

Appendix C: Interview Guides

Participant topic guide – worded for young people

1. Can you tell me a bit about your chronic fatigue?

Prompts: Impact on your life?

Journey before the specialist service/trial?

Previous treatment/ management to help it- what worked/ didn't work?

Provision and acceptability of patient information & recruitment process:

2. How did you hear about the study?

Prompts: What did you think when you were told about it?

What kinds of things did you like about it?

What kind of things were you/they worried about?

Online information?

3. What did you think about the information you were given about the study?

Prompts: PIS? Did you read it?, understand it?, enough information/too much?

Things missing? Seek information elsewhere (what)?

How did you find the phone calls with the research team? Any things missing, did not understand?

Online consent

4. What were you told about the treatments?

Prompts: Both FITNET & AM- what did you think? What did you already know (from where)?

Did you understand? Understand what was going to happen next?

Feelings?

5. What were the most important messages told to you by the research team?

Prompts: Treatment plan? Benefits/risks? Recordings? Recovery?

6. What did you think about having treatments allocated by randomisation, i.e. by chance?

Prompts: How do you feel about this way of deciding your treatment? Happy?

Did you wonder why this is done? Did you think you were likely to get one treatment rather than the other? Is there a better way? Why?

7. Did you discuss the study with anyone else e.g. your/their GP?

Prompts: Local CFS/ME specialist? Are you getting any advice about your/their CFS/ME from anyone else? E.g. Online? Other sources of information?

Reasons for accepting participation:

8. What did you think when you were told you got [FITNET-NHS/AM]?

Prompts: How did you feel?

Was it what you expected/wanted? Favoured a treatment?

What would you have done if allocated the other treatment? Worries?

9. What did you think about when deciding whether or not to take part in the study?

Prompts: Treatments offered? Randomisation? What did you already know? Favoured a particular treatment? Helping other people or not? Worries?

Acceptability of FITNET-NHS:

10. What were your first thoughts about following an online treatment programme?

Prompts: Did you think it would work? Any worries?

11. Tell me about the FITNET treatment you are/were receiving?

Prompts: What you expected? What has happened?

What is good/bad about it? Would you change anything about it (what)?

How are you/they doing (is it working)?

12. How are you getting on with the FITNET-NHS online chapters?

Prompts: How do you find using it? Is it age appropriate? Any technical problems? Any benefits? Worries? What do you think about modules? How do you feel about the frequency of the e-consultations? How do you feel about the advice you get? How do you feel about the homework you are asked to do? Do the modules make you feel more or less anxious, or about the same?

13. Are there any things we need to consider for people your age when using it?

Prompts: Text? Chapters? E-consultations? Homework? Advice?

Acceptability of the AM Skype Calls:

14. What were your initial thoughts about speaking to a doctor/ being treated using Skype?

Prompts: Did you think it would work? Any worries?

15. Tell me about the AM you are/were receiving?

Prompts: What you expected? What has happened?

What is good/bad about it? Would you change anything about it (what)?

How are you/they doing (is it working)?

16. How are you getting on with the video (e.g. Skype) calls?

Prompts: How do you find using it? Is it age appropriate? Any technical problems? Any benefits? Worries? What do you think about video (e.g. Skype) calls? How do you feel about the frequency of the video calls? How do you feel about the advice you get? How do you feel about the homework you are asked to do?

17. Are there any things we need to consider for people your age when using it?

Prompts: Calls? Assessments? Advice?

And finally:

18. What do you think now about being involved in the FITNET-NHS study?

Prompts: Would you do it again? Would you recommend it to a friend if they had CFS/ME? What do you think about the study for others your age?

19. Is there anything else you would like to tell me?

Prompts: About the study? Things we need to improve/ change? Taking part in research in general? Are there any questions you would like to ask?

Participant topic guide – worded for parents

1. Can you tell me a bit about [child's] chronic fatigue?

Prompts: Impact on your life?

Journey before the specialist service/trial?

Previous treatment/ management to help it- what worked/ didn't work?

Provision and acceptability of patient information & recruitment process:

2. How did you hear about the study?

Prompts: What did you think when you were told about it?

What kinds of things did you like about it?

What kind of things were you/they worried about?

Online information?

3. What did you think about the information you were given about the study?

Prompts: PIS?- read it?, understand it?, enough information/too much? Things missing? Seek information elsewhere (what)? How did you find the phone calls with the research team?- things missing, did not understand?

4. What were you told about the treatments?

Prompts: Both FITNET & AM- what did you think? What did you already know (from where)? Did you understand? Understand what was going to happen next? Feelings?

5. What were the most important messages told to you by the research team?

Prompts: Treatment plan? Benefits/risks? Recordings? Recovery?

6. What did you think about having treatments allocated by randomisation, i.e. by chance?

Prompts: How do you feel about this way of deciding your child's treatment? Happy? Did you wonder why this is done? Did you think you were likely to get one treatment rather than the other? Is there a better way? Why?

7. Did you discuss the study with anyone else e.g. your/their GP?

Prompts: Local CFS/ME specialist? Are you getting any advice about your/their CFS/ME from anyone else? E.g. Online? Other sources of information?

Reasons for accepting participation:

8. What did you think when you were told your child got [FITNET-NHS/AM]?

Prompts: How did you feel? Was it what you expected/wanted? Favoured a treatment? Would you have done if allocated the other treatment? Worries?

