collating national data on the numbers of patients referred and treated for HCV infection (and the outcome of their treatment), and looking at opportunities to explore novel ways to estimate the numbers of individuals undergoing treatment for HCV infection in England using national data sources that are already in existence.

## Summary

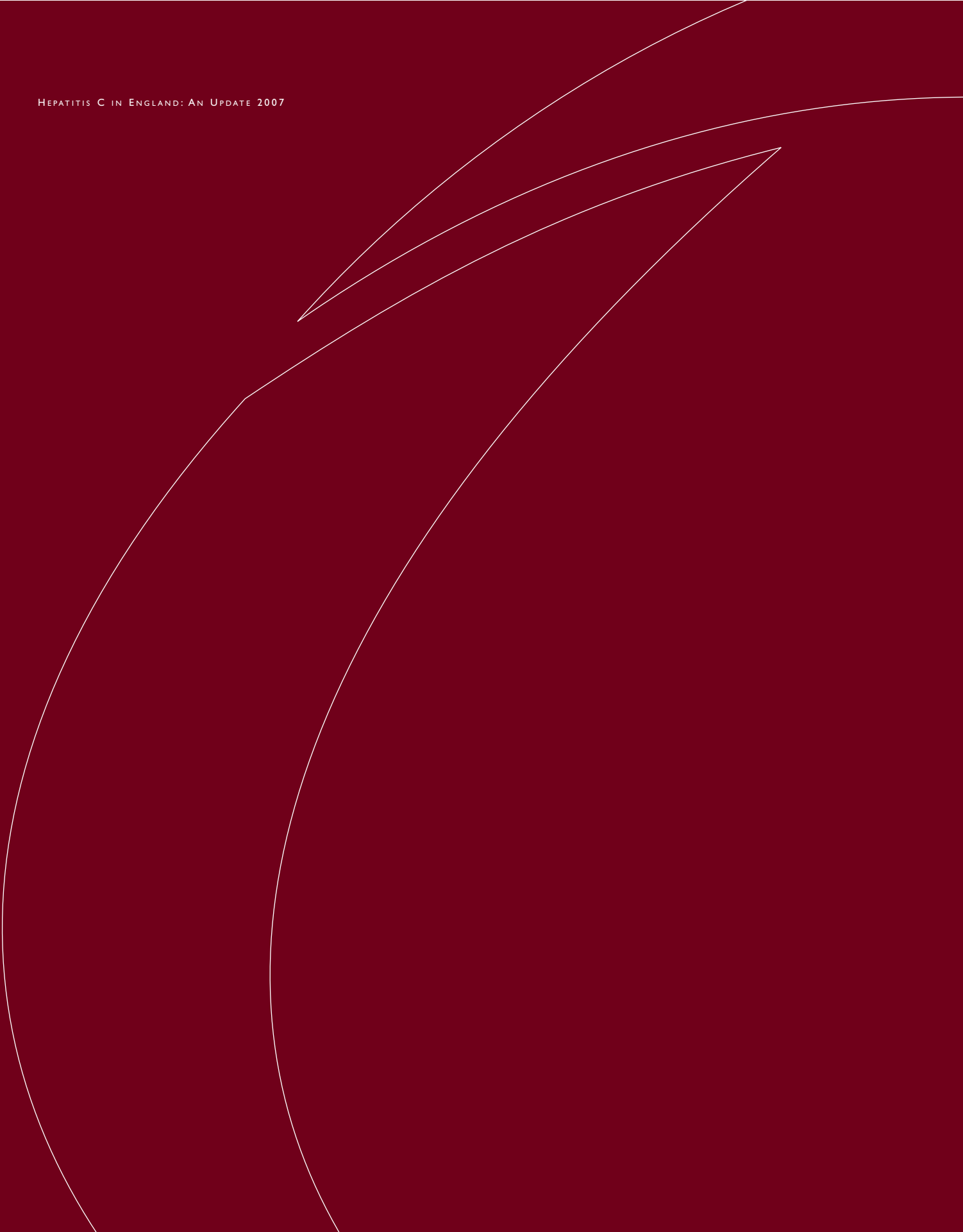
Research undertaken by the HPA alone, in collaboration with others, and by external groups, continue to inform the natural history of HCV infection in England. Recent studies have helped to define the morbidity and mortality from HCV-related disease and have identified risk factors for progressive disease in both adults and children. It is also encouraging to see that the therapeutic combination of interferon and ribavirin is associated with improved rates of survival in the HCV-infected population.

Routine sources of national data - deaths, transplants and hospital admissions - all show that HCV-related end stage liver disease in England is continuing to rise. Similarly, statistical models developed in collaboration with the MRC predict that the number of people living with HCV-related decompensated cirrhosis and/or hepatocellular carcinoma in England will increase to 2,670 by 2015. This is a real cause for concern, particularly when the true number of people in England suffering from severe HCV-related liver disease is known to be under-estimated in routinely recorded hospital and death data.

Continuing increases in the burden of HCV-related disease show that there is no room for complacency in tackling this infection; despite increases in the awareness and diagnosis of HCV infection, there is still some considerable way to go if the burden of HCV infection is to be reduced in the future. National data on referral, uptake and outcome of treatment will be key (and are urgently required) if local hepatitis C services are to be planned effectively and the HPA is investigating how this might be taken forward.







