



# The Uncomfortable Truth

Hepatitis C in England: The State of the Nation

OCTOBER 2013

THE HEPATITIS  TRUST

This report was written by The Hepatitis C Trust  
with support from MSD and Janssen†

# Foreword

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*“If we act now, we can eradicate hepatitis C from the UK within a generation”*

**Charles Gore, Chief Executive, The Hepatitis C Trust**

There must be no more excuses for the rising tide of deaths from hepatitis C. Hepatitis C is a preventable and curable virus. The fact that deaths from the virus have nearly quadrupled since 1996 is a scandal. It is absolutely unacceptable that half of those living with hepatitis C are still undiagnosed and a mere 3% of those infected are treated each year.

This report reveals plainly the link between hepatitis C and deprivation. Almost half of patients with hepatitis C who go to hospital are from the poorest fifth of society.

It begs the question: has hepatitis C been overlooked for all these years, resulting in spiralling hospital admissions and deaths, because of the people it impacts? Has it been ignored and under-prioritised because most of the people living with, and dying from, the virus are from the most marginalized, vulnerable, deprived groups of society?

One thing is certain: if the health service is to reduce health inequalities and “improve the health of the poorest, fastest”, hepatitis C must be addressed.

Almost ten years ago a ‘Hepatitis C Action Plan for England’ was published by the Department of Health, recognising hepatitis C as an overlooked condition, a “Cinderella service”. However, the Action Plan did not contain any benchmarks, targets, timelines, monitoring or evaluation measures to ensure implementation of the actions. As a result, implementation was patchy at best

and now, almost a decade on, many hepatitis C patients are never assessed for liver damage or offered potentially life-saving treatment.

However, the future could be bright. Treatments for hepatitis C have improved in recent years and new drugs with almost 100% cure rates and very few side effects are expected to be approved in the next few years. Furthermore, the emphasis on addressing public health and health inequalities in the recent NHS reforms should make tackling hepatitis C a priority.

Public Health England, local authorities, NHS England and clinical commissioning groups have a tremendous opportunity to work together to tackle hepatitis C. This report summarises the current ‘state of the nation’ of hepatitis C in England and challenges the new NHS to work together to provide hepatitis C patients with the care they need and deserve and in too many cases have not been receiving.

With coordinated and effective action to diagnose and offer treatment and care to everyone with hepatitis C, The Hepatitis C Trust believes that the virus could be effectively eradicated in England within a generation. Let’s stop talking about it. Let’s do it.

**Charles Gore**

Chief Executive, The Hepatitis C Trust

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## Abbreviations

<b>ALT test:</b> Liver function test measuring amount of alanine aminotransferase in the blood	<b>HPA:</b> Health Protection Agency
<b>APPHG:</b> All Party Parliamentary Hepatology Group	<b>IDU:</b> Intravenous (or injecting) drug user
<b>BASL:</b> British Association for the Study of the Liver	<b>LJWG:</b> London Joint Working Group for Substance Misuse and Hepatitis C
<b>BSG:</b> British Society of Gastroenterology	<b>MSM:</b> Men who have sex with men
<b>CCG:</b> Clinical Commissioning Group	<b>NHS:</b> National Health Service
<b>DBS:</b> Dry blood spot (test)	<b>NICE:</b> National Institute for Health and Clinical Excellence
<b>DH:</b> Department of Health	<b>ONS:</b> Office for National Statistics
<b>ESLD:</b> End-stage liver disease	<b>PCT:</b> Primary Care Trust
<b>GP:</b> General Practitioner	<b>PHE:</b> Public Health England
<b>HCC:</b> Hepatocellular carcinoma	<b>PCR:</b> Polymerase chain reaction
<b>HCV:</b> Hepatitis C virus	<b>PWID:</b> People who inject drugs
<b>HES:</b> Hospital episode statistics	<b>RCGP:</b> Royal College of General Practitioners
<b>HIV:</b> Human Immunodeficiency Virus	<b>SVR:</b> Sustained Virological Response

## Acknowledgements

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# 1 | Executive Summary

Around 160,000 people in England have chronic hepatitis C,<sup>1</sup> a preventable and treatable blood-borne virus that can lead to potentially fatal cirrhosis or cancer of the liver if left untreated. However, barriers to diagnosis, effective referral and treatment mean that many of these people are undiagnosed, and an increasing number are developing potentially fatal end stage liver disease.

Hepatitis C was acknowledged by the Department of Health as an overlooked ‘Cinderella’ disease almost a decade ago. It is a disease that disproportionately affects some of the most deprived and marginalised communities in England. But nearly ten years on, the disease continues to be overlooked and under-prioritised despite all national data sources showing that hepatitis C-related hospital admissions and deaths are increasing.<sup>3</sup>

- Despite being a curable infection, only 3% of people with hepatitis C receive treatment each year.<sup>4</sup>
- Almost half of the admissions to hospital for hepatitis C in 2010-11 were unplanned admissions, potentially costing the NHS between £15 and £22 million and indicating poor planning and wasted resources.<sup>5</sup>
- Almost half of people going to hospital for hepatitis C are from the poorest fifth of society.<sup>6</sup>
- In England, half of those living with hepatitis C are undiagnosed, at risk of transmitting the virus to others and developing life threatening liver disease.<sup>7</sup>
- It is essential to treat patients before the virus causes potentially fatal liver damage, but two thirds of surveyed patients believe that they had hepatitis C for ten years or more before their actual diagnosis.<sup>8</sup>
- Hospital admissions for hepatitis C-related end stage liver disease and liver cancer have risen year-on-year, almost quadrupling between 1998 and 2012.<sup>9</sup>
- Liver disease is the only major cause of mortality in England where deaths are rising, and it is deaths from hepatitis C that are rising fastest,<sup>10,11</sup> having nearly quadrupled since 1996.<sup>12</sup>
- Hepatitis C patients face a postcode lottery of care due to the lack of a national liver strategy. The last Government Action Plan for hepatitis C was published almost a decade ago,<sup>13</sup> and with no accountability mechanisms, implementation was patchy at best. Four years after it was promised, the Government is yet to confirm a publication date for a National Liver Strategy.

The NHS reforms could be a critical turning point in the battle against hepatitis C. There are now new incentives to prioritise the condition:

- The Government has recognised the importance of supporting early diagnosis in primary care, as part of its ambition to avoid 30,000 premature deaths per annum, and promote universal access to treatment.<sup>14,15</sup>
- The new NHS aims to ‘improve the health of the poorest fastest’<sup>16</sup> and addressing health inequalities is now a statutory requirement for all health and social care commissioners and providers.<sup>17</sup>

This report makes recommendations to improve prevention and awareness initiatives, to normalise testing and increase diagnoses, and to remove the barriers to treatment and care.

