EPF European Patients Forum

# EUROPEAN PATIENTS' FORUM

# Work Plan 2022

*Driving Better Health for Patients in Europe*

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**A STRONG PATIENTS' VOICE TO DRIVE BETTER HEALTH IN EUROPE**

# Content

# Executive Summary

This Work Plan 2022 outlines the strategic work path that the EPF Secretariat will carry out in its operations during the year 2022. All objectives and tactics align with the EPF Strategic Plan 2021-2026 and will be implemented accordingly by the EPF team with oversight by EPF's Management Board and Special Adviser. A shortened and condensed version of this work plan is also available for review.

# Introduction

The **European Patients' Forum (EPF)** is an independent non-profit, non-governmental 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. As a result, we are the leading voice of patient organisations in Europe.

**Our Vision** is: A Europe where patient organisations are valued partners in creating equitable, person-centered, 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.

# Target Groups

The primary target groups of EPF's activities in 2022 will be:

- Our member patient organisations
- The wider patient community and the general public
- European-level policymakers (Members of the European Parliament, officials of the European Commission key DGs and Commissioners)
- Member States' representatives in Brussels as well as nationally, also in the context of the EU Council Presidencies of Slovenia (end of 2021), and the upcoming EU Presidency Trio: France, Czech Republic, and Sweden
- The European Medicines Agency (EMA), Fundamental Rights Agency (FRA) and European Centre for Disease Control (ECDC)
- International organisations: OECD, WHO European Region
- Health stakeholders, including public health NGOs, medical professionals' organisations, academia/research community, scientific/professional bodies, and the healthcare industry
- The European Patient Academy on Therapeutic Innovation (EUPATI) and the Patient Focused Medicines Development Initiative (PFMD)
- Health media/press at EU and national levels.

## Added Value and Impact

Patient involvement in healthcare policy brings value from a moral perspective - as decisions directly impact patients' lives and well-being – and, equally from a first-hand perspective - as policy and practice should focus on what matters most to patients. A meaningful definition of "what matters" in healthcare is achievable only with the involvement of patients.

EPF is the unique European-level, non-disease specific umbrella patient organisation: it provides a vital cross-disease perspective from the wider patient community into EU policymaking on issues that directly impact patients' lives in a national and/or regional context. We have a unique and privileged position linking patient communities across the EU with EU-level developments. We focus on empowering patient organisations to become effective, credible civil society actors and on strengthening their capacity to partner in national health policy and practice, supporting participatory and inclusive health systems. Through our Youth Group, we nurture a future generation of patient leaders, covering a wide range of chronic conditions and nationalities.

In health system performance and quality of care, measuring the right indicators will require a critical exploration of "what matters to patients," and how/whether this can be measured. Similarly, an accurate evaluation of the added therapeutic value of new medicines, will require a meaningful patient input.

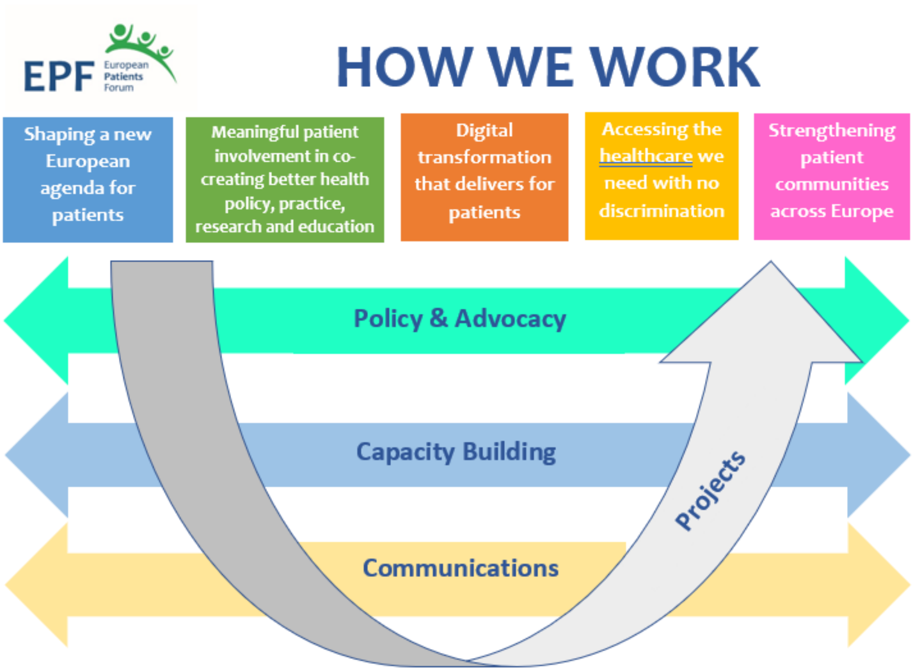
Our evidence-based advocacy helps strengthen patient involvement and recognition of patients as partners in health policy and practice, thus supporting participatory and inclusive health systems. Our work on patients' rights and responsibilities goes beyond disease- or country-specific initiatives. It has the credibility of being supported by a wide cross-EU patient movement; thus, enhancing meaningful implementation of good practices in patient empowerment and involvement by practitioners as well as policymakers.

