



Public Health  
England

Protecting and improving the nation's health

# **Patient re-engagement exercise for those who have been diagnosed with hepatitis C - information for GPs**

# About Public Health England

Public Health England exists to protect and improve the nation's health and wellbeing, and reduce health inequalities. We do this through world-leading science, knowledge and intelligence, advocacy, partnerships and the delivery of specialist public health services. We are an executive agency of the Department of Health and Social Care, and a distinct delivery organisation with operational autonomy. We provide government, local government, the NHS, Parliament, industry and the public with evidence-based professional, scientific and delivery expertise and support.

Public Health England  
Wellington House  
133-155 Waterloo Road  
London SE1 8UG  
Tel: 020 7654 8000  
[www.gov.uk/phe](http://www.gov.uk/phe)  
Twitter: [@PHE\\_uk](https://twitter.com/PHE_uk)  
Facebook: [www.facebook.com/PublicHealthEngland](https://www.facebook.com/PublicHealthEngland)



© Crown copyright 2018  
You may re-use this information (excluding logos) free of charge in any format or medium, under the terms of the Open Government Licence v3.0. To view this licence, visit [OGI](https://www.ogilicence.gov.uk). Where we have identified any third party copyright information you will need to obtain permission from the copyright holders concerned.

Published September 2018  
PHE publications  
gateway number: 2018110

PHE supports the UN  
Sustainable Development Goals



# Contents

About Public Health England	2
Patient re-engagement exercise of those who have been previously diagnosed with hepatitis C	4
What is the purpose of this re-engagement exercise?	4
Why is this exercise being done now?	5
How is this exercise being implemented?	5
When will the exercise be launched?	5
What are the implications for GP workload?	6
What resources on hepatitis C and this exercise are available for GPs?	6
What will I be asked to do?	6
Who do I inform if the patient information is incorrect?	7
Who will be contacting the patients and testing them for HCV RNA?	7
Will all correctly identified patients require treatment?	7
Will I be informed of what happens to my patient?	7
What do I do if I have patients who may have hepatitis C but are not on the list given to me?	7
How does this exercise affect management of newly diagnosed hepatitis C patients?	8
How do I manage close household or sexual contacts of patients with hepatitis C?	8
How do I manage patients at risk of hepatitis C?	8
Where can I get information for patients on hepatitis C?	8
How do I explain to a patient why PHE has their information and has shared it with another doctor?	8

# Patient re-engagement exercise of those who have been previously diagnosed with hepatitis C

Information for General Practice about the NHS England (NHSE) and Public Health England (PHE) initiative to support finding and treatment of diagnosed patients.

Untreated hepatitis C infection causes cirrhosis and liver cancer. Very effective, well tolerated oral therapies are now available on the NHS. PHE and NHSE are keen to ensure that all patients with hepatitis C are offered these curative therapies.

To enable people previously diagnosed with hepatitis C to be treated for their infection, NHSE and PHE have organised a national 'patient re-engagement exercise' to help find and treat people with hepatitis C virus (HCV) infection. This document provides further information about this important initiative.

## What is the purpose of this re-engagement exercise?

Public Health England (PHE) and NHS England (NHSE) estimate that there are tens of thousands of people currently living with diagnosed hepatitis C infection who are not in contact with treatment services. Many of these people may have been diagnosed when little about the natural history of HCV-related disease was less certain and/or when treatment options were limited with sub-optimal outcomes.

Now that new direct acting antiviral drugs (DAAs) are available that can lead to a rapid cure in the vast majority of patients, it is important that every effort is made to re-engage people with treatment services so they can consider the treatment options available to them. As many of those infected with HCV come from vulnerable populations (migrants, people who inject drugs) who experience poorer access to treatment and outcomes, an active approach is likely to be of particular benefit.

NHS England, with its ambition to deliver treatment and care to infected eligible patients, Public Health England with its duty to monitor and control communicable diseases, and The Hepatitis C Trust, with its advocacy role as the national charity for people with hepatitis C, are all committed to re-engage previously diagnosed people with treatment services. This is part of wider concerted efforts to eliminate hepatitis C as a major public health threat in England before 2030.

With this in mind, PHE has obtained Caldicott permission to share with the lead hospital clinician of operational delivery networks (ODN) (a network with a central coordinating hepatology clinical service), a list of people resident in their ODN area who have been

Patient re-engagement exercise of those who have been previously diagnosed with hepatitis C

previously diagnosed with HCV in NHS laboratories between 1996-2017 (inclusive) and reported to PHE (for surveillance purposes). As laboratory reports contain patient identifiable information PHE can match these patients to the NHS Spine patient demographic service (PDS), and to other national surveillance datasets (deaths, transplants, HCV treatment) to generate a list of patients who are known to be alive registered with a GP and not known to be already under specialist care or completed treatment with the new DAAs.

