Are Guidelines Needed? International Perspectives on Decision-Making and Practice Variation in the Care of Extremely Preterm Infants

Running title: international views on EPI care guidelines

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Abstract

Objective: To examine international perspectives on the necessity of guidelines for the care of extremely preterm infants (EPIs), what forms such guidance should take, and the extent of practice variation neonatologists find acceptable.

Study Design: Anonymous, online, cross-sectional international survey among neonatologists, exploring current and preferred guidelines and hypothetical scenarios testing acceptance of practice variation in EPI decision-making.

Results: We analyzed 127 responses from 47 countries. Most respondents (55%) preferred a guideline using gestational age (GA) alongside other prognostic factors; 13% preferred no guideline. In scenarios involving borderline viability, variation was accepted when based on parental wishes, cultural norms, or resource constraints, but not when reflecting hospitals or individual differences. Views on directive counseling were divided.

Conclusions: Neonatologists support flexible, structured guidelines that consider more than GA alone. Variation is acceptable when reflecting parental values, cultural norms, or resource constraints but not when driven by individual or institutional preferences.

Introduction

Outcomes for the most premature infants are highly uncertain, making decisions about initiating intensive care or providing palliative care particularly challenging. To support such decisions, many countries have developed perinatal care protocols. However, there's substantial global variation in both outcomes and the content of these protocols with no universal consensus on their structure or scope[1, 2, 3]. Moreover, even when guidance is in place, its implementation can vary, and deviations from the guidelines in practice are common[4, 5, 6, 7, 8]. Existing guidelines can be broadly grouped into four categories[9]: (1) gestational age (GA)-based guidelines, (2) GA-based *plus* guidelines, (3) prognosis-based guidelines and (4) no formal guideline.

Each approach offers distinct advantages and limitations. GA-based guidelines are straightforward to apply, reduce practice variation and provide clear thresholds, but they overlook other important prognostic factors such as birth weight, sex, and antenatal steroid exposure[10, 11, 12, 13]. Furthermore, they rely heavily on GA, an inherently imprecise measure that may be inaccurate by several days in well-resourced settings, and even less precise without access to early ultrasonography as common in low and middle income countries (LMICs)[14, 15]. The proposed use of the term "estimated GA (e-GA)" to account for this uncertainty has seen limited adoption[12]. GA-based plus guidelines incorporate additional prognostic indicators to refine risk estimates. For example, the 2019 UK BAPM practice framework combines GA with other clinical variables to differentiate between extremely high and moderate risks of poor outcome [currently under revision][11]. Prognosis-based guidelines go further, using numerical outcome predictions to guide decisions. While this approach is arguably the most transparent model, it faces challenges in defining what constitutes a ‘favorable’ outcome, reaching consensus on cut-off values and ensuring consistency in prognostic models[15, 16, 17, 18]. Notably, no international validated model exists for extremely preterm infants (EPIs), and predictions vary across centers and countries[19, 20, 21]. Lastly, some clinicians argue that no guideline is needed at all, and care should be individualized[13].

All types of guidelines may include a ‘grey zone’ or 'transition area' where the decision to initiate intensive care is neither strongly recommended nor discouraged[22, 23]. In this zone, parental values and preferences increasingly shape decision-making, reflecting the high degree of uncertainty and deeply personal nature of these choices[22, 24, 25, 26].

Despite their widespread use, the necessity of EPI resuscitation guidelines has been questioned[10, 27, 28]. Critics argue that rigid thresholds based on imperfect proxies may impede ethically appropriate, individualized care and risk unequal treatment of similar cases[28]. Furthermore, to our knowledge, EPIs represent the only patient group with survival and morbidity rates comparable to those of other patients who do receive intensive care, yet whose access is restricted by such age-based policies—an approach that some consider unjust to both infants and their families[29, 30, 31].

While numerous studies have compared GA-based guidelines across countries and professionals[5, 32, 33, 34], a more fundamental question remains: are such guidelines needed at all? Moreover, if so, how much practice variation is acceptable? These issues lie at the heart of ongoing debate over how to balance standardization with individualized decision-making in perinatal care, as was highlighted in a recent Dutch and American work[4, 9]. Existing literature is dominated by perspectives from North America and Europe, leaving cultural and resource-related considerations from other regions underrepresented[32, 35, 36, 37, 38].

This study addresses these gaps by examining, from an international perspective, whether resuscitation guidelines for EPIs are needed, what types are deemed most appropriate, and the extent of practice variation neonatologists view as acceptable.

Subjects and Methods

Study Design

We conducted a cross-sectional, international study using an anonymous online questionnaire to explore neonatologists' view on guidelines for initiating intensive care in EPIs. The survey, adapted from a previously published Dutch study was available from May 2023 to January 2024[9].

