

Appendix 2: Pregnant, obstetrician, and pediatrician participant interview guides.

Pregnant participant interview guide:

Hello, my name is _____. I am a research assistant with the study. Thank you for taking the time to meet with me today. Our research team is trying to understand what pregnant women think is important in making decisions about a common treatment option for women who are at risk for preterm birth: Antenatal corticosteroid medication. Is it okay if we proceed?

Antenatal corticosteroid is a medication that may be offered to a pregnant woman if doctors believe she might deliver preterm. It's usually recommended if a woman is at risk of delivering very early (for example, more than 6 weeks early), because of a clear balance of benefits over risks, but as women get closer to term, it's unclear if the benefits of the medication still outweigh the potential risks.

Some experts think pregnant women should use this medication if they are at risk of delivering between 34-36 weeks of gestation (about 4 to 6 weeks early), while others disagree. There is controversy about this decision because different people weigh the risks and benefits of this medication differently. **We would like to understand what information patients want to help them decide whether to use this medication or not.** Your answers will help us create a tool that patients and doctors can use together to help them discuss this treatment and make the best decision for each patient.

Please answer the following questions:

1. Imagine you were told you might deliver your baby four to six weeks early. The doctor tells you that this means the baby may need some help with breathing after the delivery. The doctor also tells you there is a medication you can take before the baby is born (2 intramuscular injections, 1 day apart) to help mature the baby's lungs and prevent breathing problems.

What would you want to know about this medication?

2. The doctor tells you the medication is safe for you and can help prevent breathing problems for the baby. This might mean the baby will not have to be admitted to the special care nursery or will not have to stay in the nursery for too long. But one side effect might be that your baby will have low blood sugar after birth.

a) How would you feel after hearing this information?

b) What would you want to know about these outcomes?

c) Which risks and benefits do you think are the most important?

d) What follow up questions would you have?

3. The doctor tells you that this medication has been shown to reduce a diagnosis called Respiratory Distress Syndrome in newborns, which means breathing problems that require treatment (for example: extra medications and/or extra help with breathing after birth). Imagine that without the medication, about 11 in 100 babies born at your stage of pregnancy are diagnosed with this condition, and with the medication, 8 in 100 babies born at your stage of pregnancy are diagnosed with this condition.

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Does this difference in risk matter to you?

4. The majority of studies have not found any long-term harmful effects of antenatal corticosteroids. In very preterm infants, antenatal steroids lead to less developmental disability. But, getting weekly or biweekly antenatal corticosteroids has been linked to decreased weight at birth or in childhood, and an isolated study found that those who got biweekly steroids and delivered at term had more vision and hearing problems in childhood. Also, some animal studies have found that antenatal steroids could lead to learning changes in childhood. These study findings have made some experts concerned about the possible long-term risks of antenatal steroids, but it's still unclear if women getting one course of antenatal corticosteroids at 34 to 36 weeks of gestation really leads to any of these long-term risks.

a) How would you feel after hearing this information?

b) Would you want to know more or less information?

c) Overall, do these potential risks sound concerning to you?

5. Sometimes the information we have from studies is uncertain. When studies only have a small number of participants, we have to leave a margin for error or wiggle room around the risks we get. For example, 8 in 100 babies might be our best guess for the risk of breathing problems with the use of antenatal corticosteroids, but when we add in the wiggle room, the risk might be anywhere from 6 in 100 babies to 10 in 100 babies. In situations where we are uncertain about the exact numbers, what information would you want?

6. Do you think you would want to be involved in making this decision? Or would you prefer that your doctor makes this decision for you? Why or why not?

7. If you think you would want to be involved in making this decision...

a) What information or tools might help you make this decision?

b) Are there tools that would help you share your concerns and values with your physician when making this decision?

8. Do you have any other suggestions for how we can help women and families decide whether or not to receive this medication if they were in this situation?

Obstetrician participant interview guide:

Hello,

My name is _____. I am a research assistant with the study. The purpose of this interview is to help us understand clinician decision-making processes. Is it okay if we proceed?

