A CALL TO ACTION

Open access to key facility-level TB indicators

TB
Accountability Consortium

Stellenbosch UNIVERSITY
IYUNIVESITHI
UNIVERSITEIT
forward together
sonke siya phambili
saam vorentoe

Acknowledgements

The authors acknowledge inputs and feedback from David Harrison, Candy Day, Alex van der Heever, Andrew Boulle, Andy Gray, Mark Blecher and Lynn Woolfrey. We credit Lynn Woolfrey with the definition of open access principles. These advisors, however, bear no responsibility for the content of this document or any remaining mistakes. We thank Vera Smit for research assistance.

TBAC

The TB Accountability Consortium was established in 2021 as an advocacy platform aimed at enhancing accountability in improving South Africa's tuberculosis response. Since its inception, the project has built valuable partnerships with organisations including the SANAC TB Task Team, Rural Health Alliance, Treatment Action Campaign, and the University of Stellenbosch, which serves as its knowledge partner.

The TBAC secretariat operates under the Rural Health Advocacy Project (RHAP), a division of the WITS Health Consortium. Dedicated to promoting equitable access to quality healthcare for rural communities across South Africa.

Executive summary

Access to data is essential for public benefit and for transparency, accountability and good governance. But it is difficult to balance the right to know with the right to privacy. Two pieces of South African legislation illustrate these conflicting rights: the Protection of Personal Information Act (POPIA) of 2013 and the Promotion of Access to Information Act (PAIA) of 2000.

POPIA, designed to protect people's personal information, has the potential downside of hindering research. It can impede the sharing of valuable data from public health facilities. This is a serious problem in the case of research on TB, South Africa's leading cause of death. Researchers need access to individual-level data to assess the prevalence of the disease, the efficiency of testing and what progress is being made.

Eagerness to conform to the requirements of POPIA can encourage gatekeeping. Bureaucratic and technical impediments are set up to block or delay access to personal health information.

In this brief we argue that open data – data that anyone can freely use, modify and share for any purpose – is a public good. It enables better health system decisions. It obliges government and public service providers to be transparent and accountable.

We provide evidence-based motivation for open access to key TB indicators in South Africa, while acknowledging concerns about privacy and the complexities of the POPIA legislation. To minimise barriers to data access, we propose a data governance framework.

Privacy can be respected if data is anonymous and aggregated. The data must be reliable, accessible, available on time and analysable. It must be user-friendly for health care providers. It must also be available in a form that patients can understand, as their input matters too.

We acknowledge the need for some control. Researchers can be asked to state their reason for using the data and to be open about the methods they use.

We suggest measures to ensure the accuracy and reliability of the data. Rapid release of data is also vital. It became clear during the Covid-19 pandemic that data can be made available quickly when governments see the urgency.

A further benefit of better access to data is that it can help make the data better. Scrutiny and review brings errors and discrepancies to light and they can then be corrected.

Other countries, particularly New Zealand, the UK and Sweden, have shown that improved access to data encourages better governance and more effective, efficient and equitable resource allocation. We can learn from best practice in data sharing in those countries. Making vital data accessible is essential to help combat the scourge of TB in South Africa.

List of acronyms

CBO	community-based organisation
CDC	Centre for Disease Control
Covid	coronavirus disease
DHIS	District Health Information System
DHS	Demographic and Health Survey
GP	general practitioner
HIV	human immunodeficiency virus
JAMA	Journal of the American Medical Association
NHS	National Health Services
NICD	National Institute for Communicable Diseases
NGO	non-governmental organisation
NPO	non-profit organisation
NHI	National Health Insurance
OECD	Organisation for Economic Co-operation and Development
PAIA	Promotion of Access to Information Act
POPIA	Protection of Personal Information Act
RHAP	Rural Health Advocacy Project
SAMJ	South African Medical Journal
TB	tuberculosis
TBAC	TB Accountability Consortium
UNICEF	United Nations Children's Emergency Fund
WHO	World Health Organisation

A call to action:

Open access to key facility-level TB indicators

Data can be a critical resource for improving public services and aligning priorities to the needs of citizens. Research has provided evidence of the transformative power of transparency and access to data. These studies offer a hopeful narrative of how data can strengthen governance, democracy and accountability and give the poor and marginalised a voice. Access to data can make resource allocation more equitable, effective and efficient. This is something we urgently need in South Africa, especially in recent years with tighter constraints on government spending.

Over the past few years, this hopeful narrative has been overshadowed by anxiety about big data. How can we safeguard personal information amidst the challenges of the rapid growth of social media, new technology and artificial intelligence? New technology and social media have created additional urgency for data protection and data privacy legislation and guidelines.

A person's need for privacy can conflict with the public need for transparency. In the field of health, for instance, sharing people's medical information can threaten their privacy and autonomy. But at the same time access to anonymised and aggregated health information can be of great public benefit.

South Africa's response to the need for data privacy was to introduce the Protection of Personal Information Act (POPIA). But there is concern that the lack of clear guidelines for interpreting this legislation can impede the sharing of valuable data from public health facilities such as clinics and hospitals. For facility-level data, privacy concerns would rarely be applicable since POPIA refers only to person information that can be used to identify a particular data subject.

In this Brief, we provide evidence-based motivation for open access to key TB indicators in South Africa, responding to the concerns about privacy while acknowledging the complexities of the POPIA legislation.

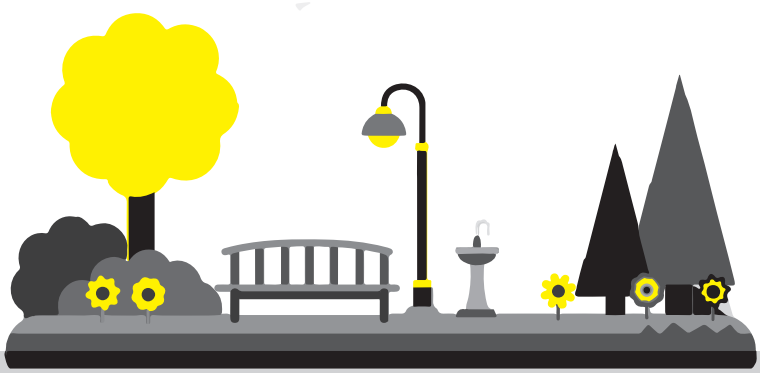
It is disappointing that we receive no regular public updates telling us how indicators like TB testing are recovering since the Covid-19 pandemic. The Department of Health, for example, did not include any TB testing data in its annual report for the 2021/22 financial year. There are widespread concerns about a crisis in TB data, since TB remains the leading cause of death in South Africa. TIER.Net routine data is shared only as national aggregates. The Health System Trust's District Health Barometer reports and its linked district-level data releases in Excel were not published in 2020, 2021 or 2022. This hampered efforts to track TB testing at district or provincial level during a period when the health system was under pressure, and highlights the risk to the health system when the accountable department does not take responsibility for making critical public health data sources available. For aggregated data such as TB indicators from health care facilities (clinics and hospitals), there are unlikely to be any serious privacy concerns. Unless routine data reports on very rare diseases or is broken down into cell sizes below 10 where the information could violate the privacy of individuals, facility-level data does not affect personal privacy and the POPIA legislation is not a concern. Routine data tends to report on high-prevalence diseases that are public health priorities such as TB and HIV. Yet lengthy and burdensome applications impede access to this data.

Open data as a public good

‘Public goods’ are goods that provide benefits that are ‘non-rivalrous’, which means that one person’s use of it and benefit does not prevent others from benefitting or using it. Public goods also have the feature of providing benefits that are ‘non-excludable’, which means that it is difficult or impossible for one person to exclude another from benefitting or using it.

Examples of public goods are street lights, clean air and public parks. Open data is often described as a public good because the benefit it yields is both ‘non-rivalrous’ and ‘non-excludable’. Open data is non-rivalrous because one person’s access to it does not prevent another’s access. Because open data is defined as data that anyone can freely use, modify and share for any purpose – with minimal or no restrictions – open data is also non-excludable. Open data models are based on an internationally accepted core set of principles that have been expressed through open data charters and transparency guidelines.

