

## Premature Birth in Canada: An Environmental Scan

Prepared for:  
Canadian Premature Babies Foundation –  
Fondation pour Bébés Prématurés Canadiens

Report – Final

*The ICU is such an intensive environment and such a medical environment, and yet what these babies need is their parents more than anything. So that's not machines, it's not technology, it's not sexy, but it's needed. And I think there's a greater and greater awareness of the critical nature of that need.*

*- Neonatologist*

*Our primary nurses made sure we learned how to take care of our daughter as soon as possible (diapers, temperatures, baths, medication). At the end, they were proud to say we were very much independent! I loved it, it made me feel like a mom. A NICU mom, but a mom. It normalized it all a little.*

*- Parent*

# Table of Contents

<b>ACKNOWLEDGEMENTS</b>	<b>IV</b>
<b>EXECUTIVE SUMMARY</b>	<b>V</b>
<b>INTRODUCTION</b>	<b>1</b>
<b>METHODOLOGY</b>	<b>4</b>
LITERATURE REVIEW	4
INTERVIEWS AND FOCUS GROUPS	4
DATA ANALYSIS	5
<b>FINDINGS</b>	<b>7</b>
<b>ABOUT PREMATURE BIRTH</b>	<b>7</b>
❖ DEFINITION	7
❖ PREMATURE BIRTH IN CANADA	7
❖ RISK FACTORS	10
<b>THE IMPACTS OF PREMATURE BIRTH</b>	<b>11</b>
❖ MORBIDITY AND MORTALITY	11
❖ IMPACTS ON PARENTS AND FAMILIES	13
❖ LONG-TERM OUTCOMES	14
<b>SUCCESSES IN THE DELIVERY OF CARE RELATED TO PREMATURE BIRTH</b>	<b>16</b>
❖ HIGH QUALITY CLINICAL CARE	17
❖ PROGRESS IN IMPLEMENTING FAMILY-CENTRED CARE	19
❖ SUPPORTS FOR FAMILIES WHILE IN HOSPITAL	21
❖ RESEARCH AND QUALITY IMPROVEMENT	22
❖ DISCHARGE PLANNING AND FOLLOW-UP	23
❖ ELEMENTS OF HEALTH CARE PROVIDER EDUCATION WORKING WELL	23
❖ ORGANIZATION OF CARE	24
❖ PEER SUPPORT	25
❖ SUPPORT FOR BREASTFEEDING	25
<b>CHALLENGES IN THE DELIVERY OF CARE RELATED TO PREMATURE BIRTH</b>	<b>26</b>
❖ LACK OF CONSISTENCY AND CONTINUITY IN CARE	26
❖ BARRIERS TO FAMILY-CENTRED CARE	27
❖ AREAS FOR IMPROVEMENT IN CLINICAL CARE	28
❖ INSUFFICIENT SUPPORT DURING AND AFTER DISCHARGE HOME	29
❖ LIMITED EMOTIONAL AND PRACTICAL SUPPORTS FOR FAMILIES	30
❖ TRANSFERS BETWEEN FACILITIES	32
❖ BARRIERS TO ACCESSING CARE	33
❖ GAPS IN EDUCATION FOR THOSE WORKING WITH PRETERM BABIES	34
❖ ATTITUDES OR APPROACHES OF HEALTH CARE PROVIDERS	34
❖ FINANCIAL BURDEN FOR FAMILIES	35
❖ LIMITED SUPPORTS FOR LATE PRETERM BABIES	36
❖ LACK OF LONG-TERM FOLLOW-UP	37
❖ LIMITED RESOURCES DEVOTED TO ADDRESSING PREMATURE BIRTH	37
❖ LACK OF AWARENESS ABOUT PREMATURE BIRTH	38
<b>BEST PRACTICES AND SUPPORTS REQUIRED</b>	<b>38</b>

❖	PREVENTION OF PREMATURE BIRTH	39
❖	INCREASING AWARENESS OF PREMATURE BIRTH	41
❖	DECISION-MAKING AROUND PREMATURE BIRTH	41
❖	CLINICAL CARE	43
❖	FAMILY-CENTRED CARE	47
❖	SUPPORTS FOR FAMILIES	50
❖	TRANSFER AND DISCHARGE HOME	54
❖	LONG-TERM FOLLOW-UP AND CARE	57
❖	EDUCATION FOR THOSE WORKING WITH PREMATURE BABIES	59
❖	QUALITY IMPROVEMENT AND RESEARCH	61
<b>ANALYSIS AND RECOMMENDATIONS</b>		<b>65</b>
<b>1.</b>	<b>AWARENESS AND PREVENTION</b>	<b>65</b>
❖	PREVENTION	65
❖	AWARENESS OF PREMATURE BIRTH	65
❖	RECOMMENDATIONS	66
<b>2.</b>	<b>BIRTH AND CARE IN HOSPITAL</b>	<b>66</b>
❖	CLINICAL CARE	66
❖	FAMILY-CENTRED CARE	66
❖	DECISION-MAKING RELATED TO PREMATURE BIRTH	67
❖	RECOMMENDATIONS	68
<b>3.</b>	<b>DISCHARGE AND FOLLOW-UP</b>	<b>68</b>
❖	RECOMMENDATIONS	69
<b>4.</b>	<b>ACROSS THE CONTINUUM</b>	<b>69</b>
❖	FAMILY SUPPORT	70
❖	RESEARCH AND QUALITY IMPROVEMENT	70
❖	HEALTH CARE PROVIDER EDUCATION	71
❖	RECOMMENDATIONS	71
<b>SUMMARY OF ALL RECOMMENDATIONS</b>		<b>72</b>
<b>CONCLUSION</b>		<b>73</b>
<b>APPENDIX A: INTERVIEW AND FOCUS GROUP PARTICIPANTS</b>		<b>74</b>
<b>APPENDIX B: INTERVIEW AND FOCUS GROUP GUIDES</b>		<b>76</b>
<b>KEY INFORMANT INTERVIEW GUIDE</b>		<b>76</b>
<b>PARENT FOCUS GROUP GUIDE</b>		<b>79</b>
<b>HEALTH CARE PROVIDER FOCUS GROUP GUIDE</b>		<b>82</b>
<b>CANADIAN PREMATURE BABIES FOUNDATION BOARD FOCUS GROUP GUIDE</b>		<b>84</b>
<b>BIBLIOGRAPHY</b>		<b>87</b>

## **Table of Figures**

Figure 1: Rates of Preterm Birth in Canada, 2011/12.....	7
Figure 2: Premature Babies admitted to NICU*, 2012.....	9
Figure 3: Length of Stay in NICU, 2012 .....	10
Figure 4: Survival Rates at Discharge by Gestational Age, 2012.....	12
Figure 5: Average In-Patient Hospital Costs (2005/06 cost data) .....	15

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## Executive Summary

Premature birth in Canada is a growing issue, with rates of premature birth on the rise across the country, and particularly among Aboriginal populations. Babies born prematurely have both immediate health and supportive care needs, and may also experience long-term impacts such as increased risk of developmental or physical challenges. The economic burden of prematurity in Canada is significant, at \$587.1 million.<sup>1</sup>

The government of Canada has joined global efforts to address the issue of maternal and child health at the international level. Around the world, a number of different groups are working to raise awareness about premature birth and advocate for change. In Canada, the Canadian Premature Babies Foundation-Fondation pour Bébés Prématurés Canadiens (CPBF-FBPC) is the national organization for premature babies. In order to support their work going forward, CPBF-FBPC has commissioned this environmental scan on the issue of premature birth. The environmental scan included a review of the grey and academic literature and focus groups and interviews with key informants from across the country.

While the environmental scan identified areas where care for premature babies and their families is working well (such as the provision of high quality clinical care; progress in implementing family-centred care; and an increasing emphasis on research and quality improvement activities national and at the local level), gaps or challenges and areas where care could be improved were also identified. The greatest areas of need included addressing issues related to consistency and continuity of care; improving provision of family-centred care, including appropriate supports that will facilitate family participation in care (e.g., on-site accommodations, parent and health care provider education); increasing supports for families, particularly supports that will address families' emotional needs, the financial burden of an extended hospital stay, and the period immediately following discharge home;

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<sup>1</sup> K. M. Johnston et al., "The Economic Burden of Prematurity in Canada," *BMC Pediatr* 14(2014).

improving planning for and family supports when a baby is transferred to another facility; and increasing access to long-term follow-up and care for all premature babies.

Based on the findings from the environmental scan, ten recommendations have been developed that span the continuum of care for premature babies and their families. These recommendations, if implemented, can help to increase awareness of premature birth in Canada and improve the care and support received by families who experience a preterm birth.

- 1.1 It is recommended that provincial governments and other health authorities identify and implement initiatives that have been shown to reduce or prevent premature birth. This includes interventions at the level of primary prevention as well as secondary and tertiary prevention.
- 1.2 It is recommended that stakeholders in the area of premature birth work together to increase awareness of premature birth among the general public.
  
- 2.1 It is recommended that hospitals continue their efforts to improve clinical care. Priority areas include reducing barriers to developmental care and improving the consistency and continuity of care across facilities and between health care providers.
- 2.2 It is recommended that hospitals work to reduce barriers to family-centred care through initiatives that address physical barriers (e.g., lack of place for family to stay at the hospital while the baby is there) and improve staff support (e.g., staff education and training on empowering parents to provide care, inclusion of the family perspective in staff orientation/training, etc.). Hospitals should also examine their policies and approaches to ensure that care is as family-centred as possible.
- 2.3 It is recommended that Canadian standards or guidelines for family-centred care be developed and implemented to help ensure consistency in the approach across facilities.
  
- 3.1 It is recommended that hospitals review their discharge planning policies and processes to ensure that families are sufficiently prepared to go home (or to another facility) and

that adequate planning for discharge is conducted well in advance of the time of discharge. Families should be actively involved in the discharge planning process.

- 3.2 It is not likely possible to completely eliminate the need for emergency transfers of premature babies to other facilities. However, it is recommended that hospitals make every effort to alleviate the stress associated with an emergency transfer by discussing the possibility with families in advance, and obtaining the family's preference for the transfer location.
- 3.3 It is recommended that governments and hospitals explore extending long-term follow-up care and support to include more premature babies (i.e., the moderate and late preterm babies), and to cover a longer period of time, into the preschool years at a minimum.
- 4.1 It is recommended that governments work with hospitals to support expanding the supports available to families with premature babies. These could include physical supports such as accommodations, financial supports such as extended parental leave, and social and emotional supports such as peer support or access to counselling services. Families that are particularly vulnerable would benefit from additional supports.
- 4.2 It is recommended that hospitals and research institutions enhance support for research and quality improvement. This could include additional research funding, financial and staff support for quality improvement activities, and continued support for the Canadian Neonatal and Neonatal Follow-up Networks.

# Introduction

About 8% of babies born in Canada are born prematurely (before 37 weeks gestation), and this proportion has been increasing over time.<sup>2</sup> A premature birth can be traumatic and stressful for both the baby and family. Some babies may require a long hospital stay (weeks or months) before they are able to go home with their families, and immaturity is the largest cause of infant death in Canada, causing approximately a third of all infant deaths.<sup>3</sup> While many babies born prematurely are able to survive and thrive with the right care and support, the effects of prematurity can have long-term impacts, including both physical and developmental challenges. Children born prematurely have a higher likelihood of requiring supports such as more intensive health care services, psychological supports, special education, developmental services, etc.<sup>4</sup> The total economic burden of prematurity in Canada is estimated to be a total of \$587.1 million.<sup>5</sup>

The issue of maternal and child health, including prematurity, has been receiving increased attention in the international arena and in Canada. The United Nations' Millennium Development Goals (MDGs) for 2015 and beyond include targets related to improving maternal health and reducing infant mortality, both of which are linked to the issue of premature birth. In 2010, the UN launched the Every Woman Every Child initiative, focused on saving the lives of 16 million women and children worldwide. The government

<sup>2</sup> The rate of premature birth has increased from 6.6% in 1991 to 7.9% in 2010/11. Canadian Institute for Health Information (CIHI), "DAD/HMDB Childbirth Indicators by Place of Residence and DAD/HMDB Newborns Born in Hospital," in *CIHI Quick Stats* (Ottawa, ON2011-12). A. Berard, M. Le Tiec, and M. A. De Vera, "Study of the Costs and Morbidities of Late-Preterm Birth," *Arch Dis Child Fetal Neonatal Ed* 97, no. 5 (2012).

<sup>3</sup> Public Health Agency of Canada, "Perinatal Health Indicators for Canada 2013: A Report of the Canadian Perinatal Surveillance System," (Ottawa, ON2013). Note: data excludes Ontario.

<sup>4</sup> K. C. Wade et al., "Pediatric Care for Preterm Infants after NICU Discharge: High Number of Office Visits and Prescription Medications," *J Perinatol* 28, no. 10 (2008); I. Leijon et al., "Use of Healthcare Resources, Family Function, and Socioeconomic Support During the First Four Years after Preterm Birth," *Arch Dis Child Fetal Neonatal Ed* (2002). European Foundation for the Care of Newborn Infants (EFCNI), "Caring for Tomorrow: EFCNI White Paper on Maternal and Newborn Health and Aftercare Services," (Karlsfeld, Germany2012).

<sup>5</sup> K. M. Johnston et al., "The Economic Burden of Prematurity in Canada."

of Canada has made a strong commitment to this initiative, providing a total of \$2.85 billion to support the work by 2015.

In addition to efforts made by governments to address preterm birth, parent groups from around the world also play a critical role in raising awareness and advocating for change. For example, the European Foundation for the Care of Newborn Infants (EFCNI) released a white paper in 2011 (*Caring for Tomorrow: the EFCNI White Paper on Maternal and Newborn Health and Aftercare Services*) which included 13 key recommendations for European countries to address premature birth. EFCNI has been successful in increasing visibility, political attention and policy change for preterm birth in Europe.<sup>6</sup>

Here in Canada, the Canadian Premature Babies Foundation-Fondation pour Bébés Prématurés Canadiens (hereafter referred to as CPBF-FBPC) is the first national, Canadian-based organization for premature babies. CPBF-FBPC works to prevent preterm birth through education and research; to support the best standards of care for premature babies; and to give premature babies and their families a voice across Canada. CPBF-FBPC also aims to increase awareness of premature birth.

In order to better understand the context of premature birth in Canada, CPBF-FBPC has engaged Research Power Inc. (RPI), a health research and consulting firm, to conduct an environmental scan on the issue. The environmental scan had the following objectives:

- Increase awareness of the issue of prematurity and how it impacts children and families;
- Identify existing gaps across Canada in delivery of care for premature babies; and
- Identify best practices related to premature birth.

The environmental scan included a review of the grey and academic literature and focus groups and interviews with key informants from across the country. The literature review addressed the full continuum of care, including prenatal care; birth, care provided in

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<sup>6</sup> March of Dimes et al., "Born Too Soon: The Global Action Report on Preterm Birth," ed. C. Howson, M. Kinney, and J. Lawn (Geneva, Switzerland 2012).

hospital, and short term follow-up care (i.e., discharge and follow-up in infancy); and long-term care and follow-up for all premature babies. The focus groups and interviews focused only on birth, care provided in hospital, discharge, and immediate follow-up. This report presents the findings from the environmental scan, and concludes with recommendations for addressing premature birth in Canada based on these findings. CPBF-FBPC intends to use the information gathered through the environmental scan to help identify priorities and support the work of the Foundation going forward.

# Methodology

## Literature Review

A comprehensive multi-jurisdictional review of the grey and academic literature related to premature birth in Canada was conducted in March and April 2014. Electronic databases (PubMed, Cumulative Index of Nursing and Allied Health (CINAHL), Cochrane Library, and Canadian Public Policy Collection) publishing English language articles since 2004 were searched. The search used appropriate terminology, alternative spellings and synonyms, Boolean operators and relevant syntax for the requirements of each database. Grey literature was identified using hand searching and scanning of relevant government and institutional websites as well as the reference lists of other identified documents. The literature review covered the areas of prenatal care; birth, care provided in hospital, and short term follow-up care (i.e., discharge and follow-up in infancy); and long-term care and follow-up for premature babies.

## Interviews and Focus Groups

Interviews and focus groups with key informants were also conducted as part of the environmental scan. The purpose of the interviews and focus groups was to gather feedback and input on the existing gaps across Canada in delivery of care for premature babies and support for families, as well as on the best practices and critical supports related to premature birth. Twelve interviews and four focus groups were conducted in May 2014 with a total of 29 key informants. The roles/perspectives of the key informants and the geographic distribution of key informants are described in the two tables below.

**Table 1: Interview/Focus Group Key Informants by Stakeholder Type**

<i>Stakeholder Type</i>	<i># of Key Informants*</i>
Parents	15
Neonatologists	6
Other health care providers (nurses, lactation consultants, etc.)	7
Other stakeholders (policy makers, non-profit representatives, researchers, etc.)	8

\* Note that the numbers sum to more than the 29 individual key informants as some stakeholders represented and spoke from multiple perspectives (e.g., a parent and a health care provider).

**Table 2: Interview/Focus Group Key Informants by Province/Region**

<i>Province/Region</i>	<i># of Key Informants</i>
BC & Alberta	9
Ontario	15
Quebec	3
Atlantic Provinces	2

Criteria for selecting key informants were established, and potential key informants were identified primarily by the Canadian Premature Babies Foundation (CPBF-FBPC). A list of key informants is provided in Appendix A. All potential key informants were sent a letter of invitation to participate in an interview or focus group by CPBF-FBPC. The consultant then followed up to coordinate logistics. In any situation where the proposed key informants were not able to participate, an alternative informant was identified by the client.

All interviews and focus groups were conducted by telephone and took 30-70 minutes. Interview and focus group guides were developed with the input of CPBF-FBPC and other key stakeholders to help ensure that all areas of interest were addressed. Copies of the interview and focus group guides are presented in Appendix B. All interviews and focus groups were audio-recorded (with participants’ permission) and transcribed verbatim.

## **Data Analysis**

Information collected through the literature review and key informant interviews was thematically analyzed, which involves identifying common threads across sources (i.e., literature and transcripts). Sources were first coded to reveal broader themes, as well as sub-themes/categories that illuminate the data in ways not provided by the main themes/concepts. The themes and sub-categories were then compared and contrasted across data sources to further formulate the themes and categories. Systematic comparisons and

verifications ensure that important categories are not overlooked, and that emerging categories and concepts are properly identified.

Verbatim quotes are provided after the descriptions of each theme, and the strength of response is reflected in the order the themes are presented, as well as through the use of descriptors such as “many”, “some” and “a few”.

Trustworthiness of the findings was assured through the use of well-established qualitative research procedures by the consultants conducting the interviews and analysis.

Trustworthiness was assured through:

- Regular peer debriefing with the team of analysts;
- Independent and systematic coding and data analysis;
- The use of verbatim quotations/excerpts from the interviews and focus groups and sufficient descriptions of themes to illustrate the findings; and
- Completion of a log of methodological decisions made throughout the analysis process.

Qualitative methods, including interviews and focus groups, are exploratory in nature and thus provide rich and valuable insight into people’s views and feelings, but results are not intended to be generalized or quantified.

# Findings

## About Premature Birth

### ❖ Definition

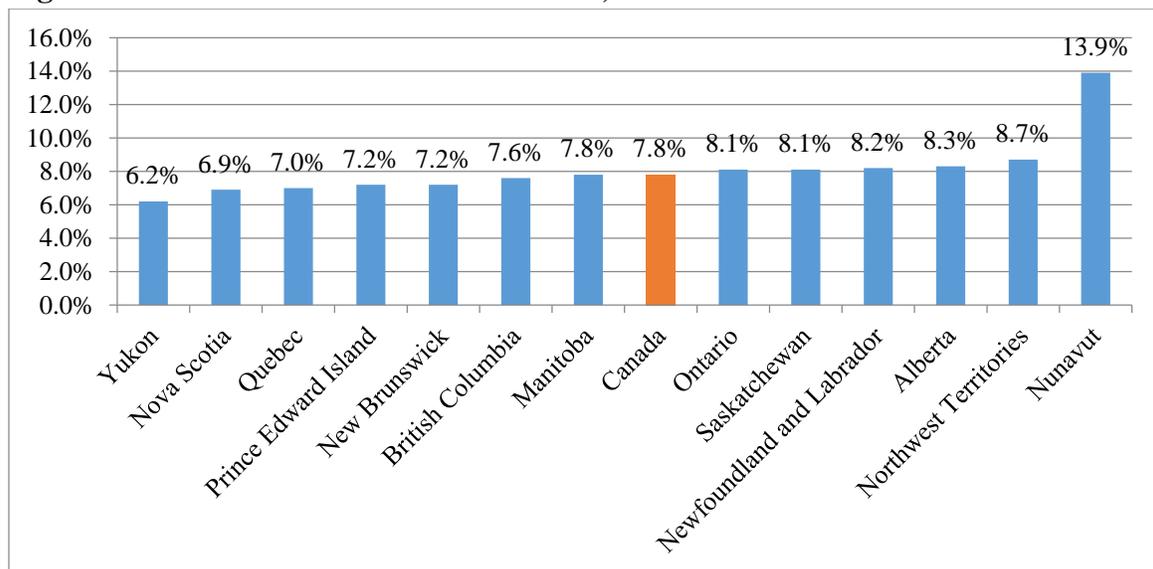
The World Health Organization defines preterm birth as “babies born alive before 37 weeks of pregnancy are completed”.<sup>7</sup> Preterm babies are divided into three main categories based on gestational age (GA):

- Extremely preterm (<28 weeks GA)
- Very preterm (28 to <32 weeks GA)
- Moderate to late preterm (32 to <37 weeks GA)

### ❖ Premature Birth in Canada

Globally, more than 10% of babies are born preterm.<sup>8</sup> In Canada, approximately 8% of babies are born preterm (representing about 29,000 babies), although the rates vary significantly across the country (see Figure 1 below).<sup>9</sup>

**Figure 1: Rates of Preterm Birth in Canada, 2011/12<sup>10</sup>**



<sup>7</sup> Ibid.