Antenatal corticosteroids are routinely administered between 24- and 34-weeks' gestation to reduce neonatal respiratory and other morbidities. We are doing these interviews because in the past few years, there has been new evidence for and against the use of antenatal corticosteroids in the late preterm period (34-36 weeks' gestation).

We are trying to understand care provider perceptions regarding the decision to administer steroids in the late preterm period, ranging from 34+0 to 36+6 weeks. Part of that is talking to physicians like you about your day-to-day practice. Knowing what physicians do can help us understand what physicians feel are the most important things to consider in these clinical decisions. All the questions we are asking about are debated in the literature, so there are no right or wrong answers.

First, can you tell me about how you generally approach the decision of whether or not to use antenatal steroids?

Okay. So, now, I want to ask you some more specific questions because of research showing that the decision approach may change with gestational age. In these next questions, I'm going to ask you about specific gestational ages: 34-, 35-, and 36-weeks' gestation.

[Note: if possible, tie into their response – “As you said, the decision can really vary by gestational age. Because of that, in these next questions, I am going to ask you about specific gestational ages.”]

1. Do you routinely offer the option of antenatal steroids to women at high risk of preterm birth at the 34th week of gestation, (34+0 to 34+6 weeks)?

If yes:

a) Why do you routinely offer this?

- risks and benefits
- which are most important
- do they believe benefits outweigh the risks?

b) Are there any groups of patients or scenarios at 34+0 to 34+6 weeks in which you think the risks of antenatal steroids outweigh the benefits? (For example, situations where you wouldn't offer steroids?)

If no:

a) What are the main factors which influence your decision not to routinely offer the option of antenatal steroids to women at 34+0 to 34+6 weeks' gestation?

- risks and benefits
- which are more important
- do risks outweigh benefits

b) Would you offer antenatal steroids at 34+0 to 34+6 weeks' gestation in select cases? If so, can you describe the situations in which you would offer them?

2. How would your recommendations or patient counselling change if the patient were 35+0 to 35+6 weeks' gestation?

- Are there different risks and benefits (*specify as per previous answer*) at this gestational week?
- Does the balance of risk and benefit change?

a) Do you routinely offer antenatal corticosteroids at 35+0 to 35+6 weeks' gestation?

If yes, are there certain circumstances or situations in which you would not offer them? (Exceptions)

If not, are there certain circumstances or situations in which you would offer them? (Exceptions)

3. How would your recommendations or patient counselling change if the patient were 36+0 to 36+6 weeks' gestation?

- Are there different risks and benefits (*specify as per previous answers*) at this gestational week?
- Does the balance of risk and benefit change?

a) Do you routinely offer antenatal corticosteroids at 36+0 to 36+6 weeks' gestation?

If yes, are there certain circumstances or situations in which you would not offer them?

If not, are there certain circumstances or situations in which you would offer them?

4. Recent evidence suggests that antenatal steroids in the late preterm period reduces the risk of neonatal respiratory morbidity but increases the risk of neonatal hypoglycemia. Some researchers are also concerned about an unknown increased risk of neurodevelopmental disability. Which of these risks (short-term hypoglycemia, long-term neurodevelopment) and benefits (reduced risk of respiratory morbidity) do you think are the most important?

Why?

5. Are there any additional risks or benefits of antenatal steroids which are important to you?

6. If antenatal corticosteroids decrease the risk of Respiratory Distress Syndrome in infants born at 34 weeks' gestation from 11 in 100 to 8 in 100, would you find this risk difference meaningful?

7. We are interested to know what you think about potential long-term harms of antenatal steroids administered to late preterm gestations. To help us discuss this, I'll go over a few of the main evidence points: [show written]

Evidence that suggests long-term safety:

- The 2017 Cochrane review looking at one course of antenatal steroids did not find a difference in neurodevelopmental delay in childhood among those who got antenatal steroids compared with those who got placebo or no treatment.
- Another review published in the green journal in 2015 found that antenatal steroids led to less developmental disability, especially in very preterm infants.

Evidence that suggests long-term harm:

- A recent meta-analysis of individual participant data showed that getting repeat (weekly or biweekly) antenatal corticosteroids decreased birth or childhood weight.
- The Canadian MACS study found that those who got biweekly steroids and delivered at term had more vision and hearing problems in childhood.

