DECISION MAKING AROUND RESUSCITATION OF EXTREMELY PRETERM INFANTS IN THE PHILIPPINES: A CONSENSUS GUIDELINE

The Philippine Society of Newborn Medicine

16TH APRIL 2019

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DISCLAIMER

The clinical practice guideline (CPG) presented in this document was developed to assist clinicians with decisions about appropriate health care for extremely premature infants.

This CPG is targeted for clinicians only. Patients, parents or other community members using this CPG should do so in conjunction with a health professional and should not rely on the information in this guideline as professional medical advice.

This CPG deliberately provides little explanation or background to the conditions and treatment outlined. This is however designed to acquaint the reader rapidly with the clinical problem and provide practical advice regarding assessment and management.

This CPG was developed by a multidisciplinary team of practicing neonatologists and ethicists by consensus based on the evidence available and represent the views of majority of the members of the Philippine Society of Newborn Medicine.

The recommendations contained in this CPG do not indicate an exclusive course of action or standard of care. They do not replace the need for application of clinical judgment for each individual presentation, or variations based on locality and facility type.

The authors of this CPG have made considerable efforts to ensure the information upon which they are based is accurate and up to date. Users of this CPG are strongly recommended to confirm that the information contained is correct by way of independent sources. The authors accept no responsibility for any inaccuracies, information perceived as misleading, or the success or failure of any course of action detailed in the CPG .

EXECUTIVE SUMMARY

- In decisions around the resuscitation for Extremely Preterm infants (EPI), the best interests of infants are of primary consideration. Health professionals should also take into consideration the views and wishes of the infant's parents, and the availability of resources to treat the newborn infant.

- It is ethical to withhold or withdraw life- prolonging treatment for a newborn infant, when that treatment would not be in the infant's best interests or would be unduly burdensome or disproportionate.

- Decisions about treatment should be ethically consistent. Different decisions may be justified where there are ethically relevant differences (e.g. in the outcome expected or the resources available). However, disparities in resource availability are themselves an ethical concern for neonatologists and should be a stimulus for advocacy, and quality care improvement.

- In making decisions about whether or not to resuscitate an extremely preterm infant, health professionals should assess the realistic chance of survival and of severe morbidity if resuscitation and intensive care are attempted. This assessment should include all known risk factors relevant to the infant and the resources available to provide treatment at the time of delivery and beyond.

- Where extremely preterm birth is anticipated, midwives and obstetricians are obliged to provide measures that would improve the outcome for the preterm infant including antenatal steroids, magnesium sulfate and the possibility of in-utero transfer. They should refer early to neonatologists to help facilitate antenatal counselling and decision-making.

- For preterm infants at lower risk of poor outcome, it would usually be appropriate to attempt resuscitation at delivery and to admit to the neonatal intensive care unit. For example, this would apply to most infants ≥28 weeks gestation in the Philippines.

- Active management would be appropriate to provide for potentially viable preterm infants at moderate to high risk of poor outcome, where parents have expressed their wish for this (and where there are resources available to provide this treatment). For such infants, where parents have expressed their wish to withhold active management, palliative management would also be appropriate to provide.

- For extremely preterm infants at extremely high risk of death and severe disability, it would usually be appropriate to provide palliative management (comfort care) at delivery. For example, this would apply to most infants born <24 weeks gestation in the Philippines.

INTRODUCTION

The consensus guideline was developed in February 2019 during the 13th Annual Meeting and 4th International Conference of the Philippine Society of Newborn Medicine (PSNbM) in Crowne Plaza, Pasig City (see Appendix 1: Consensus methodology).

Aim: The aim of this guideline is to support a consistent ethical approach to decision-making for extremely preterm infants. This document provides a guideline for decision-making, but all decisions should take into account the specific circumstances of an individual child and family, as well as the resources, skills and expertise available to provide treatment. The guideline is aspirational – it aims to set standards for newborn care in the Philippines; however, it also aims to be practical - providing guidance to health professionals currently providing neonatal intensive care in the Philippine setting.

Scope: This guideline relates to the neonatal care of critically ill newborns, focussing on those born extremely preterm where gestational age is uncertain. The perinatal care of such infants should be provided by neonatal health professionals in partnership with midwifery, nursing and obstetric professionals. This guideline includes some recommendations around antenatal management where preterm delivery at this gestation is anticipated; however, it does not cover obstetric management. The focus of the guideline is on decision-making; it does not provide medical details of how to resuscitate preterm infants. Some practical guidance on providing palliative (comfort) care is included.

Definitions: For the purposes of this guideline, *Extremely Preterm Infants (EPI)* refers to infants born <28 weeks gestation. *Potential Viability* in the context of the Philippines refers to extremely preterm birth from 24-28 weeks gestation (or 500-1000g, where gestational age is uncertain). See section 3.1 for assessment of risk for potentially viable infants.

