STOP EXTRACTING

OUR DATA, OUR EVIDENCE, OUR DECISIONS

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n the 1990s, I was working in central Mozambique as the country coordinator of an international NGO. My team worked closely with district health management teams, the branch of local government responsible for health service delivery in the communities where we operated. We found that these teams spent significant amounts of time collecting data and submitting it to their bosses at the provincial or national level of the health system. The whole system was very opaque for the district teams. As far as they were concerned, they collected data and waited for decisions to be made elsewhere. The teams themselves did not have an appreciation for the potential power of these data to catalyze immediate action and drive local public health improvement.

The teams we were working with spent a lot of time collecting data on immunization rates, for example. This information was painstakingly captured at health facilities, which, in post-war Mozambique, lacked even the most basic infrastructure, like electricity and running water. These paper records were sent to provincial health offices, but it was not clear to the teams at the health facilities what happened next, or what happened to the paper forms they submitted to their bosses. It was important to them that

they collected the data because they knew they would be in trouble with their bosses when they did not submit their forms on time. But beyond that, what happened to all that information was a bit of a mystery.

In response, we designed and implemented a program to support these teams to work with the data they were collecting before passing it up the chain to provincial level. We taught the teams how to look at the data, how to perform relatively simple analyses, and how to identify potential local actions *they* could take in response to those data without waiting for feedback from provincial or national health officials, which could take over a year or might never happen at all. If the data showed immunization rates were falling at one specific health facility, we taught them to ask the kinds of questions that might allow them to solve problems themselves. Were there sufficient supplies of vaccines and syringes? Were there enough appropriately trained staff on duty? Could it be a transport issue? Or, perhaps mothers are preoccupied with harvest time. Are there any social or cultural reasons people might not trust vaccines?

At the time, this program, which we called using data for decision making, seemed at once a simple and radical concept. Now, more than twenty years later, there is an enormous focus on "big data" in global health. Unfortunately, much of this discourse has played out in the conference rooms of wealthy countries, far from the halls of the ministries of health that are, ultimately, responsible for the analysis and use of public health data, and even farther from the front-line district health teams collecting those data. In fact, "data" has become big business and, in many ways, has come to resemble an extractive industry. Large and powerful organizations fund and push for the collection (or extraction) of data from lower-resource settings, which are then collated, analyzed, and published, often in prestigious international journals and with much fanfare and celebration about the power of big data to drive evidence-based programming.

The disconnect we saw in Mozambique all those years ago is too often still at play: data collection is something local healthcare workers do. Using data to make decisions is something that happens in a boardroom somewhere else. We collect. We submit. They analyze. They decide. By treating the generation of evidence as an extractive industry, we risk entrenching patterns of exploitation that have been in place since colonial times. As long as we continue to do so, we will reinforce the divide between health care workers who collect data and the academics, funders, governments, and companies that use those data to make decisions.

How, then, can we make the process of collecting data and building evidence better serve the needs of the people affected by the decisions these data are used to inform? In the remainder of this chapter, we focus on two key areas in need of reform: *building grassroots capacity* to more effectively analyze data and build evidence, and *increasing transparency* of the process of transforming data into evidence.

BUILDING GRASSROOTS CAPACITY

The front-line staff collecting data at peripheral levels of health systems continue to lack opportunities to learn and develop data analysis skills, and, therefore, see their role as one of submitting the data to the next level of the system before getting scolded for failing to do so. They do not see it as within their remit to use those data to inform *their* decision making in the service of setting and advancing *their* objectives. By failing to foster and enable the transformation of data into evidence for informed decision making at the front lines of health systems, the development community perpetuates this unfortunate cycle. The sort of work we were doing in Mozambique remains largely unfunded and unfinished.

While data and digital technologies for health have strong potential to catalyze improvement in health systems and health outcomes, the people tasked with managing these technologies often do not fully understand the potential of these systems to inform *their* decision making. Too often, well-meaning providers of technical assistance have started with a new tool, or have shown up with evidence for a particular intervention, and expected the receiving team to respond promptly and positively to either adopt the tool or create new policies and programs. They come with a solution to a problem they believe they understand rather than coming to the table seeking first to understand the specific contexts, challenges, and opportunities present in that country, region, district, or community. Those local contexts, challenges, and opportunities are precisely what Ministry of Health professionals working at various levels in the system are best poised to provide expertise in.

We believe there is a missed opportunity to bolster a fundamental understanding of the intrinsic value and potential of data, evidence, and digital tools. Specifically, we think it is critical that Ministry of Health officials and cadres *first* appreciate the importance of timely and accurate data for decision making in managing their work, *then* the possibilities presented by

digital systems and tools to use that data and evidence to drive better decision making and more effective management.

While we should not be Luddites, we should be skeptical of individuals and groups selling tools and technologies that promise to provide near-magical solutions to problems. Instead, we believe that if Ministry of Health teams at all levels of the system develop an appreciation and understanding of the power of data and evidence, the skills to analyze and transform data into evidence, and how to use that evidence to drive programmatic improvement, then they will be able to broker the sort of partnerships and request the types of tools needed to support *their* efforts *in their* contexts.

