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Nunavut Information and Privacy Commissioner
Nunavunmi Tuhaqtauyukhaliqinirmun Kanngunaqtuliqinirmun Kamisina
Commissaire à l’information et à la protection de la vie privée du Nunavut

Commissioner’s Final Report

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Summary

[1] The Applicant requested annual tuberculosis statistics, broken down by community, age and gender. The Department of Health refused under section 23 of the ATIPPA to disclose the statistics, on the grounds that the small numbers might permit identification of individuals. The department also argued that the statistics should be withheld because TB is stigmatized. The Commissioner finds that there is no serious possibility of re-identification. Section 23 therefore does not apply. The issue of stigma is real, but Health offers insufficient evidence, and does not relate the issue of stigma to any exemption enumerated in the ATIPPA. The Commissioner recommends the requested statistics be disclosed, with some restrictions for cross-tabulations. The Commissioner also recommends that Health consider a consultation process to explore how Inuit Qaujimajatuqangit and Inuit societal values may inform the department’s decisions on the release of medical statistics, including TB statistics.

Nature of Review and Jurisdiction

[2] This is a review of disclosure under the *Access to Information and Protection of Privacy Act* (ATIPPA). The request was made under section 28(1) of the ATIPPA. I conducted my review under section 31(1).

[3] The Commissioner has jurisdiction over the Department of Health: ATIPPA, section 2, definition of "public body".

Issues

[4] The issues in this review are:

a. What is the legal test for non-disclosure of medical statistics?
b. Who has the onus of proof in a case about medical statistics?
c. Should records showing TB case counts by community be disclosed?
d. Should records showing TB case counts by age be disclosed?
e. Should records showing TB case counts by gender be disclosed?
f. Should records showing current-year TB case counts be disclosed?
g. Should records showing case counts for TB-related deaths be disclosed?
h. What role could Inuit Qaujimajatuqangit and Inuit societal values have in resolving the issues in this case?

Facts

[5] Tuberculosis (TB) is a communicable disease caused by bacteria in the *Mycobacterium tuberculosis* complex. It spreads through the air from person to person. It is usually an illness of the lungs or airways, though it can spread to other parts of the body. It can be active or latent. It can be cured with appropriate treatment. Left untreated, it can result in death.

[6] The TB incidence rate in Nunavut is much higher than in the rest of Canada. According to the Public Health Agency of Canada, in 2017 the rate of active tuberculosis in Canada was 4.9 per 100,000 population, which is among the lowest in the world. But in Nunavut, the rate was 265.8 per 100,000 population.

[7] The Chief Public Health Officer (CPHO), an employee of the Department of Health, has "comprehensive authority to investigate and manage communicable diseases": *Public Health Act*, S.Nu. 2016, c. 13, section 20(1). The CPHO also has general authority to collect statistical information: section 17. Health care professionals must report to the CPHO all cases of active or latent tuberculosis: *Reporting and Disease Control Regulations*, R-051-2019, section 2 and Schedules 1 and 3. I will say more about the *Public Health Act* in the Law section below.

[8] The Applicant requested the following information from the Department of Health:

> 1. I am requesting the number of active cases of tuberculosis reported in Nunavut, broken down by community, for the years 2016, 2017, 2018, 2019, 2020 and 2021, so far. (I understand that active cases of TB have to be reported, by law, within 24 hours of diagnosis.) I am also seeking the active TB rate per 100,000 people, Nunavut-wide, for each of those years. I am requesting the gender and age breakdowns, or age range, of cases for each of those years.
> 2. I am also requesting the number of cases of latent TB reported since such reporting became law at the start of 2020. I am looking for those cases broken down by community, gender and age as well.
> 3. Finally, I am seeking the number of TB deaths recorded in Nunavut for 2016, 2017, 2018, 2019, 2020 and 2021 so far. Again, broken down by community, gender and age (or age range if privacy concerns are an issue).

[9] On November 29, 2021, the deputy minister of the Department of Health sent a response letter to the Applicant. The department did not include any records. Instead, the department provided the following information in the body of the letter:

a. In response to the first request, the department provided the territory-level case counts and active TB rate per 100,000 population for 2016 to 2020.

b. In response to the second request, the department provided the territory-level case count for latent TB for 2020.

c. In response to the third request, the department's full response reads as follows: "There were fewer than five TB-related deaths between 2016 to 2020 among active TB patients receiving treatment in Nunavut."

[10] On November 30, 2021, the Applicant applied to this office for review of the disclosure. On the same day, I wrote to the Department of Health requesting the TB statistics and posing some questions to better understand the department's reasoning.

[11] On December 9, 2021, the department responded to my questions. I forwarded a copy to the Applicant, and invited their response.

[12] On January 5, 2022, the Applicant responded to the department's submission. The Applicant also narrowed their request. They said they would accept not receiving a breakdown by age and gender. They also said they would accept community statistics showing only case counts greater than five. I forwarded a copy to the department, and invited any final reply they wished to make.

[13] On February 4, 2022, the Department of Health replied to the Applicant's submission. The department maintained its position that no statistics would be disclosed, other than those already released in the deputy minister's letter of November 29, 2021.

Law

[14] There are two statutes with relevant provisions: the ATIPPA, and the *Public Health Act*.

The ATIPPA

[15] In an access case, the onus of proof is on the public body: ATIPPA, section 33(1). If the disclosure contains personal information, the onus switches to the applicant: section 33(2). I will have more to say about onus in the Analysis section below.

[16] There is no <u>explicit</u> test for the release of medical (or other) statistics in the ATIPPA. To the extent that statistics are mentioned, it is in favour of disclosure: sections 14(2)(d) and 20(4)(d). Statistics are also mentioned in sections 40(d) and 49, but those references are not relevant to the present case.

[17] The <u>implicit</u> test for the release of statistics is in section 23. I have written that section 23 is probably the most commonly-cited exemption in Nunavut ATIPPA cases, and it is also the most difficult to interpret: *Nunavut Arctic College (Re)*, 2021 NUIPC 17 (CanLII) at paragraph 24; *Department of Justice (Re)*, 2021 NUIPC 23 (CanLII) at paragraph 23 (CanLII). I have previously outlined the correct interpretive approach to section 23: *Department of Human Resources (Re)*, 2021 NUIPC 4 (CanLII).

