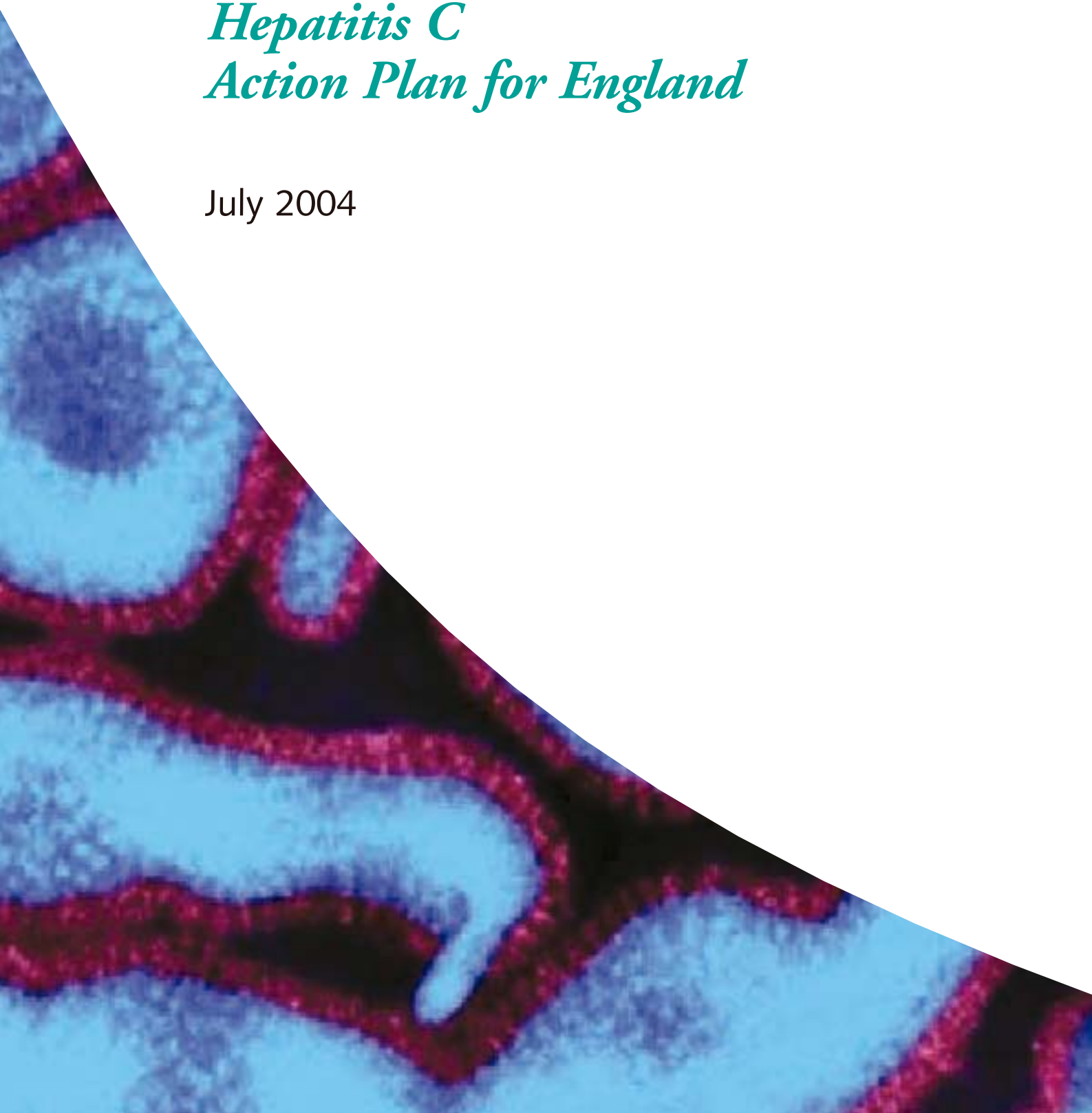


*Hepatitis C
Action Plan for England*

July 2004



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Action Plan for England

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READER INFORMATION

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Contact Details	Mrs Helen Hamlet General Health Protection Room 631B, Skipton House 80 London Road, London SE1 6LH 020 7972 6061 helen.hamlet@doh.gsi.gov.uk
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Contents

