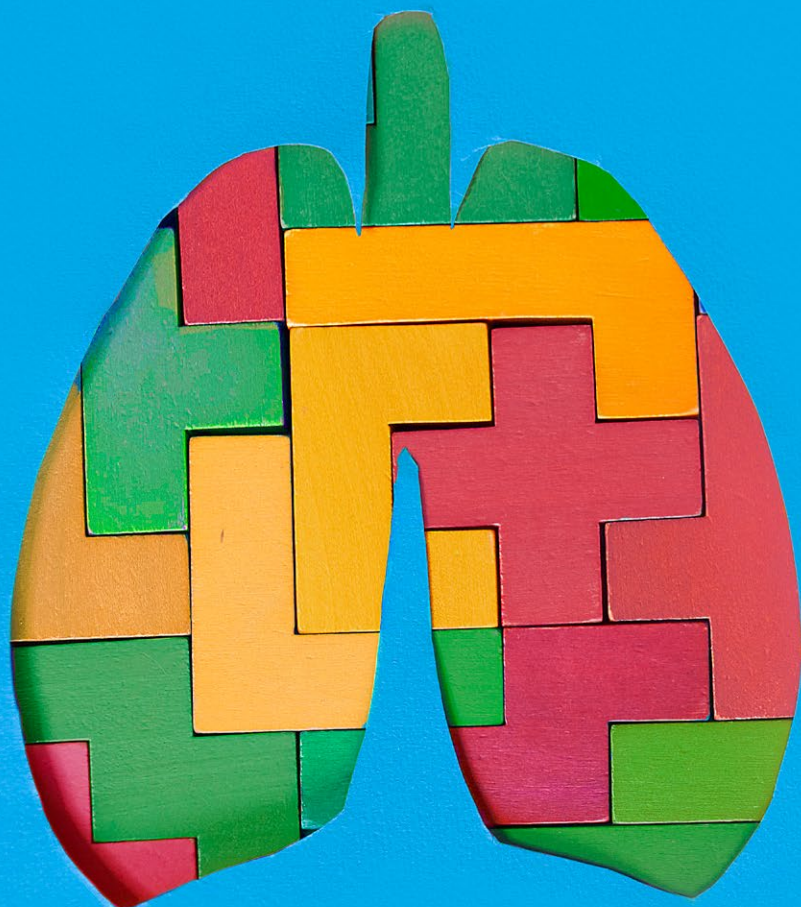


Tackling TB Stigma



Developing a cross-sectoral
approach to reducing
tuberculosis (TB) stigma
and improving TB care
for vulnerable newcomer
populations in Canada

An Access Alliance
“Health with Dignity” Project

Full Report





Contents

Authorship

Access Alliance Multicultural
Health and Community Services

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Executive Summary



70%

Reported cases of active TB accounted for by the immigrant population in 2016



According to the Public Health Agency of Canada (PHAC), in 2016, the immigrant population (approximately 22% of the Canadian population) accounted for 70% of reported cases of active TB, highlighting the need to address TB in this country and how we respond, as a system, to illnesses like TB in relation to the burden and impact of stigmatization they bring to systemically vulnerable populations and their access to care and support.

“Tackling TB Stigma: Developing a cross-sectoral approach to reducing TB stigma and improving TB care for vulnerable newcomer populations in Canada” was undertaken by Access Alliance Multicultural Health and Community Services (Access Alliance) to address the lack of awareness and high levels of stigma attached to TB and increase access to quality resources, support and care for immigrants and refugees in Canada who are living with or who are at risk of acquiring a communicable disease.

The project took a cross sectoral approach engaging representatives from primary care, settlement and public health, along with community members from three populations experiencing the highest incidence of TB in Toronto: Chinese, Indian and Filipino born.

Project Findings

Some of the key project findings include:

- The newcomer journey is influenced by family and community members as well as formal systems that extend well beyond healthcare and include employment, settlement, legal and education; newcomers tend to prioritize other parts of the settlement journey over healthcare and TB, namely the other social determinants of health including employment and housing.
- TB education, screening, treatment and care should be centered in interdisciplinary team based primary care settings; access provided through coordinated and clear service pathways, and offered in collaboration with core partners – Public Health, TB specialists, settlement and social service providers.
- TB services and resources need to be client centered, culturally appropriate, and accessible in terms of language, cost, location and safety in order to provide effective and efficient customer service friendly care, address misconceptions about TB in diverse communities and stop the spread of TB stigma that perpetuates isolation.
- Misconceptions exacerbate the impact of TB-related stigma in newcomer communities, and the lack of knowledge and understanding about the disease gives rise to increased fear and isolation.

Project Recommendations

1. Education: Enhancing TB related awareness and knowledge among newcomers

- A.** The Public Health Agency of Canada should partner with organizations that work within health equity frameworks to undertake health communications strategies and activities that will raise awareness about and combat TB-related discrimination and stigma.

- B.** To promote TB screening, informed consent and compliance with TB care, ensure that all TB information that is produced and disseminated by publicly funded organizations is culturally appropriate and linguistically accessible.

- C.** Provide education and training for staff in client facing and support roles working in settlement and primary care organizations that will: improve awareness of TB related stigma that leads to isolation and discrimination as well as their knowledge of TB and related misconceptions; increase support to newcomers who experience stigmatization while remaining attentive to the needs of newcomers who are living with or at risk of TB.

2. Practice: Improving service provider competencies and practices

- A.** Provincial Ministries of Health should invest in interdisciplinary team based primary care organizations or structures that increase access to team based care as the preferred setting for serving systemically vulnerable (socially isolated) populations – like newcomers – in order to facilitate their access to stigma-free TB prevention, screening and treatment services and supports that address the person from a “whole person” care perspective.

- B.** All primary care settings that serve newcomer clients should implement measures to deliver TB services and supports in locations and times that are accessible for clients.

- C.** All primary care settings serving systemically vulnerable clients like newcomers should implement measures (policies and services) that enhance client centered and culturally competent TB care and support that intentionally combats TB-related stigma (discrimination and isolation).

- D.** Primary Care with Public Health test and implement an evidence-based LTBI clinical

pathway for use in interdisciplinary team based primary care settings to improve clinical decision-making at point of care, the quality of patient care and clinical efficiency that eliminates stigma in the provision of TB care and support.

E. Public health, primary care, and the settlement service sectors should improve coordination and collaboration that increases access to interdisciplinary and team based primary care so that providers are better able to support systemically vulnerable populations like newcomers who are living with or at risk of TB and face isolation and discrimination due to stigma.

F. The provincial Ministries of Health should ensure that Information Technology/Information Management (ITIM) systems across the health continuum, including primary care and public health, are designed to promote service coordination, quality of care and improve outcomes for systemically vulnerable populations like newcomers at risk of and living with TB and related stigma.

