Supplementary materials
Community Engagement Workshop November 2023

File I:
Summary of examples of CE strategies across the world for building impact

No	Initiative name and location	Website	Summary
1	Antibiotic Smart Sweden	https://www.folkhalsomyndigheten.se/antibiotikasmart-sverige/in-english/	Antibiotic Smart Sweden is a mission-oriented initiative that seeks to engage the whole Swedish society to take action to keep antibiotics working. Core to the initiative is the development and testing of "antibiotic-smart criteria" for different sectors and workplaces, together with stakeholders and staff that are to implement the criteria. This far there are criteria for pre-schools, schools, long-term care facilities, primary care centers, hospitals and wastewater treatment plants, as well as on governance level for regions and municipalities. Over 60 pilot sites have been involved in the testing. The initiative is led by the Swedish Public Health Agency, RISE Research Institutes of Sweden, ReAct Europe and Strama (the Swedish strategic programme against antibiotic resistance).
2	Community Engagement for Antimicrobial Resistance (CE4AMR), Leeds. UK	https://ce4amr.leeds.ac.uk/	The network CE4AMR drives several projects which include **COSTAR** (Community Solutions to Antibiotics Resistance) in Nepal. This project utilized the existing resources with the health system to embed the Community Dialogue Approach, which means that first time communities are engaged in an intervention to address AMR. However other challenges emerged in such a project, such as involving WASH and the environment sector as one health partners; facilitators struggling to comprehend the complex messages of AMR; some facilitators dropping out due to migration to other areas in Nepal. Some of the **Policy implications** were related to how CE needs to be addressed as a key strategy for awareness, education and promotion of rational use of antimicrobials to tackle AMR in NAP.
3	Global Network of People Living with HIV (GNP+), Amsterdam(the Netherlands) and Cape Town (Africa)	https://gnpplus.net/	GNP+ is a good example of a strategy having had a people-centered response. This example of a strategy **addresses CE in different ways,** by (1) Constantly redefining what it means for communities to be at the center of the response, (2) Community accepts that they are

			responsible for their own positive health outcomes. (3) Being consistent, respectful, deliberate about CE. (4) Uses lived experience from a majority of people: organize into graphs, data sets that can be useful to quantify, and to make program changes.
4	Students against Superbugs Africa	https://www.studentsagainstsuperbugs.org/	Mitigating the threat of AMR in African communities through One Health approach, based on 2 pillars: (1) Capacitating young people to initiate AMR initiatives at the grassroot level, (2) Direct CE especially engaging youth. **Example of projects**: - Establishing AMR clubs in universities and AMR non-profit organizations. -Institutionalizing AMR into university curriculum. - Developing a handbook for training secondary school students, protesting, and conducting implementation research - Sustainable framework on AMR media engagement. - Developing an onsite platform for engaging youth in AMR. **Examples of Key considerations:** For One Health approach: how do we ensure inclusivity, and community ownership? How do we measure impact?
5	Antibiotic Smart Communities project, Kerala, India	https://www.reactgroup.org/news-and-views/news-and-opinions/year-2022/react-asia-pacific-antibiotic-smart-communities-as-a-way-forward/ https://www.mdpi.com/2079-6382/13/1/63?fbclid=IwAR3V7mjGy70GLjRZw2VXhw_ZE0bjR-dNOVUrw5lw61tmK1JXTeu-FJpizF8	This project, run by ReAct Asia Pacific, aims at supporting communities to engage on antibiotic resistance and evaluate the effects. **Activities**: A novel 15-indicator framework and scoring-system covering the human, animal, and environmental domains has been developed and tested in an 11,000-inhabitants community in Kerala, India. CE exercises were conducted to involve and build trust in the community, such as consultations and focus group discussions with key stakeholder groups. Based on base-line scores for the community using the indicator framework, an action agenda was developed and implemented together with the community. The indicator framework has also been piloted in other states of India and found to be adoptable.
6	Union for International Cancer Control (UICC), Geneva, Switzerland	https://www.uicc.org/.	**Community targeted:** lived experience of cancer, their families, those affected by cancer and those providing cancer care. This program of work is guided by **3 policy asks**: (1) Data collection and surveillance: collecting data on the impact of resistant infections on cancer patients. (2) Access to treatment: availability, affordability and sustained access to quality assured

