

A photograph of a newborn baby's foot being held by a hand in a purple nitrile glove. The background is a blurred hospital room with other people and medical equipment. The overall color palette is dominated by soft blues and purples.

RIGHT TO HOPE

**THE WILBERFORCE
PROJECT**



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INTRODUCTION

In 2019, twin boys were born in Alberta, Canada at 21 weeks gestational age. The hospital denied these boys treatment, and they died in less than two hours. Tragically, the family of these twin boys — Thunder and Cloud — are not alone in grieving the loss of their extremely premature babies who have been denied medical care. In Alberta, these babies are not given a chance at life, and are left to die.

The purpose of this project is to report on why these tragedies occur in Alberta, while they do not in many other healthcare jurisdictions; and ultimately, to provide a remedy to this. This project will survey the current healthcare protocols in Alberta regarding extremely premature babies, and determine whether these protocols are supported by the existing data on preterm births, and comment on their ethicality. This project will provide a comprehensive basis of what policy makers, legislators and health care providers must know in order to structure sound and ethical health policy on the treatment of extremely premature babies.



Image of Thunder and Cloud, obtained from <https://www.facebook.com/events/2596225980486629/?ref=newsfeed>

UNDERSTANDING THE LANGUAGE

There are several terms surrounding neonatal care used frequently throughout this report and those studies referenced by this report, most of which are defined by reference to gestational age. For sake of clarity and continuity, this section provides a brief overview of these terms. *Neonatal* simply refers to the period shortly after birth, while a *neonate* is a child within the first four weeks after birth. *Perinatal* refers to the time surrounding birth, it can refer to a gestational age as early as 20 weeks¹ to the first month after birth. *Antenatal* simply means before birth.

Gestational age is written with both weeks and days; for example, a child whose gestational age is 21 weeks and 3 days would be written as 21 3/7. Qualifiers for early preterm/premature birth or extremely preterm/premature birth are not universal. Using the Alberta Health Services (AHS) definitions, *early preterm birth* is defined as birth at a gestational age between 22 0/7 and 31 6/7 weeks. *Preterm Birth* is defined as birth at a gestational age between 32 0/7 and 33 6/7 weeks. *Late Preterm Birth* is defined as birth at a gestational age between 34 0/7 and 36 6/7 weeks.² The term *extremely preterm/premature* is not used by AHS as a formal term, however, in studies included in this report, the definition varies, from 22-25 weeks,³ 22-26 weeks,⁴ to 23-28 weeks.⁵

A *viable* baby is one able to survive outside the womb, either naturally or induced. AHS procedural documents follow a very specific definition of *viability* (will be discussed in the “AHS NICU Regulation” section of this report) which are by no means universal. *Periviability* is the period of time surrounding viability, known as the threshold of viability. *Perivable births* are typically defined as those occurring between 20 0/7 and 25 6/7 weeks of gestation.⁶

Obstetrics is the branch of medicine focused on the care of a woman during and after childbirth. *Pediatrics* is the branch of medicine dealing with infants, children and adolescents. *NICU* stands for Neonatal Intensive Care Unit, typically NICUs are given classifications by number to refer to the level of care they provide. These classifications are not universal, and in fact, even vastly differ between health jurisdictions in Canada.

¹ See, [AHS Perinatal Grief Management Form](#)

² [CRITERIA TO SUPPORT APPROPRIATE LEVEL OF OBSTETRICAL CARE guideline HCS-201-01](#), pg. 3-4.

³ [Outcomes at 18 to 22 Months of Corrected Age for Infants Born at 22 to 25 Weeks of Gestation in a Center Practicing Active Management](#)

⁴ [The Limit of Viability: A Single Regional Unit's Experience | Clinical Pharmacy and Pharmacology | JAMA Pediatrics](#)

⁵ [Cost of neonatal intensive care for extremely preterm infants in Canada - Rolnitsky - Translational Pediatrics](#)

⁶ [Survival of Infants Born at Perivable Gestational Ages - PMC](#) and [Perivable Birth | ACOG](#)

EXTREMELY PREMATURE BABY DATA

It is important to have an overview of the statistics on preterm births before continuing on with this report. This data tells us how many extremely premature babies are born in Canada, therefore, how many children would benefit from robust and evidence-based NICU policy and procedure.

The Government of Canada data on extremely premature births is severely lacking.⁷ The primary reason for the gap in their data is that the number of births by week of gestation is not broken down enough. Therefore, by Government of Canada published statistics, we are unable to properly assess the actual number of extremely premature births in the time frame relevant to this report; from the 21-week to 23-week gestational age range. Reports that aggregate births across multiple gestational ages obscure important information.

The latest data on live births, as summarized in the following table obtained from Statistics Canada, only reports births as low as “less than 37 weeks.”

Characteristics ⁷	Number of live births				
Geography, place of residence of mother ⁸	Canada, place of residence of mother ⁹ (map)				
Sex	Both sexes				
Weeks of gestation ¹⁰	2016	2017	2018	2019	2020
	Number				
Total, weeks of gestation	383,102	377,308	374,049	372,038	358,604
Gestation, 42 weeks or more	1,387	1,316	1,238	985	938
Gestation, 37 to 41 weeks	351,351	346,098	342,745	339,879	328,887
Gestation, less than 37 weeks	30,128	29,715	29,898	29,998	28,138
Weeks of gestation, not stated	236	179	168	1,176	641

Table 1. Obtained from <https://www150.statcan.gc.ca/t1/tbl1/en/tv.action?pid=1310042501>

⁷ [PERINATAL HEALTH INDICATORS FOR CANADA 2017](#) and [Perinatal Health Indicators for Canada 2017](#) This data is also available for reference, however, gestational age in these studies are not broken down enough. As such, from these Government of Canada databases, we have no idea what the death/survival/complication rates are for extremely preterm births, around the 21-23 week mark.

Overview

Extremely Premature Baby Data

The most comprehensive data on extremely premature births in Canada is published by The Canadian Neonatal Network (CNN). While government funded, the CNN is the collaborative effort of a group of researchers across Canada.⁸ Their 2020 Annual Report features “data collected from 33 Health Care Organizations that were members of the Canadian Neonatal Network™ during the year 2020.” The following tables⁹ show a breakdown of admitted neonates by week of gestation. Table 2 summarizes this data for the year 2020, while Table 3 shows the trend over the past eleven years. The gestational window this report is focused on is around the 22-week mark.

GA in completed weeks at birth	Frequency	Percent	Cumulative percent
22	15	0.1	0.1
23	127	0.9	1.0
24	201	1.4	2.4
25	236	1.7	4.1
26	265	1.9	5.9
27	310	2.2	8.1
28	402	2.8	10.9
29	491	3.4	14.3
30	593	4.2	18.5
31	634	4.4	22.9
32	834	5.8	28.8
33	730	5.1	33.9
34	1 151	8.1	42.0
35	1 068	7.5	49.5
36	1 177	8.3	57.7
37	1 387	9.7	67.4
38	1 534	10.8	78.2
39	1 470	10.3	88.5
40	1 084	7.6	96.1
41	538	3.8	99.8
≥42	24	0.2	100.0
Total included	14 271	100.0	
Total # of missing GA	0		
Total # of neonates	14 271		

As we can see from Table 2, across the CNN in Canada in 2020, only 15 neonates were born at 22 weeks. This is below the average birth rate over the past eleven years for 22 weekers. In both 2019 and 2018, 25 neonates born at 22 weeks are recorded. As we can see from the first chart on Table 3, 187 neonates have been born across the CNN network over the past eleven years. The second chart on Table 3 is important because, as we will see later in this report, the threshold of viability is defined not only by gestational age, but also by weight at birth. In 2020, 43 neonates are recorded as being born with a birth weight of less than 500g. Over the past eleven years, 449 neonates weighing less than 500g have been born across the CNN.

Table 2: Titled, “Gestational age distribution: All sites and all admitted neonates.” Obtained from [Annual Report 2020 Rapport Annuel](#). Note, “The GA distribution of neonates is shown here. Term babies (≥37 weeks) represent 42.3% of the total number of neonates. Twenty-four sites collected data on all eligible admissions whereas nine sites collected data on a selected cohort of eligible admissions.”

⁸ “The CNN infrastructure is funded by the Canadian Institutes of Health Research.” [Annual Report 2020 Rapport Annuel](#), Pg. i

⁹ “These include data from 14 271 eligible neonates admitted to 33 sites. 24 of these sites submitted complete data (n=13 043) on all eligible admitted neonates and 9 sites submitted data on a selected cohort of eligible admitted neonates (n=1 228).” [Annual Report 2020 Rapport Annuel](#), Pg. 13

Overview

Extremely Premature Baby Data

Number of neonates by admission year and GA

Year	Number of Sites	GA											Total
		<23	23	24	25	26	27	28	29	30	31	32	
2010	27	9	73	172	270	333	388	371	480	611	678	788	4173
2011	30	15	86	166	242	318	332	391	467	553	643	828	4041
2012	30	28	85	184	285	294	348	416	510	610	738	872	4370
2013	29	16	76	197	247	267	357	434	479	620	733	836	4262
2014	31	8	81	226	250	332	362	412	517	585	743	871	4387
2015	30	14	99	177	248	289	317	425	470	536	662	793	4030
2016	30	16	79	214	275	272	380	431	437	551	722	861	4238
2017	31	16	133	215	257	294	325	434	467	606	743	868	4358
2018	32	25	132	215	271	334	380	424	518	576	744	863	4482
2019	32	25	118	217	279	297	342	440	470	613	740	905	4446
2020	33	15	127	201	236	265	310	402	491	593	634	834	4108

Number of neonates by admission year and birth weight

Year	Number of Sites	Birth weight					Total
		< 500	500 - 749	750 - 999	1000 – 1249	1250 – 1499	
2010	27	32	436	792	819	879	2958
2011	30	31	383	660	680	794	2548
2012	30	48	441	696	815	922	2922
2013	29	36	428	651	842	919	2876
2014	31	36	458	760	804	922	2980
2015	30	40	406	680	792	864	2782
2016	30	40	472	710	744	901	2867
2017	31	38	478	678	806	920	2920
2018	32	55	508	739	807	977	3086
2019	32	50	482	685	802	937	2956
2020	33	43	436	668	731	878	2756

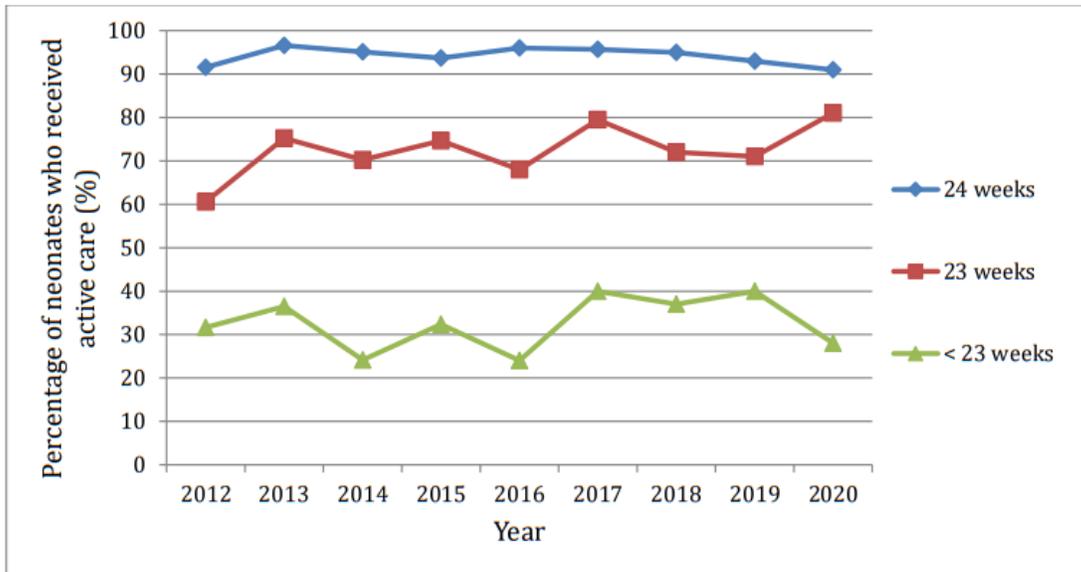
Table 3: Titled, “Trend Analyses over last 11 years.” Obtained from [Annual Report 2020 Rapport Annuel](#). Note, “This section includes trend analyses of specific outcomes from the last 11 years (2010-20) for neonates <33 weeks’ GA in CNN sites. The following table describes the number of neonates in the respective GA categories that were included in these trend analyses. Delivery room deaths were excluded.”

The following tables show trends over the past nine years for the proportion of neonates who received active care; this includes those neonates who received active care and died before being admitted into the NICU and those who were admitted into the NICU. Delivery room deaths include neonates who either received palliative care, as well as those who received active care and died before being admitted into the NICU. Policy supporting a more advanced level of care for extremely premature neonate could save the lives of those who died in the delivery room, as well as improve outcomes for those neonates who are admitted into the NICU. Across the CNN network from 2012 to 2020, there have been a total of 433 neonates born prior to 23 weeks, 365 neonates born at 23 weeks, and 114 neonates born at 24 weeks

Overview

Extremely Premature Baby Data

who received palliative care. The data is not available as to why these neonates received palliate care; it is possible that treatment was available but the family did not elect active care for their infant, or because treatment was not provided as an option for those infants. In 2020, there have been fewer neonates born prior to 23 weeks who received active care than in the past four years. One possibility for this result is limited medical resources and ventilators due to the COVID-19 pandemic.



		2012	2013	2014	2015	2016	2017	2018	2019	2020
<23 weeks	Number of neonates who received active care $(a-c) + e$	25	23	14	22	16	26	35	35	18
	Total number of neonates including DR deaths $a+d+e$	79	63	58	68	67	65	95	88	64
	Percentage of neonates who received active care	32%	37%	24%	32%	24%	40%	37%	40%	28%
23 weeks	Number of neonates who received active care $(a-c) + e$	83	85	92	106	82	136	133	127	131
	Total number of neonates including DR deaths $a+d+e$	137	113	131	142	121	171	185	178	162
	Percentage of neonates who received active care	61%	75%	70%	75%	68%	80%	72%	71%	81%
24 weeks	Number of neonates who received active care $(a-c) + e$	185	200	233	178	217	221	224	224	199
	Total number of neonates including DR deaths $a+d+e$	202	207	245	190	227	231	235	240	218
	Percentage of neonates who received active care	92%	97%	95%	94%	96%	96%	95%	93%	91%

Table 4: Titled, “Proportion of neonates who received active care out of all (including delivery room (DR) deaths).” Obtained from [Annual Report 2020 Rapport Annuel](#). Note, “The alphabet notations used in the table above are carried from [Tables 12 and 13, which will be provided and discussed in “The Research on Viability” section of this report]. Information should be interpreted with caution as not all sites provided data on delivery room deaths. Active care refers to infants who received cardiopulmonary resuscitation at birth.



CURRENT PRACTICE

ALBERTA NICU LEVELS AND DATA

As of March 2021, Alberta has 316 NICU Level II and III beds. The breakdown by zone can be found in the following table:

Zone Overview of Bed Numbers

Summary of Bed Numbers by Zone and Detailed Facility Listing

Number of Beds/Spaces as of March 31, 2021	South Zone	Calgary Zone	Central Zone	Edmonton Zone	North Zone	Provincial
Hospital Acute & Sub-Acute Care						
Hospital Acute Care	521	2,179	925	2,412	861	6,898
Neonatal Intensive Care (NICU Levels II and III)	23	126	17	140	10	316
Special Care (includes ICU, SCU, CCU, CVICU and PICU)	24	136	18	202	12	392
Palliative Beds in Acute Care	0	29	51	25	21	126
Sub-acute in Acute Care	9	32	32	22	0	95
Psychiatric in Acute Care	72	287	50	237	40	686
TOTAL HOSPITAL ACUTE & SUB-ACUTE CARE	649	2,789	1,093	3,038	944	8,513

Table 5. Obtained from [2020-21 AHS Annual Report](#)

AHS does not formally define Alberta NICU Levels, however, provides the following recommendations for NICU Levels per gestational age;

Early Preterm Birth is defined as gestational age between 22 0/7 and 31 6/7 weeks.

- a) Gestational age between 22 0/7 and 29 6/7 weeks are to be transferred to a level three (3) NICU.
- b) Gestational age between 30 0/7 and 31 6/7 weeks may be transferred to a level two (2) NICU if no level three (3) NICU beds are available or accessible.

Preterm Birth is defined as a gestational age between 32 0/7 and 33 6/7 weeks. Consultation and transfer of care to a facility with any level NICU is required.

Late Preterm Birth is defined as a gestational age between 34 0/7 and 36 6/7 weeks.

- a) Gestational age between 34 0/7 and 34 6/7 weeks are to be transferred to a level two (2) NICU.
- b) Gestational age between 35 0/7 and 36 6/7 weeks may be transferred to level two (2) NICU following consultation between the MRHP at level one (1) hospital and neonatal/pediatric consultant at referral hospital. This population is at high risk for readmission if not cared for in a NICU.¹⁰

¹⁰ CRITERIA TO SUPPORT APPROPRIATE LEVEL OF OBSTETRICAL CARE guideline HCS-201-01, Pg. 3-4

Current Practice: Alberta

Alberta NICU Levels and Data

AHS provides formal definitions of Hospital Levels, geared to obstetrics. (See Appendix A for further AHS transfer recommendations.) For preterm labour between 22 and 30 weeks gestation, AHS recommends a Level 3 (L3) Hospital, meaning, a hospital with full obstetrics, surgical and neonatal services including L2 and 3 NICU.

Service Delivery Model by Level of Hospital

- Level 0 Hospital = hospital that does not routinely provide obstetrical support
- Level 1 A Hospital = hospital with no operating room capability
- Level 1 B Hospital = hospital with 24/7 Operating Room (OR) and Cesarean section capability
- Level 1 C Hospital = hospital with 24/7 OR plus obstetrical specialist
- Level 2 Hospital = hospital with full obstetrics, surgical and pediatric services including L2 NICU
- Level 3 Hospital = hospital with full obstetrics, surgical and neonatal services including L2 & 3 NICU

Summary of Recommended Care Locations by Gestational Age

Gestational Age (weeks)	Level 1A Hospital	Level 1B Hospital	Level 1C Hospital	Level 2 Hospital	Level 3 Hospital	Level 2 NICU	Level 3 NICU
22 ^{0/7} to 29 ^{6/7}							✓
30 ^{0/7} to 31 ^{6/7}						2 nd Choice	1 st Choice
32 ^{0/7} to 33 ^{6/7}				✓	✓	✓	✓
34 ^{0/7} to 34 ^{6/7}				✓	✓	✓	✓
35 ^{0/7} to 36 ^{6/7}	With special considerations			✓	✓	✓	✓
37 ^{0/7} to 40 +	✓			✓	✓	✓	✓

Table 6. Obtained from [CRITERIA TO SUPPORT APPROPRIATE LEVEL OF OBSTETRICAL CARE guideline HCS-201-01](#)

Alberta also has several provincial initiatives focused on extremely premature neonates. The University of Alberta and AHS have partnered together on the Northern Alberta Neonatal Program, in order to “care for infants who require special medical or surgical attention, including extremely premature newborns.”¹¹

¹¹ See, [Northern Alberta Neonatal Program](#), Pg. 5

AHS NICU REGULATION

AHS publishes policy and procedural documents outlining expectations and guidance for patient care. This section will cover several AHS procedural documents pertaining to neonatology, focusing on how AHS recommends care for extremely premature babies, around 21-23 weeks gestational age. The documents reviewed in this section are the following: *Obstetrical Triage Acuity Scale (OTAS)*,¹² *Clinical Assessment of 'At Risk' or Actual Preterm Labor for Triage*,¹³ *AHS Neonatal Palliative Care Guide for Neonatal Intensive Care Units*,¹⁴ and *Advance Care Planning and Goals of Care Designation*.¹⁵

The purpose of the AHS *Obstetrical Triage Acuity Scale (OTAS)* guideline is “to provide a standardized and consistent approach for rapidly identifying obstetrical patients with urgent, life threatening conditions to the mother or fetus.”¹⁶ It states that, “All obstetrical patients, who are *greater than or equal to twenty weeks gestational age* who present to or are transferred to a LD/OB (Labour and Delivery Obstetric) assessment area at level 1A or greater hospitals, shall be assigned a primary and secondary assessment OTAS score.” (Emphasis added.)^{17 18}

AHS' *Clinical Assessment of 'At Risk' or Actual Preterm Labor for Triage* guideline is an extremely important document for understanding what level of care AHS prescribes for extremely premature neonates. The purpose of the document is, “To provide obstetrical opinion and guidance to most responsible health practitioners [MRHP] in the assessment, care and management of the pregnant patient (maternal-fetal pair) presenting with threatened preterm labour (TPL) or “at risk” for TPL.”¹⁹ The document states that, “Compliance with this document is *required* by all Alberta Health Services employees, members of the medical and midwifery staffs, Students, Volunteers, and other persons acting on behalf of Alberta Health Services (including contracted service providers as necessary), working in Women’s Health.” (Emphasis added.)²⁰

¹² AHS. (2017). *Obstetrical Triage Acuity Scale (OTAS)*. Guideline HCS-207-01.

<https://extranet.ahsnet.ca/teams/policydocuments/1/clp-womens-obstetrical-triage-acuity-scale-otas-gdl-hcs-207-01.pdf>

¹³ AHS. (2016). *Clinical Assessment of 'At Risk' or Actual Preterm Labor for Triage*. Guideline HCS-183-

01. <https://extranet.ahsnet.ca/teams/policydocuments/1/clp-womens-health-preterm-clin-assess-at-risk-hcs-183-01.pdf>

¹⁴ AHS. (2020). *Neonatal Palliative Care Guide for Neonatal Intensive Care Units*. Maternal Newborn Child & Youth SCN. <https://www.albertahealthservices.ca/assets/about/scn/ahs-scncmncy-neonatal-palliative-care-guide-nicu.pdf>

¹⁵ AHS. (2014). *Advance Care Planning and Goals of Care Designation*. Guideline HCS-38-01.

<https://extranet.ahsnet.ca/teams/policydocuments/1/clp-advance-care-planning-hcs-38-01-procedure.pdf>

¹⁶ OBSTETRICAL TRIAGE ACUITY SCALE (OTAS) Guideline HCS-207-01, Pg. 1

¹⁷ *Ibid.*, Pg. 2

¹⁸ The MNCY SCN Antenatal Pathway document echoes this as well, by recommending the following; “Transfer-Preterm labor- Between 22 and 30-316/7 weeks’ gestation. → L3” (pg. 15)

¹⁹ CLINICAL ASSESSMENT OF 'AT RISK' OR ACTUAL PRETERM LABOUR FOR TRIAGE guideline HCS-183-01, Pg. 1

²⁰ *Ibid.*, Pg. 1

Current Practice: Alberta

AHS NICU Regulation

Section 6 of this guideline is titled, “Preterm Labour with Pre-Viable Gestational Age Fetus – Practice Considerations.”²¹ In this section it states that, “Parents facing the birth of an extremely preterm infant should have the opportunity to meet with the most responsible health practitioners from both the obstetrical and paediatric/ neonatal care to *receive accurate information about their infant’s prognosis*. This information should be provided with clarity and compassion.” (Emphasis added.)²² The document specifies that, “Pregnant patients at *greater than or equal to 23 0/7 and up to 32 0/7 weeks gestation should be transferred to a tertiary centre with Level III NICU*, despite the perceived intentions for neonatal management. *The decision to transfer should be patient-specific and factor in gestational age, estimated fetal weight, and parental preferences.*” (Emphasis added.)²³ Continuing on with “practice considerations,” the following points are specified: “*The survival of infants born before or at 22 6/7 completed weeks of gestation remains uncommon. A non-interventional approach is recommended*”;²⁴ “*All extremely preterm infants who are not resuscitated, or for whom resuscitation is not successful, shall receive compassionate palliative care*”;²⁵ and, “*Community practitioners should be educated about the management options for extreme prematurity and should have the option to call specialist practitioners for advice in managing these cases.*” (Emphasis added.)²⁶

The guideline states that, “Infants born between greater than or equal to 23 0/7 weeks and 24 6/7 weeks of gestation with a birth weight of 500 to 599 grams (threshold of viability) *present the greatest uncertainty surrounding infant survival and outcome: The line between patient autonomy and medical futility is blurred*. [And] If the birth weight is less than 500 grams, resuscitation should only be performed after most careful consideration.” (Emphasis added.)²⁷

The following flow charts are provided in the document’s appendices:²⁸

²¹ Ibid., Pg. 10. This document also provides an “Assessment of Preterm Labour Guideline Bibliography,” see that document’s reference 26 and 27 for sources informing AHS recommendations: ACOG Obstetric Care Consensus: Pre-viable Birth. *Obstet Gynecol* 2015;126:e82—94, and, Chari R (presentation ‘Extreme Prematurity The Considerations’ March 17, 2016 NICU Calgary).