The aim of this exercise is to improve case-finding and engagement of patients to establish whether they are currently infected and would benefit from curative HCV treatment.

### Why is this exercise being done now?

The hepatitis C treatment options have changed in the last few years. Previously treatments were injection-based, with long treatment durations, moderately effective and poorly tolerated. However, since 2015 new, funded, highly effective oral drugs (Direct Acting Antivirals (DAA)) are available on the NHS that cure hepatitis C infection in most people.

NHS England has invested significant sums each year to roll-out these new drugs to patients through ODNs. This year NHSE are undertaking strategic drug procurement with the ambition to achieve elimination goal of hepatitis C well before 2030. To scale up treatment to the levels required for elimination, case-finding needs simultaneously to ramp up to identify and refer undiagnosed and previously diagnosed patients who have not engaged in specialist care.

### How is this exercise being implemented?

PHE's national hepatitis surveillance team at Colindale will share with ODNs lists of patients (under a Memorandum of Understanding on use of the data). ODNs will do further data quality checks with their local IT systems (e.g. laboratory, patient administrative, and treatment databases). ODNs will then write to advise GPs that they will be contacting their patients to offer confirmatory testing (HCV RNA) and assessment for HCV treatment. This will give GPs an opportunity to raise any concern they may have about the patient being contacted directly.

In parallel PHE, NHSE and the Hepatitis C Trust together with RCGP will launch communications to raise awareness among key stakeholders and patient groups.

### When will the exercise be launched?

PHE will release patient lists to the ODNs in September (and it is expected the ODNs will start informing GPs and contacting patients over the subsequent months).

Patient re-engagement exercise of those who have been previously diagnosed with hepatitis C

## What are the implications for GP workload?

Patient contact is being led by the ODNs, however, GPs will want to know which of their patients are likely to be contacted and to have an opportunity to raise a concern if there are factors that would make contact from the service inadvisable. From over 170,000 laboratory reports received by PHE between 1996 to 2017, following successful matching to the NHS Spine patient demographic service and exclusion of those who have died or been treated, approximately 55,000 patient details will be shared with ODNs. If these patients are evenly distributed across 7,000 GP practices in England (which undoubtedly they are not), this equates to around 8 patients per practice.

ODNs are being asked to minimise the burden on GP practices and support GPs and CCGs with a large number of patients.

## What resources on hepatitis C and this exercise are available for GPs?

To support GPs, PHE and NHSE have developed a suite of materials including:

- hepatitis C re-engagement exercise FAQ for GPs
- hepatitis C FAQ for GPs
- hepatitis C FAQ for patients

RCGP has developed a liver disease toolkit which includes resources for healthcare professionals and free e-training modules on hepatitis C (and B)

<http://www.rcgp.org.uk/clinical-and-research/resources/toolkits/liver-disease-toolkit.aspx>

To raise general awareness of hepatitis C (and B) and prompt testing (if at risk) during European hepatitis testing week, PHE has also developed materials (quiz, video, social media banners, posters, flyers) which are endorsed by the Hepatitis C Trust, British Liver Trust and World Hepatitis Alliance, and are available at: <https://publichealthengland-immunisati.app.box.com/s/iptxtlziu57evyejw8zgvhimh0pjwa05>

These resources are all available free of charge and can be used to promote awareness of the risks, the availability of treatment and signpost potential patients to the quiz.

## What will I be asked to do?

The ODN clinical lead will write to you about patients identified by PHE as having had a HCV diagnosis according to NHS laboratory reports. If you have any concerns about the appropriateness of this contact (e.g. if patient has a terminal diagnosis or already treated and cured) please let the ODN know. In the absence of any primary care concerns (allowing 4 weeks from the letter) the ODN will contact the patient.

## Who do I inform if the patient information is incorrect?

Please inform your ODN lead so they can update their and PHE Colindale's systems. Alternatively you can email PHE's national hepatitis team directly and securely from an nhs.net email address to [phe.hepcdiagnoses@nhs.net](mailto:phe.hepcdiagnoses@nhs.net)

## Who will be contacting the patients and testing them for HCV RNA?

To minimise burden on GP services, the default position (unless other arrangements have been agreed locally) is that the ODN clinical lead will contact the patient and offer confirmatory testing (HCV RNA) and assessment of treatment if HCV infected. The ODNs will follow-up patients who do not respond with multiple attempts of contact as is practically possible.

