This toolkit has been created to support healthcare professionals working within primary care with knowledge about hepatitis C, resources they can use, access to training, and ideas for those wanting to be more involved in eliminating hepatitis C in England.

Brief facts about hepatitis C Page 1
Hepatitis C elimination Page 4
Hepatitis C training Page 6
The hepatitis C national testing portal Page 7
Resources for patients Page 8
Guidelines, data and key information Page 9
Other hepatitis C elimination initiatives Page 11
Support and information for patients Page 12
Get involved Page 13
GP Champions Page 15
GP hepatitis C case finding initiative example Page 16
Pharmacies and Dental Practices Page 18
Operational delivery networks Page 19
Stigma Page 20
Lets say Hep C U Later Page 21
**Brief facts about hepatitis C**

**What is hepatitis C?**
Hepatitis C is a blood borne virus. It is transmitted when infected blood enters another person’s blood stream. If left untreated it can cause liver disease, liver cancer and death.

**Risk factors:**
There are a number of risk factors for hepatitis C...

- Sharing drug injecting equipment or other drug using equipment (including syringes, needles, spoons, water or filters for drawing up, crack pipes, or snorting straws/notes).
- Blood transfusion before 1996.
- Dental or medical treatment abroad in unsterile conditions.
- Piercing, tattoo, electrolysis, semi-permanent make up or acupuncture using equipment which may have not been sterilised.
- Vertical transmission (from mother to baby during childbirth).
- Unprotected sex with someone who may have had hepatitis C (especially if there were opportunities for blood to blood contact during sex).
- Needle stick injury.

**Symptoms:**
Not everyone experiences symptoms of an early hepatitis C infection. Symptoms can be misinterpreted as another illness.

- Jaundice (yellowing of eyes and skin)
- High temperature (above 38C)
- Tiredness
- Feeling sick
- Loss of appetite
- Abdominal pain
Brief facts about hepatitis C

Testing:
There are different ways to get tested. Testing is easy and the time to get results can vary depending on the method of testing used. If a person has been exposed to hepatitis C it can take up to 3 months before there is a hepatitis C antibody positive result. In some cases it can take up to 6 months.

Test 3 months after a potential exposure to the virus, then 3 months after that. If a person remains at risk from hepatitis C it’s good practice to test them every 12 months.

If a person has a positive hepatitis C result, in some cases, further tests and investigations may be required.

Venous blood sample = getting a sample from a vein - can take lots of tests at the same time

Capillary Blood Test (CBT) = finger prick of blood into a small tube - great for when it’s hard to access a vein

GeneXpert Cepheid machine = finger prick of blood into a machine - tests for active hepatitis C RNA in 60 minutes

Dry blood spot testing (DBST) = finger prick of blood dropped onto a card - great for when it’s hard to access a vein
Brief facts about hepatitis C

Hepatitis C Results:
Roughly 25% of people who acquire a hepatitis C infection spontaneously clear the virus in the first 6 months, however, 75% go on to develop chronic hepatitis C. Spontaneous clearance is where the body’s immune system automatically fights the virus.

Hep C Antibody positive + Hep C RNA negative = Previously came into contact with hepatitis C, does not have current infection

Hep C Antibody negative + Hep C RNA negative = Has not come into contact with the hepatitis C virus

Hep C Antibody positive + Hep C RNA positive = Has the active hepatitis C virus

There may be some cases when a person may have had hepatitis C virus where the hepatitis C anitbody is not picked up on some forms of testing.

If a person has had successful treatment, or has cleared the virus spontaneously, they are not protected from being infected if they come into contact with the virus again – it’s important to reduce the risk of coming into contact with the virus again.

Genotypes:
There are 6 main types of hepatitis C known as genotypes. Some genotypes are more common in different areas of the world. All genotypes can be treated.

Treatment:
Hepatitis C can be cured with Direct Acting Antiviral treatments (DAAs). They are effective 90-95% of the time (usually one tablet a day for 8-12 weeks). Treatment is available to everyone.

12 weeks after a person finishes their treatment a viral load/Hep C RNA test will be taken to check if the virus has been eliminated from their system.
Hepatitis C elimination

There is a global aim to eliminate hepatitis C by 2030, and NHS England aim to eliminate ahead of the 2030 target. England may be the first country in the world to reach hepatitis C elimination.

