EPF European Patients Forum

EUROPEAN PATIENTS' FORUM

Impact Report 2023

Seizing the moment: fast-tracking patient and healthcare advocacy in 2022

Marco Greco, EPF President

2022 was an eventful year at the European Patients' Forum, during which we continued important work from the previous years of our strategic plan while preparing to celebrate the 20th anniversary of EPF.

Following the two extraordinary and intensive years of the COVID-19 pandemic, 2022 was the year in which the European Patients' Forum community seized the moment in shaping a new European agenda for patient advocacy, co-created better health policy and practice, reinforced research and education through meaningful patient involvement, and worked on building a digital transformation that delivers for patients.

This impact report shows the results of our activities and tracks the missions, goals, and milestones of that endeavour. In it, we look back on many important highlights in 2022. For example, as we aimed to bring the patient perspective to legislative and non-legislative EU actions to advance the European Health Union, we held regular meetings with EU institutions and stakeholders, participated in strategic meetings and discussions, and took part in joint activities within alliances and coalitions we are part of such as the EU4Health Civil Society Alliance, the EU Health Coalition, All Policies for a Healthy Europe, the AMR Patient Group, the European Health Parliament and many, many more.

We were heavily involved in conversations on the European Health Data Space, as we engaged extensively with key players in the EU institutions, stakeholders, and EPF members and succeeded in convincing policy makers in the European Parliament to take on board our proposals for making the EHDS regulation more patient-centric.

2022 also marked a successful EPF Congress gathering 150 participants onsite in Brussels, and gaining impressive media and social media traction. Our Congress continued the conversation on digital transformation and brought forward patient-centred solutions and in-depth explorations of digital health challenges.

I am proud of what we have already achieved in working towards our vision of creating a Europe where patient organisations are valued partners in creating equitable, person-centred, accessible, and sustainable healthcare systems, based on patients' unique expertise. We increased our reach, engaged and collaborated with more and more diverse stakeholders to achieve our objectives.

2023 is already shaping up to be equally impactful. As our journey towards meaningful patient involvement in healthcare policymaking is ongoing with renewed forces, we need continued commitment and collaboration from policymakers, healthcare professionals, industry and patient representatives alike. This is not a small feat but a considerable request, which is why we thank our community greatly for your support. We are grateful to have been able to count on your collaboration in 2022 and we hope to keep up the good work together.

Our story so far

Reflections on the current state of patient involvement in healthcare policy

The current state of patient involvement in healthcare policy in Europe is characterised by a growing recognition of the importance of including patients in decision-making processes. Over the past two decades, since the foundation of the European Patients' Forum there has been a significant shift towards a more patient-centred approach, driven by the understanding that patients are experts in their own experiences and possess valuable insights that can contribute to improving healthcare systems.

However, challenges remain in fully integrating patient involvement into healthcare policy. There is still a need to ensure meaningful and equal participation of patients from diverse backgrounds, including those with limited resources or marginalised populations. Moreover, efforts are required to bridge the gap between patient input and policy implementation, ensuring that patient perspectives are not merely tokenistic but genuinely incorporated into healthcare reforms.

While progress has been made, the journey towards comprehensive patient involvement in healthcare policy in Europe is ongoing, demanding continued commitment and collaboration from policymakers, healthcare professionals, and patient representatives alike.

How does EPF strategically address these challenges?

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

... and the stories we foster

I attended the European Patients' Forum's Summer Training for Young Patient Advocates (STYPA) in 2019. Before this I'd acted as an Expert by Experience in Finland, but a European level of lived experience was new. As the course was drawing to an end I felt happy of our time together but also perplexed. Patient advocacy was and still is in many ways different in Finland.

Wonderfully enough, EPF's STYPA is a community of peer support, personal growth and guidance. Expressing my hesitations I received a warm smile from a course leader and an advice to look deeper: what is Patient Advocacy for me. Looking back, I think that was a game changer question for me.

