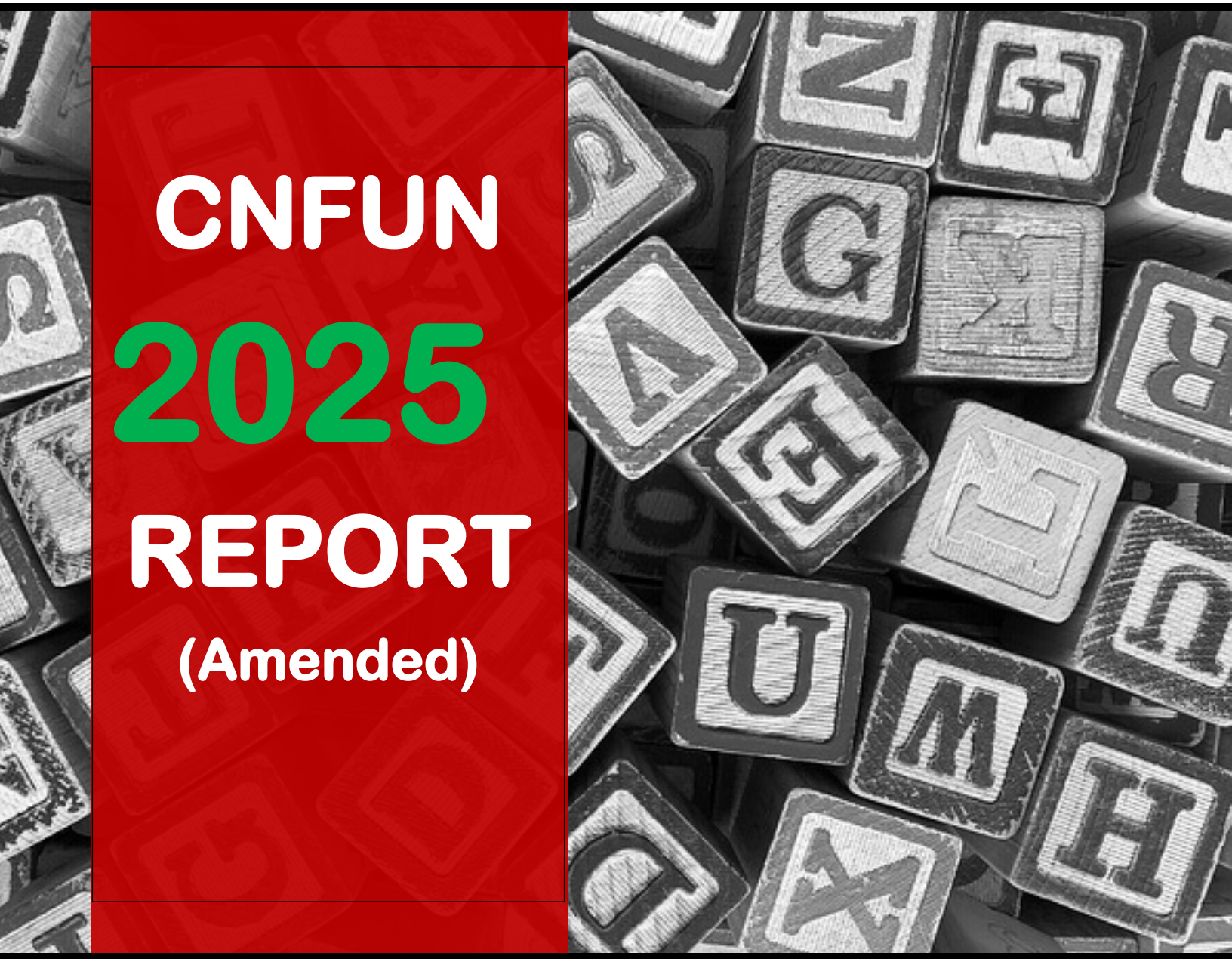
Canadian Neonatal Follow-Up Network
Réseau Canadien de Suivi Néonatal

CNFUN 2025 REPORT

(Amended)



The Canadian Neonatal Follow-Up Network

The Canadian Neonatal Follow-Up Network (CNFUN) is a collaboration between 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, and to improve the quality of care and long-term outcomes of children seen in their programs.

Mission
To be a network of health care professionals dedicated to improving the care of children requiring neonatal intensive care to optimize their long-term health and neurodevelopment.

Goals

- To establish a network of Canadian health care professionals involved in neonatal and perinatal follow-up programs (FUPs)
- To develop a standardized set of validated developmental assessments done at standardized ages with common definitions
- To develop a national electronic database (CNFUN-DB) of the CNFUN dataset that is linkable to neonatal and perinatal databases
- To 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
- To advocate for our population of children by ensuring that 1) the best evidence is translated into practice, 2) early screening is used for developmental problems, 3) early referral are made to interventions and services known to improve function and quality of life, and 4) empowering and supporting parents and families to help their children achieve their best potentials.

Administrative Structure
A Steering Committee oversees the CNFUN activities and makes policy decisions. Site representatives from participating institutions provide representation, input, and liaison with the Steering Committee and CNFUN Director.

The Steering Committee was appointed for the first 5 years and there have been elections every 2 years. Members serve 4-year terms.

The CNFUN Steering Committee is composed of 12 members:

- The director of the network.
- The past director of the network.
- A co-director chosen by the CNFUN Steering Committee.
- Seven (7) members representing different geographic regions of Canada.
- Three (3) members representing allied health professions in the fields of nursing, psychology, occupational therapy, physiotherapy or speech and language therapy. One of these professionals must be familiar with the Bayley Scales of Infant and Toddler Development.

The Network Coordinating Centre provides administrative support to CNFUN, its committees and institutional and individual members.

Membership

Membership is open to all health care professionals with an interest in neonatal/ perinatal follow-up. There are two types of membership – institutional and individual.

1. Institutional Membership is open to all Canadian institutions with a neonatal or perinatal follow-up program.

- **Application**: To be submitted to the Chair of the Steering Committee.
- **Membership fee**: None.
- **Obligations**: Membership requires commitment by the institution to collect and contribute data to the CNFUN database with research ethics board approval. Institutional members agree that their data may be used at the discretion of the network, within guidelines agreed upon between network members.
- **Benefits**: (1) The database will be maintained, and error checked by the CNFUN Database Working Group and the MiCare (Maternal Infant Care Network) Coordinating Center. An institution's own data will be available for its own use. Research projects and resultant manuscripts using network data need to be approved by the Steering Committee. (2) The CNFUN allows for a community of practice that mobilizes and facilitates implementation of evidence-based knowledge from research to clinic.
- **Representation**: The Site investigator at each institution will act as a liaison between the participating institution and the CNFUN Director and Steering Committee. The number of members who can vote for members of the Steering Committee shall be proportional to the amount of participant data submitted to the CNFUN database.
- **Renewal and Termination**: Institutional membership is ongoing until terminated by the institution, by written notice to the Chair of the Steering Committee.

2. Individual Membership is open to all health care professionals with an interest in neonatal / perinatal follow-up.

- **Application**: To be submitted to the Chair of the Steering Committee and be endorsed by an existing member.
- **Membership fee**: None for Canadian members, fees for non-Canadian members TBD.
- **Obligations**: Members agree to abide by the rules governing research conduct and use of the data.
- **Benefits**: Canadian members may use network infrastructure for research collaboration. Research projects using network data must be approved by the Steering Committee. Members can also access knowledge mobilization activities.
- **Renewal and termination**: Individual membership will need to be renewed every four years.

Sources of Funding

The network was initiated with the support received from the Canadian Institutes of Health Research (CIHR) through a grant to the CIHR Team in Maternal-Infant Care (CTP 87518). The study coordinating center, the Maternal-Infant Care Research Centre, is supported by program funding from the Ontario Ministry of Health and Long-Term Care.

Participating sites contribute to additional funding for patient outcome assessments. Data collection for the CNFUN research database occurs on a continuous basis independent of ongoing project grants from funding agencies.

The following projects have also facilitated funding of the CNFUN Research Infrastructure including the database:

- *CIHR SPOR grant "CHILD-BRIGHT" (Child Health Initiatives Limiting Disability - Brain Research Improving Growth and Health Trajectories) for the "Parent-EPIQ" project*

  This project evaluated the feasibility of using an EPIQ (evidence-based practice to improve quality) approach in neonatal follow-up programs to promote early-family integrated interventions known to improve cognitive and language abilities. Parents were also engaged to identify and redefine important outcomes to be collected and reported within CNFUN. ***The Parents' Voice Project*** has highlighted the importance of functioning and quality of life over diagnoses. The project has also allowed the parents to express their concerns about the current value-based classification system. What people with lived and living experience with prematurity label as a 'severe' health condition significantly differs from definitions used by several neonatal follow-up research networks. The perception of people with lived and living experience is usually more optimistic. Moreover, by combining in the same category death

and neurodevelopmental impairment, this classification contributes to the negative stigma associated with outcomes of prematurity.

- *CIHR Pan-Canadian Network to Improve Outcomes of Preterm Birth (PBN 150642)*

  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.

- *CIHR-CHILD-BRIGHT Phase 2 Implementation Science Project "Parent Voices"*

  As part of the ***CHILD-BRIGHT Phase 2 Parents' Voice Project*** (2023-2026), we are implementing standardized and validated family important outcome measures (FIOMs) that reflect child functioning. This new information to be integrated into the CNFUN data collection should provide complementary perspective to preterm birth outcomes. This work is performed in collaboration with the Canadian Premature Babies Foundation.

- *CIHR Project Grant on "Implementation of best practices for earlier diagnosis of cerebral palsy in very preterm infants" (PJT 190177).*

  The aim is to study whether implementing an evidence-based clinical practice guideline[1] improves clinicians' ability in identifying the early signs of CP in preterm infants <29 weeks' gestation across neonatal follow up programs in Canada (2023-2028). The goal of early identification is to allow for earlier initiation of targeted intervention to improve long-term functioning. This guideline includes implementing the Hammersmith Infant Neurological Examination (HINE), which requires performing the HINE with high reliability, interpreting scores within the clinical context, and communicating findings with families using best standards. Outcomes are measured at 24 ± 3 months corrected age (CA). Data on HINE and the General Movement Assessment (GMA – optional) scores are included in the updated CNFUN case report form.

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

CNFUN Steering Committee

Thuy Mai Luu, MD – Pediatrician / director (Québec)
Jehier Afifi, MD – Neonatologist / co-director (Nova Scotia)
Anne Synnes, MD – Neonatologist / past director (British Columbia)
Rudaina Banihani, MD – Neonatologist / developmental behavioral pediatrician (Ontario)
Lindsay Colby, RN – Nurse (British Columbia)
Matthew Hicks, MD – Neonatologist / developmental behavioral pediatrician (Alberta)
Florencia Ricci, MD – Developmental behavioral pediatrician (Manitoba)
Marie-Noëlle Simard, Ph.D – Occupational therapist/ researcher (Quebec)
Karen Thomas, MD– Neonatologist / developmental behavioral pediatrician (Ontario)
Jill Zwicker, Ph.D– Occupational therapist / researcher (British Columbia)

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Arsalan Butt, Data Abstractor (British Columbia)
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Karen Thomas, MD– Neonatologist / developmental behavioral pediatrician (Ontario)
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Seungwoo Lee, MiCare Coordinating Centre, Analyst (Ontario)
Isabelle Lahaie, MSc- CNFUN National Coordinator (Quebec)

2025 CNFUN Annual Report Working Group

Thuy Mai Luu, MD – Pediatrician, neonatal follow-up (Québec)
Jehier Afifi, MD– Neonatologist, neonatal follow-up (Nova Scotia)
Jarred Garfinkle, MD – Neonatologist, neonatal follow-up (Québec)
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Heather Kehler, MSc – Research Coordinator, neonatal follow-up (Alberta)
Marie-Noëlle Simard, Ph.D – Occupational therapist/ researcher (Quebec)
Isabelle Lahaie, MSc- CNFUN National Coordinator

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I. Summary of Publications

A. Executive Summary

We are pleased to provide the seventh CNFUN report. In this report, we are including 18–24-month outcomes for year 2025 (ie: birth cohort of year 2022).

CNFUN aims to provide accurate up to date information on the outcomes of children at 18-24 months corrected age born very preterm across Canada. This report provides national and site-specific data from the start of CNFUN data collection with births from April 1, 2009, until December 31, 2022. Information is included for 14744 survivors and non-survivors and 11043 infants assessed at a CNFUN site with linked neonatal data from the Canadian Neonatal Network.

Improving the health and daily functioning of the children we care for is our goal. Measuring, reporting, and sharing outcomes is important to monitor the quality of the care we provide during the perinatal period and beyond, identify targets for future preventative or therapeutic interventions, and advocate for health care services after neonatal discharge that are critical to support optimal health and child development as well as family well-being.

Follow up clinics involved in CNFUN have been essential in assessing infant outcomes for clinical and research purposes in very preterm children born at less than 29 weeks' gestational age. Their dedicated work is central to our collective success. We are very grateful to all CNFUN participating sites for their engagement.

Since the 2022 Annual Report, the following changes have been introduced and are reconducted:

- Value-based labels of severity are replaced with objective descriptions (e.g., cerebral palsy with a gross motor function classification system of 3-4-5, instead of 'severe' cerebral palsy).
- Mention of '*severe*' neurodevelopmental impairment (NDI) is restricted to health conditions likely to persist over time and have an impact on child functioning[2]. However, we are currently reviewing this construct as it carries important stigma. Children with '*severe*' NDI can thrive and have a good quality of life.
- The outcomes of survival without NDI, survival without significant NDI and survival without severe NDI were added.
- The composite outcome of death and NDI is no longer used in CNFUN annual reports (see explanation page 17).

In this 2025 report, key findings are highlighted below. It is important to note that during the years 2020-2022, at the heart of the COVID pandemic, decreased follow-up rates were observed. Children with higher biological risk for neurodevelopmental challenges were more likely to be seen in follow-up clinics. This

[2] This is different from significant NDI which encompasses milder conditions. The level of functioning, quality of life and well-being of children living with a severe NDI are not currently assessed to establish a more comprehensive picture of health.

potentially led to an overestimation of rates of cerebral palsy, neurosensory disabilities and developmental delays during these years.

- The majority (9115/14637 = 62%) of infants born <29 weeks' gestational age survives without significant NDI (see definition page 16).
- Visual impairment at 18-24 months corrected age is now a rare complication of prematurity. There are also trends towards lower rates of requirement for hearing aids/cochlear implants.
- About one third of infants are re-admitted after NICU discharge, with respiratory problems being the most common cause of hospitalization.
- Almost one in 4 infants use aids at home after NICU discharge, but the majority are discontinued by 18-24 months of corrected age.

Please note that this report was amended on June 10, 2026 for presentations 25 to 27 for variables included in the adjustment of Standardized Risk Ratios. Ajustment for parental education and corrected age at assessment were not included due to missingness (values more than 10%).

In the next years, as we are implementing parent-reported outcome measures to assess child functioning as well as standardized neurological assessments prior to the 24 month-visit with the Hammersmith Infant Neurological Examination and, for certain sites, the General Movement Assessment, we will be integrating these measures in the CNFUN database and report on these outcomes.

In addition, thanks to enriching discussions with families and individuals with lived and living experience, pioneers in neonatal follow-up research, and many people of the CNFUN community, we are gradually shifting away from the composite outcome of neurodevelopmental impairment (NDI) to prioritize individual outcomes (e.g., hearing loss, cerebral palsy, developmental delay). Indeed, reporting on individual outcomes provides clearer, more actionable insights for clinicians, researchers and families. Conversely, composite outcomes often lack methodological rigor and can distort the interpretation of intervention effects. On page 17, the limitation of the concept of NDI is discussed.

We would like to thank the people who have contributed to making this 2025 CNFUN report possible: the CNFUN Annual Report Working Group, the CNFUN Steering Committee, the CNFUN site investigators and data abstractors, the MiCare Coordinating site including Sonny Yeh for developing and supporting the database, Seungwoo Lee for the analyses, and Dr. Marc Beltempo for his leadership. Finally, we want to express our deepest appreciation for the families of preterm children for their attendance at the follow-up visits.

Thuy Mai Luu MD, MSc
Director, CNFUN

Jehier Afifi MbBCh, MSc
Co-Director, CNFUN

B. Participation Sites

Presentation No 1: CNFUN Site descriptions*

Site (East to West)	Site Investigator	Members (n)
IWK Perinatal Follow-Up Program Health Centre regional Hospital *Halifax, NS*	Jehier Afifi	11
JCHC High-Risk Follow-Up Clinic Charles Janeway Children's Health and Rehabilitation Center *St. John's, NL*	Nadine McEvoy	
ECH Neonatal Follow-Up Program Dr. Everett Chalmers Hospital *Fredericton, NB*	Hala Makary	
SEHC Neonatal Follow-Up Clinic Moncton Hospital *Moncton, NB*	Maad Bakr Saleem	
SJRH Neonatal Follow-Up Program Saint John Regional Hospital *Saint-John, NB*	Alana Newman	
CHUS Clinique de suivi néonatal Centre hospitalier universitaire de Sherbrooke *Sherbrooke, QC*	Alyssa Morin	2
CHUL Clinique de suivi néonatal Centre hospitalier universitaire de Québec – Université Laval *Québec, QC*	Sylvie Belanger Christine Drolet	3
HSJ Clinique de suivi néonatal Centre hospitalier universitaire Sainte-Justine *Montréal, QC*	Thuy Mai Luu	12
HMR Clinique de suivi néonatal Hôpital Maisonneuve-Rosemont *Montréal, QC*	Marie St-Hilaire	2
JGH Clinique de suivi néonatal Jewish General Hospital *Montréal, QC*	Kim-Anh Nguyen	5
MUHC	May Khairy	19

Clinique de suivi néonatal Centre universitaire de santé McGill *Montréal, QC*	Jarred Garfinkle	
CHEO/OTTA Neonatal Follow-Up Clinic Children's Hospital of Eastern Ontario *Ottawa, ON*	Jana Feberova	
KGH Special Infant Clinic Kingston General Hospital *Kingston, ON*	Sarah McKnight	3
WRH Neonatal Neurodevelopment Follow up Program Windsor Regional Hospital *Windsor, ON*	Sajit Augustine (interim)	6
SJHC (LHSC) Developmental Follow-Up Clinic London Health Sciences Centre *London, ON*	Judy.Seesahai	10
SUNY Neonatal Follow-Up Program Sunnybrook Health Sciences Center *Toronto, ON*	Rudaina Banihani	10
MSH Neonatal Follow-Up Program Mount Sinai Hospital *Toronto, ON*	Kamini Raghuram	10
HSC Neonatal Follow-Up Program Hospital for Sick Children *Toronto, ON*	Linh Ly	7
HHSC Neonatal Follow-Up Clinic Hamilton Health Sciences Centre- McMaster Children's Hospital *Hamilton, ON*	Karen Thomas	9
HSCC High Risk Newborn Follow-Up Program Health Science Center of University of Manitoba *Winnipeg, MB*	Florencia Ricci	7
SBGH High Risk Newborn Follow-Up Program St Boniface General Hospital of University of Manitoba *Winnipeg, MB*	Cecilia de Cabo	6
RUH Neonatal Follow-Up Program, Saskatoon Jim Pattison Children's Hospital *Saskatoon, SK*	Anna Donovan	

RQHR Developmental Assessment Clinic Regina General Hospital *Regina, SK*		
EDM Neonatal and Infant Follow-Up Clinic Glenrose Rehabilitation Hospital *Edmonton, AB*	Amy Shafey	9
ACH/FMC Neonatal Follow-up Clinic Foothills Medical Centre *Calgary, AB*	Amina Benlamri	7
VGH/GVS Neonatal Follow-Up Team Queen Alexandra Centre for Children's Health *Victoria, BC*	Thevanisha Pillay	4
BCWH Neonatal Follow-Up Program BC Women's Hospital & Health Centre *Vancouver, BC* enters data for: **RCH** Royal Columbian Hospital (RCH) **SMH** Surrey Memorial Hospital	Jessie Van Dyk Miroslav Stavel Rebecca Sherlock	10 3 4

*Sites in grey are currently not contributing data, but some are in the process of contributing data again in the near future.

