

Speak up for elimination:

General Election 2017





A manifesto for elimination

This manifesto outlines what we would like the next UK Government to do in order to ensure that we eliminate hepatitis C as a major public health threat by 2030, in line with our global commitment to do so.

No matter the make-up of the next Government, hepatitis C must receive the attention that it deserves as a serious public health issue that affects some of the poorest and most disadvantaged people in our society.

Despite the seriousness of the issue, hope springs from the fact that hepatitis C is one public health issue we really can do something about in a very short space of time. By diagnosing, treating and curing more people, we can eliminate hepatitis C by 2030, so let's get on and do it.



About The Hepatitis C Trust

The Hepatitis C Trust is the national UK charity for people with hepatitis C. Founded in 2001, we are patient-run and most of our board, staff and volunteers either have or have had hepatitis C.

We provide a range of support services to people affected by hepatitis C, and work with frontline services (such as prisons and substance misuse services) to improve their response to hepatitis C. We also campaign for a more ambitious approach to be taken to addressing the virus, and engage with policy-makers across the four nations of the UK to ensure that increased numbers of people are tested, diagnosed and treated for this preventable and curable condition. Our overarching goal is for hepatitis C to be eliminated as a serious public health concern in the UK by 2030.

Key facts



214,000 people

in the **UK** are estimated to be chronically infected with hepatitis C.



An estimated

50% of people

with hepatitis C remain **undiagnosed**.



Over the last decade, hospital admissions from hepatitis C-related liver disease have nearly tripled and deaths have doubled.



Almost **half** of people who go to hospital for hepatitis C are from the **poorest** fifth of society.





In May 2016, the UK Government pledged its support for the WHO's goal of eliminating hepatitis C as a major public health threat by 2030.



What is hepatitis C?

Hepatitis C is a blood-borne virus affecting the liver. Four-fifths of those infected develop chronic hepatitis C, which can cause fatal cirrhosis and liver cancer if untreated. Around 214,000 people are chronically infected with hepatitis C in the UK, with 160,000 of these in England.

Hepatitis C is transmitted through contact with infected blood. The majority of cases arise through injecting drug use, though there are other causes, including overseas medical care, tattooing and receipt of a blood transfusion or blood products in the UK prior to 1991.

People are able to live without symptoms for decades after infection, but untreated cases can lead to severe liver problems. Liver disease is one of the five 'big killers' in the UK and is the only one of these where mortality is rising. Hepatitis C is the

third most common cause of liver disease.

Hepatitis C disproportionately affects disadvantaged and marginalised communities, with almost half of people who attend hospital for hepatitis C coming from the poorest fifth of society. 50% of injecting drug users in England are infected with the virus. Other groups who are disproportionately affected include homeless people, prisoners and migrant communities from countries with a high prevalence of hepatitis C, such as Pakistan and Poland.



Our vision

- People living with hepatitis C no longer have to face stigma or discrimination as a result of the virus.
- People diagnosed with hepatitis C receive appropriate support in order to ensure they are able to cope with their diagnosis and be supported into the care pathway.
- Hepatitis C testing is considered a routine part of healthcare, and healthcare professionals have a comprehensive knowledge of hepatitis C.
- New, curative hepatitis C treatments are available to everyone.
- National plans for eliminating hepatitis C exist in each nation of the UK, with a view to eliminating hepatitis C by 2030.

Current policy landscape

In May 2016, the UK joined 193 other member states at the 69th World Health Assembly in committing to eliminate hepatitis C globally by 2030.

New drug treatments for hepatitis C have been approved as cost-effective for use on the NHS in England by the National Institute for Health and Care Excellence (NICE). With high cure rates and few side-effects, these new treatments offer the opportunity to treat more people and eliminate hepatitis C as a serious public health concern in England. However, in many respects England is falling behind in terms of international efforts to address hepatitis C. Despite previous commitments by the Government to produce a national strategy for tackling the virus in England, no such strategy has emerged.

