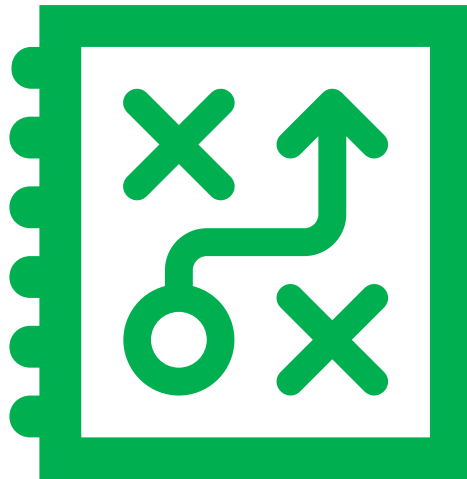


# EUROPEAN PATIENTS' FORUM

## Work Plan 2023



*Driving Better Health for Patients in Europe*

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## Executive Summary

This Work Plan describes the work that the EPF will carry out in 2023 in line with its Strategic Plan 2021-2026.

The work plan will be implemented by the EPF Secretariat, in consultation and collaboration with member organisations and other stakeholders as appropriate, and with oversight by EPF's Management Board.

In 2023 work will continue along the five pillars of the 2021-2026 Strategic Plan, as well as on the horizontal areas of membership, capacity building, and communications. 2023 will mark our 20<sup>th</sup> anniversary, so EPF will plan activities not only to mark this milestone but also to propose a vision of the future of patient advocacy in the next 20 years. This will also rely on our activities to undergo a mid-term review of the Strategic Plan.

On the first pillar "Shaping a new European Agenda for Patients" EPF will continue its engagement activities with key European and international organisations including the EU institutions, WHO, OECD etc. Our projects on patient reported outcomes, as well as a renewed strand of activities on antimicrobial resistance will underpin our engagement. In 2023 we will also kick off a campaign to bring the patients voice into the European Elections of 2024.

On the second pillar "Meaningful Patient Involvement in Co-creating Better Health Policy, Practice, Research and Education" 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 projects. EPF will also continue preparations and will build capacity amongst its members for the implementation of the HTA regulation. We will continue our partnerships with PEOF, EUPATI, the EFPIA Patient Think Tank, EIT Health etc. where we bring meaningful patient engagement.

On the third pillar "Digital Transformation that Delivers for Patients" EPF will summarise the key learnings and call for action from the 2021-2022 congress into a set of principles for patient-driven digital health. We will engage in the European Health Data Space legislative process to ensure that the EHDS is developed with patients' interests at the centre. Through Data Saves Lives, we will continue activities to raise awareness, improve understanding and about the importance of health data, and build a trusted environment for multi-stakeholder dialogue. Through projects such as EHDEN and Gravitare Health we will aim to improve digital access to accurate real world and health information.

On the fourth pillar "Accessing the Healthcare We Need with No Discrimination" EPF will mostly focus on the revision of the pharmaceutical legislation undergoing a study on unmet health needs from a patient perspective and will conduct a member survey to understand the main barriers faced by patients in access to healthcare and bring them to policy makers. Through the PERISCOPE project, we will map and analyse the unintended impacts of the COVID-19 outbreak on patients.

On the fifth pillar "Strengthening Patient Communities across Europe" EPF will continue to invest in its successful capacity building programme investing in new leaders in patient advocacy, and further develop its memberships' and our members' capacity to engage in policy and advocacy at EU and national level.

EPF will continue to strengthen its communications and engagement to reach three major goals. These broad goals have been set as a result of the communication activities developed in the past by EPF, but also considering its 2021-2026 Strategic Plan. Each goal holds together several specific and measurable objectives. In addition to the three communication strategic goals for the upcoming year, EPF will be heavily involved in the activities, campaigns, and events related to EPF's 20<sup>th</sup> Anniversary.

EPF's work in 2023 will rely on its strong membership and governance structure, as well as on our strong ethical and transparency framework.

## Introduction

The European Patients' Forum (EPF) the leading voice of patient organisations in Europe.

We are an independent non-profit, non-governmental umbrella organisation of patient organisations across Europe and across disease-areas. Our 78 members include disease-specific patient groups active at EU level and national coalitions of patients.

**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.

### TARGET GROUPS

The primary target groups of EPF's activities in 2023 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 Sweden, Spain, and Belgium
- EU agencies, including the European Medicines Agency (EMA), the Health Emergency Preparedness and Response (HERA), the European Centre for Disease Control (ECDC) and the Fundamental Rights Agency (FRA)
- International organisations, including the OECD and the WHO Regional Office for Europe
- Health stakeholders, including public health NGOs, medical professionals' organisations, academia/research community, scientific/professional bodies, and the healthcare industry
- Health media/press at EU and national levels.

### ADDED VALUE AND IMPACT

EPF is the unique European-level, umbrella patient organisation providing the vital cross-disease perspective from the wider patient community into EU policymaking on issues that impact patients' lives in a national and/or regional context. We link 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.

Through its nearly 20 years of activity EPF has consolidated its credibility by being supported by a wide cross-EU patient movement and by relentlessly pursuing meaningful implementation of good practices in patient empowerment and involvement by practitioners as well as policymakers. EPF is a strong advocate for the value