EPF is also a strong advocate for the value of Europe in health and brings added value to the discussion on health in Europe, through its engagement with high-level strategic issues such as a European Health Union, and trusted partnerships with diverse actors. We link with both EU and international bodies and can point out relevant synergies or gaps. We participate in collaborative initiatives and policy debates at European and international level, helping to define health priorities in which the patient community can contribute and reap benefit.

EPF is committed to the highest level of integrity and ethics in its interactions with all partners.

## How We Work

EPF's work comprises three mutually reinforcing "areas": policy and advocacy; capacity-building and communications.  Our extensive project work represents a platform underpinning these three areas.



## EPF’s 2022 Work Plan

Our Work Plan for 2022 will focus on the five strategic goals of our Strategic Plan 2021-2026, which are complemented by cross-cutting activities.

In this section we describe the activities under each goal, although it should be kept in mind that our activities are highly complementary and often address more than one of the five goals. In addition, our 2022 work plan includes the follow up in-person event to our second patient-led Congress, which was initiated in 2021 as a virtual event, with the theme of the **digital transformation of healthcare**.

### 1. SHAPING A NEW EUROPEAN AGENDA FOR PATIENTS

### HIGH-LEVEL EU AND INTERNATIONAL HEALTH ADVOCACY

### European Health Union (EHU)

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| ***Need*** | Advocacy actions to ensure that health initiatives at EU level falling under the EHU develop in the right direction, looking beyond pandemic preparedness and response, towards sustainable, resilient, equitable and people-centred health systems. Initiatives include reinforcement of ECDC and EMA, the establishment of the new HERA agency, the Pharmaceutical Strategy. Meaningful patient involvement in EHU discussions will be needed, to help shape future thinking on health at EU level |

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| ***Deliverables*** | On-going dialogue with the EU Institutions, and EU health stakeholders, through the EU4Health Civil Society Alliance and the EHU initiative (Gastein)<br>Ad-hoc statements and follow up actions on specific health initiatives under the EHU |
| ***Objective/ Impact*** | To influence legislative and non-legislative EU proposals and actions to advance a European Health Union with patients and citizens at the centre |
| ***Timeframe*** | Ongoing |
| ***Region*** | Europe |
| ***Targets*** | policymakers, EPF members, NGOs and health stakeholders |

## EU4HEALTH programme and patient organisations' funding

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| ***Need*** | Operating grants for civil society organisations were excluded from the EU4Health Work Programme 2021. Following extensive advocacy co-led by EPF, a commitment was subsequently received from the commission to reinstate these, but without precise details. Furthermore, the EU4Health Work Programme 2021 is somewhat narrow in scope with a focus on limited disease areas. |
| ***Deliverables*** | Participation in EC consultation on Work Programmes development; continuing advocacy in coordination with public health and patient organisations to ensure future funding for patient organisations is relevant and sustainable. |
| ***Objective/ Impact*** | To restore meaningful operating grants and enhance the grant mechanism, improve consultation with patient organisations, to ensure a broader scope for the EU4Health Work Programmes and more impactful funding opportunities. |
| ***Timeframe*** | 2021-2022 |
| ***Region*** | Europe |
| ***Targets*** | policymakers |

## Engagement with WHO European Regional Office

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| ***Need*** | EPF is an accredited non-state actor and contributed to the shaping of the European Programme of Work. Initial discussions took place in 2019 around EPF's extended mandate to encompass some countries of the European region, and potential collaborations to engage patient organisations there. |
| ***Deliverables*** | Strategic meeting with Director of WHO European Regional Office and/or topic-focused meetings with WHO representatives |
| ***Objective /Impact*** | To strengthen the cooperation between the WHO European Regional Office and EPF, and advocate for the inclusion of patient representatives in policymaking |
| ***Timeframe*** | Depending on public health situation and WHO priorities |
| ***Region*** | Europe (WHO region) |
| ***Targets*** | WHO |

## Engagement with the European Medicines Agency (EMA)

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| ***Need*** | To ensure the patient perspective is brought in EMA's regulatory and public engagement activities and to ensure EPF's membership is informed about and engaged with EMA at all relevant levels. |
| ***Deliverables*** | EMA's Patients' and Consumers' Working Party (PCWP) regular meetings<br>Participating at ad hoc meetings, providing input to deliverables as requested<br>Regular information to EPF's members about EMA activities |
| ***Objective /Impact*** | To continue to foster meaningful patient involvement in medicines regulation and foster a continued working relationship with EMA |
| ***Timeframe*** | Ongoing |

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| ***Region*** | Europe |
| ***Targets*** | EU pharmaceutical regulators, patient community |

## QUALITY AND SAFETY OF HEALTHCARE

### Engagement with OECD

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| ***Need*** | Continuing collaboration with OECD and representation of the patient voice on the HCQO working party, PaRIS Advisory Panel, PROMS work |
| ***Deliverables*** | Participation in meetings (as required) |
| ***Objective*** | To bring patient voice into OECD health-related initiatives |
| ***Timeframe*** | Ongoing |
| ***Region*** | Europe |
| ***Targets*** | OECD, policymakers, EPF members where relevant |

