

## Focus Group Guide – Patient Groups

### Introduction

Thanks for taking the time to participate in this study! Today, we're interested in how your Neurofibromatosis (NF1) has affected your pain. We want to hear from you because you are the individuals living with the disease and the pain symptoms.

The information we get from you today will help us customize a mobile application for individuals with NF1. The application has been previously used to help with pain in other diseases. However, before we customize the mobile application, it is important to understand what is needed to make the application as user-friendly and attractive and useful as possible. Thus, we are asking you, the experts, what is needed in this mobile application.

We will be asking you several questions. We would like to set up a few ground rules to ensure we hear from everyone as each of your voices are important to be heard: We ask 1) that you let every individual complete their sentence before you begin speaking, and 2) please say your name before you speak.

As a reminder we will be observing and taking notes. This session will be audio-recorded so that we can go back and review what was said during the session. Please remember you are the experts, and we want to hear your open and honest thoughts.

Do you have any questions before we begin?

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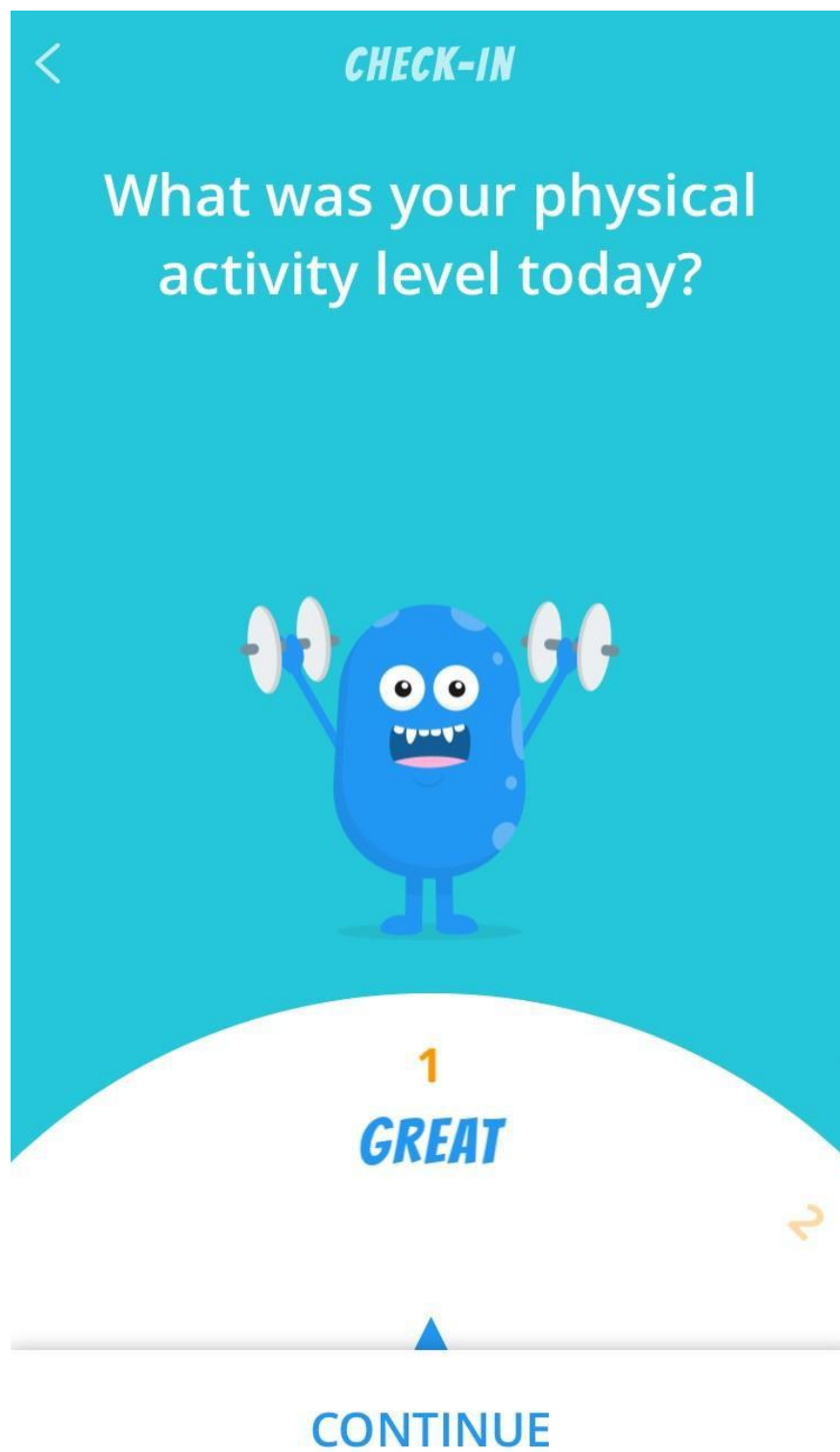
1. How many of you own a smart phone?
  - a. Do you have any experience in using applications to manage any health-related symptoms, i.e. checking your sleep patterns?
  - b. If yes, what features do you especially like and dislike in those apps
2. How would you feel about using a smart phone based app to help track and manage your pain related to NF1?
  - a. What would motivate you to use it, what key features would it need to have?
  - b. What would stop you from using it?

