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

EDITORIAL

The Patient Organisations' Manifesto

Road to the European Elections 2024

Towards a truly participatory, democratic and impactful involvement of patient organisations.



#Vote4Patients

Dear readers,

February marked the launch of EPF's **Vote4Patients campaign**, in the lead up to the EU Elections 2024, that will take place between 6-9 June. Why are the European Elections important to patients? MEPs take decisions that affect the daily lives of everyone, a considerable amount covering important healthcare issues that have a direct impact on patient organisations and patients' lives. The upcoming mandate will be particularly filled with policy dossiers that set out to change the healthcare landscape, such as the revision of the pharmaceutical legislation or the roll out of the European Health Data Space.

EPF believes that this is a key moment to make the governance of healthcare more inclusive, truly democratic, and sustainable. To achieve this, the Vote4Patients campaign aims to ensure that the significant challenges faced by patients are given central attention by candidates and, ultimately, by the European Parliament.

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community's vision for European patient advocacy and serves as a roadmap for the broader patient movement in Europe.

Key Messages of the Campaign:

1. **Strengthening Involvement:** EPF is dedicated to enhancing the role of patient organisations in shaping healthcare policies at both national and regional levels.
2. **Ensuring Participation:** The campaign highlights the importance of fostering participation grounded in solidarity, equity, mutual trust, sustainability, empowerment, and responsibility.
3. **Meaningful Participation:** EPF emphasises the need for a meaningful and viable involvement of patient organisations, identifying effective channels and mechanisms in collaboration with patients.
4. **Broadening Horizons:** Beyond healthcare, EPF calls for the involvement of patient organisations in other policy areas related to public health and quality of life.
5. **Inclusive Policy Development:** The campaign calls on policy makers to enable patient organisations to participate actively in all stages of policy development, ensuring their voices are heard and considered.
6. **Institutionalising Participation:** EPF calls for the institutionalisation of participatory processes, diversifying opportunities for patient organisations to contribute meaningfully.
7. **Health Technology Assessment Inclusion:** The campaign advocates for the inclusion of patient organisations in health technology assessment and related processes, recognising their unique perspectives.
8. **Formalised Decision-Making:** EPF seeks to formalise patients' participation in any decision-making body on health and related policies.
9. **Stable Funding:** EPF is committed to ensuring that patient organisations have access to long-term and unrestricted operational funding.
10. **Key Partnerships:** The campaign calls on policymakers to recognise patient organisations as key partners in improving patient education and building capacities and skills.

You can join EPF in shaping the future of healthcare in the European Union by [signing our petition](#).

POLICY CORNER

February Highlights from Team Policy

High-level meetings and important policy developments have kept the EPF's policy team very busy in these first three weeks of February. We concluded the previous month with the participation of our Executive Director Anca Toma at a roundtable on the review of the pharmaceutical organised by MEP Adam Jarubas, where she reiterated the importance of involving patients and their representatives in shaping this crucial legislation. Negotiations on the file are currently in full swing, with the Parliament hoping to agree on the negotiating mandate in mid-April. Our Head of Policy, Claudia Louati and Policy Officer Julie

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error, EPF applied to join the [Critical Medicines Alliance](#) which brings together the relevant stakeholders to discuss challenges and define priorities for action on the issue of shortages of critical medicines in the EU.

Speaking of shortages, this time in the realm of medical devices, EPF has reacted to the Commission's [proposal](#) to postpone once again the deadlines for full application of the In Vitro Diagnostic Medical Devices Regulation (IVDR) and speed up the launch of some elements of EUDAMED, the European database on medical devices, in view of the reports of risks of shortages of essential in-vitro diagnostics (IVDs). Our feedback to the public consultation and our [reaction to the proposal](#) emphasise that that these essential devices must remain available, but more needs to be done to address the bottlenecks and achieve implementation of a fit-for-purpose regulatory framework that improves patient safety.

On the digital health front, February has seen significant progress in the negotiations on the European Health Data Space (EHDS) between the European Parliament and the Council. The talks, which started in early February, are nearing conclusion, with the final agreement between the two co-legislators expected for early March and the official vote in both institutions in early April. Our team is closely following and reacting to the updates coming from the closed-door negotiations, to ensure that EHDS will benefit patients and the healthcare systems. Patients' voices have also been represented by our policy officer Milana Trucl at two important meetings in the area of digital health: the Commission e-health stakeholder group and the roundtable with high-level policy and industry representatives at the Masters of Digital event.

