



The UK vs. Europe:
Losing the Fight Against Hepatitis C

The
Hepatitis C
Trust



University
of Southampton

“ The Government must take much more effective action now to prevent unnecessary deaths from this serious, but treatable disease. The biggest hurdle we are facing is that hepatitis C has not been made a priority ”

Charles Gore,
Chief Executive, The Hepatitis C Trust

The Hepatitis C Trust, the UK's leading hepatitis patient group, commissioned the University of Southampton to produce this report, with valuable contributions from:

Dr Matthew Cramp – Derriford Hospital, Plymouth, Professor Peter Hayes – Royal Infirmary of Edinburgh, Professor Stefan Zeuzem – Saarland University Hospital, Germany, Dr Mireen Friedrich-Rust – Saarland University Hospital, Germany, Professor Ramon Planas – Universitari Germans Trias I Pujol, Spain, Professor Alfredo Alberti – University of Padova, Italy, Professor Christian Trepo – Hôpital de l'Hôtel-Dieu, France, Professor Patrick Marcellin – Hôpital Beaujon, France.

The UK vs. Europe: Losing the fight against hepatitis C

The UK is one of the worst countries in Europe at dealing with the deadly hepatitis C (HCV) virus.¹

It is estimated that 466,000 people in the UK are infected with hepatitis C.²

Only one in seven of those infected have been diagnosed with the disease, the remaining 86% of people are unaware of their status – putting themselves and others at risk.³

In the UK only 1-2% of those infected with hepatitis C have been identified and treated with NICE approved drugs,⁴ which can cure between 40-80% of those with moderate to severe hepatitis C.⁵

“We must realise that many of the predicted deaths from hepatitis C are avoidable. We must open our eyes to this epidemic and take the right preventative measures to curb the consequences. We know what these measures are, we can learn from Europe.”

Dr Matthew Cramp, UK

This report is a summary of interim findings – the full results will be published in 2006 with a set of recommendations. Urgent action is required to:

- **Increase diagnosis of hepatitis C through:**
 - A government awareness campaign of appropriate magnitude to identify those at risk and to reduce the stigma of a positive diagnosis
 - Setting annual diagnosis targets
 - Removing the emphasis on the route of transmission of infection
- **Increase the number of patients that are treated, and bring the UK in line with the rest of Europe through:**
 - Streamlining the process between diagnosis and treatment – such as shortening waiting times for appointments, combining diagnostic tests and removing bottlenecks
 - Developing additional awareness activities to underline the health consequences of remaining untreated and highlighting the routes of transmission
 - Providing ring-fenced funding to support NICE guidance on hepatitis C treatments

In short – hepatitis C should be a government PRIORITY. We must look to what our European neighbours have achieved and learn from their success before it is too late.

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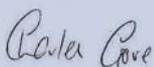
Foreword from Charles Gore, Chief Executive, The Hepatitis C Trust and Prof. William Rosenberg, Professor of Hepatology, University of Southampton

About this report

Hepatitis C is a treatable infectious disease that potentially threatens tens of thousands of lives in the UK. Through limited public awareness, the UK is facing a significant public health disaster. We believe that 466,000 people in the UK are infected² but only one in seven has been positively identified.^{6,7}



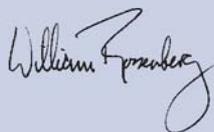
The Hepatitis C Trust is the national charity set up by people with the illness who were concerned at the lack of information and support available. It now runs a range of services that provide support, information and representation for people with Hepatitis C. It is also committed to raising awareness and lowering the stigma of this disease amongst the general population.



Charles Gore,
Chief Executive, The Hepatitis C Trust



William Rosenberg is Professor of Hepatology at the University of Southampton. He combines leading an active research group with clinical practice as a Hepatologist. His research interests are focused on hepatitis C and span epidemiology, clinical trials and studies of the immune response to HCV.



Prof. William Rosenberg,
Prof. of Hepatology, University of Southampton

There is low awareness of hepatitis C, not only amongst the general public, but also amongst the medical profession. With so little understanding of how the virus is spread, those who may have been exposed to it are not coming forward for testing or being identified by their GPs. They remain unaware, undiagnosed and untreated, putting themselves at risk of serious liver disease and potentially infecting others.

