Canadian Neonatal Follow-Up Network
Réseau Canadien de Suivi Néonatal

CNFUN 2023 2024 REPORT

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 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 last election was held June 2023.

The CNFUN Steering Committee is composed of 11 members:

- The director of the network.
- The past director of the network.
- A co-director chosen by the CNFUN Steering Committee.
- Five (5) 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**: The database will be maintained, and error checked by the CNFUN Database Working Group and the MiCare (Maternal Infant Care Network). 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.
- **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. Membership may also be terminated by the Steering Committee if an institution fails to maintain data contribution to the CNFUN database.

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.
- **Obligations**: Members agree to abide by the rules governing research conduct and use of the data.
- **Benefits**: Members may use network infrastructure for research collaboration. Research projects using network data must be approved by the Steering Committee.
- **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 important outcomes to be collected and reported within CNFUN and to redefine neurodevelopmental impairment. ***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 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 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 parent reported outcome measures (PROMs) that reflect child functioning and quality of life. 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). 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 when counselling parents and families. Outcomes are measured at 24 ± 3 months corrected age (CA). Data on HINE and GMA scores are included in the updated CNFUN case report form.

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[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)

CNFUN Database Working Group

Jehier Afifi, MD– Neonatologist, neonatal follow-up (Nova Scotia)
Arsalan Butt, Data Abstractor (British Columbia)
Matthew Hicks, MD – Neonatologist, developmental behavioral pediatrician (Alberta)
Karen Thomas, MD– Neonatologist / developmental behavioral pediatrician (Ontario)
Sonny Yeh, MiCare Coordinating Centre, Database Manager (Ontario)
Seungwoo Lee, MiCare Coordinating Centre, Analyst (Ontario)
Isabelle Lahaie, MSc- CNFUN National Coordinator (Quebec)

2023/2024 CNFUN Annual Report Working Group

Thuy Mai Luu, MD – Pediatrician, neonatal follow-up (Québec)
Jehier Afifi, MD– Neonatologist, neonatal follow-up (Nova Scotia)
Matthew Hicks, MD – Neonatologist, developmental behavioral pediatrician (Alberta)
Leonora Hendson, MD – Neonatologist, neonatal follow-up (Alberta)
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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A. Executive Summary

We are pleased to provide the sixth CNFUN report. In this report, we are including 18–24-month outcomes for both 2023 and 2024, birth cohorts 2020 and 2021.

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, 2021. Information is included for 13659 survivors and non-survivors and 10218 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. They have pursued their dedicated work, including during the most challenging years of the pandemic. 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].
- 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)

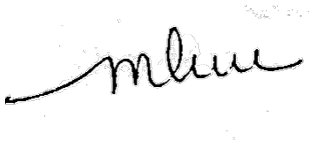
In this 2023-2024 report, key findings are highlighted below. It is important to note that during the years 2020-2022, at the heart of the COVID pandemic, decreased follow-up rates were observed. Children with higher biological risk of NDI or presenting challenges were more likely to be seen in follow-up clinics. This potentially led to an overestimation of NDI rates during these years.

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

- The majority (6954/11079 = 63%) of infants born <29 weeks' gestational age survives without significant NDI (see definition page 16).
- Significant NDI rates have remained stable over time.
- 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

In the next years, as we are implementing parent-reported outcome measures to assess child functioning and quality of life 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.

We would like to thank the people who have contributed to making this 2023-2024 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. Prakesh Shah and Dr. Marc Beltempo for their leadership. We also would like to thank Dr Anne Synnes, the Founding member and past director of CNFUN, who continues to share her time, passion and wisdom with us, despite her retirement from clinical work. Finally, we want to express our deepest appreciation for the families of children born preterm' attendance at their 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	9
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	6
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	10

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*	Judy.Seesahai	6
SJHC (LHSC) Developmental Follow-Up Clinic St. Joseph's Health Care *London, ON*	Kevin Coughlin	10
SUNY Neonatal Follow-Up Program Sunnybrook Health Sciences Center *Toronto, ON*	Rudaina Banihani	8
MSH Neonatal Follow-Up Program Mount Sinai Hospital *Toronto, ON*	Kamini Raghuram	9
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*	J.P Bodani	
EDM Neonatal and Infant Follow-Up Clinic Glenrose Rehabilitation Hospital *Edmonton, AB*	Amber Reichert	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*	Nisha 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

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

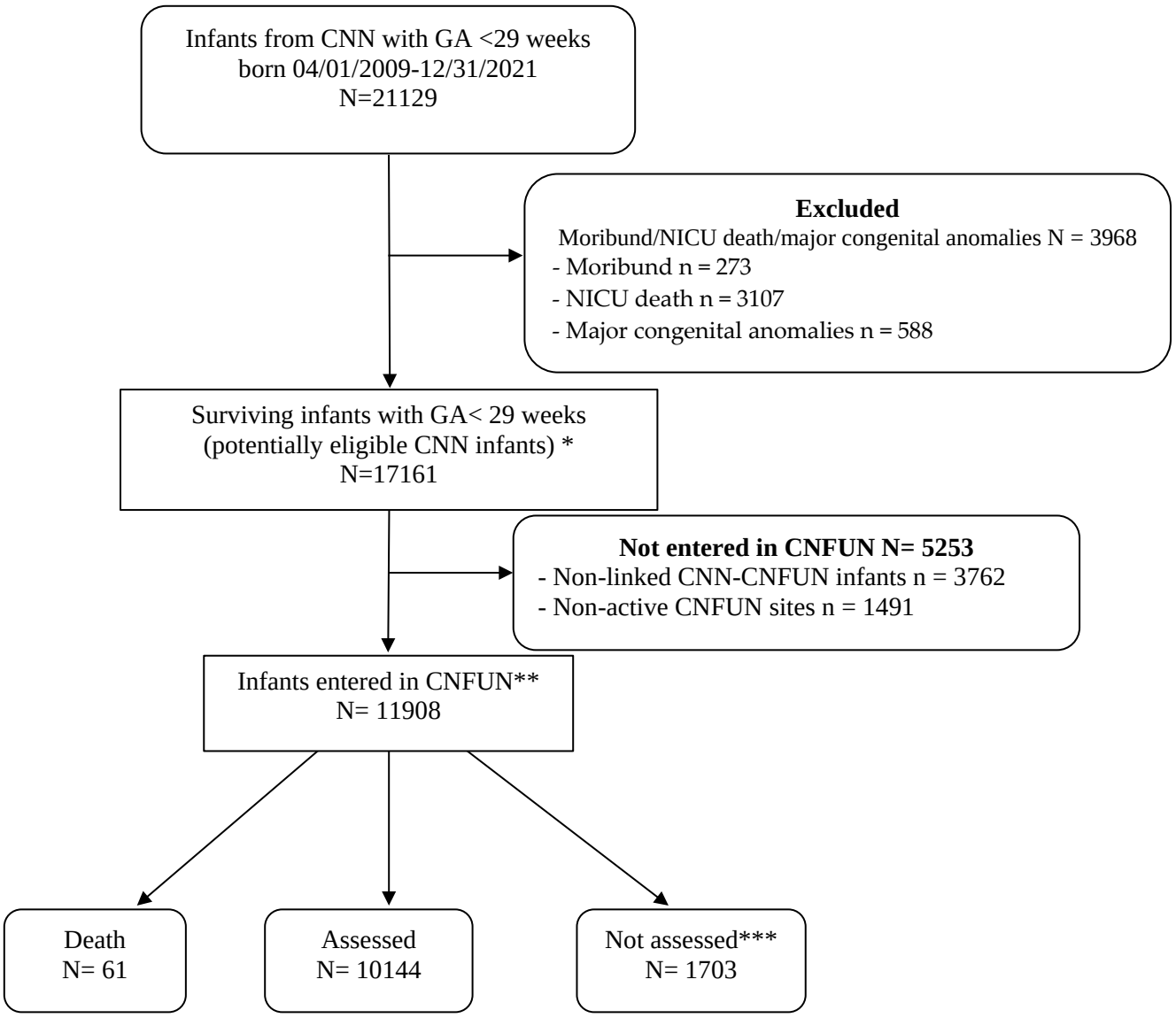
Presentation No 2: CNFUN Sites Participation and Follow-up Rates[3]

CNFUN Site	Epoch 1 Follow-Up Rate (Births April 1, 2009 – September 30, 2011) n/N (%)	Epoch 2 Follow-Up Rate (Births October 1, 2011 – December 31, 2021) n/N (%)	Overall Follow-Up Rate (Births April 1, 2009 – December 31, 2021) n/N (%)
1	146/192 (76)	512/682 (75.1)	658/874 (75.3)
2	123/136 (90.4)	441/538 (82)	564/674 (83.7)
3	10/13 (76.9)	133/197 (67.5)	143/210 (68.1)
4	13/17 (76.5)	8/60 (13.3) *	21/77 (27.3)
5	221/257 (86)	339/1145 (29.6) *	560/1402 (39.9)
6	218/249 (87.6)	908/1216 (74.7)	1126/1465 (76.9)
7	30/50 (60)	83/216 (38.4) *	113/266 (42.5)
8	153/210 (72.9)	66/884 (7.5) *	219/1094 (20)
9	63/110 (57.3)	100/210 (47.6) *	163/320 (50.9)
10	56/68 (82.4)	216/355 (60.8)	272/423 (64.3)
11	181/223 (81.2)	614/707 (86.8)	795/930 (85.5)
12	85/103 (82.5)	330/389 (84.8)	415/492 (84.3)
13	23/38 (60.5)		23/204 (11.3)*
14	105/134 (78.4)	416/521 (79.8)	521/655 (79.5)
15	31/51 (60.8)	17/149 (11.4) *	48/200 (24)
16	251/304 (82.6)	1070/1504 (71.1)	1321/1808 (73.1)
17	79/163 (48.5)	7/627 (1.1) *	86/790 (10.9)
18	42/47 (89.4)	10/186 (5.4) *	52/233 (22.3)
19	17/66 (25.8)	6/266 (2.3) *	23/332 (6.9)
20	78/98 (79.6)	384/508 (75.6)	462/606 (76.2)
21	56/59 (94.9)	169/243 (69.5)	225/302 (74.5)
22	13/20 (65)	14/108 (13) *	27/128 (21.1)
23	141/167 (84.4)	317/534 (59.4)	458/701 (65.3)
24	7/14 (50)		7/49 (14.3)*
25	241/312 (77.2)	1163/1584 (73.4)	1404/1896 (74.1)
26	19/23 (82.6)	73/117 (62.4)	92/140 (65.7)
27		101/121 (83.5)	101/121 (83.5)
28	55/87 (63.2)	116/357 (32.5) *	171/444 (38.5)
29	19/28 (67.9)	129/297 (43.4) *	148/325 (45.5)

*****Sites may have low follow up rates due to interruption in data contribution to the CNFUN database after MiCare project (2009-2011).

[3] Follow-up rate denominator: infants with GA<29 weeks discharged alive from NICU (infants with moribund or major congenital anomalies were excluded).

Presentation No 3: CNN and CNFUN flow diagram for births Apr 1, 2009 – Dec 31, 2021[4]



[4] 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. Children not entered in CNFUN as they could not be linked with CNN (n=5253).

**CNFUN children are recruited locally by a CNFUN site and recorded in the CNFUN database as assessed, not assessed, or deceased.

***Children were not assessed for the following reasons: declined/consent not obtained (n=430), no contact information (n=32), unable to reach (n=354), missed appointment (n=290), other reason (n=553), missing information (n=44).

C. Outcomes Definitions

CP: cerebral palsy defined as per Rosenbaum *et al.* Dev Med Child Neurol suppl 2007; 109:8-14: *"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."*
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 impairment: determined from ophthalmology consult if available and 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)[5]	**Significant neurodevelopmental impairment (sNDI)** (Any one or more of the following)[6]	**Severe neurodevelopmental impairment (severe NDI)** (Any one or more of the following)[7]
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	Not included
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
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

[5] Children are also included in this category if they could not be tested using the Bayley and obtained a Bayley Adaptive Behavior Score <85
[6] **Score <70 or were considered to have a developmental delay which did not allow completion of the Bayley.
[7] Severe NDI: using definition of severe neurodevelopmental disability by 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 developmental delay which did not allow completion of the Bayley.

On the outcome of death or NDI

When thinking about the composite outcome of death or 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 (Montori VM et al. BMJ. 2005; 330 (7491):594).

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);
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 (Manja V, AlBashir S, Guyatt G. J Clinical Epidemiol 2007;82: 4-11).

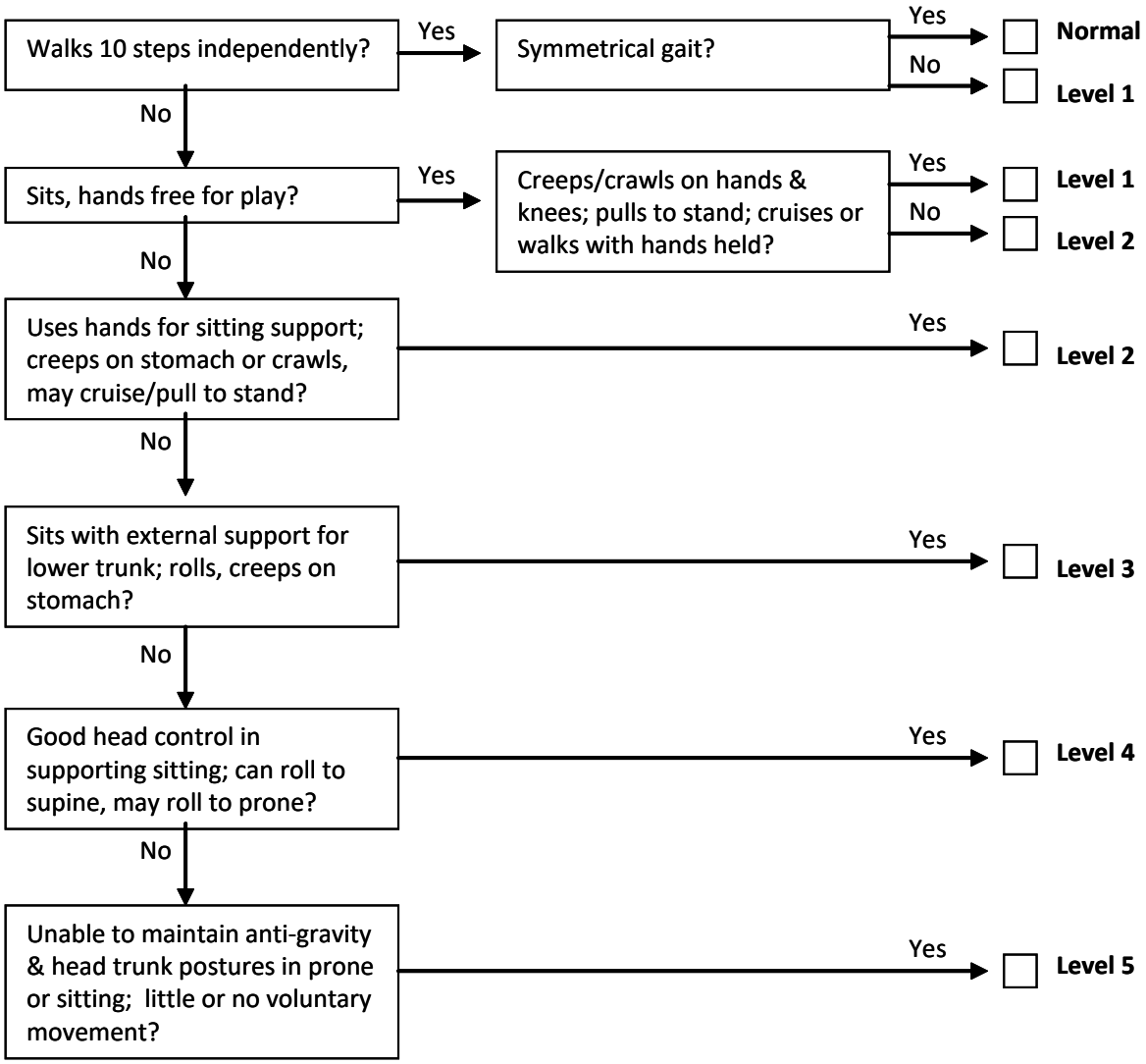
However, in neonatal outcome research, one could argue that if an intervention/exposure significantly increased mortality, this would be the primary concern and therefore, the longer-term outcome would become less relevant unless extreme. The problem is that each individual will define ‘extreme’ based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

Furthermore, based on 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 (Synnes A et al. Children (Basel);10(5):880). Therefore, reporting death or significant NDI in the same composite outcome is not clinically meaningful nor philosophically appropriate.

There is therefore a need to identify novel methodological approaches to address competing risk in neonatal outcome research.

Algorithm based on Palisano, et al (1997)[8]

Gross Motor Function Classification System (GMFCS)



[8] 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 and 2021).