Chapter 1	Introduction	3
	• The background	3
	• Action to date	3
	• What is hepatitis C?	5
Chapter 2	National outlook: where we are now	6
	• The number infected	6
	• Who and where are they?	6
	• Knowing the risks	7
	• Paying the price	8
	• Pathways of care	8
Chapter 3	International outlook: how do we compare?	9
Chapter 4	The future	10
Chapter 5	The actions	11
	• Action 1: Surveillance and research	11
	• Action 2: Increasing awareness and reducing undiagnosed infections	12
	• Action 3: High-quality health and social care services	13
	• Action 4: Prevention	14
References		15

Chapter 1

Introduction

The background

- 1.1 Hepatitis C is often referred to as the ‘silent epidemic’. Many of those who have the infection show no symptoms over a long period. Estimates indicate that around 200,000 people in England are chronically infected with hepatitis C – yet only 38,000 diagnoses have been reported. If left untreated, hepatitis C can cause serious liver disease in some patients, including cirrhosis and liver cancer.
- 1.2 For this reason, hepatitis C was identified in the Chief Medical Officer’s Infectious Diseases Strategy for England, *Getting Ahead of the Curve*¹, as needing ‘intensified action’ to improve its prevention, diagnosis and treatment.
- 1.3 Until the Strategy was published, the control of infectious diseases was often seen as a ‘Cinderella service’ – one that had a relatively low profile compared with other areas of health service development. *Getting Ahead of the Curve* set out to bring the control of infectious diseases into the mainstream of service improvement.
- 1.4 The growing importance of hepatitis C as a public health issue in this country was highlighted in 2002 with the publication of the Government’s *Hepatitis C Strategy for England*². It brought together existing initiatives to tackle hepatitis C and suggested how prevention, diagnosis and treatment could be improved. This Action Plan, which is based on best practice, serves as a broad framework for implementation of the *Hepatitis C Strategy for England*. It reflects ongoing work that needs to be sustained and intensified and also identifies new areas for action.
- 1.5 It also links in with the Government’s 10-year strategy for addressing drug misuse, *Tackling Drugs to Build a Better Britain*³, *Alcohol Harm Reduction Strategy for England*⁴, *The National Strategy for Sexual Health and HIV*⁵ and *The NHS Cancer Plan*⁶.
- 1.6 Implementation of the Action Plan will be assessed via ongoing epidemiological surveillance and performance management.

Action to date

- 1.7 A great deal has already been done to control hepatitis C. Comprehensive guidance has been issued to help the NHS.
- 1.8 Achievements include the following:
 - Prospective blood donors who may have been at risk of infection with hepatitis C have been asked not to donate and all blood, tissue and organ donors are screened for hepatitis C^{7, 8}.
 - Blood products have been treated to inactivate blood-borne viruses since 1985, and screening of all blood donations for hepatitis C began in 1991.

