Canadian Neonatal Follow-Up Network
Réseau Canadien de Suivi Néonatal

CNFUN ANNUAL REPORT 2020

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, 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 provision 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 (once Dr. Anne Synnes has stepped down).
- 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 centre, 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.

2019-2020 CNFUN Steering Committee

Dr. Anne Synnes – Neonatologist / founding director (British Columbia)
Dr. Thuy Mai Luu – Pediatrician / co-director (Québec)
Dr. Jehier Afifi – Neonatologist (Nova Scotia)
Dr. Kevin Coughlin – Neonatologist (Ontario)
Dr. Rudaina Banihani – Neonatologist (Ontario)
Lynn Whitty – Nurse (Ontario)
Dr. Diane Moddemann – Neonatologist (Manitoba)
Dr. Ruth Grunau – Psychologist / researcher (British Columbia)
Dr. Jill Zwicker – Occupational therapist / researcher (British Columbia)

New 2021 CNFUN Steering Committee

Dr. Thuy Mai Luu – Pediatrician / director (Québec)
Dr. Anne Synnes – Neonatologist / past director (British Columbia)
Dr. Jehier Afifi – Neonatologist (Nova Scotia)
Dr. Rudaina Banihani – Neonatologist (Ontario)
Dr. Karen Thomas – Neonatologist (Ontario)
Dr. Florencia Ricci*– Neonatologist (Manitoba)
Dr. Matthew Hicks* – Neonatologist / epidemiologist (Alberta)
Dr. Ruth Grunau – Psychologist / researcher (British Columbia)
Dr. Jill Zwicker – Occupational therapist / researcher (British Columbia)
Lindsay Colby – Nurse (British Columbia)

*There was a tie in the election results so both Dr. Hicks and Dr. Ricci joined the Steering Committee.

2020 CNFUN Annual Report Review Committee

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 & behavioral pediatrics (Alberta)
Dr. Leonora Hendson – Neonatologist, neonatal follow-up (Alberta)
Lindsay Richter – CNFUN National Coordinator (British Columbia)

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I. Summary of Publications

A. Executive Summary

We are pleased to provide the third 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 2009 until Dec 31, 2017. Information is included for 6485 infants assessed at a CNFUN site and 7091 survivors and non-survivors with linked neonatal data from the Canadian Neonatal Network.

Improving health and health care of the children we care for is our ultimate goal. Without measuring the outcomes, as we do in this report, we will not know whether we are achieving our goal.

CNFUN's Parent-EPIQ (Evidence-based Practice to Improve Quality) is one of 13 studies in the CIHR SPOR (Strategy for Patient Oriented Research) CHILD-BRIGHT research collaborative. We are tremendously grateful to CHILD-BRIGHT for giving us the opportunity to implement interventions at participating sites to improve either language or cognitive outcomes, explore what aspects of health and neurodevelopment that parents of children born very preterm identify as being the most important, and publish this annual report. Parent-EPIQ has facilitated working with our parent partners.

2020 has been a challenging year with the COVID-19 pandemic requiring Neonatal Follow-Up Programs to adapt very quickly to provide optimal care for preterm children in a pandemic situation. Neonatal Follow-Up Programs demonstrated creativity and innovation to deal with the pandemic constraints, which included virtual visits. For some families, this has proven very helpful by reducing travel time. However, CNFUN standardized assessments have not been possible virtually. CNFUN has responded with widening the acceptable age range for the standard assessment to 18 to 36 months corrected age. Most of the CNFUN data collection in this report occurred prior to the pandemic. We thank sites for finding the time to upload results for this report despite all the challenges in the last year. Your diligent work and collaborative efforts are priceless. The results you find in this report required the commitment and effort to recruit, track and book appointments, arrange for the expert health care professionals to assess the children according to CNFUN standardized criteria and upload the data as well as maintaining research ethics board approval.

Thank you to the CNFUN annual report working group and 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.

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 Program 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 contribution.

Dr. Thuy Mai Luu assumed leadership of CNFUN on February 8, 2021 and has been working closely with Dr. Anne Synnes in the last year to assure a smooth transition.

Anne Synnes MDCM, MHSc
Past Director, CNFUN

Thuy Mai Luu MD, MSc
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	8
	VGH/GVS	Neonatal Follow-Up Team, Victoria	Victoria General Hospital	Thevanisha Pillay	2
AB	**ACH/FMC**	Perinatal 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	**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	5
	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	9
	WRH	Neonatal Neurodevelopment Follow-Up Program, Windsor	Windsor Regional Hospital	Mohammad Adie	4

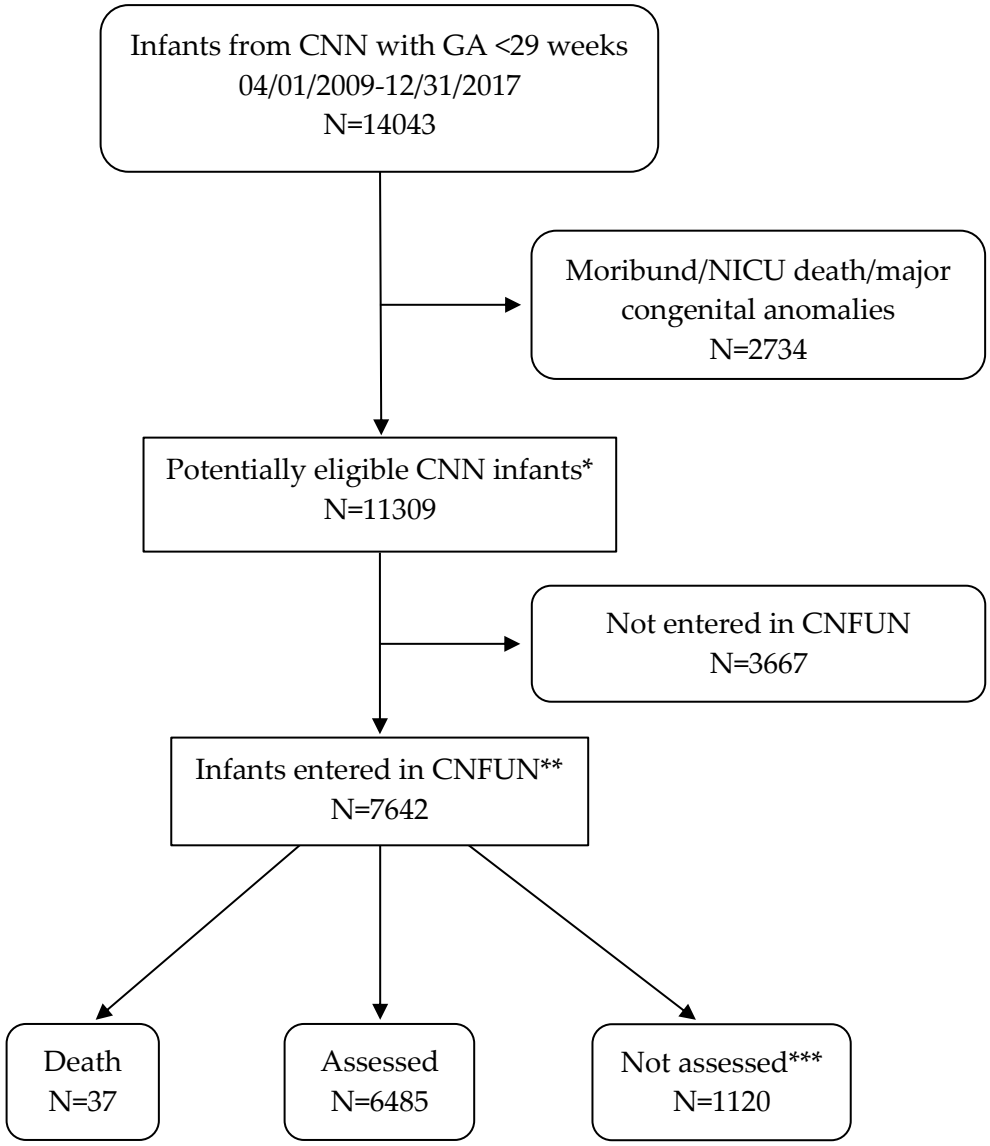
QC	**CHUS**	Clinique de suivi néonatal, Sherbrooke	Centre Hospitalier Universitaire de Sherbrooke	Alyssa Morin	3
	CHUQ	Centre Mère Enfant, Centre Hospitalier de L'Université Laval, Québec	Centre Hospitalier Universitaire de Québec (Laval Site)	Sylvie Bélanger	3
	HMR	Clinique de suivi néonatal, Montréal	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	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	8
New members					
Province	**Abbreviation**	**NFUP Program Name / City**	**Hospital Site**	**Site Investigator**	**Number of CNFUN Members**
BC	**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
ON	**HHSC**	Neonatal Follow-Up Clinic, Hamilton	Hamilton Health Sciences Centre, McMaster Children's Hospital	Karen Thomas	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 n/N (%)	Post-MiCare Follow-Up Rate n/N (%)	Parent-EPIQ Intervention Site (Yes/No)
Active CNFUN sites				
1	Yes	170/222 (76.6)	368/486 (75.7)	Yes
2	Yes	115/131 (87.8)	278/345 (80.6)	No
3	Yes	11/13 (84.6)	75/133 (56.4)	No
5	Yes	205/256 (80.1)	7/737 (0.9)	Yes
6	Yes	213/249 (85.5)	529/744 (71.1)	Yes
7	Yes	30/53 (56.6)	20/130 (15.4)	No
8	Yes	145/203 (71.4)	3/509 (0.6)	No
9	Yes	53/110 (48.2)	30/166 (18.1)	No
10	Yes	56/69 (81.2)	123/197 (62.4)	Yes
11	Yes	178/223 (79.8)	409/468 (87.4)	Yes
12	Yes	84/102 (82.4)	215/260 (82.7)	Yes
14	Yes	103/135 (76.3)	237/346 (68.5)	Yes
15	Yes	31/51 (60.8)	14/101 (13.9)	No
16	Yes	250/301 (83.1)	520/866 (60)	Yes
20	Yes	79/101 (78.2)	209/272 (76.8)	Yes
21	Yes	55/59 (93.2)	118/158 (74.7)	Yes
23	Yes	132/166 (79.5)	89/322 (27.6)	Yes
25	Yes	241/308 (78.2)	790/961 (82.2)	No
26	Yes	18/22 (81.8)	51/66 (77.3)	No
27	No	-	20/23 (87)	No
28	Yes	56/88 (63.6)	44/227 (19.4)	No
29	Yes	19/29 (65.5)	28/136 (20.6)	No
Inactive Sites				
4	Yes	13/17 (76.5)	6/41 (14.6)	No
13	Yes	21/37 (56.8)	0/104 (0)	No
17	Yes	64/163 (39.3)	5/375 (1.3)	No
18	Yes	43/47 (91.5)	9/119 (7.6)	No
19	Yes	17/66 (25.8)	5/155 (3.2)	No
22	Yes	13/20 (65)	9/64 (14.1)	No
24	Yes	7/13 (53.8)	0/24 (0)	Yes

Presentation No 3: CNN and CNFUN flow diagram for births Apr 1, 2009 – Dec 31, 2017



*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.

**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= 313), no contact information (n=23), unable to reach (n=210), missed appointment (n=183), other reason (n=353), missing information (n= 35).