PART 1: BACKGROUND

Decision-making about the care of Extremely Premature Infants (EPI) is ethically complex. The most premature infants have a high chance of dying, even with provision of intensive care. To survive, such infants often require a prolonged period of high intensity and costly medical treatment, with high rates of serious short-term complications including nosocomial infection, intraventricular haemorrhage, bronchopulmonary dysplasia, retinopathy of prematurity, and necrotising enterocolitis.[1,2] Long-term, a proportion of surviving extremely premature infants have severe disability. Because of the uncertain outcome and significant burden of treatment, resuscitation and intensive care for the most premature infants is regarded as ethically optional. However, that raises questions for professionals about when this should apply.

Published guidelines relating to decision-making and resuscitation of extremely preterm infants largely focus on High-Income Countries and set aside considerations of limited resources.[3,4] However, the vast majority of preterm births globally occur in low and middle-income countries (LMICs), where resource limits can affect the provision of medical care.[5]

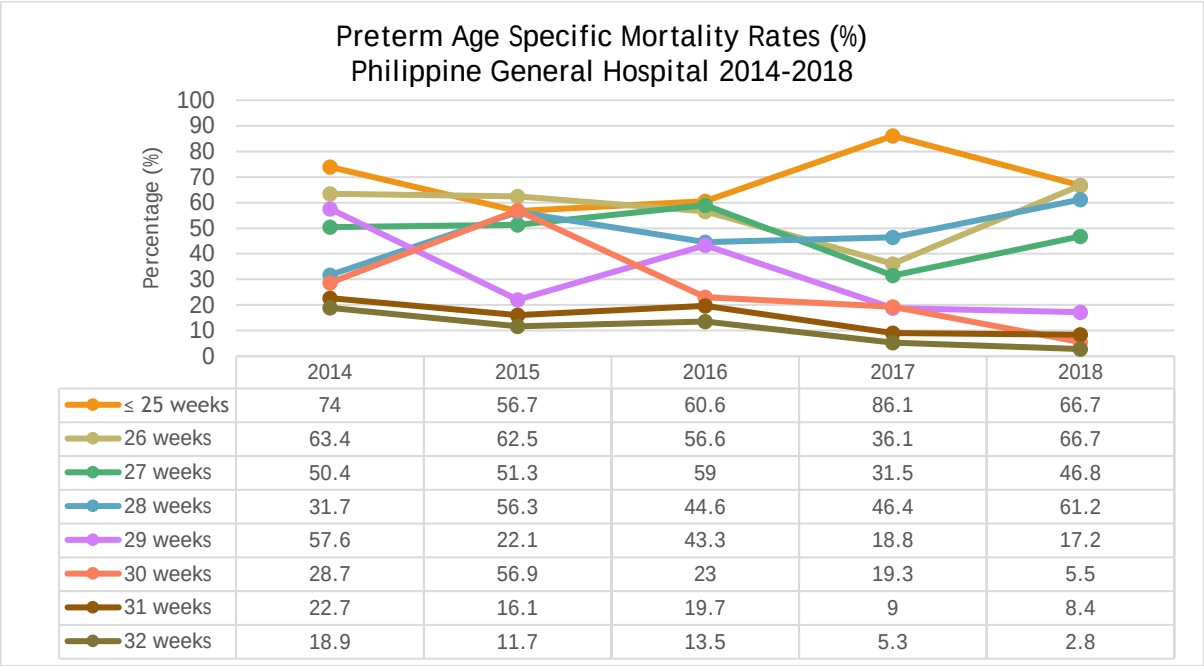
Most existing resuscitation guidelines indicate thresholds based on the gestational age (GA) of the infant.[6] A ***lower threshold*** marks the gestational age below which treatment will not usually be provided. An ***upper threshold*** marks the gestational age above which treatment is considered mandatory. Between these ages lies a '***grey zone'***, where active treatment may or may not be provided, and parents' wishes are important. In high-income countries, resuscitation guidelines vary in their specific details, however, there is considerable overlap in approach. Most such guidelines indicate a lower threshold at 22-23 weeks gestation, and an upper threshold of 24-25 weeks gestation. There is general agreement that parents' views should be taken into account in decisions at 23-24 weeks.

An international systematic review of resuscitation guidelines relating to EPI was unable to identify any guidelines from low or middle-income countries.[3] Studies from low-middle income countries report that a range of different gestational age thresholds are used by doctors in those settings.[7-14] As an example, a study from El Salvador reported variable lower thresholds for resuscitation from 25-28 weeks.[9] Practitioners reported a median threshold of 26 weeks for intubation and ventilation and 27 weeks for cardiac massage or pharmacologic resuscitation. A study from India indicated that resuscitation would be considered from 28 weeks, while it would usually or always be provided from 32 weeks gestation.[15]

The Republic of the Philippines has a population of 105 million and a GDP per capita of US$2,989. Worldwide, it ranks 8th highest in number of preterm births. There are approximately 350,000 preterm births per year in the Philippines (this would include an estimated 36,000 very preterm infants (28-32 weeks) and approximately 18,000 extremely premature infants (<28 weeks)). The neonatal mortality rate (NMR) is estimated to be 14 deaths per 1000 live births, though there are large regional variations (9 neonatal deaths/1000 live births in urban areas, 18/1000 in rural areas).[16] Overall child mortality rates in the Philippines are higher than average for East Asia and the Pacific. A total of 1,441 hospitals provide for the entire population, of which approximately 67% (966) are privately owned. As in many other LMICs, for both private

