

IJTL: editorial (500-1400 words, 1-2 figures/tables, 25 refs)

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Dear Editors,

At the September 2023 UN General Assembly, world leaders set new five-year targets to end TB by 2030. These targets address testing, healthcare access, financial and social protection, vaccine and vaccination development, and securing additional funding for implementation research and development (1). Despite laudable support for equity in the global TB response, no numeric targets have been set to address social, structural, and economic inequities in TB (2). Attention to reducing inequities in testing, access to care, social protection, and the scientific process is essential to ending TB. There is growing recognition that people most affected by tuberculosis face systemic disadvantages related to gender, socio-economic position, race, ethnicity, geographical location, migration and other social identifiers. TB then compounds illbeing, catastrophic costs, food insecurity and vulnerabilities, such as loss of revenues, poverty, stigma, and discrimination (3-7). Yet, biomedical, clinical and public health-driven strategies continue to govern responses to this disease of social inequity.

Since the COVID-19 pandemic, global policy approaches increasingly discuss universal healthcare coverage, human rights, social protection and guaranteed basic income. This appeal, alongside greater attention to community engagement and advocacy, invites acting on the social determinants and consequences of TB.

But current approaches and targets to equity in TB are narrowly focused on diagnosing and treating as many people as possible, with limited considerations for social, contextualized or structural solutions that could prevent TB and bolster the capacity of people to access care and stay on treatment. The paucity of numeric targets to guide work on social, structural and economic inequities reflects a gaping lack of imagination (8). Expansion of social science methods, evidence and expertise (9-11) into mainstream designs and evaluations of TB responses can help to ensure that political commitments to equity are not merely symbolic. Social scientists, including but not limited to anthropologists, sociologists, lawyers, ethicists and historians, play a crucial role in studying and addressing the complexity of tangible and sometimes intangible ‘factors’ that reinforce the conditions and processes of social inequity in TB (12, 13).

In November 2023, using the platform of a borderless network on “social sciences and health innovations for tuberculosis” ([SSHIFTB](#)), we convened in Geneva to discuss equity within the global TB response. Participants included TB-focused anthropologists, sociologists, health economists, ethicists, lawyers and social epidemiologists, as well as civil society members, community and health workers, policymakers, funders, and technical agencies (i.e. WHO, ILO, FIND, GFATM). The objectives were to scrutinize nascent policy changes, discuss social science-driven approaches and interventions, envisage a research agenda, and reflect on equity in TB care and prevention. Based on these discussions, we outline several points through which a social science lens can contribute to a more equitable and people-centred TB response that reconciles the public health threat with principles of social justice.

In order to leverage the social sciences for an equitable response to TB we call to action the following principles:

### **1. An expanded view on equity**

An equitable response to TB can be conceptualized as placing emphasis on the absence of unfair, avoidable or remediable differences, including in their capacities, among and within countries, including between groups of people, whether those groups are defined socially, economically, demographically, geographically or by other dimensions of inequality. Effective and holistic tuberculosis prevention, diagnosis, treatment, and care must go beyond promoting equitable access to medical innovations to address the underlying social and structural drivers.

Writing on ‘equity’ in policy documents and funding reports is often limited to equity assessment of access to medical products and technologies, risk of developing disease, and health outcomes. While the End TB Strategy has a target of “zero catastrophic costs” for TB affected families, it offers little guidance on how to achieve this equity-related target beyond humanitarian responses and biomedical measures (14). The approaches taken to equity assessments in these reports are generally quantitative, with data gathered through large scale surveys using closed-ended questions or scales (REF needed).

