



Patient and physician informational and decisional needs for administration of late preterm antenatal corticosteroids: a qualitative study

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Complete List of Authors:	Foggin, Hannah; The University of British Columbia, Department of Obstetrics and Gynaecology Metcalfe, Rebecca; The University of British Columbia, School of Population and Public Health Hutcheon, Jennifer; The University of British Columbia, Department of Obstetrics and Gynaecology Bansback, Nick; The University of British Columbia, School of Population and Public Health Burrows, Jason; The University of British Columbia, Department of Obstetrics and Gynaecology Karacabeyli, Eda; The University of British Columbia, Department of Obstetrics and Gynaecology Shivananda , Sandesh; The University of British Columbia, Department of Pediatrics Boutin, Amelie; The University of British Columbia, Department of Obstetrics and Gynaecology Liauw, Jessica; The University of British Columbia, Department of Obstetrics and Gynaecology
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Abstract:	<p>Background It is unclear whether the benefits of antenatal corticosteroid administration at late preterm gestations outweigh potential harms, and a decision support tool may be useful for clinical decision-making. We aimed to elicit patient and physician perspectives on informational and decisional needs for late preterm antenatal corticosteroid administration.</p> <p>Methods Individual, semi-structured interviews were conducted with 20 pregnant individuals, 10 obstetricians, and 10 pediatricians in Vancouver, Canada in 2019. Interview transcripts were coded, and coded fragments were grouped in themes. Framework analysis addressed: (i) how are patients</p>

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	<p>currently counselled about late preterm antenatal corticosteroids?; (ii) what information content would patients want to know to decide on their administration?; (iii) do patients want to participate in this decision?; and (iv) would a decision support tool help decision-making, and how would patients and physicians want information formatted?</p> <p>Results</p> <p>Physician counselling practice varied in recommendations and discussion of outcomes. Pregnant study participants wanted information on the medication, respiratory distress, hypoglycemia, parent-neonate bonding, and long-term neurodevelopment. Almost all participants favored shared decision-making and a decision support tool. Responses suggested that two distinct tools would be needed: for physicians, a guide of discussion points; for patients, a presentation of treatment options. Participants desired clear descriptions of risk magnitude and uncertainty.</p> <p>Interpretation</p> <p>The informational and decisional needs elicited by our study inform patient-oriented clinical counselling for late preterm antenatal corticosteroid administration. Our findings also suggest that the creation of a decision support tool is justified for this intervention.</p>



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3 **Patient and physician informational and decisional needs for administration of late preterm**
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7 **antenatal corticosteroids: a qualitative study**
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13 Hannah Foggin, MD¹; Rebecca Metcalfe, PhD²; Jennifer A Hutcheon, PhD¹; Nick Bansback,
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16 PhD²; Jason Burrows, MD¹; Eda Karacebeyli, MD¹; Sandesh Shivananda, MD³; Amelie Boutin,
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19
20 PhD¹; Jessica Liauw, MD¹.
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26
27 ¹Department of Obstetrics and Gynaecology, University of British Columbia, Vancouver,
28
29
30
31 Canada.
32

33
34 ²School of Population and Public Health, University of British Columbia, Vancouver, Canada.
35

36
37 ³Department of Pediatrics, University of British Columbia, Vancouver, Canada.
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42
43

44 **Corresponding author:** Hannah Foggin. Email: hannah.foggin@gmail.com.
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10 Liauw contributed to data collection. Hannah Foggin, Rebecca Metcalfe, and Jessica Liauw
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13 made substantial contributions to the analysis and interpretation of data and drafted the
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17 manuscript. All authors revised the manuscript critically for important intellectual content, gave
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20 final approval of the version to be published, and agree to act as guarantors of the work.
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40 only members of the research team have access to the data.
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Confidential

ABSTRACT

Background

It is unclear whether the benefits of antenatal corticosteroid administration at late preterm gestations outweigh potential harms, and a decision support tool may be useful for clinical decision-making. We aimed to elicit patient and physician perspectives on informational and decisional needs for late preterm antenatal corticosteroid administration.

Methods

Individual, semi-structured interviews were conducted with 20 pregnant individuals, 10 obstetricians, and 10 pediatricians in Vancouver, Canada in 2019. Interview transcripts were coded, and coded fragments were grouped in themes. Framework analysis addressed: (i) how are patients currently counselled about late preterm antenatal corticosteroids?; (ii) what information content would patients want to know to decide on their administration?; (iii) do patients want to participate in this decision?; and (iv) would a decision support tool help decision-making, and how would patients and physicians want information formatted?

