

NO TURNING BACK



Justice and equity for people
affected by hepatitis C

In the next Parliament, this country has the opportunity to right a huge historic wrong, and to achieve a world-leading public health success.

We are calling on the next UK Government to:

1 Deliver justice for the Infected Blood community:

a) Pay compensation to everyone given hepatitis C, B, and/or HIV through infected blood, and to those affected

b) Respond in full to the recommendations of the Infected Blood Inquiry by the end of 2024

2 Eliminate hepatitis C by 2030:

a) Continue to support NHS England's Hepatitis C Elimination Programme until elimination status is confirmed

b) Rebuild harm reduction services, preventing hepatitis C, HIV and other blood-borne viruses

c) Develop a national action plan to ensure hepatitis C can never return

d) Tackle severe health inequalities and exclusion from healthcare

The Infected Blood Inquiry

On 20th May 2024, the Infected Blood Inquiry set out its Final Report.¹ Across its seven volumes, the Inquiry report sets out how “systemic, collective and individual failures” led to tens of thousands of hepatitis B, C and HIV infections through the UK’s blood system; this has caused at least 3,000 deaths to date.²

Inquiry Chair Sir Brian Langstaff made twelve recommendations,³ carefully constructed both to address the injustice done to the people affected and to redress some of the organisational and systemic failings which enabled this to happen and to remain unaddressed for almost fifty years.



This disaster was not an accident. People put their faith in doctors and the Government to keep them safe – and their trust was betrayed.”

- Sir Brian Langstaff, Chair of the Infected Blood Inquiry, speaking at the report's launch on 20th May 2024

First and foremost, Sir Brian calls for compensation to be paid to those affected. The compensation body announced by the current Government will be in place and have clear recommendations by the initiation of the next Government.

Compensation payments are both symbolic – a gesture from the state to those infected and affected of the profound wrong done to them – and are critically important to many people living in inappropriate homes, or who cannot afford to pay for their home care. It is vitally important the Infected Blood Compensation Authority (IBCA) is fully operational, independent, transparently-run and able to deliver compensation payments as quickly as possible, in line with the recommendations of the Second Interim Report of the Infected Blood Inquiry.



It's the uncertainty that's killing me. I want to know my family will be financially stable when I go.”

- Infected blood survivor.⁴

ASK

We are calling on the next Government to pay compensation to everyone given hepatitis C, hepatitis B and/or HIV through infected blood, and those affected, with the IBCA operational and paying compensation within 100 days.

But addressing this wrong requires more than compensation. Sir Brian highlights how much failings identified within the Infected Blood Inquiry repeat those of earlier inquiries, and how profoundly these reflect failings in the workings of the state. Sir Brian's report contains important recommendations the next Government must take forward to ensure comparable crises never happen again, including introducing a Duty of Candour for health service leaders and taking steps to increase openness and accountability in Government and the civil service.

ASK

We are calling on the next Government to respond to every Inquiry recommendation by the end of 2024.

Eliminating hepatitis C

The UK is on track to be one of the first countries to eliminate hepatitis C by the World Health Organization's (WHO) 2030 target.⁵ We have become a pilot country under the WHO elimination strategy, recognising the UK as one of the countries closest to achieving elimination worldwide. This reflects the exceptional work that has been undertaken to engage and educate communities nationally, resulting in more than 80,000 people being treated and cured in the UK since modern direct-acting antiviral drugs were made available in 2015.⁶ This is already leading to mortality reductions from liver cancer, and a significant drop in the need for liver transplants, saving both lives and the financial cost of these to the NHS.

Eliminating hepatitis C represents a significant public health victory and a crucial milestone in tackling health inequalities, with hepatitis C primarily affecting disadvantaged and marginalised groups including homeless people, people who inject drugs, and people in prisons.

The 2024 general election comes at a pivotal point for hepatitis C elimination nationally. There is an opportunity to take a strategic approach focused on prevention and harm reduction to ensure elimination is not only achieved, but maintained over the long term. However, to achieve this we need a renewed strategic plan to enable us to reach and then maintain elimination, with a particular focus on prevention.

The World Health Assembly agreed a global goal to eliminate hepatitis C as a public health threat in 2016. Every country in the world signed up to this, including the UK. This sits alongside goals to eliminate hepatitis B, and to end HIV transmission.

Since 2019, NHS England has committed £1bn to its hugely successful Hepatitis C Elimination Programme which by the end of 2022 had seen a more than 50% drop in national hepatitis C prevalence and more than 25% drop in cancer deaths caused.⁷ Wales, Scotland and Northern Ireland are also committed to hepatitis C elimination, and NHS Tayside in Scotland was the first region in the world to declare hepatitis C elimination.⁸

It is vital that political commitment to elimination remains in all nations, ensuring that we achieve elimination during this parliament. We must not lose this opportunity to save thousands of lives.