These broad principles would include:



- **accessibility**: data must be free and equitably available, online, in open formats and licensed as open
- **completeness**: entire datasets must be made available, not just data subsets
- **sustainability**: persistent access
- **primacy**: data must be made available as confidentialised primary data, or individual-level data
- **interpretability**: data must be shared with explanatory metadata
- **timeliness.**

Open data has been shown to improve lives by boosting economic growth, strengthening democracy, accelerating innovation and increasing well-being. Open data delivers public benefits in many ways. It helps people make better decisions and motivates them to perform well. It enhances transparency and accountability. It discourages corruption by intensifying public scrutiny. And we can argue that because our multi-stakeholder health system is so complex, open data is essential for understanding, managing and improving the system.

As a public sector doctor, it feels like TB is the most important public health disease we are facing. Treatment of TB is complicated by many socioeconomic factors that are often beyond the realm of the managing dr to assist with. Poverty, housing, food security, substance abuse and social support directly impacts the TB program. What is frustrating is that clinicians on the ground don't have access to regular data about the TB program. We don't know how many human resources are allocated or finances that are allocated to the program. We can't compare areas that have a high TB burden to areas with lower TB burden, to see how to improve outcomes. More importantly, we don't get prompt data about TB death rates, cure rates or defaulter rates across the country. If this data was available on a widespread, regular basis, it would probably have a positive impact on how the program is managed and the outcomes. It might also force a more holistic approach to managing TB, to also take into account the many social factors....a real time TB dashboard for each hospital or region would be amazing!".

FAMILY PHYSICIAN
Amathole District, Eastern Cape

Open data enables better health system decisions

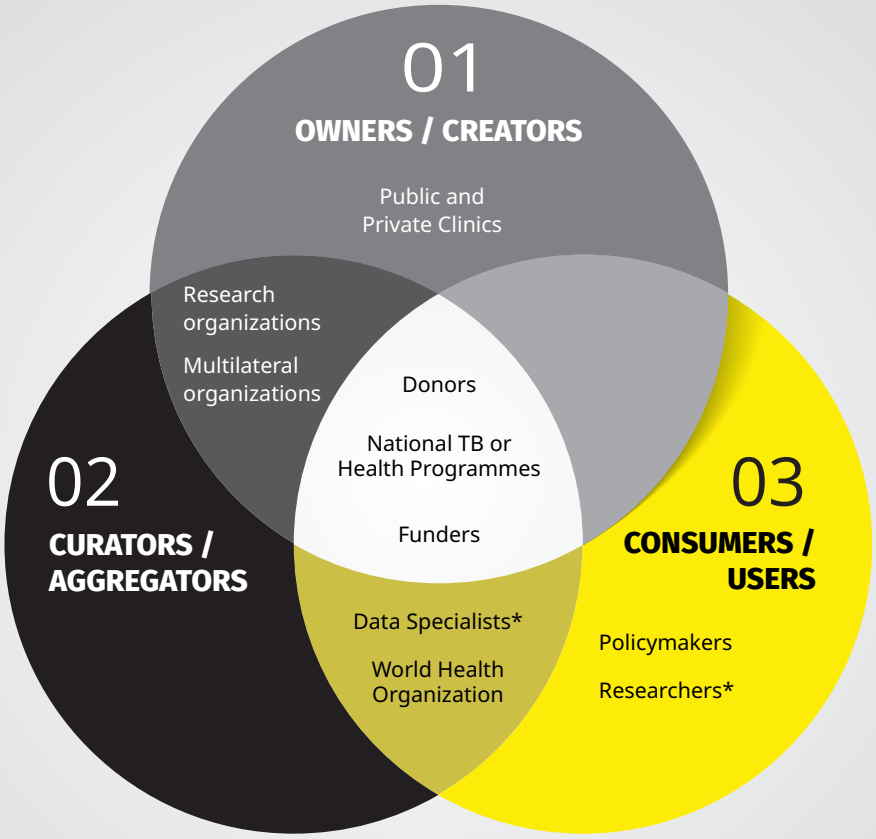
Open data shows us how our health system is performing at various levels. It provides information that enables government, NGOs, NPOs, CBOs, and patients to raise awareness of poor performance and see that it is rectified.

Technological advances hold much promise in this regard. Dr Jean Kaseya, the director general of the Africa Centres for Disease Control and Prevention (Africa CDC), recently urged the acceleration of the digitalisation of biomonitoring, telemedicine and real-time health data management. He said this is critical for the advancement of health systems in Africa. He said transparency is essential for equity. A 2023 opinion piece by Sandro Galea and Salma Abdalla in the Journal of the American Medical Association (JAMA) Forum says much the same: the lack of data on health equity is one of the main obstacles to improving health equity. This aligns with bioethical concerns (ethical, social and legal issues related to health), which today are increasingly about how health care resources are allocated. The Western Cape have demonstrated how consolidated person level health data improves TB surveillance and patient care. The whole-of-society approach includes raising awareness through inter alia a public facing TB dashboard and collaboration across sectors.

The government and the Department of Health have a responsibility for collecting and analysing public health care data to make the best resource allocation choices and ensure that all South Africans have access to high-quality health services. However, the experience during the pandemic made it clear that the health system is not owned by the government, but is much broader and more encompassing. It is only by working together that we can improve health outcomes. Information sharing is vital. The pandemic experience also showed us that the health system is not well served by the biomedical model, which sees health only in terms of biological factors and focuses narrowly on medical expertise.

Figure 1, the diagram below shows a more inclusive and broader perspective, bringing in a wider range of TB data stakeholders who need access to this data, beyond just hospitals and doctors. To improve health outcomes, we need to acknowledge that those outcomes depend on many economic and social factors. We need to invite a broad spectrum of stakeholders to participate. If we want South Africans to use and trust data, then, we need to involve everyone, and in particular marginalised communities, in conversations about what data to collect and how to use it.

Figure 1: Schematic of TB programmatic data stakeholders.



*Including bioinformaticians.

Source: Taaffe et al. (2021)

Open data keeps government and public service providers on their toes

In a democracy, people have a responsibility to hold the government accountable. To do this effectively they need data. Health workers and policymakers need to be responsive and accountable to the people they are appointed to serve. When people have access to information they can put pressure on the government to perform well and allocate resources well. An informed populace is a disincentive to corruption. Open data helps to bring the decisions and actions of those who control resources in line with people's interests.

When people have access to data, this can make politicians more responsive to people's needs and rights. In 2008, Nobel prize winning author Abhijit Banerjee and his colleagues showed that publishing politicians' 'report cards' in local Indian newspapers got those politicians to allocate resources in line with people's needs and preferences. The data on the Delhi state politicians' performance was collected via right-to-information laws. Similarly, Ritva Reinnikka and Jakob Svensson showed in 2011 that corruption and leakages of funds were reduced when information about funding allocated to schools were published in newspapers in Uganda. Previously, no more than 7% of the funding had been reaching the schools. Afterwards, between 62% to 102% of the funding was reaching them. The increased resource allocation boosted enrolment and learning outcomes.

Public service providers can use data as a tool to help them offer the best possible services. Better systems for collecting, using and sharing that data could lead to better targeted and more efficient services and more widespread benefits for society.

Measures to assure the reliability of open data

The most obvious and important way to boost transparency is to provide access to public sector data. This is essential if civil society and legal and media watchdogs are to be able to monitor government institutions. A government institution is transparent only as far as its functioning is open to public scrutiny.