²² Ibid., Pg. 10, Sect. 6.2

²³ Ibid., Pg. 11, Sect. 6.4

²⁴ Ibid., Pg. 11, Sect. 6.5

²⁵ Ibid., Pg. 11, Sect. 6.6

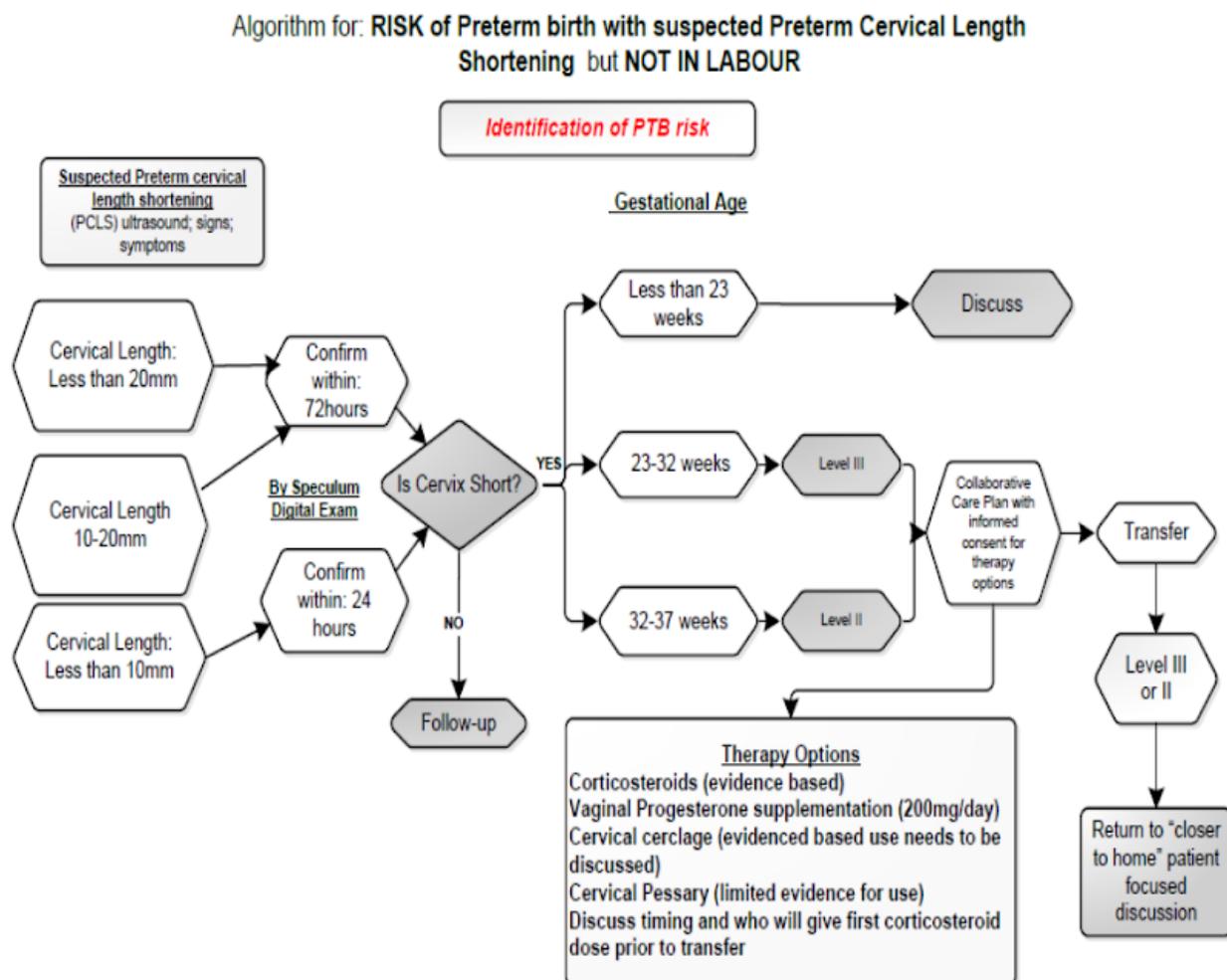
²⁶ Ibid., Pg. 11, Sect. 6.7

²⁷ Ibid., Pg. 11, Sect. 6.9

²⁸ Ibid., Pg. 15-16

Current Practice: Alberta

AHS NICU Regulation



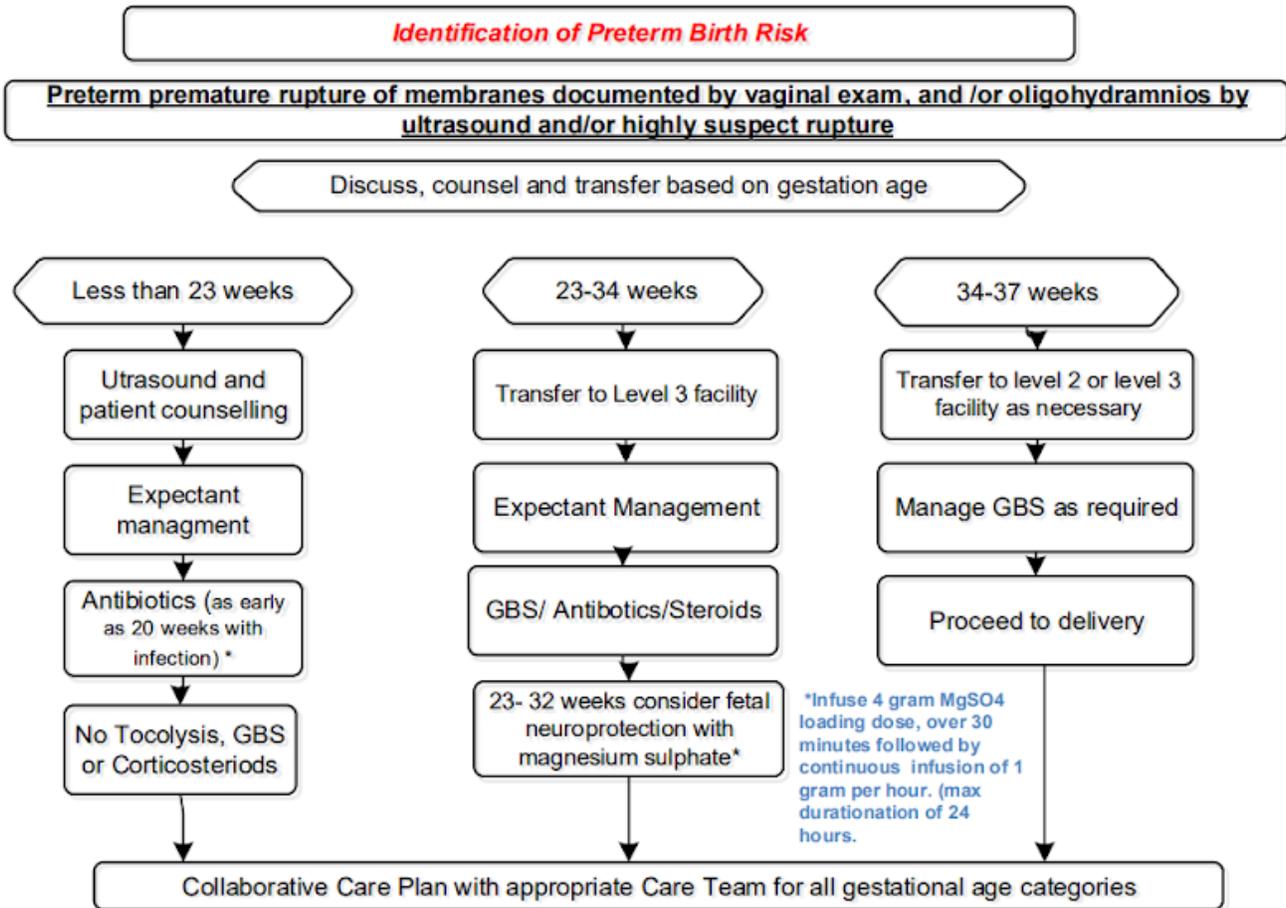
Clinical experience, the use of the Obstetrical Triage Acuity Scale (OTAS), maternal history, assessment, examination, uterine, fetal assessment, laboratory testing and imaging if available play a role in determining risk of PTB

Image 1. Obtained from [CLINICAL ASSESSMENT OF 'AT RISK' OR ACTUAL PRETERM LABOUR FOR TRIAGE guideline HCS-183-01, Appendix C](#)

Current Practice: Alberta

AHS NICU Regulation

Algorithm for: RISK of Preterm birth with Premature Rupture of Membranes but NOT IN LABOUR



October 6, 2016

*= see guideline for specific antibiotic recommendations

Clinical experience, the use of the Obstetrical Triage Acuity Scale (OTAS), maternal history, assessment, examination, uterine, fetal assessment, laboratory testing and imaging if available play a role in determining risk of PTB

Image 2. Obtained from [CLINICAL ASSESSMENT OF 'AT RISK' OR ACTUAL PRETERM LABOUR FOR TRIAGE guideline HCS-183-01, Appendix C](#)

Current Practice: Alberta

AHS NICU Regulation

The next document reviewed here is the *AHS Neonatal Palliative Care Guide for Neonatal Intensive Care Units*. “The following document *provides information to health care providers with consensus-based guidance on best palliative care practices for infants with life-limiting conditions* and to support their families served in the Neonatal Intensive Care Unit (NICU).” (Emphasis added.)²⁹ As well, all AHS staff and volunteers, “who are involved with palliative care delivery within the NICU *should become familiar with the information in this guide.*” (Emphasis added.)³⁰ This AHS document lists palliative care considerations as the following;

Palliative care should be considered for an infant when it becomes apparent that treatment aimed at curing or prolonging life is leading to a significant reduction of an infant’s quality of life... Conditions appropriate for palliative care may be categorized as follows:

- a) Life-limiting: any condition clearly associated with a limited life span with no curative treatment available (e.g., anencephaly).
- b) Life-threatening: Treatment may be feasible but may not be successful: (e.g., extreme prematurity irrespective of additional risk factors).
- c) Progressive conditions: Treatment is available for symptom control but no curative option exists currently (e.g., spinal muscular atrophy).
- d) Burden of disease or treatment outweighs the benefits as perceived by the health care team including the family (e.g., trisomy 13 or 18).³¹

It states that, “Alternate decision makers (ADMs) or guardians are the primary caregivers and should be involved as partners in the care of their hospitalized infant(s) in the NICU...The ADM or guardian(s) are surrogate decision-makers in what treatment choices are perceived to be in the best interests of their infant.”³²

The document acknowledges that conflict may arise between parents and members of the health care team. When this is the case, “the health care team should meet as often as needed and *consider seeking additional opinions and investigations.*” As well, the health care team “shall review the risks and benefits of the recommended treatment plan(s) with the guardian(s), and family (when applicable) in order to *address any concerns and to try to resolve conflict and build consensus* so that agreement for the treatment can be obtained.” (Emphasis added.)³³

The AHS *Advance Care Planning and Goals of Care Designation* policy document outlines Goals of Care Designations (GCD) and GCD Orders. It defines them as the following;

Goals of Care Designation means one of a set of short-hand instructions by which health care providers describe and communicate general care intentions, specific clinically

²⁹ [MNCY SCN Neonatal Palliative Care Guide](#), Pg. 5

³⁰ *Ibid.*, Pg. 5

³¹ *Ibid.*, Pg. 6. This document provides advice to health care providers on what language to use surrounding palliative care, what to say and not say to parents.

³² *Ibid.*, Pg. 7

³³ *Ibid.*, Pg. 8

Current Practice: Alberta

AHS NICU Regulation

indicated health interventions, transfer decisions, and locations of care for a patient as established after consultation between the most responsible health practitioner and patient or alternate decision-maker. Goals of Care Designation order³⁴ means the documented order for the goals of care designation as written by the most responsible health practitioner (or designate).³⁵

The document states that goals of care conversations “shall take place, where clinically indicated with the patient, as early as possible in a patient’s course of care and/or treatment. These discussions explore the patient’s wishes and goals for clinically indicated treatment framed within the therapeutic options that are appropriate for the patient’s clinical condition.”³⁶ As the others, this policy document also states that, “Compliance with this document is required by all Alberta Health Services employees.”³⁷

According to this set of guidelines, every GCD conversation should include “the role of life support interventions and/or life sustaining measures and their expected degree of benefit.”³⁸ The document divides “Degree of Clinical Benefit” into the following three categories;

- a) Likely to Benefit: In the opinion of the most responsible health practitioner, there is a reasonable chance that cardiopulmonary resuscitation, physiological support and life support interventions will restore and/or maintain organ function. The likelihood of the person being discharged from an acute care hospital is high.
- b) Benefit is Uncertain: It is unknown or uncertain whether cardiopulmonary resuscitation, physiological support and life support interventions will restore functioning. The subsequent prognosis or the likelihood of adverse consequences is also unknown or uncertain.
- c) Certainly will not Benefit: There is no reasonable chance that the person will benefit clinically from cardiopulmonary resuscitation, physiological support, and life support interventions.³⁹

Like the previous document reviewed, it also acknowledges that conflict can arise between the health care team and the patient / alternate decision makers. The following steps are provided for the MRHP in situations of conflict;

Where all efforts to reach consensus regarding appropriate interventions and/or a Goals of Care Designation have failed, and an impasse is reached, the most responsible health practitioner shall, in accordance with the Alberta Health Services Dispute Prevention and Resolution in Critical Care Settings Procedure:

³⁴ A GCD Order form can be found here: <https://www.albertahealthservices.ca/frm-103547.pdf>

³⁵ Advanced Care Planning and Goals of Care Designation Procedure HCS-38-01, Pg. 10

³⁶ *Ibid.*, Pg. 2, Sect. 2.1

³⁷ *Ibid.*, Pg. 1

³⁸ *Ibid.*, Pg. 3, Sect. 2.4.c

³⁹ *Ibid.*, Pg. 13, Appendix B

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- a) write a Goals of Care Designation order, including notification of the date and time the order shall come into effect;
- b) provide a written copy of the order to the patient and/or alternate decision maker, with reasonable advance notice; and
- c) inform the patient and/or alternate decision maker of their right to seek legal advice.⁴⁰

The document states that, “Where no legal proceedings have been initiated by the patient or alternate decision maker prior to the date and time of effect of the Goals of Care Designation order, the most responsible health practitioner and the health care team may proceed with treatments and interventions consistent with the Goals of Care Designation order at that date and time of effect (refer to Alberta Health Services Dispute Prevention and Resolution in Critical Care Settings Procedure).” (Emphasis added.)⁴¹

AHS CONFLICT RESOLUTION REGULATION

As we saw in the previous section, conflict can arise between the health care team and the patient / alternate decision makers. This section will review the following AHS documents on conflict resolution: *Complex and Essential Pediatric Medical Process*⁴² and *Dispute Prevention and Resolution in Clinical Settings*.⁴³

Like the previously reviewed AHS guidelines, the *Complex and Essential Pediatric Medical Process* document stipulates that compliance with the following guidelines is required by all AHS employees. The principle informing these guidelines is given as the following; “Addressing the best interests of the child through a philosophical lens of reducing harm through collaboration between AHS, CS [Children’s Services], the guardian(s), and the child (to the extent appropriate), is seen as the most appropriate approach for complex and essential pediatric medical decision making....the involvement of legal processes in medical decision making regarding children is the least favourable option when trying to ensure their safety and well-being.”⁴⁴ The document clarifies that, “Harm means, for the purpose of this guideline, an outcome for the patient, resulting from the care and/or services provided or lack thereof, that negatively affects the patient’s health and/or quality of life.”⁴⁵

“For situations involving potentially end-of-life treatment withdrawals and/or if the child is being cared for in an Intensive Care Unit (ICU) environment, health care providers shall follow the *AHS Dispute*

⁴⁰ Ibid., Pg. 8, Sect. 7.4

⁴¹ Ibid., Pg. 9, Sect. 7.8

⁴² AHS. (2019). *Complex and Essential Pediatric Medical Process*. Guideline HCS-230-01.

<https://extranet.ahsnet.ca/teams/policydocuments/1/clp-prov-comp-essen-ped-med-proc-hcs-230-01.pdf>

⁴³ AHS. (2013). *Dispute Prevention and Resolution in Clinical Settings*. Procedure PRR-03-01.

<https://extranet.ahsnet.ca/teams/policydocuments/1/clp-dispute-prevention-and-resolution-in-critical-care-settings-procedure.pdf>

⁴⁴ COMPLEX AND ESSENTIAL PEDIATRIC MEDICAL PROCESS - HCS-230-01 guideline, Pg. 2

⁴⁵ Ibid., Pg. 9

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Prevention and Resolution in Critical Care Settings Policy and Procedure, and the *AHS Advanced Care Planning and Goals of Care Designation Policy and Procedure*.⁴⁶ (The second document listed here was reviewed in the previous “AHS NICU Regulation” section, and the first will be reviewed in this section.) When the situation above arises, the health care team, specifically the MRHP, “shall consult with AHS Social Work (where available) to involve CS and potentially initiate the Complex Pediatric Medical Situations Involving CS Process.”⁴⁷

This document outlines the “Essential Pediatric Medical Needs Conflict Prevention and Resolution Process.” (See Appendices B and C.) This process stipulates that, “Specialist opinions should be sought as appropriate. When multiple physicians within a specialty are involved in the child’s care, a consensus opinion should be obtained within the specialty group.”⁴⁸ The process includes the following discussion on harm;

Medical discussions should include identifying or determining if harm is being done to the child due to lack of agreement about the course of care for the child.

i) The legal system and CS will consider the best interests of the child. From a medical perspective, the best interests of a child considers a number of factors including but not limited to:

- the child’s condition and prognosis;
- the medical treatment that is recommended; and
- the wishes, values and beliefs of the child as expressed by the child or the guardian(s), and family.

ii) *The courts, in general, support parental decision-making unless their decision results in harm to the child* including when the decision is determined to not be in the best interests of the child per the Child, Youth and Family Enhancement Act. *This is different than the subjective perspective of the guardian(s) or family regarding what is best for the child which is influenced by a host of personal factors.*

External second opinions should be considered to help determine best practice, any other clinical recommendations and any resulting harm to the child given the clinical scenario. Second opinions can also assess the potential for another site to agree to provision of care that aligns with the values and input of the guardian(s), child and family (when applicable). (Emphasis added.)⁴⁹

In situations where conflict is not resolved, “the MRHP shall initiate the Joint Advisory Group to assist with prevention and resolution of the conflict through ongoing communication with the health care providers and the guardian(s), child and family (when applicable) to attempt to resolve the conflict. *The*

⁴⁶ Ibid., Pg. 3, Sect. 1.3.b.i

⁴⁷ Ibid., Pg. 3, Sect. 2.1

⁴⁸ Ibid., Pg. 5, Sect. 3.5.d

⁴⁹ Ibid., Pg. 5-6, Sect. 3.5.e-f

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group should include at a minimum, medical representatives, Site Administration, Children Services (CS), and Clinical Ethics.” (Emphasis added.)⁵⁰

The document also states that, “In situations of impasse, when the guardian(s), child or family (when applicable) is requesting treatment or interventions considered by the health care team to be harmful, or futile, or not clinically indicated, or not in the child’s best interests, and does not agree with the MRHP determination of appropriate treatment options, Section 3.8 of the AHS Dispute Resolution in Critical Care Settings Procedure should apply.” (Emphasis added.)⁵¹

The final AHS document reviewed in this section is the *Dispute Prevention and Resolution in Clinical Settings* procedure. Again, compliance with this document is required by AHS employees. This procedural document states that, “All reasonable means shall be undertaken to reach consensus with the patient / alternate decision-maker(s) that respects the health care professionals’ clinical judgment and ethical obligations, and to reach resolution at the point of care closest to the patient.”⁵² This procedure emphasizes the importance of timely decisions, “allowing adequate time for all parties to understand and consider the choices and implications. Patients / alternate decision-makers and health care professionals should be given *adequate time* in keeping with the clinical situation, and *not be subjected to coercion or undue pressure regarding the decision and alternate options.*” (Emphasis added.)⁵³

The procedure is divided into three sections; dispute prevention: optimizing communication and decision-making; complex decision-making processes prior to escalation to dispute; and dispute resolution. Key triggers indicating a potential dispute include; “the *refusal by the patient / alternate decision-maker(s) to the provision of treatment or the withdrawal of treatment*; [and] incongruence between the patient’s / alternate decision-maker(s) / family’s and care providers’ beliefs and expectations regarding clinically appropriate care (e.g., a *disagreement with the health care team’s plan to withhold further treatment*).” (Emphasis added.)⁵⁴

A key part to dispute resolution is acknowledgement of the dispute. Once the dispute is acknowledged, the procedure states that the dispute resolution mechanism shall be activated as follows:

- a. operational leaders, including the responsible administrative leader and the accountable leader, shall be informed and consulted;
- b. the AHS Health Law Team shall be informed and consulted;
- c. Physicians involved in the care of the patient are strongly encouraged to consult the CMPA [Canadian Medical Protective Association] for guidance;
- d. and the Critical Care Physician shall ensure the AHS Dispute Prevention and Resolution Procedure Checklist is initiated, if not already in progress.⁵⁵

⁵⁰ Ibid., Pg. 6-7, Sect. 3.8.e

⁵¹ Ibid., Pg. 8, Sect. 3.10.d

⁵² DISPUTE PREVENTION AND RESOLUTION IN CLINICAL SETTINGS procedure PRR-03-01, Pg. 5, Sect. 2.2

⁵³ Ibid., Pg. 7, Sect. 2.6

⁵⁴ Ibid., Pg. 7, Sect. 3.1.b-c

⁵⁵ Ibid., Pg. 8, Sect. 3.2

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Following acknowledgement of a dispute, the formal AHS process for dispute resolution includes, but is not limited to the following processes;

- a. Negotiation: The Critical Care Physician or MRHP or designated members of the health care team should attempt to negotiate a plan of treatment that is *acceptable to the patient / alternate decision-maker(s)* and the health care team who are actively involved in the patient's care.
- b. *Second opinion: If not already undertaken, the patient / alternate decision-maker(s) should be given the opportunity to request an additional opinion and AHS shall take all reasonable steps to facilitate one.*
 - i. A range of options should be provided along with the constraints and challenges associated with each option.
 - ii. The range of consultation could extend from a medical subspecialty or a second Critical Care Physician, *to medical opinions from another institution outside the Zone or province.*
 - iii. The Critical Care Physician or MRHP and the patient / alternate decision-maker(s) should decide, *based on consensus*, what would be most appropriate. Their decision should be based on content expertise required, clinical scenario, perceived need for objectivity, risks of transporting the patient and timeliness.
 - iv. The consultation should be based on direct assessment of the patient and *review of the relevant investigations and other data*, and documented in the patient's health record.
 - v. The patient / alternate decision-maker(s) should also be provided with a copy of pertinent information from the health record to facilitate a second opinion. (Emphasis added.)⁵⁶

Despite steps taken during the dispute prevention and resolution processes, the health care team and the patient / alternate decision makers may find themselves in situations of impasse. The following procedure is given by AHS;

Where the above procedural steps have been followed, and there is an impasse at which treatment or interventions requested by the patient / alternate decisionmaker(s) are considered by the health care team to be harmful, futile, not clinically indicated or not in the patient's best interests, and does not agree with the MRHP's determination of appropriate treatment options, or the patient / alternate decision-maker(s) wishes treatment which AHS does not offer/provide, the Critical Care Physician shall proceed as follows:

- a. Together with the health care team and in consultation with the AHS Health Law Team, ensure that appropriate steps in this Procedure have been undertaken by completing the AHS Dispute Prevention and Resolution Procedure Checklist.

⁵⁶ Ibid., Pg. 9-10, Sect. 3.5

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- b. *The Critical Care Physician or MRHP shall develop a proposed treatment plan in consultation with the unit Medical Director and the unit Patient Care Manager. The unit Medical Director and the unit Director / Executive Director will notify relevant senior leadership as identified in the Checklist for the purpose of information and consultation. These stakeholders include the relevant facility and Zone physician and administrative leads. It is the responsibility of each level of leadership to ensure that their senior lead is informed and consulted as appropriate.*
- c. *The Facility Medical Director, in consultation with the relevant stakeholders including the Zone Medical Lead, shall prepare the Checklist and the proposed treatment plan as recommended by the Critical Care Physician or MRHP, which may be accompanied by a briefing note. This package will require sign-off by the Zone Medical Lead and AHS Health Law Team.*
- d. *The AHS Dispute Prevention and Resolution Procedure Checklist, proposed treatment plan and briefing note (as applicable), collectively the “package”, is then forwarded to the Chief Medical Officer. The Chief Medical Officer will review the package, consider whether actions taken align with AHS values and the objectives and standards set by the Policy and Procedure. Having assessed the package, the Chief Medical Officer shall proceed as follows:*
 - i. *inform the AHS executive, and other AHS stakeholders as appropriate, of the circumstances and the intention to change the patient’s care in accordance with the Critical Care Physician or MRHP’s assessment of appropriate treatment; and*
 - ii. *inform the Critical Care Physician or MRHP of AHS’ support and any additional recommended actions for their consideration and decision to proceed with the proposed treatment plan.*
- e. *Once the above steps have been completed, in consultation with the AHS Health Law Team, the Critical Care Physician or MRHP informs the patient / alternate decision-maker(s) and/or family of the intent to pursue the proposed treatment plan and provides the patient / alternate decisionmaker(s) and/or family with written reasonable advance notice of when the treatment plan will be implemented.*
 - i. *The notice above shall include a statement that the patient / alternate decision-maker(s) and/or family are entitled to seek legal advice.*
 - ii. *Once the notice period has expired and if no legal proceedings have been initiated by the patient / alternate decision-maker(s) and/or family, the consulting Critical Care Physician or MRHP and the health care team may, in appropriate circumstances, proceed with the treatment plan after obtaining legal advice (e.g., from AHS Health Law Team and CMPA). (Emphasis added.)⁵⁷*

⁵⁷ Ibid., Pg. 9-10, Sect. 3.8

ONTARIO

As does AHS, Critical Care Services Ontario (CCSO) publishes procedural documents outlining expectations and guidance for patient care. This section will review several CCSO procedural documents pertaining to neonatology, focusing on how CCSO recommends care for extremely premature neonates, around the 21-23 week gestational age. The CCSO documents reviewed in this section are the following: *Practice Standards for Neonatal Nursing in Ontario*,⁵⁸ *Neonatal Critical Care Indicator and Reports Guide*,⁵⁹ and *Neonatal Intensive Care Unit (NICU) Levels of Care*.⁶⁰

Unlike AHS, CCSO formally and fully defines each NICU level by type of care provided. The CCSO *Practice Standards for Neonatal Nursing in Ontario*, “have been developed to identify optimal neonatal nursing knowledge, skills, and competencies with the intent to establish a common standard for neonatal nursing practice within the province of Ontario.”⁶¹ For comparison to AHS’ categorization of preterm birth by NICU transfer recommendations, only CCSO’s NICU definitions pertaining to gestational age are included here. These standards of care define a Level 2a Neonatal Unit as one for the “provision of care to infants with a gestational age greater than or equal to 34 weeks and 0 days and birth weight greater than 1800 grams.” A Level 2b Neonatal Unit is for “infants with a gestational age of greater than or equal to 32 weeks and 0 days and birth weight greater than 1500 grams.” A Level 2c Neonatal Unit is for “infants with a gestational age greater than or equal to 30 weeks 0 days and birth weight of greater than 1200 grams.” And most important to our discussion, a Level 3a Neonatal unit is one “capable of providing the highest level of service to meet the needs of infants of *any gestational age or weight*.” (Emphasis added.) A Level 3b Neonatal Unit has the “same criteria as Level 3a but includes on-site surgical capabilities.”⁶²

The CCSO *Neonatal Critical Care Indicator and Reports Guide* provides the following NICU levels of care definitions; Level 3a and 3b Acute Care Criteria is for, “Babies born of any gestational age and birth weight.”⁶³ For a more detailed description of NICU levels, health care practitioners are directed to CCSO’s *Neonatal Intensive Care Unit (NICU) Levels of Care* guidance document.