ASK

We are calling on the next Government to drive forward hepatitis C elimination, working with national NHS and Public Health bodies, until UK elimination status is confirmed.⁹

Preventing cases of blood-borne viruses such as hepatitis C, hepatitis B and HIV is highly cost-effective, reduces pressure on the NHS, and saves lives.¹⁰ But at present, specialist harm reduction services and pharmacy-based needle exchanges are not well coordinated, are not addressing key risks such as synthetic opioids and increasing crack cocaine use, and are under-utilised as an opportunity to deliver healthcare and drug treatment.

Recent UK Health Security Agency reports have indicated that, despite the excellent programmes to eliminate hepatitis C, there has been no meaningful reduction in the rate of new hepatitis C infections in the last decade.^{11 12}



More needs to be done to prevent new infections and reinfections; provision of adequate harm reduction remains a challenge and poses a threat to the UK's ability to achieve and maintain elimination."

- UK Health Security Agency

ASK

We are calling on the next Government to rebuild harm reduction services and prevent new cases of hepatitis C, B and HIV, starting with a commitment to a year-on-year increase in local authority public health budgets and to establish an independent commission to review what works in reducing harm.

Realising our elimination ambitions within the next Parliament will also require a more coordinated approach across a variety of services and organisations, tying together efforts to prevent, diagnose, treat and monitor hepatitis C.

To achieve and – crucially – to maintain hepatitis C elimination, we need concerted work across Government, NHS, local and national public health, the voluntary sector, justice sector, and drug service providers. We need a clear national plan which sets out how we can do this and where responsibilities lie, and to identify the most cost-effective and efficient strategies for sustained elimination.

ASK

We are calling on the next Government to develop a national action plan – led by UKHSA and NHS England – to not only eliminate hepatitis C, but to ensure it cannot return.

The Department of Health and Social Care, UK Health Security Agency and NHS England must work together to ensure our elimination efforts have the greatest impact and sustain these efforts to prevent a resurgence of hepatitis C.

The UK's hepatitis C elimination programmes have achieved a step-change in engaging communities typically excluded from healthcare services. Many of the groups central to elimination face extreme inequalities and exclusion: homeless women, for example, are likely to die in their early 40s¹³ and people who inject drugs by their 50s.¹⁴ There are lessons to be drawn from this for areas of healthcare beyond hepatitis C. This should include employing people with lived experience (peer workers) to deliver services and develop outreach-based approaches, moving services into communities and building trust.



Almost every elimination initiative that NHS England manages and commissions HCV Operational Delivery Networks to provide, at local and sub-regional levels, has peer involvement. NHS England consistently finds that people with lived experience are excellent advocates and are crucial in developing therapeutic alliances to support people into testing and treatment who may have felt excluded from traditional healthcare and other settings."

- Lord Markham, Minister, Department of Health and Social Care¹⁵

A health system able to diagnose and treat hepatitis C over the long term, as outbreaks and resurgences occur, must have dedicated provision for these 'inclusion health' populations.

ASK

We are calling on the next Government to tackle severe health inequalities and exclusion from healthcare. In England this should include expanding the NHS Core20PLUS5 approach and, with UKHSA, allocating specific funding to measures designed to improve, protect and extend the lives of those with the lowest life expectancy.¹⁶

About hepatitis C

Hepatitis C is a virus that lives in the blood. People can live for many years without symptoms, but untreated cases can cause fatal cirrhosis and liver cancer, the fastest-rising cause of cancer death in the UK. Every year over 6,000 people are diagnosed with liver cancer country-wide and just 13% of them will survive for five years or more.¹⁷

Hepatitis C is transmitted when blood from an infected person gets into another person's blood stream, such as through injecting drug use or unsafe medical practices. This is easily prevented and the vast majority of hepatitis C cases in the UK need not occur. The virus is cured by taking tablets for 8-12 weeks. However, despite the progress the NHS England-led elimination drive has seen and because it has few symptoms and is most common among people with the worst healthcare access, an estimated 62,600 people in England still have an undiagnosed hepatitis C infection.¹⁸ This is not inevitable - through concerted action and preventative measures, we can eliminate hepatitis C as a major public concern in the UK.

About The Hepatitis C Trust

The Hepatitis C Trust is a charity dedicated to eliminating hepatitis C in the UK by 2030. We champion the right of every person at risk of hepatitis C in the UK to receive effective testing, treatment and care.

We achieve this by empowering people with lived experience, influencing policy and practice, and working with healthcare and treatment services to deliver support and raise awareness about hepatitis C.

We work in every English prison and community NHS team to tackle hepatitis C, and run a growing range of programmes to support the health of excluded populations including in cancer prevention and harm reduction.

