
Meaningful engagement of patients, survivors and carers in addressing antimicrobial resistance



**WHO Taskforce of
AMR Survivors**



Purpose

This document is designed to guide technical experts and policy-makers in identifying opportunities for meaningful engagement of survivors and people with lived experience of antimicrobial resistance (AMR) to advance international, national and local AMR agendas.



Background

AMR is a leading cause of death globally, with 1.3 million deaths directly from bacterial AMR alone in 2019¹. Without stronger response, over the next decade, AMR is estimated to cause an average loss of 1.8 years of life expectancy and cost the world US\$ 412 billion a year in additional healthcare costs and US\$ 443 billion per year in lost workforce productivity². Although actions such as the [Global Action Plan](#) and [the Quadripartite](#) attempt to address this multisectoral problem comprehensively, it is important to consider AMR not just from the point of view of infectious microorganisms and antimicrobial medicines but one in which people and communities are at the centre. It is therefore essential to incorporate the recently published [WHO people-centred approach](#) into global action. In this approach, people and their needs are at the centre of the AMR response and guide policy-makers in taking programmatic and global actions to mitigate AMR with a proposed package of core interventions.

How can policy-makers, researchers and health-care workers engage with AMR patients and their carers and with AMR survivors and involve them meaningfully? The aim of this document is to share the perspective of the WHO Task Force of AMR Survivors and their diverse, extensive experience to:

- define meaningful engagement,
- propose guiding principles and
- describe key opportunities.

Importance of including patients, survivors and carers in AMR action

Involving patients and the public in AMR is vital for a robust, holistic response. Patients, survivors and carers provide first-hand perspectives on antimicrobial use and its impact on their lives, which can be used in developing people- and patient-centred solutions. Engagement of survivors can raise awareness and motivate changes in the behaviour of the wider public. The current AMR narrative is considered highly technical and sometimes difficult for the public, for health-care workers who are not specialists in infectious diseases and for policy-makers. Patients' experiences can improve the narrative by "humanizing" it. Additionally, inclusion of diverse patient perspectives ensures that interventions include cultural, socioeconomic and demographic factors, thus promoting equitable, effective outcomes.

1 Antimicrobial Resistance Collaborators. Global burden of bacterial antimicrobial resistance in 2019: a systematic analysis. *Lancet*. 2022 Feb 12;399(10325):629-655. doi: 10.1016/S0140-6736(21)02724-0.

2 Global Leaders Group on AMR. Towards Specific Commitments and Action In The Response To Antimicrobial Resistance. Geneva; 2024



Reaching out to AMR patients, survivors and carers

We all know AMR survivors. They are people who were hospitalized several times for a urinary tract infection that was difficult to treat or the parent of a child who died of sepsis. Most of them may not know that they are AMR survivors, however.

Organizations that wish to engage with patients, survivors and carers must therefore identify them. Charities, professional associations and patient advocacy groups for people with HIV, cancer or immunological diseases or who have received a transplant, in whom secondary infections are common may maintain relationships with people with lived experience of AMR. Health-care professionals can also help to identify survivors, taking due care to protect their privacy. Introductions by partners and collaborators are more successful than passive efforts such as contact forms or flyers, although several methods should be used to contact participants.

People with lived experiences may reach out to organizations that are active in patient advocacy to guide them in accessing appropriate resources and in narrating their stories on relevant platforms to diverse audiences.



Strategies to strengthen engagement of patients, survivors and carers

The objective of engagement should be to strengthen the existing skills and networks of survivors to support their goals for advocacy about AMR. Engagement should promote sharing of experiences in dealing with AMR and their stories about AMR. The lived experiences of patients, survivors and carers give them the legitimacy to speak about the condition with powerful voices. Active efforts are necessary to ensure that engagement is meaningful and not “token”. Organizations could therefore also improve the ability of their staff to communicate with and engage patients, survivors and carers.

Strategies for maximizing the impact of patient, survivor and carer engagement are listed below. Differences in experience and skills can be beneficial if used appropriately. It is important to ensure that what is being asked from patients, survivors or carers is something they can do or have experience with. An in-depth conversation on how they would like to contribute and the platforms with which they are comfortable can facilitate conversations.






Proposals for engagement with patients, survivors and carers are listed below and summarized in Table 1.






- Tailor engagement to the elements that patients, survivors or carers are willing to share rather than deciding on the elements beforehand.
- Patients, survivors or carers may require certain resources to become involved, such as funding (e.g. to cover loss of wages, childcare and other resources due to their health, family responsibilities or socioeconomic situation). Therefore, start by making smaller, limited requests, and provide resources and support.
- It is important to understand any limitations to the technical capacity of patients, survivors and carers. Advocacy about scientific issues should be explained and, in some cases, mentored, rather than assuming that they are knowledgeable enough to contribute equally; for example, health literacy or language may be barriers to their contribution. Survivors are not necessarily experts in AMR; however, they are experts in their lived experience and the impact of AMR on them or their loved ones.
- Consider counselling if a patient, survivor or carer is sharing their experience for the first time or repeatedly. This may be possible through another advocate or a partner patient organization or with a designated individual. Engagement with the media can also be challenging; therefore, resources such as the Quadripartite Media Engagement Toolkit could be used.
- Once a core group of patients, survivors or carers has been identified and is active, other groups may express interest in supporting some projects. Increasing the number of patients, survivors and carers involved ensures continuity and diversity in the perspectives and stories.
- Networking among groups nationally and internationally can facilitate meaningful regional collaboration.



