



HCHS/SOL Visit 3 NIMHD Formset

(HUE, NDE, BFE, SIE, SME, SOE) - QxQ

3/11/2022

HUE - HEALTH USE AND INFORMATION [Q1-Q34]

Note: Do not complete HUE/V3 Phone Interviews for participants requiring a proxy/informant. Set these IDs aside for now and contact/re-assess at a later time.

Question by Question Instructions

Part A. Spoken English Proficiency and Preferred Language

- Q1** The goal of this question is to document a participant's self-reported English proficiency.
- Q2** The goal of this question is to document the participant's preferred language for medical care. Medical care can range from routine physicals, regular doctor's appointments, any ambulatory or in-hospital therapy, hospitalizations, acute or emergent care, filling prescriptions, and/or alternative medicine. It also includes medical care sought in the U.S. mainland (50 States), U.S. territories or any other country, and visits to alternative medicine providers.
- Q2a** The goal of this question is to determine if the participant has had a healthcare visit within the past 12 months. Those who have had visits are asked the questions in Section B., otherwise these are skipped and the questionnaire recommences at Q17.

If the participant answers Yes to Q2a, the type of healthcare visit is recorded in sub-questions **Q2a1 – Q2a3** (mark all that apply) and then the questions in Section B. are asked.

Part B. Interpersonal Processes of Care [skip this section if Q2a=0]

Q3-Q9 These questions are about participants' experiences while speaking to their doctor(s) within a 12-month period. The interviewer should emphasize that these questions pertain to their experiences with doctors or health care providers NOT the office staff. Also, if they have seen multiple clinicians, please ask them to indicate on average how often the event occurred.

Point out to participants that the next seven statements will have the same 5 response categories, which are: Never, Rarely, Sometimes, Usually, or Always. Then proceed to read each statement and each response option.

Clarification may be needed about the meaning of the response categories. If needed, the following clarifications can be provided:

- | | |
|--------------|---|
| 1. NEVER | On none of the times that you have seen your health care provider. |
| 2. RARELY | It occurred, but not more than once or twice. |
| 3. SOMETIMES | On more than a few of the times but not most that you have seen a health care provider. |
| 4. USUALLY | More often than not or on most of the times that you have seen a health care provider. |
| 5. ALWAYS | Every time that you have seen a physician or health care provider. |

Q10-Q11 These questions are intended to understand the personal interactions between the participant and his/her doctor(s) over the past 12 months.

Point out to participants that the next two statements will have the same 5 response categories, which are: Never, Rarely, Sometimes, Usually, or Always. Then proceed to read each statement and each response option.

Q12-Q16 The aim of these questions are to understand the personal interactions between the participant and his/her doctor(s) over the past 12 months.

Some of the items contain words or phrases that may be interpreted differently by individuals (e.g. 'really respect you', 'as an equal, 'pay less attention'). This is okay. The interviewer can clarify that these questions are about how the participant felt about the treatment they received from the doctor or health care provider. The interviewer should emphasize that these questions pertain to the clinician they saw, NOT the office staff.

Point out to participants that the next five statements will have the same 5 response categories, which are: Never, Rarely, Sometimes, Usually, or Always. Then proceed to read each statement and each response option.

Part C. Online Health Information Seeking

Q17-Q23 The aim of these questions are to learn if participants sought online health information for themselves or for someone else (e.g. family member, friend, etc.) in the past 12 months.

Point out to participants that the next seven statements will have the same 2 response categories, which are: Yes or No. Then proceed to read each statement and each response option.

Part D. Patient Clinician Communication Through EHR Portals

The objective of this section is to evaluate participants' experience in using patient portals. Clarification may be needed about the meaning of a patient portal. If needed, the following definition can be provided:

A patient portal is a secure online website that gives patients convenient, 24-hour access to personal health information from anywhere with an Internet connection.

Q24 This question asks if a participant's health care clinic or office has an electronic patient portal.

Q25 This question is asked of all participants, whether their current health care provider has an electronic portal or not. Those responding "no" to Q25 should proceed to Q26.