## 5.0 Prevention

# 5.0

## Prevention



# 5.0 Prevention

## KEY POINTS

- The *Music4Messages* CD developed by Offender Health to provide primary prevention information to juveniles and young offenders has been updated and sufficient CDs are available for establishments through until mid-2008.
- An estimated 194,211 people were in contact with specialist, structured drug treatment in England during 2006/07, 7 per cent higher than 2005/06, and 128 per cent higher than in 1998/99.
- The Drugs Intervention Programme - a key component of the Government's strategy for tackling drugs and related crime - has been successful and the government has extended its financial commitment to this programme.
- Enhanced clinical drug treatment has been funded in 53 prisons in England. In 27 of these, enhanced integrated psychosocial services have also been put in place.
- A new programme rolling out disinfectant tablets across the prison estate commenced in 2007.
- A national health promotion DVD on Hepatitis C - *Hepatitis C: Inside and Out* - has been developed to deliver messages on prevention, transmission, management and treatment of Hepatitis C within the prison setting.
- In 2006/07, harm reduction was one of the key themes of the joint NTA and Healthcare Commission improvement review. The worst performing areas are targeted to help them plan for improvement.
- Harm reduction findings from the NTA's 2006 survey of user satisfaction in England found that around 94 per cent of current IDUs' reported using a needle exchange service within the past 4 weeks, but harm reduction advice received was variable.
- In May 2007, the Department of Health and the NTA published an action plan - Reducing drug related harm<sup>29</sup> - to tackle the increase in HCV, other BBVs, and drug related deaths amongst IDUs.
- Hepatitis C prevention is the subject of the current Advisory Council on Misuse of Drugs (ACMD) Prevention Working Group.

Action 4 in the *Hepatitis C Action Plan*<sup>1</sup> states that:

*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.*

### 5.1 Reducing initiation of injecting drug use

Hepatitis C prevention: *Music4Messages* CD for Juveniles and Young Offenders

Offender Health have developed a *Music4Messages* CD, which includes specially commissioned rap music as well as a discussion of health issues, which provides primary prevention information to juveniles and young offenders on the risks of Hepatitis C. An evaluation team from the London School of Hygiene & Tropical Medicine have completed a rigorous evaluation of the CD. This was a controlled effectiveness trial of the activity in eight prisons addressing issues such as how the CD might affect juveniles' and young offenders' knowledge, attitudes and behaviour with respect to risk taking and BBVs.





The *Music4Messages* CD has had some impact in terms of raising awareness and education about hepatitis C. Qualitatively, the CD was found to have achieved a positive impact among some respondents, but there were a number of flaws in its design, production and distribution that could be remedied to make it more effective. These flaws have been addressed in a reprint of the CD, available for distribution from Autumn 2007. Quantitatively there were some encouraging signs that the CD was having an impact on the knowledge of respondents, but these changes were not statistically significant at the 95 per cent level of confidence. Currently, sufficient CDs are available for distribution to establishments until mid 2008.

## 5.2 Helping people to stop injecting drugs

In mid-June, 2006, the national drug treatment allocation was announced for 2007/08. The new figure of £398 million represents a 3.5 per cent increase on 2006/07. This funding will be used to invest in personnel, day-to-day running of services, and building and refurbishment of premises. The aim will be to get more people into treatment and away from a life of drugs and crime. An additional £54.9 million, for the development of inpatient and residential rehabilitation services, has been made available to selected providers to spend in 2007/08.

The Government's Public Service Agreement (PSA) target to double the participation in effective, well-managed drug treatment by 2008 was set in 1998<sup>30</sup>. Data released last year indicated that this target has already been achieved. Provisional data from the National Drug Treatment Monitoring System (NDTMS) reveal that 194,211 people were in contact with specialist, structured drug treatment in England during 2006/07, an increase of 7 per cent on 2005/06 (181,390) and 128 per cent on the 1998/99 baseline of 85,000.

### Models of Care Update 2006

*Models of Care for Treatment of Adult Drug Misusers: Update 2006* was published in June 2006<sup>31</sup> as an update to the

original *Models of Care for Treatment of Adult Drug Misusers* published in 2002<sup>32</sup>. It provides a national framework for the commissioning and provision of treatment for adult drug misusers and continues to serve as the template for promoting consistently high quality and effective drug treatment practice in England (see [http://www.nta.nhs.uk/publications/documents/nta\\_modelsofcare\\_update\\_2006\\_moc3.pdf](http://www.nta.nhs.uk/publications/documents/nta_modelsofcare_update_2006_moc3.pdf)). In particular, it covers improving engagement and retention in drug treatment, the effectiveness of drug treatment delivery, and the reintegration into communities of those completing treatment or being maintained in treatment. It is hoped that improvement in these areas will result in more people being able to stop injecting drugs and to remain free of injecting.

### Drug Interventions Programme

The Drug Interventions Programme is a key component of the Government's strategy for tackling drugs and reducing crime. The Drug Interventions Programme began as a three year initiative to encourage offenders who misuse drugs, out of crime and into treatment. The programme has been successful, and drug-related crime has fallen by a fifth since the programme started and record numbers of people are being helped with their drug misuse. As a result of its success, the Government has extended its financial commitment to this programme.

