

Supplementary Methods S1 - Interview Guide for Patients and Family Members

Thank you for agreeing to participate in this interview this that we anticipate will take 60- 90 minutes. During this session, you will be asked a number of questions about your pregnancy/ pregnancies that you have managed. There are no right or wrong answers. The purpose of this session is to determine what health outcomes are important to you and why.

Q1. During your pregnancy (pregnancies), what health outcomes are most important to you?
[Interviewer lists all outcomes as they're mentioned]

Q2. Of the outcomes you've listed, which outcome would you consider to be most important?

Q3. (If this is outcome involves mother's health), which outcome concerning baby's health would you consider most important (and vice versa)

Q4. Why do you think this is the most important outcome?

Q5. Of the outcomes listed, which outcomes would you consider 'extremely important' to include in all future studies?

Q6. Of the outcomes listed, which outcomes would you consider 'important but not vital' to include in all future studies?

Q7. (If any of the domains captured by the systematic review are not represented in the list provided by participants), introduce each domain e.g. mental health, postpartum concerns (breastfeeding, wound healing, recovery etc.) and ask, "What about ___? Would you consider this outcome as extremely important, important but not vital or not important, and why?"
[Continue until all domains are covered]

Do you have any further thoughts/ comments?

Thank you for participating in this interview.

If you are interested we could send you the results of this study, via email, when complete.

Would you like us to do that?

[If yes, note down email address]

Supplementary Methods S2 - Interview guide for healthcare providers

1. *Icebreaker Qs*: For purposes of the recording, would you be able to tell us what your main clinical role is and for how long have you been working with pregnant women with heart disease?

Assume participants will provide some experiences they have with this population.

Potential probe

Based on experience, what are some considerations you typically have with these patients?

2. Among all the pregnant women with heart disease that you look after, which group of women are you most worried about and why? Are there certain diagnoses or circumstances that are very frequent with this group? Please share both positive and negative ones where possible.

For diagnoses or specific outcomes that may emerge:

How would you define that diagnosis? (Is there a standard definition you go by or is there a non-standard definition or threshold that you personally go by/consider?)

Assume participants will share frequent outcomes they see with this population based on their experience, and definitions where possible.

3. In studies on this group of women, which short term clinical outcomes would you consider most important to consider?

Potential prompt: Are you most worried about the mother or the baby? What are you most worried about what might happen to ____? What about the other (mother or fetus)? Are you worried about this individual as well? What outcomes are you concerned about?

4. For this condition, are there any long-term outcomes to mother and/or baby that you are worried about? Which ones?
5. What questions or concerns come to your mind when you think about pregnancy in women with the following groups of heart disease? (mention the ones that have not been mentioned already)
 - a. Coronary artery disease
 - b. Cyanotic heart disease
 - c. Valvular heart disease
 - d. Pulmonary hypertension
 - e. Heart transplant
 - f. Symptomatic arrhythmias

- g. Aortopathies
- h. Cardiomyopathy
- i. Cardiac interventions during pregnancy

6. Do you believe that pregnant women have the same concerns/questions about pregnancy with their condition as you? Could you elaborate?
7. How often do you have to make a choice between the life of mother vs. baby when you look after these women?
8. When you have to make the choice, in your mind is there a clear preference for whose health takes priority?
9. Do you get the impression that pregnant women share the same concerns as you when it comes to their pregnancy? Could you elaborate or give an example of how or how not?
10. In the literature of clinical trials and retrospective studies on pregnancy and heart disease in general, the most frequently reported maternal outcomes included: maternal mortality (n=169), arrhythmias (n=115), thrombo-embolism (n=118), maternal follow up (n=110), and mode of delivery (n=190).

Upon reflecting on one, any or all of these outcomes, what are your thoughts? Do you discuss any or most of these with patients? Which ones, and how often?
Is there any outcome you would rather NOT see on this list? Are there any maternal outcomes you think should be among the top five?

11. The most commonly reported fetal/neonatal outcomes included: preterm birth (n=143), miscarriage /abortion (n=119), neonatal death (n=100), stillbirth (n=89) and small-for-gestational-age infants (n=82).

Upon reflecting on one, any or all of these outcomes, what are your thoughts? Do you discuss any or most of these with patients? Which ones, and how often?
What would your comments be about these maternal outcomes? Is there any outcome you would rather not see on this list? Are there any maternal outcomes you think should be among the top five?

Print of tables from the updated and finished tables from the SR—allow participants time to look at the tables before providing their feedback. Outcomes will be divided into fetal/obstetrical, cardiac and “other tables.” The most commonly reported outcomes in each category will be starred on the sheet and participants will be asked to provide their feedback

specifically on these outcomes- do they believe outcome should be reported, if so what definition should be used and how should it be reported?

12. From the patient interviews there were several themes that arose (complete analysis is still pending) but these themes included: mental health, hospital resources, communication with healthcare providers and congenital heart defects in their offspring (and not any of the ones that emerged in the systematic review of studies).

We will have another print out of the these 'themes' in order for participants to have a sheet to reference during the interview and in the event that they forget what has been listed.

Does this surprise you? Why or why not? Would you like to share any thoughts on the difference in outcomes considered important by clinicians and pregnant women?

13. To sum up, and after having seen the results from the SR and hearing the themes from patient interviews do you think you would add any new outcomes to the list of outcomes you initially provided as vital to consider and measure in all studies on pregnant women with heart disease? Which one(s) would this/these be?

Expect valued outcomes, hopefully from all participants.

14. Is there anything else you would like to add?

Either silence, or some minor additions.

Thank you all for attending and participating. Let any of us know if you have any questions.