EPF European Patients Forum

IMPACT REPORT

2021

Our 5-Year Roadmap

As we approached the end of our last seven-year strategic plan (2014–2020), EPF initiated a debate with our members that led to the development of a new strategic plan. The **EPF Strategic Plan (2021–2026)** will guide our work for the next five years. It will be the basis for a renewed approach towards advocacy, research participation, fundraising, a more vibrant communication plan and an enhanced project engagement strategy. EPF will expand its project portfolio, while carefully refining criteria for involvement.

This *Strategic Plan 2021–2026* reflects the latest changes in the European health and social policy environment and the new challenges and opportunities for EPF as an umbrella of patient organisations active across Europe. Overall, this plan describes who we are, what we stand for and what we want to achieve in the next five years. Amidst the ongoing COVID-19 pandemic, patients and the patient community are, more than ever before, key actors and contributors in creating equitable, person-centred, accessible, and sustainable healthcare systems in Europe. We hope that this plan outlines our proactive role and potential impact.

Our vision

Is a Europe where patient organisations are valued partners in creating equitable, person-centred, accessible, and sustainable healthcare systems, based on patients' unique expertise.

Our mission

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

Our five core strategic goals are:

Goal 1

Shaping a New European Agenda for Patients

Goal 2

Meaningful Patient Involvement in Co-Creating Better Health Policy, Practice, Research and Education

Goal 3

Digital Transformation that Delivers for Patients

Goal 4

Accessing the Healthcare We Need with No Discrimination

Goal 5

Strengthening Patient Communities Across Europe

Reinforcing the Value of Patient Advocacy

When a patient is diagnosed with a serious chronic condition, more changes than just his or her health status. Patients often face financial, logistical, and bureaucratic challenges to obtaining quality care, and need patient organisations to bring these issues to the forefront to provide solutions. In 2020, these problems were exacerbated not only in Europe but worldwide.

As the entire world came to a pause and forced us all to work remotely, socially distance and cover our faces, EPF fortified its relationships, pushed harder to reduce these challenges to accessing quality care and amplify the patients' voice. Our fundamental role is to champion patients and inform European institutional and political leaders about the urgency needed to safeguard the safety and wellbeing of the patient community and health systems at large.

Our advocacy work included efforts to ensure meaningful patient involvement in the new EU4Health Programme and the European Health Union. As a result, several of our proposed amendments were adopted in the European Parliament and are reflected in the approved regulation of the €5.1billion stand-alone programme.

As a patient representative on the European Medicines Agency's COVID-19 Task Force (ETF), we focused on supporting public communication around regulatory evaluation and approval of vaccines for COVID-19, as vaccines strategy took centre stage at the EU level. This complements the wealth of information listed on our COVID-19 Resource Point and communication channels.

One of our new strategic goals centres on digital transformation and we have been very active in policy, notably through our work on AI and the European Health Data Space, and numerous projects. We will draw on this and the experience of members and advisors to address digital health and responsible health data sharing at our upcoming Congress in October 2021.

The COVID-19 crisis has highlighted the critical importance of patient involvement in shaping health policy at national and European levels, reminding policy-makers why their unique knowledge and expertise are vital. This Impact Report showcases the achievements made over the past year as we continue our mission to advance the interests of patients' communities by strengthening their collective impact across Europe through effective advocacy, education, empowerment, and partnership.

The pandemic has had devastating effects on healthcare systems, and it shines a strong light on the importance of patient organisations and the services we provide with and on behalf of the patient community. As the leading voice of patient organisations in Europe, we thank you for your support and hope very much that you will continue to work with us for the benefit of Europe's patients.

Marco Greco
President, European Patients' Forum

Shaping a new agenda for patients

The sudden emergence of the COVID-19 pandemic changed our world and will have a deep and lasting impact on our societies and particularly on healthcare systems. In 2020, EPF added patient advocacy on responses to the pandemic as a new topic in the 2020 work plan.

EPF issued four statements demonstrating the impacts towards equal access of healthcare during the COVID-19 pandemic:

- *On the COVID-19 Pandemic*
- *Now is the Time to Protect Patients and Safeguard Access to Care*
- *The EU needs to Guarantee the Delivery and Supply of Cross-Border Medical products during the COVID-19 Outbreak*
- *Patients' safety must take precedence in EU coronavirus vaccination deals*

Stella Kyriakides
@SKyriakidesEU

#COVID19 has shown us that 🇪🇺 can and must do more in the area of #Health. Patients must be at the heart of this approach.

