

Hepatitis C Follow-Up Questionnaire 2003-2008

Telephone survey script and questionnaire:

I am calling from the NHANES program. (You/SP) participated in our examination survey in _____, <month/year>, and on _____ <date> you were mailed a letter with (your/your child's) hepatitis C test result. *Explain what report this is. Participants get preliminary results at the time of the examination, early reports of abnormal labs (liver function tests) and letters reporting other possible infection...Hepatitis B.*

HCQ.010 Did you receive a letter in the mail with (your/SP's) hepatitis C test results?

1. Yes
2. No -> <verify address, describe letter and fact sheet, if absolutely no recall, resend letter, follow-up in two months> **(if participant has questions about hepatitis C, transfer call to Medical Officer.) End interview**

I would like to ask you some questions about what you know about hepatitis C and any follow-up you may have taken (with SP) since getting the letter. The interview will take about 20 minutes. All information you provide is strictly confidential, and your participation is voluntary. Information will be used by the Centers for Disease Control and Prevention to help people with hepatitis C.

May we proceed with the interview?

If "yes", go to HCQ.020. If not - set up an appointment for a better time, or note the reason for the refusal.

HCQ.020 There are many types of hepatitis. Before receiving the letter with (your/SP's) test result, had you heard of hepatitis C?

1. Yes
2. No
3. Heard of hepatitis, but not specifically hepatitis C
7. Refused
9. Don't know

HCQ.030 Was the test result in our letter the first time you were told (you had/SP has) hepatitis C?

1. Yes (HCQ.070)
2. No
7. Refused (HCQ.070)
9. Don't know (HCQ.070)

HCQ.040 For about how long have you known that (you have/SP has) hepatitis C? Would you say...

1. One year
2. 2 to 5 years
3. More than 5 years
7. Refused
9. Don't know

If ≥ 16 years of age, skip to question HCQ.060.

HCQ.050 Why was (SP) first tested for hepatitis C? Was it because:

1. He/she had other blood tests done for a routine physical that showed he/she might have liver disease?
2. He/she was sick with symptoms like fatigue, nausea, stomach pain, yellowing of the eyes or skin (known as jaundice)?
3. He/she or your doctor thought (SP) was at risk of having hepatitis C?
4. He/she had contact with someone with hepatitis C?
5. He/she had another reason?
7. Refused
9. Don't know

Skip to question HCQ.070

HCQ.060 Why were you first tested for hepatitis C? Was it because:

1. You donated blood?
2. You had other blood tests done for a routine physical that showed you might have liver disease?
3. You were sick with symptoms like fatigue, nausea, stomach pain, yellowing of the eyes or skin (known as jaundice)?
4. You were exposed to blood while on the job?
5. You or your doctor thought you were at risk of having hepatitis C?
6. You had another reason?
7. Refused
9. Don't know

Now I'm going to ask you some questions about what you have done (with SP) since finding out that (you have/your child has) hepatitis C.

HCQ.070 Did (you/SP) see a doctor or other health professional about (your/his/her) hepatitis C test result? (*If tested before NHANES, question refers to first test; otherwise refers to NHANES test*)

1. Yes (HCQ.090)
2. No
7. Refused
9. Don't know

HCQ.080 (Do you/Does SP) have an appointment to see a doctor or other health care professional about (your/his/her) hepatitis C test result?

1. Yes (HCQ.160)
2. No (HCQ.160)
7. Refused (HCQ.160)
9. Don't know (HCQ.160)

HCQ.090 When (you/SP) saw a doctor or other health professional about (your/his/her) hepatitis C test results, did (you/he/she) have other blood tests to check how (your/his/her) liver is working?

1. Yes
2. No
7. Refused
9. Don't know

HCQ.100 Which of the following statements describes most closely what (your/SP's) doctor told you about (your/his/her) hepatitis C test result? (Read each statement and check only one)

1. (You have/He/she has) hepatitis C and need(s) regular medical follow-up.
2. (You/He/she) tested positive for hepatitis C, but (do/does) not need to do anything or worry about it. (HCQ.160)
3. (You/He/she) really (don't/doesn't) have hepatitis C because a follow-up test showed that the positive test result was in error. (End interview)
4. Other
7. Refused
9. Don't know

HCQ.110 Did (you/SP) have a liver biopsy (procedure to get a small piece of (your/his/her) liver through a needle)?

