From Evidence to Advocacy

Hard-core research to 2-min elevator pitch
….and the full knowledge management loop in between

NAR workshop
22 Feb 2023

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Objectives

- Be able to use non-stigmatizing language in communicating their research findings to wider audiences

- Be aware of different ways and formats to disseminate research findings to various stakeholders: Examples from Stop TB Canada's advocacy outputs

- Understand the importance of engaging TB survivors throughout the research process (not as an afterthought!)

Outline

1. The Theory: from evidence to advocacy (10min)
   - Overview of various communications components: data-advocacy-etc
   - Case-story TBPPM Learning Network

2. The Language (10min)
   - Words Matter
   - Stories and experiences

3. The People (10min)
   - Engagement of TB survivors and communities
   - Engagement of researchers
   - Engagement of TB professionals and implementers

4. The Practice (10min)
   - Case-study: Stop TB Canada's COVID19 report: data-to-advocacy
   - Case-study: Engaging TB survivors in research

5. Call to Action (1min)
   - Interest in researcher engagement framework
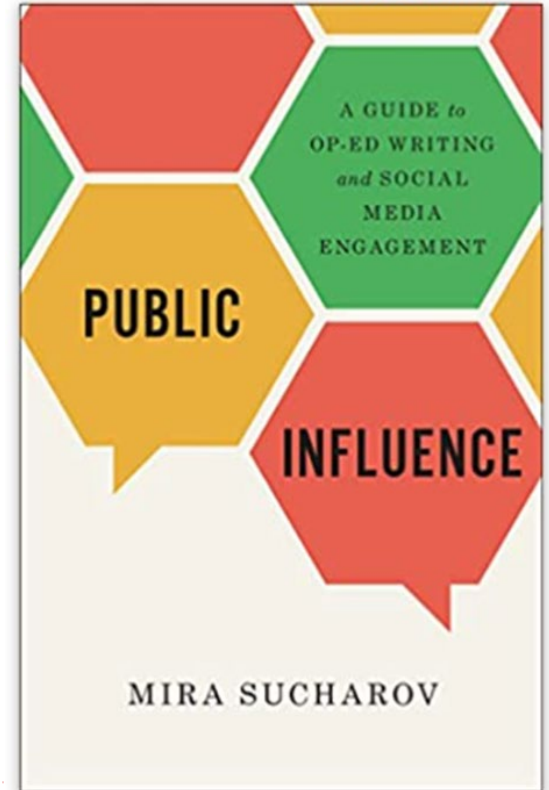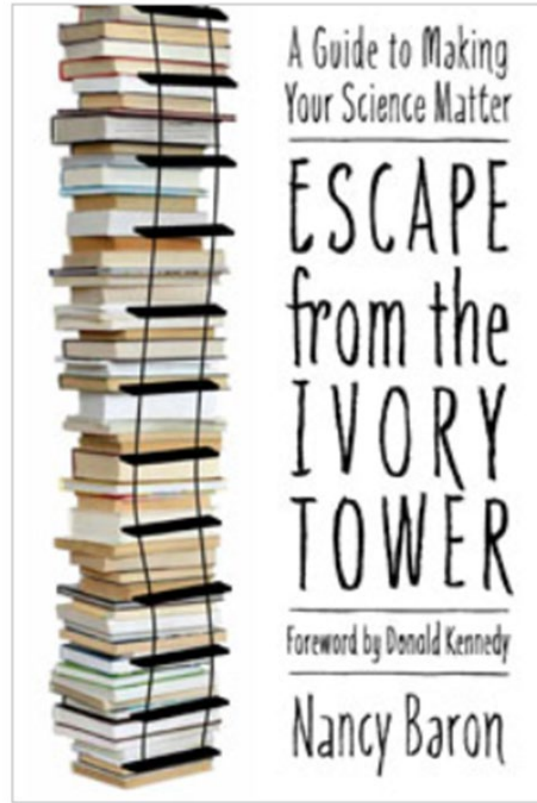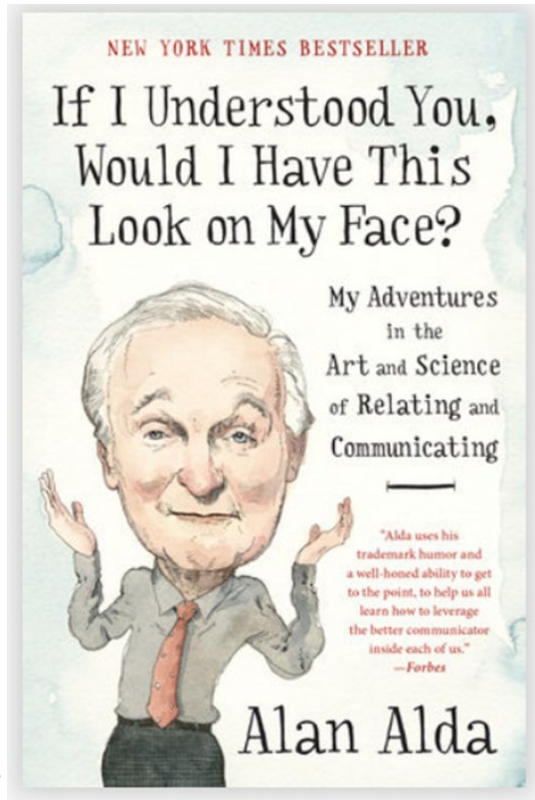   - What is ONE thing you will do to take your work from evidence to advocacy

