Attachment 1: Group Interviews Moderator's Guide
for Patients, Leaders, Caregivers, and Promotoras
Phase II

Group 1: Patients

Thank you for agreeing to participate in this group interview. You have been invited here today, because we are trying to understand what is the most important information to provide to newly diagnosed women with cancer, the best ways to provide that information, how to help people make informed decisions, and what we can do to empower patients in their care experiences. Your thoughts are greatly appreciated and will help us to improve our communication model.

In order to help us track all your responses, we'd like to record our conversation. The recording will be transcribed and reviewed but you will not be identified. All your comments will be kept private under the Privacy Act.

Educational needs and access

1. Thinking back to when you were first told about your diagnosis, what kind of information do you think is the most important? What would be the best way to receive this information?

2. What kind of information would you want to have from the time the diagnosis was first considered to when treatment is started? (e.g. treatment options, treatment side-effects, etc)

3. What kind of services and resources did you find most helpful during your treatment? (e.g. support groups, coping strategies, patient education materials, coordinated transportation, reminders, easy access to medical plan and meds, etc) (Internet, paper, doctor, nurse, friend, etc)?

Site Demonstration:

We have developed a computer program/website for women with cancer to use as a tool to access important information related to treatment, support groups, educational materials, etc. For example, the site includes video clips, FAQs (e.g. what is chemo?), patient education materials, and a way to communicate with providers. We are also adding a feature where you can report your symptoms and a nurse would contact you if you report moderate to severe symptoms. By regularly assessing your symptoms, different levels of help can be provided (from automated information to a personal call).

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What do you think? Do you have access to a computer?

System functionality and usability

1. Do you think this would be useful for you?

2. How would you feel about using such a tool to have your symptoms monitored, and to communicate with a nurse or physician when things became more difficult?

3. Would you like to see additional content? What other topics do you think are important to include?

4. What do you think about the design, colors, and layout?

5. What do you see yourself using the most on this site? Are there any other features you would like us to include?

6. What do you think are the strengths and weaknesses of using a computer program to provide patients with information?

7. What name would you give to this site?

8. Good communication between doctor and patient is important. What challenges do you think patients face when talking with their doctors? What can we do, through this computer program, to help you communicate with your healthcare team?

Group 2: Leaders of Women's Cancer Organizations

Thank you for agreeing to participate in this group interview. You have been invited to participate because you are someone who has held a leadership position for a women's cancer organization. We are trying to understand what is the most important information to provide to women recently diagnosed with cancer, the best ways to provide that information, what we can do to help people make an informed decision, and how we can empower the patient/family in this care experience. Your thoughts are greatly appreciated and will help us as we continue to draft a model that can improve the patient's channels of communication.

In order to help us track all your responses, we'd like to record our conversation. The recording will be transcribed and reviewed but you will not be identified. All your comments will be private under the Privacy Act.

Educational needs and access
1. How long have you been a part of a women's cancer organization? What do think are some of the most important educational needs among women served by your organization?

2. What is the most important information needed after diagnosis? During treatment? Survivorship issues? (e.g. treatment options, treatment side-effects, etc)

3. What are some of the most effective ways to deliver this information?

4. What are some of the services and resources most useful for women served by your organization? (e.g. support groups, transportation, educational materials, internet, etc.) How do women find these resources?

Site Demonstration:
We have developed a computer program/website for women with cancer to use as a tool to access important information related to treatment, support groups, educational materials, etc. For example, the site includes video clips, FAQs (e.g. what is chemo?), patient education materials, and a way to communicate with providers. We are also adding a feature where patients can report their symptoms and a nurse would contact them if they report moderate to severe symptoms. By regularly assessing their symptoms, different levels of help can be provided (from automated information to a personal call). What do you think? Do you think this is accessible to the women served by your organization? Do they have access to a computer and the internet?

System functionality and usability
1. Do you think this would be useful for the women served by your organization?
2. How would women feel about using such a tool to have their symptoms monitored, and to communicate with a nurse or physician when things became more difficult?
3. Do you think we need to add more content? What other topics do you think are important to include?
4. What do you think about the design, colors, and layout?
5. What do you see women using the most on this site? Are there any other features you would like us to include?
6. What do you think are the strengths and weaknesses of using a computer program to provide patients with information?
7. What name would you give to this site?
8. Good communication between doctor and patient is important. What challenges do you think patients face when talking with their doctors? What can we do, through this computer program, to help you communicate with your healthcare team?