⁵⁸ CCSO. (2021). *Practice Standards for Neonatal Nursing in Ontario*.

https://criticalcareontario.ca/wp-content/uploads/2022/03/Neonatal-Nursing-Practice-Standards_Final.pdf

⁵⁹ CCSO. (2022). *Neonatal Critical Care Indicator and Reports Guide*.

<https://criticalcareontario.ca/wp-content/uploads/2022/02/Neonatal-Critical-Care-Indicator-User-Guide-Version-1.0.pdf>

⁶⁰ CCSO. (2021). *Neonatal Intensive Care Unit (NICU) Levels of Care*.

https://criticalcareontario.ca/wp-content/uploads/2021/10/NICU-Levels-of-Care-Update_Guidance-Documents_FINAL-2021.pdf

⁶¹ *Practice Standards for Neonatal Nursing in Ontario*, Pg. 4

⁶² *Ibid.*, Pg. 24

⁶³ *Neonatal Critical Care Indicator and Reports Guide*, Pg. 25

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The purpose of CCSO’s *Neonatal Intensive Care Unit (NICU) Levels of Care* guidance document is to “outline the expected service level of care to be provided to neonates based on a NICU’s level of care.”⁶⁴ The following table is produced as the “required standard criteria for [level 3a and 3b] NICUs”:

Standard Treatment – Additional for Level 3a and 3b NICUs		
Acute Care Criteria: Babies born of any gestational age and birth weight		
Criteria	Detail Criteria	Availability
Amplitude integrated Electroencephalography (aEEG)		24/365
Echocardiography		24/365 or available within 30 minutes via on call
Unstable respiratory and cardiovascular systems	Long term management of high acuity infants and medically complex and fragile infants	24/365
Ventilation	All modalities, unlimited duration	24/365
Optional for 3a: Management of babies with Hypoxic Ischemic Encephalopathy (HIE) with the use of an active thermal device	Laboratory analysis	24/365
Pathology		
Additional Requirements Level 3b (optional for Level 3a)		
Management of babies with Hypoxic Ischemic Encephalopathy (HIE) with the use of an active thermal device		
Continuous EEG capabilities	Available within 12-24 hours	
On-site surgical and/or sub-specialty capabilities	24/365 or available on call within 30 minutes	

Table 7. Obtained from [Neonatal Intensive Care Unit \(NICU\) Levels of Care](#), Pg 13

In addition to CCSO’s guidance documents, the Provincial Council for Maternal and Child Health (PCMCH) has also released *Standardized Maternal and Newborn Levels of Care Definitions*.⁶⁵ PCMCH was created by the Ontario Ministry of Health and Long-Term Care (MOHLTC). Its mandate “is to provide evidence-based and strategic leadership for reproductive, neonatal and paediatric health services in Ontario.”⁶⁶ This PCMCH document stipulates that, “These definitions and the supporting service and human resource documents *represent minimum expectations* for each category unless otherwise specified. It is expected that maternal and newborn levels are aligned i.e. the levels are the same within each

⁶⁴ [Neonatal Intensive Care Unit \(NICU\) Levels of Care](#), Pg. 6

⁶⁵ PCMCH. (2013). *Standardized Maternal and Newborn Levels of Care Definitions*. <https://www.pcmch.on.ca/wp-content/uploads/2022/04/2013-Mat-Neo-Level-of-Care-Guidance-Document-with-Notev2.pdf>

⁶⁶ See, <https://www.pcmch.on.ca/about-us/>

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organization so that infants are not, by design, being delivered in organizations that do not have the staff, expertise and equipment to manage their care requirements.” (Emphasis added.)^{67 68}

PCMCH published the following tables defining maternal and newborn levels of care. Notice that in Table 8, the newborn care criteria for NICU Levels IIIa and IIIb is “any gestational age or weight.” In Table 9, which outlines the minimum standard type of newborn treatment, neonates admitted into NICU Levels IIIa and IIIb, are prescribed the same minimum care as other gestational groups. This is also the case concerning prescribed minimum care diagnostic tests and human resources for neonates across gestational groups:

Gestational Age	Maternal Care	Newborn Care	
Level III	Level III	Level IIIa	Level IIIb
ANY GESTATIONAL AGE OR WEIGHT	Care as above PLUS:	Care as above PLUS:	As in IIIa PLUS:
	<ul style="list-style-type: none"> High Risk maternal and/or neonatal (newborn care requirements must be within the scope of the newborn program services and resources). High maternal risk and/or complex medical, surgical and/or obstetrical complications requiring complex multidisciplinary and subspecialty critical care at any gestational age. High fetal risk complications such as diagnosis of congenital malformations that require access to: <ul style="list-style-type: none"> special fetal diagnostic or therapeutic procedures paediatric subspecialty consultation or care neonatal surgical services Neonatal intensive care services as per Neonatal Scopes of Services document. On-site adult intensive care unit services available to accept transfer and care of unstable parturients. 	<ul style="list-style-type: none"> Any gestational age or weight. Mechanical ventilation support including high frequency, and possibly inhaled nitric oxide, for as long as required. Timely access to a comprehensive range of subspecialty consultants. 	<ul style="list-style-type: none"> On site surgical capability.

Table 8. Obtained from PCMCH’s Standardized Maternal and Newborn Levels of Care Definitions, Pg. 7

⁶⁷ Standardized Maternal and Newborn Levels of Care Definitions, Pg. 2

⁶⁸ See note at beginning of document “February 15, 2022 Please Note: Critical Care Services Ontario (CCSO) has recently revised definitions and criteria related to NICU Levels 2 & 3. Please visit CCSO’s website to download the *Neonatal Intensive Care Unit (NICU) Levels of Care Guidance Document*. In this case, please note that the definitions and criteria related to Newborn Levels of Care for Levels 2 & 3 within PCMCH’s Standardized Maternal and Newborn Levels of Care Definitions are no longer applicable.” The *Neonatal Intensive Care Unit (NICU) Levels of Care Guidance Document* is the document reviewed just prior to the PCMCH document, NICU Level 3 still formally includes care for “babies born of any gestational age and birth weight.”

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Type of Treatment	Newborn						
	Level I	Level IIa	Level IIb	Level IIc	Level IIIa	Level IIIb	Accessibility
Minimum Standard							
Treatment							
Gavage feeding	NO	YES	YES	YES	YES	YES	
Lumbar puncture	NO	YES	YES	YES	YES	YES	
Phototherapy	YES	YES	YES	YES	YES	YES	
Short term O ₂ stabilization	YES	YES	YES	YES	YES	YES	
Long term O ₂ therapy - convalescent	NO	YES	YES	YES	YES	YES	
Continuous positive airway pressure management	NO	NO	YES	YES	YES	YES	
Endotracheal intubation (prior to transfer)	YES	YES	YES	N/A	N/A	N/A	
Ventilation support < 24 hours	NO	NO	YES	YES	YES	YES	
Ventilation support < 7 days	NO	NO	NO	YES	YES	YES	
Ventilation support unlimited	NO	NO	NO	NO	YES	YES	
Administration of surfactant (prior to transfer)	NO	YES	YES	YES	YES	YES	
Drainage of pneumothorax prior to transfer	YES	YES	YES	YES	YES	YES	
Chest tube initiation and maintenance	NO	NO	NO	YES	YES	YES	
Short term IV stabilization	YES	YES	YES	YES	YES	YES	
Long term IV therapy (greater than 1 week)	NO	NO	YES	YES	YES	YES	
Catheterization of umbilical vein and/or artery	YES	YES	YES	YES	YES	YES	
Umbilical central line maintenance	NO	NO	YES	YES	YES	YES	
Percutaneous IV central line maintenance	NO	NO	YES	YES	YES	YES	
PICC line insertion	NO	NO	NO	YES - timely access	YES	YES	
Arterial puncture	NO	NO	YES	YES	YES	YES	
Administer blood products	YES - prior to transfer	YES	YES	YES	YES	YES	
TPN	NO	NO	YES	YES	YES	YES	
Full range of non-invasive and invasive procedures/treatments/monitoring for tertiary care	NO	NO	NO	NO	YES	YES	
Infant surgery	NO	NO	NO	NO	NO	YES	
Neonatal Follow-Up	NO	NO	NO	YES - access	YES	YES	

Table 9. Obtained from PCMCH's Standardized Maternal and Newborn Levels of Care Definitions, Pg. 11

The final document reviewed in this section is the *Newborn Screening Manual: A Guide for Newborn Care Providers*.⁶⁹ This manual was created by Newborn Screening Ontario (NSO). The NSO Advisory Council is an “independent advisory body of health and other professionals with expertise in newborn and childhood screening with a mandate to advise the MOHLTC [Ministry of Health and Long-Term Care] and NSO on its policies and programs related to newborn and childhood screening.”⁷⁰ NSO is funded by the Government of Ontario.⁷¹ This manual is “a comprehensive guide for submitting institutions and health care providers (HCPs) to ensure that all infants born in Ontario have high quality newborn screening completed. This manual outlines recommended practices in newborn screening, along

⁶⁹ NSO. (2018). *Newborn Screening Manual: A Guide for Newborn Care Providers*.

[https://www.newbornscreening.on.ca/sites/default/files/newborn screening manual 2018 - web.pdf](https://www.newbornscreening.on.ca/sites/default/files/newborn%20screening%20manual%202018%20-%20web.pdf)

⁷⁰ *Newborn Screening Manual*, Pg. 5

⁷¹ See, <https://www.newbornscreening.on.ca/en/about-nso/privacy-and-confidentiality>

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with common challenges and solutions.”⁷² It stipulates that, “Premature infants ≥ 33 WGA and ≥ 1500 g should NOT be treated differently than term infants.” (Emphasis added.)⁷³

While extremely preterm births around the 22-week mark are rare, procedures and minimum care prescriptions published by Ontario’s MOHLTC and CCSO have resulted in success and survival stories for those neonates. As does Alberta, Ontario divides its hospitals into standardized tiers. According to Ontario’s Tiers of Maternal and Neonatal Service, a Level 3 Hospital is one that provides maternal care including “subspecialty *critical care at any gestational age*,” and “*neonatal intensive care for any gestational age and birth weight*; availability of timely access to subspecialty consultants.” (Emphasis added.)⁷⁴ The following table shows a subgroup of Tier 3 Hospitals⁷⁵ with reported cases of surviving extremely premature neonates:⁷⁶

Ontario Tier 3 Hospitals	Gestational Age of Neonate	Date (resp.)
Hamilton Hs McMaster U Med C	22 0/7	Sept 2019
London Health Sciences Centre	22 2/7	Sept 2018
Sinai Hlth Sys Mount Sinai Hosp	22 5/7, 22 4/7	May 2018, Nov 2021
Sunnybrook Hsc Sunnybrook C	22 5/7	Jan 2015
The Ottawa Hospital General C	22 6/7	-

⁷² Newborn Screening Manual, Pg. 2

⁷³ Ibid., Pg. 17

⁷⁴ CIHR. (2020). *Summary of the Tiers of Obstetric and Neonatal Service in Canadian Hospitals*. <https://med-fom-phsr-obgyn.sites.olt.ubc.ca/files/2021/03/TOSSummaryJune2020.pdf>. Pg. 18

⁷⁵ Ibid., Pg. 21

⁷⁶ Cases of surviving neonate can be found here:

https://www.google.com/maps/d/u/0/viewer?mid=1hbK8cpS_EIS_q-q4H29qGK_f1ay2g6oJ&ll=40.771547885818315%2C-101.39102249897594&z=5

UNITED STATES

The United States has robust safeguards in place across health jurisdictions for extremely premature neonates. (More on this will be discussed in “The Law” section.) There are many examples of neonates born around 22 weeks gestation surviving.⁷⁷ Dr. Edward Bell, a renowned neonatologist and specialist on care for preemies and micro-preemies, from the University of Iowa, started the Tiniest Babies Registry.⁷⁸ “Because the survival of infants with birth weights less than 400 grams (14.1 ounces) is very uncommon, it is not possible for meaningful data on the outcomes of these infants to be collected in a single neonatal intensive care unit (NICU) or even a network of NICUs. [The purpose of the Tiniest Babies Registry] to collect and collate [world-wide] data on the long-term health, growth, and development of this vulnerable group of infants.”⁷⁹ The database includes three cases of neonates born at 21 weeks;

Name	Year	Location	Birth Weight	Gestational Age
Tantivit	2006	Miami, Fla.	284g	21 weeks
Tatum	2019	Decatur, Ga.	370g	21 weeks
Kern	2020	Minneapolis, Minn.	340g	21 weeks

Gestational age is not the only indicator of extreme prematurity. The database includes 27 cases of neonates born under 10oz (283.5g), and 66 cases of neonates born under 11oz (311.8g). There are 26 cases of neonates born at 22 weeks, the average birth weight of these 22-weekers is 347.7g. Birth weight does not always correlate with gestational age. This database provides many examples of the survival of extremely small neonates, not based on gestational age alone, but also by birth weight.

The University of Iowa Stead Family Children’s Hospital, where Dr. Bell practices and teaches neonatology, “is home to a Level 4 NICU—the highest level recognized by the American Academy of Pediatrics. This means that [this] NICU is equipped to care for the tiniest and most critically ill babies, offering the greatest range of neonatal services and support.” The UI Stead Family Children’s Hospital is one of the top neonatal intensive care providers in the world, their survival rates for neonates born at 22-25 weeks are significantly higher than survival rates for extremely premature neonates born at other

⁷⁷ Ibid.

⁷⁸ See,

<https://webapps1.healthcare.uiowa.edu/TiniestBabies/index.aspx?qa=2.126716749.1926579428.1647111560-2026519896.1647111560>

⁷⁹ Tiniest Babies Registry, Note, “The infants listed in this registry include those reported in the lay media as well as medical journals. The registry also includes infants submitted directly to the registry by the patient or a family member with verification by a health provider. In addition, some infants are submitted directly by the health provider. We have not attempted to verify the information listed, since in most cases this would not be possible.”

Current Practice: Other Jurisdictions

United States

hospitals in the United States.⁸⁰ “A team from the University of Iowa recently published a paper in the *Journal of Pediatrics*...reported that 70% of babies born at 22 weeks over a 10-year period at UI Hospitals and Clinics survived.”^{81 82}

The UI team claims that, “One reason so many premature and ill babies survive and thrive at UI Stead Family Children’s Hospital is the culture of collaboration. Specially-trained doctors, nurses, respiratory therapists, nutritionists, social workers, pharmacists, lab technicians, physical therapists, and more—all with expertise in neonatology—work together to provide the most advanced care for every family.”⁸³ Dr. Bell claims the following;

When a preterm baby is born at UI Stead Family Children’s Hospital, obstetrical and neonatal care specialists—some having monitored mother and child for months in advance—know exactly how to respond. Their expertise is key to why a remarkable number of fragile infants are not only surviving but thriving... In an interview with *The New York Times* about 20 years ago, I said that 24 weeks was the youngest baby we could save, and I didn’t foresee being able to save babies born any earlier because of the rate at which the lungs develop... I’m happy to say I was wrong; I don’t like to make predictions about what we can’t do because so often ‘can’t’ turns into ‘can.’⁸⁴

Dr. Bell has become an important figure in the care of extremely premature neonates. The NICU and team at the UI Stead Family Children’s Hospital has become the gold standard in the United States for the care of these tiny babies.

While the UI Hospital is renowned for its NICU, there are hospitals throughout the United States that are reported to successfully care for extremely premature neonates.⁸⁵ This includes the University of South Alabama Children’s and Women’s Hospital, which has an advanced NICU, where they have “helped really small babies, born at 21 or 22 weeks, for more than two decades... [and at this NICU, for] preemies that age, the survival rate at the hospital is about 68 percent.”⁸⁶ As well, the USA Health Children’s & Women’s Hospital NICU in Alabama has a small baby unit. “The small baby unit is one of only nine in the United States and the only one caring for micro-preemies along the upper Gulf Coast... Separated from the rest of the NICU, the unit can accommodate up to 22 newborns... The survival rate for babies born at 22 weeks during the same time period at Children’s & Women’s Hospital was just under 70 percent.”⁸⁷

⁸⁰ [Neonatology | University of Iowa Stead Family Children's Hospital](#)

⁸¹ [New normal in neonatology | University of Iowa Stead Family Children's Hospital](#)

⁸² [15 questions you should ask about neonatal intensive care units](#)

⁸³ [UI Neonatology](#)

⁸⁴ [UI New normal in neonatology](#)

⁸⁵ Cases of surviving neonate can be found [here](#).

⁸⁶ [This preemie was born at less than a pound. He just ‘graduated’ from intensive care in a cap and gown. - The Washington Post](#)

⁸⁷ [Children's & Women's Hospital opens small baby unit for infants born at 28 weeks or younger | USA Health](#)

DISCUSSION OF CURRENT PRACTICE

Throughout AHS policy and procedural documents relating to the care of premature neonates, we notice three trends relevant to this project. First, there is the general absence of content surrounding neonates born before 23 weeks; second, when neonates born prior to the 23-week mark are mentioned, AHS guidelines recommend a non-interventional approach to care; and third, is generally how viability is defined in AHS documents.

There are very few mentions of neonates born before 23 weeks. In the AHS *Obstetrical Triage Acuity Scale (OTAS)* guideline, transfer recommendations are made for “obstetrical patients, who are greater than or equal to twenty weeks gestational age,” however, this transfer protocol is provided for obstetrical care, and does not make mention of neonatal care. Neonates born at 22 weeks gestational age are mentioned once in AHS’ *Criteria to Support Appropriate Level of Obstetrical Care*, which uses the gestational age of 22 0/7 as the lower limit of what defines “early preterm birth,” and the lower limit of what constitutes a transfer recommendation to a Level III NICU. This document alone mentions care for neonates born prior to the 23-week mark. However, in AHS’ *Clinical Assessment of ‘At Risk’ or Actual Preterm Labor for Triage*, the lower limit of what constitutes a transfer recommendation to a Level III NICU is 23 0/7 gestational age. Algorithms provided in this document for risk of preterm birth note only to “discuss” a course of action if the gestational age is less than 23 weeks. In all other AHS documents, the discussion surrounding neonatal care recommendations begins at 23 weeks gestational age.

Another recurring directive throughout AHS procedures pertaining to neonatal care is the recommendation of palliative care, or “a non-interventional approach” for neonates born before 23 weeks, or 22 6/7 completed weeks. In AHS’ *Clinical Assessment of ‘At Risk’ or Actual Preterm Labor for Triage*, the guideline goes as far as stating that, “The survival of infants born before or at 22 6/7 completed weeks of gestation remains uncommon.” This statement as fact informs the recommendation to only provide palliative care to neonates born earlier than this gestational threshold. The conditions appropriate for palliative care, as listed in *AHS Neonatal Palliative Care Guide for Neonatal Intensive Care Units*, include “extreme prematurity irrespective of additional risk factors.” With these care guidelines in mind, recall that compliance with AHS procedure is required by all AHS employees and volunteers. Regardless of the data supporting positive outcomes for neonates born before 23 weeks, AHS staff are recommended, and even directed not to resuscitate these infants.

This differs vastly from the other health jurisdictions we looked at, specifically in Ontario with CCSO. CCSO formally defines a Level III NICU as one able to “meet the needs of infants of any gestational age or weight.” This language, specifically referring to infants of any gestational age or weight is common throughout CCSO documents. In CCSO’s *Neonatal Intensive Care Unit (NICU) Levels of Care*, a standard treatment plan is provided for neonates in various windows of gestation. A specific acute care criteria for one such treatment plan is “babies born of any gestational age and birth weight.” There is

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Discussion

no gestational age limit for care provided. Some extremely premature neonates might very well be too small for active treatment, but CCSO documents do not set a specific limit on what defines a viable infant or when active treatment is not recommended. In the *Newborn Screening Manual: A Guide for Newborn Care Providers*, it states that, “Premature infants ≥ 33 WGA and ≥ 1500 g should NOT be treated differently than term infants.”

In AHS’ *Clinical Assessment of ‘At Risk’ or Actual Preterm Labor for Triage*, the guideline states that preterm birth between “23 0/7 weeks and 24 6/7 weeks of gestation with a birth weight of 500 to 599 grams” constitutes the “threshold of viability” with the “greatest uncertainty surrounding infant survival and outcome.” This procedural document makes the bioethical claim that, “The line between patient autonomy and medical futility is blurred.” In *AHS Neonatal Palliative Care Guide for Neonatal Intensive Care Units*, a condition listed as appropriate for palliative care is, “Life-threatening: [when] Treatment may be feasible but may not be successful: (e.g., extreme prematurity irrespective of additional risk factors).” If treatment that may be feasible but may not be successful defines a “life-threatening” condition, all extremely premature neonate would be recommended for palliative care, since treatment success rates are considerably below 100%. AHS documents place a high value on the infant’s quality of life. This same document states that, “Palliative care should be considered for an infant when it becomes apparent that treatment aimed at curing or prolonging life is leading to a significant reduction of an infant’s quality of life.” It also states that a condition suitable for palliative care is if the, “Burden of disease or treatment outweighs the benefits as perceived by the health care team including the family.” Since AHS defines “life-threatening” conditions so broadly, treats “quality of life” arbitrarily, and uses an unsubstantiated definition of “viability”, extremely premature neonates born in an AHS facility will not get a chance at life. If following the outlined procedures, treatment and care of an extremely premature newborn will be viewed as a burden outweighing their potential survival and chance at life. Since the line between patient autonomy and medical futility is blurred, AHS leaves significant leeway for health care providers to deny the treatment of extremely premature neonates. In this system, there are few considerations for the rights of the tiny patient and family, this is extremely obvious in AHS’ conflict resolution regulations.

Within AHS jurisdiction, if a patient — or in the context of this project, the alternate decision makers, the family of the infant — disagrees with AHS staff on their refusal to provide active care to their child born prior to 23 weeks, a procedure on conflict resolution is in place. Unfortunately for the family of the infant, the resolution process in situations of impasse favours the decisions of health care providers, and leaves them with little opportunity for recourse, especially in time sensitive situations, which all preterm births would be.

AHS’ *Complex and Essential Pediatric Medical Process* guidelines state that in attempts to resolve conflict over a treatment plan, “External second opinions should be considered to help determine best practice, any other clinical recommendations and any resulting harm to the child given the clinical scenario.” Where conflict is not resolved, a Joint Advisory Group should be initiated, which, “should include at a minimum, medical representatives, Site Administration, Children Services (CS), and Clinical

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Ethics.” Part of the dispute resolution process is to inform the AHS Health Law Team, “AHS shall take all reasonable steps to facilitate” a second opinion, and to consult “medical opinions from another institution outside the Zone or province.” Decisions should be made “based on consensus” and with “review of the relevant investigations and other data.”

In situations of impasse, a process is initiated which, as reviewed, can be summed up as the following: the MRHP writes up a recommended treatment plan and sends it up the AHS administrative/medical structure, involving the unit Medical Director, the unit Patient Care Manager, the unit Director/Executive Director, the relevant senior leadership and stakeholders including the relevant facility and Zone physician and administrative leads, the Facility Medical Director, the Zone Medical Lead, the AHS Health Law Team, the Chief Medical Officer, the AHS Executive and other AHS stakeholders. Once the Chief Medical Officer has determined if the treatment plan “actions taken align with AHS values and the objectives and standards set by the Policy and Procedure,” the Officer will inform the MRHP of AHS’ support for the treatment plan and decision to proceed with it. At this point, a notice is given to the patient and family, and they are entitled to seek legal advice. If no legal proceedings are initiated by the patient or the patient’s family, the MRHP may proceed with the treatment plan.

Specifically in the context of this project, all this means that if a child is born at 21 or 22 weeks in Alberta, health care providers are almost certainly going to deny active treatment for that child. Premature birth is an extremely time sensitive situation, active care for the extremely premature neonate must be initiated immediately after birth. If the parents disagree with the AHS health care team's decision to deny active treatment for their child born before 23 weeks, there is realistically no time to follow the AHS dispute prevention or resolution process. All recommendations made by AHS to avoid disputes in these cases must be done prior to birth. The dispute resolution process must be initiated and completed prior to birth. In situations of impasse, after the birth of the child and before active treatment must be initiated, there is no time for the family of the infant to seek out and initiate legal proceedings. This would mean that once the MRHP signs off on a treatment plan — in this case, palliative care, or the refusal to initiate active care — the family has no possible resource for their child.

In the following section, factors which ought to inform policy changes will be discussed. Recommendations will be made on how AHS policy and procedure ought to change to reflect the existing data and considerations relevant to this project.



INFORMING POLICY

THE RESEARCH ON VIABILITY

This section will review the published research surrounding extremely preterm births. The publications reviewed in this section were chosen for their comprehensiveness and relevance to the gestational window focused on in this paper, or for their relevance to previously reviewed policy. The purpose of this section is to inform the reader of the most comprehensive periviable birth data in light of what has been previously discussed. This section is meant to provide a strong basis for discussions surrounding changes to NICU procedures if the existing procedures are not supported by the data.

The first article reviewed is *Perivable Birth*,⁸⁸ jointly developed as a consensus statement by the American College of Obstetricians and Gynecologists (ACOG) and the Society for Maternal–Fetal Medicine. This article is listed as a key reference for AHS’ NICU procedure and policy, referred to in AHS documents as “ACOG Obstetric Care Consensus.”⁸⁹ It is important to understand the potential for discrepancies in the research on this subject. The authors of *Perivable Birth* provide the following clinical considerations;

It is important to realize that outcomes that have been reported in the medical literature may have some biases because of a variety of factors, including study inclusion criteria (eg, whether studies include all births or are limited to liveborn infants, non-anomalous newborns, liveborn resuscitated newborns, or neonatal intensive care unit (NICU) admissions only), variation in management between centers, and changes in NICU practices over time (eg, administration of antepartum steroids, resuscitative efforts, NICU admission criteria; ... In addition, a precise understanding of outcomes in survivors is further confounded by differing definitions of “major” and “minor” disabilities used in studies.⁹⁰

While biases in research will be discussed in further detail in the following section, this provides a brief precursor to the literature review here. This article provides the following table in summary;

⁸⁸ American College of Obstetricians and Gynecologists, & Society for Maternal-Fetal Medicine (2017). Obstetric Care consensus No. 6: Perivable Birth. *Obstetrics and gynecology*, 130(4), e187–e199. <https://doi.org/10.1097/AOG.0000000000002352>

⁸⁹ See, Reference 2 in [Key Reference Links - Supporting Document \(Clinical Assessment of 'At Risk' or Actual Preterm Labour for Triage guideline HC](#), and Reference 26 in [CLINICAL ASSESSMENT OF 'AT RISK' OR ACTUAL PRETERM LABOUR FOR TRIAGE guideline HCS-183-01](#). Note that in the latter case, they mistakenly call the article “Preivable Birth”.