**With concerted action The Hepatitis C Trust believes that hepatitis C could be eradicated within a generation. With national leadership and coordinated local action we can prevent new infections and reverse the rising mortality trend.**

*“It is a travesty that increasing numbers of patients on our wards are dying from hepatitis C when so many patients with early disease can be cured and protected from liver damage”*

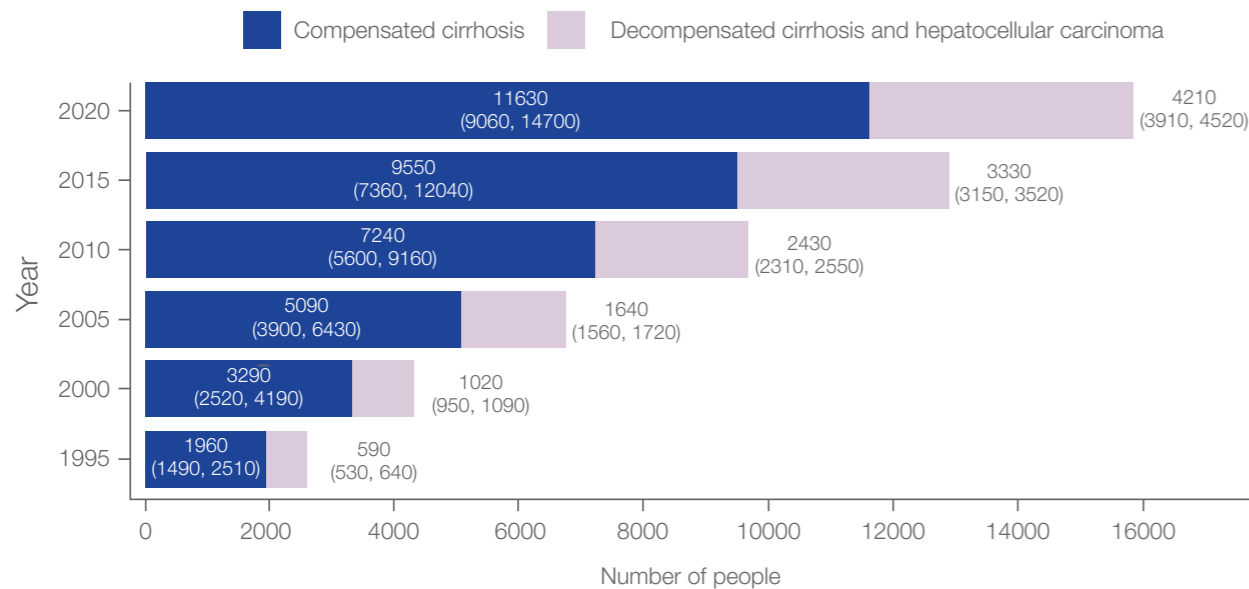
**Professor Graham Foster, President of the British Association for the Study of the Liver**



## An introduction to hepatitis C in England

Hepatitis C is a blood-borne virus that can lead to potentially fatal cirrhosis or cancer of the liver if left untreated. It has been called a “silent epidemic” as it is often asymptomatic in its early stages of chronic infection and so can be difficult to diagnose. When symptoms do present, the lack of public and professional awareness about the condition means that the virus is often misdiagnosed, or passes undetected for many years. Hepatitis C has also been continually overlooked and under-prioritised, despite all national data sources showing that hepatitis C-related hospital admissions and deaths are increasing.<sup>18</sup>

If left untreated, Public Health England predicts that, by 2020, 15,840 will be living with hepatitis C related cirrhosis or hepatocellular carcinoma (HCC). For patients developing decompensated cirrhosis or HCC, a liver transplant is required.<sup>27</sup>



Adapted from the PHE Report 2013: Estimated number of people living with HCV-related cirrhosis or decompensated cirrhosis and hepatocellular carcinoma in England: 1995-2010<sup>28</sup>

*“We cannot continue to allow people with hepatitis C to be so under-served, their voices unheard”*

Dr Paul Cosford, Director for Health Protection, Public Health England

## What is hepatitis C?

The World Health Organization first declared hepatitis C a global health problem in 2006. Worldwide an estimated 150 million people are chronically infected, and 350,000 die every year from hepatitis C-related liver disease.<sup>29</sup> Experts agree that only a small minority of people with hepatitis C have been diagnosed and treated, even within more economically developed countries.<sup>30</sup> As a result, increasing numbers of people who were infected before the scientific discovery of the virus in 1989 are now developing complications from end stage liver disease (ESLD). Hepatitis C is now the underlying cause of 25% of cases of liver cancer globally<sup>31</sup> and the leading cause of liver transplants worldwide.<sup>32</sup>

The hepatitis C virus (HCV) primarily attacks the liver, an organ which plays a crucial role in regulating important functions, such as cleansing the body of toxins and storing carbohydrates and other essential vitamins and nutrients. If left untreated, chronic hepatitis C infection can lead to scarring (cirrhosis) and sometimes tumour growth within the liver or liver failure.

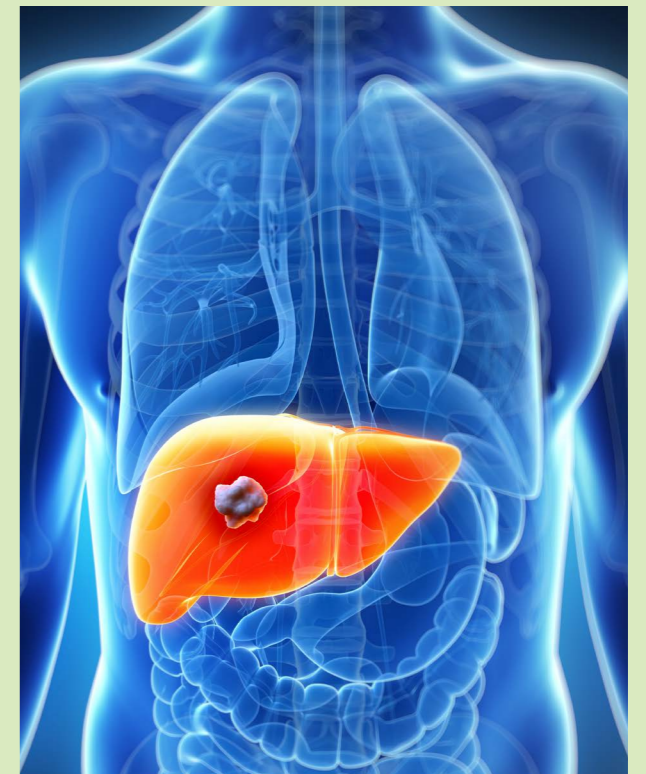
In most cases of chronic hepatitis C infection, the external warning signs are absent, mild, or more commonly non-specific. Symptoms can include:

- Chronic fatigue
- Flu-like symptoms including sweating, problems with concentration, headaches and anxiety
- Loss of appetite and/or weight loss
- Alcohol intolerance
- Pain and discomfort in the area of the liver
- Cognitive impairment

If the virus is treated, the earlier stages of liver damage (fibrosis) can be reversible. If left untreated, the virus can cause progressive liver failure termed ‘decompensation’, a point at which the functioning parts of the liver can no longer compensate for the damaged parts. Age at acquisition, being male, HIV co-infection and alcohol consumption are all associated with increased risk and speed of progression to this more advanced stage of disease.<sup>33</sup>