### CORE-MD

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| ***Need*** | Adequate measurements to compare the feasibility and impact of different high-risk medical devices to each other and their associated risks |
| ***Deliverables*** | DELPHI consultation on PROs and PROMs as part of CORE-MD to define criteria for the assessment of high-risk medical devices |
| ***Objective*** | Overview of best suited PROMs and shortcomings |
| ***Timeframe*** | March 2022 |
| ***EPF's Role*** | EPF is responsible for involving patients living with medical devices (or their carers) in the project and conduct DELPHI focus groups to determine most important PROs and PROMs for different devices<br>EPF also brings crucial patient perspectives into discussions within the WPs they are involved in |
| ***Targets*** | Patients living with high-risk medical devices |

### H2O (Health Outcomes Observatory)

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| ***Need*** | Standardised data governance and infrastructure system across Europe to incorporate and amplify patients' experiences and preferences in decisions affecting their individual health care and those of the entire patient community. |
| ***Deliverables*** | Development and adaptation of training programmes and materials for patients in the four participating countries (AT, DE, ES, NL)<br>Active engagement of national level patient organisations in promoting the adoption of H2O amongst their constituencies and with other stakeholders |
| ***Objective*** | To establish patient-centric pan-European observatories that amplify the patient voice in their own care and health systems more broadly, and ultimately improve quality of care and sustainability based on outcomes that truly matter to patients. |
| ***Timeframe*** | March – September 2022 |
| ***EPF's Role*** | EPF co-leads the work stream on patient engagement activities, bringing a total of 24 patient advisors across three condition-specific patient advisory boards. |
| ***Region*** | Europe and specifically Austria, Germany, Spain, The Netherlands |
| ***Targets*** | Patients living with Diabetes, IBD, and Cancer; long-term, the wider patient community covering a wider range of disease areas |

## 2. MEANINGFUL PATIENT INVOLVEMENT IN CO-CREATING BETTER HEALTH POLICY, PRACTICE, RESEARCH AND EDUCATION

### PATIENT INVOLVEMENT AND EU RESEARCH PROGRAMMING

In 2022, EPF will continue to strive for meaningful patient involvement in EU research and health-related programming, through actions aiming at informing the design of research opportunities and strengthening the capacity of patient organisations participating in research.

### Membership and Patient Involvement in projects

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| ***Need*** | Increasingly involve EPF member organisations and individual patient advocates in EU-funded projects, under the coordination and support of EPF to co-create a meaningful role for patient organisations and increase their direct participation in patient involvement activities in projects. |
| ***Deliverables*** | Map EPF members' expertise in EU project themes via recurrent surveys and exchanges;<br>Propose to at least 5 EPF member organisations or patient advocates to join EU project consortia;<br>Propose to join consortia from the proposal phase of projects to ensure early and meaningful involvement. |
| ***Objectives /Impact*** | To enhance an impactful patient and patient organisations' participation in projects through direct engagement of members as either full project partners, "Linked Third Parties" or through Patient Advisory Groups |
| ***Timeframe*** | Ongoing |
| ***Region*** | Europe |
| ***Targets*** | EPF member organisations and individual patient advocates |

### Patient involvement in health professionals' education

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| ***Need*** | Follow-up from survey undertaken in 2020-21 and reflection on its results |
| ***Deliverables*** | Survey report and follow-up statement |
| ***Objectives /Impact*** | To raise awareness among of the added value of involving patients in health professionals' education and continuous professional development, and what constitutes a meaningful involvement |
| ***Timeframe*** | Q1 2022 |
| ***Region*** | Europe |
| ***Targets*** | Policymakers and health professional organisations |

### HEALTH LITERACY

### Awareness-raising on antibiotic resistance

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| ***Need*** | Antibiotic resistance is an urgent public health threat and an EU policy priority |
| ***Deliverables*** | Communication and information resources |
| ***Objectives /Impact*** | Increased awareness and engagement in patient community, continued collaboration with ECDC |
| ***Timeframe*** | ongoing, focus on EAAD 2022 |
| ***Region*** | Europe |
| ***Targets*** | EPF members |

## PARTNERSHIPS

To reach the ultimate goal of meaningful patient involvement, EPF has built strategic partnerships with several organisations active in various capacities on the engagement of patients.

**Patient Engagement Open Forum** (PEOF) is one of the IMI project PARADIGM's key legacies. PEOF acts as a patient-centered multi-stakeholder environment for co-creation of solutions to practice and develop patient engagement. PEOF brings together EPF, EUPATI and the Patient Focused Medicine Development (PFMD).

**EUPATI** was established as an independent foundation in September 2020. EPF holds the chair of the EUPATI board and supports EUPATI in its mission to driving patient education in medicines R&D.

**PFMD** is a multistakeholder not-for-profit collaborative initiative focusing on patient engagement in R&D where EPF plays a vital role as member of the Board.

EPF co-chairs the **EFPIA Patient Think Tank**, which meets four times a year to discuss EU health policy developments and patient -industry collaboration.

Other relevant partnerships feature the one with **EIT Health**, focusing on the involvement of patients in the development of digital health solutions. EIT Health is a partner in several EPF-led initiatives including the **EPF Congress** and **Data Saves Lives**.

