

「でくべゅるからってつこれからって Minister of Health Ministaat Aanniaqtailinirmut Ministre de la Santé

March 11, 2022

Office of the Information and Privacy Commissioner of Nunavut Information and Privacy Commissioner P.O. Box 1000, Station 270 Igaluit, Nunavut, X0A 0H0

RE: Review Report 22-213-RR

IPC file: 21-172

Our file: 1029-20-DH26105

Dear Commissioner.

Thank you for your letter dated February 7, 2022, in which you provide recommendations regarding disclosure of tuberculosis (TB) statistics. Please find below responses to the recommendations.

The Department of Health always strives to ensure its practices are compliant with the ATIPPA while balancing the requests against the risk of harm and stigma. Sometimes the information requested would not prove useful nor would it serve the public interest, and given Nunavut's unique situation in terms of small, remote communities, Health takes risk of reidentification seriously. It is important to remember that Health is the custodian of personal health information; the information belongs to the individual, therefore the Department must be cautious when using and disclosing it. As mentioned in our February 4, 2022, letter, it is a priority for Health to ensure that stigma associated with communicable diseases does not impede access to health services and leads to distrust of the health care system. This is particularly important in Nunavut due to the historical trauma experienced by Inuit regarding TB treatment. The risk of reidentification and its consequences are real.

Recommendation 1

Health does not agree with the recommendation to disclose annual TB cases counts at the community level. It is not a national standard to release the details requested and other parts of Inuit Nunangat do not make community level numbers public (e.g., Nunavik's data are not for public consumption). Reidentification is of concern. Transmission of TB within one large close-linked group can occur in Nunavut, as it is often due to factors such as overcrowded housing and distrust of the health care system. Even in cases where the total number for a community would be higher than five, all cases could be within one close-linked group and given the size of communities, disclosure of

this information could lead to reidentification and stigma towards members of this group. Even if Health was to provide the number by region, it could be that only one community in a region has TB, which would also make it easy to identify.

Numbers at the territorial level are provided annually in the annual federal TB report.

Recommendation 2

Regarding the recommendation to disclose current case counts at the community level the concerns regarding reidentification are the same as for the first recommendation.

However, Health could release numbers of individuals diagnosed on a quarterly basis at the territory level, although, some of these individuals will have finished treatment by the time the numbers are publicly released. Health also commits to working with Hamlets and Nunavut Tunngavik Inc (NTI) to determine what communities need and want, and whether information could be provided to communities directly on a regular basis, rather than being released publicly. It should be noted that Health is currently working on an information sharing agreement regarding TB data with NTI and that Health is committed to putting this agreement in place. In the past, Hamlets have expressed concerns with releasing data publicly, once again due to stigma. Even in cases where it would not be possible to identify the individuals, increased attention and stigma have occurred towards specific communities where there were cases. There were reports of residents from these community not feeling welcome in other communities.

Health commits to looking at the Nunavik model.

A different approach will be used in situations where contact tracing is no longer adequate to find all individuals who have been exposed. In those specific cases, Health would be providing monthly numbers at the community level via public service announcements (PSAs), for risk mitigation.

Recommendation 3

Health can disclose annual TB case counts by age and gender at the territorial level. With regard to counts by age, this would be provided by age ranges such as '17-year-old and under' due to concerns with smaller numbers. Regarding counts by gender, Health can provide that information as well.

Recommendation 4

Health will consider whether to disclose cross-tabulations of annual TB statistics by community, age, and gender. The concerns mentioned above regarding reidentification and stigma apply here as well. Health will explore this and get back to your Office at a later time.

Recommendation 5

Health does track the number of deaths of people on TB treatment; however, the information could be flawed as the death of someone who died of a non-TB-related cause (e.g., a car accident) while on TB treatment would still be reported. Health does not track

the annual case counts for TB-related date and does not have the ability to do so. The Office of the Chief Coroner is not required to track diagnosis. Health will reach out to the Department of Justice (Justice) to see whether any data can be provided. For future requests we recommend contacting Justice directly.

Recommendation 6

Health's current practices are in line with how most other Canadian jurisdictions treat data. Health has and will continue to seek expertise, consult appropriate scientific literature, and look at what other jurisdictions are doing to ensure its work continues to reflect best practices. Health has been working closely with an expert on deidentification methodology who has the relevant experience in remote small communities. Indigenous Services Canada usually release data from reserves as an aggregate and Health could reach out to them to discuss methodology.

Recommendation 7

Health is currently working on the development of health information privacy legislation and your recommendation to 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, is tied to this work. Such a consultation process could include discussion with regions like Nunavik and Nunatsiavut, as well as with Tuttarviit and the Nunavut Association of Municipalities. Health would also seek engagement with NTI on this issue.

Thank you for your recommendations.

Matna.

Hon. John Main Minister of Health

cc: Linnea Ingebrigtson, Deputy Minister of Health

Dr Michael Patterson, Chief Public Health Officer

Keith Travers, TB Epidemiologist, Department of Health

Murugesh Narayanan, ATIPP Coordinator, Department of Health