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Swiss Recommendations for the Perinatal Care of Extremely Low Gestational Age Neonates

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ABSTRACT

Aim: To revise the 2011 Swiss recommendations for the perinatal care of extremely low gestational age neonates (ELGANs).

Methods: Based on review of recent literature, experts from various medical specialties involved in the perinatal care of ELGANs made suggestions for revisions. Following discussions, changes accepted by the whole working group were incorporated into the revised manuscript.

Results: The revised recommendations highlight the importance of individualised risk assessment and emphasise the importance of shared decision-making. While the care of preterm infants with a gestational age below 23 0/7 weeks should be limited to comfort-focused palliative care, risk assessment in preterm infants with a gestational age ≥ 23 0/7 weeks must be individualised by considering additional non-modifiable and modifiable risk factors; decision-making based on gestational age alone must be abandoned.

Conclusions: Management options for ELGANs will fall into three different trajectories. First, if survival-focused care is not in the patient's best interest, preference should be given to comfort-focused palliative care. Second, if survival-focused care clearly is in the patient's best interest, survival-focused care will be provided. Third, if the patient's best interest is uncertain, both survival-focused and comfort-focused palliative care can be considered and parental preferences must be explored, respected, and supported.

1 | Introduction

The first Swiss recommendations for the care of infants born at the limit of viability were published in 2002 and modified in 2011. Since then revised recommendations from North America and Europe [1–3] and new mortality and morbidity data, including results from Switzerland [4], have become available, prompting the revision of the Swiss recommendations. National recommendations are necessary because ethical decision-making is not only based on widely accepted ethical principles but is also strongly influenced by societal, economic, and legal considerations [5, 6]. This article represents an executive summary of these recommendations; the full version is available as Supporting Information in three different languages (see Appendix S1: English, Appendix S2: German, Appendix S3: French).

Abbreviations: CTG, cardiotocogram; ELGANs, extremely low gestational age neonates; HCPs, health care professionals.

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Key Notes

- The revised Swiss recommendations emphasise the limited value of risk assessment based on gestational age alone.
- The concept of a gestational age-based grey zone has been replaced by an individualised and structured risk assessment, which considers modifiable and non-modifiable risk factors
- They explain the central role of shared decision-making and emphasise the role of parental authority, particularly in situations where the infant's best interest is unclear.

While the revised recommendations continue to define a gestational age limit below which survival-focused care is not recommended (23 0/7 weeks), they no longer describe an upper gestational age limit beyond which life-sustaining therapies should always be offered. Rather than defining limits that emphasise gestational age, they highlight the importance of a structured and individualised risk assessment and decision-making process that considers all aspects that can impact on a particular infant's prognosis. The recommendations also recognise the difficulty of dichotomizing decision-making (survival-focused care versus comfort-focused palliative care) when faced with continuous and dynamic variables, such as gestational age and estimated foetal weight.

The principles of ethical decision-making are re-emphasised. The guidelines again highlight the importance of an interdisciplinary approach and shared decision-making. They discuss parental authority and strengthen the role of parents in situations where the assessment of burden and benefit of survival-focused care can reasonably be described as equivocal.

The new guidelines describe appropriate and coherent obstetrical and neonatal approaches to both survival- and comfort-focused palliative care based on current evidence. Importantly, they provide up-to-date information on mortality and morbidity rates of extremely low gestational age neonates (ELGANs) cared for in Switzerland [4]. They emphasise that decision-making must be based on mortality and morbidity rates for infants who have received survival-focused care, whereas infants who have received a priori comfort-focused palliative care must be excluded since all these infants will inevitably have died, leading to underestimation of true chances of survival.

In addition, visual aids have been developed to be used in counselling. They standardise outcome information presented by the health care professionals (HCPs) and may be useful to help parents understand the consequences of extremely preterm birth.

Finally, the authors of these recommendations acknowledge that, globally, the availability of resources and, therefore, the quality of neonatal care continue to differ enormously, leading to wide gaps regarding the definition of what is considered to be the limit of viability. The authors agree that privileged countries should recognise these inequalities and support efforts to diminish the existing gaps.

2 | Individualised Risk Assessment

2.1 | Importance and Limitations of Gestational Age Assessment

Gestational age continues to be a strong predictor of risk and must be taken into consideration when overall risk assessment is performed. However, even the best methods to estimate gestational age are not precise.

It is also important to realise that even though outcome data are stratified into segments of weeks, outcomes at either end may be closer to those of the adjacent week than those at the other end of the same week (e.g., outcomes at 23 6/7 weeks are likely more comparable to those at 24 0/7 weeks than those at 23 0/7 weeks). Defining outcomes based on completed weeks arbitrarily eliminates the differences between a foetus at 23 0/7 weeks and one at 23 6/7 weeks of gestation, as well as the similarities between a foetus at 23 6/7 weeks and 24 0/7 weeks of gestation.

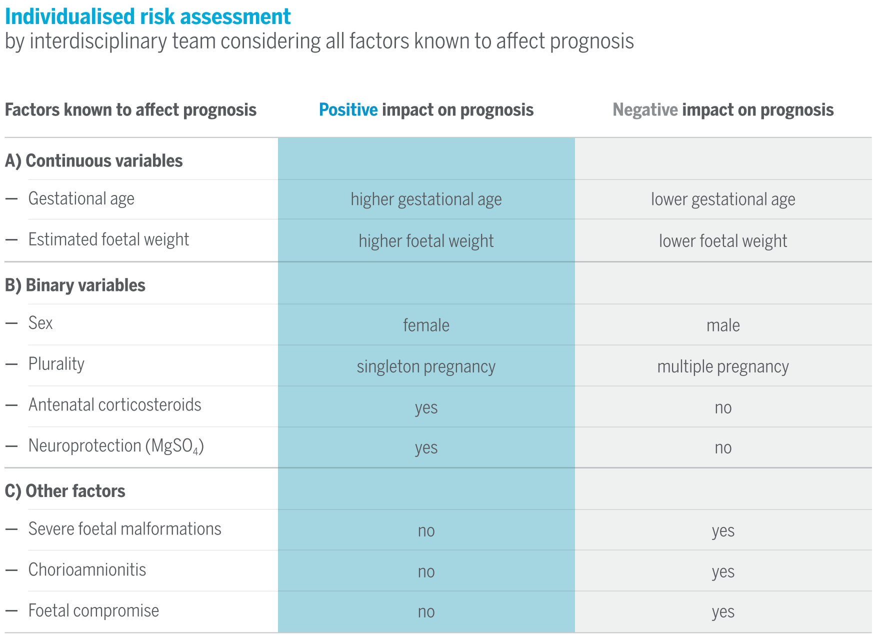
2.2 | Additional Risk Factors

Apart from gestational age, several additional risk factors that can be determined prior to delivery have been found to be associated with short- and long-term outcomes (Figure 1).

