Canadian Neonatal Follow-Up Network
Réseau Canadien de Suivi Néonatal

CNFUN ANNUAL REPORT 2021

RESEARCH MULTIDISCIPLINARY COLLABORATION DATA COLLECTION FOLLOW-UP KNOWLEDGE TRANSLATION QUALITY OF CARE OUTCOMES

KGH HSC SBGH RCH BCWH HSJ NETWORK SUNY CHUS EDM HSCC CHUQ MSH SMH HMR ACH/FMC SJHC IWK MUHC HHSC JGH WRH VGH/GVS

Introduction

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.

CNFUN's Mission

CNFUN's mission is to be a network of health care professionals dedicated to improving the care of newborns and children at high risk of adverse outcome as a result of conditions requiring intensive medical care.

CNFUN's Goals

- Establish a network of Canadian health care professionals involved in neonatal / perinatal follow-up programs.
- Develop a common standardized set of assessments to be done at standardized ages and common definitions to create the CNFUN data set.
- Develop a national electronic database of the CNFUN dataset and link it to neonatal and perinatal datasets including the Canadian Neonatal Network.
- Use the CNFUN database to improve health care and its delivery by providing accurate up to date information for decision making, identifying best practices, and facilitating the acquisition of long-term outcomes data in neonatal, perinatal and early intervention research.
- Advocate for our population of children by ensuring that the best evidence is translated into practice.

Administrative Structure

A Steering Committee oversees CNFUN activities and makes policy decisions. Site representatives from participating institutions provide representation, input, and liaison for participating institutions.

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 February 2021.

The Steering Committee is composed of 11 members:

- The director of the network.
- The past director.
- A co-director chosen by the CNFUN Steering Committee.
- 5 members representing different geographic regions of Canada.
- 3 members representing allied health professionals 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 will provide administrative support to CNFUN, its committees and institutional and individual members.

CNFUN 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.

Institutional Membership is open to all 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 CNFUN and 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 institution will appoint a liaison representative who will represent the institution for policy decisions of the Network. The number of members who can vote for members of the Steering Committee

shall be proportional to the number 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.

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.

CNFUN Funding

CNFUN was initiated with support from the Canadian Institutes of Health Research 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.

Current funding is from the CIHR SPOR grant "CHILD-BRIGHT" (Child Health Initiatives Limiting Disability - Brain Research Improving Growth and Health Trajectories) for the "Parent-EPIQ" project and the CIHR Pan-Canadian Network to Improve Outcomes of Preterm Birth.

Participating sites contribute additional funding for patient outcome assessments.

CNFUN Steering Committee

Dr. Thuy Mai Luu – Pediatrician / director (Québec)

Dr. Anne Synnes – Neonatologist / past director (British Columbia)

Dr. Jehier Afifi – Neonatologist / co-director (Nova Scotia)

Dr. Rudaina Banihani – Neonatologist / developmental behavioural pediatrician (Ontario)

Lindsay Colby – Nurse (British Columbia)

Dr. Matthew Hicks – Neonatologist / developmental behavioural pediatrician (Alberta)

Dr. Florencia Ricci – Developmental behavioural pediatrician (Manitoba)

Dr. Karen Thomas – Neonatologist / developmental behavioural pediatrician (Ontario)

Dr. Jill Zwicker – Occupational therapist / researcher (British Columbia)

2021 CNFUN Annual Report Working Group

Dr. Anne Synnes – Neonatologist, neonatal follow-up (British Columbia)

Dr. Thuy Mai Luu – Pediatrician, neonatal follow-up (Québec)

Dr. Jehier Afifi – Neonatologist, neonatal follow-up (Nova Scotia)

Dr. Matthew Hicks – Neonatologist, developmental behavioural pediatrician (Alberta)

Dr. Leonora Hendson – Neonatologist, neonatal follow-up (Alberta)

Heather Kehler – Research Coordinator, neonatal follow-up (Alberta)

Lindsay Richter – CNFUN National Coordinator (British Columbia)

Table of Contents

viii. Presentation No 15 – Survival without neurodevelopmental impairment (NDI) rates by gestational age
ix. Presentation No 16 – Hospitalization rates by gestational age
x. Presentation No 17a – Use of aids at home from discharge to follow-up visit by gestational age
xi. Presentation No 17b – Aids at home still in use at the follow-up visit by gestational age

F. Outcomes Over Time
i. Presentation No 18 – Trends in cerebral palsy rates over time
ii. Presentation No 19 – Trends in hearing status over time
iii. Presentation No 20 – Trends in visual impairment rates over time
iv. Presentation No 21 – Trends in Bayley-III Cognitive Composite scores over time
v. Presentation No 22 – Trends in Bayley-III Motor Composite scores over time
vi. Presentation No 23 – Trends in Bayley-III Language Composite scores over time
vii. Presentation No 24 – Trends in neurodevelopmental impairment rates over time

G. Post-MiCare Cohort Site Comparisons – Crude
i. Presentation No 25 – Neurodevelopmental impairment rates for post-MiCare cohort (Births Oct 1, 2011 - Dec 31, 2018)
ii. Presentation No 26 – Significant neurodevelopmental impairment rates for post-MiCare cohort (Births Oct 1, 2011 - Dec 31, 2018)

H. Post-MiCare Cohort Site Comparisons – Adjusted Standardized Ratios by Site
i. Presentation No 27 – Adjusted standardized ratios by site – Neurodevelopmental impairment – post-MiCare cohort (Births Oct 1, 2011 - Dec 31, 2018)
ii. Presentation No 28 – Adjusted standardized ratios by site – Significant neurodevelopmental impairment – post-MiCare cohort (Births Oct 1, 2011 - Dec 31, 2018)

iii. Presentation No 29 – Adjusted standardized ratios by site – Significant neurodevelopmental impairment or death – post-MiCare cohort (Births Oct 1, 2011 - Dec 31, 2018)

I. Summary of Publications

J. Appendices

Appendix I. MiCare Cohort Site Comparisons – Crude

i. Presentation No 30 – Neurodevelopmental impairment rates for MiCare cohort (Births April 1, 2009 - Sept 30, 2011)

ii. Presentation No 31 – Significant neurodevelopmental impairment rates for MiCare cohort (Births April 1, 2009 - Sept 30, 2011)

Appendix II. MiCare Cohort Site Comparisons – Adjusted Standardized Ratios by Site

i. Presentation No 32 – Adjusted standardized radio by site – Neurodevelopmental impairment – MiCare cohort (Births April 1, 2009 - Sept 30, 2011)

ii. Presentation No 33 – Adjusted standardized ratios by site – Significant neurodevelopmental impairment – MiCare cohort (Births April 1, 2009 - Sept 30, 2011)

iii. Presentation No 34 – Adjusted Standardized ratios by site – Significant neurodevelopmental impairment or death – MiCare cohort (Births April 1, 2009 - Sept 30, 2011)

A. Executive Summary

We are pleased to provide the fourth CNFUN annual report. CNFUN aims to provide accurate up to date information on the outcomes of children born very preterm across Canada and to improve health and the provision of health care. This report provides national and site-specific data from the start of CNFUN data collection with births from April 1, 2009, until December 31, 2018. Information is included for 6994 infants assessed at a CNFUN site and 9383 survivors and non-survivors with linked neonatal data from the Canadian Neonatal Network.

Improving health 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.

Sites 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. In addition, over the past four years, we have been active in (1) implementing interventions at participating sites to improve either language or cognitive outcomes, and (2) exploring the aspects of health and neurodevelopment that parents of children born very preterm identified as the most important. These Parent-EPIQ projects were supported by the CIHR SPOR (Strategy for Patient Oriented Research) CHILD-BRIGHT research collaborative, which also provides funding for this annual report.

Parent partners and parent participation were integral to Parent-EPIQ. Through our different studies and with the collaboration of CNFUN site investigators, we have surveyed close to 2000 parents of preterm children across Canada and abroad. Via Parent-EPIQ studies parents told us they are aware that their child's developmental trajectory might be different than others. Nevertheless, families would like to see a more balanced approach when discussing these neurodevelopmental outcomes. The majority of NICU graduates are happy and doing well. The results suggest we should not focus solely on deficits but also address the positive attributes of very preterm children and report on other outcomes such as physical health function, quality of life and family well-being.

Indeed, we have incorporated lessons learnt from Parent-EPIQ in this report.

What's New:

- We are removing value-based labels of severity and are using objective descriptions such as cerebral palsy levels of function and hearing status.
- Based on our preliminary results, we have restricted '*severe*' neurodevelopmental impairment (NDI) to health conditions likely to persist over time and have an impact on child functioning (page 17). This is different from significant NDI which encompasses milder conditions. Severe NDI does not imply poor quality of life.
- We removed the composite outcome of death and NDI from this report.
- We are adding the outcome of survival without NDI, significant NDI or severe NDI.

We recognize that the COVID-19 pandemic has altered how Neonatal Follow-Up Programs evaluate children and the ability and willingness of families to attend and complete CNFUN standardized assessments. CNFUN expanded the target age range for assessment from 18 up to 36 months corrected age which means not all sites have assessed children born in 2018. As a result, *follow-up rates for the birth cohort of 2018 have fallen despite all efforts and commitment deployed by CNFUN sites.* We will be looking at alternatives and solutions to facilitate data collection across the network, working together and using creativity. Therefore, **findings must be interpreted with caution, knowing that children at higher biological risk of neurodevelopmental impairment are more likely to be seen in follow-up**.

Key Findings:

- The majority (6609/9383 = 70.4%) of infants born <29 weeks' gestational age survive without severe neurodevelopmental impairment.
- Excluding the 2018 birth cohort, there has been a trend towards decreasing rates of cerebral palsy over time.
- There are also trends towards lower rates of need for hearing aids/cochlear implants and bilateral blindness.
- Significant neurodevelopmental impairment rates have remained stable over time.
- Rates of neurodevelopmental impairment vary significantly across participating sites adjusted for risk factors.
- About one third of infants are re-admitted after NICU discharge.

To conclude, we would like to thank the CNFUN Annual Report Working Group and acknowledge the support of the CNFUN Steering Committee. Thank you to the MiCare Coordinating site: Sonny Yeh for developing and supporting the database, Junmin Yang for the analyses, and Dr. Prakesh Shah for his leadership. The CIHR Team in MiCare grant provided partial funding to sites to participate for the "MiCare" cohort born April 1, 2009, to September 30, 2011. Thank you to the sites who were able to continue to contribute data despite receiving no funding for births October 1, 2011, until December 31, 2014. The cost of data abstraction, but not collection, is now covered by the Parent-EPIQ study for sites who have signed subsite agreements.

Most importantly, we want to show our appreciation for the willingness of the families of children born preterm to attend the follow-up visits. Families travel on average 100 kilometers to their Neonatal Follow-Up Programs, and some travelled over 1000 kms! Many of these families come, not just to get excellent clinical care but also to give back to their NICU and to contribute to improving neonatal care. This report recognizes their crucial contribution.

Thuy Mai Luu MD, MSc
Director, CNFUN

Anne Synnes MDCM, MHSc
Past Director, CNFUN

B. Participating Sites

Presentation No 1: CNFUN site descriptions

Active members					
Province	**Abbreviation**	**NFUP Program Name / City**	**Hospital Site**	**Site Investigator**	**Number of CNFUN Members**
BC	**BCWH**	Neonatal Follow-Up Program, Vancouver	BC Women's Hospital & Health Centre	Anne Synnes, Natalie Chan	7
	RCH	Neonatal Follow-Up Program, New Westminster	Royal Columbian Hospital	Miroslav Stavel, Anitha Moodley	5
	SMH	Neonatal Follow-Up Program, Surrey	Surrey Memorial Hospital	Rebecca Sherlock	4
	VGH/GVS	Neonatal Follow-Up Team, Victoria	Victoria General Hospital	Thevanisha Pillay	4
AB	**ACH/FMC**	Neonatal Follow-up Clinic, Calgary	Alberta Children's Hospital & Foothills Hospital, University of Calgary	Leonora Hendson	6
	EDM	Neonatal and Infant Follow-Up Clinic, Edmonton	Glenrose Rehabilitation Hospital	Amber Reichert, Matthew Hicks	8
MB	**HSCC**	High Risk Newborn Follow-Up Program, Winnipeg	University of Manitoba Health Sciences Centre / Children's Hospital	Diane Moddemann, Cecilia de Cabo	7
	SBGH	High Risk Newborn Follow-Up Program, Winnipeg	St. Boniface General Hospital	Diane Moddemann, Cecilia del Cabo	6
ON	**HHSC**	Neonatal Follow-Up Clinic, Hamilton	Hamilton Health Sciences Centre, McMaster Children's Hospital	Karen Thomas	9
	HSC	Neonatal Follow-Up Program, Toronto	Hospital for Sick Children	Linh Ly	6

	KGH	Special Infant Clinic, Kingston	Kingston General Hospital	Sarah McKnight	3
	MSH	Neonatal Follow-Up Program, Toronto	Mount Sinai Hospital	Edmond Kelly	6
	SJHC (LHSC)	Developmental Follow-Up Clinic, London	St. Joseph's Health Care London	Kevin Coughlin	10
	SUNY	Neonatal Follow-Up Program, Toronto	Sunnybrook Health Sciences Center	Paige Church, Rudaina Banihani	8
	WRH	Neonatal Neurodevelopment Follow-Up Program, Windsor	Windsor Regional Hospital	Sajit Augustine	5
QC	**CHUS**	Clinique de suivi néonatal, Sherbrooke	Centre Hospitalier Universitaire de Sherbrooke	Alyssa Morin	3
	CHUQ	Centre Mère Enfant, Centre Hospitalier de L'Université Laval, Québec	Centre Hospitalier Universitaire de Québec (Laval Site)	Sylvie Bélanger	3
	HMR	Clinique de suivi néonatal, Montréal	Hôpital Maisonneuve-Rosemont	Marie St-Hilaire	3
	HSJ	Clinique de suivi néonatal, Montréal	Université de Montréal, Hôpital Sainte-Justine	Thuy Mai Luu	7
	JGH	Neonatal Follow-Up Clinic, Montréal	Jewish General Hospital	Kim-Anh Nguyen. Ruth Mandel	6
	MUHC	Neonatal Follow-Up Program, Clinique de suivi néonatal, Montréal	McGill University Health Centre/ Montréal Children's Hospital/ L'Hôpital de Montréal pour enfants	May Khairy	7
NS	**IWK**	Perinatal Follow-Up Program, Halifax	IWK Health Centre and Cape Breton Regional Hospital	Jehier Afifi	9

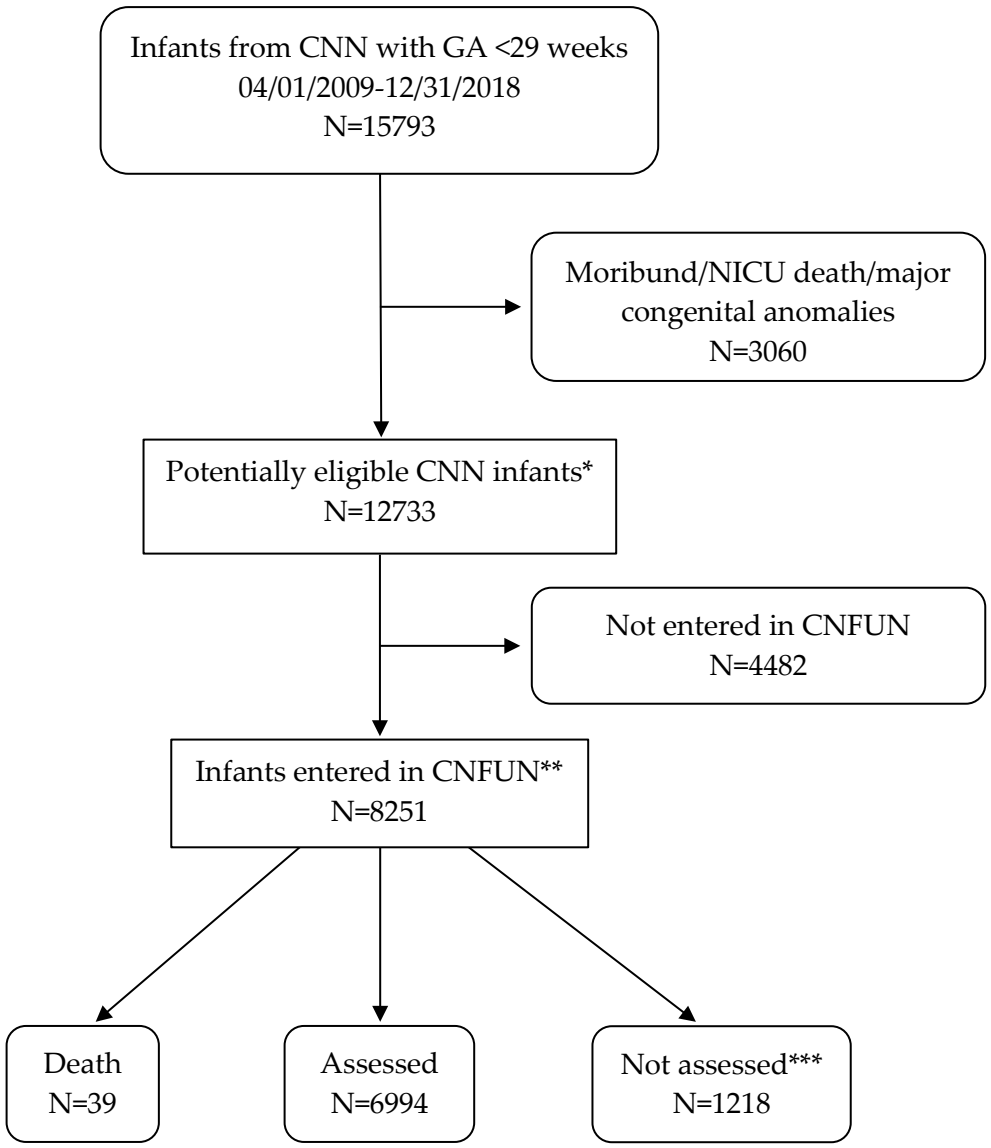
Past members				
Province	**Abbreviation**	**NFUP Program Name / City**	**Hospital Site**	**Site Investigator**
SK	**RQHR**	Developmental Assessment Clinic, Regina	Regina General Hospital	J.P. Bodani
	RUH	Neonatal Follow-Up Program, Saskatoon	Royal University Hospital	Sibasis Daspal
ON	**CHEO/OTTA**	Neonatal Follow-Up Clinic, Ottawa	Children's Hospital of Eastern Ontario	Thierry Daboval
NB	**ECH**	Neonatal Follow-Up Program, Fredericton	Dr. Everett Chalmers Hospital	Hala Makary
	SEHC	Neonatal Follow-Up Clinic, Moncton	Moncton Hospital	Roderick Canning
	SJRH	Neonatal Follow-Up Program, Saint John	Saint John Regional Hospital	Alana Newman
NFLD	**JCHC**	High-Risk Follow-Up Clinic, St. John's	Janeway Children's Health & Rehabilitation Centre	Phil Murphy

