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

EDITORIAL

Dear readers,

After the first month of 2024, we look back on something that made us very proud in 2023: we managed to build a community of 10.000 people who share EPF's values and goals, and who also are champions of our day-to-day accomplishments. As of last November, we counted 10.000 followers on LinkedIn! For us, it was a pioneering achievement, especially for what it symbolised. Reaching this milestone is a shared achievement, and we extend our gratitude to every individual who has been a part of this journey.

At the same time, this important moment came with the realisation that our community is beautifully diverse: for us, 10.000 is not just a number but a vast array of perspectives, experiences, and expertise.

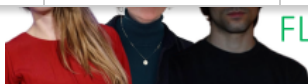
In the mosaic of the EU healthcare landscape, communication is what binds us together. Acknowledging and embracing the diversity in the way we perceive the world is not just an acknowledgment of our differences, but a profound guide that can reshape our interactions.

With the support of our members, EPF has the unique position to harness the power of communication to drive transformative change across borders and diverse healthcare systems. As a community we stand together to raise awareness about pressing health issues, to mobilise resources, and to serve as bridges between policymakers and the communities they serve.

To communicate effectively means to embark on a journey of mutual understanding for a meaningful, richer dialogue. Our community, with its wealth of perspectives and experiences, exemplifies the belief that collaboration and knowledge-sharing create a space for growth, learning, and the exchange of expertise.

As we continue this journey, EPF remains committed to fostering connections, amplifying patient voices, and driving transformative change across the EU healthcare landscape.

A big thank-you from the EPF Communications Team. Stay close in 2024!

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FLAVIA TOPAN, ANNE RENSMA & DAVIDE DURANTE

Until next month!

The EPF team wishes you a great month of February.

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

[Facebook](#) | [Twitter](#) | [LinkedIn](#) | [Anchor](#)

POLICY CORNER

January Highlights from Team Policy

The new year has not interrupted the continuity of our work on the review of the EU pharmaceutical legislation. In January, we continued to work with the Members of the European Parliament (MEPs) engaged in the review and to convey the patient perspective as part of the negotiations. We also discussed the pharmaceutical legislation, and more specifically shortages, at a meeting on January 11 with a key Member State institution, the French Senate, which is developing its position on the legislation. On the topic of shortages, we finalised a consultation of our member patient organisations to gather examples and experiences, which helped inform [our statement](#) and will feed into our advocacy in the coming months. Back in the European Parliament, on January 31, our Executive Director Anca Toma will present our views on the review of the pharmaceutical legislation at the EU pharmaceutical roundtable organised by MEP Adam Jarubas.

Beyond the pharmaceutical legislation, our Policy Officer Julie Spony travelled to Paris to participate in the OECD High-Level Policy Forum on the Future of People-Centred Health Innovation to represent the Patient Advisory Panel of the [OECD's Patient-Reported Indicator Surveys](#) (PaRIS). PaRIS is an initiative to develop a new generation of indicators for patients with chronic diseases. We also answered two public consultations at EU level, one on the review of the Health Emergency Response and Preparedness Authority (HERA), the European Commission service set up two years ago in the wake of the COVID-19 pandemic to improve EU preparedness and response to future pandemics, and one on the [EU4Health programme](#), where we highlighted the essential role of sustainable funding for patient organisations.

On the digital health front, our Policy Officer Milana Trucl gave a lecture on artificial intelligence to students enrolled in the [Master in International Patient Advocacy Management](#), as part of EPF's partnership with Cattolica University (Italy). With regards to European Health Data Space (EHDS), we continue to follow closely the interinstitutional negotiations which started in December 2023. Moreover, our policy team also provided input to a report by the European Institute of Innovation and Technology on the feasibility of implementation of EHDS, which will be published later this year. In January our focus shifted to preparations in close collaboration with the Capacity and Membership team, of the event on artificial intelligence that will take place at the EPF Annual General Meeting.

SECRETARIAT NEWS

#EU2024Elections

Health needs strong support from the Commission and its future Commissioner, and be maintained **high on the political agenda.**

EU4health
Civil Society Alliance

Discover all priorities
and manifesto:
www.eu4health.eu

#EU2024Elections | The EU4Health Civil Society Alliance launches its elections campaign

The EU4Health Civil Society Alliance has officially launched its campaign for the upcoming European elections. The coalition, comprising over 30 dedicated civil society organisations focused on healthcare, aims to bring the importance of health at the forefront of EU policy.

As the EU gears up for the elections, the coalition emphasises the imperative of keeping health high on the political agenda. To gain insights into the proposed 10 priorities, the public is encouraged to read the manifesto, accessible [here](#). Additionally, the alliance invites endorsements for the manifesto, creating a collective commitment to advancing health as a key priority in the EU. Individuals and organisations interested in supporting the cause can endorse the manifesto [here](#).

The EU4Health Civil Society Alliance's campaign signifies a concerted effort to shape the future of healthcare policy in the European Union, highlighting the importance of collaboration and advocacy in creating a healthier and more resilient society.