C. Outcomes Definitions

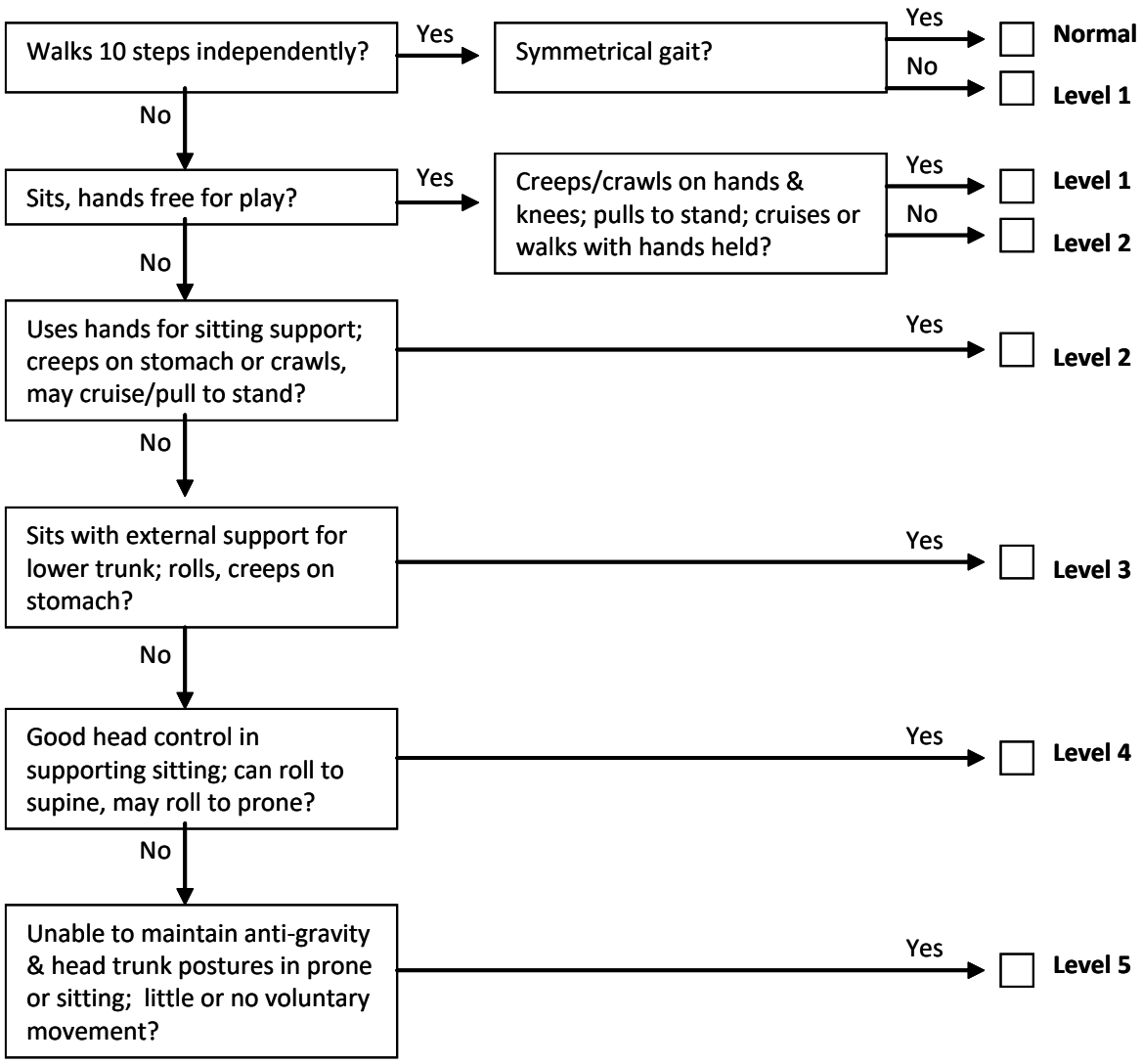
Impairments	Significant neurodevelopmental impairment (sNDI) (Any one or more of the following)*	Neurodevelopmental impairment (NDI) (Any one or more of the following)**
Motor	CP with GMFCS 3, 4 or 5	CP with GMFCS 1 or higher
	Bayley-III Motor Composite <70	Bayley-III Motor Composite <85
Cognitive	Bayley-III Cognitive Composite <70	Bayley-III Cognitive Composite <85
Language	Bayley-III Language Composite <70	Bayley-III Language Composite <85
Hearing	Hearing aid or cochlear implant	Sensorineural/mixed hearing loss
Vision	Bilateral visual impairment	Uni- or 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 loss: 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, 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 <70 or were considered to have a significant developmental delay which did not allow completion of the Bayley-III.

**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.

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)	(0.4)	659 (74.8)	876 (80.1)
2010	1613	34 (2.1)	244 (15.1)	1335 (82.8)	(0.9)	1013 (75.9)	1271 (80.4)
2011	1527	51 (3.3)	258 (16.9)	1218 (79.8)	(0.3)	852 (70 .0)	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)	(0.2)	615 (47.1)	874 (55.9)
2014	1621	70 (4.3)	232 (14.3)	1319 (81.4)	(0.1)	649 (49.2)	882 (56.9)
2015	1554	87 (5.6)	201 (12.9)	1266 (81.5)	(0.1)	686 (54.2)	888 (60.5)
2016	1678	99 (5.9)	221 (13.2)	1358 (80.9)	(0.3)	713 (52.5)	939 (59.5)
2017	1637	81 (5.0)	219 (13.4)	1337 (81.7)	(0.2)	622 (46.5)	844 (54.2)
2009-2017	14043	640 (4.6)	2094 (14.9)	11309 (80.5)	37 (0.3)	6485 (57.3)	8616 (64.3)

*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 CNFUN sites

Year of birth	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 (%)
2009*	881	774	659 (74.8)	659 (74.8)
2010	1335	1123	1013 (75.9)	1013 (75.9)
2011	1218	935	852 (70.0)	852 (70.0)
2012	938	722	676 (52.5)	651 (69.4)
2013	973	664	615 (47.1)	611 (62.8)
2014	954	708	649 (49.2)	643 (67.4)
2015	929	757	686 (54.2)	679 (73.1)
2016	1218	749	713 (52.5)	711 (58.4)
2017	1180	659	622 (46.5)	622 (52.7)
2009-2017	9626	7091	6485 (57.3)	6441 (66.9)

*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, Université de Montréal, Hôpital Sainte-Justine, Jewish General Hospital, McGill University Health Centre/ Montreal Children's Hospital/ L'Hôpital de Montréal pour enfants, Centre Hôpitalier Universitaire de Sherbrooke, Centre Mere Enfant, 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. In 2017, Royal Columbian Hospital and Surrey Memorial Hospital were also participating sites.

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	151	68 (45.0)	55 (36.4)	28 (18.5)	(0)	14 (50.0)	69 (83.1)
23	812	101 (12.4)	369 (45.4)	342 (42.1)	(0.4)	194 (56.7)	566 (79.3)
24	1699	86 (5.1)	539 (31.7)	1074 (63.2)	(0.4)	635 (59.1)	1181 (72.9)
25	2297	79 (3.4)	444 (19.3)	1774 (77.2)	(0.4)	1069 (60.3)	1521 (68.3)
26	2560	90 (3.5)	311 (12.2)	2159 (84.3)	(0.2)	1279 (59.2)	1595 (64.4)
27	3010	104 (3.5)	213 (7.1)	2693 (89.5)	(0.3)	1541 (57.2)	1763 (60.5)
28	3514	112 (3.2)	163 (4.6)	3239 (92.2)	(0.1)	1753 (54.1)	1921 (56.3)
22-28	14043	640 (4.6)	2094 (14.9)	11309 (80.5)	37 (0.3)	6485 (57.3)	8616 (64.1)

*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	354	79 (22.3)	155 (43.8)	120 (33.9)	0 (0)	78 (65.0)	233 (84.7)
500-749	3643	223 (6.1)	1041 (28.6)	2379 (65.3)	15 (0.4)	1437 (60.4)	2493 (72.6)
750-999	4994	189 (3.8)	614 (12.3)	4191 (83.9)	14 (0.3)	2518 (60.1)	3146 (65.3)
1000-1249	3719	105 (2.8)	210 (5.7)	3404 (91.5)	8 (0.2)	1867 (54.8)	2085 (57.6)
> 1250	1316	37 (2.8)	70 (5.3)	1209 (91.9)	0 (0)	580 (48.0)	650 (50.8)

*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

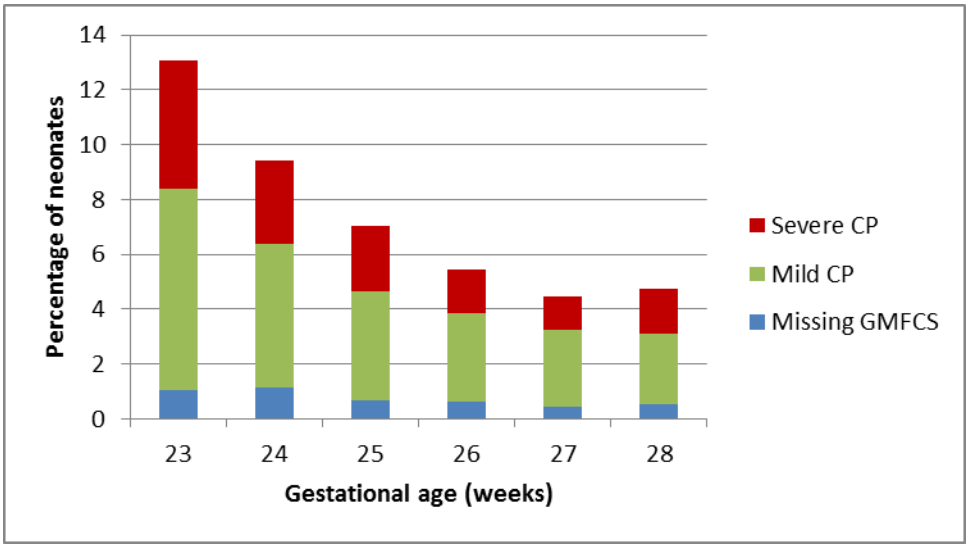
Gestational age (weeks)	**All NICU survivors** n (%)	**NICU survivors at participating sites** (n)	**CNFUN data** (n)	**Linked CNN-CNFUN data for NICU survivors** n (%)	**Follow-up rate for participating CNFUN sites** n (%)
22	28 (18.5)	21	14	14 (50.0)	14 (66.7)
23	342 (42.1)	285	196	194 (56.7)	194 (68.1)
24	1074 (63.2)	907	730	635 (59.1)	631 (69.6)
25	1774 (77.2)	1519	1132	1069 (60.3)	1059 (69.7)
26	2159 (84.3)	1842	1372	1279 (59.2)	1261 (68.5)
27	2693 (89.5)	2295	1695	1541 (57.2)	1533 (66.8)
28	3239 (92.2)	2757	1942	1753 (54.1)	1749 (63.4)
22-28	11309 (80.5)	9626	7081[†]	6485 (57.3)	6441 (66.9)

[†]10 patients missing gestational age for CNFUN data.

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 (%)	Mild-moderate CP GMFCS 1-2 n (%)	Severe CP GMFCS 3-5 n (%)	Suspected CP n (%)
22 wks	14	14	<5	0 (0)	<5	0 (0)	0 (0)
23 wks	194	191	25 (13.1)	<5	14 (56.0)	9 (36.0)	9 (4.7)
24 wks	635	625	59 (9.4)	7 (11.9)	33 (55.9)	19 (32.2)	37 (5.9)
25 wks	1069	1053	74 (7.0)	7 (9.5)	42 (56.8)	25 (33.8)	34 (3.2)
26 wks	1279	1253	68 (5.4)	8 (11.8)	40 (58.8)	20 (29.4)	47 (3.7)
27 wks	1541	1518	68 (4.5)	7 (10.3)	42 (61.8)	19 (27.9)	50 (3.3)
28 wks	1753	1731	82 (4.7)	9 (11.0)	45 (54.9)	28 (34.2)	37 (2.1)
Total	6485	6385	377 (5.9)	40 (10.6)	217 (57.6)	120 (31.8)	214 (3.4)

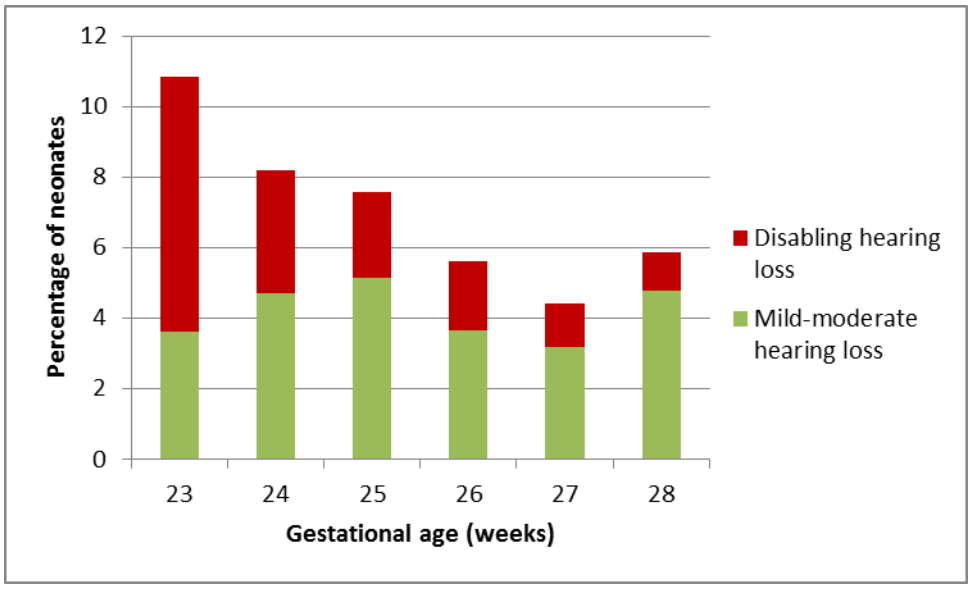


COMMENTS:

Mild cerebral palsy (CP) rates are calculated by subtracting severe CP 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.