3. Policy: Influencing systemic change

A. Eliminate barriers to health care so that newcomers can access the services and supports needed to prevent or treat TB. In Ontario, this would mean eliminating the three month wait period for the Ontario Health Insurance Plan OHIP and ensuring that care and support for systemically vulnerable populations who face stigmatization is centered within primary care that is team based, interdisciplinary and focused on serving and caring for the “whole person”.

B. Immigration, Refugees and Citizenship Canada (IRCC) should provide clear language resources and definition of medical surveillance furtherance and standardize the terminology for newcomers and providers who support newcomer populations.

C. IRCC should provide healthcare and settlement service providers with written information about the Immigration Medical Exam (IME) and Medical Surveillance (MS), including Quick Reference

Guides to the IME and ME processes, in multiple languages, and require this information be disseminated to all newcomer clients.

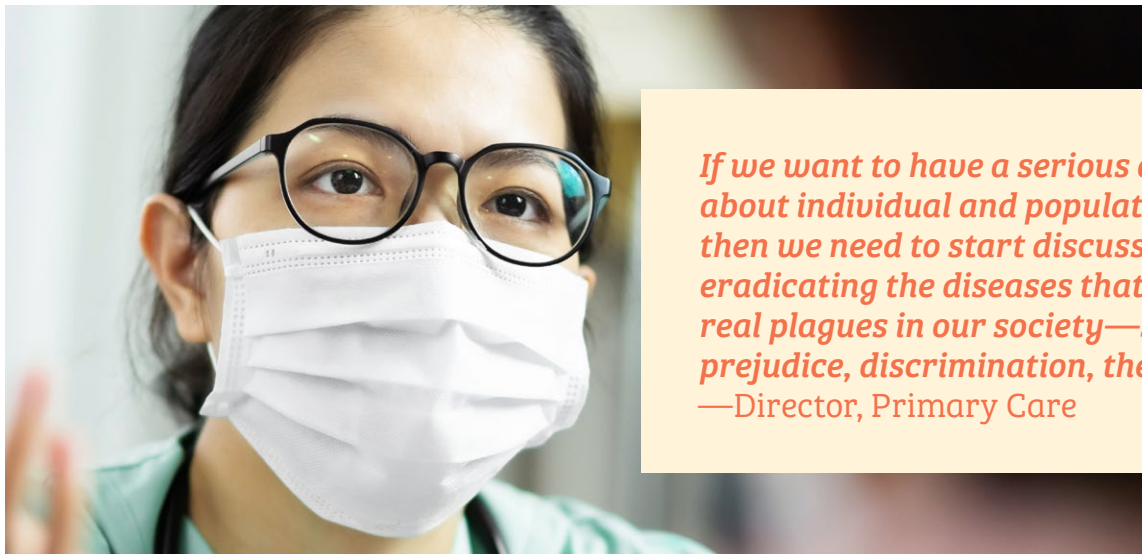
D. The Public Health Agency of Canada (PHAC) and all levels of government and public agencies should use language and have policies in place that reduce the impact of stigma on systemically vulnerable populations and refrain from using language, like “foreign born”, that contributes to the stigmatization of newcomers, in this case newcomers and newcomer families living with or at risk of acquiring TB.



Conclusion

While the project took place in Toronto the learnings are transferable. The report can provide clear guidance to practitioners and policy makers at the local, provincial and federal levels who share accountability for the health and wellbeing of newcomer Canadians and reducing or eliminating the impact of stigma on systemically vulnerable populations.

Introduction



*If we want to have a serious discussion about individual and population health, then we need to start discussing and eradicating the diseases that are the real plagues in our society—stigma, prejudice, discrimination, the “isms”.
—Director, Primary Care*

Stigma is a major social determinant of health. According to Canada’s Chief Public Health Officer, Dr. Theresa Tam, stigma is very much present in our health system, driving those most in need from getting effective care and accessing services. As such, stigma is associated with poorer physical and mental health outcomes. In *The Chief Public Health Officer’s Report on the State of Public Health in Canada 2019: Addressing Stigma Towards a More Inclusive Health System*, Dr. Tam states that “people and institutions with resources and power, including health organizations, shape laws and social norms that can influence what is considered to be normal and acceptable” (PHAC, 2019), thereby creating or perpetuating stigma.

Newcomer populations¹ are disproportionately affected by TB. According to PHAC, in 2017, populations not born in Canada (representing approximately 22% of the Canadian population) accounted for 71.8% of reported cases of active TB, demonstrating the inequitable burden of TB, and highlighting the need to address TB in newcomer communities. Adult newcomers from regions of the world with a high incidence of TB, including China, India, and the Philippines, who have latent TB infection (LTBI) are at the highest risk of developing TB disease. In Toronto, the active TB cases among those who were born outside of Canada is 92% and TB rates are highest amongst Chinese, Filipino and Indian newcomers.

Stigma has been well documented in the literature as a determinant of health leading to discrimination and social isolation, and ultimately to poor health and mental health outcomes.^{2, 3, 4} However, TB stigma and the intersection

¹ The term newcomer is the term used throughout this report to capture the broad range of people not born Canada, including but not limited to those who come to Canada via the following programs and/or categories: family, skilled worker, business, refugee, humanitarian, temporary foreign workers, international students.

² Hatzenbuehler ML, Phelan JC, Link BG. Stigma as a fundamental cause of population health inequalities. *Am J Public Health*. 2013 May;103(5):813–21. doi: 10.2105/AJPH.2012.301069. Epub 2013 Mar 14. PMID: 23488505; PMCID: PMC3682466.

³ Hatzenbuehler ML, O’Cleirigh C, Mayer KH, Mimiaga MJ, Safren SA. Prospective associations between HIV-related stigma, transmission risk behaviors, and adverse mental health outcomes in men who have sex with men. *Ann Behav Med*. 2011;42(2):227–234 [PMC free article] [PubMed] [Google Scholar]

⁴ Link BG, Struening EL, Neese-Todd S, Asmussen S, Phelan JC. Stigma as a barrier to recovery: the consequences of stigma for the self-esteem of people with mental illnesses. *Psychiatr Serv*. 2001;52(12):1621–1626 [PubMed] [Google Scholar]

between TB stigma and other social determinants of health such as newcomer identity, have not been as well researched in low burden countries such as Canada (Craig, Daftary, Engel, O'Driscoll, Ioannaki, March 2017). We know that newcomers experience different and intersecting stigma.

For example, the barriers that newcomers experience to trades and professions has been well documented as has been the impact of this on the rate of poverty among newcomers as compared to Canadian born populations. Similarly, in Toronto, newcomers face TB stigma throughout their experience with stigma at numerous points along the TB care pathway, from screening to diagnosis to TB treatment. Anyone can perpetuate TB stigma, including family members and health care professionals. And along the pathway TB stigma intersects with other forms of discrimination for example, based on issues such as race, culture, religion, income, age, gender or gender identity.



