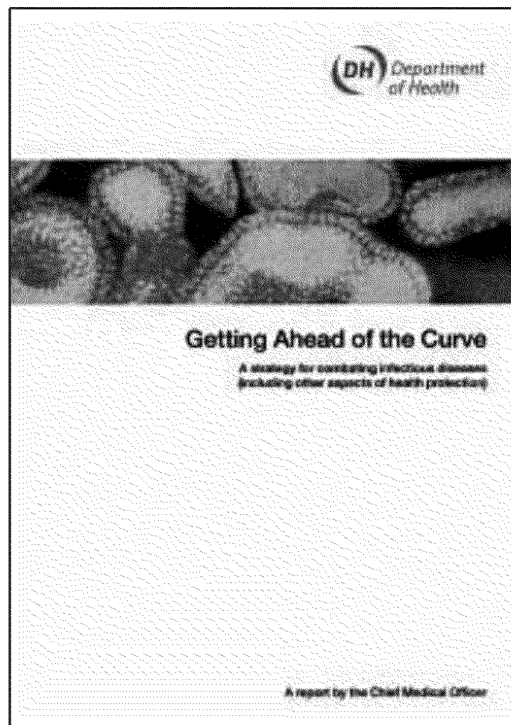


*Hepatitis C
Strategy for England*

August 2002

Implementing 'Getting Ahead of the Curve': action on blood-borne viruses



Hepatitis C Strategy for England

Contents

Foreword		3
Summary		5
Chapter 1	Context and relationship to other programmes and strategies	7
	• Relationship to the <i>NHS Plan</i> and <i>Shifting the Balance of Power</i>	7
	• Relationship to other public health strategies	8
Chapter 2	Hepatitis C – a cause for concern	9
	• Introduction	9
	• Hepatitis C infection, the disease and how it is spread	10
	The disease	10
	How it is spread	11
	• Extent of hepatitis C virus infection in England	11
	In low risk populations	11
	In high risk populations	12
	Burden of hepatitis C infection	13
	Modelling the disease burden due to hepatitis C	13
	• Surveillance – information for action	13
	• National standard and outcome indicators	14
	• Consultation questions	15
Chapter 3	Improving prevention	16
	• Introduction	16
	• Prevention of infection in injecting drug users	17
	Building on prevention that works	17
	People at risk of starting to inject	17
	Drugs education in schools	17
	Preventing infection in current injectors	18
	Needle exchange and harm reduction services	18
	A new harm reduction message	19
	Health promotion/peer education/outreach	19
	The role of health professionals	20
	Hepatitis B immunisation	21
	Treatment of drug misuse and dependency in parallel with prevention	21
	Monitoring prevention activities and National Outcome Indicators	22
	• Skin piercing	22
	• Key principles of prevention in prisons	23
	Raising professional awareness	23
	Education of prisoners	23
	Treatment for drug dependence in prison	24
	Harm minimisation	24
	Hepatitis B immunisation	24
	Partnership with the NHS	24

	• Prevention in health care settings	25
	Safety of blood, blood products, tissues, organs and cells	25
	Infection control in the health care setting	26
	Health care workers infected with hepatitis C	26
	• Sexual partners	27
	• Mother to baby	27
	• Raising awareness of hepatitis C in the general population	27
	• Consultation questions	28
Chapter 4	Improving services for people with hepatitis C	30
	• Access to health care – testing for hepatitis C	30
	• The managed clinical network for hepatitis C infected people	31
	• A specialist service for hepatitis C	33
	Components of the service	33
	Structure/organisation	33
	Management of children with hepatitis C	34
	Provision of health care within a specialist unit	35
	• Guidelines on clinical management	35
	• Complementary and alternative medicine	36
	• Social care and support for those living with and affected by hepatitis C	36
	Children and families affected by hepatitis C	37
	• Commissioning services	37
	• Consultation questions	38
Chapter 5	Actions to support change	39
	• Improving surveillance	39
	• Continuing professional training and development	40
	• Raising awareness amongst those at higher risk of hepatitis C and in the general population	40
	• Improving services for hepatitis C – scoping existing clinical networks	41
	• Equipping the professional workforce to care for people with hepatitis C	41
	• Research	42
	• Consultation questions	43
Annexes		
	• Annex 1 Hepatitis C Strategy Steering Group	44
	• Annex 2 The consultation criteria	46

Foreword

Hepatitis C has emerged over recent years as a world-wide public health problem. Although there is a relatively low prevalence of infection in this country, hepatitis C represents a major challenge in absolute numbers of people infected, the majority of whom are undiagnosed.

A lot has already been done. For example, measures to reduce the risk of blood-borne virus transmission via blood and blood products and via injecting drug use have made important inroads into tackling the problem. However, current injecting drug users remain at greatest risk of infection in this country and intensified health promotion activities are necessary to discourage people from injecting, to help current injectors to stop injecting, to minimise harm among those unable to stop and to discourage them from initiating others into injecting.

With increasingly effective antiviral drug therapy available, professional and public awareness of hepatitis C needs to be improved. This will enable those who may have been at risk of infection to come forward for testing, so that if they are found to be infected they can be referred for specialist assessment. Managed clinical networks will need to be developed across the country so that co-ordinated, high quality services are provided.

This strategy has been developed with experts and key stakeholders in line with the principles set out in the *NHS Plan*. It sets out proposals to improve the effectiveness of prevention, diagnosis and treatment services for hepatitis C. It is part of the Government's programme to modernise and reform the NHS around the needs of patients and service users, to tackle inequalities and to promote the spread of good practice. It is designed as a framework to assist local commissioners and service providers, working in partnership with local communities, in addressing this important public health challenge.



GRO-C

Hazel Blears MP

Parliamentary Under Secretary of State for Public Health

August 2002

Consultation exercise

- The criteria for all national public consultations are at **Annex 2**.
- We would welcome views on the proposals in this document and the specific consultation questions at the end of Chapters 2–5. Comments should be sent to:

Helen Christmas
Department of Health
Room 631B Skipton House
80 London Road
London SE1 6LH

Email: hcvstrategy@doh.gsi.gov.uk

by **15 November 2002**, at the latest, please.

Summary

In recognition of its public health importance, Sir Liam Donaldson, the Chief Medical Officer, recently highlighted the development of a separate strategy for hepatitis C in his overarching strategy for combating infectious diseases, *Getting Ahead of the Curve*¹.

Hepatitis C is now recognised as an important public health problem world-wide and the World Health Organisation estimates that some 170 million people are chronically infected. In England, the number of people chronically infected with hepatitis C is estimated to be around 200,000, the majority of whom are currently unaware of their infection.

Hepatitis C infection is sometimes referred to as the “hidden epidemic” because symptoms rarely occur at the time of initial infection. About 1 in 5 people recover from infection, but the majority become chronically infected. Chronic infection can lead, over a number of years, to serious liver disease and liver cancer. However, with the advent of new drug therapies, the disease can now be treated successfully in many people.

The hepatitis C strategy has been developed with the assistance of an expert group (see Annex 1) and other key stakeholders. Its main aims are to prevent new cases of hepatitis C infection, identify those who are chronically infected by increasing testing for hepatitis C and to offer specialist advice and appropriate treatment via co-ordinated pathways of patient care.

In England, hepatitis C is currently mainly spread by injecting drug users sharing blood-contaminated equipment. Other less common routes of infection include sexual intercourse, from mother to baby, and by skin piercing and tattooing when sterile equipment is not used. Theoretically, household spread is also possible via the sharing of blood-contaminated toothbrushes and razors. Prior to the introduction of viral inactivation of blood products in 1984, and before 1991 when the screening of blood donors was introduced, some recipients of blood and blood products were inadvertently infected.

As injecting drug users are at high risk of infection, health promotion activities including improving needle exchange services, the provision of harm minimisation information and activities to prevent initiation into injecting should all be strengthened. A National Outcome Indicator which monitors the prevalence of hepatitis C in recent injectors will be used to track improvements in prevention activities for this group.

Treatment for drug dependency has been shown to reduce injecting risk behaviour and a commitment to increasing this has already been set as part of the Government’s 10-year Drugs Strategy. This is also a key aim of the newly established National Treatment Agency for Substance Misuse.

As many injecting drug users pass through prisons, information of hepatitis C should be provided along with harm minimisation messages, in particular to young people entering juvenile and young offenders’ establishments. All schools should have a drugs policy, including an incident management policy and should provide information about the risks of injecting drugs and the risks of blood-borne virus infection with HIV, hepatitis B and hepatitis C.

The strategy proposes health promotion campaigns to raise awareness about hepatitis C amongst the general population and how to avoid infection. These will be designed to encourage those at current risk and those who may have been at risk in the past e.g. by experimenting with injecting drugs only once or twice, to come forward for testing. It is also proposed to provide further information to primary care health professionals in developing their awareness and knowledge of hepatitis C. Good practice guidelines for those working in skin piercing and tattooing establishments are available and these should be promoted and followed, as should infection control guidelines in clinical settings.

As many people are unaware of their infection, the offer of testing should be increased in a range of clinical settings. Injecting drug users are at highest risk of infection and all those attending drug treatment centres should be offered hepatitis C testing routinely as the national standard of good practice. Two outcome indicators will be used to monitor testing. The proportion of those attending drug treatment centres who are aware of their infection should increase, as should the total number of confirmed laboratory reports of hepatitis C infection.

If the infection is diagnosed in the early stages, advice about lifestyle changes such as reduction in alcohol intake can decrease the likelihood of progression to serious liver damage. If antiviral drug therapy is indicated, then the infection can be cleared in a significant proportion of people. There is every indication that this success rate will increase when more effective drugs become available.

To improve health services for those diagnosed, the strategy proposes the development of managed clinical networks and co-ordinated pathways of patient care, with accessible specialist treatment centres across the country. As a first step towards this goal, it is proposed that a scoping study is carried out to identify where such centres are currently operating and to identify good practice. The results of this scoping study should assist local planners and commissioners in service development.

The strategy recognises the need for social care and support for those living with and affected by hepatitis C, which should help retain their quality of life and help them maintain their independence. A range of support services may be needed, and particular care needs to be given to provide appropriate services for children in need.

This strategy will form the basis of an action plan that is being developed as part of *Getting Ahead of the Curve* and will be designed to be delivered within the new NHS framework. The identification and sharing of good practice and the development of local plans to deliver the aims of the hepatitis C strategy will be the key to its success.

Reference

1. Getting Ahead of the Curve: a strategy for combating infectious diseases (including other aspects of health protection). Department of Health 2002

Chapter 1

Context and relationship to other programmes and strategies

Relationship to the *NHS Plan* and *Shifting the Balance of Power*

1. The *NHS Plan* sets out a vision for providing better quality services designed around the needs of patients, which will be delivered by a sustained programme of investment and reform. This national strategy for hepatitis C is underpinned by the *NHS Plan's* values and principles. It is aimed at improving services for preventing hepatitis C infection and providing better quality and patient-centred care for people with hepatitis C.

The strategy will do this by:

- ***Keeping people healthy and reducing health inequalities*** – the strategy should help NHS staff to offer preventive and health promotion advice to those who may be at risk of getting hepatitis C infection or to those who already have it. Backed up by national information campaigns, this will in turn enable people to look after themselves, where appropriate.
 - ***Shaping services around patients, their families and carers*** – the strategy underlines the need for services to be responsive to those using them and to involve them in planning future developments.
 - ***Working with others*** – improvements in services will require partnership at all levels, including between health and social care agencies, central Government, prisons, the voluntary and community sector, patients and citizens.
 - ***Providing a comprehensive service*** – services for people with hepatitis C may not always be well co-ordinated and may not offer the necessary support in coping with what can be a serious and life-threatening disease. The strategy proposes how services can be provided more effectively.
 - ***Responding to the different needs of different populations*** – the strategy recognises that services should be responsive to the needs of different populations at risk of or affected by hepatitis C.
 - ***Continuously improving services*** – the effectiveness of the measures proposed in the strategy will be evaluated by better epidemiological surveillance. The development of better services will be supported by professional education, training, information and research.
2. Earlier this year, in a radical restructuring of the NHS known as *Shifting the Balance of Power*, power and resources in the NHS were decentralised and devolved to Primary Care Trusts (PCTs) to ensure better delivery of health care to patients. The hepatitis C strategy has been developed for implementation in this new world. It concentrates on what needs to be done to improve services, with examples of good practice, rather than setting detailed prescriptive requirements on how it should be done. In line with these principles, the strategy does not impose national targets.

