# Development of Nationwide Recommendations to Support Prenatal Counseling in Extreme Prematurity

Geurtzen, Rosa; van Heijst, Arno F. J.; Draaisma, Jos M. T.; Kuijpers, Lindie J. M. K.; Woiski, Mallory; Scheepers, Hubertina C. J.; van Kaam, Anton H.; Oudijk, Martijn A.; Lafeber, Harrie N.; Bax, Caroline J.

*Published in:*
Pediatrics

*DOI:*
10.1542/peds.2018-3253



*Publication date:*
2019

# Development of Nationwide Recommendations to Support Prenatal Counseling in Extreme Prematurity

Rosa Geurtzen, MD,[a] Arno F.J. van Heijst, MD, PhD,[a] Jos M.T. Draaisma, MD, PhD,[a] Lindie J.M.K. Kuijpers,[a] Mallory Woiski, MD, PhD,[b] Hubertina C.J. Scheepers, MD, PhD,[c] Anton H. van Kaam, MD, PhD,[d] Martijn A. Oudijk, MD, PhD,[e] Harrie N. Lafeber, MD, PhD,[f] Caroline J. Bax, MD, PhD,[g] Jan F. Koper, MD, PhD,[h] Leonie K. Duin, MD, PhD,[i] Marc A. van der Hoeven, MD, PhD,[j] René F. Kornelisse, MD, PhD,[k] Johannes J. Duvekot, MD, PhD,[l] Peter Andriessen, MD, PhD,[m] Pieter J. van Runnard Heimel, MD, PhD,[n] Marja van der Heide-Jalving, MD, PhD,[o] Mireille N. Bekker, MD, PhD,[p] Susanne M. Mulder-de Tollenaer, MD,[q] Jim van Eyck, MD, PhD,[r] Ellis Eshuis-Peters, MD, PhD,[s] Margo Graatsma, MD, PhD,[t] Rosella P.M.G. Hermens, MD, PhD,[u] Marije Hogeveen, MD, PhD[a]

abstract

**OBJECTIVES:** To develop a nationwide, evidence-based framework to support prenatal counseling in extreme prematurity, focusing on organization, decision-making, content, and style aspects.

**METHODS:** A nationwide multicenter RAND–modified Delphi method study was performed between November 2016 and December 2017 in the Netherlands. Firstly, recommendations were extracted from literature and previous studies. Secondly, an expert panel ($n$ = 21) with experienced parents, obstetricians, and neonatologists rated the recommendations on importance for inclusion in the framework. Thirdly, ratings were discussed in a consensus meeting. The final set of recommendations was approved and transformed into a framework.

**RESULTS:** A total of 101 recommendations on organization, decision-making, content, and style were included in the framework, including tools to support personalization. The most important recommendations regarding organization were to have both parents involved in the counseling with both the neonatologist and obstetrician. The shared decision-making model was recommended for deciding between active support and comfort care. Main recommendations regarding content of conversation were explanation of treatment options, information on survival, risk of permanent consequences, impossibility to predict an individual course, possibility for multiple future decision moments, and a discussion on parental values and standards. It was considered important to avoid jargon, check understanding, and provide a summary. The expert panel, patient organization, and national professional associations (gynecology and pediatrics) approved the framework.

**CONCLUSIONS:** A nationwide, evidence-based framework for prenatal counseling in extreme prematurity was developed. It contains recommendations and tools for personalization in the domains of organization, decision-making, content, and style of prenatal counseling.

**Disclaimer:** The guidelines/recommendations in this article are not American Academy of Pediatrics policy, and publication herein does not imply endorsement.

*Departments of [a]Neonatology and Pediatrics and [b]Obstetrics and Gynecology, Amalia Children's Hospital and [u]Scientific Institute for Quality of Care, Radboud Institute for Health Sciences, Radboud University Medical Center, Nijmegen, Netherlands; [c]Departments of Obstetrics and Gynecology and [j]Neonatology, Maastricht University Medical Center+, Maastricht, Netherlands; [d]Department of Neonatology, Emma Children's Hospital and [e]Department of Obstetrics and Gynecology, Amsterdam University Medical Center and University of Amsterdam, Amsterdam, Netherlands; [f]Departments of Neonatology and [g]Obstetrics and (Continued)*

**WHAT'S KNOWN ON THIS SUBJECT:** Parents should be counseled prenatally at imminent extreme premature birth; however, tools used to support professionals are scarce and current practice varies widely.

**WHAT THIS STUDY ADDS:** A nationwide framework with 101 recommendations for prenatal counseling in extreme prematurity was developed, involving neonatologists, obstetricians, and parents, using a Delphi method. Recommendations were formulated in the domains of organization, decision-making, content, and style and included personalization tools.

**To cite:** Geurtzen R, van Heijst AFJ, Draaisma JMT, et al. Development of Nationwide Recommendations to Support Prenatal Counseling in Extreme Prematurity. *Pediatrics*. 2019;143(6):e20183253

International guidelines on the treatment of extreme prematurity differ in both the lowest limits of gestation for which active support can be offered and the recommended role of parents in the decision-making.[1,2] Furthermore, the use of gestational age (GA) as a cutoff has been criticized[3,4] because other factors also determine outcome.[5–8] However, GA remains an important factor in treatment guidelines, and a gray zone seems to exist at 22 up to 24 or 25 weeks' GA wherein parents should be involved (through prenatal counseling) in decision-making.[1,2,9,10] Opinions on optimal prenatal counseling in extreme prematurity differ, and actual counseling practices seem to vary within and between countries.[11–17]

Although variation may be in the best interest of the patient and the parents when it is caused by different prognostic factors or based on different parental values and beliefs, it should not be because of unclear information on outcomes, physicians' personal bias regarding the outcomes, or insufficient organizational support.[6,9,18,19] Several recommendations on prenatal counseling in extreme prematurity have been published, offering guidance to the professionals providing the counseling and aiming to reduce unnecessary variation.[5,6,8,9,20–26] However, these recommendations might not always be applicable across cultures because differences may exist in health care organization, regulations, guidelines, and ethical aspects.[1,2,17,27–31] Ideally, a formal recommendation should include opinions from the involved professional groups as well as the patients' views and preferences.[32]

Our aim of this study was therefore to develop a nationwide framework with recommendations for the prenatal counseling in extreme prematurity, focusing on the organization, decision-making, content, and style of counseling, involving all Dutch stakeholders. This framework is meant to support individual professionals who need to perform prenatal counseling, as well as their teams and their patients. Furthermore, the used method may serve as a model for other countries to develop a culturally sensitive framework with recommendations.

## METHODS

### Study Design and Setting

This nationwide multicenter Dutch study was performed between November 2016 and December 2017. A RAND–modified Delphi method (an evidence-based method for consensus building by using multiple iterations to collect data from a panel of selected experts[33]) with 5 steps was used to develop a framework with recommendations on prenatal counseling in extreme prematurity. This method has been successfully used before.[34,35]

In the Netherlands, a clinical guideline is currently in place defining a GA of $24^{+0/7}$ weeks as the lower limit at which active support can be offered under the condition of parental consent.[36] However, no advice on the counseling itself was provided in this guideline. Authors of the nationwide Prenatal Counseling in Extreme Prematurity (PreCo) study subsequently assessed both the Dutch professional[18,37,38] and parental[39–41] preferences on prenatal counseling in extreme prematurity. These preferences were sought in different domains of counseling: the organization, content, decision-making process, and style of the prenatal counseling in extreme prematurity. The development of an evidence-based framework for prenatal counseling in extreme prematurity was the ultimate aim of the Dutch national PreCo study.

