

**NUNAVUT
INFORMATION AND PRIVACY COMMISSIONER**

Review Recommendation 08-041
January 14, 2008
Review File: 07-200-5

A. BACKGROUND

In a written Request for Information dated May 5th, 2007, the Applicant requested "individual level data from the Nunavut Cancer Registry". Although the Applicant did not identify himself as such, it appears from the contents of his Request for Information that he is a professor in the Department of Economics at a small Canadian University, and that he was seeking information for the purposes of a research project.

In his Request for Information, he described his project in the following words:

The research project described herein has as its main objective the projection of cancer rates and the estimation of the economic costs and benefits of cancer care for northern residents, with a particular focus on Inuit residents of the NWT and NVT (*sic*). Comparisons of the main results obtained for both Inuit and non-Inuit residents are expected to be particularly instructive in terms of informing decisions about the extent to which policy interventions should be specifically targeted at Inuit populations.

In order to complete the research "in a statistically valid way" he indicated that he needed individual (person-level) data for each person in the cancer registry.

He indicated that he was not seeking "actual individual identifiers" such as name, social insurance number or health number.

Specifically, the Applicant was asking for a computerized file of data that contained records on each person diagnosed with cancer and contained in the cancer registry for

Nunavut for the whole period for which cancer incidence data were readily available. For each person he was seeking "year of diagnosis, age at diagnosis, gender, ethnicity, residence, type of cancer first diagnosed and follow up treatment.

The public body denied access to the requested information based not on the provisions of the *Access to Information and Protection of Privacy (ATIPP) Act*, but on the "limitations" set out in the *Disease Registries Act* which they felt took precedence over the provisions of the *Access to Information and Protection of Privacy Act*. The concern expressed by the public body was that the information being requested related to very small numbers of people from very small communities which would make identifying the individual patient from the information a relatively simple exercise. The public body went on to advise the Applicant that it was collaborating on a circumpolar project to pool aggregated data from circumpolar regions to have sufficient numbers to examine cancer incidence in indigenous populations of the north and suggested that the Applicant might find that information more valuable in doing projections.

B. ISSUE

The issue here really is two-fold. Firstly is the public body correct when it states that the provisions of the *Disease Registry Act* take precedence over the *Access to Information and Protection of Privacy Act*. Secondly, was the public body justified in refusing to disclose the information requested.

C. DISCUSSION

Section 4 of the *Access to Information and Protection of Privacy Act* provides as follows:

- 4.(1) The head of a public body shall refuse to disclose information to an applicant where the disclosure is prohibited or restricted by another Act or a regulation under another Act.

- (2) If a provision of this Act is inconsistent with or in conflict with a provision of another Act, the provision of this Act prevails unless the other Act expressly provides that it, or a provision of it, prevails notwithstanding this Act.
- (3) On December 31, 2007, subsection (1) is repealed and subsection (2) comes into force.

At the time that the public body responded to the Applicant, therefore, section 4(1) was in force and section 4(2) was not. As of January 1, 2008, the situation is the opposite. In the end, however, I believe that the outcome would likely be the same whether you apply the *Disease Registries Act* or the *Access to Information and Protection of Privacy Act*.

The *Disease Registries Act* does not, in my opinion, "prohibit" the disclosure of information, but it does "restrict" it. The relevant provisions of that act provide as follows:

12. Subject to sections 14 to 18, the Registrar shall ensure that information provided to the Registrar under this Act is kept confidential and is not disclosed to any person, including employees or agents of the Government of [Nunavut].
13. No person shall review or examine a register or information provided to the Registrar under this Act unless the person is authorized to have access to the register or information by sections 14 to 18.
- 14.(1) The Minister, Registrar, Deputy Minister of the department responsible for the administration of this Act, and one or more persons designated by the Minister may review a register.

- (2) The persons referred to in subsection (1) may use the information contained in a register
 - (a) to prepare accurate estimates on the number of people in the Territories who have a reportable disease;
 - (b) to identify patterns of a reportable disease;
 - (c) to assist in determining ways to reduce the incidence of a reportable disease in the Territories; and
 - (d) to assist in the development of programs and policies designed to improve the health of the residents of the Territories.

15. The Registrar may disclose information in a register to a health care professional where, in the opinion of the Registrar, the disclosure is necessary for the treatment of the person who is the subject of the information.

- 16.(1) The Minister and the Commissioner may, on behalf of the Government of [Nunavut], enter into agreements with the Government of Canada relating to the disclosure of information contained in a register.
 - (2) The Minister may, on behalf of the Government of the [Nunavut], enter into agreements with the government of a province or the Yukon Territory relating to the disclosure of information contained in a register.
 - (3) The Registrar may disclose information in accordance with an agreement referred to in subsection (1) or (2).

- 17.(1) A person who is from a jurisdiction that has not entered into an agreement with the Government of the [Nunavut] under section 16

and has functions similar to those of the Registrar may apply to the Registrar to be provided with information contained in a register.

- (2) The Registrar may release information in the form of general statistics to a person who applies under subsection (1).

