SUMMARY REPORT

Impactful approaches for community-wide engagement on antibiotic resistance

An initiative to promote systematic and meaningful engagement of communities and civil society groups as key stakeholders in the global response to antibiotic resistance
This report summarizes key ideas and take-away messages from a workshop and two webinars held in the fall of 2023. It follows the structure of the workshop, and when relevant, integrates insights from the two webinars.

Full list of workshop participants

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Also, a special acknowledgment to the several facilitators, rapporteurs and note takers
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Camilla Björn - Antibiotic Smart Sweden; Daniel Waruingi - Students Against Superbugs Africa; Diane Ashiru - Antibiotic Guardian; Florence Anam - Global Network of People living with HIV; Rebecca King - University of Leeds/CE4AMR; Rumana Huque - Ark Foundation/CE4AMR; Satya Sivaraman - ReAct Asia Pacific; Sonali Johnson - Union for International Cancer Control; Till Bachmann - Edinburgh University.
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1. A clearer narrative on community engagement and antibiotic resistance is required to achieve meaningful change.

2. Effective strategies for impactful community engagement should be contextualized and built on national and local analysis, targeting governments and including citizens as part of the solutions.

3. Embed a One Health approach in community engagement and integrate antibiotic resistance in other established health agendas and interventions to ensure inclusion of different fields and related agendas and community ownership of the solutions.

4. The integration of antibiotic resistance into health programs and National Action Plans must include co-creation of solutions between policymakers, communities and civil society, and foster both top-down and bottom-up approaches.

5. The Political Declaration of the upcoming High-Level Meeting of the UN General Assembly on Antimicrobial Resistance should reflect the importance of community engagement and ensure meaningful civil society and community engagement. This includes fair representations in governance structures and the decision-making process, as well as the co-creation of community-led solutions.
This report presents the synopsis and outcomes of a series of webinars and a workshop that took place during the fall of 2023. The series showcased and discussed approaches to community engagement (CE) on antibiotic resistance from diverse settings and contexts across the globe. It explored different methods used, success factors, and ways to measure impact, while highlighting barriers and enablers for community engagement and harnessing key learnings from stakeholders and academics involved in the initiative.

The report summarizes key ideas and take-away messages from the in-depth discussions between the participants. The intended aim of the report is to outline key learnings and messages about CE on antibiotic resistance that can be applied in multiple contexts to support present and future community initiatives, education, and ongoing policy processes.

The discussions emphasized that first, a clearer narrative on CE and antibiotic resistance is required to achieve meaningful change. CE has various meanings for different people and actors involved in the process, and different approaches are needed that can be both community-led and community-based. The key outcomes highlighted a need for a long-term vision and funding for community initiatives, systematic assessment of initiatives and specific, measurable, achievable, relevant, and time-bound (SMART) indicators, more case studies and different pilots to test these, and a need to focus on co-creating interventions with communities and civil society organizations.

Effective strategies for impactful community engagement should be contextualized and built on national and local analysis. Including citizens as part of the solution and ensuring that the importance of CE is understood and acknowledged at the level of policymakers is part of the experts’ recommendations. Another recommendation is embedding a One Health approach in community engagement to ensure inclusion of different fields and related agendas, and a community-wide ownership of the solutions. Integrating antibiotic resistance in other established interventions and health agendas, while keeping a balance between context and scaleup, is a key strategy to achieve a strong, whole-of-society approach to antibiotic resistance. The integration of antibiotic resistance into health programs and National Action Plans must include co-creation of solutions between policymakers, communities, patients and civil society, and fostering both top-down and bottom-up approaches. Creating community-friendly narratives on antibiotic resistance should consider clarity in language and terminology for effective communication, as well as using different types of narratives, platforms and advocacy channels, including human stories.