### Study Population

The expert panel ($n$ = 21) for this study consisted of 6 (pairs of) parents, 7 obstetricians, and 8 neonatologists. The parents, who all experienced an extreme premature birth at 24 weeks' GA, previously participated in a PreCo interview study[40] and consented to participate in this expert panel. For the participation of physicians, we approached all tertiary centers and invited them to participate with a neonatologist and/or obstetrician. With this purposive sampling, we aimed to include all tertiary centers and both professions equally. Institutional review board approval was waived (Human Research Committee region Arnhem-Nijmegen, October 19, 2016). The 6 pairs of parents received counseling in 5 different hospitals in which comfort care was decided in 1 instance and active support was decided in 5 instances. From a total of 9 infants (including 3 sets of twins), 3 survived.

### Data Collection

The RAND-modified Delphi method included the following 5 steps.

### Step 1: Sources and Extraction of Recommendations

Information was available from our earlier-performed PreCo studies,[18,37–39,41] and we performed an additional literature search (R.G., M.H.) (Supplemental Fig 2). Using PubMed, we sought to include articles on prenatal counseling at extreme prematurity with recommendations (a guideline, protocol, consensus, or review) after 2001 (past 15 years). Our search terms were as follows:

((((“Fetal Viability”[Mesh] OR “Infant, Extremely Premature”[Mesh])) OR (limits of viability OR extreme prematur* OR extremely preterm OR extreme preterm OR extremely prematur* OR periviab*))) AND ((((((((((“Counseling”[Mesh]) OR “Decision Making”[Mesh])) OR conversation) OR counseling) OR counseling)) AND ((((((((“Guideline” [Publication Type]) OR “Practice Guideline” [Publication Type]) OR “Consensus”[Mesh])) OR framework) OR recommendation) OR statement) OR

protocol)) OR guideline))))) Filters: From 2001/01/01, English.

Expert opinions and guidelines only on treatment in extreme prematurity (without prenatal counseling items) were excluded. Out of 144 articles, 120 were omitted on the basis of the title because inclusion criteria were not fulfilled. On the basis of the abstracts, of the remaining 24, another 12 were excluded (because they did not fulfill the inclusion criteria or no full text was available). Seven articles were added on the basis of the references; thus, a total of 19 articles were included.[5,9,20–24,42–53] Next to the international literature, the original results (including unpublished data) of the 4 nationwide Dutch PreCo studies were included: (1) survey distributed to neonatologists and obstetricians,[37,38] (2) interviews conducted with neonatologists and obstetricians,[18] (3) survey distributed to experienced parents,[39,41] and (4) interviews conducted with experienced parents.[40] Potential recommendations on counseling from either the literature or these Dutch studies were extracted and subdivided within 4 main domains: organization, decision-making, content, and style of prenatal counseling in extreme prematurity. The large content domain was further split up into 3 subdomains to increase understanding and practical applicability: the first part of the conversation involved content considered essential to make a good decision. In the second part, information on active support and/or comfort care was considered. For each recommendation, the references were noted and a justification with background information was given if applicable. This first set of recommendations was primarily made by R.G. and M.H. and critically reviewed by A.F.J.v.H., J.M.T.D., R.P.M.G.H., and L.J.M.K.K.

Regarding the decision-making domain, shared decision-making (SDM) was clearly the recommended model in both the literature and the earlier Dutch PreCo studies, but previous results revealed limited familiarity[18] with the concept. We therefore added a stepwise approach of SDM on the basis of Stiggelbout et al[54] and slightly modified to make it applicable to prenatal decision-making in extreme prematurity.

### Step 2: Questionnaire About Potential Recommendations

Expert panel members received the questionnaire (online), which they could complete online or print, fill out, and return. They could rate the potential recommendations for selection in the framework on a Likert scale of 1 (very unimportant recommendation) to 9 (very important recommendation) and also provide a top-5 ranking of the recommendations to point out the most important recommendations per domain. Participants could also propose new recommendations and give comments at the end of each domain. The potential recommendations were evaluated by using 2 stages. In the first stage, called "preselection," a median score $\geq$7 was used as a cutoff for preselection. In the second stage, called "consensus," the consensus cutoff was for recommendations in which $\geq$70% of the participants scored a $\geq$7. For others, there was no consensus, but when $\geq$30% scored $\leq$3 and $\geq$30% scored $\geq$7, there was a conflict situation. The final decision was based on the 2 stages (preselection and consensus) leading to high-potential, low-potential, and uncertain-potential recommendations. Positive preselection and consensus meant a high-potential recommendation, no selection and no consensus meant a low-potential recommendation, and all other combinations meant uncertain-potential recommendation, similar to other studies.[34,35]

Regarding the ranking of recommendations, for all (sub) domains, a ranking (top 5) of the most important recommendations was calculated. The top recommendation received 5 points, the second 4 points, and so on, and the fifth recommendation received 1 point. Taking into account the number of recommendations per (sub)domain (as maximum potential), a weighted percentage was calculated. This weighted percentage reflected the importance of that recommendation within its domain and was included in a feedback report as the ranking score.

### Step 3: Consensus Meeting

Each member of the expert panel received a feedback report revealing all recommendations with their corresponding potential (high-, uncertain-, or low-potential recommendations, with the recommendations colored green, orange, and red, respectively), the median Likert scale scores, and the ranking score. The stepwise approach of SDM was also included in the report. The feedback report was discussed during the face-to-face consensus meeting. The uncertain-potential and newly suggested recommendations were predominantly debated, but the high- and low-potential recommendations were discussed as well. All recommendations were either included, rejected, or included after textual modification. M.H., assisted by R.G., moderated the discussion. Two other researchers (L.J.M.K.K. and R.P.M.G.H.) were present as observers of the discussion to ensure procedural validity.

### Step 4: Final Appraisal

After the consensus meeting, the new set of recommendations was determined and sent to the expert panel for final approval, with the changes compared to the first version highlighted in the final set of recommendations.

### Step 5: Transformation Into Framework and Final Approval

The approved recommendations were included in the framework. Short explanations (based on the source[s] of that recommendation) were added by the project group. Furthermore, minimal rewriting was done to improve readability and clarity. On closer inspection, some recommendations were found to be a duplicate and were skipped.

