

Appendix 1 - Focus group / interview script

One local researcher leads the discussion with 1-5 women who were critically ill while being pregnant. Expected duration 90 minutes or until no further outcomes is identified.

1. Welcome

Welcome everyone, introduce yourself and ask every attendees to introduce themselves.

2. Introduction:

Provide attendees with the introduction and outline of the focus group:

To help patients, their family, doctors and other health professionals make decisions about treatments, we need evidence about what works best. Many previous studies of treatments in the intensive care unit did not include pregnant women or involved only a small number of pregnant patients. To assess whether treatments developed and tested by researchers actually work and are safe, researchers need to look at the effects those treatments have on patients. Researchers do this by measuring an outcome. For example, in a study of how well a new asthma treatment works, outcomes might include: a measure of how fast you can blow air out of your lungs, night time wheeze or asthma quality of life measure.

If all studies in a particular health condition used the same outcomes, they could all be compared and combined. When a set of main outcomes has been agreed for a health condition, it's called a 'core outcome set'. We aim to develop a 'core outcome set' for studies of critical illness in pregnancy, by getting consensus from an international group of doctors and patients. To develop a 'core outcome set' we need to use expertise from patients, family members as well as healthcare professionals and obtain agreement on the core outcomes. Core outcome sets need to include outcomes that are most relevant to patients and carers. If all studies for this condition, namely critical illness during pregnancy, measured and reported all these core outcomes, we could bring together all the studies to get a better understanding of which treatments are best.

The goal of this focus group is to identify outcomes important to patients and partners regarding critical illness during or soon after pregnancy. We anticipate the session will last 90 minutes. Results obtained from the focus group will be anonymized and grouped together to be analyzed and used as a starting point for the next steps of the study. All discussions will be recorded for analysis and kept until study publication when it will be destroyed. If at any time you would like to avoid answering a question, take a break or dismiss from the focus group please do so.

Ask if there are any questions and clarify.

3. Discussions about outcomes

Ask participants to describe their own experience of critical illness during pregnancy, and how this episode affected their life. Prompt for specific good and bad outcomes of this event.

Then begin focusing on opinions and outcomes:

- *When you were informed of the diagnosis of critical illness in pregnancy/postpartum period, what were the that were most important to you ?*
- *Do you remember the discussion with the physician following the diagnosis? What complications do you remember them telling you about? Did any of these complications actually occur?*
- *Do you remember being told about the effects of the critical illness on the baby? What do you remember being told about? Did any of these complications occur?*

- *What were your concerns about you're the rest of your family while you were ill?*
- *What were the concerns of your family during your illness?*

When an outcome is identified: *"Why would this outcome be considered important?"*

When no further outcome is identified: *"Are there any other outcomes that could be important for women and their family which are not related to your own experience?"*

Then explore outcome importance:

- *Which outcomes would you consider important based on your own experience?*
- *Which of these would you consider extremely important?*
- *What was your rationale behind your ranking?*
- *Which outcomes would be considered essential or core to any research studying the impact of critical illness or a therapy for critically ill pregnant women?*

4. Defining outcomes

Summarize the outcomes discussed, and explore the wording to best label and explain these outcomes. Ask participants to explain the outcomes in their own words, to understand how the phrasing may be refined.

5. Closing remarks

Do you have any further thoughts/ comments?

Thank you for participating in this focus group interview.

If you are interested in participating in the next steps of the project or you would like us to send you the results of this interview, please leave your email address on the sign-out sheet.