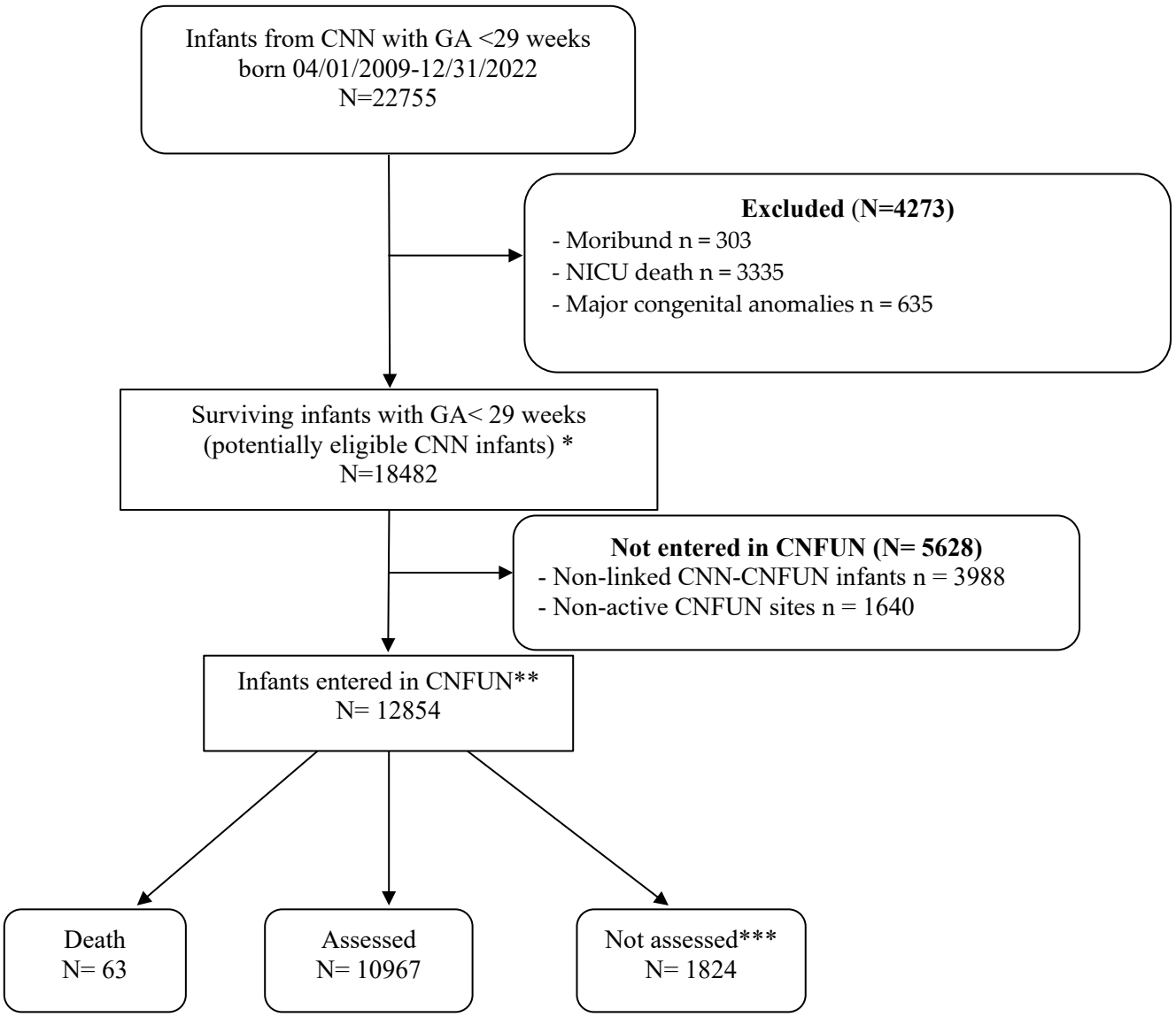
Presentation No 2: CNFUN Sites Participation and Follow-up Rates[3]

CNFUN Site	Follow-Up Rate (Births Jan 1 – Dec 31, 2022) n/N (%)	Overall Follow-Up Rate (Births April 1, 2009 – December 31, 2022) n/N (%)
1	37/60 (61.7)	694/934 (74.3)
2	44/58 (75.9)	608/732 (83.1)
3	10/24 (41.7)	153/234 (65.4)
4	0/8 (0)	21/85 (24.7) *
5	3/96 (3.1)	563/1498 (37.6) *
6	79/96 (82.3)	1205/1560 (77.2)
7	9/19 (47.4)	122/285 (42.8) *
8	62/73 (84.9)	281/1167 (24.1) *
9	3/10 (30)	166/330 (50.3) *
10	16/24 (66.7)	288/447 (64.4)
11	43/53 (81.1)	838/983 (85.2)
12	16/19 (84.2)	431/511 (84.3)
13	0/12 (0)	23/216 (10.6) *
14	41/44 (93.2)	562/699 (80.4)
15	0/15 (0)	48/214 (22.4) *
16	136/163 (83.4)	1457/1971 (73.9)
17	3/67 (4.5)	89/857 (10.4) *
18	0/19 (0)	52/252 (20.6) *
19	0/32 (0)	23/364 (6.3) *
20	42/54 (77.8)	504/660 (76.4)
21	13/19 (68.4)	238/321 (74.1)
22	0/9 (0)	27/137 (19.7) *
23	55/75 (73.3)	513/776 (66.1)
24	0/5 (0)	7/54 (13) *
25	138/162 (85.2)	1542/2058 (74.9)
26	9/14 (64.3)	101/154 (65.6)
27	14/19 (73.7)	115/140 (82.1)
28	21/26 (80.8)	192/470 (40.9) *
29	32/48 (66.7)	180/373 (48.3) *
Total	826/1323 (62.4)	11043/18482 (59.8)

*Sites may have low follow up rates due to interruption or inconsistency in data contribution to the CNFUN database.

[3] Follow-up rate denominator: infants with GA<29 weeks discharged alive from NICU (infants with moribund or major congenital anomalies were excluded).
Follow-up rate numerator: infants with GA<29 weeks enrolled in CNFUN with at least partial data entry

Presentation No 3: CNN and CNFUN flow diagram for births Apr 1, 2009 – Dec 31, 2022



*Data linkage with CNN occurs by the CNFUN site contacting the CNN data abstractor to obtain the unique identifier. When a matching unique identifier is not available in CNN and CNFUN, probabilistic matching is used. In total, **5628** children could not be entered in the CNFUN database as they could not be linked with CNN.
**CNFUN children are recruited locally by a CNFUN site and recorded in the CNFUN database as assessed (i.e. some deata entry; among the 10967 babies, 31 have missing neurodevelopmental outcomes), not assessed, or deceased.
***Children were not assessed for the following reasons: declined/consent not obtained (n=457), no contact information (n=36), unable to reach (n=366), missed appointment (n=322), other reason (n=598), missing information (n=45).

C. Outcomes Definitions

Cerebral palsy (CP): defined as 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."* [4]The Gross Motor Function Classification System (GMFCS) is used to provide a level of functioning based on Palisano et al.[5]
Bayley: Bayley Scales of Infant and Toddler Development – 3rd or 4th edition (transition in January of 2022). The Bayley scales reflect what the child was able to do during the assessment. Results can be influenced by child collaboration and behavior. The Bayley scales are not meant to predict future cognitive, language or motor functioning.
Hearing status: determined from audiology reports.
Visual function: determined from ophthalmology consult if available. Visual impairment is defined as report of ROP stage 3 (with macular drag or macular traction), 4 or 5; visual acuity of 20/70 or worse in best eye. If no report is available, impairment is defined as a small, scarred eye or sustained sensory nystagmus or lack of response to a 1 cm object (cheerio) on a white background at 30 cm.

Level of health (body function)	**Neurodevelopmental impairment (NDI)** (Any one or more of the following)[6]	**Significant neurodevelopmental impairment (sNDI)** (Any one or more of the following)[7]	**Severe neurodevelopmental impairment (severe NDI)** (Any one or more of the following)[8]
Motor	CP with GMFCS 1 to 5	CP with GMFCS 3, 4 or 5	CP with GMFCS 4 or 5
	Bayley Motor Composite <85	Bayley Motor Composite <70	Bayley Motor Composite <55
Cognitive	Bayley Cognitive Composite <85	Bayley Cognitive Composite <70	Bayley Cognitive Composite <55
Language	Bayley Language Composite <85	Bayley Language Composite <70	Bayley Language Composite <55

[4] Rosenbaum P, Paneth N, Leviton A, et al. A report: the definition and classification of cerebral palsy April 2006 [published correction appears in Dev Med Child Neurol. 2007;49(6):480]. Dev Med Child Neurol Suppl. 2007;109:8-14.
[5] Palisano R, Rosenbaum P, Walter S, et al. Development and reliability of a system to classify gross motor function in children with cerebral palsy. Dev Med Child Neurol 1997;39:214–23.
[6] Children are also included in this category if they could not be tested using the Bayley and obtained a Bayley Adaptive Behavior Score <85
[7] Score <70 or were considered to have a global developmental delay which did not allow completion of the Bayley (item or F3c).
[8] Severe NDI: adapted from Cheong et al. JAMA Pediatr 2021;175(10):1035-1042. Children are also included in this category if they could not be tested using the Bayley and obtained a Bayley Adaptive Behavior score <55 or were considered to have a global developmental delay which did not allow completion of the Bayley.

Hearing	Sensorineural/mixed hearing loss	Sensorineural/mixed hearing loss requiring a hearing aid or cochlear implant	Not included
Vision	Uni- or bilateral visual impairment	Bilateral visual impairment	Bilateral visual impairment

On the composite outcome of NDI

When thinking about the composite outcome of NDI, or even how we have defined significant NDI, a composite itself of different neurodevelopmental components, **some methodological issues arise**.

Composite outcomes were originally designed for clinical trials, not observational studies, to increase statistical efficiency. Basic rules for the appropriate use of composite outcomes are that the individual components have:

1. similar importance to patients/families;
2. comparable effect sizes;
3. comparable event rates, and;
4. similar pathophysiological mechanisms[9]

In the Parents' Voice Project, most of the components making the composite outcome of significant NDI are not perceived as severe by the majority of parents of preterm children[10]. Furthermore, individual components do not carry the same importance to families. For example, achieving a low score on the Bayley test at 18-24 months is not considered as meaningfully significant as living with bilateral blindness.

By aggregating four distinct outcomes together (ie. cerebral palsy, requirement for hearing aids/cochlear implant, bilateral blindness, Bayley score <70 on any domain of cognitive, language or motor) that have different event rates, importance is shifted towards the outcome occurring more frequently, language delay. Language development is influenced by preterm birth, but also the method and age of testing as well as the social environment in which the child evolves.

NDI was historically designed to measure the overall effect of preterm birth on infant outcomes. However, it is essential to recognize that the pathways to cerebral palsy, hearing loss, visual impairment and developmental delay may be different. **Therefore, which components to include (or not) in a composite measure of neurodevelopment requires careful thoughts about the research question and the underlying biological substrate (or physiopathological mechanisms).**

In addition, to address competing risk, experts state that it might be justified to use a composite outcome if:

1. the biology suggests that the exposure/intervention might realistically increase the more serious event, thus misleadingly reduce the less serious one (for example, reduced rates of cerebral palsy, but increased neonatal mortality);

[9] Montori VM et al. Validity of composite end points in clinical trials. BMJ. 2005; 330 (7491):594-96.

[10] Synnes A et al. Redefining Neurodevelopmental Impairment: Perspectives of Very Preterm Birth Stakeholders. Children (Basel). 2023 May 14;10(5):880.

2. the more serious outcome occurs frequently enough that, if the exposure/intervention truly increases its frequency, the result would be a misleading decrease in the less serious event[11].

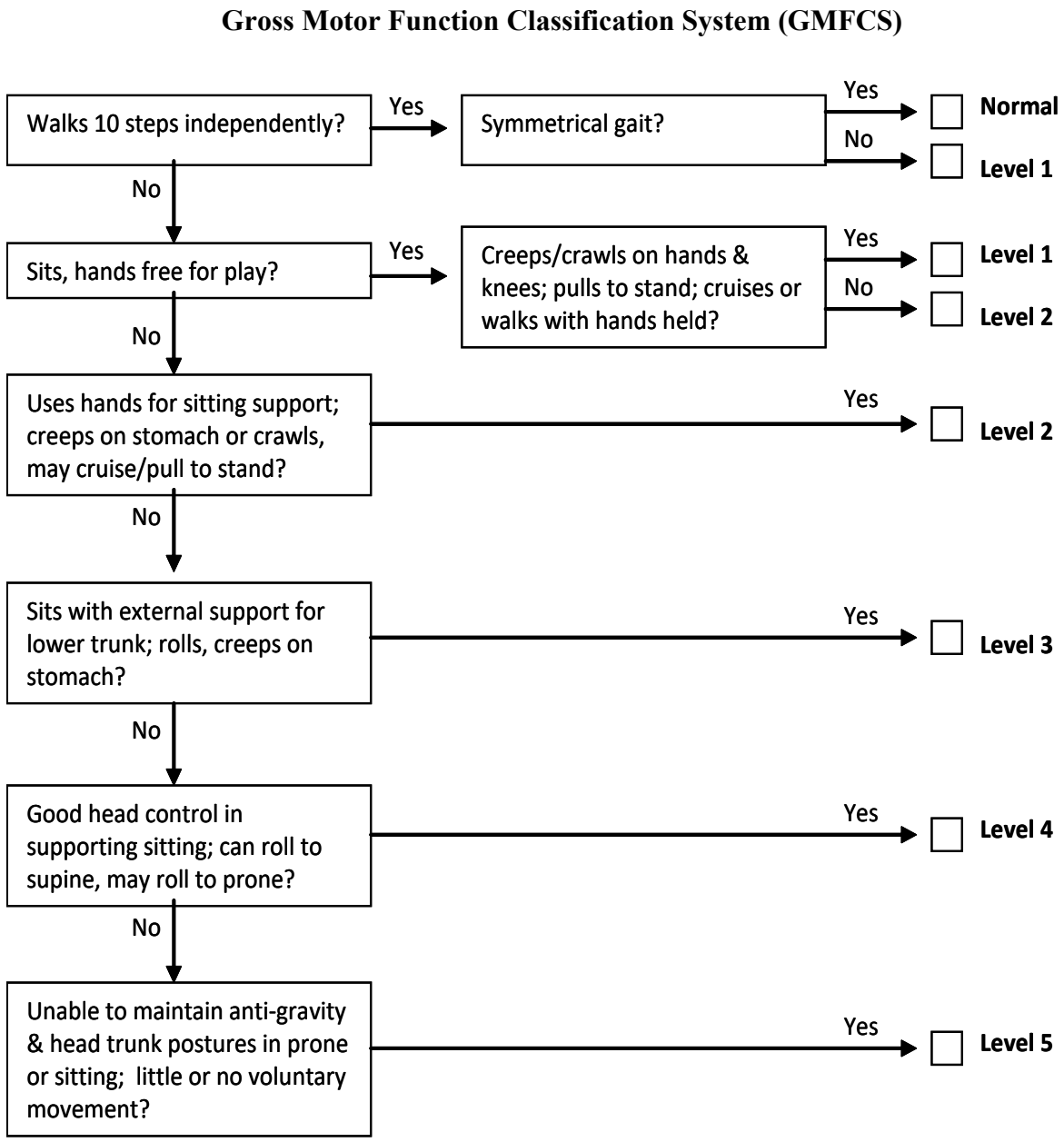
However, in neonatal outcome research, one could argue that if an intervention/exposure significantly increased mortality, this would be the primary concern and therefore, the longer-term outcome would become less relevant unless extreme. The problem is that each individual will define 'extreme' based on his/her unique beliefs and values, yielding a myriad of definitions of 'extreme', none being better or worse than the other.

Therefore, reporting death or significant NDI in the same composite outcome is not clinically meaningful nor philosophically appropriate. In addition, NDI as a standard composite measure is questionable.

There is therefore a need to identify novel methodological approaches to address competing risk in neonatal outcome research. We should also consider moving away from a **unique** neurodevelopmental outcome measure and think about the underlying research question being assessed.

[11] Manja V et al. Criteria for use of composite end points for competing risks-a systematic survey of the literature with recommendations. J Clinical Epidemiol 2007;82: 4-11.

Algorithm based on Palisano, et al (1997)[12]



[12] Palisano R, Rosenbaum P, Walter S et al. Development and reliability of a system to classify gross motor function in children with cerebral palsy. Dev Med Child Neurol 1997; 39:214-223

D. Descriptive Analyses

The following results include CNFUN sites who have contributed data at any time point since 2009.

Data collection and participation dropped significantly with no or limited funding after Oct 2011 and during the pandemic (follow up of birth cohorts 2018-2019), with notable improvement in recent years (birth cohorts of 2020 onwards).

