2025 EPF Congress

Shaping the Future of Healthcare

Preparedness for Health Systems' Resilience

26-27 November 2025

the Double Tree Hilton, Brussels, Belgium

This report captures the key insights and outcomes of the 2025 Congress, shaping EPF's strategic priorities and next steps.

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The journey *so far...*

It has been six years since the first EPF Congress in 2019. The idea was simple but transformative: to create a space that put patients at the centre of the health ecosystem.

A defining insight from that inaugural event was the recognition that patients are — and must be treated as — partners in knowledge in both medical care and policy developments.

Our second Congress, held online in 2021, brought this conversation firmly into the digital realm. Against the backdrop of COVID-19, the focus shifted to how digital transformation was rapidly reshaping healthcare and why patients must be involved not only in using new tools, but in shaping the decisions around data, access, and innovation.

In 2022, we continued that momentum by taking the digital transformation debate further, moving from reflection to action. With stakeholders coming together again, the Congress deepened the discussion on how digital health can truly deliver for patients, and highlighted trust, collaboration, and patient involvement as essential conditions for progress.

This year's Congress created space to build on these foundations, reflect on the lessons of COVID-19, and examine the steps Europe has taken — and still must take — to strengthen its future resilience. We stand at a critical juncture, and the decisions Europe makes now, and the role patients play within them, will shape the health and well-being of generations to come.

PARTNERSHIP (2019)	EDUCATION (2021)	TRUST (2022)
The move to participatory patient management puts patients at the centre	Education is essential to empowering patients and stakeholders	Trust is the foundation of digital transformation
Patients are meaningful partners in knowledge	Co-creation with patients can transform digital health	Governance must meaningfully include patients
Shared decision-making maximises value in healthcare	Trust is essential when working with patients	Digital transformation must reduce, not widen, inequalities

A snapshot:

EPF Congress 2025

02
AMAZING DAYS

37
SPEAKERS

250
DELEGATES

FROM ACROSS EUROPE

"Patient organisations are not defending private interests. They are defending public interests, they are defending European citizens interests. They are part of a vibrant European democracy."

Participant, EPF Congress 2025

Key learnings & *takeaways*

Europe must act now to protect health

We cannot let the lessons of COVID-19 fade. Geopolitical shifts are sidelining health at a time when vigilance, long-term strategy and investment are needed most.

Health threats are rising, but so are the opportunities

AMR, climate change, and misinformation are all very real risks. Europe has the expertise, data and technology to respond and it must do so ethically and responsibly.

A whole-of-society approach includes patients

Patients' needs should anchor every decision. Their health and well-being must remain a core principle of policy design and preparedness planning.

Trust shapes the uptake of public health interventions

A bridge between communities and policy makers, patient organisations help ensure reforms are relevant, understood, and accepted by the communities.

Patient involvement must be formalised and protected

Clear legal frameworks make engagement systematic rather than optional. Patients must be empowered to shape decisions from day one, not simply observe them.

Capacity and resourcing determine effectiveness

Operational funding, training, and skills development are essential for patient organisations to contribute meaningfully on complex technical issues.

Young voices are essential, not symbolic

Young patients will live longest with today's decisions. They bring key insights and expertise to policy discussions, and their voice must be embedded at every stage.

We must fight for health to have its place

Cross-sector collaboration is key to keeping health, equity and patient-centred care high on national and regional policy agendas.

Solidarity must remain Europe's guiding principle

Health is not an expense; it is an investment. Ensuring no patient becomes a "second-class citizen" requires sustained commitment to equity and universal access.

When patient voices guide decisions from the outset, we build ethical, value-driven and sustainable health systems that work.

Now more than ever, we must show resilience, make our case, and demonstrate our value — holding policymakers accountable and calling for the investment, resources, and support needed to ensure the future of health is truly patient-centred.

Event

proceedings

"Whole-of-society means 'all hands on deck'. It is extremely important that civil society organisations representing citizens are really part of this effort."

Giorgos Rossides, Senior Expert, Health Emergency Preparedness and Response (DG HERA), European Commission

Opening *keynote*

Andreas Christodoulou opened the Congress by reflecting on the power of community within the health ecosystem. He spoke of the honour of bringing together such diverse voices and reaffirmed the belief that patients are partners in shaping the system.