- Needle and syringe exchange schemes for injecting drug users were introduced in the mid-1980s; over 90% of Primary Care Trusts in England now have such programmes and more than 27 million needles are exchanged each year.
- Guidance produced jointly in 1998 by the Advisory Group on Hepatitis and the Expert Advisory Group on AIDS, set out precautions to be taken by healthcare workers to avoid occupational exposure to hepatitis C infection⁹.
- *Hepatitis C – Guidance for those Working with Drug Users*, produced in 2001, provided essential information and advice about the infection and its prevention¹⁰.
- The Specialised Services National Definition Set, published in 2001, described models for commissioning of specialised services for liver disease¹¹.
- Health and Safety Executive guidance for local authorities on skin piercing, issued in 2001, included measures to prevent transmission of hepatitis C and other blood-borne viruses¹².
- *Models of Care*, published by the National Treatment Agency for Substance Misuse in 2002, included measures to prevent transmission of blood-borne viruses between injecting drug users, which should be implemented by every local Drug Action Team¹³.
- A Health Service Circular, published in 2002, recommended that health care workers infected with hepatitis C should not perform exposure-prone procedures and provided advice about the resumption of work following successful treatment¹⁴.
- Good practice guidelines for renal dialysis and transplantation units, issued in 2002, included measures to prevent transmission of hepatitis C and other blood-borne viruses¹⁵.
- A change in the law in 2003 made it lawful to provide injecting drug users with other equipment used when injecting, e.g. spoons and filters, to reduce further the risk of infection¹⁶.
- A pilot scheme in English prisons provided prisoners with disinfectant tablets to clean drug injecting equipment and the programme is currently being extended.
- The National Institute for Clinical Excellence approved the combination treatment of pegylated interferon and ribavirin for treatment of hepatitis C in 2004 so that all Primary Care Trusts must provide funding and access to the medication by Spring 2004¹⁷.

1.9 A number of expert committees contribute to the policy on hepatitis C. These are:

- The Advisory Group on Hepatitis
- The Advisory Council on the Misuse of Drugs
- The Advisory Committee on the Microbiological Safety of Blood and Tissues for Transplantation
- The Advisory Committee on Dangerous Pathogens
- UK Advisory Panel on Healthcare Workers Infected with Blood-borne Viruses

1.10 Despite this, there is still a need for intensified action to prevent new infections, reduce the level of undiagnosed infection and provide better, more co-ordinated pathways of care for people with hepatitis C, from their initial diagnosis to specialist care and treatment, if appropriate.

What is hepatitis C?

- 1.11 Hepatitis C is an infection caused by a blood-borne virus. It is a major cause of chronic liver disease, yet it is not as well understood as other blood-borne virus infections such as HIV.
- 1.12 Most people who become infected are not aware of it at the time. Jaundice is rare. Many people with chronic infection have no symptoms, others feel unwell. Symptoms include mild to severe fatigue, loss of appetite, weight loss, depression or anxiety, poor memory or concentration, and pain or discomfort in the liver. Chronic infection with hepatitis C causes serious liver disease, including cirrhosis and liver cancer in some people.
- 1.13 In 1991 routine screening of donated blood for transfusion was introduced, in addition to viral inactivation of blood products (the main protective measure since the mid-1980s). As a result of introducing these measures, spread of the virus via blood transfusion or blood products is now rare in this country.
- 1.14 The most common route of infection in England currently is through sharing contaminated needles or injecting equipment by injecting drug users.