The researchers made a summary for which the recommendations with the

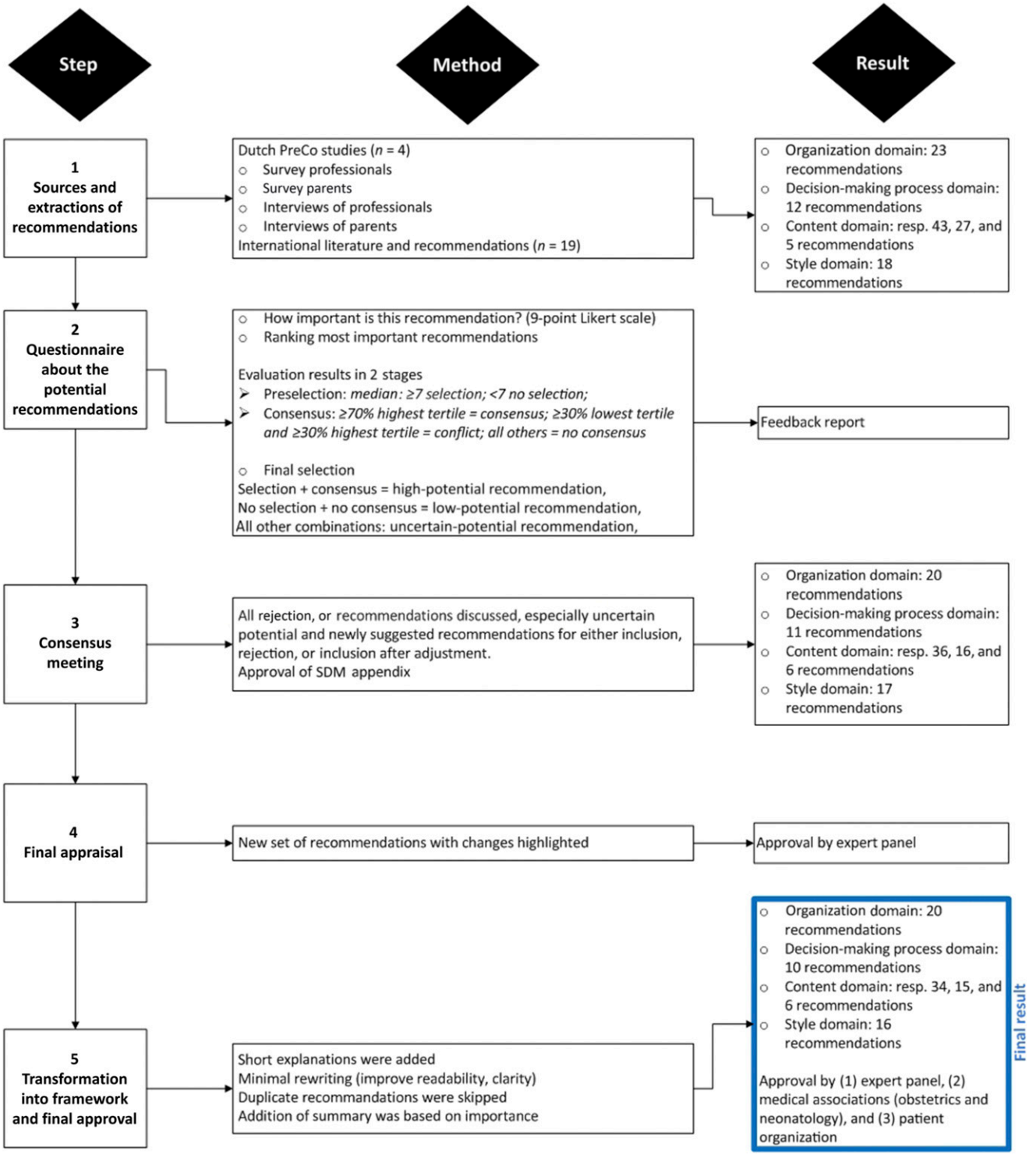


**FIGURE 1**
Summary methodology and results.

highest importance were selected. Our goal of this summary was to indicate the most important recommendations, which is useful when prioritizing within counseling conversations is necessary (eg, because of a limited availability of time or a limited capacity for parents to absorb information). The approved stepwise approach of SDM was added as an appendix to the framework. The methods and results are also summarized in Fig 1.

## RESULTS

At the first step, 128 recommendations were extracted from the literature and previous Dutch studies. The questionnaire (step 2) was completed by 20 of 21 experts (95% response rate), and the resulting feedback report was discussed at the consensus meeting (step 3), attended by 18 of 21 experts (86% response rate). After this third step, 106 recommendations remained and were approved in the fourth step by the expert panel. Finally, in the fifth step, a total of 101 recommendations were included in the framework: 20 recommendations in the domain of organization (Table 1), 10 in the domain of decision-making (Table 2), 55 in the domain of content (respectively 34, 15, and 6 in the subdomains content) (Tables 3 through 5), and 16 for the domain of style (Table 6). The appendix on SDM was included as well. These results are summarized in Fig 1. The complete framework can be found in the Supplemental Information. This final framework was approved by the expert panel, the Dutch patient organization of parents of preterm born children (Vereniging Ouders van Couveusekinderen), and the national medical associations of both obstetrics (Nederlandse Vereniging voor Obstetrie en Gynecologie) and neonatology (Nederlandse Vereniging voor Kindergeneeskunde).

In the organization domain, the most important recommendations (based on ranking) were to perform prenatal counseling by the neonatologist and obstetrician together and to have both parents present (Supplemental Tables 7–13). In the domain of decision-making, the SDM model was the recommended model used to decide between active support and comfort care, including the 4 steps as described by Stiggelbout et al[54] and in our framework appendix (in short, step 1 indicates a decision needs to be taken and parental input is important, 2 is an explanation of both options, 3 is used to determine the wishes and concerns of the parents [ie, support them], and 4 is to discuss how parents want to reach a decision and decision follow-up) (Supplemental Tables 14 and 15). In the domain of style, the main recommendations were to avoid medical jargon and adapt language to the parents, check parental understanding, and provide a summary at the end of the conversation (Supplemental Table 22

**TABLE 1** Organization of Prenatal Counseling at the Threshold of Viability

| The Expert Panel Recommendations |
|---|
| Who will conduct the discussion? |
| The counseling discussion should be performed by the neonatologist and the obstetrician together.[a] |
| The counseling discussion should be performed by staff members who are qualified to do so. |
| The neonatologist and the obstetrician should discuss the initial situation of the patient and her partner before the counseling discussion so that both parties have the same starting point. |
| An agreement should be reached between the neonatology and perinatology departments per center to guarantee joint counseling (by the neonatologist and obstetrician). |
| Both parents (assuming that there are 2 parents) should be present for the counseling discussion.[a] |
| A nurse should be present for the counseling discussion. |
| When should the discussion take place? |
| Consider providing counseling regarding potential birth at $24^{+0}$–$24^{+6}$ in a tertiary center even before $23^{+4}$ wk' gestation. A prerequisite is that the aim of the transfer is clear, namely, that it is to provide counseling and not to provide active support at an earlier stage. |
| Consider telephone advice about counseling by the neonatologist and obstetrician from the tertiary center to the treating physician in secondary care when a transfer to a tertiary center is not possible and there is the potential of impending preterm delivery at $24^{+0}$–$24^{+6}$ wk. |
| The counseling discussion should take place as soon as possible after arrival at the tertiary center, preferably <12 h after arrival even if this falls outside of working hours. |
| If the situation permits, inform the parent(s) about the time at which the counseling discussion is scheduled. |
| How often should the discussion take place? |
| If the situation permits, several discussions should take place as part of prenatal counseling. |
| The physician should actively initiate the follow-up meeting. |
| Schedule a new meeting if the situation changes (eg, fetal condition or if the pregnancy progresses). |
| Language |
| Use an interpreter if the parent(s) do not speak the same language as the professional. |
| Duration of the meeting |
| A counseling meeting should take as long as necessary for the parents. |
| Documentation of the meeting |
| Record a summary of the counseling meeting, including agreements reached about policy surrounding the birth and whether active support will be offered to the newborn. This summary should be accessible for neonatologists, obstetricians, and parents. |
| Hold a short debriefing after the counseling meeting with the professionals involved, including confirmation of the agreements that were reached. |
| Support for the meeting |
| Supporting materials should be used during the counseling discussion in addition to the verbal counseling. A tour of the NICU should be organized in addition to the meeting. |
| Training of counseling |
| Guarantee the training of professionals in counseling by each center (eg, through direct observation, education, or simulation training). |