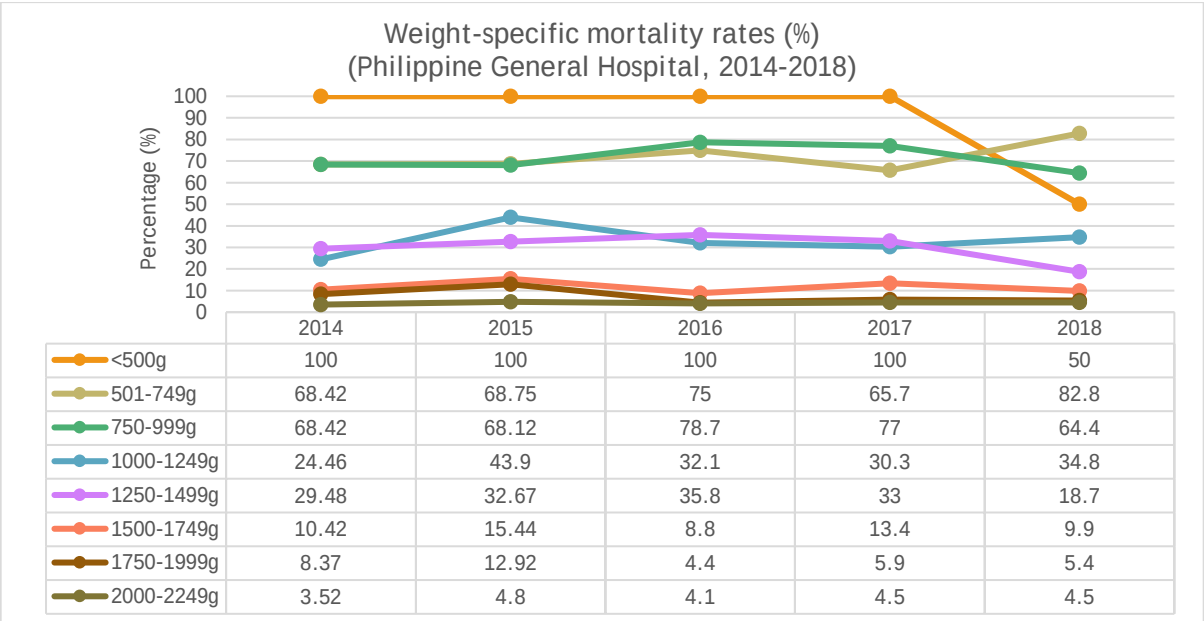
and public facilities, parents are often required to pay out-of-pocket for the care of their infant, though there have been recent government initiatives to provide full funding for newborn treatment for poor families. In the Philippines, full supportive care and ventilation of a neonate costs approximately US$200 per day in a government hospital. In comparison, the usual monthly wage is only US$300.[17] Long term specialised medical care and allied health support for children with disability is unavailable for the majority of the population.

THERE IS LIMITED PUBLISHED EVIDENCE ON THE OUTCOME FOR EPI IN THE PHILIPPINES. THE FOLLOWING FIGURES ILLUSTRATE THE REPORTED OUTCOME (MORTALITY) FOR ONE TERTIARY HOSPITAL IN MANILA. THERE IS NO AVAILABLE DATA ON LONG-TERM OUTCOME.



	2014	2015	2016	2017	2018
≤ 25 weeks	74	56.7	60.6	86.1	66.7
26 weeks	63.4	62.5	56.6	36.1	66.7
27 weeks	50.4	51.3	59	31.5	46.8
28 weeks	31.7	56.3	44.6	46.4	61.2
29 weeks	57.6	22.1	43.3	18.8	17.2
30 weeks	28.7	56.9	23	19.3	5.5
31 weeks	22.7	16.1	19.7	9	8.4
32 weeks	18.9	11.7	13.5	5.3	2.8

Figure 1: Preterm mortality according to gestational age at the Philippine General Hospital, Manila: 2014-2018. Reproduced from the Philippine General Hospital Department of Pediatrics Annual Statitistics[18]



	2014	2015	2016	2017	2018
<500g	100	100	100	100	50
501-749g	68.42	68.75	75	65.7	82.8
750-999g	68.42	68.12	78.7	77	64.4
1000-1249g	24.46	43.9	32.1	30.3	34.8
1250-1499g	29.48	32.67	35.8	33	18.7
1500-1749g	10.42	15.44	8.8	13.4	9.9
1750-1999g	8.37	12.92	4.4	5.9	5.4
2000-2249g	3.52	4.8	4.1	4.5	4.5

