CNFUN Data Abstractors Manuel
Version 8, July 2024

Table of contents

Summary of Changes to CNFUN Case Report Form (CRF)

- **Four existing variables were updated** to reflect CNFUN database reports and trends in outcomes of very preterm children in Canada.
  1. Corrected age at assessment was changed from (18-24 months) to (24 ± 3 months) to follow evidence-based recommendation for more accurate prediction of long-term outcomes in children born preterm.
  2. Caregivers' ethnicity was updated to be more inclusive and representative of diversity of our patient population.
  3. Health-services utilization was updated to include admission to intensive care units or acute/emergency care visits.
  4. Respiratory complications, being the most common reason for hospitalization post NICU discharge, were updated to include medications and referral for airway or respiratory illnesses, date of tracheostomy placement and date of discontinuation of home oxygen therapy.

- **Three new variables were introduced to collect information,** to respond to parental priorities and to standardize practices for identification of the early signs of cerebral palsy (CP).
  1. Neurologic exam: age at diagnosis of high probability of CP and the scores on the Hammersmith Infant Neurological Examination (HINE) and when applicable, on the General Movement Assessment (GMA).
  2. Parent reported outcomes with a focus on child function and quality of life.
  3. Suspected autism spectrum disorder.

- **Eight questions were removed based on quality assurance review** of the database (high number of missing values and possible redundancies).

  1. C12: blood pressure values and C17 parents rating of child development and impairment severity.
  2. D2, D3 and D4: hearing assessment dates, type of screening tests and nature of hearing impairment.
  3. E2: type of visual problems.
  4. F5c and F6: Bayley questionnaire (social emotional and adaptive behavior) and the child behavior checklist.

CNFUN Contacts

Site	Data Abstractor	Site investigator
IWK Health Centre regional Hospital *Halifax, NS*	Tara Hatfield	Jehier Afifi
Charles Janeway Children's Health and Rehabilitation Center *St. John's, NL*	Phil Murphy	Nadine McEvoy
Dr. Everett Chalmers Hospital *Fredericton, NB*	Hala Makary	Hala Makary
Hopital de Moncton Hospital *Moncton, NB*	Maad Bakr Saleem	Maad Bakr Saleem
Saint John Regional Hospital *Saint-John, NB*	Alana Newman	Alana Newman
Centre hospitalier de l'Université de Sherbrooke *Sherbrooke, QC*	Alyssa Morin	Alyssa Morin
Centre Mère-enfant du Centre hospitalier de l'Université Laval *Québec, QC*	Mylène Leblanc	Sylvie Belanger
Centre hospitalier universitaire Sainte-Justine *Montréal, QC*	Karine Fondrouge	Thuy Mai Luu
Hôpital Maisonneuve-Rosemont *Montréal, QC*	Marie St-Hilaire	Marie St-Hilaire
Centre universitaire de santé McGill (MUHC) *Montreal, QC*	Marco.Zeid Alda.Dibattista Larissa.Perepolkin Danielle.Vallerand Joanne.Dostaler	May Khairy Jared Garfinkle
Children's Hospital of Eastern Ontario (CHEO) *Ottawa, ON*		Jana Feberova
Kingston General Hospital *Kingston, ON*	Sarah Mc Knight	Sarah Mc Knight
Windsor Regional Hospital *Windsor, ON*	Jovi Asuncion	Judy.Seesahai
St. Joseph's Health Care *London, ON*	Monique Mcgahan	Kevin Coughlin
Sunnybrook Health Sciences Center *Toronto, ON*	Elizabeth Macmillan-York	Rudaina Banihani
Mount Sinai Hospital *Toronto, ON*	Elena Nikolaeva	Kamini Raghuram
Hospital for Sick Children *Toronto, ON*	Cecilia Manuel	Linh Ly
Hamilton Health Sciences Centre- McMaster Children's Hospital *Hamilton, ON*	Wendy Seidlitz	Karen Thomas

CNFUN Contacts

Site	Data Abstractor	Site investigator
Health Science Center of University of Manitoba *Winnipeg, ON*	Debbie Williams	Florencia Ricci
St Boniface General Hospital of University of Manitoba *Winnipeg, ON*	Val Rogers	Cecilia de Cabo
Jim Pattison Children's Hospital *Saskatoon, SK*	Anna Donovan	Anna Donovan
Glenrose Rehabilitation Hospital *Edmonton, AB*	Anna.Vrban-Mcrae	Amber Reichert
Foothills Medical Centre *Calgary, AB*	Heather Kehler	Amina Benlamri
Queen Alexandra Centre for Children's Health *Victoria, BC*	Erin Long	Nisha Pillay
BC Women's Hospital & Health Centre *Vancouver, BC*	Arsalan Butt	Jessie Van Dyk

Introduction and context

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.

The 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 (CNFUN-DB) that is linkable to neonatal and perinatal databases;
- Use the CNFUN-DB 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.

The national electronic CNFUN database (CNFUN-DB) host a set of data collected during a standardized assessment done at 24 ± 3 months corrected age (CA):

- The optimal range: 21-27 months
- The accepted range: 18-30 months

The requirements to access the CNFUN-DB are:

- For standardized data collection across CNFUN sites

Templates for consent forms and recruitment brochures are available by contacting CNFUN Coordinator (isabelle.lahaie.hsj@ssss.gouv.qc.ca). Once approved, templates of the protocol, consent form, the case report form (CRF) and other recruiting materials will be sent to the CNFU Site Investigator.

- For using CNFUN data by researchers

Research projects may use CNFUN-DB pending approval of the CNFUN Steering Committee. A copy of the researcher's institutional REB approval and annual renewals should be forwarded to the CNFUN Coordinator (isabelle.lahaie.hsj@ssss.gouv.qc.ca).

The CNFUN Research Projects:

The CNFUN is a part of a larger Canadian perinatal and neonatal network, such as the Canadian Neonatal Network (CNN), the Canadian Preterm Birth Network (CPTBN), the Canadian Neonatal Transport Network (CNTN) and the Canadian Perinatal Surgical Network (CAPSNet). Research projects and partners across these networks have a direct input into the CNFUN database.

- The Maternal-Infant Care project (Birth cohort April 1, 2009 – Sept 30, 2011)

The CNFUN is one of several national research networks participating in the the Canadian Institutes of Health Research (CIHR) Team in the Maternal-Infant Care (MiCare) project. 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.

→ The MiCare inclusion criteria were infants who were born 1) at less than 29 weeks' gestation, 2) between April 1, 2009 and September 30, 2011) and who were treated in a Canadian level-III NICU.

→ A standardized set of neurodevelopmental assessments was done at 18-month CA and a developmental questionnaire was completed at 36 months CA.

→ Data collection took place between approximately January 2011 and June 2013. The MiCare project continued to recruit participants without additional funding for births October 2011 onwards, where feasible.

→ The CNFUN's role in MiCare was:

▪ To establish for all babies born before 29 weeks' gestation, a standardized set of developmental

assessments done for children at 18 months CA.

- To create with other participating CNN networks, an integrated MiCare database. The main types of variables include: population-based sociodemographic, clinical practices, outcomes and resource-use data for neonates and infants from birth to infancy (and developmental follow-up). This diversity of variables enables studies on how the interactions between determinants, mechanisms and processes of care affect pregnancy and infant outcomes over the short and long-term.

- The Parent-Evidence based Practice to Improve Quality (Parent-EPIQ) Project (Birth cohort July 1, 2016 – June 30, 2019)

The Parent-EPIQ project was a study funded as part of the CHILD-BRIGHT- CIHR- Strategy for Patient Oriented Research (SPOR). The Parent-EPIQ Project and CNFUN used knowledge translation techniques to:

→ Evaluate whether proven strategies (early-family integrated interventions) to improve cognitive and language abilities, embedded in neonatal FUPs, can reduce the burden of low cognitive and language composite scores on the Bayley-III at 18-21 months CA.