Presentation No 9: Hearing loss rates 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 (%)	Disabling hearing loss n (%)
22 wks	14	14	14 (100)	0 (0)	0 (0)
23 wks	194	188	167 (88.8)	7 (3.7)	14 (7.5)
24 wks	635	625	573 (91.7)	30 (4.8)	22 (3.5)
25 wks	1069	1045	964 (92.3)	55 (5.3)	26 (2.5)
26 wks	1279	1250	1182 (94.6)	43 (3.4)	25 (2.0)
27 wks	1541	1514	1446 (95.5)	49 (3.2)	19 (1.3)
28 wks	1753	1722	1620 (94.1)	83 (4.8)	19 (1.1)
Total	6485	6358	5966 (93.8)	267 (4.2)	125 (2.0)

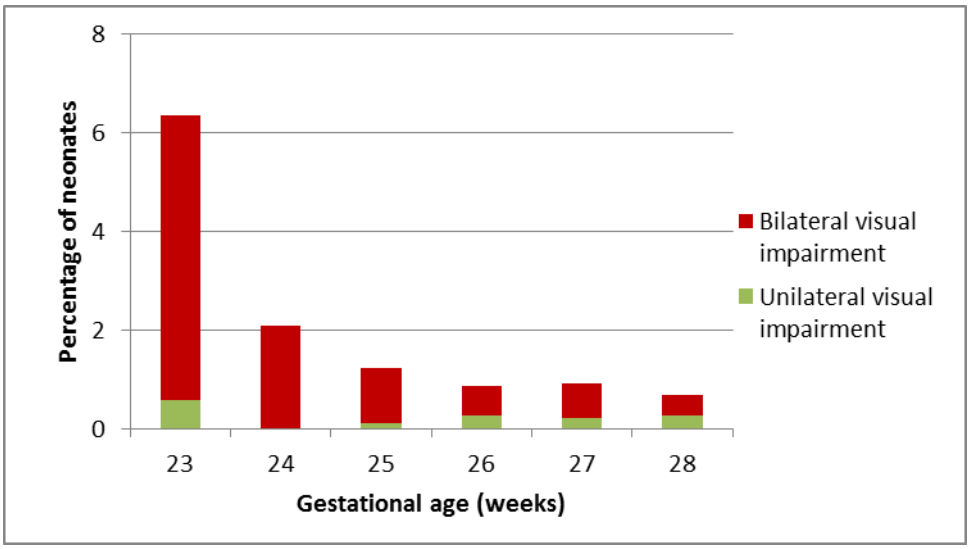


COMMENTS:

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. Disabling hearing loss incidence decreases with 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	14	13	12 (92.3)	0 (0)	<5
23 wks	194	173	162 (93.6)	<5	10 (5.8)
24 wks	635	581	569 (97.9)	0 (0)	12 (2.1)
25 wks	1069	983	971 (98.8)	<5	11 (1.1)
26 wks	1279	1175	1165 (99.2)	<5	7 (0.6)
27 wks	1541	1426	1413 (99.1)	<5	10 (0.7)
28 wks	1753	1630	1619 (99.3)	<5	7 (0.4)
Total	6485	5981	5911 (98.8)	12 (0.2)	58 (1.0)

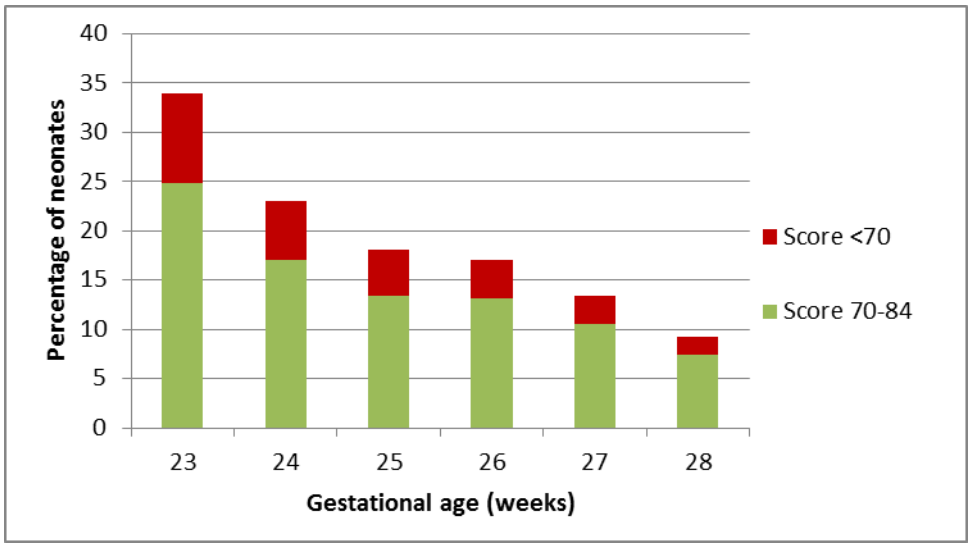


COMMENTS:

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. 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	14	14	80 (75, 90)	6 (42.9)	6 (42.9)	<5
23 wks	194	165	90 (80, 100)	109 (66.1)	41 (24.9)	15 (9.1)
24 wks	635	579	90 (85, 100)	446 (77.0)	99 (17.1)	34 (5.9)
25 wks	1069	1002	95 (85, 105)	821 (81.9)	134 (13.4)	47 (4.7)
26 wks	1279	1190	95 (85, 105)	987 (82.9)	157 (13.2)	46 (3.9)
27 wks	1541	1432	95 (90, 105)	1241 (86.7)	150 (10.5)	41 (2.9)
28 wks	1753	1623	100 (90, 105)	1472 (90.7)	120 (7.4)	31 (1.9)
Total	6485	6005	95 (90, 105)	5082 (84.6)	707 (11.8)	216 (3.6)

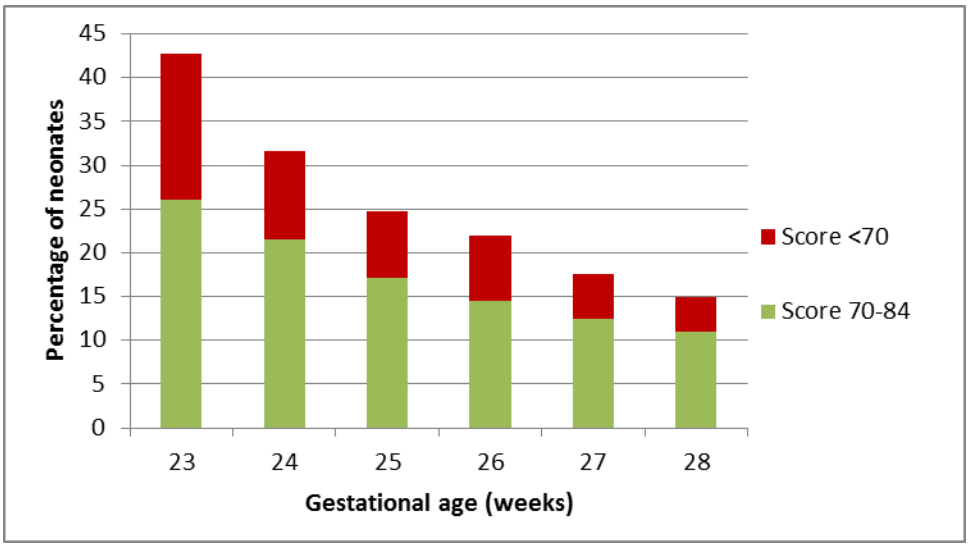


COMMENTS:

Cognitive scores on the Bayley Scales of Infant and Toddler Development – 3rd edition (Bayley-III) improve with increasing gestational age. 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	14	14	78 (70, 85)	<5	7 (50.0)	3 (21.4)
23 wks	194	157	88 (73, 97)	90 (57.3)	41 (26.1)	26 (16.6)
24 wks	635	554	91 (79, 97)	379 (68.4)	119 (21.5)	56 (10.1)
25 wks	1069	960	94 (85, 100)	722 (75.2)	165 (17.2)	73 (7.6)
26 wks	1279	1132	94 (85, 100)	884 (78.1)	164 (14.5)	84 (7.4)
27 wks	1541	1353	94 (88, 103)	1117 (82.6)	169 (12.5)	67 (5.0)
28 wks	1753	1559	97 (88, 103)	1326 (85.1)	171 (11.0)	62 (4.0)
Total	6485	5729	94 (85, 100)	4522 (78.9)	836 (14.6)	371 (6.5)

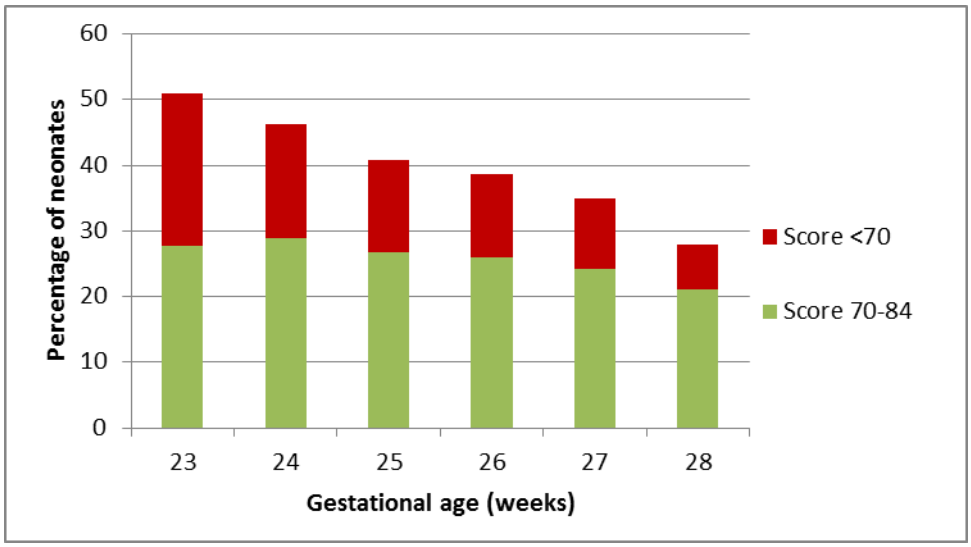


COMMENTS:

Motor scores on the Bayley Scales of Infant and Toddler Development – 3rd edition (Bayley-III) improve with increasing gestational age. 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	14	12	76 (65, 87)	<5	5 (41.7)	<5
23 wks	194	159	83 (71, 97)	78 (49.1)	44 (27.7)	37 (23.3)
24 wks	635	559	86 (74, 97)	300 (53.7)	161 (28.8)	98 (17.5)
25 wks	1069	959	89 (77, 97)	567 (59.1)	257 (26.8)	135 (14.1)
26 wks	1279	1145	89 (77, 100)	702 (61.3)	298 (26.0)	145 (12.7)
27 wks	1541	1363	91 (79, 100)	886 (65.0)	329 (24.1)	148 (10.9)
28 wks	1753	1544	91 (83, 103)	1113 (72.1)	325 (21.1)	106 (6.9)
Total	6485	5741	89 (79, 100)	3649 (63.6)	1419 (24.7)	673 (11.7)

