

**Practice recommendations  
for facilitating the antenatal shared  
decision making process with parent(s) regarding the initial  
management of their extremely preterm infant(s) at birth**

**B Lemyre, T Daboval, S Dunn, M Kekewich, G Jones, M Mason-Ward  
and GP Moore on behalf of the**

**Shared decision making for the extremely preterm  
Infant (SDM for EPI) working group**

**Ottawa**

**Version 3: January 2023**

**Version 1: September 2015**

**Practice recommendations for facilitating the antenatal shared decision making process with parent(s) regarding the initial management of their extremely preterm infant(s) at birth**

Table of Contents:	Page
1.0 Executive summary	3
2.0 Background	9
3.0 Definitions	9
4.0 Methods	10
4.1 Survival rates	11
4.2 Severe and moderate-or-severe neurodevelopment disability at 4-10 Years	11
4.3 Quality of life of adolescents born extremely preterm	12
4.4 Quality of life of parents	13
4.5 Likelihood of maternal death or long-term morbidity	13
5.0 Prognostic uncertainty	14
6.0 Communication with expectant parents	15
7.0 Shared decision making	16
8.0 Ethical considerations	17
9.0 Situations where recommendations do not apply	18
10.0 Suggested process for the consultation	18
11.0 When there is no antenatal decision	18
12.0 Recommendations	19
13.0 Tables and figures	21
14.0 References	29
Appendices (available upon request)	
Appendix 1: Working group members	
Appendix 2: Ranking of factors for decision making	
Appendix 3: Systematic review: quality of life of survivors	
Appendix 4: Systematic review: quality of life of parents	
Appendix 5: Review: maternal mortality and morbidity	
Appendix 6: Barriers and facilitators	
Appendix 7: Implementation planning template	
Appendix 8: Evaluation matrix	
Appendix 9: Links to tools to complement the guideline	
Appendix 10: Resource Implications (Cost Analysis)	
Appendix 11: Monitoring and Auditing	
Appendix 12: Funding and Disclosure Statements	
Appendix 13: Revision plan	

## **Practice recommendations for facilitating the antenatal shared decision making process with parent(s) regarding the initial management of their extremely preterm infant(s) at birth**

### **1.0 EXECUTIVE SUMMARY**

Supporting women and couples facing anticipated delivery of an extremely preterm infant (EPI) and determining the initial management for these infants is a challenging experience for all those involved. EPI have high mortality and morbidity rates compared to term infants and prognostic uncertainty exists for each individual case. Although, in general, survival rates and the percentage of survivors without moderate-or-severe neurodevelopmental disability improve as gestational age (GA) increases, other prognostic factors influence this improvement. Therefore, it is erroneous to generate care plans based solely on GA. Published clinical practice recommendations emphasize the need to individualize care and to incorporate parents' values, preferences and opinions into the decision-making process (1). A local multidisciplinary group of healthcare professionals (HCP) and parents of EPI have been working together since 2013 to: 1) review the evidence considered key for decision making at 21 through 25 weeks GA, and; 2) create and update recommendations for HCP in the Champlain Local Health Integrated Network (LHIN) to facilitate the antenatal shared decision making (SDM) process with parent(s) regarding the initial management of their EPI at birth.

HCP must recognize that many biological and socio-environmental factors influence prognosis. SDM works best in circumstances where there is more than one reasonable management option, such as for EPI where either intensive care or palliative comfort care can be options. The document includes a section on SDM and an appendix providing advice on how to facilitate SDM during the antenatal consultation. Of important note: several limitations exist regarding data on survival and morbidity; it is therefore of the utmost importance to clearly and truthfully explain any data provided to parents.

#### **Recommendations:**

#### **Referral Process (prior to patient contact with trained HCP able to perform SDM with parents)**

1. Consult with a maternal-fetal medicine (MFM) staff or fellow to discuss referral to a tertiary perinatal center when a pregnant woman is facing anticipated delivery between 22+0 and 25+6 weeks GA (based on best obstetrical estimate).
2. When prenatal maternal transfer is not possible in the opinion of the primary HCP at the referring center and the MFM staff or fellow being consulted, and delivery is anticipated at 22+0–25+6 weeks GA, the HCP at the referring center should initiate a consultation with a neonatology staff to review management options and receive guidance about facilitating the decision-making process with the parents.
3. When prenatal maternal transfer is not possible, intensive care and/or palliative comfort care will be offered as the option(s) to the parents based on estimation of the prognosis (**Table 6**) generated from the consultation with a neonatology staff and the resources available to assist the primary HCP. The management plan will be finalized after discussion between the HCP at the referring center and the parents.

**Consultation process and communication (only possible in tertiary care centre with HCP trained in this area of expertise)**

4. Consult a neonatology staff or fellow (see <b>Figure 2</b> ): a) when a pregnant woman is presenting at 21+0 to 25+6 weeks GA with a high likelihood of delivery in the next 48 hours in the opinion of the MFM staff <b>and</b> b) after the MFM staff or fellow has introduced the reasons for a neonatal consultation to the pregnant woman <b>and</b> c) after a MFM staff or fellow has verbally discussed the case with a neonatology staff or fellow.
5. Follow a SDM framework during consultation between a neonatologist or neonatology fellow and expectant parents of an EPI, except where implausible (e.g. expected imminent delivery (i.e. <1 hour)).
6. Use a decision aid and parent information handout about EPI births to facilitate comprehension and involvement of parents in the decision-making process. Some parents may decline the use of the decision aid or handbook.
7. When consulted, a neonatology staff or fellow should: <ul style="list-style-type: none"><li>○ review the fetal condition and modifiers of survival and NDD rates to determine the anticipated likelihood of mortality and severe or moderate-or-severe NDD.</li><li>○ determine the suggested level of care options based on <b>Table 6</b>.</li><li>○ complete the initial consultation (or document reasons for delaying completion) within 24 hours.</li></ul> <p>The current management plan will be decided upon after engaging in a SDM process with the parents and exchanging information about the risks and benefits of each option, clarifying the values and preferences of the family, and considering the feasibility of each option under discussion (<b>Figure 1</b>). Whenever palliative comfort care is the recommended option, or one of the usual care options, a neonatology staff should be present for the consultation.</p>
8. Ensure details of the management plan are communicated directly to the MFM staff, neonatology staff, the registered nurse caring for the mother and the parent(s) to enhance care and avoid conflicting information. Where possible, this group should meet together in the final stages of the SDM process.

**Management options for the EPI**

9. Provide palliative comfort care to babies born at <22+0 weeks GA, including those between 21+0-21+6 weeks GA, as survival at less than 22 weeks completed GA (under 22+0 weeks) has rarely been reported in the published peer-reviewed medical literature (or our own local or national data).
10. For babies born at 22+0-25+6 weeks GA, when SDM is not possible prenatally or parents cannot make a decision regarding the care of their EPI: <ul style="list-style-type: none"><li>○ Provide intensive care initially and communicate with the parents postnatally to engage them in SDM to determine the ongoing management plan, or;</li><li>○ Provide palliative comfort care if the infant is thought to be – by a neonatology staff or fellow and with a high level of confidence – at an extremely high likelihood of mortality or severe NDD (<b>Table 6</b>). This palliative comfort care plan should be communicated directly to the parent(s) prior to its provision, ideally prior to the immediate moment of delivery.</li></ul>

11. If the current management plan at the time of the EPI's birth is to provide intensive care, a neonatology staff or fellow should attend the delivery.

The guideline, decision aid, accompanying decision aid script and parent handouts can be found online at: [www.sdmforepi.com](http://www.sdmforepi.com)

**Table 6: Stratification of level of care offered based on anticipated likelihood of mortality and NDD**

Likelihood estimation for anticipated mortality or long-term NDD	Suggested level of care	Clinical examples that usually meet the likelihood estimation
Extremely high likelihood of mortality or severe NDD *	Palliative comfort care is recommended **	Infant born at 22 weeks GA, irrespective of additional risk factors*** Infant born at 24 weeks GA, with an estimated weight of 350 g
Moderate-to-high likelihood of mortality or moderate-or-severe NDD	Intensive care or palliative comfort care are both usual care options	Infant born at 23 to 24 weeks GA, irrespective of most additional risk factors*** Infant born at 25 weeks GA, with signs of fetal anemia and abnormal placental blood flow
Low likelihood of mortality or moderate-or-severe NDD	Intensive care is recommended **	Infant born at 25 weeks GA, without additional risk factors*** Infant born late in 24 <sup>th</sup> week of gestation (e.g. 24 <sup>5</sup> ), well grown with ANCS given, born in a tertiary care centre

\* In the clear majority of cases, the likelihood estimation for neurodevelopmental disability (NDD) does not reach the 'extremely high likelihood' category. Most cases where palliative comfort care is recommended usually relate to an 'extremely high likelihood' of mortality, even when providing intensive care.

\*\* Given the lack of moral authority on the suggested level of care, parents may choose a non-recommended option. HCP should engage with them to determine their infant's management plan.

\*\*\*See table 4 for additional risk factors

For further details on the suggested steps to get to this estimation, please see Sections 10.0 and 11.0.

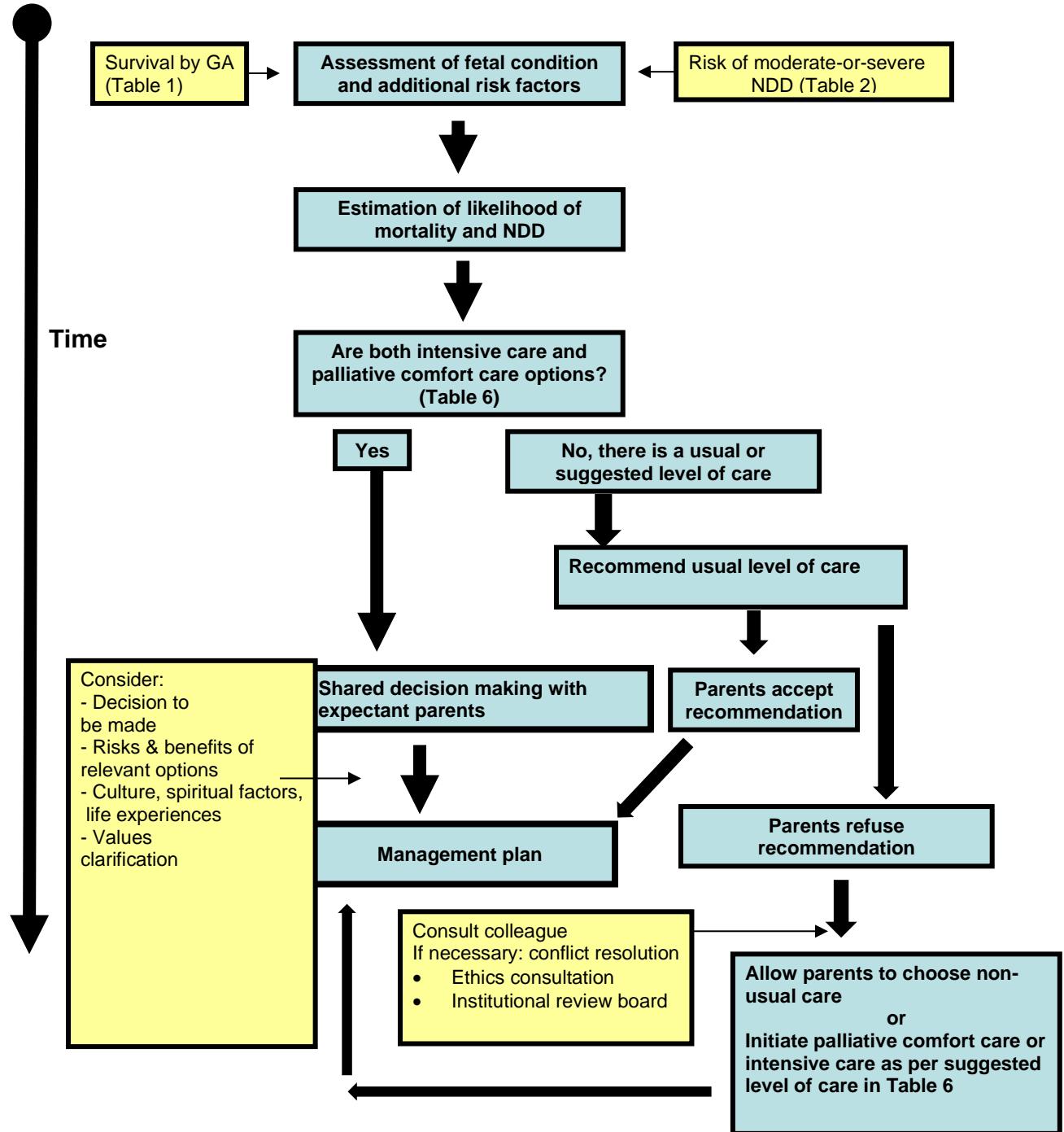
**Table 4: Factors known to affect likelihood of mortality and NDD**