Presentation No 2: CNFUN site participation and follow-up rates†

CNFUN Site	MiCare Data (Yes/No)	MiCare Follow-Up Rate (Births April 1, 2009 – September 30, 2011) n/N (%)	Post-MiCare Follow-Up Rate (Births October 1, 2011 – December 31, 2018) n/N (%)	Parent-EPIQ Intervention Site (Yes/No)
Active CNFUN sites				
1	Yes	170/222 (76.6)	413/550 (75.1)	Yes
2	Yes	115/131 (87.8)	310/394 (78.7)	No
3	Yes	11/13 (84.6)	84/143 (58.7)	No
5	Yes	205/256 (80.1)	7/844 (0.8)	Yes
6	Yes	213/249 (85.5)	607/852 (71.2)	Yes
7	Yes	30/53 (56.6)	20/152 (13.2)	No
8	Yes	145/203 (71.4)	5/620 (0.8)	No
9	Yes	53/110 (48.2)	46/188 (24.5)	No
10	Yes	56/69 (81.2)	141/233 (60.5)	Yes
11	Yes	178/223 (79.8)	455/531 (85.7)	Yes
12	Yes	84/102 (82.4)	244/294 (83.0)	Yes
14	Yes	103/135 (76.3)	249/393 (63.4)	Yes
15	Yes	31/51 (60.8)	15/114 (13.2)	No
16	Yes	250/301 (83.1)	636/1025 (62.0)	Yes
20	Yes	79/101 (78.2)	246/334 (73.7)	Yes
21	Yes	55/59 (93.2)	126/180 (70.0)	Yes
23	Yes	132/166 (79.5)	89/372 (23.9)	Yes
25	Yes	241/308 (78.2)	813/1134 (71.7)	No
26	Yes	18/22 (81.8)	57/81 (70.4)	No
27	No	-	31/45 (68.9)	No
28	No	-	6/32 (18.8)	No
29	No	-	11/44 (25.0)	No
Inactive Sites				
4	Yes	13/17 (76.5)	6/45 (13.3)	No
13	Yes	21/37 (56.8)	-	No
17	Yes	64/163 (39.3)	5/375 (1.3)	No
18	Yes	43/47 (91.5)	9/144 (6.3)	No
19	Yes	17/66 (25.8)	5/185 (2.7)	No
22	Yes	13/20 (65.0)	12/83 (14.5)	No
24	Yes	7/13 (53.8)	-	No

†Follow-up rate denominator: infants with GA<29 weeks discharged live 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, 2018



*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 could not be linked with CNN (n=2695) or are followed in non-participating sites (n=1787).

**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=329), no contact information (n=26), unable to reach (n=222), missed appointment (n=196), other reason (n=407), missing information (n=38).

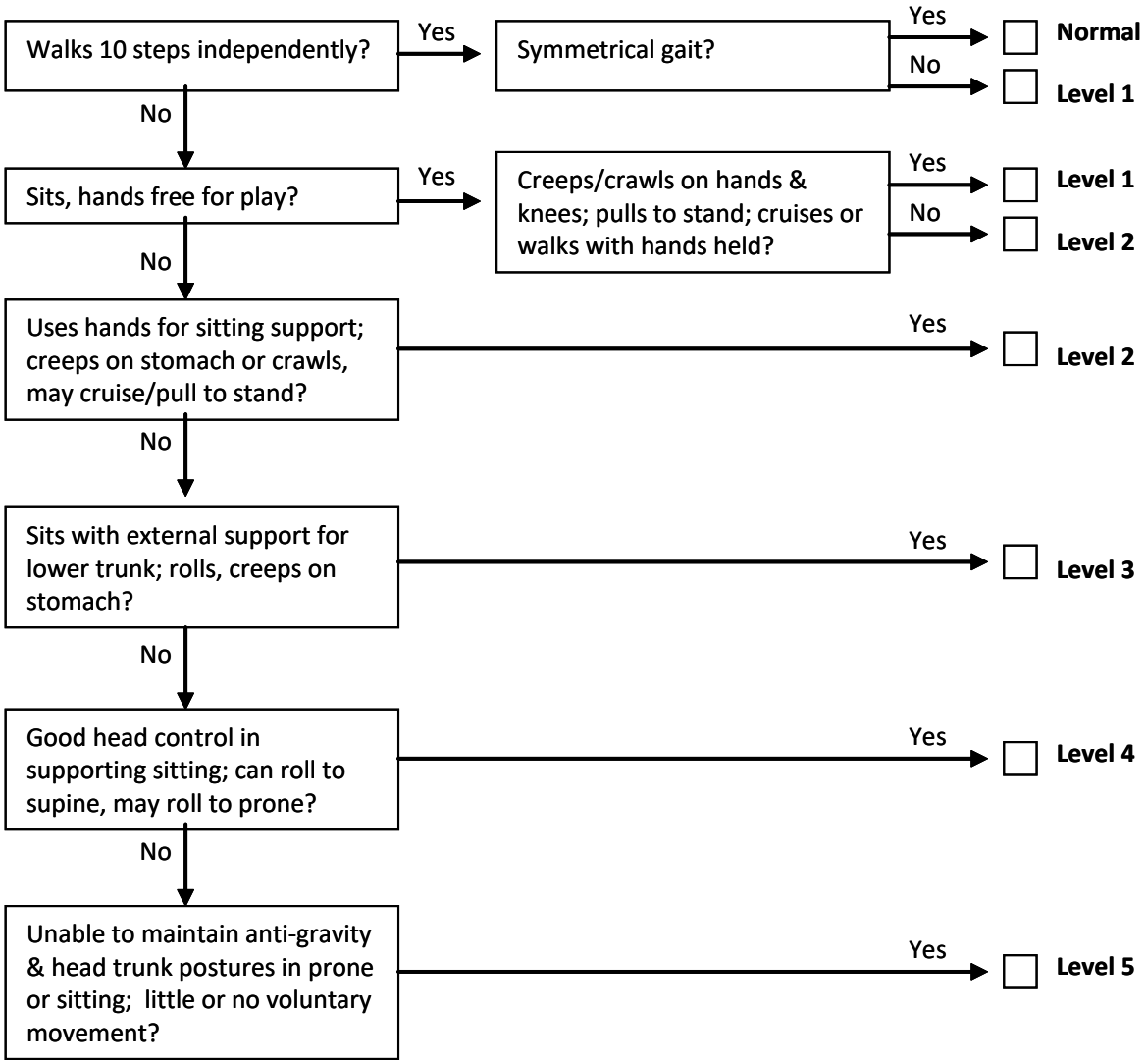
C. Outcomes Definitions

Impairments	Neurodevelopmental impairment (NDI) (Any one or more of the following)*	Significant neurodevelopmental impairment (sNDI) (Any one or more of the following)**	Severe neurodevelopmental impairment (Any one or more of the following)***
Motor	CP with GMFCS 1 or higher	CP with GMFCS 3, 4 or 5	CP with GMFCS 4 or 5
	Bayley-III Motor Composite <85	Bayley-III Motor Composite <70	Not included
Cognitive	Bayley-III Cognitive Composite <85	Bayley-III Cognitive Composite <70	Bayley-III Cognitive Composite <55
Language	Bayley-III Language Composite <85	Bayley-III Language Composite <70	Bayley-III Language Composite <55
Hearing	Sensorineural/mixed hearing loss	Hearing aid or cochlear implant	Not included
Vision	Uni- or bilateral visual impairment	Bilateral visual impairment	Bilateral visual impairment

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-III: Bayley Scales of Infant and Toddler Development – 3rd edition. Of note, 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.

*Children are also included in this category if they could not be tested using the Bayley-III and obtained a Bayley-III Adaptive Behavior score <85.
**Children are also included in this category if they could not be tested using the Bayley-III and obtained a Bayley-III Adaptive Behavior score <70 or were considered to have a significant developmental delay which did not allow completion of the Bayley-III.
***Severe NDI defined as per Cheong *et al.* JAMA Pediatr 2021;175(10):1035-1042.

Gross Motor Function Classification System (GMFCS)



The algorithm is based on Palisano[1].

1) 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

Presentation No 4: Survival and participant 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 (%)	**CNN-CNFUN data for NICU survivors** n (%)	**Known outcome** for NICU deaths and survivors** n (%)
2009*	1201	108 (9.0)	212 (17.7)	881 (73.4)	5 (0.4)	659 (74.8)	876 (80.1)
2010	1613	34 (2.1)	244 (15.1)	1335 (82.8)	14 (0.9)	1013 (75.9)	1271 (80.5)
2011	1527	51 (3.3)	258 (16.9)	1218 (79.8)	5 (0.3)	852 (70)	1115 (75.5)
2012	1590	51 (3.2)	251 (15.8)	1288 (81.0)	0 (0)	676 (52.5)	927 (60.2)
2013	1622	59 (3.6)	256 (15.8)	1307 (80.6)	3 (0.2)	615 (47.1)	874 (55.9)
2014	1621	70 (4.3)	232 (14.3)	1319 (81.4)	1 (0.1)	649 (49.2)	882 (56.9)
2015	1554	87 (5.6)	201 (12.9)	1266 (81.5)	1 (0.1)	686 (54.2)	888 (60.5)
2016	1678	99 (5.9)	221 (13.2)	1358 (80.9)	5 (0.3)	713 (52.5)	939 (59.5)
2017	1637	81 (4.9)	219 (13.4)	1337 (81.7)	3 (0.2)	622 (46.5)	844 (54.2)
2018	1750	70 (4.0)	256 (14.6)	1424 (81.4)	2 (0.1)	509 (35.7)	767 (45.7)
2009-2018	15793	710 (4.5)	2350 (14.9)	12733 (80.6)	39 (0.2)	6994 (54.9)	9383 (62.2)

*April 1, 2009 to December 31, 2009.

**Children with known long-term composite 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.

COMMENTS:

These results include participating and non-participating sites. Partial funding by the CIHR team in MiCare for data collection and abstraction was provided for the April 1, 2009 – September 30, 2011 birth cohort. Data collection and participation dropped significantly with no funding and limited funding has been available to the Parent-EPIQ study from the CHILD-BRIGHT CIHR SPOR grant since 2016.

Presentation No 5: 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*	881	774	659 (74.8)
2010	1335	1123	1013 (75.9)
2011	1218	935	852 (70.0)
2012	938	722	651 (69.4)
2013	973	664	611 (62.8)
2014	954	708	643 (67.4)
2015	929	757	679 (73.1)
2016	1218	749	711 (58.4)
2017	1180	659	622 (52.7)
2018	1265	552	506 (40.0)
2009-2018	10891	7643	6947 (63.8)

*April 1, 2009 to December 31, 2009.
**Not all CNFUN patients can be linked to CNN.
#For 2012-2015, participating sites 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, Hôpital Sainte-Justine, Jewish General Hospital, Montreal Children's Hospital, Centre Hospitalier Universitaire de Sherbrooke, Centre Hospitalier de l'Université Laval, IWK Health Centre, Cape Breton Regional Hospital, and Winnipeg Health Sciences Centre Children´s Hospital. In 2016, Edmonton, Hamilton Health Sciences Centre, Kingston General Hospital and Hôpital Maisonneuve Rosemont were also participating sites. Since 2017, Royal Columbian Hospital and Surrey Memorial Hospital are also participating sites. No additional sites were added in 2018.

COMMENTS:

Analyses using the MiCare cohort are more reliable than the post-MiCare cohort due to larger attrition bias in the later period.

Presentation 6a: Survival and participant 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 NICU survivors** n (%)	**Known outcome* for NICU deaths and survivors** n (%)
22	184	78 (42.4)	66 (35.9)	40 (21.7)	0 (0)	17 (42.5)	83 (78.3)
23	945	106 (11.2)	433 (45.8)	406 (43.0)	4 (0.4)	220 (54.2)	657 (78.3)
24	1913	100 (5.2)	586 (30.6)	1227 (64.1)	8 (0.4)	707 (57.6)	1301 (71.8)
25	2566	90 (3.5)	493 (19.2)	1983 (77.3)	8 (0.3)	1134 (57.2)	1635 (66.0)
26	2891	95 (3.3)	343 (11.9)	2453 (84.8)	5 (0.2)	1396 (56.9)	1744 (62.4)
27	3377	114 (3.4)	246 (7.3)	3017 (89.3)	9 (0.3)	1639 (54.3)	1894 (58)
28	3917	127 (3.2)	183 (4.7)	3607 (92.1)	5 (0.1)	1881 (52.1)	2069 (54.6)
22-28	15793	710 (4.5)	2350 (14.9)	12733 (80.6)	39 (0.2)	6994 (54.9)	9383 (62.2)

*Death or CNFUN neurodevelopmental outcomes.

#Newborns admitted moribund or with major congenital anomalies are excluded.

Presentation 6b: Survival and participant 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 NICU survivors** n (%)	**Known outcome* for NICU deaths and survivors** n (%)
< 500	413	87 (21.1)	179 (43.3)	147 (35.6)	1 (0.2)	84 (57.1)	264 (81)
500-749	4118	248 (6.0)	1169 (28.4)	2701 (65.6)	16 (0.4)	1585 (58.7)	2770 (71.6)
750-999	5625	214 (3.8)	682 (12.1)	4729 (84.1)	14 (0.2)	2703 (57.2)	3399 (62.8)
1000-1249	4150	116 (2.8)	242 (5.8)	3792 (91.4)	8 (0.2)	1992 (52.5)	2242 (55.6)
> 1250	1470	38 (2.6)	74 (5.0)	1358 (92.4)	0 (0)	625 (46.0)	699 (48.8)
All	15776	703 (4.5)	2346 (14.9)	12727 (80.7)	39 (0.2)	6989 (54.9)	9374 (62.2))

*Death or CNFUN neurodevelopmental outcomes.

#Newborns admitted moribund or with major congenital anomalies are excluded.

