COMMUNITY ENGAGEMENT: Lessons learned from Tuberculosis research

IDEAS Workshop Tuesday March 25, 2025

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uOttawa.ca

Tuberculosis is the WORLD'S LEADING INFECTIOUS DISEASE KILLER

1.25 MILLION TB DEATHS INCLUDING

161 000 DEATHS AMONG PEOPLE WITH HIV

TB is also the leading cause of deaths among people with HIV and a major contributor to deaths associated with antimicrobial resistance.





79 MILLION LIVES SAVED SINCE THE

YEAR 2000 DUE TO GLOBAL EFFORTS TO COMBAT TB



WHO GLOBAL TB REPORT 2024



THE C-WORD: TACKLING THE ENDURING LEGACY OF COLONIALISM IN GLOBAL HEALTH



By Sudipta Saha, Purvaja Kavattur, Amina Goheer

COLONIZING COBAL HEALTH 2020

Duke Decolonize Global Health



Calls to "decolonize" global health

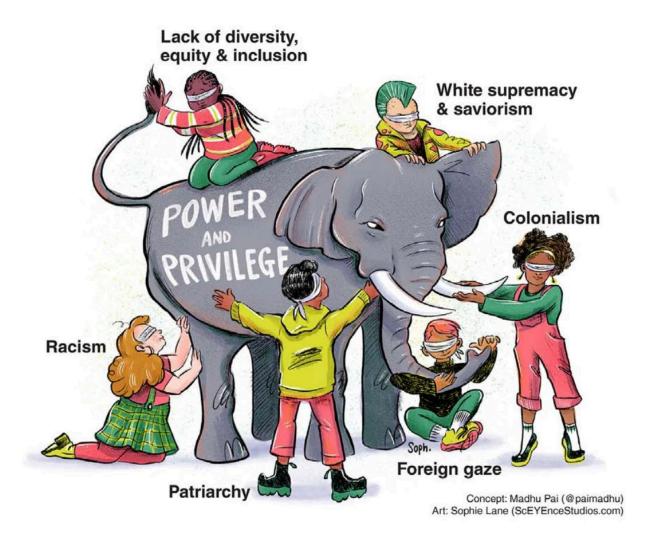


Decolonizing Global Health - Sweden

BMJ Global Health Decolonising global health: if not now, when?

Ali Murad Büyüm,¹ Cordelia Kenney,¹ Andrea Koris,² Laura Mkumba O,³ Yadurshini Raveendran O⁴ "The preference for use of the term global health where international health might previously have been used runs parallel to a shift in philosophy and attitude that emphasizes the mutuality of real partnership, a pooling of experience and knowledge, and a <u>two-way flow between</u> <u>developed and developing countries</u>. Global health thus uses the resources, knowledge, and experience of diverse societies to address health challenges throughout the world."

- Koplan, 2009



"Global health is a discipline that holds within itself a deep contradiction—global health was birthed in supremacy, but its mission is to reduce or eliminate inequities globally"

Abimbola & Pai, Lancet 2020

Why bother with community engagement?

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To end TB, meaningful community engagement is necessary to acknowledge the strengths and aspirations of affected communities, such as people with TB and TB survivors. Harnessing the experiences, skills and insights of affected communities allows better tailoring of programmes and interventions, making them more community-centred and context-specific.

WHO Civil Society Task Force on TB

Guidance on engagement of communities and civil society to end tuberculosis

"Meaningful community and civil society engagement to end TB requires that **people affected by TB are equal partners in the TB response**, with ministries of health and their NTPs. As equal partners, community members are empowered as experts on local needs and priorities."



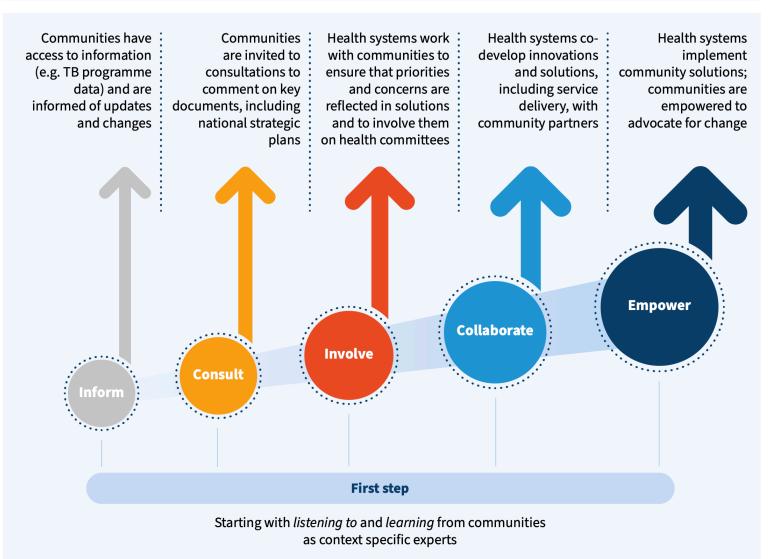
WHO 2023



Meaningful engagement is based on understanding that communities are not just mere recipients of care but are valuable partners in the TB response. All decision-making mechanisms must include an informed member of the community to bring lived experience and ground realities to the table.

