

## CANADIAN NEONATAL NETWORK TM

### NETWORK REPORT 2012-2017

### **DECEMBER 2017**

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- 1. Ms. Martine Claveau, McGill University Health Centre, QC (2010-2019)
- 2. Dr. Kimberly Dow, Kingston General Hospital, ON (2008-2017)
- 3. Dr. Walid El-Naggar, IWK Health Centre, NS (2015-2018)
- 4. Dr. Abhay Lodha, Foothills Medical Centre, AB (2011-2017)
- 5. Dr. Vibhuti Shah, Mount Sinai Hospital, ON (2010-2018)
- 6. Dr. Joseph Ting, British Columbia Women's Hospital, BC (2016-2019)
- 7. Dr. Prakesh Shah, Mount Sinai Hospital, ON

## **CNN Chairman:**

Dr. Shoo K. Lee, Mount Sinai Hospital, ON

## **EXECUTIVE SUMMARY**

Founded in 1995 by Dr. Shoo Lee, the Canadian Neonatal Network<sup>TM</sup> (CNN) is a group of more than 200 researchers from 31 hospitals and 17 universities across Canada who collaborates on research projects related to neonatal care on a national and international scale. Health care professionals, health services researchers and health administrators participate actively in quality improvement, clinical, epidemiologic, outcomes, health services, health policy and informatics research aimed at improving the efficacy and efficiency of neonatal care. CNN enables research by maintaining a database that contains information on maternal and infant characteristics; antenatal, delivery, and neonatal care practices; and infant outcomes on all infants admitted to 31 tertiary neonatal intensive care units (NICU) in Canada. CNN members publish their research in the CNN Annual Report and peer-reviewed journals, and their success has allowed Canada to become a world leader in reducing neonatal mortality and morbidities.

## CNN highlights from 2012 to 2017 (Appendix 1)

CNN membership and data requests

- CNN membership rose by 27% since 2012.
- Data requests increased between 2012 and 2016, particularly site-specific requests.
- Ten CNN committees met via virtual, teleconferences and face-to-face meetings.

# Benchmarking and trend evaluation

- Completed 5 annual reports and made changes to improve the usability of results.
- Continually evaluated trends and benchmarked NICUs for major morbidities and mortality Research Platform
  - CNN members presented 117 abstracts and published 76 CNN peer-reviewed publications.
  - Executed and secured CIHR funding for expansion and involvement of CNN in various aspects of neonatal care, such as transport network and other project specific questions.
  - Secured funding to establish Canadian Preterm Birth Network, an expansion to include perinatal and developmental pediatrics investigators and parents across the country.
  - Formed and obtained funding for the International Network for Evaluating Outcomes (iNeo) in Neonates collaboration to compare neonatal outcomes between 11 countries.
  - Established collaborations with the Provincial Council for Maternal and Child Health (PCMCH) and Better Outcomes Registry & Network Ontario (BORN Ontario).
  - Maintained collaborations with the Canadian Pediatric Surgery Network (CAPSNet) by providing database maintenance and statistical support in CAPSNet-related activities.
  - Completed a privacy impact assessment in 2013 to analyze privacy risks and safeguards.

# Building Research Capacity - Education and Training

- Established the CNN Awards program to encourage junior investigators and trainees to conduct research
- At the CNN coordinating centre, CNN leadership and staff trained and mentored 4 neonatologists, 4 fellows, 5 international trainees, and 12 students over the past 5 years on patient-oriented research using CNN data.

## Partnership with stakeholder patient organization

• Entered into a collaborative relationship with the Canadian Premature Babies Foundation and several other national and provincial perinatal organizations.

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## CANADIAN NEONATAL NETWORK: AN OVERVIEW

The Canadian Neonatal Network<sup>TM</sup> is a network of Canadian healthcare professionals who provide neonatal care and collaborate on various projects related to improving neonatal care in Canada. The network is comprised of all 31 level 3 NICUs in the country. Network membership includes multidisciplinary health professionals such as neonatologists, maternal fetal medicine specialists, obstetricians, nurses, nurse practitioners, respiratory therapists, health informatics specialists, health economists and epidemiologists. The CNN was founded in 1995 by Dr. Shoo Lee, and now includes over 200 members from 31 hospitals and 17 universities across Canada. The current CNN organizational structure includes a Chair of the Board, Board members, a CNN Director, Executive Committee Members, and a Coordinator.

The CNN's activities are spread in many domains. The **core function of the CNN is to provide benchmarking and trend evaluations** of therapeutic procedures, interventions and outcomes of neonates who require high levels of care immediately after birth. Benchmarking allows participating sites to compare their performance to peers on a regular basis. Members learn from each other by identifying and implementing best practices in the care of at-risk neonates in a collaborative way. Trend evaluations create opportunities for caregivers to assess how changes in practices affect outcomes. In order to conduct benchmarking and trend evaluations, the CNN maintains a standardized, custom-made, modifiable, and versatile NICU database. Each participating site collects and enters data on all neonates admitted to their NICU in a cohesive and structured fashion.