Presentation 7: Follow-up rates among CNFUN sites by gestational age

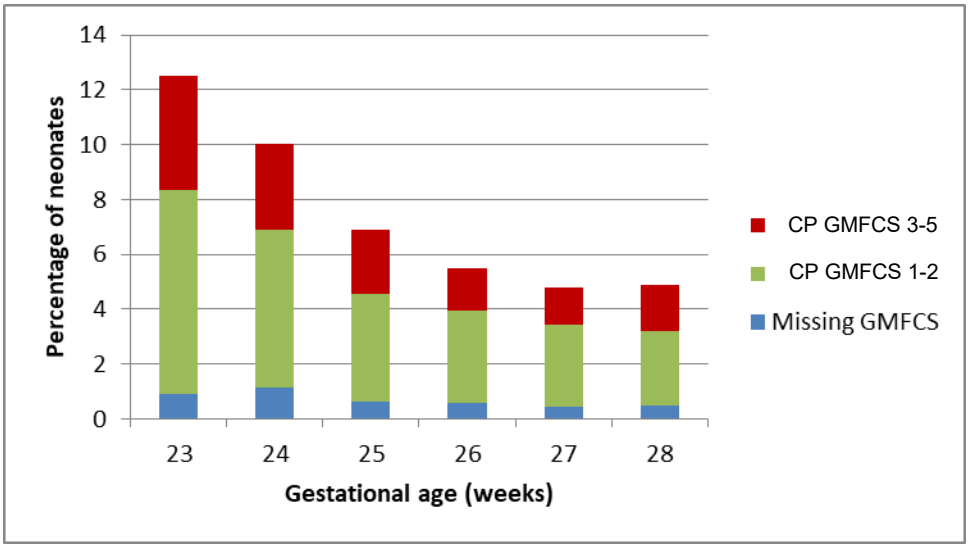
Gestational age (weeks)	**All NICU survivors** n (%)	**NICU survivors at participating sites#** (n)	**CNFUN data** (n)	**Linked* CNN-CNFUN data for NICU survivors** n (%)	**Follow-up rate for participating CNFUN sites** n (%)
22	40 (21.7)	33	19	17 (42.5)	17 (51.5)
23	406 (43)	343	220	220 (54.2)	220 (64.1)
24	1227 (64.1)	1046	810	707 (57.6)	702 (67.1)
25	1983 (77.3)	1708	1202	1134 (57.2)	1123 (65.7)
26	2453 (84.8)	2113	1493	1396 (56.9)	1377 (65.2)
27	3017 (89.3)	2567	1807	1639 (54.3)	1631 (63.5)
28	3607 (92.1)	3081	2084	1881 (52.1)	1877 (60.9)
22-28	12733 (80.6)	10891	7635	6994 (54.9)	6947 (63.8)

*Reasons for the non-linked babies: no CNN patient ID or cannot be linked with CNN data.
#For 2012-2015, participating sites 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, Hôpital Sainte-Justine, Jewish General Hospital, Montreal Children's Hospital, Centre Hospitalier Universitaire de Sherbrooke, Centre Hospitalier de l'Université Laval, IWK Health Centre, Cape Breton Regional Hospital, and Winnipeg Health Sciences Centre Children´s Hospital. In 2016, Edmonton, Hamilton Health Sciences Centre, Kingston General Hospital and Hôpital Maisonneuve Rosemont were also participating sites. Since 2017, Royal Columbian Hospital and Surrey Memorial Hospital are also participating sites. No additional sites were added in 2018.

E. Gestational Age Based Outcomes

Presentation No 8: Cerebral palsy rates by gestational age

GA	CNN-CNFUN linked cases (n)	CNN-CNFUN linked cases with CP data (n)	Definitive CP n (%)	Missing CP GMFCS n (%)	CP with GMFCS 1-2 n (%)	CP with GMFCS 3-5 n (%)	Suspected CP n (%)
22 wks	17	17	<5	0 (0)	<5	0 (0)	0 (0)
23 wks	220	216	27 (12.5)	2 (7.4)	16 (59.3)	9 (33.3)	10 (4.6)
24 wks	707	697	70 (10.0)	8 (11.4)	40 (57.1)	22 (31.4)	40 (5.7)
25 wks	1134	1118	77 (6.9)	7 (9.1)	44 (57.1)	26 (33.8)	37 (3.3)
26 wks	1396	1368	75 (5.5)	8 (10.7)	46 (61.3)	21 (28.0)	50 (3.7)
27 wks	1639	1612	77 (4.8)	7 (9.1)	48 (62.3)	22 (28.6)	54 (3.4)
28 wks	1881	1857	91 (4.9)	9 (9.9)	50 (55.0)	32 (35.2)	40 (2.2)
Total	6994	6885	418 (6.1)	41 (9.8)	245 (58.6)	132 (31.6)	231 (3.4)

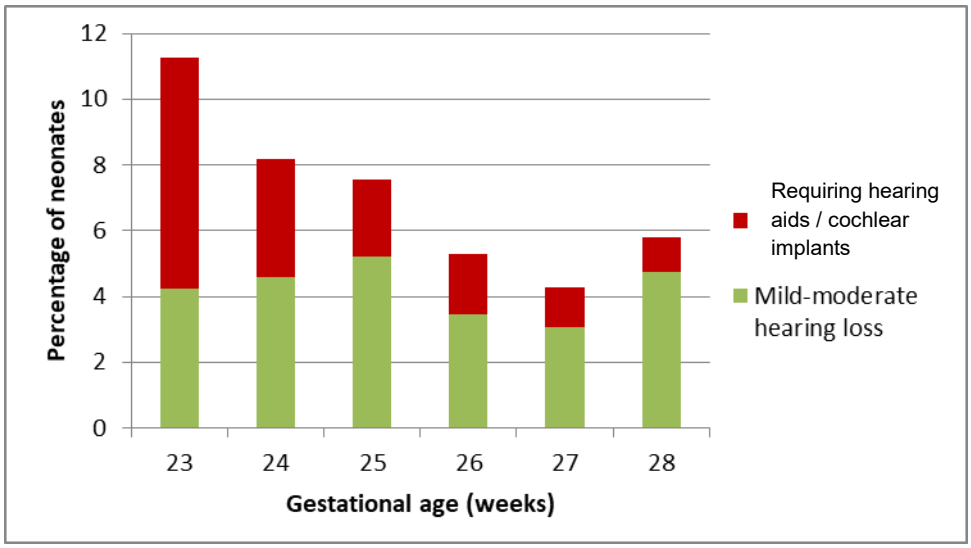


COMMENTS:

Rates for cerebral palsy (CP) with GMFCS 1-2 are calculated by subtracting number of children with CP with GMFCS 3-4-5 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	CNN-CNFUN linked cases (n)	CNN-CNFUN linked cases with data for hearing (n)	Normal hearing n (%)	Mild-moderate hearing loss n (%)	Requiring hearing aids / cochlear implants n (%)
22 wks	17	17	17 (100)	0 (0)	0 (0)
23 wks	220	213	189 (88.7)	9 (4.2)	15 (7.0)
24 wks	707	696	639 (91.8)	32 (4.6)	25 (3.6)
25 wks	1134	1110	1026 (92.4)	58 (5.2)	26 (2.3)
26 wks	1396	1363	1291 (94.7)	47 (3.5)	25 (1.8)
27 wks	1639	1608	1539 (95.7)	49 (3.1)	20 (1.2)
28 wks	1881	1849	1742 (94.2)	88 (4.8)	19 (1.0)
Total	6994	6856	6443 (94.0)	283 (4.1)	130 (1.9)

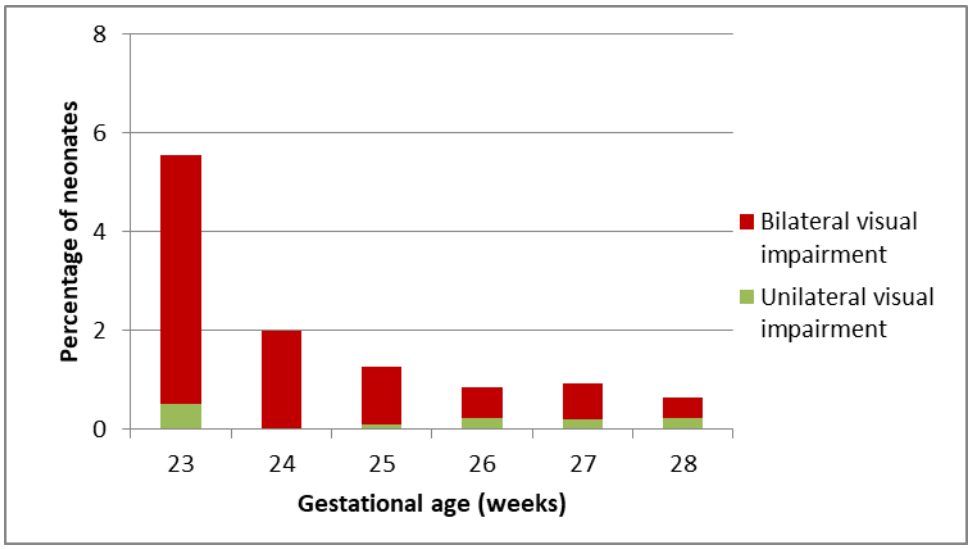


COMMENTS:

Hearing loss was determined at CNFUN sites based on audiology reports. Hearing loss is infrequent 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. Milder loss may be transient (e.g., conductive). Due to small numbers, 22 weeks gestation was not included in the bar graph.

Presentation No 10: Visual impairment rates by gestational age

GA	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 wks	17	16	15 (93.7)	0 (0)	< 5
23 wks	220	198	187 (94.4)	< 5	10 (5.1)
24 wks	707	649	636 (98.0)	0 (0)	13 (2.0)
25 wks	1134	1048	1035 (98.8)	< 5	12 (1.2)
26 wks	1396	1287	1276 (99.2)	< 5	8 (0.6)
27 wks	1639	1520	1506 (99.1)	< 5	11 (0.7)
28 wks	1881	1755	1744 (99.4)	< 5	7 (0.4)
Total	6994	6473	6399 (98.9)	12 (0.2)	62 (1.0)

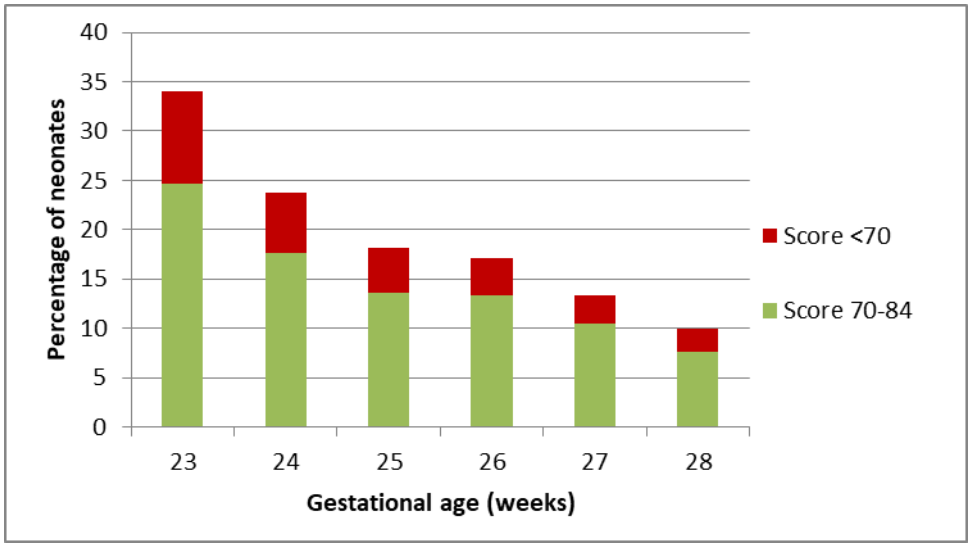


COMMENTS:

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-III Cognitive Composite scores rates by gestational age

GA	CNN-CNFUN linked cases (n)	CNN-CNFUN linked cases with cognitive data (n)	Median score (IQR)	Bayley-III ≥85 n (%)	Score 70-84 n (%)	Score <70 n (%)
22 wks	17	15	80 (75, 95)	7 (46.7)	6 (40.0)	< 5
23 wks	220	182	90 (80, 100)	120 (65.9)	45 (24.7)	17 (9.3)
24 wks	707	626	90 (85, 100)	477 (76.2)	110 (17.6)	39 (6.2)
25 wks	1134	1041	95 (85, 105)	851 (81.8)	142 (13.6)	48 (4.6)
26 wks	1396	1259	95 (85, 105)	1044 (82.9)	167 (13.3)	48 (3.8)
27 wks	1639	1502	95 (90, 105)	1303 (86.8)	157 (10.5)	42 (2.8)
28 wks	1881	1719	100 (90, 105)	1548 (90.0)	130 (7.6)	41 (2.4)
Total	6994	6344	95 (90, 105)	5350 (84.3)	757 (11.9)	237 (3.7)

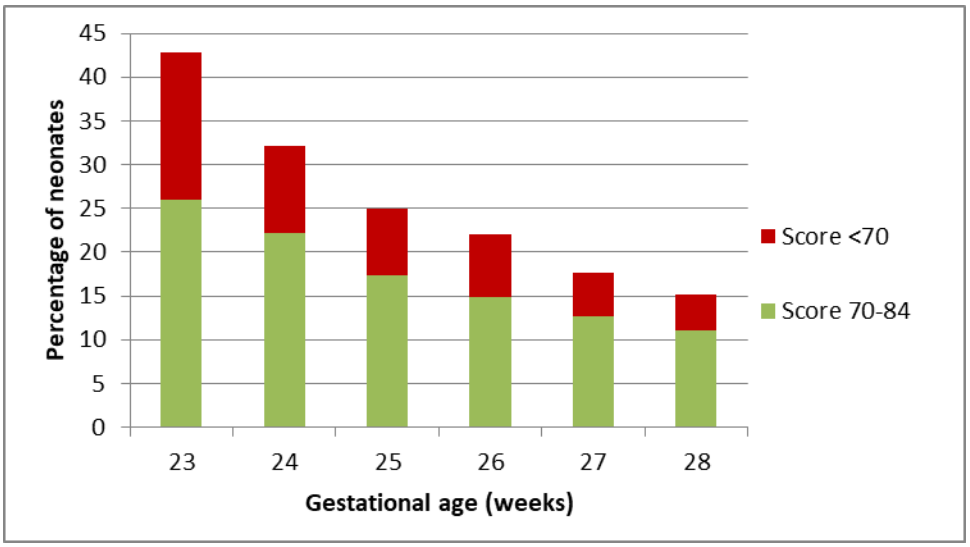


COMMENTS:

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

Presentation No 12: Bayley-III Motor Composite scores rates by gestational age

GA	CNN-CNFUN linked cases (n)	CNN-CNFUN linked cases with motor data (n)	Median score (IQR)	Bayley-III ≥85 n (%)	Score 70-84 n (%)	Score <70 n (%)
22 wks	17	15	79 (70, 88)	5 (33.3)	7 (46.7)	< 5
23 wks	220	173	88 (73, 97)	99 (57.2)	45 (26.0)	29 (16.8)
24 wks	707	599	91 (79, 97)	407 (67.9)	133 (22.2)	59 (9.9)
25 wks	1134	997	94 (85, 100)	748 (75.0)	173 (17.4)	76 (7.6)
26 wks	1396	1198	94 (85, 100)	933 (77.9)	177 (14.8)	88 (7.3)
27 wks	1639	1422	94 (88, 103)	1170 (82.3)	181 (12.7)	71 (5.0)
28 wks	1881	1650	97 (88, 103)	1398 (84.7)	182 (11.0)	70 (4.2)
Total	6994	6054	94 (85, 100)	4760 (78.6)	898 (14.8)	396 (6.5)

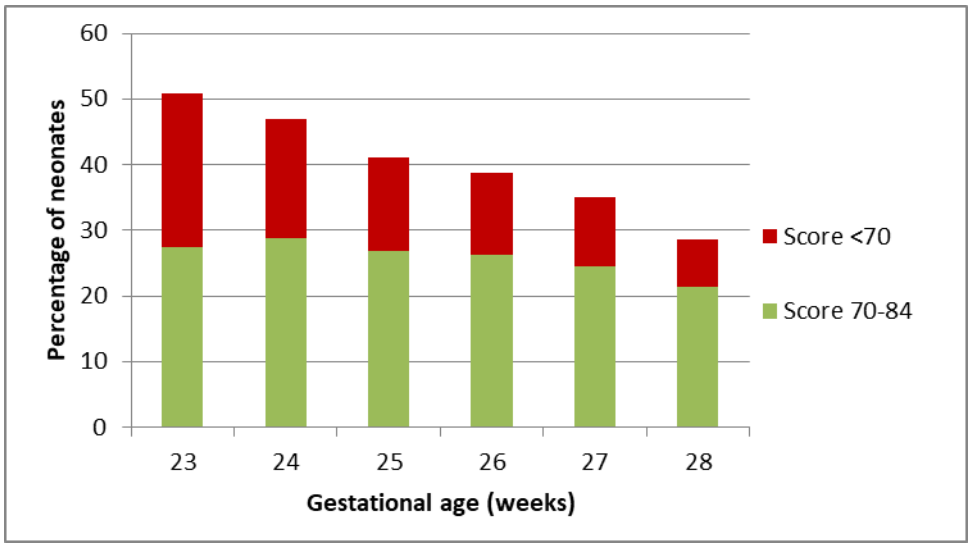


COMMENTS:

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

Presentation No 13: Bayley-III Language Composite scores rates by gestational age

