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July 26, 2023

Ms. Janet Brewster MLA, Iqaluit-Sinaa Legislative Assembly of Nunavut P.O. Box 1200 Iqaluit, NU X0A 0H0

RE: Clarification on Question 436 – 6(2): Use of Health Information (Tuberculosis)

Dear Ms. Brewster,

I am writing to provide clarification and further information in response to your question on May 25, 2023, during the sitting of the Legislative Assembly regarding the use and release of health information, specifically in relation to tuberculosis (TB).

In terms of releasing data, the Department of Health (Health) has to balance public health needs alongside the right to privacy for Nunavummiut. In order to release information surrounding communicable diseases, the information must be of tangible public benefit and also must not cause harm or increased stigma toward individuals or communities.

The current practice of public reporting of TB data is to annually release aggregated data for the entire territory. This is done through the reporting of annual case counts to the federal government, specifically the Public Health Agency of Canada, who then publishes the data. Release of aggregated, anonymous data is regulated through the *Public Health Act* (PHA). The PHA does make provision for the Chief Public Health Officer (CPHO) or Deputy Chief Public Health Officer (DCPHO) to release information in greater detail if warranted, under specific conditions, so long as this disclosure does not: unduly violate the privacy or confidentiality of one or more individuals; stigmatize one or more individuals or groups; and/or, cause behaviour that that would result in increased risk to public health [Public Health Act 50(2) a, b,& c].

Epidemiologists, public health officials, and disease surveillance programs commonly practice "the rule of five" - any data with five or less cases increase the risk of identification of individuals. The risk of public identification of individuals is regularly weighed against the need for public communication about a communicable disease. When officials consider the risks and benefits of public disclosure of disease information, some important considerations include:

- Risk of stigmatization;
- Historical trauma; and,
- Inaccurate assessment of risk (high or low).

Health is working to find ways to make statistical and education materials more accessible, including by gathering current and historical statistics on TB by age and gender. It is expected to be released publicly before the end of this fiscal year. Further, there is a recognition about the stigma and fear surrounding TB. Health is working to develop culturally appropriate tools to address that stigma and provide more education on TB to Nunavummiut. In accordance with Inuuqatigiitsiarniq, Health is respectful of privacy and is working to build trust with Nunavummiut through developing well-informed health programs.

The Government of Nunavut (GN) and Nunavut Tunngavik Inc. (NTI) have signed the Information Sharing Agreement (ISA) which is a guide to both parties for the collection, use, disclosure, retention, protection, disposal and destruction of relevant data related to TB in Nunavut. This agreement will help both organizations in developing TB related programming and support.

On May 8, 2023, Health in partnership with NTI announced a community wide screening (CWS) for TB in Pangnirtung. Screenings will begin in September 2023 and continue through November to ensure access and availability to as many residents as possible. Planning is underway for this screening and a steering committee has been established. Health and NTI are also working with the Public Health Agency of Canada (PHAC), and Indigenous Services Canada (ISC) to set up and run this clinic.

During the CWS in Qikiqtarjuaq, the number of individuals diagnosed with active TB was released publicly. After each CWS there was a high level debrief completed within the community, this included information on the percentage of the community screened. For Pangnirtung, Health has committed to releasing the number of individuals diagnosed with both active and latent TB every three months until the outbreak is declared over.

I hope the above information addresses the question you raised during oral questions, and I thank you for advocating on behalf of Nunavummiut.

Sincerely,

Hon. John Main Minister of Health

cc: Megan Hunt, Deputy Minister of Health