



## Task Force organizes a webinar on “widening the engagement of patient advocacy groups and networks in AMR action” during World AMR Awareness Week (WAAW) 2024

The WHO Task Force of AMR Survivors organized a virtual Global Roundtable on 21 November 2024 – a significant step towards amplifying the voices of patient advocacy groups in this critical global health challenge.



The round-table began with an introduction by Rob Purdie, a member of the Task Force. Felix Liauw, also a Task Force member, then presented the crucial role of meaningful engagement with patients, survivors and caregivers in addressing AMR, emphasizing the importance of their unique perspectives and lived experiences. Brandon Jaka then described the "*AMR is invisible. I am not.*" campaign, a powerful initiative for raising awareness about AMR through the personal stories of the members of the Task Force.

The next segment consisted of a series of insightful “lightning talks” by representatives of leading patient advocacy organizations working on cancer, cystic fibrosis, HIV, tuberculosis and sepsis. The presentations described the diverse approaches and strategies being used globally to expand patient-led advocacy in specific diseases and programmes. Philip Mathew, Technical

Officer, WHO, provided an overview of the Organization's initiatives on AMR public engagement.

A highlight of the event was a panel discussion moderated by Vanessa Carter, Chair of the WHO Task Force of AMR Survivors, which explored strategies to broaden the engagement of patient groups and networks in AMR action and ways to humanize the narrative on the issue. The event concluded with remarks by Yukiko Nakatani, Assistant Director-General a.i. of the WHO AMR Division, who emphasized the critical importance of strengthening survivor engagement in AMR and outlined a vision for the way forward.

The recording of the webinar can be [accessed here](#). (passcode:1p\$!ql5n)

## Task force represented at the 4th Global High-level Ministerial Conference on AMR



The Fourth Global High-level Ministerial Conference on Antimicrobial Resistance (AMR) was convened in Jeddah, Saudi Arabia, on 15–16 November 2024, hosted by His Excellency the Minister of Health, Fahad Al-Jalajel. Nour Shamas, member of the WHO Task Force of AMR Survivors, was invited to the conference.

On 14 November, on non-state actor day, Nour Shamas moderated a panel discussion on the crucial roles of public–private partnerships, awareness-raising, a One Health approach and engagement of patient groups in addressing AMR.

A video shown on the first day of the ministerial conference was on the story of Nour Shamas's mother, which illustrated the profound impact of AMR on individuals and families worldwide. On the second day of the conference, Nour Shamas delivered a speech advocating for immediate collaborative action in addressing AMR, emphasizing the importance of strong partnerships with grassroots initiatives and civil society. During the conference, Nour Shamas was honoured by receiving the AMR One Health Emerging Leaders and Outstanding Talents Award.

The [Jeddah Commitments](#) endorsed at the ministerial conference underscored a collective commitment to listening to diverse voices, including patient advocates. This inclusive approach reflects innovation and collaborative action in mitigating the AMR crisis.

## Task Force represented at the WHO Fungal Priority Pathogens List Implementation Blueprint Meeting



WHO, with support from the US Centers for Disease Control and Prevention (CDC), convened a group of experts in Istanbul, Türkiye, on 3–5 October 2024 to develop a blueprint for accelerating action on the Fungal Priority Pathogen List (FPPL), released in 2022. The FPPL was the first document to address the growing global threat of fungal diseases, which are now complicated by AMR. The event was a crucial step in developing new tools to reduce the mortality and morbidity associated with fungal diseases and to prevent further spread of antifungal resistance.

Rob Purdie, member of the WHO Task Force of AMR Survivors and a survivor of Valley fever, was invited to participate in the meeting as a patient advocate. During the 3 days, he contributed to discussions on prioritizing patient needs with recognition of the disparities in resources between high- and low-middle-income countries. A blueprint for implementation based on the discussions during the meeting is now being reviewed and refined.

### Key events attended by the members of the Task Force during the last quarter of 2024

- **Anthony Darcovich and Ella Balasa** attended the [AMR Summit](#), hosted by Biomerieux and other partners in Tampa, Florida, USA.
- **Bhakti Chavan** narrated her story at a webinar organized by the Access to Medicines Foundation on [Mobilising pharma to act on the AMR Political Declaration](#)
- **Bhakti Chavan** was a panelist in a round-table discussion, “Patients and community engagement in addressing AMR” on 29 November, during the Global AMR Youth Summit 2024.
- **Brandon Jaka** spoke at a WHO meeting on Accelerating the development of affordable HIV drug resistance testing for use in LIMCs. He participated in a panel discussion on accelerated development of affordable testing for HIV drug resistance for use in low-middle-income countries.
- **Brandon Jaka** was a guest presenter at a webinar on HIV drug resistance organized by the WHO’s Division of Health Systems and Services on 18 November, where he shared his story and highlighted its importance in shaping AMR narratives. He made suggestions on use of stories and experiences in amplifying narratives on AMR.



- **Mashood Lawal** was a guest at the [launch of the NAP 2.0 of Nigeria](#). The event in Abuja brought together stakeholders from Government health and environmental sectors and international partners, including the WHO Country Office for Nigeria. The event was launched officially by the coordinating Minister of Health and Social Welfare, Muhammad Pate.



