

# Neonatal Follow-Up Implementation Strategy



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# ACKNOWLEDGEMENTS

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# Executive Summary

In 2013 the Neonatal Follow-Up Clinics Work Group was convened to examine the current state of neonatal follow-up in the province and to make recommendations to best address the needs of the population as well as to leverage existing resources within the current healthcare system.

In 2015 the Neonatal Follow-Up Implementation Work Group was struck to create and employ an implementation strategy for the recommendations of the original Neonatal Follow-Up Clinics Work Group.

The goals of the Implementation Work Group were to:

1. Reduce variability of practice among Neonatal Follow-Up Program (NFUP) clinics and align standards
2. Create a strategy and implement the clinic recommendations in collaboration with NFUP clinics
3. Create a strategy and implement the broader system recommendations in collaboration with NFUP clinics
4. Develop an evaluation framework with indicators to assess the process and impact of applying the recommendations

The work of the Implementation Work Group refers to the neonatal follow-up clinics collectively as a 'Neonatal Follow-Up Program (NFUP)' in order to reflect that the clinics do not operate in silos, but rather, are part of a larger, provincial collaborative system.

To achieve their goals and foster a truly collaborative provincial system, the Implementation Work Group developed a series of clinic tools and communication tools to be used amongst NFUP clinics and with the families they see. These tools include:

## *Clinic Tools*

- List of assessment tools
- Post-natal mental health screening forms
- Shared care form
- Levels of neonatal follow-up reference sheet
- Patient flow charts

## *Communication Tools*

- Letter to health care providers and physicians
- Information package for parents and families
- Brochure about the neonatal follow-up program
- Visit schedule poster
- Graduation letter

In addition, both short-term and long-term implementation strategies were developed. The former outlines the immediate release and dissemination of the tools and the latter involves the development of a cohesive provincial NFUP that ensures equitable access to high quality care for all patients and adequate support for their families and support systems.

Finally, an evaluation framework was developed to measure both the process and outcomes intended by the development of the implementation tools.



# Section 1: Background

## Neonatal Follow-Up in Ontario

Neonatal Follow-Up occupies a critical role in Ontario’s health care system. It has evolved from a system of monitoring outcomes of mainly pre-term children to one that monitors and offers early intervention in high risk infants with varying diagnoses. Neonatal Follow-Up serves several purposes, including:

- Following and assessing high risk infants to improve guidelines and care provided to these populations;
- Providing information and education to parents and families;
- Identifying early markers for possible future conditions;
- Providing, in some cases, long-term monitoring to address issues that may take longer to arise.

In 2012/2013, the clinics that provide neonatal follow-up in Ontario’s had approximately 14,000 visits and an enrollment of 3,000 new patients. Their role within the system of care in Ontario is essential in addressing the needs of infants and children who have, or are at risk of having a physical, developmental and/or behavioural disability.

## Neonatal Follow-Up “Program”

The work of the Neonatal Follow-up Implementation Work Group refers to neonatal follow-up clinics collectively as the Neonatal Follow-Up Program (NFUP). The intention of this is to reflect that these clinics do not operate in silos, but rather, are part of a larger, provincial, collaborative system. The

ultimate goal of this work is to develop a cohesive system of neonatal follow-up that includes collaboration amongst the clinics and other relevant care providers, placing families at the centre of care. Instead of the clinics working in isolation of each other, this work aims to leverage and pool system resources and standardize key functions to ensure that children across the province have equitable access to high quality care.

### The ‘Neonatal Follow-Up Clinics Work Group’ – 2015 Report

In November 2013, the Provincial Council for Maternal and Child Health (PCMCH) convened the ‘Neonatal Follow-Up Clinics Work Group’, to examine the current state of neonatal follow-up in the province and to make recommendations to best address the needs of the population as well as to leverage existing resources within the current healthcare system.

Through their work, it was found that neonatal follow-up across the province is made up of individual clinics working independently from one another, with varied clinical resources, procedures, practices and financial resources. The diversity in care poses multiple challenges as there are discrepancies in the types of care/assessments made, duplication of services, inconsistent program catchments, gaps in care, and ongoing stress and cost to the families who may receive discrepant messaging and/or have to travel significant distances to receive follow up care. To begin addressing these issues, the work group published their final report in May 2015, outlining a number of program-specific and broader system recommendations (see Table 1) to standardize and optimize Ontario’s neonatal follow-up system.

**Table 1: ‘Neonatal Follow-up Clinics Work Group’ 2015 Recommendations**

Neonatal Follow-Up Clinic Recommendations
Recommendation 1 – Levels of neonatal follow-up should follow/be paired with NICU levels of care. Routine care of low-risk pre-terms in Level I and IIa care can take place by a primary care team or community paediatrician.
Recommendation 2 – A shared care model should be implemented across neonatal follow-up clinics. If a clinic is unable to provide neonatal follow-up, arrangements must be made by the hospital of birth to provide referral to a clinic within a reachable distance for the family following a shared care model.
Recommendation 3 – All neonatal follow-up clinics should follow a standardized visit schedule that has been developed around anticipated developmental ‘touch points’, using assessment tools tailored to identify the specific developmental touch point.
Recommendation 4 – The intervention provided by neonatal follow-up clinics should be mainly in the form of parental and family coaching, teaching to be self-advocates, as well as intervention through community linkages, prompt referral to community resources, resource navigation and education.
Recommendation 5 – Data collection should occur at select developmental touch-points, with standardized assessment tools. A committee of experts should be struck, including Better Outcomes and Registry Network (BORN) Ontario and Canadian Neonatal Follow-Up Network (CNFUN), to determine the touch-points at which to collect data, and the assessment tools that should be used.
Recommendation 6 – Create an online forum for ongoing communication, collaboration and education amongst neonatal follow-up clinics and their clinicians. This should include a central contact list for all neonatal follow-up

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clinics in the province to ensure timely and consistent contact between clinics and to facilitate communication in the shared model of care, as well as an online repository whereby clinicians can share clinical and educational materials as well as conference opportunities with colleagues throughout the province.

