EUROPEAN PATIENTS' FORUM

Work Plan 2026

'Healthcare: the next generation'

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 **82 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 target groups of EPF's activities in 2026 will be:

- Our member patient organisations, and through them, the wider patient community and the public
- European-level policymakers, Member States' representatives in Brussels as well as nationally, also in the context of the EU Council Presidencies of Cyprus, Ireland and Lithuania; Regulatory and executive EU agencies, including the EMA, HERA, HTA Coordination Group and ECDC
- Regional and international organisations, including the OECD and the WHO Regional Office for Europe
- Health systems stakeholders, including public health NGOs, health professionals' organisations, academia and researchers, organisations representing national health authorities and payers, scientific and professional bodies, and healthcare industry associations and companies
- Health media/press at EU and national levels

ADDED VALUE AND IMPACT

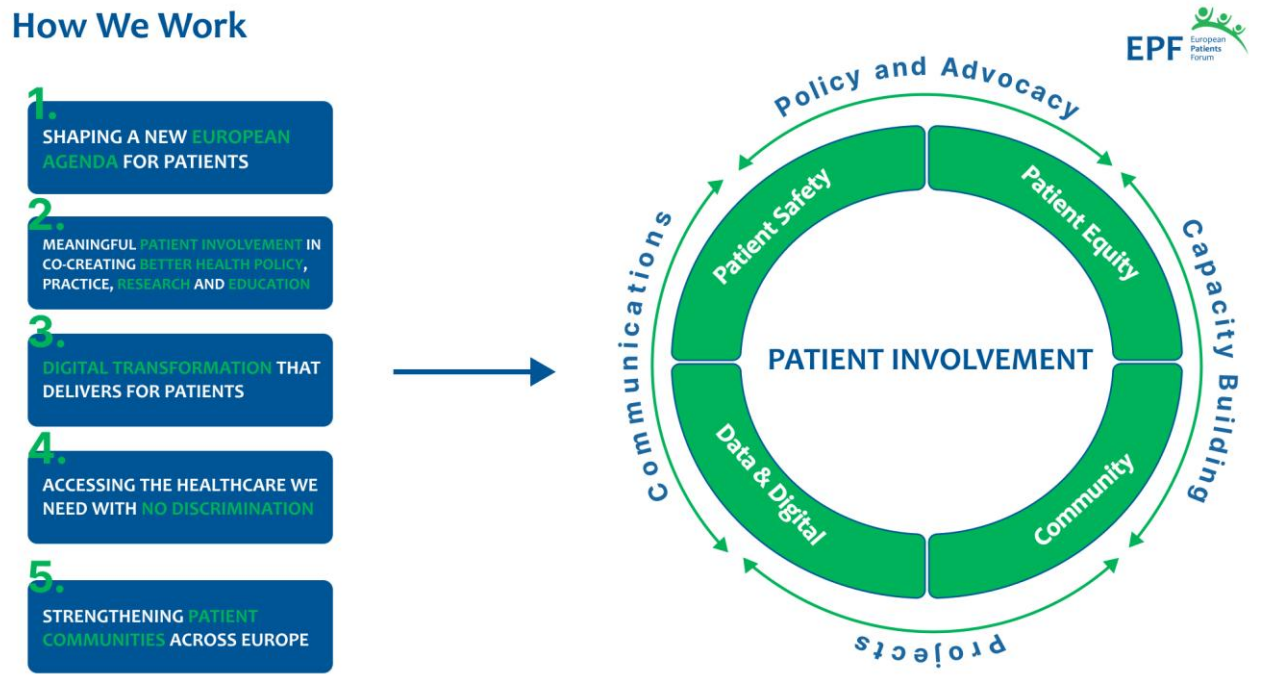
EPF is the unique European-level, umbrella patient organisation for the wider community of patients living with chronic conditions and their careers. We provide this vital cross-disease perspective from our communities into EU policymaking on issues that impact patients' lives. We link patient communities across the EU with EU-level developments. We are committed to 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 over 20 years of activity, EPF has consolidated its credibility, legitimacy and representativeness and pursued the implementation of good practices in patient empowerment and involvement by practitioners and policymakers. EPF supports the value of Europe in health and brings its community's perspective to high-level strategic issues such as the European Health Union and the EU's 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 2026 will rely on our extensive experience and strong, credible position through our engagement to bring the patient voice in crucial legislative processes concerning the pharmaceutical market as well as the implementation of EU legislation such as on the European Health Data Space, Health Technology Assessment, medical devices, all of which 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 in the design of policies, as well as in their implementation.

EPF is committed to the highest level of transparency, integrity and ethics throughout all its areas of activity.



Executive Summary

Our Work Plan for 2026 closes our **Strategic Plan 2021-2026**, looking at the future of healthcare and building on the outcomes of the EPF Congress 2025. Cross cutting activities will include a **Youth Congress**, looking at young patients as shared decision makers of the future, advocacy for **continued investment in health** and a strong health programme, finalisation and dissemination of our **Barometer on Patient Involvement in Health Policy**, and the formulation of our **Strategic Plan 2027-2032**. EPF will continue to raise awareness on patient safety issues such as **antimicrobial resistance**, collaborating and advocating for ambitious policy and building capacity within its membership on the global problem, as well as supporting the implementation of a fit-for-purpose **medical devices** regulatory framework, highlighting the need for continuous improvement of the quality and safety of devices on the EU market and patient involvement. EPF will monitor developments related to **medicines shortages** and other **pharmaceutical issues**, to support a patient-centred regulatory framework for medicines and improved patient **access**, particularly in view of the 2030 SDG deadline, also addressing capacity building needs on **HTA**, to foster meaningful patient involvement. **Digital health** remains a priority for EPF with the emerging use of AI, continuing advocacy and capacity building on patient-centric EU digital policies and use of data, including the European Health Data Space and AI. Our **Capacity Building Programme** looks ahead to future-proof the EPF membership with the advocacy and health literacy skills required for a resilient patient network, flanked by the **EPF Youth Group**; our next generation of patient leaders for a future-ready Europe. EPF continues its strategic involvement in **EU projects**, which act as a cross-cutting platform, underpinning our advocacy, education and communication pillars. Our aim is to maintain a relevant and impactful project portfolio, which is strongly aligned to our EPF key values, providing a framework for member organisations to join forces with EPF and increase their direct participation, collaboratively ensuring meaningful patient involvement in projects. Do read on to see exactly what will be keeping EPF busy in 2026!

