

WHO TASKFORCE OF AMR SURVIVORS

Guidance note on meaningful engagement of survivors published



The WHO Task Force of AMR Survivors published a [guidance note on meaningful engagement](#) of patients, survivors and carers in addressing antimicrobial resistance. 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 centered solutions. The Task Force members believe that 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 and for policymakers to understand. Patients' experiences can improve the narrative by "humanizing" it.

The document is designed to guide technical experts and policymakers in identifying opportunities for meaningful engagement of survivors and people with lived experience of AMR to advance international, national and local AMR agendas.

Task Force session at the evening reception 'AMR affects us all: Stories & solutions from the community' in NY

On the margins of the 2024 UN multi-stakeholder hearing on antimicrobial resistance (AMR), the UN Foundation, Union for International Cancer Control, Fleming Centre, and World Health Organization organized an evening reception on 15 May 2024, to showcase stories and solutions from AMR-impacted communities. The program examined AMR through a range of unique human-centered perspectives, including first-hand experiences of the members of the WHO Task Force of AMR Survivors, insights from



medical providers, and striking photographs that tell the story of AMR infections among the world's most vulnerable.

Vanessa Carter, Chair of the WHO Task Force of AMR Survivors and Anthony Darcovich, Member, spoke at the event. Vanessa presented the mandate and activities of the Taskforce and explained the contents of the guidance note on meaningful patient engagement. Vanessa and Anthony narrated their personal experiences with AMR and outlined the advocacy activities that they are a part of. The 20-minute session was moderated by Cecilia Mundaca Shah, Senior Director of Global Health, UN Foundation.

The evening reception had more than 100 attendees, with several permanent missions being a part of the event. H.E. François Jackman, Permanent Representative of Barbados to the UN and H.E. Vanessa Frazier, Permanent Representative of Malta to the UN congratulated the members of the Task Force in bravely coming forward to share their stories and for the great work they are doing.

‘AMR is invisible. I am not.’ campaign launched



The World Health Organization (WHO) has launched an [awareness campaign titled ‘AMR is invisible. I am not’](#) based on the stories of the members of the WHO taskforce of AMR survivors, in a run up to the United Nations General Assembly High-Level Meeting on AMR (UNGA-HLM). The campaign is meant to simplify the narrative, and show that behind every number, there is real human cost.

The campaign is anchored on several [communication assets](#) like social media tiles, quote cards, carousels, posters, videos, and more. It has a campaign guide outlining strategies to use the assets effectively and a media toolkit which could help journalists report on AMR

challenges from a lived experience perspective rather than only a scientific one. The communication products of the campaign are available in the 6 UN languages. The videos that are a part of the campaign were extensively screened during the 77th World Health Assembly in Geneva, and posted on WHO's corporate social media handles.

By sharing real-life experiences of AMR, WHO aims to illustrate its tangible impact and promote global action. WHO urges governments, NGOs, civil society groups, youth and student organizations, universities, healthcare professionals, private stakeholders and media to act and engage local communities in raising awareness around this global health crisis.

Survivors at the 'The world together solving the antibiotic emergency' event held at the Royal Society, London

On 16 May 2024, the Royal Society, in partnership with His Majesty's Government and Dame Sally Davies FRS, UK Special Envoy on AMR, hosted an event titled '[The world together solving the antibiotic emergency](#).' The event featured speakers from over 30 countries, including the Prince of Wales and the UK Chancellor of the Exchequer. Ministerial representation from the UK, Bangladesh, Saudi Arabia, and Italy, highlighting the progress that has been made to National Action Plans (NAPs)

so far. The WHO Task Force of AMR Survivors had a 20-minute session, during which three members (Felix Liauw, Mashood Lawal and Nour Shamas) narrated their experiences as survivors and explained their advocacy activities. Later, the members had a private audience with the Prince of Wales, and the HRH congratulated the survivors on the resilience shown by them. He also encouraged the members to stimulate others and highlight various dimensions of AMR to members of the public



During the meeting, the Prince of Wales highlighted the necessary link between AMR and climate change, noting that *"climate change is a system problem, just like AMR"*. Dame Sally encouraged delegates to keep stepping up to make bold commitments, requesting people to *"step up, overcome those barriers, keep going... don't let the bugs win!"* Key commitments announced during the event included the UK Government pledging up to £85 million to combat AMR, including up to £10 million to help establish a global independent scientific panel for AMR, with Saudi Arabia offering to match this pledge.

Task Force and patient engagement highlighted in the WHO webinar series on National Action Plan implementation

Several Task Force members were part of a webinar series organized by WHO on implementation of NAPs on AMR. The webinar was held on 27 June 2024, and it highlighted the work of the Task Force and meaningful patient engagement.

