



THE EPF
European Patients Forum

PATIENT PERSPECTIVE

SEPTEMBER 2023

EDITORIAL

Dear reader,

Every year, 17 September marks World Patient Safety Day (WPSD). This is an important day – and month – to remember that while safe and high-quality care is a fundamental patient right, much progress is still needed to ensure reality meets expectations. This was confirmed by Nick Klazinga, one of the authors of an OECD Health Working Paper on “Patient Engagement for Patient Safety” launched on 17 September, who was the guest speaker of our WPSD **podcast**. According to the surveys the OECD team conducted, between 4 and 17% of patients reported safety incidents, depending on the country. These figures also hide important disparities, with different levels of patient information and awareness and levels of reporting.

So how do we do better? How do we ensure that patients not only *are* but also *feel* safe when using healthcare services? The World Health Organization’s theme for WPSD this year was “Engaging patients for patient safety”, with “Elevate the Patient Voice” as the slogan. This reflects the crucial role that patients, families, and carers play and the vital need to involve them at all levels to improve safety. Patients are experts through lived experience and their involvement can prevent harm, signal potential risks for themselves or others, and lead to meaningful improvements for the future. Research has shown that patient engagement creates a virtuous cycle, where improved patient safety and trust lead to more empowerment, which continuously enhances safety and trust.

The broad recognition across international institutions, highlighted by this year’s WPSD, of the value of patient engagement for safer healthcare systems is a long-standing strategic priority for EPF. Some of our work on patient safety in recent years ranges from developing a proposal on Key Competencies for Patients, Families and Carers in Patient Safety to participating in the OECD’s Patient-Reported Indicator Surveys (PaRIS) initiative, which aims to assess primary care quality and outcomes from the patients’ perspective. Patient safety is also at the core of our engagement across policy dossiers. The EU pharmaceutical legislation proposals will lay the foundation of the regulatory framework for safe, effective medicines for years to come. Policy action to address antimicrobial resistance is essential to mitigating growing patient safety risks as AMR threatens our ability to treat even the most common infections.

On all these issues, continuously “elevating the patient’s voice” will be crucial. As this year’s WPSD campaign comes to a close, let’s make sure we continue leveraging the momentum and holding decision-makers accountable: patient engagement and meaningful involvement across the healthcare continuum is a prerequisite for better and safer healthcare.



EPF HEAD OF POLICY CLAUDIA LOUATI

The EPF team wishes you a great month of October.

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

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POLICY CORNER

September in review

After an eventful summer, the month of September took on a hectic pace. The EPF policy team was busy on several fronts.

In the field of digital health, we started the month with the World Health Organization's second symposium on the future of digital health systems, where we emphasised that meaningful patient engagement should be a priority for policymakers when formulating digital health policy. Discussions on the European Health Data Space also kept us on our toes, as both co-legislators aim to soon adopt their official positions before entering trilogue negotiations.

As in previous months, we continued our work on the revision of the EU pharmaceutical legislation, with discussions having officially begun in the European Parliament. If you have not already done so, take a look at [our recommendations](#) for a revision that truly meets the needs of those who benefit from the authorised medicines: the patients.

In addition to our work on the review, we have joined forces and taken part in several multi-stakeholder forums, such as the European Commission's AMR One Health Network, to discuss what can be done to tackle antimicrobial resistance (AMR). Everyone has to do their bit, and patient organisations have a key role to play in raising awareness of the issue, promoting the prudent use of antimicrobials and improving patient safety.

We reiterated the need for antibiotic stewardship and prudent use of antibiotics in all settings at the European Health Forum Gastein, the key conference for EU health policy stakeholders. Discussions on the immediate actions that can be taken to tackle AMR and what can be done to avoid shortages of medicines, particularly antibiotics, rounded off this busy month.