Results

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3 Physician counselling practice varied in recommendations and discussion of outcomes. Pregnant
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7 study participants wanted information on the medication, respiratory distress, hypoglycemia,
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10 parent-neonate bonding, and long-term neurodevelopment. Almost all participants favored
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13 shared decision-making and a decision support tool. Responses suggested that two distinct tools
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16 would be needed: for physicians, a guide of discussion points; for patients, a presentation of
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19 treatment options. Participants desired clear descriptions of risk magnitude and uncertainty.
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23 **Interpretation**

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27 The informational and decisional needs elicited by our study inform patient-oriented clinical
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30 counselling for late preterm antenatal corticosteroid administration. Our findings also suggest
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33 that the creation of a decision support tool is justified for this intervention.
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INTRODUCTION

It is unclear whether the benefits of administering antenatal corticosteroids at 34+0 to 36+6 weeks' (i.e., late preterm) gestation outweigh the harms of this treatment¹. While this treatment is associated with neonatal respiratory benefits, it is also associated with an increased risk of hypoglycemia². In addition, the absolute benefit of antenatal corticosteroids at later preterm gestations is lower than at earlier preterm gestations³. Some studies on long-term impacts suggest an association with impaired neurodevelopment^{4,5}, although there are conflicting results^{4,6,7}.

Considering the uncertainty in the balance of harms and benefits of this intervention, Canadian guidelines recommend routine administration of antenatal corticosteroids until 34+6 weeks' gestation and make the conditional recommendation 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)"⁸. In contrast, current American guidelines advise routine administration of antenatal corticosteroids until 36+6 weeks gestation⁹.

In these "grey" clinical decisions, clinicians can support informed patient decisions using decision aids^{10,11}. These tools can help physician-patient dyads make context- and preference-

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3 specific decisions. However, a crucial first step is understanding the informational and decisional
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7 needs for this treatment decision, which, to our knowledge, have not previously been explored.
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10 We refer to informational needs as the required content to decide on the intervention and format
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13 of presenting information; we refer to decisional needs as preferences for shared decision-
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16 making and utility of a decision support tool, recognizing this does not represent the full scope of
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19 decisional needs¹². We aimed to examine patient and physician decisional and informational
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22 needs when choosing whether to administer late preterm antenatal corticosteroids to pregnant
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27 individuals at risk of preterm birth.
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34 **METHODS**

35 36 37 *Context*

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40 We conducted this study in one tertiary teaching hospital in Vancouver, Canada with an annual
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43 delivery volume of over 7000 births. At this center, pregnant patients at high risk of late preterm
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46 birth are typically assessed by a general obstetrician or a maternal fetal medicine specialist.
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50 During the study period, Canadian guidelines recommended routine administration of antenatal
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53 corticosteroids to 34+6 weeks' gestation, with a conditional recommendation between 35+0 and
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3 36+6 weeks' gestation⁸. Prior to their December 2018 update, these guidelines recommended
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7 routine administration "to 34 weeks' gestation"¹⁴, which in many jurisdictions was interpreted as
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10 an upper threshold of 33+6 weeks' gestation¹⁵.

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20 We included pregnant individuals at any gestation, regardless of pregnancy risk profile, due to
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23 the unfeasibility of interviewing patients in the context of imminent late preterm birth. We also
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26 included obstetricians and pediatricians providing neonatal care. Participants were recruited by
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29 convenience sampling via posters, social media, and announcements at clinical meetings within
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34 this hospital.

35 36 37 38 39 40 *Study procedures*

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43 We aimed to conduct semi-structured, one-on-one interviews with 20 pregnant individuals, 10
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46 obstetricians, and 10 pediatricians. This sample size was planned based on saturation of concepts
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49 achieved with similar sizes in other studies of physician and patient preferences^{16,17}. We planned
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54 to extend recruitment if new concepts were still being introduced.

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7 Interview guides for each participant group (Appendix 1) were developed in conjunction with
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10 obstetricians (JB, EK, JL), a neonatologist (SS), decision scientists and qualitative
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13 methodologists (NB, RM), and perinatal epidemiologists with expertise in antenatal
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16 corticosteroids (JAH, AB). Pregnant individuals were asked to imagine a scenario in which they
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19 were at risk for late preterm birth. We reviewed the first few transcripts to ensure the interview
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22 questions elicited the participant response topics we sought, and we made minor revisions
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25 accordingly.
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34 Two study members (JL, HF) conducted the interviews in-person, at the hospital campus or
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36 another site preferred by the participant. After observing JL (at the time a clinical fellow in
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38 maternal fetal medicine) conduct two interviews, HF (then a medical student) conducted two
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41 interviews, and JL reviewed these recordings for quality. JL and HF then divided conducting the
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44 remaining interviews.
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4 At the start of each interview, the interviewer introduced herself, background in the subject, and
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7 reasons for doing the research; then participants provided written consent and completed a
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10 written questionnaire of demographic information. Only the interviewer and participant were
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13 present during each interview, and there were no repeat interviews. After each interview, audio
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16 recordings were transcribed verbatim by a transcription service, and these were reviewed for
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19 accuracy. We did not return transcripts to participants for their review. The interviewers kept
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22 written field notes after each interview.
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30 *Data analysis*

