

Antimicrobial Resistance Through Patients' Eyes: Stories and Insights

Policy Paper with Testimonials from patients and stakeholders on AMR issues

December 2024

In its latest report, the [European Centre for Disease Prevention and Control \(ECDC\)](#) notes that little progress has been made in recent years towards the [EU's antimicrobial consumption reduction targets](#). As 90% of total human consumption of antibiotics takes place in the community sector, there is a clear need to prioritise awareness-raising, health literacy, and community engagement. There is also a need, in line with some [initiatives](#) as part of this year's antimicrobial resistance week, to put a face on antimicrobial resistance. Empowering patients and patient organisations to tell their real-life stories of AMR makes the issue visible and highlights its urgency.

At EPF, the year 2024 has been filled with exchanges with patient advocates, patient organisations and stakeholders on AMR. In particular, we organised [three webinars](#) in collaboration with [The AMR Narrative](#) to discuss how to empower patients to engage in the AMR debate. We also convened [young patient advocates to hear their experiences of AMR](#), inform them about its impacts, and give them the tools to become active advocates in this field. The work undertaken has enabled us to better understand how AMR affects patients' lives and how the patient community can actively contribute to effective solutions to address this growing public health issue. This report outlines some of the key themes that emerged from the patient's perspective.

HOW DOES AMR AFFECT PATIENTS' LIVES?

Patients are particularly **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. The reality of AMR for specific patient communities is not always understood by the general public. Solid organ transplant recipients are at increased risk of infections due to their weakened immune systems caused by the use of immunosuppressive medications¹. Around 50% of cancer deaths are

"I am a renal patient from birth. Over the years, I had multiple major surgeries. I am preparing for a kidney transplant. Ironically, the post-surgery infections led to more hospitalisations and hard times than the kidney disease itself." Gavin Schranz, Malta, Patient and WHO Europe Youth4Health Network Member

"My experience of AMR was not caused by an accident or injury. It was caused by one of the many fungi that are constantly inhaled by people around the world, so all I did is take a breath." Rob Purdie, USA, Antifungal resistance survivor and Founder of MyCARE

¹ <https://www.efpia.eu/news-events/the-efpia-view/blog-articles/amr-and-its-impact-on-solid-organ-transplant-recipients/>

actually linked to infections². AMR also puts more people at risk for developing sepsis and threatens our ability to treat it³. People with cystic fibrosis are more susceptible to microbial infections, and antibiotics' continued effectiveness is crucial to safeguard the survival gains achieved over the previous decades for CF patients⁴.

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. The diminishing effectiveness of antibiotics over time on a patient creates anxiety on top of the stress already caused by treating the disease. Stories of AMR can also begin with ordinary illnesses or incidents and a one-time interaction with the healthcare system to receive care. AMR threatens all patients' access to safe care – not in a distant future, but right now.

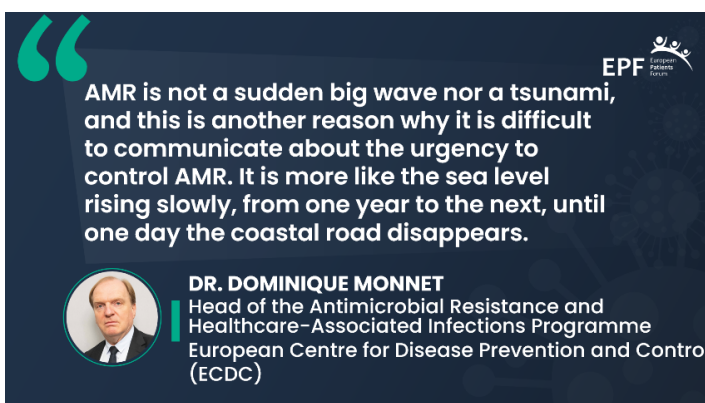
I was infected with streptococcus spigene bacteria, suffered multi-organ failure and developed sepsis, which led to septic shock and I remained in a coma for a month and a half, being resuscitated several times. I survived, but not without consequences: I had a double knee amputation. What saved me was that a cardiologist prescribed a broad-spectrum antibiotic at a very early stage. Antibiotics are really essential in the treatment of patients with sepsis, which is why AMR is a kind of sword of Damocles for us.” **Krista Bracke, Belgium, Journalist and Advocate, Global Sepsis Alliance**

“I had an accidental slip and fall, leading to a surgical procedure. I caught a resistant bacteria triggering a bloodstream infection which led to a five-month stay in hospital. The medical team found that only 1 out of 18 antimicrobials worked on me. My experience of AMR had a lasting impact and very debilitating consequences. For instance, I used to play football, now I can only watch. I can no longer meet socially as much as I did before.” **John Kariuki, Kenya, Bloodstream infection survivor, WHO Taskforce of AMR survivors**

WHAT ARE SOME OF THE SOLUTIONS FOR EFFECTIVELY ADDRESSING AMR?