Understanding how TB stigma specific to newcomer communities manifests in the everyday practices of service

providers, including healthcare providers and other newcomer service providers, can help to inform the development of effective interventions for addressing TB stigma with a social determinants of health framework. “Tackling TB Stigma: Developing a cross-sectoral approach to reducing TB stigma and improving TB care for vulnerable newcomer populations in Canada” was undertaken by Access Alliance Multicultural Health and Community Services (Access Alliance) to address stigma attached to TB and increase access to quality resources, support and care for immigrants and refugees in Canada who are living with or who are at risk of acquiring a communicable disease.

Harnessing collective power through collaboration and engagement

Tackling TB Stigma used an inclusive, cross sectoral approach whereby over 150 individuals representing primary care, public health, settlement and newcomers from the three highest risk communities in Toronto were engaged in all phases of the project, especially in the collection and analysis of information and development of the project recommendations. This approach provided the project with many important perspectives and lived experiences to ensure that the project recommendations are relevant, evidence-informed and impactful. Critical to the process were the following:

- Three Community Reference Groups (CRGs), each composed of newcomers from India, China and the Philippines, were established.
- Two Settlement Agency Reference Groups (SARG), one comprised of front line service providers and the other of managers
- A Primary Care Reference Group (PCRG) comprised of various health service providers (HSPs) including nurses, nurse practitioners, physicians from TB Clinics, community health centres (CHCs), a Refugee Health Clinic and Toronto Public Health TB Program
- Project Advisory Committee comprised of representatives from the settlement and health sectors as well as other sectors that newcomers engage with including education and libraries, academic researchers and policy makers

Stigma as a Determinant of Health



Stigma is a mark of disgrace that sets a person apart from others. When a person is labeled by their illness they are no longer seen as an individual but as part of a stereotyped group. Negative attitudes and beliefs toward this group create prejudice which leads to negative actions and discrimination. Stigma brings experiences and feelings of:

- shame, blame, hopelessness, distress
- secrecy, loneliness, isolation and social exclusion
- stereotyping and derogatory labels
- misrepresentation in the media
- being treated differently than the rest of society
- discrimination in housing, employment or services

Stigma harms people's health. When stigma is connected to a medical condition (such as HIV/AIDs or tuberculosis), it stops an individual from getting tested, seeking medical care, disclosing diagnosis and in adhering to treatment and follow-up, and as a result poorer health outcomes, including death.

The TB community and TB stigma researchers has long recognized that TB is stigmatizing, and have put forwarded numerous policy and practice

recommendations for addressing this (Reitmanova, Gustafson, Ahmed, 2015). They have also called for more explicit recognition that stigma is a social determinant of health and have recommended that communities affected by TB should be leading these efforts (Craig GM, Daftary A, Engel N, O'Driscoll S, Ioannaki A. Tuberculosis stigma as a social determinant of health: a systematic mapping review of research in low incidence countries. *Int J Infect Dis*. 2017 Mar;56:90-100. doi: 10.1016/j.ijid.2016.10.011. Epub 2016 Oct 27. PMID: 27810521). Possible changes to be considered as promising practices include using words and phrases that are positive ie. words/wording that doesn't stigmatize people with or at risk of TB; ensuring that people with TB have employment protection while undergoing treatment and is not jeopardized due to a positive test or the need to be away from work.

Notably, several researchers have suggested that learnings from the study of HIV practices be applied to help to make TB care and policies more patient-centered rather than bio-medically focused (Daftary, Frick, Venkatesan, et al., 2017). Researchers have also recommended the development of more evidence-based tools for effectively measuring TB stigma (Macintyre, Mitchell, Daftary, and Craig, 2018).

Reduce TB stigma → Improve access to the determinants of health → Improve TB care for vulnerable newcomer populations

Tackling TB Stigma is grounded in a social determinants of health framework, which acknowledges that when TB stigma intersects with discrimination based on newcomer identity, health outcomes are worse. The complex intersection between stigma, other identities and the determinants of health cannot be underestimated. In the Canadian context, studies have shown that newcomers, particularly racialized newcomers experience barriers to healthcare services, often because of their unfamiliarity with the healthcare system, language and culture differences, leading to a decline in their health (Ahmed, Shommu, Rumana, Barron, Wicklum and Turin, 2016; Gurrola, Ayón, 2018).

In addition to socioeconomic and healthcare barriers, newcomers face anti-immigrant sentiment. A recent poll shows that 57% of Canadians believe that immigrants are a strain on public services (Ipsos Global Public Affairs, 2019). Research has also shown that the media often portrays newcomers, particularly those who are racialized, negatively as people who bring in diseases to Canada and that they disproportionately access government supports (Daftary, Frick, Venkatesan, et al., 2017).

From the outset, Tackling TB Stigma developed a newcomer TB care pathway to help organize our conversations with newcomers. The first iteration of the pathway was based on the Project Team's review of Toronto Public Health's TB care pathway and resulted in a very "medical" understanding of the newcomers TB journey. Through co-design activities with the project participants, the pathway evolved to capture the complex relationships that influence newcomers' settlement and integration experiences, including their interaction with the healthcare system. As the project progressed, and newcomers shared their stories, included the ones documented here and throughout the report, the TB pathway evolved to reflect the influence of family and community members and touch points with formal

systems that extend well beyond health to include employment, settlement, legal and education.

Newcomers are faced with various challenges when acclimating to life in a new country. Based on the findings of this project, securing employment, establishing permanent housing, augmenting English language proficiency and getting connected to ongoing primary care services were the priorities for Indian, Chinese, and Filipino newcomers. In fact, newcomers tend to prioritize other parts of the settlement journey over TB and even healthcare. This speaks to the importance of better appreciating the barriers that newcomers face and the need for a more integrated and coordinated newcomer TB care pathway that includes the determinants of health.

TB Stigma

→ A live-in nanny from the Philippines was fired by her employer almost instantly when her employer discovered she had active TB. What's more surprising is that her employer was a physician, who should have had better understanding of TB disease and infection. Furthermore, the nanny's termination resulted in her losing her health insurance. She then became homeless. She received no support from the panel physician who oversaw her immigration medical exam.

→ A Sri Lankan woman, diagnosed with latent TB, refused to take her medication because she had plans to travel to India for her daughter's wedding. She was afraid that the airport staff would not allow her to travel, because of her latent TB diagnosis. She was also afraid that her family would find out about her diagnosis, and isolate her. In addition, she feared what her daughter's husband's family would think about her and her family based on her TB diagnosis.

What We Learned from Newcomers



Filipino Community Reference Group members

Participants from all three CRGs engaged for this project agreed that TB-related stigma exists. When asked to write down words to describe TB, they consistently used negative terms such as poverty, fatal, fear, isolation, hopeless, afraid, careful, prevention, and panic.