### Broader System Recommendations

Recommendation 7 – Resources for children in neonatal follow-up need to be established for successful school transition, including follow-up to school age, when warranted.

Recommendation 8 - Consideration be given to the needs of parents and children born less than 37 weeks gestation for enrollment in school to be based on the input of parents with the option of enrollment by corrected/adjusted age (due date), not chronological age (birth date).

Recommendation 9 – Linkages between neonatal follow-up clinics and the Ministry of Education should be established and maintained to facilitate the transition to school for individual high-risk children and to generate knowledge to create programs and interventions to maximize the chances of school success.

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## Neonatal Follow-Up Implementation Work Group and Process

The Neonatal Follow-Up Implementation Work Group was struck in December 2015 to create and employ an implementation strategy for the recommendations of the original Neonatal Follow-Up Clinics Work Group.

The goals of the Implementation Work Group were to

1. Reduce variability of practice among NFUP clinics and align standards unifying the system as a single program;
2. Create a strategy and implement the clinic recommendations in collaboration with NFUP clinics;
3. Create a strategy and implement the broader system recommendations in collaboration with NFUP clinics;
4. Develop an evaluation framework with indicators to assess the process and impact of applying the recommendations.

The Implementation Work Group consisted of neonatal follow-up clinicians and administrators, as well as representation from children’s treatment centres, research and a patient advocate (see Appendix A for the full membership). Efforts were made to ensure representation from across the province, including both tertiary and community hospitals.

As a first step, a current state analysis survey was undertaken to obtain input from NFUP clinics on the feasibility of implementing the report’s recommendations and to understand the existing system enablers and barriers to implementation.

To begin the implementation planning process, sub-groups were convened to undertake SWOT (Strengths-Weaknesses-Opportunities-Threats) analyses of the recommendations made in the 2015 report. The work group then reconvened to discuss their findings and divided their work as follows:

1. Implementation tools to be used by NFUP clinics
2. Communication materials to inform other health care providers of the role of NFUP clinics and to educate and empower parents/caregivers.



3. Data to measure aspects of neonatal follow-up in the province.
4. Evaluation metrics to evaluate the Neonatal Follow-Up Implementation Work Group's work and for system monitoring.

Work under these themes was completed over a series of meetings of both the Implementation Work Group and smaller sub-group meetings. All materials created were then brought back to the Implementation Work Group for review and approval.



## Section 2: Current State Analysis

In September of 2015 a current state analysis survey was undertaken. An online survey was sent to the province's 25 NFUP clinics (see Table 2 for a full list) for the purpose of understanding what the clinics were currently doing in accordance with the 2015 recommendations and to identify existing barriers to adopting the recommendations. The survey was completed by 22 clinics and the results were reviewed by the Implementation Work Group. Information from the survey helped to frame the work group's understanding of the system's capacity and existing strengths and weaknesses.

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**Table 2: List of Provincial NFUP Clinics**

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Children's Hospital of Eastern Ontario
Children's Hospital, London Health Sciences Centre
Hotel Dieu - NICU Follow-up Clinic
Lakeridge Health Corporation
Mackenzie Health
Markham Stouffville Hospital
McMaster Children's Hospital
Mount Sinai Hospital

NEO Kids, Health Sciences North
North York General Hospital
Orillia Soldiers Memorial Hospital
Rouge Valley Health System
Royal Victoria Regional Health Centre
Southlake Regional Health Centre
St. Joseph's Health Centre
St. Michael's Hospital
Sunnybrook Health Sciences Centre
The Hospital for Sick Children
The Scarborough Hospital
Toronto East General Hospital
Trillium Health Partners Credit Valley Hospital
Trillium Health Partners Mississauga Hospital Site
Humber River
William Osler Health Centre
Windsor Regional Hospital

## Key Findings

Standard information was collected from each of the NFUP clinics to develop a snapshot of the state of Neonatal Follow-Up in Ontario. Illustrated below, Table 3 outlines the number of NFUP clinics in each LHIN and Figure 1 details the number of programs operating at each level of care.

