

Canadian Neonatal Follow-Up Network Réseau Canadien de Suivi Néonatal



CNFUN Annual Report 2019

Introduction

The Canadian Neonatal Follow-Up Network (CNFUN) is 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 include:

- 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.
- Be advocates 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 has been elected every 2 years since. It is be composed of 9 members:

- The director of the network
- 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 or physiotherapy or speech and language. One of these professionals must be familiar with the Bayley-III.

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

Membership

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

Institutional Membership is open to all institutions, which have 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 the data to the CNFUN data set. 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 on-going 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:** should be submitted to the chair of the Steering Committee and should 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 three 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.

CNFUN steering committee

Dr. Anne Synnes – Neonatologist / neonatal follow-up- founding director (British Columbia)

Dr. Thuy Mai Luu – Co-director Neonatal follow-up (Québec)

Dr. Diane Moddemann –Neonatal follow-up (Manitoba)

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

Dr. Kevin Coughlin-Neonatologist / neonatal follow-up (Ontario)

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

Dr. Ruth Grunau – Psychologist / researcher (British Columbia)

Lynn Whitty-Nurse / neonatal follow-up (Ontario)

Dr. Rudaina Banihani -Neonatologist / neonatal follow-up (Ontario)

Annual report review committee

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

Dr. Thuy Mai Luu –Neonatal follow-up (Québec)

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

Dr. Matthew Hicks – Neonatologist, developmental & behavioral pediatrics (Alberta)

Carolina Segura- CNFUN National Coordinator (British Columbia)

Table of Contents

- A. Executive Summary
- B. Participating Sites
 - i. Presentation No 1 - CNFUN site descriptions
 - ii. Presentation No 2 - CNFUN site participation and follow-up rates
 - iii. Presentation No 3 - CNN and CNFUN flow diagram for births April 1, 2009- Dec 31, 2016
- C. Outcomes Definitions
- D. Descriptive Analyses
 - i. Presentation No 4 - Survival and participant assessment-all CNN
 - ii. Presentation No 5 - Follow-up rates at CNFUN sites
 - iii. Presentation No 6 - Survival and participant assessments among all CNN sites by gestational age
 - iv. Presentation No 7 - Follow-up rates among CNFUN sites by gestational age
- E. Gestational Age based Outcomes
 - i. Presentation No 8 - Cerebral palsy rates by gestational age
 - ii. Presentation No 9 - Hearing impairments rates by gestational Age
 - iii. Presentation No 10 - Visual impairment rates by gestational age
 - iv. Presentation No 11 - Bayley- III cognitive composite scores rates by gestational age
 - v. Presentation No 12 - Bayley- III motor composite scores rates by gestational age
 - vi. Presentation No 13 - Bayley- III language composite scores Rates by Gestational Age
 - vii. Presentation No 14 - Neurodevelopmental impairment rates by gestational age
 - viii. Presentation No 15 – Death or neurodevelopmental impairment rates by gestational age
- F. Outcomes Over Time
 - i. Presentation No 16 - Trends in cerebral palsy rates over time

- ii. Presentation No 17 -Trends in hearing impairment rates over time
- iii. Presentation No 18- Trends in visual impairment rates over time
- iv. Presentation No 19 - Trends in Bayley- III cognitive composite scores over time
- v. Presentation No 20 - Trends in Bayley- III motor composite scores over time
- vi. Presentation No 21 - Trends in Bayley- III language composite scores over time
- vii. Presentation No 22 - Trends in NDI and sNDI over time

G. Site Comparisons - Crude

- i. Presentation No 23-Neurodevelopmental outcomes for MiCare cohort (Births April 1, 2009-Sept 30, 2011)
- ii. Presentation No 24 - Significant outcomes for MiCare cohort (Births April 1, 2009-Sept 30, 2011)
- iii. Presentation No 25 -Neurodevelopmental outcomes for post MiCare Cohort (Births Oct 1, 2011- Dec 31, 2016)
- iv. Presentation No 26 - Significant neurodevelopmental outcomes for post MiCare cohort (Births Oct 1, 2011- Dec 31, 2016)

H. Site Comparisons- Adjusted Standardized Ratios by Site

- i. Presentation No 27 -Adjusted standardized ratio by site NDI MiCare cohort
- ii. Presentation No 28 - Adjusted standardized ratios by site – significant NDI- MiCare cohort
- iii. Presentation No 29 -Adjusted Standardized ratios by site – significant NDI or Death- MiCare cohort
- iv. Presentation No 30 - Adjusted standardized ratios by site - NDI- post- MiCare cohort
- v. Presentation No 31 - Adjusted standardized ratios by site – significant NDI- Post MiCare cohort
- vi. Presentation No 32 - Adjusted standardized ratios by site – significant NDI or death post- MiCare cohort

I. Summary of Publications

A. Executive summary

We are pleased to provide the second annual CNFUN 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 unprecedented national and site specific data. Since the start of CNFUN data collection in April 2009, 6432 children have participated in CNFUN and 5863 of these have linked neonatal data from the Canadian Neonatal Network™.

Improving health and health care is our ultimate goal but the first step is identifying where we are now. Our CNFUN community is addressing this goal in many ways. The titles of our publications, listed at the end of this report, exemplify how we are identifying practices such as use of bevacizumab, oxygen concentration for resuscitation in the delivery room, admission temperature, antibiotic utilization in the NICU and early caffeine to identify potential best practices.

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 brought us closer together with our parent partners.

In this second report we have strived to improve on our first one. Importantly we have reached out to all our participating sites to increase data accuracy and completeness. Thank you to all the sites for your diligent work and collaborative efforts. The results you find in this report required much more than collecting existing data and we recognize your faithful commitment since much of the effort is unfunded. Our goal is to demonstrate the importance of our work so that it can be incorporated into clinical care and quality improvement.

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 April 1, 2016. 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.

I am thrilled to introduce Dr. Thuy Mai Luu as the CNFUN co-director. CNFUN is growing and striving to do more. Mai brings both clinical and research expertise in neonatal follow-up and we look forward to working together.

Anne Synnes MDCM, MHSc

Director, CNFUN

Thuy Mai Luu MD, MSc

Co-Director, CNFUN

B. Participating sites

Presentation No 1: CNFUN site description

Active members				
Abbreviation	NFUP Program Name / City	Hospital Site	Site Investigator	Number of CNFUN members
BCWH	Neonatal Follow-Up Program, vancouver	BC Women's Hospital & Health Centre	Anne Synnes	7
VGH/GVS	Neonatal Follow-Up Team, Victoria	Victoria General Hospital	Thevanisha Pillay	3
ACH/FMC	Perinatal Follow-up Clinic, Calgary	Alberta Children's Hospital & Foothills Hospital, University of Calgary	Leonora Hendson	5
EDM	Neonatal and Infant Follow-Up Clinic, Edmonton	Glenrose Rehabilitation Hospital	Amber Reichert, Matt Hicks	3
SBGH	High Risk Newborn Follow-Up Program, Winnipeg	St. Boniface General Hospital	Diane Moddemann, Cecilia del Cabo	4
HSCC	High Risk Newborn Follow-Up Program, Winnipeg	University of Manitoba Health Sciences Centre / Children's Hospital	Diane Moddemann, Cecilia de Cabo	6
HHSC	Neonatal Follow-Up Clinic, Hamilton	Hamilton Health Sciences Centre, McMaster Children's Hospital	Karen Thomas	2
KGH	Special Infant Clinic, Kingston	Kingston General Hospital	Sarah McKnight	2
SJHC (LHSC)	Developmental Follow-Up Clinic, London	St. Joseph's Health Care London	Kevin Coughlin	2
SUNY	Neonatal Follow-Up Program, Toronto	Sunnybrook Health Sciences Center	Paige Church	2
MSH	Neonatal Follow-Up Pogram, Toronto	Mount Sinai Hospital	Edmond Kelly	2
WRH	Neonatal Neurodevelopment Follow-Up Program, Windsor	Windsor Regional Hospital	Chukwuma Nwaesei	2
CHUS	Clinique de suivi neonatal, Sherbrooke	Centre Hopitalier Universitaire de Sherbrooke	Alyssa Morin, Charlotte Demers	2

Active members				
Abbreviation	NFUP Program Name / City	Hospital Site	Site Investigator	Number of CNFUN members
CHUQ	Centre Hospitalier Universitaire de Quebec (Laval Site)	Centre Mere Enfant, Centre Hospitalier de L'Université Laval	Sylvie Bélanger	2
HSJ	Clinique de suivi neonatal, Montréal	Universite de Montreal, Hôpital Sainte-Justine	Thuy Mai Luu, Veronique Dorval	3
JGH	Neonatal Follow-Up Clinic, Montréal	Jewish General Hospital	Ermelinda Pelausa, Kim-Anh Nguyen	3
MUHC	Neonatal Follow-Up Program, Clinique de Suivi Neonatal, Montréal	McGill University Health Centre/ Montreal Children's Hospital/ L'Hôpital de Montréal pour enfants	May Khairy, Marc Beltempo	2
IWK	Perinatal Follow-Up Program, Halifax	IWK Health Centre and Cape Breton Regional Hospital	Jehier Afifi	4
HMR	Montréal	Hôpital Maisonneuve-Rosemont	Marie St-Hilaire	1
New members				
Abbreviation	NFUP Program Name / City	Hospital Site	Site Investigator	Number of CNFUN members
RCH	Neonatal Follow-Up Program, New Westminster	Royal Columbian Hospital	Miroslav Stavel, Anitha Moodley	2
SMH	Neonatal Follow-Up Program, Surrey	Surrey Memorial Hospital	Rebecca Sherlock	1

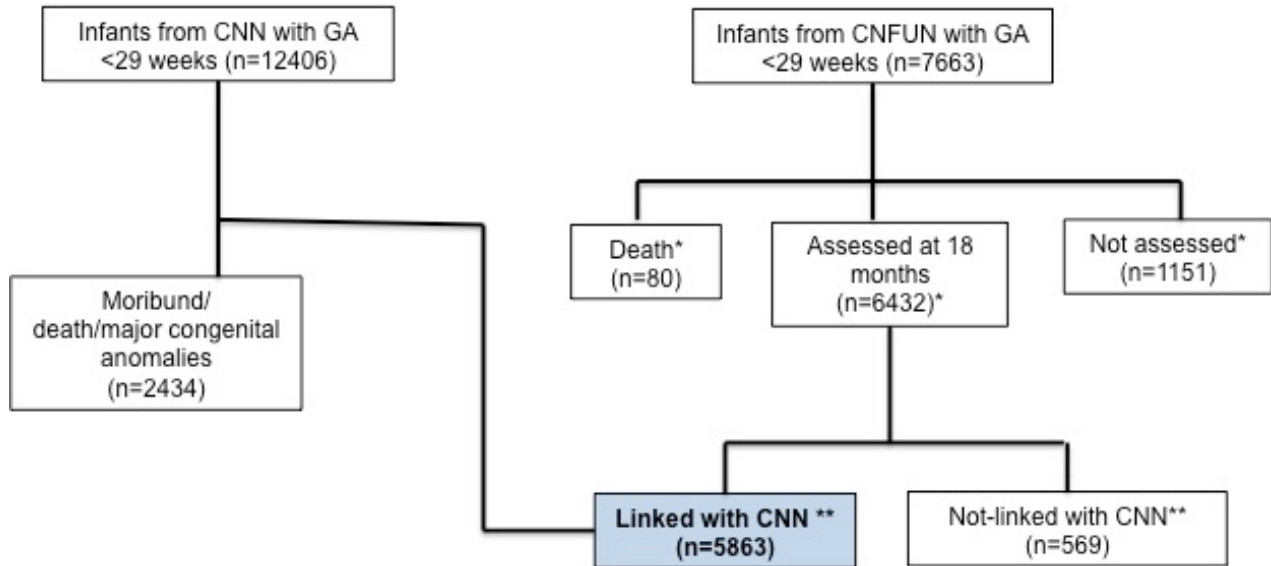
Past members				
Abbreviation	NFUP Program Name / City	Hospital Site	Site Investigator	Number of CNFUN members
ECH	Fredericton	Dr. Everett Chalmers Hospital	Ramaiyer Krishnaswamy	1
SEHC	Neonatal Follow-Up Clinic, Moncton	Moncton Hospital	Roderick Canning	3
SEHC	Neonatal Follow-Up Program, Saint John	Saint John Regional Hospital	Luis Monterrosa	2
JCHC	High-Risk Follow-Up Clinic, St. John's	Janeway Children's Health & Rehabilitation Centre	Phil Murphy	2
HSC	Neonatal Follow-Up Program, Toronto	Hospital for Sick Children	Linh Ly	1
CHEO/OTTA	Neonatal Follow-Up Clinic, Ottawa	Children's Hospital of Eastern Ontario	Thierry Daboval	1
RQHR	Developmental Assessment Clinic, Regina	Regina General Hospital	Zarin Kalapesi, J.P. Bodani	3
RUH	Saskatoon	Royal University Hospital	Sibasis Daspal	2