Relationship to other public health strategies

3. *Saving Lives: Our Healthier Nation*, the comprehensive Government-wide public health strategy for England, has the twin goals of improving health and reducing the health gap (health inequalities). The national strategy for hepatitis C shares these goals and is one of a series of strategies that is complementary to *Saving Lives: Our Healthier Nation*. It is also relevant to action proposed to tackle cancer, as chronic hepatitis C infection may cause primary liver cancer in some cases.
4. One of the main aims of the Government's 10-year strategy for tackling drug misuse, *Tackling Drugs to Build a Better Britain*, is to enable people with drug problems to overcome them and live healthy and crime-free lives. Hepatitis C presents a significant health risk for injecting drug users and the national strategy for hepatitis C sets out action needed to strengthen prevention activities in this area and to identify injecting drug users already infected with hepatitis C.
5. The Chief Medical Officer's strategy for infectious diseases, *Getting Ahead of the Curve*, has identified the need to intensify measures to control serious infectious disease problems, including hepatitis B and hepatitis C. The national strategy will form the basis of the action proposed for hepatitis C and will be an important component of the blood-borne virus action plan. This action plan will link to relevant action being taken as a result of *The National Strategy for Sexual Health and HIV*.

Chapter 2

Hepatitis C – a cause for concern

Key messages

- *Hepatitis C infection is an important public health problem. It is estimated that around 200,000 people in England are chronically infected with hepatitis C, the majority of whom are unaware of their infection*
- *In developed countries, transmission is now **mainly** by injecting drug users sharing blood-contaminated equipment*
- *Other less efficient routes of transmission include sexual intercourse and from mother to baby*
- *Initially infection often occurs without symptoms. 1 in 5 people recover and the rest become chronically infected*
- *Chronic infection can lead to severe liver disease and liver cancer, but moderate to severe disease can be treated successfully in at least 50% of people*
- *Surveillance of hepatitis C infections and especially chronic disease will be improved*
- *Professional and public awareness-raising about hepatitis C will be increased to help in encouraging people at risk to seek testing*
- *A routine offer of a hepatitis C test to all injecting drug users attending drug treatment centres should be the national standard of good practice*
- *Increase in testing will be tracked using two outcome indicators*

Introduction

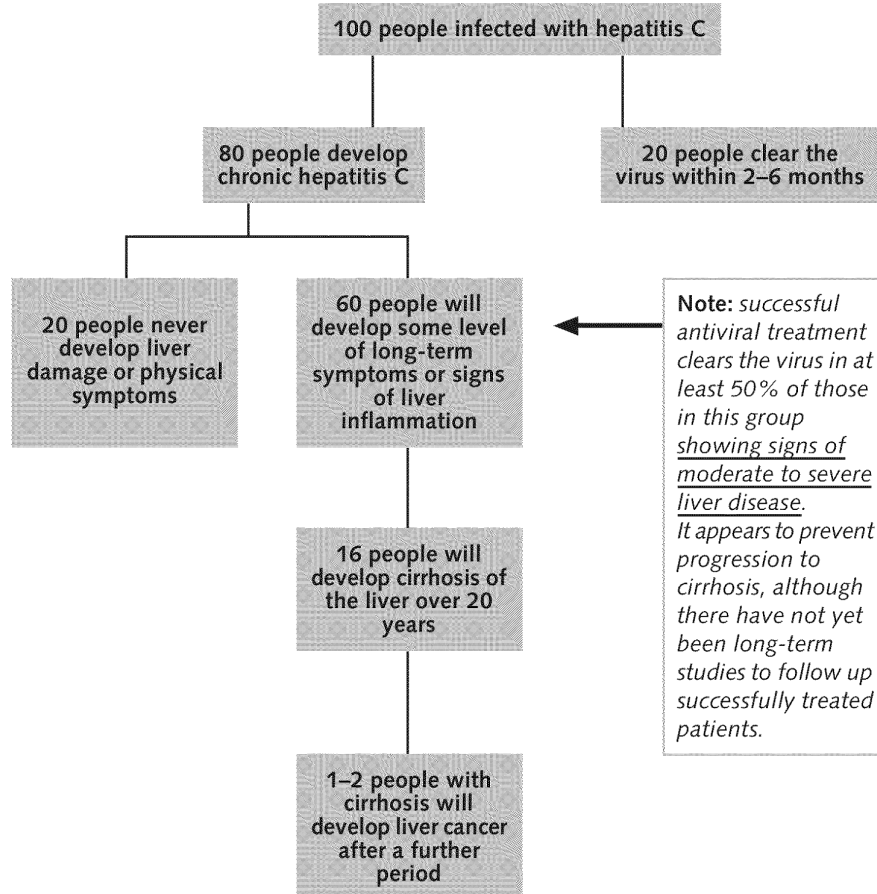
1. The hepatitis C virus, which was only identified in 1989, is now a global public health problem. The World Health Organisation has estimated that around 3% of the world population have been infected. This means there are more than 170 million chronic carriers of the virus world-wide.
2. The prevalence of the virus varies around the world and estimates of those who have been infected include around 1.8% of people in the United States and around 1% of people in France. Other countries in the Middle East, Asia and Africa have much higher prevalences. In comparison, England is a low prevalence country. Although there is no study of the prevalence of hepatitis C in the general population in this country, information on the overall prevalence of infection can be derived from studies of low risk populations. These studies suggest that 0.5% of the general population in England has been infected with hepatitis C.

Hepatitis C infection, the disease and how it is spread

The disease

3. The hepatitis C virus is an RNA virus and there are six genotypes based upon differences in molecular structure. The incubation period of acute hepatitis C is commonly between 6 to 9 weeks, with specific antibody usually present by 3 months.
4. The vast majority of people suffer no symptoms when they become infected and for this reason there is only scant information about the occurrence of new infections (incidence). About 80% of people who acquire the infection become chronically infected. The rest appear to clear the infection spontaneously. **Figure 1** illustrates an example of the estimated overall progression of hepatitis C infection.
5. Some people who are chronically infected will live out their normal life-span, others only develop symptoms of chronic liver disease many years after initial infection. Around 20% of chronically infected people may develop serious liver disease such as cirrhosis after 20 years, of whom 1–4% per year will develop liver cancer.
6. Certain factors are associated with more rapid progression to severe liver disease. These are: being over 40 years old at infection, alcohol consumption and male gender. However, there are many unanswered questions about the natural history of hepatitis C infection and further work needs to be done. In particular, the natural history and clinical significance of hepatitis C in children is variable and poorly defined (see Chapter 5, Actions to support change).

Figure 1: An example of the estimated overall progression of hepatitis C infection



How it is spread

7. Currently, the greatest risk of acquiring hepatitis C in this country is through the sharing of blood-contaminated needles and injecting equipment among injecting drug users. Around 90% of reports of hepatitis C infection to the Public Health Laboratory Service, in which risk factors have been reported, are related to current or previous injecting drug use, see **Table 1**.
8. Mother to baby transmission occurs at about a rate of 6%. This may be greater in highly infectious mothers and in those who are also infected with HIV². Transmission of infection most probably occurs around the time of delivery; breast feeding is currently thought not to play a role in transmission.
9. Other less common routes include in the health care setting, for example, when needlestick/sharps injuries occur or when infection control procedures are not observed. Tattooing and other forms of skin piercing, as well as sharing of toothbrushes and razors, are potential routes of transmission. Antibody to hepatitis C is detected in around 5% of regular sexual partners of infected individuals.
10. Before screening of blood donations for hepatitis C was introduced in 1991, some blood recipients were inadvertently infected. Viral inactivation of blood products for HIV, introduced in 1984, also inactivated hepatitis C, but prior to this inadvertent infections by this route also occurred. The comprehensive measures now in place mean that the chances of being infected with hepatitis C through blood transfusion are extremely low³.

Table 1: Transmission of hepatitis C – laboratory reports of infection

Risk factor (where reported)	Percentage
Injecting drug use	92.3%
Blood product recipient	1.0%
Transfusion	1.4%
Sexual exposure	1.5%
Renal failure	0.5%
Vertical household (mother to baby)	0.9%
Other known	2.4%
Total	100%

Source: Public Health Laboratory Service

Extent of hepatitis C virus infection in England

In low risk populations

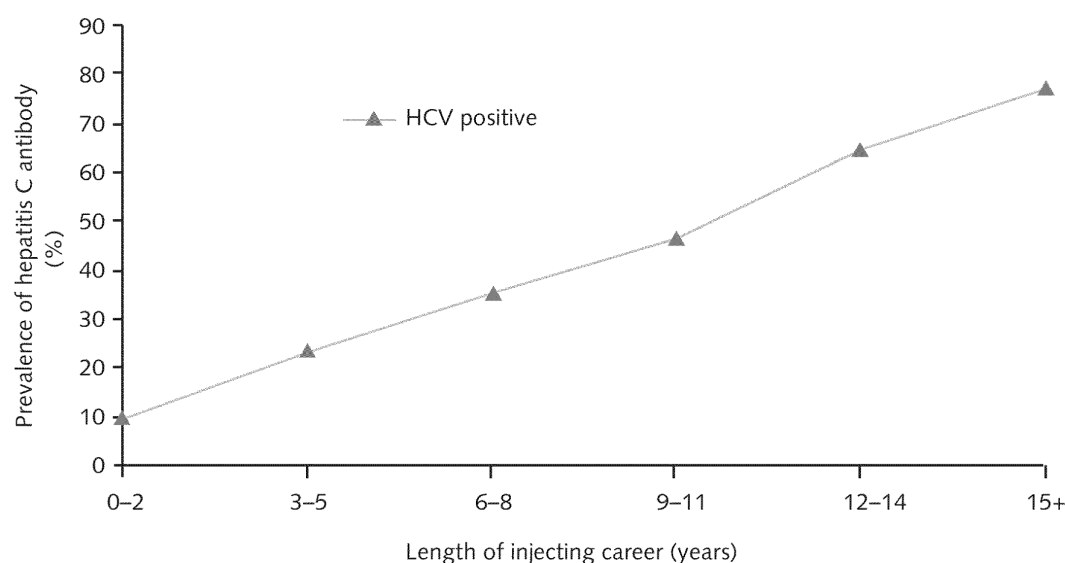
11. The largest studies of antibody prevalence in low risk populations have been conducted amongst antenatal women. As pregnant women are generally healthy and at low risk of exposure to hepatitis C infection, the prevalence in antenatal women is expected to be lower than the general population. In a study of over 40,000 specimens, the prevalence was found to be 0.4% in London and 0.2% in the Northern & Yorkshire region⁴. These results are similar to another large study in North Thames in which a prevalence of 0.4% and 0.2% was seen in inner London and outer London districts respectively⁵. Two smaller studies in single centres found prevalence rates of 0.1% in the West Midlands and 0.8% in inner London.

12. Sera from residual specimens from adult patients submitted to 17 laboratories in England and Wales were tested for antibody to hepatitis C virus in an attempt to assess prevalence in an unselected population. As these specimens are generally obtained for clinical purposes, the prevalence of infection is expected to be higher in this group than in healthy individuals. The overall prevalence in 1996 was 0.7%. Prevalence was higher in males compared to females and in London compared to outside of London.

In high risk populations

13. Injecting drug use is known to be the most important risk, for acquiring hepatitis C infection. In a recent large study of 3,000 current injecting drug users, recruited from both the community and from treatment agencies, the prevalence of antibody to hepatitis C was 30%⁶. Prevalence was highest in London and in those who had injected for longer (see **Figure 2**). Hepatitis C prevalence is lower among injecting drug users in England than in many other countries.
14. The low prevalence and incidence may reflect current patterns of risk behaviour and the effectiveness of current prevention activities. Although there is insufficient information available to monitor changes in such risk behaviour, it is clear that the provision of needle exchange schemes will continue to play a key role in reducing transmission (see Chapter 3, Improving prevention).
15. In a study of the prevalence of blood-borne viruses in prisoners, 29% of women, 24% of men and 4% of young offenders reported injecting drugs at some time in their lives. Nearly a third of men who had ever injected drugs had done so in prison, and three quarters of those who injected in prison reported sharing needles and syringes while in prison. In this study, the prevalence of antibody to hepatitis C was found to be around 10% in both men and women and 0.6% in young offenders⁷.

Figure 2: Prevalence of antibody to hepatitis C amongst injecting drug users by length of injecting career



Source: Public Health Laboratory Service

16. Information on the overall prevalence of infection, derived from studies of low-risk and unselected populations, suggest that around 0.5% of the English population has antibody to hepatitis C virus. As around 20% of infected individuals would be expected to clear the infection, this suggests that around 0.4% of the population is chronically infected, i.e. 200,000 individuals.

