Moderator's Guide
Genetics Home Reference (GHR) Website
ghr.nlm.nih.gov

Author:

Script (session length):

Participant Name/ID:

Time/Date:

Groups: ☐ Group 1 (LYNCH SYNDROME, All major sections open)

☐

Group 2 (COWDEN SYNDROME, Only description section open)

Participant Type: ☐ General User
☐ Health Professional

(This statement will be sent to participants with instructions one day prior to the interview.)

Links Needed

https://ghr.nlm.nih.gov/

https://ghr.nlm.nih.gov/primer

https://ghr.nlm.nih.gov/condition/

http://5hx9jn.axshare.com/#g=1&p=test_1

https://s3.amazonaws.com/media.nngroup.com/media/editor/2014/08/18/thinking-aloud-demo.mp4

Log into JOIN.ME

Login: XXXXXX

PW: XXXXXXX

Script

Introduction

1.   Thank you for coming. My name is [MODERATOR NAME], and I am a researcher with a company called ICF working for the Genetics Home Reference, a service of the National Library of Medicine (or NLM), which is part of the National Institutes of Health. Genetics Home Reference provides consumer-friendly information about the effects of genetic variation on human health. I'm going to be walking you through the session today. We also have [NOTE TAKER NAME] taking notes.

2.   The session should take less than an hour.

3.   Before we go any farther, I would like to explain what we'll be doing today and get your consent regarding your participation.

Verbal Consent Information

Procedures

- First, you will be given a number of tasks to complete on the site, and then you will be asked questions about what you liked and disliked about the experience, about the process of finding relevant information, and if you have any thoughts about how the website can be improved.

- This interview will be audio and screen recorded. We will be able to see your screen and everything on it once you share your screen with us.

- The sessions will not be observed by NLM staff; however NLM staff will have access to the recordings. The recordings will not include any personally identifiable information.

- Only one person will be interviewed at a time.

- Your name and any other personally identifiable information will not be tied to any reports related to this study.

Do we have your permission to start audio and screen recording?

Start recording Audio and Video Screen Capture

Voluntary Participation

You can choose not to answer any question and you can stop the interview at any time, for any reason.

Do you agree to participate in this interview?

Do you have any questions?

Guidelines

1. Before we begin the session, here are a few things to keep in mind:

   a. First of all, it's important for you to know that we are testing the design of the site and not you. There are no right or wrong answers. If there is confusion, it's the fault of the design and not you. In no way are we judging your performance and it does not reflect on your abilities as a user. Through our observations we will be able to improve the website and make a better product for the site's visitors. It is also important to note that we were not involved with the design of the site, so if you find problems with it, it will not hurt our feelings if you tell us about it.

2. During the test, please:

   a. Think aloud and say what you are doing. Thinking aloud helps us understand your thought process and how you approach using the site.

   b. Tell us what you are looking at on the screen, what your thoughts are, what your expectations are, what you like and what don't you like, or if you are confused at any point.

   c. Here is a short video example of what we mean by "think aloud"

https://s3.amazonaws.com/media.nngroup.com/media/editor/2014/08/18/thinking-aloud-demo.mp4

Are you ready?

Pass Join.me presenters role to participant

General Questions

On an average day, how many hours do you spend online?

When was the last time you visited the Genetics Home Reference site?

      Do you remember why were you visiting?

      At your last visit, did you find what you were looking for?

I'm going to send you a link to the Genetics Home Reference website.

Please do not click on any links yet

> *Send GHR HOMEPAGE link to participant via join.me chat*
>
> *https://ghr.nlm.nih.gov/*

Where is your eye drawn to first?

What are your first impressions?

Now, let's move to some more specific tasks. We will ask you to pretend to be a person who is visiting the site with specific tasks in mind. Here is the scenario:

Tasks Part 1a (for General User)

Start at the homepage

Randomize condition & section (open/close) tabs

Group 1: LYNCH SYNDROME | All major sections open

Success: https://ghr.nlm.nih.gov/condition/lynch-syndrome/

Group 2: COWDEN SYNDROME | Only description section open

Success: https://ghr.nlm.nih.gov/condition/cowden-syndrome/

For this session, let's pretend that at a recent visit, you mentioned to your doctor that multiple people in your family have been diagnosed with a particular type of cancer. After telling the doctor more about your family history, she tells you that she suspects that runs in your family.

[*Group 1: Lynch syndrome*]

[*Group 2: Cowden syndrome*]

You want to go online and:

- Learn more about this health condition
- Get more details about the genes associated with the condition
- Print information you'd want to share with family

If user cannot find the syndrome due to misspelling, send them the name through chat.