However, ways must be found to prevent people misusing the data. To ensure public trust in the data being collected and the interpretation of the data, we need protection against data falsification (distorting data), data fabrication (inventing data), and erroneous analysis or misleading presentation of the data. Such misuse could have catastrophic consequences. Public sector data is key to informing policy. It enables the government to make good policy decisions. If decisions are made on the basis of falsified or fabricated data, the resulting policy may be not just ineffective but damaging. Fortunately there are many ways to assess the accuracy of health data and guard such data against misuse. For example, health care files could be randomly audited to ensure that the reported data is accurate or analysis can be conducted to identify data quality issues. Organisations using the data may be asked to state clearly their purposes for processing the data and make their methods available for verification of their results. Best practice for effective data governance in the public sector must be identified and implemented to ensure that the health care system is accountable and transparent.

> "Access to reliable data has truly transformed our ability to make meaningful decisions in our organisation. By building a solid data management system, we can track our projects more accurately, see where we're succeeding or falling short, and take action based on real insights. It's not just about collecting data; it's about using it to improve our impact and better serve our community."
>
> **BULUNGULA INCUBATOR**
> Data Monitoring, evaluation, and learning (MEL) Manager, community-based nonprofit organisation

The right to know and participate in health decisions

People have a right to play an active role in maintaining, promoting and restoring their health and a right to participate in the planning, organisation, operation and control of primary health care.

These rights were recognised in the 1978 Declaration of Alma-Ata and updated in the 2018 Declaration of Astana – and both declarations were endorsed at global conferences jointly convened by the WHO and UNICEF. This implies partnership between the decision makers and the beneficiaries. The health system must allow for all stakeholders to be involved. Patient autonomy and dignity are upheld by including patients in decisions about how resources are allocated to health care facilities. Their participation in service delivery governance encourages accountability and responsiveness to needs and enhances equity and social justice.

'Accountability' is a word we see used regularly in health policy statements and documents today. Accountability is universally accepted as essential for good governance. But what exactly do we mean by 'accountability'? Sometimes we see it used vaguely as a synonym for 'good governance'. It can be simply defined as a provider's obligations to the people who need its services, such as a government's obligations to the public, or a hospital's to its patients. (We discuss this further in Appendix 1, in relation to government providers in the health system.)

In South Africa we urgently need more community ownership and better provider accountability. So we often have to rely on accountability channels outside of government, such as the media and advocacy NPOs, and in the last resort on the judicial system.

Three things are hampering efforts to improve the current accountability channels:

THE LIMITED DEVOLUTION OF DECISION-MAKING AND POWER IN THE PUBLIC HEALTH SYSTEM;

PEOPLE'S FEELINGS OF DISEMPOWERMENT AND LOW EXPECTATIONS OF HEALTH PROVIDERS;

AND LACK OF ACCESS TO INFORMATION ABOUT LOCAL FACILITIES AND PROVIDERS.

These problems need to be addressed. Devolution, the government's transferring or delegating decision-making and power to the local level, is crucial for local accountability. Health care facilities cannot be held to account if they do not have the authority to make their own decisions and deal with people's complaints. If people feel disempowered and expect little of the health care provision, they will not be in a position to raise objections. They can only make effective use of the available accountability channels if they know their rights and what they should be able to expect of health services. And they can do nothing if they lack information that is accurate, easy to access and regularly updated. Such data is essential to help communities and patients assess and evaluate local service provision.

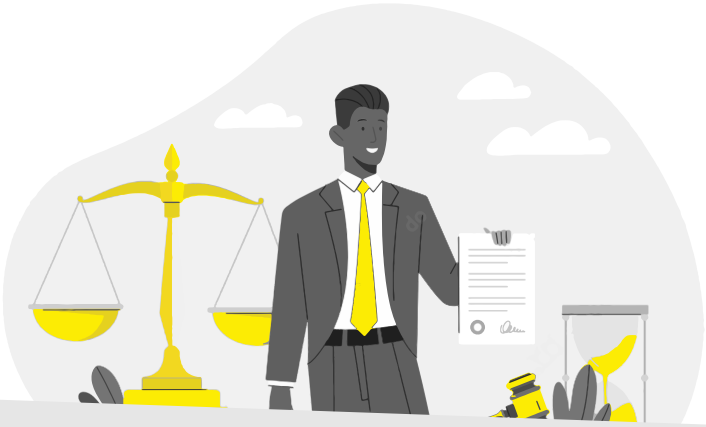
Devolution, the government's transferring or delegating decision-making and power to the local level, is crucial for local accountability.

The best place to start is with the third of these problems: lack of access to data.

The best place to start is with the third of these problems: lack of access to data. The right to participate in health decisions implies the right to know about health decisions. Over recent decades we have seen a rapid expansion of Freedom of Information Acts, from a small number of countries in northern Europe to over 100 countries worldwide. Such Acts can safeguard people's rights to be informed about government decisions and performance. Government policies and practices supporting access to open data have also been introduced.

"The world is failing to children with TB, we need to joint forces to improve access to diagnosis and care for children with TB and we need to ensure that our M&E systems integrate that to monitor progress and success"

SENIOR HIV/TB ADVISOR,
Southern Africa Medical Unit (SAMU), MSF



Balancing the right to know against the right to privacy

The right to privacy limits the right to information. In South Africa these two general rights are outlined in three pieces of legislation: the Bill of Rights contained in the Constitution of the Republic of South Africa (1996), the Promotion of Access to Information Act (2000) and the Protection of Personal Information Act (2013). The South African common law also protects the right to privacy. Moreover, there are specific privacy protections contained in legislation regulating various industries, including the healthcare sector.

The Constitution of the Republic of South Africa (1996) is the supreme law. Chapter 2, the Bill of Rights, includes the right to privacy (Section 14), and the right to access to information (Section 32). As with all rights enshrined in the Constitution, these rights enjoy equal status and can only be limited if such limitation is reasonable and justifiable in accordance with Section 36. But public officials in the health sector often withhold or limit access to patient-level data (regardless of whether it identifies individual patients or is anonymised). They attempt to justify this action by saying they are protecting patients' privacy. This creates tension between the right to information and the right to privacy. They fail to take into account that allowing access to information is essential for transparency, accountability and good governance. Access to information, in turn, makes it possible to enjoy and protect other rights enshrined in the Bill of Rights. For example, to enjoy the right to education, Section 29, people might need to access details about public providers and facilities.

The Promotion of Access to Information Act (PAIA) of 2000 gives legislative effect to Section 32. Legal expert Richard Calland has pointed out difficulties that government officials could encounter in the implementation of this Act (Calland 2009). He says PAIA recognises that to promote access to information we will have to tackle the secretive and unresponsive culture in the public sector that was inherited from the apartheid government. and more recently the risk aversion of the public officials who are custodians of our information. Some of them have been disciplined in recent years for releasing information in contravention of public service regulations. This has led to unjustifiable withholding of information. Calland says that reasons for this excessive fear of risk are failure to understand the relevant legislation, worry that they might be exposing poor quality or incomplete information, and general unwillingness to share information.

To further protect the right to privacy and govern the sharing of personal data, the Protection of Personal Information Act (POPIA) was introduced in 2013 and came into force in July 2020. This Act came at a time when, internationally and in South Africa, there was a large increase in administrative data that could be used for public policy and to improve lives. At the same time there was a move towards more open science. These changes made it necessary to update and strengthen data privacy laws. In South Africa, an additional reason for this was an attempt to align the local governance of privacy protection and the push for greater access to data with the regulations and policies of international stakeholders like funders of health research.

POPIA prohibits the processing of 'special personal information' unless a limited exemption applies. This includes individuals' health related information. Health information can be released only if it is aggregated to facility level or if it has been anonymised. Aggregating and anonymising public records requires time investment by government and in-house skills and knowledge.

The processing of health information is allowable under the exemptions contained in Sections 27, 32 and 37. These include:

Consent from the data subject [the individual whose data is collected] is obtained for the processing of the information;

The processing of the personal information is required for the exercising, protection or enjoyment of a right or obligation stemming from South African law or international public law;

Public interest or benefit is ensured when personal information is processed for historical, statistical or research purposes; and

The benefit derived by the data subject or third party from processing personal information outweighs the costs or interference that arise as a result from the infringement of the privacy of the data subject or third party.

