



# DATA GOVERNANCE FOR EARLY WARNING SYSTEMS

## Approaches to Community Engagement

Issue Brief

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## INTRODUCTION

The threat of infectious diseases is increasing because of climate change. Temperature shifts are making it easier for diseases to spread to new geographic areas. And as natural habitats disappear, some animal species are expanding into new habitats that increase opportunities for contact between humans and animals and for the potential spread of zoonotic diseases. For example, warmer temperatures give mosquitoes more time to reproduce and spread diseases such as dengue fever, malaria, and Zika virus.

Early warning systems for pathogens are critical to detecting zoonotic spillover to humans and capturing disease outbreaks at their earliest stage. Over the last three years, FasterCures has brought together global experts in health, finance, data, and technology to articulate a vision and key considerations for global coordination of early warning systems, which are captured in two reports: [\*A Global Early Warning System for Pandemics: Mobilizing Surveillance for Emerging Pathogens\*](#) and [\*A Global Early Warning System for Pandemics: A Blueprint for Coordination\*](#).

The proliferation of new data sources and new datasets, along with advances in analytics, has created unprecedented opportunities to establish early warning systems that not only have capabilities to predict and detect pathogens that could spill over from animals to humans but also can help translate data into action for the whole of society. Recently launched efforts, such as the World Health Organization's (WHO) International Pathogen Surveillance Network, aim to build collaborative systems to identify outbreaks early and prevent them from spreading. As these and other public health data efforts continue, creating pathways for communities to engage in data governance has never been more urgent. Communities play essential roles in early warning. Responsibility for collecting the information that underpins public health data systems often falls to community workers, and, as the eyes and ears on the ground, people living within a community can detect anomalies and potential threats much earlier than formal surveillance systems.

This issue brief reports the findings from three virtual consultations conducted in July 2023 with community health advocates and workers in several African countries. The consultations were designed to explore critical aspects of community engagement in health data governance. They addressed topics such as the involvement of communities in data stewardship, community training for data governance, and the potential for data trusts, and made recommendations for further action.



## BACKGROUND

In 2022, FasterCures, in collaboration with Market Access Africa, initiated a series of consultations on the future of early warning systems in the wake of the COVID-19 pandemic. These consultations were intended to contribute to ongoing efforts to construct a more resilient global health architecture in preparedness for future pandemics and to strengthen the capacity to detect, track, and analyze pandemic threats in real time, especially where they are most likely to occur. These consultations, conducted under the Chatham House Rule and attended by leaders of scientific, research, and community-centered organizations based in Africa, highlighted, among other issues, a trust deficit between communities and global health ambitions in the execution of “all-of-society approaches” to combatting pandemics.

To address this deficit and contribute community perspectives for improving global health policymaking, FasterCures convened three roundtable consultations in July 2023 with leading frontline community health advocates and workers from across the African continent. They represented perspectives from the Democratic Republic of Congo, Kenya, Malawi, Mali, Nigeria, South Africa, Uganda, and Zimbabwe.

## APPROACHES TO COMMUNITY ENGAGEMENT IN DATA GOVERNANCE

Data governance refers to the standards, policies, and processes guiding data collection, management, and sharing. Robust processes for data governance can increase efficiency, facilitate quality management, and streamline the end-to-end processes for collecting, storing, analyzing, disseminating, and using data. More fundamentally, data governance is the foundation on which trust and confidence in data systems are built by ensuring that activities are conducted in a responsible, ethical, and equitable manner.

