

Optimizing Adolescent Engagement in TB Care

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Background Question: “How can adolescents with tuberculosis (TB) or eligible for TB preventive treatment be optimally engaged in care?”

1. Narrative review on experiences and perspectives of TB-affected adolescents
2. Consensus recommendations for optimally engaging adolescents in TB care (experts/stakeholders: TB and adolescent health clinicians and researchers, adolescent TB survivors, and youth advocates)

Literature Review – Data Sources

1. Searched 6 databases: PubMed, PsycInfo, CINAHL, Global health, Web of Science, Google Scholar
2. Reviewed published and unpublished data known to the authors
3. Conducted outreach through WHO Child and Adolescent TB Working Group to identify additional relevant studies

Key Data Sources

- Qualitative studies – 7 countries
 - Gaborone, Botswana
 - Cape Town, South Africa
 - Mumbai, India
 - Lima, Peru
 - Kyiv City, Ukraine
 - Tomsk, Russia
 - Harare, Zimbabwe
- Historical and modern clinical cohorts of adolescents with TB
- Unpublished survey data from ongoing cohort studies
 - Lima, Peru
 - Delhi, India

Part I: Impact of TB on Adolescent Well-Being



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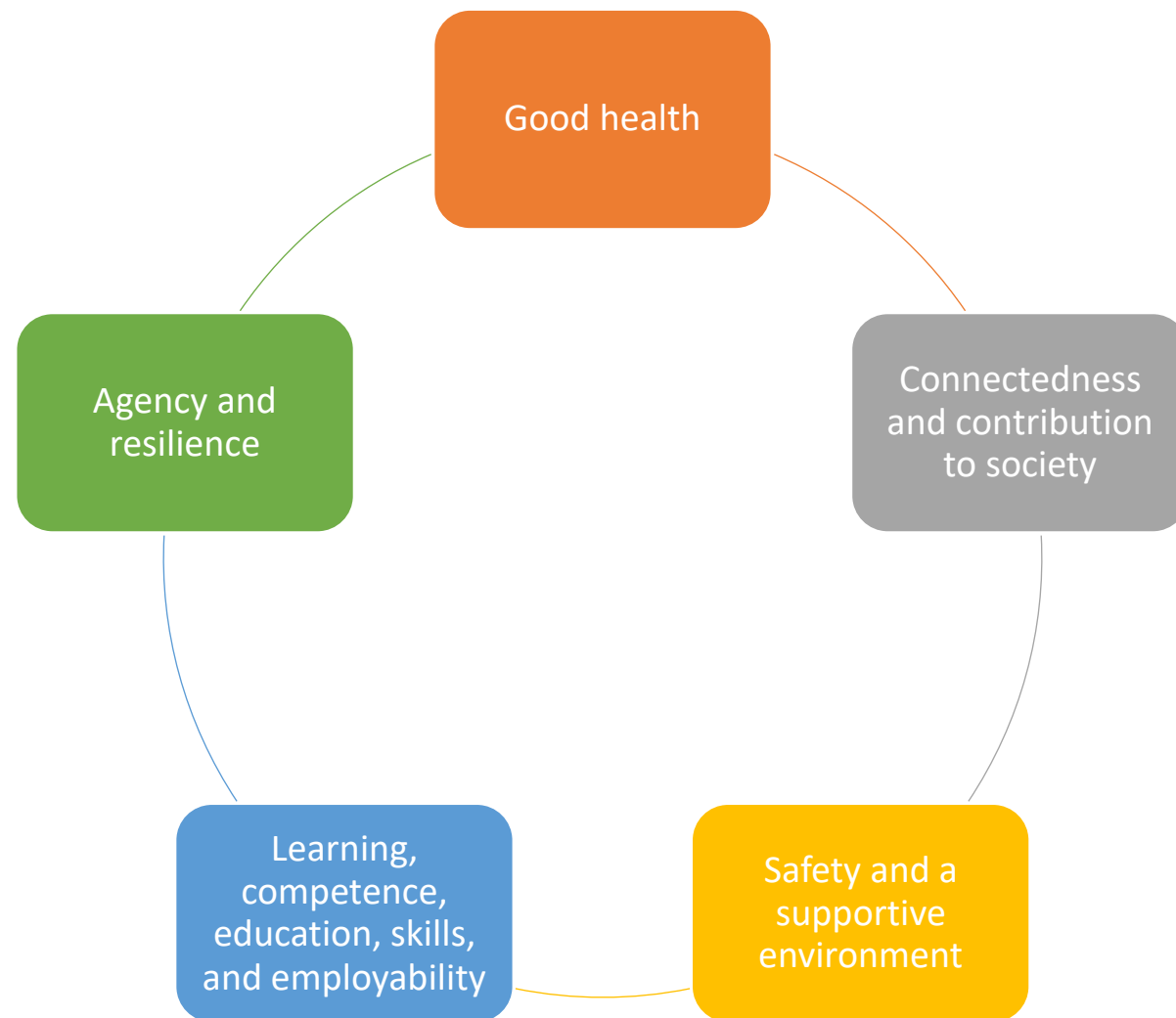
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Commentary