Recounting his own experience with cancer, Andreas reminded participants that healthcare is more than treatment. It is also empathy, access, and the feeling of being seen. With this, he described the power of the collective voice and reinforced how movements like EPF can change systems from within.

He also noted that this year's Congress arrives at a difficult and defining moment for Europe. The geopolitical landscape is uncertain, and the policy decisions made this year will define our future.

That's why EPF matters.

When the landscape is uncertain, our collective voice must be strong, clear, and united. Yet increasingly, civil society and patient organisations are being forced to do more with less. The next two days, he argued, are more than a programme. They are a commitment to strengthening that ecosystem and reinforcing the role of patient organisations within it.

"The challenge is to make sure that every reform, every innovation, and every policy starts with one question: what does this mean for patients?"

PLENARY SESSION 1

COVID-19 five years later:

have our health systems recovered?

Aim: To assess current preparedness, share cross-sector perspectives, and discuss patient-centred strategies to strengthen resilience and support alignment between national and EU-level planning.

Key takeaways

- **COVID-19 impacted every dimension of care**

  Emergency systems were overwhelmed, continuity of care collapsed, and structural weaknesses were exposed. In the scramble to find solutions, the engagement of patient organisations was sidelined — an oversight that weakened communication, fuelled mistrust, and undermined public health interventions.

- **Europe is better positioned, but far from prepared**

  The European Health Union, HERA, and the EU Preparedness Union Strategy strengthened cross-border collaboration, surveillance, and resilience. But these gains are fragile, and health and preparedness risk being deprioritised amid mounting geopolitical pressures.

- **Preparedness must be "dual-track"**

  Systems must be able to manage outbreaks, ensure access to diagnostics, therapeutics, and public health intelligence, all while maintaining routine services and protecting vulnerable patients.

- **Resilience depends on people**

  Preparedness means protecting those most affected in a crisis, including patients, communities, young people and healthcare professionals. Supporting their physical and mental well-being, inclusion, and resilience is key to delivering real-world protection.

- **Cross-border threats need cross-border action**

  Diseases do not respect borders. Stronger alignment between EU and national preparedness systems is essential for timely information sharing, joint action, and equitable protection across Member States.

Patient organisations are trusted messengers and a vital bridge between health systems and communities. Formalising their engagement through proactive legislation is key to ensuring a whole-of-society approach to pandemic preparedness.

Moderated by **Nicola Bedlington,** CEO and Founder, Millwater Partners, with:

Ole Johan Bakke, President, Standing Committee of European Doctors (CPME)

Pierre-Yves Brevet, Senior Manager IVD, MedTech Europe

Marko Korenjak, President, European Liver Patient Association (ELPA)

Prof. Karine Lacombe, Professor, Sorbonne University

Willy Palm, Senior Advisor, Representation Office to the European Union, WHO

Giorgos Rossides, Senior Expert, DG HERA, European Commission

PLENARY SESSION 2

Human-centred innovation:

rethinking care in the age of digital health & AI

Aim: To assess how digital and AI can strengthen sustainable, human-centred care, and the conditions needed to protect compassion, accountability and human connection.

Key takeaways

- **Innovation must deliver real improvements**

  AI and digital tools can streamline diagnostics, improve continuity and strengthen clinical decisions. For patients, point-of-care testing, wearables and disease-specific GPTs support self-management and the democratisation of healthcare.

- **Technology must amplify humanity, not replace it**

  Effective innovation should free time for meaningful patient–clinician exchanges, reflect the nuances of lived experience, and position the patient as an equal partner in their healthcare journey.

- **Data is proxy for trust**

  The Council of Europe's Framework Convention on AI sets binding rules to ensure it is developed and used in ways that safeguard people's rights. A complementary report underscores the need to protect patient autonomy, inform patients when AI is used, and give them the option to see non-AI alternatives.

- **Innovation requires legislation and investment**

  Europe's regulatory approach underpins the development of new technologies, with examples including GDPR, the AI Act, the European Health Data Space Regulation, cybersecurity rules, the Medical Devices Regulation (MDR) and Health Technology Assessment (HTA) regulation. This must be paired with investment in data infrastructure and digital literacy.