GA	CNN-CNFUN linked cases (n)	CNN-CNFUN linked cases with language data (n)	Median score (IQR)	Bayley-III ≥85 n (%)	Score 70-84 n (%)	Score <70 n (%)
22 wks	17	13	77 (68, 91)	< 5	5 (38.5)	< 5
23 wks	220	175	83 (71, 97)	86 (49.1)	48 (27.4)	41 (23.4)
24 wks	707	603	86 (74, 97)	320 (53.1)	174 (28.9)	109 (18.1)
25 wks	1134	997	89 (77, 97)	587 (58.9)	268 (26.9)	142 (14.2)
26 wks	1396	1212	89 (77, 100)	742 (61.2)	317 (26.2)	153 (12.6)
27 wks	1639	1432	91 (79, 100)	930 (64.9)	352 (24.6)	150 (10.5)
28 wks	1881	1633	91 (83, 103)	1165 (71.3)	349 (21.4)	119 (7.3)
Total	6994	6065	89 (79, 100)	3834 (63.2)	1513 (25.0)	718 (11.8)



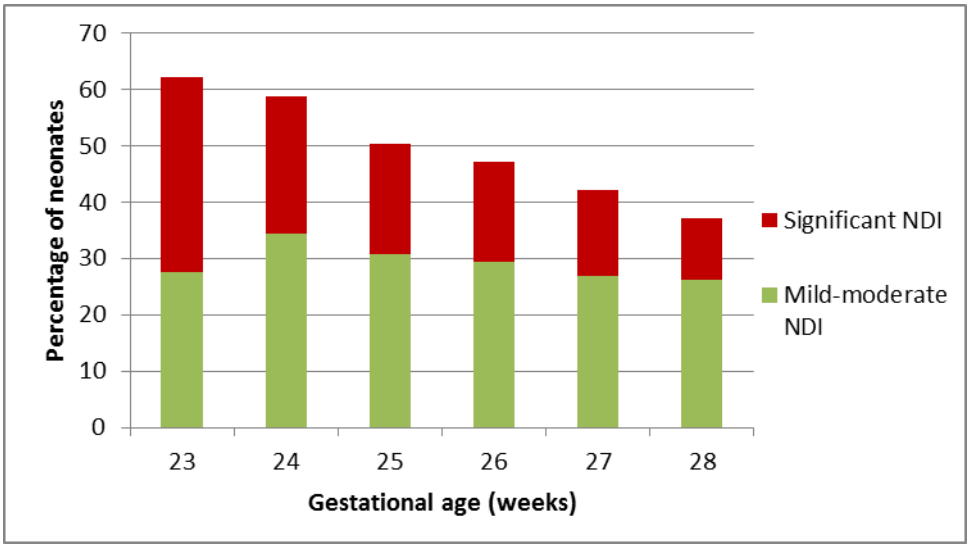
COMMENTS:

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

Presentation No 14: Neurodevelopmental impairment (NDI) rates by gestational age among survivors

GA	CNN-CNFUN linked cases with complete data (n)	No NDI n (%)	Mild-moderate NDI n (%)	Significant NDI	
				All n (%)	Severe only* n (%)
22 wks	17	5 (29.4)	7 (41.2)	5 (29.4)	< 5
23 wks	219	83 (37.9)	62 (28.3)	74 (33.8)	26 (11.9)
24 wks	706	296 (41.9)	236 (33.4)	174 (24.7)	65 (9.2)
25 wks	1126	564 (50.1)	345 (30.6)	217 (19.3)	75 (6.7)
26 wks	1394	749 (53.7)	405 (29.1)	240 (17.2)	66 (4.7)
27 wks	1631	944 (57.9)	446 (27.3)	241 (14.8)	66 (4.1)
28 wks	1877	1176 (62.6)	493 (26.3)	208 (11.1)	85 (4.5)
Total	6970	3817 (54.8)	1994 (28.6)	1159 (16.6)	385 (5.5)

*Severe NDI, a sub-category of significant NDI, includes children with any of the following: CP with GMFCS 4-5, Bayley-III cognitive, language or adaptive behavior composite <55, or bilateral visual impairment.



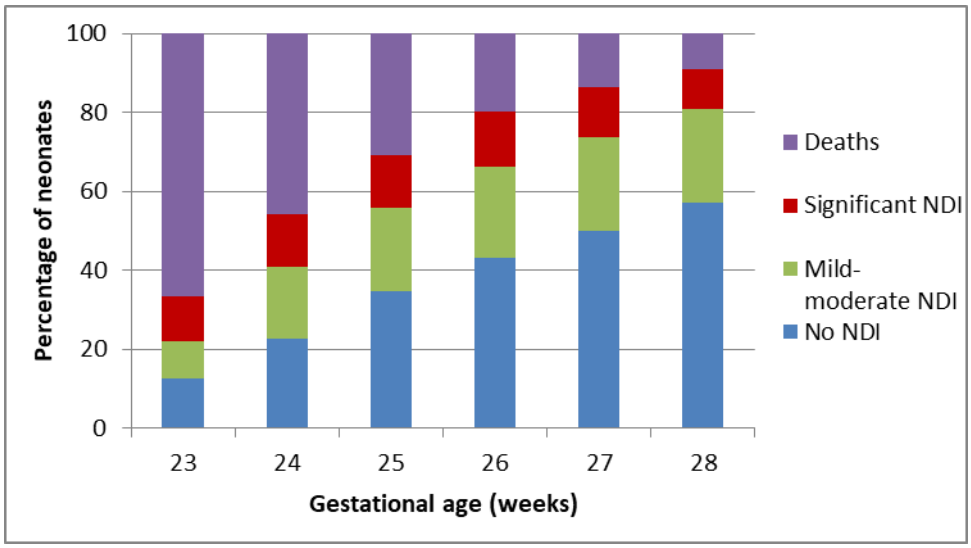
COMMENTS:

See page 16 for NDI definitions. Neurodevelopmental impairment rates decrease with increasing gestational age. Mild-moderate NDI includes children with any of the following: CP with GMFCS 1-2, Bayley-III motor, cognitive or language composite between 70-84, sensorineural/mixed hearing loss not requiring any amplification or implants, or unilateral visual impairment. Significant NDI includes children with any of the following: CP with GMFCS 3-4-5, Bayley-III motor, cognitive, language or adaptive

behavior composite <70, sensorineural/mixed hearing loss requiring amplification or implants, or bilateral visual impairment. Children considered to have a significant developmental delay which did not allow completion of the Bayley-III are also included. 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	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 wks	83	17	5 (29.4)	12 (70.6)	5 (29.4)	5 (6.0)	12 (14.5)
23 wks	657	220	83 (37.9)	136 (62.1)	74 (33.8)	83 (12.6)	146 (22.2)
24 wks	1301	707	296 (41.9)	410 (58.1)	174 (24.7)	296 (22.8)	533 (41.0)
25 wks	1635	1134	564 (50.1)	562 (49.9)	217 (19.3)	564 (34.5)	917 (56.1)
26 wks	1744	1396	749 (53.7)	645 (46.3)	240 (17.2)	749 (42.9)	1156 (66.3)
27 wks	1894	1639	944 (57.9)	687 (42.1)	241 (14.8)	944 (49.8)	1398 (73.8)
28 wks	2069	1881	1176 (62.6)	701 (37.4)	208 (11.1)	1176 (56.8)	1673 (80.9)
Total	9383	6994	3817 (54.8)	3153 (45.2)	1159 (16.6)	3817 (40.7)	5835(62.2)



This figure shows outcome distribution for all CNN-CNFUN-linked cases including death.

Presentation No 16: Hospitalization rates by gestational age

GA	CNN-CNFUN linked cases (n)	Any hospital admission n (%)	One hospital admission n (%)	>1 hospital admission n (%)
22 wks	17	7 (41.2)	< 5	< 5
23 wks	220	105 (47.7)	56 (25.5)	48 (21.8)
24 wks	707	324 (45.8)	184 (26.0)	138 (19.5)
25 wks	1134	424 (37.4)	238 (21.0)	185 (16.3)
26 wks	1396	473 (33.9)	243 (17.4)	226 (16.2)
27 wks	1639	520 (31.7)	324 (19.8)	193 (11.8)
28 wks	1881	549 (29.2)	352 (18.7)	192 (10.2)
Total	6994	2402 (34.3)	1400 (20.0)	986 (14.1)

Presentation No 17a: Use of aids at home from discharge to follow-up visit by gestational age

GA	CNN-CNFUN linked cases (n)	Use of any aids at home* n (%)	Gavage feeding, gastrostomy or jejunostomy n (%)	Tracheostomy n (%)	Any mobility aid n (%)
22 wks	17	8 (47.1)	4 (23.5)	0 (0)	1 (5.9)
23 wks	220	108 (49.1)	47 (21.4)	8 (3.6)	25 (11.4)
24 wks	707	283 (40.0)	105 (14.9)	8 (1.1)	46 (6.5)
25 wks	1134	328 (28.9)	109 (9.6)	15 (1.3)	54 (4.8)
26 wks	1396	313 (22.4)	105 (7.5)	8 (0.6)	68 (4.9)
27 wks	1639	297 (18.1)	96 (5.9)	10 (0.6)	103 (6.3)
28 wks	1881	290 (15.4)	109 (5.8)	10 (0.5)	90 (4.8)
Total	6994	1627 (23.3)	575 (8.2)	59 (0.8)	387 (5.5)

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

Presentation No 17b: Aids at home still in use at the follow-up visit by gestational age

GA	CNN-CNFUN linked cases (n)	Use of any aids at home* n (%)	Gavage feeding, gastrostomy or jejunostomy n (%)	Tracheostomy n (%)
22 wks	17	1 (5.9)	0 (0)	0 (0)
23 wks	220	36 (16.4)	20 (9.1)	6 (2.7)
24 wks	707	100 (14.1)	50 (7.1)	5 (0.7)
25 wks	1134	89 (7.9)	42 (3.7)	12 (1.1)
26 wks	1396	89 (6.4)	43 (3.1)	4 (0.3)
27 wks	1639	100 (6.1)	35 (2.1)	5 (0.3)
28 wks	1881	90 (4.8)	30 (1.6)	4 (0.2)
Total	6994	505 (7.2)	220 (3.2)	36 (0.5)

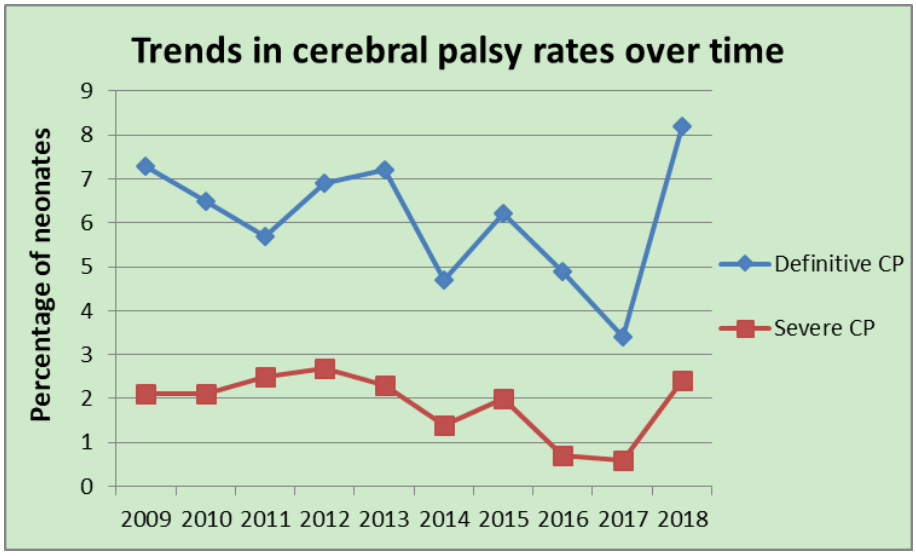
*Aids at home include the use of any of the following items: apnea monitor; pulse oximeter; supplemental O2; respiratory/CPAP; gavage feeding; gastrostomy or jejunostomy; ileostomy/colostomy; tracheostomy; adapted wheelchair or stroller; braces, splints, or orthoses; and walker.

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

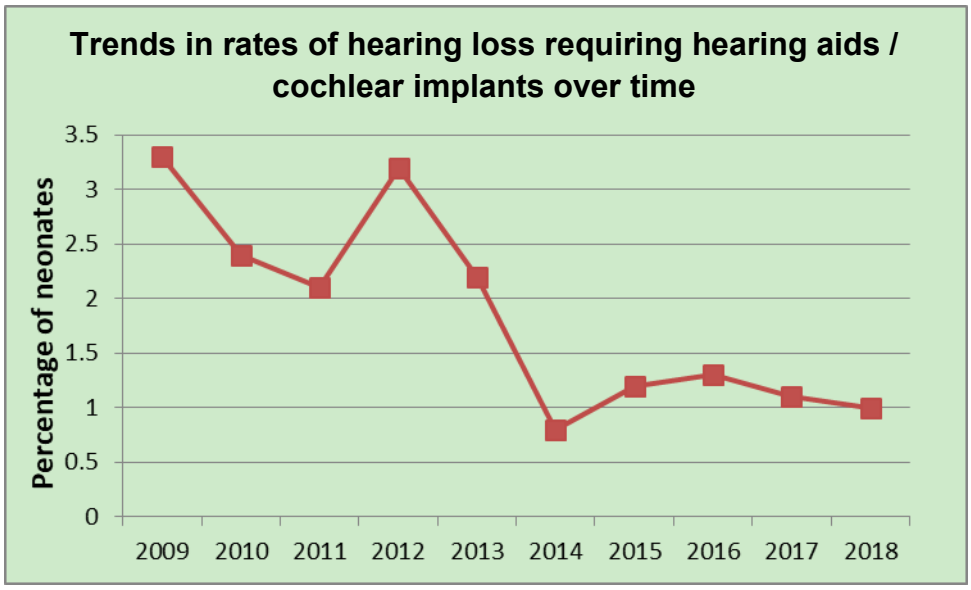
Year of birth	CNFUN complete data (n)	Missing CP data (n)	No CP n (%)	Suspected CP n (%)	Definitive CP n (%)	Missing CP GMFCS (n)	CP GMFCS 1-2 n (%)	CP GMFCS 3-5 n (%)
2009	647	12	581 (89.8)	19 (2.9)	47 (7.3)	7	26 (4.0)	14 (2.1)
2010	997	16	890 (89.3)	42 (4.2)	65 (6.5)	11	33 (3.3)	21 (2.1)
2011	827	25	754 (91.2)	26 (3.1)	47 (5.7)	4	22 (2.6)	21 (2.5)
2012	669	7	598 (89.4)	25 (3.7)	46 (6.9)	3	25 (3.7)	18 (2.7)
2013	607	8	544 (89.6)	19 (3.1)	44 (7.2)	2	28 (4.6)	14 (2.3)
2014	641	8	593 (92.5)	18 (2.8)	30 (4.7)	1	20 (3.1)	9 (1.4)
2015	674	12	610 (90.5)	22 (3.3)	42 (6.2)	2	26 (3.8)	14 (2.0)
2016	711	2	657 (92.4)	19 (2.7)	35 (4.9)	9	21 (3.0)	5 (0.7)
2017	612	10	567 (92.7)	24 (3.9)	21 (3.4)	1	16 (2.6)	4 (0.6)
2018	500	9	442 (88.4)	17 (3.4)	41 (8.2)	1	28 (5.5)	12 (2.4)
2009-2018	6885	109	6236 (90.6)	231 (3.4)	418 (6.1)	41	245 (3.5)	132 (1.9)



COMMENTS: Cerebral palsy rates fell until 2017 births. In 2018, COVID-19 restrictions may have biased towards seeing more children with CP. Data are not adjusted for risk factors. The majority of cerebral palsy cases are mild with GMFCS ≤2. Higher attrition rates in the later years may impact the results.