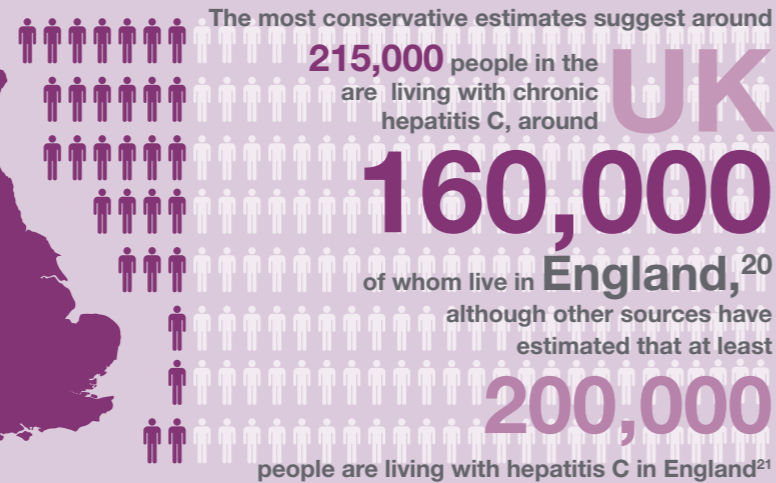
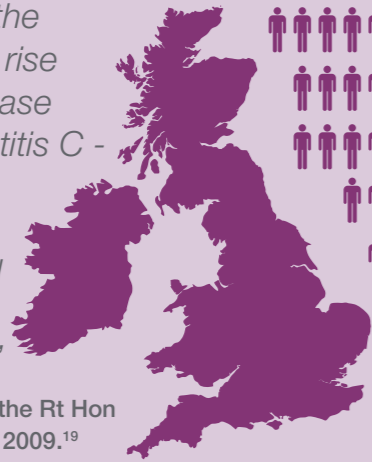
End stage liver disease has poor survival prospects unless liver transplantation is available. Even then, in the UK nearly 100 people die on the waiting list for a liver transplant every year, and many are not even placed on the waiting list because they are diagnosed too late.<sup>34</sup> For those that do receive a transplant, if infection has not been completely eradicated the patient’s new liver is eventually re-infected by the hepatitis C virus in nearly all cases.<sup>35</sup> Unfortunately, the course of recurrent disease is accelerated after transplantation, with up to 20% of transplant patients developing cirrhosis within five years.<sup>36</sup> In addition, the standard anti-viral drugs currently used to treat hepatitis C prior to the onset of ESLD are poorly tolerated after liver transplantation, leaving these patients with few options.<sup>37</sup>

**It is thus crucial that hepatitis C is identified and treated as early as possible, prior to the onset of advanced liver disease.**



“And perhaps the most shocking rise in modern disease has been hepatitis C - since 1997 the number of cases reported each year has almost trebled”

The Prime Minister, the Rt Hon David Cameron MP, 2009.<sup>19</sup>



Public Health England estimates that only **3%** of hepatitis C patients receive treatment each year<sup>23</sup>



In England, **half** of those living with hepatitis C are undiagnosed, at risk of transmitting the virus to others and developing life threatening liver disease<sup>22</sup>

**1996-2012**

Deaths from hepatitis C quadrupled between 1996 and 2012<sup>26</sup>



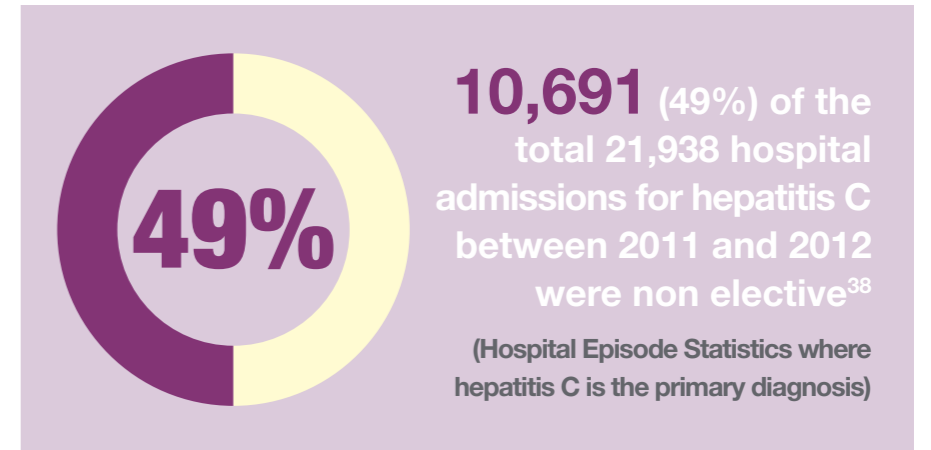
Nearly **1 in 5** liver transplants carried out in 2011 arose from hepatitis C-related cirrhosis and between 1996 and 2012 the number of registrations for liver transplants in England from hepatitis-C related cirrhosis increased nearly three-fold<sup>25</sup>



**Hospital admissions**

As a preventable and curable infection, non-elective hospital admissions for complications related to hepatitis C should be extremely low. Patients should ideally be visiting hospital only for scheduled monitoring or anti-viral treatment appointments.

**New analysis of hospital statistics reveals around half of all recorded hospital admissions for hepatitis C are non-elective.**



The president of the British Association of the Study of the Liver, Professor Graham Foster states that, “hepatitis C patients who are diagnosed with cirrhosis or liver cancer have been failed by the NHS. People with hepatitis C should be diagnosed and offered treatment before the onset of serious liver damage. With concerted national and local efforts to address hepatitis C, emergency admissions for hepatitis C related complications could be minimal.”

Non-elective hospital admissions are also expensive.

The average cost of a non-elective in-patient admission, including both short and long stays, is £1,436 excluding excess bed days and £2,052 including excess bed days. Therefore, the estimated financial cost to the NHS of these avoidable 10,691 non-elective hospital admissions was between £15 million and £22 million in the NHS year 2011-2012.<sup>39</sup>

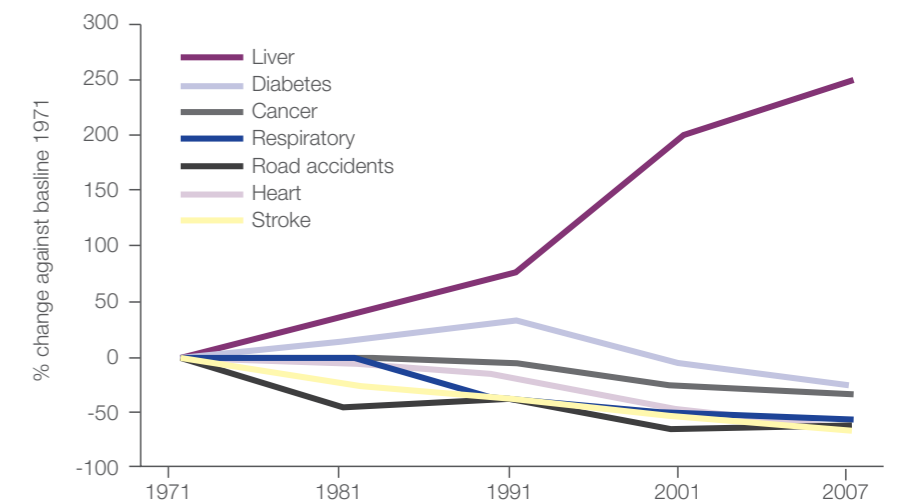
With better planning, including diagnosing and treating patients earlier, the vast majority of these non-elective admissions could be avoided.

**Hepatitis C and Liver Disease**

Liver disease is the only major cause of mortality in England where deaths are rising, and in the area of liver disease it is deaths from hepatitis C that are rising fastest. Liver disease is now the fifth biggest killer in the UK, with alcohol-related liver disease and viral hepatitis as the principal contributors.<sup>42</sup> Addressing hepatitis C is therefore crucial to any efforts to reduce mortality from liver disease.

The Office of National Statistics has listed hepatitis C as the only type of liver disease that is ‘amenable’ to healthcare, meaning that deaths can be avoided through good quality healthcare.<sup>44</sup> As a curable virus, hepatitis C is arguably the only area of liver disease where significant progress can be made in a short period of time.

Adapted from HPA and NHS Liver Care. Figure 1.3: Trend in Mortality from Liver Disease in Relation to trends in Mortality from Other Causes in England, 1971-2007<sup>43</sup>





**Marie from Shropshire**

Over 22 years ago, Marie had a caesarean section following the birth of her second child. When she subsequently developed septicaemia, she received a blood transfusion which contained the hepatitis C virus. This happened in 1991, before bloods were routinely screened. Only 18 years later did Marie start to experience symptoms which prompted her GP to perform tests. She now wants to share her experience to raise awareness and dispel any myths about the virus. “When I was diagnosed, I was frightened that I may have passed it on to my children and husband. Thankfully they all came up negative. People need to know hepatitis C is not infectious outside of blood to blood contact. I’d hate to think others should go through the same discrimination I have, or not be able to talk openly about their condition with loved ones and friends”.