Q26 This question is asked of all participants. We want to know if they have ever used a patient portal with the help of someone else (e.g. caregiver, family member, friend, etc.)

If a participant responds "no" to both Q25 AND "no" to Q26, skip to Q32.

Q27-Q31 Point out to participants that the next five statements will have the same 2 response categories, which are: Yes or No. Then proceed to read each statement and each response option.

Self-Reported Health Literacy

The objective of this section is to evaluate a participant's experience with written information that they may have received at a clinic or hospital.

Q32-Q33 Point out to participants that the next 2 statements will have the same 5 response categories, which are: Never, Rarely, Sometimes, Often, or Always. Then proceed to read each statement and each response option.

Q34 Point out to participants that the following statement will have a 5 level response to assess their level of confidence in filling out medical forms on their own. Extremely confident, Quite a bit, Somewhat, A little, or Not at all confident. Then proceed to read each statement and each response option.

NDE - NEIGHBORHOOD DESCRIPTION [Q35-49]

Note: Do not complete NDE/V3 Phone Interviews for participants requiring a proxy/informant. Set these IDs aside for now and contact/re-assess at a later time.

Part E. NEIGHBORHOOD

The neighborhood stress scale is a measure of stress associated with conditions of one's external living environment. These items assess as factors such neighborhood support, safety, cleanliness, noise level, and accessibility to resources. Note that this measure has multiple parts and that items have very different response options.

Read the script exactly as it appears. Carefully and slowly read the description of what 'neighborhood' refers to in the instructions. If they ask any questions about how they should define neighborhood, you should prompt participants to define neighborhood in whatever way is most meaningful to them. Proceed by asking each question and then reading each response category. You may re-read the response options if the participant requests so. When asking these questions, you should be careful to not comment on respondent's answers and to record answers in a non-judgmental manner.

Q35 Question asks about how many blocks the participant considers to be his or her neighborhood. Participants should define their neighborhood in whatever manner is most meaningful to them. SPANISH: Se debe definir 'barrio' en cualquier manera que prefiera. May be confusing to a participant. If asked what the word "bloques" is defined as, it is ok to provide a more common local term such as "cuadras" that has the same meaning as intended.

Q36-36a Participants are asked how long they have lived in their neighborhood in years and months. If the participant only states the answer in years, ask them if they can tell you months as well. For example, if the participant states that they lived in their neighborhood for five years, ask: And how many months? SPANISH: ¿Cuántos meses? If answer is only in years, enter "0" for months.

Q37-Q41 Point out to participants that the next five statements will have the same five response categories, which are: strongly agree, agree, neither agree nor disagree, disagree, and strongly disagree. Then proceed to read each statement and each response option.

Q42 Ask participants to rate safety "on a scale of 1 to 5, with 1 being Not safe at all, 3 safe, and 5 Very safe". Clarify response items 2 and 4 if asked.

Q43-Q49 Point out to participants that the next seven statements will have the same four response categories, which are: very serious problem, somewhat serious problem, minor problem, and not really a problem. Then proceed to read each statement and each response option.

Q48 May be confusing to a participant. If asked what the word “aceras” is defined as, it is ok to provide a more common local term such as “banquetas” that has the same meaning as intended.

BFE - BEHAVIOR AND FINANCE [Q50-67]

Part F. BEHAVIOR

Sleep Disturbance

The objective of this section is to understand participants' sleep habits. Pay special attention to the timeframe for each question, as Q50-Q53 ask about the past 7-day time period, while Q54 asks about the past 4 weeks. **Note:** Answer choice ‘numbers’ for Q50 and Q51 are in reverse order (5 to 1) while Q52-Q53 are in the usual order (1 to 5). This is intentional. If reading out answer choices to the participant, please read them in the order presented.

Q50 Point out to participant that the following statement will have a five level response category, which are: Very poor, Poor, Fair, Good, or Very good. Then proceed to read each statement and each response option.