Non-modifiable perinatal risk factors include estimated foetal weight, infant gender, ethnicity, and plurality (single vs. multiple gestation). Less well explored and therefore less quantifiable, but likely to be of significance, are early (i.e., second trimester) premature rupture of membranes, anhydramnios, clinical evidence of amnion infection syndrome, placental insufficiency, complications of monochorionic twin pregnancies, as well as severe congenital malformations (e.g., congenital heart disease requiring early interventions, abdominal wall defects, congenital diaphragmatic hernia).

In addition, there are potentially modifiable perinatal factors that can have a significant impact on the prognosis of ELGANs. Modifiable obstetric practices include antenatal interventions (e.g., antenatal corticosteroids for foetal maturation, tocolysis, antibiotics for (prolonged) premature rupture of membranes, magnesium sulphate ($MgSO_4$) for neuroprotection, delayed cord clamping), as well as the site and mode of delivery. Following delivery, the site of neonatal care, initial neonatal resuscitation in the delivery room, subsequent care in the neonatal intensive care unit and approaches to redirection of care are potentially modifiable neonatal practices.

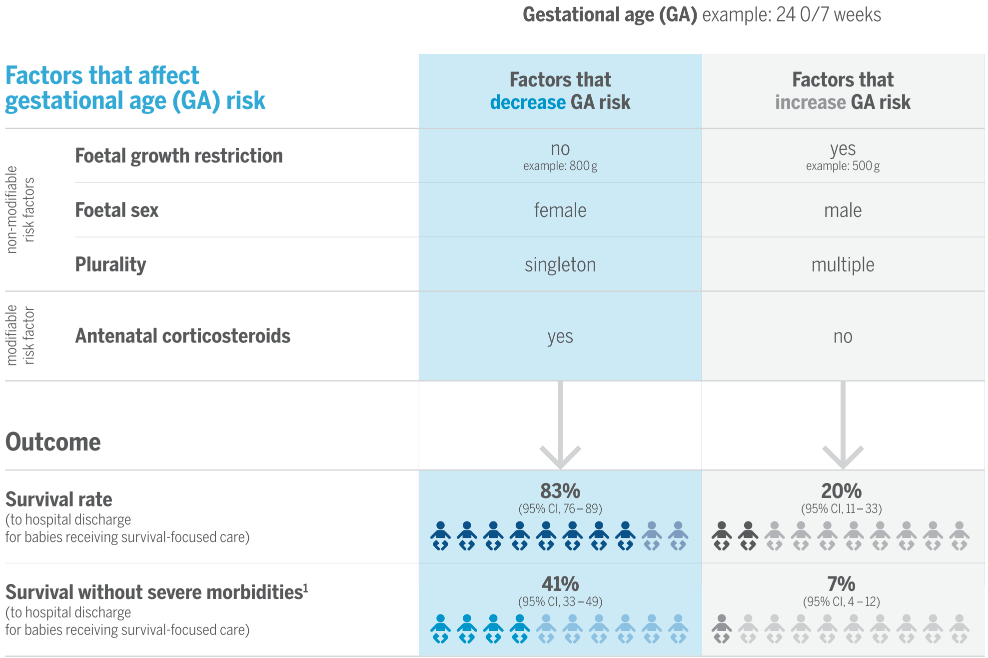
The Swiss Neonatal Network has developed an Outcome Calculator (https://www.neonet.ch/outcome-calculator/calculation-form) that, in addition to gestational age, considers estimated foetal weight, gender, plurality, and antenatal corticosteroids for foetal maturation (Figure 2).



Individualised risk assessment
by interdisciplinary team considering all factors known to affect prognosis

Factors known to affect prognosis	**Positive** impact on prognosis	**Negative** impact on prognosis
A) Continuous variables		
— Gestational age	higher gestational age	lower gestational age
— Estimated foetal weight	higher foetal weight	lower foetal weight
B) Binary variables		
— Sex	female	male
— Plurality	singleton pregnancy	multiple pregnancy
— Antenatal corticosteroids	yes	no
— Neuroprotection ($MgSO_4$)	yes	no
C) Other factors		
— Severe foetal malformations	no	yes
— Chorioamnionitis	no	yes
— Foetal compromise	no	yes

FIGURE 1 | Individualised risk assessment for the perinatal management of ELGANs with a gestational age ≥ 23 0/7 weeks.



Gestational age (GA) example: 24 0/7 weeks

	Factors that affect gestational age (GA) risk	**Factors that decrease GA risk**	**Factors that increase GA risk**
non-modifiable risk factors	**Foetal growth restriction**	no example: 800 g	yes example: 500 g
	Foetal sex	female	male
	Plurality	singleton	multiple
modifiable risk factor	**Antenatal corticosteroids**	yes	no
	Outcome		
	Survival rate (to hospital discharge for babies receiving survival-focused care)	**83%** (95% CI, 76 – 89)	**20%** (95% CI, 11 – 33)
	Survival without severe morbidities[1] (to hospital discharge for babies receiving survival-focused care)	**41%** (95% CI, 33 – 49)	**7%** (95% CI, 4 – 12)

FIGURE 2 | Prognostic impact of prenatally known risk factors on gestational age-specific outcomes: example of extremely preterm delivery at 24 0/7 weeks of gestation. Estimates displayed are based on prospectively collected data (2018–2022) from the Swiss Neonatal Network (see Outcome Calculator), including all infants born with a gestational age < 32 0/7 weeks and/or a birth weight of 400 to 1500 g. [1]Necrotizing enterocolitis Bell's stages 2–3, intra/periventricular hemorrhage grade 3–4, moderate to severe bronchopulmonary dysplasia, retinopathy of prematurity stages 3–4.

3 | Decision-Making Process

3.1 | Ethical Considerations

There is consensus regarding the importance of the relevant ethical principles (i.e., beneficence, non-maleficence, autonomy, and justice), but several conflicts can arise when these principles are applied to ELGANs.

One major conflict arises from the question of how the physician's duty to preserve life could be modified by thoughts about the achievable quality of life. If it is not permissible to take the quality of life into account, and human life must be supported with all available means, there is a risk of inappropriate or even excessive therapy. On the other hand, to only accept life-sustaining therapies if a certain quality of life can be guaranteed could be regarded as discrimination toward the disabled. A possible compromise between those two extreme positions might be to ask the question if the burden imposed on the patient by the various interventions can be ethically justified when confronted with a very unfavourable prognosis. In such situations, the decision to withhold or withdraw life-sustaining therapies is motivated by the desire to protect the patient from undue suffering.

