

WHO Taskforce of AMR Survivors

Report of the Inaugural meeting
10-11 October 2023
WHO Headquarters, Geneva



World Health
Organization

Introduction

WHO launched a task force of “survivors of antimicrobial resistance” (AMR) to provide a platform for the voices of people who experienced complications of drug-resistant infections. The members of the task force serve as “champions” to help in shaping the AMR narrative globally and to influence policies on AMR. They are also expected to contribute to improving messages about AMR to ensure that the “human face” of AMR is included to increase awareness of AMR.

The task force is constituted of people who have survived AMR infections or have cared for people with serious drug-resistant infections. The task force has a wide, global representation, including people who have survived drug-resistant bacterial infections, extensively drug-resistant tuberculosis, resistant infections associated with immune-compromised conditions such as HIV and cystic fibrosis, urinary tract infections, complications during routine surgery and fungal infections.

Survivors of AMR infections and their caregivers have unique perspectives on the diagnosis, treatment and care they received (or did not receive). Their ideas and experiences on how patients, health-care providers and communities can better address AMR infections are invaluable and can help shape people and patient-centred care. Patients’ stories can make a complex, technical health and development challenge more human.

The [inaugural meeting](#) of the WHO task force of AMR survivors was held on 10–11 October 2023 at WHO headquarters in Geneva, Switzerland, and was attended by 11 of the 12 members of the task force.

Functions of the WHO task force of AMR survivors

The functions of the task force are to:

- **share their stories in ways that reach a global audience, in both formal media and social media;**
- **engage AMR survivors in WHO events and discussions on AMR;**
- **raise awareness about AMR and advocate for relevant improvements in clinical, research, development and policy spheres;**
- **advocate for increased funding and donor commitment to the AMR response at all levels; and**
- **develop a framework for patient advocacy and identify priorities to guide continuing activities.**

Inaugural meeting

Opening session: The meeting was officially opened by Dr Haileyesus Getahun, Director, Global Coordination and Partnership Department, AMR Division, WHO, who commented that the issue of AMR should be framed better in order to mobilize stakeholders and increase political commitment. He outlined the progress of international policy on AMR since the launch of the Global Action Plan in 2015. He exhorted task force members to be champions by using their experiences to advocate for greater attention to the issue. The United Nations General Assembly high-level meeting on AMR, to be held in 2024, should be an immediate target for advocacy, and the task force members should expect bold commitments by all countries. In a pre-recorded speech, Dr Tedros Adhanom Ghebreyesus, Director-General of WHO, commented that lack of understanding about AMR adversely affects investment in prevention and mitigation and encouraged the task force members to share their stories, experiences and expertise.

Briefing: Thomas Joseph, Unit Head, AMR Awareness, Campaigns and Advocacy, WHO, briefed the members of the task force on their terms of reference, functions and mandate and the expected outcomes of the inaugural meeting. Vanessa Carter, a member of the WHO Strategic Technical and Advisory Group on AMR, was appointed Chair of the task force by consensus.

Introductory presentations: All members of the task force briefly presented themselves and their stories to ensure that WHO and other members of the task force understood the challenges faced by those with AMR infections. They described the clinical course of their infection, the personal impact and system challenges. Short versions can be found in this link.

Sessions: On day 1, the discussion centred on use of patients' stories to shape the global narrative on AMR, including existing and new platforms that could be used to share survivors' stories. A further discussion addressed "de-jargonizing" and simplifying patients' stories for the public to ensure that interest is maintained. A method could be devised to ensure that patients' stories are framed in such a way that they influence the universal narrative about AMR and convey that a drug-resistant infection can occur in anyone at any time. Breakout discussions addressed promoting a human face in all awareness-raising activities on AMR and possible actions as task force survivors and as individual patient advocates. It was concluded that the narrative could be improved by stating that AMR stops medicines from working against infections and on the universality of drug-resistant infections. The personal, social and economic impacts of AMR on a person's

life could also be highlighted in order for people to understand the gravity of the issue. Thomas Joseph, Unit Head, AMR Awareness, Campaigns and Advocacy, WHO, then presented the landmark events and policies that have shaped the global AMR response and the priorities of WHO and other institutions, such as the Global Leaders Group on AMR, especially in the run up to the United Nations General Assembly high-level meeting on AMR in 2024.

On the second day, the Chair summarized the discussions on day 1, which was followed by a breakout group discussion on priorities for AMR advocacy from the perspective of patients. The main conclusions were that interventions should be patient-centred and that patient advocates should be involved in international and national decision-making. The Chair then led discussions on the agenda and work plan for the group for the next year and working arrangements. Mimi Melles-Brewer, Technical Officer, AMR Awareness, Campaigns and Advocacy Unit, WHO, closed the meeting with a summary of the discussions and emphasized the importance of the platform to increase attention to AMR.