Introduction:

3 perspectives, 1 goal!

"People love to hear from academics, but not academic information"

The Theory: From Evidence to Advocacy

Knowledge translation: moving research (from the laboratory, the research journal, and the academic conference) into the hands of people and organizations who can put it to practical use.

- a dynamic and iterative process that includes synthesis, dissemination, exchange and ethically-sound application of knowledge
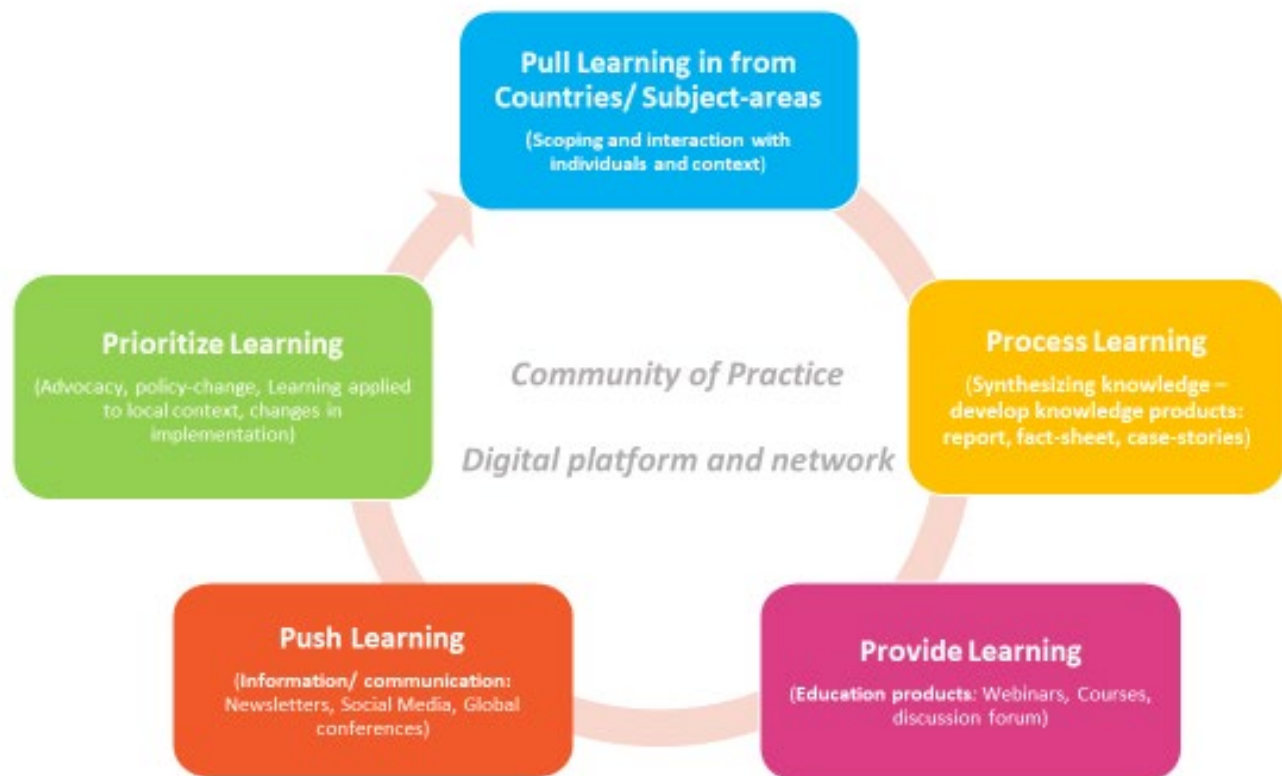
Key Questions to guide knowledge translation:

- *Message:* What should be transferred?
- *Audience*: To whom should research knowledge be transferred;
- *Messenger*: By whom should research knowledge be transferred;
- *Means/ channel:* How should research knowledge be transferred;
- *Purpose/ Outcome:* With what effect should research knowledge be transferred?