Table 1.

Areas of involvement of patients, survivors and carers that could be meaningful

Area of involvement	Strategy	Support
Public awareness 	Sharing experiences with the media (e.g. broadcast, traditional and digital media), engaging in educational initiatives, advocating for responsible antimicrobial use and infection prevention and participating in community outreach	Provide platforms for interaction with health-care workers, other patients and the media. Train survivors and patient advocates in engaging with the media and use of social media tools, and equip them with the competence to train other patients, survivors and carers.
Health worker education 	Patients, survivors and carers can contribute actively to training health workers about AMR before and after finishing their training and while employed by sharing their experiences, perspectives and insights on antimicrobial use, AMR and its impact on health.	Hold sessions for structured patient and survivor interaction during pre-service education. Modify curricula to address good communication skills and patient engagement. Develop pathways and policies to promote their engagement in planning and delivering AMR awareness campaigns for health-care workers.
Health-care delivery 	Patient advocates can help to improve health-care delivery by facilitating communication, navigating administrative processes and promoting health literacy. Advocates can also contribute to culturally competent, sensitive care, address ethical dilemmas and offer feedback for quality improvement.	Build their capacity to intervene at system level to make health-care delivery accessible, equitable, ethical and based on justice. Ensure patient representation in health-care facility committees that oversee AMR-related issues.
Policy-making 	Their involvement can complement data-based policy-making on AMR by adding basic perspectives such as issues of access and the quality of health care. This can promote creation of health-care policies aligned with patient needs and ensure strategies that address the complex health-care challenges associated with AMR. They can also ensure accountability by policy-makers and play a critical role in evaluation of impact.	Conduct formal consultations with survivors to ensure that their feedback is built into AMR policy-making and impact evaluation. Provide national and subnational platforms for patients, survivors and carers to advocate for people-centred approaches to AMR for policy-making and impact evaluation.
Advocacy 	They can advance the advocacy agenda through the power of their lived experiences. Similarly, they can play a critical role in ensuring the quality of and access to health care, including for novel diagnostic and therapeutic options.	Facilitate meetings of survivors and patient advocates to discuss AMR-related issues that affect health-care delivery. Prepare briefing documents to increase their understanding of the priorities for AMR advocacy. Link them to any available advocacy support groups for early identification and training of survivors interested in advocacy. Link survivor groups in different geographical areas to increase cross-regional learning.

Area of involvement	Strategy	Support
National action plans (NAPs) 	They can be powerful champions for accountability and resource mobilization for NAPs. They have the greatest legitimacy in asking governments about their commitment to advancing the AMR agenda.	<p>Formalize a mechanism for identifying and engaging them in all NAPs.</p> <p>Provide resources for developing and capacitating patient advocacy organizations to intervene actively on AMR issues.</p>
Publications 	Patient involvement in studies published in peer-reviewed journals provides unique perspectives, enhances the relevance and applicability of the research findings to the real world and ensures that research is aligned with the needs and priorities of those directly impacted by health-care interventions.	<p>Invite them as guest reviewers or co-authors, and provide support to enable their involvement.</p> <p>Journals should encourage authors to include an explanation of the relevance of their study in simple, non-technical language.</p>
Medical conferences 	They should be invited to conferences on AMR, as they bring diverse, real-world perspectives to access and equity and ensure that discussions are firmly grounded in reality.	<p>Hold specific sessions in various formats (such as presentations and “fireside chats”) where they can narrate their stories.</p> <p>Organizers should consistently ensure sessions that include them in all conferences on AMR, infectious diseases, HIV, oncology, patient safety and other relevant issues and allocate funding for their participation. The patient’s health status, visa requirements, carer costs and other financial barriers such as loss of wages should be considered when soliciting their participation.</p>
Public health innovation 	Patients are essential to AMR innovation, from digital tools to real-world interventions, as their involvement ensures that interventions are co-created and grounded in experience, address specific challenges and promote development of more effective, patient-centred solutions.	<p>Involve them during conceptualization, design and testing of innovations through means such as user experience surveys and cognitive testing.</p> <p>Use a human-centred design approach for AMR-related public health innovations.</p>
Research and development 	They can contribute actively to research on AMR due to their unique insights into the challenges of antimicrobial use, the need for better diagnostics tests and the broader impact of AMR, ensuring that research is aligned with real-world concerns and contributes to effective strategies for combating AMR.	<p>Include them on committees for evaluation of proposals for funding for research and in the design of clinical trials.</p> <p>Engage them in research prioritization.</p> <p>Their stories can be used to explain why research and development are necessary for better, more timely diagnosis and treatment.</p>



Conclusion

Meaningful involvement and engagement of patients, survivors and carers is crucial for advancing global and national AMR agendas. More work is needed to raise awareness about the need and opportunities for engagement among technical experts, policy-makers and the survivors themselves. This guidance can be used to define clear expectations from engagement and to contextualize the strategies.



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Scan the QR code to learn more about the WHO Taskforce of AMR Survivors