EPF 2019
SUMMARY REPORT

A STRONG PATIENTS' VOICE IN EUROPE

150
MILLION
PATIENTS

70%
OF EU
CITIZENS

74
MEMBERS
ACROSS
EUROPE

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THE PATIENT AT THE CENTRE OF FUTURE HEALTHCARE

Over the last year we focussed our efforts on achieving our mission of putting the patient voice at the heart of European health policy and practice. Taking a structured approach and working in partnership with our members and network, I would like to outline achievements within the following four areas:

***Research**. Understanding 'what good looks like' drives the research work undertaken at EPF. Examples of our work include PRO-STEP, which has the aim of developing learning on how to improve self-management for patients with chronic conditions, whilst CHRODIS+ has paved the way in enabling us to support member states to reduce the burden of chronic diseases, while assuring health systems efficiency. We are also leaders on advancing patient engagement in medicine developments through PARADIGM, an IMI project.*

***Education and training**. Increasing the capacity and capability of patients and patient organisations to exercise voice is a central part of the work undertaken by EPF.*

The EUPATI programme for instance has materially helped increase the capabilities of patients to understand and contribute to medicine research and development, having now reached 1.7 million users. EPF has also designed a toolkit and run a workshop on vaccination for our members in order to support the dissemination of effective practices within their respective countries. Too many children and adults die or suffer avoidable complications resulting from low levels of vaccine uptake; it's our duty to help increase patient understanding of the vaccines agenda.

Our policy and advocacy work seeks to ensure that the patient perspective forms an integral part of the European health policy agenda.

Ensuring that patients have access to affordable healthcare is a central focus for the work that the EPF Secretariat undertakes in Brussels and within the network of European institutions. Drawing upon the knowledge and expertise of our member organisations our advocacy work at EPF helps ensure that equitable and universal healthcare will become a reality for European citizens. Our work over the last twelve months has included promoting better inclusion of people with chronic conditions in the workplace by reaching out to employers directly. We collaborate with PACT, an information and knowledge transfer platform, aimed at improving the measurement of access to healthcare in Europe.

*Within the field of **regulation**, EPF continuously calls for a patient-centred EU framework on HTA. Moreover, it is a priority for us to implement the 2016 roadmap on inclusion, and disseminate it in member states. EPF has also continued to play an important role in medicines regulation, where I alongside our Director of Policy Kaisa represent the patient perspective.*

Of course, this is not it. Our vision is to ensure that the patient voice is front and centre within the health policy agenda of the new European Parliament, where we will build on a highly productive European election campaign. Last but not least our keynote event in November, the EPF Congress, will be a unique opportunity to develop your thinking about patient involvement – an event which has been designed to put the patient at the forefront in the drive to more effective health systems and healthcare.

Marco Greco
President of the European Patients' Forum

EPF AT A GLANCE

The European Patients' Forum is the leading voice of patient organisations in Europe.

What we do

We act as an intermediary between the patient community and EU policymakers, by providing a crucial cross-disease perspective based on issues that have a direct impact on patients' lives in a national and regional context.

We represent our members as well as patients with chronic conditions, occasional patients, and their carers, by working with EU stakeholder and expert groups, whom we see as reliable and trusted partners.

We bring together people, knowledge and expertise. Together we work to enhance the capacity and capability of patients to play an active role in all aspects of their treatment and care.

We support a wider movement to ensure Europe's citizens are able to access affordable health and social care.

We strive to make health literacy and patient empowerment high on the agenda, while driving towards a profound change over the healthcare landscape.

Our vision is that all patients in Europe have equal access to high-quality, patient-centred health and related care.

Our mission is to be the collective influential patient voice in European health and related policies, and a driving force to advance patient empowerment and equitable patient access to care in Europe.

EPF European Patients Forum

Towards a wider Europe

Our ambition is to become a reference point for the EU, European organisations and other stakeholders such as WHO Europe, healthcare professionals and health minded organisations seeking patients' and patient groups' opinions. Developments following Brexit and the increased interest in developing an even wider pan European cooperation led us to adopt a new Constitution, now allowing organisations based in all of Europe to become members of EPF.

Our membership is our raison d'être

Our members are the backbone of our work: their perspective brings an irreplaceable added value to our policy and advocacy activities. We currently represent 74 patient organisations (50 pan-European umbrellas and 24 organisations are active at national levels, representing 19 countries) and an estimated 150 million patients across Europe.

