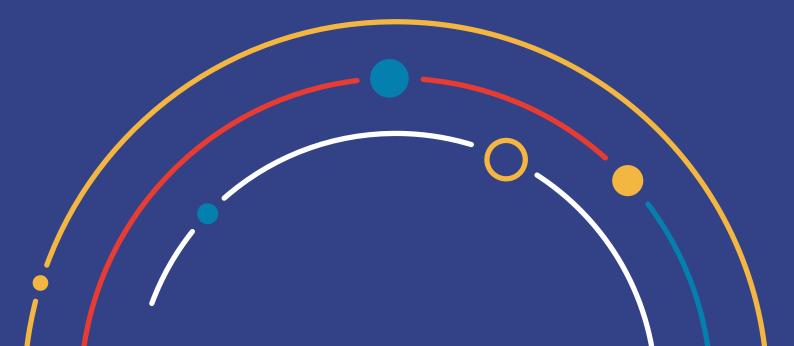




Using Citizen-Generated Data in Kenya

The Power of Public Engagement



insight was the power of people's knowledge that we take for granted.

Government representative



Citizen-generated data (CGD) is a critical complementary data source, expanding what gets measured, how, and for what purpose. It facilitates community engagement, community-based problem solving, planning, and improvements to public services. CGD initiatives create new types of relationships between individuals, civil society organizations, and public institutions.

The Global Partnership for Sustainable Development Data collaborated with Africa's Voices Foundation to pilot the use of CGD in Kenya to better understand and address antimicrobial resistance (AMR). Despite the growing threat of antimicrobial resistance globally, there is a dearth of comprehensive data on the drivers and impacts. In Kenya, national and subnational efforts to address AMR are guided by the AMR National Action Plan, with a focus on improving awareness of AMR and strengthening the evidence base to inform decision-making. Reflecting this, the project saw a dual data collection and information dissemination approach using interactive radio shows, mobile text messages, listening group discussions, and key informant interviews, across three counties in Kenya—Kilifi, Kiambu, and Bungoma.

We've spoken to people involved across this project—government officials, researchers, civil society organizers, and the media—to discuss the impact of this work, and have drawn out four findings around the use of CGD:

- 1. CGD can build public awareness of key health issues.
- 2. CGD allows public insights to drive decisions.
- **3.** CGD provides a complimentary data source to triangulate and deepen understanding.
- 4. CGD facilitates collaboration between sectors.



Despite the growing threat of antimicrobial resistance globally, there is a dearth of comprehensive data on the drivers and impacts.

Above: A listening group of mothers in Kilifi county, Kenya. Photo: Elphas Nguqi, GPSDD

A tool for building public awareness of key health issues

LE Storytelling is something that's impactful, it makes people change behaviors. Numbers alone are not relatable.

Gilbert Nakweya, Journalist

CGD is characterized by people's active engagement in the data production and consumption process. Participants recognize CGD as a critical driver in building public knowledge and awareness of AMR. After 10 weeks of interactive radio broadcasting and citizen interaction via SMS and listening group sessions, the project saw an 11% increase in participants feeling they were well informed about AMR.

Through the radio shows, healthcare professionals and government representatives saw high levels of public engagement around AMR and a desire for more knowledge. "[I] was surprised that so many people were listening in and they all had many questions", said Dr. Emmah Nyaboke, Ministry of Health (MoH) and AMR focal person for Bungoma County. CGD is increasingly seen by many policymakers as a useful way to surface the many questions around AMR the public is grappling with, but don't have a platform to engage with.

Policymakers and healthcare professionals noted that public engagement through CGD is a good way to share accurate information about AMR, especially given limited resources at health facilities. In particular, they noted the value in increasing citizens' knowledge about their role in reducing AMR. "With more CGD... policymakers can understand that people do want to learn, to know what it means and what they can do... in tackling AMR. They can't do that if they don't have that information," mentioned Kenya Medical Research Institute's (KEMRI) Dr. Anne Amulele.

Public health experts also highlighted the power of CGD in reducing misconceptions and driving action on public health issues that don't get as much political visibility. "In terms of its ability to create awareness and to reach a wide audience, [CGD] is quite useful... I see it as a means where you can demystify some of the things that are poorly understood at community level... in the health sector setting," said Dr. Edna Mutua, Health Systems Researcher at the KEMRI-Wellcome Trust. This includes using public engagement mechanisms to explain the need for diagnostic testing and trends in AMR. As a result of the project's insights being shared during World Antimicrobial Awareness Week, one county has already taken action to distribute AMR materials to patient waiting areas.



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Using public insights to drive decision-making

After interaction with this project, I believe that now even at the point of policy development, the community or citizens need to be onboard because a lot of the solutions are actually going to be driven by the citizens.

