



# IMPACT REPORT

2020



# EPF: A brief history

## 2003–2015 – Laying the Foundations for Collective European Patient Advocacy

In 12 short years, EPF grew from 13 to 63 patient organisations. During this time, patient groups built alliances and trust while laying the foundations for patient advocacy in **crucial policy areas** such as: patient safety, health literacy, pharmaceutical legislation and access to healthcare.

EPF led its 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. **The Capacity Building Programme** to share knowledge and enable our members to become effective actors in driving positive change in all issues affecting patients at both national and European levels.

In 2012, we launched, together with over 30 partners, the European Patient Academy on Therapeutic Innovation, a major Public-Private Partnership on patient education. 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–Present – Making Patient Involvement a Reality

EPF introduced a campaign approach focusing on our key pillars: **patient empowerment** and **access to healthcare**, to complement our core advocacy and projects work.

EPF continued its campaign approach with its 2019 **EU Elections Manifesto**, #EuropeForPatients, designed by its members, which captured the five priorities that matter to patients. 2019 also saw the first ever **EPF Congress**, completely driven and led by patients and patient organisations. This, and subsequent events are focusing on the gaps in EU health policy from the patients' perspective and making meaningful patient involvement a concrete reality.

In the wake of the **COVID-19** pandemic, EPF has taken a leading role in providing state of the art information for our members and sharing the real life experiences of our communities. We also called on the European Commission and the health industry to act to ensure that patients' rights are respected in the pandemic response and that patients' expertise is used to learn from the pandemic in building resilient and people-centred health systems for the future.



# Making a difference, impacting lives

The ultimate and essential purpose of patient advocacy is to "make a difference" and change the status quo. We strive for a world where healthcare systems are not only designed around the patient, but where the solutions are co-created with patients through participatory processes, leading to more efficient, accessible and friendly healthcare environments.



Step by step, project by project, we are closer to achieving our overall goal. Trust me, it is not an easy exercise. It requires patience, tenacity and resilience. Above all, this requires a strong desire to change the world into a better one. This vision is what makes a patient organisation, at its core, different from any other NGO. As patients working for themselves and for other patients, these organisations are learning from their experience while continuing forward, knowing that the road ahead is paved with obstacles. These seemingly insurmountable impediments truly test the strength of conviction.

Patient advocacy is not only made up of vision, iron will and hard work. Patient organisations are developing into highly professional entities. They need to live (not just survive) in a challenging world, which is why it is essential to openly and honestly assess the quality of our work, our projects, and our relevance.

There are many ways and perhaps too many indicators for assessing our work. After all, the one question we are trying to answer is always the same: are we actually making an impact?

This report aims to answer to this question. But we also want to raise the bar. We want to involve you, to extend the range of our activities, to create partnerships, to grow and to make an even greater impact in the future. Transformation of European healthcare systems – that overall goal of patient advocacy – is in reality, achieved little by little. It sometimes manifests itself in seemingly small improvements that are shared and adopted by others. Patient organisations are an indispensable actor in making sure that patients' knowledge is shared, and that policymakers, practitioners and industry alike truly hear, value and act on that knowledge.

Reflecting on how far we have come, my mind wanders over to a couple of our most recent highlights. Another successful **Summer Training Course Programme for Young Patient Advocates** was organised in 2019. This programme is invaluable in nurturing the fearless patient advocates of the future. The past year also saw another milestone of patient advocacy in its prime, with the resounding success of the first-ever large-scale **EPF Congress** on meaningful patient involvement organised by patients, with patients and for patients. The first of many.

We have been innovative, whilst continuing to reinforce, and improve our existing activities. This has made us stronger and ready to flourish in a fast-changing environment. The **COVID-19 pandemic** has called upon us to learn, to adapt smartly and to overcome without compromise.

We are the European voice of the patients' movement: thank you for believing in us, in what we stand for and where we want to go.