Survey Design

The original Dutch survey was based on literature and clinical practice around extreme prematurity. For international use, selected sections were translated into English and refined through iterative feedback with the research team. The translation was pilot tested by native and non-native English speaking healthcare professionals, to ensure clarity and contextual accuracy. The survey was developed in LimeSurvey (GmbH, version 1.91) and was tested for technical functionality. All pilot testers were health care professionals who were not eligible to complete the final survey (e.g., retired or no longer in clinical practice).

The questionnaire included multiple-choice questions and open-text fields, to capture nuanced perspectives. Participants were asked to interpret the concept of 'borderline viability' in the clinical scenarios based on their own local context, recognizing that it could vary widely between countries and clinical settings. For some items, background information and relevant literature references were provided to ensure that respondents could give informed opinions. The final survey consisted of three parts: demographics (7 questions), current and preferred guidelines (6 questions), and clinical scenarios exploring reasons for (non)acceptance of practice variation (7 questions).

The four types of guidelines, as described in the introduction (GA-based / GA-based plus / prognosis-based / no guideline), were explained in the second subsection (Online Supplemental Appendix A).

Setting and Participants

The survey targeted neonatologists, however in the invitation text we stated: *“Help us find a neonatologist (or pediatrician) in every country in the world to fill out our questionnaire!”* This phrasing was chosen deliberately to ensure inclusion of relevant expertise from settings with few formally trained neonatologists, where others may provide neonatal intensive care. Participants were recruited using a snowball sampling strategy through professional networks, social media, neonatal mailing lists and targeted outreach to authors of related publications from outside Europe and North America[35, 38, 39]. Emphasis was placed on including respondents from a diverse range of regions and countries, rather than achieving a very high response solely from high-income countries, and additional recruitment efforts during the survey period were pragmatically focused on countries that were underrepresented or not yet represented. Support came from the European Society for Pediatric Research (ESPR) by endorsing this survey and mentioning in their newsletter.

Ethical Considerations

Participation was voluntary and anonymous; no identifiable data was collected. Informed consent was obtained in the opening page of the survey. According to national regulations, Institutional Review Board (IRB) approval was waived, as the study did not involve patient data or interventions (CMO Radboudumc file 2022-15942).

Data Analysis

Survey responses were analyzed using descriptive statistics. Results are presented as proportions of respondents for each completed item. Open-ended responses were reviewed (SK, RG) for thematic content. All quantitative analyses were performed using IBM SPSS Statistics (Version 29, Armonk, NY: IBM Corp.).

Results

We received 127 completed surveys from 47 countries across all continents.

I Demographics

The majority of respondents worked in Europe (62%) and the vast majority were practicing neonatologist (80%) (Table 1). Thirty-nine respondents (31%) worked in LMICs. A small number of other respondents identified as pediatricians or nurse (managers) involved in neonatal care.

Participants worked in level II to IV neonatal units, most had a Christian affiliation, and the majority were from the 40–60-year age category. Two countries had >10 participants (United Kingdom n=13, the Netherlands n=11), four countries had 5-9 participants (Hungary and Romania both n=7, South Africa and USA both n=6), 18 countries had 2-4 participants (Czechia, Germany, Greece, Nigeria, Sweden and Turkey each n=4, Australia, Austria, Ireland, Italy, Lebanon and Spain each n=3, Brazil, Canada, Ethiopia, Indonesia, Mexico and Switzerland each n=2). The remaining 23 countries had one participant each (Bangladesh, Belgium, China, Curacao, Denmark, El Salvador, Iceland, Israel, Liberia, Madagascar, Malawi, New Zealand, North Macedonia, Norway, Serbia, Singapore, Slovenia, Suriname, Tanzania, Tunisia, Ukraine, Zambia, and Zimbabwe).

II Current and preferred guidelines

One quarter of respondents (24%) reported having no guideline for perinatal treatment in extreme prematurity. The majority (55%) reported access to a national guideline, while others indicated the presence of institutional (30%) or a regional (9%) guideline.

When asked about preferred guideline types, over half favored a GA-based plus guideline (55%), followed by prognosis-based guideline (19%), no guideline (13%) and GA based (10%) (Table 2). Open comments revealed widespread opposition to rigid cut-off thresholds, with many advocating for approaches that integrate additional prognostic factors. Some responses showed reluctance to rely on (any) formal guideline.

Respondents were also asked to indicate GA boundaries of the grey zone, defined as the range where active treatment is neither strongly recommended nor routinely withheld. As shown in Figure 1, most respondents placed the lower limit between 22- and 24-weeks GA, and the upper limit between 24- and 25-weeks GA, although responses varied substantially.

III Clinical scenarios to explore reasons for the (non)acceptance of practice variation.