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Interim evaluation of the EU4Health Programme 2021-2027

Interim Evaluation | The EU4Health Programme 2021-2027

The EU4Health programme is a unique opportunity to make a significant contribution to the post-COVID-19 recovery and build stronger, more resilient, and patient centred health systems. It has the potential to boost cooperation in health and pave the way for a true European Health Union that provides real added value to all patients.

Since 2021, EU4Health Work Programmes have enabled meaningful progress in areas where there is EU added value such as digitalisation, the fight against chronic diseases, and strengthening of the EU's preparedness and response capabilities. Moving forward, we support continued efforts in these areas as well as increased emphasis on health literacy and patient information, which are essential in the fight against many cross-border health threats and in achieving sustainable, well-functioning healthcare systems.

Most importantly, one area where the Programme needs considerable strengthening is support and sustainable funding to patient organisations and other health-focused civil society organisations (CSOs) to allow them to fulfil their core public health mission.

[Read our interim evaluation of the programme here.](#)

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EPF European Patients Forum

Call for action to ensure patients' continued access to safe, high-quality medicines across the EU

Call for action | Ensuring patients' continued access to safe, high-quality medicines across the EU

Shortages are major public health issues that can seriously harm patients and healthcare systems.

Across Member States, many patients have experienced, and continue to experience, difficulties in accessing the medicines and treatments they need.

At EPF, we call for a comprehensive, multi-stakeholder approach to understanding the root causes of shortages and finding appropriate long-term solutions.

[Read what we believe should be done to tackle this issue!](#)



Julie Spony at the [OECD](#) High-Level Policy Forum on The Future of People-Centred Health

Julie Spony, our Policy Officer, represented EPF at the [OECD-OCDE](#) High-Level Policy Forum on The Future of People-Centred Health, held in Paris.

During the event, panelists addressed the Patient-Reported Indicator Surveys (PaRIS), the first international survey assessing patients' experiences of primary care in 20 countries around the world.

As the voice of patients in Europe, the [EPF](#) is part of the PaRIS Patient Advisory Panel, working to integrate essential patient needs into the broader initiative for establishing patient-focused healthcare systems.

[Read the survey](#) and [discover more about the event](#).

PROJECTS PORTAL



Take our online survey!

If you are a...



Citizen or Patient



Health professional



Policy-maker



Researcher



Survey: Join PROPHET in their goal to improve personalised prevention

In the European Union, more than 900,000 individuals die prematurely each year due to preventable disease risk factors. Transitioning from conventional disease treatment methods to a "person-centred" emphasis on prevention and early diagnosis could curb this trend.

Although prevention is nowadays a high priority at EU level, personalised preventive strategies are not as widely used as other personalised medicine approaches. To address this gap, we invite you to participate in a survey designed by **PROPHET** on the perceived barriers, challenges, and enablers for the adoption of personalised prevention strategies in the EU and beyond.

The survey was developed by researchers of the **National Institute of Health Doutor Ricardo Jorge** (INSA), in collaboration with the **Università Cattolica del Sacro Cuore** (UCSC), and the **Karolinska Institute** (KI), and based on the literature and on interviews with experts in the area of personalised medicine.

Funded by the European Commission under the Horizon EUROPE Programme, **PROPHET** aims to support the definition and implementation of innovative, sustainable and high-quality personalised strategies that effectively tackle chronic diseases.

- You can access the survey [here](#).

The results will contribute to the development of a Strategic Research and Innovation Agenda (SRIA) for personalised prevention. Read more [here](#)!



The European Patients' Forum attends the first Gravitate Health Hackathon!

Last week, EPF attended the first **Gravitate Health** Hackathon, in Athens!

Gravitate Health's goal is to empower and equip patients with health information for active personal health management and adherence to treatment. To achieve this, the project is working on a **Federated Open-Source Platform** (FOSP), currently still in development.

Part of the **Athens Digital Health Week**, this event provided a great opportunity to showcase the platform, test its usability and contribute to its improvement.

Participants were asked to solve the following challenges:

- Identify rules to personalise patient information.
- Design aligned medicine information visualisations for patients.

The different teams tapped into their skills to propose innovative solutions and improve the existing features of the application.

Who proposed the best ideas? Let's take a look at the winners:

🏆 The 1st Prize went to the Gnomon Informatics SA and University of Thessaly (UTH) team.

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🏆 Code Creators and eHealth Forum were awarded with 3rd prize.

Well done to all other teams for your amazing work and effort!

Learn more about Gravitare Health [here](#).

