

CARDIOMAN study

TOPIC GUIDE (Parent/Guardian)

First interview

INTRODUCTION

My name is XXX and I am a researcher at the University of Bristol. Firstly I would like to thank you for agreeing to take part in an interview for our study. In this interview I would like to discuss your son's experience of the treatment he has been receiving over the first four months of the study and how you have found taking part in the study.

At the start of this first interview I would also like to ask you some brief questions about your experiences of the types of treatment that your son has been given since diagnosis. This will help us to get an idea of any particular issues your son and your family have personally faced in living with Barth Syndrome since diagnosis.

I understand that some of the issues you might want to talk about today might be quite personal or sensitive but I want to assure you that we will treat this discussion as confidential. If you want to stop the interview at any time just let me know.

Explain consent process and give opportunity for participant to ask questions.

TAKE WRITTEN CONSENT

1) Background/Personal experience

So first I wonder if you could just tell me a little bit about your son and about your family?

Prompts:

Age of son

Where you live

Work/school/study

2) Barth Syndrome

Could you now please tell me a little bit about your son's condition and the kind of treatment that he was receiving before the study started?

Prompts:

Diagnosis

Consultant/nurses/dietitian/psychologist

Clinic visits

Medication/experience of taking medication/any problems or difficulties – *before the study started*

3) Living with Barth Syndrome

Could you tell me about the physical impacts of Barth Syndrome for your son?

Prompts: Fatigue

Muscle weakness/body aches

Growth/size

Getting infections – *coming into hospital*

Appetite

Diarrhoea

Headache

Anything else?

What about the impact on your son psychologically?

Prompts: How do you think it makes him feel?

Does he see clinical psychologist? –*depending on prior answer at 2*

Impact on you as a parent

Anything else?

Has having Bath Syndrome had an impact on your son/family socially?

Prompts: Work

Going out socially, your social life

Exercise

Travel

Anything else?

4) Support

Do you belong to the BS support group?

Prompts: Reasons for joining/not joining

Ever been to support group meetings/go regularly

Support received

Kind of help/support you would like/any gaps

5) Experience of first four months of treatment

How has your son felt during the first four months of the new treatment?

Prompts:

Physically – any changes over the four months

[Follow up on issues mentioned at (3)]

Improvements/problems

Coping with any changes

Psychologically – any changes over the four months

[Follow up on issues mentioned at (3)]

Improvements/problems

Coping with any changes

Has your son experienced any problems with the new medication?

Prompts:

Side effects – diarrhoea/loss of appetite/any other side effects

Taste/size/ease of swallowing

Fitting into daily routine

Taking with other medication

Remembering to take it

Any concerns about taking the new medication

How long willing to take it for – permanently?

Is there anything else you would like to say about the first four months of treatment?

6) Anything else?

Are there any issues we haven't covered that you would like us to include when we write up our report?

7) Thanks and arrangements for next interview

CARDIOMAN study

TOPIC GUIDE (14+/adult)

First interview

INTRODUCTION

My name is XXX and I am a researcher at the University of Bristol. Firstly I would like to thank you for agreeing to take part in an interview for our study. In this interview I would like to discuss your experience of the treatment you have been receiving over the first four months of the study and how you have found taking part in the study.

At the start of this first interview I would also like to ask you some brief questions about your experiences of the types of treatment you have been given since your diagnosis. This will help us to get an idea of any particular issues you have personally faced in living with Barth Syndrome since your diagnosis.

I understand that some of the issues you might want to talk about today might be quite personal or sensitive but I want to assure you that we will treat this discussion as confidential. If you want to stop the interview at any time just let me know.

Explain consent process and give opportunity for participant to ask questions.

TAKE WRITTEN CONSENT

1) Background/Personal experience

So first I wonder if you could just tell me a little bit about yourself?

Prompts:

Age

Where you live

Work/school/study

2) Barth Syndrome

Could you now please tell me a little bit about your condition and the kind of treatment that you were receiving before the study started?

Prompts:

Diagnosis

Consultant/nurses/dietitian/psychologist

Clinic visits

Medication/experience of taking medication/any problems or difficulties – *before the study started*

3) Living with Barth Syndrome

Could you tell me about the physical impacts of Barth Syndrome for you?

Prompts: Fatigue

Muscle weakness/body aches

Growth/size

Getting infections – *coming into hospital*

Appetite

Diarrhoea

Headache

Anything else?

What about the impact on you psychologically?

Prompts: How does it make you feel?

Do you see clinical psychologist? –*depending on prior answer at 2*

Anything else?

Has having Bath Syndrome had an impact on you socially?

Prompts: Work

Going out socially, your social life

Exercise

Travel

Anything else?

4) Support

Do you belong to the BS support group?

Prompts: Reasons for joining/not joining

Ever been to support group meetings/go regularly

Support received

Kind of help/support you would like/any gaps

5) Experience of first four months of treatment

How have you felt during the first four months of the new treatment?

Prompts:

Physically – any changes over the four months

[Follow up on issues mentioned at (3)]

Improvements/problems

Coping with any changes

Psychologically – any changes over the four months

[Follow up on issues mentioned at (3)]

Improvements/problems

Coping with any changes

Have you experienced any problems with the new medication?

Prompts:

Side effects – diarrhoea/loss of appetite/any other side effects

Taste/size/ease of swallowing

Fitting into daily routine

Taking with other medication

Remembering to take it

Any concerns about taking the new medication

How long willing to take it for – permanently?

Is there anything else you would like to say about the first four months of treatment?

6) Anything else?

Are there any issues we haven't covered that you would like us to include when we write up our report?

7) Thanks and arrangements for next interview