Q51-Q53 Point out to participants that the next three statements will have the same five response categories, which are: Not at all, A little bit, Somewhat, Quite a bit, or Very much. Then proceed to read each statement and each response option.

Q54 This question asks about number of hours slept each night in the past 4 weeks.

Alcohol Use

This section asks about the use of alcohol. Interviewers should read the questions slowly and emphasize bolded words as they help distinguish each question.

Q55 This item asks about the frequency of consumption of any kind of drink containing alcohol in the past 12 months. Participant may ask what is meant by a drink. By a drink we mean a 12 ounce can or glass of beer or cooler, a 5-ounce glass of wine, or a drink containing 1 shot of hard liquor.

Q56 This question is collecting information on the average number of drinks that the respondent normally consumes on the days that they drank alcohol in the past 12 months. Please record the answer in the unit specified by the respondent.

Q57 Men are asked if they have had 5 or more drinks in a single day in the past 30 days. Women are asked if they have had 4 or more drinks in a single day in the past 30 days. PROBE for a response if participant does not recall.

Q58 This is a sensitive item, which seeks to obtain information on the number of times the respondent drank four or five drinks in a 2 hour period in the past 30 days. Females will be asked about the number of times she drank four or more drinks in a 2 hour period while men will be asked about five or more drinks.

Note: Every 2 hour time frame is considered “1 time.” For example, if a female respondent had 4 or more drinks from 8:00 pm – 10:00 pm and 4 or more drinks again from 10:00 pm – 12:00 am, it would count as 2 times even though it occurred during the same day.

Physical Activity

- Q59** Interviewer should clarify that the question refers to the number of days (answers should range from 0 to 7) in a typical week that they do vigorous physical activities for at least 10 minutes at a time. If the answer is "0," skip to Q 61
- Q60** The question is asking participants to indicate how many minutes they engage in vigorous activity on a typical day during a typical week. If the participant has trouble answering this question, he/she can be prompted to recall his/her previous week's activity so long as they also confirm that the previous week is representative of his/her normal week of activity. The time must be entered as the total number of minutes in a typical day. Thus, if the response is "about a half an hour," the entry is 30 Minutes. A response of an hour-and-a-half would be entered as "90 Minutes". An entry of less than 10 Min is not allowed.
- Q61** Interviewer should clarify that the question refers to the number of days (answers should range from 0 to 7) in a typical week that they do moderate physical activities for at least 10 minutes at a time. If the answer is "0", skip to Q 63
- Q62** The question is asking participants to indicate how many minutes they engage in moderate activity on a typical day during a typical week. If the participant has trouble answering this question, he/she can be prompted to recall his/her previous week's activity so long as they also confirm that the previous week is representative of his/her normal week of activity. The time must be entered as the total number of minutes in a typical day. Thus, if the response is "about a half an hour," the entry is 30 Minutes. A response of an hour-and-a-half would be entered as "90 Minutes." An entry of less than 10 Min is not allowed.

Definitions

Vigorous Physical Activity: Physical activities of high intensity; greater than 6 METs. Participation in these activities results in high heart rates and breathing rates. The participant is usually aware of her/his heart rate (can usually feel the heart pounding) or breathing, and typically cannot carry on a normal conversation while participating at this intensity. The participant usually tires from these activities in as little as 5-10 minutes, or can sustain these activities for 30 minutes or more if physically trained. These may include things like heavy lifting, climbing stairs, running, or soccer.

Moderate Physical Activity: Physical activities of 3 to 6METs. These make the participant breathe somewhat harder than normal. These activities can be typically completed with the participant being able to complete an active conversation. Moderate intensity activities may include activities like carrying light loads, brisk walking or cycling, dance, or weightlifting.

Part G. INSECURITY**Financial Insecurity**

- Q63** Question asks if there has been a period of time within the last 12 months when the participant was unable to meet their daily needs because they did not have enough money. Basic needs refers to things like food, water, clothing, and housing.
- Q64** Question asks if there has been a period of time within the last 12 months when the participant did not have enough money to pay their monthly bills.