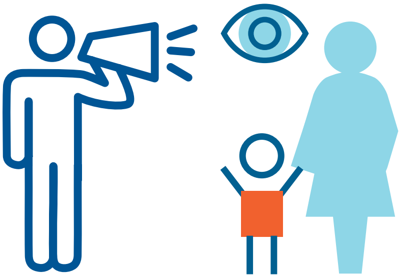
EMPOWERING THE PATIENT VOICE

EPF's project portfolio enables us to support the development of innovative methods to incoporate the patient voice in health policy and practice and to incorporate these methods in projects designed to improve patient experience and outcomes. In 2018, EPF engaged in six EU-funded projects. Here are some of last year's highlights:

PRO-STEP. PRO-STEP developed a framework for action to enhance self-care at EU level, and develop strategies to support its broader implementation. In practice, the project explored the added value of self-management in chronic diseases, and developed a set of key recommendations for policymakers.

The results indicated need for the following:

- An EU-wide mission and vision on self-care and self-management;
- A strategic approach at policy level, based on developing knowledge and skills among relevant healthcare professionals, and on promoting of changes in societal attitudes;
- An assessment of the cost-effectiveness of self-management from a societal perspective;
- Health literacy as a policy priority;
- Investment in communication;
- Supporting innovation and digital technology as enablers of improved self-care.



COMPAR-EU

With **COMPAR EU**, we moved forward in identifying, comparing, and ranking the most effective and cost-effective self-management interventions (including preventive and management domains) for adults living with four high-priority chronic diseases: type II diabetes, obesity, chronic obstructive pulmonary disease, and heart failure.

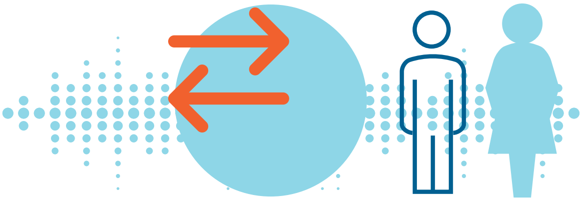
Improving health systems' performance. In 2018, EPF continued to advocate for more effective measures to better evaluate health systems' performance from a patient's perspective.

We collaborated with the OECD and helped shape the PaRIS project under a specific task force. PaRIS is a partly EU-funded initiative that builds on a mandate from member states' health ministers aiming to develop comparable, cross-country indicators for patient-reported outcome measures (PROMs) for chronic conditions, and measures to assess patients' experiences of care (PREMs). We also continued working with the WHO on strengthening health systems, more specifically by bringing the perspective of patients and exploring the role of patient empowerment as a concept and as a strategy to contribute to sustainable and quality health systems for the future.

CHRODIS+
IMPLEMENTING GOOD PRACTICES FOR CHRONIC DISEASES

Joint Action CHRODIS+ builds on the cross-national good practices identified in the previous JA CHRODIS project, and aims to transfer valuable knowledge and capacity to the national level and ultimately reduce the burden of chronic diseases, while ensuring health systems sustainability and responsiveness.

In 2019 EPF visited pilot sites in Slovenia, Finland, Croatia, Greece and Serbia. Each of these study visits included events, attended by national stakeholders presenting the pilot actions' implementation plans. EPF promptly ensured that the patient voice was embedded in each of these activities.
Follow-up EPF tasks include the production of a comprehensive report, describing the pilot actions and sharing lessons learnt and good practices.



PARADIGM
Patients Active in Research and Dialogues for an Improved Generation of Medicines

A year into PARADIGM
Patient engagement in medicines R&D is a hot topic but not yet engrained in the culture of the drug development process, even though there is a clear momentum to make patient engagement in medicines R&D the norm. PARADIGM is based on the premise that the ultimate impact of patient engagement will be a more robust response to true unmet medical needs – medicines developed faster, safer and more cost effectively that will support the healthcare systems to achieve better health outcomes. This is a win for all, a win for the society at large.

The activities of PARADIGM during this first year focused on important ground work to deliver the most impactful outcomes and reach its overall mission. In 2018, PARADIGM worked on the development of tangible solutions to advance patient engagment in R&D that are fit for purpose for the community of medicine developers at large. It will slowly but surely support a much-needed cultural change.

"By working in partnership with those who are living with health conditions, great things can be achieved, from raised awareness, to empowered individuals, better access to healthcare, research that is fit-for-purpose, and future care is relevant for society." - Simon Stones, Patient advocate and consultant

Looking ahead...

