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PSC DATA & DIAGNOSTIC PAPER SERIES

Strengthening the TB Ecosystem through Data & Diagnosis

LEVERAGINING THE CLOUD FOR HEALTH SYSTEM RESILIENCE AND TB PROGRAMMING



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THE ROLE OF DATA INTEROPERABILITY IN THE FIGHT AGAINST TB

IMPROVING THE CONNECTIVITY TO ENHANCE THE FIGHT AGAINST TB

> UNLEASHING THE POWER OF AI AT THE COUNTRY LEVEL

APPLYING COVID-19 TOOLS AND INFRASTRUCTURE TOWARDS THE TB FIGHT

INTRODUCTION TO HEALTH DATA & INTEROPERABILITY

What is interoperability?

Interoperability is the ability of two or more systems to exchange health information and use the information once it is received.¹

Currently, national health data ecosystems are disjointed, driven primarily by a lack of standardization of collection processes, Electronic Health Records (EHR) systems, and patient identifiers. Additionally, there is an overall lack of interconnectedness between healthcare data systems. Yet, despite these challenges, many low- and middle-income countries (LMICs) have been working to make their health care systems more interoperable in recent years.

The advantages for countries to improve interoperability are clear. In TB endemic settings, greater interoperability would permit information to flow across systems, allowing for a consolidation and synchronization of data which can then be used to pinpoint outbreaks, identify and track varying strains of TB, optimize resource allocation, and more. Thus, the adoption of measures and mechanisms to enhance data interoperability will massively increase the potential utility of health data in the fight against TB.² Advantages of interoperability besides enabling use of data also include significant cost savings due to the reduction in:⁴

- (a) the number of duplicate tests;
- (b) repetitive data entry efforts; and
- (c) resources to ensure data validation across systems.

Countries and health systems are overseeing TB digitization initiatives, with a goal of consolidating and better leveraging data to enhance their TB programs

As health care systems continue to undergo digital transformation broadly, the use of digital data surveillance to specifically combat TB is also increasing. The WHO reports that as of August 2021, 130 countries had a digital case-based surveillance system for all TB cases (drugsusceptible and drug-resistant), which accounted for 72% of TB notifications in 2019. An additional 14 countries had a digital case-based surveillance system only for drug-resistant TB infections.⁵

Further, through the Sustainable Development Goals (SDGs) Target 3.3, the World Health Organization (WHO) End TB Strategy, and UN high-level meetings on TB, the international health community has also been facilitating increased cooperation with country-level programs to help accelerate and enhance TB-relevant digital transformations.^{6 7}

Through resolutions WHA58.28 on eHealth, WHA66.24 on standardization and

interoperability, and WHA71.7 on digital health, the WHO has urged Member States to develop and strengthen their digital health systems.⁸ WHO Member States have now also adopted a comprehensive Global Strategy on Digital Health for 2020-2025. The strategy consists of guiding principles, strategic objectives, action items, milestones, and a monitoring and evaluation framework to advance the "development and adoption of appropriate, accessible, affordable, scalable and sustainable person-centric digital health solutions to prevent, detect, and respond to epidemics and pandemics."⁹

CURRENT CHALLENGES IN MAKING NATIONAL HEALTH DATA ECOSYSTEMS MORE INTEROPERABLE

Unfortunately, systems for processing this data are not sufficiently interoperable, limiting the potential of digital transformations underway

In order to optimize the benefits of digitalization, these disparate systems must be able to seamlessly share data with one another (referred to as electronic health information exchange (HIE). Currently, however, there are a number of barriers hindering the interoperability of these systems. First, data is often collected in an unstandardized fashion. Second, systems do not speak to one another. Third, patient identifiers are not uniform and are often inadequate, with data quality that is variable.¹⁰ Fourth, there might be a lack of trust in sharing data with each other. 1. TB data is collected in an unstandardized fashion.