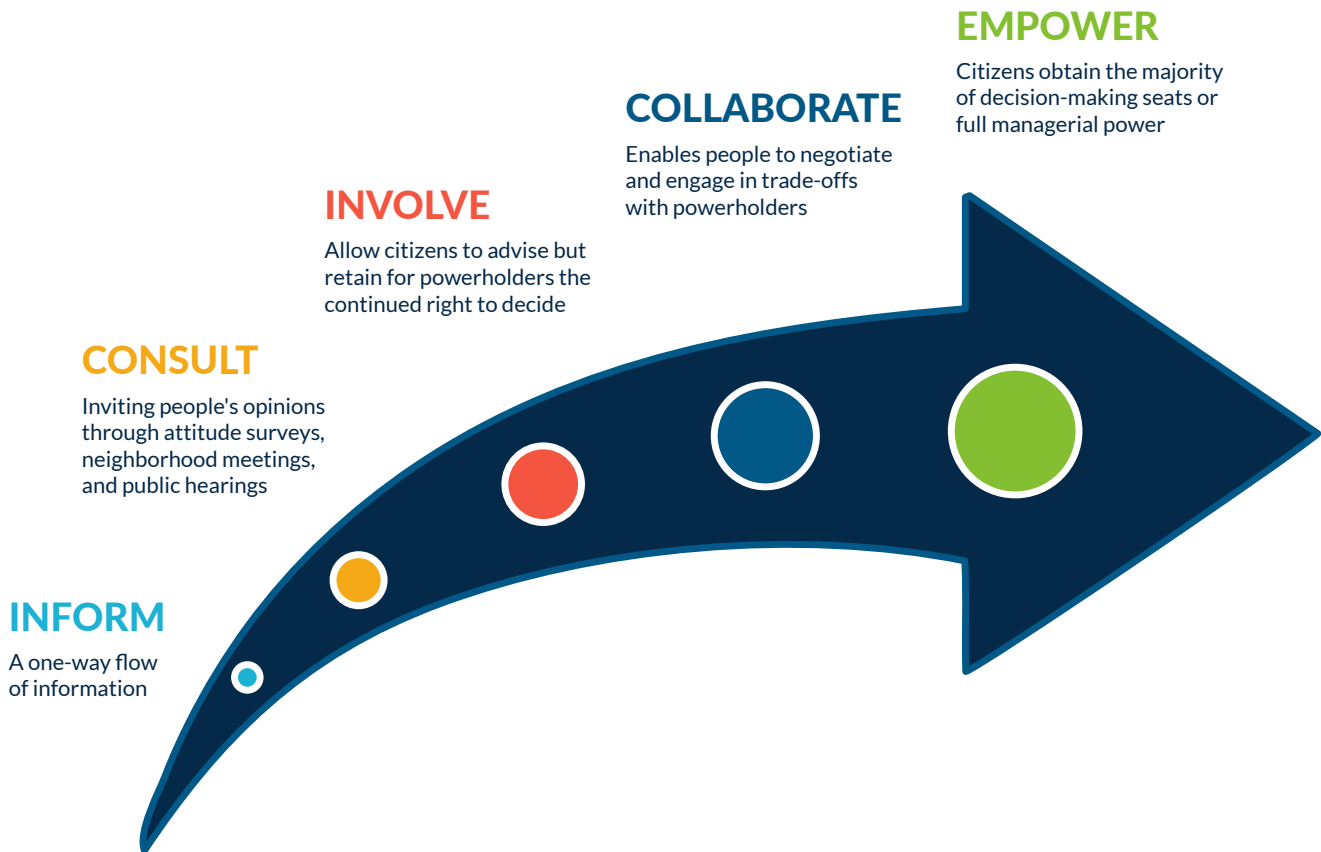
Much has been written about the challenges of data governance; however, less is known about what makes for a “good data governance practice” in the context of community engagement. To provide a framework for roundtable consultations with community health experts, the FasterCures team examined the peer-reviewed and gray literature to identify best practices and guidelines for community engagement. We grounded our review in the principles (see Figure 1) and levels (see Figure 2) of community engagement from the WHO publication [Community Engagement: A Health Promotion Guide for Universal Health Coverage in the Hands of the People](#).

**Figure 1. Principles of Community Engagement**




Source: Milken Institute, adapted from the WHO's *Community Engagement* (2020)

**Figure 2. Levels of Community Engagement**



Source: Milken Institute, adapted from the WHO's *Community Engagement* (2020) and Ada Lovelace Institute's *Participatory Data Stewardship* (2021)



Through the literature review, we identified a mix of practices and guidelines relating to community engagement in data but did not identify any that could be characterized as a “best practice.”