Presentation No 4: Survival and 18–24-month assessments among all CNN sites

Year of birth	**NICU admission** (n)	**Major congenital anomalies.** n (%)	**NICU death** n (%)	**NICU survivors#** n (%)	**Death after NICU** n (%)	**Linked CNN-CNFUN data** for survivors** n (%)	**Known outcome*** for NICU deaths and survivors** n (%)
2009 [a]	1218	66 (5.4)	231 (19)	921 (75.6)	7 (0.6)	700 (76)	938 (81.4)
2010	1653	28 (1.7)	260 (15.7)	1365 (82.6)	15 (0.9)	1064 (77.9)	1339 (82.4)
2011	1579	36 (2.3)	282 (17.9)	1261 (79.9)	5 (0.3)	898 (71.2)	1185 (76.8)
2012	1652	36 (2.2)	282 (17.1)	1334 (80.8)	< 5*	701 (52.5)	984 (60.9)
2013	1697	40 (2.4)	282 (16.6)	1375 (81)	< 5*	666 (48.4)	951 (57.4)
2014	1673	57 (3.4)	258 (15.4)	1358 (81.2)	< 5*	682 (50.2)	941 (58.2)
2015	1614	51 (3.2)	244 (15.1)	1319 (81.7)	< 5*	747 (56.6)	992 (63.5)
2016	1740	59 (3.4)	275 (15.8)	1406 (80.8)	7 (0.4)	767 (54.6)	1049 (62.4)
2017	1693	64 (3.8)	241 (14.2)	1388 (82)	5 (0.3)	752 (54.2)	998 (61.3)
2018	1751	46 (2.6)	279 (15.9)	1426 (81.4)	< 5*	757 (53.1)	1039 (60.9)
2019	1664	32 (1.9)	259 (15.6)	1373 (82.5)	< 5*	750 (54.6)	1011 (61.9)
2020	1551	33 (2.1)	243 (15.7)	1275 (82.2)	6 (0.4)	828 (64.9)	1077 (70.9)
2021	1641	39 (2.4)	244 (14.9)	1358 (82.8)	5 (0.3)	905 (66.6)	1154 (72)
2022	1629	48 (2.9)	258 (15.8)	1323 (81.2)	< 5*	826 (62.4)	1086 (68.7)
2009-22	22755	635 (2.8)	3638 (16)	18482 (81.2)	63 (0.3)	11043 (59.8)	14744 (66.7)

* Cells with less than 5 reported as < 5.

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[a] April 1, 2009 to December 31, 2009.

#Newborns admitted to NICUs who were moribund or had major congenital anomalies are excluded.

** Note the low rates as some sites stopped contributing data to CNFUN since 2012, following the completion of MiCare fund (2009-2011).

*** Children with known long-term outcomes (death or neurodevelopmental outcomes as per CNFUN definition) at 18-24 months corrected age. Of note, 570 children (6.8%) were seen between 24-36 months corrected age during the COVID pandemic after March 2020.

Presentation No 5a: Survival and 18–24-month assessments among all CNN sites by gestational age

Gestational age (weeks)	NICU admission (n)	Moribund or with major congenital anomalies n (%)	NICU death n (%)	NICU survivors# n (%)	Death after NICU n (%)	Linked CNN-CNFUN data for survivors n (%)	Known outcome* for NICU deaths and survivors n (%)
22	313	7 (2.2)	231 (73.8)	75 (24)	0 (0)	44 (58.7)	275 (89.9)
23	1426	26 (1.8)	751 (52.7)	649 (45.5)	8 (0.6)	426 (65.6)	1185 (84.6)
24	2768	73 (2.6)	870 (31.4)	1825 (65.9)	10 (0.4)	1175 (64.4)	2055 (76.3)
25	3635	104 (2.9)	692 (19)	2839 (78.1)	15 (0.4)	1782 (62.8)	2489 (70.5)
26	4089	113 (2.8)	470 (11.5)	3506 (85.7)	11 (0.3)	2156 (61.5)	2637 (66.3)
27	4777	151 (3.2)	355 (7.4)	4271 (89.4)	12 (0.3)	2498 (58.5)	2865 (61.9)
28	5747	161 (2.8)	269 (4.7)	5317 (92.5)	7 (0.1)	2962 (55.7)	3238 (58)
22-28	22755	635 (2.8)	3638 (16)	18482 (81.2)	63 (0.3)	11043 (59.8)	14744 (66.7)

Presentation No 5b: Survival and 18–24-month assessments among all CNN sites by birth weight for neonates <29 weeks' gestation

Birth Weight (grams)	NICU admission (n)	Moribund or with major congenital anomalies n (%)	NICU death n (%)	NICU survivors n (%)#	Death after NICU n (%)	Linked CNN-CNFUN data for survivors n (%)	Known outcome for NICU deaths and survivors n (%)**
< 500	630	12 (1.9)	375 (59.5)	243 (38.6)	< 5*	155 (63.8)	532 (86.1)
500-749	6000	167 (2.8)	1827 (30.5)	4006 (66.8)	28 (0.5)	2563 (64)	4418 (75.7)
750-999	7946	256 (3.2)	954 (12)	6736 (84.8)	23 (0.3)	4154 (61.7)	5131 (66.7)
1000-1249	5979	149 (2.5)	359 (6)	5471 (91.5)	10 (0.2)	3144 (57.5)	3513 (60.3)
> 1250	2180	50 (2.3)	111 (5.1)	2019 (92.6)	0 (0)	1022 (50.6)	1133 (53.2)
All	22735	634 (2.8)	3626 (15.9)	18475 (81.3)	63 (0.3)	11038 (59.7)	14727 (66.6)

* Cell with less than 5 reported as < 5.

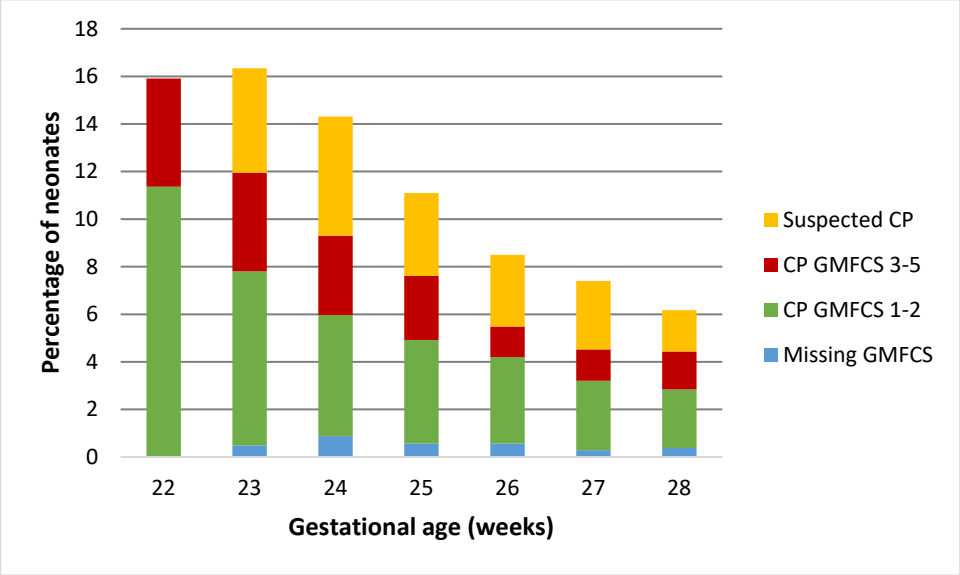
** Children with known long-term outcomes (death or neurodevelopmental outcomes as per CNFUN definition) at 18-24 months corrected age.
#Newborns admitted moribund or with major congenital anomalies are excluded.

E. Gestational Age Based Outcomes

Presentation No 6: Cerebral palsy by gestational age

GA in weeks	CNN-CNFUN linked cases (n)	CNN-CNFUN linked cases with CP data (n)	Definitive CP n (%)	Suspected CP n (%)	CP with GMFCS 1-2 n (%)	CP with GMFCS 3-5 n (%)	Missing CP GMFCS n (%)
22	44	44	7 (15.9)	0 (0)	5 (71.4)	< 5*	0 (0)
23	422	410	49 (12)	18 (4.4)	30 (61.2)	17 (34.7)	< 5*
24	1163	1139	106 (9.3)	57 (5)	58 (54.7)	38 (35.8)	10 (9.4)
25	1770	1748	133 (7.6)	61 (3.5)	76 (57.1)	47 (35.3)	10 (7.5)
26	2138	2095	115 (5.5)	63 (3)	76 (66.1)	27 (23.5)	12 (10.4)
27	2472	2431	110 (4.5)	70 (2.9)	71 (64.5)	32 (29.1)	7 (6.4)
28	2927	2883	128 (4.4)	50 (1.7)	71 (55.5)	46 (35.9)	11 (8.6)
Total	10936	10750	648 (6)	319 (3)	387 (59.7)	209 (32.3)	52 (8)

* Cells with less than 5 reported as < 5.

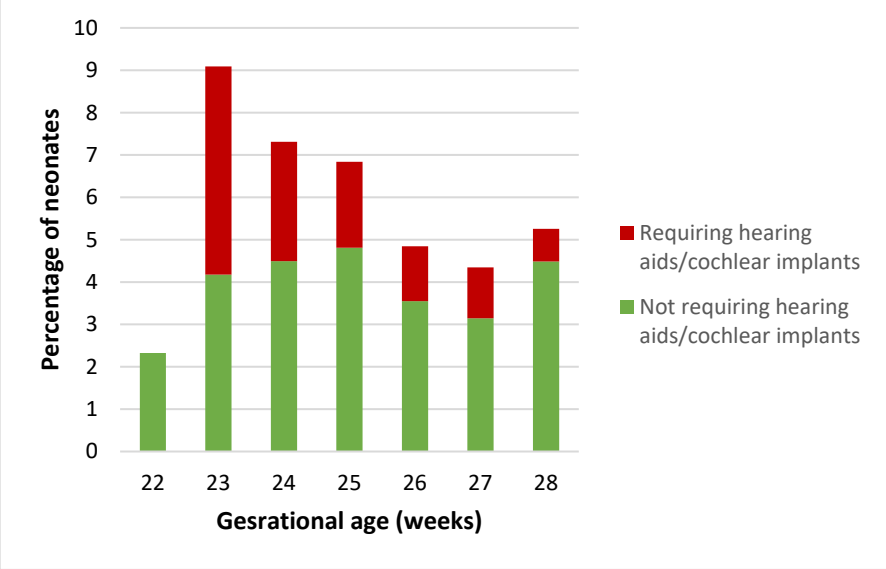


COMMENTS:
Rates for cerebral palsy (CP) with GMFCS 1-2 are calculated by subtracting number of children with CP with GMFCS 3-5 from definitive CP cases. CP rates decrease with increasing gestational age. (GMFCS: Gross Motor Function Classification System).

Presentation No 7: Hearing status by gestational age

GA in weeks	CNN-CNFUN linked cases (n)	CNN-CNFUN linked cases with data for hearing (n)	Normal hearing n (%)	Hearing loss not requiring hearing aids/cochlear implants n (%)	Requiring hearing aids / cochlear implants n (%)
22	44	43	42 (97.7)	< 5*	0 (0)
23	422	407	370 (90.9)	17 (4.2)	20 (4.9)
24	1163	1135	1052 (92.7)	51 (4.5)	32 (2.8)
25	1770	1725	1607 (93.2)	83 (4.8)	35 (2)
26	2138	2084	1983 (95.2)	74 (3.6)	27 (1.3)
27	2472	2415	2310 (95.7)	76 (3.1)	29 (1.2)
28	2927	2854	2704 (94.7)	128 (4.5)	22 (0.8)
Total	10936	10663	10068 (94.4)	430 (4)	165 (1.5)

* Cell with less than 5 reported as < 5.

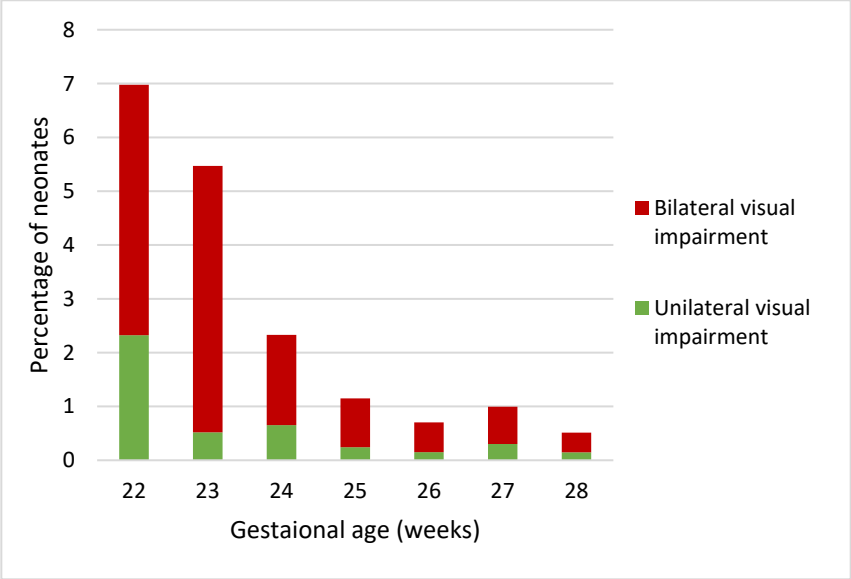


COMMENTS:
Hearing loss was determined at CNFUN sites based on audiology reports. Hearing loss is an infrequent outcome, but approximately 10 times as frequent in the very preterm infant than in the general population. Rates of hearing loss requiring hearing aids or cochlear implants decrease with increasing gestational age. Due to small numbers, outcome data for infants born at 22 weeks' gestation must be interpreted with caution.

Presentation No 8: Visual function by gestational age

GA in weeks	CNN-CNFUN linked cases (n)	CNN-CNFUN linked cases with data for vision (n)	Normal vision n (%)	Unilateral visual impairment n (%)	Bilateral visual impairment n (%)
22	44	43	40 (93)	< 5*	< 5*
23	422	384	363 (94.5)	< 5*	19 (4.9)
24	1163	1073	1048 (97.7)	7 (0.7)	18 (1.7)
25	1770	1651	1632 (98.8)	< 5*	15 (0.9)
26	2138	1991	1977 (99.3)	< 5*	11 (0.6)
27	2472	2310	2287 (99)	7 (0.3)	16 (0.7)
28	2927	2727	2713 (99.5)	< 5*	10 (0.4)
Total	10936	10179	10060 (98.8)	28 (0.3)	91 (0.9)

* Cells with less than 5 reported as < 5.

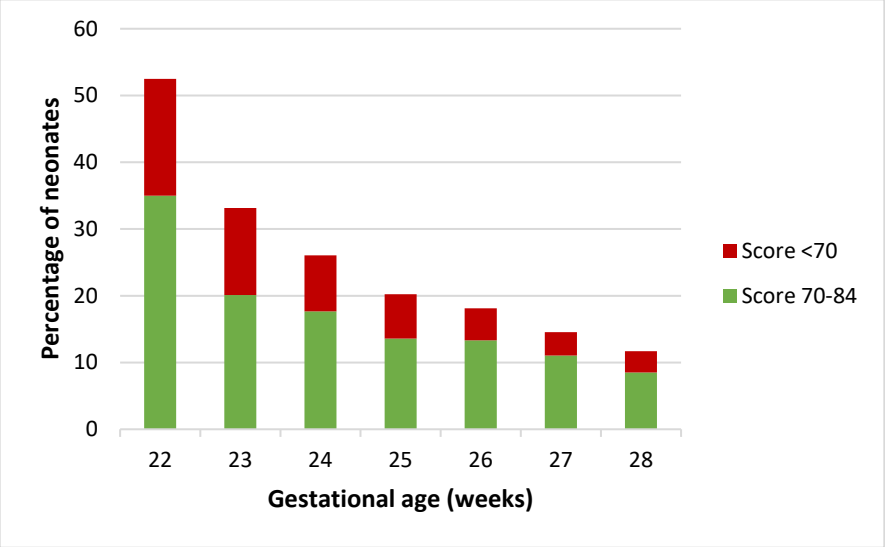


COMMENTS:

Visual impairment was determined from ophthalmology reports. If no report was available, impairment was defined as a small, scarred eye, sustained sensory nystagmus or lack of response to a 1cm object (cheerio) on a white background at 30cm . Visual impairment is an infrequent outcome. Bilateral visual impairment rates decrease with increasing gestational age. Due to small numbers, outcome data for infants born at 22 weeks' gestation must be interpreted with caution.

Presentation No 9: Bayley cognitive composite scores by gestational age

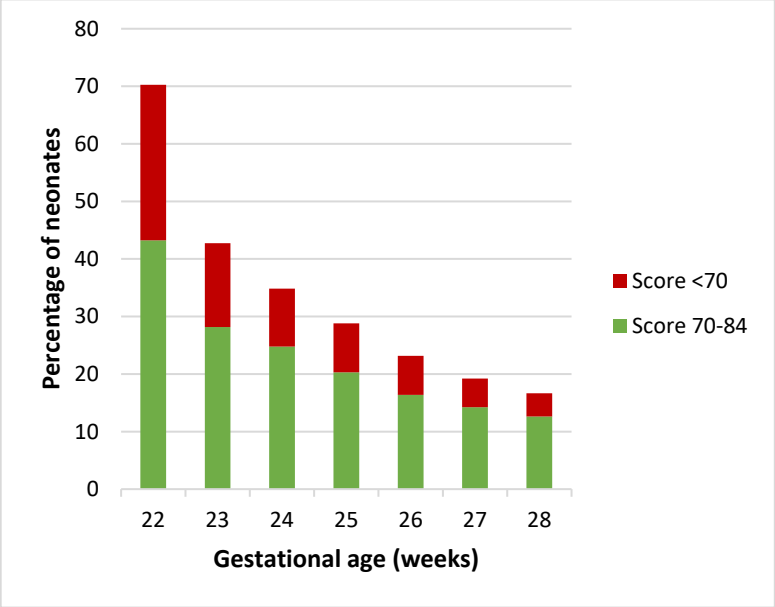
GA in weeks	CNN-CNFUN linked cases (n)	CNN-CNFUN linked cases with cognitive data (n)	Median score (IQR)	Score ≥85 n (%)	Score 70-84 n (%)	Score <70 n (%)
22	44	35	80 (73, 95)	19 (47.5)	14 (35)	7 (17.5)
23	422	315	90 (80, 100)	236 (66.9)	71 (20.1)	46 (13)
24	1163	929	90 (80, 100)	743 (74.2)	177 (17.7)	84 (8.4)
25	1770	1477	95 (85, 100)	1274 (79.8)	217 (13.6)	106 (6.6)
26	2138	1762	95 (85, 105)	1542 (82.2)	250 (13.3)	90 (4.8)
27	2472	2068	95 (90, 105)	1900 (85.6)	245 (11)	78 (3.5)
28	2927	2408	100 (90, 105)	2320 (88.5)	223 (8.5)	84 (3.2)
Total	10936	8994	95 (85, 105)	8034 (82.7)	1197 (12.3)	495 (5.1)



COMMENTS:
Bayley scores tend to underestimate developmental delay and have limited predictive ability. Cognitive scores on the Bayley Scales of Infant and Toddler Development – 3rd or 4th edition (Bayley) improve with increasing gestational age and are skewed in this population. The Bayley scales have a mean score of 100 and standard deviation of 15 (less than 70 is therefore < -2 standard deviations).