Since STYPA, I've succeeded as Chair for the 5th Edition of European Health Parliament - Committee for Mental Health and Healthy Workforce lobbying for a psychosocially more wellbeing work life. Soon after I completed studies in Finland for a profession in mental health care wanting to understand a professionals' perspective and to be able to contribute from my point of view with a similar vocabulary. I've collaborated with GAMIAN-Europe, Young Gastein and Helsinki University Hospital HUS among others and I was a member of Eurordis Rare2030 Young Citizens Panel.

by *Fanni-Laura Mäntylä*

My personal goals are to encourage cross-sectoral collaboration, mutual learning and more talk about health in a holistic way.

For the past three years I've been a member of the Patient Advisory Board for the IMI project EU-PEARL. At the moment I am studying a Bachelor of Humanities to become Workplace Developer.

Now, I'm eager to see where my path leads me next!

Fanni-Laura Mäntylä is a patient advocate and a STYPA alumni. Her story is one of empowerment, growth, and giving back. Her story is our story.

Our 2022 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 to create a comprehensive strategy that would help us achieve our five year strategic goals. With the collective knowledge and experience of our team, we were able to move closer to achieving these goals in a timely manner. Through team work and an unwavering commitment to our members, we are now one year closer to reaching these goals.

1

Shaping a New European Agenda for Patients

Empowering Patients: Forging a European Agenda to Prioritise Patient Engagement

What we set out to do	What we achieved
To influence legislative and non-legislative EU proposals and actions to advance a European Health Union with patients and citizens at the centre	• Regular meetings with EU institutions and stakeholders • Participation in the European Health Forum 2022 in Gastein, including interventions in several sessions • Joint statements with the EU4Health Civil Society Alliance
To restore meaningful operating grants and enhance the grant mechanism, improve consultation with patient organisations, .	• Contribution to the consultation on the EU4Health 2023 work programme and beyond • Reinstatement of the Operating Grants for 2023 as the results of the Joint advocacy with the EU4Health Civil Society Alliance
To strengthen the cooperation between the WHO European Regional Office and EPF, and advocate for the inclusion of patient representatives in policymaking	• Collaboration with WHO Digital Health flagship team on a session at EPF Congress • Follow-up of developments with WHO, in particular the Oslo initiative on medicines
To continue to foster meaningful patient involvement in medicines regulation and foster a continued working relationship with EMA	• Patients' and Consumers' Working Party (PCWP) regular meetings • Participating at ad hoc meetings, providing input to deliverables as requested • Regular information to EPF's members about EMA activities
To bring patient voice into OECD health-related initiatives	• Participation in OECD working groups on quality and outcomes in health care and on patient-reported safety indicators, as well as in the International Patient Advisory Committee for PaRIS
To establish patient-centric pan-European observatories that amplify the patient voice in their own care and health systems	• Launching the H2O observatories H2O HEALTH OUTCOMES OBSERVATORY

2

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

Inclusive Collaboration: Driving Positive Change in Health Policy, Practice, Research, and Education through Meaningful Patient Engagement

What we set out to do	What we achieved
To foster patient involvement and EU Research Programming	• We involved our members in our existing project and also in new proposals • We facilitated patient involvement in health professionals' education
To increase health literacy: • Awareness-raising on antibiotic resistance	• We marked European Antibiotics Awareness Day by hosting a podcast episode featuring a guest from ECDC and supported the campaign on social media
Patient involvement in R&D and Health Systems: • To involve patients in the EU's Health Technology Assessment (HTA) Agenda	• We prepared a successful project proposal: European Capacity Building for Patients (EUCAPA). It will ensure that patients and patient organisations have the necessary knowledge of the HTA process to be meaningfully involved in HTA
COMPAR-EU	• The project ended in December 2022, a final conference was held in November in Brussels, hosted by EPF. Together with the Patient Panel, lay summaries and communication materials were produced and translated in multiple languages
PERMIT PERsonalised MedicIne Trials	• EPF joined a series of collaborative workshops and trainings with all relevant stakeholders and co-developed the project's final conference event. We also produced lay summary materials of key project outcomes to ensure outreach to a wider public, including methods used to assign treatment options to patient clusters and clinical trials design.