- **Mind the digital divide**

  With around 40% of people lacking digital access or skills, equal access is essential. Greater focus on affordability, usability and patient-centred design is needed to ensure innovation reaches everyone.

> *Embedding lived experience from the outset helps ensure technologies are accessible, representative and genuinely human-centred, grounding them in empathy and partnership so patients feel seen, heard and validated.*

Moderated by **Katriona Brooksbank,** Regional Head of Innovation, NHS Greater Glasgow and Clyde, with:

Prof. Lara Bloom, CEO & President, The Ehlers-Danlos Society

Tomáš Doležal, Chair, Council of Europe Steering Committee for Human Rights in the fields of Biomedicine and Health (CDBIO)

Marco Marsella, Director, Digital, EU4Health and Health systems modernisation, DG SANTE, European Commission

John Soto, Senior Vice President - International, Butterfly Network

PLENARY SESSION 3

Building a culture of *patient-centred innovation*

Aim: To define patient-centred innovation and identify the barriers and solutions to meaningful patient involvement.

Key takeaways

- **Innovation must make a difference to the patient**

  Competitiveness must be driven by equity rather than speed. True innovation responds to patient needs and delivers the right product, at the right moment, and at an affordable price. Achieving this demands innovation in systems and processes as well as in technologies and medicines.

- **Structural reforms are boosting competitiveness**

  Europe's competitiveness is under pressure, with fears that regulation hinders innovation. HTA regulation and Joint Clinical Assessments help mitigate this by aligning assessments and accelerating shared evaluations across Member States.

- **Europe's strength lies in patient-centred innovation**

  Universal health systems, patient registries, and a long-standing tradition of involving patient advocates give Europe a unique competitive advantage we must leverage.

- **Innovation requires richer patient evidence**

  Patient-reported outcomes and lived experience data must sit alongside clinical evidence to shape trial design, regulatory decisions, impact assessments, and organisational pathways.

- **We must remove the barriers to patient involvement**

  Despite their value, patient experts face barriers including funding cuts, restrictive conflict-of-interest rules and low compensation. Meaningful involvement requires sustainable funding, clear frameworks, and a cultural shift that treats patients as equal partners.

Real competitiveness depends on patient involvement. Embedding expert patient voices throughout development cycles will cement Europe's position as a leader in value-driven, patient-centred innovation that delivers results people can feel.

Moderated by **Valentina Strammiello,** Interim Executive Director, EPF, with:

Marco Greco, President, EPF

Marco Marchetti, Director, HTA Department, National Agency for Regional Healthcare Services (AGENAS) and Co-Chair, HTA Member State Coordination Group (HTACG)

Monica Hildegard Otto, Director for Executive Education in Government, Health & Non Profit Division, SDA Bocconi

Vanessa Pott Semêdo, Head of Global Patient Engagement, Boehringer Ingelheim

Prof. Steffen Thirstrup, Chief Medical Officer, European Medicines Agency (EMA)

DAY 1 WORKSHOPS

1. AMR preparedness:

how healthcare systems and patient organisations can work together

AMR is advancing faster than systems can respond. Tools like the WHO Roadmap on AMR for the European Region and Accountability Index provide a framework for action, yet many countries still lack the basic build blocks to respond, with national action plans lacking visibility and funding.

Diagnostics are an essential part of this, especially for people with chronic conditions, but they must be paired with prevention and stewardship approaches that are tailored to different conditions, settings and needs. This requires meaningful patient engagement and a clearer understanding of how AMR affects people's lives.

"The patient experiences could really bring fresh perspectives, and new life to the issue... Those voices and characteristics could lead on to renewed advocacy."

Ulrica Dohnhammar,
Swedish Research Council

Start with the basics: implement national action plans, embed patient engagement early, and deliver clear, targeted information that supports effective AMR stewardship.

2. Healthcare delivery:

public health, patient care, and the environment: a solvable equation?

Health and climate are locked in a negative cycle. Breaking this loop means building health systems that are both climate-resilient and environmentally sustainable.