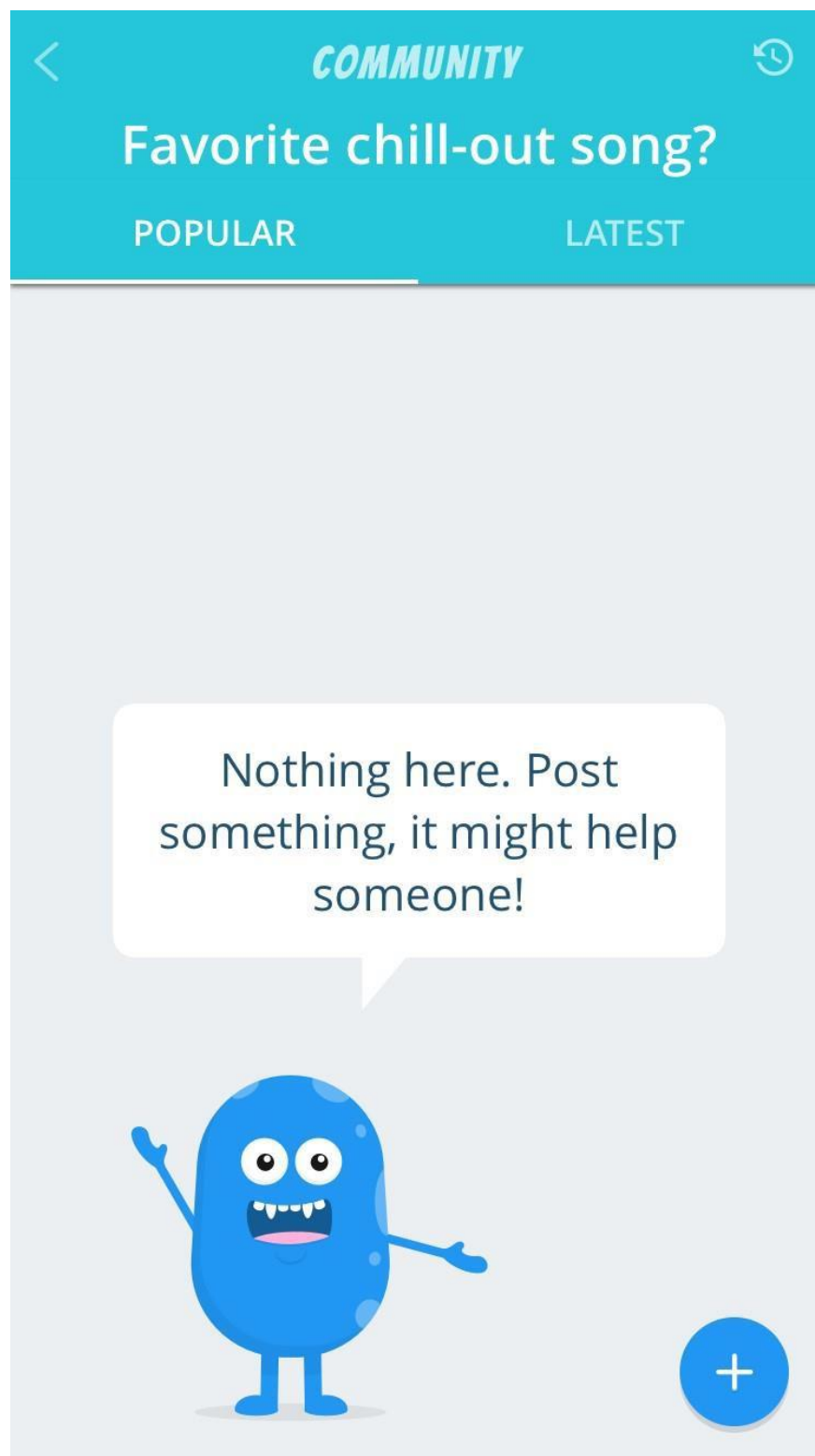
### Description of the proposed APP

- The mobile application is a customized pain self-management mobile application that is designed to empower people to better manage their pain through symptom tracking, goal setting, coping strategies, and social support. Additionally, the mobile application will provide strategies to reduce pain symptoms through empirically based treatments, i.e. yoga and stretching. **(SEE ATTACHED PICTURES)**
3. What would you envision the mobile application would be like?
    - a. What needs to be changed to make it motivating for you to use a pain-related mobile application?
    - b. In your opinion, what is the value to have a pain-related mobile application?

4. How likely would you be to use a mobile application specifically for your pain symptoms due to NF1?
  - a. Is there a situation where you would use the mobile application more regularly?
  - b. What time of day would you be most likely to use the mobile application and why?
  - c. If we were going to personalize it for you, what would you have?
5. Is there anything else you want to tell us about your pain experience and using mobile app to help track and manage your pain

**FIRST  
PICTURE**

**SECOND  
PICTURE**

**THIRD  
PICTURE**

**FOURTH  
PICTURE**

## Bridge Pose (Setu Bandhasana)

PHYSICAL

### Watch

In this video, you'll learn how to come into the bridge pose. Follow the written instructions below, or watch the video for a short demonstration.

## Focus Group Guide – Expert Groups

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We will be asking you several questions. We would like to set up a few ground rules to ensure we hear from everyone as each of your voices are important to be heard: We ask 1) that you let every individual complete their sentence before you begin speaking, and 2) please say your name before you speak.

As a reminder we will be observing and taking notes. This session will be audio-recorded so that we can go back and review what was said during the session. Please remember you are the experts, and we want to hear your open and honest thoughts.