In England both the Dept. of Health's National Hepatitis C Strategy,⁸ published in August 2002, and the ensuing Hepatitis C Action Plan for England,⁹ published in June 2004, promised a public awareness campaign. However, when it was launched in July 2004, the 'FaCe It' campaign's small budget (£2.5 million over 2 years compared to £50 million to raise public awareness of sexually transmitted diseases) made it clear that the Dept. of Health's overriding concern was not to over-tax existing services. Indeed, the proposed Scottish Hepatitis C Action Plan calls for 'a low key information campaign through the press to improve public awareness of hepatitis C'. The Welsh Action Plan, currently being developed, may not call for any public awareness at all, hoping that campaigns in other parts of the UK will be enough.

Although there has been no proper surveillance of the incidence of new cases, with such low levels of awareness, particularly about transmission routes and prevention, and such small numbers being treated, it is certain not only that the pool of infection continues to grow but that the long term consequences of doing too little now become ever more severe.

The Hepatitis C Trust commissioned the University of Southampton to examine the different approaches to hepatitis C in four comparable European countries. A meeting of leading experts from across Europe was convened and research gathered to highlight in particular the successful strategies that have allowed those countries to diagnose and treat so many more people than the UK.

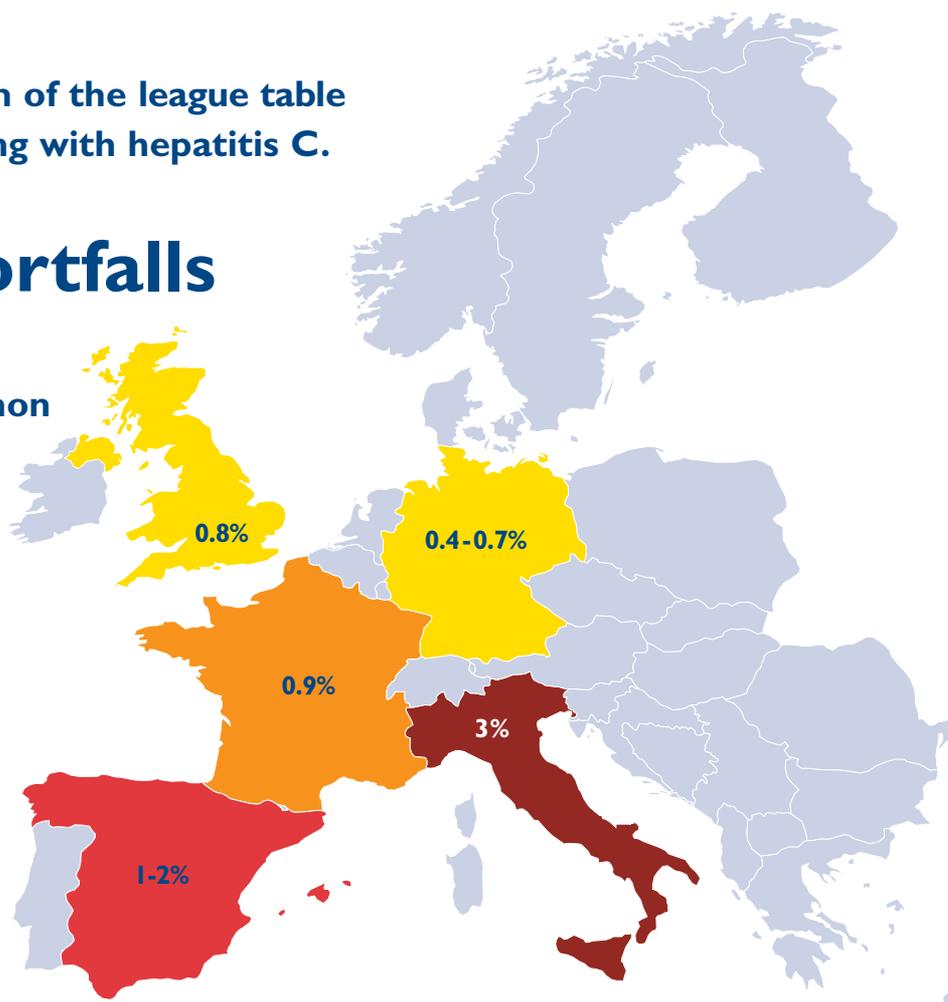
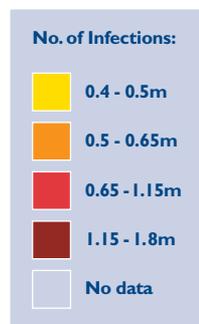
This report is a powerful assessment of the current state of managing hepatitis C in Europe and provides clear lessons which can be learned from our European neighbours. We hope that it will propel decision-makers into giving this potentially devastating disease the priority it deserves because we believe that if politicians and medical opinion leaders make the correct decisions before it is too late, the growing threat of hepatitis C can be significantly reduced.