DATA SAVES LIVES

Data Saves Lives. EPF believes that research into chronic diseases and their management is increasingly reliant on data generated by patients, physicians and other healthcare workers. For this reason, it is in the mission of EPF and allied organisations to develop a European Health Data Portal, in the framework of the "Data Saves Lives" multi-stakeholder initiative. The aim of this portal is to build and improve public awareness and knowledge of data in health research, and to create a trusted environment for dialogue about the use of health data. Data Saves Lives is one of a portfolio of projects focussed on patients and digital health, which includes Digital Health Europe, IMMUcan and EHDEN.

ENHANCING THE PATIENT VOICE THROUGH EDUCATION AND TRAINING

Helping empower patients and patient organisations has a positive impact not only on their own individual wellbeing but of the community as a whole and allow them to play their legitimate role as equal partners in the healthcare environment. As a result we have been developing our educational seminars, policy initiatives and projects further, via capacity-building initiatives and by exchanging best practices and information. Here is a brief overview of the main highlights of the year:

EUPATI
European Patients' Academy
on Therapeutic Innovation

EUPATI. In 2018, the Patients' Academy of the future, the EPF-led European Patient Academy on Therapeutic Innovation (EUPATI), continued to provide education to the patient community and beyond to ensure effective and impactful patient involvement in Europe and worldwide.

Key milestones include the EUPATI Toolbox, which was launched in early 2016 and reached over 1.7 million users as of May 2019. Over 150 participants who had completed the EUPATI Patient Expert Course, had the chance to increase their understanding of the R&D topic with a view becoming an even more informed patient advocate. Lastly, EUPATI published peer-reviewed guidance for patient involvement in key areas of medicines research and development: this was published in the prestigious journal "Frontiers in Medicine". EUPATI plans to update and grow the training portfolio to offer education to all stakeholders in patient engagement, by ensuring the continuous sustainability on national, European and global level.

Educational workshop on pharmaceutical incentives

EPF organised an educational workshop to build knowledge about the complex topic of pharmaceutical incentives, to further empower patient organisations and help them contribute meaningfully to the EU political debate from a patient perspective. This working session included an overview of the EU process by representatives of the European Commission (DG SANTE), a keynote by a legal expert, and the perspectives of both originator and generic medicines provided by EFPIA and Medicines for Europe.

Leaders from twelve patient organisations from the EPF community attended, representing diverse disease areas. EURORDIS provided the patient perspective focusing on rare diseases and orphan drugs. As a follow up, EPF compiled and published a report to help members get a better understanding of the current policy discussions on this topic.

The importance of vaccination for patients

EPF started an initiative in 2018 to provide information and support patient organisations' advocacy on the importance of vaccination. We developed information resources in several languages that together form a toolkit primarily aimed at supporting the advocacy efforts of national patient groups, including a manifesto on the importance of vaccination for patients. Additionally, EPF held a pilot workshop with the patient community in Bucharest, Romania, in collaboration with our member organisation COPAC, attended by more than 40 participants from the patient community, academia, national institutions and the industry.

Looking ahead...

This initiative will continue in 2019 with the development of further resources and to national workshops. EPF is also participating in the stakeholder forum of the EU Joint Action on vaccination (EU-JAV).

Preparing the next generation of patient advocates

EPF believes the voice of youth needs to be taken into account in order to guarantee a better future for the entire patient community. This is why we set up the Youth Group almost a decade ago, with the aim to embed the youth perspective into our core values, strategy and workstream, and raise awareness about young patients' lives, and address cross-cutting issues affecting their quality of life.

In 2018, we were active in the field of discrimination, patient engagement, cross-border healthcare and digital health.

The Youth Group has always brought and still brings the young patients' needs on the EU agenda, and is advancing its work on improving young patients' employment, particularly through the findings from the WAYS (Work and Youth Strategy) project.

We also held our second Summer Training Course for Young Patient Advocates (STYPA) who have the motivation to learn more about advocacy and maximise their leadership potentials in real environment. This second edition aimed at developing Count Us In, an Advocacy Campaign on Inclusion and Non-Discrimination.

In total, 39 participants from 23 European countries joined us last year for three days of intensive but inspiring and fun training sessions. STYPA is now recognised as a key, well established programme nurturing a platform where young patient advocates would empower, inspire and learn from each other.

THE PATIENT PERSPECTIVE

EPF supports the principle of 'equity and health in all policies', and our core value of equitable access to high-quality healthcare for all patients is what feeds into our policy work on health inequalities. Our unique position as a reliable and trusted partner of the European institutions and other health stakeholders allows us to advocate for improvements in health systems to enable equitable access to sustainable and high-quality healthcare designed and delivered to meet patients' and their carers' needs at all levels of care.