These exemptions are still subject to the further requirements of POPIA, including (among other things) the implementation of technical and organisational safeguards to protect personal information, disclosure of certain information to data subjects concerning the manner in which their personal information is to be processed and the overriding commitment to process personal information in a manner that is reasonable and not unnecessarily invasive to a data subject.

The Act contemplates the publication of Codes of Conduct as guidance on how to implement and comply with POPIA in specific sectors. To date, no Code of Conduct has been approved by the Information Regulator. This has created uncertainty in the application of POPIA. People are concerned that this lack of guidance can be used as a smokescreen for not releasing public data.

There is a debate raging in the academic arena arising from the publication in 2023 of the legal opinion of Victoria Bronstein and Daphine Nyachowe in the South African Medical Journal (SAMJ). They say the purpose of POPIA was to enact legislation that provides for the governance of data protection in areas where such governance is lacking or inadequate. In areas where such governance is already in place and is 'more extensive' than the governance provided by POPIA, then, say Bronstein and Nyachowe, according to Section 3(2)(b) of POPIA the provisions of POPIA would be overridden by the existing legislation. They argue that the collection of legislation, regulations, guidelines and structures[1] already in place to govern the processing of personal information for health research satisfies the 'more extensive'[2] requirement. They say that 'structures for the regulation of health research are more rigorous than the requirements in POPIA' (Bronstein & Nyachowe, 2023:1320). Consequently, people who solely rely on the provisions of POPIA to justify restricting access to health data could contravene the law if they ignore specific requirements that may be imposed by other pieces of legislation of regulation. In this context, it is important to reiterate that POPIA permits the processing of special personal information where it is necessary to exercise, protect or enjoy a right or obligation stemming from South African law or international public law.

The Bronstein and Nyachowe interpretation has been challenged in a reply in the SAMJ by Donrich Thaldar. He disagrees with Bronstein and Nyachowe's interpretation, saying it relies on a misinterpretation of 'more extensive'. He argues that 'more extensive' does not mean whether there is more legislation or more detailed legislation but whether this legislation provides more extensive protection of the data subject. He says the amount of protection provided by the various pieces of existing legislation, in comparison with POPIA, should be assessed on the basis of specific conditions, such as the guidelines they provide for the use of data for research. He argues that what Section 3(2)(b) in the POPIA legislation is asking is whether there are any specific legal rules in the existing health research legislation that provide 'more extensive protection of the rights of the data subjects than any of POPIA's conditions' (Thaldar 2023:1454).

---

[1] Prior to the enactment of POPIA, the processing of personal information for health research in South Africa was governed by the following: National Health Act No. 61 of 2003; National Department of Health 2015,'Ethics in health research: Principles, processes and structures'; Health Professions Act No. 56 of 1974; Health Professions Council of South Africa guidelines that include general ethical guidelines for health researchers; Promotion of Access to Information Act No. 2 of 2000 guidelines on keeping patients' records; and the South African Medical Research Council's guidelines on the responsible conduct of research (Bronstein & Nyachowe, 2023:1319).

[2] See https://www.samedical.org/file/2048 for a more detailed comparison of POPIA and the existing legislation.

An issue that complicates access to personal health data is who gives access to it. Ciara Staunton and her colleagues say this is usually the person who collected it, but it may also be 'a gatekeeper who is difficult to identify'. They note that 'certain individuals hold considerable power in deciding access and they can block access to the personal health information without any justification or accountable process in place' (2021:10). This goes against the spirit of POPIA and the Constitution. POPIA has shortcomings, but it does permit the sharing of personal health data in specific instances, especially when the public interest and benefit of the data subjects outweigh interference with their privacy, or where the sharing is specifically permitted under other legislation.

What this all comes down to is how to decide between what is permitted and what is required; in other words, what data the law permits data owners or custodians to make available, and what data the law obliges them to make available.

> "Having a real time TB dashboard would be motivating for programs like contact tracing- imagine visibly being able to show that households have been traced and followed up. Kind of like a barometer of how much work has been done".
>
> **FAMILY PHYSICIAN,** Eastern Cape

DATA GOVERNANCE:

Learning from best practice

In deciding between what is permitted and what is required, decision makers may naturally gravitate towards minimal risk taking and provide no more than what the law requires. A data governance framework can prevent this gravitation towards minimal risk taking and minimum disclosure.

A health data governance brief created in 2015 by the OECD (Organisation for Economic Co-operation and Development) lists eight mechanisms for governing data: health information systems, a legal framework, public communication, certification or accreditation of processors, project approval processes, data de-identification guidelines, data security and management, and data governance review cycles. The OECD surveyed the health data governance practices of 22 of its member countries and found that eight of them had independent ethics review boards to advise them. Nine of them had a process for accessing anonymised public health data. Finland and Iceland had full transparency about decisions to allow access to individual data, with the outcomes of the applications being published on a website. For best practice in data sharing and governance, there is general consensus that New Zealand, the UK and Sweden are the leaders. For instance, the website NHS England allows the public to download provider-level indicators and for some of the indicators this is available monthly with a delay of about two months. Anyone can download monthly provider-level cancer treatment waiting time statistics from in a readily analysable (Excel) file.

Despite PAIA, too few public and private health databases are made available to the public in a timely manner in South Africa. Many databases of public importance are accessible in principle but effectively protected from widespread scrutiny by long-drawn-out or unpredictable bureaucratic processes. The law requires that the data be provided when requested, but technical and bureaucratic impediments make it difficult to access. Technical impediments are such things as lack of capacity to routinely produce and publish standard anonymised data extracts, inconvenient formats or websites that are hard to navigate. Bureaucratic impediments are such things as the time and cost burden of requesting the data, which may involve paperwork, and waiting for it to arrive. In many other countries, such as England and Australia, the same data is downloadable from government websites without any paperwork being required.

In South Africa public entities such as the national and provincial departments of health often incur high costs to collect and store data. This is wasted expenditure if they fail to release this data to stakeholders promptly. Data is often released only after long delays. Recent examples have been the Demographic and Health Survey (25 months), the National TB Prevalence Survey (19 months), the National Immunisation Coverage Survey (2020, where the report was published in March 2022 even though fieldwork ended in June 2019) and the Statistics South Africa publication 'Mortality and causes of death in South Africa: Findings from death notification 2019', which was released on 13 December 2023. The most updated report released by the NICD is the National TB Surveillance Report 2004–2015,. Timely and evidence-based policy decisions cannot be made when there are delays like this.

The response to the Covid-19 pandemic may have shifted expectations and norms. The real-time collection and release of district-level data on Covid-19 testing and positive cases showed that data can be released quickly, promoting transparency and evidence-based decision-making. The rapid surveys and surveillance systems set up during the pandemic demonstrated the value of timely data. They showed that the processes of data cleaning, preparation, curation and analysis can be expedited when governments see the value in data release.

What TB data do we need to improve TB health outcomes?

To deal with the scourge of TB in South Africa, we need good quality data that is reliable, accessible, available on time and analysable. Rapid release is vital. Public health care data that is two years out of date cannot lead to effective and informed decision making. It cannot ensure accountability. Table 1 lists criteria that data (in the form of indicators, such as the numbers of TB tests, that analysts can use to interpret the current or future state of health care) must meet to promote accountability. The first group of criteria applies to the accountability of health care providers and facilities. The second group applies to patients. Patients can hold providers and facilities to account only if the data is available in a suitable form. When patients share their evaluations of service delivery, their voices are more likely to be heard and their views taken seriously when they have access to data that is easy to interpret and understand and that matters to most people. For instance, an increase in a composite measure such as an index could be difficult to interpret, while a rise in avoidable deaths among children under five is easily recognised as an indicator that matters.

