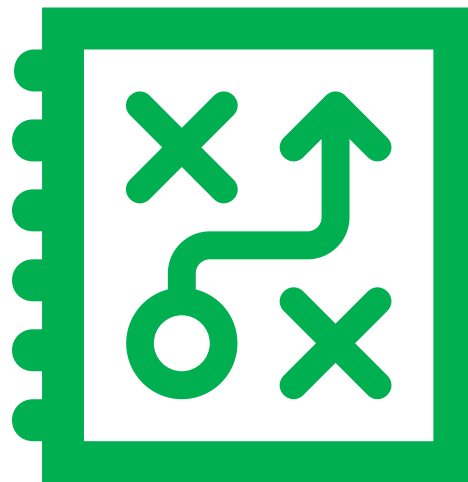


EUROPEAN PATIENTS' FORUM

Work Plan 2024 'Patient involvement'



Driving Better Health for Patients in Europe

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Executive Summary

This Work Plan describes the work that the European Patients’ Forum (EPF) will carry out in 2024 in line with its [Strategic Plan 2021-2026](#).

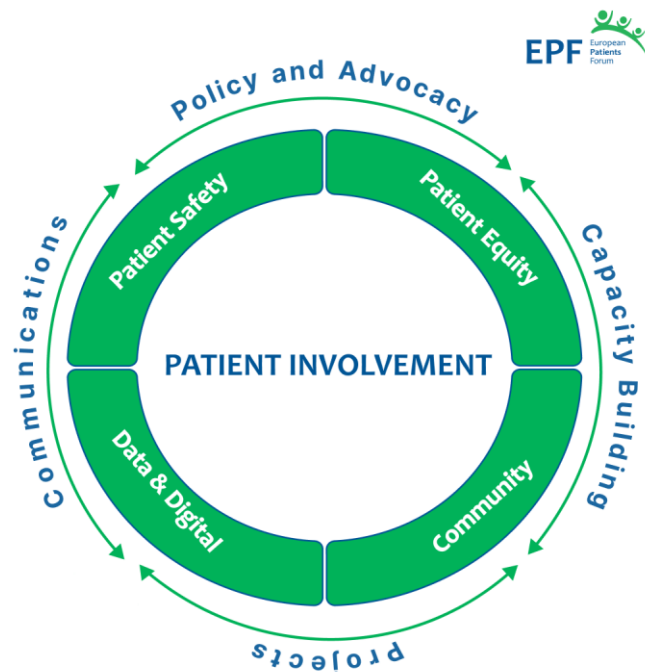
The work plan will be implemented by the EPF Secretariat, in consultation and collaboration with member organisations and other stakeholders as appropriate, and with oversight by EPF’s Management Board. EPF’s work in 2024 will rely on its strong membership and governance structure, as well as on our strong ethical and transparency framework.

In April 2023, EPF shared its European Parliamentary Elections Manifesto with the participants of the EPF 20th Anniversary policy event. Our Manifesto asks for the democratic participation of patient organisations in health policy making to ensure better outcomes and improve healthcare systems, and with the European Parliamentary Elections coming up in June 2024, it deemed appropriate to broadcast this message of **Patient Involvement** throughout our work in 2024, already the essence of EPF.

Following an internal review of the Strategic Plan in 2023, EPF found that the strategic objectives remain relevant, and restructured the annual work in a way that better expresses the cross-cutting nature of the work we carry out. The 2024 Work Plan will focus on Patient Involvement throughout our activities, but also via the themes of **patient safety, patient equity, data & digital health** and **community**. The activities under these four themes will encompass the work of four mutually reinforcing areas; policy & advocacy, capacity building, projects and communications, all the while executing our five strategic goals.

How We Work

1. SHAPING A NEW EUROPEAN AGENDA FOR PATIENTS
2. MEANINGFUL PATIENT INVOLVEMENT IN CO-CREATING BETTER HEALTH POLICY, PRACTICE, RESEARCH AND EDUCATION
3. DIGITAL TRANSFORMATION THAT DELIVERS FOR PATIENTS
4. ACCESSING THE HEALTHCARE WE NEED WITH NO DISCRIMINATION
5. STRENGTHENING PATIENT COMMUNITIES ACROSS EUROPE



Highlights in 2024 include the **European elections campaign**, followed by an **EPF flagship event**, the **#DataSavesLives 5th anniversary**, awareness and advocacy on **antimicrobial resistance**, capacity building and advocacy on patient involvement in **Health Technology Assessment**, continued advocacy on the **Pharmaceutical Strategy** and **Medical Devices Regulation**, continued capacity building and advocacy on the **European Health Data Space** and **Artificial intelligence** and of course our dedicated **Capacity-building programme**. Many of these areas of focus will also be worked on beyond 2024. Please read on to see on what else EPF will be working hard to achieve!

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 **79 members** include disease-specific patient coalitions 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 2024 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 Belgium, Hungary, and Poland
- 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 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 2024 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.

EPF'S 2024 WORK PLAN - 'PATIENT INVOLVEMENT'

Our Work Plan for 2024 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 theme, although it should be kept in mind that our activities are highly complementary and often address more than one of the five strategic goals.