Presentation No 10: Bayley motor composite scores by gestational age

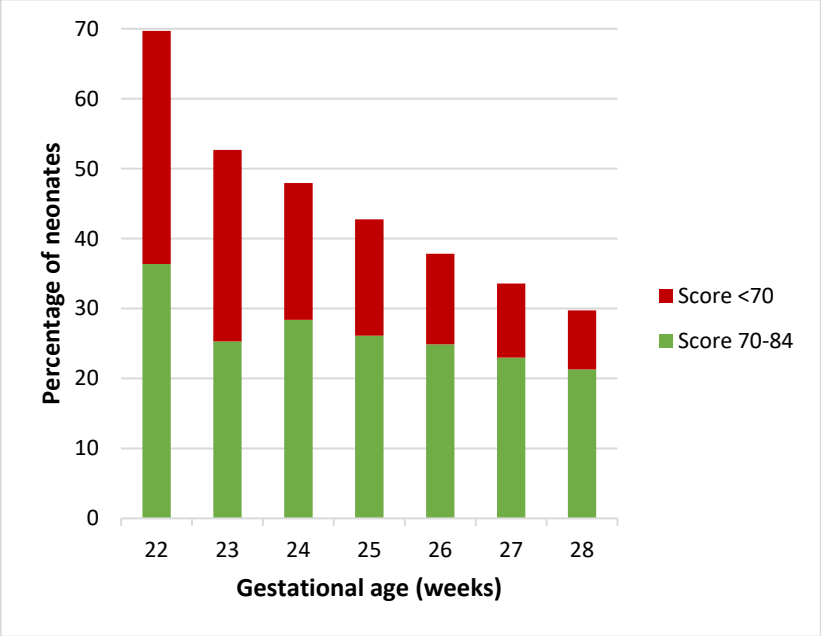
GA in weeks	CNN-CNFUN linked cases (n)	CNN-CNFUN linked cases with motor data (n)	Median score (IQR)	Score ≥85 n (%)	Score 70-84 n (%)	Score <70 n (%)
22	44	33	82 (70, 88)	12 (32.4)	16 (43.2)	10 (27)
23	422	296	88 (76, 97)	190 (57.6)	93 (28.2)	48 (14.5)
24	1163	876	90 (79, 97)	618 (65.5)	234 (24.8)	95 (10.1)
25	1770	1398	91 (82, 100)	1077 (71.7)	305 (20.3)	128 (8.5)
26	2138	1659	94 (85, 100)	1364 (77.1)	290 (16.4)	120 (6.8)
27	2472	1950	94 (87, 102)	1690 (81)	297 (14.2)	104 (5)
28	2927	2299	97 (88, 103)	2089 (83.7)	315 (12.6)	101 (4)
Total	10936	8511	94 (85, 100)	7040 (76.8)	1550 (16.9)	606 (6.6)



COMMENTS:
Bayley scores tend to underestimate developmental delay and have limited predictive ability. Motor scores on the Bayley Scales of Infant and Toddler Development – 3rd or 4th edition (Bayley) improve with increasing gestational age and are skewed in this population. The Bayley scales have a mean score of 100 and standard deviation of 15 (less than 70 is therefore < -2 standard deviations).

Presentation No 11: Bayley language composite scores by gestational age

GA in weeks	CNN-CNFUN linked cases (n)	CNN-CNFUN linked cases with language data (n)	Median score (IQR)	Score ≥85 n (%)	Score 70-84 n (%)	Score <70 n (%)
22	44	31	79 (68, 91)	12 (36.4)	12 (36.4)	11 (33.3)
23	422	299	83 (68, 96)	162 (48.2)	85 (25.3)	92 (27.4)
24	1163	886	86 (74, 97)	503 (52.9)	270 (28.4)	186 (19.6)
25	1770	1414	89 (77, 100)	883 (58.2)	396 (26.1)	252 (16.6)
26	2138	1689	91 (77, 100)	1128 (62.9)	446 (24.9)	232 (12.9)
27	2472	1972	91 (79, 103)	1409 (66.9)	484 (23)	223 (10.6)
28	2927	2297	94 (83, 103)	1767 (70.6)	533 (21.3)	211 (8.4)
Total	10936	8588	91 (77, 100)	5864 (63.5)	2226 (24.1)	1207 (13.1)

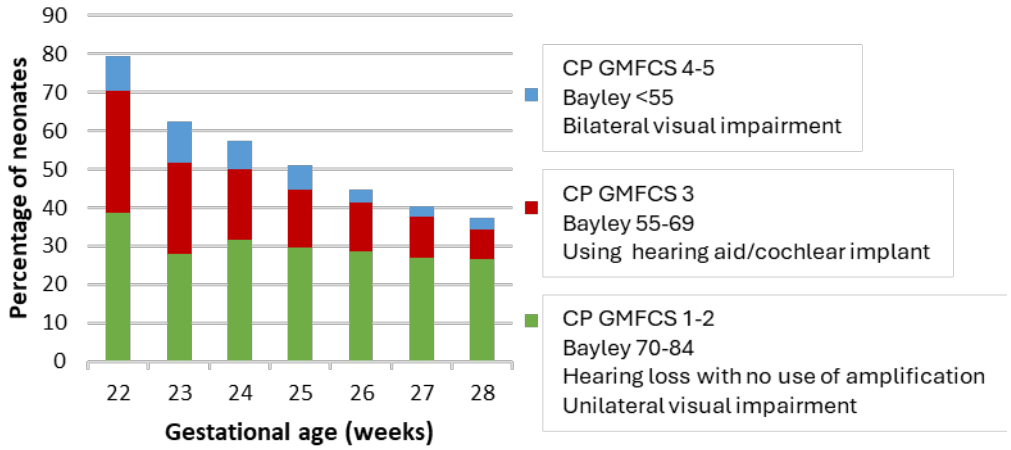


COMMENTS:
Bayley scores tend to underestimate developmental delay and have limited predictive ability. Language scores on the Bayley Scales of Infant and Toddler Development – 3rd or 4th edition (Bayley) improve with increasing gestational age and are skewed in this population. The Bayley scales have a mean score of 100 and standard deviation of 15 (less than 70 is therefore < -2 standard deviations).

Presentation No 12: Neurodevelopmental outcomes by gestational age among survivors

GA in weeks	CNN-CNFUN linked cases with complete data (n)	No NDI n (%)	Mild-moderate NDI n (%)	Significant NDI	
				All n (%)	Severe only n (%)
22	44	9 (20.5)	17 (38.6)	18 (40.9)	< 5*
23	422	159 (37.7)	118 (28)	145 (34.4)	45 (10.7)
24	1163	495 (42.6)	367 (31.6)	301 (25.9)	87 (7.5)
25	1770	868 (49)	523 (29.5)	379 (21.4)	109 (6.2)
26	2138	1186 (55.5)	614 (28.7)	338 (15.8)	70 (3.3)
27	2472	1473 (59.6)	669 (27.1)	330 (13.3)	68 (2.8)
28	2927	1839 (62.8)	778 (26.6)	310 (10.6)	81 (2.8)
Total	10936	6029 (55.1)	3086 (28.2)	1821 (16.7)	464 (4.2)

* Cell with less than 5 reported as < 5.

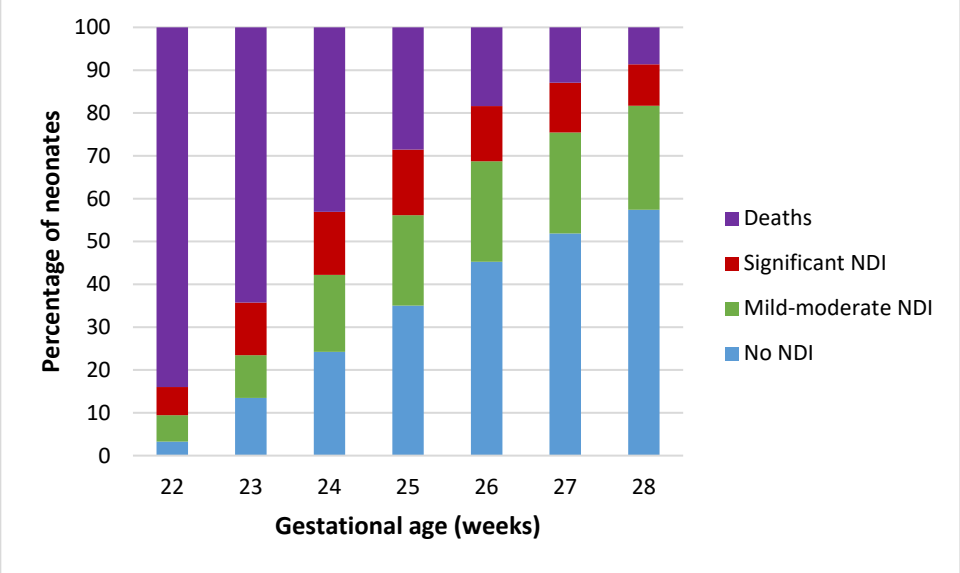


COMMENTS:

Rates of NDI decrease with increasing gestational age. Mild-moderate NDI includes children with any of the following: CP with GMFCS 1-2, Bayley motor, cognitive, language or adaptive behavior composite between 70-84, hearing loss not requiring hearing aids or cochlear implants, or unilateral visual impairment. Significant NDI includes children with any of the following: CP with GMFCS 3-4-5, Bayley motor, cognitive, language or adaptive behavior composite <70, hearing loss requiring hearing aids or cochlear implants, or bilateral visual impairment. Severe NDI, a subcategory of significant NDI, includes children with any of the following: CP with GMFCS 4-5, Bayley cognitive, language or adaptive behavior composite <55, or bilateral visual impairment. Children considered to have significant and severe NDI if they have developmental delay which did not allow completion of the Bayley and obtained a Bayley Adaptive Behavior Score <70 or < 55, respectively. **We advise against using composite outcomes at 18-24 months for family counseling. It is preferable to report on individual outcomes.**

Presentation No 13: Survival without neurodevelopmental impairment (NDI) rates by gestational age

GA in weeks	CNN-CNFUN linked cases or deaths (n)	Survivors n (%)	No NDI n (%)	Any NDI n (%)	Significant NDI n (%)	Survival without significant NDI n (%)
22	275	44 (16)	9 (3.3)	35 (12.7)	18 (6.5)	26 (9.5)
23	1181	422 (35.7)	159 (13.5)	263 (22.3)	145 (12.3)	277 (23.5)
24	2043	1163 (56.9)	495 (24.2)	668 (32.7)	301 (14.7)	862 (42.2)
25	2477	1770 (71.5)	868 (35)	902 (36.4)	379 (15.3)	1391 (56.2)
26	2619	2138 (81.6)	1186 (45.3)	952 (36.3)	338 (12.9)	1800 (68.7)
27	2839	2472 (87.1)	1473 (51.9)	999 (35.2)	330 (11.6)	2142 (75.4)
28	3203	2927 (91.4)	1839 (57.4)	1088 (34)	310 (9.7)	2617 (81.7)
Total	14637	10936 (74.7)	6029 (41.2)	4907 (33.5)	1821 (12.4)	9115 (62.3)



COMMENTS:
This figure shows outcome distribution for all CNN-CNFUN-linked cases including death. Death decreased with increasing gestational age. Survival without any NDI (blue), or without significant NDI (blue and green) increased with increasing gestational age.

Presentation No 14a: Hospitalization rates by gestational age

GA in weeks	**CNN-CNFUN linked cases** (n)	**No hospital admission** n (%)	**One hospital admission** n (%)	**>1 hospital admissions** n (%)
22	44	28 (63.6)	9 (20.5)	7 (15.9)
23	422	237 (56.2)	102 (24.2)	83 (19.7)
24	1163	645 (55.5)	287 (24.7)	231 (19.9)
25	1770	1100 (62.1)	384 (21.7)	286 (16.2)
26	2138	1412 (66)	402 (18.8)	324 (15.2)
27	2472	1695 (68.6)	484 (19.6)	293 (11.9)
28	2927	2112 (72.2)	510 (17.4)	305 (10.4)
Total	10936	7229 (66.1)	2178 (19.9)	1529 (14)

COMMENTS:

About one third of preterm infants in our cohort are re-admitted between discharge from the neonatal intensive care unit and the 18-24 month-visit. One out of 8 children is re-admitted more than once. The main reasons for re-admission, which may be elective in nature (for example, planned surgery), are: 1. respiratory (infectious), 2. surgery, and 3. respiratory (non-infectious). Missing data for n=18.

Presentation No 14b: Referral to health services by gestational age

GA in weeks	CNN-CNFUN linked cases (n)	Any referral** n (%)	Referral to occupational therapy n (%)	Referral to physical therapy n (%)	Referral to psychology n (%)	Referral to a rehabilitation program n (%)	Referral to speech/language therapy n (%)
22	44	41 (93.2)	29 (65.9)	29 (65.9)	< 5*	6 (13.6)	29 (65.9)
23	422	367 (87)	235 (55.7)	264 (62.6)	22 (5.2)	87 (20.6)	244 (57.8)
24	1163	1008 (86.7)	571 (49.1)	640 (55)	47 (4)	191 (16.4)	591 (50.8)
25	1770	1415 (79.9)	711 (40.2)	836 (47.2)	49 (2.8)	171 (9.7)	732 (41.4)
26	2138	1664 (77.8)	769 (36)	957 (44.8)	42 (2)	202 (9.4)	749 (35)
27	2472	1849 (74.8)	773 (31.3)	1019 (41.2)	61 (2.5)	173 (7)	813 (32.9)
28	2927	2081 (71.1)	776 (26.5)	1075 (36.7)	68 (2.3)	216 (7.4)	811 (27.7)
Total	10936	8425 (77)	3864 (35.3)	4820 (44.1)	292 (2.7)	1046 (9.6)	3969 (36.3)

* Cell with less than 5 reported as < 5.

**Any referral includes any of the following health services (seen or waiting): occupational therapy, physical therapy, psychology, rehabilitation program, or speech/language therapy.

COMMENTS:

Majority of infants a referred for developmental services. Receiving multiple services is common.

Presentation No 15a: Use of aids at home from discharge to follow-up visit by gestational age

GA in weeks	CNN-CNFUN linked cases (n)	Use of any aids at home* n (%)	Home supplemental O2	Gavage feeding, gastrostomy or jejunostomy n (%)	Tracheostomy n (%)	Any mobility aid n (%)
22	44	22 (50)	15 (34.1)	9 (20.5)	< 5*	< 5*
23	422	191 (45.3)	135 (32)	85 (20.1)	16 (3.8)	38 (9)
24	1163	449 (38.6)	304 (26.1)	182 (15.6)	17 (1.5)	71 (6.1)
25	1770	524 (29.6)	346 (19.5)	191 (10.8)	24 (1.4)	86 (4.9)
26	2138	483 (22.6)	267 (12.5)	186 (8.7)	14 (0.7)	98 (4.6)
27	2472	430 (17.4)	195 (7.9)	172 (7)	14 (0.6)	121 (4.9)
28	2927	436 (14.9)	149 (5.1)	179 (6.1)	12 (0.4)	124 (4.2)
Total	10936	2535 (23.2)	1411 (12.9)	1004 (9.2)	98 (0.9)	539 (4.9)

* Cells with less than 5 reported as < 5.

Presentation No 15b: Aids at home still in use at the follow-up visit at 18-24 months by gestational age

GA in weeks	CNN-CNFUN linked cases (n)	Use of any aids at home** n (%)	Home supplemental O2	Gavage feeding, gastrostomy or jejunostomy n (%)	Tracheostomy n (%)	Any mobility aid n (%)
22	44	6 (13.6)	< 5*	< 5*	< 5*	0 (0)
23	422	67 (15.9)	11 (2.6)	39 (9.2)	13 (3.1)	32 (7.6)
24	1163	163 (14)	42 (3.6)	81 (7)	13 (1.1)	55 (4.7)
25	1770	159 (9)	32 (1.8)	83 (4.7)	20 (1.1)	65 (3.7)
26	2138	146 (6.8)	29 (1.4)	73 (3.4)	10 (0.5)	60 (2.8)
27	2472	144 (5.8)	12 (0.5)	56 (2.3)	9 (0.4)	82 (3.3)
28	2927	142 (4.9)	14 (0.5)	50 (1.7)	6 (0.2)	84 (2.9)
Total	10936	827 (7.6)	143 (1.3)	386 (3.5)	72 (0.7)	378 (3.5)

* Cells with less than 5 reported as < 5.

**Aids at home include the use of any of the following items: supplemental O2; respiratory/CPAP; gavage feeding; gastrostomy or jejunostomy; ileostomy/colostomy; tracheostomy; apnea monitor; pulse oximeter; adapted wheelchair or stroller; braces, splints, or orthoses; and walker.

COMMENTS:

Almost one in 4 infants use aids at home after NICU discharge, but the majority are discontinued by 18-24 months of corrected age.

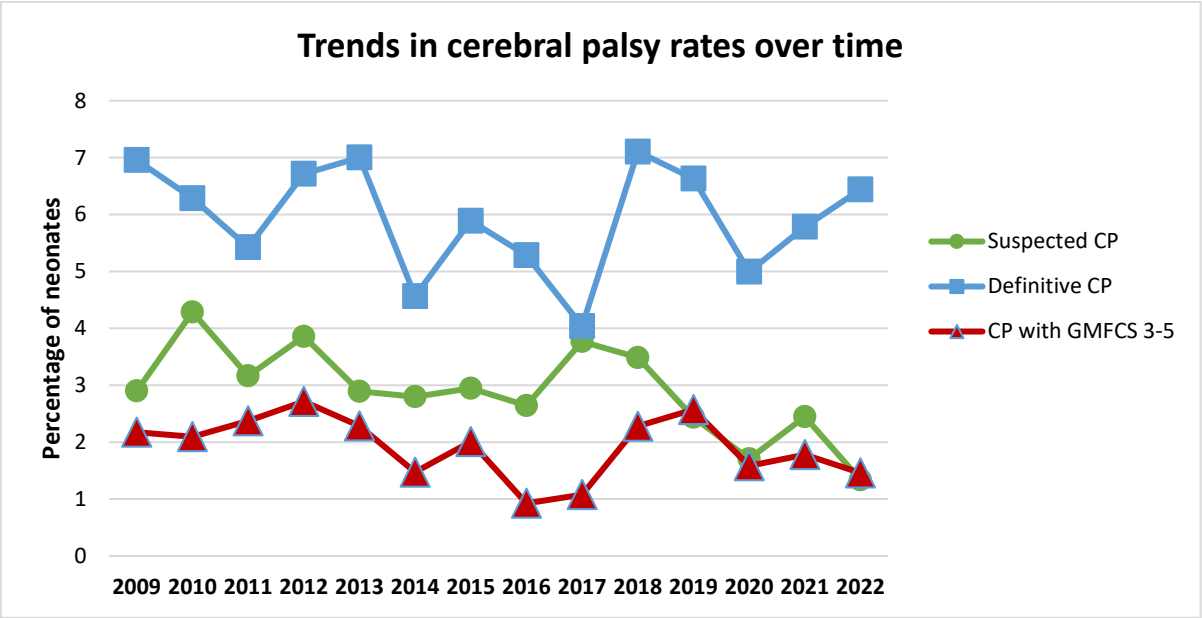
F. Outcomes Over Time

The data presented in this section have not been adjusted for confounding variables. There is variability in attrition rates. Therefore, no statistical analyses for changes over time were conducted.