Within this document, we describe our 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.

Work Plan 2026

Outline of the work path the EPF Secretariat will carry out in its operations throughout 2026, according to our 5 strategic goals

HEALTHCARE: THE NEXT GENERATION

- Barometer on Patient Involvement in Health Policy
- 23-24 Oct
- EPF Youth Congress, Brussels
- Formulation of EPF Strategic Plan 2027-2032
- Future Health Funding Campaign
- Partnerships & Comms

1/ PATIENT SAFETY

- Anti-Microbial Resistance
- AMR hackathon & policy event
- Sept
- Medical Devices Regulation & in-Vitro Diagnostics Regulation
- MDR Capacity Building Workshops
- Immucan
- EUP OHAMR
- READI
- Prophet
- ENKORE
- PROACT
- HEU-EFS
- IMMUNIVERSE

2/ PATIENT EQUITY

- Pharmaceutical Legislation
- Access
- HTA & Patient Involvement
- Capacity Building Workshops, Training Materials & Toolkit on Conflict of Interest
- Access Working Group
- EDiHTA
- IDERHA

3/ DATA & DIGITAL HEALTH

- Digital Health policies
- AI Survey Results
- Digital Health Working Group
- Gravitate Health
- H2O
- UNIFIED

4/ COMMUNITY (CAPACITY BUILDING PROGRAMME)

- Skills Training for Young Patient Advocates (STYPA)
- 10 YEARS
- Youth Group
- E-Learning
- Members' Circles (EU policy & innovation)
- Data Saves Lives
- Membership Capacity Building Survey
- Master's Programme on International Patient Advocacy Management

CROSS CUTTING ACTIVITIES

EPF YOUTH CONGRESS – Securing the Future of Young Patient Advocacy in Times of Multiple Crises

Need	The resilience of Europe's health systems is being tested by global crises, demographic shifts, and increasing pressure on healthcare infrastructure. A sustainable response to these challenges must include meaningful participation from those most affected - especially the next generation of patients. Young patient leaders bring fresh perspectives, lived experience, and innovative thinking to health policy discussions. Yet, their involvement remains underleveraged. This event seeks to position young patient advocates as co-creators of health policy and system solutions, building their capacity to lead while enabling institutional stakeholders to benefit from their insights.
Deliverables	Convening of young patient advocates and stakeholders, written report and video summary
Objective/ Impact	To contribute to the development of a resilient and inclusive European health system by elevating youth voices and embedding young patient leadership in decision-making processes
Timeframe	23-24 October 2026
Region	Brussels, Belgium
Targets	Young patient leaders across EPF's youth group and STYPA alumni, and broader networks, European-level health policy stakeholders (EU institutions, national representatives), healthcare professionals and provider networks, civil society organisations and youth-led platforms, industry and private sector partners committed to patient-centred innovation, EPF members and strategic partners

BAROMETER ON PATIENT INVOLVEMENT

Need	While the notion of patient involvement and engagement across all aspects of healthcare seems to be gaining traction in particular in international forums, there is a lack of evidence on how it is implemented in practice at national level and how to measure it. As such, there is a need for tools to better assess the reality of patient engagement across all aspects of healthcare, from policy to research and development of new products, and to compare and contrast national practices. In 2025, EPF **collected information from our members to support the** development of a Barometer on patient involvement in health policy across 2**3** European countries, highlighting best practices

	and areas for improvement. In 2026, EPF will focus on the finalisation of the report and dissemination of the findings.
Deliverables	1) Official launch of the Barometer on Patient involvement in Health Policy on 4 June 2026 at Patient Engagement Open Forum (PEOF); 2) Dissemination activities, including a webinar for members and engagement with EU and international organisations to leverage the results 3) development of the concept for a 360 Barometer that covers patient involvement in a broader sense, including in research and HTA
Objective/ Impact	Provide evidence and best practices for improved patient involvement
Timeframe	Ongoing
Region	EU/European region
Targets	EPF members and patient organisations; collaboration with international or national decision-makers

FUTURE HEALTH FUNDING

Need	The unprecedented investment in health in the EU Multiannual Financial Framework 2021-2027 is under threat, both in the short term through budget reallocations, and in the future MFF. The July 2024 European Commission proposal for a new MFF does not include a specific budget line for health and no structural support for civil society. Yet, health systems' resilience depends on significant, coherent investment in the coming years as well as democratic engagement with civil society, with a particular focus on patient organisations, to ensure health policies meet the needs of those they aim to serve.
Deliverables	Advocacy campaign with the EU institutions to reinstitute operating grants under the current EU4Health Programme and ensure a strong health budget in the next MFF, leveraging existing platforms and coalitions such as the EU4Health Civil Society Alliance. This will also include mobilising national coalition members to amplify outreach to member states' officials and identifying best practices/case studies of the value of patient organisations for healthcare systems , leveraging the dissemination of the Barometer on Patient Involvement in health policy.
Objective/ Impact	To advocate for continued investment in health and a strong health programme, to support the modernisation of health systems towards better, patient-centric healthcare
Timeframe	2026-2027
Region	EU

Targets	Policymakers, foundations and other donors for health, civil society organisations