CROSS-CUTTING ACTIVITIES

HIGH LEVEL POLICY EVENT – PATIENT INVOLVEMENT IN THE NEW MANDATE

Need	In 2023 EPF and its members and stakeholder community celebrated our 20 th anniversary. On this occasion, EPF adopted the <i>Patient Organisations' Manifesto towards a truly participatory, democratic and impactful involvement of patient organisations</i> . The Manifesto starts from the premise that democratic participation of patient organisations in health policy making is needed to ensure better outcomes and improve healthcare systems. The Manifesto built on EPF's years of working on patient and patient organisation empowerment through its many campaigns ranging from awareness raising, through involvement in research and innovation, to stakeholder relationships and policy advocacy. The Manifesto sets out a vision for a next natural step towards embedding patient organisations as key actors in health systems. The Manifesto will serve as the guiding principles EPF and its member community will advocate for towards EU elections candidates. This event will serve to bring the Manifesto back to the European Parliament in Brussels as the new legislature takes shape and the next European commission mandate is under discussion.
Deliverables	<p>Convening of community leaders and key stakeholders</p> <p>Written report and video summary</p>
Objectives /Impact	<p>To continue highlighting the value of patient involvement in research, policy development, and healthcare implementation</p> <p>To establish the principles of patient and patient organisation involvement firmly in the new legislature and Commission mandate</p> <p>To establish the profile and relationships of EPF with newly elected policymakers.</p>
Timeframe	Sept/ Oct 2024
Region	Brussels
Targets	EPF membership and stakeholders

PARLIAMENTARY ELECTIONS CAMPAIGN 2024

Need	In May 2024, European citizens will vote to elect a new European Parliament, which will then hold hearings and vote on a new European Commission. EU elections will provide an important opportunity for the patient community to make its voice heard by current and future policymakers. EPF will engage its membership in disseminating its manifesto and build the patient community’s capacity for political engagement at national level.
Deliverables	<p>Communication and outreach campaign around the EPF manifesto</p> <p>Capacity building sessions for EPF members</p> <p>EPF political engagement toolkit for members</p>
Objectives /Impact	<p>Elevate the patient voice, by highlighting the importance of patient involvement in EU policies and securing MEPs’ support to the EPF manifesto;</p> <p>Build capacity among patient organisations for advocacy and engagement at the political level</p>
Timeframe	2023-24

PATIENT INVOLVEMENT IN EU PROJECTS, REGULATORY ACTIVITIES AND HEALTH POLICIES

Need	In the proposed new EU pharmaceutical legislation, there is some recognition of the value of patients’ involvement in regulatory activities, but lack of clarity remains on some aspects (e.g. inclusion in scientific working parties). In addition, patients and patient organisations are not remunerated for their contribution to EMA’s work. At national level, there is still limited involvement of patients in health policy development. EPF aims to 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	<p>Continue mapping exercise of EPF members’ expertise in EU project themes via recurrent surveys and exchanges and propose to EPF member organisations or patient advocates to join EU project consortia and ensure their early and meaningful involvement.</p> <p>Consider an event on “best practices” of patient involvement in regulatory decisions, with EMA, international regulators, and/or national competent authorities; the event’s report will feed into EPF’s advocacy as part of the pharma legislation</p> <p>Preparatory work to develop a barometer on patients’ involvement and engagement in health policies at national level</p>
Objectives /Impact	To ensure appropriate and impactful involvement of patients in EU projects and EMA’s regulatory activities, including scientific groups and scientific advice, in the context of the

pharmaceutical legislation and support advocacy on patient involvement in national health policies as part of the EU elections.

Timeframe	2024
Region	Europe
Targets	EPF member organisations, EU and national policy-makers and regulators, and individual patient advocates

EU FUNDING PROGRAMMES FOR PATIENT ORGANISATIONS

Need	Post pandemic, the EU’s framework for health funding has changed, with significant funding now available to support projects and programmes, with a focus on health systems resilience and sustainability. On the one hand, this had offered multiple opportunities for patient organisations to obtain funding for crucial activities; on the other, uncertainties remained about the availability of operational funding for health civil society organisations in general, and in particular about the apparent exclusion of patient organisations that had industry support from applying for operating grants. While it appears that from 2024 stable and longer-term operating funds may again be available, 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. In addition, EPF has been active in recent years advocating for patient-centric priorities across all EU health policy and research funding, to ensure that patient communities’ views are considered across projects and programmes.
Deliverables	Participation in public and stakeholder consultations on EU4Health, Horizon Europe, IHI, as relevant; Continuing advocacy and coordination with the EU4Health Civil Society Alliance; coordination and alignment with members and other health organisations.
Objectives /Impact	To contribute with knowledge on the priorities that are important for the patient community for health policy and research funding programmes; to restore and consolidate meaningful, accessible and multi-annual operating grants for which EPF and other patient organisations could apply.
Timeframe	2024 and beyond
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, 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.

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

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 re (PERC). The PERC was delivered under the **EATRIS-Plus** project that finished in December 2023.