Adolescent Well-Being: A Definition and Conceptual Framework

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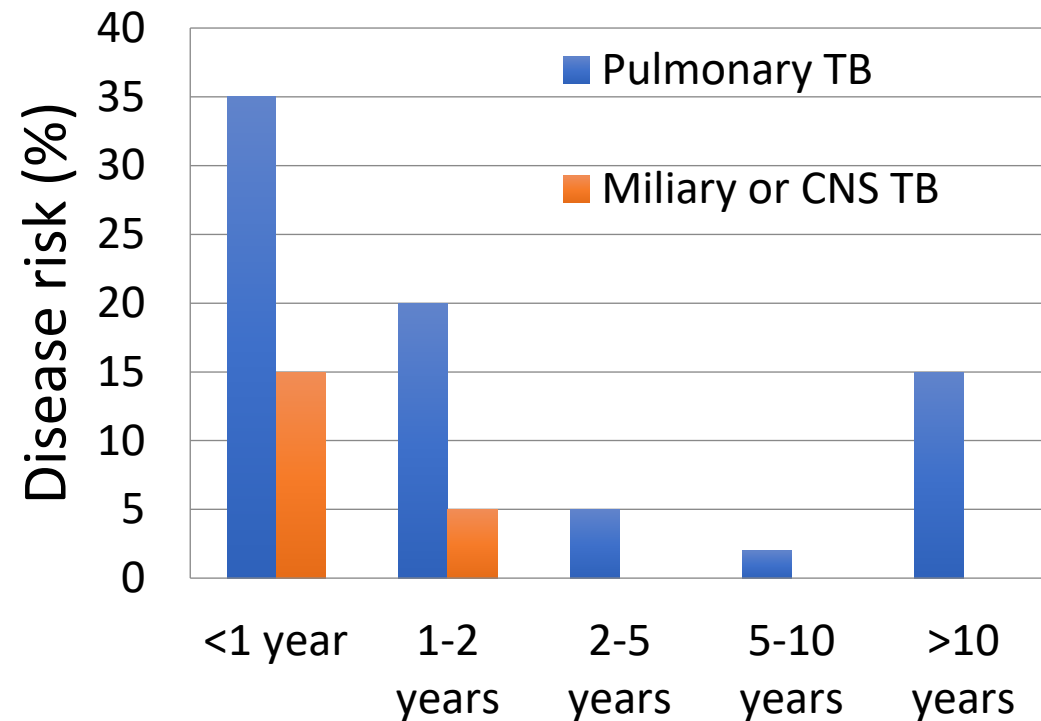