9. What did you think about when deciding whether or not to take part in the study?

Prompts: Treatments offered? Randomisation? What did you already know? Favoured a particular treatment? Helping other people or not? Worries?

Acceptability of FITNET-NHS:

10. What were your first thoughts about following an online treatment programme?

Prompts: Did you think it would work? Any worries?

11. Tell me about the FITNET treatment you are/were receiving?

Prompts: What you expected? What has happened? What is good/bad about it? Would you change anything about it (what)? How are you/they doing (is it working)?

12. How are you getting on with the FITNET-NHS online chapters?

Prompts: How do you find using it? Is it age appropriate? Any technical problems? Any benefits? Worries? What do you think about modules? How do you feel about the frequency of the e-consultations? How do you feel about the advice you get? How do you feel about the homework you are asked to do? Do the modules make you feel more or less anxious, or about the same?

13. Are there any things we need to consider for your child's age group when using it?

Prompts: Text, Chapters? E-consultations? Homework? Advice?

Acceptability of the AM Skype Calls:

14. What were your initial thoughts about [child] speaking to a doctor/ being treated using Skype?

Prompts: Did you think it would work? Any worries?

15. Tell me about the AM you are/were receiving?

Prompts: What you expected?

What has happened?

What is good/bad about it? Would you change anything about it (what)?

How are you/they doing (is it working)?

16. How are you getting on with the video (e.g. Skype) calls?

Prompts: How do you find using it? Is it age appropriate? Any technical problems? Any benefits? Worries? What do you think about video (e.g. Skype) calls? How do you feel about the frequency of the video calls? How do you feel about the advice you get? How do you feel about the homework you are asked to do?

17. Are there any things we need to consider for your child's age when using it?

Prompts: Calls? Assessments? Advice?

And finally:

18. What do you think now about being involved in the FITNET-NHS study?

Prompts: Would you do it again? Would you recommend it to a friend if they had CFS/ME? What do you think about the study for others your age?

19. Is there anything else you would like to tell me?

Prompts: About the study? Things we need to improve/ change? Taking part in research in general? Are there any questions you would like to ask?

Clinician topic guide

General questions about the study:

1. What is your role on the FITNET-NHS study?

Prompts: Recruitment/ treatment?

How did you come about being involved?

Previous experience of research?

2. What are your thoughts generally about the FITNET-NHS study?

Prompts: How it came about, why it's being done, evidence behind it

How do you think it's going? Expectations? Feelings? Worries?

Interventions offered?

Randomisation?

3. Can you tell me a bit about recruiting into the trial?

Prompts: Eligibility criteria: screening patients (local service, severity, complex)?

Easy/ difficult- different from clinical role?

How do you decide who should take part?

How do you introduce the trial to patients- explain uncertainty?

4. What happens after a patient gets referred to the specialist service?

Prompts: Recruitment pathway?

Referral problems?

Eligibility criteria?- screening patients (local service, severity)

Who do patients see?

Who do they talk with?

Who introduces the study?

Problems/ things that go well?

5. What do you think about the interventions [FITNET-NHS and AM] being allocated at random, i.e. by chance?

Prompts: How do you feel about this way of deciding what treatment a patient will ? Why?

How do you explain randomisation to patients?

6. How do you think the two interventions compare in terms of effectiveness?

Prompts: Feelings? Expectations? Which one works better? Worries?

7. Do you think that families might favour one of the interventions or not?

Prompts: How do you respond when patients have a preference?

Publicity affect preference?

Delivery of Interventions FITNET-NHS/AM:

8. How has it been delivering treatment via an on-line platform/Skype?

Prompts: Successes/ problems?

How have you/ patients been doing?

Is it different from delivering the interventions to older teenagers?

Feelings? Worries? Expectations?

Do you think using the FITNET-NHS online modules will increase or decrease patient/parent anxiety?

Technical problems?

9. Does delivering FITNET-NHS/ activity management differ to what you deliver outside of the study?

Prompt: Feelings about this?

10. Do you think any changes need to be made to the intervention[s]?

Prompts: How they are currently offered?

Optimal frequency of interventions, engagement, and compliance?

Acceptability of FITNET-NHS/Skype:

11. How are families getting on with the Skype calls?

Prompts: Are there any particular issues we need to consider?

Any benefits?

Worries? Patient/parent anxiety?

Technical problems?

12. Can you talk me through a recent initial appointment with a family who are new to the service?
[If applicable: some don't see new patients]

Prompts: What was said?

How was the study introduced to the patient?

How was uncertainty about the best treatment explained?

How was randomisation explained?

How do patients react to this information?

How do you respond if a patient states a preference?

Did the family have particular questions?

Did they understand what was being said?

Feelings about the session?

13. Can you talk me through a consultation that did not go as smoothly as others/was less comfortable than others?

Prompts: What was said? How was it different? Did the family have particular questions? Feelings about the session?

14. Can you talk me through the conversation you had with them about the FITNET-NHS study? [If applicable: some don't see new patients]

Prompts: How was the study introduced? What was said? Did they understand what was being said? Feelings about conversation?

General question about the study:

15. Is there anything else you would have liked to have been told about the FITNET-NHS study by the research team?

Prompts: What was this? What did you think? Who have you asked about this?

16. What do you think the FITNET-NHS study will show?

Prompts: What/who informed your views?