

Hepatitis C Follow Up Questionnaire

Survey Years: 2003 to 2004

SAS Transport File: HCQ_C.XPT



First Published: Last Revised:

September 2006 April 2008

NHANES 2003–2004 Data Documentation

Questionnaire Section: Hepatitis C Follow Up Questionnaire (HCQ_C)

First Published: September 2006

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. Two questions (HCQ.121 and HCQ.126) were added to the 2003-2004 follow up questionnaire to ask about awareness of medications available to treat hepatitis C and when told no treatment is needed, to learn about the reason the doctor said they should not be treated. One question was re- numbered (from HCQ.120 to HCQ.124) and re-ordered. The researcher should be aware of the change in skip patterns resulting from these changes. 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_C)

Contact Number: 1-866-441-NCHS

Years of Content: 2003–2004

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 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)

Questionnaire Section: Hepatitis C Follow Up Questionnaire (HCQ_C)

First Published: September 2006 Last Revised: April 2008



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

HCASCST1			Target			
nensesti	L		B(6 Yrs. to 150 Yrs.)			
Hard Edits			SAS	Label		
			Interview S	Status Code		
English Text: Intervie	w Status C	ode				
English Instructions:						
Code or Value	I	Description	Count	Cumulative	Skip to Item	
1		Complete	44	44	HCQ020	
2		Partial	2	46	HCQ020	
3		Not done	41	87		
		Missing	0	87		

HCASCCT1		Target					
10115001			B(6 Yrs. to 150 Yrs.)				
Hard Edit	S		SAS	Label			
			Reasons f	for Not Done			
English Text: Reason	ns the Intervi	ew was not done					
English Instructions	:						
Code or Value	Description		Count	Cumulative	Skip to Item		
1	Unable to contact SP		37	37	End of Section		
2	Refusal		1	38	End of Section		
3	Communication problem or cognitive impairment		1	39	End of Section		
4	SP expired		1	40	End of Section		
5	Did not receive letter		1	41	End of Section		
6	Other		0	41	End of Section		
•		Missing	46	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?

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	S Label		
			First time told	l had Hepatitis C?		
English Text: Was the	test result	in our letter the firs	at time you were to	ld (you had/SP has) hepatitis C?	
English Instructions:						
Code or Value	Description		Count	Cumulative	Skip to Item	
1		Yes	20	20	HCQ070	
2	2		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	5 Label	
			How long k	nown infected?	
English Text: For about	ut how long	, have you known th	nat (you have/SP l	nas) hepatitis C? W	ould you say
English Instructions:					
Code or Value	D	Description	Count	Cumulative	Skip to Item
1		One year	4	4	
2	2	to 5 years	9	13	
3	Mor	e than 5 years	11	24	
7		Refused	0	24	
9	Γ	Don't know	1	25	
· [Missing	62	87	

HCQ060	Target		
ine Quoto	B(16 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:

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		Ta	Target				
nequu		B(6 Yrs. to 150 Yrs.)					
Hard Edits		SAS Label					
		Have a doctor's appointment?					
English Text: (Do you/D (your/his/her) hepatitis C	ooes SP) have an appointme test result?	ent to see a doctor of	r other health care	professional about			
English Instructions:							
Code or Value	Description Count Cumulative Skip to Item						
1	Yes	1	1	HCQ160			
2	No	14	15	HC0160			

2	No	14	15	HCQ160
7	Refused	0	15	HCQ160
9	Don't know	0	15	HCQ160
•	Missing	72	87	

HCQ090	Target				
in Quite	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?

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		
negno	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?					

