

SUPPLEMENTARY MATERIAL

Appendix 1: Topic Guide used during qualitative interviews



Pain in Paediatric Chronic Fatigue Syndrome (CFS/ME)

Extended Qualitative Interview Topic Guide

This topic guide details the areas that will be covered in the extended qualitative interviews. The interviewer may ask additional questions during the interview to clarify information given by participants.

Prior to commencing the interview the interviewer must confirm that informed consent/assent has been given for the interview and for the audio recording.

Introduction

Thank the participant for taking part in the interview.

Explain that the interview is being done to discuss the participant's experiences of the quantitative sensory testing and that they have been asked to answer more questions about pain so that we can understand more about pain in CFS/ME.

Remind the participant that they can stop the interview or turn off the recorder at any time without giving an explanation.

Topics to be covered during the interview

Warm up:

Can you tell me about your CFS/ME
[prompts - how it started, impact on life, treatment so far]

Part A: Pain

- Can you tell me about the pain you get with CFS/ME

OR

- How would you describe the pain you get with CFS/ME
[prompts – where, what does it compare to, type of pain]
- What things that makes the pain better or worse?
- How does pain impact you?
- Does the pain affect your mood?
- What have you or your doctor tried to make the pain better?
[prompts – behavioural interventions, cognitive interventions, medications, how effective these interventions have been, length of benefit, did anything help?]

Part B: Measuring Pain

- Does your pain change or stay the same?
- Can you tell me about how your pain changes?
[prompts- over the course of a day or week, change in intensity/ how bad it is, how often you get it].
- Do you use anything to keep track of your pain and how it changes?
[prompts – such as a diary, a computer document/phone note, an app]
- How would you feel about keeping track of your pain and how it changes on a daily/weekly basis?
[prompts – using a diary, apps for example]
- Do you feel it would be helpful to track your pain?
- Tell me what you thought about the questionnaires we asked you to complete about pain
[prompts – description of modified brief pain inventory, visual analogue scale, body map, are these useful, what is missing, what would you change]
- What do you think would be a good way to measure pain in CFS/ME?
- What do you think could be done to help people understand pain in CFS/ME better?

Part C: Experiences of Quantitative Sensory Testing

- Tell me about the testing
[prompts – how they felt during testing, why they felt this way, difficult parts]
- Is there anything you think would make the testing easier or better?

- Did the testing have any effect on your CFS/ME symptoms?
[prompts – acute effects, subacute effects]
- How would you feel if we asked you to come back for more testing?

Closing the interview

Ask the participant if there is anything else that they would like to say.

Thank the participant for their time and contribution to the study.