Social science approaches allow us to look at equity from diverse yet complementary vantage points to better articulate the various ways equity matters in efforts to end TB. For example, in law, equity is used as a governing principle orientating the development and content of laws and regulations on issues considered as determinants of TB. In bioethics, equity involves asking how best to distribute the benefits and burdens of clinical and public health measures in addressing TB, while upholding key values, including justice, autonomy, solidarity, and reciprocity. Health economics can support an equity agenda through analyses of expenditures, health impacts and access beyond the health system, to assess the social justice value of TB related interventions. In sociology and anthropology, equity and inequity are examined through the lens of lived experience and analysis of multiple global and local sites where inequities are produced, reproduced and intersect, including intersections between colonialism, TB and reproduction of colonial medicine. From the community lens, equity begs an appreciation of and willingness to address disparate interpretations of access, people-centeredness, and meaningful inclusion of community voices that represent the marginalized in all TB-related decisions.

This demands tackling inequity in the various spaces in which it emerges (see Table 1). Building equity requires us to unravel these often unspoken layers of relational and situational inequity, and surface unheard voices.

Table 1: The multiple spaces in which (in)equity emerges

<b>Equity within households and communities</b>	where equity unfolds along intersecting lines of poverty, gender, race, language, literacy, urban/rural, housing, employment, access to balanced food, age and generation, healthcare and essential social services.
<b>Equity in health facilities and in the health workforce</b>	where global-level agreements and forms of institutionalized inequality (systematic underfunding of health sector, prioritization of active pulmonary TB), intersect with local issues of bias, discrimination, and scarcity.
<b>Equity at borders and for people on the move</b>	where people face multiple pressures and stigmas tied to migration, undocumented status, racial discrimination, language, and cultural integration.
<b>Equity in the boardroom</b>	where decision-making is shaped by power differentials so that distinct “voices” are systematically represented merely in a consultative manner i.e. to inform or represent, as opposed to decide and collaborate.

<b>Equity in funding and priority-setting across sectors</b>	where agenda-setting is dominated by power differentials, two- or multi-tiered systems; where public funding does not result in publicly owned products; where universal social protection and welfare is being constricted; where equity competes with high profile and more profitable issues
<b>Equity in innovation and the laboratory</b>	where innovation may be agnostic to the user, their infrastructure and resources, and siloed against broader strengthening of the health system; where the benefits of innovation may be enjoyed by some but not all people in need
<b>Equity in research, trials and evidence-building</b>	where politics of participation (inclusion criteria but also engagement in community advisory board (CABs)) and of metrics (what gets measured, what gets asked, what forms of knowledge production) decide what is prioritized for research and counts as evidence
<b>Equity in global discourses, values, (implementation) processes, methods, practices</b>	where equity is neither a starting point nor an explicit target, rather seen as a luxury (in NSPs and GFATM and PEPFAR applications)

## 2. New and expanded equity indicators

Developing more person-centred metrics for equity within work to end TB requires understanding 1) who is affected by what forms of inequity, 2) how, where, and when they are affected (the mechanisms and the relevant factors at play and how these intersect or mediate each other), and 3) what interventions explicitly address existing inequities, and how these interventions are experienced.

Building upon the existing frameworks, particularly the recent work in community-led monitoring and multisectoral accountability framework, and indicators of universal healthcare and social protection (14-19), these indicators would capture nuance and expanded factors that constitute equity and develop feasible approaches for integration with existing TB data collection and data sources from different social sector programs. These indicators could, for instance, increase visibility of TB's link to poverty and vulnerability to ongoing economic, social, and psychological morbidity beyond cure of TB or DALY's; link TB-specific indicators with broader democratic, governance, and socio-economic indicators (including through use of big, open-access data (20)); add process and outcome indicators of authentic participation and engagement infrastructure (in CABs, in collaborations with NTPs); capture available funding (how national TB burden aligns with national TB budget and debt relief or SAPs/IMF programs (21, 22)); provide integrated analysis of available metrics including community derived data: epidemiological review, locally authorized community-led monitoring reports and programmatic surveillance data; and include, at achievable strategic intervals, a cycle of standalone in-depth qualitative research to understand the how and why of TB related inequity and document adaptive strategies.