Burden of hepatitis C infection

17. Little routine information is available on the current burden of chronic hepatitis C infection in the UK. Routine death statistics suggest that around 100 people die each year from an underlying cause of hepatitis C, but hepatitis C infection also contributes to a proportion of the 5,000 deaths each year from the complications of chronic liver disease, including cirrhosis and hepatocellular carcinoma⁸. Of those people receiving liver transplants in this country, about 15% have hepatitis C.
18. The National Hepatitis C Register is providing valuable information about the natural history of infection in those people whose date of infection is known, mainly in those infected by contaminated blood and blood products⁹. However, better surveillance of chronic disease is needed for estimating the future disease burden (see Chapter 5, Actions to support change).

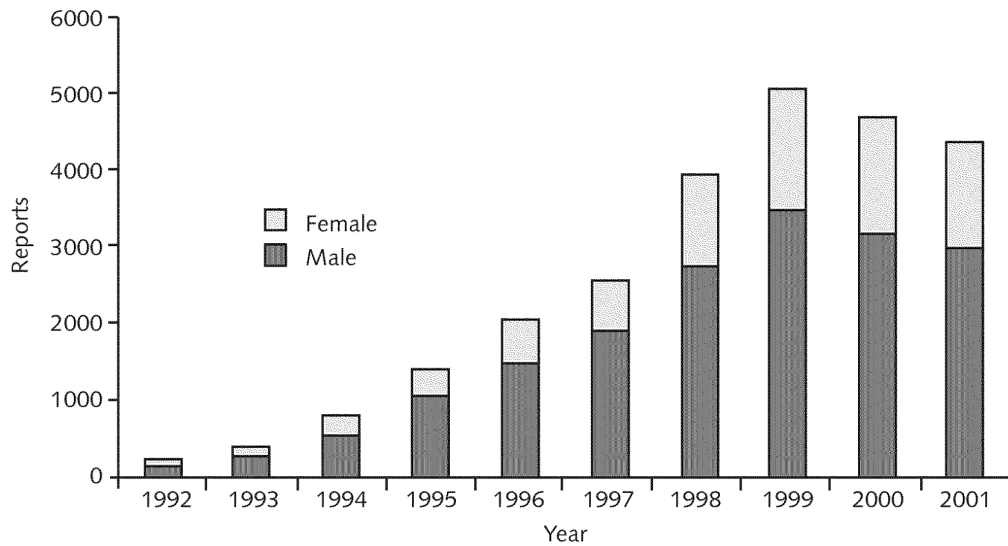
Modelling the disease burden due to hepatitis C

19. Estimation of the numbers of new infections and burden of hepatitis C disease can be facilitated by the use of mathematical modelling. Using existing data sources on hepatitis C transmission, patterns of injecting drug use and rates of progression to liver disease, it may be possible to make preliminary estimates of the current and future disease burden. More accurate data sources will be needed in certain areas to inform the modelling process. The modelling work will inform central and local planning of treatment and care services and prevention activities.

Surveillance – information for action

20. Although “viral hepatitis” is a notifiable disease, the reporting of a confirmed laboratory diagnosis of hepatitis C infection is more complete. Surveillance is essential to inform prevention and control activities and to monitor their effectiveness and impact.
21. Including provisional data up to the end of 2001, a cumulative total of around 26,500 infections have been reported in England to date (**Figure 3**). The majority of reports were in the 25-44 year age group and more than twice as many reports were in males as in females. The cumulative total is around one-tenth of the number of infections estimated from seroprevalence studies. Even with under-reporting taken into account, this suggests that a significant proportion of hepatitis C infections have not been diagnosed.

Figure 3: Laboratory reports of confirmed hepatitis C infections by year and sex, England 1992–2001



Source: Public Health Laboratory Service

22. It is therefore important to increase the proportion of hepatitis C infected individuals who are diagnosed in order for them to benefit from specialist medical assessment and advice about avoidance of alcohol, which may increase the risk of progression to chronic liver disease. Combination drug treatments have been shown to clear the infection in at least 50% of those with moderate to severe liver disease (see Chapter 4, Improving services for people with hepatitis C).
23. It will be necessary to encourage more people in the general population who have been or are at risk of infection to come forward for testing. This will be achieved by increasing awareness about hepatitis C amongst health professionals so that they are more likely to offer testing to appropriate patients. In parallel, awareness raising in the general public will mean that they are more likely to seek testing and/or accept testing when it is offered (see Chapter 3, Improving prevention).

National standard and outcome indicators

24. As injecting drug users are the highest risk group in the country **a national standard of good practice should be that all those attending specialist drug treatment services¹⁰ for their drug addiction are offered hepatitis C testing routinely.**

Monitoring data: how to collect data on the offer/acceptance is being considered by the National Treatment Agency for Substance Misuse (NTA)

25. The routine offer of a test to injecting drug users and health promotion activities to encourage others to seek testing should increase the proportion of people who have their infection diagnosed. This will be reflected in the laboratory reports of hepatitis C infection (see Figure 3).

26. **Two National Outcome Indicators** will be used to track increased testing, both indicators should increase:
- **The proportion of those attending treatment and support agencies for injecting drug users who are aware of their hepatitis C infection**
Monitoring data: Unlinked Anonymous Prevalence Monitoring Programme
 - **The total number of laboratory confirmed hepatitis C infection reports**
Monitoring data: Laboratory reports to the Public Health Laboratory Service
27. In parallel with increasing testing activities, services should be ready to provide advice and specialist assessment for increasing numbers of people with diagnosed hepatitis C infection (see Chapter 4, Improving services for people with hepatitis C).

Consultation questions

Does the national standard of good practice (paragraph 24) seem appropriate and feasible?

Are the National Outcome Indicators (paragraph 26) the right ones and will they allow monitoring at local as well as national level?

References

2. Thomas SL, Newell ML, Peckham CS, Ades AE, Hall AJ. A review of hepatitis C virus vertical transmission: risks of transmission to infants born to mothers with and without HCV viraemia or HIV. *Int J Epidemiol* 1998; 27(1): 108-117
3. Serious Hazards Of Transfusion: Annual Report 2000/2001
4. Balogun MA, Ramsay ME, Parry JV, Donovan L, Andrews NJ, Newham JA, Cliffe S, Harris KA, Teo CG. The prevalence and genetic diversity of hepatitis C infection in antenatal clinic attenders in two regions of England. *Epidemiol Infect* 2000;125(3):705-712
5. Ades AE, Parker S, Walker J, Cubitt WD, Jones R. HCV prevalence in pregnant women in the UK. *Epidemiol Infect* 2000;125(2):399-405
6. Hope VD, Judd A, Hickman M, Lamagni T, Hunter G, Stimson GV, Jones S, Donovan L, Parry JV, Gill ON. Prevalence of hepatitis C among injection drug users in England and Wales: is harm reduction working? *Am J Public Health* 2001;91(1):38-42
7. Unlinked Anonymous Surveys Steering Group – Prevalence of HIV in England and Wales in 1997. London. Department of Health, Public Health Laboratory Service, Institute of Child Health (London) 1998
8. Harris HE, Ramsay ME, Balogun K, Alexander GJ. Trends in deaths from malignant neoplasia of liver are poor indicator of hepatitis C infection. *BMJ* 1999;318:808-809
9. Harris, HE, Ramsay ME, Heptonstall J, Soldan K, Eldridge KP. The HCV National Register: towards informing the natural history of hepatitis C infection in the UK. *J Viral Hepatitis* 2000; 7:420-427
10. Models of Care: A framework for drug misuse treatment. National Treatment Agency/Department of Health 2002

Chapter 3

Improving prevention

Key messages

- *The main aims are to prevent new cases of hepatitis C infection and to reduce the risks of those infected progressing to serious liver disease*
- *Injecting drug users are at high risk of infection, and health promotion activities including needle exchange schemes, harm minimization information and prevention of initiation into injecting should all be strengthened*
- *Treatment for drug dependency should be increased as this reduces injecting risk behaviour*
- *All schools should have a drugs education and incident management policy*
- *A national campaign will be developed to raise public awareness of hepatitis C and provide information about avoiding infection*
- *As many injecting drug users pass through prisons, information about hepatitis C should be provided along with harm minimization messages*
- *Needle exchange services should be monitored*
- *Rates of hepatitis C transmission in injecting drug users who started to inject in the last 3 years will be used as a national outcome indicator of prevention activities*

Introduction

1. The principal way of controlling hepatitis C infection is to prevent exposure to the virus, as there is no likelihood of a vaccine in the near future. Preventing infection avoids subsequent costs to the individual, the NHS and wider society from impact on people's capacity to fulfil their roles in their families and in the workplace.
2. Many of the people now at risk of hepatitis C infection engage in behaviours that attract social disapproval, or are in population groups that are stigmatised e.g. injecting drug users. A climate needs to be created that supports the prevention of hepatitis C, by ensuring that people at risk can receive the information and help that they need without fear of stigma or embarrassment. This requires a positive attitude to affected groups by all those involved in prevention and service delivery.
3. Another aim of prevention is to reduce the risks of those already infected progressing to chronic liver disease. This can be achieved by providing clinical management with antiviral therapy where indicated. There is also an opportunity to inform people with hepatitis C how they can minimise further damage to their liver, such as by limiting alcohol intake, and how they can prevent transmitting infection to others.

Prevention of infection among injecting drug users

Building on prevention that works

4. The UK has helped to lead the world by preventing significant HIV transmission through injecting drug use. This was achieved by the active promotion of information and advice about the risks of sharing injecting equipment, the introduction of needle exchanges in the mid-1980s, outreach work and the expansion of specialist drug treatment services. These prevention measures will also have contributed to our low prevalence of other blood-borne infections like hepatitis C and hepatitis B, compared to some other European countries such as Spain and Italy¹¹.
5. Even so, the prevalence of hepatitis C in this country is higher than that of HIV. This may be due to a number of factors;
 - the virus was already established in the injecting drug user population before the introduction of measures to reduce risk;
 - individuals with chronic hepatitis C may be more infectious than those with HIV; and
 - the virus may be more robust – it may be able to survive longer outside the body, and injecting paraphernalia as well as contaminated needles and syringes may also pose a risk of infection.
6. This may mean that measures that were effective against HIV may not always be adequate to protect against the hepatitis C virus, which appears to be more easily transmitted¹².

People at risk of starting to inject

7. Clear information should be available to those at risk of beginning to inject. This includes young people vulnerable to becoming problem drug users and non-injecting drug users who may start injecting. These groups need to be made aware of the risks of injecting and of sharing injecting equipment.
8. People at risk of beginning to inject are initiated into injecting by existing injecting drug users. The relatively high prevalence of hepatitis C amongst existing injecting drug users puts new injectors at risk if injecting paraphernalia is shared. Awareness of this risk is likely to be low amongst new injectors, many of whom will not be in contact with services connected with their drug use. Therefore a range of innovative measures should be developed to raise their awareness of the risk they run of acquiring hepatitis C infection.

Drugs education in schools

9. Drugs education is a compulsory part of the National Curriculum, with head teachers able to use their discretion about provision for drug education beyond the statutory requirement. All schools should have a drugs education and incident management policy. This policy will be beneficial to the school and should cover: the school's commitment to tackling drug abuse, the aims of the school's programme of drugs education, and what to do if drugs or drug taking are discovered.
10. Currently there is no framework for delivering drugs education to young people above Key Stage 4 (over 16 years) and no specific reference to hepatitis C and injecting drug use in existing drugs education programmes. Information about hepatitis C is likely to be more relevant to those who are no longer within formal education and who are likely to be both socially and educationally excluded. This may require a range of health promotion activities directed at young people, using a variety of methods, that will reach them via non-educational environments, for instance in clubs, pubs, or gyms.

Preventing infection in current injectors

11. Overall, about 60% of injecting drug users are not currently infected, and this rises to 90% of newer injectors. This means that there is a window of opportunity to prevent further infections and existing practices of delivering health promotion need to be enhanced and invigorated. Experience in HIV prevention has shown the importance of outreach, peer education, mobile services and other measures to help change an individual's injecting behaviour, particularly with regard to sharing of injecting equipment.