It is estimated that liver disease directly causes **12,000** deaths, and contributes to a further **36,000** deaths per annum<sup>45</sup>

The average age of death for someone dying from liver disease is **59**, and getting younger<sup>46</sup>

Liver disease already costs the NHS at least **£500 million** a year, a cost rising by 10% annually<sup>46</sup>

League Tables	
10	
11	United Kingdom
12	

The UK has declined from 6th to 11th position in the league table of 18 comparable countries for years of life lost to cirrhosis<sup>48</sup>

To be able to deliver against their requirements to reduce under-75 mortality from liver disease, commissioners will need to **focus** on hepatitis C

# 3 | C for Cinderella

## The neglect of hepatitis C and health inequalities consequences

The Department of Health first described hepatitis C as a ‘Cinderella’ disease area – “one that has a relatively low profile compared with other areas of health service development” – in 2004.<sup>50</sup> Despite numerous calls from hepatitis C related charities and professional bodies for concerted national action,<sup>51</sup> and the availability of NICE approved treatments that can cure the virus in around 70-80% of patients,<sup>52</sup> little has changed ten years on.

The 2004 National Action Plan for Hepatitis C made recommendations in four areas: surveillance and research; increasing awareness and reducing undiagnosed infections; high-quality health and social care services; prevention. The Plan claimed that it would be “possible to...achieve a reduction in morbidity and mortality” if its recommendations were enacted.<sup>53</sup> Unfortunately, the Plan did not specify a timetable, nor provide any benchmarks, surveillance systems, accountability mechanisms or targets. As a result, implementation has been patchy at best. Indeed, an audit conducted by the All Party Parliamentary Hepatology Group in 2006 found that only 8% of PCTs (16 out of 191 who responded) were effectively implementing the Plan’s recommendations and that “hepatitis C care depends on where you live – it is a matter of chance”.

Following calls for stronger action by the British Association for the Study of the Liver, the British Society of Gastroenterologists, the British Liver Trust and The Hepatitis C Trust, in 2009 the Labour Government announced that a National Liver Strategy encompassing hepatitis C would be developed.<sup>55</sup> In 2010, after the election, the Coalition Government recommitted to a National Strategy.<sup>56</sup>

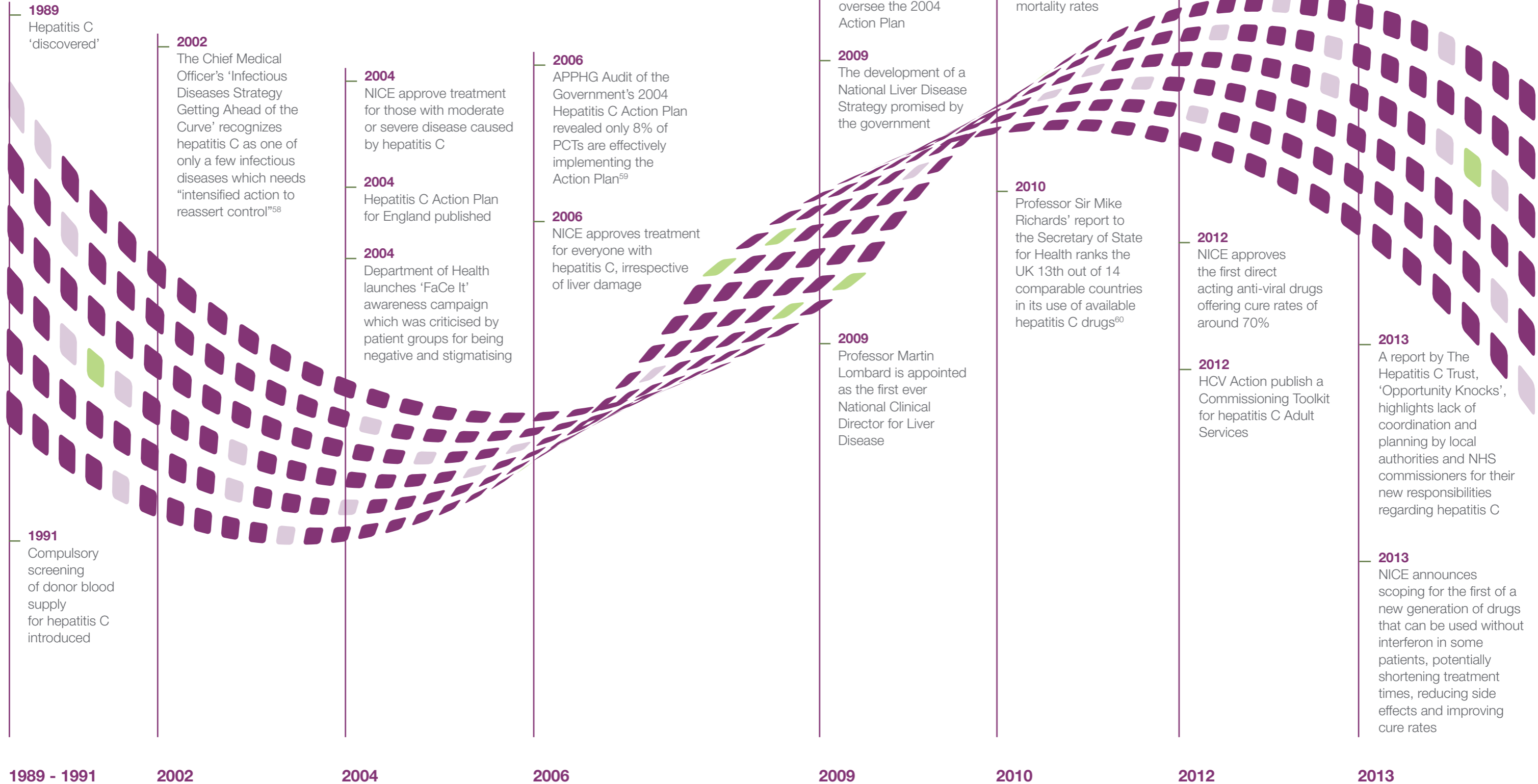
Four years on, however, there is still no National Liver Strategy.<sup>57</sup> As of April 2013, NHS England assumed responsibility for developing a Liver Disease Outcomes Strategy, but have yet to announce even a publication date.

*“Unless vastly more vigorous efforts are made now at local level by PCTs, encouraged by targets and a timetable set out nationally by the Department of Health, we predict that hepatitis C will in the future become a crushing burden to our health service and that we will look back and know that we could have prevented that happening”<sup>61</sup>*

All Party Parliamentary Hepatology Group, 2006



## Hepatitis C in England Timeline



## THE NEW NHS: A CHANCE FOR CHANGE

The implementation of the Health and Social Care Act 2012 provides an opportunity for change, if hepatitis C is prioritised by public health and NHS commissioners.

### Addressing Premature Mortality

In March 2013 the Secretary of State for Health, the Rt Hon Jeremy Hunt MP, launched ‘Living Well for Longer: a call to action to reduce avoidable premature mortality’.<sup>62</sup> Within the consultation paper, the government highlighted the importance of supporting early diagnosis in primary care, as part of its ambition to avoid 30,000 premature deaths per annum, and promote universal access to treatment.<sup>63,64</sup>

Addressing hepatitis C will therefore help achieve the high-level outcome of reducing premature mortality from liver disease as specified in both the NHS Outcomes

Framework and the Public Health Outcomes Framework for England 2013-2016.<sup>65</sup>

Reducing the prevalence and transmission of hepatitis C in England will also help secure improvements in several of the key outcome areas, including:

- Reducing mortality from cancer
- Improving early diagnosis
- Reducing mortality from communicable disease and from preventable causes
- Improving the quality of life for individuals with long-term conditions
- Reducing health inequalities



#### Sharon from East Sussex

Sharon, who works for a government department, to this day still does not know how she contracted hepatitis C. She never received a blood transfusion, or had a tattoo or body piercing outside of registered premises within the UK and hasn't used drugs of any kind. Most likely she caught it from medical treatment she received as a child spending a number of years growing up in Dubai and Bahrain.