Since 2015 the NHSE Hepatitis C Elimination Programme has led an unprecedented level of elimination initiatives across wide reaching programme partnerships.

Read the latest report here.

The impact so far:

- The number of people living with hepatitis C has fallen dramatically
- 52% reduction in the number of liver transplants
- 37% reduction in deaths from hepatitis C
- 102% increase in hepatitis C testing in drug services
- 140% increase in the number of people accessing treatment
The remaining challenges in reaching hepatitis C elimination:
To reach the goal of hepatitis C elimination it is essential we support professionals, such as primary care staff, who may come into contact with people unaware of having a hepatitis C infection.

Hear from Sir Stephen Powis:
Click the screen to watch a video where NHS Medical Director Professor Sir Stephen Powis visits St Mungo’s hostel where NHS England are supporting efforts to screen vulnerable populations for hepatitis C, and providing those who need it.

Graham Foster, the former Clinical Lead for NHS England’s Hepatitis C Elimination Programme talks about why primary care staff are important to help NHSE reach the goal of hepatitis C elimination: Professor Graham Foster on hepatitis C elimination - YouTube
Hepatitis C training

There are many options for online training which can be accessed at a time that suits you.

**INHSU Hepatitis C in Primary Care and Drug and Alcohol Settings:**
The INHSU hepatitis C online modules are available should you want to complete further training at an intermediate level. It includes information on epidemiology, liver disease staging, treatment options, monitoring and follow-up. This training provides a certificate but is not CPD accredited.

**Hep C U Later CPD Accredited Hepatitis C Awareness Training – Foundation Level:**
Below is the Hep C U Later CPD accredited online Hepatitis C Awareness Foundation Level Module. It includes basic information about hepatitis C, transmission risk factors, testing methods, results and treatment. The training is a foundation level option, provides a certificate and is suitable for all staff working within primary care.

Click here to view
Did you know anyone in England can order a free at home hepatitis C test kit?
The majority of our resources link to the hepatitis C testing portal, giving patients the ability to access testing easily. Displaying our patient resources can help your patients to self-identify risks and access testing and treatment.

It couldn’t be simpler:
› Scan the QR code on our resources/or visit Get tested - HEP C U Later
› Fill in the basic information
› Test sent to the person’s home address
› Complete the simple capillary blood test
› Send it back in the post
› Notified of the result within 2 weeks
› If the result is positive the individual is automatically linked in with their local Hepatology team for treatment
Hep C U Later have developed a number of resources for healthcare professionals to use. These resources are available via:

- **Our website** – [www.HepCULater.com](http://www.HepCULater.com)
- **LinkedIn** - Follow the Hep C U Later LinkedIn page
- **Or Email** – connect.HepCULater@mpft.nhs.uk to request printed copies
Key facts and figures:
It is estimated that around 70,000 people in England may still be unaware of having a hepatitis C infection.

The number of people with an active hepatitis C infection in the UK has fallen dramatically by 47% due to the increased access to newer hepatitis C treatments (Direct Acting Antivirals, DAAs) and the increase in identification and elimination initiatives.

The UK has exceeded the World Health Organisation’s 2020 target of a 10% reduction in mortality compared to 2015. To reduce hepatitis C related mortality further there is a need to identify people who may be unaware they have come into contact with hepatitis C.

Guidance:
The National Institute of Health and Clinical Excellence (NICE) published guidance ‘Hepatitis B & C testing – people at risk of infection (PH43)’ (2013). The guidance provides recommendations to GPs and nurses within primary care on actions to take for people accessing their services including:

• Offering testing to adults/children at risk of infection (migrants from medium or high prevalence countries and people with a history of injecting drugs)
• Offering testing to new registrants who may be at risk.
• Offering annual testing for hepatitis C to people who may be at ongoing risk of infection.
• Referring people diagnosed as hepatitis C positive for ongoing care.
• Raising awareness of hepatitis C
• For those offering antenatal services, discussing risk factors and offering testing for those at risk.

The guidance can be accessed here: [Hepatitis B and C testing: people at risk of infection (nice.org.uk)]
Guidelines, data and key information

Data:
The UK Health & Security Agency (UKHSA) have published reports on the progress towards eliminating hepatitis C in England.

The latest report ‘Hepatitis C in the UK - working to eliminate hepatitis C as a public health threat’ was published in 2023 and includes data up to the end of 2021. The report covers prevalence in the UK, mortality, awareness of infection, prevention and access to treatment.