EPF has built a strong and steadily growing partnership with **EATRIS** (the European Infrastructure for Translation Medicine) aiming at embedding the patient perspective in translational research. The partnership involves a wide range of joint activities including the implementation of the **EATRIS-Plus** project, and EATRIS active participation in the EPF Congress.

**EUROPEAN HEALTH NETWORKS** EPF is involved in several formal and informal bodies and networks, including the EU Health Policy Platform, EU4HEALTH Civil Society Alliance, Civil Society Europe, All Policies for a Healthy Europe, the EU Health Coalition, the European Health Parliament, the Alliance for Value-Based Healthcare, the Patient Access Partnership (PACT), Dialogues with Medtech and Medicines for Europe, SDG Watch Europe and The Social Platform. Engagement in these platforms and groups of varying degrees of formality serves to both feed into our policy analyses and to disseminate our key advocacy messages effectively to targeted audiences.

## PATIENT INVOLVEMENT IN R&D AND HEALTH SYSTEMS

### Patient Involvement in the EU's Health Technology Assessment (HTA) Agenda

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| ***Need*** | Patient involvement in health technology assessment (HTA) is an evolving discipline that includes both well-documented approaches and less publicised ones. In all cases, there remains a gap in evidence on how each stakeholder experiences and perceives the processes in place for patient involvement in HTA. |
| ***Deliverables*** | Cooperation on a multi-stakeholder report including analysis and evidence-based recommendations on valuable processes for all consulted stakeholders.<br>Wide promotion of the report and key messages for further uptake by stakeholders. |
| ***Objectives*** | To understand the stepwise patient involvement processes used across Europe |

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| ***/Impact*** | To capture experiences and perspectives on patients experiences in HTA practices. |
| ***Timeframe*** | Throughout 2022 |
| ***Targets*** | EPF members, individual patient advocates, and other EU Health advocacy organisations. |

### COMPAR-EU

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|---|---|
| ***Need*** | To identify, compare and rank the most effective and cost-effective self-management interventions for adults living with four high-priority chronic diseases (Type 2 Diabetes Mellitus, COPD, Obesity, and Heart Failure) |
| ***Deliverables*** | Producing lay language materials of key project deliverables, mainly dedicated to cost-effectiveness of self-management interventions across various landscapes in Europe (June) |
| ***Objectives /Impact*** | Contributes to the increased focus placed by governments and health systems on developing effective strategies for promoting self-care to effectively manage incoming healthcare challenges (ageing populations, increase in chronic diseases, rapid technological development, constrained finances) |
| ***Timeframe*** | June – December 2022 |
| ***Region*** | Europe |
| ***Targets*** | Patients living with four widespread chronic diseases, policymakers, patient organisations |

### EU PEARL

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|---|---|
| ***Need*** | Involvement of patients as partners in platform trials |
| ***Deliverables*** | Beta version of Patient Engagement Platform for platform trials |
| ***Objectives /Impact*** | Creation of a repository for patients, academia and industry that provides guidance and supporting tools in involving patients actively |
| ***Timeframe*** | October 2022 |
| ***Region*** | Europe, for eventual international use |
| ***Targets*** | Researchers, industry, patient advocates and patients enrolled in platform trials |

### PERMIT

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| ***Need*** | Improve personalised medicines research through a series of expert consultations (workshops) to establish recommendations on methodology that can be widely accepted. |
| ***Deliverables*** | EPF will join a series of collaborative workshops and trainings with all relevant stakeholders in March and May ;<br>Co-develop the project’s Final Conference event (June );<br>Lay summary materials of key project outcomes to ensure outreach to a wider public, including methods used to assign treatment options to patient clusters and clinical trials design (March) |
| ***Objectives /Impact*** | These recommendations will ensure the scientific excellence, validity, robustness and reproducibility of results generated by personalised medicine programmes. |
| ***Timeframe*** | March – June 2022 |
| ***Region*** | Europe |
| ***Targets*** | Patients that may benefit from personalised medicine in the future. |

# 3. DIGITAL TRANSFORMATION THAT DELIVERS FOR PATIENTS

## Digital Health Working Group membership and terms of reference

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| ***Need*** | Revision of the Digital Health working group mandate and membership (postponed in 2020) |
| ***Deliverables*** | Revised mandate and membership<br>Min. 2 meetings in 2022 |
| ***Objectives /Impact*** | Renew the membership while maintaining continuity and enhancing expertise,<br>Further shape EPF's policy contribution to digital health transformation |
| ***Timeframe*** | 2022 |
| ***Region*** | Europe |
| ***Targets*** | Digital Heath Working Group members, EPF members |

## European Health Data Space (EHDS)

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| ***Need*** | EHDS *C*ommission legislative proposal expected in Q1 2022. EPF will follow up on its extensive consultation engagement in 2020/21 to further shape a EHDS which responds to patients' needs and goals. |
| ***Deliverables*** | Participation in European Commission's eHealth Stakeholders Group activities and working groups<br>Policy statements/reactions/contributions in response to the legislative process vis a vis European Parliament and Council<br>Promote EPF position on the EHDS in projects, including through our participation in the stakeholder forum of the Joint Action on the European Health Data Space (TEHDAS) |
| ***Objectives /Impact*** | Development of a EHDS responding to patient-needs and goals on health data, digital health services and AI in healthcare |
| ***Timeframe*** | 2022 |
| ***Region*** | Europe |
| ***Targets*** | Policymakers, digital health stakeholders, EPF members, EPF Digital Health working group |