[a] Recommendations were selected in the summary on the basis of their ranking.

**TABLE 2** Decision-making Process in the Prenatal Counseling at the Threshold of Viability

| The Expert Panel Recommendations |
|---|
| Desired decision model and/or steps to decision-making |
| The decision between active support or comfort care should be made on the basis of the principles of SDM. See Supplemental Information for a more detailed explanation.[a] |
| Step 1: Inform (the parents) about the fact that a decision needs to be taken in which the input of the parent(s) is important.[a] |
| Step 2: Explain the options (active support and comfort care), including the benefits and disadvantages of each.[a] |
| Step 3: Determine what the wishes and concerns of the parent(s) are and what is important to them to support parent(s) in making decisions.[a] |
| Step 4: Discuss how parent(s) want to reach a decision (make the decision themselves, leave the decision to the physician, or make the decision together) and whether they want to discuss the follow-up of this decision.[a] |
| Decision-making otherwise |
| Both options (comfort care and active support) should be presented equally; there is no right or wrong decision. The physician may only emphasize 1 of the options if there are factual factors that could have a positive or negative effect on the individual prognosis of the unborn child. |
| If a decision has already been made before the counseling discussion (by the parent[s] or, for example, a physician from the referring center), then a counseling discussion should still be performed by the neonatologist and obstetrician to explore the decision that has been made and the way in which the decision-making process took place. Where necessary, the previous decision should be supplemented and amended. |
| Comfort care should be mentioned again at the end of the discussion because it usually takes more time to explain active support than to explain comfort care. |
| Active support should be provided in cases in which there is absolutely no opportunity for counseling (because of immediate delivery) and if there are no contraindications, although preferably after informing the parent(s). (Of course, the situation and the treatment options should then be discussed after the birth.) |
| Use a decision aid as an addition to the conversation. |

[a] Recommendations were selected in the summary on the basis of their ranking.

In the domain of content, the expert panel emphasized that the natural course of the counseling conversation, the individual parents, and the individual medical situation should determine the actual conversation. However, the most important recommendations regarding topics that need to be discussed with the parents to involve them in the decision-making were determined as follows: explanation of 2 options (active support versus comfort care), the possibility of survival or death, the impossibility to predict an individual course, the risk of permanent consequences of surviving preterm birth, the fact that after a decision for active support, multiple decision moments may follow, and a discussion on parents' values and standards. The recommended content consistent with the decision for active support (Table 4) could either be used when a decision for active support is made, with the goal of preparing the parents for the (near) future, but could also be used when, for example, parents want more detailed information on active support to support their decision-making. The same applies to the comfort care recommendations (Table 5). The main recommendations to discuss for active support were potential cesarean delivery and information about the course of events surrounding birth and postnatal risks for breathing problems, life-threatening infections, and a cerebral hemorrhage. The main topics recommended to discuss for comfort care were information about the course of events surrounding birth, the fact that the infant may be born alive, and the possibility of recording memories (Supplemental Tables 16–21).

## DISCUSSION

We made a balanced framework with evidenced-based extraction of recommendations for prenatal counseling in extreme prematurity to guide professionals performing prenatal counseling. The recommendations were based on both international literature and national studies and were evaluated and adapted by a multidisciplinary expert panel, which included both professionals and parents. The most important recommendations were to have both parents involved in counseling by both the neonatologist and obstetrician (regarding organization) and to use the SDM model to decide between active support and comfort care. Main recommendations regarding conversational content were the explanation of treatment options, information on survival and death, the risk of permanent consequences, the impossibility to predict an individual course, the fact that multiple decision moments may follow, and a discussion on parental values and standards. Regarding the domain of style, it was considered most important to avoid jargon, check understanding, and provide a summary. The framework contains these collectively agreed recommendations for prenatal counseling and tools for personalization. As such, it can serve as an excellent starting point for personalized prenatal counseling consultations.

During the Rand-modified Delphi method, especially in the domain content of counseling, many topics were mentioned as important to discuss with parents. However, parents can never absorb all suggested information,[55] and variation existed between parents in their need for information: some would have liked to receive detailed information, some had specific questions, whereas others did not, and some wanted statistics, whereas

**TABLE 3** Content of the Prenatal Counseling at the Threshold of Viability: Making the Decision About Active Support or Comfort Care

| The Expert Panel Recommendations |
|---|
| Start |
| Start by discussing that there are 2 options so it is clear that there is a decision to be made regarding the policy surrounding the birth at this stage of gestation (active support or comfort care).[a] |
| Mortality |
| Discuss possible survival and possible death.[a] |
| Express the chance of survival and death (in a comprehensible manner) in numbers if the parent(s) want numbers. |
| Mention both numbers regarding the chance of survival and the chance of death (positive and negative perspective). |
| Use recent numbers about the chances of survival and death (preferably <10 y old). |
| Use the chance of survival and death on the basis of the infant being born alive. |
| In addition, discuss survival without severe handicaps. |
| When possible, use national figures about the chance of survival and death. |
| Inform (the parents) that the figures and chances for a group cannot be used to predict the eventual outcome for their infant.[a] |
| Express the chances in different ways, depending on the preference of the parent(s). |
| Consistently use the same denominator for the different outcomes when discussing chances. |
| Discuss the fact that treatment in the NICU is a major burden for the infant, with potential suffering for the infant. |
| Long-term morbidity |
| Discuss the risk of permanent consequences of preterm birth.[a] |
| When discussing the risk of handicaps or limitations, clarify what is considered to be a handicap. |
| Discuss the risk of physical consequences of preterm birth. |
| As far as the physical consequences are concerned, discuss the risk of spasticity or other problems with movement. |
| As far as the physical consequences are concerned, discuss the risk of problems with vision (poor vision, blindness). |
| As far as the physical consequences are concerned, discuss the risk of hearing problems (poor hearing, deafness). |
| Discuss the risk of reduced mental development. |
| Discuss the risk of long-term lung problems. |
| Discuss the risk of behavioral problems. |
| Discuss the risk of emotional problems. |
| Discuss the risk of learning and concentration problems. |
| Making the decision about active support or comfort care |
| Discuss the fact that if the prenatal decision is to offer active support, then more decision points may follow in the postnatal period regarding whether to continue with or start treatments.[a] |
| Inquire about the opinion of the parent(s) regarding quality of life and their standards and values.[a] |
| Exude neutrality and offer the parent(s) support regardless of their decision. |
| Discuss the unpredictability and the volatile nature of the disease progression facing their infant. |
| Discuss the fact that despite the current options in the field of neonatal intensive care, a poor outcome cannot always be avoided (death or handicap). |
| Explain how the child will be treated in the case of active support (the child will leave with the physicians immediately and go straight to the NICU) and how the child will be treated at birth in the case of comfort care (the child can remain with the mother). |
| Articulate the decision clearly and check with the parent(s) whether it is correct. |
| Influencing factors |
| In the context of personalization, we recommend (where applicable) discussing factors that could influence (positively or negatively) the prognosis (outcome) of the unborn child. These factors include the following: |
| Growth retardation (IUGR) |
| Preparation with antenatal corticosteroids |
| Signs of infection in the womb (chorioamnionitis) |
| Severe congenital defects |