⁹⁰ [Perivable Birth | ACOG](#)

Informing Policy: Viability and Biases

The Research on Viability

Variable	Effect
<i>Factors Affecting Reliability of Estimates of Probability of Clinical Outcomes</i>	
Data source	International, national, regional, and single-institution data reflect variations in regional and local practices.
Cohort selection	Exclusion of newborns not surviving to NICU admission results in inclusion of those with higher potential for survival and higher reported rates of survival. Inclusion of nonresuscitated infants or stillbirths reduces overall reported rates of survival. Inclusion of anomalous infants may decrease reported survival estimates.
Gestational age assignment	In vitro fertilization and ovulation induction provide accurate gestational age assignment. Dating by last menstrual period assumes accurate recollection of this date as well as conception on day 14. Ultrasonography initially performed at less than 24 weeks of gestation estimates gestational age within 5–14 days.*
<i>Factors Potentially Affecting Clinical Outcomes</i>	
Nonmodifiable risk factors	Race and ethnicity, plurality (singleton versus multiple gestation), infant sex, birth weight, gestational age
Modifiable obstetric practices	Antenatal interventions (eg, corticosteroids, tocolysis, antibiotics for preterm PROM, or magnesium for neuroprotection), site and mode of delivery
Modifiable neonatal practices	Initial resuscitation and subsequent care (eg, approaches to ventilation and oxygenation, nutritional support, and treatment of newborn infections)
Approaches to comfort care	Influenced by institutional and physician philosophies, parental wishes, and religious convictions
Regional/hospital legal and practice guidelines	Policies concerning neonatal resuscitation

Abbreviations: NICU, neonatal intensive care unit; PROM, premature rupture of membranes.

*Method for estimating due date. Committee Opinion No. 611. American College of Obstetricians and Gynecologists. *Obstet Gynecol* 2014;124:863–6.

Modified from Raju TN, Mercer BM, Burchfield DJ, Joseph GF Jr. 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;123:1083–96.

Table 10: Titled, “Factors That Affect the Reliability of Estimates of Survival or the Actual Outcomes Among Perivable Births.” Obtained from [Perivable Birth | ACOG](#)

There are many considerations one must have when reviewing data on perivable births. *Perivable Birth* provides the following explanation for why prediction models are not always reliable;

Prediction models for estimating neonatal outcomes after perivable birth were developed based on populations of neonates born during a given period, but as medical care advances, these models (if not updated based on more recent information) may not provide estimates with an accuracy equivalent to that initially reported. Prediction of outcome frequencies based on gestational age, birth weight, or both in combination with other predictors provides only a point estimate reflecting a population average and cannot predict with certainty the outcome for an individual newborn. Further, gestational age is a key component of any predictive model and may not be known accurately in all cases. Also, defining outcomes based on completed weeks arbitrarily eliminates the differences between a fetus at 23 0/7 weeks and one at 23 6/7 weeks of gestation as well as the similarities between a fetus at 23 6/7 weeks and one at 24 0/7 weeks of gestation. Furthermore, before delivery, newborn birth weight can only be estimated. The inherent inaccuracy of ultrasound-estimated fetal weight introduces a degree of uncertainty to the prediction of newborn outcomes. In addition, how parents weigh and value these potential outcomes (ie, death, degree of neurodevelopmental impairment) can vary widely, and individual values need to be incorporated into decision making. Finally, the response of an individual neonate to resuscitation can never be known with certainty before delivery.

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Thus, when a specific estimated probability for an outcome is offered, it should be stated clearly that this is an estimate for a population and not a prediction of a certain outcome for a particular patient in a given institution.⁹¹

These considerations should be kept in mind for the remainder of this section.

The authors of *Perivable Birth* provide recommendations for obstetric and pediatric resources that should be available in institutions that provide care for extremely preterm births. “Perivable infants do not survive without life-sustaining interventions immediately after delivery,” thus, “hospitals without the optimal resources for maternal, fetal, and neonatal care needed for perivable birth should have policies and procedures in place to facilitate timely transport to a receiving hospital.” The article notes that, “The American Academy of Pediatrics has stated that parents should be *given the choice for palliative care alongside the option to attempt resuscitation*. Clinicians should recognize that *parental goals of care may be oriented toward optimizing survival or minimizing pain and suffering* and should formulate an antenatal plan of care in accordance with these parental goals.” (Emphasis added.)⁹²

The following table outlines recommended care by gestational age. Recall that this article is a key reference for AHS NICU policies;

	20 0/7 weeks to 21 6/7 weeks	22 0/7 weeks to 22 6/7 weeks	23 0/7 weeks to 23 6/7 weeks	24 0/7 weeks to 24 6/7 weeks	25 0/7 weeks to 25 6/7 weeks
Neonatal assessment for resuscitation*	Not recommended 1A	Consider 2B	Consider 2B	Recommended 1B	Recommended 1B
Antenatal corticosteroids	Not recommended 1A	Not recommended 1A	Consider 2B	Recommended 1B	Recommended 1B
Tocolysis for preterm labor to allow for antenatal corticosteroid administration	Not recommended 1A	Not recommended 1A	Consider 2B	Recommended 1B	Recommended 1B
Magnesium sulfate for neuroprotection	Not recommended 1A	Not recommended 1A	Consider 2B	Recommended 1B	Recommended 1B
Antibiotics to prolong latency during expectant management of preterm PROM if delivery is not considered imminent	Consider 2C	Consider 2C	Consider 2B	Recommended 1B	Recommended 1B
Intrapartum antibiotics for group B streptococci prophylaxis [†]	Not recommended 1A	Not recommended 1A	Consider 2B	Recommended 1B	Recommended 1B
Cesarean delivery for fetal indication [‡]	Not recommended 1A	Not recommended 1A	Consider 2B	Consider 1B	Recommended 1B

Abbreviation: PROM, premature rupture of membranes.

*Survival of infants born in the perivable period is dependent on resuscitation and support. Between 22 weeks and 25 weeks of gestation, there may be factors in addition to gestational age that will affect the potential for survival and the determination of viability. Importantly, some families, concordant with their values and preferences, may choose to forgo such resuscitation and support. Many of the other decisions on this table will be linked to decisions regarding resuscitation and support and should be considered in that context.

[†]Group B streptococci carrier, or carrier status unknown

[‡]For example, persistently abnormal fetal heart rate patterns or biophysical testing, malpresentation

Table 11: Titled, “General Guidance Regarding Obstetric Interventions for Threatened and Imminent Perivable Birth by Best Estimate of Gestational Age.” Obtained from [Perivable Birth | ACOG](#)

⁹¹ Ibid.

⁹² Ibid.

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The *Canadian Neonatal Network Annual Report 2020*⁹³ which was reviewed earlier breaks down survival to discharge and the proportion of neonates who receive active care by both gestational age and birth weight. As can be seen in Table 12, at the gestational age of 22 weeks, only 28% of all neonates in the CNN in 2020 received active care in the delivery room, and 81% at 23 weeks. Of those neonates born at 22 weeks, 6% of all neonates and 22% of neonates who received intensive care survived. At 23 weeks, 38% of all neonates and 47% of neonates who received intensive care survived.

Table 13 shows us the same categories by birth weight. In 2020, there were only 13 neonates born with a birth weight of less than 400g, of which 46% received active care in the delivery room, and only 17% of those neonates who received intensive care survived. Due to the very low number of births in that weight category, the 400-499g range provides much more insight. In 2020 in the CNN, there were 70 neonates born in this weight category. Of those neonates born at 400-499g, 59% received active care in the delivery room. In this weight category, 33% of all neonates and 56% of neonates who received intensive care survived. At 500-599g, 81% of neonates received active care in the delivery room. In this weight category, 49% of all neonates and 60% of neonates who received intensive care survived.

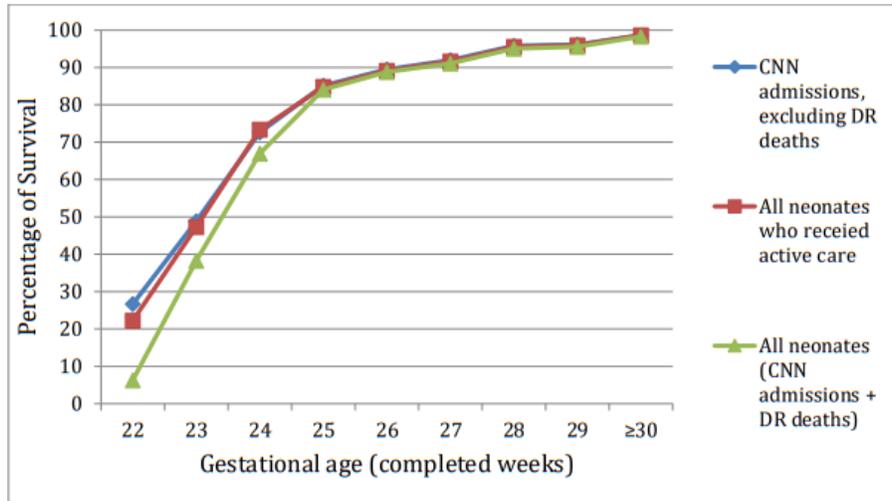
Birth weight is an important criterion to use and understand, for several reasons. As we saw in AHS NICU procedures, viability is often defined by both gestational age and birth weight. Gestational age alone does not determine whether active care is recommended or withheld; for example, twins can weigh significantly less than their singleton counterparts. In 2020, there were roughly the same number of neonates born at 22 weeks and neonates born in the 400-499g birth weight category (64 and 70, resp.). However, only 28% of the 22-weekers received active care, while 59% of those neonates born at 400-499g received active care. Since the CNN did not provide information on how these categories overlapped, or how many of the neonates in these categories are twins or singleton births, we don't know how many 23-weekers were small for gestational age and who received active care, or how many 22-weekers were large for gestational age but did not receive active care because of their gestational age. Neonates who are small for their gestational age (SGA) may just be small, but can also have developmental concerns, which would classify them as having fetal growth restriction (FGR). Among FGR SGA neonates, developmental concerns are not uniform,⁹⁴ and as such, there should be case specific decisions about whether to provide active care or palliative care in the delivery room. Regardless, this data is significant for our analysis of how current viability thresholds are defined.

⁹³ [Annual Report 2020 Rapport Annuel](#)

⁹⁴ [Small for Gestational Age - StatPearls - NCBI Bookshelf](#)

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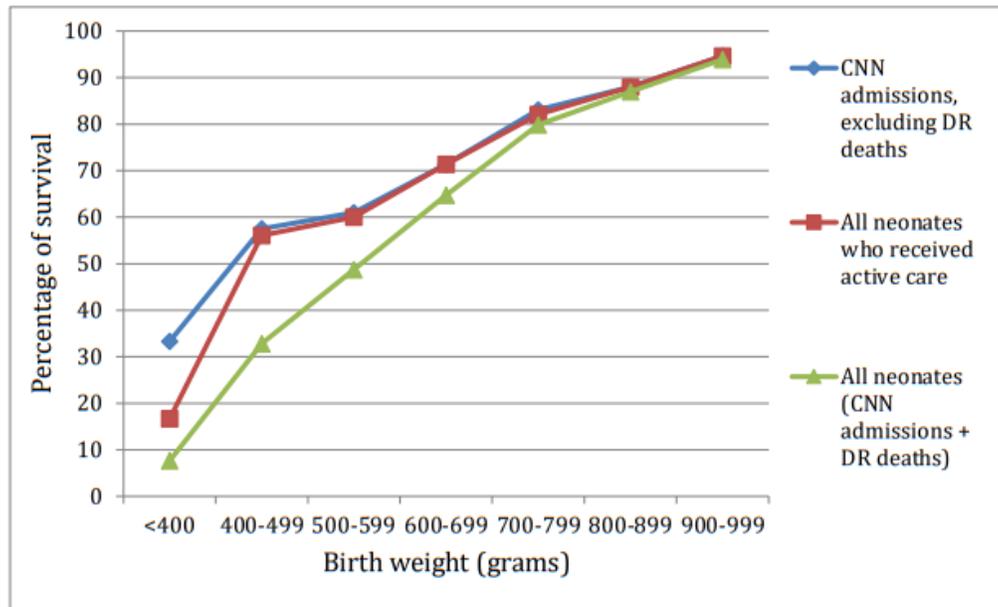
GA (completed weeks)	CNN admissions, excluding delivery room deaths				Delivery room deaths*		Total CNN admissions including delivery room deaths*				
	#of neonates	#of survivors	Percent survival among CNN admissions, excluding DR deaths	#of neonates who received comfort care	Palliative care	Active care **	Total	#of neonates who received comfort care	# of neonates who received active care**	Percent survival among those who received active care	Percent survival among all neonates (CNN admissions + DR deaths)
	<i>a</i>	<i>b</i>	<i>b/a</i>	<i>c</i>	<i>d</i>	<i>e</i>	<i>a+d+e</i>	<i>c+d</i>	<i>(a-c) +e</i>	<i>b/ (a-c)+e</i>	<i>b/(a+d+e)</i>
22	15	4	27	0	46	3	64	46	18	22	6
23	127	62	49	0	31	4	162	31	131	47	38
24	201	146	73	3	16	1	218	19	199	73	67
25	236	201	85	0	2	1	239	2	237	85	84
26	265	237	89	0	1	1	267	1	266	89	89
27	310	285	92	0	2	1	313	2	311	92	91
28	402	385	96	0	2	1	405	2	403	96	95
29	491	472	96	0	2	1	494	2	492	96	96
≥30	12 224	12 053	99	7	31	7	12 262	38	12 224	99	98
Total included	14 271	13 845	97	10	133	20	14 424	143	14 281	97	96
Missing GA	0				0	1	1	0	1		
Total	14 271				133	21	14 425	143	14 282		

*Please note that delivery room deaths are only included in Presentations #4, #6, and #6b in this report. **Active care refers to infants who received cardiopulmonary resuscitation at birth.

Table 12: Titled, “Survival to discharge by GA: All admissions, including delivery room (DR) deaths.” Obtained from *Annual Report 2020 Rapport Annuel*. Note, “The results should be used cautiously for antenatal counseling. The survival rates are based upon the final discharge from the participating neonatal site. Note that these rates include only neonates admitted to the sites or dying in the delivery rooms of participating sites and thus are not reflective of the entire Canadian population. Only one CNN site did not contribute delivery room death data.”

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CNN Admissions, excluding delivery room deaths					Delivery room deaths*		Total CNN admissions + Delivery room deaths*				
BW (grams)	Number of neonates	Number of survivors	Percent survival of CNN admissions, excluding DR deaths	Number of neonates who received palliative care	Palliative care	Active care**	Total	Number of neonates who received palliative care	Number of neonates who received active care**	Percent survival of neonates who received active care	Percent survival of all neonates (CNN admissions + DR deaths)
	<i>a</i>	<i>b</i>	<i>b/a</i>	<i>c</i>	<i>d</i>	<i>e</i>	<i>a+d+e</i>	<i>c+d</i>	<i>(a-c)+e</i>	<i>b/(a-c)+e</i>	<i>b/(a+d+e)</i>
<400	3	1	33	0	7	3	13	7	6	17	8
400-499	40	23	58	0	29	1	70	29	41	56	33
500-599	123	75	61	1	28	3	154	29	125	60	49
600-699	206	147	71	2	19	2	227	21	206	71	65
700-799	248	206	83	0	7	3	258	7	251	82	80
800-899	266	234	88	0	3	0	269	3	266	88	87
900-999	261	247	95	0	2	0	263	2	261	95	94
Total included	1 147	933	81	3	95	12	1 254	98	1 156	81	74

*Please note that delivery room deaths are only included in Presentations #4, #6 and #6b in this report. **Active care refers to infants who received cardiopulmonary resuscitation at birth.

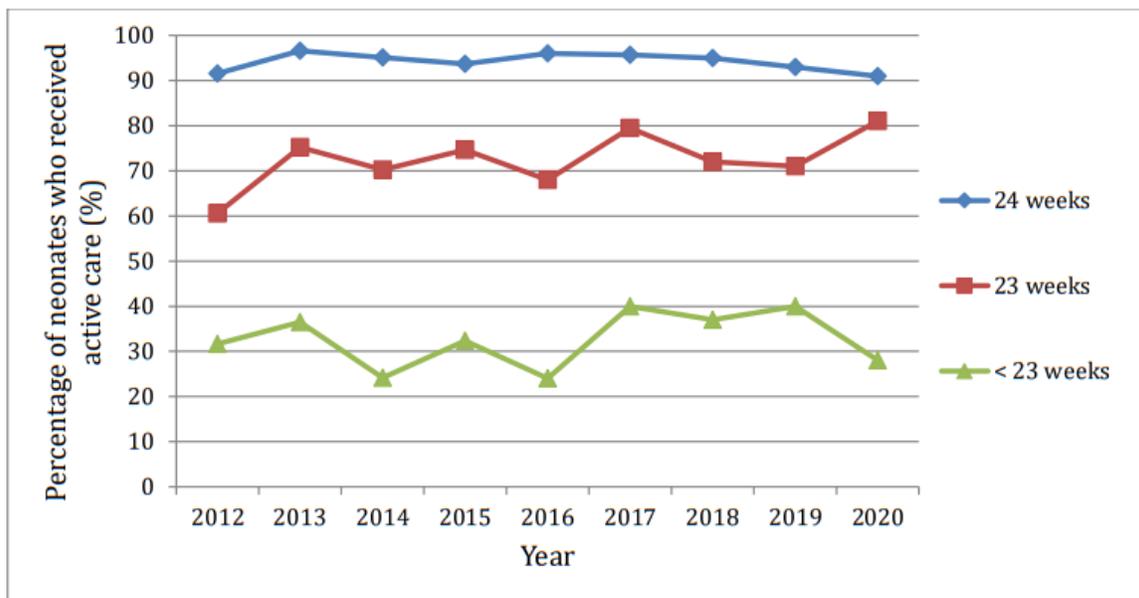
Table 13: Titled, "Survival to discharge by BW: BW <1000g including delivery room (DR) deaths." Obtained from [Annual Report 2020 Rapport Annuel](#). Note, "The results should be used cautiously for antenatal counseling. The survival rates are based upon the final discharge from the participating neonatal site. Note that these rates include only neonates admitted to the sites or died in delivery room of participating sites and thus are not reflective of the entire Canadian population. Only one CNN site did not contribute delivery room death data."

The following tables (Table 14 is a repeat of Table 4, and has been reviewed earlier) show trends over the past nine years for the proportion of neonates who received active care, and survival rates among those who were admitted to NICU. In Table 14, we see that in 2020, there have been fewer neonates born at less than 23 weeks who received active care than in the past four years. In Table 15, we also see a significant decrease over the past four years in the survival rate for neonates born at less than 23 weeks who were admitted to NICU. This four-year trend is surprising, as one would expect there to be an increase in or steady active care and survival rates with increases in technology and knowledge of extremely

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premature neonatology. As was mentioned earlier, one possibility for there being fewer neonates born prior to 23 weeks who received active care in 2020 than in the past four years is limited medical resources and ventilators due to the COVID-19 pandemic. However, this does not explain the results over *the past four years* as evident in these tables:



		2012	2013	2014	2015	2016	2017	2018	2019	2020
<23 weeks	Number of neonates who received active care $(a-c) + e$	25	23	14	22	16	26	35	35	18
	Total number of neonates including DR deaths $a+d+e$	79	63	58	68	67	65	95	88	64
	Percentage of neonates who received active care	32%	37%	24%	32%	24%	40%	37%	40%	28%
23 weeks	Number of neonates who received active care $(a-c) + e$	83	85	92	106	82	136	133	127	131
	Total number of neonates including DR deaths $a+d+e$	137	113	131	142	121	171	185	178	162
	Percentage of neonates who received active care	61%	75%	70%	75%	68%	80%	72%	71%	81%
24 weeks	Number of neonates who received active care $(a-c) + e$	185	200	233	178	217	221	224	224	199
	Total number of neonates including DR deaths $a+d+e$	202	207	245	190	227	231	235	240	218
	Percentage of neonates who received active care	92%	97%	95%	94%	96%	96%	95%	93%	91%

Table 14: Titled, “Proportion of neonates who received active care out of all (including delivery room (DR) deaths).” Obtained from [Annual Report 2020 Rapport Annuel](#). Note, “The alphabet notations used in the table above are carried from [Table 12 and 13]. Information should be interpreted with caution as not all sites provided data on delivery room deaths. Active care refers to infants who received cardiopulmonary resuscitation at birth.

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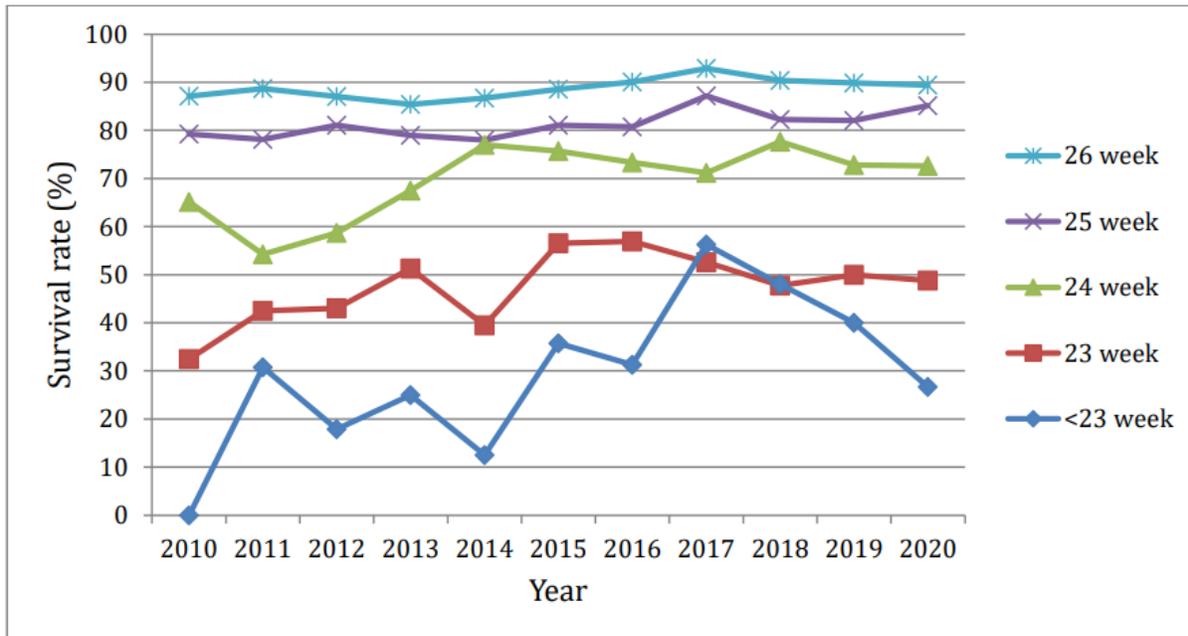


Table 15: Titled, “Survival rate among those who were admitted to NICU: 22-26 weeks’ GA.” Obtained from [Annual Report 2020 Rapport Annuel](#).

Renowned neonatologist, Dr. Bell, has collaborated on many research projects concerning outcomes of active treatment for extremely premature neonates. A 2019 study from a group of neonatologists in Iowa, which Dr. Bell contributed to is, *Outcomes at 18 to 22 Months of Corrected Age for Infants Born at 22 to 25 Weeks of Gestation in a Center Practicing Active Management*.⁹⁵ This paper studied “255 infants born at 22-25 weeks of gestation between 2006 and 2015 at a single study institution.” In the 22-23 weeks subgroup, “survival to hospital discharge of those surviving to NICU admission was 78%,” and, “no or mild neurodevelopmental impairment in surviving infants was 64%.”⁹⁶ While this study shows strong survival rates and outcomes, the subgroup of neonates born at 22 weeks gestational age was small, only including 24 infants. Of the 24, two neonates died before admission to the NICU, and by family decision two neonates were given palliative care. Thus, only 20 neonates at 22 weeks survived admission to the NICU, and of those, 14 neonates survived to hospital discharge. The type and frequency of morbidities for the 22-23 week group was not noticeably different from the 24-25 week group. At 18-24 months, 82% of the 22-week cohort had no, mild, or moderate neurodevelopmental impairments.⁹⁷

⁹⁵ Watkins, P. L., Dagle, J. M., Bell, E. F., & Colaizy, T. T. (2020). Outcomes at 18 to 22 Months of Corrected Age for Infants Born at 22 to 25 Weeks of Gestation in a Center Practicing Active Management. *The Journal of pediatrics*, 217, 52–58.e1. <https://doi.org/10.1016/j.jpeds.2019.08.028>

⁹⁶ Ibid.

⁹⁷ Ibid.

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An 11-year study at the Children's and Women's Hospital of South Alabama Level III NICU, titled, *The Limit of Viability: A Single Regional Unit's Experience*,⁹⁸ shows an increase in survival rates for these tiny babies. This study included 841 extremely premature neonates (BW \leq 1000g and 22 0/7 to 26 weeks), born alive at this unit from January 1998 to December 2008, “Infants who died in the delivery room (DR), with or without resuscitative efforts, were also included.”⁹⁹ This study reported the following:

In the past decade, survival rates continued to increase while neurodevelopmental impairment rates in the extremely preterm infant decreased. From epoch 1 [January 1, 1998, through June 30, 2003] to epoch 2 [July 1, 2003, through December 31, 2008], the increase in survival rate occurred in infants born at 22 weeks' estimated GA, from 20% to 40%, while the decrease in neurodevelopmental impairment (54% to 28%) and severe neurodevelopmental impairment (35% to 8%) occurred in infants born at 23 to 24 weeks' estimated GA.¹⁰⁰

The survival rate in this study is defined as survival to NICU discharge. The authors of this study, Zayek et al., acknowledge that while other studies have found positive outcomes rare for neonates born weighing less than 500g, their study found an increase in survival rates for infants born at 22 weeks or weighing less than 500g. Zayek et al. conclude that, “The striking disparity with our survival rate among the very immature ELBWIs [extremely low-birth-weight infants] suggests either differences in management and outcome among neonatal centers or a trend toward continued improvement in survival beyond the 1990s.”¹⁰¹

These two single-institution studies report exceptionally positive outcomes for extremely premature neonates. Recall from earlier that the NICUs involved in these studies are renowned for their advanced NICU facilities and expertise. However, a broader perspective of outcomes for extremely premature neonates is required for thorough discussion on NICU policy. The next article reviewed is by far the most comprehensive study of outcomes for neonates born at the gestational window under focus. *Survival of Infants Born at Perivable Gestational Ages*¹⁰² was published in 2017 by a collection of researchers and neonatologists, including Dr. Bell. This article defines perivable births “as births occurring from 20 0/7 through 25 6/7 weeks of gestation,” and includes a comparison of perivable survival rates across multiple studies (country). Bell et al. note that, “Direct comparisons of estimated

⁹⁸ Zayek, M. M., Trimm, R. F., Hamm, C. R., Peevy, K. J., Benjamin, J. T., & Eyal, F. G. (2011). The limit of viability: a single regional unit's experience. *Archives of pediatrics & adolescent medicine*, 165(2), 126–133. <https://doi.org/10.1001/archpediatrics.2010.285>

⁹⁹ Ibid.

