Priorities for TB Program Performance Measurement for First Nations in Canada

In November 2018, the National Collaborating Centre for Infectious Diseases, in partnership with the National Collaborating Centre for Indigenous Health,[1] convened a meeting of TB program representatives to undertake a conversation on performance indicator priorities in Canada. Attendees identified potential TB program performance indicators for collaborative development based on their respective experiences with program performance measurement, as well as TB elimination priorities in Inuit, First Nations, and urban dwelling and foreign-born populations in Canada. First Nations priorities for performance measurement were further discussed at *the First Nations TB Elimination Meeting* held in March 2019. A small selection of indicators from the 2018 indicator meeting were discussed, and notes from this discussion have been appended to the First Nations-specific discussions notes from the 2018 meeting below – these include additional priority indicators of interest that were proposed at the 2019 First Nations meeting.

Updated Table 3: Proposed TB program performance indicators specific to First Nations populations. Dark green box shading - indicator considered high priority during 2018 group discussions; no box shading - indicator considered lower priority during 2018 group discussions. Yellow highlighting "ADDED" – indicator not part of original indicator compilation resource presented for discussion. Blue highlighting – indicator considered shared priority across all three high burden population groups (First Nations, Inuit, Urban and foreign born). *Green highlighting and pink shading – indicator of interest added at 2019 First Nations TB Elimination Meeting. Orange font – additional notes collected from 2019 First Nations TB Elimination Meeting*.

Domain	Indicator group	Priority	Potential Indicator	Additional Stratification (beyond age & sex)	Rationale	Extra Notes
Incidence and Inequalities (Stratify by age, sex, registered status, self-identification)	Higher-risk groups – enhanced surveillance					Incidence and characteristics of TB in higher risk groups Provide departments with a list of high incidence communities – recommendation is there, but we are not there
	Inequalities		*England - Slope index of inequalities (SII) in TB rates (use index of deprivation score)* Number of people living in a bedroom / household		Difficult to quantify since the official number of people could be different than the true number of people living there	Challenge: Obtaining an appropriate measure (i.e. deprivation score, community-well-being index etc.); Potential stigma issues surrounding scores Incidence and Inequalities = challenging to obtain

[1] Previously known as National Collaborating Centre for Aboriginal Health

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	ADDED- Comorbidity		Proportion of individuals with Diabetes Proportion that have A1C test Other medical conditions?	well-managed vs uncontrolled diabetes	Diabetes is an important comorbidity for First Nations communities	Have a diabetic nurse once a week for screening Any new diabetic could be screened for TB at the same time (screen + educate all in one) Any opportunity to screen for diabetes/other chronic illnesses could be used for info sharing (holistic approach to health); Education tool; good intentions;
	ADDED- Women of child-bearing age/pregnant				Women of child-bearing age/women who are pregnant are often around children (a high-risk population); An important group that is often missed;	
	Pediatric		Proportion of individuals that are kids			
	BCG Vaccination rate					
	HIV + Hepatitis C					
	EXTRA NOTES	Target for Drug resistance- < 3% (MDR is very low among indigenous) Acquired vs primary- drug resistance = ZERO				

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Lab Reporting	Genotyping			Heffernan & Long (2018) - "*Proportion of culture positive cases with genotyping*". USA CDC (2015) - "*For TB patients with a positive culture result, the proportion who have a MTBC genotyping result reported*" % of cases diagnosed by Gene Xpert		Genotyping can be a useful tool for contact investigation in Indigenous communities – can help identify reactivation vs new infection, and help identify imported strains; can support collaboration and improve public health response.	Genotyping needs to be improved – Does not meet everyone's needs, and only certain communities have access. May be aspirational for urban and foreign-born populations – could potentially focus on Canadian born populations. Genotyping is long term goal; rely on sputum smear (not all communities have access) Target - 100% What's the barrier? Lack of knowledge; not all physicians are ordering- Engage/educate physicians. Need to educate laboratory. Challenge - Gene Xpert needs a licensed person to run it. Cost? Logistics? Should reinvigorate CHR; Use of trained pediatrics Not everyone is measuring proportion so what is the benefit? MHO decides; In terms of patient care- it makes no difference and does not impact work on the ground; Don't know current %; No reason to measure this (unrealistic to set a target/not timely) Lessons from HIV testing- Dry blood spots (use new transportation initiatives for moving samples i.e. drones to fly samples or other trucks eg) Coca-Cola or food trucks)
	ADDED- Lab reporting package	Timely lab arrival				Information could be rolled up from local programs to the national level as a combined indicator (through the use of a yes/no checkbox form) to facilitate information collection Diagnostic delay is an implementable measure if well-defined; Could provide a form with check boxes (yes/no) and define criteria to break down where the delay is (patient, HCP, or administrative) so that you know where to target	
		Timely smear					Need sensitive engagement for populations as certain aspects of TB (for example, sputum collection) can be routed in trauma and colonial history; Not all programs have access to NAAT (i.e. GeneXpert) which could lead to potential failures for implementation
		Timely NAAT					**Potential benchmark:** Ideally performed on Day 1 following a positive smear result
		Timely report back					
		Genotyping					
		DST					
		Diagnostic delay					
	Culture-during treatment			Indicator described by Heffernan & Long			To be included in "Evaluation package during treatment"
	Lab Arrival time			Time from collection to inside lab			Target - 24h