The latest report can be viewed here: Hepatitis C in the UK 2023: working to eliminate hepatitis C as a public health threat (publishing.service.gov.uk)

Strategies and Reports:
There are a number of strategies and reports relating to hepatitis C elimination. We’ve outlined some of the key reports below.

The World Health Organisation’s 2016 ‘Global health sector strategy on viral hepatitis 2016-2021’ encompassed all viral hepatitis with a specific focus on hepatitis B and C due to their health burden, and outlined the targets and priority actions required. It was a major milestone in the global effort to eliminate hepatitis C as a public health threat with hundreds of countries committing to ending hepatitis. Page 22 outlines the key targets for 2020 and 2030. The strategy can be accessed here: WHO-HIV-2016.06-eng.pdf

In 2021 the World Health Organisation published the ‘Global progress report on HIV, viral hepatitis and sexually transmitted infections’. Since 2015 a nearly 10 fold increase has been seen in the number of people accessing treatment globally and hepatitis C related mortality is declining for the first time. The progress report can be accessed here: 9789240027077-eng.pdf (who.int)

The World Health Organisation also published ‘Interim guidance for country validation of viral hepatitis elimination’. This guidance can be accessed here: 9789240028395-eng.pdf (who.int)
Other hepatitis C elimination initiatives – an overview

There have been a number of initiatives within multiple areas of healthcare to help eliminate hepatitis C. If you are interested in learning more about how partnerships and innovations have contributed to England’s goal of elimination below are a couple of examples.

Drug treatment Services and Prison Settings:
Drug treatment services and prisons across the country have joined in partnership with other organisations to increase testing, improve pathways and engage people into treatment. This has led to over 40 services so far declaring they have reached ‘micro-elimination’, the meeting of an agreed criteria for testing and treatment within a certain population.

If you want to find out more about the innovative work carried out read Hep C U Later’s latest Impact Report: NHSAPA-HepCULater-Annual-Impact-Report_April-2022-March-2023-002.pdf

Emergency Departments:
Over 30 emergency departments in England have been working tirelessly to complete opt-out hepatitis C, hepatitis B and HIV testing. With over one million tests now taken the emergency departments as of April have diagnosed over 1,860 people with hepatitis C.

You can read more about the experience of the Manchester and Eastern Cheshire Operational Delivery Network implementing opt-out testing in their case study here.
Support and information for patients

There are a number of sources for further information, both for professionals and people who have been affected by hepatitis C.

The British Liver Trust

The British Liver Trust website British Liver Trust - Pioneering Liver Health is a great resource for liver health for professionals and people who need support. As well as providing accessible resources and factsheets the British Liver Trust also deliver Love Your Liver Roadshows

Free helpline: 0800 652 7330 between 9am and 3pm Monday to Friday (excluding bank holidays)

Email: helpline@britishlivertrust.org.uk

The Hepatitis C Trust:

The Hepatitis C Trust is a charity which aims to support people living with or affected by hepatitis C. You can direct people who may have been affected by hepatitis C to their confidential phone line for support.

Website: The Hepatitis C Trust | Hep C charity (hepctrust.org.uk)

Confidential helpline: 020 7089 6221

NHS Choices:

The NHS Choices website Hepatitis C - NHS (www.nhs.uk) provides simple information on hepatitis C and is a reliable sources to direct people to.
“Testing in primary care allows us to reach patients who may not be aware of their hepatitis C risk. With new digital tools, GPs can now easily scan patient records to identify those most at risk of historic infection, test them or direct them to self-test, and refer them for treatment as soon as possible. Through the click of a button, we can rapidly accelerate our progress towards hepatitis C elimination.”

Mark Gillyon-Powell, Head of NHSE’s HCV Elimination Programme

There are so many ways to get involved and be a part of the elimination of hepatitis C in England. We’ve outlined some below.

