

ANNUAL IMPACT



REPORT

A WORD FROM OUR PRESIDENT

In 2023, we celebrated 20 years of the European Patients' Forum (EPF). In these past two decades, we have grown our patient community and strengthened our efforts to build a strong patient voice across Europe.

This community of patient organisations is the one shaping a new European agenda for patient advocacy, while creating better health policies and practices, reinforcing research and education through meaningful patient involvement, and working on building a digital transformation accessible for patients.

Our work in 2023 reflected our vision of a Europe where patient organisations are valued partners in creating equitable, person-centred, accessible, and sustainable healthcare systems. This impact report showcases the results of our activities and tracks the goals and milestones for 2023. In the following pages, you will find how we have brought together our policy efforts, project involvement, and capacity building work towards achieving our five-year strategic goals. These goals include the co-creation of better health policy, practice, research, and education through meaningful patient involvement, a digital transformation that delivers for patients, access to healthcare without discrimination, strengthening of patient communities across Europe, and shaping a new European agenda for patients.

This journey to 2024 and beyond reflects the persistence of our commitment towards meaningful patient involvement in healthcare policymaking and collaboration between policymakers, healthcare professionals, industry and patient representatives.



“This community of patient organisations is shaping a new European agenda for patient advocacy, while creating better health policies and practices, reinforcing research and education through meaningful patient involvement, and working on building a digital transformation accessible for patients.”

Marco Greco, EPF President

THE STORIES WE FOSTER



Andreas Christodoulou, EPF Board Member

Andreas Christodoulou is an EPF Board Member since 2023. His journey with EPF started back in 2017 when he attended the Summer Training for Young Patient Advocates (STYPA). Afterwards, he became a member of the EPF Youth Group and served, for two years, as the President of EPF's Youth Group.

His story is one of dedication, persistence, and the deeply rooted belief of making the world a better place. He sat with us for a short interview to speak about the impact EPF has had on his personal and professional growth.

Can you share your journey and experiences that led you to become a patient advocate and your first interactions with EPF?

My journey as a patient advocate stemmed from my personal experience as a patient with two chronic conditions, combined with my academic background in Computer Science and Human Ethics & Global Values. My involvement with the Cyprus Association of Cancer Patients and Friends (PASYKAF) provided me with firsthand exposure to the challenges faced by patients and their families. This experience ignited my passion for advocating for improved healthcare services, particularly in the areas of cancer prevention, early detection, and holistic patient care. My first interaction with the European Patients' Forum (EPF) was in 2017 where I attended the EPF's Skills Training for Young Patient Advocates (STYPA) as part of a new EPF's Youth Group member. After STYPA I was really impressed with the programme and EPF's work and I was elected as President of EPF's Youth Group, where I actively contributed to the organisation's mission of representing patients' interests and promoting patient-centered healthcare policies at the European level.

As now a Board member of EPF, can you elaborate on how this position aligns with your personal values and advocacy goals?

As a Board member of EPF, this position aligns perfectly with my personal values and advocacy goals. My commitment to holistic patient care, universal healthcare coverage, and patient empowerment resonates with EPF's mission of ensuring that patients across Europe have access to high-quality, patient-centered healthcare. By serving on the EPF Board, I have the opportunity to influence policy decisions, advocate for patient rights, and champion initiatives that address the needs of patients and their families at both national and European levels. Furthermore, with our active participation in EPF's Board our umbrella organisation in Cyprus is better equipped with the knowledge of policy lobbying and advocating for our 40 members' organisations who represents more than 80.000 patients in Cyprus.

Can you share any memorable success stories or moments from your advocacy work that have left a lasting impact on you personally or professionally?

My advocacy work has undoubtedly been marked by numerous memorable successes and impactful moments. Since 2017, after my first interaction with EPF, I was honoured to be appointed in 2023 as the Director of Operations of the Cyprus Federation of Patients' Associations (CyFPA), an EPF member whose mission is to ensure that patients in Cyprus have access to holistic, patient-centered, equitable and social healthcare. This honour has let me personally and professionally to be more impactful with my advocacy work which includes legislative victories that improved outcomes.

Lastly, what advice would you offer to individuals aspiring to become patient advocates, especially those interested in leveraging technology and innovation to improve healthcare outcomes?

For individuals aspiring to become patient advocates, especially those interested in leveraging technology and innovation, I would emphasise the importance of staying informed about the latest advancements in healthcare and digital health solutions that have the potential to transform healthcare delivery and patient outcomes. With my personal experience as Board Member of Cyprus' National eHealth Authority (the national body of Cyprus for digital health), I will also encourage aspiring advocates to actively engage with patient organisations such as EPF, professional networks, and policymaking bodies to amplify their voices and advocate for patient-centered policies and initiatives. Lastly, seek out educational resources, courses, and training programs focused on patient advocacy, healthcare innovation, and digital health. This will help you develop the knowledge, skills, and expertise needed to effectively advocate for patient-centered policies and solutions.