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	ADDED- Community access to GeneXpert		% of communities that have access to Gene Xpert			Target - Gene Xpert access > 95% Social Networking
	ADDED- Diagnosis on site		How many sites doing diagnosis? How many have x ray?			Technology is important - but if you don't think of TB, it won't work
	ADDED- Diagnosed by GeneXpert		% of cases diagnosed by Gene Xpert			
	ADDED- Diagnosis rate		% Diagnosis			Target - diagnosis is >90%
	ADDED- Home taken time				Bring testing closer (Less transportation time)	
	ADDED- Timely reporting		Time from sputum collection to reporting?			Need to measure the delays - Specimen to the lab the getting the report back Can't treat individuals without lab report Target - 24 hours (standard)
	ADDED- Delayed testing		% of individuals with 2-month cough without sputum			
Case Management and Treatment	Timely treatment initiation		Heffernan/Long (2018) – "*Proportion of smear-positive pulmonary cases starting treatment within 72 hours of NAAT report*"; PHN 2012, Fanning & Orr (2010) - "*Proportion of cases started on anti-TB drugs within 48 hours of diagnosis"* USA CDC (2015) - "*For TB patients with positive AFB sputum smear results, the proportion who initiated treatment within 7 days of specimen collection*"		Early treatment initiation is critical (even more important than the specific type of treatment). Earlier treatment translates to less infectivity, and less investment in contact tracing.	Need to define initiation (e.g. when prescription is written vs filled) Follow CTS Need "real" picture opposed to what is possible. EG) What is our current target? Treatment within 72h (but usually past by the time meds start) Potential targets - %100 or %80 Need a courier service for the north (many samples are being destroyed due to travel); Currently relying on truck service (up to 5 days before meds can start) IF meds have not been delivered within 4 days that triggers "direct drive protocol" which has financial issues for shipping Current gap for starting therapy is that some places- no treatment unless you have a bed available Contact clinicians to prescribe through a proxy (even if no bed available); virtual clinics
	Re-treatment/ Relapse		Fanning & Orr (2010) - "*Proportion of cases per year that are relapsed (re-treatment cases)*".			Information currently collected, but no timeline in reportable form.

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Case Management and Treatment (continued)			PHN (2012) - "*Re-treatment rate within two years after the end of previous treatment in Canada*" Australia Strat Plan (2015) - "*Proportion of cases initially treated in Australia who relapse within 5 years of treatment*"			May be better to be called "re-treatment" – "relapse" is nice to have, but theoretically requires whole genome sequencing. **Potential benchmark:** clinical trials use 3.8%, other sources use 3%, could use 4%. Potential Target - 0% (but <5% relapse rates are acceptable) Potential Target - 1%
	ADDED - Evaluation package- during treatment				Information should be rolled up from local programs to the national level as a combined indicator (through the use of a yes/no checkbox form) to facilitate information collection Include culture-during treatment, sputum and chest x-ray at treatment initiation as well as sputum and chest x-ray at the end of the treatment phase	
	Early Diagnosis-smear positive					
	Early Diagnosis-symptoms-to-treatment					An indicator based on symptoms is challenging since it can be subjective
	Treatment completion		Indicator described by WHO (within 12 months for drug susceptible);	Drug susceptible, drug resistant and LTBI cases	Need to stratify since each type of TB will have different treatment length requirements	
	DOT					
	Underserved populations					Difficult to quantify because needs to encompass physical, social and emotional aspects
	HIV serologic testing					Part of the "Evaluation/Completion of Investigative tests" package which could be rolled up Nationally from local programs
	ADDED- Completion of investigative tests		Proportion of patients that completed the full investigation package (identified using a checkbox format)? Or what percent of patients had a complete assessment?		Information should be rolled up from local programs to the national level as a combined indicator (through the use of a yes/no checkbox form) which could facilitate data collection Include information on chest x-ray, AFB, culture, HIV serologic	