As expected, practices and guidelines that achieve a higher level of community engagement (see Figure 2) also reflected more of the principles of community engagement (see Figure 1). In activities intended to inform audiences (e.g., **educational materials, informed consent, visualization**), there was a lack of definition on what constitutes “meaningful engagement.” In addition, the activities were unidirectional and appeared to be grounded in a view of communities and frontline health workers as passive consumers of information.

**Deliberative approaches**—such as data assemblies and workshops that facilitate co-design and co-appraisal—were widely supported in the literature and featured more robust engagement of individuals who were broadly representative of a community in a facilitated dialogue (see Figure 2, steps 2 and 3, “Consult” and “Involve”). While initial experiences with these approaches appear promising, an understanding of such approaches in different contexts is needed. Creating a **feedback loop** with communities was viewed as essential, but no practices were identified for how to set up such a loop.

**Skills and knowledge development** was agreed to be a critical step toward true collaboration and empowerment, particularly in the face of asymmetric power dynamics, but testing of such programs in the real world was not identified. Enthusiasm is expressed in the literature for **data trusts** as a bottom-up empowerment structure, but few successful examples are offered from which to learn. **Indigenous data governance**, drawn from the United Nations Declaration on the Rights of Indigenous Peoples, is a useful guide to how other communities could engage in data governance.

Our review had several limitations. Practices and guidelines were written from the perspective of the researcher, not from the perspective of the community or individual community members. There was little geographic diversity among the documented practices and guidelines; thus, the generalizability of identified practices may be limited. Formal evaluations have not been conducted, and the long-term impact of these practices on community engagement is unknown.

## FINDINGS FROM THE CONSULTATIONS

Three virtual consultations were convened in July 2023 with leading frontline community health advocates and workers across Africa. The consultations focused on the complexities of data governance, with a special emphasis on community involvement. Community health advocates and workers were invited to the consultations as both recipients of recommendations and critical contributors to offer feedback and suggestions.

A fundamental aspect of the discourse revolved around the levels of community engagement as understood by the research and public health community (see Figure 2).

During the discussions, notions of what it means to inform, consult, involve, collaborate with, and empower communities about data governance were dissected. However, the participants made a strong case that any approaches to community engagement that fall short of empowering communities will fall short of their intended goals.

The community health advocates and workers called for action-oriented strategies:

### **1. Intentional and continual community integration**

There was an unmistakable push for meaningful involvement of community health workers, advocates, and representatives. Experts in the consultations were outspoken about wanting greater autonomy in their dealings with health authorities and underscored the importance of continuing education, especially during health crises such as pandemics. They recommended iterative refinement based on feedback loops and community inputs, and emphasized the significance of returning data-driven insights back to communities.

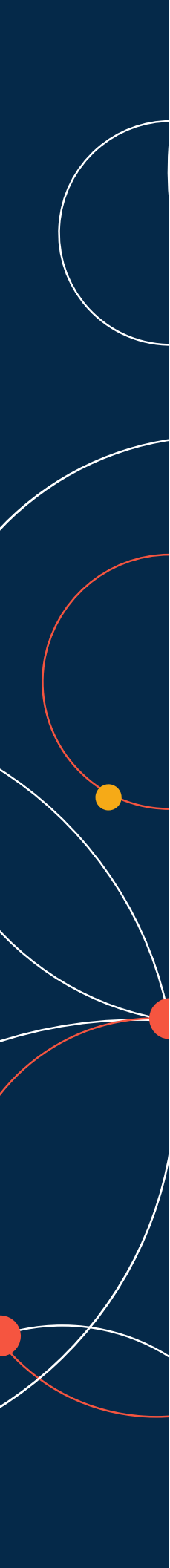
Community health workers recounted instances where feedback loops were notably absent after critical interventions. They cited examples such as HIV campaigns and pointed to a concerning trend: While they collected pivotal medium-term data post-interventions, there was an unmistakable lack of sustained engagement by health authorities. This often resulted in valuable data getting lost in translation, thus leaving health institutions blind to medium- and long-term impacts.