1 research question
2 research planning & design
3 data collection & analysis
4 tailoring & telling others about results
5 changing practice
6 re-evaluate & sustain knowlege

Knowledge Creation
Knowledge Action

Research vs Advocacy silos

	Science	Advocacy
Message	Fact & number based	People & story based
Audience	Scientist, researchers	Politicians
Mindset	Questioning, abstract	Election, power and outcomes
Messenger	Journals, articles, manuscripts	Verbal, opinion pieces, fact-sheets, speeches
Skill	Data analysis, build evidence	Political spin, investment
Outcome	Create knowledge, evidence	Commitment, action, funding
	'More is better'	**'Less is more'**

Comprehensive system of knowledge and empowerment

Pull Learning in from Countries/ Subject-areas
(Scoping and interaction with individuals and context)

Process Learning
(Synthesizing knowledge – develop knowledge products: report, fact-sheet, case-stories)

Provide Learning
(Education products: Webinars, Courses, discussion forum)

Push Learning
(Information/ communication: Newsletters, Social Media, Global conferences)

Prioritize Learning
(Advocacy, policy-change, Learning applied to local context, changes in implementation)

Community of Practice

Digital platform and network

Collaborators
Researchers
Subject experts
Subject/ Data
Lived experience
Partners

Based on TBPPM Learning Network framework: www.tbppm.org

Data: Action in countries and Community members
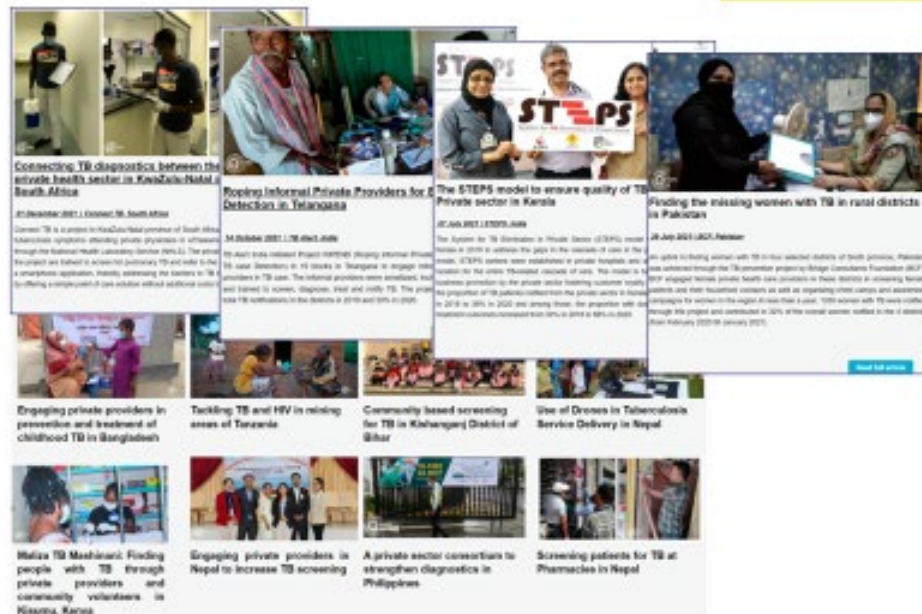

Where do data and evidence come from?

- Key experts are the implementers and community on the ground.

- Grassroots voices are central

- Build an enabling environment with people at center

- Equitable partnerships

Pulling learning in: Data and evidence are not just based on research, but also on practice and experience

Process learning from data and practice

Synthesize information

- Extracting the lessons from different implementation experiences and innovations

- Tailored product and styles (variety of 'languages')

- Amplify lessons learned and Inspire others around the world

Products: Features stories, Case-studies, Stories, Fact-sheets, practical illustrations and infographics

Knowledge Management– Understand, synthesize, own lessons

Knowledge Products:

- Information outputs
- Webinars
- Discussion Forums
- Cross-learning
  - Peer-to-peer
  - Country exchange
- Learning
  - Courses
  - E-learning platforms
  - Workshops
  - Leadership track

Information- Outputs

Knowledge Management: Tailoring quality information (webinars, publications, articles, blogs) - inspire action with audiences

Community Information:
Push information out and influence global agenda

Newsletters, email-digests, mailings to members

Social Media platforms

Conferences

Community Information: Increase the visibility in a variety of platforms, social media and in the overall global health space

Prioritize Learning – Advocate, policy change, practice change

- Understand and map the local context and stakeholders
  - Politics, governance, culture
  - Where is the power (decision-making, funding, implementation)

- Knowledge translation: tailor evidence into actionable products

- Network and build coalitions of influence
  - Involve multiple stakeholders
  - Communication is key
  - Enthusiasm, creativity and energy!