<table>
<thead>
<tr>
<th>Show support!</th>
<th>Show your support by displaying our banner on your email signature</th>
<th>Download our email banner here: HCUL-Email-Banners-3.png (1584396) (hepcu-later.com)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Educate, and direct patients to testing!</td>
<td>Display our posters, leaflets and wallet sized cards in your practice</td>
<td>Email <a href="mailto:connect.HepCULater@mpft.nhs.uk">connect.HepCULater@mpft.nhs.uk</a> to order these resources for free</td>
</tr>
<tr>
<td>Increase awareness!</td>
<td>Encourage all staff within the practice to complete the Hep C U Later CPD Accredited Hepatitis C Awareness Online Module</td>
<td>Follow this link and share it with others: <a href="https://view.pagetiger.com/Reader/Login/Default">https://view.pagetiger.com/Reader/Login/Default</a></td>
</tr>
<tr>
<td>Lead the way!</td>
<td>Are you a GP? Become a Hepatitis C GP Champion and lead others to take part in eliminating hepatitis C</td>
<td>If you’re interested in becoming a Hepatitis C GP champion email us at <a href="mailto:connect.HepCULater@mpft.nhs.uk">connect.HepCULater@mpft.nhs.uk</a></td>
</tr>
</tbody>
</table>
Get involved

Find people at risk!

- GP practices can run a case finding tools (these are already installed on systems within general practice)

| If you’re interested in running these tools with support from other organisations email us at connect.HepCULater@mpft.nhs.uk so we can link you to the right people |

Actively test more people!

- Organise a testing event in collaboration with other organisations

| Email us at connect.HepCULater@mpft.nhs.uk to explore how we can make this happen |

What is a Hepatitis C GP Champion?

“Hepatitis C is an important killing disease which no longer needs to exist. We have the technology and more importantly the clinical will to eradicate it worldwide. In my own practice we have eradicated the disease from more than ten per cent of our entire practice list saving, we estimate, about twenty lives and squillions in specialist liver services. How cool is that?!“

Dr Paul O’Reilly, London GP and Hepatitis C GP Champion

Hepatitis C GP Champions are in place to lead the way in developing local initiatives which improve awareness, testing and treatment.

Watch this video with Grace Bottoni, a GP and Hepatitis C GP champion from Lewisham explaining why she decided to get involved.

Click here to watch.
NHS England has committed to the WHO goal of eliminating Hepatitis C by 2030.

The HCV Elimination Programme gives hope that within the next few years we will be able to make history and declare the end of Hepatitis C in England as a major public health concern. Primary Care represents a key work area for the success of the programme. As part of this, expressions of interest are being sought for HCV GP Champions across England. The role offers flexible sessions per month and is an exciting opportunity to contribute to the success of a major public health intervention. It would suit any GP who is passionate about making a definitive improvement to patient outcomes whilst also diversifying their clinical role.

GP Champions take an active role in Hep C case finding in the primary care population, as well as the clinical education of colleagues and supporting patient linkage to care. The Champions lead on operational and clinical conversations with GPs alongside the Hepatitis C Operational Delivery Network (ODN). The role includes working collaboratively with local practices, requiring strong facilitation, and influencing skills. GP Champions work closely with members of the ODN (in particular, the clinical lead and programme/network) and the national NHSE Hepatitis C Elimination Programme Team. Please note the GP champion role’ remit might slightly vary within the different catchment area depending on the local need.

If you are interested in becoming a Hepatitis C GP Champion, please get in touch with the HCV Elimination Programme team to discuss the role at england.hepc-enquiries@nhs.net.
Hep C U Later alongside the Wessex Operational Delivery Network (ODN) embarked on a GP initiative with Dr Mufeed Ni’Man from the South Coast Medical Group at a practice in Boscombe to ensure people previously identified as having hepatitis C had been treated.

The initiative started in July 2022 after the practice was identified as being linked to a local rehab and therefore might have people registered who had previously used drugs but have not been linked to drug services for some time and therefore may have people who have not been treated or may be unaware of their infection.

Meetings began with the practice and the initial concerns were time and capacity. It became clear that they required additional support from the Wessex ODN Coordinator and Hep C U Later Coordinator. An MOU was signed to enable the Operational Delivery Network access to systems to update patient information and reduce the amount of resource required by the practice.

Initially the project was using the MSD Patient Search Identification (PSI) tool which is a tool built into SystmOne. The tool can look for risks where someone may have come into contact with a risk factor linked to hepatitis C. Running the search tool can give large amounts of results which have to be filtered through therefore the project focused initially on those who were known to have hepatitis C to ensure they had been offered treatment and their records were up to date, with the plan of completing further work for those identified as having a risk factor at a later stage.