Presentation No 19: Trends in hearing status over time

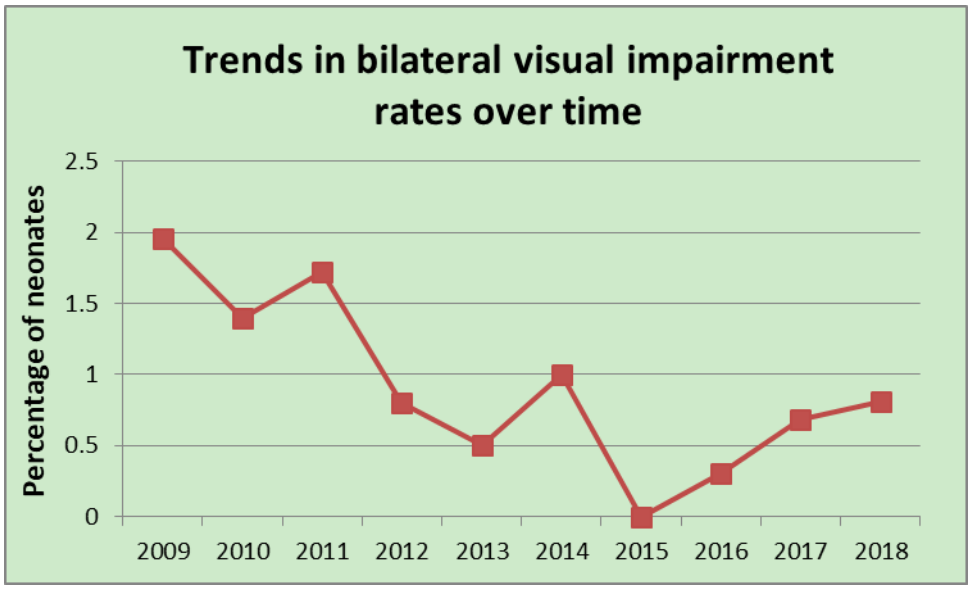
Year of birth	**CNFUN complete data** (n)	**Missing hearing data** (n)	**Normal hearing** n (%)	**Mild-moderate hearing loss** n (%)	**Requiring hearing aids/ cochlear implants** n (%)
2009	643	16	588 (91.5)	34 (5.3)	21 (3.3)
2010	988	25	911 (92.2)	53 (5.4)	24 (2.4)
2011	819	33	768 (93.8)	34 (4.2)	17 (2.1)
2012	663	13	623 (94.0)	19 (2.9)	21 (3.2)
2013	602	13	569 (94.5)	20 (3.3)	13 (2.2)
2014	641	8	619 (96.6)	17 (2.7)	5 (0.8)
2015	675	11	642 (95.1)	25 (3.7)	8 (1.2)
2016	710	3	668 (94.1)	33 (4.7)	9 (1.3)
2017	617	5	578 (93.7)	32 (5.2)	7 (1.1)
2018	498	11	477 (95.8)	16 (3.2)	5 (1.0)
2009-2018	6856	138	6443 (94.0)	283 (4.1)	130 (1.9)



COMMENTS: A mild-moderate hearing loss is any hearing loss identified by an audiologist as not requiring hearing aid(s) or cochlear implant(s). Higher attrition rates in the later years may impact the results.

Presentation No 20: Trends in visual impairment rates over time

Year of birth	CNFUN complete data (n)	Missing vision data (n)	Normal vision n (%)	Bilateral visual impairment n (%)
2009	613	46	597 (97.4)	12 (2.0)
2010	931	82	917 (98.5)	13 (1.4)
2011	755	97	741 (98.2)	13 (1.7)
2012	622	54	616 (99.0)	5 (0.8)
2013	565	50	562 (99.5)	<5
2014	599	50	592 (98.8)	6 (1.0)
2015	637	49	635 (99.7)	<5
2016	675	38	673 (99.7)	<5
2017	584	38	578 (99.0)	<5
2018	492	17	488 (99.2)	<5
2009-2018	6473	521	6399 (98.9)	62 (1.0)

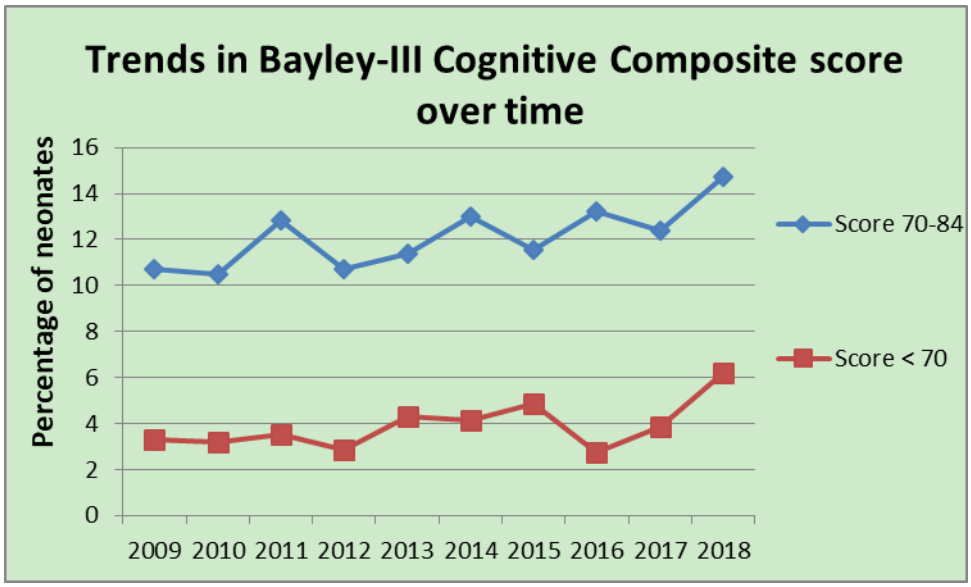


COMMENTS:

Visual impairment at 18 months corrected age is now a rare complication of prematurity. Higher attrition rates in the later years may impact the results.

Presentation No 21: Trends in Bayley-III Cognitive Composite scores over time

Year of birth	**CNFUN complete data** (n)	**Missing Bayley-III cognitive score** (n)	**Median score** (IQR)	**Bayley-III ≥85** n (%)	**Score 70-84** n (%)	**Score <70** n (%)
2009	608	51	95 (90, 105)	523 (86.0)	65 (10.7)	20 (3.3)
2010	943	71	95 (90, 105)	813 (86.3)	99 (10.5)	30 (3.2)
2011	794	58	95 (90, 105)	664 (83.6)	102 (12.9)	28 (3.5)
2012	627	49	95 (90, 105)	542 (86.4)	67 (10.7)	18 (2.9)
2013	561	54	95 (90, 105)	473 (84.3)	64 (11.4)	24 (4.3)
2014	601	48	95 (85, 105)	498 (82.9)	78 (13.0)	25 (4.2)
2015	641	45	95 (90, 105)	536 (83.6)	74 (11.5)	31 (4.8)
2016	659	54	95 (90, 105)	554 (84.1)	87 (13.2)	18 (2.7)
2017	572	50	95 (85, 105)	479 (83.7)	71 (12.4)	22 (3.9)
2018	339	170	95 (85, 105)	268 (79.1)	50 (14.7)	21 (6.2)
2009-2018	6344	650	95 (90, 105)	5350 (84.3)	757 (11.9)	237 (3.7)

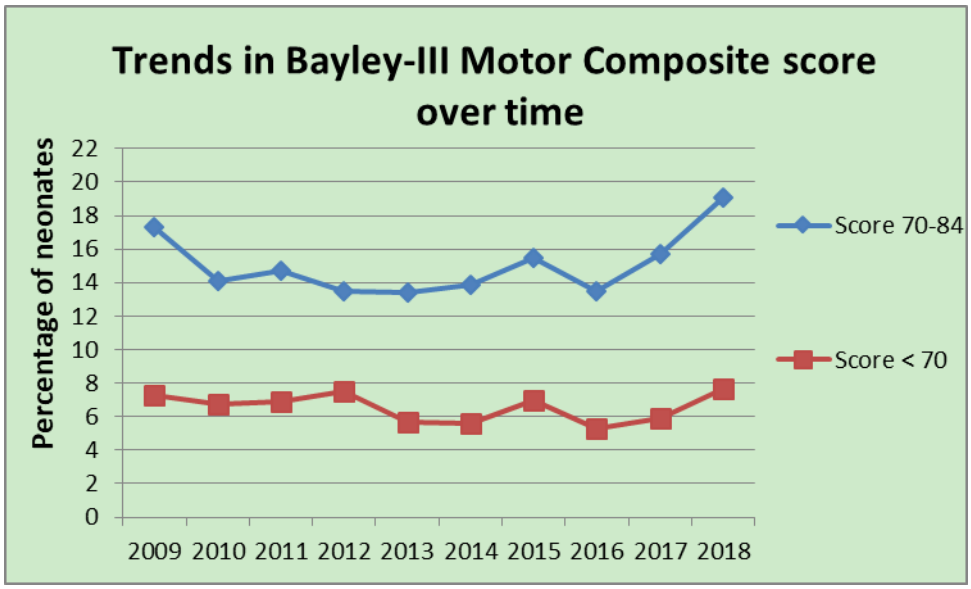


COMMENTS:

Results are not adjusted for risk factors. Rates of lower cognitive scores have not changed appreciably. Higher attrition rates in the later years may impact the results.

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

Year of birth	CNFUN complete data (n)	Missing Bayley-III motor score (n)	Median score (IQR)	Bayley-III ≥85 n (%)	Score 70-84 n (%)	Score <70 n (%)
2009	579	80	94 (85, 100)	437 (75.5)	100 (17.3)	42 (7.3)
2010	900	113	94 (85, 100)	713 (79.1)	127 (14.1)	61 (6.8)
2011	769	83	94 (85, 100)	603 (78.4)	113 (14.7)	53 (6.9)
2012	613	63	94 (85, 100)	484 (79.0)	83 (13.5)	46 (7.5)
2013	530	85	94 (85, 100)	429 (80.9)	71 (13.4)	30 (5.7)
2014	570	79	94 (88, 100)	459 (80.5)	79 (13.9)	32 (5.6)
2015	605	81	94 (85, 100)	469 (77.5)	94 (15.5)	42 (6.9)
2016	623	90	94 (88, 103)	506 (81.2)	84 (13.5)	33 (5.3)
2017	540	82	94 (85, 100)	423 (78.3)	85 (15.7)	32 (5.9)
2018	325	184	94 (82, 100)	238 (73.2)	62 (19.1)	25 (7.7)
2009-2018	6054	940	94 (85, 100)	4760 (78.6)	898 (14.8)	396 (6.5)

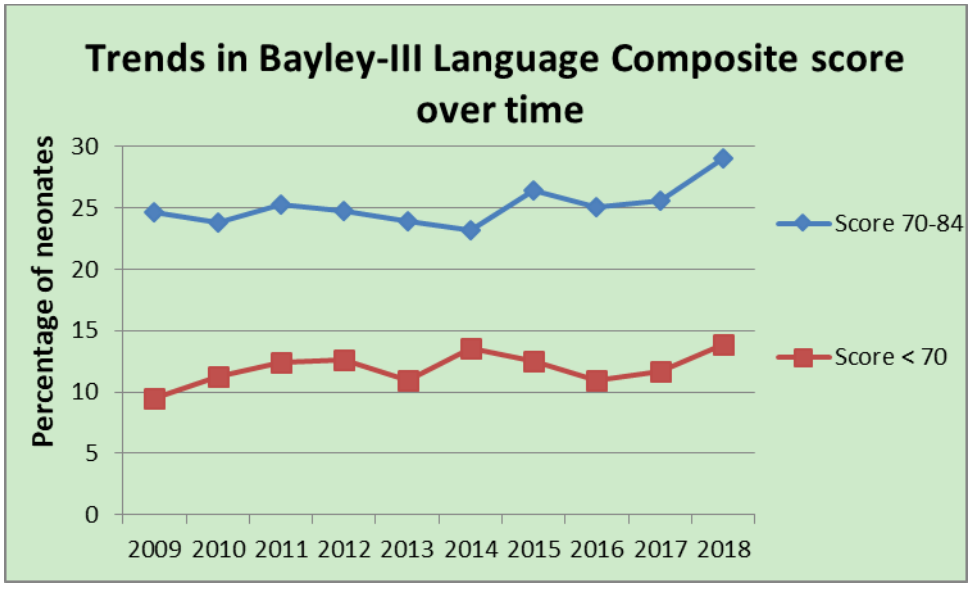


COMMENTS:

Results are not adjusted for risk factors. Rates of lower motor scores have not changed appreciably. Higher attrition rates in the later years may impact the results.

Presentation No 23: Trends in Bayley-III Language Composite scores over time

Year of birth	CNFUN complete data (n)	Missing Bayley-III language score n (%)	Median score (IQR)	Bayley-III ≥85 n (%)	Score 70-84 n (%)	Score <70 n (%)
2009	581	78	91 (79, 100)	383 (65.9)	143 (24.6)	55 (9.5)
2010	915	98	89 (79, 100)	594 (64.9)	218 (23.8)	103 (11.3)
2011	774	78	91 (77, 100)	482 (62.3)	196 (25.3)	96 (12.4)
2012	616	60	90 (79, 100)	386 (62.7)	152 (24.7)	78 (12.7)
2013	519	96	91 (79, 100)	338 (65.1)	124 (23.9)	57 (11.0)
2014	568	81	89 (77, 100)	359 (63.2)	132 (23.2)	77 (13.6)
2015	613	73	89 (77, 100)	374 (61.0)	162 (26.4)	77 (12.6)
2016	623	90	89 (79, 100)	399 (64.0)	156 (25.0)	68 (10.9)
2017	532	90	90 (77, 100)	334 (62.8)	136 (25.6)	62 (11.7)
2018	324	185	89 (77, 99)	185 (57.1)	94 (29.0)	45 (13.9)
2009-2018	6065	929	89 (79, 100)	3834 (63.2)	1513 (25.0)	718 (11.8)



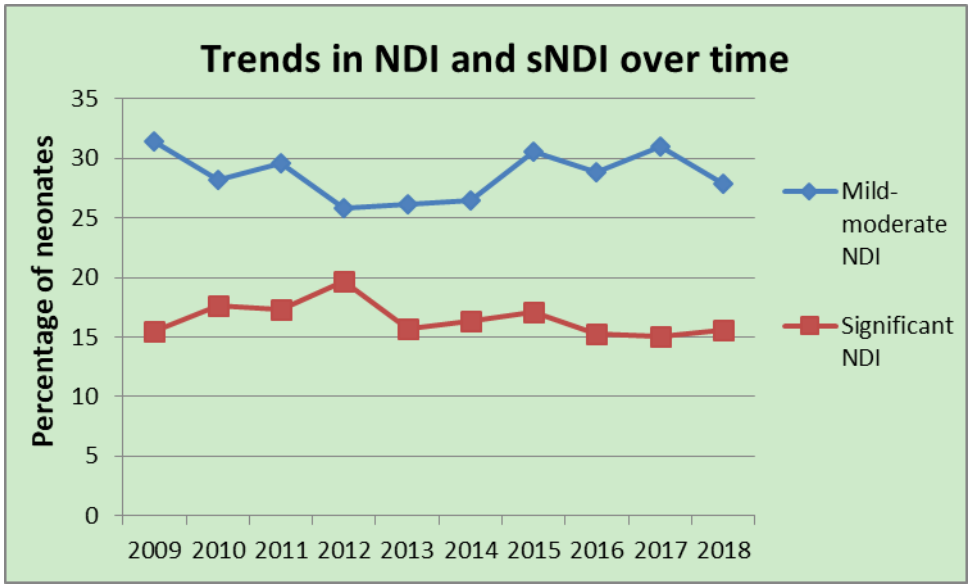
COMMENTS:

Results are not adjusted for risk factors. Rates of lower language scores have not changed appreciably. Higher attrition rates in the later years may impact the results.

Presentation No 24: Trends in neurodevelopmental impairment (NDI) rates over time

Year of birth	CNFUN complete data (n)	Missing data (n)	No NDI n (%)	Mild-moderate NDI n (%)	Significant NDI	
					All n (%)	Severe only* n (%)
2009	653	6	347 (53.1)	205 (31.4)	101 (15.5)	35 (5.4)
2010	1012	1	550 (54.3)	285 (28.2)	178 (17.6)	66 (6.5)
2011	848	4	450 (53.1)	251 (29.6)	147 (17.3)	41 (4.8)
2012	674	2	367 (54.5)	174 (25.8)	133 (19.7)	39 (5.8)
2013	612	3	356 (58.2)	160 (26.1)	96 (15.7)	34 (5.6)
2014	647	2	370 (57.2)	171 (26.4)	106 (16.4)	34 (5.3)
2015	684	2	358 (52.3)	209 (30.6)	117 (17.1)	38 (5.6)
2016	712	1	398 (55.9)	205 (28.8)	109 (15.3)	36 (5.1)
2017	620	2	335 (54.0)	192 (31.0)	93 (15.0)	30 (4.8)
2018	508	1	287 (56.5)	142 (27.9)	79 (15.6)	32 (6.3)
2009-2018	6970	24	3817 (54.8)	1994 (28.6)	1159 (16.6)	385 (5.5)

*Severe NDI, a sub-category of significant NDI, includes children with any of the following: CP with GMFCS 4-5, Bayley-III cognitive, language or adaptive behavior composite <55, or bilateral visual impairment.



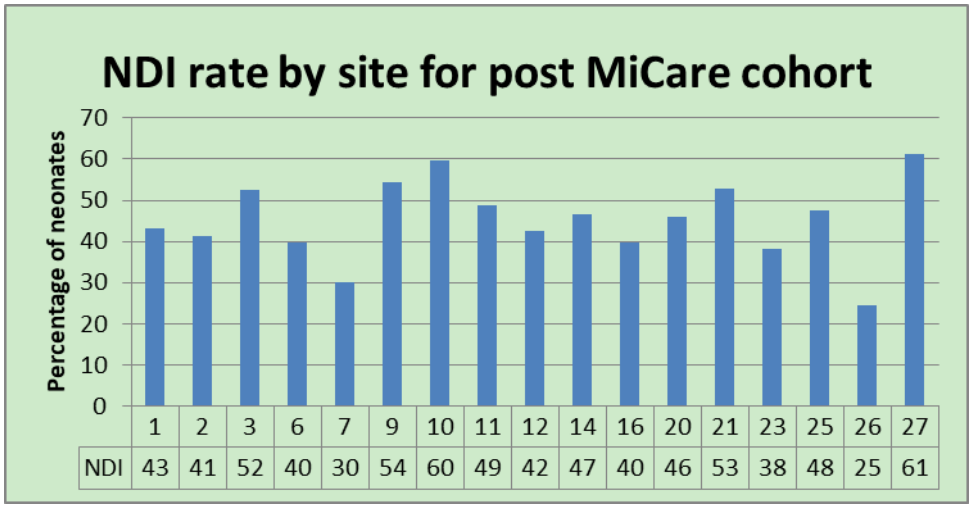
COMMENTS: See page 16 for NDI definitions. There has not been a clinically important change in NDI rates over time. Significant NDI includes children with any of the following: CP with GMFCS 3-4-5, Bayley-III motor, cognitive, language or adaptive behavior composite <70, sensorineural/mixed hearing loss requiring amplification or implants, or bilateral visual impairment. Children considered to have a significant developmental delay which did not allow completion of the Bayley-III are also included. Rates have not been adjusted for risk factors and higher attrition rates in the later years may impact the results.