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

CNFUN Site	MiCare data, Yes / No	MiCare Follow-Up Rate n (%)	Post-MiCare Follow-Up rate- n (%) preliminary	Parent-EPIQ Intervention site Yes/No
1	Yes	170/222 (76.6)	322/428 (75.2)	Yes
2	Yes	115/131 (87.8)	239/297 (80.5)	No
3	Yes	11/13 (84.6)	61/118 (51.7)	No
4	Yes	13/17 (76.5)	6/31 (19.4)	No
5	Yes	205/256 (80.1)	7/611 (1.1)	Yes
6	Yes	213/249 (85.5)	440/617 (71.3)	Yes
7	Yes	30/53 (56.6)	17/115 (14.8)	No
8	Yes	145/203 (71.4)	3/413 (0.7)	No
9	Yes	53/110 (48.2)	27/147 (18.4)	No
10	Yes	56/69 (81.2)	99/166 (59.6)	Yes
11	Yes	178/223 (79.8)	353/397 (88.9)	Yes
12	Yes	84/102 (82.4)	198/225 (88)	Yes
13	Yes	21/37 (56.8)	0/84 (0)	No
14	Yes	103/135 (76.3)	218/297 (73.4)	Yes
15	Yes	31/51 (60.8)	7/80 (8.8)	No
16	Yes	250/301 (83.1)	419/705 (59.4)	Yes
17	Yes	64/163 (39.3)	5/319 (1.6)	No
18	Yes	43/47 (91.5)	9/89 (10.1)	No
19	Yes	17/66 (25.8)	5/123 (4.1)	No
20	Yes	79/101 (78.2)	161/214 (75.2)	Yes
21	Yes	55/59 (93.2)	102/134 (76.1)	Yes
22	Yes	13/20 (65)	9/55 (16.4)	No
23	Yes	132/166 (79.5)	89/270 (33)	Yes
24	Yes	7/13 (53.8)	0/24 (0)	Yes
25	Yes	241/308 (78.2)	681/822 (82.8)	No
26	Yes	18/22 (81.8)	40/54 (74.1)	No
27	No	-	-	No

Presentation No 3

CNN and CNFUN flow diagram for births April 1, 2009- Dec 31, 2016



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

**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, probabilistical matching is attempted to link.

C. Outcomes Definitions

Impairments	Significant neurodevelopmental disability = 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

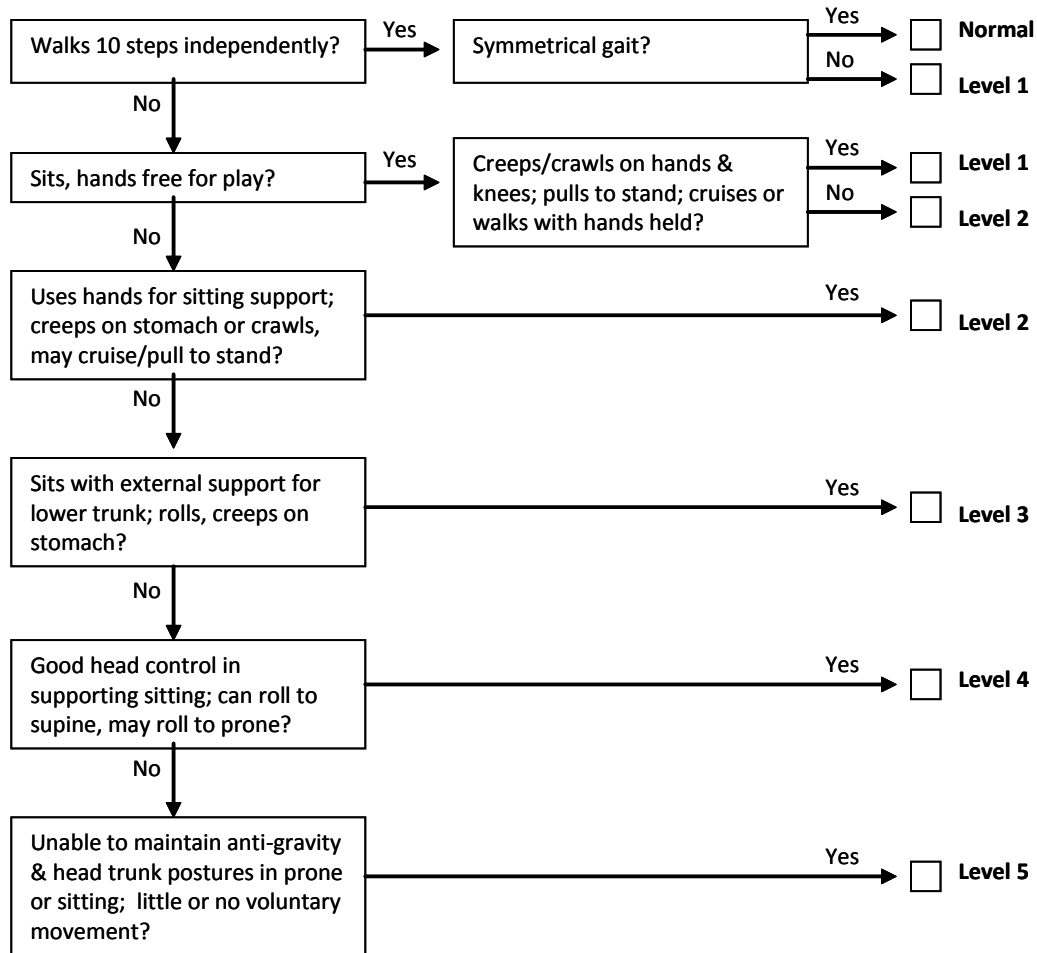
Hearing impairment- determined from audiology reports

Visual impairment is determined from ophthalmology consult if available. If no report is available, impairment is defined as a small scarred eye, sustained sensory nystagmus or lack of response to a 1cm object (cheerio) on a white background at 30 cms.

*Children who could not be tested using the Bayley-III with a Bayley-III Adaptive Behavior score < 70 or if no Bayley-III score assessed to have a significant developmental delay

**Children with a NDI or those who could not be tested using the Bayley-III with a Bayley-III Adaptive Behavior score < 85

Gross Motor Function Classification System (GMFCS)



COMMENTS:

The algorithm is based on Palisano¹

Further information is available at

<http://motorgrowth.canchild.ca/en/GMFCS/originalversion.asp>

- 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)	NICU death n (%)	NICU survivors# n (%)	Death After NICU (%)	Linked CNN-CNFUN data for NICU survivors n (%)	Known outcome** for NICU admissions n (%)
2009*	1201	212 (17.7)	881 (73.4)	(0.4)	659 (75%)	876 (73%)
2010	1613	244 (15.1)	1335 (82.8)	(0.9)	1013 (76 %)	1271 (79%)
2011	1527	258 (16.9)	1218 (79.8)	(0.3)	852 (70 %)	1115 (73%)
2012	1590	251 (15.8)	1288 (81.0)	0 (0)	676 (52%)	927 (58%)
2013	1622	256 (15.8)	1307 (80.6)	(0.2)	615 (47%)	874 (54%)
2014	1621	232 (14.3)	1319 (81.4)	(0.1)	649 (49%)	882 (54%)
2015	1544	201 (13.0)	1256 (81.4)	(0.1)	686 (55%)	888 (58%)
2016	1678	221 (13.2)	1358 (80.9)	(0.3)	713 (53%)	939 (56%)
'09-'16	12406	1875 (15.1)	9972 (80.3)	34 (0.3)	5863 (59%)	7772 (63%)

n= number

* April 1 to Dec 31

** Death or CNFUN outcomes

#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	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 (%)
2009*	881 (73.4)	881	774	659 (75%)	659 (75%)
2010	1335 (82.8)	1335	1123	1013 (76 %)	1013 (76%)
2011	1218 (79.8)	1218	935	852 (70 %)	852 (70%)
2012	1288 (81.0)	938	722	676 (52%)	651 (69%)
2013	1307 (80.6)	973	664	615 (47%)	611 (63%)
2014	1319 (81.4)	954	708	649 (49%)	643 (67%)
2015	1256 (81.4)	929	757	686 (55%)	679 (73%)
2016	1358 (80.9)	999	749	713 (53%)	710 (71%)
'09-'16	9972 (80.3)	8227	6432	5863 (59%)	5818 (71%)

n= number

* April 1 to December 31

** CNFUN sites may see patients not registered in CNN

For 2012-2015, Participating sites: 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, McMaster Children's Hospital , 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 Hospitalier Universitaire de Sherbrooke, Centre Mere Enfant, Centre Hospitalier de L'Université Laval, IWK Health Centre and Cape Breton Regional Hospital, Winnipeg Health Sciences Centre Children's Hospital.

2016: EDM, HHSC, KGH and HMR 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 6:

Survival and participant assessments among all CNN sites by gestational age

Gestational Age (Weeks)	NICU admission (n)	NICU death n (%)	NICU survivors# n (%)	Death After NICU (%)	Linked CNN-CNFUN data for NICU survivors n (%)	Known outcome* for NICU admissions n (%)
22	127	48 (37.8)	20 (15.8)	0 (0)	10 (50.0)	58 (45.7)
23	672	305 (45.4)	279 (41.5)	2 (0.3)	165 (59.1)	472 (70.2)
24	1485	476 (32.1)	931 (62.7)	6 (0.4)	565 (60.7)	1047 (70.5)
25	2045	412 (20.2)	1564 (76.5)	8 (0.4)	963 (61.6)	1383 (67.6)
26	2280	290 (12.7)	1913 (83.9)	5 (0.2)	1171 (61.2)	1466 (64.3)
27	2692	193 (7.2)	2411 (89.6)	9 (0.3)	1415 (58.7)	1617 (60.1)
28	3105	151 (4.9)	2854 (91.9)	4 (0.1)	1574 (55.2)	1729 (55.7)
22-28	12406	1875 (15.1)	9972 (80.3)	34 (0.3)	5863 (59%)	7772 (63%)

n= number

* Death or CNFUN outcomes

#Newborns admitted moribund or with major congenital anomalies are excluded

Presentation 7:

Follow-up rates among CNFUN sites by gestational age

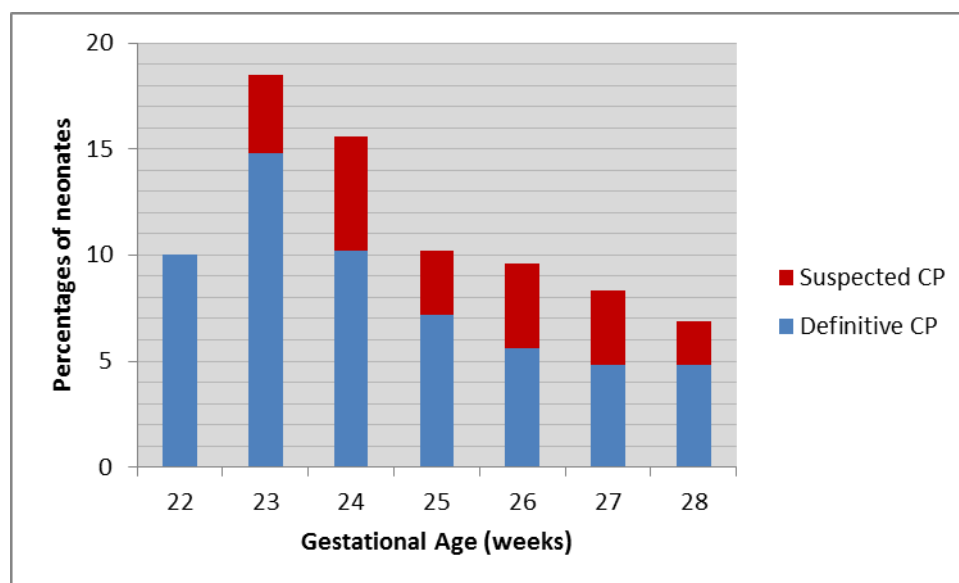
Gestational Age (weeks)	All NICU survivors n (%)	NICU survivors at participating sites# n	CNFUN data** (n)	Linked CNN-CNFUN data for NICU survivors n (%)	Follow-up rate for participating CNFUN sites n (%)
22	20 (15.8)	15	10	10 (50.0)	10 (66.7)
23	279 (41.5)	216	163	165 (59.1)	164 (75.9)
24	931 (62.7)	753	650	565 (60.7)	561 (74.5)
25	1564 (76.5)	1288	1032	963 (61.6)	953 (74)
26	1913 (83.9)	1584	1257	1171 (61.2)	1153 (72.8)
27	2411 (89.6)	2012	1551	1415 (58.7)	1407 (69.9)
28	2854 (91.9)	2359	1759	1574 (55.2)	1570 (66.6)
22-28	9972 (80.3)	8227	6422 [†]	5863 (59%)	5818 (71%)