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CORE-MD
Coordinating Research and Evidence
for Medical Devices

WEBINAR

Early clinical investigations of new high-risk medical devices – a review of European experience

8 January 2024

17h00 - 18h15 CET



Prof. Alan Fraser

ESC/Cardiff
University



Ms Claudia Louati

European Patient's
Forum



Prof. Mark Slack

CMR Surgical



Dr Gearóid McGauran

Health Products Regulatory
Authority



Prof. Peter McCulloch

University of Oxford

Learning objectives :

Understand the challenges of early clinical investigation in the context of the medical device regulation

Receive viewpoints and perspectives from patients, manufacturers and regulators

Explore possible solutions stemming from CORE-MD recommendation



Project funded by EU Horizon 2020 program - Grant 965246



Register

<https://bit.ly/coremd10>

www.core-md.eu



CORE-MD highlights the patient perspective in early clinical investigations of high-risk medical devices

What challenges do patients face in the context of the Medical Device Regulation?

On 8 January, Claudia Louati, EPF's Head of Policy joined the webinar "Early clinical investigation of new high-risk medical devices - a review of European experience", organised by **CORE-MD**.

During her interventions, she discussed the patient's perspective on early clinical

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What else was discussed?

- ◆ How lack of transparency inhibits improvement in evaluation
- ◆ New methodology for clinical evidence development
- ◆ Manufacturer's challenges in implementing the MDR

Follow [their website](#) for updates on upcoming events!

MEMBER FOCUS



EATG launches "What We Wanted was What We Needed" a documentary on the Sitges Meetings

On January 25 EATG launched "*What We Wanted was What We Needed – Rebuilding a Community of Memories and Inclusive Advocacy*", a feature documentary on the Sitges Meetings. This film documents stories, experiences, results, and lessons learned from the Sitges meetings. This documentary happened within the framework of the [Belong project](#), advocating for the inclusion of people living with HIV in non-HIV clinical trials.

The Sitges Meetings were a series of community-owned multi-stakeholder meetings, held between 2007 and 2017 in Sitges, Spain and organised by the EATG. The purpose was to promote the inclusion of people with HIV/hepatitis C (HCV) coinfection in clinical trials for emerging hepatitis treatments, and rapid access to new, safe and effective treatments.

The documentary premiered online on on 25 January 2024 at 20.00 CET. It will be available for free online streaming for one month.

[For more information read the press release here.](#)



New Campaign | [European Alliance for Cardiovascular Health](#)

The European Alliance for Cardiovascular Health has launched its campaign to promote cardiovascular health in the EU and fight against CVD.

CVD cost the EU an estimated €282 billion in 2021, topping the leaderboard as the cause of more than one-third of all deaths and impacting the lives of some 60 million people. Misperceptions plague CVD: it is often still regarded as a “man’s disease” although women are more than twice as likely to die after a heart attack than men. Cardiovascular conditions also affect children and young adults. In Strasbourg, EACH unveiled the “Vote Cardiovascular Health 2024” exhibition, hosted by MEP Elżbieta Łukacijewska (Poland) and MEP Radka Maxová (Czech Republic), long-standing supporters of cardiovascular health. The exhibition highlighted CVD’s toll on the EU, country by country, while the online media campaign is calling on leaders to #VoteHealth2024.

“Vote Cardiovascular Health 2024” is a unique initiative that zooms in on the critical issue of cardiovascular health, the leading cause of mortality in the EU and worldwide.

[Read more about the initiative here.](#)



[EUROPA DONNA](#) | Advocates Speak Out

Europa Donna's latest Advocates Speak Out video features Susanne, a courageous early breast cancer patient who shares her deeply personal journey and the compelling reasons behind her decision to become a patient advocate. In this poignant video, Susanne eloquently recounts her experience, shedding light on the challenges and triumphs she faced during her battle with breast cancer. Her narrative not only serves as a powerful testament to the resilience of individuals facing such a diagnosis but also inspires hope and solidarity within the breast cancer community.

By showcasing real-life stories like Susanne's, Europa Donna aims to create a platform for open dialogue, fostering a supportive environment where individuals can find solace, information, and inspiration. These videos, distributed across Europa Donna's [social](#)

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the breast cancer community.

Susanne's decision to become a patient advocate further underscores the importance of amplifying individual voices in the fight against breast cancer. Through her advocacy, she not only contributes to the broader conversation surrounding breast cancer awareness but also becomes a beacon of empowerment for others navigating similar challenges. Europa Donna's Advocates Speak Out series continues to be an instrumental tool in disseminating knowledge, promoting understanding, and fostering a sense of community among those impacted by breast cancer.

[Watch the video here!](#)



EURORDIS Open Academy Launches New E-Learning Course on Ethics in Clinical Trials

The **EURORDIS** Open Academy is proud to announce the launch of its newest e-learning course, "Ethics in Clinical Trials." Geared towards healthcare professionals and enthusiasts alike, this comprehensive course delves into the ethical essentials of clinical studies.

Key Features of the Course:

- Understanding the need and role of ethics in trials
- Exploring the origins of modern ethical guidelines
- Learning the four guiding principles in Western medical ethics
- Grasping the importance of informed consent

How to Enroll: Interested individuals can enroll in the "Ethics in Clinical Trials" course by visiting [EURORDIS Open Academy's course page](#).

For additional details or inquiries, please contact Sophie Gidikas at sophie.gidikas@eurordis.org.

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