Chapter 2

National Outlook: Where we are now

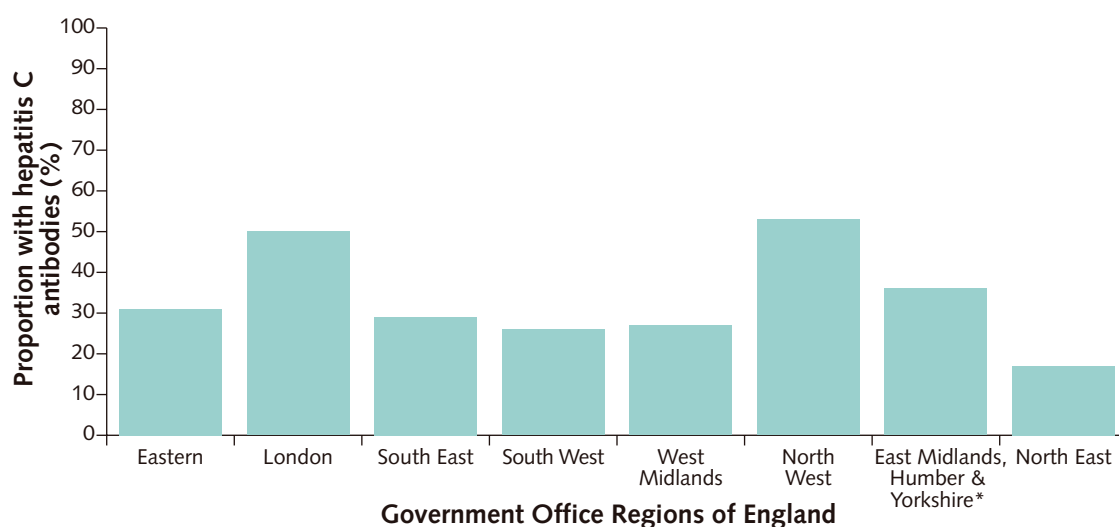
The number infected

- 2.1 An estimated 0.5% of the general population in England (approximately 250,000 people) has been infected with hepatitis C. About 20% of those infected appear to get rid of the virus naturally without treatment. Thus, 0.4% of the population (some 200,000 people) is chronically infected with hepatitis C. However, there have been only 38,000 diagnoses of hepatitis C infection reported, so it must be concluded that the majority of infected people are undiagnosed.
- 2.2 Most people with diagnosed hepatitis C infection are men aged between 25 and 45 years. This reflects the fact that men are more likely to be injecting drug users than women. Factors associated with more rapid progression of disease are male gender, infection when older (over 40 years) and alcohol consumption.
- 2.3 The relatively large number of people who are unknowingly infected will not be aware that reducing or stopping alcohol intake could help minimise the liver damage from hepatitis C infection. They also risk spreading the infection to others and may miss out on effective drug treatments.
- 2.4 Moderate to severe disease can now be treated successfully in up to 55% of cases overall. If chronic infection is left untreated, most people will eventually develop symptoms, and one in five go on to develop cirrhosis of the liver after 20 years or more. A small number develop primary liver cancer.

Who and where are they?

- 2.5 Information on laboratory tests for hepatitis C antibody in England is collected, analysed and regularly published by the Health Protection Agency (HPA). Additionally, special studies – for example on pregnant women (a low-risk population) and on injecting drug users (a high-risk population) – have been carried out.
- 2.6 The information shows that hepatitis C infection occurs across the country, with higher levels in inner city areas (probably reflecting a higher concentration of injecting drug users). Rates are highest in London and in the North West of England (see Figure 1).
- 2.7 The prevalence of hepatitis C in injecting drug users in contact with health services is estimated as 38%. The prevalence of infection is higher in long-term users, those no longer in contact with services and homeless drug users.
- 2.8 A recent study suggests that the rate of new hepatitis C infections among injecting drug users in London and the South East is increasing¹⁸.
- 2.9 Some infected people may have experimented with injecting drug use only once or twice many years ago before the introduction of needle exchange schemes and at a time when there was an increase in recreational drug use.

Figure 1: Current and former injecting drug users in England: hepatitis C prevalence by region (data for 2001/02 combined)



* Data for these two regions have been combined due to small sample sizes

Data source: Unlinked Anonymous Prevalence Monitoring Programme survey of around 3,000 injectors in contact with drug treatment and support agencies each year

Knowing the risks

2.10 Current and past injecting drug users, those who received blood products before 1986, and recipients of blood transfusions before 1991 are the highest risk groups (see Table 1).

2.11 Other less common routes of infection include:

- from hepatitis C infected women to their babies during childbirth;
- from unprotected sex with a partner who has hepatitis C infection;
- through medical and dental procedures abroad in countries where hepatitis C is common and where hygiene may be poor;
- during tattooing or skin piercing by re-using blood-contaminated equipment (or through sharing blood-contaminated toothbrushes or razors); and
- from patient to health care worker and vice versa.