Promoting a human face in AMR awareness-raising

Ensuring a human face: Messages about AMR should be clear, simple and "relatable". Although stories of difficult patient experiences are important, the stories used to raise awareness should be as diverse as possible, including infections of diverse severity, as many people would not relate only to stories of severe infections or rare conditions. Messages should include stories from physicians and caregivers. The focus should be on AMR and its impact, with less emphasis on health systems and One Health, the complexity of which could confuse or distract a public audience.

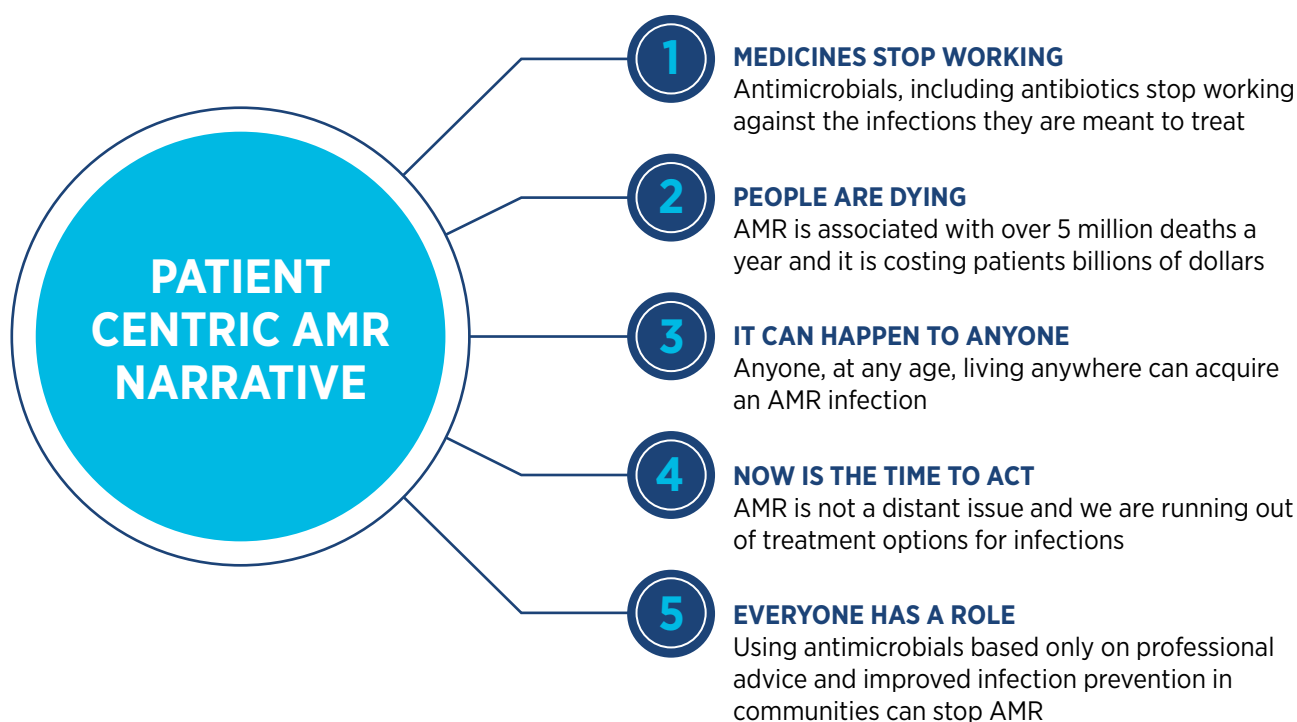
Opportunities to improve the AMR narrative: Collaboration at all levels is necessary to synthesize messages on AMR and to adapt them for various audiences. They should be designed for stakeholders who can use the messages, including groups working on, for example, cancer, organ transplantation or noncommunicable diseases. Lessons can also be learnt from the successes and experiences of advocacy groups in HIV and tuberculosis that include patients' voices on their agendas. Platforms with the greatest impact in different countries should be identified, including messages from celebrities who have been affected by AMR as a patient or a caregiver. Templates for awareness-raising by patients and health-care workers could move the narrative beyond statistics.

Possible roles for task force members: The task force could provide a platform for its members to communicate with international and national stakeholders, including institutions that are spearheading the AMR response. WHO should therefore connect task force members with national institutions and the regional and country offices of the Quadripartite organizations. Members could describe their experiences in messages on the global priorities of advocacy about AMR.