In addition to the absence of any national strategy to address hepatitis C, NHS England has also taken the unprecedented step of placing a cap on the number of patients who can access treatment, specifying a limit of 12,500 treatment initiations for 2017/18. Together with local 'run rates' for treatment to which each area must adhere, this approach denies people with hepatitis C their right to NICE-approved treatments as enshrined in the NHS constitution, and limits the potential that exists to eliminate hepatitis C as a serious public health concern.

03 Speak up for elimination: General Election 2017



What people with hepatitis C need from the next Government

Prevention

Where we are:

• The provision of hepatitis C awareness campaigns and prevention services varies across local authorities, with budgetary pressures often cited as a factor behind cuts in support.

What we need from the next Government:

• To protect and increase ring-fenced public health funding to local authorities, to ensure they are able to fulfil their duty to raise awareness of hepatitis C and providing effective prevention services, such as needle exchanges.

Testing

Where we are:

With only around half of all people with hepatitis C in England diagnosed and a large proportion
of those already diagnosed not in touch with services, we will soon run out of people to treat in
some parts of the country, despite the rationing.

What we need from the next Government:

• To develop a hepatitis C action plan focused on developing the practical steps required to increase testing and diagnosis, in order to ensure the fulfilment of the WHO's diagnosis and treatment targets. The plan must emphasise the importance of linking diagnosed patients into the treatment pathway and set out a strategy for re-engaging previously diagnosed patients who have been lost to care.

Treatment

Where we are:

• The current cap on the number of people able to receive treatment each year endangers progress towards meeting the WHO target for 80% of all people with hepatitis C to be treated by 2030. It also causes severe harm to the physical and mental health of those waiting for treatment, and risks patients disengaging from care. The most disadvantaged and marginalised people may also drop out of the care pathway entirely if made to wait for treatment.

What we need from the next Government:

• Support for a 'treat all' strategy' (focused on providing treatment in community settings) which would end the cap on the number of people who can be treated and ensure an increase in the number of patients receiving NICE-approved hepatitis C treatments.

Commissioning

Where we are:

Currently, there can exist confusion around commissioning responsibilities for hepatitis C services.
 As a result, the pathway can often fail to reward investment and commissioners at certain points of the pathway (particularly Clinical Commissioning Groups) can be less inclined to view hepatitis C as a priority area.

What we need from the next Government:

• To issue a paper clarifying hepatitis C commissioning responsibilities, and to communicate these responsibilities to all relevant commissioning bodies.

Prisons

Where we are:

Hepatitis C prevalence in prisons is estimated to be around 20%. However, testing rates in prisons remain highly variable, and the availability of treatment for prisoners is still hugely inconsistent.

What we need from the next Government:

- To engage with NHS England and prison governors on the issue, highlighting good practice examples and providing governors with data on prevalence within prisons and information about the opportunities afforded by new treatments.
- To re-introduce the Prison and Courts Bill in the new Parliament and amend it to include the requirement for the Secretary of State's annual report on prison performance to provide an update on BBV testing and treatment rates in each prison.

05 Speak up for elimination: General Election 2017



What people with hepatitis C need from the next Government

Drug services

Where we are:

- Testing for hepatitis C in drug services is variable, with some failing to offer testing despite the high prevalence of the virus among injecting drug users.
- Whilst hepatitis C treatment is delivered in some drug services, such provision is far from commonplace, with many people who are often described as 'hard to reach' still facing significant barriers to accessing treatment.

What we need from the next Government:

- To encourage local authorities to include a requirement for opt-out testing for hepatitis C in commissioning contracts with drug services and needle and syringe providers.
- To work with NHS England and local authorities to encourage the provision of hepatitis C treatment in drug services.

Elimination

Where we are:

• The UK Government has signed up to the WHO target to eliminate hepatitis C by 2030 but there currently exists no working definition of what 'elimination' may look like in an English context, and the steps towards elimination have not yet been mapped out.

What we need from the next Government:

 To develop a 'roadmap to elimination' paper, identifying the short, medium and long-term steps required to ensure the attainment of the WHO target.

07 Speak up for elimination: General Election 2017