Evidence into Action: inclusive process leads to empowered individuals and a sustained outcomes

The Language: Words Matter
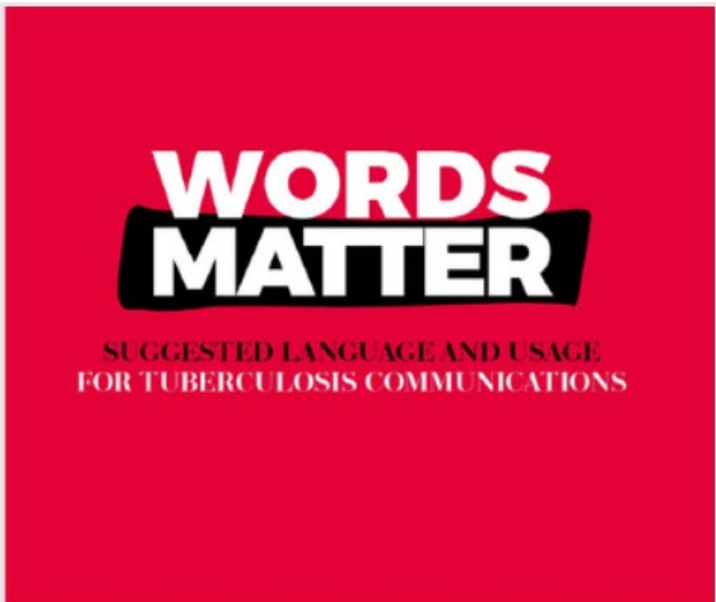
WORDS MATTER: A RESEARCHER'S OBLIGATION TO THINK BEFORE SPEAKING.

By: Carly Young   October 12, 2022

https://www.stoptb.org/words-matter-language-guide

https://newtbvaccines.org/words-matter-a-researchers-obligation-to-think-before-speaking/
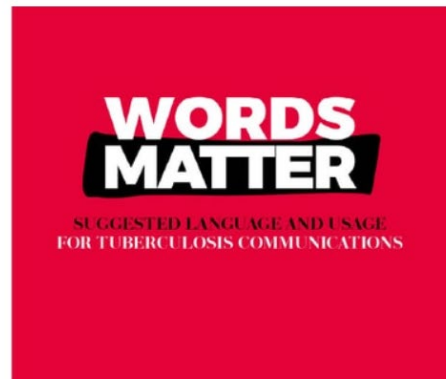
People with TB are… people.

- The most important thing to remember as a general rule is that we are talking about a PERSON, or PEOPLE outside of the context of the bacteria that might be inside them.

- It's best to start off with recognizing the person first. "Person being treated for TB" or "Person in TB treatment" sounds better than "TB Suspect" / "TB Patient". Exception is "TB Survivor".

STOP USING WORDS ASSOCIATED WITH CRIME OR CRIMINAL INVESTIGATIONS.
JUST STOP.
DO IT TODAY.

- In the USA, TB care is managed and monitored by the state. People have widely different experiences with state agencies.

- Having state agencies looking into your family's connections, living situation, employment, etc. can mean different things to different people. It can be stigmatizing or worse.

- Suspect. Investigation. Case. We can do better than this!

- Think about words like "Compliance" or "Adherence". That puts a lot of blame on the person getting the TB treatment… often the very vulnerable, sick person.
- Did they fail to adhere to treatment or did they have a lack of available nutrition? Were their side effects responded too, explained and managed?
- Were they "Non Compliant" or did your program fail to communicate why treatment was so important?

People in TB treatment rarely receive the full support they need. Financial, social or emotional.

The people: Engagement of TB survivors & communities

Personal stories and experiences have power and impact that data just doesn't.

It's really not that hard!

- There are more networks of people personally affected by TB than ever before. Active, growing networks. Most of them are on Facebook or Twitter. Most of us know of each other to some degree.
- Ask yourself why you are doing research on TB at all. Isn't it for these people? Engaging us should be a priority and it should inform how you plan your work from the start.

Things to think about

- How can you get things translated?

- How can you get people paid or recognized?

- Are you REALLY open to hearing ideas that might challenge the way you are doing things?

- Are you really involving people in ways that are meaningful, where they have a chance to change outcomes?

TREAT THEM LIKE THE TALENT.

In television when we have special guests we do everything possible to make them feel appreciated and valued – and that includes paying them and making things easy for them. You can apply this with advocates and have great results!

- DO pre-pay for things, provide per diems and avoid reimbursements whenever possible.
- DO the bookings for people. Ask about dietary & other preferences.
- DO honor people's time and ask them to participate as early as possible.

- DON'T require people to spend their money upfront.
- DON'T require people to have their own credit card for hotel bookings. Don't assume people have Uber accounts, etc.
- DON'T assume that people can drop their caregiving or job related responsibilities last minute.

Talking about a traumatic time in your life, with a condition that's stigmatized, in a language that might not be your first, with STRANGERS – is hard and intimidating! Make the rest of the process as easy as possible.