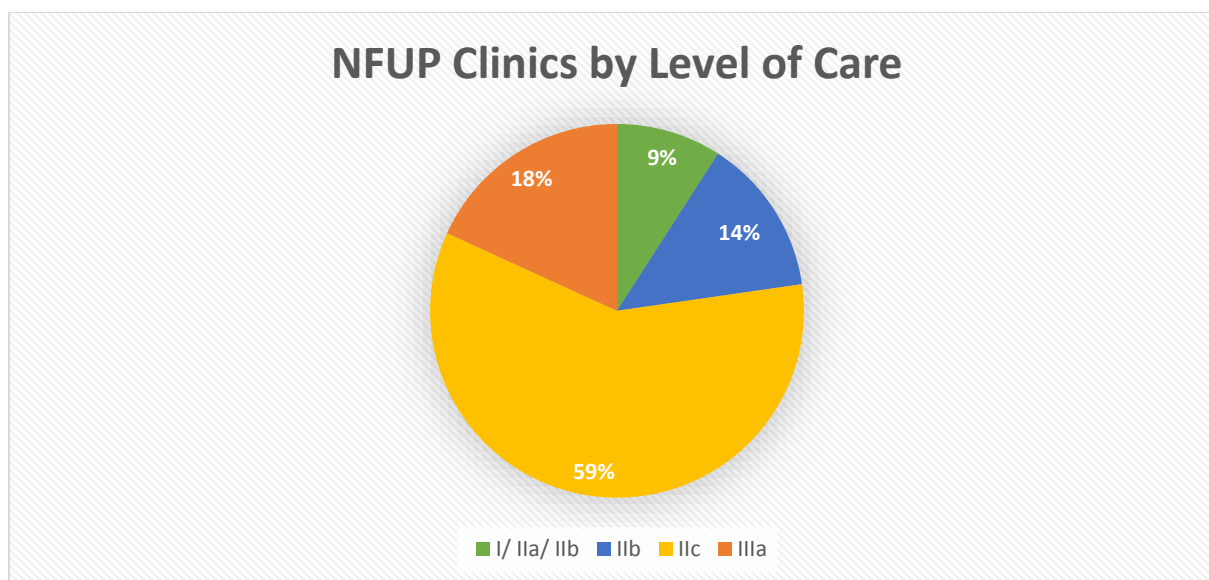
A key recommendation of the 2015 report was that a standard visit schedule of 4-8 weeks, 4 months, 8 months, 12 months, 18 months and 36 months be followed. Of the 22 survey respondents, half of the NFUPs currently follow this visit schedule.

**Table 3: NFUP Clinics by LHIN**

LHIN	Number of Responses
LHIN 1 - Erie St. Clair	0
LHIN 2 - South West	1
LHIN 3 - Waterloo Wellington	0
LHIN 4 - Hamilton Niagara Haldimand Brant	1
LHIN 5 - Central West	0
LHIN 6 - Mississauga Halton	2
LHIN 7 - Toronto Central	5

LHIN 8 - Central	5
LHIN 9 - Central East	3
LHIN 10 - South East	1
LHIN 11 - Champlain	1
LHIN 12 - North Simcoe Muskoka	2
LHIN 13 - North East	1
LHIN 14 - North West	0

**Figure 1: NFUP Clinics by Level of Care**



Survey respondents identified various strengths at both the program level and the system level to support implementation of the 2015 recommendations. For example, some NFUP clinics had established formal or informal relationships with other clinics and health care providers in their region to ensure that families could access the right care as close to home as possible. Further, NFUP clinics also worked with community partners to provide patients with access to additional care (e.g. early intervention services, children treatment centres, preschool speech and language programs, etc.) in their communities.

The 2015 report identified a number of inconsistencies across the province that resulted in inequities in the type of care accessed by patients depending on the clinic with whom they worked. Some of the key inconsistencies included differences in visit schedules, the use of shared care models by some but not others, and the inconsistent use of data to improve care and availability of clear, accessible information to educate parents and families. As the 2015 recommendations aimed to better standardize the neonatal follow-up system, NFUP clinics were asked to identify possible barriers to achieving this goal. The barriers were grouped into four themes: 1) communication, 2) resources, 3) coordination of care, and 4) different standards. See Table 4 for more information about the system barriers to implementing the recommendations.

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**Table 4: Barriers to Implementing 2015 Recommendations**

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**Communication**

- NFUP clinics do not have a consistent method or process for communicating with one another.
- Community providers do not know about the NFUP clinics, what they do, or how they can work with them.
- There is no opportunity for knowledge exchange between the clinics, such as opportunities for shared research or sharing of relevant materials.

**Resources**

- Most NFUP clinics cited insufficient resources as a key reason for why they could not implement the recommendations (e.g. insufficient staffing or funding for data entry).
- The lack of funding for some clinics also contributed to their inability to meet the standardized visit schedule recommended in the 2015 recommendations.

**Coordination of Care**

- There is no coordination across the region and across the province of the NFUP clinics.
- There is a need for greater role clarity between Level 2 and Level 3 NFUP clinics and scope of service, especially when two programs are involved in one child's care.
- Without a regularly updated list of all the NFUP clinics it is difficult to find the centre closest to families
- Some NFUP clinics do not have others in their LHIN/region to collaborate with.
- There are no linkages with other initiatives to care for children's needs in the NFUP (e.g. government strategies, schools).

**Different Standards**

- There are some activities mandated only for Level 3 NFUPs to complete (e.g. the Bayley Scale of Infant Development, uploading data to CNFUN).
- There is not a list of recommended assessments resulting in NFUPs using whichever ones with which they are familiar with.
- There are no provincial standards regarding the staffing and skill mix, with clear role descriptions, of all NFUPs.

Having an understanding of the impact and significance of these barriers helped to frame the work of the Implementation Work Group.



## Section 3: Parent Survey

In the Fall of 2016 the Canadian Premature Babies Foundation (CPBF) disseminated a national survey to learn about people’s experiences with the neonatal follow-up. The survey received 124 responses from individuals across Canada and the findings provide insight into what parents and families find are working well and what could be improved regarding their experience with the NFUP.

### Key Findings

As shown in Figure Two, most survey respondents were happy and satisfied with their experience in neonatal follow-up. Generally, respondents said that they were happy with the advice and referrals they received to support their child’s development.