Needle exchange and harm reduction services

12. Needle exchange services and other services to reduce harm caused to drug users by blood-borne infections are provided through drug services and others such as pharmacies and Accident & Emergency departments. These services have a key role to play in reducing new hepatitis C infections, as they are likely to be in contact with injecting drug users. They are also therefore in indirect contact with new initiates through the person who teaches them to inject. The current scale of needle/syringe distribution and exchange needs to be monitored locally, to be responsive to the changing local drug scene and the consequent need for provision.
13. A new mathematical model being developed at Imperial College, London has provided a preliminary indication of the potential impact of various harm reduction interventions on the transmission of hepatitis C infection among injecting drug users. The model includes assumptions on the number and growth of injectors, the cessation of drug use, the infectiousness and natural history of hepatitis C and the effectiveness of needle and syringe exchange provision on reducing the transmission of hepatitis C. It indicates that a number of measures could have an impact, such as stopping initiation into injecting and ceasing injecting, with the greatest practical impact resulting from improving the provision of needle exchange services. However, the model needs further development before reliable predictions can be made.
14. Information from a survey carried out in 1997 indicated that 98% of health authorities in England reported needle exchanges in their areas³. In 1989 there were 2,000 needle and syringe outlets in the UK distributing over 25 million syringes annually⁴. Latest data from Drug Action Teams in England for 2001/2 indicated that 96% of the reported harm reduction services included needle exchanges. Good national and local area coverage of harm reduction and needle exchange services is provided from the local drug treatment "Pooled Budget" and other health funding. This should be maintained and improved. The NTA Models of Care outlines national guidelines and standards for the commissioning and provision of harm reduction and needle exchange provision by generic services and specialist drug treatment services. Every local Drug Action Team will be required to demonstrate progress in implementing the Models of Care from 2003. Good practice should be spread about the safe disposal of used needles and syringes and an example is given in the box.

Improving practice

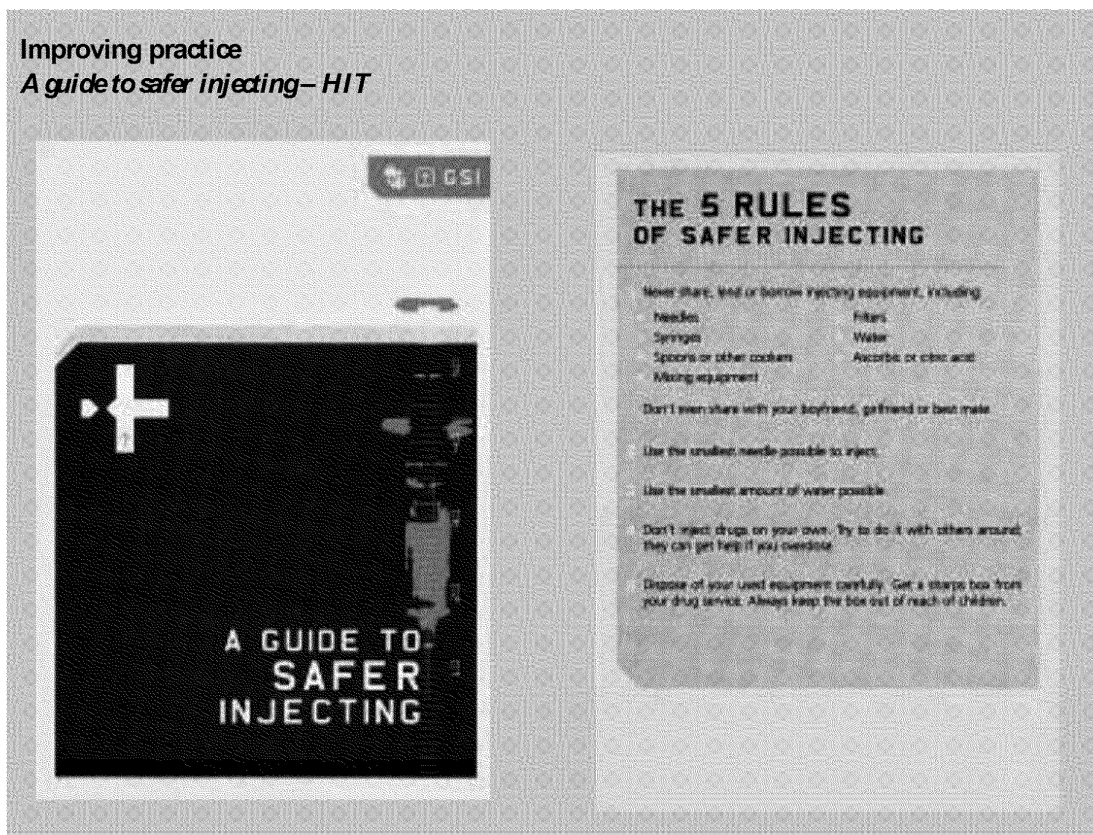
Safe disposal of used needles and syringes

- All needle exchange services should have proactive strategies which engage with communities to increase the rate of safe disposal.
- All Drug Action Teams should consider installing safe disposal bins in areas where injecting paraphernalia is routinely found e.g needle disposal bin in Cambridge Heath BR station, London E2 (partnership arrangement between WAGN railways, Tower Hamlets & AddAction Harm Reduction team).
- Needle exchanges should employ strategies to ensure safe disposal amongst their target group.

15. A system of monitoring the number of needle exchange schemes operating in different geographical locations and their throughput of needles and syringes should be established and this will be taken forward by the NTA (see paragraph 28 and Chapter 5, Actions to support change).

A new harm reduction message

16. Much of the preventive work has focused on encouraging injecting drug users to use sterile syringes and needles and to avoid sharing. This will continue to be a major part of prevention. However, there is some evidence that there is also potential for hepatitis C to be spread via other injecting equipment⁵. Therefore, people who inject drugs must be encouraged to make maximum efforts to ensure that all aspects of the injection process are either sterile or clean and disinfected. This includes cleaning the injection site with alcohol, never sharing any injecting paraphernalia (such as filters, tourniquets, mixing bowls, spoons, stirrers, shared water from a cup), and washing hands before and after injection.



Health promotion/ peer education/ outreach

17. Focused national and local campaigns are needed;
- to cover avoiding injecting, reducing the sharing of injecting equipment;
 - to encourage people to be tested for hepatitis C; and
 - to encourage presenting for treatment.

18. Health promotion campaigns need to highlight that all shared injecting equipment, including paraphernalia, is capable of transmitting hepatitis C and other blood-borne viruses. Where injecting cannot be avoided, information about safe injecting practices should be available.
19. The involvement of drug users in planning these activities should be encouraged, as they have an important contribution to make in tailoring activities for those communities that they are designed to reach. This ties in with a fundamental aim of the *NHS Plan* of working in partnership with communities to reduce inequalities. Drug Action Teams in particular may benefit from the involvement of drug users in local service development, health promotion planning and peer education.
20. Expansion of outreach and peer education services will be particularly useful in delivering health promotion messages directly to injectors, as well as bringing them into contact with services, and the offer of treatment where appropriate. Outreach and peer education approaches should be considered by Drug Action Teams in the commissioning of services as they may engage those most at risk of hepatitis C.

The role of health professionals

21. Guidance for those working with drug users has been produced by the Department of Health⁶. The guidance is based on the assumption that change in behaviour is more likely to be achieved if everyone in contact with injecting drug users has a basis of understanding of hepatitis C. They can ensure users receive consistent and constant messages about the dangers of injecting and sharing of injecting equipment.
22. The guidance is aimed at a wide range of professionals and staff working with drug users. There will be people working in a range of services, such as youth justice, juvenile and young offenders' institutions and children's and young people's services who can play their part. Primary health care teams and general practitioners who see injecting drug users can also contribute. The guidance also emphasises the importance of primary care access and appropriate referral procedures for specialist hepatological advice and treatment.
23. The guidance is aimed as well at those responsible for commissioning drug services, including Drug Action Teams and Joint Commissioning Groups, on the basis that it is a key responsibility of service commissioners to ensure that such service developments happen in a co-ordinated way.

Improving practice

Hepatitis C – guidance for those working with drug users (2001)

The key messages drug to users are:

- Do not start injecting
- If currently injecting then stop
- If unable to stop injecting then reduce harm
- Use safer injecting practices (this includes paraphernalia)
- Avoid initiating others (or as a minimum provide them with harm reduction advice)
- Use needle exchange schemes

Key messages for those already infected with hepatitis C

- Avoid re-infection
- Get vaccinated against hepatitis B
- Reduce alcohol intake

Hepatitis B immunisation

24. Hepatitis B is a co-factor for progression of hepatitis C disease. Reduction in the incidence of hepatitis B should reduce the numbers with hepatitis C progressing to severe liver disease. Targeted hepatitis B vaccination for injecting drug users is important. All Drug Action Teams should have in place arrangements for ensuring provision of hepatitis B immunisation programmes for injecting drug users.

Treatment of drug misuse and dependency in parallel with prevention

Oral drug substitution treatments

25. An overall positive effect of drug treatment services (including oral methadone treatments) has been established across a range of health and social factors including stabilisation of lifestyle¹⁷. Evidence for the effectiveness of oral methadone (and more recently buprenorphine) treatment and maintenance programmes in reducing the risk of hepatitis C infection is well documented¹⁸ and is based on the success of such treatments in reducing injecting and sharing behaviour (see box).

Improving practice

Treatment and the reduction of injecting risk behaviour

The majority of clients in the recent National Treatment Outcome Research Study (NTORS)¹⁹ had used drugs intravenously prior to treatment. Almost a quarter of the drug injectors reported sharing injecting equipment in the three months before entering their NTORS treatment episode. Rates of injecting and of sharing equipment were all substantially reduced one year after treatment entry and remained low throughout the five-year follow-up period. The rate of injecting fell from 60% at intake to 37% at 4–5 years. The rate of sharing fell from 14% to 5%. These reductions were found among drug users admitted to both the community methadone treatment and the residential treatment programmes.

26. The Government set the following target as part of the Drugs Strategy in the light of the success of treatment for drug dependency in reducing a range of harmful consequences of drug use (including injecting risk behaviour).

To increase participation of problem drug misusers in drug treatment programmes by 55% by 2004 and by 100% by 2008, and increase year on year the proportion of users successfully sustaining or completing treatment programmes.

The key aims of the NTA (see www.nta.nhs.uk) include:

- increasing the availability, quality and capacity of drug treatment in England;
- ensuring that treatment genuinely improves the lives of drug users and the community in a cost-effective manner;
- ensuring that commissioners and providers of drug treatment services meet the needs of the whole community, not just those that traditionally access services.

Other treatments

27. Psychosocial interventions with or without substitution therapies have a role to play in maintaining patients in treatment and preventing a return to a drug injecting lifestyle. Clinical information, such as advising on the harm caused by excessive use of alcohol among drug users, is particularly important in relation to hepatitis C infection.

Monitoring prevention activities and National Outcome Indicators

28. Decreasing transmission of hepatitis C in injecting drug users will be dependent on a range of prevention activities. Needle exchange activities will have a key role to play. **The NTA will be considering a means to monitor this activity** e.g. number of needles exchanged. PCTs should continue to include needle exchange facilities as part of their range of harm reduction services.
29. Tracking a reduction in new (incident) infections in injecting drug users would be an ideal means of measuring the effect of improvements in prevention of hepatitis C infection. However, as incident infections usually pass unnoticed, a reduction in the prevalence of hepatitis C in “recent injectors” is proposed as a proxy.

