

Final Report of the Neonatal Follow-Up Clinics

Work Group



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Executive Summary

Neonatal follow-up has evolved from being a means to evaluate the impact of care for infants in Neonatal Intensive Care Units (NICU), to one of focusing on continued monitoring and early intervention to promote optimal outcomes in these high risk infants. In 2012/13 there were 24 Neonatal Follow-Up Clinics in the province providing 14,000 visits a year to this high-risk group, including enrolment of 3,000 new NICU graduates¹.

Neonatal follow-up clinics (NFUCs) serve several purposes. They include:

- Following and assessing infants who are at high risk for neurodevelopmental delay/disability, for physical, motor, cognitive, social, language and learning development.
- Examining care and establishing best care guidelines for emerging populations such as congenital cardiac conditions and neonatal encephalopathies.
- Providing anticipatory guidance, teaching parents about their child and his/her developmental pattern, and fostering parental resilience.
- Providing informed surveillance of children at risk for high prevalence, low severity developmental challenges to facilitate early identification of conditions that occur as children enter school.
- Provide expertise for families, and where available, provide local expertise for communities and schools to foster earlier identification and facilitate earlier remediation and accommodations thereby minimizing disability and cost to the system.

Currently, neonatal follow-up in 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. There are discrepancies in the quality of care depending on where the neonate was born, duplication of services with inconsistent program catchments, gaps in care or suboptimal care, and ongoing stress and cost to the families who may hear discrepant messaging and/or have to travel significant distances to receive follow up care.

The Neonatal Follow-Up Clinics Work Group (NFUC-WG) was convened in November 2013 to examine NFUCs in the province and to make recommendations for best practice addressing the needs of the population as well as leveraging existing resources within the current healthcare system.

The recommendations made in this report address the following gaps and discrepancies amongst the NFUCs as well as the impact that these clinics can have in the broader system on the long-term outcomes of the population they address:

1. The primary goal of NFUCs to ensure optimal development and functional outcomes for each child as defined by providing the greatest opportunity for social participation and school performance.
2. The need for proactive monitoring for this population, including the implementation of matching levels of care for neonatal follow-up to the level of neonatal intensive care and a model of shared neonatal follow-up care.
3. Consistency in the visit schedule based on identified developmental touch points as well as suggested assessment tools.
4. The role of intervention in NFUCs to teach parents about their child, coaching, and advocacy.
5. The role of NFUCs to ensure quality assurance and data collection.
6. The need for ongoing communication amongst, and education for neonatal follow-up clinicians.

Preamble

Neonatal Follow-Up Clinics (NFUCs) provide assessment, monitoring, identification, and early intervention for high risk infants who have been cared for in Neonatal Intensive Care Units (NICUs). Their role within the system of care in Ontario that addresses the needs of infants and children who have, or are at risk of having a physical, developmental and/or behavioural disability, is essential.

This report will specifically address the NFUCs. It will provide recommendations for defining the population, standardizing the operations of NFUCs and the care they provide, as well as broader system recommendations regarding the impact these clinics can have on the long-term outcomes of the infants and children they address.

Background

Neonatal Follow-Up clinics have existed in Ontario for many years. Traditional follow-up was started as a means to examine changes in care and its impact on infants cared for in Neonatal Intensive Care Units (NICU) (primarily premature infants ≤ 32 weeks), focusing on significant severe disabilities such as cerebral palsy. Though the rates of the traditionally tracked disabilities have stabilized, significant and disabling behavioural challenges as well as school-based challenges are increasingly recognized for this preterm cohort. In addition, the need for surveillance has shifted to new populations such as congenital cardiac conditions and those with neonatal encephalopathy. As such, neonatal follow-up has now evolved from a system of monitoring outcomes of mainly preterm children to one that continues to monitor and offers early intervention to promote optimal outcomes in high risk infants.

Impact on the System

In 2012-13 Ontario saw approximately 20,000 babies born who required care in Neonatal Intensive Care NICUs². These newborns varied widely in the nature and complexity of their medical conditions, ranging from rare genetic conditions to prematurely born newborns. This population is at significant risk of high medical resource use and neurodevelopmental impairment within their lifetime³, resulting in a disproportionately high demand on fiscal, healthcare and educational resources.

In 2012-13, Ontario saw 2,000 children born at less than 32 weeks gestation with a birth weight of less than 1,500 grams². Health care costs associated with preterm birth approach \$117,000 per infant for hospitalization in the neonatal period alone⁴. Clinically, this particular group is at increased risk of long term complications such as cerebral palsy (CP), chronic lung disease, blindness, deafness, intractable seizure disorders or death. There is also well documented evidence that other complex conditions, such as visual-perceptive deficits, learning deficits, autism, ADHD, school unpreparedness, and deficits in self-regulatory behaviour are prevalent in this group^{5,6,7,8}. While there are no cures for these conditions, there is strong evidence that early identification and intervention have the greatest impact on final outcomes⁹.

In 2012/13, Ontario's 24 NFUCs had approximately 14,000 visits from these high-risk infants, and had an enrolment of 3,000 new patients¹⁰.

Role of Neonatal Follow-Up Clinics

Neonatal follow-up clinics (NFUCs) serve several purposes. Firstly, they follow and assess infants who are at high risk for neurodevelopmental delay/disability and assess physical, motor, cognitive, social, language and learning development. This information provides critical quality assurance feedback to the intensive care nurseries and public health. For emerging populations such as congenital cardiac conditions with novel treatments and managements emerging, follow up is essential to re-examine the care and establish best care guidelines. For the preterm population, with known risks for developmental disabilities, surveillance is required as shifts in incidence of neurodevelopmental disabilities will inform the care provided.

A new emerging role for NFUCs has developed as a result of the accumulated knowledge of the patterns of development of these high risk children. That role is one of providing anticipatory guidance, teaching parents about their child and his/her developmental pattern, and fostering parental resilience. Educating parents as to what to watch for regarding developmental challenges or “touch points”¹¹ allows parents to understand the child’s behaviour more effectively. Coaching of parents as to how to facilitate smooth transitions through these touch points fosters parental resiliency and empowers them to seek intervention as needed. Through providing this basic care with surveillance visits, families gain a greater understanding of their children and system utilization is spared for those needing targeted and/or ongoing direct intervention.

The majority of children discharged from a NICU will not have an overt developmental disability but are now recognized to have a pattern of high prevalence, low severity developmental problems and co-morbidities. In isolation these conditions are not severe and are not characterized by a challenge that interferes with day to day function. However, these conditions tend to occur in clusters, creating a synergistic effect, resulting in significant dysfunction. While this pattern emerges later in childhood, early markers such as disorganized attachment, busy behaviour, and dysregulation can indicate future challenges. NFUCs offer a critical role of informed surveillance looking for these markers and of early intervention, tackling these problems before they become fixed patterns of behaviour.

Lastly, three NFUC’s in the province currently provide surveillance into the preschool or early school years. While the early markers of potential behavioural difficulty can be identified and addressed, higher order cognitive processing and splintered intellectual capacities cannot be identified until the school years. Children with longstanding neurological injury and/or dysmaturation may demonstrate new onset findings as they grow, tapping networks in the brain previously not developmentally needed. This ‘Sleeper Effect’ explains how a child can appear to emerge from the NICU unscathed only to develop a complex amalgam of challenges with learning and learning strategies. These centres have provided local expertise for schools, communities, and families and foster earlier identification. In doing so, these children can be offered earlier remediation and accommodation, minimizing disability and cost to the system.

The Neonatal-Follow-Up Clinics Work Group

Currently, neonatal follow-up care in 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. There are discrepancies in the quality of care depending on where the neonate was born, duplication of services with overlapping catchments, gaps in care or suboptimal care, and ongoing stress and cost to the families who may hear discrepant messaging and/or have to travel significant distances to receive follow up care.

The Neonatal Follow-Up Clinics Work Group (NFUC-WG) was convened in November 2013 to examine the current NFUCs and to make recommendations to best address the needs of the population as well as to leverage existing resources within the current healthcare system.

Neonatal Follow-Up Clinics Work Group

The Neonatal Follow-Up Clinics Work Group (NFUC-WG) is a work group of the Maternal-Newborn Advisory Committee of the Provincial Council for Maternal and Child Health (PCMCH/Council).

PCMCH is an organization whose scope is primary, secondary, tertiary and quaternary maternal, newborn, child and youth health services, delivered in both community and hospital settings, and includes responding to the needs of disadvantaged communities across Ontario. The Council's work reflects the importance of relationships and interfaces among providers and organizations across the continuum of care.

The Council's vision is: The Best Possible Beginnings for Lifelong Health

Its mission is to:

- **Be the provincial forum** in which clinical and administrative leaders in maternal and child health can identify patterns and issues of importance in health and health care delivery for system support and advice.
- **Improve the delivery** of maternal child health care services by building provincial consensus regarding standards of care, leading practices and priorities for system improvement.
- **Provide leadership and support** to Ontario's maternal and child health care providers, planners and stewards in order to maximize the efficiency and effectiveness of health system performance.
- **Mobilize information and expertise** to optimize care and contribute to a high-performing system therefore improving the lives of individual mothers and children, providers and stewards of the system.