FORMULATION OF THE STRATEGIC PLAN 2027-2032

Need	EPF's ongoing strategic plan 2021-2026 is approaching completion. Based on an external evaluation of the ongoing strategic plan with internal and external stakeholders and a thorough analysis of the policy and political environment for EPF and its members, we will start developing, in consultation with the EPF membership, a new strategic plan to guide our activities and focus our efforts in the coming years.
Deliverables	Membership surveys on work carried out so far and on priorities for the next strategic cycle.
Objective/ Impact	To evaluate the strategic plan and to propose strategic objectives, priorities, and areas of engagement
Timeframe	Q3-4 2025, 2026
Region	EU
Targets	Members, external stakeholders and partners

PARTNERSHIPS

To pursue its mission of embedding meaningful patient involvement in health policy, research, and practice, 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). Leveraging on 2022-2025 activities including both virtual and face to face meetings, PEOF is growing and expanding geographically its network. In June 2026 a new edition of PEOF face to face event is planned in Seville, Spain. The programme will be built around Patient Engagement in connection to thematic areas such as innovation and patient-centred technologies, empowerment of communities, sustainability, inclusive engagement and multi-stakeholder engagement in patient engagement, with support from a multi stakeholder Programme Committee.

EUPATI was established as an independent foundation in September 2020 to promote patient education and facilitate the provision of patient expertise 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 is involved in formal and informal **health-focused, multi-stakeholder networks and alliances**, including the EU Health Policy Platform, the Eu4Health Civil Society Alliance, Civil Society Europe, the EU Health Coalition, the European Alliance for Value in Health, The Social Platform, the PharmaLedger Association, Darwin EU, EIT Health, HealthData@EU Pilot, HTAi, ISPOR 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	As an "eligible patients' organisation", EPF is part of EMA's Patients and Consumers Working Party (PCWP) and co-chairs it since September 2025. 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. In 2026, the implementation of the pharmaceutical legislation will require close engagement with EMA. This will ensure the relevant provisions related to patient engagement meaningfully strengthen patient involvement throughout the regulatory process, thereby improving health and regulatory outcomes for all.
Deliverables	1) Help shape the next PCWP mandate to ensure it serves the needs of PCWP members 2) Participation in PCWP meetings and ad-hoc webinars 3) Dissemination of meeting outcomes and consultations to membership on relevant topics 4) Involvement in specific activities based on EPF's priorities 5) Support the nomination of patient experts and other issues related to the implementation of the pharma legislation
Objective/ Impact	Facilitate and strengthen interactions between EMA and the patient community and help shape a patient-centred regulatory system in the EU
Timeframe	Ongoing
Region	EU
Targets	EPF members, patient organisations, EU policy-makers, EU regulators

ENGAGEMENT WITH WHO EUROPEAN REGIONAL OFFICE

Need	EPF is an accredited regional 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. WHO Europe is particularly active on issues related to access to medicines, digital health, and organisation of healthcare

	systems, however, cuts in WHO funding have significantly weakened the organisation's capacity.
Deliverables	1) Resources allowing, 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; 3) Continued involvement in relevant activities (e.g. Novel Medicines Platform, Strategic Partners' Initiative for Data and Digital Health)
Objective/ Impact	Maintain the cooperation between the WHO European Regional Office and EPF and advocate for patient involvement in healthcare systems
Timeframe	Ongoing
Region	WHO European region
Targets	EPF members, patient organisations, WHO, policy-makers

ENGAGEMENT WITH OECD

Need	OECD supports the development and implementation of evidence-based policies that improve access, efficiency, and quality of healthcare. As such, EPF will continue its ongoing collaboration with OECD to bring a patient perspective into the OECD's work and encourage increased patient engagement.
Deliverables	1) Attendance of relevant meetings; 2) contribution to relevant initiatives including OCED's expert group on AI in health
Objective/ Impact	To convey the patient voice into OECD health-related initiatives and strengthen OECD engagement with patient organisations
Timeframe	Ongoing
Region	Europe
Targets	EPF members, OECD, policy-makers

COMMUNICATIONS AND MEMBERSHIP ENGAGEMENT

BRAND UPDATE

Need	To remain relevant and influential in a rapidly evolving healthcare landscape shaped by digital transformation, demographic change, and rising transparency expectations, EPF must modernise its communications. This rebranding will align with the new strategic

plan and values, strengthen advocacy and dissemination, refresh its visual and narrative identity, ensure consistency across platforms, and enhance strategic clarity so stakeholders clearly understand EPF's purpose and impact.

Deliverables

Brand Audit: Review visual assets and tone; assess messaging consistency across channels; benchmark against peers and health NGOs.
Narrative Review: Co-create refreshed key messages aligned with the strategic plan and define core themes and content pillars.
Visual Identity Refresh: Refine or redesign logo, fonts, colours, and guidelines; develop flexible templates for social, events, policy, and community use.

Objective/ Impact

- **Engage New and Existing Audiences:** Expand reach and engagement with patient groups, young advocates, and the public through authentic, human-centred storytelling.
- **Strengthen Strategic Alignment:** Ensure EPF's identity supports its 2026 goals and thought leadership role.
- **Build Brand Awareness:** Position EPF as a trusted, forward-looking voice through consistent and creative communication.

Timeframe 2026

Region Europe

Target audiences

- EPF Members and patient organisations
- European policymakers and institutions
- Healthcare stakeholders (researchers, professional associations, industry)

ONGOING COMMUNITY GROWTH

Need

To expand EPF's online presence and make the patient voice more visible and influential across Europe, building an engaged digital community that amplifies advocacy, showcases projects and members' work, strengthens stakeholder relationships, and positions EPF as a leading hub for patient-centred health policy dialogue.

