



THE **EPF** European Patients Forum  
PATIENT PERSPECTIVE  
NOVEMBER 2023

## EDITORIAL

Dear reader,

Every year, November 18 marks European Antibiotic Awareness Day (EAAD), an initiative coordinated by the **European Centre for Disease Prevention and Control** (ECDC) to promote the prudent use of antimicrobials. This day gives us the opportunity to understand why **Antimicrobial Resistance** (AMR) is such a problem and, more importantly, what patients can do about it.

First, what is AMR? AMR, defined by the ECDC as "*the ability of bacteria to combat the action of one or several antimicrobials*", is on the rise and is already responsible for over 35,000 deaths in the European Union (EU), Iceland and Norway – as many as influenza, tuberculosis and HIV/AIDS combined.

A future characterised by increasingly ineffective antibiotics would threaten the foundations of modern medicine, which is heavily dependent on antibiotics, and would put patient safety at great risk. This is especially the case for patients with chronic illnesses, who are particularly vulnerable to AMR because they spend more time in healthcare settings and because many routine healthcare procedures often require the use of antibiotics to prevent or treat infections.

In practice, AMR would make it difficult to safely perform organ transplants, cancer chemotherapy, intensive care or surgical procedures. Simple infections could become difficult or impossible to treat without effective antibiotics or other antimicrobials, causing long-lasting sickness or death. To avoid a world where antibiotics are increasingly ineffective, stewardship and prudent use of antimicrobials are the main means of tackling the issue in a comprehensive way.

This is where patients come in. Patients have a role to play, for example by taking antibiotics exactly as prescribed, avoiding self-medication and not taking antibiotics for infections caused by viruses, such as colds, flu, or COVID-19. Good health literacy and patient empowerment can contribute to the fight against AMR, along with increased focus on hand hygiene, proper disposal of medicines, and vaccination. This was confirmed by Vivian Leung, Antimicrobial Consumption Expert for the ECDC, who was the guest speaker of our **EAAD podcast**.

In addition, according to recent studies, vaccination could prevent hundreds of thousands of deaths at global level by protecting people against vaccine-preventable diseases that are increasingly affected by resistance. However, the link between vaccination and the fight against AMR is not always understood, and awareness of AMR itself could be improved.

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again the importance of public awareness campaigns in achieving the Council of the EU's objective of reducing antibiotic consumption in humans by 20% in 2030. In this respect, patient organisations play a crucial role in improving health literacy and act as multipliers in public awareness campaigns as well as participating in the development of policy solutions at all levels.

With its 79 members representing the interests of patients with chronic diseases, EPF is the voice of those who are directly threatened by AMR. EPF is a committed player in the field of AMR and is stepping up its efforts through awareness-raising, collaboration, and advocacy activities.

Together, we can make a difference!



EPF POLICY OFFICER  
YANN HEYER

Until next month!

The EPF team wishes you a great month of December.

In the meantime, make sure you follow us on social media:

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## POLICY CORNER

### November in review

Following the publication of the two European Parliament rapporteurs' draft reports on EU pharmaceutical legislation in October, we were pleased to see that many Members of the European Parliament (MEPs) highlighted the importance of a patient-centred regulatory system for medicines during a committee debate in November, in line with our [position](#). Amendments will be published in the coming days, which will kick-start the negotiation process between all political groups to agree on a final report. We will continue advocating for a revision that achieves more equitable access to medicines, increased patient safety and patient involvement.

Beyond the EU pharmaceutical legislation, other issues the policy team closely followed this month relate to pandemic preparedness, through the development of joint discussion papers as part of the Stakeholder Forum of the Health Emergency Preparedness and Response Authority (HERA), implementation of the medical devices regulation, and the European regulation on health technology assessment (HTA). On the latter, EPF participated in the HTA Stakeholder Network to bring the expertise of patient organisations to Member State HTA bodies on issues related to the management of conflicts of interest of patients involved in HTA and the identification of emerging health technologies.

On 14-15 November, EPF participated in the European Medicines Agency's (EMA) Patient and Consumer Working Party, where the Agency updated member organisations on a range of activities, including the development of an EU list of essential medicines and EMA's communication campaign on biosimilars (full agenda [here](#)). As part of our collaborative activities on antimicrobial resistance (AMR), we also joined the 'AMR Multi-stakeholder Partnership Platform', a new initiative led by the Food and Agriculture Organization of the United Nations (FAO), the UN Environment Programme (UNEP), the World Health Organization (WHO) and the World Organisation for Animal Health (WOAH), to encourage cooperation between stakeholders from different sectors in a 'One Health' approach to tackling AMR.