## Artificial Intelligence in Healthcare

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|---|---|
| ***Need*** | Improve the inclusion of an informed patients' voice in the discussion on AI in healthcare, from policy to projects, to ensure that potential negative impacts, risks and needs as well as opportunities, are taken into full consideration. |
| ***Deliverables*** | Update of the EPF AI Knowledge hub<br>Dissemination and use of research findings (EU AI Fund tenders)<br>Development of a dedicated EPF position statement on AI in Healthcare<br>Involvement in EU AI policies (EHDS and AI horizontal legislation) |
| ***Objectives /Impact*** | EPF's actions will equip the patient community to play their role in AI, supported by knowledge and appropriate resources, and enable meaningful involvement in data and AI related projects and advocacy capacity. |
| ***Timeframe*** | Throughout 2022 |
| ***Region*** | Europe |
| ***Targets*** | Policymakers, EPF members, stakeholders, EPF Digital Health Working Group |

## EPF Congress 2022 – Continuing the Conversation (23-24 June 2022)

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| ***Need*** | Follow-up on the Congress 2021 in a face to face, or hybrid meeting, depending on the public health situation |
| ***Deliverables*** | Conference event and Report |
| ***Objectives /Impact*** | To provide a unique opportunity for dialogue and engagement with a wide range of health players who aspire to showcase patient-led innovation. Together, we will explore what meaningful patient involvement means in a rapidly changing healthcare environment using new technologies, and why it is critical to successful innovation. |
| ***Timeframe*** | 23-24 June 2022 |
| ***Region*** | Brussels, Belgium |
| ***Targets*** | All stakeholders |

## Data Saves Lives

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| ***Need*** | Raise public/patient awareness about the potential and importance of health data, improve understanding of how it is used, establish a trusted environment for multistakeholder dialogue and good practice. |
| ***Deliverables*** | Multi-stakeholder engagement activities such as social media, webinars, workshops, and providing materials such as toolkits, glossaries, etc, co-created with patients/patient advocates. |
| ***Objectives /Impact*** | Stimulating a structured and meaningful discourse about the responsible use of health data, and to capture, share and discuss views on other data issues.<br>Scaling up the initiative at national level in different national contexts |
| ***Timeframe*** | Ongoing |
| ***Region*** | Europe and beyond |
| ***Targets*** | Patients, patient representatives, patient organisations, carers, companies, health authorities, the wider public. |

## Gravitate Health

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|---|---|
| ***Need*** | To equip and empower citizens with digital tools that enable them to be confident, active, and responsive in their patient journey, specifically by encouraging the safe use of medicines, reducing risks, and for better health outcomes and improved quality of life. |
| ***Deliverables*** | Establish and coordinate a User Advisory Group to contribute the patient/user perspective throughout the project<br>Deliver a Citizen Toolkit by April 2022<br>Co-lead capacity building and multistakeholder engagement, especially as regards digital health literacy for patients, citizens and healthcare professionals. |
| ***Objectives /Impact*** | Develop a public information tool (called the G-Lens) that will share approved information on medicines in an understandable format. |
| ***Timeframe*** | Throughout 2022 |
| ***Region*** | Europe |
| ***Targets*** | Patients/citizens needing to read and understand their medicines information, which is traditionally provided in the form of a paper leaflet |

## PharmaLedger

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| ***Need*** | Support to increase the speed of innovation in the health sector by driving the early-adoption of block-chain based technology. |

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| ***Deliverables*** | Contribute to the project's patient advocacy through involvement in the governance, legal/data framework and engagement streams<br>Ongoing coordination of advisory board<br>Contributing to the work of the project Collaboration Platform (November)<br>Ensure Patient Engagement in use cases where possible (June) |
| ***Objectives /Impact*** | Creation of a widely used and trusted platform for the healthcare sector that integrates the supply chain of medicines, clinical trials and health data as case studies. |
| ***Timeframe*** | Throughout 2022 |
| ***Region*** | Europe / International |
| ***Targets*** | All patients and medicine users; policy makers in health, legislation, and technology; pharma industry; researchers; pharmacists (and staff) |

### EHDEN

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| ***Need*** | Respond to the current challenges in generating insights and evidence from real-world clinical data at scale, to support patients, clinicians, payers, regulators, governments, and the pharmaceutical industry in understanding wellbeing, disease, treatments, outcomes and new therapeutics and devices |
| ***Deliverables*** | Support the outreach efforts and strategic engagement and buy-in of external parties, particularly patients and people donating their health data<br>In 2022, EPF will begin to develop and deliver a series of online lay-language courses on key project themes and health data terminology for non-experts; the first course was delivered in autumn 2021, with the final 4th course expected for May. |
| ***Objectives /Impact*** | Develop a federated and equitable ecosystem of institutions generating clinical data and harmonising clinical data and creating a network technology for real-world research that upholds privacy and ethical guidelines; and, to harmonise 100 million anonymised health records. |
| ***Timeframe*** | Throughout 2022 |
| ***Region*** | Europe |
| ***Targets*** | Patients and people sharing their health data, researchers, industry partners, healthcare professionals. |