Deliverables

12 editions of the Patient Perspective newsletter (monthly) to engage and inform stakeholders.
At least 10 podcast episodes under the Eu Patients' Podcast format;
10% increase in social media followers across all platforms (baseline: December 2025).
Minimum 3 strategic digital campaigns linked to key awareness days or policy events to drive traffic and engagement.
Two engagement **c**hallenges, such as "1 Question, 100 Answers" on social media, to crowdsource patient perspectives

	Bi-annual “State of the Patient Voice” bulletins: a LinkedIn post (article) reflecting on media narratives and key debates in the health policy space, positioning EPF as a media-aware and opinion-responsive organisation.
Objective/ Impact	• Greater visibility for EPF’s mission, positioning the organisation as a key voice in patient advocacy and health policy. • Stronger advocacy power through a connected, informed, and mobilised community. • Enhanced dissemination opportunities for EPF-led projects and member initiatives through broader reach and improved platform performance. • Improved stakeholder perception, showing EPF’s commitment to transparency, collaboration, and digital innovation.
Timeframe	2026
Region	Europe (primary), with extended outreach to North America for partnership-building and international advocacy alignment
Target audiences	• EPF Members and patient organisations • European policymakers and institutions • Healthcare stakeholders (researchers, professional associations, industry)

STRATEGIC SUPPORT

Need	EPF’s credibility as a patient advocacy platform relies on the trust and visibility it builds within its membership. To strengthen its network, EPF will foster inclusive two-way communication, amplify members’ achievements, create opportunities for shared learning and visibility, and reinforce its role as the central voice of the European patient movement.
Deliverables	3% increase in average open rate for the *Weekly Insiders* newsletter, achieved through enhanced personalisation, tailored content, and member-driven headlines. At least 2 podcast episodes featuring members in the spotlight, with interviews or co-hosted segments highlighting their impact, challenges, and strategic priorities. Minimum 6 dedicated social media posts annually showcasing members' initiatives, campaigns, or publications
Objective/ Impact	• Strengthen communication pathways between EPF and its members by increasing regular, relevant, and co-owned communications. • Amplify members' visibility across EPF’s digital ecosystem, elevating grassroots advocacy

- Foster a sense of ownership and representation, ensuring members see themselves reflected in EPF's messaging and strategic direction.
- Create shared visibility opportunities that reinforce collective identity that highlight both unity and diversity within the patient community.

Timeframe	2026
Region	Europe
Target audiences	• EPF member organisations and their networks • Broader patient community • Civil society partners • Health advocacy influencers and community builders

POSITIONING AND REPUTATION MANAGEMENT

Need	As a leading voice in European patient advocacy, EPF must actively shape its public image, build media trust, and maintain a unified, credible presence across channels. Sustaining its influence requires strategic storytelling, consistent visibility, and transparent communication that reinforce EPF's credibility, showcase its impact, and strengthen brand consistency and alignment with its community.
Deliverables	At least 15 website news items, including member stories, policy updates, major announcements, and reactive commentary on relevant EU developments. Minimum 2 press releases, timed with high-impact moments, supported by tailored outreach to targeted media lists. Annual Report and Impact Report Event reports (as needed), with timely summaries of EPF-led events Reputation & Reach Scorecard: a branded 1-pager (appendix to Annual Report or standalone) summarising EPF's public visibility
Objective/ Impact	• Increase positive media visibility through stronger storytelling and targeted outreach. • Enhance journalist engagement and press coverage. • Demonstrate transparency through clear and accessible reporting • Reinforce EPF's institutional profile by consistently showcasing strategic relevance, thought leadership, and high-quality results.
Timeframe	2026
Region	Europe (primary)
Target audiences	• General public and patient communities

- Policymakers at national and EU levels
- Health stakeholders (industry, academia, NGOs)
- Scientific and medical communities
- Funders and philanthropic organisations

PATIENT SAFETY

ANTI-MICROBIAL RESISTANCE

Need	AMR is a vital issue for chronic diseases patients. They are particularly vulnerable to AMR because they have to spend more time in healthcare settings and because many routine healthcare procedures often require the use of antibiotics to prevent or treat infections. Patient organisations have a key role to play in raising awareness of AMR as a patient safety issue. Patient organisations should be empowered to advocate for ambitious AMR policy actions.
Deliverables	1) Continued advocacy for ambitious AMR policy action; 2) Continue populating the AMR Info Point on EPF website; 3) Tailored support to members and other patient organisations wanting to engage in AMR policy at national level, as requested; 4) continued engagement with key stakeholders to foster collaboration In addition, EPF will organise a **hackathon & high-level policy roundtable on AMR in September 2026**. The objective will be to bring together key stakeholders to discuss concrete solutions to address the threat of AMR across the patient journey, with a particular focus on how patient organisations can engage at every step.
Objective/ Impact	Increase policy focus on the urgent threat of AMR and increase engagement of patient organisations in the debate through awareness and advocacy actions, and strengthen the translation and uptake of AMR research and innovation outcomes by connecting researchers and patients in a co-creative process that identifies real needs, practical barriers, and opportunities for impact.
Timeframe	Ongoing
Region	Europe
Targets	EPF members, EU and international policy makers

ADVOCACY AND CAPACITY BUILDING ACTIVITIES ON MEDICAL DEVICES AND COMBINATION PRODUCTS

Need	In 2025, the European Commission undertook a review of the medical devices and in-vitro diagnostic medical devices regulations, in view of significant implementation delays and difficulties. A targeted revision is likely to be confirmed. Ensuring that improving the quality and safety of devices on the EU market remains a priority objective as part of this initiative will be a key focus for EPF. In addition, education of patient organisations on the regulations and relevant provisions to improve patient information (such as EUDAMED) is crucial to enable them to engage on the topic in a meaningful way. Finally, there is a continued need to raise awareness of the need for patient involvement in the research and development of new devices that meet their needs, as well as in the governance of the system and regulatory processes.
Deliverables	1) Attendance and engagement in Medical Devices Coordination Group; 2) Advocacy activities related to ongoing development on MDR/IVDR; 3) Capacity-building activities/tools on key MDR/IVDR features (e.g. EUDAMED) 4) Explore potential activities to foster more systematic patient engagement in medical devices R&D. In addition, on 17 March 2026, EPF will organise **capacity building workshops (one in-person, two online follow up sessions).**
Objective/ Impact	Support the implementation of a fit-for-purpose medical devices regulatory framework; support increased patient engagement in medical devices R&D and regulation; strengthen members' knowledge and ability and capacity to engage on the issue at national level
Timeframe	Throughout 2026
Region	Europe
Targets	EPF members, patient organisations