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Data Space (ENDS), although the legislative process has been delayed. We continued leveraging our [statement](#) on opt-out, which urges co-legislators to strengthen the rights of individuals to control their own health data. Following the publication of our position paper on [artificial intelligence \(AI\) in healthcare](#) last month, November also marked the start of preparatory work for the leadership event on AI scheduled for April 2024. We had the opportunity to discuss our recommendations on AI at a joint EMA-Heads of Medicines Agency workshop on "Smart regulation in a rapidly evolving world" on Nov 20-21, where we were pleased to convey the patients' voice on this important topic.

## SECRETARIAT NEWS



## MONTHLY ROUNDUP



Our agendas are usually very busy! We attend various policy and stakeholder events and appear in publications, always voicing the patient perspective.

### Here are some highlights from our work on patient engagement:



EPF's [Borislava Ananieva](#) presented the work of the Health First Europe AMR patient group at "Antimicrobial resistance targets: how can we reach them by 2030?", an event organised by the European Centre for Disease Prevention and Control (ECDC).

"It's crucial to raise awareness on the dangers of misuse of antibiotics and improve the AMR health literacy in chronic patients across Europe. The European AMR Patient Group is focusing on these issues and broadening the debate on antimicrobial resistance to include infection prevention and control measures."

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(STYPA) and Youth Group at the European Medicines Agency's Patient and Consumer Working Party.

This year's edition of **STYPA** focused on strengthening participant's knowledge on shortages and equipping young patients with the necessary knowledge to engage in advocacy on this matter.

As the advocate of patients in Europe, our goal is to highlight and strengthen the youth perspective from different patient communities. The aim of the EPF's Youth Group is to become the reference point for the young patient community, and to communicate the needs and expectations of young patients to EPF's members.



At the presentation of the report "Self-Care in Europe: Economic and Social Impact on Individuals and Society" published by AESGP, EPF's **Ingrid Weindorfer** noted the importance of investing in health literacy to foster self care.

"Health literacy can truly empower patients, both with long and short term conditions. Investing in this field is key to promote effective self care and reduce pressure on the healthcare system."

Producing real-world evidence and giving access to information to patients is paramount to raise awareness of self care, and its impact on health and society at large.



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EPISODE 8

PODCAST

EPF  
European Patients Forum

European Antibiotic Awareness Day

With special guest:  
**Vivian Leung**  
Antimicrobial Consumption  
Expert (ECDC)

ecdc  
EUROPEAN CENTRE FOR  
DISEASE PREVENTION  
AND CONTROL

## Listen to The EU Patients' Podcast with Antimicrobial Consumption Expert Vivian Leung (ECDC)

The 2023 theme of European Antibiotic Awareness Day, an initiative of the European Centre for Disease Prevention and Control (ECDC), was centred around the antimicrobial resistance targets and how we can reach them by 2030.

Similar to a year ago, EPF had a chat with ECDC's Antimicrobial Consumption Expert Vivian Leung in The EU Patients' Podcast. What goals are reached and what challenges remain? What does the road to 2030 look like?

[Tune in and learn more.](#)

EU NEWS

## UPDATES FROM THE EMA

### HMA, the European Commission, and EMA published the first electronic product information (ePI) for selected human medicines

On 10 November, the [Heads of Medicines Agencies \(HMA\)](#), the European Commission and EMA published for the first time [electronic product information \(ePI\) for selected human medicines](#) harmonised across the European Union (EU).

The [product information](#) of a medicine includes its [summary of product characteristics](#), [labelling](#) and [package leaflet](#). These documents accompany every medicine authorised in the EU and explain how they should be prescribed and used. Digital platforms open new possibilities to share this information electronically, keep it constantly updated and make it more accessible to end users such as healthcare professionals and patients.

The creation and testing of ePIs in real regulatory procedures is being explored through a one-year [pilot initiative by HMA, EMA and the European Commission](#) to enable the transition to the electronic system for medicines evaluated both nationally and at European level.

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with digital information that meets their needs. You can also read our [recommendations](#) on ePI in the context of the pharmaceutical legislation.

Read more [here](#).

## PROJECTS PORTAL



Data  
Saves  
Lives

### Data Saves Lives released its new toolkit on health data

The [Data Saves Lives](#) team is pleased to announce that the DSL Toolkit 2.0 is now available to download!

The toolkit aims to equip patient groups and health influencers with the information and materials they need to have a positive dialogue with their communities about health data and to potentially launch their own health data initiatives.

A copy of the toolkit can be downloaded [here](#).

We invite you to share it with your community!