The CNN database allows members to be engaged in clinical, epidemiologic, outcomes, health services, health policy and informatics-related **research aimed at improving the efficacy, quality and efficiency of neonatal care**. Research results are published in the CNN Annual Reports and peer-reviewed journals. The CNN members constantly participate, support, facilitate and lead collaborative research and quality improvement (QI) activities with various investigators, both nationally and internationally, which result in a better understanding of neonatal care and improved delivery of care. The CNN is recognized as the leading neonatal research organization for international collaboration and plays a **key role in our continuous QI efforts across the country**.

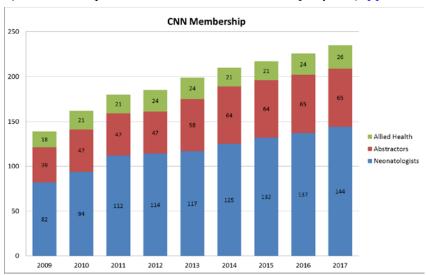
The network also provides a **solid platform for** students, trainees, and junior investigators **to learn research methods**, and execute projects. Trainees from multidisciplinary backgrounds of clinical care, epidemiology, biochemistry, geographical information systems, advocacy, and informatics all utilize the unique learning opportunity provided by the CNN leaders.

The CNN leadership has partnered with the Canadian Premature Babies Foundation to form a direct relationship where leaders of both organizations provide collaborative support to each other on issues related to advocacy for parents and families of neonates admitted to NICUs. This alliance was able to advocate for and successfully obtain extended leave benefits for parents of critically ill children from the federal government.

Finally, CNN is involved in the **evaluation of health services** and organization of care for newborns at the provincial and federal levels. CNN provides recommendations to respective ministries of the current status, future planning and anticipated needs related to neonatal care.

## **CNN MEMBERSHIP**

Currently, 235 Canadian healthcare professionals are members of the CNN. Since 2012, overall CNN membership increased by 27% (16% neonatologists, 10% abstractors, 1% allied health professionals) and data requests increased to more than 20 per year (Appendix 2).



The success of the CNN depends on the active participation of its membership. The executive committee is composed of six members who, along with the CNN director, meet twice a year by teleconference and once a year in person. The CNN Database and Annual Report Review Committee (Appendix 3) meets three times per year by teleconference and is responsible for reviewing, making recommendations and approving the CNN Annual Report. National meetings of CNN Data Abstractors and Site Investigators that focus on database improvements are held twice per year by teleconference and once per year in person. QI projects are overseen by the Evidence-based Practice for Improving Quality (EPIQ) Steering Committee composed of 11 CNN members who meet quarterly (Appendix 4). Also, 1 to 2 members of the EPIQ Steering Committee chair each of the 6 EPIQ Outcome Groups which are focused on improving specific outcomes including bronchopulmonary dysplasia, extremely low gestational age, intraventricular hemorrhage, necrotizing enterocolitis, nosocomial infection, and retinopathy of prematurity. Each of the 6 EPIQ Outcome Groups meet quarterly and is composed of 40 to 90 CNN members (Appendix 4).

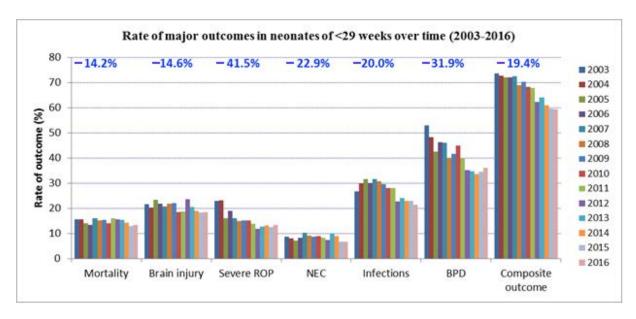
## **BENCHMARKING AND TREND EVALUATION**

The CNN's activities are spread into many domains. However, the **core activity of the CNN is to provide benchmarking and trend evaluations** of therapeutic procedures, interventions, and outcomes of neonates who need high levels of care immediately after birth. The benchmarking

allows sites to compare their performance with peers, learn from each other in a collaborative way, and identify and implement best practices in the care of at-risk neonates. The trend evaluation creates an opportunity for care givers to assess how changes in practices affect outcomes and at the same time provides an impetus to perform better over time. In order to conduct benchmarking and trend evaluation, the CNN maintains a standardized, custom-made, modifiable, and versatile NICU database. Each site across the country collects and enters data on all neonates admitted to their NICU in a cohesive and structured fashion. The participating NICUs are responsible for accurate data entry and in return they receive an annual report of their performance in relation to peers and the entire country.