Table 1: Transmission of hepatitis C, England 1992–2002

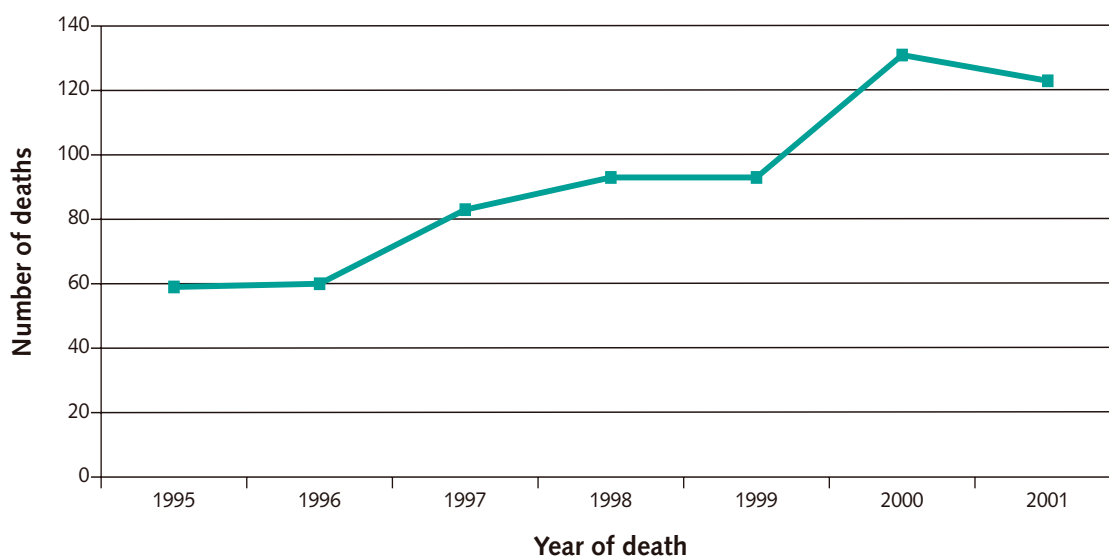
Risk factor (where reported)	Number of laboratory reports of hepatitis C infection	Percentage
Injecting drug use	10,057	91.1
Blood transfusion	279	2.5
Blood product recipient	249	2.3
Sexual exposure	195	1.8
Renal failure	108	0.9
Other known (i.e. organ/tissue transplant, surgical/medical, skin piercing, occupational)	90	0.8
Vertical (mother to baby) or family/household	67	0.6
	11,045	100

Data source: Health Protection Agency

Paying the price

- 2.12 Hepatitis C infection is the underlying certified cause of death in around 100 people each year (see Figure 2). It also contributes to some of the 5,000 deaths each year from the complications of chronic liver disease, including cirrhosis and primary liver cancer.

Figure 2: Hepatitis C mortality in England and Wales, 1995–2001



- 2.13 About 15% of liver transplants in England are undertaken because of liver damage caused by chronic hepatitis C infection. The consequences of hepatitis C infection are extremely serious. The impact on society is also significant. High costs of drug treatments (up to about £12,000 per patient), other medical interventions and liver transplants represent a substantial burden on the NHS. This underlines the importance of prevention of infection and disease progression.

Pathways of care

- 2.14 A clear pathway of care for patients diagnosed with chronic hepatitis C infection is necessary, from diagnosis to specialist assessment and treatment. Patients may receive care from hepatologists, gastroenterologists, or infectious diseases physicians. The National Institute for Clinical Excellence has issued guidance on combination antiviral drug therapy for the treatment of chronic hepatitis C in patients with moderate to severe liver damage¹⁷.
- 2.15 There is variation in the current delivery of care across the country and geographical inequalities in access to health care for people with hepatitis C¹⁹. Some groups of the population suffer from these inequalities more than others. There is a higher prevalence of chronic hepatitis C among prisoners, as the majority (60%) of injecting drug users pass through the prison system at some point. A window of opportunity exists while they are in prison to take preventive action and to improve their access to health care services.
- 2.16 Further development of specialised services is needed for the treatment and care of current and future patients. This will maximise the opportunities to reduce the serious consequences of infection with hepatitis C.

Chapter 3

International Outlook: How do we compare?