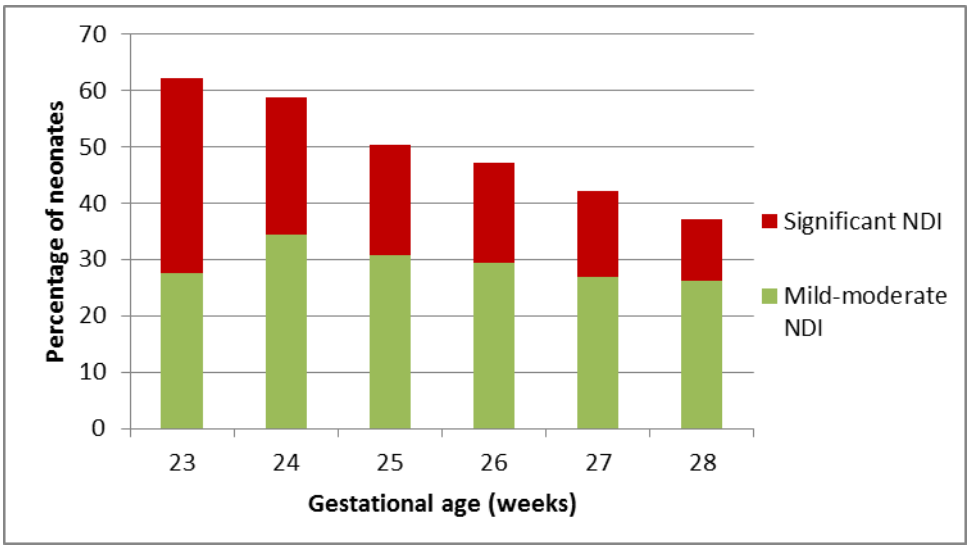


COMMENTS:

Language scores on the Bayley Scales of Infant and Toddler Development – 3rd edition (Bayley-III) improve with increasing gestational age. Language is the domain on the Bayley-III with the highest frequency of low scores. 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

GA	CNN-CNFUN linked cases with complete data (n)	No NDI n (%)	Mild-moderate NDI n (%)	Significant NDI n (%)
22 wks	14	<5	7 (50.0)	5 (35.7)
23 wks	193	73 (37.8)	53 (27.5)	67 (34.7)
24 wks	634	262 (41.3)	218 (34.4)	154 (24.3)
25 wks	1061	528 (49.8)	326 (30.7)	207 (19.5)
26 wks	1277	675 (52.9)	375 (29.4)	227 (17.8)
27 wks	1534	889 (58.0)	413 (26.9)	232 (15.1)
28 wks	1749	1101 (63.0)	460 (26.3)	188 (10.8)
Total	6462	3530 (54.6)	1852 (28.7)	1080 (16.7)

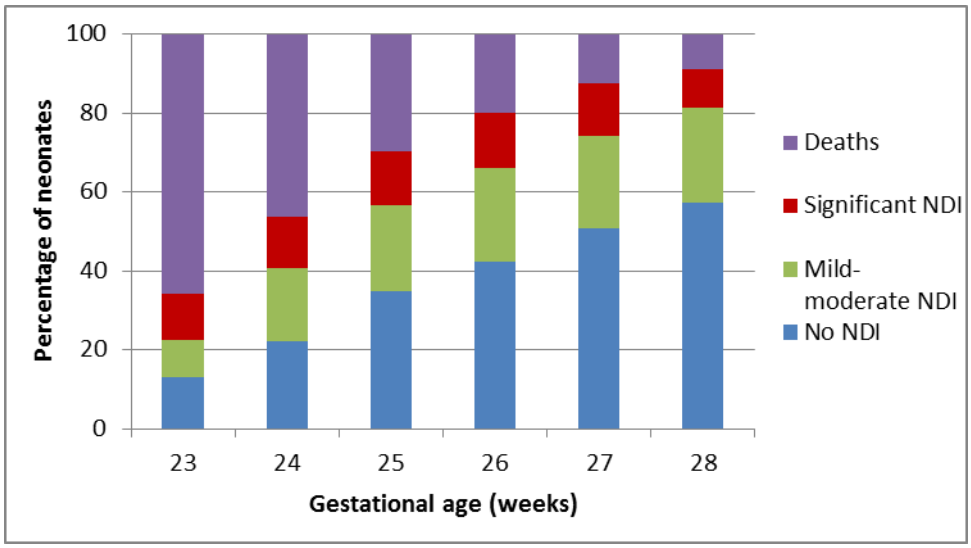


COMMENTS:

Neurodevelopmental impairment rates decrease with increasing gestational age. Mild-moderate NDI include 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. 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 (%)	Death or significant NDI n (%)
22 wks	69	14 (20.3)	<5	12 (17.4)	5 (7.3)	<5	60 (87.0)
23 wks	566	194 (34.3)	73 (12.9)	120 (21.2)	67 (11.9)	73 (12.9)	439 (77.6)
24 wks	1181	635 (53.8)	262 (22.2)	372 (31.5)	154 (13.1)	262 (22.2)	700 (59.3)
25 wks	1521	1069 (70.3)	528 (34.9)	533 (35.2)	207 (13.7)	528 (34.9)	659 (43.3)
26 wks	1595	1279 (80.2)	675 (42.4)	602 (37.8)	227 (14.3)	675 (42.4)	543 (34.0)
27 wks	1763	1541 (87.4)	889 (50.6)	645 (36.7)	232 (13.2)	889 (50.6)	454 (25.8)
28 wks	1921	1753 (91.3)	1101 (57.4)	648 (33.8)	188 (9.8)	1101 (57.4)	356 (18.5)
Total	8616	6485 (75.3)	3530 (41.1)	2932 (34.1)	1080 (12.6)	3530 (41.1)	3211 (37.3)



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 (%)	Admission for respiratory causes n (%)	Admission for surgery n (%)	Other reasons for admission* n (%)
22 wks	14	6 (42.9)	<5	<5	<5	<5	0 (0)
23 wks	194	94 (48.5)	48 (24.7)	45 (23.2)	46 (23.7)	28 (14.4)	20 (10.3)
24 wks	635	289 (45.5)	169 (26.6)	118 (18.6)	168 (26.5)	69 (10.9)	52 (8.2)
25 wks	1069	395 (37.0)	223 (20.9)	171 (16.0)	202 (18.9)	110 (10.3)	83 (7.8)
26 wks	1279	433 (33.9)	220 (17.2)	209 (16.3)	249 (19.5)	119 (9.3)	65 (5.1)
27 wks	1541	488 (31.7)	310 (20.1)	175 (11.4)	278 (18.0)	117 (7.6)	93 (6.0)
28 wks	1753	506 (28.9)	319 (18.2)	182 (10.4)	266 (15.2)	132 (7.5)	108 (6.2)
Total	6485	2211 (34.1)	1292 (19.9)	903 (13.9)	1213 (18.7)	577 (8.9)	421 (6.5)

*Other reasons for admission include the following categories: central nervous system (CNS) issue; infections; growth, feeding or nutrition issues; and accident or trauma.

Presentation No 17: Use of aids at home 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	14	8 (57.1)	<5	0 (0)	<5
23 wks	194	92 (47.4)	31 (16.0)	3 (1.6)	18 (9.3)
24 wks	635	257 (40.5)	77 (12.1)	6 (0.9)	42 (6.6)
25 wks	1069	313 (29.3)	85 (8.0)	13 (1.2)	52 (4.9)
26 wks	1279	285 (22.3)	71 (5.6)	6 (0.5)	63 (4.9)
27 wks	1541	274 (17.8)	61 (4.0)	<5	92 (6.0)
28 wks	1753	266 (15.2)	79 (4.5)	8 (0.5)	83 (4.7)
Total	6485	1495 (23.1)	407 (6.3)	40 (0.6)	351 (5.4)

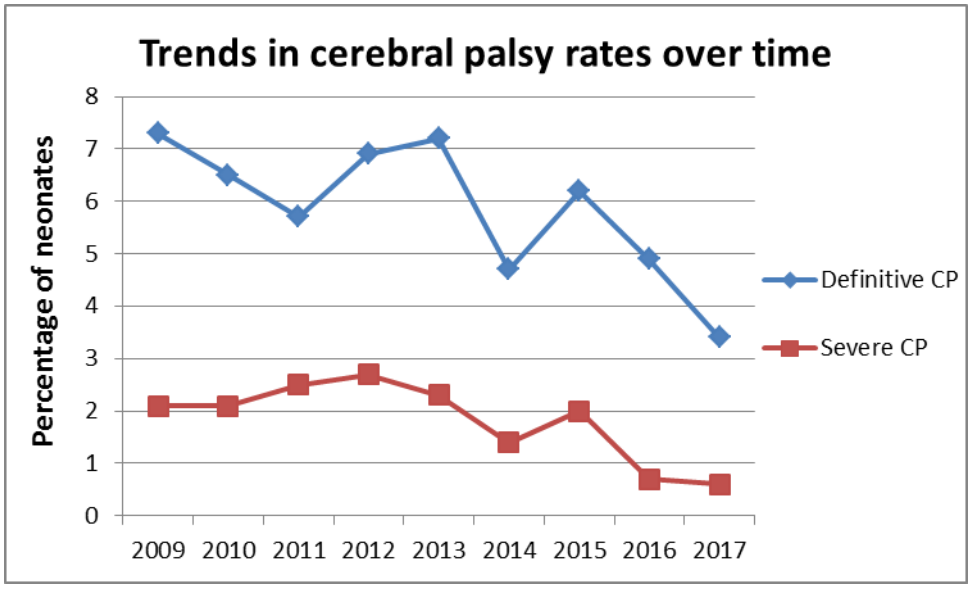
*Aids at home include the use of any of the following items: apnea monitor; pulse oximeter; supplemental O2; respiratory/CPAP; gavage feeding; gastrostomy or jejunostomy; ileostomy/colostomy; tracheostomy; adapted wheelchair or stroller; braces, splints or orthoses; and walker.