Lastly, opportunities for involving and mobilizing civil society and communities in the lead-up to United Nations General Assembly High Level Meeting (UNGA HLM) on Antimicrobial Resistance in 2024 include identifying efficient narratives to connect with a wider group of communities, such as co-defining strategies and interventions together with community representatives and aligning the antibiotic resistance agenda with other health agendas. The UN 2024 declaration should reflect the importance of community engagement as well as a move beyond awareness, away from unidirectional top-down approaches towards meaningful participation of civil society and communities with co-creation of solutions and fair representations in governance structures and the decision-making process.
Antibiotic resistance is one of the major current global health challenges, directly resulting in the deaths of more than 1.2 million people in 2019 (Antimicrobial Resistance Collaborators, 2022). Given its complex nature, addressing antibiotic resistance requires input from multiple disciplines, including medical, economic, and social sciences to develop effective, sustainable solutions. Antibiotic resistance cannot be solved by single actors in isolation but requires a whole-of-society response. Community and civil society mobilization is especially critical for promoting people-centered services in health, supporting quality of services, assuring the sustainability of health advocacy, and the responsiveness of health systems (Greer et al., 2017). Hence, communities are key legitimate actors in holding stakeholders accountable, advocating for behavior change, and identifying solutions that meet their specific needs. Community representatives with the potential to anchor initiatives addressing antibiotic resistance and create bottom-up action, such as participation in decision-making, governance and delivery of services, are often not mobilized, resulting in missed opportunities.

Building on current work and experiences involving community engagement (CE) and civil society mobilization, the initiative Impactful approaches for community-wide engagement on antibiotic resistance, developed in collaboration between the Uppsala Antibiotic Center, ReAct - Action on Antibiotic Resistance and Antibiotic Smart Sweden, aimed to explore impactful and effective approaches for CE to address antibiotic resistance in diverse settings and contexts across the globe.

Thus far the initiative has featured two webinars and one hybrid workshop. The two webinars recorded over 400 registered participants from more than 60 countries. There were 31 expert participants in the hybrid workshop, 13 onsite and 18 online, representing both low- and middle-income countries (16) and high income countries (15), of which 16 were women and 15 men.
The first webinar, *A conversation about approaches to community engagement on antibiotic resistance across the globe*, provided insights from several ongoing CE initiatives in the context of antibiotic resistance. It presented strategies, challenges, and success factors, and also explored key learnings from related fields.

The second webinar, *A conversation on evaluation and impact of community engagement on antibiotic resistance*, explored what “success” looks like for CE initiatives. Building on the learnings from the first webinar and experiences from the panellists, this event discussed potential ways and indicators for measuring and evaluating the impact and benefits that these initiatives have for society and in addressing global challenges such as antibiotic resistance.

The third event, *An exchange on effective strategies for impactful community engagement in the global response to antibiotic resistance*, was a hybrid workshop held online and in-person in Uppsala, Sweden. This workshop explored current challenges and gaps, potential solutions, and strategies related to CE for a strong, whole-of-society approach to antibiotic resistance. It also discussed recommendations for CE on antibiotic resistance within a wider political context, in particular intending to inform the 2024 UNGA HLM on AMR.

This report summarizes key ideas and take-away messages from the in-depth discussions between the participants. The report follows the structure of the workshop, and when relevant, insights from the webinars have been integrated within the text.

**Initiatives presented during the webinars and keynote speakers**

- **Antibiotic Smart Sweden**, Camilla Björn
- **Community Engagement for Antimicrobial Resistance (CE4AMR)**, Rebecca King & Rumana Huque
- **Global Network of People Living with HIV (GNP+)**, Florence Anam
- **Students Against Superbugs (SAS) Africa**, Daniel Waruingi
- **Antibiotic Smart Communities project India**, Satya Sivaraman
- **Union for International Cancer Control (UICC)**, Sonali Johnson
- **Antibiotic Guardian**, Diane Ashiru
- **Diagnostics for One health and user driven Solutions for Antimicrobial resistance (DOSA)**, Till Bachmann

More details on the initiatives presented and examples of strategies used and impact can be found in *Supplementary File 1.*
3. Challenges and suggested solutions to the current approach to community engagement on antibiotic resistance

**Aims**
The first session aimed at collecting ideas and perspectives from a wide range of experts (such as community representatives, civil society representatives, community-led and -based initiatives, social scientists, antibiotic resistance experts, public agencies, and funders) on challenges, gaps, and limitations in the current approach to CE on antibiotic resistance. The following session aimed at elaborating on sustainable solutions and strategies for a meaningful engagement of communities and civil society groups on antibiotic resistance.