3.2 | Recent Outcome Data

3.2.1 | Mortality Rates

Developments in perinatal care in recent decades have dramatically increased survival rates of ELGANs [7]. For a variety of reasons (e.g., different ethical positions regarding the initial care of infants born at less than 24 0/7 weeks of gestation, and varying practices of redirection of care when severe complications occur), comparisons of various national recommendations from high-income countries and current national [4] and international [8–14] outcome data reveal considerable differences.

It is important to note that calculation of mortality risk among ELGANs will differ depending on the denominator used [15, 16]. This is particularly evident for infants born at 23 weeks of gestation, where the calculated mortality risk in Switzerland, for example, decreases from 73% (denominator: all liveborn infants) to 42% (denominator: infants receiving survival-focused care) (Table 1).

3.2.2 | Long-Term Outcomes

Although neurodevelopment remains highly relevant for the assessment and classification of newborn outcomes, other physical and psychological outcomes are also important. In recent years, research has also shown associations between prematurity and long-term respiratory [17], cardiovascular [18], and renal morbidity [19]. In addition, a typical behavioural phenotype has been described in children born very preterm, including internalising symptoms (such as anxiety), attention deficits, and problems with peer relationships [20]. Moreover, prematurity is associated with an increased risk of autism spectrum disorder [21].

Swiss and international population-based data on mid- to long-term outcomes of infants born at 22 to 25 weeks' gestation are shown in Tables 2 and 3. While this representative data allows for descriptive comparison among Switzerland and other high-income countries, some have been published more than 10 years ago, describing outcomes of babies born more than 15 years ago (Table 2) [4, 9, 11, 12, 14, 22, 23].

Relying solely on outcomes at 2 to 3 years runs the risk of misclassifying long-term cognitive or neuromotor findings. From early school age, a more accurate assessment of cognitive functioning and motor and sensory outcomes is possible, and developmental trends of individuals are becoming more discernible. For this reason, data on outcomes evaluated at ages 5 to 6.5 years are provided separately (Table 3) [4, 24, 25]. Limiting factors include the small sample size at 22–23 weeks' gestation and loss to follow-up of 20% to 40% [4, 9, 11, 12, 14, 22–25].

At the corrected age of 2 to 3 years (Table 2), about 40% to 50% of survivors after preterm birth at 22 weeks of gestation have a favourable neurodevelopmental outcome (i.e., without moderate-to-severe impairment); this rate increases by approximately 10% points for each additional gestational week. Reported outcome figures vary largely between countries.

At the corrected age of 5 to 11 years (Table 3), population-based, gestational age-specific data about neurodevelopmental outcomes is scarce, especially for children born most prematurely. One study reported a favourable outcome in 40% of survivors who had been born at 22 weeks' gestation. This rate increases by about 10% points for each additional week of gestation. The rate of severe neurodevelopmental impairment, which is 20%–30% in surviving children who had been born at 22 to 23 weeks' gestation, decreases to 6%–12% in children who had been born at 25 weeks of gestation. The high outcome variability between various countries may be partly explained by different study methodologies (differences in the age of assessment and the assessment tools used, e.g., classic developmental diagnosis versus parent questionnaires).

3.3 | Trajectories Following Individualised Risk Assessment

While the revised recommendations state that risk assessment based on gestational age alone must be abandoned, they do not recommend initiating life-sustaining therapies at less than 23 0/7 weeks of gestation given an extremely high risk of adverse outcome.

In contrast, when gestational age is ≥23 0/7 weeks, interdisciplinary individualised risk assessment is recommended. Depending on the result of these deliberations, it may lead to three different trajectories.

First, if it is concluded that the imposed burden clearly exceeds the anticipated benefit for a particular patient, survival-focused care is not indicated. Parents should be informed that comfort-focused palliative care will be provided. Parental authority is limited, and they cannot insist that survival-focused interventions be administered to their child if they are considered futile.

Second, if the anticipated benefit clearly exceeds the imposed burden in a particular patient, non-initiation of life-sustaining therapies would not be ethically justifiable. Again, parental authority is limited, and they cannot insist that beneficial interventions are withheld.

Third, in between the above-mentioned situations, individual risk assessment can be equivocal. In those situations, parental authority plays a central role and is decisive. It is imperative to explore their attitudes, to respect their authority, and to support their final decision (Figure 3).

3.4 | Shared Decision-Making

Since the preterm infant cannot communicate his/her preferences, decisions must be made by proxy. This surrogate

TABLE 1 | Gestational age-specific mortality rates among ELGANs in Switzerland, the USA, Japan, Sweden, France, Norway, the UK, and the Netherlands. Impact of different denominators: "all liveborn infants" (1A), "infants receiving survival-focused care," or "infants admitted to a neonatal intensive care unit" (1B).

1A

	Switzerland	**USA**	**Japan**	**Sweden**	**France**	**Norway**	**UK**	**Netherlands**
Gestational age (weeks)	**2019–2023**	**2013–2018**	**2008–2012**	**2004–2007**	**2011**	**2013–2014**	**2006**	**2018–2020**
	SNN [4]	NICHD [9]	NDJN [11]	EXPRESS [10]	EPIPAGE-2 [8]	NEPS [13]	EPICure 2 [12]	EPI-DAF [14]
	($N = 710$)	($N = 4635$)	($N = 1839$)	($N = 501$)	($N = 641$)	($N = 191$)	($N = 1454$)	($N = 568$)
Denominator	All liveborn infants							
22 0/7–22 6/7	100%	81%	54%	90%	100%	82%	98%	—
23 0/7–23 6/7	73%	51%	27%	48%	99%	71%	81%	—
24 0/7–24 6/7	37%	30%	15%	33%	69%	44%	60%	58%
25 0/7–25 6/7	18%	21%	—	19%	41%	16%	34%	31%

1B

	Switzerland	**USA**	**Japan**	**Sweden**	**France**	**Norway**	**UK**	**Netherlands**
Gestational age (weeks)	**2019–2023**	**2013–2018**	**2008–2012**	**2004–2007**	**2011**	**2013–2014**	**2006**	**2018–2020**
	SNN [4]	NICHD [9]	NDJN [11]	EXPRESS [10]	EPIPAGE-2 [8]	NEPS [13]	EPICure 2 [12]	EPI-DAF [14]
	($N = 533$)	($N = 4117$)	($N = 1796$)	($N = 432$)	($N = 405$)	($N = 168$)	($N = 1265$)	($N = 485$)
Denominator	Infants receiving survival-focused care				Infants admitted to a neonatal intensive care unit			
22 0/7–22 6/7	100%	70%	49%	74%	100%	40%	84%	—
23 0/7–23 6/7	42%	44%	25%	35%	86%	65%	70%	—
24 0/7–24 6/7	31%	29%	15%	27%	49%	42%	53%	46%
25 0/7–25 6/7	17%	20%	—	17%	36%	14%	31%	25%

role may be played by the HCPs, the parents of the infant or by a societal body, such as an ethics committee or, in some rare cases, a court of law. Ideally, such decisions should not be made by a single party at a particular point in time but should rather be developed in an ongoing dialogue between all parties involved, namely physicians, midwives, nursing staff, and parents within a shared decision-making process [26].