Priorities for change include better education on the link between health and the environment, more accessible communication, and stronger cooperation across stakeholders. Prevention also emerged as a tool to ease pressure on national health systems, especially when supported by system changes and regulations that enable sustainable models of care.

Patients must be co-creators of sustainable healthcare. EPF has a key role to play in driving this change and convening stakeholders at community, national and EU levels.

3. Health and wealth:

can the EU budget drive a resilient future?

Integrating health across the EU new Competitiveness Fund may reflect a wider trend towards deprioritisation. To counter this, we need to reshape the narrative and position health as a strategic asset for society and the economy — not just as an expense or "competitive" advantage.

Prevention, early detection and repurposing show how health policy delivers long-term benefits, while the EU can also add value in areas such as the ageing workforce. Strengthening programmes like the Innovative Health Initiative (IHI) and cross-border research could further reinforce this.

All of the above requires a clear and robust evidence base. Protecting the role of civil society is equally important, as the loss of operating grants risks seeing patient voices removed from key conversations.

Stakeholders must unite behind a clear, coordinated narrative that demonstrates the social and economic value of health.

With thanks to

our workshop moderators and speakers

WORKSHOP: 1

Claudia ***Louati***

Head of Policy, EPF

Borislava ***Ananieva***

Capacity Building Officer and Patient Advocate, EPF

Ulrica ***Dohnhammar***

Senior Research Officer, Swedish Research Council

Dr. Danilo Lo ***Fo Wong***

Regional Adviser Control of Antimicrobial Resistance, World Health Organization/ Europe (WHO/ Europe)

Jo ***Taylor***

Vice President Corporate Affairs, Shionogi Europe

Christian ***Terreaux***

Public Affairs Director, OM Pharma

WORKSHOP: 2

Anke-Peggy ***Holtorf***

Secretary of the Board at Health Technology Assessment international (HTAi)

Gabriella ***Abruzzo***

Climate Projects Officer, Health Care Without Harm Europe (HCWH)

Susanna ***Palkonen***

Director, European Federation of Allergy and Airways Diseases Patients' Associations (EFA)

Jurate ***Svarcaite***

Director General, Association of the European Self-Care Industry (AESGP)

WORKSHOP: 3

Yann ***Heyer***

Policy Officer, EPF

Florence ***Berteletti***

Secretary General, The European Alcohol Policy Alliance (Eurocare)

Dominika ***Domanska Baer***

Director Government Affairs & Policy Medtech EMEA, Johnson & Johnson

Marie ***Morfouace***

Scientific Lead, Gustave Roussy

Loredana ***Simulescu***

Executive Director, Biomedical Alliance in Europe

DAY 2 WORKSHOPS

4. No one left behind:

equity and solidarity in cross-border crisis response

Equity in crisis research is about more than equal treatment; it is about giving people what they need to achieve comparable outcomes. For patients, this means making sure all groups have the information and support they need to participate meaningfully.

Despite this, low health literacy, weak interoperability and communication, poor data sharing, and unequal access to prevention, diagnostics and treatment persists. Overcoming these barriers demands coordinated action across stakeholder groups, together with dedicated patient engagement. Improved health literacy, stronger communications and adaptive trial designs were identified as key enablers of this.

"Trust is a key concept: we need to demystify clinical trials and involve patients as co-creators, not just participants."

Maria Dutarte,
Executive Director, European Patients' Academy on Therapeutic Innovation (EUPATI)

Establish an EU-level taskforce to coordinate cross-border crisis research and develop a framework that embeds meaningful patient engagement in all stages of crisis research and clinical trial development.

5. Value in crisis:

rethinking what matters in health

Rising healthcare demand and limited capacity puts forth the need to phase out low-value care and redirect resources to what patients truly value. Patients are essential partners in defining this, yet fragmented pathways, inconsistent data sharing, and outdated tools hinder meaningful involvement.

Collaboration is key to creating a shared definition of value and success that works across different stakeholders and therapeutic areas. This must be supported by evidence that goes beyond metrics to capture real patient experience, ensuring decisions are grounded in a holistic understanding of need.

Improve how evidence is collected and presented, ensure sustainable funding for patient organisations, and embed a patient-centred understanding of value across health systems.

