IMPROVING THE TB PATIENT JOURNEY: FOCUS ON DIAGNOSTICS AND DATA
Although considerable substantial efforts have been taken by various actors across the TB ecosystem in recent years [0], health systems continue to struggle with a number of challenges, including: providing integrated, patient-centered care, implementing robust prevention initiatives; marshaling political support for crucial investments in TB care infrastructure, securing greater community involvement from a range of stakeholders to ensure patients are cared for across the duration of their treatment, and facilitating the further development and distribution of vital TB innovations. The COVID-19 pandemic has exacerbated these challenges while further widening gaps in the TB care system. Despite the parallels between the two diseases - including in how symptoms present themselves and which vulnerable populations are most impacted - and despite the fact that much of the pandemic response efforts are being undertaken on platforms built for TB, resources to combat this disease are being diverted away. One study from Stop TB estimates that if the pandemic continues, we could see an additional 6.3 million infections and 1.4 million deaths [1]

The Private Sector Constituency of the Stop TB Partnership (PSC) is a forward-looking consortium of private sector organizations from various industries working together to alleviate some of the most pressing problems in TB management. The workstream’s core objective is to support improvements to TB care – at the patient and provider levels. Our member companies leverage their expertise, network and resources to collectively tackle challenges in two key areas of the fight against TB: Data and Diagnostics.
KEY TB CHALLENGES ADDRESSED

**Improper Resource Allocation**
Poor distribution of TB resources, driven by the general decentralization of TB data – across many systems, and siloed databases – and lack of cooperation (unwillingness or inability to share aggregate-level data appropriately, lack of standards and guidance).

**Reduced Responsiveness**
Inability to respond rapidly to TB challenges, due to lack of real-time data collection [2] and difficulty getting an accurate understanding of specific patient and community needs.

**Constrained Capacity**
Reduced capability to fully leverage data and diagnostics to address TB challenges, driven by poor IT infrastructure, and widely divergent systems and processes for the collection, transmission and sharing of data.

**Slowed Innovation**
Delayed adoption of digital health innovations, due to limitations of human and technological capacity and inadequate investments in analytics, data and informatics.

**Inadequate Access to Tools**
Inability of providers to affordably [3], and efficiently access lifesaving diagnostics tools and treatments, due to program inefficiencies and a poor allocation of resources (geographic misalignment between capacity and needs), insufficient support for innovation [4] and the absence of a rapid screening test for TB.

**Weakened Programming**
Missed, delayed and improper diagnoses [5], and underreporting of TB cases [6], driven by poor implementation of diagnostics programs. [7]
THE PSC ROADMAP TO OPTIMAL LINKAGE TO CARE

Linkage to care plays a key role in the tuberculosis care continuum—it is a necessary precursor to therapy initiation and lays the groundwork for future adherence to and retention in TB care. When care systems are underdeveloped and insufficiently integrated with broader healthcare infrastructure, patients are most directly harmed in several ways.

Delays. TB patients experience delays across the care continuum, including in securing referral for TB diagnostics tests, due to improper screening by providers, in the ordering of TB diagnostic tests which may be due to mismanagement and supply constraints [8], in the delivery or results to clinicians and patients, driven by poor data and patient management systems, and in the initiation of needed treatment due to the challenges of interpreting complex results and the unavailability of appropriate drugs for treatment [9], and in the start of proactive longitudinal monitoring programs designed to help prevent drug resistance and negative outcomes and support the effective completion of treatment regimens. [10]

Quality of Care. TB patients often receive care in a variety of settings that contributes to lower quality of care, driven primarily by the adoption of improper diagnostic and treatment protocols [11] and the use of ineffective and varying drug regimens, which can lead to unsuccessful treatment of TB [12].

Insufficient Linkages. Insufficient linkage can also undermine national and regional prevention campaigns, which rely on health information systems to provide accurate and thorough patient-level data to inform decision making.

These delays prolong illness, multiply opportunities for transmission, fuel the outbreak of drug resistant TB, and constrain efforts to improve patient outcomes. Reducing these delays requires a stronger link between laboratory and clinic. New diagnostics and drugs are critical, but if they do not connect into a patient-centered model of care—the right diagnostic or drug, for the right patient, at the right time—they will have limited impact.

PSC members remain committed to leveraging existing technologies to make meaningful improvements across the patient care journey—from prevention to diagnosis to management to follow up. In our view, tangible solutions that can help improve TB patient outcomes should create considerable cost savings by creating a full picture of the patient journey from diagnosis through treatment outcome.

PSC members believe that adequate monitoring and use of the data created by interconnected systems contributes to improved patient outcomes. Furthermore, this integrated system, with appropriate data sharing permissions, can track return on investment for the donor community and also bring critical insights to diagnostic manufacturers and pharmaceutical companies as they develop improved products for those affected by TB.
Data Linkages Across Patient Patway

Proposed Solutions

- Digitally connect existing (and future) diagnostics (molecular, culture, and X-ray) to centralized data platforms
- Deploy clinical decision support tools
- Interface diagnostic data into TB case management systems
- Link diagnostic and case management data with contact tracing systems and treatment adherence technologies
- Migrate treatment outcome data into centralized health information systems.

