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ClinicalTrials.gov
Focus Group Moderator Guide

Moderator:

Hello. Thank you very much for coming to participate in this focus group. You are here to help National Library of Medicine improve their web site that reports on clinical trials. The National Library of Medicine is one of the NIH institutes. It is also the world's largest biomedical library, and an organization that produces electronic information resources on a wide range of topics that are searched by millions of people around the world. Thank you very much for being here to help its mission.

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1. Let's all start by taking a look at this web page – Background information – and we will go through each section.

   See next page for sample screenshots of webpage with 2 navigation design options:

ClinicalTrials.gov Background

+	What is ClinicalTrials.gov?
+	What can ClinicalTrials.gov be used for?
+	What information about clinical studies can be found on ClinicalTrials.gov?
+	Is every research study listed in the ClinicalTrials.gov database?
+	What laws cover ClinicalTrials.gov?

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ClinicalTrials.gov background

What is ClinicalTrials.gov?

What can ClinicalTrials.gov be used for?

What information about clinical studies can be found on ClinicalTrials.gov?

Is every research study listed in the ClinicalTrials.gov database?

What laws cover ClinicalTrials.gov?

What is ClinicalTrials.gov?

ClinicalTrials.gov lists up-to-date information about clinical research studies in a database. A database is like a library on the internet where people can submit and find information. It is free for anyone to use on the internet and contains information about more than 300,000 research studies and more than 40,000 research results.

These research studies:

- Take place in all 50 U.S. states and in 209 countries
- Are privately and publicly funded
- Have human volunteers in them

ClinicalTrials.gov is operated by the U.S. National Library of Medicine. Although it isn't the only database of research studies information, It is the largest in the world. More than 100,000 people use ClinicalTrials.gov each day. Information on ClinicalTrials.gov is provided by study sponsors and investigators, and they are responsible for ensuring that the studies follow all applicable laws and regulations. Listing a study on this site does not mean it has been evaluated by the U.S. Federal Government.

Next: What can ClinicalTrials.gov be used for? ›

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NOTE: Use headers to designate sections when they are finalized.
Ask these questions for every section.

      a. What is the most important information in this section?
      b. What is the least important information in this section?
      c. Is there anything missing that should be there?
      d. Is there anything there that shouldn't be there?
      e. On a scale of 1 to 10 where 1 is least informative and 10 is most informative to you – how informative would you say this section is?

2. Please just tell me – and you don't all have to answer every time – About this web page labeled Learn About Studies … can you tell me:

About studies

What is clinical research and why is it done?

What types of clinical research are there?

Why do people volunteer to join clinical research?

What happens during clinical research?

What about safety during clinical research?

Who can take part in clinical research?

How can people find information about clinical research?

If someone is thinking of joining a research study, what questions should they ask?

Who carries out clinical research?

Where does clinical research take place?

What is clinical research and why is it done?

Clinical research is a type of medical study that involves people. Clinical research is one way that scientists, doctors, and other health care providers can learn about:

- How the human body works
- The causes of illness
- How illness develops in people, such as how diseases get better or worse over time
- Other ways to treat illness
- How the body handles a possible treatment
- What behaviors or ways of living help people stay healthy, such as what they eat or whether they smoke

Clinical research uses science to improve people's health and health care over time. For example, because of clinical research, we know that:

- Insulin pumps can work to control blood sugar
- Vaccines, such as the chickenpox shot, are safe and work to prevent illness
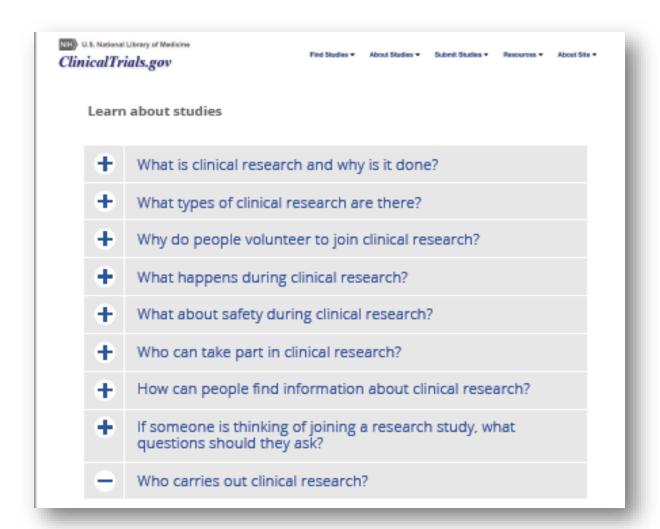- Mammograms can find breast cancer early, when it is easier to treat

Next: What types of clinical research are there? ❯

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Ask these questions for every section.

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3. Ok, we've gone through these pages section by section – tell me your overall impressions of these two web pages. What do you think about the information?

PROBES

- o Do you think these web pages will help people like you?
- o What did you learn from these web pages?
- o What would your family and friends learn from these web pages?
- o What would you or your family and friends do differently in their lives because of these web pages?
- o Was there anything we haven't already talked about that was missing?
- o Overall, let's score these web pages now – each person please - On a scale of 1 to 10 where 1 is least informative and 10 is most informative to you – how informative would you say these web pages are for you?

COMPARE DESIGNS

Now, let's look at a different design of the same content. (Show second design of Background page – show each section on screen scrolling slowly down the page)

4. What would you say are the main differences between each design?

5. Rate both on a scale from 1 to 4 – with 1 being the best to navigate and 4 being the worst to navigate each design. (Collect responses from all)

6. Now, tell me why you rated each page the way they did. What are the major differences to each of you?

Now, let's look at a different design of the same content. (Show second design of Learn About Studies – show each section on screen scrolling slowly down the page)

7. What would you say are the main differences between each design?

8. Rate both on a scale from 1 to 4 – with 1 being the best to navigate and 4 being the worst to navigate each design. (Collect responses from all)

9. Now, tell me why you rated each page the way they did. What are the major differences to each of you?