We also made sure to keep the focus on the important topic of anti-microbial resistance (AMR) with participation at two high-level events. Our policy officer Yann Heyer participated in the launch meeting of the Joint Action on Antimicrobial Resistance and Healthcare Associated Infections (EU-JAMRAI 2), which brings together 30 countries and 128 partners over a four-year programme, with the common goal of supporting Member States in combating AMR through stewardship, diagnosis, access to antibiotics and public awareness campaigns. Our calls for exploring new ways of involving the patient community at European and global levels to ensure a global approach to AMR have also been reiterated by our head of policy Claudia Louati at the Evidence for Action (E4A) Dialogue on Antimicrobial Resistance, in Valletta.

EPF has also been very active on the vital issue of public financing for civil society organisations and risks that health is once again deprioritised. Following the announcement by the European Council of a planned redeployment of EUR 1 billion from the EU4Health programme, EPF has [joined forces with numerous health stakeholders](#) via the EU4Health Civil Society Alliance to express our concerns and reiterate the importance of such funding. While we appreciated the united front among all relevant stakeholders and support from several MEPs, our concerns and calls for greater support to public health civil society organisations – and continued investment in health – must continue to resonate.

Last but not least, EPF has taken the opportunity to contribute to the [consultation](#) on Health Emergency Preparedness and Response Authority's (HERA) mission mandate, tasks, structure and resources, by reiterating that HERA's role and mandate could be further strengthened by adopting a comprehensive approach to pandemic preparedness which includes continuity of care, supports member states' actions to improve access to critical medicines, and improved coordination at global level.

SECRETARIAT NEWS



EPF reacts to the European Commission proposal on transitional provisions under the IVDR and roll-out of EUDAMED

MEDICAL DEVICES | Reaction to the delay of IVDR

EPF notes the publication of a European Commission proposal to postpone once again the deadlines for full application of the In Vitro Diagnostic Medical Devices Regulation (IVDR) and speed up the launch of some elements of EUDAMED, the European database on medical devices.

In view of the reports of risks of shortages of essential in-vitro diagnostics (IVDs), EPF supports the main objective of this proposal, namely ensuring that patients continue to have access to the diagnostic tests they need. IVDs are a crucial part of patients' care, as they play an essential role in e.g. screening and diagnosing diseases, guiding treatment decisions, monitoring disease progression, and identifying disease predisposition. As a result, it is essential that these devices remain available and that healthcare systems have an accurate view of potential supply disruptions to mitigate impacts on patients. Reporting requirements may also help clarify the reasons for device shortages or withdrawals, namely because devices are unsafe or outdated, or due to delays and inefficiencies outside a manufacturer's control.

That said, we are concerned that this is the third time in four years that the EU institutions consider or proceed with an extension of the timelines for full implementation of one or both medical devices regulations. While some conditions are in place, we note that some devices would now benefit from a transition period of over 12 years, until December 2029. While we understand the complexity of this overhaul of the system, these timelines would likely not be considered proportionate in any other public health context.

Learn more and also continue reading about EUDAMED. Find our [full statement](#).

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EPF European Patients Forum **IS LOOKING FOR A COMMUNICATIONS OFFICER**

Send your cover letter and CV to:
recruitment@eu-patient.eu

VACANCY | Are you or do you know our new Communications Officer? One more week to apply

Join our communications team! The European Patients' Forum is currently looking for a Communications Officer. Applications for this vacancy remain open until 3 March 2024.

Our new Communications Officer is responsible for helping develop and deliver excellent communications on EPF's and our projects' work.

Are you our new colleague? Learn more about the full job description below and let us know about your interest in the position by sending your resume and cover letter to recruitment@eu-patient.eu.

We look forward to meeting you!

Find more information [here](#).

YOUTH GROUP UPDATES



YOUTH GROUP | Friendships throughout our Experiences of Being Involved in the EPF Youth Group and STYPA

By: Anastasia Semaan

The month of February is viewed by many as the month to celebrate Valentine's Day and love, however the strength and development of friendships deserves just as much love and recognition, especially within the patient community. Within the EPF Youth Group we have the opportunity to work and collaborate with many people from around Europe and this provides us with the chance to work and learn from each other, but also to develop long lasting friendships and working relationships. A significant contributing factor that plays a role in the strength of many of the relationships is the unity that we all feel as young patients or as individuals who work with or have a connection to someone who is a patient themselves. I can recall from my first STYPA in 2019 that it was through the deep conversations and discussions around the challenges that many of us admitted that we have faced as people within the young patient community, which brought us closer together and in a very short amount of time. Furthermore, since joining the EPF Youth Group and collaborating with young patients on an even deeper level, I have found that it has been through honest communication and admitting our challenges, which contributes to our tight bond as a team and as friends.

