

People Power

Using Citizen-Generated Data
to Address Antimicrobial
Resistance in Kenya



Global
Partnership
for Sustainable
Development Data



AFRICA'S
VOICES

Acknowledgements

This report was produced by the Global Partnership for Sustainable Development Data team: Karen Bett, Charu Vijaykumar, and Jenna Slotin. The Africa's Voices Foundation team contributed significantly to the data collection and research findings: Anna Colom, Agnes Gakuru, Samatar Abdi, Muna Mohammed, Sharon Njeri, Salahweli Harun, Derrick Ngaira, and Isaack Mwendwa. For this project, Ladama Manjara was the project manager, Amy Leach managed the communications, and Colleen Wile managed the administrative process.

This work would not have been possible without the support of external contributors.

Our sincere thanks go to Professor Samuel Kariuki, Acting Director General of Kenya Medical Research Institute, and Dr. Sam Akech of the KEMRI-Wellcome Trust, who provided their technical expertise across the entire project and reviewed this report. We are also grateful to the members of the Antimicrobial Resistance Advisory Committee, who volunteered their time to review this work: Danny Lämmerhirt, Dr. Victor Yamo, Dr. Jessica Mitchel, Dr. Stella Kiambi, Dr. Evelyn Wesangula, Dr. Emmanuel Tanui, and Hannah Wheatley.

We thank the Wellcome Trust for the funding that enabled this work. We especially recognize Lucy McDowell, Mandy Costello, and Dr. Janet Midega for their guidance.

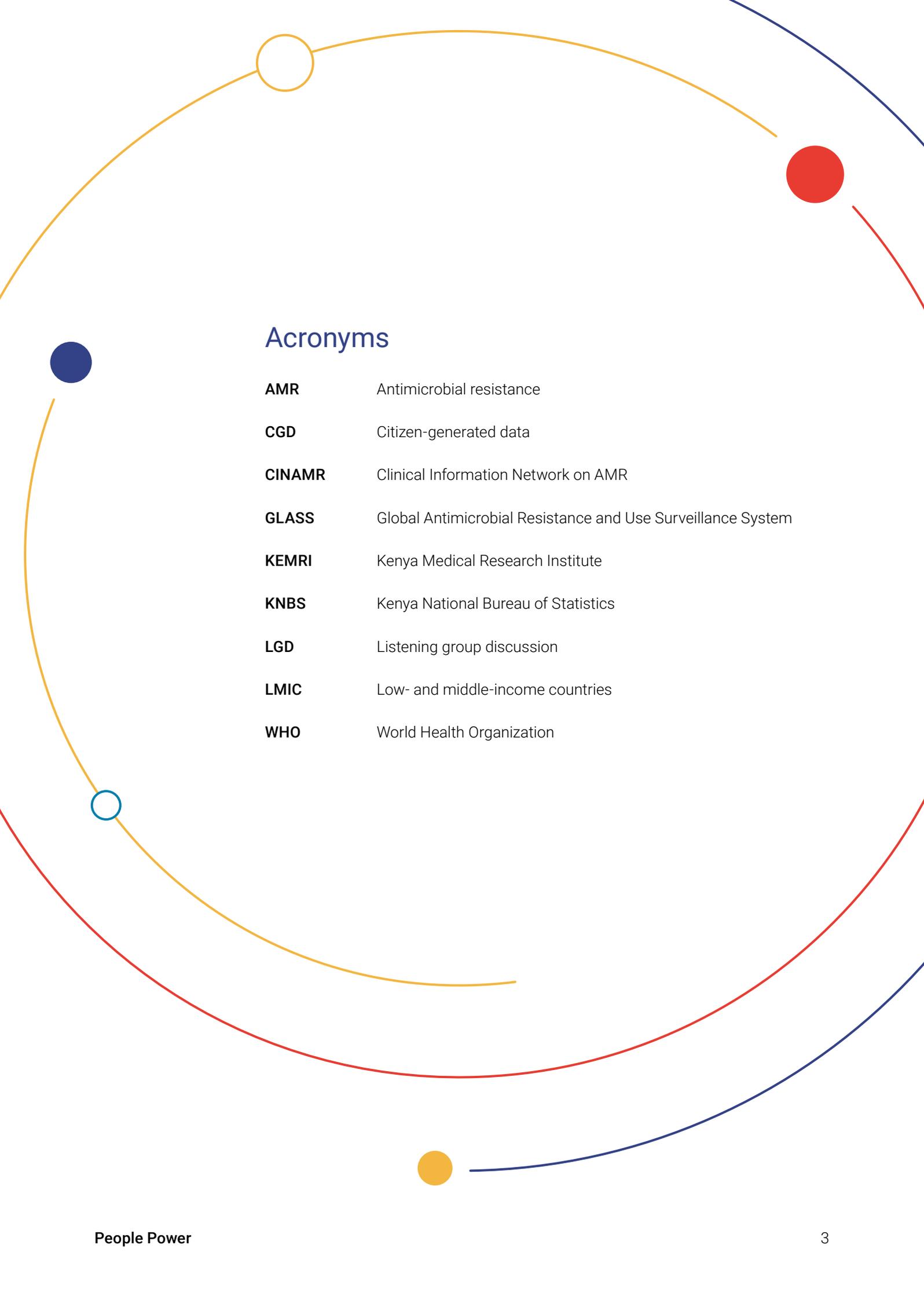
The Africa's Voices Foundation executed the data collection, and we are grateful to the entire team that made this a success, including the leadership of Samuel Kimeu and Damaris Ndegwa. We are also grateful for the county facilitators, the radio stations that hosted the shows, and the guests who participated in the shows.

In a very special way, we thank the citizens who participated in this study and contributed to the data to generate the insights in this report.

Finally, we are indebted to the Government of Kenya's antimicrobial resistance (AMR) focal points at the national and subnational levels: Dr. Evelyn Wesangula, Dr. Emmanuel Tanui, and the entire AMR secretariat. Kiambu County: Dr. Hillary Kagwa; Kilifi County: Dr. Nigel Madara; and Bungoma County: Dr. Emmah Nyaboke. We are grateful to the Kenya National Bureau of Statistics for its continued stewardship in strengthening the use of citizen-generated data.

Contents

Acronyms	3
Executive Summary	4
Chapter 1: The context	8
Antimicrobial resistance: A creeping pandemic	8
The data challenges of AMR	9
A citizen-generated data approach to AMR	10
Using citizen-generated data to understand AMR in Kenya	11
Project overview	14
Chapter 2: Methodology	15
Research gaps	15
CGD methods	16
Design and data collection	17
Feedback loops	19
Methodological limitations	19
Chapter 3: Findings	20
1. Citizens' knowledge of AMR and its consequences	20
2. The drivers of antimicrobial resistance	25
3. Cross-cutting issues	30
Chapter 4: Recommendations	32
Recommendations for citizens and communities	32
Recommendations for national and subnational government policymakers	33
Recommendations for health care workers	33
Recommendations for the research community	33
Chapter 5: Conclusion	34
Annex A: Detailed methodology	36
Annex B: Detailed data gaps identified during the scoping phase	40
Annex C: List of figures	43
Endnotes	48
People Power	2



Acronyms

AMR	Antimicrobial resistance
CGD	Citizen-generated data
CINAMR	Clinical Information Network on AMR
GLASS	Global Antimicrobial Resistance and Use Surveillance System
KEMRI	Kenya Medical Research Institute
KNBS	Kenya National Bureau of Statistics
LGD	Listening group discussion
LMIC	Low- and middle-income countries
WHO	World Health Organization

Executive Summary

Antimicrobials, including antibiotics, underpin modern medicine. But they are becoming less and less effective because of antimicrobial resistance (AMR) – a condition that occurs when infections become resistant to the drugs designed to treat them. AMR is a growing global threat. It is estimated that infections that are resistant to antibiotics could cause 10 million deaths each year by 2050. By 2030, antimicrobial resistance could force up to 24 million people into extreme poverty.

Yet data on AMR is lacking, which limits our understanding of its burden, hobbles efforts to communicate the urgency of the crisis, and slows national and global efforts to address AMR effectively. To tackle this challenge, the Global Antimicrobial Resistance and Use Surveillance System (GLASS) was launched in 2015. GLASS collects official national AMR data primarily through surveillance systems. However, data remains patchy. More than half of countries in Africa do not submit data on AMR to GLASS. In low- and middle-income countries (LMICs), AMR surveillance capability is variable for a range of reasons, with limited laboratory capacity to support diagnostic microbiology a major factor. As countries strengthen surveillance data systems and new research on AMR is conducted, complementary approaches are urgently needed to generate quality data on AMR.

Citizen-generated data (CGD) can play a crucial role in plugging these gaps, but it is also critical to gather data that surveillance data will never capture, such as citizen knowledge levels, as well as perceptions and drivers of behavior. Engaging citizens on AMR – and in the process generating data with them – can help close AMR data gaps, support citizens to take action on AMR, and spur data-driven action by political leaders.

Citizen-generated data (CGD) is defined by CIVICUS as:

Data that people or their organizations produce to directly monitor, demand or drive change on issues that affect them. It is actively given by citizens, providing direct representations of their perspectives and an alternative to datasets collected by governments or international institutions.

Below: Mothers engaged in a listening group in Kilifi county, Kenya. Photo: Elphas Ngugi, GPSDD



CGD can provide timely and granular data on community issues. It empowers citizens by engaging them in one – or several – stages of the data value chain. While it is a powerful data source on its own, it is also a useful complement to official government data. National statistical offices across the world, including the Kenya National Bureau of Statistics (KNBS), are already providing data stewardship to producers of CGD, with CGD used to complement official statistics and inform decision-making.

The Global Partnership for Sustainable Development Data collaborated with Africa’s Voices Foundation to generate and disseminate insights on AMR in Kenya using CGD. The CGD methods used were a combination of interactive radio shows in local languages and SMS/mobile text messaging service, listening group discussions, and key informant interviews across three counties: Kiambu, Kilifi, and Bungoma. Over ten weeks, the study hosted 38 interactive radio shows and generated 20,272 SMS from 5,313 individuals.



The experience from this project is that translating medical concepts such as antimicrobials and AMR into local languages is a challenge. Most citizens find the term “antibiotics” more accessible than “antimicrobials.”

Figure 1: Summary of data collected



AMR is a global issue. However, for this project we chose to focus on Kenya because of ongoing commitments to strengthening AMR capacity and the progressive efforts of the KNBS in using CGD as an alternative data source to complement official statistics. While the findings and recommendations are for a Kenyan context, they have broad applications in other countries for AMR response and the use of CGD in decision-making.



Key findings

Poor knowledge about antibiotics and their proper use is associated with misuse. While most citizens obtain their information on antibiotics or on AMR through interactions with health workers, there is a need to address any barriers to interaction between health workers and the citizens.

Insights point to poor, and even risky, health-seeking behaviors for antibiotics among citizens in Kenya. Most patients seek care too late — when other means, such as self-treatment, fail — or else immediately upon noticing symptoms of a fever, when antibiotics may not be needed.

The challenges of access and availability of health facilities, as well as the high costs of seeking medical care, lead to poor health-seeking practices, which exacerbate AMR. This cycle is further reinforced by inadequate and under-resourced health facilities, leading to long hospital queues and health workers having no time to engage meaningfully with citizens on AMR.

Although medication regulations exist, study participants expressed the opinion that the level of awareness about and enforcement of them is low, and the perception is that currently these regulations are not responsive to the needs of the health sector.

Our findings demonstrate that there is a discernible benefit to public engagement on AMR. Even within the span of 10 weeks, the project saw an increase in knowledge on AMR. Citizens have a genuine quest for knowledge on AMR — indicated by the number of questions they asked during the radio shows. This interest indicates that targeted and consistent public engagement on AMR can reduce knowledge gaps and ultimately influence behavior change to address AMR.

Generating data with citizens through public engagement provides an understanding of citizen knowledge and behavior and informs ideas to influence that behavior via engagement. It creates new spaces for citizens and government to engage and include citizens in public decision-making at different levels of government.



The challenges of access and availability of health facilities, as well as the high costs of seeking medical care, lead to poor health-seeking practices, which exacerbate AMR.

Above: Dr. Evelyn Wesangula is the National Antimicrobial Resistance Focal Point in Kenya's Ministry of Health. Photo: Elphas Ngugi, GPSDD

Key recommendations

Tackling AMR is a shared responsibility. Citizens, policymakers, health care workers, and the research community all have important roles to play.



Citizens should feel empowered to play a role in tackling AMR by changing their practices in accessing, using, and misusing antimicrobials. With civil society, they should proactively engage in efforts to gather citizen-generated data.



National and subnational government policymakers should make investment in AMR a public health priority. Specifically, investment should target strengthening laboratory networks. They should promote AMR stewardship. Policymakers should embrace citizen-generated data as a critical data source on a par with official data sources and partner with civil society organizations to collect, analyze, and use CGD to inform programs, monitor their effectiveness, and engage citizens.



Health care workers should drive quality patient engagement on AMR to tackle misinformation and improve levels of trust with citizens. They should also take a holistic view of addressing AMR by understanding the role of community engagement and drawing on lessons from CGD to inform their engagement with patients.



The **AMR research community** should explore ways of incorporating citizens' voices in research studies that target challenges on AMR, especially in hard-to-reach areas such as arid and semi-arid lands.