Housing Insecurity

- Q65** Question asks if there has been a period of time within the last 12 months when the participant was unable to for their rent, mortgage or similar housing costs because they did not have enough money.
- Q66** Question asks if there has been a period of time within the last 12 months when the participant was unhoused, that is, they did not have a regular place of residence, lived in a homeless shelter, or lived in a place nor ordinarily used as a sleeping arrangement (e.g. on the street or in a car).

Food Insecurity

- Q67** Question asks if there the participant went without eating within the last 30 days because they did not have money to buy food.

SIE – SENSITIVE INFORMATION [Q68-102]

PART H. SENSITIVE TOPICS

Cognitive Function

- Q68-Q71** Point out to participant that the following four questions will ask about their thinking process and that all items have the same five response categories, which are: Never, Rarely, Sometimes, Often and Very often. Then proceed to read each statement and each response option.

Social Isolation

- Q72-Q75** Point out to participant that the following four statements will ask about how often they felt alone and that all items have the same five response categories, which are: Never, Rarely, Sometimes, Usually and Always. Then proceed to read each statement and each response option.

Chronic Stress

- Q76-Q83b** The Chronic Stress Scale is a measure of ongoing stress in several life domains. The measure asks about daily stress regarding problems related to health, work, finances, personal relationships, alcohol or drug abuse, and one unspecified domain. For each domain, there are two additional questions about whether the stressor has persisted for six months or more, and how stressful the participant found the stressor to be. If the time frame is still unclear, be aware that this measure is referring to **current** chronic stress – i.e., do they have a given ongoing problem right now, and if so, has it been going on for at least six months.

Read the script exactly as it appears. Be aware of skip patterns for several of the questions and be sure to follow them as directed. You may re-read the answer options if the participant requests so. When asking these questions, be careful to not comment on respondent's answers and to record answers in a non-judgmental manner. If you are asked about the meaning of specific questions (e.g., "what classifies as someone close to me"), you should encourage participants to interpret questions in the way that makes the most sense to them.

- Q76-77** If participant asks for further information or an example of a chronic health problem, you can state the following: "this would include problems like a heart attack or cancer."

SPANISH: *Esto incluiría problemas como un infarto o cáncer.*

Stress of Immigration

Q84-Q87 Point out to participant that the following four statements will have the same five response categories, which are: No Stress, A little stress, Moderate amount of stress, A lot of stress, Severe stress. Then proceed to read each statement and each response option.

Ethnic Discrimination

Q88 Indicate to participants that questions ask about experiences they have **had throughout their lifetime “because of your ethnicity or race.”** If participants inquire, you may tell them that we are referring both to the time they have spent in the US and in their country of origin (i.e., for immigrants). Point out that all questions should be answered by indicating how often each experience has occurred during the participant’s lifetime with response options of “never, sometimes, often, and very often.” Proceed by asking each question and then reading each response category. You may re-read the answer options if the participant requests so. When asking these questions, you should be careful to not comment on respondent’s answers and to record answers in a non-judgmental manner.

Brief Resilience Scale

Q89-Q94 These questions ask about how participants tend to respond to hard or stressful times. Point out to participants that the following six statements will have the same five response categories, which are: Strongly agree, Agree, Neutral, Disagree, Strongly disagree. Then proceed to read each statement and each response option. You may re-read the answer options if the participant requests so. When asking these questions, you should be careful to not comment on respondent’s answers and to record answers in a non-judgmental manner.

Depression Screener

Q95-Q102 Point out to participant that the following eight statements will have the same four response categories, which are: Not at all, Several days, More than half the days, Nearly every day. Still then proceed to read each statement and each response option.

[SME-Sexuality and Gender Identity Part 1Q103-107a]

J. SEXUAL ORIENTATION AND GENDER IDENTITY

PART 1. SOGI SCREENING QUESTIONS FOR SGM SOL

Q103: Sex at birth

The goal of this question is to capture what sex (male/boy or female/girl) was identified for them, either by a doctor or their parents/guardians/family, when they were born. This can differ from the gender the participant currently identifies with as well as their current sex.