[†] 10 patients missing GA for CNFUN data

E. Gestational Age based Outcomes from CNFUN participating sites

Presentation No 8: Cerebral palsy rates by gestational age

GA	CNN- CNFUN linked cases or deaths n	Death or definitive CP n (%)	CNN- CNFUN linked cases with CP data for n	Definitive CP n (%)	Missing CP GMFCS	GMFCS ≤2 N (%)	GMFCS 3-5 N (%)	Suspected CP n (%)
22 wks*	58	49 (84%)	10	(10.0)	0	(100)	0 (0)	0 (0)
23 wks	472	331 (70%)	162	24 (14.8)	2	13 (59.1)	9 (40.9)	6 (3.7)
24 wks	1047	539 (51%)	577	57 (10.2)	7	32 (64.0)	18 (36.0)	30 (5.4)
25 wks	1383	488 (35%)	948	68 (7.2)	7	36 (59.0)	25 (41.0)	28 (3.0)
26 wks	1446	359 (24%)	1149	64 (5.6)	7	37 (64.9)	20 (35.1)	46 (4.0)
27 wks	1617	269 (17%)	1393	67 (4.8)	7	41 (68.3)	19 (31.7)	48 (3.5)
28 wks	1729	230 (13%)	1554	75 (4.8)	9	41 (62.1)	25 (37.9)	32 (2.1)
Total	7772	2265 (29%)	5773	356 (6.2)	39	201 (63.4)	116 (36.6)	190 (3.3)



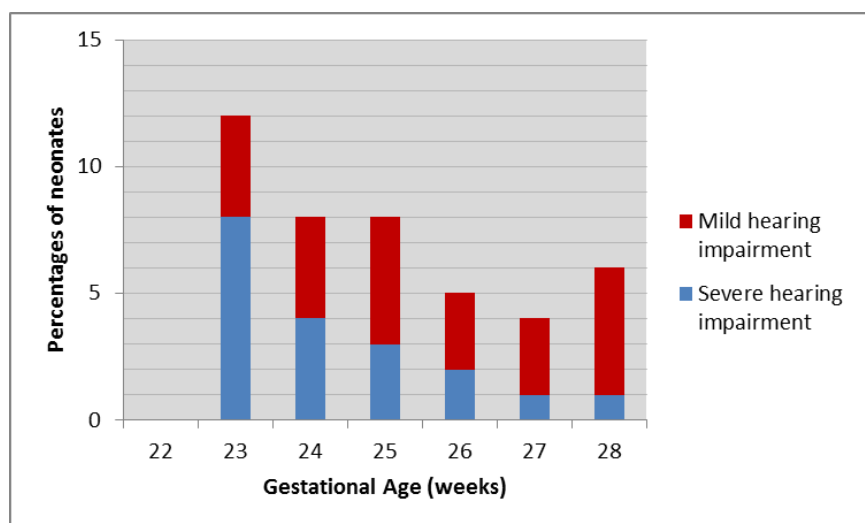
COMMENTS:

Cerebral palsy rates decrease with increasing gestational age. * Due to small numbers at 22 weeks gestation, results should be interpreted with caution.

Presentation No 9:

Hearing impairments rates by gestational age

GA	CNN- CNFUN linked cases or deaths n	Death or any hearing impairment n (%)	CNN- CNFUN linked cases with data for hearing	Normal hearing n (%)	Mild hearing impairment n (%)	Severe hearing impairment n (%)
22 wks	58	48 (83%)	10	10 (100)	0 (0)	0 (0)
23 wks	472	327 (69%)	160	140 (87%)	7 (4%)	13 (8%)
24 wks	1047	526 (50%)	556	512 (92%)	23 (4%)	21 (4%)
25 wks	1383	496 (36%)	940	864 (92 %)	50 (5%)	26 (3%)
26 wks	1446	355 (24%)	1143	1083 (95 %)	37 (3%)	23 (2%)
27 wks	1617	264 (16%)	1388	1326 (96 %)	44 (3%)	18 (1%)
28 wks	1729	246 (14%)	1544	1453 (94 %)	74 (5%)	17 (1%)
Total	7772	2262 (29%)	5741	5388 (94 %)	235 (4 %)	118 (2%)



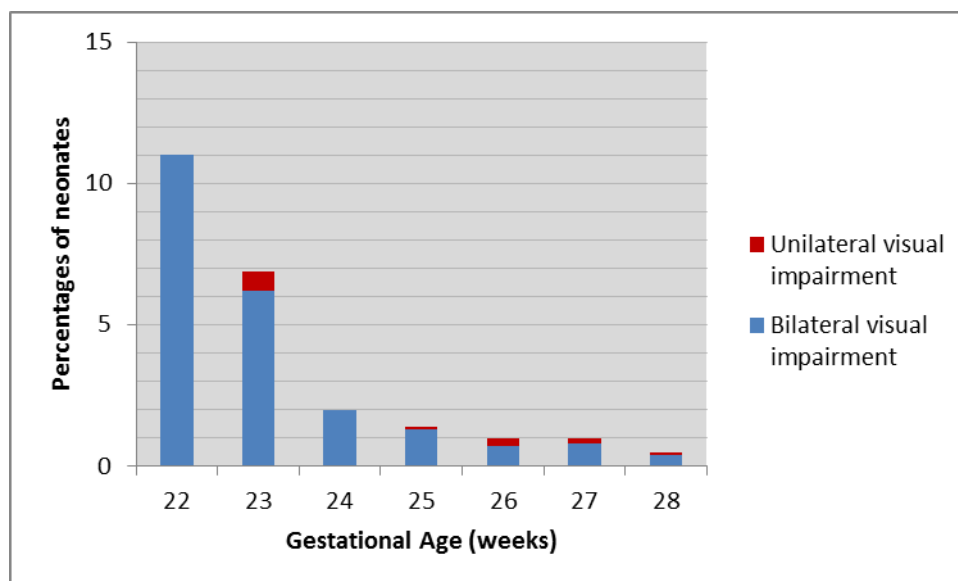
COMMENTS:

Hearing impairment was determined at CNFUN sites based on audiology reports. Hearing impairment is infrequent but approximately 10 times as frequent in the very preterm infant than in the normal population. Severe hearing impairment incidence decreases with gestational age. Mild impairment is often transient.

Presentation No 10:

Visual impairment rates by gestational Age (GA)

GA	CNN- CNFU N linked cases or deaths n	Death or any visual impairment n (%)	CNN- CNFUN linked cases with data for vision n	Normal Vision n (%)	Unilateral visual impairment n (%)	Bilateral visual impairment n (%)
22 wks	58	49 (85%)	9	8 (89%)	0 (0)	(11%)
23 wks	472	317 (67%)	146	136 (93%)	(0.7%)	9 (6.2%)
24 wks	1047	492 (47%)	513	503 (98%)	0 (0)	10 (2.0%)
25 wks	1383	432 (31%)	882	870 (99%)	(0.1%)	11 (1.3%)
26 wks	1446	305 (21%)	1078	1068 (99%)	(0.3%)	7 (0.7%)
27 wks	1617	215 (13%)	1309	1296 (99%)	(0.2%)	10 (0.8%)
28 wks	1729	163 (9%)	1460	1452 (99%)	(0.1%)	6 (0.4%)
Total	7772	1973 (25%)	5397	5333 (99%)	10 (0.2%)	54 (1.0%)

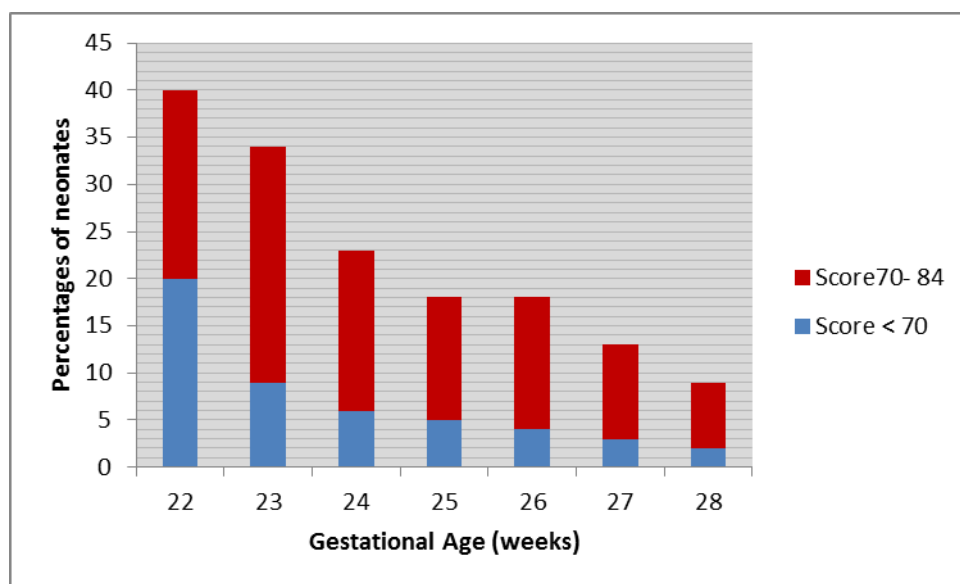


COMMENTS:

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 30 cms. Visual impairment is an infrequent outcome.

Presentation No 11:
Bayley- III cognitive composite scores rates by gestational age

GA	CNN- CNFUN linked cases or deaths n	Death or cognitive score < 85 n (%)	CNN- CNFUN linked cases with cognitive data n	Median score (IQR)	Bayley-III ≥ 85 n (%)	Score70- 84 n (%)	Score < 70 n (%)
22 wks	58	52 (90%)	10	88 (80, 95)	6(60%)	(20%)	(20%)
23 wks	472	355 (75%)	141	90 (80, 100)	93 (66%)	35 (25%)	13 (9%)
24 wks	1047	601 (57%)	516	90 (85, 100)	397 (77%)	89 (17%)	30 (6%)
25 wks	1383	583 (42%)	900	95 (85, 105)	737 (82%)	118 (13%)	45 (5%)
26 wks	1446	484 (33%)	1090	95 (85, 105)	901 (83%)	149 (14%)	40 (4%)
27 wks	1617	376 (23%)	1314	95 (90, 105)	1140 (87%)	137 (10%)	37 (3%)
28 wks	1729	288 (17%)	1462	100 (90, 105)	1329 (91%)	106 (7%)	27 (2%)
Total	7772	2739 (35%)	5433	95 (90, 105)	4603 (85%)	636 (12%)	194 (4%)



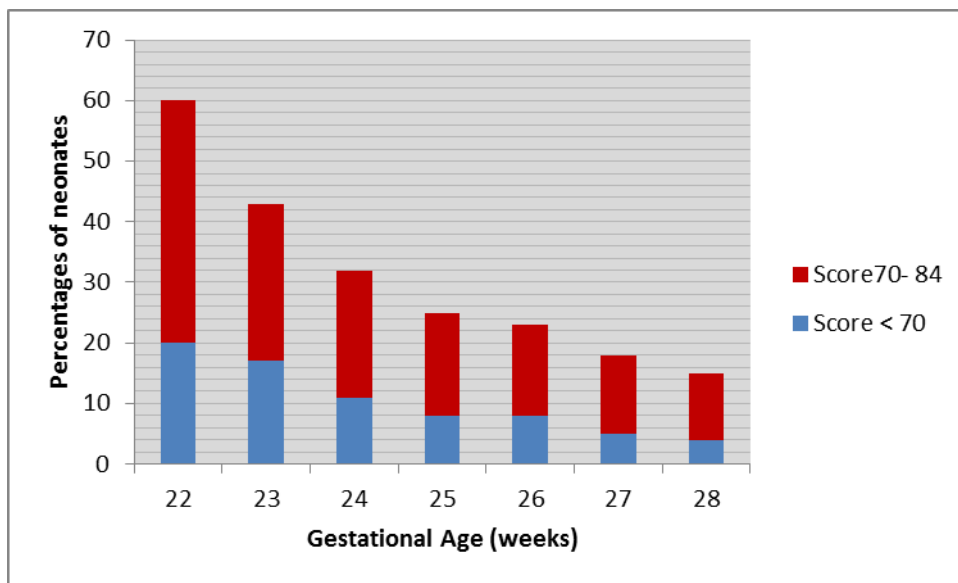
COMMENTS:

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.