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

Year of birth	**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 (%)
2009*	1218	66 (5.4)	231 (19.0)	921 (75.6)	7 (0.6)	700 (76.0)	938 (81.4)
2010	1654	28 (1.7)	260 (15.7)	1366 (82.6)	15 (0.9)	1064 (77.9)	1339 (82.3)
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 (81.0)	< 5	666 (48.4)	951 (57.4)
2014	1674	57 (3.4)	259 (15.5)	1358 (81.1)	< 5	682 (50.2)	942 (58.3)
2015	1615	52 (3.2)	244 (15.1)	1319 (81.7)	< 5	747 (56.6)	992 (63.5)
2016	1739	59 (3.4)	274 (15.8)	1406 (80.9)	7 (0.4)	767 (54.6)	1048 (62.4)
2017	1694	64 (3.8)	241 (14.2)	1389 (82.0)	5 (0.3)	752 (54.1)	998 (61.2)
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)	829 (65.0)	1078 (71.0)
2021	1641	39 (2.4)	244 (14.9)	1358 (82.8)	5 (0.3)	905 (66.6)	1154 (72.0)
2009-2021	21129	588 (2.8)	3380 (16.0)	17161 (81.2)	61 (0.3)	10218 (59.5)	13659 (66.5)

Cells with less than 5 reported as < 5.

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* 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	276	6 (2.2)	205 (74.3)	65 (23.6)	0 (0)	39 (60.0)	244 (90.4)
23	1291	25 (1.9)	694 (53.8)	572 (44.3)	8 (0.6)	380 (66.4)	1082 (85.5)
24	2576	69 (2.7)	811 (31.5)	1696 (65.8)	9 (0.3)	1084 (63.9)	1904 (75.9)
25	3390	96 (2.8)	647 (19.1)	2647 (78.1)	15 (0.4)	1650 (62.3)	2312 (70.2)
26	3829	106 (2.8)	438 (11.4)	3285 (85.8)	10 (0.3)	2015 (61.3)	2463 (66.2)
27	4440	138 (3.1)	330 (7.4)	3972 (89.5)	12 (0.3)	2325 (58.5)	2667 (62.0)
28	5327	148 (2.8)	255 (4.8)	4924 (92.4)	7 (0.1)	2725 (55.3)	2987 (57.7)
22-28	21129	588 (2.8)	3380 (16.0)	17161 (81.2)	61 (0.3)	10218 (59.5)	13659 (66.5)

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	570	11 (1.9)	344 (60.4)	215 (37.7)	<5	137 (63.7)	483 (86.4)
500-749	5539	158 (2.9)	1689 (30.5)	3692 (66.7)	26 (0.5)	2371 (64.2)	4086 (75.9)
750-999	7429	236 (3.2)	902 (12.1)	6291 (84.7)	23 (0.3)	3858 (61.3)	4783 (66.5)
1000-1249	5564	136 (2.4)	331 (5.9)	5097 (91.6)	10 (0.2)	2926 (57.4)	3267 (60.2)
> 1250	2007	46 (2.3)	102 (5.1)	1859 (92.6)	0 (0)	921 (49.5)	1023 (52.2)
All	21109	587 (2.8)	3368 (16)	17154 (81.3)	61 (0.3)	10213 (59.5)	13642 (66.5)

* 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.

Presentation No 6: Follow-up rates among active CNFUN sites

Year of birth	NICU survivors at participating sites# (n)	CNFUN data** (n)	Follow-up rate for participating CNFUN sites n (%)
2009*	921	865	700 (76)
2010	1366	1310	1064 (77.9)
2011	1261	1113	898 (71.2)
2012	926	850	701 (75.7)
2013	972	812	666 (68.5)
2014	949	837	682 (71.9)
2015	921	860	747 (81.1)
2016	1208	944	767 (63.5)
2017	1172	958	752 (64.2)
2018	1267	943	757 (59.7)
2019	1248	887	750 (60.1)
2020	1138	965	829 (72.8)
2021	1216	1066	905 (74.4)
2009-2021	14565	12410	10218 (70.2)

The MiCare cohort includes all CNFUN sites (2009-2011).

For 2012-2015, active sites contributing data include Victoria General Hospital, BC Women's Hospital & Health Centre, Alberta Children's Hospital & Foothills Hospital, University of Calgary, University of Manitoba Health Sciences Centre/ Children's Hospital, St. Boniface General Hospital, Windsor Regional Hospital, St. Joseph's Health Care London, Mount Sinai Hospital, Sunnybrook Health Sciences Center, Centre Hospitalier Universitaire Sainte-Justine, Jewish General Hospital, Montreal Children's Hospital, Centre Hospitalier Universitaire de Sherbrooke, Centre Hospitalier Universitaire de Québec – Université Laval, IWK Health Centre and Cape Breton Regional Hospital.

In 2016, Edmonton, Hamilton Health Sciences Centre, Kingston General Hospital and Hôpital Maisonneuve Rosemont were also active sites contributing data.

Since 2017, Royal Columbian Hospital and Surrey Memorial Hospital are also contributing data.

No additional sites were added during the period of 2018 - 2021.

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*April 1, 2009 to December 31, 2009.
#Newborns admitted moribund or with major congenital anomalies are excluded.
**Not all CNFUN patients can be linked to CNN.

Presentation No 7: Follow-up rates among CNFUN sites by gestational age

Gestational age (weeks)	**All NICU survivors** n	**NICU survivors at active contributing sites#** (n)	**CNFUN data** (n)	**Follow-up rate for active contributing CNFUN sites^** n (%)	**Linked* CNN-CNFUN data for all NICU survivors** n (%)
22	65	55	57	38 (69.1)	39 (60.0)
23	572	499	451	376 (75.4)	380 (66.4)
24	1696	1442	1309	1055 (73.2)	1084 (63.9)
25	2647	2269	1896	1610 (71.0)	1650 (62.3)
26	3285	2792	2365	1973 (70.7)	2015 (61.3)
27	3972	3345	2883	2283 (68.3)	2325 (58.5)
28	4924	4163	3395	2678 (64.3)	2725 (55.3)
22-28	17161	14565	12356	10013 (68.7)	10218 (59.5)

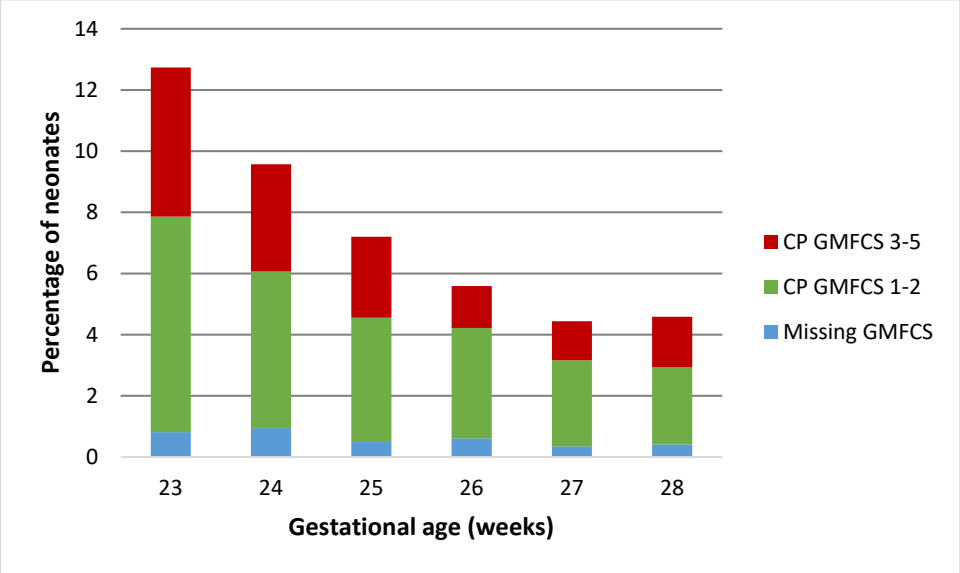
^ Denominator is NICU survivors referred for follow up at CNFUN sites.
* Reasons for the non-linked babies: no CNN patient ID or cannot be linked with CNN data.
# Newborns admitted moribund or with major congenital anomalies are excluded.

E. Gestational Age Based Outcomes

Presentation No 8: Cerebral palsy rates 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 (%)	**Missing CP GMFCS** n (%)	**CP with GMFCS 1-2** n (%)	**CP with GMFCS 3-5** n (%)
22	39	39	6 (15.4)	0 (0)	0 (0)	< 5	< 5
23	380	369	47 (12.7)	17 (4.6)	< 5	26 (55.3)	18 (38.3)
24	1084	1055	101 (9.6)	55 (5.2)	10 (9.9)	54 (53.5)	37 (36.6)
25	1650	1625	117 (7.2)	57 (3.5)	8 (6.8)	66 (56.4)	43 (36.8)
26	2015	1967	110 (5.6)	64 (3.3)	12 (10.9)	71 (64.5)	27 (24.5)
27	2325	2276	101 (4.4)	68 (3.0)	8 (7.9)	64 (63.4)	29 (28.7)
28	2725	2659	122 (4.6)	49 (1.8)	11 (9.0)	67 (54.9)	44 (36.1)
Total	10218	9990	604 (6.0)	310 (3.1)	52 (8.6)	352 (58.3)	200 (33.1)

* Cells with less than 5 reported as < 5.

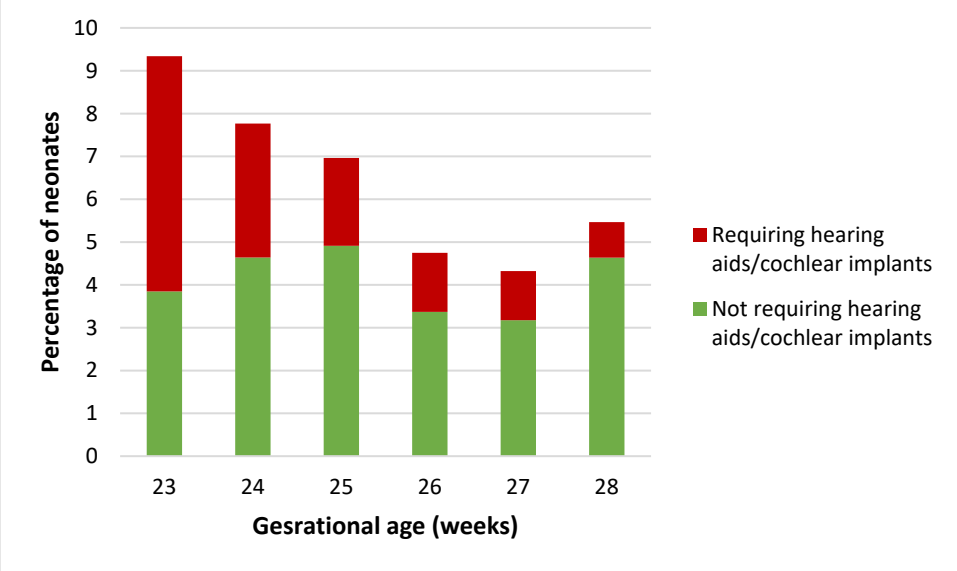


COMMENTS:
Rates for cerebral palsy (CP) with GMFCS 1-2 are calculated by subtracting number of children with CP with GMFCS 3-5 from definitive CP cases. CP rates decrease with increasing gestational age. Due to small numbers, 22 weeks' gestation was not included in the bar graph. (GMFCS: Gross Motor Function Classification System).

Presentation No 9: 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	39	38	37 (97.4)	< 5	0 (0)
23	380	364	330 (90.7)	14 (3.8)	20 (5.5)
24	1084	1056	974 (92.2)	49 (4.6)	33 (3.1)
25	1650	1608	1496 (93)	79 (4.9)	33 (2.1)
26	2015	1959	1866 (95.3)	66 (3.4)	27 (1.4)
27	2325	2268	2170 (95.7)	72 (3.2)	26 (1.1)
28	2725	2653	2508 (94.5)	123 (4.6)	22 (0.8)
Total	10218	9946	9381 (94.3)	404 (4.1)	161 (1.6)

* Cells with less than 5 reported as < 5.



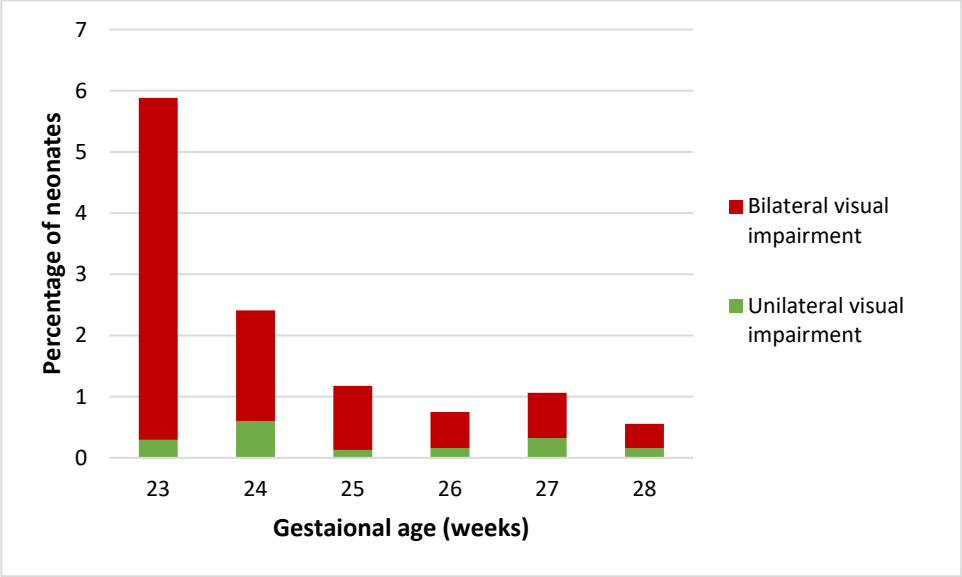
COMMENTS:

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, 22 weeks' gestation was not included in the bar graph.

Presentation No 10: 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	39	38	35 (92.1)	< 5	< 5
23	380	340	320 (94.1)	< 5	19 (5.6)
24	1084	996	972 (97.6)	6 (0.6)	18 (1.8)
25	1650	1532	1514 (98.8)	< 5	16 (1.0)
26	2015	1867	1853 (99.3)	< 5	11 (0.6)
27	2325	2161	2138 (98.9)	7 (0.3)	16 (0.7)
28	2725	2522	2508 (99.4)	< 5	10 (0.4)
Total	10218	9456	9340 (98.8)	24 (0.3)	92 (1.0)

* Cells with less than 5 reported as < 5.

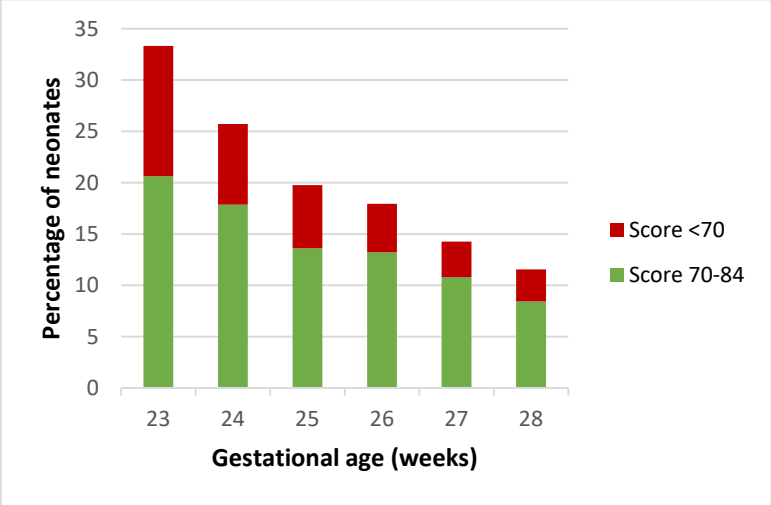


COMMENTS:

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, 22 weeks' gestation was not included in the bar graph.