In general, the perceptions among CRG members of TB and their experiences with the Canadian healthcare system are strongly influenced by their cultural beliefs,

past experiences with TB and prior experiences with the healthcare system in their home countries. Public health infrastructure in many of the high-TB incidence countries is weak, and often non-existent. As such many newcomers may have never heard of preventive treatment for TB, and may only associate TB with death and suffering. For example, participants from the Indian CRG stated that TB is associated with lower classes, that there is a strongly-held belief that wealthy people are shielded from getting TB and that publicly-

What We Learned From Newcomers



funded healthcare is less esteemed than privately-run institutions that require out-of-pocket payments. Primary care providers should be aware of the diverse cultural beliefs and experiences that their clients may hold and be equipped to address these issues in a culturally-competent manner.

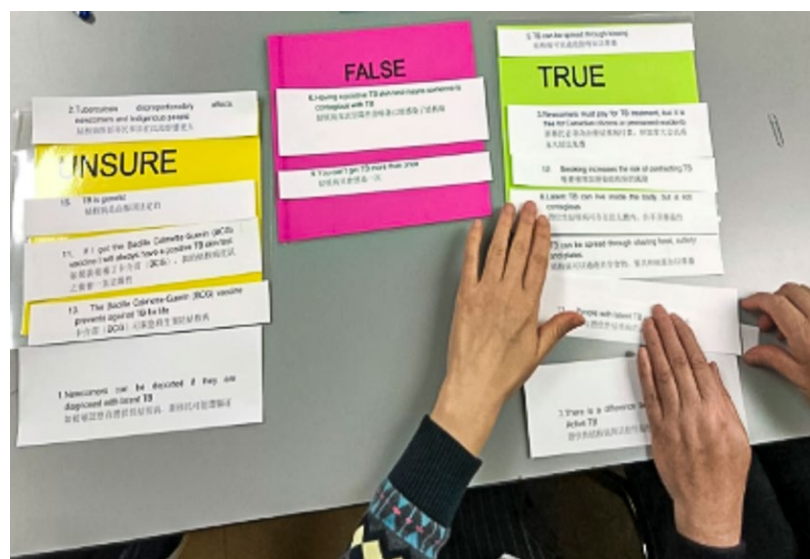
In general, the newcomers engaged in the project lacked clear knowledge and awareness about TB/LTBI and that it was a public health concern in Canada. Moreover, participants had not received clear information about TB/LTBI in Canada and, up until this project, some had not thought about TB/LTBI risk since their arrival in Canada 9 years previously. CRG members agreed that in Canada, more could be done to raise awareness that TB as a priority public health issue. They felt that while there might be a substantial amount of TB information available, it is not reaching the intended newcomer communities in a meaningful way.

Several key misconceptions about TB stigma were identified by participants from all three CRG groups:

- BCG vaccine protects against TB for life - **false**;
- Getting a BCG vaccine may be the reason why you test positive (positive skin test) for LTBI later, not because you have LTBI - **true**;
- Newcomers must pay for treatment - **false**;
- People cannot get TB more than once - **true**; and
- TB can be transmitted by kissing, and/or sharing drinks or cutlery - **false**.

Interestingly, TB stigma expressed by CRG participants was low, but their awareness of the prevalence of TB stigma in society was high:

<p>77%</p> <p>responded False to the statement: people with TB are usually poor</p>	<p>69%</p> <p>stated False to the statement: people with TB usually live in an unclean house</p>	<p>45%</p> <p>responded True to the statement: “If a friend of mine had TB, people would avoid him/her”.</p>
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Highlights - Community Reference Group Perspectives



Newcomers from China

Perception that TB is not curable, and if you catch it, you might fall very ill and/or die

"Their past experiences. They've [our parents] seen a lot of people die with this disease not a lot of people who were cured."

"Reason is that we don't have enough knowledge to support us to clear the fear."

Lack of awareness or education which results in othering community members and gossip

"Don't eat with this person together. Don't touch what the person touched, stuff. Also keep distance from that person."

Reluctance to admit stigma

"I think even though they say: I wouldn't discriminate or I would treat them as usual, but they would be reluctant to tell people I caught this. They would not talk about this openly and frankly. So gives me an idea they don't want to disclose this information to others. I feel there is stigma even if they admit it or not"



Newcomers from Philippines

Belief in people who are not healthcare professionals (i.e., referred to by some participants as "quack doctors")

"We Filipinos always believe what we hear, especially from our parents and elders."

"In the Philippines there's still a lot of people who believe in quack doctors than physicians."

Self-conscious about being judged by Canadians

Believe that there is less support in Canada for people with TB in comparison to the Philippines where TB is common

Fear or caution about catching TB

"I have some not really relatives, but relatives of relatives, who I know who have TB. So we're really cautious about them. Especially with the kids. We will tell them to don't go near there, don't go to their house, because they have this, you know."

Community gossip

"They're just spreading the story and it's becoming like having wings."



Newcomers from India

Belief in the supernatural and fake doctors and that natural remedies can cure TB

Lack of factual information about TB compounded by the spread of inaccurate information about health and healthcare that is accepted as "factual"

People who have had TB are viewed with less respect than people who don't have TB

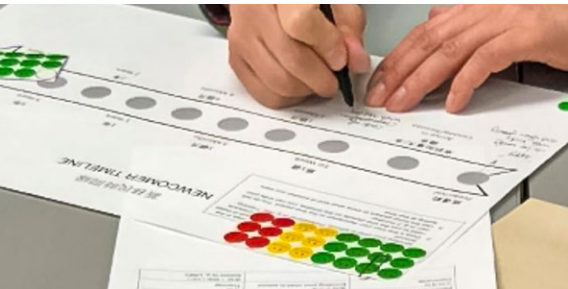
"People will see people differently if they've had TB, they are tainted."

Fear/caution about catching TB

"I think, irrespective of whether you're educated, if you're aware or not....I know TB is curable, I've seen someone with TB getting cured and living fine but if I see someone with TB I will restrict myself from being in contact with that person, it's not like I'm ethically or personally looking down on that person, I just want to prevent myself, I'm not going to treat the other person differently or look down upon them, nothing like that. I just want to protect myself so that I don't get affected."