**7 December 2023, 12:30 CET**

**SAVE THE DATE | WEBINAR:  
"IT'S TIME WE TALK ABOUT  
PATIENT ENGAGEMENT"**

This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 871096

**EATG** European  
AIDS Treatment  
Group

**EPF** European  
Patients  
Forum

**eatris**  
European infrastructure  
for translational medicine

**eulife**

**"IT'S TIME WE TALK ABOUT PATIENT ENGAGEMENT" - Will you join the webinar on 7 December?**

EATRIS, the European AIDS Treatment Group, EU-Life-Alliance, and EPF are organising a

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This webinar will serve as an introduction to researchers who are new to patient engagement and curious to learn more about good practices. While academic researchers are gradually involving patients and citizens in their research, meaningful patient engagement practices are challenging to develop in academia for various reasons such as lack of human and financial resources or limited awareness of the tools and services available to guide researchers in their patient engagement journey.

Register [here](#).



**If you are a...**



Citizen or Patient



Health professional



Policy-maker



Researcher

**Take our online survey!**



It will take 15 minutes of your life!

### We need your collaboration!

Please take part on the [survey](#) about the **challenges** to the adoption of **personalized prevention strategies**.

You can share this survey with your family, friends and colleagues.

Preventing disease based on our own information may lead to a **longer healthy life!**



## **Exciting opportunity: Partake in PROPHET's survey on personalised prevention strategies**

Participate in the online **PROPHET** survey that aims to map the barriers, challenges, and enablers for the adoption of personalised preventive approaches in health systems in Europe. "Personalised prevention strategies are only possible if citizens, health professionals, researchers, and policy makers are all aware of their potential and have the knowledge and resources to design and implement them."

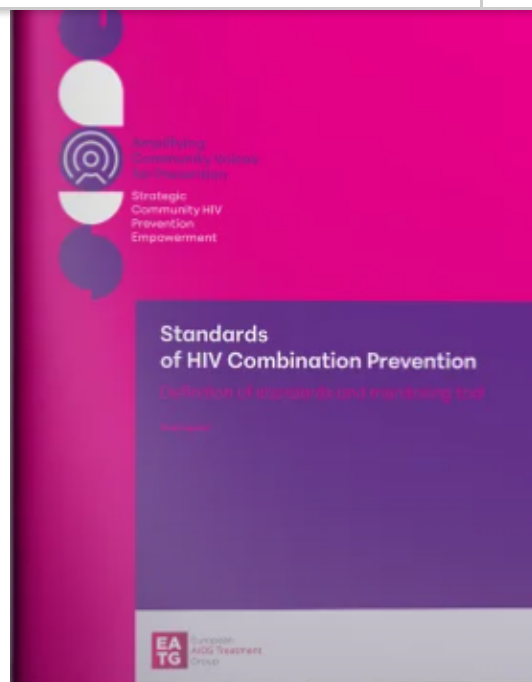
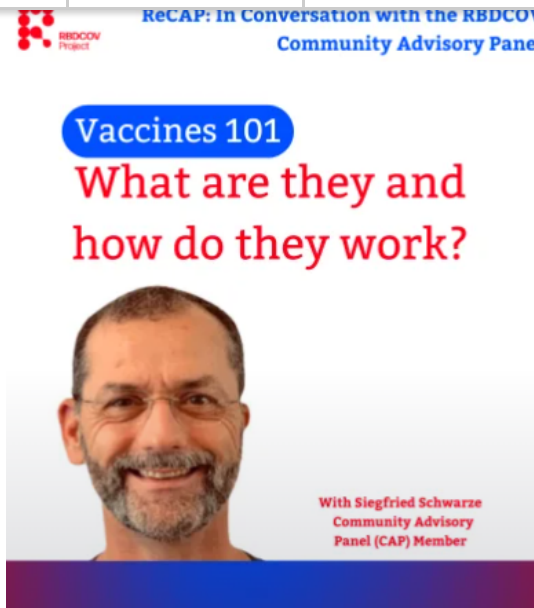
To complete the survey scan the QR code in the visual or partake [here](#).

# MEMBER FOCUS

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## Stigma-Free: video reporting from EACS 2023 'Empowering communities and clinicians for harm reduction and mental health' session

At EACS 2023 conference in Warsaw, EATG organised a special session on "Empowering communities and clinicians for harm reduction and mental health". After the session panelists were asked to tell us more about their work around stigma and mental health.