[18] The section 23 test for the release of medical statistics is derived from the following building blocks:

a. Information is “personal information” if it is about an “identifiable individual”: section 2, definition of “personal information”. That includes medical information about an identifiable individual: see paragraph (f) of the definition.

b. “Personal information” is exempt from disclosure under section 23 if it would be an “unreasonable invasion of a third party’s personal privacy”.

c. Subsections 23(2), (3) and (4) provide guidance about how to interpret “unreasonable invasion of…personal privacy” in subsection 23(1). The public body must consider “all relevant circumstances”: subsection (3). The circumstances listed in subsection (2) create a rebuttable presumption that an invasion of personal privacy is unreasonable. One of those circumstances is that the personal information “relates to a medical…history, diagnosis, condition, treatment or evaluation.” The circumstances in subsection (4) create a conclusive presumption an invasion of personal privacy is not unreasonable.

[19] The section 23 test for medical statistics therefore has two steps. The first step is to ask whether the requested information is the personal information of an identifiable information. If the answer is no, section 23 does not apply, and a section 23 exemption cannot be claimed to redact the information. If (and only if) the answer is yes, the inquiry moves to the second step: whether release of the information would be an unreasonable invasion of a third party's personal privacy. It is important to keep the two steps distinct.

[20] Statistical information is about an identifiable individual where there is a "serious possibility" that an individual could be identified through the use of that information, alone or in combination with other available information: *Gordon v. Canada (Minister of Health),* 2008 FC 258 (CanLII).

[21] The "serious possibility" test from *Gordon*, which is widely cited by courts and information commissioners in Canada, was elaborated upon in *Canada (Information Commissioner) v. Canada (Public Safety and Emergency Preparedness)*, 2019 FC 1279 (CanLII). "Serious possibility" means:

> …a possibility that is greater than speculation or a "mere possibility," but does not need to reach the level of "more likely than not" (i.e., need not be "probable" on a balance of probabilities). Applying such a standard recognizes the importance of access to information by not exempting information from disclosure on the basis of mere speculative possibilities, while respecting the importance of privacy rights and the inherently prospective nature of the analysis by not requiring an unduly high degree of proof that personal information will be released.

[22] I note in passing that health-specific privacy legislation, which Nunavut does not have, typically addresses the same issue directly. In Saskatchewan, for example, section 3(2) of *The Health Information Protection Act* reads as follows:

> 3(2) This Act does not apply to:
>
> (a) statistical information or de-identified personal health information that cannot reasonably be expected, either by itself or when combined with other information available to the person who receives it, to enable the subject individuals to be identified; ….

Essentially the same result is reached in Nunavut through correct interpretation of section 23 of the ATIPPA.

[23] In summary: statistics are not, in general, exempt from disclosure under section 23, provided the statistical information is sufficiently de-identified. However, statistics <u>must</u> be withheld under section 23 if there is a "serious possibility" that they could, alone or in combination with other available information, lead to individuals being identified.

The Public Health Act

[24] The *Public Health Act* of Nunavut was enacted in 2016. Most of it came into force on January 1, 2020. Several provisions deal with privacy and personal information.

[25] Section 18 addresses the issue of aggregate or anonymous health information:

> 18. Subject to section 19, health information collected under this Act shall only be disclosed in the form of
>
> (a) aggregate health information that relates only to groups of individuals in the form of statistical information or aggregated, general or anonymous data; or
>
> (b) anonymous health information that relates to an unidentifiable individual.

[26] Section 19 goes on to list the limited circumstances in which "personal health information" may be disclosed. "Personal health information" is defined in section 3 to mean "health information related to a specific, identified individual or that could identify a specific individual". None of the listed circumstances applies to the present case.

[27] In my view, sections 18 and 19 of the *Public Health Act* produce the same legal result as section 23 of the ATIPPA. Personal information about an identifiable individual (including anonymous information if there is a serious possibility of re-identification) must not be disclosed. Otherwise, the information may be disclosed.

[28] If there is a conflict between the disclosure requirements of the ATIPPA and the *Public Health Act*, the ATIPPA prevails: *Public Health Act*, section 5(2); ATIPPA, section 4(2).

[29] Moreover, Section 16(3)(c) of the *Public Health Act* permits disclosure of health information for any purpose authorized under the ATIPPA.

Analysis

[30] Tuberculosis in Nunavut is an important, complex, and emotional public-policy issue.

[31] Combatting TB has attracted dedicated efforts from, among others, the Government of Canada, the Government of Nunavut, Nunavut Tunngavik Inc. (NTI) and Inuit Tapariit Kanatami (ITK). In 2013, ITK and its public health partners launched the *Inuit-Specific Tuberculosis Strategy*. NTI has the *Taima TB* program and website. In 2014, the Government of Canada published *Tuberculosis Prevention and Control in Canada: A Federal Framework for Action*. On World TB Day, March 24, 2018, the Government of Canada and ITK vowed to eliminate tuberculosis among Inuit communities by 2030.

[32] Tuberculosis in Nunavut is frequently the subject of news stories. To name only recent ones, see Marc Godbout, “Figé dans le temps” (Radio-Canada, October 30, 2021); and Maija Kappler, “Tuberculosis is making a comeback as Nunavut battles the infectious disease” (London Free Press, January 21, 2022). There have been many others over the years.

[33] On November 25, 2021, the Chief Public Health Officer declared a TB outbreak in Pangnirtung. The GN issued a news release about the outbreak, which led to more news stories. On the same day, Nunavut’s new premier mentioned “the tuberculosis rates” as an issue of concern in connection with housing: Mélanie Ritchot, “Nunavut premier talks 1st week on the job” (Nunatsiaq News, November 25, 2021).

[34] Tuberculosis in Nunavut is also frequently the subject of journal articles and opinion pieces: for example, Rachel Kiddell-Monroe and Madlen Nash, “Nunavut should tackle TB the way they have COVID-19 – by sharing better data” (CBC.ca, April 26, 2021); Pamela Orr, “Tuberculosis in Nunavut: looking back, moving forward” (CMAJ 2013; DOI:10.1503/ cmaj.121536); N Macdonald et al., “Tuberculosis in Nunavut: a century of failure” (CMAJ 2011; 183: 741-743).