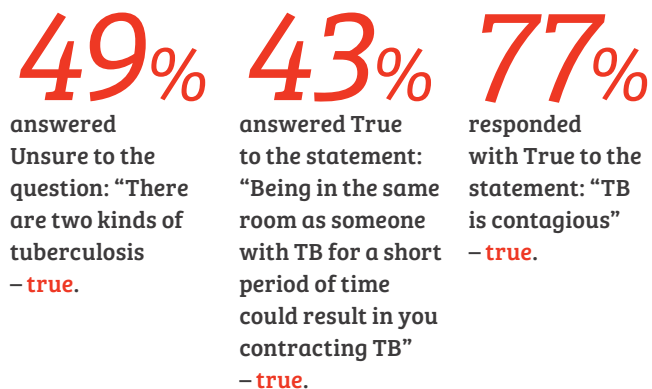
Gossip contributing to the spread of misinformation

How CRG Member Perspectives Differ from a Random Sampling of Torontonians



As a part of this project, 100 Torontonians were surveyed regarding their knowledge of TB. As a point of comparison, low awareness

and poor knowledge of TB was also found among this sample as demonstrated by responses to a series of *True/False/Unsure* questions about TB. For example:



Community Reference Group Recommendations

1. Education

A. Health Care Providers (HCPs) who provide care to newcomers, such as their own doctors or nurses, should be the primary source of TB-education, advice and care while acknowledging and valuing alternative cultural medicine approaches that they suggest. CRG members trust HCPs, particularly their primary care providers, for health information. Primary care providers should continue to use one-on-one visits with newcomer

clients to provide TB education, and emphasize to newcomers from high TB incidence countries the importance of TB screening and prevention.

B. TB-educational content for newcomers at-risk of LTBI needs to prioritize the following:

- Culturally-appropriate myths and misconceptions about TB
- Oral traditions (acknowledge newcomers' intergenerational stories and personal experiences)
- Difference between active and latent TB
- TB transmission (e.g. how TB is spread - not through cutlery or glassware)
- Relationship between BCG vaccine and TB skin test
- TB treatment for newcomers is free, but may need to pay out-of-pocket for diagnostic tests

C. Public figures (e.g. celebrities, politicians) should be featured in TB awareness/education campaigns. Showing public figures interacting with people who have TB can raise awareness and reduce stigma. Governments should work with respective MPs and MPPs, particularly those who are Indian, Chinese or Filipino, who serve communities with higher numbers of at-risk people, to be part of anti-stigma campaigns, to meet with people currently undergoing TB treatment and to speak publicly about the importance of preventing active TB.

2. Practice

All primary care settings and primary care providers should apply a cultural safety and care approach:

- Acknowledging client's knowledge, beliefs, attitudes, values and traditions and their interpretation of illness and wellness
- Validating the client's experience with poverty and discrimination and the impact of these on their ability to access and utilize health resources
- Promoting client autonomy and counseling clients regarding their rights to access treatment
- Safeguarding client confidentiality

What We Learned from the Settlement Sector



Health is a Settlement Issue

The Current Landscape

In Toronto, there are over 50 organizations that provide settlement services for newcomers. Settlement agencies are mandated to facilitate the full and equitable participation of newcomers in Canadian society. They help newcomers find housing, employment and childcare, complete forms and applications, provide language classes, orientation programs and skill-building workshops. They are

often the first points of service access, connecting clients to government and community resources, programs, and services, including health services.

Settlement Agency Reference Group (SARG) participants consistently noted that healthcare often slips through the cracks in newcomers' priorities. They note that newcomers are first and foremost focused on earning income and securing affordable housing. In terms of timing, newcomers tend to address housing and

employment needs within the first one to two months of their arrival in Canada, then turn to address their health-related needs in the third month and onwards.

SARG participants agreed that connecting clients to continuous, ongoing primary care is a priority in the settlement sector. One manager in the SARG stated, *“it's very important. We make referrals but we want to make sure the referral is appropriate and that the client actually went to get services. So follow up is very important”*.

At the same time, SARG participants agreed that TB is not a priority for newcomers, and consequently, is also not prioritized by settlement service providers. Considering this, it is unsurprising that frontline settlement workers and managers tend to have low knowledge of the two types of tuberculosis, how tuberculosis is transmitted, and implications of receiving the BCG vaccine.



“I literally had to Google [tuberculosis] when you sent me that email.”
—Settlement worker

“In my 13 year experience, I haven't seen anyone asking about TB.”
—Settlement worker

Gaps and Challenges

TB Knowledge/Understanding of Medical Surveillance

Managers and frontline employees from the settlement sector acknowledged their low awareness and knowledge of TB and identified a need for education in this area. Additionally, SARG participants pointed to tuberculosis as a low priority for their clients. At the same time, they noted that their clients are often confused about medical surveillance requirements and are not aware of the policies, procedures, and processes associated with medical surveillance. Participants noted that clients may need to report to public health as part of the medical surveillance process, but because they do not understand the process or were not given adequate information about the process, they are not sure about how to proceed and ultimately do not report to public health.

SARG participants stated that settlement workers in general are also lacking knowledge about the medical surveillance process, requirements, and implications of not complying with medical surveillance, and as such they are unable to fully support newcomers with medical surveillance questions. SARG participants did express interest in enhancing their knowledge about TB and medical surveillance to be able to better direct clients to appropriate resources. They also advocated for the inclusion of health-related information on the IRCC website to help educate newcomers on what to expect from the healthcare system and medical surveillance prior to arriving in Canada.

Newcomer Access to Settlement Services

Settlement workers and their managers noted that many newcomers are not connected to settlement agencies or workers. One manager noted, *“They go to church for support or to their families and friends or to other social organizations. So we don't know what kind of support they're getting”*.

Settlement and Community Health Sector Collaboration and Partnerships

A lack of information sharing between the settlement and health sectors was reported as a gap by project participants, all of whom agreed upon the need for improved collaboration between the two sectors. Health information sessions and onsite health screening were just two opportunities identified for enhancing health settlement collaboration. One manager stated, *“It would be nice if there were more health resources (staff) available to interact with the clients themselves. It’s always good to have the expert in the room with the people... and they can build those relationships.”* SARG participants noted that partnering with health agencies would help to increase the level of knowledge and information available for both settlement staff and newcomers to draw upon.

Referral Structures and Information Resources

The settlement sector relies heavily on having up to date information and good referral pathways to primary care. Settlement workers often refer to the Ontario website, Health Care Connect, a repository of family physicians and nurse practitioners who are accepting patients in the community. SARG participants noted that the site is often outdated. They also suggested more availability of health information resources in clients’ preferred languages.

Funding Model

Inadequate and highly prescriptive funding emerged as a challenge in the settlement sector, especially among managers. SARG participants noted that the types of funding they receive comes with strict limitations on the services they are able to provide and who can receive those services meaning that some people may do without access to needed services. Participants explained that federal eligibility criteria prevents settlement agencies from providing services to people without an official immigration status. As such settlement agencies are limited in their capacity to serve many newcomers who may in fact be at greatest risk for TB and other health issues. Managers and

settlement workers regularly advocate for program and service enhancements to improve service delivery and enhance collaboration. They also noted the importance of providing pre-arrival services to newcomers in their home country, prior to arrival in Canada, to enhance their knowledge about the Canadian health care system and to promote their full and equitable participation in Canadian society.