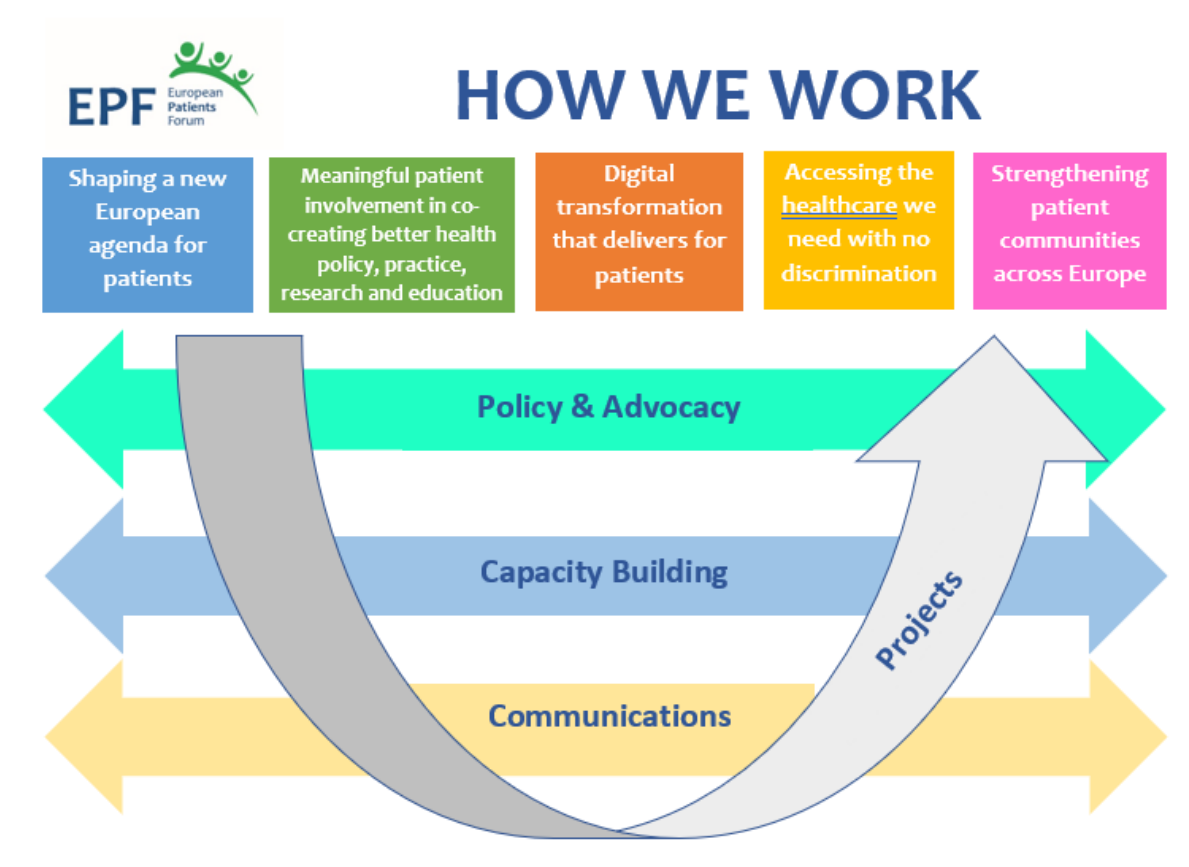
of Europe in health and brings added value to the discussion on health in Europe, through its engagement with high-level strategic issues such as the European Health Union and the EU’s strategic programmes in health and health research. EPF relies on trusted partnerships with diverse actors, helping to define health priorities in which the patient community can contribute and reap benefit.

EPF’s work in 2023 will rely on our extensive experience and strong, credible position through our engagement to bring the patient voice in crucial processes on the legislation governing data sharing, the pharmaceutical market and the implementation of health technology assessment that will shape the healthcare environment for many years to come. Our evidence-based advocacy helps strengthen patient involvement and recognition of patients as partners in health policy and practice, bringing the perspective of **what matters to patients** in the design of policies, as well as in their implementation.

EPF is committed to the highest level of transparency, 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 2023 Work Plan

Our Work Plan for 2023 aims to continue progress towards the 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.

### CROSS-CUTTING ACTIVITIES

#### EPF’S 20TH ANNIVERSARY

In 2023, EPF will celebrate 20 years since its establishment. This will be an opportunity to reflect on the impact the organisation has made in 20 years of its existence and on the path ahead for advancing patient advocacy, engagement, and recognition of patients as a key and equal partner in health policymaking.

|                                     |   |
|-------------------------------------|---|
| <b>Need</b>                         | EPF has grown into the leading patient organisation in Europe representing patients across overarching policy areas and advancing the representation of patients in healthcare policy and practice. Its 20-year anniversary is a key milestone for its mission and vision to represent the voice of patients. |
| <b>Deliverables</b>                 | 20-year anniversary identity, specific logo re-design, anniversary policy event, event report, 20-year impact highlights report, podcasts, and dedicated newsletters  |
| <b>Objectives</b><br><b>/Impact</b> | To build on EPF’s past impact to develop a roadmap for advancing the EPF mission and vision in a dialogue with our members and wider stakeholder community.   |
| <b>Timeframe</b>                    | Throughout 2023 with an event in Brussels, 28 April 2023  |
| <b>Region</b>                       | Europe  |
| <b>Targets</b>                      | EPF members, stakeholders, policymakers   |

#### MID-TERM REVIEW OF THE STRATEGIC PLAN 2021-2026

In 2023 EPF will be half-way through its strategic plan 2021-2026. It would be therefore appropriate to carry out a mid-term review of the strategic plan to ensure continued alignment with the environment we operate in.

|                     |  |
|---------------------|--|
| <b>Need</b>         | Mid-way through its strategic plan, EPF should assess the continued relevance of its strategic priorities to its members, stakeholders and overall environment in order to continue or to make adjustments to its priorities, ways of working, and expected deliverables. This will be carried out through an initial internal assessment, a consultation with our members, and collecting varied stakeholder views. |
| <b>Deliverables</b> | Mid-term strategic plan review report  |

|                   |  |
|-------------------|--|
| <b>Objectives</b> | To secure the continued focus of EPF's activities on its most relevant and impactful activities to patients, within its staff time and capacity. |
| <b>/Impact</b>    |  |
| <b>Timeframe</b>  | Q3/4 2023  |
| <b>Region</b>     | Europe   |
| <b>Targets</b>    | EPF members  |