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33 We analyzed transcribed data from interviews and written data from field notes using a
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36 framework analysis¹³, whereby data were coded based on topics mapping to our study's 4 main
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39 questions: (i) how are patients currently counselled about late preterm antenatal corticosteroids?;
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43 (ii) what information would patients and physicians want to know to decide on late preterm
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46 antenatal corticosteroid administration? (i.e., information content); (iii) do patients want to
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49 participate in this decision? (i.e., decisional need); and (iv) would a decision support tool be
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3 helpful to patients and physicians, and if so, how would they want information to be presented
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7 (i.e., information format)?
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13 Three research team members (JL, HF, RM) developed a code book using field notes and a
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17 sample of interview transcripts. Initial coding took place in a group setting – with each team
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20 member coding the same transcripts independently, then discussing codes together – so that any
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23 inconsistencies, misunderstandings, or gaps in the code book could be addressed immediately.
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27 After initial coding, the remaining transcripts were divided among the three team members and
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30 coded independently. Questions arising during coding were resolved by consensus. Transcripts
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33 were coded using NVivo 12. We summarized transcript data within coded topics. We did not ask
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37 participants for feedback on summarized findings.
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44 *Ethics approval*

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47 Ethics approval was obtained from the UBC C&W Research Ethics Board (H18-03721).
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RESULTS

We interviewed 40 participants: 20 pregnant individuals, 10 obstetricians, and 10 pediatricians.

No participants withdrew after giving informed consent. Each interview lasted 30 to 60 minutes, and no new concepts emerged in the final interviews. The pregnant individuals had a range of number of prior pregnancies; however, all had a bachelor's degree or higher. The physicians had a wide range of years of clinical experience. See Table 1 for participant demographics.

We organized data into the following topics: (i) current counselling practice; (ii) preferred information content in this decision context; (iii) preference for shared decision making, and (iv) utility of a decision support tool and preferred information format. These topics are expanded below, with illustrative quotes in Tables 2-8.

Current counselling practice

Illustrative quotes are in Table 2. Among obstetricians, half stated they routinely offered antenatal corticosteroids to patients in the 34th week of gestation (34+0 to 34+6) at high risk of preterm birth. In the 35th week, most obstetricians stated they did not routinely offer antenatal

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3 corticosteroids and the remainder offered this treatment only in select clinical contexts. In the
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7 36th week, none of the obstetricians routinely offered antenatal corticosteroids.
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13 **Informational needs**

14 *General informational needs*

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20 Illustrative quotes are in Table 3. Pregnant individuals wanted clear information about outcomes
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22 associated with taking and not taking antenatal corticosteroids. Many stated they would want to
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24 know the method of administration, side effects, contraindications, interactions, mechanism of
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31 action, and cost of the medication.
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Respiratory distress and hypoglycemia

40 Illustrative quotes are in Table 4. Almost all pregnant individuals wanted to know more about the
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42 range of severity and the management of both respiratory outcomes and hypoglycemia. Many
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45 also wanted to know about nursery admissions, parent-child bonding, and likelihood of long-
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51 term complications. Many considered potential respiratory benefit to be more significant than
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3 potential hypoglycemic harm; some stated they would need more information to personally
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7 weigh these benefits and harms.
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13 All physician participants said they discuss respiratory benefits when counseling patients on late
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16 preterm antenatal corticosteroids. Some obstetricians stated they also discussed the increased risk
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19 of hypoglycemia; among pediatricians, many said it was important to discuss the management
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22 and significance of hypoglycemia, but others said the significance of this outcome was
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25 controversial. Most physicians also mentioned that patients should be made aware of possible
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28 intensive care, impacts on parent-child bonding, and long-term outcomes.
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40 *Neurodevelopment*

41 Illustrative quotes are in Table 5. After hearing a brief synthesis of evidence on the association of
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44 antenatal corticosteroids and impaired neurodevelopment, most participants said that knowing
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47 about neurodevelopmental outcomes would help them feel more informed in the decision.
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50 However, they were divided on whether they felt this information would ultimately change their
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54 decision. Notably, many participants also said it would be important to learn about these
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4 outcomes from their healthcare provider instead of coming across the information through
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7 independent research (i.e., on the internet).
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13 Physician participants similarly thought the evidence on neurodevelopmental outcomes was
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16 uncertain, noting division within their practice communities about how to interpret it, poor
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19 quality of current evidence, and difficulty in obtaining quality data on child development. About
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22 half of physicians said this outcome was difficult to counsel patients on because of the
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27 uncertainty of the evidence, but ultimately most said it should be discussed.
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34 *Perceived balance of harms and benefits*

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37 Illustrative quotes are in Table 6. We elicited participants' perceptions of the balance of benefits
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40 (neonatal respiration) and harms (neonatal hypoglycemia and long-term neurodevelopment) of
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43 antenatal corticosteroids. Around half of pregnant participants reported they felt that benefits
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46 outweighed harms because of the manageability of hypoglycemia, the uncertainty of the
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49 evidence on neurodevelopment, and the immediacy of respiratory outcomes. The other pregnant
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3 participants stated they would not choose administration of antenatal corticosteroids or were
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7 unsure of what they would decide.
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13 Perceptions of the harm-benefit risk balance also differed among both obstetricians and
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17 pediatricians, with some saying the benefits outweighed manageable and uncertain harms, and
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20 others saying that the possibility for harm outweighed an insignificant benefit (with one
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23 physician quoting “First, do no harm”).
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30 **Preferences for shared decision making**