IUGR, intrauterine growth restriction.

[a] Recommendations were selected in the summary on the basis of their ranking.

others did not.[41,56,57] Thus, the panel concluded that personalization is essential. However, before the counseling, doctors often lack knowledge about the specific needs of these parents and need to start the conversation at some point. The expert panel chose to be rather complete in their recommendations on the content domain to take into account all potentially important information. The exact informational need of the parents must guide the actual content of the conversation. The framework summary is used to provide the most important recommendations according to the expert panel in the content domain and is therefore considered to provide a good starting point for the aforementioned personalized prenatal counseling conversations. Of course, this information needs to be imbedded in the SDM model, and the provision of information, together with the clarification of parents' values and parents' need for information, is a circular, reiterative process.[58]

The recommendations in our framework reveal similarities with other published guidelines and recommendations on prenatal counseling,[9,22,24] even when they have been published after our study period,[6,8] which is logically explained by the use of common literature sources. For example, the SDM model has been widely promoted,[5,9] but our framework is the only recommendation that includes a practical elaboration on this model, which was motivated by the local input revealing insufficient familiarity with this model.[18] The most important practical difference from other recommendations is that our framework is only on periviability counseling and is separated from the treatment guideline. Furthermore, only authors of a few recommendations included input from patients or patient organizations like we did.[59] Also, our framework is

**TABLE 4** Content of the Prenatal Counseling at the Threshold of Viability: Potentially Important Content Consistent With the Decision for Active Support

| The Expert Panel Recommendations |
|---|
| Problems in the short-term |
| Discuss the risk of breathing problems.[a] |
| With regards to breathing, discuss the IRDS. |
| With regards to breathing, discuss artificial ventilation. |
| Discuss the risk of potentially life-threatening infections.[a] |
| Discuss the risk of cerebral hemorrhage.[a] |
| Discuss the risk of a life-threatening intestinal infection (NEC). |
| Discuss eye problems associated with preterm birth (ROP). |
| Method of delivery |
| Discuss the benefits and disadvantages of a cesarean delivery for this early stage of gestation.[a] |
| Discuss possibilities with regard to monitoring of the infant's condition before birth and what should or should not be done if the infant's condition deteriorates. |
| Practical matters |
| Provide information about the course of events surrounding the birth (eg, their child will leave immediately with the physicians, be placed in a bag, receive respiratory support and IV lines, etc).[a] |
| Discuss who will be present at the birth. |
| Inform parents that they may need to be transferred to a different tertiary center just before the birth because of lack of space locally. |
| Consider providing information about the course of events for the mother and/or possible illness of the mother during the counseling meeting. |
| Discuss procedures that may be performed immediately after delivery and after admission to the NICU, such as intubation, IV line, umbilical line, radiographs, etc. |
| If the mother's situation permits, discuss breastfeeding and the need to pump breast milk. |

IRDS, infant respiratory distress syndrome; IV, intravenous; NEC, necrotizing enterocolitis; ROP, retinopathy of prematurity.
[a] Recommendations were selected in the summary on the basis of their ranking.

more extended than some other recommendations, providing practical recommendations on all aspects of counseling, whereas, for instance, only the minority of recommendations included style recommendations.[22,24]

The strength of our framework is determined by the joint, national collaborative process in its development, thus creating awareness and increasing knowledge among professionals and parents.[60] In this way, we raised public support among the main stakeholders. This is an important step in the national implementation of the framework. In addition, after dissemination of the framework via newsletter, e-mails, and/or Web sites, implementation tools must be developed, depending on existing barriers for implementation. Currently, we do not know the exact barriers, but we expect difficulties at the patient and professional level regarding applying personalized decision-making.

**TABLE 5** Content of the Prenatal Counseling at the Threshold of Viability: Potentially Important Content Consistent With the Decision for Comfort Care

| The Expert Panel Recommendations |
|---|
| The decision for comfort care |
| Provide information about the course of events during the birth, such as the fact that the child can remain with the mother, that an active approach will be taken that is aimed at providing comfort for the child, and that the parent(s) will receive support during the period in which their infant dies.[a] |
| Discuss who will and will not be present at the birth. |
| Explain that their infant can be born alive.[a] |
| Inform the parents about the possibilities of recording memories.[a] |
| Mention the availability of social workers and/or psychologists to support the parent(s). |
| Provide information about the possible course of events and how long the process of dying may take. |

[a] Recommendations were selected in the summary on the basis of their ranking.

Therefore, a decision aid (based on the framework) used to support patients and professionals in their personalized decision-making is an important implementation tool and has already proven to be beneficial,[61,62] as is education on SDM.[63]

An advantage of a framework is that it may help to exclude interprofessional variance because many differences among health care providers seem to exist.[13,14,38,64] Variation in prenatal counseling is welcome when it is based on different parental values or different risk factors determining an individual prognosis.[4,8,19] It should not be based on the different values of doctors. We also included tools to support personalization, such as the practical steps in SDM, which allow for varying parental preferences in decision-making. The recommendation on asking whether parents would like to receive statistics is another example of personalization.