Presentation No 12:

Bayley- III motor composite scores rates by gestational age

GA	CNN- CNFUN linked cases or deaths n	Death or motor score < 85 n (%)	CNN- CNFUN linked cases with motor data n	Median score	Bayley-III ≥ 85 n (%)	Score 70- 84 n (%)	Score < 70 n (%)
22 wks	58	54 (93%)	10	82 (70, 88)	(40%)	(40%)	(20%)
23 wks	472	364 (77%)	133	88 (73, 97)	76 (57%)	34 (26%)	23 (17%)
24 wks	1047	637 (61%)	494	91 (79, 97)	339 (69%)	103 (21%)	52 (11%)
25 wks	1383	633 (46%)	863	94 (85, 100)	650 (75%)	147 (17%)	66 (8%)
26 wks	1446	525 (36%)	1038	94 (85, 100)	808 (78%)	151 (15%)	79 (8%)
27 wks	1617	422 (26%)	1241	94 (88, 103)	1021 (82%)	158 (13%)	62 (5%)
28 wks	1729	364 (21%)	1410	97 (88, 103)	1201 (85%)	154 (11%)	55 (4%)
Total	7772	2999 (39%)	5189	94 (85, 100)	4099 (79%)	751 (14%)	339 (7%)



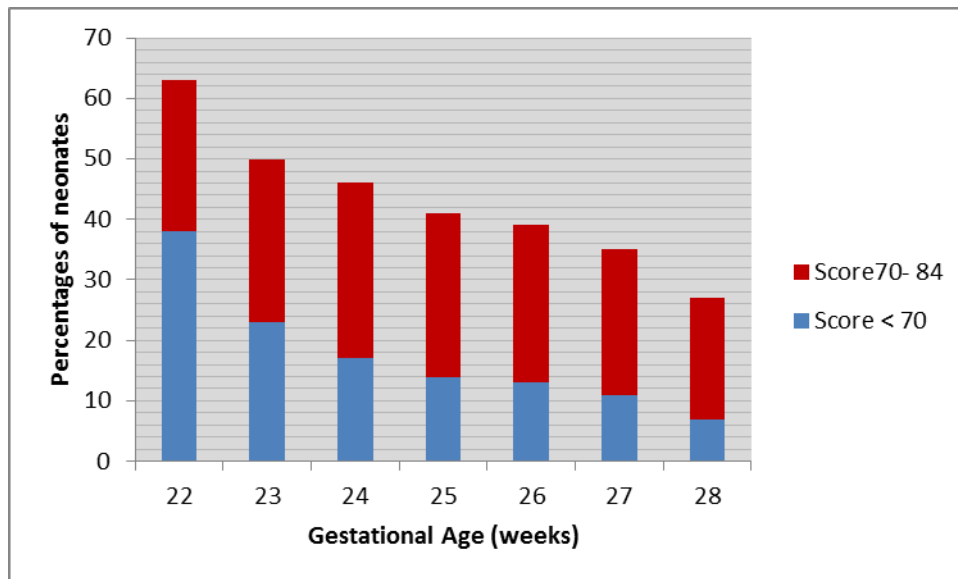
COMMENTS:

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.

Presentation No 13

Bayley- III language composite scores rates by gestational age

GA	CNN- CNFUN linked cases or deaths n	Death or language score < 85 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	58	53 (91%)	8	77 (65, 94)	(38%)	(25%)	(38%)
23 wks	472	374(79%)	135	86 (71, 97)	68 (50%)	36 (27%)	31 (23%)
24 wks	1047	710(68%)	499	86 (74, 97)	271 (54%)	143 (29%)	85 (17%)
25 wks	1383	772(56%)	862	89 (77, 97)	510 (59%)	232 (27%)	120 (14%)
26 wks	1446	710(48%)	1058	89 (77, 100)	643 (61%)	278 (26%)	137 (13%)
27 wks	1617	648(40%)	1255	91 (79, 100)	809 (64%)	307 (24%)	139 (11%)
28 wks	1729	536(31%)	1392	94 (83, 103)	1011 (73%)	285 (20%)	96 (7%)
Total	7772	3803(49%)	5209	89 (79, 100)	3315 (64%)	1283 (25%)	611 (12%)



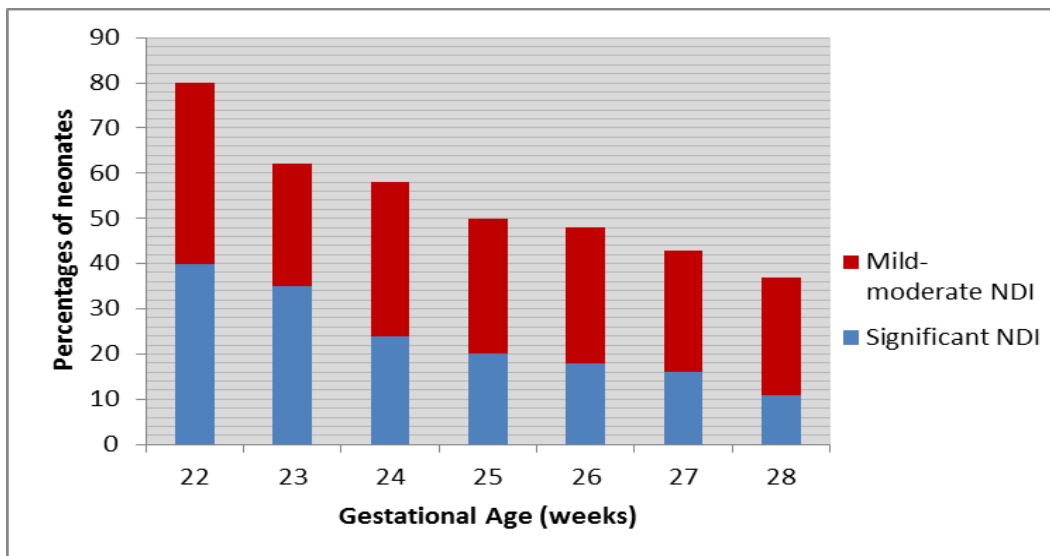
COMMENTS:

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 < 70 is worse than - 2 standard deviations. Bayley-III scores tend to underestimate language delay and have limited predictive ability.

Presentation No 14

Neurodevelopmental impairment (NDI) rates by gestational age (GA)

GA	CNN-CNFUN linked cases or deaths n	Death or any NDI n (%)	CNN-CNFUN linked cases with complete data n	No NDI n (%)	Mild-moderate NDI n (%)	Significant NDI n (%)
22 wks	58	56 (97%)	10	(20%)	(40%)	(40%)
23 wks	472	408 (86%)	164	63 (38%)	44 (27%)	57 (35%)
24 wks	1047	812 (78%)	565	235 (42%)	192 (34%)	138 (24%)
25 wks	1383	900 (65%)	956	476 (50%)	291 (30%)	189 (20%)
26 wks	1446	854 (58%)	1169	610 (52%)	347 (30%)	212 (18%)
27 wks	1617	801 (50%)	1408	809 (57%)	379 (27%)	220 (16%)
28 wks	1729	725 (42%)	1570	1000 (64%)	403 (26%)	167 (11%)
Total	7772	4556 (59%)	5842	3195 (55%)	1660 (28%)	987 (17%)



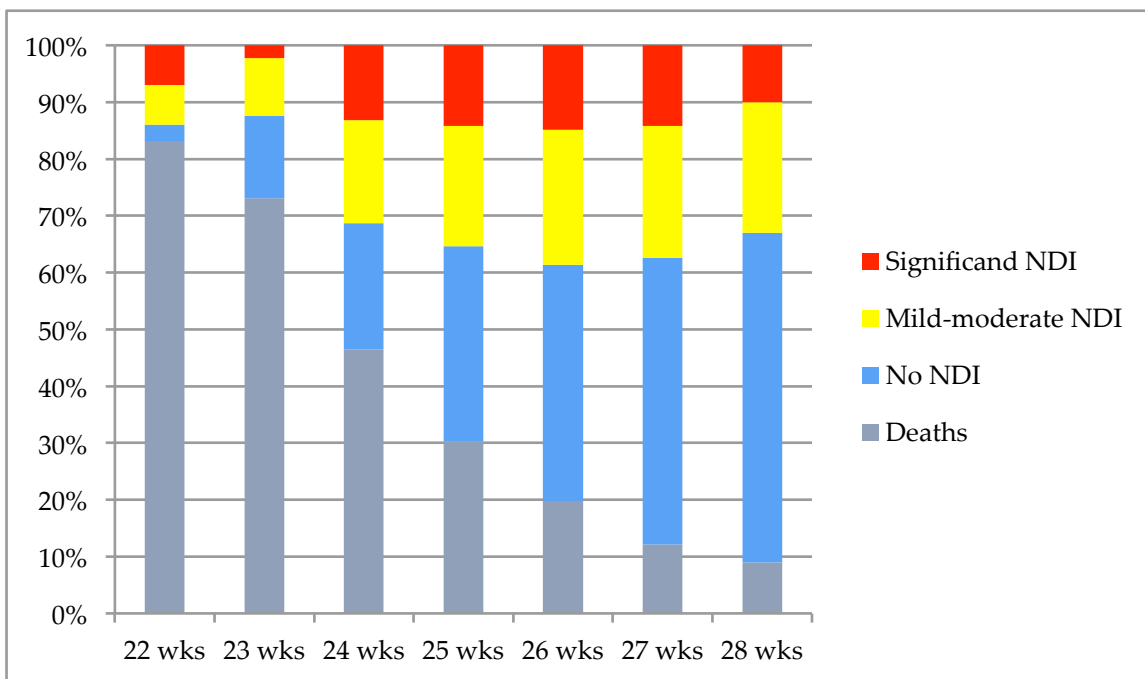
COMMENTS:

Neurodevelopmental impairment rates decrease with increasing gestational age. * Due to small numbers at 22 wks the percentage is uncertain and results should be interpreted with caution

Presentation No 15:

Death or Neurodevelopmental impairment (NDI) rates by gestational age (GA)

GA	CNN-CNFUN linked cases or deaths n	Deaths n (%)	No NDI n (%)	Mild-moderate NDI n (%)	Significand NDI n (%)
22 wks	58	48 (83)	2 (3)	4 (7)	4 (7)
23 wks	472	307 (65)	63 (13)	44 (9)	57 (2)
24 wks	1047	482 (46)	235 (22)	192 (18)	138 (13)
25 wks	1383	420 (30)	476 (34)	291 (21)	189 (14)
26 wks	1446	295 (20)	610 (42)	347 (24)	212 (15)
27 wks	1617	202 (12)	809 (50)	379 (23)	220 (14)
28 wks	1729	155 (9)	1000 (58)	403 (23)	167 (10)

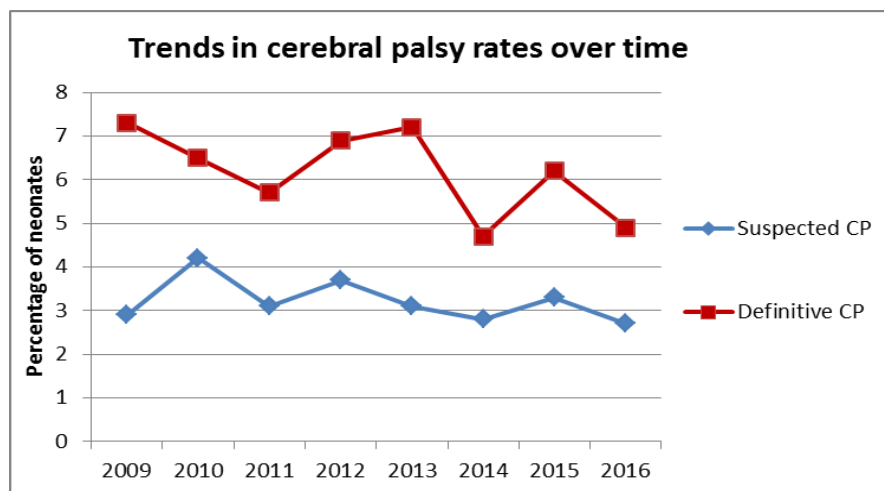


F. Outcomes Over Time

The data presented in this section have not been adjusted for confounding variables