Presentation No 16: Trends in cerebral palsy rates over time

Year of birth	**CNFUN complete data** (n)	**Missing CP data** (n)	**No CP** n (%)	**Suspected CP** n (%)	**Definitive CP** n (%)	**CP GMFCS 1-2** n (%)	**CP GMFCS 3-5** n (%)
2009	690	6	616 (89.3)	20 (2.9)	48 (7)	26 (3.8)	15 (2.2)
2010	1050	16	923 (87.9)	45 (4.3)	66 (6.3)	33 (3.1)	22 (2.1)
2011	885	21	788 (89)	28 (3.2)	48 (5.4)	23 (2.6)	21 (2.4)
2012	700	4	622 (88.9)	27 (3.9)	47 (6.7)	25 (3.6)	19 (2.7)
2013	657	5	587 (89.3)	19 (2.9)	46 (7)	29 (4.4)	15 (2.3)
2014	679	6	623 (91.8)	19 (2.8)	31 (4.6)	20 (2.9)	10 (1.5)
2015	747	12	669 (89.6)	22 (2.9)	44 (5.9)	27 (3.6)	15 (2)
2016	757	2	695 (91.8)	20 (2.6)	40 (5.3)	28 (3.7)	7 (0.9)
2017	743	8	677 (91.1)	28 (3.8)	30 (4)	20 (2.7)	8 (1.1)
2018	746	7	660 (88.5)	26 (3.5)	53 (7.1)	35 (4.7)	17 (2.3)
2019	739	8	664 (89.9)	18 (2.4)	49 (6.6)	29 (3.9)	19 (2.6)
2020	821	74	692 (84.3)	14 (1.7)	41 (5)	24 (2.9)	13 (1.6)
2021	899	10	815 (90.7)	22 (2.4)	52 (5.8)	32 (3.6)	16 (1.8)
2022	823	7	752 (91.4)	11 (1.3)	53 (6.4)	36 (4.4)	12 (1.5)
2009-2022	10936	186	9783 (89.5)	319 (2.9)	648 (5.9)	387 (3.5)	209 (1.9)

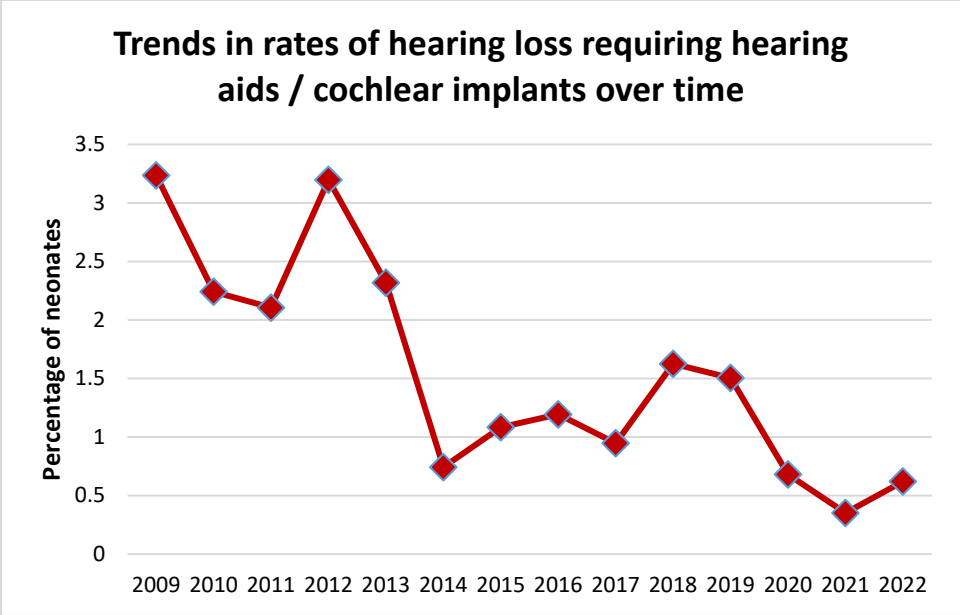
COMMENTS: Cerebral palsy rates fell until 2017 births. In 2018 and 2019, COVID restrictions may have biased towards seeing more children with CP. Starting with birth cohort 2020 and onward, CNFUN members started receiving training on the Hammersmith Infant Neurological Examination; this may explain the increase in definitive CP rate, which mirrors the decrease in suspected CP rate, with examinors feeling more confident with their diagnosis. Data are not adjusted for risk factors. The majority of children with cerebral palsy have a GMFCS $\leq$2 (missing GMFCS data for 52/604 children).


Trends in cerebral palsy rates over time
Percentage of neonates
0
1
2
3
4
5
6
7
8
2009 2010 2011 2012 2013 2014 2015 2016 2017 2018 2019 2020 2021 2022
Suspected CP
Definitive CP
CP with GMFCS 3-5

Presentation No 17: Trends in hearing status over time

Year of birth	**CNFUN complete data** (n)	**Missing hearing data** (n)	**Normal hearing** n (%)	**Hearing loss not requiring aids/cochlear implants** n (%)	**Hearing loss requiring aids/ cochlear implants** n (%)
2009	690	10	622 (91.5)	36 (5.3)	22 (3.2)
2010	1050	24	948 (92.4)	55 (5.4)	23 (2.2)
2011	885	30	803 (93.9)	34 (4)	18 (2.1)
2012	700	12	645 (93.8)	21 (3.1)	22 (3.2)
2013	657	10	612 (94.6)	20 (3.1)	15 (2.3)
2014	679	6	650 (96.6)	18 (2.7)	5 (0.7)
2015	747	9	703 (95.3)	27 (3.7)	8 (1.1)
2016	757	3	707 (93.8)	38 (5)	9 (1.2)
2017	743	4	693 (93.8)	39 (5.3)	7 (0.9)
2018	746	8	702 (95.1)	24 (3.3)	12 (1.6)
2019	739	8	694 (94.9)	26 (3.6)	11 (1.5)
2020	821	86	706 (96.1)	24 (3.3)	5 (0.7)
2021	899	46	810 (95)	40 (4.7)	< 5*
2022	823	17	773 (95.9)	28 (3.5)	5 (0.6)
2009-2022	10936	273	10068 (94.4)	430 (4)	165 (1.5)

* Cell with less than 5 reported as < 5.

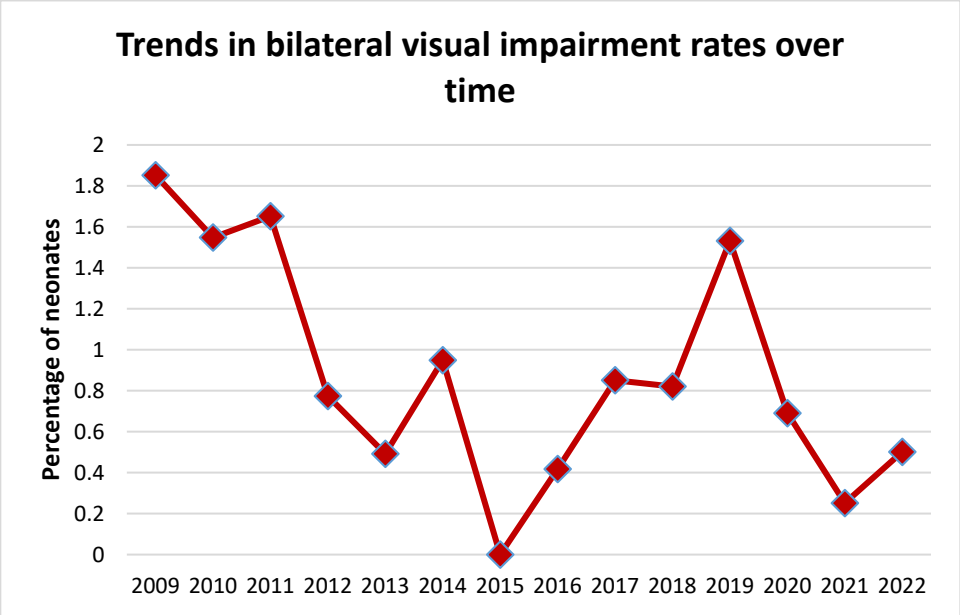


COMMENTS: There is a trend toward decreasing rates of hearing loss requiring hearing aid(s) or cochlear implant(s) over time. Higher attrition rates during the COVID pandemic may impact the results.

Presentation No 18: Trends in visual function over time

Year of birth	**CNFUN complete data** (n)	**Missing vision data** (n)	**Normal vision** n (%)	**Bilateral visual impairment** n (%)
2009	690	42	632 (97.5)	12 (1.9)
2010	1050	81	953 (98.3)	15 (1.5)
2011	885	98	773 (98.2)	13 (1.7)
2012	700	54	640 (99.1)	5 (0.8)
2013	657	47	607 (99.5)	< 5*
2014	679	47	625 (98.9)	6 (0.9)
2015	747	47	698 (99.7)	0 (0)
2016	757	39	715 (99.6)	< 5*
2017	743	38	696 (98.7)	6 (0.9)
2018	746	15	724 (99)	6 (0.8)
2019	739	21	703 (97.9)	11 (1.5)
2020	821	97	716 (98.9)	5 (0.7)
2021	899	105	789 (99.4)	< 5*
2022	823	26	789 (99)	< 5*
2009-2022	10936	757	10060 (98.8)	91 (0.9)

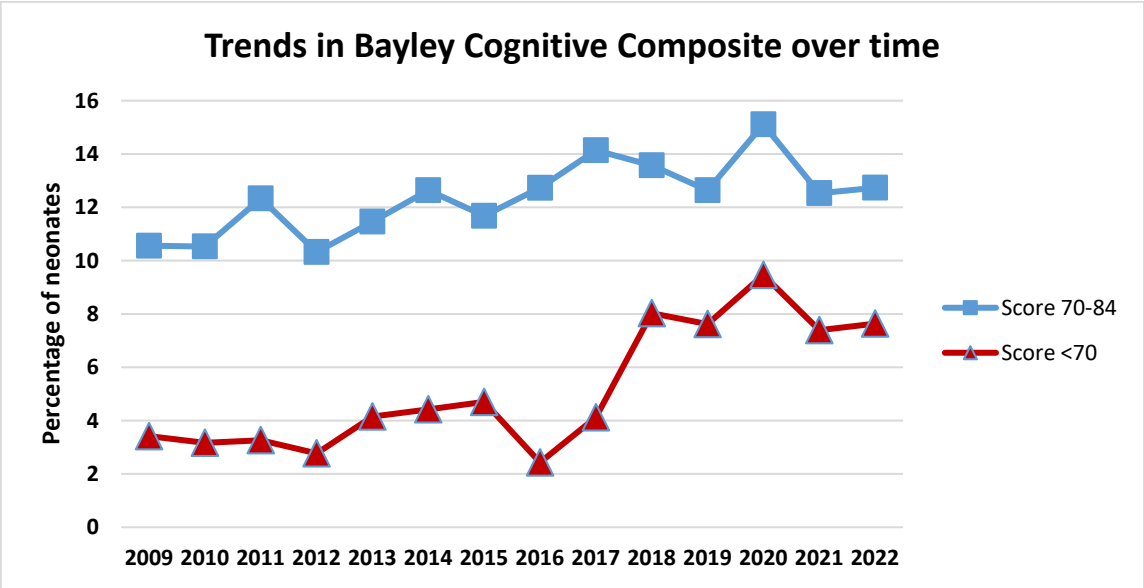
* Cells with less than 5 reported as < 5.



COMMENTS:
Visual impairment at 18-24 months corrected age is now a rare complication of prematurity. Higher attrition rates during the COVID pandemic may impact the results.

Presentation No 19: Trends in Bayley Cognitive Composite scores over time

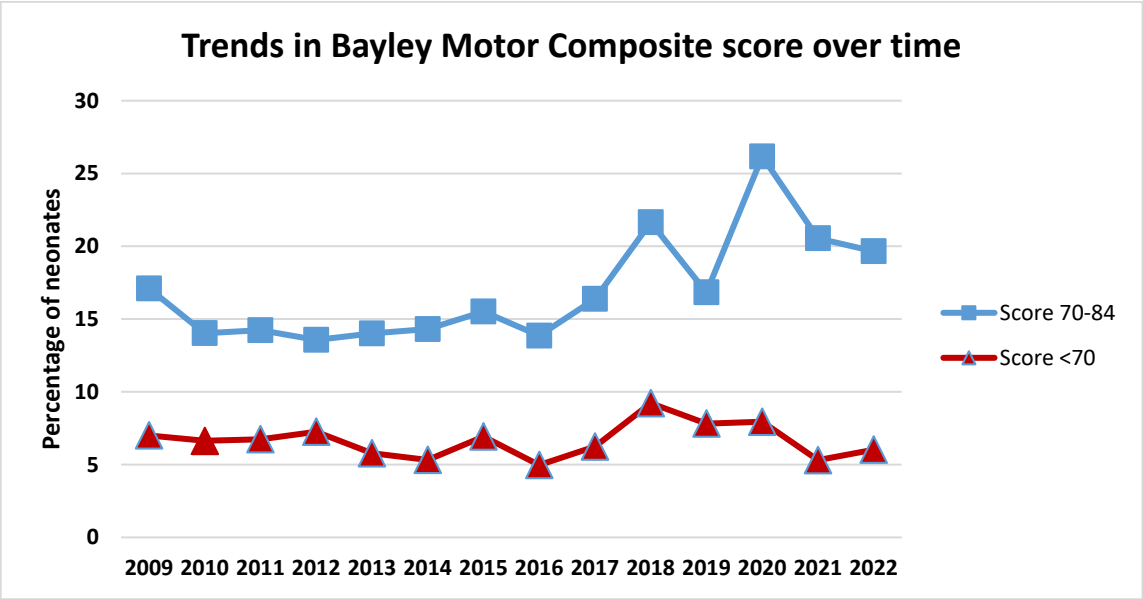
Year of birth	**CNFUN complete data** (n)	**Missing Bayley cognitive score** (n)	**Median score** (IQR)	**Bayley≥85** n (%)	**Score 70-84** n (%)	**Score <70** n (%)	**Median corrected age of assessment** (months)
2009	690	46	95 (90, 105)	554 (86)	68 (10.6)	22 (3.4)	18.67
2010	1050	72	95 (90, 105)	844 (86.3)	103 (10.5)	31 (3.2)	18.59
2011	885	58	95 (90, 105)	698 (84.4)	102 (12.3)	27 (3.3)	18.52
2012	700	51	95 (90, 105)	564 (86.9)	67 (10.3)	18 (2.8)	18.56
2013	657	55	95 (90, 105)	508 (84.4)	69 (11.5)	25 (4.2)	18.79
2014	679	46	95 (85, 105)	525 (82.9)	80 (12.6)	28 (4.4)	18.75
2015	747	45	95 (90, 105)	587 (83.6)	82 (11.7)	33 (4.7)	18.95
2016	757	58	95 (90, 105)	593 (84.8)	89 (12.7)	17 (2.4)	19.05
2017	743	64	95 (85, 105)	555 (81.7)	96 (14.1)	28 (4.1)	18.98
2018	746	223	95 (85, 105)	410 (78.4)	71 (13.6)	42 (8)	20.48
2019	739	201	95 (85, 105)	429 (79.7)	68 (12.6)	41 (7.6)	19.64
2020	821	113	95 (85, 100)	534 (75.4)	107 (15.1)	67 (9.5)	20.67
2021	899	101	95 (85, 105)	639 (80.1)	100 (12.5)	59 (7.4)	21.38
2022	823	77	95 (85, 105)	594 (79.6)	95 (12.7)	57 (7.6)	21.84
2009-2022	10936	1210	95 (85, 105)	8034 (82.6)	1197 (12.3)	495 (5.1)	19.15



COMMENTS:
Rates of cognitive scores <70 appear to increase; no statistical analyses for trend were conducted. Higher attrition rates during the COVID pandemic may impact the results, with infants displaying greater developmental challenges more likely to be seen in follow-up clinics. Additionally, later corrected age at assessment in 2020-2022 may have uncovered more cognitive delay (Garfinkle J, Khairy M, Simard MN, et al. Corrected Age at Bayley Assessment and Developmental Delay in Extreme Preterms. Pediatrics. 2024 Jan 1;153(2): e2023063654.) Finally, the Bayley 4 was introduced starting with birth cohort 2019. There is currently little data comparing the Bayley 3 versus the Bayley 4 in preterm populations.