Presentation No 11: 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	39	35	85 (75, 95)	18 (51.4)	11 (31.4)	6 (17.1)
23	380	315	90 (80, 100)	210 (66.7)	65 (20.6)	40 (12.7)
24	1084	929	90 (80, 100)	690 (74.3)	166 (17.9)	73 (7.9)
25	1650	1477	95 (85, 100)	1185 (80.2)	201 (13.6)	91 (6.2)
26	2015	1762	95 (85, 105)	1446 (82.1)	233 (13.2)	83 (4.7)
27	2325	2068	95 (90, 105)	1773 (85.7)	223 (10.8)	72 (3.5)
28	2725	2408	100 (90, 105)	2130 (88.5)	203 (8.4)	75 (3.1)
Total	10218	8994	95 (85, 105)	7452 (82.9)	1102 (12.3)	440 (4.9)

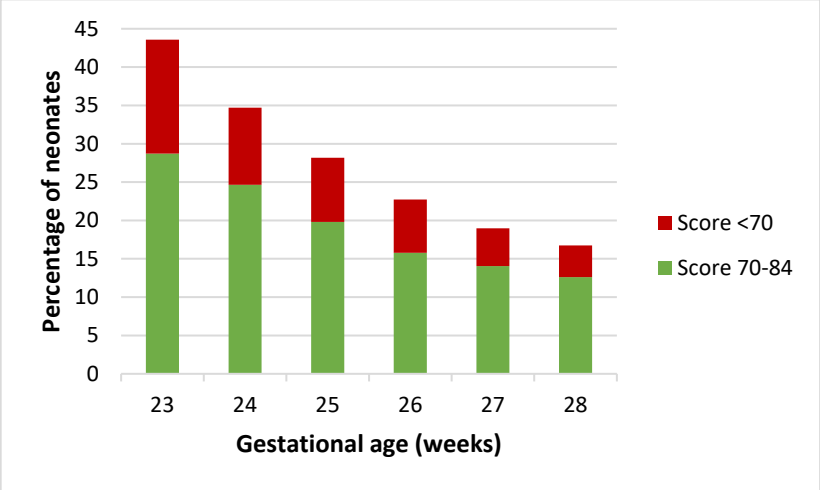


COMMENTS:

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). Due to small numbers, 22 weeks' gestation was not included in the bar graph.

Presentation No 12: 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	39	33	79 (70, 90)	10 (30.3)	13 (39.4)	10 (30.3)
23	380	296	88 (76, 97)	167 (56.4)	85 (28.7)	44 (14.9)
24	1084	876	90 (79, 97)	572 (65.3)	216 (24.7)	88 (10.0)
25	1650	1398	91 (82, 100)	1004 (71.8)	277 (19.8)	117 (8.4)
26	2015	1659	94 (85, 100)	1282 (77.3)	262 (15.8)	115 (6.9)
27	2325	1950	94 (88, 102)	1580 (81.0)	274 (14.1)	96 (4.9)
28	2725	2299	97 (88, 103)	1914 (83.3)	290 (12.6)	95 (4.1)
Total	10218	8511	94 (85, 100)	6529 (76.7)	1417 (16.6)	565 (6.6)

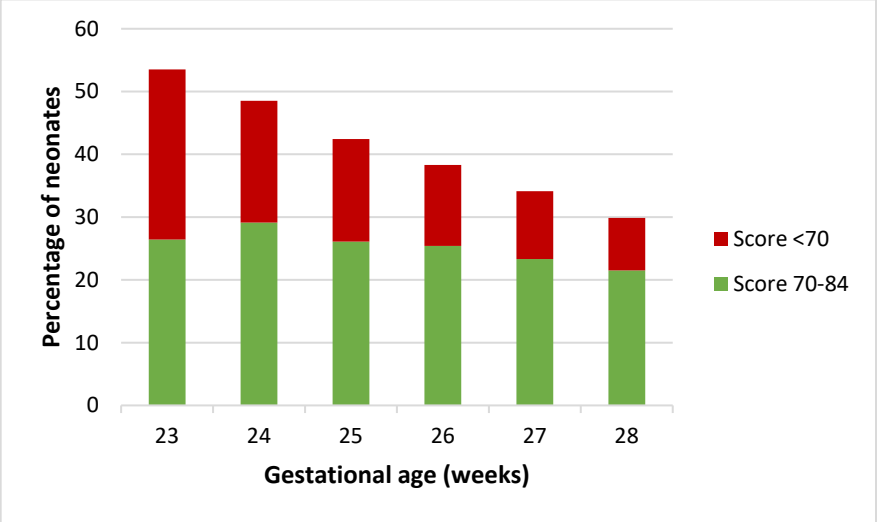


COMMENTS:

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). Due to small numbers, 22 weeks' gestation was not included in the bar graph.

Presentation No 13: 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	39	31	77 (68, 91)	10 (32.3)	11 (35.5)	10 (32.3)
23	380	299	83 (68, 94)	139 (46.5)	79 (26.4)	81 (27.1)
24	1084	886	86 (74, 97)	456 (51.5)	258 (29.1)	172 (19.4)
25	1650	1414	89 (77, 100)	814 (57.6)	369 (26.1)	231 (16.3)
26	2015	1689	91 (77, 100)	1042 (61.7)	429 (25.4)	218 (12.9)
27	2325	1972	91 (79, 100)	1299 (65.9)	460 (23.3)	213 (10.8)
28	2725	2297	94 (83, 103)	1611 (70.1)	494 (21.5)	192 (8.4)
Total	10218	8588	91 (77, 100)	5371 (62.5)	2100 (24.5)	1117 (13)



COMMENTS:

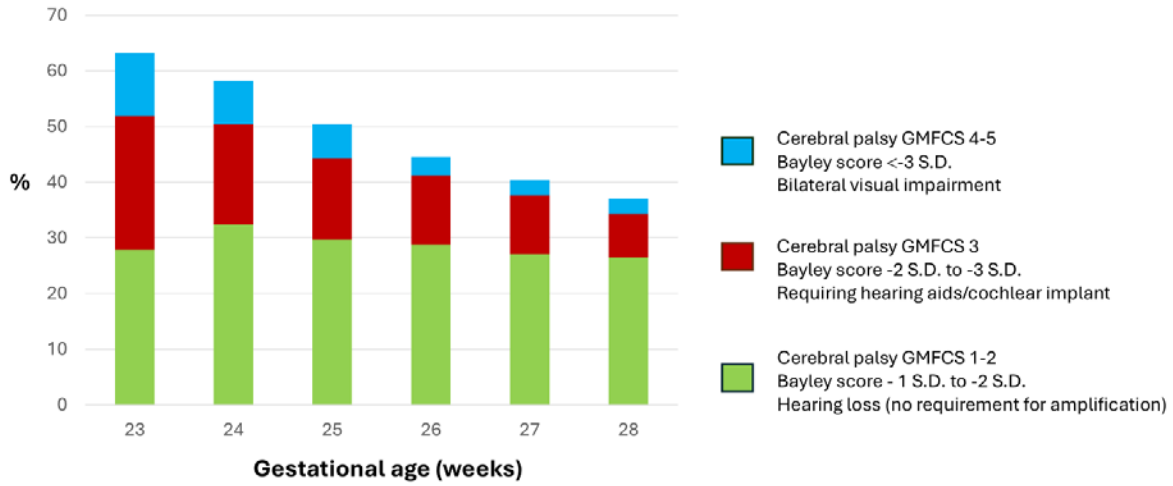
Bayley scores tend to underestimate developmental delay and have limited predictive ability. Language scores on the Bayley Scales of Infant and Toddler Development – 3rd or 4th edition (Bayley) improve with increasing gestational age and are skewed in this population. The Bayley scales have a mean score of 100 and standard deviation of 15 (less than 70 is therefore < -2 standard deviations). Due to small numbers, 22 weeks' gestation was not included in the bar graph.

Presentation No 14:

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	39	9 (23.1)	14 (35.9)	16 (41.0)	< 5
23	380	140 (36.8)	106 (27.9)	134 (35.3)	43 (11.3)
24	1084	453 (41.8)	351 (32.4)	280 (25.8)	83 (7.7)
25	1650	816 (49.5)	490 (29.7)	344 (20.8)	103 (6.2)
26	2015	1116 (55.4)	580 (28.8)	319 (15.8)	69 (3.4)
27	2325	1386 (59.6)	629 (27.1)	310 (13.3)	63 (2.7)
28	2725	1716 (63.0)	721 (26.5)	288 (10.6)	76 (2.8)
Total	10218	5636 (55.2)	2891 (28.3)	1691 (16.5)	441 (4.3)

* Cells with less than 5 reported as < 5.

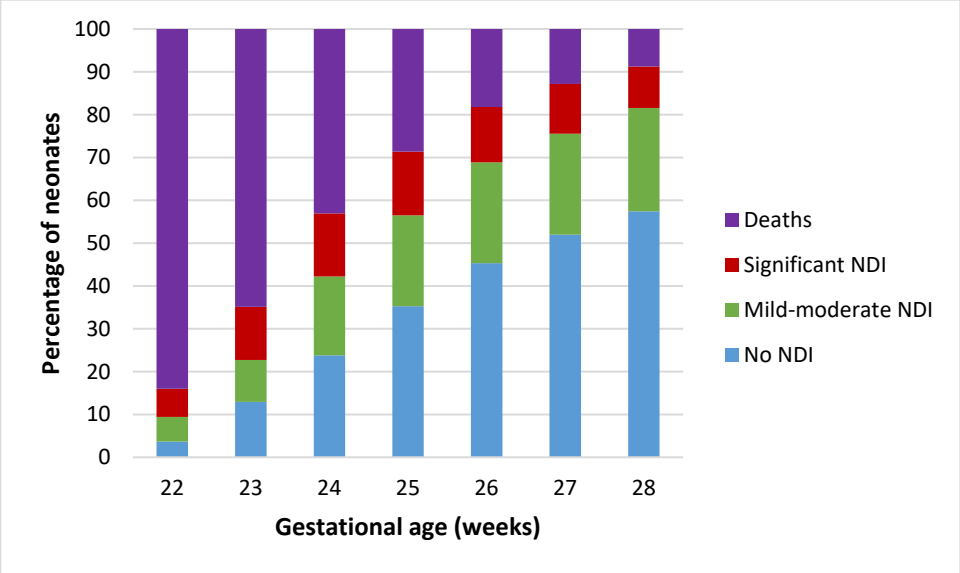


COMMENTS:

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. Due to small numbers at 22 weeks gestation, results should be interpreted with caution, and 22 weeks was not included in the bar graph.

Presentation No 15:
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 any NDI** n (%)	**Survival without significant NDI** n (%)
22	244	39 (16.0)	9 (3.7)	30 (12.3)	16 (6.6)	9 (3.7)	23 (9.4)
23	1082	380 (35.1)	140 (12.9)	240 (22.2)	134 (12.4)	140 (12.9)	246 (22.7)
24	1904	1084 (56.9)	453 (23.8)	631 (33.1)	280 (14.7)	453 (23.8)	804 (42.2)
25	2312	1650 (71.4)	816 (35.3)	834 (36.1)	344 (14.9)	816 (35.3)	1306 (56.5)
26	2463	2015 (81.8)	1116 (45.3)	899 (36.5)	319 (13.0)	1116 (45.3)	1696 (68.9)
27	2667	2325 (87.2)	1386 (52.0)	939 (35.2)	310 (11.6)	1386 (52.0)	2015 (75.6)
28	2987	2725 (91.2)	1716 (57.4)	1009 (33.8)	288 (9.6)	1716 (57.4)	2437 (81.6)
Total	13659	10218 (74.8)	5636 (41.3)	4582 (33.5)	1691 (12.4)	5636 (41.3)	8527 (62.4)



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 16a: 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	39	25 (64.1)	8 (20.5)	6 (15.4)
23	380	213 (56.1)	93 (24.5)	73 (19.2)
24	1084	600 (55.4)	266 (24.5)	215 (19.8)
25	1650	1030 (62.4)	352 (21.3)	265 (16.1)
26	2015	1328 (65.9)	374 (18.6)	308 (15.3)
27	2325	1597 (68.7)	450 (19.4)	275 (11.8)
28	2725	1964 (72.1)	478 (17.5)	280 (10.3)
Total	10218	6757 (66.1)	2021 (19.8)	1422 (13.9)

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).

Presentation No 16b: 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	39	35 (89.7)	25 (64.1)	26 (66.7)	< 5	6 (15.4)	24 (61.5)
23	380	308 (81.1)	217 (57.1)	241 (63.4)	21 (5.5)	81 (21.3)	214 (56.3)
24	1084	830 (76.6)	521 (48.1)	593 (54.7)	44 (4.1)	183 (16.9)	547 (50.5)
25	1650	1095 (66.4)	643 (39.0)	757 (45.9)	43 (2.6)	153 (9.3)	663 (40.2)
26	2015	1279 (63.5)	709 (35.2)	892 (44.3)	40 (2.0)	187 (9.3)	693 (34.4)
27	2325	1394 (60.0)	707 (30.4)	939 (40.4)	61 (2.6)	168 (7.2)	743 (32.0)
28	2725	1487 (54.6)	710 (26.1)	988 (36.3)	66 (2.4)	203 (7.4)	724 (26.6)
Total	10218	6428 (62.9)	3532 (34.6)	4436 (43.4)	278 (2.7)	981 (9.6)	3608 (35.3)

*Any referral includes any of the following health services (seen or waiting): occupational therapy, physical therapy, psychology, rehabilitation program, or speech/language therapy.
* Cells with less than 5 reported as < 5.

Presentation No 17a:
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	39	19 (48.7)	12 (30.8)	9 (23.1)	< 5	< 5
23	380	171 (45.0)	120 (31.6)	77 (20.3)	13 (3.4)	36 (9.5)
24	1084	423 (39.0)	286 (26.4)	173 (16.0)	16 (1.5)	68 (6.3)
25	1650	485 (29.4)	324 (19.6)	172 (10.4)	22 (1.3)	77 (4.7)
26	2015	458 (22.7)	260 (12.9)	170 (8.4)	13 (0.6)	92 (4.6)
27	2325	405 (17.4)	184 (7.9)	157 (6.8)	14 (0.6)	118 (5.1)
28	2725	411 (15.1)	145 (5.3)	162 (5.9)	11 (0.4)	118 (4.3)
Total	10218	2372 (23.2)	1331 (13)	920 (9.0)	90 (0.9)	510 (5.0)

Presentation No 17b:
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	39	5 (12.8)	< 5	< 5	< 5	0 (0)
23	380	61 (16.1)	11 (2.9)	35 (9.2)	11 (2.9)	30 (7.9)
24	1084	154 (14.2)	40 (3.7)	77 (7.1)	12 (1.1)	52 (4.8)
25	1650	142 (8.6)	30 (1.8)	74 (4.5)	18 (1.1)	56 (3.4)
26	2015	135 (6.7)	28 (1.4)	67 (3.3)	9 (0.4)	54 (2.7)
27	2325	135 (5.8)	12 (0.5)	50 (2.2)	9 (0.4)	78 (3.4)
28	2725	134 (4.9)	15 (0.6)	47 (1.7)	5 (0.2)	78 (2.9)
Total	10218	766 (7.5)	138 (1.4)	354 (3.5)	65 (0.6)	348 (3.4)

*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.
* Cells with less than 5 reported as < 5.

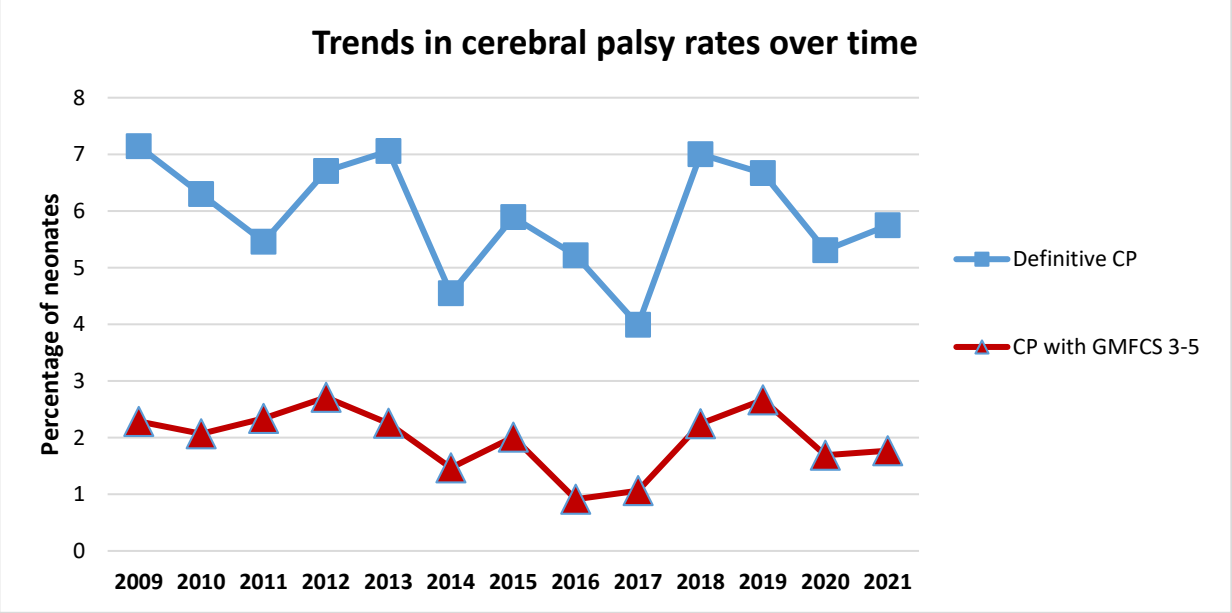
Almost one in 4 infants use aids at home after NICU discharge, but the majority are discontinued by 18-24 months of corrected age.