Framing and “de-jargonizing” AMR survivors’ stories for the public

- AMR should be reframed, as there is currently too much emphasis on mortality and morbidity statistics. The challenges to changing the narrative include the fact that AMR is multifactorial and multisectoral: AMR is not a disease per se, AMR is complex and technical, and AMR is not readily visible to the public eye.
- The issues with terminology include the fact that “antimicrobials” are not readily recognized as antibiotics, and different organizations and countries use different terms for the same condition (e.g. antimicrobial resistance, antibiotic resistance, superbug, drug-resistant infections), with no appropriate translation in several languages. WHO uses the term “antimicrobial resistance”, and recent global consultations on rebranding of World AMR Awareness Week should start popularizing this term.
- Knowledge increases with time. Therefore, it is important to start with the basics, giving the public two or three points, and then adding more points and layers. The idea of awareness-raising is to start simple, allow people to familiarize themselves and then broaden their knowledge. Repetition of key messages should be accompanied by simple, action-oriented stories.
- Use of an #AMR hashtag is challenging, because the abbreviation AMR is not widely recognized. The WHO social media team is actively discouraging abbreviated hashtags for social media.
- Three questions could be used in explaining AMR: What is it? What is your risk? And what action is necessary? These questions will help break down the issue for public consumption and provide specific, simple information. The cost of AMR is another important dimension, especially when speaking to policy-makers.
- Patient advocates have the greatest legitimacy to speak about AMR, and their stories should be leveraged fully to improve the narrative. The principles for making the AMR narrative more patient-centred are illustrated in Fig. 1.

Fig. 1. **Principles for making the AMR narrative more patient-centred**



Priorities for patient advocacy on AMR

Priorities for patient advocacy: Humanizing the AMR issue and transforming the narrative into one that is more people- and patient-centred is the priority for patient advocacy. All dialogue and policy for AMR should ensure active involvement of patient groups and patient advocates. Access to health care, access to newer, expensive, effective antimicrobials and to diagnostics are important components of patient advocacy.

Strategies for mobilizing support for advocacy priorities: Patient advocacy groups working on AMR must have legitimacy to advance their agenda, which may require support from WHO. More patient advocacy groups and patient advocates are required at regional, national and subnational levels, with national task forces to identify priorities and guide action. A guiding document might be useful for identifying the role of national patient advocacy groups and the platforms available for their active involvement. At international level, there should be a plan for engaging groups such as the G7 and the G20. A process could be designed to identify priorities for advocacy regionally and globally. Patient advocates should present their stories in different venues, including technical conferences, which attract a global audience. The Global Leaders Group on AMR and the Quadripartite organizations should be familiar with and support patient advocacy, with active communication with the task force.

Defining the success of the task force: A clear AMR narrative with patients at the centre and clear demands for the United Nations General Assembly high-level meeting in 2024 are critical. In addition, the task force should formalize their engagements with national and international stakeholders, with the support of WHO, to ensure that they are invited to meetings and events where they could share their experiences. All members of the task force should be involved in global discussions of AMR.

Agenda and work plan for the taskforce

The agenda of the task force was decided from the list of expected functions in the terms of reference. After extensive deliberations, it was proposed that the task force face more externally, with limited internal activities and meetings. This would increase the visibility of AMR patients' stories, with fewer internal processes. WHO will act as the secretariat for the task force.

The following priorities were decided for the task force:

- Launch the task force during World AMR Awareness Week 2023 at an event, preferably in a webinar.
- Ensure that the task force has a web presence, ideally on the WHO website, to establish its digital identity and footprint.
- Through WHO, all members should be in contact with the WHO country and regional offices and national agencies that are implementing action plans on AMR.
- The task force should deliver clear messages to identified target audiences during the next year in preparation for the forthcoming high-level meeting on AMR in 2024.
- The task force members should “package” their stories and experiences with communication professionals and decide on how to disseminate them.
- The task force should prepare brief guidance for countries about opportunities and strategies for engaging patient voices in implementing their national action plans.

Overall, patient advocates should be considered as representing the voice of the public, and engagement with WHO should be bidirectional. The task force members, through their organizations and networks, could broadcast the policies and positions of WHO, while WHO should seek the opinions of survivors in developing technical products and policies.

Two sets of messages should be developed: “activation messages” based on the stories and experiences of AMR survivors and “engagement messages” to lead the target audience to action.

A chair and a co-chair were nominated to lead a webinar during World AMR Awareness Week. It was decided to host the online event with the survivors on Tuesday, 21 November 2023 at 16:00–17:30 CET.