Textbox. Hypothetical case and situations

A pregnant woman (G1P0) has been admitted to a specialized center with cervical shortening and contractions. She is carrying a single female fetus at borderline viability**. Antenatal corticosteroids have not been administered yet. In situation A the choice is made to implement palliative comfort care if the labor progresses today. In situation B the choice is made to implement neonatal intensive care / resuscitation if the labor progresses today, and to administer corticosteroids. We have provided a number of (hypothetical!) explanations for the difference between situation A and situation B. Please indicate whether you find this acceptable or not.

*** Borderline viability is defined here as a GA that is (in your setting) in the grey zone, and could for example be a GA of* $23^{+2/7}$ *weeks in the United Kingdom (link) or a GA of* $25^{+2/7}$ *weeks in the Philippines (link).*

Participants were presented with a clinical scenario involving a pregnant woman, where two different management decisions were described: palliative comfort care (Scenario A) versus neonatal intensive care including corticosteroid administration (Scenario B) (see textbox). Six hypothetical explanations were provided for the difference in care decisions. Participants were asked to indicate whether they found the explanation acceptable. As shown in Table 3 three explanatory factors; parental wishes, cultural or social values, and resource availability, were commonly regarded as acceptable. Opinions on directive counseling towards intensive care (to improve survival) were divided, with 47% considering it acceptable and 42% considering it unacceptable. However, two explanatory factors were considered unacceptable: variation between individual hospitals (62% unacceptable), and variation between individual physicians (73% unacceptable). A detailed overview of all clinical scenarios is provided in Appendix A.

Numerous open-text comments were provided in response to the clinical scenarios. Several themes emerged across responses: a key theme was the tension between ethical ideals and practical constraints. While treatment differences due to resource availability were acknowledged as ethically concerning, they were also recognized as, at times, unavoidable. In LMICs, the provision of active intensive care is particularly restricted due to limited infrastructure and resources. *“Based on the reality of conditions in many LMICs. Many hospitals do not even have a NCU, or offer essential newborn care. First priority should be to improve essential newborn care and implement effective evidence-based practices, then when this is in place offer intensive care treatment.”* Another participant stated *“as motivation for the difference between offering active care or not it* [resource availability] *is acceptable, however the* *disparity in resources is not acceptable."* Several participants emphasized the need to work toward greater equity in neonatal care, both within and across countries. *"I find the global wealth/access to healthcare gap ethically very difficult to accept. Ideally, we should work towards closing the gap within countries and globally rather than having the current trend of opening up this gap."*

Some respondents literally emphasized that clinicians, both within individual hospitals and across countries, should uniformly adhere to guidelines. Furthermore, some respondents highlighted the importance of informing parents about the availability of centers that do offer care. *"So one center might choose not to routinely apply care below a certain threshold, but should inform parents about the availability of those centers were care is undertaken if it was within the same country."* Involving parental preferences was regarded as essential in the decision-making process*. "Majority of we Neonatologist/Obstetricians from LMIC Countries have poor, inadequate equipment so our GA of viability cannot be lowered to less than 28 weeks. How ever, when a baby is born at GA below 28 weeks will be discussed with parents and take a next decision together with them after they have been informed."* Some participants emphasized that care decisions should not be applied universally, but rather be individualized, considering a range of contextual factors such as parental age, religious beliefs, and prevailing social norms. *"...many factors should be considered aside from the GA alone and the chances for survival. Parents' age, education level, history of infertility treatment(s), desirability for the future baby, religiosity, social norms, available resources, parental support immediate and future etc.... Each case should be treated individually."* Finally, legal regulations were mentioned to play a role. "*Questions should be asked about the legal regulations in the country because it might affect the answers. For example, in Hungary, there is no legally* *acceptable way to withdraw intensive care or change to palliative care in case of very poor conditions. Legally, all the newborn patients should receive active intensive care if they show signs of life. Neither the parents nor the medical team can decide otherwise, even if they agree that the baby's best interest is palliative care.”*

Discussion

This study provides new insights into international perspectives on the role and necessity of guidelines in managing EPIs at the threshold of viability. We systematically explored not only where to set limits regarding neonatal intensive care in extreme prematurity, but also whether and why guidelines are needed at all—questions that, despite extensive debate on thresholds, have received little empirical attention.

While most respondents reported access to guidelines and supported their continued use, there was strong preference for flexible GA-plus frameworks that integrate prognostic factors, rather than strict GA thresholds. The results indicate that neonatologists value structured guidance but not at the expense of individualized care. And, despite concerns about the ethical limitations of current guidelines, few respondents support abandoning them entirely. At the same time, variation in practice is generally accepted—indicating that guidelines were not seen as absolute directives, but as frameworks that should explicitly allow contextual adaption. Respondents clearly distinguished between acceptable and unacceptable sources of variation. Differences based on parents’ wishes, societal norms, or healthcare resources were broadly tolerated, while inconsistencies between hospitals or individual clinicians were not. This highlights the importance of consistency within systems and the ethical imperative to ensure equitable access to care.

