

## **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?
  - I. 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?