National Health and Nutrition Examination Survey 2003-2004

Documentation, Codebook, and Frequencies

Phone Follow-Up Questionnaire Component: Hepatitis C Follow-Up Questionnaire Data

Survey Years:
2003 to 2004

SAS Export File:
HCQ_C.XPT

September 2006

NHANES 2003–2004 Data Documentation

Questionnaire Section: Phone Follow-Up

Name: Hepatitis C Follow-Up Questionnaire (HCQ_C)

Years of Coverage: 2003–2004 **First Published:** September 2006 **Last Revised:** NA

Component Description

Participants 6 years and older testing positive for antibody to hepatitis C virus (anti-HCV) (LBXHC) are sent a report of findings (ROF) letter informing them of their HCV test result and encouraging them to follow-up with a health care provider to determine if any other tests or procedures are needed. The follow-up phone questionnaire occurs 6 months after their examination (approximately 4-5 months after the ROF letter was mailed). The purpose of the questions is to assess what proportion of NHANES participants testing positive for infection with hepatitis C virus (HCV) already knew of their infection status, what they know about hepatitis C, and what actions they take after becoming aware of their infection status.

The HCV follow-up questionnaire is mentioned in the informed consent and also in the reporting letter for positive HCV letters. Trained interviewers contacted those participants with positive HCV results by telephone for an interview.

An automated system for managing calls (i.e., setting up appointments, tracking the calls to contact the participant, and reasons for refusal) is maintained in the Field Follow up Management System (FFMS). Responses to interview questions are keyed directly into the FFMS, a web based application of the Integrated Survey Information System (ISIS) software used for other NHANES components

Participants who live in households with no telephones were sent a letter asking them to call a toll free number to answer a few questions about their Hepatitis C results.

Eligible Sample

Participants age 6 years and older testing positive for hepatitis C virus (anti-HCV). Parents or guardians are interviewed for participants with hepatitis C who are under the age of 18 years or adults who cannot respond for themselves.

Exclusion Criteria: Circumstances when communication or cognitive difficulties make it impossible for the participant to respond to questionnaire and a parent or guardian is not available to complete the interview would result in exclusion.

Interview Setting and Mode of

Bilingual (English and Spanish) trained interviewers contacted participants with positive hepatitis C results by telephone to request an interview. Call attempts were scheduled 6 months after the date of examination,

Administration	approximately 4-5 months after participants receive the results notification letter. In order to determine what actions persons take with the information that they are infected, it is necessary to allow time to have initiated or implemented such actions after notification of infection. Therefore, the telephone interview occurs at least a few months after notification.
Quality Assurance & Quality Control	The hepatitis C follow-up questions were evaluated in NCHS's Questionnaire Design Research Laboratory before the final questionnaire was approved by the NHANES Ethics Review Board (ERB).
Data Processing and Editing	NA
Analytic Notes	These data should be linked to the laboratory data (Lab 02, LBXHC) by sequence number. Examples of reasons for non-response coded as "communication problem or cognitive impairment" may include hearing impairment, poor memory recall, and language barrier.
References	NA

Locator Record

Title: HCQ_C

Contact Number: 1-866-441-NCHS

Years of Content: 2003–2004

First Published: September 2006

Revised: NA

Access Constraints: None

Use Constraints: None

Geographic Coverage: National

Subject: Hepatitis C Follow-Up Questionnaire

Record Source: NHANES 2003–2004

Survey Methodology: NHANES 2003–2004 is a stratified multistage probability sample of the civilian non-institutionalized population of the U.S.

Medium: NHANES Web site; SAS transport files

National Health and Nutrition Examination Survey
Codebook for Data Production (2003-2004)

Hepatitis C Follow-Up Questionnaire (HCQ_C)
Person Level Data

September 2006

SEQN	Target
	B(6 Yrs. to 150 Yrs.)
Hard Edits	**SAS Label**
	Respondent sequence number
English Text: Respondent sequence number.	
English Instructions:	

HCASCST1	Target
	B(6 Yrs. to 150 Yrs.)
Hard Edits	**SAS Label**
	Interview Status Code
English Text: Interview Status Code	
English Instructions:	

Code or Value	Description	Count	Cumulative	Skip to Item
1	Complete	43	43	LBDHCV
2	Partial	2	45	LBDHCV
3	Not done	42	87	
.	Missing	0	87	

