Data Ethics Canvas for the Kenya AMR Project

The data collection for this project involves the use of interactive radio shows. This entails a hybrid approach (both quantitative and qualitative) and is both a research method and citizen engagement mechanism. In order to ensure that the project incorporates ethical considerations in collecting, using, and sharing data, we use the ODI Data Ethics Canvas to manage our activities. The project runs to September 2021.

Item	Description	Comment
1. Data sources	Name/describe your project's key data sources, whether you're collecting data yourself or accessing via third parties. Is any personal data involved, or data that is otherwise sensitive	Main source: SMS feedback sent by community members to a free short code in response to radio dialogues. Additional sources: key informant interviews, listening groups, engagement with key stakeholders through co-design workshops. The data is collected by AVF and analyzed using a mixed method approach specific to AVF's interactive radio methodology. Some of the personal data involved are phone numbers, age, gender and location. However, phone numbers are automatically de-identified by AVF's technology pipelines and never shared or seen by AVF staff unless strictly necessary for operational needs, in which case only a limited number of members are authorized to view them. The demographics are shared only at an aggregate level as part of the analysis process. When individual-level data sharing is requested and considered appropriate, the number of demographics available needs to be limited to avoid any risks of participants being re-identified. Participation is voluntary. Consent is requested via SMS and citizens can opt out of the analysis at any point. AVF adheres to its Data Protection policy and is also an endorser of the Principles for Digital Development.
2. Limitations in data sources	Are there limitations that could influence your project's outcomes? Consider: • Bias in data collection, inclusion/exclusion, analysis, algorithms • Gaps or omissions in data • Provenance and data quality • Other issues affecting decisions, such as team composition	Those who participate are self-selected amongst potential audiences based on a range of factors such as phone ownership, media habits, literacy, and gender roles. Therefore, unlike surveys, the data gathered using this method constitutes a non-probabilistic sample. Instead of pursuing quantitative aggregates of individual perspectives as done in traditional surveys, our research seeks to complement and strengthen qualitative analysis by understanding how opinions are shared - and vary - at the group level. This allows us to identify how these ideas might circulate beyond the specific radio participants as they are indicative of a wider group. From a statistical point of view the lack of representativeness is less important for a study based on associations as we look at the type of views

		existing in society at the group level and how these are associated across groups rather than to the specific extent in which these views are held at an individual level.
		For more information on the differences of the interactive radio methodology when compared to probabilistic or purely qualitative methods, please see: Riha, J., Lopes, C. A., Ibrahim, N. A., & Srinivasan, S. (2021). Media and Digital Technologies for Mixed Methods Research in Public Health Emergencies Such as COVID-19: Lessons Learned from Using Interactive Radio – SMS for Social Research in Somalia, 1–23. https://doi.org/10.1177/1558689820986748
3. Sharing data with others	Are you going to be sharing data with other organizations? If so, who? Are you planning to publish any of the data? Under what condition?	AVF shares the research findings with key project stakeholders such as the participants (in a synthesized way via SMS), county government officials, research community, health experts and GPSDD. This is done in dissemination workshops to ensure that the study findings can lead to informing policy and the design of action plans.
		When the data itself is requested, it is important to ensure it does so within AVF's data protection policy. This means ensuring that participants cannot be reidentified. This may require limiting the demographics that are shared and ensuring complete anonymization.
4. Ethical and legislative context	What existing ethical codes apply to your sector or project? What legislation, policies, or other regulation shape how you use data? What requirements do they introduce? Consider: the rule of law; human rights; data protection; IP and database rights; anti-discrimination laws; and data sharing, policies, regulation and ethics codes/frameworks specific to sectors (e.g., health, employment, taxation)	AVF has a Data protection policy in place and follows the following laws and regulations: • UK: The Data Protection Act (2018) • EU: General Data Protection Regulation (2018) • Kenya: The Data Protection Act (2019) AVF has obtained ethics approval from Amref International University in Kenya's' ESRC as well as from the National Commission for Science, Technology and Innovation (NACOSTI). AVF's Data Protection policy takes a security by design approach. No phone numbers are stored in datasets. Only aggregated data (key themes, prevalence and differences across demographics) is shared. When individual SMS are included in reports or dissemination outputs these are anonymized, so that there are no names or phone numbers.