**Marco Greco**  
EPF President

# Shaping a new European agenda for health

In 2019, EPF continued to advocate for truly **universal access to healthcare**, including medicines, as one of our core priorities. Supported by the Universal Access to Healthcare working group, in its *reaction to the 2019 European Semester country specific recommendations* published in June, EPF promoted recommendations set out in its *Roadmap to achieving universal health coverage* and emphasised that health must be made a political priority both at European and national levels to enhance healthcare access and sustainability.

## Putting What Matters to Patients at the Heart of EU Policy

In 2019, EPF called on political leaders of the EU, Parliament candidates and the future Commission, to take action and ensure health is an EU policy priority in the 2020 mandate.

[www.europeforpatients.eu](http://www.europeforpatients.eu)

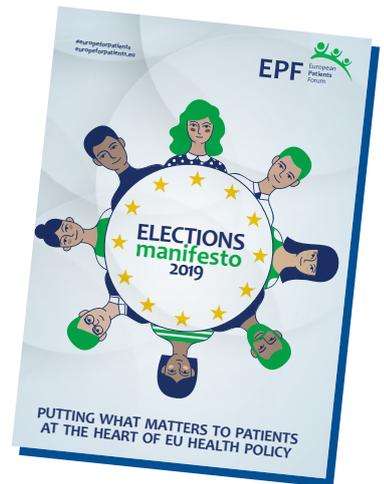
EPF's pledge was supported and signed by multiple MEPs

## Our 2019 EU Elections Manifesto

Our manifesto calls on the political leaders of the EU to ensure health is an EU policy priority and that patients' rights are implemented across the EU, by taking concrete action on the issues that matter most to patients. The manifesto and its five priorities will be our guide

in our work with the new Parliament. EPF has already gained new and enthusiastic supporters among MEPs and will continue to build on this in the next years. The manifesto's five priorities are:

- Accessing the healthcare we need with no discrimination
- Being empowered
- Driving the development of digital health
- Being a partner in driving better research
- Helping make better health policy



Translated into **8 languages**



**60 signatures** gathered from MEP Candidates



**5 patient videos** produced

### Case Study: Malta

Malta Health Network directly took action by translating our manifesto, procuring the signatures of 10+ MEP candidates and reuniting all candidates and stakeholders at a national event to discuss collaborative work in the next mandate.



# Strengthening the European patient movement

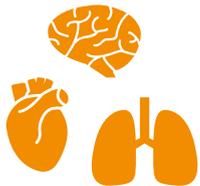
## Summer Training Course for Young Patient Advocates (STYPA)

Another successful edition of STYPA! This three-day experience offered a **tailored high-quality** training to young patient advocates or representatives of young patient advocates with motivation to learn more about advocacy and maximise their leadership potential. Following on from previous years, this edition helped to strengthen the bonds within this diverse, motivated, and inspiring community of young patient advocates and led to the creation of the *Code of Conduct for Young Patient Advocates*.



**37** young patient advocates were a part of STYPA 2019.

Participants from **18** different EU member states



Representing around **30** different chronic conditions, keeping in mind that many of the participants live with a few chronic conditions at once

Watch the **STYPA 2019** video!

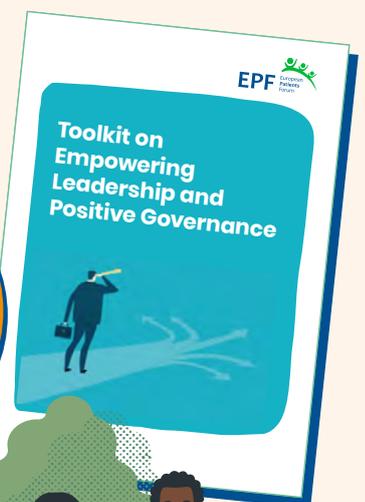


## Empowering Leadership and Positive Governance Module

This module aimed at strengthening patient organisations by **enhancing their leaders' leadership skills** and consequently **enabling positive governance in their organisation**. The overall objective was to support patient organisations in positioning themselves as legitimate stakeholders, strong advocates and reliable partners in the national and European health policy environment.