## 4. ACCESSING THE HEALTHCARE WE NEED WITH NO DISCRIMINATION

### Universal Access to Healthcare Working Group membership and terms of reference

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|---|---|
| ***Need*** | Revision of the working group mandate and membership (postponed in 2020) |
| ***Deliverables*** | Revised mandate and membership<br>Minimum 2 physical or virtual meetings in 2022 |
| ***Objectives /Impact*** | Renew the membership while maintaining continuity and enhancing expertise: |
| ***Timeframe*** | 2022 |
| ***Region*** | Europe |
| ***Targets*** | Universal Access Working Group members, EPF members |

## CROSS-BORDER HEALTHCARE

### Monitoring the European Commission’s evaluation of the Directive 2011/24/EU

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| ***Need*** | The European Commission evaluated the functioning of the Directive during 2021. This evaluation is expected to measure and impact patients’ rights. The results of the evaluation will consider various policy options. The European Commission’s adoption is expected for Q2 2022. |
| ***Deliverables*** | Monitor actions deriving from the evaluation of the Directive and engage with the European Commission - advocacy activities (to be defined) |
| ***Objectives /Impact*** | To ensure that the steps that derive from the evaluation of the Directive improve patients’ rights for seeking cross-border healthcare, inform EPF members of developments |
| ***Timeframe*** | 2022 |
| ***Region*** | Europe |
| ***Targets*** | Policymakers and EPF Members |

## MEDICINES AND MEDICAL DEVICES

### Engagement with the ongoing revision of the EU general pharmaceutical legislation

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| ***Need*** | The European Commission, as part of the EU pharmaceuticals strategy, started evaluating and revising the EU’s general legislation on medicines for human use to ensure a future-proof and crisis-resistant medicines regulatory system in 2021 – an endeavour which will last until Q4 2022. The final form of the legislative instrument(s) resulting from the revision is yet to be decided. The development of an implementation plan by the EU Commission will depend on the final decision. |
| ***Deliverables*** | Statements and/or other contributions and reactions to developments of the revision of the EU general pharmaceutical legislation. |
| ***Objectives /Impact*** | Conduct advocacy activities to ensure patient perspectives are heard, ensure EPF membership is informed about EU policy and regulatory framework on medical devices. |
| ***Timeframe*** | 2022 |
| ***Region*** | Europe |
| ***Targets*** | Policymakers, stakeholders, patient organisations |

### Engagement on the Pharmaceutical Strategy for Europe

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| ***Need*** | The pharmaceutical strategy contains several priority actions, including defining “medical unmet needs” and revising the regulation on paediatric medicines. Patients’ voices need to be central to this process. The European Commission does not yet have an agreed definition of “medical unmet needs”. |
| ***Deliverables*** | Policy “roundtable” event co-produced with EPF members including a summary report<br>Engaging EPF’s Youth Group on the paediatric regulation |
| ***Objectives /Impact*** | To see whether a consensus emerges on the potential criteria or definition to be used at EU level. |
| ***Timeframe*** | 2022 |
| ***Region*** | Europe |
| ***Targets*** | EU and national policymakers, regulators, industry, HTAs, payers, patient organisations, health NGOs |

## Medical devices and In Vitro Diagnostics

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| ***Need*** | To monitor and communicate about the implementation of the Medical Device Regulation (MDR) and In Vitro Diagnostic Regulation (IVDR), including timeline. Policy work will be highly synergetic with participation in the CORE-MD project |
| ***Deliverables*** | Participation in meetings of European Commission's coordination group sub-groups on post-market surveillance and clinical investigations. |
| ***Objectives /Impact*** | Patient perspective in the discussions on implementation of MDR and IVDR |
| ***Timeframe*** | 2022 |
| ***Region*** | Europe |
| ***Targets*** | EPF Members, policymakers |

## Monitoring the ongoing impact of the COVID-19 pandemic in patients/patient orgs.

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| ***Need*** | The COVID-19 pandemic has had an unprecedented impact on the functioning of patient organisations and on individual patients with chronic diseases. This impact needs to be monitored and communicated. |
| ***Deliverables*** | Second round of EPF's COVID-19 Survey. |
| ***Objectives /Impact*** | To examine how the ongoing pandemic continues affecting patient organisations and individual patients with chronic diseases.<br>To draft fit-for-purpose policy recommendations to policymakers. |
| ***Timeframe*** | 2022 |
| ***Region*** | Europe |
| ***Targets*** | Policymakers, EPF members, patients, other health advocacy organisations |

## PERISCOPE

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|---|---|
| ***Need*** | To conduct multi-disciplinary research on the impacts of the COVID-19 outbreak from different viewpoints: clinic and epidemiologic; humanistic and psychologic; socio-economic and political; statistical and technological. |
| ***Deliverables*** | Development of content and implementation and testing of training modules and materials for different audiences**.** Enhance effectiveness and uptake of training materials by December. |
| ***Objectives /Impact*** | To map and analyse the unintended impacts of the COVID-19 outbreak; develop solutions and guidance for policymakers and health authorities on how to mitigate the impact of the outbreak; enhance Europe's preparedness for future similar events; and reflect on the future multi-level governance in health and other domains affected by the outbreak. |
| ***Timeframe*** | 2022 |
| ***Region*** | Europe |
| ***Targets*** | Patients, policymakers, patient organizations, healthcare professionals, country governments and health authorities outside Europe. |