## 1. Shaping a new European Agenda for Patients

### 1.1 HIGH-LEVEL EU AND INTERNATIONAL HEALTH ADVOCACY

#### 1.1.1 PARLIAMENTARY ELECTIONS CAMPAIGN 2024

|                     |  |
|---------------------|--|
| <b>Need</b>         | In 2024, European citizens will be voting to elect a new European Parliament. Shortly after, a new European Commission will be nominated. To make sure the patient community's priorities are heard by the policymakers, EPF will engage its membership in developing its manifesto and build the patient community's capacity for political engagement at national level. |
| <b>Deliverables</b> | Elections campaign strategy and implementation plan  |
| <b>Objectives</b>   | To call policymakers' attention on what matters to European patients in health policy and position patient organisations as a key stakeholder in health policy both at EU and nationally; to reinforce EPF's position as the respected, collective voice of patients at European level.  |
| <b>/Impact</b>      |  |
| <b>Timeframe</b>    | 2023-24  |
| <b>Region</b>       | Europe   |
| <b>Targets</b>      | EPF members, policymakers  |

#### 1.1.2 EU4HEALTH PROGRAMME AND PATIENT ORGANISATIONS' FUNDING

|                     |   |
|---------------------|---|
| <b>Need</b>         | Operating Grants for health civil society organisations were included in the EU4Health Work Programme 2022, but with eligibility criteria that excluded EPF and many patient organisations. In addition, funding from 2023 and beyond is uncertain. EPF will continue to engage with the European Commission with a view towards adjusting the operating grant conditions to enable patient organisations to benefit from core funding. |
| <b>Deliverables</b> | Participation in European Commission consultations on EU4Health Work programme development and priorities, as relevant; Continuing advocacy in coordination with other members of the EU4Health Civil Society Alliance.   |



|                   |  |
|-------------------|--|
| <b>Objectives</b> | To contribute to EU4HEALTH Work Programme priorities that are important for the patient community; to restore meaningful and realistic operating grants for which EPF could apply, with feasible eligibility criteria and preferably through a multi-annual framework agreement. |
| <b>/Impact</b>    |  |
| <b>Timeframe</b>  | 2023 and beyond  |
| <b>Region</b>     | Europe   |
| <b>Targets</b>    | EPF members  |

### 1.1.3 ENGAGEMENT WITH WHO EUROPEAN REGIONAL OFFICE

|                     |  |
|---------------------|--|
| <b>Need</b>         | EPF is an accredited non-state actor of the WHO European Regional Office and has actively engaged in consultations on the European Programme of Work and advised WHO representatives on working with NGOs. As such, we need to continue developing our working relationship with WHO services.   |
| <b>Deliverables</b> | 1) Strategic meetings with WHO European Regional Office representatives to support the implementation of relevant objectives of the European Programme of Work; 2) Joint dissemination campaigns on topics relevant for the patient community; facilitation of WHO engagement with patient organisations in the Western Balkans, subject to planning and capacity. |
| <b>Objectives</b>   | To strengthen the cooperation between the WHO European Regional Office and EPF, and advocate for the inclusion of patient representatives in policymaking.   |
| <b>/Impact</b>      |  |
| <b>Timeframe</b>    | 2023 and beyond, with further planning subject to WHO priorities   |
| <b>Region</b>       | WHO European region  |
| <b>Targets</b>      | EPF members, patient organisations, WHO, policymakers  |

## 1.2 QUALITY AND SAFETY OF HEALTHCARE

### 1.2.1 ANTIMICROBIAL RESISTANCE

|             |  |
|-------------|--|
| <b>Need</b> | Antibiotic resistance (AMR) is an urgent public health threat and an EU policy priority. The Council is planning to publish a recommendation on AMR in 2023, and there is a need for the patient community to be more aware of AMR and to build capacity for advocacy. EPF has an established collaboration with the European Centre for Disease Prevention and Control around the European Antibiotic Awareness Day and has recently joined a group of patient organisations working together on AMR. |
|-------------|--|

|                                     |   |
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| <b>Deliverables</b>                 | Communication and information activities, including a statement on the forthcoming recommendation and communications around the EAAD 2023.  |
| <b>Objectives</b><br><b>/Impact</b> | 1) To raise awareness among the patient community on the importance of AMR; 2) To actively engage with partners in the AMR Patient Group, contributing to deliverables and disseminating them; 3) To liaise with the ECDC on communications during the EAAD |
| <b>Timeframe</b>                    | 2023  |
| <b>Region</b>                       | Europe  |
| <b>Targets</b>                      | EPF members, ECDC, policymakers   |

### 1.2.2 ENGAGEMENT WITH OECD

|                                     |   |
|-------------------------------------|---|
| <b>Need</b>                         | Continuing the collaboration with OECD to bring a patient perspective on the OECD's work and encourage more patient involvement.  |
| <b>Deliverables</b>                 | Attendance at regular meetings of the HCQ0 working party, continuing participation in the international PaRIS Advisory Panel, supporting OECD in getting patient input on PROMs and PREMs work where relevant, continuing participation in the PRIMs working group. |
| <b>Objectives</b><br><b>/Impact</b> | To bring patient a voice into OECD health-related initiatives and strengthen OECD engagement with patient organisations.  |
| <b>Timeframe</b>                    | Ongoing   |
| <b>Region</b>                       | Europe  |
| <b>Targets</b>                      | EPF members, OECD   |

### 1.2.3 CORE-MD (EU PROJECT)

|                                     |  |
|-------------------------------------|--|
| <b>Need</b>                         | The inclusion of patient-reported outcome measures (PROMs) in the evaluation of high-risk medical devices.                 |
| <b>Deliverables</b>                 | A consensus-based investigation (DELPHI process) into patient preferences and priorities for different implantable devices |
| <b>Objectives</b><br><b>/Impact</b> | Identifying the most adequate PROMs to evaluate high-risk medical devices  |
| <b>Timeframe</b>                    | Full year, DELPHI to be conducted in February/March 2023   |
| <b>EPF's role</b>                   |  |

Identifying patients; preparing (inclusive of gaining ethical approval) and conducting DELPHI; summary of results for publication; supporting academic partners at the University of Gothenburg in underlying literature review

**Region** Europe

**Targets** Patients, Academia, Physicians, Policymakers, HTA bodies

#### 1.2.4 H2O (HEALTH OUTCOMES OBSERVATORY)

**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) Active engagement of national level patient organisations in promoting the adoption of H2O amongst their constituencies and with other stakeholders.