Domain 1: Good Health

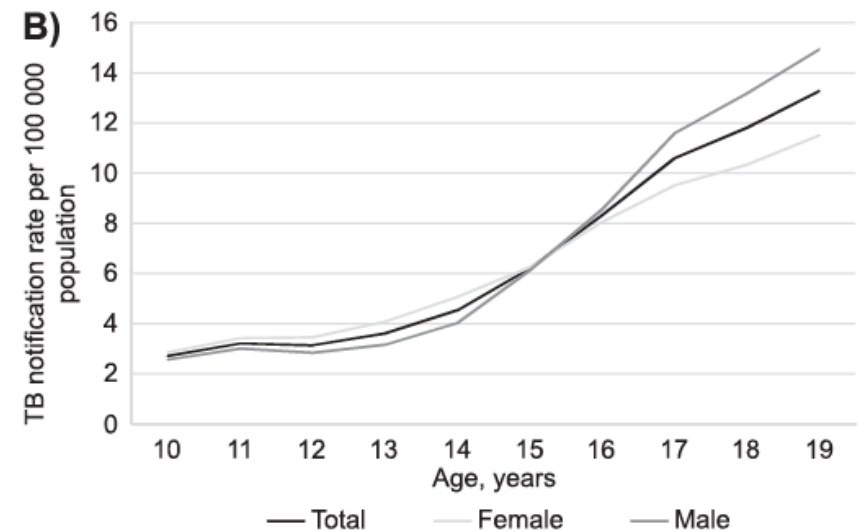
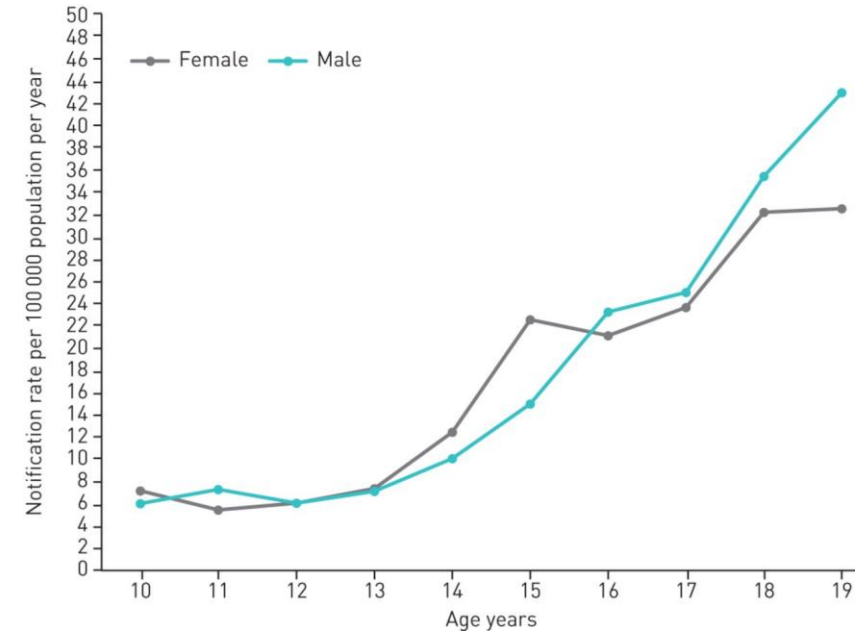
- Physical and mental health
- During illness, after illness



Increased TB Risk



Disease risk increased for HIV+ adolescents, worse if not on ART



Mortality and Morbidity

- Overall mortality low
 - Higher when HIV-positive, even on ART
 - Higher for DR-TB
 - Likely higher for those lost to follow-up (no data)
- Chronic respiratory impairment
 - Growing evidence of post-TB lung disease in adults
 - Likely in adolescents; preliminary studies in progress
- Neurological sequelae from TB meningitis
 - 54-66% of children and adolescents who survive have neurological sequelae



High Risk of Poor Treatment Adherence

- DS-TB studies using programmatic data in Haiti, South Africa, European Union, Brazil, Peru:
 - In ≥ 1 setting: HIV co-infection, age 15-19 years, prior TB treatment, male gender associated with *worse* adherence
- Treatment for TB infection: shorter regimens associated with *better* adherence (almost all data from high-income settings)

Treatment Adherence

Qualitative research

- Gaborone, Botswana
- Cape Town, South Africa
- Lima, Peru
- Lack of family support due to severe poverty, family conflict, parental neglect including substance use, family's misunderstanding of TB diagnosis and treatment, adolescent left home

Facilitators

Family support

Good rapport with health providers

Barriers

School/work conflicts, travel
– exacerbated by DOT

Pill fatigue, worse with
TB/HIV, DR-TB

Symptom resolution

Stigma – do not want to be
seen at TB clinic

Adverse Treatment Events

First-line:

- Fatigue
- Headache
- Abdominal pain/nausea
- *Mostly intermittent, temporary*

Second-line:

- Pain from injectable agents
- Hearing/vision loss
- Psychiatric adverse events
- Skin discoloration from clofazimine → experiences of stigma

Mental Health

Prevalence of mental health disorders in adolescents with TB largely unknown

- Toronto, Canada: 22% had mood symptoms
- Smolensk, Russia: 61% had anxiety, compared to 35% of healthy adolescents
- Lima, Peru: 31% with moderate or severe depression; about half TB-related
- Impacts likely worse for DR-TB and TB/HIV, but no data

Mental Health Impact of Prolonged Home Isolation or Hospitalization



Karayeva E. Master's Thesis. Providence, U.S.A.:
Brown University, 2020.
Chiang SS, et al. Unpublished data.

Home isolation

“[The health providers] told me, ‘You are not going to skate, you are not going to play matches, you are not going to go outside, you are not going to be with your friends. You cannot do anything. You are going to be in your room, in your bed with open windows and open doors.’”