<sup>8</sup> Ibid.

<sup>9</sup> Canadian Institute for Health Information (CIHI), "DAD/HMDB Childbirth Indicators by Place of Residence and DAD/HMDB Newborns Born in Hospital."

<sup>10</sup> Ibid.

As illustrated in Figure 1, there are differences in preterm birth rates between provinces. There are also variations among different populations within provinces. One key area of difference is in rates of preterm birth between Aboriginal and non-Aboriginal populations.<sup>11</sup> In particular, Inuit-inhabited areas of Canada had substantially higher rates of preterm birth and neonatal death than the rest of Canada, and even compared with other northern or remote areas.<sup>12</sup> Other sub-groups may also be at increased risk – for example, lower socioeconomic status has been consistently associated with a higher rate of preterm birth.<sup>13</sup>

Late preterm births (births between 34 weeks and 36 weeks and 6 days of gestation) are the majority of all preterm births (approximately 85%).<sup>14</sup> Many late preterm babies do not need intensive hospital care immediately after birth. However, they still comprise a large proportion of admissions to Neonatal Intensive Care Units (NICUs).

Across Canada, there are 30 NICUs (attached to 13 academic centres) and approximately 100 neonatologists who provide care for premature babies.<sup>15</sup> In total, 135 hospitals across the country had either a special care nursery or NICU.<sup>16</sup> In 2012 in Canada, 14,224 babies were admitted to NICUs at participating sites in the Canadian Neonatal Network (CNN), and 61% of these babies were preterm.<sup>17</sup> As illustrated in Figure 2 below, the majority of premature babies admitted to the NICU were late preterm babies (32-36 weeks).

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<sup>11</sup> A. Janvier and P. S. Shah, "The Premature Lottery in the Canadian Grey Zones," *Current Pediatric Reviews*, 9(2013).

<sup>12</sup> Z. C. Luo et al., "Birth Outcomes in the Inuit-Inhabited Areas of Canada," *CMAJ* 182, no. 3 (2010).

<sup>13</sup> C. P. Larson, "Poverty During Pregnancy: Its Effects on Child Health Outcomes," *Paediatr Child Health* 12, no. 8 (2007).

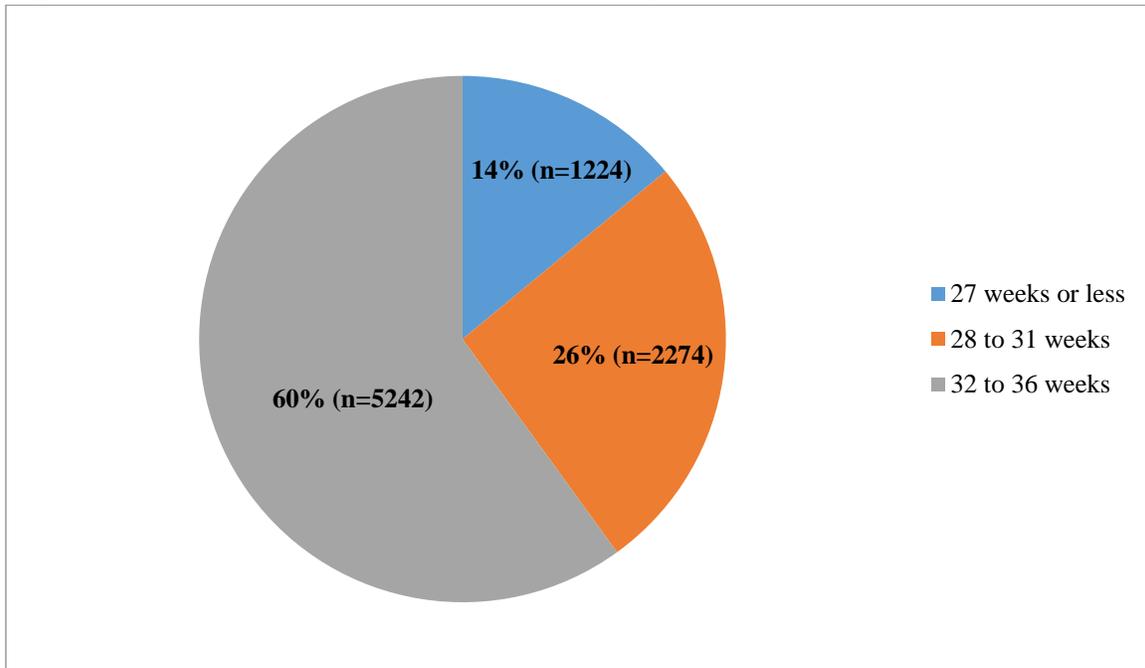
<sup>14</sup> Public Health Agency of Canada, "Perinatal Health Indicators for Canada 2013: A Report of the Canadian Perinatal Surveillance System; Better Outcomes Registry & Network (BORN) Ontario, "Perinatal Health Indicators for Ontario 2012," (Ottawa, ON2012).

<sup>15</sup> A. Janvier and P. S. Shah, "The Premature Lottery in the Canadian Grey Zones."

<sup>16</sup> Public Health Agency of Canada, "Canadian Hospitals Maternity Policies and Practices Survey," (Ottawa, ON2012).

<sup>17</sup> Canadian Neonatal Network (CNN), "The Canadian Neonatal Network Annual Report 2012," (Toronto, ON2012).

**Figure 2: Premature Babies admitted to NICU\*, 2012<sup>18</sup>**



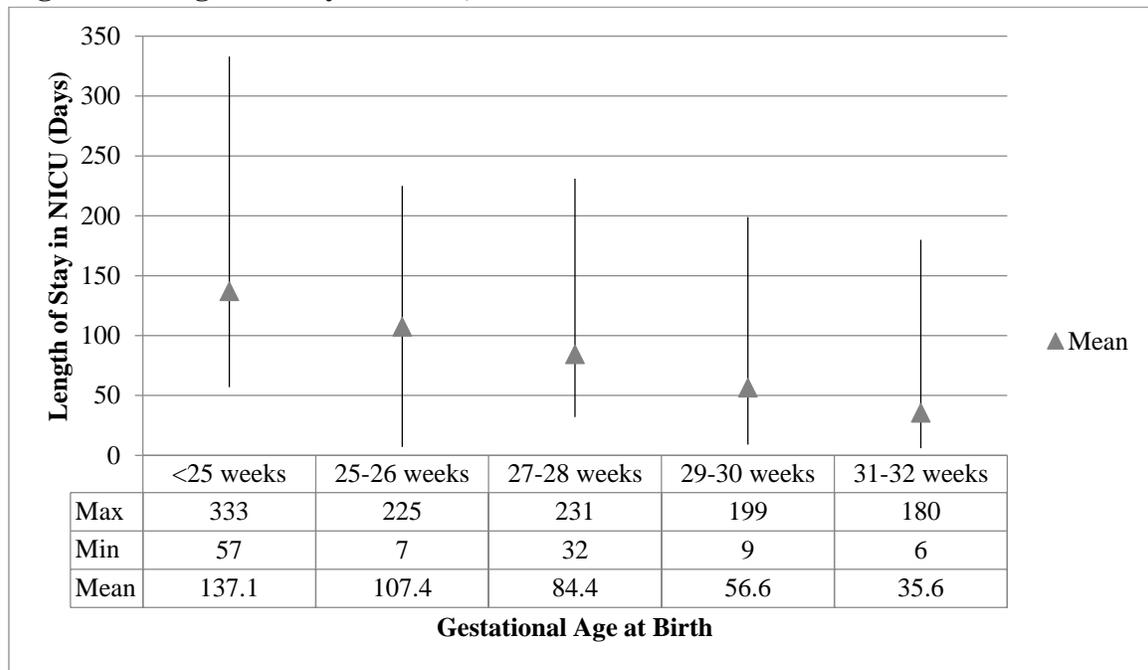
\* The chart above only shows babies born prematurely and admitted to the NICU. Premature babies represent 62% of total NICU admissions. The other 38% of babies admitted to NICU (5,481 babies) were born at term.

Babies born at an earlier gestational age have longer stays in hospitals and intensive care (see Figure 3). However, even though babies born moderately or late preterm tend to have shorter stays in hospital, because there are a larger number of these babies, this group still has a significant impact on bed utilization in the NICU.<sup>19</sup>

<sup>18</sup> Ibid.

<sup>19</sup> A. L. Jefferies et al., "Impact of Late Preterm Birth on Neonatal Intensive Care Resources in a Tertiary Perinatal Center," *Am J Perinatol* 30, no. 7 (2013).

**Figure 3: Length of Stay in NICU, 2012<sup>20</sup>**



### ❖ Risk Factors

In about half of all cases of premature birth, it is not possible to establish a specific cause. However, there are known risk factors for preterm birth. These include the following:<sup>21</sup>

- Factors related to behaviours such as smoking, alcohol or drug use, and lack of prenatal care.
- Factors related to the social determinants of health such as stress, lack of social support, poverty, and ethnicity (maternal stress is estimated to account for about a third of preterm births).
- Medical conditions such as infections, high blood pressure, diabetes, clotting disorders, underweight, obesity, multiple pregnancy, history of preterm birth, and uterine/cervical abnormalities.
- Demographic factors such as age (i.e., mother over 35 or under 17).

<sup>20</sup> Canadian Neonatal Network (CNN), "The Canadian Neonatal Network Annual Report 2012." Excludes babies with congenital anomalies.

<sup>21</sup> European Foundation for the Care of Newborn Infants (EFCNI), "Caring for Tomorrow."

Most preterm births happen spontaneously (spontaneous onset of labour or pre-labour premature rupture of membranes (pPROM)). Some preterm births may result from early induction of labour or caesarean birth, for medical reasons such as maternal or fetal health (e.g., maternal hypertensive disorder or poor fetal growth), or non-medical reasons.<sup>22</sup>

## **The Impacts of Premature Birth**

Premature birth can have many negative impacts on children and families, including increased mortality rates for babies born prematurely, financial and emotional stresses for parents, and long-term impacts on a premature child's health and development. Despite the potential negative impacts of premature birth, children born prematurely and their families are still able to lead productive, happy lives.

### **❖ Morbidity and Mortality**

Approximately a third (29%) of all infant deaths (deaths in the first year of life) are due to immaturity. This includes over a third (38%) of neonatal deaths (in the first 27 days of life) and 6% of postneonatal deaths (day 28 to 364).<sup>23</sup> Survival rates increase with gestational age. While in 2012 the survival rate at discharge for a baby less than 23 weeks gestational age admitted to a NICU in Canada was only 18%, survival rates increase rapidly as gestational age increases (see Figure 4).<sup>24</sup>

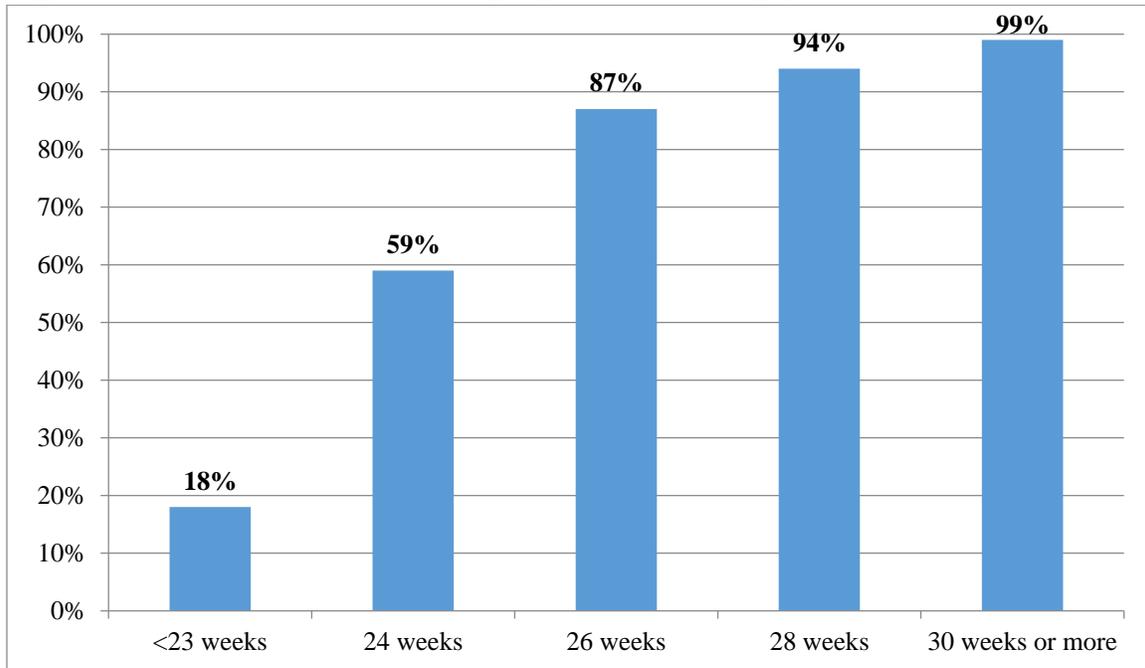
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<sup>22</sup> March of Dimes et al., "Born Too Soon."

<sup>23</sup> Public Health Agency of Canada, "Perinatal Health Indicators for Canada 2013: A Report of the Canadian Perinatal Surveillance System." Note: data excludes Ontario.

<sup>24</sup> Canadian Neonatal Network (CNN), "The Canadian Neonatal Network Annual Report 2012."

**Figure 4: Survival Rates at Discharge by Gestational Age, 2012<sup>25</sup>**



Children born preterm are at a higher risk for a range of morbidities, and prematurity is responsible for an estimated three-quarters (75%) of neonatal morbidity.<sup>26</sup> Premature infants are immunocompromised and are at increased risk of infection. Respiratory syncytial virus (RSV) infection is the leading cause of lower respiratory tract infections in young children.<sup>27</sup> Children born preterm are at greater risk for neurodevelopmental disabilities such as cerebral palsy, mental retardation, vision impairments, and hearing loss. There is also an increased risk of cognitive and language delays, hyperkinetic disorders, behavioural and emotional problems, and learning disabilities.<sup>28</sup> Neonatal lung disease and reduced lung function, and an increase in cardiovascular risk factors are also of concern.<sup>29</sup>

<sup>25</sup> Ibid.

<sup>26</sup> A. Berard, M. Le Tiec, and M. A. De Vera, "Study of the Costs and Morbidities of Late-Preterm Birth."

<sup>27</sup> Canadian Paediatric Society, J. Robinson, and Infectious Diseases and Immunization Committee, "Preventing Respiratory Syncytial Virus Infections," (2011).

<sup>28</sup> K. M. Benzies et al., "Key Components of Early Intervention Programs for Preterm Infants and Their Parents: A Systematic Review and Meta-Analysis," *BMC Pregnancy Childbirth* 13 Suppl 1(2013).

<sup>29</sup> European Foundation for the Care of Newborn Infants (EFCNI), "Caring for Tomorrow."

The earlier the baby is born, the greater the morbidity rates. Half of babies born at 24-25 weeks will have altered brain development leading to learning/cognitive problems, compared to only 6-7% of babies born at 36 weeks.<sup>30</sup> However, even moderate to late preterm babies (between 33 and 37 weeks GA) have higher rates of neonatal morbidity than babies born at term.<sup>31</sup> The most common morbidities among late preterm babies include hyperbilirubinemia, respiratory compromise, hyperglycemia and poor feeding, temperature instability, and infection.<sup>32</sup>

Neonatal care in Canada and other developed countries has changed significantly over the last 20 years, resulting in improvements in outcomes for preterm babies. Changes have included advances in both technology and treatment techniques and approaches.<sup>33</sup> These advances mean that babies born as early as 22-23 weeks can be offered active treatment. Although mortality rates have decreased, morbidity rates have remained fairly stable, leading to a larger absolute number of babies born prematurely who are affected by long-term health and developmental challenges.<sup>34</sup>

### ❖ **Impacts on Parents and Families**

The premature birth of a baby can be very difficult for parents and families. Experiencing a preterm birth can leave the parents, especially the mother, with many difficult feelings such as guilt, anxiety, anger, or grief. Parents can experience increased levels of distress, including anxiety, depression, and other trauma symptoms.<sup>35</sup> Having a baby in the NICU can result in decreased confidence and self-efficacy in parenting, and difficulties with

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<sup>30</sup> Ibid.

<sup>31</sup> Ibid.

<sup>32</sup> E. S. Forsythe and P. J. Allen, "Health Risks Associated with Late Preterm Infants: Implications for Newborn Primary Care," *Pediatric Nursing*, 39, no. 4 (2013).

<sup>33</sup> European Foundation for the Care of Newborn Infants (EFCNI), "Caring for Tomorrow."

<sup>34</sup> F. Groenendaal and C. Uiterwaal, "Long Term Follow-up of Extremely Preterm Neonates," *British Medical Journal* (2012).

<sup>35</sup> H. M. Obeidat, E. A. Bond, and L. C. Callister, "The Parental Experience of Having an Infant in the Newborn Intensive Care Unit," *J Perinat Educ* 18, no. 3 (2009).

forming attachment and taking on appropriate parenting roles as parents may not be able to be actively involved in the care of their child.<sup>36</sup>

*I guess I would just mirror what everyone else has said, as a parent feeling somewhat isolated, almost like the buoy in the ocean bobbing around looking for help kind of feeling.*

*- Parent*

*At least half of the population, 55 percent at least, the families whose infants are pre-term and require intensive care, this is highly, highly challenging and stressful. And then at least 55 percent has depressive symptoms. They have high anxiety and would benefit from more support.*

*- Other Health Care Provider*

There is also an increased financial burden for families, which is described more fully in the section of the report on *Challenges in the Delivery of Care Related to Premature Birth*. Financial impacts may include the immediate costs of a hospital stay for the baby (e.g., food, accommodations, transportation, childcare for other children, etc.) as well as long-term financial effects as parents may postpone their return to work or leave the workforce to care for their child.<sup>37</sup>

### ❖ Long-term Outcomes

The impact of preterm birth can have long-term consequences for a child's health and development well beyond the neonatal period. For example, the risk of a reduced capacity to work due to disability is twice as likely in moderate and late preterm babies, and seven times as likely in extremely preterm babies compared to full term births.<sup>38</sup> However, although babies born prematurely are more likely than their full term counterparts to see differences in outcomes, "the majority of young adult preterm survivors function within the normal range and are indistinguishable from their peers of similar sociodemographic status."<sup>39</sup> In addition to being born prematurely, other factors such as family

<sup>36</sup> M. Boykova and C. Kenner, "Transition from Hospital to Home for Parents of Preterm Infants," *J Perinat Neonatal Nurs* 26, no. 1 (2012).

<sup>37</sup> Bliss, "It's Not a Game: The Very Real Costs of Having a Premature or Sick Baby," (London, England 2014); European Foundation for the Care of Newborn Infants (EFCNI), "Caring for Tomorrow."

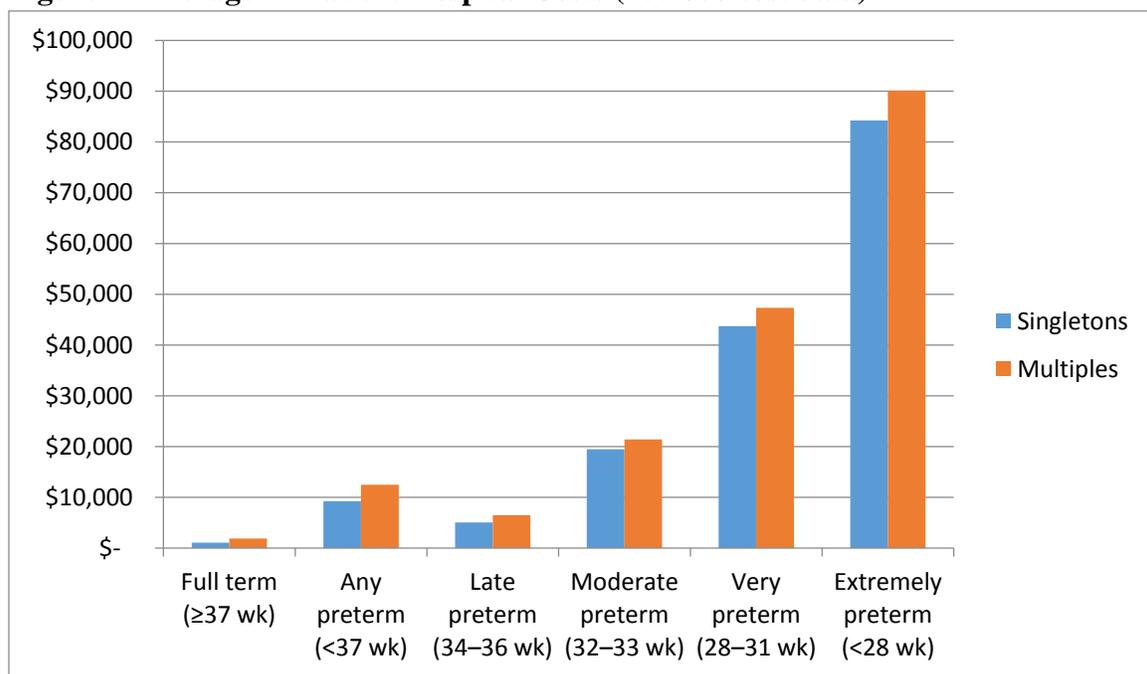
<sup>38</sup> "Caring for Tomorrow."