The NFUC-WG was convened in November 2013 to examine the current state of neonatal follow-up clinics (NFUCs) across the province, to identify any gaps or variations in practice and to make recommendations aimed at strengthening and optimizing the system of neonatal follow-up for the province. Refer to appendix A for the NFUC-WG terms of reference.

The work group consists of NFUC clinicians and administrators, as well as representation from children's treatment centres, the Ministry of Child and Youth Services and research. Efforts were made to ensure representation from across the province, including both tertiary and community hospitals. Refer to appendix B for the NFUC-WG membership.

Process Used to Address the Work Group's Mandate

NFUC-WG members report that although NFUCs should be working towards the same principles and goals, they are actually quite different with regards to the available resources, populations served and clinical practices. In order to gain more empirical evidence about the current state of NFUCs across the province the NFUC-WG undertook a current state analysis, surveying all NFUCs in Ontario.

Based on the results of the current state analysis and the expertise of the NFUC-WG, the work group identified the following key areas on which to focus their work:

- Development of key pillars for NFUCs
- The role of the NFUCs in providing proactive monitoring for neonatal intensive care graduates
- Standardization of the visit schedule around the child and family's needs through an emphasis on developmental "touch points" with the use of assessment tools specific to those touch points.
- The role of intervention in NFUCs
- The importance of quality assurance and data collection
- The needs of the NFUC and its clinicians for ongoing communication and learning
- The role of the NFUCs in providing the best opportunities for social inclusion and scholastic performance

This work was completed over a series of NFUC-WG work group meetings and smaller sub-group meetings. Where sub-groups were used to develop pieces of work, the NFUC-WG reviewed the work and approved it as a group.

Current State Analysis

In December of 2013 a survey was sent to the 46 Level II and Level III maternal-newborn programs in Ontario to inquire about the current state of NFUCs in the province. The survey addressed the following areas:

- Number of NFUCs in the province and their locations
- Clinic funding and resources
- Admission criteria
- Services provided
- Visit schedule
- Assessments used
- Data collection

Responses were received from 42 of the 46 target hospitals. Further investigation confirmed that the 4 non-respondents did not have NFUCs associated with their hospitals. Some responses were incomplete, therefore the results discussed below are based on the number of NFUCs who provided responses to the particular question.

Neonatal Follow-Up Clinics

For the 2013/14 fiscal year, there were 24 identified NFUCs in Ontario. See figure 1 and table 1. The majority of the clinics are located in LHINs 7, 8 and 9, with each having 6, 4 and 4 NFUCs in their LHIN respectively. A new NFUC at Markham-Stouffville Hospital (LHIN 9) was scheduled to be opening in 2014/15.

Figure 1: Map of Ontario NFUCs

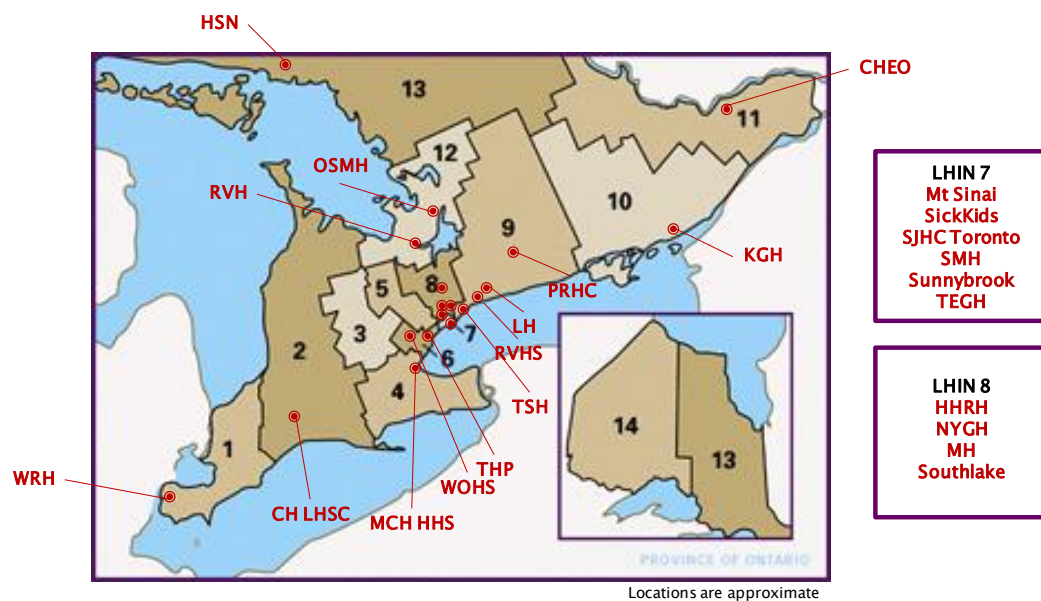


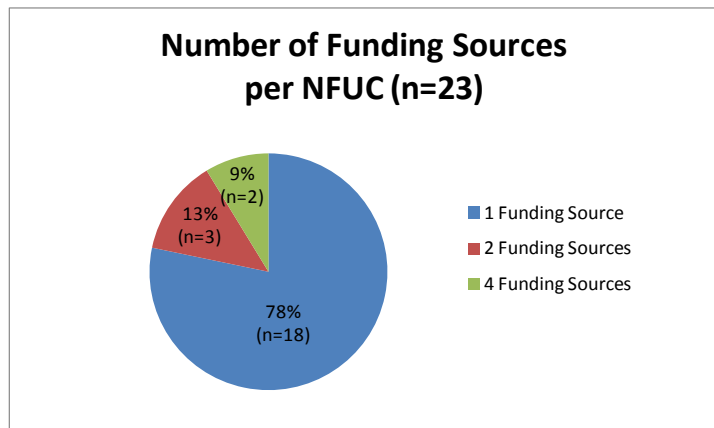
Table 1: List of Ontario NFUCs

Neonatal Follow-Up Clinics	LHIN
Windsor Regional Hospital (WRH)	1
Children's Hospital-London Health Sciences Centre (CH LHSC)	2
McMaster Children's Hospital, Hamilton Health Sciences (MCH HHS)	4
Trillium Health Partners (THP)	6
William Osler Health Centre (WOHC)	6
Mount Sinai Hospital (Mt Sinai)	7
St. Joseph's Health Centre (SHJC Toronto)	7
St. Michael's Hospital (SMH)	7
Sunnybrook Health Sciences Centre (Sunnybrook)	7
The Hospital for Sick Children (SickKids)	7
Toronto East General (TEGH)	7
Humber River Regional Hospital (HRRH)	8
North York General Hospital (NYGH)	8
Mackenzie Health (MH) with York Region Early Intervention Services (YR EIS)	8
Southlake Regional Health Centre (Southlake) with York Region Early Intervention Services (YR EIS)	8
Rouge Valley Health System (RVHS)	9
Lakeridge Health Corporation (LH)	9
Peterborough Regional Health Centre (PRHC)	9
The Scarborough Hospital (TSH)	9
Kingston General Hospital (KGH)	10
Children's Hospital of Eastern Ontario (CHEO)	11
Orillia Soldier's Memorial Hospital (OSMH)	12
Royal Victoria Regional Health Centre (RVH)	12
Health Sciences North (HSN)	13

Neonatal Follow-Up Clinic Funding and Resources

Seventy-eight percent of NFUCs (18 of 23) identified that they receive their funding from one funding source. The remaining 22% of NFUCs identified receiving their funding from 2 or more sources. See figure 2. The predominant source of funding identified by 20 of the NFUCs was global hospital funding. Other sources of funding identified included Ministry of Child and Youth Services and foundation funds (identified by 2 NFUCs each), as well as research dollars, other Ministry of Health and Long-Term Care funds, donations and Canadian Neonatal Network funding (identified by one NFUC each).

Figure 2: Number of NFUC Funding Sources



Staffing resources varied significantly by NFUC. Table 2 provides details regarding the dedicated/budgeted resources identified by NFUCs, and their FTE range. Most clinics also identified that they had resources available to them (unfunded) where required. The availability of these unfunded resources varied greatly from clinic to clinic.