People who misuse Class A drugs often commit crimes to fund their drug habit. As a result, they can get caught in a cycle of drug misuse, crime and prison. The Programme aims to break this cycle by making every stage in the criminal justice system, and beyond, an opportunity to encourage offenders into treatment. The Programme brings together the police, the courts, the Prison Service, the Probation Service, treatment providers, aftercare support services, government departments and Drug Action Teams (DATs). These partners work together to provide tailored solutions for drug-misusing offenders from arrest, court, sentencing and prison through to post-prison and post-treatment settings. Where necessary, the Programme also ensures that offenders face some tough choices if they are reluctant to engage in the programme.

Introduced in 2003, with new elements having been phased in each year since, the Programme has interventions which

operate right across England and Wales, while additional 'intensive' elements operate in those areas with the highest acquisitive crime. More than £149 million per year is now being invested to expand the Programme until its processes are adopted as part of routine practice with adult drug-misusing offenders across England and Wales.

The Home Office and the NTA continue to be jointly committed to achieving their target of engaging 1,000 offenders per week into drug treatment via the Drug Interventions Programme, by March 2008.

### Clinical management of drug dependence in the adult prison setting

In July 2006, a national programme of prescribed substitute medication was introduced by Prison Health as part of the Integrated Drug Treatment System (IDTS) for prisons. In addition, a number of prisons received funding for prison drug clinical services and to date, enhanced clinical drug treatment has been funded in 53 prisons, nearly all of whom will be delivering the service by November 2007. Twenty seven of the 53 prisons also have enhanced psychosocial services to provide an integrated service. For the remaining 83 prisons in England IDTS funding is uncertain, but prison drug treatment funding in its entirety is currently under review. This work may identify how enhanced integrated treatment can be provided in all prisons in the future. Results of this review should be available in December 2007.

One of the main aims of this improved provision of substitute prescribing and managed withdrawal is a reduction in the injecting of illegal drugs within prisons: clinical treatment in this regard is backed up by specific inputs from a structured psychosocial programme which, amongst other activities, focuses on blood borne viruses, harm minimisation and safer injecting.

## 5.3 Promoting safer injecting drug use

### Use of disinfection tablets in the prison setting

A new programme rolling out disinfectant tablets across the prison estate commenced in 2007. The use of disinfectant tablets, as a means to control and prevent transmission of BBVs in prisons, has been previously independently evaluated by the London School of Hygiene and Tropical Medicine.

This pilot study in 1998 found the use of disinfectant tablets to be effective and acceptable, and their widespread use was recommended. However, health and safety concerns regarding their use in the prison environment were raised subsequently, which significantly delayed implementation. These concerns have now been fully investigated to the satisfaction of Her Majesty's Prison Service, the Health and Safety Executive and Occupational Health Services and it is believed that any potential risk is very low and can be managed effectively through new innovations such as specially designed dispensers, as well as through the usual security measures already in place in all prisons concerning control of substances potentially hazardous to health.

There are currently no plans to introduce needle-exchange programmes in prisons in England, but plans are constantly under review. There is a plan to run a pilot programme in a single prison in Scotland, and the outcome of this programme will be used to judge any future role of such interventions in the rest of the UK prison estate.

### Health Promotion in the prison setting

A new national health promotion DVD on Hepatitis C, called *Hepatitis C: Inside and Out*, produced by Offender Health in collaboration with Munro & Forster Media Company (who have also worked on the national Hepatitis C awareness campaign - *FaCe It*), has been developed for use specifically in prisons.

The DVD uses a combination of 'dramatic vignettes' and 'talking heads' interspersed with interesting visuals to present complex information concerning the prevention, transmission, management and treatment of Hepatitis C in a way accessible to prisoners (see Section 3.1).

### Recommendations for good practice: the NTA/Healthcare Commission National Improvement Review on Harm Reduction

In 2006/07 the NTA and the Healthcare Commission carried out a joint improvement review. The themes of this review were harm reduction and commissioning. The development of the assessment framework for harm reduction involved conducting a pilot improvement assessment exercise for harm reduction services. A set of criteria for harm reduction were written based on the piloting, and questions were established for each criterion. Criteria broadly covered commissioning of harm reduction services, provision of



needle exchange services, provision of services for the prevention of blood-borne viruses and drug related death, and staff safety, capacity and confidence. The data review has been completed and all DATs, PCTs, and SHAs have received provisional embargoed results. The final results will be available to the partnership areas by December 2007, followed by a report in early 2008.

## Needle exchange services

The NTA's 2006 annual user satisfaction survey ([http://www.nta.nhs.uk/publications/documents/nta\\_2006\\_survey\\_of\\_user\\_satisfaction\\_in\\_england.pdf](http://www.nta.nhs.uk/publications/documents/nta_2006_survey_of_user_satisfaction_in_england.pdf)) focused on harm reduction, the subject of the joint NTA/Healthcare Commission Reviews for that year. Questionnaires were received from 10,070 respondents from tier 2 to 4 interventions (including 1,305 from clients of pharmacy-based needle exchange services).

Approximately 70 per cent of respondents had a history of injecting and more than a third injected at the time of the survey (injected in past 4 weeks). The majority of the latter (94 per cent) reported using a needle exchange service in the past 4 weeks. A third of respondents reported using the mixed economy of needle exchange facilities (both pharmacy and non-pharmacy-based needle exchanges).