<sup>39</sup> M. Hack, "Adult Outcomes of Preterm Children," *Journal of Developmental & Behavioural Pediatrics* 30, no. 5 (2009).

sociodemographic status also have an impact on the long-term outcomes for premature babies. For example, preterm babies born to families in poor socioeconomic environments are at increased risk of developmental disabilities.<sup>40</sup>

There are also costs to society related to preterm birth. As illustrated in Figure 5 below, based on 2005/06 data, the average in-patient hospital costs for preterm babies was significantly higher than for those born full-term (nine times more).<sup>41</sup>

**Figure 5: Average In-Patient Hospital Costs (2005/06 cost data)<sup>42</sup>**



While the initial hospital stay is the most significant contributor to the total costs of preterm birth, there are ongoing medical and indirect costs after discharge from hospital. Preterm infants tend to have higher health care utilization after release from hospital<sup>43</sup> and may also

<sup>40</sup> Susan K. Ritchie, "Primary Care of the Premature Infant Discharged from the Neonatal Intensive Care Unit," *MCN* 27, no. 2 (2002).

<sup>41</sup> G. Lim et al., "Hospital Costs for Preterm and Small-for-Gestational Age Babies in Canada," *Healthcare Quarterly* 12, no. 4 (2009).

<sup>42</sup> Ibid.

<sup>43</sup> K. C. Wade et al., "Pediatric Care for Preterm Infants after NICU Discharge: High Number of Office Visits and Prescription Medications; I. Leijon et al., "Use of Healthcare Resources, Family Function, and Socioeconomic Support During the First Four Years after Preterm Birth."

require other supports such as psychological support, developmental services, special education, respite and/or residential care, etc.<sup>44</sup> A recent study of the economic burden of prematurity in Canada found that the total national costs are \$123.3 million for early preterm infants, \$255.6 million for moderate preterm infants, \$208.2 million for late preterm infants, and \$587.1 million for all infants (based on an estimated cost per child over the first ten years of life of \$67,467 for early preterm babies, \$52,796 for moderate preterm babies, and \$10,010 for late preterm babies).<sup>45</sup> Although the costs per infant are substantially lower for late preterm babies, they are still a significant contributor to total costs because of the population size.

## **Successes in the Delivery of Care Related to Premature**

### **Birth**

This section describes the successes in the delivery of care related to premature birth identified by key informants participating in the environmental scan. These success include the provision of high quality clinical care; significant progress being made in implementing family-centred care; providing families with supports such as accommodations and parent lounges; increasing emphasis on research and quality improvement activities national and at the local level; coordinated discharge planning and follow-up supports for babies; education for health care providers, especially focusing on simulation and practical learning; a well-organized system of care for premature babies and mothers; peer support programs and services for families; and strong support for breastfeeding. The findings are presented in order of strength of response (i.e., the most frequently mentioned theme is presented first).

Some of the areas identified as successes are also noted in the section on challenges. In many cases key informants both highlighted successes and indicated that there was still more work to be done. For example, high quality clinical care was noted as a success, but

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<sup>44</sup> European Foundation for the Care of Newborn Infants (EFCNI), "Caring for Tomorrow."

<sup>45</sup> K. M. Johnston et al., "The Economic Burden of Prematurity in Canada."

challenges in consistency of care and some gaps in clinical care were also described. Areas described as working well may therefore also be included as a challenge or needed support, which are described in the later sections of this report.

### ❖ High Quality Clinical Care

Many key informants said that the high quality of clinical care provided to premature babies in Canada was a key success. Hospitals have the right equipment and staff have the right skills to deliver quality clinical care. Key informants also noted that clinical care has improved significantly, resulting in better survival rates for premature babies.

*I think we have great neonatal intensive care units in the country, I think they're world class. There's nowhere else in the world that you can go that the system for caring for newborn babies is any better than it is in Canada.*

– Other Health Care Provider

*I think over the years our outcomes of premature babies has just progressively got better and better in terms of survival in the long-term. So I think we're doing something right. We don't always exactly know what it is. So the way we do our initial stabilization of babies has been improving, and that works better and better. And the care once the baby gets into the NICU has been improving everywhere.*

– Neonatologist

Although respondents were quite positive about the clinical care provide to premature babies, areas for improvement were also identified, and these are further described in the sections on *Lack of Consistency and Continuity in Care* (p. 26) and *Areas for Improvement in Clinical Care* (p. 28).

### **Immunizations**

Almost all key informants felt that immunizations for premature babies are working well and proceed according to the established immunization schedules.

*There are such clear guidelines as to what the recommendations are, and there's an infrastructure for children after they go home with respect to immunizations. So it's probably from that perspective, one of the areas I have the least concern.*

– Neonatologist

*I think the general immunizations are done well. The public health nurses come into the hospital to provide those to babies that are still in the hospital when they're due. So I think that's well organized right now.*

– Other Health Care Provider

### **Developmental Care**

Developmental care encompasses a group of interventions and design features that are intended to reduce the stress of the NICU environment. Developmental care practices may include reducing stimuli such as sound and lights, appropriate positioning of the infant, and limiting exposure to toxins in the NICU environment.<sup>46</sup> Some key informants highlighted the integration of developmental care practices in the NICU as a success.

*I think now people are starting to pay a lot more attention to outcomes, and be more considerate of a family and the family-centeredness of the care, and looking at optimizing the developmental care for the babies in the unit, which was not a focus 15 years ago as well as out of the unit.*

– Neonatologist

*The newly built NICU was only one year old and you could tell there had been lots of thought behind every choice they had made. From the colors to the fabrics and finishes you could tell it was meant to be comforting and soothing. They had good sized individual rooms . . . the lighting was soft but it could be more intense if staff needed it for procedures. It was noisy in the first few weeks because of all the machines but at least it was only [my child's], not all the babies' alarms.*

– Parent

### **Primary Nursing**

Some key informants spoke about the importance of having one or more primary nurses identified who provide the majority of the care for the baby. Having a consistent nursing presence helped reassure parents that their babies were being well cared for, especially when they were not able to be there. It also helped to support the parents in learning how to care for their baby. The importance of the primary nursing team was mentioned most commonly by parents and less frequently by other key informants.

<sup>46</sup> R. D. White, "Designing Environments for Developmental Care," *Clin Perinatol* 38, no. 4 (2011); Bliss, "The Bliss Baby Charter Standards," (London, England: Bliss, 2011); European Foundation for the Care of Newborn Infants (EFCNI), "Caring for Tomorrow."

*We have primary care nursing, which is wonderful . . . we really think that that works as long as there's a good fit . . . it really helps everyone when they're comfortable with the care of their baby, and they know the nurse and it's not another new nurse. We're a big unit with 150 nurses so you can pretty much have a different nurse every single day, if you're not so lucky. Now that doesn't happen very often, but primary care nursing is really a bonus for the baby.*

– Other Health Care Provider

*Our primary nurses made sure we learned how to take care of our [child] as soon as possible (diapers, temperatures, baths, medication). At the end, they were proud to say we were very much independent! I loved it, it made me feel like a mom. An NICU mom, but a mom. It normalized it all a little.*

– Parent

### ❖ Progress in Implementing Family-Centred Care

Many key informants highlighted the fact that significant progress has been made in implementing a family-centred care approach in NICUs across Canada, although they did also indicate that more work needs to be done in this area (further described in the section on *Barriers to Family-centred Care*, p. 27). Family-centred care involves treating all family members with dignity and respect, sharing information and providing education to family members, encouraging family collaboration and input into decision-making, offering the family appropriate emotional support, and facilitating family participation in the care of the infant.<sup>47</sup> Key informants said that having an approach to care that recognizes the needs of families and works to integrate them into the process of providing care for their infant was a key success.

*That model of care that integrates families and parents primarily into caring for their infants as premature babies in the NICU before they even go home, making them accountable and responsible for their care there first, that has come a hugely long way, just in two years. Just in two years it has come leaps and bounds, it's exponentially increased its practice. I think that that is something that is going on that's very, very good and it's being done well.*

– Other Stakeholder

*I think that the care given and emphasis placed on the role of the families of premature babies has seen an incredible improvement over the last twenty years within the units. I think that we're a lot more sensitive to the space that we need to give to the families, I think that the large majority of caregivers realize that the place of the parents is beside their baby, and*

<sup>47</sup> S. D. Berns et al., "Results of the Premature Birth National Need-Gap Study," *J Perinatol* 27 Suppl 2(2007).

*that more and more the care is oriented around the family. And that for me, as a mother, is very comforting.*

– Parent

Some key informants highlighted the current study on the Family Integrated Care initiative<sup>48</sup> led by clinicians and researchers at Mount Sinai Hospital in Toronto as an important development in the implementation of family centred care principles and approaches across Canada. However, family-centred approaches are also being used/implemented in many other facilities across the country. In Canada, 79% of hospitals with a special care nursery or NICU reported that they encourage skin-to-skin contact between the parent and baby, and 75% indicated that the mother could spend 24 hours a day with their infant (but with no rooming in).<sup>49</sup>

### ***Parent Empowerment***

Some key informants described the critical role that family centred care plays in empowering and supporting families, both in the NICU as well as in other health care facilities and once they go home.

*I think looking back now, what helped us the most was that the main hospital where we were was a family-centered care unit. So we weren't treated as visitors, we were treated as patients with our daughter. We could talk, we were listened to, we could participate in rounds and ask as many questions as we could. It always felt safe. We felt we were part of the team actually, which I think that made a great, great impact on us, to get to know all the medical terms and get comfortable with what's going on . . . getting used to that new reality.*

– Parent

*The family integrated care model, I don't think the value is just at discharge. I think the value is bringing families in as equal partners in care as soon as possible, because parents tend to be the ones who know the most about their babies, so it improves outcomes even within the NICU. It shortens length of stay, so that's an immediate bonus to it. It helps with stress and all that right away, and then you also see the benefits during discharge and post-discharge.*

– Other Stakeholder

<sup>48</sup> K. O'Brien et al., "A Pilot Cohort Analytic Study of Family Integrated Care in a Canadian Neonatal Intensive Care Unit," *BMC Pregnancy Childbirth* 13 Suppl 1(2013).

<sup>49</sup> Public Health Agency of Canada, "Canadian Hospitals Maternity Policies and Practices Survey."

### ***Participation in Rounds***

A few key informants highlighted the importance of parents being active participants in the daily medical rounds for their children. Parents should have the opportunity to hear the updates and medical information and to share their own information and ask questions. Participation in rounds was seen as a good way to support information sharing and an important tool in empowering parents and having them participate in their child's care.

*What we do here is we do have bedside rounds, and that's primarily due to the fact that we believe in family-centered care. And as a part of family-centered care, parents are always involved. So when we start rounds every morning, the parents are there, the bedside nurse is there and the whole team is there. Parents are involved in the decision making process and also in sharing of the information. We make sure that confidentiality is maintained to the utmost. So I think that the system, the NICU management of newborn babies according to family-centered care, from that perspective, it's working quite well.*

– Neonatologist

*Attending rounds was also a great way to understand what was going on . . . making us feel we were a part of that team was empowering. We were always more than welcomed to ask questions and interact with the team. As time passed and our [child] got older we were more and more comfortable at sharing our own opinions and observations. Each time we were listened to, and our input made some difference in the care plan at times . . . Plus, in the end, once we were discharged, we left ready to take care of [our child] despite the challenges. We felt ready to do all the follow-ups needed. We felt in control.*

– Parent

### **❖ Supports for Families While in Hospital**

Many key informants identified services and supports available to families as aspects of the system that was working well. Most of these comments focused on physical supports like accommodations (on or off site) and other hospital facilities like parent lounges. A few key informants also mentioned other supports such as parent education sessions, financial supports (e.g., free parking), and support provided by social work. While key informants were very appreciative of existing supports, they did also describe areas where further support was needed (see section on *Limited Emotional and Practical Supports for Families*, p. 30).

#### ***Physical Supports***

*The other thing that was really helpful was the social work and the first hospital . . . they have mother rooms . . . with beds and phones and sinks in them, and shared bathrooms. And*

*for those of us, like we're six hours away from the hospital, is our home, so I had a place to live for those six months and I didn't have to pay for it.*

– Parent

*[The parent lounge] was amazing. It was a place where we felt safe, we could take a break, sit down, watch TV, or if we had visitors it was a nice place to sit down with them outside of our baby's room. And it was nicely decorated as well, so it didn't feel like – it felt almost like a living room at home. You felt welcome there. You felt safe, and that's where we connected with other moms as well over lunch or coffee.*

– Parent

### **Financial Supports**

*We are working on ways to try to decrease parking costs, things like that.*

– Other Health Care Provider

*Social workers were great help to understand how to apply for sickness benefit so I could delay my maternity leave.*

– Parent

### **Parent Education**

*[Once a week] they had an information session, where you're going to learn about bringing your baby home from the NICU, or how to breastfeed or bathe your baby. I found them very informative and you got to meet with some of the moms, and have some cookies. It was nice.*

– Parent

## **❖ Research and Quality Improvement**

Many key informants talked about strengths in research and quality improvement activities related to premature birth. A few key informants identified Canada as having a leadership role in research related to premature birth. The Canadian Neonatal Network and the Canadian Neonatal Follow-Up Network were both identified as important supports for research and quality improvement, providing a national voice and picture, as well as providing individual hospitals with benchmarking data for their own facility. Key informants also spoke about work within their own institutions that was an important support for continuous quality improvement, such as quality improvement staff, committees or databases.

*Canada punches above its weight when it comes to research in preterm birth. We're about equal to the United States in terms of what we contribute to the preterm birth field. I think that the best science in the world is done in Canada, or as good as any place in the world . . . our basic research investigation is really excellent.*

– Other Health Care Provider

*I think a huge step forward for Canada has been the establishment of the Canadian Neonatal Network. So establishing a national benchmarking database so that we can compare our outcomes within our own country, and compare them to other countries. That's a huge accomplishment. And the Canadian Follow-up Network as well, so I mean, for the first time we're looking at our own outcomes within a national database, and exploring them. And I think that there's real success to that . . . and then using that data for quality improvement or other projects, has been a hugely helpful thing.*

– Neonatologist

### ❖ Discharge Planning and Follow-up

Some participants in the environmental scan highlighted aspects of the process for discharging babies from the NICU and/or elements of follow-up care that were working well. For example, respondents mentioned the use of checklists or other tools to ensure all discharge-related tasks were completed. A few participants noted follow-up supports such as the follow-up care clinic, or assistance with coordinating appointments and referrals prior to being discharged. Key informants did also note that this positive experience with discharge and follow-up is not necessarily consistent across the country, and highlighted challenges related to transfers in particular (further described in the section *Transfers between Facilities*, p. 32).

*I think our discharge plan works quite well. Once the baby is admitted we start working on our discharge planning quite early, and the bedside nurse coordinates it. And we have a checklist for the discharge so that everything gets done in a timely fashion.*

– Neonatologist

*We also have [a follow-up clinic]. That would be your immediate follow-up. Parents can come there for eye examinations, for NBR tests, for jaundice tests, for breastfeeding follow-up, weight check ins. There's a pediatrician available if they weren't able to get a pediatrician right away, they can come back to our clinic. And that clinic . . . it's really resourced, so the people that are in there are RNs [Registered Nurses] as well as LCs [Lactation Consultants], so their skills are definitely used. – Other Health Care Provider*

### ❖ Elements of Health Care Provider Education Working Well

Some key informants identified success related to health care provider education. These included having parents involved in providing education from the parent perspective, increasing education in support of breastfeeding, and offering very practical and hands on

educational opportunities through use of simulation. Gaps in education were also identified, and these are further described in the section *Gaps in Education for Those Working with Preterm Babies* (p. 34).

*I think our obstetricians and our care providers to pregnant women are as well informed as any in the world. They read the literature and we have professional and public organizations that monitor trends and developments in the area as much as anyone. And they deal with policies and guidelines at an international level.*

– Other Health Care Provider

*We have recently purchased a new [simulation program], so we do a simulation every week. I have found that simulation is very helpful for the whole staff, nursing and physicians, including residents. We have built up a number of different scenarios and we go through them every week or sometimes every two weeks. The feedback that I got is that everyone feels that these simulations are quite helpful. And it gives them an opportunity for hands-on training.*

– Neonatologist

### ❖ Organization of Care

Some key informants highlighted the organization of the health system as an important success factor in caring for premature babies. They noted that the system works well in terms of identifying women that may be at risk for or in preterm labour and transferring them appropriately. The way that care is structured (i.e., the regionalized model) provides the opportunity for specialization and development of expertise in caring for premature babies.

*I think some of the big picture system things that are working well are the way that neonatal structures are highly organized. So I think in some ways, neonatology and obstetrics work really well together, so that if a mother goes into premature labor or needs to be delivered early, those services are well organized and put together so it fits the early part of a neonatal life is really well organized.*

– Other Health Care Provider

*I think in terms of what's working, the most obvious thing is there's certainly the regionalization of care, so stratifying levels of care into level two and level three, and really implementing that. It helped tremendously because you build capacity within the levels of care for the levels of babies they're caring for. So that's made a huge difference.*

– Neonatologist

## ❖ Peer Support

A few respondents noted that peer support programs worked well and offered parents new to the NICU a formal way of connecting with and receiving support from other parents who have had a similar experience. A couple of key informants spoke about the role played by a parent coordinator, who was either a staff person or volunteer in the NICU. The parent coordinator was a veteran parent themselves and worked to both provide and coordinate peer-to-peer support for parents, as well as help parents access supports elsewhere when required.

*We also had veteran parents who worked bedside and worked in groups with parents. And I think that was critical for our survival on the unit because we got information from people who had been there, and had been through it. So I think parent to parent support is huge, and is an integral part of all of this, as well as the physical and psychosocial supports.*

– Parent

*The unit also had a Parent coordinator. We loved her. She was herself a mom of preemies so we could relate to one another. I learned a lot from her. She also helped us many times and referred us to the right staff in certain situations. She also set up many activities for parents in the unit and it was always a great moment to bond with other parents, share experiences and learn about the preemie world.*

– Parent

## ❖ Support for Breastfeeding

A few key informants highlighted the strong support for breastfeeding that was available in some units. This support included lactation consultants on site, provision of equipment and supplies in support of pumping, and in some areas access to donor milk through a milk bank.

*Even though . . . I would probably not breastfeed for some time, I was very much encouraged to do pumping. And I was able to get going even though I was . . . really sick. And they said you know, just pump it for now and we can dump it when you've got the meds in you, and when the meds are gone you can start keeping it, and when it is ready we'll have it. And I ended up pumping for 18 months.*

– Parent

*In our unit, we have availability of a lactation consultant seven days a week. And it's not appointment, it's not formal, it's available. So the nurses, the staff, the moms, they know that [the lactation consultants] are accessible. We also make sure that we do consults with every mom that comes in. So breast milk is we feel, one of the most important things for babies' outcomes, and I would have to say our neonatologists are incredibly supportive of*

*breastfeeding and breast milk here in the NICU . . . We also have 17 pumps that we can loan out for free.*

*– Other Health Care Provider*

## **Challenges in the Delivery of Care Related to Premature**

### **Birth**

This section describes the challenges for families and health care providers in providing care for premature babies. Similar to the previous section on successes in care, this section draws primarily from the findings from the interviews and focus groups rather than the literature review. The challenges identified include a lack of consistency and continuity in care; barriers to family-centred care such as physical structure and staff buy-in; variability in clinical care; insufficient support for babies and families during and after discharge home; a lack of emotional and practical support for families while in hospital; problems with transfers between hospitals; barriers to accessing care due to distance or other factors; gaps in education for health care providers; attitudes or approaches of health care providers, particularly in providing information before and immediately after birth; the financial burden for families; the limited supports available for late preterm babies; the lack of long-term follow-up care for premature babies; limited resources to support research and care delivery; and a lack of awareness about premature birth among the general population. The findings are presented in order of strength of response (i.e., the most frequently mentioned theme is presented first).

#### **❖ Lack of Consistency and Continuity in Care**

Many respondents noted that there was a lack of consistency and continuity of care provided for premature babies. This inconsistency was identified in many areas: inconsistency in NICU staff caring for the baby due to scheduling; inconsistency in practices and approaches between hospitals (this was noted particularly in relation to differences between level two and level three centres); lack of continuity between hospital and follow-up care; and variations in the level and type of follow-up care provided in

different locations across Canada. Variability in the care provided between facilities or from different members of staff was also identified as a challenge in the literature.<sup>50</sup>

*One of the challenges is the way we schedule nurses, the way we schedule and organize care in the neonatal intensive care unit . . . we try, but it doesn't embrace continuity, embrace strengthened relationships . . . You really have to fight a lot of barriers around being able to provide a continuous presence, a key person, a key navigator and to break those silos.*  
– Other Health Care Provider

*Across Canada, the follow-up clinics are very different. They're different in how they're staffed, they're different in how much resources are allocated to them, they're different in their mandates, they're different in necessarily the measurements they're going to use and/or the lengths of care they're going to provide. And to me, that's a shame. You shouldn't have your outpatient follow-up care be driven by where you're born.*  
– Neonatologist

### ❖ Barriers to Family-centred Care

Although there is certainly success in terms in improving family-centred care (as described in the earlier section, *Progress in Implementing Family-Centred Care*, p. 19), many key informants also identified barriers to providing family-centred care. The barriers identified primarily focused around physical barriers such as lack of space for parents both at the bedside and in terms of accommodations to facilitate access; and a lack of staff buy-in and support for a family-centred approach, as well as not having adequate staff resources and training to support family-centred care.

