

## Introduction

Thanks for seeing me today. I'll ask you to tell me about the things that matter to you and the child you look after, what are the things related to your child's health and your family's support that you care about most. If you want to stop or take a rest please tell me. Is that OK?

We can start now and I will switch on this machine.

## Guide

To start can you please tell me a little about the history of your child's illness, when did you first become aware of it? And now, what do you think are your child's main symptoms and concerns? PROMPT: physical, psychological, social spiritual?

Do your care team routinely ask about these problems? Do you tell them? Does your child tell them? Why?

How about you, can you tell me what your main care and support needs are for your child?

What are your main concerns?

PROMPT: Physical, psychological, social spiritual?

Do you tell your care team? DO they ask you? Why?

How about information – do you feel you have questions you'd like answering- what and why don't you know these things yet?

What would you say matters MOST to you as carer to your child?

Do you think that the child's siblings or other children in the house are affected by the care your child needs? How? How does the sibling/other child show you what they need in terms of support? Is there anything that could be done for them? Do they get asked? What do you think they would say matters to them?

We are thinking about how to develop a simple measure that routinely asks you and your child about the main symptoms and concerns that affect people in your situation. The idea is that it makes sure you get asked about the important things, helps your care team to know where to focus their efforts, and allows us to measure how things are changing over time.

Do you think that would be useful?

How would it be best to complete this- child alone, you and child together, just you?

Which professionals do you think you'd like to complete it with? Who should have access to the information- just the care team- you, your child?

What do you think would be useful? Any challenges?

How could it be made easiest for your child to participate in the completion of the tool?

How could we best measure change- pictures, scores, iPad- what do you think would be easiest and most appealing?

If we were to ask each time if they were better or worse since last time, what words could we use?

Is there anything else you would like to tell us?

Thank you.