

# National Health and Nutrition Examination Survey 2001–2002

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## Documentation, Codebook, and Frequencies

### Hepatitis C Follow Up Questionnaire

**Survey Years:**  
**2001 to 2002**

**SAS Transport File:**  
**HCQ\_B.XPT**



**First Published:** September 2006  
**Last Revised:** April 2008

# NHANES 2001–2002 Data Documentation

## Questionnaire Section: Hepatitis C Follow Up Questionnaire (HCQ\_B)

First Published: September 2006

Last Revised: April 2008

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### 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) were eligible to participate. 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  
Administration**

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, 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 IRB.

**Data  
Processing  
and Editing**

NA

**Analytic  
Notes**

Combination of these data with other cycles is recommended when doing analysis. These data should not be used with sample weights to make national estimates due to small eligible sample size and low response rates.

The 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:** Hepatitis C Follow Up Questionnaire (HCQ\_B)

**Contact Number:** 1-866-441-NCHS

**Years of Content:** 2001–2002

**First Published:** September 2006

**Revised:** April 2008

**Access Constraints:** None

**Use Constraints:** None

**Geographic Coverage:** National

**Subject:** Hepatitis C Follow Up Questionnaire administered to survey participants who test positive for hepatitis C.

**Record Source:** NHANES 2001–2002

**Survey Methodology:** NHANES 2001–2002 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 (2001-2002)**

**Questionnaire Section:  
Hepatitis C Follow Up Questionnaire (HCQ\_B)**

First Published: September 2006

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

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

Code or Value	Description	Count	Cumulative	Skip to Item
1	Complete	58	58	HCQ020
2	Partial	0	58	HCQ020
3	Not done	54	112	
.	Missing	0	112	

<b>HCASCCT1</b>		<b>Target</b>		
		B(6 Yrs. to 150 Yrs.)		
<b>Hard Edits</b>		<b>SAS Label</b>		
		Reasons for Not Done		
<b>English Text:</b> Reasons the Interview was not done				
<b>English Instructions:</b>				
<b>Code or Value</b>	<b>Description</b>	<b>Count</b>	<b>Cumulative</b>	<b>Skip to Item</b>
1	Unable to contact SP	50	50	End of Section
2	Refusal	2	52	End of Section
3	Communication problem or cognitive impairment	2	54	End of Section
4	SP expired	0	54	End of Section
5	Did not receive letter	0	54	End of Section
6	Other	0	54	End of Section
.	Missing	58	112	

<b>HCQ020</b>		<b>Target</b>		
		B(6 Yrs. to 150 Yrs.)		
<b>Hard Edits</b>		<b>SAS Label</b>		
		Heard of Hepatitis C prior to letter?		
<b>English Text:</b> There are many types of hepatitis. Before receiving the letter with (your/SP's) test result, had you heard of hepatitis C?				
<b>English Instructions:</b>				
<b>Code or Value</b>	<b>Description</b>	<b>Count</b>	<b>Cumulative</b>	<b>Skip to Item</b>
1	Yes	41	41	
2	No	14	55	
3	Heard of hepatitis, but not specifically hepatitis C	3	58	
7	Refused	0	58	
9	Don't know	0	58	
.	Missing	54	112	

<b>HCQ030</b>		<b>Target</b>		
		B(6 Yrs. to 150 Yrs.)		
<b>Hard Edits</b>		<b>SAS Label</b>		
		First time told had Hepatitis C?		
<b>English Text:</b> Was the test result in our letter the first time you were told (you had/SP has) hepatitis C?				
<b>English Instructions:</b>				
<b>Code or Value</b>	<b>Description</b>	<b>Count</b>	<b>Cumulative</b>	<b>Skip to Item</b>
1	Yes	33	33	HCQ070
2	No	24	57	
7	Refused	0	57	HCQ070
9	Don't know	1	58	HCQ070
.	Missing	54	112	