There was variability in respondents having received the range of harm reduction advice and interventions from drug key-workers, needle exchange staff and/or needle exchange pharmacies in the past three months. Current injectors were more likely to have received this advice than non-injectors, but not all did. More than 60 per cent received advice on the risks of sharing needles and syringes, filters and injecting water and approximately 60 per cent were given advice on the increased risk of overdose resulting from injecting. Respondents were much more likely to have received advice on sharing needles/syringes and other paraphernalia than any other type of harm reduction advice.

The unmet needs of a substantial number of injectors were also highlighted by the study as current injectors were asked to report on receipt of a wide range of interventions in the past three months that they felt were relevant to them (see Table 9).

**Table 9: Percentage of current injectors who reported not receiving an intervention that they felt relevant to them**

Question: Have not received the intervention but it is still relevant to you	Percentage of respondents answering 'yes'
Training in dealing with overdose	33.1
General health assessment	27.7
Checking injecting sites	24.3
Advice on storing medicines safely	20.5
HBV immunisation	20.5
Advice on risk of heart problems from crack	20.4
HIV testing	18.2
Advice on problems from smoking crack	18.6
Hepatitis C testing	17.3
Safer injecting techniques	16.5
Wound and abscess dressing	16.6
Advice on safer sex	16.8
Advice on increased risk of overdose from injecting	14.0
Advice on harm of alcohol for HCV+ people	14.0
Advice on BBVs	13.7
Advice on risks of sharing water	12.7
Advice on risk of sharing cookers	13.7
Advice on risks of overdose from mixing substances	12.6
Advice on risks of overdose when tolerance is low	12.3
Advice on alcohol-related harm	13.0
Advice on risks of sharing filters	11.9
Advice on risks of sharing needles and syringes	10.3
Daily alcohol intake discussed	7.7

Data also confirm that organisations other than specialist drug services continue to have an important role in providing HCV and HIV testing, as well as hepatitis B immunisation (see Table 10). Although the survey did not investigate who these 'other' organisations were, they are likely to include prisons, general practitioners and Genitourinary Medicine clinics.

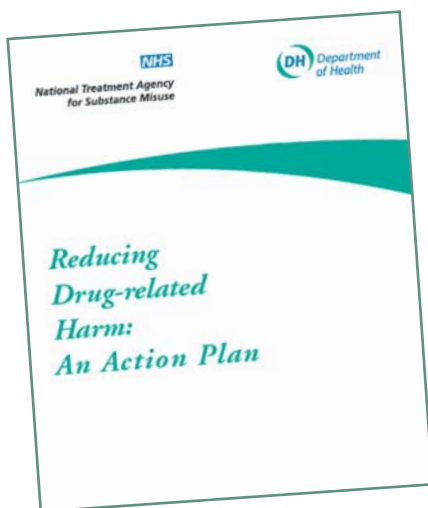
**Table 10: Source of harm reduction interventions received in the past three months by current injectors**

	Specialist drug services (drug key-workers, needle exchange staff or pharmacy)	'Other' organisations
HCV testing	45%	28%
HIV testing	40%	28%
Hepatitis B immunisation	44%	23%

Following on from the audit, the HPA met with the National Treatment Agency for substance abuse (NTA) to discuss on-going surveillance requirements. Surveillance data is needed in order to monitor needle exchange activity and to allow estimation of coverage of syringe distribution. The NTA is proposing to launch a simple on-going data collection system by 1 April 2008.

### Development of 2006 Action Plan to reduce drug related harm

In May 2007 the Department of Health and the NTA published *Reducing drug related harm: an action plan*<sup>29</sup>. This action plan was drawn-up following a two-day meeting of the Reducing Drug Related Deaths expert National Steering Group. This group was reconvened in response to the increase in infections with hepatitis C and other blood-borne viruses and drug related deaths observed amongst injecting drug users. The action plan is available at [http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_074850](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_074850).



The action plan targets those most at risk of drug related deaths and/or of contracting blood borne viruses, including the following:

- Service users
- Homeless drug users
- Heroin and crack injectors (speedballers)
- Potential or new injectors
- People in contact with the criminal justice system

The plan has three main strategic aims: to increase the amount and quality of surveillance information;

to improve the delivery of services to those at risk; and to commission a number of campaigns to inform users, carers, and service providers of ways and means of reducing harm.

### The Advisory Council on Misuse of Drugs (ACMD) Inquiry into the prevention of HCV

Hepatitis C prevention is the subject of the current Advisory Council on Misuse of Drugs (ACMD) Prevention Working Group. ACMD members and co-opted experts, including HPA staff, are undertaking an inquiry into the Prevention of HCV among Injecting Drug Users which aims to report to ACMD and Government in 2008. The Terms of Reference of the ACMD can be found at <http://www.drugs.gov.uk/drugs-laws/acmd/terms-of-reference>.

The rationale for the enquiry is that injecting drug use is the main transmission route for HCV; that HCV occurrence among IDUs remains high; that current coverage of prevention seems insufficient to reduce HCV transmission among IDUs; and advice to policy makers on how much extra intervention maybe required to prevent HCV is unclear. The first meeting of the group took place in January 2007.