Health Insurance

Settlement workers’ ability to link recent newcomers to health resources is limited due to the three month waiting period for OHIP. Further, many newcomers, particularly those who are unemployed or precariously employed, do not have access to healthcare benefits and struggle to afford basic health needs such as prescriptions. Feedback from SARG participants validates much of the research that has shown how a lack of access to health insurance means that newcomers delay seeking care, ultimately leading to greater health care needs down the road.



“Newcomers have a waiting period (for OHIP) ... there’s a waiting list for appointments (for free services) ... so if they’re sick and need to go to the emergency, but can’t pay, they will wait.”
–Manager

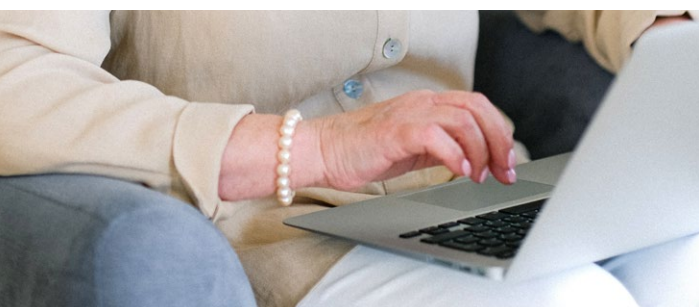
Settlement Agency Reference Group Recommendations

1. Education

A. When providing TB education to settlement workers, content should address the following:

- Difference between active and latent TB
- TB transmission (e.g. how TB is spread)
- Relationship between BCG vaccine and TB skin test
- Medical surveillance (MS) requirements and processes

B. Education for managers and settlement workers should be provided as a part of existing knowledge-sharing platforms that are already well attended by members of the settlement community (e.g. conferences, mandatory employer training). Information should focus on the basics of active and latent TB and additional resources for where to direct clients should be provided.



2. Practice

A. Settlement agencies should review all of their service offerings, including LINC programs, to identify opportunities to integrate information about TB and health care. Where feasible, settlement agencies should partner with health care providers to enhance the provision of TB and health information and education.

B. The settlement and health sectors should identify and pursue opportunities to leverage and enhance existing resources to better connect these two sectors.

One existing infrastructure that can be built upon is the Refugee HealthLine. This is a Ministry of Ontario funded initiative to connect refugees to healthcare providers for transitional healthcare services. Similar to Health Care Connect, healthcare providers can register and indicate the number of refugee clients they can accommodate in their practice. This line would be accessible to refugees and settlement-related agencies. The Refugee HealthLine could be expanded to include other marginalized groups including under-insured populations. The goal of this initiative would be to connect vulnerable individuals with providers who have more experience and understanding working with socially and medical complex clients.

3. Policy

A. IRCC should provide healthcare and settlement providers with written information about the Immigration Medical Exam (IME) and Medical Surveillance (MS), in multiple languages, to disseminate to their newcomer clients. This information should include:

- Definition and purpose of IME and MS-related tests and assessments
- Costs of completing IME and MS-related tests
- Emphasize that a normal chest x-ray does not mean you do not have TB infection
- Difference between active and latent TB

B. Provincial Ministries of Health and/or Health Canada should collaborate with IRCC to invest in improving/enhancing TB/health information and services offered through pre-arrival and settlement agencies. Priority investment opportunities:

- Improve the welcome package so that it includes TB/health information
- Incentivize collaboration between settlement agencies to increase the distribution of welcome packages to newcomers upon arrival, and
- Revise the provincial orientation workshops to include information about TB and other health issues

What We Heard from Health Service Providers



Reshaping TB Care is about Reshaping Health Care

The Current Landscape

In comparison to other provinces such as Alberta and British Columbia, TB care and services in Ontario operate in a decentralized system. A number of different clinicians and agencies provide care to TB patients, there are gaps in patient care, funding for TB programs lacks consistency and while TB is reportable to public health, front-line providers and public health units work quite autonomously.

As such there are often misconceptions and lack of knowledge about the role of public health in supporting TB care. These challenges, echoed by the primary care reference group (PCRG), have huge implications for TB screening and treatment uptake. Furthermore, not all primary care providers have experience managing TB due to the low incidence rates and, as one health care provider puts it, “it’s a very niche speciality”.

Gaps and Challenges

Immigration Medical Exam, Medical Surveillance and TB Screening

All permanent residents and refugees are required to undergo an Immigration Medical Exam (IME), during which they are screened for TB and other illnesses that pose a public health risk. IMEs can be conducted either in Canada or in the applicant's home country by a panel physician designated by IRCC. This is the first point of contact that a newcomer has with the Canadian healthcare system, however, because newcomers seem to receive very little information from IRCC and panel physicians who conduct IMEs, this process is a source of confusion, frustration and fear for newcomers.

Following the IME, newcomers who require additional follow-up for TB must connect with their public health unit to undergo the TB Medical Surveillance (TBMS) process. Depending on the urgency of the follow-up, newcomers have anywhere between 7 and 30 days to get in touch with their local public health unit following the IME or upon arrival in Canada. Newcomers then have an additional 3 months to complete the tests required as part of the TBMS. Like the IME, newcomers and primary care providers expressed that this process is also confusing, frustrating and fear-provoking, particularly for newcomers who do not speak English. HSPs recommended better communication and transparency between the IRCC, healthcare providers and newcomers, particularly regarding IME and TBMS requirements and processes.

Although some newcomers are screened for TB during their IMEs, most are only screened for the "infectious" form, that is active TB. This practice is not consistent with recommendations from the Canadian Collaboration for Immigration and Refugee Health (CCIRH) and the Canadian Tuberculosis Standards 7th edition which suggest that there should be targeted latent TB screening for select high-risk groups (Pottie, et. al., 2011; Menzies, et. al., 2014). The CCIRH recommends latent TB screening for refugees coming from countries with



high TB incidence as soon as possible after arrival. The Canadian TB Standards classifies the development of active TB into risk categories, with the highest risk among those who have recent TB infection, HIV status and abnormal chest X-rays (Greenaway, et. al, 2014). These recommendations identify that refugees are at a two-fold risk of developing active TB when compared to immigrants who are both within the first 5 years of arrival due to barriers in accessing and navigating the healthcare system and the stressors during the resettlement process (Pottie et al. (2011)). Both active and latent TB are reportable diseases under the Health Protection and Promotion Act, however latent TB cases are disproportionately underreported. This can be attributed to the lack of latent TB screening, and the underreporting of cases by primary care providers when their clients refuse prophylactic treatment. HSPs agreed that both active and latent TB screening, particularly in high-risk groups, should be routinely conducted.

Diagnosis and Treatment

According to HSPs, one of the main barriers they face in supporting newcomers with TB diagnosis and treatment is fear about the impact of a TB diagnosis on their employment and on their immigration status. Public health nurses shared numerous stories and spoke about the fear expressed by clients who worry about losing their jobs and subsequently housing and immigration status because of TB.



