



POLICY AND PROCEDURE MANUAL

Governing Use of and Access to the Niday Perinatal Database for the Greater Toronto Area

**Developed by:
The Child Health Network for the Greater Toronto Area**

**In partnership with the:
Perinatal Partnership Program of Eastern and Southeastern Ontario
Toronto Public Health
Durham Region Health Department
Halton Regional Health Department
Region of Peel Health Services
York Region Health Services
Central East Health Information Partnership
Criticall Ontario Bed Registry**

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Policy and Procedure¹

Governing Use of and Access to the Niday Perinatal Database

1.0 INTRODUCTION

The *Niday Perinatal Database for the Greater Toronto Area* is an Internet-based system that enhances the ability of health care providers in different parts of the region and within different service sectors to work together to improve the perinatal health of the community. It is the only database in Ontario that provides immediate access to real-time population-based perinatal data for an entire region.

A. Participation

The *Niday Perinatal Database* is comprised of data from all hospitals with obstetrics and/or neonatal services that are members of the Child Health Network for the Greater Toronto Area (CHN). Hospitals involved in the database include:

Cluster Designations and Levels of Care for CHN Hospitals		
CLUSTER	HOSPITAL	LEVELS
CENTRAL	Humber River Regional Hospital (Church site)	I
	Humber River Regional Hospital (Finch site)	II
	St. Joseph's Health Centre	II
	St. Michael's Hospital	II
	Toronto East General Hospital	II
	Mount Sinai Hospital	III
EAST	Lakeridge Health Corporation (Port Perry site)	I
	Lakeridge Health Corporation (Oshawa site)	II+
	Rouge Valley Health System (Ajax/Pickering site)	I
	Rouge Valley Health System (Centenary site)	II+
	Markham Stouffville Hospital	II
	Scarborough Hospital (General site)	II
	Scarborough Hospital (Grace site)	II
NORTH	Southlake Regional Health Centre	II
	York Central Hospital	II
	North York General Hospital (General site)	II+
	Sunnybrook and Women's College Health Sciences Centre (Women's College Site)	III
WEST	William Osler Health Centre (Georgetown site)	I
	William Osler Health Centre (Etobicoke site)	II
	William Osler Health Centre (Brampton site)	II+
	Halton HealthCare Services Corporation (Milton site)	I
	Halton HealthCare Services Corporation (Oakville site)	II
	Trillium Health Centre	II
	The Credit Valley Hospital	II+
	Joseph Brant Hospital ***	

*** Although not an official member of the CHN, Joseph Brant Hospital (West Cluster) will be participating as a member of the Niday Database Project.²

¹ This document was adapted from the policy and procedures developed by the Perinatal Partnership Program of Eastern and Southeastern Ontario (PPESO).

B. Data Entry

- As of April 1, 2003, data is entered into a secure, encrypted program via the Internet.
- All participating organizations (hospitals) will collect the agreed upon variables that form the Niday perinatal dataset using the on-line data entry screens via CritiCall (<https://www.criticalcall.com>). It is advised that data entry be performed on a daily or a weekly basis to prevent backlogs.
- Data entry should be completed no later than two (2) weeks following the month's end.
- Organizations already using an information system that captures data variables that are part of the Niday perinatal dataset have the option of uploading data provided criteria related to the *Niday Perinatal Database* are met (i.e., definitions, data quality, etc.). To upload data, contact the Niday Perinatal Database Manager at the CHN Secretariat for further details (416-813-6718).

C. Requesting Changes to the Niday Perinatal Database

- Organizations interested in adding or modifying a data element to the *Niday Perinatal Database*, should forward their requests/suggestions to the Database Manager at the CHN Secretariat. Requests for new data variables (elements) should include the definition of the variable, and the rationale for inclusion.
- Significant changes to the database (i.e., new variables) will be considered every two (2) years, based on review and advice received from regional and provincial consultation groups. This streamlined process will ensure that users do not need to constantly change their forms and processes, and will help contribute to enhancing the quality and rigor of the data collection process.
- Minor changes (i.e., modifying font size, colours, etc.) will be performed “as-needed” and will not require a full consultation with partners. Impact of such changes will be minor, and will be done when the change(s) are deemed to contribute to improvements in efficiency or quality of data with little/no negative impact on users.