EPF is involved in several formal and informal **health-focused networks and alliances**, including the EU Health Policy Platform, the Eu4Health Civil Society Alliance, Civil Society Europe, the EU Health Coalition, the European Health Parliament, the European Alliance for Value in Health, the Patient Access Partnership (PACT), SDG Watch Europe, The Social Platform, Self-Management Europe Initiative, PharmaLedger Association, Darwin EU, EIT Health, HealthData@EU Pilot, HTAi and DIA. 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.

ENGAGEMENT WITH EUROPEAN MEDICINES AGENCY

Need	EPF President Marco Greco continues to serve as a member of EMA's Management Board, ensuring EPF brings the voice of patients into policy making and EMA's decisions. As an "eligible patients' organisation", EPF is also part of EMA's Patients and Consumers Working Party (PCWP). As such, it provides input to the Agency on all matters of interest in relation to medicines, to ensure a more patient-centred regulatory process and convey relevant information to the membership.
Deliverables	1) Participation in PCWP meetings and ad-hoc webinars 2) Dissemination of meeting outcomes and consultations to membership on relevant topics 3) Involvement in specific activities based on EPF's priorities
Objectives /Impact	To strengthen the cooperation between EMA and EPF and help shape a patient-centred regulatory system in the EU. This is particularly relevant as the EU is revising its pharmaceutical legislation which will have a significant impact on EMA.
Timeframe	2024 and beyond

Region	EU
Targets	EPF members, patient organisations, EU, policymakers

ENGAGEMENT WITH WHO EUROPEAN REGIONAL OFFICE

Need	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.
Deliverables	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.
Objectives /Impact	To strengthen the cooperation between the WHO European Regional Office and EPF, and advocate for the inclusion of patient representatives in policymaking.
Timeframe	2024 and beyond, with further planning subject to WHO priorities
Region	WHO European region
Targets	EPF members, patient organisations, WHO, policymakers

ENGAGEMENT WITH OECD

Need	Continuing the collaboration with OECD to bring a patient perspective on the OECD's work and encourage more patient involvement.
Deliverables	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.
Objectives /Impact	To bring patient a voice into OECD health-related initiatives and strengthen OECD engagement with patient organisations.
Timeframe	Ongoing
Region	Europe
Targets	EPF members, OECD

COMMUNICATIONS, ENGAGEMENT & MEMBERSHIP

For 2024, the Communications team will channel its efforts into four main direction/ strategic goals. These broad goals have been set because 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 four communication strategic goals for the upcoming year, the Communication team will be heavily involved in the activities and events related to 2024 Elections Campaign and around the 2024 Congress. Most of the communications around these events will be focused on EPF's vision for the next decade of patient advocacy, centred around the Manifesto.

COMMUNITY GROWTH

Need	By growing EPF's online community we create a means to increase our visibility, while amplifying and multiplying the voice of patients across Europe. At the same time, a strong online presence allows us to more efficiently disseminate cross-cutting EPF activities, such as capacity building initiatives (AI project or STYPA2024) and policy campaigns. Moreover, an increased online presence offers better dissemination opportunities for our member organisations and our involvement in projects.
Deliverables	500 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)
	12 issues of the Patients' Perspective Newsletter, create a fresh and user-friendly design for the newsletters, publish more reflection pieces, encourage member content and dissemination
Objectives	To achieve an increase of 2% across all social media channels, compared to 2023, with a more significant growth on YouTube and Instagram
/Impact	To achieve an increase of approximately 2% in website traffic (number of pageviews)
	To increase with 2% the number of subscriptions to the Patients' Perspective Newsletter
Timeframe	Throughout 2024
Region	Europe
Targets	EPF members, general audience, health stakeholders

POSITIONING & REPUTATION MANAGEMENT

Need	<p>After celebrating its 20th Anniversary in 2023, EPF steps up into the next decade of patient advocacy, guided by the Manifesto principles. These principles will also guide EPF's work in the 2024 elections campaign, empowering member organisations across Europe in improving their advocacy efforts. Under these circumstances, EPF's reputation plays a major role in building our organisation's credibility and reliability.</p> <p>As such, we identified the need of further strengthening our position withing the EU ecosystem and, at the same time, gain more visibility in member states.</p>
Deliverables	<p>4 press releases, minimum 15 news items on the website</p> <p>Annual and Impact Reports, event reports (as needed)</p> <p>An annual report with data generated from Google Analytics and social media analytical tools to track communication campaign performance</p> <p>A five-minute video showcasing EPF's activities in the previous year (pre-read for the Partners' Roundtable)</p>
Objectives	To increase media presence by 10% compared to 2023 (increase in mentions and/or picked up press releases/ statements)
/Impact	To strengthen stakeholder and sponsor relationship
Timeframe	Throughout 2024
Region	Europe, North America
Target	EPF members, general audience, health stakeholders, funders, scientific community

STRATEGIC SUPPORT

Need	The communication flow between EPF and its member organisations requires constant optimisation and revising. The need to streamline the communication processes is crucial for supporting the previous pillars of the communication strategy
Deliverables	<p>An increase of 3% in the number of opens/ issue for the Weekly Insiders</p> <p>Minimum 12 posts shared on social media highlighting members' activities</p> <p>Minimum 3 podcast episodes with members in the spotlight</p> <p>Minimum 5 articles about EPF updates/ events published in members' newsletters</p> <p>Ongoing meetings with communications teams from EPF membership</p>