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

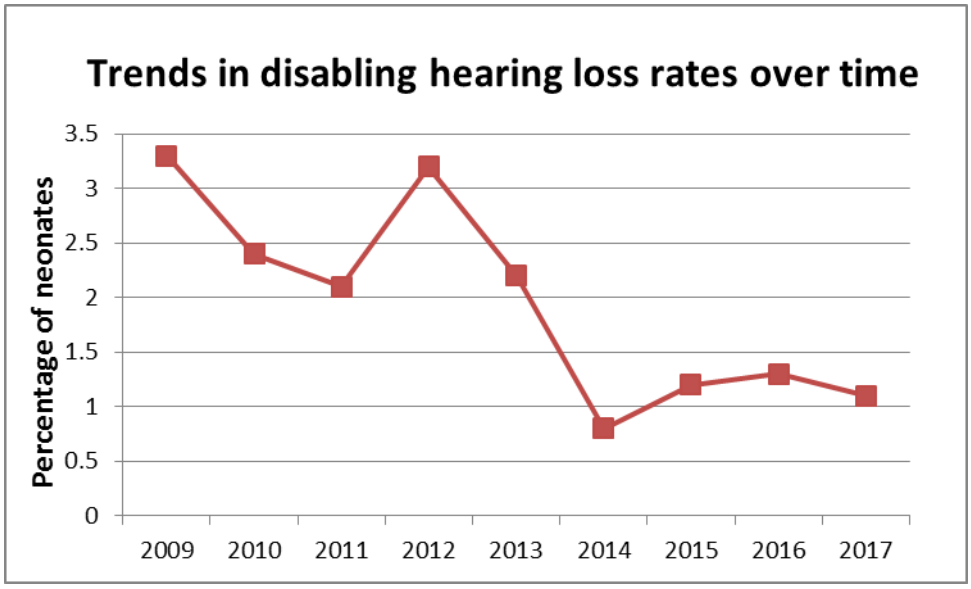
Year of birth	CNFUN complete data (n)	Missing CP data (n)	No CP n (%)	Suspected CP n (%)	Definitive CP n (%)	Missing CP GMFCS (n)	CP GMFCS 1-2 n (%)	CP GMFCS 3-5 n (%)
2009	647	12	581 (89.8)	19 (2.9)	47 (7.3)	7	26 (4.0)	14 (2.1)
2010	997	16	890 (89.3)	42 (4.2)	65 (6.5)	11	33 (3.3)	21 (2.1)
2011	827	25	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)
2009-2017	6385	100	5794 (90.7)	214 (3.4)	377 (5.9)	40	217 (3.4)	120 (1.9)



COMMENTS: Cerebral palsy rates have fallen. 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 loss rates over time

Year of birth	CNFUN complete data (n)	Missing hearing data (n)	Normal hearing n (%)	Mild-moderate hearing loss n (%)	Disabling hearing loss 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)
2009-2017	6358	127	5966 (93.8)	267 (4.2)	125 (2.0)

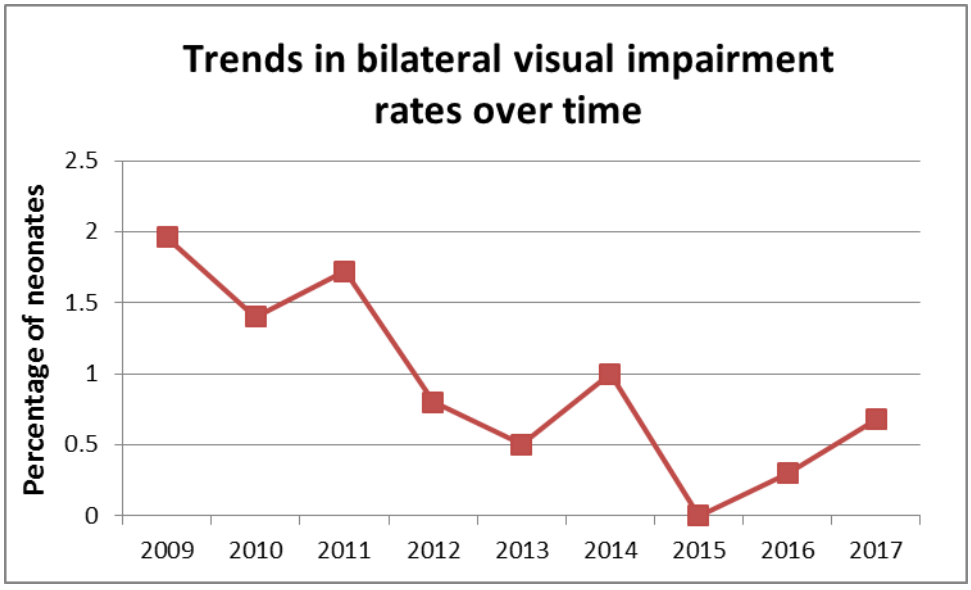


COMMENTS:

Disabling hearing loss was defined as prescribed hearing aid(s) or cochlear implant(s). 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
2009-2017	5981	504	5911 (98.8)	58 (1.0)

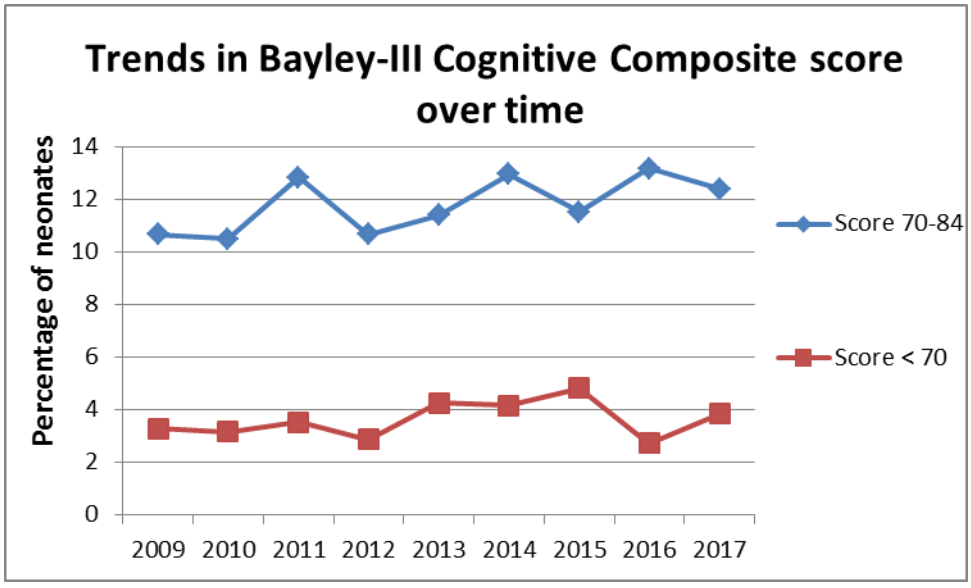


COMMENTS:

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)
2009-2017	6005	480	95 (90, 105)	5082 (84.6)	707 (11.8)	216 (3.6)

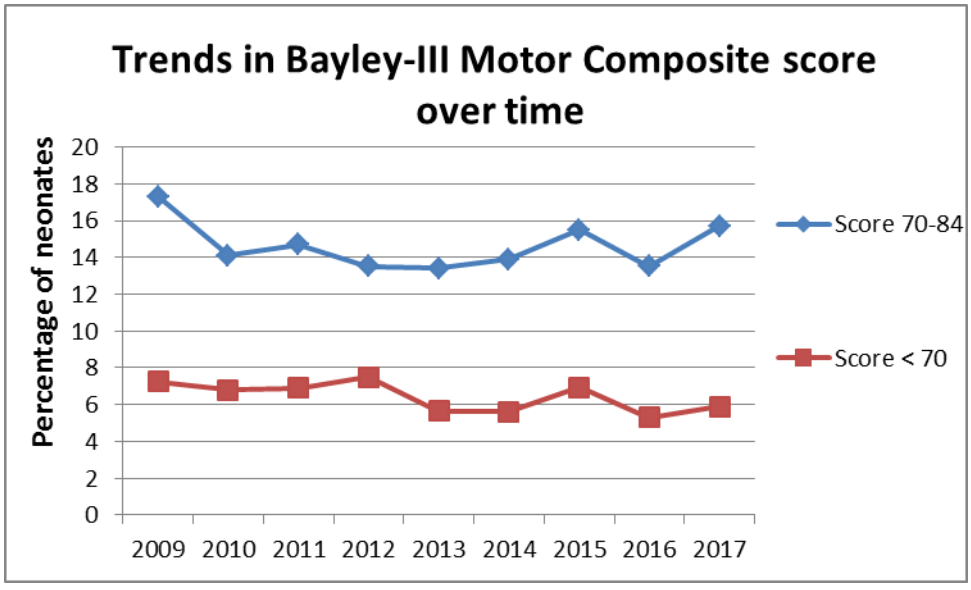


COMMENTS:

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)
2009-2017	5729	756	94 (85, 100)	4522 (78.9)	836 (14.6)	371 (6.5)

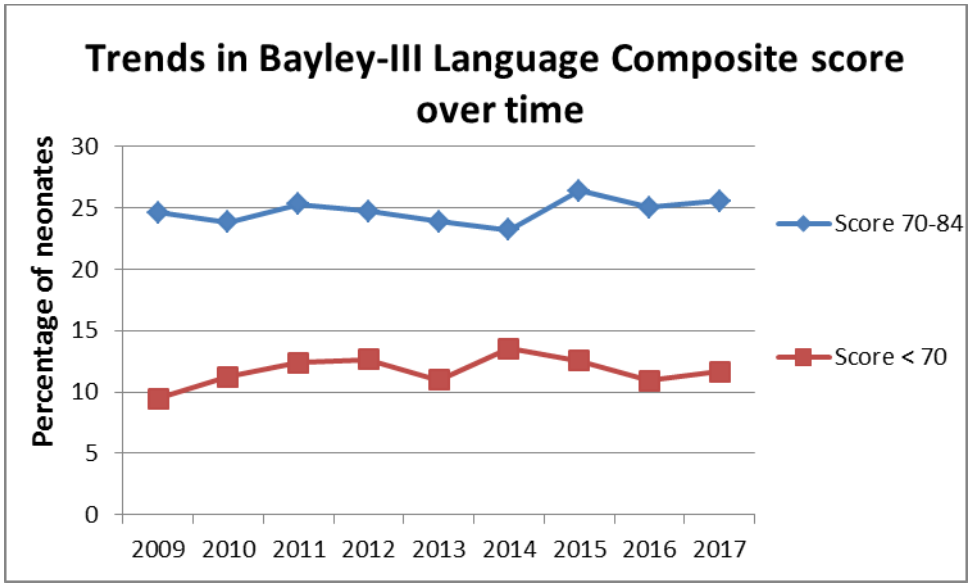


COMMENTS:

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)
2009-2017	5741	744	89 (79, 100)	3649 (63.6)	1419 (24.7)	673 (11.7)

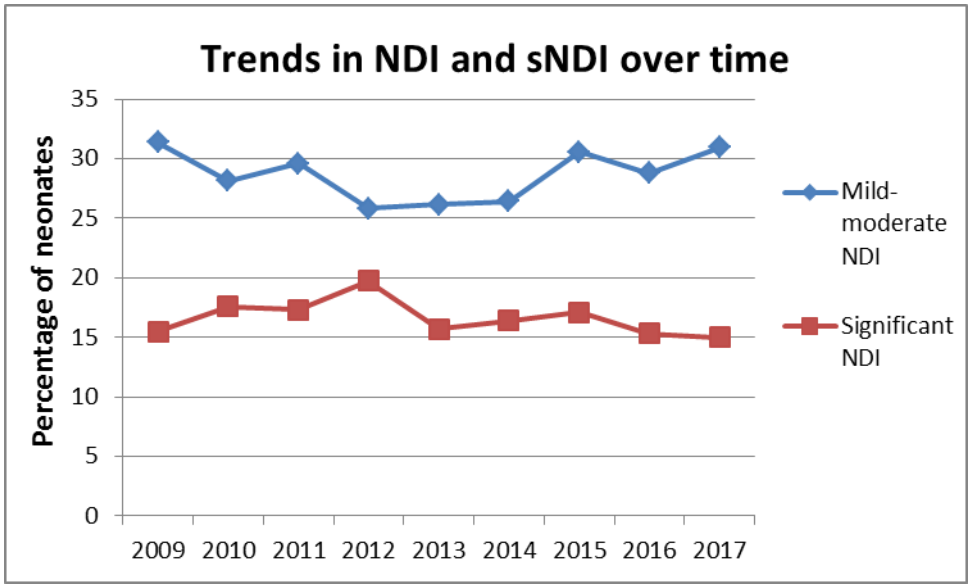


COMMENTS:

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 n (%)
2009	653	6	347 (53.1)	205 (31.4)	101 (15.5)
2010	1012	1	550 (54.3)	285 (28.2)	178 (17.6)
2011	848	4	450 (53.1)	251 (29.6)	147 (17.3)
2012	674	2	367 (54.5)	174 (25.8)	133 (19.7)
2013	612	3	356 (58.2)	160 (26.1)	96 (15.7)
2014	647	2	370 (57.2)	171 (26.4)	106 (16.4)
2015	684	2	358 (52.3)	209 (30.6)	117 (17.1)
2016	712	1	398 (55.9)	205 (28.8)	109 (15.3)
2017	620	2	335 (54.0)	192 (31.0)	93 (15.0)
2009-2017	6462	23	3530 (54.6)	1852 (28.7)	1080 (16.7)



COMMENTS:

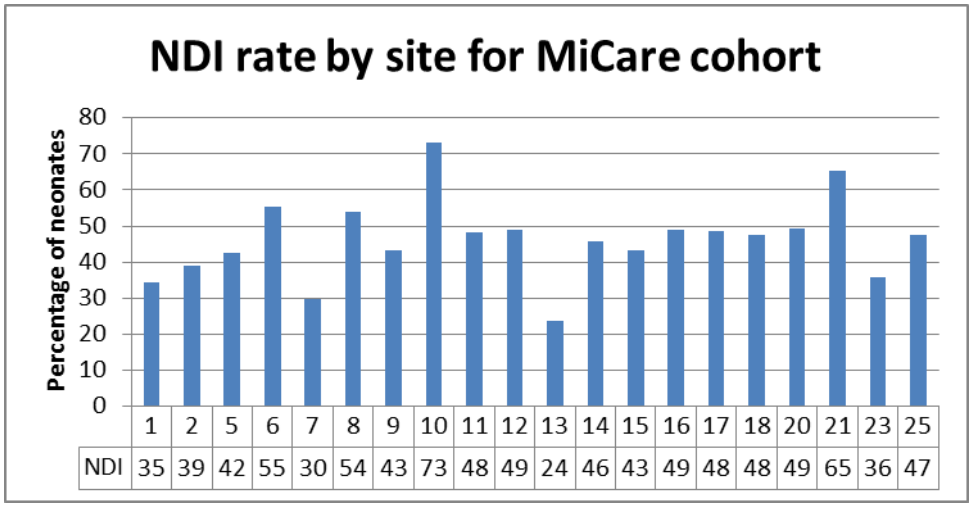
See page 16 for NDI definitions. Rates have not been adjusted for risk factors and higher attrition rates in the later years may impact the results. There has not been a clinically important change in NDI rates.