Thank you @eupatientsforum for the continued support towards our shared objective ➡️ providing our patients with the support they need. #StrongerTogether

An open memo to the health industry

Given the profound concerns of EPF member organisations regarding the impact of COVID-19 on their communities, EPF shared an Open Memo to health industry representatives outlining the main challenges for patients with chronic diseases and our expectations regarding their on-going commitment and contribution in these unprecedented times. The Open Memo emphasises the importance of extracting key learnings from the COVID-19 situation that will help us move forward, collectively, towards deeper health cooperation at European level, for the benefit of patients and citizens. We received favourable responses from *Health Industry representatives*.

EFPIA
Medicines for Europe
MedTech Europe
AESGP
EUCOPE
COCIR
EUROPABIO

COVID-19 Patient survey

View the Survey Report here

EPF issued a **patient survey** on the *Impact of COVID-19 on patients and patient organisations*. This survey is part of EPF's continued efforts to gather COVID-19 related experiences and insights from the patient community. **Some key insights and findings:**

72% indicated that personal safety from COVID-19 was their main concern

69% of patient organisations had to revise the organisation's 2020 work plan to ensure the survival throughout the pandemic

35% indicated the clarity of communication from healthcare providers on the availability and accessibility of healthcare services/treatments was average

50% found protective measures were not appropriate and had a negative impact on the patients they represent

EU4Health Civil Society Alliance

Launched in 2017 and co-led by EPF and the European Public Health Alliance (EPHA), EU4Health Civil Society Alliance brings together organisations that share the vision of a Europe where all people are as healthy as they can be throughout their lives.

In 2020, the Alliance issued *five joint statements* related to the EU4Health Programme, the European Health Union and the future of health. Our advocacy actions were listed amongst the key inputs in the *recently published European Parliament's overview* on the EU4Health Programme legislative procedure.

#VaccinesWork

In January 2020, EPF also kicked off an important pilot project funded through a tender from the European Commission. The **VAC-PACT pilot project**, which EPF is leading with a small consortium, focuses on vaccination information and confidence especially for patients with chronic conditions and their carers. EPF developed the patient toolkit *"Let's Talk About Vaccination"* and launched it in January 2021. VAC-PACT is set to deliver its results and a final report at the end of August 2021.

A patient-centred EU4Health Programme

Drawing conclusions from the current COVID-19 pandemic, the EU4Health Programme with a budget of €5.1billion will be the **largest European health programme ever**. EPF strongly supports this important recognition of the **need to invest in Europe's health**.

EPF began its advocacy work, issuing a statement proposing *a progressive and patient-centred EU4Health Programme* and engaged with the European Parliament on the report, sharing amendments and *voting suggestions*.

Several of our **proposed amendments and inputs were adopted** by Members of the European Parliament (MEPs) following our outreach work and led to final approved EU4Health Programme regulation that includes many crucial principles for EPF, for instance:

- Enhanced focus of accessibility and affordability alongside of healthcare services and products
- Inclusion of health literacy, patient rights and patient safety
- Inclusion of mandatory consultation with representatives of civil society and patient organisations
- Further scale up of European Reference Networks to other chronic diseases
- Strengthening citizens' access to and control over their health data

Meaningful patient involvement:

Co-creating better health policy, practice, research and education

Patient involvement is an underused but indispensable element of high-quality, person-centred care. EPF's unique position enables us lead several patient advisory groups across several disease and focus areas in different projects and initiatives to create a common understanding on what is needed and how to move forward to put meaningful patient involvement into practice.

EATRIS-Plus

EPF leads the work on Stakeholder engagement in EATRIS-Plus – a project which aims to shape the operational process of translational medicine, and advance personalized medicine by strengthening the sustainability of the EATRIS-ERIC infrastructure. EPF leads the seven-person Patient Advisory Committee that aims to drive patient empowerment at the heart of EATRIS operations. As part of the new project portfolio strategy, EPF brought on board its member, EATG, to support in the coordination of the activities of the Patient Advisory Committee.