Read more [here!](#)

## WEBINAR | Stigma-Free: Mental Health within HIV Guidelines

On 9 November, EATG hosted the 'Mental Health within HIV care guidelines' webinar. It was a follow-up webinar to explore some of the issues involved in updating existing standards of mental health care for people living with HIV in Europe and Central Asia. Here is the recording of the webinar: <https://bit.ly/3QWbq7D>

## Why Belong? | Community Perspectives on why people living with HIV must be included in non-HIV clinical trials

In September 2022, EATG published a position paper titled 'Why people living with HIV must be included in non-HIV clinical trials'.

This paper seeks to clarify our stance in the debate advocating against the systematic exclusion of people living with HIV and for their increased participation in non-HIV clinical trials. Building upon the Position Paper, EATG has been implementing **Belong**, a project aimed at advocating for regulatory authorities in Europe to adopt clinical guidelines that include people living with HIV in trials relating to other health conditions that affect people living with HIV.

We sat down with Brian West & Alessandra Cerioli, EATG members and members of the Belong Community Advisory Group, to understand the vision behind the Belong project and explore from a community perspective why people living with HIV must be included in non-HIV clinical trials. Take a look at the video here: <https://bit.ly/3SSbyaz>

## RECAP with the RBDCOV Community Advisory Panel | Vaccines 101

This month we published the *Vaccines 101* series of blogs by EATG member Siegfried Schwarze. With these blogs we aim to clarify fundamental information about vaccines and



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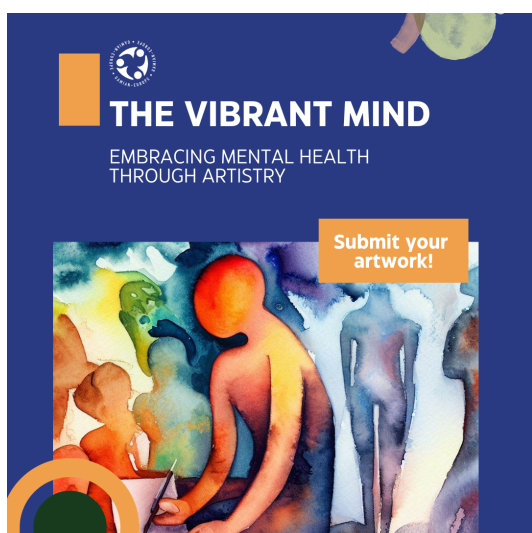
- [What are they and how do they work?](#)
- [Debunking myths and understanding vaccine hesitancy](#)
- [The importance of including people living with immunocompromising conditions](#)

### **SCOPE: Standards of HIV Combination Prevention – Definition of Standards and Monitoring Tool**

EATG is publishing a report on community defined standards for HIV combination prevention and a tool to help expand and strengthen the delivery of effective services for populations most affected by HIV. [Read more here!](#)

### **TGEU: Trans Day of Remembrance 2023 Joint Statement | We Mourn and Call to End the Violence**

On Trans Day of Remembrance 2023, EATG endorsed the [Joint Statement: We Mourn and Call to End the Violence](#) coordinated by Transgender Europe (TGEU).



### **Join GAMIAN-Europe's digital workshop on "Digital peer support: interventions and innovations" and be part of "The Vibrant Mind"!**

- Save the date: 13 December 2023 | 14:00 – 15:45 (CET)! As part of the GAMIAN-Europe [Peer Support Project](#), we are hosting a series of workshops exploring different aspects of peer support as well as sharing best practices. Don't miss the last workshop, focusing on the digital peer support and the innovative effect of these interventions. Register [here](#) to join the conversation.

- Last chance to be part of **"The 'Vibrant Mind'"!** GAMIAN-Europe promotes mental health through creativity and art by hosting an art competition. Mental health patients across Europe are invited to submit their artwork by the 10<sup>th</sup> of December 2023 and seize the opportunity to see their art featured in galleries across Europe. Submit your artwork [here](#).

## Paving the way: a roadmap to the successful implementation of shared decision-making in heart valve disease

[Read now](#)

#HeartSDM



The Health Policy Partnership



### Global Heart Hub publishes roadmap - read it here

Global Heart Hub, the international alliance of heart patient organisations, has published an implementation roadmap, **Paving the way: a roadmap to the successful implementation of shared decision-making in heart valve disease**, created in collaboration with 19 international, multidisciplinary experts, including heart valve disease patients and advocates, along with cardiac surgeons, cardiologists, researchers and nurses.

"This global roadmap is designed to support patient organisations and advocates who wish to implement shared decision-making for people facing heart valve disease treatment options. Furthermore, it is designed to be applicable across different countries and health systems, but its practical applications may vary depending on local context."

Read more [here](#).