The **National Outcome Indicator** is therefore:

- **A reduction in the prevalence of hepatitis C in injecting drug users who started to inject in the last 3 years (recent injectors)**

Monitoring data: Unlinked Anonymous Prevalence Monitoring Programme

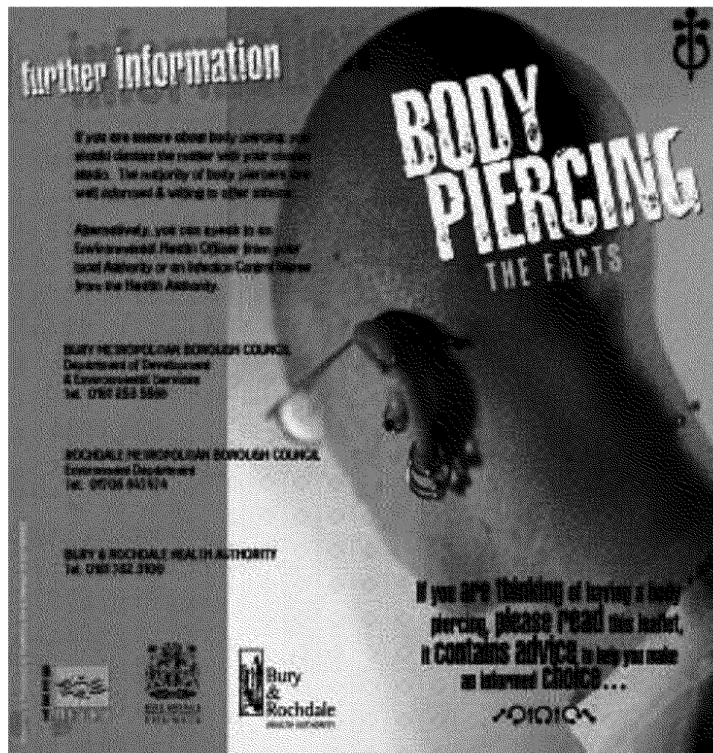
Skin piercing

30. Local authorities have specific powers to regulate the hygiene and cleanliness of acupuncture, ear piercing, electrolysis and tattooing businesses. Only local authorities in London currently have specific powers to regulate businesses providing cosmetic body piercing (i.e. piercing of parts of the body other than the ear), semi-permanent make-up (or micropigmentation) and temporary tattooing. Local authorities can also use enforcement powers under health and safety at work legislation for these businesses. The Government plans to bring in similar legislation for outside London when Parliamentary time allows.
31. Many, and perhaps most, cosmetic body piercing businesses also carry out tattooing or ear piercing, which local authorities outside London do have powers to regulate. Local authorities, therefore, have the opportunity to work with businesses also offering cosmetic body piercing to promote safe and hygienic practices.
32. Local authorities are increasingly introducing good practice guidelines and, in some areas, voluntary registration schemes for cosmetic body piercing businesses. They are also advising the public of potential health risks and how to choose a reputable business. The Health and Safety Executive has recently published guidance for local authorities on health and safety issues related to skin piercing²⁰.

Improving practice

Body piercing

Bury & Rochdale Health Authority and Bury and Rochdale Metropolitan Borough Councils have developed good practice guidelines for body piercing businesses and produced a leaflet for potential clients to help them make an informed decision.



Key principles of prevention in prisons

33. Surveys of prisoners have shown very high rates of drug use and dependence before imprisonment. Among remand prisoners, both men and women, some 50% reported some drug dependency in the year before imprisonment and more than 40% in sentenced prisoners³¹.
34. Many injecting drug users pass through prison and need access to the same services and the same harm minimisation and prevention activities that are available in the community setting. If prisoners feel supported and trust the principles of the organisation, this will result in better compliance with the system as a whole.

Raising professional awareness

35. Information about the natural history, epidemiology, prevention and treatment for hepatitis C was made available to all prison medical officers in 1996. The Prison Service has an ongoing commitment to maintain high levels of expertise and awareness of the issues around prevention of blood-borne viruses amongst all prison staff. The Department of Health guidance documents *Hepatitis C – guidance for those working with drug users (2001)*⁶ and *Hepatitis C: essential information for professionals (2002)*²² were also distributed to the prison sector.

Education of prisoners

36. The integrated counselling, assessment, referral, advice and throughcare service (CARATs) is available in all establishments. This service provides information about the risks of drug use, especially injecting, and the risk of infection with blood-borne viruses including hepatitis C. CARATs also provides advice on harm minimisation and advice if drug use will continue on return to the community. CARATs will also make prisoners aware of other transmission routes, including tattooing and body piercing, fighting between men where there is trauma and blood-to-blood contact, and the sharing of toothbrushes or razors.

37. As at least 10,000 young people aged 15-21 years are in prison on a daily basis. This provides an excellent opportunity for targeted health education, aimed at prevention of using drugs and harm minimisation.

The national standard of good practice for all prisons and their local PCTs should be that health promotion information about avoiding hepatitis C and other blood-borne viruses and the risks of injecting drugs is provided to all young people entering juvenile and young offenders' establishments

Monitoring data: arrangements will be put in place by the Prison Service

Treatment for drug dependence in prison

38. The Prison Service's drugs strategy aims to offer support and treatment to any prisoner with a drug problem through an equitable distribution of basic and enhanced/specialist services. Its key components are treatment, reduction of supply and education. All remand centres and local prisons provide detoxification services. A range of rehabilitation programmes are provided across the Prison Service estate for women, young offenders and adult males. These programmes target prisoners with the most severe drug misuse and related offending behaviour.
39. Clinical management of opiate misusers aims to provide effective evidence-based management⁸. The provision of oral methadone therapy is proven to reduce the amount of injecting and risk behaviour. However, there is currently a lack of uniformity in its provision in prisons and this may lead to increased illicit drug use. Prison guidelines for maintenance prescribing include those on remand or with a short sentence and for pregnant women. The Prison Service will examine the provision of methadone substitution treatment programmes, including the commencement of prisoners into treatment.

Harm minimisation

40. The effects of physical and chemical agents on hepatitis C have not been studied extensively, but it is likely the virus is susceptible to the same physical or chemical agents as hepatitis B, which is inactivated by several moderately potent disinfectants including sodium hypochlorite (500ppm free chlorine). In order to reduce the transmission of blood-borne viruses, a pilot study was undertaken of making such disinfectants available in tablet form so that those prisoners who continued to inject drugs could clean their equipment between uses. A project is now underway to make such tablets available at all establishments.
41. A small number of needle exchange schemes have been initiated in prisons across Europe. The schemes themselves do not appear to cause operational problems or breach safety or security in the prisons themselves. As a result, the Prison Service will continue to monitor developments with regard to needle exchanges in custodial systems throughout the world and keep its own strategy under review.

Hepatitis B immunisation

42. The Prison Health Policy Unit is undertaking a programme to offer a super-accelerated vaccination programme (0, 7 and 21 days) to prisoners, especially those in high risks groups, young offenders and prisoners on remand. The programme will run for three years and will be fully evaluated.

Partnership with the NHS

43. Since 1999, a formal NHS/Prison Service partnership has been working to secure better health services in prisons. All prisons have been working with their local Health Authorities and latterly PCTs to conduct joint health needs assessments for the local prison population and to formulate improvement plans.

44. All prisoners should have access to clinical investigation, NHS treatment and care for hepatitis B and C and HIV infections. Responsibility for funding combination drug treatment for hepatitis C infection should fall to the PCT of residence of the prisoner, in the same way as funding for HIV combination drug treatments. Hepatitis C health services for prisoners include pre and post-test discussion, and the provision of psychosocial support. Those testing positive should be referred to local NHS specialist services who will also manage those prisoners who are currently undergoing treatment or monitoring.
45. Local public health departments throughout England will be requested to report to Government on the adequacy of local prison policies to reduce blood-borne virus transmission. For each prison there should be a report on the viability of methadone maintenance treatment and other actions to reduce the spread of blood-borne virus infections. Each prison should also be required to report to the Prison Health Policy Unit as part of monthly monitoring returns on the percentage of prisoners with hepatitis C attending specialist services for the assessment and treatment of hepatitis C.

Prevention in health care settings

Safety of blood, blood products, tissues, organs and cells

Safety of transfused blood

46. The National Blood Service takes a wide range of measures to secure the safety of blood and blood products. The UK Blood Transfusion Services and the National Institute of Biological Standards and Control prepare detailed professional guidelines for the UK²³. These are used as the authoritative source of rules on safety. The guidelines require blood centres to:
 - *screen donors*: to ensure that the potential donor is in good health to identify any medical conditions or risk factors that might lead to the transmission of disease. For example, people with hepatitis C and injecting drug users are permanently excluded from giving blood;
 - *test donated blood* for HIV, hepatitis B & C and syphilis. Currently all blood donations are screened for hepatitis C using Nucleic Acid Amplification Technology testing. This enables signs of the infection to be picked up much earlier than with serological screening.
47. Plasma collected for the manufacture of blood products goes through a similar series of checks to ensure safety:
 - donors are screened for viruses, including hepatitis C, each time they donate;
 - plasma is not released until the donor returns to give blood and is screened for a second time. This reduces the risk of plasma being donated during the window period when viruses such as hepatitis C cannot be detected through screening;
 - the products themselves are virally inactivated.

The comprehensive measures now in place mean that the chances of being infected with hepatitis C through blood are extremely low.

Organs and tissues for transplantation

48. Updated guidance on the microbiological safety of human tissues, organs and cells used in transplantation was issued by the Advisory Committee on Microbiological Safety of Blood and Tissues for Transplantation (MSBT) in August 2000²⁴. This includes the microbiological testing of all donors for hepatitis C.

Infection control in the health care setting

49. In the health care setting, possible ways for the spread of hepatitis C are from patient to patient due to a failure of infection control procedures, through occupational exposure of health care workers to the blood of infected patients, and from infected health care workers to patients.

Person to person transmission

50. Person to person transmission of hepatitis C via contaminated equipment has occurred when there has been a breakdown of infection control procedures, such as with the use of multidose vials, following colonoscopy and via anaesthetic equipment. Transmissions have also been reported among patients in renal dialysis units.

Infection control

51. The key to preventing transmission of hepatitis C in clinical settings is the strict observance of infection control measures which treat all blood, body fluids and body tissues from all patients as potentially infectious at all times. The Department of Health has issued guidelines for preventing hospital-acquired infections²⁵, and is funding regional workshops for health care workers to help facilitate their implementation. The guidelines include standard principles on infection control precautions which cover advice about the safe handling and disposal of sharps. The Department of Health has also issued more specific advice about decontamination and sterilisation of instruments²⁶ and will shortly be issuing good practice guidelines for the prevention and control of blood-borne virus infection in renal dialysis units²⁷.

Occupational exposure

52. Health care and laboratory workers remain at risk of occupational exposure to the blood of infected patients. The risk of transmission following a single percutaneous exposure from a hepatitis C antibody positive source is probably between 1.2 and 3.0%. It is important that health care workers (e.g. surgeons and paramedics) and other workers in high risk situations (e.g. prison officers), report all occupational exposures to blood to their occupational health departments or GP and that these are followed up appropriately. Any exposed health care workers who acquire markers of hepatitis C infection during the follow up period should be referred promptly to a specialist for further advice. The Public Health Laboratory Service has published guidance on the management of occupational exposure to hepatitis C²⁸ and carries out surveillance of occupational exposure to blood-borne viruses to help inform national and local prevention initiatives.
53. It is important to minimise the risks of occupational exposure as far as possible. Staff should be fully trained in the safe handling and disposal of sharps. The Department of Health has issued guidance for clinical health care workers on protection against occupational infection with blood-borne viruses²⁹ and the Department of Health and the Health and Safety Executive have also issued general advice from the Advisory Committee on Dangerous Pathogens about protection against occupational exposure to HIV and viral hepatitis in the workplace³⁰.

Health care workers infected with hepatitis C

54. Recently a small number of incidents have been reported in which health care workers infected with hepatitis C have been associated with transmission of infection to patients during surgery. The Department of Health has recently published guidelines on the management of hepatitis C infected health care workers³¹. These guidelines recommend that health care workers currently infected with hepatitis C should be restricted from carrying out clinical procedures that might pose a risk of infection to patients.

Sexual partners

55. Studies addressing the risk of sexual transmission of hepatitis C have often yielded contradictory results. The divergent findings may partly be explained by confounding non-sexual routes of transmission such as unrecognised or undisclosed exposure via shared needles and syringes or other paraphernalia when injecting drugs, or the sharing of toothbrushes or razors.
56. There is evidence that both homosexual and heterosexual transmission of hepatitis C may occasionally occur. People with hepatitis C should be informed of this and advised to discuss the use of condoms with their regular sexual partners. The sexual partners of those infected should be counselled and offered testing. All people with multiple sexual partners should be advised to use condoms as a protection against sexually transmitted infections.
57. It is important that appropriate information concerning the risk and potential consequences of hepatitis C transmission during sexual intercourse is provided by health professionals. Those infected should be advised to forewarn and practice safer sex with new partners.