→ Invite parents to identify:
  - the outcomes which should be collected and reported within CNFUN,
  - how neurodevelopment should be defined.

The 2018 revision of this manual incorporated a question for parents regarding their perception of their child's development and if the child had neurodevelopmental impairment to describe its severity.

- The Canadian Preterm birth network (CPTBN) (Birth cohort January 2018 onwards)

The CIHR funded grant preterm birth network includes the Obstetric and the Maternal-Fetal Medicine community. The main goal of the CPTBN is to provide data from pregnancy up to 18-21 months post-delivery follow-up; it also includes complementary initiatives to improve both short term (NICU) and long-term (CNFUN) outcomes. CNFUN takes part of this network by measuring the effect of perinatal strategies on early childhood outcomes. For birth cohort 2022 onwards, the target CA at assessment is changed to 24 ± 3 months (range 21-27 month).

- The Early CP Project: Implementing best practices for earlier diagnosis of cerebral palsy in very preterm infants (Birth cohort January 2022 onwards)

This CIHR funded project grant aims to study whether implementing a clinical practice guideline (based on evidence by Novak et al, 2017)[1] improves clinicians 'ability in identifying the early signs of cerebral palsy (CP) in preterm infants <29 weeks' CA across neonatal FUPs in Canada.
This guideline includes implementing the Hammersmith Infant Neurological Examination (HINE), ± General Movement Assessment (GMA), clinical care pathways for early diagnosis of CP or high probability of CP, and a communication toolkit. Outcomes are measured at 24 ± 3 months CA. Data on HINE and GMA scores are included in CNFUN case report form (CRF).

- The CHILD-BRIGHT Parents' Voice Project: Implementing parent reported outcome measures in neonatal follow-up programs (Birth cohort January 2022 onwards)

This study funded as part of the CHILD-BRIGHT CIHR-SPOR is a follow-up to the Parent-EPIQ project which identified parent important outcomes. The goal of the Parents' Voice Project is to implement at the 24 ± 3 months CA visit standardized Parent Reported Outcome Measures (PROMs) that assess child functioning and quality of life. These PROMs will be integrated, moving forward, into the CNFUN research database. In doing so, new measures reflecting parental priorities will become available for outcome ascertainment.

[1] Novak I, Morgan C, Adde L, et al. Early, Accurate Diagnosis and Early Intervention in Cerebral Palsy: Advances in Diagnosis and Treatment. JAMA pediatrics. Sep 1, 2017;171(9):897-907.

I. Child Screening

1.1. Ethics approval

Each participating site must have ongoing ethics approval from their local Institutional Review Board (IRB or REB) to start screening children. Before starting to screen children, a copy of the approval and annual renewal needs to be forwarded to the CNFUN Coordinator (isabelle.lahaie.hsj@ssss.gouv.qc.ca).
. Templates of recruiting materials, such as CNFUN Research Database Protocol, consent and case report form (CRF), are available by contacting the CNFUN Coordinator (isabelle.lahaie.hsj@ssss.gouv.qc.ca).

However, an exemption letter provided by the local institution could be accepted if the CNFUN database is considered under the umbrella of quality assurance and quality improvement (QA/QI) initiatives, with data used exclusively for assessment, management, or improvement purposes as per the *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans* (TCPS 2 Article 2.5)[2].

1.2. 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 (isabelle.lahaie.hsj@ssss.gouv.qc.ca) if assistance is needed.

1.3. Eligibility criteria

CNFUN will primarily follow all Canadian level-III neonatal intensive care units (NICUs) survivors born before 29 weeks' gestation (i.e., 28 weeks or less) when they are 24 ± 3 months CA. However, data collection can include other high-risk neonatal groups and can span from neonatal discharge to school entry.

[2]https://ethics.gc.ca/eng/policy-politique_tcps2-eptc2_2018.html

1.4. 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.
- Child having complex medical issues.
- Child is followed by another program or service.

Please remember that:

- At 24 months CA (range 21-27 months), 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 24 ± 3 months CA (range 21-27 months) (exceptionally was 18 to 36 months CA during the COVID pandemic).
- The assessment should be completed as close to 24-months CA as possible.
- If the family cannot attend the clinic during this window, the assessment may be completed as early as 18 months CA and up to 30 months CA (24 ± 6 months). The latter 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.

At least some details on **all** eligible infants **MUST** be entered into the database for tracking purposes:

- Keep a running master log of babies who meet CNFUN's inclusion criteria.
- Do not include any information that would identify the patient such as names or birthdates.

Screening template can be provided to sites to help track number of eligible CNFUN infants, number of participants approached, reasons for participants declining contribution to research or data collection, and reasons for not approaching participants.

1.4.1 Strategies

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 or emails.
- ***Check with the Canadian Neonatal Network (CNN) Data Abstractor at your site to ensure your master log is complete or to generate a list of eligible patients, including the CNN Unique patient Identifier (CNN-UI).***
- If your clinic has other scheduled follow-up visits with the family, verify contact information at each visit and remind them about the 24-month CA 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.
- Previous research indicated that the most frequent point of drop-out from neonatal follow-up is between NICU discharge and the first scheduled appointment (up to 16% of eligible infants may NOT attend).[3] Screen families in the NICU to identify those at risk for not attending FUP visits and intervene early. The following are examples of perceived high-risk groups:
  - → Single mothers, parents experiencing social, educational, and economic challenges;
  - → Language barriers;
  - → 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;
  - → Language barriers.

[3] Ballantyne, M., Stevens, B., Guttmann, A., Willan, A. R., & Rosenbaum, P. (2014). Maternal and infant predictors of attendance at Neonatal Follow-Up programmes. Child: care, health and development, 40(2), 250–258.

1.4.2 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 these families as early as possible. Let the family know that follow-up is important, and that their child can be followed at any 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-UI and contact information to the new clinic, which must confirm they have made contact with the family and will be following the child for CNFUN (and will therefore receive funding for the 24-month assessment when applicable);
  - → Email the CNFUN Coordinator (isabelle.lahaie.hsj@ssss.gouv.qc.ca) and MiCare Database manager (Sonny.Yeh@sinaihealth.ca) 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 FUP/clinic to transfer medical and contact information.
  - → Email the CNFUN Coordinator (isabelle.lahaie.hsj@ssss.gouv.qc.ca) and MiCare Database manager (Sonny.Yeh@sinaihealth.ca) 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.

1.4.3 Deaths

In case of death, ***do not contact the family.*** However:

- → If a baby died PRIOR to discharge from the NICU: they should NOT be included in CNFUN.

If a baby died AFTER NICU discharge but PRIOR to 24 months CA: collect information in the CNFUN database such as date and cause of death, **only if you have access to hospital or clinic records, i.e do not contact the family.**

II. Recruitment for the 24-Month Corrected Age Assessments

2.1 Obtaining informed consent

The procedure for obtaining consent will vary by program and REB requirements. CNFUN clinics **MUST** ensure these requirements are met. Parents of eligible infants need to consent for data collection by CNFUN for research, benchmarking and quality improvement. All documents that will be shared with families must be approved by local IRB prior to use.

Clinics may send the consent form to parents of eligible infants 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 CNFUN database to the parents and/or provide preliminary information (such as a brochure https://www.cpbf-fbpc.org/neonatal-followup) 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.

2.2 Scheduling appointments

CNFUN's goal is for a follow-up rate of at least 80% of eligible infants. All attempts should be made to assess each eligible child at 24 ± 3 months CA. 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 following section outlines possible strategies.

2.3 Families with special circumstances

The goal of CNFUN 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, practices and 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.

2.3.1 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, the 24-month CA 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 participation in CNFUN but is still unable to attend a FUP, you may try to obtain as much information as possible over the telephone from parents and/or a community health provider or conduct a virtual clinic appointment, if feasible.
- Telecommunication technology (e.g., Telehealth): Some regions can provide follow-up in collaboration with community health care providers.
- Flexible scheduling.