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 18: 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	700	9	621 (88.7)	20 (2.9)	50 (7.1)	26 (3.7)	16 (2.3)
2010	1064	19	933 (87.7)	45 (4.2)	67 (6.3)	33 (3.1)	22 (2.1)
2011	898	28	793 (88.3)	28 (3.1)	49 (5.5)	23 (2.6)	21 (2.3)
2012	701	5	622 (88.7)	27 (3.9)	47 (6.7)	25 (3.6)	19 (2.7)
2013	666	11	589 (88.4)	19 (2.9)	47 (7.1)	29 (4.4)	15 (2.3)
2014	682	6	626 (91.8)	19 (2.8)	31 (4.5)	20 (2.9)	10 (1.5)
2015	747	12	669 (89.6)	22 (2.9)	44 (5.9)	27 (3.6)	15 (2.0)
2016	767	9	698 (91.0)	20 (2.6)	40 (5.2)	28 (3.7)	7 (0.9)
2017	752	14	680 (90.4)	28 (3.7)	30 (4.0)	20 (2.7)	8 (1.1)
2018	757	13	665 (87.8)	26 (3.4)	53 (7.0)	35 (4.6)	17 (2.2)
2019	750	12	669 (89.2)	19 (2.5)	50 (6.7)	29 (3.9)	20 (2.7)
2020	829	76	695 (83.8)	14 (1.7)	44 (5.3)	25 (3.0)	14 (1.7)
2021	905	14	816 (90.2)	23 (2.5)	52 (5.7)	32 (3.5)	16 (1.8)
2009-2021	10218	228	9076 (88.8)	310 (3)	604 (5.9)	352 (3.4)	200 (2.0)

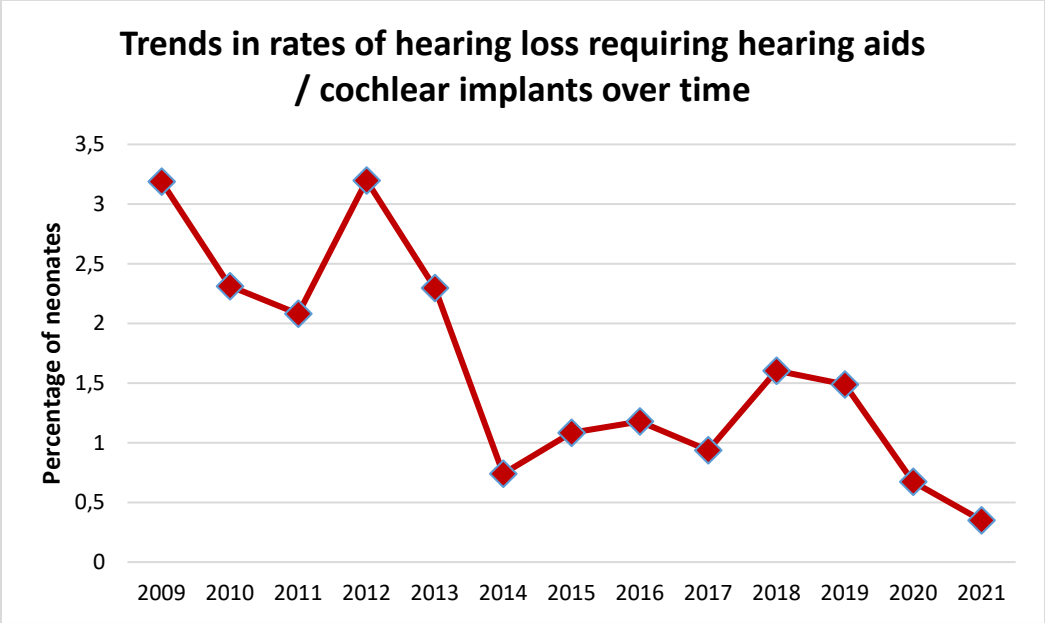


COMMENTS: Cerebral palsy rates fell until 2017 births. In 2018 and 2019, COVID restrictions may have biased towards seeing more children with CP. Data are not adjusted for risk factors. The majority of cerebral palsy cases are with a GMFCS $\leq$2 (missing GMFCS data for 52/604 children).

Presentation No 19: 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	700	10	631 (91.4)	37 (5.4)	22 (3.2)
2010	1064	26	958 (92.3)	56 (5.4)	24 (2.3)
2011	898	33	813 (94)	34 (3.9)	18 (2.1)
2012	701	13	645 (93.8)	21 (3.1)	22 (3.2)
2013	666	13	618 (94.6)	20 (3.1)	15 (2.3)
2014	682	7	652 (96.6)	18 (2.7)	5 (0.7)
2015	747	9	703 (95.3)	27 (3.7)	8 (1.1)
2016	767	< 5	717 (93.8)	38 (5.0)	9 (1.2)
2017	752	5	701 (93.8)	39 (5.2)	7 (0.9)
2018	757	9	712 (95.2)	24 (3.2)	12 (1.6)
2019	750	11	702 (95)	26 (3.5)	11 (1.5)
2020	829	86	714 (96.1)	24 (3.2)	5 (0.7)
2021	905	47	815 (95)	40 (4.7)	< 5
2009-2021	10218	272	9381 (94.3)	404 (4.1)	161 (1.6)

* Cells with less than 5 reported as < 5.

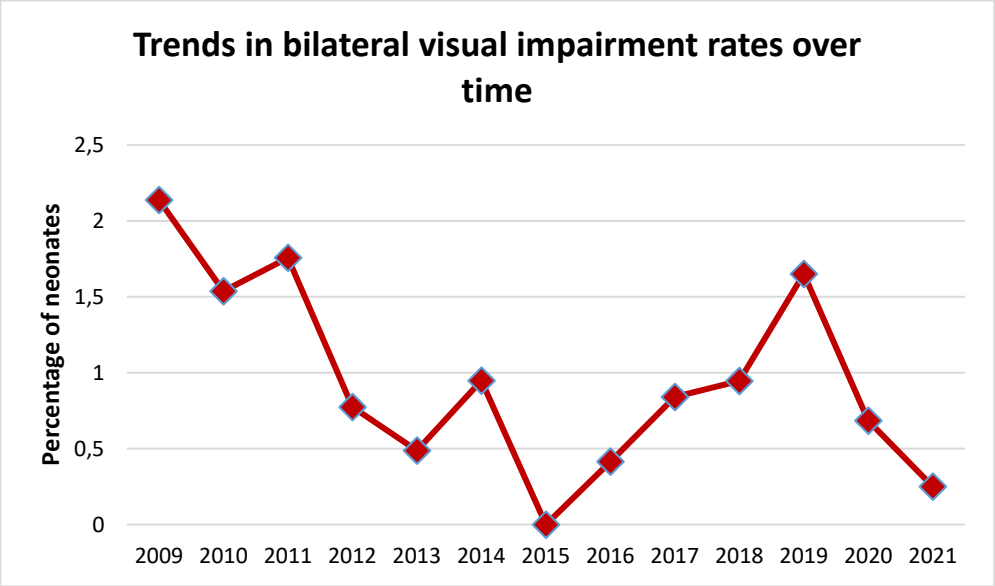


COMMENTS: There is a trend toward decreasing rates of hearing loss requiring hearing aid(s) or cochlear implant(s) over time. Higher attrition rates during the COVID pandemic may impact the results.

Presentation No 20: 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	700	45	637 (97.3)	14 (2.1)
2010	1064	88	960 (98.4)	15 (1.5)
2011	898	101	782 (98.1)	14 (1.8)
2012	701	55	640 (99.1)	5 (0.8)
2013	666	51	612 (99.5)	< 5
2014	682	49	626 (98.9)	6 (0.9)
2015	747	47	698 (99.7)	0 (0)
2016	767	43	721 (99.6)	< 5
2017	752	38	705 (98.7)	6 (0.8)
2018	757	17	732 (98.9)	7 (0.9)
2019	750	23	711 (97.8)	12 (1.7)
2020	829	98	723 (98.9)	5 (0.7)
2021	905	107	793 (99.4)	< 5
2009-2021	10218	762	9340 (98.8)	92 (1.0)

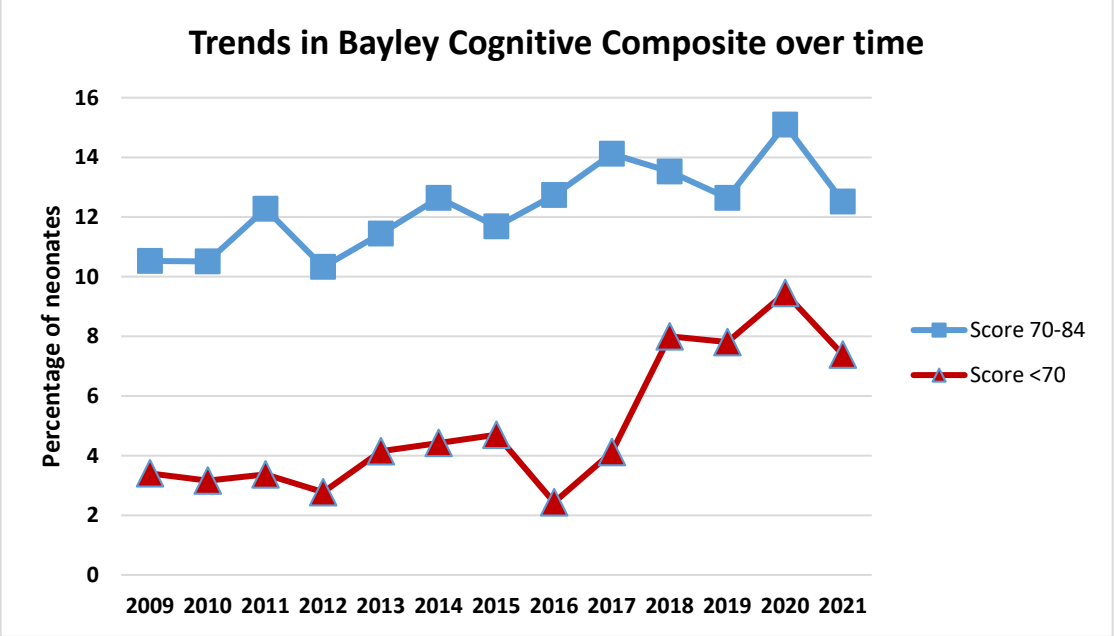
* Cells with less than 5 reported as < 5.



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 21: Trends in Bayley Cognitive Composite scores over time

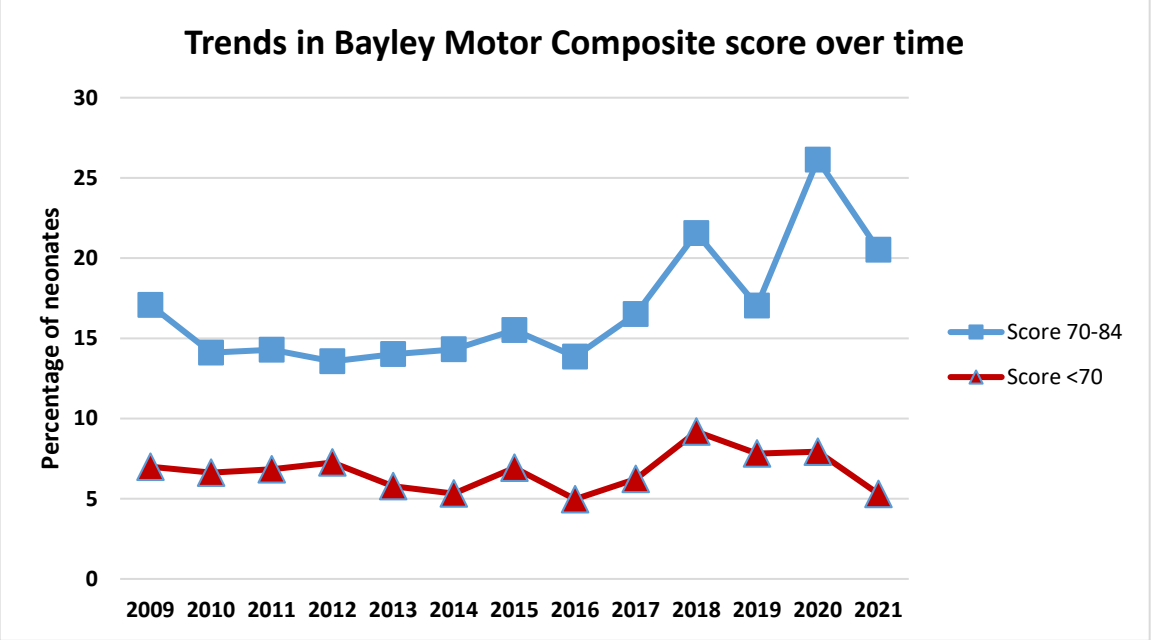
Year of birth	**CNFUN complete data** (n)	**Missing Bayley cognitive score** (n)	**Median score** (IQR)	**Bayley≥85** n (%)	**Score 70-84** n (%)	**Score <70** n (%)	**Median age of assessment** (months)
2009	700	54	95 (90, 105)	556 (86.1)	68 (10.5)	22 (3.4)	21.87
2010	1064	84	95 (90, 105)	846 (86.3)	103 (10.5)	31 (3.2)	21.79
2011	898	67	95 (90, 105)	701 (84.4)	102 (12.3)	28 (3.4)	21.74
2012	701	52	95 (90, 105)	564 (86.9)	67 (10.3)	18 (2.8)	21.74
2013	666	63	95 (90, 105)	509 (84.4)	69 (11.4)	25 (4.1)	21.97
2014	682	49	95 (85, 105)	525 (82.9)	80 (12.6)	28 (4.4)	21.97
2015	747	45	95 (90, 105)	587 (83.6)	82 (11.7)	33 (4.7)	22.16
2016	767	68	95 (90, 105)	593 (84.8)	89 (12.7)	17 (2.4)	22.20
2017	752	72	95 (85, 105)	556 (81.8)	96 (14.1)	28 (4.1)	22.36
2018	757	232	95 (85, 105)	412 (78.5)	71 (13.5)	42 (8.0)	23.87
2019	750	212	95 (85, 105)	428 (79.6)	68 (12.6)	42 (7.8)	22.85
2020	829	120	95 (85, 100)	535 (75.5)	107 (15.1)	67 (9.4)	23.90
2021	905	106	95 (85, 105)	640 (80.1)	100 (12.5)	59 (7.4)	24.56
2009-2021	10218	1224	95 (85, 105)	7452 (82.9)	1102 (12.3)	440 (4.9)	22.23



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 2020-2021 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.)

Presentation No 22: Trends in Bayley Motor Composite scores over time

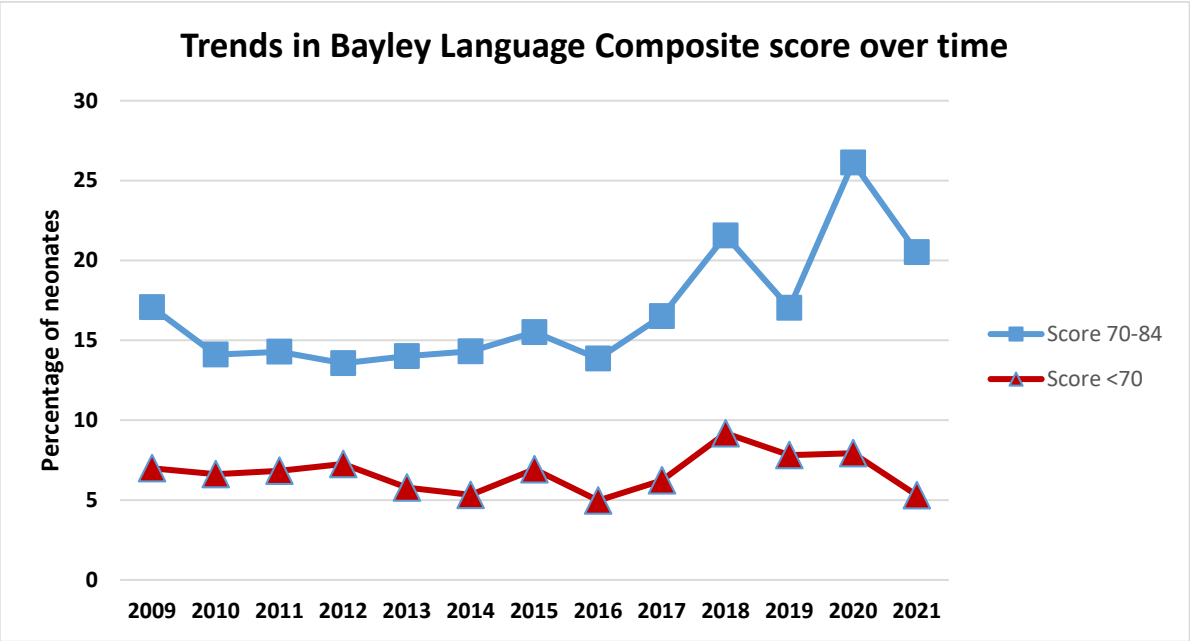
Year of birth	**CNFUN complete data** (n)	**Missing Bayley motor score** (n)	**Median score** (IQR)	**Bayley≥85** n (%)	**Score 70-84** n (%)	**Score <70** n (%)
2009	700	85	94 (85, 100)	467 (75.9)	105 (17.1)	43 (7)
2010	1064	128	94 (85, 100)	742 (79.3)	132 (14.1)	62 (6.6)
2011	898	93	94 (85, 100)	635 (78.9)	115 (14.3)	55 (6.8)
2012	701	67	94 (85, 103)	502 (79.2)	86 (13.6)	46 (7.3)
2013	666	95	94 (85, 100)	458 (80.2)	80 (14)	33 (5.8)
2014	682	81	94 (88, 100)	483 (80.4)	86 (14.3)	32 (5.3)
2015	747	83	94 (85, 103)	515 (77.6)	103 (15.5)	46 (6.9)
2016	767	103	94 (88, 103)	539 (81.2)	92 (13.9)	33 (5.0)
2017	752	110	94 (85, 100)	496 (77.3)	106 (16.5)	40 (6.2)
2018	757	256	94 (82, 100)	347 (69.3)	108 (21.6)	46 (9.2)
2019	750	251	94 (85, 103)	375 (75.2)	85 (17.0)	39 (7.8)
2020	829	186	91 (82, 98)	424 (65.9)	168 (26.1)	51 (7.9)
2021	905	169	94 (84, 100)	546 (74.2)	151 (20.5)	39 (5.3)
2009-2021	10218	1707	94 (85, 100)	6529 (76.7)	1417 (16.6)	565 (6.6)



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 2020-2021 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.)