EU PROJECTS

ENKORE

Need	There is a clear need to accelerate innovation in patient solutions through an **ecoDesign framework** that embeds circularity, safety, and sustainability from the outset. Building on the Safe and Sustainable by Design (SSbD) approach, ENKORE promotes the development of packaging and single-use devices that reduce environmental impact, lower carbon emissions, and use resources efficiently, while

	ensuring patient safety.This lifecycle-based framework supports the creation of future products that are both environmentally responsible and industrially viable.
Deliverables	The project will propose a set of evidence-based policy recommendations, guidelines, protocols, and tools for greening hospital devices and primary packaging material, tailored to different lead-users (practitioners, manufacturers, hospital managers), end-users (patients, healthcare providers) and decision-makers on macro- (national and supra-national), meso- (regional) and micro- (local) level.
Objectives/Impact	Develop comprehensive approaches for healthcare facilities and patients (at their home) to adopt sustainable practices from procurement to waste management. The project will establish a reliable framework for monitoring and reducing the environmental footprint of packaging and single-use medical devices through the value chain of manufacturing and healthcare services while ensuring the safety for citizens and users.
Timeframe	48 months (January 2025- December 2028)
Region	Europe
Targets	Patients, healthcare professionals, hospitals, manufacturers, decision makers

EUROPEAN PARTNERSHIP ONE HEALTH ANTIMICROBIAL RESISTANCE (EUP OHAMR)

Need	Antimicrobial resistance (AMR) is a growing threat to public health, making infections harder to treat and increasing the risk of complications and death. Despite ongoing efforts, actions remain too fragmented across sectors and countries. The European Partnership on One Health Antimicrobial Resistance (EUP OHAMR) is urgently needed to bring together key actors across human, animal, and environmental health. By strengthening collaboration, supporting research, and aligning national and EU efforts, the Partnership will help deliver effective, coordinated responses to AMR and enhance Europe's capacity to protect health now and in the future.
Deliverables	The project will deliver a coordinated research agenda on antimicrobial resistance across human, animal, and environmental health. It will support joint research calls, improve surveillance and data sharing, and strengthen policy alignment across Europe. The project will also raise awareness and build capacity through training, stakeholder engagement, and tools to ensure long-term impact.
Objectives/Impact	Reduce the burden of antimicrobial resistance by promoting coordinated action across sectors and countries. Its impact will include more effective prevention and monitoring of AMR, stronger research capacity, informed policies, and improved health outcomes across Europe.

Timeframe	120 months (June 2025 to May 2035)
Region	Pan-European
Targets	Patients, healthcare professionals, hospitals, manufacturers, decision makers

A EUROPEAN PROACTIVE ADAPTIVE CLINICAL TRIALS NETWORK (EU PROACT)

Need	Recent pandemics revealed the critical need for proactive health measures in Europe to ensure medical countermeasures are available during crises. A coordinated network is required to enable rapid response through large-scale clinical trials.
Deliverables	A strengthened network of clinical centres, laboratories, and social science researchers across Europe. Enhanced preparedness tools, community engagement, and education on health issues.
Objective/Impact	To prepare Europe for future pandemics by building an integrated network capable of quickly conducting multi-country therapeutic trials, ultimately reducing mortality, morbidity, and economic costs.
Timeframe	60 months (1 January 2025 – 31 December 2029)
Region	Europe, involving organisations and research centres from multiple EU and associated countries.
Targets	Patients and citizens, healthcare professionals, policy makers, researchers, NGOs, and tech providers to promote proactive health actions and systemic engagement.

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

Need	There is currently no standardised framework in the EU for conducting Early Feasibility Studies (EFS) for medical devices, which can support the device development process, better evidence generation, and earlier access for patients.
Deliverables	The project will deliver a harmonised EFS methodological framework, EFS templates (e.g. informed consent form), database for recording and monitoring EFS, improved clinical evidence quality, and increased patient involvement in medical device development.
Objective/Impact	The project aims to standardise EFS procedures across the EU, thereby increasing the number and quality of studies, fostering innovation, and ensuring that medical devices are better tailored to patient needs.

Timeframe	48 months (1 October 2023 – 30 September 2027)
Region	European Union (EU) member states.
Targets	Healthcare providers, patient organisations, health technology developers/medtech companies, regulators, and research institutions across the EU.

INTEGRATED IMMUNOPROFILING OF LARGE ADAPTIVE CANCER PATIENTS COHORTS (IMMUCAN)

Need	Current cancer immunotherapies often fail to provide long-lasting responses and can cause significant side effects. There is a need to better understand the interactions between the immune system and cancer cells at the molecular level to improve treatment outcomes.
Deliverables	The project will deliver a comprehensive analysis of tumour tissues, blood, stool, and saliva samples, along with clinical data from approximately 3,000 cancer patients. The insights gained may identify biomarkers predicting patient responses to immunotherapies and suggest new treatment strategies.
Objective/Impact	The objective is to gain a detailed understanding of the tumour microenvironment and its response to immunotherapy, aiming to refine existing treatments and develop new ones. The impact could be more personalized and effective cancer treatments with reduced side effects.
Timeframe	78 months (1 March 2019 – 31 August 2026 (with a 6-month extension))
Region	The project is based in Europe, involving multiple countries and clinical centres across the continent.
Targets	The primary targets are cancer patients with colorectal, lung, head and neck, breast, gastric, and renal cancers, particularly focusing on those undergoing or eligible for immunotherapy.

BETTER CONTROL AND TREATMENT OF IMMUNE-MEDIATED DISEASES THROUGH MICROENVIRONMENTAL TISSUE SIGNATURES AND LIQUID BIOPSIES (IMMUNIVERSE)

Need	Immune-mediated diseases (IMIDs) present significant medical challenges due to their heterogeneity in disease outcomes and treatment responses, necessitating a more precise approach to patient management.
Deliverables	The project will deliver validated biomarkers for disease control and therapy response, new non-invasive liquid biopsy methodologies, and a comprehensive understanding of tissue-immune cell interactions in IMIDs.

