



THE **EPF** European Patients Forum
PATIENT PERSPECTIVE
SEPTEMBER 2024

EDITORIAL

Building a Healthier Future: Insights from the European Health Forum Gastein

As September wraps up, we get first-hand news and rich insights gained from the **European Health Forum Gastein**. This year, the European Patients' Forum (EPF) was represented by Anca Toma, Executive Director, and Julie Spony, Policy Officer, while Milana Trucl, Policy Officer, contributed to the *Special Eurohealth Gastein Issue*, with [an article on EHDS](#).

At the heart of these discussions, Anca Toma engaged in several panels on safeguarding civil society participation in EU health policymaking, renewing Europe's social contract, and ensuring access to essential medicines. Simultaneously, Julie Spony brought fresh perspectives through her participation in the Young Forum Gastein programme.

In Anca Toma's words during the session on renewing the social contract, *"Europe should prioritise not only economic competitiveness but also social competitiveness. Our historically well-performing social systems are under threat, and their sustainability can only be ensured if a broader range of voices are heard. Patient organisations play a crucial part in this, particularly in education, fostering democratic engagement, and improving health literacy."*

From a patient organisation perspective, active civil society participation is indispensable for democratic policy-making. It urges a collaborative effort: governments must engage and sustain a vibrant civic space, while civil society organisations work to uphold transparency, accountability, and sound governance.

SECRETARIAT NEWS

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Keynote speaker:

**Stella
Kyriakides**

High-Level Policy Event

16 October

Renaissance Hotel, Brussels



Policy Event

We are excited to announce that Stella Kyriakides, European Commissioner for Health and Food Safety, will join us on 16 October for our High-Level Policy Event. [Learn more about the event and read the agenda.](#)



CALL FOR GREATER INVOLVEMENT OF PATIENT ORGANISATIONS TO ADDRESS AMR

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

EPF and The AMR Narrative welcome the emphasis on tackling Antimicrobial Resistance through a comprehensive approach highlighted during the High-Level Meeting on AMR on 26th September 2024 and call for stronger patient and civil society participation in national AMR policies. [Read the joint statement.](#)



EU4HEALTH CIVIL SOCIETY ALLIANCE CONCERNED ABOUT THE ROLE OF HEALTH IN THE NEXT COMMISSION MANDATE

Open Letter to European Commission President Ursula von der Leyen

On 25th September 2024, the [EU4Health Civil Society Alliance](#), of which EPF is part of, sent a letter to European Commission President Ursula von der Leyen calling for a meeting to discuss health in the next Commission mandate. [Read the letter here.](#)



REFLECTIONS ON WORLD PATIENT SAFETY DAY

World Patient Safety Day 2024

Like every year, EPF joined the World Health Organization in observing World Patient Safety Day. Patients are not only users of healthcare services: they have valuable

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EMPOWERING PATIENTS IN HTA

Joint Initiative by OPEN Health, EPF, and EAMDA to Optimise PICO Scoping

EPF joins forces with Open Health and EAMDA for an initiative dedicated to improving PICO scoping and to ensure it encompasses the diverse perspectives and needs of patients. [Read more.](#)



NEW EPISODE THE HTA REGULATION

The EU Patients' Podcast | New Episode

On the latest episode of the EU Patients' Podcast, we are taking a closer look at the upcoming Health Technology Assessment (HTA) Regulation, set to roll out early next year. [Listen to the full episode.](#)

PROJECTS PORTAL



Driving Innovation in Cancer Research: A Postdoctoral Journey with IMMUCan

Dr Jane Merlevede is currently a postdoctoral researcher at Institut Curie in Paris, contributing to the IMMUCan project's efforts to decipher immune mechanisms across various cancers, with the goal of improving patient outcomes.

A unique aspect of IMMUCan is its integration of diverse data types, including tumour DNA, imaging, and clinical data. This multi-modal approach is vital for developing precision medicine strategies that can more accurately predict patient outcomes and inform treatment decisions. [Read more about the work of the project.](#)

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Bridging the Gap: The New Pan-European Observatory as a Catalyst for the European Health Data Space

On 26th September 2024, on the sidelines of its annual General Assembly, **H2O** hosted a hybrid event in Vienna and online, bringing together Health Technology Assessment (HTA) agencies, researchers, industry representatives and patients from across Europe.