#### **Physical Environment**

*It also has to do with the environment, and on our unit right now the rooms are on the small side and we have two babies in each room, and there's actually not a lot of room for a mother or a father to actually come and feel welcome and stay there a lot.*  
– Neonatologist

*The hospital that we were at, there was no lounge and there was no place for me to sit, or me to go, or me to do anything really. So I wandered the halls between times when I could go in and visit my [child]. And I felt really in the way. Because the NICU is so small and I felt in the way, and I really felt that because of that, it inhibited my emotional state and my own recovery . . . not even being around my [child] or getting to hold [him/her], getting that kangaroo care, let alone having a place to sit for a couple of minutes and gather my thoughts or talk to other parents that were there.*  
– Parent

<sup>50</sup> W. El-Naggar and P. J. McNamara, "Delivery Room Resuscitation of Preterm Infants in Canada: Current Practice and Views of Neonatologists at Level Iii Centers," *J Perinatol* 32, no. 7 (2012).

**Staff Buy-in and Support**

*They're trying to give the parent the authority and the training that they need to switch alarms off when the alarms sound, and to change the diaper for the baby even when they're in the incubator and all that, and all sorts of things parents could easily do with a little bit of help with training, which right now we don't do very much. Largely because of that pre-historical situation on our unit, it's hard to get people to change. But also because it takes time, and it takes resources to do that as well. It's a lot.*

– Neonatologist

*I am a firm believer of both kangaroo care and just plain touching and holding our children. Obviously, if one of them was too ill, we understood it was not feasible. However, on occasion it seemed like it was too much work for the staff to take them out with all the wires etc. This was unfortunate...*

– Parent

**❖ Areas for Improvement in Clinical Care**

Although key informants were generally positive about the clinical care provided to premature babies (as noted in the section *High Quality Clinical Care*, p. 17), many also identified areas where clinical care could be improved. There continues to be variability in uptake of best practices in clinical care, and this should be addressed. A lack of appropriate developmental care and challenges with ensuring that premature babies receive prophylaxis for RSV (respiratory syncytial virus) were also noted by a couple of respondents.

*There are challenges in terms of trying to make sure everybody has the best practices everywhere, and the lung injury is a big issue, so trying to make sure that our best practices in terms of actually how we manage the ventilation, and how ventilation changes are made. There's all sort of good details that I think can be super important in terms of how we do that.*

– Neonatologist

*Where we do fall down though is during wintertime when respiratory viruses are prevalent and we're forced to transfer babies out to paediatric wards because of our neonatal beds shortages. We have seen some of our high risk patients that have been transferred out acquire a respiratory infection from a paediatric ward. So I think we really need to think about what we're doing, and perhaps the use of Synagis to prevent RSV if a patient is being transferred to a paediatric ward. To be a little bit more proactive with that immunization in particular.*

– Other Health Care Provider

*What I found difficult in that big room were the lights on all the time. Not so much the noise, it didn't bother me so much because I'm used to that kind of environment, but inside the box, the kids on ventilators that are pulsing, they hear that thumping all the time. So the little kind of beep, beep, beeps aren't going to bother them because they probably can't hear them, but the bright lights all the time and then dimmed in the evening, actually we were quite concerned about because when he shifted into a crib we ended up covering his crib over, and put in a nice black and white checker to stimulate his vision and give the nurses migraines.*  
– Parent

### ❖ Insufficient Support During and After Discharge Home

Many key informants described the support provided during the discharge planning process as well as during the initial time at home to be inadequate. The following issues were identified:

- Some key informants described a gap in support between when babies first go home and the first follow-up appointment (which may not be for several months), yet this is a time when parents and children are vulnerable and need support.

*We don't start neonatal follow-up until the babies have been home for four months. During that time, there are so many things that can go wrong. Sometimes just issues with feeding and trying to access support for that, it can be very challenging and really, you need someone to help you navigate through the system to get what you need at that time. But sometimes you don't even know what you need because you don't have the knowledge of what can go wrong.*  
– Other Stakeholder

*When I was released with the [twins], which were [released] on different days, I felt like I was in a panic. I was scared, and when I got home I was given the list of meds, I was given the list of the specialty people that we had to see, the follow-up appointments, but I didn't have anybody that I could run to . . . I didn't have anybody to support me emotionally. It was very stressful; lack of sleep.*  
– Parent

- Some people noted that parents do not receive enough information/education/preparation about what to expect when they go home. Hospital staff may not be well enough informed about programs and services in the community.

*My experience to date has been when I speak to people in the NICU, they have no clue about community, they have no clue about the resources that are available, they don't have a clue about what their own neonatal follow-up program does, and don't have an understanding of*

*the complexity that families are facing. So for example, families of pre-term infants may have 10 to 15 services involved. And how does that look?*

*– Other Health Care Provider*

*The problem is as somebody mentioned, you don't know the questions to ask. You don't realize something is already in place because at the time of discharge no one said, by the way, touch base with this group or call this woman, or whatever the situation is for that particular baby . . . no one spoke to me about what to expect next, like what happens within the next month or what happens within the next three months and so forth . . . We were also never told about potential funding or supports available to children with our needs.*

*– Parent*

- Some key informants said that families sometimes have difficulty accessing primary care providers.

*I think once the babies actually go home and they leave the hospital, there's a bit of a gap. Especially there's a shortage of paediatricians who are willing to take new patients. We sometimes have to plead with them to take a patient, and certainly the more complex babies we can usually find someone to do that, but the more straightforward preemies who still need more help and more surveillance than a baby born at term, it's really quite difficult to find paediatricians. And we don't have like an outpatient clinic that they can come back to if there's a problem in the first few days.*

*– Neonatologist*

- A few respondents stated that discharge planning is not well coordinated.

*Discharge home for the complex babies, I feel that sometimes the planning is left until the last minute, and then we're scrambling to get all the teaching done at the last minute. So there's certainly a lot that can be improved upon with regards to discharge planning.*

*– Other Health Care Provider*

*My discharge was terrible with my twins. We had twins being discharged on different days, and the discharge summary and documentations were written differently, the language used was slightly different because it was different people dictating and doing up the paperwork. But one baby would get referred for one service and then the other baby didn't get referred for a service. – Parent*

### ❖ **Limited Emotional and Practical Supports for Families**

Many key informants described limited supports for families while their babies were in hospital as a challenge, particularly in the area of emotional support. The lack of access to support was noted in the following areas:

- Mental health supports (e.g., psychologist, social worker).

*One of the issues that comes up time and time again is the support for mental health. Parents, particularly mothers, many at home have post-traumatic stress disorder, and it's very difficult to get that kind of support because neonatologists are not able to write referrals for the mothers. There's no access to have mental health support, so that's definitely lacking and I think it's lacking in most places.*

*– Other Stakeholder*

*While I was in the hospital there was no social worker coming by to see how I was. I didn't realize how high my anxiety was, and that I was in a place that I could have really used some emotional and mental health support at that time.*

*– Parent*

- Peer support (i.e., formal and informal connections to other parents who either have had or currently have children in the NICU, ideally with similar situations/diagnoses). While a few respondents noted that parents who did have access to peer support programs were very positive about this experience (as described in the section, *Peer Support*, p. 25), others noted that parents did not always have access to strong peer supports.

*The other thing [families] talked about was the whole missing peer to peer support. So you professionals are fabulous, you're there, you've got the information . . . but I really want to talk to another family who's going through this experience.*

*– Other Health Care Provider*

*We did not have any sort of support group for parents or buddy programs, or anything like that. Once we were discharged, we were just free to go home with our baby, and we had no additional equipment with us . . . we were very isolated.*

*– Parent*

- Support for breastfeeding.

*I think breastfeeding has been a huge [challenge] . . . by the time they're getting transferred that's a lot of what the parents are focused on, is the baby feeding? And what is hugely frustrating for the parents is when we have them breastfeeding as soon as they're extubated. Sometimes we have them on at 28, 29 weeks. And then they go to another hospital and say, well no, they're 34, 35 weeks, so they're too little to breastfeed. Really? They've been doing it for three weeks, four weeks already.*

*– Other Health Care Provider*

*. . . I didn't have the breastfeeding and lactation support there for me [following the birth]. Obviously I couldn't hold my child immediately and breastfeed, which is what I wanted, but*

*in regards to pumping or hand expressing . . . I didn't get my pump until nine hours later, it was a structural thing where the lactation nurses weren't available until morning. There were no pumps available or any information for me to read or to see or anything like that. So despite the fact I was in a hospital, there was no pump for me to use or any information on how to get my milk going.*

– Parent

Insufficient supports were noted particularly for those families who faced other barriers such as lower socioeconomic status, lack of education, limited ability to communicate in the dominant language, etc. As previously discussed, rates of preterm birth are higher among those with lower socioeconomic status, so this gap in supports becomes even more significant.

*I think one of the big barriers and challenges is . . . related to supporting what I would consider to be the higher risk families . . . people with less social advantage, families that may be moms alone with limited support. Be it limited support because they're not connected with their family of origin, or they don't have a lot of friends, they don't have a lot of finances, they don't have transportation, they have cumulative, cumulative stress . . . I am specifically concerned that we have huge barriers and challenges for these high risk families.*

– Other Health Care Provider

*Not all families have the same support, some people have two parents who are working and one of the parents has to hold down two jobs to bring in enough income, and some people have a large extended family, and some families have none. And obviously there's a variation in the educational background, whether they speak English, but the approach to the access of services doesn't really take that into consideration.*

– Neonatologist

## ❖ Transfers Between Facilities

Many key informants described challenges related to transferring premature babies between health care facilities. Transfers occurred when babies were being moved from a level three to a level two facility (i.e., stepping down care), to a hospital closer to home, or to another hospital to receive a specific service (such as surgery). Respondents noted that transfers were often made under emergency conditions, with little notice, due to pressure for beds. Therefore, the transfer process was not well planned and parents had very little preparation or notice of the transfer.

*I think transfer is one of the hardest experiences for NICU families. I think that most hospitals, I don't think we do a great job of preparing families for it . . . we're saying to*

*people, this is an important and great step on the road home, but the truth is, is that the standards of care at many level two hospitals are not what parents would choose for their children. So you know, they're safe, but they don't have the developmental care, they don't have the feeding expertise, so you have to move big babies out so that we have room for the littlest and sickest who need the level three spaces. But you know, selling it like it's a good thing for the families, that's not true. There are many good level twos out there, but they're not all good.*

*– Other Stakeholder*

*I think the challenge however though is that because of the pressure for beds, because it's the pressure for efficiency, then as much as one tries to prepare a family and transition them in a smooth, continuous caring manner, that isn't often how it plays out because bed pressures are dependent upon an emergency. So emergency happens in A and B is in the bed, and B is close enough to go, then it becomes an emergency transfer as opposed to an organized transfer. So that's the complexity of it to me.*

*– Other Health Care Provider*

### ❖ **Barriers to Accessing Care**

Some key informants described barriers faced by families that make it more difficult to access care for their children and themselves. Many families of premature babies receiving care in hospital do not live in the same city as the hospital. Parents travelling from a distance to be with their baby may face barriers to accessing care both in hospital and in their local communities once discharged home. Other barriers to accessing care may include limited access to transportation, having to care for other children without access to childcare, and reduced ability to go out because of the vulnerability of your child to infection. Those families experiencing multiple barriers (e.g., distance, low socioeconomic status, language barrier) may have a much more difficult experience.

*I know that a lot of the children [from First Nations reserves who are born prematurely] are left in the hospitals because of the lack of support in their own communities or the remote areas. So these children, they're just put into care and the parents, they've got three kids at home and they stay at home. I see the struggles.*

*– Other Stakeholder*

*We get a lot of families from outside of the [metropolitan] area that have to travel to be with their baby. And I think we forget that those families are completely disrupted. So what accommodations do we have? We have very, very limited accommodations where a whole family could stay together. And then looking at things like kitchen facilities so that they could go grocery shopping and have food, rather than spending hundreds and hundreds of dollars in restaurants, that type of thing.*

– *Other Health Care Provider*

### ❖ **Gaps in Education for those Working with Preterm Babies**

Some key informants identified gaps in education and training for those working with preterm babies, especially health care providers. This was noted in relation to education both for those in the hospital setting and in the community setting. A few respondents indicated that primary care providers may not be well informed about the challenges and needs of babies born prematurely. A few also identified barriers to ongoing training for hospital staff, such as a lack of resources or staff to support training.

*For many of these babies, they go from a unit where we are all experts in an area, to a place where the family physician does not have the same access to being educated about issues related to the care of the premature baby.*

– *Neonatologist*

*It's kind of related to our budget and, but having the time for the nurses to attend ongoing education-related sessions. So right now they have to attend on their days off, so you get a limited number of people coming to education updates.*

– *Other Health Care Provider*

### ❖ **Attitudes or Approaches of Health Care Providers**

Some parents who participated as key informants in this work highlighted the approaches and attitudes of some health care providers as a challenge. This was particularly noted in relation to discussion and decision-making immediately before or after a preterm birth. Families emphasized that they felt health care providers focused only on negative information and did not provide them with the potential positive outcomes of a baby born prematurely. Some parents also said they felt pressured to take a decision to terminate or not to resuscitate their child. This issue was not widely discussed by health care providers who participated in the environmental scan.

*This is about the prenatal information and diagnosis, and those prenatal conversations, so before the baby is born. Because I think most places aren't doing a very good job of it. And part of it is because medical professionals, and it's kind of interesting to look in the literature, they have a really limited idea of what it is, the value of a life lived with disability. And so part of these conversations sometimes or even after birth if a baby has, if something shows up in the head ultrasound, and the vision of life that gets painted for families is really negative. I know a lot of families who are living life with [premature] kids, and some of the*

*kids don't have big issues, and some of the kids do have big issues, but they don't regret their choices, they're very happy that their kids are with them, and they feel that their kids' lives have value.*

*– Other Health Care Provider*

*. . . we needed to know the information about what a [extremely premature baby] could face. But we definitely felt really pressured to take an end of care route or a palliative route right away, and we weren't offered very much hope . . . it was very negative and in hindsight a lot of it was right, but just the tone in which it was shared was really, really detrimental to my emotional and mental well-being . . .*

*– Parent*

The challenges of ethical decision-making and providing parents with appropriate information and support, especially in the case of extremely premature infants, are also discussed in the literature. Research shows that parents often feel that their initial consultation about premature birth is overwhelmingly negative.<sup>51</sup> In an article examining the topic of decision-making for extremely premature babies, Janvier and Shah note that there is a relationship between values, policies and facts, where decisions made regarding intervention in turn affect statistics for babies of that gestation, which will affect future decisions made for babies in similar circumstances (e.g., if the baby receives only comfort care, this will contribute to the mortality rate, which may influence other families to also choose comfort care).<sup>52</sup> Policy-making on this topic is therefore extremely complex.

### ❖ Financial Burden for Families

Some key informants noted that families can experience a significant financial burden as a result of having a baby born prematurely. This is especially the case with a long hospital stay if the family is from out of town, but other families are also affected. The financial burden of having a baby in hospital has been assessed in the literature, although Canadian data on direct costs for families is not available. A 2014 UK study found that parents spent £282 a week (approximately \$515 CDN at current exchange rates [May 2014]) on expenses

<sup>51</sup> D. Pepper et al., "More Than Information: A Qualitative Study of Parents' Perspectives on Neonatal Intensive Care at the Extremes of Prematurity," *Adv Neonatal Care* 12, no. 5 (2012).

<sup>52</sup> A. Janvier and P. S. Shah, "The Premature Lottery in the Canadian Grey Zones."

such as food, transportation, accommodations, parking, childcare, etc.<sup>53</sup> In addition, parents may postpone their return to work or leave the workforce completely in order to care for their child, which can reduce family income.<sup>54</sup> This may especially be true when families have to use their maternity/parental leave time while their baby is in hospital, leaving less time to spend with their child once they come home.

*It had an impact financially on us. Ronald McDonald House is 15 dollars a day, it's not huge . . . we had to pay for parking at the hospital, and then parking in downtown [city]. In parking only it was over 400 dollars a month, and that doesn't include the fees at Ronald McDonald House, and then we had to pay for our own expenses, meals and extra stuff that we had to take care of. So there was a burden financially, of course.*

– Parent

*Some families have very few resources and just getting here to the hospital to visit, even if it's just a three dollar bus ride on [public transit], can actually be taxing on some families. And then having to go and eat in our expensive cafeteria once they're here – so that's just some of it. And there are some times that there are issues with a place for them to stay.*

– Neonatologist

### ❖ Limited Supports for Late Preterm Babies

Some participants in the environmental scan noted that there were very limited supports for moderate to late preterm babies (those born between 32 and 36 weeks). Respondents indicated that these babies did not have access to the same follow-up care and support as babies born at an earlier gestational age, even though there is clear research evidence that moderate to late preterm babies need additional support.<sup>55</sup>

*Babies born between 32 and 37 weeks really get no neonatal follow-up whatsoever, and this is just a disgrace because these children have very similar issues in school than the micro preemies, and they really haven't had that support of a follow-up clinic when they've been discharged. And those families often don't have that information, and don't even know what to look for and what to advocate for.*

– Other Stakeholder

*So my [child] was that in between premie age, 33 weeks and we fell through the cracks. So the neonatologist wasn't interested in our case unless he had a bad day, which of course he did. The medical staff just kind of ignored, so a lot of times we had no idea what was going*

<sup>53</sup> Bliss, "It's Not a Game."

<sup>54</sup> European Foundation for the Care of Newborn Infants (EFCNI), "Caring for Tomorrow."

<sup>55</sup> E. S. Forsythe and P. J. Allen, "Health Risks Associated with Late Preterm Infants: Implications for Newborn Primary Care; A. Berard, M. Le Tiec, and M. A. De Vera, "Study of the Costs and Morbidities of Late-Preterm Birth."

*on. And even the support, we were low priority even though we did need that support. Their hands were tied at that point, unless something bad happened, then we could finally get some answers . . . we fell through the cracks because he was just that in between, so they just let us go and we were on our own. So no support whatsoever.*

*– Parent*

### ❖ Lack of Long-term Follow-up

Some key informants mentioned that long-term follow-up for premature babies was insufficient. Respondents said that follow-up often ends too early (clinics do not follow beyond school age and often end much earlier) and/or is not provided to all premature babies that need the support.

*There's very good literature that supports that these babies have ongoing issues into school and yet clinics notoriously end between three and six.*

*– Neonatologist*

*To me, I think that's where there's a big gap in the system is follow-up continuing. I think it should go on to at least five years old, if not seven. I think there needs to be education in the school system about how to understand premature babies and what they do differently with learning differences, etc.*

*– Parent*

### ❖ Limited Resources Devoted to Addressing Premature Birth

Some key informants described how the resources available to address premature birth in various forums are limited. Resource limitations were identified to cause challenges related to availability of staff and beds in NICUs, availability of research funding, follow-up care, and support for activities such as staff education or quality improvement. A lack of attention and investment from private sector health companies was also noted as a barrier, as private companies play an important role in the development of new technologies and medications that can help to address premature birth.

*The funding [for research] could be better. So some of the barriers are that women's health and newborn health and women's pregnancy health have historically been near the bottom of the totem pole in terms of dollars. It's way less than in cancer, cardiovascular or mental health, or any adult diseases. Actually there are several adult diseases that have incidence that are lower than preterm birth, which is about one in 10 babies or 10 percent, and have consequences that aren't so dire.*

*– Other Health Care Provider*

*One [of the challenges] is lack of adequate nursing staff numbers. Right now we're very challenged with being told to run a certain number of beds without an adequate number of nursing staff to run those beds . . .it's a budget issue.  
– Other Health Care Provider*

### ❖ Lack of Awareness about Premature Birth

A few key informants highlighted the lack of awareness about premature birth among the general public as a challenge, in part because it leads to fewer resources provided to address the issue.

*Prematurity is not recognized appropriately by the general population for the importance. First of all I don't think, if you pick an average person off the street, I don't think they would have any idea what the issues related to preterm birth are or the incidence in the population. And so it is a lack of public awareness, consciousness.  
– Other Stakeholder*

*The other thing that's happening from a society perspective is that everybody . . . is very focused on elderly care to the jeopardy of paediatric care, to the jeopardy of people who are starting the beginning of their lives. I'm deeply worried about that from a policy perspective, and because vulnerable families and pre-term infants . . . these kids don't vote. They're not powerful, and so I'm really worried about that.  
– Other Health Care Provider*

## Best Practices and Supports Required

This section describes the best practices related to caring for premature babies and their families, as well as the additional supports required to improve care. The findings presented here are drawn from both the interviews/focus groups and the literature review. The themes are grouped by the area addressed rather than just by strength of response (as in the previous sections), as some themes are drawn much more from the literature than from findings from key informants. When key informant findings are referenced, the strength of response is noted using the terms “many”, “some”, and “a few”.

The best practices and needed supports address the following areas: prevention, screening and prenatal care; clinical care; family-centred care; supports for families; transfer and

discharge home; long-term care and follow-up; education for those working with premature babies; quality improvement and research; and increasing awareness about premature birth.

## ❖ Prevention of Premature Birth

### *Primary Prevention*

As described earlier in this report, risk factors for premature birth include factors such as behaviour, social determinants of health, demographics, and medical conditions. Population-based programs that address these health and behavioural concerns can contribute to improving the chance of healthy birth outcomes.<sup>56</sup> Although key informants were not specifically asked about prevention of premature birth, a few commented on the importance of population-level interventions to help support healthy pregnancy and birth.