## Summer Training for Young Patient Advocates (STYPA)

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| ***Need*** | STYPA is a tailored high-quality training programme for young patient advocates. The overarching theme for 2022 will be "sexual health and wellbeing". |
| ***Deliverables*** | F2F training, Virtual courses and STYPA report |
| ***Objectives /Impact*** | Training future patient leaders<br>Foster EPF Young Patients' Alumni and Ambassador Programme, creating a powerful network of 'graduates' from STYPA, to able to collaborate and champion EPF and its work with young people. |

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| ***Timeframe*** | May - October 2022 |
| ***Region*** | Europe |
| ***Targets*** | Young patients and EPF Youth Group |

## 5. STRENGTHENING PATIENT COMMUNITIES ACROSS EUROPE

### STRENGTHEN AND SUPPORT NEW GENERATIONS OF EUROPEAN PATIENT ADVOCATES

#### Patient Advocacy 101 for Young Patient Advocates online

Building on EPF STYPA experience, EPF will create an online self-learning course for young patients advocates, that will touch upon the basics of patient advocacy. The course will be available on EPF website all year round and participation will be free of charge.

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| ***Need*** | STYPA is not able to accommodate all applicants for it. Therefore, EPF decided to reach out to a greater number of young patients advocates wanting to learn more about patient advocacy. |
| ***Deliverables*** | Online course on EPF website |
| ***Objectives /Impact*** | Training future patient leaders in the basics of patient advocacy and reaching out to a greater audience |
| ***Timeframe*** | January - May 2022 |
| ***Region*** | Europe |
| ***Targets*** | Young patients and EPF Youth Group |

#### Master's Programme on Patient Advocacy

In 2022, EPF will launch an International Master’s Degree Programme on Patient Advocacy in partnership with Cattolica University, the first ever recognised of its kind.

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|---|---|
| ***Need*** | Offer to the European Patient community the possibility to join an accredited master’s degree on international patient advocacy. |
| ***Deliverables*** | Master Curriculum |
| ***Objectives /Impact*** | Professionalise the leaders and future leaders of European patients' organisations |
| ***Timeframe*** | March 2022 - April 2023 |
| ***Region*** | Europe |
| ***Targets*** | Patients, POs, patient representatives, health stakeholders |

#### Mapping report of patients organisations in Western Balkans

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|---|---|
| ***Need*** | Have a clear idea of the key Pos in Western Balkans to better understand their needs and how EPF could actively and properly support them. |
| ***Deliverables*** | Internal report |
| ***Objectives /Impact*** | Support patients' organisations in the Western Balkans to get active locally and regionally |
| ***Timeframe*** | Spring- Summer 2022 |
| ***Region*** | Western Balkans |
| ***Targets*** | Patients, POs, patient representatives, health stakeholders |

### Regional event in Western Balkans

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|---|---|
| ***Need*** | Liaising with Western Balkans POs to better understand their needs and how EPF could actively and properly support them. |
| ***Deliverables*** | Event, Event Report & Pictures |
| ***Objectives /Impact*** | Support patients' organisations in the Western Balkans to get active locally and regionally |
| ***Timeframe*** | Autumn 2022 |
| ***Region*** | Western Balkans |
| ***Targets*** | Patients, POs, patient representatives, health stakeholders |

### EPF Youth Group

As per the new EPF Constitution, one youth group representative is elected as EPF board member, thus the Youth Group is also involved in ensuring the good governance of EPF.

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| ***Need*** | Providing space for the voice of young patients in Europe/ Foster the future European patient advocacy leaders |
| ***Deliverables*** | Meeting minutes, Project Report on “Sexual Health and Wellbeing and newsletter articles |
| ***Objectives /Impact*** | To recognise, understand, meet, and effectively represent the needs and expectations of young patients through their meaningful involvement and empowerment |
| ***Timeframe*** | Throughout 2022 |
| ***Region*** | Europe |
| ***Targets*** | Young patients from EPF Youth Group |

### EPF Members’ Circle

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|---|---|
| ***Need*** | Increasing members’ awareness and familiarity of the EU health policy developments and key actors (stakeholders) and discussing potential actions to be undertaken by the patient community. |
| ***Deliverables*** | 2-4 webinars recording available on EPF YouTube channel |
| ***Objectives /Impact*** | Increase members’ awareness and familiarity of the EU health policy developments and key actors (stakeholders) and undertaken actions by the patient community. |
| ***Timeframe*** | Throughout 2022 |
| ***Region*** | Europe |
| ***Targets*** | EPF Members and other patient advocates/organisations |