This framework was made by using an evidence-based, stepwise consensus methodology and fulfills many quality criteria.[65,66] The methodology is unique and based on strong empirical grounds, including all stakeholders. Next to the international sources, national sources were incorporated, making it more likely that it is nationally applicable, which will support implementation. A high-quality expert panel was used, with a nationwide representation of perinatal professionals and parents who made various decisions and received various outcomes regarding their infants. The response rates in both the questionnaire round and consensus meeting were high. A limitation of our study is the national character of the framework, making it difficult to know whether the framework itself is internationally applicable. However, clear similarities with recommendations in recent guidelines from both Canada and the

**TABLE 6** Style of the Prenatal Counseling at the Threshold of Viability

| The Expert Panel Recommendations |
|---|
| Speak to the parent(s) at eye level (sitting down). |
| Introduce yourself. |
| Do not use too many medical terms and adapt to the language level of the parent(s).[a] |
| Give the parent(s) the opportunity to ask questions throughout the counseling session. |
| Check whether the parent(s) have understood what they have been told.[a] |
| Ask open questions to give the parent(s) the opportunity to give their opinion. It is important to interrupt the parent(s) as little as possible. |
| Provide a summary of the facts that have been discussed at the end of the counseling discussion.[a] |
| Ask whether the parent(s) know anything yet about extreme preterm birth. |
| Ask whether the parent(s) have support from loved ones and/or have a network to support them. |
| Exude an attitude that says you want to be of service to children. |
| Be open and honest. |
| Stick to the key facts and try to be concise. More detail can be provided at the request of the parent(s). |
| Take the time for the counseling meeting and exude calmness. |
| Show empathy. |
| The expert panel also indicates the following: |
| The physician should be competent. |
| The physician should avoid eliminating all hope that the parent(s) may have. |

[a] Recommendations were selected in the summary on the basis of their ranking.

United States exist, suggesting that the common ground may outweigh the cross-cultural differences.[5,8,24] Furthermore, the methodology is universally applicable. One may also consider broadening the literature search to also include articles on other prenatal consultations or NICU conversations. By including all results from our previously performed nationwide studies among a much larger and more varied group of parents and doctors and by working together with the professional and patient associations, we believe that our framework is fueled and broadly supported by all stakeholders. However, we are unsure whether purposive sampling specifically aiming to include a (more) diverse expert panel (both doctors and parents) and more families who decided comfort care could have potentially enriched our framework.

## CONCLUSIONS

An evidence-based, nationwide framework used to guide professionals in prenatal counseling in extreme prematurity was developed, involving neonatologists, obstetricians, and parents. It contains both collectively agreed recommendations for prenatal counseling, as well as tools for personalization in the domains of organization, decision-making, content, and style. It can serve as an excellent starting point for personalized prenatal counseling consultations in extreme prematurity.

## ABBREVIATIONS

GA: gestational age
PreCo: Prenatal Counseling in Extreme Prematurity
SDM: shared decision-making

Gynecology, Vrije Universteit Medical Center and Vrije Universteit Amsterdam, Amsterdam, Netherlands; [h]Departments of Neonatology and [i]Obstetrics, Gynecology, and Prenatal Diagnosis, University Medical Center Groningen and University of Groningen, Groningen, Netherlands; [k]Department of Neonatology, Sophia Children's Hospital and [l]Department of Obstetrics and Gynecology, Erasmus University Medical Center, Rotterdam, Netherlands; [m]Departments of Neonatology and [n]Obstetrics and Gynecology, Máxima Medical Centre, Veldhoven, Netherlands; [o]Departments of Neonatology and [p]Obstetrics and Gynecology, Wilhelmina Children's Hospital, University Medical Centre, Utrecht, Netherlands; [q]Departments of Neonatology and [r]Obstetrics and Gynecology, Isala Woman and Children's Hospital Zwolle, Zwolle, Netherlands; and [t]Divisions of Obstetrics and Gynecology and [s]Neonatology, Department of Pediatrics, Leiden University Medical Center, Leiden, Netherlands

Drs Geurtzen and Hogeveen conceptualized the study, conducted the literature review, made the first set of recommendations, designed all Delphi rounds, supervised all data analysis, interpreted all data and drafted the framework, drafted the initial manuscript, and reviewed and revised the manuscript; Drs van Heijst and Draaisma supervised and critically revised the first set of recommendations, all Delphi rounds, and data analysis, critically revised the framework and the initial manuscript, and reviewed and revised the manuscript; Ms Kuijpers assisted with the literature review, critically revised the first set of recommendations, assisted with all Delphi rounds, did the initial data analysis, and reviewed and revised the manuscript; Drs Scheepers and Woiski critically revised the framework and the initial manuscript and reviewed and revised the manuscript; Dr Hermens conceptualized the study, supervised and critically revised the first set of recommendations, all Delphi rounds, and data analysis, critically revised the framework and the initial manuscript, and reviewed and revised the manuscript; Drs van Kaam, Oudijk, Lafeber, Bax, Koper, Duin, van der Hoeven, Kornelisse, Duvekot, Andriessen, van Runnard Heimel, van der Heide-Jalving, Bekker, Mulder-de Tollenaer, van Eyck, Eshuis-Peters, and Graatsma helped with data acquisition and critically reviewed the manuscript for important intellectual content; and all authors approved the final manuscript as submitted and agree to be accountable for all aspects of the work.

The study protocol was waived by the central institutional review board (Human Research Committee region Arnhem-Nijmegen, October 19, 2016).

**DOI:** https://doi.org/10.1542/peds.2018-3253

Accepted for publication Mar 25, 2019

Address correspondence to Rosa Geurtzen, MD, Department of Pediatrics, Amalia Children's Hospital, Radboud University Medical Center, PO Box 9101, Internal Code 804, 6500HB Nijmegen, Netherlands. E-mail: rosa.geurtzen@radboudumc.nl

PEDIATRICS (ISSN Numbers: Print, 0031-4005; Online, 1098-4275).



**FINANCIAL DISCLOSURE:** The authors have indicated they have no financial relationships relevant to this article to disclose.