Britain is at the bottom of the league table in every aspect of dealing with hepatitis C.

The UK shortfalls

HCV infection is common

European Prevalence (%)¹

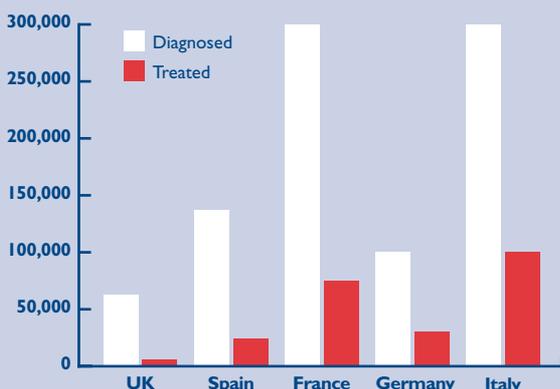


UK vs. Europe – Patients treated in 2004



Source: IMS Data 2004.

European figures for patients ever diagnosed and treated for hepatitis C¹



Of the 67,877 patients who are actually diagnosed as antibody positive in the UK,^{6,7} only one in 20 receives treatment each year.¹ Of the total number infected this treatment rates falls to only 1-2%.⁴

This compares to France where 13% of the total number infected receive treatment. In France, 6-12 times as many people diagnosed with hepatitis C are likely to receive treatment than those diagnosed in the UK.¹

The Hepatitis C Trust



The incidence of hepatitis C in the UK is steadily increasing. In contrast to the rest of Europe, where effective action has been taken to prevent new infections.

The UK hepatitis C epidemic

“If we do not act now, we risk the burden of hepatitis C bankrupting our healthcare systems.”

Professor Peter Hayes, Scotland

Should we accept a bleak future?

Unless we act now to increase screening:

- Large numbers of infected people will be capable of unknowingly transmitting the virus to others
- The level of hepatitis C infection in the UK population will escalate
- Thousands of people will remain unaware that they are living with a liver that is progressively deteriorating and will therefore be unable to make informed decisions about lifestyle and treatment options
- The rate of potentially fatal liver complications will continue to rise

The UK has the lowest percentage of people treated for hepatitis C when compared to her European neighbours, with 1-2% of those infected receiving NICE approved treatments.⁴ In any other therapeutic area, let alone one involving an infectious disease, a situation where more than 98% of patients are not treated with drugs that can prevent progression to fatal conditions would not be tolerated.

“The harsh reality is that hepatitis C infection is a serious public health problem that the UK is not equipped to address.”

Charles Gore, Chief Executive, The Hepatitis C Trust

If we continue to ignore the problem the impact on the NHS caused by the influx of patients with severe liver disease will be unmanageable. This could be wholly avoidable if action is taken.

Hepatitis C is viewed by some as the hidden killer, with most of those infected showing no symptoms over a long period of time.

Unless these people are identified and treated there will be an explosion of severe liver disease including cirrhosis and liver cancer, affecting 20% to 30% of those with the hepatitis C virus.¹⁰ More disturbingly, latest research in the UK suggests the explosion of severe liver disease may be as high as 70% or over 300,000 people.¹¹ Without a liver transplant many of these patients will die, yet the number of livers available for transplantation which is around 700 annually, is out of proportion to the potential demand.

“If nothing is done, in 10 to 20 years we are going to end up with tens of thousands of people needing liver transplants.”

Professor William Rosenberg, UK

Almost 90% of those people living with the hepatitis C virus remain unaware, undiagnosed and untreated.

In the UK less than half of all patients who are detected are referred to a specialist centre.¹² The remainder either never return to the GP to get results of the laboratory blood test or fall out of the system due to poor awareness of the long-term consequences of the virus. With early detection and treatment up to 80% of patients could be stabilised or cured.⁵

The Government has an obligation to avoid this burden and relieve society of the epidemic that has been predicted for the near future.