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. 1	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	D	escription	Count	Cumulative	Skip to Item		
1		Yes	8	8	HCQ130		
2 No 3 11							
7		Refused 0 11 HCQ					
9	Γ	Don't know	3	14	HCQ150		

73

87

Missing

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HCQ126A		Target				
			B(6 Yrs.	to 150 Yrs.)		
Hard Edits			SAS	Label		
]	Not treated: liver en	nzymes were norm	nal?	
English Text: What reason did your doctor or health care professional give you when he/she told you that should not be treated? Was it because your liver enzymes were normal?					he told you that you	
English Instructions:						
Code or Value	D	escription	Count	Cumulative	Skip to Item	
1		Yes	1	1		
2		No	2	3		
7		Refused 0 3				
9	Ľ	on't know	0	3		
		Missing	84	87		

HCQ126B	HCO126B		Target				
11001200			B(6 Yrs. t	o 150 Yrs.)			
Hard Edits			SAS	Label			
			Not treated: did no	t have liver diseas	se?		
English Text: What reason did your doctor or health care professional give you when he/she told you				she told you that you			
should not be treated?	Was it beca	t because you did not have liver disease?					
English Instructions:							
Code or Value	Ι	Description	Count	Cumulative	Skip to Item		
1		Yes	1	1			
2		No	2	3			
7		Refused 0 3					
9	Ι	Don't know	0	3			
		Missing	84	87			

HCQ126C	HC0126C		Target				
110 21200			B(6 Yrs. t	o 150 Yrs.)			
Hard Edits			SAS	Label			
			Not treated: not not	eed to do anything	g?		
English Text: What reason did your doctor or health care professional give you when he/she told you that should not be treated? Was it because you do not need to do anything for hepatitis C? English Instructions:					he told you that you		
Code or Value	I	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	HCO126D		Target				
			B(6 Yrs. to	o 150 Yrs.)			
Hard Edits			SAS	Label			
			Not treated: can	be treated later?			
English Text: What reason did your doctor or health care professional give you when he/she told you that yo should not be treated? Was it because you can wait to be treated at a later time? English Instructions:							
Code or Value	Ι	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		
	Not treated: no reason given		

English Text: 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... No reason specified.

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			SA	S Label	
			Treated with	these medicines?	
English Text: Did (you	SP) get treat	ted with these me	edicines?		
English Instructions:					
Code or Value	Des	cription	Count	Cumulative	Skip to Item
1		Yes	4	4	HCQ150
2		No	7	11	
7	R	efused	0	11	HCQ150
9	Do	n't know	0	11	HCQ150
	Ν	lissing	76	87	

HCQ140A		Target				
nequin		B(6 Yrs.	to 150 Yrs.)			
Hard Edits		SAS Label				
		Not treated: unpleasant side effects				
English Text: Why did (y unpleasant?	you/SP) not get treated? Wa	as it because the sid	e effects to the trea	atment are		
English Instructions:						
Code or Value	Description	Count	Cumulative	Skip to Item		
1	Yes	1	1			
2	No	5	6			

2	No	5	6	
7	Refused	1	7	
9	Don't know	0	7	
•	Missing	80	87	

HCQ140B		Target				
nequit		B(6 Yrs. t	to 150 Yrs.)			
Hard Edits		SAS	Label			
		Not treated: treated	tment self injected			
English Text: Why did (you/SP) not get treated? Wa	s it because the trea	atment 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	Refused 1 7				
9	Don't know	0	7			
•	Missing	80	87			

HCQ140C		Target				
			B(6 Yrs. 1	to 150 Yrs.)		
Hard Edits			SAS	Label		
			Not treated: treat	ment too expensiv	e	
English Text: Why di	English Text: Why did (you/SP) not get treated? Was it because the treatment is too expensive?					
English Instructions:						
Code or Value	Ι	Description	Count	Cumulative	Skip to Item	
1		Yes	1	1		
2		No	5	6		
7 Refused		Refused	1	7		
9]	Don't know	0	7		
		Missing	80	87		

HCQ140D		Target				
пецічор		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? Was it because there is a hope of better treat 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