WHO Civil Society Task Force on TB

Fig. 4. Levels of community engagement



What does meaningful engagement look like?

Source: Adapted from WHO (2)

Case finding at Pagodas





Closing TB GAPS- for people living with HIV: TB Guidance for Adaptable Participant-Centered Service



Closing -**TB GAPS** - for people living with HIV: TB Guidance for Adaptable Participant-Centered Service



Play (k)

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Photo credit: S Shrestha & Baylor Uganda COE



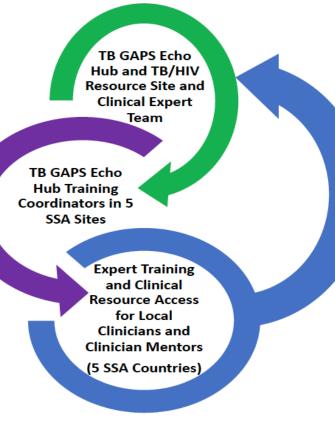
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Aim 4: Sustain Advances

- Set up ECHO Hub
- Support dissemination and promote uptake of evidence based best practices targeting CDC priority countries.
- Focus on HIV Network countries engaged in the TB GAPS project



Aim 4: HIV Network provides the perfect framework for a Child TB/HIV Echo Hub



Approach

ECHO is all teach, all learn

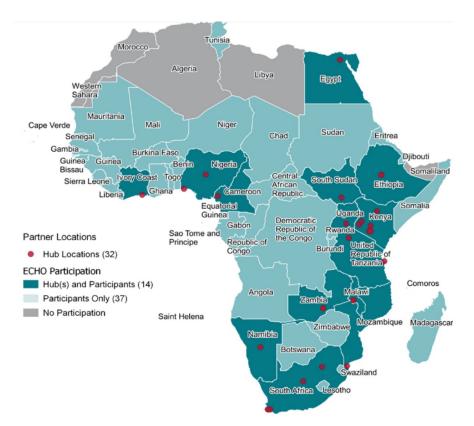


Co-management of cases

Peer-to-peer learning

Collaborative problem solving

Why Echo?



Child TB/HIV Focus

'She was my only girl': Nunavut teen's death sheds light on failures in fighting TB

Despite territory's high rate of tuberculosis, Ileen Kooneeliusie was not diagnosed in time to save her life



Nick Murray, CBC · CBC News · Posted: Mar 23, 2017 5:00 AM EDT | Last Updated: March 23, 2017



Matthew Kilabuk, left, and Geela Kooneeliusie visit their daughter's grave outside of Qikiqtarjuaq, Nunavut.



North

Major effort underway to fight tuberculosis outbreak in Qikiqtarjuaq, Nunavut

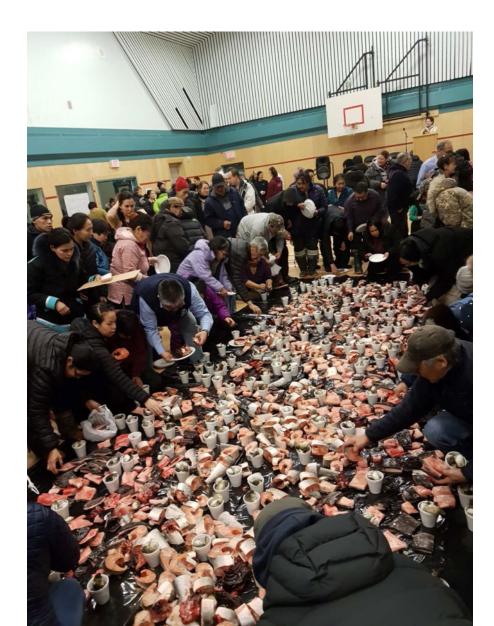
The number of active tuberculosis cases in the territory nearly doubled from 2016 to 2017

Sara Frizzell, Kieran Oudshoorn · CBC News · Posted: Jan 29, 2018 4:00 AM EST | Last Updated: January 29, 2018



An emergency medical team is setting up in Qikiqtarjuaq, Nunavut, to screen for tuberculosis. The number of active tuberculosis cases in the territory nearly doubled from 2016 to 2017. (Nick Murray/CBC)