The webinar began with an introduction video for the 'AMR is invisible. I am not' campaign. Following that, Felix Liauw, Bhakti Chavan and John Kariuki, all members of the WHO Taskforce of AMR Survivors shared their personal stories and their advocacy efforts in their countries. Vanessa Carter introduced the strategic guidance note on 'meaningful engagement of patients, survivors, and carers in addressing AMR.' National AMR Focal Points from Brazil (André Luiz de Abreu) and Indonesia (Ibu Yanti Herman) discussed engaging patient advocates for awareness-raising and advocacy. Both countries are committed to co-opting survivors and patient advocacy groups in NAP implementation. Diriba Mosissa, Technical Officer, WHO AMR Division, presented the ['AMR is invisible. I am not' campaign](#) based on survivors' stories. The event concluded with a Q&A session and reflections. Rob Purdie, member of the Taskforce, provided a summary and closing remarks. The event was moderated by Philip Mathew, Technical Officer, WHO AMR Division. Most of the participants were from National AMR Coordination Committees, so the webinar was an opportunity to demonstrate the impact of survivor engagement and encourage them to replicate efforts at the national level.

Task Force represented at high-level meetings in New York and Geneva



Vanessa Carter, Chair of the WHO Task Force of AMR Survivors, represented survivors and patient advocates at the opening session of the [Multistakeholder hearing on AMR, organized by the Office of the President of UN General Assembly](#) on 15 May 2024, at the UN Headquarters in New York. Other speakers at the opening session were H.E. Dennis Francis, President of the General Assembly, Ms. Amina J. Mohammed,

Deputy Secretary-General of the United Nations and Dr. Tedros Adhanom Ghebreyesus, Director-General, World Health Organization. Vanessa's opening address was praised by all, since it brought out the human side of the problem and influenced the proceedings of the day.

In addition to narrating her experience with AMR and the work of the Task Force, Vanessa called on everyone to listen to the underheard voices of patients, carers, survivors and the public. *"While I stand here as a patient survivor, lucky enough to be alive and share my story, I think of my fellow patients and people who have suffered and perhaps are unaware of why. In our pursuit to combat AMR, it is paramount that we listen to the voices that often go unheard – those who have lost a loved one to an untreatable infection, those who are left in the aftermath of its destructive path. I am only one voice, together we are many voices, but on the greater scale of things, the outcome must reflect the complexity of AMR and the diversity of its impact on global populations",* she said.

Vanessa Carter was also a speaker at the [strategic roundtable on antimicrobial resistance \(AMR\)](#)

organized by the Director General of WHO during the 77th World Health Assembly. This high-level event convened Member State delegations, including Ministers of Health, to deliberate on specific priorities

outlined in the World Health Organization's strategic and operational plans for addressing drug-resistant bacterial infections. Among the distinguished speakers were H.E. Mia Amor Mottley (Prime Minister of Barbados and Chair of the Global Leaders Group on AMR), Dr. Tedros Adhanom Ghebreyesus (WHO Director-General), Professor Dame Sally Davies (Special Envoy on AMR for the United Kingdom and Global Leaders Group on AMR member), and H.E. Dr. Jean Kaseya (Director-General of Africa CDC). Their collective insights and dialogue aimed to accelerate the global response to AMR, emphasizing the critical importance of coordinated efforts in safeguarding human health. Vanessa presented her story and highlighted the work of the Task Force, including the recently published guidance note on meaningful patient engagement.



Members of the Task Force publish a comment in The Lancet on engaging survivors

Comment

Antimicrobial resistance survivors: calling the world to action

Antimicrobial resistance (AMR) remains a global threat. Researchers and advocates have attempted to prompt changes to social and health policies and augment research and funding of AMR mitigation efforts, but progress is slow. Evidence from this 2024 Lancet Series¹ will be important to inform this discussion. The Series highlights once again the increasing burden of AMR (particularly in low-income and middle-income countries), the crucial role of vaccination programmes, access to water, sanitation, and hygiene, and infection control and prevention; and the need to develop antimicrobials for priority pathogens and other pathogens (eg, neglected infectious diseases), depending on the needs of affected populations. The Series underscores the impact of AMR on vulnerable populations, including neonates, older people, and people with chronic illness, but everyone is at risk of AMR due to the spread of resistant organisms in the environment. Beyond the statistics of AMR, a crucial aspect often hidden from the public is the individual stories and voice of AMR survivors and their caregivers (caregivers). We want the world to not only think of us as numbers affected by AMR but also to see us as daughters, sisters, brothers, and sons and hear our plea for change, as we shared in our recently launched campaign² and our recommendations for meaningful patient engagement in the AMR agenda.³