[35] Tuberculosis among Inuit evokes a painful history. Much has been written about it: see especially Pat Grygier, *A Long Way from Home* (1997), the first comprehensive study of federal TB policy and its effect on Inuit. Starting in the 1940s, the treatment protocol required people with active TB to go to specialized hospitals called TB sanatoriums, almost all of which were in southern Canada. Families were separated, sometimes for long periods. When a patient died in a sanatorium, the families were not always notified. Their burial places were not always recorded. There is a legacy of separation and loss.

[36] TB and its impact on Inuit have even been the subject of an award-winning, feature-length movie, *Ce qu’il faut pour vivre* (2008, directed by Benoît Pilon; released in English as *The Necessities of Life*).

[37] On March 8, 2019, the prime minister of Canada issued a formal apology for the federal policy on tuberculosis. Part of the apology was the launching of the Nanilavut Initiative to help find the gravesites of Inuit who did not return from medical treatment in the South. Nanilavut is an Inuktitut word meaning “let us find them”. That initiative is ongoing.

[38] The position of the Department of Health is that TB statistics will not be disclosed, other than case counts at the territorial or regional level.

Health's submissions in this case

[39] The initial response from Health's deputy minister to the Applicant was brief. Essentially, the letter stated Health's decision, but did not offer much explanation for the decision.

[40] As part of this review, Health made a written submission to me on December 9, 2021, and a reply submission on February 4, 2022. These submissions, and especially the latter, are more direct in their statement of Health's position. They have been helpful in rounding out Health's arguments.

[41] The department agrees that its disclosure obligation must be decided according to section 23 of the ATIPPA. Their most direct argument is that disclosing TB case counts makes it possible to re-identify people with TB. That is why they have adopted the practice that small numbers (anything less than or equal to five) will not be disclosed.

[42] Beyond that, however, the department's arguments do not hew closely to the words of section 23. They may be summarized as follows:

a. TB is "highly stigmatized". Releasing community-level case counts creates a risk of further stigma.

b. Trust between patients and health-care providers is an essential component in the treatment of TB. Releasing CGA case counts creates a risk of broken trust.

c. People with TB who hear about community-level case counts may believe, even if mistakenly, that the department has released their personal health information.

d. Case counts that include patients currently receiving treatment cannot be disclosed because it could negatively impact treatment outcomes.

Health's submissions in Review Report 19-148

[43] A similar request for information was considered in *Review Report 19-148 (Re)*, 2019 NUIPC 1 (CanLII). It was decided three years ago by my predecessor.

[44] The applicant's request was for community-level TB statistics for the years 2011 to 2017. The applicant did not request a breakdown by age or gender. The Department of Health provided territorial and regional (Kivalliq, Kitikmeot, Qikiqtaaluk) statistics, but not community statistics. The applicant requested review.

[45] The essence of Health's argument against disclosure is in the following passage from page 4 of the Review Report:

> [The Department of Health notes] that maintaining a patient's confidentiality is vital to maintaining the trust of the patient. If the confidentiality of even one patient is breached, this sends a message throughout Nunavut and that individuals will be less likely to seek treatment for TB if there is a chance that the department might disclose that information (or information that might identify them) to a member of the public or the media. They argue that maintaining the trust of the public is vital in the fight against TB, especially as TB is a highly stigmatized disease.

[46] The department acknowledged that it was not being asked to release names, but "they also have to be careful not to reveal enough other information to allow identification". The department therefore had a policy of not releasing cell counts of five or fewer. They noted that this policy was used by Statistics Canada and the Canadian Institute of Health Information, as well as other Canadian jurisdictions and several other organizations.

[47] The Commissioner found that there cannot be a "blanket rule" of withholding statistics when the cell count is five or fewer, citing Order No. FI-15-010 of the Information and Privacy Commissioner for Prince Edward Island. There is no "magic number" that marks the cut off in any case (page 12). The Commissioner continued:

> Each situation must be assessed on its own merits, taking into account not only the number in the statistical outline, but also a whole range of factors that could result in the identification of individuals.

[48] Unfortunately, the Commissioner moved directly from that statement to a conclusion that “most of the numbers have been properly withheld” (page 13). She does not state which of “the whole range of factors” led her to that conclusion. In the end, the Commissioner recommended that the department release the TB case counts for communities in which the number was greater than five.

[49] The minister, in a decision dated March 5, 2019, and issued under section 36(a) of the ATIPPA, declined to accept the Commissioner’s recommendation:

> The Department of Health remains concerned about the risk of stigma caused by releasing the numbers of active cases for specific communities as suggested. As a result, the Department of Health will not be releasing the information.

[50] A follow-up process promised by the minister resulted in a letter dated March 2, 2020, but the department maintained its position. Nevertheless, the minister kept the door open to future change: “As a long-term solution, rigorous disclosure control methods will be revisited periodically and follow necessary legislative, policy and ethical frameworks.”

[51] Previous Review Reports from this office are useful guidance, but they are not binding precedents. The former Commissioner did not elaborate on the factors that led to her conclusion. Moreover, the former minister acknowledged the need to periodically revisit the methodology. This review offers the opportunity to take another look.

Applicant’s submissions

[52] The Applicant’s initial submissions focused on the lack of explanation in the deputy minister’s letter. The deputy minister did not cite any specific exemption in the ATIPPA. The refusal to disclose current case counts did not make sense, argued the Applicant. The Applicant also noted that detailed statistics were being released for COVID-19, and argued that TB statistics should not be treated differently from COVID-19 statistics.

[53] In their written submission of January 5, the Applicant narrowed the scope of their request to community-level information, and only where there is a case count greater than five. The Applicant also elaborated on their initial arguments:

a. The release of community-level statistics is supported by Review Report 19-148.

b. If the GN is concerned about misleading information, then the best solution is to release accurate information.

c. The GN itself announces TB outbreaks, as it did in Pangnirtung in the fall of 2021, so stigma cannot be as much of a concern as the GN says.

d. The differences between COVID-19 and TB do not justify treating statistics differently.

e. Health's argument based on current treatment does not make much sense. There is no link between disclosing current TB statistics and treatment; "an active case of TB is an active case of TB".

[54] In my view, the Applicant's narrowing of the scope of their request does not bind me to consider only the narrowed request, nor does it bind the Applicant to accept less information than the law allows. I say this for two reasons.