2.3.2 Children with significant 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.

2.3.3 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. However, because they are eligible, they must be included in CNFUN database.

- 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 24-month assessment or eliminate it completely. However, you **must** ensure that parents or guardians have provided informed consent (if required by REB) and that the other clinic or program uses the same definitions of neurodevelopmental outcomes as CNFUN prior to entering data.

2.3.4 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 complete the assessment in that language. Parents or other close relatives are not optimal interpreters.

III.CNFUN Database

The CNFUN database was developed by the Database Working Group led by Dr. Anne Synnes, using the work of the *Consortium Québécois de recherche sur les enfants extrêmement prématurés* as a foundation. Participating sites contributing data to CNFUN use the data sharing agreement between their site investigator and MiCare/CPTBN or CNFUN. Data collected by CNFUN are securely stored, managed and analysed at the MiCare Coordinating Centre, at Mount Sinai Health. A collaborative method of review and development was used in order to ensure that the CNFUN dataset is nationally relevant and to facilitate linkage with other sources.

3.1 Overview of the data collection

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

Section A: 24-Month status	This section contains identifiers, 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 CNN database.
Section B: Family	This section captures sociodemographic information about the child's family and primary and secondary 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 record. 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 24-months CA assessment. If an audiologist visit is not part of your standard clinical protocol at 24-months CA, 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 24-months CA assessment. If an ophthalmologist visit is not part of your standard clinical protocol at 24- months CA, 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: Neurodevelopmental assessment	The focus of this section is the Bayley Scales of Infant and Toddler Development (Bayley 4) and the PROMs about child function and quality of life. 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.

3.2 Features of the CNFUN database

The following features are available

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

3.3 System requirements & installation

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

Software requirements: • Windows 10 or later • NET Framework 3.5 • Microsoft Access 2013 or later (for Query Database use only)	**Hardware requirements**: • Updated Intel or AMD CPU • 4 GB memory and above • Screen resolution of 1024 x 768 and above

3.4 Linkage with CNN

One of the CNFUN's database main features is its ability to link with the CNN and its sisters networks. This will allow analysis of the relationships between maternal, perinatal and neonatal variables (including NICU interventions) with early childhood outcomes.

Data will be linked using the **CNN Unique Identifier** (CNN-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 MiCare Database manager (Sonny.Yeh@sinaihealth.ca) or the CNFUN Coordinator (isabelle.lahaie.hsj@ssss.gouv.qc.ca)

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

- CNN unique identifier (A1)
- Date of birth (A3)
- Gestational age (A4)
- Birth weight (A5)

3.5 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 a paper form during the assessment and enter it into the CNFUN database at a later time. Information on the case report form. (CRF) for data entry can be found in the list of resources in Appendix C.

3.6 Data entry

Instructions for data entry and general database use are available in the CNFUN Research Database Protocol at CNFUN website or contact the CNFUN Coordinator (isabelle.lahaie.hsj@ssss.gouv.qc.ca). Each site should develop a system for data entry that works for their particular circumstances. It is strongly recommended that one person at each clinic takes on the responsibility for CNFUN data entry.

3.7 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 performed and a list of any errors 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 MiCare Database manager (Sonny.Yeh@sinaihealth.ca) or CNFUN Coordinator (isabelle.lahaie.hsj@ssss.gouv.qc.ca)

3.8 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, so that CNFUN can compile a national annual report using data from all sites. Detailed instructions on uploading data are available in the CNFUN Research

Database Protocol and on CNFUN website. If you have any questions, please contact the CNFUN Coordinator (isabelle.lahaie.hsj@ssss.gouv.qc.ca).

3.9 Confidentiality

There are several levels of confidentiality that must be maintained. First, the data in the site computer contains personal 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 MiCare coordinating center (CC). The database manager will be able to identify patients by their **CNN unique identifier** (UI), but only personnel at the local site will be able to match the CNN-UI 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 CNFUN database 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 assurance.

For more information on the CNFUN Research database, please refer to CNFUN Research Database Protocol available on the CNFUN website.

IV. CNFUN Case Report Form (CRF) definitions

Following are the CRF variables and their 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 these definitions, you are still unsure how to code a variable, please contact the CNFUN Coordinator (isabelle.lahaie.hsj@ssss.gouv.qc.ca).

Section A: 24 months status

The CNFUN database collects information on the child's general health and development at 24 ± 3 months CA (post-term) months (range 21 - 27 months), which is the target window for the assessment.

- Completing the assessment as close to 24 months CA as possible is preferable.
- If the child cannot be seen in this age window; the assessment may be completed as early as 18 months CA and up to 30 months CA (24 ± 6 months).
- If the child was assessed more than once between the 18- and 30-months time period: select the data from the most recent visit at or before 24 months CA.

The two main sources of information to complete Section A are:

- Hospital records that FUPs use to track patients
- The CNN database

The CNN Unique Patient Identifier (CNN-UI) is:

- Provided by local site's CNN data abstractor or site investigator.
- A coded number assigned to the infant at the time of entry into the CNN database.
- Used to track the baby and to link records between CNN and CNFUN databases.
- Uploaded to the MiCare office in order to link the child's follow-up and NICU data.

The optional variables:

- Information such as the infant's name and hospital identification number are for use by local site only if accepted by the local institutional review board (IRB). Some IRBs may require that paper CRF is completely de-identified.

- Identifying information will not be uploaded to the MiCare office or included in the CNFUN database with the rest of the data entry.

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.

A1a: CNFUN unique patient identifier	The CNFUN unique patient identifier (CNFUN-UI) is a generic number automatically assigned by the program. No data entry is required.
A1b: CNN unique patient identifier	Obtain the **CNN-UI** from the CNN Data Abstractor at your site. Each baby has only one UI, even if transfer occurred between NICUs. The UI that should be used is the one generated at the hospital of the baby's **first** admission. UI is optional: If patient not eligible for MiCare study
A2a: First name **A2b: Last name** **A2c: Hospital number**	These 3 variables are optional - Only for tracking purposes at the local site. - Stored only on your hospital server and will not be uploaded to the MiCare office.
A3: Date of birth	Enter the child's date of birth.
A4: Gestational age (GA)	*CNN calculates the GA according to an algorithm that uses data on early ultrasounds, the last menstrual period, expected date of confinement as well neonatal and obstetric estimates as inputs.* Obtain the baby's GA in weeks and days from your site's CNN database. If the GA obtained from the CNN database is different from the records: please enter the GA used by the follow up program. Please inform the MiCare Database Manager and CNFUN Coordinator with the list of those participants with discrepancy between their assigned GA in CNN database and in CNFUN clinic.
A5a: Birth weight	Obtain the child's birth weight from your site's CNN database in grams. If a birth weight is unavailable: use the first weight taken in the first 24 hours of life. If the only weight available is an estimate: please record the estimate.
A5b: Sex	Sex refers to sex assigned at birth. Check one from the following list: *Male, Female, Intersex, Unknown.*

A6: First level-III NICU hospital	Select from the drop-down list. If the child had not cared for in one of the hospitals on the list, select *Other.*
A7: Date of discharge home	This variable is optional. You can obtain this information from discharge summaries or hospital records (before obtaining from parents). Date: Day the child was discharged home from the last hospital.
A8: Weight at discharge home	This variable is optional. You can obtain this information from discharge summaries or hospital records (before obtaining from parents). Weight: Last weight in grams obtained within 5 days prior to discharge from the last hospital. In Québec, this can often be found in the child's vaccination booklet.
A9 : Neonatal FUP clinic responsible for the child's follow-up	Select the FUP clinic/program where the child is seen, from the list. Some FUP responsible for follow-up may not actually see a child (eg. geographic distance): some details on where the child was assessed need to be entered in Section C: Medical History & Physical Examination.
A10 : Reason for follow- up	Select all that apply: • MiCare: Born at < 29 weeks GA. *In addition, the following options have been built into the database for possible future projects:* *- Entry for cases meeting these criteria is completely optional (no upload to MiCare)* *- CNFUN will only ask sites to enter these cases after a protocol has been defined and IRB has been obtained.* • Congenital Diaphragmatic Hernia (CDH): The child was diagnosed with CDH within the first 7 days of life. • Hypoxic-Ischemic Encephalopathy (HIE): The child was diagnosed as HIE during his or her NICU course. This information will be used as part of a registry on therapeutic hypothermia (cooling) used in patients with HIE in partnership with CNN. • Local FUP criteria: The child meets your FUP's inclusion criteria. • Other: Select and specify if applicable.
A11: Current postal code	Enter the first three characters of the postal code where the child currently resides.
A12: Date of visit	Enter the date of the child's assessment. • If it took place over more than one day: date when most of the data was collected. • If the child was not seen in CNFUN clinic and information is from other means (i.e., phone interviews, family physician, etc.): date when records were obtained.
A13a:	*The CNFUN database collect information on child's general health and at 24 months CA (post-term) ±3 months (range 21 - 27 months) as the target window for the assessment:*