Objectives	To strengthen the member community and increase the visibility of EPF member organisations and their activities
/Impact	
Timeframe	Throughout 2024
Region	Europe
Target	EPF members, general audience, health stakeholders, funders, scientific community

INVOLVEMENT IN PROJECTS

Need	EPF's project portfolio acts as a cross-cutting platform underpinning our advocacy, education, and communication pillars. Much of EPF's involvement in projects revolves around either patient engagement (such as involvement in patient advisory boards and/ or dissemination of project results and production of lay language materials to promote the projects' activities/ deliverable in an appealing format for patients.
Deliverables	<p>Minimum 12 social media posts highlighting EPF's work in projects</p> <p>20 project themed articles in the Patient Perspective & Weekly Insiders</p> <p>Minimum 3 podcast episodes highlighting projects</p> <p>Reports or other communication related deliverables/ milestones, according to the project requirements and grant agreements</p>
Objectives	To shape a coherent overview of EPF's involvement in EU funded projects
/Impact	To showcase EPF's efforts for patient engagement in projects
Timeframe	Throughout 2024
Region	Europe
Target	Project partners, member organisations, European stakeholders

I. Patient Safety

POLICY & ADVOCACY

ANTI-MICROBIAL RESISTANCE

Need	Anti-microbial Resistance is recognised as a growing public health threat. It needs to be addressed urgently through a variety of actions and multi-stakeholder efforts, from better data collection on antibiotics' use to the development of new diagnostics, new antimicrobials, and improved guidelines. Patient organisations have a key role to play in raising awareness of AMR, improving health literacy, and contributing to national guidelines for antibiotic treatment
Deliverables	Through events, public speaking opportunities, and participation in relevant forums and networks, EPF will actively contribute to raising awareness and provide capacity tools about AMR and advocate for high-priority actions at European, national and local level.
Objectives /Impact	Improve patients' and the healthcare community's awareness of AMR, continuously advocate to prioritise AMR on the EU's/member states' policy agenda and support global cooperation and develop strategic collaborations and partnerships.
Timeframe	2024
Region	Europe
Target	Patients and other relevant stakeholders

IMPLEMENTATION OF THE MEDICAL DEVICES REGULATORY FRAMEWORK

Need	In May 2017, the EU adopted its updated regulatory framework for medical devices and in-vitro diagnostics medical devices. 6 years later, the full implementation of the regulations has been considerably delayed. While ensuring the continued availability of critical devices on the EU market is a priority, it is important to ensure that the regulations also fulfil their objective to improve the quality and safety of devices, thereby improving patient safety.
Deliverables	EPF will continue to participate in the relevant working groups of the Medical Devices Coordination Group (MDCG) and engage in relevant initiatives aimed at evaluating the impacts of the legislation. EPF will also engage its members through various initiatives (members' circle, webinars, taskforce TBC) to collect their experiences, build knowledge, and contribute to developing EPF positions.
Objectives /Impact	Strengthen members' knowledge and ability to engage on the issue; Contribute to a safe and fit-for-purpose regulatory framework for medical devices in Europe
Timeframe	Ongoing

Region Europe
Target Patients and EU policy-makers

PROJECTS

CORE-MD

Need The inclusion of patient-reported outcome measures (PROMs) in the evaluation of high-risk medical devices.

Deliverables A consensus-based investigation (DELPHI process) into patient preferences and priorities for different implantable devices

Objectives /Impact Inform the further development and assessment of high-risk medical devices with benefits-risk trade-off evidence collected from and with patients

Timeframe 1 April 2021 to 31 March 2024
EPF supports the consortium in identifying the best suited PROMs to discriminate between well-performing and under-performing high-risk medical devices and how to adapt them.

EPF's role These measures ensure that patient engagement is part of this task from the very beginning of establishing PROMs.

Region Europe

Targets Patients, Academia, Physicians, Policymakers, HTA bodies

HEU-EFS (HARMONISED APPROACH TO EARLY FEASIBILITY STUDIES FOR MEDICAL DEVICES IN THE EUROPEAN UNION)

Need EFS (Early Feasibility Studies) aim to increase the efficiency and the effectiveness of the whole evidence generation process for MDs market access, providing a unique opportunity to collect relevant data at an early stage to inform the business case and maximize the chances to develop innovative, cost-effective, safe high-risk MDs in the interest of patients, end-users, payers, and policymakers.

The ambition of the HEU-EFS project is to develop a novel innovative and harmonized framework for EFS in the EU, as one integrated step of the evidence generation cycle. HEU-EFS will coordinate with the ongoing initiative of the EU Horizon 2020 CORE-MD (Coordinating Research and Evidence for Medical Devices).