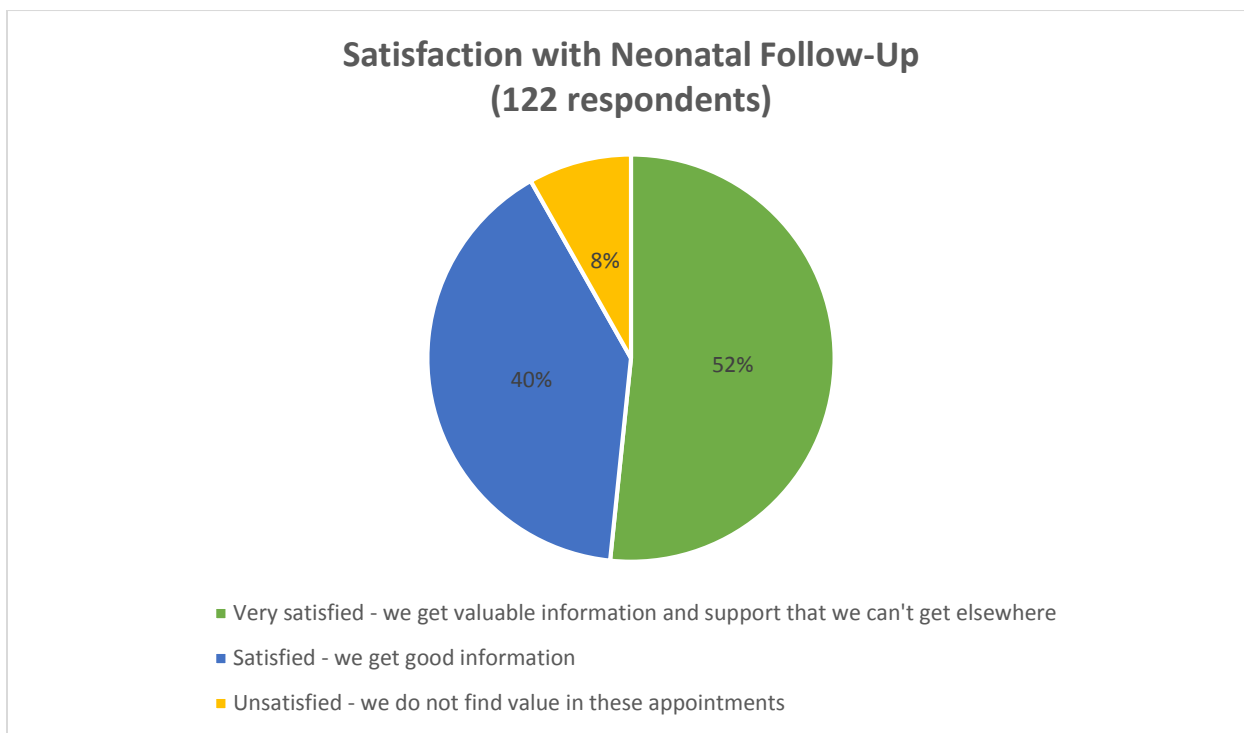
*“They were wonderful with my son and very informative with my son’s progression and meeting milestones. He is now 4 years old and doing well”. – Survey Respondent*

Although general satisfaction was high, survey respondents also provided feedback on areas of improvement:

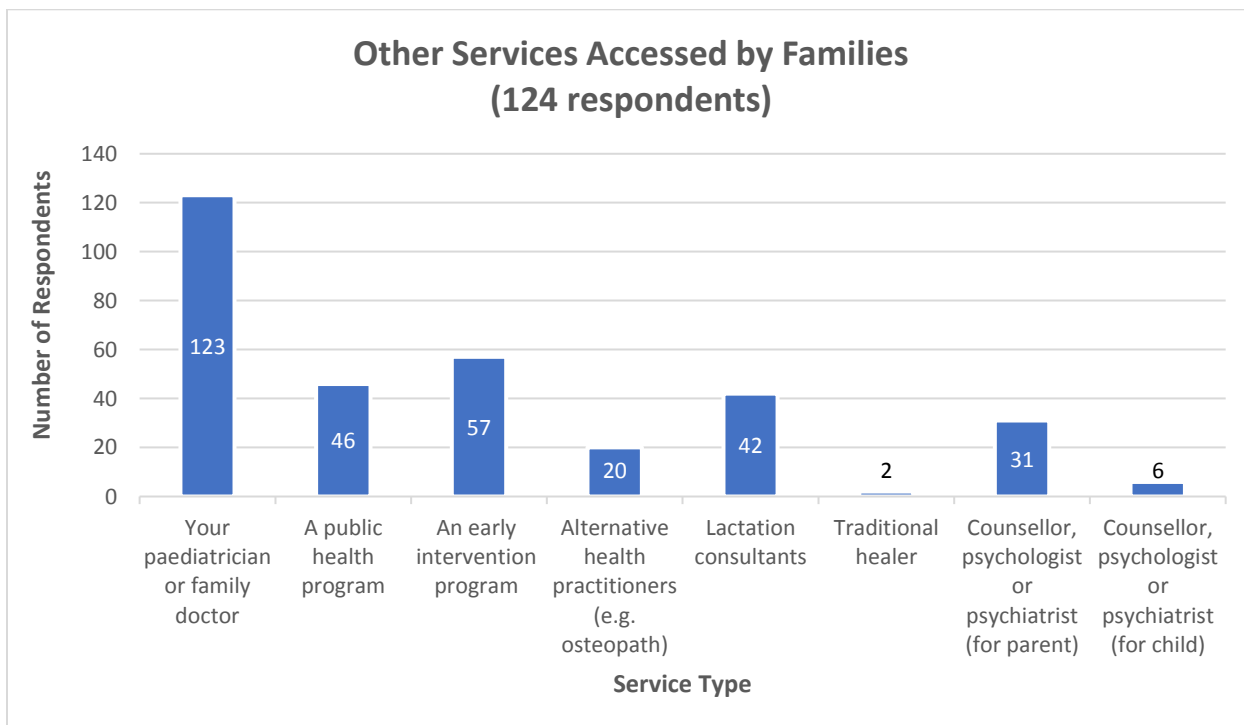
- Neonatal follow-up care focuses on the child, however parents also need support. Respondents spoke to the importance of mental health screening and referrals for parents and linkages to parent or family support groups.