24 months follow-up status	- *completing the assessment as close to 24 months CA as possible is preferable.* - *If the child could not be seen during this age window: the assessment may be completed as early as 18 months CA up to 30 months CA* (24 ± 6 months). - *If the child was assessed more than once between 18 and 30 months time period: select the data from the most recent visit at or before 24th month of corrected age.* Check one from the following list: • Seen*:* the child has been seen in clinic (or by a health professional outside the CNFUN clinic) and the assessment is complete. • Seen but incomplete: the child came to clinic, but the assessment was not completed (because family had to leave, child was uncooperative, etc.) • Not seen: The assessment was not attempted. If you select this option, you must specify why by choosing one of the following reasons: - Declined/consent not obtained: Select if information was provided, but the MiCare consent form was not signed. - No contact information: Select if your program is unable to find contact information for the family or guardians. - Unable to reach: Select if your program has tried to contact the family but was unable to connect with them. - Missed appointment: Select if an appointment was made but the family did not attend and subsequent attempts to reschedule were unsuccessful. - Deceased: Select if a child has died after discharge from the NICU but before follow-up. See A13b-d on how to enter details - Other: Select and specify if follow-up was not completed for a reason other than those listed above.
A13b: Details of death known	This field will only be activated if "Deceased" is selected in A13a: 24-month follow-up status. **Do not contact the family just to obtain this information** • Select Yes: Both the date and cause of death are known (medical certificate of death, autopsy report or other hospital records). The following details are mandatory: - A13c: Date of death - A13d: Cause of death (free text field) • Select No: Details of death are not known and are not expected to be available or obtained.

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 sociodemographic information of caregivers and the diverse family environment in Canada. Where possible, we have used definitions from Statistics Canada and other MiCare Networks to maintain consistency.

Primary Caregivers

Most of the variables in this section are related to the child'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 database can store information on up to 2 caregivers. If the family has one primary caregiver, check the box next to "Primary Caregiver #2 – as 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. Here are some examples to help illustrate how data should be entered:

A child lives with his biological parents who both work full-time.

a. Primary caregiver #1: Mother. *Gender* = female, *Type of caregiver* = biologic parent.
b. Primary caregiver #2: Father. *Gender* = male, *Type of caregiver* = biologic parent.

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* = biologic parent.

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* = biologic parent.
b. Primary Caregiver #2: Not applicable.

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* = biologic parent.
b. Primary Caregiver #2: Not applicable.

B1a/B2a: **Gender**	*Gender of caregiver refers to current gender which may be different from:* - *sex assigned at birth* - *what is indicated on legal documents.* Choose: Male OR Female OR Non-binary OR Prefer not to answer.
B1b/B2b: **Type of caregiver**	Select one from the following list: • Biological parent • Parent (with donor egg or sperm) • Step-parent • Adoptive parent • Other family member • Foster parent • Other (if this is selected, specify this person's relationship to the child)
B1c/B2c: Birth year	Enter birth year in the format YYYY
B1d/B2d: Education	Select the highest level of education completed from the following list. *'Some postsecondary education': If the caregiver has started some additional education after obtaining a high school diploma, but did not obtain any certificate, diploma or degree.* *Postsecondary certificates: from a college, a vocational school, a CEGEP (in Quebec), or a university.* • Less than high school • Completed high school • Some postsecondary education: some college, CÉGEP or university • Postsecondary certificate, diploma or degree: complete college, CÉGEP or university • Unknown
B1e/B2e: **Current**	Choose one from the following list: • Employed: Select if employed full- or part-time or if self-employed. • Unemployed: 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

employment status	household responsibility, select *Full-time Homemaker*. If she/he is not available for work due to injury or disability, select Other. • Student: 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 *Employed*. • Stay at home caregiver: Select if she/he is not available for paid employment due to childcare and household responsibilities. • Unknown: Select if employment status is unknown. • Other (specify)
B1f/B2f: Current occupation	This variable is optional. If employed is selected in B1/2f, enter the caregiver's occupation or job title.
B1g/B2g: Employment status at time of birth	Select one from the following list: • Same as current: 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. • Not applicable: Select if caregiver was not involved with the child at the time of delivery (e.g., an adoptive or foster parent). All other definitions remain the same as above, in B1e/B2e.
B1h/B2h: Occupation at the time of birth	This variable is optional This will be activated only if the employment status or occupation is different from the person's current employment.
B1i/B2i: Country of birth	Select: Canada or Other.
B1k/B2k: New immigrant	If other is selected (a surrogate for immigrant status): indicate if new immigrant to Canada (< 5 years).

B1j/B2j: Ethnic group	Select all ethnic group (s) from the following list that apply to the caregiver: • White • Black • First Nations, Metis or Inuit • Hispanic/Latinx • East Asian: Mainland China, Hong Kong, Japan, Macau, Mongolia, North Korea, South Korea, Taiwan • South Asian: Afghanistan, Bangladesh, Bhutan, India, Iran, the Maldives, Nepal, Pakistan, Sri Lanka, Tibet, and the British Indian Ocean Territories. • Southeast Asian: Brunei, Burma (Myanmar), Cambodia, Indonesia, Laos, Malaysia, Philippines, Singapore, Thailand, Vietnam and Timor-Leste. • West Asian (excluding Arab): Armenia, Azerbaijan, Cyprus, Georgia, Israel and Turkey. • Asian (region unknown): Select if Asian is mentioned but East or South is not specified. • Arab: Algeria, Bahrain, Djibouti, Egypt, Iraq, Jordan, Kuwait, Lebanon, Libya, Mauritania, Morocco, Oman, Palestine, Qatar, Saudi Arabia, Somalia, Sudan, Syria, Tunisia, United Arab Emirates and Yemen. • Other group, specify: • Unknown or do not wish to provide.

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.

B3: Number of people living in the home ≥ 3 days per week	Specify the number of adults and children living in the home at least three days per week. If this child's parents are under the age of 18, include them in the number for adults. If one the sibling is above the age of 18, include them in the number for adults.
B4: Does someone other than the caregiver(s) in B1/B2 above regularly care	If the child is cared for by someone other than the primary caregiver(s) listed in B1/B2 for at least more than 10 hours per week since at least 3 months, select one from the following list. • Yes, inside the home (the child is cared in own home by a relative or a non-relative) • Yes, outside the home by a relative or a non-relative (informal childcare)

for the child ≥ 10 hours per week?	• Yes, outside the home in a regulated childcare center (the child is care in a family-based or group-based childcare center). Otherwise, select No.
B5: What is the primary language spoken most often to the child at home?	The primary language is the one used by the family either predominantly or exclusively at home. Select one from the following: • English • French • Other
B5b: Number of languages to which the child is exposed	This variable is optional. 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
B6: **What are the family's sources of financial support?**	Check all that apply to the family's current situation[4]: • Paid employment: Select also if self-employed. • Employment insurance: includes benefits for unemployment, sickness, maternity, paternity and adoption. • Social welfare or other governmental benefits: 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, ware veteran's allowance, pensions to widows and dependants of veterans, and workers compensation. Includes sickness, maternity, paternity, adoption, work sharing, retraining, social assistance, pensions, and veterans' allowances.