The findings from this study have reinforced the value of CGD in providing insights on issues that matter to citizens, as a means to get the voices of citizens heard, hold the government accountable, and ensure citizens' experiences are reflected in policy and decision-making. The value of CGD applies especially to phenomena that are driven by human behavior, such as AMR, as well as many other social, economic, and environmental issues. CGD empowers community members by engaging them in one or several stages of the data value chain. Citizens should engage with civil society groups, be part of the process, and contribute data. While CGD is a powerful data source on its own, it is also a useful complement to official government or statistical data, including surveillance data. Policymakers and the research community should embrace CGD as a critical data source on a par with others. They should consider partnering with civil society organizations to collect, analyze, and use CGD to inform programs, monitor their effectiveness, and engage citizens. By following rigorous standards and methods, CGD can be more easily used by decision-makers and national statistical offices and systematically implemented by all data providers.



Citizens should engage with civil society groups, be part of the process, and contribute data.



Chapter 1: The context

Antimicrobial resistance: A creeping pandemic

Antimicrobials, including antibiotics, are among the most important discoveries of modern medicine. However, the continued benefits of their use are severely hampered by the emergence of antimicrobial resistance (AMR).

AMR arises when infections – caused by bacteria, viruses, fungi, or parasites – become resistant to the drugs designed to treat them. AMR can be inherent or acquired by the inappropriate use of medicines. It is a growing threat to public health and to the sustainability of an effective global response to infectious diseases. In fact, the World Health Organization (WHO) classifies AMR as one of the 10 greatest global public health threats humanity faces.¹

The Global Action Plan on AMR² highlights that the systematic misuse and overuse of antimicrobials have put every country at risk. Without harmonized and immediate action on a global scale, the world is heading toward a post-antibiotic era in which common treatable infections could once again be fatal.



**AMR is one of the
10 greatest global
public health threats
humanity faces.**

Above: Macknophear Mose and her youngest child in Kilifi county, Kenya. Photo: Elphas Ngugi, GPSDD

Globally, at least 700,000³ people die every year due to infections that are resistant to antimicrobials. It is estimated that drug resistant infections could cause 10 million deaths each year by 2050. By 2030, antimicrobial resistance could force up to 24 million people into extreme poverty.⁴

AMR is not only a human health problem. The health conditions of people, animals, and the environment are inextricably linked since antimicrobial use and resistance in any one of these spheres can potentially impact the others. Antimicrobials administered to both people and animals inevitably end up in the environment, which can simultaneously impact ecosystem health and potentially foster a reservoir for resistant organisms. A “One Health” approach – which takes a holistic perspective – is therefore essential to fully understanding the drivers, limiting emergence, and mitigating the impact of AMR in different ecosystems.

“AMR is a growing pandemic, similar to the current COVID-19, and poses a great challenge, as most citizens and community members are unaware of the risk associated with over- or underdosing of drugs and buying drugs over the counter without a prescription.”

Professor Samuel Kariuki,
KEMRI

The data challenges of AMR

There is a lack of data and information about AMR, especially in low- and middle-income countries (LMICs). These data gaps limit understanding of the burden of AMR, hobble efforts to communicate the urgency of the crisis, and slow down national and global efforts to address it effectively.⁵ Health surveillance systems and research provide a foundation for a better understanding of the spread of antimicrobial resistance and consumption, but AMR surveillance capability is variable in LMICs. Sub-Saharan Africa and South and Southeast Asia have the least developed surveillance coverage compared with high-income countries like the United States and many of those in Europe.⁶ LMICs have challenges, including weak laboratory infrastructure to support diagnostic microbiology, lack of trained and qualified staff, and heavy reliance on external funding to support efforts to combat AMR. However, multiple socioeconomic and behavioral drivers of resistance, as well as regulatory and other health system challenges, are also common.

In 2015, the WHO launched the Global Antimicrobial Resistance and Use Surveillance System (GLASS). GLASS is the first global system to collect official national AMR data for selected priority bacterial pathogens causing common infections in humans. GLASS generates AMR data primarily through surveillance systems managed at the national level.

Below: Kiambu county AMR healthcare workers engaged in capacity-building training. Photo: Elphas Ngugi, GPSDD



People Power

Table 1: The main data sources on AMR⁷

Data source	Description
National AMR surveillance programs (contributing to GLASS)	<p>GLASS enables standardized data collection, reporting, and sharing of official national AMR data worldwide in a timely and comprehensive way. GLASS is designed to generate different types of surveillance data:</p> <ul style="list-style-type: none"> • Routine surveillance: Antimicrobial resistance and antimicrobial consumption. • Focused surveillance: Supports the timely detection, reporting, risk assessment, and monitoring of emerging resistance. • Surveys and studies: Examples include point prevalence surveys⁸ of antibiotic use at the hospital level, and studies estimating the public health impact of AMR.
Academia and research networks	<p>These networks target a clinical and policy topic and offer in-depth information for a specific population.</p>
Pharmaceutical companies	<p>Pharmaceutical companies establish networks to generate high-quality data mainly to evaluate drug performance and fulfill regulatory requirements. Over the years, a number of global networks have come into existence funded by pharmaceutical companies.</p>
Private laboratories	<p>Private laboratories may play a role in the provision of high-quality data on AMR surveillance if they are accredited and provide quality-assured services compared with public laboratories.</p>

While these data sources are important, they are complex and require highly technical skills to interpret. This makes it even more difficult for decision-makers and citizens to understand AMR and take appropriate action.

While continuing to strengthen quality routine surveillance data is important, complementary approaches are needed to address the limitations of this approach, especially where it fails to capture data from the wider population affected by AMR. Citizen-generated data is an essential tool in expanding datasets and knowledge on AMR. Engaging citizens in generating data on AMR can further help close data gaps in addition to mobilizing citizens to take action on AMR.

Existing data collection tools in most African countries do not collect or indicate the right type of data to inform decision-making. This is a challenge to estimating the global burden of AMR.

Janet Midega, Wellcome

A citizen-generated data approach to AMR

Global action to address AMR is not happening at the scale and urgency needed because public understanding of antimicrobial resistance and its impact is low.⁹ AMR is a social issue driven by human behavior and should be tackled by engaging with communities to understand the local context of antimicrobial use and misuse. Empowering communities with knowledge in turn facilitates the co-development of actions to minimize the negative effects of AMR.¹⁰ Community engagement can and should be data driven to spur action by policymakers to make AMR a priority.

CIVICUS,¹¹ a global alliance of civil society organizations and activists, defines citizen-generated data as “data that people or their organizations produce to directly monitor, demand, or drive change on issues that affect them. It is actively given by citizens, providing direct representations of their perspectives and an alternative to datasets collected by governments or international institutions.”

Civil society organizations are often the stakeholders convening citizen-generated data projects. CGD is characterized by people’s active involvement in the data production process. It can provide timely and granular data on community issues, supplementing other data sources and helping to shape policies that are responsive to community needs. It creates new spaces for citizens and government to engage and fosters the inclusion of citizens in public decision-making at different levels of government. CGD empowers community members by engaging them in one or several stages of the data value chain: collection, publication, uptake, and impact. While it is a powerful data source on its own, it is also a useful complement to official government or statistical data.

CGD is gaining traction. Many national statistical offices now recognize it as a valuable data source in pursuing sustainable development to help fill evidence gaps. While the approach does not always rely on representative population samples, it is valuable in identifying patterns and guiding official policymaking and monitoring systems. This process of actively engaging citizens through a data generation and use process provides rich, personal insights from citizens and communities that cannot be gained through routine surveillance systems.



CGD is characterized by people’s active involvement in the data production process.

Using citizen-generated data to understand AMR in Kenya

Kenya has made great strides on AMR and CGD. As outlined in the AMR profile of the country in Box 1 below, the country has a national AMR action plan approved by the Government with a budgeted operational plan and monitoring arrangements. KNBS has developed quality criteria for using CGD to complement its official statistics.

Right: Macknophear Mose takes part in a Kilifi country listening group of mothers. Photo: Elphas Ngugi, GPSDD



Box 1: An AMR profile of Kenya

Kenya has carried out AMR surveillance as far back as the 1980s – led by Kenyatta Hospital, the national referral hospital. But because most health facilities are not well equipped with microbiology laboratories to measure AMR, almost all AMR data is generated by academic research scientists at the Kenya Medical Research Institute (KEMRI) and sentinel sites that have been set up to address specific pathogens of interest. There is limited microbiology diagnostic capacity, but there are ongoing efforts to expand microbiological testing capacity. There is a lack of routine surveillance data, and the few data from hospitals often represent samples taken from patients not responding to treatment. Therefore, local data on antibiotic usage and antibiotic resistance are not generalizable because of limitations in methods. Consequently, the situation of AMR in the country is uncertain.¹²

A situation analysis on AMR in Kenya conducted by the Global Antibiotic Resistance Partnership in 2011,¹³ and updated in 2016, recommended a coordinated national surveillance mechanism and strengthened laboratory capacity to provide the necessary data for risk assessment of AMR. Since then, Kenya has made significant efforts to put in place governance and national surveillance data systems for AMR.

However, there is certainly still room for improvement. Dr Evelyn Wesangula, the national AMR focal point, reflects on the current state of AMR monitoring:

“ We have not had a national report that will tell us this is where we are at in terms of AMR. What we have relied on over a period of time is data that has been generated by different researchers. And this has probably been done in different parts of the country, but it’s not regular or routine data that’s coming in through a national database... When you don’t have concrete data, then making decisions becomes a problem. You cannot make policy decisions, sometimes, without local evidence. So that has been a gap, but is currently being addressed through the efforts of various partners.”



Governance

The AMR National Action Plan 2017–2022 is the national guide for coordinated response against AMR. It is modeled on the Global AMR Action Plan, which was developed in 2015. The five key objectives of the national action plan are:

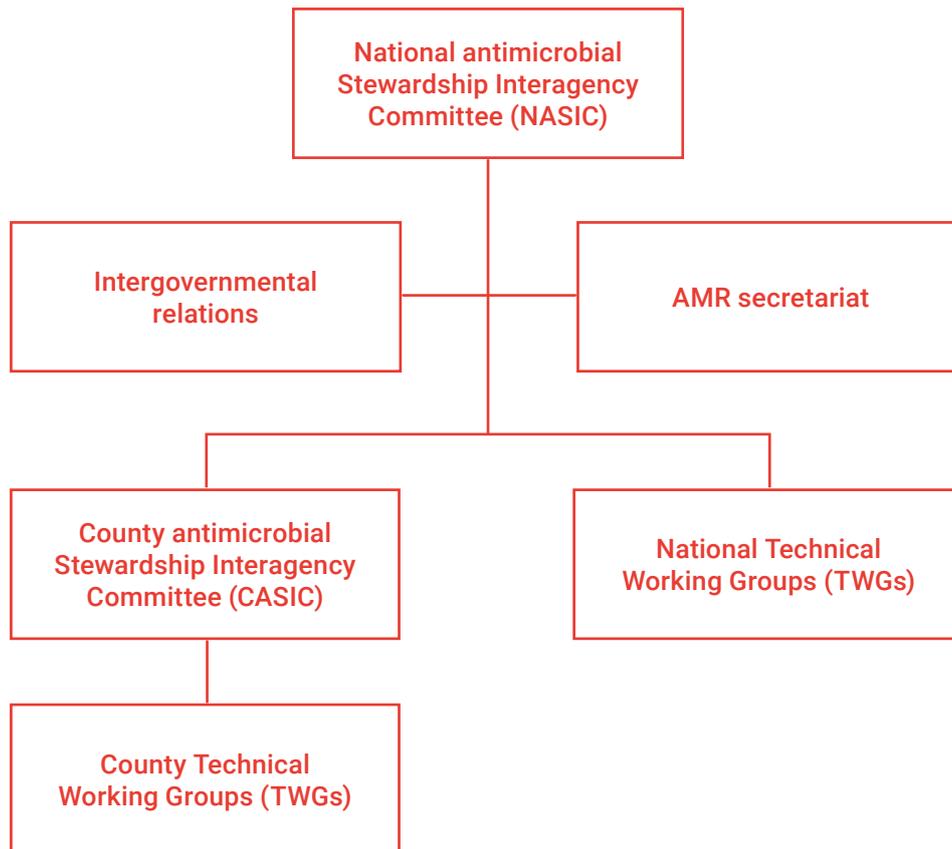
1. Improve awareness and understanding of AMR through effective communication, education, and training;
2. Strengthen the knowledge and evidence base through surveillance and research;
3. Reduce the incidence of infection through effective sanitation, hygiene, and infection prevention and control measures;
4. Optimize the use of antimicrobials in animals and humans; and
5. Develop an economic case for sustainable investment that takes into account Kenya’s needs, and increase investment in new medicines, diagnostic tools, vaccines, and other interventions.



Leadership

Kenya has put in place leadership structures to implement the National Action Plan at the national and subnational (county) levels. Not all counties have put in place AMR governance mechanisms. The AMR action plan and governance structures take a One Health approach that encompasses human, animal, and environmental health.

Figure 2: AMR leadership framework ¹⁴



Data on AMR

The country has reported to GLASS for two consecutive years. The 2021 GLASS report¹⁵ indicates that Kenya has five AMR surveillance sites participating in the national surveillance system, but no AMR data has been submitted from the country.