Table 2: NFUC Dedicated/Budgeted Resources

Dedicated/Budgeted Resources	% of Tertiary Hospital NFUC with Resource	FTE Range	% of Community Hospital NFUC with Resource	FTE Range
Behavioural Consultant	14%	1	0%	0
Developmental Paediatrician	57%	0.1-0.5	12%	0.4
Dietician	43%	0.2-0.6	24%	0.1-0.2
Educational Consultant	0%	0	12%	-
Neonatologist	100%	0.4-1.0	59%	0.1-0.4
Nurse Practitioner	57%	0.2-1.0	6%	0.2
Occupational Therapist	71%	0.4-1.4	71%	0.2-0.4
Paediatrician	29%	0.2-0.45	41%	0.1-1
Paediatric Neurologist	0%	0	0%	0
Psychologist/Psychometrist	71%	0.2-1.0	0%	0
Physiotherapy Practitioner	14%	0.3	0%	0
Physiotherapist	71%	0.2-2.0	35%	0.2-0.3
Registered Nurse	57%	0.6-1.2	59%	0.2-0.4
Social Worker	0%	0	12%	-
Speech Language Pathologist	57%	0.2-0.4	41%	0.1-0.3
Other	29%		18%	
Secretary/Clerical	14%	0.4	6%	0.5
OT Clinical Specialist	14%	-	0%	0
Early Interventionists	0%	0	12%	-

Dash (-) indicates no response provided

Services Provided

NFUCs were asked to identify the services they provide. The identified services included:

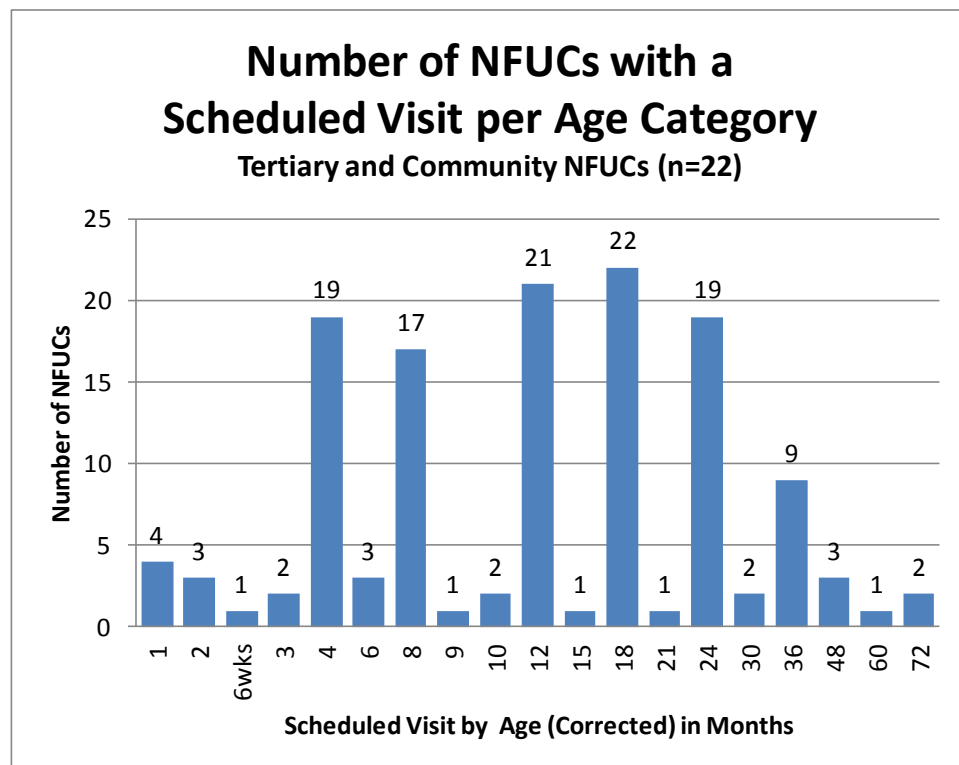
- Screening for developmental delays/any domain of development - 21 NFUCs
- Referrals to treatment centres - 21 NFUCs
- Referrals to community programming, therapy or early intervention - 20 NFUCs
- Follow-up - 18 NFUCs
- Diagnosis of developmental disability - 13 NFUCs
- Treatment - 10 NFUCs
- Resource assistance - 9 NFUCs

Visit Schedule

The visit schedules utilized by the NFUCs varied significantly. Only 36% NFUCs (8 of 22) had the same visit schedule, which included scheduled visits at 4, 8, 12, 18, and 24 months of age (corrected). The remaining 64% of NFUCs had differing schedules that included anywhere between 4 to 10 scheduled visits. Three NFUCs in the province offered visits that followed patients to the start of school, 4 years and 6 years of age.

The most common ages at which scheduled visits occur are 4, 8, 12, 18 and 24 months of age (corrected). Visits at these ages took place at about 80% or more of the NFUCs. See figure 3.

Figure 3: NFUC Scheduled Visits by Age



Assessments Used

In total, 30 different assessment tools were identified as being used by the NFUCs surveyed. The most frequently used assessment tools, meaning those used the most frequently across all NFUCs and all visits were identified as:

- Gross Motor Performance Classification System
- Communication and Symbolic Behaviour Scales Development Profile (CSBS)
- Posture and Fine Motor Assessment of Infants (PFMAI)
- The Bayley Scales of Infant and Toddler Development
- Alberta Infant Motor Scale
- Infant Neurological International Battery (INFANIB)

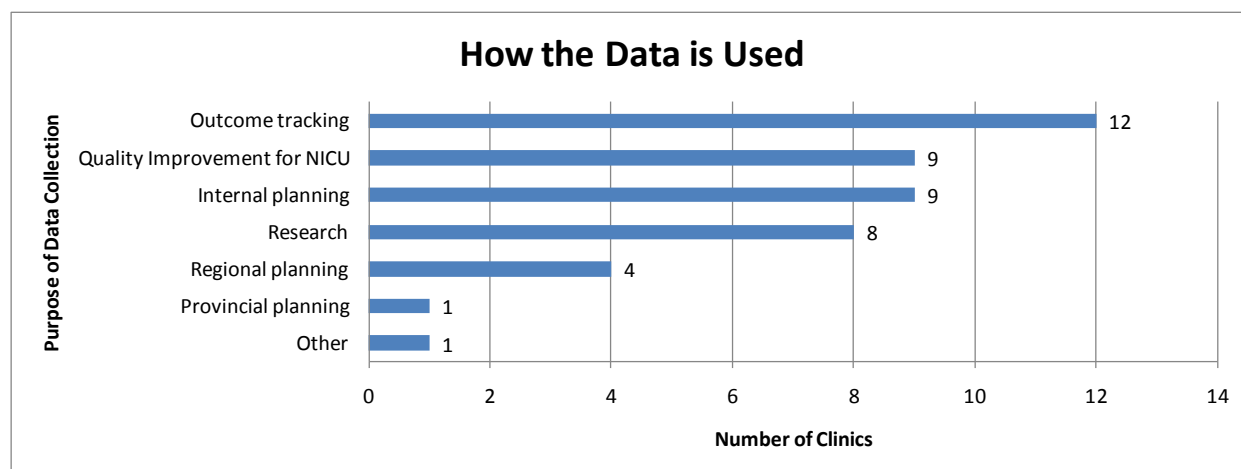
Data collection

Seventy-one percent of NFUCs (15 of 21) identified that they collect data. Four clinics noted that they collect data in more than one database. The data bases used by the NFUCs are:

- Custom internal database - 10 NFUCs
- Canadian Neonatal Network database - 6 NFUCs
- Vermont Oxford Network database - 3 NFUCs
- Canadian Neonatal-Follow-up Network database - 1 NFUC

The data collected by the NFUCs was identified as being used for a number of different purposes. They include outcome tracking, NICU quality improvement, internal planning, research, as well as regional and provincial planning. See figure 4.

Figure 4: NFUC Data Usage



In addition, it was found that the use of custom internal databases in a high number of NFUCs precludes any large-scale comparative analyses across clinics as the databases and the data they collect are not standardized across clinics.

5-Pillars of Neonatal Follow-Up

The current state analysis provided a snapshot of the complex and wide-ranging scope of work currently undertaken at the NFUCs throughout the province. Given this variation in scope the NFUC-WG proposes a set of guiding “pillars” for neonatal follow-up care. It is expected that these guiding pillars will provide a core focus for the care to be provided in NFUCs across the province, making the best use of available resources and expertise, standardizing scope of practice, reducing practice variation and preventing duplication of services of those available within the broader community.

The 5 pillars of neonatal follow-up are as follows:

5 Pillars of Neonatal Follow-Up	
1)	Scope: Neonatal follow-up includes assessment, identification, and early identification . It can also include diagnosis or suspicion of issues.
2)	Intervention: Neonatal follow-up interventions should be primarily in the form of: <ul style="list-style-type: none"> a. Coaching for families – Providing the information, education and/or coaching parents need to work with their child and help them succeed b. Referral/recommendation for services
3)	Advocacy: Neonatal follow-up will advocate on behalf of their patients and families.
4)	Auditing/Quality Assurance: Neonatal follow-up clinics should collect data to support quality assurance within their clinic and across clinics province-wide.
5)	Education: Ongoing education for neonatal follow-up providers is integral and opportunities to share knowledge should be encouraged.
<i>Neonatal follow-up should not be primarily concerned with medical management or treatment.</i>	

Neonatal Follow-Up Clinic Recommendations

The following recommendations focus on standardizing the function of the NFUCs in the province. Implementation of these recommendations will be dependent on individual regional resources and planning.

Proactive Monitoring for Neonatal Intensive Care Graduates – Levels of Neonatal Follow-up and a Model for Shared Neonatal Follow-Up Care

Unique to NICU admissions, the brains of neonates are at an active point in neurodevelopment and the underlying reason for admission is often associated with toxic stress to that neurodevelopmental process. As a result, admission to the NICU, in addition to the underlying reason for that admission, poses significant risk factors for adverse future neurodevelopment¹².