Communicating complex issues in an appropriate way, which is adapted to the parent's current level of understanding, requires competence and experience. Therefore, these discussions must always be led by experienced and appropriately trained senior obstetricians/foetomaternal medicine specialists and neonatologists. The goal of these conversations is to establish and maintain a trusting relationship between parents and HCPs. Parents should be provided with adequate

TABLE 2 | Gestational age-specific mortality rates and rates of permanent neurosensory impairment of liveborn infants at a corrected age of 2 to 3 years among ELGANs in Switzerland (2017–2021, *N* = 742), Sweden, France, Netherlands, USA, the UK, and Japan.

2A

Gestational age				
22 0/7–22 6/7 weeks	**Mortality rates**	**Survival with severe impairment**[a]	**Survival with moderate impairment**[b]	**Survival without severe**[a] **or moderate**[b] **impairment**
Denominator	**All live born infants**	**Survivors at follow-up**		
SNN [4]	100%	—	—	—
EXPRESS [22]	90%	40%	20%	40%
EPIPAGE-2 [23]	100%	—	—	—
The Netherlands [14]	—	—	—	—
NICHD [9]	81%	31%	24%	45%
EPICure [12]	98%	10%	42%	48%
Japan [11]	54%	54%		46%

2B

Gestational age				
23 0/7–23 6/7 weeks	**Mortality rates**	**Survival with severe**[a] **impairment**	**Survival with moderate**[b] **impairment**	**Survival without severe**[a] **or moderate**[b] **impairment**
Denominator	**All live born infants**	**Survivors at follow-up**		
SNN [4]	79%	19%	23%	58%
EXPRESS [22]	49%	21%	30%	49%
EPIPAGE-2 [23]	100%	—	—	—
The Netherlands [14]	—	—	—	—
NICHD [9]	51%	34%	35%	31%
EPICure [12]	81%	29%	18%	53%
Japan [11]	27%	42%		58%

2C

Gestational age				
24 0/7–24 6/7 weeks	**Mortality rates**	**Survival with severe**[a] **impairment**	**Survival with moderate**[b] **impairment**	**Survival without severe**[a] **or moderate**[b] **impairment**
Denominator	**All live born infants**	**Survivors at follow-up**		
SNN [4]	38%	4%	25%	71%
EXPRESS [22]	34%	13%	21%	66%
EPIPAGE-2 [23]	69%	74%		26%
The Netherlands [14]	58%	13%		87%
NICHD [9]	30%	29%	30%	41%

(Continues)

TABLE 2 | (Continued)

2C

Gestational age **24 0/7–24 6/7 weeks**	**Mortality rates**	**Survival with severe[a] impairment**	**Survival with moderate[b] impairment**	**Survival without severe[a] or moderate[b] impairment**
Denominator	**All live born infants**	**Survivors at follow-up**		
EPICure [12]	60%	19%	16%	65%
Japan [11]	15%	35%		65%

2D

Gestational age **25 0/7–25 6/7 weeks**	**Mortality rates**	**Survival with severe[a] impairment**	**Survival with moderate[b] impairment**	**Survival without severe[a] or moderate[b] impairment**
Denominator	**All live born infants**	**Survivors at follow-up**		
SNN [4]	17%	9%	14%	77%
EXPRESS [22]	19%	10%	17%	73%
EPIPAGE-2 [23]	41%	45%		55%
The Netherlands [14]	31%	13%		87%
NICHD [9]	21%	18%	30%	52%
EPICure [12]	35%	16%	12%	72%
Japan [11]	—	—		—

[a] Severe impairment: developmental score < −3SD and/or cerebral palsy level 3 to 5 GMFCS (Gross Motor Function Classification System) and/or bilateral deafness and/or bilateral blindness.

[b] Moderate impairment: developmental score < −2SD and/or cerebral palsy level 2 GMFCS (Gross Motor Function Classification System) and/or bilateral vision and/or hearing disability.

information so that they can actively participate in decision-making regarding pre- and postnatal maternal and infant care. This information should be precise, comprehensive, and unbiased; it should be presented using appropriate terms and understandable language. It has been shown that the way messages are relayed (so-called message framing) significantly influences the parent's perception of their child's condition and their treatment decisions [27].

Visual aids may help parents to better understand statistical data on various outcomes. Moreover, the use of visual decision aids has been associated with improvements in the quality of decisions due to a closer alignment of values and choices [28]. To avoid any bias, both chances of survival and survival without severe impairment and risks of mortality and survival with severe morbidity should be displayed. Ideally, most recent local centre-specific (rather than national) outcome data should be used (Figure 4).

4 | Survival-Focused Care

4.1 | Obstetrical Aspects

4.1.1 | Consultation at a Level III Perinatal Centre at < 22 0/7 Weeks of Gestation

Outpatient consultation at a level III perinatal centre for outpatient specialised risk assessment can support the referring obstetric team in their care of the pregnant woman. Furthermore, and if appropriate, risks and benefits of potential future perinatal interventions can be discussed with the parents. The goal of these discussions is to establish a trusting relationship between the parents and the team at the level III perinatal centre. This will facilitate timely transfer to the level III perinatal centre should this become necessary at a later point in time.

4.1.2 | Referral to a Level III Perinatal Centre at ≥ 22 0/7 Weeks of Gestation

Parents must be told that the prognosis regarding mortality and morbidity of an ELGAN is better if referral to a level III perinatal centre occurs prior to delivery. Ideally, following discussion with the referral centre, women who are at high risk for extremely preterm delivery should be transferred to such a centre as early as 22 0/7 weeks of gestation. Such in utero transfers do not automatically mandate survival-focused perinatal care but allow for detailed counselling of the parents for shared decision-making and optimising perinatal care.

4.1.3 | Active Obstetric Interventions Prior to Delivery

When it has been agreed that survival-focused care might be considered, active obstetric interventions are indicated to ensure the baby is born in the best possible condition [29]. This includes,

TABLE 3 | Gestational-age-specific mortality rates and rates of permanent neurosensory impairment of live born infants at age 5–11 years among ELGANs in Switzerland (2013–2017, $N=746$), Sweden, and France.