**Objectives /Impact** 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** January – December 2023

**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 (type 1 & type 2), IBD, and various types of cancer; 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

### 2.1 PATIENT INVOLVEMENT AND EU RESEARCH PROGRAMMING

#### 2.1.1 MEMBERSHIP AND PATIENT INVOLVEMENT IN PROJECTS

**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** Continue mapping exercise of EPF members' expertise in EU project themes via recurrent surveys and exchanges.

Propose to EPF member organisations or patient advocates to join EU project consortia and ensure their early and meaningful involvement.

Develop a Barometer for Patient Engagement in Research.

**Objectives /Impact** To enhance an impactful patient and patient organisations' participation in projects through direct engagement of members as either full project partners, "Affiliated entities" or through Patient Advisory Groups.

**Timeframe** Ongoing

**Region** Europe

**Targets** EPF member organisations and individual patient advocates

### 2.1.2 PATIENT INVOLVEMENT IN THE EU'S HEALTH TECHNOLOGY ASSESSMENT (HTA) AGENDA

**Need** Preparedness in the European-wide patient community for the implementation of the HTA Regulation and increasing capacity of patient organisations to contribute to HTAs.

**Deliverables** Strategy and action plan to ensure a systematic interaction with EPF membership to meaningfully inform the perspective of patients on HTA including capacity building activities.

Capacity building of EPF members on the implementation of the HTA Regulation at national level.

**Objectives /Impact** Ensure robustness of arguments and legitimacy of positions of patient organisations during HTA consultation at EU level, raising awareness about the relevance of the HTA Regulation, increasing the capacity of EPF membership on HTA, increasing the quantity and quality of patient organisations' contributions to HTA assessments.

**Timeframe** January- December 2023

**Region** Europe

**Targets** EPF members with specific focus on national coalitions

### 2.1.3 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, including:

**Patient Engagement Open Forum (PEOF)** is one of the IMI project [PARADIGM](#)'s key legacies. PEOF acts as a patient-centred 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.

**Self-Management Europe Initiative**, a collaboration emerging from the COMPAR-EU project (coming to an end in December 2022) that aims to achieve strong uptake and understanding of self-management support initiatives.

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 include **EIT Health**, EATRIS, PharmaLedger Association, and a number of formal and informal **health-focused networks and alliances**, where engagement serves to both feed into our policy analyses and to disseminate our key advocacy messages effectively to targeted audiences.

## 2.2 EATRIS-PLUS

|                           |   |
|---------------------------|---|
| <b>Need</b>               | Build capacity of academic researchers on Patient Engagement  |
| <b>Deliverables</b>       | <p>Policy position statement co-developed with EATRIS on a relevant topic such as Artificial Intelligence.</p> <p>Exploitation and further development of the Policy position statement co-developed with EATRIS on a relevant topic such as Artificial Intelligence.</p> <p>Exploitation and further development of the toolkit for Patient Engagement in Research.</p> <p>Capacity building activities with EATRIS national nodes toolkit for Patient Engagement in Research.</p> <p>Capacity building activities with EATRIS national nodes.</p> |
| <b>Objectives /Impact</b> | Advocate for Patient Engagement in pre-clinical research; Strengthen researchers' capacity in Patient Engagement. Wider awareness and understanding of the value of Patient Engagement among researchers  |
| <b>Timeframe</b>          | Ends December 2023  |
| <b>Region</b>             | Europe/ Global  |
| <b>Targets</b>            | Patients, Patient Advocates, Pre-clinical Researchers, Academia, Funders  |

## 2.3 EU-PEARL

|                                     |  |
|-------------------------------------|--|
| <b>Need</b>                         | Educate and engage patients with Clinical Platform Trials (PT); provide tools for engagement and education to organisations running such trials; ensuring patient engagement/co-creation in platform trials  |
| <b>Deliverables</b>                 | A fully operational Patient Engagement Platform plus documentation; supported by an integrated advocacy strategy running until the end of the project, to communicate about the project results, and the engagement platform.  |
| <b>Objectives</b><br><b>/Impact</b> | Create a repository with materials on patient engagement (PE) in platform trials (PT) that supports researchers and funders in creating meaningful PE in PTs; and likewise patient and patients to understand what PTs are, how they work, and how to get engaged. Wider understanding and acceptance of PTs, basis for PE in future trials. |
| <b>Timeframe</b>                    | Ends April 2023  |
| <b>Region</b>                       | Europe/ Global   |
| <b>Targets</b>                      | Patients, Patient Advocates, Clinical researchers, Pharma Industry, Academia   |

## 2.4 PROPHET

|                                     |  |
|-------------------------------------|--|
| <b>Need</b>                         | PROPHET will be centred around stakeholder engagement and the SRIA co-creation process in relation to three main strands of activities: Mapping, Assessment and Building.  |
| <b>Deliverables</b>                 | Task Co-Leader together with other partners, not linked to a deliverable.  |
| <b>Objectives</b><br><b>/Impact</b> | Capacity building activities for patient communities, organised by EPF to train their member organisations, define guidelines and definition of best model for patients, citizens, and health professionals' engagement best examples through surveys with different target populations. |
| <b>Timeframe</b>                    | 1 September 2022 - 31 August 2026  |
| <b>Region</b>                       | Europe (4 countries specifically Finland, Estonia, the Netherlands, and Italy)   |
| <b>Targets</b>                      | Patients   |