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33 Illustrative quotes are in Table 7. Except for one pregnant participant who said they would want
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37 the doctor to make the decision about late preterm antenatal corticosteroid administration, all
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40 others wanted to be involved in the decision. Some stated they would want to hear the
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44 physician’s recommendation and rationale to help make the decision.
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51 One physician stated that many patients facing a preterm delivery want the physician to decide
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54 whether to administer late preterm antenatal corticosteroids. All other physicians thought patients
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3 would want to be involved in the decision; many said this is especially true in this “grey zone”
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7 where the balance of harms and benefits is less clear.
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13 **Utility of a decision support tool and preferences for information format**

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17 Illustrative quotes for these sections are in Table 8.
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23 *Utility of a decision support tool*

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27 Most participants said a decision support tool would be useful in deciding whether to administer
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30 late preterm antenatal corticosteroids. Some pregnant participants said it would be useful as a
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33 reference document after the clinical encounter. Several physicians mentioned the value of a
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36 separate tool designed for physicians, that could serve as a counselling guide, with discussion
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39 points and risk information. A few participants did not think that – or were unsure if – a tool
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43 would help decision-making.
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50 *Uncertainty of the evidence*

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4 Many pregnant participants stated that presenting the range of estimates or uncertainty of the
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7 evidence would be meaningful. Some said that presenting confidence intervals would make the
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10 information more confusing and would not help decision-making, but that uncertainty should be
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13 expressed somehow (e.g., “limited sample size”).
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20 Although some physicians said confidence intervals for risk estimates should be presented in
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23 patient decision support tools, most said this would not be helpful, adding that confidence
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26 intervals could be confusing, could lead patients to “anchor” on one end of the interval, or were
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29 unnecessary to report because uncertainty is intrinsic to medicine. In contrast, for physician-
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32 geared decision support tools, most physicians said confidence intervals should be included.
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40 *Desired risk information*

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44 Physician and pregnant participants both stated that it was important to know the baseline risks
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47 of outcomes, how those risks vary by gestational age, and the gestational age-specific effects of
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50 antenatal corticosteroids. While relative risks were described as more “impactful” than absolute
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3 risks, responses varied on whether absolute or relative risk measures were more helpful in risk
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7 communication.

13 *Format of a decision support tool*

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17 Most participants preferred visual risk presentations with graphics, saying this would make
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20 complex information easier to understand. Overall, participant responses suggested that two
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23 distinct tools would be needed: one for physicians and one for patients. Physicians expressed
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26 preference for a tool to guide counselling with specific risk information, and patients expressed
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29 preference for a hard-copy, visual presentation of treatment options.
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40 **INTERPRETATION**

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43 Our study elicited patient and physician perspectives on informational and decisional needs for
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46 late preterm antenatal corticosteroid counselling. Physician participants reported varied practices
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49 in discussing late preterm antenatal corticosteroids, which differed according to gestational age.
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54 Pregnant study participants wanted information content on the medication, the severity and
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3 management of respiratory distress and hypoglycemia, impacts on parent-neonate bonding and
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6 long-term neurodevelopment, and uncertainty of the evidence. There were varying perceptions of
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10 how best to format information on risk and uncertainty. Most participants thought a decision
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13 support tool outlining gestational age-specific risks would help guide counselling and decision-
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16 making.
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24 Our finding that almost all participants favored shared decision making in this context is
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26 consistent with a study of patients' preferences for maternity care decision making¹⁸. Participants
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28 had variable preferences for how risk magnitude and uncertainty should be presented. However,
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31 previous studies have shown limited statistical literacy in interpreting absolute and relative risk
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34 comparisons among patients and obstetrician-gynecologists,¹⁹⁻²² and current risk communication
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37 guidelines recommend that risk information should be presented using absolute measures (e.g.,
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40 absolute risk differences), rather than relative risk formats, to prevent inflated treatment effects¹⁹⁻
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44 ²¹. To prevent misinterpretation of uncertainty, risk communication guidelines also recommend
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47 that confidence intervals should be explained when presented; alternatively, the uncertainty of
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50 risk estimates can be represented by the sample size and quality of studies^{23,24}.
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7 Our study identified information that would be helpful for decision-making about late preterm
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10 antenatal corticosteroid administration and suggested that the creation of a decision support tool
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13 to provide this information is justified. As a next step, creating such a tool with clear risk
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16 information could improve shared decision-making.²⁵ This tool could be particularly useful
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20 alongside clinical practice guidelines¹¹²⁶ to help clinicians and patients make context and
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23 preference-sensitive decisions in this treatment “grey zone”.
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30 *Limitations*