G. Site Comparisons – Crude

Presentation No 25: 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%.

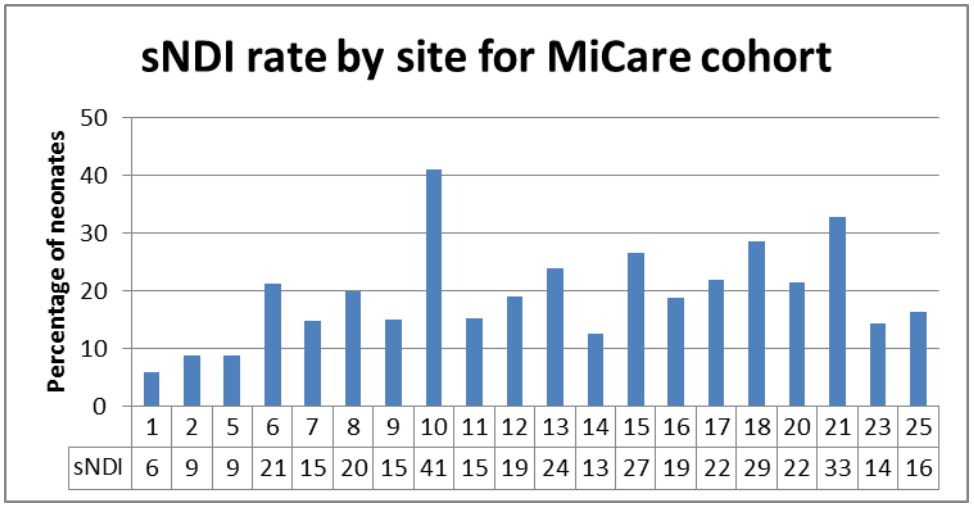


	1	2	5	6	7	8	9	10	11	12	13	14	15	16	17	18	20	21	23	25
NDI	35	39	42	55	30	54	43	73	48	49	24	46	43	49	48	48	49	65	36	47

Presentation No 26: 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%.

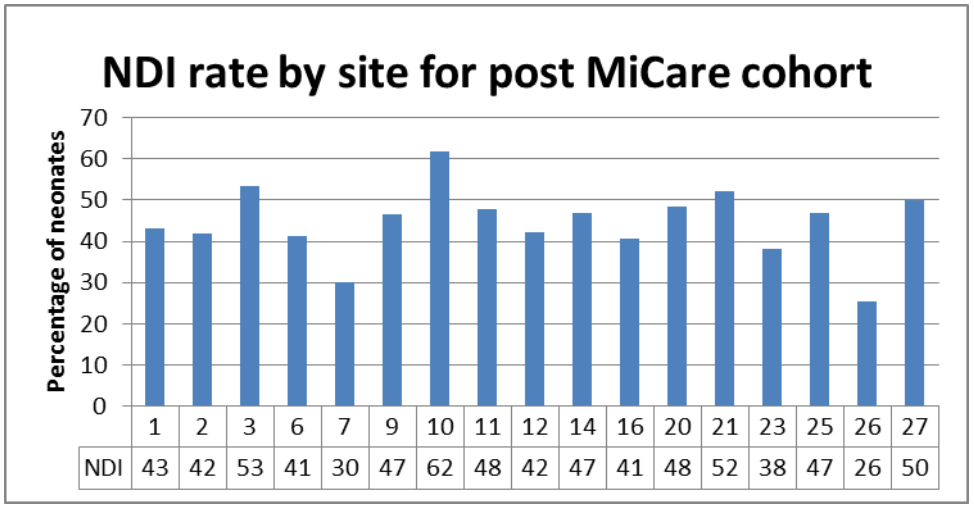


	1	2	5	6	7	8	9	10	11	12	13	14	15	16	17	18	20	21	23	25
sNDI	6	9	9	21	15	20	15	41	15	19	24	13	27	19	22	29	22	33	14	16

Presentation No 27: Neurodevelopmental impairment rates for post-MiCare cohort (Births October 1, 2011- December 31, 2017)*

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	365	208 (57)	157 (43)	23 (6.3)	17 (4.7)	< 5%	65 (17.8)	105 (28.8)	34 (9.3)
2	277	161 (58.1)	116 (41.9)	14 (5.1)	29 (10.5)	0 (0)	29 (10.5)	79 (28.5)	25 (9)
3	75	35 (46.7)	40 (53.3)	< 10%	< 5%	< 5%	17 (22.7)	30 (40)	12 (16)
6	529	311 (58.8)	218 (41.2)	18 (3.4)	18 (3.4)	7 (1.3)	109 (20.6)	142 (26.8)	75 (14.2)
7	20	14 (70)	6 (30)	0 (0)	0 (0)	0 (0)	< 15%	6 (30)	< 15%
9	30	16 (53.3)	14 (46.7)	< 5%	< 5%	0 (0)	6 (20)	6 (20)	5 (16.7)
10	123	47 (38.2)	76 (61.8)	9 (7.3)	12 (9.8)	< 5%	33 (26.8)	65 (52.8)	22 (17.9)
11	409	214 (52.3)	195 (47.7)	30 (7.3)	34 (8.3)	< 5%	97 (23.7)	133 (32.5)	69 (16.9)
12	214	124 (57.9)	90 (42.1)	20 (9.3)	< 5%	< 5%	49(22.9)	59 (27.6)	29 (13.6)
14	237	126 (53.2)	111 (46.8)	11 (4.6)	14 (5.9)	5 (2.1)	45 (19)	78 (32.9)	23 (9.7)
16	520	309 (59.4)	211 (40.6)	24 (4.6)	21 (4)	< 5%	60 (11.5)	157 (30.2)	80 (15.4)
20	207	107 (51.7)	100 (48.3)	10 (4.8)	25 (12.1)	< 5%	41 (19.8)	69 (33.3)	35 (16.9)
21	115	55 (47.8)	60 (52.2)	0 (0)	< 5%	0 (0)	26 (22.6)	49 (42.6)	23 (20)
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	789	418 (53)	371 (47)	22 (2.8)	22 (2.8)	< 5%	137 (17.4)	305 (38.7)	141 (17.9)
26	51	38 (74.5)	13 (25.5)	< 5%	< 10%	0 (0)	7 (13.7)	10 (19.6)	< 15%
27	20	10 (50)	10 (50)	< 5%	0 (0)	0 (0)	< 20%	7 (35)	< 5%

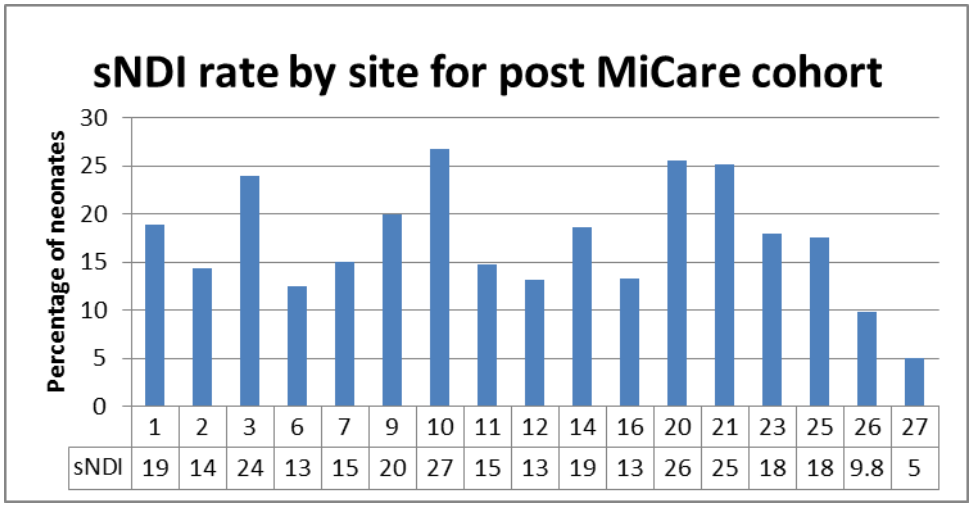
*Cells with less than 5 show only % , rounded up to a multiple of 5%.



Presentation No 28: Significant neurodevelopmental impairment rates for post-MiCare cohort (Births October 1, 2011- December 31, 2017)*

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	365	296 (81.1)	69 (18.9)	13 (3.6)	11 (3)	< 5%	23 (6.3)	23 (6.3)	31 (8.5)
2	277	237 (85.6)	40 (14.4)	5 (1.8)	5 (1.8)	0 (0)	6 (2.2)	6 (2.2)	27 (9.7)
3	75	57 (76)	18 (24)	< 5%	< 5%	0 (0)	5 (6.7)	5 (6.7)	13 (17.3)
6	529	463 (87.5)	66 (12.5)	5 (0.9)	< 5%	< 5%	23 (4.3)	23 (4.3)	51 (9.6)
7	20	17 (85)	< 15%	0 (0)	0 (0)	0 (0)	< 15%	< 15%	< 15%
9	30	24 (80)	6 (20)	0 (0)	0 (0)	0 (0)	< 10%	< 10%	< 5%
10	123	90 (73.2)	33 (26.8)	< 5%	< 5%	< 5%	10 (8.1)	10 (8.1)	27 (22)
11	409	349 (85.3)	60 (14.7)	7 (1.7)	< 5%	< 5%	33 (8.1)	33 (8.1)	30 (7.3)
12	214	186 (86.9)	28 (13.1)	< 5%	< 5%	< 5%	13 (6.1)	13 (6.1)	21 (9.8)
14	237	193 (81.4)	44 (18.6)	6 (2.5)	< 5%	5 (2.1)	19 (8)	19 (8)	20 (8.4)
16	520	451 (86.7)	69(13.3)	5 (1)	9 (1.7)	< 5%	19 (3.7)	19 (3.7)	42 (8.1)
20	207	154 (74.4)	53 (25.6)	< 5%	< 5%	< 5%	17 (8.2)	17 (8.2)	40 (19.3)
21	115	86 (74.8)	29 (25.2)	5 (4.3)	< 5%	0 (0)	11 (9.6)	11 (9.6)	22 (19.1)
23	89	73 (82)	16 (18)	5 (5.6)	< 5%	< 5%	6 (6.7)	6 (6.7)	8 (9)
25	789	650 (82.4)	139 (17.6)	11 (1.4)	15 (1.9)	< 5%	34 (4.3)	34 (4.3)	95 (12)
26	51	46 (90.2)	5 (9.8)	0 (0)	< 5%	0 (0)	< 5%	< 5%	< 10%
27	20	19 (95)	< 10%	0 (0)	0 (0)	0 (0)	< 5%	< 5%	0 (0)