EU-PEARL

In 2020, EPF worked to launch a Patient Advisory Group (PAG) for EU-PEARL – a project that aims to make clinical trials more efficient and patient-friendly by standardizing and simplifying trial platforms. Throughout 2020, EPF led:

- A patient-centric session at the Annual General Meeting, where we leveraged our experience on the PARADIGM project on patient engagement
- A training session on patient engagement, focusing on improving consortium members' understanding of the value of patients as partners
- A Stakeholder Workshop on Patient Engagement for Integrated Research Platforms, which was attended by 183 registrants

PARADIGM

In November 2020, the Patients Active in Research and Dialogues for an Improved Generation of Medicines **(PARADIGM)** project ended. **Two main outputs of the project were released in 2020:**

The Patient Engagement Toolbox, which centralises the project recommendations, *The Monitoring and Evaluation Framework with metrics* which connects the dots between Metrics to understand how patient engagement translates into impact and why initiatives fail or succeed.

Patient Engagement Open Forum (PEOF2020)

Patient Engagement Open Forum (PEOF2020) went virtual providing a holistic perspective of patient engagement, the landscape and actors, and foster collaboration and co-creation. 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. **1500 registered participants! Will continue in 2021.**

EPF leads several patient advisory groups

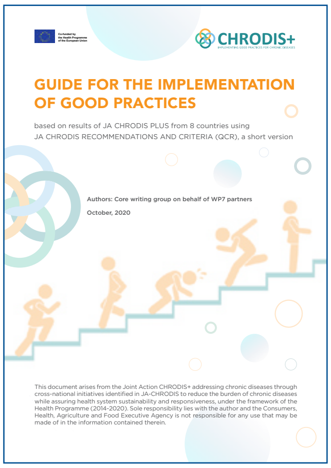
CHRODIS PLUS

EPF has been at the heart of the project, since day one, to contribute the patients' unique experience, and emphasise the importance of empowerment and the creation of supportive work environments.

One valid example of our collaborative efforts is the *CHRODIS-PLUS Workbox on Employment and Chronic Conditions*, which supports EU member states and their workplaces in creating working conditions that foster wellbeing, health, and work ability; prevent the development of chronic diseases; and help individuals with chronic health problems to continue working.


CHRODIS+
WORKBOX
On Employment and Chronic Conditions

Left: Training Tool for Managers and Toolkit for Workplaces *video* and *booklet*


Co-funded by the Health Programme of the European Union

CHRODIS+
IMPLEMENTING GOOD PRACTICES FOR CHRONIC DISEASES

GUIDE FOR THE IMPLEMENTATION OF GOOD PRACTICES

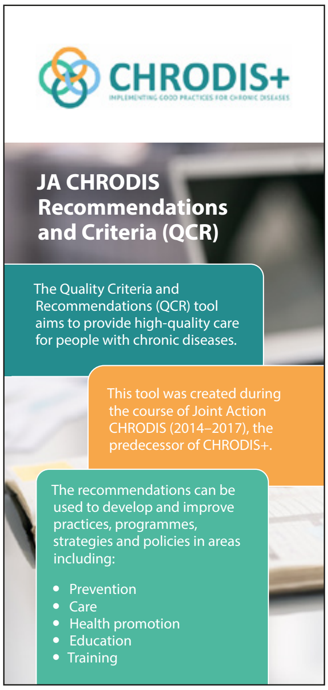
based on results of JA CHRODIS PLUS from 8 countries using
JA CHRODIS RECOMMENDATIONS AND CRITERIA (QCR), a short version

Authors: Core writing group on behalf of WP7 partners

October, 2020

This document arises from the Joint Action CHRODIS+ addressing chronic diseases through cross-national initiatives identified in JA-CHRODIS to reduce the burden of chronic diseases while assuring health system sustainability and responsiveness, under the framework of the Health Programme (2014-2020). Sole responsibility lies with the author and the Consumers, Health, Agriculture and Food Executive Agency is not responsible for any use that may be made of in the information contained therein.

Guide for the implementation of Good Practices to improve the quality of care for people with chronic diseases.


CHRODIS+
IMPLEMENTING GOOD PRACTICES FOR CHRONIC DISEASES

JA CHRODIS Recommendations and Criteria (QCR)

The Quality Criteria and Recommendations (QCR) tool aims to provide high-quality care for people with chronic diseases.