Factors decreasing the likelihood of mortality and NDD	Factors increasing the likelihood of mortality and NDD
Birth in tertiary care center	Small for gestational age (SGA)
Increasing GA	Multiple birth
Appropriate for GA weight	Male gender

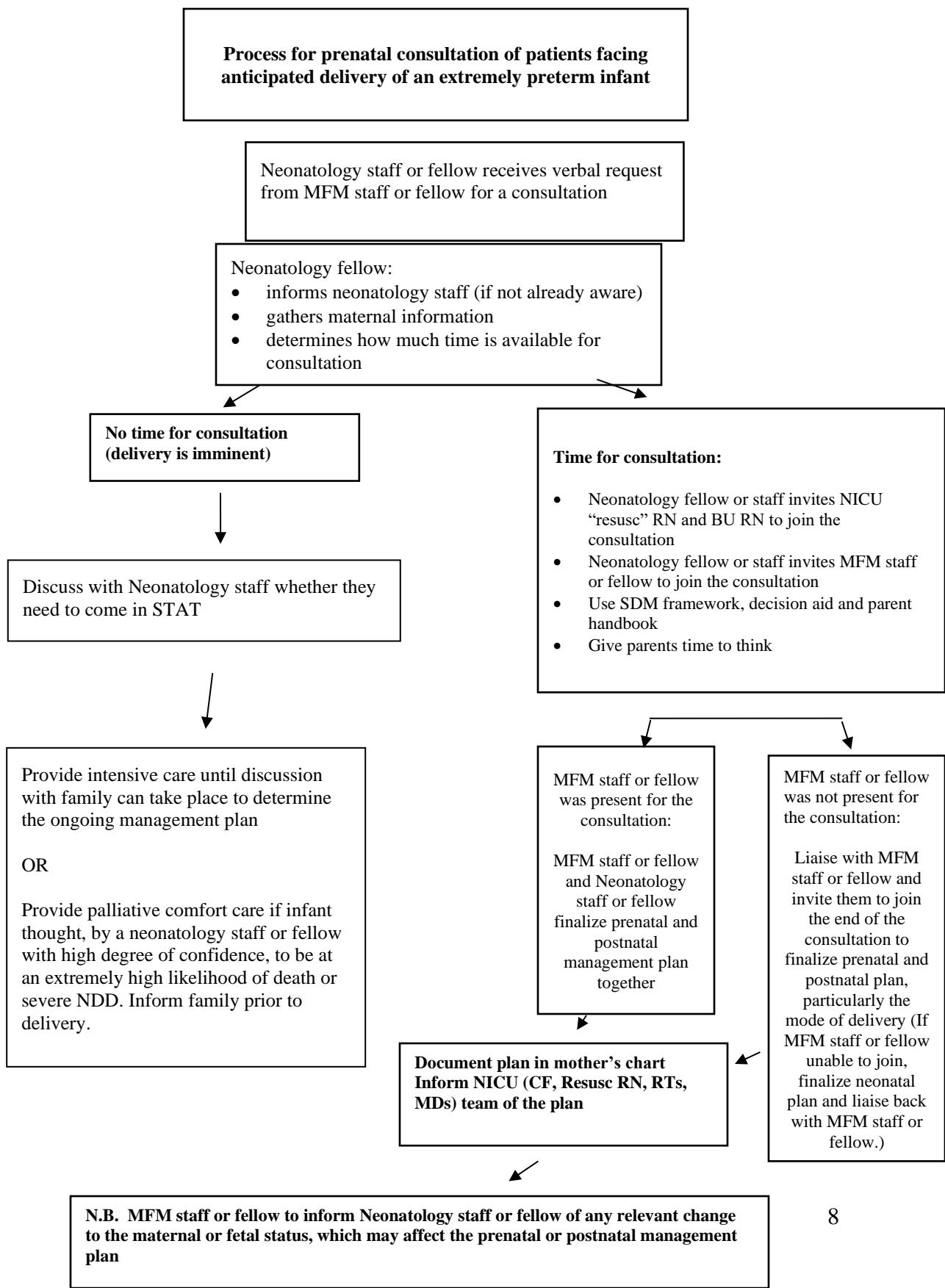
Singleton	Acute chorioamnionitis
Female gender	Prenatal ultrasound findings of anomalies, fetal anemia or poor placental flow to fetus
Exposure to prenatal steroids	Birth early within the week of gestation (as opposed to late)

Please refer to Section 5.0 for details and limitations

**Figure 1: Process to determine management plan for anticipated extremely premature infant**



**Figure 2: Pragmatic process for consultation, when there is time and when there isn't**



## 2.0 BACKGROUND

Early preterm birth poses medical, social, ethical and legal challenges. Although extremely preterm infants (EPI) have high mortality and morbidity rates when compared to term infants, prognostic uncertainty exists for each individual case(2). Supporting women and couples facing the likely delivery of an EPI and determining the initial management for these infants is a challenging experience for all those involved. Each infant, situation, family and healthcare professional (HCP) is unique such that decisions and management can vary substantially between patients (1,3–5).

Many published guidelines and position statements regarding the initial care for EPI exist (6–21). In Canada, 22+0 weeks to 25+6 weeks generally constitutes the gestational age (GA) window of EPI. **In this GA window, the preferences, opinions and values of parents play an integral role in management decisions (e.g. whether intensive care or palliative comfort care should be provided for the EPI).** The 2017 position statement of the Fetus and Newborn Committee of the Canadian Pediatric Society (CPS) emphasizes the need for individualizing the approach and making decisions through an informed and shared process between parents and HCP (20).

In view of the above considerations, regional recommendations that consider perinatal care service delivery and resource availability are necessary. Expected benefits are: 1) minimization of center-to-center variability in care options offered to EPI, 2) optimization of the shared decision making (SDM) process, 3) parental engagement in the decision making and 4) parent and HCP satisfaction with the process.

The intent of this document is to provide a framework for supporting parent(s) facing the likely delivery of an EPI and determining initial management options for the infant, should s/he be born extremely preterm. Evidence forms the basis for the recommendations whenever possible; however, as every decision should also reflect individual assessment of each case, these recommendations should be considered non-prescriptive. They are intended for HCP (neonatologists, pediatricians, obstetricians, maternal-fetal medicine specialists, family physicians, midwives and nurses) who are involved in the care of women facing anticipated delivery of an EPI and/or the care of the EPI in the Champlain LHIN region.

## 3.0 DEFINITIONS AND EXPLANATION OF KEY TERMS USED IN THIS DOCUMENT

**Gestational age (GA):** completed days and weeks from the first day of the last menstrual period (or by early ultrasound). For example, 22 weeks refers to the period between 22 weeks and 0 days and 22 weeks and 6 days.

**Extremely Preterm Infant (EPI):** infant born between 22+0 weeks and 25+6 weeks of gestation.

**Morbidity:** diseased state, disability or poor health due to any cause. For preterm infants surviving their NICU admission, this usually refers to ongoing medical needs and therapies due to their prematurity (e.g., chronic lung disease, difficulty feeding and growing, challenges with their development and behavior, etc.).

**Neurodevelopmental disability (NDD):** disability in one or more of the following functions: motor (walking, sitting, posture control), cognitive (thinking, communicating, learning), vision or

hearing. This definition excludes other disabilities that may or may not have a great effect on the life of a child or family (e.g. coordination disorder, autism, anxiety, etc ...).

**Severe neurodevelopmental disability:** disability where a child will likely be highly dependent on his/her caregivers for an extended, and possibly lifelong, period of time. Includes **one or more** of the following: 1) severe cerebral palsy (unable to walk or able to walk short distances with a walker), 2) severe cognitive disability (>3SD below the mean on a standardized intelligence test leading to major challenges in the ability to learn, communicate or engage in interpersonal relationships), 3) blindness or no useful vision, or 4) deafness that cannot be corrected (profound hearing loss) (22).

**Moderate neurodevelopmental disability:** disability where a child will likely reach some (perhaps even a large) degree of independence. Includes **one or more** of the following: 1) moderate cerebral palsy (difficulty with walking or another part of movement), 2) moderate cognitive disability (2-3 SD below the mean on a standardized intelligence test leading to some challenges in the ability to learn, communicate or in interpersonal relationships), 3) impaired vision without blindness, or 4) correctable hearing loss (22).

**Palliative comfort care:** care that aims at achieving comfort but not cure. It is expected that the infant will die when comfort care is provided. This care includes drying, swaddling, and cuddling the baby. It may include oral sucrose, medications to sedate or treat pain, oral fluids or milk.

**Intensive care:** care that aims at achieving survival. This care involves life-sustaining measures that may include positive pressure ventilation (PPV) with intubation and ventilation, chest compressions, epinephrine and/or other acute interventions (e.g. intravascular access, fluid boluses, blood transfusion, etc). Ongoing assessment of the infant takes place in the minutes, hours, days, and weeks after initiation of intensive care in order to obtain further information regarding prognosis and facilitate continued discussions with the family.

## 4.0 METHODS

A voluntary multidisciplinary working group (**Appendix 1**), with representation from neonatology, maternal-fetal medicine, nursing (neonatal and obstetrical), ethics, knowledge translation, social work and parents of EPI developed and updated this Clinical Practice Guideline. Decisions within the group were made by consensus.

The methods used to create the first implemented version of this guideline (Version 1: September 2015) and tools are described in several full-text publications (23–29). Our group ranked factors judged to be most important in making a decision regarding the management of EPI; systematic reviews were performed for each (**Appendix 2**). Additionally, a systematic review on parent communication needs regarding antenatal consultations was performed (30).

The revised recommendations were approved by the Working Group, in November 2018 and approved by the Division of Neonatology (Children's Hospital of Eastern Ontario and The Ottawa Hospital) in May 2020.

### 4.1 Survival Rates

One systematic review of survival focused on infants weighing <1000 g or <28 weeks GA at birth (31). Out of 51 studies, large variation in survival rates was found, particularly depending on the denominator used. Variation was also possibly caused by differences in baseline risk, antenatal and postnatal therapies, and/or approaches to withholding or withdrawing life-sustaining interventions. The last two variables depend on individual HCP and/or variation in approved practices in a particular institution or society (8). Such potential for selection bias underlines the need for HCP to understand the limitations of survival data and acknowledge them during discussions with parents.

As advocated by many experts (7,11,13,15), our group considered the most relevant data for parents to be our local survival rates (see **Table 2**), and current Canadian data (**Table 1**). Between 2010 and 2018, the units providing data to the Canadian Neonatal Network recorded a total of 6054 live births at <26 weeks GA. **Table 1** shows survival data to time of discharge from NICU (stillbirths excluded). CNN reports data for babies born at ≤22 weeks GA as a group. Survival at <22 weeks GA is extremely rare, with 4 reported survivors at <22 weeks GA between 2010 and 2016 (P. Chan, personal communication). The CNN website ([www.canadianneonatalnetwork.org](http://www.canadianneonatalnetwork.org)) provides up-to-date data. The denominator used in the far-right column of **Table 1** is the number of infants who received intensive care after birth; all members, including the parents, of our working group considered this the most relevant. Rates are displayed by GA. The denominator is the same for the Ottawa data. Currently, in Canada (Canadian Neonatal Network 2018), about 40% of EPI at 22 weeks, 75% at 23 weeks, 95% at 24 weeks and 98% at 25 weeks receive intensive care.