HCASCCT1	Target
	B(6 Yrs. to 150 Yrs.)
Hard Edits	**SAS Label**
	Reasons for Not Done
English Text: Reasons the Interview was not done	
English Instructions:	

Code or Value	Description	Count	Cumulative	Skip to Item
1	Unable to contact SP	37	37	
2	Refusal	1	38	
3	Communication problem or cognitive impairment	1	39	
4	SP expired	1	40	
5	Did not receive letter	1	41	
6	Other	1	42	
.	Missing	45	87	

LBDHCV	Target
	B(6 Yrs. to 150 Yrs.)
Hard Edits	**SAS Label**
	Hepatitis C antibody
English Text: Hepatitis C antibody	
English Instructions:	

Code or Value	Description	Count	Cumulative	Skip to Item
1	Positive	87	87	
2	Negative	0	87	
5	Indeterminate	0	87	
.	Missing	0	87	

HCQ020	Target
	B(6 Yrs. to 150 Yrs.)
Hard Edits	**SAS Label**
	Heard of Hepatitis C prior to letter?

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

English Instructions:

Code or Value	Description	Count	Cumulative	Skip to Item
1	Yes	41	41	
2	No	3	44	
3	Heard of hepatitis, but not specifically hepatitis C	1	45	
7	Refused	0	45	
9	Don't know	0	45	
.	Missing	42	87	

HCQ030	Target
	B(6 Yrs. to 150 Yrs.)
Hard Edits	**SAS Label**
	First time told had Hepatitis C?

English Text: Was the test result in our letter the first time you were told (you had/SP has) hepatitis C?

English Instructions:

Code or Value	Description	Count	Cumulative	Skip to Item
1	Yes	20	20	HCQ070
2	No	25	45	
7	Refused	0	45	HCQ070
9	Don't know	0	45	HCQ070
.	Missing	42	87	

HCQ040	Target
	B(6 Yrs. to 150 Yrs.)
Hard Edits	**SAS Label**
	How long known infected?

English Text: For about how long have you known that (you have/SP has) hepatitis C? Would you say ...

English Instructions:

Code or Value	Description	Count	Cumulative	Skip to Item
1	One year	4	4	
2	2 to 5 years	9	13	
3	More than 5 years	11	24	
7	Refused	0	24	
9	Don't know	1	25	
.	Missing	62	87	

HCQ060	Target
	B(6 Yrs. to 150 Yrs.)
Hard Edits	**SAS Label**
	Reason first tested for Hepatitis C?

English Text: Why were you first tested for hepatitis C? Was it because:

English Instructions:

Code or Value	Description	Count	Cumulative	Skip to Item
1	You donated blood?	3	3	
2	You had other blood tests done for a routine physical that showed you might have liver disease?	12	15	
3	You were sick with symptoms like fatigue, nausea, stomach pain, yellowing of the eyes or skin (known as jaundice)?	2	17	
4	You were exposed to blood while on the job?	0	17	
5	You or your doctor thought you were at risk of having hepatitis C?	1	18	
6	You had another reason?	6	24	
7	Refused	0	24	
9	Don't know	1	25	
.	Missing	62	87	

HCQ070	Target
	B(6 Yrs. to 150 Yrs.)
Hard Edits	**SAS Label**
	Seen a doctor about test result?

English Text: Did (you/SP) see a doctor or other health professional about (your/his/her) hepatitis C test result?

English Instructions: 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. INTERVIEWER: If tested before NHANES, question refers to first test; otherwise refers to NHANES test.

Code or Value	Description	Count	Cumulative	Skip to Item
1	Yes	30	30	HCQ090
2	No	15	45	
7	Refused	0	45	
9	Don't know	0	45	
.	Missing	42	87	

HCQ080	Target
	B(6 Yrs. to 150 Yrs.)
Hard Edits	**SAS Label**
	Have a doctor's appointment?

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

English Instructions:

Code or Value	Description	Count	Cumulative	Skip to Item
1	Yes	1	1	HCQ160
2	No	14	15	HCQ160
7	Refused	0	15	HCQ160
9	Don't know	0	15	HCQ160
.	Missing	72	87	

HCQ090	Target
	B(6 Yrs. to 150 Yrs.)
Hard Edits	**SAS Label**
	Did doctor do additional tests?

English Text: 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?