— 16-year-old male, Lima, Peru

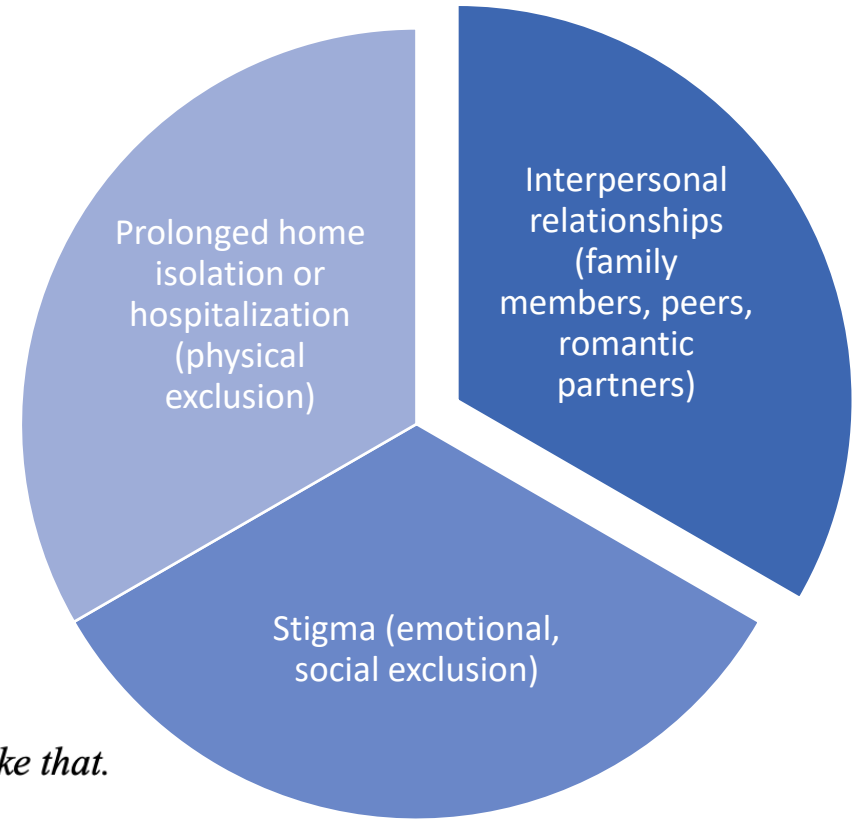
Hospitalization

“I really felt very lonely here. It was like I was all alone on this whole earth, and that no one could help me with anything . . . no one could talk with me . . . I would call [my mother] and say, ‘Mama, mama, please take me home!’

— 14-year-old female, Kyiv City, Ukraine

Domain 2: Connectedness and Contribution to Society

- Meaningful interpersonal relationships
- Being valued, respected, and accepted as part of the community



“[The children in the neighborhood] call me names and they hit me and stuff like that. [They say] ‘TB thing, just go away.’ They think I’m going to infect them.”

— 12-year-old adolescent, Cape Town, South Africa

Domain 3: Safety and a Supportive Environment

- Safety and a supportive environment <-> human rights
- TB burdens are greatest in settings of poverty and inequality, i.e. settings where basic rights often are not fulfilled
- TB disease may further jeopardize adolescent rights



Human Rights in Jeopardy

- Income for basic needs
 - Costs of TB diagnostic tests, transportation, supplemental food
 - Lost wages (adolescents, caregivers)
- Right to privacy – inadvertent disclosure of TB status
 - Patients easily spotted entering TB area of neighborhood health center
 - Clofazimine-associated skin discoloration
- Others

Domain 4: Learning, Competence, Education, Skills, and Employability



TB treatment and disease interrupt schooling

- Prolonged home isolation or hospitalization
- Limited clinic hours, long wait times conflict with school schedules
- Worse for HIV-positive adolescents (two clinics)



Consequences

- Regression of knowledge, skills
- Impaired learning due to medication side effects
- Need to retake semester/year
- Dropping out of school or vocational training
- Disruption or redirection of career trajectory (additional impact of TB-related stigma)

“I couldn’t read Afrikaans [anymore].”

— 12-year-old female, Cape Town, South Africa

“It’s not easy when you have a child with MDR, because those tablets were making him very, very dizzy. I was worried in the morning when he must go to school, you can see he is dizzy.”

— Caregiver of a 14-year-old male, Mumbai, India

“I was just a month away from finishing university. So, it was shocking to me because a single month, getting sick and no longer going [to school] shakes you quite a bit. And yes, I had to miss that month. I practically missed the semester and had to retake it again just this year.”

— 20-year-old male, Lima, Peru

“I felt bad because I was doing fine in everything, grades [and] all that, and to leave all that . . . Yes, I lost the year . . . I had to leave my vocational [school] and then dedicate myself to the health center.” |

— 17-year-old male, Lima, Peru

“I spent 4 years with TB. I wanted to study more, become a teacher. This disease has taken important years of my life.”