The challenges facing this pandemic are numerous and long standing, including insufficient funding, research, motivation, and knowledge. AMR is not one disease and can be caused by different infectious organisms, which makes labelling AMR difficult and challenges accurate data collection. For example, deaths due to antimicrobial resistant pneumonia acquired during hospitalisation for a car accident can be labelled as trauma related although the main cause is the resistant pneumonia (Shams, unpublished). Patients might not even realise they have a resistant infection as medical literacy surrounding the subject is poor. In some settings, the scarcity of data collection leads AMR rates to appear low and consequently research and intervention funding is not prioritised.⁴ At a larger scale, the cross-cutting nature of AMR and its solutions makes mitigation interventions

challenging. Several ministries and governmental entities would be required to communicate and collaborate effectively and eventually secure funds for intervention implementation. To further highlight the complex nature of AMR, the definition of antimicrobial stewardship from a One Health perspective is still being constructed.⁵ These challenges, among others, make prioritising AMR difficult.

As survivors, we have suffered first-hand the medical, social, financial, and psychological burden of AMR. How can AMR survivors change national and global AMR strategies to focus on the patient experience and garner enough support to improve diagnostics, infection prevention and control, health systems, and access to good quality and effective medicine to prevent and treat drug-resistant infections? Unlike HIV and tuberculosis,^{6,7} patient engagement in AMR has been generally low. To address this glaring gap in

Panel: Personal accounts of the 12 AMR survivors

We represent a young university student in India who developed extremely drug-resistant tuberculosis and who had to search for treatment and struggle through 2 years of therapy; the case of a 65-year-old Lebanese woman who developed a multidrug-resistant (MDR) *Escherichia coli* urinary tract infection (UTI) after surgery and continues to have recurrent infection in a setting where health systems are collapsing due to economic crisis and UTIs and AMR continue to disproportionately affect women;⁸ a young woman with cystic fibrosis from Virginia, USA, with chronic MDR *Pseudomonas aeruginosa* whose case of antibiotic resistance in the UK with chronic genetic condition affecting her lungs, leading to multiple MDR *Pseudomonas* lung infections and resulting in many hospitalisations and a near death experience; and a young student who was born with HIV in Zimbabwe who was diagnosed late and who developed drug-resistant HIV infection. We also represent the multiple faces of delayed diagnosis—eg, due to scarce resources leading to multiple hospital admissions; a hospital-acquired MDR infection in a Kenyan university; a Nigerian hospital pharmacy director who was hospitalised for kidney stones and developed both COVID-19 and an MDR and UTI while hospitalised; and a young father whose son died of an infection that was resistant to multiple antibiotics and needed the medical diagnosis that might have changed the course. We represent an unexpected and severe health-care resistant *Staphylococcus aureus* infection in a young award-winning gymnast from North Carolina, USA, whose diagnosis was delayed despite her subsequent athletic injuries, a student health clinic, and a local emergency department; and a South African who overcame a similar health-care-resistant *S aureus* bone infection that caused substantial damage to her face due to poor care coordination, poor communication, and delayed diagnosis; and as drug resistance spans beyond oral and bacterial infections, we also represent all those afflicted with a difficult to treat fungal infection, such as a husband and father from California, USA, who developed candidaemia that was resistant to all drugs.

The members of the WHO Task Force of AMR Survivors published a [linked comment](#) in The Lancet as a part of the journal's [Antimicrobial Resistance Series](#) published in May 2024. The comment focused on the need for engaging patient advocates to amplify AMR messages; and suggests survivors as a medium to inform policymakers about the suffering caused by AMR. It also outlined the objectives of the Task Force and achievements so far.

The series emphasized that while AMR (antimicrobial resistance) can affect anyone at any stage of life, it has the most severe impact on the very young, the elderly, and those who are critically ill. Using innovative modeling data, the series demonstrated that improving vaccination,

The series emphasized that while AMR can affect anyone at any stage of life, it has the most severe impact on the very young, the elderly, and those who are critically ill. Using innovative modeling data, the series demonstrated that improving vaccination, water, and sanitation could not only prevent a substantial number of deaths caused by AMR in low- and middle-income countries but also reduce antibiotic use, thereby preserving their effectiveness.

Additionally, the series highlighted the need for a new approach to drug development to encourage investment in antibiotics, diagnostics, and vaccines based on infection and resistance burdens. Lastly, the series called for the establishment of targets to foster political commitment and expedite progress in tackling AMR.

Nour Shamas, member, WHO Task Force of AMR Survivors, was a speaker at the event in Geneva where the series was launched. Nour also coordinated the publication of the linked comment.