Limitations of this data include the exclusion of EPI that die in utero either during or just prior to delivery, their retrospective nature (where intent to resuscitate or not may be difficult to interpret) and the small number of infants for the lowest GA (particularly if only considering our local Ottawa data), where an additional death or survival may notably change the rate of death or survival. A further limitation includes the variability between centers in offering intensive care to infants <24 weeks GA, as recently highlighted (32). These limitations and the findings from Guillen et al (31) highlight the importance of clearly and truthfully explaining data to parents.

#### **4.2 Moderate and severe neurodevelopmental disability at 4-10 years of age**

Several working group members published a systematic review and meta-analysis of the literature on this topic and recently updated it (33,34). The review included 15 high quality cohorts. **Table 3** summarizes the findings. There was no statistically significant difference in the likelihood of severe or moderate NDD by week of GA. There was a statistically significant reduction in the likelihood of moderate-or-severe NDD of 8% by each increasing week of GA. The most commonly observed disability is diminished cognitive function, followed by cerebral palsy. Vision and hearing deficits occur less frequently.

The multiple limitations of the data discussed in the publication must be understood by HCP and parents in order to facilitate SDM. They include: small sample sizes with wide confidence intervals at 22 and 23 weeks GA, an unknown number of children with one versus multiple disabilities, definitions and labeling (i.e. 'moderate', 'severe') of NDD by the medical community which may not reflect parents' or any given individual's views, and the lack of correlation between degree of NDD and quality of life (QOL). An example that demonstrates these limitations is as follows: both a child with severe cognitive disability and severe cerebral palsy and a child with isolated uncorrectable deafness would be classified as having severe NDD.

### 4.3. Quality of life of survivors

A systematic review of the literature prior to 2007 examined the health related QOL of preschool-aged children to young adults who were born preterm and/or at very low birth weight (35). Findings of this review showed that health related QOL improved over time. The authors concluded that some of these results may be attributed to the use of parent proxy scoring at the younger ages versus self-report by the former preterm infant at older ages.

Given the need for more recent data and the desire for self-reported data only by EPI themselves, we performed another systematic review on this topic in 2014. The systematic review used PubMed/Medline and a screening protocol (see **Appendix 3** for details) and resulted in a detailed review of seven relevant articles (36–42). The seven studies were all prospective cohort studies that assessed the self-reported QOL of adolescents/adults (aged 17–23 years) who were born as extremely low birth weight (ELBW) or very low birth weight (VLBW) infants. Many of the studies agree that assessment of QOL is multifaceted and includes physical, mental and emotional health status and socio-economic conditions. The studies also agreed that the best source of QOL evaluation is likely the individual themselves but the perspective of the parents regarding their child's QOL is also valuable. The QOL measurement tools identified varied and each ranged in the specific outcomes they assessed.

Findings in one small study found that the former ELBW/VLBW infants scored lower than the control (former full-term infants) group on the physical and emotional aspects of QOL elements (40). One study did perform a parent proxy analysis of QOL of their former ELBW/VLBW children that were severely disabled and unable to complete the QOL measures (42). These parents reported a significantly lower QOL score compared to the scores of the other former VLBW/ELBW infants themselves. There were no studies that focused solely on infants born at 22–25 weeks; one study did provide a GA breakdown and found no significant difference in the QOL scores between adolescents who were born at 23 through 27 weeks (41). Studies that reflected on self-esteem, sense of coherence and other terms that can be related to QOL were beyond the scope of this review.

The table in **Appendix 3** describes some of the details and possible limitations of the studies. Overall, QOL definitions and measures are complex as is the interplay between QOL and one's health status; a detailed review describes some of these complexities (43).

The outcomes of nearly all seven studies were similar: there was no significant difference in the self-rated QOL scores of former ELBW/VLBW infants compared to the scores of their former full-term counterparts. It is important to acknowledge that some of the former ELBW/VLBW infants had died and that the self-reporting nature of the data collection prevented the most severely disabled former ELBW/VLBW infants from participating in some of the studies. One further major limitation is that the data comes from VLBW/ELBW infants born in the 1970–1995 time period and thus may not be as applicable to a baby born today. Also, overlap exists in terms of the QOL measure results – for example, a 'former VLBW/ELBW' adolescent with a severe NDD may rate their QOL high or low, just like a 'former term baby' adolescent with no disability.

More recent publications (since our 2014 systematic review) on QOL of former ELBW/VLBW infants demonstrate the limitations and difficulties with interpretation of such data (44–48). Several studies now report on adulthood QOL and suggest a potential worsening of QOL over time. Different methods for measuring QOL also yield different results. Though the broad results suggest that a majority of former VLBW/ELBW infants rate their QOL quite well as

adolescent/young adults, the actual QOL measures of individuals are varied. Measurements of QOL taken indirectly (i.e. not the direct patient perspective) generally do show that the former VLBW/ELBW infants have a worse QOL than their term counterparts, most notably if NDD exists. HCP should use caution when using QOL as part of the SDM process.

#### **4.4 Quality of life of parents**

A systematic review using PubMed/Medline and a screening protocol (see **Appendix 4** for details) resulted in a detailed review of 13 relevant studies (49–61). The literature appears heterogeneous with different timing of and tools for the evaluation of QOL in caregivers (generally a parent) of children born as VLBW or ELBW infants. The timing of the parents' QOL self-assessments ranged from when their child was 1 to 25 years of age. Mothers largely completed the assessments. In general, most of the studies suggest increased parent stress (i.e. parent perception of the degree of stress related to the parenting role) and a negative impact on family functioning (i.e. impact on domains such as problem solving, communication etc.) and finances in parents of children born as VLBW/ELBW infants compared to parents of children born as full-term infants. Mothers of children born as VLBW/ELBW infants also attained fewer additional years of education after the birth of their child compared to controls; this appears to be correlated with the degree of NDD in the child. Some of these negative effects do seem to improve over time (60).

One cohort following the children into early adulthood showed that parents of children born as VLBW/ELBW infants felt that their child improved family bonds, enhanced parent self-perception and improved their parenting abilities (49,50). The effect of having a child born as a VLBW/ELBW infant on divorce rate is also equivocal: one study found no difference in divorce rate compared to parents with children born at term while another found it to be a major factor in separation and divorce (50,56). Many of the studies also made note that despite finding an overall negative effect compared to term controls, many of the parents of children born as VLBW/ELBW infants do not endorse distress or burden.

Overall, definitive conclusions on the long-term effect of raising children born as preterm VLBW/ELBW infants on the QOL of their parents are lacking. It is probably individualized and highly dependent on specific family situations and characteristics. Parents should understand and be prepared for effects on their level of parenting stress and overall family functioning. As per the QOL studies on the former VLBW/ELBW infants themselves, a major limitation is the fact that many of the cohorts were born before 2000 and the results may not be applicable today.

#### **4.5 Likelihood of maternal death or long-term morbidity**

We performed a systematic review of the literature examining the likelihood of maternal morbidity related to giving birth extremely prematurely (see **Appendix 5**).

Labour and delivery at any GA carries some risk of death or long-term morbidity for all mothers, albeit small. It remains challenging to isolate any increased risk solely attributable to an extremely preterm birth. Such excess attributable risk will be principally due to either the underlying pathology leading to the early delivery (such as abruptio, chorioamnionitis or pre-eclampsia) or to obstetric decisions made regarding mode of delivery. The underlying pathology can usually only be reversed by delivery. The risks attributable to the underlying

pathology may increase with time and so the level of maternal risk may be modified by the timing of delivery.

In the context of extremely preterm births, 15-20% of caesareans below 26 weeks GA will necessitate a classical / vertical incision on the uterus (62). These incisions are associated with a further increase in short term complications for the mother, including hemorrhage, infection and ileus (62-65). Due to increased intra-abdominal adhesion formation, vertical incisions may be associated with an increased likelihood of subsequent subfertility, although recent work suggests that there may be a large component of “voluntary” subfertility in this situation. Most importantly, vertical uterine incisions carry a substantially increased likelihood of rupture during future pregnancies with recent evidence suggesting a likelihood of approximately 2% (62-65). Delivery by repeat caesarean after a classical caesarean section is considered mandatory. Adhesions will also increase operative challenges and complications in subsequent deliveries. There is also evidence that women who have had a prior vertical uterine incision deliver at an earlier GA in subsequent pregnancies (66,67).

Risks associated with the mode of delivery are entirely modifiable. As delivery is ultimately inevitable, the excess maternal risk is almost entirely attributable to decisions to deliver via caesarean section. Recent position statements, including a Canadian one, have made it clear that currently available evidence does not consistently support routine cesarean sections to improve neonatal outcome in extremely preterm births (2,68,69). Discussions regarding the mode of delivery should occur in cases where the fetus is malpositioned, especially when there is a significant reduction in amniotic fluid volume. Additionally, discussion around if or when a caesarean section should be performed if there are signs of acute fetal compromise should occur in all cases. These individualized discussions should take into consideration the maternal risks and possible fetal benefits. If the decision is not to perform caesarean section for suspected compromise, some form of modified monitoring may help inform neonatal HCP as to fetal wellbeing in the period immediately before birth. It must be recognized that this monitoring can be distressing to both parents and obstetric HCP, as no direct action is being taken upon it.

Overall, although maternal mortality and morbidity are a consideration for expectant parents, these factors are not directly related to the decision to provide intensive care or palliative comfort care; rather, they are inherently related to the mode of delivery considered. Caregivers and parents must make challenging decisions about the relative benefit to the fetus of avoiding vaginal delivery versus the increased short term and long-term risk to maternal health, fertility and subsequent pregnancy outcomes associated with delivery by caesarean. The limited strength of the available evidence must also be acknowledged.

## **5.0 EPI: MEDICAL PROGNOSTIC UNCERTAINTY**

Although, in general, survival rates and the percentage of survivors without moderate-or-severe NDD improve as GA increases, this improvement can be influenced by other prognostic factors, making it erroneous to generate care plans based solely on GA (15,33,70,71).

A recent review article summarizes these influencing biological factors (**Table 4**) (72). The antenatal factors, besides GA, found to most strongly influence survival (and survival without NDD) in a large cohort of infants born <26 weeks are birth weight (in 100g increments, using estimated fetal weight as a surrogate marker antenatally), singleton (vs. multiple) birth, antenatal corticosteroids and gender (73,74). Each of the non-GA factors may individually improve outcomes by as much as one additional week of gestation. For example, a 25 week,

650 g male twin who receives intensive care but who did not receive antenatal corticosteroids has a 49% chance of survival and, if he survives, a 32-52% chance of moderate-or-severe NDD at 18-26 months, which is identical to a 23 week, 550 g female singleton who receives antenatal corticosteroids and intensive care (49% survival; if survives, 32-52% chance of moderate-or-severe NDD). The database used to generate these observations excluded infants with major anomalies, with birth weights greater than the 97<sup>th</sup> percentile, or who were not born at participating hospitals (noting that 79 Level 1 NICUs were included). The included infants were born in 2006-2012. Furthermore, outcomes generated by this NICHD Extremely Preterm Birth Outcomes Tool are for 18-26 months CGA, which has been shown to overestimate the degree of disability (75). There are (at least) three further points to remember: significant center-to-center variability exists in rates of survival of EPI, the data represent outcomes for similar groups of infants (and thus do not represent the outcome of an actual individual infant), and the predicted outcome is solely for at the time of birth (see next paragraph) (32,74,76).

Finally, the postnatal clinical course of the EPI in the NICU also influences long term outcome. Intracranial bleeding, periventricular leukomalacia, retinopathy of prematurity, bronchopulmonary dysplasia, sepsis and days on mechanical ventilation have been shown to influence outcome (74,77-80). Therefore, the EPI's prognosis should be reviewed and discussed and the care plan re-evaluated in the days and weeks after birth. Specific recommendations for the postnatal course are beyond the scope of this guideline.