Dr. Evelyn Wesangula, Head of the Patient Safety Unit at the MoH and MoH AMR Focal Point

Public engagement enables policymakers and researchers to better understand citizen needs and perceptions and directly inform solutions. As the journalist Gilbert Nakweya noted, "we get the most valuable data that has been neglected for a long time in policymaking from the citizens themselves."

The project helped generate high-level buy-in on CGD across the Kenyan government. The MoH has committed to continue using CGD, with the AMR Steering Committee planning to include CGD as a data source in the next iteration of the National Action Plan. There is also ongoing action at the county level. "As the Kiambu County AMR Stewardship Committee, we can use that data [to inform our] work plan for sensitization and awareness of the public on AMR aspects and... close knowledge gaps," affirmed Dr. Hillary Kagwa, Acting County Director of Health, Kiambu County, adding, "we want to continue accessing the data because it is valuable to us."

The Kenya National Bureau of Statistics (KNBS) is also committed to incorporating CGD to complement official statistics. One concrete way they are doing this is through putting out a call for data from civil society organizations (CSO) to establish quality standards. As KNBS's Sarah Omache explained, "we have set the threshold for official statistics guided by United Nations Fundamental Principles, which we intend to extend to CGD once we have inspected samples of the data. We sent out a questionnaire to CSOs producing CGD and will analyze and list the data available... We will discuss the thresholds with the CSOs before we finalize on the quality criteria." Data from this project is part of the review exercise. KNBS is also exploring the development of a platform for data sharing between CSOs and the government to facilitate greater collaboration.

Members of the research community also recognized the power of CGD for informing people-centered research design. As one researcher reflected, "researchers need to be aware of [CGD] because it's one thing to do research on what you think is a problem, but if you hear what's actually happening, it should shape the research." Another researcher highlighted, "the change that [the project] prompts in my thinking and my future work in terms of designing studies is that there is an important aspect of inclusion of the community."



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CGD as a critical complementary data source

Estimate Beyond empowering the citizens, [CGD] is a very key component in supporting countries to implement national action plans... because, without evidence it's very difficult to change anything. And this is one key gap that we have, especially in Africa, where sometimes we tend to rely on external studies that are not really contextualized to the settings where we work.

Julian Nyamupachitu, Program Officer, ReACT Africa

CGD captures data that is beyond the scope of other data, helping to contextualize and bolster insights from surveillance data. As Dr. Janet Midega, Senior Research Manager at Wellcome, observed, "there is a lot of antibiotic use that goes on that is not captured through the normal formal medical system or health systems processes. [CGD] helps us to understand some of the reasons behind why citizens obtain antibiotics without prescriptions... their practices... and why those who sell it do so. Just to have those conversations helps us understand them."

For many in the government and research community working on AMR in Kenya, this project was the first time they had heard about citizengenerated data—through targeted social media and Whatsapp campaigns, workshops, video storytelling, and events at World Antimicrobial Awareness Week 2021. Ninety-one percent of participants across project workshops are now interested in supporting or using CGD to address AMR and other policy issues. This has been particularly striking at the county level: 77% of workshop participants now understand what CGD is, and 83% recognize the value of CGD in closing knowledge gaps.

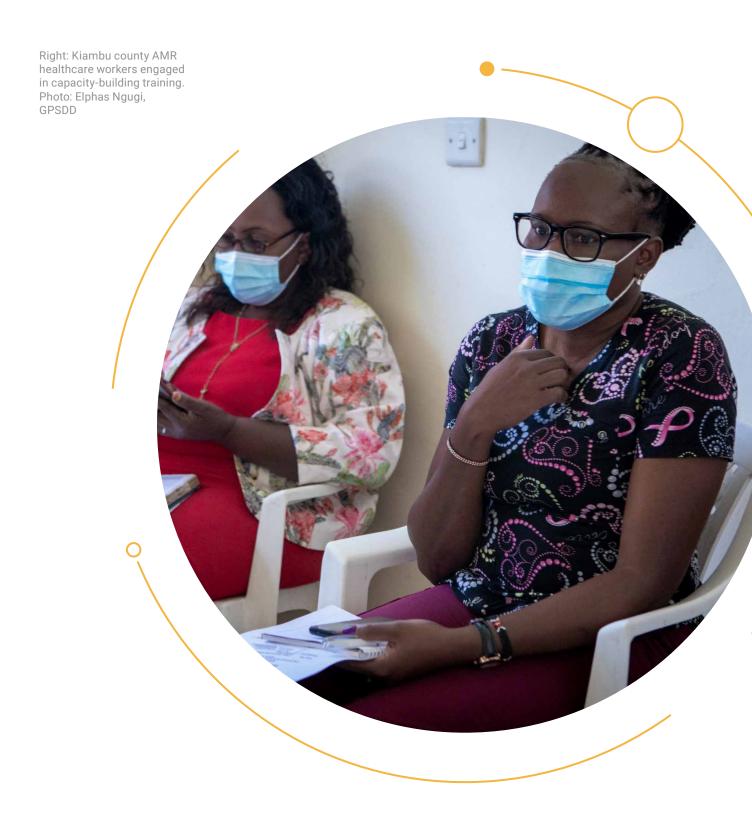
Dr. Midega reflected, "[the project] has taught me that while we design hospital-based studies, we also need to seek knowledge and opinions of citizens to augment the data that we have from the hospital." Government stakeholders, particularly the MoH also demonstrated buy-in to the data source. For example, they invited a county-level official involved in the project to share insights about CGD and its transformative capabilities during an international conference on AMR stewardship, and said "we think [CGD] is one way we can cause change at the grassroots level."