In addition, HSPs identified unique challenges that deter newcomers from starting and completing treatment. First, the TB Skin Test (TST), which is the most commonly used diagnostic test, requires that a client make two separate visits to their healthcare provider, at least 48-72 hours apart, to complete their diagnosis. This presents a barrier to those newcomer clients who are unable to take time off work or who experience barriers to travel. Further, traditional latent TB treatment can require a client to take medication daily for up to 9 months, with regular follow-up appointments with a primary care provider throughout treatment. As discussed earlier, newcomers can be consumed with many competing priorities during their settlement journey, including employment, housing, legal, English language acquisition, transitioning children to schools, etc. For many newcomers, it is not practical to prioritize personal health needs. Further, primary care providers who do not have experience with TB lack the knowledge and experience needed to help their clients, particularly non-insured clients, to navigate TB care.

Immigration Context

During what is often a long and daunting immigration process newcomers receive a significant amount of information from many different sources. They may not understand the importance of TB or may not feel the need to prioritize TB during this time. Newcomers who do not speak English face additional challenges accessing, understanding and prioritizing TB information. Primary care providers and public health nurses agreed that many newcomer clients do not understand how their TB status affects their immigration case or status. They shared stories about newcomer clients trembling and crying in their offices after learning that they need to undergo further investigations to complete their TBMS.

When considered in isolation taking a TB test may not seem like an unreasonable task. However, the newcomer context is unique. Newcomers to Canada may not be able to speak English or French the languages in which they would be receiving health information, they may have few social contacts; they may be consumed with securing basic necessities like housing, employment and food, and may be navigating the school system for their children.

Being asked to complete numerous tests for TB provokes anxiety for many newcomers, first because TB is associated with suffering and death in their home country, and second because of the deep fear that any delay in obtaining TB clearance will jeopardize their immigration status. Given all of this, the complexity surrounding the TB experience for many newcomers simply heightens the vulnerability they experience during their settlement journey.

HSPs agreed that connecting newcomers to primary healthcare as soon as possible after arrival can help to address misconceptions about TBMS. Newcomers who are connected to primary care, particularly at community health centres that offer interdisciplinary care and language interpretation services can ensure that newcomer clients receive comprehensive high-quality healthcare in which TB care is just one aspect of their well-being.

“I’ve always felt that people should be connecting to primary care, in terms of refugees. People should be connected to primary care within that first month of arrival. And that’s sometimes a tough sell and that’s a tough sell because there’s a lot of competing priorities ...”

—Physician, Refugee Health

Health Service Provider Knowledge

Due to the low incidence of TB in Canada, many primary care providers rarely see cases of TB in their everyday practice. The majority of TB cases are seen and managed through specialized TB clinics, immigration panel physicians, public health and/or primary care providers who serve the immigrant and refugee populations. Providers with limited exposure to TB may perpetuate misconceptions about TB; they may not understand the intricacies of TB management or that TB treatment is free for newcomers, or they may not know how to provide care to newcomers who are not insured or under-insured. As a result, TB clinics which are meant to handle complex TB cases, are often inundated with inappropriate referrals and requests from primary care providers who are inexperienced in TB, do not want to manage clients without insurance, or feel that latent TB care and treatment is too time consuming and labour-intensive.

“It takes like a PhD to figure [it] out – how to enroll someone in TB UP, how to get forms from TPH, how to order medication. And that’s all invisible work that the clinician is not billing for. If I was a primary care provider – to really treat the TB infection – it’s just easier to refer on [to specialists].”

—Nurse Practitioner, TB Clinic

Stigma

HSPs agreed that TB-related stigma exists among healthcare providers regardless of their familiarity with TB. Many primary care providers automatically

think of active TB when they hear the word “TB”, and as seen in the quote, active TB invokes feelings of fear due to the infectious nature of the disease among healthcare providers.

“Many times I have physicians call me [and say]: ‘patient has an abnormal X-Ray and the radiologist can’t rule out TB. I don’t want them here. I don’t want to see this patient, I don’t have the capacity! You got to take care of it!’ There’s stigma very much in our health care providers when it comes to TB. And it’s fear. TB, again, makes very rational people completely irrational and just melt.”

—Nurse practitioner, TB clinic



Collaboration

Echoing the statements made by SARG participants, a common theme expressed by the HSPs is the lack of communication and collaboration between different sectors involved in newcomer health care. Project participants from Toronto Public Health proposed increased collaboration between public health, the settlement sector and other newcomer serving sectors. They encouraged frontline settlement workers to inquire about their clients’ need for TB follow-up and improved communications with public health.

Public Health Programs

Budget cuts to public health units have resulted in a reduction in TB services and programs. For example, Toronto Public Health's TB outreach team used to conduct TB education at ESL/LINC classes. These were ideal locations for TB education because the students were newcomers often from high risk countries. Further, students were engaged in the material because TB information was delivered in a practical format whereby students enhanced their English language skills while learning about TB.

The TB-UP program, funded by the Ministry of Health, provides coverage for TB screening, diagnostic tests and physician care for non-insured and under-insured newcomers. Unfortunately, HSPs stated that there is a lack of awareness about this program among primary care providers, and further that the program is difficult to navigate as public health regions across the province do not apply the program consistently.



Health Insurance

Historically, a significant barrier to healthcare access for newcomers has been the 3-month waiting period for OHIP. Although the TB-UP program offers coverage for TB-related care and services to newcomers without insurance, a newcomer's access to the TB-UP often depends on whether their primary care provider has knowledge of the program. Further, once a newcomer secures OHIP, they are still not covered for all of the diagnostic testing that is required for latent TB.

There are two methods for latent TB screening: the TB skin test (TST) and the Interferon-Gamma Release Assays (IGRA). The TST is an established diagnostic

test that can determine if a person has ever been exposed to the TB bacteria, however, there is high potential for inaccurate results. The IGRA test, on the other hand, is a much newer blood test that many TB clinicians have suggested be used instead of the TST. Unfortunately, the IGRA test is not covered by OHIP, and commonly costs about \$85. According to one TB expert who participated in this project, IRCC recently introduced changes to the IME process making mandatory IGRA testing for all applicants who are medically at high risk for TB, including individuals who are in contact with an active TB case; HIV positive; have end-stage renal failure, head and neck cancer, or who are transplant clients. Individuals who come from a high TB incidence country are not included in the inclusion criteria which severely limits the accessibility of latent TB testing for economically, socially and medically vulnerable newcomers.

Health Service Provider Recommendations

1. Education

Provide education and training for staff who are client facing and in support roles in relevant settings and organizations. Doing this would improve awareness of TB related discrimination and stigma as well as their knowledge of TB. The result could/would be better practices to support newcomers and their families who experience multiple and intersecting stigmas. And, at the same time remain attentive to the unique needs of newcomers who are living with or at risk of living with TB. Minimally, all service providers should have an understanding of active and latent TB and be knowledgeable about local referral resources. Specific to the Toronto context, the Lung Association and Toronto Public Health should create an updated version of the LTBI Quick Reference Guide and circulate it to all newcomer serving and primary care providers on a regular basis.