This tool was created during the course of Joint Action CHRODIS (2014–2017), the predecessor of CHRODIS+.

The recommendations can be used to develop and improve practices, programmes, strategies and policies in areas including:

- Prevention
- Care
- Health promotion
- Education
- Training

QCR **video** and *leaflet*

EPF awarded the RAPS patient-centred health award

The Regulatory Affairs Professionals Society (RAPS) Patient-Centred Health Award recognises groups, organizations or individuals who have made a significant impact to advance patient-centred policy, product development or regulatory decision making. EPF is honoured to have been rewarded with this reputable and prestigious honour.

6 projects and initiatives have EPF led Patient Advisory Groups

These include: EU-PEARL, COMPAR-EU, Health Outcomes Observatory (H2O), Gravitate Health, EATRIS Plus, and Data Saves Lives.

EU-PEARL
EU PATIENT-CENTRIC CLINICAL TRIAL PLATFORMS

COMPAR-EU

eatris+

Data Saves Lives

H_2O HEALTH OUTCOMES OBSERVATORY

Gravitate Health

Digital transformation that delivers for patients

Health is an area where Europe can undoubtedly benefit from the data and Artificial Intelligence revolution. The renewal of EPF's voice in the digital health policy debate resulted in increased opportunities for stronger collaboration and consultation in digital health. In 2020, EPF worked on several cross-cutting initiatives and publications addressing some of the most important updates in this field.

Preparing the EU for Digital Health

The future development of the European Health Data Space should be subject to particular attention and a sector specific approach, inclusive of patients' views. In 2020, EPF undertook several efforts underscore the patient perspective in digital health policy.

Responded to **two** key public consultations on the *European Commission's Data Strategy* and its *White Paper on Artificial Intelligence*.

Survey on AI, developed with the support of the **Digital Health Working Group**, that explored perceptions and basic knowledge on the topic in the patient community.

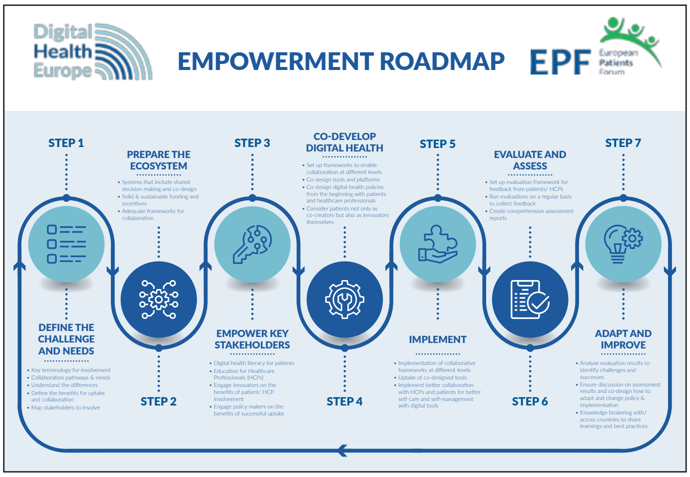
Published an *EU Policy Briefing* on Big Data and Artificial Intelligence plus a *summary report* from our recent survey on Electronic Health Records. The first results were presented at the European Patients Innovation Summit at the end of October.

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.

First multi-stakeholder workshop (virtual): Digital Tools for Patient Empowerment and Person-Centred Care

- Participants discussed the key recommendations of the *EPF Empowerment Roadmap* for more successful collaboration between patients and health systems, validated the in-depth analyses developed by EPF, and helped to further identify barriers and enablers to the procurement, adoption, trust and integration of digital health solutions. Identified enablers include:
  - Integration of patient involvement through structured frameworks as facilitator of systems
  - Recognition of patients as co-creators and innovators



EMPOWERMENT ROADMAP

STEP 1
DEFINE THE CHALLENGE AND NEEDS
- Key terminology for involvement
- Collaboration pathways & needs
- Understand the differences
- Define the benefits for uptake and collaboration
- Map stakeholders to involve

STEP 2
PREPARE THE ECOSYSTEM
- Systems that include shared decision making and co-design
- Solid & sustainable funding and incentives
- Adequate frameworks for collaboration

