National Library of Medicine
WHR Consumer Focus Group Survey

Consumer Focus Group Moderator's Guide

Welcome/Opening Remarks (10 minutes)

[The moderator will greet participants as they arrive, directing everyone to sign in and create a personal name badge. The moderator will offer participants refreshments and point out directions to the restrooms.]

[When all the participants are seated comfortably, the moderator will begin the session with the following introduction]:

Welcome everyone and thank you for joining us today. My name is _____ and this is [note-taker]. We are here to lead this discussion group on behalf of the National Institutes of Health's (NIH) National Library of Medicine (NLM). NLM will be redesigning a website about women's health research. A large portion of the information on the website is for the public, so we are conducting research on the type of information that is the most useful to people like you.

The ideas and information you share with us are very important. What you tell us today will help many people like you in the future. With your help, we hope to improve the existing website and related materials so that they are helpful, clear, and engaging.

Before we begin, I'd like to make a few things very clear and explain how the discussion will work.

1. We are not trying to sell or promote any product or service to you.

2. There are no right or wrong answers—we want your opinions.

3. ____ will be taking notes and audio recording the discussion. We have to write a report on your suggestions to inform the redesign of the website. Audio recording the discussion will help us write the report. We will not use your names in the report. We will only share the report with people working on this project.

4. In order to make sure everyone's thoughts and opinions are heard, it is important that you only speak one at a time. I may occasionally interrupt you when two or more people are talking at once in order to be sure we hear everyone's suggestions and opinions.

5. This discussion will last approximately an hour and a half. I want to be sure not to keep you here much longer, so I may occasionally interrupt you to keep the discussion focused.

6. Please turn off your beepers and cell phones. Should you need to go to the restroom during the discussion, please feel free to leave, but we'd appreciate it if you would go one at a time.

[The moderator will hand out informed consent forms, saying:]

> Your participation in this discussion is voluntary. You may stop the discussion at any time. Your names will NOT be used in any report. The audio recorder is here only to be sure that we get all your opinions and ideas.
>
> If you understand everything I've said and you agree to participate, please read, sign, and date the informed consent form.

[Participants will then read and sign the informed consent statement assuring them that information provided during the discussion group will be kept confidential and only be used for the redesign of the WHR website and related materials. The form will also contain language explaining that signing the form confers permission to be audio recorded.]

Introduction and Warm-up (5 minutes)

First, let's go around and introduce ourselves. Tell us:
- Your first name
- One women's health issue/topic you have read about recently?

I'll start and then we'll go around the room. Again my name is _____.

We're going to start with a few warm-up questions.

- What comes to mind when you think about women's health?

- Anything different come to mind when you think or hear about women's health research?
- Have you heard of sex difference research before? If so, what have you heard or read about it? [If none of the participants indicate that they know what sex differences research is then the moderator will provide a few examples.]

Discussion of Women's Health Research (30 minutes)

Now we're going to talk a little about women's health research. I'm going to ask some questions for the group to answer and discuss. Remember, there are no right or wrong answers.

- Have you heard about scientific studies or research findings related to women's health in the news before?
    - o In general, what do you think about research findings related to women's health topics you hear about in the news? (Potential prompt: do you trust them?)
    - o Do you ever look for more information about research findings online? If so, where do you look? If no, why not?

- Do you think women's health research is important?
    - Why or why not?

- Recount the last time you discussed or thought about women's health research.
    - Describe the conversation or thought process that lead to thinking about women's health.

- Thinking back to the last time you searched for health information for yourself or your loved ones, can you tell us about how you searched for it?
    - o What did you use the information for?
    - o Did you check to see if the information you found was backed by research? Why or why not?
    - o Are there certain online health information sources you use most often? Why do you like them?
    - o Have you ever used a social media website to search for health information?

- Do you ever read research about women's health?

[If Yes:]
- What type of information do you read?

- How frequently do you read about this type of research?

- When thinking about women's health research you read, do you look for a specific research topic, age group, or focus on other characteristics (such as pregnancy)? If so, what do you look for and why?

- Can you tell us about the last time you searched for women's health research information?
    - How did you use the information you read?
    - How did you find the information you were looking for?

- Where do you usually go to get information about women's health or sex differences research?
    - What do you like about the sources you use?
    - What do you dislike about the sources?
    - What types of materials/information do you find most useful? Why?
    - What organizations, sources, or sites do you trust when looking for information?

[If No:]
- If you do not read about women's health research, why is that?
- Do you ever read about other types of research? If so, what types?

Information Ranking Activity (20 minutes)

[For this exercise, the moderator will ask participants to choose the most and least important items from a list of WHR types of information from most to least important. Results will be used in a discussion of why certain types of information are most or least useful for consumers.]

[Moderator hands out sheets of paper with list to each participant]

Now I'm going to show you a list of some types of information you might find on a women's health research website. On the sheet of paper we pass out, circle 3 items that are the most important to you and cross out 3 items that are the least important to you. Do this on your own. Then, we will go around and you can tell us which ones you picked and why. I'll give you a few minutes to complete this now.

- Which type of information is most important and why?
    - Out of the 3 items you circled, put a star next to the item that is the most important to you. Why did you star that item?
- Which type of information is the least important and why?
    - Out of the 3 items you crossed out, put an X next to the item that is the least important to you. Why did you put an X next that item?
- Are there any types of information not on the list that you think should be added or that you would like to see on a women's health research website?

Please keep your sheet of paper to give to me at the end of the session.

Collaging Activity (20 minutes)

[For this exercise, the moderator will ask participants to pick 1-2 pictures that represents a quality/qualities they would want in a women's health research website and 1-2 pictures that represents a quality/qualities they would not want in a women's health research website.]