## 3. Digital Transformation that Delivers for Patients

### 3.1 CALL FOR ACTION ON PATIENT-DRIVEN DIGITAL HEALTH

|                                     |  |
|-------------------------------------|--|
| <b>Need</b>                         | The EPF Congress 2021 and 2022 yielded rich outputs, and these will be consolidated into a Set of principles for patient-driven digital health, in line with EPF’s core commitment to drive meaningful patient involvement in policy, projects and practice of healthcare. |
| <b>Deliverables</b>                 | Call for action on patient-driven digital health   |
| <b>Objectives</b><br><b>/Impact</b> | Consolidate the insights and learnings from the EPF Congress 2021 and 2022 into a concise set of recommendations for policymakers and practitioners to realise digital transformation in digital health that is patient-driven and delivers for patients, with patients.   |
| <b>Timeframe</b>                    | Q2/3 2023  |
| <b>Region</b>                       | Europe   |
| <b>Targets</b>                      | EPF members, policymakers, stakeholders  |

### 3.2 EUROPEAN HEALTH DATA SPACE

|                                     |   |
|-------------------------------------|---|
| <b>Need</b>                         | The legislative proposal for a regulation on the EHDS is being discussed in the European Parliament and the Council. EPF will continue its extensive and consistent engagement with policymakers to ensure that the EHDS is developed with patients’ interests at the centre. |
| <b>Deliverables</b>                 | Engagement with responsible MEPs, assistants, and health attaches to communicate EPF’s statements and positions on major legislative developments.  |
| <b>Objectives</b><br><b>/Impact</b> | EU legislation to create a health data space that responds to patients’ needs, including participation of patient representatives in the governance of the EHDS.  |
| <b>Timeframe</b>                    | 2023  |
| <b>Region</b>                       | Europe  |
| <b>Targets</b>                      | EPF members, policymakers, stakeholders   |

### 3.3 ARTIFICIAL INTELLIGENCE

|             |   |
|-------------|---|
| <b>Need</b> | Discussions on AI in healthcare need to incorporate informed patient voices, from policy to projects, to ensure that potential negative impacts, risks and needs as well as opportunities, are taken into full consideration. There is a continuing need for capacity-building on this topic. |
|-------------|---|

|                     |   |
|---------------------|---|
| <b>Deliverables</b> | Update of the EPF AI Knowledge hub; dissemination and use of findings from research commissioned by EPF; representation of patient perspective in EU policy debates, and engagement with EHDS and AI horizontal legislation where relevant. |
| <b>Objectives</b>   | To enable the patient community to play their role in debates on AI, supported by knowledge and appropriate resources, and enable meaningful involvement in data and AI-related projects and advocacy.                                      |
| <b>/Impact</b>      |   |
| <b>Timeframe</b>    | 2023  |
| <b>Region</b>       | Europe  |
| <b>Targets</b>      | Polymakers, EPF members, stakeholders, EPF Digital Health Working Group   |

### 3.4 DATA SAVES LIVES

|                     |   |
|---------------------|---|
| <b>Need</b>         | Data Saves Lives is a multi-stakeholder initiative with the aim of raising wider patient and public awareness about the importance of health data, improving understanding of how it is used and establishing a trusted environment for multi-stakeholder dialogue about responsible use and good practices across Europe.  |
| <b>Deliverables</b> | Continuing core activities, continuing bootcamp activities, promotion of 2.0 Toolkit, extending DSL to national level contexts  |
| <b>Objectives</b>   | Data Saves Lives has a crucial role in exploring societal questions about the uses of health data and supporting stakeholder dialogue, with a view to enhancing trust and cooperation. The initiative aims to stimulate a structured and meaningful discourse within the health data community about responsible use of data and to capture, share and discuss views on other data related issues |
| <b>/Impact</b>      |   |
| <b>Timeframe</b>    | Ongoing   |
| <b>Region</b>       | Europe  |
| <b>Targets</b>      | EPF members   |

### 3.5 GRAVITATE HEALTH

|                     |   |
|---------------------|---|
| <b>Need</b>         | Gravitate-Health aims to equip and empower citizens with digital information tools that make them 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. |
| <b>Deliverables</b> | Further engagement of User Advisory Group (UAG) members in the activities of other workstreams such as user scenarios, study-a-thons, connect-a-thons, ePI/G-lens.  |



Development of a user survey for the consortium partners with the UAG members to further build a public version of the toolkit. Continues work on Capacity Building and Multi-Stakeholder Engagement, sustainability plans, communication, and dissemination activities.

|                   |  |
|-------------------|--|
| <b>Objectives</b> | The Gravitare Lens (G-Lens), which focuses on approved electronic product information (ePI) content, aims at offering a direction for patients to access trustworthy, up-to-date information that better meets their individual needs. |
| <b>/Impact</b>    |  |
| <b>Timeframe</b>  | Throughout 2023  |
| <b>Region</b>     | Europe   |
| <b>Targets</b>    | Patients   |

### 3.6 EHDEN

|                     |  |
|---------------------|--|
| <b>Need</b>         | Reduce the time needed to provide answers in real world, health research.  |
| <b>Deliverables</b> | EHDEN Academy Course 5 – 6 scripting and dissemination. Sustainability plan for the future of EHDEN – Revision of the value proposition for POs.   |
| <b>Objectives</b>   | To build a trusted observational research ecosystem to enable better health decisions, outcomes, and care. Be part of creation of a large-scale federated network of data sources standardised to a common data model. |
| <b>/Impact</b>      |  |
| <b>Timeframe</b>    | Throughout 2023  |
| <b>Region</b>       | Europe   |
| <b>Targets</b>      | Researchers  |

### 3.7 LABEL2ENABLE

|                     |  |
|---------------------|--|
| <b>Need</b>         | An EU quality label for health and wellness apps co-designed with patients, citizens, and carers.  |
| <b>Deliverables</b> | Create two focus groups (UAG and UAB) to engage Patients, Citizens, and Carers to achieve TRUST, USE, and ADOPTION of an EU quality label for health apps. |
| <b>Objectives</b>   | Enabling patients, citizens, and carers to make more use of trusted mHealth solutions for promoting their health and self-managing their health needs.     |
| <b>/Impact</b>      |  |
| <b>Timeframe</b>    | Throughout 2023  |
| <b>Region</b>       | Europe   |
| <b>Targets</b>      | Citizens   |

## 4. Accessing the Healthcare We Need with No Discrimination

EPF’s work on access encompasses access to a holistic and comprehensive range of healthcare and services, as well as access to medicines as a specific area of policy.