DAY 2 WORKSHOPS

6. Addressing access needs

through innovative models for pricing & reimbursement

There are deep inequalities in access to medicines across Europe. Innovative pricing and reimbursement models — such as adaptive cost-effectiveness thresholds, value-based approaches, managed entry agreements, joint procurement, and risk- or outcome-based contracts — can help narrow these gaps. But they are not a quick fix for deeper structural issues. Strengthening data infrastructure, clarifying evidence requirements, and modernising outcome measures are essential to making these approaches work in practice.

Although the topic is complex, patient engagement is critical, providing insight into what outcomes mean in real life and ensuring that decisions remain relevant and fair.

"Collaboration between different stakeholders is key. We have to work together to find solutions for the patients, because the patients cannot wait."

Luca Morlotti,
Vice President and Head of International Market Access, MSD International

To build on the lessons of COVID-19, we must advance innovative financing models that can better manage uncertainty and predictability, address high medicine costs, and improve timely patient access, deepen collaboration especially at the EU level and equip patient representatives with the training to have the knowledge to contribute meaningfully to the decision that determine whether patients will ever access the treatments they need.

With thanks to

our workshop moderators and speakers

WORKSHOP: 4

Amanda ***Bok***

Chief Partnership Officer, The Synergist

Niklas ***Blomberg***

Executive Director, Innovative Health Initiative Joint Undertaking (IHI JU)

Pauline S. ***Delahaye***

Researcher & Populariser, Vaccination et Lien Social (VLS)

Maria ***Dutarte***

Executive Director, European Patients' Academy on Therapeutic Innovation (EUPATI)

Melanie ***Hoste***

Implementation Scientist & Qualitative Researcher, University of Antwerp

WORKSHOP: 5

Valentina ***Strammiello***

Interim Executive Director, EPF

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President, European Federation of Neurological Associations (EFNA)

Marco ***Boeri***

Director of Preference Research & Global Lead Patient-Centered Outcomes, OPEN Health

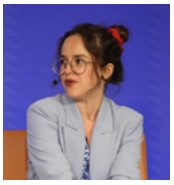
Michele ***Calabrò***

Executive Director, European Regional and Local Health Authorities (EUREGHA)

Rasmus ***Møgelvang***

CEO, Rigshospitalet

WORKSHOP: 6



Solène ***Jouan***

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Board Chair, Czech National Association of Patient Organisations (NAPO) and Board Member, EPF

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Policy Officer, Unit D.2 "Medical products: quality, safety, innovation," Directorate-General for Health and Food Safety (DG SANTE), European Commission

Luca ***Morlotti***

Vice President and Head of International Market Access, MSD International Business GmbH

Valérie ***Paris***

Senior Economist, Organisation for Economic Co-operation and Development (OECD)

Prof. Carin Uyl-de ***Groot***

Professor, Erasmus University Rotterdam

Measuring patient involvement

in national healthcare policies

50%

of patient organisations have a legal or policy basis for involvement; one third have none.

2 in 3

report a lack of transparent criteria for accessing decision-making.

91%

cite "lack of resources" as the main barrier to involvement.

The EPF Barometer on Patient Involvement provides the first comparative snapshot of patient organisation engagement across Europe. Early findings show that despite widespread consultation, gaps in transparency, implementation and resourcing still limit meaningful involvement and that quality relies on clear frameworks, partnership and resourcing.

"It institutionalised patients' rights"

Charlotte Roffiaen,
European Affairs Advisor, France Assos Santé

France's legal framework embeds patient and user representation across the health system and gives accredited organisations a formal role. These structures make involvement systematic rather than optional, even if consultation is not always consistent.

"We [patients] are partners together with the State"

Nikos Dedes,
Secretary General, Greek Patients' Organisation

In Greece, legal recognition enables patient organisations to co-design and evaluate health policies, and has shown that patients are champions of sustainable rather than maximalist demands. Their push for user-led evaluation is helping anchor policymaking in real experience and strengthen system-wide accountability.

"If we lose the solidarity-based approach, then we really need to worry about universal coverage"

Stefan Eichwalder,
Deputy Director-General, Federal Ministry of Labour, Social Affairs, Health, Care and Consumer Protection, Austria

Breaking silos and sharing responsibility are key to scaling best practices. With the increasing risk of health system financialisation, protecting solidarity and universal health coverage, requires a shared commitment from policymakers and patient organisations.