*I am trying to discover new fancy treatments for BPD [bronchopulmonary dysplasia] and I think a lot and maybe even more can be achieved by prevention. So education. Educate so that we don't get teen pregnancies, or that this many people take drugs, or that fewer people are obese because that complicates the outcome. And finally, I think there was the first paper that was actually published last week that shows that obesity in pregnant mothers is a problem for the offspring, right? So here lots can be done at the social level and educational level.*

*– Neonatologist*

*What I think would have been more helpful is that if there was more information before when I was pregnant. That awareness, how common prematurity actually is, because before that the only time that I ever heard of a NICU was watching ER. That was it. I never heard of prematurity, first time pregnancy, I thought, oh, just the same as everybody else – no idea what was going to happen.*

*– Parent*

The importance of ensuring that women have access to pre-conceptional and information that will support a healthy pregnancy,<sup>57</sup> and to high quality prenatal care is also described in the literature. Reproductive assistance programs should avoid or limit multiple pregnancies, as this is a risk factor for premature birth.<sup>58</sup> Once women are pregnant, high

<sup>56</sup> D. E. White et al., "The Content of Prenatal Care and Its Relationship to Preterm Birth in Alberta, Canada," *Health Care Women Int* 27, no. 9 (2006).

<sup>57</sup> European Foundation for the Care of Newborn Infants (EFCNI), "Caring for Tomorrow; March of Dimes et al., "Born Too Soon."

<sup>58</sup> European Foundation for the Care of Newborn Infants (EFCNI), "Caring for Tomorrow."

quality prenatal care should be available, and this should include providing women with information at 18-20 weeks about the signs and symptoms of preterm labour.<sup>59</sup> In order to reduce the potential impact of risk factors, women with high risk pregnancies should have access to appropriate supports such as starting their leave (pregnancy leave, disability, etc.) earlier, without financial disadvantage.<sup>60</sup>

### ***Secondary and Tertiary Prevention***

Early detection and appropriate response to preterm labour is an important strategy for preventing or reducing the impact of preterm birth and should follow evidence-based guidelines.<sup>61</sup> This includes recognition of the signs and symptoms of preterm labour (secondary prevention) and provision of corticosteroids (tertiary prevention).<sup>62</sup> Other elements of treatment include providing tocolytics (anti-contraction medications) to slow down labour and antibiotics for preterm premature rupture of the membranes (pPROM).<sup>63</sup>

Women who are at risk of preterm birth should receive a prenatal consultation with a neonatologist. The purpose of this consultation would be to inform women and their families about prematurity and discuss potential options and care. Neonatologists can provide information on survival rates, anticipated length of stay in hospital, and the risks of health and developmental problems.<sup>64</sup> Ideally this would occur at a time when women and their families have time to understand and process the information, although this is not

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<sup>59</sup> British Columbia Reproductive Care Program, "Obstetric Guideline 2a," in *PRETERM LABOUR* (British Columbia 2005); European Foundation for the Care of Newborn Infants (EFCNI), "Caring for Tomorrow; D. E. White et al., "The Content of Prenatal Care and Its Relationship to Preterm Birth in Alberta, Canada; Best Start: Maternal Newborn & Early Child Development Resource Centre, The Perinatal Partnership Program of Eastern and Southeastern Ontario, and The Society of Obstetricians and Gynaecologists of Canada, "Preterm Birth: Making a Difference Clinical Practice Guidelines," (2002).

<sup>60</sup> European Foundation for the Care of Newborn Infants (EFCNI), "Caring for Tomorrow."

<sup>61</sup> Ibid; March of Dimes et al., "Born Too Soon."

<sup>62</sup> Best Start: Maternal Newborn & Early Child Development Resource Centre, The Perinatal Partnership Program of Eastern and Southeastern Ontario, and The Society of Obstetricians and Gynaecologists of Canada, "Preterm Birth: Making a Difference Clinical Practice Guidelines."

<sup>63</sup> March of Dimes et al., "Born Too Soon."

<sup>64</sup> N. Gaucher and A. Payot, "From Powerlessness to Empowerment: Mothers Expect More Than Information from the Prenatal Consultation for Preterm Labour " *Paediatr Child Health*, 16, no. 10 (2011); E. Young and A. O'Riordan, "A Qualitative Study of Predelivery Counselling for Extreme Prematurity," *ibid.* 17, no. 8 (2012); A. L. Jeffries et al., "Counselling and Management for Anticipated Extremely Preterm Birth," *ibid.*

always possible. A few key informants spoke about strategies for providing women with information about premature birth.

*We're always thinking about meeting with [women at risk of preterm birth] for a half hour at a time, and we don't have a lot of resources developed for them, so that we could leave printed material with them, that kind of thing. So if they forget to ask a question or if they want to read something again, that we definitely need to develop something better. We're also thinking of developing a video of the NICU.*  
– Other Health Care Provider

### ❖ Increasing Awareness of Premature Birth

A few respondents highlighted the importance of increasing awareness of premature birth among the general public, and emphasized the role that foundations like the Canadian Premature Babies Foundation could play in that work.

*. . . this is the first time ever in either Europe or in Canada that we've had parents' organizations actually making people aware of [the issue of prematurity]. So it can only get better. Before this time there was never any advocacy for the children themselves or their parents and families. And this advocacy is very, very important . . . public knowledge of preterm delivery should change because of their excellent efforts. These groups have now created November 17th as worldwide prematurity awareness day.*  
– Other Stakeholder

*I think the first thing to do is get people talking about premature babies in the media. To talk about it frequently, to get people talking about it, to spread the word that premature babies have certain needs, but generally turn out well. To promote that the percentage of recovery is good.*  
– Parent

### ❖ Decision-making around Premature Birth

As described in the challenges section, decision-making related to preterm birth, especially for extremely preterm babies (i.e., 26 weeks gestation or earlier) can be complex. A gestational age that is considered to be viable or futile in one region/country may be seen differently in other places or by different health professionals. The Canadian Paediatric Society (CPS) has issued a position statement recommending a non-interventional approach for infants born before or at 22 weeks gestation.<sup>65</sup> However, a position statement

<sup>65</sup> "Counselling and Management for Anticipated Extremely Preterm Birth."

based on gestational age is somewhat controversial, as assessment of gestational age can be unreliable.<sup>66</sup> A few parents in the focus groups also noted that the CPS statement was problematic.

*The Canadian Paediatric Society, they've made a statement about suggesting if resuscitation should be made at 23, 24 or 25 weeks, etc. And I don't think the parents' voice is being taken into account very much. And their statement is made by gestational age, which means that when you know that 95 percent of pregnancies are not quite precise. It can be like five days more or five days less, it's a huge impact. So to say the statement that at 23 weeks they don't recommend resuscitation, but what if the baby is 23 and six, and another one is 24? So why wouldn't we recommend resuscitating a 23 and six, and we would recommend a 24 and one? But the 24 and one could actually be younger than the 23 weeks because there's no way to know exactly the precise day of conception. So I think that's another sensitive subject that needs to be discussed, and I think parents need to have their voice in that area. I know it's being discussed right now in the neonatology world, but I think we need to keep an eye on it.*  
 – Parent

Ultimately, regardless of gestational age, the decision-making process should include both parents and health professionals and should be individualized to the needs and circumstances of each individual patient, taking into account the research evidence, prognosis, and needs and desires of the family.<sup>67</sup> A few key informants (primarily parents) described the importance of receiving not only facts and statistics (which can be overwhelmingly negative, especially for extremely preterm babies), but also being offered hope, positive information, and a realistic picture of what the future may hold (for example, through connection to another family living with similar disabilities).

*I think the key piece for me would be to employ means to connect parents with hopeful visions of the future . . . I think if I had been invited to or brought to a better understanding of a range of wellness . . . if somebody said, let's take you here and let's go talk about kids with brain bleeds, and kids with CP [cerebral palsy], and kids with this, that and the other thing . . . You know, parents whose children are in wheelchairs who are completely in love with their children and happy. That really would have helped.*  
 – Parent

*We also need to bring the voices of families into these discussions, and think about sensitive ways of doing that. So that people who are facing these huge decisions and discussions, they aren't just hearing this one, very limited point-of-view . . . Thinking about collaborating with people, the rehab centres, doing video interviews with families, and just really getting truthful stories out there. So this is what it might look like. So if your kid has a grade four*

<sup>66</sup> A. Janvier and P. S. Shah, "The Premature Lottery in the Canadian Grey Zones."

<sup>67</sup> Ibid.

*bleed, we don't know what the future's going to look like, but here's some possibilities. I could be from here to here, and this is what the families who are living with it have to say.*  
– Other Stakeholder

A few key informants noted the importance of more education or training for health care providers in delivering unbiased information to families and supporting the decision-making process. This need for training was also described in the literature.<sup>68</sup>

*In terms of the education piece, I would say, how to engage parents in a conversation, both pre and post-term and the most sensitive way to do that. They're providing them with the information that they need, but not in such a way that diminishes all hope, and also being able to gauge how much information a parent can handle. Some parents want more, some want less. That is an education piece that I think would be very important.*  
– Other Stakeholder

*I think communication skills need to be improved in many, many units . . . I know [there is work being done on] giving advice to doctors, how to talk about tough subjects to parents, and how to conduct a discussion. I think that's something that more and more doctors need to read about.*  
– Parent

## ❖ Clinical Care

This section describes some of the best practices and supports needed related to provision of clinical care for premature babies. It is not intended to provide clinical guidance or an exhaustive overview of all clinical issues. Neonatal care techniques should be evidence-based and draw from the best available clinical standards.<sup>69</sup>

### *Organization of Care*

Centralisation and specialisation of care in fewer centres has been done in a few countries. This can have advantages as medical professionals in the specialized centres see a greater number of cases and have the opportunity to further develop and increase their level of skill and knowledge. The challenge with a more centralized system of care such as the Canadian system is that it can pose problems related to access to care due to distance, as noted earlier in this report (see *Barriers to Accessing Care* section). It is therefore critical that

<sup>68</sup> Bliss, "Baby Charter Standards."

<sup>69</sup> European Foundation for the Care of Newborn Infants (EFCNI), "Caring for Tomorrow."

appropriate supports are in place for families in order to ensure equitable access to care. For example, in Portugal, the system of care was centralised, and at the same time, a nationwide transport system for pregnant women and newborn babies was also established.<sup>70</sup> The importance of providing appropriate supports for families is further discussed in a subsequent section (*Supports for Families*, p. 50).

Care for mothers and babies should be provided at the appropriate level facility based on patient condition and prognosis. In Canada, level three facilities provide care for the smallest and sickest babies. Where possible and medically appropriate, birth and subsequent care of late preterm babies should take place at level 2 centres in order to improve bed availability at level 3 centres for those infants requiring that level of care.<sup>71</sup>

### ***Staffing***

Care for preterm infants should be provided by a multi-disciplinary team that includes (as appropriate) neonatologists, paediatric/neonatal nurses, paediatric surgeons and anaesthesiologists, pharmacists, dietitians, physical and/or occupational therapists, speech and language therapists, lactation consultants, social workers, psychologists, etc.<sup>72</sup> Sufficient/appropriate levels of properly trained and educated staff should be available to provide clinical care.<sup>73</sup> Staff training and competency is described further in a subsequent section. A few key informants specifically highlighted the role that nurse practitioners can play in caring for premature babies.

*What I liked in [city] was the nurse practitioners for example, they were very well trained, skilled and had lots of experience. And I think they also were really good when they talked with the parents. They work at the interface between the nurses and the physicians, and I think their nursing background gives them this additional advantage of being still very close with the parents, and being able to talk and relate to them.*  
– Neonatologist

<sup>70</sup> "Too Little, Too Late? Why Europe Should Do More for Preterm Infants - EU Benchmarking Report 2009-2010," (2010).

<sup>71</sup> A. L. Jefferies et al., "Impact of Late Preterm Birth on Neonatal Intensive Care Resources in a Tertiary Perinatal Center."

<sup>72</sup> European Foundation for the Care of Newborn Infants (EFCNI), "Caring for Tomorrow; Bliss, "Baby Charter Standards; NHS England, "Toolkit for High-Quality Neonatal Services," (2009).

<sup>73</sup> Bliss, "Baby Charter Standards; NHS England, "Toolkit for High-Quality Neonatal Services."

### ***Care & Referral Pathways***

Clinical pathways are “clinical and quality tools that support the organization of patient care delivery for a specific population through the use of a consistent multidisciplinary process.” The development and implementation of clinical pathways can be an important tool to support quality improvement. Development of clinical pathways should engage a multidisciplinary group (i.e., physicians, nurses, allied health, etc.) and requires appropriate staff education and support to implement, as well as parent education about the pathway and clinical care.<sup>74</sup> Standardized physician order sets (admission, discharge) can also be created to support and complement the care pathway(s).<sup>75</sup> Only a few key informants described the care pathways in use in their facility.

*We have a number of care protocols, particularly for the extremely premature baby. We have what we call the tiny baby protocol, which is sort of a standardized set of admission orders, and then we have a ventilator weaning protocol, and we have some feeding protocols. We've really standardized how we feed the very premature babies when we start and so on.*  
– Neonatologist

Countries/provinces/regions should have appropriate defined pathways to guide referrals and neonatal care. Pathways should cover the following: identifying pregnant women at high risk for preterm labour and referring appropriately; providing clinically appropriate and evidence-based care to pregnant women and babies; providing safe and suitable transfers for newborn babies to specialised care units as required (i.e., identifying the care network and what services are provided at which facilities); and identifying the steps in the pathway for discharge and aftercare.<sup>76</sup> Care pathways related to preterm birth should be integrated with other maternity and newborn network guidelines and pathways.<sup>77</sup>

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<sup>74</sup> M. A. Campbell, "Development of a Clinical Pathway for near-Term and Convalescing Premature Infants in a Level Ii Nursery," *Adv Neonatal Care* 6, no. 3 (2006).

<sup>75</sup> Ibid.

<sup>76</sup> European Foundation for the Care of Newborn Infants (EFCNI), "Caring for Tomorrow."

<sup>77</sup> National Institute for Health and Clinical Excellence, "Quality Standard for Specialist Neonatal Care," in *Quality Standards Programme*.

### *Developmental Care*

Babies in the NICU should receive appropriate developmental care. This includes reducing exposure to loud sounds and bright lights to reduce the sensory stimulation of infants.<sup>78</sup> Often there are physical barriers to developmental care due to facility structure (e.g., all babies together in a loud, brightly lit room). Where possible, NICUs should be rebuilt or renewed to more closely meet the current guidelines/standards for developmental care. These standards typically require a significantly greater amount of space.<sup>79</sup>

Kangaroo care (i.e., skin-to-skin contact between an infant and parent) is also an important part of providing appropriate developmental care. Kangaroo care has been shown to be positively associated with cardiorespiratory and temperature stability, sleep organization and duration of quiet sleep, neurodevelopmental outcomes, breastfeeding and reduced pain in preterm infants.<sup>80</sup>

A few key informants emphasized the importance of providing appropriate developmental care to premature babies.

*When you're looking at the research and you're looking at things like the importance of kangaroo care, and how that really significantly impacts especially these tiny little 23, 24, 25 week babies that have such significant brain development ahead of them, and that kangaroo care, which is so simple and cheap is making a huge difference. And you're looking at these studies, the newest study out of Quebec that they're looking at the original kangaroo site in Colombia, and showing that these kids have identical brain development as full-term healthy babies. Like at 12 and 15 years old.*  
– Other Health Care Provider

<sup>78</sup> R. D. White, "Designing Environments for Developmental Care; Bliss, "Baby Charter Standards; European Foundation for the Care of Newborn Infants (EFCNI), "Caring for Tomorrow."

<sup>79</sup> R. D. White, "Designing Environments for Developmental Care; Bliss, "Baby Charter Standards; European Foundation for the Care of Newborn Infants (EFCNI), "Caring for Tomorrow."

<sup>80</sup> March of Dimes et al., "Born Too Soon; NHS England, "Toolkit for High-Quality Neonatal Services; R. D. White, "Designing Environments for Developmental Care; A. Jefferies, Canadian Pediatric Society, and Fetus and Newborn Committee, "Kangaroo Care for the Preterm Infant and Family," *Paediatr Child Health*, 17, no. 3 (2012); A. Conde-Agudelo, J. Belizan, and J. Diaz-Rossello, "Kangaroo Mother Care to Reduce Morbidity and Mortality in Low Birthweight Infants (Review)," in *The Cochrane Database of Systematic Review* (2011).

### ***Palliative Care***

If a decision is made to provide palliative or comfort care to a baby, parents should receive appropriate information and support for palliative care, including connection with hospice care, discharge home, connection to bereavement groups or other psychological supports, spiritual supports if requested, etc.<sup>81</sup> A few key informants noted the importance of a palliative care team that can support the family and provide coordinated care.

*Once we know that this child is for palliative care, we refer these families to the palliative care team who gets involved, and then everybody on board gets involved and takes care of the family . . . [the team should be] trained, and the physician involved must have some sort of education and training in palliative care . . . I think it's quite an important issue, especially in the NICU where we see a lot of morbidities and mortalities also from time to time. I feel it's important that we should not leave these families in a traumatized state, and so a palliative care team would be an important aspect to look at.*  
 – Neonatologist

### **❖ Family-centred Care**

Having a child in the NICU can be a very scary experience for parents. Family-centred care (FCC) is an important part of supporting parents whose preterm infants require intensive care. FCC is a philosophy and approach that includes treating all family members with dignity and respect, sharing information and providing education to family members, encouraging family collaboration and input into decision-making, offering the family appropriate emotional support, and facilitating family participation in the care of the infant.<sup>82</sup> Care is planned around the family and each family member is recognized as having a role in care.<sup>83</sup> Family-centred care has been shown to support a decreased length of hospital stay, enhanced infant-parent attachment and improved long-term outcomes for the baby.<sup>84</sup> Other positive outcomes may include improved weight gain and increased rates of breastfeeding.<sup>85</sup>

<sup>81</sup> Bliss, "Baby Charter Standards; European Foundation for the Care of Newborn Infants (EFCNI), "Caring for Tomorrow."

<sup>82</sup> S. D. Berns et al., "Results of the Premature Birth National Need-Gap Study."

<sup>83</sup> S. Cockcroft, "How Can Family Centred Care Be Improved to Meet the Needs of Parents with a Premature Baby in Neonatal Intensive Care?," *Journal of Neonatal Nursing* 18, no. 3 (2012).

<sup>84</sup> Ibid.

<sup>85</sup> K. O'Brien et al., "A Pilot Cohort Analytic Study of Family Integrated Care in a Canadian Neonatal Intensive Care Unit."

As described earlier, Mount Sinai Hospital in Toronto, Canada has implemented a Family Integrated Care initiative, which includes daily provision of care to infants by the mother/parent, as well as daily educational sessions and participation in medical patient rounds. This initiative has been shown to be effective in delivering family-centred care that results in improved parental knowledge about and preparation for caring for their infant.<sup>86</sup>

The importance of implementing and increasing support for the provision of family-centred care was the most frequently mentioned needed support/best practice, emphasized by almost all key informants. Key informants described how family-centred care should be provided not just in the NICU but across the continuum of care, and emphasized that some sort of standards or guidelines could help ensure that the principles are applied consistently across settings.

*The ICU is such an intensive environment and such a medical environment, and yet what these babies need is they need their parents more than anything. So that's not machines, it's not technology, it's not sexy, but it's needed. And I think there's a greater and greater awareness of the critical nature of that need.*

– Neonatologist

*I think there should be a standardized model of care . . . the basic properties of family-centered care about open rounds and respect for parents first, and dignity and all of those things . . . you have to follow the basic guidelines that constitute family-centered care that are national. So I think that's really important that there are standards at each hospital, and that somehow across Canada that can be unified.*

– Parent

Some key informants highlighted the role that family-centred care can play in improving outcomes for babies. Key informants noted that the family-centred approach and engaging parents in providing care for their babies can play a critical role in increasing parental knowledge, comfort and empowerment, which will support babies and families both in the NICU and beyond.

*The family integrated care model . . . I think the value is bringing families in as equal partners in care as soon as possible, because parents tend to be the ones who know the most about their babies, so it improves outcomes even within the NICU. It shortens length of stay, so*

<sup>86</sup> M. Bracht et al., "Implementing Family-Integrated Care in the NICU: A Parent Education and Support Program," *Adv Neonatal Care* 13, no. 2 (2013).

*that's an immediate bonus to it. It helps with stress and all that right away, and then you also see the benefits during discharge and post-discharge.*

*– Other Stakeholder*

*So for example, parent coping and parent resiliency, if we take a strength-based approach earlier in the NICU, building their confidence, building their parenting capacity, engaging them to do more hands-on, engaging them so that they are more involved . . . so that they're an equal partner in the care and communicating at all levels, communicating in rounds, communicating in decisions at the beginning, [that] does not create parents eight months out who have no confidence, who are struggling to make decisions. If they've been involved in decision-making and supported along the way, it would be a completely different mechanism.*

*– Other Health Care Provider*

Physical contact, including both touch and providing care, are important to promote bonding and form part of family-centred care. Parents should be actively involved in the care of their child in the NICU.<sup>87</sup> This can help to increase parental knowledge and decrease stress.<sup>88</sup> The Nordic countries, particularly Sweden, are leaders in this area.