3A				
Gestational age				
22 0/7–22 6/7 weeks	**Mortality rates**	**Survival with severe[a] impairment**	**Survival with moderate[b] impairment**	**Survival without severe[a] or moderate[b] impairment**
Denominator	**All live born infants**	**Survivors at follow-up**		
SNN [4]	100%	—	—	—
EXPRESS [24]	90%	20%	40%	40%
EPIPAGE-2 [25]	100%	—	—	—

3B				
Gestational age				
23 0/7–23 6/7 weeks	**Mortality rates**	**Survival with severe[a] impairment**	**Survival with moderate[b] impairment**	**Survival without severe[a] or moderate[b] impairment**
Denominator	**All live born infants**	**Survivors at follow-up**		
SNN [4]	90%	29%	21%	50%
EXPRESS [24]	50%	22%	35%	43%
EPIPAGE-2 [25]	99%	—	—	—

3C				
Gestational age				
24 0/7–24 6/7 weeks	**Mortality rates**	**Survival with severe[a] impairment**	**Survival with moderate[b] impairment**	**Survival without severe[a] or moderate[b] impairment**
Denominator	**All live born infants**	**Survivors at follow-up**		
SNN [4]	50%	11%	26%	63%
EXPRESS [24]	35%	19%	21%	60%
EPIPAGE-2 [25]	69%	34%		66%

3D				
Gestational age				
25 0/7–25 6/7 weeks	**Mortality rates**	**Survival with severe[a] impairment**	**Survival with moderate[b] impairment**	**Survival without severe[a] or moderate[b] impairment**
Denominator	**All live born infants**	**Survivors at follow-up**		
SNN [4]	28%	6%	28%	66%
EXPRESS [24]	20%	12%	18%	70%
EPIPAGE-2 [25]	41%	26%		74%

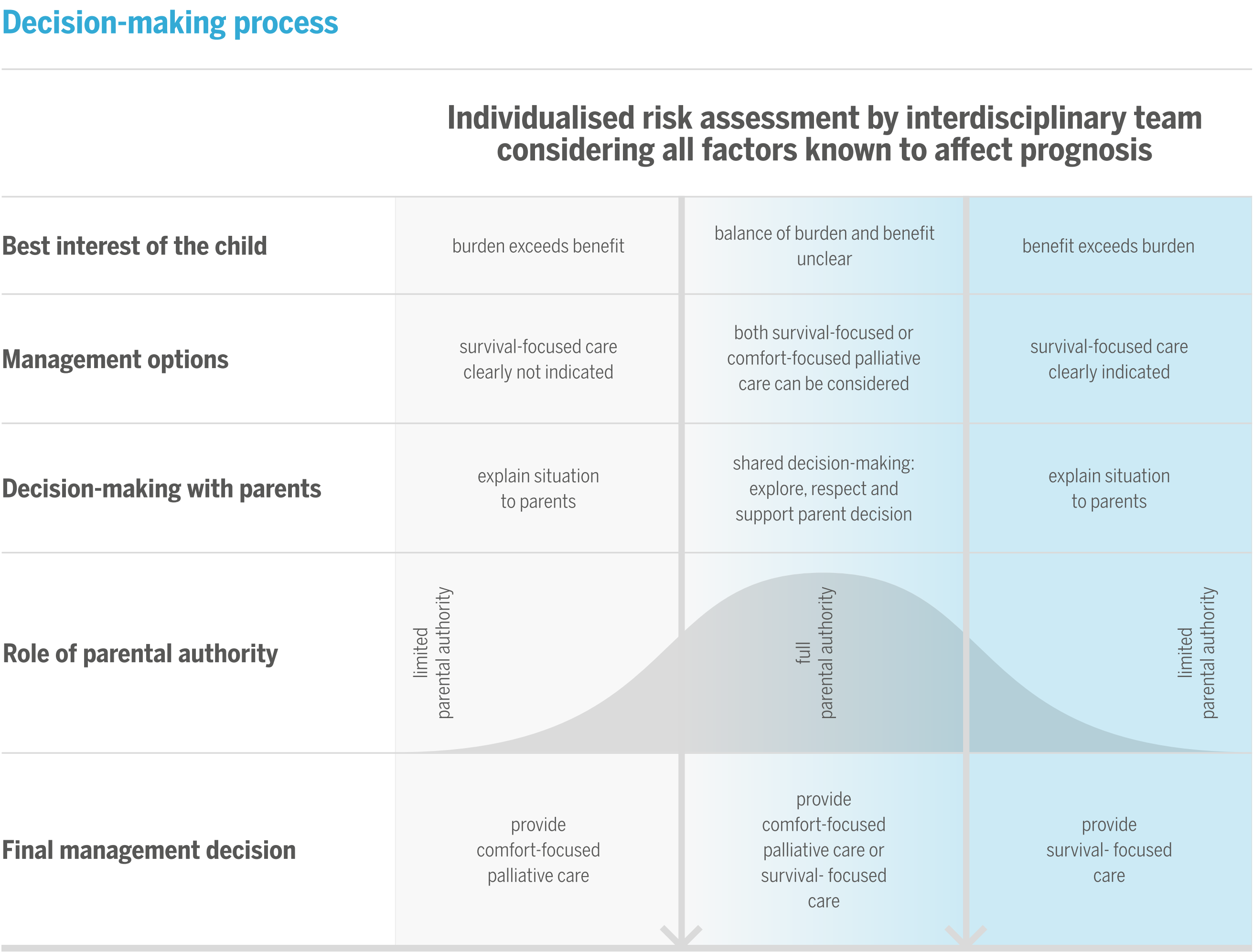
[a] Severe impairment: developmental score < −3SD and/or cerebral palsy level 3 to 5 GMFCS (Gross Motor Function Classification System) and/or bilateral deafness and/or bilateral blindness.

[b] Moderate impairment: developmental score < −2SD and/or cerebral palsy level 2 GMFCS (Gross Motor Function Classification System) and/or bilateral vision and/or hearing disability.

but may not be limited to, timely administration of antenatal corticosteroids, tocolysis, antibiotics following (prolonged) premature rupture of membranes, cervical cerclage, and neuroprotection with magnesium sulphate ($MgSO_4$). In addition, an extended ultrasound examination should be performed to assess foetal weight, gender, and wellbeing. This examination can also exclude severe malformations which could potentially alter perinatal management. Even though there is scarce evidence for its usefulness, cardiotocography (CTG) monitoring should be considered once survival-focused care has become an option.