English Instructions:

Code or Value	Description	Count	Cumulative	Skip to Item
1	Yes	24	24	
2	No	4	28	
7	Refused	0	28	
9	Don't know	2	30	
.	Missing	57	87	

HCQ100	Target
	B(6 Yrs. to 150 Yrs.)
Hard Edits	**SAS Label**
	What doctor told about test result?

English Text: Which of the following statements describes most closely what (your/SP's) doctor told you about (your/his/her) hepatitis C result?

English Instructions: Read each statement and check only one.

Code or Value	Description	Count	Cumulative	Skip to Item
1	(You have/He/She has) hepatitis C and need(s) regular medical follow-up.	14	14	
2	You/He/She) tested positive for hepatitis C, but (do/does) not need to do anything or worry about it.	8	22	HCQ160
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.	3	25	End of Section
4	Other	2	27	
7	Refused	1	28	
9	Don't know	1	29	
.	Missing	58	87	

HCQ110	Target
	B(6 Yrs. to 150 Yrs.)
Hard Edits	**SAS Label**
	Ever had a liver biopsy?

English Text: Did (you/SP) have a liver biopsy (procedure to get a small piece of (your/his/her) liver through a needle)?

English Instructions:

Code or Value	Description	Count	Cumulative	Skip to Item
1	Yes	7	7	
2	No	9	16	
7	Refused	0	16	
9	Don't know	2	18	
.	Missing	69	87	

HCQ121	Target
	B(6 Yrs. to 150 Yrs.)
Hard Edits	**SAS Label**
	Doctor advised about medications?

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

English Instructions:

Code or Value	Description	Count	Cumulative	Skip to Item
1	Yes	14	14	
2	No	2	16	HCQ150
7	Refused	0	16	HCQ150
9	Don't know	2	18	HCQ150
.	Missing	69	87	

HCQ124	Target
	B(6 Yrs. to 150 Yrs.)
Hard Edits	**SAS Label**
	Doctor advised you should be treated?

English Text: 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?

English Instructions:

Code or Value	Description	Count	Cumulative	Skip to Item
1	Yes	8	8	HCQ130
2	No	3	11	
7	Refused	0	11	HCQ150
9	Don't know	3	14	HCQ150
.	Missing	73	87	

HCQ126A	Target
	B(6 Yrs. to 150 Yrs.)
Hard Edits	**SAS Label**
	Reason 1 for not being treated

English Text: What reason did your doctor ot health care professional give you when he/she told you that you should not be treated? (Choose all that apply) Was it because your liver enzymes were normal?

English Instructions:

Code or Value	Description	Count	Cumulative	Skip to Item
1	Yes	1	1	
2	No	2	3	
7	Refused	0	3	
9	Don't know	0	3	
.	Missing	84	87	

HCQ126B	Target
	B(6 Yrs. to 150 Yrs.)
Hard Edits	**SAS Label**
	Reason 2 for not being treated

English Text: What reason did your doctor ot health care professional give you when he/she told you that you should not be treated?(Choose all that apply) Was it because you did not have liver disease?

English Instructions:

Code or Value	Description	Count	Cumulative	Skip to Item
1	Yes	1	1	
2	No	2	3	
7	Refused	0	3	
9	Don't know	0	3	
.	Missing	84	87	

HCQ126C	Target
	B(6 Yrs. to 150 Yrs.)
Hard Edits	**SAS Label**
	Reason 3 for not being treated

English Text: What reason did your doctor ot health care professional give you when he/she told you that you should not be treated?(Choose all that apply) Was it because you do not need to do anything for hepatitis C?

English Instructions:

Code or Value	Description	Count	Cumulative	Skip to Item
1	Yes	0	0	
2	No	3	3	
7	Refused	0	3	
9	Don't know	0	3	
.	Missing	84	87	

HCQ126D	Target
	B(6 Yrs. to 150 Yrs.)
Hard Edits	**SAS Label**
	Reason 4 for not being treated

English Text: What reason did your doctor ot health care professional give you when he/she told you that you should not be treated? (Choose all that apply) Was it because you can wait to be treated at a later time?

English Instructions:

Code or Value	Description	Count	Cumulative	Skip to Item
1	Yes	0	0	
2	No	2	2	
7	Refused	0	2	
9	Don't know	1	3	
.	Missing	84	87	

HCQ126E	Target
	B(6 Yrs. to 150 Yrs.)
Hard Edits	**SAS Label**
	Reason 5 for not being treated

English Text: What reason did your doctor ot health care professional give you when he/she told you that you should not be treated? (Choose all that apply) Was it because... No reason specified.