**FUNDING:** No external funding.

**POTENTIAL CONFLICT OF INTEREST:** The authors have indicated they have no potential conflicts of interest to disclose.

## REFERENCES

1. Guillén Ú, Weiss EM, Munson D, et al. Guidelines for the management of extremely premature deliveries: a systematic review. *Pediatrics*. 2015; 136(2):343–350
2. Gallagher K, Martin J, Keller M, Marlow N. European variation in decision-making and parental involvement during preterm birth. *Arch Dis Child Fetal Neonatal Ed*. 2014;99(3):F245–F249
3. Janvier A, Lantos J. Delivery room practices for extremely preterm infants: the harms of the gestational age label. *Arch Dis Child Fetal Neonatal Ed*. 2016;101(5):F375–F376
4. Hendriks MJ, Lantos JD. Fragile lives with fragile rights: justice for babies born at the limit of viability. *Bioethics*. 2018;32(3):205–214
5. Raju TN, Mercer BM, Burchfield DJ, Joseph GF Jr. Periviable birth: executive summary of a joint workshop by the Eunice Kennedy Shriver National Institute of Child Health and Human Development, Society for Maternal-Fetal Medicine, American Academy of Pediatrics, and American College of Obstetricians and Gynecologists. *Obstet Gynecol*. 2014;123(5):1083–1096
6. American College of Obstetricians and Gynecologists; Society for Maternal-Fetal Medicine. Obstetric care consensus no. 6: periviable birth. *Obstet Gynecol*. 2017;130(4):e187–e199
7. Tyson JE, Parikh NA, Langer J, Green C, Higgins RD; National Institute of Child Health and Human Development Neonatal Research Network. Intensive care for extreme prematurity–moving beyond gestational age. *N Engl J Med*. 2008;358(16):1672–1681
8. Lemyre B, Moore G. Counselling and management for anticipated extremely preterm birth. *Paediatr Child Health*. 2017;22(6):334–341
9. Cummings J; Committee on Fetus and Newborn. Antenatal counseling regarding resuscitation and intensive care before 25 weeks of gestation. *Pediatrics*. 2015;136(3):588–595
10. Wilkinson D, Verhagen E, Johansson S. Thresholds for resuscitation of extremely preterm infants in the UK, Sweden, and Netherlands. *Pediatrics*. 2018;142(suppl 1):S574–S584
11. Grobman WA, Kavanaugh K, Moro T, DeRegnier RA, Savage T. Providing advice to parents for women at acutely high risk of periviable delivery. *Obstet Gynecol*. 2010;115(5):904–909
12. Martinez AM, Partridge JC, Yu V, et al. Physician counselling practices and decision-making for extremely preterm infants in the Pacific Rim. *J Paediatr Child Health*. 2005;41(4):209–214
13. Mehrotra A, Lagatta J, Simpson P, Kim UO, Nugent M, Basir MA. Variations among US hospitals in counseling practices regarding prematurely born infants. *J Perinatol*. 2013;33(7):509–513
14. Bastek TK, Richardson DK, Zupancic JA, Burns JP. Prenatal consultation practices at the border of viability: a regional survey. *Pediatrics*. 2005; 116(2):407–413
15. Keenan HT, Doron MW, Seyda BA. Comparison of mothers' and counselors' perceptions of predelivery counseling for extremely premature infants. *Pediatrics*. 2005;116(1):104–111
16. Schrijvers NM, Geurtzen R, Draaisma JMT, Halamek LP, Yamada NK, Hogeveen M. Perspectives on periviability counselling and decision-making differed between neonatologists in the United States and the Netherlands. *Acta Paediatr*. 2018;107(10):1710–1715
17. Geurtzen R, Hogeveen M, Rajani AK, et al. Using simulation to study difficult clinical issues: prenatal counseling at the threshold of viability across American and Dutch cultures. *Simul Healthc*. 2014;9(3):167–173
18. Geurtzen R, van Heijst A, Draaisma J, et al. Professionals' preferences in prenatal counseling at the limits of viability: a nationwide qualitative Dutch study. *Eur J Pediatr*. 2017;176(8): 1107–1119
19. Kaempf JW, Kockler N, Tomlinson MW. Shared decision-making, value pluralism and the zone of parental discretion. *Acta Paediatr*. 2018;107(2): 206–208
20. Griswold KJ, Fanaroff JM. An evidence-based overview of prenatal consultation with a focus on infants born at the limits of viability. *Pediatrics*. 2010;125(4). Available at: www.pediatrics.org/cgi/content/full/125/4/e931
21. Jefferies AL, Kirpalani HM; Canadian Paediatric Society Fetus and Newborn Committee. Counselling and management for anticipated extremely preterm birth. *Paediatr Child Health*. 2012;17(8):443–446
22. Srinivas SK. Periviable births: communication and counseling before delivery. *Semin Perinatol*. 2013;37(6): 426–430
23. Kaempf JW, Tomlinson MW, Campbell B, Ferguson L, Stewart VT. Counseling pregnant women who may deliver extremely premature infants: medical care guidelines, family choices, and neonatal outcomes. *Pediatrics*. 2009; 123(6):1509–1515
24. Lemyre B, Daboval T, Dunn S, et al. Shared decision making for infants born at the threshold of viability: a prognosis-based guideline. *J Perinatol*. 2016;36(7):503–509
25. Haward MF, Gaucher N, Payot A, Robson K, Janvier A. Personalized decision making: practical recommendations for antenatal counseling for fragile neonates. *Clin Perinatol*. 2017;44(2): 429–445

26. Kaempf JW, Tomlinson MW, Tuohey J. Extremely premature birth and the choice of neonatal intensive care versus palliative comfort care: an 18-year single-center experience. *J Perinatol*. 2016;36(3):190–195

27. Cuttini M, Nadai M, Kaminski M, et al; EURONIC Study Group. End-of-life decisions in neonatal intensive care: physicians' self-reported practices in seven European countries. *Lancet*. 2000; 355(9221):2112–2118

28. Orfali K. Parental role in medical decision-making: fact or fiction? A comparative study of ethical dilemmas in French and American neonatal intensive care units. *Soc Sci Med*. 2004; 58(10):2009–2022

29. Lantos JD. International and cross-cultural dimensions of treatment decisions for neonates. *Semin Fetal Neonatal Med*. 2015;20(5):368–372

30. Fanaroff JM, Hascoët JM, Hansen TW, et al; International Perinatal Collegium (IPC). The ethics and practice of neonatal resuscitation at the limits of viability: an international perspective. *Acta Paediatr*. 2014;103(7):701–708

31. Laventhal N, Verhagen AAE, Hansen TWR, et al. International variations in application of the best-interest standard across the age spectrum. *J Perinatol*. 2017;37(2):208–213

32. AGREE Collaboration. Development and validation of an international appraisal instrument for assessing the quality of clinical practice guidelines: the AGREE project. *Qual Saf Health Care*. 2003; 12(1):18–23

33. Jones J, Hunter D. Consensus methods for medical and health services research. *BMJ*. 1995;311(7001):376–380

34. Grypdonck L, Aertgeerts B, Luyten F, et al. Development of quality indicators for an integrated approach of knee osteoarthritis. *J Rheumatol*. 2014;41(6): 1155–1162

35. Woiski MD, Scheepers HC, Liefers J, et al. Guideline-based development of quality indicators for prevention and management of postpartum hemorrhage. *Acta Obstet Gynecol Scand*. 2015;94(10):1118–1127

36. de Laat MW, Wiegerinck MM, Walther FJ, et al; Nederlandse Vereniging voor Kindergeneeskunde; Nederlandse Vereniging voor Obstetrie en Gynaecologie. Practice guideline 'Perinatal management of extremely preterm delivery' [in Dutch]. *Ned Tijdschr Geneeskd*. 2010;154:A2701

37. Geurtzen R, Draaisma J, Hermens R, et al. Perinatal practice in extreme premature delivery: variation in Dutch physicians' preferences despite guideline. *Eur J Pediatr*. 2016;175(8): 1039–1046

38. Geurtzen R, Van Heijst A, Hermens R, et al. Preferred prenatal counselling at the limits of viability: a survey among Dutch perinatal professionals. *BMC Pregnancy Childbirth*. 2018;18(1):7

39. Geurtzen R, Draaisma J, Hermens R, et al. Prenatal (non)treatment decisions in extreme prematurity: evaluation of decisional conflict and regret among parents. *J Perinatol*. 2017;37(9): 999–1002

40. Geurtzen R, van Heijst A, Draaisma J, et alet al. Prenatal counseling in extreme prematurity - Insight into preferences from experienced parents. *Patient Educ Couns*. 2019;S0738-3991(18)30701-8

41. Geurtzen R, Draaisma J, Hermens R, et al. Various experiences and preferences of Dutch parents in prenatal counseling in extreme prematurity. *Patient Educ Couns*. 2018; 101(12):2179–2185