Presentation 16: Trends in cerebral palsy rates over time

Yr of birth	CNFUN with complete CP data (n)	Missing CP data (n)	No CP n (%)	Suspected CP n (%)	Definitive CP n (%)	Missing CP GMFCS n	CP GMFCS \leq 2 n (%)	CP GMFCS 3-5 n (%)
2009	647	12	581 (90%)	19 (2.9%)	47 (7.3%)	7	26 (65%)	14 (35%)
2010	997	16	890 (89%)	42 (4.2%)	65 (6.5%)	11	33 (61%)	21 (39%)
2011	827	25	754 (91%)	26 (3.1%)	47 (5.7%)	4	22 (51%)	21 (49%)
2012	669	7	598 (89%)	25 (3.7%)	46 (6.9%)	3	25 (58%)	18 (42%)
2013	607	8	544 (90%)	19 (3.1%)	44 (7.2%)	2	28 (67%)	14 (33%)
2014	641	8	593 (93%)	18 (2.8%)	30 (4.7%)	1	20 (69%)	9 (31%)
2015	674	12	610 (91%)	22 (3.3%)	42 (6.2%)	2	26 (65%)	14 (35%)
2016	711	2	657 (92%)	19 (2.7%)	35 (4.9%)	9	21 (81%)	5 (19%)
'09-'16	5773	90	5227 (91%)	190 (3.3%)	356 (6.2%)	39	201 (63%)	116 (37%)



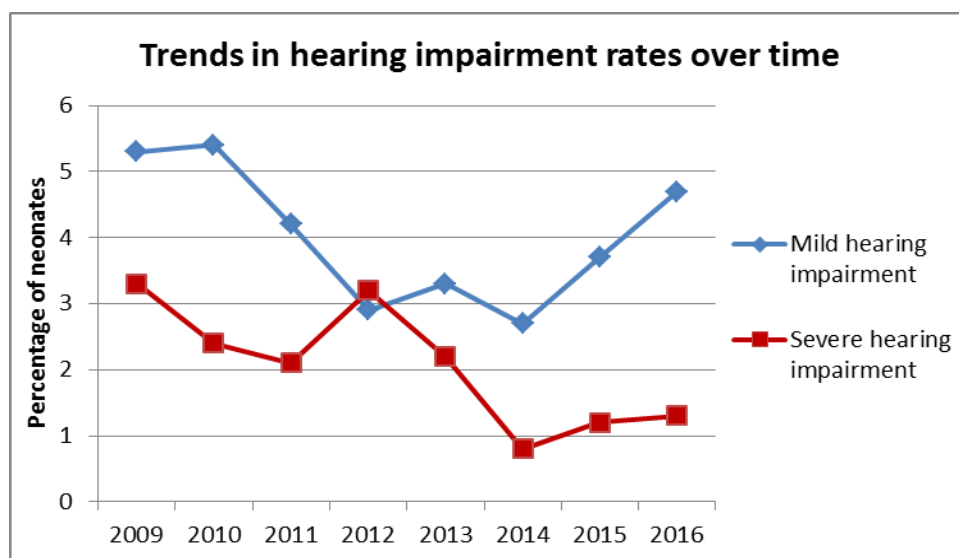
COMMENTS:

Higher attrition rates in the later years may impact the results. The majority of cerebral palsy cases are mild with GMFCS \leq 2.

Presentation No 17:

Trends in hearing impairment rates over time

Yr of birth	CNFUN complete data (n)	Missing hearing data (n)	Normal hearing n (%)	Mild hearing impairment n (%)	Severe hearing impairment* n (%)
2009	643	16	588 (91%)	34 (5.3%)	21 (3.3%)
2010	988	25	911 (92%)	53 (5.4%)	24 (2.4%)
2011	819	33	768 (94%)	34 (4.2%)	17 (2.1%)
2012	663	13	623 (94%)	19 (2.9%)	21 (3.2%)
2013	602	13	569 (95%)	20 (3.3%)	13 (2.2%)
2014	641	8	619 (97%)	17 (2.7%)	5 (0.8%)
2015	675	11	642 (95%)	25 (3.7%)	8 (1.2%)
2016	710	3	668 (94%)	33 (4.7%)	9 (1.3%)
'09-'16	5741	122	5388 (94%)	235 (4.1%)	118 (2.1%)



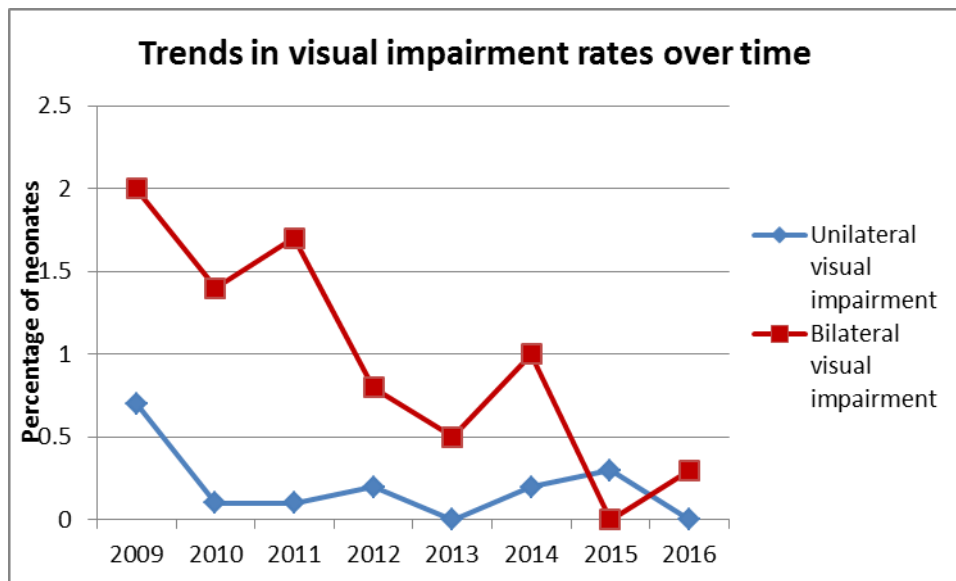
COMMENTS:

Severe hearing impairment was defined as prescribed hearing aid(s) or cochlear implant(s). A mild hearing impairment is any hearing impairment identified by an audiologist as not requiring hearing aid(s) or cochlear implant(s).

Presentation No 18:

Trends in visual impairment rates over time

Yr of birth	CNFUN complete data (n)	Missing vision data (n)	Normal Vision n (%)	Unilateral visual impairment n (%)	Bilateral visual impairment n (%)
2009	613	46	597 (97%)	(0.7%)	12 (2.0%)
2010	931	82	917 (98%)	(0.1%)	13 (1.4%)
2011	755	97	741 (98%)	(0.1%)	13 (1.7%)
2012	622	54	616 (99%)	(0.2%)	5 (0.8%)
2013	565	50	562 (99%)	0 (0)	(0.5%)
2014	599	50	592 (99%)	(0.2%)	6 (1.0%)
2015	637	49	635 (99.7%)	0 (0.3)	0 (0)
2016	675	38	673 (99.7%)	0 (0)	(0.3%)
'09-'16	5397	466	5333 (99%)	10 (0.2%)	54 (1.0%)



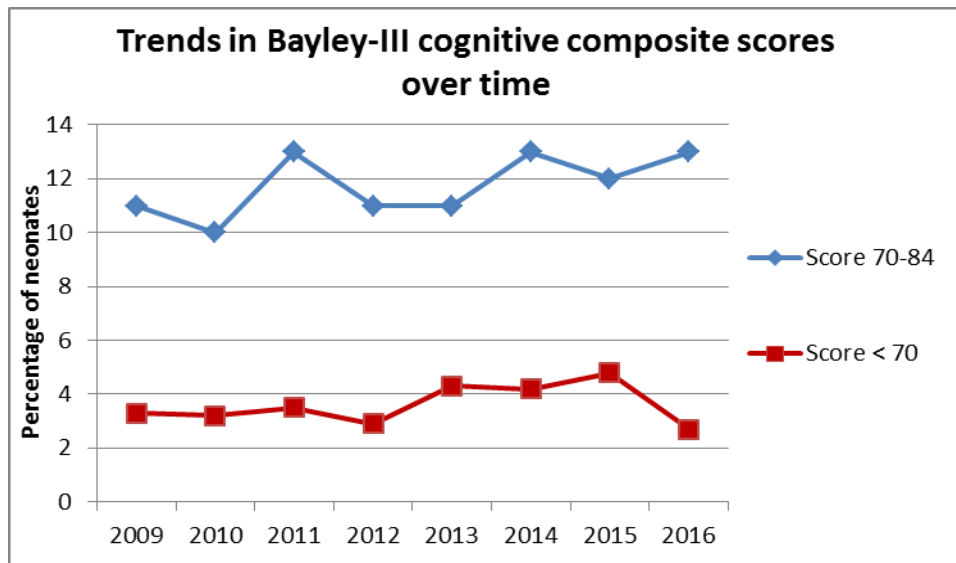
COMMENTS:

Visual impairment at 18 months corrected age is now a rare complication of prematurity.

Presentation No 19:

Table 4: Trends in Bayley- III cognitive composite scores over time

Yr of birth	CNFUN with complete data (n)	Missing Bayley cognitive (n)	Median score (IQR)	Bayley-III \geq 85 n (%)	Score 70-84 n (%)	Score < 70 n (%)
2009	608	51	95 (90, 105)	523 (86%)	65 (11%)	20 (3.3%)
2010	943	71	95 (90, 105)	813 (86%)	99 (10%)	30 (3.2%)
2011	794	58	95 (90, 105)	664 (84%)	102 (13%)	28 (3.5%)
2012	627	49	95 (90, 105)	542 (86%)	67 (11%)	18 (2.9%)
2013	561	54	95 (90, 105)	473 (84%)	64 (11%)	24 (4.3%)
2014	601	48	95 (85, 105)	498 (83%)	78 (13%)	25 (4.2%)
2015	641	45	95 (90, 105)	536 (84%)	74 (12%)	31 (4.8%)
2016	659	54	95 (90, 105)	554 (84%)	87 (13%)	18 (2.7%)
'09-'16	5433	430	95 (90, 105)	4603 (85%)	636 (12%)	194 (3.6%)

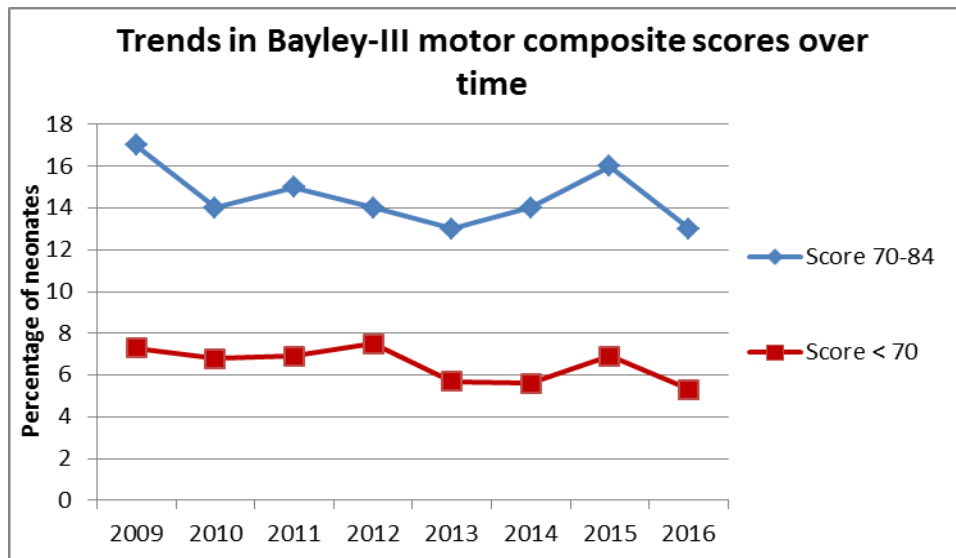


COMMENTS:

Higher attrition rates in the later years may impact the results. The Bayley-III has a poor predictive value.