The CNN produces annual reports, available at the CNN website www.canadianneonatalnetwork.org, that contain benchmarking and trend evaluation data. In the reports, NICUs are labeled by letters and numbers to retain anonymity. Several examples of benchmarking individual NICUs for outcomes can be found in the <a href="CNN Annual Report">CNN Annual Report</a> or on the CNN website listed above.

**Trend evaluation**: Over the past 14 years, all adverse outcomes of Canadian preterm neonates were significantly reduced as a result of our national quality improvement projects.



Brain injury: Intraventricular hemorrhage ≥ grade 3; Severe ROP: Retinopathy of prematurity ≥ stage 3, NEC: Necrotizing enterocolitis, death of tissue in the intestine which can lead to death; Infections: Positive blood or cerebrospinal fluid culture after 2 days of age; BPD: Bronchopulmonary dysplasia; Composite outcome: Mortality or any of the above mentioned outcomes. Blue numbers: Percent change in outcome rate between 2003 and 2016.

The CNN Annual Meetings serve as a forum for CNN members to review the outcome trends. We welcome inputs from members and implement changes to the database and reporting methods in the following year. The major database modifications that were implemented between 2012 and 2017 can be found in <u>Appendix 5</u>.

## RESEARCH INVOLVEMENT AND OUTPUTS

Having a solid infrastructure and database enables CNN members to be engaged in clinical, epidemiologic, outcomes, health services, health policy and informatics-related **research aimed at improving the efficacy and efficiency of neonatal care**. The CNN members constantly participate, support, facilitate, and lead collaborative research activities with various investigators, both nationally and internationally, that result in a better understanding of neonatal care or improved care delivery.

The CNN has been recognized as the leading neonatal research organization for international collaboration and the national outcomes rates produced by CNN serve as a **benchmark for our QI efforts across the country**. Active collaboration between CNN members has resulted in a significant number of research funding successes, applications, presentations at meetings, and published manuscripts. Many of the research findings have led to practice changes and the development of new national and international collaborations, as highlighted below.

# Research funding collaboration and success

Project	Grant	CNN Role	Funding	Duration
Improving Outcomes for Preterm	CIHR Team	Central	\$4,250,000	2016-2021
Infants and their Families: A	Grant	Coordinating		
Canadian Collaborative Network		Centre		
A systems approach for enhancing	CIHR Team	PI	\$1,000,000	2016-2021
perinatal care regionalization	Grant: Perinatal			
	Healthcare			
	System			
	Improvement			
International Network for	CIHR Applied	Central	\$925,000	2013-2019
Evaluation of Outcomes (iNeo) of	Chairs Program	Coordinating		
Neonates:	in Maternal and	Centre		
	Child Health			
	Services			
	Research			
Regional and temporal variations in	CIHR Operating	Co-I	\$46,415	2015-2017
incidence, prevalence and outcomes	Grant			
of critical illness among pregnant				
and post-partum women and				
newborns in Canada				
Improving quality of care during	CIHR	Central	\$524,643	2013-2016
transport of sick neonates: A	Partnerships for	Coordinating		
national collaborative partnership	Health System	Centre,		
for outcome improvement and	Improvement	Partner		
system enhancement	Grant	Network		

Spatial data mining exploring co-	CIHR Operating	Partner	\$801,858	2013-2016
location of adverse birth outcomes	Grant	Network		
and environmental variables				
Outcomes of infants born between	Provincial	Central	\$135,000	2012-2015
31 and 32 weeks' gestational age	Council on	Coordinating		
based on location of birth in	Maternal and	Centre		
Ontario	Child Health			
CHILD-BRIGHT SPOR Network	CIHR Strategy	Coordination	\$30,000	2016-2022
<ul> <li>Parent Integrated Evidence-</li> </ul>	for Patient-			
Based Practice to Improve Quality	Oriented			
("PARENT- EPIQ")	Research			
·	(SPOR)			

## Research funding applications

Project	Grant	CNN Role	Funding	Duration
Hi Lo Oxygen at	CIHR	Coordination	\$3,000,000	2018-2023
resuscitation: a cluster crossover RCT				
Comparison of curosurf and BLES surfactant for neonates with respiratory distress syndrome	AHSC innovation grant, Children Hospital of Eastern Ontario	Coordination	\$100,000	2018-2020

### **Presentations**

The results obtained from CNN database projects have been presented at various international and national meetings. Over the past five years we have reported 117 abstracts in either poster or platform presentations. (Appendix 6)