Project overview

From August 2020 to July 2021, with funding from the Wellcome Trust, the Global Partnership for Sustainable Development Data collaborated with Africa's Voices Foundation to generate and disseminate insights on AMR in Kenya using CGD. The CGD methods used included a combination of interactive radio shows and SMS/mobile text messaging service across three counties: Kiambu, Kilifi, and Bungoma. These methods were chosen to ensure that data generation involved public engagement and a parallel information dissemination mechanism to increase awareness of AMR while simultaneously collecting insights about citizens' knowledge, attitudes, and practices relating to AMR.

This report presents the findings from the 10 weeks of interactive radio broadcasting and citizen interaction, which generated over 20,272 SMS from 5,313 individuals. Although AMR is a global issue, we chose Kenya because of ongoing efforts to strengthen AMR and CGD capacity there. While the findings and recommendations in this report are for a Kenyan context, they have broad applications in other countries.



This report presents the findings from 10 weeks of interactive radio broadcasting and citizen interaction, which generated over 20,000 SMS from more than 5,000 people.

Left: Josephine Amina takes part in a listening group of mothers in Kilifi, Kenya.
Photo: Elphas Ngugi, GPSDD



Chapter 2: Methodology

This chapter outlines the methodology used, beginning with an overview of CGD. More information on the methodology, including quality assurance and ethical clearance, can be found in Annex A.

CGD expands what gets measured, how, and for what purpose. CGD initiatives cover areas from cartography to government policies, public services, and environmental research. CGD initiatives create new types of relationships between individuals, civil society organizations, and public institutions. These initiatives include local development and educational programs, community outreach, and collaborative strategies for monitoring, auditing, planning, and decision-making. CGD can inform several areas, including community engagement and community-based problem solving, planning, and strategy development, as well as improvement to public services. The quality of CGD can be comparable to official data collections, provided the quality of tools is high enough, there is sufficient training on the tools, and quality assurance is provided.¹⁶



CGD initiatives create new types of relationships between individuals, civil society organizations, and public institutions.

Research gaps

This project began with a scoping phase to understand the AMR landscape in Kenya. This phase involved a literature review to identify the data gaps (full details are in Annex B) and interviews with key stakeholders, and it culminated in a workshop in October 2020.

Through this process, the following key data gaps and research questions were prioritized:

1. Knowledge around disease and drug resistance

- What is citizens' knowledge of AMR and its consequences?
- What is citizens' knowledge of antimicrobials and reasons for seeking antimicrobials?

2. Reason for use/misuse of antimicrobials

- What are citizens' practices in using antimicrobials?
- What are the prescribing and dispensing habits on antimicrobials?
- What is the level of adherence to regulations on drug use and misuse?

3. Accessibility and availability of antimicrobials (especially in public sector)

- What are the drivers for stocking and selecting antimicrobials at the pharmacy or health facility?

A One Health approach and the gendered dimensions to AMR were also identified as cross-cutting issues to interrogate.

Below: Two women sharing information on a mobile phone. Photo: Kehinde Olufemi Akinbo, Shutterstock

CGD methods

This study used interactive radio, SMS, listening group discussions, and key informant interviews to generate data. These methods were used for the following reasons:

- **Radio is the most consumed media source in Kenya** and is a powerful medium for influencing culture, beliefs, and values, and it is a tool for economic growth and development.
- **Most Kenyans also have access to a mobile phone** and could therefore interact with the radio shows through free SMS.
- **Radio is the right medium for translating technical subject matter into everyday language.** For a complex topic like AMR, the use of radio was important to simplify the language and interact with a wide range of citizens.
- **The realities of COVID-19 meant that remote data collection was essential.** Given the COVID-19 restrictions on in-person gatherings and travel, interactive radio and SMS were a workaround to face-to-face meetings.



Box 2: The value of interactive radio and SMS

Africa's Voices Foundation has been using interactive radio, in which radio debates are driven by citizen input via SMS, since 2015. This is a mixed-media engagement technique to create actionable social evidence. By curating inclusive discussions through digital, interactive channels, Africa's Voices Foundation empowers citizens to share their voices, on their own terms and language, at scale.

The significant improvements in knowledge while engaging in interactive radio programming — as a citizen-generated data approach — are well documented.¹⁷ Interactive radio builds social spaces in which audiences can perceive and actualize change through interactivity and audience engagement. Its outcome is twofold: creating awareness on a health issue like AMR and increasing knowledge on the same. Audience members hear positive narratives from others in their own communities. Moreover, content is informed in real time based on analyses of audience perspectives — by, for example, involving specific health experts to provide knowledge and highlight government policy on AMR as well as to answer questions from citizens.

Listening group discussions (LGDs) targeting mothers and both human and animal health care workers were conducted in tandem with live radio shows. LGDs were useful to capture insights from these specific target groups, as they are key stakeholders in addressing AMR. Through the LGDs, participants discussed the radio show topics and responded to the weekly questions. Key informant interviews were conducted with human and animal health experts, health care workers and decision-makers to complement the data from the radio shows and add contextual information to the insights.

Design and data collection

At the beginning of the data collection phase, the research team identified the most appropriate radio stations for the project. The selection of radio stations was informed by existing working relationships, the stations' popularity, value for money, programming in the local languages spoken in the counties of study (Kiswahili, Kikuyu, and Luhya), and their coverage areas. The project deployed 10 weeks of radio programming in the three targeted counties of Kiambu, Kilifi, and Bungoma. The choice of the three counties was guided by the following requirements:

1. To align and inform a Clinical Information Network on AMR (CINAMR) project that includes these three counties;¹⁸
2. To represent socioeconomic and geographical diversity, as these counties have a mix of rural and urban populations;
3. To select counties with existing investments in AMR stewardship¹⁹ and activities.
4. To conduct the project in a county with some level of budget transparency based on the Kenya County Budget Transparency Survey.²⁰

The research team developed a strategy to help inform the design of the radio series and the questions to be asked of listeners on every show. The radio shows were designed to be one-hour sessions that aired during prime-time hours and included guest speakers who were AMR health experts or policymakers.



The project deployed 10 weeks of radio programming in the three targeted counties of Kiambu, Kilifi, and Bungoma.

Box 3: The power of language: the challenge of describing antimicrobials and AMR

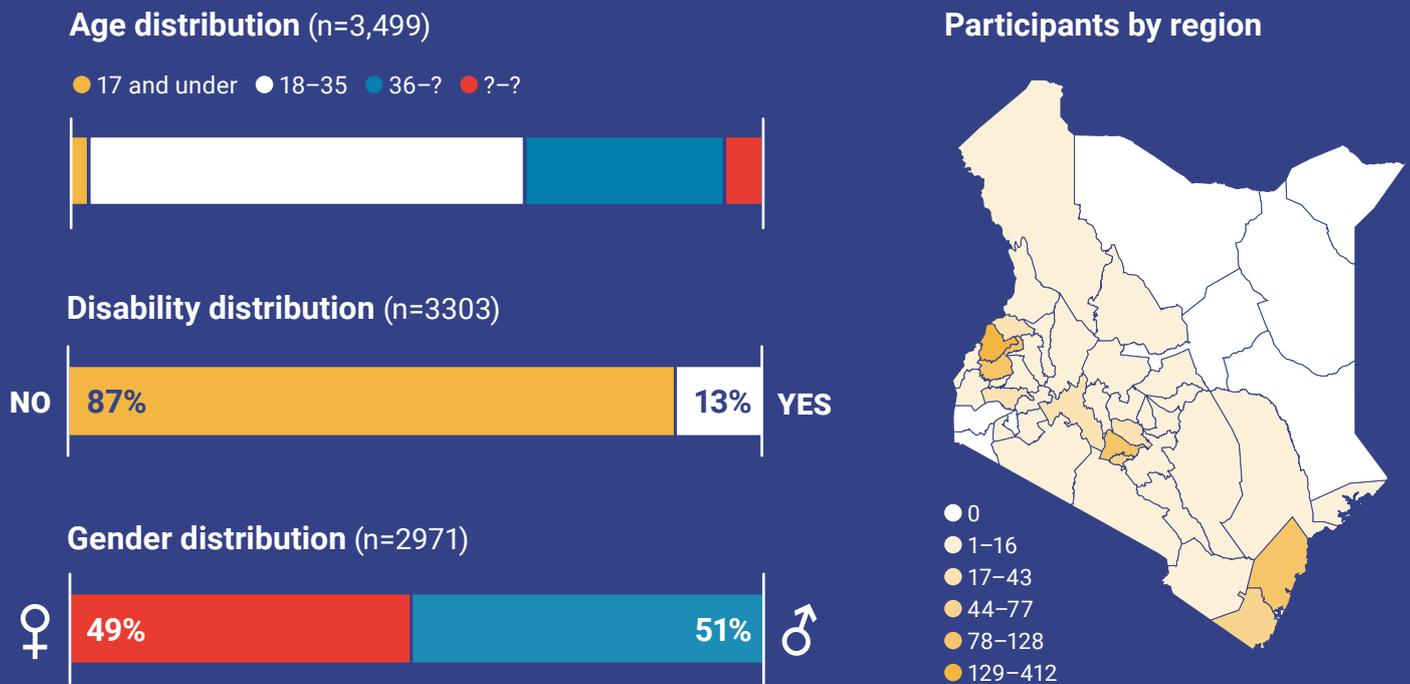
The experience from this project is that translating medical concepts such as antimicrobials into local languages is a challenge. The programming of the radio shows required a very descriptive approach to ensure the messaging in Kiswahili, Kikuyu, and Luhya was understood by listeners.

Some listeners understand antimicrobial drugs as antibiotics, by their brand names or how they look (mostly as capsules), and that they cure ailments such as flu and malaria. For example, mothers in the listening group discussions could identify some popular brands that are common at the chemists based on the ailments they treat (e.g., tonsils or “ugonjwa wa maziwa,” which is *Brucellosis*), but could not tell whether these are antimicrobials.

Most citizens find the term “antibiotics” more accessible than “antimicrobials.” For this reason, radio questions focused on “antibiotics” because it was easier for citizens to understand these terms in their local languages. The radio shows’ guest experts used the term “antimicrobial” and gave examples using the common antimicrobials known by communities. During the shows, guests highlighted specific bacterial infections and specific types or brands of antibiotics, such as amoxicillin, to ensure better understanding by audiences.

According to the health professionals engaged in this study, community members do not have a specific name for antimicrobials. They use terms like *dawa ya joto*, translated as “medicine for fever” or “the medicine that treats,” to differentiate them from painkillers.

Figure 3: Summary of data collected disaggregated by age, gender, location, and disability



Feedback loops

This project deliberately included an information dissemination phase to ensure that the data generated was shared back with the communities and key stakeholders at local and national levels to increase knowledge and drive data use and action. At the end of the 10 weeks, the research team sent an SMS to participants providing information on the main insights resulting from the study. In addition, we held a town hall meeting in each of the counties (except in Bungoma, due to COVID-19 restrictions) and at the national level. These outreach efforts were designed to share the findings, validate them, and come up with joint recommendations. These meetings brought together our target stakeholders: citizens who participated in the study, community leaders, county and national government officials (including those responsible for AMR prevention and control in human and animal health), civil society, and the media. In addition, a brown bag lunch was hosted with the AMR research community to share the findings and promote CGD as a complement to AMR surveillance data.



These outreach efforts were designed to share the findings, validate them, and come up with joint recommendations.

Methodological limitations

Like other research with community engagement components, CGD relies on self-reporting, and therefore the data can often be subjective. Not all participants respond to all demographic questions, and this limits the level of detailed disaggregated analysis against all demographic indicators.

Information about knowledge, attitudes, and practices by nature is subject to change and must be treated as a snapshot in time. However, because this project included data collection over a period of several weeks, some insights indicating changes in knowledge over time are useful in understanding patterns and trends.

The project had the dual objectives of disseminating information and collecting data. However, it was not designed to measure the impact of the information via the radio shows. Behavior change often takes a long time to manifest. While this project was designed with the hope that it would contribute to behavior change through an increase in knowledge on AMR, the time frame of the project limits any measurement of the interventions' effectiveness.

While care was taken in selecting radio stations that cover the three counties, radio frequencies go beyond geographical boundaries to reach neighboring counties; listenership therefore went beyond the three counties. It also does not ensure a representative sample of the population given access and variations in use of radio. Given these factors, the findings are not intended to be interpreted as statistically significant or representative of the populations in those counties, but rather as general insights that indicate patterns in knowledge and drivers of AMR.



Chapter 3: Findings

This chapter presents findings based on the three research questions and the cross-cutting themes. Section one responds to the first question around citizens' knowledge on AMR and their reasons for seeking antimicrobials. Section two responds to the second and third questions and presents these as the drivers of AMR to cover practices, regulations, access, availability, and stocking of antimicrobials. Section three covers the cross-cutting themes of the One Health approach and the gendered dimensions of AMR.²¹

1. Citizens' knowledge of AMR and its consequences

Understanding the scope of citizens' knowledge is critical to address AMR challenges at individual, community, and societal levels. After the first and last radio shows aired, participants received short SMS surveys (baseline and endline surveys) to measure the level of knowledge about AMR over the duration of the project. This approach allowed us to build on an existing sample of participants who have chosen and consented to participate.