Do you have any questions before we begin?

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I want to provide a quick overview of Neurofibromatosis Type 1 (NF1) is an autosomal dominant genetic condition affecting 1 in 2500 individuals. Multiple studies have reported over 50% of individuals with NF1 report significant pain and discomfort which can be associated with tumors, but is often not localized to a structural lesion, thus presenting treatment challenges for patients and their medical caregivers. Due to the complexity of the disorder (e.g., location, severity, number, and type of tumors), there are limited effective therapeutic options for treating pain symptomatology.

1. Can you tell me what strategies do you typically recommend to self-manage chronic pain?
  - a. Are they effective in your opinion?
2. Do you have any personal experience in using applications to manage any health-related symptoms (e.g., checking your sleep patterns)?
  - a. If yes, what features do you especially like or dislike in those apps?
3. Have you recommended using applications to manage any health-related symptoms (e.g., checking your sleep patterns)?
  - a. Did your patients take your recommendations? If no, why not?

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The mobile application is a customized pain self-management mobile application that is designed to empower people to better manage their pain through symptom tracking, goal setting, coping strategies, and social support. Additionally, the mobile application will provide strategies to

reduce pain symptoms through evidence-based treatments (e.g., yoga and stretching). **(SEE ATTACHED PICTURES)**

4. How would you feel about giving a smartphone-based app to help track and manage your clients' chronic pain?
  - a. In your opinion, is there value to have a pain-related mobile application?
5. What key features would the mobile application need to have to treat individuals with chronic pain?
  - a. What content would be needed to make this helpful for your patients?
    - i. Sleep, mood, treatment?