### 4.1 EQUITABLE ACCESS TO HEALTHCARE

#### 4.1.1 REPORT ON BARRIERS EXPERIENCED BY PATIENTS IN ACCESSING HEALTHCARE

|                           |   |
|---------------------------|---|
| <b>Need</b>               | Equitable access to healthcare is one of EPF’s strategic goals. Patients across Europe continue to face inequalities and disparities in all aspects of healthcare access, including waiting times for accessing appointments, access to timely and accurate diagnosis, follow up treatment, reimbursement, as well as access to a range of supporting services and integrated care. EPF surveyed its members in 2016 on access to healthcare, and in 2023 we will repeat the survey in adjusted form to understand changes, if any, in the landscape and to inform our advocacy towards policymakers. |
| <b>Deliverables</b>       | Member survey to understand the main barriers faced by patients in access to healthcare; a survey report will be published together with advocacy materials, such as an updated position statement.   |
| <b>Objectives /Impact</b> | To ensure policymakers understand the patients’ experiences of barriers to access to healthcare and put access high on policymakers’ and health stakeholders’ political agendas.  |
| <b>Timeframe</b>          | 2023  |
| <b>Region</b>             | Europe  |
| <b>Targets</b>            | EPF members, policymakers, stakeholders   |

#### 4.1.2 NUTRITION AS PART OF A HOLISTIC APPROACH TO CHRONIC DISEASE CARE

|                     |  |
|---------------------|--|
| <b>Need</b>         | Nutrition forms an essential component of chronic disease management. EPF has highlighted the importance of food and nutrition in the prevention and management of chronic and long-term conditions in a position statement taking a life-span approach and focusing on nutrition’s role in primary prevention and the management of chronic conditions, as well as access to appropriate medical nutrition for all patients whose health condition requires it. |
| <b>Deliverables</b> | Continuing collaboration with ESPEN on the production and dissemination of lay summaries of clinical guidelines on selected disease-areas; embedding nutrition into our work on access to healthcare, including health literacy and information for patients.  |

|                   |  |
|-------------------|--|
| <b>Objectives</b> | To highlight the importance of nutrition as part of chronic disease care, coordinate patient perspectives on this topic, and coordinate patient involvement in the development of clinical guidelines. |
| <b>/Impact</b>    |  |
| <b>Timeframe</b>  | 2023   |
| <b>Region</b>     | Europe   |
| <b>Targets</b>    | EPF members, policymakers, stakeholders  |

#### 4.1.3 PERISCOPE

|                     |   |
|---------------------|---|
| <b>Need</b>         | 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.  |
| <b>Deliverables</b> | Training materials for different audiences. EPF will be contributing to the development of the content and to the implementation and testing of training modules with health authorities and other public bodies, as well as with social workers and patients. Furthermore, after the post-covid-19 impact survey is done, EPF would be including parts of the results into a dedicated deliverable in WP1. |
| <b>Objectives</b>   | To map and analyse the unintended impacts of the COVID-19 outbreak via surveys; 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.                                       |
| <b>/Impact</b>      |   |
| <b>Timeframe</b>    | Throughout 2023   |
| <b>Region</b>       | Europe  |
| <b>Targets</b>      | Patients, policymakers, patient organizations, healthcare professionals, country governments and health authorities outside Europe.   |

## 4.2 ACCESS TO MEDICINES

### 4.2.1 ENGAGEMENT WITH THE ONGOING REVISION OF THE EU GENERAL PHARMACEUTICAL LEGISLATION

|             |   |
|-------------|---|
| <b>Need</b> | As part of the Pharmaceutical Strategy for Europe, the European Commission is evaluating the current EU general pharmaceutical legislation, with a legislative proposal expected in Q1 2023. The legislation should deliver improved access to high-quality, safe, effective, and affordable innovative therapies that meet patients' needs, so it is critical that the legislative review is |
|-------------|---|

informed by a strong patient perspective and that patient involvement is embedded throughout.

|                                     |  |
|-------------------------------------|--|
| <b>Deliverables</b>                 | Engagement with the legislative file, including proposals for amendments, recommendations, and/or position statements on issues important for the patient community.             |
| <b>Objectives</b><br><b>/Impact</b> | Contribution of a patient perspective into the legislative debates; ultimately achieving a revised legislative framework that delivers on the expectations of European patients. |
| <b>Timeframe</b>                    | 2023   |
| <b>Region</b>                       | Europe   |
| <b>Targets</b>                      | EPF members, policymakers, stakeholders  |

#### 4.2.2 DEFINING THE CONCEPT OF UNMET NEEDS FROM A PATIENT PERSPECTIVE

|                                     |  |
|-------------------------------------|--|
| <b>Need</b>                         | Unmet needs is a key concept in the review of the EU pharmaceutical legislation. There is an interest in investing in areas of significant unmet need, while authorities may be willing to pay for innovations addressing high unmet need. However, the definition of unmet need is still under debate. EPF will implement a patient-led initiative to understand the European patient community's perception of unmet medical needs and their views regarding the use of this concept in healthcare policy decision-making. |
| <b>Deliverables</b>                 | The project will comprise background research, stakeholder interviews, one or more consultation events with EPF's membership, a survey and final report. Additional communication resources may be developed.  |
| <b>Objectives</b><br><b>/Impact</b> | To arrive at a common understanding that centres strongly around patients' priorities and is accepted by a wide community of patients while also being useful for policymakers.  |
| <b>Timeframe</b>                    | Q1-Q3 2023   |
| <b>Region</b>                       | Europe   |
| <b>Targets</b>                      | EPF members, policymakers, stakeholders  |