[4] https://www12.statcan.gc.ca/census-recensement/2021/ref/98-500/004/98-500-x2021004-eng.cfm

	• Other: Includes alimony, child support, periodic support from other persons not in the household, investment income, scholarships, student loans or bursaries, etc. • Unknown: Select if you don't know or if the family does not want to answer.

Section C: Medical history & physical examination

This section is used to obtain the child's medical history (questions C1-C8) as well as 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, including the Hammersmith Infantile Neurologic Exam (HINE), and reviewing the child's medical chart where applicable.

C1: **Date of exam**	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.
C2: **Where was this child assessed?**	• Specify the location (s) where the 24 months (±3 months) CA assessment was completed. • If the child was seen more than once in the clinic between 18-30 months, please select the most recent visit at or before 24 months CA (post-term). • Specify how the assessment took place: - In person: in a clinic (follow up, travel, child development center) or in the office (community pediatrician, family physician, nurse practitioner, etc.) - Virtually: using telehealth, zoom, etc.
C3a: **Since discharge home, has the child been re-hospitalized for at least 1 night?**	Indicate (yes/no/unknown), select *Yes* if the child was admitted on a short- or long-term unit for at least one night after the initial hospitalization. The initial hospitalization refers to the continuous time the baby is in a hospital prior to first discharge home. Record this information from the date of discharge home up to the date of the 24th month follow up clinic assessment (range 18-30 months). 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 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.

C3b: Total number of re-hospitalizations	Enter the total number of re-hospitalizations as per the definition above (C3a). If you are unable to obtain this information via hospital records: - ask the parents or guardians. - If parents are unsure: enter their best estimate.
C3c: Length of stay (number of hospitalization days)	For each re-hospitalization: - report the actual number of days the child stayed in the hospital. - if the length of hospitalization is not provided: select *Unknown*[5,6].
C3d: Primary reason	For each re-hospitalization, select the diagnosis most responsible for it: • Respiratory (infectious): Includes bronchiolitis, upper or lower respiratory tract infections including laryngitis/croup, bronchitis and pneumonia, bronchospasm and asthma following a respiratory infection. • Respiratory (non-infectious): Includes apnea, acute life threatening event (ALTE), wheezing or asthma not following respiratory infection, and unstable bronchopulmonary dysplasia (not due to respiratory infection). • Growth, feeding or nutrition: Poor weight gain, failure to thrive, gavage or ostomy problems, GERD, feeding intolerance or food allergy, etc. • Accident/trauma: Investigation for possible child abuse, fractures, skull trauma, burns, toxic ingestion, etc. • Surgery: Includes shunt for hydrocephalus or revision, ENT or eye surgery, tracheostomy, gastrostomy, other digestive surgery, hernia repair, etc. More details on surgeries will be entered in C4a. • Infection: Includes infections that are not respiratory in nature, such as sepsis, bacteremia, fever, gastroenteritis, urinary tract infection, otitis, meningitis, shunt infection, etc. • Central nervous system (CNS) issue: Includes febrile and afebrile seizures, shunt malfunctions, etc. • Other: Specify in the text field. • Unknown

[5] Lamarche-Vadel A, Blondel B, Truffert P, Burguet A, Cambonie G, Seltons D, Arnaud C, Lardennois 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 Pediatrics 2004, 93, 1340-1345.
[6] Underwood MA, Danielsen B, Gilberts WM. Cost, causes and rates of rehospitalization of preterm infants. J Perinatol (2007)

C3e: Requirement for intensive care admission	**For each re-hospitalization**, indicate (yes/no/unknown) if the child required admission to an intensive care unit (pediatric intensive care unit, neonatal intensive care unit, critical care unit).
C3f: Requirement for supplemental oxygen	**For each re-hospitalization**, indicate (yes/no) if the child required supplemental oxygen. If the child is already on home oxygen, answer 'yes' if oxygen needs exceeded usual requirement.
C3g: Over the <u>past 3 months</u>, how many times has the child had a sick visit (urgent) because of breathing problems?	*A sick visit includes urgent visit to the doctor's office, clinic or Emergency Room*. • <u>None</u>: no sick visits over the past 3 months. • Select the number of times over the past 3 months, the child had sick visits because of breathing problem: ☐ 1-3 time ☐ > 3 times
C4a: Has the child had any surgeries requiring anesthesia since discharge from the NICU?	*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 <u>should not be</u> included here.* <u>Yes:</u> the child has had any surgical procedures since discharge from the NICU that have required anesthesia that was administered by an anesthetist.
C4b: Type of surgery	Check all that apply: • Shunt (VP shunt) or shunt revision for hydrocephalus if yes (total number of surgeries/revisions) • ENT surgery (including tympanostomy) • Eye surgery • Tracheostomy • Gastrostomy: Either endoscopic or radiological • Hernia repair • Anti-reflux surgery: Nissen fundoplication or done by endoscopy • Other abdominal surgery • Other: Specify in the text box provided.
C5: Has the child had non-febrile seizures since discharge?	• <u>Yes:</u> the child has had non-febrile seizures since discharge home.

	• No: 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).
C6: Is the child currently being immunized according to provincial guidelines?	This variable is optional. • Yes: the child is up-to-date with their immunization according to the public health guidelines in his or her province of residence OR the child's immunizations are incomplete but the parents/caregivers intend to complete them. • No: the child has not had any immunizations OR the parents do not intend to immunize their child according to public health guidelines.
C7a: In the last three months, had the child taken any of the following medications on regular basis? ?	For each item of the following list: - Inhaled steroids: Flovent, Pulmicort, Alvesco, Advair, etc. - Inhaled bronchodilators: Ventolin, Serevent, Advair, etc. - Diuretics - Anticonvulsants - Antibiotics - Anti-reflux drugs: Maxeran, Domperidone, Cisapride, Zantac, Prevacid, etc. - Vitamin supplements - Iron - Other: specify in the text box provided. For each medication, please indicate: • No: medication was not used (even if it was prescribed) within the 3 months preceding the assessment. • Yes, still using it: 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 24-months visit and will continue to do so after the visit. • Yes, but stopped it: 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 24-month visit but has stopped or will stop on the day of the visit. • Unknown
C7b: Since discharge home, has the child taken any of the following on a regular basis?	Check all that apply: • Antihypertensive • Oral corticosteroids for acute disease (e.g: dexamethasone, prednisone, prednisolone) for breathing problem not controlled by other medications. • Oral corticosteroids for replacement therapy in case of adrenal insufficiency (e.g. daily hydrocortisone or Cortef). • Sildenafil/Bosentan (for pulmonary hypertension)

	For each medication, specify if: Yes, still using it, Yes but stopped it, NO or Unknown.
C8: Since discharge home, has the child used any of the following aids at home?	*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.* For each item of the following list specify if: Yes, still using it OR Yes, but stopped it • Apnea monitor • Pulse oximeter • Supplemental O2 If oxygen was stopped, indicate the date of discontinuation: ☐ month ☐ year • Respirator/CPAP • Gavage feeding • Gastrostomy or jeujunostomy • Ileostomy/Colostomy • Tracheostomy If yes: indicate the date of tracheostomy placement: ☐ month ☐ year • Adapted wheelchair or stroller • Braces, splints or orthoses • Walker • Other mobility aids: specify in the text box provided.
C9: Weight	Child's weight in kg. If you only have the weight in pounds, enter that and the database will automatically convert for you.
C10: Height	Child's height in cm. If you only have the height in feet and inches, enter that and the database will automatically convert for you.
C11: Head circumference	Child's head circumference in centimeters.
C12: Are you aware of other diagnoses or issues that are likely affecting development?	This variable is optional. Other diagnoses or issues likely affecting child development (check all that apply): • Fetal Alcohol Spectrum Disorder • Chromosomal or genetic abnormalities • Extensive hospitalization: the child has remained hospitalized for a continuous period of at least three months after their EDC or NICU discharge. • Congenital heart disease (congenital heart defect or CHD): - the child has a congenital heart defect requiring open-heart 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). • Exposure to illicit drug use or alcohol use during pregnancy or parent with substance use disorder (i.e. regardless of the effect it may have on development). This includes drugs such as cocaine, crystal meth, heroin, marijuana, etc. • Other: please specify in the related text box.