1. Yes
2. No
7. Refused
9. Don't know

HCQ.121 Did (your/SP's) doctor or health care professional tell you that there are medicines that can be used to treat hepatitis C?

1. Yes
2. No (HCQ.150)
7. Refused (HCQ.150)
9. Don't know (HCQ.150)

HCQ.124 Did (your/SP's) doctor or health care professional tell you that your hepatitis C should be treated with medication such as Interferon and Ribavirin?

1. Yes (HCQ.130)
2. No
7. Refused (HCQ.150)
9. Don't know (HCQ.150)

HCQ.126 What reason did your doctor or health care professional give you when he/she told you that you should not be treated? Was it because...

- A. Your liver enzymes were normal
 - 1. Yes
 - 2. No
 - 7. Refused
 - 9. Don't Know

- B. You did not have liver disease
 - 1. Yes
 - 2. No
 - 7. Refused
 - 9. Don't Know

- C. You don't need to do anything for hepatitis C
 - 1. Yes
 - 2. No
 - 7. Refused
 - 9. Don't Know

- D. You can wait to be treated at a later time
 - 1. Yes
 - 2. No
 - 7. Refused
 - 9. Don't Know

- E. No reason specified
 - 1. Yes
 - 2. No
 - 7. Refused
 - 9. Don't Know

HCQ.130 Did (you/SP) get treated with these medicines?

- 1. Yes (HCQ.150)
- 2. No
- 7. Refused (HCQ.150)
- 9. Don't know (HCQ.150)

HCQ.140 Why did (you/SP) not get treated? Was it because...

A. The side effects to the treatment are unpleasant.

1. Yes
2. No
7. Refused
9. Don't Know

B. The treatment shots must be self injected.

1. Yes
2. No
7. Refused
9. Don't Know

C. The treatment is too expensive,

1. Yes
2. No
7. Refused
9. Don't Know

D. There is a hope of better treatment in the future.

1. Yes
2. No
7. Refused
9. Don't Know

E. Or is there some other reason?

1. Yes
2. No
7. Refused
9. Don't Know

HCQ.150 Did (your/SP's) doctor or health care professional tell (you/him/her) to avoid or limit alcoholic beverages (in the future) because of (your/his/her) hepatitis C?

1. Yes
2. No
7. Refused
9. Don't know

We would like to know what you have learned about hepatitis C. Please tell me if you believe the following statements are true or false, or if you don't know whether they are true or false.

HCQ.160 If someone is infected with hepatitis C virus, they will most likely carry the virus all their lives.

1. True
2. False
7. Refused
9. Don't know

HCQ.170 Infection with the hepatitis C virus can cause the liver to stop working.

1. True
2. False
7. Refused
9. Don't know

HCQ.180 Someone with hepatitis C can look and feel fine.

1. True
2. False
7. Refused
9. Don't know

HCQ.190 You can get hepatitis C by getting a blood transfusion from an infected donor.

1. True
2. False
7. Refused
9. Don't know

HCQ.200 You can get hepatitis C by shaking hands with someone who has hepatitis C.

1. True
2. False
7. Refused
9. Don't know

HCQ.210 You can get hepatitis C by kissing someone who has hepatitis C.

1. True
2. False
7. Refused
9. Don't know

- HCQ.220 You can get hepatitis C by having sex with someone who has hepatitis C.
1. True
 2. False
 7. Refused
 9. Don't know
- HCQ.230 You can get hepatitis C by being born to a woman who had hepatitis C when she gave birth.
1. True
 2. False
 7. Refused
 9. Don't know
- HCQ.240 You can get hepatitis C by being stuck with a needle or sharp instrument that has hepatitis C infected blood on it.
1. True
 2. False
 7. Refused
 9. Don't know
- HCQ.250 You can get hepatitis C by working with someone who has hepatitis C.
1. True
 2. False
 7. Refused
 9. Don't know
- HCQ.260 You can get hepatitis C by injecting illegal drugs, even if only a few times.
1. True
 2. False
 7. Refused
 9. Don't know

HCQ.270 Who was the main respondent for the questionnaire?

1. SP
2. Parent/guardian
3. SP and Parent/guardian

End Interview

Thank you for your time. We want to emphasize that everything you have told us will be held strictly confidential. We appreciate your participation in the National Health and Nutrition Examination Survey.