## 5. Strengthening Patient Communities across Europe

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

#### 5.1.1 SUMMER TRAINING FOR YOUNG PATIENT ADVOCATES (STYPA)

|                     |   |
|---------------------|---|
| <b>Need</b>         | STYPA is a tailored high-quality training programme for young patient advocates. STYPA is a 6-month programme including an in-person 3-day training, and online webinars with the EPF team and specialised trainers designed to support young patient advocates to develop their leadership, advocacy, policy, communications skills. |
| <b>Deliverables</b> | F2F training, Virtual courses and STYPA report  |
| <b>Objectives</b>   | Training future patient leaders   |
| <b>/Impact</b>      | 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.  |
| <b>Timeframe</b>    | February - October 2023   |
| <b>Region</b>       | Europe  |
| <b>Targets</b>      | Up to 40 young patients and EPF Youth Group   |

#### 5.1.2 MASTER'S PROGRAMME ON INTERNATIONAL PATIENT ADVOCACY

In 2023, EPF will continue to support the organisation of the International Master's Degree Programme on Patient Advocacy, the first ever recognised of its kind, in partnership with Cattolica University of Rome. The first edition of the master will start in March 2023 and EPF along with the University, will be working to design and launch a second edition.

|                     |  |
|---------------------|--|
| <b>Need</b>         | Offer to the European Patient community the possibility to join an accredited master's degree on international patient advocacy. |
| <b>Deliverables</b> | Master Curriculum  |
| <b>Objectives</b>   | Professionalise the leaders and future leaders of European patients' organisations   |
| <b>/Impact</b>      |  |
| <b>Timeframe</b>    | 1 <sup>st</sup> edition March 2023-March 2024, second edition September 2023-september 2024 (tbc)                                |
| <b>Region</b>       | Europe   |
| <b>Targets</b>      | Patients, POs, patient representatives, health stakeholders  |

### 5.1.3 EPF YOUTH GROUP

EPF established the Youth Group and ensured its involvement in the governance of the organisation by establishing a Board seat for a Youth Group representative. The Youth Group has established working processes, regular meetings, and has developed awareness raising projects to communicate the experiences and needs of young patients to wide audiences. In 2021-2022, the Youth Group worked on developing communications on sexual health and wellbeing, also helping to build the topic into the STYPA programme.

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| <b>Need</b>         | Providing space for the voice of young patients in Europe/ Foster the future European patient advocacy leaders  |
| <b>Deliverables</b> | Meeting minutes, Project Report on “Sexual Health and Wellbeing” and newsletter articles  |
| <b>Objectives</b>   | To recognise, understand, meet, and effectively represent the needs and expectations of young patients through their meaningful involvement and empowerment |
| <b>/Impact</b>      |   |
| <b>Timeframe</b>    | Throughout 2023   |
| <b>Region</b>       | Europe  |
| <b>Targets</b>      | Young patients from EPF Youth Group   |

## 5.2 BUILD PATIENT ORGANISATION CAPACITY IN WESTERN BALKANS

|                     |   |
|---------------------|---|
| <b>Need</b>         | Build contacts and relationships with Patient Organisations in Western Balkans to better understand their needs and how EPF could actively and properly support them. |
| <b>Deliverables</b> | Mapping report<br>Regional event, event report  |
| <b>Objectives</b>   | Support patients' organisations in the Western Balkans to get active locally and regionally, including by exploring collaborations with WHO EURO                      |
| <b>/Impact</b>      |   |
| <b>Timeframe</b>    | Throughout 2023 and beyond  |
| <b>Region</b>       | Western Balkans   |
| <b>Targets</b>      | Patients, POs, patient representatives, health stakeholders   |

## 5.3 EPF MEMBERS' CIRCLE

|             |  |
|-------------|--|
| <b>Need</b> | 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. |
|-------------|--|

|                     |   |
|---------------------|---|
| <b>Deliverables</b> | 2-4 webinars recording available on EPF YouTube channel   |
| <b>Objectives</b>   | Increase members' awareness and familiarity of the EU health policy developments and key actors (stakeholders) and undertaken actions by the patient community. |
| <b>/Impact</b>      |   |
| <b>Timeframe</b>    | Throughout 2023   |
| <b>Region</b>       | Europe  |
| <b>Targets</b>      | EPF Members and other patient advocates/organisations   |

## 5.4 IMPROVING EPF MEMBERSHIP PARTICIPATION MONITORING TOOL

|                     |  |
|---------------------|--|
| <b>Need</b>         | EPF developed in 2022 the membership participation monitoring tool. In 2023 EPF will focus on improving the tool and increase its use among different teams from finance to policy. FA |
| <b>Deliverables</b> | Improved EPF Monitoring Tool Template and Analytics  |
| <b>Objectives</b>   | Better serve EPF members and ensure maximum engagement and membership retention.   |
| <b>/Impact</b>      |  |
| <b>Timeframe</b>    | Throughout 2023  |
| <b>Region</b>       | Europe   |
| <b>Targets</b>      | EPF Members  |

## 5.5 EPF BOARD INDUCTION PACKAGE

|                     |   |
|---------------------|---|
| <b>Need</b>         | Provide newly elected EPF board member with a user-friendly induction package to support their active participation as Board members. The package could include, e.g. the main governance documents, a repository of standing Board decisions, summaries of the strategic and annual work plan, EPF's policies relating to ethics and transparency, and Board planning documents. |
| <b>Deliverables</b> | EPF Board induction package   |
| <b>Objectives</b>   | Better serve EPF Board members end members and ensure maximum engagement and knowledge assimilation by newly elected EPF Board members.   |
| <b>/Impact</b>      |   |
| <b>Timeframe</b>    | January-June 2023   |
| <b>Region</b>       | Europe  |
| <b>Targets</b>      | EPF Board Members   |

## 6. Communications, Engagement & Membership

### 6.1 COMMUNICATIONS & ENGAGEMENT

For 2023, the Communications team aims to reach three major goals. These broad goals have been set as a result of the communication activities developed in the past by EPF, but also considering its 2021-2026 Strategic Plan. Each goal holds together several specific and measurable objectives.