Presentation No 20: Trends in Bayley Motor Composite scores over time

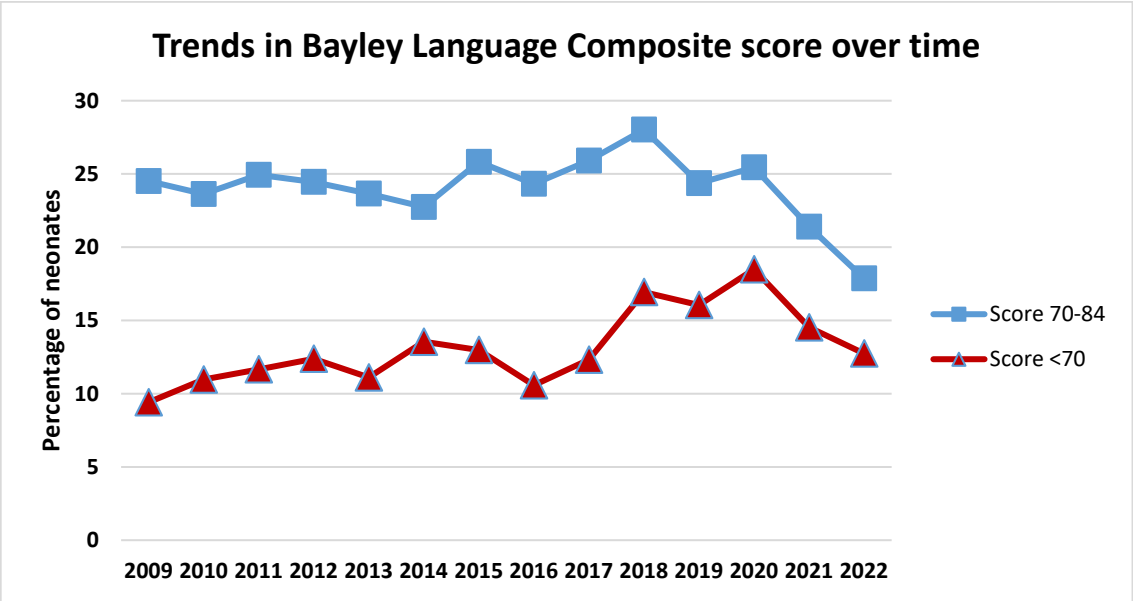
Year of birth	**CNFUN complete data** (n)	**Missing Bayley motor score** (n)	**Median score** (IQR)	**Bayley≥85** n (%)	**Score 70-84** n (%)	**Score <70** n (%)	**Median corrected age of assessment** (months)
2009	690	76	94 (85, 100)	466 (75.9)	105 (17.1)	43 (7)	18.67
2010	1050	116	94 (85, 100)	741 (79.3)	131 (14)	62 (6.6)	18.59
2011	885	84	94 (85, 100)	633 (79)	114 (14.2)	54 (6.7)	18.52
2012	700	66	94 (85, 103)	502 (79.2)	86 (13.6)	46 (7.3)	18.56
2013	657	86	94 (85, 100)	458 (80.2)	80 (14)	33 (5.8)	18.79
2014	679	78	94 (88, 100)	483 (80.4)	86 (14.3)	32 (5.3)	18.75
2015	747	83	94 (85, 103)	515 (77.6)	103 (15.5)	46 (6.9)	18.95
2016	757	93	94 (88, 103)	539 (81.2)	92 (13.9)	33 (5)	19.05
2017	743	102	94 (85, 100)	496 (77.4)	105 (16.4)	40 (6.2)	18.98
2018	746	247	94 (82, 100)	345 (69.1)	108 (21.6)	46 (9.2)	20.48
2019	739	240	94 (85, 103)	376 (75.4)	84 (16.8)	39 (7.8)	19.64
2020	821	179	91 (82, 98)	423 (65.9)	168 (26.2)	51 (7.9)	20.67
2021	899	164	94 (84, 100)	545 (74.1)	151 (20.5)	39 (5.3)	21.38
2022	823	126	94 (86, 102)	518 (74.3)	137 (19.7)	42 (6)	21.84
2009-2022	10936	1740	94 (85, 100)	7040 (76.6)	1550 (16.9)	606 (6.6)	19.15



COMMENTS:
Rates of motor scores between 70-84 appeared to increase; no statistical analyses for trend were conducted. Higher attrition rates during the COVID pandemic may impact the results, with infants displaying greater developmental challenges more likely to be seen in follow-up clinics. Additionally, later corrected age at assessment in 2020-2022 may have uncovered more motor delay (Garfinkle J, Khairy M, Simard MN, et al. Corrected Age at Bayley Assessment and Developmental Delay in Extreme Preterms. Pediatrics. 2024 Jan 1;153(2): e2023063654.) Finally, the Bayley 4 was introduced starting with birth cohort 2019. There is currently little data comparing the Bayley 3 versus the Bayley 4 in preterm populations.

Presentation No 21: Trends in Bayley Language Composite scores over time

Year of birth	**CNFUN complete data** (n)	**Missing Bayley language score** n (%)	**Median score** (IQR)	**Bayley ≥85** n (%)	**Score 70-84** n (%)	**Score <70** n (%)	**Median corrected age of assessment** (months)
2009	690	74	91 (79, 100)	407 (66.1)	151 (24.5)	58 (9.4)	18.67
2010	1050	102	91 (79, 100)	620 (65.4)	224 (23.6)	104 (11)	18.59
2011	885	79	91 (79, 103)	511 (63.4)	201 (24.9)	94 (11.7)	18.52
2012	700	62	91 (79, 100)	403 (63.2)	156 (24.5)	79 (12.4)	18.56
2013	657	99	91 (79, 100)	364 (65.2)	132 (23.7)	62 (11.1)	18.79
2014	679	81	89 (77, 100)	381 (63.7)	136 (22.7)	81 (13.5)	18.75
2015	747	77	89 (77, 100)	410 (61.2)	173 (25.8)	87 (13)	18.95
2016	757	95	91 (79, 100)	431 (65.1)	161 (24.3)	70 (10.6)	19.05
2017	743	110	89 (77, 100)	391 (61.8)	164 (25.9)	78 (12.3)	18.98
2018	746	250	89 (77, 100)	273 (55)	139 (28)	84 (16.9)	20.48
2019	739	222	89 (77, 103)	308 (59.6)	126 (24.4)	83 (16.1)	19.64
2020	821	145	89 (75, 100)	379 (56.1)	172 (25.4)	125 (18.5)	20.67
2021	899	142	92 (77, 103)	485 (64.1)	162 (21.4)	110 (14.5)	21.38
2022	823	101	98 (79, 108)	501 (69.4)	129 (17.9)	92 (12.7)	21.84
2009-2022	10936	1639	91 (77, 100)	5864 (63.1)	2226 (23.9)	1207 (13)	19.15



COMMENTS: Rates of language delays appeared to decrease from birth cohort 2020 to 2022; no statistical analyses for trend were conducted. Higher attrition rates during the COVID pandemic may impact the results, with infants displaying greater developmental challenges more likely to be seen in follow-up clinics. Additionally, the Bayley 4 was introduced starting with birth cohort 2019. The Bayley 4 allows for parents to report on expressive language, which may better reflect the child's ability. There is currently little data comparing the Bayley 3 versus the Bayley 4 in preterm populations.

Presentation No 22: Trends in neurodevelopmental outcomes over time

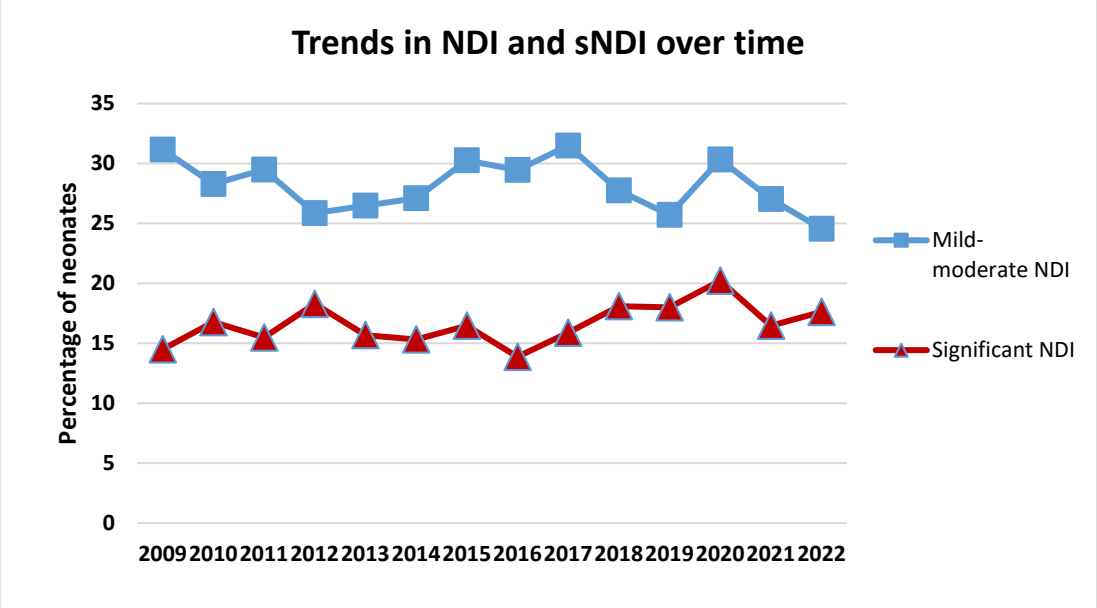
Year of birth	CNFUN complete data (n)	Missing data (n)	No NDI n (%)	Any NDI n(%)	Mild-moderate NDI# n (%)	Significant NDI*	
						All n (%)	Severe only** n (%)
2009	690	0	375 (54.3)	315 (45.7)	215 (31.2)	100 (14.5)	32 (4.6)
2010	1050	0	577 (55)	473 (45)	297 (28.3)	176 (16.8)	56 (5.3)
2011	885	0	487 (55)	398 (45)	261 (29.5)	137 (15.5)	31 (3.5)
2012	700	0	391 (55.9)	309 (44.1)	181 (25.9)	128 (18.3)	32 (4.6)
2013	657	0	380 (57.8)	277 (42.2)	174 (26.5)	103 (15.7)	32 (4.9)
2014	679	0	391 (57.6)	288 (42.4)	184 (27.1)	104 (15.3)	29 (4.3)
2015	747	0	398 (53.3)	349 (46.7)	226 (30.3)	123 (16.5)	33 (4.4)
2016	757	0	429 (56.7)	328 (43.3)	223 (29.5)	105 (13.9)	27 (3.6)
2017	743	0	391 (52.6)	352 (47.4)	234 (31.5)	118 (15.9)	33 (4.4)
2018	746	0	404 (54.2)	342 (45.8)	207 (27.7)	135 (18.1)	45 (6)
2019	739	0	416 (56.3)	323 (43.7)	190 (25.7)	133 (18)	44 (6)
2020	821	0	406 (49.5)	415 (50.5)	249 (30.3)	166 (20.2)	26 (3.2)
2021	899	0	508 (56.5)	391 (43.5)	243 (27)	148 (16.5)	22 (2.4)
2022	823	0	476 (57.8)	347 (42.2)	202 (24.5)	145 (17.6)	22 (2.7)
2009-2022	10936	0	6029 (55.1)	4907 (44.9)	3086 (28.2)	1821 (16.7)	464 (4.2)

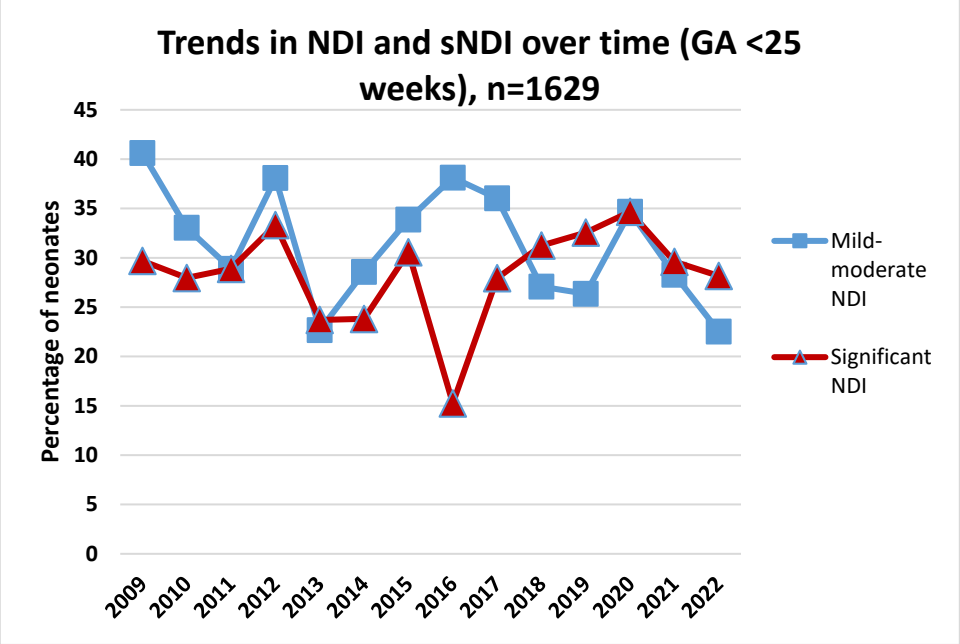
Refer to pages 17-18 for NDI definitions

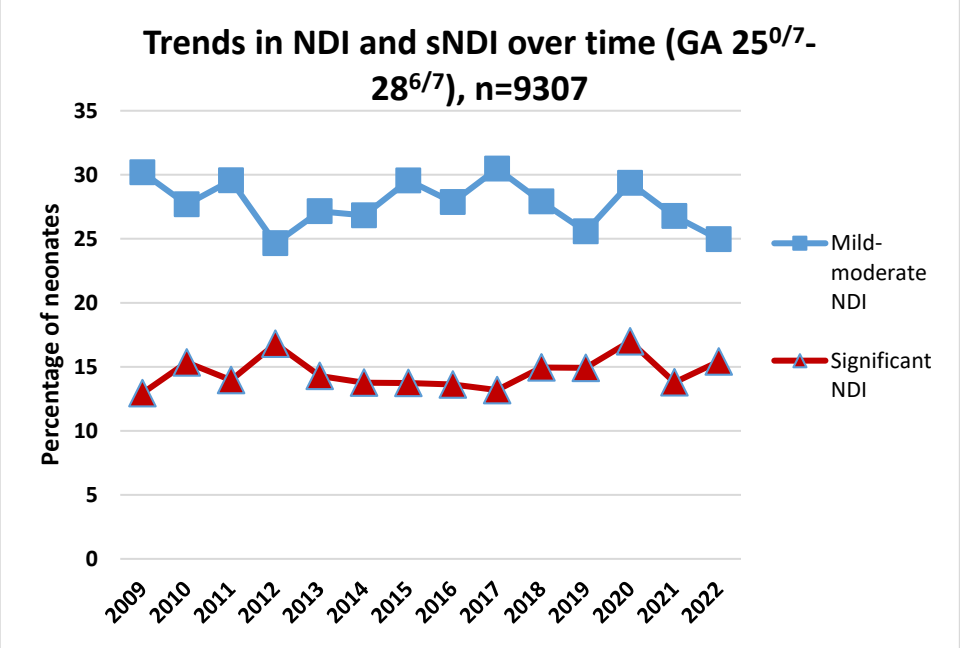
Mild-moderate NDI is calculated by subtracting significant NDI from any NDI.

*Significant NDI includes children with any of the following: CP with GMFCS 3-4-5, Bayley motor, cognitive, language or adaptive behavior composite <70, hearing loss requiring hearing aids or cochlear implants, or bilateral visual impairment. Children considered to have a significant developmental delay which did not allow completion of the Bayley are also included.

**Severe NDI, a sub-category of significant NDI, includes children with any of the following: CP with GMFCS 4-5, Bayley cognitive, language or adaptive behavior composite <55, or bilateral visual impairment. Children considered to have a severe developmental delay which did not allow completion of the Bayley are also included.


Trends in NDI and sNDI over time
Percentage of neonates
35
30
25
20
15
10
5
0
2009 2010 2011 2012 2013 2014 2015 2016 2017 2018 2019 2020 2021 2022
Mild-moderate NDI
Significant NDI


Trends in NDI and sNDI over time (GA <25 weeks), n=1629
Percentage of neonates
45
40
35
30
25
20
15
10
5
0
2009 2010 2011 2012 2013 2014 2015 2016 2017 2018 2019 2020 2021 2022
Mild-moderate NDI
Significant NDI



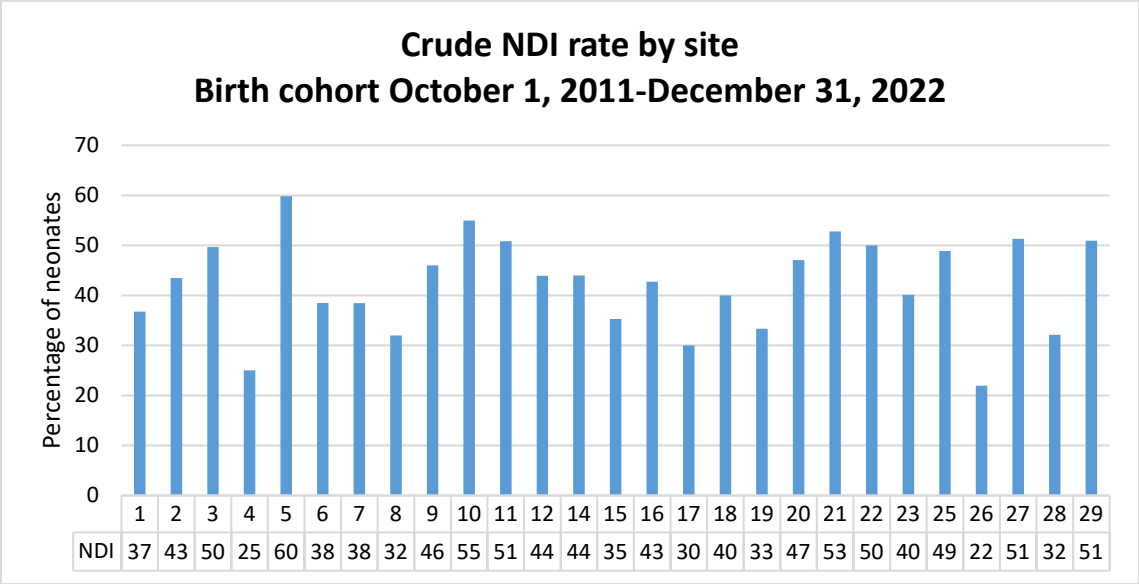
COMMENTS: There has not been a clinically important change in overall NDI rates over time. For infants born <25 weeks, there is a trend toward lower rates of mild-moderate NDI; no statistical analyses for trend were conducted.