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					testing, hemoglobin A1CC [diabetes], ALT [liver function], and renal function	
	smear positive cases		Proportion of smear positive cases (bacterial)			
	Treatment completion rate		Proportion of individuals who completed treatment within recommended time frame			Target - 90% Need good patient relationships Building and nurturing relationships; No more working in silos
	ADDED- Case load		# of TB cases/Case Worker			
Contacts	ADDED – High Priority Contact Examination		Percent of high priority contacts which have been assessed; Measure pediatrics (< 5 years old) or other high priority contacts in household over a period of time Need to standardize - define priority/close contact, infectious case, and assessment	High priority/high risk contacts (children < 5 years old, HIV, women of childbearing age/pregnant and those with high exposure)	Important at a programmatic/ regional level; Need to prioritize high risk and close contacts (household, close contact, immunocompromised, young children < 5 years old)	**Potential benchmark**: >90% high-risk priority; **Potential benchmark:** Household contacts and children < 5 years old should be admitted to program for symptom assessment within 48 hours. Dependent on initial information collected; Infectious cases should have a contact list established within a week; Challenges with applying social networking to genomic systems- relapse and reinfection in high incidence community- contacts for multiple source cases. How many times have they been exposed? children < 5 years old Need to add timeline to make it concrete Target - 100% Screen more contacts to ensure that # of open contacts decreases by (eg) 20%) per month); Ensure active case finding Contacts are well defined but are not screened Need a dedicated nurse on site for TB Analyze Contact data that is already being collected, paper lists already kept in community
	Contacts - LTBI Identification		FNIHB (2015) - "*Of the number of contacts screened for LTBI, the number with a new positive TST/IGRA or TST/IGRA conversion (i.e. number of newly identified LTBI*"	Priority contacts (exposure vs risk, previously positive, women of	Helps us understand burden of TB infection	Could be part of *LTBI Cascade* - How many contacts within last 2 years; Proportion of TB contacts that have been tested for LTBI; Total screened; total LTBI; proportion treatment recommended; proportion LTBI treatment initiated; completed, accurate adherence and timeframe;

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				child-bearing age/ pregnant)		Could look at 90-90-90 or 80-80-80 for LTBI Contact investigation information chould be rolled up from local programs to the national level as a combined indicator (LTBI identification, treatment recommended, initiated, completed Should include number that have been assessed/educated Should be total LTBI diagnosed that is eligible for prophylaxis (exclude individuals > 65 yrs old) AIM – 90% of actual contacts, 90% of those are tested: plus at each point of cascade Build patient relationships Legislation on reporting active TB, not LTBI. Should have surveillance system for LTBI –> proportion diagnosed/treated Should be part of larger indicator domain called "Cascade of care for LTBI – Contact Tracing"
	Contacts - LTBI Treatment Initiation		PHN (2012) - "*Proportion of contacts with a dx of LTBI who begin Tx*" FNIHB (2015) - "*Of the number of contacts accepting treatment for LTBI, the number who started treatment (without contraindications to INH or RMP)"* Heffernan/Long (2018) - "*Proportion of close contacts recommended Tx LTBI, who start Tx (<5yrs, and ≥5yrs of age)"* USA CDC (2015) -*"Proportion of contacts to sputum AFB smear-positive TB cases diagnosed with latent TB infection, who start treatment."* WHO (2015) – "*Percentage of eligible people living with HIV and children aged under-five who are contacts of TB patients being treated for LTBI"*			Could use a measure for "was the prescription dispensed?" **Challenge**: LTBI is not always reportable