## Will all correctly identified patients require treatment?

Not all patients identified will be currently infected with hepatitis C and require treatment as laboratory reports to PHE are mostly HCV antibody (ever infected) positive results, not HCV RNA (currently infected) test results which would indicate a need for treatment consideration. Of those patients anti-HCV positive, around 1 in 5 will have spontaneously cleared infection while others may have been treated and cured. PHE have excluded as far as possible those patients known to be treated with new DAAs. However, all patients identified in this re-engagement exercise should have confirmatory HCV RNA testing for viraemia, if not done recently.

## Will I be informed of what happens to my patient?

Yes, the ODN lead will keep you informed of any care provided to your patient by them with patient permission, as per routine practice.

## What do I do if I have patients who may have hepatitis C but are not on the list given to me?

The PHE patient list being shared with ODNs is based on past laboratory reports from 1996-2017 (inclusive) and matching to the PDS; it is therefore not exhaustive – i.e. some patients will be missing or not matched to a GP. It is possible that you may have patients who may benefit from HCV assessment and referral for treatment who are not on the list or have recently been diagnosed.

Please refer patients with confirmed hepatitis C infection (HCV RNA positive) to specialist services for treatment assessment, following agreed local pathways.

If you have patients who are HCV antibody positive only, please arrange for them to have confirmatory HCV RNA testing done, and refer to specialist services as appropriate. If HCV RNA negative they should be informed that they have had past infection and advised about ongoing risks and measures to prevent reinfection.

## How does this exercise affect management of newly diagnosed hepatitis C patients?

This retrospective matching exercise does not replace current processes for new laboratory diagnoses of hepatitis C being reported to the requesting clinician and /or direct laboratory reporting to ODNs as part of routine clinical care and locally agreed pathways.

## How do I manage close household or sexual contacts of patients with hepatitis C?

Hepatitis C is mainly spread through direct blood to blood contact e.g. through sharing needles and other injecting equipment. Sexual transmission is less common. Household contacts are therefore at low risk of infection, but all household and sexual contacts and contacts who inject illicit drugs with the patient should be offered testing.

## How do I manage patients at risk of hepatitis C?

If you have patients who you think may be at risk of hepatitis C but have never been tested, please offer them anti-HCV testing followed by HCV RNA testing (preferably on the same sample to minimise visits), or as per locally agreed pathways. Resources and information on hepatitis C who is at risk, testing, prevention and treatment is available in the hepatitis C GP factsheet enclosed (and below).

## Where can I get information for patients on hepatitis C?

Patient resources are available at the following websites:

NHS choices: <https://www.nhs.uk/conditions/hepatitis-c/>

The Hepatitis C Trust: [www.hepctrust.org.uk](http://www.hepctrust.org.uk)

The British Liver Trust: <https://www.britishlivertrust.org.uk/liver-information/liver-conditions/hepatitis-c/>

PHE (for posters, social media banners, videos): <https://publichealthengland-immunisati.app.box.com/s/iptxtlziu57evyejw8zgvhimh0pjwa05>

## How do I explain to a patient why PHE has their information and has shared it with another doctor?

Doctors and laboratory directors are mandated by law to report to PHE any new diagnoses of hepatitis C as it is a notifiable disease. PHE collects this information as part of disease surveillance to carry out its legal duty to monitor, prevent and control the spread of infectious diseases to protect and improve the public's health.

PHE holds this sensitive information confidentially and securely and following Caldicott principles, does not share personal identifiable information with any third party (except with the clinician responsible for the care of the patient, like the patient's GP)

Patient re-engagement exercise of those who have been previously diagnosed with hepatitis C

PHE has a leaflet entitled 'Public Health England: what we do, how we use personal information, and your options' that is available at:

[https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/421854/PHE\\_fair\\_processing\\_notice.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/421854/PHE_fair_processing_notice.pdf)

Hepatitis C infection can lead to serious liver disease and cancer if untreated. Past treatments have not been so effective or well tolerated. In recent years new highly effective hepatitis C treatments have become available on the NHS that can cure patients, have fewer side effects and are a shorter oral tablet course. However there is concern that not all those patients who would benefit are aware of their diagnosis or the new treatment options.

PHE has therefore asked for specific Caldicott approval to share a list of patients who have had a previous laboratory diagnosis of hepatitis C with specialist hospital doctors so they may contact the patient for assessment for curative treatment.