## **6.0 COMMUNICATION WITH EXPECTANT PARENTS**

Parents facing the birth of an EPI should, ideally, have several opportunities to meet with HCP to share information and consider a care plan, particularly as pregnancy progresses or new information becomes available. Parents value follow-up conversations, after some time to reflect, when the situation allows it. Many parents report feeling distressed, disempowered and grief-stricken when faced with the possibility of delivering extremely preterm (81-83). A recent systematic review provides a narrative summary outlining how to support the parents in these delicate situations and who should approach them (30). The article included a list of proposed strategies to facilitate communication during the antenatal consultation for EPI.

Providing written information improves parental understanding and recall (84). Consistency and accuracy in provided information is crucial for expectant parents (27). Communication between obstetrical and neonatal teams concerning consultations, along with clear documentation of the joint plan in the mother's medical chart, promotes consistency and adherence to the plan (1,68). Communicating with parents about periviability, potential outcomes and difficult decisions requires specialized training (85-87). Trainees must demonstrate expert competence before performing consultations without supervision. Involving trained peer counsellors may provide further support to parents.

## **7.0 SHARED DECISION MAKING**

The main characteristics of SDM (88) are that HCP and parent(s) take part in the decision making process together. Both parties share essential information. The HCP shares medical information about the decision to be made, the treatment options, benefits and harms, probabilities and scientific uncertainties. They also may share their values and preferences. The parents share information about their personal circumstances and specific socio-familial characteristics that may influence future outcome (89). They also share their values and

preferences and the personal importance they attach to the benefits, risks and scientific uncertainties of the options. Both parties build consensus about the preferred management; and a consensus agreement is reached on the management plan to be implemented.

SDM is most effective for *preference-sensitive decisions*, when there is uncertain or no clear evidence supporting one treatment over another, where options have different inherent benefits/risks or when patient values are important in optimizing decision making. SDM has been shown to reduce parental grief after end of life decisions (90), improve patient satisfaction (91–93), improve individual's knowledge of their options (including the benefits and harms of those options), assist people in reaching choices that are more consistent with their informed values and foster collaboration with their HCP (94).

Parents want to be involved in the decisions made during antenatal consultations (5,81,95), and for their EPI in the NICU, seeking to take responsibility for their own health and well-being as well as the health and well-being of their baby (95,96). Clinicians must recognize that parents' preferences for how to participate in decision making may take different forms; this can range from asking for a recommendation to being involved in the deliberation about the risks and benefits of each option to making an informed choice following consultation with the HCP. In addition, parents' expectations with regards to their role during the decision making process cannot be assumed (97) and willingness to participate is a dynamic (not static) feeling that builds and changes over time during the consultation depending on many factors (1,98). If the proper conditions are not in place, parents may not be comfortable to participate. Decision support should be provided in a non-directive way to facilitate parents' involvement in decision making to the degree they are comfortable with. The most important factor facilitating parents' participation in SDM is the HCP's openness in their communication and attitude towards engagement of parents in the process. Building a trustworthy relation between parents and the clinician is crucial (98).

Formal training in SDM and decision coaching enables HCP to optimally engage parents in the process (30). Patient decision aids can support patient participation in the decision making process and facilitate the adoption of SDM by providers (94). In the perinatal context, a locally developed decision aid has shown reductions in decisional conflict (28). In some circumstances when a medical recommendation is made, the HCP should divulge their own values and the reasoning behind their recommendation and ensure parents understand. HCP must provide opportunities to parents to share their views, values and preferences in regards to the recommendation made, keeping in mind that a recommendation does not preclude parents from participating in the decision making or expressing a different opinion (99).

**Table 5** lists strategies for communicating effectively with parents, engaging parents in decision making, clarifying their values and preferences, and guiding the prenatal consultation. SDM is the goal but may not always be possible due to clinical circumstances (e.g., a rapidly progressing labour, or when a medication heavily alters a mother's level of consciousness).

## 8.0 ETHICAL CONSIDERATIONS

The recommendations proposed in this document recognize the importance of ethical principles and decision making. Specifically, these recommendations take into account the four traditionally cited principles of biomedical ethics (100). These principles, presented without hierarchy, include:

1. Beneficence: the obligation to do good

2. Non-maleficence: the obligation to do no harm
3. Autonomy: the right of capable individuals to make their own decisions
4. Justice: treating like cases alike, fairness

Ethically, one of the most important issues relative to management of EPI is the concept of best interests; this concept intersects in some way with each of the principles listed above. In Ontario, a physician or HCP must take reasonable steps to obtain consent from substitute decision-makers before administering any treatment. Additionally, the Health Care Consent Act (Health Care Consent Act 1996, Section 21 (2)) requires that substitute decision-makers act in the patient's best interests, though trying to ascertain whether a certain care plan will meet these goals in the context of EPI can be extremely challenging.

The traditional four principles of bioethics, while essential, do not address the manner in which the best interest of the EPI is determined, nor do they address the legitimacy of parents' perceptions or of parents' participation in these decisions (101). Therefore, the recommendations in this guideline are also informed by the rules of communicative ethics, which describe the modalities to reach ethically justified shared decisions (98,100–102). In the context of SDM and family centered care, communicative ethics proposes rules to ensure open and honest participation of each person in the decision making process to reach a consensus (98). These rules require individuals to: 1) recognize and promote each person's participation in the discussion; 2) recognize the differences among participants; and, 3) accept that everyone is morally equivalent to one another.

The determination of best interests is complex and includes many concepts including not only the medical prognosis, but also the clinical and societal context and how the different stakeholders taking part into the decision perceive the situation. In large part, the difficulties in determining what is in the best interests of a particular EPI can be attributed to the prognostic uncertainty. Parents, neonatologists and other HCP each have their own personal experiences, value systems and interpretation of the medical data that shape their own moral judgments regarding what is in the best interests of the EPI.

Balancing all the clinical considerations can also be challenging. The medical labeling and definition of disability (moderate, severe, profound, significant ...) may not resonate with some parents for their child. For example, the medical community labels cerebral palsy requiring a wheelchair as severe NDD, but some parents or individual HCP may (correctly) see it as a challenge that, despite its difficulties, will not (necessarily) stop a child from enjoying life. Secondly, behavioral problems in school are not labeled as severe or moderate NDD at present by some of the medical community but may be viewed as such by some parents. This uncertainty reinforces the need to engage in SDM by seeking parental views and have a values-based discussion about the various treatment options.

## **9.0 SITUATIONS WHERE RECOMMENDATIONS DO NOT APPLY**

Cases exist at any GA where a devastating congenital lesion or clinical situation leads to the consideration of palliative comfort care antenatally or postnatally. **The recommendations in this document specifically focus on preference-sensitive decisions where there is prognostic uncertainty and no clear evidence to definitively support the provision of only one of the options for the EPI (i.e. only intensive care or only palliative comfort care).**

When there is low likelihood (**Table 6**) of mortality or moderate-or-severe NDD in survivors, intensive care is presently the suggested care option. Discussions with parents and SDM in these cases might revolve around the length or intensity of resuscitation (e.g. chest compressions and epinephrine versus no chest compressions and epinephrine), or other choices the parents can make. Similarly, when there is extremely high likelihood (**Table 6**) of mortality or severe NDD, palliative comfort care is the suggested care option. In both situations, the HCP will explain the situation to the parents, provide information, seek parents' values and preferences and encourage them to express their thoughts and opinions, listen to and respect their input, ensure that they have understood the information provided and seek informed consent to proceed. The HCP has a responsibility to explain the reasons why certain options are not applicable to their situation; the HCP may also need to express their own values when making a recommendation (103).

Some parents may disagree with a proposed care option recommended by the HCP or couples may differ in their views when facing a preference-sensitive decision; given the lack of a moral authority on the standard of care in this complex area, the "non-usual" option may be chosen after further discussion, time to think and conflict resolution (104). HCP may consider seeking a second opinion from a colleague and/or support from an ethics consultation, or may wish to explore the possibility of a Consent and Capacity Board application to review questions around best interests (105).

## 10.0 SUGGESTED PROCESS FOR THE CONSULTATION

It is not expected that each HCP involved in the care of mothers and babies will be trained in SDM and neonatal consultation. However, all clinicians providing care to pregnant women should be knowledgeable about expected outcomes if extremely preterm birth occurs, be able to answer general questions from expectant parents and be knowledgeable about the concept of decision making.

As a starting point, clinicians involved in SDM with parents are encouraged to review the point estimate of mortality (**Tables 1 and 2**), the point estimates of long-term moderate-or-severe, moderate and severe NDD of survivors (**Table 3**) for the EPI(s) and the modifiers of survival and NDD (**Table 4**). Clinicians are also encouraged to consult the NICHD Extremely Preterm Birth Outcomes Tool (see Section 5.0 for limitations regarding its use):

<https://www.nichd.nih.gov/research/supported/EPBO> Depending on the estimated likelihood of survival or moderate-or-severe (or severe) NDD at school age in survivors, intensive care or palliative comfort care may be options at the outset, or initially one approach may be recommended (but not at the exclusion of the other option being chosen after an SDM process) (**Table 6**).

These anticipated likelihood estimations serve as a starting point. Each case is unique, and the HCP must use their expertise and experience to generate the best possible likelihood estimation. It is expected that during the SDM process, the parents' values and preferences will further delineate the level of care that is appropriate for their baby. This process will ideally occur over time (**Figure 1**).

## 11.0 WHEN THERE IS NO ANTENATAL DECISION

In some instances, women present in advanced labour or there is an urgent need to deliver the EPI (due to concerns regarding maternal or fetal health) with no time for SDM consultation. In other instances, despite best efforts, parents are simply unable to make a decision regarding the care they wish for their EPI prior to his/her delivery. In these instances, the suggested approach is to provide intensive care. This means initially erring on the side of life (while still having palliative care available as a postnatal option) and starting a trial of intensive care. Early reassessment of the EPI's status and further discussions with parents regarding the future direction of care should occur as soon as possible. **Figure 2** suggests a pragmatic consultation process.

If the prognosis, as established by a senior MD, clearly places the EPI in the category of having an extremely high likelihood of mortality or severe NDD (**Table 6**), a decision may be made to forego attempting intensive care since palliative comfort care would be the suggested approach.

## 12.0 RECOMMENDATIONS

The recommendations below take into account prognostic uncertainty and the uniqueness of each infant and family; they are not meant to be prescriptive. Not every recommendation can be based on high quality evidence from systematic reviews, either due to the lack of a systematic review, or lack of useable data despite a systematic review. When high quality evidence from a systematic review is unavailable, the recommendations below are based on the review of other regional and national guidelines (2,7,8,11,13,16,17,19,20,106,107) regarding the perinatal care of EPI, expert opinion in bioethics and neonatology (4,18,89,108–111), and/or consensus opinion from our working group (see **Appendix 1 & 2**).