Members participating in strategic meetings/events

- **Rob Purdie** and **Vanessa Carter** attended the European Society of Clinical Microbiology and Infectious Diseases ([ESCMID](#)) global congress held in Barcelona during 27-30 April 2024 where they each participated in a side event to share their patient perspectives as well as more about the Task Force.
- **Rob Purdie** and **Vanessa Carter** shared their lived experiences of AMR at the Presidential Advisory Council on Combating Antibiotic Resistant Bacteria ([PACCARB](#)), USA on the 21st of May 2024.
- **Sue Charles** attended and spoke at a reception organized by the Fleming Initiative and Youtube Health at the UK House of Lords on 29 April 2024. The Fleming Initiative team have been working closely with YouTube Health to design and deliver a series of research projects investigating the impact of video content and aiming to create AMR related content that helps inspire behaviour change. The organizers included the 'AMR I invisible, I am not' campaign flyers as handouts during the event.
- **Vanessa Carter** was a panelist at the ReAct - Uppsala University event to highlight the role of Communities and CSOs in global AMR agenda and the launch of the Call for Global Action towards the 2024 UNGA HLM on AMR. The event was held online on 22nd April 2024
- **Ella Balasa** shared her patient story and **Vanessa Carter** participated in a panel discussion in a webinar titled "Amplifying patient voices for AMR", hosted jointly by the European Patients Forum and The AMR Narrative on the 20th of June 2024.
- **Ella Balasa** attended a conference co-hosted by bioMérieux and the Embassy of France in the United States on May 14 titled, "Rising to the Challenge: United Against Antimicrobial



Resistance.” The conference featured renowned speakers from various sectors, including government agencies, academia, and industry, who discussed the latest global policies and initiatives to tackle antimicrobial resistance (AMR)

- **John Kariuki** attended a panel discussion on AMR convened by East Central and Southern Africa Health Community, on 16th May held at Argyle Hotel, Nairobi Kenya.
- **Anthony Darcovich, Nour Shamas** and **Vanessa Carter** was in Geneva for the World Health Assembly 2024, and attended various side events on AMR
- **Sue Charles** and UK BioIndustry Association (BIA) organized a [webinar](#) to coincide with the launch of UK’s new 5-year plan to combat AMR and the roll out of the UK’s innovative Antimicrobial Products Subscription Model across NHS England. Sue provided an overview of the Task Force and a preview of the ‘AMR I invisible, I am not’ campaign. Speakers covered progress in push, pull and nudge initiatives, and agreed that by working together we can make a difference.
- **Mashood Lawal** participated at a one-day Commonwealth Partnership for AMS (CwPAMS) workshop on community antimicrobial stewardship for members of the Association of Community Pharmacists of Nigeria (ACPN), held at Ibadan, Oyo State, Nigeria on 30th May 2024.
- **Mashood Lawal** had a meeting with the Director General of the Nigeria Centre for Disease Control and Prevention (NCDC) on 4th June 2024 to seek an avenue to domesticate Task Force in the country.



Members featured in media

- **Vanessa Carter** featured in a [TV interview on an investigative journalism programme called Carte Blanche](#) in South Africa where she shared her struggles around AMR in the country during her journey to recovery.
- **Nour Shamas** was quoted in a news item, about the importance of water, sanitation, hygiene and vaccination in preventing AMR: [Handwashing, disinfection, and vaccines could prevent 750,000 annual superbug deaths | Health | EL PAÍS English \(elpais.com\)](#).
- **Bhakti Chavan** was quoted in a news item in the Indian Express, about AMR and the recently published Lancet Series: [Anti-microbial resistant bacteria kills 5 million people every year, says Lancet study: How to prevent this? | Health and Wellness News - The Indian Express](#)
- **Bhakti Chavan** was featured in a [podcast and YouTube live](#) interview titled AMR Dialogue Series, led by Citizen News Service (CNS) founder and managing editor Shobha Shukla. Shobha is also the chairperson of the [Global AMR Media Alliance \(GAMA\)](#).
- **Bhakti Chavan** was quoted in stories on AMR, published in [The Sangai Express](#) and [Good Morning Kashmir](#). She focused on the importance of timely and accurate diagnosis to stop misuse and overuse of antimicrobials, drawing on her experience as an XDR-TB survivor
- **Tori Kinamon** [narrated her experiences](#) as a sepsis survivor in a video compilation being put together by the Sepsis Alliance. “Faces of Sepsis” stories allow those affected by sepsis to share their experiences of illness, treatment, recovery, and loss.



Scan me



For more information on the Task Force:



<https://www.who.int/groups/task-force-of-amr-survivors>



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