SECRETARIAT NEWS

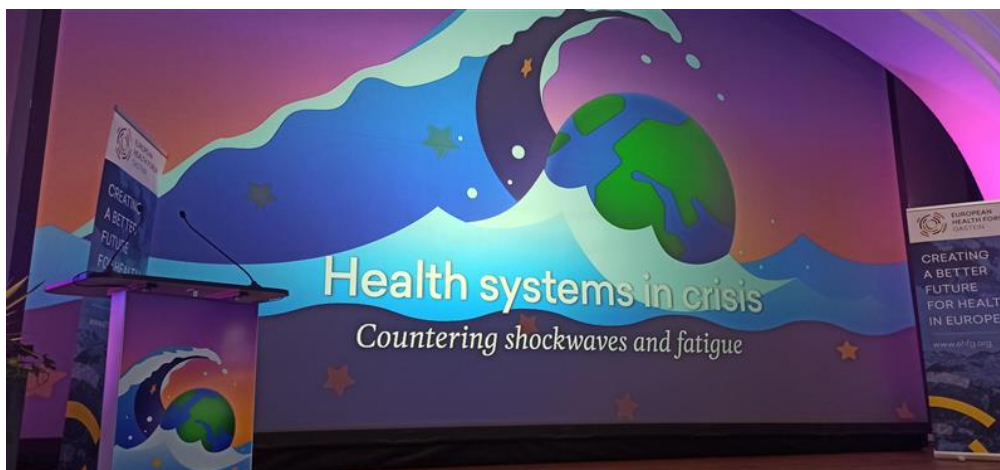


Welcome, Yann!

Hello, Yann! The EPF Secretariat welcomes new Policy Officer in September

Yann Heyer joined EPF in September 2023. In his role as Policy Officer, he contributes to EPF's policy and advocacy work, including providing timely policy information, formulating positions in consultation with members and engaging with external stakeholders.

Yann is Franco-German and holds a Franco-German degree from Sciences Po Lille and the University of Münster. Before joining the EPF, he worked for the healthcare industry in Paris and Brussels.



It's early Autumn, and that means... Gastein!

This year's edition of the European Health Forum Gastein took place from 25 to 29 September 2023. From the EPF Secretariat, both **Milana Trucl** and **Anca Toma** joined for a week of interesting and important sessions on the topic of "Health systems in crisis: Countering shockwaves and fatigue".

Some highlights?

On Wednesday, Anca joined a session on the global health threat of AMR, diving into insights on priority actions that could reduce the emergence and spread of resistant bacteria, while supporting a strong and sustainable AMR R&D ecosystem.

Anca's main takeaways from the session:

"Antibiotic resistance can affect anyone, but chronic patients, as more intensive users of healthcare, are most exposed to bacteria and most vulnerable to infection.

We need to bring this reality to wider society and to policymakers through patients' voices to ensure that antimicrobial resistance is recognised and addressed as one of the largest threats to modern medicine as we know it.

Antibiotic stewardship and prudent use of antibiotics in all settings are crucial in slowing down resistance. We need a sustainable incentive system to encourage continuous innovation, but also to ensure that approved antimicrobials, existing or new, are available to patients who need them."

On the same day, Milana joined the Tallinn Roundtable meeting, with WHO Regional Office for Europe and the European Observatory on Health Systems and Policies.

Milana: "During the roundtable, we discussed solutions for health systems, involving patients, health professionals, and decision-makers in (re-)designing services. I brought the perspective of patients and young Gasteiners to the table, with a focus on meaningful co-design and the importance of health literacy."

What else happened this week? Check our social media pages to stay in the loop!

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THE EU
PATIENTS'
PODCAST

World Patient Safety Day Episode 7

Niek Klazinga

Advisor OECD on Healthcare
Quality and Outcomes



New podcast alert: listen to the World Patient Safety Day podcast special with Niek Klazinga

This month, we marked World Patient Safety Day.

On this important awareness day, EPF welcomed OECD's Niek Klazinga on The EU Patients' Podcast for an in-depth conversation on the OECD's recent report on patient engagement in patient safety, strategies to support cross-national sharing and learning of the topic, and ensuring that patient safety is at the core of healthcare systems.