Mother to baby

58. Pregnant women who are chronically infected with hepatitis C may transmit their infection to their infants at or around the time of birth. The risk of transmission of hepatitis C to infants born to infected mothers has been estimated at between 5–6%. Transmission appears to be largely restricted to women who have hepatitis C viraemia during pregnancy or delivery and mainly in women with high levels of virus.
59. In mothers who are co-infected with HIV, the rate of transmission of hepatitis C to their infants can be increased by three times to 14–17%. However, significant differences are found in transmission rates even after allowing for co-infection and viraemia. Internationally co-ordinated research is needed to investigate the reasons for these differences, with a view to determining measures to reduce the risk of transmission.
60. Although hepatitis C has been isolated from breast milk, the role of breast feeding in mother to infant transmission is unclear and a number of studies have recorded no significant differences in transmission rates between breast-fed and bottle-fed infants.
61. Unlike HIV, there are currently no drugs that can be offered to reduce the risk of mother to infant transmission of hepatitis C. In the absence of a proven safe and effective intervention to prevent infant infection and limited evidence about the treatment of children infected with hepatitis C, antenatal screening for hepatitis C is not currently recommended. This is in line with European and US consensus statements. Antenatal settings might, however, provide an opportunity for offering testing to women at increased risk of hepatitis C infection.

Raising awareness of hepatitis C in the general population

62. In order to encourage those people in the general population that might have been at risk of contracting hepatitis C in the past, for instance as a result of sporadic injecting drug use many years previously, there should be a hepatitis C awareness raising campaign. The type of campaign and approach should be carefully designed not to be alarmist and to target particularly those groups that may need to come forward for testing and advice. In identifying those who may be chronically infected but without symptoms, it will be possible to provide lifestyle advice i.e. decreasing alcohol intake which, if followed, would significantly delay the progression to chronic liver disease.

63. An additional advantage of raising awareness in the general population is that this should help to destigmatise the disease for those people who are living with hepatitis C.
64. Hepatitis C infection is a global public health problem. There is no vaccine to protect international travellers against hepatitis C infection. Therefore it is important that travellers are aware of hepatitis C infection and how it is transmitted. Taking precautions to prevent hepatitis C infection will also reduce the risk of acquiring HIV and hepatitis B infection, given their similar routes of transmission, and also reduce the risk of sexually transmitted infection and unplanned pregnancy. The need for more explicit information about how to avoid hepatitis C infection when travelling abroad will be explored.

Consultation questions

Are the measures proposed to improve prevention in injecting drug users likely to be effective?

Is a national campaign to raise public awareness of hepatitis C necessary? If so, what are likely to be the most effective means of doing this?

Is the National Outcome Indicator (paragraph 29) appropriate and will it allow monitoring at local as well as national level?

Is the action taking place and proposed for prisons, including the national standard (paragraph 37), likely to make an impact?

Are there any major gaps in prevention not identified in this chapter?

How should the actions identified in the chapter be prioritised?

References

11. European Monitoring Centre for Drugs and Drug Addiction. Annual report on the state of the drugs problem in the European Union 2001. Luxembourg 2002
12. Goldberg D, Cameron S, McMenamin J. Hepatitis C virus antibody prevalence among injecting drug users in Glasgow has fallen but remains high. *Commun Dis Public Health* 1998; 1(2):95–7
13. Parsons J, Hickman M, Turnbull P, McSweeney T, Stimson GV, Judd A, Roberts K. Over a decade of syringe exchange: results from 1997 UK survey. *Addiction* 2002; 97(7):845–850
14. Hunter, G, Stimson G, Judd A, Jones S and Hickman, M. Measuring injecting risk behaviour in the second decade of harm reduction: a survey of injecting drug users in Britain. *Addiction* 2000; 95(9): 1351–61
15. Green S, Mohsen A, McKendrick M, Dawes Y, Prakasam S, Walberg R, Schmid M. Potential for hepatitis C transmission among non-needle/syringe sharing Sheffield drug injectors through the sharing of drug preparation paraphernalia. *Commun Dis Public Health* 2001; 4: 38–41
16. Hepatitis C – guidance for those working with drug users. Department of Health 2001
17. The Task Force to Review Services for Drug Misusers. Report of an Independent Review of Drug Treatment Services in England. Department of Health 1996
18. Drug misuse and dependence – guidelines on clinical management. Department of Health 1999
19. Gossop M, Marsden J, Stewart D. NTORS after five years. National Addiction Centre 2001

20. Health and Safety Executive/Local Authorities Enforcement Liaison Committee (2001). Local Authority Circular 76/2: Enforcement of skin piercing activities. See <http://www.hse.gov.uk/lau/lacs/76-2.htm>
21. Singleton N, Farrel M, Meltzer H. Substance misuse among prisoners in England and Wales. Further analysis of data from the ONS survey of psychiatric morbidity among prisoners in England and Wales carried out in 1997 on behalf of the Department of Health
22. Hepatitis C: Essential information for professionals. Department of Health 2002
23. Guidelines for the Blood Transfusion Services in the United Kingdom, 2001: ISBN 0117025550
24. Guidance on the Microbiological Safety of Human Organs, Tissues and Cells used in Transplantation. Advisory Committee on the Microbiological Safety of Blood and Tissues for Transplantation 2000
25. Standard principles for preventing hospital-acquired infections. J Hosp Infect 2001; 47: S21–S37
26. Sterilization, Disinfection and Cleaning of Medical Equipment: Guidance on Decontamination from the Microbiology Advisory Committee to Department of Health, Medical Devices Agency 2001
27. Good practice guidelines for the prevention and control of blood-borne virus infection in renal dialysis units. Department of Health (in press)
28. Ramsay ME on behalf of the PHLS Advisory Committee on Blood Borne Viruses. Guidance on the investigation and management of occupational exposure to hepatitis C. Commun Dis Public Health 1999; 2: 258–262
29. UK Health Departments (1998). Guidance for Clinical Health Care Workers: Protection Against Infection with Blood-borne Viruses Recommendations of the Expert Advisory Group on AIDS and the Advisory Group on Hepatitis
30. Advisory Committee on Dangerous Pathogens (1996). Protection against blood-borne infections in the workplace: HIV and hepatitis
31. Health Service Circular (HSC) 2002/010. Hepatitis C infected health care workers. Department of Health

Chapter 4

Improving services for people with hepatitis C

Key messages

- *Identify those who are chronically infected by increased testing for hepatitis C*
- *Offer specialist advice and treatment*
- *Develop managed clinical networks to enable co-ordinated pathways of care*
- *Provide social care for families and children affected by hepatitis C*

Access to health care – testing for hepatitis C

1. Estimates currently indicate that the majority of people with chronic hepatitis C infection have not yet been diagnosed. It is therefore important that testing is offered to those who have been at risk of infection. Individuals who are infected may benefit from specialist medical assessment, advice about lifestyle changes (e.g. avoidance of alcohol which may increase the risk of chronic liver disease), and antiviral therapy where indicated.
2. People may undergo their first test for hepatitis C antibody in a number of clinical settings. Antibody testing may take place in general practice surgeries, genito-urinary medicine clinics, drug treatment centres, prison medical services and other more specialist settings such as hepatology, gastroenterology, infectious diseases or renal units. As hepatitis C infection can be associated with a number of diseases such as renal, rheumatological or skin conditions or even diabetes, hepatitis C infection may also be diagnosed in a range of other specialist medical services. Therefore clear pathways of referral to hepatitis C specialists are needed. In order to encourage people to come forward for testing, there may be a role for open access confidential testing sites and the most appropriate clinical setting for this needs to be explored.
3. Diagnostic testing for hepatitis C infection should be offered to people who have otherwise unexplained liver disease. In the absence of clinical features of liver disease, testing for evidence of hepatitis C infection should be offered to people with the following risk factors:
 - past or current history of injecting drug use, irrespective of how long ago or how frequent that usage was (i.e. including those who have experimented with injecting);
 - history of receiving transfusion of blood or blood products, especially in childhood and particularly if multiple transfusions, prior to the introduction of blood donor screening in the UK (September 1991) or prior to viral inactivation of blood products in 1985;
 - organ transplant before the introduction of donor screening in September 1991;
 - needlestick injury from a known or likely hepatitis C-infected source;
 - regular sexual partners of people with hepatitis C;

- tattoos or ear- or body-piercing where infection control measures may not have been adequate;
 - babies of hepatitis C infected mothers. (The presence of antibody to hepatitis C virus in sera from such babies may be maternally derived in the first year of life, therefore testing strategies and timing should be discussed with the testing laboratory beforehand);
 - past and present attendees at renal dialysis units²⁷;
 - exposure to infection in other countries with high prevalence rates of infection e.g. by medical or dental treatment where infection control measures might not have been adequate.
4. Individuals who are concerned that they might have been at risk of hepatitis C infection should seek advice about testing through their general practitioners and in other settings where they may access health care (see paragraph 2 above). For current injecting drug users, testing for antibody to hepatitis C should be seen as part of a wider package of health and drug treatment care, involving discussion of harm reduction and disease prevention strategies including hepatitis B immunisation (see Chapter 3).
 5. All testing should be carried out in a setting of confidentiality. Testing of individuals concerned about or deemed to be at risk of hepatitis C infection needs to be accompanied with an appropriate discussion to ensure informed consent. Broad guidance on this area of practice has recently been provided by the Department of Health and can be accessed via www.doh.gov.uk/consent. More detailed information on hepatitis C testing and pre- and post-test discussion will be published separately as guidance for the NHS.

The managed clinical network for hepatitis C infected people

6. Once a positive test result is obtained, primary care teams should have a clear pathway of referral to a specialist team within a geographically accessible managed clinical network. It may be possible for GPs, especially those involved in the management of injecting drug users, to improve hospital attendance and engagement in the treatment plans for their patients. (See improving practice box – GPs). Continuing management and care should involve close links with specialist teams and may be facilitated through specialist hepatitis nurses.

Improving practice

GPs

Actions found to improve rates of hospital attendance and engagement in treatment plans for hepatitis C antibody positive clients (St Martin's Practice, Leeds).

- Discussion of joint referral guidelines with specialist hepatology service.
- Inclusion of more information in guidelines on pre- and post-test discussion on the implications of a positive test, the nature and purpose of likely investigations and treatments offered by the hospital. Development of the role of nursing staff in the practice in pre-referral discussion.
- Improvement of the readability and suitability of written backup information given to clients.
- Formation of a nurse-facilitated monthly hepatitis C support group.
- Development of pre-referral medical 'work up' to include a full range of relevant blood tests, to facilitate clinical decision making at the first hospital appointment.
- Development of a referral pro forma to ensure the transfer of good quality and standardized information at the time of referral. Client's address rechecked at the time of referral – many were not receiving appointments due to changing address frequently, or having an insecure postal address, or being functionally homeless, in which case the practice's address would be used for correspondence.
- Improvement of communication from the hospital services. The hepatology department offers an appointment within 4 weeks of receiving a referral, i.e. while client well motivated. The hospital informs the practice of the date and time of the appointment, so that they can encourage the client to attend.

7. In collaboration with the British Association for the Study of the Liver (BASL), and other interested parties, the Department of Health, has recently published specialist service definitions for hepatology³² (see www.doh.gov.uk/specialisedservicesdefinitions/index.htm). One of the principal roles of the specialist hepatology units is the assessment and treatment of patients with viral hepatitis. Although these definitions are not service specifications and do not prescribe service models or set service standards, they have been produced as guides for commissioners for planning and procurement of specialist services. The services will cover planning populations similar in size to or greater than that of a new (soon to be called Strategic) Health Authority* population (i.e. 1-2 million), which consequently require some form of collective commissioning.
8. It is envisaged that specialist hepatology units will be at the hub of managed clinical networks for a variety of conditions including cirrhosis and liver cancer and will be responsible for co-ordinating the management of patients with hepatitis C. Work needs to be done scoping the existing networks, identifying good practice and developing other networks across the country. Each network will need to cover geographically defined areas, served by several different hospitals, which may or may not be co-terminous with (Strategic) Health Authority boundaries.

* Introduced by section 1 of the NHS Reform and Health Care Professionals Act 2002, which is expected to be commenced in October 2002

A specialist service for hepatitis C

Components of the service

9. In order to provide the necessary level of health care, a specialist service for hepatitis C will need to have the following components;
 - **An expert clinician who is experienced in the diagnosis and management of viral hepatitis.** Most often these will be hepatologists or gastroenterologists with an interest in liver disease, although this role may also be filled by a consultant in infectious diseases working closely with other colleagues.
 - **Hepatitis nurse(s):** these clinical nurse specialists provide an individualized service to patients being referred, managed and treated for chronic hepatitis C, for example by counselling patients after a positive test result and monitoring side effects during antiviral treatment. Currently, there are no pre- or post-registration courses for viral hepatitis in nursing (see Chapter 5, Actions to support change).
 - **Access to an accredited virology laboratory** – which provides a routine diagnostic service, is overseen by the new Inspector of Microbiology (as set out in *Getting Ahead of the Curve*) and is capable of providing the following groups of tests:
 - confirmatory antibody testing for hepatitis C
 - qualitative hepatitis C RNA detection and hepatitis C genotyping
 - quantitation of hepatitis C RNA.
 - **Access to a liver pathologist** – for routine assessment of liver biopsies, grading and staging of liver histology according to internationally established criteria.
 - **Access to a radiology department** for routine diagnosis and monitoring of patients with liver diseases.