**Methods**
Participants first individually brainstormed challenges, gaps, and limitations based on their knowledge, experience, and background. The “brainwriting” exercise was followed by a voting step, where participants had the opportunity to select a few challenges, including the ones posted by other participants, to be discussed in the next session. Secondly, participants were divided into groups and discussed the challenges most voted for and identified solutions and ways forward, ultimately reporting back in plenary.

During the workshop, participants posted over 140 challenges/gaps/limitations under five predetermined categories: financial, political, structural, narrative/communication, and overarching/others (the full list is available in the Supplementary File II). The four most voted-for challenges were lifted for in-depth discussion on solutions and are presented below.

**Challenge 1**
**Difficulties to show a direct return on investment for CE initiatives, which discourages donors’ and governments’ investments in this area, especially long-term investments**

Monitoring and evaluating success in CE is a challenging process, for example considering the differing understanding of what return of investment is and defining what that means for CE initiatives, the lack of indicators, the often lack of a monitoring and evaluation process in planning CE interventions, and the time span before seeing effects. Given the above, showing a direct return of investment on communities and of CE initiatives is complicated, which may discourage investors from funding such interventions.

**Suggested solutions**
There is a clear need to develop a strong investment case showcasing the power of communities and community-based interventions, emphasizing improved health and financial outcomes. In the context of CE, it is important that return of investment is
understood broader than only economic impact/savings. To support this, there is a need to adopt a transdisciplinary approach, to develop clear and quantifiable indicators, and to communicate the investment case/s widely. This can involve communicators and media, experts, and champions from different sectors. There could be a global investment case, but it will have increased chances to succeed if also contextualized to national level, building on national and local analysis. Developing a compendium of best practices and case studies could be conducive towards making such case/s.

Challenge 2
Lack of targeted advocacy efforts towards policymakers to include citizens as part of the solution and understand and acknowledge the importance of CE

The participants highlighted an insufficient focus on targeted advocacy towards policymakers and the inclusion of citizens as integral parts of the solution through CE. Key issues include a lack of understanding of which policymakers to engage with and their priorities, resulting in a failure to align CE narratives with their agendas, including within existing antibiotic resistance interventions. Additionally, in policy- or decision-making, citizens are often overlooked as contributors and are not seen as part of the solution, causing further disconnection between community needs and policy dialogues. Lastly, a specific challenge lies in embedding a One Health approach in CE and ensuring community ownership, and clarity on measuring impact.

Suggested solutions
Capitalizing on existing CE efforts is one of the keys to solving this challenge. By connecting CE national initiatives with interventions at the global level (and vice versa), the potential impact on decision-makers could substantially increase. When implementing an advocacy strategy, it is paramount to identify and target the right stakeholders which include policy and community leaders, as well as to operate across sectors, and adapt to language and general cultural aspects that might be relevant in certain settings and contexts.

Some of the suggested types of leaders mentioned by the participants were influencers and religious leaders, ambassadors and experts to speak to Parliamentarians, as well Members of Parliament, for instance Cross-Parliamentary Action Groups on antibiotic resistance in the European Parliament, analysts, advocates, media, and stakeholders in other areas such as climate change.

Finally, participants suggested using previous experience from other fields to extrapolate in new settings, for instance co-created toolkits, inspired by other health areas, such as citizen panels; or using different narratives, for instance food narratives, but also new media such as films, animations, and arts as well as briefings in local language(s).

Challenge 3
Lack of integration of antibiotic resistance in existing health programs at the community level, including in national and subnational frameworks

The participants identified the lack of integration of community engagement on antibiotic resistance into health programs and National Action Plans (NAPs) in many countries
as a key challenge. Many NAPs lack a comprehensive strategy for engaging the community to address antibiotic resistance, which has led to a disconnection between public health needs and policy design, as well as missed opportunities to capitalize on antibiotic-specific and non-specific interventions. In addition, the lack of a strong global community identifying with the challenges of antibiotic resistance has created a void in bottom-up approaches.

CE initiatives are often driven by donors or organizations, and their sustainability relies on the funders’ financial support. Hence when funding stops, the engagement also stops. Additionally, communities don’t have the opportunities for engaging in antibiotic resistance in the same way as they have with for instance climate change, due for example to the lack of dialogue, platforms, as well as a clear understanding of the issue.