G. Post-MiCare Cohort Site Comparisons – Crude

Presentation No 25: Neurodevelopmental impairment rates for post-MiCare cohort (Births October 1, 2011- December 31, 2018)*

Site	CNFUN (n)	No NDI n (%)	Any NDI n (%)	CP 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	410	233(56.8)	177(43.2)	26(6.3)	18(4.4)	< 5%	73(17.8)	117(28.5)	38(9.3)
2	309	181(58.6)	128(41.4)	15(4.9)	31(10)	0(0)	31(10)	89(28.8)	27(8.7)
3	84	40(47.6)	44(52.4)	< 5%	< 5%	< 5%	17(20.2)	33(39.3)	15(17.9)
6	607	366(60.3)	241(39.7)	21(3.5)	20(3.3)	8(1.3)	113(18.6)	146(24.1)	76(12.5)
7	20	14(70)	6(30)	0(0)	0(0)	0(0)	<1 5%	6(30)	< 15%
9	46	21(45.7)	25(54.3)	5(10.9)	< 5%	0(0)	11(23.9)	14(30.4)	8(17.4)
10	141	57(40.4)	84(59.6)	10(7.1)	15(10.6)	< 5%	38(27)	71(50.4)	26(18.4)
11	455	233(51.2)	222(48.8)	39(8.6)	37(8.1)	< 5%	107(23.5)	149(32.7)	77(16.9)
12	243	140(57.6)	103(42.4)	23(9.5)	< 5%	< 5%	58(23.9)	68(28)	36(14.8)
14	249	133(53.4)	116(46.6)	11(4.4)	14(5.6)	5(2)	48(19.3)	83(33.3)	24(9.6)
16	636	384(60.4)	252(39.6)	34(5.3)	22(3.5)	< 5%	74(11.6)	184(28.9)	101(15.9)
20	243	131(53.9)	112(46.1)	12(4.9)	30(12.3)	< 5%	45(18.5)	76(31.3)	39(16)
21	123	58(47.2)	65(52.8)	12(9.8)	< 5%	0(0)	29(23.6)	53(43.1)	26(21.1)
23	89	55(61.8)	34(38.2)	9(10.1)	5(5.6)	< 5%	12(13.5)	23(25.8)	13(14.6)
25	812	426(52.5)	386(47.5)	22(2.7)	22(2.7)	< 5%	145(17.9)	318(39.2)	144(17.7)
26	57	43(75.4)	14(24.6)	< 5%	< 10%	0(0)	7(12.3)	11(19.3)	< 10%
27	31	12(38.7)	19(61.3)	< 5%	0(0)	0(0)	7(22.6)	14(45.2)	5(16.1)

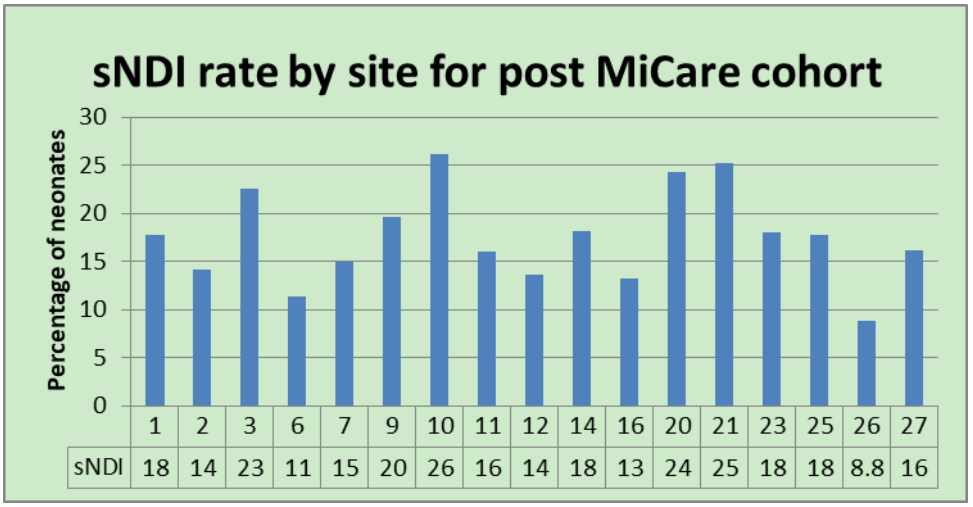
*Cells with less than 5 show only % , rounded up to a multiple of 5%.



Presentation No 26: Significant neurodevelopmental impairment rates for post-MiCare cohort
(Births October 1, 2011- December 31, 2018)*

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	410	337(82.2)	73(17.8)	15(3.7)	11(2.7)	< 5%	24(5.9)	32(7.8)	8(2)
2	309	265(85.8)	44(14.2)	6(1.9)	5(1.6)	0(0)	6(1.9)	29(9.4)	9(2.9)
3	84	65(77.4)	19(22.6)	< 5%	< 5%	0(0)	5(6)	14(16.7)	< 5%
6	607	538(88.6)	69(11.4)	5(0.8)	5(0.8)	5(0.8)	23(3.8)	52(8.6)	18(3)
7	20	17(85)	< 15%	0(0)	0(0)	0(0)	< 15%	< 15%	< 10%
9	46	37(80.4)	9(19.6)	< 5%	0(0)	0(0)	< 10%	< 10%	< 10%
10	141	104(73.8)	37(26.2)	< 5%	5(3.5)	< 5%	12(8.5)	30(21.3)	7(5)
11	455	382(84)	73(16)	10(2.2)	< 5%	< 5%	39(8.6)	35(7.7)	17(3.7)
12	243	210(86.4)	33(13.6)	< 5%	< 5%	< 5%	17(7)	24(9.9)	10(4.1)
14	249	204(81.9)	45(18.1)	6(2.4)	< 5%	5(2)	20(8)	21(8.4)	7(2.8)
16	636	552(86.8)	84(13.2)	6(0.9)	10(1.6)	< 5%	21(3.3)	51(8)	21(3.3)
20	243	184(75.7)	59(24.3)	< 5%	< 5%	< 5%	19(7.8)	46(18.9)	11(4.5)
21	123	92(74.8)	31(25.2)	6(4.9)	< 5%	0(0)	13(10.6)	23(18.7)	10(8.1)
23	89	73(82)	16(18)	5(5.6)	< 5%	< 5%	6(6.7)	8(9)	< 5%
25	812	668(82.3)	144(17.7)	11(1.4)	15(1.8)	< 5%	34(4.2)	100(12.3)	33(4.1)
26	57	52(91.2)	5(8.8)	0(0)	< 5%	0(0)	< 5%	< 10%	0(0)
27	31	26(83.9)	5(16.1)	< 5%	0(0)	0(0)	< 5%	< 10%	< 10%

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

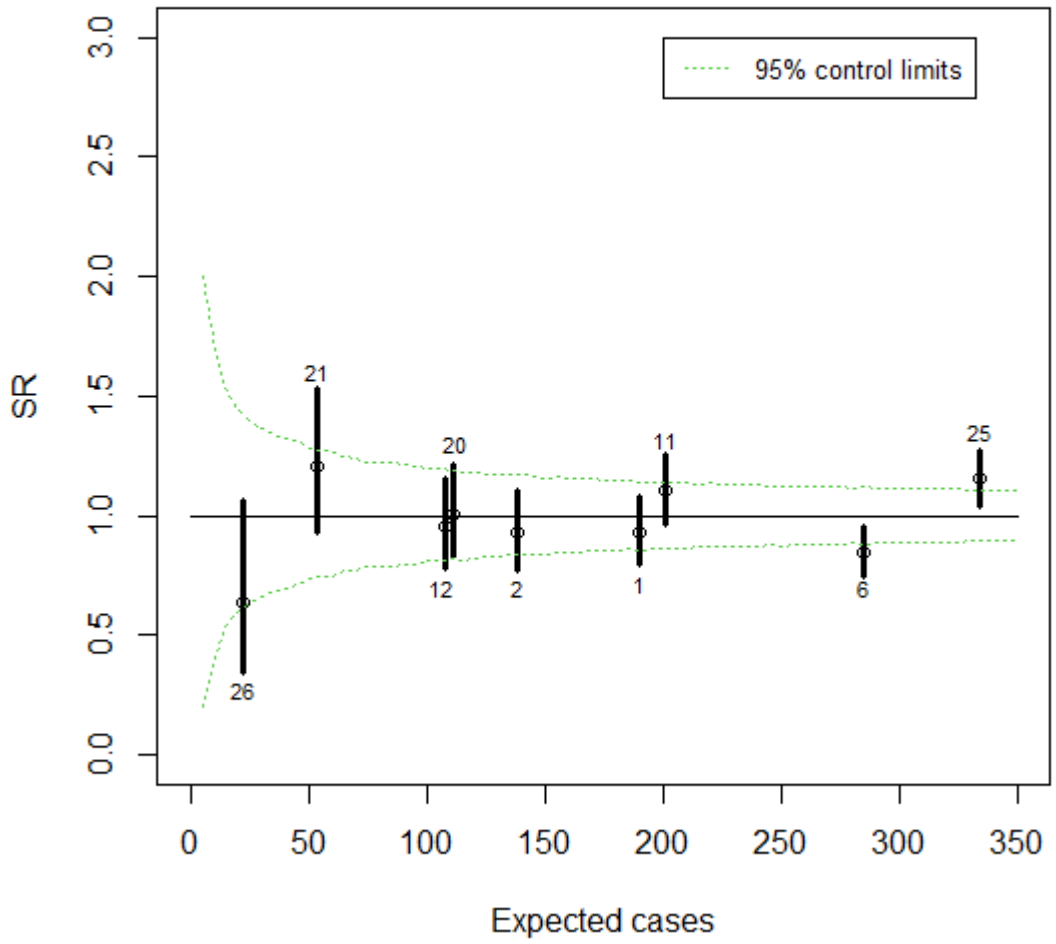


H. Post-MiCare Cohort Site Comparisons – Adjusted Standardized Ratios by Site

Presentation No 27: Adjusted standardized ratios by site
Neurodevelopmental impairment (NDI) – Post-MiCare cohort
(Births October 1, 2011- December 31, 2018)

Site	Children (n)	Follow-up rate (%)	Included (Yes/No)	NDI (n)	Adjusted expected NDI (n)	Adjusted standardized ratio (95%CI)
1	410	75.1	Y	177	190	0.93 (0.80, 1.08)
2	309	78.7	Y	128	138	0.93 (0.77, 1.10)
3	84	58.7	N	44		
4	6	13.3	N	1		
5	7	0.8	N	6		
6	607	71.2	Y	241	285	0.85 (0.74, 0.96)
7	20	13.2	N	6		
8	5	0.8	N	2		
9	46	24.5	N	25		
10	141	60.5	N	84		
11	455	85.7	Y	222	201	1.10 (0.96, 1.26)
12	243	83	Y	103	108	0.95 (0.78, 1.16)
14	249	63.4	N	116		
15	15	13.2	N	5		
16	636	62	N	252		
17	4	1.3	N	0		
18	9	6.3	N	5		
19	5	2.7	N	2		
20	243	73.7	Y	112	111	1.01 (0.83, 1.21)
21	123	70	Y	65	54	1.20 (0.93, 1.53)
22	12	14.5	N	5		
23	89	23.9	N	34		
25	812	71.7	Y	386	334	1.16 (1.04, 1.28)
26	57	70.4	Y	14	22	0.64 (0.35, 1.07)
27	31	68.9	N	19		

1. Sites with <20 participants for the 6 year post MiCare cohort period 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 ≥10 mm, intraparenchymal hemorrhage or periventricular leukomalacia.

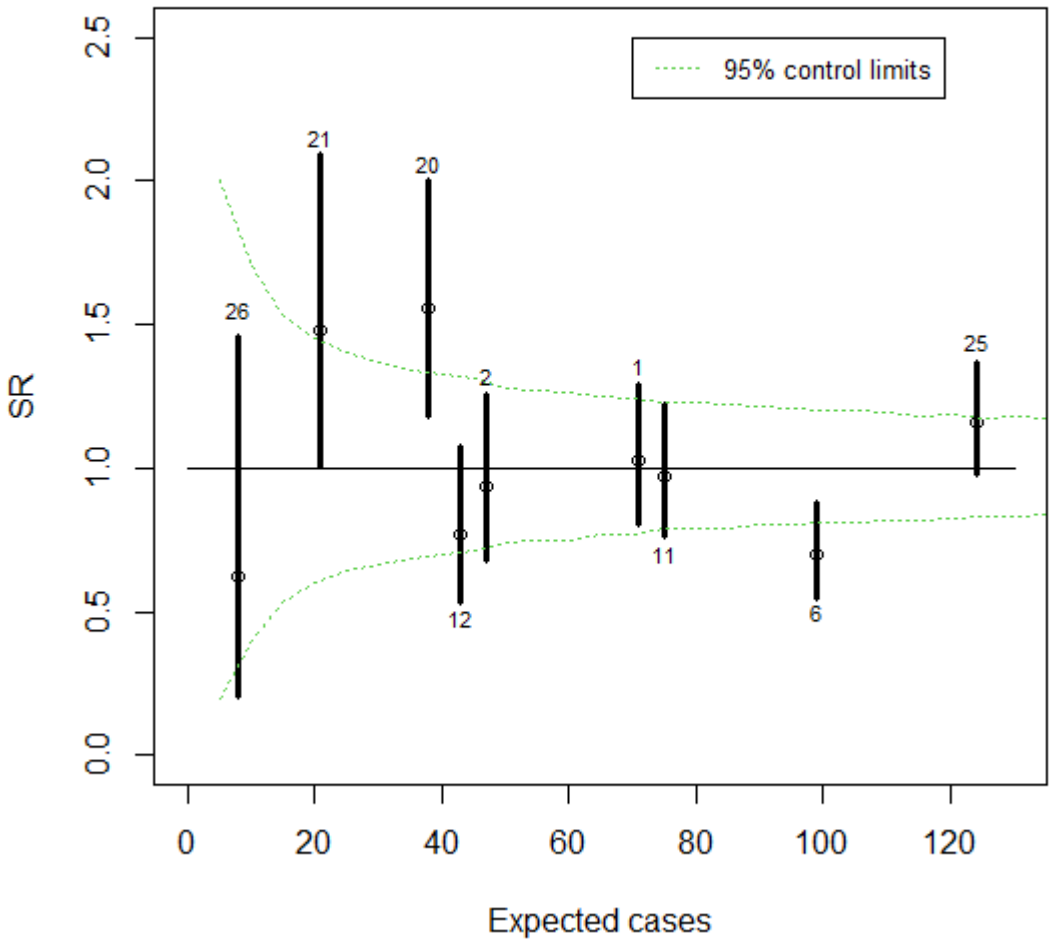


COMMENTS:
Sites with points outside the green "funnel" represent higher or lower adjusted NDI rates than expected. When the 95% confidence interval does not cross 1, the results are statistically significant. Therefore, one site (25) has a statistically higher NDI rate, and one site (6) has a statistically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

Presentation No 28: Adjusted standardized ratios by site
Significant neurodevelopmental impairment (sNDI) – Post-MiCare cohort
(Births October 1, 2011- December 31, 2018)

Site	Children (n)	Follow-up rate (%)	Included (Yes/No)	sNDI (n)	Adjusted expected sNDI (n)	Adjusted standardized ratio (95%CI)
1	410	75.1	Y	73	71	1.03 (0.81, 1.29)
2	309	78.7	Y	44	47	0.94 (0.68, 1.26)
3	84	58.7	N	19		
4	6	13.3	N	0		
5	7	0.8	N	3		
6	607	71.2	Y	69	99	0.70 (0.54, 0.88)
7	20	13.2	N	3		
8	5	0.8	N	1		
9	46	24.5	N	9		
10	141	60.5	N	37		
11	455	85.7	Y	73	75	0.97 (0.76, 1.22)
12	243	83	Y	33	43	0.77 (0.53, 1.08)
14	249	63.4	N	45		
15	15	13.2	N	2		
16	636	62	N	84		
17	4	1.3	N	0		
18	9	6.3	N	2		
19	5	2.7	N	1		
20	243	73.7	Y	59	38	1.55 (1.18, 2.00)
21	123	70	Y	31	21	1.48 (1.00, 2.10)
22	12	14.5	N	4		
23	89	23.9	N	16		
25	812	71.7	Y	144	124	1.16 (0.98, 1.37)
26	57	70.4	Y	5	8	0.63 (0.30, 1.46)
27	31	68.9	N	5		

1. Sites with <20 participants for the 6 year post MiCare cohort period and/or <70% follow-up rates are excluded.
2. Model is adjusted for gestational age, sex, antenatal steroids, severity of illness (SNAP>20), severe retinopathy of prematurity defined as stage 3 or greater in either eye or treatment with laser or injections of anti-vascular endothelial growth factor, nosocomial infection and brain injury, defined as any grade 3 or 4 intraventricular hemorrhage, ventricular dilatation ≥10 mm, intraparenchymal hemorrhage or periventricular leukomalacia.