Objective/Impact	The project aims to enhance precision medicine in IMIDs by improving diagnostics, treatment monitoring, and patient management, ultimately leading to better patient outcomes and reduced socioeconomic burdens.
Timeframe	72 months (1 January 2020 – 31 December 2026)
Region	European-based consortium with partners from multiple countries, including Italy, Austria, Germany, the United Kingdom, Belgium, the Netherlands, Denmark, Luxembourg, France, and Switzerland.
Targets	The primary targets are patients with ulcerative colitis and atopic dermatitis, with a broader goal of advancing IMID diagnostics and treatment across various conditions.

PERSONALISED PREVENTION ROADMAP FOR THE FUTURE HEALTHCARE IN EUROPE (PROPHET)

Need	The project addresses the need to integrate Personalised Prevention approaches into EU health systems to prevent chronic diseases and improve healthcare outcomes.
Deliverables	PROPHET will produce a Strategic Research Innovation Agenda, a Personalised Prevention Roadmap co-created with stakeholders, and educational measures for citizens, healthcare professionals, and policymakers.
Objective/Impact	The project aims to support the adoption of innovative and sustainable personalised prevention strategies across Europe, empowering stakeholders in health self-management and contributing to the reduction of preventable chronic diseases.
Timeframe	48 months (1 September 2022 – 31 August 2026)
Region	Europe, with particular focus on Italy, Netherlands, Portugal, Finland, and Estonia through case studies and action plans.
Targets	Citizens, healthcare professionals, policymakers, and patient organisations, with a focus on enhancing engagement and capacity in personalised prevention practices.

RESEARCH IN EUROPE AND DIVERSITY INCLUSION (READI)

Need	Clinical studies often fail to include diverse populations, leading to knowledge gaps and limited access to experimental health technologies for underrepresented and underserved groups. Enhancing inclusiveness in clinical studies is critical for addressing healthcare disparities and improving research quality.

Deliverables	A digital platform for increasing inclusiveness in clinical studies, a toolbox for stakeholders, and a comprehensive training and capacity-building program to better engage and recruit diverse populations.
Objective/Impact	The project aims to create a more inclusive ecosystem for clinical studies in Europe by promoting the participation of underserved populations, ultimately transforming clinical research practices and improving healthcare access.
Timeframe	60 months (1 January 2025 – 31 December 2030)
Region	Europe, with a focus on expanding clinical research inclusivity across all European regions, especially in underserved and underrepresented areas.
Targets	The project is addressed to researchers, industry stakeholders, clinical investigators, patient organizations, healthcare professionals, and underserved/underrepresented populations. It includes community-based sites, regulators, and clinical networks involved in clinical studies.

PATIENT EQUITY

PHARMACEUTICAL POLICY

Need	EPF will continue to follow developments related to medicines shortages, in particular the finalisation of negotiations and implementation of the Critical Medicines Act. It will also follow the finalisation and implementation of the pharmaceutical legislation and its impacts on access to safe and effective medicines for all patients. This review must be seen in conjunction with other important regulatory and policy developments, including the Life Sciences Strategy, the EU Biotech Act, and international developments with potential high impacts on patients' access to medicines. .
Deliverables	1) Continued advocacy activities and engagement with policy-makers/relevant stakeholders on relevant legislation; 2) EPF continued involvement in the Accelerating Clinical Trials in the EU initiative (ACT-EU); 3) continued monitoring of members' experiences with medicines shortages and advocacy for patient engagement in policy solutions; 4) engagement with members through the Universal Access Working Group.

Objective/ Impact	Support a patient-centred regulatory framework for medicines and improved patient access to medicines and clinical trials in the EU
Timeframe	Ongoing
Region	EU
Targets	EPF members, EU policy-makers, regulators, and broader health stakeholders

ACCESS TO HEALTHCARE

Need	With just five years remaining to the 2030 SDG deadline, Europe is at risk of failing its political commitment to universal access to healthcare. The Covid-19 pandemic worsened gaps and systemic risks in patient access and care, evidenced by persistent inequities within and between European countries and greater financial difficulties for patients and their families. In parallel, cross-border access to care remains limited, with low awareness among the patient community of their rights under the cross-border healthcare (CBHC) directive.
Deliverables	1) Facilitate and activate the EPF Working Group on Access; 2) Redefine EPF's position on access to healthcare and what it means in the context of the Life Sciences Strategy, international developments, and other EC initiatives focusing on competitiveness; 3) Reflect on the development and roll-out of a campaign based on members' testimonies to identify key issues in access to care and provide recommendations (concept note).
Objective/ Impact	Identify barriers to healthcare access and propose policy solutions that reflect the needs of patients, carers, and communities.
Timeframe	2026
Region	EU
Targets	EPF members, EU policy-makers

PATIENT INVOLVEMENT IN THE EU'S HTA AGENDA

Need	Foster meaningful involvement of patients in the HTA agenda
Deliverables:	1) Landing page on the EPF website to ensure higher visibility of training materials and templates on HTA (EUCAPA, HTA4PAtients, HTAi); 2) Organise capacity building course on conflicts and competing interests, which includes 4 online, one F2F capacity building session and a policy roundtable (to be delivered in 2027); 3) Toolkit about conflict-of-

	interest management; 4) Coordinate the engagement of Patient Organisations involved in the HTA Stakeholder Network ; 5) Advocate for and further promote meaningful patient involvement in HTA through awareness raising activities and the HTAi project on EU HTA Patient Involvement in Joint Clinical Assessments.
Objective/ Impact	Raise awareness about the relevance of the HTA Regulation with EPF members and non EPF member patient organisations**;** Promote patient involvement in HTA**;** address potential barriers to patient involvement in HTA
Timeframe	2026- early 2027
Region	Europe
Targets	EPF members, Patient organisations