Presentation No 20:
Trends in Bayley- III motor composite scores over time

Yr of birth	CNFUN complete data (n)	Missing Bayley motor scores (n)	Median score (IQR)	Bayley-III \geq 85	Bayley-III 70-84	Bayley-III < 70
				n (%)	n (%)	n (%)
2009	579	80	94 (85, 100)	437 (75%)	100 (17%)	42 (7.3%)
2010	900	113	94 (85, 100)	713 (79%)	127 (14%)	61 (6.8%)
2011	769	83	94 (85, 100)	603 (78%)	113 (15%)	53 (6.9%)
2012	613	63	94 (85, 100)	484 (79%)	83 (14%)	46 (7.5%)
2013	530	85	94 (85, 100)	429 (81%)	71 (13%)	30 (5.7%)
2014	570	79	94 (88, 100)	459 (81%)	79 (14%)	32 (5.6%)
2015	605	81	94 (85, 100)	469 (78%)	94 (16%)	42 (6.9%)
2016	623	90	94 (88, 103)	506 (81%)	84 (13%)	33 (5.3%)
'09-'16	5189	674	94 (85, 100)	4099 (79%)	751 (15%)	339 (6.5%)

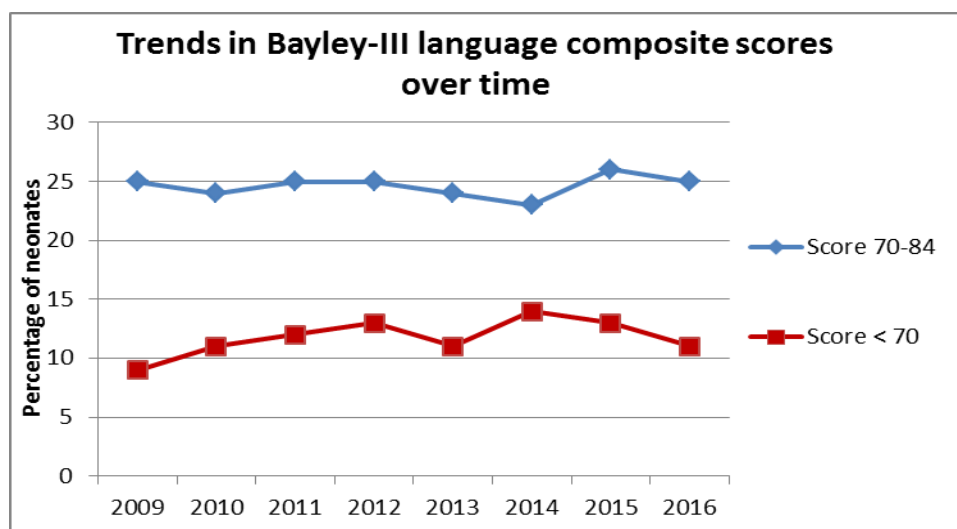


COMMENTS:

Higher attrition rates in the later years may impact the results. The Bayley-III has a poor predictive value.

Presentation No 21:
Trends in Bayley- III language composite scores over time

Yr of birth	CNFUN with complete data (n)	Missing Bayley language scores n (%)	Median score (IQR)	Bayley-III \geq 85 n (%)	Bayley-III 70-84 n (%)	Bayley-III < 70 n (%)
2009	581	78	91 (79, 100)	383 (66%)	143 (25%)	55 (9%)
2010	915	98	89 (79, 100)	594 (65%)	218 (24%)	103 (11%)
2011	774	78	91 (77, 100)	482 (62%)	196 (25%)	96 (12%)
2012	616	60	90 (79, 100)	386 (63%)	152 (25%)	78 (13%)
2013	519	96	91 (79, 100)	338 (65%)	124 (24%)	57 (11%)
2014	568	81	89 (77, 100)	359 (63%)	132 (23%)	77 (14%)
2015	613	73	89 (77, 100)	374 (61%)	162 (26%)	77 (13%)
2016	623	90	89 (79, 100)	399 (64%)	156 (25%)	68 (11%)
'09-'16	5209	654	91 (79, 100)	3315 (64%)	1283 (25%)	611 (12%)

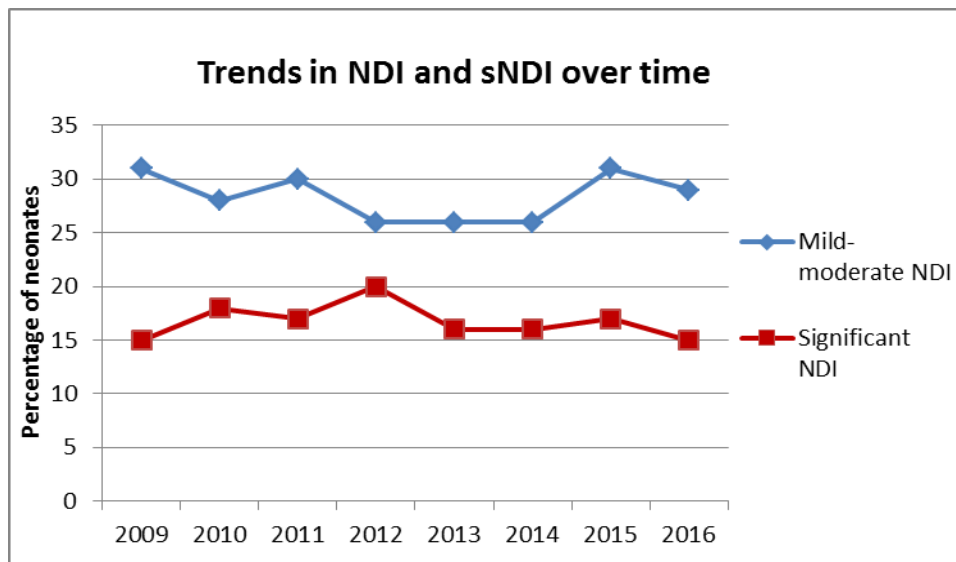


COMMENTS:

Higher attrition rates in the later years may impact the results. The Bayley-III has a poor predictive value.

Presentation No 22:
Trends in NDI and sNDI over time

Yr of birth	CNFUN with complete data (n)	Missing data n (%)	No NDI n (%)	Mild-moderate NDI n (%)	Significant NDI n (%)
2009	653	6	347 (53%)	205 (31%)	101 (15%)
2010	1012	1	550 (54%)	285 (28%)	178 (18%)
2011	848	4	450 (53%)	251 (30%)	147 (17%)
2012	674	2	367 (54%)	174 (26%)	133 (20%)
2013	612	3	356 (58%)	160 (26%)	96 (16%)
2014	647	2	370 (57%)	171 (26%)	106 (16%)
2015	684	2	358 (52%)	209 (31%)	117 (17%)
2016	712	1	398 (56%)	205 (29%)	109 (15%)
'09-'16	5842	21	3195 (55%)	1660 (28%)	987 (17%)



COMMENTS:

See page 15 for definitions. Higher attrition rates in the later years may impact the results. There has not been a clinically significant change in neurodevelopmental impairment rates.

G. Site Comparisons-Crude

Presentation No 23:

Neurodevelopmental impairment for MiCare cohort (Births April 1, 2009-Sept 30, 2011)*

Site	CNFUN (n)	No NDI n (%)	Any NDI n (%)	CP with GMFCS 1-5 n (%)	Any hearing Impairment n(%)	Any visual Impairment n(%)	Bayley score <85m 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%

Presentation No 24:

Significant neurodevelopmental impairment for MiCare cohort (Births April 1, 2009-Sept 30, 2011)*

Site	CNFUN (n)	No NDI n (%)	Significant NDI n (%)	CP GMFCS 3-5 n (%)	Severe hearing Impairment 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 only show %, rounded up to a multiple of 5%

Presentation No 25:

Neurodevelopmental impairment for post MiCare cohort (Births Oct 1, 2011- Dec 31, 2016)*

Site	CNFUN (n)	No NDI n (%)	Any NDI n (%)	GMFCS 1-5 n (%)	Any hearing Impairment n(%)	Any visual Impairment n(%)	Bayley score <85m motor n(%)	Bayley score <85 Language n(%)	Bayley score <85 Cognitive n(%)
1	320	183 (57.2)	137 (42.8)	23 (7.2)	15 (4.7)	< 5%	55 (17.2)	90 (28.1)	30 (9.4)
2	238	145 (60.9)	93 (39.1)	11 (4.6)	23 (9.7)	0 (0)	21 (8.8)	62 (26.1)	20 (8.4)
3	61	27 (44.3)	34 (55.7)	< 5%	< 5%	0 (0)	16 (26.2)	26 (42.6)	8 (13.1)
6	440	257 (58.4)	183 (41.6)	16 (3.6)	16 (3.6)	7 (1.6)	91 (20.7)	120 (27.3)	65 (14.8)
9	27	14 (51.9)	13 (48.1)	1 (3.7)	0 (0)	0 (0)	6 (22.2)	6 (22.2)	5 (18.5)
10	99	34 (34.3)	65 (65.7)	7 (7.1)	11 (11.1)	< 5%	29 (29.3)	58 (58.6)	20 (20.2)
11	353	189 (53.5)	164 (46.5)	27 (7.6)	25 (7.1)	< 5%	85 (24.1)	112 (31.7)	56 (15.9)
12	197	112 (56.9)	85 (43.1)	19 (9.6)	< 5%	< 5%	45 (22.8)	58 (29.4)	28 (14.2)
14	218	115 (52.8)	103 (47.2)	10 (4.6)	13 (6)	< 5%	40 (18.3)	72 (33)	21 (9.6)
16	419	248 (59.2)	171 (40.8)	22 (5.3)	17 (4.1)	0 (0)	51 (12.2)	131 (31.3)	65 (15.5)
20	160	82 (51.3)	78 (48.8)	8 (5)	16 (10)	< 5%	35 (21.9)	57 (35.6)	32 (20)
21	99	48 (48.5)	51 (51.5)	9 (9.1)	< 5%	0 (0)	24 (24.2)	42 (42.4)	20 (20.2)
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	680	367 (54)	313 (46)	21 (3.1)	20 (2.9)	< 5%	107 (15.7)	256 (37.6)	112 (16.5)
26	40	29 (72.5)	11 (27.5)	< 5%	< 5%	0 (0)	6 (15)	8 (20)	<10%
Total	3440	1905 (55.4)	1535 (44.6)	188 (5.5)	173 (5.0)	23 (0.7)	623 (18.1)	1121 (32.6)	498 (14.5)

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

Presentation No 26:

Significant neurodevelopment for post MiCare cohort (Births Oct 1, 2011- Dec 31, 2016)*

Site	CNFUN (n)	No NDI n (%)	Significant NDI n (%)	CP 3-5 n (%)	Severe hearing Impairment n(%)	Bilateral visual Impairment n(%)	Bayley score <70 Motor n(%)	Bayley score <70 Language n(%)	Bayley score <70 Cognitive n(%)
1	320	183 (57.2)	62 (19.4)	13 (4.1)	11 (3.4)	< 5%	21 (6.6)	25 (7.8)	8 (2.5)
2	238	145 (60.9)	32 (13.4)	5 (2.1)	< 5%	0 (0)	< 5%	20 (8.4)	7 (2.9)
3	61	27 (44.3)	16 (26.2)	< 5%	< 5%	0 (0)	5 (8.2)	11 (18)	0 (0)
6	440	257 (58.4)	59 (13.4)	5 (1.1)	< 5%	< 5%	22 (5)	46 (10.5)	18 (4.1)
9	27	14 (51.9)	6 (22.2)	0 (0)	0 (0)	0 (0)	< 10%	< 5%	< 10%
10	99	34 (34.3)	28 (28.3)	< 5%	< 5%	< 5%	8 (8.1)	25 (25.3)	5 (5.1)
11	353	189 (53.5)	51 (14.4)	5 (1.4)	< 5%	< 5%	28 (7.9)	27 (7.6)	9 (2.5)
12	197	112 (56.9)	26 (13.2)	< 5%	< 5%	< 5%	13 (6.6)	20 (10.2)	8 (4.1)
14	218	115 (52.8)	39 (17.9)	5 (2.3)	< 5%	< 5%	16 (7.3)	17 (7.8)	7 (3.2)
16	419	248 (59.2)	56 (13.4)	5 (1.2)	9 (2.1)	0 (0)	15 (3.6)	34 (8.1)	17 (4.1)
20	160	82 (51.3)	43 (26.9)	< 5%	< 5%	< 5%	14 (8.8)	32 (20)	9 (5.6)
21	99	48 (48.5)	26 (26.3)	< 5%	< 5%	0 (0)	10 (10.1)	20 (20.2)	8 (8.1)
23	89	55 (61.8)	16 (18)	5 (5.6)	< 5%	< 5%	6 (6.7)	8 (9)	< 5%
25	680	367 (54)	119 (17.5)	11 (1.6)	13 (1.9)	< 5%	27 (4)	81 (11.9)	19 (2.8)
26	40	29 (72.5)	10%	0 (0)	< 5%	0 (0)	< 5%	< 5%	0 (0)
Total	3440	1905 (55.4)	583 (16.9)	64 (1.9)	59 (1.7)	19 (0.6)	192 (5.6)	369 (10.7)	119 (3.5)

