

Newfoundland and Labrador Centre for Health Information Research and Development Division

Privacy Impact Assessment To be completed for all requests for person-identifying data

The Research and Development team works closely with local, provincial, and national research organizations such as Memorial University of Newfoundland and Health Canada in carrying out applied health research. As a regular activity, Research and Development provides researchers with aggregate data. If a researcher requires person-identifying data, NLCHI requires a Privacy Impact Assessment (PIA) to be completed before approval is sought from the custodian and in addition to approval by a research ethics board.

To ensure that the confidentiality of individuals is maintained, NLCHI is committed to conducting PIAs for all of its activities, including research using person-identifying information. The completed PIA provides evidence that privacy issues associated with the research project, and other activities, have been identified and best efforts have been made to resolve or mitigate any risk to the privacy of the individual.

NLCHI maintains several person specific databases on behalf of the provincial health system. More information on these databases is available at <u>www.nlchi.nf.ca</u>. NLCHI will require written authorization from the custodial government department before it releases person-identifying data.

Person-identifying data includes, but is not limited to:

Full name, last name, home address, telephone number, postal code, and MCP number. In some cases data such as gender, date of birth, and community name may be considered 'probabilistic' identifiable information.

The database custodians are

The Department of Health and Community Services

- Clinical Database Management System (hospital discharge summaries)
- Newfoundland Medical Care Plan (MCP) medical claims database (physician billings)
- National Diabetes Surveillance System (in partnership with Health Canada)
- Canadian Community Health Surveys Share File (in partnership with Statistics Canada)
- National Population Health Survey (in partnership with Statistics Canada)

The Department of Government Services and Lands (Vital Statistics Division)

- Live Birth Notification System
- Mortality Surveillance System

NLCHI Data Request Privacy Impact Assessment Form

When requesting person-identifying data from the Newfoundland and Labrador Centre for Health Information, the following information is to be provided to the Director, Research and Development.

Completed/	
Attached	
	1. Original study proposal

2. Research staff Include contact information of telephone number, and ema to from NLCHI. Note: It is th of new hires.	il. Indicate what o	data they will h	ave access
	Name, etc	All Data	De-identified data
Investigators /Co-investigators			
Research Assistant			
Research Coordinator			
Programmer/Biostatistician			
Administrative Support			
Other (e.g., Consultant)			
	•	•	•

3.	What is the source of the data b	eing requested?	
		Dates to/from (mm/yyyy)	Variables (Note: Description of variables is available from NLCHI)
CDM	MS (hospitals)		
MCI	P (fee-for-service physicians)		
NDS	SS (diabetes)		
Can	nadian Community Health Survey		
Nati	ional Population Health Survey		
Live	e Birth Surveillance System		

Mortality Surveillance System	
Other – please specify	

4	List the person-identifying data that is requested from other	
	sources (e.g., health number, date of birth).	

If you have signed consent from the individuals participating in the study, please attach a copy of each one.	е
study, please attach a copy of each one.	

 6. Privacy Risk Assessment Were there any alternative methods considered that might be less privacy-invasive for achieving the desired objective? If so, why were these rejected? 	
 What is the rationale for this study, i.e., why are you doing this study? 	
• Describe the level at which the results will be disclosed within and outside the research team (e.g., provincial, regional or community).	
• Describe the ways this study might identify, stigmatize, or otherwise harm patients, practitioners, and/ or institutions, in any publications or presentation of results, and your strategies to mitigate these.	

r	
	7. Ethics Approval
	This completed PIA should be included with any request for ethics approval.
	Is ethics approval required?
	Yes, if not why?
	Which research ethics board will you be submitting this to
	Human Investigations Committee, MUN
	Other in NL
	If ethics approval was received from a REB outside NL, was NLCHI
	identified as a data source. Yes No
	If yes, please attach a copy of the Application and Letter of Approval. If no,
	explain why not.

 What computer set-up is being used to store data provided by NLCHI for this study? € Networked computer € Stand alone desktop computer € Laptop computer Indicate if you have written procedures to protect the data. These do not need to be attached, but must be available upon request. € Laptop lock-up policy € Password protected computer € Backing-up computer files € Passwords changed regularly € Retention period has been clearly stated € Disposal polices for shredding and destruction of all data € Have all staff received training on privacy standards 	8. Data Safeguards (mark appropriate box) The data must be protected by administrative, technical, and physical safeguards to prevent unauthorized access. In the event of unauthorized access, the safeguards should detect how the breach occurred and by whom.
need to be attached, but must be available upon request. € Laptop lock-up policy € Password protected computer € Password-protected files and programs € Backing-up computer files € Passwords changed regularly € Retention period has been clearly stated € Disposal polices for shredding and destruction of all data	 € Networked computer € Stand alone desktop computer
	 need to be attached, but must be available upon request. € Laptop lock-up policy € Password protected computer € Password-protected files and programs € Backing-up computer files € Passwords changed regularly € Retention period has been clearly stated € Disposal polices for shredding and destruction of all data

9. If you plan to transmit data over public lines, describe the encryption methods and protections.

10. Attach copies of confidentiality agreements signed by all members of the research team.
11 All nersen identifying date from NLCHLie recorded on a CD DOM

11. All person-identifying data from NLCHI is recorded on a CD-ROM.
The CD is picked up in person by the investigator and a receipt signed.
Please give details if you wish to receive the data in some other
manner.

12. Signature Investigator

13. Date