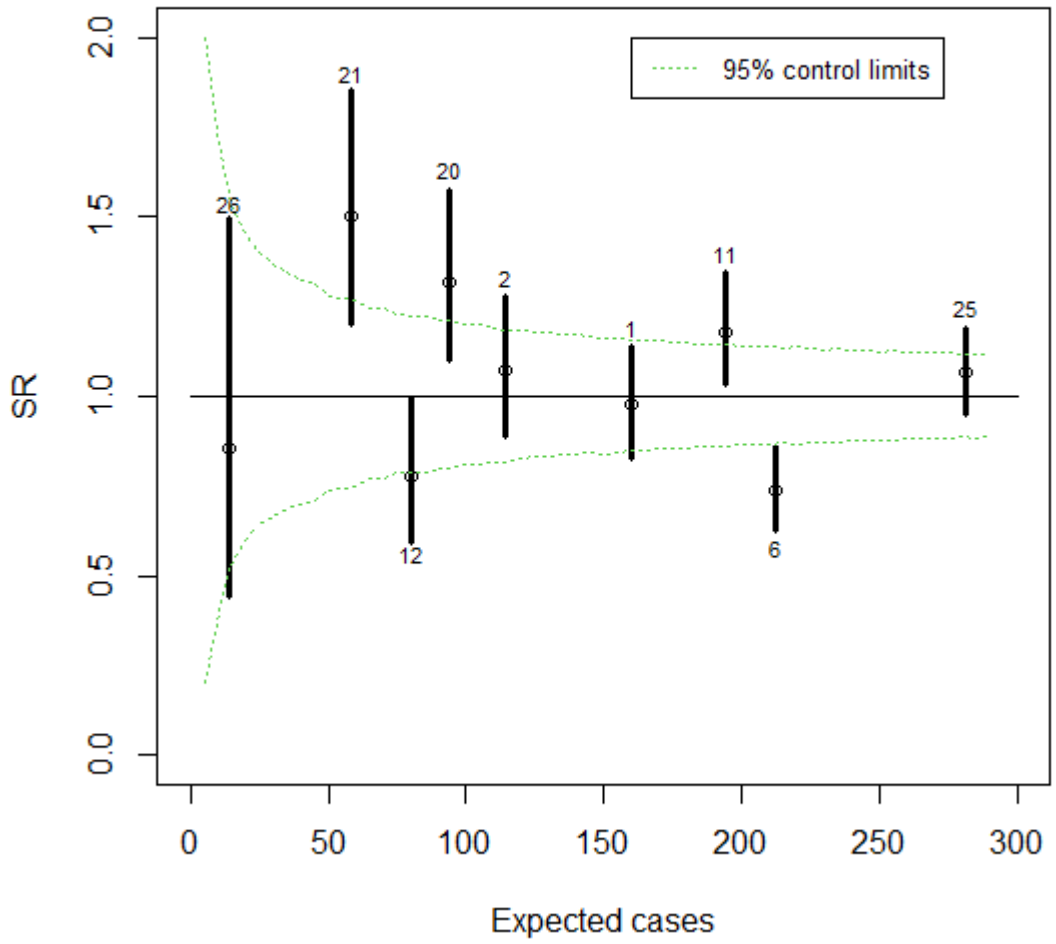


COMMENTS:
Sites with points outside the green "funnel" represent higher or lower adjusted sNDI rates than expected. When the 95% confidence interval does not cross 1, the results are statistically significant. Therefore, two sites (20 and 21) have a statistically higher, and one site (6) has a statistically lower sNDI rate.

Presentation No 29: Adjusted standardized ratios by site
Significant neurodevelopmental impairment (sNDI) or death – Post-MiCare cohort
(Births October 1, 2011- December 31, 2018)

Site	Children (n)	Follow-up rate (%)	Included (Yes/No)	sNDI or death (n)	Adjusted expected outcome (n)	Adjusted standardized ratio (95%CI)
1	496	75.1	Y	156	160	0.98 (0.83, 1.14)
2	388	78.7	Y	122	114	1.07 (0.89, 1.28)
3	119	58.7	N	54		
4	16	13.3	N	10		
5	154	0.8	N	150		
6	694	71.2	Y	156	212	0.74 (0.62, 0.86)
7	34	13.2	N	17		
8	116	0.8	N	112		
9	73	24.5	N	36		
10	188	60.5	N	84		
11	611	85.7	Y	229	194	1.18 (1.03, 1.34)
12	273	83	Y	62	80	0.78 (0.59, 0.99)
14	314	63.4	N	110		
15	51	13.2	N	38		
16	841	62	N	289		
17	71	1.3	N	66		
18	40	6.3	N	33		
19	32	2.7	N	28		
20	311	73.7	Y	124	94	1.32 (1.10, 1.57)
21	182	70	Y	87	58	1.50 (1.20, 1.85)
22	32	14.5	N	24		
23	182	23.9	N	109		
25	968	71.7	Y	299	281	1.06 (0.95, 1.19)
26	64	70.4	Y	12	14	0.86 (0.44, 1.50)
27	35	68.9	N	9		

1. Sites with <20 participants for the 6 year post MiCare 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 ≥10 mm, intraparenchymal hemorrhage or periventricular leukomalacia.



COMMENTS:
Sites with points outside the green "funnel" represent higher or lower adjusted sNDI or death rates than expected. When the 95% confidence interval does not cross 1, the results are statistically significant. Therefore, 3 sites (11, 20 and 21)have statistically higher sNDI or death rates and 2 sites (6 and 12) have statistically lower sNDI or death 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;197:75-81.
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;135:57-65.

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 Sep;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. Synnes A, Petrie J, Grunau RE, Church P, Kelly E, Moddemann D, Ye XY, Lee SK, O'Brien K on behalf of the Canadian Neonatal Network and Canadian Neonatal Follow-up Networks. Family Integrated Care: Very Preterm Neurodevelopmental Outcomes at 18 Months. Arch Dis Child Fetal Neonatal Ed. Published Online First: 18 June 2021; doi: 10.1136/archdischild-2020-321055.
5. Ghotra S, Feeny D, Barr R, Yang J, Saigal S, Vincer M, Afifi J, Shah PS, Lee S, Synnes A on behalf of Canadian Neonatal Follow-Up Network. Parent-Reported Health Status of Children Born Preterm in the Canadian Neonatal Follow-Up Network Cohort. 2021 Jun 23:fetalneonatal-2021-321635. doi: 10.1136/archdischild-2021-321635. Epub ahead of print. PMID: 34162693.
6. 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.
7. Chevallier M, Debillon T, Darlow BA, Synnes AR, Pierrat V, Hurrion E, Yang J, Ego A, Ancel PY, Lui K, Shah PS, Luu TM; Australian and New Zealand Neonatal Network (ANZNN); Canadian Neonatal Network (CNN); Canadian Neonatal Follow-Up Network (CNFUN); Etude Epidémiologique sur les Petits Ages Gestationnels (EPIPAGE-2) Investigators. Mortality and significant neurosensory impairment in preterm infants: an international comparison. Arch Dis Child Fetal Neonatal Ed. 2021 Sep 11:fetalneonatal-2021-322288. doi: 10.1136/archdischild-2021-322288. Epub ahead of print. PMID: 34509987.

CNFUN Manuscripts submitted:

1. Synnes A, Zhang-Jiang S, Butt A, Colby L on behalf of the Canadian Neonatal Follow-Up Network. Sociodemographic characteristics of children with and without neurodevelopmental impairment in a Canadian cohort of very preterm children. Submitted to CHILD: Care, Health and Development.

CNFUN Manuscripts in final draft or for resubmission:

1. McRae L et al. Impact of Home Respiratory Support on Developmental Outcomes. J Neonatal-Perinatal Medicine.
2. DaSilva M et al. The Incidence of and Risks Factors for Inguinal Hernia in Preterm Infants. Acta Paediatrica.

3. Synnes A et al. Cerebral palsy rates after a magnesium sulphate knowledge translation intervention. Resubmission.
4. Ricci, MF et al. Neurodevelopmental Outcomes of Infants <29 Weeks' Gestation in Canada Between 2009 and 2016. Resubmission to J Pediatrics.

Parent-EPIQ Manuscripts 2021:

1. Luu TM, Pearce R. Parental voice - what outcomes of preterm birth matter most to families? Seminars in Perinatology. 2021 Nov 11;000(151550). doi: 10.1016/j.semperi.2021.151550.
2. Jaworski M, Janvier A, Bourque CJ, Mai-Vo TA, Pearce R, Synnes AR, Luu TM. Parental perspective on important health outcomes of extremely preterm infants. Arch Dis Child Fetal Neonatal Ed. 2021 Nov 23:fetalneonatal-2021-322711. doi: 10.1136/archdischild-2021-322711. Epub ahead of print. PMID: 34815239.

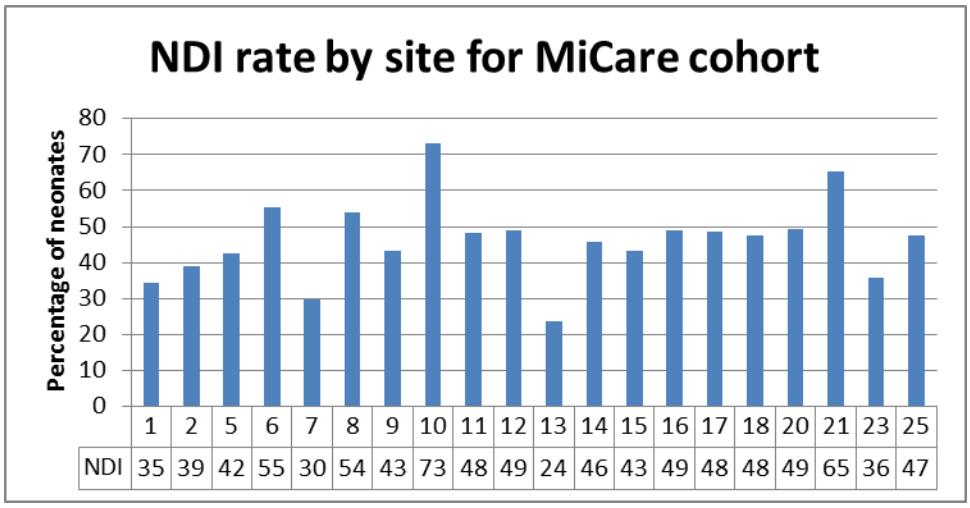
J. Appendices

Appendix I. MiCare cohort Site Comparisons – Crude

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	168	110 (65.5)	58 (34.5)	< 5%	9 (5.4)	0 (0)	23 (13.7)	40 (23.8)	8 (4.8)
2	115	70 (60.9)	45 (39.1)	< 5%	12 (10.4)	0 (0)	17 (14.8)	29 (25.2)	10 (8.7)
5	205	118 (57.6)	87 (42.4)	7 (3.4)	29 (14.1)	< 5%	24 (11.7)	57 (27.8)	21 (10.2)
6	212	95 (44.8)	117 (55.2)	11 (5.2)	25 (11.8)	11 (5.2)	58 (27.4)	76 (35.8)	30 (14.2)
7	27	19 (70.4)	8 (29.6)	< 5%	0 (0)	< 5%	5 (18.5)	7 (25.9)	< 10%
8	145	67 (46.2)	78 (53.8)	14 (9.7)	< 5%	< 5%	41 (28.3)	53 (36.6)	31 (21.4)
9	53	30 (56.6)	23 (43.4)	5 (9.4)	< 5%	0 (0)	< 10%	10 (18.9)	9 (17)
10	56	15 (26.8)	41 (73.2)	< 10%	9 (16.1)	< 5%	19 (33.9)	34 (60.7)	18 (32.1)
11	178	92 (51.7)	86 (48.3)	9 (5.1)	13 (7.3)	< 5%	45 (25.3)	55 (30.9)	20 (11.2)
12	84	43 (51.2)	41 (48.8)	12 (14.3)	< 5%	< 5%	25 (29.8)	26 (31)	14 (16.7)
13	21	16 (76.2)	5 (23.8)	< 15%	< 15%	0 (0)	0 (0)	< 5%	0 (0)
14	103	56 (54.4)	47 (45.6)	6 (5.8)	< 5%	0 (0)	17 (16.5)	42 (40.8)	12 (11.7)
15	30	17 (56.7)	13 (43.3)	< 5%	6 (20)	0 (0)	< 15%	9 (30)	5 (16.7)
16	250	128 (51.2)	122 (48.8)	18 (7.2)	16 (6.4)	< 5%	48 (19.2)	75 (30)	44 (17.6)
17	64	33 (51.6)	31 (48.4)	0 (0)	< 5%	< 5%	18 (28.1)	22 (34.4)	12 (18.8)
18	43	23 (53.5)	20 (46.5)	< 10%	< 5%	< 5%	9 (20.9)	14 (32.6)	9 (20.9)
20	79	40 (51.3)	39 (48.7)	5 (6.3)	< 5%	< 5%	14 (17.7)	34 (43)	9 (11.4)
21	55	19 (34.5)	36 (65.5)	5 (9.1)	10 (18.2)	< 5%	19 (34.5)	29 (52.7)	15 (27.3)
23	132	85 (64.4)	47 (35.6)	10 (7.6)	11 (8.4)	< 5%	17 (12.9)	27 (20.5)	10 (7.6)
25	238	125 (52.5)	113 (47.5)	0 (0)	13 (5.5)	< 5%	40 (16.8)	95 (39.9)	33 (13.9)
Total	2258	1198 (53.1)	1055 (46.8)	123 (5.4)	174 (7.7)	38 (1.7)	446 (19.8)	735 (32.6)	312 (13.8)

