National Library of Medicine <u>WHR Professionals Focus Group Survey</u>

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.

Participant Questionnaire

- 1. What is the highest level of education you have completed?
 - _____ Grade school
 - _____ Less than high school graduate/some high school
 - ____ High school graduate or completed GED
 - _____ Some college or technical school
 - _____ Received four-year college degree
 - _____ Some post graduate studies
 - ____Received advanced degree
 - ____ Other: ___
- 3. 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
- 4. 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]

5. Would you use a mobile version of a website on women's health research?

- _____Yes
- _____ No
- 7. Which types of information have you searched for online in the past 12 months? (Check all that apply) ______ Clinical trials
 - _____ Research funding
 - Pharmaceutical information
 - _____ Diagnostic testing
 - _____ Journal/peer-reviewed article
 - Health focused government agency website
 - _____ Legislation or policy related to health
 - Complementary/alternative medical treatments
- 8. 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
- 10. Do you have one or more of the following? (Check all that apply)
 - _____ 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
 - _____ An iPod or other MP3 player
- 11. Have you ever used any professional networking sites?
 - Yes
 - If so, please list the sites you have used
 - No
- 12. Please tell me your race or ethnic background. Are you? (Check all that apply)
 - Ethnicity:
 - Hispanic or Latino
 Not Hispanic or Latino

Race:

- _____ White
- _____ Black or African-American
- _____ American Indian or Alaska Native
- _____ Native Hawaiian or Other Pacific Islander
- _____ Asian

Welcome/Opening Remarks

[The moderator will greet everyone as people join the session remotely.]

Thank you for joining us today. My name is ______ I will be facilitating this discussion group on behalf of the National Institutes of Health's (NIH) National Library of Medicine (NLM). NLM will be redesigning the Women's Health Resources Web Portal – a website that provides information and resources related to women's health and sex differences research. A portion of the information on the website is aimed at [indicate audience group – researchers, advocacy group members, media professionals]. We are conducting research on the information needs of the various types of users that visit the NLM Women's Health Resources Web Portal.

The ideas and information you share with us are very important. What you tell us today will help us better understand the unique information needs of professionals in your field when it comes to women's health research. 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 <u>not</u> 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 90 minutes. 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.

[The moderator will refer to previously emailed informed consent form, saying:]

Your participation in this discussion is voluntary. You may stop the discussion at any time. Your name will NOT be used in any report.

Has everyone read, signed, and returned the consent form that was previously emailed to you? [Get a "yes" from all participants before continuing.]

[The participants will be emailed the informed consent statement form 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

First, let's go around and introduce ourselves. Tell us:

- a. Your first name (only)
- b. One thing you do in your job or advocacy work that is related to women's health research

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

- What comes to mind when you think about women's health?
- What comes to mind when you hear the phrase 'women's health research'?
- Have you heard of sex differences research before? If so, what do you know 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

Now we're going to start talking 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.

[For all researchers]

- In what way is research about women's health important to you as a researcher?
- Where do you usually go to find research information?
- What is most important about a research area or study that you need to know for your job as a researcher (such as methodology, effects of treatments, participant characteristic, etc.)? Why?
- If a publication came out detailing the findings of a new study, what would you need to know to help you apply it to your work?

[For women's health researchers only]

- What specific women's health topics within your research area of expertise are important to you? Why?
- Where do you usually go to get the information about women's health research?
 - o What do you like about the sources you use?
 - o What do you dislike about the sources?
 - o Have you ever searched for health research using a mobile device?
- What types of materials/information do you find most useful? Why?
 - o What organizations, sources, or sites do you trust when looking for information?

[For non-women's health researchers only]

- Is there a particular women's health research area topic that you think is important to your work? Why?
- Where do you usually go to get the information about health and biomedical research?
 - o What do you like about the sources you use?
 - o What do you dislike about the sources?
 - o Have you ever searched for health research using a mobile device?
- What types of materials/information do you find most useful? Why?
 - o What organizations, sources, or sites do you trust when looking for information?

[For advocacy group, and media/communication participants]

• Is women's health research important to you? 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 research.
- Do you ever search for information on women's health research as part of your work?

[If Yes:]

- What information are you typically looking for?
- How frequently do you look for or read about this type of research?
- What type of information is most important to you about this type of research? For example, rigor of the study, funding sources, type of health condition, age or specific characteristics of the women included, etc. Why?
 - o Is there a specific population of women you think is important? Why?
- Can you tell us about the last time you searched for women's health research information?
 o How did you find the information you were looking for?
 - o How did you use the information you found?
- Where do you usually go to get the information about women's health research?
 - o What do you like about the sources you use?
 - o What do you dislike about the sources?
 - o Have you ever searched for health research using a mobile device?
 - o Have you ever used a social media website to search for health information?
- What types of materials/information do you find most useful? Why?
 - o What organizations, sources, or sites do you trust when looking for information?

[If No:]

- What type of health research do you use or read about for you work?
- Do you ever read about other types of research as part of your work? If so, what types?
- How do you think women's health research relates to the work you do as a [insert role per target audience]?
 - What about women's health is important to your work as a [insert field for target audience]? Why?

Information Ranking Activity

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

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 a sheet of paper, write down the 3 items that are the most important to you in your work and 3 items that are the least important to you in your work. 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?
 - o Out of the 2-3 items you wrote down as important, put a star next to the item that is the most important to your work. Why did you star that item?
- Which type of information is the least important and why?

- o Out of the 2-3 items you wrote down as not important, put an X next to the item that is the least important to your work. 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?

Thank You and Closing

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

Participant Questionnaire

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