English Instructions:

Code or Value	Description	Count	Cumulative	Skip to Item
1	Yes	0	0	
2	No	3	3	
7	Refused	0	3	
9	Don't know	0	3	
.	Missing	84	87	

HCQ130	Target
	B(6 Yrs. to 150 Yrs.)
Hard Edits	**SAS Label**
	Treated with these medicines?
English Text: Did (you/SP) get treated with these medicines?	
English Instructions:	

Code or Value	Description	Count	Cumulative	Skip to Item
1	Yes	4	4	HCQ150
2	No	7	11	
7	Refused	0	11	HCQ150
9	Don't know	0	11	HCQ150
.	Missing	76	87	

HCQ140A	Target
	B(6 Yrs. to 150 Yrs.)
Hard Edits	**SAS Label**
	Not treated: unpleasant side effects
English Text: Why did (you/SP) not get treated? (Choose all that apply). Was it because the side effects to the treatment are unpleasant?	
English Instructions:	

Code or Value	Description	Count	Cumulative	Skip to Item
1	Yes	1	1	
2	No	5	6	
7	Refused	1	7	
9	Don't know	0	7	
.	Missing	80	87	

HCQ140B	Target
	B(6 Yrs. to 150 Yrs.)
Hard Edits	**SAS Label**
	Not treated: treatment self injected
English Text: Why did (you/SP) not get treated? (Choose all that apply). Was it because the treatment shots must be self injected?	
English Instructions:	

Code or Value	Description	Count	Cumulative	Skip to Item
1	Yes	1	1	
2	No	5	6	
7	Refused	1	7	
9	Don't know	0	7	
.	Missing	80	87	

HCQ140C	Target
	B(6 Yrs. to 150 Yrs.)
Hard Edits	**SAS Label**
	Not treated: treatment too expensive
English Text: Why did (you/SP) not get treated? (Choose all that apply). Was it because the treatment is too expensive?	
English Instructions:	

Code or Value	Description	Count	Cumulative	Skip to Item
1	Yes	1	1	
2	No	5	6	
7	Refused	1	7	
9	Don't know	0	7	
.	Missing	80	87	

HCQ140D	Target
	B(6 Yrs. to 150 Yrs.)
Hard Edits	**SAS Label**
	Not treated:waiting for better treatment

English Text: Why did (you/SP) not get treated? (Choose all that apply). Was it because there is a hope of better treatment in the future?

English Instructions:

Code or Value	Description	Count	Cumulative	Skip to Item
1	Yes	0	0	
2	No	5	5	
7	Refused	1	6	
9	Don't know	1	7	
.	Missing	80	87	

HCQ140E	Target
	B(6 Yrs. to 150 Yrs.)
Hard Edits	**SAS Label**
	Not treated: some other reason

English Text: Why did (you/SP) not get treated? (Choose all that apply). Was it because there is some other reason?

English Instructions:

Code or Value	Description	Count	Cumulative	Skip to Item
1	Yes	4	4	
2	No	2	6	
7	Refused	1	7	
9	Don't know	0	7	
.	Missing	80	87	

HCQ150	Target
	B(6 Yrs. to 150 Yrs.)
Hard Edits	**SAS Label**
	Did doctor limit alcohol?

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

English Instructions:

Code or Value	Description	Count	Cumulative	Skip to Item
1	Yes	10	10	
2	No	6	16	
7	Refused	0	16	
9	Don't know	2	18	
.	Missing	69	87	

HCQ160	Target
	B(6 Yrs. to 150 Yrs.)
Hard Edits	**SAS Label**
	T/F: infection is permanent

English Text: If someone is infected with hepatitus C virus, they will most likely carry the virus all their lives.

English Instructions: 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.

