



## Topic guide for interviewing mothers and birth partners (SOCIAL MEDIA)

### Introduction, obtaining consent and any questions

#### Demographics

- For administration reasons please could you tell me your:
  - DOB (*check that they are over 18 years*),
  - Occupation,
  - First part of post code,
  - Ethnic background,
  - How many children do you have and their ages?
  - Where you saw the study advertised?

#### Monochorionic (MC) Pregnancy Experience

*If known:* My notes from when you registered interest in taking part in this interview state that you had identical twins in (*insert month and year*). Is that correct?

- Please tell me a little bit about your pregnancy?
- When were you admitted to hospital? (*Prompt confirm gestation in weeks*)
- At what point were you made aware that there may be a problem with your pregnancy and that one of your twins was smaller than the other? (*explore how and when this was explained*).
- Who spoke to you about the problem with your pregnancy?
- Can you recall what they told you?
- How did the doctor explain the options you had at that point in time? (*Explore: What the options were and at what timepoint these were presented? (e.g. Wait and see, selective termination [cord occlusion] or laser treatment- note only one option may have been presented so amend prompts below accordingly*).
- How were you feeling at that point in time?
- What information was presented to you at that point in time to help to inform your decision? (*e.g. written information or numbers/probabilities of survival*)
- Where any potential risks discussed for the options presented? (*if so, what risks were discussed for the options presented?*)
- Where any potential benefits discussed for the options presented? (*if so, what advantages or benefits were discussed for the options presented?*)
- Did you discuss potential options with anyone else?
- What type of things did you consider when making the decision about which option to take?
- Could you tell me what happened next? (*Leave this to parent to discuss and tell as much as they would like. Ultimately, we need survival information (may already have this from background question) and how child/children are now*).

#### FERN Study (refer to draft information sheet)

Have you had chance to look at the draft participant information sheet I sent to you for the proposed FERN study? (If no- read through sheet with parent)

Based on the participant information sheet please describe your understanding of what the FERN study is aiming to do?

What are your initial thoughts about this proposed study?

Would you have any concerns about the FERN study? (*Prompt: after exploring concerns- would you raise these concerns with the nurse or doctor?*)

Would you have any questions about the FERN study?

Looking at the information sheet, are there any parts of the study design that you think parents may find difficult to understand? (*explore language/jargon*).



Are there sections of the information sheet which you would prioritise when making your decision about whether or not to consent? (*Prompt: were there any parts of the information sheet that stood out to you in terms of influencing your decision as to whether or not you would like to take part?*)

Is there anything you would find useful when deciding whether or not you would like to take part?)

What kind of support do you think you would need when deciding whether to participate or not in the trial?

Who else would you need to talk to before making your decision? (*doctors, midwives, research nurses, partner, other family members, friends?*)

Would there be any other information that you would need to help make this decision?

Would you have given your permission to take part in the FERN study?... Could you tell me a bit more about your reasons for this?

How would you feel if you were randomised to 'watch and wait' (expectant management) in the proposed FERN trial?

How would you feel if you were randomised to receive cord occlusion (selective termination) in the proposed FERN trial?

How would you feel if you were randomised to receive laser treatment in the proposed FERN trial?

*[If cord occlusion doesn't seem like a viable option],* How would you feel if the study were to only have two options – 'watch and wait' and laser treatment? Would this make you more likely to hypothetically take part in the trial?

When do you think is the best time to approach a family to discuss the FERN Study? (*Prompt: we are suggesting within 24 hours*)

How much time would you need to consider the information before making a decision about the FERN Study?

Who do you think would be the best person to approach a family and when should this person go back or call the family again? (*look into where potential participants would be*).

### Outcomes

As we have discussed, in the FERN study we want to find out the best way to manage monochorionic (MC) twin pregnancies.

To do this we will collect information *on (read through outcome measures list sent prior to interview)*. By collecting information on these main things, we hope to find out which approach to managing MC twin pregnancies should be used in the future. These are called outcome measures.

It is important that we include outcome measures that matter to parents.

Thinking about your pregnancy what would you hope the outcome of your pregnancy management would be? (*Prompt: what effect would the approach to managing your pregnancy have to be most effective?*)

- What would you be looking for as an indicator that your pregnancy was being managed well?
- What do you think about the outcome measures (*re-cap measures in the list provided*)?
- Is there another outcome measure that you think is important to families which we should be collecting information about in the FERN Study? (*prompt: present identified outcome measures based on responses to first two questions*)

Recap on outcomes measured and ask them to put in order of importance (*e.g. So far, you have mentioned x outcomes, X, Y & Z. Which would you say is the most important for this study? Second most important for this study?*)

**Finally, is there anything else you would like to say about this proposed new study?**