

Patient/Parent Guide

Interview Guide | May 2021 | Duchenne's Interactive Tool

About

The Live Well team is currently in the process of creating an interactive tool for PPMD patients and families. We wanted to ask you a couple of questions and gain insights to help us better understand Duchenne's and the appropriate content for it.

Activity 1 (30 minutes) | Introduction

To get started, we would like to understand a little bit more about you, your lifestyle and how you've adapted to life with Duchenne's.

1. Tell us a little bit about your story/background.
2. How old are you?
3. What kinds of assistive devices do you use to view websites and digital content?
 - 3.1. Are there any plugins or extensions you install to make sites more accessible and easier to use?

Activity 2 (20 Minutes) | Wireframe Testing

Intro: We've developed a rough prototype that we'd like to get your feedback on. This is a working prototype so as we walk through it with you, think out loud about the changes you would want to make based on your journey/experiences, your initial thoughts and how you would go about navigating the screens.

Figma clickthrough questions for each screen:

1. Initial thoughts? What do you see?
2. What do you think the purpose of this page is?
3. What information are you drawn to right away? Where would you click first? Why?

Wireframe Probes:

1. Currently the content is organized by age, what are your thoughts on that? Is there a different way you would want to see content organized by? (Linear vs. non-linear?)
2. How would you feel if there were testimonials where patients and families share their experiences with different treatments?
 - 2.1. What kind of information would you want to hear from other patients?
 - 2.2. Where have you looked for advice from other people? What kind of groups/community things are you involved with relating to Duchenne?

Content Mapping and Card Sorting

Intro: We've collected some of the topics and themes we have heard in conversations with men with Duchenne and we'd like to get a better understanding of how you would sort or categorize them based on your own understanding.

Open the Miro card sort section and ask them to take a few minutes to read over the cards.

1. Any initial questions/thoughts/feedback?
2. How would you begin to sort and categorize these cards?
3. Are there cards that you feel should be added?
4. Is there any information you feel like shouldn't be included? What cards are low priority to you?

Additional Probes:

5. When you were diagnosed, where did you turn for information or resources?
 - 5.1. For someone who just received a diagnosis, what resources would you recommend to them? Why?
 - 5.2. Looking back, how has that changed?
 - 5.3. Are there any resources you wish you had during this process and how would that have impacted your decision making process?
6. At what points did you search for things? And what were those things?

Activity 3 (10 Minutes) | Layout Ranking

Intro: Here are a few examples we've created of different ways the information could be laid out. Think back to when each of you were first looking for information. Please rank the layout types based on which would be most to least helpful. Also, think out loud about your initial thoughts and reasoning for your rankings.

Probes

1. Tell us about the last time you searched online for resources or information? What were you looking for and how did it go?
2. When you've searched online in the past, have there been any exceptionally great resources, or any frustrations that you've encountered? What were they and why?

Leftover Questions

1. What do you like to do for fun? (i.e. video games, hanging out with friends)