2

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

EPF's project portfolio acts as a cross-cutting platform underpinning our advocacy, education, and communication pillars. Our aim is to maintain a relevant and impactful portfolio, which is strongly aligned to our key values, strategic goals, and priority topics to the patient community and provides a framework for member organisations to join forces with EPF and increase their direct participation, collaboratively ensuring meaningful patient involvement in projects.

Currently, we are implementing 13 EU projects and play a key role in three multi-stakeholder initiatives. In 2022 we concluded three projects (COMPAR-EU, PERMIT, PharmaLedger) and started two new ones (PROPHET and Label2Enable).

In 2022, the milestones achieved in some of our projects have truly illustrated the power of patient engagement.

- Patients and community representatives were partners in the project who actively contributed to the creation a truly patient-centred framework for platform trials. This is reflected in the design of the EU-PEARL Patient and Community Engagement Platform and the informational materials it hosts
- In 2022, we held a second public "Patient and Community Engagement Day" online, informing interested participants about what platform trials are and how patients can benefit

- The taskforce for patient engagement kicked off and met multiple times. EATRIS and EPF have developed a joint communication strategy (led by EPF) to raise awareness on the need for early involvement of patients in translational research.
- This work shaped the launch of the Patient Engagement Resource Centre, which took place in 2023

- The Patient Engagement Open Forum (PEOF) is as a patient-centered multi-stakeholder environment for co-creation of solutions to practice and develop patient engagement. PEOF is powered by EPF, EUPATI and the Patient Focused Medicine Development (PFMD).
- In 2022, PEOF brought together various stakeholders and experts to advance patient engagement, with three online events and one in-person reunion.

3

Building digital transformation that delivers for patients

Empowering Patients: Unleashing the Potential of Digital Transformation in Healthcare

What we set out to do	What we achieved
To renew the Digital Health Working Group membership and terms of reference	• We revised the mandate and the composition of the Digital Health working group, which is now composed of 16 members • .The EPF Congress replaced the spring meeting and a virtual meeting was held in December 2022
To shape an European Health Data Space that puts patients at the centre	• We engaged extensively with key players in the EU institutions, stakeholders and EPF members and we succeeded in influencing the European Parliament on several issues that will make the EHDS regulation more patient-centric
To increase our members' capacity to to better engage in debates, projects and initiatives on Artificial Intelligence in Healthcare	• We updated the EPF AI Knowledge Hub and organised three webinars with experts in the field of AI. The webinars were attended by over 300 participants • We published the reports on "Artificial Intelligence in Healthcare from a Patient's Perspective" and on "the EU Policy and Legislative Framework on Artificial Intelligence" • We monitored the legislative process on AI and included the topic in our EHDS advocacy activities
Data Saves Lives	• Data Saves Lives (DSL) Germany was approved by the Ministry of Health. DSL helped with a workshop at the F2F EPF Congress. The outcomes fed into the 2.0 version of the toolkit. DSL has also held its first F2F bootcamp with 20 patient organisation representatives in October 2022
EHDEN EUROPEAN HEALTH DATA & EVIDENCE NETWORK	• As part of the work we delivered for EHDEN, we launched a fourth course, focusing on patient reported outcomes (PROs) for patients. This fourth episode is co-created with H2O project partners and Patient Advisory Boards representatives. It expands on the first three courses produced by EPF

4 Accessing the Healthcare We Need with No Discrimination

Equal Opportunities in Healthcare: Breaking Barriers and Promoting Inclusive Access for All