### 12.1 Referral Process (prior to patient contact with trained HCP who are able to perform SDM with parents)

<p>1. Consult with a maternal-fetal medicine (MFM) staff or fellow to discuss referral to a tertiary perinatal center when a pregnant woman is facing anticipated delivery between 22+0 and 25+6 weeks GA (based on best obstetrical estimate). <i>Evidence supporting recommendation: consensus from working group, position statement (20)</i></p>
<p>2. When prenatal maternal transfer is not possible in the opinion of the primary HCP at the referring center and the MFM staff or fellow being consulted, and delivery is anticipated at 22+0–25+6 weeks GA, the HCP at the referring center should initiate a consultation with a neonatology staff to review management options and receive guidance about facilitating the decision-making process with the parents. <i>Evidence Supporting recommendation: consensus from working group</i></p>
<p>3. When prenatal maternal transfer is not possible, intensive care and/or palliative comfort care will be offered as the option(s) to the parents based on estimation of the prognosis (<b>Table 6</b>) generated from the consultation with a neonatology staff and the resources available to assist the primary HCP. The management plan will be finalized after discussion between the HCP at the referring center and the parents. <i>Evidence supporting recommendation: consensus from working group.</i></p>

## 12.2 Consultation process and communication (only possible in tertiary care center with HCP trained in this area of expertise)

<p>4. Consult a neonatology staff or fellow (see <b>Figure 2</b>):</p> <ul style="list-style-type: none"><li>a) when a pregnant woman is presenting at 21+0 to 25+6 weeks GA with a high likelihood of delivery in the next 48 hours in the opinion of the MFM staff <b>and</b></li><li>b) after the MFM staff or fellow has introduced the reasons for a neonatal consultation to the pregnant woman <b>and</b></li><li>c) after a MFM staff or fellow has verbally discussed the case with a neonatology staff or fellow.</li></ul> <p><i>Evidence supporting recommendation: position statement (20), consensus from working group</i></p>
<p>5. Follow a SDM framework during consultation between a neonatologist or neonatology fellow and expectant parents of an EPI, except where implausible (e.g. expected imminent delivery (i.e. &lt;1 hour)).</p> <p><i>Evidence supporting recommendation: guideline and position statement (19,20), expert opinion (95)</i></p>
<p>6. Use a decision aid and parent information handout about EPI births to facilitate comprehension and involvement of parents in the decision-making process. Some parents may decline the use of the decision aid or handbook.</p> <p><i>Evidence supporting recommendation: systematic review (94), position statement (20), consensus from working group</i></p>
<p>7. When consulted, a neonatology staff or fellow should:</p> <ul style="list-style-type: none"><li>o review the fetal condition and modifiers of survival and NDD rates to determine the anticipated likelihood of mortality and severe or moderate- or-severe NDD.</li><li>o determine the suggested level of care options based on <b>Table 6</b>.</li><li>o complete the initial consultation (or document reasons for delaying completion) within 24 hours.</li></ul> <p>The current management plan will be decided upon after engaging in a SDM process with the parents and exchanging information about the risks and benefits of each option, clarifying the values and preferences of the family, and considering the feasibility of each option under discussion (<b>Figure 1</b>). Whenever palliative comfort care is the recommended option, or one of the usual care options, a neonatology staff should be present for the consultation.</p> <p><i>Evidence supporting recommendation: guideline (19), expert opinion (15,71), consensus from working group</i></p>
<p>8. Ensure details of the management plan are communicated directly to the MFM staff, neonatology staff, the registered nurse caring for the mother and the parent(s) to enhance care and avoid conflicting information. Where possible, this group should meet together in the final stages of the SDM process.</p> <p><i>Evidence supporting recommendation: guideline and position statement (19,20)</i></p>

## 12.3 Management options for the EPI

9. Provide palliative comfort care to babies born at <22+0 weeks GA, including those between 21+0-21+6 weeks GA, as survival at less than 22 weeks

<p>completed GA (under 22+0 weeks) has rarely been reported in the published peer-reviewed medical literature (or our own local or national data).</p> <p><i>Evidence supporting recommendation: Systematic review (31)</i></p>
<p>10. For babies born at 22+0-25+6 weeks GA, when SDM is not possible prenatally or parents cannot make a decision regarding the care of their EPI:</p> <ul style="list-style-type: none"> <li>a. Provide intensive care initially and communicate with the parents postnatally to engage them in SDM to determine the ongoing management plan, or;</li> </ul> <p>Provide palliative comfort care if the infant is thought to be – by a neonatology staff or fellow and with a high level of confidence – at an extremely high likelihood of mortality or severe NDD (<b>Table 6</b>). This palliative comfort care plan should be communicated directly to the parent(s) prior to its provision, ideally prior to the immediate moment of delivery.</p> <p><i>Evidence supporting recommendation: consensus from working group.</i></p>
<p>11. If the current management plan at the time of the EPI's birth is to provide intensive care, a neonatology staff or fellow should attend the delivery.</p> <p><i>Evidence supporting recommendation: guideline and position statement (18,20)</i></p>

## 13.0 TABLES AND FIGURES

**Table 1: Survival rates in Canada in 2010-2018**

GA (weeks + days)	Number of live births (n)	Infants who received palliative care at birth (n, (% of live births))	Infants who received intensive care at birth (n, (% of live births))	Delivery room deaths in those who received intensive care (n, (% of resuscitated infants))	Survivors to NICU discharge in those who received intensive care (n, (%; 95% CI))
≤22+6	559	376 (67%)	183 (34%)	29% (2018)	45 (25%; 19, 31%)
23+0-23+6	1200	322 (27%)	878 (73%)	2% (2018)	396 (45%; 42, 48%)
24+0-24+6	1893	99 (5.2%)	1794 (94.8%)	4% (2018)	1230 (68%; 67, 71%)
25+0-25+6	2402	40 (1.7%)	2362 (98.3%)	1.8% (2018)	1894 (80%; 78, 82%)

Please refer to Section 4.1 and decision aid script for details and limitations. This table should not be used in isolation to recommend intensive care or comfort care.

**Table 2: Survival rates in Ottawa for October 2015- December 2019**

GA (weeks + days)	Infants who received intensive care at birth (n)	Delivery room deaths in those who received intensive care (n, (% of resuscitated infants))	Survivors to NICU discharge in those who received intensive care (n, %)
22+0- 22+6	12	2 (17%)	3 (25%)
23+0- 23+6	19	3 (16%)	9 (47%)
24+0- 24+6	40	1 (2.5%)	27 (69%)
25+0- 25+6	51	2 (4%)	36 (73%)

Please refer to Section 4.1 and decision aid script for details and limitations. This table should not be used in isolation to recommend intensive care or comfort care.

**Table 3: Severe and moderate-or-severe neurodevelopmental disability rates at school age in survivors**

Gestational age	Rate of moderate NDD (%, 95% CI)	Rate of severe NDD (%, 95% CI)	Rate of moderate-or-severe NDD (%, 95% CI)
22 weeks (n=19 for both moderate and moderate-or-severe NDD; n=24 for severe NDD)	21% (8, 45)	17% (6, 37)	42% (23, 64)
23 weeks (n=137 for moderate NDD; n=143 for severe NDD; n=186 for moderate-or-severe NDD)	26% (16, 40)	17% (12, 24)	41% (31, 52)
24 weeks (n=331 for moderate NDD; n=346 for severe NDD; n= 506 for moderate-or-severe NDD)	17% (13, 21)	17% (12, 23)	32% (25, 39)
25 weeks (n=337 for moderate NDD; n= 544 for severe NDD; n=807 for moderate-or-severe NDD)	12% (8, 19)	11% (7, 16)	23% (18, 29)
*Most children have no or mild NDD with estimates of: 58% at 22 weeks GA, 59% at 23 weeks, 68% at 24 weeks and 77% at 25 weeks. Mild NDD include neurobehavioral difficulties (e.g., autism, attention-deficit) that could challenge a child and their family.			

Please refer to Section 4.2 and decision aid script for details and limitations. This table should not be used in isolation to recommend early intensive care or comfort care.

**Table 4: Factors known to affect likelihood of mortality and NDD**

Factors decreasing the likelihood of mortality and NDD	Factors increasing the likelihood of mortality and NDD
Birth in tertiary care center	Small for gestational age (SGA)
Increasing GA	Multiple birth
Appropriate for GA weight	Male gender
Singleton	Acute chorioamnionitis
Female gender	Prenatal ultrasound findings of anomalies, evidence of fetal anemia or poor placental flow to fetus
Exposure to prenatal steroids	

Please refer to Section 5.0 for details and limitations

**Table 5: Strategies to facilitate communication with expectant parents during a prenatal consultation (to reorder and adapt as needed)**

Consultation phases	Key points
<b>To prepare for consultation</b>	
Preparation and setting	<ul style="list-style-type: none"><li>• Speak with the mother's HCP, obtain all relevant information regarding maternal and fetal health</li><li>• Use interpretive services by a professional translator, if required</li></ul>
Create a comfortable environment	<ul style="list-style-type: none"><li>• Talk with both parents, if feasible</li><li>• Make sure the consult is not disturbed (e.g., turn pager to vibrate, close the door or curtains, let the nurse know)</li><li>• Sit down, shake hands (if appropriate) and introduce yourself first, slowly and clearly</li><li>• Demonstrate openness to communication with and involvement of parents (by carefully listening to parents and facilitating their participation)</li><li>• Ask about participants (e.g., use names, including the infant's name, if known, and if parents agree you can use it)</li></ul>
Assess parental knowledge of prematurity issues, along with perspectives, concerns, expectations, needs and preferences	<ul style="list-style-type: none"><li>• Ask what the parents know about prematurity</li><li>• Acknowledge the parents' values, perspectives and concerns about prematurity (e.g., cultural/social background, religious beliefs, family structure)</li><li>• Adjust ways of communicating information, by adapting the content of the information to respect their values and preferences</li><li>• Support their involvement in decision making with inclusive wording (e.g., <i>"How can I support you?"</i>; <i>"We can make this decision together"</i>)</li></ul>
<b>During consultation</b>	
Ensure factors that are important to parents	Typically, parents want to know about likelihood of survival, likelihood of NDD (with related challenges and opportunities), what

are discussed (e.g., Ask what is important to them)	medical problems might be encountered, possible treatments, what a preterm baby looks like, what it is like to be in the NICU, what happens after birth, how to manage breastfeeding, and their own role in the NICU (with explanations)
Discuss different choices or options	<ul style="list-style-type: none"> <li>Identify the decision that needs to be made</li> <li>Clearly and accurately describe the appropriate management options based on the clinical situation</li> </ul>
Share weighted or balanced (unbiased) information and Disclose uncertainty	<ul style="list-style-type: none"> <li>Include both positive and negative aspects of care, pros and cons of the options, treatable and non-treatable conditions</li> <li>Disclose potential outcomes <b><i>according to parental preferences of information:</i></b></li> <li><i>Use grading words (majority, most, significant, some, a minority) and numbers when possible (6 out of 10, rather than 60%)</i></li> <li><i>Use a consistent denominator when presenting different options, outcomes or event rates, to make the information easier to understand, interpret or compare (XX out of 10, 100 or 1000). For example, saying "Out of 100 babies, 20 will die, 20 will survive with NDD, and 60 will survive with no NDD," is better than saying 20 out of 100 for one outcome, then 1 out of 5 for another.</i></li> <li>Disclose the limits of statistics when applied to a particular baby</li> </ul>
Additional strategies to build trust	<p>Allow parents to lead the conversation:</p> <ul style="list-style-type: none"> <li>Use their verbal, nonverbal cues to pace discussion</li> <li>Ask how you can support them</li> <li>Invite them to share how they see the situation</li> <li>Use open-ended questions ("How...?", "Could you tell me more?", "Can you describe...?")</li> <li>Always ask whether parents have questions or need clarification</li> </ul> <p>Listen for concerns and emotions, and be empathetic and supportive:</p> <ul style="list-style-type: none"> <li>Validate the difficulty of their situation</li> <li>Use a soft voice, allow silences, use appropriate touch</li> <li>Acknowledge and be sensitive to emotional reactions and concerns</li> <li>Support parental needs and values</li> </ul> <p>Answer questions and be sure parents have received and understand the information to the extent they want to</p> <p>Maintain eye contact with both parents</p> <p>Offer time to think and reflect</p> <p>Avoid interrupting. Be quiet as parents describe perspectives, values or preferences</p> <p><b>Note:</b> Obtaining informed consent for a management plan requires – at a minimum – sharing accurate information tailored to the parents'</p>