The people: Engaging TB Researchers

Engaging TB survivors / TB affected community in research / TB professionals and providers

Evidence

Action

Collaborating with advocates, community organizations, TB survivors and TB professionals/ organizations to take action

The people: Engaging TB Researchers

Why engage TB researchers in **community-centered research**?
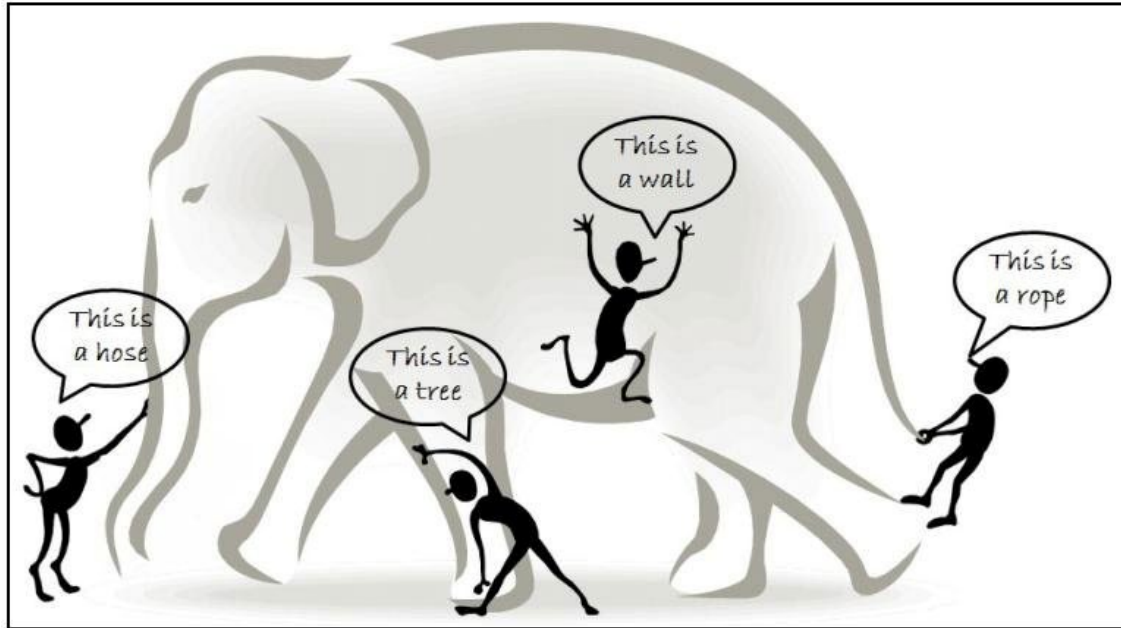
The people: Engaging TB Researchers

Why engage TB researchers in **advocacy**?

- Science communication, public awareness
- Greater impact if collaborating with community organizations / advocates etc. to bring issues to policymakers' attention
- Motivating to see research contribute to advocacy goals

The people: Engaging TB Researchers

Going from evidence to action: challenges for researchers

Community-centered research:

- **Lack of frameworks** / guidelines for engaging TB survivors in their research
  - How to reach out, how to seek input, standards for offering honoraria, etc
- **Lack of training** in academia on how to incorporate TB survivor perspectives into research (esp. if quantitative research area)
- **Timing** - reality of research process (grant applications, approvals, study implementation) often means TB survivors engaged too late in the process, when research questions and analysis plans are already set out

Advocacy:

- **Silos** - Advocacy often not seen as researcher's role
- **Lack of partnerships** / collaborative networks between academia and community / advocacy organizations
- **Communication** - lay language, gaining public /policymakers' interest
- **Processes** in the advocacy world unfamiliar to researchers (MP meetings, social media outreach, etc)

The people: Engaging TB Professionals and Implementers

Why engage TB professionals in research and advocacy?

- Data and evidence built on practice
  - TB professional or practitioners have data and evidence (practical data and dashboards)
  - Know what works and does not work?

- Advocacy needs evidence & practice
  - Illustrate data with lived experience and stories

- Engage grassroots voices to have research outcomes implemented and change practice