Participation led to an improvement in knowledge of AMR

At the start of the study, community awareness of AMR across the three counties was reported as low. Overall, 89% of participants thought that the community was not informed at all or informed only a little bit. In Kiambu, Kilifi, and Bungoma this was 78%, 94%, and 93%, respectively. By the end of the study, 78% of participants reported that the community was not informed at all on AMR or only a little bit informed.



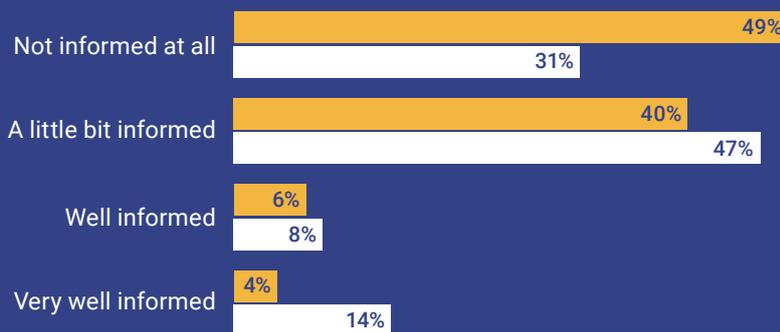
Overall, 89% of participants thought that the community was not informed at all or informed only a little bit.

Above: A listening group in Kiambu, Kenya. Photo: Elphas Ngugi, GPSDD

Figure 4: Citizens' perceptions of their communities' knowledge about the appropriate use of antibiotics at the start and end of the project

How well informed do you think your community is on the appropriate use of antibiotics?

- Baseline (n=156)
- Endline (n=684)



Women reported feeling more informed about AMR than men. This gendered difference was also reflected in the engagement around community awareness. Over the duration of the radio shows, there was a positive increase in the perception by women of the levels of community awareness of AMR. This measure rose from 5.8% at the beginning to 26.9% at the end of the programming. Men did not report a significant change in knowledge over the course of the project.

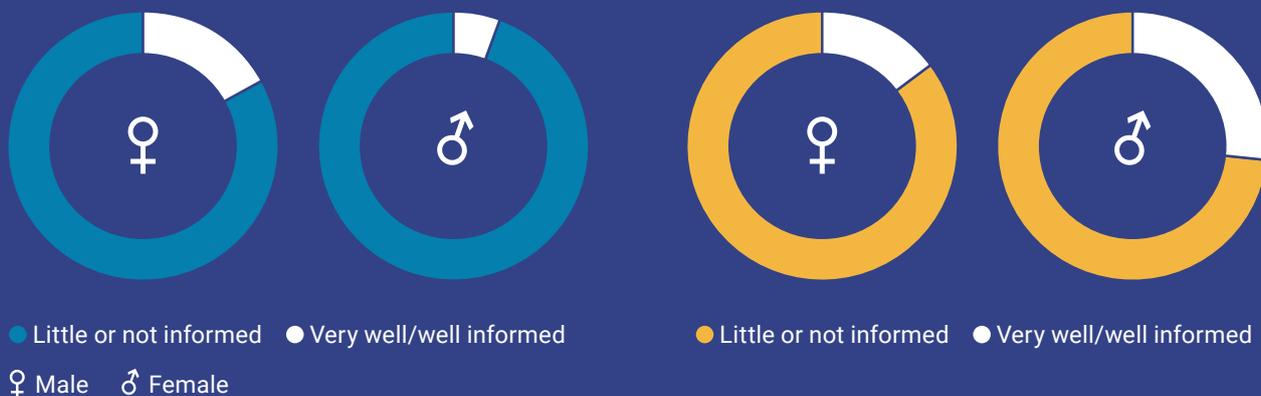
Between 17% to 26%²² of the participants each week texted to ask questions, and an additional 16% on average every week asked for the community to be educated. By the end of the radio shows, women and participants who had engaged in the study three or more times asked fewer questions than before. This suggests a possible relationship between being engaged and higher knowledge levels.

Figure 5: Gendered differences on community knowledge

Gender differences on perceived community knowledge

Baseline

Endline



A general awareness of AMR and antibiotics in theory, but limited in practice

In addition to the baseline and endline questions, we used the weekly radio shows to further measure citizens' general AMR knowledge level. The findings indicate widespread perceived lack of knowledge about AMR among the general public, highlighted by 31.4% of the respondents. Respondents also reported that there was a need to educate the community on the importance of better understanding AMR and the appropriate health practices.

When asked when antibiotics should be used, over half of participants said that antibiotics should only be taken according to a prescription — a third explicitly said a doctor's prescription, and almost a quarter of respondents said more broadly that a prescription needs to be followed. A quarter of the respondents said that antibiotics need to be taken when sick or infected, without specifying the illness or the need for a prescription and diagnosis by a health professional.

The LGDs and key informant interviews showed that while respondents know that antibiotics should be taken according to a prescription, this does not translate into practice. A majority of patients do not follow doctors' prescriptions; they prefer to purchase medications without prescription by a qualified health worker. They have easy access to over-the-counter antibiotics. They fail to adhere to the recommended dosage (e.g., not completing their course of medication). Some do not use medication at all and rely on traditional healers. Institutional barriers like difficulties in accessing hospitals, low numbers of health practitioners resulting in long queues, and the high cost of health care also mean that knowledge is often not put into practice.

One widely shared view is that the time of the day is important when taking antibiotics. Most respondents identified morning hours and after evening meals as the ideal times to take antibiotics. However, these perceptions do not always tally with prescriptions, since medications are prescribed to be administered at intervals, or more than twice per day, which may not coincide with the morning and evening meals.

Below: Dr. Robert Kamau is a clinical pharmacist at Kiambu county Level 5 Hospital.
Photo: Elphas Ngugi, GPSDD

“ There is a lack of awareness and knowledge on [anti] microbial drugs.”

Man, Bungoma

“ People should be sensitized on the importance of finishing the doses.”

Vipingo, Kilifi

People Power



What did the citizens we reached want to know about AMR?

Of note during this study was the number of questions that citizens asked as they participated in the interactive radio programming. This is a strong indication that there is an interest in the topic and that interactive formats such as radio are needed to provide citizens with accurate information on AMR. We analyzed respondents' questions to break down the specific knowledge gaps related to AMR.

Over half (56.6%) of the questions were on AMR, while the remaining questions (43.4%) were on general medical topics such as causes of flu and children's ailments, given that the radio show guests were health professionals.

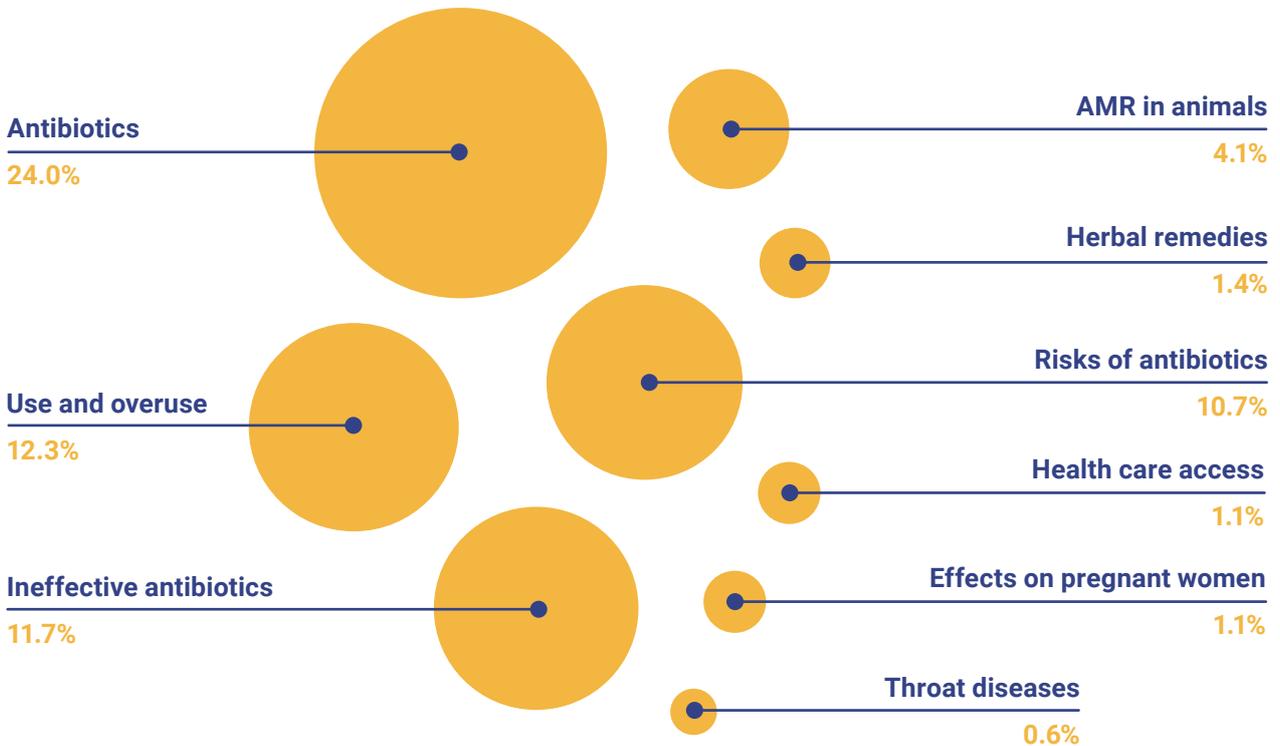
Of the questions on AMR, citizens sought general information about antibiotics such as what antibiotics are, how and when they are used, the difference between antibiotics and painkillers, where certain drugs are sold, and whether particular drugs they were using were antibiotics. They wanted to understand use and overuse of antibiotics, why some of the antibiotics they used were ineffective, and the risks associated with misuse of antibiotics. Others asked questions about AMR in animals, herbal medicines, and how they could access health services.

Female respondents in particular asked about whether antibiotics are safe for pregnant women, their side effects, whether antibiotics can harm unborn babies, and their effects on children.



Participants wanted to understand use and overuse of antibiotics, why some of the antibiotics they used were ineffective, and the risks associated with misuse of antibiotics.

Figure 6: What do citizens want to know about AMR? (n=845)





“ Doctor, are pregnant women allowed to use these drugs? ”

Man, 24, Kilifi South



“ Can prolonged use of the same type of antibiotic cause that condition? ”

Man, 47, Subukia

“ My question to the doctor is, using different antibiotics often for the same ailment for a long time, are there any side effects? ”

Man, 49, Rabai



“ My question is, my child has been coughing for a very long time and has been using antibiotics all the time, but he is not recovering. What is the problem? ”

Woman, 28, Kisauni

“ Is it advisable for a child to use one antibiotic when sick and get another one if they don't get well? ”

Woman, 33, Kiambu



“ What problems will I develop if I don't follow prescriptions for antibiotics? ”

Woman, 29, Machakos

“ What happens if you take your medicine for a few days, then break for a while, then continue for, like, three days? ”

Man, 22, Kikuyu-Kiambu

“ Can antibiotics be used to treat chest infections? ”

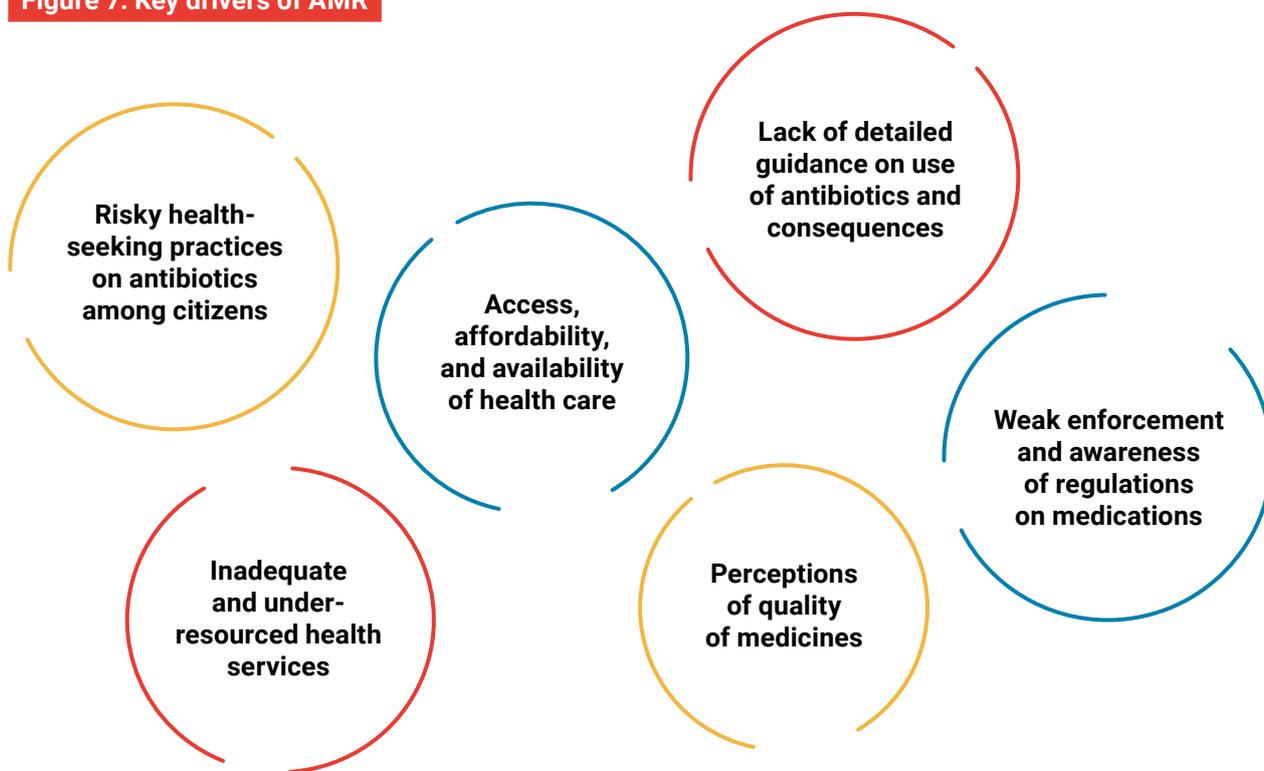
Kikuyu



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

2. The drivers of antimicrobial resistance

Figure 7: Key drivers of AMR



AMR and risky health-seeking behaviors

Respondents were asked via radio: *If some bacterial infections become resistant to antibiotics, what are the risks for you and your community?*

They identified a number of risks associated with antibiotics use. Respondents reported that medication will not perform well to fight the infections. Secondly, misuse of antibiotics will lead to severe health deterioration, and eventually death. The respondents also reported that misuse of antibiotics will lead to high intake of medication without addressing the underlying health problems, which in turn leads to lowered immunity and even death. Drug misuse was mentioned as a factor in increasing the cost of medication.

