

# **General Instructions**

The participant's name, address, phone number, and social security numbers are confidential data items that are recorded on the HCHS Personal Identifiers Form (IDE). As part of informed consent, study participants indicate their willingness to voluntarily provide this confidential information, as well as equivalent information for contacts that HCHS is authorized to approach to locate the study participant, if necessary. The HCHS also requests the *voluntary* disclosure of the participant's social security number for purposes of medical record linkage and verification. If provided, the social security number is recorded on the Identifiers and Addresses form and is stored as a secure, encrypted database file separately from other study information.

The information collected on this form is a sign of the trust placed by the participant in the HCHS, and in our commitment and ability to protect this confidential information. It is also information that is critical to our ability to re-contact the HCHS participants and to conduct a long-term follow-up of a population known to be mobile. An additional purpose of the information on the participant's place of residence is the ability of the HCHS to convert the addresses to a code defined by longitude and latitude that will then be used to estimate aggregate information of the area of residence of the participant.

The goal for completing this form is to have at least two valid phone numbers for the participant, a full current address, and contact information for local individuals who can always help locate or ascertain the vital status of the participant.

Before you administer this questionnaire, make sure to select the form in the language of preference for the participant, which is prefilled by CDART in the ELE form Q1.

**Note:** Click on the magnifying glass icon in CDART to view the ELE form in "read only" mode. Otherwise, if you access the ELE to determine preferred language for the V3 Phone Interview in edit mode, open the form, view the preferred language in Q1 and then please click on the browser "Back" arrow to exit the form but not save it. If you Save and Close instead, you will save a blank ELE form that is not needed for the V3 Phone Interview.

# **QxQ Instructions**

# A. Identifying information

It will be common for participants to be members of the same household and to be related to each other. Because it is possible that offspring are given a parent's name and because many Hispanic surnames are quite common it is important to fully identify each study participant. The study's ability to protect confidentiality and to ensure completeness of follow-up will be critically dependent on our ability to uniquely identify each individual.

- **Q1.** Items 1a-1g will be prefilled from the latest data entry information present in the CDART system. Proceed to confirm the participant's full and legal name.
  - These fields are editable, and the name(s) can be changed by clicking on the lock symbol and typing in the new information. You will still want to ask for and record the respondent's preferred title and their middle name, if any. Do not use abbreviations or nicknames; ask them for their official (legal) name.
  - If the participant has a preferred first name or nickname, enter a Notelog in Q1b to note the preferred name. It is also recommended that you enter this information in the site's local tracking system. We should keep the legal name in our records to ensure that the

medical records teams have the information that will facilitate them get the correct medical records.

- Title: The participant's title (Mr., Ms., Mrs., Dr., etc.) is optional but may be preferred by some sites and/or participants. If there appears to be a discrepancy between participant's pre-filled title, name, dress, and/or physical appearance, it may be appropriate to confirm the participant's title. Ask the participant, "I see that our records from your first HCHS/SOL examination list you as Ms./Mr. <\_Name\_>. Is that correct?" If no title has been previously recorded, ask participant what title they prefer to use, giving examples if needed.
- Ask men if they use an extension (or suffix) to their name such as Sr. or Jr, record this in 1g.
- **Q2.** Social Security number
  - First, read the <u>Disclosure Statement</u> present in the IDE/S, just before Q2, out loud to the participant. Read it slowly, allowing enough time for the participant to comprehend the statement as stated in the paper and the CDART form.
  - Ask if the participant has questions about this statement or any reservations about providing a social security number.
  - If the participant hesitates, mention that providing a social security number is entirely voluntary and that there are no penalties or consequences to not providing a number. If asked about the purpose of the social security number in the study, indicate that it will only be used to link with health data made available by health care providers and government agencies that prepare health reports.
  - After the participant agrees, then ask if the participant has a social security number. If 'Yes', proceed to Q2a otherwise skip to Q3.

<u>Note</u>: If Q2=Yes (1), the system will preload the Social Security number previously provided by the participant. In this case, proceed to confirm the number with the participant. For V3 Phone Interviews, if participant is unwilling to provide SSN or confirm the last four digits over the phone, attempt to collect/confirm when participant comes for in person clinic visit. This information is extremely valuable to the study.

Q2a. Ask if the participant is willing to provide or to confirm their social security number.

- If a number is prefilled, confirm the number.
- The social security number can be added or corrected by clicking the lock icon to open the field.
- If the participant refuses to confirm or provide a social security number (but answers 'Yes' for Q2), set CDART <u>Field Status</u>="Refusal".
- If the participant mentions that his/her SSN is an Individual Taxpayer Identification number (ITN) or is for purposes of work (or uses equivalent wording that suggests that the SSN is *not* genuine), thank the participant and indicate that we don't need to have that number in our records. Answer 'No' for Q2a and proceed to Q3.
- **Q3.** Do you have a driver's license issued in a U.S. state or Puerto Rico?
  - If 'No', 'Don't know/Not sure' or 'Refused' on Q3, go to Q4.
  - If =Yes (1), the system will preload a driver's license number if the participant has provided one in the past in Q3b.
  - Q3a. Other ID, specify
    - Note the type of ID in Q3a and enter the number in Q3b if they are willing to provide or confirm it.

- **Q3b.** The system will preload a driver's license number if the participant provided one in the past **AND** answers 'Yes' on Q3.
  - Ask if they are willing to provide or to confirm the number in Q3b.
  - If the participant refuses to confirm or provide a number, set CDART <u>Field</u> <u>Status</u>="Refusal".
  - This field is editable, and a new driver's license number can be added or corrected by clicking the lock icon to open the field.