- 3.1 According to the World Health Organisation (WHO) there are 170 million people across the world (some 3% of the world's population) with chronic hepatitis C infection. This compares to 40 million infected with HIV.
- 3.2 In the United States, it has been estimated that 1.8% of the population (approximately 4 million people) has been infected with hepatitis C. In France, the figure is around 1%.
- 3.3 In some parts of the Middle East, Asia and Africa, the prevalence is much higher. In Egypt, around 18% of the population has the virus. This could have been caused, in part, by the re-use of contaminated needles for treatment for schistosomiasis in the Egyptian population between 1961 and 1986²⁰.
- 3.4 Although England, by comparison, is a low prevalence country (see Table 2), the risks of complacency are high.

Table 2: Estimated prevalence and number of people with antibody to hepatitis C

	Hepatitis C antibody prevalence (%)	Population in millions	Number of people with hepatitis C antibody
England	0.5	50	250,000
France	1.2	57	684,000
Italy	3.0	57	1,710,000

- 3.5 In Canada, a predictive model of the hepatitis C epidemic, in the absence of treatment, has been used. Based on 240,000 people currently infected, Canadian figures predict almost a doubling in cases of serious liver disease (cirrhosis) between 1998 and 2008, with a similar rate of increase in cases of liver failure and liver cancer over the same period. These projections highlight the importance of both preventing new infections and controlling disease progression²¹. Other countries, including the United States, Australia and France, have developed national strategies to this end.

Chapter 4

The Future

- 4.1 There is no vaccine available to protect against hepatitis C infection. The structure and biology of the virus make the development of an effective vaccine difficult. There are active research programmes here and in other countries which aim to overcome these problems. In the absence of a vaccine the focus must be on the prevention of infection by other means.
- 4.2 In the short term (five to ten years), illness and death due to hepatitis C are likely to increase. Infections acquired many years ago will show themselves and some people will develop serious liver disease.
- 4.3 When the actions set out in this Action Plan begin to take effect, it should be possible to turn this situation around and achieve a reduction in morbidity and mortality.

Chapter 5

The Actions

Action 1: Surveillance and research

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

Ongoing actions

- The HPA will strengthen epidemiological surveillance of hepatitis C infection to provide:
 - better estimates of prevalence and incidence in both the general population and in injecting drug users, so that the impact of prevention measures can be detected and evaluated; and
 - a better picture of the burden of liver disease to inform the planning of health services for patients.
- Cohort studies of hepatitis C infected patients will continue to provide more information on natural history of the infection which will also inform modelling studies designed to project future numbers of patients needing specialist treatment and care.
- The HPA will carry out molecular studies to detect any change in the circulating genotypes of hepatitis C and to investigate development of antiviral drug resistance.

New actions

- The National Treatment Agency for Substance Misuse (NTA) will develop a system for monitoring the offer and uptake of hepatitis C testing to all those attending specialist drug treatment and support services and the provision of needle exchange services, including throughput of needles and syringes across the country;
- The HPA will work with other stakeholders to produce an annual report on hepatitis C that will include progress on the National Outcome Indicators as set out in the *Hepatitis C Strategy for England*, which are:
 - total number of laboratory-confirmed hepatitis C infection reports;
 - proportion of those attending specialist drug treatment and support services for injecting drug users who are aware of their hepatitis C infection;
 - prevalence of hepatitis C in injecting drug users who started to inject in the last 3 years (recent injectors).
- Modelling techniques will be developed to assist in projecting the future numbers of patients needing specialist treatment and care for hepatitis C to inform planning of health services.
- The HPA will investigate the prevalence of cosmetic body piercing and the associated risks of infection.

Action 2: Increasing awareness and reducing undiagnosed infections

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

Ongoing actions

- The Department of Health will continue to develop professional awareness of hepatitis C in collaboration with other stakeholders.
- The Department of Health will work with other stakeholders, including the voluntary sector, to produce and launch a sustained public awareness-raising campaign on hepatitis C that is non-alarmist and non-stigmatising, specifically targeting affected groups.
- Hepatitis C testing facilities will be provided by NHS organisations in a range of clinical and community settings e.g. genito-urinary medicine clinics, general practice and drug treatment centres, in a way that will overcome barriers to access for marginalised groups like injecting drug users.