### **Publications**

The results obtained from CNN database projects have been published in various peer-reviewed national and international journals and have paved the way for prediction, diagnosis, prognosis and therapeutic changes in the care of sick neonates. Over the past five years we have published 76 such publications. (Appendix 7)

### Research collaborations

1. Canadian Preterm Birth Network (2016): The Canadian Preterm Birth Network (CPTBN) is an initiative recently funded by CIHR to improve the outcomes of preterm infants over a five-year period. The CPTBN is led by Prakesh Shah, CNN Director, and is a collaboration of the existing neonatal networks (CNN, CNFUN, CNTN, CAPSNet) with MFM/OB specialists across the country. The aim of CPTBN is to improve the delivery of health care from pregnancy to early childhood. This initiative aims to build a sustainable pan-Canadian network to improve the outcomes of preterm birth by identifying and developing strategies to implement

and evaluate interventions for mothers in preterm labor, preterm infants during their NICU stay and after discharge, and families affected by preterm birth. The primary goal of the CPTBN is to translate new and existing knowledge generated by clinical, QI, and health services research into optimal pan-Canadian practices and policies that will substantially improve both short and long-term outcomes of preterm infants and their families. A total of 17 projects will be carried out by the large study team.

- 2. The International Network for Evaluating Outcomes (iNeo) in Neonates (2013): In 2013, Prakesh Shah received the CIHR Applied Chairs Award in Reproductive, Child and Youth Health Services and Policy Research to support the iNeo research and training activities. iNeo is a collaboration of population-based national neonatal networks from Australia-New Zealand (ANZNN), Canada (CNN), Finland (FinMBR), Israel (INN), Japan (NRNJ), Spain (SEN1500), Sweden (SNQ), Switzerland (SwissNeoNet), Tuscany (TuscanNN, Italy) and the United Kingdom (UKNC). Each of these networks includes all of the tertiary-level NICUs within their country. Data from these networks allowed the comparison of neonatal outcomes between countries and analysis of practice variations associated with improved outcomes. All of the networks work together to implement and continually evaluate the impact of data-informed and evidence-linked clinical and organizational practice changes in NICUs. In addition, iNeo has provided a solid platform to train junior researchers in the field of Perinatal-Neonatal Medicine and Health Services Research. Currently there are eleven countries participating in iNeo. Many variations in outcomes and practices were identified. Six papers have been published to date and several studies are in the pipeline.
- 3. Provincial Council for Maternal and Child Health (PCMCH) (2016): Between 2011 and 2015, CNN and BORN Ontario (Better Outcomes Registry & Network Ontario) data were linked in a study evaluating outcomes of pre-term infants between 30 and 31 weeks gestation receiving care in Level III vs Level IIc NICUs. The final report was submitted to BORN Ontario and PCMCH in 2016. This was the first attempt at such a data linkage and the aim was to foster a partnership between BORN and CNN to develop a reciprocal data sharing system. BORN's data collection for level II has expanded. Going forward, the CNN database will include some BORN data elements for Ontario sites.
- 4. **Better Outcomes Registry & Network Ontario (BORN Ontario) (2016):** BORN Ontario is a prescribed registry under Ontario's Personal Health Information Protection Act and collects NICU data from all Level 2 NICUs/SCNs in Ontario. In order to gain the complete the picture of NICU care in Ontario, BORN Ontario and CNN collaborated to create data extraction tool that retrieves a portion of the NICU data already collected in the CNN database and added 23 new data elements required by BORN. This has alleviated the burden of duplicated data entry at each hospital as most of the NICU data are routinely collected by the CNN. The data extraction tool allows NICU data to be transferred directly from the hospital's CNN database to BORN Ontario.
- 5. Canadian Neonatal Transport Network (CNTN) (2012): In 2012, CNN investigators, led by Dr Kyong-Soon Lee from the Hospital for Sick Children, received funding to develop a national network of neonatal transport teams in Canada (CNTN). CNTN aims to share current knowledge regarding neonatal transport, generate new knowledge, examine and improve the neonatal transport processes, benchmark transport programs across the country, and enhance

- neonatal outcomes. Key indicators were developed to evaluate the transport programs and set standards to guide changes to the organization and the performance of neonatal transport systems. Sixteen transport teams participated in data collection over the first three years of the project. These data will be used to analyze the referral and transport process with the goal of improving neonatal outcomes.
- 6. Canadian Pediatric Surgery Network (CAPSNet): CAPSNet is a collaborative national network that collects data on two birth defects, congenital diaphragmatic hernia (CDH) and gastroschisis (GS), with the goal of identifying variations in clinical practices that are associated with patient outcomes. The information gained is then used to put forward new recommendations for patient care. Between 2012 and 2016, CNN continued to provide database maintenance and statistical support for CAPSNet-related activities.