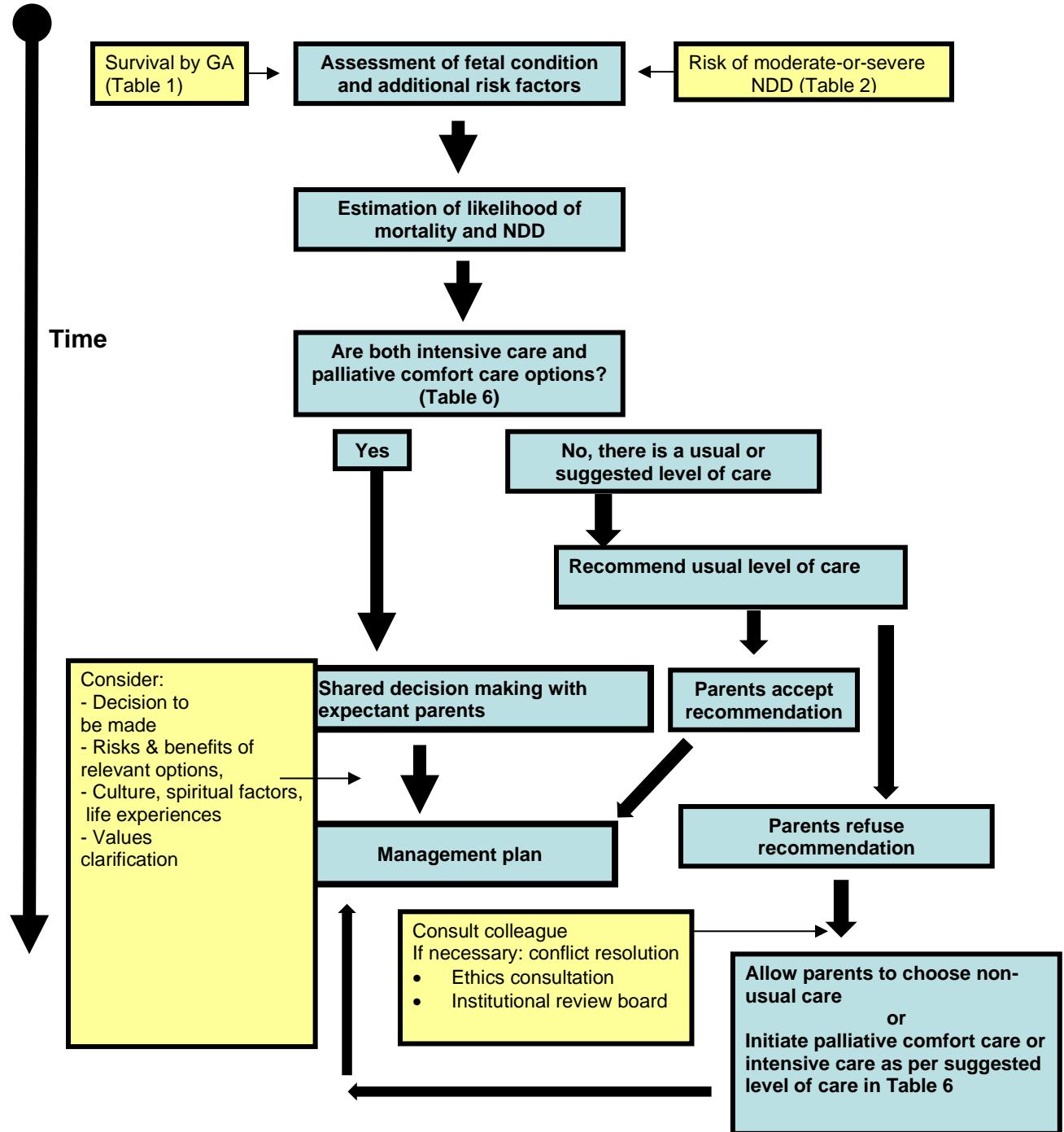
	needs regarding the likelihood of death and NDD, and the opportunity of having a surviving child with or without NDD
Show compassion and acknowledge parental distress	<p>Reassure parents that they did not do anything to cause preterm birth</p> <p>Confirm the uniqueness of their family and of the unborn baby</p> <p>Acknowledge their baby as a being, not a GA</p> <p>Provide value-neutral information (i.e., by including the positives of having an infant they can love and cherish)</p> <p>Be honest</p>
<b>Concluding the consultation</b>	
Provide support and give parents realistic hope	<ul style="list-style-type: none"> <li>• Validate their situation as very difficult and their reactions as understandable</li> <li>• Tell them that every hour, day and week that the pregnancy continues (with baby and mom in stable condition) has positive effects</li> <li>• Make sure they know that they are not alone</li> <li>• Make sure they understand that you are there to provide more information and answer new questions</li> <li>• Invite them to write their questions down as they think of them, for next time</li> </ul> <p>Meet with parents the following day, if possible, or at any time after the initial consultation</p>

**Table 6: Stratification of level of care offered based on anticipated likelihood of mortality and NDD**

<b>Likelihood estimation for anticipated mortality or long-term NDD</b>	<b>Suggested level of care</b>	<b>Clinical examples that usually meet the likelihood estimation</b>
Extremely high likelihood of mortality or severe NDD *	Palliative comfort care is recommended **	Infant born at 22 weeks GA, irrespective of additional risk factors*** Infant born at 24 weeks GA, with an estimated weight of 350 g
Moderate-to-high likelihood of mortality or moderate-or-severe NDD	Intensive care or palliative comfort care are both usual care options	Infant born at 23 to 24 weeks GA, irrespective of most additional risk factors*** Infant born at 25 weeks GA, with signs of fetal anemia and abnormal placental blood flow
Low likelihood of mortality or moderate-or-severe NDD	Intensive care is recommended **	Infant born at 25 weeks GA, without additional risk factors*** Infant born late in 24 <sup>th</sup> week of gestation (e.g. 24 <sup>5</sup> ), well grown with ANCS given, born in a tertiary care centre
<p>* In the clear majority of cases, the likelihood estimation for neurodevelopmental disability (NDD) does not reach the 'extremely high likelihood' category. Most cases where comfort care is recommended usually relate to an 'extremely high likelihood' of mortality, even when providing intensive care.</p> <p>** Given the lack of moral authority on the suggested level of care, parents may choose a non-recommended option. HCP should engage with them to determine their infant's management plan.</p> <p>*** See table 4 for additional risk factors</p>		

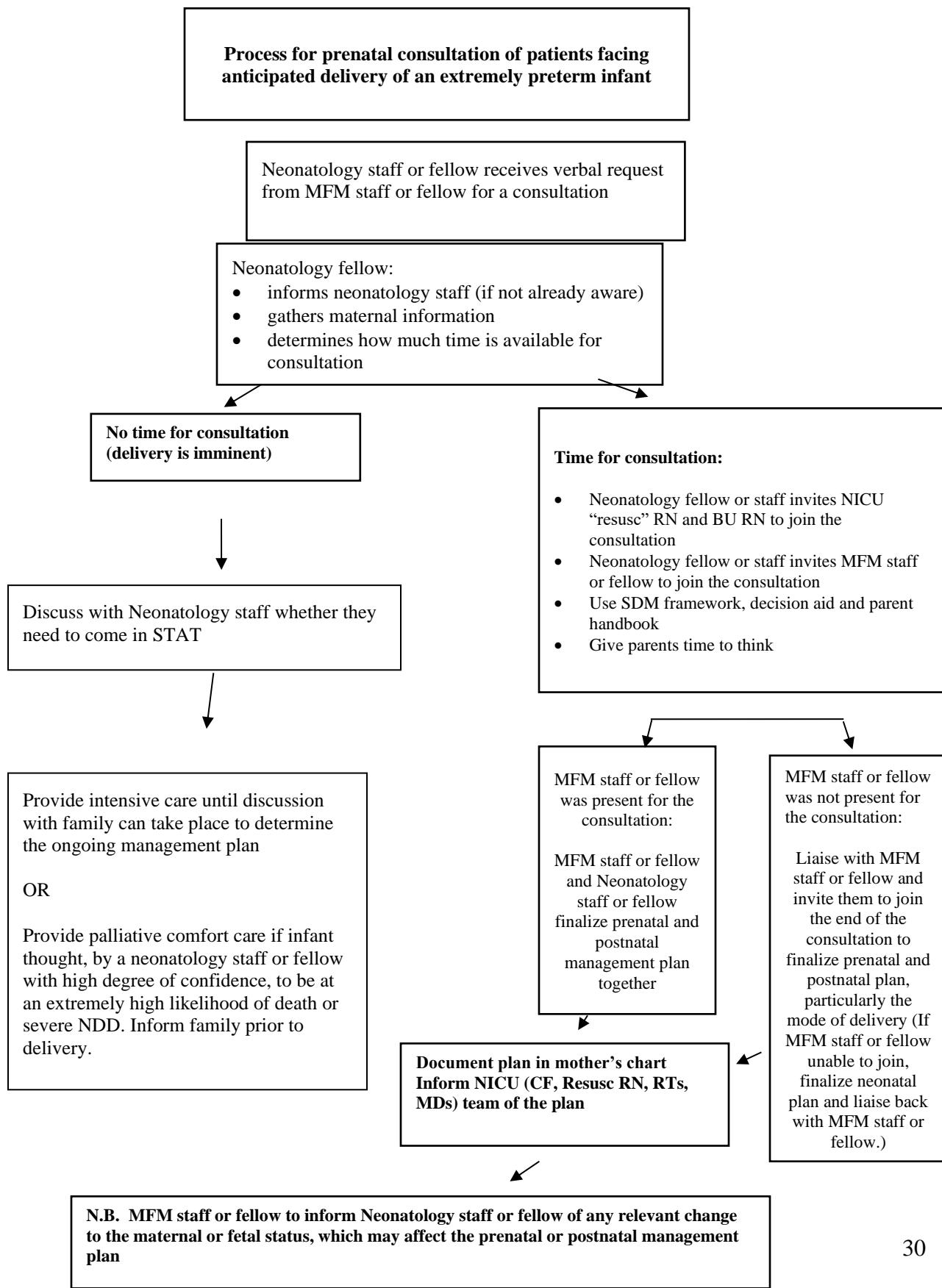
For further details on the suggested steps to get to this estimation, please see Sections 10.0 and 11.0.

**Figure 1: Process to determine management plan for anticipated extremely premature infant**



Consider using the NICHD Extremely Preterm Birth Outcomes Tool (see Section 10.0) in estimating the risk, being aware of its limitations (see Section 5.0).

**Figure 2: Pragmatic process for consultation, when there is time and when there isn't**



## 14.0 References

1. 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):429–45.
2. Raju TNK, Mercer BM, Burchfield DJ, Joseph GF. Perivable 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 May;123(5):1083–96.
3. Daboval T. Discute de la prématûrité: une conduite éthique possible. *Paediatr Child Health.* 2005 Feb;10(2):87–94.
4. Lorenz JM. Management decisions in extremely premature infants. *Semin Neonatol SN.* 2003 Dec;8(6):475–82.
5. Bastek TK, Richardson DK, Zupancic JAF, Burns JP. Prenatal consultation practices at the border of viability: a regional survey. *Pediatrics.* 2005 Aug;116(2):407–13.
6. Kaempf JW, Tomlinson M, Arduza C, Anderson S, Campbell B, Ferguson LA, et al. Medical staff guidelines for periviability pregnancy counseling and medical treatment of extremely premature infants. *Pediatrics.* 2006 Jan;117(1):22–9.
7. American College of Obstetricians and Gynecologists. ACOG Practice Bulletin: Clinical Management Guidelines for Obstetrician-Gynecologists: Number 38, September 2002. Perinatal care at the threshold of viability. *Obstet Gynecol.* 2002 Sep;100(3):617–24.
8. 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 Jan;19(1):31–4.
9. Newborn Clinical Network. New Zealand Consensus Statement on the care of mother and baby(ies) at perivable gestations [Internet]. Starship. [cited 2020 Sep 29]. Available from: <https://www.starship.org.nz/guidelines/new-zealand-consensus-statement-on-the-care-of-mother-and-baby-ies-at>
10. SA Maternal, Neonatal & Gynaecology Community of Practice. South Australian Perinatal Practice Guidelines: Perinatal Care at the Threshold of Viability [Internet]. [cited 2020 Sep 29]. Available from: <https://www.sahealth.sa.gov.au/wps/wcm/connect/Public+Content/SA+Health+Internet/Clinical+Resources/Clinical+Programs+and+Practice+Guidelines/Womens+and+Babies+Health/Perinatal/Perinatal+Practice+Guidelines/Perinatal+Practice+Guidelines>
11. Lui K, Bajuk B, Foster K, Gaston A, Kent A, Sinn J, et al. Perinatal care at the borderlines of viability: a consensus statement based on a NSW and ACT consensus workshop. *Med J Aust.* 2006 Nov 6;185(9):495–500.
12. de Laat MWM, Wiegerinck MM, Walther FJ, Boluyt N, Mol BWJ, van der Post JAM, et al. [Practice guideline 'Perinatal management of extremely preterm delivery']. *Ned Tijdschr Geneeskd.* 2010;154:A2701.
13. British Association of Perinatal Medicine. Perinatal Management of Extreme Preterm Birth Before 27 weeks of Gestation (2019) | British Association of Perinatal Medicine [Internet]. [cited 2020 Sep 29]. Available from: <https://www.bapm.org/resources/80-perinatal-management-of-extreme-preterm-birth-before-27-weeks-of-gestation-2019>
14. Nuffield Council on Bioethics. Critical care decisions in fetal and neonatal medicine: ethical issues. London: Nuffield Council on Bioethics; 2006.

15. Wilkinson AR, Ahluwalia J, Cole A, Crawford D, Fyle J, Gordon 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 Jan;94(1):F2-5.
16. Pignotti MS, Donzelli G. Perivable babies: Italian suggestions for the ethical debate. *J Matern-Fetal Neonatal Med Off J Eur Assoc Perinat Med Fed Asia Ocean Perinat Soc Int Soc Perinat Obstet.* 2008 Sep;21(9):595-8.
17. Synnes AR, Buchanan L, Ruth C, Albersheim S. Management of the newborn delivered at the threshold of viability. *BC Med J.* 2008 Nov;50(9):498-508.
18. Batton DG, Committee on Fetus and Newborn. Clinical report--Antenatal counseling regarding resuscitation at an extremely low gestational age. *Pediatrics.* 2009 Jul;124(1):422-7.
19. Berger TM, Bernet V, El Alama S, Fauchère J-C, Hösli I, Irion O, et al. Perinatal care at the limit of viability between 22 and 26 completed weeks of gestation in Switzerland. 2011 revision of the Swiss recommendations. *Swiss Med Wkly.* 2011;141:w13280.
20. Lemyre B, Moore G, Canadian Paediatric Society Fetus and Newborn Committee. Counselling and management for anticipated extremely preterm birth. *Paediatr Child Health.* 2017;22(6):334-41.
21. Cummings J, COMMITTEE ON FETUS AND NEWBORN. Antenatal Counseling Regarding Resuscitation and Intensive Care Before 25 Weeks of Gestation. *Pediatrics.* 2015 Sep;136(3):588-95.
22. Marlow N, Wolke D, Bracewell MA, Samara M, EPICure Study Group. Neurologic and developmental disability at six years of age after extremely preterm birth. *N Engl J Med.* 2005 Jan 6;352(1):9-19.
23. Doucette S, Lemyre B, Daboval T, Dunn S, Akiki S, Barrowman N, et al. Effect of an Educational Presentation about Extremely Preterm Infants on Knowledge and Attitudes of Health Care Providers. *Am J Perinatol.* 2017;34(10):982-9.
24. Lemyre B. Response to "Frameworks are pretty on paper but often don't fit reality." *J Perinatol Off J Calif Perinat Assoc.* 2017;37(6):747.
25. Barker C, Dunn S, Moore GP, Reszel J, Lemyre B, Daboval T. Shared decision making during antenatal counselling for anticipated extremely preterm birth. *Paediatr Child Health.* 2019 Jul;24(4):240-9.
26. Moore G, Reszel J, Daboval T, Lemyre B, Barker C, Dunn S. Qualitative evaluation of a guideline supporting shared decision making for extreme preterm birth. *J Matern-Fetal Neonatal Med Off J Eur Assoc Perinat Med Fed Asia Ocean Perinat Soc Int Soc Perinat Obstet.* 2020 Mar;33(6):973-81.
27. Mardian E, Bucking S, Dunn S, Lemyre B, Daboval T, Moore GP. Evaluating parental perceptions of written handbooks provided during shared decision making with parents anticipating extremely preterm birth. *J Matern-Fetal Neonatal Med Off J Eur Assoc Perinat Med Fed Asia Ocean Perinat Soc Int Soc Perinat Obstet.* 2020 Jul 29;1-8.
28. Moore GP, Lemyre B, Daboval T, Ding S, Dunn S, Akiki S, et al. Field testing of decision coaching with a decision aid for parents facing extreme prematurity. *J Perinatol Off J Calif Perinat Assoc.* 2017;37(6):728-34.
29. Lemyre B, Daboval T, Dunn S, Kekewich M, Jones G, Wang D, et al. Shared decision making for infants born at the threshold of viability: a prognosis-based guideline. *J Perinatol Off J Calif Perinat Assoc.* 2016;36(7):503-9.
30. Kharrat A, Moore GP, Beckett S, Nicholls SG, Sampson M, Daboval T. Antenatal Consultations at Extreme Prematurity: A Systematic Review of Parent Communication Needs. *J Pediatr.* 2018;196:109-115.e7.

31. Guillen U, DeMauro S, Ma L, Zupancic J, Wang E, Gafni A, et al. Survival rates in extremely low birthweight infants depend on the denominator: avoiding potential for bias by specifying denominators. *Am J Obstet Gynecol.* 2011 Oct;205(4):329.e1-7.
32. Rysavy MA, Li L, Bell EF, Das A, Hintz SR, Stoll BJ, et al. Between-hospital variation in treatment and outcomes in extremely preterm infants. *N Engl J Med.* 2015 May 7;372(19):1801–11.
33. Moore GP, Lemyre B, Barrowman N, Daboval T. Neurodevelopmental outcomes at 4 to 8 years of children born at 22 to 25 weeks' gestational age: a meta-analysis. *JAMA Pediatr.* 2013 Oct;167(10):967–74.
34. Ding S, Lemyre B, Daboval T, Barrowman N, Moore GP. A meta-analysis of neurodevelopmental outcomes at 4-10 years in children born at 22-25 weeks gestation. *Acta Paediatr Oslo Nor* 1992. 2019;108(7):1237–44.
35. Zwicker JG, Harris SR. Quality of life of formerly preterm and very low birth weight infants from preschool age to adulthood: a systematic review. *Pediatrics.* 2008 Feb;121(2):e366-376.
36. Baumgardt M, Bucher HU, Mieth RA, Fauchère J-C. Health-related quality of life of former very preterm infants in adulthood. *Acta Paediatr Oslo Nor* 1992. 2012 Feb;101(2):e59-63.
37. Can G, Bilgin L, Tatli B, Saydam R, Coban A, Ince Z. Morbidity in early adulthood among low-risk very low birth weight children in Turkey: a preliminary study. *Turk J Pediatr.* 2012 Oct;54(5):458–64.
38. Darlow BA, Horwood LJ, Pere-Bracken HM, Woodward LJ. Psychosocial outcomes of young adults born very low birth weight. *Pediatrics.* 2013 Dec;132(6):e1521-1528.
39. Gaddlin P-O, Finnstrom O, Sydsjo G, Leijon I. Most very low birth weight subjects do well as adults. *Acta Paediatr Oslo Nor* 1992. 2009 Sep;98(9):1513–20.
40. Methusalemsdottir HF, Egilson ST, Guethmundsdottir R, Valdimarsdottir UA, Georgsdottir I. Quality of life of adolescents born with extremely low birth weight. *Acta Paediatr Oslo Nor* 1992. 2013 Jun;102(6):597–601.
41. Roberts G, Burnett AC, Lee KJ, Cheong J, Wood SJ, Anderson PJ, et al. Quality of life at age 18 years after extremely preterm birth in the post-surfactant era. *J Pediatr.* 2013 Oct;163(4):1008-1013.e1.
42. Saigal S, Stoskopf B, Pinelli J, Streiner D, Hoult L, Paneth N, et al. Self-perceived health-related quality of life of former extremely low birth weight infants at young adulthood. *Pediatrics.* 2006 Sep;118(3):1140–8.
43. Saigal S, Tyson J. Measurement of quality of life of survivors of neonatal intensive care: critique and implications. *Semin Perinatol.* 2008 Feb;32(1):59–66.
44. Gire C, Resseguier N, Brévaut-Malaty V, Marret S, Cambonie G, Souksi-Medioni I, et al. Quality of life of extremely preterm school-age children without major handicap: a cross-sectional observational study. *Arch Dis Child.* 2019;104(4):333–9.
45. Stahlmann N, Eisemann N, Thyen U, Herting E, Rapp M. Long-Term Health Outcomes and Health-Related Quality of Life in Adolescents from a Cohort of Extremely Premature Infants Born at Less Than 27 Weeks of Gestation in Northern Germany. *Neuropediatrics.* 2016 Dec;47(6):388–98.
46. Baumann N, Bartmann P, Wolke D. Health-Related Quality of Life Into Adulthood After Very Preterm Birth. *Pediatrics.* 2016;137(4):e20153148.
47. Båtvik B, Vederhus BJ, Halvorsen T, Wentzel-Larsen T, Graue M, Markestad T. Health-related quality of life may deteriorate from adolescence to young adulthood after extremely preterm birth. *Acta Paediatr Oslo Nor* 1992. 2015 Sep;104(9):948–55.
48. Saigal S, Ferro MA, Van Lieshout RJ, Schmidt LA, Morrison KM, Boyle MH. Health-Related Quality of Life Trajectories of Extremely Low Birth Weight Survivors into Adulthood. *J Pediatr.* 2016;179:68-73.e1.

