

Bone & Joint Open



Supplementary Material

Material 1. BASIS Communication Study – topic guide for parents/guardians

The list of questions below are just indications of the sorts of topics we plan to explore. We will always tailor questions for each person depending on their situation (e.g. whether the family participated in BASIS or not) and what is important for them as an individual.

As we interview more people over the course of the study and learn what questions are the most important to ask, we will usually refine or change questions.

Setting the scene

- 1. How is [child's name] doing at the moment?**
- 2. What led to [child's name] receiving a brace?**

Prompts: When did you/[child's name] first realise there was a problem with her/his spine/posture? Symptoms? Duration? Pathway to seeking help? Who did you speak to? How was the scoliosis diagnosed? Did you experience any delays in receiving treatment? What was discussed around treatment prior to BASIS? If so, what did you think of those treatments that were discussed? Had you heard about bracing before? Did you expect bracing to be offered (explore why/why not/preferred treatments)? What did the doctor say about why a brace would be the best treatment option going forward?

Thoughts about the BASIS study?

- 3. What were your first thoughts about the BASIS study?**

Prompts: What was your understanding of what would be discussed at the consultation? Who first mentioned the study/how did you first hear about it? When was this? What did you think/feel when you first heard about it? Was there anything you/child liked about it – tell me about this? Was there anything you/child worried about?

How staff explained the study

- 4. I'd be really interested to hear a little more about how the doctor/nurse explained the study to you – could you talk me through this?**

Prompts: What did they tell you? What did they say was the aim of doing the study? Was there anything unclear or surprising? What questions did you have/did you ask these/were they answered? Did you feel people were able to take the time you/your child needed to decide? Were they interested in what you/your child thought thought? What other information did you get about the study – verbal and written (PIS, website with info and animations)? Did you read/watch it? What did you think of it? Did it give you the information you needed; enough information/too much? Is there anything we could do to improve how we explain the study to make it better for other patients in future? Were there things you thought they had forgotten to include? Did they say what sort of brace it would be if you decided not to take part in the BASIS study?

5. What did the [doctor/nurse] tell you about the two types of bracing in the BASIS study?

Prompts: What were your first thoughts? When did you find this out? What did they say about what day-to-day life would be like with this brace? What did you know about this type of brace before this? Depending on which brace they talk about first: What did [they] mention about the other brace? (Benefits? Risks?) [Repeat questions for other brace] Was it explained what was going to happen next? Was there anything said that wasn't very clear? Did you get an impression as to whether your doctor or nurse would have preferred you to have one brace or the other? What did you feel were the most important messages that the doctor or nurse told you about the study?

6. What did you think about how it was decided which brace your child would have in the BASIS study? (i.e. 50:50 by chance?)

Prompts: How did the doctor/nurse describe this process? How do you feel about this way of deciding what brace you get? Did you prefer the sound of one brace or the other? What about [child's name?]? Were you okay for [child] to be randomised? What did your partner think [if applicable]?

Deciding whether to take part

7. What did you think about when deciding whether to take part in the BASIS study?

Prompts: Benefits? Worries? Did you discuss it with [child]? Did you decide together as a family or did you find it best to decide for [child]? Did you feel any pressure to take part? Any other pressures? Wider family views? How long did you have to decide? Did you seek other sources of information when thinking it through? Did you have any further discussions with a member of the research /medica team before making a decision?

PARTICIPANTS [EVEN IF WITHDREW]...

8. What did you think when you were told [child's name] got [allocated arm]?

Prompts: How did you feel? Was it what you expected/wanted? Did it change your view on the brace when you were told that you got [allocated arm]? What would you have done if

allocated the other brace? *If applicable... I understand you decided to withdraw at randomisation – could you tell me about that decision?* When you were told you got [allocated arm] what were your expectations? And did you have any worries going forward?

IF WITHDREW...

9. Could I ask about how you decided to stop participating in the study [withdraw]?

Prompts: Would you tell me about what influenced your decision? Feelings? Expectations? Worries? Braces offered? Randomisation? Favoured a particular brace? What did you already know? When withdrew?

IF DECLINED...

10. Could I ask about how you decided not to take part in the study?

Prompts: Would you tell me about what influenced your decision? Timing of study? Braces offered? Randomisation? Favoured a particular brace? Personal circumstances?

Experience of brace so far

11. Can you tell me about how [child] is getting on with his/her brace?

Prompts: How was the brace and what to do with it explained to you? How did the doctor/nurse explain how it works and how it might help [child]?

How has it been on a day-to-day for [child] wearing the brace? How does that compare with what you were told/expected? How long has [child] been wearing the brace for so far? How much longer is it thought that [child] will be wearing the brace for? What do they think of the brace? What advice did you get about wearing the brace? Are there times when [child] finds it hard to wear the brace as advised by the doctor/nurse? How often is this, what happens when s/he feels like that? How have you responded to X when they are finding it hard to wear the brace? (If applicable, have you found it to cause any conflict in the family?) What advice would you give other parents whose child is being treated with a brace?

Does wearing the brace impact on [child] in any other ways at all - school, activities, clothes/appearance, being with friends, life in general, pain/discomfort, sleeping? Any other problems?

What support is available to help with these problems, or make life easier for [child]? What could be done to better support young people in wearing the brace in future? Is there anything that you have found positive about the brace so far?

Thinking about the two types of braces in the study, are there any other reasons why some children and young people might prefer one brace over the other (that we've not already mentioned)?

12. Looking to the future – what are your best hopes by having the brace?

Prompts: What would you look for to know the brace is working? Can you tell me about anything that worries you at all? If the brace doesn't work, how do you feel about further treatment, like surgery [Concerns re curve worsening]? How do you feel about the doctors following your child up on the study? Reflecting on it now, are you happy with your decision to take part or not? Would you recommend the study to a family member / friend in the same situation? Is there anything you would have liked to have known when BASIS was first discussed that you know now? Anything else we could do to improve the study for patients in future?

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

Prompts: About the study? Brace? Taking part in research in general? Are there any questions you would like to ask about this study? How would you prefer us to feed back the results?

Thank you for taking part in this sub-study!