- *My child was exceptionally well cared for. It was me (mother) who was suffering from PTSH and panic disorders stemming from [my] NICU stay. Help was hard to find once I recognized I was not right”. – Survey Respondent*
- Parents said that they do not want to feel rushed through appointments and want to feel like their concerns are heard and addressed.
  - *“For the most part everything is amazing. But don’t rush us out and take the time to listen to our concerns. You may hear the same concerns countless times, but this is new to us.” – Survey Respondent*
- Some respondents asked that neonatal follow-up staff be careful with their language and to offer parents encouragement even when their child is experiencing some difficulties.
  - *“Remember parents are struggling. Be compassionate. Be mindful of your tone when giving advice. Being told my child wasn’t gaining fast enough made me feel like a terrible parent. Choose words wisely”. – Survey Respondent*
  - *“We are grateful for all the support we received when our children were small. Please try to always tell parents what our children do well as well as where they may be slipping behind or may require extra support. We often leave appointments feeling like we have failed our children somehow by not doing enough or knowing enough or engaging them in appropriate activities, etc. We need to also hear what we are doing well.” – Survey Respondent*
- Some of the respondents identified the need for support and assistance for children beyond the ages of two or three, especially as children enter school age.
  - *“More focus needs to be done on children after the age of 2 years. There are many issues that arise after this. Both my twins showed effects of their prematurity after age 2. And there needs to be more support for premature children entering schools and helping schools understand the effects prematurity can have on learning”. – Survey Respondent*
- Many responses spoke of the need for collaboration across different people including clinic staff, parents, and other community providers (see Figure Three for other services accessed by families).
  - *I felt like it was a top down management instead of feeling like we were working together collaboratively. I felt like I was not equipped or encouraged that I could do it, that I was doing fine”. – Survey Respondent*
- Respondents also identified services they considered important to them as part of the NFUP. See Figure Four for details.

**Figure Two: Satisfaction With Neonatal Follow-Up**

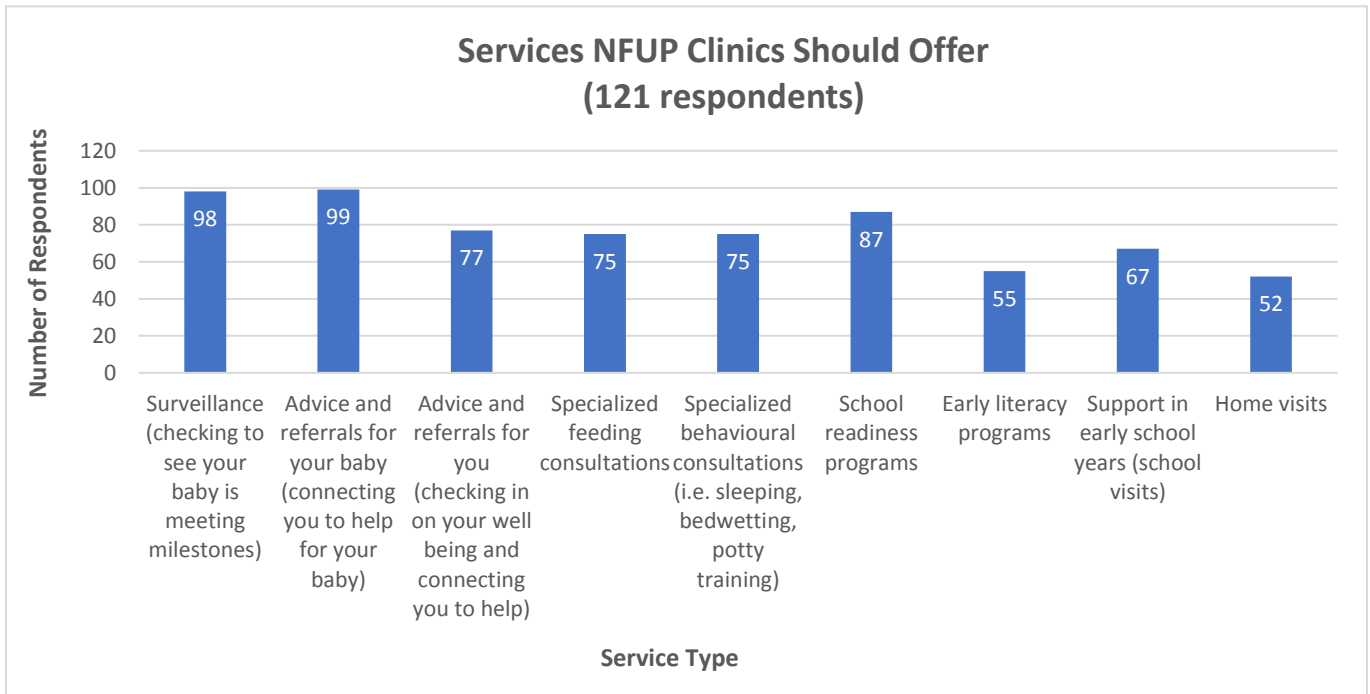


**Figure Three: Other Services Accessed by Families**





**Figure Four: Services NFUP Clinics Should Offer**





## Section 4: Implementation Tools and Plan

In order to facilitate the implementation of the 2015 recommendations, the Implementation Work Group created a number of tools and communication documents with the purpose of standardizing and optimizing the care provided by NFUP clinics, as well as strengthening the operations and effectiveness of the larger neonatal follow-up system. A description of the implementation tools created for NFUP clinics can be found in Table 5 and a description of the communication materials to be used by NFUP clinics to inform and educate families and other health care providers can be found in Table 6.