¹⁰⁰ Ibid.

¹⁰¹ Ibid.

¹⁰² Patel, R. M., Rysavy, M. A., Bell, E. F., & Tyson, J. E. (2017). Survival of Infants Born at Perivable Gestational Ages. *Clinics in perinatology*, 44(2), 287–303. <https://doi.org/10.1016/j.clp.2017.01.009>

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survival rates among these studies are limited, however, by potential biases introduced from differences in the data sources, ascertainment of death, selection of denominators, and definitions of live birth.”¹⁰³

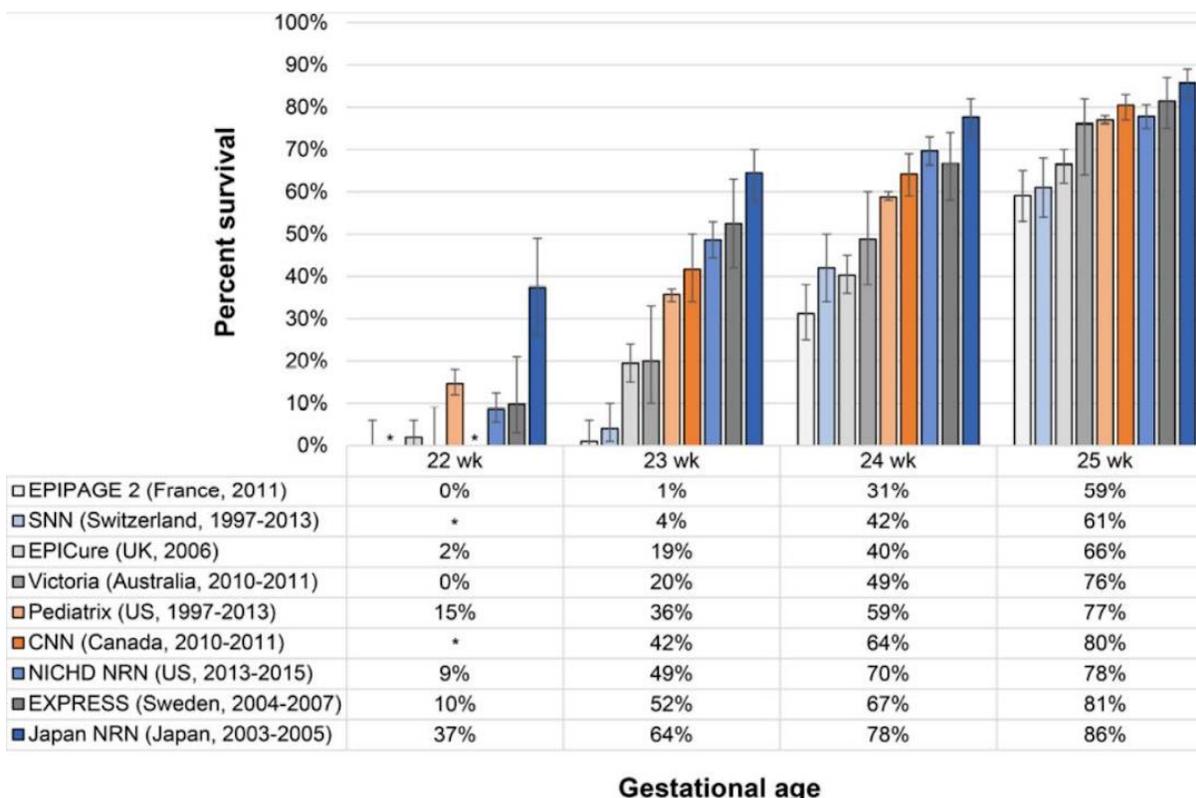


Table 16: Titled, “Gestational Age-Specific Survival following Live Birth by Study Type.” Obtained from [Survival of Infants Born at Perivable Gestational Ages - PMC](#). Note, “Data are shown for population-based cohorts (gray hues), center-based cohorts reporting survival for live births (blue hues) and center-based cohorts reporting survival for infants admitted to the NICU (orange hues) ... Whisker bars indicate 95% confidence intervals calculated with the Clopper-Pearson method. *Estimates not reported by the study.”

There is significant variation in survival rates between studies, most noticeably in the 22-week category where survival rates range from 0-37%. The authors of this report have “categorized this variation as resulting from between-study differences in: national and institutional recommendations and guidelines for perinatal care, cohort characteristics, maternal-infant characteristics, and antenatal and postnatal treatment, including decisions about the initiation and withdrawal of care.”¹⁰⁴ Because some of the variation is due to differing “guideline statements from professional organizations and scientific societies” on neonatal care and recommended active treatment for extremely premature neonates, this study includes a “systematic review of 31 national or international guidelines for perinatal care of perivable births in highly developed countries.” The review found substantial variation in active care recommendations: “Sixty-eight percent of guideline statements supported comfort care at 22 weeks’ of gestation and 65% supported active treatment and resuscitation at 25 weeks’ of gestation. At 23 and 24 weeks’ of gestation,

¹⁰³ Ibid.

¹⁰⁴ Ibid.

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there was more variability among recommendations, including for comfort care, routine active treatment, individualized care, and active treatment based on parental wishes.”¹⁰⁵

When interpreting gestational age survival rates, another factor to understand is cohort characteristics; referring to what is included in the numerator and denominator. Bell et al. point out that another significant reason for the variation is that often reports on survival rates will use inconsistent cohort characteristics. Examples of “different numerators [include:] death in the delivery room, death before 28 d, death before hospital discharge, death before 1 year[,] and denominators [include:] fetus alive at maternal admission and >20 weeks’ of gestation, all live births, inborn live births, live births receiving active treatment, infants admitted to the NICU.” (See Appendix D for comparison of numerators and denominators across studies included in Table 16 above.) Bell et al. provide the following chart to emphasize that, “For a woman pregnant with a fetus alive at 20 weeks’ of gestation, studies reporting outcomes with a denominator of infants admitted to the NICU do not reflect all of the potential birth outcomes of her fetus.”¹⁰⁶

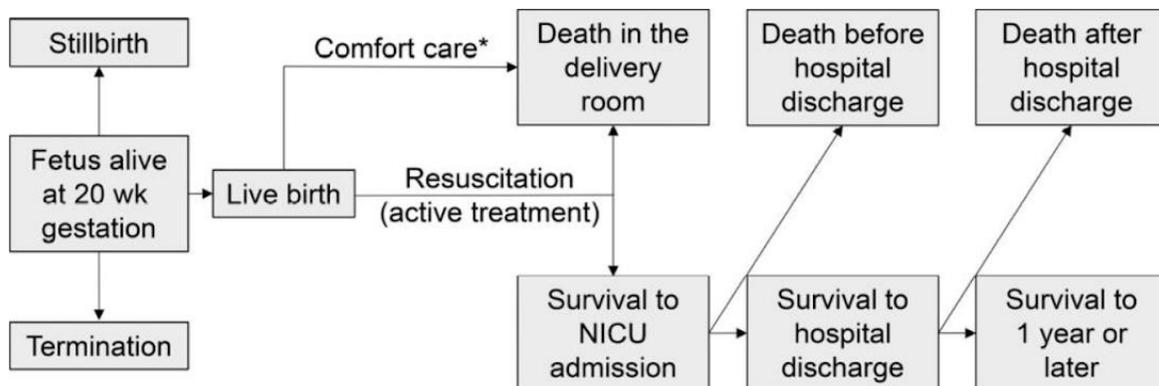


Image 3: Titled, “Potential Birth Outcomes for a Fetus Alive at 20 weeks’ of Gestation.” Obtained from [Survival of Infants Born at Perivable Gestational Ages - PMC](#).

Similarly, this study notes that the exclusion of stillbirths or infants not admitted to the NICU also obscure reported outcomes. Bell et al. note that, “If the population of interest is infants receiving active treatment after live birth, the stillbirth rate has ordinarily been assumed to be irrelevant. However, exclusion of stillbirths can lead to imperfect risk adjustment when comparing populations that differ in prenatal and antepartum care and the proportion of fetuses at high risk for death after birth.”¹⁰⁷

¹⁰⁵ Ibid.

¹⁰⁶ Ibid.

¹⁰⁷ Ibid.

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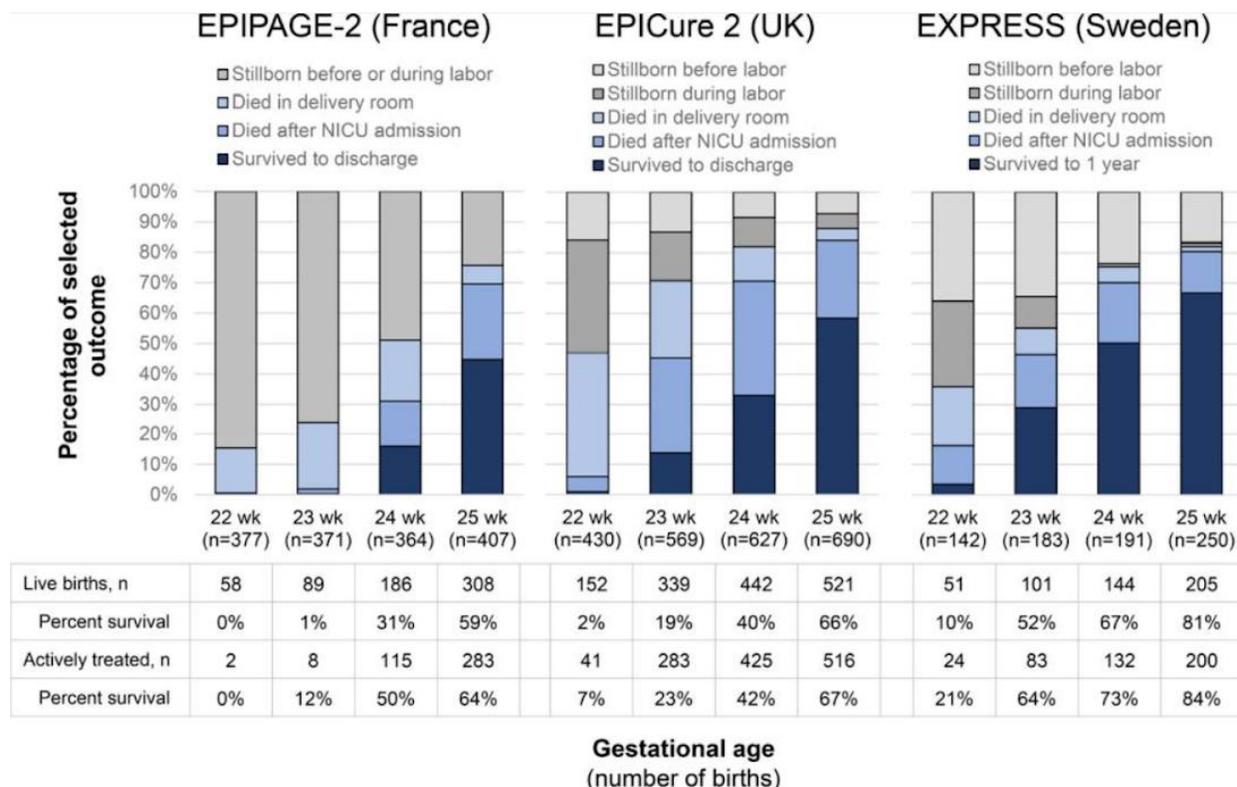


Table 17: Titled, “Perivable Birth Outcomes by Gestational Age in Population-based Studies.” Obtained from [Survival of Infants Born at Perivable Gestational Ages - PMC](#). Note, “Pregnancies with termination not included. Active treatment definitions vary by study but include measures of delivery room intervention or admission for neonatal care.”

Recall that this study has categorized variation in reported outcomes as the following: national and institutional recommendations and guidelines for perinatal care; cohort characteristics; maternal-infant characteristics; and antenatal and postnatal treatment, including decisions about the initiation and withdrawal of care. The variation in the provision of active treatment is one of the most important determinants of reported outcomes, but beyond variation in statistics, of the survival of extremely premature neonates. In a comprehensive study¹⁰⁸ of 24 academically-affiliated hospitals in the United States, the following was reported:

The proportion of live births receiving active treatment at 22 and 23 weeks’ of gestation ranged from 0 to 100% and 25 to 100%, respectively, among individual hospitals. The variation in hospital rate of active treatment accounted for 78% of the observed differences in hospital survival rates for infants born at 22 or 23 weeks’ of gestation. In contrast, only 22% and 1% of the differences in survival rates at 24 and 25 weeks’ of gestation, respectively, could be explained by variation in the hospital rate of active treatment. At

¹⁰⁸ Rysavy, M. A., et al., & Eunice Kennedy Shriver National Institute of Child Health and Human Development Neonatal Research Network (2015). Between-hospital variation in treatment and outcomes in extremely preterm infants. *The New England journal of medicine*, 372(19), 1801–1811. <https://doi.org/10.1056/NEJMoa1410689>

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some of the hospitals, most infants born at 22 weeks' of gestation received active treatment whereas at others no infants born at 22 weeks' did, a difference that may be reflective of institutional policies, clinician attitudes, or parental preferences.¹⁰⁹

Not only does Bell et al. emphasize the variation in active treatment actually delivered, but also the variation in reported survival rates depending on cohort characteristics. Their research found the following:

[O]verall survival rates at 22 weeks' of gestation increased four-fold when restricting the denominator of analysis from all live births to those receiving active treatment, from 5% (95% CI 3–8) to 23% (95% CI 14–34), highlighting the importance of this factor to the survival estimate. All infants born alive at 22 to 25 weeks' of gestation who did not receive active treatment died before hospital discharge, with nearly all (97–100% depending on gestational age at birth) dying within 12 hours of birth and all dying within 24 hours of birth. In contrast, among those that received active treatment, 41% of infants born alive at 22 weeks' of gestation, and 20% of infants born alive at 23 weeks' of gestation died within 12 hours of birth, with a much smaller proportion (2–8%) dying within the first 12 hours at 24 and 26 weeks' of gestation.¹¹⁰

This is not the only study highlighting the variation in survival rates between extremely premature neonates who received active care, and those who did not. A study¹¹¹ of infants at 22 to 26 weeks of gestation in France reported the following:

96% of those infants who had neonatal intensive care withheld or withdrawn died in the delivery room compared to 1% of those who received intensive treatment, including oxygen therapy and endotracheal intubation. At 22 weeks' and 23 weeks' of gestation, 96% and 91% of live births, respectively, had intensive care withheld or withdrawn and the limitation in active treatment mirrored the 96% and 92% of live births at these gestational ages that died in the delivery room.¹¹²

Both of these studies emphasize the importance of reporting survival rates among neonates who receive active care, and those who do not.

The type and quality of active care delivered is also a determining factor in the survival of extremely premature neonates. With each day and week, the changes in the type of care received by the neonate are crucial to survival. The rate of survival increases significantly if the neonate survives the first

¹⁰⁹ [Survival of Infants Born at Perivable Gestational Ages - PMC](#)

¹¹⁰ Ibid.

¹¹¹ Perlberg, J., et al., & Epipage-2 Ethics group (2016). Delivery room management of extremely preterm infants: the EPIPAGE-2 study. *Archives of disease in childhood. Fetal and neonatal edition*, 101(5), F384–F390. <https://doi.org/10.1136/archdischild-2015-308728>

¹¹² [Survival of Infants Born at Perivable Gestational Ages - PMC](#)

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few days of life. A study¹¹³ conducted of neonates born at 22 weeks between 2000 and 2011 found that, “90% of all in-hospital deaths occurred within 12 hours of life and 1.4% occurred after 28 days of age, based on data from a multicenter study from the NICHD [Eunice Kennedy Shriver National Institute of Child Health and Human Development] NRN¹¹⁴ [Neonatal Research Network]. The high frequency of early mortality likely reflects the frequent approach of comfort care for these infants.”¹¹⁵

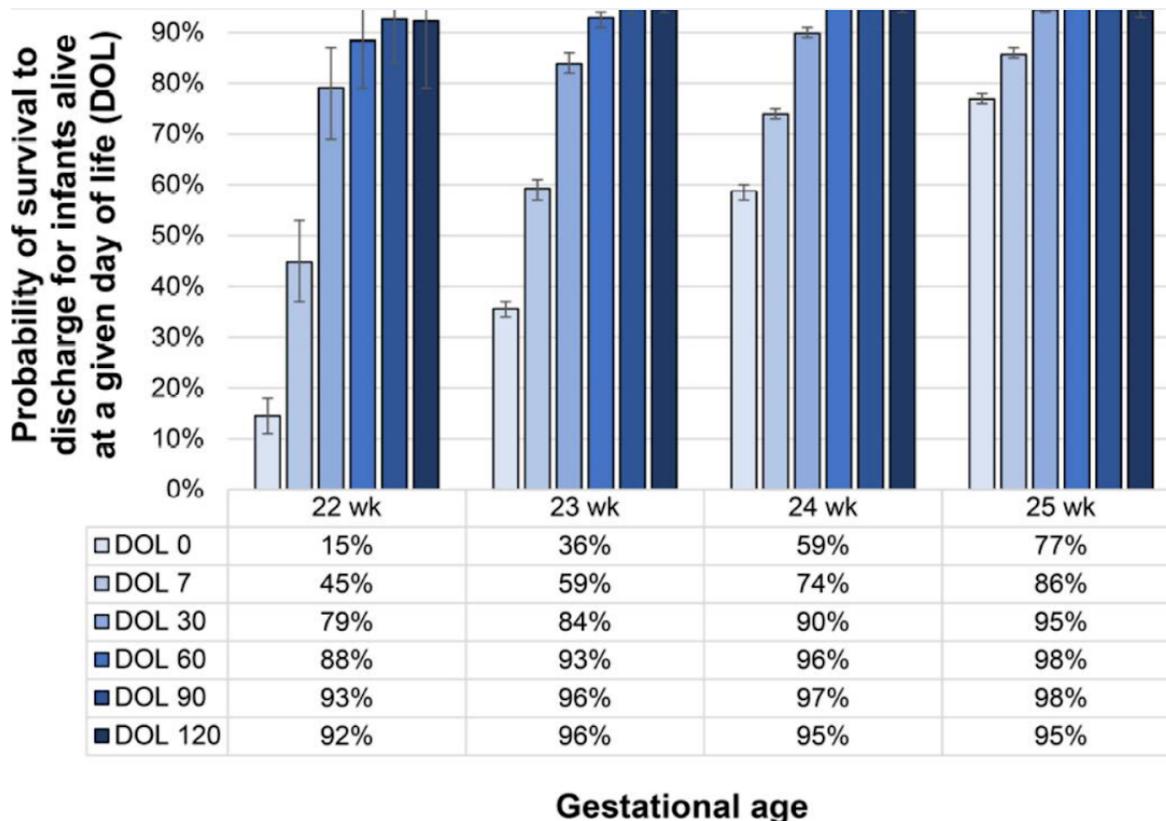


Table 18: Titled, “Changes in Probability of Survival to Discharge Among Infants Alive at a Given Day of Life.” Obtained from [Survival of Infants Born at Perivable Gestational Ages - PMC](#). Note, “Figure denotes changes in probability of survival to hospital discharge for infants who survive to 7 days of life (DOL) and beyond from a cohort of 64,896 infants in 362 US NICUs. Whisker bars indicate 95% confidence intervals calculated with the Clopper-Pearson method.”

The primary cause of death for extremely premature neonates after they enter the NICU is withdrawal of active care. “Variation in the percentage of deaths following end-of-life decisions among European population-based cohorts varied significantly, with 81% of deaths following end-of-life decisions at ≤ 24 weeks’ of gestation in France compared to 55% at ≤ 25 weeks’ of gestation in the UK.”¹¹⁶

¹¹³ Patel, R. M., et al., & Eunice Kennedy Shriver National Institute of Child Health and Human Development Neonatal Research Network (2015). Causes and timing of death in extremely premature infants from 2000 through 2011. *The New England journal of medicine*, 372(4), 331–340. <https://doi.org/10.1056/NEJMoa1403489>

¹¹⁴ More on NRN center locations can be found here: <https://neonatal.rti.org/index.cfm?fuseaction=about.map>

¹¹⁵ [Survival of Infants Born at Perivable Gestational Ages - PMC](#)

¹¹⁶ Ibid.

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In Canada, a study¹¹⁷ of 19 NICUs found that, “84% of all deaths occurred following a discussion of withdrawal of life-sustaining support and 41% were due to a prognosis of poor quality of life in the event of survival, while 35% were due to inevitability of death in the short-term and 24% to prevent prolonged suffering with death likely.”¹¹⁸

The final study reviewed in this section on extremely premature survival rates is *An Immature Science: Intensive Care for Infants Born at ≤23 Weeks of Gestation* from Rysavy et al.¹¹⁹ This study analyzed care for extremely premature neonates around the world, and found that clinicians in Japan may have the most experience caring for infants born at less than 23 weeks gestational age. They published the following:

[I]n 1991, the Japanese Society of Pediatrics recommended changing the limit for providing intensive care from 24 weeks to 22 weeks based on the survival of infants at 22 and 23 weeks reported in a national study.¹²⁰ From 2003 to 2015, among dozens of tertiary perinatal centers in the Japanese Neonatal Research Network, survival¹²¹ for live births exceeded 60% at 22 weeks and 70% at 23 weeks of gestation. In 2012, a national survey of a majority of Japanese neonatal intensive care units (NICUs) reported that active resuscitation of infants born at 22 and 23 weeks of gestation occurred in 81% and 85% of NICUs, respectively, and 42% and 75% of these NICUs had a universal resuscitation policy.¹²²

Rysavy et al. also review recommended care and outcomes in Sweden, and reported the following:

[I]n Sweden in 2014, the national board of health and welfare recommended centralization of care for all extremely preterm births at university hospitals with an emphasis on maternal transfer to these hospitals prior to delivery. Subsequently, in 2014–2016 compared with 2004–2007, one year survival for all liveborn infants at 22 weeks of gestation in the nation tripled (from 10% to 30%) and the rate of stillbirths was nearly halved (from 65% to

¹¹⁷ Hellmann, J., et al., & Canadian Neonatal Network End of Life Study Group (2016). Neonatal deaths: prospective exploration of the causes and process of end-of-life decisions. *Archives of disease in childhood. Fetal and neonatal edition*, 101(2), F102–F107. <https://doi.org/10.1136/archdischild-2015-308425>

¹¹⁸ [Survival of Infants Born at Perivable Gestational Ages - PMC](#)

¹¹⁹ Rysavy, M. A., Mehler, K., Oberthür, A., Ågren, J., Kusuda, S., McNamara, P. J., Giesinger, R. E., Kribs, A., Normann, E., Carlson, S. J., Klein, J. M., Backes, C. H., & Bell, E. F. (2021). *An Immature Science: Intensive Care for Infants Born at ≤23 Weeks of Gestation*. *The Journal of pediatrics*, 233, 16–25.e1. <https://doi.org/10.1016/j.jpeds.2021.03.006>

¹²⁰ Nishida, H., & Ishizuka, Y. (1992). Survival rate of extremely low birthweight infants and its effect on the amendment of the Eugenic Protection Act in Japan. *Acta paediatrica Japonica : Overseas edition*, 34(6), 612–616. <https://doi.org/10.1111/j.1442-200x.1992.tb01020.x>

¹²¹ Original article is written in Japanese. Unable to specify how exactly survival is defined. Default is typically survival to discharge.

¹²² [An Immature Science: Intensive Care for Infants Born at ≤23 Weeks of Gestation](#)

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35%).¹²³ Swedish guidelines published in 2016 recommend that, starting at 22 weeks of gestation, a neonatologist is present at birth and intensive care may be considered; starting at 23 weeks of gestation, intensive care is generally recommended.¹²⁴

As previously reviewed, the American Academy of Pediatrics emphasizes the parent’s wishes and an individualized approach to initiation of active treatment for births at the 22-24 week mark. This study reports the following in the United States:

Research has shown that provision of intensive care at 22–23 weeks vary by US region (with higher rates in the South and Midwest compared with the West and Northeast) and by hospital of birth. At US hospitals participating in the Vermont Oxford Network (VON),¹²⁵ the rate of active treatment for infants born at 22 weeks more than doubled since 2014; in 2019, the majority of infants born at 22 weeks in these hospitals received active treatment [Figure X]. During the same period, the rate of survival after birth at 22 weeks of gestation tripled, with 17% of liveborn infants in 2019 surviving to hospital discharge or 1 postnatal year.¹²⁶

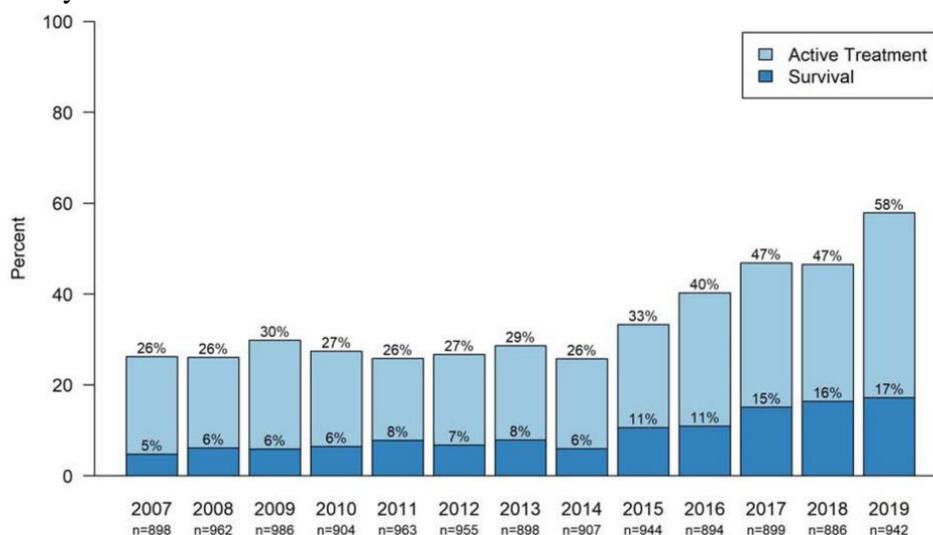


Table 19: Titled, “Active Treatment and Survival for Liveborn Infants at 22 Weeks in the US.” obtained from [An Immature Science: Intensive Care for Infants Born at ≤23 Weeks of Gestation](#). Note, “Active treatment is defined as respiratory support (including face mask ventilation, nasal continuous positive airway pressure, endotracheal intubation, surfactant therapy, or mechanical ventilation), chest compressions, or epinephrine. Survival is to hospital discharge or 1 year. The denominator includes all live births, including deaths that occurred in the delivery room. Data are from hospitals participating in the Vermont-Oxford Network.”