Suggested solutions
Integrating antibiotic resistance in other public health issues requires both top-down and bottom-up approaches. Co-creation needs to be considered from the outset to collectively unpack this challenge and think around solutions. Integration at the national level depends on structural and regional differences from one country to another. For instance, considering the complexity of systems in urban/rural perspectives and that programs are implemented by different types of providers, such as private actors and/or the government. It is important to embed CE on antibiotic resistance into the health system rather than it being a separate approach.

From a bottom-up perspective it is also important to engage policymakers in the conversation and find the language that resonates with them, since communities are not operating in isolation as they are linked to national and global structures. NAPs are usually framed in the national capital without reference to what is happening on the ground and lacking a patient perspective.

The example of responsive community dialogues, piloted in Malawi, Thailand and Zambia, proved to be successful, but these need government buy-in to be able to influence NAPs, with appropriate funding and a structure for continuous engagement.

Other examples from working in conflict zones and humanitarian settings emphasize the need for cross-sectoral collaboration and working through primary care facilities. This way antibiotic resistance can be anchored into community health promotion. Another example from healthcare centres for women and faith-based organizations highlights a particular need to engage community leaders and train the trainers to ensure ownership and start implementation.

To be able to provide solutions, it is also important to involve stakeholders beyond the health sector, for example in the

Keynote speaker - Tiina Likki: WHO Europe, Behavioral and cultural insights unit

Tiina is an applied behavioral scientist. She provided insights about behavioral change, social sciences and WHO Europe’s work, showing how behaviors are at the heart of antibiotic resistance, summarised in three key elements:

Context: how structural factors drive behavior (example: access to antibiotics).

Culture: social context, beliefs, norms, social practices, traditions.

Community: approaches when understanding the problems and creating solutions.

“Community, awareness and enabling behaviors are increasingly valued by the WHO”.

“We have to address the actual behaviors that drive antibiotic resistance holistically, using theoretical frameworks and models to prevent us from basing our interventions on assumptions and creating interventions that don’t address the core drivers.”

A working framework for “behavioral diagnosis” includes:

1. Capability (individual)
2. Opportunity (contextual) and

Watch Tiina’s keynote here.
agriculture sector, civil society, communities and academia. It is also relevant to consider creative approaches on how to reach out, raise awareness, and start the conversation. For instance, by mapping areas or health programs where conversations on antibiotic resistance can happen or the topic can be integrated, that are of relevance and influenced by communities. Examples are programs for child health, vaccination, screening, and animal health. Fostering more bottom-up approaches and engaging with communities, for instance through elementary school training and using children as change-agents, should also be considered as part of the solution.

Challenge 4
Lack of understanding of antibiotic resistance, specifically lack of community-friendly narratives

The current scientific language often used to talk about antibiotic resistance does not match the terms and language used in the communities. Language is an important challenge, with problems such as the complexity of the concept of antibiotic resistance, leading to difficulties in, for example, classifying medications and types of antimicrobials and antibiotics. Another gap in the narrative are the consequences of antibiotic resistance for individuals, such as disabilities, a side effect that is not often talked about. Less importance has been given to a holistic approach which involves multiple actors and stakeholders, not only human health, which instead is essential to avoid working in silos and implement concerted actions across sectors.

Suggested solutions
CE is a value on its own, like democracy and gender equality, and it needs to be seen as a way to generate results and a platform to ensure that community members’ voices are heard. Sustainable funding needs to be part of the solution as well as providing clarity about the terms being used for effective communication to raise awareness to support a change in attitude, practice and behavior for patients, their families, pharmacists, and healthcare providers.

Communities can be placed in different contexts in relation to health, and this should be used accordingly in the narratives chosen. For instance, facing a community with healthy people means focusing on prevention, such as managing the repercussions from a physical and mental health perspective. It is also important to use education, films, music, arts, and communication materials in places such as school curricula, and media, to engage with wider audiences. People who are informed about the topic can then communicate in, and educate, their own communities, by identifying and conveying a positive narrative that can resonate with the local communities. It is equally important to include other types of expertise in the communication process than medical and natural sciences experts, for instance from social sciences, communication, marketing, and anthropologists. Additionally, it is important that advocacy and engagement deliver a clear and impactful message, such as, human stories through antibiotic resistance survivors and patient advocates as well as their families. An example is provided to the right.