Niek Klazinga is a medical doctor by training and professor of social medicine at the Academic Medical Centre at the University of Amsterdam since 1999. Niek has been coordinating the Health Care Quality Indicator work of the OECD in Paris since 2007. Over the past 25 years, he has been involved in numerous projects and publications on quality of healthcare. Since his retirement in September 2022, he works as strategic advisor to the OECD's HCQO programme, i.e., the Health Care Quality and Outcomes programme.

Join us - tune in!

 bit.ly/48gRwMs



NEW WATCH | Our recommendations for the revision of the EU pharmaceutical legislation

The European Patients' Forum policy team is happy to present the ins and outs! 🗣️

It's been a few months since the revision of the EU pharmaceutical legislation was published. EPF's Claudia Louati, Julie Spony, and Milana Trucl share with you the recommendations that follow from our position paper.



EUROPEAN PATIENTS' FORUM YOUTH GROUP: GOALS FOR OUR FALL MEETING 2023!!!

By: Blaž Urbanč

On behalf of the European Patients Forum (EPF) Youth Group, we are excited to announce that we are meeting in Brussels for our Fall Meeting, which is scheduled for this upcoming October. This event will be an in-person gathering, providing an opportunity for our recently recruited new members to connect virtually with the rest of the group and contribute to our ongoing projects.

Some of our goals during the Fall Meeting include, but are not limited to:

Welcoming our New Members

One of the highlights of the Fall Meeting will surely be the introducing and welcoming of the newly recruited members to the EPF Youth Group. This will be an excellent opportunity for these individuals to familiarise themselves with the group's objectives and ongoing initiatives and current projects. It will also allow existing members to meet and interact with our new colleagues virtually, fostering a sense of community and shared purpose.

Making Progress on our Young Patients' Involvement in Patient Organisations Project

The Fall Meeting will also serve as an opportunity for the group to continue our work on the Young Patient Involvement in Patients' Organisations project. The meeting will provide an occasion for us to review the progress we have made so far and plan for the next steps.

The upcoming Fall Meeting promises to be a productive and engaging one, furthering the EPF Youth Group's mission of promoting youth involvement in patient advocacy. By welcoming new members and advancing our project work, the more the group continues to foster a vital and active community dedicated to improving patient advocacy across Europe and broader. We look forward to summarising and reflecting on the outcomes and conclusions of the Fall Meeting in the following monthly article!

To find out what we are achieving during our Fall Meeting, follow us on our social media channels on [Facebook](#), [Twitter](#) and [Instagram](#) and stay tuned!!!

PROJECTS PORTAL

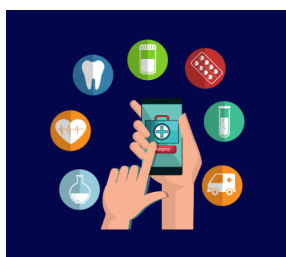
PROPHET

a PeRsOnalized Prevention roadmap for the future HEAlThcare

PROPHET annual meeting in Valencia

After one year of PROPHET work, all project partners will meet in **Valencia, Spain, 2-3 October 2023**, for the **annual project meeting**. This two-days, in-person event is the moment and the opportunity for partners to meet and also to exchange and discuss the PROPHET activities and on-going work but also the strategy to be adopted in the coming months.

On the 3rd of October, a **stakeholder session** will be organized. The first session will focus on mapping results on basic and transnational sciences in Personalised Prevention and the second will focus on the concept paper and SRIA development. The primary aim of these sessions is to gather inputs from external stakeholders.



Do you work at a **health app developer, healthcare provider, health authority, HTA body, or health insurer?**

**LABEL2
ENABLE** 

Please share your opinion on value propositions for health app assessments!

 [EMP.ONL/L2ESURVEYASSESSMENT](https://emp.onl/L2ESURVEYASSESSMENT)

 Funded by
the European Union

Label2Enable is looking for respondents: survey on value propositions for health app assessments

Are you a health app developer, healthcare provider or represent a health authority, health technology assessment body, or health insurer?

Label2Enable developed a survey to support the selection of a suitable business model for the CEN-ISO 82304-2 health app certification and the draft of the European Health Data Space (EHDS) regulation, which includes labeling of apps.