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80

87

HCQ140E		Target				
педног	IICQ140E		B(6 Yrs	. to 150 Yrs.)		
Hard Edits			SA	S Label		
			Not treated:	some other reason		
English Text: Why did	d (you/SP)	not get treated? Wa	s it because there	is some other reaso	n?	
English Instructions:						
Code or Value	Ι	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				
noquo		B(6 Yrs. 1	to 150 Yrs.)			
Hard Edits		SAS	Label			
		Did doctor	limit alcohol?			
	r/SP's) doctor or health pr		n/her) to avoid or 1	limit alcoholic		
) because of (your/his/her) nepatitis 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				
nequo		B(6 Yrs.	to 150 Yrs.)			
Hard Edits		SAS	5 Label			
		T/F: infectio	on is permanent			
English Text: If someor	ne is infected with hepatitus	C virus, they will m	nost likely carry the	virus all their lives.		
0	Ve would like to know what tements are true or false, or	•	1	•		
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				
noqui			B(6 Yrs.	to 150 Yrs.)		
Hard Edits			SAS	Label		
			T/F: Hep	C stops liver		
English Text: Infection	with the l	nepatitis C virus car	n cause the liver to	stop working.		
English Instructions:						
Code or Value	Ι	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					
nequo			B(6 Yrs. to 150 Yrs.)				
Hard Edits			SAS	Label			
			T/F: look	and feel fine			
English Text: Someon	e with hep	atitis C can look an	d feel fine.				
English Instructions:							
Code or Value	I	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				
noqui			B(6 Yrs	. to 150 Yrs.)		
Hard Edits			SA	S Label		
			T/F: HepC fro	m blood transfusion		
English Text: You can	n get hepati	tis C by getting a b	lood transfusion f	rom an infected don	or.	
English Instructions:						
Code or Value	Ι	Description	Count	Cumulative	Skip to Item	
1		True	37	37		
2		False	1	38		
7	7 Refused		1	39		
9	Ι	Don't know	1	40		
		Missing	47	87		

HCQ200		Target				
110 2200			B(6 Yrs	. to 150 Yrs.)		
Hard Edits			SA	S Label		
			T/F: HepC fi	om shaking hands		
English Text: You car	n get hepati	tis C by shaking ha	nds with someone	e who has hepatitis	C.	
English Instructions:						
Code or Value	I	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				
noqui			B(6 Yrs	s. to 150 Yrs.)		
Hard Edits			SA	S Label		
			T/F: HepC by k	issing infected perso	on	
English Text: You can	get hepati	tis C by kissing sor	neone who has he	epatitis C.		
English Instructions:						
Code or Value	Ι	Description	Count	Cumulative	Skip to Item	
1		True	5	5		
2		False	26	31		
7 H		Refused	1	32		
9	Ι	Don't know	8	40		
		Missing	47	87		

HCQ220		Target				
nequi	110,0220		B(6 Yrs	. to 150 Yrs.)		
Hard Edits			SA	S Label		
			T/F: HepC from	n infected sex partne	er	
English Text: You can	n get hepati	tis C by having sex	with someone wh	no has hepatitis C		
English Instructions:						
Code or Value	I	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				
110 Q230			B(6 Yrs. t	o 150 Yrs.)		
Hard Edits			SAS	Label		
			T/F: HepC from bi	rth, infected moth	er	
English Text: You can	get hepati	tis C by being born	to a woman who ha	ad hepatitis C whe	n she gave birth.	
English Instructions:						
Code or Value	Ι	Description	Count	Cumulative	Skip to Item	
1		True	21	21		
2		False	3	24		
7 Refused		1	25			
9	I	Don't know	15	40		
		Missing	47	87		

HCQ240	Target
IICQ240	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.

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	

НСQ250		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	Ι	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	I	Description	Coun	t	Cumulative	Skip to Item		
1		True	36		36			
2		False			37			
7		Refused			38			
9]	Don't know			40			
		Missing	47		87			

НСQ270		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				