EU PROJECTS

EUROPEAN DIGITAL HEALTH TECHNOLOGY ASSESSMENT FRAMEWORK CO-CREATED BY ALL STAKEHOLDERS ALONG THE VALUE CHAIN (EDIHTA)

Need	There is a growing need for a comprehensive, flexible, and inclusive Health Technology Assessment (HTA) framework that can effectively evaluate various Digital Health Technologies (DHTs) to ensure they enhance healthcare quality and delivery across Europe.
Deliverables	The project will deliver – among others – a validated HTA framework tailored for DHTs that integrates new and existing assessment methods.
Objective/Impact	EDiHTA aims to create a validated HTA framework that captures the true added value of DHTs, ensuring that these technologies meet the needs of both healthcare providers and patients, ultimately improving healthcare services in Europe.
Timeframe	48 months (1 January 2024 – 31 December 2027)
Region	The project will be implemented across Europe, with real-world testing in five prominent European hospitals and involvement from stakeholders across ten European countries.
Targets	Key targets include DHT developers, HTA agencies, clinical partners, and patient organizations, with a focus on ensuring that patients' needs are prioritized in the development and assessment of digital health technologies.

INTEGRATION OF HETEROGENEOUS DATA AND EVIDENCE TOWARDS REGULATORY AND HTA ACCEPTANCE (IDERHA)

Need	IDERHA addresses significant challenges in accessing, sharing, using, and reusing lung cancer data across the EU, which is critical for advancing healthcare innovation.
Deliverables	The project will develop a scalable system to connect various data sources, create policy recommendations for data sharing, and extend standards for data quality, ethics, and transferability.
Objective/Impact	IDERHA aims to enhance healthcare innovation by improving data management, leading to better public health outcomes, reduced patient burden, and optimized healthcare costs through personalized care.
Timeframe	60 months (1 April 2023 – 31 March 2028)
Region	IDERHA is a pan-European initiative involving 38 partners from 11 countries across the EU.
Targets	The project focuses on improving lung cancer patient outcomes through enhanced risk prediction, remote monitoring, and personalized care, while also engaging regulatory and HTA agencies to assess health data acceptability.

DATA & DIGITAL HEALTH

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

Need	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. EPF's activities related to the AI Act and European Health Data Space (EHDS) will continue to focus on implementation at EU and national level, including ensuring patients' access to safe and effective digital health tools, patients' inclusion in the governance of the system, and patient empowerment.
Deliverables	1) Continued engagement in the EPF digital health working group; 2) Continued participation in relevant stakeholder forums, including the eHealth stakeholder group; 3) Continued advocacy activities; 4) partnership with the University of Leuven for the 2025/2026 update of the AI survey

Objective/ Impact	Ensure patient-centred digital health policies and EHDS implementation – including a strong focus on health literacy – and promote patient involvement in the digital healthcare transition; ensure patient involvement in the development and regulation of AI tools
Timeframe	Ongoing
Region	EU
Targets	EPF members, EU policy-makers

EU PROJECTS

GRAVITATE-HEALTH

Need	There is a need to empower citizens with digital tools that make medical information more accessible and understandable, addressing challenges with traditional paper leaflets, especially for aging patients and those with chronic conditions.
Deliverables	Gravitate-Health will deliver a digital information tool called the Gravitate Lens (G-Lens) for trustworthy, understandable medicine information and a white paper with strategies for the future use of digital services in healthcare.
Objective/Impact	The project aims to improve patient health outcomes and quality of life by enhancing the accessibility and comprehension of medicine information, leading to safer and more effective medicine use.
Timeframe	60 months (1 November 2020 – 30 June 2026)
Region	The project involves partners from across Europe and beyond, including countries such as Norway, the United Kingdom, Sweden, Germany, Spain, and the United States.
Targets	The project targets patients, healthcare professionals, and citizens, focusing on improving digital health literacy and ensuring better adherence to medical advice through enhanced information accessibility.

HEALTH OUTCOMES OBSERVATORY (H2O)

Need	The project addresses the need to amplify the patient voice in healthcare by creating patient-centric observatories that allow patients to report health outcomes in a standardized manner.

Deliverables	Establishment of health outcomes observatories in Germany, Spain, Austria, and the Netherlands, covering diabetes, inflammatory bowel disease, and cancer. Provision of digital tools for patients to report their health outcomes. In 2025, H2O delivers the final national patient engagement event in Spain.
Objective/Impact	The project aims to improve patient care by enhancing communication between patients and healthcare providers and by providing data that informs clinical decisions. The long-term goal is to expand these observatories across Europe and to additional disease areas.
Timeframe	60 months (1 October 2020 – 30 March 2026)
Region	Germany, Spain, Austria, and the Netherlands, with potential future expansion across Europe.
Targets	The primary targets are patients with diabetes, inflammatory bowel disease, and cancer, along with healthcare providers and broader healthcare systems.

UNIFIED

Need
Deliverables
Objective/Impact
Timeframe
Region
Targets

COMMUNITY (CAPACITY BUILDING PROGRAMME)

DATA SAVES LIVES

Need	Patients and their organisations need clear, accessible tools to understand the European Health Data Space (EHDS) and the integration of Artificial Intelligence (AI) in healthcare. As these frameworks develop, there is a pressing need to build digital health literacy, trust, and capacity among patients to engage meaningfully in related discussions and decision-making. The Data Saves Lives (DSL) initiative provides a platform to meet this need through targeted resources and outreach.
Deliverables	The initiative will prioritise the translation of the EHDS explainer toolkit into five European languages to support accessibility and local use. The initiative will also

	feature in one to two national-level events to raise awareness and build capacity among patient communities.
Objective/Impact	To enhance digital health literacy, increase patient awareness and trust in the EHDS and AI, and support meaningful engagement with digital health policy at national and EU levels.
Timeframe	2026
Region	Europe
Targets	Patient organisations, EPF members and their networks/members, national stakeholders, and underrepresented groups including younger and digitally underserved communities.