Figure 2: Preterm mortality according to birthweight at the Philippine General Hospital, Manila: 2014-2018. Reproduced from the Philippine General Hospital Department of Pediatrics Annual Statitistics[18]

To aid the development of the consensus guideline, a survey of neonatologists in the Philippines was conducted in 2018.* The 2018 survey† found that at 23-24 weeks GA, most institutions (66%) would 'never' or 'rarely' initiate resuscitation, while in a small proportion of hospitals (14%) EPI would 'always' or 'often' be resuscitated (Figure 3). At 25-26 weeks gestation, 41% of hospitals would 'always' resuscitate, while 21% would 'often', and 23% would 'sometimes' resuscitate. At 27–28 weeks GA, 16% of respondents indicated that they would not always resuscitate. In cases of uncertain gestation, the most frequent birthweight threshold cited was 500g, though some institutions cited thresholds up to 800g or as low as 400g.

Clinicians' decision to limit resuscitation was commonly influenced by a desire to respecting the parent's wishes, though also influenced by the 'probability of infant's death', 'clinician's morals', 'risk of poor quality of life' and 'financial cost for family'. (Each of these were cited by more than 60% of neonatologists surveyed).

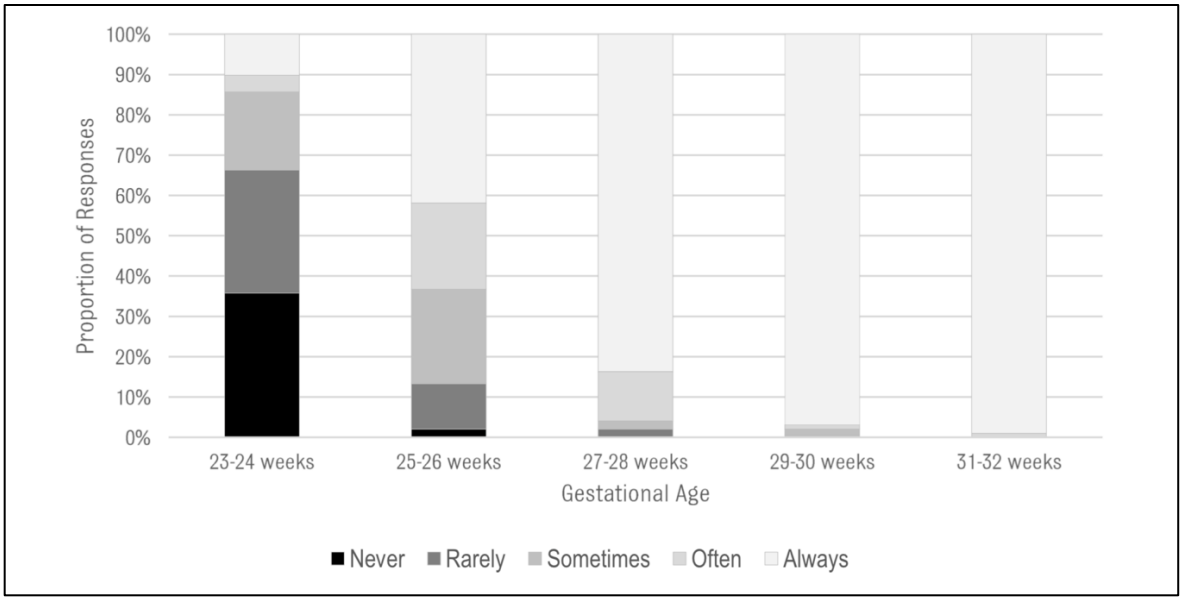


Figure 3 – Frequency of initiating resuscitation for a given gestational age as reported in 2018*

There were significant differences between hospitals in the resources available (e.g. availability of surfactant, frequency of all ventilators being in use) and in the reported outcome for EPI.

A high proportion of public hospitals (85%) reported that they often or almost always encountered situations where all ventilators are in use and at least one other infant needed ventilator support. A higher proportion of provincial or district hospitals reported often or always being at maximum ventilator capacity. Forty per cent of

* Hayden D, Uy ME, Mendoza MK, Wilkinson D. Resuscitation of preterm infants in the Philippines: a national survey of resources and practice [Manuscript submitted for publication] 2019.

† Of the 228 hospitals providing neonatal care in the Philippines, 103 responses were received (overall response rate: 45%).

public hospitals, and 48% of level III/IV hospitals reported that surfactant was only available if parents were able to pay.

PART 2: ETHICAL FRAMEWORK FOR THE CONSENSUS GUIDELINE

The following ethical principles underlie the development of the consensus guideline and were endorsed at the consensus meeting.

BEST INTERESTS

i. In decisions about medical treatment for a very premature infant, the best interests of the child should be the primary consideration.

FAMILY INVOLVEMENT

ii. Where there is a high risk for an infant death or survival with severe morbidity, parents' wishes about resuscitation should be sought.
iii. The views and values of parents are an important factor in determining whether intensive treatment or comfort care is in the infant's best interest. The child and family should be considered together.
iv. Parents should be supported to make the best decision that they can for their child and their family. They should not be made to feel guilty for a decision to withhold or discontinue treatment.
v. While parents' have moral authority over decisions regarding care for their child, such authority is not absolute. The clinician should always advocate for the child's best interest.