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

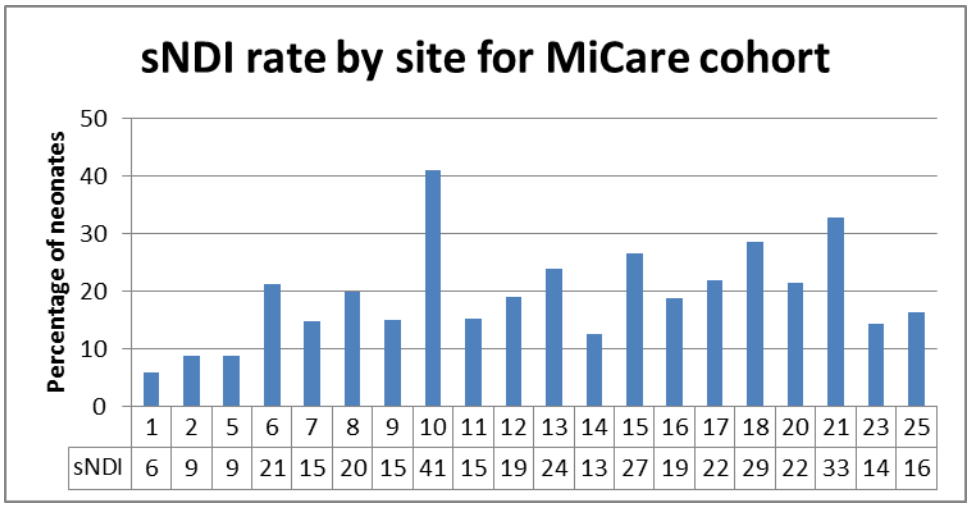


	1	2	5	6	7	8	9	10	11	12	13	14	15	16	17	18	20	21	23	25
NDI	35	39	42	55	30	54	43	73	48	49	24	46	43	49	48	48	49	65	36	47

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	168	110 (65.5)	10 (6)	< 5%	0 (0)	0 (0)	6 (3.6)	7 (4.2)	< 5%
2	115	70 (60.9)	10 (8.7)	0 (0)	< 5%	0 (0)	< 5 %	< 5 %	< 5%
5	205	118 (57.6)	18 (8.8)	< 5%	< 5%	< 5 %	5 (2.4)	9 (4.4)	< 5%
6	212	95 (44.8)	45 (21.2)	< 5%	< 5%	9 (4.2)	15 (7.1)	32 (15.1)	5 (2.4)
7	27	19 (70.4)	< 15%	< 5%	0 (0)	< 5%	< 15%	< 15%	< 5%
8	145	67 (46.2)	29 (20)	6 (4.1)	< 5%	< 5%	13 (9)	14 (9.7)	7 (4.8)
9	53	30 (56.6)	8 (15.1)	0 (0)	< 5%	0 (0)	< 5%	< 10%	< 5%
10	56	15 (26.8)	23 (41.1)	0 (0)	0 (0)	< 5%	8 (14.3)	22 (39.3)	< 10%
11	178	92 (51.7)	27 (15.2)	5 (2.8)	5 (2.8)	< 5%	13 (7.3)	16 (9)	7 (3.9)
12	84	43 (51.2)	16 (19)	< 5%	< 5%	< 5%	9 (10.7)	6 (7.1)	< 5%
13	21	16 (76.2)	5 (23.8)	< 15%	< 15%	0 (0)	0 (0)	< 5%	0 (0)
14	103	56 (54.4)	13 (12.6)	< 5%	< 5%	0 (0)	6 (5.8)	8 (7.8)	0 (0)
15	30	17 (56.7)	8 (26.7)	< 5%	< 15%	0 (0)	< 10%	< 15%	0 (0)
16	250	128 (51.2)	47 (18.8)	8 (3.2)	10 (4)	< 5%	10 (4)	24 (9.6)	9 (3.6)
17	64	33 (51.6)	14 (21.9)	0 (0)	0 (0)	0 (0)	6 (9.4)	10 (15.6)	< 5%
18	43	23 (53.5)	12 (27.9)	< 10%	0 (0)	< 5%	6 (14)	7 (16.3)	< 10%
20	79	39 (48.7)	17 (21.5)	< 5%	< 5%	< 5%	< 10%	12 (15.2)	< 5%
21	55	19 (34.5)	18 (32.7)	< 5%	< 5%	< 5%	9 (16.4)	15 (27.3)	6 (10.9)
23	132	85 (64.4)	19 (14.4)	5 (3.8)	9 (6.8)	< 5%	5 (3.8)	5 (3.8)	< 5%
25	238	125 (52.5)	39 (16.4)	0 (0)	10 (4.2)	< 5%	9 (3.8)	26 (10.9)	< 5%
Total	2258	1198 (53.1)	380 (16.8)	49 (2.2)	58 (2.6)	34 (1.5)	133 (5.9)	228 (10.1)	67 (3)

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



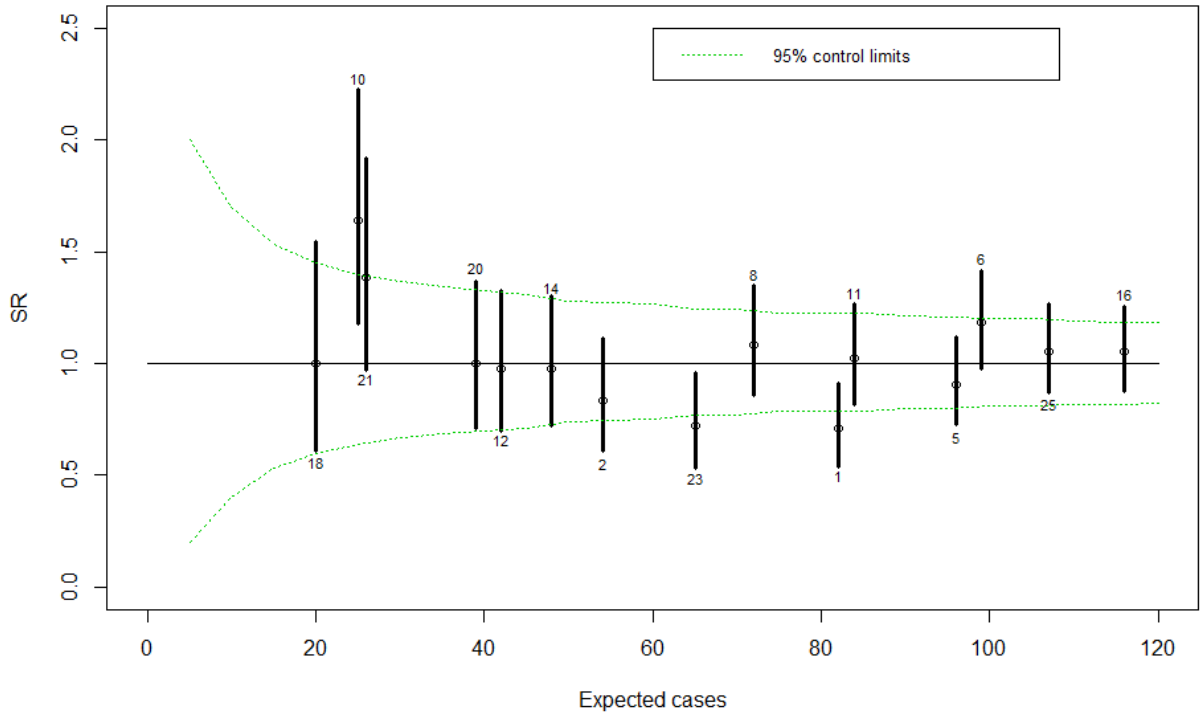
	1	2	5	6	7	8	9	10	11	12	13	14	15	16	17	18	20	21	23	25
sNDI	6	9	9	21	15	20	15	41	15	19	24	13	27	19	22	29	22	33	14	16

Appendix II. MiCare cohort Site Comparisons – Adjusted Standardized Ratios by Site

Presentation No 32: Adjusted standardized ratios by site Neurodevelopmental impairment (NDI) – 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	168	76.6	Y	58	82	0.71 (0.54, 0.91)
2	115	87.8	Y	45	54	0.83 (0.61, 1.12)
3	10	84.6	N	7		
4	13	76.5	N	3		
5	205	80.1	Y	87	96	0.91 (0.73, 1.12)
6	212	85.5	Y	117	99	1.18 (0.98, 1.42)
7	27	56.6	N	8		
8	145	71.4	Y	78	72	1.08 (0.86, 1.35)
9	53	48.2	N	23		
10	56	81.2	Y	41	25	1.64 (1.18, 2.22)
11	178	79.8	Y	86	84	1.02 (0.82, 1.26)
12	84	82.4	Y	41	42	0.98 (0.70, 1.32)
13	21	56.8	N	5		
14	103	76.3	Y	47	48	0.98 (0.72, 1.30)
15	30	60.8	N	13		
16	250	83.1	Y	122	116	1.05 (0.87, 1.26)
17	64	39.3	N	31		
18	43	91.5	Y	20	20	1.00 (0.61, 1.54)
19	17	25.8	N	5		
20	79	78.2	Y	39	39	1.00 (0.71, 1.37)
21	55	93.2	Y	36	26	1.38 (0.97, 1.92)
22	13	65	N	2		
23	132	79.5	Y	47	65	0.72 (0.53, 0.96)
24	7	53.8	N	4		
25	238	78.2	Y	113	107	1.06 (0.87, 1.27)
26	18	81.8	N	9		

1. Sites with <20 participants for the 2.5year MiCare cohort period 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 ≥10 mm, intraparenchymal hemorrhage or periventricular leukomalacia.



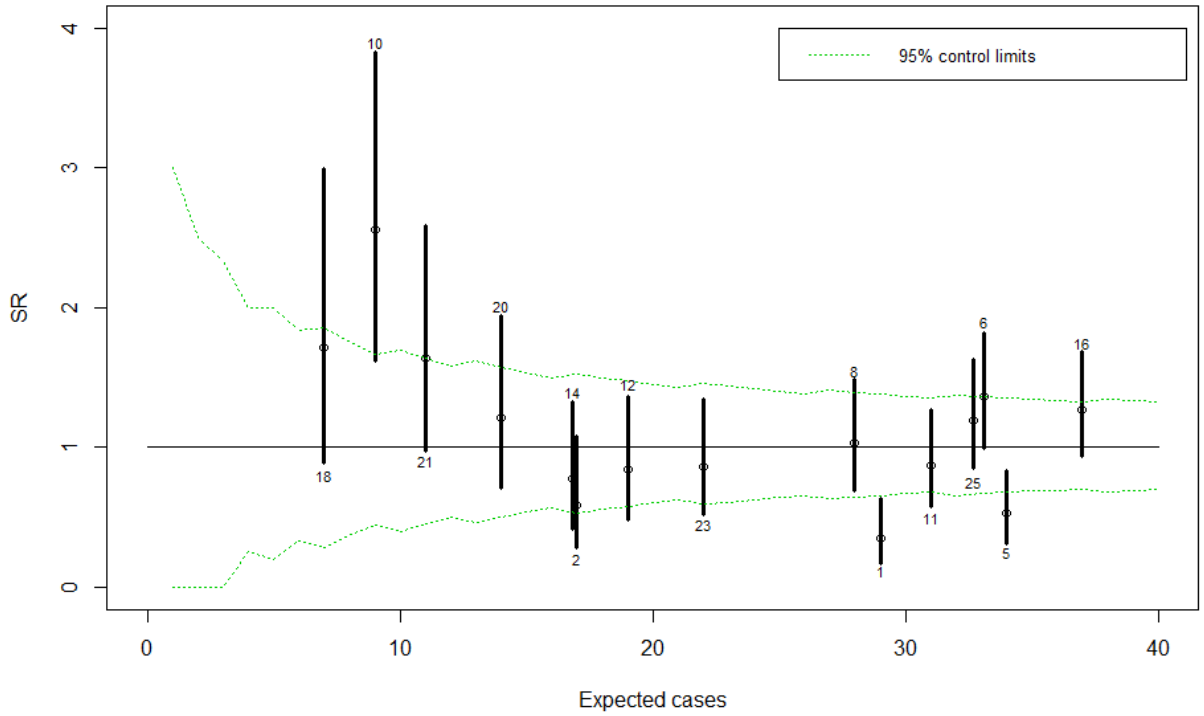
COMMENTS:

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, 3 sites have statistically higher or lower NDI rates.

Presentation No 33: Adjusted standardized ratios by site
Significant neurodevelopmental impairment (sNDI) – 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	168	76.6	Y	10	29	0.34 (0.17, 0.63)
2	115	87.8	Y	10	17	0.59 (0.28, 1.08)
3	10	84.6	N	3		
4	13	76.5	N	0		
5	205	80.1	Y	18	34	0.53 (0.31, 0.84)
6	212	85.5	Y	45	33	1.36 (0.99, 1.82)
7	27	56.6	N	4		
8	145	71.4	Y	29	28	1.04 (0.69, 1.49)
9	53	48.2	N	8		
10	56	81.2	Y	23	9	2.56 (1.62, 3.83)
11	178	79.8	Y	27	31	0.87 (0.57, 1.27)
12	84	82.4	Y	16	19	0.84 (0.48, 1.37)
13	21	56.8	N	5		
14	103	76.3	Y	13	17	0.76 (0.41, 1.31)
15	30	60.8	N	8		
16	250	83.1	Y	47	37	1.27 (0.93, 1.69)
17	64	39.3	N	14		
18	43	91.5	Y	12	7	1.71 (0.88, 2.99)
19	17	25.8	N	0		
20	79	78.2	Y	17	14	1.21 (0.71, 1.94)
21	55	93.2	Y	18	11	1.64 (0.97, 2.59)
22	13	65	N	1		
23	132	79.5	Y	19	22	0.86 (0.52, 1.35)
24	7	53.8	N	1		
25	238	78.2	Y	39	33	1.18 (0.84, 1.62)
26	18	81.8	N	4		

1. Sites with <20 participants for the 2.5 year MiCare cohort period and/or <70% follow-up rates are excluded.
2. Model is adjusted for gestational age, sex, antenatal steroids, severity of illness (SNAP>20), severe retinopathy of prematurity defined as stage 3 or greater in either eye or treatment with laser or injections of anti-vascular endothelial growth factor, nosocomial infection and brain injury, defined as any grade 3 or 4 intraventricular hemorrhage, ventricular dilatation ≥10 mm, intraparenchymal hemorrhage or periventricular leukomalacia.



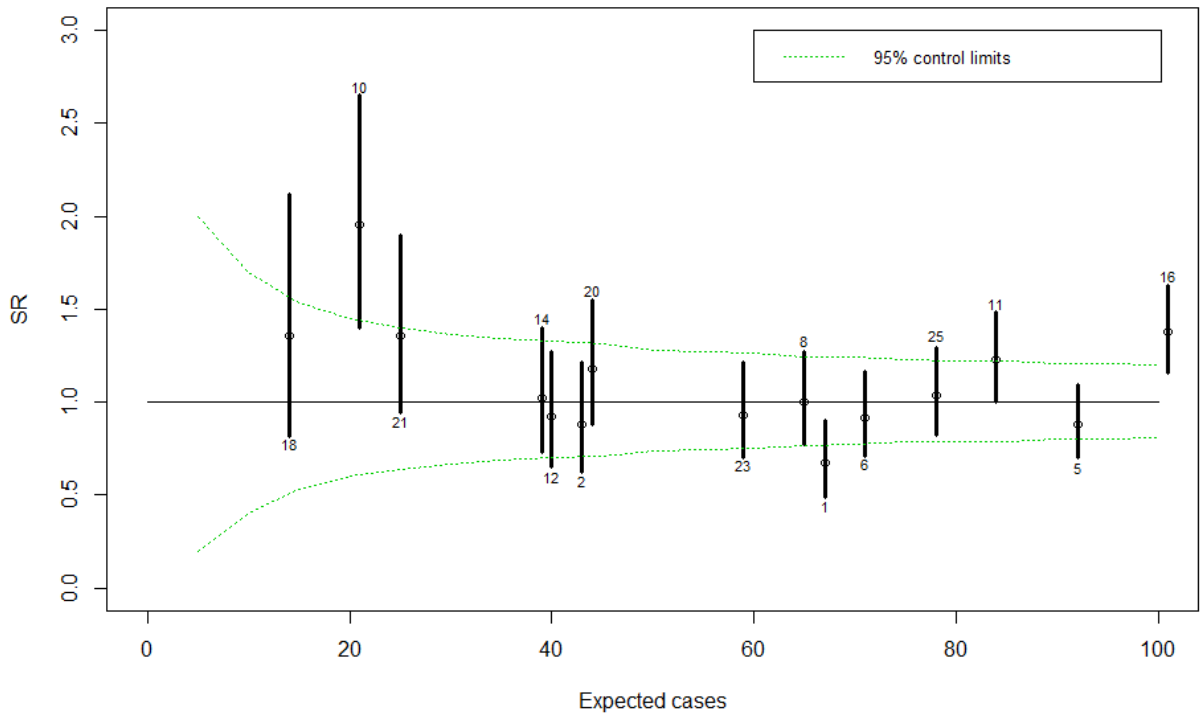
COMMENTS:

Sites with points outside the green "funnel" represent higher or lower adjusted sNDI rates than expected. When the 95% confidence interval does not cross 1, the results are statistically significant. Therefore, 3 sites have statistically higher or lower sNDI rates.

Presentation No 34: Adjusted standardized ratios by site
Significant neurodevelopmental impairment (sNDI) or death – MiCare cohort
(Births April 1, 2009 – September 30, 2011)

Site	Children (n)	Follow-up rate (%)	Included (Yes/No)	sNDI or death (n)	Adjusted expected outcome (n)	Adjusted standardized ratio (95%CI)
1	205	76.6	Y	45	67	0.67 (0.49, 0.90)
2	143	87.8	Y	38	43	0.88 (0.63, 1.21)
3	11	84.6	N	3		
4	16	76.5	N	3		
5	268	80.1	Y	81	92	0.88 (0.70, 1.09)
6	233	85.5	Y	65	71	0.92 (0.71, 1.17)
7	33	56.6	N	7		
8	181	71.4	Y	65	65	1.00 (0.77, 1.27)
9	80	48.2	N	35		
10	74	81.2	Y	41	21	1.95 (1.40, 2.65)
11	254	79.8	Y	103	84	1.23 (1.00, 1.49)
12	105	82.4	Y	37	40	0.93 (0.65, 1.27)
13	30	56.8	N	14		
14	130	76.3	Y	40	39	1.03 (0.73, 1.40)
15	44	60.8	N	21		
16	342	83.1	Y	139	101	1.37 (1.16, 1.62)
17	115	39.3	N	65		
18	50	91.5	Y	19	14	1.36 (0.82, 2.12)
19	28	25.8	N	11		
20	114	78.2	Y	52	44	1.18 (0.88, 1.55)
21	71	93.2	Y	34	25	1.36 (0.94, 1.90)
22	15	65	N	3		
23	168	79.5	Y	55	59	0.93 (0.70, 1.21)
24	13	53.8	N	7		
25	283	78.2	Y	81	78	1.04 (0.82, 1.29)
26	19	81.8	N	5		

1. Sites with <20 participants for the 2.5 year MiCare 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 ≥10 mm, intraparenchymal hemorrhage or periventricular leukomalacia.



COMMENTS:

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