These friendships and relationships that we have developed through working with one another has often led to us, once leaving the Youth Group, collaborating with one another in advocacy projects if we come from the same patient organisation or disease area background. However, on a more personal and social level, they have often led to many of us staying in contact as friends to check-in and arranging get-togethers purely for fun and outside any work commitments. The connection between us as patients is one whereby there is usually already a level of empathy and understanding that already exists. This usually is based on some of the experiences that we both resonate with, whether they be those that have been empowering, but also those that have been challenging and depleting. The ability to then develop these friendships or relationships, whereby they are also based on interests and passions, only strengths and takes these bonds further.

"Some of my strongest friendships today have come from attending STYPA and working intensely and purposefully within the EPF Youth Group. I genuinely feel that I have made life-long friends and I am looking forward to seeing how they develop." - Anastasia Semaan

Within the Youth Group, some of our other members have also contributed the following regarding their views of friendship within their time in STYPA and in the EPF Youth Group:

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involved in EPF youth group activities which require a lot of invested energy and spending time together, I realised that I would make amazing friendships. Trust is the value that has enormous potential to plant a great seed of honest and mutual friendship. I have exchanged a couple first-hand experiences and information on advocacy skills and advocacy related projects in the past that I would not be familiar with without knowing people who feel excited to share their experiences and knowledge. I am most proud of having the opportunity to be informed about patient-oriented policy, healthcare system, and advocacy virtues possessed by YG colleagues. It's crucial to be encouraged to imitate it in your own societal and organisational environment. I hope the fruit of seeds will last indefinitely." - Blaž Urbanč

"Through STYPA, I've discovered the YG community, a circle of souls I cherish deeply. I am endlessly grateful for this journey, a testament to the transformative power of shared experiences and the incredible friendships that have blossomed along the way."
- Cornelia Pauna

As sad as it is to say goodbye to our youth group members as they "age-out" or move forward in their careers or advocacy journeys, it is amazing to hear when members stay in touch and maintain a strong communication. Ultimately, it can be said that it has been through collaborating on a common goal of wanting to strengthen the young patient voice that has brought us together as young patients. However, it has then been through our open communication and the exchanging of our experiences, which has helped us learn about each other and furthered our will and drive on wanting to make the world a better place, that I think is the glue to the development and growth of our friendships. To find out more about what we are working on and collaborating in as a team, continue to follow us on our social media channels on [Facebook](#), [X](#) and [Instagram](#).

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.

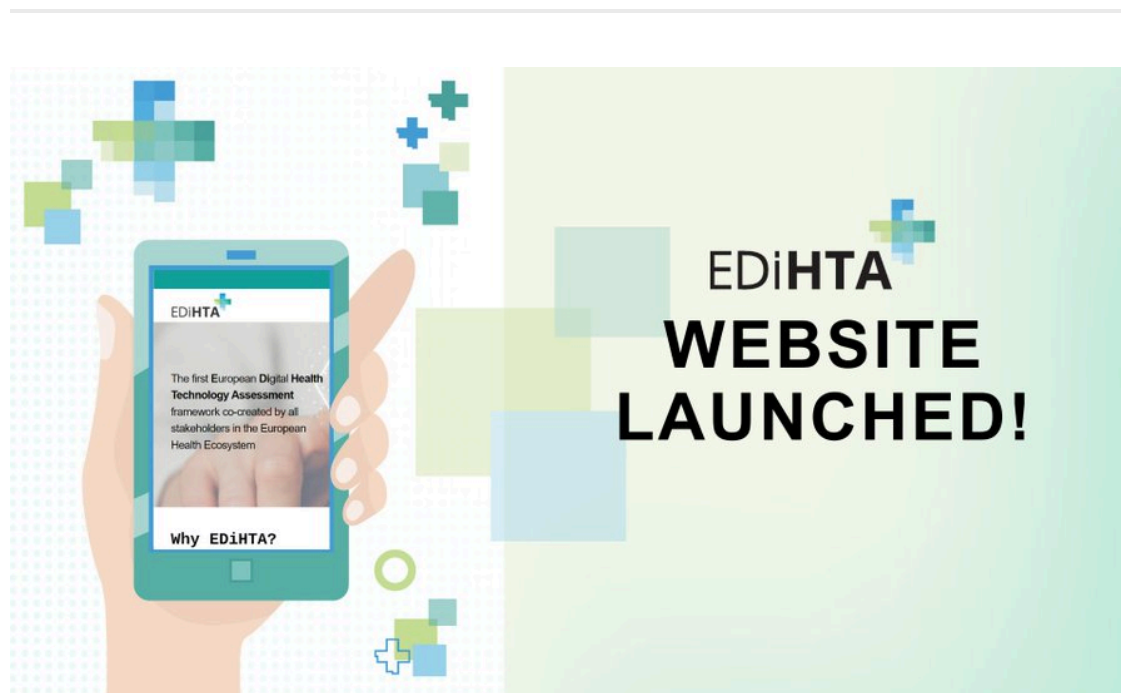
Although prevention is nowadays a high priority at EU level, personalised preventive strategies are not as widely used as other personalised medicine approaches. To address this gap, we invite you to participate in a survey designed by **PROPHET** on the perceived