Sharon's infection was first detected in 2001, after offering to give blood. However, the specialist she was subsequently referred to incorrectly told her that she couldn't be cured. When her liver biopsy results came back without any anomalies she was told she would be fine. Regarding alcohol intake, she was told "as long as you don't become an alcoholic, you'll be OK".

Eight years after her diagnosis, Sharon happened to speak to her dentist about her hepatitis C and it was he who advised her to seek additional medical advice. She was finally referred to her local hospital and offered treatment. However, Sharon recounts instances of cancelled appointments with her doctor, receiving inadequate information about anti-viral drugs, and an incident where she was given the wrong blood test results, and told the virus was undetectable when in fact the results were unclear. "This was all very frustrating and I eventually made a complaint to my health care provider".

### Addressing Health Inequalities

Health inequalities cost England £31-33 billion every year in productivity losses and additional NHS healthcare costs well in excess of £5.5 billion per year.<sup>66</sup> The NHS reforms have made addressing health inequalities a statutory requirement for all health and social care commissioners and providers.<sup>67</sup> Sir Michael Marmot's DH commissioned review of health inequalities in England found that the more socially deprived people are, the higher the chance of premature mortality.<sup>68</sup> The Public Health England's 'Living Longer' Atlas recently confirmed this finding.<sup>69</sup>

If the government, public health and NHS managers are serious about reducing health inequalities, addressing hepatitis C must become a priority. Hepatitis C disproportionately affects some of the most marginalised groups in society such as the homeless, men who have sex with men, injecting drug users, prisoners and first generation migrants.

The Chief Medical Officer has already highlighted the fact that mortality rates for infectious hepatitis were significantly higher among people from the most deprived fifth of society, than the least deprived fifth between 2001-2010.<sup>73</sup>

**New analysis of hospital episode statistics reveals almost half (48%) of people with hepatitis C admitted to hospital are from the most deprived fifth of society (the lowest socio-economic quintile) and nearly three quarters are from the two most deprived quintiles.<sup>74</sup>**

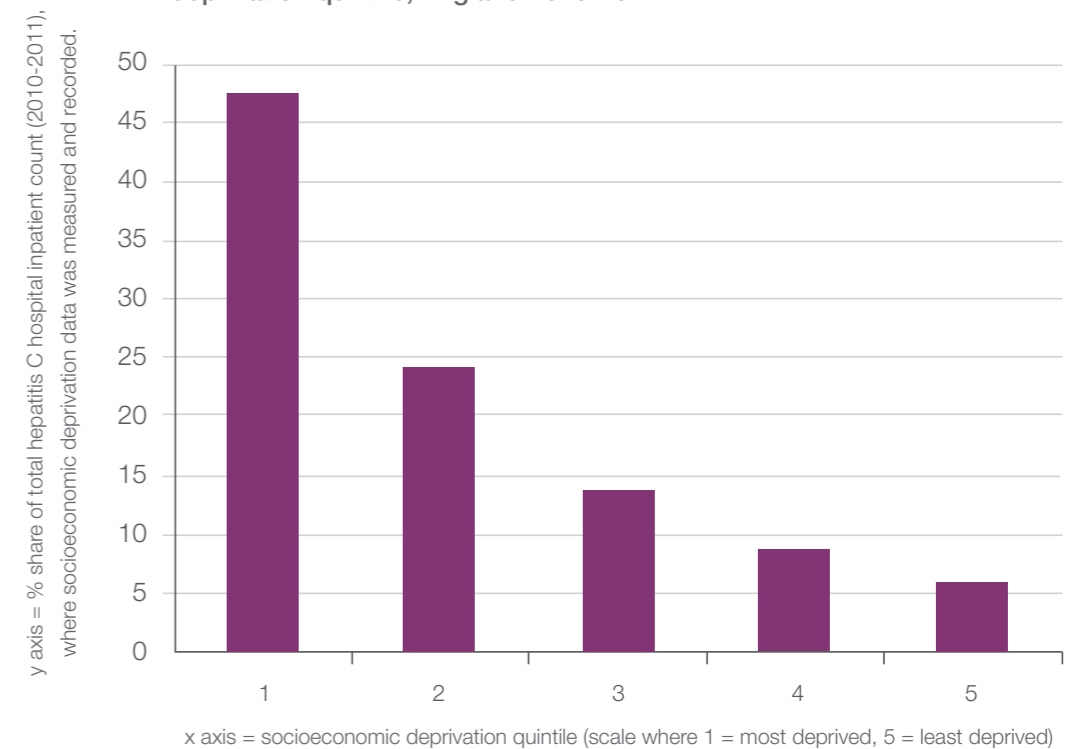
*"Everyone should have the same opportunity to lead a healthy life; no matter where they live or who they are"*

**The Rt Hon Jeremy Hunt MP, Secretary of State for Health<sup>71</sup>**

*"There can be no more chilling form of inequality than someone's social status at birth determining the timing of their death"<sup>72</sup>*

**Diane Abbott MP, Shadow Minister for Public Health**

**Proportion of hepatitis C hospital inpatients from each socio-economic deprivation quintile, England 2010-2011<sup>75</sup>**





The need to tackle health inequalities is one issue all political parties agree on:

*“Our overall vision [is] to improve and protect the nation’s health while improving the health of the poorest fastest” - Public Health Outcomes Framework for England 2013-16<sup>70</sup>*

## THE NEED TO NETWORK

As of April 2013, local authorities assumed responsibility for addressing hepatitis C from a public health standpoint. NHS England is now responsible for commissioning specialist treatment, and CCGs have undertaken the responsibility of commissioning all other hepatitis C-related non-complex treatments. The absence of a National Liver Strategy means there is a real danger that the new NHS reforms could allow hepatitis C to be further under-prioritised and fragmented. For example, an audit conducted by The Hepatitis C Trust in 2012-13 found that only 24% of NHS commissioners had done an assessment of current and future need relating to hepatitis C.<sup>76</sup>

Clinical networks will be vital to ensuring people with hepatitis C receive ‘joined up’ care from multiple providers. The All Party Parliamentary Hepatology Group and The Hepatitis C Trust have recommended that NHS England pilots the establishment of liver networks as part of their supported strategic clinical networks programme to drive improvements in the structuring of services across the country.<sup>77</sup> Unfortunately, liver disease is not yet one of the disease areas for the Strategic Clinical Networks that are being developed. There are several informal networks of different sizes across the country trying to bridge this gap by connecting care across primary, secondary and tertiary services with public health services, virology, social care, prison healthcare, and mental health services.