<b>HCQ040</b>		<b>Target</b>		
		B(6 Yrs. to 150 Yrs.)		
<b>Hard Edits</b>		<b>SAS Label</b>		
		How long known infected?		
<b>English Text:</b> For about how long have you known that (you have/SP has) hepatitis C? Would you say ...				
<b>English Instructions:</b>				
<b>Code or Value</b>	<b>Description</b>	<b>Count</b>	<b>Cumulative</b>	<b>Skip to Item</b>
1	One year	3	3	
2	2 to 5 years	10	13	
3	More than 5 years	10	23	
7	Refused	1	24	
9	Don't know	0	24	
.	Missing	88	112	

<b>HCQ060</b>	<b>Target</b>			
	B(16 Yrs. to 150 Yrs.)			
<b>Hard Edits</b>	<b>SAS Label</b>			
	Reason first tested for Hepatitis C?			
<b>English Text:</b> Why were you first tested for hepatitis C? Was it because:				
<b>English Instructions:</b>				
<b>Code or Value</b>	<b>Description</b>	<b>Count</b>	<b>Cumulative</b>	<b>Skip to Item</b>
1	You donated blood?	3	3	
2	You had other blood tests done for a routine physical that showed you might have liver disease?	9	12	
3	You were sick with symptoms like fatigue, nausea, stomach pain, yellowing of the eyes or skin (known as jaundice)?	3	15	
4	You were exposed to blood while on the job?	0	15	
5	You or your doctor thought you were at risk of having hepatitis C?	2	17	
6	You had another reason?	5	22	
7	Refused	0	22	
9	Don't know	2	24	
.	Missing	88	112	

<b>HCQ070</b>	<b>Target</b>			
	B(6 Yrs. to 150 Yrs.)			
<b>Hard Edits</b>	<b>SAS Label</b>			
	Seen a doctor about test result?			
<b>English Text:</b> Did (you/SP) see a doctor or other health professional about (your/his/her) hepatitis C test result?				
<b>English Instructions:</b> 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	48	48	HCQ090
2	No	10	58	
7	Refused	0	58	
9	Don't know	0	58	
.	Missing	54	112	

<b>HCQ080</b>	<b>Target</b>			
	B(6 Yrs. to 150 Yrs.)			
<b>Hard Edits</b>	<b>SAS Label</b>			
	Have a doctor's appointment?			
<b>English Text:</b> (Do you/Does SP) have an appointment to see a doctor or other health care professional about (your/his/her) hepatitis C test result?				
<b>English Instructions:</b>				
Code or Value	Description	Count	Cumulative	Skip to Item
1	Yes	2	2	HCQ160
2	No	8	10	HCQ160
7	Refused	0	10	HCQ160
9	Don't know	0	10	HCQ160
.	Missing	102	112	

<b>HCQ090</b>	<b>Target</b>			
	B(6 Yrs. to 150 Yrs.)			
<b>Hard Edits</b>	<b>SAS Label</b>			
	Did doctor do additional tests?			
<b>English Text:</b> 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?				
<b>English Instructions:</b>				
<b>Code or Value</b>	<b>Description</b>	<b>Count</b>	<b>Cumulative</b>	<b>Skip to Item</b>
1	Yes	40	40	
2	No	5	45	
7	Refused	0	45	
9	Don't know	2	47	
.	Missing	65	112	

<b>HCQ100</b>	<b>Target</b>			
	B(6 Yrs. to 150 Yrs.)			
<b>Hard Edits</b>	<b>SAS Label</b>			
	What doctor told about test result?			
<b>English Text:</b> Which of the following statements describes most closely what (your/SP's) doctor told you about (your/his/her) hepatitis C result?				
<b>English Instructions:</b> Read each statement and check only one.				
<b>Code or Value</b>	<b>Description</b>	<b>Count</b>	<b>Cumulative</b>	<b>Skip to Item</b>
1	(You have/He/She has) hepatitis C and need(s) regular medical follow-up.	24	24	
2	You/He/She) tested positive for hepatitis C, but (do/does) not need to do anything or worry about it.	14	38	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.	1	39	End of Section
4	Other	6	45	
7	Refused	0	45	
9	Don't know	2	47	
.	Missing	65	112	