Table 1: Requirements for health system data to enhance accountability

Accountability dimension	Data must…
Local facilities and providers	Be available timeously, to ensure early detection of problems and a rapid response.
	Be widely perceived as credible, reliable and accurate.
	Be available at regular intervals (at least yearly) to enable tracking over time.
	Be available from the area where people will be affected and need support, such as at facilities or district level.
	Allow early identification of problems, for example an increase in obesity in children rather than diabetes or cardiovascular disease decades later.
	Provide comprehensive coverage of health system inputs, performance and outcomes.
Patients' voice	Be easy to understand and interpret.
	Show clearly why the data matters, and why communities and patient groups care about it and want to work towards finding solutions to the problems it reveals.

Source: Authors' synthesis from the literature

Applying the criteria in Table 1, we propose a list of priority TB indicators. This is shown in Table 2. As these include only data that has already been collected, no one can argue that timely and regular public release is impossible, unreasonable or unaffordable. All the indicators listed in this table are, as far as we know, available at regular intervals and sufficiently standardised that they can be tracked over time. Currently they are released only after a long delay, if at all. We need to understand what is preventing a speedier release.

These indicators are based on information available at either facility or district level. At the moment, access to facility-level and district-level routine public-sector TB indicators requires well-motivated applications stating the intended use of the data. Typical processing times are reported to vary between three and twelve months.

This bureaucratic obstruction is not in the public interest. Facility-level and district-level data is needed to track equity in access to TB diagnosis and treatment and to identify districts and facilities that may need more support if TB health outcomes are poor there. Providing TB data only at national or provincial level obscures these differences. A further problem is that only aggregated data is available. A Lancet Commission report on the future of health in sub-Saharan Africa noted that for local monitoring and accountability we need disaggregated data.

We also need to know that the data is credible, reliable and accurate.

Many policy documents on the benefits of data sharing assume that this is the case. This is a risky assumption. Inaccurate data can lead to misallocation of funds and poor decisions. Better access to data could help make the data better. Scrutiny and review will bring errors and discrepancies to light and they can then be corrected. More attention needs to be paid to accuracy in data capturing.

Facilities could be given targets and benchmarks to help achieve this. Digitisation should bring improvements as it can make it easier to avoid or flag data processing errors.

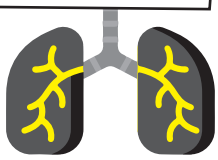
Table 2: Priority TB indicators for open access

Area	Indicator	Value of this indicator and availability	Data source
TB prevention	TB contacts started on TB Preventive therapy (TPT) as a proportion of asymptomatic TB contacts	Tracks strength of TB prevention initiatives. Currently only tracked in DHIS for children under 5 years, but Recovery Plan is broader and includes adults	DHIS
	TB screening	Clients screened for TB symptoms as a proportion of PHC headcount 5 years and older	DHIS
Testing	TB tests administered (facility records)	Creating demand for TB testing through advocacy and communication, to increase finding undiagnosed TB is a key objective of the TB Recovery Plan	NHLS, DHIS
	TB tests conducted (laboratory tests)	Scale up of routine testing of high risk groups is a key objective for accelerated implementation of TUTT (targeted universal TB testing)	
	TB cases diagnosed through testing (DS, Rif resistant, MDR, XDR)	Key measure of case finding, and denominator for linkage to care and treatment outcome indicators	
	TB symptomatic individual screened in facility rate	Monitors trends in early identification of TB symptomatic clients in health care facilities	
Linkage to care (Treatment)	HIV positive TB cases on ART	All co-infected clients must be on ART to reduce mortality. This includes clients already on ART at TB treatment initiation and those started on ART during TB treatment. Monitors ART coverage for TB clients	EDRWeb, NHLS Xpert, DHIS, TIER.net
	Treatment started as share of TB DS positive	Linking patient-level positive laboratory testing with patient-level TIER.net treatment initiation	
	TB Rifampicin resistant/MDR/XDR treatment start rate	TB Rifampicin Resistant/MDR/ XDR clients started on treatment as a proportion of TB Rifampicin Resistant/MDR/XDR confirmed clients	

Area	Indicator	Value of this indicator and availability	Data source
Retention in care (Loss to follow-up)	TB DS client loss to follow-up rate	Important to improve retention in care and avoid development of drug resistance, infection of other people, as well as morbidity and mortality.	ETR/ Tier.Net, EDRWeb
	TB MDR client loss to follow-up rate		
	TB XDR client loss to follow-up rate		
Treatment success	TB DS treatment success rate	A key outcome measure of successful management of TB patients	ETR/ Tier.Net, EDRWeb
	TB MDR treatment success rate		
	TB XDR treatment success rate		
Death	TB DS death rate	A key outcome measure of overall success of the TB programme, including TB prevention, timely identification and effective treatment of TB	ETR/ Tier.Net, EDRWeb, MRC Burden of Disease Unit, Stats SA Causes of Death
	TB MDR client death rate		
	TB XDR client death rate		
	%YLL lost due to HIV and TB	An important measure of the relative burden of HIV and TB for priority setting. This is important, but does lag by some years due to delay in cause of death data, and requires a substantial amount of data processing that has been done by MRC in collaboration with HST for the District Health Barometer.	
TB expenditure	Total cost estimates for TB by intervention and by year (ZAR billions), by prevention, case finding, TB DS diagnosis, treatment and care, TB MDR/XDR diagnosis, treatment and care	Indicator of resource allocation and budget prioritisation. Difficult to track since not ringfenced in provincial budgets. The available estimates are often projected based on intervention costs and targeted volumes.	BAS

To give patients a voice, the health care system indicators need to be straightforward and easy to interpret and their impact should be clear. For this purpose, it is difficult to think of a more compelling TB indicator than deaths and death rates. TB remains the leading cause of death in South Africa. Between 6 and 8% of patients on TB treatment die of TB. Preventing theseoften avoidable deaths is at the heart of many advocacy campaigns motivating for more resources and a greater focus on improving TB service delivery. With the slow progress in reducing deaths from TB, an annual report showing the underlying causes and trends in TB deaths would be useful – perhaps something similar to the Saving Mothers and Saving Babies audits.

6-8%
of patients on TB treatment die of TB.



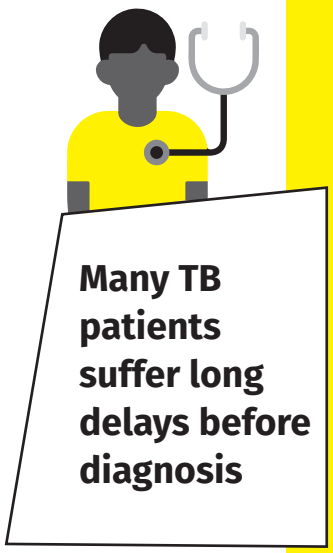
The indicators need to provide comprehensive coverage of TB prevention, active case finding, diagnosis and treatment. The list in Table 2 has some obvious shortcomings. Firstly, the variability in the data completeness of death reporting across the country is a challenge hence the focus on a relative measure rather than disease-specific mortality rates. Nonetheless, mortality rates can be produced for metro areas where completeness is higher and numbers per disease are high enough to calculate rates. These could also be published directly by Stats SA (causes of death reports), although these are 'raw' without the data processing adjustments done by MRC, and the problem of timeous release remains a challenge. There is some imperative to improve the coverage and quality of cause of death reporting, as well as timeousness and release of data disaggregated by district.

Additionally, there are also important shortfalls in data availability. Our table does not include active case finding. It does not cover patients' collection of medicine or failure to collect. It also does not cover the adequacy of TB-specific staffing, but the latter has become more difficult to estimate with efforts to move past a disease-specific focus and embrace a more integrated care perspective. It does not cover stocks of TB medicines, to identify shortages, but civil society reporting

websites such as **https://stockouts.org** can potentially help to supplement this shortfall. Additionally, we can potentially also obtain information from the Central Chronic Medicines Dispensing and Distribution (CCMDD) programme – colloquially known as DablapMeds -- for the areas of the country covered, for stable patients using the service.