D. Consent to Collect Data

- Data collected as part of the *Niday Perinatal Database* project is solely for the purposes of monitoring perinatal outcomes at an aggregate level, not at a patient specific level and therefore patient identifiers will not be used.
- Data collected in the *Niday Perinatal Database* is considered to be “non-personal” (i.e., it cannot be used to identify an individual). As such, data included in the database will not fall under the federal *Personal Information Protection and Electronic Documents Act* (PIPEDA) or the provincial *Personal Health Information Privacy Act* (PHIPA) given that it will not contain any unique patient information (i.e., name of patient, OHIP number) that

² Joseph Brant Hospital is not an official member of the CHN. However, the hospital is participating as a partner in the Niday Perinatal Database project given that the hospital is part of Halton Region Health Department. Compilation and analysis of data from this hospital is required to complete the analysis of data from the Halton Region.

can be traced directly back to a specific individual. Patient consent will **not** be required to collect data included in the database since the patient's privacy has not been violated.³

E. Data Quality

- Organizations will be expected to ensure that data entered into the *Niday Perinatal Database* is accurate.
- Regular audits should be undertaken periodically by each organization to confirm that records are consistent with the health records.
- The CHN Secretariat will conduct verification checks for data accuracy on a monthly basis.
- Reports highlighting issues related to erroneous or questionable data will be issued to the relevant organization. Corrections to the data should be completed within two (2) weeks of notification received from the CHN.
- The CHN, or other organizations (i.e., CEHIP), will also perform additional audits for the region annually.

2.0 OWNERSHIP & ACCESS

A. Hospitals

- Each organization owns its own data. Within an organization, access to the data is limited to individuals with approval from the organization. A senior representative from each organization (or perinatal committee from the organization) will be responsible for approving who will have password access to enter their data on-line and who will have access to the reports and raw data.
- Access to the system may be limited to data entry only, reports only, or both.
- All individuals with permission to access the system will receive training by the CHN, or by an individual who has been trained by the CHN.
- Individuals who request access to their own organization's data must obtain permission from the designated individual from their organization. Login accounts will be created by the CHN upon confirmation of permission from the organization.
- All CHN member hospitals have agreed to share data with each other and will be able to access aggregate data from each hospital as needed. Data **will not** include baby numbers or chart numbers.

³ It is understood, however, that a chart number (or other arbitrary numbering system) may make it possible to link data back to a specific patient through the original chart of the hospital. This will, however, require, internal access to hospital records.

B. Project Manager

- The CHN's Niday Perinatal Database Manager will have full access to the data for verification and report purposes only.

C. Public Health Units in the Greater Toronto Area (GTA) / Central East Health Information Partnership (CEHIP)

- Public health units in the GTA (Toronto Public Health, Durham Region Health Department, Halton Regional Health Department, Region of Peel Health Services, and York Region Health Services) and CEHIP will have access to online record-level data and aggregate data at the health unit and regional levels, as needed.
- The data will not include hospital specific information, baby numbers, or chart numbers.
- Regional data for use by GTA public health units and CEHIP are all records in the database that have residential postal codes belonging in the areas serviced by the GTA public health departments (i.e., data will not be used from records with postal codes outside the GTA).
- Toronto Public Health will work with the CHN to undertake analysis and reporting of the data during the first year of the project and, as a result, an epidemiologist at the Health Unit will have full access to the data for verification and report purposes only.
- The Durham Region Health Department will work with the CHN for database quality verification and monitoring purposes during the first year of the project and, as a result, an epidemiologist at the Health Unit will have full access to the data for verification and report purposes only.

D. Auditor

- The database will be audited annually or following significant changes.
- The auditor will have temporary full access to the database, hospital logbooks, and hospital charts for data verification purposes only.

E. CritiCall

- As system administrators, CritiCall may need to view data if quality or technical issues arise with respect to the data.
- CritiCall may access data for technical or quality assistance only.

F. Access by Other Parties

- To protect the security of the database, no hospital or person **outside of the CHN organization** will have access to another organization's data without written permission from that agency. Each agency will designate an individual or group responsible for authorizing access to the *Niday Perinatal Database*.

- Other organizations (i.e., District Health Councils, the Ministry of Health and Long-Term Care), will not be able to access the data without following the data request procedures described in this document.
- Aggregate data for the region that does not identify individual organizations or patients can be accessed via the procedure outlined below.

3.0 PROCEDURE

A. *Internal Requests for Data*

1. Hospitals

It is the responsibility of each organization to oversee internal requests for access to data. Existing organizational/hospital policies should be followed and approval should be granted by the “most responsible person” or group identified by the organization. Since the request for access to data is limited to the data available at that one particular site, no formal requests should be forwarded to the CHN.

Internal users of the database may include but are not limited to:

- Employees of the institution as defined by that organization.
- Students (medical, nursing) at the institution who wish access to this one site’s data only and have followed the hospital’s internal access to information process.
- CHN staff, at the request of the hospital, who will assist the hospital with data utilization (e.g., interpretation for an internal project).