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- Some animal studies have found that antenatal steroids could lead to learning changes in childhood.

[Only if needed: These study findings have made some experts concerned about the possible long-term risks of antenatal steroids, but it's still unclear if women getting one course of antenatal corticosteroids at 34 to 36 weeks of gestation really leads to any of these long-term risks.]

[Check in]: Do these points seem clear?

- Is there any other information you think is important when considering the long-term impacts of antenatal steroids? How about for those born at 34-36 weeks specifically?
- Overall, do you find this information concerning with regards to administration of one course of antenatal steroids at late preterm gestations?
- Do you think it is important for patients to hear this information to make a decision about late preterm antenatal steroids?

*(MACS: Multiple courses for antenatal corticosteroids for preterm birth. Kellie Murphy, 2008.)

8. The SOGC and ACOG have different clinical practice recommendations regarding late preterm antenatal corticosteroids. SOGC recommends them routinely up to 34+6 weeks gestation, and states that they may be administered between 35+0 and 36 + 6 weeks gestation in select clinical situations after risks and benefits are discussed with the woman and the pediatric care provider(s). ACOG recommends routine administration of antenatal steroids in the late preterm period, up to 36+6 weeks' gestation.

- What are your thoughts regarding these different recommendations?

9. In general, do you think patients want to be involved in the decision of whether or not to receive antenatal steroids? Or would they prefer their physician make the decision?

If respond, yes, they would want to be involved:

What do you think are the key factors which influence how much a patient wants to or is able to be involved in this decision?

If respond, no, they would prefer their physician make the decision:

Why do you think this is the case?

10. Would a decision tool summarizing the risks and benefits of steroids at various gestational ages, that could be used with patients, be helpful to your clinical practice in caring for those presenting at high risk for preterm birth at 34+0 to 36+6 weeks' gestation?

If yes:

- would it be helpful to have a separate tool for each gestational age week?
- what information would you like to find in this tool?
- would you want this tool to include a summary of the uncertainty around risk estimates (i.e., confidence intervals associated with risk estimates)?

If no:

a) why not?

b) would it be useful in specific contexts or for specific patients?

Pediatrician participant interview guide:

Hello,

My name is _____. I am a research assistant with the study. I have no medical expertise in antenatal corticosteroids, but I am here to collect information about clinician opinions and decision-making processes. Is it okay if we proceed?

Antenatal corticosteroids are routinely administered between 24- and 34-weeks' gestation to reduce neonatal respiratory and other morbidities. In the past few years, there has been new evidence for and against the use of antenatal corticosteroids in the late preterm period (34+0-36+6 weeks' gestation).

We would like to develop a tool that summarizes the most recent evidence to help clinicians and patients decide whether to administer steroids at late preterm gestations. As an initial step, we are trying to understand care provider perceptions regarding the decision to administer or not to administer steroids in the late preterm period, ranging from 34+0-36+6 weeks.

1. In general, do you think obstetricians are offering the option of antenatal corticosteroids to women at high risk of preterm birth at 34- (*i.e.*, 34+0 to 34+6), 35- or 36-weeks' gestation?

a) If not, why do you think this is the case?

2. Which benefits, if any, of steroid treatment at late preterm gestations do you think are important for patients to know about?

3. Which risks, if any, of steroid treatment at late preterm gestations do you think are important for patients to know about?

4. On average, do you think the benefits outweigh the risks or do the risks outweigh the benefits?

5. If antenatal corticosteroids reduce the risk of Respiratory Distress Syndrome from 11 in 100 babies born at 34 weeks' gestation to 8 in 100 babies born at 34 weeks' gestation, is this risk difference meaningful?

6. In general, do you think patients want to be involved in making a decision about this treatment option? Or do you think they prefer that their physician make the decision?

7. Are there are there some groups of patients who would not be willing or able to engage in making this decision?

8. In creating a tool to help clinicians and patients make a decision on late preterm steroids, what information would be important to include?

a) Would it be important to include information regarding the uncertainty associated with risk estimates (*i.e.*, information regarding confidence intervals)?

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