Structure/organisation

10. It is envisaged that the treatment and care of viral hepatitis will either be an integral part of a specialised hepatology unit, which provides a full range of hepatology services including management of liver cancer, or will have ready access to/work in collaboration with such a unit (e.g. where the service is delivered primarily by consultants in infectious diseases). The anticipated increase in the number of patients with hepatitis C means that services for viral hepatitis C cannot be restricted to specialist hepatology units.
11. Specialised hepatology units should liaise and establish formal links with both primary and other secondary care services, including paediatric, renal and prison services. Through consultation with these other services, units should devise management protocols which will include care pathways for “special” groups of patients including those HIV co-infection, children with hepatitis C, prisoners, patients on renal dialysis and injecting drug users.
12. While the recommended treatments should all be instigated as a specialist activity, it is likely that there will be some shared care with secondary and primary care services, including prison services. It is therefore likely that staff in these services will require additional education and training (see Chapter 5, Actions to support change).

Improving practice

Developing a framework for best practice in delivering hepatitis C prevention, treatment and care services

A multi-agency group, which was set up by the London Communicable Disease Control Group, has produced a best practice guide for hepatitis C in London for consultation.

It is intended to be used by London's health organisations as a framework for improving the prevention, testing, treatment and care of hepatitis C. It aims to facilitate a strategic and consistent approach to hepatitis C in London, to avoid unnecessary duplication of work and promote good practice. It suggests an overall model for London-wide service delivery.

13. Other potential benefits of specialist services for viral hepatitis include;

- The auditing and monitoring of standards of care e.g. the use of interferon and ribavirin according to NICE guidelines³³;
- Further development of management guidelines beyond those for the use of combination antiviral therapy;
- Development of robust audit tools.

Improving practice

Development of a managed clinical network

The Liver and Anti-viral Centre at St Mary's Hospital, London co-ordinates a network that provides a service for patients with chronic hepatitis C in three different parts of West London. Patients with chronic hepatitis C are referred by GPs to one of the participating hospitals (Charing Cross, Hammersmith, Northwick Park, Ealing, and St Mary's) where the patients receive appropriate counselling and support from a team of hepatitis nurse specialists.

To ensure that those who are actively using drugs have full access to medical services, drug workers have direct access to two named consultants and clients can be referred directly from drug worker to consultant without the need for referral via the client's general practitioner. Patients with on-going addictions have access to services via a consultant-led outreach clinic that is held once a week.

West London has two large genito-urinary medicine (GUM) clinics, centred around St Mary's and Chelsea & Westminster Hospitals, and patients with hepatitis C who are seen at these clinics are referred to an infectious disease physician with an interest in viral hepatitis. These consultants provide a service for patients who are co-infected with hepatitis C and HIV, as well as patients with hepatitis C alone.

Since there is a high prevalence of hepatitis C in women in West London, all pregnant women attending St Mary's for antenatal care are offered testing for hepatitis C infection. Those who are infected are followed up by a dedicated midwife in a 'Family Clinic' run by a consultant hepatologist and a consultant paediatrician. Discussions with local commissioners are on-going with regards to the provision of a service for the local prison population.

Management of children with hepatitis C

14. Acute hepatitis C is uncommon in childhood. Most chronically infected children are asymptomatic with normal growth and development, but should be referred to a paediatric liver unit to be seen by the multidisciplinary team. In addition to clinical management, potential psychosocial issues may need to

be addressed. A nurse specialist with paediatric experience or other health professional will need to counsel the child and family about infection risk, the natural history of hepatitis C, including the risk of cirrhosis and liver cancer in the long term and the need for future treatment. Work needs to be done scoping referral patterns to the existing specialist paediatric liver centres. This will then inform the basis for the managed clinical networks for infected children, identifying good practice and developing other networks across the country.

Provision of healthcare within a specialist unit

15. The overall aim of a specialist service for the management of patients with viral hepatitis is ideally:

- **Selection of patients for treatment** according to established guidelines and the severity of the liver disease.
- **Provision of combination antiviral drug treatment** currently consisting of interferon and ribavirin as recommended by NICE³³ for moderate to severe hepatitis C in patients over the age of 18 years. The Government has recently introduced a statutory obligation on the NHS to provide funding for the treatments and drugs recommended by NICE. From January 2002 the NHS will need to ensure funds are available, three months from the date of publication of the NICE recommendations (Technology Appraisal Guidance), for the provision of drug treatments, where clinically indicated.
- **Interferon monotherapy** is recommended only where ribavirin is contraindicated. Assessment of a longer-acting version of interferon alpha, **pegylated interferon**, which can also be used in combination with ribavirin, is included in NICE's work programme.
- The **primary aims of treatment** are to achieve normal liver function tests and sustained clearance of hepatitis C virus (i.e. negative PCR test). This needs to be sustained for at least 6 months after treatment has stopped. Patients with a sustained response will have an improved quality of life and a reduced risk of cirrhosis and liver cancer.

Guidelines on clinical management

16. The British Society of Gastroenterology has produced clinical guidelines on the management of hepatitis C³⁴. As the guidelines point out, clinical management may need to vary for different groups of patients. For example, the UK Haemophilia Centre Directors Organisation has produced guidelines on the management of hepatitis C in people with haemophilia³⁵, and the British HIV Association on the management of patients co-infected with hepatitis C and HIV³⁶.

Improving practice

Inter-agency working

Southampton University Hospitals NHS Trust has been running inter-agency hepatitis C consensus meetings for the past 4 years. These meetings bring together agencies working with individuals with hepatitis C in and around the Southampton area (covering Portsmouth, Isle of Wight, Winchester, Salisbury and Bournemouth). Organisations involved include drug agencies, local charities and support groups, homeless health care teams, prisons and local hospitals. As a consequence of these meetings, better referral systems are now in place and joint education days are planned. Outreach hepatitis C clinics have been held in the prisons on the Isle of Wight since January 2000.

Complementary and alternative medicine

17. There has been some support expressed by service users for the provision of complementary and alternative medicine (CAM). However, the evidence base for the majority of these treatments is either limited or absent, although there is some anecdotal evidence that CAM may enhance well-being, personal control, and symptom relief, aiding nutrition, sleep and social involvement.
18. Research evidence from large and well-designed studies will be needed to evaluate the effectiveness of CAM in the management of hepatitis C.

Social care and support for those living with hepatitis C and affected by hepatitis C

19. People with hepatitis C and their families may need social care and support to help retain their quality of life and maintain their independence. This will include those who are experiencing symptoms that may not be directly related to the progression of liver disease, but which may reduce their quality of life significantly e.g. fatigue, joint and muscle pain and depression. Medical input to assessment for services and liaison with health care providers will therefore be important. People with hepatitis C may be eligible for social security benefits if their ability to carry out day-to-day activities is significantly affected.
20. Social care and support may include:
 - Information in appropriate formats and languages;
 - Advocacy in order to access further social care support;
 - Advice concerning welfare rights, housing, employment and training etc;
 - Peer support and advice;
 - Post diagnosis support;
 - Support in adhering to drug regimens for treating hepatitis C;
 - Support and information for carers;
 - Home care for personal needs and essential domestic tasks;
 - Respite care in residential and other settings;
 - Direct Payments to purchase and manage own care.
21. The legislative framework for the provision of social care services to disabled adults and those with long-term illness is provided by the National Assistance Act 1948, the Chronically Sick and Disabled Persons Act 1970 and the NHS and Community Care Act 1990. The Disability Discrimination Act 1995 and the Human Rights Act 1998 also have implications for the provision of social care services (and for public sector provision generally). The Department of Health's guidance on Fair Access to Care Services³⁷ should lead to more consistent service provision by providing a common framework to determine eligibility for social care.

Improving practice***Specialist hepatitis C social worker***

The Infectious Disease Unit at the Royal Hallamshire Hospital, Sheffield and Sheffield City Council have collaborated to employ a hepatitis C specialist social worker to support clients referred to the hepatitis C clinic. The social worker provides a wide range of support such as pre- and post-test discussion; information about hepatitis C, including risk reduction; advice on housing, financial and employment issues; liaison with other agencies e.g. drugs and mental health services; adherence to treatment, home visits, and facilitating a self-help group.

Children and families affected by hepatitis C

22. Local authorities have responsibilities under the Children Act 1989, to identify and, where appropriate, support and provide services to children in need. This could include children and families affected and/or infected by blood-borne viruses, including hepatitis C. The interests and welfare of the child must always remain the paramount consideration for all those working with children and their families in whatever capacity. When parents or carers are infected with and are significantly disabled by their illness, this may limit their capacity to care for their child or they may increasingly depend on the child for help and support. This may include respite care and family placements for children.
23. When support is necessary, the needs of children affected by hepatitis C should be assessed by local authorities in accordance with *The Framework for the Assessment of Children in Need and their Families* (2000) and plans made to address these needs. It is important that adult and children's services work closely together to ensure that they are meeting the needs of children and parents/carers. Approaches to assessment, provision and review should be family-centred with the involvement of staff with expertise in hepatitis C. Children should be supported to be involved in making decisions as far as is reasonable.
24. The Department of Health has recently completed consultation on draft guidance for local authorities and the NHS on *Children in Need and Blood-borne Viruses – HIV and hepatitis*³⁸. This is intended to assist local authorities and the NHS in promoting and safeguarding the welfare of children in need.

Commissioning services

25. Effective local planning and commissioning of services are essential to the delivery of improved services for people at risk of hepatitis C or already infected with hepatitis C. The integration of these services with those needed to cope with the increase in mortality from alcohol-related cirrhosis and cancer of the bile ducts will be necessary. The development of managed clinical networks, as suggested in paragraphs 6 to 8 of this chapter and informed by the results of scoping studies, should result in the co-ordinated management and care of patients with hepatitis C.
26. Each PCT or a group of PCTs should develop a local plan for prevention of hepatitis C which links into other related initiatives such as those on drug misuse. Such local plans should establish a patient care pathway for the treatment of those with hepatitis C. These local plans should include prisons where relevant. A local multi-agency group should be set up to oversee and monitor commissioning of prevention and treatment services. Planning of services should be carried out in partnership with voluntary organisations, service users and others who represent users and potential users. (Strategic) Health Authorities, in their performance management function, should ensure that comprehensive local plans are in place.

27. Hepatitis C prevention plans should demonstrate how resources will be targeted on groups at increased risk of hepatitis C; what the planned outcomes are and how services will be monitored and evaluated.
28. From April 2002, PCTs are responsible for commissioning specialised services on a collective basis. (Strategic) Health Authorities will performance manage the collective commissioning of specialised services by PCTs.

Consultation questions

What are likely to be the most effective ways of identifying people who may have been exposed to hepatitis C infection and of providing testing?

Is there a role for open access confidential hepatitis C testing sites?

What degree of change in current service provision does the development of managed clinical networks require?

Is the approach suggested for commissioning likely to be effective?