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	Contacts - LTBI Treatment Completion		PHN (2012) – "*Proportion of contacts beginning treatment for LTBI who complete treatment*" FNIHB (2015) – "*Of the number of contacts starting treatment of LTBI above (and without contraindications to INH or RMP), the number completing treatment at the time of reporting (irrespective of length of treatment)"* Heffernan/Long (2018) – *"Proportion of close contacts accepting TX LTBI who complete treatment (< 5 years of age and ≥ 5 years of age)"* Fanning & Orr (2010) – *"Percent completion of prophylaxis among those who accept"* USA CDC (2015) – "*Proportion of contacts to sputum AFB smear-positive TB cases who have started treatment for latent TB infection, who complete treatment."* Need to define completion. Definition depends on drugs used and length of time needs to be defined for each LTBI regimen	Children <5 years old vs adults; High priority vs all contacts		Part of cascade of care/ contact investigation package: Proportion of priority contacts assessed, proportion offered LTBI treatment, proportion accepted treatment and proportion that completed treatment; timelines for providers to follow. Example: 3-, 6- and 9-month follow-ups; Certain contacts may require tighter timelines Loss to follow-up
	Contact Identification		*PHN - Proportion of infectious TB cases where initial list of contacts is completed within seven calendar day* *FNIHB - Total number of reported contacts of active TB cases diagnosed in (year)* *CDC/England - Proportion of TB patients with positive AFB sputum-smear results, who have contacts elicited.*			

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	Contacts - Close		Indicator by Heffernan & Long but modified it to, "Number of close contacts of active TB cases diagnosed in (year)";	Household vs non-household contacts	Prioritize high risk contacts (individuals with risk factors, close contacts, children < 5 years old, etc.);	When contact investigations are incomplete, can miss a large group of people that don't enter into LTBI cascade Challenging to examine all contacts –see shared indicator for high-priority contacts
	Contacts - LTBI Treatment Recommended (offered)					Not every case is high risk and should be a priority for treatment;
	Contacts - LTBI Treatment Acceptance					
	ADDED - Contacts- Secondary cases		Proportion of children who are household contacts that have progressed to disease by the time they are tested Total number of cases identified		Using secondary cases as an indicator allows the program to assess how well its doing at preventing transmission	
	BCG Vaccination rate					HPV vaccine introduced to high school girls and university, then boys - Huge public health victory
	EXTRA NOTES	Too much LTBI, so once active cases are reduced, we need to eliminate pool of disease Data collection is a challenge as a lot of information is not currently systematically collected				
Screening and Follow up	People Living with HIV					Difficult for Public Health and TB programs to monitor since many people are managed by primary care
	People with Impaired Immunity					Organizational challenges and difficulty with follow-ups due to lack of manpower
	ADDED - Screening Delay					Need to measure delays in screening people and clinical screening
Other programmatic	BCG - Community				Relevant at the local level	
	BCG - Administered				Relevant at the local level	
	BCG - Eligible				Relevant at the local level	
	BCG - Adverse Reactions				Relevant at the local level	
	Outbreaks - New				Relevant at the local level	
	Ongoing Outbreak - Active Cases				Relevant at the local level	
	Evaluation and Strategic Planning		Indicator described by Fanning & Orr		Can ask high incidence communities if they felt that they had meaningful engagement in their TB program;	**Note**: Specific for community consultation activities; Need to consider that communities are fluid and should think of them as community areas;

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			Potential indicator specific for FNIHB/FNHA/NITHA and could report quarterly (like FNHA)		Programs have a duty to engage communities to participate in program decision making;	
	Education- Health care provider				Relevant at the local level	We need to create a sheet for other physicians on TB - we make assumptions about what they know when they start working with remote communities
	Education - Community		Proportion of schools that have TB in their curriculum		Relevant at the local level	Opportunities to screen + provide information at the same time (e.g. Diabetic nurse who comes 1x/Week who could screen and provide info at the same time.)
	Ethics		Indicator described by Fanning & Orr selected			May look different for different communities/regions; Reconciliation and nation-to-nation are essential practices; Need to determine a data-sharing agreement and where data should be kept
	ADDED – Community access to data		% that have access to electronic data that are user friendly and accessible			If collect all this data and it sits in someone's office on paper- it isn't useful- needs to be shared
	ADDED – Report back to community		% of stats being reported back to the community			e.g.) monthly or yearly numbers
	EXTRA NOTES	Community needs to have capacity/ability to observe, measure and assess their own indicators				