Keynote speaker - Rhea Lobo: Filmmaker and TB survivor, from the organization ‘Bolo Didi’ (Say Sister), India

Rhea provided insights from TB community engagement and antibiotic resistance, and the patient perspective. She spoke about the power of using Arts for CE and healthcare. Rhea emphasized how filmmaking is a form of communication that breaks stigma, as in many cases TB is thought of as a poor person’s disease.

“I am not just a TB patient, I can contribute to ending the suffering of TB”.

“We as communities are experts in our own rights, we are equal partners, not passive recipients of care.”

Watch Rhea’s keynote here.
Aim
The aim of this session was to explore opportunities for involving and mobilizing civil society and communities in the lead up to the UNGA HLM on AMR 2024.

Method
The last session of the workshop featured presentations from key speakers as well as plenary discussions with all the participants, both online and onsite.

The UNGA HLMs provide a unique opportunity to mobilize funding, renew political momentum, and reach agreement on concrete measures and solutions on topics of global concern. The commitments are made at the head of state level. In September 2024, the UNGA HLM will be focused on antimicrobial resistance for the second time in history. This is an important event for setting the future direction of the global response to AMR and represents an opportunity to set some of the concrete targets that have been missing in the previous UN HLM and declaration in 2016.

The 2016 HLM was a major milestone for AMR - the resulting UN declaration contained eight key commitments, however there were no specific targets. There was high attendance from governments; but civil society presence was much less prominent than for other HLMs such as HIV, TB or other health areas. Several concerns were highlighted in terms of progress since the meeting, such as the fact that only 10% of countries have a budget for NAPs, the fact that access to antibiotics is inequitable, and development is stagnant.

In terms of governance, the 2016 UN declaration mandated the then Tripartite (WHO, FAO, and OIE/WOAH) to create an ad-hoc Interagency Coordination Group (IACG) on AMR. This group in 2019 recommended establishing a One Health Global Leadership Group on AMR (established in 2020), an independent panel on evidence for action (not yet established), and a multi-stakeholder partnership platform (launched in 2023). Progress in this area is required to have a fully formed governance structure for AMR.

Key messages from earlier discussions organized by ReAct in May 2023 regarding civil society and community engagement are presented in the Uppsala Dialogue Meeting summary report.

Proposals for an efficient narrative to connect with a wider group of communities towards the UNGA HLM on AMR 2024
Participants shared several ideas on narratives for connecting with a wider group of stakeholders. One suggestion was to move from the term “resistance” to “access”, in line with changing the narrative from technical language to people-centred. As the term ‘access’ refers to access to antibiotics or medical countermeasures, it could be mentioned more broadly as multiple groups in the society, including patients, might relate more to this compared to “resistance”, which is considered a more medical word. As the target for improving
health systems is indeed the society in a broader sense, communities play a central role, and co-defining strategies and interventions together with community representatives is imperative. In terms of advocacy, it was suggested to place antibiotic resistance in the agendas of other health issues such as HIV, TB or cancer, for instance, that would help to connect to and involve a wide range of communities. And equally important is to engage with the people who have the experience in these fields and who can advocate for these agendas. Another key suggestion emphasized the importance of financing antibiotic resistance across all sectors, since it needs to be understood as a systemic and equity issue, hence it is crucial to interlink it to other health problems.

Proposals for how communities can be mobilized in the lead-up to the UN HLM 2024

Participants highlighted the importance for communities to have a clear value proposition and motivation for engaging in the UN HLM. This includes a clear understanding of the significance of the UN HLM and the need to communicate this efficiently. These would then help to build momentum in the media, and to engage with the youth before the UN HLM. It was also suggested that having AMR champions, advocates and several people of influence could be another way for communities to mobilise successfully in the lead-up to the next UN HLM.

Lastly, arts was also highlighted as a major form of engaging with and mobilizing communities. For instance, in Latin America, communities have been engaged in art installations and performances including examples such as “dancing with bacteria”.

Proposals for what the UN 2024 declaration should reflect in terms of community engagement

UN HLMs provide a good momentum for movement building. It is important that civil society and communities come together with overall alignment on goals and make their voices heard. Nonetheless, learning from previous experience with other HLMs, inclusive consultations have not always been held or been sufficiently accessible for civil society and communities. It would be critical to ensure meaningful and constructive engagement with civil society and communities beyond simple descriptions in the declaration.