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

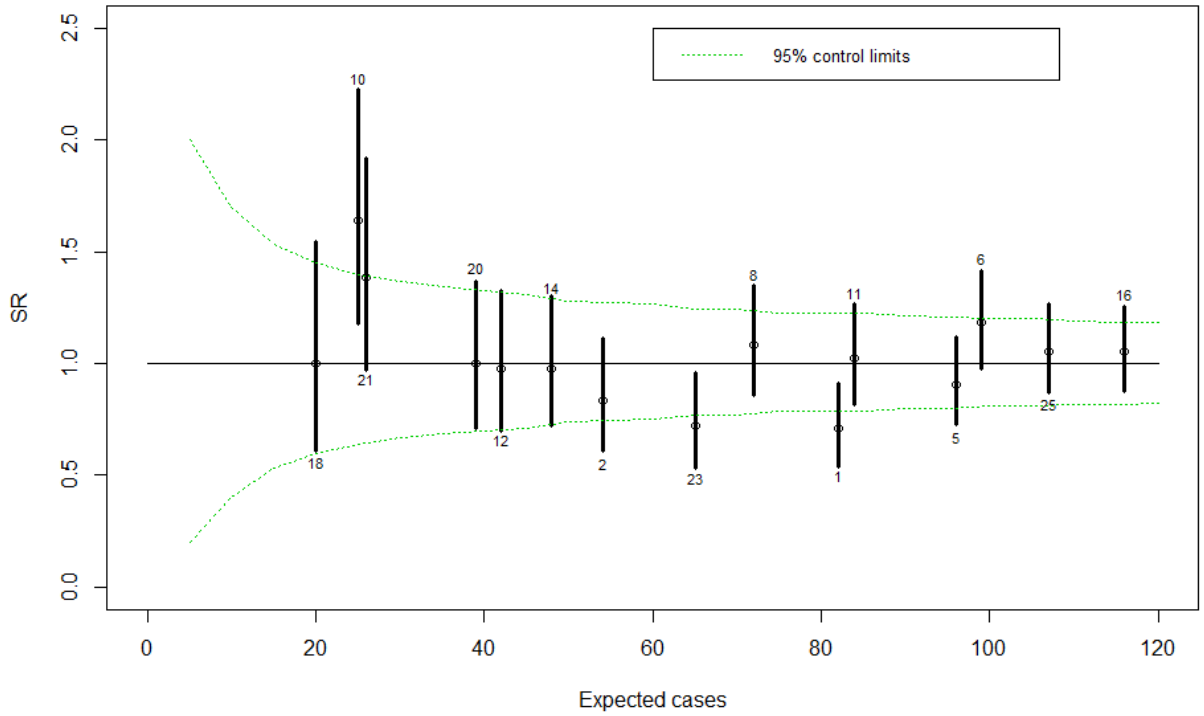


H. Site Comparisons – Adjusted Standardized Ratios by Site

Presentation No 29: Adjusted standardized ratios by site
Neurodevelopmental impairment (NDI) – MiCare cohort

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.



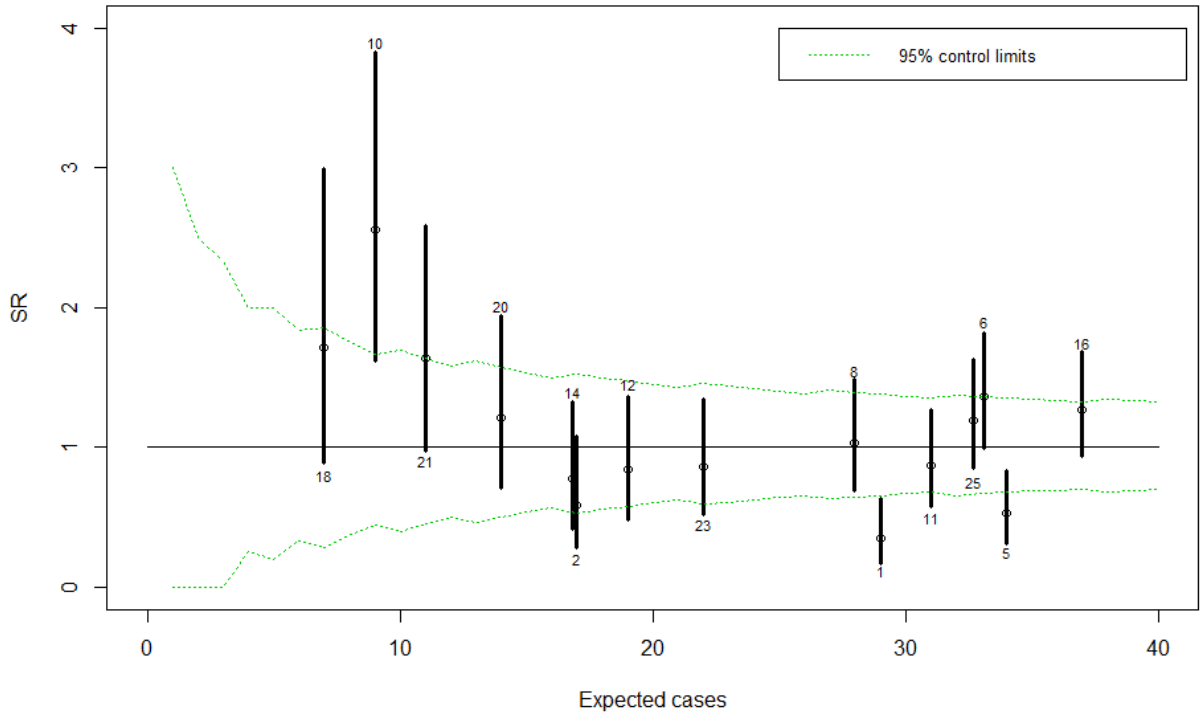
COMMENTS:

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

Presentation No 30: Adjusted standardized ratios by site
Significant neurodevelopmental impairment (sNDI) – MiCare cohort

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.



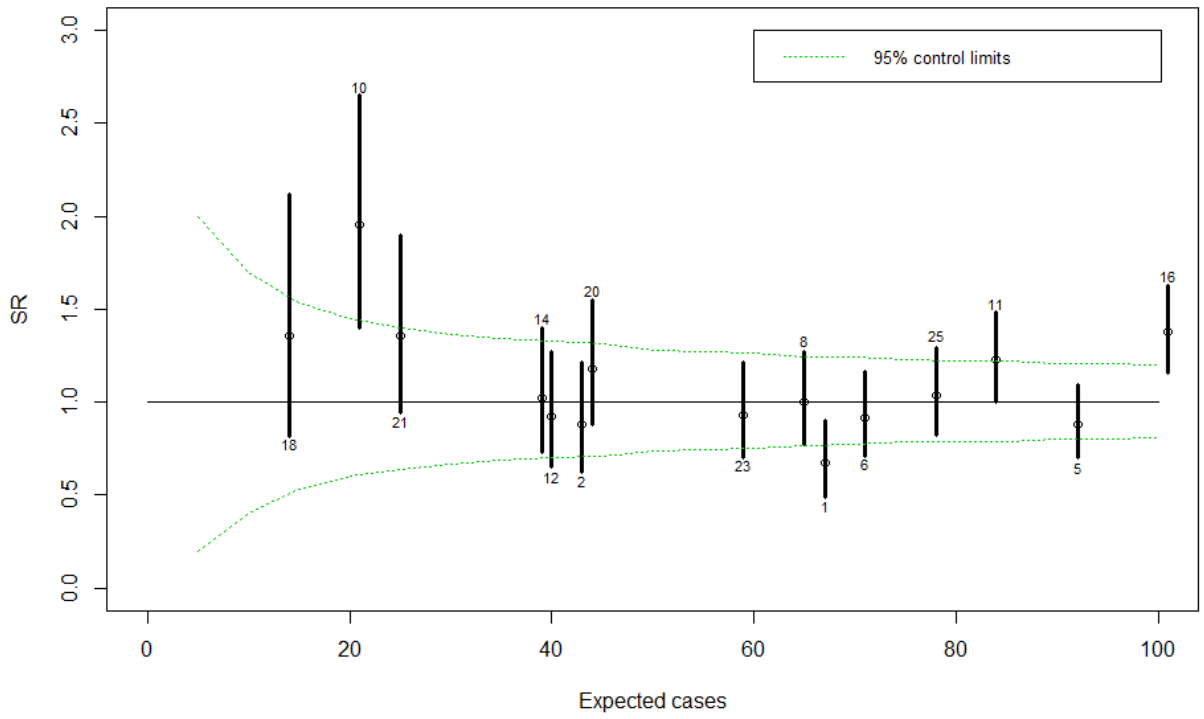
COMMENTS:

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

Presentation No 31: Adjusted standardized ratios by site
Significant neurodevelopmental impairment (sNDI) or death – MiCare cohort

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.



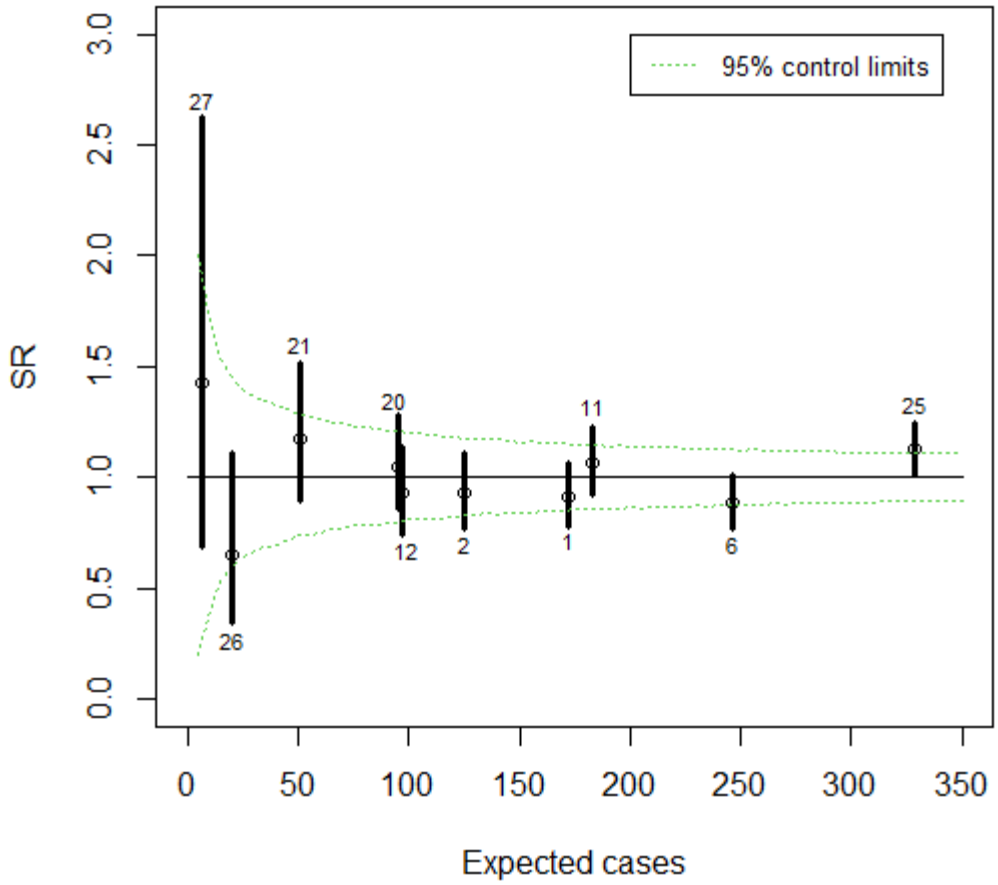
COMMENTS:

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

Presentation No 32: Adjusted standardized ratios by site
Neurodevelopmental impairment (NDI) – Post-MiCare cohort

Site	Children (n)	Follow-up rate (%)	Included (Yes/No)	NDI (n)	Adjusted expected NDI (n)	Adjusted standardized ratio (95%CI)
1	368	75.7	Y	157	172	0.91 (0.78, 1.07)
2	278	80.6	Y	116	125	0.93 (0.77, 1.11)
3	75	56.4	N	40		
4	6	14.6	N	1		
5	7	0.9	N	6		
6	529	71.1	Y	218	246	0.89 (0.77, 1.01)
7	20	15.4	N	6		
8	3	0.6	N	1		
9	30	18.1	N	14		
10	123	62.4	N	76		
11	409	87.4	Y	195	183	1.07 (0.92, 1.23)
12	215	82.7	Y	90	97	0.93 (0.75, 1.14)
14	237	68.5	N	111		
15	14	13.9	N	4		
16	520	60	N	211		
17	5	1.3	N	0		
18	9	7.6	N	5		
19	5	3.2	N	2		
20	209	76.8	Y	100	95	1.05 (0.86, 1.28)
21	118	74.7	Y	60	51	1.18 (0.90, 1.51)
22	9	14.1	N	4		
23	89	27.6	N	34		
25	790	82.2	Y	371	329	1.13 (1.02, 1.25)
26	51	77.3	Y	13	20	0.65 (0.35, 1.11)
27	20	87	Y	10	7	1.43 (0.69, 2.63)

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.