Interviews highlighted the duality of CGD as both data collection and information dissemination. As World Animal Protection Africa's Dr. Victor Yamo reflected, "you are enlightening the audience, but you're



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also asking them in a subtle way what they know and what their feelings around certain things are." People valued this method of data collection in surfacing everyday conversations that are happening in communities and what citizens actually know or think. CGD stands in contrast to more traditional methods of data collection where respondents are more likely to respond with what they believe the enumerator wants to hear. As one researcher put it: "a key learning was that data and findings can be directed by the public, rather than the researcher."



Facilitating collaboration across sectors

up a conversation, and it was a very wide conversation. It brought in expert government officials at the national level and county focal points... ••

Samuel Kimeu, Executive Director, Africa's Voices Foundation

The project engaged with citizens, healthcare professionals, government representatives, researchers, CSOs, and the media. Stakeholders across all groups highlighted the value they found in engaging with each other. Government representatives noted the value of collaborating with CSOs. Civil society representatives noted their surprise at the national government's buy-in to the project evidenced by their active engagement and the high premium they placed on the data. In particular, they remarked that, as a result of this engagement, they will have a much easier time working with national and subnational government institutions in the future.

Government officials heeded the project report's recommendations on driving patient engagement on AMR at the community level. "We work with community units a lot in other public health programs... Moving forward in terms of AMR, one of the objectives of the National Action Plan [is to] bring Community Health Workers on board so they can walk with the message from house to house even as they are tackling other topics, like malaria and maternal health," stated Dr. Emmah Nyaboke.

All stakeholders also noted that for AMR specifically, this project highlighted both the intersectional nature of the various factors contributing to AMR and the need for action from across multiple groups of stakeholders to effectively address it. "The study exposed the fact that there is an intersection of factors that have to be taken into consideration in order to completely solve the problem of AMR," said one researcher, while Dr. Sam Akech, Principal Investigator at the Health Services Unit, KEMRI-Wellcome Trust, added, "it needs people acting at different levels because one group of actors is unlikely to succeed."



Stakeholders across all groups highlighted the value they found in engaging with each other.

Driving long-term impact

The Global Partnership has managed to create a more robust system for CGD, as sometimes it can be seen to be a bit wooly and not thorough enough, but I think [the project has] given validity to it as a tool, and that's really exciting.

Lucy McDowell, Wellcome

This project was instrumental in highlighting the power of CGD in the context of AMR: driving engagement and high-level buy-in across Kenyan government, civil society, the research community, and the media. The findings also highlight broader potential for CGD as an essential tool in tackling wide-ranging public health issues. KEMRI's Professor Sam Kariuki reflected: "one of the lessons I got very quickly from this study is the fact that we must be able to engage citizenry in a very direct way and be able to provide them with a platform for continuous engagement going forward." He sees the potential of CGD in tackling other diseases: "there is work going on in the intervention of typhoid vaccine and going forward there is no way we'd be able to roll out the project even in its pilot phase unless we've taken up citizengenerated data on their knowledge, attitudes, and perspectives."

Across sectors, there was strong interest expressed in continuing engagement around data and insights from the project to inform additional CGD activities. The report and anonymized dataset are now available on governments platforms: the Maarifa Center website and the Kenya Health and Research Observatory. The report has been viewed more than 1,000 times since its publication on the Global Partnership website in September 2021. Africa's Voices Foundation plans to push for more open access to the CGD they produce. Through working with government stakeholders, they have recognized the value of developing processes with technology to enable more efficient data cleaning and aggregating methods to make data sharing easier.

AMR, like many other public health and social issues, is complex and driven by human behavior. As the impact of this project demonstrates, to both effectively understand and address these public health issues like AMR, actively engaging with people and communities is critical. CGD is a key tool for doing this. Generating data by the communities and for the communities empowers citizens with knowledge and in turn facilitates the co-development of actions to ensure effectiveness of interventions.



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This piece draws on considered citizen insights from the project alongside additional interviews with project stakeholders from national and local government, the research community, civil society organizations, and media. The workshops mentioned brought together 98 people. The survey asked them to indicate responses on a scale of 1-10, with response scores of 7 or higher being used to indicate the "high" category.