SKILL TRAINING FOR YOUNG PATIENT ADVOCATES (STYPA)

Need	STYPA is a tailored high-quality training programme for young patient advocates, executed via a 6-month programme including an in-person 2-day training, several learning materials, 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 on specific topics chosen yearly. This year we celebrate the 10th edition of STYPA, and the topic of focus is *Health Literacy: Empowering young patients to shape tomorrow's healthcare.*
Deliverables	F2F training, Virtual courses and STYPA report
Objectives /Impact	Training future patient leaders. Creating a powerful network of 'graduates' from STYPA, to enable them to collaborate and engage with EPF and beyond STYPA.
Timeframe	February - November 2026
Region	Europe

EPF YOUTH GROUP

The EPF Youth Group (YG) is a cohort of 10 advocates under 30 from across Europe, coming from the EPF membership. Each year they lead one flagship, youth-designed project and convene two strategic, in-person meetings (Spring & Fall) with EPF staff and Board to steer the work, strengthen governance, and amplify youth perspectives across EPF. In 2026, they will ensure youth representation, present a youth-led proposal to the EPF Board, strengthen collaboration with EPF member organisations and represent EPF externally, becoming Europe's next generation of patient leaders, equipped to influence health policy today.

Need	The young patient voice is under-represented where decisions are made. The YG turns that gap into a pipeline of skilled, networked, and influential young leaders who co-design solutions with policymakers, clinicians, and other actors of the health system.
Deliverables	A youth-designed project and two strategic, in-person meetings (spring & fall) with EPF staff and Board
Objective/ Impact	Increase young patient involvement in the patient advocacy arena on both national and European level
Timeframe	Throughout 2026
Region	Europe

E-LEARNING

Digital learning is now core to capacity building. It scales reach, lowers barriers, and meets advocates wherever they are, asynchronously, and with accessible formats. EPF's online platform advances our mission to make healthcare inclusive, equitable, and truly patient-centred by equipping diverse communities with practical advocacy skills.

Need	Reach and equip diverse patient communities with the tools to advocate for themselves and others
Deliverables	Two flagship, self-paced online courses on *Advocacy 101* and *Youth Engagement in Patient Organisations* easily available on our platform with optional live touchpoints, designed for busy schedules and varied access needs**.** A report will follow with insights on key statistics on the course (geography, number of students, etc).
Objective/ Impact	To build and strengthen the advocacy knowledge and capacities of young patients, in a flexible and accessible way. 300+ participants complete *Advocacy 101* and 20 Patient Organisations complete the *Youth Engagement in Patent Organisations course*, have EPF members use the materials in their own capacity building work, paving the way for an additional e-learning course.
Timeframe	Throughout 2026
Region	Europe as main target but the course is available worldwide

MEMBER CAPACITY BUILDING AND ENGAGEMENT MAPPING SURVEY

Need	To support the development of the next EPF Strategic Plan, EPF needs to conduct a comprehensive survey of its members. This exercise will specifically map members' capacity building needs and interests, identify areas of expertise, highlight current gaps in capacity and support, and explore emerging areas of interest. Furthermore, the survey will assess the quality of engagement between members and EPF, exploring how it can be strengthened. It will seek input on what additional efforts EPF could undertake, and how current engagement practices could be improved or adapted to better serve the membership.
Deliverables	An internal-use survey report that synthesises members' feedback on capacity building priorities and engagement expectations.
Objective/Impact	This project is designed to enhance the sense of ownership, alignment, and community within EPF. By actively listening to members and reflecting their views in strategic planning, EPF will not only strengthen its support structures but also deepen member engagement and co-create a more responsive and sustainable network.
Timeframe	2026
Region	Europe
Targets	EPF Member Organisations

EPF MEMBERS' CIRCLES

Need	Patient organisations require better access to EU health policy and research developments to engage effectively. Strengthening their understanding is essential to ensure meaningful patient involvement in EU decision-making and innovation.
Deliverables	2-4 webinars
Objectives /Impact	Increase members' understanding of EU health policy and key stakeholders through EPF's involvement in EU projects (Horizon Europe, IHI, Erasmus+), using project activities to build capacity, support participation, and strengthen the patient voice in research and innovation.
Timeframe	Throughout 2026
Region	Europe
Targets	EPF Members and other patient advocates/organisations

Targets	EPF Members

MASTER'S PROGRAMME ON INTERNATIONAL PATIENT ADVOCACY

In 2026, 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. While the 4th edition is not planned for 2026, EPF along with the University, will work to update and improve the curriculum to better align it with the current health policy landscape and acknowledge the new reality in patient advocacy.

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	February 2026-December 2026
Region	Europe

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 82 in 2026. 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 2026:

1. **Increase contact with potential new members**: EPF will constantly update the map/list of potential members, based on the 2025 EPF membership.
2. **Wider Europe approach**: 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**: EPF will continue to support national coalitions through training and exchange of best practices.
4. **Increase involvement of EPF member organisations in EU funded and other international project:** EPF will inform the membership about EU funded and other international project opportunities to ensure the patient perspective is present, and support their diversification of funding.

GOVERNANCE

A robust governance system is core to everything we do. Through our Constitution, EPF established several governing bodies that meet regularly:

Annual General Meeting (AGM) EPF's highest governance body is the Annual General Assembly where each member is represented by one delegate.

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.

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.

Secretariat The EPF Secretariat currently with a staff of 19, executes the annual work plan based on the EPF Strategic Plan and works to support and inform the members.

In addition, we rely on dedicated groups to capture knowledge and expertise and consult members on advocacy campaigns, including the following:

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. Ad-hoc **taskforces** such as on paediatrics and (possibly) on medical devices might continue or be created with members that have interest and expertise, to inform EU and national level advocacy on these issues.

TRANSPARENCY & 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.