It is proposed that the Inquiry will have three components. Two Working Groups will be established, one to describe the current epidemiology of HCV in the UK, and draw upon relevant international literature with respect to risk factors associated with infection, and another to identify the range of potential interventions to prevent HCV infection. The latter will include health education and outreach, syringe and paraphernalia distribution programmes, opiate substitution therapy and other specialist drug treatments, and treatment of HCV. The Working Group will consider which interventions have the greatest potential for prevention, and priorities for development and investigation. The third stage will be to combine the evidence generated from the two Working Groups probably supported by the development of transmission models to develop the implications for policy and practice. This will lead to recommendations for future action, surveillance and research.

### Summary

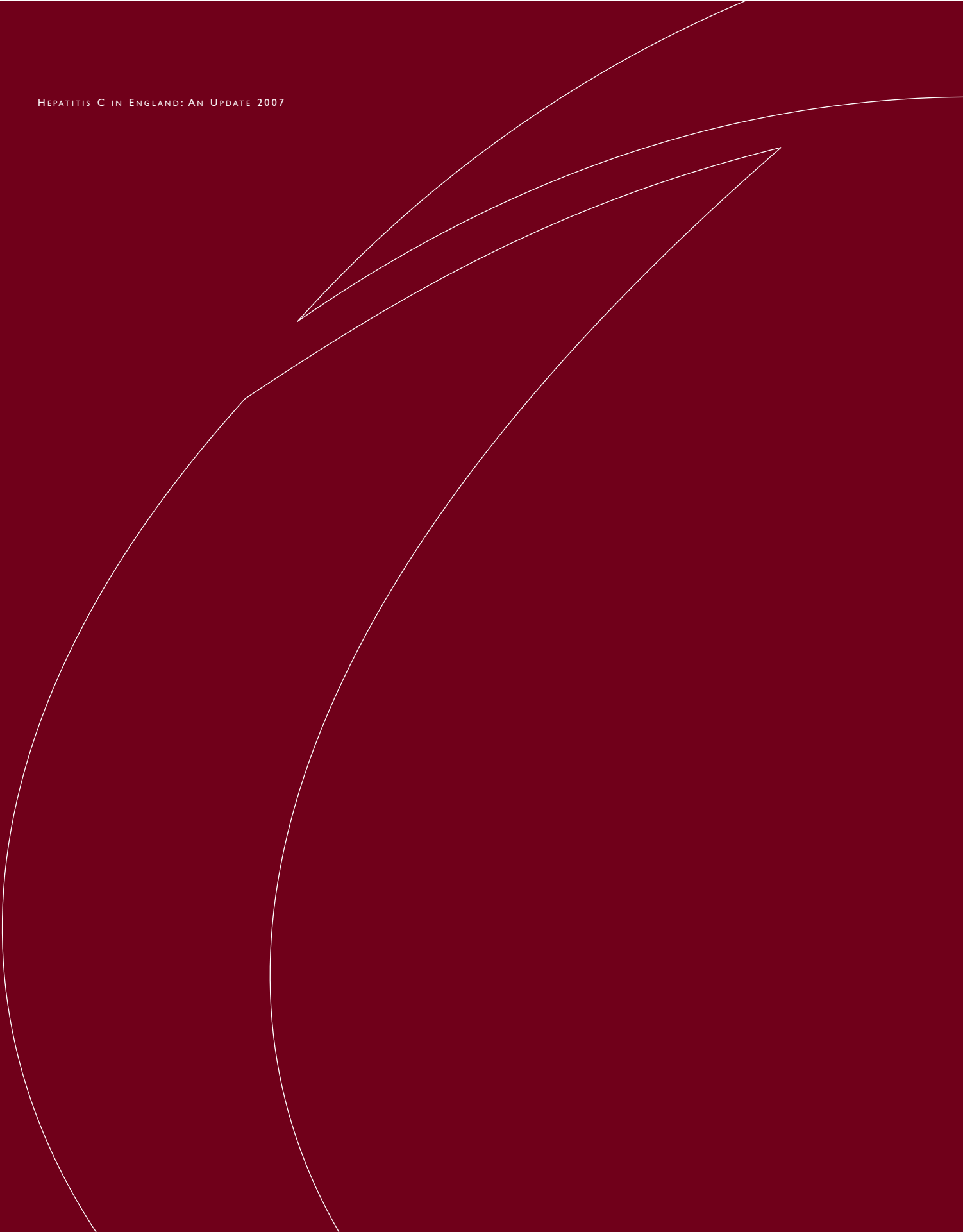
Continued increases in the funding allocation of national drug treatment services should help to get more people into treatment and away from a life of drugs and crime. This is

significant as injecting drug use remains the principal driver of HCV infection in England.

Prevention strategies continue to target those groups at greatest risk of infection, and new initiatives centre on: reducing initiation of injecting drug use, helping IDUs to quit injecting, and harm minimization strategies for those who continue to inject. The core work in this area has necessarily centered on injecting drug users themselves as well as around settings, like prisons, where injecting drug use is concentrated.