- +100** applications
- 24** patient organisation leaders
- 6** trainers and coaches
- +10** countries
- 3** participants from the Western Balkans
- 2** face-to-face trainings
- 6** months of online coaching
- 1** *toolkit*

A new **toolkit** was launched



# Meaningful patient involvement:

## Being a valued partner in better policy, research and education

**P**atient involvement is an underused but indispensable element of high-quality, person-centred care. Despite recognition of its importance, action has been lacking. EPF's unique position enabled us to successfully organise the first large-scale European-level event on patient involvement in different settings. The Congress helped create a common understanding on what is needed and how to move forward to put meaningful patient involvement into practice: the next Congress, planned for 2021, will dig in depth into patient involvement in the digital transformation of healthcare.

### EUPATI

The *European Patients' Academy on Therapeutic Innovation* (EUPATI) has concluded its bridging-period and first year of the **IMI-EFOEUPATI (Ensuring the Future of EUPATI)**.

The key focus of EUPATI in 2019 has been sustainability, and these efforts have led to the decision to establish EUPATI as an independent legal entity, with the continued support and leadership from EPF.



### PARADIGM

The mission of IMI-funded project *PARADIGM* (March 2018 – August 2020) is to participate in the co-creation of a sustainable ecosystem that allows systematic, meaningful and ethical patient engagement in medicines R&D. PARADIGM is a public-private partnership co-led by EPF and EFPIA.



More information on the EUPATI 2019 highlights can be found [here](#).