In addition to the three communication strategic goals for the upcoming year, the Communication team will be heavily involved in the activities, campaigns, and events related to EPF's 20<sup>th</sup> Anniversary. Most of the communication around this event will be focused on EPF's story and impact over the years.

#### 6.1.1 COMMUNITY GROWTH

**Need** Growing EPF's online community represents a means to increase our visibility, while amplifying and multiplying the voice of patients across Europe. Moreover, an increased online presence offers better dissemination opportunities for our member organisations.

**Deliverables**

1. 300 social media posts across all platforms, 10 podcast episodes. Create consistent, targeted, and meaningful messaging and social media campaigns. Move towards a more person-centred storytelling, with more video content. Continue the growth over new channels (Instagram and Anchor)
2. An annual report with data generated from Google Analytics, consistent website updates, (with a special emphasis in the Western Balkans Region)
3. 12 issues of the Patients' Perspective Newsletter, create a fresh and more user-friendly design for the newsletters, publish more reflection pieces, encourage member content and dissemination

**Objectives** 1. To achieve an increase of 3% across all social media channels, compared to 2022

**/Impact** 2. To achieve an increase of approximately 2% in website traffic (number of pageviews)

3. To achieve an increase of Increase of 5% of total opens for the Patients' Perspective Newsletter

**Timeframe** Throughout 2023

**Region** Europe

**Targets** EPF members, general audience, health stakeholders

#### 6.1.2 POSITIONING & REPUTATION MANAGEMENT

**Need** As EPF is approaching its 20-year anniversary, it's become clear that our role as an opinion leader among European patient organisations has gained more and more traction. Therefore, this pillar of the communication strategy is set out to strengthen EPF's presence in media and



scientific community and to position EPF as the “go to” source for both media and scientific community, when it comes to patient involvement.

Moreover, we have also identified a need for a clearer and more structured communication with sponsors and other stakeholders.

|                     |   |
|---------------------|---|
| <b>Deliverables</b> | <ol style="list-style-type: none"> <li>1. 4 press releases, 4 published interviews &amp; articles about EPF, up-to-date media contacts database</li> <li>2. Scientific articles/ studies/ conference proceedings and mentions in articles published in scientific journals, monitor EPF’s presence on Google Scholar</li> <li>3. Annual and Impact Reports, quarterly reports, event reports</li> </ol> |
| <b>Objectives</b>   | <ol style="list-style-type: none"> <li>1. To increase media presence by 25% compared to 2022</li> <li>2. To engage with the scientific community and consolidate EPF’s presence in scholarly articles by at least 15%</li> <li>3. To strengthen stakeholder and sponsor relationship</li> </ol>   |
| <b>/Impact</b>      |   |
| <b>Timeframe</b>    | Throughout 2023   |
| <b>Region</b>       | Europe, North America   |
| <b>Targets</b>      | EPF members, general audience, health stakeholders, funders, scientific community   |

### 6.1.3 STRATEGIC SUPPORT

|                     |   |
|---------------------|---|
| <b>Need</b>         | Both the internal Secretariat communication flow and the communication flow between EPF and its member organisations require constant optimisation and revising. The need to streamline the communication processes is crucial for supporting the previous pillars of the communication strategy. |
| <b>Deliverables</b> | <ol style="list-style-type: none"> <li>1. Weekly internal newsletters, social media posts, 1-1 staff training</li> <li>2. An overview report, EPF members annual communications teams meeting</li> </ol>  |
| <b>Objectives</b>   | <ol style="list-style-type: none"> <li>1. To provide strategic support across EPF teams</li> <li>2. To strengthen the member community</li> </ol>   |
| <b>/Impact</b>      |   |
| <b>Timeframe</b>    | Throughout 2023   |
| <b>Region</b>       | Europe  |
| <b>Targets</b>      | EPF members, general audience, health stakeholders, funders, scientific community   |

## 6.2 MEMBERSHIP GOVERNANCE

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 78 in 2022. 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 2023:

1. **Increase contact with potential new members:** EPF will constantly update the map/list of potential members, based on the 2022 EPF membership.
2. **Wider Europe approach:** In 2023, 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 2023, EPF will continue to support national coalitions through training and exchange of best practices.

Effective and transparent governance is core to everything we do. 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 AGM will happen within the frame of the EPF 2023 Leadership Meeting in April 2023 as an in-person event.

**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 of 23, 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. In 2023 EPF full members will elect a new Ethics committee during the 2023 EPF AGM.

**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 of funding

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.

EPF remains committed to [transparency and independence](#) in accordance with our [Constitution](#), as well as our [Code of Conduct](#). Last updated in 2018, our [Framework for Cooperation with Funding Partners](#) 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.

EPF publishes its annual financial information related on our website. Our [Annual Reports](#) and [Financial Statements](#) outline the activities carried out as well as the sources of our funding and the amount received. Our [Impact reports](#) provide an evaluation, conducted by our team, of the change we effected in our working environment.

EPF adheres to the [EU Code of Conduct](#) for transparency of interactions between policy-makers and interest representatives and is registered in the Commission's Transparency Register under the identification number [61911227368-75](#).