



# **18-MONTH CORRECTED AGE ASSESSMENT MANUAL**

**February 2022 VERSION 7**

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## **February 2022 VERSION 7**

### **Highlights of Manual Update:**

- Section A: new variable for infant sex
- Section B: updated variable for caregiver gender
- Section E: added anti-VEGF treatment
- Section F: updated for Bayley 4

## Introduction to the Canadian Neonatal Follow-Up Network

The Canadian Neonatal Follow-Up Network (CNFUN) is made up of neonatal and perinatal follow-up programs in Canada and their multidisciplinary team members. It was developed in liaison with the Canadian Neonatal Network (CNN) to facilitate collaboration in research, integrated data collection and knowledge translation. CNFUN's mission is to be a network of health care professionals dedicated to improving the care of newborns and children at high risk of adverse neurodevelopmental outcomes as a result of perinatal conditions requiring intensive medical care after birth.

CNFUN's goals are to:

- Establish a network of Canadian health care professionals involved in neonatal and perinatal follow-up programs (FUPs)
- Develop a standardized set of validated developmental assessments done at standardized ages with common definitions
- Develop a national electronic database of the CNFUN dataset that is linkable to neonatal and perinatal databases (e.g., CNN)
- Use the CNFUN database to improve health care by providing accurate up-to-date information for decision making, identifying best practices and facilitating the acquisitions of long-term outcomes data in neonatal, perinatal and early intervention research
- Advocate for our population of high-risk children by ensuring that the best evidence is translated into practice

CNFUN involves a standardized assessment done at 18 months corrected age. Research projects may use CNFUN data pending approval of the CNFUN Steering Committee.

## Before Data Collection: Who to Follow and When to Assess

### **Ethics approval**

Each participating site must have ongoing ethics approval from their local Institutional Review Board (IRB or REB). A copy of the approval and annual renewal should be forwarded to the CNFUN coordinator and/or the MiCare office. Templates of the protocol, consent form, and other recruiting aids are available by contacting the CNFUN coordinator.

### **Inclusion Criteria**

CNFUN will follow all Canadian level-III neonatal intensive care unit (NICU) survivors born before 29 weeks gestation (i.e., 28<sup>+6</sup> weeks or less) when they are 18 months corrected age.<sup>1</sup> There may be specific criteria for research projects such as Parent-EPIQ and MiCare.

### **Responsibility for Follow-Up**

The default clinic responsible for tracking patients and follow-up assessments is the program linked to the location of the child's first level-III NICU care. In some cases, it will be necessary to coordinate with other clinics, such as in cases where the child was cared for in more than one NICU or if there is a FUP that is more convenient for the family. FUPs should continue to use their existing protocols for coordinating with other clinics. Please contact the CNFUN coordinator if assistance is needed.

### **Tracking Eligible Patients**

It is crucial that every family with an eligible infant is tracked and offered the opportunity to be a part of the study, regardless of their geographic location, language spoken, or whether their child has complex medical issues and/or is followed by another program or service. At least some details on all eligible infants must be entered into the database for tracking purposes.

Please keep a running master log of babies who meet CNFUN's inclusion criteria. We recommend following the same protocol used by your FUP or clinic to track eligible babies. This likely involves a combination of the following strategies:

- Check the NICU admission and triage logs regularly.
- Prior to discharge (or as soon after discharge as possible), obtain contact information such as the full name of both parents, home address, phone numbers.
- Check with the Canadian Neonatal Network (CNN) Data Abstractor at your site to ensure your master log is complete or generate a list of eligible patients.
- If your clinic has other scheduled follow-up visits with the family, verify contact information and each visit and remind them about the 18-month assessment.
- If your program accepts referrals from another level-III NICU, please ensure that a process is in place to share information on eligible babies.
- Maintain contact with the family at periodic but regular intervals. Some families may move out of your area without notice and may be difficult to track. Try websites such as Canada 411.ca (<http://www.canada411.ca>) or Canpages (<http://www.canpages.ca>) that contain free searchable databases of public phone listings across Canada. Remember to search by both the mother and father's last name.

Research indicates that the most frequent point of drop-out from neonatal follow-up is between NICU discharge and the first scheduled appointment (up to 16% may NOT attend).<sup>2</sup> Screen families in the NICU to identify those at highest risk for not attending FUP visits and intervene early:

Single mothers;

Parents experiencing social, educational, or economic challenges;

Language barriers; and

Families with greater travel distance to follow-up visits.

The second most frequent point of drop-out from neonatal follow-up is following the first appointment. Maintain periodic contact with the families at highest risk for not attending:

Employment outside the home or returning to work;

Social mobility and frequent address changes; and

Language barriers.

### ***Families Who Move To or From Your Area***

There may be situations where you need to transfer CNFUN follow-up from one clinic to another. For example, a family may move to another region or there may be a follow-up clinic in a more convenient location. Try to identify those families as early as possible. Let the family know that follow-up is important, and that their child can be followed at CNFUN- FUP closest to their new location.

If a family is moving out of your area, you should:

Obtain consent for the transfer of medical records and contact information to the new FUP;

Send all relevant medical records (including the CNN unique patient identifier (UI)) and contact information to the new clinic, which must confirm they have contacted the family and will be following the child for CNFUN (and will therefore receive funding for the 18-month assessment).

Email the CNFUN coordinator with the CNN-UI of the patient and confirm the new clinic that will assume responsibility for follow-up. Please do not include any information that would identify the patient such as names or birthdates.

If you become aware that an eligible child is moving into your area, you should:

Verify that the child's date of birth and location of NICU care meet the inclusion criteria.

Contact the original clinic to transfer medical and contact information.

Email the CNFUN coordinator with the patient CNN-UI and confirm the clinic where the patient will be followed. Please do not include any information that would identify the patient such as names or birthdates.

<sup>2</sup> Ballantyne ML. Maternal-Infant Predictors of Attendance at Neonatal Follow-Up Programs [doctoral thesis]. Toronto, ON: The University of Toronto; 2010.

## **Deaths**

If a baby died prior to discharge from the NICU, they should not be included in CNFUN. If a baby died after a CNN NICU discharge but prior to 18 months corrected age, some information should be included in the CNFUN database. Information on the date and cause of death should be obtained from hospital or clinic records; **do not contact the family just to get this information.**

## **18-Month Corrected Age Assessments**

At 18 months corrected age, all babies meeting the inclusion criteria should attend a participating CNFUN clinic for their assessment. The target window for the assessment is when the child is 18-21 months corrected age (except 18 to 36 months corrected age during the COVID pandemic); completing the assessment as close to 18-months corrected age as possible is preferable.

If the family cannot attend the clinic during this window, the assessment may be completed earlier or up to 24 months corrected age. This should be used only in extenuating cases, such as when families live at a substantial geographic distance from the follow-up clinic and cannot attend earlier.

## **Obtaining Informed Consent**

The procedure for obtaining consent will vary by program and REB requirements. CNFUN clinics must ensure these requirements are met. Templates for consent forms and recruitment brochures are available by contacting the CNFUN coordinator. All documents that will be shared with families must be approved by your IRB prior to use.

Clinics may send the consent form to the parents in advance of the appointment, either by mail or (if applicable) at an earlier clinic date. Alternatively, parents/guardians could review and sign the consent form in the clinic prior to their appointment starting. It is imperative that parents have sufficient time to read the consent form and ask questions before the assessment begins.

If a baby is not normally followed by your clinic, it is recommended that a clinic nurse or coordinator mention the study to the parents and/or provide preliminary information (such as a brochure) when the infant is in the NICU. More detail should be provided closer to the time of booking the clinic appointment.

If a family does not consent to participate, some basic information must be entered into the database for tracking purposes.

## **Scheduling Appointments**

CNFUN's goal is for a follow-up rate of at least 80% of eligible patients. All attempts should be made to assess each eligible child between 18-21 months corrected age. Parents or guardians should be contacted at least three times via telephone, mail and/or email. If an appointment needs to be rescheduled, all attempts should be made to ensure that it is rescheduled within the acceptable time frame.

Flexibility will be important to reduce burden on the family and the FUP. In cases where a clinic visit is not possible, alternate measures to obtain information should be made. The Families with Special Circumstances section outlines possible strategies.

## **Overview of the Assessment**

FUPs are responsible for ensuring that appropriately trained and experienced personnel complete the assessment. The team involved will depend on the make-up of each FUP and will likely involve a combination of different health care professionals, such as nurses or nurse practitioners, neonatologists or pediatricians, psychologists or psychometrists, physical or occupational therapists, etc.

### **Section A: 18-Month Status**

This section contains identifiers, some demographic information and follow-up status. It serves to track all eligible participants. Data will be obtained from a combination of hospital records and the Canadian Neonatal Network (CNN) database.

### **Section B: Family**

This section captures demographic information about the child's family and primary caregivers.

### **Section C: Medical History and Examination**

This section provides information on the child's medical history and status at the time of the visit. A follow-up nurse, nurse practitioners, pediatrician or suitably trained delegate should obtain the history of the child and family. Ideally, information obtained from caregivers should be checked by reviewing the child's medical chart.

The physical and neurological examination should be performed by a health professional with adequate training and experience in the neurodevelopmental assessment of extremely preterm infants. It is expected that physicians have expertise in performing neurological examinations.

### **Section D: Auditory Assessment**

This section uses information from audiology reports completed by the time of the 18-month assessment. If an audiologist visit is not part of your standard clinical protocol at 18 months corrected age, you may enter information from any report completed prior to the visit or one that is completed after the assessment but within the specified time period if results are available to you.

### **Section E: Visual Assessment**

This section uses information from ophthalmology reports completed by the time of the 18-month assessment. If an ophthalmologist visit is not part of your standard clinical protocol at 18 months corrected age, you may enter information from any report completed prior to the visit or one that is completed after the assessment but within the specified time period if results are available to you.

### **Section F: Psychological Assessment**

The focus of this section is the Bayley Scales of Infant and Toddler Development (Bayley- III or 4). Clinics are responsible for ensuring their Bayley examiner meets the publisher's qualification requirements, is well-trained and experienced with the Bayley and in the testing of young children.



## Families with Special Circumstances

The goal of CNFUN and the MiCare project is to create a national database that captures outcomes for all children born at <29 weeks gestation. In order to accurately study how biological, sociodemographic, environmental and treatment outcomes vary across the country, it is imperative that all eligible infants are followed and given the opportunity to participate. Some strategies routinely used by FUPs across Canada to help recruit families with special circumstances include the following:

### ***Families that live in Rural or Remote Areas***

There are several strategies that can be used for families that live in rural or remote areas that may make it difficult for them to attend clinic appointments:

Travel clinics: If your clinic holds travel clinics at outlying areas, 18-month corrected age assessments can be done at that time.

Facilitate travel: A FUP may be able to facilitate travel to a clinic appointment by negotiating with First Nation Bands (or use existing arrangements made with your hospital), or obtaining funding through charitable organizations such as your hospital's foundation or travel organizations such as [Hope Air](#). Your provincial government may have arrangements such as the [BC Family Residence Program](#) or the [Travel Grants program](#) for residents of northern Ontario.

Telephone interviews: If, despite attempts to make arrangements, the family has provided consent for the study but is still unable to attend a FUP, you may try to obtain as much information as possible over the telephone or a virtual appointment from parents and/or a community health provider.

Telecommunication technology (e.g., Telehealth): Some regions can provide follow-up in collaboration with community health care providers.

Flexible scheduling

### ***Children with Severe Delays or Complex Medical Issues***

It is important that children who have already been identified as having significant delays or complex medical issues are included in CNFUN. For these children, some parts of the clinic visit may need to be modified (i.e., it may not be appropriate to complete the Bayley) in order to meet the child's needs.

### ***Children Assessed by a Non-CNFUN Clinic or Program***

Some children who meet the CNFUN criteria may be followed by a non-CNFUN clinic, program or service. Because they are eligible, they must be included in CNFUN. If you are able to obtain some data from the other program or service, you can reduce the length of the time needed for the 18-month assessment or eliminate it completely. However, you **must** ensure that parents or guardians have provided informed consent and that the other clinic or program uses the same definitions as CNFUN prior to entering data.

### ***Language Barriers***

When the child's primary language differs from the official language(s) used by the CNFUN site, they should be assessed in the presence of a professional interpreter. If the examiner is fluent in the child's primary language, he or she may assess complete the assessment in that language. Parents or other close relatives are not optimal interpreters.

## **The MiCare Project (Birth Cohort April 1, 2009 – Sept 30, 2011)**

CNFUN is one of several national research networks participating in the CIHR Team in Maternal-Infant Care (MiCare) project awarded funding in 2008. The MiCare research program was designed to improve outcomes and reduce costs through a better understanding of how different practices and risks affect long-term outcomes of preterm infants, and how improved methods of knowledge translation can enhance quality of care.