References

32. National Specialised Services Definition Set; Definition no:19 Specialised Services for Hepatology, Hepatobiliary and Pancreatic Surgery, obtainable from www.doh.gov.uk/specialisedservicesdefinitions/19hepat.htm
33. Guidance on the use of Ribavirin and Interferon Alpha for Hepatitis C. National Institute of Clinical Excellence, 2000
34. Booth J, O'Grady J, Neuberger J (on behalf of British Society of Gastroenterology). Clinical guidelines on the management of hepatitis C. *Gut* 2001; 49 (Suppl 1): i1–i21.
35. Guidelines on the diagnosis, management and prevention of hepatitis in haemophilia. UKHCDO *Haemophilia* 2001;7(4):339–345
36. British HIV Association (BHIVA) guidelines for the treatment of HIV-infected adults with antiretroviral therapy. *HIV Med* 2001;2(4):276–313
37. Local Authority Circular (LAC) (2002)13: Fair access to care services. Department of Health. <http://www.doh.gov.uk/scg/facs/lac200213.htm>
38. Children in Need and Blood-borne Viruses: HIV and Hepatitis. Department of Health 2002 <http://www.doh.gov.uk/childrenbbvs/>

Chapter 5

Actions to support change

Key messages

Actions needed to support change identified in the Strategy are;

- *Surveillance of hepatitis C infection and associated liver disease will be improved*
- *Professional and public awareness of hepatitis C will be improved*
- *Treatment for drug misuse and dependency will be increased in line with NTA guidelines as this reduces injecting risk behaviour and consideration will be given to monitoring needle exchange activity*
- *As many injecting drug users pass through prisons, information about hepatitis C will be provided along with harm minimisation measures*
- *A scoping study of managed clinical networks will be carried out*
- *Commissioning further research on hepatitis C by all agencies should be encouraged*

Improving surveillance

1. A better epidemiological profile and ability to monitor hepatitis C infection and the effect of prevention initiatives are needed, in particular:
 - regular monitoring of the prevalence of hepatitis C among current injecting drug users, including those who are not attending drug services and injectors with short injecting careers;
 - obtaining a better estimate of the prevalence of hepatitis C infection within the general population of the UK over time (because many people with hepatitis C are ex-injectors and cannot be sampled using methods to survey injectors);
 - improve the surveillance of the burden of hepatitis C-related disease by development of a pilot scheme for assessing both hepatitis C and hepatitis B-related severe liver disease;
 - study of the injecting risk and protective behaviours associated with the transmission of hepatitis C;
 - use new methods to detect newly acquired infections in order to monitor the impact/effectiveness of prevention measures;
 - to help interpret any increase in the number of positive laboratory reports of hepatitis C, in the future denominator studies should be set up in four English regions to analyse laboratory reporting patterns;
 - modelling the transmission dynamics of hepatitis C among current injecting drug users and the likely impact of different harm reduction strategies;
 - modelling the historical epidemic of injecting drug use and hepatitis C in order to forecast future health needs;
 - monitoring the coverage of needle exchange provision linked to information about hepatitis C to determine the impact of such services and plan future prevention activities.

2. Specialist hepatology units should provide data to the Communicable Disease Surveillance Centre of the Public Health Laboratory Service. This will help the construction of the national picture of the natural history of hepatitis C. Such units will also be best placed to provide information to inform modelling to estimate the future burden on health care services.

Continuing professional training and development

3. Raising professional awareness of hepatitis C is necessary to help prevent new cases and to identify individuals who may be infected with hepatitis C, so that they can be referred for specialist assessment and treatment. National hepatitis C strategies in France, Australia, Canada and the United States have all recognised the importance of this activity.
4. The Department of Health recently published guidance on hepatitis C for those working with drug misusers¹⁶. The NTA Models of Care builds on this work and provides a framework for all those commissioning and providing services in a local area. The new National Occupation Standards for drug and alcohol treatment (DANOS) have recently been approved – including competencies for harm reduction and needle exchange service delivery. A range of new training initiatives are available and a new qualification framework will be in place by March 2003. The NTA and local commissioners will require all drug treatment practitioners to be able to demonstrate their competence against national standards by 2004.
5. A more general awareness-raising programme about hepatitis C targeted at primary care professionals has been started, with regional conferences backed up with briefing packs. These packs were sent early in 2002 to all GPs and practice nurses in England and to other relevant professionals such as Consultants in Communicable Disease Control and those in drugs, GUM and prison services. The pack consisted of a professional briefing paper plus a leaflet for patients to be used in consultations².

Improving practice

Raising professional awareness

In Portsmouth and South East Hampshire, hepatitis C workshops for staff in primary care are provided by the Community Clinical Nurse Specialist HIV (Department of Genitourinary Medicine, Portsmouth Hospitals NHS Trust). The workshops cover issues such as transmission and testing, disease progression, treatment and care, health promotion and issues for specific patient groups with hepatitis C (e.g. current and ex-drug users, prisoners and people with haemophilia). Nearly 400 staff have attended such workshops since February 1998, including staff from substance misuse, health promotion, community health, mental health and social services.

Raising awareness amongst those at higher risk of hepatitis C and in the general population

6. Raising awareness of those at higher risk of infection, particularly injecting drug users and those in prison, should be via health professionals and outreach workers backed up with health promotion materials and information. This will supplement existing sources of information such as the British Liver Trust and the National Hepatitis C Resource Centre (run by Mainliners).

7. A health promotion campaign for the general population to raise awareness about hepatitis C will be developed and carried out in a focused, measured and non-alarmist fashion. This will provide information about:
 - How the infection is transmitted, and the means to prevent transmission.
 - How those who may have been at risk of infection in the past can access testing and advice about treatment and care.
8. This campaign will build on the existing activities within schools and with young people in relation to injecting drug misuse.

Improving services for hepatitis C – scoping existing clinical networks

9. In order to encourage people in the general population who may have been at risk of hepatitis C in the past (e.g. ex-injectors) to come forward for testing in a confidential environment, there may be a need for some open access testing sites. Currently it is unclear which clinical setting e.g. GPs, GUM clinics or specialist hepatology units, would be the most appropriate to provide this service. This needs to be piloted and evaluated.
10. Once diagnosed, people with hepatitis C should have access to a clear patient care pathway from the clinical setting where they are diagnosed to the specialist service. Local plans are needed to establish how patients are linked into the nearest managed clinical network. It is proposed that a scoping study is carried out to identify existing specialist services and clinical networks, and good practice. The results of this study should assist local planners and commissioners in service development.
11. As prevention of disease progression is important in all those infected, studies will be needed to identify strategies for service delivery that most effectively improve the treatment of hepatitis C in all patient groups, including current injecting drug users. Such studies should include the patient's experience of treatment.
12. Clinical trials of new antiviral therapies are on-going and co-ordinated at a national and international level. Specialist hepatology units should allow the efficient recruitment of patients for clinical trials of new antiviral therapies. In particular:
 - Injecting drug users are the largest single identifiable group of those infected with hepatitis C and the majority of clinical trials have omitted this group; research related to their treatment is therefore needed.
 - Clinical trials of newer therapies are needed for patients who have not responded to current therapy.
13. Prospective clinical audit programmes should record the adherence to current clinical guidelines for the treatment of chronic hepatitis C infection. In order to improve patient care more effectively, such programmes should be an integral part of formal clinical governance arrangements.

Equipping the professional workforce to care for people with hepatitis C

14. Specialist nurses in hepatitis have an important role in the clinical care of people infected with hepatitis C. The number of nurses attached to the managed clinical networks may need to increase to enhance the quality of patient care and to improve communication links with other agencies. The Department of Health will discuss with the Nursing and Midwifery Council the need to develop nursing curricula on the care of people infected with hepatitis B and hepatitis C.

15. The Joint Committee on Higher Medical Training has recently recommended to the Department of Health the establishment of hepatology as a formal sub-speciality of gastroenterology. This will require specialist registrars to spend at least 2 years of their gastroenterology training on a liver unit, which, subject to Specialist Training Authority approval, will be recognised as particular expertise, over and above the Certificate of Completion of Specialist Medical Training in gastroenterology, for the purposes of annotation on the specialist register.

Research

16. During the course of the Strategy development some gaps have become particularly apparent and these are identified below.

Survival of hepatitis C virus

17. Uncertainty remains about how long the virus survives in different items of injecting equipment, and whether equipment can be decontaminated by cleaning or the virus killed by easily available items such as household bleach. In the interim it is clear that equipment should not be shared and that injection should be hygienic. Inevitably, some injectors will not be able to heed this advice all the time, and some settings (such as injecting in prisons) may put them at higher risk. Therefore further research is needed to identify methods for effectively rendering injecting equipment safe using readily available products.

Mother to baby transmission

18. In view of the uncertainties about the vertical transmission of hepatitis C from mother to child, and measures to prevent this, internationally co-ordinated research is needed to determine if elective caesarean section or other obstetric interventions reduce the risk of transmission during pregnancy and/or childbirth.

Modelling the effectiveness of different prevention activities

19. Some preliminary work was undertaken during the course of the Strategy development and is outlined in Chapter 3 on prevention. Mathematical modelling could be a useful adjunct to decisions about where to target prevention resources to have maximum effect.

Behavioural research

20. Measures to prevent transition into injecting are not well known or well proven. Research into 'prevention of initiation to injection' is needed to inform harm reduction work. This could be investigated using evaluated pilot demonstration studies that investigate how injecting can be reduced.

Complementary and alternative medicine (CAM)

21. Research evidence is needed from large and well-designed studies to evaluate the effectiveness of CAM in the management of hepatitis C.

Consultation questions

Are there any important gaps in the actions identified to support change?

How should the actions identified be prioritised?

How might professional awareness of hepatitis C be further developed?

Are the research needs identified the most important ones, are there any others?

Annex 1

Hepatitis C Strategy Steering Group

Terms of reference

To oversee development of the Department's strategic approach to hepatitis C by bringing together issues relating to prevention, control and treatment and to produce a document within the year, for consultation with the NHS, professional bodies and the voluntary and community sectors.

Membership

Chairman

Professor Howard Thomas, Imperial College School of Medicine, London and Chairman, Advisory Group on Hepatitis

Members

John Bryce, lay member

Jim Camp, Needle Exchange Forum

Hannah Cinamon, formerly Health Promotion England (now at the Department of Health)

Professor Chris Day, Medical School, Newcastle University

Manlio Fahrni, Chair of *Re-act* and vice-chair of the recently launched national forum, the UK Assembly on Hepatitis C

Jo Guy, Hepatology Nurse Specialist, Southampton General Hospital

Dr Paul Hatton, Consultant in Communicable Disease Control, Leeds Health Protection Unit, Leeds North East Primary Care Trust and member, Advisory Group on Hepatitis

Lorraine Hewitt*, Action on Hepatitis C and member, Advisory Council on the Misuse of Drugs

Nigel Hughes, British Liver Trust

Professor Will Irving, Department of Microbiology, University of Nottingham and member, Advisory Group on Hepatitis

Tania Machell, Head of National Hepatitis C Resource Centre, Mainliners

Grant McNally, National Drug Users Development Agency

Dr Mary Ramsay, Public Health Laboratory Service Communicable Disease Surveillance Centre

Professor Gerry Stimson, Centre for Research on Drugs and Medicine, Imperial College School of Medicine, London

Professor John Strang, Director of the National Addiction Centre, Maudsley Hospital, London and member of the Advisory Council on the Misuse of Drugs

Dr Martyn Wake, General Practitioner, south west London

* Recently deceased

Department of Health officials

Secretariat

Dr Vicki King

Dr Hugh Nicholas

Gerry Robb

Sara Johnston

Helen Christmas

Observers

Dr Peter Doyle

Carole Fry

Charles Lister

Dr Mary O'Mahony

Dr Mary Piper

Dr Mark Prunty

Annex 2

The consultation criteria

The criteria for all UK national public consultations is set out in the Code of Practice for Written Consultations* published by the Cabinet Office. This requires that:

1. Timing of consultation should be built into the planning process for a policy (including legislation) or service from the start, so that it has the best prospect of improving the proposals concerned, and so that sufficient time is left for it at each stage.
2. It should be clear who is being consulted, about what question, in what timescale and for what purpose.
3. A consultation document should be as simple and concise as possible. It should include a summary, in two pages at most, of the main questions it seeks views on. It should make it as easy as possible for readers to respond, make contact or complain.
4. Documents should be made widely available, with the fullest use of electronic means (though not to the exclusion of others), and effectively drawn to the attention of all interested groups and individuals.
5. Sufficient time should be allowed for considered responses from all groups with an interest. Twelve weeks should be the standard minimum period for a consultation.
6. Responses should be carefully and open-mindedly analysed, and the results made widely available, with an account of the views expressed, and reasons for decisions finally taken.
7. Departments should monitor and evaluate consultations, designating a consultation co-ordinator who will ensure the lessons are disseminated.

We confirm that these criteria have been, and will continue to be followed.

* Code of Practice on Written Consultation, Cabinet Office November 2000



© Crown Copyright
Produced by Department of Health
28874 1p 5k August 02 (WOO)
CHLORINE FREE PAPER

The text of this document may be reproduced without formal permission
or charge for personal or in-house use.

First published: August 2002

If you require further copies of this publication
quote 28874/*Hepatitis C Strategy for England* and contact:

Department of Health Publications
PO Box 777
London SE1 6XU
Tel: 08701 555 455
Fax: 01623 724 524

28874/*Hepatitis C Strategy for England* can also be made available on
request in braille, on audio cassette tape, on disk, in large print, and in other
languages on request.

28874/*Hepatitis C Strategy for England* is available on the department's
website at: www.doh.gov.uk/cmo/hcvstrategy