Another shortcoming is the lack of longitudinal data, that is, data recorded over an extended period. We need to track TB patients over time to assess continuity of care and the quality of patient management. It is, for instance, difficult to understand the 'transferred out' category of TB 'lost-to-follow-up' patients because we cannot see whether those who are 'lost' at one facility may have continued their treatment at another facility.

The Western Cape Provincial Health Data Centre does allow us to track patients. It links data on case detection, laboratory assessments, treatment access and outcomes. Its database can be accessed with minimal delays, which allows it to function as a shared electronic health record (through a web-based Single Patient Viewer application) and as a surveillance system for specific diseases. Such a system can serve many purposes, including tracking TB patients who are lost in the handover between hospitals and clinics. Tracking across hospital and clinic data systems makes it possible to monitor patients and discover why they get lost. Many TB patients suffer long delays before diagnosis and treatment because they first consulted a private GP. Integrating private and public data systems could provide some oversight of private GP patients with TB symptoms and this may help to address this problem.



A further shortcoming of the current list of TB indicators is its failure to capture health facility performance. Most of these indicators are collected from communities affected by poverty and social problems. This makes it difficult to find indicators that can assess facility performance. For instance, if a facility has a high percentage of patients who drop out of treatment, this could be because nurses fail to follow up with patients, but it could also be a patient problem due to alcohol or drug abuse or mental health problems, or any of the other social problems of a poor community. Indicators with a large range of possible causes are not very useful for promoting accountability. To remedy this problem, the list of TB indicators can be supplemented with patient experience and satisfaction measures and TB nurse compliance metrics linked to TB clinical outcomes. For example, data can be collected on whether the nurses perform essential tasks like reminding patients to come back to the clinic for their tests results or informing about the dangers of TB.

The Ritshidze Project is gathering patient experience data. It aims to use data to boost people's voices so as to hold government and funders accountable for inadequacies in TB and HIV prevention, diagnosis and treatment. The organisers have set up a quarterly community-led monitoring system (covering 400 facilities in 27 districts and eight provinces) that tracks health care indicators such as facility hours and waiting times, clinic conditions, access to medicines and shortages, contraception services and access, and HIV related services. This system could be expanded to cover health worker tasks that are linked to clinical outcomes and to consider whether a mobile survey could collect a broader spread of data.

A final point to consider is the format in which the data is made available. If it is hard copy or a pdf, this means time is wasted before it can be entered into a system and analysed. Dashboards, in which visual data is displayed in one place, are helpful for users, but data displayed in this way often cannot be downloaded for analysis. We need to consider not only what data is required but in what format it should be released. The NHS practice of making databases downloadable in an analysable format such as Excel or comma separated values is ideal. The Data First portal is a good example of a local mechanism to democratise access to open data.

Conclusion

Given the crisis in TB service delivery and TB data, we must all take action to improve access to essential national and disaggregated TB statistics. Our call in this Brief for improved access to TB data is based on a hopeful narrative of achieving large social benefits by minimising barriers to data access, while still respecting privacy concerns. Other countries have shown that improved access to data encourages better governance and more effective, efficient and equitable resource allocation. Their example can provide hope to South Africa's people at a time of fiscal austerity, cutbacks and efforts to fight corruption.

APPENDIX 1:

Accountability framework

The government's obligation derives directly from its election by the people as their representative. This is called the 'short arm' of accountability. Health service providers' obligation has a more indirect derivation, known as the 'long arm' of accountability. It comes from the government's appointment of them, their contractual obligation to the government, the government's obligation to the people, and patients' health needs. Providers can be contracted via salaried employment or via services rendered for a fee. The important point here is that while the government can contract providers to deliver a service, the responsibility for this service remains the government's.

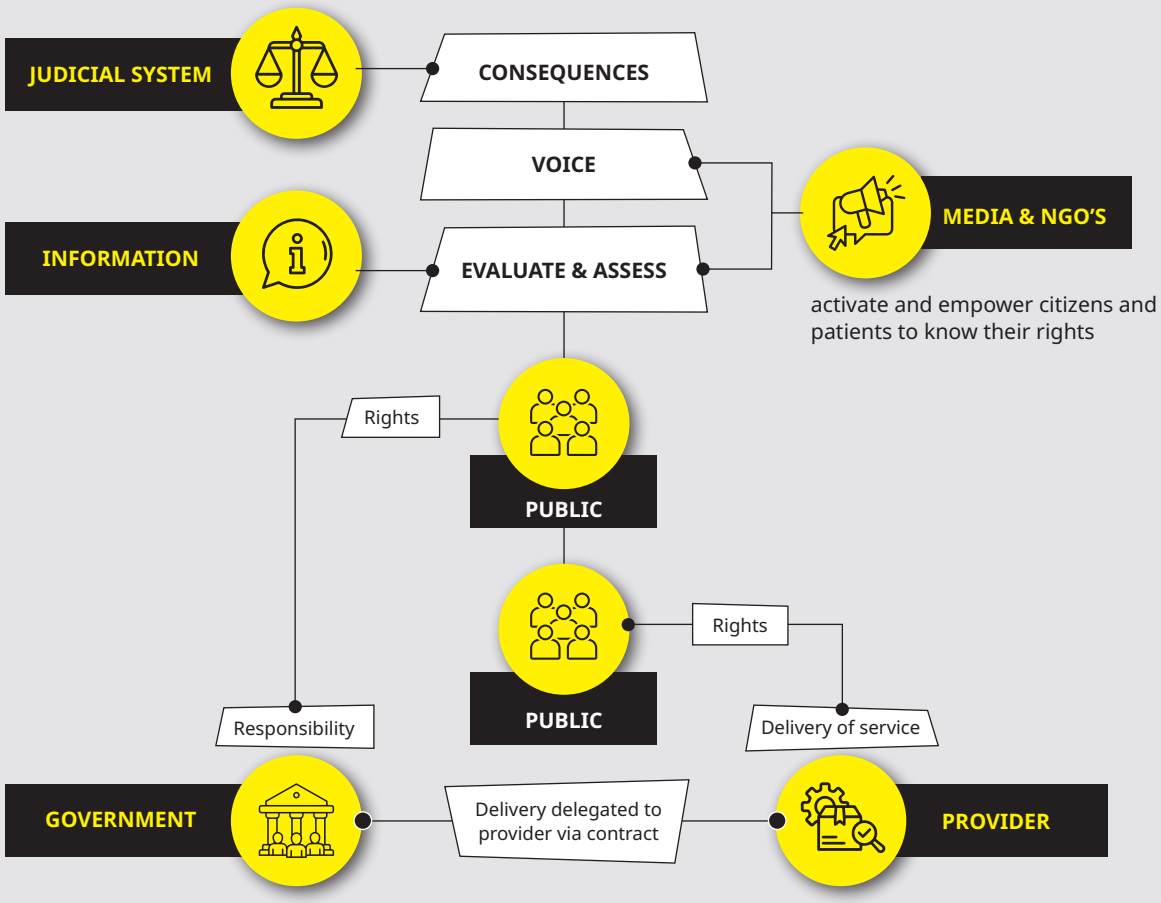
This responsibility implies that people -- in the case of this Brief, patients -- have the right to ask the state to explain why a provider made specific decisions and took certain actions. They can evaluate the decisions and actions and use their voice to complain to the state and call for reform and for penalties and mobilise communities to demand reforms, and also to give positive feedback. Figure 2 illustrates these roles and relationships. In line with the framework proposed by the Lancet Global Health Commission on High Quality Health Systems, we have placed citizens and patients at the centre of this diagram.

Various institutional accountability support mechanisms can support, enhance and strengthen these accountability relationships. Media reporting can help to assess whether the government and providers are meeting their responsibilities. It can give prominence to patients' grievances and reform agendas, making it more likely that their voices will be heard. NGOs play a similar role, using different channels. NGOs and the media can make patients aware of their rights and what they can expect (and demand) from providers and the government. The judicial system can enforce accountability in cases where responsibilities and obligations have been acknowledged as legal rights. In South Africa, research suggests that all three of these mechanisms have been used well and effectively.