<b>HCQ110</b>	<b>Target</b>			
	B(6 Yrs. to 150 Yrs.)			
<b>Hard Edits</b>	<b>SAS Label</b>			
	Ever had a liver biopsy?			
<b>English Text:</b> Did (you/SP) have a liver biopsy (procedure to get a small piece of (your/his/her) liver through a needle)?				
<b>English Instructions:</b>				
<b>Code or Value</b>	<b>Description</b>	<b>Count</b>	<b>Cumulative</b>	<b>Skip to Item</b>
1	Yes	6	6	
2	No	25	31	
7	Refused	0	31	
9	Don't know	1	32	
.	Missing	80	112	

<b>HCQ120</b>	<b>Target</b>			
	B(6 Yrs. to 150 Yrs.)			
<b>Hard Edits</b>	<b>SAS Label</b>			
	Doctor advised about medications?			
<b>English Text:</b> Did (your/SP's) doctor or health care professional tell you that (your/his/her) hepatitis C should be treated with medication such as Interferon and Ribavirin?				
<b>English Instructions:</b>				
<b>Code or Value</b>	<b>Description</b>	<b>Count</b>	<b>Cumulative</b>	<b>Skip to Item</b>
1	Yes	6	6	
2	No	25	31	HCQ150
7	Refused	0	31	HCQ150
9	Don't know	1	32	HCQ150
.	Missing	80	112	

<b>HCQ130</b>		<b>Target</b>		
		B(6 Yrs. to 150 Yrs.)		
<b>Hard Edits</b>		<b>SAS Label</b>		
		Treated with these medicines?		
<b>English Text:</b> Did (you/SP) get treated with these medicines?				
<b>English Instructions:</b>				
Code or Value	Description	Count	Cumulative	Skip to Item
1	Yes	4	4	HCQ150
2	No	2	6	
7	Refused	0	6	HCQ150
9	Don't know	0	6	HCQ150
.	Missing	106	112	

<b>HCQ140A</b>		<b>Target</b>		
		B(6 Yrs. to 150 Yrs.)		
<b>Hard Edits</b>		<b>SAS Label</b>		
		Not treated: unpleasant side effects		
<b>English Text:</b> Why did (you/SP) not get treated? Was it because the side effects to the treatment are unpleasant?				
<b>English Instructions:</b>				
Code or Value	Description	Count	Cumulative	Skip to Item
1	Yes	1	1	
2	No	1	2	
7	Refused	0	2	
9	Don't know	0	2	
.	Missing	110	112	

<b>HCQ140B</b>		<b>Target</b>		
		B(6 Yrs. to 150 Yrs.)		
<b>Hard Edits</b>		<b>SAS Label</b>		
		Not treated: treatment self injected		
<b>English Text:</b> Why did (you/SP) not get treated? Was it because the treatment shots must be self injected?				
<b>English Instructions:</b>				
<b>Code or Value</b>	<b>Description</b>	<b>Count</b>	<b>Cumulative</b>	<b>Skip to Item</b>
1	Yes	0	0	
2	No	2	2	
7	Refused	0	2	
9	Don't know	0	2	
.	Missing	110	112	

<b>HCQ140C</b>		<b>Target</b>		
		B(6 Yrs. to 150 Yrs.)		
<b>Hard Edits</b>		<b>SAS Label</b>		
		Not treated: treatment too expensive		
<b>English Text:</b> Why did (you/SP) not get treated? Was it because the treatment is too expensive?				
<b>English Instructions:</b>				
<b>Code or Value</b>	<b>Description</b>	<b>Count</b>	<b>Cumulative</b>	<b>Skip to Item</b>
1	Yes	0	0	
2	No	2	2	
7	Refused	0	2	
9	Don't know	0	2	
.	Missing	110	112	

<b>HCQ140D</b>	<b>Target</b>			
	B(6 Yrs. to 150 Yrs.)			
<b>Hard Edits</b>	<b>SAS Label</b>			
	Not treated:waiting for better treatment			
<b>English Text:</b> Why did (you/SP) not get treated? Was it because there is a hope of better treatment in the future?				
<b>English Instructions:</b>				
<b>Code or Value</b>	<b>Description</b>	<b>Count</b>	<b>Cumulative</b>	<b>Skip to Item</b>
1	Yes	0	0	
2	No	2	2	
7	Refused	0	2	
9	Don't know	0	2	
.	Missing	110	112	