EPF AT A GLANCE



- 1 **We convey** the patients and their informal carers' unique experiences and expertise through representative member organisations bringing together national, regional and local patient organisations throughout Europe.
- 2 **We adopt** a holistic and patient-centered approach by focusing primarily on the patient experience of healthcare while building alliances with other actors to ensure that all core issues in a patient's life are addressed effectively.
- 3 **We drive** and advance the patient agenda by acting both as a catalyst for positive change in European health systems and a watchdog.
- 4 **We are** a credible and expert partner for cooperation and dialogue with a broad range of stakeholders in the EU and internationally.
- 5 **We promote** the building and sharing of patient-centred good practices, through leading or partnering in projects that are at the heart of our vision and mission.
- 6 **We engage** actively in developing the capacity of patient organisations at European and national levels to channel their expertise and knowledge in order to be effective actors in the healthcare arena.

Our Vision

A Europe where patient organisations are valued partners in creating equitable, person-centered, accessible, and sustainable healthcare systems, based on patients' unique expertise.

Our Mission

To advance the interests of patients and patients' communities by strengthening their collective impact across Europe through effective advocacy, education, empowerment, and partnership.

OUR 2023 OBJECTIVES

- 1** To shape a new European agenda for patients
- 2** To co-create better health policy, practice, research, and education through meaningful patient involvement
- 3** To build digital transformation that delivers for patients
- 4** To access the healthcare we need with no discrimination
- 5** To strengthen patient communities across Europe
- 6** To raise awareness and improve communication

We brought together our policy efforts, project involvement, and capacity building work towards achieving our five-year strategic goals.

With the collective knowledge and experience of our team, through team work and an unwavering commitment to our members, we moved closer to achieving these goals.

20 YEARS STRONGER

EPF’s 20th Anniversary Event – The Path of Patient Advocacy: Past, Present, and Future

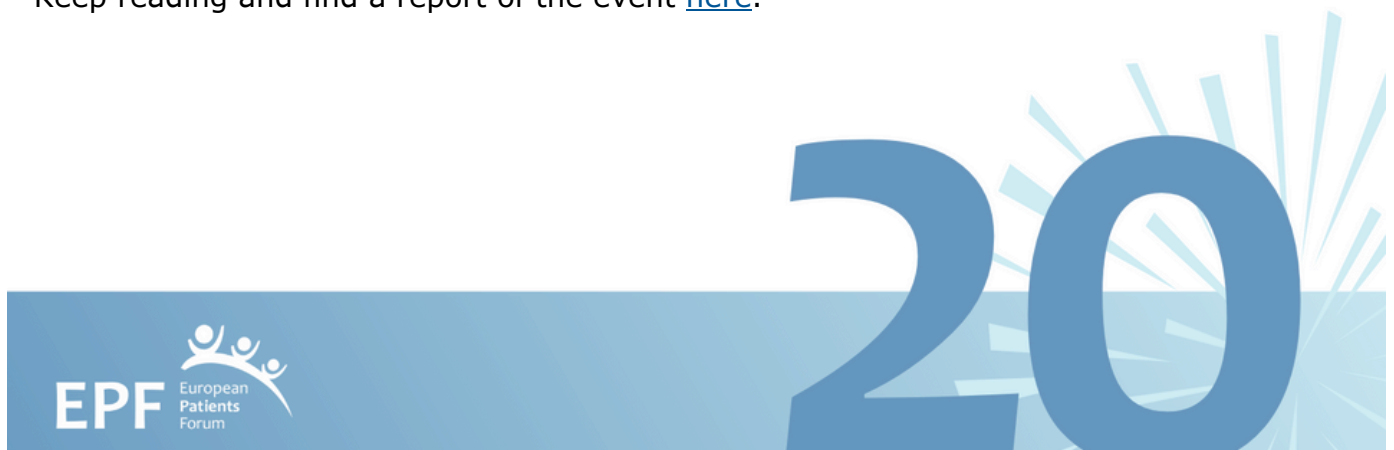
In April 2023, the European Patients’ Forum (EPF) celebrated 20 years of building a strong patient voice across Europe. The anniversary event brought together EPF members, partners, key figures from its two-decade history, and staff members.

EPF’s activity throughout its 20 years of existence has seen and triggered profound transformation in the role of patients and patient organisations in healthcare policy and practice. EPF has a track record of highly effective advocacy campaigns on policy and unique multi-stakeholder collaborations that brought the patient perspective to the design of health policies over the years.