## **BUILDING RESEARCH CAPACITY - EDUCATION AND TRAINING**

The CNN provides a **solid platform for** students, trainees, and junior investigators **to learn research methods, execute projects, and successfully lead collaborations**. Trainees from multidisciplinary backgrounds utilize the opportunity to learn and grow under the support of CNN leaders. The CNN has provided a platform to 18 trainees over the past five years (Appendix 8).

## Trainee recognition: CNN Awards Program

The CNN Awards Program was created in 2016 with an aim to encourage and recognize trainees and early career investigators who use CNN resources as a foundation for excellence in research. The eligibility criteria can be found in Appendix 9.

## Evidence-based Practice for Improving Quality (EPIQ) Training Program

In an effort to support continuous improvements in neonatal quality of care, the CNN conducts annual training workshops using the EPIQ method. Workshop participants discuss the evidence for practice changes, are trained in the Plan-Do-Study-Act method for implementing practice changes, and develop team building skills. Between 2012 and 2016, 168 people from across Canada and around the world participated in the EPIQ training workshop.

## **QUALITY IMPROVEMENT**

Since 2002, CNN member sites have heavily engaged in continuous nationwide QI efforts under the umbrella program "Evidence-based Practice for Improving Quality (EPIQ)" with extremely favorable results. Throughout EPIQ implementations, the emphasis was on the three principal components of the PARIHS (Promoting Action on Research Implementation in Health Services) framework: Evidence – by conducting constant review of the literature and providing the group with the most up-to-date information; Context – by allowing units to test interventions/processes that are important and relevant from a local context; and Facilitation – by identifying local and systemic barriers, using local or national expertise to tackle barriers and providing units the capacity to evaluate their performance on a regular basis.

In **EPIQ-1** (2002-05), we tested the effectiveness of QI in improving two pre-defined outcomes via a cluster randomized controlled trial in 16 NICUs. Though a particular NICU was free to choose their intervention program, they were asked to reduce a specific outcome (either NI or chronic lung disease). This QI approach was proven to be effective at improving outcomes. We also demonstrated that targeting one outcome may lead to change in other outcomes. 7 units that were not involved in EPIQ-1 participated in **EPIQ-PHSI** (2006-07). These 7 units were provided with the bundles of interventions that were identified as beneficial in EPIQ-1, but they were not provided with immersive engagement in the QI process and monitoring of QI activities. We found that outcomes in NICUs that previously participated in EPIQ-1 continued to improve, but outcomes in NICUs that were not part of EPIQ-1 did not improve, leading to the understanding that successful QI requires both continuous engagement, and behavioral and cultural change at the local-level.

EPIQ-2 (2008-13) was designed to address the central issue of local-level behavioral and cultural change. We expanded the program to include 25 of the 28 NICUs in Canada and targeted multiple outcomes simultaneously, i.e. mortality and five major morbidities. EPIQ-2 further allowed significant unit-level flexibility to adapt and revise their QI processes based on review of NICU-level data. EPIQ-2 resulted in significant reductions in necrotizing enterocolitis, retinopathy of prematurity and nosocomial infection. Although there were also reductions in chronic lung disease, neurological injury or mortality, they were not statistically significant. In addition, we learned that the majority of the outcome improvements occurred in neonates ≥26 weeks' gestational age. EPIQ-2 demonstrated that a QI program could be scaled to the national population level.

The EPIQ program was modified again based on the EPIQ-2 experiences. EPIQ-3 (2014-17) was conducted in 25 of the 30 NICUs in Canada. We encouraged NICUs to specifically target two outcomes where they underperformed compared to their peers, and implemented sentinel event reviews to permit in-depth examination of care processes that may be modified to improve outcomes. We challenged NICUs to target eradication of these adverse outcomes locally (i.e. drive to zero). Moreover, sites had the opportunity to visit two peer NICUs that presented better outcome rates than their own. By learning from peers with better target outcomes, NICUs implemented Plan-Do-Study-Act (PDSA) cycles locally and received benchmarking reports from the coordinating centre. We intensified the engagement of unit administrators in QI activities such that NICU-level support could be garnered. In summary, over the course of 12 years, we expanded QI activities from selected Canadian NICUs to the national level; advanced from a traditional QI approach to a broader, healthy and competitive approach; and later adopted many QI techniques that are utilized routinely in the industry. We plan to launch EPIQ-4 soon where we will tackle issues related to systems and resources, embrace the use of point-of-care ultrasound and the use of registry trials. We plan to constantly engage units in improving care by testing common, yet diverse, approaches with the goal to improve outcomes.