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

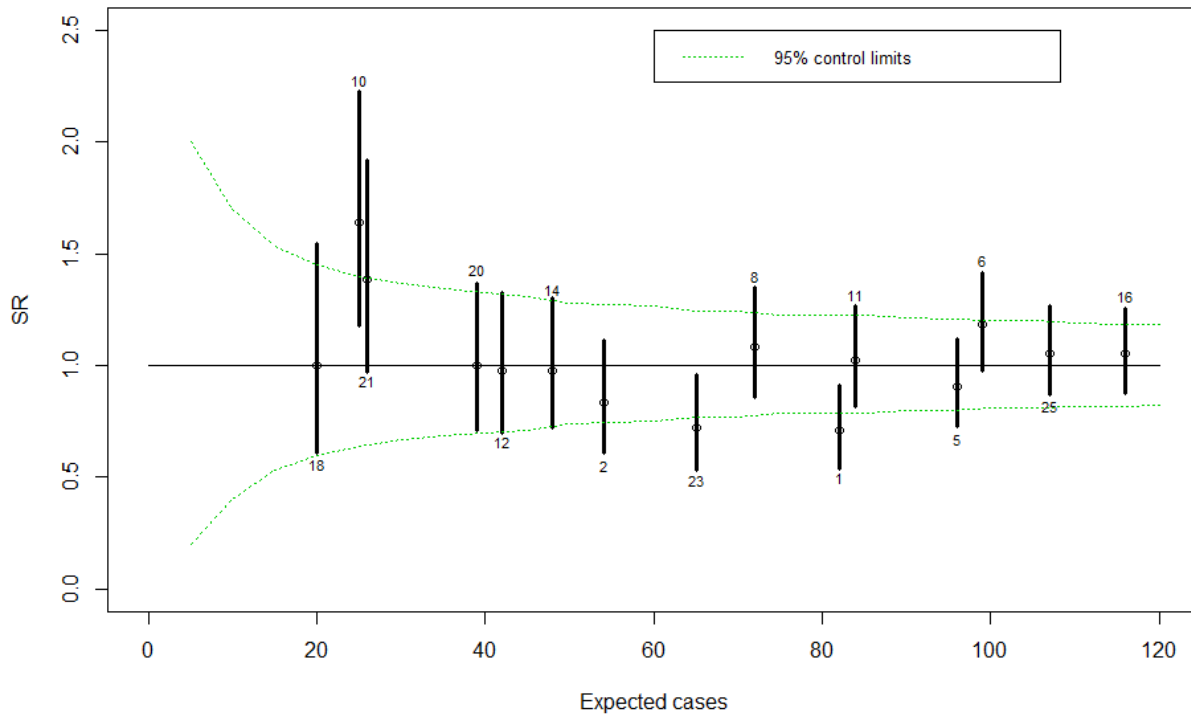
H.Site Comparisons- Adjusted Standardized Ratios

Presentation No 27:

Adjusted Standardized ratios by site – Neurodevelopmental Impairment (NDI)- MiCare cohort

Site	No. of children	Follow-up Rate (%)	Included Yes/ No	NDI n	Adjusted Expected NDI	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. "stage 2 or 3 necrotizing enterocolitis (NEC), defined according to Bell's criteria;[13] severe retinopathy of prematurity (ROP), defined as stage 3 or greater[14] in either eye or treatment with laser or injections of anti-vascular endothelial growth factor; and severe brain injury, defined as any grade 3 or 4 intraventricular hemorrhage (IVH)[15], ventricular dilatation \geq 10 mm, intraparenchymal hemorrhage or periventricular leukomalacia[16]. "



COMMENTS:

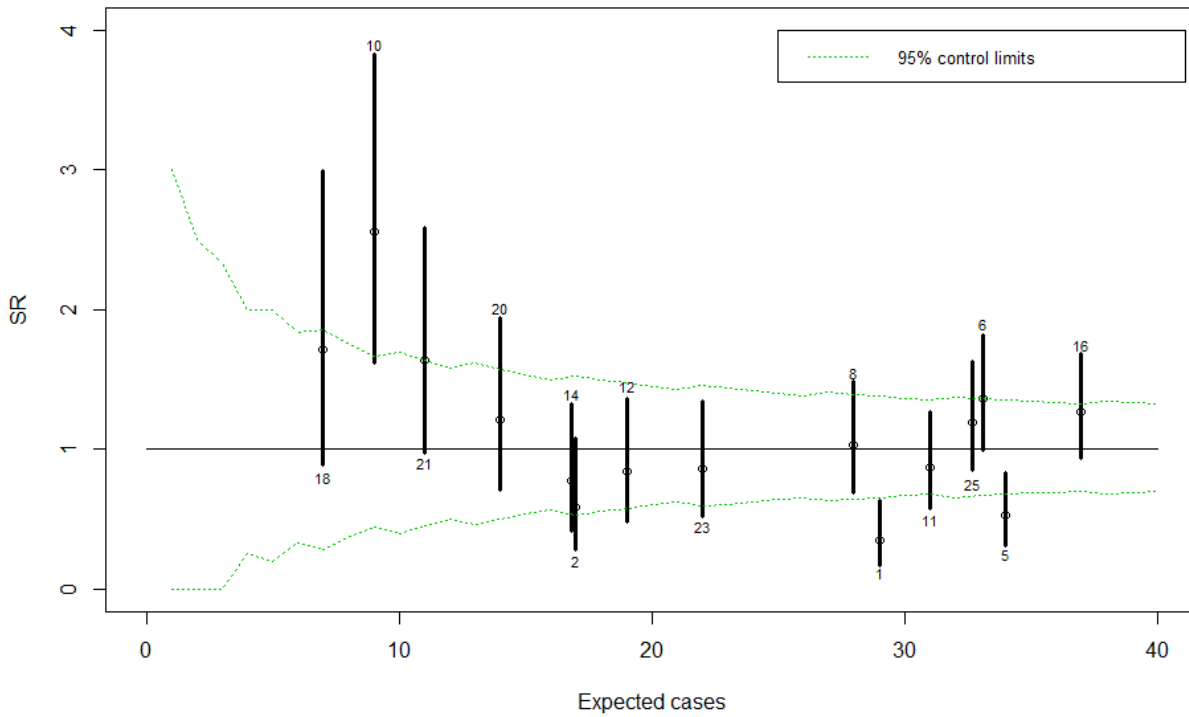
Sites with points outside the green “funnel” represent higher or lower adjusted NDI rates than expected. When the 95% confidence interval doesn’t cross 1, the results are statistically significant. Therefore 3 sites have statistically higher or lower NDI rates.

Presentation No 28:

Adjusted standardized ratios by site – Significant NDI- 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), retinopathy of prematurity, nosocomial infection and brain injury



COMMENTS:

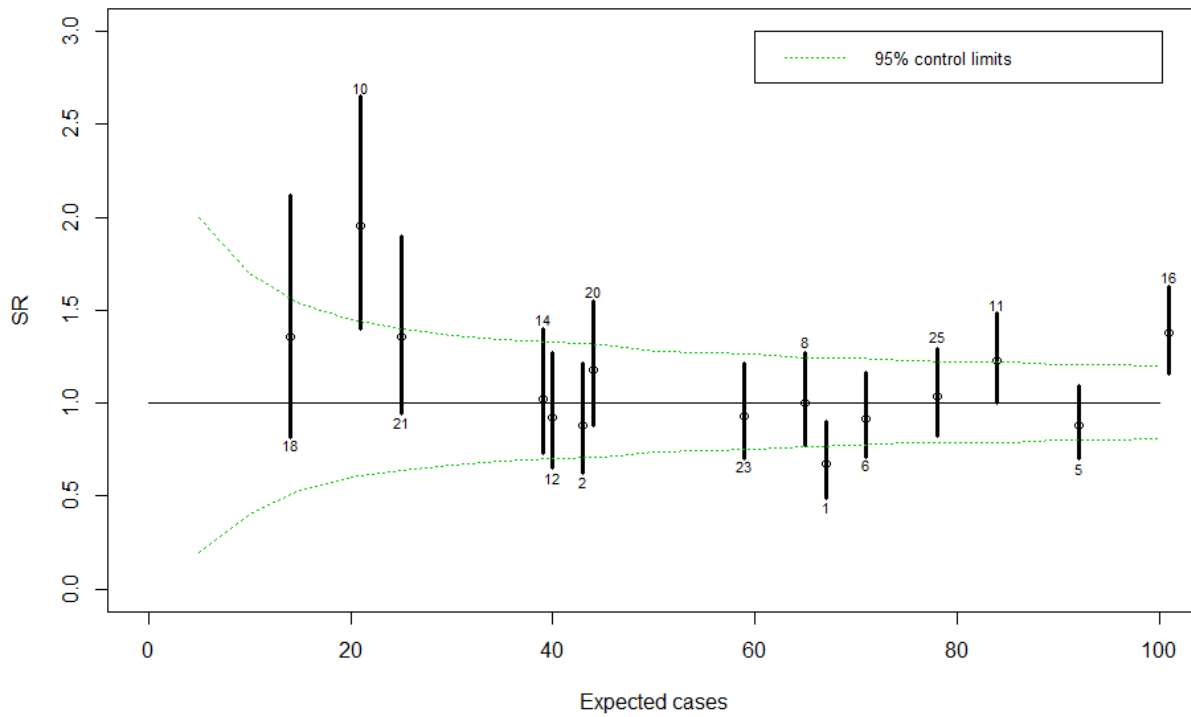
Sites with points outside the green “funnel” represent higher or lower adjusted sNDI rates than expected. When the 95% confidence interval doesn’t cross 1, the results are statistically significant. Therefore 3 sites have statistically higher or lower sNDI rates.

Presentation No 29:

Adjusted standardized ratios by site – significant NDI 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



COMMENTS:

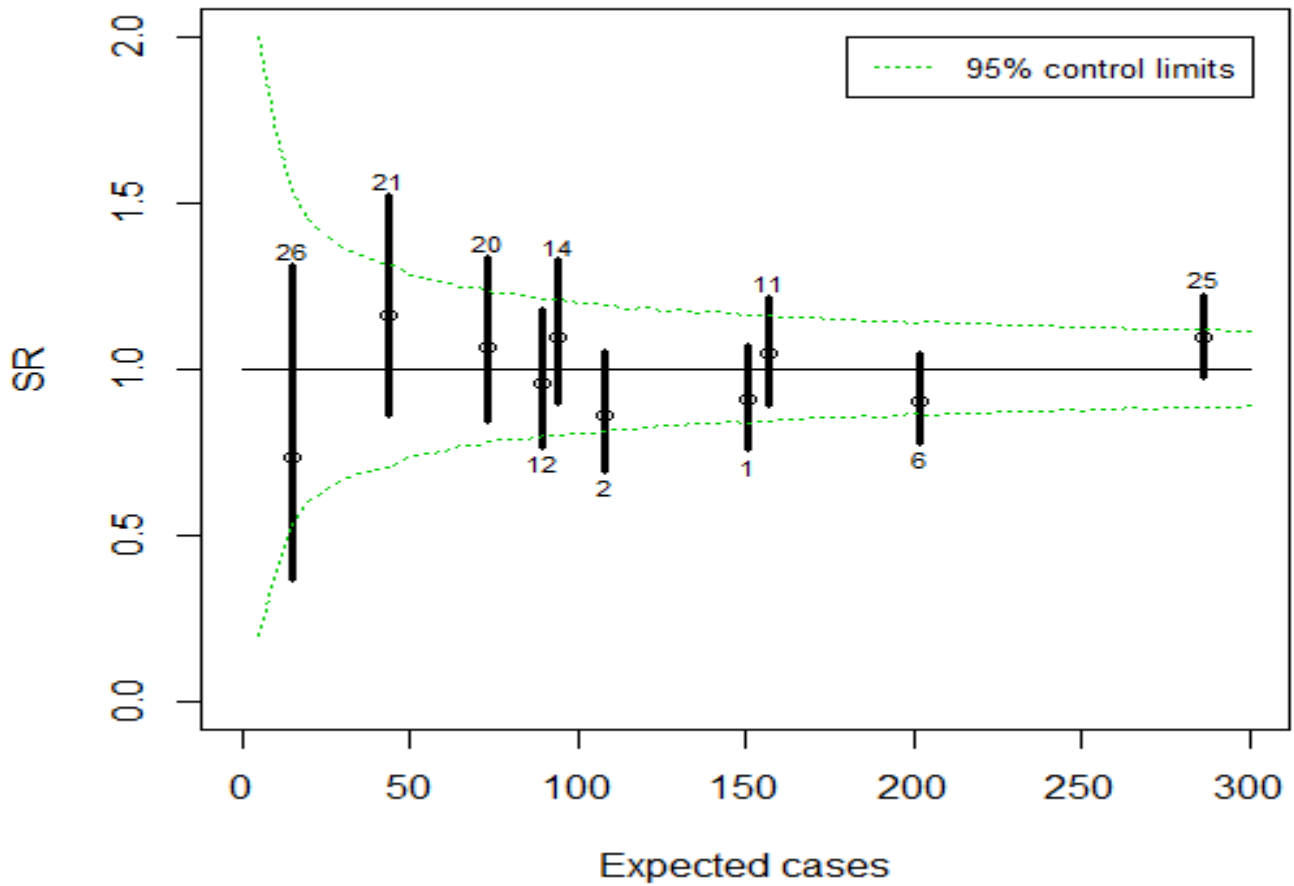
Sites with points outside the green “funnel” represent higher or lower adjusted significant NDI or death rates than expected. When the 95% confidence interval doesn’t cross 1, the results are statistically significant. Therefore 3 sites have statistically higher or lower significant NDI or death rates.