<b>HCQ140E</b>	<b>Target</b>			
	B(6 Yrs. to 150 Yrs.)			
<b>Hard Edits</b>	<b>SAS Label</b>			
	Not treated: some other reason			
<b>English Text:</b> Why did (you/SP) not get treated? Was it because there is some other reason?				
<b>English Instructions:</b>				
<b>Code or Value</b>	<b>Description</b>	<b>Count</b>	<b>Cumulative</b>	<b>Skip to Item</b>
1	Yes	1	1	
2	No	1	2	
7	Refused	0	2	
9	Don't know	0	2	
.	Missing	110	112	

<b>HCQ150</b>		<b>Target</b>		
		B(6 Yrs. to 150 Yrs.)		
<b>Hard Edits</b>		<b>SAS Label</b>		
		Did doctor limit alcohol?		
<b>English Text:</b> 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?				
<b>English Instructions:</b>				
Code or Value	Description	Count	Cumulative	Skip to Item
1	Yes	23	23	
2	No	7	30	
7	Refused	1	31	
9	Don't know	0	31	
.	Missing	81	112	

<b>HCQ160</b>		<b>Target</b>		
		B(6 Yrs. to 150 Yrs.)		
<b>Hard Edits</b>		<b>SAS Label</b>		
		T/F: infection is permanent		
<b>English Text:</b> If someone is infected with hepatitis C virus, they will most likely carry the virus all their lives.				
<b>English Instructions:</b> 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	44	44	
2	False	3	47	
7	Refused	0	47	
9	Don't know	10	57	
.	Missing	55	112	

<b>HCQ170</b>		<b>Target</b>		
		B(6 Yrs. to 150 Yrs.)		
<b>Hard Edits</b>		<b>SAS Label</b>		
		T/F: HepC stops liver		
<b>English Text:</b> Infection with the hepatitis C virus can cause the liver to stop working.				
<b>English Instructions:</b>				
<b>Code or Value</b>	<b>Description</b>	<b>Count</b>	<b>Cumulative</b>	<b>Skip to Item</b>
1	True	37	37	
2	False	3	40	
7	Refused	0	40	
9	Don't know	17	57	
.	Missing	55	112	

<b>HCQ180</b>		<b>Target</b>		
		B(6 Yrs. to 150 Yrs.)		
<b>Hard Edits</b>		<b>SAS Label</b>		
		T/F: look and feel fine		
<b>English Text:</b> Someone with hepatitis C can look and feel fine.				
<b>English Instructions:</b>				
<b>Code or Value</b>	<b>Description</b>	<b>Count</b>	<b>Cumulative</b>	<b>Skip to Item</b>
1	True	50	50	
2	False	2	52	
7	Refused	0	52	
9	Don't know	5	57	
.	Missing	55	112	

<b>HCQ190</b>		<b>Target</b>		
		B(6 Yrs. to 150 Yrs.)		
<b>Hard Edits</b>		<b>SAS Label</b>		
		T/F: HepC from blood transfusion		
<b>English Text:</b> You can get hepatitis C by getting a blood transfusion from an infected donor.				
<b>English Instructions:</b>				
<b>Code or Value</b>	<b>Description</b>	<b>Count</b>	<b>Cumulative</b>	<b>Skip to Item</b>
1	True	53	53	
2	False	0	53	
7	Refused	0	53	
9	Don't know	4	57	
.	Missing	55	112	

<b>HCQ200</b>		<b>Target</b>		
		B(6 Yrs. to 150 Yrs.)		
<b>Hard Edits</b>		<b>SAS Label</b>		
		T/F: HepC from shaking hands		
<b>English Text:</b> You can get hepatitis C by shaking hands with someone who has hepatitis C.				
<b>English Instructions:</b>				
<b>Code or Value</b>	<b>Description</b>	<b>Count</b>	<b>Cumulative</b>	<b>Skip to Item</b>
1	True	4	4	
2	False	51	55	
7	Refused	0	55	
9	Don't know	2	57	
.	Missing	55	112	