Fundamentally impeding data interoperability is a lack of standardization in data collection. In digitized health systems, EHRs are used to collect patients' data, which is then presented through a Continuity of Care Document (CCD) format, most frequently in the specific type of CCD called Consolidated Clinical Document Architecture (C-CDA). The information included in CCDs and C-CDAs includes a patient's history, diagnosis, demographics, medications, allergies, past procedures, lab results, immunizations, health risks, concerns, etc.¹¹

Healthcare providers, however, often fill out only selective fields of a CCD based on individual assessments of relevant data, rather than inputting information using widely agreed upon standards. The differences in various EHR systems' interfaces for recording patient information is one reason providers may input information in different data fields. Even when the same EHR systems are being utilized across a network, practitioners may enter information in a distinct way. For example, a provider may choose to use location-specific terms or may arbitrarily decide to enter certain patient information in different fields.¹²

Systematic data discrepancies can be driven by a lack of emphasis on the importance of record standardization within an organization, or by the absence of an overarching, enforced and collectively agreed upon set of guidelines for data entry. Due to lack of sufficient oversight and training, individuals may continuously make inputting errors, without fully understanding the impact these discrepancies may have on the overall utility of the data.¹³

Whereas each inconsistency is minor in and of itself, in the aggregate, health systems are unable to reconcile the hundreds of thousands of discrepancies in patient data recording. Compounded discrepancies such as these are felt at the national and international levels, as inconsistent data can hinder epidemiological models for TB management, preventing individuals from receiving adequate care.

2. Systems do not connect or speak to one another.

Though several international organizations have compiled robust TB datasets at the country-level, such as in the WHO's "Global Tuberculosis Report 2021,"¹⁴ localized data is often unable to be integrated into these larger global datasets due to a lack of interoperability. In their review of US hospitals' progress towards interoperability, Holmgren et al. found that digital health infrastructure is frequently more focused on ensuring that data can be transferred between locations, but not on ensuring the data can then be integrated into other locations' systems.¹⁵

Lack of standardization also can exist within a hospital system, with different

departments utilizing their own vendors for HER and HIE projects, which not only inhibits systems from integrating external data, but also prevents them from fully leveraging their internal data.¹⁶

3. Patients' identifiers are inadequate, inaccurate, duplicative, or otherwise compromised.

Patients often receive care from multiple sources in vertical health structures, necessitating the transfer of CCDs amongst different sets of providers. To retrieve the correct CCDs, providers must use some form of patient identification. However, identifiers are not currently standardized, forcing providers to make educated guesses based on holes or discrepancies, leading to errors in evaluation of patient forms, and making it impossible for organizations to meaningfully link data across disease streams. Erroneous identification can have serious consequences, as a lack of incomplete or inaccurate information could result in misdiagnosis, duplicative care, inadequate care, or unnecessary treatments.¹⁷ Further, inaccurate patient data resulting from misidentification will skew results in secondary data analysis, which often informs public health decisionmaking.18

While identification issues impact all diseases, the impact on TB care is acute. A survey of 135 individuals involved with TB clinical care or TB research in high-burden countries revealed that lack of unique patient identifiers is one of the top three data-related barriers to proper TB care. Inadequate patient identifiers leads to incorrect patient matching, which can delay treatment and research. Delays and confusion in treatment processes can also allow prolonged opportunity for patients to transmit or experience serious side effects.¹⁹

The ideal patient identifier is unique, permanent, and available for all individuals. Problems arise when patients do not have an identifier, have a non-unique identifier, or have multiple identifiers. Around the world, various patient identification techniques are utilized; however, these systems have yet to achieve perfect accuracy.²⁰

A number of countries have implemented standardized unique patient identifiers (UPIs), including England, Denmark, Estonia, Spain, Ireland, New Zealand, China, and Israel. UPIs, though, can present their own challenges. In Singapore, the National Registration Identity Card was chosen as the UPI, excluding the 28% of habitants without an identity card. In this case, the identifier was unique but not accessible to all. In the US, UPIs have been consistently shot down over privacy and security concerns.

Countries have also experimented with a number of UPI alternatives. Algorithmic approaches, for example, combine a multitude of patient-specific identifiers – such as name, birthday, address, gender, etc. – to match patients to their CCDs. A lack of standardization of the inputted traits limits the success rate of identifier matching. Other identification methods include referential matching software, biometric identification systems, and radio frequency identification. Each has its own flaws, such as exclusion of certain demographics, inaccuracy on younger age groups, and privacy concerns, respectively.²¹

Finally, the quality of health data can be compromised, either unintentionally or intentionally.²² Inaccurate data leads to inaccurate insights, which can misinform TB alleviation efforts, across the care pathway.

4. There is a lack of trust in sharing data with each other.

Some healthcare providers and system developers have been found to intentionally manipulate or withhold data, through a practice called information blocking. Until recently, hospitals and laboratories used to assume that the data they collect from the patients are "owned" by them and hence, they can choose to share it with others or not. However, there is a growing consensus that this data really belongs to the patient. In this case, different healthcare facilities (public or private in laboratories or treatment centers) will be increasingly expected to come together to develop a framework for sharing data with each other.

