

3. Has the patient taken part in any antiviral drug trials? Yes No

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

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

4. Has the patient received any other treatments for HCV (eg. herbal treatments etc)? Yes No

If yes, please give details: _____

Section 5: CURRENT MANAGEMENT

1. During the last 12 months what care has the patient received for **HCV-related illness**?

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

If the patient received inpatient care in the last 12 months for HCV-related illness, please give date and reason 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. What was the patient's alcohol intake at first diagnosis (in units of alcohol/week, if possible)? _____ Not known

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

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

REGISTRATION 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 registration form should be directed to either:

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

Register number: _____

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

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

- Patient NHS number:** _____
- Date of birth (dd/mm/yy):** ____/____/____
- Sex:** Male Female
- Ethnic group:** White Black-Caribbean Black-African Black, other Indian Pakistani
Bangladeshi Chinese Asian, other Other, please specify: _____
- Country of birth:** _____
- If you are not the patient's GP, please give the name and address of their GP below:**
Name: _____
Address: _____
- Has the patient ever injected drugs (even if only once)?** Yes No Not known
- Does the patient have any other known risk factors for HCV infection?** Yes No Not known
If **yes**, please give details: _____
- To your knowledge, does the patient have any other significant chronic viral infection?** Yes No
If **yes**, please specify: _____
- Does the patient suffer from any other significant medical conditions?** Yes No
If **yes**, please specify: _____
- 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: _____

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.

- 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: _____
- 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): _____
- Is the patient obese (BMI ≥30)?** Yes No

Section 3: TEST RESULTS

- Date of last consultation for HCV (dd/mm/yyyy):** ____/____/____
- Has the patient been tested for hepatitis B infection, and if so, what were the results?**
HBsAg: Positive Negative Not tested Not sure
anti-HBc: Positive Negative Not tested Not sure
- Has the patient ever had a positive HCV PCR test?** Yes No Not tested Not known
If **yes**, please give date of first known positive test (dd/mm/yyyy): ____/____/____
- Date of latest HCV PCR test results (dd/mm/yyyy):** ____/____/____ Not done Not known
Results (please tick box): Positive Negative Other (eg. viral load): _____ Not known
- Date of latest HCV antibody test results (dd/mm/yyyy):** ____/____/____ Not done Not known
Results (please tick box): Positive Negative Equivocal Not known
- Please insert the HCV genotype or serotype if known:** _____ Not known
- Date of latest liver function tests (dd/mm/yyyy):** ____/____/____ Not done Not known
Results (please tick box or enclose copy of report form): Normal Abnormal Not known
If **abnormal**, please give results and test ranges: ALT _____ Range _____ AST _____ Range _____
Bilirubin _____ Range _____ Albumin _____ Range _____
- Date of latest haematology tests (dd/mm/yyyy):** ____/____/____ Not done Not known
Please give results and test ranges: INR/PTT _____ Range _____ Platelets _____ Range _____
- Date of latest liver biopsy (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: _____
- 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

- Has the patient had any antiviral treatment for HCV?** 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 (mL)			
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)			

- 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)