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](#)!



NEW WEBSITE | Have a look at the brand-new EDiHTA website

EDiHTA is online!

With the goal to capture the real added value of Digital Health Technologies and provide a general framework for their inclusion in Health Technology Assessment (HTA), EDiHTA is a recently-launched project under the Horizon Europe framework. Through the newly launched website, EDiHTA will provide updates on the development of innovative solutions to make DHTs accessible and fit for patients.

Coordinated by the **Università Cattolica del Sacro Cuore**, EDiHTA brings together a multi-disciplinary consortium of 16 partners from 10 European countries with key expertise in HTA research.

EDiHTA aims at reaching the following goals:

- Promote a holistic approach involving all stakeholders for consensus building at national and European levels

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Define a common terminology, harmonise and enrich existing HTA frameworks and create an open repository with frameworks, guides, articles and HTA methodologies

- Follow a multi-stakeholder, multi-domain and modular approach
- Co-create EDiHTA solutions
- Provide a validated and ready-for-use digital HTA framework for DHT

Check out [their website](#), and follow them on [X](#) and [LinkedIn](#)!

Don't miss the chance!

Enrol in our Extended & Fast-Track Training programmes!

Registrations are still open

Find out more here: eucapa.com/fast-track



EUCAPA
EUROPEAN CAPACITY BUILDING FOR PATIENTS

Take a look at EUCAPA Fast-Track and Extended Training!

EUCAPA is an educational platform specifically designed to equip patients and their representatives with the necessary skills in HTA.

Being at the intersection of complex and different disciplines, Health Technology Assessment (HTA) can feel inaccessible at times. EUCAPA's mission is to reduce this knowledge gap and centre the evaluation of Health Technology around the ultimate recipient of healthcare: Patients.

Check out our the courses:

- In this comprehensive 8-hour online training program, patients and patient representatives are equipped with the skills, tools, insights, and expertise they need to engage in joint clinical assessments and scientific consultations within the EU HTA regulation.
- A 3-Day in-person training program in HTA for patients and patient representatives at **UMIT TIROL - University for Health Science and Technology**, in Austria. An in-depth training program designed to deepen your knowledge of the principles and methods of HTA, health decision sciences, and patient involvement. You will learn about communication and personal skills, such as presenting and discussing patient-relevant topics.

EUCAPA's programmes are mainly designed for cancer and rare disease patients, but also other patient categories will be considered! Attending the Fast-Track training is a

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Enrol in the Fast Track Training: <https://bit.ly/3NpX8Lv>
 Enrol in the Extended Training: <https://bit.ly/3NpX8Lv>

MEMBER FOCUS

Mental Health & Wellness Living with Cardiovascular Disease



Anna Mierzyńska
Ph.D. in Medicine & Health Sciences
Clinical Psychologist



Jackie Ratz
HeartLife Canada -
Women's Champion



Marcin Ruciński
Cardiology Patient
and "Serce na Banacha"
Association President



Translations
available in
Polish



Wednesday, March 13



12:00 EST | 16:00 GMT | 17:00 CET



Global Heart Hub Announces Upcoming Empower Webinar Addressing Mental Health & Wellness Amid Cardiovascular Disease

On Wednesday, March 13, **Global Heart Hub** is set to host an empowering webinar focused on the intersection of mental health and cardiovascular disease. Scheduled for 12:00 EST | 16:00 GMT | 17:00 CET, the event will feature English presentations alongside live Polish translations.