[55] First, this is not the first ATIPP review of the disclosure of TB statistics, and it is unlikely to be the last. TB statistics will be a matter of public interest for as long as Nunavut's TB rates are so much higher than the rest of Canada. It is better to consider the issue in full now, as guidance both for this Applicant and for future applicants.

[56] Second, the Applicant's original request was reasonable in scope and not, on its face, overly broad. Nevertheless, Health firmly resisted disclosure. I do not know what time constraints the Applicant may be working under, but the Applicant was put in the position of narrowing their request for the sake of getting <u>something</u>. Applicants should not be put in a position of being forced into compromise, thereby accepting less than the law allows.

[57] If, at the end of this review process, the Applicant chooses to accept less than the law allows, that is their choice. But in fairness to the Applicant, they should not be asked to make that choice until they know what they are giving up.

Some terminology

[58] The concepts of "de-identification" and "re-identification" are common in this area of law, and I use them throughout this decision. I define them as follows:

a. De-identification is the processing of a dataset containing personal information to create a new dataset where the original individuals can no longer be identified, in reasonably foreseeable circumstances, from the de-identified dataset alone or in combination with other available datasets.

b. Re-identification is the processing of a de-identified dataset to create a new dataset where at least some of the original individuals can be identified, in reasonably foreseeable circumstances, from the de-identified dataset alone or in combination with other available datasets.

[59] Information that has been <u>de-identified</u> is not about an identifiable individual. De-identified information is not "personal information" for purposes of section 23 of the ATIPPA, and section 23 does not apply.

Onus of proof

[60] As I mentioned in the Law section above, the onus of proof in an access case is normally on the public body. The exception is when the information sought is personal information about a third party; in that case, the onus is on the requester to show why the personal information should be released: ATIPPA, section 33.

[61] One way to think about onus is to ask, “If there is no evidence on a key issue, who prevails?”

[62] Onus is not an obscure legal point. The issue of onus comes up often in ATIPP cases in Nunavut, because Nunavut public bodies routinely offer little or no evidence to support the exemptions they are claiming. The former Commissioner commented on this deficiency as early as 2006: *Review Report 06-24 (Re)*, 2006 NUIPC 3 (CanLII)). She repeated it often, as in *Review Report 13-65 (Re)*, 2013 NUIPC 4. In the year that I have held the position, I have also frequently commented on the lack of explanation for non-disclosure. Several my Review Reports have turned on the question of onus of proof.

[63] In a de-identification/re-identification case under section 23, the onus of proof is on the public body to show that there is a serious possibility of re-identification. If (and only if) that is established, the onus of proof shifts to the applicant, who then must establish that the invasion of privacy is reasonable in the circumstances.

Section 23: Identifiable individuals

[64] As discussed in the Law section above, Step 1 in the section 23 analysis is to ask whether the requested information is about an identifiable individual, and therefore “personal information”.

[65] The Applicant has not requested any names of TB patients, only TB statistics. On the simplest level, the requested information is not about identifiable individuals. But that is <u>too</u> simplistic; the protection of privacy requires we go further.

[66] Sometimes statistics are presented in a way that permits a reasonably accurate inference about the identity of an individual. Sometimes the statistics can be combined with other available information to produce the same result. If there is a “serious possibility” (the *Gordon* test) that could happen, then the information is personal information about an identifiable individual, and section 23 applies.

[67] Health’s first argument is that disclosing TB statistics could <u>indirectly</u> lead to identification of individuals. It follows, they argue, that section 23 requires that the data be withheld. In the jargon of de-identification, this is known as data suppression. I turn now to an analysis of when, for ATIPPA purposes, data may be suppressed.

Data suppression: Background

[68] The Nunavut Department of Health has a data-suppression policy. The policy is that it will not release any statistic that is less than or equal to five. (In this decision, to save repetition, I will refer to this data-suppression policy as “the Rule of Five”.) Sometimes Health is explicit about its Rule of Five, sometimes not. It has been explicit about its policy in the past, such as its submission to my predecessor in Review Report 19-148.

[69] In this case, the department at first was not explicit about its Rule of Five, except for one indirect reference. In response to the Applicant’s request for the number of TB-related deaths by year, the deputy minister’s letter said, “There were fewer than five TB-related deaths between 2016 to 2020 among active TB patients receiving treatment in Nunavut.” There was no further explanation.

[70] Fortunately, the Rule of Five is stated explicitly in Health’s reply submission of February 4. There can be no doubt, then, that Health is applying the Rule of Five.

[71] A data-suppression policy may, if properly explained and applied, constitute an acceptable component of a de-identification policy. Depending on the circumstances, the threshold number may be five, or eleven, or sixteen, or some other number. In the past, the Rule of Five has been common. Currently the Public Health Agency of Canada uses a Rule of Eleven for reporting of clinical trials: “Public Release of Clinical Information: guidance document”, available on the PHAC website, Section 6.2, Step 2.

[72] Whatever the risk-suppression policy is, the number represents a threshold for acceptable risk. The Rule of Five implies a risk threshold of 0.20. The Rule of Eleven implies a risk threshold of 0.09. A risk threshold of zero, on the other hand, is not in keeping with the “serious possibility” test discussed in the Law section above. In any event, it is in practical terms impossible to eliminate all risk of re-identification.

[73] For the reasons that follow, I have concluded that Health has not offered an adequate explanation for its data-suppression policy; and moreover, that its data-suppression policy does not conform to best-practice de-identification methodology. It is, in a nutshell, overbroad and inflexible.

Data suppression: Lack of adequate explanation

[74] De-identification can, in the right circumstances, include data suppression. But in the context of the ATIPPA, which leans towards disclosure, data suppression should be a last resort. Data should be suppressed only if there is no reasonable alternative. Other techniques, such as generalization of quasi-identifiers, are to be preferred.

[75] In a de-identification case, the onus of proof is on Health to show the requested information is about an identifiable individual. An explanation is required. The explanation must include factors like the risk threshold, the classification of quasi-identifiers, the calculated risk, and the reference population. If an adequate explanation is offered, I am not likely to second-guess the choices Health makes.

[76] In this case, Health offered none of the background to its Rule of Five. On that ground alone, I find that Health has not discharged the onus of proof. But I would go further.