The 20th Anniversary Policy Event looked back over these two decades, explored learnings, and built on these to inform and inspire a dialogue with participants about the future direction for the patients’ voice and patients’ advocacy in Europe. The event resulted in a vision for what the patient movement could achieve in 10 years: [the EPF Manifesto - towards a truly participatory, democratic and impactful involvement of patient organisations](#). The Patient Organisations' Manifesto lies at the heart of the EPF EU elections advocacy campaign launched at the end of 2023.

This was the largest ever structured discussion to determine a roadmap and a manifesto for the overall patient movement in Europe in a multistakeholder format. It aimed to bring key past and current stakeholders that have helped to shape EPF into the impactful organisation it has become, and, crucially, the next generation of young patient leaders to help carve out the future.

Keep reading and find a report of the event [here](#).



Shaping a new European agenda for patients

What we set out to do

- To contribute to EU4HEALTH Work Programme priorities that reflect the needs of the patient community;
- To strengthen the cooperation between EPF and stakeholders such as WHO European Regional Office, the European Medicines' Agency (EMA), or the Organisation for Economic Cooperation and Development (OECD);
- To raise awareness among the patient community on the importance of antimicrobial resistance and to actively engage with different partners active on this topic.

What we achieved

The EU4Health Programme

- Provided [recommendations](#) on the priorities of the EU4Health 2024 work programme;
- Collaborated with other civil society organisations to keep the issue of sustainable funding for patient organisations high on the EU agenda.

Cooperation with WHO

- Highlighted the importance of patient involvement in healthcare systems' reform at two milestone WHO meetings:
 - The 73rd session of the WHO Regional Committee for Europe in Astana;
 - The Tallinn Charter 15th Anniversary Health Systems Conference.

Cooperation with OECD

- Contributed to the Patient-Reported Indicator Surveys (PaRIS).

Antimicrobial Resistance (AMR)

- Joined and actively participated in various alliances and partnerships on antimicrobial resistance (AMR), such as the [AMR Stakeholder Network](#), the [AMR Patient Group](#), [AMR Multi-Stakeholder Partnership Platform](#), and the [Global AMR R&D Hub](#);
- Conveyed the patient voice in the European Commission's [AMR One Health Network](#);
- Coordinated with the European Centre for Disease Prevention and Control to mark European Antibiotics Awareness Day and published a [statement on the role of patients in combatting AMR](#).

Co-creating better health policy, practice, research, education through meaningful patient engagement

What we set out to do

- To enhance an impactful patient and patient organisations' participation in projects through direct engagement of members.



- Ensure robustness of arguments and legitimacy of positions of patient organisations during the Health Technology Assessment (HTA) consultations at EU level, raising awareness about the relevance of the HTA Regulation, increasing the capacity of EPF membership on HTA, increasing the quantity and quality of patient organisations' contributions to HTA assessments.

What we achieved

- Through projects such as Label2Enable, HEU-EFS, IDERHA, Gravitate Health, and H2O, patients took active roles in informing, designing, developing, and disseminating various project work streams. They contributed to the development of these projects via Patient Advisory Boards, User Advisory Groups, or Patient Advisory Groups.

- Through EUCAPA, we have raised awareness about the HTA Regulation and reached almost 20.000 people on social media, while building the training curriculum on HTA together with EURORDIS and UMIT Tirol;
- The HTA Simulation Workshop, which involved diverse EPF members and national patient organisations, led to a better understanding of the issues around patient involvement in HTA. The participants evaluated the workshop as being crucial in informing and preparing European patient organisations for the new processes.

Digital transformation that delivers for patients

What we set out to do

- To create a health data space that responds to patients' needs, including participation of patient representatives in the governance of the European Health Data Space (EHDS);
- To support a digital transformation that enhances patient outcomes and experiences and includes targeted initiatives to promote digital health literacy;
- To enable the patient community to play their role in debates on AI, supported by knowledge and appropriate resources, and enable meaningful involvement in data and AI-related projects and advocacy.

What we achieved

European Health Data Space (EHDS)

Noted the adoption of the European Parliament report on EHDS, particularly welcoming:

- The changes which included an opt-out mechanism for sharing health data;
- The increased focus on digital health literacy of patients and citizens;
- The provisions on judicial remedies of patients and citizens whose rights have been infringed;
- The provisions on uptake of real-world data and real-world evidence, application of digital health ethical principles, prevention of conflict of interest in EHDS governance and decision-making structures, and penalties for any infringement of the Regulation.