The gathering explored how the recently launched H2O Pan-European Observatory can play a pivotal role in aligning digitally captured patient outcomes with the European Health Data Space (EHDS) legislation.



Join the PROPHET Stakeholder Session and contribute to advancing personalised prevention!

PROPHET aims to develop a European **Strategic Research and Innovation Agenda (SRIA)** for the implementation of personalised prevention approaches focused on stakeholder engagement.

On 1st October 2024 from 13:30 to 17:30, join the PROPHET Stakeholder Session in Stockholm and contribute with your expertise to building the SRIA!

The workshop will include group discussions, presentations, and focus groups, to gather inputs from you on the **SRIA**. The participants will automatically be registered in the **PROPHET Stakeholder Forum**, an ad-hoc platform created for the project's members to easily share information.

MEMBER FOCUS

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Fertility Europe launches the platform Coalition for Fertility

Infertility and involuntary childlessness are significant challenges in Europe, affecting one in six couples. These issues extend beyond personal struggles - they impact the future of our societies and test our collective commitment to fairness and equality.

To address these challenges, **Fertility Europe** is launching the Coalition for Fertility, a partnership of 12 organisations (including EPF) from across Europe and beyond. This coalition unites those affected by involuntary childlessness, medical professionals, and advocates for women's rights, mental health, and reproductive rights.

Visit the [Fertility Europe website](#) and learn more about our initiative.

Don't miss out: participate in the event "Advocating for Comprehensive and Inclusive Fertility Policies in Europe"

Fertility Europe invites you to their inaugural event, "Advocating for Comprehensive and Inclusive Fertility Policies in Europe" taking place on 15 October 2024 at 4:00 PM CET at the Renaissance Hotel (Rue du Parnasse 19, 1050 Brussels, Belgium).

To register, please fill out [this form](#) or email anita.fincham@fertilityeurope.eu



European
AIDS Treatment
Group

[EATG](#) | News from the European AIDS Treatment Group

Reporting from Living 2024 Community Workshop 'Why people living with HIV must be included in non-HIV clinical trials'

On July 20, 2024, as part of the [Living 2024](#) conference and ahead of the [International AIDS Society's AIDS 2024](#) conference in Munich, Germany, the European AIDS

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members and Deloitte Community Advisory Group (CAG) representatives **Dhan West, Alain Volny-Anne, Memory Sachikonye,** and **Luís Mendão** shared community perspectives on the current exclusion criteria for people living with HIV in clinical research and discussed the implications of these practices. [Read more here.](#)

The Global Tuberculosis Community Advisory Board launches its new website

The Global Tuberculosis Community Advisory Board (TB CAB) [announced the launch](#) of its new website, www.globaltbcab.org. EATG has been supporting the TB news service delivered by TB Online since 2012, thus contributing to increasing TB literacy and community involvement in the global tuberculosis response. [Visit the website here.](#)

Upcoming events

Ending HIV in Europe - Can the EU lead the global path forward to 2030?

Nicoletta Policek, EATG's Executive Director, will join the debate at the event "[Ending HIV in Europe - Can the EU lead the global path forward to 2030?](#)", hosted by EURACTIV.

CORE Workshop #8 | Chemsex: From issues to interventions

On 30 September, CORE will host a workshop on the global phenomenon of chemsex. What is it and how does it differ across different contexts? Does everyone experience issues and what are the most common? How can interventions be categorised and offered to chemsex participants? [Follow this link to register.](#)

Endorsement

EU Manifesto for Women's Health 2024

EATG endorses the EU Manifesto for Women's Health 2024 by the European Institute of Women's Health.

[Read more here.](#)

EATG signs an open letter launched by Civil Society Europe

EATG and more than 400 CSOs co-sign the open letter 'Ensuring a vibrant civic space in the European Union – civil society's expectations for the next five years' initiated by [Civil Society Europe](#).

[Read the full letter here.](#)

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