In addition, a provincial directory of NFUP clinics was developed that can be used by health care providers, parents, caregivers and families to assist both in clinical collaboration or finding resources closest to home.

**Table 5: NFUP Tools**

Tool	Description	Purpose
<b>List of Assessment Tools</b>	A list of commonly used assessment tools organized by developmental domain, administration time, qualifications required to administer and strengths/limitations.	To allow clinicians to select an appropriate assessment tool to meet the specific goals/touch points of visits.
<b>Post-natal Screening Forms</b>	A set of three mental health screening tools to screen for postpartum in mothers, and anxiety or depression in other caregivers.	To allow clinicians to screen parents and caregivers for mental health issues.
<b>Shared Care Form</b>	A form designed to facilitate communication between two NFUPs providing care to a child.	To improve the coordination of care for patients and families.
<b>Levels of Neonatal Follow-Up Reference Sheet</b>	A reference sheet outlining the neonatal follow-up levels of care, including admission criteria, goals, and recommended resources.	To provide details on the different levels of care to ensure that babies receive care at the appropriate level.
<b>Patient Flow Charts</b>	A series of flow charts that depict the most common referral processes for children with motor, behavior, cognitive and social issues	To illustrate the most common referral processes for children with motor, behaviour, cognitive and social concerns.

**Table 6: Communication Tools**

Communication	Description	Purpose
<b>Letter to Health Care Providers and Physicians</b>	A letter directed to community health care providers and physicians explaining the role of the NFUP.	To make clinicians aware of the role of the NFUP, why it is important and how external providers can work with programs to ensure that babies get proper, comprehensive care.
<b>Information Package for Parents and Families</b>	An informational booklet directed to parents and families.	To provide parents and families answers to frequently asked questions about the NFUP, and links to resources for key issues relevant to a baby's healthy development.
<b>Brochure About the Neonatal Follow-Up Program</b>	An informational brochure directed to parents and caregivers.	To provide parents and caregivers with a brief summary of information regarding what the NFUP is, why it is important, the contact information of a family's program and space to write down details for a first appointment.
<b>Visit Schedule Poster</b>	A poster directed to parents and caregivers to provide information about the standard neonatal follow-up visit schedule.	To shows parents and caregivers the recommended visit schedule of the NFUP and provide some information on what to expect at each visit.
<b>Graduation Letter</b>	A brief letter congratulating parents and families on completing their time with a NFUP.	To provide NFUP clinics with a brief note to parents to which they can attach a list of community resources to help families as they transition away from the NFUP.

## Short-Term (Immediate) Implementation

The short-term implementation plan for this work includes the dissemination of these tools on the PCMCH Website, readily available for download free of charge. Dissemination will take place using the following means:

- E-mail communication
- Webinar
- Social media
- Partnerships (e.g. Canadian Premature Babies Foundation, peer support groups)

## Long-Term Implementation (Network Collaborative)

The Implementation Work Group's ultimate goal is to develop a cohesive provincial NFUP that ensures equitable access to high quality care for all patients and adequate support for their families and support systems. To best address the current discrepancies amongst NFUP clinics and to ensure that all patients have equitable access to quality care across the province, the long-term implementation plan is to develop a network collaborative that creates a system of care across all of Ontario's NFUP clinics.

A network collaborative is "a network consisting of a variety of entities (e.g. organizations and people) that are largely autonomous, geographically distributed, and heterogeneous in terms of their operating environment, culture, social capital and goals, but that collaborate to better achieve common or compatible goals, thus jointly generating value."<sup>1</sup> By developing a neonatal follow-up network collaborative, the NFUP clinics can work collectively to improve and standardize care across the province.

Table 7 below summarizes potential activities to support a collaborative network for the province's NFUP.

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<sup>1</sup> L.M. Camarinha-Matos et al. Collaborative networked organizations – Concepts and practice in manufacturing enterprises. *Computers & Industrial Engineering* 57 (2009) 46–60