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33 Our physician participants were from a single tertiary teaching hospital, and pregnant
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36 participants were from the same metropolitan area and had generally attained higher-level
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39 education; thus, our study population’s medical and statistical literacy may not generalize to the
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42 whole population. Additionally, we described a hypothetical situation to pregnant participants
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45 who were not admitted to hospital; their informational and decisional needs may differ from
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48 those of pregnant individuals in a true clinical context (i.e., facing an imminent risk of late
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51 preterm birth).
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7 *Conclusion*
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10 Pregnant individuals and physician participants wanted clear information on harms and benefits
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13 of late preterm antenatal corticosteroids to make an informed decision about whether this
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16 treatment should be administered. Our findings indicate a need for improved risk communication
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19 in this “grey zone”, and the opportunity to potentially achieve this through the creation of a
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24 decision support tool for late preterm antenatal corticosteroids.
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Table 1. Study participant characteristics as reported by participants on a written questionnaire prior to each interview

Pregnant patient participants (N=20)	
Age, years (SD)	34.05 (3.33)
Gestational age at the time of the interview, n(%)	
<12 weeks	0 (0)
12-27 weeks	5 (25)
>28 weeks	15 (75)
Highest level of education, n(%)	
Bachelor's degree or higher	20 (100)
Parity, n(%)	
0	15 (75)
1	5 (25)
Had previous baby admitted to NICU, n(%)	
No or not applicable if para 0	20 (100)
Yes	0 (0)
Had previous preterm baby	
No or not applicable if para 0	17 (85)
Yes	1 (5)
Unsure	2 (10)
Ever received antenatal corticosteroid treatment before (in current / previous pregnancy), n(%)	
No or not applicable if para 0	18 (90)
Yes	0 (0)
Unsure	2 (10)
Also identifies as an obstetrical care provider (e.g., physician, midwife, or nurse), n(%)	
Yes	2 (10)
No	18 (90)
Physician participants (N=20)	
Age, years (SD)	42.63 (9.08)
Discipline, n(%)	
Obstetrician	10 (50)
Pediatrician	10 (50)
Gender, n(%)	

Male	6 (30)
Female	14 (70)
Years in practice, n(%)	
Currently in fellowship training	1 (5)
<5 years post completion of training	8 (40)
5-10 years post completion of training	2 (10)
>10 years post completion of training	9 (45)

Notation: Mean (SD) or n(%)

Table 2. Current counselling practice – illustrative quotes.

Obstetrician responses: “Do you routinely offer the option of antenatal steroids to women at high risk of preterm birth at ...”

34+0 to 34+6 weeks’ gestation? “To 34 and 6, I generally recommend steroids if I think that the patient is at high risk of delivering within seven days.” (*Obstetrician, OB 7*)
 “It’s in those cases that I would typically speak to MFM – just a phone call and ask their opinion. And I get varying opinions. It’s not consistent.” (*OB 8*)

35+0 to 35+6 weeks’ gestation? “After 35, I wouldn’t necessarily even bring it up – unless the patient perhaps asked about it.” (*OB 6*)
 “That’s my grey zone.” (*OB 4*)

36+0 to 36+6 weeks’ gestation? “After 36 weeks, I wouldn’t even bring it up” (*OB 6*)

Pediatrician responses: “Do you think obstetricians are offering the option of antenatal steroids to women at high risk of preterm birth between 34+0 and 34+6 (at the 34th week), and then in the 35th week or in the 36th weeks, specifically?”

“Frankly, I don’t know.” (*Pediatrician, Peds 9*)

“I think it’s variable.” (*Peds 8*)

“I certainly do not think there’s any consensus amongst them, so it’s very operator dependent, from what my experience is in coming and meeting these parents.” (*Peds 6*)

Table 3. General informational needs – illustrative quotes.

Pregnant individuals:

“I would want to know side effects for myself [...] how am I going to feel?” (*Pregnant, Pr 17*)

“How it has this effect on the lungs, and how we know it’s safe” (*Pr 4*)

“Do I need to stay bedridden? Do I need to be mobile during the time the medication is working?” (*Pr 2*)

“Is that covered by my health insurance?” (*Pr 20*)

Physicians:

“I often tell them about how long it takes for the steroids to reach their maximum benefit.” (*OB 10*)

“There are some inconveniences [...] the injection, [...] having to come to the hospital earlier” (*Peds 9*)

Table 4. Respiratory distress and hypoglycemia – illustrative quotes.Pregnant individuals:

“I’d have more questions, more about the breathing problems [...] what that means, how long the baby would need to be in some kind of care unit. Can I take the baby home, or does it have to stay in hospital for a period of time? What’s the average or usual period of time [...] how long the period is of these concerns” (*Pr 2*)

“Sounds pretty straightforward [...] if it’s something that would help the baby breathe afterwards, then I would think that’s positive.” (*Pr 3*)

“At first, low blood sugar does not sound scary. But [...] I’d need more clarification on what does that mean for a newborn?” (*Pr 14*)

Physicians:

“I talk about how the benefits would be decreased respiratory distress, decrease in intraventricular hemorrhage, and decrease in needing ventilation, and a decrease in NEC [necrotizing enterocolitis] [...] over 34 weeks, there probably is a higher risk of hypoglycemia” (*OB 7*)

“RDS [respiratory distress syndrome] and requiring oxygen or even CPAP [continuous positive airway pressure] or intubation [...] and time spent in NICU.” (*OB 10*)

“Hypoglycemia is bad. And that may be a risk for- that may be part of the long-term risks for the developing brain [...] If you monitor well, it should be preventable, minimized for the most part. [...] the neonatal or the perinatal brain is very vulnerable to that kind of insult.” (*Peds 9*)

“There is absolutely nothing that proves that [association with hypoglycemia and potential long-term neurodevelopmental outcome]. The only thing that is proven is an association between persistent, symptomatic, severe hypoglycemia and long-term outcome.” (*Peds 7*)

Table 5. Neurodevelopmental outcomes – illustrative quotes.

