



HCHS/SOL- Genetic Testing Awareness GTE

2019 New Version QxQ ver 11/8/2019

Introduction

These questions have been adapted from the 2017 Health Information National Trends Survey (HINTS). These questions are being added to the current HCHS/SOL Annual Follow-Up to determine whether SOL participants have heard about genetic testing to identify disease predispositions, to identify risks for offspring, to inform treatment decisions, and to optimize medication choices. Participants who answer 'yes' to knowing about any of those tests are asked whether they have ever been offered these tests and whether they have received them.

For this new version, to avoid participant confusion on us offering these tests, we have remove the question asking if they would be interesting in them if offered.

Instructions:

Paper forms should be used to collect the revised questions in this form. Once the data is collected in paper, CDART data entry should be made using specific recommendations made in this document.

Note: These Interviews cannot be done with the existing CDART form. We have incorporated notes in the paper form to help guide the interviewer with the CDART data entry.

Read the introductions in the UPDATED paper survey and the items in order, utilizing the paper form skip patterns. Provide Yes or No responses only if necessary. Select the options "refuses to answer or does not know" when necessary, do not provide as options.

INTRODUCTION in paper form, not present in CDART form

DNA is found inside the cells in your body and contains the instructions needed to direct how your body grows, develops, and functions. Doctors use genetic tests to analyze someone's DNA for health reasons. We are interested in knowing if people know about genetic tests or have received a genetic test in the past.

NEW QUESTION

Present in Paper form, not present in CDART.

Enter the answer to this question in the Notelog for Q0a:

- no, yes or rta
- Please make sure to enter only these specific words
- Do not enter any comments in this Notelog, only yes, no or rta.

0c. Have you heard or read about this type of genetic test?

No 0 ☐ **[End Questionnaire]**

Yes 1 ☐

Refuse to answer 9 ☐ **[End Questionnaire]**

- If the answer to this question is Yes, then continue with the interview, using the paper form.
- If the answer is **No** or the participant refuses to answer: Thank the participant for their time. CDART data entry for these cases: Enter date and Notelog in 0a; enter staff ID; Save and Close the CDART form.

QXQ Instructions

0a. Date should be from Nov 11 on. For this new form-version the completion date cannot be prior to Nov 11, 2019. This would be the day we will use as the cut off date for the administration of this new version of the form.

Notelogs of 0a. will hold the answer to question 0c. present only in the paper form. See above for instructions.

DATA ENTRY CDART INSTRUCTIONS.

Ignore Q1c, 2c, 3c and 4c in CDART. They will be ignored in the missing fields report.

1. Have you heard of a genetic test to determine the risk or likelihood of getting a particular disease?
If **No** or **Refused**, **Go to item 2**, i.e. IGNORE Q1c
 - 1a. Have you ever been offered such test?
No or **Don't know** **Go to item 2**, i.e. skip IGNORE Q1c.
If **Refused**, set 1b Field-Status=Not applicable, **Go to item 2**
 - 1b. Have you ever received this kind of test?
Go to next question for every answer
2. Have you heard of a genetic test to determine the likelihood of passing an inherited disease to your children?
If **No** or **Refused**, **Go to item 3**, i.e. skip Q2a-b
 - 2a. Have you ever been offered such test?
No or **Don't know** **Go to item 3**, i.e. skip IGNORE Q2c.
If **Refused**, set 2b Field-Status=Not applicable, **Go to item 3**
 - 2b. Have you ever received this kind of test?
Go to next question for every answer
3. Have you heard of a genetic test to determine how a disease should be treated after diagnosis?
If **No** or **Refused**, **Go to item 4**, i.e. skip Q3a-b
 - 3a. Have you ever been offered such test?
No or **Don't know** **Go to item 4**, i.e. skip IGNORE Q3c.
If **Refused**, set 3b Field-Status=Not applicable, **Go to item 4**
 - 3b. Have you ever received this kind of test?
Go to next question for every answer
4. Have you heard of a genetic test to determine which drugs may or may not work for an individual?
If **No** or **Refused**, **Go to item 5**, i.e. skip Q4a-b
 - 4a. Have you ever been offered such test?
No or **Don't know** **Go to item 5**, i.e. skip IGNORE Q4c.
If **Refused**, set 4b Field-Status=Not applicable, **Go to item 5**
 - 4b. Have you ever received this kind of test?
Go to next question for every answer
5. On a scale of 1 to 10, where 1 is "not at all" and 10 is "extremely", how useful do you think genetic testing is for managing a person's health? [use CDART field status if they refused to answer]

__ __ (Enter the number participant responds)