



HCHS-SOL Participant Information

[Participant Identifiers and Demographics]– IDME –QxQ

Updated on 5/14/2026

BACKGROUND

The IDME(S) (Participant Identifiers and Demographics) form is a participant-level form that can be updated at any time. It is used to capture participant identifiers including the participant's name, aliases if applicable, social security number/ITIN, driver's license number. It also is used to update demographic information including sex assigned at birth, date of birth, and marital status. It replaces the use of the IDE(S) and DEM forms during the main study clinic visit.

The participant identifiers collected on this form are confidential. As part of informed consent, study participants indicate their willingness to voluntarily provide this confidential information. 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 IDME(S) 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.

The IDME(S) allows for unlimited occurrences. Each update to the IDME(S) should be made using a new occurrence. The first occurrence available in CDART will be pre-populated by the CSCC with existing participant information, in either the IDME or the IDMS form, depending on the participant's preferred language. When updates or corrections need to be made, the FC staff member should use the "copy form" feature to create a new occurrence in CDART. Then update only the fields that reflect the new information.

For most participants, the information in the IDME(S) will change infrequently or not at all. However, there will be certain times, for example during the main study clinic visit, when the information needs to be confirmed with the participant. To confirm the information with the participant when changes are not expected, first ask the participant if they have had any changes to their name, driver's license, or marital status. If the participant answers "No", open the form in read-only mode and then confirm the answer to each question with the participant. If it turns out that updates are needed, close the read-only version of the form and then create a new occurrence of the form using the copy form feature, and make the necessary changes.

ADMINISTRATIVE INFORMATION

Q0a. Enter the date the form is updated.

Q0b. Enter Staff ID.

A. PARTICIPANT NAME

Q1. Confirm the participant's name. Questions 1a-1g contain the participant's name. It is 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.

Q1a. 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.

Error! Reference source not found.

Q1b. First Name: This should be the participant's legal first name. If they use a nickname, this should be recorded in the participant aliases section.

Q1c. Middle Name

Q1d. Paternal Last Name

Q1e. Maternal Last Name

Q1f. Legal Last Name

Q1g. Ask men if they use an extension (or suffix) to their name such as Sr. or Jr, record this in 1g.

B. PARTICIPANT ALIASES

It is important to capture any participant aliases or names that may be associated with their medical records. Participant aliases might include a nickname or preferred name, a maiden name, a married name, or a name that they used earlier in life but no longer use.

Q2. If participant has an alias, enter "Yes". This will enable Q3a-3d (text fields for Alias 2) and Q4 (whether or not participant has a second alias).

Q3. Enter the participant's first alias in Q3a-3d, then proceed to Q4.

Q4. If participant has another alias, enter "Yes". This will enable Q4a-4d (text fields for Alias 2) and Q5 (whether or not participant has a third alias). Enter the second alias in Q4a-4d, then proceed to Q5.

. If the participant has no additional aliases, select "No" and go to Q8.

Complete Q5-Q7d as above.

For each alias, enter the full name, even if some components are the same as the participant listed in Section A. For example, if someone's name is Alison "Ally" Smith and their maiden name is Jones, then enter:

- "Alison Smith" in Q1 under "Participant Name"
- "Ally Smith" in Q2
- "Alison Jones" in Q3
- "Ally Jones" in Q4

C. SOCIAL SECURITY AND DRIVER'S LICENSE INFORMATION

Read the Disclosure Statement present in the IDME/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 or Individual Taxpayer Identification Number (ITIN). If the participant hesitates, mention that providing a social security number/ITIN 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.

Q8. Ask if the participant has a social security number or ITIN. If the participant already has an SSN on record with the study, this field will already be set to 1 (Yes, SSN).

Error! Reference source not found.

- If 'Yes', proceed to Q8a or Q8b; otherwise skip to Q9.
- If the participant refuses or states that they do not have an SSN, but there is an SSN already recorded, leave Q8 as "Yes". A note log may be entered to note the participant refusal or response of "No".

Q8a. Social security number: This field will be enabled in CDART if Q8=1 or 3. Enter the SSN as a 9-digit number with dashes; for example; 123-45-6789. If only a partial SSN is provided, enter unknown digits as "X", for example, XXX-XX-1234.

- If the participant provides a correction to the existing SSN, move the "old" SSN to one of Q8a1-8a3. Enter the corrected SSN in Q8a.
- If the participant states that they do have a SSN, but do not agree to provide it to the study, set the field status to "Refused".

Q8a1-8a3. Alternate social security numbers: Q8a1 will be enabled if a SSN is entered in Q8a. *Do not ask the participant if they have additional social security numbers.* However, these fields may be used to enter additional SSNs that may be associated with the participant. These additional SSNs may help the study locate medical records and/or death information in the future. An alternate SSN may be entered in the following circumstances:

- A participant states that they use or have used more than one SSN; for example, due to an administrative error or if they were assigned a new SSN as protection against ongoing identity theft.
- If a participant provides a correction to their SSN, the "old" SSN may be entered as an alternate SSN in case the incorrect one was used in another context as well.

Q8b. ITIN (Individual Taxpayer Identification Number): This field will be enabled in CDART if Q8=2 or 3. Enter the ITIN as a 9-digit number with dashes; for example; 999-99-9999.

- If the participant provides a correction to the existing ITIN, move the "old" ITIN to one of Q9a1-9ac. Enter the corrected ITIN in Q9a.
- If the participant states that they do have a ITIN, but do not agree to provide it to the study, set the field status to "Refused". If only a partial ITIN is provided, enter unknown digits as "X", for example, XXX-XX-9999.

Q9. Do you have a driver's license issued in a U.S. State or territory?

Q9a. If the participant states "Other" in Q9, indicate if this is a non-driver state-issued ID, a passport, or another type of ID. If "Other" specify in Q9a1.

Q9b. This field will be enabled if Q9= "Yes" or "Other ID". Select the state from the dropdown menu. The two-letter USPS code may be typed in the dropdown menu in order to select the state more quickly. For example, for "Florida" enter "FL" and Florida will be selected from the dropdown menu.

Q9c. This field will be enabled if Q9= "Yes". Confirm, correct, or enter the driver's license number or other ID number. If the participant answered that they do have a driver's license or other ID, but refuses to provide the number, enter a field status of "Refused".

D. DEMOGRAPHIC INFORMATION

Q10. Confirm the participant's sex assigned at birth. *This may be different than the participant's legal, preferred, and/or apparent gender.* It is important to capture the correct sex at birth for analysis purposes. Since sex at birth does not

Error! Reference source not found.

change, this field should only be updated if the information was previously incorrect and needs to be corrected. Click the lock button to open this field and correct the data. Clicking the lock button again will reset the value.

Q11. Confirm the participant's date of birth (DOB) in Q11. If the participant provides a correction to their DOB, or states that they have or use more than one DOB, enter the most "official" DOB in Q11, and enter alternate DOB(s) in Q11a-11c as needed.

Q12. Current age in years: This field uses a script to calculate the participant's current age using the form completion date in Q0a and the official DOB entered in Q11. *This field is used for FC staff reference only, and not for analysis.* After entering the DOB in Q11, click the "refresh" wheel or "Save and Reload" to run the script and populate this field.

Q13. Marital status: Confirm the participant's marital status and correct if needed.

FORM CLOSE OUT

Save the form. Check the missing fields report, and make corrections as needed. The save and close the form.