4.1.4 | Mode of Delivery

Caesarean sections should not be performed routinely to deliver ELGANs [29]. If the foetus is in a cephalic position and there are no maternal and/or foetal contraindications, vaginal delivery under continuous CTG surveillance can be considered, depending on the overall clinical situation (e.g., vaginal bleeding, (prolonged) premature rupture of membranes, foetal presentation, multiple gestation, etc.) and maternal preference.



Decision-making process

Individualised risk assessment by interdisciplinary team considering all factors known to affect prognosis

Best interest of the child	burden exceeds benefit	balance of burden and benefit unclear	benefit exceeds burden
Management options	survival-focused care clearly not indicated	both survival-focused or comfort-focused palliative care can be considered	survival-focused care clearly indicated
Decision-making with parents	explain situation to parents	shared decision-making: explore, respect and support parent decision	explain situation to parents
Role of parental authority	limited parental authority	full parental authority	limited parental authority
Final management decision	provide comfort-focused palliative care	provide comfort-focused palliative care or survival- focused care	provide survival- focused care

FIGURE 3 | Decision-making process for the perinatal management of ELGANs with a gestational age ≥ 23 0/7 weeks.

4.1.5 | Delayed Cord Clamping

There is robust evidence that placental-neonatal transfusion through delayed cord clamping is associated with improved haemodynamic stability, decreased need for blood transfusions, and a lower incidence of intraventricular/periventricular haemorrhage. Importantly, delayed cord clamping lowers the mortality rates of preterm infants [29].

4.1.6 | Maternal Autonomy

The decisional autonomy of the pregnant woman must be respected. From a legal standpoint, all decisions regarding obstetric interventions are made by the woman (not by the obstetric HCPs and not by the partner). Therefore, any obstetric interventions, such as foetal surveillance or Caesarean section, always require her explicit informed consent.

4.2 | Neonatal Aspects

4.2.1 | Initial Resuscitation in the Delivery Room

Once a decision has been made that survival-focused neonatal care should be provided, delivery of ELGANs must be attended by an experienced neonatology team. Initial stabilisation should not be compromised by a priori exclusion of interventions that are considered effective in more mature infants with lower risks. It has been demonstrated that the clinical condition of the infant after birth and the response to resuscitative measures are not reliable prognostic factors [30]. Except for extreme situations (i.e., asystole), it should not deter from the agreed upon survival-focused care.

Generally, such infants will benefit from interventions that include, but are not limited to, prevention of hypothermia by meticulous control of the thermal environment (e.g., designated resuscitation area with a high ambient temperature, plastic wraps), lung protective respiratory support (often including endotracheal intubation and early surfactant administration), and establishing vascular access (usually by placing umbilical venous and arterial catheters) to draw blood, continuously monitor blood pressure, and administer fluids and drugs.

4.2.2 | Provisional Intensive Care in the Neonatal Intensive Care Unit

Intensive care measures that are initiated in the delivery room and continued in the neonatal intensive care unit are based on the primary therapeutic goals, that is, to help the infant survive,

Outcome of babies born alive who receive survival-focused care

23 weeks of gestation

Survival and mortality rates to discharge from hospital

Cohort 2019 – 2023

Live-births (N=142)
Infants with survival-focused care (N=65)

6 in 10 babies **survive**
(59%)

4 in 10 babies **die**
(41%)

Severe disability among survivors who presented to follow-up (2 years)

Cohort 2017 – 2021

N at birth 160
N at follow-up 27

8 in 10 survivors
do not have severe disability
(81%)

2 in 10 survivors
have severe disability
(19%)

24 weeks of gestation

Survival and mortality rates to discharge from hospital

Cohort 2019 – 2023

Live-births (N=241)
Infants with survival-focused care (N=217)

7 in 10 babies **survive**
(69%)

3 in 10 babies **die**
(31%)

Severe disability among survivors who presented to follow-up (2 years)

Cohort 2017 – 2021

N at birth 236
N at follow-up 113

9 in 10 survivors
do not have severe disability
(96%)

1 in 10 survivors
have severe disability
(4%)

FIGURE 4 | Visual aids to illustrate both chances for survival and risk of mortality (data shown reflects national outcome data from ELGANs born in Switzerland between 2019 and 2023 who received survival-focused care), as well as chances for survival without severe disability and risks of survival with severe disability (data shown reflects national outcome data from ELGANs born in Switzerland between 2017 and 2021 who were admitted to a neonatal intensive care unit; overall follow-up rate 79%). Data shown does not consider the impact of additional risk factors (Figures 1 and 2); therefore, prognosis from individualised risk assessment may deviate considerably from data shown above. Mortality: expressed as mortality at hospital discharge. Severe impairment: expressed as developmental score < -3SD and/or cerebral palsy level 3 to 5 GMFCS (Gross Motor Function Classification System) and/or bilateral deafness and/or bilateral blindness.

Outcome of babies born alive
who receive survival-focused care

25 weeks of gestation

Survival and mortality rates to discharge from hospital

Cohort 2019 – 2023

Live-births (N=248)
Infants with survival-focused care (N=244)

8 in 10 babies **survive**
(83%)

2 in 10 babies **die**
(17%)

Severe disability among survivors who presented to follow-up (2 years)

Cohort 2017 – 2021

N at birth 257
N at follow-up 175

9 in 10 survivors
do not have severe disability
(91%)

1 in 10 survivors
have severe disability
(9%)

26 weeks of gestation

Survival and mortality rates to discharge from hospital

Cohort 2019 – 2023

Live-births (N=298)
Infants with survival-focused care (N=294)

9 in 10 babies **survive**
(88%)

1 in 10 babies **die**
(12%)

Severe disability among survivors who presented to follow-up (2 years)

Cohort 2017 – 2021

N at birth 326
N at follow-up 222

9 in 10 survivors
do not have severe disability
(91%)

1 in 10 survivors
have severe disability
(9%)

FIGURE 4 | (Continued)

to promote normal development and minimise permanent impairments. If a decision is made to provide provisional intensive care, the treatment should be optimised to avoid secondary injuries at all costs. Refraining from applying certain interventions that are routinely used in more mature preterm infants is not justified.

The infant's condition should be re-evaluated frequently under the supervision of experienced neonatologists to determine if the risk assessment made prior to delivery, which led to the decision to provide survival-focused care, still appears justified. Parents should be informed regularly about the infant's clinical course. As long as there is reasonable hope that the primary goal can be reached and the burden of the interventions used appears justified, all necessary therapies are continued.