#### **B.** Participant address and telephone

Read the script as shown and, if the respondent has no questions, proceed to confirm the current home address. If the participant has more than one residence or lives at more than one location, ask the participant to provide the address where she/he lives most of the time. It is important to obtain and record a complete and accurate address. <u>Please note</u>: we want to collect a <u>physical</u> address for the participant (which allows for future demographic analyses). Mailing addresses can be noted in a Notelog and in the site local tracking system.

- **Note**: The system will preload the latest address provided by the participant during clinic visits, AFU and/or any interview phone call. Confirm the address information with the participant and update the information as needed. These fields are editable by clicking the lock icon in the field.
- Q4 Q4f. Current home address data fields have been separated into two main address fields:
  - Address 1(Street number, name, prefix, suffix, street type)
  - Address 2 (unit subtype, PO box, route or rural zone, other)
  - Followed by country, state, city, county, US state/territory, out of country state, and zip code.
  - Confirm information with participant and update as needed.

#### Q4a1. Country Codes, also for Questions 14a1, 19a1, 24a1

Use the dropdown list to select the Country for the participant's address.

Q4a2. If 67-Other Country is selected, confirm the pre-filled data imported by CDART. If the Other Country listed in no longer correct or if the field is blank, click on the lock icon to unlock the field and correct/enter the country of residence.
Note: This process will also apply to Q14a2, 19a2, and 24a2 for Contacts 1, 2, and 3.

# Q4d. US States and Territories, Questions 4d, 14d, 19d, 24d, use 2 letter codes listed below:

AL=Alabama	IA= Iowa	NJ=New Jersey
AK= Alaska	KS= Kansas	NM= New Mexico
AZ= Arizona	KY= Kentucky	NY= New York
AR= Arkansas	LA= Louisiana	NC= North Carolina
CA= California	ME= Maine	ND= North Dakota
CO= Colorado	MD= Maryland	OH= Ohio
CT= Connecticut	MA= Massachusetts	OK= Oklahoma
DE= Delaware	MI= Michigan	OR= Oregon
DC= District of Columbia	MN= Minnesota	PA= Pennsylvania
FL= Florida	MS= Mississippi	RI= Rhode Island
GA= Georgia	MO= Missouri	SC= South Carolina
HI= Hawaii	MT= Montana	SD= South Dakota
ID= Idaho	NE= Nebraska	TN= Tennessee
IL= Illinois	NV= Nevada	TX= Texas
IN= Indiana	NH= New Hampshire	UT= Utah

VT= Vermont	WV= West Virginia	<u>Territories</u>
VA= Virginia	WI= Wisconsin	PR= Puerto Rico
WA= Washington	WY= Wyoming	VI=Virgin Islands

- **Q5.** Length of residence.
  - Ask the participant about how long she/he has lived at the current address and prompt the participant by asking "Since ...."?
  - Record the year, and if provided, the month and day.
  - If month and day is not provided enter 99.
- Q6-Q9. Phone number information
  - The system will preload the latest phone numbers available in CDART.
  - Ask the participant to confirm or provide a primary and secondary phone number, the type of phone, and the best times to reach the participant at each of these numbers.
  - Remember, you can edit the preloaded information by clicking in the lock icon.

#### Q10-10a. Emails

- The system will preload the latest information available in CDART for Email address 1.
- Ask the participant to confirm or provide a primary email address and a backup email address.

**Q11.** Ask the participant by which method they prefer to be contacted. If Other, please specify.

## C. Local contact 1, 2, 3

All local contacts have the same fields. Some of these fields will be pre-filled by CDART, others need to be collected at the time of contact. Please confirm/obtain as complete information as you can; it is important to record as much accurate contact information as possible.

The latest data on file for Contacts 1, 2, and 3 will be pre-filled by CDART from participant contact information provided during previous study visits, AFU contacts, and/or phone interviews. Please ask the participant to confirm or provide information for local contacts 1, 2, and 3. Update the information as needed.

#### Mention to the participant:

"The HCHS / SOL center will contact you by mail or telephone once a year to answer a brief questionnaire about your health. Please provide the name and address of a relative or another person who can help us get in touch with you if we are unable to reach you at your current address."

If the participant has the information, the interviewer asks which person is the preferred contact and enters the information as Contact 1 and gets clarification from the participant if the details are unclear. See **Q13a** below for clarification.

If the participant does not have a written record of the addresses and phone numbers of possible contacts and is unable to provide a complete address and phone number for at least two contacts, the interviewer needs to make arrangements for a follow up phone call to obtain the information.

#### Note:

At the discretion of field centers <u>at the time of scheduling a field center visit</u>, participants are asked to select three persons who can help us get in touch with him/her if in the future we are unable to reach the participant at their current address. This is done to give participants time to write down the addresses and phone numbers of the contact persons of their choice. With their

instructions for the visit to the field center participants are reminded to have that information with them on the day of the visit.

If the field center practice is to ask for selection of contacts at time of scheduling, the interviewer should ask at time of visit:

"Since HCHC/SOL center will contact you once a year, we would like to have the name and address of a relative or another person who can help us get in touch with you if we are unable to reach you at your current address. Did you bring this information with you?"

# Q12-Q16a Local Contact 1 information

Q13a Is this an Alternate Respondent contact (ARE)?
If the participant has assigned this contact as an Alternate Respondent-ARE, select "Yes". If the participant is not clear see ARE form QxQs and MOP 16 for additional information on ARE contacts, otherwise select "No".
It is preferred to have the ARE contact information in the local Contact 1. Additional AREs should be assigned to Contact 2 & 3 in the order of preference/importance.

### Q17-21a. Local Contact 2 information

Q22-26a. Local Contact 3 information