Cerebral Palsy and Motor Development

Sections C13-C16 report data on the physical and neurological examination, including early screening tests for cerebral palsy (CP) such as the Hammersmith Infantile Neurologic Exam (HINE) or the General Movements Assessment (GMA).

The physical and neurological exam should be performed by a healthcare professional with adequate training and experience in neurodevelopmental assessment of extremely preterm infants.

C13: According to your exam, does the the child have abnormal neurological signs?	• Yes: the clinician thinks there is a clinically significant neurological abnormality that is affecting the child's development. • No: the only abnormalities present are mild or transient, with no significant impact. • Not examined
C14: Does the child have cerebral palsy?	*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 CP are often accompanied by disturbances of sensation, cognition, communication, perception, and/or behaviour, and/or by a seizure disorder.*[7] According to the definition above, select: • Yes: the clinician is confident that the child has CP based on physical exam or standardized tests (HINE or GMA). • High probability of CP: the clinician thinks the child may have CP based on physical exam or standardized tests (HINE or GMA), but not comfortable making a firm diagnosis at this time. If yes, questions C14 a, c, d are mandatory.

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

	• No: clinician thinks the child does not have CP based on the physical exam or standardized tests (HINE or GMA). • Unknown • If Yes, questions C14a- C14f, C15 and C16 are mandatory • If High probability of CP, questions 14 a,c,d are mandatory • If No is selected, move to question C15 (HINE exam).
C14a: **Does the child have cerebral palsy (CP)?**	- C14a: Date referral made for diagnosis (YYYY/MM/DD): _____ ☐ Follow-up team made the CP diagnosis - C14b: Date of CP diagnosis (YYYY/MM/DD): _____ - C14c: Date of referral for rehabilitation services (YYYY/MM/DD): _____ ☐ No referral made • For the above calendar dates for CP diagnosis/referral, if the exact day is unknown (but the month and year are known), please select the 15th day of the month (accurate by ± 2 weeks). - C14d: Cerebral MRI requested for CP? ▪ Yes, new request was made ▪ No, cerebral MRI was already available ▪ No
C14e: **Specify type of CP**	***Appendix A*** *contains an algorithm that will assist in classify the type of CP.* Specify the type of CP from the following list: • Spastic: it is optional to specify whether it is: - Diplegia: Involves all four limbs, but legs more than arms - Triplegia: Involves three limbs - Quadriplegia: Equal involvement of all four limbs - Left hemiplegia: Involves the left arm and/or leg. The child may have an abnormal gait and/or an exaggerated hand preference. - Right hemiplegia: Involves the right arm and/or leg. The child may have an abnormal gait and/or an exaggerated hand preference. • Non-Spastic: it is optional to specify whether it is: - Ataxic: 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).

	- Dyskinetic CP (predominantly dystonic): presence of involuntary, uncontrolled, repetitive sometimes stereotyped movements. There is sometimes decreased movements and hypertonia. - Dyskinetic CP (predominantly athetoid): presence of involuntary, uncontrolled, repetitive, sometimes stereotyped movements. There is increased movement and hypotonia. - Hypotonia: Decreased muscle tone without motor coordination abnormalities. • Indeterminate: 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.
C14f: Gross Motor Function Classification System (GMFCS)	*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 **Appendix B** for:* *- the full instructions, frequently asked questions, motor curves and percentiles.* *- an algorithm to help classify the level of motor function using the GMFCS.* Select the Level of Motor Function, as indicated by the GMFCS from the drop-down menu.
C15 (a-k): Hammersmith Infantile Neurologic Exam (HINE)	*Early diagnosis of CP is important as meta-analyses have shown that targeted intervention initiated prior to 6-12 months corrected age improves motor and cognitive function in children with CP and reduces rates of secondary complications[8]. CP is typically diagnosed between 12-24 months of CA. Evidence supports combining standardized tests (HINE and GMA) with brain MRI to increase the diagnostic accuracy of CP and to enable early diagnosis at 9 months CA[9][10].* The HINE: • 26 items assessing: cranial nerves, posture, movements, tone and reflexes. • each item: scored 0-3 (total 78). • global scores cut-off for high probability of CP: ≤56 at 3months CA and ≤65 at 12 months CA • high (~90%) sensitivity and specificity for CP and correlate with Bayley scores at 2 years CA[11].

[8] Spittle A, Treyvaud K. The role of early developmental intervention to influence neurobehavioral outcomes of children born preterm. Semin Perinatol. Dec 2016; 40 (8):542-548.
[9] Bosanquet M, Copeland L, Ware R, Boyd R. A systematic review of tests to predict cerebral palsy in young children. Developmental medicine and child neurology. May 2013; 55(5):418-26.
[10] Maitre NL, Burton VJ, Duncan AF, et al. Network Implementation of Guideline for Early Detection Decreases Age at Cerebral Palsy Diagnosis. Pediatrics. May 2020;145(5)
[11] Romeo DM, Ricci D, Brogna C, Mercuri E. Use of the Hammersmith Infant Neurological Examination in infants with cerebral palsy: a critical review of the literature. *Developmental medicine and child neurology*. Mar 2016

	C15a: Has the HINE been completed since birth? ☐Yes ☐No ☐Unknown C15b: If yes, how many HINE assessments were completed? _____ For each HINE assessment, specify the following. If unknown, please specify. <u>HINE Assessment 1:</u> C15c: Date of assessment: (YYYY/MM/DD)_____ C15d: Total Global Score (max 78, minimum score 10): _____ Total Scores of each of the categories: - C15e: Cranial nerve function score (max 15) _____ - C15f: Posture score (max 18) _____ - C15g: Movements score (max 6) _____ - C15h: Tone score (max 24) _____ - C15i: Reflexes and reactions score (max 15) _____ C15j: Number of asymmetries on the right side: _____ C15k: Number of asymmetries on the left side: _____ Add additional HINE assessments as needed and for each, complete questions 15c-15k HINE Assessment 2 HINE Assessment 3 Etc.
C16 (a-c): **General Movement Assessment (GMA)**	*The GMA is based on Prechtl's framework on the development of spontaneous movements of infants. Specific movement patterns (e.g. fidgety movements) are expected during specific time windows and are altered with brain injury.* *Observation and assessment of these general movements can predict CP with high accuracy. This is done by videotaping an infant in the supine position for 3-5 minutes. Detailed review of the recording is then performed by trained staff. In preterm infants, the absence of fidgety movements, which typically occurs between 9 weeks post-term and 25 weeks + 6 days post-term, predicts CP with a sensitivity of 87-100% and a specificity of 82-95%.* C16a: Was the GMA for fidgety movements assessment completed at 9-20 weeks' CA? ☐Yes ☐ No ☐Unknown C16b: If yes, date of assessment: (YYYY/MM/DD)_____ C16c: If yes, what were the Fidgety Movements (FMs)?

