

ToSCiN Social Media Parent interview topic guide

Intro: My name is Tracy Mitchell and I am a researcher from the University of Liverpool. Many thanks for agreeing to help us with the design of the proposed ToSCiN trial.

Just to let you know that I am not a clinician so I may ask for more explanation during your interview.

Before we begin the interview I need to obtain your consent for the study is that ok? (*Refer to instructions at top of Participant Consent Form (re: reading 8 statements, sending a copy and consent for audio recording of this discussion).* **OBTAIN CONSENT HERE.**

You can stop the interview at any time. Before we start do you have any questions?

Section one- Parent details and experience

1.1	For administrative purposes please could you tell me: your age, occupation, first part of post code, ethnic background, number of children and their ages. Where saw study advertised.
1.2	Please could you give me an outline of how your child ended up in intensive care/ needed stoma surgery?
1.3	I have a few questions about your child's stoma experience is that ok? <ul style="list-style-type: none"> • When did your child have surgery to create a stoma (year and month of surgery and number of days/weeks after birth)? • What hospital? • What was your child's gestation at birth (e.g., how many weeks)? • What had caused the stoma? (e.g., blockage, NEC) • When was the stoma closure surgery first discussed (in days or weeks after birth)? • Were the doctors waiting for anything before they were happy for your child to have the stoma closure surgery (e.g., age/feeding/weight gain)? • When did your child have the stoma closure surgery? • How did the surgery go? • How is your child now?

Section two- Baseline Knowledge of ToSCiN

2.1	Have you had chance to look at the draft participant information sheet I sent to you for the proposed ToSCiN clinical trial? (If no- read through sheet with parent)
2.2	Based on the participant information sheet please describe your understanding of what the ToSCiN trial is aiming to do?

Section 4- ToSCiN

3.1	Talk through the draft PIS <i>Prompt:</i> Is each of these sections clear? Is there anything we need to add/ change?
3.2	Looking at the information sheet, are there any parts of the trial design that you think parents may find difficult to understand?
3.3	<ul style="list-style-type: none"> • What would you think if someone approached you about a trial like this, whilst your child was in intensive care? • What would be your initial thoughts about this proposed trial? • When do you think would be best time to be approached about the trial? (<i>Prompt, after initial response explore views on time frame proposed</i>)
3.4	Would you have any concerns about the proposed TOSCIN trial?
3.5	Would you have any questions about the TOSCIN trial?

3.6	How much time would you need to consider the information before making a decision about the proposed TOSCIN trial?
3.7	How acceptable do you feel it is to close a stoma early (e.g., 6 weeks) Please explain your answer.
3.8	How acceptable do you feel it is to close a stoma late (e.g., 12 weeks). Please explain your answer- Prompt- explore potential barriers and facilitators including timing and approach to recruitment if their child was randomised to the late arm.
3.8a	Based on your response of (6/12 weeks), how would you feel if your child had been allocated to the (other 6/12 week) arm?
3.9	Is there anything you would find useful when deciding whether or not to allow your child's participation?
3.10	Would you have given your permission for your child to take part in the TOSCIN Trial? (Prompt: <i>Could you tell me a bit more about your reasons for this?</i>)
Section 4- Outcome measures	
<p>As we have discussed, in the ToSCiN trial we want to find out when is the best time to close stomas to improve outcomes for babies.</p> <p>To do this we will collect information on outcomes (read through outcomes list sent prior to interview). By collecting information on these main things, we hope to find out which should be used in the future. These are called outcome measures.</p> <p>However, these outcomes have come from research papers and don't really give us much information on how children or families feel, or what is important to them. It is important that we include outcome measures that matter to children and their families.</p>	
4.1	Thinking about your experience of your child being admitted to NICU, what would you hope the stoma closure surgery would do to help your child? (Prompt: <i>what effect would the approach to feeding measurement have to be useful?</i>)
4.2	What would you be looking for as an indicator that your child was getting better?
4.3	What do you think about the outcome measures (<i>re-cap measures in the list provided</i>) Is there another outcome measure that you think is important to families which we should be collecting information about in the ToSCiN Trial?
4.4	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 trial? Second most important for this trial?)
Section 5- Concluding comments	
5.1	Finally, is there anything else you would like to say about this proposed trial?
5.2	If we do find that it is feasible to do a trial, would you potentially be interested in being on a parent advisory group for the trial? We would of course contact you to check this with you again as it may be some time in the future.