Presentation No 30:

Adjusted Standardized ratios by site – Neurodevelopmental Impairment (NDI)- Post- MiCare cohort (Oct 1 2011- Dec 31, 2016 births)

Site	Children (n)	Follow-up Rate %	Included Yes/ No	NDI (n)	Adjusted Expected NDI (n)	Adjusted standardized ratio (95%CI)
1	320	74.8	Y	137	151	0.91 (0.76, 1.07)
2	238	80.1	Y	93	108	0.86 (0.70, 1.05)
3	61	51.7	N	34		
4	6	19.4	N	1		
5	7	1.1	N	6		
6	440	71.3	Y	183	202	0.91 (0.78, 1.05)
7	17	14.8	N	5		
8	3	0.7	N	1		
9	27	18.4	N	13		
10	99	59.6	N	65		
11	353	88.9	Y	164	157	1.04 (0.89, 1.22)
12	197	87.6	Y	85	89	0.96 (0.76, 1.18)
14	218	73.4	Y	103	94	1.10 (0.89, 1.33)
15	7	8.8	N	1		
16	419	59.4	N	171		
17	4	1.3	N	0		
18	9	10.1	N	5		
19	5	4.1	N	2		
20	160	74.8	Y	78	73	1.07 (0.84, 1.33)
21	99	73.9	Y	51	44	1.16 (0.86, 1.52)
22	9	16.4	N	4		
23	89	33	N	34		
25	680	82.7	Y	313	286	1.09 (0.98, 1.22)
26	40	74.1	Y	11	15	0.73 (0.37, 1.31)

1. Sites with < 20 participants for the 5 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



COMMENTS:

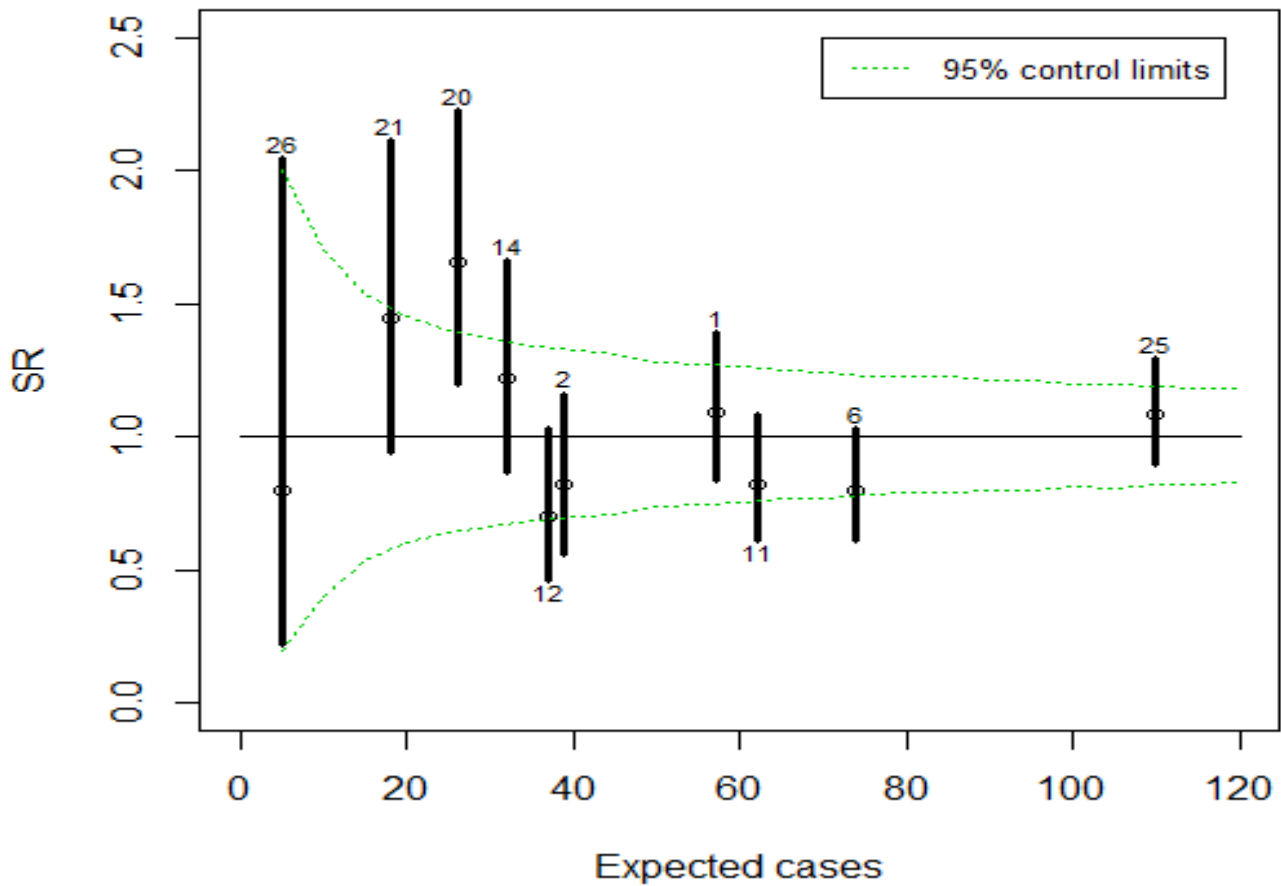
Sites with points outside the green “funnel” represent higher or lower adjusted NDI rates than expected. When the 95% confidence interval doesn’t cross 1, the results are statistically significant. Therefore no sites have statistically higher or lower NDI rates.

Presentation No 31:

Adjusted standardized ratios by site – significant NDI- post MiCare cohort

Site	No. of children	Follow-up Rate (%)	Included Yes/ No	No. with sNDI	Adjusted/Expected sNDI (n)	Adjusted standardized ratio(95%CI)
1	320	74.8	Y	62	57	1.09 (0.83, 1.39)
2	238	80.1	Y	32	39	0.82 (0.56, 1.16)
3	61	51.7	N	16		
4	6	19.4	N	0		
5	7	1.1	N	3		
6	440	71.3	Y	59	74	0.80 (0.61, 1.03)
7	17	14.8	N	3		
8	3	0.7	N	0		
9	27	18.4	N	6		
10	99	59.6	N	28		
11	353	88.9	Y	51	62	0.82 (0.61, 1.08)
12	197	87.6	Y	26	37	0.70 (0.46, 1.03)
14	218	73.4	Y	39	32	1.22 (0.87, 1.67)
15	7	8.8	N	1		
16	419	59.4	N	56		
17	4	1.3	N	0		
18	9	10.1	N	2		
19	5	4.1	N	1		
20	160	74.8	Y	43	26	1.65 (1.20, 2.23)
21	99	73.9	Y	26	18	1.44 (0.94, 2.12)
22	9	16.4	N	3		
23	89	33	N	16		
25	680	82.7	Y	119	110	1.08 (0.90, 1.29)
26	40	74.1	Y	4	5	0.80 (0.22, 2.05)

1. Sites with < 20 participants for the 5 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, nosocomial infection and severe brain injury



COMMENTS:

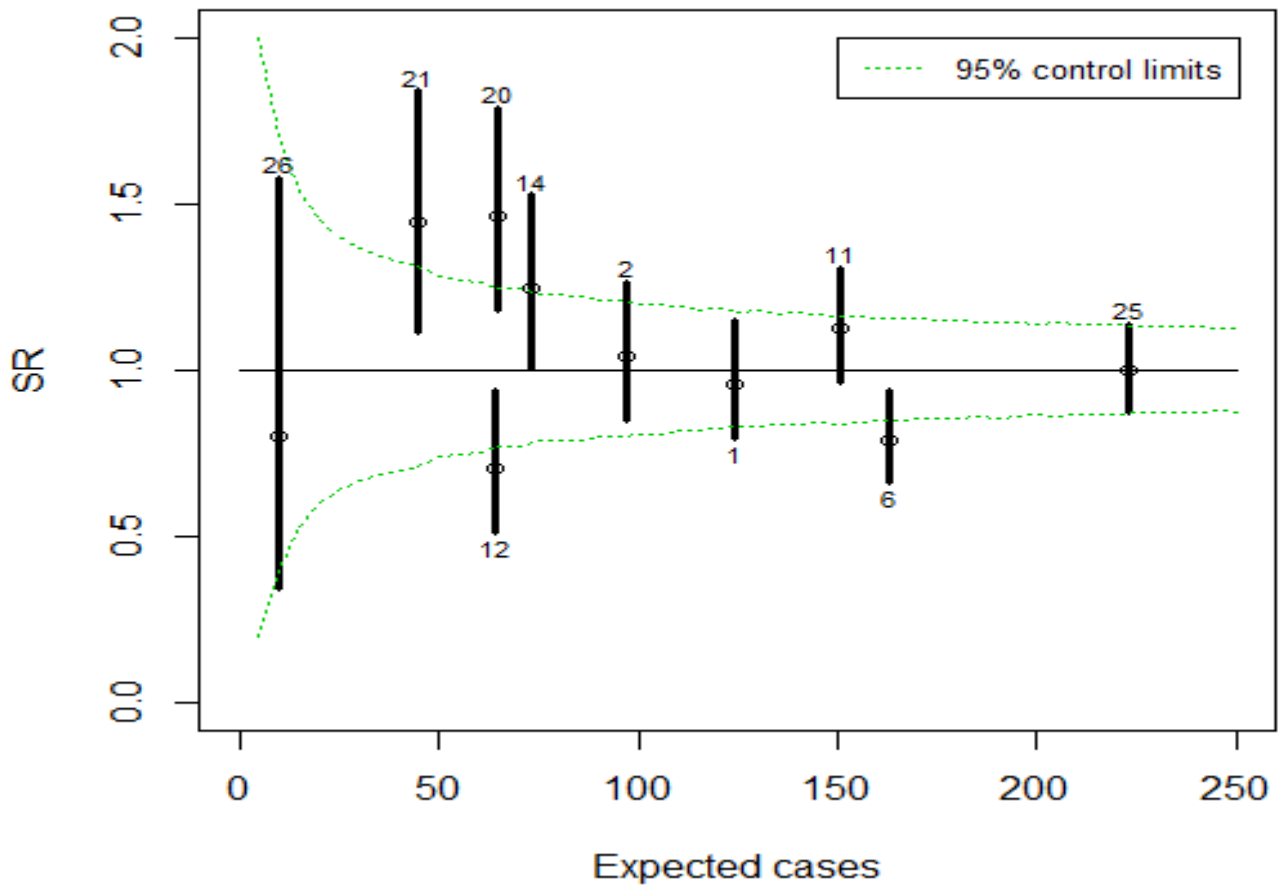
Sites with points outside the green “funnel” represent higher or lower adjusted sNDI rates than expected. When the 95% confidence interval doesn’t cross 1, the results are statistically significant. Therefore one site has a statistically higher sNDI rate.

Presentation No 32:

Adjusted Standardized ratios by site – significant NDI or Death post- MiCare cohort

Site	No. of children	Follow-up Rate (%)	Included Yes/ No	No. with outcome	Adjusted/Expected outcome (n)	Adjusted standardized ratio (95%CI)
1	379	74.8	Y	119	124	0.96 (0.80, 1.15)
2	308	80.1	Y	101	97	1.04 (0.85, 1.27)
3	91	51.7	N	46		
4	16	19.4	N	10		
5	100	1.1	N	96		
6	510	71.3	Y	129	163	0.79 (0.66, 0.94)
7	27	14.8	N	13		
8	81	0.7	N	78		
9	47	18.4	N	26		
10	128	59.6	N	57		
11	472	88.9	Y	170	151	1.13 (0.96, 1.31)
12	217	87.6	Y	45	64	0.70 (0.51, 0.94)
14	270	73.4	Y	91	73	1.25 (1.01, 1.53)
15	37	8.8	N	31		
16	560	59.4	N	197		
17	61	1.3	N	56		
18	28	10.1	N	21		
19	24	4.1	N	20		
20	213	74.8	Y	95	65	1.46 (1.18, 1.79)
21	141	73.9	Y	65	45	1.44 (1.11, 1.84)
22	23	16.4	N	17		
23	158	33	N	85		
25	785	82.7	Y	223	223	1.00 (0.87, 1.14)
26	44	74.1	Y	8	10	0.80 (0.35, 1.58)

1. Sites with < 20 participants for the 5 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



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:

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