¹²³ Norman, M., et al. (2019). Association Between Year of Birth and 1-Year Survival Among Extremely Preterm Infants in Sweden During 2004-2007 and 2014-2016. *JAMA*, 321(12), 1188–1199.

<https://doi.org/10.1001/jama.2019.2021>

¹²⁴ [An Immature Science: Intensive Care for Infants Born at ≤23 Weeks of Gestation](#)

¹²⁵ The Vermont Oxford Network includes 1016 centers in the United States. The full member list can be found here: <https://public.vtoxford.org/member-map/>

¹²⁶ [An Immature Science: Intensive Care for Infants Born at ≤23 Weeks of Gestation](#)

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The authors of *An Immature Science: Intensive Care for Infants Born at ≤ 23 Weeks of Gestation* also make recommendations on clinical care. They emphasize that care begins prior to birth, including routine prenatal care and transfer to at least a Level III NICU prior to birth. “Rates of morbidity due to extreme prematurity are higher in outborn infants than in infants born at the same hospital where they receive NICU care, even when including only infants transferred on the day of birth and after adjustment for illness severity.”¹²⁷ For future policy direction, Rysavy et al. discuss the following challenges:

Challenges to the study and care of infants born at 22–23 weeks include that: their numbers are often small at any single hospital; their birth is often unplanned and urgent; and their inpatient care is often prolonged. Infants born at 22–23 weeks often require 5 or more months of in-hospital care (a period approximately as long as their duration of in utero gestation) before reaching maturity adequate for discharge, with many events and decisions during their inpatient course impacting their clinical needs and outcomes. Despite the lack of evidence to support many aspects of clinical care, the authors agree that several key factors need to be taken into account at centers considering providing intensive care for infants born at 22–23 weeks.¹²⁸

How do neonatologists and obstetricians collaborate in the care of the maternal-child dyad? Are decisions about antenatal corticosteroids and c-section considered separately?
How do healthcare providers communicate and collaborate with parents and caregivers? Are mechanisms for shared decision-making and ongoing communication in place?
Is appropriately sized equipment available for respiratory support and intravenous access?
Do all team members in the neonatal intensive care unit (e.g., physicians, nurse practitioners, nurses, respiratory therapists, nutritionists, and others) agree that intensive care for such immature infants is not futile?
Do clinicians recognize the unique physiological challenges and vulnerabilities of infants ≤ 23 weeks—that they are not just smaller preterm infants?
Is multidisciplinary long-term follow-up in place to provide support for these vulnerable patients after they are discharged from the hospital?
Are outcomes tracked, benchmarked, and monitored to identify areas for improvement in this nascent area of practice?

Table 20: Titled, “Considerations for clinicians offering intensive care for infants ≤ 23 weeks.” obtained from [An Immature Science: Intensive Care for Infants Born at \$\leq 23\$ Weeks of Gestation](#)

¹²⁷ Ibid.

¹²⁸ Ibid.

BIASES AGAINST NEONATES

This section reviews a well documented bias against extremely premature neonates in the literature. The previously discussed article, *Outcomes at 18 to 22 Months of Corrected Age for Infants Born at 22 to 25 Weeks of Gestation in a Center Practicing Active Management*, showcased very positive outcomes of active treatment for 22 and 23 week neonates. When the article was published in the *Journal of Pediatrics*, it was titled, *The eye of the beholder: Perivable outcomes in Iowa*.¹²⁹ The editor wrote that, “The reported outcomes will be interpreted as good or bad through the eye of the beholder.”¹³⁰ Dr. Keith Barrington, a neonatologist from Montreal, immediately responded to the disappointing editorial comment, saying, “I don’t know what kind of beholder would see the survival of babies as a bad thing, even if the survival means that some of them might have cerebral palsy or developmental delay... Any reasonable human eye would surely behold a 60 to 70% survival, with encouraging long term outcomes, as a good thing.”¹³¹ Positive outcomes for perivable neonates in Iowa had been showcased in bad light. Unfortunately, this is not an isolated case.

Several articles are reviewed here which shed light on this bias against the tiniest babies. One survey of pediatric residents and neonatal nurses, *Provider Perspectives Regarding Resuscitation Decisions for Neonates and Other Vulnerable Patients*,¹³² has shown that, “When making life and death decisions, participants considered (1) patient characteristics (96%), (2) personal experience/biases (85%), (3) family's wishes and desires (81%), (4) disease characteristics (74%), and (5) societal perspectives (36%).”¹³³ The study reported the following about these considerations:

These factors were not in favor of sick neonates: of the participants, 85% reported having negative biases toward neonates and 60% did not read, misinterpreted, and/or distrusted neonatal outcome statistics. Additional factors used to justify comfort care for neonates included limited personhood and lack of relationships/attachment (73%); prioritization of family's best interest, and social acceptability of death (36%). When these preconceptions were discussed, 70% of respondents reported they would change their answers in favor of neonates.¹³⁴

This illustrates a clear bias among pediatric health care practitioners, the very caregivers charged with protecting a vulnerable population.

¹²⁹ DeRegnier, R. (2020). The eye of the beholder: Perivable outcomes in Iowa. *The Journal of Pediatrics*, Volume 217, Pages 1-3, ISSN 0022-3476. <https://doi.org/10.1016/j.jpeds.2019.11.040>

¹³⁰ Ibid.

¹³¹ Barrington, K. (2020). The Jaundiced Eye of the Beholder. *Neonatal Research*. <https://neonatalresearch.org/2020/02/03/the-jaundiced-eye-of-the-beholder/>

¹³² Dupont-Thibodeau, A., et al. (2017). Provider Perspectives Regarding Resuscitation Decisions for Neonates and Other Vulnerable Patients. *The Journal of pediatrics*, 188, 142–147.e3. <https://doi.org/10.1016/j.jpeds.2017.03.057>

¹³³ Ibid.

¹³⁴ Ibid.

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Biases Against Neonates

A study from Laventhal et al., *International Variations in Application of the Best-Interest Standard Across the Age Spectrum*,¹³⁵ surveyed physicians, asking them to triage eight hypothetical critically-ill patients, including two neonates. This study reported the following:

In all countries and scenarios, participants did not accept to withhold resuscitation if they estimated it was in the patient's best interest, *except for scenarios involving neonates*. Young children (other than neonates) were given high priority for resuscitation, regardless of existing disability. *For neonates, surrogate autonomy outweighed assessment of best interest*. In all countries, a 2-month-old-infant with meningitis and a multiply disabled 7-year old were resuscitated first in the triage scenario, with more variable ranking of the two neonates, *which were ranked below patients with considerably worse prognosis*. (Emphasis added.)¹³⁶

Laventhal et al., concluded that, “The value placed on the life of newborns is less than that expected according to predicted clinical outcomes and current legal and ethical theory relative to best interests.”¹³⁷

The next article reviewed is an ethics-based study, *Should Extremely Premature Babies Get Ventilators During the COVID-19 Crisis?*¹³⁸ The authors here, Haward et al., provide an extensive review of the literature surrounding the bias against premature neonates, that can cause neonatal caregivers to forgo intensive care for the tiniest babies. They write that, “When considering treatment of premature infants, doctors, and parents both often focus on the possibility of survival with disabilities, rather than on the chances of survival alone... [and this] bias is usually not present in treatment decisions for older children.” According to Haward et al., there are several theoretical explanations for this bias: “They may reflect patient characteristics (lack of personhood, lack of social relationships), considerations of the interests of other family members or the family as a whole, overestimations of the likelihood of severe neurodevelopmental impairment, and presumptions of societal permissibility and status quo.”¹³⁹

The other consideration factoring into this bias against extremely premature neonates is the cost of intensive care. However, this study suggests that, “Two points are relevant to arguments about cost and cost-effectiveness. First, numerous studies have shown that NICUs are remarkably cost-effective, even for the tiniest and sickest babies... Most babies who survive have long and happy lives. As previously noted, most babies who die will die quickly, without a long and expensive hospital stay.”¹⁴⁰

While this article was an ethics review in the context of pandemic triage, the authors suggest that outside the context of a shortage of ventilators and healthcare capacity, extremely premature neonates

¹³⁵ Laventhal, N., et al. (2017). International variations in application of the best-interest standard across the age spectrum. *Journal of perinatology: official journal of the California Perinatal Association*, 37(2), 208–213. <https://doi.org/10.1038/jp.2016.168>

¹³⁶ Ibid.

¹³⁷ Ibid.

¹³⁸ Haward, M. F., et al. (2020). Should Extremely Premature Babies Get Ventilators During the COVID-19 Crisis?. *The American journal of bioethics: AJOB*, 20(7), 37–43. <https://doi.org/10.1080/15265161.2020.1764134>

¹³⁹ Ibid.

¹⁴⁰ Ibid.

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have already been triaged. Neonates born at 22 weeks, “would have a 23% chance of survival (10–50% depending on where [they are] born) and 42% chance of long-term neuro-morbidity.” However, “before the pandemic, the majority of these infants at 22 weeks receive palliative comfort care.”¹⁴¹ The following is a crucial discussion of the ethics of these sorts of triage decisions:

Interestingly, for populations other than preterm infants, our society is compelled toward rescue: there has been a massive reallocation of resources to save COVID-19 victims, building stadiums and mobilizing ships. We rally around these efforts on intuitive, humanitarian grounds—it seems unthinkable not to try to save the sick. Society has rightfully recruited and organized services. However, it is important to note that these efforts have not been faced with the same scrutiny as the provision of intensive care to extremely premature infants. The use of age, alone, is generally not an ethically defensible approach to triage decisions. We should perhaps ask ourselves: if we used the decision-making standards of neonatologists for withholding life-sustaining interventions, would stadiums be built at all? ... Would parents feel reassured things will “return to normal” after the pandemic if we suggest extremely premature infants are expendable? The concept of expendability seems only to apply to extremely premature infants, as witnessed by advocacy groups uniting to argue inequity in allocation guidelines during the current pandemic... These continued discrepancies in the public and ethical discourse between extremely premature infants and other populations perpetuate biases in society.¹⁴²

One suggestion for triage protocol has been to prioritize based on Quality-Adjusted Life Years (QALY), a measure that takes into account both quantity and quality of life. Haward et al. warn against this, since, “They incorporate too many biases about the value of life with disabilities. The net effect of using QALYs, rather than expected years of survival alone, would be to achieve the survival of a disproportionate number of people without disabilities.” Policies that “limit treatment by gestational age without considering the true survival rates for babies at various gestational age limits” are both ageist and ableist.¹⁴³

The final article reviewed in this section is, *How Do We Regard the Premie at the Margins of Viability?*¹⁴⁴ In this study, Carter found that most pediatric residents and NICU nurses are uninformed or misinformed on the outcomes for extremely premature neonates. This is partially because NICU staff rarely attend follow-up appointments for these infants, and “the focus of pediatricians, developmental specialists, and neonatologists seeing these children in follow-up clinics is different than their colleagues practicing acute care neonatology.”¹⁴⁵ Carter discusses “the prematurity stereotype,” and makes the following observation:

¹⁴¹ Ibid.

¹⁴² Ibid.

¹⁴³ Ibid.

¹⁴⁴ Carter B. S. (2017). How Do We Regard the Premie at the Margins of Viability?. *The Journal of pediatrics*, 188, 5–6. <https://doi.org/10.1016/j.jpeds.2017.05.042>

¹⁴⁵ Ibid.

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Biases Against Neonates

Perhaps stereotypes and bias undergird the differences in how respondents acknowledge and respond to any patient's moral claim. Bias may emanate from an individual provider's life experience, a perceived framing effect of the case vignette, a presumed assumption of what is normative versus exceptional practice, or even an (inappropriate) consideration of societal resource use and priorities that is meted out at the bedside. They may also stem from religious, metaphysical, or philosophical beliefs. Such biases are likely present, too, when caregivers consider disability as an outcome that is not acceptable, especially when caregivers believe that they have contributed to such an outcome during a lengthy NICU stay. How do clinicians justify their responsiveness to certain patients, and not to others? Could it be that the respondents entertained assessments of “personhood,” or the potential for retaining or developing it, across the different vignettes? In such context, the premie may have more to prove before she or he can be seen to hold the potential already ascribed to older patients. These beliefs may be deeply held, but poorly explored; they may not even be raised to a level of conscious thought. How each of us determines the nature of others' being, accepts them as “one of us,” and responds to them are variable. Do we need certain biological criteria to be met—pertaining to origin, human form and anatomy, or physiologic function? Is it our genetic composition? Or is it functional in a manner of development, or psychological and cognitive potential?¹⁴⁶

Additionally, this study found that considerations about active treatment for extremely premature neonates also includes the personal experience of any single NICU provider. Carter discusses the negative bias effect, which is the tendency to remember negative results more than positive ones. “Pediatric residents see NICU graduates readmitted to the pediatric ICU, creating a ready recall of the worst outcomes, but do not see the greater number of premies who thrive.” Another consideration is the “difficulties caregivers have in truly being able to empathize with a premie... NICU nurses are sensitive to the condition and comfort of their premature charge to be sure, but it is not possible to know how the premie feels. Such considerations have never been explored in pediatric medicine.” Emphasized here is the acknowledgement that even the tiniest neonate is one of us. “This is relevant in the delivery room and in the NICU. It shapes our views toward life with different abilities—or morbidities resulting from extreme prematurity and its management—as transitions to home are contemplated.”¹⁴⁷ Carter concludes with this thought:

Acknowledging the value of others—our response to their being, regardless of how fragile, or different, needy, or disabled—is telling about us as caregivers, and even more broadly as societies. And it will help to incline us toward listening, understanding, and valuing parental concerns as we discern our best response to the new one's dignity. It may reflect our need for a revised notion of best interests, one based on safeguarding trust and equal moral worth.¹⁴⁸

¹⁴⁶ Ibid.

¹⁴⁷ Ibid.

¹⁴⁸ Ibid.

NICU COSTS

This section covers the most recent data on NICU costs. The study, *Cost of Neonatal Intensive Care for Extremely Preterm Infants in Canada*,¹⁴⁹ analyzes data on total cost and length of hospital care in Canada for premature neonates (23-28 weeks) from 2011-2015. The results are summarized in the following table:

GA (weeks)	Median Length of Stay (days)	Median Total Costs	Median Daily Costs
All infants	41	\$66,669	\$1,940
All infants*	61	\$91,137	\$1,806
23*	72	\$147,835	\$2,381
24*	88	\$154,736	\$2,204
25*	78	\$130,317	\$2,038

* surviving >3 days. Data obtained from [Cost of neonatal intensive care for extremely preterm infants in Canada - Rolnitsky - Translational Pediatrics](#)

Regarding the costs of care for neonates born at 23-25 weeks, the authors, Rolnitsky et al., provide the following discussion:

We found that in the micropremature [23-25 weeks] population who survived more than 3 days, the total cost was not different between 23- and 24-week infants and the daily cost differed little. This likely reflects the difference between the lower cost for infants born at 23 weeks gestation who had low survival rates due either palliative care (leading to 1 day of admission until death) or early mortality due to extreme prematurity, and the higher survival rates in the 24–25-week population. Indeed, modelling the relationship of cost to gestational age, we found that age was a poor predictor of cost, while survival of more than 3 days was a better predictor.¹⁵⁰

Rolnitsky et al. emphasize that although the total and daily costs of neonatal intensive care are high, since the total cost for neonates between 23-25 weeks were not substantially different, “These findings highlight

¹⁴⁹ Rolnitsky, A., et al. (2021). Cost of neonatal intensive care for extremely preterm infants in Canada. *Translational pediatrics*, 10(6), 1630–1636. <https://doi.org/10.21037/tp-21-36>

¹⁵⁰ Ibid.

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NICU Costs

the need for a funding strategy for the routine support of these fragile infants [on the lower limit of this range].”¹⁵¹

One thing to consider in addition to NICU costs is “later life healthcare expenses secondary to complications related to preterm birth that are common in this cohort.” Because these costs are not included in this study, the results are an underestimate of true total cost to the healthcare system. Rolnitsky et al. write, “Our study was designed to describe the costs associated with extreme preterm birth in hospital care with an aim to measure the cost to the payor. A formal cost-effectiveness analysis could provide further details on cost per-outcome.” The cost of NICU care for extremely premature neonates is high, however, similar between 23 and 25 weeks. “Our current knowledge of preterm outcomes demonstrates this cost is associated with high and increasing survival rates and a good quality of life in this population later in life.” The authors of this study conclude that because the cost of intensive care for extremely premature neonates born around the 23-week mark is not substantively different from the cost of care for slightly older neonates, this “may be an argument for or reassurance to continue the practice of life support for this gestational age group for policymaker and funding authorities... Indeed, the advances that ‘push the envelope’ in the care of these fragile newborns do not appear to come with markedly different costs.”¹⁵²

Preterm births aren’t the only consideration for NICU programs, infants who are small for their gestational age (SGA) and multiple-birth babies (twins or triplets) also require attention in this discussion. The report *Too Early, Too Small: A Profile of Small Babies Across Canada*,¹⁵³ from the Canadian Institute for Health Information provides an analysis of these factors. The report found that birth weight, gestational age and multiple-births increased hospital costs. The following is a summary of this report:¹⁵⁴

In 2005–2006, the average in-hospital cost for a low birth weight baby (less than 2,500 grams) was more than 11 times higher than for those weighing 2,500 grams or more—\$12,354 compared to \$1,084.

Among singletons, the average in-hospital cost associated with preterm babies (less than 37 weeks) was nine times higher than for full-term babies—\$9,233 versus \$1,050. Among multiples, the average cost for a preterm baby was about seven times higher—\$12,479 versus \$1,871.

In contrast, the average cost of an SGA baby was less than twice the cost of a non-SGA baby—\$2,297 versus \$1,407. Our analyses suggest that SGA status alone may not be a strong predictor of hospital utilization and in-hospital costs at the time of birth—while the average hospital cost for a singleton non-SGA baby born extremely preterm (less than 28

¹⁵¹ Ibid.

¹⁵² Ibid.

¹⁵³ CIHI. (2009). *Too Early, Too Small: A Profile of Small Babies Across Canada*. Ottawa, Ont.

https://secure.cihi.ca/free_products/too_early_too_small_en.pdf

¹⁵⁴ “Please note that these costs are limited to costs incurred for typical newborns in their hospital of birth and exclude payments to physicians from provincial/territorial health insurance plans.”

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weeks gestation) was \$85,103, this estimate rose to \$109,286 for a singleton SGA baby born at 28 weeks or less gestation.¹⁵⁵

While this report was published in 2009, over a decade ago, and costs have since inflated, these numbers give us a general idea of the cost to the healthcare system for the care of premature, SGA and multiple birth babies.

JURISDICTIONAL PROGRAMS

This section reviews NICU programs and considerations specific to healthcare jurisdiction. The report *Too Early, Too Small: A Profile of Small Babies Across Canada*, also found that in Canada, “Among the provinces, Alberta and Newfoundland and Labrador demonstrated the highest preterm birth rates, at 8.7% and 8.6%, respectively. The highest provincial SGA rates occurred in Ontario (8.9%) and Alberta (8.7%).”¹⁵⁶

Preterm birth rates are rising around the world. In Canada, the Canadian Neonatal Network (CNN) was established to help improve neonatal outcomes in a publicly funded healthcare system, and includes all 31¹⁵⁷ Level III NICUs across Canada. The CNN launch a national Evidence-based Practice for Improving Quality (EPIQ) program¹⁵⁸ in 2003. The CNN EPIQ program was developed because there are “large variations in practice among Canadian neonatal intensive care units (NICU) and suitable models for implementing practice change based on evidence and data are lacking.”¹⁵⁹

The study, *Outcomes and care practices for preterm infants born at less than 33 weeks’ gestation: a quality-improvement study*,¹⁶⁰ reports the outcomes of premature neonates (born at 23-32 weeks gestational age) in the EPIQ program from 2004 to 2017. The study found that for neonates born across all gestational ages over that time period, “survival without major morbidity increased significantly,” from 56.6% to 70.9%. For neonates born at 23-25 weeks, survival rates increase from 70.8% to 74.5%. “For this analysis, the primary outcome was survival to NICU discharge without major morbidities, selected based on frequency and potential for long-term neurodevelopmental impact... [and] stillbirths, delivery room deaths and infants moribund on admission were excluded.” The objective of the EPIQ program is “quality-improvement interventions” and “to improve short-term hospital-based outcomes”; as such, this

¹⁵⁵ Ibid. See report, Figure 13 and Tables 3-5 for specifics.

¹⁵⁶ Ibid.

¹⁵⁷ In 2020, according to [Outcomes and care practices for preterm infants born at less than 33 weeks' gestation: a quality-improvement study](#)

¹⁵⁸ [EPIQ](#)

¹⁵⁹ Ibid.

¹⁶⁰ Lee, S. K., et al., & Evidence-based Practice for Improving Quality Investigators (2020). Outcomes and care practices for preterm infants born at less than 33 weeks' gestation: a quality-improvement study. *CMAJ : Canadian Medical Association journal = journal de l'Association medicale canadienne*, 192(4), E81–E91. <https://doi.org/10.1503/cmaj.190940>

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report focuses on neonates when admitted to the NICU, and does not report long-term outcomes. The authors, Lee et al., specify that, “since individual NICUs made different practice interventions at different times, ... [they could not] provide analyses of specific interventions responsible for changes in outcomes.” The report concludes that, “Participation in the EPIQ program was associated with a 25% increase in survival without major morbidity among very preterm infants and a 5% increase in survival among infants born at 23–25 weeks’ gestation.”¹⁶¹

In Alberta, the Managing Obstetrical Risk Efficiently (MORE^{OB}) Program¹⁶² has been developed as a “comprehensive patient safety, quality improvement, and professional development program for caregivers and administrators in hospital obstetrical units. The mission of the MORE^{OB} Program is to create a model of care where patient safety is the priority and everyone’s responsibility.” The program has been adopted by 64 hospitals in Alberta, and first received support from Alberta’s Ministry of Health for the implementation of the program on a provincial basis in 2004.¹⁶³ A result of the MORE^{OB} Program for newborn outcomes is that severe morbidity was significantly reduced.¹⁶⁴

¹⁶¹ Ibid.

¹⁶² See, <https://www.moreob.com/>

¹⁶³ See, <https://www.moreob.com/images/pdf/july2010impactofmoreob.pdf>

¹⁶⁴ Thanh N., et al. (2010). Outcomes of the Introduction of the MOREOB Continuing Education Program in Alberta. *Journal of obstetrics and gynecology Canada*, 32 (8), Pg 749-755. ISSN 1701-2163. [https://doi.org/10.1016/S1701-2163\(16\)34615-1](https://doi.org/10.1016/S1701-2163(16)34615-1)

LEGISLATION IN CANADA

This section will review the existing legislation in Canada, and specifically in Alberta, relevant to this project. In 1991, the Government of Canada ratified the Convention on the Rights of the Child (CRC).¹⁶⁵ “Ratification implies that the ratifying State will adhere to the norms set out in the CRC in its domestic law.”¹⁶⁶ The following explains the place of the CRC in Canadian law:

[T]here has to be legislative action in order to incorporate Canada's international commitments into domestic law. While it is generally recognized that the federal government has the exclusive authority to enter into international treaties, implementation must, as a rule, be done in a way that is consistent with the division of powers between the two levels of government. The CRC contains provisions relating to matters within both federal jurisdiction (such as divorce and criminal law) and provincial and territorial jurisdiction (such as education and health). Thus, it is up to all jurisdictions to take measures to meet Canada's obligations under the Convention. The CRC has not been explicitly incorporated into domestic law through a particular statute or statutes, and therefore cannot form the basis of a cause of action in Canadian courts. This is consistent with the usual Canadian approach to implementing international human rights treaties which it has ratified, which is to rely on a wide range of existing measures at the federal, provincial and territorial levels – including the Canadian Charter of Rights and Freedoms, legislation, policies and programs – to comply with its treaty obligations.¹⁶⁷

Even though the CRC has not been explicitly incorporated into Canadian law and has no mandatory effect, it may still be cited and its principles asserted in Canadian Courts for interpretive purposes.¹⁶⁸

In the preamble of the CRC, it states that, “the child, by reason of his physical and mental immaturity, needs special safeguards and care, including appropriate legal protection, before as well as after birth.” The CRC defines a child as, “every human being below the age of eighteen years unless under the law applicable to the child, majority is attained earlier.”¹⁶⁹

¹⁶⁵ *Convention on the Rights of the Child*, UN-CN, Dec. 12, 1991.

¹⁶⁶ See, <https://www.justice.gc.ca/eng/rp-pr/fl-lf/divorce/crc-crde/conv2a.html>. The implementation of the CRC in Canada is subject to two reservations, neither of which affect the project of this paper. See, <https://www.canada.ca/en/canadian-heritage/services/rights-children.html> for more details on the rights of children in Canada.

¹⁶⁷ *The Convention on the Rights of the Child - Topics in Family Law: A Collection of Articles*

¹⁶⁸ *Ibid.*

¹⁶⁹ *Convention on the Rights of the Child*, Art. 1

Article 3 of the CRC states the following:

1. In all actions concerning children, whether undertaken by public or private social welfare institutions, courts of law, administrative authorities or legislative bodies, *the best interests of the child shall be a primary consideration.*
2. States Parties undertake to *ensure the child such protection and care as is necessary for his or her well-being*, taking into account the rights and duties of his or her parents, legal guardians, or other individuals legally responsible for him or her, and, to this end, shall take all appropriate legislative and administrative measures.
3. States Parties shall ensure that the *institutions, services and facilities responsible for the care or protection of children shall conform with the standards* established by competent authorities, particularly in the areas of safety, health, in the number and suitability of their staff, as well as competent supervision. (Emphasis added.)¹⁷⁰

Article 6 of the CRC declares that, “States Parties recognize that every child has the *inherent right to life*. [And,] States Parties shall ensure to the *maximum extent possible the survival and development of the child.*” (Emphasis added.)¹⁷¹

Article 24 sets out the following:

1. States Parties recognize the right of the child to the enjoyment of the *highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health*. States Parties shall strive to ensure that *no child is deprived of his or her right of access to such health care services*.
2. States Parties shall pursue full implementation of this right and, in particular, shall take appropriate measures: (a) *To diminish infant and child mortality*; (b) *To ensure the provision of necessary medical assistance and health care to all children with emphasis on the development of primary health care*; ... (Emphasis added.)¹⁷²

Although, as previously mentioned, the CRC is not explicitly incorporated into Canadian law, because it is ratified, it is up to jurisdictions to meet their obligations under the CRC. The CRC’s discussion of the rights of a child, as well as the obligation of institutions to protect these rights, is pertinent to this project and future policy relating to the protection of extremely premature neonates.