Community wide screening in Nunavut



- Community meeting with clinic staff
- Community feasts (2)
- Q&A session on radio and continual PSAs
- Community leaders & champions (e.g. mayor)
- Messages on community Facebook page
- Appointment cards sent out to each person/household
- Incentives for screening
- High motivation already in community to address TB
- Access to medical care
- Inuktitut speaking staff and messaging

Photo credit: A Shertzer and M Patterson





Opportunities for tuberculosis elimination in the Canadian Arctic: cost-effectiveness of community-wide screening in a remote Arctic community

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Summary

Background In response to a tuberculosis (TB) outbreak in the remote community of Qikiqtarjuaq Nunavut, Canada, community leaders and the territorial government initiated community-wide screening (CWS) for tuberculosis, an expensive undertaking given the high cost of providing medical services in the Canadian arctic. Our study aim was to assess the cost-effectiveness of the Qikiqtarjuaq CWS.

Methods We developed a hybrid decision analysis and Markov model to replicate the experience and extrapolate CWS outcomes over a 20-year time horizon. Following a hypothetical cohort with patient characteristics reflecting the



Naluyunakhiyutit TBkaktutit - ihivgiuktaulutit, Munagiyaulutit. ⁵bやみL[®]介つΔ[®] 血へダもやつパンペニン[®] 血やつがわるく-5bやみなしやい,ムゥームやハン⁵のマムらん いかでしたやかのです You may not know you have TB – get tested, get treated before you get sick Yous ne savez peut-etre pas que vous avez la tuberculose. Faites-vous tester, faites vous traiter avant d'etre malade.

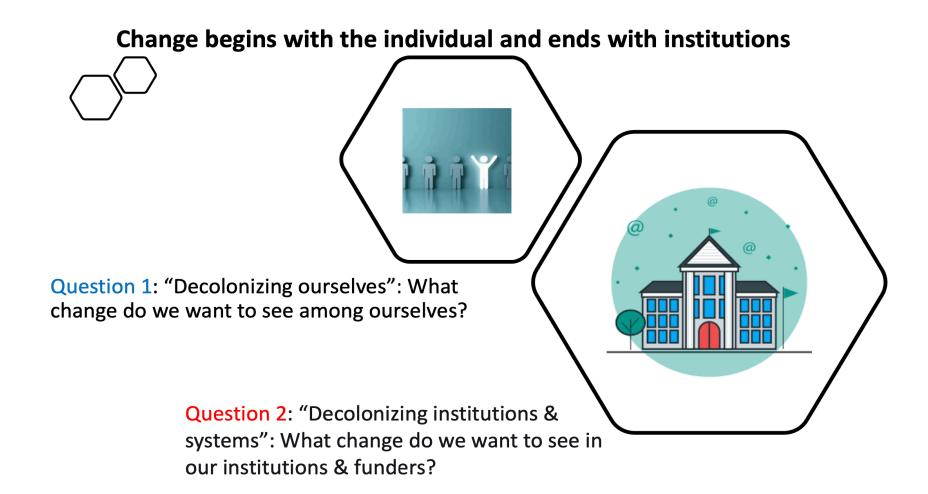






"In this imagined future, global health practitioners in HICs and those who are otherwise privileged, have embraced an appropriately modest view of their importance, and mastered the art of critical allyship, where they see their primary role as allies and enablers rather than leaders."

https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(20)32417-X/fulltext?dgcid=raven_jbs_etoc_email#.X8FyyWOPX2M.twitter



Tokenism? Let's strive for true and authentic inclusion

Meaningful engagement requires intentional, deliberate actions. It must be costed and be included from planning throughout the national TB programme cycle, including monitoring and evaluation. **Clear articulation of how this is envisaged** will be key.

WHO Civil Society Task Force on TB

THANK YOU

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uOttawa.ca

Extra slides

Key findings:

• commendable progress in community engagement, as evidenced by the number of countries reporting community contributions to TB notification, successful treatment of people who received community support for adherence to treatment, and the number of health centres that engaged communities in referring people with TB symptoms

Challenges:

- lack of a sustainable, systemic approach to community engagement;
- insufficient investment in community system development;
- major focus on service delivery;
- weak institutional and managerial capacity of community networks and community organizations; and
- insufficient indicators to track community engagement beyond service delivery and insufficient use of community-related data for programme planning.

Way forward:

- sustainable system approach to community engagement aligned with global health priorities based on the PHC framework for universal health coverage;
- an enabling environment, including sustainable financing for community engagement;
- definition of meaningful engagement with the full spectrum of community engagement;
- capacity-building in communities and civil society for meaningful engagement to end TB; and
- indicators to track meaningful engagement of civil society and communities beyond service delivery.