## Updates from **Europa Donna**

"On 28 and 29 October some 200 breast cancer advocates gathered from all around Europe for Europa Donna's 16th Pan-European Conference in the charming and vibrant city of Zagreb to network, share ideas, gain inspiration, and acquire the knowledge necessary to break barriers and improve services in their countries. A very powerful conference session was dedicated to Europa Donna's Cancer Currency Campaign ([www.thecancercurrency.com](http://www.thecancercurrency.com)) to draw attention to the unmet needs of women with metastatic breast cancer. The protagonists of the campaign personally presented the Commissioner of Health and Food Safety, Stella Kyriakides, with their own banknotes tailor-made for the campaign to tell their stories and to represent the value of their lives. Each presentation ended with a specific policy ask to European institutions: see me, count me, treat me, support me, act now! The Commissioner—who was clearly moved by these women's stories—replied to these calls for change with a surprise announcement: specific funds for metastatic cancer has now been included in Europe's Beating Cancer Plan. Europa Donna applauds this great leap forward in public policy at the European level.

The weekend of 17-19 November, Europa Donna held its Advocacy Training Course, hosting more than 60 advocates and experts from over 30 countries for a super energetic and engaging weekend in Milan! We are incredibly grateful for all the valuable time the experts and speakers dedicated to us and for their unwavering support to ED! As we gathered, experts and patient representatives both emphasized why it is important to work together to advocate effectively. We covered all scientific aspects of breast cancer from epidemiology to biology to pathology, screening surgery and treatment options, the importance of being involved in research and clinical trials, and how to use ECIBC guidelines to advocate for positive change in your country. As every year, we are happy to welcome new advocates into the Europa Donna family! □□□"

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## Fertility Europe: Minds Matter. Empowering Infertility Patients with Psychological Support

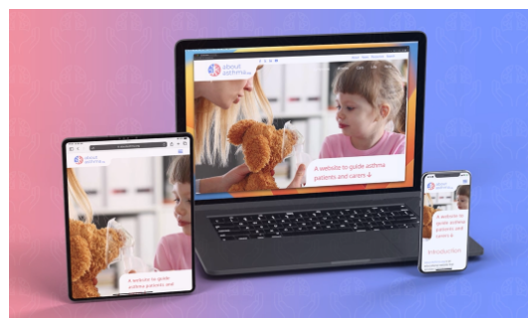
European Fertility Week 2023 event in the European Parliament, Brussels

"On November 7, 2023, as part of our annual European Fertility Week, we held an event in the European Parliament hosted by MEP Eleni Stavrou (EPP, Cyprus) and MEP Estrella Dura Ferrandis (S&D, Spain).

We took the opportunity to present the psychological burden as one of the implications of infertility. Prolonged yet unsuccessful attempts to conceive or even undergoing long-awaited and much-desired fertility treatment are closely associated with emotional distress, anxiety or depression. Infertility affects more than 25 million EU citizens alone. Every sixth person of reproductive age experiences the condition. We all know someone who struggles with it but we may not know the real weight of infertility burden. It is therefore crucial to see infertility as a comorbidity to mental health issues and acknowledge the need for psychological support services across Europe for all individuals facing infertility and struggling with emotional burdens and distress. Thanks to our honourable hosts and amazing speakers we managed to achieve exactly that.

During this well-attended event, we aimed to push the process of easing the emotional burden of infertility and encourage much-needed conversations about all aspects of psychological support throughout the infertility journey, notably the importance of post-treatment support and destigmatising infertility.

Find out more about the event [here](#)."



## Updates from EFA: New website and webinar - About Asthma care and knowledge sharing

"Watch the replay of our webinar and learn more about how information on asthma care can become more accessible. We presented a new educational resource:



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Patient and carers' knowledge about asthma management is key to improving treatment efficacy and patients' quality of life. However, healthcare professionals do not always have the needed time and communication training to fully involve patients in this educational effort.

How to facilitate communication and help patients be at the steering wheel of their health? What are the key factors to make patients and doctors develop a true partnership?

These key questions were discussed in the webinar 'Sharing is caring: exchanging knowledge on asthma care', where EFA and GAAPP launched a new educational web source for patients and carers - [AboutAsthma.org](#). Patient advocates and healthcare professionals came together to exchange on health literacy and asthma management in different countries. Read the main takeaways from the webinar on [EFA's website](#).

[AboutAsthma.org](#) is addressed to asthma patients and carers with lay content to help better understand the disease across five areas (symptoms, attacks, care, life with asthma, and help) as well as improve disease management and ultimately patients' quality of life. A dynamic glossary is available and [a web form](#) to collect questions and suggestions from the users. The content will be soon published in other languages. Bookmark [AboutAsthma.org](#) and check it regularly!"

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