When front-line staff have a greater appreciation of the fundamental value of data to support their work, they will have a greater stake in ensuring that accurate, timely information is captured. This will create a virtuous circle, where data leads to better decisions, which leads to better outcomes, which increases the demand for good quality data.

One example of how this can work has emerged from Ethiopia's Community-Based Data for Decision Making (CBDDM) strategy. Under this program, community health workers collect data to create maps of the households they support. These maps also display information relating to each household's reproductive, maternal, newborn, and child health needs. Meetings are then held at community health facilities to review the data to identify barriers to access to services and implement solutions. This allows health workers to set targets, plan and prioritize more effectively, and monitor progress. An evaluation of the program found that the intervention led to significant improvements in the uptake of maternal and child healthcare services.¹

INCREASING TRANSPARENCY

There also needs to be greater transparency concerning the transformation of data into evidence. While we often refer to data and evidence in the same breath, there is not much transparent discourse on the process by which, for example, epidemiological data are turned into evidence. And, generally, that transformation is taking place far from where the data are collected. In some cases, the statistical methodologies and modelling being used are so complex that even specialists are not capable of understanding the process and, therefore, cannot question it or the underlying assumptions used.

This evidence is then used to set targets that countries are expected to meet, further disempowering public health leaders at national and peripheral levels.

In addition, not all sources of data are given equal weight. Randomized controlled trials have emerged as the "gold standard" of evidence for health and many other domains. And while well-designed RCTs can, indeed, be powerful sources of evidence, overly focusing on them risks ignoring other highly relevant and more easily (and inexpensively) collected data that could allow for more local hypothesis generation and testing to drive programmatic decision making.

This work of increasing transparency in evidence building can be time consuming and resource intensive, and does not produce the sort of quick wins generally attractive to large development funders. Therefore, despite all the talk about the importance of data in recent years, not much has changed. Only in the last few years have we seen a surge in discussions about the power of data (especially big data) and its translation into evidence to drive public health programming and accelerate achievement of ambitious global health goals.

Meanwhile, back in the countries and communities from which the data were collected, little action is likely to have been taken in response to the data. As I learned in Mozambique, feedback takes such a long time to reach the initial source (if it ever does get there) that these data-turned-evidence may seem irrelevant.

There are, however, some notable examples of approaches that use inexpensive, community-based approaches to data collection and use these data to hold service providers accountable. In South Africa, for example, a coalition of civil society organizations analyzed the local government's budget for sanitation in a major city's informal settlements and compared it to actual services received on the ground by carrying out a "social audit." The civil society organizations mobilized residents of a poor neighborhood to take stock of public sanitation infrastructure projects in their community and compare their findings to the official figures provided by the city government.

The social audit concluded the city was failing to monitor contractors, leading to wasteful expenditures and human rights violations.² After a presentation of the coalition's findings, the local municipality agreed to repair and better maintain sanitation facilities for 5,000 informal settlement residents, including the installation of new doors, taps, and drains.

Partnerships like this demonstrate what is possible when citizens are given access to information and provided with the skills to interrogate it. It also shows how government transparency might lead to improved levels of trust in government.

DATA FOR DEMOCRACY

The examples of health workers in rural Mozambique or a civil society organization in South Africa may seem removed from the daily reality of many, particularly in wealthier countries. But the broader point is relevant whether you live in Chicago or Chimoio: being able to engage with data has the potential to enable practitioners to make better decisions. More than that, it enables practitioners to translate data into meaningful information and evidence.

Access to information is critical for a functioning democracy. It allows citizens to participate in decisions that shape their lives, to influence the way those in power make decisions, and to hold them accountable for those decisions. Quality information is an indispensable tool in advocating for equal treatment and enabling people to fully participate in civic life. It allows health workers to make timely, informed decisions on where to focus their resources, and enables civil society organizations to hold governments to account for their spending.

Democracy is about more than holding regular elections. At its core, it is about giving people greater control over the decisions that affect their lives. This chapter has argued that greater transparency combined with concerted effort to build data literacy skills of local practitioners will allow people to take greater ownership of their evidence and make more informed decisions. It also gives people the skills they need to hold governments accountable. Ultimately, this will contribute to a deepening of democracy.

Achieving this, however, will require both significant investment and a shift in mindset. Funders looking to support development projects that focus on the use of data are often interested in high-tech tools and innovative technologies with the potential to disrupt old ways of doing things. However, if the appropriate data skills are not in place, these projects are unlikely to build traction over the long term. This implies a need for a longer-term and more practitioner-centric approach, recognizing that building data skills locally is essential to ensuring the sustainability of any

investments. Practitioners, for their part, must recognize their own role: Our data. Our evidence. Our decisions.

NOTES

- 1. A. M. Karim, N. Fesseha Zemichael, T. Shigute, and others, "Effects of a Community-Based Data for Decision-Making Intervention on Maternal and Newborn Health Care Practices in Ethiopia: A Dose-Response Study," *BMC Pregnancy Childbirth* 18, no. 359 (2018), https://doi.org/10.1186/s12884-018-1976-x.
- 2. Social Justice Coalition, "Report of the Khayelitsha 'Mshengu' Toilet Social Audit," International Budget, 2013, www.internationalbudget.org/wp-content/uploads/Social-Justice-Coalition-Report-of-the-Khayelitsha-Mshengu-Toilet-Social-Audit.pdf.