<b>HCQ210</b>	<b>Target</b>			
	B(6 Yrs. to 150 Yrs.)			
<b>Hard Edits</b>	<b>SAS Label</b>			
	T/F: HepC by kissing infected person			
<b>English Text:</b> You can get hepatitis C by kissing someone who has hepatitis C.				
<b>English Instructions:</b>				
<b>Code or Value</b>	<b>Description</b>	<b>Count</b>	<b>Cumulative</b>	<b>Skip to Item</b>
1	True	7	7	
2	False	37	44	
7	Refused	0	44	
9	Don't know	13	57	
.	Missing	55	112	

<b>HCQ220</b>	<b>Target</b>			
	B(6 Yrs. to 150 Yrs.)			
<b>Hard Edits</b>	<b>SAS Label</b>			
	T/F: HepC from infected sex partner			
<b>English Text:</b> You can get hepatitis C by having sex with someone who has hepatitis C				
<b>English Instructions:</b>				
<b>Code or Value</b>	<b>Description</b>	<b>Count</b>	<b>Cumulative</b>	<b>Skip to Item</b>
1	True	42	42	
2	False	5	47	
7	Refused	0	47	
9	Don't know	10	57	
.	Missing	55	112	

<b>HCQ230</b>		<b>Target</b>		
		B(6 Yrs. to 150 Yrs.)		
<b>Hard Edits</b>		<b>SAS Label</b>		
		T/F: HepC from birth, infected mother		
<b>English Text:</b> You can get hepatitis C by being born to a woman who had hepatitis C when she gave birth.				
<b>English Instructions:</b>				
Code or Value	Description	Count	Cumulative	Skip to Item
1	True	36	36	
2	False	5	41	
7	Refused	0	41	
9	Don't know	16	57	
.	Missing	55	112	

<b>HCQ240</b>		<b>Target</b>		
		B(6 Yrs. to 150 Yrs.)		
<b>Hard Edits</b>		<b>SAS Label</b>		
		T/F: HepC from sharp instrument		
<b>English Text:</b> You can get hepatitis C by being stuck with a needle or sharp instrument that has hepatitis C infected blood on it.				
<b>English Instructions:</b>				
Code or Value	Description	Count	Cumulative	Skip to Item
1	True	56	56	
2	False	0	56	
7	Refused	0	56	
9	Don't know	1	57	
.	Missing	55	112	

<b>HCQ250</b>		<b>Target</b>		
		B(6 Yrs. to 150 Yrs.)		
<b>Hard Edits</b>		<b>SAS Label</b>		
		T/F: HepC from coworkers		
<b>English Text:</b> You can get hepatitis C by working with someone who has hepatitis C.				
<b>English Instructions:</b>				
<b>Code or Value</b>	<b>Description</b>	<b>Count</b>	<b>Cumulative</b>	<b>Skip to Item</b>
1	True	4	4	
2	False	48	52	
7	Refused	0	52	
9	Don't know	5	57	
.	Missing	55	112	

<b>HCQ260</b>		<b>Target</b>		
		B(6 Yrs. to 150 Yrs.)		
<b>Hard Edits</b>		<b>SAS Label</b>		
		T/F: HepC from injecting drugs		
<b>English Text:</b> You can get hepatitis C by injecting illegal drugs, even if only a few times.				
<b>English Instructions:</b>				
<b>Code or Value</b>	<b>Description</b>	<b>Count</b>	<b>Cumulative</b>	<b>Skip to Item</b>
1	True	47	47	
2	False	5	52	
7	Refused	0	52	
9	Don't know	5	57	
.	Missing	55	112	

<b>HCQ270</b>	<b>Target</b>			
	B(6 Yrs. to 150 Yrs.)			
<b>Hard Edits</b>	<b>SAS Label</b>			
	Main respondent			
<b>English Text:</b> Who was the main respondent for the questionnaire?				
<b>English Instructions:</b>				
<b>Code or Value</b>	<b>Description</b>	<b>Count</b>	<b>Cumulative</b>	<b>Skip to Item</b>
1	SP	52	52	
2	Parent/guardian	4	56	
3	SP and Parent/guardian	1	57	
.	Missing	55	112	