In some instances, decisionmakers might not want to share disease or treatment data that could be misunderstood by other stakeholders. An increase in the number of diagnosed cases, for example, may not always reflect program failure; instead, it could mean that a TB campaign is successfully screening and treating a greater number of patients. In this instance, nevertheless, program administrators may refrain from sharing certain types of data for fear that doing so could give the false impression that their program or initiative is performing poorly. ²³

In TB-endemic environments in which case finding and treatment processes are already less efficient, purposeful withholding of information poses a large threat to the ability to properly manage TB overall. At the country-level, policymakers may also feel that more transparently reporting TB data could lead to decreases in funding from large institutional donors.

BENEFITS OF IMPROVING DATA INTEROPERABILITY FOR TB

Improving interoperability will make TB initiatives more robust and integrated

Enhanced data interoperability would yield many benefits to the fight against TB and to global healthcare systems in general. These benefits span all aspects of TB management, including case finding, resource allocation, treatment administration, and insight derivation.

1. Improving Case Finding

Case finding, the process of identifying and beginning treatment of individuals with TB, is one of the most basic and crucial steps of TB management. Unfortunately, because case data is often reported by geographical units that tend to be disconnected and to not systematically share data with one another, traditional case tracking programs can be inhibited. Improved interoperability, conversely, allows for more timely and accurate aggregation of that data, leading to insights about case clusters, contact tracing, and movement of cases. Such insights can be used not only to track ongoing cases but also to predict future cases and clusters, guiding preventive interventions.²⁴

Efficiency in case finding is also beneficial in identifying, tracking, and treating drugresistant and mutant strains of TB. Due to the prevalence of bacteria that do not respond to the most effective TB treatments, drug-resistant and mutant cases present particular difficulties in the treatment process.²⁵ The ability to pinpoint and prevent the spread of these cases would yield game-changing results, as currently only 57% of multidrug-resistant cases are successfully treated.²⁶

2. Optimizing Resource Allocation

Identifying and filling health product resource gaps is an integral part of TB management. And as global TB funding allocations equate to only half of the estimated funding required to end TB, those resources must be dispensed with a high degree of optimization.²⁷ Better systems for analyzing global health data would allow for more efficient identification of areas with inadequate levels of health products, health professionals, and other resources needed to combat TB.²⁸ Further, data analysis would efficiently allocate those resources to optimize limited funds to achieve the best possible outcomes.²⁹

3. Strengthening Treatment Administration

Successfully treating TB requires patients to follow a meticulous drug intake plan over a period of weeks or even months. Deviation from the correct drug course can have severe consequences. Thus, many health professionals recommend direct observation of patients' drug intake, faceto-face or through telehealth appointments. TB treatment can be hindered by potential medication interactions, requiring health providers and drug monitors to have accurate and comprehensive information of a patients' prescriptions and medical history.³⁰ Interoperability is essential to ensuring patients' medical providers have accurate information regarding TB and other medications, including date of prescription, dates of administrations, and dosage.³¹

4. Deriving Insights from Data

Currently, a wide range of organizations, such as international NGOs, national governments, grassroots health initiatives, and more, track TB data and make programmatic decisions about insights from these databases. Enhanced interoperability of systems would allow for a robust and connected dataset that spans geographic and sectoral boundaries.³² Such a comprehensive dataset would drive insights beyond case tracking. A more complete dataset would help national and international bodies better guide policies, program implementation, and initiative planning. Further, artificial intelligence could be leveraged to automate learnings and suggestions about case finding, resource allocation, and treatment administration.^{33 34}

In addition to improving interoperability between different systems used to gather information on TB, linking TB systems with overall healthcare database, too, would help gather other helpful types of data. For example, linking TB databases with nonhealth databases, such as demographic databases, would help to understand social determinant of health in countries. This could help authorities with their case finding campaigns, as research as shown that people with lower incomes, poor housing, unhealthy environmental conditions but also people with HIV have a higher probability of developing the disease. TB databases could also be linked with HIV databases, with the objective to overlay HIV-test results with TB diagnostics results to identify possible synergies in tackling HIV/TB coinfection.