Participants emphasized the importance of different meanings and implications of CE: it should not only be seen as public outreach and a campaign. In different regions of the world, CE is often perceived as sensitizing communities on key issues, rather than asking community members to co-create their own solutions and participate in decision-making processes.

Thus, the declaration should reflect a move beyond awareness, away from unidirectional top-down approaches where community engagement means to inform the community and instead move towards bottom-up approaches with co-creation of community-led solutions and fair participation. This implies giving communities a voice to co-create interventions on AMR and sustainable resources for CSOs to participate and sustain CE on antibiotic resistance, not just going in and sensitizing communities.

Participants also argued that the declaration should specify actionable and concrete steps on CE that will require global action. Suggestions included the launch of an annual point prevalence study during World AMR Awareness Week involving communities, and asking for data on health funding on community engagement to ensure sustainable resources for community engagement (see following section for more detailed next steps).
5. Concluding remarks

This initiative brought together a wide range of stakeholders and experiences to discuss CE and antibiotic resistance, bringing forward several important messages and recommendations.

To achieve meaningful change, a clearer narrative on community engagement and antibiotic resistance is required. Different, multi-sectoral approaches for CE are needed that can be both community-led and community-based and must be embedded into strategies for health systems strengthening. Measuring impact needs to focus on a long-term vision and funding for community initiatives, a systematic assessment of initiatives and SMART indicators, and co-creating interventions with communities and civil society organizations.

Effective strategies for impactful community engagement should be contextualized and built on national and local analysis, targeting the government. Including citizens as part of the solution and understanding and acknowledging the importance of CE at the level of policymakers are a part of the solutions recommended, as well as embedding a One Health approach in CE to ensure inclusion of different fields and related agendas and ensuring community ownership of the solutions. Integrating AMR in other established interventions, while keeping a balance between context and scaleup, is a key strategy to achieve a strong, whole-of-society approach to antibiotic resistance. The integration of AMR into health programs and NAPs must include co-creation of solutions between policy makers, communities, patients and civil society and fostering both top-down and bottom-up approaches. Creating people-centered narratives on antibiotic resistance should consider clarity in language and terminology for effective communication, as well as using different types of narratives, platforms and advocacy channels, including human stories.

Opportunities for involving and mobilizing civil society and communities in the lead up to UNGA 2024 include identifying efficient narratives to connect with wider group of communities, such as co-defining strategies and interventions together with community representatives and aligning the antibiotic resistance agenda with other health agendas. The political declaration from the upcoming UNGA HLM on AMR should reflect the importance of different meanings and implications of community engagement as well as a move beyond awareness, away from unidirectional top-down approaches and moving towards bottom-up approaches with co-creation of community-led solutions and equal participation.
Several ideas were shared by the participants on the next steps including:

1. **Broader CSOs engagement**, such as through a petition to ask for a multi-stakeholders hearing for AMR ahead of the UNGA HLM on AMR, using the AMR multi-stakeholder partnership platform and an establishment of a civil society and community engagement mechanism for the HLM.

2. **Strengthening bottom-up approaches**, for instance by creating CSO community of practice on AMR, identifying a coordinating organization for CSOs leading up to the HLM and beyond and engaging communities from the bottom and providing them with the right funding opportunities; creating an evidence base for value of community engagement in terms of health and economic outcomes.

3. **Joint advocacy efforts** by promoting community engagement in underrepresented regions and learning from other advocacy groups regionally and internationally; advocating for domestic investment in antibiotic resistance at national level; encouraging CSOs to advocate and engage policy makers to include community members in AMR solutions; and asking for NAPs to address CE on AMR in decision making fora as part of advocacy and influencing.

ReAct, the Uppsala Antibiotic Center, and Antibiotic Smart Sweden highly appreciate the input and recommendations and will take these outcomes into consideration in the planning of the next steps of the initiative.

We look forward to building on the connections made and mobilizing communities and civil societies more broadly towards the 2024 UNGA HLM on AMR.
6. Supplementary material
*(available as a separate document)*

File I: Summary of examples of CE strategies across the world for building impact
File II: List of all challenges, gaps, and limitations to CE on antibiotic resistance
File III: List of next steps proposed by the participants

Uppsala Antibiotic Center: Podcast episode on community engagement in AMR.

7. References