Tools like the national health promotion DVD - *Hepatitis C: Inside and Out* – have been developed to deliver messages on the prevention, transmission, management and treatment of Hepatitis C within the prison setting and existing resources have been updated. Other recently introduced strategies around harm minimisation include: a new programme rolling out disinfectant tablets across the prison estate; a joint NTA/Healthcare Commission improvement review leading to the development of criteria for harm reduction and the publication of a joint Department of Health/NTA action plan to tackle the increase in BBVs, including HCV, amongst IDUs.

Recent surveys highlight the fact that a significant number of injecting drug users have insufficient contact with needle exchange services and amongst those that do, harm reduction advice is variable. Because HCV prevalence among IDUs remains high and the current coverage of prevention seems insufficient to reduce HCV transmission among IDUs, Hepatitis C prevention has been made the subject of the current Advisory Council on Misuse of Drugs (ACMD) Prevention Working Group.



## 6.0 HPA initiatives

# 6.0

## HPA initiatives



# 6.0 HPA initiatives

## KEY POINTS

- The HPA Prison Network are currently undertaking an exercise to map joint Health Protection Unit and prison activity on screening, referral and commissioning of hepatitis C services.
- The HPA has developed a tool to provide local estimates of HCV prevalence, and predictions of the likely number of individuals requiring treatment, to help commissioning of local services for hepatitis C.
- The HPA are currently preparing a report on the feasibility and acceptability of self-testing for HCV.
- The HPA has set up a network of designated HPA hepatitis leads for each region (and local Health Protection Units) to provide a local point of contact for viral hepatitis for disseminating information and coordinating work.
- The HPA is currently evaluating its surveillance systems, including those for hepatitis C, to assess their effectiveness and efficiency and identify any important gaps.

## 6.1 Hepatitis risk in prisons

### Mapping joint Health Protection Unit (HPU) and prison activity

Following on from the symposium held in March 2006 to discuss collaboration between the HPA and prisons in reducing hepatitis<sup>6</sup>, the HPA Prison Network are currently undertaking an exercise to map joint Health Protection Unit-Prison activity in this area.

A questionnaire is being developed which includes questions on HCV screening in prisons and referral pathways. All HPUs will be asked to complete a questionnaire for every prison in their patch; the questionnaires will seek to establish whether HPUs have been advocating HCV screening of prisoners and whether HPUs have been advocating or advising on commissioning of specialist services for prisoners found to be positive on screening. It is hoped that the results of this survey will be available by the end of the year.

## 6.2 Estimating the local need for hepatitis C services

The HPA has identified the need for data on the prevalence and burden of hepatitis C to be made available for commissioners at a local level. The National Institute for Health and Clinical Excellence (NICE) provided a template to estimate the number of individuals likely to be needing treatment for mild hepatitis C to accompany their guidance for treatment. However, this extrapolates from national prevalence which fails to account for local variation.

The Agency has attempted to develop a similar template to take into account variation in the prevalence of drug use, the location of local prisons and the ethnic make up of the local population, which can all make major differences to the local prevalence of hepatitis C. The template which has been developed, automatically calculates an estimate of the number of HCV-infected individuals when a PCT code is entered into the spreadsheet. This can then be refined further by using local data such as DAT local needs assessments on referral rates and compliance with treatment.





A pilot of the template in several Health Protection Units gave feedback on the estimates produced and the availability of local data that could be used to enhance the calculated estimate. This tool was presented in April 2007 at The Hepatitis C Trust conference for commissioners; the tool was rolled out shortly afterwards to help PCTs calculate their local HCV burden before the next audit of progress on the *Hepatitis C Action Plan*<sup>1</sup> by the All Party Parliamentary Hepatology Group in September 2007. The tool can be accessed via a downloadable Excel file from the HPA website ([http://www.hpa.org.uk/infections/topics\\_az/hepatitis\\_c/hcvtemp.xls](http://www.hpa.org.uk/infections/topics_az/hepatitis_c/hcvtemp.xls)).

### 6.3 Access to diagnostic HCV testing

The HPA is currently undertaking a review of the accuracy, feasibility, acceptability, ethical and practical issues around self-testing for HCV. It is still unclear what the contribution of self-testing, point of care tests and non-invasive testing could make to improving the proportion of HCV infected individuals who are diagnosed. The review will examine the international literature on such testing for hepatitis C and for other blood borne viruses, and undertake semi-structured interviews with key stakeholders.

Following successful evaluation of dried blood spot technology for testing drug users in specialist services, the potential demand for roll out of this technology to regional HPA laboratories will be discussed through the Regional Microbiology Network. A protocol for PCR testing of samples is currently being developed by the Virus Reference Department at the HPA Centre for Infections.

Another easy way to provide a sample for initial testing is by oral swab. The Agency is currently working with the commercial company Altrix Healthcare Ltd, Warrington, UK, who provide an oral fluid testing service, to ensure that oral fluid test results are available for national surveillance.

### 6.4 Hepatitis Leads Network following up hepatitis C

In 2006, a network of designated HPA hepatitis leads for each region and for each local Health Protection Unit was established to support the work of the HPA Hepatitis Programme Board. The aim of this was to provide a local point of contact for viral hepatitis that can disseminate information to local interested stakeholders, coordinate work and share models of good practice (see Case Study). The first task for the leads was to implement the standards for local surveillance and follow-up of hepatitis B and C within the HPA. The standards aim to:

- Reduce the incidence and prevalence of hepatitis B and C
- Prevent onward transmission from infected persons
- Facilitate the appropriate clinical management of individuals with acute and chronic hepatitis

This is progressing well and an agreed minimum dataset to be collected is in place. A training day on hepatitis follow up was held for local units in October 2007.