Benefits

- Offers insights into: device utilization, number of tests being run, test results (DR and DS TB).
- Provides insights into gaps and drop-off between first and second-line diagnostics
- Ensures the treatment selected is best for the patient based on test results and other relevant factors
- Offers user-friendly interfaces to enhance patient experience
- Provides more detailed information on how many positive cases were initiated onto treatment
- Helps providers determine which adherence platforms might be best for the patient
- Supports contact tracing initiatives
- Helps public health officials optimize decision making and better allocate critical TB resources
DATA INTEROPERABILITY TO DRIVE THE TB CARE CASCADE

A major problem in healthcare is the lack of interoperability - an inability for data systems to communicate and connect with one another. By gathering patient information from multiple databases, interoperable systems make it easier for providers to access a patient's medical history and make informed recommendations. [1]

Despite widespread agreement around the need for greater systems-level connectivity, the current global framework for collecting, maintaining, sharing and analyzing TB data is disjointed. Due to the absence of universal standards for TB data collection, there is a lack of uniformity in the data fields being collected across regions, and wide variation at the national and regional levels in terms of methodologies, processes and even systems usage. Further, differences in data processing infrastructure and capacity also can make it difficult to put TB data to use even when available. The resulting data siloing can create major systemic challenges for TB care providers, including: a sub-optimal allocation of resources, improper patient prioritization, program redundancies and overlapping initiatives, and an overall failure to address important care gaps.

The lack of interoperability also inhibits the adoption of critical health care innovations, slows the development and integration of people-centered innovations and interventions [14], and thwarts the ability of health care administrators to make needed comprehensive improvements to their TB care models. [15] Most importantly, it undermines the ability of health systems to rapidly respond to emerging and dynamic TB challenges, due to the unavailability of real-time data and difficulty in getting an accurate understanding of specific patient and community needs.

[1] https://apps.who.int/iris/bitstream/handle/10665/329368/9789241565714-eng.pdf?ua=1
[8] Stop TB Partnership PSC Data Working Group Concept solution #2
[9] Stop TB Partnership PSC Data Working Group Concept solution #2
PSC Members are committed to implementing tangible solutions to address the lack of interoperability and to spearheading projects aimed at helping to better integrate and consolidate the highly fragmented ecosystem of TB data. In particular, PSC Members will work to:

- **Promote the use of universal TB data and diagnostics standards** to facilitate easier exchange of aggregate-level TB data and ease tracking of cases across geographic boundaries.

- **Advocate for the establishment of an innovation fund to improve interoperability** by supporting private and public sectors organizations in their efforts to consolidate TB data, which would help with the identification of health resources gaps [16], optimize resource allocation, and improve both the efficiency of case-finding interventions and the identification, tracking, and management of drug-resistance and mutations. [17]

- **Promote the adoption of cloud technologies** by articulating the key benefits of real-time data sharing and demonstrating how adoption of these systems would specifically help managers circumvent infrastructure-related barriers to care and reduce the cost burdens associated with running TB programs.

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FIGHTING TB IN PARTNERSHIP

Implementing the proposed solutions requires sustained multi-stakeholder collaboration and a commitment to helping facilitate the adoption of critical technologies in three ways. First, we must acknowledge and address the serious and legitimate concerns surrounding data privacy, including the use, sharing and storage of patient data, by prioritizing the adoption of robust data security measures, and implementing transparent, reliable and consensus-driven safeguards that effectively protect individual and aggregate-level patient data. Second, we must find creative ways of overcoming resource and budgetary constraints and help stakeholders better communicate the benefits of TB tools to key decisionmakers in their respective organizations. Third, to combat the underutilization of new systems, we must work to ensure that when innovative technology is adopted, users have a clear understanding of its benefits.

The successful implementation of data and diagnostics projects will yield two critical benefits in the global health communities’ ongoing efforts to combat TB in the coming years: cost savings and improved patient outcomes.

Cost savings can be attained by making improvements across the care continuum. Key sources of savings from implementing proposed solutions include: reductions in the amount of resources spent on each individual patient; lowered costs associated with follow-up and retesting of TB patients, decreases in aggregate testing costs due to reduced person-to-person transmission, improved allocation of vital TB resources – at the country and program-levels, an elimination of inefficient, overlapping and redundant programs, and increased overall success rates and efficiency of ongoing TB initiatives.

Patients stand the most to gain from the implementation of proposed workstream solutions. Primary benefits include: an improvement in the overall patient experience across the TB care ecosystem, an aggregate increase in diagnostic rates along with a widespread reduction in the number of missed, delayed or improper diagnoses, enhanced clinical decision-making on the part of medical professionals, the ability for public health planners to better track and predict spikes in TB cases and to reallocate needed resources accordingly, and an improved ability to combat mutations and drug-resistance.
We are at a key inflection point in the fight against tuberculosis. The ongoing COVID-19 pandemic is poised to seriously accelerate TB-related challenges in the coming years, by directly cannibalizing funding for TB programs in the short-term and by reducing the willingness of decisionmakers to hold firm on financial commitments to TB programs in the long-term. Patients, too, will struggle with accessing TB care, across the entire continuum. As governments wrestle with managing both the pandemic and projected spikes in TB cases, private sector organizations must play an even larger role in identifying creative, cost-effective solutions to emerging TB-related challenges.

Stop TB PSC’s Data and Diagnostics Workstream: Advancing Private-Sector Led Solutions to Address Pressing TB Challenges

This position was developed through the engagement of the members of the PSC D&D workstream, convened to empower private-sector TB leaders to make meaningful progress towards improving patient outcomes and reducing incidence rates in impacted communities around the world.

Our members’ extensive experience in combating infectious diseases makes them well suited to tackle the most complex challenges in the TB space. Utilizing a collaborative approach, the workstream leverages members’ innovative ideas, institutional knowledge, and professional connections to address pressing TB data and diagnostic gaps. Our aim is to deliver tangible solutions for patients, providers and administrators around the world.