STEP 3
EMPOWER KEY STAKEHOLDERS
- Digital health literacy for patients
- Education for Healthcare Professionals (HCPs)
- Engage innovators on the benefits of patient/ HCP involvement
- Engage policy makers on the benefits of successful uptake

STEP 4
CO-DEVELOP DIGITAL HEALTH
- Set up frameworks to enable collaboration at different levels
- Co-design tools and platforms
- Co-design digital health policies from the beginning with patients and healthcare professionals
- Consider patients not only as co-creators but also as innovators themselves

STEP 5
IMPLEMENT
- Implementation of collaborative frameworks at different levels
- Uptake of co-designed tools
- Implement better collaboration with HCPs and patients for better self-care and self-management with digital tools

STEP 6
EVALUATE AND ASSESS
- Set up evaluation framework for feedback from patients/ HCPs
- Run evaluations on a regular basis to collect feedback
- Create comprehensive assessment reports

STEP 7
ADAPT AND IMPROVE
- Analyse evaluation results to identify challenges and successes
- Ensure discussion on assessment results and co-design how to adapt and change policy & implementation
- Knowledge brokering with/ across countries to share learnings and best practices

Data Saves Lives

In 2020, the *Data Saves Lives initiative* was formally launched. As EPF being the secretariat, Data Saves Lives worked to raise wider patient and public awareness about the importance of health data. It was crucial to improve the understanding of how health data is used to establish a trusted environment for dialogue. Key stats:

- *2 webinars*
- *2 tweet chats*
- 7 *blog-posts* from guest writers on highlighted health data questions.
- 1 two-hour *workshop* with patient experts, patient organisations, association and industry partners

TWEET CHAT: Health data sharing in the ...

DataSavesLives @DataSaves_Lives

June 5, 2020

TWEET CHAT: Health data sharing in the time of COVID-19

On 4 June 2020, we held our first #DSLChat on the topic of #healthdata and how it can be best communicated by patient groups during these unprecedented times, with our superb expert panel: @PatientenNL, @Birgitpower, @AngeBradshaw_AE & @inpdr_tweets.

Photo via @DataSaves_Lives

#DigitalHealth Webinar Series

Capacity-building is critical. Empowering individuals is crucial. Only through clear and dedicated information and education opportunities, patients can better understand and exercise their rights while exploiting the full benefits of the digitalisation of care. With this in mind, our Capacity Building, Projects and Policy team collaborated on a five-part webinar series on digital health for our members.

- Digital Health 101
- Role of Health Data in Medicines Regulation
- Health Data Sharing
- E-Health & Telemedicine
- Artificial Intelligence in Healthcare

Example of digital therapeutics software from Webinar 1

5 sessions • 274 participants
• 50,000 impressions

The Digital Transformation of Healthcare

2021 EPF Congress

From **26–29 October 2021**, the European Patients' Forum (EPF) will virtually convene experts, professionals, and patients to tackle the topic of digitalised healthcare. Following the success of the first Congress held in 2019, EPF will hold a **four-day virtual event** that will explore **the digital transformation of healthcare** and reflect on our engagement in EU policies focusing on digital health, and the experience of the COVID-19 pandemic. **Live follow-up event planned for Spring 2022 in Brussels.**

#EPFCongress2021

Register at
www.epfcongress.eu

…so much more

+500
participants expected

4
inspiring days of learning, exploring and co-creating solutions

9
high level advisors

3
plenary sessions

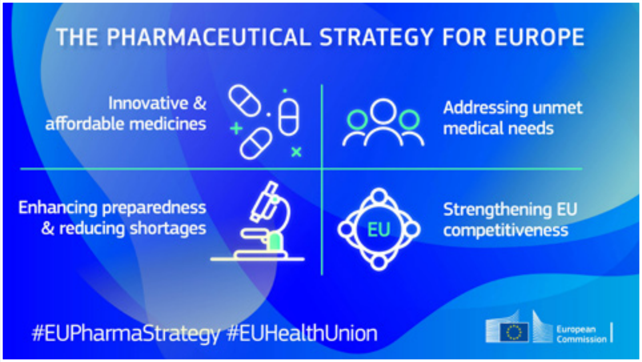
Virtual event –
26–29 October 2021

Accessing the healthcare we need with no discrimination

All of our advocacy work on COVID-19 highlighted issues regarding patients' access to healthcare services and medicines. In addition, we contributed a patient perspective to a European Parliament report on medicines shortages.