Deliverables	Identification of patient contribution to EFS. The final output will be a Roadmap for structured patient contribution to EFS - a research report summarizing recommendations regarding EU EFS Program eligibility criteria and patients' role and contribution to EFS.
Objectives /Impact	Provide recommendations for structured patient contribution to EFS
Timeframe	1 st of October 2023 – 30 th of September 2027 (48 months)
EPF's role	Our role is to foresee the recruitment, onboarding and engagement of a panel of ten patients. Members of the patients' panel will be carefully selected to ensure representation of profiles from different geographies, disease areas (in accordance with the scope of the project), gender, age range, and level of health literacy (including both patient-experts with levels of technical knowledge and lay patients). In addition, EPF needs to disseminate the project results and raise awareness of the future EU EFS Program throughout the social media communications.
Region	Europe
Targets	Patients and other relevant stakeholders such as HTA bodies

IMMUCAN

Need	IMMUcan aims to study the tumor microenvironment in a bid to gain a deeper understanding of how the immune system and cancer cells interact at the molecular level. EPF is the communication lead (together with EORTC) within the project. EPF joins the monthly general board meeting and has follow-up communication calls with other consortium partners after.
Deliverables	Production of communication material targeting a lay audience, including GIFs, infographics, social media content, and videos. EPF's Communications team is working on solidifying IMMUCan's online presence, by increasing the posting frequency and by generating more quality content. EPF has a goal frequency of posting twice a week.
Objectives /Impact	By comparing patients who are going through immune therapy with patients who are not, the project hopes to build up a detailed picture of the tumor and its microenvironment, and the impact of current treatments. This information could be used to further improve existing treatments and to develop new ones. In the longer term, the project results could lead to the identification of biological markers that will show which patients are most likely to respond well to immune therapies, and which patients would benefit from a combination of immune therapies and conventional treatments.

Timeframe	1 March 2019 - 31 August 2024 (extended to August 2025)
EPF's role	EPF's role remains focused on communications via the digital channels and dissemination to patient groups, general audiences, and the scientific community as a whole. There are plans in the pipeline to create a campaign around patient recruitment
Region	Europe
Targets	Patients and other relevant stakeholders

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 advocacy campaigns and materials with support from the Patient Advisory Boards targeting patients in the four participating countries (AT, DE, ES, NL). Foster 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 and national 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	1 October 2020 to 30 September 2025
EPF's role	<p>EPF co-leads the work stream on patient engagement activities, bringing together a total of 24 patient advisors across three condition-specific patient advisory boards.</p> <p>In 2024, EPF will coordinate a workshop to further strengthen synergies on Patient Engagement activities at European and national level. The event will gather experts from the national observatories and the Patient Advisory Boards.</p>
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.

PROPHET

Need	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.
Deliverables	Task Co-Leader together with other partners, not linked to a deliverable.
Objectives /Impact	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.
Timeframe	1 September 2022 - 31 August 2026
EPF's role	In 2024 EPF will launch the conception and design of capacity building activities targeting patients.
Region	Europe (4 countries specifically Finland, Estonia, the Netherlands, and Italy)
Targets	Patients

II. Patient Equity

POLICY & ADVOCACY

PHARMACEUTICAL STRATEGY

Need	The European Commission's proposal to review the general pharmaceutical legislation represents a unique opportunity to ensure a more patient-centred regulatory system at EU level and address inequalities in access to medicines across the EU within the remit of the legislation.
Deliverables	1) Continue activating and shaping the EPF Working Group on access for regular input; 2) EPF amendments and positions supported and taken up by EU policy-makers; 3) development of a toolkit for EPF membership to engage with decision-makers at national level, including key messages, documents and visuals to be adapted to the local context; 4) joint activities as appropriate with other EU stakeholders in line with EPF's priorities
Objectives /Impact	Ensure the future framework for pharmaceutical regulation in the EU is patient-centred and includes provisions for improved patient equity. Continued development of EPF's positions on specific aspects of the pharmaceutical strategy (shortages, procurement, etc.). Build and strengthen relationships with key EU policymakers, including in the next European Parliament.

Timeframe	2023-2025
Region	Europe
Targets	EU policy makers and public health stakeholders; EPF members

HEALTH TECHNOLOGY ASSESSMENT

Need	<p>The HTA Regulation will come become operational as of January 2025. Till then several Implementing Acts need to be delivered to ensure the feasibility of the provisions.</p> <p>Several European patient organisations are members of the HTA Stakeholder Network. While it is not formally requested by the HTAR governance, there is an identified need for coordination of the patients stakeholder group to ensure mutual support and continuous oversight of the work programmes.</p> <p>Overcome the potential fragmentation of inputs arising from the engagement with patient organisations active at national level.</p>
Deliverables	<p>EPF input and positions supported and taken up by EU policy-makers. EPF to coordinate the engagement from patient organisations involved in the Stakeholder Network and channel the voice of those who are not directly involved (either national coalitions or European Disease Specific Platforms). In consideration of the potential fragmentation of inputs arising from the engagement with patient organisations active at national level, EPF may support consensus building processes aimed at prioritising needs and relevant patient outcomes. The prioritisation exercise may be organised at regional level and will inform the scoping stage in Joint Clinical Assessments.</p>
Objectives /Impact	<p>Ensure the future framework for the HTA regulation in the EU is patient-centred and includes provisions for improved patient involvement in HTA.</p>
Timeframe	2024
Region	Europe
Targets	EU policy makers and public health stakeholders; EPF members