18.(1) A person, other than a person referred to in subsection 17(1), who wishes access to the information contained in a register for the purposes of medical, epidemiological or other research may apply to the Registrar, on a form approved by the Registrar, for that access.

- (2) In an application, an applicant shall
 - (a) state his or her qualifications to conduct the research;
 - (b) state the purpose for which the information is to be used;
and
 - (c) provide any other information that the Registrar considers necessary.
- (3) The Registrar may provide an applicant with access to a register if
 - (a) the Registrar is satisfied that the applicant is qualified to do the research and that the research may benefit the residents of the Territories; and
 - (b) the applicant pays the fee determined by the regulations.

The relevant provisions of the *Access to Information and Protection of Privacy Act* are as follows:

- 23.(1) The head of a public body shall refuse to disclose personal information to an applicant where the disclosure would be an unreasonable invasion of a third party's personal privacy.

- (2) A disclosure of personal information is presumed to be an unreasonable invasion of a third party's personal privacy where
- (a) the personal information relates to a medical, psychiatric or psychological history, diagnosis, condition, treatment or evaluation;
 - (j) the personal information indicates the third party's race, religious beliefs, colour, gender, age, ancestry or place of origin

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.

In my opinion, at least in this case, there is no inconsistency or any conflict between the two acts. While the *Disease Registries Act* provides restrictions with respect to the disclosure of information in the registry for research purposes, it does not prohibit such disclosure. Similarly, although the *ATIPP Act* provides that certain conditions must be met when disclosing personal information for research purposes, it does not prohibit such disclosure. If this request had been made after December 31, 2007, I would have said that there is no inconsistency and both acts apply and must be complied with before a public body can disclose the personal health information being requested.

However, this request was made prior to December 31st, which, by my reading of section 4(1), means that the public body must refuse to disclose the information requested under the *Access to Information and Protection of Privacy Act* because the *Disease Registries Act* restricts the disclosure of the information. Although the wording of section 4(1) suggests that disclosure of information is prohibited under the *ATIPP Act* even where the disclosure would be merely "restricted" under another Act, I would suggest that the intent was probably simply that the other act, in this case the *Disease Registries Act* apply to any disclosure.

Under the *Disease Registries Act*, there is a process for applying for personal information collected under that Act for the purposes of research. It is not my role to comment on whether or not the public body properly interpreted the provisions of the *Disease Registries Act*. What I will say is that there is a process provided for and it gives the public body a large amount of discretion as to whether or not to comply with such a request. It seems to me that is the process that should have been followed in this case. The decision then, would be entirely in the hands of the public body as to whether or not they felt that the research was sufficiently beneficial to Nunavummiut. If so, an agreement for the disclosure of the information might be negotiated and such an agreement would have to comply with section 49 of the *Access to Information and*

Protection of Privacy Act as well as the provisions of the *Disease Registries Act* with respect to the use of the information requested, at least after January 1st of this year and presumably prior to that as well. That is not what happened in this case.

In this case, the Applicant chose, instead, to request the information under the *Access to Information and Protection of Privacy Act*. Assuming for the purposes of this discussion that the *ATIPP Act* applies, it is my opinion that the public body properly refused to disclose the information requested. Prior to December 31st, 2007, section 4(1) prohibited the disclosure of information where such disclosure was "restricted" by another Act. *The Disease Registries Act* clearly restricts the disclosure of the information requested and section 4(1), therefore, served to prohibit disclosure at the time that the request was made. Furthermore, in my opinion, such a disclosure would also have been prohibited pursuant to section 23 of the Act. The details requested would, in Nunavut, be sufficient to identify the individuals affected and, consequently, disclose their personal health information. I agree with the Department when they suggest that the disclosure of the information requested, even though it would not provide identifiers such as name, Social Insurance Number or Health Care Number, would be more than sufficient to identify the individuals involved because of the very small population of Nunavut in general and even more so of Nunavut communities. I am cognizant of the need for medical research and for researchers to have access to demographic information for the purposes of that research. There are, however, processes and procedures in place to ensure that that information is available for researchers, even in identifiable form, provided that it is sufficiently important to Nunavummiut and appropriate safeguards are put into place to protect that information from further dissemination. In my opinion, however, in this case the Applicant did not follow the correct procedure.

D. RECOMMENDATIONS

In my opinion, the public body in this case was justified in refusing to disclose and, in fact, was prohibited from disclosing the information requested pursuant to section 4 of

the *Access to Information and Protection of Privacy Act*, and if not by section 4, then pursuant to section 23. As far as the application of the *ATIPP Act*, therefore, I recommend no further action be taken with respect to this Request for Information. If the Applicant still wishes to have the information in question for the purposes of research, he should make that request under the *Disease Registries Act* and, if the public body is considering the disclosure of some or all of the information requested for research purposes, an agreement will have to be entered into to comply with section 49 of the *ATIPP Act*, as well as the requirements for disclosure under the *Disease Registries Act*.

Elaine Keenan Bengts
Information and Privacy Commissioner