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.

The minority of neonates who are eligible for enrolment with a NFUC will have overt disabilities, such as CP, vision/hearing impairment, and intellectual disability. These children are identified early and the system provides well defined resources for them. More commonly however, the neonates admitted to neonatal follow-up have well documented risks to their development and may present with subtle findings indicative of future developmental challenges. Generally, the risk correlates to the extent of dysmaturity and gestational age as well as severity of illness. Through proactive monitoring geared to the extent of risk (aligned with NICU levels of care), early signs can be identified and coaching and intervention can then be provided to parents to redirect the trajectory to one of greater self-regulation and success.

See appendix C for details regarding the neonatal follow-up levels of care.

Recommendation 2 – A shared care model should be implemented across NFUCs. If a NFUC is unable to provide neonatal follow-up, arrangements must be made by the hospital of birth to provide referral to a NFUC within a reachable distance for the family following a shared care model.

A child may be born in a facility with, or near a NFUC that is unable to provide the appropriate level of neonatal follow-up (i.e. Level III care) or at a facility lacking a NFUC. In such a case, arrangements must be made by the hospital of birth to provide appropriate referral to the appropriate level of NFUC care within reachable distance for the family.

When the circumstance arises whereby the distance or cost to travel may be prohibitive for multiple trips or undue stress may be caused to the family, the NFUC-WG endorses the use of a shared care model.

In a shared care model, care for the patient is shared between a Level II and a Level III NFUC. The NFUC-WG has developed principles for guiding this shared care model. The principles are intended to promote patient-centred care, enhanced compliance to the NFUC visit schedule, enhancement of the patient/family experience through easier visits and consistency of messaging, avoidance of redundancy, and best use of available resources.

The proposed guiding principles for shared NFUC Care are as follows:

NFUC Shared Care Guiding Principles	
1)	<p>Communication/collaboration is essential between NFUCs in any shared care model</p> <ul style="list-style-type: none"> • A contact/point person for each clinic is required and should be available to one another by email/phone/fax • The point people will make contact upon the initiation of shared care between two NFUCs, i.e. the Level II centre is to initiate contact with Level III centre and plan for the patient together. • The site providing the primary responsibility for surveillance and care should be clear to both NFUCs and understood by the families.
2)	<p>Prior to the patient's discharge from the NICU, a discussion between Level II and Level III NFUCs should occur to determine where the patient should start their care.</p> <ul style="list-style-type: none"> • If possible, introduction to both teams should occur early so that families understand the teams and the roles as well as available resources.
3)	<p>For patients meeting Level III criteria, the 18-month visit should take place at a Level III NFUC</p> <ul style="list-style-type: none"> • Education for the parents is required to ensure they are aware of the importance of going to the Level III NFUC for the 18-month visit. • Facilitation of the visit should be undertaken by both teams to maximize compliance
4)	<p>If there are discrepancies in the frequency of visits or services provided between the NFUCs, the family has the right to choose what they would like from each of the NFUCs, thereby maximising the services they can receive from their assigned level. This should occur with both teams understanding so as to avoid duplication of services.</p>
5)	<p>Using OTN/video conferencing is a viable option to address discrepancies in care across levels or if there is a likelihood of a patient not of being able to attend a Level III visit.</p>

Standardizing Practice at Neonatal Follow-Up Clinics – Identification of Developmental Touch Points, Recommended Neonatal Follow-Up Visit Schedule and Assessment Tools

Developmental ‘touch points’ represent moments in development marked by the child working toward or achieving a new skill.

Recommendation 3 – All NFUCs 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.

The current state analysis identified that the visit schedules utilized by the NFUCs were varied, based primarily on resource availability. The NFUC-WG proposes a recommended standardized visit schedule as a series of planned interdisciplinary team visits scheduled around developmental ‘touch points’ for the child and family.

Fundamental to healthy development is parent-child attachment – the first touch point to be assessed. Developmental research has demonstrated attachment as an early and foundational developmental skill. Successful attachment assists in early sleep and feeding regulation, and later, is a fundamental foundation for social development and behavioural regulation. Starting with this touch point, and then moving forward with an emphasis on the child and family focused assessments, allows for identification and intervention to occur at key points in a child’s and family’s development, while maximizing the use of resources currently available.

Accompanying the visit schedule is a menu of assessment tools that are recommended for use to address the specific goals of each NFUC visit. The NFUC-WG does not endorse the use of any specific assessment, rather, the menu was collated by the Work Group to provide the best assessments available for the specified goal and allows the individual NFUCs and clinicians to select the tools to be used in their particular setting/circumstance with attention to the specific goal/touch point of the visit. See appendix D for the menu of assessment tools.

Establishing a standardized visit schedule also offers the potential for future evaluation utilizing specific assessment tools to evaluate system usage or other system based questions.

Neonatal Follow-Up Clinic Recommended Visit Schedule		
Visit Timing	Goals	Coaching and Intervention Goals
1 week post-discharge	<ul style="list-style-type: none"> Transition home safely 	<ul style="list-style-type: none"> Transition to primary MD/establishing the relationship
4-8 weeks post-discharge	<ul style="list-style-type: none"> Attachment Regulation (feeding, sleeping) Positioning (safety and beginning of intervention) Maternal/family wellbeing/depression and link to primary care if needed 	<p>Coaching:</p> <ul style="list-style-type: none"> Signs and symptoms of depression and help available Safe sleep Normalizing infant's need for external support for regulation Developmental cues for feeding <p>Intervention:</p> <ul style="list-style-type: none"> Community or maternal support as indicated
4 months	<ul style="list-style-type: none"> Attachment Gross Motor Development as a reflection of overall development with the main goal being identification of early concern (vision, hearing, cognition, motor) Introduce concept of coaching Provide feedback to parents re: feeding, motor development 	<p>Coaching:</p> <ul style="list-style-type: none"> Motor strategies <p>Intervention:</p> <ul style="list-style-type: none"> Referral for community resources as indicated
8 months	<ul style="list-style-type: none"> Change from stationary to dynamic movement as a marker for overall development (gross and fine motor development) <ul style="list-style-type: none"> Assessment and coaching, not diagnosis Feeding to eating – shift to becoming an independent eater Temperament Attachment Sleep regulation 	<p>Coaching:</p> <ul style="list-style-type: none"> Movement as it relates to temperament Transition postures Mealtime strategies Sleep hygiene <p>Intervention:</p> <ul style="list-style-type: none"> Refer to community resources as needed
12 months	<ul style="list-style-type: none"> Social development as child becomes upright Motor development Communication Regulation-eating, sleep hygiene 	<p>Coaching:</p> <ul style="list-style-type: none"> Limit screen time Engage child on topics of their interest and expand that topic rather than redirect Red flags Sleep hygiene Mealtime strategies

		<p>Intervention:</p> <ul style="list-style-type: none"> Refer to community resources as indicated
18 months	<p>Comprehensive Developmental Assessment:</p> <ul style="list-style-type: none"> Documentation of CP Moderate to severe motor delay Behaviour & management strategies Cognition Language Social development Coaching 	<p>Coaching:</p> <ul style="list-style-type: none"> Discipline introduced Behaviour management strategies reviewed Community group activities available (library, early years, daycare) and benefits of peer exposure <p>Intervention:</p> <ul style="list-style-type: none"> Referral to community resources as needed
36 months	<p>School readiness preparation</p> <ul style="list-style-type: none"> Documentation of Global Developmental Delay Behaviour & management Social development Health checks in place (eyes, dental) 	<p>Coaching:</p> <ul style="list-style-type: none"> Behaviour management reviewed and reinforced Emphasize need for peer exposure and group activities as school preparation Sleep hygiene as it relates to behaviour <p>Intervention:</p> <ul style="list-style-type: none"> Referral to community resources as needed
6-7 years*	<ul style="list-style-type: none"> School Assessment Intellectual Delay/Disability Identify learning disability\ Identify attention issues/executive issues Developmental coordination disorder 	<p>Coaching:</p> <ul style="list-style-type: none"> School resources, process and legal rights Resources for learning and attention <p>Intervention:</p> <ul style="list-style-type: none"> Referral for further testing (ideally through Ministry of Ed) Identify concerns to school

*This visit is currently undertaken by 3 NFUCs in the province. For clinics that are not able to include this visit it is important that they work with local partners and resources to ensure that there is follow-up of these children at 6-7 years of age.

The Role of Intervention in Neonatal Follow-Up Clinics

Neonatal Follow-Up Clinics are not just a tool for surveillance. They provide anticipatory guidance, proactive instruction, self-advocacy, referral to resources and resource navigation.

Recommendation 4 – The intervention provided by NFUCs 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.