Follow this link to take the survey.

MEMBER FOCUS



White Paper

Cancer and family planning



Europa Donna news: whitepaper on Cancer and Family Planning and roundtable on Breast Cancer and Lymphoedema

"Europa Donna's **White Paper on Cancer and Family Planning** was developed after an Europa Donna Policy event held at the European Parliament in February 2023, which was co-hosted by MEP Frances Fitzgerald and the Commissioner for Health and Food Safety Stella Kyriakides. It aims to address the significant challenges faced by young people, particularly women, diagnosed with breast cancer in Europe regarding their fertility preservation and family planning options. These challenges include concerns about the impact of cancer treatment on fertility, lack of awareness and access to fertility preservation methods, psychological and emotional distress, and the need for improved support from healthcare professionals. The White Paper aims to highlight these issues and advocate for policy changes and legislative actions at both the European Union (EU) and national levels. It underscores the importance of recognizing fertility preservation as a fundamental right for cancer patients and seeks to promote and protect this right through concrete actions.

We also held a Roundtable on Breast Cancer and Lymphoedema led by Gemma Pons MD, PhD, Head of the Microsurgery Unit at the Hospital de la Santa Creu I Sant Pau. We learned how lymphoedema is an underrepresented and prevalent problem that many women face after breast cancer surgery and how it can be managed in a number of European institutions. Around 300,000 women get Lymphoedema as a side effect of Breast



EFA launches new video series featuring patients on their daily journey with atopic dermatitis

On 14 September, **World Atopic Eczema Day**, the European Federation of Allergies and Airways Disease Patients' Associations (EFA), in collaboration with GlobalSkin, mobilised patient communities across the globe to raise awareness of the psychosocial burden of children and youth living with Atopic Eczema through the #IfYouOnlyKnew campaign.

To mark the day, EFA has also released new video series as part of their **Atopical Lives** project, showcasing the reality of patients living with atopic eczema. The new series consists of two episodes, **"Under the skin you see"** featuring adult patients and their families, and **"Skin in the game"**, which tells the story of two young girls and their loved ones supporting their continuous search for wellbeing. The video series is available on EFA's [website](#) and on [YouTube](#).



European Lung Health Group launches #KeepBreathing campaign for better lung policy in Europe

Nine European organisations representing 179 patients' and doctors' associations across 34 countries joined forces to present #KeepBreathing, a new pan-European initiative to raise awareness about lung health at the European Respiratory Society International Congress 2023.

As the European Lung Health Group, patient groups and societies of healthcare professionals advocate for improved policies to address lung health and tackle respiratory disease prevalence and cost in Europe by 2030. Through #KeepBreathing, the nine

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action asking European policymakers for investment in lung health prevention, better respiratory care, and increased research on lung health, setting the vision for future lung health policies.

The organisations leading the initiative are Alpha-1plus Belgium, CF Europe, EFA, ELF, ERS, EU-PFF, Lung Cancer Europe, PHA Europe and TB Europe.

Learn more on the #KeepBreathing campaign on [Breathevision.eu](https://www.breathevision.eu), X (@EuroLungHealthGroup) and LinkedIn (@European Lung Health Group).



European
AIDS Treatment
Group

EATG at the EACS (European AIDS Clinical Society) 2023 conference

EATG is present at the **19th European AIDS Conference** taking place in Warsaw from the 18th until the 21st of October. The biennial conference organised by the **European AIDS Clinical Society (EACS)** is a key event for all stakeholders working in the field of HIV/AIDS in Europe.

This year, EATG is hosting a special sessions at the main **scientific programme** and is also curating the activities at the Community Corner. At the Exhibition hall delegates can visit EATG's **booth** and check out our **e-posters**.

<https://www.eatg.org/events/eacs-2023-community-corner/>

STEP-UP Massive Open Online Course: A year in review

Since January 2022, the European AIDS Treatment Group (EATG) in partnership with Alliance for Public Health (APH – Ukraine) have been delivering their first Massive Open Online Course.