CASE STUDY: THE GLOBAL DIGITAL HEALTH PARTNERSHIP WORK STREAM ON INTEROPERABILITY

The Global Digital Health Partnership (GDHP) is a collaboration among national governments, territories, and agencies and the WHO to support global digital health advancements, such as data sharing, EHRs, ePrescribing, patient access, and more, through the best practice exchanges and knowledge transfer.³⁵

The GDHP runs a work stream on interoperability in healthcare, through which it publishes a series of white papers recognizing member countries' actions to expand interoperability, suggesting best practices for improving interoperability nationwide, and proposing strategic recommendations for local and national policy makers. Two recent white papers, *Connected Health: Empowering Health through Interoperability* and *Advancing Interoperability Together Globally*, represent dozens of national governments' findings in the pursuit of interoperable health systems.³⁶

Throughout the GDHP papers, adopting an internationally recognized standards body is identified as a common best practice for improving interoperability. These bodies provide frameworks, standards, and guidance to member organizations to aid their implementation of interoperable health systems. As countries begin integration of their healthcare systems, working with a standards body provides a useful roadmap for doing so.³⁷

Additionally, the papers help to identify the most common barriers to interoperability and the steps national governments are taking to overcome them. For example, Canada, the Netherlands, Australia, Austria, the US, and India are creating and enforcing nationally-shared EHR terminologies, which help them overcome a key obstacle - the inability of end-users to use or interpret data that has already been exchanged.³⁸ As integrating interoperable standards can be costly, another barrier governments face is achieving both public and private sector buy-in. The GDHP's papers show how some governments are using legislation and incentives to help shore up cross-sectoral support for interoperability measures.³⁹

CALLS TO ACTION

National governments should agree on standard use-cases to enable crossplatform sharing of patient and nonpatient data

Standardization of systems and methods is one of the most crucial aspects of improving interoperability. National governments should take this lesson into consideration by agreeing upon standard use-cases for exchange of health information. Patient identifiers are a crucial aspect of this process. Governments must establish either standardized or highly interoperable patient identifiers. Further research should be done into feasible patient identification methods to determine and commit to a best path forward. By doing so, public and private health organizations' ability to share health data related to patients, trends, treatments, and more will be eased. The GDHP white papers demonstrate the value in erecting international standards bodies. National governments can join these organizations to learn pre-existing guidelines and implementation best practices, as well as to gain a support network of other countries facing similar challenges.

Global health organizations should craft high-level standards for data collection, management, and organization.

Global health organizations play an essential role in setting international health practice precedents. To enable worldwide adoption of interoperable standards for TB data, global health organizations should establish high-level and forward-looking guidelines for TB data management. By offering guidelines on TB data collection, management, and organization, health organizations can ensure the public and private sectors are aligned to advance interoperability. Although the private sector will often lead data-related tech innovations, global health organizations can ensure both present and future practices are held to common standards. International standardization of data collection would mitigate a glaring issue in current TB data management, which is the disparity between types of data collected. Importantly, these guidelines should be

'living,' in that they are dynamically able to account for new information, innovations, and technologies.

Global health organizations, specifically the World Health Organization and Global Fund, should fund health system strengthening

Until individual countries' health system infrastructure has been advanced, these TB data standards will not be scaled easily. Global health organizations can support the strengthening of countries' health systems monetarily. Global organizations that have funding bodies, such as the Global Fund, should make strategic investments to build out health infrastructures to ensure adequate TB treatment and data management.

The private sector should design and develop new systems with interoperability in mind

As private healthcare providers and health system manufacturers are key stakeholders in the pursuit of interoperability, these entities should design and update systems to be more interoperable. National governments and international organizations can inform private sector efforts to improve interoperability. Private organizations should increase collaboration with the public and NGO sectors to best learn how to achieve interoperability of health systems. The private sector can also help inform global data standards through their own research, recommendations, and thought leadership.

CONCLUSION

Massive amounts of data are produced every day in the fight against TB. This data can be utilized to track cases, contact trace, derive insights, manage resource allocation, and more. Currently, however, much of this data remains fragmented and siloed due to unstandardized data collection, isolated health systems, and insufficient patient identifiers. With help from multi-sector stakeholders, we envision a future where this information is more easily shared across geographic and sectoral boundaries. As more interoperable exchanges of data would have invaluable benefits in TB treatment around the world, we encourage national governments, global health organizations, and private sector partners to do their part in enhancing interoperability of systems to help end TB.

End Notes

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¹⁰ Miriam Reisman, "EHRs: The Challenge of Making Electronic Data Usable and Interoperable," *P&T* 42, no. 9 (2017): p. 573, https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5565131/pdf/ptj4209572.pdf.

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