— 15-year-old female, Mumbai, India

Franck C. Master’s Thesis. London, U.K.: LSHTM, 2012.

Das M, et al. PLoS One 2021; 16: e0248408.

Chiang SS, et al. Unpublished data.

Domain 5: Agency and Resilience

Agency = ability to initiate change, make choices, resist demands

- TB → internalized stigma → low self-esteem → impaired agency
- Paternalistic approaches to DOT may impair agency

Resilience = potential to develop positively when exposed to adversity

- Some adolescents in Kyiv City reported adapting healthier habits, gaining more direction for the future as a result of TB illness

Consensus Recommendations

Objectives of consensus process

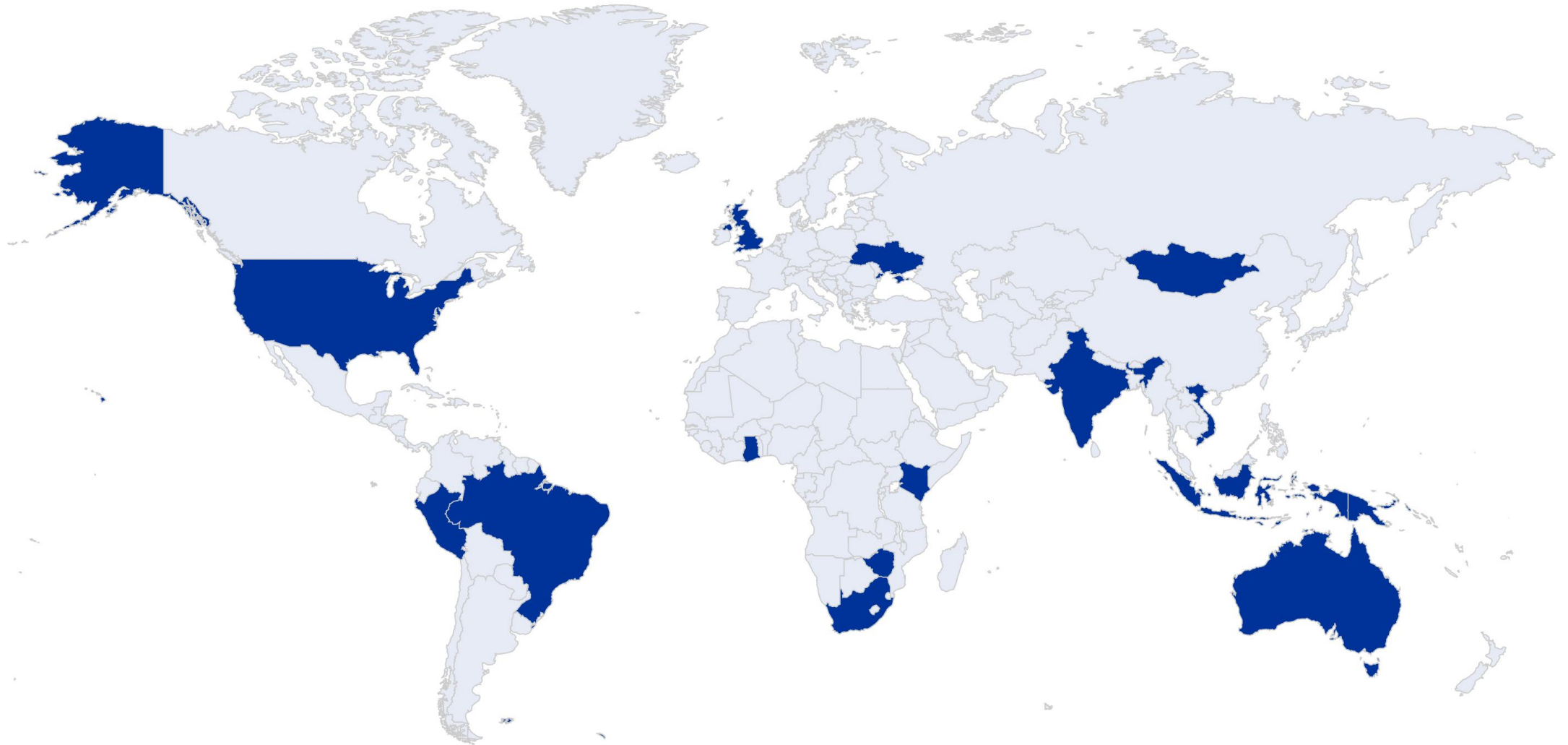
1. Supplement findings of narrative review with participants' experiences
2. Reach consensus on recommendations that would reflect and be applicable in diverse settings

