

Application for Access to CNN Data

Name of Applicant:

Address:

Phone:

Fax:

Email:

Institutional Affiliation:

Department:

Position:

Academic Advisor (if student):

Please send the completed application and a research proposal (guidelines on page 2) to:

Priscilla Chan, CNN Coordinator Mount Sinai Hospital 700 University Avenue, Room 8-500 Toronto, Ontario M5G 1X6

Email:Priscilla.Chan@sinaihealthsystem.caTel:416-586-4800 ext 3833Fax:416-586-8546

*Contact the Coordinating Centre if you do not hear back within 2 weeks of submission

Office Use Only:			REQ#
Date application received: Request Approved:	Y	Ν	Date:



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Project Title:

Primary Investigator & Institution:

Co-investigator(s):

Please attach a research proposal including:

- 1. Background
- 2. Research question
- 3. Proposed research & statistical methodologies
- 4. Timeframe (years of data)
- 5. Inclusion/exclusion criteria
- 6. Expected outcomes & mock tables
- 7. Possible impact of results
- 8. Specific variables requested

Project Reviews:

No

- 1. Has the project been approved following a formal ethics committee review?
 - *Please seek approval from your local Research Ethics Board
 - Pending *Please update status of the application to the MiCare Research Centre
 - Yes *Please attach a copy of the ethics approval certificate
- 2. Is the project funded by a recognized grant funding agency?
 - No
 - Yes *Please attach a copy of the funding letter from the granting agency
- 3. Is the project a thesis/dissertation?
 - No
 - Yes *Please attach a letter from the committee chair
- 4. Is the project done under contract?
 - No

Yes *Please specify the contracting organization's contact below Organization: Name: Phone: Email:



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Terms of Reference

- 1. The undersigned will comply with the Freedom of Information and Protection of Privacy Act (FIPPA), the Privacy Act and the Personal Information Protection and Electronic Documents Act (PIPEDA), the Ontario Personal Health Information Protection Act and the regulations made under these Acts.
- 2. The primary investigator is responsible for obtaining ethics approval for the project from his/her primary institution. Copy of such approval should be forwarded to the Canadian Neonatal Network[™] Coordinating Centre at Mount Sinai Hospital.
- 3. The Canadian Neonatal Network[™] (CNN) will provide the undersigned with definitions and limitations of the data upon its release. The undersigned will provide the CNN with copies of final manuscripts intended to be published or distributed. Abstracts submitted for presentation to meetings are welcome for review by the CNN Executive Committee but this responsibility will be delegated to the Senior Investigator on the application. The CNN has the authority to remove elements considered inappropriate for publication or distribution.
- 4. In accordance with privacy regulations, the CNN will not provide raw data to any investigators. Only aggregate results will be provided and any small cell size (≤ 5) will be suppressed due to risk of reidentification. Individual patient data can be released to investigators only after investigators obtained REB approval from participating site(s) for which they are seeking data.
- 5. The undersigned understands that s/he is responsible for maintaining the security and confidentiality of all information provided to them by the CNN. Results provided will be used by the undersigned only. The undersigned shall ensure that there is no unauthorized access to or modification of the results, misuse of results or breach of confidentiality. In the event that confidentiality of results or the security of any computer systems/networks is suspected to be jeopardized, the undersigned will notify the CNN immediately.
- 6. The undersigned will have up to two years from the time when results are released to produce a scientific work. Lack of substantial progress (as evidenced by production of an abstract, a significant body of analyses and first draft of manuscript) will relinquish their authorship priority.
- 7. The undersigned will not use the information for any purpose other than the purposes described in this application. Secondary analysis requires additional request for approval.
- 8. The undersigned will appropriately reference the Canadian Neonatal Network[™] as the source of the data for all reports, presentations or publications using data from the CNN Database.

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9. Fees may be charged as defined in schedules to this Terms of Reference.

I have read and agree to abide by the Terms of Reference.

Applicant Signature

Date