

1. What care has the patient received for HCV-related illness since the date of the last report?

None Outpatient only Inpatient (assessment only, eg. liver biopsy) Inpatient (medical care)

If the patient has received **any inpatient care for HCV-related illness** since the last report, please supply the following information for each admission:

Care episode	Date of admission (dd/mm/yy)	Date of discharge (dd/mm/yy)	Ward type, eg. General Medical, ICU, Liver Unit, HDU etc	Reason for admission	
				Tick if liver biopsy	Other (please state)
1				<input type="checkbox"/>	
2				<input type="checkbox"/>	
3				<input type="checkbox"/>	
4				<input type="checkbox"/>	

2. If the patient has had any outpatient care for HCV since the date of the last report, how many outpatient appointments have they had?

Please state the number of appointments: _____

3. Has the patient had a liver Ultrasound Scan (US) since the date of the last report? Yes No

4. Has the patient undergone any other procedures (like therapeutic banding gastroscopy, TIPPS, alcoholic injection of the liver, laser ablation of the liver, etc.) for their HCV-related liver disease? Yes No

If **yes**, please specify the procedures and the number of times each procedure has been undergone: _____

5. What is the patient's current alcohol intake (in units of alcohol/week, if possible)? _____ Not known

Section 6: COMMENTS

If you have any comments that you would like to make, please do so in the space below:

Please print your details below so that we can contact you if we need more information about this patient:

Your name: _____

Date (dd/mm/yyyy): ____/____/____ Telephone number: _____

Email address: _____

THANK YOU VERY MUCH FOR YOUR HELP
ALL THE INFORMATION YOU PROVIDE WILL BE TREATED IN CONFIDENCE

PLEASE RETURN THIS FORM USING REPLY PAID ENVELOPE TO:

Annastella Costella, Immunisation, Hepatitis and Blood Safety Department, Health Protection, Public Health England, 61 Colindale Avenue, London, NW9 5EQ

The HCV National Register is operated by Public Health England

V May 14

NATIONAL REGISTER OF HCV INFECTIONS WITH A KNOWN DATE OF ACQUISITION

FOLLOW-UP FORM

The national register contains information on HCV infections with known dates of acquisition/exposure, and provides a facility for the future monitoring and long term assessment of HCV infection within the UK.

- No patient names are held in the HCV National Register. It is therefore very important that you retain the register number in your records and that you are able to trace the patient from either the register number or the identifier/reference number that you supply on the form (Question 1).
- Ethical approval for the register has been obtained from the North Thames Multi-Centre Research Ethics Committee.

Enquiries regarding either the HCV National Register or completion of the form should be directed to:

Dr Helen Harris (Register Co-ordinator)
 Telephone: 020 8327 7676
 Email: helen.harris@phe.gov.uk

Ms Annastella Costella (Hepatitis Scientist)
 Telephone: 020 8327 7086
 Email: annastella.costella@phe.gov.uk

DATE OF LAST REPORT: ____/____/____

Register number: _____

Date of birth: ____/____/____

Soundex/initials: _____

Your reference: _____

NHS No: _____


Section 1: PATIENT DETAILS (please insert details or tick boxes as appropriate)

1. Identifier by which you can recognise the patient in current and future correspondence (eg. hospital number):

Patient NHS number: _____

2. Are you still responsible for the HCV-related care of the patient?

Yes  Please continue

No  Please give the name and address of the clinician now responsible for the HCV-related care of this patient (and then return the form to us). Please also ensure that you insert your details at the end of this form so that we can contact you if we need more information about this patient.
THANK YOU VERY MUCH FOR YOUR HELP.

Name: _____

Address: _____

3. Has this patient been seen, treated, or tested for HCV-related illness since their last report (see front of form for date of last report)?

Yes  Please complete the rest of the form

No  Please go straight to Section 6

Section 2: CURRENT CLINICAL STATUS

The next questions ask about the patient's current clinical status. In this context, clinical status is intended to reflect the patient's signs and/or symptoms of liver disease, not their test results.