The insights from health providers, however, point to poor and even risky health-seeking behavior among citizens. While some seek antimicrobial treatment for any slight illness, most patients seek medical care from health care facilities, where antibiotics are prescribed, too late – when other means (self-treatment through home remedies, herbal treatment, and over-the-counter drugs [which might be antibiotics]) fail. Men are especially reluctant to seek medical care until they are very ill.

“ An interesting dimension is men avoiding going to hospitals could be an aspect of how society stigmatizes weakness in men by going to hospitals. ”

AMR researcher

Access, affordability, and availability of health care

Respondents reported that challenges in availability and accessing health facilities, as well as high costs of seeking medical care, discouraged people from going to health facilities when sick. This resulted in self-medication, purchasing drugs over the counter, sharing medication among different children and among neighbors, reusing unfinished medications from previous treatments, purchasing insufficient dosages, and failing to dispose of unfinished medication. Mothers in particular seek antibiotics from chemists for their children. Health care workers were of the opinion that people share medication because it saves them the cost of purchasing their own medication and prevents them from incurring additional costs from the visit required to obtain prescriptions.

“ [The lack of] accessibility to health facilities makes people buy drugs from nearby shops. ”

Man, 35, Bungoma

Citizens are aware that misuse of antibiotics has higher cost implications. In the third week of programming, 17.2% of respondents indicated that they thought that misuse of antibiotics will lead to high intake of the drugs, which means increased costs.

“ Increased morbidity and mortality due to ineffective antibiotics leads to poverty due to the cost of treating resistant strains. ”

Man, Kiambu

“ It will be difficult to treat such ailments. Medical costs will escalate, as the dosage required when the ailments are tough to treat are higher than others. ”

Man, 38, Kiambu

“ The government should empower people economically so as to be able to cater for costs that come along with seeking medication at the hospitals. Many cannot afford it, hence the shortcut. ”

Man, 40, Kanduyi

“ The second problem is the cost of treatment will go up. ”

Man, 26, Kilifi

“ Yes, due to prolonged sickness, which increases the cost of treatment. ”

Woman, Bungoma

Left: Macknophear Mose consulting with a nurse.
Photo: Elphas Ngugi, GPSDD



Guidance is often too vague or missing completely

Citizens often obtain knowledge about AMR only through interactions with health workers. While this signifies an appropriate reliance on health care professionals, these interactions are not sufficient for patients to properly follow the advice provided during prescription; this lack ultimately leads to misinterpretation and misuse.

For example, a prescription may indicate that a patient should take one tablet three times a day. If the patient misses taking a tablet at the correct time, he or she may end up taking the remainder of the day's dosage all at once. Furthermore, citizens frequently perceive the state of their health in terms of how they are feeling, and therefore do not demand laboratory tests or seek a professional diagnosis (which would cost more). In addition, as soon as a patient is feeling better, he or she may end treatment prematurely without understanding how the medication works.

“They are not aware. We are still waiting for guidance from the health department.”

Man, Bungoma

“Lack of complete knowledge.”

Man, Kiambu

“Is it necessary to go to a hospital, or should I just buy medicines from a chemist?”

Woman, 32, Kilifi South

Box 4: An adult patient's experience of antimicrobial misuse

“During my interaction with patients in this clinic, I have had stories of AMR. And one specific one is a HIV-positive mother [who would not come to the hospital for her own medication when she finished her drugs]. Since her husband is also HIV positive, she would [share] her husband's antiretroviral drugs (ARVs). After some time, I realized that her viral load was not suppressing. So that means she was no longer responding to the antiretroviral medication. So ... it was concluded that we need to take her to the second line ARV regimen. ... If she fails to respond to the second line regimen, we'll not have any other thing to go to. And that will be very catastrophic for her.”

Nurse, Kilifi County

Weak enforcement and awareness of medication regulations

Citizens were asked, “What should the county government do to ensure there is an appropriate use of antibiotics in the county?” Among participants, 13.3% said that the government should put in place and enforce regulations on the sale and use of antimicrobials.

Citizens feel that effective regulation is important in addressing AMR, but this can only work if the health systems are functional as well. For instance, respondents reported that in a significant number of public health facilities, patients are often asked to buy drugs from specific private pharmacies. This type of prescription presents various risks, such as pharmacies selling only specific types of drugs or being promoted while operating without proper licensing.

Although regulations exist, the level of enforcement and awareness was said to be low. Respondents also perceive existing regulations as unresponsive to the needs of the health sector. For example, some health practitioners felt that while it is advisable for people not to buy drugs over the counter, when citizens have no health facilities near them, pharmacies become their first call for assistance. Perhaps if regulations required these pharmacies to be licensed and have a qualified health expert to dispense medication, some of the gaps can be addressed.

“The government should provide full direction, including legislation on the procurement of antibiotics.”

Man, 36, Emuhaya

Perceptions of the quality of medicines

Close to 10% of citizens who responded via SMS think that infections are becoming resistant to antibiotics because of the poor quality of medications in the market. For example, some believe drugs to be of poor quality because they are generic and therefore cause further resistance. Health care workers also reported that some citizens relied on traditional health care practices and herbal remedies to treat infections.

“People know that we have generic drugs and original one, so generic ones cause resistance.”

Man, 46, Kanduyi

The quality of medicines is also perceived to be partly driven by the profit seeking of pharmaceutical businesses, especially at the community level, where regulation enforcement is weak.

Inadequate and under-resourced health services

During the LGDs, participants said that health care workers do not have time to provide adequate information on how to use drugs due to long queues and heavy workloads. Health professionals' limited numbers restricts the time they have to interact with patients and share knowledge on AMR, how to use drugs, and other good health practices. The dearth of health care workers also means that not all citizens have access to health professionals. Kenya's Human Resource for Health capacity stands at 13.8 per 10,000 population, while the WHO recommended ratio is 44.5 per 10,000 population, indicating a significant gap.²³

Respondents, particularly from Kiambu County, also pointed to the need to equip and resource public health facilities across the country. Currently, they rate services in most public health facilities as poor. With more functional health facilities, citizens will be able to access professionals who can give reliable prescriptions and work within an enforcement framework. Improved health services will reduce the use of unregulated pharmacies.

“By setting laws and regulations that will govern the purchase of antibiotics.”

Woman, 32, Navakholo

“The manufacturing companies are making less strong drugs.”

Man, 34, Kanduyi

Lack of trust in health professionals

Health care workers in the listening group discussions reported that it is common for citizens to demand specific medication in a specific form — for example, an injection — and when they don't receive the requested treatment, they get frustrated and question the competence of health care workers. This lack of trust in health care workers is cited as one reason that citizens avoid health facilities. Mistrust is also driven by traditional beliefs, such as in the value of healers and herbal medicine, which often lead to treatments that conflict with those of medical professions. It is also worth noting that these practices result in citizens delaying seeking appropriate medical care.

“ The aspect of AMR and herbal medicines really stood out for me in your study. Most communities in Kenya use traditional medicines as part of care, and it becomes very difficult to change people’s mindset.”

AMR researcher



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

3. Cross-cutting issues

A One Health approach to AMR

AMR can spread through the food chain and the environment. Therefore, understanding the role that animal health and the environment play in AMR (a One Health approach) is crucial in preventing infections and the further development and spread of AMR. While this study emphasized the effects of AMR on human health, we also looked at the One Health approach as a cross-cutting issue.

Our respondents reported misuse of antibiotics on animals, largely due to a lack of knowledge.

Antibiotics are used to treat various ailments among chicken and dairy cows (such as respiratory illnesses and mastitis). When animals are undergoing antibiotic treatment, owners are often advised to avoid consuming or distributing the products from these animals (meat, milk, or eggs), but many farmers do not adhere to these withdrawal periods, thus exposing consumers to AMR. In addition, farmers don't always seek professional veterinary services due to costs, and instead obtain medication from agrovet supply outlets.



“ I think abuse of antibiotics is majorly caused by ignorance in its uses. There should be civic education and awareness by extension officers on their use.”

Woman, Kanduyi

“ Government should conduct civic education for the farmers to make use of veterinary services.”

Man, 47, Subukia

“ Through forums farmers get skills and knowledge concerning drugs that help in animal curing that prevent the spread of infections.”

Woman, Kisii

“ Explain to farmers the facts about the use of antibiotics.”

Man, Mtwapa

Left: A freelance veterinarian in Kilifi county, Kenya. Photo: Elphas Ngugi, GPSDD

Box 5: Insights from a veterinary researcher during a Kiambu County listening group discussion

“ AMR is a huge issue in communities, but it is poorly understood and difficult to put a face to it. The problem is caused by imprudent use of antibiotics by people who are not trained to use them. Sometimes, even those that trained just rely on clinical diagnosis instead of lab diagnosis hence treating the wrong disease using wrong antibiotics. In my community, we have problems emanating from outlets where farmers treat their animals by going to agrovets and buying over-the-counter medications. There are also unqualified people who are responsible for providing service in the agrovets. There are serious knowledge gaps both on AMR issues at local and global levels. Part of addressing these problems includes targeting both veterinary and human health professionals for prudent use of drugs. Citizens need to be sensitized not to treat their own animals and practice good animal husbandry to prevent diseases.”

Gendered dimensions of AMR

In this research, we looked at the gendered dimensions of AMR as a cross-cutting issue. While most women reported a lack of knowledge, more men reported having some knowledge on AMR. As this information was self-reported, this disparity might also indicate a gendered difference in the willingness to admit lack of knowledge.

In terms of health-seeking behaviors, men are largely reluctant to seek health services until they are seriously ill, which may drive them to buy over-the-counter medication.

Due to concerns about their reproductive health, women asked more questions regarding effects of antimicrobial drugs during pregnancy.

As reported in the LGDs, women use antimicrobials when their children fall ill. Some practices, such as home-based treatment, use of over-the-counter medication, and sharing or borrowing of medication were reported by women when caring for their sick children. Younger mothers or single mothers with low incomes are particularly likely to be excluded from accessing professional health services.

When it comes to AMR in animal health, male respondents are more likely to be involved in decision-making because they are largely involved in livestock farming.

In the counties we studied, there were more female health care workers at the nursing level than fully qualified medical doctors. As nurses are the first line of contact with citizens at the facility level, they can play a critical part in the AMR conversation and educate citizens.



Men are largely reluctant to seek health services until they are seriously ill, which may drive them to buy over-the-counter medication.



Left: Kiambu county AMR healthcare workers engaged in capacity-building training. Photo: Elphas Ngugi, GPSDD

Chapter 4: Recommendations

The findings from this study offer recommendations for action, drawing on a combination of feedback from the radio shows, SMS, brown bag with the research community, and town hall meetings. While these recommendations are drawn from a Kenyan context, they have global applications.

Recommendations for citizens and communities

- 1. Feel empowered to play a role in tackling AMR by changing practices in accessing, using, and misusing antimicrobials.** This includes following prescriptions, maintaining hygiene, and educating other community members. As exemplary citizens, people can help to dispel inaccurate information on antimicrobials by sharing accurate information with others in the community.
- 2. Proactively engage in efforts to gather citizen-generated data.** CGD is an important means to get the voices of citizens heard, hold the government accountable, and ensure that citizens' experiences are reflected in policy and decision-making. Civil society organizations should engage with citizens as part of the process and draw on them as an important data source.



People can help to dispel inaccurate information on antimicrobials by sharing accurate information with others in the community.



Recommendations for national and subnational government policymakers

- 1. Make investment in AMR a public health priority.** Specifically, investment should target strengthening laboratory networks to enable access to surveillance and monitoring of infections; equipping health facilities with sufficient medication and health care workers; and making health services affordable. *As an example of making health care more affordable, Kilifi County is exploring mechanisms to cost medications per dosage and not per tablet, as the latter increases prices.*
- 2. Promote AMR stewardship.** Specifically, policymakers should incorporate citizen engagement in AMR decision-making, policies, and budgets. The involvement of citizens will support sustained impact and increase government attention/political will on AMR. Additionally, there should be a focus on enforcing and raising awareness of regulations to tackle AMR.
- 3. Embrace citizen-generated data as a critical source on a par with official data sources.** Policymakers should consider partnering with civil society organizations to collect, analyze, and use CGD to inform programs, monitor their effectiveness, and engage citizens.