Pregnant individuals:

“If it’s uncertain what the risk of neurodevelopmental outcome is, that’s kind of less important” (*Pr 1*)

“It may or may not change the decision, but at least having, knowing that you made a decision based with as much information as you could possibly have.” (*Pr 17*)

“[Patients] go home and do their own research and then come up with this, then they might want to hear it from the doctor first [...] rather than looking up something on Google and saying that ‘Oh, now my baby is gonna have, like, learning disability from getting the steroids,’ where you’re misinterpreting the information.” (*Pr 20*)

Physicians:

“I’m trying not to place too much emphasis on neurodevelopmental problems because it’s very fuzzy” (*OB 5*)

“Low blood sugar, like, that doesn’t really mean as much to [parents] as, like, oh, a small head or [...] lower test scores. [...] I think any evidence that there could be harm is concerning to a degree.” (*OB 6*)

“Long-term neurodevelopmental outcomes are [...] a very challenging thing to study.” (*Peds 1*)

“We have the same dilemma with postnatal corticosteroids, and we bring it up all the time. It’s out there. It’s in the literature. Someone will google and find it. And we’ve, in our practice in the NICU, we’ve always been completely transparent. And I think parents understand the – they probably feel more reassured that we talk about it.” (*Peds 9*)

Table 6. Perceived balance of harms and benefits – illustrative quotes.

Pregnant individuals:

“The things that are mentioned seem very small and [...] relatively insignificant in comparison to the risk of a respiratory problem.” (*Pr 17*)

“The neurodevelopment [...] that the baby’s brain is still developing, and those neural paths and everything is still developing [...] those would be the kind of risks that I’d be most concerned about.” (*Pr 5*)

“I’m not sure. I really need some help to understand, long-term, which one is- which problem is worse, which one is harder treat [...] I’m unable to determine, you know, assign a greater weight to either problem.” (*Pr 14*)

Physicians:

“Our Canadian organization and a lot of people in the world feel that the benefits outweigh the risks.” (*OB 5*)

“If this was a child that was otherwise going to have a totally normal respiratory course, we gave the antenatal corticosteroid just because that’s what we now do [...] they end up needing a nursery stay for hypoglycemia.

That seems like morbidity, to me, in a child that otherwise [...] may not have happened for.” (*Peds 1*)

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4 “I don’t think that there is a clear, obvious thing, where I say, ‘This is really bad, and this is the worse
5 outcome you should be worried about.’ I think that the biggest risk is something that only the patient and her
6 or his support network can understand, right?” (OB 7)
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22 **Table 7. Preferences for shared decision making – illustrative quotes.**
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24 Pregnant individuals:

25 “I would prefer that they make the decision and counsel me through it [...] because I think it’s, it’s still a lot of
26 information to parse.” (Pr 11)
27

28 “Given that we don’t know the long-term risks of antenatal steroids, and that this is later on where the benefits
29 aren’t as clear – it becomes, I think, more of an individual choice into what is important to you. And so, it
30 feels like something that I would be better suited to decide [...] with the doctor’s guidance and help.” (Pr 1)
31
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34 Physicians:

35 “To put that onto a mom who’s staring down delivering a baby early and not knowing what that’s all going to
36 mean, and so on – my guess is, honestly, most people put their faith in you [the doctor] to help make
37 decisions.” (Peds 5)
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41 “Women are often more invested in the well-being of their infants than they are in their own well-being, so
42 [...] I think they’d want to be part of the decision-making.” (OB 3)
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44 “I think especially at this gestation, families would want to be involved because it’s kind of, it’s less of a clear-
45 cut area [...] it’s more a grey zone.” (Peds 6)
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49 **Table 8. Utility of a decision support tool and how should information be presented – illustrative
50 quotes.**
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52 *Utility of a decision support tool*
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Pregnant individuals:

“I could go away, read it, talk it over with my husband [...] cover enough of the considerations that I wouldn't feel like I need to go down the rabbit hole of going through the internet, finding information that I may or may not trust.” (*Pr 2*)

Physicians:

“It's important that we present it in a more, in a uniform way [...] what would be really helpful is something more geared towards physicians about how to understand the risks and benefits [...] If I had those figures, I think that that would be really helpful for me in order to have a conversation where I felt a bit more confident in being able to make a recommendation or being able to present all the data. [...] if somebody wanted something to read about or to think about, then you could give it to them. They could read it on their own with their partner, with their family, and then come back to you with other questions [...] There may be two opportunities. One is a way to provide the information to clinicians.” (*OB 7*)