We would like for you to try to find this information on the Genetics Home Reference website and show how you would print it. Once you believe you have found all of the above-mentioned information, let us know. Please don't forget to narrate your mouse movements and thoughts.

Tasks Part 1b (for Health Professional)

Randomize condition & Section (open/close) tabs

Group 1: LYNCH SYNDROME | All major sections open

Success: https://ghr.nlm.nih.gov/condition/lynch-syndrome

Group 2: COWDEN SYNDROME | Only description section open

Success: https://ghr.nlm.nih.gov/condition/cowden-syndrome/

For this session, let's pretend that you see patients and that, at an office visit, a patient mentions to you that she has multiple family members who have been diagnosed with a particular type of cancer. After telling you more about her family history, you suspect runs in her family.

[*Group 1: Lynch syndrome*]

 [*Group 2: Cowden syndrome*]

You want to:

- Read more about this health condition
- Get more details about the genes associated with the condition
- Provide a printed handout with relevant information to this patient

If user cannot find the syndrome due to misspelling, send them the name through chat.

We would like for you to try to find this information on the website, and show how you would print it. Once you believe you have found all of the above-mentioned information, let us know. Please don't forget to narrate your mouse movements and thoughts.

Tasks Part 1c - Follow up

For all groups, after completing task, follow up with the following questions as needed and as appropriate based on their previous actions, to ensure all testing goals are met.

General

How else might you share the information you found on the site?

Was there any particular section heading that you thought was confusing?

What other information on this page would you be interested in exploring? Why?

For Group 2 Only

What did you think of the expand collapse options on the **health condition page**?

    Is it clear how to open and close the sections?

If you wanted to expand all of them or close all of them, how would you do that?

Section Labels for Health Conditions

When looking at the name of each section, can you tell me what information you would expect to find?

- Frequency
- Genetic Changes
- Inheritance Pattern
- Diagnosis & Management
- Other Names for This Condition
- Additional Information & Resources
- Sources for This Page

Do you have a better descriptive name for any of these sections?

If so, what word/phrase would best represent the content to you?

Description Section

Related information Box

When you were looking around the page, did you notice the right side box with links?

What do you think about it?

What does **Related Information** mean to you?

Gene pages

Under the section "Heath conditions related to genetic changes," is it clear what the subsections represent?

After opening a subsection, what do you expect to happen if you click on "More about this condition"?

Search/Browse option

Why did you choose to search? (Or, why did you choose to browse?) Did you notice there was a search option available? Did you notice there was a browse option available?

If you wanted to search the site for specific piece of information, how would you do that?

What do you think about the filtering options? Are those clear?

If you wanted to browse through all the possible health conditions, how would you do that?

What do you think about it?

Specific example: Is the distinction between the synonym (A-alpha lipoprotein Neuropathy and the preferred name ([Tangier disease](#)) clear?

Help Me Understand Genetics

What would you expect to find on this page? Why?

Can you find information about the importance of knowing your family medical history?

How would you share information from it?

Tasks Part 1d – Homepage

Main Navigation

What would you expect to find under each one of the main headings/sections/areas?

Why? Can you think of a better name?

About Us / Contact Us

Can you find Information about the Genetics Home Reference website (for example, the site's terms and conditions)? Why did you look there?

If you wanted to get in touch with somebody from the site, how would you do that?

Right Sidebar

New & Updated Pages Section

What do you think this section is about? Why?

Bulletins / Features

What do you think each section is about?

What do you think is the difference between a bulletin and a feature?

Can you think of a better name for these sections?

Tasks Part 2 – Wireframes

Send SECTION TABS WIREFRAMES link to participant via join.me chat

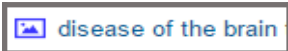*http://5hx9jn.axshare.com/#g=1&p=test_1*

Randomize the order of conceptual wireframes presented to participant.

Now we are going to look at some mock-up designs for the same site. I'm going to send you a link to sample web pages through the chat window.

We are first just going to look at some things, please don't click on anything until I ask you to.

Section 1 – *Description* Section

Open the ***Description*** section and tell me what you think will happen if you click on

disease of the brain

Go to the next section

Section 2 – *Genetic Changes* Section

Open the ***Genetics Changes*** section and tell me what you think will happen if you click on

amyloid plaques

Go to the next section

Section 3 - Inheritance Pattern Tab

Open the ***Inheritance Pattern*** section and tell me what you think will happen if you click on

autosomal dominant

Let's go back now and actually click on the icons

Is this what you expected? Does it make sense?

Do you find any of them more clear/helpful than others? Do you find any of them distracting when you're trying to read the text of the paragraph?

Do you have any ideas of how to make this better?

END OF INTERVIEW

This is the end of the interview. Do you have any questions?

Do you have any final comments on the website, and how we can make it better?