This is a year in review for the STEP-UP MOOC:

<https://www.eatg.org/news/step-up-massive-open-online-course-a-year-in-review/>

All you need to know about HIV Istanbul 2023 MENA/EECA Community Conference

EATG endorses the HIV Istanbul 2023 MENA/EECA Community Conference, organised by Red Ribbon Istanbul. The conference will take place online from 5 until 7 October 2023. EATG hosts the session 'Ageing with HIV and unmet needs of people living with HIV: Community perspectives'

<https://www.eatg.org/hiv-news/all-you-need-to-know-about-hiv-istanbul-2023-mena-eeeca-community-conference/>

ECDC | Stigma: survey of people living with HIV | Monitoring implementation of the Dublin Declaration on partnership to fight HIV/AIDS in Europe and Central Asia –2022 progress report

To improve the understanding of experienced HIV stigma in the community, ECDC — in collaboration with the European AIDS Treatment Group (EATG) and AIDS Action Europe (AAE) — initiated an exploratory survey in 2021 to measure HIV-related stigma across Europe and Central Asia. This is the final progress report.

<https://www.eatg.org/publications/ecdc-stigma-survey-of-people-living-with->

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Open letter of Coalition on Sex Workers' Rights and Inclusion to Members of the European Parliament RE: Prostitution Report

EATG endorses the open letter of Coalition on Sex Workers' Rights and Inclusion to Members of the European Parliament regarding the report *Regulation of Prostitution in the EU*.

<https://www.eatg.org/endorsements-and-sign-ons/open-letter-of-coalition-on-sex-workers-rights-and-inclusion-to-members-of-the-european-parliament-re-prostitution-report/>



PROTECT study survey - round 2

About a year ago, EUFAMI has taken part in a project on Priorities for Future Research on Reducing and Stopping Psychiatric Medicines (PROTECT).

"The project at the time started off with a survey aiming to solve unanswered questions about the process of reducing and stopping psychiatric medicines and how best to do it.

The Round 2 survey is now LIVE and will run until mid-October.

The survey should take approximately 10-15 minutes to complete."

Full details about the study and the project team can be found using the [link](#).



SAVE THE DATE! EUFAMI will be holding a Congress centred around Conflict and Recovery in Mental Health on 28-29 June 2024 in Vilnius, Lithuania

"The Congress will be carried out in collaboration with our Lithuanian member-organisation **LSPŽGB**.

Against a background of disruption and conflict in Europe over the past few years, mainly due to the Covid-19 pandemic, and also due to the significant displacement of war and cultural refugees, families have been the centre of, and most affected by, these crises.

The sub-themes of the Congress are:

Helping Families to Recover from Mental illness
Migration/Immigration and Mental Health – Cultural issues
Reducing Coercion in Mental Health Services
Better communication through Digital Mental Health Services

The Congress will be constructed around a plenary session during a period of two days, followed by a series of parallel workshops based on the sub-themes.

For more information please see [here](#) for our brochure."



Register today for the EUPATI 2023 – 2024 Patient Expert Training Programme!

Registrations for the 2023 - 2024 Patient Expert Training Programme are open [here](#).

Would you like to become a patient expert? Are you interested in learning about the medicines' development process? Would you like to meet and study with others from all over the world and beyond your network?

By registering now, you can join and start learning as part of Cohort 7 of the EUPATI Patient Expert Training Programme!

This programme is tailored for patients and patient representatives (e.g. caregivers and people working in patient organisations). The programme does not focus on any specific disease areas, examples and case studies are provided from a variety of different disease areas.

Programme is composed of

- 6 online modules
- 2 training events (4 days each, 1 online and 1 F2F event)
- All modules and events are compulsory
- Completing the programme usually takes 12 - 14 months
- Proficiency in English is required as training is provided in English

The overall objective of the programme is to obtain a thorough understanding of the medicines R&D process, the patients' role within and build capacity among the patient community to take on an active role in collaboration with the other involved stakeholders.

Access information on the entire EUPATI Patient Expert Training Programme [here](#).

Download our new programme brochure [here](#).

Register today and join over 250+ EUPATI Fellows from all over the world!

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