Policymakers should incorporate citizen engagement in AMR decision-making, policies, and budgets.



Recommendations for health care workers

- 1. Drive quality patient engagement on AMR to tackle misinformation and improve levels of trust with citizens.** This includes providing patients with comprehensive information, such as explaining the importance of adhering to prescriptions and dosage so that patients use antibiotics properly. This may be done by providing regular health talks, as well as relevant materials and signage on AMR. *For example, health facilities in Kiambu County have introduced medication therapy management rooms to engage patients who have serious infections.*
- 2. Take a holistic approach in addressing AMR.** This requires understanding the role of community engagement and drawing on lessons from CGD to inform interactions with patients and communities.



Recommendations for the research community

- 1. Explore ways to incorporate citizens' voices in research studies that target challenges on AMR,** especially in hard-to-reach areas such as arid and semi-arid lands.

Chapter 5: Conclusion

There is a clear association between knowledge and the use and misuse of antimicrobials. Most citizens in Kenya are not knowledgeable about antimicrobials or AMR. Often, the only accurate information they obtain is through interactions with health workers. Strengthening these engagements will pay off.

This project demonstrates a discernible benefit to public engagement on AMR. Even within the span of 10 weeks, the project in Kenya saw an increase in knowledge on AMR across the three counties we targeted. Citizens have a genuine quest for knowledge on AMR, as indicated by the number of questions they asked during the radio shows. This indicates that targeted and consistent public engagement can reduce knowledge gaps and, ultimately, influence behavior change to address AMR.

Our findings indicate that the challenges of access and availability of health facilities, as well as the high costs of seeking medical care, lead to poor health-seeking practices that exacerbate AMR. This harmful dynamic is further reinforced by inadequate and under-resourced health facilities, leading to long hospital queues and leaving health care workers no time to engage meaningfully with patients on AMR. Citizens feel that effective regulation, enforcement, and awareness are important in addressing AMR, but these solutions can only work if the health systems are functional as well.



There is a clear association between knowledge and the use and misuse of antimicrobials.

Right: Josephine Amina is a poultry and livestock farmer in Kilifi county, Kenya. Photo: Elphas Ngugi, GPSDD



The recommendations highlight that AMR is a shared responsibility. Citizens, policymakers, health care workers and the AMR research community all have important roles to play in tackling AMR in their communities, their countries, and beyond. As expected, an engaged citizenry leads to more emphasis on government responsibility in prioritizing investments and policies to tackle AMR and strengthening health systems. Citizens know that the onus is on them to change their practices on AMR but to also hold the government to account on prioritizing AMR and the regulation of antimicrobials. Health care workers need to properly engage and inform citizens on AMR and its dangers. The AMR research community needs to embrace CGD in understanding nuances on AMR and filling data gaps where surveillance data may not suffice.

This study has reinforced the value of citizen-generated data in providing insights on issues such as AMR that matter to citizens and closing data gaps. By following rigorous standards and methods, the findings resonate with what the AMR research community has found using other types of data collection.

AMR is a social issue driven by human behavior and should be tackled by engaging with communities to influence their behaviors. Empowering communities with knowledge in turn facilitates the co-development of actions to minimize the negative effects of AMR. CGD is a valuable approach, as it creates new spaces for citizens and government to engage and include citizens in public decision-making at various levels of government. CGD empowers community members by engaging them in one or several stages of the data value chain – collection, publication, uptake, and impact. It offers an important complement to official data produced by national statistical offices in driving forward a data revolution for sustainable development.

Looking forward, the value of CGD can be further supported through national statistical offices providing stewardship to producers of CGD. Stakeholders in AMR can tap into CGD more deeply to help them understand and influence the knowledge, attitudes, and practices of citizens on AMR.

“ Really interesting work. Not far off from the findings from a questionnaire with communities.”

AMR researcher

Annex A: Detailed methodology

Design

Using media and free SMS short code in tandem enables community engagement at scale, raising awareness on AMR while at the same time identifying drivers and barriers promoting or hindering community knowledge and best practices in relation to AMR. This intervention was deployed in the counties of Kiambu, Kilifi, and Bungoma:

1. To align and inform a Clinical Information Network on AMR (CINAMR) project that includes these three counties;
2. To represent socioeconomic and geographical diversity, as these counties have a mix of rural and urban populations;
3. To select counties with existing investments in AMR stewardship and activities.
4. To conduct the project in a county with some level of budget transparency based on the Kenya County Budget Transparency Survey

At the beginning of the data collection phase, the research team hosted a co-design workshop to identify the most appropriate radio stations for the project. The selection of radio stations was informed by existing working relationships, the stations' popularity, value for money, programming in local languages, and their wider coverage areas.

The research team developed a communication framework identifying the specific issues to be addressed and how the radio shows would be run. The radio shows were designed to be one-hour sessions that aired during prime-time hours (7–10am and 5–6pm) and included guest speakers who were AMR health experts or policymakers. Each show addressed a specific topic and posed questions to the public. The public could respond to the questions or interact with the guest speakers through SMS. This method ensured that information was being disseminated about AMR, while simultaneously gathering data about listeners' knowledge, attitudes, and practices relating to AMR via the SMS interaction. The radio hosts were trained at the beginning of the project and had a guided script to run the shows.

Table 2: Weekly radio questions*

Week 1	Some infections are becoming resistant to antibiotics and cannot be treated like they could be treated before. What do people in your community know about this issue?
Week 2	In your understanding, when and how should antibiotics be used?
Week 3	If some bacterial infections become resistant to antibiotics, what are the risks for you and your community?
Week 4	What should be done to reduce antibiotic misuse, which causes antibiotics to become less effective in killing germs?
Week 5	How can the use of antibiotics for animals be better controlled to avoid overuse, which results in infections becoming resistant to antibiotics?
Week 6	One of the biggest causes of resistance to antibiotics is people buying antibiotics over the counter. What can the government do to control this?
Week 7	What can an individual or the community do to prevent infections from becoming resistant to antibiotics?
Week 8	How can health care workers communicate with patients when giving antibiotics to increase awareness of antibiotic resistance?
Week 9	What is the role of the community in addressing the challenges caused by resistance of germs (bacteria) to antibiotics?
Week 10	Over the last nine weeks, we have been talking about how to prevent infections from becoming resistant to antibiotic drugs. Moving forward, what are you going to do differently when it comes to antibiotic use?

**For ease of understanding, the radio questions used "antibiotics" rather than "antimicrobials," as this is what citizens could easily relate to. During the shows, this discrepancy needed further elaboration with examples.*

The radio shows consisted of three distinct segments: (a) presenters discussing the radio topic and an incorporation of human-interest stories and voices on lived AMR experiences to elicit para-social interaction with the radio audiences; (b) AMR guest experts giving their input; and (c) audience feedback through SMS, to which the AMR experts would respond.

The study obtained ethical approval from the Amref Health Africa Ethics and Scientific Review Committee, as well as from the National Commission for Science, Technology and Innovation, and developed a data ethics canvas as a tool for ethical frameworks and guidance around the project.

Data collection

The research team organized virtual meetings for radio presenters from all three target locations to orient them on the approach and discuss the communication framework. Each week, detailed scripts were provided, and a dedicated expert was available to guide the presenters and radio guests during the live shows.

As the radio shows were hosted in local languages, a team of researchers fluent in the languages of Bukusu, Kiswahili, and Kikuyu were recruited to interpret the SMS messages and monitor the live radio shows.

Citizens reached during the programming shared their views via free SMS in the language with which they were most comfortable. Once a listener sent an SMS in response to the radio show, a consent SMS flow was automatically triggered. This informed the participant that SMS are analyzed to help understand people's views on AMR and that the findings are used to inform policy in Kenya. It provided participants who sent an SMS the opportunity to deny consent. Anyone who withdrew or denied consent was removed from the database. Participants in listening group discussions and key informant interviews completed informed consent sheets that followed the ethical guidelines. The radio scripts were explicit about the intentions of the study.

Data processing

Once data was received, the messages were grouped according to different themes following a qualitative thematic analysis approach. This grouping concluded in a "coding frame," and each SMS was then labelled with the relevant code/theme.

The research data protection policy took a security-by-design approach. No phone numbers, names, ID cards, locations, or any other form of identification were stored in datasets. All data was anonymized before sharing. The same went for quotes used in the reports – all these were anonymized and only indicate the demographic information (obtained upon consent).

Data analysis

SMS messages received during the shows formed a weekly data stream and contributed to an overall series dataset that was analyzed using in-depth qualitative and quantitative analysis, including regression analysis, to identify statistical associations across topics, demographic groups, and levels of participation. The content of the weekly data streams informed the content of subsequent shows.

Data dissemination and closing the loop

At the end of the 10 interactive radio shows, the research team sent an SMS to participants providing information on the main insights resulting from the study. This ensured the sharing of data was two-way. The method facilitated citizen-generated data and provided participants with accurate information.

In addition, the insights were shared in dissemination workshops with relevant county-level stakeholders and a national workshop to ensure the findings were validated and the recommendations were a joint effort.

Quality assurance

The study obtained ethical approval from the Amref Health Africa Ethics and Scientific Research Committee and the National Commission for Science, Technology and Innovation. The team also developed a data ethics canvas as a tool for ethical frameworks and guidance around the project. All participants were given an opportunity to provide informed consent for their data to be analyzed in this study with assured confidentiality.²⁴

Two AMR specialists, one from the Government and the other from the research community in Kenya, were part of the project team to provide expert guidance. Additionally, an advisory committee composed of experts from CGD and AMR sectors in Kenya and internationally was constituted during key milestones in the project to provide quality assurance. To ensure quality of the data collection process, the activities were designed to follow guidelines in producing CGD.²⁵

Annex B: Detailed data gaps identified during the scoping phase

Knowledge, attitudes, and practices	Category	Topic/question	Target group
Attitude	Need for Antibiotics	Reason for (seeking or providing) antibiotic prescription	Community member, health care worker
Attitude	Need for Antibiotics	Perception of what illness the patient has relating to the need for antibiotics	Community
Attitude	Antibiotic selection	Reasons/drivers for stocking antibiotics (what clients ask for, marketing by drug companies, etc.)	Health care workers, pharmacies
Attitude	Antibiotic selection	Drivers of which antibiotics are selected/purchased (prescription vs. advice from operator of over-the-counter drug shop, own knowledge, etc.)	Community
Attitude	Antibiotic selection	Influence of medical or pharmaceutical representatives (frequency of visits)	Health care worker
Attitude	Antibiotic selection	Level of trust/confidence in quality of antibiotics	Community member, health care worker
Attitude	Patient-health care system relationship	Level of trust/confidence in health care workers' recommendations	Community member
Attitude	Patient-health care system relationship	Level of trust/confidence in laboratory results	Health care worker
Attitude	Information about antibiotics	Perception of antibiotic strength and potency	Community, health care worker
Knowledge	Patient-health care system relationship	Awareness of and request for diagnostics; communication of lab results	Community, health care worker

Knowledge	Information about antibiotics	Knowledge of various antibiotics (specific vs. broad) and point at which you switch tiers	Community, health care worker
Knowledge	Information about antibiotics	Do citizens know them based on appearance, color, size, package, or name?	Community
Knowledge	Information about antibiotics	Distinction between medications intended for children/adults; humans/animals	Community
Knowledge	Information about antibiotics	Purpose of antibiotics and risks of self-medication, sharing medicine, over-the-counter drugs, disposal of expired antibiotics	Community, health care worker
Knowledge	Information about antibiotics	Source of knowledge about antibiotics/AMR	Community, health care worker
Knowledge	Drug resistance	Awareness of drug resistance as a possibility, reasons, individual vs. community level	Community, health care worker
Knowledge	Drug resistance	Role of infection prevention and control in affecting AMR	Health care workers (including management)
Knowledge	Antimicrobial stewardship	Awareness of antimicrobial stewardship programs	Health care worker, policy decision-makers
Knowledge	Antimicrobial stewardship	Knowledge of antibiotic guidelines (awareness of tiers and control guidelines from community perspective)	Health care worker, pharmacists, community
Knowledge	Hygiene	Role of hygiene practices in AMR	Community; health care worker
Practice	Use/misuse	Antibiotic prescribing and dispensing habits (frequency, purpose, type)	Community member, health care worker
Practice	Use/misuse	Use of antibiotics without prescription	Community member
Practice	Use/misuse	Frequency of use of antibiotics (prescribed and non-prescribed)	Community
Practice	Use/misuse	Completion of full antibiotic courses (keep for future use)	Community member, health care worker
Practice	Use/misuse	Use of antibiotics in food production: agriculture, livestock, food processing, use of human antibiotics on animals	Community
Practice	Access – availability	Distance to source of antibiotics (pharmacy, clinic, etc.)	Community member