### **ADVOCACY**

The CNN leadership has partnered with the Canadian Premature Babies Foundation to form a direct relationship where leaders of both organizations provide collaborative support to each other in issues related to advocacy for parents and families of neonates admitted to NICUs. Through

this collaboration, the alliance was able to advocate for and successfully obtain extended leave benefits for parents of critically ill children from the federal government. The CNN also works closely with the Canadian Academic Pediatric Health Centers (CAPHC) in strategic planning and the development of activities and services as they relate to Canadian children's health. Similar collaborations are planned with several other stakeholder organizations in various provinces, including the Provincial Council on Maternal and Child Health, Ontario; Provincial Perinatal Program of Newfoundland; Alberta Perinatal Health, British Columbia Perinatal Health, and Nova Scotia Perinatal Program (Atlee Database).

## **HEALTH SERVICES EVALUATION**

CNN has actively engaged in producing health services evaluation for local, provincial and national organizations. We have recently studied the perinatal regionalization status in Canada and conducted analyses on how resource allocation may affect practices and patient outcomes.

Provincial variations in physical and human resources per 1000 births											
	вс	АВ	SK	МВ	ON	QC	NB	NS	NL	PE	Canada
Total number of births	44495	58035	15969	17372	147244	86850	6718	8670	4325	1306	390984
Total number of level 3 funded beds	76	103	50	22	214	157	27	24	8	0	681
Number of level 3 funded beds per 1000 births	1.7	1.8	3.1	1.3	1.5	1.8	4.0	2.8	1.8	0.0	
Total number of level 2 funded beds	138	206	13	76	568	226	52	39	18	12	1348
Number of level 2 funded beds per 1000 births	3.1	3.5	0.8	4.4	3.9	2.6	7.7	4.5	4.2	9.2	
Total level 2 & Level 3 funded beds	214	309	63	98	782	383	79	63	26	12	2029
Number of level 2 & 3 funded beds per 1000 births	4.8	5.3	3.9	5.6	5.3	4.4	11.8	7.3	6.0	9.2	
Total NICU physicians (neonatologists and pediatricians)	83	117	15	19	367	140	30	20	4	8	802
Number of staff NICU physicians per 1000 births	1.9	2.0	0.9	1.1	2.5	1.6	4.5	2.3	0.8	6.1	

## **CONCLUSIONS**

The CNN has become the premier collaborative network for neonatal care, outcomes and process improvement, both nationally and internationally. With an emphasis on evidence-based outcomes and improvement through collaboration, the CNN is a model for building, developing, and supporting strong national partnerships. The CNN's commitment to continuous trend evaluations and benchmarking to improve quality, along with its solid research infrastructure and output, have allowed Canada to become a world leader in reducing neonatal mortality and morbidities. Furthermore, the strong advocacy partnerships built by the CNN ensure that the patient is always the priority and policy decisions regarding patient care must be evidence-based. The CNN is committed to maintaining collaborations and expanding them into the future with the goal of using evidence-based practices to improve neonatal outcomes. To this end, the CNN plays an active role in fostering the next generation of investigators to ensure that research will continue to address the current and future issues of neonatal care while meeting the needs of Canadian neonates.

## **APPENDIX 1: 2012-2017 CNN MILESTONES**

### 2012-2013 Milestones

- CNN investigators were instrumental in coordinating the establishment of the Canadian Neonatal Transport Network (CNTN) funded by the Canadian Institutes for Health Research.
- Establishment of the International Network for Evaluating Outcomes (iNeo) in Neonates.

### 2013-2014 Milestones

- A privacy impact assessment was performed for the CNN Coordinating Centre in 2013.
   Procedures pertaining to data privacy and information security were reviewed and updated.
   There were no major concerns arising from the assessment.
- The CNTN database was established using the CNN database platform and data collection was initiated.

## 2014-2015 Milestones

— The CNN database was linked to the newly established CNTN database, which contains 2 years of data (2014 and 2015) from 16 transport teams across Canada. Ongoing linkages with newly collected data are performed on a regular basis.

### 2015-2016 Milestones

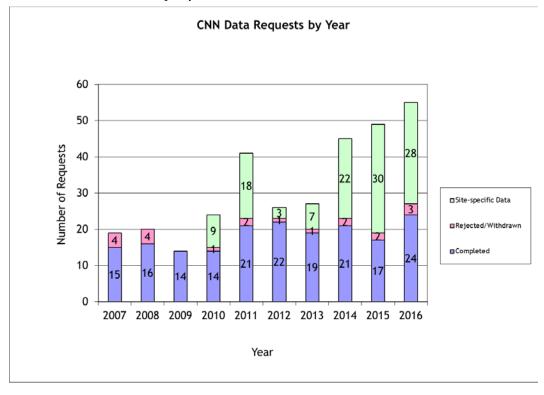
 Completion of the PCMCH project in collaboration with BORN Ontario, which evaluated outcomes of preterm infants between 30 and 31 weeks gestation receiving care in Level III vs Level IIc NICUs.