Data suppression: Incorrect application

[77] Even on its own terms, Health has followed an incorrect data-suppression methodology.

[78] The appropriate methodology for de-identification is set out in a publication of the Ontario Information and Privacy Commissioner: "De-identification Guidelines for Structured Data" (June 2016); see also "Use and Disclosure of Personal Health Information for Broader Public Health Purposes" (July 2021). Although based on different legislation, these documents represent the state of the art of de-identification in Canada. The principles in this publication are as applicable in Nunavut as they are in Ontario, and I adopt this publication for purposes of my analysis.

[79] Dr Khaled El Emam is one of the world's leading experts on de-identification. He is the Canada Research Chair (Tier 1) in Medical Artificial Intelligence in the School of Epidemiology and Public Health at the University of Ottawa. He is also a Senior Scientist at the Children's Hospital of Eastern Ontario Research Institute. (CHEO is, by coincidence, where many children from Eastern Nunavut receive medical care.) The Ontario IPC acknowledges Dr El Emam's contribution to the publication mentioned in the previous paragraph.

[80] Among his many publications, Dr El Emam is the lead author on a paper that shows how de-identification methodology can be applied to a request for disclosure of medical information: K El Emam et al., "Evaluating the Risk of Re-identification of Patients from Hospital Prescription Records", Can J Hosp Pharm 2009;62(4):307-319. I found this publication to be especially useful to my understanding of de-identification and re-identification of a dataset involving real medical patients.

[81] When a dataset is being de-identified, a crucial question is what the identifiers are, and whether they are direct identifiers (such as name or health card number) or indirect identifiers (such as age, gender, or community). These identifiers can be sorted and quantified.

[82] For purposes of data suppression, the cell counts in issue are the cross-tabulations of the identifiers. These cross-tabs are then compared to a reference population, to determine the risk of re-identification.

[83] In the present case, the error made by Health is to apply its data-suppression policy to the final statistic (the number of TB cases), which is not itself an identifier. There is no reference population. I can illustrate the error with two examples.

[84] First, suppose there are four TB cases in a hamlet of 200 people and four in the Greater Toronto Area, where there six million people. If the Rule of Five is applied without a reference population, then the data will be suppressed in both places. But there is obviously no serious possibility of re-identification in the GTA. A policy that would suppress that statistic cannot be right.

[85] Second, suppose that the entire population of a hamlet has TB. If we know that an individual lives in that hamlet, we know they have TB. The risk of re-identification is 100%. Yet the Rule of Five would not suppress that statistic, because the number is greater than five. A de-identification policy that would release that statistic cannot be right.

[86] Correct application of a data-suppression policy requires a correct understanding of what is a “cell count” for purposes of the policy. It also requires a reference population. If TB statistics are released by community only, with no other identifiers, then the reference population is the population of each community. The risk of re-identification can then be calculated, and if the resulting value exceeds the risk threshold, the statistic can be suppressed.

[87] In the Toronto example, it is obvious that the TB statistics for Toronto would be released because, when compared with the population of Toronto, the risk of re-identification is far below any reasonable risk threshold. That is the correct result.

[88] In the 100% incidence example, the risk of re-identification is 100% and exceeds any risk threshold that might be chosen. That statistic would therefore be suppressed. That is the correct result.

[89] The situation becomes less clear if TB statistics are released with cross-tabulations. Cross-tabulations are statistics with more than one identifier. In that case, the reference population for each cell is the number of people who share all the identifiers. For example, if TB statistics for a hamlet of 200 people are further broken down by 10-year age groups and by gender, it is likely that some of the cells (for example, women aged 80-90) might fall above the risk threshold. In that case, the statistics could be further generalized (e.g. by larger age groupings) until all cells are below the threshold. The age statistic would need to be suppressed only if there was no other way to bring the risk of re-identification below the risk threshold.

[90] The point is that there is a best-practice de-identification methodology. A data-suppression policy assumes a proper methodology that is correctly applied. As demonstrated in the El Emam et al. paper cited above, it should be a relatively rare case when an entire case count needs to be suppressed. When de-identification methodology is followed correctly, data suppression is truly a last resort.

[91] Health does not apply the Rule of Five as a last resort. It applies the Rule of Five as an inflexible, front-end screen. That is a methodological error. It is also a legal error.

Data suppression: COVID-19

[92] One of the Applicant's arguments is that detailed statistics were released by the CPHO for COVID-19, and so the same thing can and should be done for TB.

[93] The CPHO has consciously taken a different approach to different public-health issues: see, for example, "Here's why Nunavut will name a small community with a COVID-19 case" (CBC.ca, April 8, 2020). In that article, the CPHO is quoted as contrasting the approach to COVID-19 statistics to the approach for tuberculosis and syphilis.

[94] In the context of COVID-19, it is worth noting that the CPHO's initial position was that vaccination statistics would not be released at the community level: Trevor Wright, "GN not divulging community-level vaccination numbers" (Nunavut News, March 9, 2021). That position was later reversed: Dustin Patar, "Nunavut releases COVID-19 vaccination stats for communities" (Nunatsiaq News, May 14, 2021).

[95] Now, almost two years into the COVID-19 pandemic, the GN daily releases very detailed statistics, including case counts and vaccination counts by community. Those statistics invariably include cells with five or fewer cases.

[96] I agree with Health's argument that adopting a certain statistical reporting practice for COVID-19 does not mean that the same reporting practice <u>must</u> be adopted for other infectious diseases. Nevertheless, there are lessons to be learned from Nunavut's COVID-19 experience.

[97] For example, I am not aware of any reports that the detailed COVID-19 statistics have resulted in the re-identification of any individual, nor has my office received any privacy breach complaints based on those statistics. This is evidence that releasing community-level statistics does not, in fact, create a serious possibility of re-identification.

[98] The COVID-19 experience also demonstrates that statistical reporting is a matter of policy, not law. Neither the ATIPPA nor the *Public Health Act* requires the withholding of tuberculosis data.

[99] Later in this decision, on the subject of stigma, I will have more to say about lessons that can be learned from Nunavut's COVID-19 experience.

Data suppression: Concluding comments

[100] The Department of Health applies the Rule of Five to medical statistics. The Rule of Five is not a rule of law. It is not in the ATIPPA, the *Statistics Act*, the *Public Health Act*, or any other Nunavut legislation. The Rule of Five (or any similar data-suppression policy) may be a legitimate component of a de-identification process, provided a proper methodology is adopted and correctly applied.