49. Saigal S, Pinelli J, Streiner DL, Boyle M, Stoskopf B. Impact of extreme prematurity on family functioning and maternal health 20 years later. *Pediatrics*. 2010 Jul;126(1):e81-88.
50. Saigal S, Burrows E, Stoskopf BL, Rosenbaum PL, Streiner D. Impact of extreme prematurity on families of adolescent children. *J Pediatr*. 2000 Nov;137(5):701-6.
51. Eiser C, Eiser JR, Mayhew AG, Gibson AT. Parenting the premature infant: balancing vulnerability and quality of life. *J Child Psychol Psychiatry*. 2005 Nov;46(11):1169-77.
52. Gray PH, Edwards DM, O'Callaghan MJ, Cuskelley M, Gibbons K. Parenting stress in mothers of very preterm infants -- influence of development, temperament and maternal depression. *Early Hum Dev*. 2013 Sep;89(9):625-9.
53. Indredavik MS, Vik T, Heyerdahl S, Romundstad P, Brubakk A-M. Low-birthweight adolescents: quality of life and parent-child relations. *Acta Paediatr Oslo Nor* 1992. 2005 Sep;94(9):1295-302.
54. Lee C-F, Hwang F-M, Chen C-J, Chien L-Y. The interrelationships among parenting stress and quality of life of the caregiver and preschool child with very low birth weight. *Fam Community Health*. 2009 Sep;32(3):228-37.
55. Moore M, Gerry Taylor H, Klein N, Minich N, Hack M. Longitudinal changes in family outcomes of very low birth weight. *J Pediatr Psychol*. 2006 Dec;31(10):1024-35.
56. Singer LT, Fulton S, Kirchner HL, Eisengart S, Lewis B, Short E, et al. Parenting very low birth weight children at school age: maternal stress and coping. *J Pediatr*. 2007 Nov;151(5):463-9.
57. Singer LT, Fulton S, Kirchner HL, Eisengart S, Lewis B, Short E, et al. Longitudinal predictors of maternal stress and coping after very low-birth-weight birth. *Arch Pediatr Adolesc Med*. 2010 Jun;164(6):518-24.
58. Taylor HG, Klein N, Minich NM, Hack M. Long-term family outcomes for children with very low birth weights. *Arch Pediatr Adolesc Med*. 2001 Feb;155(2):155-61.
59. Treyvaud K, Doyle LW, Lee KJ, Roberts G, Cheong JLY, Inder TE, et al. Family functioning, burden and parenting stress 2 years after very preterm birth. *Early Hum Dev*. 2011 Jun;87(6):427-31.
60. Treyvaud K, Lee KJ, Doyle LW, Anderson PJ. Very preterm birth influences parental mental health and family outcomes seven years after birth. *J Pediatr*. 2014 Mar;164(3):515-21.
61. Witt WP, Litzelman K, Spear HA, Wisk LE, Levin N, McManus BM, et al. Health-related quality of life of mothers of very low birth weight children at the age of five: results from the Newborn Lung Project Statewide Cohort Study. *Qual Life Res Int J Qual Life Asp Treat Care Rehabil*. 2012 Nov;21(9):1565-76.
62. Bethune M, Permezel M. The relationship between gestational age and the incidence of classical caesarean section. *Aust N Z J Obstet Gynaecol*. 1997 May;37(2):153-5.
63. Patterson LS, O'Connell CM, Baskett TF. Maternal and perinatal morbidity associated with classic and inverted T cesarean incisions. *Obstet Gynecol*. 2002 Oct;100(4):633-7.
64. Chauhan SP, Magann EF, Wiggs CD, Barrilleaux PS, Martin JN. Pregnancy after classic cesarean delivery. *Obstet Gynecol*. 2002 Nov;100(5 Pt 1):946-50.
65. Gyamfi-Bannerman C, Gilbert S, Landon MB, Spong CY, Rouse DJ, Varner MW, et al. Risk of uterine rupture and placenta accreta with prior uterine surgery outside of the lower segment. *Obstet Gynecol*. 2012 Dec;120(6):1332-7.
66. Lannon SMR, Guthrie KA, Reed SD, Gammill HS. Mode of delivery at perivable gestational ages: impact on subsequent reproductive outcomes. *J Perinat Med*. 2013 Nov;41(6):691-7.
67. Bakhshi T, Landon MB, Lai Y, Spong CY, Rouse DJ, Leveno KJ, et al. Maternal and neonatal outcomes of repeat cesarean delivery in women with a prior classical versus low transverse uterine incision. *Am J Perinatol*. 2010 Nov;27(10):791-6.

68. RCOG. Perinatal Management of Pregnant Women at the Threshold of Infant Viability – the Obstetric Perspective (Scientific Impact Paper No. 41) [Internet]. Royal College of Obstetricians & Gynaecologists. [cited 2020 Sep 29]. Available from: <https://www.rcog.org.uk/en/guidelines-research-services/guidelines/sip41/>

69. Ladhani NNN, Chari RS, Dunn MS, Jones G, Shah P, Barrett JFR. No. 347-Obstetric Management at Borderline Viability. *J Obstet Gynaecol Can JOGC J Obstet Gynecol Can JOGC*. 2017 Sep;39(9):781–91.

70. Nguyen TP, Amon E, Al-Hosni M, Gavard JA, Gross G, Myles TD. “Early” versus “late” 23-week infant outcomes. *Am J Obstet Gynecol*. 2012 Sep;207(3):226.e1-6.

71. Lantos JD, Miles SH, Silverstein MD, Stocking CB. Survival after cardiopulmonary resuscitation in babies of very low birth weight. Is CPR futile therapy? *N Engl J Med*. 1988 Jan 14;318(2):91–5.

72. Dupont-Thibodeau A, Barrington KJ, Farlow B, Janvier A. End-of-life decisions for extremely low-gestational-age infants: why simple rules for complicated decisions should be avoided. *Semin Perinatol*. 2014 Feb;38(1):31–7.

73. 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 Apr 17;358(16):1672–81.

74. Rysavy MA, Horbar JD, Bell EF, Li L, Greenberg LT, Tyson JE, et al. Assessment of an Updated Neonatal Research Network Extremely Preterm Birth Outcome Model in the Vermont Oxford Network. *JAMA Pediatr*. 2020 May 1;174(5):e196294.

75. Hack M, Taylor HG, Drotar D, Schluchter M, Cartar L, Wilson-Costello D, et al. Poor predictive validity of the Bayley Scales of Infant Development for cognitive function of extremely low birth weight children at school age. *Pediatrics*. 2005 Aug;116(2):333–41.

76. Alleman BW, Bell EF, Li L, Dagle JM, Smith PB, Ambalavanan N, et al. Individual and center-level factors affecting mortality among extremely low birth weight infants. *Pediatrics*. 2013 Jul;132(1):e175–184.

77. Schmidt B, Asztalos EV, Roberts RS, Robertson CMT, Sauve RS, Whitfield MF, et al. Impact of bronchopulmonary dysplasia, brain injury, and severe retinopathy on the outcome of extremely low-birth-weight infants at 18 months: results from the trial of indomethacin prophylaxis in preterms. *JAMA*. 2003 Mar 5;289(9):1124–9.

78. Payne AH, Hintz SR, Hibbs AM, Walsh MC, Vohr BR, Bann CM, et al. Neurodevelopmental outcomes of extremely low-gestational-age neonates with low-grade periventricular-intraventricular hemorrhage. *JAMA Pediatr*. 2013 May;167(5):451–9.

79. Mitha A, Foix-L'Hélias L, Arnaud C, Marret S, Vieux R, Aujard Y, et al. Neonatal infection and 5-year neurodevelopmental outcome of very preterm infants. *Pediatrics*. 2013 Aug;132(2):e372–380.

80. Andrews B, Myers P, Lagatta J, Meadow W. A Comparison of Prenatal and Postnatal Models to Predict Outcomes at the Border of Viability. *J Pediatr*. 2016 Jun;173:96–100.

81. Payot A, Gendron S, Lefebvre F, Doucet H. Deciding to resuscitate extremely premature babies: how do parents and neonatologists engage in the decision? *Soc Sci Med* 1982. 2007 Apr;64(7):1487–500.

82. Zupancic J a, Kirpalani H, Barrett J, Stewart S, Gafni A, Streiner D, et al. Characterising doctor-parent communication in counselling for impending preterm delivery. *Arch Dis Child Fetal Neonatal Ed*. 2002 Sep;87(2):F113-117.

83. 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 Sep;122(3):583–9.

84. Muthusamy AD, Leuthner S, Gaebler-Uhing C, Hoffmann RG, Li S-H, Basir MA. Supplemental written information improves prenatal counseling: a randomized trial. *Pediatrics*. 2012 May;129(5):e1269-1274.

85. Daboval T, Moore GP, Ferretti E. How we teach ethics and communication during a Canadian neonatal perinatal medicine residency: an interactive experience. *Med Teach*. 2013;35(3):194–200.

86. Stokes TA, Watson KL, Boss RD. Teaching antenatal counseling skills to neonatal providers. *Semin Perinatol*. 2014 Feb;38(1):47–51.

87. Boss RD, Urban A, Barnett MD, Arnold RM. Neonatal Critical Care Communication (NC3): training NICU physicians and nurse practitioners. *J Perinatol Off J Calif Perinat Assoc*. 2013 Aug;33(8):642–6.

88. Charles C, Gafni A, Whelan T. Shared decision-making in the medical encounter: what does it mean? (or it takes at least two to tango). *Soc Sci Med* 1982. 1997 Mar;44(5):681–92.

89. Haward MF, Kirshenbaum NW, Campbell DE. Care at the edge of viability: medical and ethical issues. *Clin Perinatol*. 2011 Sep;38(3):471–92.

90. Caeymaex L, Jousselme C, Vasilescu C, Danan C, Falissard B, Bourrat M-M, et al. Perceived role in end-of-life decision making in the NICU affects long-term parental grief response. *Arch Dis Child Fetal Neonatal Ed*. 2013 Jan;98(1):F26-31.

91. Scheibler F, Janssen C, Pfaff H. [Shared decision making: an overview of international research literature]. *Soz Praventivmed*. 2003;48(1):11–23.

92. Suh WS, Lee CK. [Impact of shared-decision making on patient satisfaction]. *J Prev Med Public Health Yebang Uihakhoe Chi*. 2010 Jan;43(1):26–34.

93. Swanson KA, Bastani R, Rubenstein LV, Meredith LS, Ford DE. Effect of mental health care and shared decision making on patient satisfaction in a community sample of patients with depression. *Med Care Res Rev MCRR*. 2007 Aug;64(4):416–30.

94. Stacey D, Légaré F, Lewis K, Barry MJ, Bennett CL, Eden KB, et al. Decision aids for people facing health treatment or screening decisions. *Cochrane Database Syst Rev*. 2017 12;4:CD001431.

95. Kavanaugh K, Savage T, Kilpatrick S, Kimura R, Hershberger P. Life support decisions for extremely premature infants: report of a pilot study. *J Pediatr Nurs*. 2005 Oct;20(5):347–59.

96. Seefat-van Teeffelen A, Nieuwenhuijze M, Korstjens I. Women want proactive psychosocial support from midwives during transition to motherhood: a qualitative study. *Midwifery*. 2011 Feb;27(1):e122-127.

97. Daboval T, Shidler S, Thomas D. Shared Decision Making at the Limit of Viability: A Blueprint for Physician Action. *PLoS One*. 2016;11(11):e0166151.

98. Daboval T. Participation des parents au processus de décision lors de la consultation anténatale pour l'enfant à risque de naître à la limite de la viabilité [Internet] [Masters Thesis]. [Rouyn-Noranda]: Université du Québec en Abitibi-Témiscamingue; 2013 [cited 2020 Sep 29]. Available from: <https://depositum.uqat.ca/id/eprint/574/>

99. Tucker Edmonds B, Torke AM, Helft P, Wocial LD. Doctor, What Would You Do? An ANSWER for Patients Requesting Advice About Value-Laden Decisions. *Pediatrics*. 2015 Oct;136(4):740–5.

100. Beauchamp T, Childress J. Principles of biomedical ethics. 5th ed. New York, NY: Oxford University Press; 2001.

101. Daboval T, Shidler S. Ethical framework for shared decision making in the neonatal intensive care unit: Communicative ethics. *Paediatr Child Health*. 2014 Jun;19(6):302–4.

102. Durand G. Introduction générale à la bioéthique: histoire, concepts et outils. Les Editions Fides; 2005. 580 p.

103. Tucker Edmonds B, Torke AM, Helft P, Wocial LD. Doctor, What Would You Do? An ANSWER for Patients Requesting Advice About Value-Laden Decisions. *Pediatrics*. 2015 Oct;136(4):740–5.
104. Muirhead P. When parents and physicians disagree: What is the ethical pathway? *Paediatr Child Health*. 2004 Feb;9(2):85–6.
105. Consent and Capacity Board - Information Sheets [Internet]. [cited 2020 Sep 29]. Available from: <http://www.ccboard.on.ca/scripts/english/publications/infosheets.asp#capacity>
106. Verloove-Vanhorick SP. Management of the neonate at the limits of viability: the Dutch viewpoint. *BJOG Int J Obstet Gynaecol*. 2006 Dec;113 Suppl 3:13–6.
107. 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 Jun;123(6):1509–15.
108. Mercurio MR. The ethics of newborn resuscitation. *Semin Perinatol*. 2009 Dec;33(6):354–63.
109. Batton D, Batton B. Advocating for equality for preterm infants. *CMAJ Can Med Assoc J J Assoc Medicale Can*. 2013 Dec 10;185(18):1559–60.
110. Janvier A, Leblanc I, Barrington KJ. The best-interest standard is not applied for neonatal resuscitation decisions. *Pediatrics*. 2008 May;121(5):963–9.
111. Janvier A, Mercurio MR. Saving vs creating: perceptions of intensive care at different ages and the potential for injustice. *J Perinatol Off J Calif Perinat Assoc*. 2013 May;33(5):333–5.