Practice	Access – availability	Antibiotics in stock	Community member, health worker
Practice	Access – source	Source of antibiotics (pharmacy, clinic, informal sellers)	Community
Practice	Access – affordability	Cost of antibiotics	Community member, policy decision-makers
Practice	Patient-health care system relationship	Follow-up/consistency of care with same health care provider	Community member, health care worker
Practice	Patient-health care system relationship	Point at which they seek care	Community, health care worker
Practice	Prevalence of resistance	Non-response of medicines/antibiotics; recurrent and secondary infections; magnitude of the AMR problem	Community, health care worker, policy decision-makers

Annex C: List of figures

Figure 1: AMR leadership framework ²⁶

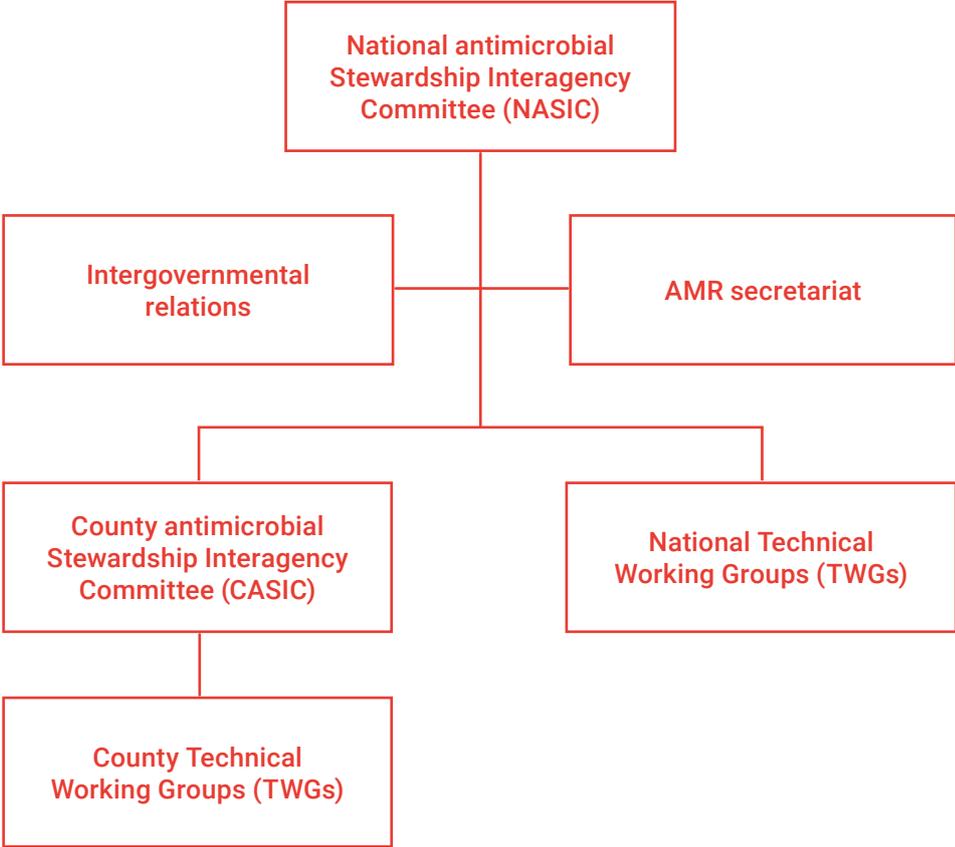


Figure 2: Summary of data collected disaggregated by age, gender, location, and disability

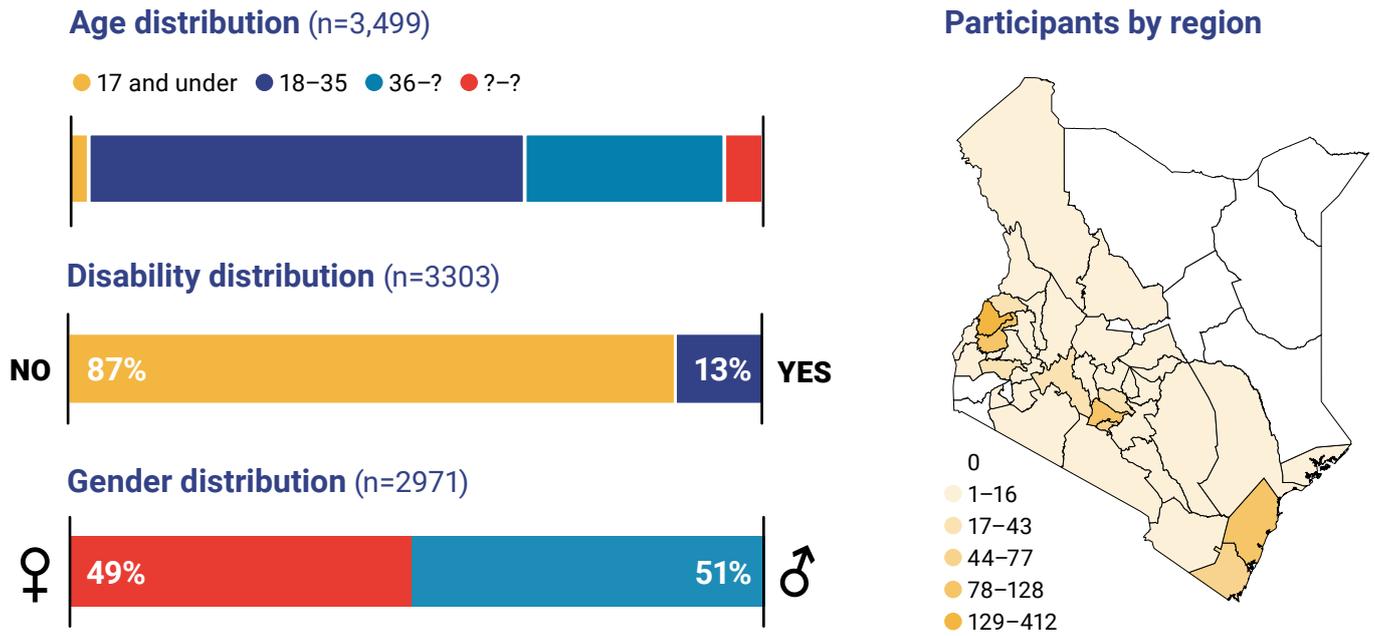


Figure 3: Citizens' perceptions of their communities' knowledge about the appropriate use of antibiotics at the start and end of the project

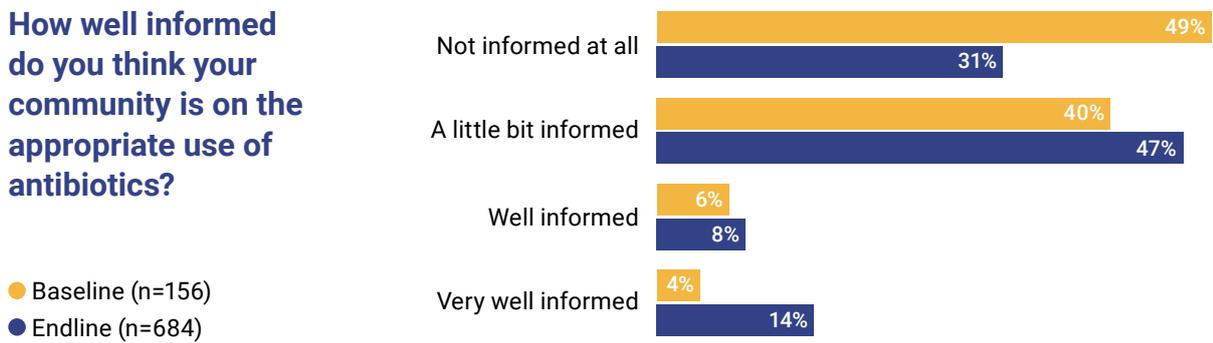


Figure 4: Gendered differences on community knowledge

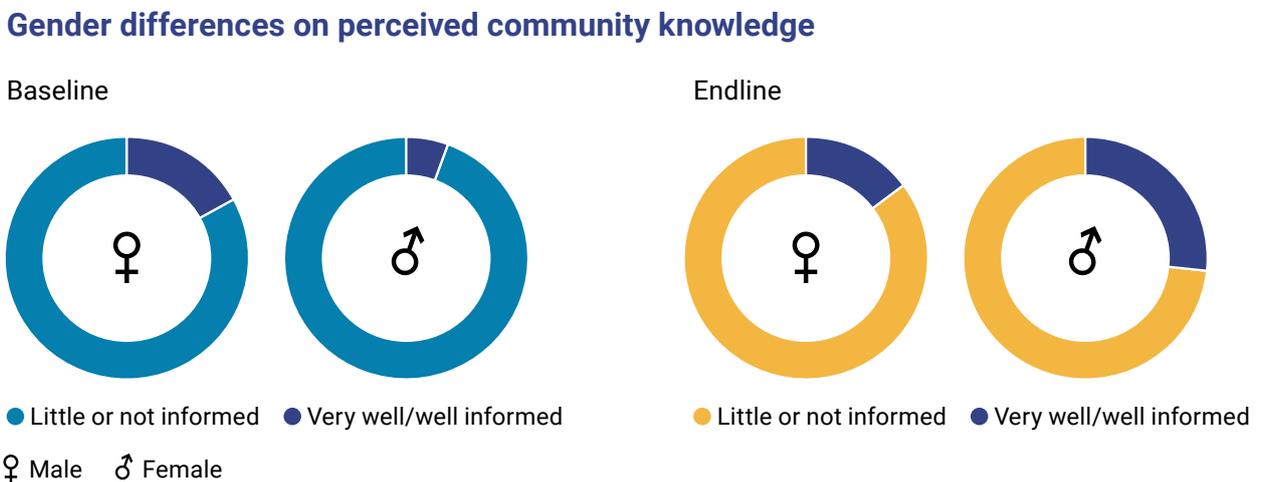


Figure 5: What do citizens want to know about AMR? (n=566)