**+3 million**  
toolbox  
users



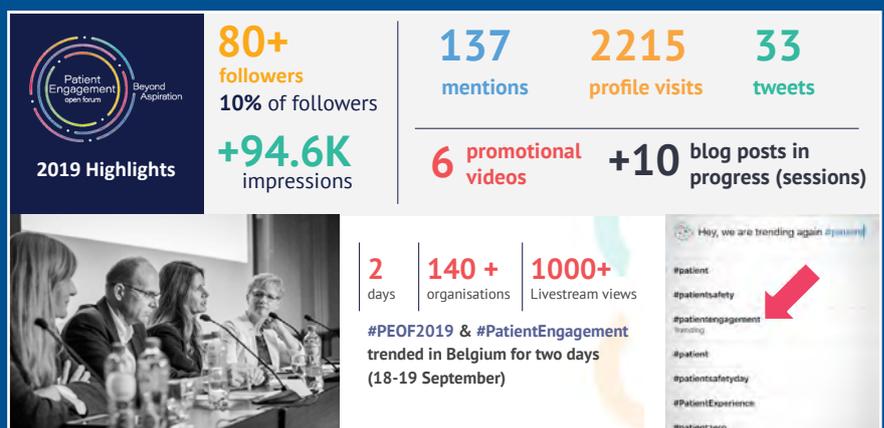
**28**  
consortium  
partners

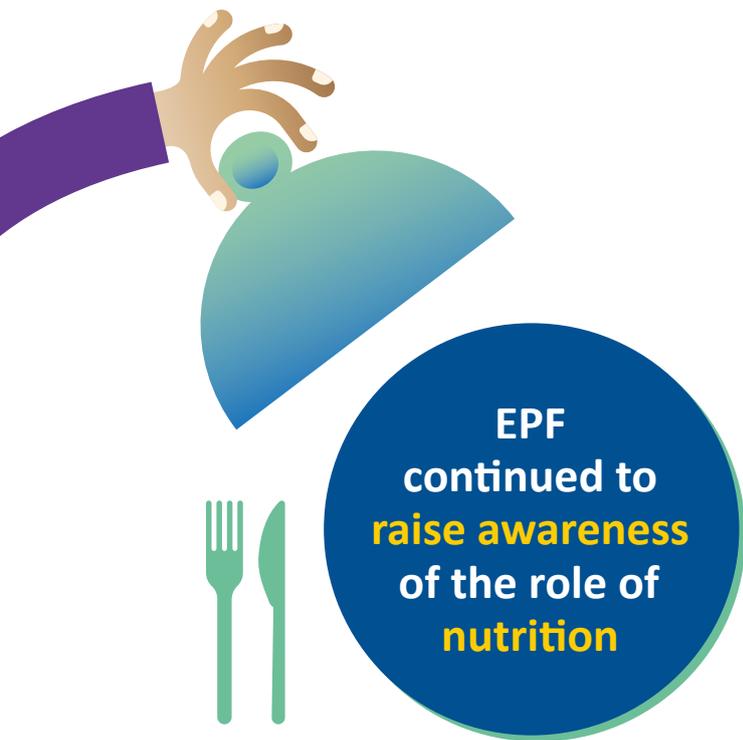


**9 toolbox**  
languages  
(4 more in  
development)

### Patient Engagement Open Forum

The importance of collaboration and alignment and why it takes a village to achieve meaningful patient engagement was the opening call to action at the recent Patient Engagement Open Forum – organised with PFMD and EUPATI – delivering patient engagement beyond aspirations. The delegates at the Patient Engagement Forum were not just passive recipients of information but active partners in co-creating the next tools for implementation of patient engagement.





**EPF**  
continued to  
**raise awareness**  
of the role of  
**nutrition**

### Clinical Nutrition

In past years, EPF has made significant progress raising awareness of the role of nutrition and diet in managing chronic and long-term conditions. In 2019, EPF focused its efforts on the application of meaningful patient involvement in:

- Guidelines for effective clinical nutrition for patients with chronic conditions
- Collaboration with European Nutrition Health Alliance
- Appointment of Ms Tunde Koltai to Board of Trustees to represent patients
- Webinar on the benefit and value of patient involvement in developing clinical nutrition guidelines and lay summaries
- Involvement of patient representatives in the development of two (2) new clinical guidelines – home enteral nutrition and home parenteral nutrition.

### Up next:

The joint development of clinical guidelines for 14 disease and care areas with the European Society for Clinical Nutrition and Metabolism (ESPEN).



# 2019 EPF Congress

12-14 November 2019  
Brussels

Advancing *meaningful* patient **involvement**

**+300**  
delegates in attendance

**3**  
Plenary Sessions

**4**  
Working Sessions

**2**  
Videos

**147K**  
Twitter impressions

**4**  
Keynote Speakers

**1000**  
Web streaming views

**5**  
Media mentions

**1**  
Report

**80%**  
App downloads

2019 EPF Congress

Advancing *meaningful* patient **involvement**  
A path to more effective health systems

Summary report

# Digital transformation that delivers for patients

EPF worked on digital health on two fronts: policy advocacy, and through our involvement in several projects. In 2019, two new EU projects kicked off: the IMI2 project *European Health Data and Evidence Network (EHDEN)* and H2020 project *Digital Health Europe*. The year also saw the launch of a new "*Data Saves Lives*" Platform. With the support of our internal digital health working group, in 2019 we worked on a briefing on digital health for our members as well as an analysis of our survey on electronic health records, both published in early 2020. EPF was invited as a member of the renewed **eHealth Stakeholder Group** of the European Commission for 2019–2022.

## Digital Health Europe

Digital Health Europe provides comprehensive, integrated and centralised support to the Digital Health and Care Innovation initiative in the context

of the Digital Single Market Strategy. The project is structured across two actions – providing support to the large scale deployment of solutions for person-centred integrated care, and supporting innovation in the digital transformation of health and care through multi-stakeholder collaborations.



1000 projects assessed;  
236 identified relevant;

65 met all five selection criteria  
(Importance, Relevance, Added Value, Maturity & Transferability)

EPF assessed these 65 solutions against  
the person-centredness criterium

### 2019 Highlights:

1. Undertook a thorough analysis and gathered a **concise portfolio of useful case studies**, showing the benefits of digitally-empowered patients.