[Moderator hands each participant the 25 picture set]

We're going to do a short activity now. I would like you to circle 1-2 pictures that represents qualities you would like to see in a women's health research website. Then I would like you to cross out 1-2 pictures that represent qualities you would NOT like to see in a women's health research website.

Under each picture you choose, please write a very brief reason why you chose that picture.

Remember that the pictures you choose are symbolic and represent qualities about a women's health research website and not actual pictures for the website.
[Moderator demonstrates the activity.]

I'll give you a few minutes to choose and once you are done we will discuss why you chose each picture.

[Wait for everyone to complete her collage.] Let's talk about which pictures you each chose and why.

Is there anything else you would like to share before we end the group discussion?

Thank You and Closing

The moderator will conclude each session by thanking participants for offering their opinions and suggestions.

Participant questionnaire (5 minutes)

The moderator will pass out questionnaire, read instructions out loud and answer any questions.

Participant Questionnaire

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1. When you look for health information, where do you go? (Check all that apply)
    _____ Books
    _____ Brochures, pamphlets, etc.
    _____ Organization
    _____ Family
    _____ Friend/Co-Worker
    _____ Health care provider
    _____ Internet
    _____ Library
    _____ Magazines
    _____ Telephone information number (1-800-Number)
    _____ Complementary or alternative practitioner
    _____ Other: _____
    _____ Do not look or go anywhere

2. How often do you find general information via the following channels?
    _____ Print: [never, sometimes, often, always]
    _____ Web: [never, sometimes, often, always]
    _____ Mobile sites: [never, sometimes, often, always]
    _____ Mobile apps: [never, sometimes, often, always]
    _____ Social media: [never, sometimes, often, always]

3. Would you use a mobile version of a website on women's health research?
    _____ Yes
    _____ No

4. The most recent time you looked for health information was it for:
    _____ Yourself
    _____ Someone else you care for or take care of, such as a spouse/partner, child,
           parent, relative, or friend

_____ Both?

5. In the past 12 months, have you done the following things while using the Internet? (Check all that apply)
     _____ Bought medicine or vitamins on-line?
     _____ Participated in an on-line support group for people with a similar health or medical issue?
     _____ Used Email or the Internet to communicate with a doctor or a doctor's office?
     _____ Used a Web site to help you with your diet, weight, or physical activity?
     _____ Looked for a healthcare provider?
     _____ Downloaded information to a portable device, such as an iPod, cell phone, or tablet?
     _____ Visited a "social networking" site, such as "Facebook" or "LinkedIn"?
     _____ Wrote in an online diary or "blog" (i.e., Web log)?
     _____ Kept track of personal health information, such as care received, test results, or upcoming medical appointments?
     _____ Listened to a pod or web cast about health information?

6. About how often do you use the Internet?
     _____ Several times a day
     _____ About once a day
     _____ 3-5 days a week
     _____ 1-2 days a week
     _____ Every few weeks
     _____ Less often
     _____ Never
     _____ Don't know/refused

7.   As I read the following list of items, please tell me if you, personally, happen to have each one, or not.
     _____ A desktop computer
     _____ A laptop computer
     _____ A cell phone
     _____ A 'smart' mobile phone, e.g., an iPhone, Droid, or Blackberry
     _____ A tablet computer, e.g., an iPad or Kindle
     _____ A personal digital device, like a Sidekick, Palm Pilot or Blackberry
     _____ An iPod or other MP3 player

Consent Form

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Public reporting burden for this collection of information is estimated to average 90 minutes per response, including the time for reviewing instructions, searching existing data sources, gathering and maintaining the data needed, and completing and reviewing the collection of information. **An agency may not conduct or sponsor, and a person is not required to respond to, a collection of information unless it displays a currently valid OMB control number.** Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden, to: NIH, Project Clearance Branch, 6705 Rockledge Drive, MSC 7974, Bethesda, MD 20892-7974, ATTN: PRA (0925-0476). Do not return the completed form to this address.

___

I, _____, agree to take part in this focus group study.

I understand that I do not have to be in this study. I can leave at any time without penalty. I can agree to be in the study and then change my mind later.

I allow the National Institutes of Health (NIH) to use the information from this study. I understand that the information is for research only, and that my name will not be shared with anyone else.

I agree to ask questions about the study if I don't understand something. If I have questions after the study is over, I can contact Ana Tellez at talk@communicatehealth.com or at 413-582-0425.

Audio Recording Release

I understand that I will be audio recorded during this study. I allow NIH to use the recordings of me for research purposes only. I understand that my name will not be used for any other purpose.

I give up any rights to the recording and understand the recording may be copied and used by NIH without my permission.

Summary

I have read and understood this consent form. I understand that I will get a copy of this form.

Print Name: _____

Signature: _____

Date: _____

Ranking Activity

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Women's Health Research Information List

- Latest women's health research news

- Health topic: Complementary/Alternative medicine

- Current women's health clinical trials

- How to join a clinical trial

- Clinical trial results

- Press releases

- Health topic: Violence against women

- Impact of research on new treatments

- Impact of research on new testing methods

- Detailed information on specific health topics

- Health topic: Substance abuse

- Research information specific to different age groups

- Research information specific to difference ethnic/racial groups

- Health topic: Autoimmune diseases
- Women's Health related events at NIH
- How to contact someone about women's health questions at NIH
- Health topic: Heart disease
- Twitter or Facebook page for NIH women's health research
- Info about who NIH is as an agency
- Health topic: Reproductive health
- Links to other government agencies
- Links to other women's health research websites
- Women's health research conference information
- Health topic: Cancer