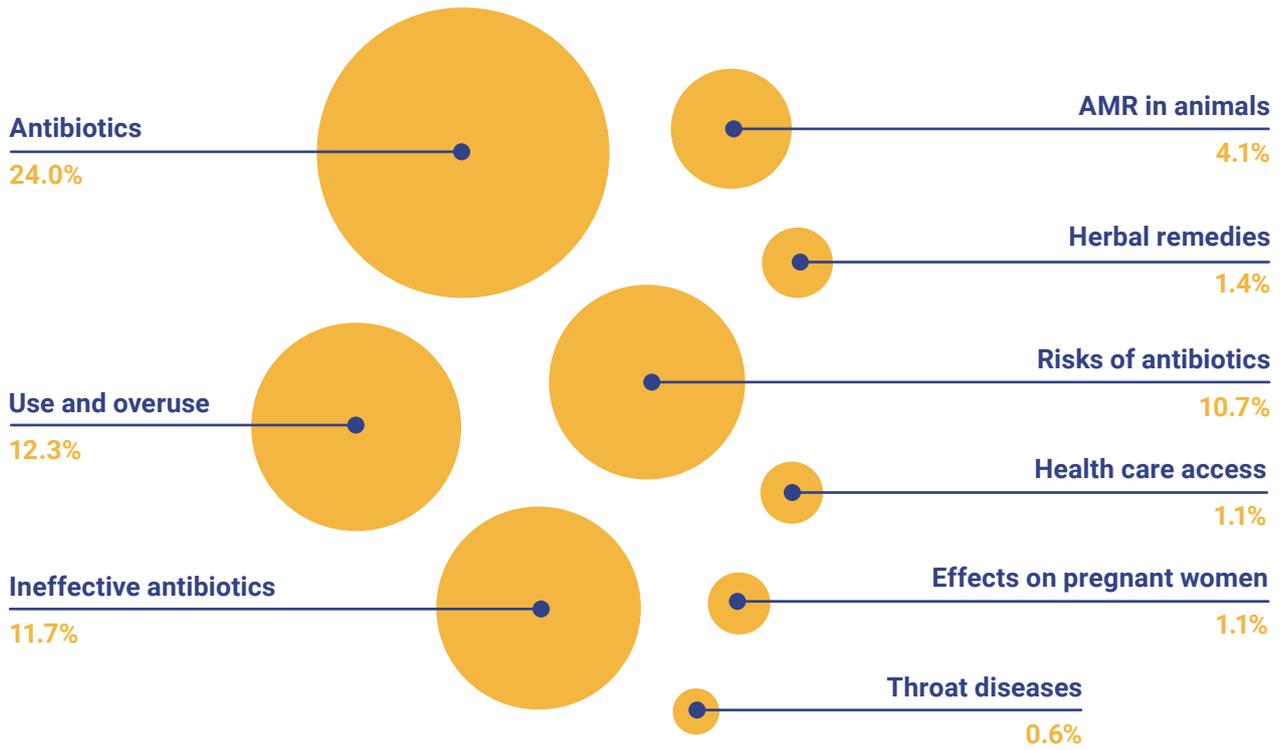


Figure 6: Key drivers of AMR

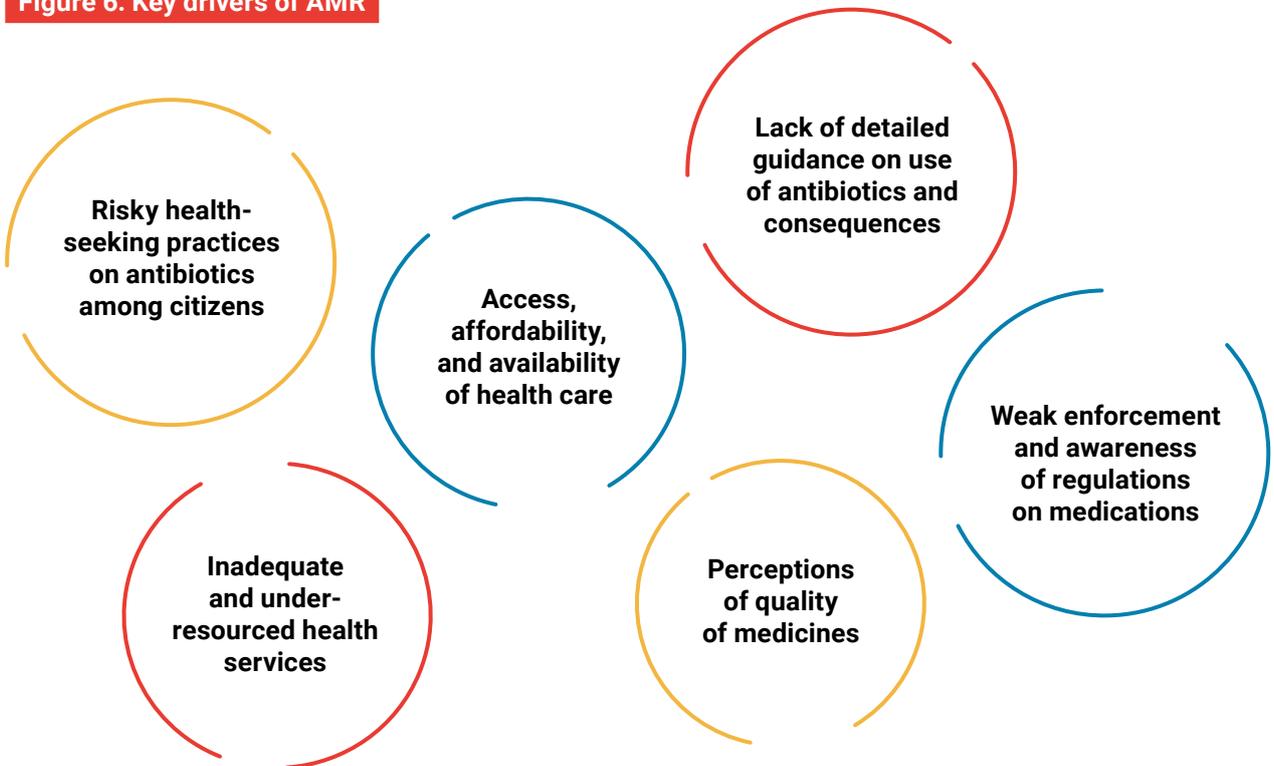


Figure 7: Summary of data collected



38
live interactive radio
shows hosted on 4 local
radio stations across
the targeted locations



48
listening group
discussions
conducted

20,272
messages received
from 5,313 participants
who opted to have
their views analyzed



Deployed a short baseline-
endline SMS survey
to track any change in
knowledge and priorities

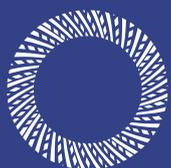
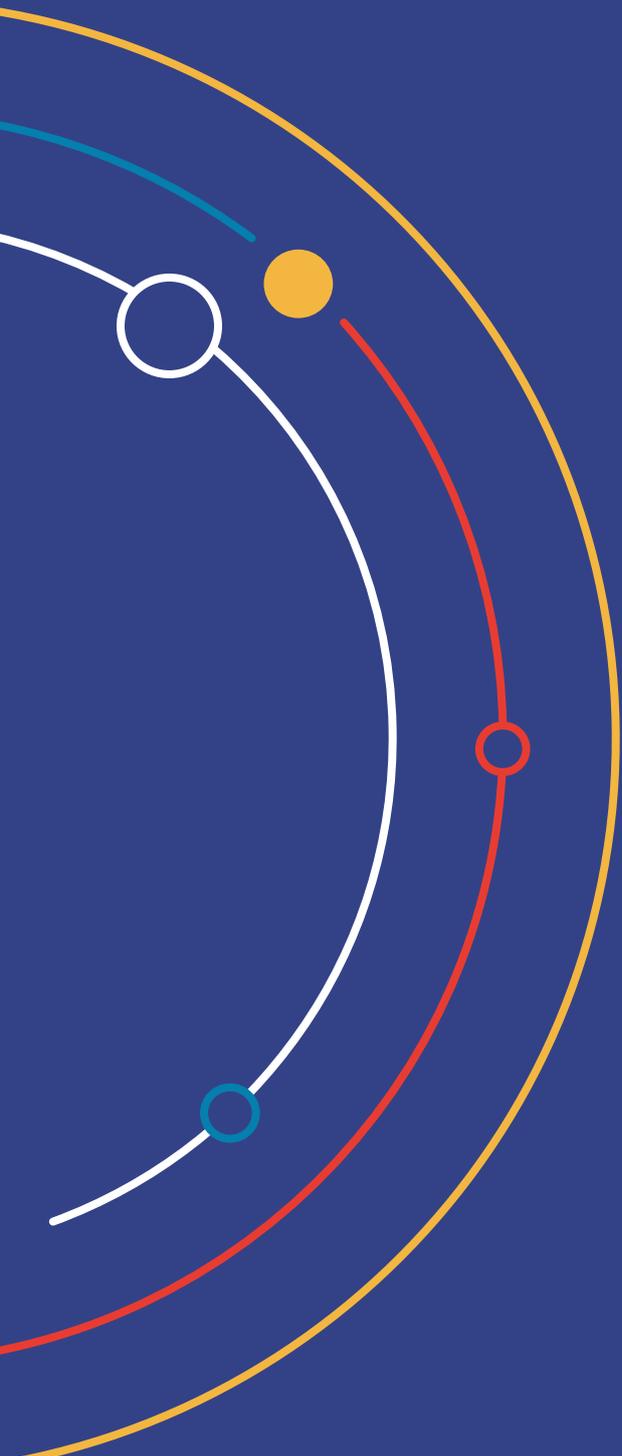


16
key informant
interviews
conducted

Endnotes

- 1 World Health Organization, *Global Antimicrobial Resistance and Use Surveillance System (GLASS) Report: 2021* (Geneva). <https://www.who.int/publications/i/item/9789240027336>
- 2 World Health Organization, *Global Action Plan on Antimicrobial Resistance* (Geneva, 2015). https://apps.who.int/iris/bitstream/handle/10665/193736/9789241509763_eng.pdf
- 3 World Health Organization, *New Report Calls for Urgent Action to Avert Antimicrobial Resistance Crisis* (April 29, 2019). <https://www.who.int/news/item/29-04-2019-new-report-calls-for-urgent-action-to-avert-antimicrobial-resistance-crisis>
- 4 Molly Moss, *Antimicrobial Resistance Warnings of the Next Pandemic* (UN Foundation Global Health Blog, May 10, 2021). <https://unfoundation.org/blog/post/antimicrobial-resistance-warnings-of-the-next-pandemic/>
- 5 ReAct, *The Threat of the Unknown: Is Lack of Global Burden Data Slowing Down Work on Antibiotic Resistance?* (January 28, 2021). <https://www.reactgroup.org/news-and-views/news-and-opinions/year-2021/the-threat-of-the-unknown-is-lack-of-global-burden-data-slowing-down-work-on-antibiotic-resistance>
- 6 Anna C. Seale and others, *Supporting Surveillance Capacity for Antimicrobial Resistance: Laboratory Capacity Strengthening for Drug Resistant Infections in Low and Middle Income Countries* (Wellcome Open Res., September 26, 2017). <https://pubmed.ncbi.nlm.nih.gov/29181453/>
- 7 Information for this table is draw from <https://www.who.int/initiatives/glass>; and Katia Iskandar and others, *Surveillance of Antimicrobial Resistance in Low- and Middle-Income Countries: A Scattered Picture*, *Antimicrobial Resistance and Infection Control* (vol. 10, no. 63, March 31, 2021). <https://aricjournal.biomedcentral.com/articles/10.1186/s13756-021-00931-w>
- 8 ReAct, *Generating Data for Policy and Practice* (February 19, 2019). <https://www.reactgroup.org/news-and-views/news-and-opinions/year-2019/generating-data-for-policy-and-practice/>
- 9 Wellcome, *Reframing Resistance: How to Communicate about Antimicrobial Resistance Effectively* (London, 2019). <https://wellcome.org/reports/reframing-antimicrobial-resistance-antibiotic-resistance>
- 10 Jessica Mitchell and others, *The Values and Principles Underpinning Community Engagement Approaches to Tackling Antimicrobial Resistance (AMR)*, *Global Health Action* vol. 12, No. SUP1, (2019). <https://www.tandfonline.com/doi/epub/10.1080/16549716.2020.1837484?needAccess=true>
- 11 CIVICUS led a consultation among national campaigners, international civil society organizations, donors, and researchers on how citizen-generated data could be used to track progress and hold decision-makers to account on sustainable development, including the Sustainable Development Goals, as well as the opportunities and challenges for promoting the role of citizen-generated data in sustainable development. The CIVICUS definition is the standard approach used.
- 12 Information in this paragraph is drawn from G. Revathi and C. Mailu, *Kenya's Perspective on Antibiotic Resistance*, *International Journal of Infectious Diseases*, vol. 45, supp. 1, S1-500 (April 2016). [https://www.ijidonline.com/article/S1201-9712\(16\)30033-9/fulltext](https://www.ijidonline.com/article/S1201-9712(16)30033-9/fulltext)
- 13 Global Antibiotic Resistance Partnership – Kenya Working Group, *Situation Analysis and Recommendations: Antibiotic Use and Resistance in Kenya* (Washington, DC and New Delhi: Center for Disease Dynamics, Economics & Policy, 2011). https://cddep.org/publications/situation_analysis_and_recommendations_antibiotic_use_and_resistance_kenya/
- 14 Adapted from the AMR Kenya National Action Plan 2017–2022
- 15 WHO, *GLASS Report: 2021*. <https://www.who.int/publications/i/item/9789240027336>
- 16 Danny Lämmerhirt and others, *Advancing Sustainability Together? Citizen-Generated Data and the Sustainable Development Goals* (Global Partnership for Sustainable Development Data, 2018). <https://www.data4sdgs.org/resources/advancing-sustainability-together-citizen-generated-data-and-sustainable-development>
- 17 Kristina Granger and others, *Community Media for Social and Behavior Change: Using the Power of Participatory Storytelling to Improve Nutrition* (Arlington, VA: Strengthening Partnerships, Results, and Innovations in Nutrition Globally (SPRING) project, 2018). <https://www.spring-nutrition.org/publications/reports/community-media-social-and-behavior-change>
- 18 CINAMR is a pilot AMR surveillance using a hub-and-spoke approach, where 12 public hospitals with insufficient microbiology diagnostic capacity (spokes) have their microbiology samples transported and tested at three KEMRI laboratories (hub). CINAMR is funded by Wellcome Trust and will be conducted by researchers from KEMRI beginning September 2021 after delays due to the COVID-19 pandemic.

- 19 Antimicrobial stewardship is one of three pillars of an integrated approach to strengthening health systems. The other two are infection prevention and control, and medicine and patient safety. Implementing AMR stewardship includes development of an AMR action plan; creation of a stewardship committee; putting in place an AMR governance structure; identifying AMR champions; and facilitating knowledge and engagement on AMR. See World Health Organization, *Antimicrobial Stewardship Programmes in Health-Care Facilities in Low- and Middle-Income Countries: A WHO Practical Toolkit* (Geneva, 2019). <https://www.who.int/publications/i/item/9789241515481>.
- 20 Kenya County Budget Transparency Survey (International Budget Partnership).
<https://www.internationalbudget.org/ibps-work-in-countries/kenya/kenya-county-budget-transparency-survey-2020/>
- 21 “Antibiotics” and “antimicrobials” are used interchangeably in this report. For ease of understanding, the radio questions used “antibiotics” instead of “antimicrobials,” as most citizens found the former term more accessible. During the shows, this difference needed further elaboration with examples. The findings therefore refer to “antibiotics” more than “antimicrobials.”
- 22 17% was the lowest percentage of participants with questions in a week, and 26% was the highest. As the program progressed, the engagement rate grew; therefore, different weeks had different denominators.
- 23 Robert Masibo and others, *Human Resources for Health; Gaps and Opportunities for Strengthening* (Kenya Ministry of Health Health Sector Monitoring and Evaluation Unit, 2019). <https://www.health.go.ke/wp-content/uploads/2019/01/Human-Resource-for-Health-Policy-Brief-fin.pdf>
- 24 Global Partnership for Sustainability Development Data, Data Ethics Canvas for the Kenya AMR Project. https://www.data4sdgs.org/sites/default/files/file_uploads/Data%20Ethics%20Canvas_GPSDD_1.pdf
- 25 Global Partnership for Sustainability Development Data, *Citizen-Generated Data in Kenya: A Practical Guide* (June 9, 2021). <https://www.data4sdgs.org/resources/citizen-generated-data-kenya-practical-guide>
- 26 Adapted from the AMR Kenya National Action Plan 2017–2022



**Global
Partnership**
for Sustainable
Development Data