### **2. Community autonomy in data stewardship**

In the community health advocates' and workers' views, health authorities seem not to give adequate consideration to the importance of feedback and community involvement in data collection and, in particular, to the way that lack of such involvement can affect ongoing and future interactions between community health workers and their communities. They also highlighted that the timing of these data collection activities should consider the potential to overload both data collectors and the target populations. They should further consider the complexity of contexts, such as in communities facing challenges like internal displacement and interactions with communities receiving displaced populations.

The consultations introduced the concept of data trusts as legal structures for independent data stewardship. Under a data trust, an appointed trustee would bear a legally binding responsibility to ensure that data benefited specific groups of people and stakeholders. The trustee would decide who has access to data and under what conditions.

Local data trusts, managed by entities such as health posts or nongovernmental organizations, have been proposed in the literature as potential mechanisms for ensuring community autonomy, informed consent, and control over data, along with equitable benefit sharing, capacity building, and cultural sensitivity.



Some of the experts in the consultations believed that such a structure could be workable if validated by community leaders and government health departments. Others were concerned that identifying a trustee could be challenging and that a trust could inadvertently impose more barriers on the community and health authorities. Work remains to be done on exploring the feasibility and utility of this concept.

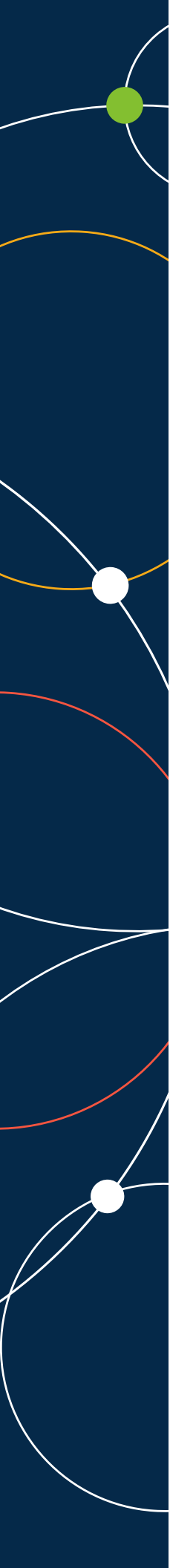
### 3. Differentiated community-level training for *all* involved in community health

The community health advocates and workers emphasized that every stakeholder, from local citizen to policymaker, required training tailored to their unique roles and responsibilities. Such differentiated training ensures that everyone adheres to best practices in data collection, maintains respect and confidentiality, ensures data integrity, and effectively utilizes the collected data. In addition, adopting such an approach was viewed as a meaningful driver of community empowerment.

Differentiated training executed through a community-level training approach was particularly resonant. Encompassing community members and leaders, policymakers, researchers, and other stakeholders, such an inclusive approach would foster mutual understanding, promote transparency in how data are used, and facilitate active participation by the community. Moreover, it would bring into focus the political aspects of data governance and underscore the importance of ongoing interactions. Such training would center community health workers as vital connectors between communities and health authorities, and consequently afford them specialized training, covering topics ranging from understanding specific health issues and ensuring data confidentiality and integrity, to mastering communication, negotiation skills, and even legal protection. It would also recognize and respect the distinctions between community health workers and the general community in data collection.

Community health workers have specific roles, higher data literacy, trust, and motivation tied to their job responsibilities, while the general community's involvement may vary according to interest, availability, and the perceived relevance of data collection for their lives. Nevertheless, it would be critical to ensure the creation and maintenance of transparent and trusting relationships between communities and their community health workers because the primary interface for data collection is between community health workers and local members of the community.