Presentation No 23: 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 (%)
2009	700	82	91 (79, 100)	409 (66.2)	151 (24.4)	58 (9.4)
2010	1064	114	91 (79, 100)	621 (65.4)	225 (23.7)	104 (10.9)
2011	898	88	91 (79, 103)	514 (63.5)	202 (24.9)	94 (11.6)
2012	701	63	91 (79, 100)	403 (63.2)	156 (24.5)	79 (12.4)
2013	666	108	91 (79, 100)	364 (65.2)	132 (23.7)	62 (11.1)
2014	682	84	89 (77, 100)	381 (63.7)	136 (22.7)	81 (13.5)
2015	747	77	89 (77, 100)	410 (61.2)	173 (25.8)	87 (13.0)
2016	767	105	91 (79, 100)	431 (65.1)	161 (24.3)	70 (10.6)
2017	752	118	89 (77, 100)	391 (61.7)	165 (26.0)	78 (12.3)
2018	757	259	89 (77, 100)	274 (55.0)	139 (27.9)	85 (17.1)
2019	750	233	89 (75, 103)	307 (59.4)	126 (24.4)	84 (16.2)
2020	829	152	89 (75, 100)	380 (56.1)	172 (25.4)	125 (18.5)
2021	905	147	92 (77, 103)	486 (64.1)	162 (21.4)	110 (14.5)
2009-2021	10218	1630	91 (77, 100)	5371 (62.5)	2100 (24.5)	1117 (13)



COMMENTS: Rates of language 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 2020-2021 may have uncovered more language 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.)

Presentation No 24: Trends in neurodevelopmental outcomes over time

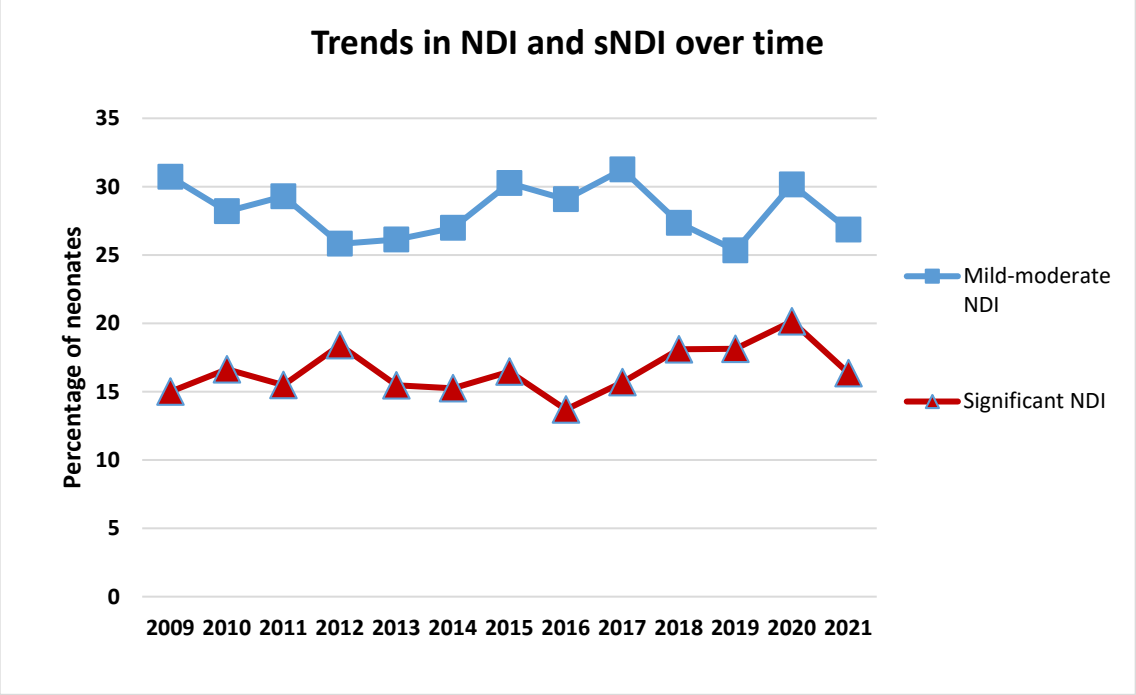
ar of birth	**CNFUN complete data** (n)	**Missing data** (n)	**No NDI** n (%)	**Any NDI n(%)**	**Mild-moderate NDI#** n (%)	**Significant NDI***	
						All n (%)	**Severe only**** n (%)
2009	700	0	380 (54.3)	320 (45.7)	215 (30.7)	105 (15.0)	34 (4.9)
2010	1064	0	587 (55.2)	477 (44.8)	300 (28.2)	177 (16.6)	56 (5.3)
2011	898	0	496 (55.2)	402 (44.8)	263 (29.3)	139 (15.5)	31 (3.5)
2012	701	0	391 (55.8)	310 (44.2)	181 (25.8)	129 (18.4)	31 (4.4)
2013	666	0	389 (58.4)	277 (41.6)	174 (26.1)	103 (15.5)	32 (4.8)
2014	682	0	394 (57.8)	288 (42.2)	184 (27.0)	104 (15.2)	28 (4.1)
2015	747	0	398 (53.3)	349 (46.7)	226 (30.3)	123 (16.5)	33 (4.4)
2016	767	0	439 (57.2)	328 (42.8)	223 (29.1)	105 (13.7)	27 (3.5)
2017	752	0	399 (53.1)	353 (46.9)	235 (31.3)	118 (15.7)	33 (4.4)
2018	757	0	413 (54.6)	344 (45.4)	207 (27.3)	137 (18.1)	44 (5.8)
2019	750	0	424 (56.5)	326 (43.5)	190 (25.3)	136 (18.1)	45 (6.0)
2020	829	0	412 (49.7)	417 (50.3)	250 (30.2)	167 (20.1)	25 (3.0)
2021	905	0	514 (56.8)	391 (43.2)	243 (26.9)	148 (16.4)	22 (2.4)
2009-2021	10218	0	5636 (55.2)	4582 (33.5)	2891 (28.3)	1691 (16.5)	441 (4.3)

Refer to page 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.



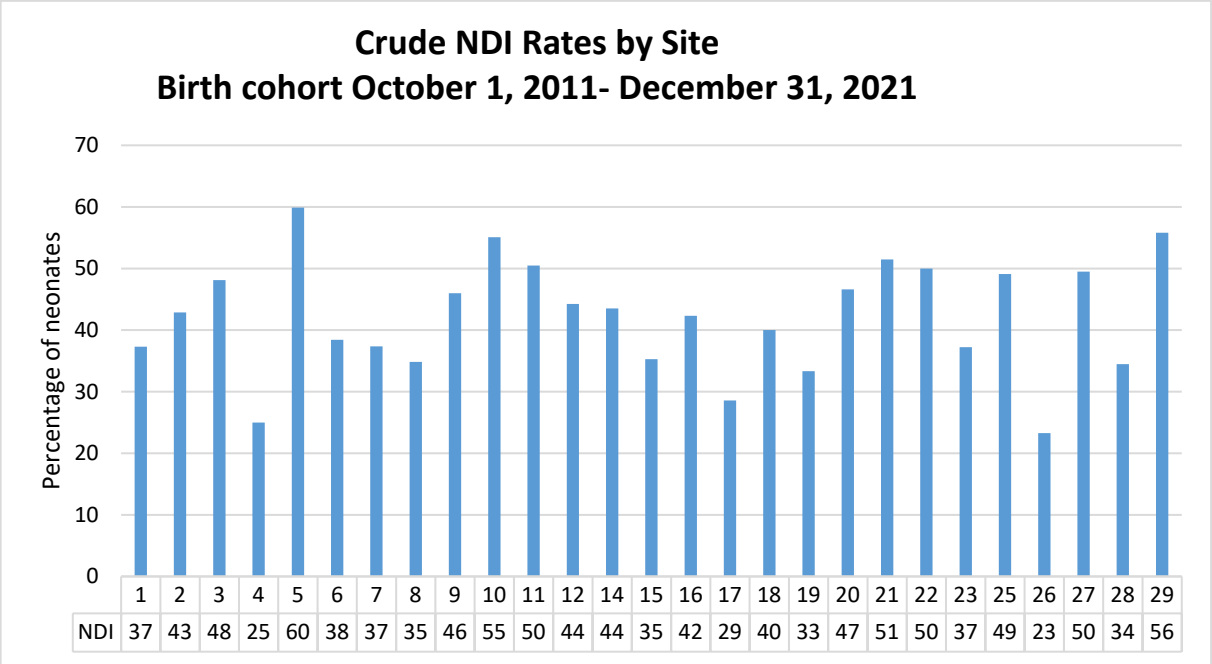
COMMENTS: There has not been a clinically important change in NDI rates over time. Higher attrition rates during the COVID pandemic may impact the results.

G. Sites Comparisons – Crude Rates

Presentation No 25:
Neurodevelopmental impairment rates by site
(Birth cohort of October 1, 2011 – December 31, 2021) *

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	512	321 (63)	191 (37)	31 (6)	18 (4)	< 5%	79 (15)	131 (26)	37 (7)
2	441	252 (57)	189 (43)	22 (5)	33 (7)	< 5%	39 (9)	143 (32)	38 (9)
3	133	69 (52)	64 (48)	6 (5)	7 (5)	< 5%	28 (21)	47 (35)	18 (14)
4	8	6 (75)	< 25%	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	< 25%
5	339	136 (40)	203 (60)	15 (4)	23 (7)	< 5%	117 (35)	136 (40)	91 (27)
6	908	559 (62)	349 (38)	46 (5)	28 (3)	14 (2)	145 (16)	192 (21)	107 (12)
7	83	52 (63)	31 (37)	< 5%	< 5%	< 5%	13 (16)	21 (25)	10 (12)
8	66	43 (65)	23 (35)	< 5%	0 (0)	< 5%	10 (15)	17 (26)	13 (20)
9	100	54 (54)	46 (46)	10 (10)	< 5%	0 (0)	22 (22)	32 (32)	16 (16)
10	216	97 (45)	119 (55)	14 (6)	17 (8)	< 5%	50 (23)	99 (46)	40 (19)
11	614	304 (50)	310 (50)	55 (9)	56 (9)	5 (1)	144 (23)	211 (34)	110 (18)
12	330	184 (56)	146 (44)	32 (10)	5 (2)	6 (2)	80 (24)	96 (29)	55 (17)
14	416	235 (56)	181 (44)	17 (4)	27 (6)	7 (2)	70 (17)	133 (32)	46 (11)
15	17	11 (65)	6 (35)	0 (0)	< 10%	< 10%	5 (29)	3 (18)	< 10%
16	1070	617 (58)	453 (42)	63 (6)	36 (3)	8 (1)	161 (15)	304 (28)	204 (19)
17	7	5 (71)	< 30%	< 15%	0 (0)	0 (0)	< 15%	< 30%	< 30%
18	10	6 (60)	< 40%	0 (0)	0 (0)	0 (0)	< 10%	< 40%	< 10%
19	6	< 70%	< 35%	0 (0)	0 (0)	0 (0)	0 (0)	< 35%	0 (0)
20	384	205 (53)	179 (47)	16 (4)	56 (15)	< 5%	65 (17)	123 (32)	56 (15)
21	169	82 (49)	87 (51)	19 (11)	5 (3)	0 (0)	45 (27)	68 (40)	40 (24)
22	14	7 (50)	7 (50)	< 15%	0 (0)	0 (0)	< 15%	6 (43)	< 25%
23	317	199 (63)	118 (37)	30 (9)	14 (4)	6 (2)	50 (16)	61 (19)	35 (11)
25	1163	592 (51)	571 (49)	40 (3)	27 (2)	< 5%	258 (22)	435 (37)	216 (19)
26	73	56 (77)	17 (23)	< 5%	< 5%	0 (0)	8 (11)	12 (16)	5 (7)
27	101	51 (50)	50 (50)	5 (5)	< 5%	< 5%	21 (21)	39 (39)	16 (16)
28	116	76 (66)	40 (34)	6 (5)	8 (7)	< 5%	20 (17)	24 (21)	6 (5)
29	129	57 (44)	72 (56)	10 (8)	7 (5)	< 5%	31 (24)	50 (39)	12 (9)
Total	7742	4280 (55)	3462 (45)	448 (6)	379 (5)	70 (1)	1465 (19)	2391 (31)	1180 (15)

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

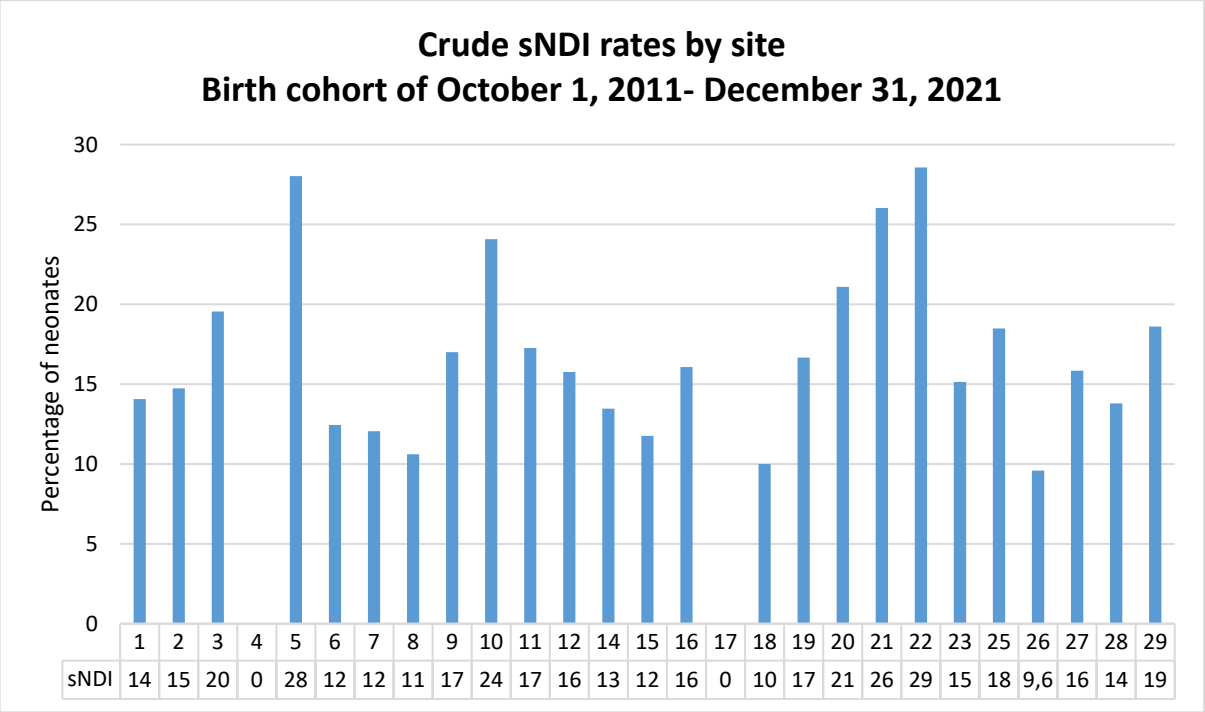


	1	2	3	4	5	6	7	8	9	10	11	12	14	15	16	17	18	19	20	21	22	23	25	26	27	28	29
NDI	37	43	48	25	60	38	37	35	46	55	50	44	44	35	42	29	40	33	47	51	50	37	49	23	50	34	56

Presentation No 26:
Significant neurodevelopmental impairment rates by site
(Birth cohort of October 1, 2011 – December 31, 2021) *