## 2016-2017 Milestones

- An internal audit of the CNN database was performed in all 31 NICUs and confirmed the reliability of the CNN database. The results were published in the *American Journal of Perinatology*.
- An initiative to form the Canadian Preterm Birth Network, a collaboration between neonatal, obstetric, maternal-fetal medicine and follow-up investigators to improve neonatal outcomes, received \$4.25 million of funding from CIHR.

# **APPENDIX 2: DATA REQUESTS**

Data requests continued to increase between 2012 and 2016, particularly site-specific data requests which rose to more than 20 per year between 2014 and 2016.



# APPENDIX 3: CNN DATABASE AND ANNUAL REVIEW COMMITTEE

### **Members**

- Dr. Alexander Allen, Dalhousie University
- Dr. Keith Barrington, University of Montreal
- Dr. Marc Beltempo, McGill University
- Dr. Orlando da Silva, Western University
- Dr. Akhil Deshpandey, Memorial University
- Dr. Michael Dunn, University of Toronto
- Ms. Wendy Seidlitz, Hamilton Health Sciences
- Dr. Mary Seshia, University of Manitoba
- Dr. Prakesh Shah, University of Toronto (Chair)
- Dr. Nalini Singhal, University of Calgary

## **APPENDIX 4: EPIQ STEERING COMMITTEE AND OUTCOME GROUPS**

# **Steering Committee Members**

Dr. Shoo Lee, Mount Sinai Hospital, Toronto, Ontario

Dr. Prakesh Shah, Mount Sinai Hospital, Toronto, Ontario

Dr. Anne Synnes, University of British Columbia, Vancouver, British Columbia

Dr. Vibhuti Shah, Mount Sinai Hospital, Toronto, Ontario

Dr. Akhil Deshpandey, Janeway Children's Hospital and Rehabilitation Centre, St. John's, Newfoundland

Dr. Michael Dunn, Hospital for Sick Children, Toronto, Ontario

Dr. Khorshid Mohammad, University of Calgary, Calgary, Alberta

Dr. Wendy Yee, Foothills Medical Centre, Calgary, Alberta

Dr. Amit Mukerji, Hamilton Health Sciences Centre, Hamilton, Ontario

Dr. Eugene Ng, Sunnybrook Health Sciences Centre, Toronto, Ontario

Dr. Brigitte Lemyre, Children's Hospital of Eastern Ontario, Ottawa, Ontario

## **Outcome Groups and Chairs**

Bronchopulmonary dysplasia (73 members)

Co-Chair: Dr. Wendy Yee, Foothills Medical Centre, Calgary, Alberta

Co-Chair: Dr. Amit Mukerji, Hamilton Health Sciences Centre, Hamilton, Ontario

Extremely low birth weight (81 members)

Co-Chair: Dr. Eugene Ng, Sunnybrook Health Sciences Centre, Toronto, Ontario

Co-Chair: Dr. Brigitte Lemyre, Children's Hospital of Eastern Ontario, Ottawa, Ontario

Intraventricular hemorrhage (72 members)

Co-Chair: Dr. Bruno Piedbeouf, Centre Hospitalier Universitaire de Quebec, Quebec

Chair: Dr. Khorshid Mohammad, University of Calgary, Calgary, Alberta

Necrotizing enterocolitis (66 members)

Co-Chair: Dr. Kim Dow, Kingston General Hospital, Kingston, Ontario

Co-Chair: Dr. Akhil Deshpandey, Janeway Children's Hospital and Rehabilitation Centre, St.

John's, Newfoundland

Co-Chair: Ms. Cindy Ulrich, London Health Sciences Centre, London, Ontario

Nosocomial infection (85 members)

Co-Chair: Dr. Michael Dunn, Hospital for Sick Children, Toronto, Ontario

Co-Chair: Ms. Nely Amaral, Mount Sinai Hospital, Toronto, Ontario

Retinopathy of prematurity (40 members)

**Co-Chair:** Dr. Vibhuti Shah, Mount Sinai Hospital, Toronto, Ontario **Co-Chair:** Ms. Judy Hawes, Hospital for Sick Children, Toronto, Ontario

### **APPENDIX 5: CNN DATABASE UPDATES**

**Database operation:** Several changes to the overall operation of the database have been made, which now include one face-to-face meeting and two teleconferences per year with abstractors and site investigators. Only one database update at the beginning of the year (in January) is performed, as opposed to previous multiple updates throughout the year.

