

# Appendix 1: *For Patients Website* Interview Guide

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## INTRODUCTION

Hi, *name of participant*. My name is \_\_\_\_\_ and I'm with FDA's Patient Affairs Staff. I'm going to be walking you through this session today.

Before we begin, I have some information for you, and I'm going to read it to make sure that I cover everything. We're asking patients, caregivers and advocates to use our website and give us your feedback. The session should take approximately 60 minutes.

First, I want to share that we're testing the website, not you. You can't do anything wrong here. We want to know your thoughts and opinions on everything. Also, please don't worry that you're going to hurt our feelings. We're doing this to improve the website, so we need to hear your honest reactions.

As you use the website, I'm going to ask you as much as possible to try to think out loud: to say what you're looking at, what you're trying to do, and what you're thinking. This will be a big help to us.

When we are done getting feedback from all website testers, we will combine all the feedback into a recommendations report. Your name will not be used in connection with your thoughts and feedback. Based on your feedback and all the other participants, the Patient Affairs Staff will make updates to our website so it is more "patient friendly."

If you have any questions as we go along, just ask them. I may not be able to answer them right away, since we're interested in how people do when they don't have someone sitting next to them to help. But if you still have any questions when we're done, I'll try to answer them then. And if you need to take a break at any point, just let me know.

With your permission, we're going to record what happens on the screen and our conversation. The recording will only be used to help us figure out how to improve the site, and it won't be seen by anyone except the people working on this project. Once we review everything and the project is finished, we will destroy the recording.

Now that you know more about the project and what you will do, would you mind reviewing and signing a permission form? It says that we have your permission to record you, and that the recording will only be seen by the people working on the project.

Thank you for signing our permission form in advance and allowing us to record this session. *(If any observers)* Also, there are a few FDA staff observing this session online. *Insert first name(s) of observer(s)* are observing today.

Do you have any questions so far?

If I were to tell you that FDA has a website for patients, what type of information would you expect to see? What type of actions would you expect to be able to take on this website? *(e.g., request information, post a comment, sign up for meetings, etc.)* What tasks might you be able to complete on the website?

We often use the term "patient engagement". What does that term mean to you? Is there a better term we can use to capture the idea of having patient involvement and input in the regulatory process?

OK, great. We will begin now.

## **WEBSITE REVIEW AND FEEDBACK**

*Click on the bookmark for the **For Patients** website.*

Just look around the website and share your initial thoughts with me out loud. For example:

- First, I'm going to ask you to look at this page and tell me what would you click on first? *(30 seconds max.)*
- OK. Now let's look around the page a little more. You can scroll if you want to, but don't click on anything yet. Briefly, what do you think the purpose of this site is? *(30 seconds max.)*
- What interests you the most? Why?
- What might you be able to find on this website?
- Why would someone come to this website?
- Do you see someone like you using this website? Why? Why not? Who also might use this website?
- What do you think of the overall look and feel of the website? What do you like/what could be improved?

*Below are some additional questions/prompts (if necessary).*

- Can you identify with the images and visuals on the page? Why or why not? Do the visual elements help reinforce the information presented? Why or Why not?

- How does the organization of the (content, layout?) seem to you? Does the website seem well organized at first glance? If not, what might help with organization or layout of the website?
- Does any information appear to be missing? Anything else you think should be added?

## **WRAP UP**

Thank you, your insights today were very helpful. If you'll excuse me for a minute, I'm just going to see if the people on the team have any follow-up questions they'd like me to ask you. *Check to see if the observers have any additional questions. Ask the observers' questions, then probe anything you want to follow up on.*

Do you have any final questions for me? Anything else you'd like to share with us regarding the website? We appreciate you helping us with this important project and providing your honest opinions. It's feedback like yours that helps FDA improve our website. Thanks again for your time today. If you think of any additional information you'd like to share or have any questions, please contact us [patientaffairs@fda.gov](mailto:patientaffairs@fda.gov).