For policymakers, the crux of a community-level training approach would be to arm them with the skills to navigate the complexities of data governance. This would include understanding data handling across all health-care levels, being alert to the risks of political influences, and recognizing the vital roles that both community health workers and communities enact in data collection. Additionally, policymakers would be equipped to identify and account for power



dynamics. Researchers, for their part, would be trained in transitioning from data collection to generating valuable insights and collaboration techniques with communities and policymakers. Last, training modules designed for both policymakers and researchers would include the importance of data integrity, ethics, collaboration, and a community-focused approach to data governance.

In all, tailored training programs for all stakeholders involved in health data governance would ensure that each group was well equipped to collaborate and maintain data integrity.

#### **4. Fair benefit sharing and sustainability of community involvement in data governance**

In an age of data as currency, the community health workers and advocates expressed concerns about communities' abilities to benefit from sharing their data for science and/or public health imperatives and—to a degree—to leverage their data for monetary benefit. This raises additional uncertainties regarding trust in the people gathering the data, as well as questions about data authenticity. While offering incentives, particularly financial ones, for data collection has been explored, the experts warned that such incentives must be context-specific. Alongside this, the experts stressed the importance of being vigilant about potential ethical issues for current and future exercises, and the possible repercussions such incentives might present to crucial public health objectives.

## **RECOMMENDATIONS FOR ACTION**

The series of consultations with community health advocates and workers on health data governance underscores the importance of transparent and ethically sound communication of health data and its uses to and by communities.

As efforts advance toward early warning surveillance, such as the International Pathogen Surveillance Network, communities must be engaged at the very beginning. To leverage the full scope of data needed to establish robust early warning systems, we must institutionalize data governance practices that include community participation and collaboration because early detection and warning typically occur first at the community level, long before a potential threat is perceived as having pandemic potential.

Community involvement in data governance requires holistic and collaborative approaches to training for data governance that prioritize trust-building, together with ongoing querying of data for relevance, quality, and local data utilization. Support for community health workers is a vital element, recognizing these key contributors to the success of the health-care and disease surveillance system. These consultations have yielded key foundational areas for action to foster community involvement in data governance:



1. **Articulating social charters** among communities, community health advocates and workers, researchers, and governments whenever data collection is undertaken. There must be a mutual understanding of the benefits, risks, and likely impact of the data collection activities.
2. **Investing in community-level training for all stakeholders.** This would be a departure from the assumption that any single stakeholder or group alone, especially community health workers, should be the target of unidirectional training. Rather, it would involve tailored training at all levels and include researchers and policymakers.
3. **Incorporating quality control measures** within training programs to prevent politicization of data and ensure that data collection, storage, and use continue to be appropriate and beneficial to the community.
4. **Creating data feedback loops and closing data gaps** as near to the site of action as possible, directly benefiting community health workers and communities and fostering a sense of ownership.
5. **Providing tangible support** to community health workers, including technical, legal, and social provisions, to incentivize and sustain community health work.





## CONCLUSION

Early warning surveillance for pandemics is a key aspect of pandemic prevention and global health security. This issue brief aims to bring greater focus to the role of communities in data governance for early warning systems. Institutionalization of data governance practices must consider and encompass all stakeholders, including communities. The literature offers some practices worthy of exploration, such as deliberative approaches and data trusts. But the experts in the consultations provide the clearest path forward: through shared social charters, bidirectional communication, community-level training, and ongoing engagement.

## APPENDIX

### Consultation Participants

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## ABOUT THE MILKEN INSTITUTE

The Milken Institute is a nonprofit, nonpartisan think tank focused on accelerating measurable progress on the path to a meaningful life. With a focus on financial, physical, mental, and environmental health, we bring together the best ideas and innovative resourcing to develop blueprints for tackling some of our most critical global issues through the lens of what's pressing now and what's coming next.

## ABOUT FASTERCURES

FasterCures is working to build a system that is effective, efficient, and driven by a clear vision: patient needs above all else. We believe that transformative and life-saving science should be fully realized and deliver better treatments to the people who need them.

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