UNCERTAINTY

vi. If there is uncertainty about whether or not to provide life-prolonging treatment for a newborn, and there is no time to resolve that uncertainty, it would be prudent to start treatment in the first instance.

WITHHOLDING TREATMENT

vii. It is ethical to withhold resuscitation from a newborn if that treatment would not be in the best interest of the newborn, would impose an unreasonable burden on the child or family, or would constitute an unreasonable use of limited medical resources.

WITHDRAWING TREATMENT

viii. There is an ethical obligation to carefully consider for every treatment whether it is proportionate and beneficial.[‡]
ix. After embarking on resuscitation and intensive care, it is ethical to stop potentially life-prolonging treatment if the burdens of that treatment, for that infant or for the infant's family, outweigh the benefits.

[‡] According to Christian theology, proportionate means are those that in the judgment of the patient offer a reasonable hope of benefit and do not entail an excessive burden or impose excessive expense on the family or the community. Disproportionate means are those that in the patient's judgment do not offer a reasonable hope of benefit or entail an excessive burden or impose excessive expense on the family or the community.[19]

x. There is no ethical obligation to provide or continue treatments that are unduly burdensome, extraordinary or disproportionate. Decisions to stop (withdraw) extraordinary treatment are *not* equivalent to euthanasia.[§]

CONSIDERATION OF FINANCIAL ASPECTS OF CARE

xi. Health professionals should aim to provide the best treatment that they can for all newborn infants regardless of the family's ability to pay

xii. In considering whether treatment is proportionate, it is ethical to consider the costs of treatment, both for the family, and for society. It can be disproportionate and burdensome to provide highly expensive treatment.

COLLECTION OF RELEVANT DATA

xiii. Ethically informed decisions for very premature infants require accurate, up to date information on the outcome of treatment. There is, therefore, an ethical imperative for those working in newborn care to collect data on the outcomes of patients receiving treatment, to inform future decisions.

COMFORT CARE

xiv. Where there has been a decision to stop intensive care because that is no longer considered to be in the best interests of the child and family, there is an ethical imperative to provide high quality palliative care (comfort care).[**]

The above ethical principles are informed by and complementary to the UNICEF rights of the child.

UNICEF – AFFIRMATION OF RIGHTS RELATED TO PROVISION OF NEWBORN CARE UNDER THE CONVENTION OF THE RIGHTS OF THE CHILD[21]

xv. Article 2 (Non-discrimination): It doesn't matter where children live, what language they speak, what their parents do, whether they are boys or girls, what their culture is, whether they have a disability or whether they are rich or poor. No child should be treated unfairly on any basis.

xvi. Article 3 (Best interests of the child): The best interests of children must be the primary concern in making decisions that may affect them. All adults should do what is best for children. When adults make decisions, they should think about how their decisions will affect children. This particularly applies to budget, policy and law makers

xvii. Article 6 (Survival and development): Children have the right to live. Governments should ensure that children survive and develop healthily.

xviii. Article 24 (Health and health services): Children have the right to good quality health care – the best health care possible – to safe drinking water, nutritious food, a clean and safe environment, and information to help them stay healthy. Rich countries should help poorer countries achieve this.

[§] Excerpt from *Evangelium vitae*, Pope John Paul II: "To forego extraordinary or disproportionate means is not the equivalent of suicide or euthanasia; it rather expresses acceptance of the human condition in the face of death."[20]

[**] Palliative care is an active, holistic approach that includes avoiding interventions that would do more harm than good, providing symptom management and analgesia for the child, and providing support for the parents and family. It may be provided in hospital, or in the community. It should include spiritual and pastoral care of the infant and family.

PART 3: CONSENSUS GUIDELINE

1. Antenatal management.

Where delivery of a *potentially viable* very premature infant is anticipated, the obstetric and midwifery team should provide measures to improve the outcome for the premature infant. This includes:

1.1. **Antenatal steroids.** Antenatal steroids should be considered where preterm labour is apparent, gestational age can be accurately assessed, there is no clinical evidence of maternal infection, active management of the newborn would be planned, and there are facilities available to provide medical care for the preterm newborn.[22]

1.2. **Transfer.** Assess the facilities available to provide medical care for the preterm newborn. If possible and appropriate, arrange timely transfer of the mother to a facility with the ability to provide level 3 or 4 newborn intensive care since this may substantially improve the chances for infant survival and health outcomes. Decisions on maternal transfer should take into account the wishes of the parents (including for resuscitation, see below), the safety for the mother, and the costs and availability of transfer.

1.3. **Magnesium Sulfate.** Provide magnesium sulfate where preterm labour is apparent, delivery is imminent, and where there is a plan to provide resuscitation of the preterm infant.