4.2.3 | Redirection of Care

If both the neonatal HCPs and the parents recognise that the primary therapeutic goal can no longer be reached and life-sustaining therapies are no longer justified, other aspects of care must be prioritised (i.e., redirection of survival-focused care to comfort-focused palliative care). Whenever life-sustaining therapies are withdrawn, everything must be done to allow the infant to die peacefully and with dignity. If necessary for adequate control of any distress (e.g., pain, dyspnoea), appropriately dosed opiates should be used. Following redirection of care, parents should be supported by experienced HCPs.

5 | A Priori Comfort-Focused Palliative Care

As outlined above, given an extremely high risk of adverse outcomes, these guidelines do not recommend initiating life-sustaining therapies at less than 23 0/7 weeks. At higher gestational ages, individualised risk assessment and shared decision-making may also lead to the conclusion that the burden likely exceeds the potential benefits. In such situations,

TABLE 4 | Comparison of different recently published European guidelines on the perinatal care of extremely low gestational age neonates [1–3].

Country (year)	GA limits (weeks)	Risk assessment	Result of risk assessment	Parental decisional authority
Switzerland (2025)	Lower: 23 0/7	Individualized (including non-modifiable and modifiable risk factors)	"Three trajectories"	
	Upper: none		(a) Burden clearly exceeds benefit	Parental authority limited
			(b) Risk assessment equivocal	Full parental authority
			(c) Benefit clearly exceeds burden	Parental authority limited
France (2020) [1]	Lower: 23 0/7	Individualized (including non-modifiable and modifiable risk factors)	"Four situations"	
	Upper: 25 6/7		(a) Resuscitation unreasonable	Parents cannot demand resuscitation
			(b) Resuscitation not recommended	Resuscitation acceptable on parental request
			(c) Resuscitation recommended	Resuscitation can be withheld on parental request
			(d) Resuscitation reasonable	Parents cannot refuse resuscitation
Germany (2020) [2]	Lower: 22 0/7	Based on GA and birth weight	"Gray zone" (b and c)	
	Upper: 24 6/7		(a) GA < 22 0/7 or GA 22 0/7–23 6/7 and birth weight < 400 g	Parental authority limited
			(b) GA 22 0/7–23 6/7 and birth weight ≥ 400 g	Full parental authority
			(c) GA 23 0/7–24 6/7 and birth weight < 400 g	Full parental authority
			(d) GA ≥ 24 0/7 and birth weight ≥ 400 g or GA ≥ 25 0/7	Parental authority limited
UK (2020) [3]	Lower: 22 0/7		"Three risk categories"	
	Upper: 26 6/7		(a) Extremely high risk for adverse outcome (> 90%)	Parental authority limited
			(b) High risk for adverse outcome (50%–90%)	Full parental authority
			(c) Moderately high risk for adverse outcome (< 50%)	Parental authority limited

survival-focused care is not indicated, and preference should be given to a priori comfort-focused palliative care.

5.1 | Obstetrical Aspects

When a decision has been made prenatally to abstain from survival-focused care and to provide comfort-focused palliative care, foetal surveillance and other obstetric interventions such as Caesarean section for foetal indications are not indicated.

5.2 | Neonatal Aspects

The parents should be informed that the infant might show signs of life after delivery, such as some movements and/or some respiratory effort, including gasping respiration. The infant should not be separated from the parents.

The fact that the dying process may last several hours must be explained. They need to be assured that every effort will be made to minimise any potential suffering (provision of warmth (ideally through skin-to-skin contact), swaddling, and opiates, if needed).

6 | Discussion and Limitations

The new Swiss recommendations share many similarities with other recently published European guidelines [1–3] but differ from some of them in three important aspects (Table 4). First, given very high mortality and morbidity rates, they suggest 23 0/7 weeks rather than 22 0/7 weeks of gestation as the lower limit for considering initiation of survival-focused care. Second, given the limitations of gestational age assessment, they strongly discourage risk assessment based on gestational age alone and emphasise individualised risk assessment. Third, while giving parents full authority in situations where risk assessment is equivocal, they suggest that parental authority is limited in situations where the patient's best interest is clear: they cannot demand survival-focused care in futile situations, nor can they refuse such care when the benefit clearly exceeds the burden.

Great care must be taken when various statistical data sources (Tables 1–3) are used for individualised risk assessment and visual aids (Figure 4) are presented for shared decision-making with parents. It is important for clinicians to recognise that these tools present different facets of outcome (e.g., short-term morbidities vs. longer-term functional impairments) that do not have a one-to-one correlation with each other. In addition, they do not capture the subjective experience of quality of life, which should remain the central focus of a relational and individualised counselling process with parents.

Author Contributions

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Conflicts of Interest

The authors declare no conflicts of interest.

Data Availability Statement

The data that support the findings of this study are available from the corresponding author upon reasonable request.

References

1. P. Y. Ancel, G. Breart, H. Bruel, et al., "Propositions for Perinatal Care at Extremely Low Gestational Ages—Working Group on "Extremely Low Gestational Ages" for SFMP, CNGOF, and SFN," *Gynécologie Obstétrique Fertilité & Sénologie* 48, no. 12 (2020): 850–857.

2. C. Bührer, U. Felderhoff-Mueser, U. Gembruch, et al., "Frühgeborene an der Grenze der Lebensfähigkeit (AWMF-Leitlinien-Register Nr. 024/019, Juni 2020)," *Zeitschrift für Geburtshilfe und Neonatologie* 224 (2020): 244–255.

3. H. Mactier, S. E. Bates, T. Johnston, et al., "Perinatal Management of Extreme Preterm Birth Before 27 Weeks of Gestation: A Framework for Practice," *Archives of Disease in Childhood. Fetal and Neonatal Edition* 105, no. 3 (2020): F232–F239.

4. Swiss Neonatal Network, on behalf of the Swiss Society of Neonatology, "Data Extracted From Swiss Neonatal Network," (2024).

5. J. C. Fauchère, S. D. Klein, M. J. Hendriks, R. Baumann-Hölzle, T. M. Berger, and H. U. Bucher, "Swiss Neonatal Caregivers Express Diverging Views on Parental Involvement in Shared Decision-Making for Extremely Premature Infants," *Acta Paediatrica* 110, no. 7 (2021): 2074–2081.

6. M. J. Hendriks, S. D. Klein, H. U. Bucher, R. Baumann-Holzle, J. C. Streuli, and J. C. Fauchère, "Attitudes Towards Decisions About Extremely Premature Infants Differed Between Swiss Linguistic Regions in Population-Based Study," *Acta Paediatrica* 106, no. 3 (2017): 423–429.