[101] The science of de-identification has developed rapidly over the past decade or so, keeping pace with the growth in the number and size of publicly-available databases. It has moved beyond simple rules. The Rule of Five, as currently applied by Nunavut's Department of Health, is a blunt, outdated approach.

[102] I note also that any data-suppression policy will have a disproportionate impact in jurisdictions with a small population. The 2016 census population of Nunavut was just under 36,000. Today it is probably around 40,000. With a population that small, the inflexible approach adopted by the Nunavut Department of Health will result in more statistics being suppressed here than elsewhere.

[103] Nunavummiut deserve the same accountability from their government, and the same opportunity for debate on important public-policy issues, as the residents of larger jurisdictions. That is why it is especially important that any data-suppression policy adopted by Health be clearly explained and correctly applied. In this case, that did not happen. Health's data-suppression policy does not comply with the ATIPPA.

Stigma: Background

[104] Health's second argument is based on the fact that TB is a "highly stigmatized" disease.

[105] In some ways the stigma argument is Health's main argument, because the argument is that the risk of stigma justifies suppression of <u>all</u> statistics below the territorial level, even if those statistics otherwise satisfy Health's interpretation of the Rule of Five.

[106] TB stigma is real, and is a social determinant of health: G.M. Craig et al., "Tuberculosis stigma as a social determinant of health: a systematic mapping review of research in low incidence countries", International Journal of Infectious Diseases 56 (2017) 90-100.

[107] However, that cannot be the end of the discussion. Health has the onus of proof, and must bring forward evidence sufficient to satisfy the legal standard that is appropriate for any specific exemption. I will start by considering where stigma fits within the legal framework of the ATIPPA, and then I will consider the available evidence.

Stigma: Legal Framework

[108] The Department of Health does not attempt to relate the stigma argument to any specific exemption in the ATIPPA. This is problematic: any exemption to disclosure must be located <u>somewhere</u> in the Act.

[109] When a claimed exemption is unmoored from the words of the ATIPPA, or when an exemption has vague or subjective criteria, there is a danger of creating a "black hole". That is a term used by Justice Charron in the Supreme Court of Canada in *Canada (Information Commissioner) v. Canada (Minister of National Defence),* 2011 SCC 25 (CanLII) at paragraphs 51-54. A "black hole" is created if an exception or exemption or interpretation makes it too easy for a public body to re-arrange its affairs to avoid disclosure: see *Department of Health (Re)*, 2021 NUIPC 7 (CanLII) at paragraph 42; and *Department of Justice (Re)*, 2021 NUIPC 23 (CanLII) at paragraph 54.

[110] Stigma is not mentioned at all in the ATIPPA.

[111] Stigma is mentioned once in the *Public Health Act*, in section 50(2)(b). Section 50 concerns the CPHO's duty to warn of risks to public health (emphasis added):

> 50. (1) If the Chief Public Health Officer has reasonable grounds to believe that the public in general or a specific group or individual is threatened by a serious risk to public health, the Chief Public Health Officer shall, without delay, take reasonable steps to
>
> (a) warn the public, group or individual by disclosing the nature and source of the risk to public health, except where disclosure is prohibited by law; and
>
> (b) protect the public, group or individual from the risk to public health.
>
> (2) The Chief Public Health Officer is not required to disclose information under paragraph (1)(a) if he or she believes that such disclosure would result in a clear and overriding adverse effect, including circumstances where
>
> (a) disclosure unduly violates the privacy and confidentiality rights of one or more individuals;
>
> (b) <u>disclosure unduly stigmatizes one or more individuals or groups</u>; or
>
> (c) disclosure would likely cause behaviour that would result in an increased risk to public health.

[112] It is worth noting that even subsection 50(2) puts boundaries around the CPHO's actions. Non-disclosure must be based on "a clear and overriding adverse effect". Stigmatizing an individual or group is acceptable to a degree, but not "unduly". If there were ever a challenge to non-disclosure under section 50(2), the CPHO would have to produce evidence supporting their decision.

[113] In any event, section 50(2)(b) does not justify non-disclosure under the ATIPPA. Even if it did, the ATIPPA overrides the *Public Health Act* when there is a conflict between the two: *Public Health Act*, section 5(2); ATIPPA, section 4(2).

[114] Where, then, does stigma fit into an ATIPPA analysis? Health does not say, and I should not have to speculate. Nevertheless, I can think of two possible arguments.

[115] The first argument comes at Step 1 of the section 23 analysis. (The two steps of the section 23 analysis are discussed in the Law section above.) The argument would be that since TB is so highly stigmatized, the only acceptable risk of re-identification is zero. The only way to ensure zero risk is a strict policy of non-disclosure. That comes close, in my view, to Health's position.

[116] I cannot accept this argument. It does not comply with section 23. As discussed in the Law section above, the legal test for re-identification under section 23 is a "strong possibility" of re-identification. That test forecloses the possibility of a zero-risk policy. That result is in keeping with the objectives and scheme of the ATIPPA. Disclosure is favoured; exemptions are limited.

[117] The second place where stigma might fit into the ATIPPA is at Step 2 of the section 23 analysis. The argument would be that since TB is stigmatized, any invasion of privacy would be unreasonable.

[118] This argument is certainly plausible. It reinforces the (rebuttable) presumption created by section 23(2)(a) that disclosing medical information is an unreasonable invasion of personal privacy.

[119] For the sake of clarity, however, I will repeat that Health's argument for non-disclosure fails at Step 1 of the section 23 analysis. Medical statistics that are properly de-identified are not "personal information", and so section 23 does not apply. Health has a good argument at Step 2 of the section 23 analysis, but we do not get to Step 2 because the argument for non-disclosure fails at Step 1.

Stigma: Evidence

[120] No matter where stigma fits in the legal framework of the ATIPPA, Health offers little evidence of the mechanics of TB stigma or of how disclosure of TB statistics might be correlated with stigma.

[121] Health's reply submission of February 4 refers to anecdotal evidence from a Nunavut community in 2017; but even that anecdotal evidence is brief and vague. The ATIPPA requires more. The onus of proof is on Health.