			medicines and diagnostics, for existing essential medicines and diagnostics but to also include R&D for new medicines and diagnostics. (3) Emphasis on the importance of AMR in parallel to cancer treatment and streamlining AMR into national policy documents.
7	Antibiotic Guardian, UK	https://antibioticguardian.com/	**Online platform,** journey of 10 years. launched in 2014, with 10,000 pledges the first year. The Webpage: Video gives a key message and action: choose a pledge and become an AB guardian. 2017: mass media campaign, "keep antibiotics working". **Three core communities focused on**: health or social care professional, member of the public, student, educator or scientist. Also pledges for pets or horse owners, farmers, families, adults. **One health approach**: pledges for human and animal health. It started national, then became global. **Impact**: Campaign increased commitment among members of public and healthcare workers, changed self-reported behaviour. It used social media actively and engaged with health students, healthcare workers, scientists, children: go to schools, provide tools and resources. Virtual/physical awards, others can learn from what they have done. In 2020 policy made a big difference about people pledging. Organizations can register activities. Now there are over 193,000 pledges.
8	Diagnostics for One health and user driven Solutions for Antimicrobial resistance (DOSA). UK/India	https://dosa-diagnostics.org/About-2	Project addressing the issue of communities reaching healthcare. **Objectives**: three community settings. human, dairy and aquaculture. Point-of-care diagnostic assays for UTI, mastitis, AMR, pathogens, antibiotic residues. Used mapping studies. Regarding CE, the project used a **different design to a diagnostics intervention** focused on (1) low cost, environmental stability (2), testing in community not healthcare center (home test), (3) provide meaningful information (easy to understand). The UTI diagnostic solution was raising awareness of AMR and own health through identification of symptoms, connecting to UTI (sensitive topic, can't speak about it). Guidance on how to act on these results. Looking into data to capture systems and to make results available.

File II:
List of all challenges, gaps, and limitations to CE on antibiotic resistance

Organised in 5 sections:
(1) financial (2) political (3) structural (4) narrative and communication (5) overarching

Section 1 – Financial challenges

- Lack of funding: Both for community lead initiatives and advocates as individuals working in the community.
- Limited financing to support community engagement initiatives to address AMR issues.
- Limited financing of M&E joint activities to assess the quality of implementation of diverse interventions of Community Engagements to address AMR issues.
- Lack of Funding for CSOs: CSOs are facing a shortage of financial resources to support its activities related to raising awareness about a particular issue, in this case, antibiotics and AMR.
- Lack of commitment by community unless there's a remuneration.
- Donor dependence.
- Competition between disease areas for funding instead of synergy.
- Financial autonomy for last mile populations. Financial challenges do not exclude bottom-up approaches. We need to empower communities with microfinance programs. Especially in Low-income contexts, where there is no UHC.
- Working with the antibiotic resistance issue cannot lean on external funding but needs to be built in, in the system, for long term sustainability.
- Limited funding allocated to AMR interventions at national level.
- Antibiotics cost less (money, time...) at private pharmacies or over the counter shops than at hospitals.
- Fighting AMR doesn't make money in the short run and even in the long run, private institutions won't benefit from addressing AMR.
- Limited resources to reach out to the remote areas where they resort to take whatever medicines are available; self-prescription.
- Lack of government commitment: While AMR NAPs exist in most countries, there is limited government commitment to financial strategic activities in the NAPs.
- Other scientific disciplines competing for funding.
- There must be better incentives for the pharma industry to produce new antibiotics.
- (Lack of) evidence on costing and cost effectiveness of CE approaches to addressing AMR: There is currently a lack of evidence to demonstrate the costs and / or cost effectiveness of CE approaches to address AMR. This may be a key factor that relates to a lack of global / national research / health, animal, environmental systems funding for CE. So we need to develop that evidence base.
- Too much money is at stake with antibiotics to animals and the agricultural sector.
- Sustained funding and funding for scalability donor supported projects have a short time frame. And typically are small scale pilots. Difficult to have enough funding for both scaling and continued engagement. Need government support.
- Clearly not enough funding is dedicated to AMR globally.
- Short term funding and not long-term funding commitments.
- Lack of funding to community-led initiatives.
- Difficult to show impact hence advocating for funding.
- Difficult to show a direct return on investment The difficulty to show a direct return on investment discourages donor and government investment in the area. Maybe we could explore and redefine what "success" is? Behaviour change is quite a complex issue and takes time, we need to re-shift the perspective and appreciate the small milestones achieved.
- TB is a special case. For antibiotics in general there are still very few groups engaged to be able to support. This is in a way a vicious circle. It needs to start from the bottom up, connecting CCOs and communities that are willing to work on ABR and call for funding.