Participants (n = 34) identified by

- Lead authors
- WHO steering committee
- Other invited participants

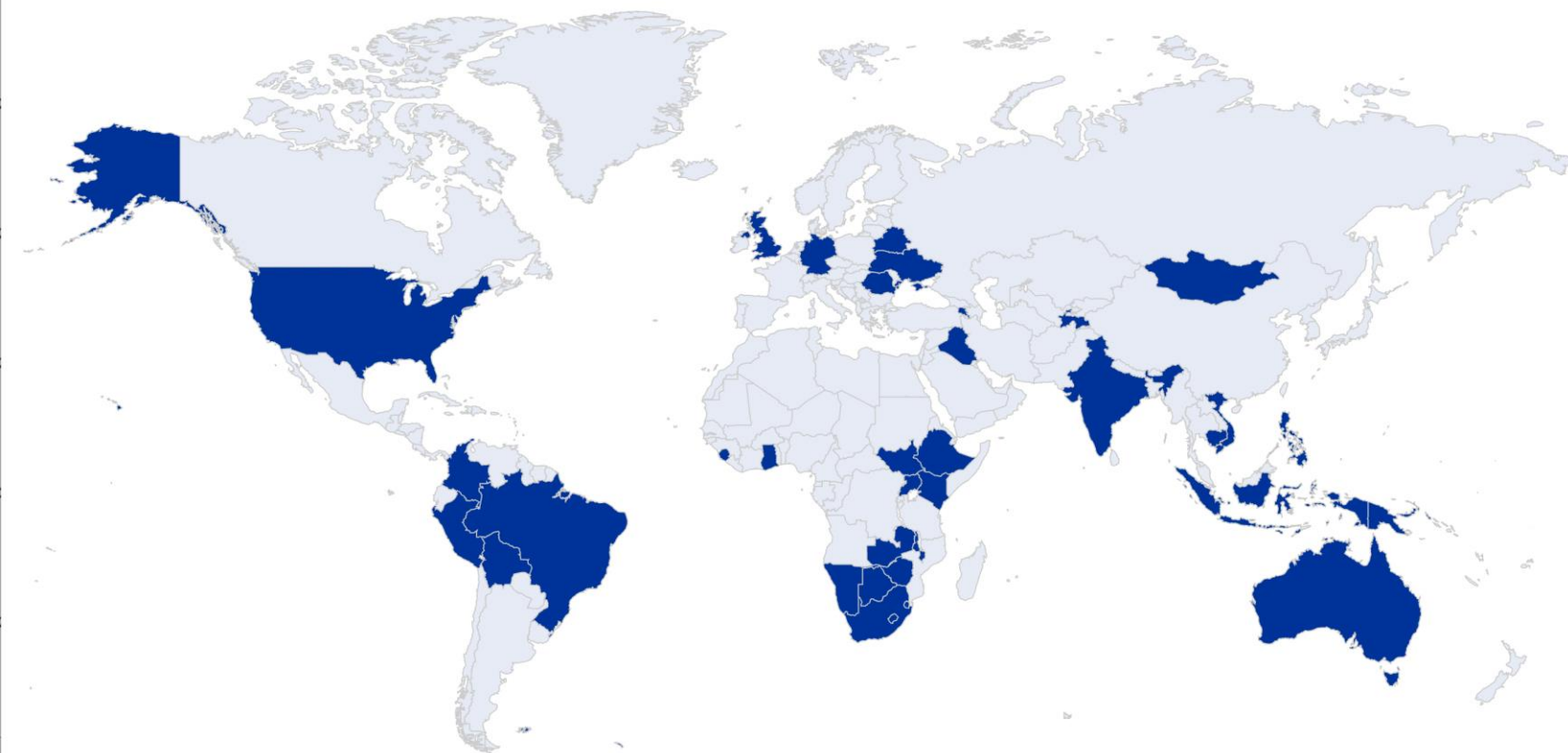
Aimed to recruit participants from all WHO Regions