2. Public Health Units

See Section 2.0, subsection C.

B. *External Requests for Data*

Requests for access to all or parts of the *Niday Perinatal Database* by external users must go through a formal review process. The Maternal and Newborn Services Task Force (a subcommittee of the CHN) will regulate this process.

External users of the database may include but are not limited to:

- Organizations outside of the CHN who want to access all or parts of the aggregate database or raw data (the data will not include baby numbers or chart numbers).
- Non-members of the Network (e.g., Master’s students, Fellows, etc.).

Each request will be evaluated on an individual basis. However, all principles of confidentiality will apply:

- If hospital specific data is requested, users must receive written consent from each of the relevant hospitals before the CHN will release the data.

- Use of the data will be limited to the duration of the research project and for the purpose(s) of the research project only.
- External users of the data must expunge all forms of the data after its use.
- Acknowledgement of the source of data as the *Niday Perinatal Database for the Greater Toronto Area* shall be made.
- The Maternal and Newborn Services Task Force must authorize any linkages of the data with other databases.
- If data access is permitted, the CHN will typically provide an Excel file containing the requested information.

Before any information can be released, the following must be submitted to the **CHN's Niday Perinatal Database Manager** who will be responsible for forwarding all requests to the Maternal and Newborn Services Task Force (see attached appendix). Requests should include:

- A letter describing the purpose for collection/use of the data.
- A description of plans to ensure confidentiality of information.
- A description of how data will be used.
- A copy of completed ethical approval (i.e., from educational institution and/or hospital(s) ethics review committees) if access to hospital specific data (i.e., non-aggregate data) is requested.
- A letter of approval to release data from each hospital involved.

Upon completion, a copy of any report(s) generated must be forwarded to the **CHN's Niday Perinatal Database Manager**. Submissions will be reviewed by a working group of the **Maternal and Newborn Services Task Force** and the applicant(s) will be notified of the results in writing.

C. Publication of Reports

The following guidelines will be followed when generating reports:

1. Individual record level information cannot be published.
2. Results must be suppressed for data that is based on cell sizes of <5 or as assessed on an individual basis when items are context sensitive.
3. Each organization can generate reports at any time, using the Online Manager Functions. An organization can choose to distribute these reports as appropriate, providing the conditions described in guidelines 1 and 2 are met.
4. Organization specific reports prepared by the CHN cannot be shared or distributed to other organizations outside the CHN without the written consent of the source

organization. The only exception to this is the number of births per hospital – this information can be shared without consent from the hospital.

5. City and regional level reports (i.e., no hospital specific information) prepared by the CHN, Public Health Units, or other users with access to the *Niday Perinatal Database* system can be shared publicly, providing the conditions described in items i) and ii) are met.
6. Data from the *Niday Perinatal Database* may not be linked with other databases without the consent of the CHN.
7. Any individual or organization who wishes to publish a document for distribution (i.e., peer review journal) using data from the *Niday Perinatal Database* must consult the CHN prior to publication. All requests for publication should be forwarded to:

Niday Perinatal Database Manager
Child Health Network for the Greater Toronto Area
180 Dundas Street West, 17th Floor, Suite 1700
Toronto, Ontario M5G 1Z8
Telephone: (416) 813-6718
Fax: (416) 813-8309



Child Health Network for the Greater Toronto Area

NIDAY PERINATAL DATABASE FOR THE GREATER TORONTO AREA

APPENDIX A: EXTERNAL REQUESTS FOR DATA

Requests for access to all or parts of the *Niday Perinatal Database for the Greater Toronto Area* by external users must go through a formal review process. Individuals or organizations interested in accessing data must complete the following form and submit it to:

Niday Perinatal Database Manager
Child Health Network for the Greater Toronto Area
180 Dundas Street West, 17th Floor, Suite 1700
Toronto, Ontario M5G 1Z8
Telephone: (416) 813-6718
Fax: (416) 813-8309

1. Please indicate the name and contact information of the individual(s) submitting this request.

2. Please attach a brief letter describing the intended purpose for collection/use of the data and specify the data you are requesting access to.
3. Please describe your plans to ensure confidentiality of the data/information received.

4. Please describe how the data will be used.

5. Please attach a copy of a completed ethical approval form/letter (i.e., from educational institution and/or hospital(s) ethics review committee) if access to hospital specific data (i.e., non-aggregate data) is requested.
6. If hospital specific data is requested, please attach a letter from each hospital involved for approval to release their data.

Upon completion, a copy of any report(s) generated must be forwarded to the **CHN's Niday Perinatal Database Manager**. Submissions will be reviewed by a working group of the **Maternal and Newborn Services Task Force**. The applicant(s) will be notified of the results in writing.