Section 2: Political challenges

- Strong political will: Advocacy efforts should target more public policy makers. Influencing their decisions can be a very strong catalyst.
- We need long term strategic solutions, and this does not match with the political cycle, typically a 3-5 year mandate period. Having an AMR ambassador embedded into the government can help bridge this!
- Target specific communities that can act as multipliers of AMR awareness.
- Needs to be a mental shift from "technical fix" to "citizens being part of the solution".
- Lack of trust in the government / health system People may not wish to engage if they do not feel it will lead to meaningful change.
- Equitable partnership: How can we create equitable partnerships between different stakeholders engaged in addressing AMR? How can we distribute power, and ensure that there is genuine decision making happening at community level?
- In some countries, community engagement in general is very limited, and people don't know that their voice matters or are scared to speak up - or are busy making sure they can provide basic needs and there is no time for advocacy or engagement. "Community engagement is for the rich".
- Difficulties accessing the policy realm. It can be expensive to dedicate time to policymaking which again goes back to funding. Also, a potential lack of knowledge around AMR to interact at that level.
- Lack of political will.
- There's no political will as there is little funding allocated to health. AMR is unknown by most top-ranking government officials.
- Make politicians understand the problem and inform them what their role can be.
- No meaningful Engagement and therefore disconnect.
- Communities do not necessarily seek political impact.
- LMIC government priorities: We need to see data from our countries before we can make decisions.
- The invisibility in the projection of the impacts of AMR on health, if no intervention measures are taken.
- Power differences between communities, health care workers or other actors and policy makers, difficulties to consider voice of communities as important as others,
- Many competing issues: climate change, wars, economy, elections etc.
- Lack of political interest and lack of political commitment to CE in AMR.
- The political will and understanding of AMR must be much higher.
- The political context does not allow for communities to express their voices.
- Lack of understanding of community importance in policy making.

Section 3: Structural challenges

- If you look into other health issues that require global mobilisation, AMR would fit in many of them, yet it's rarely mentioned while it's a leading cause of death. There is a big structural barrier which may also be caused by the fact the funding availability for other health issues are not featuring the focus of AMR.
- To prevent something that may be worse in the future. You need to convince organisations, people etc. that it is worth investing resources now and it will not "cost" as much in the future.
- Often, the most affected are the weakest, least powerful members of society. Inequality is a key issue.
- Health care workers particularly lay health care workers not equipped with AMR information and tools to sensitize communities.
- Implementation of a NAP cannot be done top down, it needs a whole of society engagement. Giving mandate and financial support to civil society to help drive areas in the NAP implementation such as education, awareness raising etc. is cost effective.
- In the Cancer, HIV or TB realms, there are more advocacy voices which amplify a much more powerful unified voice, we are lacking that for AMR. e.g. those different voices are not coming together enough for AMR.
- Organisations do not understand their role and what they can do.
- Not enough coordination between actors - we are where the climate was 20 years ago.

- Difference between resistant TB & HIV and antibiotic resistance - the latter is not necessarily long-term illness, nor is it as "identity-defining" as the former.
- WASH is not possible in areas where water is rationalized for cooking, drinking and bathing.
- AMR is a systems issue, and needs many actors to work together. Unless there is an economic incentive, they are unlikely to do so, unfortunately.
- Weak anchorage of AMR coordination at subnational/ community level. The coordination of AMR remains largely at the national level. Lower administrative structures of governance and grassroot organizations are largely excluded from AMR. This explains why at grassroot, AMR activities remain weak and unsustainable,
- Poor infrastructure in healthcare facilities in rural areas.
- As antibiotic resistance is not a disease, groups working on related health, animal and environmental issues need to be convinced to take ABR on board, which needs funding and mandate.
- Few groups and communities are taking this on as a self-given task (to compare with patient groups other community driven initiatives).
- Big organisations like WASH organizations could prioritize AMR but they don't - it falls between too many stools when it comes to organizational agendas.
- Not clear who constitutes "community" - even more so across sectors affected by and contributing to AMR.
- Lack of spaces and/or mechanisms of accountability and social participation for communities to monitor the use of antibiotics and enforce the implementation of effective legislation.
- AMR Focal Points within governments are over stretched, so community engagement is a low priority.
- Lack of integration of AMR in existing programs at community level.
- (Perceived) challenge to connect quantitative with qualitative research.
- Community means so different things to different groups, begging a need to always qualify what community one is targeting. What's community?
- CE may not be seen as 'real science' by the traditional AMR research community.
- You have to include a variety of organizations in the fight of AMR.
- Poor coordination- duplication of efforts: We are swimming in the same pools.
- Hierarchy - physicians are considered more relevant than pharmacists , who are more relevant than nurses etc... and patients come at the very end.
- Not one organization taking the lead on AMR (not just for community engagement).
- Lack of clarity on how to exploit existing channels for community engagement on topical issues such as AMR.
- The difficulty of reaching different groups/cultures in the society.
- Siloed working within funders and governments between animal health and human health.
- Lack of understanding of how the antibiotic narrative fits into other public health issues.
- Lack of platforms for sharing community engagement initiatives.
- Lack of inclusivity of different groups within the community.