G. Sites Comparisons – Crude Rates

Presentation No 23: Neurodevelopmental impairment rates by site (Birth cohort of October 1, 2011 – December 31, 2022)

Site	CNFUN (n)	No NDI n (%)	Any NDI n (%)	CP GMFCS 1-5 n (%)*	Any hearing impairment n (%)	Any visual impairment n (%)	Bayley score <85 Motor n (%)	Bayley score <85 Language n (%)	Bayley score <85 Cognitive n (%)
1	547	346 (63)	201 (37)	32 (6)	19 (3)	< 5%*	86 (16)	137 (25)	38 (7)
2	483	273 (57)	210 (43)	22 (5)	35 (7)	< 5%*	47 (10)	160 (33)	46 (10)
3	143	72 (50)	71 (50)	7 (5)	9 (6)	< 5%*	32 (22)	53 (37)	21 (15)
4	8	6 (75)	< 25%	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	2 (25)
5	341	137 (40)	204 (60)	15 (4)	23 (7)	< 5%*	117 (34)	137 (40)	91 (27)
6	967	595 (62)	372 (38)	47 (5)	29 (3)	15 (2)	156 (16)	201 (21)	117 (12)
7	91	56 (62)	35 (38)	< 5%*	< 5%*	< 5%*	15 (16)	24 (26)	12 (13)
8	125	85 (68)	40 (32)	< 5%*	< 5%*	< 5%*	18 (14)	26 (21)	24 (19)
9	100	54 (54)	46 (46)	10 (10)	< 5%*	0 (0)	22 (22)	32 (32)	16 (16)
10	231	104 (45)	127 (55)	18 (8)	17 (7)	< 5%*	54 (23)	103 (45)	16 (7)
11	657	323 (49)	334 (51)	57 (9)	61 (9)	6 (1)	161 (25)	229 (35)	42 (6)
12	346	194 (56)	152 (44)	32 (9)	5 (1)	6 (2)	82 (24)	102 (29)	125 (36)
14	457	256 (56)	201 (44)	21 (5)	31 (7)	7 (2)	83 (18)	146 (32)	58 (13)
15	17	11 (65)	6 (35)	0 (0)	< 10%	< 5%*	5 (29)	< 20%	54 (318)
16	1193	683 (57)	510 (43)	73 (6)	38 (3)	8 (1)	188 (16)	340 (28)	< 5%*
17	10	7 (70)	< 30%	< 10%	< 10%	0 (0)	< 20%	< 30%	231 (2310)
18	10	6 (60)	< 40%	0 (0)	0 (0)	0 (0)	< 10%	< 40%	< 30%
19	6	< 70%	< 35%	0 (0)	0 (0)	0 (0)	0 (0)	< 35%	6 (100)
20	423	224 (53)	199 (47)	20 (5)	63 (15)	< 5%*	72 (17)	132 (31)	< 5%*
21	180	85 (47)	95 (53)	22 (12)	6 (3)	0 (0)	51 (28)	74 (41)	0 (0)
22	14	7 (50)	7 (50)	< 15%	0 (0)	0 (0)	< 15%	6 (43)	64 (457)
23	364	218 (60)	146 (40)	38 (10)	17 (5)	< 5%*	62 (17)	69 (19)	47 (13)
25	1289	659 (51)	630 (49)	46 (4)	29 (2)	< 5%*	289 (22)	470 (36)	< 5%*
26	82	64 (78)	18 (22)	< 5%*	< 5%*	0 (0)	8 (10)	12 (15)	41 (50)
27	115	56 (49)	59 (51)	5 (4)	< 5%*	< 5%*	22 (19)	47 (41)	13 (11)
28	137	93 (68)	44 (32)	6 (4)	8 (6)	< 5%*	22 (16)	28 (20)	249 (182)
29	161	79 (49)	82 (51)	13 (8)	8 (5)	< 5%*	37 (23)	53 (33)	5 (3)
Total	8497	4697 (55)	3800 (45)	496 (6)	412 (5)	76 (1)	1634 (19)	2593 (31)	1326 (16)

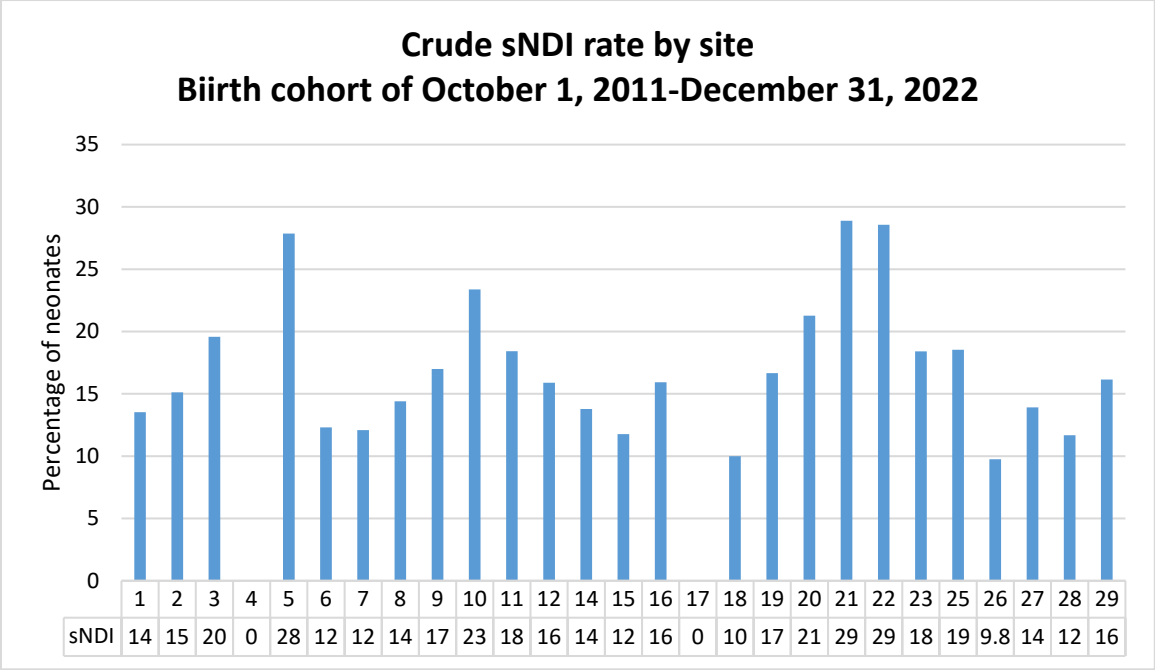
*Cells with less than 5 show only %, rounded up to a multiple of 5%.


Crude NDI rate by site
Birth cohort October 1, 2011-December 31, 2022
Percentage of neonates
70
60
50
40
30
20
10
0
1 2 3 4 5 6 7 8 9 10 11 12 14 15 16 17 18 19 20 21 22 23 25 26 27 28 29
NDI 37 43 50 25 60 38 38 32 46 55 51 44 44 35 43 30 40 33 47 53 50 40 49 22 51 32 51

Presentation No 24: Significant neurodevelopmental impairment rates by site (Birth cohort of October 1, 2011 – December 31, 2022)

Site	**CNFUN** (n)	**No NDI** n (%)	**Significant NDI** n (%)	**CP GMFCS 3-5** n (%)	**Hearing aids/Cochlear implants** n (%)	**Bilateral visual impairment** n (%)	**Bayley score <70 Motor** n (%)	**Bayley score <70 Language** n (%)	**Bayley score <70 Cognitive** n (%)
1	547	473 (86)	74 (14)	15 (3)	11 (2)	< 5%*	29 (5)	36 (7)	11 (2)
2	483	410 (85)	73 (15)	7 (1)	5 (1)	< 5%*	8 (2)	63 (13)	17 (4)
3	143	115 (80)	28 (20)	< 5%*	< 5%*	0 (0)	9 (6)	24 (17)	< 5%*
4	8	8 (100)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)
5	341	246 (72)	95 (28)	< 5%*	11 (3)	< 5%*	29 (9)	68 (20)	43 (13)
6	967	848 (88)	119 (12)	14 (1)	5 (1)	11 (1)	27 (3)	82 (8)	32 (3)
7	91	80 (88)	11 (12)	0 (0)	0 (0)	< 5%*	< 5%*	11 (12)	< 5%*
8	125	107 (86)	18 (14)	0 (0)	< 5%*	0 (0)	8 (6)	14 (11)	14 (11)
9	100	83 (83)	17 (17)	< 5%*	0 (0)	0 (0)	5 (5)	11 (11)	5 (5)
10	231	177 (77)	54 (23)	5 (2)	5 (2)	< 5%*	17 (7)	41 (18)	13 (6)
11	657	536 (82)	121 (18)	17 (3)	5 (1)	< 5%*	57 (9)	75 (11)	37 (6)
12	346	291 (84)	55 (16)	8 (2)	< 5%*	< 5%*	24 (7)	32 (9)	20 (6)
14	457	394 (86)	63 (14)	6 (1)	5 (1)	7 (2)	31 (7)	46 (10)	24 (5)
15	17	15 (88)	< 15%	0 (0)	< 10%	< 10%	< 10%	< 10%	0 (0)
16	1193	1003 (84)	190 (16)	16 (1)	14 (1)	< 5%*	60 (5)	116 (10)	65 (5)
17	10	10 (100)	0 (0)	0 (0)	0 (0)	0 (0)	< 10%	< 10%	< 10%
18	10	9 (90)	< 10%	0 (0)	0 (0)	0 (0)	0 (0)	< 20%	0 (0)
19	6	5 (83)	< 20%	0 (0)	0 (0)	0 (0)	0 (0)	< 20%	0 (0)
20	423	333 (79)	90 (21)	7 (2)	5 (1)	< 5%*	30 (7)	74 (17)	25 (6)
21	180	128 (71)	52 (29)	8 (4)	< 5%*	0 (0)	22 (12)	41 (23)	21 (12)
22	14	10 (71)	< 30%	< 15%	0 (0)	0 (0)	< 15%	< 10%	< 10%
23	364	297 (82)	67 (18)	15 (4)	7 (2)	6 (2)	18 (5)	21 (6)	9 (2)
25	1289	1050 (81)	239 (19)	16 (1)	16 (1)	< 5%*	53 (4)	172 (13)	64 (5)
26	82	74 (90)	8 (10)	< 5%*	< 5%*	0 (0)	6 (7)	6 (7)	< 5%*
27	115	99 (86)	16 (14)	< 5%*	< 5%*	0 (0)	< 5%*	14 (12)	6 (5)
28	137	121 (88)	16 (12)	< 5%*	< 5%*	< 5%*	8 (6)	8 (6)	< 5%*
29	161	135 (84)	26 (16)	6 (4)	< 5%*	< 5%*	10 (6)	12 (7)	< 5%*
Total	8497	7057 (83)	1440 (17)	156 (2)	106 (1)	54 (1)	462 (5)	973 (11)	422 (5)

*Cells with less than 5 show only %, rounded up to a multiple of 5%.



	1	2	3	4	5	6	7	8	9	10	11	12	14	15	16	17	18	19	20	21	22	23	25	26	27	28	29
sNDI	14	15	20	0	28	12	12	14	17	23	18	16	14	12	16	0	10	17	21	29	29	18	19	9.8	14	12	16

H. Sites Comparisons –Adjusted Standardized Ratios

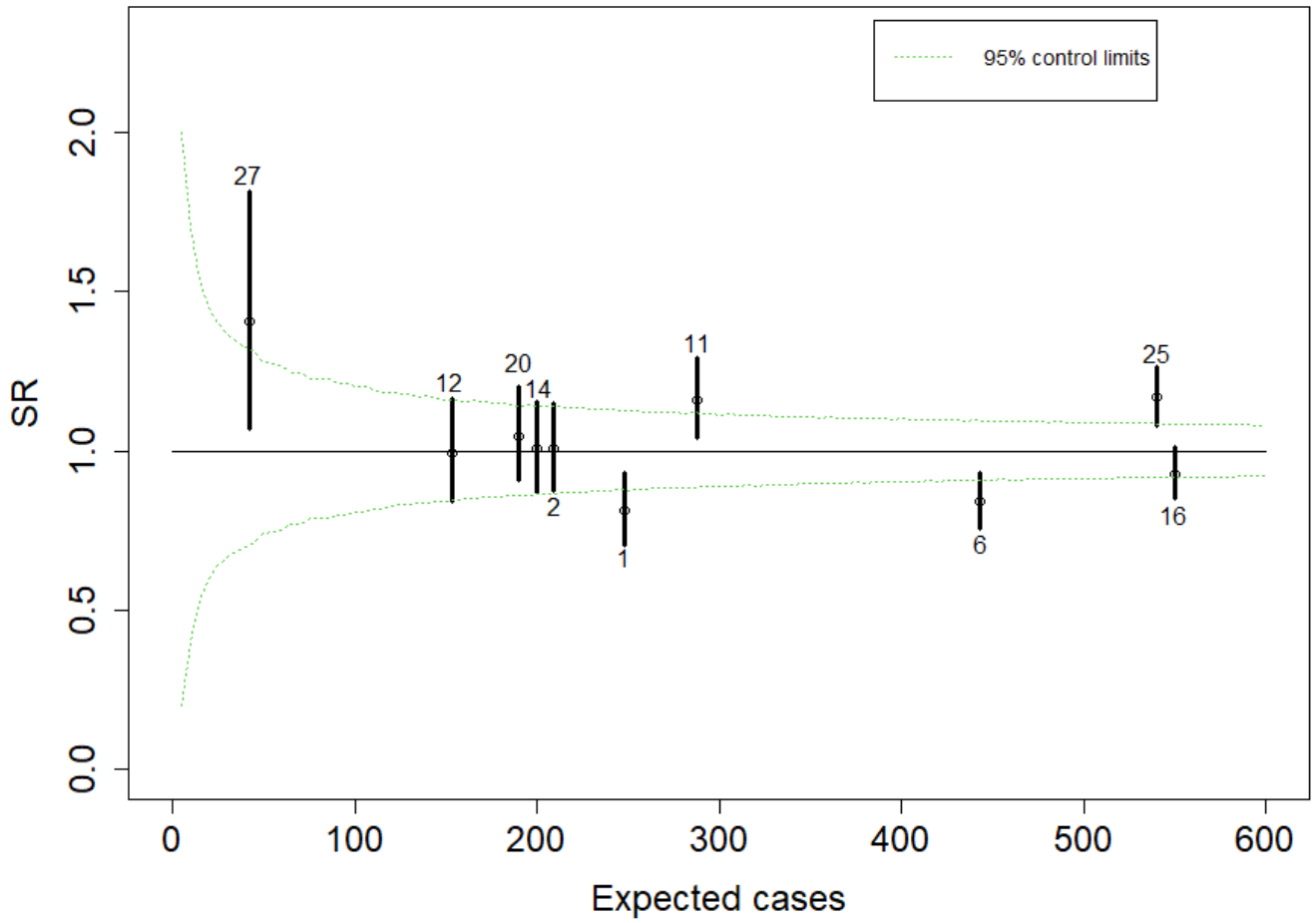
Presentation No 25: Adjusted standardized ratios of neurodevelopmental impairment by site (Birth cohort of October 1, 2011 – December 31, 2022) Amended

Site	Children (n)	Follow-up rate (%)	Included (Yes/No)	NDI (n)	Adjusted expected NDI (n)	Adjusted standardized ratio (95%CI)*
1	548	73.9	Yes	201	248	0.81 (0.70, 0.93)
2	485	81.4	Yes	210	209	1.00 (0.87, 1.15)
3	143	64.7		71		
4	8	11.8		2		
5	342	27.6		204		
6	987	75.2	Yes	372	443	0.84 (0.76, 0.93)
7	92	39.1		35		
8	128	13.4		40		
9	103	46.8		46		
10	232	61.2		127		
11	657	86.4	Yes	334	288	1.16 (1.04, 1.29)
12	346	84.8	Yes	152	153	0.99 (0.84, 1.16)
14	457	80.9	Yes	201	200	1.00 (0.87, 1.15)
15	17	10.4		6		
16	1206	72.3	Yes	510	550	0.93 (0.85, 1.01)
17	10	1.4		3		
18	10	4.9		4		
19	6	2		2		
20	426	75.8	Yes	199	190	1.05 (0.91, 1.20)
21	182	69.5		95		
22	14	12		7		
23	372	61.1		146		
25	1301	74.5	Yes	630	540	1.17 (1.08, 1.26)
26	82	62.6		18		
27	115	82.1	Yes	59	42	1.40 (1.07, 1.79)
28	137	35.8		44		
29	161	46.7		82		

* Cells with less than 5 reported as < 5.

1. Sites with <20 participants and/or <70% follow-up rates are excluded.

2. Model is adjusted for gestational age, sex, outborn status, severity of illness (SNAP>20), bronchopulmonary dysplasia, necrotizing enterocolitis Bell's stage 2 or greater and severe brain injury, (defined as any grade 3 intraventricular hemorrhage, intraparenchymal hemorrhage, moderate-severe posthemorrhagic ventricular dilatation or periventricular leukomalacia).



COMMENTS:

Sites with points outside the green "funnel" represent higher or lower adjusted NDI rates than expected. When the 95% confidence interval does not cross the green boundaries, the results are statistically significantly different from other sites.

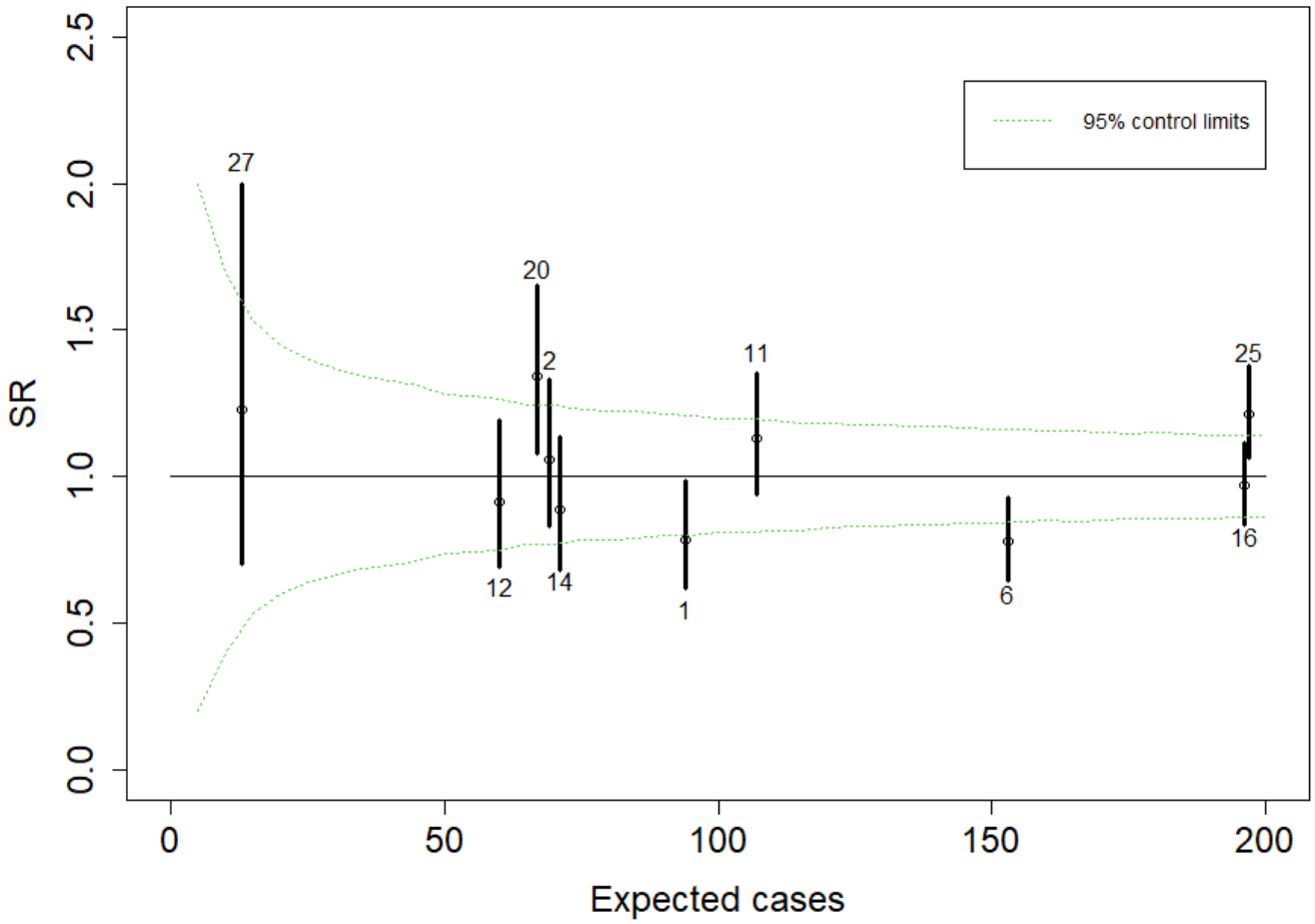
Presentation No 26:
Adjusted standardized ratios of significant neurodevelopmental impairment by site (Birth cohort of October 1, 2011 – December 31, 2022) Amended

Site	Children (n)	Follow-up rate (%)	Included (Yes/No)	sNDI (n)	Adjusted expected sNDI (n)	Adjusted standardized ratio (95%CI)*
1	548	73.9	Yes	74	94	0.79 (0.62, 0.98)
2	485	81.4	Yes	73	69	1.06 (0.83, 1.31)
3	143	64.7		28		
4	8	11.8		0		
5	342	27.6		95		
6	987	75.2	Yes	119	153	0.78 (0.64, 0.92)
7	92	39.1		11		
8	128	13.4		18		
9	103	46.8		17		
10	232	61.2		54		
11	657	86.4	Yes	121	107	1.13 (0.94, 1.34)
12	346	84.8	Yes	55	60	0.92 (0.69, 1.17)
14	457	80.9	Yes	63	71	0.89 (0.68, 1.12)
15	17	10.4		2		
16	1206	72.3	Yes	190	196	0.97 (0.84, 1.11)
17	10	1.4		0		
18	10	4.9		1		
19	6	2		1		
20	426	75.8	Yes	90	67	1.34 (1.08, 1.64)
21	182	69.5		52		
22	14	12		4		
23	372	61.1		67		
25	1301	74.5	Yes	239	197	1.21 (1.06, 1.37)
26	82	62.6		8		
27	115	82.1	Yes	16	13	1.23 (0.70, 1.91)
28	137	35.8		16		
29	161	46.7		26		

* Cells with less than 5 reported as < 5.