Full findings of the Patient Involvement Barometer will be published in 2026.

KEYNOTE SPEECH

Welcoming

Olivér Várhelyi,
EU Commissioner of Health & Animal Welfare

The Commissioner opened by recognising that Europe stands at a critical juncture, and by reaffirming the values that make its health system unique: universal coverage, and the principle that every patient should have access to the latest, state-of-the-art therapies.

He went on to outline the major EU initiatives set for adoption by the end of the year, including the upcoming pharmaceutical reform, which will streamline access to safe and effective medicines through a patient-centred approach. He also highlighted the role of the Critical Medicines Act — shaped by input from patient organisations like EPF — which is designed to reduce dependencies on essential medicines, strengthen supply chains, and minimise drug shortages.

Looking forward, Várhelyi also previewed a major new health package, which includes a Biotech Act to expedite lab-to-patient breakthroughs, a comprehensive cardiovascular health plan, and a review of medical device rules to ensure new technologies reach people quickly and safely.

Throughout his remarks, he returned to a simple principle: reform only succeeds when it works on the ground. Continued dialogue with patient organisations, he stressed, is key to ensuring that Europe delivers for every patient.

"For innovation to be successful, it must focus on patients. This is precisely where biotech, AI and big data offer vast opportunities: they allow us to deliver personalised prevention and tailored, cutting-edge therapies. To turn these opportunities into reality for patients, we need to reshape Europe's health framework quickly."

Youth in *focus*

"Young people are called leaders of tomorrow, but we are active advocates today... Let our voices shape what happens now."

Erato Markantoni
on crisis preparedness post COVID-19

For young patients the threat of COVID-19 was two-fold: the fear of contracting the virus and disruptions to regular care. Recovery is not about replacing what was lost. It's about building systems that are shaped by the lessons learned. This means embedding young patient voices into preparedness planning, investing in the health workforce to protect continuity of care, and ensuring stockpiling and crisis-communication strategies are inclusive.

Young patients cannot be last in line again. Europe will only be prepared when we have built systems that are ready to listen, and that young people know they can trust.

"When innovation and empathy move together, technology is not just a tool, it becomes a true form of support."

Aedan Kaal
on the role and future of digital health

Health doesn't just happen in hospitals or clinics. It's on our phones, in portals, and in the data flows that shape our care. The advantages are obvious. For health professionals, digital technology can take over standard tasks, reduce human error, and strengthen clinical decision-making. For patients, digital tools improve early detection, create new ways to access care, and empower us through remote monitoring.

But there are challenges too. Digital health carries a risk of bias, misinterpreted symptoms, and the prioritisation of speed over human connection. As we move forward, we must embed trust as a core design principle, build systems that reflect a diversity of patients, and that remain simple, ethical, and transparent.

"Young people are ready to contribute meaningfully. We are not the future of patient involvement, we are part of the present."

Konstantina Boumaki
on youth involvement

Young patients experience health systems during some of the most important parts of their life. We see when systems work, and when they don't, and it is when young people feel left out of these systems that trust starts to weaken.

We must counter this by making sure young people are involved in health policy and delivery — and that involvement starts at an early stage, not once agendas are set.

Young patients don't lack ability. They lack support, trust and respect. It is a gap that EPF is determined to help bridge.

Closing *remarks*

EPF President Marco Greco closed the Congress with an honest reflection on how difficult this year has been for patient organisations and for EPF itself. There were moments when holding the Congress felt almost impossible — and that, he said, became a reason to go ahead.

He offered an overview of the themes explored, recognising the gaps and challenges but also the opportunity for Europe to become a leader in patient-centred healthcare.

The event closed with a clear recognition of the role and value of patient organisations. He underscored the need for greater resources, and urged the community to show resilience, demonstrate value, strengthen its collective voice, and work together towards a true European Health Union.

"A Europe where no patient's access to quality care depends on their country, income or disease area — and where patient organisations are recognised as essential partners in decision-making — is possible and has to be pursued."

Marco Greco
EPF President

With thanks

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