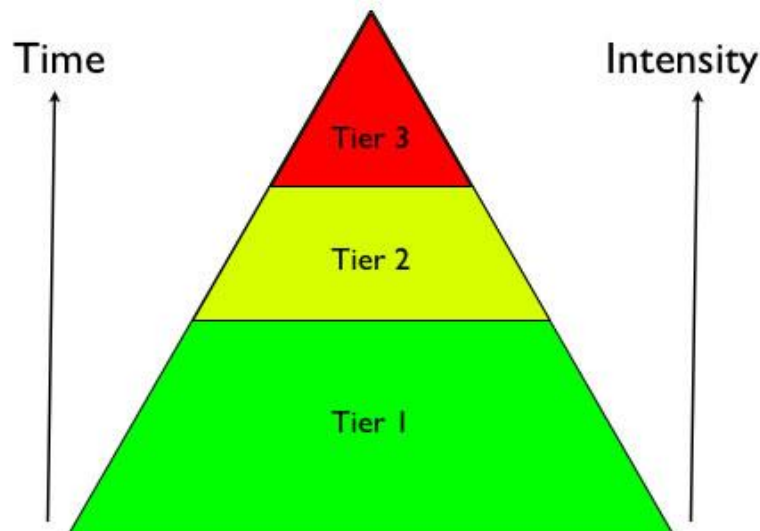
Intervention can take many forms. The most basic and yet effective format is through teaching the parents about their child's temperament, strengths and challenges in the context of the child's admission to the NICU. Using this information, parents can be taught strategies (specific exercises, community resources available to access, system navigation tips) to capitalize on the child and family's strengths and to support the child in achieving skills despite individual or family challenges. This type of anticipatory guidance and parental coaching has proven to be efficient and cost effective and is one focus of NFUCs¹³.

Levels of Intervention

Tier 1: Anticipatory Guidance provided through NFUCs

Tier 2: Referral for community resources such as therapy or early intervention

Tier 3: Individualized intensive services for those identified as in need (i.e. referral to treatment centre)



For those needing greater support, NFUCs should make prompt referrals to access community resources. For those children presenting with greater or specific degrees of challenge, referral may be

made to Children's Treatment Centres (CTCs) for more intense, individualized support over a longer period of time. The NFUCs should provide a bridge for the family and the child from the acute care setting to the community. See appendix E for guidelines for referral to CTCs.

Quality Assurance and Data Collection

Through information gathered at every visit, the developmental and functional levels of children assessed at NFUCs can be collated and organized to inform the local NICU, as well as the provincial and the national stakeholders about the outcomes of these children. Examination of outcomes yields critical information on the effect of care provided and trends developing, and offers direct feedback for quality improvement.

Recommendation 5 – Data collection should occur at select developmental touch-points, with standardized assessment tools. A committee of experts should be struck, including BORN Ontario and Canadian Neonatal Follow-Up Network (CNFUN), to determine the touch-points at which to collect data, the data to collect from these visits, and the assessment tools that should be used.

As noted in the current state analysis much of the data collection currently underway is not standardized – it does not take place at standard times or with standardized tools. In addition, it takes place in clinic specific databases thereby making cross clinic analysis unfeasible. A method by which to collect a standard dataset from all clinics is key to ensuring quality assurance in neonatal follow-up care across the province.

BORN is currently working with the Canadian Neonatal Network to incorporate Level III NICU data into their data holdings. This opens the opportunity for discussion regarding the potential inclusion of neonatal follow-up data. Such a database would permit provincial analysis across clinics and would be fundamental in creating a quality assurance mechanism for NFUCs.

Participation in network databases allows for important evaluation of outcomes. Through collaboration at provincial and national levels, a larger cohort of children with varying conditions can be examined with attention to potential confounders. This provides essential feedback regarding potential interventions in the NICU that are proven safe and may be beneficial (i.e. caffeine, limited systemic steroids) and allows for examination of other trends.

Ongoing Communication and Education for Neonatal Follow-up Clinicians

Through the course of the NFUC-WG, ongoing discussion arose regarding the lack of communication, collaboration, education, and shared resource space available for NFUC clinicians. This includes the inability to readily/easily contact clinicians in other NFUCs regarding patients, a lack of an electronic resource for sharing materials and resources across NFUCs, a lack of a mechanism to share learning and educational opportunities across NFUCs. In order to foster and support ongoing communication, collaboration and education amongst NFUCs the NFUC-WG makes the following recommendations:

Recommendation 6 – Create an online forum for ongoing communication, collaboration and education amongst NFUCs and their clinicians. This should include a central contact list for NFUCs in the province to ensure timely and consistent contact between NFUCs and to facilitate communication in the shared model of care, as well as an online repository whereby NFUC clinicians can share clinical and educational materials as well as conference opportunities with colleagues throughout the province.

Broader System Recommendations

NFUCs are a component of a larger system of care that addresses the needs of infants and children who have or are at risk of having a physical, developmental and/or behavioural disability. Their role within this system is essential and local collaboration with the Ministry of Education, Children's Treatment Centres and Infant Development is important in facilitating transitions and providing background and context for this population.

The following recommendations are broader system recommendations beyond the scope of solely the NFUCs. The role of the NFUCs in these recommendations, however, demonstrate the longer-term impact NFUCs can have on the outcomes of the infants and children they address.

Promoting Optimal Social and Scholastic Performance

The majority of the children born preterm will not be identified as having a clear disability during their time in neonatal follow-up however, the medical community recognizes that these survivors are often left with developmental challenges. These children are at risk of falling through the cracks as they do not qualify for direct treatment and the identification of the patterns of challenge requires specific and informed surveillance. If left without monitoring, these children's challenges create increasing dysfunction, require greater allocation of school resources and contribute to school failure.¹⁴

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

Currently there are three NFUCs in the province that provide neonatal follow-up to school aged children identified as at risk for school failure. These clinics follow children into school entry and provide services that emphasize assessment and identification of early school readiness skills. While this is not the standard of care and is not feasible to implement across the province, these NFUCs are valuable resources of expertise and service provision and can represent a resource to the community, the local educational system, and the province.

Where follow-up to school age is not possible NFUCs should initiate local conversations and collaborations with other health service and educational providers to develop local solutions that take advantage of local resources/partnerships.

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).

Prematurity is defined as birth less than 37 completed weeks gestation. A critical characteristic of premature delivery is neurologic immaturity of increasing significance with decreasing gestational age. Despite that, and the extensive data confirming that these children demonstrate an increased risk of school failure and grade retention, the practice in Ontario has been and remains one of enrolment by birth date. For children delivered preterm at the end of the calendar year, with an anticipated confinement date of early in the upcoming year, this practice results in the highest risk child being enrolled by his or her birth date, being the youngest in the class neurodevelopmentally by over a year.

There is a benefit to early peer exposure and opportunity to participate in a structured curriculum. This recommendation would support that any child who enrolls in school based on their corrected age still have the opportunity for peer exposure via enrolment in a daycare setting, or an extra year of kindergarten if the school allows.

Recommendation 9 – Linkages between NFUCs 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.

Currently, there is no system in place to share the vast information collected about a child's learning style, strengths and challenges between the NFUC and the educational system. Links are needed to better facilitate transition to the educational system and to avoid gaps in service or unnecessary duplications in assessments. Furthermore, there is an identified gap in knowledge for educators about the issues of children born preterm¹⁵

In addition, parents are often reluctant to identify that a child was born preterm fearing that the label might lead to marginalizing their child unnecessarily, adding to the challenge for the educator.

The result of this is a 'perfect storm' resulting from missed opportunities for knowledge sharing with educators and ongoing developmental vulnerability and dysmaturation mistaken for developmental variability in children. Failure to identify and respond to the special needs of these children in a timely manner can lead to a cascade of failure and frustration that ultimately results in unmet potential and increased costs to the system.

As a result, there is an urgent need to alert the educational system to this knowledge gap, to leverage existing resources at an individual and system level (through collaborative relationships with NFUCs and Early Intervention programs), and to educate the educators on this developmental pattern. Linkages could be established at the individual level with schools having access to the NFUC contact list to allow for them to reach the appropriate clinic and person without excessive effort.

It also is needed at the system level with greater education and awareness of this pattern through education sessions, written material, and references.

Summary of Recommendations

The NFUC-WG makes the following recommendations to standardize practice and optimize the neonatal follow-up system in the province:

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 NFUCs. If a NFUC is unable to provide neonatal follow-up, arrangements must be made by the hospital of birth to provide referral to a NFUC within a reachable distance for the family following a shared care model.
Recommendation 3 – All NFUCs 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 NFUCs 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 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 NFUCs and their clinicians. This should include a central contact list for NFUCs in the province to ensure timely and consistent contact between NFUCs and to facilitate communication in the shared model of care, as well as an online repository whereby NFUC 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 NFUCs 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 NFUCs 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.

Conclusion

The NFUC-WG has developed a series of recommendation to improve and better standardize neonatal follow-up in the province. It is recognized that NFUCs are one component of a larger system of care in Ontario that addresses the needs of infants and children who are at risk of having, or who have a physical, developmental and/or behavioural disabilities, however their potential to impact the long-term wellbeing of these children is significant.

Moving forward, the NFUC-WG should explore strategies, collaborations, and systems to provide optimal surveillance, identification, and response to these fragile children throughout their childhood. This should come in the form of aligning with existing resources and educating on the unique features of these children's behavioural patterns and sharing of information and resources to best provide care for these families and children.

Acknowledgements

PCMCH would like to thank and acknowledge all those who participated in and supported the work of the NFUC-WG:

Dr Paige Church, Director, Neonatal Follow-Up, Sunnybrook Hospital, NFUC-WG Co-Chair

Dr Vincent Ho, Director of NICU and Neonatal Follow-Up Clinic, Royal Victoria Regional Health Centre, NFUC-WG Co-Chair

Doreen Day, Senior Project Manager, Provincial Council for Maternal and Child Health

The members of the NFUC-WG Work Group

Also, thank you to Stephannie Leveillé, Speech Language Pathology Student, Laurentian University, for assisting with the review of assessment tools.

Appendix A –Neonatal Follow-Up Work Group Terms of Reference



Provincial Council for Maternal and Child Health Maternal-Newborn Advisory Committee Neonatal Follow-Up Clinics Work Group Terms of Reference

Background:

The Maternal-Newborn Advisory Committee (M-NAC) of the Provincial Council for Maternal and Child Health (PCMCH) has requested a work group be convened to examine the current state of neonatal follow-up clinics across the province, to identify any gaps or variations in practice and to make recommendations aimed at strengthening the system of neonatal follow-up for the province.

Purpose:

To convene a panel of experts in neonatal care to provide a comprehensive understanding of the current neonatal follow-up system within Ontario and to identify the variations that exist between the clinics and the gaps within the system. The work group will also be charged with making recommendations to optimize the system for neonatal follow-up across the province.

Objectives:

The Neonatal Follow-Up Clinic Work Group will:

- Define the current state of neonatal follow-up clinics including:
 - Access
 - Patient inclusion criteria
 - Scope of practice
 - Human resources
 - Data collection
- Make recommendations regarding:
 - Mandate and scope of practice for neonatal follow-up clinics
 - Clinical practice
 - Human resources
 - Data collection and utilization to inform neonatal care

Accountability:

The Work Group will report to the Maternal-Newborn Advisory Committee of PCMCH.

Membership:

In order to ensure a comprehensive approach, Work Group members will be chosen from Neonatology, Developmental Medicine, Paediatrics, primary care, and the Ministry of Child and Youth Services. Members will represent the level of care, geographical and professional diversity of the stakeholders involved and/or interested in the work of Neonatal Follow-Up Clinics.

Members:

- Clinicians who work in Neonatal Follow-Up Clinics and/or Neonatal Intensive Care Units.
- Developmental Paediatrics Clinicians
- Primary Care Clinicians
- Representation from the Ministry of Child and Youth Services, 18-month Enhanced Well Baby Visit

Decision Making Process:

Members share accountability for decisions. There should be open and direct communication based on honesty, respect and transparency, to ensure that all perspectives are heard. Decisions should be evidence or most-promising practice based. Decisions will be made by consensus whenever possible. If voting is required, all members will have one vote.

Conflict of Interest:

Members of the Work Group shall disclose, to the co-chairs of their group, without delay, any actual or potential situation that may be reasonably interpreted as either a conflict of interest or a potential conflict of interest.

Communication and Confidentiality:

Work Group material should be treated as confidential. It will be clearly stated when this material is no longer confidential.

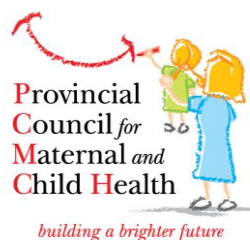
Meeting Schedule:

TBD

Timeline:

October 2013 – June 2014.

Appendix B – Neonatal Follow-Up Work Group Membership



Provincial Council for Maternal and Child Health Maternal-Newborn Advisory Committee

Neonatal Follow-Up Clinic Work Group Membership

Title	First Name	Last Name	Job / Title / Function / Demographic	Organization	LHIN
Ms.	Heather	Ryan	Nurse Coordinator, Neonatal Follow-Up Program	Windsor Regional Hospital	1
Ms.	Jamie	Fanning	Physiotherapist	London Health Sciences Centre	2
Dr.	Jane	Gloor	Staff Paediatrician, Developmental Follow-Up Clinic	Children's Hospital, London Health Sciences Centre	2
Ms.	Barb	Flaherty	Clinical Specialist, NICU Network Leader and Neonatal Follow-Up Clinic Coordinator	McMaster Children's Hospital	4
Ms.	Boyd	Heather	Occupational Therapist, Neonatal Follow-Up Clinic (Replacing Barb Flaherty, June 2014)	McMaster Children's Hospital	4
Dr.	El Helou	Salhab	Medical Director, Neonatal Follow-Up	McMaster Children's Hospital	4
Ms.	Mary Lou	Bingham	RN Coordinator, Neonatal Follow-Up Program	Trillium Health Partners	6
Dr.	Paige	Church (Co-Chair)	Medical Director, Neonatal Follow-Up	Sunnybrook Health Sciences Centre	7
Dr.	Linh	Ly	Medical Director, Neonatal Follow-Up Clinic	The Hospital for Sick Children	7
Dr.	Steven	Miller	Division Head, Neurology	The Hospital for Sick Children	7
Dr.	Ed	Kelly	Director, Neonatal Follow-Up Clinic	Mount Sinai Hospital	7
Ms.	Fernanda	Galli	Occupational Therapist	St. Joseph's Health Centre, Toronto	7
Dr.	Colleen	Doherty	Paediatrician, Neonatal Follow-Up Clinic	Southlake Regional Health Centre	8
Dr.	Marilyn	Ballantyne	Chief Nurse Executive & Clinician Investigator	HollandBloorview Kids Rehabilitation Hospital	N/A

Dr.	Golda	Milo-Manson	Vice President, Medicine and Academic Affairs	Holland Bloorview Kids Rehabilitation Hospital	8
Dr.	Shaheen	Doctor	Medical Director, Neonatal Follow-Up Clinic	North York General Hospital	8
Ms.	Lorraine	Smith	Occupational Therapist - Coordinator	Kingston General Hospital - Child Development Centre, NICU Follow-up Clinic	10
Dr.	Jana	Feberova	Neonatologist	Children's Hospital of Eastern Ontario	11
Ms.	Carol	Lenz	Nurse Coordinator, Neonatal Follow-Up Program	Children's Hospital of Eastern Ontario	11
Dr.	Michelle	Gordon	Paediatrician	Orillia Soldiers' Memorial Hospital	12
Dr.	Vincent W. G.	Ho (Co-Chair)	Medical Director of NICU and Neonatal Follow-Up Clinic	Royal Victoria Regional Health Centre	12
Ms.	Roxanne	Belanger	Speech Language Pathologist, Neonatal Follow-Up Clinic	Health Sciences North	13
Ms.	Nancy	Novak	Program Consultant, Youth Development Unit	Ministry of Children and Youth Services	N/A
Ms.	Doreen	Day	Senior Project Manager	Provincial Council for Maternal and Child Health	N/A

Appendix C – Neonatal Follow-Up Levels of Care

Levels of Neonatal Follow-Up Care				
Level	Definition	Admission Criteria	Goal	Resource Requirements
I IIa IIb (Primary/ Community Care)	Low risk of neuro-developmental impairment	<ul style="list-style-type: none"> GA 34+0-36+6 wks BW >2000g BW >3rd Percentile Healthy infants Uncomplicated neonatal course No history of maternal drug use OR some drug exposure but no withdrawal and do not get treatment	<ul style="list-style-type: none"> All premature infants have the opportunity for early developmental screening All low risk babies get screened by 18-months Routine developmental care by primary care practitioner 	<ul style="list-style-type: none"> Primary care physician/nurse practitioner or general pediatrician (for screening) Notes: <ul style="list-style-type: none"> Level IIc NFUC consult is available for early concerns in infants under 8 months. Referral to a paediatric consultant, to children's treatment centres or early intervention can be made depending on age and available resources. Those with complex developmental issues that cannot be adequately assessed or who require multidisciplinary consultation could be considered for referral to a LII NFUC.
IIc (Regional)	Low-moderate risk of neuro-developmental impairment Focus on early assessment and major morbidities: <ul style="list-style-type: none"> Vision 	<ul style="list-style-type: none"> GA >30+0 to 33+6wks BW <3rd percentile or Head Circ <3rd percentile Hyperbilirubinemia – Severe > 425 µmol/L or exchange transfusion Symptomatic Hypoglycemia <2.2mmol/l over 6 hours, requiring intensive care 	<ul style="list-style-type: none"> Screening, diagnosis, education, coaching (not intervention/treatment/traditional therapy), Linkage/referral/ 	<ul style="list-style-type: none"> Access to a physician/ pediatrician knowledgeable in early childhood development Access to therapy support such as a motor-based therapist or interdisciplinary team, i.e. OT, PT, SLP, RN

Levels of Neonatal Follow-Up Care				
Level	Definition	Admission Criteria	Goal	Resource Requirements
	<ul style="list-style-type: none"> Hearing Cerebral Palsy/ Gross Motor Impairment Cognitive Impairment/ Global Developmental Delay Autism Spectrum Disorder 	<p>monitoring and treatment.</p> <ul style="list-style-type: none"> Intrauterine death of one twin (if surviving twin is <36+6wks GA) Maternal drug use/Neonatal Abstinence Syndrome (NAS) requiring pharmacological treatment Meningitis, not requiring Level III care Multiples ≥ 3, >30wks GA Perinatal acidosis (pH<7 plus or Apgar <5 @ 10mins) Sarnat Level 1/Mild neonatal encephalopathy or Level 2 encephalopathy that does not require Level III NUCU Periventricular leukomalacia >30wks GA, up to and including term Seizures – Any neonatal seizure Twin-to-twin transfusion syndrome – requiring laser ablation, born between 30+0 to 36+6 wks GA Moderate/late pre-term infant failing to establish full oral feed at term equivalent 	<p>facilitation to community services, medical subspecialties, therapeutic interventions</p>	

Levels of Neonatal Follow-Up Care				
Level	Definition	Admission Criteria	Goal	Resource Requirements
IIla (Tertiary)	<p>Moderate-High risk of neuro-developmental impairment</p> <p>Extreme-pre-terms and those Children at risk of school-aged issues/ learning disabilities</p> <p>Comprehensive assessments at 18-mos and school age.</p> <p>Ability to collaborate with tertiary level providers</p>	<ul style="list-style-type: none"> GA <30 wks gestation BW < 1250g Bronchopulmonary dysplasia– oxygen dependence / respiratory support at 36 wks corrected GA Hypoxic ischemic encephalopathy Sarnat Level 2 or 3/Moderate or severe encephalopathy Therapeutic hypothermia Intraventricular hemorrhage ≥ Grade III Meningitis – Fungal or Bacterial (excluding staph epidermis) requiring Level 3 support Necrotizing enterocolitis requiring surgery or penrose drain Neonatal stroke Periventricular leukomalacia <30 wks Twin-to-twin transfusion syndrome – requiring laser ablation, born at <30 wks GA Viral encephalitis requiring tertiary NICU care Other: Based on site specific capacity 	<ul style="list-style-type: none"> Developmental surveillance, screening and assessment Diagnosis and intervention (referral, coaching, etc.) Education Research 	<ul style="list-style-type: none"> Developmental pediatrician/ pediatrician, neonatologist, nursing, therapists, psychologist, and potentially a psychometrist with expertise in early childhood and a behavioural therapist. <p>Notes:</p> <ul style="list-style-type: none"> Additional resources/ subspecialty consultations as needed

Levels of Neonatal Follow-Up Care				
Level	Definition	Admission Criteria	Goal	Resource Requirements
IIIb/ Children's Hospital (Quaternary)	<p>Moderate-High risk of neuro-developmental impairment</p> <p>Different subspecialty needs</p>	<ul style="list-style-type: none"> • Congenital diaphragmatic hernia • Omphalocele • Cyanotic congenital heart disease requiring pump or extracorporeal membrane oxygenation within the neonatal period • Extracorporeal membrane oxygenation • Children with medical complexity ≥ 3 subspecialists involved 	<ul style="list-style-type: none"> • Same as Level III • Linkage with sub-specialty services 	<ul style="list-style-type: none"> • Sub-specialists • Interdisciplinary team associated with the diagnoses

Appendix D – Menu of Assessment Tools

Screening Tool Name	Domain	Administration Time	Qualification Required to Use the Assessment	Strengths/ Limitations/ Comments	Age/Visit Timing							
					1 wk	4 to 8 wks	4	8	12	18	36	6 to 7 years
Autism Diagnostic Observation Schedule (ADOS)	Autism	30-45 min	MA (psych, SLP, OT) BA (OT) with license or certification from an agency/organization that requires training and experience in assessment	Strengths: Best diagnostic assessment for autism. Limitations: Time and training required						X	X	X
Ages and Stages Questionnaire 3 (ASQ-3)	Developmental Social/Emotional	10-15 min; 1-5 minutes to score	No training required	Strengths: Easy to use –clear drawings and instructions for families. New version covers all ages correlating with recommended WCC ages. Asks about specific skills, in addition to parent concerns . Limitations: Some studies indicate good identification of severe delay in premature infants; less sensitive with mild delay. Study comparing PEDS with ASQ indicated discordance in children identified by each screen.		X	X	X	X	X	X	
ASQ: Social-Emotional Questionnaire	Social/Emotional	10-15 min	No training required				X	X	X	X	X	
Alberta Infant Motor Scale (AIMS)	Motor	20-30 min	Any health professional with a background in infant motor development and an understanding of the essential components of movement.	Strengths: High risk infants Easy to use Predictive of developmental disability at 9 months. May increase surveillance skills indirectly. Delays in motor development often the first sign easily detectable in global developmental delay. Limitations: Not as discriminating after about 9 months or weight bearing well-achieved. Some training required. Tested on Canadian children. Not necessarily valid for other cultures, Dutch norms significantly different. Preterm infants shown to have different gross motor developmental trajectories which may vary from stated norms.		X	X	X	X	X*	*Only tests skill development until ambulation/ walking	

Screening Tool Name	Domain	Administration Time	Qualification Required to Use the Assessment	Strengths/ Limitations/ Comments	Age/Visit Timing							
					1 wk	4 to 8 wks	4	8	12	18	36	6 to 7 years
Battelle Developmental Inventory - 2 (BDI-II)	Developmental	10-30 min	OT, PT, MD, NP, RN, home health care workers for infants & young children, and head start specialists. And specific undergraduate level training in one or more of the following: Intelligence/Cognitive, testing, basic tests and measurements, speech, hearing, language assessments, education diagnostics, developmental milestone assessment	Strengths: Well standardized 2nd edition normalized tables cover smaller age ranges. Limitations: Higher level of skill needed in assessment. Can be challenging to administer. 4-6 hours of training required. Screening inventory over or under referred. Children who were close to the limits in age bracket. Few items per domain per age bracket.	X	X	X	X	X	X	X	X
The Bayley Scales of Infant and Toddler Development 3	Developmental Motor	30-90 min	PhD (psych, education) or related field with formal training in the ethical administration, scoring, and interpretation of clinical assessments related to the intended use of the assessment. OR, licensure or certification to practice in your state in a field related to the purchase. OR, certification by or full active membership in a professional organization (such as APA, NASP, NAN, INS) that requires training and experience in the relevant area of assessment.	Strengths: Tested in high risk populations. Limitations: Developmental background skills helpful. Training required.						X* *18 to 24 months	X	
Brigance early Childhood Screens	Developmental	10-15 min; 5 min to score		Strengths: 0-2 year old can be done as all parent report Website has training materials Limitations: Developmental background skills helpful Training required	X	X	X	X	X	X	X	X
Child Behaviour Checklist (CBCL) Achenback System	Social/Emotional		No training required	Strengths: Extensive use and reporting Multi-informant with comparative reporting. Limitations: Lengthy for parents to complete Training required for interpretation						X	X	

Screening Tool Name	Domain	Administration Time	Qualification Required to Use the Assessment	Strengths/ Limitations/ Comments	Age/Visit Timing							
					1 wk	4 to 8 wks	4	8	12	18	36	6 to 7 years
Clinical Evaluation of Language Fundamentals/ Preschool (CELF-P)	Language	Level 1: 15-20 min. Entire test: variable.	MA (psych, education, OT, SW) or in a field closely related to the intended use of the assessment, and formal training in the ethical administration, scoring, and interpretation of clinical assessments. OR, certification by or full active membership in a professional organization (such as ASHA, AOTA, AERA, ACA, AMA, CEC, AEA, AAA, EAA, NAEYC, NBCC) that requires training and experience in the relevant area of assessment. OR, a degree or license to practice in the healthcare or allied healthcare field. OR, formal, supervised mental health, speech/language, and/or educational training specific to assessing children, or in infant and child development, and formal training in the ethical administration, scoring, and interpretation of clinical assessments.								X	X
Communication and Symbolic Scales Developmental Profile-Infant Toddler Checklist (CSBS DP)	Language	5-10 min	Caregivers and professionals trained to assess young children (SLP, Early Interventionists, psychologists)	Strengths: Addresses social communication & language issues in children <24 mo. Sensitive to communication delays and identifying children with ASD plus communication delay.				X	X	X		
Child Development Inventory	Developmental	30-50 min	No training required	Strengths: May be more suitable for assessment versus screening. Limitations: Relatively high reading level required Long administration time.						X	X	X
Developmental Coordination Disorder Questionnaire (DCDQ)	Developmental coordination	10-15 min	No training required									X
Early Intervention Developmental Profile	Developmental Social/Emotional Motor Language Cognition					X	X	X	X	X	X	

Screening Tool Name	Domain	Administration Time	Qualification Required to Use the Assessment	Strengths/ Limitations/ Comments	Age/Visit Timing							
					1 wk	4 to 8 wks	4	8	12	18	36	6 to 7 years
Early Language Milestone Scale -2 (ELMS-2)	Language	1-10 min		Strengths: Fairly easy to administer Format and form similar to Denver. Limitations: Small group of children (191) used to establish norms. Not necessarily representative of general population.		X	X	X	X	X	X	
General Movements Assessment of Infants	Motor	10-30 min	Extensive training Required (4-5d training with GMs Trust)/lots of expertise needed	Limitations: Restrictive of age, best used at 2.5mos, does not follow child for long		X	X					
Gross Motor Function Classification System	Motor			Limitations: Is a five-level classification system to determine functional level after diagnosis of CP.						X	X* *Reco mmed betwe en 2-3 years of age	X
Infant Development Inventory (IDI)	Social/Emotional Language Self-help Motor	5-10 min	No training required	Strengths: Easy to use Developmental chart similar to Denver – “visual chart” of milestones for age Limitations: Tool appropriate up to age 18 months only	X	X	X	X	X	X		
Infant Neurological International Battery (INFANIB)	Neurological	Untimed	MA (psych, education, OT, SW) or in a field closely related to the intended use of the assessment, and formal training in the ethical administration, scoring, and interpretation of clinical assessments. OR, certification by or full active membership in a professional organization (such as ASHA, AOTA, AERA, ACA, AMA, CEC, AEA, AAA, EAA, NAEYC, NBCC) that requires training and experience in the relevant area of assessment. OR, a degree or license to practice in the healthcare or allied healthcare field. OR, formal, supervised mental health, speech/language, and/or educational training specific to assessing children, or in infant and child development, and formal training in the ethical administration, scoring, and interpretation of clinical assessments.				X	X	X	X		

Screening Tool Name	Domain	Administration Time	Qualification Required to Use the Assessment	Strengths/ Limitations/ Comments	Age/Visit Timing							
					1 wk	4 to 8 wks	4	8	12	18	36	6 to 7 years
Language Development Survey	Language	10 min	Can be completed by parents							X	X	
Movement Assessment Battery for Children (MABC)	Motor	20-40 mins	MA (psych, education, OT, SW) or in a field closely related to the intended use of the assessment, and formal training in the ethical administration, scoring, and interpretation of clinical assessments. OR, certification by or full active membership in a professional organization (such as ASHA, AOTA, AERA, ACA, AMA, CEC, AEA, AAA, EAA, NAEYC, NBCC) that requires training and experience in the relevant area of assessment. OR, a degree or license to practice in the healthcare or allied healthcare field. OR, formal, supervised mental health, speech/language, and/or educational training specific to assessing children, or in infant and child development, and formal training in the ethical administration, scoring, and interpretation of clinical assessments.								X	X
Modified Checklist for Autism in Toddlers (M-CHAT)	Autism	5-10 min		Strengths: Easy to use Most frequently used autism screener Intended to expand the CHAT to identify a greater range of children with ASD/PDD Limitations: Over identifies children with language and developmental delays Improved specificity with use of follow up questionnaire						X		
Movement Assessment of Infants (MAI)	Motor	30-60 min	No training required		X	X	X	X	X			
McArthur-Bates Communication Development Inventories	Language	20-40 min to complete, 10-15 min to score	No training required					X	X	X	X	
Miller Assessment for Preschoolers (MAP)		30-40 min	MA (psych, SLP, OT, MS, SW, CAGS) OR, BA (OT, BS) in fields listed above & licence or certification from an agency/organization that requires training and experience in assessment.								X	X
The Neurological, Sensory, Motor, Developmental Assessment (NSMDA)	Motor	10-30 min	No training required			X	X	X	X	X	X	X

Screening Tool Name	Domain	Administration Time	Qualification Required to Use the Assessment	Strengths/ Limitations/ Comments	Age/Visit Timing							
					1 wk	4 to 8 wks	4	8	12	18	36	6 to 7 years
Parent's Evaluation of Developmental Status (PEDS)	Social/Emotional Motor Language Self-Help Behaviour Early Academic Skills	2-10 min	No training required	Strengths: Easy to use and short Elicits parent concerns and evidence based guidance on what to do with results Strength may be as a surveillance tool Limitations: Not best tool for high risk population Secondary screener recommended if positive area of concern identified (or referral) May not always be possible to use second level screener – creating risk for under or over referral.	X	X	X	X	X	X	X	X
Parents Evaluation of Developmental Status (PEDS): Developmental Milestones	Social/Emotional Motor Language Self-Help Behaviour Early Academic Skills Psychosocial risk Resilience Autism	3-10 min	No training required	Strengths: Longitudinal scoring, can be followed over time Includes Level 2 screens from PEDS + PEDS:DM e.g MCHAT, Pictorial Pediatric Symptom Checklist behavioural screen and Vanderbilt rating scale. Limitations: Test materials seem somewhat cumbersome Subject to misinterpretation with “sometime” response option	X	X	X	X	X	X	X	X
Peabody Developmental Motor Scales - 2 (PDMS-2)	Motor	45-60 min	OT, PT, EI specialists, diagnosticians, adapted physical education teachers, psychologists, others who are interested in examining the motor abilities of young children.				X	X	X	X	X	
Posture and Fine Motor Assessment of Infants (PFMAI)	Motor	25-30 min	MA (psych, education, OT, SW) or in a field closely related to the intended use of the assessment, and formal training in the ethical administration, scoring, and interpretation of clinical assessments. OR, certification by or full active membership in a professional organization (such as ASHA, AOTA, AERA, ACA, AMA, CEC, AEA, AAA, EAA, NAEYC, NBCC) that requires training and experience in the relevant area of assessment. OR, a degree or license to practice in the healthcare or allied healthcare field. OR, formal, supervised mental health, speech/language, and/or educational training specific to assessing children, or in infant and child development, and formal training in the ethical administration, scoring, and interpretation of clinical assessments.			X	X	X	X			

Screening Tool Name	Domain	Administration Time	Qualification Required to Use the Assessment	Strengths/ Limitations/ Comments	Age/Visit Timing							
					1 wk	4 to 8 wks	4	8	12	18	36	6 to 7 years
Receptive-Expressive Emergent Language (REEL)	Language	20-30 min			X	X	X	X	X	X	X	
Rossetti Infant Toddler Language Scale	Language (Preverbal and Verbal)	Varies	Any member of the infant-toddler assessment team or intervention team regardless of primary academic discipline.		X	X	X	X	X	X	X	
Rourke Baby Record -Physical Assessment Feeding/ Social	Nutrition				X	X	X	X	X	X	X	
Test of Infant Motor Performance (TIMP)	Motor	20-40 min	Instructional DVD available for self-education		X	X	X					
Toddler and Infant Motor Evaluation (TIME)	Motor	15-55 min	No training required				X	X	X	X		
Vanderbilt Assessment Scale	ADHD	10 min	No training required									X
Weschler Intelligence Scale for Children (WISC)	Intellectual abilities	60-90 min	PhD (psych, education) or closely related field with formal training in the ethical administration, scoring, and interpretation of clinical assessments related to the intended use of the assessment. OR, licensure or certification to practice in your state in a field related to the purchase. OR, certification by or full active membership in a professional organization (such as APA, NASP, NAN, INS) that requires training and experience in the relevant area of assessment.									X

Appendix E – Guidelines for Referral to Children’s Treatment Centres

Guidelines for Referral to Children’s Treatment Centres	
Population	Guideline
All Cerebral Palsy/ Gross Motor Impairment	<ul style="list-style-type: none"> Referral to CTC by 12-18 months If concerns for severe and there is an overt motor delay, earlier referral to CTC is warranted If wait times for CTC are long (8-12 months), an interim appointment with the NFUC should be made
Severe/Global Developmental Delay	<ul style="list-style-type: none"> All NFUCs should refer out to: Early Years Centres, Early Intervention, and/or Infant Development in order to ensure services for a minimum standard of care Prior to discharge from NFUC, all referrals to CTC should be followed up by a telephone confirmation that the parents have linked with the CTC If wait times for CTC are long (8-12 months), an interim appointment with the NFUC should be made
Neurosensory Impairment	<ul style="list-style-type: none"> Referral should be made to blind and low vision programs/ ophthalmology or local hearing impairment services (local audiologist can provide guidance) If co-morbid with another developmental disorder refer to CTC
Autism Spectrum Disorder	<ul style="list-style-type: none"> Referral patterns should follow local resources for expedited assessment and services-in many cases this may be the CTC For the extreme pre-term population a confirmatory assessment should be considered
Other Guiding Principles	<ul style="list-style-type: none"> Gaps in CTC services can be supplemented by NFUCs, however there should not be any overlap or duplication of services Children not picked up by a CTC should be followed by an NFUC or another local resource for surveillance Where follow-up to school age by an NFUC is not possible NFUCs should initiate local conversations and collaborations with other health service and educational providers to develop local solutions that take advantage of local resources/partnerships. Preschool assessments should take place prior to the child entering school It is imperative that ongoing dialogue and sharing of resources (i.e. assessment results) between NFUC and CTC takes place

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