*In Sweden, they have the bed in with the incubator, so that they're actually nursing the child off a family member's chest, 24 hours a day . . . they try and actually not have the baby in the incubator at all, and they're having extremely good results with that, so they're very advanced in all of those areas . . . they basically only try to take them off for significant procedures, you know, intubations and things like that. But other than that, most of the procedures take place on the chest of a family member.*

*– Other Health Care Provider*

The physical structure of a facility is also an important factor in the ability to provide family-centred care. As noted in the challenges section, physical barriers such as lack of space for parents can reduce their ability to be involved in the care of their child. Construction/renovation of NICUs should therefore take into consideration the space/physical needs that support family-centred care. The provision of single family rooms when possible (i.e., a room that can accommodate the baby and any multiple birth siblings as well as the parents) promotes skin-to-skin contact and parental involvement in care, as well as offering increased privacy.<sup>89</sup>

<sup>87</sup> Bliss, "Baby Charter Standards; European Foundation for the Care of Newborn Infants (EFCNI), "Caring for Tomorrow; S. Cockcroft, "How Can Family Centred Care Be Improved to Meet the Needs of Parents with a Premature Baby in Neonatal Intensive Care?."

<sup>88</sup> H. M. Obeidat, E. A. Bond, and L. C. Callister, "The Parental Experience of Having an Infant in the Newborn Intensive Care Unit."

<sup>89</sup> R. D. White, "Designing Environments for Developmental Care."

*Increasingly, new neonatal intensive care units that are being built around the world actually have individual family units, not a big noisy room with a lot of technology and a whole bunch of bassinets or cribs with plexi-glass covers for the baby. Now you have those into individual rooms where the parents can actually live in. The mother is given a lot of responsibility for the basic care of her newborn preterm infant, including things like, obviously a lot of holding, but also if there's any bathing involved or feeding, or just daily measurements of weight and things like that, the mother can do. So the mother feels a lot closer to her baby . . . these new units are really designed for family-centered care, and I guess we could advocate for those wherever we go. They're quite expensive obviously to create, but I think the parents feel much better about it, and I'm sure that the health of the child is probably improved as well because there's a lot of bonding that occurs between mother and the child.*

*– Other Health Care Provider*

### ❖ **Supports for Families**

In addition to ensuring that the family-centred care philosophy is practiced within hospitals, it is also critical to provide appropriate supports for parents and families. Many key informants highlighted the need for increased support to address practical and financial concerns, information needs, and the social and emotional needs of parents. Most of the supports described in this section go hand-in-hand with family-centred care (e.g., providing parents with information/education, having accommodations on site so parents can spend time with their babies, etc.). It is also important to note that most of these supports should continue following discharge from hospital (e.g., peer connections, financial supports, information and education, etc.).

#### ***Financial and Other Practical Supports***

As described earlier in the report, parents with premature babies in the hospital may face a significant financial burden due to the additional associated expenses for things like travelling to and from the hospital, eating at the hospital cafeteria, accommodations away from home, etc. It is therefore critical to provide families with assistance around these costs.<sup>90</sup> Many key informants noted the need for these types of supports and most frequently emphasized providing assistance with parking costs and accommodation costs.

<sup>90</sup> Bliss, "Baby Charter Standards; NHS England, "Toolkit for High-Quality Neonatal Services; Bliss, "It's Not a Game."

Families should have access to appropriate accommodations in order to stay near their baby (ideally on site) and participate in care (part of the family-centred care philosophy). Accommodation facilities should include beds, bathroom facilities, space to store belongings, space to prepare food, an area to care for any siblings, etc. and these accommodations should be free of charge.<sup>91</sup> Other practical supports might include extended maternity/parental leave or daycare facilities that can accommodate the needs of preterm babies.<sup>92</sup>

*We really feel like parents shouldn't have to be paying for parking or very little. It is a huge barrier for our families, well it's huge. You can practically mortgage a house on parking. It's crazy. One of the [other] things that I think we need to improve on is access to nutrition. It's a hospital, there are places to eat, but again you're talking about families that are here for months.*

– Other Health Care Provider

*It's very important for the babies to be near their families and their mother, as this is major in the development and recovery. And to manage that, I think all the neonatal units should have accommodation rooms for the families. They should all have places for the family to sleep but still be very near the babies, places to sit, places to relax, kitchens for cooking, fridges, microwaves, everything basic you need, everything they need so that the family can be there, be comfortable and provide the love and comfort the babies need.*

– Parent

### ***Improve Information and Education for Parents***

Adequate communication with parents and providing parental information and education is a key support for parents, and also an important component of family-centred care. Areas of information and support that have been identified by parents as important include infant health, infant care, coping, positive parenting, attachment, and adapting to having a child in the NICU.<sup>93</sup> Facilities may offer parents a welcome package that provides information upon admission to the NICU.<sup>94</sup>

<sup>91</sup> "Baby Charter Standards; NHS England, "Toolkit for High-Quality Neonatal Services; Bliss, "It's Not a Game."

<sup>92</sup> European Foundation for the Care of Newborn Infants (EFCNI), "Caring for Tomorrow."

<sup>93</sup> M. Bracht et al., "Implementing Family-Integrated Care in the NICU: A Parent Education and Support Program."

<sup>94</sup> D. Discenza, "Welcome to the NICU: Helping Parents Adjust to NICU Life," *Neonatal Network*, 28, no. 2 (2009); M. A. Campbell, "Development of a Clinical Pathway for near-Term and Convalescing Premature Infants in a Level II Nursery."

Staff should provide consistent information on clinical care, diagnoses, tests, etc. and use strategies such as beside charting/notes or a communication board to facilitate information sharing as it is critical to provide written as well as verbal information.<sup>95</sup> Supports to communication and information such as interpretation or cultural supports should be provided where required.<sup>96</sup>

Some key informants highlighted the need for improved education and informational supports. As described in an earlier section on successes, having the opportunity to participate in patient rounds was seen by a few key informants as an important strategy for increasing communication and information sharing between parents and health care providers. Information provided to parents should be consistent, and should be presented in a way that is understandable and appropriate for the parents' level of literacy and health literacy.

*I think we need to communicate more with our families, probably if we have the time before their baby is born or shortly after their baby is born about what is available. So not just making it dependent on the nurse that's assigned to their baby to tell them that it's important they attend rounds every day, or that it's important that they spend time with their baby, and can do kangaroo care, that every single family gets the same information.*

– Other Health Care Provider

*I think there should be a continuum of care education, but it starts antenatally and goes all the way through to follow-up, there's so much lacking in education. I think there needs to be a bridge to fill the gap. It shouldn't just be antenatal, NICU and follow-up. It should all bridge together. Obviously you're going to have give information in small chunks at the appropriate time because you can't overwhelm people.*

– Parent

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<sup>95</sup> S. Cockcroft, "How Can Family Centred Care Be Improved to Meet the Needs of Parents with a Premature Baby in Neonatal Intensive Care?." Bliss, "Baby Charter Standards; European Foundation for the Care of Newborn Infants (EFCNI), "Caring for Tomorrow; NHS England, "Toolkit for High-Quality Neonatal Services."

<sup>96</sup> Bliss, "Baby Charter Standards; European Foundation for the Care of Newborn Infants (EFCNI), "Caring for Tomorrow."

### ***Social and Emotional Supports***

Social and psychological supports such as peer support (one-to-one or support group), bereavement support, and formal counselling (e.g., to deal with issues such as anxiety, trauma, depression, etc.) should be available to parents.<sup>97</sup> The importance of this type of support, particularly peer support and the opportunity to connect with veteran parents, was also described by some key informants.

*One of the best practices that I've seen is having someone like a parent support person who's actually employed by the hospital, employed by the unit and able not just to advocate, but to help offer perspective from the parents' point-of-view. And this sort of re-solidifies the family-centered philosophy.*

– Other Stakeholder

*I think what we underestimate is the social isolation. And I think we also underestimate that when most people have a baby, they go home to their friends and their family, and that becomes sort of their social support. But when our moms have babies we tell them, don't bring a lot of people in, don't come in if you're sick, and so what happens is the nurses and the incredible team in the ICU becomes their family, and then they're just cut off. All of a sudden, everyone they've become so close to and so intensely attached to, it's gone. So how do we provide a better process? A process that has less anxiety, less stress for the families, and is it that prior to discharge at every single centre a parent is contacted by another parent in the community that says, hey, I know where you're at, and I'm here, and I'm going to wait for you on the other side, and you're going to call me the day you go home. And then I'm going to call you the next day, and I'm going to call you the next day, and I'm going to help guide you through this and be your point person.*

– Neonatologist

### ***Breastfeeding Support***

Breastfeeding premature infants can be challenging, so mothers should receive appropriate support for breastfeeding and expression of breast milk. This should include a breastfeeding policy at the facility; provision of practical support to the mother (e.g., private space for feeding, assistance with latch or pumping, provision of necessary equipment such as a breast pump, etc.); access to donor breast milk where available; having staff who are trained in and supportive of breastfeeding; support with transition from tube

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<sup>97</sup> Bliss, "Baby Charter Standards; European Foundation for the Care of Newborn Infants (EFCNI), "Caring for Tomorrow; NHS England, "Toolkit for High-Quality Neonatal Services."

feeding to breastfeeding, etc.<sup>98</sup> All Canadian hospitals with a special care nursery or NICU reported that they encouraged mothers to breastfeed and/or express their milk.<sup>99</sup>

## ❖ Transfer and Discharge Home

### *Transfers*

Transfers of premature babies between different hospital settings prior to being discharged home was not identified in the literature as a particular gap, but was noted as an area of challenge by many key informants. A few key informants also spoke about improving the transfer process by ensuring parents are aware of the possibility of transfer and identifying their preferred transfer sites, and by working to better prepare parents for the new environment they are going into.

*I think we could be more proactive. So closer to admission times, alert them to the fact there's a good chance their baby eventually will be transferred out of the unit. So what would be the most convenient level two nursery in the province to transfer them to?*

– Other Health Care Provider

*I've recently started . . . doing some site visits [to other hospitals] so that I can know where I'm sending our families, so that we know specifically what their resources are, and who some of those people are . . . it's been helpful for us to kind of understand it . . . it would be good if we had a little bit more to share with [parents].*

– Other Health Care Provider

### *Discharge Planning and Preparation*

When a baby is discharged home from the hospital, there are two transitions involved – the transition from hospital to home, and the transition into parenthood.<sup>100</sup> Adequate preparation for discharge is critical as poor preparation is associated with poorer outcomes for the baby.<sup>101</sup> Preparation for discharge should begin well before discharge by providing parents with information and increasing their skill and confidence level (through family-

<sup>98</sup> Bliss, "Baby Charter Standards; NHS England, "Toolkit for High-Quality Neonatal Services."

<sup>99</sup> Public Health Agency of Canada, "Canadian Hospitals Maternity Policies and Practices Survey."

<sup>100</sup> M. Boykova and C. Kenner, "Transition from Hospital to Home for Parents of Preterm Infants."

<sup>101</sup> V. C. Smith et al., "Are Families Prepared for Discharge from the NICU?," *J Perinatol* 29, no. 9 (2009).

centred care practices).<sup>102</sup> Strategies such as rooming in at the hospital can help to support preparation for discharge.<sup>103</sup> Facilities should also have a detailed discharge planning policy in place to guide the discharge process.<sup>104</sup>

Some key informants spoke about the need for more coordinated discharge planning. Respondents suggested that planning should be supported with appropriate tools (e.g., checklists of tasks to be completed) and staff resources (e.g., a designated discharge coordinator), and that families should be actively engaged in the process. A few key informants also mentioned the idea of having a person or team of navigators that would be familiar with both the NICU/hospital and community resources and act as a support and liaison during the transition from the NICU to home.

*I think if we incorporate some tools for the staff to use and the families, so that we have active engagement with the families to plan discharge as well. I think it's basically right now left up to the nursing staff . . . I think incorporation of some type of discharge planning tools would be helpful.*

– Other Health Care Provider

*I think some crossing silos is really important . . . in Calgary they have a transition team of neonatal nurses . . . it's fascinating because not only do some of these nurses work in a neonatal intensive care unit, but they also work in the neonatal follow-up program and they also work in the transition team. So the parents as they're transitioning home are followed for the first three to four to six weeks, and it's people who understand the community, who also understand the NICU and it's also people that families are familiar with. So it eases them gently into the community. It navigates them into services. It helps them get those referrals, it helps them problem solve, it helps them understand and interpret their baby's symptoms, their baby's cues. It helps them make decision about whether you seek care or do you not seek care, and is this a normal variation of a pre-term infant? So I think that's a really lovely model that's worked really well in that region.*

– Other Health Care Provider

Discharge planning should also engage other health care providers who will be providing care to the baby in the community.<sup>105</sup> Ideally, the community primary care provider can

<sup>102</sup> S. D. Berns et al., "Results of the Premature Birth National Need-Gap Study," *ibid.* 27 Suppl 2(2007).

<sup>103</sup> Bliss, "Baby Charter Standards."

<sup>104</sup> *Ibid.*; European Foundation for the Care of Newborn Infants (EFCNI), "Caring for Tomorrow."

<sup>105</sup> "Caring for Tomorrow."

meet with the child and family in the NICU prior to discharge.<sup>106</sup> Engagement of the community care provider (often a paediatrician) who will be looking after the baby once they go home was also seen as important by a few key informants.

*I think we have a need to involve the community paediatrician into the discharge process. So instead of him or her just receiving a discharge summary letter in the mail, that they actually meet the family before the discharge, and know a little bit about that baby in person.*  
– Other Health Care Provider

### ***Supports at Home***

Once a baby is discharged and goes home, families still need many different types of supports. Some of these supports were described in earlier sections; for example, ongoing peer connection and support, financial supports, continuing information/education, etc. When bringing a baby home from the NICU, parents may be responsible for interventions such as tube feeding or administering oxygen or medications, and may require training to ensure parental readiness.<sup>107</sup> Appropriate and adequate supports in the community should be identified in advance to offer ongoing care and support for premature babies and their families.<sup>108</sup> Some key informants highlighted the need for a different type of follow-up clinic that would offer assistance and support to families in the period immediately following discharge, rather than just bringing babies in for their first follow-up appointment 3 or 4 months after discharge.

*I was reading a paper recently where what they had done through a follow-up program in the United States is, for their NICU graduates, I think particularly for those who had been more sick or where there were more concerns, now they had a clinic that was available for 40 hours a week, and they had 24 hour sort of a phone hotline where people could call. And I think they reduced their post-discharge deaths or paediatric intensive care unit admissions by 40 percent . . . there is a need for a tertiary level support service for community physicians. They may never have seen kids like this . . . kids where between the community healthcare providers or the parents to be able to access specialty advice when needed.*  
– Neonatologist

<sup>106</sup> R. P. Verma, S. Sridhar, and A. R. Spitzer, "Continuing Care of NICU Graduates," *Clinical Pediatrics* 42, no. 4 (2003); Susan K. Ritchie, "Primary Care of the Premature Infant Discharged from the Neonatal Intensive Care Unit."

<sup>107</sup> G. L. Lopez, K. H. Anderson, and J. Feutchinger, "Transition of Premature Infants from Hospital to Home Life," (NIH Public Access, 2012).

<sup>108</sup> National Institute for Health and Clinical Excellence, "Quality Standard for Specialist Neonatal Care; NHS England, "Toolkit for High-Quality Neonatal Services."

*I know some other centres do have much better resources post-discharge. So they've got essentially clinics for babies that are discharged from NICU. So it's neonatal staff that run the clinics so that those babies can then come back to staff that are familiar with them, for ongoing follow-up care. So that's certainly something that seems appealing to me, that you know, they're not discharged and the strings are completely cut.*

*– Other Health Care Provider*

In addition to the supports mentioned above, home visits by a nurse can also be an important element in easing the transition from hospital to home. Parents should have access to either home visits, or other regular methods of communication with a nurse (e.g., via videoconferencing).<sup>109</sup>

As previously described, vulnerable families (e.g., those at risk due to violence, socioeconomic status, language or cultural barriers, education levels, etc.) should be identified and additional supports provided where required.<sup>110</sup> Nurses, who have a lot of close contact with parents, are likely in the best position to screen for any concerns or vulnerabilities (e.g., difficulties with transportation).<sup>111</sup>

## ❖ Long-term Follow-up and Care

### *Follow-up and Screening*

Because babies born prematurely are at higher risk for a number of issues, including behavioural and cognitive problems later in life, it is critical to have long-term care and follow-up supports in place for children and families. Extra social supports (e.g., extended maternity/parental leave) and formal aftercare and follow-up programs are important.<sup>112</sup> Programs/follow-up should include evidence-based routine screening for behavioural and learning issues and cover at least the first two years of life, ideally extending beyond that

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<sup>109</sup> G. L. Lopez, K. H. Anderson, and J. Feutchinger, "Transition of Premature Infants from Hospital to Home Life; A. Gund et al., "A Randomized Controlled Study About the Use of Ehealth in the Home Health Care of Premature Infants," (2013).

<sup>110</sup> NHS England, "Toolkit for High-Quality Neonatal Services."

<sup>111</sup> L. Phillips-Pula and J. M. McGrath, "Follow-up Care for the Neonatal Intensive Care Unit Graduate," *Newborn and Infant Nursing Reviews* 12, no. 4 (2012).

<sup>112</sup> European Foundation for the Care of Newborn Infants (EFCNI), "Too Little, Too Late?."

to offer support throughout the preschool period (since many impairments may not be detected until children are closer to school aged).<sup>113</sup> Longer term follow-up is especially important for the extremely premature group as they are at higher risk for problems.<sup>114</sup>

Although long-term follow-up was not explicitly covered in the interviews and focus groups, some key informants did talk about the importance of follow-up services. Key informants emphasized the need to provide follow-up into the school years and beyond, as many issues (e.g., learning disabilities) may not be evident until a child starts school. A few key informants also talked about the importance of having long-term follow-up data in order to support research around the long-term outcomes of premature birth.

*I think some of the big things are, in the United States they have a lot more guidelines and expectations for surveillance, screening, early diagnosis intervention – I'm thinking neuro-developmental problems, but it also applies to other things as well.*

– Neonatologist

*The other thing is extending services, follow services . . . now that my kids are in school I'm realizing that the fact that most follow-up services end at two is a disgrace. Because for a lot of these kids, the ones who have the sort of minor morbidities, they are going to run into school issues, and if there isn't support from someone who knows what they're talking about, they're going to be mislabelled. And we see a lot of kids ending up on drugs that they don't really need, things like that. So we need to figure out, how do we offer appropriate support to those who need it, into the school-age years?*

– Other Stakeholder

### ***Intervention and Support***

Any follow-up program should be connected with appropriate programs and resources so that if any issues or concerns are identified, children/families should be referred to intervention programs as appropriate. Interventions may include education support, counselling, physical or occupational therapy, nursing or other medical supports, vision services, speech therapy, and/or early intervention programming and supports.<sup>115</sup> Home visiting interventions for preterm babies where the family receives home-based services

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<sup>113</sup> "Caring for Tomorrow."

<sup>114</sup> Ibid.

<sup>115</sup> D. Mohl, "Guidelines for the Late Preterm Infant," *The Clinical Advisor* February(2010); R. P. Verma, S. Sridhar, and A. R. Spitzer, "Continuing Care of NICU Graduates."

related to health, infant development, and social support from a trained professional/para-professional have been shown to support parent-infant interaction and infant development, and there is some evidence that they support improved physical growth.<sup>116</sup>

Once children leave the hospital, they may interact with many other people such as health care providers, day care workers, teachers, or special needs coordinators. Evidence-based guidelines for treatment/counselling for those working with the preterm population should be developed and implemented. Appropriate facilities, educational interventions, and training should be available to support people in all fields working with preterm children.<sup>117</sup>

### ❖ **Education for those Working with Premature Babies**

Education, training and ongoing professional development are all important supports for delivering high quality care for premature babies. In the hospital setting, training programs for health care providers should follow the recommended standards of the relevant professional associations/societies (e.g., Society of Obstetricians and Gynaecologists of Canada),<sup>118</sup> and all staff members providing care for preterm infants should be appropriately educated/trained in order to enable them to deliver high-quality care.<sup>119</sup> Continuous training and practice on neonatal resuscitation should also be provided.<sup>120</sup>

The UK's National Health Service recommends that each facility or unit have a staff competency framework that is used to assess staff and provide training. The framework should include the required clinical competencies as well as competencies related to developmental care, breastfeeding and discharge planning.<sup>121</sup> This type of competency

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<sup>116</sup> N. K. Goyal, A. Teeters, and R. T. Ammerman, "Home Visiting and Outcomes of Preterm Infants: A Systematic Review," *Pediatrics* 132, no. 3 (2013).

<sup>117</sup> European Foundation for the Care of Newborn Infants (EFCNI), "Caring for Tomorrow."

<sup>118</sup> *Ibid.*

<sup>119</sup> Bliss, "Baby Charter Standards; European Foundation for the Care of Newborn Infants (EFCNI), "Caring for Tomorrow; NHS England, "Toolkit for High-Quality Neonatal Services."

<sup>120</sup> European Foundation for the Care of Newborn Infants (EFCNI), "Caring for Tomorrow; NHS England, "Toolkit for High-Quality Neonatal Services."

<sup>121</sup> Bliss, "Baby Charter Standards; NHS England, "Toolkit for High-Quality Neonatal Services."

framework can help to identify areas where more training may be needed to support staff in meeting desired behaviours.

Two countries that have been able to successfully reduce their preterm birth rate (Sweden and Portugal) included interventions related to increasing training for health care providers as part of their suite of interventions (e.g., in Portugal, post graduate education in neonatology increased).<sup>122</sup> This supports the importance of providing high quality education to those working with babies born prematurely.