EPF strives to make equitable access and universal health coverage a reality

During the last twelve months we have made achievements in a number of areas:

Throughout the year, EPF seized many opportunities to repeatedly urge different health actors to take responsibility in implementing the recommendations set in our roadmap on Universal Access to Healthcare, guided by our member-based working group on UHC.

Further to our recommendations made to the European Commission to link existing funding mechanisms to health-related Country Specific Recommendations, we were pleased to see that health recommendations were attributed to 12 EU countries.

Finally, as a member of SDG Watch Europe, EPF urged the EU to take leadership in the implementation of the 2030 Agenda for Sustainable Development.

EPF contributed to the work of PACT and improved the measurement of access to healthcare in Europe

In 2018, the MEP Interest Group on Access hosted an event to showcase the results of the pilot project 'Towards a fairer and more effective measurement of access to healthcare across the EU', carried out on behalf of the European Commission (DG SANTE). The meeting provided a platform to present the results to health stakeholders as well as discussing with them the challenges and opportunities for implementation. The next steps will consist of the development of an extensive accompanying strategy and roadmap, as a basis for sound policy development and implementation.

New initiatives in the area of digital health

2018 laid the groundwork for many promising new initiatives in the area of digital health. Many thoughts and ideas we had around the topic became concrete actions.

EPF welcomed the European Commission's communication on digital health and contributed to the European Parliament's draft motion for a resolution on enabling the digital transformation of heath and care in the Digital Single Market.

Our new working group on digital health developed a survey on Electronic Healthcare Records.

We also participated in the Commission's eHealth Stakeholder Group and many other debates, high-level events and meetings.

Looking ahead...

Two new EU projects have kicked off: the IMI project for European Health Data and Evidence Network (EHDEN), and Digital Health Europe. 2019 also saw the launch of a new "Data Saves Lives" Platform, as well as the publication of a briefing on digital health.

> **"We play an integral part of the European policy process, working to ensure that the patient perspective is included and fully considered."**

EPF active on medicines and medical devices

In 2018, EPF was again active in bringing the patient perspective into debates on medicines and medical devices at European level. The main highlights include:

- A dialogue between members of EPF and Medicines for Europe took place in October to discuss the EPF Roadmap on universal health coverage and the role of generics and biosimilars;
- We participated in the 4th stakeholder conference on biosimilar medicines, organised by the European Commission (DG GROW), and in a similar meeting at the European Parliament;
- We worked on initiatives on access to medicines, including various conferences to express the patient perspective;
- We undertook a revision of our 2016 position paper on the value of medicine pricing, due to be published in 2019;
- EPF became a member of a new international working group of CIOMS on patient involvement in the development and safe use of medicines;
- EPF continued to be active at the European Medicines Agency through our representatives on the PCWP and PRAC, and contributed to several initiatives, including on electronic product information and a draft reflection paper on enhancing patient input in regulatory decision-making.

EPF promotes better inclusion of people with chronic conditions in the workplace

In 2018, EPF intensified its advocacy for the development and implementation of policies and initiatives that eliminate discrimination, reduce stigma and promote the inclusion of patients with chronic diseases in healthcare, employment and society at large.

On a policy front, most of our proposals were unanimously adopted in a European Parliament Report and motion for a Resolution on Pathways for the Reintegration of Workers Recovering from Injury and Illness into Quality Employment. EPF also supported the launch of a new MEP focus group on employment and health.

As a partner of the Joint Action on Chronic Diseases, EPF has been particularly active in the work package on employment, which aims to develop a toolkit and training tool for employers.

Looking ahead...

EPF will focus on promoting its recommendation on equal treatment in the workplace to employers and policy-makers by organising a multi-stakeholder meeting on the integration of patients in the work place. We will also help combat discrimination in the framework of the European Pillar of Social Rights.

EPF called for a patient-centred EU framework on HTA

In 2018, we welcomed the publication of a legislative proposal on a future EU-level collaborationon health technology assessment (HTA), as we acknowledge its impact on access, quality and safety of care for all patients across Europe. Throughout the year we have regularly released public and joint statements to recentralise the focus of the proposal on: meaningful patient involvement in the process: it is the only way to ensure assessment results truly take into account the patients' experience with health technologies.

CROSS CUTTING ACTIVITIES

Our journey towards ensuring that all patients in Europe have access to high-quality health and related care continues and we have some major projects in the horizon. Here is an overview of three highlights of our work:

Shaping the future EU policy framework for health

2018 was an important year in terms of influencing the future shape of major EU programmes – the EU budget, the future EU health programme, and the next framework programme on research. Major decisions are pending finalisation in 2019, which we will continue to follow closely. The new programme for health will be included in a wider framework titled "European Social Fund Plus" (ESF+), which EPF broadly welcomed, but also worked on with the European Parliament to improve the original proposal. The same goes for the new research framework programme, Horizon Europe. It was not an easy battle, but the result was that both texts are now more patient-oriented.

In 2019, EPF will continue to drive the #EU4HEALTH campaign, to ensure health remains a priority at EU level which complements our own patient-led campaign for the 2019 elections. We were also active in a number of other initiatives focussed on a future vision for health at EU level, including the European Health Summit, that took place in November 2018, which has led to the Health Coalition, and "All Policies for a Healthy Europe" which focussed on intersectoral collaboration on health within the EU Institutions.

The European Health Parliament

The European Health Parliament (EHP) is led by a multi-disciplinary and multi-stakeholder partnership which includes EPF, Politico, the College of Europe, the MEP group "EU40", Johnson & Johnson, and Porter Novelli as the new communication partner.
The 2018/2019 edition of the EHP had as overarching topic "We Run 4 Health: Rediscovering Health in Europe", which was strongly linked to the 2019 European Elections. Its purpose was to stimulate conversations on five specific topics relating to data for healthy societies, disease prevention and management, innovation and value, health literacy and self-care, as well as environmental and human health.

EPF Congress 19

In November 2019, EPF will organise the first ever European Congress on patient involvement, driven by leading representatives of the patient community, and patient experts. The event will provide a unique opportunity for dialogue, engagement with a wide range of health players who aspire to make patient involvement a reality. Together, we will explore why this will lead to better outcomes for patients and society, and how we can achieve meaningful patient involvement in practice across the European Union.

Visit www.epfcongress.eu and stay informed about this exceptional opportunity for dialogue, engagement with a wide range of health players who aspire to make patient involvement a reality.

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EPF European Patients Forum

ELECTIONS manifesto 2019

PUTTING WHAT MATTERS TO PATIENTS AT THE HEART OF EU HEALTH POLICY

Europe for patients 2019 elections campaign
EPF was campaigning for the European Elections, to put what matters to patients at the heart of the EU health policy and make health a priority in the EU post 2020. To achieve these goals, EPF mobilised collaborators, member organisations and supporters on issues that matter to patients and citizens, and encouraged candidates to adopt the manifesto nationally. More concretely, EPF hosted a launch event, and attended a conference held by the Patient Access Partnership (PACT) at the European Parliament: both events were filmed and captured on video (available on our Youtube channel). As a result EPF gathered a total of 59 MEP candidate supporters, and a concrete follow-up plan to be implemented together with elected MEPs, to ensure collaboration post-2020.

Visit www.europeforpatients.eu for more information about our campaign.

#europeforpatients

A VIBRANT ORGANISATION

EPF is a vibrant network of organisations representing the voice of patients. EPF Members constantly communicate and exchange to put forward the voice of European patients.

Capacity Building - a look at 2018

6 Breakfast Briefings and 6 Webinars*

This year's webinar topics:
- **Transparency in Advocacy**
- **Transparency and Funding**
- **EUPATI**
- **PFMD**
- **EU Institutions**
- **Block Chain**

EPF Leadership Meeting

71 participants from 28 countries

Publications

- **EPF Transparency Guidelines****
- **Toolkit on Empowering Leadership and Positive Governance** (forthcoming).

Training

Module on Empowering Leadership and Positive Governance – 24 participants from 17 countries

Patient Advocates' Seminar – 30 participants from 20 countries

Members

- Two new members
- 95% retention rates
- 29 Weekly Insider editions

Governance

- **Board**
  Nine Patient Representatives
  Four Board Meetings
- **Youth Group**
  21 young patient advocates
- **Secretariat**
  20 policy professionals, communications experts, project managers, analysts and researchers.

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* available on our Youtube channel: www.youtube.com/eupatient
** available on our website

Outreach

174 events

Attended 178 and spoke at 174 high-level events

108,022 people

108,022 people reached on Facebook (+2.5%)

150,000 impressions

Nearly 150,000 impressions on LinkedIn (+90%)

57,900 visitors

on our website (+12,000 in one year)

+1,000,000 impressions

Over one million impressions on Twitter (+13%)

4,650 subscribers

4,650 subscribers to our monthly newsletter

16 videos published

Six press statements

Three recommendations for good practices

Three position papers

Three factsheets produced

One impact report

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