### EPF Membership Participation Monitoring Tool

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|---|---|
| ***Need*** | Simplify and track membership participation to various EPF activities and initiatives |
| ***Deliverables*** | EPF Monitoring Tool Template and Analytics |
| ***Objectives /Impact*** | Better serve EPF members and ensure maximum engagement and membership retention. |
| ***Timeframe*** | Throughout 2022 |
| ***Region*** | Europe |
| ***Targets*** | EPF Members |

### EPF Board Induction Package

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|---|---|
| ***Need*** | Provide newly elected EPF board member with a user-friendly induction package |
| ***Deliverables*** | EPF Board induction package sample |

| | |
|---|---|
| ***Objectives /Impact*** | Better serve EPF Board members end members and ensure maximum engagement and knowledge assimilation by newly elected EPF Board members. |
| ***Timeframe*** | Throughout2022 |
| ***Region*** | Europe |
| ***Targets*** | EPF Board Members |

# 6. COMMUNICATIONS, ENGAGEMENT & MEMBERSHIP

## Communications & Engagement

The goal of the Communications team in 2022 is to transition from a support system to a strategic partner with all parts of the organisation. In addition to maintaining our fresh brand approach from the past two years, including the use of video and infographics to make our content more digestible, our plans for 2022 include:

1. **Grow our Online Community** Through consistent, targeted and meaningful messaging and campaigns, continue the growth of our communication channels based on the strategic communications strategy 2022 objectives.
2. **Widen our Member Network** Collaborate with Membership Team on a video campaign to attract further members and showcase the benefits of EPF.
3. **Amplify the Patients' Voice** Utilize our existing communication channels to reinforce and louden the patients' voice. Leverage our podcast to include more membership activities and conversations with policymakers to ensure patients are connected to decision-makers. Employ our media influence to continue to ensure that EPF is the go-to-source for the patient perspective in Brussels and Europe.
4. **Connect with Stakeholders** Provide quarterly updates to our sponsors/partners via a dedicated newsletter and create video materials to attract potential partners to the EPF networks.
5. **Strengthen Communication through Training** Set up bi-annual training sessions with EPF Secretariat and Members to provide tips and tricks for better advocacy and campaign communications. Track improvements via surveys and other engagement tools. Create further "How-To-Guides" and Guidelines for internal and external use.
6. **Prepare for 20 Years of EPF** Liaise with Secretariat, Membership and Board to prepare a campaign in 2023 to celebrate the 20th Anniversary of EPF.

## Membership

EPF members are the heart of EPF. They shape the strategy and priorities of our organisation. EPF's membership has grown considerably from 13 in 2003 to 77 in 2021. Our objective is to welcome all eligible organisations to reinforce our collective disease and geographical representativeness. To achieve this objective, we will undertake the following actions in 2022:

1. **Increase contact** with potential new members: EPF will constantly update the map/list of potential members, based on the 2021 EPF membership mapping.

2. **Wider Europe approach**: In 2022, EPF will continue to reach out to new potential members through communications campaigns and build connections with existing patient organisations in Europe.
3. **Support emerging national coalitions**: In 2022, EPF will continue to support national coalitions through training and exchange of best practices.

## Governance

Effective and transparent governance is core to everything we do at EPF. EPF has several governing bodies that meet regularly during the calendar year:

- **Annual General Meeting (AGM)** EPF's highest governance body is the Annual General Assembly where each member is represented by one delegate. The meeting takes place in April, this year in a virtual setting.
- **Management Board** EPF is administered by Board Members, who are elected by the Annual General Meeting for a term of two years. The Board meets around four times a year, physically or virtually to provide political leadership, ensure the good running of the Secretariat and oversee the implementation of the annual work plan. The Board is composed of 9 members. Since April 2020 EPF has an elected Board representative coming from the Youth group.
- **Secretariat** The EPF Secretariat executes the annual work plan based on the EPF Strategic Plan and works to support and inform the members.
- **Advisory Working Groups** EPF has two topic specific Advisory Working Groups to guide and support two of its priority areas of work: Universal Access to Healthcare and Digital Health.
- **Ethics Committee** The EPF Ethics Committee is responsible for issuing opinions or advice upon written request from the Board; recommending appropriate handling of conflict of interests and providing general advice on wider ethical issues that EPF needs to address, in the context of legislation or practice. It is comprised of five members holding a three-year term, who are nominated by an EPF member and voted by the AGM Members of the organisation.
- **Youth Group** The EPF Youth Group (YG) is made up of young patient representatives between 15-29 years old with different chronic conditions from all over the EU. The aim of the YG is to represent the young patient community and to communicate the needs and expectations of young patients to EPF and its members.

## Transparency and Independence

Since our inception, we have been committed to ameliorate our transparency and independence in accordance with our Code of Conduct as well as our Constitution and Internal Rules. Updated in 2018, our Framework for Cooperation outlines how EPF works with partners who provide unrestricted sustainable funding to contribute to EPF’s strategic and annual work plan, and why this is important.

In line with our commitment to transparency, all financial information related to EPF's activities is available on our website. Our Annual Report outlines the source of our funding and the amount received. EPF is also a registered NGO on the Commission's new Transparency Registry.

EPF's funding strategy is to focus on the longer-term sustainability of the organisation by looking into diversification of funds from public and private sourcing, as well as trusts and foundations, to ensure the future and financial sustainability.