42. Simard M, Gagné AM, Lambert RD, Tremblay Y. A transdisciplinary approach to the decision-making process in extreme prematurity. *BMC Res Notes*. 2014;7:450

43. Brunkhorst J, Weiner J, Lantos J. Infants of borderline viability: the ethics of delivery room care. *Semin Fetal Neonatal Med*. 2014;19(5):290–295

44. Arora KS, Miller ES. A moving line in the sand: a review of obstetric management surrounding periviability. *Obstet Gynecol Surv*. 2014;69(6):359–368

45. Chervenak FA, McCullough LB. Ethical issues in periviable birth. *Semin Perinatol*. 2013;37(6):422–425

46. Haward MF, Kirshenbaum NW, Campbell DE. Care at the edge of viability: medical and ethical issues. *Clin Perinatol*. 2011; 38(3):471–492

47. Wilkinson AR, Ahluwalia J, Cole A, et al. Management of babies born extremely preterm at less than 26 weeks of gestation: a framework for clinical practice at the time of birth. *Arch Dis Child Fetal Neonatal Ed*. 2009;94(1): F2–F5

48. Keogh J, Sinn J, Hollebone K, Bajuk B, Fischer W, Lui K; Consensus Workshop Organizing Committee. Delivery in the 'grey zone': collaborative approach to extremely preterm birth. *Aust N Z J Obstet Gynaecol*. 2007;47(4):273–278

49. Ohlinger J, Kantak A, Lavin JP Jr, et al. Evaluation and development of potentially better practices for perinatal and neonatal communication and collaboration. *Pediatrics*. 2006; 118(suppl 2):S147–S152

50. Lui K, Bajuk B, Foster K, et al. Perinatal care at the borderlines of viability: a consensus statement based on a NSW and ACT consensus workshop. *Med J Aust*. 2006;185(9):495–500

51. Kaempf JW, Tomlinson M, Arduza C, et al. Medical staff guidelines for periviability pregnancy counseling and medical treatment of extremely premature infants. *Pediatrics*. 2006; 117(1):22–29

52. Verlato G, Gobber D, Drago D, Chiandetti L, Drigo P; Working Group of Intensive Care in the Delivery Room of Extremely Premature Newborns. Guidelines for resuscitation in the delivery room of extremely preterm infants. *J Child Neurol*. 2004;19(1):31–34

53. American College of Obstetrics and Gynecology. ACOG practice bulletin. Perinatal care at the threshold of viability. Number 38, September 2002. American College of Obstetrics and Gynecology. *Int J Gynaecol Obstet*. 2002; 79(2):181–188

54. Stiggelbout AM, Pieterse AH, De Haes JC. Shared decision making: concepts, evidence, and practice. *Patient Educ Couns*. 2015;98(10):1172–1179

55. Kessels RP. Patients' memory for medical information. *J R Soc Med*. 2003; 96(5):219–222

56. Janvier A, Lorenz JM, Lantos JD. Antenatal counselling for parents facing an extremely preterm birth: limitations of the medical evidence. *Acta Paediatr*. 2012;101(8):800–804

57. Boss RD, Hutton N, Sulpar LJ, West AM, Donohue PK. Values parents apply to decision-making regarding delivery room resuscitation for high-risk newborns. *Pediatrics*. 2008;122(3): 583–589

58. Lantos JD. Ethical problems in decision making in the neonatal ICU. *N Engl J Med*. 2018;379(19):1851–1860

59. Moore GP, Daboval T, Moore-Hepburn C, Lemyre B. 'Counselling and management for anticipated extremely preterm birth': informing CPS statements through national consultation. *Paediatr Child Health*. 2017;22(6):330–333

60. Fischer F, Lange K, Klose K, Greiner W, Kraemer A. Barriers and strategies in guideline implementation-a scoping review. *Healthcare (Basel)*. 2016;4(3): E36

61. Guillén Ú, Suh S, Munson D, et al. Development and pretesting of a decision-aid to use when counseling parents facing imminent extreme premature delivery. *J Pediatr*. 2012; 160(3):382–387

62. Moore GP, Lemyre B, Daboval T, et al. Field testing of decision coaching with a decision aid for parents facing extreme prematurity. *J Perinatol*. 2017; 37(6):728–734

63. Stacey D, Légaré F, Lewis K, et al. Decision aids for people facing health treatment or screening decisions. *Cochrane Database Syst Rev*. 2017;4: CD001431

64. Taittonen L, Korhonen P, Palomäki O, Luukkaala T, Tammela O. Opinions on the counselling, care and outcome of extremely premature birth among healthcare professionals in Finland. *Acta Paediatr*. 2014;103(3):262–267

65. Brouwers MC, Kho ME, Browman GP, et al; AGREE Next Steps Consortium. AGREE II: advancing guideline development, reporting and evaluation in health care. *J Clin Epidemiol*. 2010; 63(12):1308–1311

66. Binepal N, Lemyre B, Dunn S, et al. Systematic review and quality appraisal of international guidelines on perinatal care of extremely premature infants. *Curr Pediatr Rev*. 2015;11(2):126–134

# Development of Nationwide Recommendations to Support Prenatal Counseling in Extreme Prematurity

Rosa Geurtzen, Arno F.J. van Heijst, Jos M.T. Draaisma, Lindie J.M.K. Kuijpers, Mallory Woiski, Hubertina C.J. Scheepers, Anton H. van Kaam, Martijn A. Oudijk, Harrie N. Lafeber, Caroline J. Bax, Jan F. Koper, Leonie K. Duin, Marc A. van der Hoeven, René F. Kornelisse, Johannes J. Duvekot, Peter Andriessen, Pieter J. van Runnard Heimel, Marja van der Heide-Jalving, Mireille N. Bekker, Susanne M. Mulder-de Tollenaer, Jim van Eyck, Ellis Eshuis-Peters, Margo Graatsma, Rosella P.M.G. Hermens and Marije Hogeveen

*Pediatrics* 2019;143;
DOI: 10.1542/peds.2018-3253 originally published online May 31, 2019;

PEDIATRICS®
OFFICIAL JOURNAL OF THE AMERICAN ACADEMY OF PEDIATRICS

# Development of Nationwide Recommendations to Support Prenatal Counseling in Extreme Prematurity

Rosa Geurtzen, Arno F.J. van Heijst, Jos M.T. Draaisma, Lindie J.M.K. Kuijpers, Mallory Woiski, Hubertina C.J. Scheepers, Anton H. van Kaam, Martijn A. Oudijk, Harrie N. Lafeber, Caroline J. Bax, Jan F. Koper, Leonie K. Duin, Marc A. van der Hoeven, René F. Kornelisse, Johannes J. Duvekot, Peter Andriessen, Pieter J. van Runnard Heimel, Marja van der Heide-Jalving, Mireille N. Bekker, Susanne M. Mulder-de Tollenaer, Jim van Eyck, Ellis Eshuis-Peters, Margo Graatsma, Rosella P.M.G. Hermens and Marije Hogeveen

*Pediatrics* 2019;143;
DOI: 10.1542/peds.2018-3253 originally published online May 31, 2019;