Three key insights emerge from these survey results: First, guidelines cannot remove all variation. Even when guidelines are present, variation persists due to parental values and local context. Well-designed guidelines can explicitly accommodate such factors—for example, by defining grey zones in which parental preferences guide decisions, or by allowing flexibility to account for cultural or resource-related differences. Moreover, guideline updates should assess non-adherence to identify structural barriers and potential evolving clinical realities that warrant guideline revision. Second, international uniformity is neither realistic nor necessary. As Wilkinson and Haydn have argued, decisions at the threshold of viability are so ethically and culturally complex that complete international consistency is neither realistic nor ethically necessary[40]. National policies will inevitably reflect different societal priorities, such as giving more weight to parental autonomy or to cost control, and these differences can be ethically legitimate. Third, equity remains a central concern. The global disparity in neonatal care, as also recently addressed in this review on global survival of EPIs[3], raises significant ethical concerns. Policy efforts should focus on reducing these disparities—though the most significant and feasible gains in survival and health outcomes are likely to be achieved not among the most vulnerable infants at the edge of viability, but among critically ill infants who are not extremely premature whose baseline prognosis is better[41, 42].

Our findings align with previous work calling for a shift away from GA-only approaches towards individualized, prognosis-based decision-making[9, 11, 43]. While each additional day of gestation can significantly affect outcomes, many decisions in practice still hinge on completed weeks. The persistence of the “Cinderella effect”—where decisions depend on completed weeks rather than days—highlights the difficulty of translating nuanced ethical reasoning into daily practice[7, 15, 44]. Even in the most advanced frameworks, such as the BAPM guidelines, evaluations reveal ongoing inconsistency in how recommendations are interpreted and applied[8].

A further unresolved issue is whether the potential for better outcomes with proactive treatment justifies limiting parental choice. In our survey, respondents were divided on this question, underscoring the ethical tension between striving for improved survival and respecting parental autonomy. While studies such as Backes et al[45, 46] demonstrate that institutional commitment to active treatment at the edge of viability can lead to better outcomes, it remains contested whether such approaches should outweigh parents' preferences in situations of profound uncertainty. Furthermore, responses could also be influenced by cultural norms around whether to include parents in decision-making at all.

Strengths and limitations

The main strength of this study is its focus on practice variation, a dimension often neglected in prior research. Furthermore, its international approach is a strength, specifically the inclusion of respondents from LMICs which have been understudied historically. However, the sample size was modest, with underrepresentation from LMICs despite targeted recruitment. The distribution of respondents across countries was uneven, reflecting both pragmatic recruitment choices and differences in the size and accessibility of national neonatal communities, which may have introduced sampling bias. Additionally, while efforts were made to include LMIC respondents, the survey questions themselves may have been framed in ways more typical of high-income settings, potentially limiting their relevance. These factors constrain generalizability and underscore the need for future studies conducted in closer collaboration with neonatal societies in underrepresented regions.

Conclusion

Perinatal decision-making at the threshold of viability remains ethically and clinically complex. Neonatologists broadly support the use of structured but flexible guidelines that move beyond GA alone. While contextual variation—influenced by parental preferences, cultural values, or resource availability—is widely accepted, inconsistencies between hospitals or individual clinicians are not.

Future efforts should focus on developing frameworks that balance consistency with flexibility, promote equity across diverse healthcare settings, and foster shared decision-making with parents.

Box: Key considerations for guidelines on decision-making in extremely and very premature infants

For Policy-Makers

- *Develop flexible GA-plus frameworks that include a clearly defined grey zone to support shared decision-making.*
- *Promote system-wide consistency while recognizing that legitimate variation may stem from cultural or resource-related factors.*
- *Strengthen equity by reducing disparities in access to care and outcomes, especially between regions and across socioeconomic settings.*
- *Acknowledge limits to transferability: recommendations from high-income settings may not directly apply to low- and middle-income settings due to differences in resources, infrastructure, and cultural norms.*

For Healthcare Providers

- *Use guidelines as structured support tools rather than rigid rules, integrating relevant prognostic factors alongside GA.*
- *Engage in transparent, values-based decision-making with parents, especially when cases fall within the grey zone,.*
- *Strive for consistency across colleagues and institutions, while openly communicating any limitations imposed by available resources.*
- *Monitor guideline non-adherence, examine its causes, and help refine*

future guidelines to reflect evolving realities and contexts.

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Figure and table legends

Table 1. Background characteristics of the study population (n=127).

Table 2. Current guidelines and preferences

Table 3. Hypothetical explanations for differences in strategy (n=127).

Figure 1. GA boundaries of the grey zone—below which only palliative comfort care is offered and above which NICU treatment is initiated by default—assuming GA as the primary guiding criterion. The size of the bubbles reflects the relative amount out of all responses.