CNFUN's role in MiCare was to establish for all babies born at less than 29 weeks gestation, a standardized set of neurodevelopmental assessments to be done at 18 months corrected and a questionnaire to be completed at 36 months corrected age.

The CNFUN database can be linked with other participating networks such as the [Canadian Neonatal Network \(CNN\)](#) and the [Canadian Pediatric Surgery Network \(CAPSNet\)](#) to create the MiCare database. This will link population-based sociodemographic, clinical practice, outcomes and resource- use data for neonates and infants from birth to infancy and developmental follow-up. This unique, integrated database will enable study on how the interactions between determinants, mechanisms and processes of care affect pregnancy and infant outcomes over the short- and long-term.

### ***MiCare Inclusion Criteria***

Infants born at less than weeks 29 gestation between April 1, 2009 and September 30, 2011 who were treated in a Canadian level-III NICU. Every potential participant in this cohort must be tracked. Our target rate of follow-up for this cohort is a minimum of 80% of all eligible participants. The 18-month corrected age assessments should take place between (approximately) January 2011 and June 2013.

MiCare continued to recruit participants for individual sites without additional funding for births October 2011 onwards, where feasible.

## **Parent-EPIQ Project (Birth cohort July 1, 2016 – June 30, 2019)**

Parent-EPIQ, a study funded as part of the CHILD-BRIGHT Canadian Institute for Health Research “SPOR” (Strategy for Patient Oriented Research) uses the CNFUN foundation, the Evidence based Practice to Improve Quality (EPIQ) and knowledge translation to evaluate whether proven strategies of early family-integrated interventions to improve cognitive and language abilities embedded in Neonatal Follow-Up Programs can reduce the burden of low Cognitive and Language Composite scores on the Bayley-III at 18-21 months corrected age. Parents are integrated into EPIQ teams from ten participating CNFUN sites. Parental input will be elicited broadly to identify the outcomes which should be collected and reported within CNFUN and how neurodevelopmental impairment should be defined. The 2018 manual revision incorporated a question for parents regarding their perception of whether their child has a developmental impairment and if so, the severity.

## Canadian Preterm Birth Network (CPTBN)

CIHR funded grant preterm birth network to include the Obstetric and the Maternal-Fetal Medicine community to provide data from pregnancy up to 18-21 month post-delivery follow-up, with complementary initiatives to improve both short term (NICU) and long term (CNFUN) outcomes. CNFUN is integral to this study to measure the effect of perinatal strategies on early childhood outcomes.

## CNFUN Database

The CNFUN database was developed by the Database Working Group and created by the MiCare coordinating centre using the work of the *Consortium Québécois de recherche sur les enfants extrêmement prématurés* as a foundation. A collaborative method of review and development was used in order to ensure that the dataset is nationally relevant and to facilitate linkage with other sources.

### **Features of the CNFUN database**

*Mandatory and optional variables:* Mandatory data fields must be completed before the case can be validated and uploaded to the MiCare Coordinating centre. All variables are mandatory unless the definition is in a shaded grey box in this manual, or they appear in regular text (i.e., not bold) in the database. In those cases, variables are optional and do not need to be entered in order to validate and upload the case.

*Language options:* Users may change their settings to display the database screens in English or French.

*Customization:* Users may change the display settings for searches as well as date and time fields according to their preference.

## System Requirements & Installation

To use the CNFUN database, the following system requirements must be in place:

### **Software requirements:**

- Windows XP SP2 (Windows 2000 not supported)
- NET Framework 3.5
- Microsoft Access 2000/2003

### **Hardware requirements:**

- Pentium 2.4 GHz and above
- 512 MB memory and above
- Screen resolution of 1024 x 768 and above

Instructions for users on how to install the database were included with the database release. If you would like another copy, please contact the CNFUN coordinator.

## Linkage with CNN

One of the CNFUN database main features is its ability to link with the Canadian Neonatal Network (CNN) database. This will allow analysis of the relationships between neonatal and perinatal variables (including NICU interventions) as well as early childhood outcomes.

Data will be linked using the Unique Identifier (UI) issued at the time of initial entry in the CNN database. Each baby should have only one UI, even if he or she was transferred between NICUs. Linkage will occur at the MiCare coordinating centre after the data has been entered and uploaded.

In order for this linkage to occur, CNFUN-FUPs will have to obtain some data from the CNN database at your local site. It is a good idea to identify someone in your FUP to liaise with your site's CNN Data Abstractor or Site Investigator (or the CNN contacts at the sites from which your program received referrals) and create a process to easily share information. If you don't know who the CNN Abstractor is at your site, please consult the [CNN website](#) .

The following fields need to be obtained from the CNN Data Abstractor:

CNN unique identifier (A1)

Date of birth (A3)

Gestational age (A4)

Birth weight (A5)

### **Data Collection**

Data collection will be conducted either by follow-up chart review or by collecting data in real-time. Preferably, data will be entered directly into the CNFUN database, in order to help save time and reduce the risk of error.

In some cases, clinic staff may find it easier to record data on paper during the assessment and enter it into the CNFUN database at a later time. Information on data entry forms can be found in the list of resources in Appendix C.

### **Data Entry**

Instructions for data entry and general database use are available in English and in French on the CNFUN website.

Each site should develop a system that works for their particular circumstances. It is strongly recommended that one person at each clinic take on the responsibility for CNFUN data entry.

### **Data Checks**

The database application has several error checking systems in place. The program performs error checks during data entry, to help ensure accurate data capture. For instance, there are automatic validity checks (i.e., if you enter 66:66 for a time, the computer will generate an immediate error message prompting you that this is not a valid entry). Also, once you have completed the entire patient file and are ready to submit your data, a final validation will be performed and a list of errors (if any) will be generated. Finally, a check occurs after your data has been submitted to the MiCare office, in which you may be contacted to confirm any unusual entries.

If you receive an error message that is not self-explanatory or have any questions about how to enter values, please contact the CNFUN coordinator.

## **Uploading Data**

Uploading data means sending it electronically to the MiCare coordinating centre. You should upload your data on a regular basis (i.e., at least monthly). On occasion, the CNFUN coordinator will ask all sites to enter all available data and upload it by a certain time. This is followed, so CNFUN can compile a national database using data from all sites.

Detailed instructions on uploading data are available on the CNFUN website. If you have any questions, please contact the CNFUN coordinator.

## **Confidentiality**

There are several levels of confidentiality that must be maintained. Firstly, the data in the site computer contains personal health information about patients. To maintain full confidentiality, no personal identifiers (except date of birth which is considered a unique identifier in some provinces) are transmitted to the coordinating center. The coordinating center will be able to identify patients by their CNN-UI, but only the personnel at the local site will be able to match that number to a specific patient.

For data confidentiality and accountability, each abstractor will be issued a user ID and password, only known to him or her to log in to the application. Every record created or updated using a given user ID will be marked in the backend database with that user ID and the created/updated date. This audit trail information can be used for security purposes as well as quality improvement.

## CNFUN Data Entry Definitions

Following are the definitions for the CNFUN database, organized by section. All variables are mandatory unless they are shaded in grey, in which case they are optional (e.g., not required to validate a case). If, after reading the definitions, you are still unsure how to code something, please contact the CNFUN coordinator.

### Section A: 18-Month Status

**Section A: 18-Month Status**

**A1a: CNFUN unique patient identifier** F00000004

**A1b: CNN unique patient identifier**

A2a: First Name

A2b: Last Name

A2c: Hospital Number

**A3: Date of birth** [Enter Date]

**A4: Gestational age**  Weeks  Days

**A5a: Birth weight (g)**

**A5b: Sex**

Male

Female

Intersex

Unknown

**A6: First Level III NICU hospital**

If Other, please specify

**A7: Date of discharge home** [Enter Date]

**A8: Weight at discharge home (g)**

**A9: NFUP responsible for follow-up**

**A10: Reason for follow-up**

MiCare (<29 weeks GA at birth)

Congenital Diaphragmatic Hernia (CDH)

Hypoxic-Ischemic Encephalopathy (HIE)

Local FUP criteria

Other

**A11: Current postal code (first 3 characters only)**

**A12: Date of visit** [Enter Date]

**A13a: 18-month follow-up status**

Seen

Seen but incomplete

Not seen

Declined/consent not obtained

No contact information

Unable to reach

Missed appointment

Deceased

Other

Hospital records that FUPs use to track patients and the CNN database are the two main sources of information needed in order to complete Section A. Identifying information such as the infant's name and hospital identification number are optional and are for the use of the local site only. They will not be uploaded to the MiCare office or included in the national database with the rest of the data.

The CNN Unique Patient Identifier (UI) is a coded number assigned to the infant at the time of entry into the CNN database. It will be uploaded to the MiCare office in order to link the child's follow-up CNFUN data with NICU data. You must obtain this number from your site's CNN abstractor.

### Children who do not receive CNFUN follow-up

Follow-up clinics are responsible for abstracting every eligible infant into the CNFUN database, regardless of whether they are followed for CNFUN or not. It is important to track all eligible children, so we understand why some infants are not being followed. The only entry required for these patients is the mandatory fields of Section A.

<b>A1a: CNFUN unique patient identifier</b>	The CNFUN unique patient identifier (CNFUN-UI) is a generic number automatically assigned by the program. No data entry is required.
<b>A1b: CNN unique patient identifier</b>	Obtain the CNN unique patient identifier (CNN-UI) from the CNN Abstractor at your site. The CNN-UI will be used to track this baby and to link records between databases. Each baby will only have one UI, even if she/he was transferred between NICUs. The UI that should be used is the one generated at the hospital of the baby's first admission.  If this patient is not eligible for the MiCare study, then the UI is optional.
<b>A2a: First name</b>	These variables are optional and to be used for tracking purposes at the local site only. Data will be stored on your hospital server and will not be uploaded to the MiCare office.
<b>A2b: Last name</b>	
<b>A2c: Hospital number</b>	
<b>A3: Date of birth</b>	Enter the child's date of birth.
<b>A4: Gestational age</b>	Obtain the baby's gestational age (GA) in weeks and days. If possible, please obtain the GA from your site's CNN database. CNN calculates the GA according to an algorithm that uses data on the last menstrual period, expected date of confinement, early ultrasounds as well neonatal and obstetric estimates as inputs.  If the GA from the CNN is different from the records your follow-up program has and would use clinically, please enter the GA used by the follow-up program.
<b>A5a: Birth weight</b>	Obtain the child's birth weight (grams). If a birth weight is unavailable, use the first weight taken in the first 24 hours of life. If the only weight available in that time period is an estimate, please record the estimate. If possible, please obtain the birth weight from your site's CNN database.
<b>A5b: Sex</b>	Check one from the following list: <i>Male, Female, Intersex, Unknown</i> Sex refers to sex assigned at birth.
<b>A6: First level-III NICU hospital</b>	Select from the drop-down list. If the child was not cared in one of the hospitals on the list, select <i>Other</i> .
<b>A7: Date of discharge home</b>	This variable is optional. Enter date the child was discharged home from the last hospital. Try to obtain this information from discharge summaries or hospital records first before obtaining from parents.
<b>A8: Weight at discharge home</b>	This variable is optional. Enter the last weight (grams) obtained within 5 days prior to discharge from the last hospital. Try to obtain this information from discharge summaries or hospital records first before obtaining from parents.  In Québec, this can often be found in the child's vaccination booklet.
<b>A9: NFUP responsible for follow-up</b>	Select the Perinatal or Neonatal Follow-up Program (NFUP) that is responsible for the child's follow-up from the list. When a family is unable to attend a CNFUN clinic due to geographic distance, the NFUP responsible for follow-up may not actually see the child. More details on where the child was assessed will be entered in Section C.
<b>A10: Reason for follow-up</b>	Select all that apply: <i>MiCare: Born at &lt; 29 weeks GA.</i>  The following options have been built into the database for possible future projects. Entry for cases meeting these criteria is completely optional and data <b>will</b> not be uploaded to the MiCare Coordinating Centre. CNFUN will only ask sites to enter these cases after a protocol has been defined and IRB has been obtained.