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	512	440 (86)	72 (14)	15 (3)	10 (2)	< 5%	27 (5)	35 (7)	11 (2)
2	441	376 (85)	65 (15)	7 (2)	5 (1)	< 5%	6 (1)	54 (12)	14 (3)
3	133	107 (80)	26 (20)	< 5%	< 5%	0 (0)	9 (7)	22 (17)	< 5%
4	8	8 (100)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)
5	339	244 (72)	95 (28)	< 5%	11 (3)	< 5%	29 (9)	68 (20)	43 (13)
6	908	795 (88)	113 (12)	15 (2)	5 (1)	10 (1)	26 (3)	79 (9)	30 (3)
7	83	73 (88)	10 (12)	0 (0)	0 (0)	< 5%	< 5%	10 (12)	< 5%
8	66	59 (89)	7 (11)	0 (0)	0 (0)	0 (0)	5 (8)	6 (9)	8 (12)
9	100	83 (83)	17 (17)	< 5%	0 (0)	0 (0)	5 (5)	11 (11)	5 (5)
10	216	164 (76)	52 (24)	< 5%	5 (2)	< 5%	16 (7)	41 (19)	13 (6)
11	614	508 (83)	106 (17)	16 (3)	5 (1)	< 5%	51 (8)	62 (10)	27 (4)
12	330	278 (84)	52 (16)	8 (2)	< 5%	5 (2)	24 (7)	30 (9)	19 (6)
14	416	360 (87)	56 (13)	6 (1)	5 (1)	7 (2)	28 (7)	41 (10)	19 (5)
15	17	15 (88)	< 15%	0 (0)	< 10%	< 10%	< 10%	< 10%	0 (0)
16	1070	898 (84)	172 (16)	15 (1)	14 (1)	< 5%	55 (5)	104 (10)	58 (5)
17	7	7 (100)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)
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	384	303 (79)	81 (21)	5 (1)	5 (1)	< 5%	26 (7)	68 (18)	20 (5)
21	169	125 (74)	44 (26)	8 (5)	< 5%	0 (0)	16 (9)	33 (20)	16 (9)
22	14	10 (71)	4 (29)	< 15%	0 (0)	0 (0)	< 15%	< 10%	< 10%
23	317	269 (85)	48 (15)	12 (4)	6 (2)	6 (2)	14 (4)	16 (5)	5 (2)
25	1163	948 (82)	215 (18)	15 (1)	15 (1)	< 5%	51 (4)	158 (14)	57 (5)
26	73	66 (90)	7 (10)	< 5%	< 5%	0 (0)	6 (8)	6 (8)	< 5%
27	101	85 (84)	16 (16)	< 5%	< 5%	0 (0)	< 5%	14 (14)	6 (6)
28	116	100 (86)	16 (14)	< 5%	< 5%	< 5%	6 (5)	8 (7)	< 5%
29	129	105 (81)	24 (19)	5 (4)	< 5%	< 5%	10 (8)	12 (9)	< 5%
Total	7742	6440 (83)	1302 (17)	146 (2)	101 (1)	52 (1)	420 (5)	883 (11)	366 (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	11	17	24	17	16	13	12	16	0	10	17	21	26	29	15	18	9,6	16	14	19

H. Sites Comparisons –Adjusted Standardized Ratios

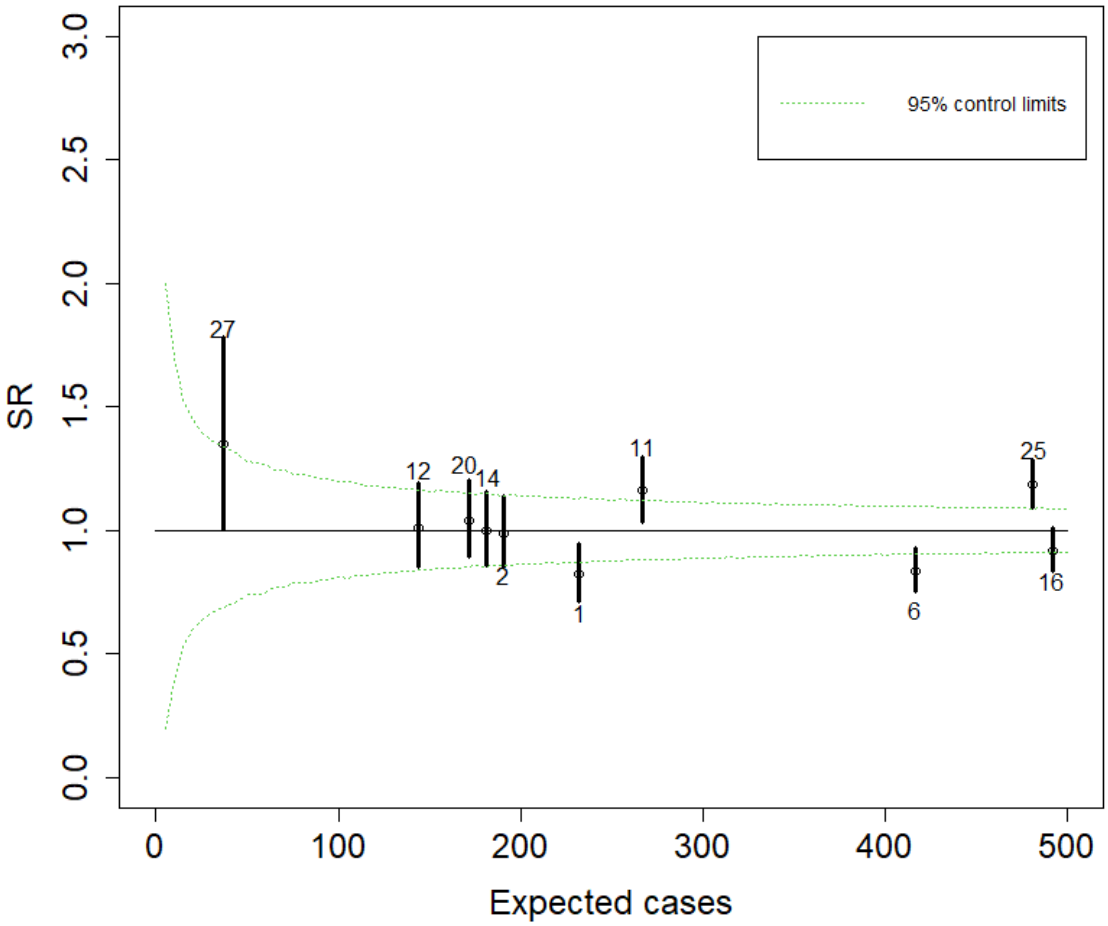
Presentation No 27:
Adjusted standardized ratios of neurodevelopmental impairment by site
(Birth cohort of October 1, 2011 – December 31, 2021) *

Site	**Children** (n)	**Follow-up rate** (%)	**Included** (Yes/No)	**NDI** (n)	**Adjusted expected NDI** (n)	**Adjusted standardized ratio** (95%CI)
1	512	75.1	Yes	191	232	0.82 (0.71, 0.94)
2	441	82	Yes	189	191	0.99 (0.85, 1.14)
3	133	67.5		64		
4	8	13.3		< 5		
5	339	29.6		203		
6	908	74.7	Yes	349	417	0.84 (0.75, 0.93)
7	83	38.4		31		
8	66	7.5		23		
9	100	47.6		46		
10	216	60.8		119		
11	614	86.8	Yes	310	267	1.16 (1.04, 1.29)
12	330	84.8	Yes	146	144	1.01 (0.86, 1.19)
14	416	79.8	Yes	181	181	1.00 (0.86, 1.15)
15	17	11.4		6		
16	1070	71.1	Yes	453	492	0.92 (0.84, 1.01)
17	7	1.1		< 5		
18	10	5.4		< 5		
19	6	2.3		< 5		
20	384	75.6	Yes	179	172	1.04 (0.89, 1.20)
21	169	69.5		87		
22	14	13		7		
23	317	59.4		118		
25	1163	73.4	Yes	571	481	1.19 (1.09, 1.29)
26	73	62.4		17		
27	101	83.5	Yes	50	37	1.35 (1.003, 1.75)
28	116	32.5		40		
29	129	43.4		72		

* 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 1, the results are statistically significant. Therefore, two sites (11 and 25) have a statistically higher NDI rate, and two sites (1 and 6) have a statistically lower NDI rate.

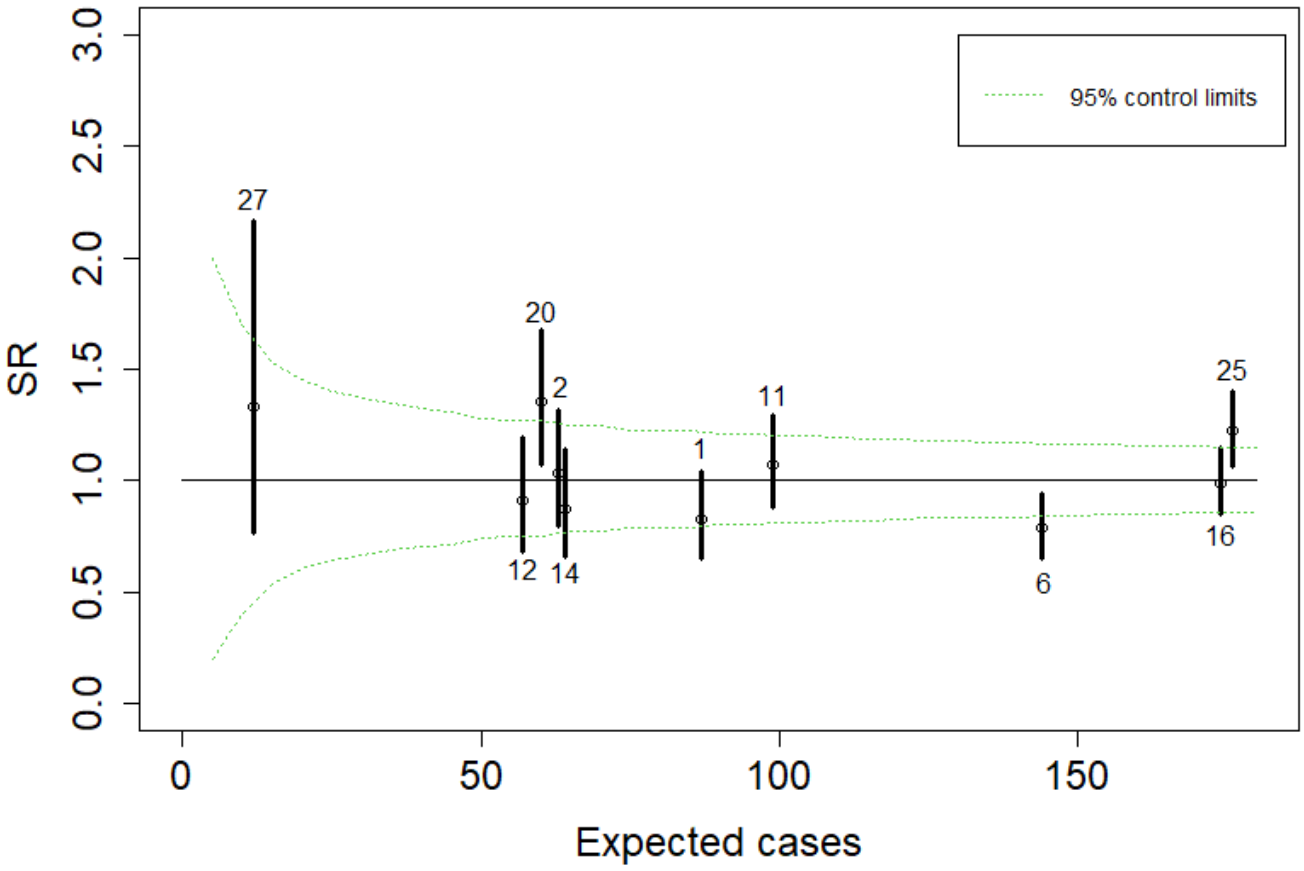
Presentation No 28:
Adjusted standardized ratios of significant neurodevelopmental impairment by site (Birth cohort of October 1, 2011 – December 31, 2021) *

Site	**Children** (n)	**Follow-up rate** (%)	**Included (**Yes/No)	**sNDI** (n)	**Adjusted expected sNDI** (n)	**Adjusted standardized ratio** (95%CI)
1	512	75.1	Yes	72	87	0.83 (0.65, 1.03)
2	441	82	Yes	65	63	1.03 (0.80, 1.30)
3	133	67.5		26		
4	8	13.3		0		
5	339	29.6		95		
6	908	74.7	Yes	113	144	0.78 (0.65, 0.94)
7	83	38.4		10		
8	66	7.5		7		
9	100	47.6		17		
10	216	60.8		52		
11	614	86.8	Yes	106	99	1.07 (0.88, 1.28)
12	330	84.8	Yes	52	57	0.91 (0.68, 1.18)
14	416	79.8	Yes	56	64	0.88 (0.66, 1.12)
15	17	11.4		< 5		
16	1070	71.1	Yes	172	174	0.99 (0.85, 1.14)
17	7	1.1		0		
18	10	5.4		< 5		
19	6	2.3		< 5		
20	384	75.6	Yes	81	60	1.35 (1.07, 1.66)
21	169	69.5		44		
22	14	13		< 5		
23	317	59.4		48		
25	1163	73.4	Yes	215	176	1.22 (1.06, 1.39)
26	73	62.4		7		
27	101	83.5	Yes	16	12	1.33 (0.76, 2.07)
28	116	32.5		16		
29	129	43.4		24		

* 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 $\geq$10 mm, intraparenchymal hemorrhage or periventricular leukomalacia).

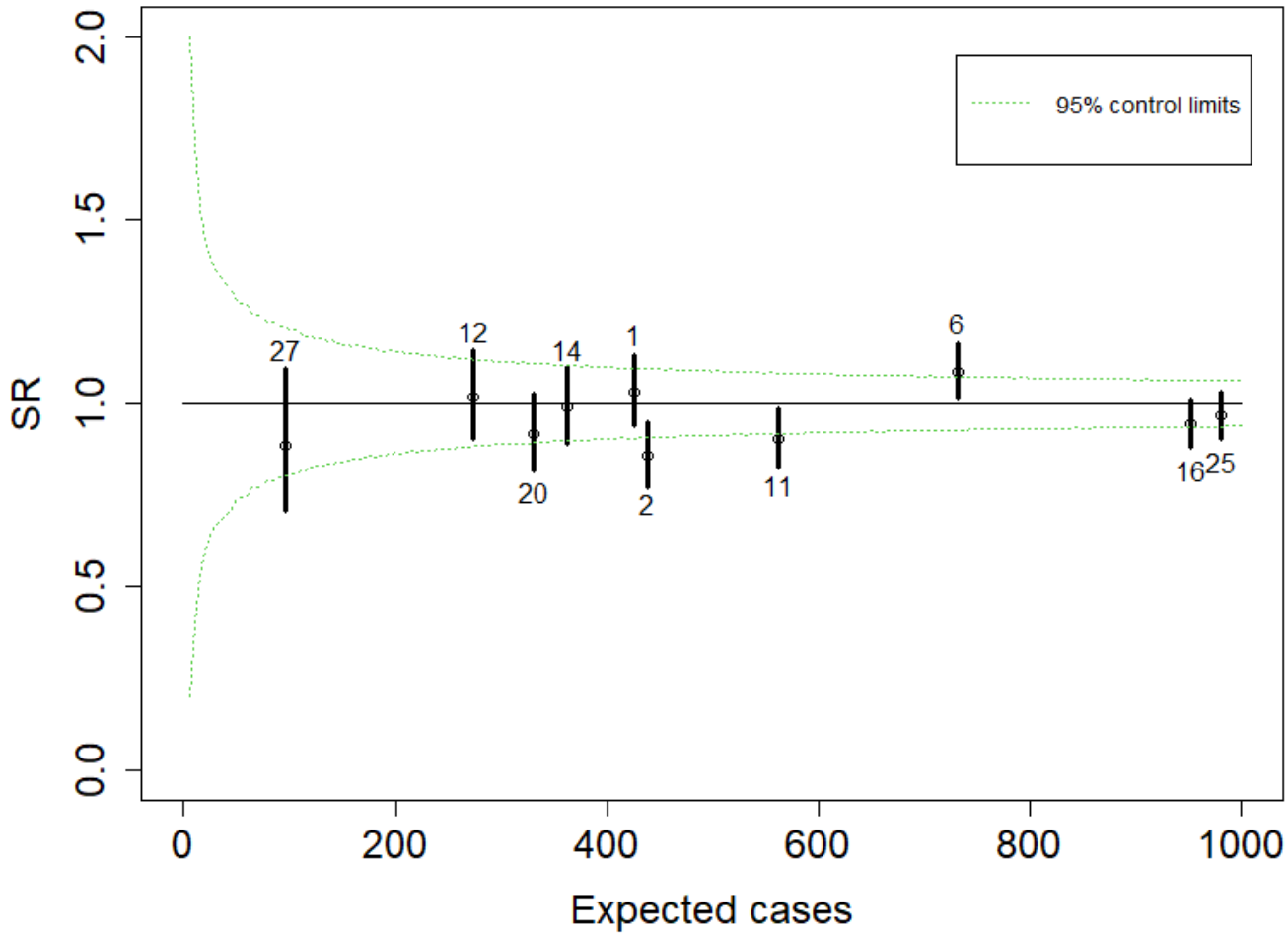


COMMENTS:
Sites with points outside the green "funnel" represent higher or lower adjusted sNDI rates than expected. When the 95% confidence interval does not cross 1, the results are statistically significant. Therefore, two sites (20 and 25) have a statistically higher, and one site (6) has a statistically lower sNDI rate.