Many participants in the environmental scan also emphasized the importance of high quality, ongoing training and education for health care providers. A few key informants noted the need for more resources to support education. Some key informants highlighted the need for health care providers to be better educated about the realities for families that have a premature baby, including what their life may be like beyond their time in the NICU. A few respondents also suggested other areas where more education and support was needed (e.g., feeding/breastfeeding).

*Well education is huge. So better preparing healthcare professionals both throughout the NICU and post-discharge to understand and accommodate the needs of preterm infants and their families.*

*– Other Stakeholder*

*Having a very broad understanding of development and child development, and the resources that are available, the networks that are available for children who are diagnosed with a disability, having an understanding of what life, not just childhood, their infancy, but life looks like with the disability, provides you with a deeper level of insight, then provides you with better counseling for families, a greater awareness of what is possible instead of what is not possible if you have a disability. So I think it should be encouraged and it certainly is not the standard at this point.*

*– Neonatologist*

In addition to education for those in the hospital setting, other health and community professionals working with preterm infants/children and their families (e.g., those providing aftercare to preterm children, those supporting families after discharge, etc.)

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<sup>122</sup> European Foundation for the Care of Newborn Infants (EFCNI), "Too Little, Too Late?."

should be informed about the risks and consequences of preterm birth and be able to support families as needed.<sup>123</sup> A few key informants also mentioned the importance of providing education for those outside the hospital setting, such as primary care providers, allied health providers (e.g., dietitians, physiotherapists), and teachers and others in the education system.

*Teachers – we spend a huge amount of medical resource dollars on these infants in the NICU and yet, as far as I can see, none of that knowledge is translated to the school system. And yet, that’s where they’re going to live the majority of their lives, is going to be in the education system. So how do you translate that knowledge so that the teachers are operating with the same level of capacity and insight that the parents are?*  
– Neonatologist

### ❖ Quality Improvement and Research

A few key informants emphasized the importance of continuing to conduct formal research related to premature birth as research is a key strategy for improving care. Key informants also had suggestions for specific topics or approaches to research, including conducting a cost benefit analysis around premature birth, opening research up to greater participation by families, and developing a deeper engagement with industry related to premature birth.

*I think there needs to be an environment to do [research]. I think certainly as all of the hospitals fall under greater constraints, the greatest temptation is to start cutting that academic resource, that research-related, from a nursing and team standpoint. And I think that that needs to be made sure it’s fostered because that’s how care is going to get better.*  
– Neonatologist

*If we can make industry aware of the importance of the problem . . . one of the things that we’re trying to do from the science point-of-view is creating a preterm birth industry meeting . . . it’ll make the industry aware of the parents’ issues and their needs, and I think that would inspire industry and investors to get more involved in this area.*  
– Other Health Care Provider

In addition to formal research projects, ongoing monitoring and benchmarking is also a critical part of delivery of care. Units/facilities should have plans in place to guide data collection and quality improvement activities.<sup>124</sup> Where possible, data should be collected

<sup>123</sup> "Caring for Tomorrow."

<sup>124</sup> Bliss, "Baby Charter Standards."

so that it is comparable across regions/countries.<sup>125</sup> In Canada, the Canadian Neonatal Network (CNN) plays this role in collecting and sharing key metrics that help to support quality improvement. All of Canada's 30 NICUs report at least partial data to CNN who publicly publishes the data annually.

Many key informants also spoke about the important role of ongoing quality improvement, primarily in the hospital setting but also in the community.

- A few key informants emphasized the importance of assigning adequate resources and supports for quality improvement, including both financial and staff resources.

*In every unit we should have a champion who does that [leads quality improvement]. And the champion can be a physician, can be a nurse practitioner, it can be a nurse, or someone who has been trained to implement that, and you just need one person who's then on the ball making sure that every day this is being implemented.*  
– Neonatologist

- A few key informants noted the importance of taking small actions to continuously improve quality, and that these improvements in delivery of care do not always have to come from large research studies (i.e., clinical trials).

*. . . quality improvement, what do units that have very low incidence of chronic lung disease or sepsis, what do they do well, and how can we implement it across the nation. And can you then show before and after, whether that actually works. And you know how always the highest level of evidence comes from randomized control trials, the problem is you can only test one intervention. If you do that for every single intervention, then in 10 years from now we will still not have an answer. And that's where the advantage of these quality improvements come in . . . this is pretty good and cheap compared to randomized control trials, so let's do it.*  
– Neonatologist

- A few key informants highlighted the important role that the Canadian Neonatal Network plays in supporting quality improvement.

*I think having the national networks and being a part of any network – you know, there's the Vermont Oxford Network, there's the Canadian Neonatal Network. When you get into those sort of collaboratives, the opportunity for QI [quality improvement] and benchmarking becomes really important and advantageous. Because you can start to look at your practices and compare and contrast . . . I think the idea of now looking at bundles of care, so instead*

<sup>125</sup> European Foundation for the Care of Newborn Infants (EFCNI), "Caring for Tomorrow."

*of focusing on that one thing, because I don't think any one thing changes outcomes, now when you start to look at bundles of care, I think that is an interesting way to look at how does that change outcome?*

– Neonatologist

- A few key informants spoke about the importance of having more research to support protocols around immunizations and vaccinations.

*The RSV prophylaxis, which isn't the immunization but the Synagis, whether we give it to babies while they're still hospitalized, so with what frequency and timing and what the schedule should be, and exactly when you should start if the baby is unstable. Those are things that we really don't know much about as yet.*

– Neonatologist

### ***Evaluation Metrics***

Each facility/program should develop its own indicators that will be used to measure outcomes and drive quality improvement. The National Institute for Health and Clinical Excellence and the Centre for Clinical Practice in the UK have developed a Quality Standards Programme for specialist neonatal care. Some of the indicators they assess in this programme include:<sup>126</sup>

- Proportion of babies born at less than 28 weeks of gestation who receive intensive care in a neonatal intensive care unit (NICU) within the network
- Proportion of babies who are transferred back to their local neonatal unit within 24 hours of request for repatriation
- Evidence of local arrangements to ensure specialist neonatal staff are compliant with competency levels
- Proportion of babies born at less than 33 weeks of gestation who remain in hospital and still receive their mother's breast milk at 6 weeks
- Evidence of multiagency discharge planning with input from community neonatal outreach services

<sup>126</sup> National Institute for Health and Clinical Excellence, "Quality Standard for Specialist Neonatal Care."

- Proportion of babies born at less than 30 weeks of gestation who receive specialist neonatal care who have no functional impairment at 2 years when corrected for gestational age
- 2-year survival rates within and compared with other networks

## Analysis and Recommendations

This section provides analysis of the findings previously described and makes recommendations based on those findings. The analysis and recommendations presented are organized into sections based on the continuum of care. There is also a section addressing issues that cut across the continuum (e.g., health care provider education, clinical care, etc.).

### 1. Awareness and Prevention

#### ❖ Prevention

The report findings show that supports that will help all women have a healthy pregnancy are an important part of preventing premature birth. These supports may include population-level interventions that focus on addressing risk factors such as social determinants of health (e.g., socioeconomic status) or health behaviours (e.g., smoking). All women should also have access to high quality pre-conception and prenatal information, resources, and care. Once a woman is pregnant, appropriate secondary and tertiary prevention that follows evidence-based medical guidelines should be available (e.g., recognition and prevention of preterm labour).

#### ❖ Awareness of Premature Birth

A lack of awareness of and attention to premature birth and the needs of premature babies and their families was described in the report as a gap. This gap could be addressed by providing information to the general public as well as providing targeted information for pregnant women around 18-20 weeks gestation on the signs and symptoms of preterm labour. Increased awareness of premature birth among the public at large may help to contribute to pressures for additional resources to support premature babies and their families.

## ❖ Recommendations

- 1.1 It is recommended that provincial governments and other health authorities identify and implement initiatives that have been shown to reduce or prevent premature birth. This includes interventions at the level of primary prevention as well as secondary and tertiary prevention.
- 1.2 It is recommended that stakeholders in the area of premature birth work together to increase awareness of premature birth among the general public.

## 2. Birth and Care in Hospital

### ❖ Clinical Care

High quality clinical care, including access to the appropriate staff and equipment/technology, was identified in the report as a strength of Canada's system. The regionalized model used to provide care generally works well, although this approach can result in barriers to access for those in more remote or rural locations. With appropriate supports such as accommodations and financial support (described in the subsequent section *Family Support*, p. 70), the barriers can be reduced.

While developmental care and strategies such as primary nursing (one or more primary nurses identified who provide the majority of the care for the baby) were noted as strengths in clinical care, there is still room for improvement as care varies between facilities and across regions. Improving the consistency and continuity of care (between health care providers, between facilities and levels of care) and reducing barriers to developmental care (i.e., reducing bright lights and loud sounds in the NICU, increasing use of kangaroo care) were two key areas identified.

### ❖ Family-Centred Care

Family-centred care, a philosophy/approach that plans care around the needs of the family and encourages and supports family involvement in the daily care and decision-making for their child, can play an important role in improving outcomes for premature babies and

their families. While family-centred care was most frequently discussed in the context of hospital and NICU care, the principles of family-centred care can be applied across the continuum. The report demonstrated that significant progress has been made in implementing a family-centred care approach. The Family Integrated Care initiative led by clinicians and researchers at Mount Sinai Hospital in Toronto is one initiative that was highlighted, but efforts to provide family-centred care are certainly being made in hospitals across the country. However, barriers to family-centred care still exist, including physical barriers and a lack of staff support. Physical barriers may include a lack of on-site accommodations for parents or insufficient space at the bedside for parents to have frequent and prolonged contact with their child. A lack of staff support may be related to limited time to teach and support parents in providing care or to a lack of education or training on the principles of family-centred care. Addressing barriers to family-centred care is key to improving the experience of families and could have an impact on long-term outcomes for children as well.

### ❖ **Decision-making Related to Premature Birth**

Decision-making related to premature birth can be ethically challenging and emotionally difficult, both for parents and health care providers, especially in the case of extremely preterm babies. Discussion and counselling immediately before or after a preterm birth can be overwhelmingly negative, leaving parents without any sense of hope or possibility. Women at risk of preterm birth should receive as much factual information about survival rates, anticipated length of stay in hospital, and the risks of health and developmental problems as they need, but this report has also highlighted the need for families to receive more positive messages. These messages should include hope, positive information, and connection to or information about families living with similar diagnoses. Additional education for health care providers (addressed in the subsequent section *Health Care Provider Education*, p. 71) may help to improve some of the communication around decision-making related to premature birth.

## ❖ Recommendations

- 2.1 It is recommended that hospitals continue their efforts to improve clinical care. Priority areas include reducing barriers to developmental care and improving the consistency and continuity of care across facilities and between health care providers.
- 2.2 It is recommended that hospitals work to reduce barriers to family-centred care through initiatives that address physical barriers (e.g., lack of place for family to stay at the hospital while the baby is there) and improve staff support (e.g., staff education and training on empowering parents to provide care, inclusion of the family perspective in staff orientation/training, etc.). Hospitals should also examine their policies and approaches to ensure that care is as family-centred as possible.
- 2.3 It is recommended that Canadian standards or guidelines for family-centred care be developed and implemented to help ensure consistency in the approach across facilities.

## 3. Discharge and Follow-up

While there are aspects of the process for discharging babies from the NICU and elements of follow-up care that are working well, there are still many gaps and challenges in this area. The key gaps identified in the report included NICU discharge to another facility that can often occur on short notice and without sufficient planning due to the need for a bed; a lack of consistency in available follow-up services between facilities or regions; a gap in support for families in the first few weeks after a baby first goes home; a lack of long-term follow-up and screening for children born prematurely; and very limited supports and services for babies who are only moderate-late preterm (those born between 32 and 36 weeks).

Efforts should be made to address these gaps. More proactive discharge planning that uses flow sheets or checklists to ensure nothing is missed, as well as empowering families to care for their child while in hospital can help to ensure families feel as prepared as possible to go home. Connection to medical supports once at home is also key, particularly in the

early weeks. These might include a primary care provider, a premature baby follow-up clinic, or a person or team of navigators that can support referral and access to services. Access to non-medical supports such as peer support, financial support, or ongoing education and information are also important. For example, home visiting programs have been demonstrated to offer parents of premature babies important support from both medical and social/emotional perspectives. Finally, follow-up services should be extended so that all children born prematurely have access to support, screening, and referral to other services as needed at least into the preschool years and ideally beyond that until school age.

### ❖ **Recommendations**

- 3.1 It is recommended that hospitals review their discharge planning policies and processes to ensure that families are sufficiently prepared to go home (or to another facility) and that adequate planning for discharge is conducted well in advance of the time of discharge. Families should be actively involved in the discharge planning process.
- 3.2 It is not likely possible to completely eliminate the need for emergency transfers of premature babies to other facilities. However, it is recommended that hospitals make every effort to alleviate the stress associated with an emergency transfer by discussing the possibility with families in advance, and obtaining the family's preference for the transfer location.
- 3.3 It is recommended that governments and hospitals explore extending long-term follow-up care and support to include more premature babies (i.e., the moderate and late preterm babies), and to cover a longer period of time, into the preschool years at a minimum.

## **4. Across the Continuum**

This section examines the findings in several areas that extend across the continuum, including family support, research and quality improvement, and health care provider education.

## ❖ **Family Support**

The environmental scan did find that some supports are already in place for families, such as accommodations, parent lounges, or financial supports such as access to free parking. Some hospitals have peer support programs which can help to provide parents with emotional support, in addition to more formal hospital supports such as social workers or psychologists. However, respondents consistently noted that much more needs to be done in the area of family support to address practical and financial concerns, information needs, and the social and emotional needs of parents. These supports are needed across the continuum, both while the baby is in hospital and after discharge home. Strategies that can help to address these needs include practical and logistical supports such as providing accommodations on site or support to reduce transportation costs; providing parents with opportunities for education and information sharing, for example through parent information sessions or having parents participate in medical rounds; providing appropriate and adequate breastfeeding support; and ensuring access to more formal social and emotional supports such as counselling services and/or a peer-support network including veteran parents. Families that face additional barriers such as distance, language, health literacy or socioeconomic status, should be provided with further supports specific to their needs.

## ❖ **Research and Quality Improvement**

This report identified many strengths related to research and quality improvement. Canada was seen as a leader in research on topics related to premature birth, and the Canadian Neonatal Network and the Canadian Neonatal Follow-Up Network were both identified as important supports for research and quality improvement activities. Additional support, including more research funding and internal support within facilities and units for continuous quality improvement, could certainly be beneficial. Staff, resources, and policies that support quality improvement activities should be in place in each facility.

## ❖ **Health Care Provider Education**

Some gaps in health care provider education across the continuum of care were described in this report. At the hospital level these included a lack of resources to support ongoing training and education for NICU and other hospital staff, while the community-level gaps focused more on a lack of information among primary care providers and others who may not frequently care for children born prematurely. In addition to clinical skills, medical staff should be aware of health issues commonly faced by premature babies. Development and use of a competency framework that includes both medical and other competencies (e.g., developmental care, family-centred care) can help to identify areas where hospital staff may need additional education or support.

One key area where a need for additional education or training was identified was in relation to counselling families around decision-making at the time of birth. Families would like health care providers to be better informed and able to provide them with unbiased information as well as more connection with and information about living with a child born at the same gestational age. In addition to health care providers in the hospital, education was also noted as a need for other health and community professionals working with preterm infants/children and their families such as primary care providers, allied health care providers, childcare staff, or teachers in the school system.

## ❖ **Recommendations**

- 4.1 It is recommended that governments work with hospitals to support expanding the supports available to families with premature babies. These could include physical supports such as accommodations, financial supports such as extended parental leave, and social and emotional supports such as peer support or access to counselling services. Families that are particularly vulnerable would benefit from additional supports.
- 4.2 It is recommended that hospitals and research institutions enhance support for research and quality improvement. This could include additional research funding,

financial and staff support for quality improvement activities, and continued support for the Canadian Neonatal and Neonatal Follow-up Networks.

## **Summary of All Recommendations**

- 1.1 It is recommended that provincial governments and other health authorities identify and implement initiatives that have been shown to reduce or prevent premature birth. This includes interventions at the level of primary prevention as well as secondary and tertiary prevention.
- 1.2 It is recommended that stakeholders in the area of premature birth work together to increase awareness of premature birth among the general public.
  
- 2.1 It is recommended that hospitals continue their efforts to improve clinical care. Priority areas include reducing barriers to developmental care and improving the consistency and continuity of care across facilities and between health care providers.
- 2.2 It is recommended that hospitals work to reduce barriers to family-centred care through initiatives that address physical barriers (e.g., lack of place for family to stay at the hospital while the baby is there) and improve staff support (e.g., staff education and training on empowering parents to provide care, inclusion of the family perspective in staff orientation/training, etc.). Hospitals should also examine their policies and approaches to ensure that care is as family-centred as possible.
- 2.3 It is recommended that Canadian standards or guidelines for family-centred care be developed and implemented to help ensure consistency in the approach across facilities.
  
- 3.1 It is recommended that hospitals review their discharge planning policies and processes to ensure that families are sufficiently prepared to go home (or to another facility) and that adequate planning for discharge is conducted well in advance of the time of discharge. Families should be actively involved in the discharge planning process.
- 3.2 It is not likely possible to completely eliminate the need for emergency transfers of premature babies to other facilities. However, it is recommended that hospitals make every effort to alleviate the stress associated with an emergency transfer by discussing

the possibility with families in advance, and obtaining the family's preference for the transfer location.

3.3 It is recommended that governments and hospitals explore extending long-term follow-up care and support to include more premature babies (i.e., the moderate and late preterm babies), and to cover a longer period of time, into the preschool years at a minimum.

4.1 It is recommended that governments work with hospitals to support expanding the supports available to families with premature babies. These could include physical supports such as accommodations, financial supports such as extended parental leave, and social and emotional supports such as peer support or access to counselling services. Families that are particularly vulnerable would benefit from additional supports.

4.2 It is recommended that hospitals and research institutions enhance support for research and quality improvement. This could include additional research funding, financial and staff support for quality improvement activities, and continued support for the Canadian Neonatal and Neonatal Follow-up Networks.

## **Conclusion**

This report has presented the findings from an environmental scan of premature birth in Canada which was conducted from March to May 2014. While there are many aspects of the system that have improved over the years and are felt to be working well, there are other areas where gaps remain. Even in areas where significant progress has been made, more can be done to help improve support for families and outcomes for premature babies. This report has outlined a series of recommendations flowing from the findings, as well as next steps for CPBF-FBPC in using the information gathered through this environmental scan. CPBF-FBPC, together with their partners, can use the environmental scan to support efforts to increase awareness of premature birth and enhance care for premature babies and their families across Canada.

## Appendix A: Interview and Focus Group Participants

<i>Contact Name</i>	<i>Title</i>	<i>Organization</i>	<i>Province</i>
Dr. Anne Synnes	Neonatologist	BC Children's Hospital	British Columbia
Lisa Torreggiani	Director of Fundraising and Donor Relations	Canadian Premature Babies Foundation	British Columbia
Joselyn Porciuncula	Parent		British Columbia
Dr. David Olson	Professor, Department of Obstetrics and Pediatrics and Physiology	University of Alberta	Alberta
Heather Chinnery	Clinical Nurse Specialist	Royal Alexandra Hospital	Alberta
Erika Kalke	RN, NP	Synergy Women's Wellness Centre	Alberta
Katharina Staub	President and Chair of CPBF-FBPC	Canadian Premature Babies Foundation	Alberta
Ali Martens	Parent		Alberta
Char Cardinal	Parent		Alberta
Marilyn Ballantyne	RN, PhD	McMaster	Ontario
Dr. Bernard Thébaud	Neonatologist, Professor	University of Ottawa, Ottawa Hospital Research Institute	Ontario
Lynn M. Menard	Team Lead, Maternal and Child Health Policy and Programs	Division of Children, Seniors and Healthy Development, Public Health Agency of Canada	Ontario
Dr. Paige Church	Neonatologist/ Developmental Pediatrician	Sunnybrook	Ontario
Dr. Prakesh Shah	Neonatologist	University of Toronto	Ontario
Tammy McBride	Lactation Consultant	Mount Sinai	Ontario
Luisa King	Breastfeeding Resource Nurse	Sunnybrook	Ontario
Kate Robson	Director of National Family and Peer Support	Canadian Premature Babies Foundation	Ontario
Carolyn Leighton-Hilborn	Director of Communications	Canadian Premature Babies Foundation	Ontario
Nicole Lyons	Parent		Ontario
Lesley Donaldson-Reid	Parent		Ontario

<i>Contact Name</i>	<i>Title</i>	<i>Organization</i>	<i>Province</i>
Lindsay Wood	Parent		Ontario
Mandy Lau	Parent		Ontario
Jack Hourigan	Parent		Ontario
Kristine Stolar	Parent		Ontario
Ginette Mantha	Founder Prémaquébec	Prémaquébec	Quebec
Dr. Keith Barrington	Neonatologist, NICU Director	Ste. Justine's University of Montreal	Quebec
Karine Canuel	Parent		Quebec
Dr. Farrukh Javed	Neonatologist, Division of Newborn Medicine, Memorial University	Janeway Hospital	Newfoundland
Pauwlina McGrath	Director of Governance, Pharmacist	Canadian Premature Babies Foundation	New Brunswick

# Appendix B: Interview and Focus Group Guides

## Key Informant Interview Guide

### Introduction and Purpose

The Canadian Premature Babies Foundation (CPBF) is the first national, Canadian-based organization for premature babies. CPBF is a voice and source of information for families and their children. In order to help increase awareness of the issue of prematurity and how it impacts children and families; identify existing gaps across Canada in delivery of care for premature babies; and identify best practices related to premature birth, CPBF has engaged Research Power Inc. (RPI), a health research and consulting firm, to conduct an environmental scan related to premature birth in Canada. The findings from the environmental scan will then be used to advocate for changes to care and supports for children and their families.