A number of local initiatives have resulted, some of which are described below:

#### Case Study: Development of a hepatitis C care pathway in the North East

Since June 2005, staff in the HPA North East have been leading the development of a hepatitis C care pathway for residents of County Durham and Darlington Primary Care Trusts (PCTs), which includes four prisons. The PCTs have the lead for commissioning care pathways locally.

In response to the DH *Hepatitis C Action Plan for England*<sup>1</sup>, the health community in County Durham and Darlington identified the need for more focused action in order to prevent HCV

continued overleaf..

infections and to reduce the level of unidentified undiagnosed HCV infection. They also aimed to provide more co-ordinated care pathways for people with HCV, from initial diagnosis to specialist care and treatment.

A steering group chaired by a Consultant in Health Protection from HPA North East with representatives from the PCTs, prison health, the acute NHS trust, substance misuse services and genitourinary medicine services have developed an agreed pathway, from testing to treatment, for patients diagnosed in both the prison and community settings. The pathway is based on best practice and evidence. This has resulted in the commissioning of a new local HCV treatment service at the University Hospital North Durham since March 2007 which includes a HCV nurse specialist who can provide outreach support within prisons.

The availability of a care pathway and a local service should ensure easier, more equitable access to hepatitis C assessment and treatment for County Durham and Darlington residents. Work is ongoing with regional specialised commissioners to assess the feasibility of expanding the care pathway to cover the entire North East with a network of treatment services provided by two specialist hepatitis C centres (providing treatment for complicated cases including those with HIV co-infection) and a number of other more local hepatitis C treatment providers, providing treatment and support in a variety of settings.

This work was partly informed by a North East research study funded by the National Treatment Agency for Substance Misuse that used qualitative methods to explore the barriers to uptake of hepatitis C testing within the prison settings<sup>33</sup>. The study identified personal barriers including fears, lack of knowledge about HCV, low motivation for testing, lack of awareness about the testing procedure, and concerns about confidentiality and stigma. Institutional barriers included the way a prisoner had to apply for the test, inadequate pre- and post-test discussion, lack of pro-active approaches to offering testing, and lack of continuity of care on discharge and transfer.

For further information on these initiatives please contact Dr Fu-Meng Khaw or Dr Deb Wilson at HPA North East (fu-meng.khaw@ntwha.nhs.uk and deborah.wilson@cdd.nhs.uk).

### Case Study: Setting up a local Hepatitis C database in the Humber region

The Humber HPU has set up a Hepatitis C database, which links screening test and PCR results on an individual basis. The database was set up in 2003 and includes records from 1999 onwards for the 4 PCTs in the Humber region. A total of 2462 individual records are currently stored (1836 males, 626 females) in the database. When the number of infected individuals in each PCT is compared to the predicted numbers provided by the HPA template for each PCT (see section 6.2 [http://www.hpa.org.uk/infections/topics\\_az/hepatitis\\_c/hcvtemp.xls](http://www.hpa.org.uk/infections/topics_az/hepatitis_c/hcvtemp.xls)), it suggests that between 39 and 81 per cent (depending on the PCT) of the predicted infected individuals have been diagnosed.

A total of 846 people (27 per cent of the estimated RNA positive proportion) are currently known to be chronic cases. A total of 220 were never RNA positive while 80 are known so far to have cleared the virus over the years as result of treatment. More accurate information on outcome from treatment should be available once the secondary care providers have set up their own databases.

The database, which includes demographic and risk factor data, allows the local HPU to monitor carefully the epidemiology of Hepatitis C in the area and support in a meaningful way the local economies commissioning processes.

For further information on these initiatives please contact Dr Autilia Newton at Humber Health Protection Unit (autilia.newton@hullpct.nhs.uk).

## 6.5 Evaluation of HPA Surveillance Systems

The HPA Surveillance Strategy Development Programme Board (SSDPB) is responsible for determining how the Health Protection Agency will collect and use information to support surveillance activities in the future. In order to inform this strategy the SSDPB have initiated a process to evaluate all surveillance information systems, including those for hepatitis C, within the HPA.

The evaluation process is a two stage process. The first

stage will focus on public health aims and objectives, surveillance objectives, stakeholder engagement, and evidence for effectiveness. The second will investigate the operational and technical aspects of data management systems that support surveillance. This work should determine what is in place for surveillance within the HPA, how effective and efficient the HPA surveillance systems are, and where there are important gaps.

With respect to hepatitis C, all of the hepatitis C surveillance systems will be put forward for evaluation. These include the national laboratory surveillance of hepatitis C, the sentinel surveillance of hepatitis C testing, and the surveillance of end stage liver disease (as a result of hepatitis C infection). Other surveillance systems to be evaluated include the Unlinked Anonymous Prevalence Monitoring Programmes surveillance of hepatitis C in injecting drug users and the surveillance of transfusion transmitted infections and infections in blood donations (surveillance systems jointly run by the National Blood Service and the HPA).

## Summary

The HPA has increased its activity on hepatitis C over the last year, expanding its initiatives and networks on a local and national level. This work is overseen by the HPA Hepatitis Programme board, with input from external agencies and other stakeholders to ensure coordination with wider initiatives.