2. Practice

A. All primary care settings that serve newcomer clients should implement measures to deliver TB services and supports in settings that are accessible for clients. This includes:

- Providing access to interpretation and translation as a customer service standard for care and support to systemically vulnerable populations as well as service availability in both official languages.
- Providing flexibility in terms of access to related services outside of standard business hours of operation particularly in relation to treatment and support.
- Ensuring that longer appointment times are available for clients with complex needs, and
- Creating physical spaces and environments that foster inclusion through use of pictures that feature diverse populations, LGBTQ2S+-friendly stickers, toys for children etc.

B. All primary care settings that serve newcomer clients should implement measures to deliver client centered and culturally competent TB care and services that intentionally combat TB-related discrimination and stigma. This includes:

- Acknowledging client's knowledge, beliefs, attitudes, values and traditions and their interpretation of illness and wellness
- Validating the client's experience with poverty and discrimination and the impact of these on their ability to access and utilize health resources
- Promoting client autonomy and counseling clients regarding their rights to access treatment
- Safeguarding client confidentiality
- Including TB literacy to promote self-management
- Providing family education and counseling

C. Create and implement an evidence-based LTBI clinical pathway for use in community based multidisciplinary primary care settings to improve clinical decision-making at the point of care, the

quality of patient care and clinical efficiency. In the Toronto context, an LTBI treatment algorithm could be added to supplement the Quick Reference Guide.

D. Improve coordination and collaboration between public health, primary care and settlement service providers to better support newcomers and newcomer families who are living with or at risk of acquiring TB.

3. Policy

Eliminate financial barriers to primary care services so that newcomers can access the services and supports needed to prevent or treat TB. In Ontario, this means eliminating the three month wait for OHIP for landed immigrants.

Tools and Resources

These are useful tools that were used or identified by the Tackling TB Stigma project.

➔ This web page by Toronto Public Health includes general information about tuberculosis, facts about the disease and resources for screening, testing, and treatment toronto.ca/community-people/health-wellness-care/health-programs-advice/tuberculosis-tb

➔ This infographic provides common myths and misconceptions about tuberculosis peelregion.ca/health/tb/pdfs/common-myths-surrounding-tb.pdf

➔ This web page is an international repository of tuberculosis resources stoptb.org/resources

➔ This web page provides general information about tuberculosis and links to Canadian tuberculosis resources canada.ca/en/public-health/services/diseases/tuberculosis

Our Vision for Tomorrow



Equitable, Ongoing, Team and Community Based Primary Care

Notably, this project sought to explore TB-related stigma experienced by newcomers with a focus on people who had immigrated from India, China, and the Philippines. We engaged with a number of key groups to understand that experience including people with lived experience, healthcare professionals, settlement agencies, and members of the general public.

Our discussions and interactions with these groups found that the current practice and pathway for TB care and support can and must be improved. The current state of TB care and support does not fully take into account the settlement journey of new populations nor does it consider how stigma and the broader determinants of health impact access to TB care for newcomers.

The project confirms that stigma is complex and has a negative impact that can be best understood within a determinants of health framework that takes into consideration the intersections of stigma played out in the current state of TB care and support. To move closer to a future state in which newcomers have access to a coordinated continuum of community based resources

and interdisciplinary health care that is evidence based, culturally competent and grounded in equity, requires a system wide intervention composed of education, training, practice, and policy change.

Moreover, the project calls for a future state that supports newcomers who have or are at risk of contracting TB to be able to successfully navigate stigma free settlement process and with timely access to interdisciplinary team based primary care and support that addresses their health issues from a holistic model of care. Public health and specialist care would be well connected and accessible within this care and support pathway.

Furthermore, the improved future state would emphasize TB awareness and knowledge among primary care providers, settlement workers, the general public and newcomers from high-incidence countries; enhancing competencies among settlement and health service providers for effectively and equitably working with diverse newcomer populations; and strengthening the relationships and collaboration between IRCC, settlement, primary care, public health and specialists in order to streamline information sharing and referral pathways.

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The Project Advisory Committee

Alliance Alliance, Cliff Ledwos

Alliance for Healthier Communities, Sané Dube

Canadian Association for Community Health Centres, Scott Wolfe

Change Foundation, Yinka Macaulay

JobStart/Toronto West Local Immigration Partnership, Yasmine Tian

The Neighbourhood Group/Toronto Local Immigration Partnership, Paulina Wyrzykowski

Toronto Public Health, Elizabeth Rea

Toronto Public Library, Craig Todd-Langille

University Health Network Open Lab, Shoshana Hahn-Goldberg

Warden Woods/Toronto East Local Immigration Partnership, Isobel Goddard

York University, Amrita Dafarty, Tania Xerri

Access Alliance Tackling TB Stigma Project Team

Access Alliance Multicultural Health and Community Services:

- Cliff Ledwos
- Gurjit Toor
- Jessica Kwan
- Shafeeq Armstrong
- Tujuanna Austin

Project Management:

- Sonja Nerad, SN Management

Volunteers:

- Yvonne Su and Sarita Pandit

The Primary Care Reference Group (PCRG) participants

Parkdale-Queen West CHC: Ann Michele Daniels, Falko Schroeder

South Riverdale Community Health Centre: Dr. Angela Wong, Danielle Kenyon

Toronto Public Health: Anita Yellapah, Elizabeth Hoang, Lilanath Pandey, Maria Cecilia Serquina Marilou Noack, Sally Suen, Shyam Shrestha

Unity Health Toronto/St. Michael's Hospital, Julie Seemangal

University Health Network/Toronto Western Hospital: Andrea Ackery-Moore, Judith Lang

Women's College Hospital Crossroads Clinic, Dr. Meb Rashid

The Settlement Agency Reference Group (PARG) participants

Catholic Crosscultural Services, Monica Zheng

Culture Link Settlement and Community Services: Maria Guiao, Lisa Randall

Dixon Hall Neighbourhood Services, Catherine Skene

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Tackling TB Stigma

Developing a cross-sectoral approach to reducing tuberculosis (TB) stigma and improving TB care for vulnerable newcomer populations in Canada

TB information resources are available in multiple languages at RIOMIX.ca. Enter as guest and type “tb” in the keyword search field. New materials are being added each week so please check back in for more TB resources and other health related materials.

For additional project materials, including Settlement Service Provider, Health Service Provider and Policy Maker Fact Sheets, please see: accessalliance.ca/tacklingTBstigma

Access Alliance Multicultural Community Health Centre
340 College Street, Suite 500, Toronto ON M5T 3A9
Tel: 416-324-8677
Email: TalkToUs@accessalliance.ca

Connect with us:

