

impact report

2018

We represent
the interests of
150m
patients and carers
in Europe



Credit: Adrienne Gilligan

Building communities



When you have a disease or a condition that influences your life, you learn a lot about patience. The queues are endless, the diagnoses are many and finding the best care plan for you just takes time. But patients are the most resilient people I know and when they face challenges, they don't stop. They transform them into opportunities. That's why patient organisations are the essence of active community engagement. They are the impatient patients that don't only look at their individual advantage, but look at how we can advance healthcare for all.

Patient organisations are invaluable partners in society and in the policy process. They are co-designers, facilitators, innovators, peer supporters, researchers and advocates. They are unique in helping policy-makers and industry understand the personal experience of living with a disease or a condition.

In the last 15 years, the European Patients' Forum has been an active player in bringing people together to (re-)define the role of patients

in society and (re-)think how our healthcare systems can be more resilient, patient-driven, accessible and affordable for all. Our reach has grown alongside our work portfolio. From 13 members, who started the journey in 2003, we have today 72 members, representing the interests of more than 150 million patients and their carers. Throughout, we have been working with the same enthusiasm and commitment on patient empowerment, health literacy, healthcare access, non-discrimination, digital health and sustainable patient organisations.

As we continue to grow, we remain committed to represent the patient voice in a united, coherent and influential way and to drive better health in Europe. We want to grow even further reaching out with impactful programmes and activities. The future is ours.

Marco Greco
President,
European Patients' Forum

15 years of EPF

2003–2006

Our members: the starting point

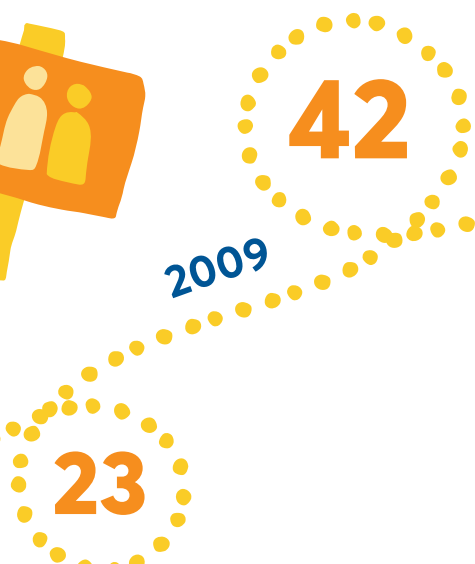
In 2003, thirteen patient organisations created EPF. A permanent Secretariat was established in Brussels, and patient groups had new opportunities to build alliances and trust, and to lay the foundations for patient advocacy on cross-cutting issues.



2009–2012

Higher visibility, higher representativeness

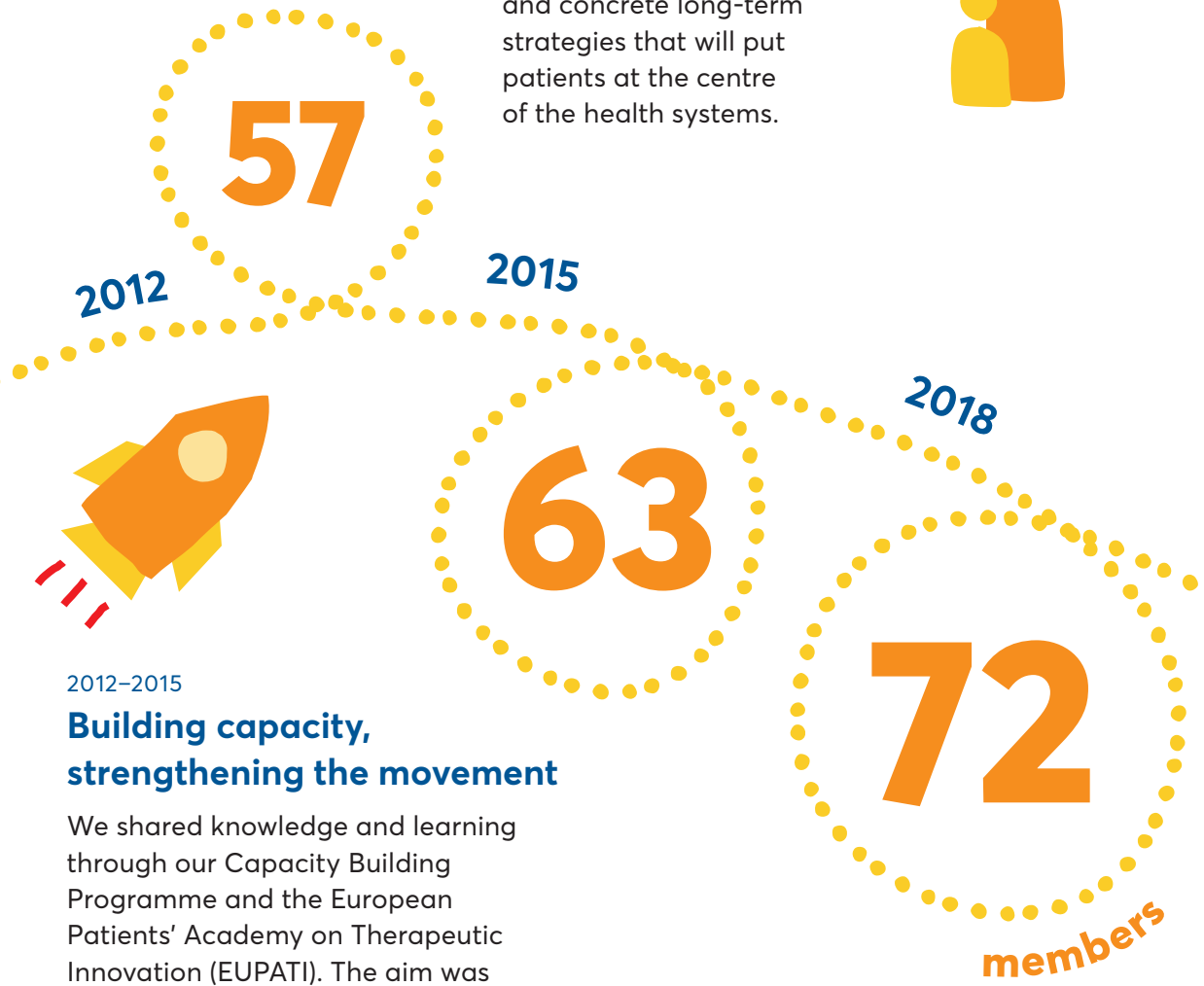
We reaped the benefits of the year-long European elections campaign “150 Million Reasons to Act” and our Patient Manifesto. Many MEPs committed to support our mission. In addition, the Youth Group was established as the backbone of the EPF Youth Strategy to explore how young patients’ needs could be better recognised by patient organisations through their effective involvement and empowerment.



2015–2018

Campaigning for our key pillars

We ran major thematic campaigns focusing on our key pillars: patient empowerment and patient access. Our goals were to achieve political commitment and concrete long-term strategies that will put patients at the centre of the health systems.



2012–2015

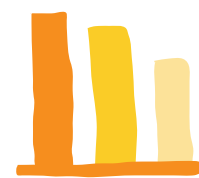
Building capacity, strengthening the movement

We shared knowledge and learning through our Capacity Building Programme and the European Patients’ Academy on Therapeutic Innovation (EUPATI). The aim was to reinforce patient groups’ capacity to inform and advocate in order to enable them to become effective actors in driving positive change in all issues affecting patients at both national and European levels.

2006–2009

Policy focus and new challenges on the horizon

We engaged in crucial policy areas (patient safety, health literacy, pharmaceutical legislation) and led our first EU-funded project: Value+. This marked the start of our involvement in European projects to gather evidence-based information from patients to substantiate our policy work.



Patient empowerment

From patient-centred to patient-driven

Patient empowerment is one of the key elements of patient-centred healthcare, and one of EPF's strategic goals. Patients are more than their health condition. They are people with needs, expertise, values and rights. Patient empowerment is about building patient-driven care where the patient is not only at the centre of their care, but they are the most important member of their care team.

The EPF Roadmap for Action on Patient Empowerment focuses on 8 priority areas for action: health literacy & information, professional training & skills, self-management support, patient-driven technology solutions, patient involvement in patient safety, patient-centredness in healthcare, patient involvement across the R&D lifecycle, and patient involvement in health policy.

From doing things to the patient... to doing things *with* the patient.

Going forward we think that patient empowerment needs to be put into action through **meaningful, systematic** and **structured** patient involvement in healthcare at all levels. Patients must be recognised as vital partners in improving the quality, effectiveness and efficiency of health systems, and patient organisations should be supported in their important roles: awareness-raising, peer support, capacity-building. They should be supported through adequate resources in a transparent, diversified mix of public and private funds.

Collective empowerment: the untapped potential of patient organisations

Empowerment should not happen only at individual level, but also as a collective action: the empowerment of the community of patients. In 2017, we published the report "The Added Value of Patient Organisations". The report emphasises the unique value of patient organisations in representation, mobilisation and empowerment of patients and provides specific recommendations to maximise the potential of patient organisations. ●

Our flagship projects

Building on patients' knowledge to make patient engagement a reality



EUPATI is an innovative patient-led academy aiming at developing educational material, training courses and a public Internet library to educate patient representatives and the lay public about all processes involved in the development of medicines.

6 years of EUPATI

- **630.831** users since launch
- **216** countries used the EUPATI Toolbox
- **96** graduated EUPATI fellows
- **54** EUPATI trainees in Cohort III
- **613** modules
- **6** webinars

www.eupati.eu

PARADIGM stands for Patients Active in Research and Dialogues for an Improved Generation of Medicines. To make patient engagement a reality, we work together with industry, institutions, academia and other patient organisations to create a unique framework enabling structured, effective, meaningful, ethical, innovative and sustainable patient engagement, demonstrating the 'return on engagement' for all.

www.imi-paradigm.eu



Universal access to healthcare



Access to healthcare is a basic human right

Patients' access to equitable, high-quality, patient-centred health and related care is a long-standing priority at the heart of our vision. We strive to eliminate disparities and barriers related to access and address standards of care and health inequalities within the EU.

Access to healthcare is a basic human right and one of the fundamental principles of European health systems, yet research provides evidence of the systematic failure of European health systems for many patients currently living within the region, particularly people in situations of precarity, poverty, social isolation, exclusion or vulnerability. Persistent inequities and growing health inequalities in the region undermine such values and carry a significant personal as well as societal cost.

According to our survey (2016) too many patients in the EU are confronted with financial hardship as a result of healthcare costs:

41% reported reducing household spending on essential needs, such as food or clothing to be able to cover healthcare costs, 40% of respondents reported forgoing or postponing healthcare visits due to costs at least once in the past year.

As a founding member of the Patient Access Partnership (PACT), a patient-led multi-stakeholder network, we work to develop and move forward on innovative solutions to reduce inequities in access to quality healthcare in the European Union.

Equal treatment for patients in the workplace and ending discrimination

Discrimination in the workplace as a result of health status is another big issue when it comes to inclusion of patients. Following EPF's position statement on "Equal treatment for patients in education and employment" (2016), in 2017 we set up a task force on non-discrimination in the workplace and on the employment market.

"We can't afford to leave anyone behind. Without equality in healthcare, we cannot obtain longer-term sustainable development"

Katharine Wheeler, Lupus Europe

They worked on recommendations for policy-makers on better inclusion of people with chronic conditions in the workplace, in the context of the European Pillar of Social Rights. This resulted in the production of a digital leaflet for employers, informing them on how to foster inclusive and supportive work places for employees with chronic conditions. We work to promote the development of EU and national policies that tackle discrimination faced by people with chronic conditions in education and employment. ●



Articulating our vision

In 2017, we developed a Roadmap entitled 'Taking Action – A Roadmap to Achieving Universal Health Coverage for All by 2030'.

Survey on access to healthcare

Developed in 2016, it reached 395 patients in 28 EU member states and provided important insight on health inequalities and access barriers for patients.

5 A's

Our position paper on defining and measuring access to healthcare (2016) is based on the 5 A's: Adequate, Accessible, Affordable, Appropriate, and Available.

Stronger patient organisations

Since 2012, we've been supporting patient organisations to strengthen their role as equal players in the healthcare environment.

The EPF Capacity Building Programme supports the development of organisational capacities and advocacy skills of European patient organisations, to enable them to be more effective in achieving their objectives and aspirations, feeding their experiences and expertise into the work of EPF and utilising the outcomes of our collective work in a national, and/or disease specific context.

Online and offline opportunities

We offer a long-term programme that combines training workshops with individual coaching. This approach allows beneficiary organisations to meet and exchange experiences and good practices with other peer organisations, while offering the opportunity to address each organisation's individual needs.

Since 2012, the Capacity Building Programme is being implemented in Bulgaria, Hungary, Romania, Slovakia, and since 2017 also in Poland. In addition, in 2017,

we conducted a situational analysis focusing on healthcare systems, patients' rights and patient organisations' involvement in healthcare policy and programme development in the Western Balkans.

Our national trainings are complemented by a European programme dedicated to cross-cutting topics that are of interest and benefit to all patient organisations, such as transparency, strategic communications, governance and leadership.

Additionally, we offer regular online streamed sessions or '*Breakfast Briefings*', focused on increasing patient organisations' awareness and familiarity with EU health policy and discussing potential actions for the patient community. ●

2017 in numbers

- 76 organisations involved from 5 countries
- 25 patient national coalitions reached
- 8 breakfast briefings
- 1 leadership meeting with 70 participants

Youth leadership programme

Young patients have an important place in the patient community. Empowering them means making the patient movement stronger. With our Youth Strategy and leadership programme, we aim at creating a space where young patients can inspire and get inspired and learn from each other. As such, the young advocates programme intersects with all EPF thematic areas, namely patient empowerment, patient involvement, and sustainable organisations.

The Youth Group is a diverse group of young patients who engage in EPF to share first-hand experiences and good practices with young patients from all over the EU. They work to raise awareness about the challenges young patients face in their daily lives and advocate with policy-makers and stakeholders. The Youth Group runs projects, such as the Summer Training Course for Young Patient Advocates and works to provide insight into the lives of young patients in the EU to all members and external stakeholders.

Vienna

Summer Training Course for Young Patient Advocates

- 40 young patients (18–30 years old)
- 23 represented countries
- 22 represented disease areas
- 3 days of interactive sessions



Digital health & e-health

Healthcare systems are being transformed by digital technologies. As patients we are closely involved in the discussions around digital health and e-health. The digital transformation and big data offer an incredible opportunity to improve and integrate health and care. However, we need to remember that patients are and should always be at the centre.

Patient-driven digital health

Patient-centeredness is a core component of high-quality healthcare. Digital health can enable care to be structured around a person's needs and preferences, improve the coordination of care and have more effective exchange of information between care professionals and patients.

Patients want healthcare systems that address the outcomes that matter to them; systematic collection and use of data such as patient-prioritised clinical and quality-of-life outcomes will be of vital importance. The advancement of research, faster diagnosis, and ensuring better patient relevant outcomes are key

for patients. Patients are usually willing to share their data as long as appropriate safeguards are in place. To build trust, protection of personal data must be ensured, and its use must not result in discrimination on the grounds of health status. Patients should also have a say in how their data is shared and used, as true co-owners of their data.

Digital health and e-health must be patient-driven to really empower people, build trust, improve research and reduce costs of health systems. ●

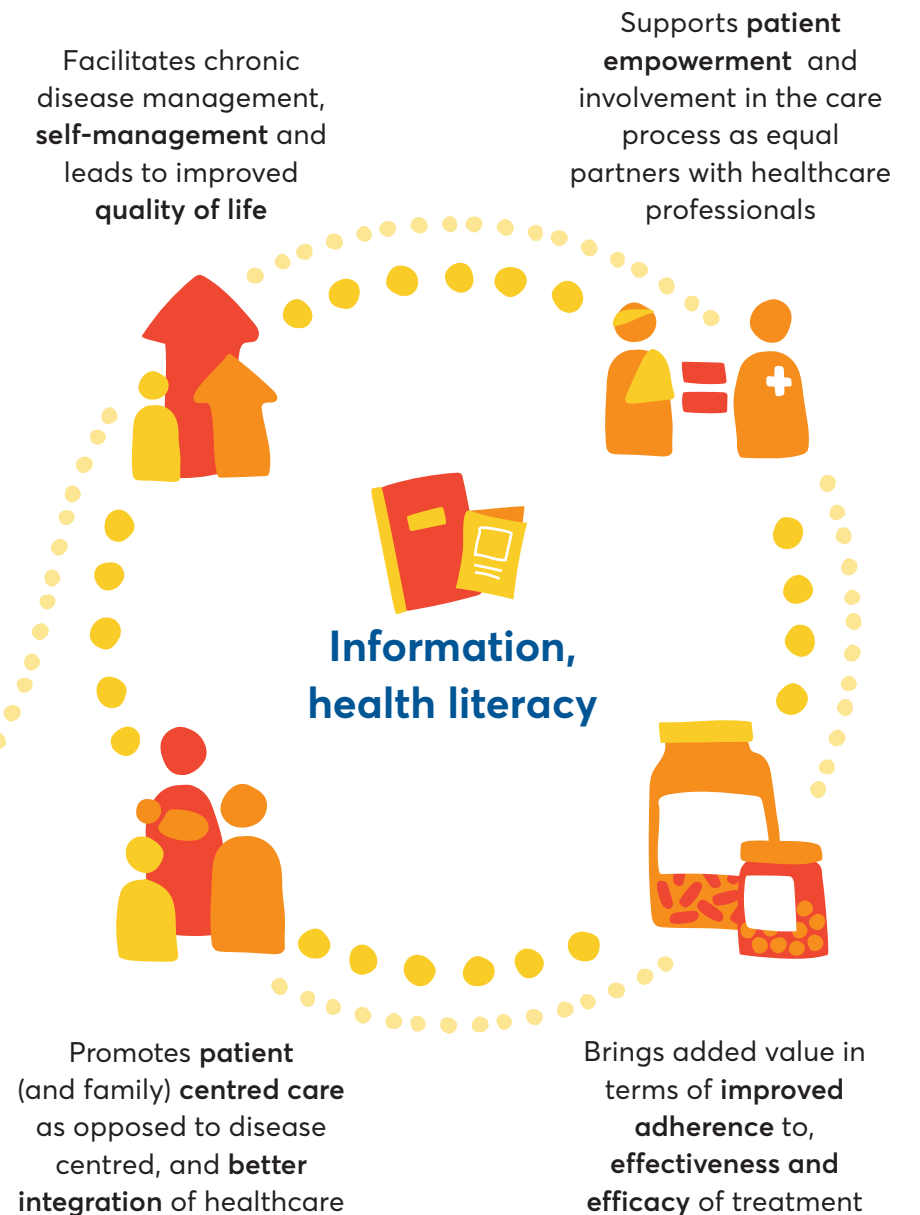


Digital Health Working Group

In 2018, we established an expert working group to bring forward the patients' perspective on digital health and work on a survey on electronic health records.

EPF Position statement on eHealth (2016)

This consolidated position includes patients' expectations on access to e-health, safety and quality of e-health.



Making an impact

By 2030: universal access to healthcare

In light of the 2030 Agenda for sustainable development, there has never been a stronger case, or a more vital moment for Europe to work together to protect our health.

Healthcare is a complex issue and we need to work together with all players involved to make a real impact. Patients and patient organisations are arguably the most untapped resource that we have to unlock the path in designing more efficient healthcare systems. They are the experts through their own knowledge and experience.

There is much potential in better involving patients and making them the real drivers for better health in Europe. Despite the progress we've made, it's early days, and the truth is that we've still got a long way to go. And yet, this change, this shift in how patients are increasingly engaged in health policy and medicine development is real.

Since our inception, the European Patients' Forum has been advocating for patient rights and access to high-quality, patient-centred health and related care for all patients with chronic conditions. For us, getting patients involved across policy, research and development of medicines is at the heart of our daily work.

We're out to work with our partners, healthcare professionals, policy-makers, industry, researchers, and, well, everyone, to empower patients to take an active role in improving healthcare. Our doors are open. Join us in making an impact for sustainable patient-centred health systems of the future!



70%

of European citizens
want the EU to do
more on health

The European Patients' Forum (EPF) is the united patient voice in Europe. Since 2003, we work with patients' groups in public health and health advocacy across Europe. Our 72 members are national coalitions of patients or represent specific chronic disease groups at EU level.



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