	☐Normal FMs ☐Abnormal exaggerated ☐Absent/Sporadic ☐Unknown
C16d: General Movement Optimality Score (GMOS)	This variable is optional. *The Motor Optimality Score Revised (MOS-R) assessments are applicable from 9 weeks + 0 days to 25 weeks + 6 days post-term age, with the optimal assessment window falling between 14 to 17 weeks post-term.* C16 d: Was the MOS-R done with GMA? ☐Yes ☐ No ☐Unknown If yes, complete the following: What was the global composite score (maximum 28, minimum 5): _____ Repertoire of coexisting movements:☐ Present ☐ Reduced ☐Absent Observed movement patterns: ☐ Normal > Atypical ☐Normal = Atypical ☐Normal < Atypical Postural patterns: ☐ Normal > Atypical ☐Normal = Atypical ☐Normal < Atypical Movement characters: ☐ Smooth and fluent ☐Abnormal, but not CS ☐CS
C17: Has the child been referred for treatment to any of the following services since NICU discharge?	• Seen: 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 24-month assessment. • Waiting: the child is on a waiting list or is waiting for a referral: - Alternative care: Complementary or alternative medicine such as acupuncture, chiropractic services, massage therapy, homeopathy etc., that are not performed by a physician. - Dietitian: Services provided by Registered Dietitians or qualified nutritionists. - Early intervention program: Programs that provide screening and services in children at risk of a neurodevelopmental disability. - Neurologist - Occupational therapist - Physiatrist: Physicians specializing in physical medicine and rehabilitation. - Physical therapist - Psychologist - Rehabilitation program: Programs that provide treatment to child with an identified neurodevelopmental or neurosensory impairment.

	- Social worker - Speech or language therapist • Visiting or community nurse: - 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). - Home care was required after NICU discharge for children with complex health needs. • ENT (for airway problems, including vocal cords) • Respirology • Other: Please specify any other programs or specialties that provide services for this child.
C18: Additional comments	This variable is optional. 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 (isabelle.lahaie.hsj@ssss.gouv.qc.ca).

Section D: Auditory Assessment

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 24-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 24 months assessment and a referral is made, please include the report that resulted from the referral.

D1: Has the child's hearing ever been tested or screened in NICU or after discharge?	Select: Yes OR No OR Unknown.
D2: Does the child have a hearing loss?	Select: Yes OR No OR Unknown If Yes is selected, complete the next question.
D3: Does the child require a hearing aid(s) or cochlear implant(s)[12][13]?	Select: Yes OR No OR Unknown 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 aid,s but does not currently have or use them, it would be scored as Yes.

[12]Joint Committee on Infant Hearing. Year 2007 Position Statement: Principles and Guidelines for Early Hearing Detection and Intervention Programs. Pediatrics 2007; 120; 898-921.

[13] 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

If a visual assessment is not regularly part of the 24 months 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 24 months 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

E1a: Treatment for ROP after discharge	• Yes: the child has been treated for Retinopathy of Prematurity (ROP) since discharge from the NICU. • No: if the child was diagnosed with ROP and/or treated for ROP in the NICU but has had no further treatment since discharge.
E1b: Highest stage of ROP	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): • Stage 1: Characterized by a demarcation line between the normal retina near the optic nerve and the non-vascularized retina more peripherally. • Stage 2: 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. • Stage 3: Increased size of the vascular ridge, with growth of fibro-vascular 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. • Stage 4: 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. • Stage 5: 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. • Not applicable: Select if the child did not have treatment for ROP in that eye.

E1c: Plus disease?	If Yes in E1a above, indicate for each eye, 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.*
E1d: Type of treatment	If Yes in E1a above, check all the applicable treatment(s) the child has received for ROP since NICU discharge: • Laser therapy • Anti-VEGF • Cryotherapy • Buckle • Other • Unknown
E2: **Visual function**	*At 24 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.* *Note that cortical visual impairment (CVI) may present differently than other forms of visual impairment. 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.* Indicate whether the child's visual function is: • Normal: Responds appropriately to the 1 cm object • Normal with prescription glasses: Responds appropriately to the 1 cm object while wearing prescription glasses. • Visual impairment (unilateral or bilateral): Select if the child meets one or more of the following criteria: - No response to the 1 cm object; - On physical exam: small eye, corneal scarring, sustained sensory nystagmus; - Ophthalmologist report of ROP stage 3 (with macular drag or macular traction), 4 or 5; - A report of visual acuity of 20/70 or worse. Unknown.

Section F: Neurodevelopmental Assessment

Neurodevelopmental Assessment (Bayley)

This section focuses on neurodevelopment and the use of the Bayley Scales of Infant and Toddler Development, Third or Fourth Edition (Bayley-III or 4).[14] 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 (isabelle.lahaie.hsj@ssss.gouv.qc.ca).

- 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.15.16. 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

[14] Bayley N. The Bayley Scales of Infant and Toddler Development, Third Edition. San Antonio, TX: The Psychological Corporation; 2006.

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.

Social Communication Development and Parent Reported Outcomes

- Section F6 focuses on child socio-emotional development asking questions on child social/emotional and communication in relation to suspected or confirmed autism spectrum disorder.
- Section F7 focuses on child function, quality of life and parent reported outcomes using parental questionnaires:
  - → The Pediatric Evaluation of Disability Inventory (PEDI-CAT) measures daily activities, mobility, social-emotional and cognitive development, and responsibility. It takes ~10-20 minutes to complete and yields normative standard scores (age percentiles and T scores) and scaled scores.
  - → The Pediatric Quality of Life Inventory (Peds-QL) assesses health-related quality of life (Physical, Emotional and Social Health). It takes < 5 minutes to complete and yields 3 summary scores (Total Scale Score, Physical Health Summary Score, Psychosocial Health Summary Score).
  - → About My Baby assesses child function and health complexity, to 'aid in determining child and family services priorities'. It yields a score of complexity (0-60), based on number of areas of concern. It takes 10 minutes to complete, but it is designed to be integrated as part of clinical history taking.

F1: Assessment date	The default date is the one specified in Section A (A12). This can be changed if necessary, by entering a new date.
F2a: Chronological age	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.
F2b: Corrected age	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.
F3a: Were you able to test the child?	Select: • Yes if the Bayley was completed in its entirety. • No if the Bayley was not attempted. • Incomplete if the Bayley was partially completed with some scores available. - Please enter all of the Bayley scores you were able to obtain. - No or Incomplete: ▪ question F3b will be activated. ▪ specify why the child could not be assessed or assessment could not be completed.
F3b: If no, why?	If No selected in F3a, check all the reasons that apply: • Child was uncooperative: the child was too tired or uncooperative to complete the Bayley and was unable to be re-booked within the specified time period. • Illness: the child had an acute illness and another assessment could be booked within the time period for the assessment. • Interpreter not available: 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. • Blindness or deafness: the child has a severe visual or auditory impairment. • Severe developmental delays: 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.

	• Other: Specify in the text box 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).
F3c: If no, does the child have a global developmental delay?	If Bayley scores cannot be obtained: select from the following list the clinician's opinion on whether the child has a global developmental delay: • Yes: the clinician believes a global developmental delay is present. Enter the name of test and cut-offs used to determine delay - along with any other relevant notes - in the comments box (C17). • Suspect: the clinician believes a delay is present but cannot be confirmed by a standardized test. • No: there is no evidence of a global develomental delay.
F4: **Language of test administration**	Select all that apply from the following list: • English • French: 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. • Other: Specify
F5a: Bayley edition	Select the Bayley version administered: • Bayley 3 • Bayley 4
F5b: Bayley scales	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": • Cognitive composite: Total Raw Score, Scaled Score, Composite Score • Language composite: Scaled Score, Composite Score - Receptive communication subtest: Total Raw Score, Scaled Score - Expressive communication subtest: Total Raw Score, Scaled Score • Motor composite: Scaled Score, Composite Score - Gross motor subtest: Total Raw Score, Scaled Score - Fine motor subtest: Total Raw Score, Scaled Score If the Bayley assessment can only be partially completed: enter any available scores here. *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.*

F6 (a-b): **Based on your assessment today, do you suspect autism spectrum disorder (ASD) in this child (or social-communication problems)?**	F6a: Select Yes, No, or Unknown. Yes: if the clinician made a referral or planned for further diagnostic assessment for ASD. F6b: If yes, what action was taken? (check all that applies) • No action • ASD diagnosis made in the PFU clinic • Earlier follow up in the clinic (without ASD assessment) • Referral to external autism diagnostic assessment • Referral to other services (speech and language therapist, OT, psychologist…etc)
F7 (a-c): **Did parent(s) complete the self-assessment questionnaires of their child functions (PEDSQL/PEDICAT/ About my baby/About my toddler)?**	• F7a Select Yes, No, or Unknown. • F7b: If yes, what action was taken: none, earlier follow up in the clinic, referral to other services