Our framework makes it clear how responsibilities and rights are linked to data. Data provides evidence that patients can use to assess and evaluate the health care system and verify the basis for their grievances and demands. Examining the data from the point of view of governance and accountability is a step beyond simply considering whether the data is adequate for planning or decision-making purposes.

Figure 2: Health system relationships for service provider accountability

Source: Author's diagram



APPENDIX 2:

Risks and public benefits associated with data sharing

We need to examine how the risks and public benefits associated with data sharing are recognised, quantified and evaluated by stakeholders to better understand the data trade-offs that are currently being made every day across local government and civil society, and the reasons for these decisions.

The main reason for the drive to make data more accessible in public service provision is to:

Directly benefit patients by making it possible to provide more personalised and targeted services.

Benefit society by increasing the efficiency and effectiveness of public services.

Deliver social outcomes that enhance the well-being of people and communities.

Among the important public benefits of access to data are informing the public about social and economic matters and assisting in the development and evaluation of public policy.

A study commissioned by the Carnegie Trust (2018) identifies three groups that benefit from data-sharing initiatives: individuals benefiting directly from the use of data collected about them, service providers deriving benefits from the use of data about service users, and communities deriving broader benefits. These groups benefit in the following ways:

INDIVIDUALS

- Continuity of care and support.
- The right services offered at the right time.

- Shared information coordinating interventions and providing integrated support services.
- Identification of new or different services to offer.
- Service providers (short term)

SERVICE PROVIDERS (SHORT-TERM)

- Reduction of duplication and waste.
- Support for effective, better targeted front-line service delivery.
- Resources accurately allocated.
- Monitoring of demand and delivery patterns.
- Improved levels of customer satisfaction.

SERVICE PROVIDERS (LONG-TERM)

- Better monitoring and evaluation of service impacts.
- Evidence-based policy and decision making.
- Root cause of problems identified.
- Future service needs predicted.
- Indicators and outcomes shared across service providers.
- Increased public trust in government.

COMMUNITIES

- Intrinsic benefits to society through access to better public services.
- Knock-on effects for everyone, even if they do not use the services, because the increase in overall effectiveness and savings gained from efficiency relieve pressure on the public purse.
- Outcomes for communities improved – through community safety, reduced inequality and community regeneration.

References

Ataguba, J.E., Day, C. & McIntyre, D. 2014. Monitoring and evaluating progress towards universal health coverage in South Africa. PLoS Medicine, September 22. https://doi.org/10.1371/journal.pmed.1001686

Agyepong, I.A., Sewankambo, N., Binagwaho, A., Coll-Seck, A.M., Corrah, T., et al. 2017. The path to longer and healthier lives for all Africans by 2030. The Lancet Commission on the future of health in sub-Saharan Africa. Lancet, 390(10114): 2803–2859. doi:10.1016/S0140-6736(17)31509-X

Banerjee, A., Kumar, S., Pande, R. & Su, F. 2011. Do informed voters make better choices? Experimental evidence from urban India. Unpublished manuscript. URL: https://www.povertyactionlab.org/sites/default/files/research-paper/142%20-%20informed%20voters%20Nov2011.pdf [In the text we refer to work they did in 2008 because this is when the fieldwork occurred.]

Borgesius, F.Z., Gray, J. & van Eechoud, M. 2015. Open data, privacy, and fair information principles: Towards a balancing framework. Berkeley Technology Law Journal, 30(3), 2073–2131. https://www.jstor.org/stable/26377585

Bronstein, V. & Nyachowe, D.T. 2023. Streamlining regulatory processes for health researchers: To what extent does POPIA apply? South African Medical Journal. 113(8): 1319–1321. http://dx.doi.org/10.7196/samj.2023.v113i8.781

Burger, R., Gray, A. & Hompashe, D. 2022. Information and indicators for accountability. In Matsoso, P., Chikte, U., Makubalo, L., Pillay, Y. & Fratt, R. (eds). South African health reforms: 2015–2020: The road ahead. https://issuu.com/janineroper/docs/sahr_final_03.11.22_final_edit?fr=sNjJhMTU1MDY1NTE

Calland, R. 2009. Illuminating the politics and the practice of access to information in South Africa. Chapter 1 in Allan, K. (ed.), Paper wars: Access to information in South Africa, Wits University Press.

Galea, S. & Abdalla, S.M. 2023. Data to improve global health equity: Key challenges. Jama Health Forum, 4(11): p.e234433. doi.org/10.1001/jamahealthforum. 2023.4433

Global Health Strategies. 2021. Strengthening accountability for TB care in South Africa. (PowerPoint presentation.) https://docs.google.com/presentation/d/1GaSg_Xu-FzZ5gWZQhAq1O4nhMyMvgMIt/edit#slide=id.p1

Graham, F.S., Gooden, S.T. & Martin, K.J. 2014. Navigating the transparency–privacy paradox in public sector data sharing. American Review of Public Administration, 46(5): 569–591. https://doi.org/10.1177/0275074014561116

Hammer, J., Aiyar, Y. & Samji, S. 2007. Understanding government failure in public health services. Economic and Political Weekly, 42(40): 4049–4057. https://www.jstor.org/stable/40276648

Health Justice Initiative. 2022. South Africa's National Health Insurance Bill and the future of medicine selection, pricing and procurement: Some critical questions for affordable patient access. National Health Insurance Series, Issue Paper 1, October.

Human, W., Nathavitharana, R., Giddy, J., Schoeman, I. & van der Westhuizen, H.-M. 2023. Opinion: Making good on the promise of SA's TB Recovery Plan. Spotlight. https://www.spotlightnsp.co.za/2023/03/23/opinion-making-good-on-the-promise-of-sas-tb-recovery-plan/

International Open Data Charter. 2015. ODC Principles https://opendatacharter.org/principles/

Involve, The Carnegie UK Trust & Understanding Patient Data. 2018. Data for public benefit: Balancing the risks and benefits of data sharing. https://www.involve.org.uk/resource/data-public-benefit-balancing-risks-and-benefits-data-sharing

Kaseya, J. 2023. A new deal for African health security. Africa Centers for Disease Control and Prevention. https://africacdc.org/news-item/a-new-deal-for-african-health-security/

KnowledgeHub. 2018. The First National TB Prevalence Survey – South Africa 2018. https://knowledgehub.health.gov.za/elibrary/first-national-tb-prevalence-survey-south-africa-2018

Kruk, M.E, Gage, A.D., Arsenault, C., Jordan, K., Leslie, H.H., et al. 2018. High-quality health systems in the Sustainable Development Goals era: Time for a revolution. Lancet Global Health, 6(11): e1196–e1252. doi:10.1016/S2214-109X(18)30386-3

Makamba-Mutevedzi, P.C., Madhi, S., Burnett, R. 2022. Republic Of South Africa Expanded Programme On Immunisation (Epi) National Coverage Survey Report 2020, South Africa: Pretoria. Available from: https://www.health.gov.za/wp-content/uploads/2022/03/National-EPI-Coverage-Survey_Final-full-report-Dec-2020.pdf

Manatu Hauora Ministry of Health, New Zealand. 2021. Improving data management for better health. https://www.health.govt.nz/news-media/media-releases/improving-data-management-better-health

Mayibuye Health Consultancy and Rural Health Advocacy Project. 2022. Health system strengthening post-COVID-19. Johannesburg: Rural Health Advocacy Project.

MEASURE Evaluation. 2018. Barriers to use of health data in low- and middle-income countries: A review of the literature. MEASURE Evaluation Working Paper. https://www.measureevaluation.org/resources/publications/wp-18-211.html

National Department of Health. 2018. Annual Report 2018/19. Pretoria: National Department of Health.

National Department of Health. 2021. Annual Report 2021/22. Pretoria: National Department of Health.