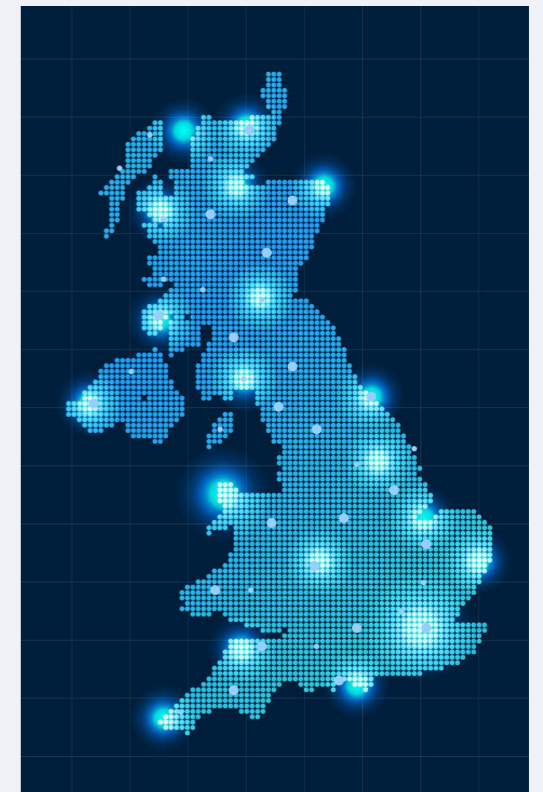
## Yorkshire and Humber Liver Network

Whilst Strategic Clinical Networks for the liver are not to be commissioned centrally, at this stage the NHS Commissioning Board has recommended the setting up of networks for other conditions based upon local need. The need for a formal ‘liver network’ across Yorkshire and the Humber has been evidenced through the work of the Regional Hepatitis B and C Steering Group and the West and East Yorkshire Hepatology Network. These two groups have now been merged to create a more encompassing Yorkshire and the Humber Liver Network to allow a range of stakeholders to be brought together to identify priorities and agree a work programme across the region. The Network consists of public health specialists (both LA and PHE), commissioners, consultants and nurses, drug and alcohol services as well as other agencies with relevant expertise and service users.

The aim of the Network is to introduce a strategy to reduce the burden of liver disease in Yorkshire and the Humber through providing a multi-disciplinary network to advise on the key themes of:

- Awareness raising for professionals and the public
- Training and education for professionals
- Prevention strategies for individuals at risk
- Early detection in high risk groups
- Timely provision of accessible treatments in line with national and local guidance

Members of the Network are expected to agree and approve any guidelines, protocols and policies and are the source of expertise for any strategic decisions and developments (as they relate to the remit of the group) with regards to the liver across Yorkshire and the Humber.



## HCV Action: a growing network of hepatitis C health professionals

HCV Action is a partnership between healthcare and pharmaceutical industry professionals who are committed to championing care for hepatitis C patients. This growing national network includes consultants, specialist nurses, GPs, drug service staff, prison healthcare staff, psychiatrists, public health specialists and commissioners working across the UK. In order to help commissioners maximise the opportunities presented by the NHS reforms, HCV Action has developed a commissioning toolkit for public health and NHS commissioners. As well as providing a strategic overview of the services required, it helps generate the detail required for service specifications, providing important links to details on service redesign, care pathways, quality standards, outcome frameworks and performance management.<sup>78</sup>

[www.hcvaction.org.uk](http://www.hcvaction.org.uk)

## THE BURDEN OF HEPATITIS C

Hepatitis C is a significant national public health problem. However, there are also alarming and unwarranted regional variations in its burden. Referral pathways, clinical practice and the local prevalence of co-morbidities such as alcohol and drug misuse can all shape local rates of infection or progression to end stage liver disease.

The recent NHS Atlas of Variation in Healthcare for People with Liver Disease states that such unwarranted variation is also potentially shaped by disparities in the reach and quality of hepatitis C services across England.<sup>79</sup>

## TOP TEN CCGs FOR HOSPITAL ADMISSIONS FOR HEPATITIS C, 2011-12

CCG	ADMISSIONS 2011-2012
NHS Liverpool CCG	805
NHS Cambridgeshire And Peterborough CCG	506
NHS North, East, West Devon CCG	505
NHS Newham CCG	383
NHS East Lancashire CCG	371
NHS Southampton CCG	363
NHS Bristol CCG	345
NHS North Manchester CCG	344
NHS Hull CCG	334
NHS Sheffield CCG	333

## ESTIMATED NUMBER OF PEOPLE LIVING WITH HEPATITIS C<sup>80</sup>

North West  
**39,991**

East Midlands  
**12,327**

West Midlands  
**14,832**

South West  
**19,705**

South East  
**16,061**

North East  
**6,773**

Yorkshire and Humber  
**19,258**

East of England  
**12,759**

London  
**40,000**

The capital of hepatitis C



Half of those living with hepatitis C are undiagnosed



There are over **40,000** people living with hepatitis C in London, with more individuals being infected every year.

The London Joint Working Group (LJWG) on Substance Misuse and Hepatitis C is currently piloting recommendations aimed at improving rates of access to assessment and treatment for people with a history of drug misuse in four London boroughs: Lambeth, Haringey, Croydon and Islington. More information at [www.ljwg.org.uk](http://www.ljwg.org.uk).



## Prevention, awareness and testing

The World Hepatitis Alliance, a global network of patient groups, has adopted the “See no evil, Hear no evil, Speak no evil” proverb to highlight how viral hepatitis is being ignored around the world. This proverb applies equally well to the state of awareness, testing and prevention in England.

To truly address hepatitis C in England, the remaining half of people who are living with an undiagnosed infection must be found and referred to specialist care.<sup>83</sup> Diagnosing people early is essential to ensuring they can access the treatment needed to clear the virus, or make the necessary lifestyle changes to slow its progression. Importantly, they will also be able to take measures to ensure they do not transmit the virus to others.

The Hepatitis C Trust recently conducted an online ‘Route to Diagnosis’ survey amongst people with hepatitis C.<sup>84</sup> It found that:

- Too many people are being diagnosed late: 76% believed that they had hepatitis C for ten years or more before their actual diagnosis.<sup>85</sup>
- Too many people are developing potentially fatal liver disease as a consequence of being diagnosed too late: 51.2% had already developed fibrosis or cirrhosis by the time of their first appointment with a specialist consultant.<sup>86</sup>

To improve rates of testing and diagnosis in England a real step change in public and professional awareness is needed.

Recognising this need, in December 2012 the National Institute for Health and Care Excellence (NICE) issued guidance on ways to promote and offer testing for hepatitis B and C.<sup>87</sup> The guidance covers recommendations for actions and improvements by local authorities, GPs, midwives, obstetricians, prison staff, drugs services and sexual health services. This guidance should be vigorously promoted and its uptake should be monitored.

## Guidance for local authorities: Normalising testing

- As part of their public health responsibilities, local authorities must lead initiatives to test and diagnose people with hepatitis C in high-risk communities, such as current or former injecting drug users, baby boomers, migrant communities from high prevalence countries, and the homeless.
- To help embed and normalise hepatitis C testing, commissioners should include hepatitis C testing (with consent) whenever bloods are tested for hepatitis B or HIV as the risk factors often overlap. Hepatitis C testing should also be included as a routine opt-out test for pregnant mothers when they are offered testing for hepatitis B and HIV.
- Testing should be made easily accessible and offered through outreach work in the community without the need to go to the hospital for a full blood test. Dried blood spot tests and oral swab tests should be available if the person prefers not to have a full venous blood test.

## New technologies improving access to testing

Alternative testing technologies to venepuncture, such as dried blood spot (DBS) or oral fluid testing, have been increasingly used for hepatitis C testing in recent years. Indeed, the number of individuals tested in England using these two methods increased year on year between 2007 and 2010, from 4,433 to 8,519 per annum (although these alternative methods have been used mainly by specialist drug services). Many former or current IDUs have described poor venous access and euphoric recall as two reasons for avoiding venepuncture screening, expressing a preference for DBS.<sup>88</sup>

The development of alternative testing technologies also allows testing to be performed more easily in the community, making it easier to find and test ‘hard to reach’ high risk groups. There have been successful pilots of testing in pharmacies and using a mobile testing unit.<sup>90,91</sup> Local authorities should explore opportunities for embedding testing in the community in high prevalence areas as part of their new public health remit.