1. Sites with <20 participants and/or <70% follow-up rates are excluded.

2. Model is adjusted for gestational age, sex, antenatal steroids, severity of illness (SNAP>20), severe retinopathy of prematurity defined as stage 3 or greater in either eye or treatment with laser or injections of anti-vascular endothelial growth factor, nosocomial infection and brain injury (defined as any grade 3 or 4 intraventricular hemorrhage, ventricular dilatation ≥10 mm, intraparenchymal hemorrhage or periventricular leukomalacia).

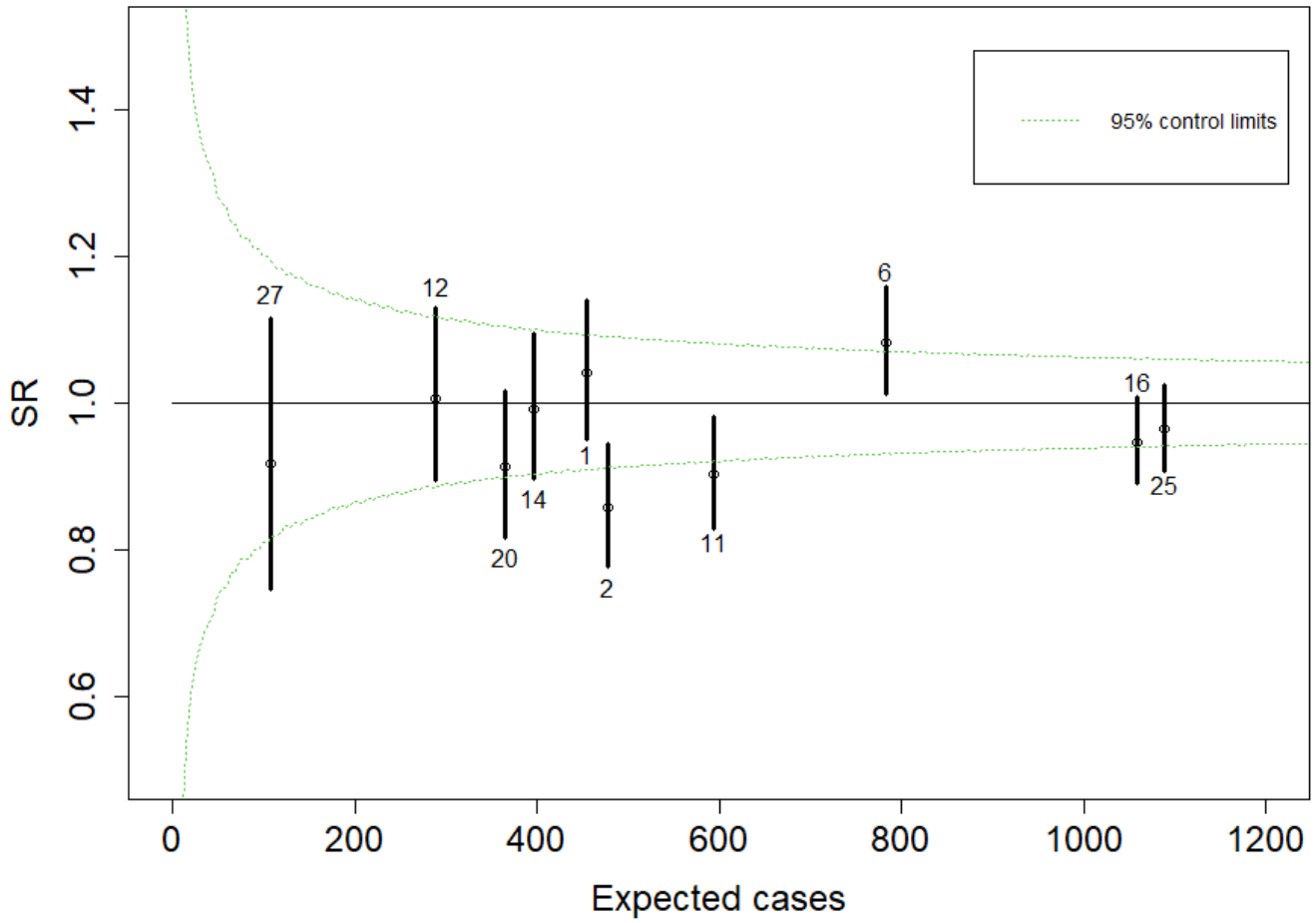


COMMENTS:
Sites with points outside the green "funnel" represent higher or lower adjusted sNDI rates than expected. When the 95% confidence interval does not cross the green boundaries, the results are statistically significantly different from other sites.

Presentation No 27:
Adjusted standardized ratios of survival without significant neurodevelopmental impairment by site (Birth cohort of October 1, 2011 – December 31, 2022) Amended

Site	Children (n)	Follow-up rate (%)	Included (Yes/No)	Survival without sNDI (n)	Adjusted expected outcome (n)	Adjusted standardized ratio (95%CI)
1	653	73.9	Yes	473	454	1.04 (0.95, 1.14)
2	663	81.4	Yes	410	478	0.86 (0.78, 0.94)
3	199	64.7		115		
4	22	11.8		8		
5	548	27.6		246		
6	1100	75.2	Yes	848	783	1.08 (1.01, 1.16)
7	124	39.1		80		
8	330	13.4		107		
9	134	46.8		83		
10	309	61.2		177		
11	868	86.4	Yes	536	594	0.90 (0.83, 0.98)
12	410	84.8	Yes	291	289	1.01 (0.89, 1.13)
14	556	80.9	Yes	394	397	0.99 (0.90, 1.09)
15	78	10.4		15		
16	1539	72.3	Yes	1003	1059	0.95 (0.89, 1.01)
17	174	1.4		10		
18	56	4.9		9		
19	63	2		5		
20	520	75.8	Yes	333	365	0.91 (0.82, 1.01)
21	276	69.5		128		
22	40	12		10		
23	596	61.1		297		
25	1526	74.5	Yes	1050	1089	0.96 (0.91, 1.02)
26	99	62.6		74		
27	131	82.1	Yes	99	108	0.92 (0.74, 1.11)
28	186	35.8		121		
29	205	46.7		135		

1. Sites with <20 participants and/or <70% follow-up rates are excluded.
2. Model is adjusted for gestational age, sex, antenatal steroids, 5 minutes Apgar score <7, multiples, outborn, severity of illness (SNAP>20), necrotizing enterocolitis Bell's stage 2 or greater and severe brain injury (defined as any grade 3 or 4 intraventricular hemorrhage, ventricular dilatation ≥10 mm, intraparenchymal hemorrhage or periventricular leukomalacia).



COMMENTS:
Sites with points outside the green "funnel" represent higher or lower adjusted survival without significant NDI rates than expected. When the 95% confidence interval does not cross the green boundaries, the results are statistically significantly different from other sites.

I. Summary of Publications

CNFUN Manuscripts 2016:

1. Morin J, Luu TM, Superstein R, Ospina LH, Lefebvre F, Simard MN, Shah V, Shah PS, Kelly EN; Canadian Neonatal Network and the Canadian Neonatal Follow-Up Network Investigators. Neurodevelopmental Outcomes Following Bevacizumab Injections for Retinopathy of Prematurity. Pediatrics 2016 Apr;137(4) pii: e20153218. doi: 10.1542/peds.2015-3218.

CNFUN Manuscripts 2017:

1. Isayama T, Lee SK, Yang J, Lee D, Daspal S, Dunn M, Shah PS; Canadian Neonatal Network and Canadian Neonatal Follow -Up Network Investigators. Revisiting the Definition of Bronchopulmonary Dysplasia: Effect of Changing Panoply of Respiratory Support for Preterm Neonates. JAMA Pediatr. 2017 Mar 1;171(3):271-279.
2. Asztalos E, Church PT, Riley P, Fajardo C, Shah PS, Canadian Neonatal Network and Canadian Neonatal Follow-Up Network investigators. Neonatal factors associated with a good neurodevelopmental outcome in the very preterm infant. Am J Perinatol. 2017 Mar;34(4):388-396.
3. Asztalos E, Church PT, Riley P, Fajardo C, Shah PS, Canadian Neonatal Network and Canadian Neonatal Follow-Up Network investigators. Association between Primary Caregiver Education and Cognitive and Language Development of Preterm Neonates. Am J Perinatol. 2017 Mar;34(4):364-371.
4. Synnes A, Luu TM, Moddemann D, Church P, Lee D, Vincer M, Ballantyne M, Majnemer A, Creighton D, Yang J, Sauve R, Saigal S, Shah P, Lee S, CNN, CNFUN. Determinants of developmental outcomes in a very preterm Canadian cohort. Arch Dis Child Fetal Neonatal Ed. 2017 May;102(3):F235-F234.
5. Raghuram K, Yang J, Church PT, Cieslak Z, Synnes A, Mukerji A, Shah PS, CNN and CNFUN. Canadian Neonatal Network and Canadian Neonatal Follow-Up Network Investigators. Head growth trajectory and neurodevelopmental outcomes in preterm neonates. Pediatrics. 2017 Jul;140(1) pii: e20170216. doi: 10.1542/peds.2017-0216.
6. Soraisham AS, Rabi Y, Lodha AK, Shah PS, Synnes A, Yang J, Singhal N, CNN, CNFUN Neurodevelopmental outcomes of preterm infants resuscitated with different oxygen concentration at birth. J Perinatol, 2017 Oct;37(10):1141-1147.

CNFUN Manuscripts 2018:

1. Shah P, McDonald S, Barrett J, Synnes A, Robson K, Foster J, Pasquier JC, Joseph KS Piedboeuf B, Lacaze-Masmonteil T, O'Brien K, Shivananda S, Chaillet N, Pechlivanoglou P, for the Canadian Preterm Birth Network Investigators. The Canadian Preterm Birth Network: a study protocol for improving outcomes for preterm infants and their families. doi: 10.9778/cmajo.20170128 CMAJO January 18, 2018 vol. 6 no. 1 E44-E49.
2. Amer R, Moddemann D, Seshia M, Alvaro R, Synnes A, Lee KS, Lee SK, Shah PS; Canadian Neonatal Network and Canadian Neonatal Follow-up Network Investigators. Neurodevelopmental Outcomes of Infants Born at <29 Weeks of Gestation Admitted to Canadian Neonatal Intensive Care Units Based on Location of Birth. J Pediatr. 2018 May; 196:31-37, e1.
3. Haslam MD, Lisonkova S, Creighton D, Church P,Yang J, Shah PS, Joseph KS, and Synnes A**;** Canadian Neonatal Network and the Canadian Neonatal Follow-Up Network. Severe Neurodevelopmental Impairment in Neonates Born Preterm: Impact of Varying Definitions in a Canadian Cohort. J Pediatr. 2018 Jun;1 97:75-81.
4. Ting JY, Synnes AR, Lee SK, Shah PS Canadian Neonatal Network and Canadian Neonatal Follow-Up Network. Association of admission temperature and death or adverse neurodevelopmental outcomes in extremely low-gestational age neonates. J Perinatol. 2018 Jul;38(7):844-849.

5. Ting JY, Synnes A, Roberts A, Deshpandey AC, Dow K, Yang J, Lee KS, Lee SK, Shah PS; Canadian Neonatal Network and Canadian Neonatal Follow-Up Network. Association of Antibiotic Utilization and Neurodevelopmental Outcomes among Extremely Low Gestational Age Neonates without Proven Sepsis or Necrotizing Enterocolitis. Am J Perinatol. 2018 Aug;35(10):972-978.
6. Kelly EN, Shah VS, Levenbach J, Vincer M, DaSilva O, Shah PS; Canadian Neonatal Network and Canadian Neonatal Follow-Up Network Investigators. Inhaled and systemic steroid exposure and neurodevelopmental outcome of preterm neonates. J Matern Fetal Neonatal Med.2018 Oct;31(20):2665-2672.
7. Stockley EL, Ting JY, Kingdom JC, McDonald SD, Barrett JF, Synnes AR, Monterrosa L, Shah PS; Canadian Neonatal Network; Canadian Neonatal Follow-up Network; Canadian Preterm Birth Network Investigators. Intrapartum magnesium sulfate is associated with neuroprotection in growth-restricted fetuses. Am J Obstet Gynecol. 2018 Dec;219(6): 606.e1-606.e8.
8. Iwami H, Isayama T, Lodha A, Canning R, Abou Mehrem A, Lee SK, Synnes A, Shah PS; Canadian Neonatal Network and Canadian Neonatal Follow-Up Network Investigators. Outcomes after Neonatal Seizures in Infants Less Than 29 Weeks' Gestation: A Population-Based Cohort Study. Am J Perinatol. 2018 Jul 17. doi: 10.1055/s-0038-1667107. [Epub ahead of print] PMID:30016820.
9. Nassel D, Chartrand C, Doré-Bergeron MJ, Lefebvre F, Ballantyne M, Van Overmeire B, Luu TM; Canadian Neonatal Network and the Canadian Neonatal Follow-Up Network.Very Preterm Infants with Technological Dependence at Home: Impact on Resource Use and Family. Neonatology. 2019 Mar 25;115(4):363-370.

CNFUN Manuscripts 2019:

1. Lodha A, Entz R, Synnes A, Creighton D, Yusuf K, Lapointe A, Yang J, Shah PS; investigators of the Canadian Neonatal Network (CNN) and the Canadian Neonatal Follow-up Network (CNFUN). Early caffeine administration and neurodevelopmental outcomes in preterm infants. Pediatrics. 2019 Jan;143(1).
2. Fischer N, Soraisham A, Shah PS, Synnes A, Rabi Y, Singhal N, Ting JY, Creighton D, Dewey D, Ballantyne M, Lodha A; Canadian Neonatal Network™ (CNN); Canadian Neonatal Follow-up Network (CNFUN); Investigators. Extensive cardiopulmonary resuscitation of preterm neonates at birth and mortality and developmental outcomes. Resuscitation. 2019 Feb;1 35:57-65.
3. Ediger K, Hasan SU, Synnes A, Shah J, Creighton D, Isayama T, Shah PS, Lodha A; Canadian Neonatal Network; Canadian Neonatal Follow-Up Network. Maternal smoking and neurodevelopmental outcomes in infants <29 weeks gestation: a multicenter cohort study. J Perinatol. 2019 Apr 17. doi: 10.1038/s41372-019-0356-3. [Epub ahead of print].
4. Shafey A, Bashir RA, Shah PS, Synnes A, Kelly E, Canadian Neonatal Network and Canadian Neonatal Follow-Up Network Investigators. Outcomes and resource usage of infants born at ≤ 25 weeks gestation in Canada. Accepted to Paediatrics & Child Health. Feb 7, 2019.
5. Synnes A, Gillone J, Majnemer A, Lodha A, Creighton D, Moddemann D, Shah PS; Canadian and Neonatal Network; Canadian and Neonatal Follow-up Network. Preterm children with suspected cerebral palsy at 19 months corrected age in the Canadian neonatal follow-up network. Early Hum Dev. 2019 Sep;136:7-13.
6. Morgan-Feir M, Abbott A, Synnes A, Creighton D, Pillay T, Zwicker JG, on behalf of the Canadian Neonatal Follow-Up Network. Comparing Standardized and Parent-Reported Motor Outcomes of Extremely Preterm Infants. Children (Basel). 2019 Aug 1;6(8). pii: E90. doi: 10.3390/children6080090.
7. Albaghli F, Church P, Ballantyne M, Girardi A, Synnes A. Neonatal follow-up programs in Canada: A national survey. Paediatr Child Health. 2019 Nov 29;26(1), e46-e51. doi: 10.1093/pch/pxz159. PMID: 33542778; PMCID: PMC7850286.
8. Puthattayil ZB, Luu TM, Beltempo M, Cross S, Pillay T, Ballantyne M, Synnes A, Shah P, Daboval T; Canadian Neonatal Follow-Up Network. Risk factors for re-hospitalization following neonatal discharge of

extremely preterm infants in Canada. Paediatr Child Health. 2019 Dec 3;26(2) e96-e104. doi: 10.1093/pch/pxz143. eCollection 2021 Feb. PMID: 33747317; PMCID: PMC7962711.

CNFUN Manuscripts 2020:

1. Shafey A, Bashir RA, Shah P, Synnes A, Yang J, Kelly EN; Canadian Neonatal Network and Canadian Neonatal Follow-Up Network Investigators Outcomes and resource usage of infants born at ≤ 25 weeks gestation in Canada. Paediatr Child Health. 2020 Jun;25(4):207-215.
2. DiLabio J, Zwicker JG, Sherlock R, Daspal S, Shah PS, Shah V; Canadian Neonatal Network and Canadian Neonatal Follow-Up Network. Maternal age and long-term neurodevelopmental outcomes of preterm infants < 29 weeks gestational age. J Perinatol. 2021 Jun;41(6):1304-1312. doi: 10.1038/s41372-020-0735-9. Epub 2020 Jul 21. PMID: 32694856.
3. Grass B, Ye XY, Kelly E, Synnes A, Lee S. Association between Transport Risk Index of Physiologic Stability in Extremely Premature Infants and Mortality or Neurodevelopmental Impairment at 18 to 24 Months. J Pediatr. 2020 Sept;224: 51-56. e5. PMID: 32442448.

CNFUN Manuscripts 2021:

1. Zozaya C, Shah J, Pierro A, Zani A, Synnes A, Lee S, Shah PS; Canadian Neonatal Network and the Canadian Neonatal Follow-Up Network Investigators. Neurodevelopmental and Growth Outcomes of Extremely Preterm Infants with Necrotizing Enterocolitis or Spontaneous Intestinal Perforation. J Pediatr Surg. 2021 Feb;56(2): 309-316 doi: 10.1016/j.jpedsurg.2020.05.013 PMID: 32553453
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