What we set out to do	What we achieved
To monitor and engage with the EU Medical Devices Regulation (2017/745)	• In the context of emerging reports of disruptions in the availability of many medical devices in the EU, we issued a call for action in order to ensure patients' continued access to safe, high-quality medical devices across the EU
To engage with the legislative initiative on cross-border activities of associations	• EPF welcomed the proposal and joined other civil society organisations via the Civil Society Europe network in issuing a position statement supporting the creation of a new legal form for associations, allowing recognition in all Member States to fully benefit from the single market as well as to adopt common minimum standards based on fundamental rights
To renew the Universal Access to Healthcare Working Group membership	• We revised the mandate and the composition of the Universal Access to Healthcare Working Group
To raise awareness on patient safety as a global health priority	• EPF supported WHO's 2022 campaign for Medication Without Harm. Our work has particularly called attention to the need to empower patients and family members as active contributors to patient safety in healthcare environments, and in self-care
To engage with the ongoing revision of the EU general pharmaceutical legislation	• In the context of emerging concerns over antimicrobial resistance, we called for five key points to be included in the forthcoming proposal for a Council Recommendation on AMR. At the same time, we noted that the upcoming review of the EU general pharmaceuticals legislation will further provide a unique opportunity to encourage research and development of new antibiotics and support sustainable and affordable access to both old and new antibiotics

5

Strengthening Patient Communities across Europe

Fostering Unity and Empowerment: Building Strong Patient Communities throughout Europe

What we set out to do

To strengthen and support new generations of European patient advocates

To provide young patients with the strategic skills for patient advocates

To provide a professional training to develop management skills for patients' organisations

What we achieved

THE SUMMER TRAINING COURSE FOR YOUNG PATIENT ADVOCATES (STYPA) 6TH EDITION

In 2022, EPF conducted the sixth edition of STYPA held in the European Youth Centre, in Strasbourg, France. In 2022, STYPA was back to its original structure having both online and face-to-face modules. The topic was “Sexual Health and Well-Being for Young Patients”. The training continued for 3 days and brought together 38 young patient advocates, coming from different European countries such as: Italy, Georgia, Romania, Spain, Bosnia & Herzegovina, Greece, Croatia, Cyprus, Belgium, Germany, the UK, Turkey, Sweden, Portugal, Poland, Czech Republic, Slovenia, Switzerland, Bulgaria, Ireland, Serbia, Albania, and others. The young patients represented different disease areas and chronic conditions (many of them living with multiple conditions)

ADVOCACY 101

We launched the Advocacy 101, online course: an easy-to-access, tailored training course to help young patients to build a solid base of knowledge and understanding of patient advocacy. The entire training is available on a dedicated online platform. Once on the platform, participants have access to videos, interactive activities, exercises, bite-sized informational content, and a library of advocacy resources. The content provides participants with key elements to help them start their journey into patient advocacy

MASTER IN INTERNATIONAL PATIENT ADVOCACY MANAGEMENT

We partnered with Cattolica University (Patient Advocacy Lab, of the Graduate School of Economics and Management of Healthcare Organizations (ALTEMS), of the Graduate School of Psychology Agostino Gemelli (ASAG), in collaboration with EngageMinds Hub and the Foundation Policlinico universitario “Agostino Gemelli” IRCCS) to launch this unique Master Programme. The course will provide to the student the management skills required for a successful coordination and development of the activities of patients' organisations