CAPACITY BUILDING & MEMBERSHIP

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

Need	<p>Prepare the European-wide patient community for the implementation of the HTA Regulation and increasing capacity of patient organisations to contribute to HTAs.</p>
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Deliverables	A multi-stakeholder engagement simulation exercise along the lines of the one run in 2023, to assess the feasibility and identify bottlenecks in the implementation of EU level HTA and build capacity 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	2024
Region	Europe
Targets	EU policy makers and public health stakeholders; EPF members

PROJECTS

EDIHTA (EUROPEAN DIGITAL HEALTH TECHNOLOGY ASSESSMENT)

Need	Health systems worldwide are under constant pressure to provide high quality services in an era of shortage of healthcare professionals, aging populations and limited financial resources while expectations from patients, governments and society are increasing. Digital Health Solutions can be gamechangers in improving the quality of healthcare services, leading to more sustainable healthcare systems in Europe.
Deliverables	EDIHTA will offer a flexible, inclusive, validated and ready-for-use innovative framework: flexible because it will allow assess to different DHTs, at different TRLs, at different territorial levels (national, regional and local) and from different perspectives (payer, society, hospital, etc.). It will be inclusive as all relevant stakeholders will contribute to its design, development and validation. The digital framework will be validated with pilots conducted in real healthcare settings in several major European hospitals and through an open piloting scheme with European technology providers. EPF will mainly contribute to Stakeholder Engagement and outreach activities and will inform the synergies with HTA EHDS and AI legislative dossiers.
Objectives /Impact	The overall goal of EDiHTA is to deliver a fit-for-purpose HTA framework for DHTs that integrates existing assessment domains and methods with new ones in order to inform decision-making.
Timeframe	January 2024- December 2028
Region	Europe
Targets	EU policy makers and public health stakeholders, technology developers, patients

EUCAPA

Need	Contribute to ensuring that the HTA Cooperation established at the European level includes the patient perspective from the start, as foreseen by the new EU legislative framework.
Deliverables	Regular dissemination of the project updates via social media, website and newsletter. Information about the shaping of the HTA Regulation implementation. List of patient organisations in Europe.
Objectives /Impact	Equip patients and patient experts with the knowledge and skills needed to actively participate in HTA at the EU level.
Timeframe	March 2023 - February 2025
Region	Europe
Targets	Patients with cancer, patients who need access to ATMPs, wider patient community

III. Data & Digital Health

POLICY & ADVOCACY

CONTINUED ADVOCACY ON PATIENT-CENTRED EU DIGITAL POLICIES, INCLUDING ARTIFICIAL INTELLIGENCE

Need	The EU continues to develop and implement its framework for the creation of a European Health Data Space (EHDS) and for the regulation of digital health technologies, including AI. Digital health creates significant opportunities to improve patients' lives, but patient involvement, awareness, and literacy are key to ensuring new tools and systems meet their needs.
Deliverables	1) Continue coordinating EPF's engagement through the Digital Health Working Group and activating it on issues of interest; 2) depending on the timeline for the finalisation of the interinstitutional negotiations and emergence of new initiatives, continue engaging in the policymaking process to convey EPF's position; 3) preparatory work on a toolkit for patients' organisations to explain the EHDS and PO's role in its implementation; 4) continue participating in the eHealth stakeholder group and other relevant fora
Objectives /Impact	Ensure the new framework for the EHDS and for digital health technologies more broadly is patient-centred and addresses patients' concerns; ensure patient involvement in the development and regulation of AI tools

Timeframe	Ongoing
Region	Europe
Targets	EPF members, EU policymakers

CAPACITY BUILDING & MEMBERSHIP

DATA SAVES LIVES 5TH ANNIVERSARY EVENT

To mark 5 years of Data Saves Lives initiative, an anniversary celebration event will be organised.

Need	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.
Deliverables	<ul style="list-style-type: none"> ▪ Various networking opportunities including a dedicated booth area where stakeholders can showcase their work to the wider DSL community ▪ Engaged speakers and facilitators from a range of different stakeholder groups ▪ Relevant online/electronic materials during and post-event ▪ A comprehensive summary report of the event and workshop sessions will be developed post-event to capture key insights and learnings
Objectives /Impact	<ul style="list-style-type: none"> ▪ An awareness of the important role health data literacy plays in communicating the benefits of health data to the community ▪ Confidence to handle challenging questions from the community about the EHDS ▪ Confidence to respond to collaboration requests and to assess whether to engage in an opportunity ▪ An understanding of how patient groups can position themselves as true partners in health data projects and the development of digital health tools to improve outcomes for people living with disease ▪ An understanding of the potential benefits of AI and the role of patient groups in influencing how AI is designed ▪ An understanding of the benefits of community-governed patient registries and how they can be established ▪ An opportunity to learn from peers including from those who have localized DSL in their regions
Timeframe	Q4 2024
Region	Europe

Targets Members of the DSL community with previous Bootcamp participants, DSL Germany, DSL Netherlands, EPF members, data/digital EU policy networks, academia, healthcare professionals (HCPs)

PROJECTS

GRAVITATE HEALTH

Need 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.

Deliverables Further engagement of User Advisory Group (UAG) members in the activities of other workstreams such as testing scenarios, hack-a-thon, ePI/G-lens front end user requirements.