RECOGNISING AND ADDRESSING COMMUNICATIONS CHALLENGES

AMR is a **complex issue** that must be explained in simple terms for the wider public. The term “antimicrobial resistance” itself is difficult to communicate; studies have showed that it is ineffective as regards both memorability and risk association⁵. Alternatives could include ‘antibiotic resistance’ and ‘drug-resistant infections’, but this shows the need for a comprehensive approach to AMR that also includes a strong communications and behavioral science component.



AMR is not a sudden big wave nor a tsunami, and this is another reason why it is difficult to communicate about the urgency to control AMR. It is more like the sea level rising slowly, from one year to the next, until one day the coastal road disappears.

DR. DOMINIQUE MONNET
Head of the Antimicrobial Resistance and Healthcare-Associated Infections Programme
European Centre for Disease Prevention and Control (ECDC)

² <https://cancerpatientseurope.org/cancer-and-amr-a-shared-crisis-that-calls-for-urgent-action/>

³ <https://www.sepsis.org/power-the-amrevolution/#:~:text=Sepsis%20can%20lead%20to%20tissue,at%20risk%20for%20developing%20sepsis.>

⁴ <https://www.ecfs.eu/sites/default/files/general-content-files/working-groups/AMR%20progress%20report%20March%202019.pdf>

⁵ <https://www.nature.com/articles/s43856-023-00379-6>

Other **communication challenges** related to AMR include the need to balance what can appear as conflicting messages, for example promoting stewardship and reducing consumption of antimicrobials, while ensuring that people take antibiotics as prescribed and finish their full course. Outcomes of the [EU Joint Action on Antimicrobial Resistance and Healthcare Associated Infections 2](#) also highlight the importance of basing communication on positive concepts, referring to individual empowerment and community for example, with terms such as ‘building’, ‘together’, ‘prevention is in the hands of each and every one of us’, etc. Warlike concepts such as ‘fight’, ‘struggle’, ‘defeat’ should be avoided. It is crucial to adapt communication campaigns to the target audience and take into account of local needs and diversity.

Communicating about the burden of AMR is also part of a broader strategy to raise awareness and inform about the issue. This is closely linked to data collection and the need to ensure that AMR figures account for all **AMR-related deaths**⁶.

“My daughter’s death was recorded on her death certificate as being due to cystic fibrosis, but what killed her was a superbug. Until people understand that you can die of AMR, they will not understand the seriousness of the situation.” Diane Shader Smith, USA, Communications Professional and AMR Advocate

IMPROVING PATIENTS’ AND THE PUBLIC’S HEALTH LITERACY

Further efforts are needed to inform patients of the **measures** they can take to **prevent and control AMR**. These include using antibiotics only when prescribed, understanding for what types of infections antibiotics are warranted, practising hand and general hygiene, vaccination, and rapid diagnostic tests to optimise treatment. Institutions and public health agencies have a key role to play in this area by disseminating evidence-based public health messages and countering misinformation. To be successful, these efforts must rely on extensive community engagement and leveraging civil society organisations’ reach and expertise. Patient organisations in particular are experts at developing and adapting public campaigns targeting patient communities and the wider public, sharing patient stories, and disseminating information.

“Four days after I gave birth, I learned that my two twins were sick. They were given antibiotics. Both ended up with sepsis and Kirsty died at eight days old. My two twins had been treated differently. Kirsty died because she got two different sort of antibiotics, while Freya survived because she got four different kinds of antibiotics with broad spectrum. I ended up with post-traumatic stress disorder, not allowed to go out because Freya was so sick. I decided to turn trauma into positive changes. I created my foundation and started to advocate for certain infection prevention and control measures in healthcare settings, such as single rooms in neonatal intensive care units (NICUs).” Pernilla Rönholm, Sweden, Patient survivor and Founder of Prematurföreningen Mirakel