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Determinants	ADDED - Housing		Potential indicator "number of people per bedroom / household"		Density/ventilation/ housing repair are all important considerations for TB risk. Need to consider both individual and community overcrowding and housing repairs	Bring housing to program – homes/shelters/hotels/ correctional facilities Canada TB guide; PC Satisfaction survey Need to understand overcrowding Engage CMHC to help them understand Should look at CMHC tenants agreements Monitor changes and supports Homelessness/couch surfing, transient population EG) 5 households with 180 ppl going through the house; social houses (gathering places) Only housing info that we have comes from client interview; # of ppl/ household- challenging Housing quality House condition (do they have water, mold); (air quality, ventilation system)
	ADDED- Partnerships		What is the relationship between the program and the community? (details to be determined)		Need to have a way to measure community partnerships since these partnerships are essential for success of the program; Creates a mechanism to advocate for self-determination	Collaboration between agencies- policy; eliminate jurisdictional red tape; i.e. TB workers/staff would like to reach out to community but fear of reprimand
	ADDED- Community Resources		Is there a capitation system in place to access the amount and appropriateness of resources for the community		Communities need to be properly resourced to deal with TB;	
	ADDED - Employment/ unemployment					Unemployment (mean/median income)
	ADDED – Education (attainment and quality of primary and secondary education)					Educational attainment and literacy
	ADDED - Community wellness indicator		Indicator to measure self-assessed status (i.e. nourishment, tobacco smoking etc.) (details to be determined)			Need a wellness-based indicator/surveillance Water quality
	ADDED - Catastrophic costs		Proportion of cases that became unemployed during treatment; OR		If the "cost" of TB is known (social, mental, physical, and economical) this may help	**Challenge**: Difficult to define and capture.

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			measure homelessness/isolation (details to be determined)		acquire funding for disease management and prevention	
	ADDED- Stigma reduction		How are physicians normalizing TB care to reduce stigmatization?			**Challenge**: Finding a meaningful "high level measurement" Heavy stigma No difference between stigma b/w LTBI and active TB
	ADDED- Movement in/out of communities					Migration
	ADDED- Community Poverty/Income					
	ADDED- Effective Community Engagement					Need more community engagement Create champions People don't know how to engage/struggling with effective engagement
	ADDED- Food security					
	Nutrition					How do we get better measures for nutrition indicators?
	Traditional foods and preparation					
	ADDED- Addiction/ Mental health and Wellness					Addiction confounds TB care (competing priorities), The children are the ones who suffer Disconnect b/w MH and housing
	ADDED- Presence of land-based healing					
	ADDED- Access to services or health care					Need dedicated nurse on site for TB (not just being flown in)
	ADDED- The voice of community is represented					Community needs to have the capacity/ability to observe/measure and asses their own indicators
	ADDED- Social habits (HIV, smoking) Smoking and Cannabis					
	EXTRA NOTES		All social determinants of health should be represented in the performance indicators. Challenge - Determinant list could be huge Cost-benefit in terms of what sort of SDOH indicators can we describe, and what ways of quantifying Population approaches; Public health policies (upstream primary prevention) Advocate for healthy public policy, not public health policy Need collaborations between all departments i.e. working in a group- the barrier is that we currently do not know how to work together, mandate change or take action.			

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Overall Notes	More clarification for indicators are required; Do we have the data for all of these indicators? Need good data; Don't hold on to data or analysis - data needs to be shared to facilitate; Data capacity and Management is important - Currently a barrier to describing/tracking new and more helpful indicators (pertains more to SDOH) Need to reference or defer to FN Expertise (FNIGC) and data management for FN as an objective. Don't add too many indicators; Need to make sure data is used - "Burden of chronic illness database"- database is now defunct Need things that are relevant and attainable; Should look at outcomes; In order to have targets, we need a better baseline Decisions being made at the top but the frontline people not part of this and it doesn't always make sense for those on the ground→ how does info filter down to the communities/front-line workers? If there are cure targets- front line staff don't know about them; what are measurable targets? Targets for smaller/rural/remote/northern FNs might be unrealistic, but shouldn't they have equitable health services given the high TB incidence within their communities? (e.g. transportation of samples and medications) Can't implement change if you don't have any "teeth" - Groups need teeth to enact change Should focus on elimination targets, but particularly for Indigenous TB in Canada Where does TB rank in terms of issues? - Competing priorities - TB is not the only disease communities need to worry about - pressure from patients is low Many measures/indicators are used (and are good) for quantifying positive cases and providing epidemiological data; however, there is a great need/ challenge to develop indicators and measures that pertain more to prevention, promotion and screening. (e.g. access to portable x-ray) – need to avoid epidemiological tunnel vision - Need a general framework for prevention, promotion and treatment indicators					