



## Antimicrobial resistance (AMR): developing patient stories

### Background

As part of the European Antibiotic Awareness Day, ECDC will launch a new series of patient stories to highlight the critical issue of antimicrobial resistance (AMR). The patient stories will be developed in collaboration with the European Patients' Forum (EPF) and Health First Europe (HFE), leveraging the three organisations' networks to identify patients with compelling stories. These narratives aim to personalize and deepen public understanding of AMR's impact on individual lives, their families and societies at large.

These patient stories are integral to our efforts to combat AMR by putting a human face on a global health challenge. Through vivid personal narratives and diverse media formats, we aim to provoke thought, and inspire change. This initiative not only educates but also empowers individuals to participate actively in the narrative and discussion on AMR.

### Objectives

The development of patient stories seeks to:

- Broaden public knowledge about AMR through real-life stories that illustrate its impact on individuals' lives their families and societies at large;
- Emphasise that everyone, from healthcare professionals to patients and policymakers, has a crucial role in ensuring the continued effectiveness of antimicrobials;
- Promote prudent use of antimicrobials by demonstrating, through patient narratives, the consequences of misuse of these medicines;
- Demystify AMR for general audiences by breaking down complex scientific concepts related to AMR into understandable, relatable content.

### Structure and format of the patient stories

Each story will follow a structured format to ensure consistency and impact:

- Introduction of the patient/former patient: background and initial health status.
- Infection description: details of the infection, with a focus on its resistance to standard antimicrobial treatments.
- Treatment journey: challenges and successes in the treatment process using, e.g. last-line antibiotics, and the impact of such infections on primary diseases, e.g. was a cancer treatment prolonged due to the infection?
- Outcome: Emphasising recovery and any long-term health implications.
- Aftermath: life after treatment of the infection, including any lasting effects and lifestyle changes.

## Key themes and patient selection criteria

The focus of the stories will be on a diverse array of patient experiences, including:

- Difficult-to-treat infections: highlighting the use of last-line antibiotics.
- Travel-related infections: showcasing infections acquired on other continents, but treated in Europe.
- Need for consecutive or combined use of several antimicrobials: exploring the complexities and challenges of treatments that involve multiple antimicrobials.
- Diversity of patients: including female and male patients, from oncology, intensive care unit (ICU), transplantation, and cystic fibrosis contexts, for whom effective antimicrobials are life-saving medicines.

## Formats

To maximise reach, these stories will be presented in various formats:

- Written narratives: in-depth articles detailing each patient's journey.
- Video testimonials or other audiovisual products upon availability: personal and engaging visual stories, in the patient's national language, and with subtitles in English.
- Social media cards: designed for easy use and sharing, these will highlight the patient story, as well as key messages and statistics on AMR.

## Timeline

The first set of five patient stories is scheduled for release in November 2024, to coincide with European Antibiotic Awareness Day. This timing is strategic to maximise the impact and reach of the narratives, aligning with broader public health messaging about AMR and prudent antimicrobial use.

## Media engagement and support

Media exposure helps transform AMR from an abstract, scientific issue into a personal issue that people can relate to. Patient stories provide a human face to the statistics, making the issue more tangible and urgent for the general public and other target groups in the countries where the patients come from.

The patients who share their stories should expect some level of media exposure, although this is not a 'must'. The ECDC press office will provide necessary support for media interactions, ensuring that patients are well-prepared and their stories are respectfully handled. The patients would need to inform us as soon as we start to develop the story about their preferences in this area.

These are the options:

- No media appearances: for maximum privacy, although the story and a photo will be published on the ECDC, EPF and HFE websites and social media channels.
- Single national media outlet: for focused and impactful storytelling, ECDC would pitch the story to one of the main national media outlets, including TV, print or online media.
- Open for extensive media coverage: for broad outreach and advocacy, including interviews for several outlets (national, other countries) if there is interest.

## Patient stories in practice

### Patient outreach (July to mid-September):

- Patient outreach and selection: the three organisations reach out to potential patients to explain the purpose and impact of their participation.

- Consent process: ensure that all participants provide informed consent, understanding how their stories will be used and shared.

**Production (mid-September to end of October):**

- Interviews: ECDC will conduct thorough interviews with the selected patients to gather detailed insights into their experiences. These can be done in English or in the patients' national languages upon availability.
- Story development: based on the interviews, produce the written narratives in a factual, engaging and empathetic way, with a focus on the human aspect while incorporating the scientific content about AMR.
- Photo provision and selection: the patient involved would need to provide at least one image to be used on websites and social media cards.
- Multimedia content creation: translate the written narratives into various formats, including videos and social media posts.

**Review (first week of November):**

- ECDC expert review: by experts in the Antimicrobial Resistance and Healthcare-associated Infections (ARHAI) Section.
- Patient review: all patients will be able to review their stories before publication to ensure accuracy and comfort with the shared content.
- Medical review: healthcare professionals, if possible those who followed the patient journey, will have time to comment on the story. If not the patients' doctors, then other experts will be consulted.
- Review by the ECDC National Focal Points (AMR, antimicrobial consumption, communication, and healthcare-associated infections) in the patient's country of origin.

**Launch and dissemination (18 November):**

- The release will take place during European Antibiotic Awareness Day, on 18 November 2024.
- Multiple channels for distribution will be used, including social media platforms, websites and press releases. Interviews with media will be planned ahead of this day, and media training for those who will engage with outlets will take place at the end of October 2024.

**Additional information**

In the past, ECDC has produced several patient stories in a written format. These are available on the European Antibiotic Awareness Day website:

- [Areti](#)
- [Mohammed](#)
- [Lill-Karin](#)
- [Paolo](#)