**Table 7: Potential Network Collaborative Activities**

Activity	Description	Benefit
<b>Neonatal Follow-Up Online Space</b>	<p>A functional website that would allow for:</p> <ul style="list-style-type: none"> <li>• Message board for NFUP providers to post/reply to questions</li> <li>• Resource sharing capabilities (posting and downloading of resources)</li> <li>• Forum to share continuing education opportunities for NFUP clinicians</li> <li>• An area for families to find resources</li> </ul>	<ul style="list-style-type: none"> <li>• Two way communication and sharing of resources between NFUP providers across the province, which does not currently exist.</li> <li>• Given the province’s large geography, an online would help link the NFUP clinics.</li> </ul>
<b>Annual Teleconference/ Webinar Meeting</b>	<ul style="list-style-type: none"> <li>• An annual meeting of NFUP providers</li> </ul>	<ul style="list-style-type: none"> <li>• Bringing NFUP providers together to discuss issues and share best practices in neonatal follow-up.</li> <li>• Provides an opportunity to connect with other relevant meetings and invite speakers.</li> </ul>
<b>System Monitoring/ Quality Assurance</b>	<p>System monitoring for quality assurance and system improvements requires coordinated data collection and evaluation. Appropriate system metrics will be key for system monitoring and to ensuring that all partners are performing adequately.</p>	<ul style="list-style-type: none"> <li>• Mechanism for harnessing collective experience</li> <li>• Facilitate data collection and evaluation</li> <li>• Can use data to drive quality improvement and outcomes in short time</li> <li>• Especially useful paediatric populations where there are limited numbers/resources</li> </ul>
<b>Network Support</b>	<p>Specific expertise and skillsets would be required to maintain the work of the NFUP including a program manager, data analyst and website support/maintenance.</p>	<ul style="list-style-type: none"> <li>• A dedicated program manager would ensure that communication occurs between the NFUP clinics and information is kept up to date. The manager would also coordinate/organize network activities (e.g. annual conference, regular meetings, education opportunities, etc).</li> <li>• A data analyst will work with a group of experts for system monitoring.</li> </ul>
<b>Online community for parents and care givers</b>	<p>An online support system for parents and care givers. Offer a way for them to connect with others who have gone through similar experiences or are currently going through the process.</p>	<ul style="list-style-type: none"> <li>• Parents/ caregivers can sometimes feel isolated going through the system on their own. They may also benefit from hearing about others’ experiences. An online community can help them feel supported.</li> </ul>



## Section 5: Data Recommendation

The 2015 report of the Neonatal Follow-Up Clinic Work Group recommended that “data collection should occur at select developmental checkpoints, with standardized assessment tools. A committee of experts should be struck, including BORN Ontario and the Canadian Neonatal Follow-Up Network to determine the touch-points at which to collect data, and the assessment tools that should be used.”

The Implementation Work Group struck a sub-committee to follow-up on this recommendation. The sub-group concluded that there are currently a number of points in the system where neonatal follow-up data (clinical outcomes and clinic processes) is collected or could be collected. There is also potential to bridge these points together and build a data collection set into an already existing infrastructure. The sources of neonatal follow-up data that currently exist and which were discussed included BORN Ontario, Canadian Neonatal Follow-up Network (CNFUN), CNN (Canadian Neonatal Network), and NFUP clinics.

### ***Better Outcomes and Registry Network (BORN) Ontario***

BORN is Ontario’s pregnancy, birth and childhood registry and network.

BORN currently has an “encounter” set up to collect neonatal follow-up data. This encounter is not currently live, but has fields to collect demographic, birth information, health information, and information regarding status in follow-up. The encounter could be enhanced to include other pertinent data points. NFUP clinics currently do not have access to the BORN database.

### ***Canadian Neonatal Follow-Up Network (CNFUN)***

CNFUN is a voluntary collaboration between Neonatal and Perinatal Follow-Up Programs in Canada and their multidisciplinary team members. Level 3 NFUP clinics currently submit data to CNFUN. The data collected occurs at the 18-month corrected age and previously collected data from questionnaires at 36-months corrected age.

CNFUN is leading a new research project entitled “Parent Integrated Evidence –based Practice to Improve Quality” to identify meaningful parent identified outcomes to be collected by CNFUN and to integrate interventions to improve cognitive and language outcomes in 12 participating neonatal follow-up clinics. In addition, a new Canadian Preterm Birth Network study will create a national expanded network from pregnancy to neonatal to follow-up which will create an expanded database and new quality improvement projects. In addition to linkage between CNN and CNFUN, there will be enhanced information from the pregnancy.

### ***Canadian Neonatal Network (CNN)***

The Canadian Neonatal Network encompasses Canadian neonatologists and researchers from all the tertiary level NICUs who collaborate on quality improvement and research issues. CNN maintains a detailed national database of NICU admissions with a standardized protocol and definitions.

### ***Neonatal Follow-Up Programs***

All tertiary level NFUPs submitted data to CNFUN for births April 2009 to September 2011 when there was research funding and many continue to do. Most neonatal follow-up programs collect data in their own internal databases.

The data collected in internal databases is not standardized across NFUP clinics and most programs do not have adequate human resources to input or maintain an up-to-date data repository.

## **Data Recommendation**

The synergies between these data sources is evident and the potential impact of unifying the neonatal follow-up data collection system, for both clinical practice and research, is significant. Thus, this sub-committee recommends that an expert work group be struck to establish:

- How best to utilize/bridge/link the current data collection resources. Would a partnership between BORN and CNFUN be a possibility? Further investigation regarding structure, ownership and privacy are required.
- A minimal dataset to collect consistent data from all NFUP clinics in the province. Clinics would not be required to use the same measurement tools, however data collection would focus on measuring the same domains.
- Standardized time intervals at which the data should be collected.
- How to resource ongoing data collection and analysis.



## Section 6: Evaluation Framework

The Implementation Work Group struck a sub-committee to develop evaluation metrics for the implementation strategy. The primary goal of the implementation strategy is to reduce variability of practice among NFUP clinics and align standards, thus, the metrics proposed intend to measure both the process, and the desired outcomes to achieve this goal.