	<p><i>Congenital Diaphragmatic Hernia (CDH)</i>: The child was diagnosed with CDH within the first 7 days of life.</p> <p><i>Hypoxic-Ischemic Encephalopathy (HIE)</i>: The child was diagnosed as HIE during his or her NICU course. This information will be used as part of a registry on cooling used on patients with HIE in partnership with CNN.</p> <p><i>Local FUP criteria</i>: The child meets your FUP's inclusion criteria.</p> <p><i>Other</i>: Select and specify if applicable.</p>
<b>A11: Current postal code</b>	Enter the first three characters of the postal code where the child currently resides. The variable is optional.
<b>A12: Date of visit</b>	Enter the date of the child's assessment. If it took place over more than one day, enter the date when most of the data was collected. If the child did not visit a CNFUN clinic and the information is being obtained by other means (i.e., phone interviews, records from family physician, etc.), enter the date that these records were obtained.
<b>A13a: 18-month follow-up status</b>	<p>Check one from the following list:</p> <p><i>Seen</i>: Select if the child has been seen in clinic (or by a health professional outside the CNFUN clinic) and the assessment is complete.</p> <p><i>Seen but incomplete</i>: Select if the child came to clinic but the assessment was not completed (because family had to leave, child was noncompliant, etc.)</p> <p><i>Not seen</i>: If the assessment was not attempted. If you select this option, you must specify why by choosing one of the following reasons:</p> <p><i>Declined/consent not obtained</i>: Select if information was provided, but the MiCare consent form was not signed.</p> <p><i>No contact information</i>: Select if your program is unable to find contact information for the family or guardians.</p> <p><i>Unable to reach</i>: Select if your program has tried to contact the family but was unable to connect with them.</p> <p><i>Missed appointment</i>: Select if an appointment was made but the family did not attend and subsequent attempts to reschedule were unsuccessful.</p> <p><i>Deceased</i>: Select if a child has died after discharge from the NICU but before follow-up. See A13b-d on how to enter details</p> <p><i>Other</i>: Select and specify if follow-up was not completed for a reason other than those listed above.</p>
<b>A13b: Details of death known</b>	<p>This field will only be activated if <i>Deceased</i> is selected in A13: 18-month follow-up status.</p> <p>Select Yes if both the date and cause of death are known from the medical certificate of death, autopsy report or other hospital records. <b>Do not contact the family just to obtain this information.</b> If you select Yes, the following details are mandatory:</p> <p>A13c: <i>Date of death</i></p> <p>A13d: <i>Cause of death</i> (free text field)</p> <p>Select No if the details of death are not known and are not expected to be available or obtained.</p>

If the child did not attend a follow-up appointment, no further data entry is required.



## Section B: Family

The Family section was created to capture demographic information for the many different types of family environments in Canada. Where possible, we have used definitions from Statistics Canada and other MiCare Networks in order to maintain consistency.

### Primary Caregivers

Most of the variables in this section are related to the family’s primary caregiver(s). Typically, primary caregivers would be a mother and/or father, but they could refer to any adult functioning in a parental role. The data base can store information on up to 2 caregivers. If the family has one primary caregiver, check the box next to “Primary Caregiver #2 – If not applicable” and all related fields will be disabled. If a family has more than two primary caregivers, enter data for the two that have the most active/direct role in caring for the child on a regular basis. If a family states that both caregivers have an equal role caring for the child, enter the mother as Primary Caregiver #1.

### Section B: Family

**B1: Primary Caregiver #1**

**B1a: Gender**  Male  
 Female  
 Non-binary  
 Prefer not to answer

**B1b: Type of caregiver**  Biologic parent  
 Step parent  
 Adoptive parent  
 Other family member  
 Foster parent  
 Other

B1c: Birth year

**B1d: Education**

**B1e: Current employment status**  Employed  
 Unemployed  
 Student  
 Full-time homemaker  
 Unknown  
 Other

B1f: Current occupation

**B1g: Employment status at time of birth**  Same as current  
 Employed  
 Unemployed  
 Student  
 Full-time homemaker  
 Not applicable  
 Unknown  
 Other

B1h: Occupation at birth

**B1i: Country of birth**

**B1j: Ethnic group (check all that apply)**  Caucasian/White  
 Black  
 East Asian  
 South Asian  
 Asian (Region Unknown)  
 Hispanic/Latina  
 First Nations  
 Other  
 Unknown

**B2: Primary Caregiver #2** If not applicable check

**B2a: Gender**  Male  
 Female  
 Non-binary  
 Prefer not to answer

**B2b: Type of caregiver**  Biologic parent  
 Step parent  
 Adoptive parent  
 Other family member  
 Foster parent  
 Other

B2c: Birth year

**B2d: Education**

**B2e: Current employment status**  Employed  
 Unemployed  
 Student  
 Full-time homemaker  
 Unknown  
 Other

B2f: Current occupation

**B2g: Employment status at time of birth**  Same as current  
 Employed  
 Unemployed  
 Student  
 Full-time homemaker  
 Not applicable  
 Unknown  
 Other

B2h: Occupation at birth

**B2i: Country of birth**

**B2j: Ethnic group (check all that apply)**  Caucasian/White  
 Black  
 East Asian  
 South Asian  
 Asian (Region Unknown)  
 Hispanic/Latina  
 First Nations  
 Other  
 Unknown

Here are some examples to help illustrate how data should be entered:

1. A child lives with his biological parents who both work full-time.
  - a. Primary caregiver #1: Mother. *Gender = female, Type of caregiver = biological parent.*
  - b. Primary caregiver #2: Father. *Gender = male, Type of caregiver = biological parent.*
2. A child lives with her father and stepmother who has legally adopted the child and spends more time caring for the family’s children. She visits her biological mother every other weekend.
  - a. Primary Caregiver #1: Stepmother. *Gender = female. Type of caregiver = step- parent.*
  - b. Primary Caregiver #2: Father. *Gender = male. Type of caregiver = biological parent.*
3. The family consists of a child and her mother. The grandmother babysits once a week.
  - a. Primary Caregiver #1: Mother. *Gender = female. Type of caregiver = biological parent.*
  - b. Primary Caregiver #2: Not applicable.
4. A child lives with his mother and grandmother. The grandmother babysits when she can but isn’t really involved with the care of the child. Dad visits regularly every second weekend.
  - a. Primary Caregiver #1: Mother. *Gender = female. Type of caregiver = biological parent.*
  - b. Primary Caregiver #2: Not applicable.

<b>B1a/B2a: Gender</b>	Choose <i>Male, Female, Non-binary</i> or <i>Prefer not to answer</i> . Gender refers to current gender which may be different from sex assigned at birth and may be different from what is indicated on legal documents.
<b>B1b/B2b: Type of caregiver</b>	Select one from the following list: <i>Biological parent</i> <i>Step parent</i> <i>Adoptive parent</i> <i>Other family member</i> <i>Foster parent</i> <i>Other</i> (if this is selected, specify this person’s relationship to the child)
<b>B1c/B2c: Birth year</b>	Enter birth year in the format YYYY.
<b>B1d/B2d: Education</b>	Select the highest level of education completed from the following list. If the caregiver has completed CÉGEP and some university, please select <i>Some college, CÉGEP or university</i> . <ul style="list-style-type: none"> <li style="display: inline-block; width: 45%;">• 6 years or less</li> <li style="display: inline-block; width: 45%;">• Completed college, CÉGEP or university</li> <li style="display: inline-block; width: 45%;">• 7-9 years (junior high)</li> <li style="display: inline-block; width: 45%;">• Post-graduate training</li> <li style="display: inline-block; width: 45%;">• 10-12 years (some high school)</li> <li style="display: inline-block; width: 45%;">• Unknown</li> <li style="display: inline-block; width: 45%;">• Completed high school</li> <li style="display: inline-block; width: 45%;">• Some college, CÉGEP or university</li> <li style="display: inline-block; width: 45%;">• Some college, CÉGEP or university</li> </ul>

<b>B1e/B2e: Current employment status</b>	<p>Choose one from the following list:</p> <ul style="list-style-type: none"> <li>• <i>Employed</i>: Select if employed full- or part-time or if self-employed.</li> <li>• <i>Unemployed</i>: Select if the caregiver is available to work but does not have paid employment and is either actively looking for paid work, on temporary lay-off and expecting to return to their job or has arrangements to start a new job in four weeks or less. If she/he is not available for work due to childcare and other household responsibility, select <i>Full-time Homemaker</i>. If she/he is not available for work due to injury or disability, select <i>Other</i>.</li> <li>• <i>Student</i>: Select if the caregiver spends most of his/her time attending classes or works part-time while attending full-time classes. If he/she works full-time but attends night classes, select <i>Employed</i>.</li> <li>• <i>Full-time Homemaker</i>: Select if she/he is not available for paid employment due to childcare and household responsibilities.</li> <li>• <i>Unknown</i>: Select if employment status is unknown.</li> <li>• <i>Other (specify)</i></li> </ul>
<b>B1f/B2f: Current occupation</b>	<p>If <i>Employed</i> is selected in B1/2f, enter the caregiver's occupation or job title. This variable is optional.</p>
<b>B1g/B2g: Employment status at time of birth</b>	<p>Select one from the following list:</p> <ul style="list-style-type: none"> <li>• <i>Same as current</i>: Choose if current employment status is same as it was at the time of the child's birth. If a caregiver was on maternal leave during pregnancy, this question would be scored according to the occupation from which s/he was on leave.</li> <li>• <i>Not applicable</i>: Select if caregiver was not involved with the child at the time of delivery (e.g., an adoptive or foster parent).</li> </ul> <p>All other definitions remain the same as in B1/2e.</p>
<b>B1h/B2h: Occupation at the time of birth</b>	<p>This will be activated only if the employment status or occupation is different from the person's current employment. This variable is optional.</p>
<b>B1i/B2i: Country of birth</b>	<p>Select <i>Canada</i> or <i>Other</i>. This variable is optional.</p>
<b>B1j/B2j: Ethnic group</b>	<p>Select all ethnic group (s) from the following list that apply to the caregiver:</p> <ul style="list-style-type: none"> <li>• <i>Caucasian/White</i></li> <li>• <i>Black</i></li> <li>• <i>East Asian</i>: Mainland China, Hong Kong, Japan, Macau, Mongolia, North Korea, South Korea, Taiwan</li> <li>• <i>South Asian</i>: Bangladesh, Bhutan, India, the Maldives, Nepal, Pakistan, Sri Lanka, Afghanistan, Burma, Tibet, the British Indian Ocean Territories and Iran.</li> <li>• <i>Asian (region unknown)</i>: Select if Asian is mentioned but East or South is not specified.</li> <li>• <i>First Nations</i></li> <li>• <i>Hispanic/Latino</i></li> <li>• <i>Other</i></li> <li>• <i>Unknown</i>: Select if unknown or the caregiver wishes not to provide.</li> </ul>

If there is only one primary caregiver in the family, check the not applicable box next to Primary Caregiver #2 to disable those fields and proceed to B3.

<b>B3: Number of people living in the home <math>\geq</math> 4 days per week</b>	Specify the number of adults and children living in the home at least four days per week. If this child's parents are under the age of 18, include them in the number for adults.
<b>B4: Does someone other than the caregiver(s) in B1/B2 above regularly care for the child <math>\geq</math> 3 days per week?</b>	If the child is cared for by someone other than the primary caregiver(s) listed in B1/B2 for at least 3 times per week for a period of at least 8 hours per day, choose all that apply: <ul style="list-style-type: none"> <li>• Yes - <i>inside the home</i> (the child's residence)</li> <li>• Yes - outside the home</li> </ul> Otherwise, select No.
<b>B5: What is the primary language spoken most often to the child at home?</b>	The primary language is the one used by the family either predominantly or exclusively at home. Select one from the following list: <ul style="list-style-type: none"> <li>• English</li> <li>• Spanish</li> <li>• French</li> <li>• Other</li> </ul>
<b>B5b: Number of languages to which the child is exposed</b>	Enter the number of languages to which the child is regularly exposed. This should include the total number of languages that are spoken at home and if applicable, at daycare or other childcare facilities. If a child is exposed to a language only through television, radio, etc., do not include it here. This variable is optional.
<b>B6: What are the family's sources of financial support?</b>	Check all that apply to the family's current situation <sup>3</sup> : <ul style="list-style-type: none"> <li>• <i>Paid employment</i>: Select also if self-employed.</li> <li>• <i>Employment insurance</i>: includes benefits for unemployment, sickness, maternity, paternity and adoption. <i>Social welfare or other governmental benefits</i>: Such as social assistance payments received by persons in need, such as mothers with dependent children, persons temporarily or permanently unable to work, elderly individuals, the blind and persons with disabilities. Also included are veterans' pensions, war veteran's allowance, pensions to widows and dependants of veterans, and workers compensation. Includes sickness, maternity, paternity, adoption, work sharing, re-training, social assistance, pensions, and veterans' allowances.</li> <li>• <i>Other</i>: Includes alimony, child support, periodic support from other persons not in the household, investment income, scholarships, student loans or bursaries, etc.</li> <li>• <i>Unknown</i>: Select if you don't know or if the family does not want to answer.</li> </ul>

