Eliminating Hepatitis C in England

Key information

- 160,000 people in England are estimated to be chronically infected with hepatitis C, a blood-borne virus that can cause fatal liver damage and cancer if left untreated.

- Hepatitis C is preventable, treatable and curable, but testing and diagnosis rates are still far too low, and only around 27,000 people are thought to be diagnosed and in touch with services.

- England has made progress in recent years, with the introduction in 2013 of opt-out testing for blood-borne viruses in prisons across England by PHE, NHSE and NOMS. However, with the long-awaited hepatitis C improvement framework recently abandoned by NHS England and an unprecedented cap placed on treatment access, in other respects it is falling behind many other nations.

- With new, curative drug treatments approved as cost-effective for use on the NHS, hepatitis C can be eliminated as a serious public health concern in England by 2030, provided there is commitment by the UK Government and health bodies to do so.

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. Recent estimates suggest that around 214,000 people are chronically infected with hepatitis C in the UK, with 160,000 of these in England.¹

Hepatitis C is mainly transmitted through contact with infected blood.² The majority of cases arise through injecting drug use, though overseas medical care, tattooing and receipt of a blood transfusion in the UK prior to 1991 are also potential causes.³

People are able to live without visible symptoms for decades after infection. If patients do become ill with the complications of hepatitis C, this can be very severe. Liver failure and liver cancer require urgent hospital care and patients can require liver transplantation.

As highlighted by the All-Party Parliamentary Group on Liver Health’s Inquiry report into improving outcomes in liver disease, liver disease is one of the five ‘big killers’ in the UK and is the only one of these where mortality is rising.⁴ Hepatitis C is the third most common cause of liver disease, and whilst the consequences of continued inaction will be catastrophic in terms of wasted human lives and NHS resources spent on treating liver cancer and providing transplants, hepatitis C is in fact an area of liver disease that is extremely amenable to healthcare intervention.

Crucially, hepatitis C is preventable, treatable and curable for the majority of patients.
Hepatitis C Patient Perspective: Mark’s Experience

- Mark has found living with hepatitis C to be a daily struggle: “I find it hard to live with for lots of reasons... knowing that my risk of getting cirrhosis, liver cancer and a list of other life-threatening goes up every passing day. Clock’s ticking. I also live with reduced energy and some days hit a wall where I just plain run out of gas. The brain fog is another difficult symptom of hepatitis C, with a loss of concentration, focus and memory and a tendency towards depression and low moods. I feel a reduced ability to cope with stress, and I live with the knowledge that I could infect someone else. I’m a reservoir for a fast mutating virus and I could hurt someone else.”

- Treatment experiences: “I had the Interferon dual therapy with Ribavirin. The virus was undetectable for the final 36 weeks of my treatment and once I got over the side effects I felt fantastic for about three months. Most of my symptoms were gone and I felt really happy and full of life. Sadly, that didn’t last and the virus was back in my six-month test. That experience shows me how much better my life could be if I was free of the virus, and it saddens me that I can’t get access to the new drugs. I know the new drugs are expensive but does that really stack up against the cost of liver transplants, ongoing treatment, deaths and day-to-day misery for thousands of people?”

Who are the risk groups?

Hepatitis C disproportionately affects disadvantaged and marginalised communities, with almost half of people going to hospital for hepatitis C from the poorest fifth of society and with the latest figures showing that 50% of injecting drug users in England are infected with hepatitis C.

Other groups who are disproportionately affected include migrant communities from countries with a high prevalence of hepatitis C, such as Pakistan and Poland, and homeless people.

Eliminating hepatitis C is therefore a highly effective way of contributing towards a fairer and more equal society, and is essential if health and social care commissioners are to meet their statutory requirement to address health inequalities.

Elimination of hepatitis C: A moral, social and economic imperative

With a raft of new drug treatments having recently been approved as cost-effective for use on the NHS by the National Institute for Health and Care Excellence (NICE), the elimination of hepatitis C as a serious public health concern in England is now a wholly achievable goal.