5.	Rights around data sources	Where did you get the data from? Is it produced by an organization or collected directly from individuals? Was the data collected for this project or for another purpose? Do you have permission to use this data, or other basis on which you're allowed to use it? What ongoing rights will the data source have?	Data is collected directly from individuals who decide to send an SMS to answer the question asked in the radio show or via SMS advert. Participants therefore self-select to take part if they have listened to the radio show and feel compelled to answer the question. Once their message is received, AVF automatically triggers a consent flow that explains the intention to use the data to inform health policy in Kenya. It also states that data will be anonymized Then, participants are given the option to opt out by texting STOP (all SMS are free of charge for participants). If they text STOP, their data is removed from our databases.
6.	Your reason for using data	What is your primary purpose for collecting and using data in this project? What are your main use cases? What is your business model? Are you making things better for society? How and for whom? Are you replacing another product or service as a result of this project?	1. To understand people's knowledge, attitudes and practices related to AMR through the use of CGD 2. To explore best ways to engage local policymakers' and the research community with CGD for informing AMR research, policies and budget decisions 3. To investigate how the use of CGD methods can improve the evidence-base on AMR research and policies. Public-engagement and CGD can complement AMR research and policies
7.	Communicating your purpose	Do people understand your purpose – especially people who the data is about or who are impacted by its use? How have you been communicating your purpose? Has this communication been clear? How are you ensuring more vulnerable individuals or groups understand?	The purpose will be communicated to interactive radio participants through a consent SMS flow. The SMS format limits the amount of information that can be provided. Our ethics application suggests the following flow: ● Thanks for your answer and hello from Africa's Voices! We are doing a study to understand your community's knowledge and needs on some drugs like antibiotics. ● We will send you some questions over 2 months. This is voluntary and unpaid. We will keep your data anonymous and share it to improve the health response in your county. ● We will share findings with you through SMS and include participants' views in the next radio show. ● If you prefer not to participate, reply STOP and you will receive no questions and your messages will not be analyzed. ● If you consent to be part of this study, please respond to the following questions. In addition, Africa's Voices will organize and run a total of 6 weekly listening groups (LGs) in each location (a total of 18 groups) with a maximum of 15 participants per group with women, local clinicians and/ or health professionals. These will run in parallel to the 8 weeks of radio broadcast to raise awareness and increase

knowledge on AMR. AVF will also organize key informant interviews (KIIs) to assess with the key stakeholders the value of the study and the ways in which CGD may be used. For both LGs and KIIs, AVF has a consent form that follows Amref International University's ESRC guidelines.

At the end of the eight interactive radio shows, AVF will send an SMS to participants providing information on the main insights resulting from the study as well as key health information on antibiotics use and resistance which will be agreed with our partners. This ensures the process of data is two-way. The method will facilitate citizen-generated data as well as share back with participants accurate information on the use of medicines.

In addition, the insights will be shared in dissemination workshops with relevant county-level stakeholders and GPSDD to ensure the data collection leads to informing policy and the design of action plans.

8. Positive effects on people	Which individuals, groups, demographics or organizations will be positively affected by this project? How? How are you measuring and communicating positive impact? How could you increase it?	AVF expects the CGD from this study will be of benefit to AMR specialists in Kenya, relevant county government health departments and the general public. To qualitatively assess the impact, we are conducting KIIs with the mentioned key stakeholders. In addition, we organize dissemination sessions. We will capture the learnings from these activities and further disseminate the learning and impact in our website and social media in order to amplify the role that CGD can have to inform policy and research on AMR.
9. Negative effects on people	Who could be negatively affected by this project? Could the way that data is collected, used or shared cause harm or expose individuals to risk of being re-identified? Could it be used to target, profile or prejudice people, or unfairly restrict access (e.g., exclusive arrangements)? How are limitations and risks communicated to people? Consider: people who the data is about, people impacted by its use and organizations using the data.	The data collected doesn't cause harm or expose engaged individuals to risks. This is because the nature of the topic is not highly sensitive but also because we only share anonymized data.
10. Minimizing negative impact	What steps can you take to minimize harm? How could you reduce any limitations in your data sources? How are you keeping personal and other sensitive information secure? How are you	The data collected is stored in datasets that only AVF staff has access to, and which do not contain phone numbers. AVF has strict internal controls to minimize harm or expose individuals to risk of being re-identified. When individual SMS are

		measuring, reporting and acting on potential negative impacts of your project? What benefits will these actions bring to your project?	included in reports or dissemination outputs these are anonymized, so that there are no names or phone numbers.
11.	Engaging with people	How can people engage with you about the project? How can people correct information, appeal or request changes to the product/service? To what extent? Are appeal mechanisms reasonable and well understood?	People can engage with us by sending an SMS to a free short code after listening to a radio advert, show or receiving an SMS ad if they have engaged with us already. The questions posed on the radio shows are deliberately open ended to allow for people to freely express their views on a topic in their or own terms and language.
12.	Openness and transparency	How open can you be about this project? Could you publish your methodology, metadata, datasets, code or impact measurements? Can you ask peers for feedback on the project? How will you communicate it internally? Will you publish your actions and answers to this canvas openly?	Our methodology is available on our website and our peers can freely give feedback on the project. AVF is happy to openly publish the answers included in this canvas.
13.	Ongoing implementation	Are you routinely building in thoughts, ideas and considerations of people affected in your project? How? What information or training might be needed to help people understand data issues? Are systems, processes and resources available for responding to data issues that arise in the long-term?	Including participants' feedback into our approach and methodology is at the core of AVF. By analyzing all the SMS sent and complementing this method with Key Informant Interviews, Listening Groups and co-design workshops, we ensure people's views are informing the project on an ongoing basis. The data is stored safely and anonymized to minimize risks on participants, but we routinely check our systems to address any data issues that come up.
14.	Reviews and iterations	How will ongoing data ethics issues be measured, monitored, discussed and actioned? How often will your responses to this canvas be reviewed or updated? When?	Continuous monitoring of the strategies and improving them constantly. Responses to this canvas can be updated on a monthly basis.
15.	Your actions	What actions will you take before moving forward with this project? Which should take priority? Who will be responsible for these actions, and who must be involved? Will you openly publish your actions and answers to this canvas?	Ethical approval has been obtained from Amref International University's ESRC involving research only with human subjects as well as from Kenya's NACOSTI. Due to delays caused by this process, the first co-design workshop went ahead with GPSDD and Kemri AMR specialists. AVF is happy to openly publish answers to this canvas.