Professionals and practitioners bridge evidence and advocacy, even better when linked in a community
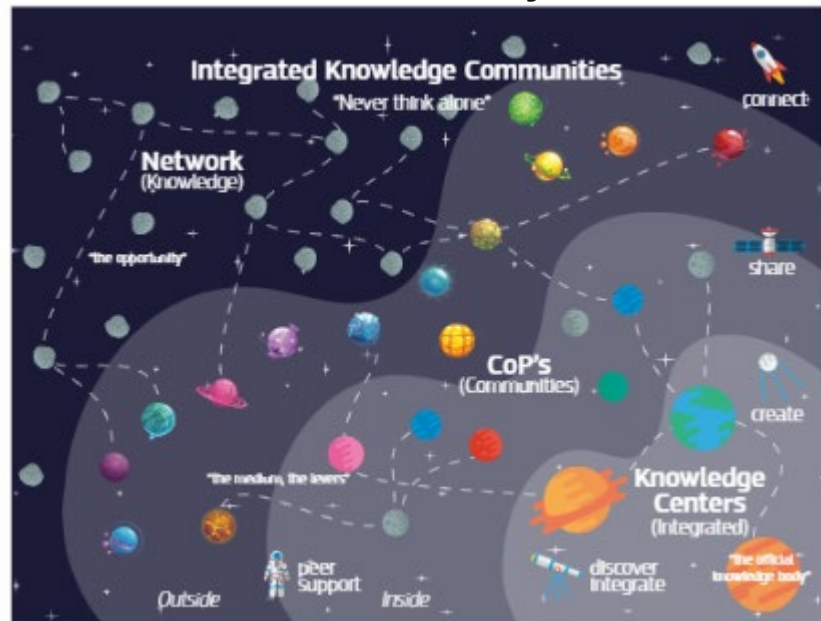
The Practice: Case-study - Stop TB Canada's COVID19 report

From data to advocacy

Problem

Identified knowledge gap

Data

Leveraged TB community network to collect data

Report

Collaboratively drafted report (including all Stop TB Canada steering committee members - researchers, healthcare providers, advocates, etc)

Advocacy

Used report as advocacy tool in meetings with policymakers

The Practice: Case-study - Stop TB Canada's COVID19 report

Problem

Identified knowledge gap
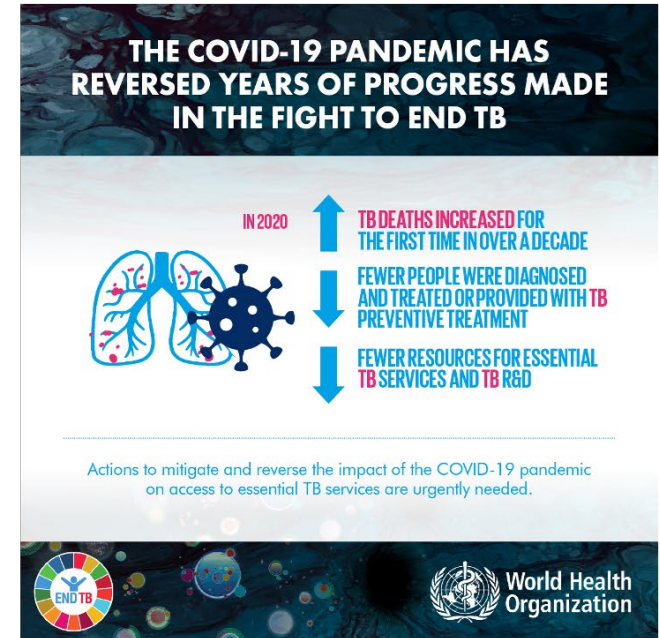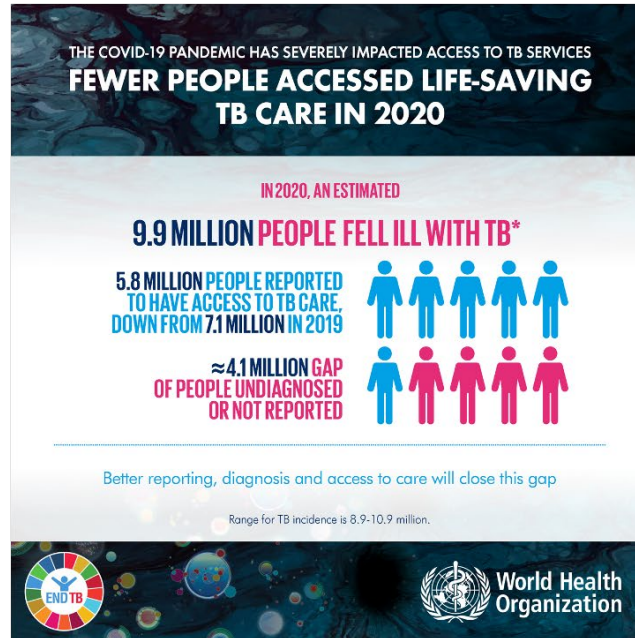
The Practice: Case-study - Stop TB Canada's COVID19 report