The Criminal Code¹⁷³ of Canada is also relevant to this project. The Criminal Code states that, “A child becomes a human being within the meaning of this Act when it has completely proceeded, in a living state, from the body of its mother, whether or not (a) it has breathed; (b) it has an independent circulation; or (c) the navel string is severed.”¹⁷⁴

¹⁷⁰ [Convention on the Rights of the Child](#), Art. 3

¹⁷¹ [Convention on the Rights of the Child](#), Art. 6

¹⁷² [Convention on the Rights of the Child](#), Art. 24

¹⁷³ [Criminal Code](#), RSC 1985, c. C - 46

¹⁷⁴ [Criminal Code Code criminel](#), Sect. 223 (1)

The Criminal Code addresses the killing of a child as well as a newly born child. In the context of a child, “death that might have been prevented” is defined as, “Where a person, by an act or omission, does any thing that results in the death of a human being, he causes the death of that human being notwithstanding that death from that cause might have been prevented by resorting to proper means.”¹⁷⁵ The Criminal Code makes the following statement regarding infanticide: “A female person commits infanticide when by a wilful act or omission she causes the death of her newborn child, if at the time of the act or omission she is not fully recovered from the effects of giving birth to the child and by reason thereof or of the effect of lactation consequent on the birth of the child her mind is then disturbed.”¹⁷⁶

The Criminal Code also comments on “neglect to obtain assistance in childbirth,” about which it states the following:

A female person who, being pregnant and about to be delivered, with intent that the child shall not live or with intent to conceal the birth of the child, fails to make provision for reasonable assistance in respect of her delivery is, *if the child is permanently injured as a result of the failure or dies immediately before, during or in a short time after birth, as a result of the failure, guilty of (a) an indictable offence and liable to imprisonment for a term of not more than five years; or (b) an offence punishable on summary conviction. (Emphasis added.)*¹⁷⁷

The manner in which the Criminal Code defines these terms is relevant to future legislated protections for extremely premature neonates, and provides a sound base for discussion on the rights of the tiniest babies.

The final piece of legislation reviewed here is the Alberta Child, Youth and Family Enhancement Act.¹⁷⁸ This Act defines a “child” as, “a person under the age of 18 years and includes a youth unless specifically stated otherwise.” A guiding principle of the Act, in which the Act “must be interpreted and administered in accordance with,” is that “the best interests, safety and well-being of children are paramount.”¹⁷⁹

¹⁷⁵ Criminal Code Code criminel, Sect. 224

¹⁷⁶ Criminal Code Code criminel, Sect. 233. The Criminal Code also addresses the killing of an unborn child in Section 238; however, this is not relevant to this project.

¹⁷⁷ Criminal Code Code criminel, Sect. 242

¹⁷⁸ Child, Youth and Family Enhancement Act, RSA 2000, c C-12

¹⁷⁹ Child, Youth and Family Enhancement Act, Guiding principles 1.1(a)

LEGISLATION IN THE UNITED STATES

In the United States, former President Donald Trump issued an Executive Order on Protecting Vulnerable Newborn and Infant Children¹⁸⁰ in September 2020. The purpose of the Executive Order is stated as the following:

Every infant born alive, no matter the circumstances of his or her birth, has the same dignity and the same rights as *every other individual and is entitled to the same protections under Federal law*. Such laws include the Emergency Medical Treatment and Labor Act (EMTALA), 42 U.S.C. 1395dd, which guarantees, in hospitals that have an emergency department, *each individual's right to an appropriate medical screening examination and to either stabilizing treatment or an appropriate transfer*. They also include section 504 of the Rehabilitation Act (Rehab Act), 29 U.S.C. 794, which *prohibits discrimination against individuals with disabilities* by programs and activities receiving Federal funding. In addition, the Born-Alive Infants Protection Act, 1 U.S.C. 8, makes clear that *all infants born alive are individuals* for purposes of these and other Federal laws and are therefore afforded the same legal protections as any other person. *Together, these laws help protect infants born alive from discrimination in the provision of medical treatment, including infants who require emergency medical treatment, who are premature, or who are born with disabilities. Such infants are entitled to meaningful and non-discriminatory access to medical examination and services, with the consent of a parent or guardian, when they present at hospitals receiving Federal funds.*

Despite these laws, some hospitals refuse the required medical screening examination and stabilizing treatment or otherwise do not provide potentially lifesaving medical treatment to extremely premature or disabled infants, even when parents plead for such treatment. *Hospitals might refuse to provide treatment to extremely premature infants — born alive before 24 weeks of gestation — because they believe these infants may not survive, may have to live with long-term disabilities, or may have a quality-of-life deemed to be inadequate.* Active treatment of extremely premature infants has, however, been shown to improve their survival rates. *And the denial of such treatment, or discouragement of parents from seeking such treatment for their children, devalues the lives of these children and may violate Federal law.* (Emphasis added.)¹⁸¹

This Executive Order is meant to ensure that each child is protected under the law, recognizing “the human dignity and inherent worth of every newborn or other infant child, regardless of prematurity or disability.”¹⁸²

¹⁸⁰ Exec. Order No. 13952, 85 Fed. Reg. 62187 (September 25, 2020).

¹⁸¹ Federal Register :: Protecting Vulnerable Newborn and Infant Children, Sect. 1

¹⁸² Ibid., Sect. 2

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Legislation in the United States

The Order also states that, “The Secretary of Health and Human Services (Secretary) shall ensure that individuals responsible for all programs and activities under his jurisdiction that receive Federal funding are aware of their obligations toward infants, including premature infants or infants with disabilities.”¹⁸³ This includes ensuring that these individuals are aware that they are not excused from complying with the obligations set out in the Order. These individuals “may not unlawfully discourage parents from seeking medical treatment for their infant child solely because of their infant child’s disability,”¹⁸⁴ and if a facility is unable to provide the appropriate treatment, the infant must be stabilized and transferred to a more suitable facility. “The Secretary shall take all appropriate enforcement action against individuals and organizations found through investigation to have violated applicable Federal laws, up to and including terminating Federal funding for non-compliant programs and activities.”¹⁸⁵ The Order also states that the United States Department of Health and Human Services must allocate funding toward research and treatment that may improve outcomes for these infants, and toward hospitals for the purpose of training health care practitioners in the provision of these treatments.

¹⁸³ *Ibid.*, Sect. 3 (a)

¹⁸⁴ *Ibid.*, Sect. 3 (a)

¹⁸⁵ *Ibid.*, Sect. 3 (b)(ii)

DISCUSSION OF POLICY CONSIDERATIONS

One of the key studies informing AHS policy is *Perivable Birth*, in which active care for neonates is not recommended until 24 0/7 weeks gestational age, and only considered for neonates born in the 23rd week. This position document was last updated in 2017, and is considered the “ACOG Obstetric Care Consensus.” However, these recommendations for active care are certainly not the consensus among neonatologists. The various studies published by renowned neonatologist Dr. Bell, among others, show very positive outcomes for active treatment of neonates born at 22 weeks gestational age, and encroaching on 21-week territory.

Studies informing future policy on neonatal care must be viewed in light of the causes for variation and limitations previously discussed at length. The most important factor to consider with survival rates for extremely premature neonates is the denominator. Decisions about whether to recommend active care for neonates at the 21-22 week mark must use survival rates where the denominator is restricted to only those neonates which received active treatment. As reported in *Survival of Infants Born at Perivable Gestational Ages*, survival rates for neonates born at 22 weeks gestational age range from 0% to 37%. We saw a significant range of survival rates for 22-weekers between individual studies: In, *Outcomes at 18 to 22 Months of Corrected Age for Infants Born at 22 to 25 Weeks of Gestation in a Center Practicing Active Management*, Dr. Bell reports a 70% survival rate for a small cohort of 22-week neonates who received active treatment. The *Canadian Neonatal Network Annual Report 2020* reported that of those neonates born at 22 weeks, 22% of neonates who received intensive care survived. The study, *The Limit of Viability: A Single Regional Unit’s Experience*, reported up to a 40% survival rate among 22-week neonates who both received and did not receive active care. *An Immature Science: Intensive Care for Infants Born at ≤23 Weeks of Gestation* reported a survival rate of over 60% for 22-weekers in Japan, however, as noted, in this case I was unable to obtain how survival rates were defined.

A 2013 study from Japan (See Appendix D) reported a 37% survival rate for neonates, and used all live births as a denominator. Theoretically, using all live births as a denominator should result in a lower survival rate than if they had only included NICU submissions, since deaths in the delivery room would be excluded. Consider the 15% survival rate reported by the United States *Pediatrics* study which used only NICU admissions as the denominator. Both of these studies exclude transfers and birth defects, which can significantly impact survival rates. Both studies also use survival to NICU discharge as their numerator. As reported in *An Immature Science: Intensive Care for Infants Born at ≤23 Weeks of Gestation*, Japan may have, by far, the most experience caring for extremely premature neonates, and their survival rates emphasize this. Despite the variation in survival rates for neonates born prior to 23 weeks, there are positive outcomes for active care reported from around the world. However, this variation emphasizes that health policy regarding care for neonates born prior to 23 weeks should account for differences in experience and technology at each individual NICU.

In Alberta, AHS policy on treatment recommendations for these neonates is outdated and in need of considerable revision to account for the survival rates of neonates born at 22 weeks, and possibly at 21 weeks. AHS also needs to amend its definition of the threshold of viability, which currently states that, “Infants born between greater than or equal to 23 0/7 weeks and 24 6/7 weeks of gestation with a birth weight of 500 to 599 grams (threshold of viability) present the greatest uncertainty surrounding infant survival and outcome.” The following discussion from *Survival Rate of Extremely Low Birthweight Infants and its Effect on the Amendment of the Eugenic Protection Act in Japan*, is given on viability:

The term ‘viability’ does not simply mean ‘the ability to be born alive’ but does mean ‘the capability to grow and to develop normally in extrauterine environments’... Therefore, the discussion on viability should include the ultimate outcome of these ELBW [extremely low birthweight] infants from the viewpoints of physical and neurological growth and development... While there is a viability limit for ELBW infants, once they survive they should have the potential to grow and develop normally. If premature infants suffered from major sequelae, it was not because they were forced to live by modern technology in spite of their fatal destiny but because the antenatal, perinatal and postnatal management of them was inappropriate.¹⁸⁶

AHS’ discussion of viability needs to be reconsidered in this light.

The evidence of biases against extremely premature neonates is well documented. The primary reason for its inclusion and relevance to this project is to shed light on the extreme variation in neonatal active care policies, as well as to show both legislators and health care providers their own biases in discussion of these policies. Exposing one’s potential for bias against these tiny babies will remove barriers to achieving the policy changes needed. A 2015 National Post article, titled, *Canadian pediatricians recommend letting 22-week-old preemies die. Should doctors try to save the tiny newborns?*,¹⁸⁷ clearly highlighted these biases. This article includes stories of health care providers pressuring parents to take their premature infants off of life support or simply refusing to provide active care. It includes a story of 22-week twins being saved only because a health care worker intentionally changed their gestational age to 23 weeks.

The Canadian Pediatric Society (CPS) recommends palliative care for babies born at 22 weeks,¹⁸⁸ this National Post article interviewed neonatologist Dr. Annie Janvier, who is critical of the CPS position. Janvier says, “Doctors don’t actually say, ‘We don’t think it’s worth [treating a 22-week preemie].’ They say, ‘It doesn’t work,’ and that’s a lie. It’s not true ... When you realize you have been lied to by doctors,

¹⁸⁶ Nishida, H., & Ishizuka, Y. (1992). Survival rate of extremely low birthweight infants and its effect on the amendment of the Eugenic Protection Act in Japan. *Acta paediatrica Japonica : Overseas edition*, 34(6), 612–616. <https://doi.org/10.1111/j.1442-200x.1992.tb01020.x>

¹⁸⁷ [Canadian pediatricians recommend letting 22-week-old preemies die. Should doctors try to save the tiny newborns? | National Post](#)

¹⁸⁸ Lemyre, B., & Moore, G. (2017). Counselling and management for anticipated extremely preterm birth. *Paediatrics & child health*, 22(6), 334–341. <https://doi.org/10.1093/pch/pxx058>. Also see, [Counselling and management for anticipated extremely preterm birth | Canadian Paediatric Society](#)

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Discussion

it's extremely hurtful." The head of the CPA Fetal and Newborn Committee at the time, admitted that the CPA guideline based on gestational age was flawed and arbitrary, since gestational age is quite difficult to determine. Canadian bioethicist and previous NICU ethics consultant, Arthur Schafer, has no problem with this arbitrary recommendation, since it still provides some guidance. He is reported in this article as saying, "It's a kind of red flag... Maybe we shouldn't go here, maybe this is pushing our scientific, technical abilities beyond a point where they are of benefit to families and society and, most of all, the tiny babies." Schafer suggested that being born with access to care is "unlucky" for these tiny babies and their families. They would be "more fortunate if they had been living in a remote area ... where the baby would have died instead of being put through days and weeks of intensive, high-tech medicine, with virtually no chance of surviving, or surviving without overwhelming impairments."¹⁸⁹

Janvier points out the double standard at play here. "No one would balk, for instance, at trying to save an older child hurt in a car accident, even if their chances of survival were — like those 22-week preemies — 23 per cent, she said. Likewise, many adults receive intensive, costly treatment for advanced cancer despite negligible chances of cure." According to this article, Toronto-based patient advocate and researcher, Barb Farlow, notes that, "hospitals have long since ended the practice of leaving Down's syndrome babies to die, though these infants are at much more risk of cognitive impairment than extreme neonates."¹⁹⁰

The authors of *Should Extremely Premature Babies Get Ventilators During the COVID-19 Crisis?*, bring attention to the most important and under-emphasized issue pertaining to this project: for populations other than preterm infants, society is compelled toward rescue, and has engaged in massive resource reallocation in efforts to save the sick, however, extremely premature infants are treated as expendable, and decision-making standards of health care providers for withholding active care from these infants are focused on the possibility of survival with disabilities and a hesitancy to allocate resources to their care. "We should perhaps ask ourselves: if we used the decision-making standards [during the COVID-19 pandemic] of neonatologists for withholding life-sustaining interventions, would stadiums be built at all?"¹⁹¹

This question, and the "continued discrepancies in the public and ethical discourse between extremely premature infants and other populations [which] perpetuate biases in society," must be kept front of mind when discussing the cost of NICU programs and care of extremely premature neonates. There is a lack of data on the cost of treatment and hospital stay for neonates born at 22 weeks. The most likely explanation for this is the small number of babies that are born this premature, and the much smaller number of 22-weekers in Canada that actually receive active care. As reported, the cost of active treatment and the initial hospital stay for neonates around the 23-week mark is not substantively different from these costs for slightly older neonates, around the 24-25 week mark. As such, if legislators and healthcare administration are willing to allocate the amount of resources they do to the initial care for neonates born

¹⁸⁹ [Canadian pediatricians recommend letting 22-week-old preemies die. Should doctors try to save the tiny newborns? | National Post](#)

¹⁹⁰ Ibid.

¹⁹¹ [Full article: Should Extremely Premature Babies Get Ventilators During the COVID-19 Crisis?](#)

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at 24-25 weeks, resource allocation should not be a major concern for decisions surrounding the initial care of neonates born at 22 weeks, and even at 21 weeks. Costs of treatment will increase, as we saw moving from the 25-week mark to the 23-week mark, but not substantially. Considering how few infants are born at 22 weeks, and much fewer at 21 weeks, the overall cost to the healthcare system — to the taxpayers — will not substantially increase. The primary drivers of cost increases for care of these infants will come from the purchase of specialized NICU equipment, training NICU staff, and continued medical care and treatment later in life after NICU discharge. Unfortunately, there is a general absence of data on these costs, again, because of the small number of neonates born at these gestational ages, and the even smaller number of neonates that receive treatment. In 2017, the Government of Canada announced an investment of \$6.45 million through the Canadian Institutes of Health (CIHR), “to support a major research initiative focused on advancing knowledge in preterm birth research and improving the health outcomes for premature babies. This funding [was to be] matched in part by \$4.25 million of in-kind support from hospitals across Canada.”¹⁹² Providing funding to support better outcomes for preterm babies has never been contentious. If data from other healthcare jurisdictions show increasingly positive outcomes for babies born around the 22-week mark, our governments should invest equally in their treatment and care as they do for slightly older neonates.

In Canada, Alberta has one of the highest rates of preterm births and SGA births. Because of this, if the current NICU facilities in Alberta cannot accommodate the care of neonates born around the 22-week mark, it would be reasonable to establish a facility in Alberta, or to redevelop a current Alberta NICU to accommodate the care of these tiny babies. The care of extremely premature neonates in Canada would greatly benefit from national or provincial programs focused on training and standard of treatment. In Canada, the CNN EPIQ program could be further developed to provide training and standards of care for neonates born younger than 23 weeks. The same could be developed on a provincial level in Alberta through the MORE^{OB} Program. These programs, especially at a national level, ought to also standardize NICU level definitions across Canada.

Another consideration for future policy pertaining to this project is the law in Canada. Legislators must be aware of what protections for premature babies already exist, or potentially exist in current legislation. The most pertinent piece of legislation that can be used to protect extremely premature neonates is the Convention on the Rights of the Child (CRC). First, according to the CRC, the preborn baby is a child, and secondly, these children are entitled to the rights and protections set out in the CRC. CRC Article 6 states that, “every child has the inherent right to life. [And,] States Parties shall ensure to the *maximum extent possible the survival and development of the child.*” (Emphasis added.) Article 24 demands that, “States Parties recognize the right of the child to the enjoyment of the *highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health.* States Parties shall strive to ensure that *no child is deprived of his or her right of access to such health care services.*” (Emphasis added.) As well, “States Parties shall pursue full implementation of this right and, in particular, shall take appropriate measures: (a) *To diminish infant and child mortality;* [and] (b) *To ensure the*

¹⁹² [Government of Canada invests in better health for premature babies](#)

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provision of necessary medical assistance and health care to all children with emphasis on the development of primary health care.” (Emphasis added.) This, in conjunction with the protections for children listed in Article 3, exhibit the fact that current AHS procedures in relation to extremely premature neonates, are not in accordance with the rights for children laid out in this legislation.

The CRC also states that those counties which ratify this legislation must ensure that, “institutions, services and facilities responsible for the care or protection of children shall conform with the standards.” Thus, not only is AHS failing to conform with the CRC, but the Government of Canada has also failed to ensure that health institutions are implementing policies in accordance with the CRC. However, since health is provincial jurisdiction, it is the responsibility of the provinces, and in this case, the Government of Alberta, to take measures to meet Canada’s CRC obligations.

Protections for preborn children also find support in the Criminal Code of Canada. The Criminal Code gives a more specific definition of a child, stating that, “A child becomes a human being within the meaning of this Act when it has completely proceeded, in a living state, from the body of its mother, whether or not (a) it has breathed; (b) it has an independent circulation; or (c) the navel string is severed.” According to this definition, premature infants are considered children within the context of the Criminal Code. AHS policy specifically stating that active treatment is not recommended for extremely premature neonates born at 22 weeks gestational age — especially in context of the data illustrating positive outcomes for those infants who receive active treatment — constitutes “death that might have been prevented,” “neglect to obtain assistance in childbirth” and even “infanticide” as defined by the Criminal Code. While the Criminal Code often defines these acts as committed by the mother of the child, the same principle would apply to health care providers and administration who purposely deny treatment to these tiny babies. These offenses are punishable according to the law.

Policy makers can also reference the Alberta Child, Youth and Family Enhancement Act for legislated protection of the tiniest babies. AHS’ *Complex and Essential Pediatric Medical Process* stipulates that, “Medical discussions should include identifying or determining if harm is being done to the child due to lack of agreement about the course of care for the child.” This policy clarifies that, “The courts, in general, support parental decision-making unless their decision results in harm to the child including when the decision is determined to not be in the best interests of the child per the Child, Youth and Family Enhancement Act. This is different than the subjective perspective of the guardian(s) or family regarding what is best for the child which is influenced by a host of personal factors.” With this being the case, if the premature infant is considered a child in the context of the law, and is entitled to the protections of children set forth in the law, including this Act, AHS policy regarding these children is not in accordance with the law, nor this Act, which specifically states that “the best interests, safety and well-being of children are paramount.” Policy prescribing a denial of treatment for these tiny children constitutes a flagrant failure to comply with the law.

This project focused on policy regarding extremely premature neonates in Alberta, with reference to health policy in Ontario. However, these tiny babies need protection across Canada. In 2020, former President Donald Trump issued an Executive Order specifically protecting premature infants from discrimination in the provision of medical treatment. It states that health care providers must be made

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aware of their obligations towards premature infants, cannot unlawfully discourage parents from seeking medical treatment, and must transfer the premature neonate to an appropriate facility for care. If there is failure to do so, appropriate enforcement action will be taken. The Government of Canada should issue a similar Order, protecting even the tiniest babies and ensuring that they do not face discrimination in medical treatment because of their prematurity or disabilities. This Order can be predicated on Canada's commitment to the CRC, and the protection of children provided by the Criminal Code of Canada.

Finally, policy advisors, legislators and health care providers must take into account a foundational ethical consideration on policy regarding extremely premature neonates. In *How Do We Regard the Premie at the Margins of Viability?*, Carter provides the following discussion regarding the care of these infants:

Ethical motivations to care for smaller babies have included everything from beneficence—the provision of good; harm avoidance—viewing death as a greater harm than a lengthy stay in the neonatal intensive care unit (NICU) with an uncertain outcome and risk for residual health concerns; rescuing a most vulnerable person (or potential person?) from the harms of separation from the maternal life support system after premature delivery as a moral duty toward a human in need, perhaps as a step toward an opportunity for this newly born infant to have an open future; and a demonstration of empathy and compassion to the ill, similar to any other patient—a sense of compelling justice.¹⁹³

When addressing ethical questions regarding resource allocation, quality of life or uncertain outcomes, one must view the premature child as “one of us”; a human with the inherent right to life, a child with the same dignity and rights as every other individual and entitled to the same protections.

The various factors considered in the scope of this project support the active care for extremely premature neonates — as young as 22 weeks, and even those born at 21 weeks. Rolnitsky et al. concluded in *Cost of Neonatal Intensive Care for Extremely Preterm Infants in Canada*, that, “A formal cost-effectiveness analysis could provide further details on cost per-outcome... Our next steps would be to specifically evaluate regional differences and diagnoses that predict higher costs, thereby enabling a better understanding of neonatal morbidities as important determinants of societal spending on health.”¹⁹⁴ While this additional analysis can better inform future policy, if we approach our discussion of extremely premature infants as we do other in-need populations, our conclusions will support the care and treatment of these tiny babies.

¹⁹³ [How Do We Regard the Premie at the Margins of Viability? - The Journal of Pediatrics](#)

¹⁹⁴ [Cost of neonatal intensive care for extremely preterm infants in Canada - Rolnitsky - Translational Pediatrics](#)

THE RIGHT TO HOPE PROJECT

This project was inspired by the story of Thunder and Cloud, twin brothers born in Alberta who were denied medical care because of their gestational age. This section recounts their brief story, as recalled by their mother, Sonia.

Thunder and Cloud were born on July 26, 2019. While Sonia was pregnant and at clear risk for preterm birth, their OB/GYN and health care team provided no treatment to delay or prevent labour, nor did they provide any antenatal steroids. They did not offer these treatments, and when Sonia brought this up with the medical team, they refused to prescribe these treatments. The health care team explicitly told Sonia that antenatal steroids were not given before 23 weeks gestational age. Since Sonia had several episodes of bleeding, she was told that treatment to delay labour would be “controversial.” These bleeding episodes occurred between 15 and 20 weeks. When the first episode of bleeding occurred at 15 weeks, Sonia’s husband, Roy, brought her to the Edmonton Misericordia Community Hospital emergency department. She was told that she would not be admitted into Labour and Delivery until 20 weeks. Sonia was denied a wheelchair or a bed to lie down on because they were reserved for women in labour, and she “was not in labour.” When Sonia was finally admitted through the emergency department, she was dripping blood. The emergency department physician walked into Sonia’s cubicle, and without inspecting her, immediately told Sonia that she was having a miscarriage. The bedside ultrasound revealed otherwise, the physician was surprised and said, “Oh, they’re alive.” The comprehensive ultrasound examination later revealed that Sonia was suffering from a Subchorionic Hemorrhage (SHC). SHC is known to increase the risk of preterm delivery. Between 15 and 20 weeks, Sonia visited the Edmonton Misericordia Community Hospital — where her original OB/GYN worked — about four times for SHC bleeding episodes. At no point during these visits did the medical team discuss the potential of extremely preterm birth, and what would happen in that case. Every time, Sonia was told to go home and “take it easy.” At the end of the 19th week, Sonia suffered an especially bad SHC bleeding episode, and had lost part of her mucus plug. She was admitted into the Edmonton Misericordia Community Hospital for bed rest. At this point, there was an expectation of preterm birth. The Misericordia Hospital was not equipped to handle births before roughly 30 weeks gestational age, and so Sonia was transferred to the Edmonton Royal Alexandra Hospital and reassigned an OB/GYN.

Sonia stayed at the Royal Alexandra Hospital throughout her delivery. She was in labour for 19 hours. At birth, Cloud was 22 1/7 weeks and Thunder was 21 3/7 weeks, a five-day size difference. When Sonia went into delivery, her doctor told her that the NICU team was going to come in and talk with her at some point. Between 10 and 14 hours of labour, the NICU specialist and a student/assistant nurse came in to talk with Sonia and Roy. They told Sonia that her baby boys had a zero percent chance of survival. The hospital had no tubes small enough to care for the babies, besides this, babies never survived that young. If the boys received active care, Sonia and Roy would be causing them pain until they died. Sonia was told, no matter what, death would be the outcome, and her boys’ pain would only be prolonged by active treatment. Sonia and Roy pushed for care, asking many times for the NICU team to try to save their

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boys. They specifically brought up that it is normal for twins to be different sizes, and asked the NICU team why they based the recommendation for care off of the gestational age of the smallest twin. According to Sonia, the NICU team was very negative, and played with their emotions, making them feel like selfish parents for wanting treatment for their boys. This is the first time there was a conversation about neonatal treatment. Sonia and Roy did not have a Goals of Care conversation regarding neonatal treatment with any member of the health care team before this.