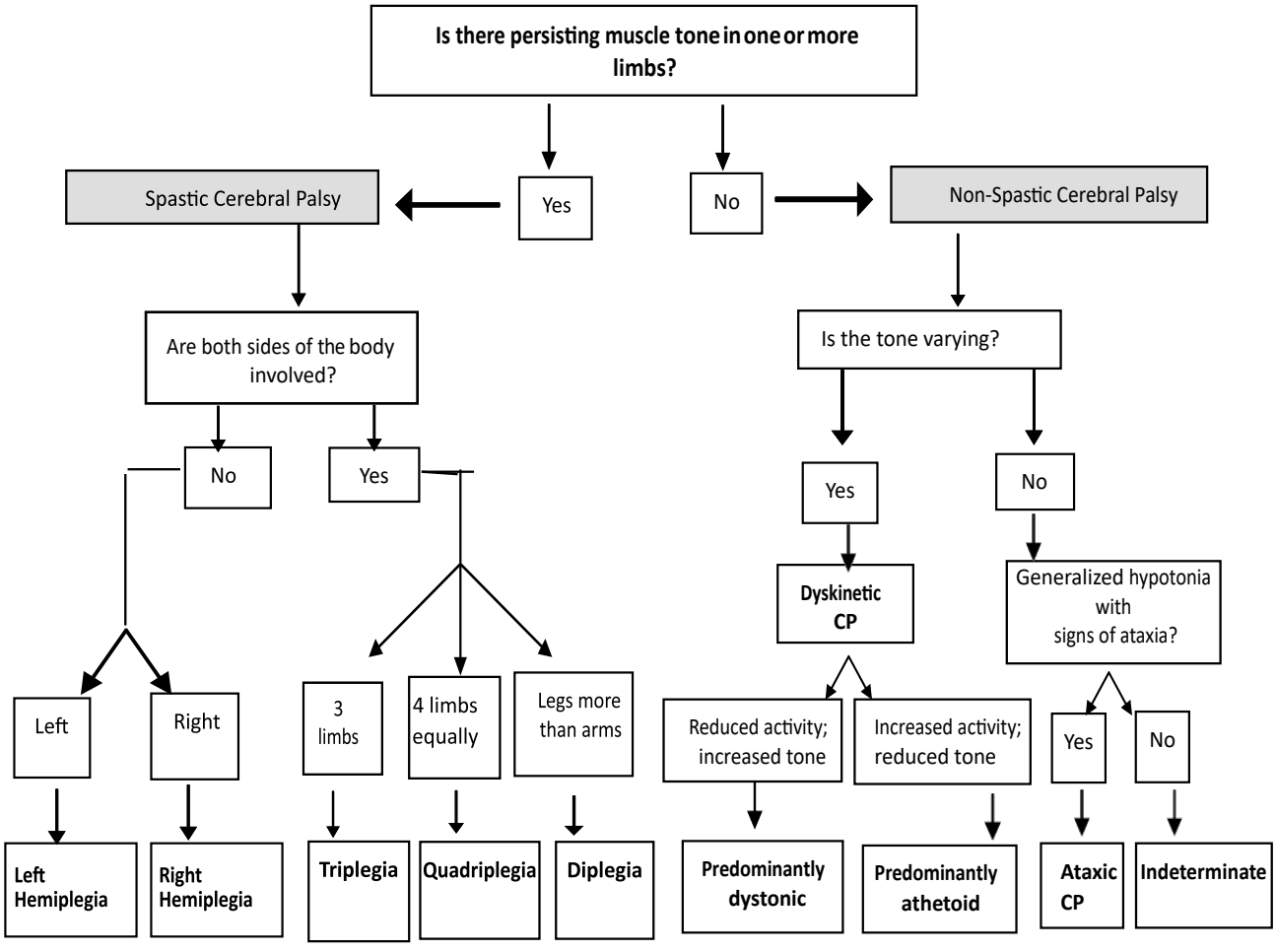
Case Validation

Once you have finished entering data, **you must validate the case.**

- Go to the validate case screen and click on the "Validate 24 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.[14]



[14] 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.

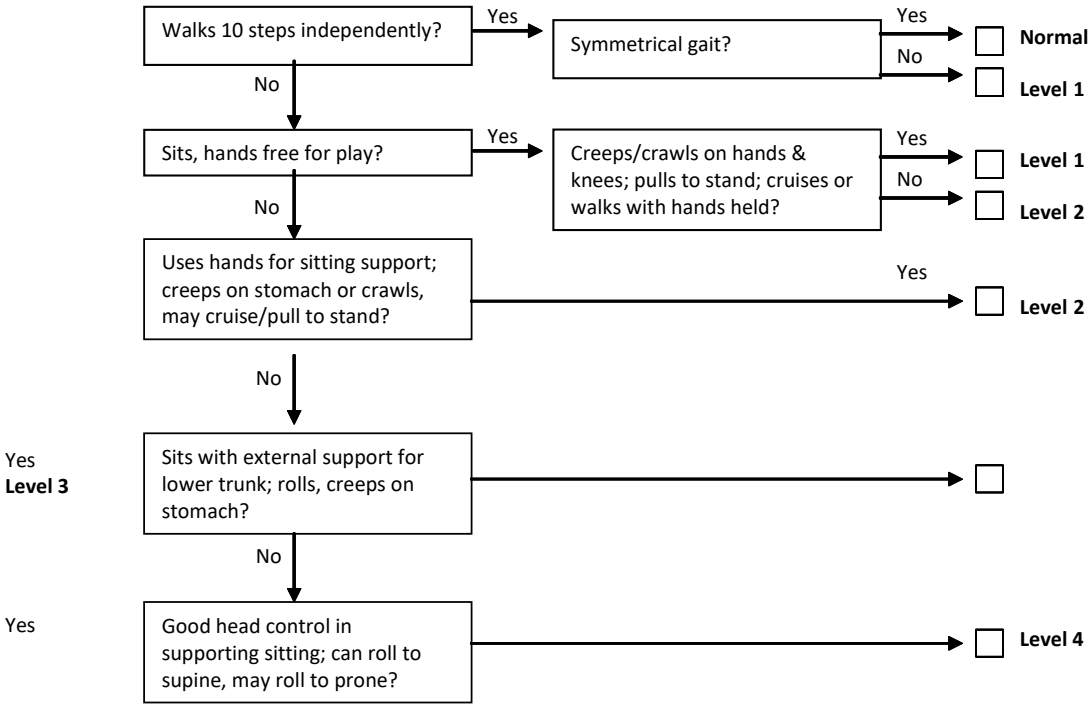
Appendix B: Gross Motor Function Classification System (GMFCS)

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

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.

The algorithm below has been adapted from the COT study.



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.

- Data Collection Forms

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

  - Data collection forms (English version) CNFUN website
  - Data collection forms (version française) CNFUN website

- CNFUN Research Database Protocol CNFUN website

- Parent Reported Outcomes Questionnaires (Original versions are avalable upon request)
  - About my baby: https://canchild.ca/en/resources/353-about-my-child
  - Pediatric Quality of Life Inventory™ Infant Scales™ (PedsQL™ Infant Scales™) https://eprovide.mapi-trust.org/instruments/pediatric-quality-of-life-inventory-infant-scales
  - Pediatric Evaluation of Disability Inventory Computer Adaptive Test PEDI-CAT https://www.pearsonclinical.ca/store/caassessments/en/pedi/Pediatric-Evaluation-of-Disability-Inventory-Computer-Adaptive-Test/p/P100008118.html

- 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 Premature Babies Foundation (CPBF)