PROMS Study Topic Guide

The questions listed below are a guide for the researcher to use in the semi-structured interviews. The questions may differ slightly between the younger (aged 8-11 yrs) and older children (aged 12-16 yrs)

Introduction: We are doing a project about the way in which CFS/ME affects children and are very interested to hear about your experiences. We want to hear about the way in which CFS/ME has affected you and continues to affect you now, about what matters to you and how CFS/ME stops you from doing things that you would like to do. We want to ask a few questions about the questionnaires you have used and whether they are relevant. We want to understand your story.

a. Tell me about being unwell with CFS/ME.
b. How does CFS/ME affect your life?
c. What would you like to do that you are unable to do at the moment?
d. How do you know if you are feeling better?
e. How do you know if you are feeling worse?
f. How do you know if strategies are working or not working?
g. What should we measure for recovery?
h. What would you want to improve if you got better?
i. What outcome would be important to you?
   I. Seeing your friends more?
   II. Feeling better?
   III. Doing more exercise?
j. Tell me about the questionnaires you have filled in.
k. Here are some other questionnaires. Do you think they are better or worse?
l. Is there anything else that you would like to tell me about the way in which the CFS/ME affects you?

A range of prompts will be used, including:

Tell me more about that …
How did that make you feel?
How did that affect you?