EU Pharmaceutical Strategy

We responded to the European Commission's consultation and reaction to the publication of the strategy, emphasising the crucial importance of developing solutions for patients' access to innovation, as well as ensuring patients are fully engaged in partnership with other stakeholders in shaping clinical research and developing pharmaceutical policies.



THE PHARMACEUTICAL STRATEGY FOR EUROPE

Innovative & affordable medicines

Addressing unmet medical needs

Enhancing preparedness & reducing shortages

Strengthening EU competitiveness

#EUPharmaStrategy #EUHealthUnion

Access to Medicines

In July 2020, we launched our revised position paper on *The Value and Pricing of Innovative Medicines*, with a webinar featuring a keynote speech from the European Commissioner for Health, Stella Kyriakides and interventions from MEPs Kateřina Konečná, Tomislav Sokol and Tiemo Wölken.

EXECUTIVE SUMMARY:

THE VALUE AND PRICING OF INNOVATIVE MEDICINES

EPF

APRIL 2020

Beating Cancer Plan

In our response on the Europe's Beating Cancer Plan, we re-emphasised patients' access to treatment, as well as the key role health literacy plays in empowering patients individually and collectively.

Health Technology Assessment (HTA)

In 2020, European policymakers recognised that health relies on a transparent, high quality and effective EU cooperation. As a result, EPF continued its contribution of the patient perspective to international networks and meetings focusing on **Health Technology Assessment (HTA)**.

On 9 September, EPF, EURORDIS and MEP Tiemo Wölken co-hosted an online event *"Lessons learnt from the COVID-19 pandemic and the future of HTA collaboration at EU level"* to relaunch a constructive debate and boost HTA cooperation at European level to effectively respond to the needs of national health systems and patients across Europe, in the context of COVID-19 response and beyond. With over 200 registrants, the event gathered key actors: Flora Giorgio, DG SANTE, European Commission, Ortwin Schulte, German Presidency as well as Marcus Guardian, EUnetHTA, and patient advocate Russell Wheeler.

Strengthening patient communities across Europe

STYPA2020 goes virtual!

STYPA2020 looked at how **patient advocacy** was evolving and facing emerging challenges and opportunities, and highlighted the importance of keeping a **strong ethical approach**. Through the online training course, EPF raised **awareness among the new generation of young patient advocates on current challenges, obstacles, opportunities and share good practices for ethical patient advocacy in complex environments**. The purpose of the training is to support young patient advocates through a high-quality tailored course, while maximizing their leadership potential in real environment settings.

STYPA2020 participants

38 young patients

18 countries represented

30 chronic diseases represented including: multiple sclerosis, epilepsy, cystic fibrosis, rare diseases, spina bifida and hydrocephalus and many others

Capacity Building Module on Leadership and Governance

- 24 participants
- 18 countries represented

Following the module, according to the feedback forms, most of the participants felt more confident and resourceful in being in their roles. Some interesting statistics include:

- **100%** of the respondents in the final evaluation survey **declared very high levels of confidence**
- **79%** of respondent declare they have **improved their knowledge and skills in managing their organisations and their relationships with key stakeholders**
- **85%** have declared **improvement of their motivation** as leaders.
- **86%** of respondents declare very **high levels of motivation to introduce new leadership style/ practices** such as empowered leadership and positive governance

WAYS

The EPF Youth Group launched its *Work And Youth Strategy (WAYS) project results* presenting all the key information they received, following the WAYS questionnaire. In the questionnaire, they asked young people with chronic conditions from all over Europe about their challenges and experience in finding employment. The results with key recommendations were then published in a *report*, *fact sheet* and *video*.

Work And Youth Strategy

21% of young people identified prejudice against their chronic condition as a barrier to finding employment

Only 5% of young people identified their wider community (outside of family and friends), as supporting them in finding employment

35% of respondents said that they would not want to disclose an ‘invisible’ condition under any circumstances

44% of those surveyed felt that finding a job was ‘Difficult’ or ‘Very Difficult’

New additions

2020 witnessed several ‘firsts’ at EPF and we’re happy to continue their mission moving forward.

Launch of ethics committee

Launched in 2020, 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.