## Hepatitis C and Prisons

There is an exceptionally high prevalence of hepatitis C in prisons. A study in 1997 showed a prevalence of 7% amongst prisoners in England.<sup>92</sup> However, according to recorded national data, only 6% of new receptions to prisons were tested for the virus in 2011.<sup>93</sup> The Hepatitis C Trust recently convened an expert panel of offender health specialists to make recommendations to NHS England, now responsible for commissioning healthcare within detention settings.<sup>94</sup> The Hepatitis C Trust has also recently launched a free prison helpline to provide much needed information and emotional support. PHE is now considering making opt-out testing for hepatitis C a normal part of the prisoner induction process, a proposal which The Hepatitis C Trust strongly supports.



### Guidance for GPs: Active Case-finding

GPs could significantly improve the number of opportunities to diagnose and support people with hepatitis C. The Hepatitis C Trust's 'Route to Diagnosis Survey' revealed that 39% of patients sought medical advice about their hepatitis C related symptoms 5 years or more before their actual diagnosis.<sup>95</sup>

### Active case finding by GPs should be encouraged. This could be done by:

- Including hepatitis C in the Quality and Outcomes Framework
- Case-finding software which can help doctors to identify patients who have been at risk and who should be offered a test
- Encouraging GPs to complete the Royal College of General Practitioners' (RCGP) module in the detection and diagnosis of hepatitis B and C in primary care to improve awareness amongst the profession
- Piloting ALT liver testing in the NHS Health Check

### Guidance for Commissioners: Effective monitoring to drive improvements

Estimating the incidence and impact of hepatitis C in England is complicated by the lack of data on prevalence, treatment rates and outcomes of the disease.<sup>96</sup>

Commissioners of services should require the following information as part of their performance management, as well as to inform local CCG and local authority public health planning and to drive improvements:

#### Drugs services and GP practices should monitor:

- Number of people accessing the drug service
- Number of people offered a hepatitis C test
- Number of people tested for the hepatitis C virus (HCV)
- Number of people HCV antibody positive
- Number of HCV antibody positive people RNA tested
- Number of people HCV RNA positive
- Number of people referred to secondary care for hepatitis C
- Number of people cured

#### Treatment services should monitor:

- Number of hepatitis C patients referred
- Number of patients cirrhotic at first assessment
- Number of hepatitis C patients initiated on treatment
- Number of current injecting drug users initiated on treatment
- Number of patients cured

#### Prison services should monitor:

- Number of people offered a hepatitis C test
- Number of people tested for the hepatitis C virus (HCV)
- Number of people HCV antibody positive
- Number of HCV antibody positive people RNA tested
- Number of people HCV RNA positive
- Number of hepatitis C patients referred to specialist care
- Number of hepatitis C patients initiated on treatment
- Number of people cured



### Guidance for Government: Raising Awareness

To drive improvements in testing and diagnosis rates, improved public awareness about the virus is necessary so that people can assess whether they have been at risk of infection, and come forward for testing. This can also help to dispel myths about the condition, and reduce stigma and discrimination which people with hepatitis C often experience.

The Department of Health's 'Get tested. Get treated' awareness campaign, initiated in 2009 made a good start at normalising and de-stigmatising testing. However, its reach was limited and funding was withdrawn in 2010. A new national campaign targeted at those who have been at risk of infection is needed.

In the meantime, The World Health Organization in collaboration with the World Hepatitis Alliance global network of patient groups run a 'KNOW IT, CONFRONT IT' campaign for World Hepatitis Day, 28th July.

### Prevention: The True Cure

It is in everyone's interest to prevent the transmission of hepatitis C.

NHS England's recent 'The NHS belongs to the people' call to action predicted that continuing with the current model of care in England will result in the NHS facing a funding gap of £30 billion between 2013/4 and 2020/1 (an estimate before taking into account any productivity improvements and assuming the health budget will remain protected in real terms).<sup>97</sup> It highlighted the importance of investment and partnering in prevention and public health: 'refocusing the NHS workforce on prevention will shape a service that is better prepared to support individuals in primary and community care settings'.<sup>98</sup>

In England, we can make the most immediate impact in reducing rates of transmission by increasing public awareness alongside treating current injecting drug users with hepatitis C. In England, around half of people who inject drugs are infected with hepatitis C, a figure which has remained relatively stable over the past 10 years.<sup>99</sup>

**1. Harm Reduction:** Improving awareness about hepatitis C, and ensuring all drug users have access to sterile needles and other drug taking paraphernalia is vital.

**2. Treatment as prevention:** By treating people we can reduce the pool of infection, as well as the likelihood of future transmissions. Modeling has also strongly suggested that even modest rates of hepatitis C

treatment among active IDUs could dramatically reduce the prevalence of hepatitis C among this group.<sup>100</sup> For a long time the assumption has been that such patients' lifestyles are too chaotic to allow them to adhere to treatment. However, there are many examples of active IDUs successfully completing treatment when given the right care and support.<sup>100</sup>

### Successfully treating drug users in a community setting

The Windmill Practice in Nottingham has successfully treated current injecting drug users through adapting the care pathway to allow hepatitis C treatment to be delivered within a primary care drug treatment clinic setting. 62% (33 of 53 patients) of its patients achieved SVR at the end of 2012, with many reporting that they would not have accessed hepatitis C treatment at any other venue.<sup>102</sup>

Hepatitis C is a preventable and curable infection, with currently available and NICE approved treatments clearing the virus in the majority of hepatitis C patients.<sup>103</sup> However, it is estimated that only 27,500 people were treated with pegylated interferon (part of the NICE recommended combination therapy) between 2006 and 2011, which equates to only 3% of the infected population per year.<sup>104</sup>

A variety of factors have contributed to this poor rate of treatment uptake: half of those living with the virus are undiagnosed; many of those who have been diagnosed have not been referred to specialist care or have been referred but are 'lost to follow up'; some people are not offered treatment for medical or lifestyle reasons; and some people choose not to do treatment, fearing the side effects or choosing to wait for new drugs to be available. A recent study by IMS Health described the cumulative effect of 'gaps' (including unwarranted variation in diagnosis rates and access to specialists,

insufficient service capacity, deficient commissioning, and variations by post-code) as "most notable in the treatment of hepatitis C" as compared to other diseases.<sup>105</sup> In 2010 an All Party Parliamentary Hepatology Group audit revealed massive variation in the proportion of hepatitis C patients being offered treatment in English hospitals, ranging from 20% to 100% of new referrals.<sup>106</sup> 12 hospitals, almost one-fifth of those participating in the audit, offered treatment to less than 50% of the patients referred to them.<sup>107</sup> There is also evidence to suggest unwarranted

national variation in waiting times to commence treatment. Only 55% of participants in The Hepatitis C Trust's 'Route to Diagnosis Survey' reported being offered treatment within a year of their diagnosis. A 2010 report to the Secretary of State for Health by Professor Sir Mike Richards ranked the UK 13th out of 14 comparable countries in its use of available hepatitis C drugs. He blamed challenges in the "organisation, planning and capacity", since UK uptake was still low even when international differences in prevalence rates were taken into account.<sup>109</sup>

### Current treatment options

Anti-viral therapies have been developed to clear the virus (known as sustained viral response – 'SVR'), thus preventing the patient's progression of liver disease. The current recommended treatment for people with genotypes 2 or 3 in the UK is a dual therapy course of 'pegylated interferon' (injected weekly under the skin) and 'ribavirin' (taken twice daily in the form of tablets). The former assists the body's immune system, and the latter helps to inhibit the replication of the virus. For genotype 1 patients, the recommended treatment course is the same with an additional direct action 'protease inhibitor' agent. A full course can last 24 - 48 weeks.<sup>110</sup>



### Delays in treating patients

The number of hepatitis C patients treated in England fell by 6% between 2010 and 2011. Public Health England speculated that this reduction could be the result of a variety of factors, including clinicians or patients waiting for new drugs, services reaching the limits of existing treatment capacity, or reaching treatment saturation of those individuals who are easy to access, leaving mostly those who are harder to reach.<sup>111</sup>

Some patients actively choose to delay treatment in the hope of enrolling on a medical trial for one of the new-generation drugs. However, it is important that patients are fully informed of the risks of delaying treatment, and are carefully monitored if they choose to delay. While there are no reliable predictors of the rate of progression on an individual level, it has been noted to be more rapid in certain patient types including those with advanced liver disease, diabetes, histories of substance misuse or other co-infections.<sup>112</sup> Furthermore, mass delays could increase the likelihood of spikes in demand in the future,

leading to 'bottlenecks' in service delivery pathways if commissioners are unprepared.