[122] Medical stigma was considered in a very recent decision of the Nunavut Court of Justice: *John Doe v Government of Nunavut*, 2022 NUCJ 1 (CanLII). The plaintiff applied for permission to file a statement of claim anonymously. One of the arguments advanced by the plaintiff was that he did not wish his mental illness to be public, because his mental illness is stigmatized. Some general evidence about the stigma of mental illness was introduced by the plaintiff. The court dismissed the application. The context is very different, but the case does demonstrate that a legal result based on stigma must be supported by evidence, and even then, an argument based on stigma is not conclusive.

[123] TB stigma in Nunavut does not appear to have been the subject of much formal study. The academic journal article cited in paragraph 106 above, published in 2017, lists only a single study from Nunavut: Helle Møller, "Tuberculosis and colonialism: current tales about tuberculosis and colonialism in Nunavut", *Journal of Aboriginal Health* 2010;5:38-48. That study, which is based on seven months of fieldwork in two Nunavut communities, is decidedly against the status quo of TB treatment. Among its conclusions are "In order to decrease the incidence of TB in Nunavut, decolonizing measures are necessary" and "Euro Canadians working in the Nunavut healthcare system must also examine the assumptions, motivations and values that inform their work." That conclusion is relevant to my analysis, later in this decision, of Inuit Qaujimajatuqangit and Inuit societal values.

[124] I also note that, according to Review Report 19-148, Health did release community-level TB statistics for 1999 to 2011, in a 2013 document titled "Report on the Epidemiology of Tuberculosis in Nunavut". The release of those statistics should have provided Health with evidence of the correlation (if any) between community-level statistics and stigma. No such evidence was brought forward by Health.

[125] In my view, Nunavut's COVID-19 experience is also relevant on the question of stigma.

[126] There is little doubt that, in the initial wave of the pandemic in 2020 and early 2021, COVID-19 was stigmatized in Nunavut. The community of Arviat was the first to be hit hard. Case counts there were significantly higher than in any other Nunavut community. Stigmatizing comments were made on social media about Arviat and its residents.

[127] However, with leadership from Nunavut's politicians and the CPHO, the initial stigma directed at Arviat was addressed directly and, I would suggest, effectively countered.

[128] At the time of this decision, we are almost two years into the pandemic. Almost all Nunavut communities have been touched by COVID-19, so there is more knowledge and understanding. Some Nunavummiut are even posting their positive status on social media, to notify their contacts. Shortly before the release of this decision, the prime minister of Canada announced that he had tested positive, as did Nunavut's member of parliament. With time, leadership, and knowledge, the initial stigma surrounding COVID-19 has largely evaporated.

[129] We cannot be certain whether or to what extent the lessening of COVID-related stigma is connected to the GN's decision to release detailed COVID case counts. Perhaps the free flow of information has demystified COVID, making it seem less secret and scary. Perhaps there is no correlation. But it is, in my view, an instructive comparison. We cannot rule out the possibility that more information has led to less stigma.

Stigma: Concluding comments

[130] Stigma is real, and TB is stigmatized. But stigma cannot become a freestanding exemption to ATIPP disclosure. Any exemption must be grounded somewhere in the words of the Act, and there must be evidence of how disclosure and stigma are linked. The onus of proof is on Health. A mere assertion is not enough.

[131] If the Legislative Assembly had intended that Health's judgment about stigma should override the legal test for disclosure, it would have said so, either in the ATIPPA or in the *Public Health Act*. It did not do so. To the contrary, the explicit choice made by the legislature is that where the ATIPPA and the *Public Health Act* are inconsistent, the ATIPPA prevails.

Health's other arguments

[132] Health makes three other arguments, based on trust, misunderstandings, and current cases. I will deal with them briefly.

[133] The trust argument is that disclosure of TB statistics might interfere in the necessary trust between patient and health-care provider. Health does not attempt to link this argument to any specific exemption in the ATIPPA.

[134] In my view, the trust argument might be admissible at Step 2 of the section 23 analysis. This argument is plausible, but Health offers no evidence to support it. In any event, Health's argument for non-disclosure fails at Step 1 of the section 23 analysis.

[135] The misunderstandings argument is that the release of statistics might lead a TB patient to conclude, though mistakenly, that their personal information has been released. Again, Health does not attempt to link this argument to any specific exemption in the ATIPPA.

[136] In my view, the misunderstandings argument does not fit anywhere in the ATIPPA. Besides, it would be what lawyers call "the perfect defence": since the possibility of misunderstandings can never be eliminated, no information would ever need to be disclosed.

[137] It is not for a public body to judge what an applicant (or anyone else) might do with the information to which they are lawfully entitled: see *Executive and Intergovernmental Affairs (Re),* 2021 NUIPC 13 (CanLII) at paragraph 62. If information is otherwise releasable under the ATIPPA, but the public body worries about misunderstandings, it may release the information with any necessary explanation or context. But it must release the information.

[138] The current-cases argument is that Health does not disclose current-case statistics "as these patients can still be on treatment" and "because it could negatively impact treatment outcomes". Again, Health does not attempt to link this argument to any specific exemption in the ATIPPA.

[139] Like the Applicant, I do not understand this argument. The fact that statistics might include patients currently receiving treatment is not relevant to disclosure of statistics that otherwise satisfy the risk threshold for re-identification. Health does not offer any evidence of a linkage between statistics and negative treatment outcomes, nor does it theorize a mechanism for such a linkage. The onus of proof is on Health.

[140] My only reservation on this point is that partial-year statistics may change the risk calculations in the de-identification methodology. I raise the possibility, but it is not necessary for me to resolve it here.

Inuit Qaujimajatuqangit and Inuit societal values

[141] There is one last topic I wish to touch on. It has not been addressed either by the Applicant or by the Department of Health.

[142] In previous decisions, I have noted that Inuit Qaujimajatuqangit and Inuit societal values have a role in decision-making under the ATIPPA: *Department of Human Resources (Re)*, 2021 NUIPC 14 (CanLII); *Department of Economic Development and Transportation (Re)*, 2021 NUIPC 24 (CanLII).