2. Antenatal counselling

As early as feasible, where delivery of a *potentially viable* very premature infant is anticipated, the obstetric and midwifery team should refer to a neonatologist or paediatrician to enable timely antenatal counselling and decision-making.

3. Decision-making

Decisions about provision of resuscitation and intensive care for an extremely preterm infant should take into account an assessment of risk for the infant, and the wishes of parents.

3.1. Assessment of risk

It is important to assess for an individual situation, the realistic chance of survival and of severe morbidity if resuscitation and intensive care are attempted. This assessment should include all known risk factors relevant to the infant and the resources available to provide treatment if/when the infant is delivered.

3.1.1. Assessment of gestational age and expected birthweight

Assess the gestational age of the preterm infant, based ideally on early ultrasound results or on dates of the last menstrual period. If gestation is uncertain, assessment of the expected birthweight may help provide a basis for decision-making. Findings of severe intrauterine growth restriction or small for gestational age are associated with a lower chance of survival and a higher chance of morbidity.

In the Philippines, infants from 24-28 weeks gestation (or with an anticipated birth weight of 500-1000g where gestational age is uncertain) are *potentially viable*. These are not absolute cut-off points. In some circumstances, prior to 24 weeks gestation,

there may be a realistic chance of survival with provision of resuscitation and intensive care. In other situations, an infant of ≥28 weeks gestation may have a high chance of dying/severe morbidity.

3.1.2. Assessment of modifiable risk factors

Consider potentially modifiable factors that may influence the outcome of the extremely preterm infant. This includes whether or not the mother has received antenatal steroids; and the resources, expertise and anticipated outcome if the preterm infant is delivered in the current location. Clinicians should consider local experience in caring for infants at a similar gestation or birth weight to assess the realistic chance of survival or severe morbidity for the infant. Wherever possible, this should be based on relevant, accurate and recent local data on the outcome for extremely preterm infants. For example, in some hospitals, preterm infants at 26 weeks gestation may have an extremely high risk of dying or of severe morbidity, while in other hospitals, at the same gestation, a lower risk of mortality would be expected.

Where possible and appropriate, these risk factors should be modified through provision of antenatal steroids and/or transfer to a facility with the ability to provide level 3 or 4 neonatal intensive care (see section 1.2). If this occurs, the risk for the infant should then be re-evaluated.

3.1.3. Assessment of non-modifiable risk factors

Consider additional risk factors (where known) that may influence the outcome of the preterm infant. This includes, for example, evidence of severe chorioamnionitis, severe or multiple congenital anomalies, fetal hydrops, multiple pregnancy and twin-to-twin transfusion.

The modifiable and non-modifiable risk factors will influence the risk and expected outcome for an individual infant. For example, the presence of adverse risk factors (e.g. severe fetal illness, or anticipated delivery in a canter with limited resources or poor outcome at this gestation) may mean that a potentially viable infant has an extremely high risk of dying or of severe morbidity if resuscitation and intensive care are attempted. The absence of adverse risk factors, or greater experience/resources at the local canter may imply a lower risk of dying or of severe morbidity for a potentially viable infant.

Figure 4 illustrates the assessment of risk for the extremely preterm infant incorporating multiple risk factors.

1. Assess gestational age/birthweight – estimate current risk of poor outcome

<24	24	25	26	27	≥28
<500g			500-1000g		>1000g
Extremely high risk			Moderate to high risk		Lower risk

2. Assess modifiable risk factors – adjust risk of poor outcome

	Higher risk		Lower risk
Antenatal steroids	No	Incomplete	Yes
Place of birth?	Outborn (non tertiary NICU/limited resources/poor outcome at this gestation)		Inborn (tertiary NICU/Experience and resources available/better outcome)

3. Assess non-modifiable risk factors – adjust risk of poor outcome

	Higher risk		Lower risk
Chorioamnionitis?	Severe chorioamnionitis		No suspicion of infection
Congenital anomalies	Multiple/ severe	Some, less severe	Normal morphology
Fetal illness (eg hydrops/twin-twin)	Severe fetal compromise	Some fetal compromise	No fetal compromise
Singleton/Multiple?	Multiple		Singleton

Figure 4 – Multi-variable model for assessment of risk for the extremely preterm infant in the Philippines

3.2. Assessment of parental wishes

The estimated outcome for the extremely preterm infant (See risk assessment section 3.1) should be sensitively but realistically conveyed to the parents. Parents should be informed about the chance of survival as well as the risks of morbidity. They should be provided with information about the nature and burden of treatment required for the infant, including the local experience with caring for infants at the expected gestation. If applicable, parents should be provided with realistic estimates of the costs that they will potentially be expected to bear for the treatment. This should also include information about assistance or external support available for those costs.

Health professionals should ascertain parents' desires about the resuscitation and initiation of intensive care if preterm delivery ensues. Whenever possible, a document on the parents' inclinations regarding this should be prepared and signed by all concerned parties. Should the parents decide otherwise after the preterm infant's delivery, the same document may be waived in consideration of the current situation.

3.3. Resuscitation decision

Following assessment of risk and of parental wishes, a decision should be reached to provide either active neonatal management or comfort care.