Participants' Countries of Primary Residence



Participant Experiences in TB

Countries Where Participants Worked in TB or Received Treatment for TB



Highcharts.com © Natural Earth

Years of Experience in TB

Median 10 (IQR 7-14) years

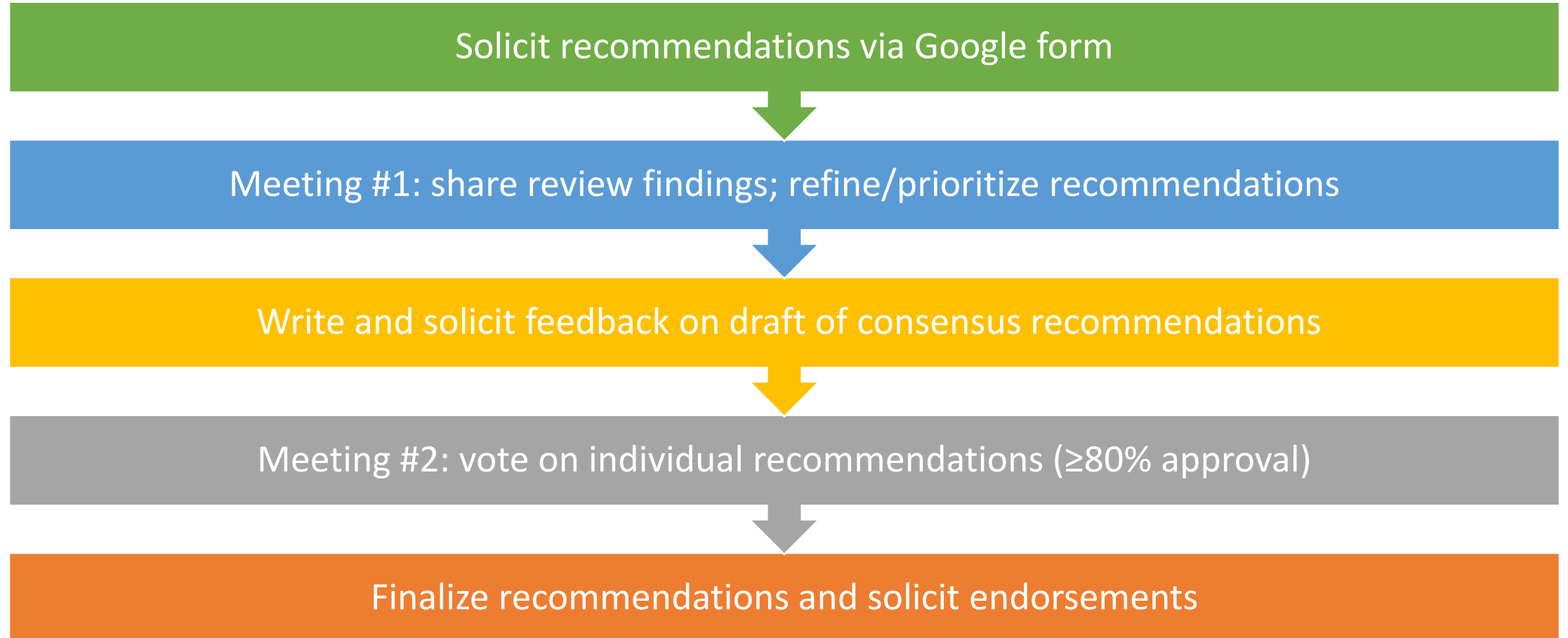
>20 years: 5 participants

>30 years: 3 participants

TB Survivors	Advocates
4	10
Clinicians	Researchers
19	26

May self-identify as ≥ 1 category

Consensus Process



Consensus Recommendations



Part A

- 9 urgent actions to modify currently harmful practices

Part B

- NTP plan to provide adolescent-friendly TB care

Part A: Urgent Actions

1. Because adolescents have unique healthcare needs and TB-related risks, NTPs should report adolescent-disaggregated data for 10-14 and 15-19 year-olds.
2. Because they have particular epidemiological risks for TB exposure and increased biological risk for developing TB disease after infection, adolescents should be a priority group for active case finding, treatment of TB infection, and TB education/awareness.

Part A: Urgent Actions

3. Daily facility-based DOT is harmful to adolescents:

- It disrupts social relationships, schooling, and work.
- It acts as a barrier to adherence because it is inconvenient and because individuals fear being seen receiving TB care.

Family-oriented, community-based models of care *should replace* daily facility-based DOT for adolescents. DOT may be delivered in a context-specific manner by a community health worker, a peer supporter, and/or by digital adherence technologies. Alternatively, medication administration by a family member who is trained and supported by health providers may be considered for selected adolescents.