Gathering input and feedback from those with expertise in this area, such as yourself, is a key component of the environmental scan. The purpose of this interview to gather your feedback and input on challenges and best practices related to premature birth in Canada. The focus of the interview questions will be on birth, care provided in hospital, and short term follow up care (i.e., discharge and follow up care planning) related to babies born prematurely (before 37 weeks gestation). Information related to this, as well as to prenatal care and prevention of premature birth, and to long-term care/follow up for premature babies is also being collected through a review of the grey and academic literature.

### Questions

1. Please tell me briefly about your background, experience, and/or areas of interest related to premature birth.
2. What elements of the system of caring for premature babies and their families are working well?

#### *Sub-Questions:*

- What elements of clinical care are working well?
- What is working well in relation to family-centred care?
- What is working well with discharge (home or to another hospital) and short term follow up once the baby goes home?
- What is working well in relation to health care provider education?
- What is working well in relation to evaluation and quality improvement?

3. What are the barriers or challenges related to caring for premature babies and their families?

*Sub-Questions:*

- What challenges are there related to clinical care? Are there any challenges specific to the area of immunizations?
  - What challenges are there related to family-centred care?
  - What challenges are there related to discharge (home or to another hospital) and short term follow up once the baby goes home?
  - What challenges are there related to health care provider education?
  - What challenges are there related to evaluation and quality improvement?
  - What challenges are there related to equity of access to services (e.g., for those in rural or remote communities)?
  - How can these challenges be overcome?
4. What are the best practices related to providing clinical care to women in preterm labour and babies born prematurely?

*Sub-Questions:*

- Are care pathways or referral pathways in place to guide care delivery? If so, please describe.
  - What are the best practices related to immunizations for preterm babies both in and out of hospital?
  - What are the priority areas for improvement in clinical care?
5. What are the best practices related to family-centred care?

*Sub-Questions:*

- How can family-centred care be improved?
  - What supports should be provided for families and who should provide these supports?
6. What are the best practices related to discharge and short term follow up?

*Sub-Questions:*

- What are the key components of discharge planning? Who should be involved in the process?
  - What are the best practices related to transfers between hospitals for premature infants?
  - What community resources are required to provide adequate support and follow up immediately after discharge?
7. What are the best practices related to education and training for those working with premature infants?

*Sub-Questions:*

- What areas of training are needed for staff working in the NICU? What about for staff in other areas of the hospital?
- What areas of training are needed for community health care providers and others who may be working with children born prematurely in community settings?

8. What are the best practices related to evaluation and quality improvement?

*Sub-Questions:*

- What metrics and outcome measures are used to assess the quality of care?
- What supports are needed to ensure quality improvement takes place?

9. Do you have any additional feedback you would like to share?

*Thank you for your time and thoughtful input.*

# Parent Focus Group Guide

## Introduction and Purpose

The Canadian Premature Babies Foundation (CPBF) is the first national, Canadian-based organization for premature babies. CPBF is a voice and source of information for families and their children. In order to help increase awareness of the issue of prematurity and how it impacts children and families; identify existing gaps across Canada in delivery of care for premature babies; and identify best practices related to premature birth, CPBF has engaged Research Power Inc. (RPI), a health research and consulting firm, to conduct an environmental scan related to premature birth in Canada. The findings from the environmental scan will then be used to advocate for changes to care and supports for children and their families.

As parents of children born prematurely, you can offer a unique and very valuable perspective on the strengths, challenges, and needed supports in the current system for addressing premature birth. Gathering your input through this focus group is therefore a very important part of the environmental scan. The focus of the questions today will be on your experiences with birth, care provided in hospital, and short term follow up care (i.e., discharge and follow up care planning). Information about these topics is also being collected through a review of the written research and evidence.

## Confidentiality

Your participation in this focus group is completely voluntary. Any information you share in the session remains confidential, meaning no one in the group has permission to share anything they hear with anyone outside of the group. With your permission, to help with the analysis of the information, the focus group will be recorded. The recording is transcribed (i.e., typed up) and used in the research. If at any time you wish to stop the recording, you may ask the interviewer to do so. The transcript of the recorded focus group does not include any identifying information – if you use names, places, etc. this information will be removed. The responses that you provide will only be reported in aggregate (summed together), and although individual responses may be used as quotations in the final environmental scan report, you will not be personally connected with the quote. An anonymous version of the focus group transcript (i.e., with no identifying information such as names or places) will also be provided to the Canadian Premature Babies Foundation.

Nothing that you share in this focus group will affect the services that you, your child, or your family, may receive from any agency or organization.

There are no right or wrong answers to questions – all feedback is welcome. It is important for us to hear everyone's experiences and opinions, both positive and negative. Please be respectful of each other. You may also choose not to answer any question. What you choose to share is up to you.

## Questions

1. Thinking back about your experience with having a premature baby, what are things that you feel were positive or worked well to support you, your child, and your family?

*Sub-Questions:*

- What made the greatest positive difference for you, your child and your family?
2. What are things that you feel didn't work well or were challenging for you, your child, and your family?

*Sub-Questions:*

- What was the most difficult or challenging part?
  - What was/were the greatest gap(s) in the care you received?
  - How could the challenges you've described be addressed?
3. How do you feel overall about the care provided to pregnant women, preterm babies and their families, during and immediately after birth?

*Sub-Questions:*

- How satisfied were you with the level of information you received before the birth? Afterwards?
  - How satisfied were you with the care and services provided by health care providers (e.g., neonatologists, nurses, etc.)?
4. How do you feel overall about the care provided to preterm babies and their families while the baby is in the NICU?

*Sub-Questions:*

- How satisfied were you with the level of information/education you received?
  - How satisfied were you with the opportunity to touch and care for your baby?
  - How satisfied were you with the ability to feed your baby (breastfeeding or other as appropriate)?
  - How satisfied were you with the environment of the NICU (e.g., lighting, privacy, sound levels, etc.)?
  - How satisfied were you with the supports available to you while your child was in the NICU, including both practical supports (e.g., rooming in, financial supports) and social/emotional supports (e.g., counselling, support groups, etc.)?
5. How do you feel overall about the support you received related to the discharge of your premature baby (discharge home and/or transfer to another hospital) and immediate follow up care at home?

*Sub-Questions:*

- How satisfied were you with the level of information/education you received?

- How prepared did you feel to care for your baby at home? Could anything have increased your level of preparation?
  - How satisfied were you with the supports available to you after your child came home, including both practical supports (e.g., maternity leave, financial supports) and social/emotional supports (e.g., counselling, support groups, etc.)?
  - If your baby was transferred between hospitals before coming home, how satisfied were you with that transfer experience?
  - How satisfied were you with the follow up care plan and supports for your child? Could anything be done to improve follow up care?
6. What are some things that you feel could be done better for families with babies born prematurely in the future?

*Sub-Questions:*

- What would have been helpful for you (tools, information, care, etc.)?
  - What did you need that you didn't receive?
7. Do you have any additional feedback you think would be helpful for us to know?

*Thank you for your time and thoughtful input.*

# Health Care Provider Focus Group Guide

## Introduction and Purpose

The Canadian Premature Babies Foundation (CPBF) is the first national, Canadian-based organization for premature babies. CPBF is a voice and source of information for families and their children. In order to help increase awareness of the issue of prematurity and how it impacts children and families; identify existing gaps across Canada in delivery of care for premature babies; and identify best practices related to premature birth, CPBF has engaged Research Power Inc. (RPI), a health research and consulting firm, to conduct an environmental scan related to premature birth in Canada. The findings from the environmental scan will then be used to advocate for changes to care and supports for children and their families.

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## Questions

1. What elements of the system of caring for premature babies and their families are working well?

### *Sub-Questions:*

- What elements of clinical care are working well?
- What is working well in relation to family-centred care?
- What is working well with discharge (home or to another hospital) and short term follow up once the baby goes home?
- What is working well in relation to health care provider education?
- What is working well in relation to evaluation and quality improvement?

2. What are the barriers or challenges related to caring for premature babies and their families?

### *Sub-Questions:*

- What challenges are there related to clinical care? Are there any challenges specific to the area of immunizations?
- What challenges are there related to family-centred care?
- What challenges are there related to discharge (home or to another hospital) and short term follow up once the baby goes home?
- What challenges are there related to health care provider education?

- What challenges are there related to evaluation and quality improvement?
  - What challenges are there related to equity of access to services (e.g., for those in rural or remote communities)?
  - How can these challenges be overcome?
3. What are the best practices related to providing clinical care to women in preterm labour and babies born prematurely?
- Sub-Questions:*
- Are care pathways or referral pathways in place to guide care delivery? If so, please describe.
  - What are the best practices related to immunizations for preterm babies both in and out of hospital?
  - What are the priority areas for improvement in clinical care?
4. What are the best practices related to family-centred care?
- Sub-Questions:*
- How can family-centred care be improved?
  - What supports should be provided for families and who should provide these supports?
5. What are the best practices related to discharge and short term follow up?
- Sub-Questions:*
- What are the key components of discharge planning? Who should be involved in the process?
  - What are the best practices related to transfers between hospitals for premature infants?
  - What community resources are required to provide adequate support and follow up immediately after discharge?
6. What are the best practices related to education and training for those working with premature infants?
- Sub-Questions:*
- What areas of training are needed for staff working in the NICU? What about for staff in other areas of the hospital?
  - What areas of training are needed for community health care providers and others who may be working with children born prematurely in community settings?
7. What are the best practices related to evaluation and quality improvement?
- Sub-Questions:*
- What metrics and outcome measures are used to assess the quality of care?
  - What supports are needed to ensure quality improvement takes place?
8. Do you have any additional feedback you would like to share?

# Canadian Premature Babies Foundation Board Focus

## Group Guide

### Introduction and Purpose

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### Questions

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- What elements of clinical care are working well?
- What is working well in relation to family-centred care?
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- What is working well in relation to health care provider education?
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2. What are the barriers or challenges related to caring for premature babies and their families?

*Sub-Questions:*

- What challenges are there related to clinical care? Are there any challenges specific to the area of immunizations?
- What challenges are there related to family-centred care?
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- What challenges are there related to health care provider education?
  - What challenges are there related to evaluation and quality improvement?
  - What challenges are there related to equity of access to services (e.g., for those in rural or remote communities)?
  - How can these challenges be overcome?
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*Sub-Questions:*

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  - What are the priority areas for improvement in clinical care?
4. What are the best practices related to family-centred care?

*Sub-Questions:*

- How can family-centred care be improved?
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5. What are the best practices related to discharge and short term follow up?

*Sub-Questions:*

- What are the key components of discharge planning? Who should be involved in the process?
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*Sub-Questions:*

- What areas of training are needed for staff working in the NICU? What about for staff in other areas of the hospital?
  - What areas of training are needed for community health care providers and others who may be working with children born prematurely in community settings?
7. What are the best practices related to evaluation and quality improvement?

*Sub-Questions:*

- What metrics and outcome measures are used to assess the quality of care?
- What supports are needed to ensure quality improvement takes place?

8. Do you have any additional feedback you would like to share?

*Thank you for your time and thoughtful input.*

## Bibliography

- Benzies, K. M., J. E. Magill-Evans, K. A. Hayden, and M. Ballantyne. "Key Components of Early Intervention Programs for Preterm Infants and Their Parents: A Systematic Review and Meta-Analysis." *BMC Pregnancy Childbirth* 13 Suppl 1 (2013): S10.
- Berard, A., M. Le Tiec, and M. A. De Vera. "Study of the Costs and Morbidities of Late-Preterm Birth." *Arch Dis Child Fetal Neonatal Ed* 97, no. 5 (Sep 2012): F329-34.
- Berns, S. D., M. D. Boyle, B. Popper, J. S. Gooding, and C. Preemie Health. "Results of the Premature Birth National Need-Gap Study." *J Perinatol* 27 Suppl 2 (Dec 2007): S38-44.
- Best Start: Maternal Newborn & Early Child Development Resource Centre, The Perinatal Partnership Program of Eastern and Southeastern Ontario, and The Society of Obstetricians and Gynaecologists of Canada, *Preterm Birth: Making a Difference Clinical Practice Guidelines*, 2002
- Better Outcomes Registry & Network (BORN) Ontario, *Perinatal Health Indicators for Ontario 2012*, 2012
- Bliss, *The Bliss Baby Charter Standards*, 2011
- , *It's Not a Game: The Very Real Costs of Having a Premature or Sick Baby*, 2014
- Boykova, M., and C. Kenner. "Transition from Hospital to Home for Parents of Preterm Infants." *J Perinat Neonatal Nurs* 26, no. 1 (Jan-Mar 2012): 81-7; quiz 88-9.
- Bracht, M., L. O'Leary, S. K. Lee, and K. O'Brien. "Implementing Family-Integrated Care in the NICU: A Parent Education and Support Program." *Adv Neonatal Care* 13, no. 2 (Apr 2013): 115-26.
- British Columbia Reproductive Care Program. "Obstetric Guideline 2a." In *PRETERM LABOUR*. British Columbia, 2005.
- Campbell, M. A. "Development of a Clinical Pathway for near-Term and Convalescing Premature Infants in a Level II Nursery." *Adv Neonatal Care* 6, no. 3 (Jun 2006): 150-64.
- Canadian Institute for Health Information (CIHI), *DAD/HMDB Childbirth Indicators by Place of Residence and DAD/HMDB Newborns Born in Hospital*, CIHI, 2011-12
- Canadian Neonatal Network (CNN), *The Canadian Neonatal Network Annual Report 2012*, CNN, 2012

- Canadian Paediatric Society, J. Robinson, and Infectious Diseases and Immunization Committee. "Preventing Respiratory Syncytial Virus Infections." Web Page, 2011.
- Cockcroft, S. "How Can Family Centred Care Be Improved to Meet the Needs of Parents with a Premature Baby in Neonatal Intensive Care?". *Journal of Neonatal Nursing* 18, no. 3 (2012): 105-10.
- Conde-Agudelo, A., J. Belizan, and J. Diaz-Rossello, Kangaroo Mother Care to Reduce Morbidity and Mortality in Low Birthweight Infants (Review), John Wiley & Sons Ltd., 2011
- Discenza, D. "Welcome to the NICU: Helping Parents Adjust to NICU Life." *Neonatal Network*, 28, no. 2 (2009): 2.
- El-Naggar, W., and P. J. McNamara. "Delivery Room Resuscitation of Preterm Infants in Canada: Current Practice and Views of Neonatologists at Level Iii Centers." *J Perinatol* 32, no. 7 (Jul 2012): 491-7.
- European Foundation for the Care of Newborn Infants (EFCNI), Caring for Tomorrow: EFCNI White Paper on Maternal and Newborn Health and Aftercare Services, EFCNI, 2012
- , Too Little, Too Late? Why Europe Should Do More for Preterm Infants - EU Benchmarking Report 2009-2010, EFCNI, 2010
- Forsythe, E. S., and P. J. Allen. "Health Risks Associated with Late Preterm Infants: Implications for Newborn Primary Care." *Pediatric Nursing*, 39, no. 4 (2013): 5.
- Gaucher, N., and A. Payot. "From Powerlessness to Empowerment: Mothers Expect More Than Information from the Prenatal Consultation for Preterm Labour ". *Paediatr Child Health*, 16, no. 10 (2011): 5.
- Goyal, N. K., A. Teeters, and R. T. Ammerman. "Home Visiting and Outcomes of Preterm Infants: A Systematic Review." *Pediatrics* 132, no. 3 (Sep 2013): 502-16.
- Groenendaal, F., and C. Uiterwaal. "Long Term Follow-up of Extremely Preterm Neonates." *British Medical Journal* (2012): 2.
- Gund, A., B. A. Sjoqvist, H. Wigert, E. Hentz, K. Lindecrantz, and K. Bry. "A Randomized Controlled Study About the Use of Ehealth in the Home Health Care of Premature Infants." 2013.
- Hack, M. "Adult Outcomes of Preterm Children." *Journal of Developmental & Behavioural Pediatrics* 30, no. 5 (2009): 460-70.
- Janvier, A., and P. S. Shah. "The Premature Lottery in the Canadian Grey Zones." *Current Pediatric Reviews*, 9 (2013): 6.

- Jefferies, A., Canadian Pediatric Society, and Fetus and Newborn Committee. "Kangaroo Care for the Preterm Infant and Family." *Paediatr Child Health*, 17, no. 3 (2012): 3.
- Jefferies, A. L., E. R. Lyons, P. S. Shah, and V. Shah. "Impact of Late Preterm Birth on Neonatal Intensive Care Resources in a Tertiary Perinatal Center." *Am J Perinatol* 30, no. 7 (Aug 2013): 573-8.
- Jefferies, A. L., H. M. Kirpalani, Canadian Pediatric Society, and Fetus and Newborn Committee. "Counselling and Management for Anticipated Extremely Preterm Birth." *Paediatr Child Health*, 17, no. 8 (2012): 2.
- Johnston, K. M., K. Gooch, E. Korol, P. Vo, O. Eyawo, P. Bradt, and A. Levy. "The Economic Burden of Prematurity in Canada." *BMC Pediatr* 14 (2014): 93.
- Larson, C. P. "Poverty During Pregnancy: Its Effects on Child Health Outcomes." *Paediatr Child Health* 12, no. 8 (2007): 673-77.
- Leijon, I., O. Finnstrom, G. Sydsjo, and M. Wadsby. "Use of Healthcare Resources, Family Function, and Socioeconomic Support During the First Four Years after Preterm Birth." *Arch Dis Child Fetal Neonatal Ed* (2002): 5.
- Lim, G., J. Tracey, N. Boom, S. Karmakar, J. Wang, J.-M. Berthelot, and C. Heick. "Hospital Costs for Preterm and Small-for-Gestational Age Babies in Canada." *Healthcare Quarterly* 12, no. 4 (2009): 5.
- Lopez, G. L., K. H. Anderson, and J. Feutchinger. "Transition of Premature Infants from Hospital to Home Life." 14: NIH Public Access, 2012.
- Luo, Z. C., S. Senecal, F. Simonet, E. Guimond, C. Penney, and R. Wilkins. "Birth Outcomes in the Inuit-Inhabited Areas of Canada." *CMAJ* 182, no. 3 (Feb 23 2010): 235-42.
- March of Dimes, PMNCH, Save the Children, and World Health Organization (WHO), *Born Too Soon: The Global Action Report on Preterm Birth*, World Health Organization (WHO), 2012
- Mohl, D. "Guidelines for the Late Preterm Infant." *The Clinical Advisor* February (2010).
- National Institute for Health and Clinical Excellence. "Quality Standard for Specialist Neonatal Care." In *Quality Standards Programme*, 18.
- NHS England, *Toolkit for High-Quality Neonatal Services*, 2009
- O'Brien, K., M. Bracht, K. Macdonell, T. McBride, K. Robson, L. O'Leary, K. Christie, *et al.* "A Pilot Cohort Analytic Study of Family Integrated Care in a Canadian Neonatal Intensive Care Unit." *BMC Pregnancy Childbirth* 13 Suppl 1 (2013): S12.

- Obeidat, H. M., E. A. Bond, and L. C. Callister. "The Parental Experience of Having an Infant in the Newborn Intensive Care Unit." *J Perinat Educ* 18, no. 3 (Summer 2009): 23-9.
- Pepper, D., G. Rempel, W. Austin, C. Ceci, and L. Hendson. "More Than Information: A Qualitative Study of Parents' Perspectives on Neonatal Intensive Care at the Extremes of Prematurity." *Adv Neonatal Care* 12, no. 5 (Oct 2012): 303-9.
- Phillips-Pula, L., and J. M. McGrath. "Follow-up Care for the Neonatal Intensive Care Unit Graduate." *Newborn and Infant Nursing Reviews* 12, no. 4 (2012): 182-83.
- Public Health Agency of Canada, Canadian Hospitals Maternity Policies and Practices Survey, 2012
- , Perinatal Health Indicators for Canada 2013: A Report of the Canadian Perinatal Surveillance System, 2013
- Smith, V. C., S. Young, D. M. Pursley, M. C. McCormick, and J. A. Zupancic. "Are Families Prepared for Discharge from the NICU?". *J Perinatol* 29, no. 9 (Sep 2009): 623-9.
- Susan K. Ritchie. "Primary Care of the Premature Infant Discharged from the Neonatal Intensive Care Unit." *MCN* 27, no. 2 (2002).
- Verma, R. P., S. Sridhar, and A. R. Spitzer. "Continuing Care of NICU Graduates." *Clinical Pediatrics* 42, no. 4 (2003): 299-315.
- Wade, K. C., S. A. Lorch, S. Bakewell-Sachs, B. Medoff-Cooper, J. H. Silber, and G. J. Escobar. "Pediatric Care for Preterm Infants after NICU Discharge: High Number of Office Visits and Prescription Medications." *J Perinatol* 28, no. 10 (Oct 2008): 696-701.
- White, D. E., N. J. Fraser-Lee, S. Tough, and C. V. Newburn-Cook. "The Content of Prenatal Care and Its Relationship to Preterm Birth in Alberta, Canada." *Health Care Women Int* 27, no. 9 (Oct 2006): 777-92.
- White, R. D. "Designing Environments for Developmental Care." *Clin Perinatol* 38, no. 4 (Dec 2011): 745-9.
- Young, E., and A. O'Riordan. "A Qualitative Study of Predelivery Counselling for Extreme Prematurity." *Paediatr Child Health*, 17, no. 8 (2012): 5.