Q104. Gender identity

The goal of this question is to capture what gender the participant personally identifies with. This can differ from the sex the participant was assigned at birth. It’s important to notice that the category of “man” includes a transgender person who currently identifies as a man, i.e. trans man. Likewise, the category of “woman” includes a transgender person who currently identifies as a woman, i.e. trans woman. If a participant asks, “What is gender

non-binary” then read the following response, “Some people think of themselves as gender non-binary when they do not identify only as a man or only as a woman.”

Q105. Age Current Gender Identity Adopted

The goal of this question is to capture the age when the participant first began to identify with the current gender captured in Q104. If the participant has a current gender that corresponds with their sex assigned at birth (Q103), please enter 00. For example, if person was assigned male at birth and currently identifies as a man, please enter 00. If a participant states that they have always been their current gender, please enter 00.

Q106. Difference of Sexual Development (DSD) or Intersex

This question seeks to capture whether the participant has been told by a medical professional that they have one or more conditions that are described “differences of sexual development or DSD” and can also be called “intersex conditions.”

If the participant asks, “What are differences of sexual development (DSD)?” then read the following response, “Doctors use the term DSD to describe a group of conditions in which a person is born with a body that doesn't fit what is expected for a typical female or male.”

If the participant asks, “What is intersex?” then read the following response, “Intersex is a term used for a group of conditions in which a person is born with a body that doesn't fit what is expected for a typical female or male.”

Q107. Ever Same Sex Attraction

The goal of this question is to capture whether the participant has even felt sexually attracted to someone who has the same sex as they do. Responses to this question should not only be based on any action the participant has taken but also on feelings on which they have not taken action. Note that thinking someone is “attractive” means they find the person pleasing to look at, being “attracted” to them means a desire for a romantic or sexual relationship.

Q107a. Age of First Same Sex Attraction

Only participants who answer YES to the previous question about whether they have ever been attracted to the same sex should be asked this question. The goal of this question is to capture the age when the participant first felt attracted to someone of the same sex. If the participant says they have always felt attraction to the same sex, please enter 00.

[SOE-Sexuality and Gender Identity Part 2 Q108-114]

PART 2: ADDITIONAL SOGI QUESTIONS FOR SGM SOL AND NIMHD (SOE)

Q108. Current Sexual Attraction

The goal of this question is to identify the gender(s) of people to whom the participant is attracted. Responses to this question should not only be based on any action the participant has taken but also on feelings on which they have not taken action. Note that thinking someone is “attractive” means they find the person pleasing to look at, being “attracted” to them means a desire for a romantic or sexual relationship.

Q109. Lifetime Romantic Partners

The goal of this question is to capture the sex of a participants romantic partners over the course of their lifetime.

If they ask for the meaning of romantic partner, please read this: “A romantic partner refers to someone whom you have dated or had a sexual relationship.”

If they ask for the meaning of romantic attraction: “A romantic attraction refers to the desire for intimate and emotional relationships with someone”

If they say they are married, remind them that the question asks about all romantic partners over the course of their lifetime and ask them to select the answer that best fits all of the relationships over their lifetime.

If a participant has ever had romantic partners who are “other genders” the interviewer should check the box for “other genders.” In other words, if the participant has had male partners and partners who have other genders, female partners and partners who are other genders, or male, female, and partners of other genders in, then please check the box to indicate “other partners.” “Other genders” includes genders such as nonbinary, transgender, genderqueer, bigender, or genderfluid.

Q110. Sexual Orientation

The goal of this question is to document the sexual orientation of the participant. If a participant asks for the definition of a response item, they are listed below. If a participant responds with a term such as “Normal”, “Regular”, or any similar term then read them the definitions below and ask them the question again.

Straight/Heterosexual: A sexual orientation that describes women who are emotionally and sexually attracted to men, and men who are emotionally and sexually attracted to women.