<sup>3</sup> Statistics Canada. Income and Earnings Reference Guide, 2006 Census. Accessed May 10, 2010 from <http://www12.statcan.ca/census-recensement/2006/ref/rp-guides/income-revenu-eng.cfm>

## Section C: Medical History & Physical Examination

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**C1: Date of exam** [Enter Date]

**C2: Where was this child assessed?**

CNFJUN follow-up clinic  
 CNFJUN travel clinic  
 Community physician  
 Child development centre/program  
 Developmental paediatrician  
 Other

**C3a: Has the child been rehospitalized for at least one night since discharge home?**  
 Yes  No  Unknown

**C3b: If Yes: Total # of Rehospitalizations**

For each hospitalization, specify

	Length of Stay	Primary Reason	Other Reason	Source of Info
*	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>

**C4a: Has the child had any surgeries requiring anesthesia since discharge from the NICU?**  
 Yes  No  Unknown

**C4b: If yes, check all that apply:**

Shunt or revision for hydrocephalus  
 ENT surgery (incl. tympanostomy)  
 Eye surgery  
 Tracheostomy  
 Gastrostomy  
 Hernia repair  
 Anti-reflux surgery  
 Other abdominal surgery  
 Other

**C5: Has the child had non-febrile seizures since discharge?**  
 Yes  No  Unknown

**C6: Is the child currently being immunized according to provincial guidelines?**  
 Yes  No  Unknown

**C7: In the last 3 months, has the child taken any of the following regularly?**

Inhaled steroids   
 Inhaled bronchodilators   
 Diuretics   
 Anticonvulsants   
 Antibiotics   
 Anti-reflux drugs   
 Vitamin supplements   
 Iron   
 Other

**C8: Since discharge home, has the child used any of the following at home?**

Apnea monitor   
 Pulse oximeter   
 Supplemental O2   
 Respirator/CPAP   
 Gavage feeding   
 Gastrostomy or jejunostomy   
 Ileostomy or colostomy   
 Tracheostomy   
 Adapted stroller or wheelchair   
 Braces, splints, or orthoses   
 Walker   
 Other mobility aids (specify)

**C9: Weight (enter one)**  
 Kilograms  Pounds  Ounces

**C10: Height (enter one)**  
 Centimetres  Feet  Inches

**C11: Head circumference**  
 Centimetres

**C12: Blood pressure**  
 Systolic  Diastolic

This section is used to obtain the child’s medical history (questions C1-C8) as well as current status after a physical examination (questions C9-C17). It is broken into two screens which can be accessed by clicking on the tabs labeled “Page 1” and “Page 2” at the top of the screen.

A follow-up nurse, nurse practitioner, pediatrician or a suitably trained delegate should obtain the history of the child and family. Information obtained from the parents or other caregivers should be checked by physical examination where applicable and reviewing the child’s medical chart where applicable.

## Section C: Medical History and Physical Examination

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**C13: Are you aware of other diagnoses or issues that are likely affecting development?**

Yes  No

If yes, check all that apply

Fetal Alcohol Spectrum Disorder  
 Chromosomal or genetic abnormalities  
 Extensive hospitalization  
 Congenital heart disease  
 Parental illicit drug use/ etoh or alcohol use during pregnancy  
 Other

**C14: According to your exam, is the child neurologically abnormal?**

Yes  No  Unknown

**C15a: Does the child have cerebral palsy?**

Yes  Suspect  No  Unknown

**C15b: If yes, specify**

Spastic  Non-spastic  Indeterminate

If spastic, please specify:

Diplegia  
 Triplegia  
 Quadriplegia  
 Right hemiplegia  
 Left hemiplegia

If non-spastic, please specify:

Ataxic CP  
 Dyskinetic CP (predominantly dystonic)  
 Dyskinetic CP (predominantly athetoid)  
 Hypotonia

**C15c: If yes, Gross Motor Function Classification System (GMFCS) level**

**C16: Has the child been referred for treatment to any of the following services since NICU discharge?**

Yes  No  Unknown

Alternative care

Dietitian

Early intervention program

Neurologist

Occupational therapist

Physiatrist

Physical therapist

Psychologist

Rehabilitation program

Social worker

Speech/language therapy

Visiting or community nurse

Other

**C17: Parent rating of impairment severity**

Normal  
 Mild  
 Moderate  
 Severe

**C18: Additional Comments**

The physical and neurological examination should be performed by a health professional with adequate training and experience in the neurodevelopmental assessment of extremely preterm infants. Ideally, neurological examinations should be performed by only one or two designated examiners per institution in situations where many examiners are potentially available.

<b>C1: Date of exam</b>	This field will default to the same date entered in Section A (A12). You may change it by entering another date. If the assessment took place over more than one day, enter the day it began.
<b>C2: Where was this child assessed?</b>	Specify the location (s) where the 18-month assessment was completed. <ul style="list-style-type: none"> <li>• CNFUN follow-up clinic</li> <li>• <i>CNFUN travel clinic</i>: Select if CNFUN FUP staff visited an external location to see the family in their home or in their community.</li> <li>• <i>Community physician</i>: Select if the assessment was completed by a community physician (i.e., family doctor) who is not part of the FUP.</li> <li>• <i>Child development centre/ program</i>: Select if the assessment was completed by a centre or program that specialized in child development. In Québec, this includes rehabilitation programs.</li> <li>• Developmental paediatrician</li> <li>• Other (specify)</li> </ul>
<b>C3a: Has the child been re-hospitalized for at least one night since discharge home?</b>	Select Yes if the child was admitted on a short- or long-term unit for at least one night after the initial hospitalization up to the date of the 18-month assessment. Re-hospitalizations include admissions from emergency to a short stay care unit (which is not an observation room) or to a Pediatric Day centre where treatment or investigation of certain diseases are ambulatory and on a daily basis for a specified period (i.e., for treatment of pyelonephritis, moderate cellulitis). An observation extended to the emergency room should not be included. If Yes is selected in C3a, the next 4 questions will be enabled and entry is mandatory.  Note that the initial hospitalization refers to the continuous time the baby is in a hospital prior to first discharge home. For example, if the baby is born at hospital 1, transferred to hospital 2 for a procedure, and then goes back to hospital 1 before being discharged home – this entire period would be considered the initial hospitalization. A re-hospitalization would only be entered if the baby is admitted after this point (i.e., he or she has already been discharged home).
<b>C3b: Total number of re-hospitalizations</b>	Enter the total number of re-hospitalizations according to the definition above. If you are unable to obtain this information via hospital records, ask the parents or guardians. If parents are unsure of the exact number (and hospital records are not available), enter their best estimate.
<b>C3c: Length of stay</b>	Select the length of stay for each hospitalization. The options are: 24 hours or less, 1-3 days, 4 days- 1 week, 1-2 weeks, over 2 weeks or Unknown. <sup>4,5</sup>
<b>C3d: Primary reason</b>	Select the diagnosis most responsible for each re-hospitalization: <ul style="list-style-type: none"> <li>• <i>Respiratory (infectious)</i>: Includes bronchiolitis, upper or lower respiratory</li> </ul>

<sup>4</sup> Lamarche-Vadel A, Blondel B, Truffert P, Burguet A, Cambonie G, Seltons D, Arnaud C, Lardinois C, du Mazaubrun C, N’Guyens S, Mathis J, Bréart G, Kaminisk M and the EPIPAGE Study Group. Re-hospitalization in infants younger than 29 weeks’ gestation in the EPIPAGE cohort. *Acta Paediatrica* 2004, 93, 1340-1345.

<sup>5</sup> Underwood MA, Danielsen B, Gilberts WM. Cost, causes and rates of rehospitalization of preterm infants. *J Perinatol* (2007) 27, 614–619.

	<p>tract infections including laryngitis/croup, bronchitis and pneumonia, bronchospasm and asthma following a respiratory infection.</p> <ul style="list-style-type: none"> <li>• <i>Respiratory (non-infectious)</i>: Includes apnea, ALTE and unstable BPD (not due to respiratory infection).</li> <li>• <i>Central nervous system (CNS) issue</i>: Includes febrile and afebrile seizures, shunt malfunctions, etc.</li> <li>• <i>Surgery</i>: Includes shunt for hydrocephalus or revision, ENT and eye surgery, tracheostomy, gastrostomy, other digestive surgery, hernia repair, etc. More details on surgeries will be entered in C4a.</li> <li>• <i>Infection</i>: Includes infections that are not respiratory in nature, such as sepsis, bacteremia, fever, gastroenteritis, urinary tract infection, otitis, meningitis, shunt infection, etc.</li> <li>• <i>Growth, feeding or nutrition</i>: Poor weight gain, failure to thrive, gavage or ostomy problems, GERD, feeding irritability, etc.</li> <li>• <i>Accident/trauma</i>: Investigation for possible child abuse, fractures, skull trauma, burns, toxic ingestion, etc</li> <li>• <i>Other</i>: Specify in the text field.</li> <li>• Unknown</li> </ul>
<b>C3e: Source of information</b>	<p>For each hospitalization, select whether you used <i>Hospital Records, Parents, or Parents &amp; Hospital Records</i> as the source of information. Hospital records are considered the preferred source of information.</p>
<b>C4a: Has the child had any surgeries requiring anesthesia since discharge from the NICU?</b>	<p>This is an optional variable. Select Yes if the child has had any surgical procedures since discharge from the NICU that have required anesthesia that was administered by an anesthetist. Minor day procedures such as correction of ankyloglossia (tongue-tie, l'exérese du frein de langue), circumcision, skin biopsies, surgical removal of an extra digit should not be included here.</p>
<b>C4b: Type of surgery</b>	<p>Check all that apply:</p> <ul style="list-style-type: none"> <li>• Shunt or revision for hydrocephalus</li> <li>• ENT surgery (including tympanostomy)</li> <li>• Eye surgery</li> <li>• Tracheostomy</li> <li>• <i>Gastrostomy</i>: Either endoscopic or radiological</li> <li>• Hernia repair</li> <li>• <i>Anti-reflux surgery</i>: Nissen fundolipcation or done by endoscopy</li> <li>• Other abdominal surgery</li> <li>• <i>Other</i>: Specify in the accompanying text field.</li> </ul>
<b>C5: Has the child had non-febrile seizures since discharge?</b>	<p>Choose from Yes if the child has had non-febrile seizures since discharge home. If the child has had febrile seizures (those associated with a sudden, significant rise in body temperature) or abnormal movements that have not been confirmed by a medical professional as seizures, select No.</p>
<b>C6: Is the child currently being immunized according</b>	<p>This variable is optional. Select Yes if the child is up-to-date with their immunization according to the public health guidelines in his or her province of residence, or if the child's immunizations are incomplete but the parents/caregivers intend to complete them.</p>



<b>to provincial guidelines?</b>	Select No if the parents do not intend to immunize their child according to public health guidelines or if the child has not had any immunizations.
<b>C7: In the last three months, had the child taken any of the following medications regularly?</b>	<p>Select <i>Yes- Still Using</i> if the child has taken any of the listed medications (either on a daily or regular basis, or if PRN on one or more occasions) in the 3 months preceding the 18-month visit and will continue to do so after the visit.</p> <p>Select <i>Yes - But Stopped</i> if the child has taken any of the listed medications (either on a daily or regular basis, or if PRN on one or more occasions) in the 3 months preceding the 18-month visit but has stopped or will stop on the day of the visit.</p> <ul style="list-style-type: none"> <li>• <i>Inhaled steroids:</i> Flovent, Plumericort, Advair, etc.</li> <li>• <i>Inhaled bronchodilators:</i> Ventolin, Serevent, Advair, etc.</li> <li>• Diuretics</li> <li>• Anticonvulsants</li> <li>• Antibiotics</li> <li>• <i>Anti-reflux drugs:</i> Maxeran, Domperidone, Cisapride, Zantac, Prevacid, etc.</li> <li>• Vitamin supplements</li> <li>• Iron</li> <li>• <i>Other:</i> If you select other, you must specify in the text box provided.</li> </ul> <p>If a medication was not used (even if it was prescribed) within the 3 months preceding the assessment, select No.</p>
<b>C8: Since discharge home, has the child used any of the following aids at home?</b>	Select <i>Yes-Still Using</i> or <i>Yes-But Stopped</i> if the child currently uses or has used each item of the following list. Only include those items prescribed or recommended by a health professional; for example, if parents purchase an apnea monitor due to their own concerns, do not enter it here.
	<ul style="list-style-type: none"> <li>• Apnea monitor</li> <li>• Pulse oximeter</li> <li>• Supplemental O<sub>2</sub></li> <li>• Respirator/CPAP</li> <li>• Gavage feeding</li> <li>• Gastrostomy or jejunostomy</li> <li>• Ileostomy/Colostomy</li> <li>• Tracheostomy</li> <li>• Adapted wheelchair or stroller</li> <li>• Braces, splints or orthoses</li> <li>• Walker</li> <li>• Other mobility aids (must specify)</li> </ul>
<b>C9: Weight</b>	Enter the child's weight (kg). If you only have the weight in pounds, enter that and the database will automatically convert for you.
<b>C10: Height</b>	Enter the child's height (cm). If you only have the height in feet and inches, enter that and the database will automatically convert for you.
<b>C11: Head circumference</b>	Enter the child's head circumference in centimeters.
<b>C12: Blood pressure</b>	Enter the child's systolic and diastolic blood pressure. This variable is optional.
<b>C13: Are you aware of other diagnoses or issues that are likely affecting development?</b>	<p>If there are other diagnoses or issues that are likely affecting development, please check all that apply.</p> <ul style="list-style-type: none"> <li>• Fetal Alcohol Spectrum Disorder</li> <li>• Chromosomal or genetic abnormalities</li> <li>• <i>Extensive hospitalization:</i> Select if the child remained hospitalized for a continuous period of at least three months after his or her EDC or NICU</li> </ul>