2. Launched a **first call for Twinning**, a mechanism for facilitating the transfer and implementation of digital health solutions with high potential for replicability and scaling up across regions, by financing their exchange of knowledge

- Twinning budget: 932,000€ available;
- Twinning call: 18 eligible applications; 14 awarded



3. Selection of Digital Health solutions with high potential for replicability and scaling up:



## EHDEN (European Health Data and Evidence Network)

EHDEN aspires to be the **trusted observational research ecosystem** to enable better health decisions, outcomes and care. It will do this by developing an infrastructure for a federated network at scale across Europe to enable data-holders to collaborate on research methodologies, and education in an open science collaboration. By doing this, EHDEN aims to reduce the time to provide an answer to challenges in real world health research.



2019 saw the **foundations of the EHDEN Academy** aimed at providing trainings for Small Medium Enterprises (SMEs). After trainings SMEs will be certified for the standardization of data to a common data model known as Observational Medical Outcomes Partnership (OMOP). Another major step was the launch of a call for DATA Sources to become EHDEN Data Partners



Data partner calls (including COVID-19 data sources):  
**29** eligible applications, **20** selected  
 (>**170 000 000** patient records)



SME calls  
**28** eligible applications  
**11** selected



Academy:  
**> 90** users  
**6** courses

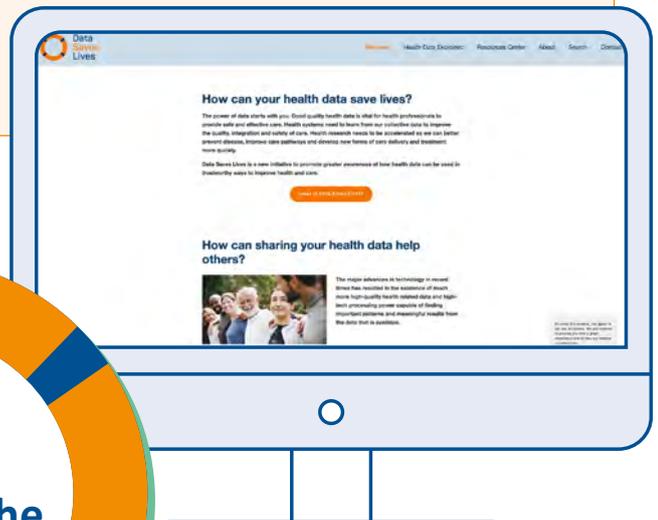


## Data Saves Lives

Data Saves Lives is multi-stakeholder initiative that aims to promote greater patient and public awareness of how health data can be used in trustworthy ways to improve health and care. **Led by EPF and the European Institute for Innovation through Health Data**, the project will contribute to establishing a trusted environment about responsible use and good health data practices, leading to a Europe where patients, carers and citizens are involved in responsible and trusted health data sharing, more effective research, improved health care and better outcomes.



2019 saw the **launch of the website** and the EPF Secretariat attending multiple events to introduce the initiative and **grow a multi-stakeholder network**. Most of the work during 2019 was done to establish our way forward with the campaign launched in 2020.



# New rules

EPF initiated a Constitutional reform process in 2018 which was finalised in 2019 with the approval of the new **EPF Constitution** at the EPF 2019 Annual General Assembly.

## Main Changes:

### 'Wider Europe' Strategy

EPF opened its membership to legitimate patient organisations based in wider Europe, not only in the European Union.



### The Best of Youth

The EPF Youth Group is now listed in the Constitution as one of the permanent Supporting Committee. As of 2020, one of the 9 elected Board Members will be Youth Group member.



### Additional Advice

EPF created the EPF Ethics Committee to issue opinions or advice regarding conflicts of interest and wider ethical issues upon written request from the Board.



For a comprehensive look at EPF's 2019 activities, you can read our Annual Report [here](#).

**There has never been a more vital moment in time for Europe to work together to protect our health.**

We will continue to work with our partners – healthcare professionals, policy-makers, industry, researchers, and others – in our mission to empower patients to take an active role in improving healthcare. Our doors are open.

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



**#WeAreEPF**

The European Patients' Forum (EPF) is an umbrella organisation of patient organisations across Europe and across disease-areas. Our 75 members include disease-specific patient groups active at EU level and national coalitions of patients.



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