- **Mashood Lawal** was invited as a guest panelist at the University of Ibadan, Nigeria, Students One Health Club to tell his AMR survival story and to contribute to the discussion.
- **Mashood Lawal** attended the third annual engagement meeting between the Nigerian CDC and chief medical directors of the Orange Network in Abuja, where he described his AMR experience and emphasized the importance of an 'Antimicrobial Stewardship culture' in health institutions.
- **Mashood Lawal** attended the Fleming Fund Grantees Quarterly Coordination Meeting on 20 December in Abuja.
- **Nour Shamas** represented survivors' voices and spoke about the importance of patient engagement at the World Health Summit in Berlin, Germany, and at the World Innovation Summit for Health in Qatar.
- **Nour Shamas** also spoke at a webinar organized by AMR Policy Accelerator, entitled [When promises aren't enough: Improving access to antimicrobials amidst global crises](#).
- **Nour Shamas** further spoke at a webinar on AMR organized by the Lebanese Pharmacist Student Association during WAAW.
- **Rob Purdie** provided patient perspectives on public engagement strategies for fungal infections during an informational interview on fungal disease at the US CDC.
- **Rob Purdie** also attended a health care roundtable with US Congressmen Brett Guthrie, Vince Fong and David Valadao on 28 October, to discuss health-care issues and priorities in the state of California.
- **Rob Purdie** also provided a public comment on inclusion of infectious diseases in work on rare diseases at the [US Food and Drug Administration Rare Disease Innovation Hub](#).
- **Sue Charles** was on a panel on AMR at the [Safety For All Conference 2024](#) organized by the Safer Healthcare and Biosafety Network.
- **Vanessa Carter** was a member of the jury for the Henri Boulard Award instituted by the Biocodex Microbiota Foundation. The award recognizes local initiatives to protect microbiota and preserve global health.
- **Vanessa Carter** was also a jury member for the [1st Global AMR Media Awards](#). The awards by the Global AMR Media Alliance acknowledge and honour journalists and other media actors who have highlighted AMR and made outstanding contributions to raising awareness about AMR.
- **Vanessa Carter** also recorded a [podcast](#) for Pharmacist Diaries during the WAAW in which she described gaps in patient communication, the need for better education on infection prevention and the importance of tracking antibiotic use.
- **Vanessa Carter** also participated in and contributed to the WAAW campaign of Patients for Patient Safety Canada.

- **Vanessa Carter**, through her charity The AMR Narrative, published a [social media advocacy toolkit](#) on AMR. The toolkit provides useful guidance for smart use of social media to improve advocacy for AMR.
- **Vanessa Carter** further participated in a panel discussion on women's health and AMR at the World Health Innovation Summit. The theme of the summit was "The future of healthcare, from sick care to health, wellbeing and economic growth".

## Interviews, videos, op-eds and publications by task force members

- **Ella Balasa** and **Rob Purdie** were a part of an [AMR Survivors Fireside Chat](#) hosted by AMR solutions.
- **Ella Balasa** contributed to an article by the American Society for Microbiology entitled "[AMR Pandemic: Breaking the Silence](#)".
- **Ella Balasa** was interviewed by Citizen News Service for an article "[Medicines save lives but not when they stop working](#)".
- **Mashood Lawal** was interviewed by Premium Times Nigeria for an article "[When medicines fail: Many Nigerians battle antimicrobial resistance, AMR](#)".
- **Nour Shamas** was interviewed by Citizen News Service for an article, "[Hospital-acquired infections are fueling antimicrobial resistance](#)".
- **Nour Shamas** co-authored a [comment](#) in Nature entitled "Tackling antimicrobial resistance needs a tailored approach – four specialists weigh in", outlining her lived experience as a carer in conflict settings.
- **Rob Purdie** [co-authored a paper](#) entitled "Development of a novel patient-reported outcome measure for disseminated coccidioidomycosis (Valley fever)" published in the *Journal of Antimicrobial Chemotherapy*.
- **Rob Purdie** also [co-authored a paper](#) entitled "Advancing patient advocacy in mycology: cultivating collaboration in education, research, and policy" published in *Mycopathologia*.
- **Vanessa Carter** [recorded a video](#) for a WHO meeting on universal health coverage for oral health by 2030.
- **Vanessa Carter** also [took part in an interview](#) for the Chronic Pain Club Talkshow, hosted by Psoriatic Disease, a UK-based charity, outlining her journey from a survivor to a patient champion.
- **Vanessa Carter** was interviewed by Dr Raj Arora of the Fleming Initiative during WAAW. The interview can be [accessed here](#).
- **Vanessa Carter** was interviewed by the Aspergillosis Trust, United Kingdom, which can be [accessed here](#). The Aspergillosis Trust, which is a patient-led charity, raises awareness about chronic aspergillosis and other fungal infections.
- **Vanessa Carter** also developed and published an educational animated video about AMR through her charity, The AMR Narrative, which can be [accessed here](#).