“We kind of take for granted that, for us, the routine, the mundane, is all new to them, and it's always anxiety-inducing. We know what happens when we're anxious. Things get shut down. Information isn't fully processed, but the tools sometimes, it's something concrete that they reference back to.” (*Peds 8*)

Presenting the uncertainty of the evidence

Pregnant individuals:

“I think saying the range is from 6 to 10 would also be meaningful.” (*Pr 11*)

“I'd be interested in the number of participants in the study [...] It makes a big difference when you are telling the story of one person versus analyzing the data of a province.” (*Pr 15*)

“Might just start to make everything kind of hazy.” (*Pr 1*)

“It just doesn't help me make the decision.” (*Pr 4*)

Physicians:

“I find that patients, when they see a range, they focus on one number. And depending on their context, it could be the lower number or the high number.” (*OB 2*)

“Doesn't necessarily need to be, like, written on the algorithm [...] there's always uncertainty, and so, that's just part of medicine.” (*Peds 1*)

“All these 95 percent confidence intervals [...] too complicated for the general people to understand” (*Peds 4*)

Desired risk information

Pregnant individuals:

“I might just want to know [...] if a baby is born at 35 weeks or 36 weeks, how many of them do have breathing problems?” (*Pr 11*)

“The 30 percent [relative risk reduction] would be, I would feel, like ‘Yeah, that’s worth it’. [...] just going from 11 to 8 [absolute risk reduction per 100 deliveries], I don’t know.” (*Pr 10*)

Physicians:

“What I’m guessing would be relevant to say is that ‘The risk of your baby having, needing to go to the NICU for respiratory distress would go from X percent to X percent’ [...] the risk without the intervention, the risk with the intervention.” (*Peds 9*)

“I think relative risk reduction from the patient’s perspective probably is more impactful.” (*OB 8*)

“A number needed to treat, for me, is a very helpful number because I think it’s easy to communicate to patients and it’s easy for me to contextualize what that means. [...] and a number needed to harm.” (*OB 7*)

“Absolute risks are probably the most useful [...] it’s like, ‘This is a real possibility.’” (*Peds 1*)

Format of a decision support tool

Pregnant individuals:

“I like to see, like, a visual representation [...] help me sort of to see ‘What are the possibilities?’” (*Pr 17*)

“A flow chart, easy [...] ‘I’m in this pathway. I belong in this category.’ [...] ‘Okay what are the important points to know when being in that category?’” (*Pr 6*)

“Something I could take away with me, something I could scribble on, whatever, write some notes on, write some questions on, and then bring that back with me.” (*Pr 2*)

“Access to as much information as I wanted in the form of references, and I’d probably dive deep if I was concerned or not so deep if I wasn’t concerned.” (*Pr 4*)

Physicians:

[Describing a previous tool with icons and colors] “Visual tools like that are really good because you can talk, talk, talk, but, you know, it’s just another way of presenting the information.” (*OB 1*)

“Give a patient information in a way that lays it out in easy-to-understand ways [...] uses plain language and is something that you could sort of go through with the patient.” (*OB 6*)

“Endorsed resources that if they want to take a little bit more on and read, that they can.” (*Peds 8*)

Appendix 1: 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

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3 11 in 100 babies born at your stage of pregnancy are diagnosed with this condition, and with the
4 medication, 8 in 100 babies born at your stage of pregnancy are diagnosed with this condition.
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6 Does this difference in risk matter to you?
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8 4. The majority of studies have not found any long-term harmful effects of antenatal corticosteroids. In
9 very preterm infants, antenatal steroids lead to less developmental disability. But, getting weekly or
10 biweekly antenatal corticosteroids has been linked to decreased weight at birth or in childhood, and an
11 isolated study found that those who got biweekly steroids and delivered at term had more vision and
12 hearing problems in childhood. Also, some animal studies have found that antenatal steroids could lead to
13 learning changes in childhood. These study findings have made some experts concerned about the
14 possible long-term risks of antenatal steroids, but it's still unclear if women getting one course of
15 antenatal corticosteroids at 34 to 36 weeks of gestation really leads to any of these long-term risks.
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18 a) how would you feel after hearing this information?
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20 b) Would you want to know more or less information?
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22 c) Overall, do these potential risks sound concerning to you?
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24 5. Sometimes the information we have from studies is uncertain. When studies only have a small number
25 of participants, we have to leave a margin for error or wiggle room around the risks we get. For example,
26 8 in 100 babies might be our best guess for the risk of breathing problems with the use of antenatal
27 corticosteroids, but when we add in the wiggle room, the risk might be anywhere from 6 in 100 babies to
28 10 in 100 babies. In situations where we are uncertain about the exact numbers, what information would
29 you want?
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32 6. Do you think you would want to be involved in making this decision? Or would you prefer that your
33 doctor makes this decision for you? Why or why not?
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36 7. If you think you would want to be involved in making this decision...
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39 a) What information or tools might help you make this decision?
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41 b) Are there tools that would help you share your concerns and values with your physician when
42 making this decision?
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44 8. Do you have any other suggestions for how we can help women and families decide whether or not to
45 receive this medication if they were in this situation?
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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+0-36+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?