The project has found multiple people who still required hepatitis C treatment and engaged with them to encourage them to complete it. Additionally some individuals have completed treatment and their record have been updated.
Reflections:

“The idea of the last treatment, Interferon, scared me and I didn’t want to do it, but the support team got in contact with me and explained about the new treatment. I was still a bit apprehensive but they offered me an opportunity for a better life...to extend my life. It took me about a week and a half after I got the tablets to take them because I was scared. My treatment’s now finished and people are telling me I look a lot better. Anybody who is thinking about it just do it.”

Anonymous Patient from the GP Project, October 2023

“The initial learning was the amount of different codes that GPs can use, the fact that I knew people on the list had been successfully treated and it hadn’t made it back onto the GP records, the joining up of everything, people that had been missed or had ‘look back letters’ and it hadn’t progressed to anything else. I very quickly identified that I could save lots of people time by recoding people’s records, for example, using ‘hep c resolved.’

“Without someone accountable and driving it forward it can slip, so having someone coordinate the process is really important.”

Louise Hansford, Hepatitis C Elimination Coordinator, Hep C U Later

“I was excited about the project as it would help more patients and increase awareness of this treatable disease. We have found patients whom we treated to improve their health and reduce their mortality, as well as reduced the inappropriate use of health resources. Partnership working is great. Don’t give up on patients with Hep C.”

Dr Mufeed Ni’Man from the South Coast Medical Group
Pharmacies and Dental Practices helping to eliminate hepatitis C

Pharmacies

Pharmacies play a key role in being able to reach people in the community who may have been at risk of hepatitis C. Some pharmacies in England have signposted people to the national hepatitis C testing portal, and others have completed testing on the community.

Listen to this podcast from Sam Uveges, Specialist Pharmacy technician for Hep C Homecare at Nottingham University Hospital Trust discussing how he has supported the elimination of hepatitis C through his role.

Dental

Colleagues within dental practices have also been involved in directing people to hepatitis C testing. The Staffordshire and Shropshire Local Dental Network engaged with Hep C U Later in 2023 which led to our printed resources (with QR code links to the national hepatitis C testing portal) being sent to over 200 community dental practices.

Get in touch if you want to explore options for getting involved!
There are currently 24 Operational Delivery Networks coordinating and providing hepatitis C treatment and case finding activities across the country, including a nationally reaching paediatric ODN.

ODNs are interested in working closely with primary care services to explore ways in which more people can be tested and treated and many will have the resources to support services to do this.

If you would like to get in touch with your local ODN email connect.HepCULater@mpft.nhs.uk and we will connect you.

Case study, Cheshire and Merseyside ODN

If you would like to hear more about the work of an ODN listen to this podcast from David Byrne, Cheshire and Merseyside ODN Network Manager.

Click here to listen.
Stigma can negatively affect the experiences and health outcomes of people who have acquired a hepatitis C infection. Stigma may be a result of an irrational fear of infection, lack of understanding or the culture within a service. As hepatitis C is an infection commonly acquired through the sharing of drug injecting equipment in the UK people might be discriminated against due to judgements about a person’s lifestyle and choices.

It is important to remember that stigma can come from multiple places such as peers, institutions, and even from healthcare staff. Stigma and fear of being judged can impact on a person’s ability to get tested for hepatitis C or their engagement with treatment. To learn more about stigma, and how to tackle it please read our Stigma Toolkit here.

There are many ways to engage people in testing and make the offer of a test as comfortable for a person as possible. Our engaging people in testing summary document, access it here, can be used as a prompt within healthcare settings or as an additional resource alongside training.

“As a person with history of both living with substance use issues and hepatitis C my experiences with stigma have been extensive, from feelings of being judged to outright discrimination. We need to remember stigma leads to disengagement and isolation. Isolation can kill.”

Tony Mullaney, Training and Development Coordinator (Hep C U Later)
Let’s say Hep C U Later

We want to help you reach hepatitis C elimination in your service ‘and say Hep C U Later’. Email us at connect.HepCULater@mpft.nhs.uk to find out how we can help.

“Eliminating hepatitis is so important because... We are making great progress - which means that we are saving lives, every day. We just need to make sure that everyone is found, and no one is left behind”

Mark Gillyon-Powell, NHSE

“Eliminating hepatitis is so important because... We have the power to achieve this and to make many lives better as a result”

Danny Hames, Inclusion