National Department of Health. 2023. Saving mothers and babies: Executive summary 2017–2019. https://www.health.gov.za/wp-content/uploads/2023/05/SAVING-MOTHERS-SAVING-BARIES-REPORT-2017-2019.pdf

National Department of Health. 2023. National Strategic Plan for HIV | TB | STIs 2023–2028. https://knowledgehub.health.gov.za/system/files/elibdownloads/2023-04/NSP-HIV-TB-STIs-2023-2028-MARCH20_23-PRINT2.pdf

National Department of Health, Republic of South Africa. National TB Recovery Plan 2.0, April 2023 – March 2024.

National Department of Health, Republic of South Africa. National TB Recovery Plan 2020.

National Treasury. 2022. Estimates of national expenditure. https://www.treasury.gov.za/documents/national%20budget/2022/ene/Vote%2018%20Health.pdf

National Institute for Communicable Diseases (NICD). 2020. Impact of COVID-19 intervention on TB testing in South Africa. Johannesburg: NICD, Centre for Tuberculosis.

National Institute for Communicable Diseases (NICD). n.d.. Yes! We can end TB. https://www.nicd.ac.za/wp-content/uploads/2023/03/World-TB-Day-2023.pdf

National Institute for Communicable Diseases (NICD). 2019. Microbiologically confirmed tuberculosis 2004–15. https://www.nicd.ac.za/wp-content/uploads/2019/11/National-TB-Surveillace-Report_2004_2015_NICD.pdf

National Institute for Communicable Diseases (NICD). 2023. Strengthening the link between people diagnosed with TB and treatment initiation. https://www.nicd.ac.za/strengthening-the-link-between-people-diagnosed-with-tb-and-treatment-initiation/

Nicholson, T.J., Hoddinott, G., Seddon, J.A., Claassens, M.M., Lopez, E., et al. 2023. A systematic review of risk factors for mortality among tuberculosis patients in South Africa. Systematic Reviews, 12(23). doi.org/10.1186/s13643-023-02175-8

Organisation for Economic Co-operation and Development (OECD). 2022. Towards an integrated health information system in the Netherlands. OECD iLibrary. Paris: OECD Publishing. doi.org/10.1787/a1568975-en

Organisation for Economic Co-operation and Development (OECD). 2015. Health data governance: Privacy, monitoring and research. https://www.oecd.org/health/health-systems/Health-Data-Governance-Policy-Brief.pdf

Osman, M., van Schalkwyk, C., Naidoo, P., Seddon, J.A., Dunbar, R., et al. 2021. Mortality during tuberculosis treatment in South Africa using an 8-year analysis of the national tuberculosis treatment register. Scientific Reports, 11(1). doi.org/10.1038/s41598-021-95331-w

Page, L. & Pande, R. 2018. Ending global poverty: Why money isn't enough. Journal of Economic Perspectives, 32(4): 173–200. https://www.jstor.org/stable/10.2307/26513501

Popescu-Ljungholm, D. 2015. The impact of transparency in enhancing public sector performance. Contemporary Readings in Law and Social Justice, 7(1): 172–178.

Reinikka, R. & Svensson, J. 2011. The power of information in public services: Evidence from education in Uganda. Journal of Public Economics, 95: 956–966. https://doi.org/10.1016/j.jpubeco.2011.02.006

Ritshidze. Community-led clinic monitoring in South Africa. https://ritshidze.org.za

RSA (Republic of South Africa). 2023. Speech by Minister of Health, Dr Joe Phaahla, at the TB Indaba, Southern Sun-Elangeni, Durban, 20 June 2023. https://www.gov.za/news/speeches/minister-joe-phaahla-tb-indaba-20-jun-2023

Silal, S. P., Groome, M. J., Govender, N., Pulliam, J. R. C., Ramadan, O. P., Puren, A., Jassat, W., Leonard, E., Moultrie, H., Meyer-Rath, K-G., Ramkrishna, W., Langa, T., Furumele, T., Moonasar, D., Cohen, C. & Walaza, S. 2022. Leveraging epidemiology as a decision support tool during the COVID-19 epidemic in South Africa. South African Medical Journal, 112(5b):361. http://www.samj.org.za/index.php/samj/article/view/13602.

Smith, M., Heekes, A., von Delft, A., Mutemaringa, T., Tiffin, N. and Boulle, A. 2020. Consolidated Person Level Health Data Improve Tuberculosis Surveillance and Patient Care, International Journal of Population Data Science, 5(5). doi: 10.23889/ijpds.v5i5.1605.

Staunton, C., Tschigg, K. & Sherman, G. 2021. Data protection, data management, and data sharing: Stakeholder perspectives on the protection of personal health information in South Africa. PLoS ONE. https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0260341

Statistics South Africa (Stats SA), 2016. South Africa Demographic and Health Survey 2016. https://dhsprogram.com/pubs/pdf/FR337/FR337.pdf

Statistics South Africa (Stats SA). 2023. Mortality and causes of death in South Africa: Findings from death notification 2019. https://www.westerncape.gov.za/text/mortality_and_caues_of_death_2019_released_2023.pdf

Svensson, J. 2005. Eight questions about corruption. Journal of Economic Perspectives, 19(3): 19–42. https://www.jstor.org/stable/4134971

Taaffe, J., Croda, J., Moultrie, H., Silva, S., Rosenthal, A. & Farhat, M. 2021. Advancing TB research using digitized programmatic data. International Journal of Tuberculosis and Lung Disease, 25(11): 890–895. http://dx.doi.org/10.5588/ijtld.21.0325

TB Accountability Consortium & Bailey, C. 2022. The state of TB in South Africa. Johannesburg: WITS Health Consortium. https://www.wits.ac.za/media/wits-university/faculties-and-schools/health-sciences/images/faculty-news-images/StateOfTB-march2022.pdf

Thaldar, D. 2023. POPIA does indeed apply to health research: A response to Bronstein and Nyachowe. South African Medical Journal, 113(11): 1453–1457. doi.org/10.7196/samj. 2023.v113i11.1345

U4 Anti-Corruption Resource Centre & Transparency International. 2018. Does more transparency improve accountability? https://www.u4.no/publications/does-more-transparency-improve-accountability.pdf

UN Global Pulse, Digital Public Goods Alliance, Global Partnership for Sustainable Development Data, Jain Family Institute, UN Global Pulse & UNICEF. 2023. Exploring data as and in service of the public good. https://digitalpublicgoods.net/PublicGoodDataReport.pdf

University of Kwazulu-Natal, College of Health Sciences. 2023. Medicines access under the National Health Insurance. Technical workshops on South Africa's National Health Insurance (NHI) Bill and the future of medicine selection, pricing and procurement: towards recommendations and solutions. Technical workshops concept note. https://ww3.chs.ukzn.ac.za/news/medicines-access-under-the-national-health-insurance/

Van der Walt, M. & Moyo, S. 2018. The First National TB Prevalence Survey, South Africa: Short report. https://www.knowledgehub.org.za/system/files/elibdownloads/2021-02/A4_SA_TPS%20Short%20 Report_10June20_Final_highres.pdf

Vital Wave Consulting. 2009. Health information systems in developing countries. Palo Alto: Vital Wave Consulting. https://vitalwave.com/wp-content/uploads/2015/09/Gates-Foundation-HIS-Analysis-2009.pdf

Western Cape Department of Health. 2023. Western Cape strengthens efforts to improve TB control in the province, 24 March 2023. Available: https://www.westerncape.gov.za/news/western-cape-strengthens-efforts-improve-tb-control-province.

World Health Organization (WHO). 2021. SCORE for health data technical package: Global report on health data systems and capacity. Geneva: WHO. https://iris.who.int/bitstream/handle/10665/339125/9789240018709-eng.pdf?sequence=1

World Health Organization (WHO). 2022. Global tuberculosis report. Geneva: WHO. https://iris.who.int/bitstream/handle/10665/363752/9789240061729-eng.pdf

World Health Organization (WHO). 2022. Guidance for national strategic planning for tuberculosis. Geneva: WHO. https://iris.who.int/bitstream/handle/10665/361418/9789240052055-eng.pdf?sequence=1


TB
Accountability
Consortium