Code or Value	Description	Count	Cumulative	Skip to Item
1	True	28	28	
2	False	4	32	
7	Refused	0	32	
9	Don't know	8	40	
.	Missing	47	87	

HCQ170	Target
	B(6 Yrs. to 150 Yrs.)
Hard Edits	**SAS Label**
	T/F: HepC stops liver
English Text: Infection with the hepatitis C virus can cause the liver to stop working.	
English Instructions:	

Code or Value	Description	Count	Cumulative	Skip to Item
1	True	32	32	
2	False	1	33	
7	Refused	1	34	
9	Don't know	6	40	
.	Missing	47	87	

HCQ180	Target
	B(6 Yrs. to 150 Yrs.)
Hard Edits	**SAS Label**
	T/F: look and feel fine
English Text: Someone with hepatitis C can look and feel fine.	
English Instructions:	

Code or Value	Description	Count	Cumulative	Skip to Item
1	True	35	35	
2	False	1	36	
7	Refused	1	37	
9	Don't know	3	40	
.	Missing	47	87	

HCQ190	Target
	B(6 Yrs. to 150 Yrs.)
Hard Edits	**SAS Label**
	T/F: HepC from blood transfusion
English Text: You can get hepatitis C by getting a blood transfusion from an infected donor.	
English Instructions:	

Code or Value	Description	Count	Cumulative	Skip to Item
1	True	37	37	
2	False	1	38	
7	Refused	1	39	
9	Don't know	1	40	
.	Missing	47	87	

HCQ200	Target
	B(6 Yrs. to 150 Yrs.)
Hard Edits	**SAS Label**
	T/F: HepC from shaking hands
English Text: You can get hepatitis C by shaking hands with someone who has hepatitis C.	
English Instructions:	

Code or Value	Description	Count	Cumulative	Skip to Item
1	True	3	3	
2	False	33	36	
7	Refused	1	37	
9	Don't know	3	40	
.	Missing	47	87	

HCQ210	Target
	B(6 Yrs. to 150 Yrs.)
Hard Edits	**SAS Label**
	T/F: HepC by kissing infected person

English Text: You can get hepatitis C by kissing someone who has hepatitis C.

English Instructions:

Code or Value	Description	Count	Cumulative	Skip to Item
1	True	5	5	
2	False	26	31	
7	Refused	1	32	
9	Don't know	8	40	
.	Missing	47	87	

HCQ220	Target
	B(6 Yrs. to 150 Yrs.)
Hard Edits	**SAS Label**
	T/F: HepC from infected sex partner

English Text: You can get hepatitis C by having sex with someone who has hepatitis C

English Instructions:

Code or Value	Description	Count	Cumulative	Skip to Item
1	True	21	21	
2	False	9	30	
7	Refused	1	31	
9	Don't know	9	40	
.	Missing	47	87	

HCQ230	Target
	B(6 Yrs. to 150 Yrs.)
Hard Edits	**SAS Label**
	T/F: HepC from birth, infected mother
English Text: You can get hepatitis C by being born to a woman who had hepatitis C when she gave birth.	
English Instructions:	

Code or Value	Description	Count	Cumulative	Skip to Item
1	True	21	21	
2	False	3	24	
7	Refused	1	25	
9	Don't know	15	40	
.	Missing	47	87	

HCQ240	Target
	B(6 Yrs. to 150 Yrs.)
Hard Edits	**SAS Label**
	T/F: HepC from sharp instrument
English Text: You can get hepatitis C by being stuck with a needle or sharp instrument that has hepatitis C infected blood on it.	
English Instructions:	

Code or Value	Description	Count	Cumulative	Skip to Item
1	True	35	35	
2	False	1	36	
7	Refused	1	37	
9	Don't know	3	40	
.	Missing	47	87	

HCQ250	Target
	B(6 Yrs. to 150 Yrs.)
Hard Edits	**SAS Label**
	T/F: HepC from coworkers
English Text: You can get hepatitis C by working with someone who has hepatitis C.	
English Instructions:	

Code or Value	Description	Count	Cumulative	Skip to Item
1	True	5	5	
2	False	23	28	
7	Refused	1	29	
9	Don't know	11	40	
.	Missing	47	87	

HCQ260	Target
	B(6 Yrs. to 150 Yrs.)
Hard Edits	**SAS Label**
	T/F: HepC from injecting drugs
English Text: You can get hepatitis C by injecting illegal drugs, even if only a few times.	
English Instructions:	

Code or Value	Description	Count	Cumulative	Skip to Item
1	True	36	36	
2	False	1	37	
7	Refused	1	38	
9	Don't know	2	40	
.	Missing	47	87	

HCQ270	Target
	B(6 Yrs. to 150 Yrs.)
Hard Edits	**SAS Label**
	Main respondent

English Text: Who was the main respondent for the questionnaire?

English Instructions:

Code or Value	Description	Count	Cumulative	Skip to Item
1	SP	38	38	
2	Parent/guardian	2	40	
3	SP and Parent/guardian	0	40	
.	Missing	47	87	