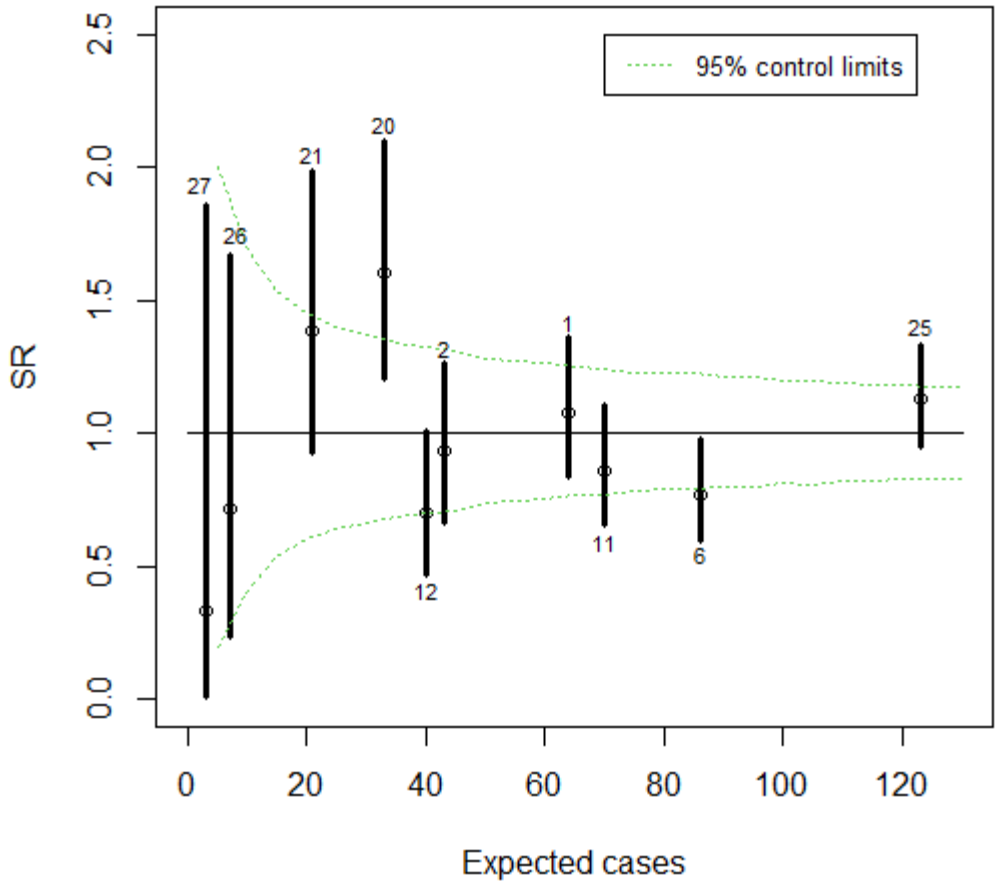


COMMENTS:
Sites with points outside the green "funnel" represent higher or lower adjusted NDI rates than expected. When the 95% confidence interval doesn't cross 1, the results are statistically significant. Therefore, one site (25) has a statistically higher NDI rate.

Presentation No 33: Adjusted standardized ratios by site
Significant neurodevelopmental impairment (sNDI) – Post-MiCare cohort

Site	Children (n)	Follow-up rate (%)	Included (Yes/No)	sNDI (n)	Adjusted expected sNDI (n)	Adjusted standardized ratio (95%CI)
1	368	75.7	Y	69	64	1.08 (0.84, 1.36)
2	278	80.6	Y	40	43	0.93 (0.66, 1.27)
3	75	56.4	N	18		
4	6	14.6	N	0		
5	7	0.9	N	3		
6	529	71.1	Y	66	86	0.77 (0.59, 0.98)
7	20	15.4	N	3		
8	3	0.6	N	0		
9	30	18.1	N	6		
10	123	62.4	N	33		
11	409	87.4	Y	60	70	0.86 (0.65, 1.10)
12	215	82.7	Y	28	40	0.70 (0.47, 1.01)
14	237	68.5	N	44		
15	14	13.9	N	1		
16	520	60	N	69		
17	5	1.3	N	0		
18	9	7.6	N	2		
19	5	3.2	N	1		
20	209	76.8	Y	53	33	1.61 (1.20, 2.10)
21	118	74.7	Y	29	21	1.38 (0.92, 1.98)
22	9	14.1	N	3		
23	89	27.6	N	16		
25	790	82.2	Y	139	123	1.13 (0.95, 1.33)
26	51	77.3	Y	5	7	0.71 (0.23, 1.67)
27	20	87	Y	1	3	0.33 (0.01, 1.86)

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.

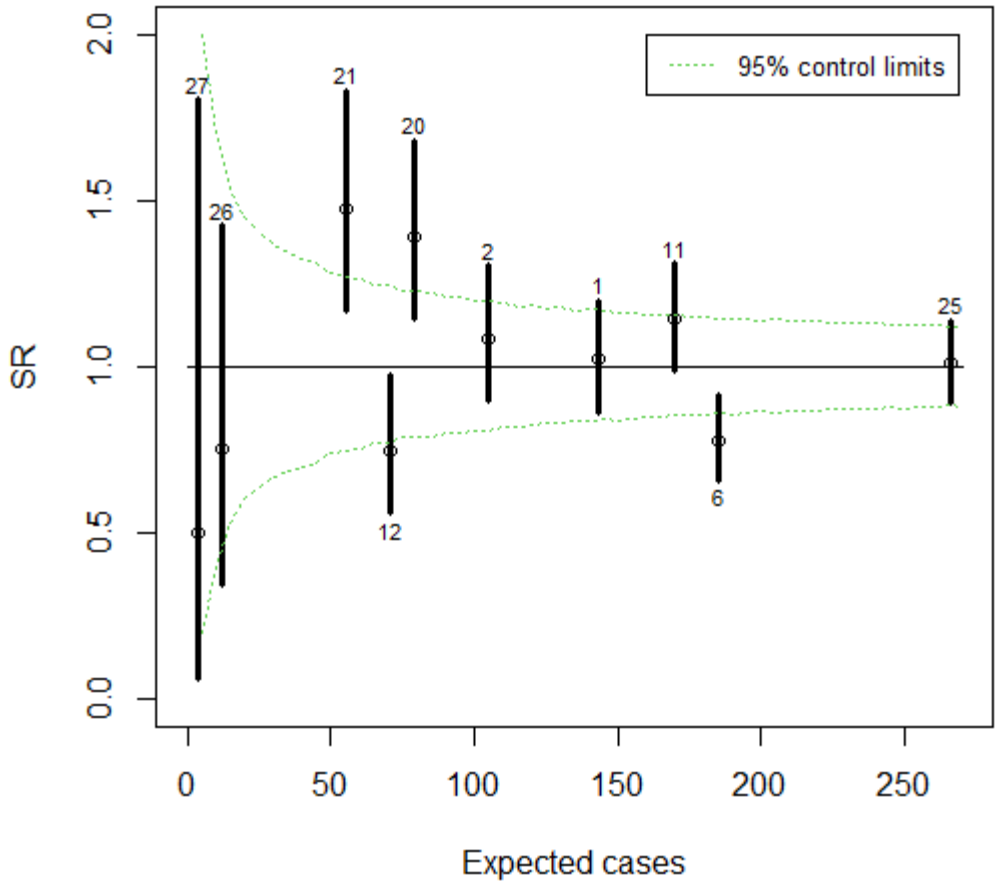


COMMENTS:
Sites with points outside the green "funnel" represent higher or lower adjusted sNDI rates than expected. When the 95% confidence interval doesn't cross 1, the results are statistically significant. Therefore, one site (20) has a statistically higher, and one site (6) has a statistically lower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

Presentation No 34: Adjusted standardized ratios by site
Significant neurodevelopmental impairment (sNDI) or death – Post-MiCare cohort

Site	Children (n)	Follow-up rate (%)	Included (Yes/No)	sNDI or death (n)	Adjusted expected outcome (n)	Adjusted standardized ratio (95%CI)
1	445	75.7	Y	146	143	1.02 (0.86, 1.20)
2	352	80.6	Y	114	105	1.09 (0.90, 1.30)
3	108	56.4	N	51		
4	16	14.6	N	10		
5	126	0.9	N	122		
6	607	71.1	Y	144	185	0.78 (0.66, 0.92)
7	31	15.4	N	14		
8	94	0.6	N	91		
9	53	18.1	N	29		
10	162	62.4	N	72		
11	543	87.4	Y	194	170	1.14 (0.99, 1.31)
12	240	82.7	Y	53	71	0.75 (0.56, 0.98)
14	293	68.5	N	100		
15	44	13.9	N	31		
16	692	60	N	241		
17	71	1.3	N	66		
18	33	7.6	N	26		
19	28	3.2	N	24		
20	266	76.8	Y	110	79	1.39 (1.14, 1.68)
21	170	74.7	Y	81	55	1.47 (1.17, 1.83)
22	24	14.1	N	18		
23	167	27.6	N	94		
25	920	82.2	Y	269	266	1.01 (0.89, 1.14)
26	55	77.3	Y	9	12	0.75 (0.34, 1.42)
27	21	87	Y	2	4	0.50 (0.06, 1.81)

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 doesn't cross 1, the results are statistically significant. Therefore, 4 sites have statistically higher or lower sNDI or death rates.

I. Summary of Publications

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.

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.

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.

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.

Manuscripts 2020:

1. Association between Transport Risk Index of Physiologic Stability in Extremely Premature Infants and Mortality or Neurodevelopmental Impairment at 18 to 24 Months. Grass B, Ye XY, Kelly E, Synnes A, Lee S. J Pediatr. 2020 Sep;224:51-56.e5. PMID: 32442448.
2. Neurodevelopmental and Growth Outcomes of Extremely Preterm Infants with Necrotizing Enterocolitis or Spontaneous Intestinal Perforation. 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. J Pediatr Surg. 2020 May; S0022-3468(20)30326-2. PMID: 32553453.
3. 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.

Manuscripts 2021:

1. Albaghli F, Church P, Ballantyne M, Girardi A, Synnes A. Neonatal Follow-up Programs in Canada: A National Survey. Paediatrics and Child Health. 2021 Feb;26(1):e46-e51.: 1-6.

Manuscripts submitted:

1. 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. Revised manuscript submitted to Pediatrics.
2. 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. Integrated Care: Very Preterm Neurodevelopmental Outcomes at 18 Months. Revision submitted to Arch Dis Child Fetal Neonatal Ed.
3. Synnes A, De Silva DA, Piedboeuf B, Brandt R, Moddemann D, Bone J, von Dadelszen P, Shah P, Magee LA and the MAG-CP Collaborative Group, Canadian Neonatal Network and the Canadian Neonatal Follow-Up Network. Cerebral palsy rates after a magnesium sulphate

knowledge translation intervention. Submitted to Arch Dis Child Fetal Neonatal Ed.

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. Revised manuscript submitted to ACOG.
5. 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.

Manuscripts in final draft:

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