The **patient-doctor relationship** is key: shared decision-making, listening, effective communication and empathy have all been shown to improve patients’ adherence to treatment and health literacy. Patients share their circumstances, concerns, and preferences; doctors share the possible treatment options with their benefits and harms.⁷ WHO Europe⁸ has developed several tools to support informed conversations between patients and healthcare professionals in the context of AMR, such as [the antibiotic-free prescription leaflet](#). When well-informed and empowered, patients can actively contribute to better antibiotic stewardship. Similarly, the role of patient organisations is key in this context, as they can partner with healthcare professionals’ organisations

⁶ [EPF The AMR Narrative webinar series on AMR patient advocacy](#)

⁷ <https://www.england.nhs.uk/personalisedcare/shared-decision-making/>

⁸ WHO Europe has also developed [Stories of AMR](#) to highlight that AMR is everyone’s responsibility.

to raise awareness and implement best practices in healthcare settings, from better infection prevention to promoting prudent use of antimicrobials.

A STRONG PATIENT VOICE ON AMR

Stronger patient organisation engagement in AMR is hindered by several factors. AMR is a cross-disease area but affects each disease area in a specific way. This has slowed the process of identifying key messages and common asks for the entire patient community. In addition, while many patient organisations are interested in AMR, they often lack the resources to engage and face conflicting priorities. While education and awareness materials are helpful, the lack of specific **capacity-building programmes on AMR** prevents patient organisations from taking ownership of the issue.

The [AMR Patient Group](#) was set up as an informal coalition to identify **common concerns and demands**. In addition, several organisations have developed tools and platforms to support patient engagement. The [World Health Organisation's Task Force of AMR Survivor](#) serves as a platform to elevate the voices of those with experience of complications from drug resistant infections and shape policy action. [The AMR Narrative](#) and [ReAct Europe](#) have also produced various materials, some of which are aimed specifically at patients.

As a patient community, it is essential that we engage in decisions that affect us and are part of AMR decision-making. Several decades ago, patient communities played a crucial role in creating **political momentum** and drawing attention to the AIDS epidemic and the burden of cancer. According to some estimates, the number of deaths due to AMR could catch up with cancer by 2050⁹. More than ever, now is the time for patient organisations to raise awareness, engage with policy-makers at national, European and international level, and empower patients to take action.

For more information about EPF's positions and recommendations on AMR, please visit our [AMR Info Point](#).

"AMR could threaten cancer treatments - for example, chemotherapy could become unviable due to AMR. AMR and cancer advocacies should not operate in silos, as this would limit their combined impact. I think that for AMR we need first to generate political will: position AMR as a health crisis, adopt a multi-stakeholder approach that would result in concrete action, such as raising awareness campaigns to prevent infections, incentives to research, and a wide EU strategy plan on AMR." Antonella Cardone, CEO, Cancer Patients Europe

"I literally left my hospital bed and became a patient advocate. I don't have a scientific background, I have a marketing background, but I had the passion to make a difference. I started very small with a blog. I then developed my networks on social media and at various medical events. Through persistent efforts over the years since 2013, my knowledge and confidence continued to expand. I later established a charity to help other patients raise their voices and was appointed Chair of the WHO Task Force of AMR Survivors. Patients who want to take action in AMR advocacy, shouldn't be afraid to 'start small' and with whatever they are comfortable with. No matter how small we think we are, our voices do matter." Vanessa Carter, AMR survivor and Executive Director of The AMR Narrative

"There are so many groups doing their own work on AMR and everyone seems to be going off on a tangent, which dilutes the effect of AMR advocacy. It would be great, if we pool our resources, come together and unite in a common effort to combat AMR." Mary Lynne Van Poelgeest-Pomfret, President of the World Federation of Incontinence and Pelvic Problems

⁹ <https://www.unep.org/resources/superbugs/environmental-action>

If you want to share your story of antimicrobial resistance, reach out to EPF at policy@eu-patient.eu

About EPF

The European Patients' Forum (EPF) is an umbrella organisation of patient organisations across Europe and across disease areas. Our 80 members include disease-specific patient groups active at the EU level and national coalitions of patients representing over 20 countries across Europe. www.eu-patient.eu



Co-funded by the
European Union

Funded by the European Union. Views and opinions expressed are however those of the author(s) only and do not necessarily reflect those of the European Union or HADEA. Neither the European Union nor the granting authority can be held responsible for them.