7. K. Helenius, G. Sjörs, P. S. Shah, et al., "Survival in Very Preterm Infants: An International Comparison of 10 National Neonatal Networks," *Pediatrics* 140, no. 6 (2017): e20171264.

8. P. Y. Ancel, F. Goffinet, P. Kuhn, et al., "Survival and Morbidity of Preterm Children Born at 22 Through 34 Weeks' Gestation in France in 2011: Results of the EPIPAGE-2 Cohort Study," *JAMA Pediatrics* 169, no. 3 (2015): 230–238.

9. E. F. Bell, S. R. Hintz, N. I. Hansen, et al., "Mortality, In-Hospital Morbidity, Care Practices, and 2-Year Outcomes for Extremely Preterm Infants in the US, 2013-2018," *Journal of the American Medical Association* 327, no. 3 (2022): 248–263.

10. V. Fellman, L. Hellström-Westas, M. Norman, et al., "One-Year Survival of Extremely Preterm Infants After Active Perinatal Care in Sweden," *JAMA* 301, no. 21 (2009): 2225–2233.

11. Y. Kono, N. Yonemoto, H. Nakanishi, S. Kusuda, and M. Fujimura, "Changes in Survival and Neurodevelopmental Outcomes of Infants Born at 25 Weeks' Gestation: A Retrospective Observational Study in Tertiary Centres in Japan," *BMJ Paediatrics Open* 2, no. 1 (2018): e000211.

12. T. Moore, E. M. Hennessy, J. Myles, et al., "Neurological and Developmental Outcome in Extremely Preterm Children Born in England in 1995 and 2006: The EPICure Studies," *BMJ* 345 (2012): e7961.

13. H. J. Stensvold, C. Klingenberg, R. Stoen, et al., "Neonatal Morbidity and 1-Year Survival of Extremely Preterm Infants," *Pediatrics* 139, no. 3 (2017): e20161821.

14. P. E. van Beek, M. Rijken, L. Broeders, et al., "Two-Year Neurodevelopmental Outcome in Children Born Extremely Preterm: The EPI-DAF Study," *Archives of Disease in Childhood. Fetal and Neonatal Edition* 107, no. 5 (2022): F467–F474.

15. M. Adams, T. M. Berger, C. Borradori-Tolsa, et al., "Association Between Perinatal Interventional Activity and 2-Year Outcome of Swiss Extremely Preterm Born Infants: A Population-Based Cohort Study," *BMJ Open* 9, no. 3 (2019): e024560.

16. F. Serenius, M. Blennow, K. Maršál, G. Sjörs, and K. Källen, "Intensity of Perinatal Care for Extremely Preterm Infants: Outcomes at 2.5 Years," *Pediatrics* 135, no. 5 (2015): e1163–e1172.

17. J. Y. Islam, R. L. Keller, J. L. Aschner, T. V. Hartert, and P. E. Moore, "Understanding the Short- and Long-Term Respiratory Outcomes of Prematurity and Bronchopulmonary Dysplasia," *American Journal of Respiratory and Critical Care Medicine* 192, no. 2 (2015): 134–156.

18. C. M. McEniery, C. E. Bolton, J. Fawke, et al., "Cardiovascular Consequences of Extreme Prematurity: The EPICure Study," *Journal of Hypertension* 29, no. 7 (2011): 1367–1373.

19. S. Akalay, M. Rayyan, T. Fidlers, L. van den Heuvel, E. Levtchenko, and F. O. Arcolino, "Impact of Preterm Birth on Kidney Health and Development," *Frontiers in Medicine (Lausanne)* 11 (2024): 1363097.

20. S. Johnson and N. Marlow, "Early and Long-Term Outcome of Infants Born Extremely Preterm," *Archives of Disease in Childhood* 102, no. 1 (2017): 97–102.

21. C. Crump, J. Sundquist, and K. Sundquist, "Preterm or Early Term Birth and Risk of Autism," *Pediatrics* 148, no. 3 (2021): e2020032300.

22. F. Serenius, K. Kallen, M. Blennow, et al., "Neurodevelopmental Outcome in Extremely Preterm Infants at 2.5 Years After Active Perinatal Care in Sweden," *JAMA* 309, no. 17 (2013): 1810–1820.

23. V. Pierrat, L. Marchand-Martin, C. Arnaud, et al., "Neurodevelopmental Outcome at 2 Years for Preterm Children Born at 22 to 34 Weeks' Gestation in France in 2011: EPIPAGE-2 Cohort Study," *BMJ* 358 (2017): 3448.

24. F. Serenius, U. Ewald, A. Farooqi, et al., "Neurodevelopmental Outcomes Among Extremely Preterm Infants 6.5 Years After Active Perinatal Care in Sweden," *JAMA Pediatrics* 170, no. 10 (2016): 954–963.

25. V. Pierrat, L. Marchand-Martin, S. Marret, et al., "Neurodevelopmental Outcomes at Age 5 Among Children Born Preterm: EPIPAGE-2 Cohort Study," *BMJ* 373 (2021): 741.

26. A. Sullivan and C. Cummings, "Historical Perspectives: Shared Decision Making in the NICU," *NeoReviews* 21, no. 4 (2020): e217–e225.

27. A. Janvier, B. Farlow, J. Baardsnes, R. Pearce, and K. J. Barrington, "Measuring and Communicating Meaningful Outcomes in Neonatology: A Family Perspective," *Seminars in Perinatology* 40, no. 8 (2016): 571–577.

28. Ú. Guillén, A. Mackley, N. Laventhal, et al., "Evaluating the Use of a Decision Aid for Parents Facing Extremely Premature Delivery: A Randomized Trial," *Journal of Pediatrics* 209 (2019): 52–60.e1.

29. Deutsche Gesellschaft für Gynäkologie und Geburtshilfe (DGGG), Österreichische Gesellschaft für Gynäkologie und Geburtshilfe (OEGGG), Schweizerische Gesellschaft für Gynäkologie und Geburtshilfe (SGGG), "Prävention und Therapie der Frühgeburt AWMF Online—Leitlinienprogramm der DGGG, OEGGG und SGGG," (2022), 1–259.

30. B. J. Manley, J. A. Dawson, C. O. Kamlin, S. M. Donath, C. J. Morley, and P. G. Davis, "Clinical Assessment of Extremely Premature Infants in the Delivery Room Is a Poor Predictor of Survival," *Pediatrics* 125, no. 3 (2010): e559–e564.

Supporting Information

Additional supporting information can be found online in the Supporting Information section. **Appendix S1:** apa70423-sup-0001-AppendixS1.pdf. **Appendix S2:** apa70423-sup-0002-AppendixS2.pdf. **Appendix S3:** apa70423-sup-0003-AppendixS3.pdf.