

**NUNAVUT  
INFORMATION AND PRIVACY COMMISSIONER**

Review Recommendation 13-069

December 2, 2013

Review File: 13-156-5

**BACKGROUND**

The Applicant sought access to:

All records pertaining to the Discharge Abstract Database and the National Ambulatory Care Reporting System for acute care hospitals in Nunavut, submitted to the health ministry and/or the health minister and/or Nunavut hospitals by the Canadian Institute for Health Information for the most recent reporting year.

The Applicant indicated he was not interested in getting personal information about patients that was contained in the records and suggested that personal identifiers contained in the records should be removed.

The Department of Health responded by indicating that the requested information pertaining to the Discharge Abstract Database (DAD) for Nunavut was publicly available through the Canadian Institute of Health Information's (CIHI) website, and provided the link to that website. They further responded that Nunavut did not currently submit data to CIHI's National Ambulatory Care Reporting System.

It appears that the Applicant followed up with a telephone call to the Department after receiving the initial response outlined above and clarified his request and pointed out that the specific information being requested was not publicly available. In a second response to the Applicant, the Department confirmed that what the Applicant was seeking was "individual level data". As a result of the clarification provided, the public body reviewed its response and refused access to any of the data on the basis that simply removing direct identifiers such as name, address, health care number and date of birth was not always going to be sufficient to ensure that patients could not be re-identified in light of the very small population base of Nunavut. They indicated that they had consulted with both CIHI and Nunavut's Chief Epidemiologist and concluded that it was not possible to render a de-identified data set in a way that they could ensure that

re-identification or data matching could not occur. They refused, based on Sections 23(1) and 23(2)(a), to disclose any of the information requested.

The Applicant sought a review of that decision. In his correspondence seeking the review, he pointed out that he had specifically asked the public body to remove personal identifiers. It was his belief that the removal of personal identifiers would make it impossible to identify any third party without making an extraordinary effort.

### **THE DEPARTMENT'S EXPLANATION**

The department was asked to provide further explanation as to their position, as well as copies of responsive records.

In providing their response, the public body did NOT provide this office with copies of the responsive records. They did, however, provide an explanation and a chart showing the various data fields in the database.

Specifically, they pointed out that the Discharge Abstract Database (DAD) is a large administrative data set. For the Fiscal Year 2011/2012 alone, there were 6,554 hospitalizations included in the data set and each record contained up to 900 unique pieces of information. Opening the database requires specialized software as well as knowledge of the programs which was not available to me. Furthermore, remote access to the database was not possible. In short, it would have been almost impossible to provide my office with the information in the database in any way that would also ensure that the information was secure and protected. The department did, however, provide me with a chart showing each of the unique pieces of information collected/recorded for each discharge which is entered into the system. This chart alone was 37 pages of very small print. The chart was sufficient for me to assess the arguments raised by the public body in their refusal to disclose the requested information.

On the issue of their decision to deny access to the database, even with personal identifier's removed, the public body provided the following detailed explanation:

a) Release of the records could potentially identify third parties

The public body pointed out that the DAD contains many personal identifiers, including but not limited to health care numbers, individual names and contact information, community of birth, community of residence, as well as other personal information. The DAD also contains information about the individual's health and health care history.

They argued that even removing direct identifiers would not guarantee that the remaining information could not be used to identify an individual because of the large number of unique data points (900 pieces of information with up to 25 diagnostic codes) and Nunavut's relatively small population base. They pointed out that a diagnostic code for a rare condition or disease could be used, fairly easily, to identify a patient. Even if the rare disease information were removed, the remaining 875 pieces of information could potentially be used to identify patients because of the amount of unique information in each record.

The department pointed out that on a national level, Statistics Canada will not release aggregate figures if the figure being released is less than five. For example, on the Statistics Canada website, cancer statistics for Nunavut are, for the most part, not available because for many cancers, there are less than five Nunavummiut diagnosed each year. The reason that these statistics are not disclosed is that Statistics Canada considers such low numbers to create a potential for breach of confidentiality because of the small population and the low number of diagnoses.

Furthermore, when the Department consulted with CIHI about the potential de-identification of the data set, the response was:

From a privacy perspective, however, it is important to understand that simply removing direct identifiers such as name, address, health care number and date of birth may not always be sufficient to ensure that the patients cannot be re-identified. The creation of a de-identified data file that would be released for public use (that is, where there are no controls over who uses it or how it is used), particularly in a jurisdiction such as Nunavut where the numbers are so small, could be very difficult, if not impossible.