Lesbian: A sexual orientation that describes a woman who is emotionally and sexually attracted to other women.

Gay: A sexual orientation that describes a person, male or female, who is emotionally and sexually attracted to people of their own gender. It can be used regardless of gender identity, but is more commonly used among men.

Bisexual: A sexual orientation that describes a person who is emotionally and sexually attracted to people of their own gender and people of other genders. Bisexual also includes the orientation of Bi.

Some other orientation: There are many other terms that can be used to describe one’s sexual orientation such as pansexual, queer, asexual, and many others. Participants selecting this option will be asked in the next question to provide additional information.

Q110a. Detail on Some Other Sexual Orientation

This question should be asked of participants who responded either “Some other identity” or “Don’t know” to the previous question about sexual orientation. The goal is to better understand what the participant means by the response of “some other identity” or “don’t know.” Please ask the person to select the one answer that best explains why they selected “don’t know” or “some other identity” in the previous question.

Q111. Transgender Identity

The goal of this question is to document if the participant identifies as being transgender. When reading this question and its response items only use the word “transgender” and not any of the following: “transgendered”, “transsexual”, “tranny”, or any other variation of the

word. This will reduce the risk of offending or upsetting a participant who may be transgender or transitioning from one gender to another.

If a participant asks, “What is transgender?” then read the following response, “Some people describe themselves as transgender when they experience a different gender identity from their sex at birth. For example, a person born into a male body, but who feels female or lives as a woman would be transgender. Some transgender people change their physical appearance so that it matches their internal gender identity. Some transgender people take hormones and some have surgery. A transgender person may be of any sexual orientation- straight, gay, lesbian, or bisexual.

If a participant asks, “What is gender non-binary” then read the following response, “Some people think of themselves as gender non-binary when they do not identify only as a man or only as a woman.

Q112. Sexual Partners Past 12 Months

The goal of this question is to document the gender(s) of people with whom the respondent has had sex. If the participant responds with a term such as, “Only my husband/boyfriend”, “Only my wife/girlfriend, or any similar response then re-read the response options again and ask the participant to identify the option that best represents their initial response.

If a participant has had sexual partners in the past 12 months who are “other genders” the interviewer should check the box for “other genders.” In other words, if the participant has had male partners and partners who have other genders, female partners and partners who are other genders, or male, female, and partners of other genders in the past 12 months, then please check the box to indicate “other partners.” “Other genders” includes genders such as nonbinary, transgender, genderqueer, bigender, or genderfluid.

Hormone Use

Q113. Ever Used Sex Hormones

The goal of this question is to capture whether transgender participants and intersex participants have ever in their lifetime taken sex hormones for their gender. Hormones used for this purpose are sometimes called hormone therapy, hormone replacement, or gender-affirming hormones. They may be prescribed by a doctor or people may get hormones in other ways. We want to capture any time the participant took hormones whether or not they were prescribed by a doctor and no matter if they took hormones by pill, injection, patch, cream, or implant.

If the participant asks what this question means, please read this explanation, “Some people take female hormones or male hormones to replace hormones their body does not make. Some people take these hormones to make their physical appearance match their gender identity. Have you ever taken hormones for either of those reasons?”

Q113a. Age at First Hormone Use

The goal of this question is to capture the age when the participant first took any hormone therapy for their gender. It does not matter if the first time they took hormones was by prescription from a doctor or from another source, we would like to capture the first time. For this question, it also does not matter if they stopped hormones or only took them for a short time.

Q114. Current Hormone Use

The goal of this question is to capture whether the person is taking hormones for their gender identity or transition right now. If the participant asks what “currently” means, please explain, “By currently, we mean have taken hormones within the last 30 days”

Q115. SGM Eligibility

The goal of this question is to screen participants for SGM ancillary study eligibility. Click “Save and Reload” in order for the question to populate. The question will populate with “Yes” if the participant is eligible, and “No” if the participant is ineligible. If participant is eligible, proceed with recruitment and consenting for SGM. All V3 participants will be screened to participate in SGM.