*“ The tragedy is
that a large number
of people in the UK
are dying through
ignorance. ”*

Professor Ramon Planas,
Spain

HÉPATITE

C

1 personne
atteinte sur 3
l'ignore encore

Pourquoi se faire dépister ?

- **Parce que vous pouvez être concerné(e)**

En France, près de 600 000 personnes sont infectées par le virus de l'hépatite C. Parlez-en avec votre médecin qui examinera avec vous si vous devez vous faire **dépister**.

- **Parce qu'il existe des traitements**

Les personnes infectées par le virus de l'hépatite C peuvent bénéficier d'un **suivi médical** et si nécessaire d'un **traitement adapté** qui est remboursé à 100%.

008 & Co. 057 500 1 317 866 405 - Photo : Frédéric Comte/PhotoA3

Parlez-en avec votre médecin

Un numéro utile : **Hépatites Info Service : 0 800 845 800**

(N° Vert ; appel anonyme et gratuit)

L'hépatite C sur Internet : **www.sante.gouv.fr** rubrique Hépatite C

Adresses des centres de dépistage anonyme et gratuit sur Minitel :

3611 code Hépatites + n° ou nom du département



MINISTÈRE DE L'EMPLOI
ET DE LA SOLIDARITÉ
SÉCRÉTARIAT D'ÉTAT À LA SANTÉ
ET AUX HANDICAPÉS

France is winning the fight against hepatitis C

Europe: The brighter picture

Prevalence of chronic liver disease and cirrhosis in France¹³



Source: WHO/Europe, HFA-MDB database, January 2005

France has significantly reduced deaths from liver disease in the last decade through the following measures:

- Having a government advocate for action on hepatitis C
- Establishing an effective hepatitis C virus specific network
- Setting clear targets for detection
- Having a clear strategy with dedicated funding
- Creating an adequate surveillance system to determine the extent of the problem and measure the impact of interventions
- Running annual media awareness campaigns aimed at anyone who might be at risk of hepatitis C
- Anonymous testing at a number of centres including family planning clinics, drug clinics, universities and prisons
- Including patient organisations at all stages of the strategy development and implementation

As a result of this government led campaign and adequate investment in hepatitis C services in France:

- Detection has more than doubled in ten years
- Patient awareness is high – four times higher than in Britain. In France 56% of those infected now know that they have the disease, compared to 24% in 1994¹
- Significant reduction in deaths from liver disease

“The action taken in France has been extremely effective. We need to follow their lead in taking a clearly planned, properly financed and well executed approach to this disease. That way we will be able to manage the future financial, as well as human cost.”