New actions

- The Department of Health will work with the Royal Colleges, professional regulatory bodies and others to promote inclusion of up-to-date information about hepatitis C in undergraduate, postgraduate and continuing education for health professionals.
- The Department of Health will produce guidance on hepatitis C testing for health professionals about who should be offered testing, the nature of pre- and post-test discussion, and referral for specialist assessment.
- The HPA will assess the need for, and feasibility of, self-collection of samples by patients in the community (home sample collection testing) as a way of broadening access to hepatitis C testing.

Action 3: High-quality health and social care services

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

Ongoing actions

- Chief Executives of Primary Care Trusts and NHS Hospital Trusts should be able to demonstrate that there are adequate services and partnerships at local level to enable models of best clinical practice to be followed, as set out in the *Hepatitis C Strategy for England*, including:
 - commissioning specialised services for hepatitis C needed for their patient population, in line with the specialised services national definition;
 - the development of clinical networks for the assessment and treatment of patients with hepatitis C, including the provision of services for particular groups of patients, such as those with hepatitis C/HIV co-infection, patients with haemophilia, children and those who may experience social exclusion, such as prisoners and injecting drug users;
 - access to accredited laboratory services able to provide the appropriate diagnostic tests, histopathology services specialising in liver histology, and radiology services suitable for the diagnosis, monitoring and management of patients with liver disease;
 - the development of local protocols between primary and secondary care centres to ensure patient pathways for both medical and social care that encompass testing, referral and the whole range of treatment services, including appropriate access to liver transplantation services;
 - Care Group Workforce Teams, the Workforce Review Team and the National Workforce Programme Board will work with Strategic Health Authority Workforce Directorates and Workforce Development Confederations to develop arrangements that take account of the need to ensure that the NHS has enough appropriately skilled staff in the future to deliver service improvements to patients with hepatitis C infection.

New actions

- Strategic Health Authorities will ensure that local NHS arrangements are in place to achieve the objectives of this action area.

Action 4: Prevention

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

Ongoing actions

- Drug Action Teams will develop local multi-agency arrangements for hepatitis C prevention, which link into other related areas such as sexual health and drug misuse.
- The NTA, Drug Action Teams and the Prison Service will review and strengthen, where necessary and appropriate, harm reduction services for the prevention of hepatitis C transmission associated with injecting drug use. These services, in line with best clinical practice as set out in the *Hepatitis C Strategy for England*, to include:
 - provision of needle, syringe and other injecting equipment exchange services in the community;
 - safe disposal of used needles and syringes;
 - provision of outreach and peer education services;
 - provision of specialist drug treatment services;
 - provision of information and advice about hepatitis C and other blood-borne viruses and the risks of injecting drugs (including stopping injecting, the risks of sharing injecting equipment and avoiding initiating others); and
 - provision of disinfecting tablets throughout the prison estate.
- All NHS organisations will minimise the risk of hepatitis C transmission within health care settings by the adoption of rigorous standard (universal) infection control precautions, occupational health checks for staff and effective management of occupational blood exposure incidents.
- Local Authorities will continue to work with NHS organisations to promote and audit good infection control practice in cosmetic skin piercing businesses, to provide information to the public about the potential health risks and how to choose a reputable business.

New actions

- The Department of Health will develop health promotion information explaining the risks of injecting drugs and how to avoid hepatitis C and other blood-borne viruses to give to all young people entering juvenile and young offenders' establishments and to other offenders.
- The Department of Health will work with stakeholders to provide information about avoiding hepatitis C infection abroad, including information for people from minority ethnic groups visiting their countries of origin.
- The NTA will develop proposals to carry out a national audit of needle exchange schemes, which will be used to inform future provision of harm reduction services for injecting drug users.
- Strategic Health Authorities will ensure that local NHS arrangements are in place to achieve the objectives of this action area.

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