For further information, please contact:

Aidan Rylatt, Policy and Parliamentary Adviser

aidan.rylatt@hepctrust.org.uk

References

- 1 Infected Blood Inquiry (2024). Infected Blood Inquiry, The Report, vols. 1-7. London: HM Government. Available at: <https://www.infectedbloodinquiry.org.uk/reports/inquiry-report> (accessed 2nd June 2024)
- 2 Ibid, vol. 1, p. 2.
- 3 Ibid, vol. 1, pp. 284-291..
- 4 The Hepatitis C Trust & Terrence Higgins Trust (2024) Briefing: The Impact of Delays to the Government Response on the Infected Blood Inquiry Interim Report on Compensation. London: The Hepatitis C Trust, 2024. Available online: www.hepctrust.org.uk/wp-content/uploads/2024/06/Briefing-on-the-Impact-of-Delays-on-Infected-Blood-Compensation.pdf. Accessed 12 June 2024
- 5 World Health Organization (2022). Global health sector strategies on, respectively, HIV, viral hepatitis and sexually transmitted infections for the period 2022-2030. Geneva: World Health Organization. Available at: <https://www.who.int/publications/i/item/9789240053779>. Accessed 12 June 2024
- 6 UK Health Security Agency (2024). Chronic hepatitis C cases in England fall by half since 2015. Available at: <https://www.gov.uk/government/news/chronic-hepatitis-c-cases-in-england-fall-by-half-since-2015>. Accessed 30 May 2024.
- 7 UK Health Security Agency (2024). Hepatitis C in England 2023. Available at: <https://www.gov.uk/government/publications/hepatitis-c-in-the-uk/hepatitis-c-in-england-2023>. Accessed 30 May 2024.
- 8 NHS Tayside (2020). NHS Tayside First Region in the World to Eliminate Hepatitis C. Available at: https://www.nhstayside.scot.nhs.uk/News/Article/index.htm?article=PROD_339892. Accessed 12 June 2024
- 9 Hepatitis C elimination as a major public health concern is defined as an 80% reduction in new chronic infections and 65% reduction in mortality compared with 2015 rates in the country in question. Hellard, M et al (2020) 'The Elimination of Hepatitis C as a Public Health Threat'. Cold Spring Harb Perspect, 1;10(4). Available at: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7117951/>. Accessed 5 June 2024.
- 10 Sweeney, Ward, Platt et al. Evaluating the cost-effectiveness of existing needle and syringe programmes in preventing hepatitis C transmission in people who inject drugs. Addiction, 114:3 (2019) <https://doi.org/10.1111/add.14519>. Accessed 12 June 2024.
- 11 UK Health Security Agency (2023). Hepatitis C in England 2022. Available at: <https://webarchive.nationalarchives.gov.uk/ukgwa/20230815223947/https://www.gov.uk/government/publications/hepatitis-c-in-the-uk>. Accessed 12 June 2024.
- 12 UK Health Security Agency (2024). Hepatitis C in England 2023. Available at: <https://www.gov.uk/government/publications/hepatitis-c-in-the-uk/hepatitis-c-in-england-2023>. Accessed 30 May 2024.
- 13 Office for National Statistics (2020) 'Deaths of homeless people in England and Wales: 2019 registrations'. Available at: <https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/bulletins/deathsofhomelesspeopleinenglandandwales/2019registrations>. Accessed 30 May 2024.
- 14 Based on an Australian study; UK life expectancy data is not available for people who inject. Lewer, Jones et al. (2020), Life expectancy of people who are dependent on opioids: A cohort study in New South Wales, Australia, Journal of Psychiatric Research, 130, pp. 435-440: <https://doi.org/10.1016/j.jpsychires.2020.08.013>. Accessed 6 June 2024.
- 15 Department of Health and Social Care answer in UK Parliament (2023) 'Hepatitis: Disease Control - UINHL6761, tabled on 22 March 2023'. Available at: <https://questions-statements.parliament.uk/written-questions/detail/2023-11-14/hl312>. Accessed 30 May 2024
- 16 NHS England (2023) 'Core20PLUS5 (adults) – an approach to reducing healthcare inequalities'. Available at: <https://www.england.nhs.uk/about/equality/equality-hub/national-healthcare-inequalities-improvement-programme/core20plus5/>. Accessed 30 May 2024.
- 17 British Liver Trust (2022) 'British Liver Trust launch of Liver Cancer UK in response to rises cases in the UK'. Available at: <https://britishlivertrust.org.uk/british-liver-trust-launch-of-liver-cancer-uk-in-response-to-rises-cases-in-the-uk>. Accessed 30 May 2024.
- 18 UK Health Security Agency (2024) 'Hepatitis C in England 2023'. Available at: <https://www.gov.uk/government/publications/hepatitis-c-in-the-uk/hepatitis-c-in-england-2023>. Accessed 30 May 2024.