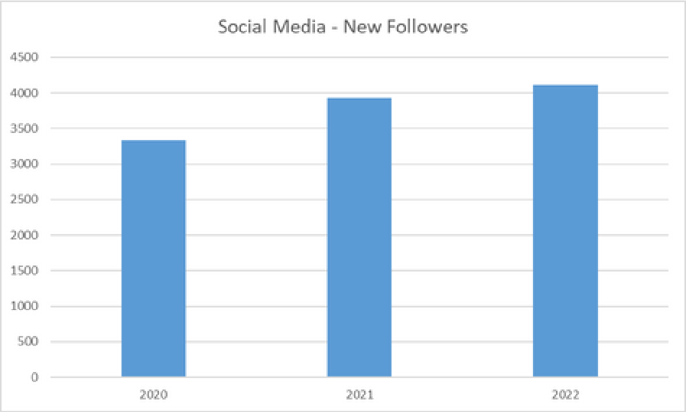
6

Raising awareness and improving communication

What we set out to do

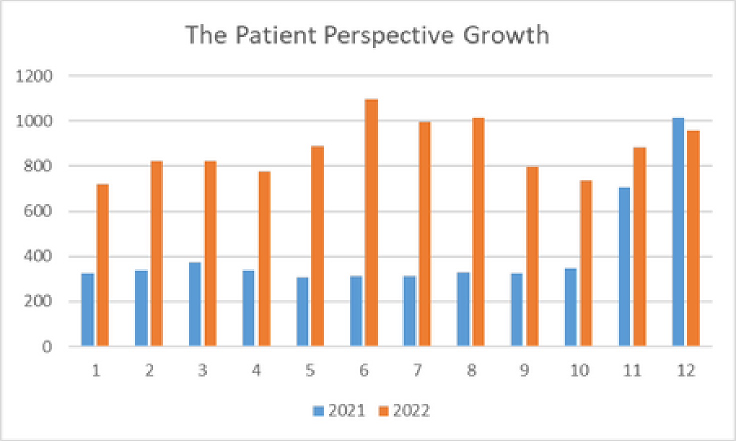
What we achieved

To grow our online community



In 2022, over 4000 new followers joined our social media channels, reinforcing the ascending trend that EPF channels have recorded over the last three years

To amplify the patients' voice



One of the main goals of the communications team was to optimise the existing channels and to use our existing communication channels to reinforce and louden the patients' voice

The Patient Perspective Newsletter has achieved a major growth in terms of number of total opens, in comparison to 2021

To host conversations on relevant healthcare topics

The EU
Patients'
Podcast

In 2022, we leveraged our podcast to include more membership activities and conversations with policymakers to ensure patients are connected to decision-makers

Key statistics – EPF Congress 2022

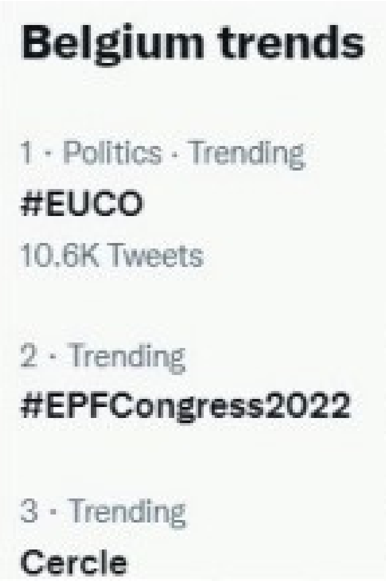
150 PARTICIPANTS ONSITE

#2 TWITTER TRENDING TOPIC IN BELGIUM

325 REGISTRANTS

2 EXCITING DAYS

40 SPEAKERS



Belgium trends

1 · Politics · Trending
#EUCO
10.6K Tweets

2 · Trending
#EPFCongress2022

3 · Trending
Cercle

Stella Kyriakides | @SKyriakidesEU
Twitter · 35 minutes ago · in English · Brussels, Belgium

Pleased to address #EPFCongress2022 today.

➡️🇪🇺 health policy is first and foremost about listening to patients and putting their needs first.

The building blocks of a strong #HealthUnion such as the European #HealthData Space will help to make this a reality.

#WeAreEPF

The patients' voice has never been more important than right now. We will continue to work with our partners – healthcare professionals, policy-makers, public health NGOs, industry, researchers, regulators and many others – in our mission to empower patients to take an active role in improving healthcare. Whether near or far, working remotely or at the office, our doors and inboxes are always open.

Join us in making an impact for sustainable and equitable patient-centred health systems of the future!

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EPF European **Patients** Forum

Let's stay in touch!