Going online

In October 2020, we held an Extraordinary General Meeting (EGM) with our members in order to change the EPF Constitution to allow **online General Meetings**, as a result of the pandemic. The proposal to hold online General Meetings (where necessary) was unanimously approved by our members.

COVID-19 Resource Point

As a response to the pandemic and our members’ requests, we launched the ***COVID-19 Resource Point***. We collaborated with Prof. Jean-Michel Dogné, Head of the Department of Pharmacy at the University of Namur, expert at the European Medicines Agency (EMA) and member of WHO’s Global Vaccine Advisory Committee for advice. We share credible figures, research articles and reports on COVID-19 and its effects on the patient community on a weekly basis.

A fresh injection of youth

For the first time ever, as per the new EPF Constitution, a seat on the Board reserved for a representative of the EPF Youth Group was appointed to **Jana Popova**.

A new voice – EU Patients Podcast

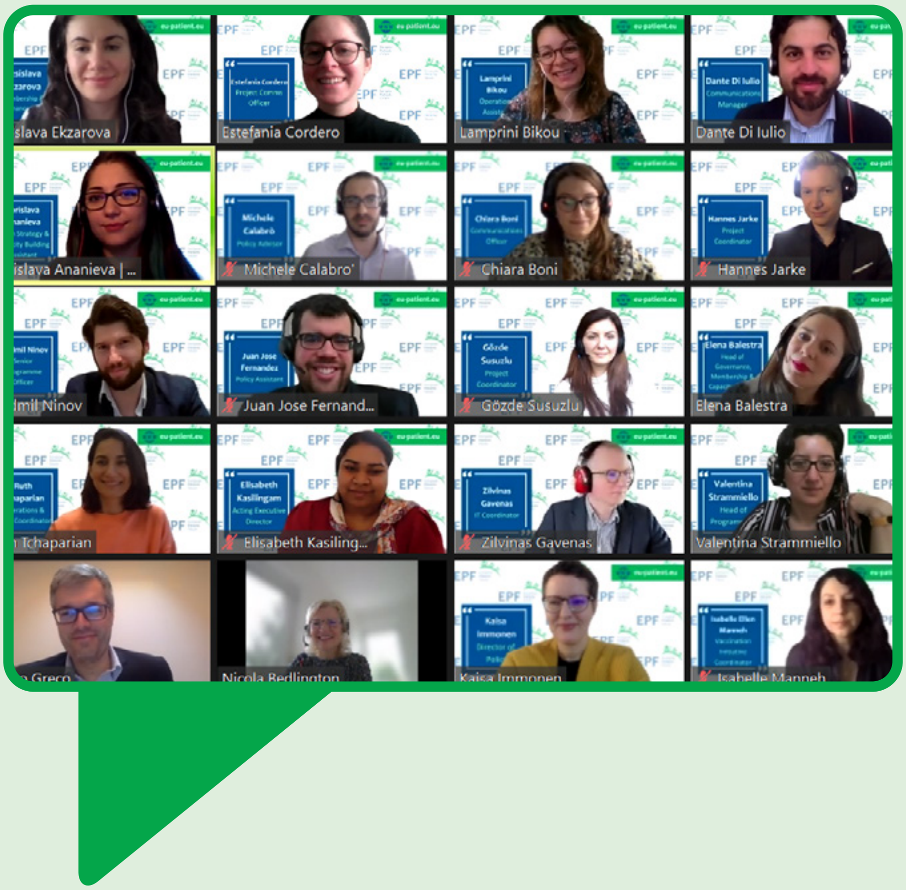
In December 2020, we launched the first episode of the ***EU Patients’ Podcast***. The objective is to feature our members, policymakers, and key stakeholders in conversation with EPF Secretariat on various issues relating to patient advocacy and empowerment. This podcast provides another important avenue for the patient voice to be heard.

For a comprehensive look at EPF’s 2020 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, public health NGOs, industry, researchers, regulators and many others – in our mission to empower patients to take an active role in improving healthcare. Whether near or far, working remotely or at the office, our doors and inboxes are always open.

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



#WeAreEPF

EPF European Patients Forum

The European Patients' Forum (EPF) is an umbrella organisation of patient organisations across Europe and across disease areas. Our 77 members include disease-specific patient groups active at EU level and national coalitions of patients.

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