Some patients have also complained that healthcare professionals have not even offered them the option of treatment. A 2010 APPHG audit of hospitals found that hospitals had widely differing, often informal policies concerning who could receive treatment. 10 hospitals refused NICE approved treatment to all injecting drug users, 55 hospitals offered it to some patients but with varying criteria, and two hospitals even refused treatment to anyone continuing to consume alcohol.<sup>113</sup> Many clinicians assert such decisions are ethical and cost-effective, as alcohol and drug use could reduce the drugs' efficacy, or the patient's likely chances of adherence to the full course of treatment. However, there is little or no evidence for this and The Hepatitis C Trust believes more could and should be done to support these patients to ensure they can adhere.

*"We must ask ourselves – are people with hepatitis C 'hard to reach' or are our services "difficult to access"?"*

Dr Helen Harris,  
Public Health England

*"Every person who goes to their doctor with hepatitis C related end stage liver disease is a missed opportunity"*

Professor the Hon. Richard Tedder  
FRCP, Head of the Blood Borne Virus  
Unit, Public Health England

Accessing treatment requires numerous hospital appointments which may be many miles from home, creating a barrier for many patients. Well-connected, well-resourced and well-monitored local care pathways with opportunities for treatment in community settings can ensure hepatitis C patients are able to access potentially lifesaving treatment and care. Networks can ensure that patients receive specialist consultant input to their treatment decisions and care, but treatment can be delivered in the community by specialist hepatitis C nurses.

**Barriers can be removed by simple steps in the local care pathway:**

**1. Reducing the number of appointments and tests required for diagnosis:** if someone tests positive for hepatitis C antibodies, the laboratory should automatically test the sample for virus RNA to see whether the person has active infection.

- 2. Ensuring all patients are referred to specialist care:** all patients with a RNA positive hepatitis C diagnosis should be able to see a specialist hepatologist to discuss their diagnosis and treatment options. Where possible, this should be in a community setting to make the service easily accessible.
- 3. Improving support:** peer-to-peer support should be developed to reduce 'did not attend' rates for hospital appointments and to reduce treatment drop-out rates.
- 4. Improving monitoring:** local monitoring of testing, diagnosis, referral, attendance and treatment rates should be collected to drive improvements in the system and highlight barriers.



## The future for hepatitis C and recommendations

*"I call on all those involved across the health and care system and beyond to come together to determine what they should be doing to support their local communities to live longer, healthier lives [...] we need to start making changes now. It is time to be bold and ambitious for health"*

The Rt Hon Jeremy Hunt MP, Secretary of State for Health, 2013<sup>114</sup>

The Hepatitis C Trust believes that the virus could be effectively eradicated in England within a generation. This is a rare opportunity to make a difference to tens of thousands of lives and to avert massive future costs to the NHS. The treatments and tools to eradicate hepatitis C are already in place; what is needed now is the political will and leadership to coordinate meaningful change.

- Hepatitis C should be prioritised by Public Health England, NHS England, local authorities and clinical commissioning groups as a major health inequalities issue
  - The National Liver Outcomes Strategy should be published as a matter of urgency
  - Public Health England, NHS England, local authorities and clinical commissioning groups should work together to commission and plan across the care pathway using HCV Action's Hepatitis C Commissioning Toolkit
- Greater public awareness is needed to reduce discrimination against people with hepatitis C, and encourage those at risk of future infection to avoid infection and those at risk of past infection to get tested
  - Targeted awareness campaigns should be rolled out for those who had blood transfusions before September 1991, those travelling to endemic countries, steroid users, those having tattoos and/or skin piercings at home or in unlicensed parlours, men who have sex with men (MSMs) and former injecting drug users
- Increasing the reach of prevention messages, improved access to sterile drugs paraphernalia and treating current injecting drug users to reduce the pool of infection must be prioritised by local authorities and Public Health England
  - All needle exchange workers, drug workers and prison staff should receive training on hepatitis C testing, prevention and treatment
  - Peer-to-peer awareness and support programmes should be made available in all drug treatment centres

- Active case finding by GPs, prisons, drugs services and local authorities should be incentivised and monitored
  - GP case finding should be incentivised through the Quality and Outcomes Framework
  - Testing should be included in the maternal screening programme, ALT liver testing should be piloted with the NHS health check and hepatitis C testing should be expanded to community settings, such as pharmacies
  - Opt-out hepatitis C testing for all inmates should be introduced in all prisons
- Local referral pathways and support mechanisms should be developed to ensure that everyone who is diagnosed is successfully referred to specialist care
  - At least one GP per practice should undertake the RCGP module in the detection and management of hepatitis B and C to improve professional awareness of hepatitis C
  - NHS England should pilot the establishment of liver networks as part of their supported strategic clinical networks programme to drive improvements in the structuring of services across the country

**Hepatitis C is a curable and preventable infection – national leadership and coordinated local action could diagnose and treat most hepatitis C patients, reversing the rising mortality trend and preventing new infections.**

## GLOBAL LEADERS IN PREVENTION, SCREENING AND TREATMENT

### USA

An estimated **3.2 million Americans** are chronically infected with the hepatitis C virus, which now causes more deaths than HIV per annum<sup>120</sup>

### FRANCE

France led the world in the proportion of its hepatitis C patients who received treatment in 2010:

**6.7% - double that in the UK<sup>124</sup>**

### SCOTLAND

Scotland launched a five year **£100 million** national program to diagnose and treat hepatitis C in 2008



In June 2013, New York State legislators became the first to pass a state bill that would require hospital and other health care providers to offer hepatitis C screening to adults born between 1945 and 1965, as recommended by the US Center for Disease Control and Prevention.<sup>121,122</sup> The US Preventative Services Taskforce also recently upgraded its recommendations to screen hepatitis C infection among adults at high risk for infection and 1-time screening for the 1945-1965 birth cohort to a B.<sup>123</sup>

- Efforts to increase in the coverage of needles/syringes, cookers and filters as well as the uptake of methadone have been accompanied by a promising downward trend in injecting risk behaviour and recent hepatitis C infection amongst people who inject drugs.<sup>115</sup>
- The proportion of chronic infections that are diagnosed has increased from 38% in 2006 to likely over 50% by 2012.<sup>116</sup>
- In each of the last three years, more than 1000 patients have commenced a course of hepatitis C therapy in Scotland, compared with up-to 450 patients per annum prior to the Action Plan Phase II.<sup>117</sup> The annual amount of patients receiving treatment has now nearly tripled since 2007.<sup>118</sup>
- "Transparency and accountability" have been crucial to success of Scotland's Action Plan, according to Professor Goldberg, Chair of Scotland's Hepatitis C Action Plan Governance Board.<sup>119</sup>



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