Data

Leveraged TB
community network
to collect data

Surveyed TB program leads, TB
staff, and people affected by TB
across Canada re experiences of TB
care disruptions
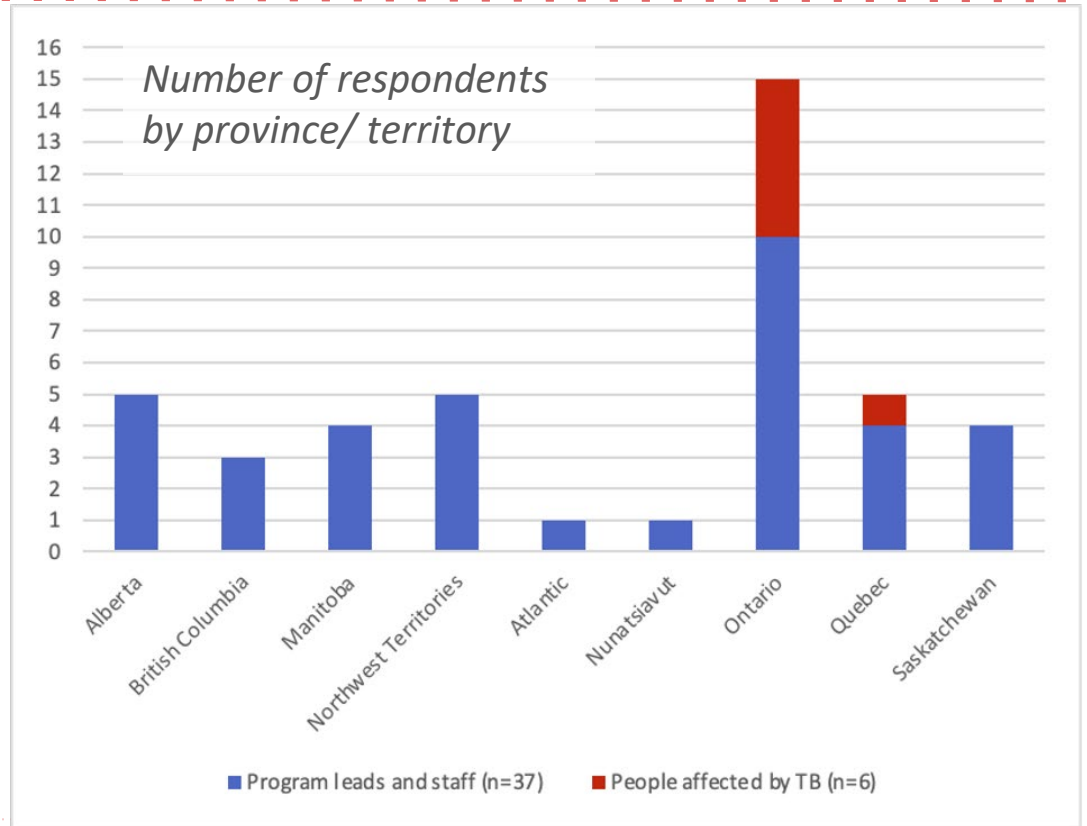
Number of respondents
by province/ territory

■ Program leads and staff (n=37)   ■ People affected by TB (n=6)

The Practice: Case-study - Stop TB Canada's COVID19 report

Report

Collaboratively drafted report (including all Stop TB Canada steering committee members - researchers, healthcare providers, advocates, etc)

STOP TB CANADA REPORT

THE IMPACT OF COVID-19 ON CANADIAN TUBERCULOSIS PROGRAMS

OCTOBER 2021

Full report here:
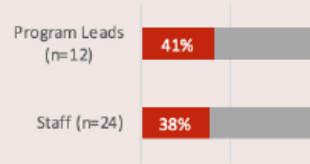https://www.stoptbcanada.com/resources/canada-specific
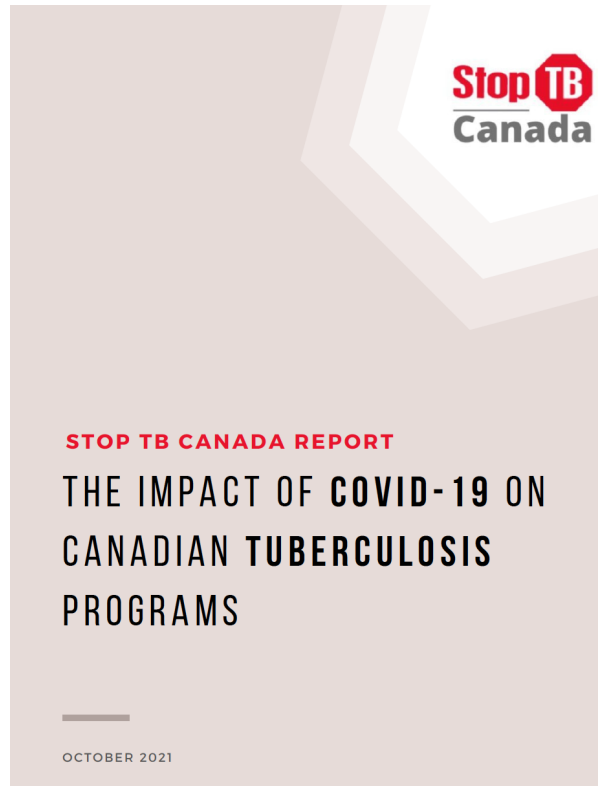
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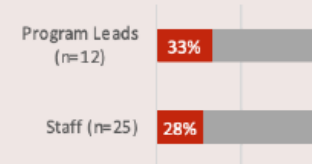
1. DIAGNOSTIC DELAYS:

41% of TB program leads and TB staff reported that **TB diagnoses were significantly delayed.**

Program Leads (n=12)   41%

Staff (n=24)   41%
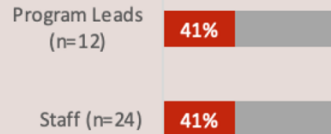
"...Classic case of pulmonary TB in an Elder who presented numerous times with pleurisy and cough over months and had three COVID-19 tests and no TB assessment or testing. [They were] finally picked up to have smear positive TB. [They] died during treatment."
~ TB program Lead

"Fewer screening opportunities are occurring; many [people] are coming to us when a person is seeing a significant decline in health."
~ TB staff

The Practice: Case-study - Stop TB Canada's COVID19 report

Report

Collaboratively drafted report (including all Stop TB Canada steering committee members - researchers, healthcare providers, advocates, etc)

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Report

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6. LATENT TB INFECTION MANAGEMENT:

LTBI care was deprioritized in the majority of provinces throughout the pandemic. Nearly **60%** of TB program leads and **68%** of TB staff reported that **LTBI treatment was significantly scaled-back** during the COVID-19 pandemic.
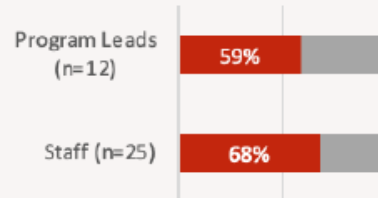
"TB elimination projects have completely stalled over the past 15 months due to COVID-19 reallocation of resources and people. Public Health Units have not been able to start people on LTBI prophylaxis because of lack of resources. TSTs are not being done unless 'urgent' because of the same reasons."
~ TB Program lead

Program Leads (n=12)   59%

Staff (n=25)   68%

The Practice: Case-study - Stop TB Canada's COVID19 report

Advocacy

Used report as advocacy tool in meetings with policymakers

Launch event
- Including high-level health officials, e.g. Dr. Tom Wong, Chief medical officer of health of ISC

STOP TB CANADA SURVEY REPORT

THE IMPACT OF COVID-19 ON CANADIAN TUBERCULOSIS PROGRAMS

Stop **TB** Canada

Join us to discuss the survey findings and calls to action!

OCT 22, 2021
1:00 PM EDT

The Practice: Case-study - Stop TB Canada's COVID19 report

Advocacy

Used report as advocacy tool in meetings with policymakers

Thank you MP Zahid for taking the time to meet with us today!

Stop TB Canada

Members of Parliament (MPs):
- Report shared with 70 MPs in regions of Canada with a relatively high incidence of TB
- Met with 6 MPs to discuss the impact of COVID-19 on TB.

Provincial/Territorial Ministers of Health:
- On World TB Day last year, report sent to Ministers of Health of various provinces and territories in which TB remains a concern
- 2 meetings with representatives from Saskatchewan and Alberta

TB in the Federal Budget:
- Submitted calls to action from the report to the Federal pre-budget consultations

The Practice: Case-study - Engaging TB Survivors in Research

TB survivor thesis advisory panel

- Sought input from TB survivors for my thesis work (on the impact of the COVID-19 pandemic on TB care in Peru and India)
- Put together a panel of TB survivors from different countries, including Peru and India
- Shared process for engagement with our research group so that others can replicate (and improve on!) this process

Key elements of engagement (work in progress!)

- The earlier the better
- Include representation from countries/areas relevant to your work
- Lay-language summaries
- Non-stigmatizing terminology
- Always offer honoraria

Next steps?

⇒ Lack of a standardized framework for engagement, co-developed by TB survivors, researchers, etc

Co-developing a framework for community engagement in TB research

The knowledge and experiences of those affected by TB are critical to informing strategies to end TB, and their voices should be central to guiding TB research.

➔ TB community advisory panels / community engagement should become standard in TB research

➔ But we currently lack a framework for equitable community engagement in TB research, co-developed by TB survivors, researchers, advocates, etc.

Are you:
- A person affected by TB
- Part of the NGO sector working on TB
- A TB advocate
- A TB researcher
- A TB healthcare provider

… And passionate about person-centered TB research?

Get in touch with Lena (lena.faust@mail.mcgill.ca) or Petra (petra.heitkamp@affiliate.mcgill.ca) and we'll reach out with next steps towards co-developing a framework for community engagement in TB research

What is one thing you will do to take your work from evidence to advocacy?