	<p>discharge.</p> <ul style="list-style-type: none"> <li>• <i>Congenital heart disease</i>: Also known as congenital heart defect or CHD. Select if the child has a congenital heart defect requiring open heart surgery (if the surgery has occurred or is planned for the next 2 years). This includes cyanotic heart defects. Do not select if the only defect present is a patent ductus arteriosus (PDA).</li> <li>• <i>Parental illicit drug use or alcohol use during pregnancy</i>: Select if there has been any parental illicit drug use during pregnancy or since the child has been born (i.e. regardless of the effect it may have on development). This includes drugs such as cocaine, crystal meth, heroin, marijuana, etc. If marijuana is used for medical purposes ( its use is authorized by Health Canada) it is not considered an illicit drug.</li> <li>• <i>Other (specify)</i>: If you select other, please specify in the related text box.</li> </ul>
<p><b>C14: According to your exam, is the child neurologically abnormal?</b></p>	<p>Select Yes if the clinician thinks there is a clinically significant neurological abnormality that is affecting the child’s development. If the only abnormalities present are mild or transient, such as mild asymmetry, select No.</p>
<p><b>C15a: Does the child have cerebral palsy (CP)?</b></p>	<p>Select Yes if the clinician is confident the child has cerebral palsy according to the following definition: <i>Cerebral palsy (CP) describes a group of disorders of the development of movement and posture, causing activity limitation, that are attributed to non-progressive disturbances that occurred in the developing fetal or infant brain. The motor disorders of cerebral palsy are often accompanied by disturbances of sensation, cognition, communication, perception, and/or behaviour, and/or by a seizure disorder.</i> <sup>6</sup></p> <p>If Yes is selected, the next two questions are mandatory.</p> <p>Select Suspect if the clinician thinks the child may have cerebral palsy, but is not comfortable making a firm diagnosis at this time.</p>
<p><b>C15b: Specify type of CP</b></p>	<p>Appendix A contains an algorithm that will assist in classify the type of CP. Specify the type of CP from the following list:</p> <ul style="list-style-type: none"> <li>• <i>Spastic</i>: If you select spastic, it is optional to specify whether it is: <ul style="list-style-type: none"> <li>○ <i>Diplegia</i>: Involves all four limbs, but legs more than arms</li> <li>○ <i>Triplesia</i>: Involves three limbs</li> <li>○ <i>Quadriplegia</i>: Equal involvement of all four limbs</li> <li>○ <i>Left hemiplegia</i>: Involves the left arm and/or leg. The child may have an abnormal gait and/or an exaggerated hand preference.</li> <li>○ <i>Right hemiplegia</i>: Involves the right arm and/or leg. The child may have an abnormal gait and/or an exaggerated hand preference.</li> </ul> </li> <li>• <i>Non-Spastic</i>: If you select non-spastic, it is optional to specify whether it is:</li> </ul>

<sup>6</sup> Bax et al. Proposed definition and classification of cerebral palsy, April 2005. Dev Med Child Neurol. 2005 Aug; 47(8): 571-6)

	<ul style="list-style-type: none"> <li>○ <i>Ataxic</i>: Hypotonia with poor motor coordination expressed as abnormal strength, rhythm or precision of movement (e.g., unsteady gait, unable to grasp an object due to imprecise hand movements).</li> <li>○ <i>Dyskinetic CP (predominantly dystonic)</i>: presence of involuntary, uncontrolled, repetitive sometimes stereotyped movements. There is sometimes decreased movements and hypertonia.</li> <li>○ <i>Dyskinetic CP (predominantly athetoid)</i>: presence of involuntary, uncontrolled, repetitive, sometimes stereotyped movements. There is increased movement and hypotonia.</li> <li>○ <i>Hypotonia</i>: Decreased muscle tone without motor coordination abnormalities.</li> <li>● <i>Indeterminate</i>: Select if the clinician is not sure of the type of CP presenting, or if he or she feels labeling the type is not appropriate at this time.</li> </ul>
<p><b>C15c: Gross Motor Function Classification System (GMFCS)</b></p>	<p>The GMFCS (original version, 1997, Palisano et al) is based on self-initiated movement with a focus on determining which level best represents the child's present abilities and limitations in motor function. It is therefore important to classify ordinary performance (not best capacity), and not to include judgments about prognosis, quality of movement or potential for improvement. Prior to using the GMFCS, please read the full instructions, frequently asked questions, motor curves and percentiles. Appendix B contains an algorithm to help classify the level of motor function using the GMFCS.</p> <p>Select the <i>Level of Motor Function</i> as indicated by the GMFCS from the drop-down menu.</p>
<p><b>C16: Has the child been referred for treatment to any of the following services since NICU discharge?</b></p>	<p>Select <i>Seen</i> if the child has been seen, cared for, or is followed (regardless of the source of referral) by any of the following programs or specialties outside of the neonatal follow-up clinic since discharge from the NICU up to the date of the 18-month assessment. Select <i>Waiting</i> if the child is on a waiting list or is waiting for a referral:</p> <ul style="list-style-type: none"> <li>● <i>Alternative care</i>: Complementary or alternative medicine such as acupuncture, chiropractic services, massage therapy, homeopathy etc., that are not performed by a physician.</li> <li>● <i>Dietitian</i>: Services provided by Registered Dietitians or qualified nutritionists.</li> <li>● <i>Early intervention program</i>: Programs that provide screening and services in children at risk of a neurodevelopmental disability.</li> <li>● <i>Neurologist</i></li> <li>● <i>Occupational therapist</i></li> <li>● <i>Physiatrist</i>: Physicians specializing in physical medicine and rehabilitation.</li> <li>● <i>Physical therapist</i></li> <li>● <i>Psychologist</i></li> <li>● <i>Rehabilitation program</i>: Programs that provide treatment to child with an identified neurodevelopmental or neurosensory impairment.</li> <li>● <i>Social worker</i></li> <li>● <i>Speech or language therapist</i></li> <li>● <i>Visiting or community nurse</i>: Select if the child was referred to community-based nursing services which are not part of routine care (i.e., well baby clinics or immunizations done by public health nurses). Select if home care</li> </ul>

	<p>was required after NICU discharge for children with complex health needs.</p> <ul style="list-style-type: none"> <li>• <i>Other (specify)</i>: Please specify any other programs or specialties that provide services for this child.</li> </ul>
<p><b>C17: Parent rating of impairment severity</b></p>	<p>Parents should be asked what they believe their child’s impairment status to be prior to any assessment by the NFU team. Appendices <b>D/E</b> contain the scripts in English and French (respectively) for asking this question. This variable is optional.</p> <p>Mark parent’s answer as:</p> <ul style="list-style-type: none"> <li>• Normal</li> <li>• Mild</li> <li>• Moderate</li> <li>• Severe</li> </ul>
<p><b>C18: Additional comments</b></p>	<p>Use this box to add any additional comments about this child and/or the medical history or physical examination. If you have a question about entering data into the database or are not sure how to code something, do not ask those questions here; instead, please contact the CNFUN coordinator. This variable is optional.</p>

## Section D: Auditory Assessment

**D1: Has the child's hearing ever been tested or screened?**  
 Yes     No     Unknown

D2: Testing completed (check all that apply)  
 Diagnostic evoked auditory brainstem potential (ABR)  
 Behavioural audiogram  
 Diagnostic oto-acoustic emissions (OAE)  
 Newborn Hearing Screening  
 Unknown

D3: Date of most recent test: [Enter Date] ▾

**D4a: Does the child have hearing loss?**  
 Yes     No     Unknown

D4b: When was the hearing loss diagnosed? (enter one)  
 Child's age (months) [ ]    Date [Enter Date] ▾

**D4c: If yes, what is the nature the loss?**

L	R
<input type="checkbox"/>	<input type="checkbox"/> Sensorineural
<input type="checkbox"/>	<input type="checkbox"/> Conductive
<input type="checkbox"/>	<input type="checkbox"/> Mixed
<input type="checkbox"/>	<input type="checkbox"/> Auditory neuropathy
<input type="checkbox"/>	<input type="checkbox"/> Unknown

D4d: If yes, describe

L	R
<input type="checkbox"/>	<input type="checkbox"/> Mild (26-40 dB)
<input type="checkbox"/>	<input type="checkbox"/> Moderate (41-55 dB)
<input type="checkbox"/>	<input type="checkbox"/> Moderately severe (56-70 dB)
<input type="checkbox"/>	<input type="checkbox"/> Severe (71-90 dB)
<input type="checkbox"/>	<input type="checkbox"/> Profound (>91 dB)
<input type="checkbox"/>	<input type="checkbox"/> Unknown/Inconclusive

**D5: Does the child require hearing aids or cochlear implants?**  
 Yes     No     Unknown

**If yes, please specify**

Hearing Aid	Cochlear Implant
<input type="checkbox"/> One ear	<input type="checkbox"/> One ear
<input type="checkbox"/> Both ears	<input type="checkbox"/> Both ears
<input type="checkbox"/> Unknown	<input type="checkbox"/> Unknown

Section D: Auditory Assessment was designed to get an overview of the child's hearing status and capture any testing or screening that has taken place since the child was in the NICU.

A complete auditory assessment is not currently part of the CNFUN protocol. If this is part of routine clinic practice at your follow-up clinic, then enter the results of the assessments done at the time of the clinic visit. However, if your clinic does not regularly include hearing screening or testing at the 18-month visit, you may enter results from the most recently completed audiologist's report.

If the child has not had an audiology assessment since discharge home and the medical exam does not identify any issues, you can select "unknown" to each question and proceed to the next section.

If a concern about hearing is identified at the 18-month assessment and a referral is made, please include the report that resulted from the referral.

<p><b>D1: Has the child's hearing ever been tested or screened?</b></p>	<p>Select Yes, No, or Unknown.</p>
<p><b>D2: If yes, type of testing completed</b></p>	<p>This variable is optional. Choose all that apply from the following list:</p> <ul style="list-style-type: none"> <li>• Diagnostic evoked auditory brainstem potential (ABR)</li> <li>• Behavioural audiogram</li> <li>• Diagnostic otoacoustic emission (OAE)</li> <li>• Newborn hearing screening: Select if a newborn hearing screen was done at any time (i.e., in the level-III NICU or at another community hospital, etc.).</li> <li>• Unknown</li> </ul>

<b>D3: Date of most recent test</b>	Enter the date of the most recent test. This variable is optional.
<b>D4a: Does the child have a hearing loss?</b>	Select <i>Yes</i> , <i>No</i> , or <i>Unknown</i> . If <i>Yes</i> is selected, complete the next three questions.
<b>D4b: If yes, date of hearing loss diagnosis</b>	If the child has a hearing loss indicated in question D4a, specify the date of diagnosis. If the exact date is unknown, enter the child's corrected age in months at the time the diagnosis was made. This variable is optional.
<b>D4c: If yes, what is the nature of the hearing loss?</b>	Specify the nature of the child's hearing loss in each ear by selecting one option from the following list: <sup>7</sup> <ul style="list-style-type: none"> <li>• <i>Sensorineural</i></li> <li>• <i>Conductive</i></li> <li>• <i>Mixed</i>: Select in cases where sensorineural and conductive hearing losses occur in combination.</li> <li>• <i>Auditory neuropathy</i>: Results from an impairment in the transmission of signals from the inner ear to the brain</li> <li>• <i>Unknown</i>: Select if the child has a hearing loss, but its etiology is unknown, or if the audiologist's report is either inconclusive or unavailable.</li> </ul>
<b>D4d: If yes, describe the degree of impairment without aids</b>	This variable is optional. Specify the degree of impairment in each ear without the use of aids using the audiologist's report (click here for help on reading an audiogram).  For each ear, select one range of hearing loss. If the loss varies across frequencies, select the category that corresponds with the average loss based on pure-tone testing at frequencies between 500-2000 Hz (if available, use up to results up to 4000 Hz). <sup>8,9</sup> If the audiologist's report only includes a description of the loss, select the worst hearing loss indicated (i.e., if "mild to moderate" is noted, select moderate). <ul style="list-style-type: none"> <li>• <i>Mild (26-40 dB)</i></li> <li>• <i>Moderate (41-55 dB)</i></li> <li>• <i>Moderately severe (56-70 dB)</i></li> <li>• <i>Severe (71-90 dB)</i></li> <li>• <i>Profound (90 dB or greater)</i></li> <li>• <i>Unknown/Inconclusive</i></li> </ul>
<b>D5: Does the child require a hearing aid(s) or cochlear implant(s)?</b>	If child needs cochlear implants or hearing aids, please specify whether they are required in one or both ears. Note that this question is based on need rather than use, so if the child needs hearing aids but does not currently have or use them, it would be scored as <i>Yes</i> .

<sup>7</sup> Robertson CMT, Howarth T, Bork DLR, Dinu IA. Permanent bilateral sensory and neural hearing loss of children after neonatal intensive care because of extreme prematurity: A thirty-year study. *Pediatrics* 2009; 123; e797-e807.

<sup>8</sup> Joint Committee on Infant Hearing. Year 2007 Position Statement: Principles and Guidelines for Early Hearing Detection and Intervention Programs. *Pediatrics* 2007; 120; 898-921.

<sup>9</sup> Canadian Working Group on Childhood Hearing. Early Hearing and Communication Development: Canadian Working Group on Childhood Hearing (CWGCH) Resource Document. Ottawa: Minister of Public Works and Government Services Canada, 2005.

## Section E: Visual Assessment

**Section E: Vision Assessment**

**E1a: Did the child have treatment for Retinopathy of Prematurity (ROP) after NICU discharge?**

Yes     No     Unknown

If yes, specify:

**E1b: Highest stage (1-5):**    L     R

**E1c: Plus disease?**

Yes     No     Unknown

**E1d: Type of treatment:**

	L	R
Laser therapy	<input type="checkbox"/>	<input type="checkbox"/>
Anti-VEGF	<input type="checkbox"/>	<input type="checkbox"/>
Cryotherapy	<input type="checkbox"/>	<input type="checkbox"/>
Buckle	<input type="checkbox"/>	<input type="checkbox"/>
Other	<input type="checkbox"/>	<input type="checkbox"/>
Unknown	<input type="checkbox"/>	<input type="checkbox"/>

**E2: Check all the vision problems that apply**

None

Astigmatism

Hypermetropia

Myopia

Retinal detachment

Strabismus

Cortical blindness

Other

Unknown

**E3: Visual function**

Normal

Normal with prescription glasses

Unilateral impairment

Bilateral impairment

Unknown

If a visual assessment is not regularly part of the 18-month corrected age assessment, enter information based on the most recent available ophthalmology or optometrist's report.

If the child's vision is assessed as part of the 18-month visit, enter those results.

If the child has not had a visual assessment since discharge home, then you can select "unknown" to each question and proceed to the next section.

<p><b>E1a: Treatment for ROP after discharge</b></p>	<p>Check Yes if the child has been treated for Retinopathy of Prematurity (ROP) since discharge from the NICU. If the child was diagnosed with ROP and/or treated for ROP in the NICU but has had no further treatment since discharge, select No.</p>
<p><b>E1b: Highest stage of ROP</b></p>	<p>Specify the maximum stage of Retinopathy of Prematurity (ROP) in each eye since NICU discharge. Score according to the grade of ROP assigned on an eye exam done by an ophthalmologist. If there is no explicit grade listed, then score according to the descriptions given by the International Committee on Retinopathy of Prematurity (ICROP):</p> <ul style="list-style-type: none"> <li>• <b>Stage 1:</b> Characterized by a demarcation line between the normal retina near the optic nerve and the nonvascularized retina more peripherally.</li> <li>• <b>Stage 2:</b> Has a ridge of scar tissue and new vessels in place of the demarcation line. The white line now has width and height, and occupies some volume. It may take on a pink color as it becomes more vascularized. Small tufts of new vessels ("popcorn vessels") may appear posterior to the ridge.</li> <li>• <b>Stage 3:</b> Increased size of the vascular ridge, with growth of fibro-vascular</li> </ul>

	<p>tissue on the ridge and extending out into the vitreous. Fibrous scar tissue is beginning to form in this stage, with attachments between the vitreous gel and the ridge.</p> <ul style="list-style-type: none"> <li>• <i>Stage 4:</i> Refers to a partial retinal detachment. The scar tissue associated with the fibrovascular ridge contracts, pulling the retina away from the wall of the eye.</li> <li>• <i>Stage 5:</i> Implies a complete retinal detachment, usually with the retina pulled into a funnel-shaped configuration by the fibrovascular scar tissue. Eyes with stage 5 ROP usually have no useful vision, even if surgical repair is performed.</li> <li>• <i>Not applicable:</i> Select if the child did not have treatment for ROP in that eye.</li> </ul>
<b>E1c: Plus disease?</b>	<p>This variable will only be selected if Yes was entered in E1a above. For each eye, indicate whether the Plus disease at any stage of ROP was present since NICU discharge. Plus disease is indicated by extreme tortuosity and redness of vessels, often accompanied by rapid progression of ROP disease.</p>
<b>E1d: Type of treatment</b>	<p>This variable will only be selected if Yes was entered in E1a above. Check all the applicable treatment(s) the child has received for ROP since NICU discharge:</p> <ul style="list-style-type: none"> <li>• <i>Laser therapy</i></li> <li>• <i>Anti-VEGF</i></li> <li>• <i>Cryotherapy</i></li> <li>• <i>Buckle</i></li> <li>• <i>Other</i></li> <li>• <i>Unknown</i></li> </ul>
<b>E2: Vision problems</b>	<p>Check all the visual problems that apply:</p> <ul style="list-style-type: none"> <li>• None</li> <li>• Astigmatism</li> <li>• Cortical blindness (or cortical visual impairment)</li> <li>• Hypermetropia</li> <li>• Myopia</li> <li>• Retinal detachment</li> <li>• Strabismus</li> <li>• <i>Other (specify):</i> Enter a specific diagnosis (e.g., cataracts)</li> <li>• <i>Unknown:</i> If no report is available.</li> </ul>
<b>E3: Visual function</b>	<p>At 18 months visual acuity can be measured electronically. However, this is not feasible for routine clinical screening. Normally, acuity is between 20/50 and 20/30 but on behavioural testing is lower. However, most ophthalmologists do not do visual acuity testing. CNFUN clinics should screen all subjects for a response to a 1 cm object (such as a cheerio) on a white background from a distance of 30 cm. Indicate whether the child's visual function is:</p> <ul style="list-style-type: none"> <li>• <i>Normal:</i> Responds appropriately to the 1 cm object</li> <li>• <i>Normal with prescription glasses:</i> Responds appropriately to the 1 cm object while wearing prescription glasses.</li> <li>• <i>Visual impairment (unilateral or bilateral):</i> Select if the child meets one or more of the following criteria: <ul style="list-style-type: none"> <li>○ No response to the 1 cm object;</li> <li>○ On physical exam: small eye, corneal scarring, sustained sensory nystagmus;</li> <li>○ Ophthalmologist report of ROP stage 3 (with macular drag or macular traction), 4 or 5;</li> </ul> </li> </ul>



	<ul style="list-style-type: none"><li>○ A report of visual acuity of 20/70 or worse.</li></ul> <p>Note that cortical visual impairment (CVI) may present differently than other forms of visual impairment.<sup>10</sup> Look for evidence of decreased visual acuity and behavioural characteristics such as light gaze, light sensitivity, a colour preference, poor visual attention, variable visual attention. Known causes of CVI are occipital lesions on neuroimaging, HIE and seizures.</p>
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<sup>10</sup> Roman-Lantzy, Christine. 2007. Cortical visual impairment: An approach to assessment and intervention. AFB Press.

## Section F: Psychological Examination (Bayley)

### Section F: Psychological Examination

**F1: Assessment date** Apr 30, 2018

**F2a: Chronological age**  Months  Days

**F2b: Corrected age**  Months  Days

**F3: Were you able to test the child?**  
 Yes  No  Incomplete

F3b: If no or incomplete, why? Check all that apply

Child was uncooperative  
 Illness  
 Interpreter not available  
 Blindness or deafness  
 Severe developmental delays  
 Other

F3c: If no, does the child have a global developmental delay?  
 Yes  Suspect  No  Unknown

**F4: Test was administered in**

English  
 French  
 With parent as interpreter  
 With an interpreter  
 Other

**F6: Child Behavior Checklist (CBCL 1 ½ - 5)**

	Total Scores	T Scores
<i>Syndrome Scales</i>		
Emotionally Reactive	<input type="text"/>	<input type="text"/>
Anxious/Depressed	<input type="text"/>	<input type="text"/>
Somatic Complaints	<input type="text"/>	<input type="text"/>
Withdrawn	<input type="text"/>	<input type="text"/>
Sleep Problems	<input type="text"/>	<input type="text"/>
Attention Problems	<input type="text"/>	<input type="text"/>
Aggressive Behavior	<input type="text"/>	<input type="text"/>
<i>Global Scales</i>		
Internalizing Problems	<input type="text"/>	<input type="text"/>
Externalizing Problems	<input type="text"/>	<input type="text"/>
Total Problems	<input type="text"/>	<input type="text"/>
<i>DSM-Oriented Scales</i>		
Affective Problems	<input type="text"/>	<input type="text"/>
Anxiety Problems	<input type="text"/>	<input type="text"/>
PD Problems	<input type="text"/>	<input type="text"/>
ADH Problems	<input type="text"/>	<input type="text"/>
OD Problems	<input type="text"/>	<input type="text"/>

**F5a: Bayley edition**

Bayley 3  
 Bayley 4

**F5b: Bayley results**

	Total Raw Score	Scaled Score	Composite /Standard Score
<i>Cognitive</i>	<input type="text"/>	<input type="text"/>	<input type="text" value="L"/>
Receptive Communication	<input type="text"/>	<input type="text"/>	
Expressive Communication	<input type="text"/>	<input type="text"/>	
<i>Language</i>	Sum	<input type="text"/>	<input type="text"/>
Fine Motor	<input type="text"/>	<input type="text"/>	
Gross Motor	<input type="text"/>	<input type="text"/>	
<i>Motor</i>	Sum	<input type="text"/>	<input type="text"/>

**F5c: Bayley Questionnaires**

	Total Raw Score	Composite/Standard Score
Social-Emotional	<input type="text"/>	<input type="text"/>
	Sum of Scaled Scores	Composite Score (GAC)
Bayley 3 Adaptive Behavior	<input type="text"/>	<input type="text"/>
		Standard Score (ADBE)
Bayley 4 Adaptive Behavior		<input type="text"/>

The main component of Section F: Psychological Assessment section is the use of the Bayley Scales of Infant and Toddler Development, Third or Fourth Edition (Bayley-III or 4).<sup>11</sup> Bayley examiners should have training and experience in the fundamental principles of assessment procedures, including to how to establish and maintain rapport, elicit optimum performance, follow standardized administration procedures, understand psychometric status, score and interpret tests, and maintain test security. It is the responsibility of each clinic to ensure that their personnel are sufficiently trained and experienced according to [Pearson Canada's qualification guidelines](#). If you have any questions, contact the CNFUN coordinator.

### **Bayley Administration Guidelines**

The total time needed to complete the assessment is approximately 90 minutes for the Bayley-III and 30-70 minutes for the Bayley-4. If possible, administer the Bayley early in the day to optimize performance and reduce fatigue.

The Bayley should be administered to all study participants in the standardized manner according to the Administration Manual.<sup>12,13</sup> Examiners should become familiar with the general testing guidelines found in Chapter 2. Use the child's corrected age to select the initial term set. If cognitive delay is suspected, the examiner should use clinical judgment in selecting the initial item set.

A child whose test was started but not completed due to behaviour problems, fatigue, or an acute illness should be re-assessed.

### **Children whose primary language differs from the local official language**

Unless the Bayley examiner is fluent in the child's primary language, arrangements for translation from a professional interpreter should be made in advance. Inform the interpreter to translate instructions as closely as possible, and not to repeat instructions unless permitted by the examiner. Relatives or friends of the child's family are not optimal interpreters but may be used if there is no other option.

### **Children with physical, sensory or cognitive impairments**

Every attempt should be made to test children with impairments. Appendix C of the Administration Manual describes the types of accommodations and adaptations that can be implemented for children with physical and/or sensory impairments. Please refer to "Testing Children with Physical or Language Impairments" in the Bayley Administration Manual.

If a child cannot be tested due to severe impairments, please complete F1-F3 of this section.

<sup>11</sup> Bayley N. The Bayley Scales of Infant and Toddler Development, Third Edition. San Antonio, TX: The Psychological Corporation; 2006.

<sup>12</sup> Bayley N. The Bayley Scales of Infant and Toddler Development, Third Edition: Administration Manual. San Antonio, TX: The Psychological Corporation; 2006.

<sup>13</sup> Bayley, N., & Aylward, G. P. (2019). Bayley Scales of Infant and Toddler Development (4th ed.) technical manual. Bloomington, MN: NCS Pearson

<b>F1: Assessment date</b>	The default date is the one specified in Section A (A12). This can be changed if necessary by entering a new date.
<b>F2a: Chronological age</b>	The chronological age in months and days is calculated automatically using the child's date of birth (Section A) and the assessment date in F1. If the calculation is not made automatically, ensure these variables have been entered.
<b>F2b: Corrected age</b>	The corrected age in months and days is calculated automatically according to the formula in the Bayley manual using the child's date of birth (section A), gestational age (Section A) and the assessment date (F1). If the calculation is not made automatically, ensure these variables have been entered.
<b>F3a: Were you able to test the child?</b>	<p>Select <i>Yes</i> if the Bayley was completed in its entirety.          Select <i>No</i> if the Bayley was not attempted.          Select <i>Incomplete</i> if the Bayley was partially completed with some scores available. Please enter all of the Bayley scores you were able to obtain.</p> <p>Once <i>No</i> or <i>Incomplete</i> has been selected, question F3b will be activated and you must specify why the child could not be assessed or assessment could not be completed.</p>
<b>F3b: If no, why?</b>	<p>This question will be activated once <i>No</i> is selected in F3a. Please check all the reasons that apply:</p> <ul style="list-style-type: none"> <li>• <i>Child was uncooperative</i>: Select if the child was too tired or uncooperative to complete the Bayley and was unable to be re-booked within the specified time period.</li> <li>• <i>Illness</i>: Select if the child had an acute illness and another assessment could be booked within the time period for the assessment.</li> <li>• <i>Interpreter not available</i>: Select if a professional interpreter is unavailable during the specified time period. If a professional interpreter is unavailable, it is still preferable to use a family member as an interpreter rather than not testing the child at all.</li> <li>• <i>Blindness or deafness</i>: Select if the child has a severe visual or auditory impairment.</li> <li>• <i>Severe developmental delays</i>: Select if the clinician feels the child has a severe cognitive delay making it inappropriate to complete the Bayley. Details on the medical diagnoses related to the delays must be entered in question C13.</li> <li>• <i>Other (specify)</i>: If there is another reason why the Bayley cannot be completed (e.g., severe cerebral palsy, or child does not attend the clinic due to geographic distance and a Bayley cannot be completed in the community), you must specify in the text box.</li> </ul> <p>If a child cannot be tested, it is strongly desired that the Bayley questionnaires are completed by a primary caregiver (see F5).</p>
<b>F3c: If no, does the child have a global developmental delay?</b>	<p>If Bayley scores cannot be obtained, please select from the following list the clinician's opinion on whether the child has a global developmental delay:</p> <ul style="list-style-type: none"> <li>• <i>Yes</i>: Select if the clinician believes a global developmental delay is present and this opinion has been confirmed by a test such as the CAT-CLAMS.<sup>13</sup> Enter the name of test and cut-offs used to determine delay - along with any other relevant notes - in the comments box (c17) in Section C.</li> </ul>

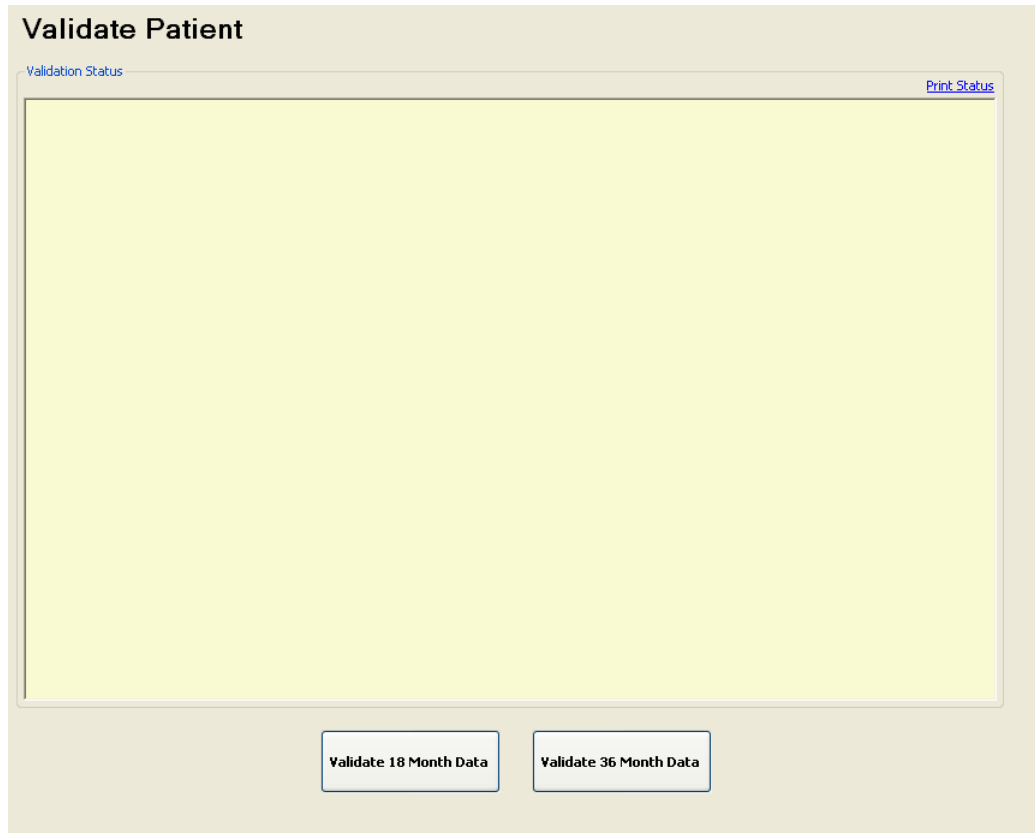
Canadian Neonatal Follow-Up Network  
Réseau Canadien  de Suivi Néonatal

	<ul style="list-style-type: none"> <li>• <i>Suspect</i>: Select if the clinician believes a delay is present but cannot be confirmed by a standardized test.</li> <li>• <i>No</i>: Select if there is no evidence of a cognitive delay.</li> </ul> <p>**Please enter any related comments in the comments box (C17) in Section C. If a test (standardized or a screening test) such as a CAT-CLAMS is used, please enter the name of the test and the cut-offs used to determine delay, so CNFUN can improve this definition at a later date.</p>
<p><b>F4: Language of test administration</b></p>	<p>Select all that apply from the following list:</p> <p><i>English</i></p> <p><i>French</i>: There is no official French version of the Bayley. Select if the examiner is fluent in French and administers the assessment while translating it into French him or herself.</p> <p><i>With an interpreter</i>: Children whose primary language differs from the local official language(s) should be assessed in the presence of a professional interpreter.</p> <p><i>With parent as interpreter</i>: Select in situations where a professional interpreter is unavailable and so a parent or family member is used as an interpreter if there are no other options.</p> <p><i>Other</i></p>
<p><b>F5a: Bayley edition</b></p>	<p>Select the Bayley version administered:</p> <ul style="list-style-type: none"> <li>• <i>Bayley 3</i></li> <li>• <i>Bayley 4</i></li> </ul>
<p><b>F5b: Bayley results</b></p>	<p>Refer to the Bayley Administration manual for scoring information. Enter the following scores from the completed Bayley assessment. You will find them on the record form under “subtest summary scores”:</p> <ul style="list-style-type: none"> <li>• <i>Cognitive composite</i>: Total Raw Score, Scaled Score, Composite/Standard Score</li> <li>• <i>Language composite</i>: Scaled Score, Composite/Standard Score <ul style="list-style-type: none"> <li>○ <i>Receptive communication subtest</i>: Total Raw Score, Scaled Score</li> <li>○ <i>Expressive communication subtest</i>: Total Raw Score, Scaled Score</li> </ul> </li> <li>• <i>Motor composite</i>: Scaled Score, Composite/Standard Score <ul style="list-style-type: none"> <li>○ <i>Gross motor subtest</i>: Total Raw Score, Scaled Score</li> <li>○ <i>Fine motor subtest</i>: Total Raw Score, Scaled Score</li> </ul> </li> </ul> <p>If the Bayley assessment could only be partially completed, please enter any available scores here.</p> <p>In some cases, administering the Bayley in a standardized manner to a child with a severe sensory or physical impairment is not appropriate. In this situation, do not administer the Bayley.</p>
<p><b>F5c: Bayley questionnaires</b></p>	<p>The Bayley questionnaires are optional for this project. However, if a child is “untestable” with the Bayley scales, it is strongly recommended that a primary caregiver complete the questionnaires, so CNFUN can obtain some standardized data on the child.</p> <p>Enter the following Bayley questionnaire scores:</p> <ul style="list-style-type: none"> <li>• <i>Social-Emotional Questionnaire</i>: Total Raw Score, Standard Score</li> <li>• <i>Adaptive Behavior Questionnaire of the Bayley 3</i>: Sum of Scaled Score,</li> </ul>

	<p>Composite Score</p> <ul style="list-style-type: none"> <li>• <i>Adaptive Behavior Questionnaire of the Bayley 4: Standard Score (ADBE)</i></li> </ul>
<p><b>F6: Child Behaviour Checklist (CBCL)</b></p>	<p>Use of the Child Behaviour Checklist (CBCL) is <b>optional and should only be entered if it is part of your clinic’s standard protocol</b>. The standard ethics approval for the MiCare project did not include the use of the CBCL.</p>

<sup>13</sup> Vincer MJ, Cake H, Graven M, Dodds L, McHugh S, Fraboni T. A population-based study to determine the performance of the Cognitive Adaptive Test/Clinical Linguistic and Auditory Milestone Scale to predict the Mental Development Index at 18 months on the Bayley Scales of Infant Development-II in very preterm infants. *Pediatrics* 116, e1864-e867.

## Case Validation



The screenshot shows a web interface titled "Validate Patient". It features a large yellow rectangular area in the center, which is the "Validation Status" section. In the top right corner of this yellow area, there is a blue link labeled "Print Status". Below the yellow area, there are two buttons: "Validate 18 Month Data" and "Validate 36 Month Data".

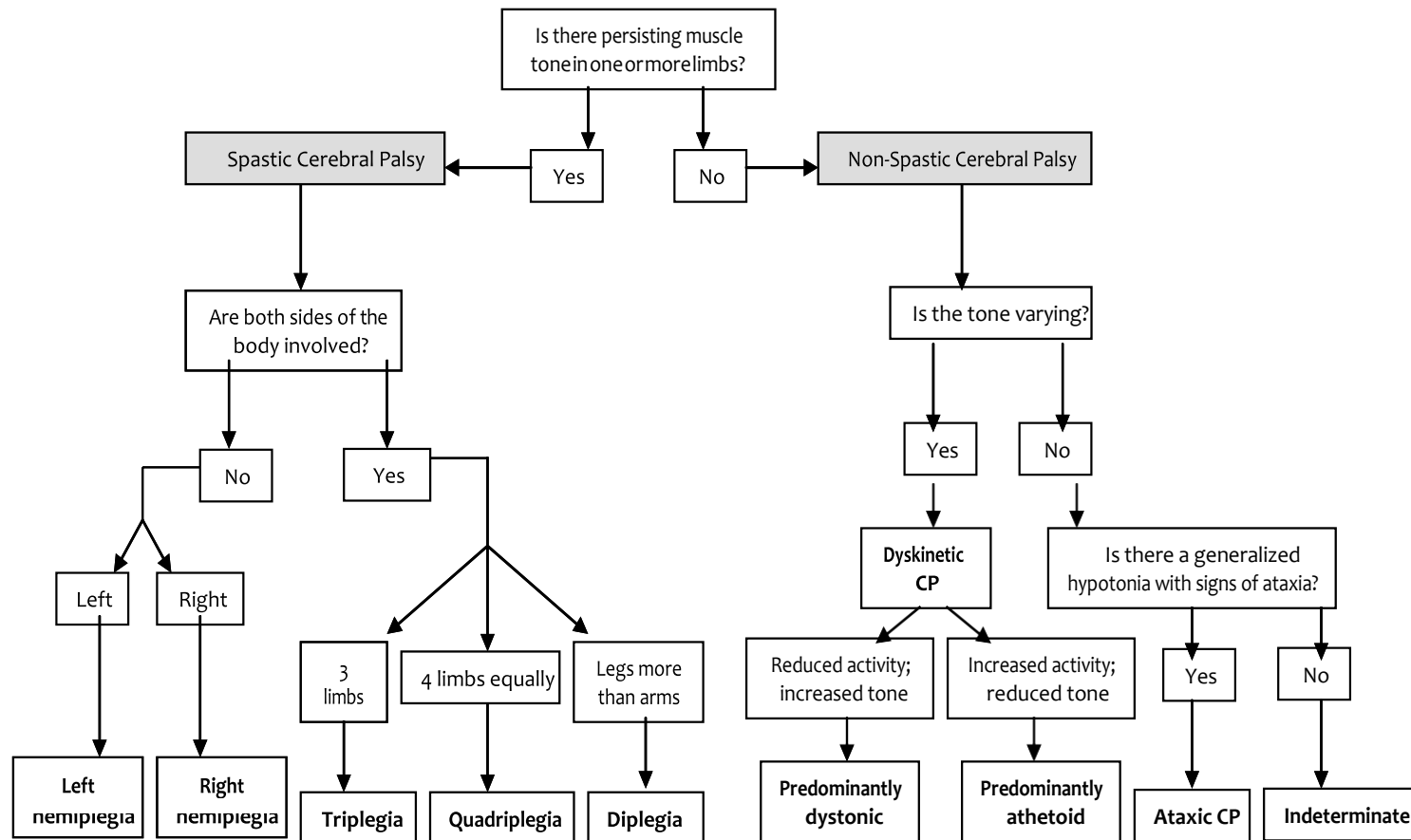
Once you have finished entering data, you must validate the case. Go to the Validate Case screen and click on the “Validate 18 Month Data” button at the bottom of the screen. The database will generate a report that will highlight missing, inaccurate or conflicting data and dates, or acknowledge of a complete, correctly entered case.

You can print off a status report if you so desire by clicking the “Print Status” link to the right of the “Validate Case” button.

You must go back to the appropriate section and make the corrections and then run the validation once more. When the validation is successful, the Validation Status in the yellow box will change to Validated for each section.

## Appendix A: Classifying the Type of Cerebral Palsy (CP)

The following algorithm can be used to help classify the type of CP.<sup>14</sup>



<sup>14</sup> Adapted from: Cans C. Surveillance of cerebral palsy in Europe: A collaboration of cerebral palsy surveys and registers. Dev Med Child Neurol. 2000 (42), 816-824.

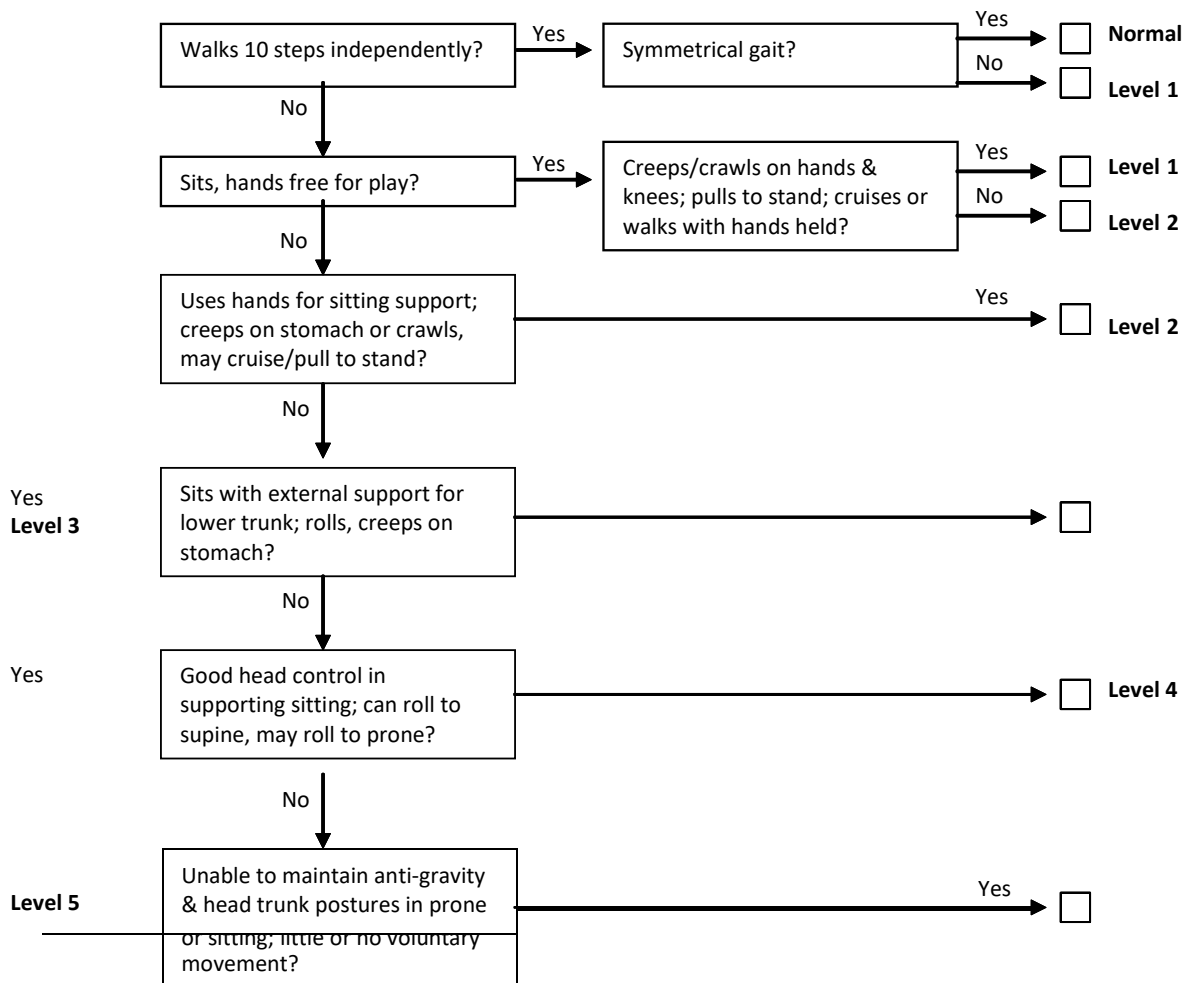


## Appendix B: Gross Motor Function Classification System (GMFCS)

Physical therapists, occupational therapists, physicians, and other health service providers familiar with movement abilities of children with cerebral palsy can use the GMFCS. No training is required; therapists and physicians can reliably use the GMFCS simply by reading the criteria. Prior to using the GMFCS, please visit <http://motorgrowth.canchild.ca/en/GMFCS/originalversion.asp> to read the full instructions, frequently asked questions, motor curves and percentiles.

Research has shown that at 18 months corrected age, the GMFCS gives a better indication of gross motor function impairment than a traditional assessment for children born at extremely low birth weight.<sup>15</sup>

The algorithm below has been adapted from the COT study.



<sup>15</sup> Vohr BR, Msall ME, Wilson D, Wright LL, McDonald S, Poole KW. Spectrum of gross motor function in extremely low birth weight children with cerebral palsy at 18 months of age. *Pediatrics* 2005;116:123-129

## Appendix C: Online resources Available to CNFUN Sites

Following is a list of resources available to support CNFUN sites as they collect and enter data. All documents listed here and contact information for the CNFUN coordinator and database manager are also available on the CNFUN website ([www.cnfun.ca](http://www.cnfun.ca)).

### **Data Collection Forms**

Using these data collection forms are optional, and are for convenience

- [Data collection forms \(English version\)](#)
- [Data collection forms \(version française\)](#)

### **Bayley**

- [Qualification requirements](#) (see level C, Q2)
- [FAQs for CNFUN examiners](#)

### **Gross Motor Function Classification System**

- [GMFCS - English version](#)
- [GMFCS - Version française](#)
- [Background information](#) (English only)
- [Motor growth curves](#) (English only)
- [Percentiles](#) (English only)

### **Additional Information on MiCare and the collaborating perinatal networks**

- [MiCare](#)
- [Canadian Neonatal Network \(CNN\)](#)
- [Evidence-based Practice for Improving Quality \(EPIQ\)](#)
- [Canadian Pediatric Surgery Network \(CAPSNet\)](#)
- [Canadian Premature Babies Foundation \(CPBF\)](#)

## Appendix D: Parent-Rating of NDI Script (English) - optional

<p style="text-align: center;"><b>Neonatal Follow-Up Clinic</b> <b>The 18-month visit</b></p>
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Dear parent,

Your child is being seen today at the Neonatal Follow-Up Clinic for a visit during which we will examine many aspects of his/her health. We will ask you questions about your child's health, we will examine your child to see how his/her body and his/her brain are growing and developing. We will also evaluate his/her development and assess whether your child is doing things he/she is supposed to do at his/her age, looking at areas of challenge and of strength. For example, we will evaluate how he/she moves, uses his/her hands, speaks, and performs different tasks.

This visit is very important for two reasons:

1. Sometimes, we find that a child needs help to reach his/her full potential. For example, some children may need help from a speech therapist or a physical therapist (specialists of speech and movement).
2. The information obtained at this visit is the same as that collected at every neonatal follow up clinic in Canada. With information from as many Canadian babies as possible, we can evaluate the best way to provide medical care for preterm children. We can also improve the short and long-term health of preterm children. This visit also allows us to better inform parents around what to expect when they have a preterm child.

Today, we will evaluate your child's overall "neurodevelopment," or how his/her body and brain are working together. In medicine, when we examine the development of children who were born preterm, we typically describe 4 possible developmental outcomes: 1) normal, 2) mildly impaired, 3) moderately impaired or 4) severely impaired. For all children, we can suggest interventions to help them develop to their full potential.

It is also important for us to have your opinion regarding your child's development. As parents, you know your child better than anybody else!

With this in mind, please tell us how you would rate your child's development:

- I think that my child is developing normally.
- I think that my child has a mild developmental impairment.
- I think that my child has a moderate developmental impairment.
- I think that my child has a severe developmental impairment.

## Appendix E: Parent-Rating of NDI Script (French) - optional

### Clinique de suivi néonatal : visite de 18 mois

Cher parent,

Aujourd'hui, votre enfant est vu à la Clinique de suivi néonatal. Pendant cette visite, nous allons examiner plusieurs aspects de sa santé. Nous vous poserons des questions sur la santé de votre enfant et nous l'examinerons afin d'évaluer la croissance et le développement de son corps et de son cerveau. Nous évaluerons aussi son développement afin de savoir si votre enfant se développe selon ce qui est attendu à son âge en identifiant ses forces et ses défis. Par exemple, nous évaluerons comment votre enfant bouge, utilise ses mains, parle et fait différentes tâches.

Cette visite est très importante pour deux raisons:

1. Parfois, nous constatons qu'un enfant a besoin d'aide pour atteindre son plein potentiel. Par exemple, certains enfants peuvent avoir besoin de l'aide d'un orthophoniste ou d'un physiothérapeute (spécialistes du langage et du mouvement).
2. L'information obtenue lors de cette visite est la même que celle obtenue dans toutes les cliniques de suivi néonatal au Canada. Avec de l'information provenant du plus grand nombre de bébés canadiens possible, nous pouvons évaluer les meilleures façons de soigner les enfants prématurés. Nous pouvons aussi améliorer leur santé à court et à long terme. Cette visite nous permet aussi de mieux informer les parents sur ce à quoi ils peuvent s'attendre quand ils ont un enfant prématuré.

Aujourd'hui, nous allons évaluer le « neurodéveloppement » global de votre enfant, ce qui veut dire comment son corps et son cerveau fonctionnent ensemble. En médecine, lorsque nous examinons le développement des enfants prématurés, nous décrivons habituellement quatre catégories possibles de développement : 1) normal, 2) incapacités légères 3) incapacités modérées ou 4) incapacités sévères. Pour tous les enfants, nous pouvons suggérer des interventions pour les aider à atteindre leur plein potentiel.

Il est aussi important pour nous de connaître votre opinion sur le développement de votre enfant. En tant que parents, vous connaissez votre enfant mieux que quiconque!

Veillez nous indiquer comment vous évaluez le développement de votre enfant:

- Je pense que mon enfant a un développement normal.
- Je pense que mon enfant a des incapacités légères dans son développement.
- Je pense que mon enfant a des incapacités modérées dans son développement.
- Je pense que mon enfant a des incapacités sévères dans son développement.