Sonia and Roy believed their doctor, and finally acceded to the NICU team's pressure. When Thunder and Cloud were born, no active treatment was provided, Thunder lived for 1 hour and 20 minutes, and Cloud lived for 1 hour and 30 minutes. When Sonia and Roy got home a few days later, they started doing their own research. They realized that their baby boys did have a chance, and they had been lied to by the NICU team.

According to the description of events by Sonia, her health care team, regulated by AHS, failed in several regards. The health care team did not have a Goals of Care conversation regarding neonatal treatment options until Sonia was between 10 and 14 hours in labour. This specifically disregards the AHS guideline found in *Advance Care Planning and Goals of Care Designation*, that "Goals of care conversations shall take place, where clinically indicated with the patient, as early as possible in a patient's course of care and/or treatment." With SHC being a known cause of preterm birth, conversations regarding whether treatment would be denied prior to a certain gestational age should have occurred at any one of the hospital visits Sonia had for her SHC bleeding episodes.

The fact that Sonia's medical team denied her antenatal steroids, or corticosteroids is in line with AHS policy to not administer this treatment prior to the 23-week mark. This policy can be found in AHS' *Clinical Assessment of 'At Risk' or Actual Preterm Labor for Triage*, where it states multiple times that, "Routine use of corticosteroids is not recommended in the pre-viable (less than 23 0/7 weeks of gestation) pregnancy"¹⁹⁵ The document does state that, "Threatened and/or actual preterm labour requires active and timely assessment and decision-making, as prophylactic treatments (corticosteroids) and management options (antibiotic; tocolytic; maternal transfer; neonatal transfer) may be required to reduce morbidity and mortality in the maternal – fetal pair."¹⁹⁶ However, since AHS uses a definition of fetal viability — "Infants born between greater than or equal to 23 0/7 weeks and 24 6/7 weeks of gestation with a birth weight of 500 to 599 grams" — that is outdated and disputed by data, this policy must be updated to reflect the most recent research. While antenatal care recommendations, including the use of corticosteroids, is beyond the scope of this project, the *Canadian Neonatal Network Annual Report 2020* does include the use of antenatal steroids prior to 23 weeks gestational age.¹⁹⁷

During the conversation Sonia and Roy had with the NICU specialist and the student/assistant nurse, they were made to feel guilty for wanting to pursue treatment for their infants. When the health care

¹⁹⁵ CLINICAL ASSESSMENT OF 'AT RISK' OR ACTUAL PRETERM LABOUR FOR TRIAGE guideline HCS-183-01, Pg. 8

¹⁹⁶ *Ibid.*, Pg. 2

¹⁹⁷ Annual Report 2020 Rapport Annuel, Pg. 22

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team told Sonia and Roy that their babies had a *zero percent chance* of survival, they were narrowly in line with AHS policy which states that, “The survival of infants born before or at 22 6/7 completed weeks of gestation remains uncommon,” as well, “Infants born between greater than or equal to 23 0/7 weeks and 24 6/7 weeks of gestation with a birth weight of 500 to 599 grams (threshold of viability) *present the greatest uncertainty surrounding infant survival and outcome.*” (Emphasis added.) To be clearly within AHS recommendations and guidelines, these health care providers should have told Sonia and Roy that survival for babies at that gestational age is “uncommon,” rather than stating there was a zero percent chance of survival. Yet, since AHS has a clear policy that active treatment prior to 23 weeks gestational age is not recommended, the health care team did provide treatment recommendations that were consistent with AHS policy. Sonia had asked the NICU team why they based the recommendation for care off of the gestational age of the smallest twin, however, regardless of which gestational age was used, neither twin, at 22 1/7 and 21 3/7 weeks, qualified for active care per AHS policy.

AHS policy, in *Clinical Assessment of ‘At Risk’ or Actual Preterm Labor for Triage* states that, “*Community practitioners should be educated about the management options for extreme prematurity and should have the option to call specialist practitioners for advice in managing these cases.*” (Emphasis added.) As well, it states that, “Parents facing the birth of an extremely preterm infant should have the *opportunity to meet with the most responsible health practitioners from both the obstetrical and paediatric/ neonatal care to receive accurate information about their infant’s prognosis.* This information should be provided with *clarity and compassion.*” (Emphasis added.) The NICU specialist who spoke with Sonia and Roy did not give an opinion on active treatment that was consistent with the existing research, or was not educated about the data supporting positive outcomes for these tiny babies who receive active treatment. It is possible that the NICU specialist who spoke with Sonia and Roy did consult with a neonatologist specializing in extremely premature births in advance. However, Sonia and Roy were not given “accurate information about their infant’s prognosis.” They were technically provided with the *option* to meet with the MRHP from both obstetrical and paediatric/neonatal care: Both in the Misericordia Community Hospital, and once admitted to the Royal Alexandra Hospital, Sonia had been assigned an OB/GYN. As well, during labour, Sonia and Roy had a single conversation with the NICU team. However, as mentioned earlier, conversations regarding potential neonatal care should have happened prior to labour. According to Sonia’s account, during her pre-labour hospital visits, her OB/GYN and health care team did not discuss the denial of active neonatal care if her boys were born prior to a certain gestational age.

In AHS’ *Dispute Prevention and Resolution in Clinical Settings* procedure, it emphasizes the importance of timely decisions in dispute prevention and resolution, “*allowing adequate time for all parties to understand and consider the choices and implications.* Patients / alternate decision-makers and health care professionals should be given adequate time in keeping with the clinical situation, *and not be subjected to coercion or undue pressure regarding the decision and alternate options.*” (Emphasis added.) The single conversation the NICU team had with Sonia and Roy was not one marked by “compassion”; Sonia distinctly felt pressured, guilty, and selfish for wanting treatment for her baby boys. This is not in line with AHS policy both in *Clinical Assessment of ‘At Risk’ or Actual Preterm Labor for Triage* and in

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Dispute Prevention and Resolution in Clinical Settings. As mentioned, a conversation about active treatment options for Sonia’s babies did not occur until she was 10 to 14 hours into labour, which does not at all allow for “adequate time for all parties to understand and consider the choices and implications.”

Sonia and Roy disagreed with the NICU team, but eventually acceded to their pressure. Had Sonia and Roy continued to demand treatment for their infants, AHS’ conflict resolution process would have been initiated. From the earlier discussion of this process, it is clear that the outcome would have remained the same. First, AHS’ conflict resolution process does not truly allow for any recourse for the patient. Once the GCD Order has passed through the entirety of AHS’ bureaucracy, Sonia and Roy’s only option would be to initiate legal proceedings, which, at 10 to 14 hours into labour, is not a realistically possible option. In this case, the treatment plan submitted by the NICU team — no treatment — would have been carried out.

Thunder and Cloud were failed by the health system in Alberta, and specifically by AHS. Had AHS policy been in line with that of other jurisdictions, such as Ontario, or had AHS staff known of the data supporting positive outcomes for babies at their gestational age, Thunder and Cloud would have received treatment. This project cannot comment on the likelihood of success of this neonatal intensive treatment. While AHS policies regarding viability based on gestational age and birth weight are not supported by the relevant data, Thunder and Cloud were extremely small babies. Thunder was born at 289.2g birth weight and measured 21 3/7 weeks, and Cloud at 340.2g birth weight and measured 22 1/7 weeks. In light of the data previously reviewed, Thunder and Cloud are exceptionally small; treatment may not have succeeded, and long-term outcomes are even more uncertain. The *Canadian Neonatal Network Annual Report 2020* reported that across the CNN in 2020, there were only 13 neonates born with a birth weight less than 400g, of which 46% received active care in the delivery room, and only 17% of those neonates survived. The Tiniest Babies Registry, a collection of neonatal survival stories from across the world dating back to 1936, includes 35 cases of neonates born under 289.2g – Thunder’s birth weight – and 114 cases of neonates born under 340.2g – Cloud’s birth weight. Twins are always smaller than single babies, it is possible that Thunder and Cloud could have been treated as SGA babies, however, as the previous discussion highlighted, there must be specific case decisions, since SGA neonates may not only just be small, but may also have developmental concerns.

There is anecdotal evidence (see Appendix E) supporting positive outcomes for babies born at extremely low birth weights (below 400g), or at 21 weeks gestational age. However, while the empirical evidence available supports positive outcomes and active treatment for babies born at or greater than 400g birth weight, or at 22 weeks gestational age, outcomes for neonates that are smaller and younger than these thresholds are not well supported. The primary reason for this is likely because so few babies are born that early, and as such, anecdotal evidence is the best data available. Providing active care for babies at 21 weeks or weighing less than 400g requires very specialized training and equipment. Had AHS policy been in alignment with merely the empirical data available, AHS would provide active care for babies born at 22 weeks. Since Thunder and Cloud were measured at different gestational ages, Cloud would have met this threshold, but Thunder would not. With this being the case, physicians would need to provide advice as to how to measure gestational age for twins at different weights. If AHS policy recommendations for

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treatment were based on birth weight rather than gestational age, specific recommendations must be made for twins at different birth weights.

Thunder and Cloud's story points to a tragic failure of Alberta's health system to protect and care for vulnerable newborn babies. It is also a unique case, as premature twin births present distinctive challenges. It was their story and the advocacy of their mother, Sonia, that inspired this project. There is no stronger call for change in the healthcare system than from the testimony of Thunder and Cloud's mother:

I share our story in honour of our sons who I carried for 22 weeks and who I will love for a lifetime. I hope no one ever again watches their infants die while they ask for help and receive no care. Babies have the right to medical assistance like anyone else, and parents should have the right to hope. In honour of our sons, and the growing number of children who survive 21 and 22 week births, I call our medical system to a higher standard of practice that offers care to any baby born alive.¹⁹⁸

¹⁹⁸ See, https://www.thewilberforceproject.ca/right_to_hope

CONCLUSION

In the discussion of policy considerations, it was emphasized that the most important consideration is whether we should treat extremely premature neonates, and extend resource allocation to their treatment, in the same manner as we do other populations. The answer is clearly yes. We are a society compelled toward rescue, however, in many places, including Alberta, we treat extremely premature babies as expendable, and the bias against them is well documented. The data strongly supports the active care and treatment of neonates born at 22 weeks, and health policy in Alberta must be changed to reflect this. Positive outcomes for babies born at 21 weeks are not well supported by the empirical data available, however, this is due to the extremely small number of babies born that early. We could only use the anecdotal evidence available to support treatment for babies born at 21 weeks. This may be controversial, however, we would extend intensive treatment for a chance of survival — even if that chance is small — to other populations, and thus, if biases are recognized and set aside, we should extend that same chance at life to these tiny babies born at 21 weeks. There will be a cost associated with this, but not significantly more than for the treatment and care of slightly older neonates. Again, if we treat these tiny babies as we do older children or adults with the same chance at survival, resource allocation is not a paramount concern in the decision-making process. If there is a chance of survival for babies born at 22 and 21 weeks, society, the healthcare system, and medical professionals, should not abandon them and leave them to die. As we are compelled toward rescue for others, we should extend the same chance at life to these tiny babies, giving parents and families the right to hope for their little ones.

Appendix A

Service Delivery Model by Level of Hospital

Obtained from CRITERIA TO SUPPORT APPROPRIATE LEVEL OF OBSTETRICAL CARE guideline HCS-201-01, Appendix A:

Service Delivery Model by Level of Hospital

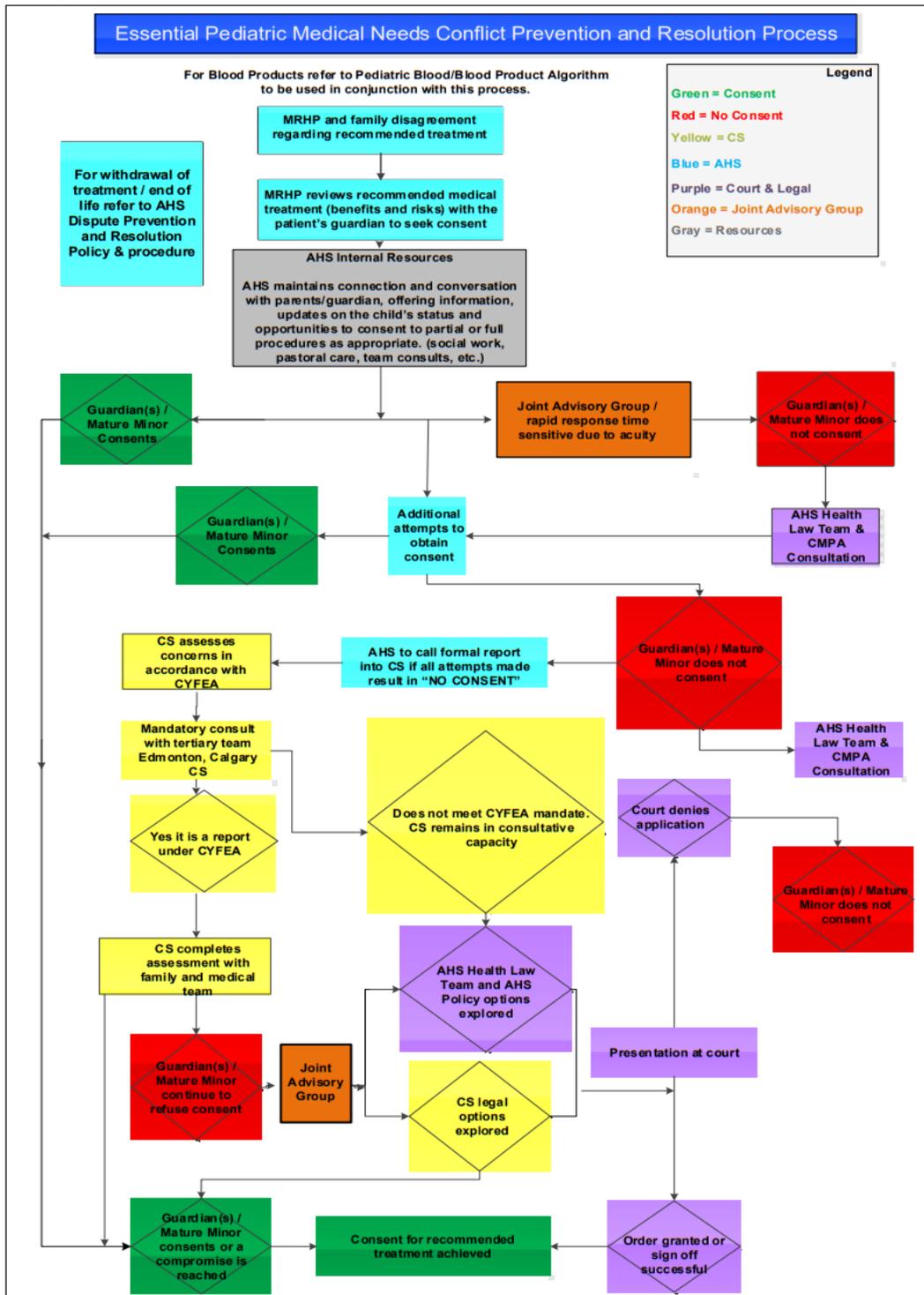
- Level 0 Hospital = hospital that does not routinely provide obstetrical support
- Level 1 A Hospital = hospital with no operating room capability
- Level 1 B Hospital = hospital with 24/7 Operating Room (OR) and Cesarean section capability
- Level 1 C Hospital = hospital with 24/7 OR plus obstetrical specialist
- Level 2 Hospital = hospital with full obstetrics, surgical and pediatric services including L2 NICU
- Level 3 Hospital = hospital with full obstetrics, surgical and neonatal services including L2 & 3 NICU

Community and Rural Maternal Services Intrapartum Pathway for Planned Birth					
Indicators	Level 1A Home or birth center No OR	Level 1B 24/7 OR	Level 1C OR + OB/GYN	Level 2 OR + OB/Gyn +L2 NICU	Level 3 Tertiary L3 NICU
Average risk obstetrics 37 to 40 or greater weeks gestation	Home, Birth Center, L1A, 1B, 1C, 2 or 3				
Planned Low Risk Induction gestation of 38 weeks or greater, multip, Bishop score of 6 or greater, established back up plan with referral hospital and patient consent	L1A, 1B, 1C, 2 or 3				
Planned caesarean of 39 weeks or greater gestation	L1B, 1C, 2 or 3				
Planned induction of labour 37weeks or greater gestation with medical indication	L1B, 1C, 2 or 3				
Women presents to hospital in labour at assessment/triage area: Professional judgement is used to assess maternal risk and need for consult and/or transfer to appropriate level of care facility.					
Consider consultation: Abnormal presentation, atypical or abnormal fetal heart, dystocia	L1B, 1C, 2 or 3				
Consultation and possible transfer Maternal tachycardia, maternal hypertension, urine protein 2+, pyrexia, significant vaginal blood loss	L1 C, 2 or 3				
Consultation and transfer Preterm labour, caesarean less than 37 weeks, rupture of membranes greater than 24 hours, non-labour pain with other risks, multiple fetuses, intrauterine growth restriction, macrosomia, oligohydramnios or polyhydramnios.	L2 or 3				
Transfer- Preterm labour- Between 22 and 30 weeks gestation	L3				
If any of the factors above are observed but birth is imminent, assess whether birth in the current location is preferable to transferring the woman to alternate level site. Consider need for neonatal transport. Any plan for transport to be preceded by cervical exam and discussion with the health care team and EMS to determine risk of on route delivery					

Appendix B

Essential Pediatric Medical Needs Conflict Prevention and Resolution Process

Obtained from AHS' COMPLEX AND ESSENTIAL PEDIATRIC MEDICAL PROCESS - HCS-230-01 guideline, Appendix B:



Appendix C

Email RE: Clarification Regarding Appendix B

This is an email conversation between myself and AHS Policy Services. I sought clarification of the dispute resolution process outlined in Appendix B and elsewhere in AHS procedures regarding an impasse in dispute. AHS Policy Services' answer to my question was far from satisfactory:

From: [REDACTED]
Sent: Tuesday, June 14, 2022 9:15 AM
To: Policy <Policy@albertahealthservices.ca>
Subject: COMPLEX AND ESSENTIAL PEDIATRIC MEDICAL PROCESS

Caution - This email came from an external address and may contain unsafe content. Ensure you trust this sender before opening attachments or clicking any links in this message

Good morning,

I have a couple questions regarding the following guideline: [COMPLEX AND ESSENTIAL PEDIATRIC MEDICAL PROCESS](#)

Per Appendix B, what is the final step if after the court denies the application, the guardian(s)/mature minor still does not consent to AHS recommended treatment/withdrawal of treatment?

If I refer to section 3.8 of the following procedure; [DISPUTE PREVENTION AND RESOLUTION IN CLINICAL SETTINGS](#), in situations of impasse, after all the appropriate parties have been notified and signed off on the AHS recommended treatment plan (section 3.8.a-d), "in consultation with the AHS Health Law Team, the Critical Care Physician or MRHP informs the patient / alternate decision-maker(s) and/or family of the intent to pursue the proposed treatment plan and provides the patient / alternate decisionmaker(s) and/or family with written reasonable advance notice of when the treatment plan will be implemented." (section 3.8.e)

To clarify, in cases of withdrawal of treatment/end of life, if the AHS proposed treatment plan concludes that treatment or palliative care is to be subsequently ended, and the patient / alternate decision-maker(s) and/or family do not have time to or choose not to seek legal advice, is it the case that treatment or palliative care will in fact be withdrawn?

I know it's a bit of a convoluted question, but I am just seeking clarification on the procedural documents!

Thank you so much, I am looking forward to your response.

Regards,

[REDACTED]

This message and any attached documents are only for the use of the intended recipient(s), are confidential and may contain privileged information. Any unauthorized review, use, retransmission, or other disclosure is strictly prohibited. If you have received this message in error, please notify the sender immediately, and then delete the original message. Thank you.

Appendices

From: [REDACTED]@albertahealthservices.ca>
Sent: June 14, 2022 11:53 AM
To: [REDACTED]
Subject: RE: COMPLEX AND ESSENTIAL PEDIATRIC MEDICAL PROCESS

Hi [REDACTED]
Thankyou for contacting policy services. These situations are very complex and in such cases there would be a health care team (including medical lead) and support from clinical legal and others for these decisions so there is not a black and white answer to your question. That is why this process has been established to support the health care team and patients and families. The process, not the procedure would provided the clarification as every case is unique.

Regards,

[REDACTED]
Senior Advisor- Policy Services
Health Professions Strategy & Practice, AHS

[REDACTED]

In the spirit of reconciliation, I acknowledge that I live, work and play on the traditional territories of the Blackfoot Confederacy (Siksika, Kainai, Piikani), the Tsuut'ina, the Îyâxe Nakoda Nations, the Métis Nation (Region 3), and all people who make their homes in the Treaty 7 region of Southern Alberta.

From: [REDACTED]
Sent: Tuesday, June 14, 2022 12:52 PM
To: [REDACTED]@albertahealthservices.ca>
Subject: Re: COMPLEX AND ESSENTIAL PEDIATRIC MEDICAL PROCESS

Hi [REDACTED]

Thank you so much for your response, I really appreciate it!

Does the AHS policy department provide any further official guidance in situations where an impasse is irresolvable after having already gone through the outlined process?

I appreciate the thoroughness of the AHS guidelines and processes, but I could use some clarification on this. The *Dispute Prevention and Resolution in Clinical Settings* document outlines a series of steps (section 3.8.a-d) for a MRHP to follow in consulting other individuals in the health care team, as you had mentioned. However, section 3.8.e essentially states that despite the uniqueness of each situation, there is a possible outcome where the health care team and the patient / alternate decision-maker(s) and/or family are at odds, and no agreement can be reached, despite all efforts. In this case, is the recommended treatment plan/withdrawal of the health care team and clinical legal team the ultimate plan of action? Section 3.8.e.i and 3.8.e.ii, specifies that if the patient / alternate decision-maker(s) and/or family have not initiated legal proceedings, "the consulting Critical Care Physician or MRHP and the health care team may, in appropriate circumstances, *proceed with the treatment plan* after obtaining legal advice (e.g., from AHS Health Law Team and CMPA)." (emphasis added). This suggests that the answer to my question above is, that at an ultimate impasse, it is the treatment plan recommended by our AHS health care team and clinical legal team that will be followed through with.

As a student, I would really like to get a clear picture of this process, and a clear answer to this problem. Health care is tricky, and you're right, often there are no black and white answers. However, in this case, the policy documents suggest that there is an answer, and I am just looking to clarify.

Again, I'm grateful for your help in trying to understand this, thank you! Hope you're staying dry today!

Appendices

From: [REDACTED]@albertahealthservices.ca>

Sent: June 14, 2022 1:09 PM

To: [REDACTED]

Subject: RE: COMPLEX AND ESSENTIAL PEDIATRIC MEDICAL PROCESS

Hi [REDACTED]

Policy Services is not the Subject Matter Expert. If there was an impasse all kinds of internal and external stakeholders would be pulled into resolve (e.g., ethics, social work, legal, medical experts, Children's services).

Good luck with your studies!

[REDACTED]

Appendix D

Recent Studies Reporting Gestational-Age Specific Survival Following Periviable Birth

Recreated from Survival of Infants Born at Periviable Gestational Ages - PMC. Note that TOP means termination of pregnancy:

Study (publication year)	EPICure (2012)	EXPRESS (2013)	EPIPAGE-2 (2015)	Victoria (2016)	NICHD NRN	Japan NRN (2013)	SNN (2016)	Pediatrix (2016)	CNN (2013)
Study Type	Population-based cohort studies				Center-based cohort studies				
Source population	National	National	National (except 1 region, 2% of births)	Regional	18 network centers	48 tertiary centers	15 NICUs (95% of births in nation)	362 NICUs	National network of NICUs
Country	UK	Sweden	France	Australia	US	Japan	Switzerland	US	Canada
Year(s)*	2006	2004–2007	2011	2010–2011	2013–2015	2003–2005	2009–2012	1997–2013	2010–2011
Sample size (at 22–25 weeks)	2034–1454	707 (501)	5169 (641)	541 (279)	2430	1057–1057	3068–450	64,896–17,085	6106–1208
GA inclusion	22–26 weeks'	<27 weeks'	22–34 weeks'	22–27 weeks'	22–25 weeks'	22–25 weeks'	23–31 weeks'	22–29 weeks'	23–30 weeks'
Minimal BW inclusion	400g	None	None	None	401g	None	None	None	None
Inception (denominator reported by study)	Live birth or stillbirth	Live birth or stillbirth	Live birth, stillbirth or TOP	Live birth	Live birth	Live birth	Live birth	NICU admission	NICU admission
Denominator	Live births							Infants admitted to center	
Outborn, % of denominator	14.7% - Included	16.5% - Included	21.0% - Included	15.5% - Included	Not reported	9.3% - Included	4.9% - Included	18.5% - Excluded	18.1% - Included
Exclusions	TOP	TOP, birth outside country	No verbal consent	TOP, birth defects	Outborn	Admitted after 28d, birth defects		Outborn, transfer, birth defects	Multiplied
Survival assessment	Survival to d/c	Survival to 1 year	Survival to d/c	Survival to d/c	Survival to d/c	Survival to d/c	Survival to d/c	Survival to to d/c	Survival to to d/c

Appendix E

Anecdotal Evidence of Perivable Birth Positive Outcomes

Survival Stories:

Everlei & Rylei, twins born at 22 2/7 weeks.

Keeley and Kambry: twins born at 22 1/7 weeks, weighing 490g and 449g.

Emma and Luna: twins born at 22 2/7, weighing 411.1g and 453.6g.

Makenzie and Makayla: twins born at 22 3/7 weeks, weighing 481.9g and 538.6g

Ruben and Jenson: twins born at 22 6/7 weeks, weighing 533g and 589.7g.

Jemarius: born at 21 0/7 weeks, weighing 368.5g

Frieda: born at 21 5/7 weeks, weighing 425.2g.

Fayth: born at 21 5/7 weeks, weighing 576g.

Avery: born at 21 6/7 weeks, weighing 350g.

Diana: born at 22 5/7 weeks, weighing 340.2g.

Lyla: born at 21 4/7 weeks, weighing 411.1g.

Additional stories of success and tragedy can be found at; TwentyTwo Matters and A Moment with Kailor and Thunder and Cloud