Presentation No 29:
Adjusted standardized ratios of survival without significant neurodevelopmental impairment by site
(Birth cohort of October 1, 2011 – December 31, 2021)

Site	**Children** (n)	**Follow-up rate** (%)	**Included** (Yes/No)	**Survival without sNDI** (n)	**Adjusted expected outcome** (n)	**Adjusted standardized ratio** (95%CI)
1	612	75.1	Yes	440	426	1.03 (0.94, 1.13)
2	609	82	Yes	376	439	0.86 (0.77, 0.95)
3	184	67.5		107		
4	22	13.3		8		
5	530	29.6		244		
6	1030	74.7	Yes	795	732	1.09 (1.01, 1.16)
7	113	38.4		73		
8	244	7.5		59		
9	133	47.6		83		
10	284	60.8		164		
11	816	86.8	Yes	508	563	0.90 (0.83, 0.98)
12	385	84.8	Yes	278	273	1.02 (0.90, 1.14)
14	507	79.8	Yes	360	363	0.99 (0.89, 1.10)
15	72	11.4		15		
16	1385	71.1	Yes	898	952	0.94 (0.88, 1.01)
17	160	1.1		7		
18	53	5.4		9		
19	60	2.3		5		
20	469	75.6	Yes	303	330	0.92 (0.82, 1.02)
21	255	69.5		125		
22	38	13		10		
23	525	59.4		269		
25	1377	73.4	Yes	948	981	0.97 (0.91, 1.03)
26	90	62.4		66		
27	117	83.5	Yes	85	96	0.89 (0.71, 1.08)
28	159	32.5		100		
29	163	43.4		105		

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 1, the results are statistically significant. Therefore, one site (6) has statistically higher, and two sites (2 and 11) have statistically lower survival without significant NDI rates.

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
2. Doucette SM, Kelly EN, Church PT, Lee S, Shah V; Canadian Neonatal Network (CNN) Investigators and CNFUN Investigators and Steering Committee. Association of inotrope use with neurodevelopmental outcomes in infants <29 weeks gestation: a retrospective cohort study. J Matern Fetal Neonatal Med. 2021 Apr 7:1-9. doi: 10.1080/14767058.2021.1904872. Epub ahead of print. PMID: 33827395.
3. Rustogi D, Synnes A, Alshaikh B, Hasan S, Drolet C, Masse E, Murthy P, Shah PS, Yusuf K; Canadian Neonatal Network and the Canadian Neonatal Follow-Up Program. Neurodevelopmental outcomes of singleton large for gestational age infants <29 weeks' gestation: a retrospective cohort study. J Perinatol. 2021 Jun;41(6):1313-1321. doi: 10.1038/s41372-021-01080-z. Epub 2021 May 25. PMID: 34035448.
4. Roychoudhury S, Lodha A, Synnes A, Abou Mehrem A, Canning R, Banihani R, Beltempo M, Yang J, Shah P, Soraisham A on behalf of Canadian Neonatal Network (CNN) and Canadian Neonatal Follow-Up Network (CNFUN). Neurodevelopmental Outcomes of Preterm Infants Conceived by Assisted Reproductive Technology. Am J Obstet Gynecol. 2021 Sep;225(3): 276.e1-276.e9.

CNFUN Manuscripts 2022:

1. Ghotra S, Feeny D, Barr R, Yang J, Saigal S, Vincer M, Afifi J, Shah PS, Lee SK, Synnes AR; Canadian Neonatal Follow-Up Network Investigators; Canadian Neonatal Network Site Investigators. Parent-reported health status of preterm survivors in a Canadian cohort. Arch Dis Child Fetal Neonatal Ed. 2022 Jan;107(1):87-93. doi: 10.1136/archdischild-2021-321635
2. Synnes AR, Petrie J, Grunau RE, Church P, Kelly E, Moddemann D, Ye X, Lee SK, O'Brien K; Canadian Neonatal Network Investigators; Canadian Neonatal Follow-Up Network Investigators. Family integrated care: very preterm neurodevelopmental outcomes at 18 months. Arch Dis Child Fetal Neonatal Ed. 2022 Jan;107(1):76-81. doi: 10.1136/archdischild-2020-321055.
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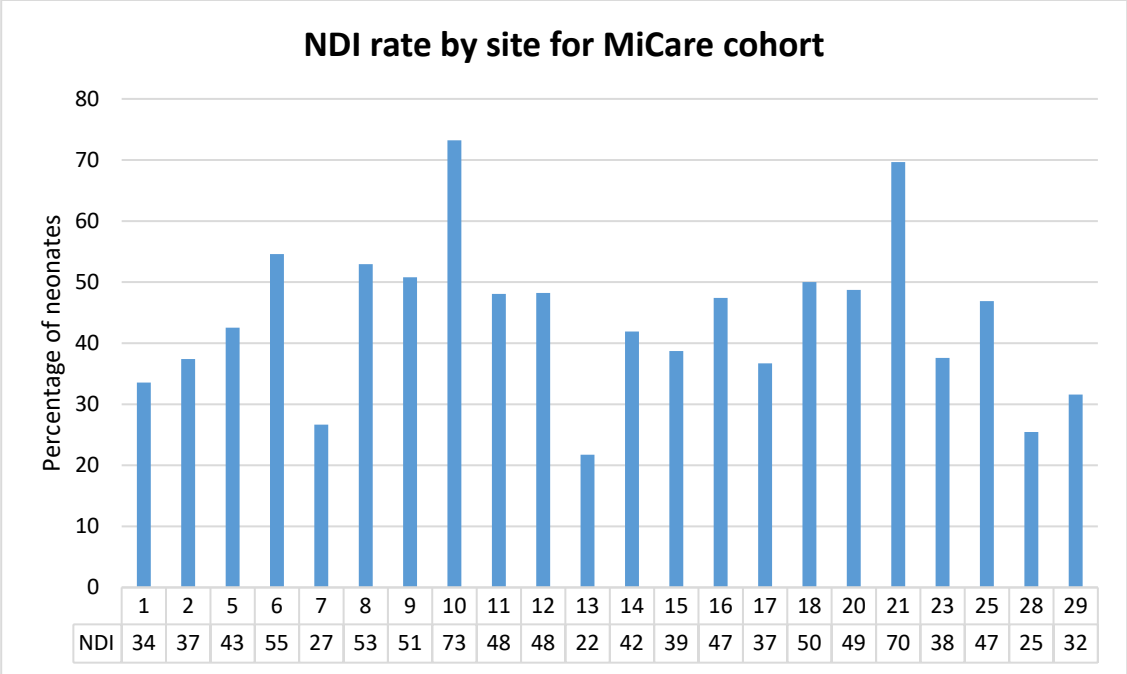
Appendix I. Site Comparisons – Crude Rates

Presentation No 30: Neurodevelopmental impairment rates for MiCare cohort (Births April 1, 2009 – September 30, 2011) *

Site	**CNFUN** (n)	**No NDI** n (%)	**Any NDI** n (%)	**CP with GMFCS 1-5** n (%)	**Any hearing loss** n(%)	**Any visual Impairment** n (%)	**Bayley score <85 Motor** n (%)	**Bayley score <85 Language** n (%)	**Bayley score <85 Cognitive** n (%)
1	146	97 (66)	49 (34)	< 5%	9 (6)	0 (0)	19 (13)	33 (23)	5 (3)
2	123	77 (63)	46 (37)	< 5%	12 (10)	0 (0)	18 (15)	31 (25)	10 (8)
5	221	127 (57)	94 (43)	9 (4)	29 (13)	< 5%)	25 (11)	60 (27)	22 (10)
6	218	99 (45)	119 (55)	11 (5)	25 (11)	11 (5)	59 (27)	77 (35)	30 (14)
7	30	22 (73)	8 (27)	< 5%	0 (0)	< 5%	5 (17)	6 (20)	< 10%
8	153	72 (47)	81 (53)	15 (10)	6 (4)	< 5%	40 (26)	53 (35)	31 (20)
9	63	31 (49)	32 (51)	8 (13)	< 5%	< 5%	5 (8)	16 (25)	12 (19)
10	56	15 (27)	41 (73)	< 10%	9 (16)	< 5%	19 (34)	34 (61)	18 (32)
11	181	94 (52)	87 (48)	9 (5)	14 (8)	< 5%	45 (25)	55 (30)	19 (10)
12	85	44 (52)	41 (48)	12 (14)	5 (6)	< 5%	26 (31)	26 (31)	15 (18)
13	23	18 (78)	5 (22)	< 15%	< 15%	0 (0)	0 (0)	< 5%	0 (0)
14	105	61 (58)	44 (42)	6 (6)	< 5%	0 (0)	15 (14)	39 (37)	12 (11)
15	31	19 (61)	12 (39)	< 5%	6 (19)	0 (0)	< 15%	8 (26)	5 (16)
16	251	132 (53)	119 (47)	16 (6)	13 (5)	< 5%	47 (19)	74 (29)	44 (18)
17	79	50 (63)	29 (37)	< 5%	< 5%	0 (0)	17 (22)	22 (28)	11 (14)
18	42	21 (50)	21 (50)	< 10%	< 5%	< 5%	9 (21)	14 (33)	9 (21)
20	78	40 (51)	38 (49)	5 (6)	< 5%	< 5%	15 (19)	33 (42)	9 (12)
21	56	17 (30)	39 (70)	5 (9)	10 (18)	< 5%	19 (34)	29 (52)	15 (27)
23	141	88 (62)	53 (38)	12 (9)	13 (9)	7 (5)	18 (13)	28 (20)	11 (8)
25	241	128 (53)	113 (47)	18 (7)	15 (6)	< 5%	38 (16)	93 (39)	32 (13)
28	55	41 (75)	14 (25)	< 5%	< 5%	0 (0)	6 (11)	11 (20)	< 10%
29	19	13 (68)	6 (32)	< 10%	0 (0)	0 (0)	2 (11)	5 (26)	< 10%
Total	2397	1306 (54)	1091 (46)	150 (6)	181 (8)	43 (2)	451 (19)	748 (31)	316 (13)

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

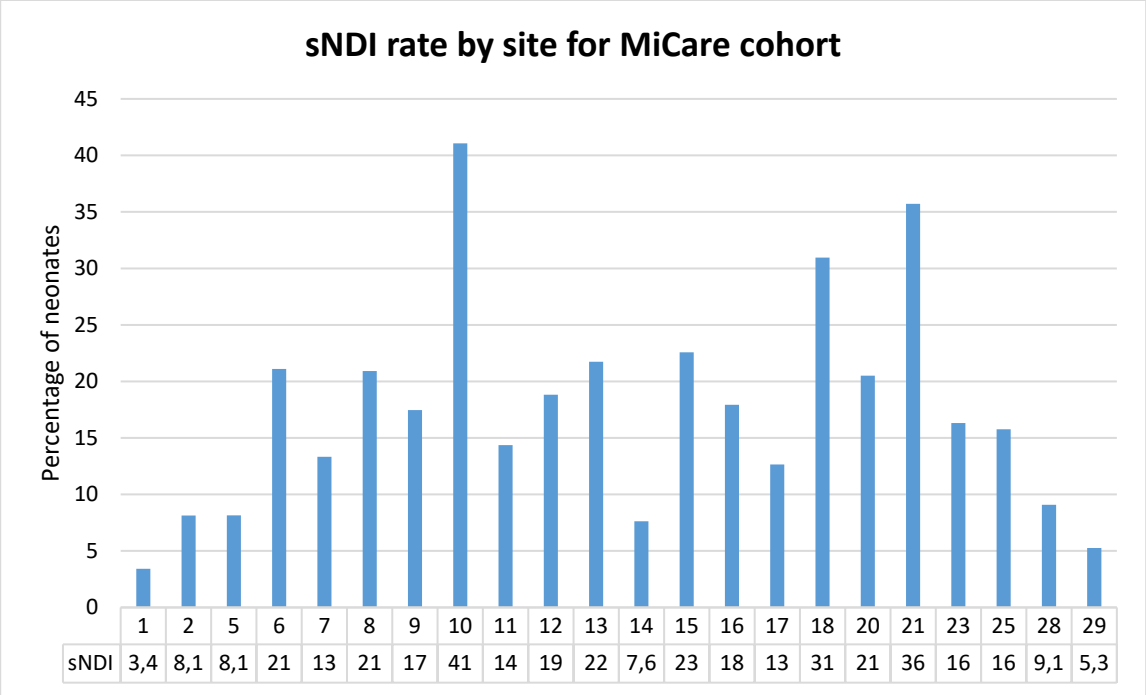


	1	2	5	6	7	8	9	10	11	12	13	14	15	16	17	18	20	21	23	25	28	29
NDI	34	37	43	55	27	53	51	73	48	48	22	42	39	47	37	50	49	70	38	47	25	32

Presentation No 31: Significant neurodevelopmental impairment rates for MiCare cohort (Births April 1, 2009 – September 30, 2011) *

Site	**CNFUN** (n)	**No NDI** n (%)	**Significant NDI** n (%)	**CP GMFCS 3-5** n (%)	**Disabling hearing loss** n (%)	**Bilateral visual impairment** n (%)	**Bayley score <70 Motor** n (%)	**Bayley score <70 Language** n (%)	**Bayley score <70 Cognitive** n (%)
1	146	141 (97)	5 (3)	0 (0)	0 (0)	0 (0)	< 5%	< 5%	< 5%
2	123	113 (92)	10 (8)	0 (0)	< 5%	0 (0)	< 5%	5 (4)	< 5%
5	221	203 (92)	18 (8)	< 5%	< 5%	< 5%	5 (2)	9 (4)	< 5%
6	218	172 (79)	46 (21)	< 5%	< 5%	9 (4)	15 (7)	32 (15)	5 (2)
7	30	26 (87)	< 15%	< 5%	0 (0)	< 5%	< 15%	< 15%	< 5%
8	153	121 (79)	32 (21)	7 (5)	< 5%	< 5%	13 (8)	14 (9)	7 (5)
9	63	52 (83)	11 (17)	< 5%	< 5%	0 (0)	< 5%	< 10%	< 5%
10	56	33 (59)	23 (41)	0 (0)	0 (0)	< 5%	8 (14)	22 (39)	< 10%
11	181	155 (86)	26 (14)	5 (3)	5 (3)	< 5%	13 (7)	16 (9)	7 (4)
12	85	69 (81)	16 (19)	< 5%)	< 5%	< 5%	10 (12)	7 (8)	5 (6)
13	23	18 (78)	5 (22)	< 15%	< 15%	0 (0)	0 (0)	< 5%	0 (0)
14	105	97 (92)	8 (8)	< 5%	< 5%	0 (0)	6 (6)	7 (7)	0 (0)
15	31	24 (77)	7 (23)	< 5%	4 (13)	0 (0)	< 10%	< 15%	0 (0)
16	251	206 (82)	45 (18)	7 (3)	8 (3)	< 5%	10 (4)	24 (10)	9 (4)
17	79	69 (87)	10 (13)	0 (0)	0 (0)	0 (0)	6 (8)	10 (13)	< 5%
18	42	29 (69)	13 (31)	< 10%	0 (0)	< 5%	6 (14)	7 (17)	< 10%
20	78	62 (79)	16 (21)	< 5%	< 5%	< 5%	5 (6)	11 (14)	< 5%
21	56	36 (64)	20 (36)	< 5%	< 5%	< 5%	9 (16)	15 (27)	6 (11)
23	141	118 (84)	23 (16)	6 (4)	9 (6)	6 (4)	5 (4)	5 (4)	< 5%
25	241	203 (84)	38 (16)	0 (0)	11 (5)	< 5%	9 (4)	25 (10)	5 (2)
28	55	50 (91)	5 (9)	< 5%	< 5%	0 (0)	< 5%	4 (7)	< 5%
29	19	18 (95)	< 10%	< 10%	0 (0)	0 (0)	0 (0)	0 (0)	< 10%
Total	2397	2015 (84)	382 (16)	51 (2)	60 (3)	39 (2)	136 (6)	229 (10)	69 (3)

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



	1	2	5	6	7	8	9	10	11	12	13	14	15	16	17	18	20	21	23	25	28	29
sNDI	3,4	8,1	8,1	21	13	21	17	41	14	19	22	7,6	23	18	13	31	21	36	16	16	9,1	5,3