3.3.1. Active neonatal management

For extremely preterm infants at lower risk of poor outcome, it would be appropriate to attempt resuscitation at delivery and to admit to the neonatal intensive care unit. For example, this would apply to most infants ≥28 weeks gestation.

Active management would also be appropriate to provide for potentially viable preterm infants at moderate to high risk of poor outcome, where parents have expressed their wish for this (and where there are resources available to provide this treatment).

Active neonatal management for extremely preterm infants includes thermal management, airway management, and respiratory support. For specific details of management see [Refer to Neonatal Resuscitation Program (NRPH+) and the American Academy of Pediatrics Neonatal Resuscitation Program]

NB. In some circumstances, after delivery, a prior plan to provide active neonatal management may be reconsidered. For example, where an extremely preterm infant is born in very poor condition or has evident multiple severe congenital abnormalities that were not suspected antenatally, it may be appropriate to discuss with parents and to shift to palliative management.

3.3.2. Palliative neonatal management

For extremely preterm infants at extremely high risk of poor outcome (i.e. of dying or of severe morbidity), it would be appropriate to provide palliative management (comfort care) at delivery. For example, this would apply to most infants born <24 weeks gestation.

Palliative management would also be appropriate to provide for potentially viable infants at moderate-high risk of poor outcome, where parents have expressed their wish to withhold active management.

Palliative neonatal management includes avoidance of interventions that would not be in the infant's best interests as well as provision of measures focused on the infant's comfort and holistic care of the needs of the family. Infants should be dried, warmed and placed skin-to-skin on the mother's (or father's) chest or wrapped for parents to cuddle, as they desire. Palliative management would not usually include airway manoeuvres, oxygen, respiratory support, or intravenous lines. (In some cases, low flow nasal cannula oxygen may be provided for the comfort of infant and parents). Very premature infants who are provided with comfort care at delivery may survive for 60 minutes or longer. Simple measures are often sufficient to provide comfort for the baby e.g., keeping the baby warm and held in kangaroo mother care position or swaddled and cuddled. If the baby has signs of hunger, he/she could be put to the breast. If the baby shows signs of distress that do not respond to the above measures, consider providing analgesia (see below).

N.B. In some circumstances, after delivery, a prior plan to provide palliative neonatal management may be reconsidered. For example, where an extremely preterm infant appears significantly more mature than expected from the antenatal assessment, or in much better condition than anticipated, it may be appropriate to re- discuss with parents and to shift to active neonatal management.

3.3.3. Situations of uncertainty

In situations where there is uncertainty about the risk for an infant, or uncertainty about parental wishes, a provisional plan for active neonatal management should be pursued. This would include assessment of the newborn infant in the delivery room, their level of maturity and their response to initial resuscitation. At that point, if there is continued uncertainty, or it appears that there would be a lower risk for the infant, active neonatal management should be pursued.

N.B. Assessment of gestation and of viability at the time of delivery is not necessarily reliable.[23]

In some situations, there may be disagreement about the management of the baby. (For example, if parents of preterm infant of >28 weeks gestation did not wish for active neonatal management, but the doctors believe this would be in the baby's interests, or if there were different views within the healthcare team.) Where possible, it can be helpful to arrange a family meeting or multi-disciplinary team meeting to listen to the concerns of all involved, address any misunderstandings and seek consensus. Support from others, including chaplains or social workers may be helpful. Where decisions need to be made urgently, and disagreement cannot be resolved, it would be usual to provide active neonatal management in the first instance, and subsequently to review decisions.

4. Subsequent decisions

As with all medical treatment, decisions to initiate active management for an extremely preterm infant should be reviewed, and reconsidered if additional information comes to light, or if circumstances change. For example, following admission to the neonatal intensive care unit, further information may become available about the infant's chance of survival or of severe morbidity. Alternatively, complications of treatment may develop. There should be continuous discussions with the newborn's family about the infant's progress and outlook.

Where it becomes apparent that an extremely preterm infant has a very low chance of survival if treatment continues, a high chance of severe morbidity, or requires treatment that would be extremely burdensome for the infant or for the family, there is no ethical obligation to continue treatment. In such circumstances, the medical team should discuss the infant's condition with the parents, and to consider withholding or withdrawing active treatment and provide palliative care.

Where there is a plan to stop intensive care and move to palliative care, arrange for privacy for the parents and family as much as possible. Provide the family with the opportunity to hold their infant. Treatments should be reviewed – those aimed at survival or recovery should be discontinued. Removal of endotracheal tubes or other devices is a medical responsibility. The family should not be required to perform this procedure.

Treatments aimed at the infant's comfort should be continued and optimized. The infant and parents should be guided to a quiet area in the NICU complex; either in a separate room or with curtains to ensure privacy. The infant may be swaddled and placed in the parent's arms or held skin-to-skin on the parent's chest. The infant may be given breastmilk dipped in a cotton swab and applied to the buccal mucosa. The grandparents or siblings may also be allowed to stay with the infant. A pastor, priest or other religious leader may be called to bless or baptize the infant. In case, the infant continues to be in pain, analgesia should be provided and titrated to the infant's

comfort. The parents should be advised that the medication is to keep the infant comfortable and free from pain.