## Collection of variables:

### 2012-2013

- Definitions of BiPAP and SiPA were updated in 2012.
- Selections for delayed cord clamping were updated, to include up to 60 seconds, in order to be in alignment with the NRP recommendations.
- Tylenol was added as an option for PDA treatment.
- Anti-fungal was added as an option for prophylactic interventions.
- Avastin/Lucentis were added as treatment options for ROP. Details with respect to agent and dose were added.
- Definition for Magnesium Sulfate administration was updated.

### 2014

- 5 new items regarding feeds were added to patient chart screen: breast milk, donor milk, formula, HMF, additives.
- Neonatal thrombosis was added.
- Selection for 4 types of diabetes was added.
- Variables removed: muscle relaxants, NOP, transfusion

#### 2015

- New variables added: exact oxygen concentration in resuscitation; umbilical cord milking; reasons for MgSO4 expanded; rescue course of steroid; oxygen reduction test.

### 2016

- New variables added: cervical sutures, ostomy; refined neurodevelopmental follow-up referral; new BPD definition.

### 2017

- <37 weeks etiology section was added.

**Database Audit:** An audit of the CNN database was conducted recently in all 31 neonatal units. The aim was to identify any problematic variables (if necessary, redefine or delete. Ninety-five data items selected for re-abstraction were classified into categories (critical, important, less important) based on predefined agreement rates. Agreement rates for each data item were calculated for individual units and across the network. A total of 155 cases and 14,725 data fields were re-abstracted. The overall agreement rates for critical, important, and less important data items were 98.0%, 96.1%, and 96.3%, respectively. Individual site variation for discrepancies ranged between 0.2% and 12.8% for all collected data items. The results were published by the *American Journal of Perinatology*. This assured sites of internal consistency and reliability of the CNN database.

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# **APPENDIX 8: CNN TRAINEES**

Trainee	Duration	Specialty	Involvement	Current position
Tetsuya Isayama, MD	2012 to 2017	Neonatology	4 projects	Neonatologist,
PhD Candidate				Japan
Marc Beltempo, MD	2016 to 2017	Neonatology	3 projects	Neonatologist,
FRQS Trainee				Montréal
Lauren Kelly, PhD	2016	Health Services	3 projects	Professor, Seneca
Postdoctoral Fellow		Research		College
Laura Gemmell	2015	Student/ Pediatrics	1 project	Medical Student
MSc, Graduate Student				
Lisa Martin, PhD	2015 to 2016	Health Services	2 projects	PDF, Mount Sinai
Postdoctoral Fellow		Research		Hospital
Yanyu Lv, PhD	2015	Health Services	2 projects	Researcher, China
Postdoctoral Fellow		Research		
Zhangbin Yu, PhD	2015	Health Services	1 project	Researcher, China
Postdoctoral Fellow		Research		
Armend Lokku	2016	Statistics	1 project	Statistician
MSc, Graduate Student				
Wen Ge	2015	Statistics	1 project	Statistician, TD
MSc, Graduate Student				Bank
Gary Ko	2013	Medical	2 projects	Medical Student
MD Candidate		Student/Pediatrics		
Laura Chiarelli	2014	Statistics	1 project	Statistician
MSc, Graduate Student				
Sadia Hossain	2014 to 2015	Health Services	3 projects	Research Assistant
PhD, Graduate Student		Research		
Kjell Helenius, MD	2016	Neonatology	2 projects	Neonatologist,
PhD, Graduate Student				Finland
Siyuchan Jiang, MD	2015	Neonatology	2 projects	Neonatologist,
PhD, Graduate Student				China
Sarah Sy, BSc	2017	Pre-med	1 project	Pre-med Student
Undergraduate Student		student/science		7. 1
Monica Dave, BSc	2017	Science	1 project	Research
Graduate Student	2017			Coordinator, TWH
Saad Alam, MBBS	2017	Science	1 project	Resident
Graduate student	2045	3.5.1' ' ' 1' '		D 11
Shruti Dave, MD	2017	Medicine/pediatrics	1 project	Resident
Graduate student				

## **APPENDIX 9: CNN AWARD ELIGIBILITY**

The eligibility criteria for the CNN Trainee Award are as follows:

- a. Be a trainee (including resident, fellow and non-clinical trainee) OR
- Early career independent investigator (including clinical and non-clinical) who are within
   years of first academic appointment as a faculty member at any Canadian institution;
   AND
- c. Have used CNN data or related initiatives (including data from CNFUN and EPIQ) in the 12 months prior to the launch date of the competition
- d. Have produced a peer-reviewed abstract and/or journal article from the project

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CNN award applications are assessed by a Selection Committee with defined guidelines as approved by the CNN Executive Committee.

## **CNN Award Recipients:**

2016 – Dr. Joseph Ting, Early Career Neonatologist, British Columbia Women's Hospital, BC 2017 – Dr. Krystyna Ediger, Resident, University of Calgary, AB