Section 4: Narrative & Communication challenges

- Communicate for change > Change/improve how we communicate about antibiotic resistance. Focus on key areas for individuals. For example (access to) effective antibiotics, treatable (bacterial) infections, cost for individual, community, and society, prevention (and make this possible via access wash and stronger health systems). Include personal experiences and also solutions.
- Lack of AMR community communication tools.
- Community friendly narrative: Speak their languages not ours.
- Lack of AMR contextualization. Communities are different and AMR affects them differently, hence it is important to develop context-specific AMR interventions in each community.
- Lack of communication for AMR issues to bottom (grassroot communities) Lack of communication for AMR issues to bottom (grassroot communities) that necessitates a need of awareness.
- There is an urgent need to bring scientists including behaviour change experts and anthropologists together to try to come up with a language that is understood by people. We know from several recent studies that AMR is not understood at all.
- Complex layers in messaging - not just asking to replace wrong behaviour with right behaviour.
- Communication is very scientific and often doesn't take place with patients and the public at all.
- Poor communities are marginalized by existing communication strategies.

- ABR curriculum.
- Translation of ABR language to local dialect.
- The people in communities do not have access to information because everything now happens online but they still use little phones to just make calls.
- Communication gap due to lack of mechanism.
- Time poverty - many issues connected to AMR and behaviour change linked to a general feeling in our societies of not having enough time!
- In the core here is the language barrier, AMR needs to be translated into contextualized patient centered messages.
- Improving communication and awareness for people in communities, especially the conflict-affected population, who are prone to misuse of Antibiotics The primary goal of the CSO in this context is to raise awareness within communities. Raising awareness involves disseminating information, educating community members, and fostering a better understanding of the issue at hand. In the case of AMR, this could include informing communities about responsible antibiotic use, the consequences of misuse, and the importance of antimicrobial stewardship.
- Very little narrative around this being a global problem for everyone on the planet.
- Too many messages focus on distal issues in the life cycle of AMR development instead of proximal issues where the role of the general community could be most valuable.
- The patient-health professional dialogue seems to be under-used as a channel for knowledge, engagement and empowerment. Not always included as a clear topic for the patient-health professional dialogue.
- Lack of AMR awareness programs in communities.
- Identify and build different approaches depending on what community you are wanting to mobilize. Ex: Communicating with politicians' community is different from communicating with Academia community or NGO's or health professionals.
- Don't blame the patient - too much emphasis on behavioural change campaigns aiming at patients.
- Long term value: Communities live day to day, difficult to see why to invest today but may only see benefits in the future.
- Focus on the problem but also on what you can do - whoever the target audience is (or person/organization you want to engage).
- Not always clear on what community mobilisation will lead to in terms of action, behavioural change or other outcomes.
- Nudging.
- Real life stories/experiences, emotions needed for stronger and wider engagement.
- Dissemination of AMR National Action Plans to grassroot communities. Dissemination of AMR National Action Plans to grassroot communities is still a gap, to have impactful community led responses.
- No big organisations with big communications teams behind community engagement on AMR.
- Ask those you are targeting - to better understand what, how and where to communicate for change. Nothing about me without me. Of course, nowadays we have online data as well.
- It's harder to communicate and mobilize communities about sustainability where healthy and treatable microbiomes are systems that need to be preserved for everyone.
- People impacted by AMR are not necessarily good and trained at communicating their experience.
- Difficult for many to understand AMR.
- Language barriers for patients - most impacted communities do not necessarily speak English which tends to be used mostly.
- Lack of a "champion" or "champions" working for and talking about AMR in public spaces.
- Not only teach about the problem but make people understand the problem What can the problem with antibiotic resistance mean to them.
- Difficult to create engagement in community for something you don't fully understand and therefore don't prioritize amongst all other competing issues.
- Engage communication experts. This is a science field itself and also think about engaging with comms experts.
- Layman's Language AMR is complex to explain (microorganisms, genes) good and bad microorganisms, pathogens.
- Many different interpretations of community engagement.
- Lack of understanding that antibiotic resistance is an issue that communities should drive.