Part A: Urgent Actions

4. Because adolescents treated for TB report loss of interpersonal relationships, education disruptions, and depression that are greatly exacerbated by prolonged isolation and/or hospitalization for TB treatment, **country-specific approaches should be re-evaluated to minimize isolation or hospitalization for TB.** Isolation policies should be implemented only on the basis of evidence for infectiousness.
5. Because adolescents younger than 18 years of age often are excluded from TB research, they are unable to benefit from new advances in TB therapeutics. **All adolescents should be prioritized in clinical trials and observational studies of treatments for infection and disease.**

Part A: Urgent Actions

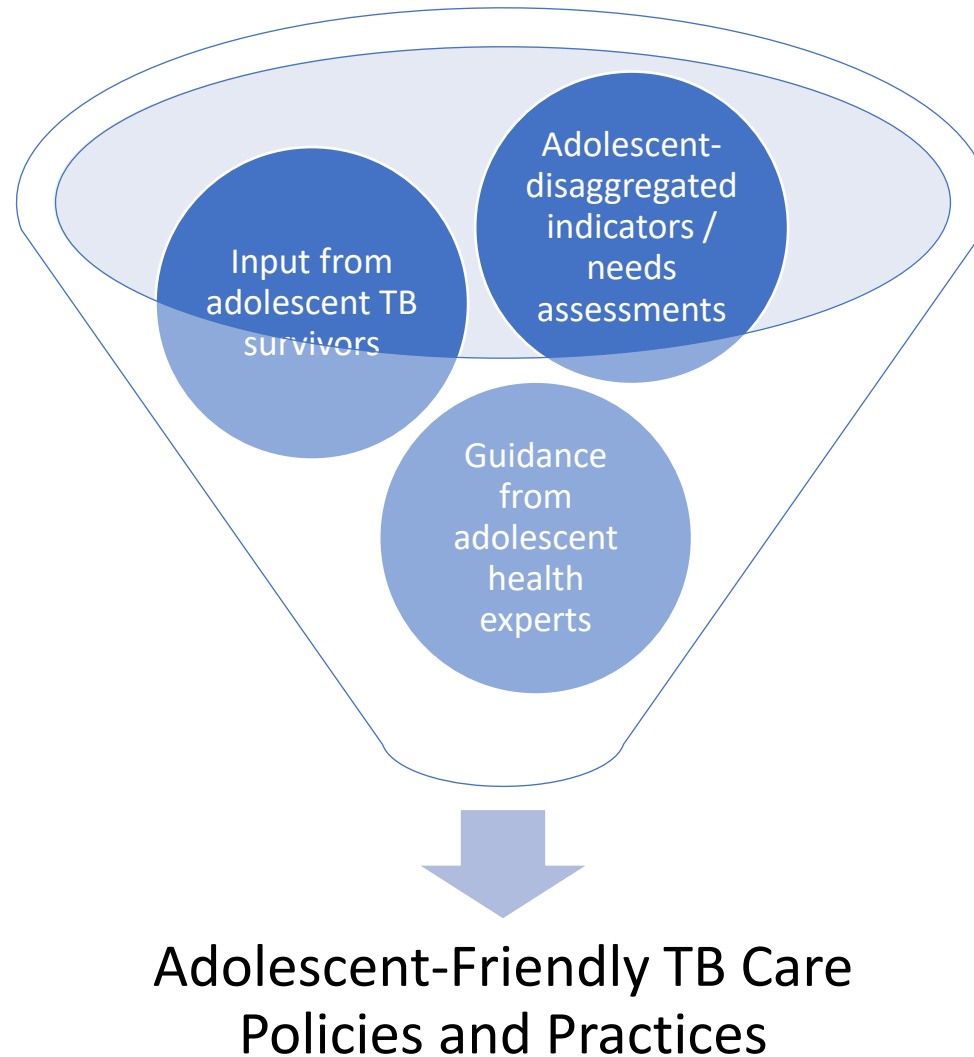
6. Because adolescents have an increased risk of poor treatment adherence, including loss to follow-up, and because TB treatment often interferes with their education, adolescents should receive the shortest effective TB treatment.
7. Adverse treatment events (e.g., reversible skin discoloration associated with clofazimine) including consideration of acceptability of a drug's effects to adolescents, should be discussed with adolescents and their caregivers prior to starting treatment.

Part A: Urgent Actions

8. Because rifamycins render hormone-based contraception less effective, TB providers should provide or help adolescents access alternative contraception methods.
7. Injectable agents are harmful to adolescents
 - Hearing loss negatively impacts adolescents' ability to learn and work
 - Facility-based daily administration interrupts schooling, vocational training, and work

Therefore, adolescents should not receive injectable agents, unless as a last resort.

Part B: NTP Plan for Adolescent-Friendly Care



Part B: NTP Plan for Adolescent-Friendly Care

Dedicated training of providers in adolescent health delivery

Increased access to TB services for adolescents

Integration of TB care with other health services

Increased awareness among other health providers of adolescent-specific TB risks and appropriate evaluation

TB education and information directed to adolescents and their caregivers

Mental health needs, including substance dependence

Empowerment of caregivers to effectively support adolescent TB treatment

Collaboration with schools to retain students with TB and promote TB screening, prevention, and treatment support

Attention to basic needs of adolescents with TB and their families

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