Paediatric palliative care pharmacopoeias can provide doses and recommendations for symptom management. For example, morphine (0.05mg/kg buccally/sublingual, or 0.05mg/kg slow intravenous/subcutaneous injection can be provided and repeated every 15 minutes if there are still signs of pain. A lower dose (0.025mg/kg) can be used for breathlessness. There is not a maximum dose of analgesia, however, if an infant has persistent or recurrent evidence of pain after 2-3 bolus doses consider providing an infusion (subcutaneous or intravenous). Seizures can be treated with midazolam 0.3mg/kg bucally or 0.1mg/kg IV repeated every 15 minutes if required. Agitation can be treated with a lower dose of midazolam (eg 0.1mg/kg bucally).

Most infants who are dying do not experience hunger. Infants should be offered the breast if they appear hungry and are able to suck. Artificial (tube) feeding should be considered if the infant appears hungry and is unable to suck, however, this may not increase the baby's comfort and is not routinely required.

Provision for emotional and spiritual support for the family according to their cultural and religious practices should be ensured. In the event of death, the body should be accorded the proper respect in accordance with the family's belief and with the local law

APPENDIX 1: CONSENSUS METHODOLOGY

The consensus meeting was held on 6th February 2019. All members of the PSNbM were invited to the meeting, held prior to the annual conference. The meeting was attended by 95 PSNbM members and representatives of other crucial stakeholders. A briefing paper was emailed to delegates and representatives prior to the event which included key data, concepts and literature relevant to the meeting.

The aim of the meeting was to assess and reach a consensus about potential guidelines relating to resuscitation of extremely premature infants in the Philippines.

STEP 1: PRESENTATION OF KEY DATA AND CONCEPTS

Relevant data and concepts were presented to form the basis for consensus discussion. This included:

- *Outcomes* – Data collected from several NICUs, mostly in tertiary centers, which included data on survival by gestational age and birthweight.
- *Current management practices* – Results of a national survey of all NICUs in the Philippines including current practices relating to initiating and withholding treatment, availability of resources (i.e. mechanical ventilators, surfactant), factors influencing clinicians' decision making and estimated outcomes.
- *Existing guidelines and possible frameworks* – Literature surrounding existing guidelines in high-income settings, current practices in other Low and Middle-Income countries and possible guideline models suitable for the Philippine context.

STEP 2: INPUT FROM KEY STAKEHOLDERS

A panel discussion involved representatives of key stakeholders to respond to the presented data and comment on posited guideline models. Representatives from Obstetrics, Midwifery, Nursing, Department of Health, UNICEF and the Catholic church were included in the panel. All members of the consensus group were invited to respond to the panel's comments and seek further clarification and input.
A statement regarding relevant Christian doctrine and theology was subsequently presented by a Catholic priest and bioethicist.

STEP 3: CONSENSUS WORKSHOP

One large interactive group session for all delegates was held, facilitated by an external facilitator. Fifty-five PSNbM members and stakeholder representatives responded to questions about guidelines for the Philippines via a live polling tool (Glisser) with the use of their smartphone devices. Consensus was sought in three distinct areas: (i) general principles (ii) specific guidelines and (iii) ethical principles. In each area, consensus was sought using the following process:

a. Presentation or summary of information and/or key concept at hand
b. Initial vote – via live polling tool with results displayed in real-time
c. Discussion – delegates invited to share their reasoning for their chosen view or submit questions and/or request clarification
d. Seeking consensus - a second vote via live polling tool, providing the opportunity for delegates to change their vote based upon preceding deliberation

The results of the consensus meeting indicated:

i. Unanimous support for the development of guidelines relating to resuscitation of EPI in the Philippines (100% agreement)
ii. Strong support for the development of a common set of guidance that could be applied in all tertiary neonatal intensive care units in the Philippines (81% agreement)
iii. Unanimous (or near-unanimous) support for a set of 6 guiding ethical principles to be the basis for guidance (>90% agreement)
iv. Strong support for the development of an individualized approach to decisions incorporating multiple risk factors into a common framework (68% agreement)
v. Strong support for a framework that accepted the importance of parental wishes in decisions across a wider range of gestational ages (wide grey zone) (73% agreement)
vi. Majority support for resuscitation/non-resuscitation being optional (depending on other factors) between 24-28 weeks gestation (>50% agreement)

STEP 4: POST-WORKSHOP REFINEMENT OF CONSENSUS STATEMENTS AND CONSULTATION WITH OTHER GROUPS

The results of the consensus statements were subsequently compiled into the above report. The report was edited and modified following consultation with the members of the Philippine Society of Newborn Medicine during its meeting during the Philippine Pediatric Society Annual Convention on April 7-10, 2019, Philippine International Convention Center, Manila.

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