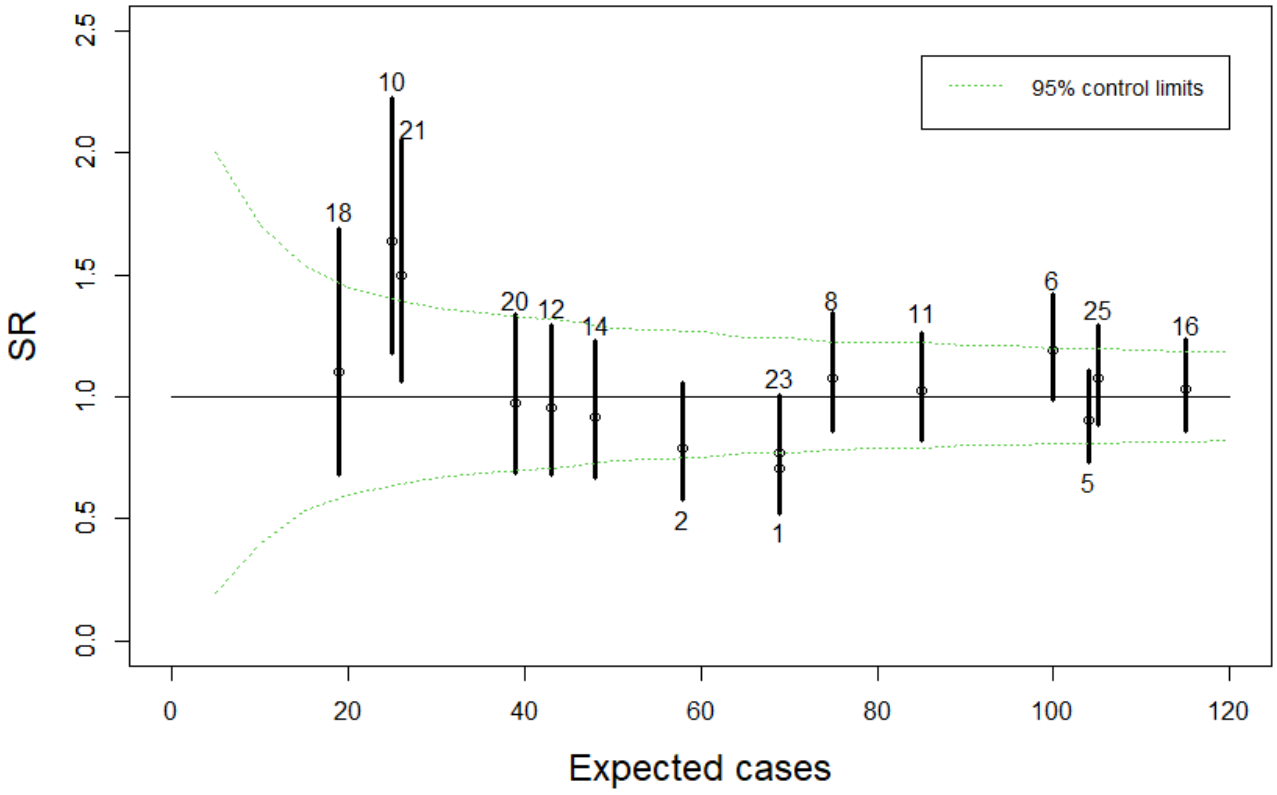
Appendix II. Sites Comparisons for MiCare Cohort – Adjusted Standardized Ratios

Presentation No 32: Adjusted standardized ratios by site. Neurodevelopmental impairment for MiCare cohort (Births April 1, 2009 – September 30, 2011)

Site	**Children** (n)	**Follow-up rate** (%)	**Included** (Yes/No)	**NDI** (n)	**Adjusted expected NDI** (n)	**Adjusted standardized ratio** (95%CI)
1	146	76	Yes	49	69	0.71 (0.49, 0.87)
2	123	90.4	Yes	46	58	0.79 (0.58, 1.04)
3	10	76.9				
4	13	76.5				
5	221	86	Yes	94	104	0.90 (0.73, 1.10)
6	218	87.6	Yes	119	100	1.19 (0.99, 1.41)
7	30	60				
8	153	72.9	Yes	81	75	1.08 (0.86, 1.33)
9	63	57.3				
10	56	82.4	Yes	41	25	1.64 (1.18, 2.18)
11	181	81.2	Yes	87	85	1.02 (0.82, 1.25)
12	85	82.5	Yes	41	43	0.95 (0.68, 1.27)
13	23	60.5				
14	105	78.4	Yes	44	48	0.92 (0.67, 1.21)
15	31	60.8				
16	251	82.6	Yes	119	115	1.03 (0.86, 1.23)
17	79	48.5				
18	42	89.4	Yes	21	19	1.11 (0.68, 1.63)
19	17	25.8				
20	78	79.6	Yes	38	39	0.97 (0.69, 1.31)
21	56	94.9	Yes	39	26	1.50 (1.07, 2.01)
22	13	65				
23	141	84.4	Yes	53	69	0.77 (0.58, 0.99)
24	7	50				
25	241	77.2	Yes	113	105	1.08 (0.89, 1.28)
26	19	82.6				
28	55	63.2				
29	19	67.9				

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

Neurodevelopmental impairment for MiCare cohort
(Births April 1, 2009 – September 30, 2011)



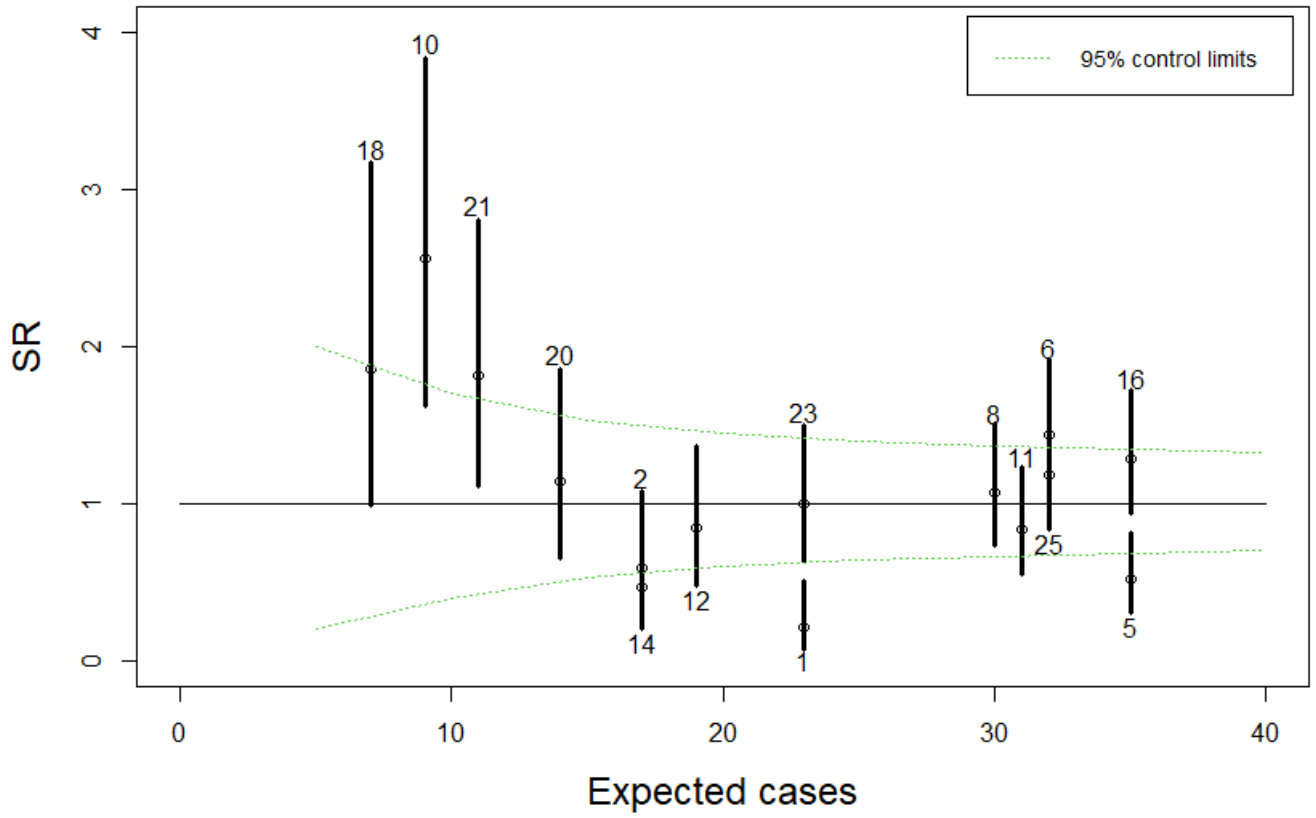
COMMENTS:
Sites with points outside the green "funnel" represent higher or lower adjusted NDI rates than expected. When the 95% confidence interval does not cross 1, the results are statistically significant. Therefore, 3 sites (1, 10 and 21) have statistically higher or lower NDI rates.

Presentation No 33: Adjusted standardized ratios by site
Significant neurodevelopmental impairment for MiCare cohort
(Births April 1, 2009 – September 30, 2011)

Site	**Children** (n)	**Follow-up rate** (%)	**Included** (Yes/No)	**sNDI** (n)	**Adjusted expected sNDI** (n)	**Adjusted standardized ratio** (95%CI)
1	146	76	Yes	5	23	0.22 (0.07, 0.45)
2	123	90.4	Yes	10	17	0.59 (0.28, 1.01)
3	10	76.9				
4	13	76.5				
5	221	86	Yes	18	35	0.51 (0.30, 0.78)
6	218	87.6	Yes	46	32	1.44 (1.05, 1.88)
7	30	60				
8	153	72.9	Yes	32	30	1.07 (0.73, 1.47)
9	63	57.3				
10	56	82.4	Yes	23	9	2.56 (1.62, 3.71)
11	181	81.2	Yes	26	31	0.84 (0.55, 1.19)
12	85	82.5	Yes	16	19	0.84 (0.48, 1.31)
13	23	60.5				
14	105	78.4	Yes	8	17	0.47 (0.20, 0.85)
15	31	60.8				
16	251	82.6	Yes	45	35	1.29 (0.94, 1.69)
17	79	48.5				
18	42	89.4	Yes	13	7	1.86 (0.98, 3.00)
19	17	25.8				
20	78	79.6	Yes	16	14	1.14 (0.65, 1.77)
21	56	94.9	Yes	20	11	1.82 (1.11, 2.70)
22	13	65				
23	141	84.4	Yes	23	23	1.00 (0.63, 1.45)
24	7	50				
25	241	77.2	Yes	38	32	1.19 (0.84, 1.60)
26	19	82.6				
28	55	63.2				
29	19	67.9				

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).

Significant neurodevelopmental impairment for MiCare cohort
(Births April 1, 2009 – September 30, 2011)



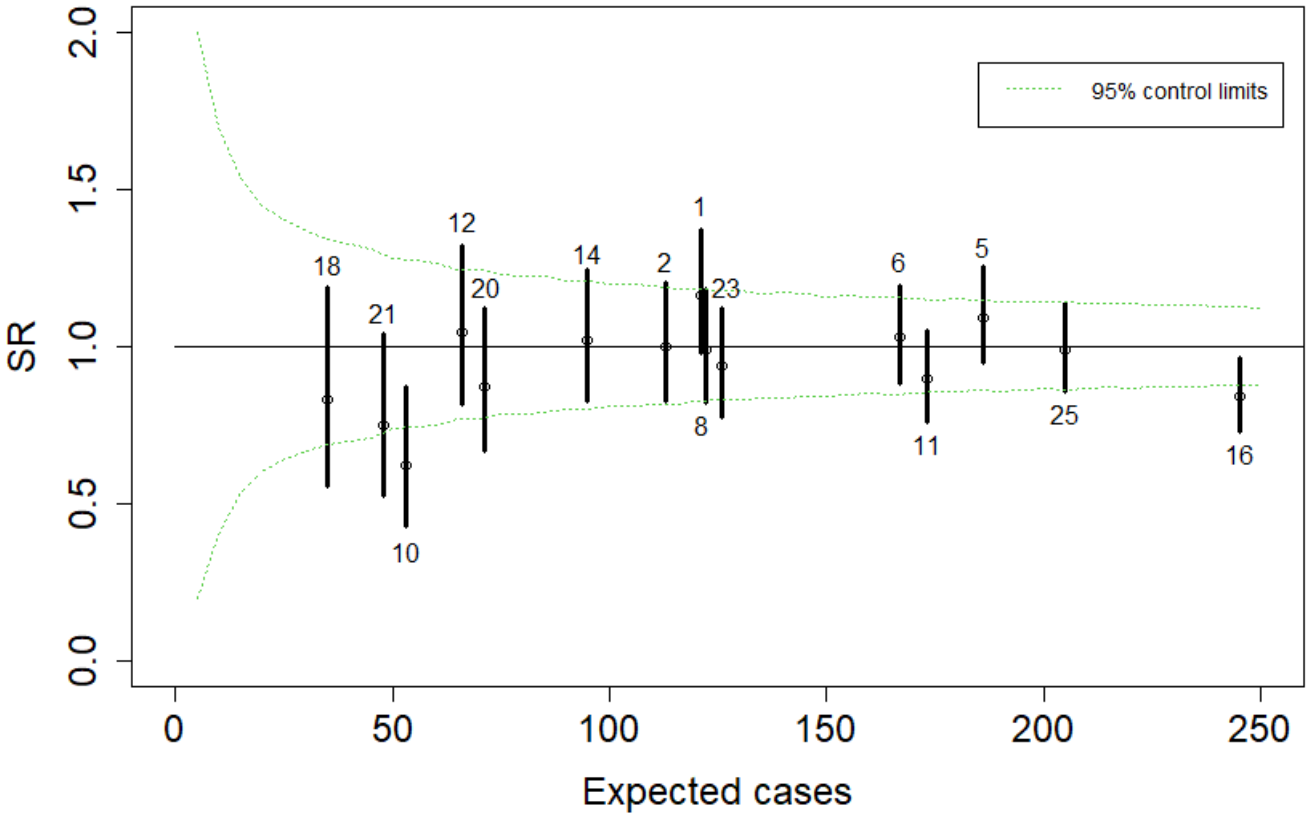
COMMENTS:
Sites with points outside the green "funnel" represent higher or lower adjusted sNDI rates than expected. When the 95% confidence interval does not cross 1, the results are statistically significant. Therefore, 4 sites (1, 5, 10, and 21) have statistically higher or lower sNDI rates.

Presentation No 34: Adjusted standardized ratios by site
Survival without significant neurodevelopmental impairment for MiCare cohort
(Births April 1, 2009 – September 30, 2011)

Site	**Children** (n)	**Follow-up rate** (%)	**Included** (Yes/No)	**Survival without sNDI** (n)	**Adjusted expected outcome** (n)	**Adjusted standardized ratio** (95%CI)
1	176	76	Yes	141	121	1.17 (0.98, 1.37)
2	161	90.4	Yes	113	113	1.00 (0.82, 1.19)
3	10	76.9		9		
4	17	76.5		13		
5	285	86	Yes	203	186	1.09 (0.95, 1.25)
6	238	87.6	Yes	172	167	1.03 (0.88, 1.19)
7	34	60		26		
8	189	72.9	Yes	121	122	0.99 (0.82, 1.18)
9	90	57.3		52		
10	74	82.4	Yes	33	53	0.62 (0.43, 0.85)
11	259	81.2	Yes	155	173	0.90 (0.76, 1.04)
12	109	82.5	Yes	69	66	1.05 (0.81, 1.31)
13	32	60.5		18		
14	136	78.4	Yes	97	95	1.02 (0.83, 1.23)
15	44	60.8		24		
16	345	82.6	Yes	206	245	0.84 (0.73, 0.96)
17	134	48.5		69		
18	50	89.4	Yes	29	35	0.83 (0.55, 1.16)
19	28	25.8		17		
20	114	79.6	Yes	62	71	0.87 (0.67, 1.10)
21	73	94.9	Yes	36	48	0.75 (0.53, 1.02)
22	15	65		12		
23	193	84.4	Yes	118	126	0.94 (0.78, 1.11)
24	13	50		6		
25	283	77.2	Yes	203	205	0.99 (0.86, 1.13)
26	20	82.6		15		
28	66	63.2		50		
29	25	67.9		18		

1. Sites with <20 participants for the 2.5year Epoch 1 cohort period and/or <70% follow-up rates are excluded.
2. Model is adjusted for gestational age, sex, antenatal steroids, Apgar <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 $\geq$10 mm, intraparenchymal hemorrhage or periventricular leukomalacia).

Survival without significant neurodevelopmental impairment for MiCare cohort (Births April 1, 2009 – September 30, 2011)



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 1, the results are statistically significant. Therefore, 2 sites (10 and 16) have statistically lower survival without significant NDI rates.