The HPA has developed a practical tool to provide local estimates of HCV prevalence, and predictions of the likely number of individuals requiring treatment. It is hoped that this initiative will help PCTs to better commission local services for hepatitis C.

The HPA Local and Regional Services Prison Network are currently undertaking an exercise to map Health Protection Unit-Prison activity on screening, referral and commissioning of hepatitis C services. The HPA have also set up a network of designated HPA hepatitis leads for each region (and local Health Protection Units) to provide a local point of contact for viral hepatitis, for disseminating information and coordinating work. Work is also in progress to assess the feasibility and acceptability of self-testing for HCV.

As part of a generic process, the HPA's systems for surveillance of hepatitis C will be evaluated. The HPA hopes to develop existing programmes and initiate new ones over the coming year.

# 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?

- The majority 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 confirmed on a second blood sample, when tests for HCV RNA can also be performed if the positive antibody results are confirmed
- 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

## What you need to know

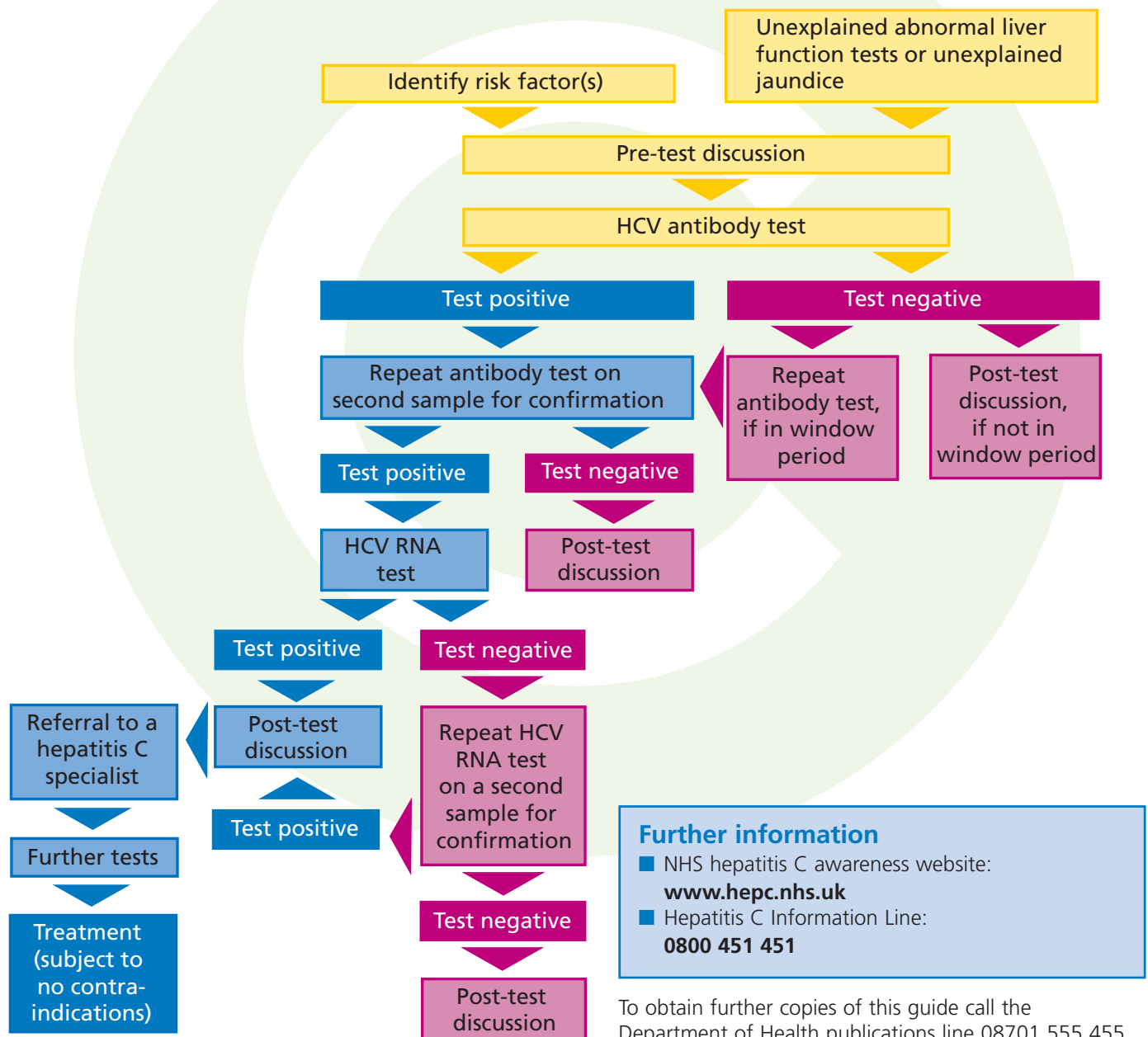
### Treatment for HCV

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.hepc.nhs.uk](http://www.hepc.nhs.uk)
- Hepatitis C Information Line: **0800 451 451**

To obtain further copies of this guide call the Department of Health publications line 08701 555 455 or email [dh@prolog.uk.com](mailto:dh@prolog.uk.com) quoting publication number 280160.



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