<u>**Group 3: Caregivers**</u>

Thank you for agreeing to participate in this group interview. You have been invited to participate because you give or have given care to a woman with cancer. We are trying to understand what is the most important information to provide to women diagnosed with cancer, the best ways to provide that information, what we can do to help people make an informed decision, and what we can do to empower patients (and caregivers) in their care experience. Your thoughts are greatly appreciated and will help us as we continue to draft a model that can improve the patient's channels of communication.

In order to help us track all your responses, we'd like to record our conversation. The recording will be transcribed and reviewed but you will not be identified. All your comments will be kept private under the Privacy Act.

Educational needs and access
1. Thinking back to when the person you care for was diagnosed, what type of information would you liked to have had to provide to the patient? Do you remember the information needed at the time? How about during treatment? Any survivorship issues you had questions on?
2. What do you think are some of the most effective ways to deliver this information to patients and their caregivers?
3. What are some of the services/ resources that you have seen most useful during the time of diagnosis and treatment? (e.g. support groups, transportation, educational materials, internet, etc.) How do women find these resources?

Site Demonstration:
We have developed a computer program/website for women with cancer to use as a tool to access important information related to treatment, support groups, educational materials, etc. For example, the site includes video clips, FAQs (e.g. what is chemo?), patient education materials, and a way to communicate with providers. We are also adding a feature where patients can report their symptoms and a nurse would contact them if they report moderate to severe symptoms. By regularly assessing their symptoms, different levels of help can be provided (from automated information to a personal call). What do you think? Do you think this is accessible to the patient you care for? Does she have access to a computer and the internet?

System functionality and usability
1. Do you think this would be useful for her?
2. How would she feel about using such a tool to have their symptoms monitored, and to communicate with a nurse or physician when things became more difficult? Do you think you could help record these symptoms?
3. Do you think we need to add more content? What other topics do you think are important to include?
4. What do you think about the design, colors, and layout?
5. What do you see women using the most on this site? Are there any other features you would like us to include? **Any other features you would like to use as a caregiver?**
6. What do you think are the strengths and weaknesses of using a computer program to provide patients with information?
7. What name would you give to this site?
8. Good communication between doctor and patient is important. What challenges do you think patients face when talking with their doctors? What can we do, through this computer program, to help you communicate with your healthcare team?

<u>**Group 4: Promotoras**</u>

Thank you for agreeing to participate in this group interview. You have been invited to participate because you are a promotoras/community health worker who currently gives or has given support to women diagnosed with cancer. We are trying to understand what is the most important information to provide to women recently diagnosed with cancer, the best ways to provide that information, what we can do to help people make an informed decision, and how we can empower the patient/family in this care experience. Your thoughts are greatly appreciated and will help us as we continue to draft a model that can improve the patient's channels of communication.

In order to help us track all your responses, we'd like to record our conversation. The recording will be transcribed and reviewed but you will not be identified. All your comments will be kept private under the Privacy Act.

Educational needs and access
1. As a promotora, what are the most common questions you are asked when a woman is recently diagnosed? How about question regarding treatment? Survivorship?
2. Do you know where to find information on the questions they ask you? What information resources have been most useful to you? Was the internet helpful?
3. What are some of the services/ resources that you have seen most useful during the time of diagnosis and treatment? (e.g. support groups, transportation, educational materials, internet, etc.) How do women find these resources?

Site Demonstration:
We have developed a computer program/website for women with cancer to use as a tool to access important information related to treatment, support groups, educational materials, etc. For example, the site includes video clips, FAQs (e.g. what is chemo?), patient education materials, and a way to communicate with providers. We are also adding a feature where patients can report their symptoms and a nurse would contact them if they report moderate to severe symptoms. By regularly assessing their symptoms, different levels of help can be provided (from automated information to a personal call). What do you think? Do you think this is accessible to the women you serve? Would they have access to a computer and the internet?

Basic System functionality and usability
1. Do you think this would be useful for the women you serve?
2. How would they feel about using such a tool to have their symptoms monitored, and to communicate with a nurse or physician when things became more difficult? Do you think you could help record these symptoms?
3. Do you think we need to add more content? What other topics do you think are important to include?
4. What do you think about the design, colors, and layout?
5. What do you see women using the most on this site? Are there any other features you would like us to include?
6. What do you think are the strengths and weaknesses of using a computer program to provide patients with information?
7. What name would you give to this site?
8. Good communication between doctor and patient is important. What challenges do you think patients face when talking with their doctors? What can we do, through this computer program, to help you communicate with your healthcare team?