- b) The request was for “line level” data

The Department further argued that line level data does not typically occur through an access to information request. The only thing that such data can be used for is statistical research, because the data must be analyzed. Data cannot be analyzed without a research question or goal in mind. They argued that whether or not the data is de-identified, if the information is line-level data and the information is being analyzed, statistical research is being conducted and statistical research generally requires the approval of a research ethics body and licensing by the Nunavut Research Institute. They say that the Department of Health will only release personal information for research purposes in accordance with section 49 of the *Access to Information and Protection of Privacy Act* and after the researchers have signed an agreement with the conditions set out in Section 49 of the Act as well as Section 8 of the ATIPP Regulations.

## **THE APPLICANT’S RESPONSE**

The Applicant was invited to respond to the Department’s comments but chose not to do so.

## **DISCUSSION**

It is important to begin any review of the *Access to Information and Protection of Privacy Act* with a review the most relevant provisions of the Act in relation to the issues raised. The starting point is always Section 1 which sets out the purposes of the Act:

1. The purposes of this Act are to make public bodies more accountable to the public and to protect personal privacy by
  - (a) giving the public a right of access to records held by public bodies;
  - (b) giving individuals a right of access to, and a right to request correction of, personal information about themselves held by public bodies;
  - (c) specifying limited exceptions to the rights of access;
  - (d) preventing the unauthorized collection, use or disclosure of personal information by public bodies;

In all cases, disclosure will be the rule and exceptions must be narrowly construed and interpreted.

Section 23 of the Act prohibits the disclosure of personal information to an applicant where the disclosure would constitute an unreasonable invasion of a third party's personal privacy. Section 23(2) provides for situations in which the disclosure of personal information is presumed to be an unreasonable invasion of the third party's privacy. The subsection being relied on by the public body in this case is 23(2)(a) which raises the presumption of an unreasonable invasion of privacy where the personal information relates to a medical, psychiatric or psychological history, diagnosis, condition, treatment or evaluation.

Section 2 of the Act provides a definition for the term "personal information".

"personal information" means information about an **identifiable individual**, including.... (emphasis added)

Section 33 of the Act provides that the onus is on the head of the public body to establish that an applicant has no right of access to a record. If the information is third party information, the onus is on the applicant to establish that the disclosure of the information would not be subject to the Act.

Section 49 deals with the disclosure of personal information for research purposes. It provides:

49. A public body may only disclose personal information for a research purpose, including statistical research, where
  - (a) the research purpose cannot reasonably be accomplished unless that information is provided in individually identifiable form;
  - (b) any record linkage resulting from the disclosure is not harmful to the individuals the information is about and the benefits to be derived from the record linkage are clearly in the public interest;
  - (c) the head of the public body has approved conditions relating to the following:
    - (i) security and confidentiality,

- (ii) the removal or destruction of individual identifiers at the earliest reasonable time,
- (iii) the prohibition of any subsequent use or disclosure of that information in individually identifiable form without the express authorization of that public body; and
- (d) the person to whom the information is disclosed has signed an agreement to comply with the approved conditions, this Act and the regulations and any of the public body's policies and procedures relating to the confidentiality of personal information.

It is to be noted that under section 33 of the Act, the public body has the initial burden of proving that the Applicant has no right of access to the information that it has withheld. In the context of section 23, this means that the public body must establish that the withheld information is the personal information of third parties and that disclosure would be an unreasonable invasion of the personal privacy of those individuals.

While the Department did not provide me with all of the responsive records to this request, they did provide me with the detailed chart showing the information gathered for each discharge from Nunavut hospital care. I am satisfied, based on the details shown in the chart, that the information being collected and collated in this database is significant, detailed and, if disclosed, invasive. I do not have to see an actual record to be able to see the nature of the records being sought and the level of detail involved. Furthermore, it is clear that the information is personal information as defined in the *Access to Information and Protection of Privacy Act*.

I also accept, without reservation, the public body's concerns about the possibility of re-identification of individuals should the line-level data be disclosed in a situation in which there are no controls on further disclosure. The numbers in Nunavut are simply too small to safely disclose health information in the kind of detail being sought in this situation to be able to ensure that re-identification is not possible. This is true whether we are talking only about relatively rare diseases/conditions or more common ailments. In a small community, there may only be one 12 year old in any one year who breaks his/her leg or only one or two pregnancies in a particular community. Some of these communities are extremely small. I am satisfied, based on the information provided to me by the public body, that there is no way to disclose the line - data information requested and still be in a position to ensure the confidentiality that

individuals using the health system expect. If this were a research project and the Applicant were seeking access to the database pursuant to section 49, there would at least be an degree of control over further dissemination of the information. In this case, however, there can be no such controls imposed.

## **CONCLUSION**

I can see no way that the public body could disclose the information requested without putting sensitive personal health information at risk, even if the public body could remove the obvious personal identifiers from the data base. If aggregate data would satisfy the Applicant's needs, it might be a different story. The detail being requested, however, is such that I am satisfied that the public body was correct in its decision not to disclose any of the data requested.

**Elaine Keenan Bengts**  
**Nunavut Information and Privacy Commissioner**