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

4 -Are there different risks and benefits (*specify as per previous answer*) at this gestational week?
5
6 -does the balance of risk and benefit change?
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9 a) Do you routinely offer antenatal corticosteroids at 35+0 to 35+6 weeks' gestation?

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

12 **If not**, are there certain circumstances or situations in which you would offer them? (Exceptions)
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15 **3. How would your recommendations or patient counselling change if the patient were 36+0 to 36+6 weeks' gestation?**

16 -Are there different risks and benefits (*specify as per previous answers*) at this gestational week?
17
18 -does the balance of risk and benefit change?
19

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

21 **If yes**, are there certain circumstances or situations in which you would not offer them?
22

23 **If not**, are there certain circumstances or situations in which you would offer them?
24

25 **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?**
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31 **Why?**
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34 **5. Are there any additional risks or benefits of antenatal steroids which are important to you?**
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36 **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?**
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39 **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]**
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43 Evidence that suggests long term safety:

- 44 • 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.
- 45
46 • Another review published in the green journal in 2015 found that antenatal steroids led to less developmental disability, especially in very preterm infants.
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50 Evidence that suggests long term harm:

- 51 • A recent meta-analysis of individual participant data showed that getting repeat (weekly or biweekly) antenatal corticosteroids decreased birth or childhood weight
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53 • 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.

a) 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 this 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:

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- a) why not?
- b) would it be useful in specific contexts or for specific patients?

Confidential

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)?

Table 1 Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist

No	Item	Guide questions/description
Domain 1: Research team and reflexivity		
Personal Characteristics		
x	1. Interviewer/facilitator	Which author/s conducted the interview or focus group?
x	2. Credentials	What were the researcher's credentials? <i>E.g. PhD, MD</i>
x	3. Occupation	What was their occupation at the time of the study?
x	4. Gender	Was the researcher male or female?
x	5. Experience and training	What experience or training did the researcher have?
Relationship with participants		
x	6. Relationship established	Was a relationship established prior to study commencement?
x	7. Participant knowledge of the interviewer	What did the participants know about the researcher? <i>e.g. personal goals, reasons for doing the research</i>
x	8. Interviewer characteristics	What characteristics were reported about the interviewer/facilitator? <i>e.g. Bias, assumptions, reasons and interests in the research topic</i>
Domain 2: study design		
Theoretical framework		
x	9. Methodological orientation and Theory	What methodological orientation was stated to underpin the study? <i>e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis</i>
Participant selection		
x	10. Sampling	How were participants selected? <i>e.g. purposive, convenience, consecutive, snowball</i>
x	11. Method of approach	How were participants approached? <i>e.g. face-to-face, telephone, mail, email</i>
x	12. Sample size	How many participants were in the study?
x	13. Non-participation	How many people refused to participate or dropped out? Reasons?
Setting		
x	14. Setting of data collection	Where was the data collected? <i>e.g. home, clinic, workplace</i>
x	15. Presence of non-participants	Was anyone else present besides the participants and researchers?
x	16. Description of sample	What are the important characteristics of the sample? <i>e.g. demographic data, date</i>
Data collection		
x	17. Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?
x	18. Repeat interviews	Were repeat interviews carried out? If yes, how many?
x	19. Audio/visual recording	Did the research use audio or visual recording to collect the data?
x	20. Field notes	Were field notes made during and/or after the interview or focus group?
x	21. Duration	What was the duration of the interviews or focus group?
x	22. Data saturation	Was data saturation discussed?
x	23. Transcripts returned	Were transcripts returned to participants for comment and/or correction?
Domain 3: analysis and findings		
Data analysis		
x	24. Number of data coders	How many data coders coded the data?
x	25. Description of the coding tree	Did authors provide a description of the coding tree?
x	26. Derivation of themes	Were themes identified in advance or derived from the data?
x	27. Software	What software, if applicable, was used to manage the data?
x	28. Participant checking	Did participants provide feedback on the findings?
Reporting		
x	29. Quotations presented	Were participant quotations presented to illustrate the themes / findings? Was each quotation identified? <i>e.g. participant number</i>
x	30. Data and findings consistent	Was there consistency between the data presented and the findings?
x	31. Clarity of major themes	Were major themes clearly presented in the findings?
x	32. Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?

(ii) Participant selection: Researchers should report how participants were selected. Usually purposive sampling is used which involves selecting participants who share particular characteristics and have the potential to provide rich, relevant and diverse data pertinent to the research question

[13, 17]. Convenience sampling is less optimal because it may fail to capture important perspectives from difficult-to-reach people [16]. Rigorous attempts to recruit participants and reasons for non-participation should be stated to reduce the likelihood of making unsupported statements [18].