Timelines and working modalities

Meeting schedule: The members of the WHO task force of AMR survivors will meet virtually every 3 months, the meetings being convened by the Chair with assistance from the secretariat. Annual meetings of the task force are to be held physically in Geneva, Switzerland, or another location, if funds can be mobilized by WHO. Preference will, however, be given to facilitating the travel of members to strategic meetings worldwide rather than organizing an annual meeting.

External relations: The task force should prepare an introductory video that can be used to publicize the group. A web presence, preferably on the WHO website, will be explored. The webpage should explain the functions of the task force, with brief biographies and contact details. The secretariat will be responsible for updating the website.

Events and publications: All events and publications by the task force will be agreed by consensus among all members and WHO. Events could be publicized through the social media sites of members and their organizations. The events will be supported by the secretariat.

Shared calendar and drive: The secretariat will prepare a calendar on which members can report events that they are attending as patient advocates to ensure that all members are aware of the activities of others and the global AMR landscape. The secretariat will also start a shared drive to store all relevant files of the task force.

Agenda of the meeting

▼ DAY 1		
Time		Chair
08:30-09:30	Registration	
09:30-09:35	Welcome and setting the scene	Philip Mathew Technical Officer, AMR Awareness, Campaigns and Advocacy, WHO
09:35-09:50	Opening Remarks	Haileyesus Getahun Director, Global Coordination and Partnership Department, WHO
9:45-9:50	Pre-recorded message	Tedros Adhanom Ghebreyesus Director General, WHO
09:50-10:00	Group photo	
10:00-10:15	Briefing of the chair and members, Expected outcomes from the meeting	Thomas Joseph Unit Head, AMR Awareness, Campaigns and Advocacy, WHO
10:15-11:00	Introductory presentations from the members of the Taskforce (7 mins per presentation) 4 presentations	All participants (Moderated by the chair)
11:00-11:15	Coffee break	
11:15-12:00	Discussion- Opportunities to enable patient stories to shape the global narrative around AMR	All participants (Moderated by the chair)
12:00-12:45	Discussion- Framing, simplifying and de-jargonizing patient stories for the public	All participants (Moderated by the chair)
12:45-14:00	Lunch (B Building)	

▼ DAY 1		
Time		Chair
14:00- 15:15	Introductory presentations from the members of the Taskforce (7-10 mins per presentation) 7 presentations	All participants (Moderated by the chair)
15:15-15:30	Coffee break	
15:30-16:20	Group work- How can we promote a human face in awareness raising on AMR? What are the actions possible as individuals and as a group? (2 groups)	All participants (Moderated by the group chairs and rapporteurs)
16:20-16:40	Group work presentations (5 mins of presentation and 5 mins of Q&A for each group)	All participants (Moderated by the chair)
16:40-17:00	Advocacy priorities for AMR	Thomas Joseph Unit Head, AMR Awareness, Campaigns and Advocacy, WHO

▼ DAY 2		
Time		Chair
09:30-09:40	Recap of the discussions on Day 1	Chair of the taskforce
09:40-10:40	Group work- What are the priorities for AMR action from a patient advocacy perspective? (2 groups)	All participants (Moderated by the group chairs and rapporteurs)
10:40-11:00	Coffee break	
11:00-11:30	Group work presentations (5 mins of presentation and 5 mins of Q&A for each group)	All participants (Moderated by the chair)
11:30-12:30	Discussion- Agenda and workplan for the taskforce for next 1 year	All participants (Moderated by the chair)
12:45-14:00	Lunch (B building)	
14:00-15:00	Timelines and working modalities of the taskforce	All participants (Moderated by the chair)
15:00	Coffee and depart	

Participants of the inaugural meeting

- Anthony Darcovich, USA
- Bhakti Chavan, India
- Brandon Jaka, Zimbabwe
- Felix Liauw, Indonesia
- Gabriella Balasa, USA
- John Kariuki Muhia, Kenya
- Mashood Lawal, Nigeria
- Nour Shamas, Lebanon
- Rob Purdie, USA
- Tori Kinamon, USA
- Vanessa Carter, South Africa/UK
- Haileyesus Getahun, WHO HQ
- Thomas Joseph, WHO HQ
- Nienke Bruinsma, WHO HQ
- Diriba Mosissa, WHO HQ
- Mimi Melles-Brewer, WHO HQ
- Naomi Wanjira-Vollet, WHO HQ
- Philip Mathew, WHO HQ

Awareness, Campaigns and Advocacy Unit

Global Coordination and Partnership Department
AMR Division



**World Health
Organization**