In order to seize this new opportunity, we must find the 50% currently undiagnosed by widening access to testing and investigating which groups can be cost-effectively screened. By increasing diagnoses, we will be able to treat and cure more people. With new treatments now available that are both highly-effective and highly-accessible (given their short treatment durations and the absence of significant side-effects), the potential exists for a rapid increase in the numbers of people treated and cured every year.
A commitment to elimination would not only bring hope to the people in England with the virus, but would allow some of the country’s most marginalised and disadvantaged citizens to recover from a debilitating illness which has a negative impact on them physically, psychologically, economically and socially. Eliminating the virus would also bring about significant economic benefits in terms of reduced healthcare and welfare costs, even though many of the savings will be in the medium to long-term. Balanced against this opportunity is the threat that, in the absence of action, the tide of mortality from hepatitis C-related liver disease and liver cancer will continue to rise and the infection will continue to be transmitted, at huge cost in terms of wasted human lives and NHS resources.

**Current policy development**

In May 2016, the UK joined 193 other member states at the 69th World Health Assembly in committing to eliminate viral hepatitis C globally by 2030. In order to achieve this goal, the UK Government needs to support the adoption of an ambitious package of measures seeking to substantially increase diagnosis and treatment rates for hepatitis C, promote joined-up working across a fragmented commissioning pathway and prevent new infections.

Clear policy progress with regards to hepatitis C has been made in recent years, in secure and detained settings in particular. Following campaigning by The Hepatitis C Trust, NHS England, Public Health England and the National Offender Management Service (NOMS) committed to a system of opt-out blood-borne virus testing for all prisons in England, with universal coverage aimed for by 2016/17.

However, in other respects England is falling behind in terms of international efforts to address hepatitis C. Since the spring of 2014, NHS England and Public Health England had been working with third sector organisations including The Hepatitis C Trust to develop a strategic approach aimed at laying the groundwork for the elimination of hepatitis C as a serious public health concern in England, entitled the ‘Hepatitis C Improvement Framework’. Numerous answers to PQs and public statements, including by the Public Health Minister Jane Ellison MP, had seen the Government promise that the improvement framework would be released. However, following successive delays, and in contrast to Scotland where the Government’s Sexual Health and Blood Borne Virus Framework includes a commitment to the elimination of hepatitis C as a serious public health concern, NHS England has now announced that it has no plans to release a strategy.

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 10,011 treatment initiations for 2016/17. Together with local ‘run rates’ for treatment that each area must abide by, 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.
Steps to elimination

- **Commitment and leadership**

Ministers and political parties must commit to the elimination of hepatitis C as a serious public health concern by 2030, and the Department of Health must assume lead responsibility for a plan to eliminate hepatitis C. As an equivalent to the task and finish group established to oversee the roll-out of opt-out BBV testing in prisons, an elimination group should be established to coordinate the joint working of relevant health organisations to tackle hepatitis C.

- **Public awareness, workforce development and peer education**

A shockingly low level of public and professional awareness currently exists with regards to hepatitis C, especially at a primary care level such as in GP practices. One step to improving awareness would be the development of a learning and development framework for hepatitis C by Health Education England, which should be widely promoted to ensure that all health and drug service professionals have a good awareness of the virus and its risk factors and treatment options.

Targeted hepatitis C awareness campaigns for particular at-risk groups should be rolled out, including for those who had blood transfusions before 1991; men who have sex with men (MSMs) and the Pakistani community.

In addition to awareness campaigns and workforce development, peer-to-peer education programmes should be widely adopted for PWIDs.

- **Increase testing and diagnosis**

The offer and uptake of testing and diagnosis among population groups at risk of infection should be markedly increased, in line with current evidence and national guidelines. A system of opt-out testing for hepatitis C should be adopted in drug services for people who inject drugs, and testing of at-risk groups should become far more widespread, especially within GP practices and other community settings such as pharmacies.

- **Expand access to treatment**

Everyone diagnosed with hepatitis C should be guaranteed a care pathway and given access to appropriate treatment, with treatment scaled up to take advantage of the new interferon-free, all-oral therapies now available and greater numbers of injecting drug users treated in settings including needle exchanges, as is the case in Scotland.

- **Improve data and intelligence**

The quality of data and intelligence on hepatitis C must be significantly improved, with the HCV in the UK report already produced on an annual basis by Public Health England used as a tool for the better collection and recording of data.
The same efforts to monitor and improve outcomes for hepatitis C patients should be directed at hepatitis C as in other disease areas such as HIV and TB, both conditions that are also disproportionately concentrated among disadvantaged populations and which benefit from clear national policy prioritisation. For example, a specific indicator on hepatitis C could be included in the Public Health Outcomes Framework to match that already in place for HIV on ‘people presenting with HIV at late stage of infection’.