1. Has the patient died (please tick box)? Yes No

If **yes**, please give date of death (dd/mm/yyyy) ____/____/____ and cause of death: _____

If **no**, does the patient have: No clinical signs or symptoms of liver disease  Please go to question 3

Clinical signs or symptoms of liver disease (HCV-related)

Clinical signs or symptoms of liver disease (not HCV-related)  Details/cause: _____

2. Please record any signs or symptoms of liver disease:

Spider naevi Hepatomegaly Splenomegaly Ascites Varices Bleeding varices Liver tumour

Palmar erythema/Liver palms Encephalopathy Jaundice

Other (please give details): _____

3. Does the patient suffer from any other significant medical conditions (please tick box)? Yes No

If **yes**, please specify: _____

4. Is the patient obese (BMI ≥ 30)? Yes No

Section 3: TEST RESULTS SINCE LAST REPORT (see front of form for date of last report)

1. Date of last consultation for HCV since last report (dd/mm/yyyy): ____/____/____

2. Date of latest HCV PCR test results since last report (dd/mm/yyyy): ____/____/____ Not done Not known

Results (please tick box): Positive Negative Not known Other (eg. viral load): _____

3. Date of latest HCV antibody test results since last report (dd/mm/yyyy): ____/____/____ Not done Not known

Results (please tick box): Positive Negative Equivocal Not known

4. Please insert the HCV genotype or serotype if known: _____ Not known

5. Date of latest liver function tests since last report (dd/mm/yyyy): ____/____/____ Not done Not known

Results (please tick box or enclose copy of report form): Normal Abnormal Not known

Please give results and test ranges: ALT _____ Range _____ AST _____ Range _____

Bilirubin _____ Range _____ Albumin _____ Range _____

6. Date of latest haematology tests since last report (dd/mm/yyyy): ____/____/____ Not done Not known

Please give results and test ranges: INR/PTT _____ Range _____ Platelets _____ Range _____

7. Date of latest liver biopsy since last report (dd/mm/yyyy): ____/____/____ Not done Not known

Results (please tick box): Normal Abnormal Not known

If **abnormal**, please give results (enclose copy of report form, if possible):

Minimal change Chronic hepatitis Cirrhosis Hepatocellular carcinoma

Fibrosis score (if known): _____ Scoring system: _____



Histopathology department biopsy reference number: _____

8. Date of latest Fibroscan (dd/mm/yyyy): ____/____/____ Not done Not known Fibroscan score: _____ kPa (range ____ - ____)

a. Date of previous Fibroscan (dd/mm/yyyy): ____/____/____ Not done Not known Fibroscan score: _____ kPa (range ____ - ____)

b. Date of previous Fibroscan (dd/mm/yyyy): ____/____/____ Not done Not known Fibroscan score: _____ kPa (range ____ - ____)

Section 4: ANTIVIRAL DRUG TREATMENT SINCE LAST REPORT (see front of form for date of last report)

1. Has the patient had any antiviral treatment for HCV since the date of the last report? Yes  Please continue with this section No  Please go to question 3

If **yes**, please insert details of treatment in the table below:

COURSE	A	B	C
Date started (dd/mm/yy)			
Date finished (dd/mm/yy)			
Interferon preparation (state if pegylated)			
Interferon dosage (mIU)			
Interferon schedule (e.g. Daily, twice weekly)			
Ribavirin dosage (please give units)			
Ribavirin Schedule (e.g. Daily, twice weekly)			
Telaprevir. If yes, date started (dd/mm/yy)			
Boceprevir. If yes, date started (dd/mm/yy)			
Other antivirals. Please give name.			
Other antivirals dosage (please give units)			
Other antivirals Schedule (e.g. Daily, twice weekly)			

2. What was the response to the latest course of treatment? (please tick **only one** of the 8 boxes below)

- Not relevant (still on treatment)
- Treatment stopped early (eg. due to side effects)
- No response (never became PCR negative)
- Response:
 - Late relapse (PCR negative >12/12 after treatment but became positive at a later date)
 - Long term response (remains PCR negative 12/12 after treatment completed)
 - Sustained response (remains PCR negative 6/12 after treatment completed)
 - Immediate/initial response (PCR negative <6/12 after treatment completed)
 - Transient response (PCR negative during treatment but became positive after treatment)

3. Has the patient taken part in any antiviral drug trials since the date of the last report? Yes No

If **yes**, please give details: Name of trial: _____

Patient registration/code number: _____ Date of entry: ____/____/____

4. Has the patient received any other treatment for HCV since the date of the last report (eg. herbal treatments)? Yes No

If **yes**, please give details: _____