**Table 8 - Evaluation Framework**

Metric	Rational	Data Source
<b>1. Visit schedule adherence</b>	To measure the success / goal of the initiative = Reduction in variability of practice among NFUP clinics and align standards	Available immediately via CNFUN Data for L3 NFUP clinics  Manual data collection via clinic specific data bases and / or survey  [Could be added to the BORN BIS]
<b>2. Usage of the tools</b>	To determine clinic awareness of tools / implementation materials	Manual data collection via survey
<b>3. Follow-up rate</b>	To determine if the tools are helping to improve follow-up rate / preventing children from missing appointments and falling through the cracks	Available immediately via CNFUN Data for L3 NFUP clinics  Manual data collection via clinic specific data bases and / or survey



<b>4. Appropriateness of NFUP location</b>	To ensure patients are being seen at appropriate level of care and/or close to home (using patient postal code and NICU(s) where cared for)	Available immediately via CNFUN Data for L3 NFUP clinics  Manual data collection via clinic specific data bases and / or survey
<b>5. Incidence of shared care taking place/forms being used</b>	To determine if the formal process of shared care is being observed	Manual data collection via survey
<b>6. Patient/caregiver satisfaction</b>	To determine if the implementation of the tools is improving the patient/caregiver experience	Manual data collection via survey
<b>7. Number of children meeting NICU follow-up criteria compared to those in NFUP care</b>	To identify the children who are not getting NFUP care	[Could be added to the BORN BIS]



## Section 7: Broader System Recommendations

The broader system recommendations that were made in the 2015 report were sent to the Ministry of Health and Long-Term care in September 2015.

### Education

Recently, the Toronto District School Board (TDSB) modified its entrance criteria to allow parents to choose to hold their child back from entrance to Junior Kindergarten. While this is a win for parents of premature babies in the TDSB who can now decide to enroll their child based on their corrected/adjusted age (due date) and not their chronological age (birth date), the Implementation Committee does not endorse a child staying home without opportunities for enrichment. The Committee advocates that for those children opting for deferred entry, structured time in parent family literacy centres, early year centres, daycare, or preschool environments is a necessity. The same opportunities need to be available for all families in Ontario, with parents having the greatest expertise on their child's readiness. For those boards not following the TDSB lead, we would encourage ongoing parental advocacy for delay of entry (and clarification that this does not equate to missing a year of

kindergarten) and to work with local developmental resources (neonatal follow up clinics, infant development programs) to provide assistance.

### **Collaboration of Ministries with the NFUP**

It should be recognized and emphasized that the NFUP is a system within a system. It brings a specific expertise to the broader provincial system, which can be leveraged to expedite services for its specific high risk population (mainly, the preterm population). In the creation and development of new provincial strategies, the NFUP should be considered.

For example, the design of strategy intake protocols should be cognisant of assessments that are already undertaken by NFUP clinics. Collaboration with the NFUP could effectively eliminate the need for a patient to be assessed by an intake professional after being assessed by similar professionals of the NFUP. This would avoid duplication of services and would also be in keeping with the Ministry of Health's universal access philosophy that "any gate is the right gate" to enter the system. NFUP collaboration, could streamline and expedite care for the pre-term population.



## Section 8: Conclusion

The Neonatal Follow-Up Implementation Work Group developed a series of tools and communications to optimize the NFUP in the province with the goals of reducing variability of practice among NFUP clinics, aligning standards, and improving the NFUP experience for patients and families.

Follow-through of the implementation strategies, both short-term and long-term, as well as evaluation of the implementation will be key to ensuring a cohesive provincial NFUP that ensures equitable access to high quality care for all patients and adequate support for their families and support systems.

# Appendix A: Project Team and Work Group Membership

Name	Title	Organization
<b>Neonatal Follow-Up Implementation Project Team</b>		
<b>Doreen Day</b>	Senior Program Manager	Provincial Council for Maternal and Child Health
<b>Vanessa Abban</b>	Program Analyst	Provincial Council for Maternal and Child Health
<b>Neonatal Follow-Up Implementation Work Group Membership</b>		
<b>Marilyn Ballantyne</b>	Chief Nurse Executive & Clinician Investigator	Holland Bloorview Kids Rehabilitation Hospital
<b>Roxane Belanger</b>	Speech Language Pathologist	NEO Kids, Health Sciences North
<b>Paige Church (Co-Chair)</b>	Medical Director, Neonatal Follow-up	Sunnybrook Health Sciences Centre
<b>Maureen Cuddy</b>	Patient Care Manager NICU, Paediatric and Neonatal Follow Up Clinic	Lakeridge Health
<b>Thierry Daboval</b>	Medical Director, Neonatal Follow-Up Clinic	Children's Hospital of Eastern Ontario
<b>Hilary De Veber</b>	Paediatrician	Michael Garron Hospital
<b>Joan Fuerth</b>	Occupational Therapist	Windsor Regional Health
<b>Michelle Gordon</b>	Paediatrician, Chief of Paediatrics and Neonatology	Orillia Soldiers' Memorial Hospital
<b>Vincent Ho (Co-Chair)</b>	Medical Director of NICU and Neonatal Follow-Up Clinic	Royal Victoria Regional Health Centre
<b>Linh Ly</b>	Staff Neonatologist, Medical Director Neonatal Follow-Up Program	Hospital for Sick Children
<b>Patricia Maddalena</b>	Neonatal Nurse Practitioner	Sunnybrook Health Sciences Centre
<b>Kate Robson</b>	Family Support Specialist	Sunnybrook Health Sciences Centre
<b>Heather Ryan</b>	NICU Program Manager	Windsor Regional Hospital
<b>Laurel Silenzi</b>	BORN Coordinator, NICU Lead	BORN
<b>Anne Synnes</b>	Director	Canadian Neonatal Follow-Up Network
<b>Cherryl Warnica</b>	Speech Language Pathologist	Royal Victoria Regional Health Centre
<b>Ethel Ying</b>	Neonatal Follow-Up Lead	St Michael's Hospital, Department of Pediatrics

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