

Call for greater involvement of patient organisations to address antimicrobial resistance

Reaction to the Political Declaration of the UN General Assembly
High-level Meeting on Antimicrobial Resistance
26 September 2024

The [European Patients' Forum \(EPF\)](#) and [The AMR Narrative](#) welcome the emphasis on tackling antimicrobial resistance (AMR) through a comprehensive approach highlighted during the High-Level Meeting on AMR on 26 September 2024. It is essential that member states and international organisations make concrete commitments to address this growing threat to patients' safety and access to healthcare. However, more focus on patient participation and civil society engagement as well as concrete targets and measures are needed to translate principles into effective actions.

The heavy toll of antimicrobial resistance on patients: 8.22 million AMR-associated deaths per year by 2050¹

Patients are most vulnerable to AMR as they spend significant time in healthcare facilities and many routine care procedures require antibiotics. They are more susceptible to infections due to weakened immune systems and invasive procedures. In view of the rise in healthcare-associated infections and resistant bacteria, patients risk facing harder to treat infections and less effective treatment options. This results in longer hospital stays, more severe outcomes, increased mortality, and significant impacts on patients' mental health and trust in the healthcare system. As recognised in the Political Declaration, AMR “undermines the effective treatment of bacterial, viral, fungal and parasitic infections, including sexually transmitted infections, as well as routine medical procedures such as surgery, neonatal care, cancer treatment and control and organ transplants”.

AMR also reflects broader global disparities in access to healthcare, with many countries still falling short of achieving the U.N.'s sustainable development goal of equitable, universal health coverage and access to safe and affordable medical products for all.

Patient organisations are at the forefront of the fight against AMR

We welcome the Declaration's references to the need for participatory, inclusive and transparent approaches to health governance for AMR, including by enhancing a meaningful whole-of-society approach and social participation. We fully support the involvement of patients, AMR survivors and carers along with other stakeholders in the “design, implementation and review of national action plans on AMR, to systematically inform decisions that affect health so that policies,

¹ Global burden of bacterial antimicrobial resistance 1990–2021: a systematic analysis with forecasts to 2050
Naghavi, Mohsen et al. *The Lancet*, Volume 0, Issue 0

programmes and plans better respond to needs, while fostering trust in health systems”. However, beyond broad principles, clear mechanisms and resources are needed to make it happen in practice.

AMR affects patients across therapeutic areas and regions. Given the multiplicity of diseases and countries impacted by AMR, patient organisations are well placed to fill the gaps. They can mobilise their communities to draw attention to AMR and advocate for enhanced action. They can collaborate with relevant stakeholders including healthcare professionals to raise awareness and implement best practices in healthcare settings, from better infection prevention to promoting prudent use of antimicrobials. Most importantly, they play a key role in raising awareness of AMR, by developing and adapting public campaigns targeting patient communities and the wider public, sharing patient stories, and disseminating information. Patient organisations’ efforts to improve patients’ health literacy is essential to achieve antibiotic use reduction targets and improve prevention practices.

As we gear towards the 4th Ministerial Conference on AMR in November 2024 in Saudi Arabia, "From Declaration to Implementation: Accelerating Actions Through Multisectoral Partnerships for the Containment of AMR", we call on decision-makers to:

- Prioritise health literacy. Reliable, relevant and understandable information is not only a person’s right, but also contributes to empowerment and increased awareness of the risks of antibiotics’ misuse. This includes developing capacity-building programmes for patient organisations to enhance their knowledge of AMR and involve patient organisations as active partners and multipliers in public awareness campaigns.
- Establish concrete mechanisms and allocate resources to achieve meaningful and systematic involvement of civil society and patient organisations in AMR policy-making. We call on Member States to support the true implementation of a patient-centred approach to healthcare and health policy, which contributes to a better quality of care and a more effective response to patients’ needs.
- Funding and investment to support all countries in achieving AMR reduction targets, including community engagement and empowerment.

Signatories

The AMR Narrative and EPF are committed to support and raise awareness of the role of patients and patient organisations in the fight against AMR. Ahead of the UNGA High-level Meeting, we developed a series of webinars that aimed to create a space for diverse groups of patients to connect with others engaged in AMR advocacy. Ultimately, the objective is to empower them to

collaborate in shaping and sharing their own experiences and finding their voice in this crucial area of global health sustainability and security. The webinar recordings are available [here](#).

About EPF

The European Patients' Forum (EPF) is an independent non-profit, non-governmental umbrella organisation of patient organisations across Europe and across disease areas. Our 79 members include disease-specific patient groups, active at EU level and national coalitions of patients. To read about our vision, mission, and strategy, visit: www.eu-patient.eu

About The AMR Narrative

Founded by a patient advocate and AMR survivor in 2022, The AMR Narrative is a UK-registered CIO (Charitable Incorporated Organisation) that is solely dedicated to promoting advocacy capacity development, education and awareness raising as well as community building for AMR globally. Visit: www.theAMRnarrative.org