Developing more person-centred metrics for equity also implies using alternative mechanisms for determining whether TB programs are successful. A 85% treatment success rate sounds good, but a focus on equity can only work if we can identify the obstacles concerning the 15% remaining individuals that do not have treatment success. If we designed programs to reach people with multiple vulnerabilities –the underserved person- then we would automatically reach the “easier” ones too.

### **3. Meaningfully engage with multiple and multisectoral stakeholders, particularly marginalized voices**

Many social science methods allow for data to be sourced from a diversity of sources or in participatory or inclusive approaches with stakeholders in line with a human rights based approach wherein participation is a central mechanism (refs?). This is true for qualitative methods (standalone research or alongside clinical trial platforms or iteratively alongside design and development processes) as well as innovative quantitative methods that include elements of social justice (extended or distributional cost-effectiveness analyses and modeling). These methods simultaneously allow for engaging with community and end-user voices, juxtaposing and then mediating different perspectives and lived experiences, as well as producing experiential evidence necessary for decision-making.

### **4. Answering uncomfortable questions about political economy, power and suppressive structures**

TB is a disease that thrives on poverty and poverty-associated undernutrition. Inequity in access to food is fueling the epidemic and nutritional support can substantially (39-48%) reduce tuberculosis incidence (23). It took a randomized clinical trial to catalyze concrete investments in addressing an inequity that scholars and TB experts have pointed out for decades (7). The same counts for social protection which took until 2023 to be fully recognized in the UN high-level meeting pledge that “100% of people with TB will have access to a health and social benefits package by 2027” (2, 8). An equity-based approach implies taking a human rights-based perspective and asking uncomfortable questions about political economy, power and resources. It demands addressing political decisions, priority setting and socio-economic and historically rooted structures of oppression regarding the distribution of and access to resources as well as benefits of innovations (13). A right to science framework, for instance, asks duty bearers to think beyond access to consider whether people can share in and enjoy science and its benefits, which requires attention to participation, non-discrimination, the inter-relation of rights and enabling conditions.

### **5. Building evidence on the values and preferences, acceptability, feasibility, sustainability and equity considerations relevant for decisions about new innovations and interventions**

Equity-oriented approaches can and should begin in TB research and innovation itself (24). When developing and evaluating interventions, technologies, and programmes, social science methods can reveal the underlying understandings, values and trade-offs at play and ensure meaningful engagement with TB affected communities and stakeholders. Oftentimes interventions are neither only or solely good nor bad (i.e., Xpert had both negative and positive impacts on equity) (25). What are the fundamental values that should inspire the negotiations related to these tradeoffs (i.e. promoting economic efficiency within health systems vs saving money vs protecting the right to healthcare or benefits of science of people)?

**We call upon policymakers and funders to:**

- Consider expanded dimensions of equity to better reflect the needs of persons and communities living with TB
- Foreground equity into agenda-setting documents and programs, such as guidance, tools, and frameworks with more comprehensive indicators and measures, so it can be addressed more explicitly
- Ensure professional development and training of TB health workers, service providers and stakeholders on fundamental equity frameworks and principles

- Integrate considerations on equity into the design and evaluation of TB innovations, programming, policy and trials
- Make increased and more effective use of social sciences to support the way that equity is integrated into guidelines, research agenda setting tools and shaping themes of action on equity
- Act on the most pressing issues in addressing the inequity in TB: global and national guidelines/efforts on comprehensive treatment support that include nutritional, psychosocial and economic support. We commit to supporting the evidence-base on the value of these interventions for PWTB and their care givers.

The UNGA high level meetings on TB have catalyzed discussions on UHC, multisectoral action, social protection and human rights (26). Through innovative partnerships that allow continuous connections between multiple stakeholders, social scientists can fruitfully complement the work of implementers, TB affected community and civil society on issues of equity. These efforts can complement the existing, often dominant, biomedical voice and explanations and reinvent how we approach equity in the global TB response.

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