[143] The new *Public Health Act*, most of which was proclaimed in force on January 1, 2020, makes explicit the role of Inuit societal values:

> 6. (1) The public health system in Nunavut shall be based on Inuit societal values.
> (2) The Minister and the Chief Public Health Officer must ensure that Inuit societal values are incorporated throughout the public health system of Nunavut.
> (3) For greater certainty, the following Inuit societal values apply under this Act:
> (a) *Inuuqatigiitsiarniq*, that is respecting others, relationships and caring for people;
> (b) *Tunnganarniq*, that is fostering good spirit by being open, welcoming and inclusive;
> (c) *Pijitsirniq*, that is serving and providing for family or community, or both;
> (d) *Aajiiqatigiinniq*, that is decision making through discussion and consensus;
> (e) *Pilimmaksarniq* or *Pijariuqsarniq*, that is the development of skills through practice, effort and action;
> (f) Piliriqatigiinniq or *Ikajuqtigiinniq*, that is working together for a common cause;
> (g) *Qanuqtuurniq*, that is being innovative and resourceful; and
> (h) *Avatittinnik Kamatsiarniq*, that is respect and care for the land, animals and the environment.

[144] The ATIPP review process is a legal process, and the common-law legal tradition has difficulty incorporating concepts like Inuit Qaujimajatuqangit and Inuit societal values because there is no direct avenue to receive the evidence: see, for example, *R. v. Itturiligaq*, 2020 NUCA 6 (CanLII), reversing 2018 NUCJ 31 (CanLII).

[145] I have the same challenge when writing a Review Report. There is no mechanism in the ATIPPA for receiving evidence about how Inuit Qaujimajatuqangit or Inuit societal values might apply to the case. It would be helpful for parties to make submissions on the point. That is easier for public bodies, most of whom have an Inuit Qaujimajatuqangit co-ordinator, than it is for the typical applicant. So far, it has not happened.

[146] In this case, I have a strong sense that Inuit Qaujimajatuqangit and Inuit societal values have something valuable to teach us, but I have no evidence in front of me. I am mindful of the Nunavut Court of Appeal's caution in *Itturiligaq* not to overreach in the absence of evidence. But if section 6 of the *Public Health Act* is to have meaning, we must all look for ways to meld its obligations with public health decision-making. That includes decisions about the disclosure of medical statistics.

[147] I therefore recommend to the Department of Health that it consider appropriate consultations to determine the role that Inuit Qaujimajatuqangit and Inuit societal values might play in the decision to disclose medical statistics.

Conclusion

[148] The legal test for non-disclosure of medical statistics, under section 23 of the ATIPPA, is whether there is a "strong possibility" of re-identification. The principal finding of this decision is that Health's policy on the disclosure of TB statistics does not comply with this test..

[149] In a medical statistics case, the onus of proof is on the public body to show that the requested records are "personal information". If that is established, the onus shifts to the applicant to show why releasing the personal information would not be an unreasonable invasion of personal privacy.

[150] In this case, the Department of Health has not established that there is a "strong possibility" of re-identification. Health has not adequately explained its data-suppression policy. Moreover, Health is not correctly applying the best-practice de-identification methodology.

[151] The stigmatization of TB is real, but Health has not established how disclosure of TB statistics is correlated to stigma. In any event, an argument based on stigma does not fit within any ATIPPA exemption.

[152] The requested TB statistics should therefore be disclosed. The only exceptions to disclosure should be those statistics that, when calculated according to a best-practice de-identification methodology, exceed a risk threshold that is equivalent to the "strong possibility" test.

[153] Based on everything I have seen during this review, it is very likely that the following TB statistics will satisfy any reasonable risk threshold:

a. Annual TB case counts, at the community level.

b. Annual TB case counts, by age, at the territorial level. The age groups may be generalized, but only to the extent necessary to satisfy the risk threshold.

c. Annual TB case counts, by gender, at the territorial level.

d. Annual case counts of TB-related deaths, at the territorial level.

[154] Cross-tabulations – that is to say, case counts by more than one factor simultaneously – must be handled more carefully. For example, a gender breakdown by community may satisfy the risk threshold. A breakdown of deaths by community almost certainly will not satisfy the risk threshold. In each case, it is a matter of calculation according to a correct methodology.

[155] Inuit Qaujimajatuqangit and Inuit societal values likely have a role in developing a disclosure policy for medical statistics. This is an avenue that the Department of Health, in compliance with section 6 of the *Public Health Act*, should explore.

[156] Nothing in this decision is intended to take away from all the good work that has been done and is being done towards the control and perhaps eradication of TB in Nunavut. That is a public-policy objective that everyone can support.

[157] Nor should anything in this decision be taken as a criticism of the Department of Health. The dedicated work of the department, and especially the Chief Public Health Officer and public health staff, has been on display throughout the COVID-19 pandemic. Whatever has been done in the past concerning the disclosure (or non-disclosure) of TB statistics has been done in good faith and with the best interests of Nunavummiut at heart.

[158] At the same time, Nunavummiut deserve to know if their government is making the right choices about TB. Is it directing the right resources to the right places at the right time? Are public funds being wisely spent? Are there other approaches that could be pursued? That is the sort of accountability envisaged in section 1 of the ATIPPA. It is almost impossible to have meaningful public discussion about these questions when almost all TB statistics are withheld by the GN.

Recommendations

[159] **I recommend** that the Department of Health disclose annual TB case counts, at the community level, for all communities.

[160] **I recommend** that the Department of Health disclose current case counts, at the community level, for all communities, provided they satisfy the risk threshold in the de-identification methodology.

[161] **I recommend** that the Department of Health disclose annual TB case counts by age and gender, at the territorial level. The age statistics may be generalized into ranges that are broad enough to satisfy the risk threshold in the de-identification methodology.

[162] **I recommend** that the Department of Health consider whether to disclose cross-tabulations of annual TB statistics by community, age, and gender. Any cross-tabulations must satisfy the risk threshold in the de-identification methodology.

[163] **I recommend** that the Department of Health disclose annual case counts for TB-related deaths, at the territorial level only.

[164] **I recommend** that the Department of Health consult with an expert on de-identification to ensure that its de-identification methodology is in keeping with current best practices, as well as being compliant with the ATIPPA.

[165] **I recommend** that the Department of Health consider a consultation process to explore how Inuit Qaujimajatuqangit and Inuit societal values may inform the department's decisions on the release of medical statistics, including TB statistics.

Graham Steele
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