In collaboration with their Polish Affiliate, Serce na Banacha, the webinar aims to provide valuable insights into managing mental health and wellness for individuals affected by cardiovascular conditions. Dr. Anna Mierzyńska, a certified clinical psychologist specializing in clinical health and cardiac psychology, will share her expertise during the session.

The webinar will also feature patient advocates Marcin Rucinski from Poland and Jackie Ratz from Canada, who will offer perspectives on mental health challenges and effective coping strategies from the patient's point of view. Additionally, they will explore the importance of community support in navigating the complexities of living with cardiovascular disease.

Registration for this event is free.



EFA launches “A vision for EU action on lung health 2024-2029” together with the European Lung Health Group

Lung health is fundamental for a healthier, stronger and more resilient society in Europe. However, respiratory disease, including asthma and chronic obstructive pulmonary disease (COPD), remains Europe’s Achilles heel - a significant burden to patients, healthcare systems and to society. Together with the European Lung Health Group (ELHG), EFA is calling on EU policymakers to address lung health in an all-round, multidisciplinary approach in a new publication – “**#KeepBreathing: A vision for EU action on lung health 2024-2029**”.

Around 1 in 8 deaths in the EU was due to a respiratory disease. Improving lung health is one of the most effective ways of alleviating the strain on EU health systems, improving quality of life, and stimulating the EU economy.

Better lung health and addressing the challenges of tomorrow

Together with the **European Lung Health Group (ELHG)**, EFA launches an EU action on lung health in a new publication: “**#KeepBreathing: A vision for EU action on lung health 2024-2029**” in the framework of the **#KeepBreathing campaign**. The document lays out immediate actions to improve EU policy on lung health across three areas: prevention, care and research & innovation.

We say the time is now for a lung health policy that helps Europe to #KeepBreathing. **[Read our recommendations here.](#)**

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associations and healthcare professionals, including the [European Federation of Allergies and Airways Diseases Patients' Associations \(EFA\)](#). Lung health groups are joining forces to raise awareness about lung health, highlighting the importance of lungs in a [#KeepBreathing campaign](#).



Updates from European AIDS Treatment Group

Introducing: CORE – Community Response to End Inequalities

EATG is leading Work Package 6 (Stakeholder Engagement) of EU-funded CORE Action. In this video from the kick off meeting you can Watch how CORE aims to strengthen community-based health services for people most affected by HIV, VH, TB and other STIs. We are working with a variety of regional and local organisations on engagement and the sustainability of country interventions.

“CORE – COmmunity REsponse to End Inequalities” is a 36-month EU Action Grant running from January 1st 2023 to December 31st 2025 and involves 24 partners from 16 EU Member States. CORE aims to reduce inequalities in the HIV, TB and viral hepatitis responses by promoting, strengthening and integrating the community responses that have proven key in reaching communities traditionally underserved by mainstream prevention and healthcare services. This approach is particularly vital in the context of countries where these responses are still inadequate compared to the EU average.

CORE is co-funded by the EU4Health Programme 2021 – 2027, the fourth and largest of the EU health programmes since their launch in 2003, with the total budget of €5,3 billion.

Meeting report from *STEPS 9: A Community Initiative to Design the Pathway to a Durable ART-Free Control of HIV Infection* is now online

We have published the summary report from STEPS 9 workshop. The workshop took place on Wednesday, 18 October 2023, in Warsaw (Poland).

Community Breakfast Club at CROI 2024 conference

The **Community Breakfast Club** are one-hour Zooms that provide an informal and friendly setting for dialogue between researchers and community advocates on the hottest #CROI2024 science being presented this year. These sessions are open to anyone interested, including people who are not registered or attending the CROI conference. Each session will be recorded and links to the recordings will be shared widely.

EATG General Assembly 2024

This year, **EATG's annual General Assembly** takes place in Frankfurt (Germany) on 10-12 May. We are taking stock of achievements and challenges from the previous 12 months as well as we are voting and deciding on our next steps and representation in the EATG bodies. This event is open to members only.

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