- Difficult jargon.

Section 5: Overarching challenges

- The norm has always been leaving community behind until recently when the value of communities is being recognized.
- Intensify engagement.
- Healthcare workers exert power over the patients instead of power with the patients. The decision to use and which antibiotics to use should be that of the health worker and the patient and not just the health worker. This gives agency to the patient.
- The power of pharmaceuticals (How) can we engage meaningfully with business? Where there is a profit motive, and this flows "down" to ordinary people making a living by selling drugs. What are the mechanisms and incentives to ensure that antimicrobials are developed and distributed in a responsible way that prioritises human, animal and environmental health?
- Community engagement should not focus only on rational antibiotics use.
- Communities are considered ignorant by large organizations, so they prefer working with them other than helping them lead.
- We are not very good at learning from each other. Need to connect better to those with advocacy and community engagement experience.
- Important to start with the individual needs - and link with family, community, social and political environment - via good communication channels and structures of support.
- Still working in Silos: One Health is difficult to operationalize/put in practice.
- A considerable part of communities and other stakeholders don't yet feel the emergency or risks of AMR because of mainly the lack of evidence and Advocacy strategies.
- Lack of creativity on how to reinvent old problems and challenges into novel issues that need renewed efforts at community level.
- No one size fits all: Needs of each community are different. Lack of consistent use of tools to engage with the community and design tailored solutions.
- Disconnect between research and communities.
- Evaluation: The challenge of evaluation - what should we measure? This was covered to some extent in webinar 2. Should we measure AMU or AMR in relation to CE? And, how - when it is extremely complicated to measure AMU (and AMR) in many settings.
- Community engagement often leads to the community being responsible and should do something: is community engagement only about improving rational use of antibiotics or does it also cover other topics?
- Lobbying and marketing of the antibiotic industry, focusing on increasing the sale and use of its products.
- AMR as a One Health problem: It is critical that we highlight that AMR is a OH problem. In order to address it, including through community engagement, we have to engage with relevant sectors including animal and environmental health. In some (or most?) settings, the infrastructure to allow that engagement is lacking and so there is a lot of work to do around capacity strengthening in order to be able to facilitate CE.
- Inadequate research on Community engagement against AMR.
- In war/conflict settings where AMR is usually a big issue, alternative priorities take precedence.
- Lack of understanding of AMR in the community, not perceived as a problem.
- Lack of collated evidence for impact of community engagement.

File III:
List of next steps proposed by the participants

Participants were asked:
How can you take the outcomes of this workshop forward? What would be the next step/s?

- Can ReAct lead a petition to ask for a multi stakeholders Hearing for AMR HLM? And an establishment of a civil society and community engagement mechanism?
    - Use the AMR multi-stakeholder partnership platform
    - Full participation of grassroots in disseminating of AMR
    - Map all settings in society where AMR-related conversations can take place.

- Mainstreaming of ARM into other health interventions
- Work on more concrete plan, interventions on how to engage communities
- Unify on a few key asks
    - Definitely

- Identify and engage key partners such TB civil society
- Engage communities from the bottom - Providing them with the right funding opportunities, using relevant context specific data for advocacy
- Highlight and publicize the key outputs to different stakeholders
- Look into ways to promote community engagement in underrepresented regions (eastern Mediterranean region for example) & learn from other advocacy groups regionally and internationally.
- Advocate for domestic investment in AMR at national level
- Identify a coordinating organization for CSOs leading up to the HLM
- Share the findings or report in different formats - for reaching out to media, civil society, governments, public; And plan the next workshop already
- Identify powerful voices relevant to different groups in societies
- React to lead further development of key asks around CE - with smart indicators... and core values.
- Encourage CSOs to adovcate and engage policy makers to include community members in AMR solutions
- Establish Community-based Organizations to promote CE initiatives on AMR.
- Refine smart measurable targets relevant for key stakeholders
    - Agree!
- Promote a strong common vision (positive messaging on access)
- Create AMR CSO community of practice
    - Yes!
- How about working on a best practices Pilot project from the lessons learnt
- Mapping the projects and actions that are being carrying out to engage communities in AMR to strengthen networks
- Push governments for hearings ahead of the HLM.
- Looking at ways of putting NAP to address the AMR in decision making fora as part of advocacy and influencing.
- Create an evidence base for value of community engagement in terms of health and economic outcomes