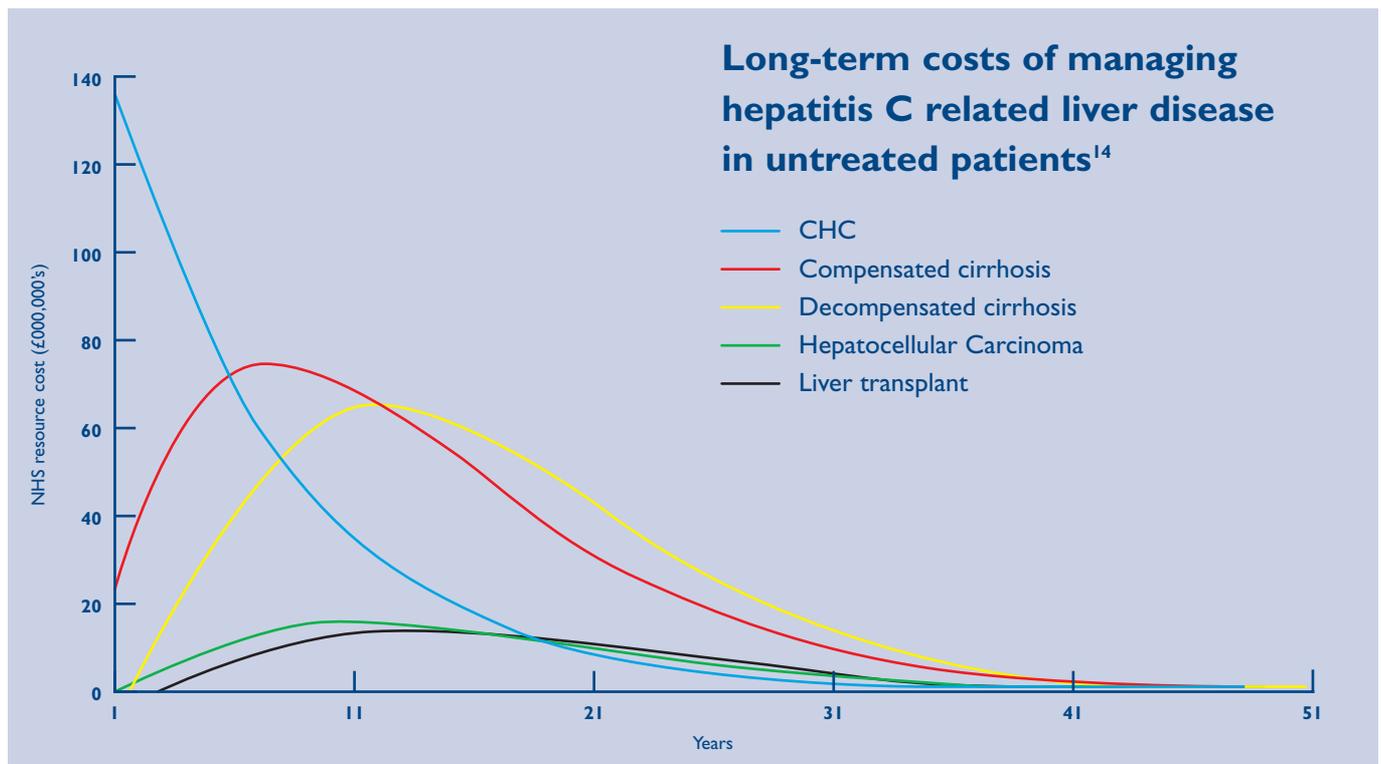
Charles Gore, Chief Executive, The Hepatitis C Trust

How the UK compares:

In the UK detection rates are static; patient awareness remains low – one in seven know that they have the disease and liver disease rates are set to rise.

By 2008 the costs of liver transplants, as a result of hepatitis C, have been projected to be £123 million in the UK.³

The financial consequences of not treating hepatitis C



Failure to treat people currently living in the UK with hepatitis C will cost the NHS an estimated £156 million to treat liver complications at one year.¹⁴

After 10 years this cost will have risen to £1.8 billion. More critically, it is estimated that it will cost the NHS £4.1 billion over the next 30 years.¹⁴ This is based on the lowest estimate of hepatitis C prevalence in the UK (24,000). The actual amount is likely to be as high as £8 billion, with 466,000 considered to be the likely number of people infected.^{1,2,14}

“Getting effective diagnosis and treatment has changed my life, yet thousands of patients do not have the chance of accessing treatment. If I hadn’t had this opportunity my future would have been quite different.”

Neil Hudson, Patient

A recent paper discussed the impending crisis for liver services, with an estimated 500% increase in the future demand for liver transplants in the UK.¹⁵

It is predicted that within 20 years time, more than three quarters of the total liver transplants performed in the UK would be required for hepatitis C alone if we fail to take action.

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Redressing the balance is simple, we can make a **START**:

Recommendations for making hepatitis C a priority

STRUCTURE – Improve the clinical infrastructure for delivery of care to hepatitis C patients through priority investment

TARGETS – Set targets for proactive screening of at risk individuals, effective referral and appropriate management

AWARENESS – Increase public awareness of the risk factors and consequences of the disease

RAPID REFERRAL – Improve referral to specialist services

TREATMENT – Offer more immediate treatment for those identified as being infected with hepatitis C

What if we don't **START** to make a difference?

- Infection rates will continue to soar
- Liver cancer rates will escalate
- Liver transplant service will be in crisis
- Patients and families will suffer
- NHS will suffer an increased and unmanageable strain on its finances

“There is no time to lose. If we are to control the hepatitis C epidemic, the time for action is now.”

Professor William Rosenberg, UK

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For further reliable information
on all aspects of hepatitis C
please visit www.hepcuk.info

or contact The Hepatitis C Trust
helpline on **0870 200 1 200**

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