Objectives /Impact UAG and EPF members' further engagement with the testing scenarios of the product/G-lenses in different disease areas and EU countries. Continues work on Capacity Building and Multi- Stakeholder Engagement, sustainability plans, communication triangle, and dissemination activities. Gravitate 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.

Timeframe November 2020 – October 2025

Region Europe

Targets Patients, carers, HPs, consumers

EHDEN

Need Reduce the time needed to provide answers in real-world health research.

Deliverables Further focus on the sustainability plan for the future of EHDEN. Bringing EHDEN Academy closer to EPF members to support them in the concept of patient registries.

Objectives /Impact To build a trusted observational research ecosystem to enable better health decisions, outcomes, and care. Be part of the creation of a large-scale federated network of data sources standardized to a common data model.

Timeframe November 2018 – April 2024 (pending amendment - 6-month prolongation)

Region Europe

Targets Researchers

LABEL2ENABLE

Need An EU quality label for health and wellness apps co-designed with patients, citizens, and carers.

Deliverables Building more focus groups from different consortium partners to work with UAG and UAB members on the topic of an EU quality label for health apps.

Objectives /Impact Enabling patients, citizens, and carers to make more use of trusted mHealth solutions for promoting their health and self-managing their health needs.

Timeframe May 2022 – May 2024

Region Europe

Targets Patients, carers, HPs, citizens

IDERHA

Need A platform that will enable remote patient monitoring by using digital biomarkers, PROMs, and connected devices, and provide data for joint patient-health professional decision making.

Deliverables Building a Patient Advisory Board together with our member LuCE (Lung Cancer Europe) to engage with the use cases positioned along the lung cancer patient pathway will be implemented using retrospective data and in a remote patient care context. We will also focus on lay communication/dissemination of project outcomes to the patient community.

Objectives /Impact To address the key obstacles to achieving appropriate access, sharing, use and reuse of digital health care data to lung cancer community with the help of lung cancer specific EPF member

Timeframe April 2023 – March 2028

Region Europe

Targets Patients

IV. Community

POLICY

EPF MEMBERS' CIRCLE

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
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 2024
Region	Europe
Targets	EPF Members and other patient advocates/organisations

CAPACITY BUILDING & MEMBERSHIP

SKILL TRAINING FOR YOUNG PATIENT ADVOCATES (STYPA)

Need	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, several self-learning modules, and online webinars with the EPF team and specialised trainers designed to support young patient advocates to develop their leadership, advocacy, policy and communications skills. This year STYPA will focus on Anti-microbial resistance.
Deliverables	F2F training, Virtual courses and STYPA report
Objectives /Impact	Training future patient leaders 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.
Timeframe	February - November 2024
Region	Europe
Targets	Up to 30 young patients and EPF Youth Group

101 COURSE ON PATIENT ADVOCACY FOR YOUNG PATIENT ADVOCATES

Throughout 2024, EPF will continue to work on the main objective of the “Advocacy 101” course, by providing young patients around Europe with an easy to understand, accessible, online course on the basics of patient advocacy which they can take at their own pace. In the course young patients have the opportunity to receive an in-depth knowledge of representative skills, learn how to engage in awareness and advocacy actions, discover the difference between advocacy, lobbying and being a patient representative and various more important topics.

Need	More young patients in Europe to have a solid base knowledge and understanding of patient advocacy on both national and European level.
Deliverables	Promotion of the course, monitoring the participation and progress of participants, providing support (if necessary) to participants, maintenance of the platform and the course.
Objectives/ Impact	More young patient involvement in the patient advocacy arena on both national and European level.
Timeframe	Ongoing
Region	Europe
Target	The young patient community

MASTER'S PROGRAMME ON INTERNATIONAL PATIENT ADVOCACY

In 2024, 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 end in May 2024 and the second edition will start in February 2024 and EPF along with the University, will improve the curriculum, select the participants and lecture the students.

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	1 st edition March 2023-March 2024, 2 nd edition February 2024-December 2024
Region	Europe
Targets	Patients, POs, patient representatives, health stakeholders

EPF YOUTH GROUP

EPF established the Youth Group (YG) back in 2012 and ensured its involvement in the governance of the organisation by establishing a seat for a YG representative, at the EPF Board. The YG 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 2023-2024 the Youth Group has been focusing on improving the young patient's involvement in patient organisations (POS).

I. COMMUNICATING THE EPF YOUTH GROUP PROJECT ON SEXUAL HEALTH AND WELLBEING (2022-2023)

- Need:** The sexual health and well-being of young patients is often disregarded or considered a taboo topic, due to the importance and urgency of their initial chronic condition. However, the topic remains of big importance to the young patient community and there is a lack of easily accessible resources and information on this delicate topic, targeted specifically to young people with chronic conditions.
- Deliverables** Wider dissemination of the 2023 materials of the project – videos, articles and podcast episodes, to the young patient community and the general public.
- Webinar, in collaboration with the European Medical Students Association (EMSA) and the European Pharmaceutical Students Association (EPSA), focusing on young patient’s communication with their healthcare providers.
- Objectives /Impact** Young patients to be able to communicate freely about their sexual health and well-being with their healthcare providers, partners (or potential partners) and the general public in order to address common misconceptions about young people with chronic conditions and their sex lives.
- Timeframe** Throughout 2024
- Region** Europe