Data Saves Lives (DSL)

- Organised two in-person bootcamps building capacity on AI and registries, one in Lisbon (Portugal) and one in Brussels (Belgium), totaling 30 participants;
- Launched DSL Germany and DSL Netherlands, equipping patients at the national level with country-specific health data information;
- Released the DSL Toolkit 2.0, providing enhanced tools and resources for patients to navigate and leverage digital health data effectively.

AI in Healthcare

- Published the first ever position paper on AI use in healthcare from a patient perspective;
- Conducted two thematic webinars, attracting over 150 online participants, to educate and inform patient representatives about the implications of AI in healthcare.

30

DSL Bootcamp participants

DSL

Toolkit 2.0

150+

Registrations for two webinars on AI in healthcare

Accessing the healthcare we need with no discrimination

What we set out to do

- To ensure policymakers understand the patients' experiences of barriers to healthcare access and put the access high on policymakers' and health stakeholders' political agendas;
- To convey the patient perspective in the legislative debates;
- To achieve a revised legislative framework that delivers on the expectations of European patients.

What we achieved

The Pharmaceutical Legislation

- Published and disseminated our [recommendations for a patient-centered revision of the legislation](#), advocating for:
 - Medicines that meet patients' needs;
 - Improved patient access to medicines;
 - Increased patient involvement in the regulatory process.
- Developed, in collaboration with our members, a [framework for a patient-centred definition of unmet medical need](#);
- Advocated for continued focus on [paediatric medicines](#) in the new pharmaceutical legislation.

Medical Devices

- Followed the implementation of the Medical Devices Regulation and reacted to ongoing developments;
- Conveyed the patient voice as an observer at the Medical Devices Coordination Group (MDCG) and as part of two MDCG subgroups;
- As part of the [CORE-MD project](#), we recruited 23 patients and carers of patients to participate in consultations to assess patients' experiences with high-risk medical devices and the utility of Patient-Reported Outcome Measures (PROMs).

Patient access to safe healthcare

- Emphasised the role of patients in improving quality of care at a Meeting of the WHO European National Focal Points Networks on Quality of Care and Patient Safety;
- Represented EPF and the patient community at the HERA Civil Society Forum to highlight the need for a patient-centred approach to crisis preparedness and response in the EU;
- The results of the survey EPF conducted as part of the [PERISCOPE project](#) on the impacts of the COVID-19 pandemic on chronic diseases patients informed EPF's contributions to the work of HERA.

Strengthening patient communities across Europe

What we set out to do

- To strengthen and support the new generations of European patient advocates;
- To provide young patients with strategic skills for their growth;
- To provide a professional training to develop management skills for patients' organisations.

What we achieved

STYPA (7th Edition)

- Held the 7th edition of the STYPA programme, which brought together 29 young patient advocates;
- The training focused on medicines shortages, equipping participants with the knowledge and skills to address this pressing healthcare challenge.



Masters' Programme in International Patient Advocacy Management

- Partnered with Cattolica University to offer a comprehensive II level University Master Course designed to equip students with the management skills necessary for effective coordination and development of patient organisations in the healthcare sector.

EPF Youth Group

- Finalised the dissemination of the "Sexual Health and Well-Being" project;
- Developed the "Youth Involvement in Patient Organisations" project;
- Held spring and fall meetings;
- Recruited two new members;
- Represented the young patients' perspective in various events.

Advocacy 101 for Young Patients

- Continued to offer the online patient advocacy training course;
- 150 participants registered for the course.



Raising awareness and improving communication

What we set out to do

- To grow and better engage our online community and to offer strategic support to members;
- To manage EPF's reputation and unique position in the European health policy ecosystem.

What we achieved

Community growth & engagement. Strategic support

- Our LinkedIn profile surpassed 10.000 followers (November 2023), with a 24% higher engagement rate than competitors;
- Our Facebook reach increased by over 250% in comparison to the previous year;
- The Weekly Insiders has increased its opening rate by 6% compared to 2022, scoring an average 31% number of opens/ issue, placing it above the 28% average in the NGO sector;
- The Eu Patients' Podcast has almost 150 followers and has recorded 3.804 all time plays;
- The Patient Perspective newsletter recorded an increase in average numbers of opens per issue of approximately 20% (compared to 2022).

Reputation management

- To mark the 20th Anniversary of EPF, we launched the #EPF20 campaign, encouraging Board members, member organisations, and key figures from EPF history to reflect on how EPF's work shaped the last two decades of patient advocacy. The campaign unfolded in the lead up to the Anniversary event, gathering well over a million impressions across social media channels.

10.000 followers
on LinkedIn

250% increase
Facebook reach

**EU Patients'
Podcast**
3.804 all time plays

20% increase
The Patient
Perspective

**1 Million
Impressions**
#EPF20
Campaign



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