II. EPF YOUTH GROUP “YOUTH INVOLVEMENT IN PATIENT ORGANISATIONS” PROJECT (2023-2025)

- Need** Patient organisations and patient networks are increasing in numbers and influence across Europe. Looking at the three main pillars of patient engagement - voice, choice and co-production - young patients are often not sufficiently or proportionately represented.
- Deliverables**
- Creation of an online course on “Youth Involvement in Patient Organisations”.
 - Template on “How to create your own Youth Strategy” within the online course.
 - “Top tips for better youth involvement in patient organisations (POS)” fact sheet, coming directly from the EPF Youth Group.

Objectives /Impact	Better youth involvement and representation in the work, decision making processes and projects of patient organisations.
Timeframe	2024-2026
Region	Europe
Targets	Patient organisation leaders and the young patients from the EPF Youth Group.

EPF YOUTH GROUP SPRING AND FALL MEETINGS

Need	The EPF Youth Group, together with the EPF Staff working with the YG to gather, update each other on the progress of their work and sit together to discuss, plan, allocate tasks and receive any support or training necessary in order to work smoothly on their projects.
Deliverables	Signed attendance lists, meeting minutes, newsletter articles and documents providing an overview of the Group's work.
Objectives /Impact	Ensuring an efficient, well-planned and smooth work of the members of the YG. And networking and team building opportunities for the YG
Timeframe	Spring and Fall 2024
Region	Europe

LEADERSHIP MEETING

The EPF Leadership Meeting is a one-day event aimed at empowering EPF members' leadership through high-level discussions and exchanges. In 2024, the event will provide EPF members with the opportunity to discuss and learn about the latest development of AI in healthcare and exchange with policy makers and experts in the field. The event will be linked to the EPF Annual General Meeting (AGM) to ensure a high level of participation.

Need	Better knowledge and insight on AI in healthcare and dialogue with policy makers and stakeholders. Ensuring that the patient organisation leaders are well-equipped to continue and improve patients' participation in shaping AI in healthcare.
Deliverables	Event agenda, event delivery
Objectives /Impact	Provide EPF members with the opportunity to discuss and learn about the latest development of AI in healthcare and exchange with policy makers and experts in the field
Timeframe	April 2024
Region	Europe
Targets	Patient organisation leaders.

DATA SAVES LIVES

Need	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.
Deliverables	Continuing core and bootcamp activities, promotion of 2.0 Toolkit, extending DSL to national level contexts
Objectives /Impact	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
Timeframe	Ongoing
Region	Europe
Targets	EPF members

RESOURCE CENTRE

Over the years and throughout the trainings, EPF has developed expertise and produced many learning materials on organisational development, cooperation, legislative processes, and policy issues. We want to build on this expertise and continue to map the learning materials produced over the past years.

Our goal is to redesign the EPF website to provide an up-to-date resource centre, providing open source, comprehensive materials, which are inclusive and accessible to all. By pooling together, the considerable training and information resources accumulated over the years and enabling the patient community to access them, we hope to multiply the impact of our advocacy and capacity building work.

EPF members and the wider patient community are encouraged to use these tools, making them their own, and to share them further. Furthermore, when possible, materials are translated in other EU languages.

In 2021 EPF developed a dedicated knowledge hub to the topic of Artificial Intelligence. In 2024 EPF would continue to populate the [AI knowledge hub](#) with audio visual and graphic content as well as adding relevant publications and resources.

Need	Open-source capacity building materials for the community
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Deliverables Updated EPF website, including a consolidated resource centre containing factsheets, toolkits, Power Point presentations, videos, position papers, briefings etc

Objectives Making organisational development tools developed by patient organisations available to the wider patient community; increasing our outreach in raising awareness about patient issues; contributing to patients' health literacy by communicating on complex policy and topics in a patient-friendly manner, and inspire others to do so; enabling self-learning

/Impact

Timeframe Throughout 2024

Region Europe

Targets Patient community

Timeframe Ongoing

Region Europe

Targets EPF members

THEMATIC WEBINARS

In 2023 EPF will organise a minimum of 4 online learning opportunities (webinars or podcasts) on topics that will vary from policy topics to organisational development, depending on the needs of the members and the policy development. Ideas for this year include: HTA, AMR, Shortages, medical devices, digital health.

Need Information on important topics for our members

Deliverables 4 webinars

Objectives To meet the needs of our members, and to increase capacity and knowledge on various topics

/Impact

Timeframe Throughout 2024

Region Europe

Targets EPF members

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 79 in 2023. 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 2024:

1. **Increase contact with potential new members:** EPF will constantly update the map/list of potential members, based on the 2023 EPF membership.
2. **Wider Europe approach:** In 2024, 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 2024, 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. 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 2024 Leadership Meeting in April 2024 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 elected a new Ethics committee during the 2023 EPF AGM that will be on duty until April 2026.

Youth Group The EPF Youth Group (YG) is made up of young patient representatives between 18-29 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](#).