EUROPEAN PATIENTS' FORUM

Work Plan 2025

'The Future of Healthcare'

Contents

Introduction

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

We are an independent non-profit, non-governmental umbrella organisation of patient organisations across Europe and across disease-areas. Our **78 members** include disease-specific patient 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 2025 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 Poland, Denmark, and Cyprus; Regulatory and executive EU agencies, including the EMA, HERA, and ECDC, and the HTA Coordination Group
- 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 carers. 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 2025 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 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

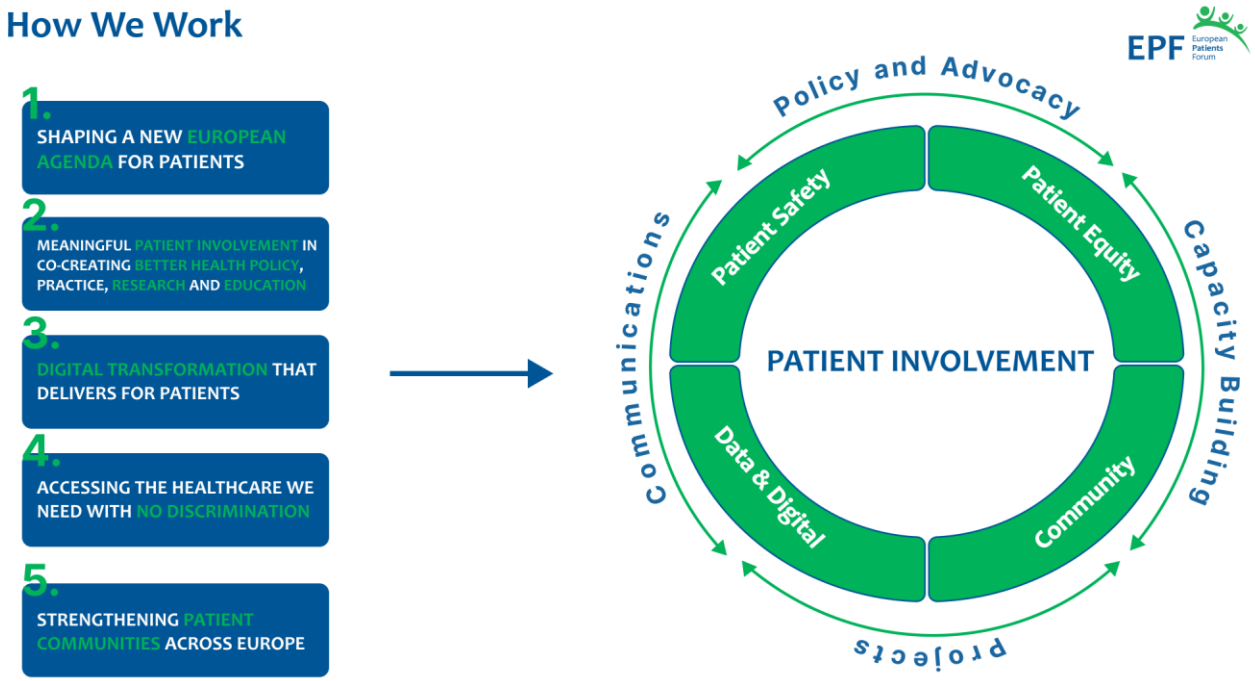
Our Work Plan for 2025 aims to continue progress towards the goals of our **Strategic Plan 2021-2026**, which are complemented by cross-cutting activities. 2025 will be a pivotal year in which our membership will be asked to take stock of the delivery of the ongoing strategic plan and to start developing a strategy for the coming years. On the legislative advocacy front, continued discussions on the review of the pharmaceutical legislation as well as other possible policy initiatives will maintain our advocacy efforts in the spotlight. Additionally, we will continue our advocacy to raise awareness and public support to measures to contain the threat of antimicrobial

resistance as well as to contribute to the development of measures and strategies to improve the availability of medical products to patients.

At the same time, EPF will invest more time and effort in capacity building and pan European coordination of patient organisations to increase the level of involvement in the implementation of EU legislation, including on HTA, EHDS, medical devices and cross-border healthcare. Our capacity building programme will deploy resources and programmes to support the sustainability, growth, and governance of patient organisations.

Our Youth Group will continue its project on promoting young leaders towards a strategy for intergenerational leadership in patient organisations, and our Congress in 2025 will aim to bringing forth our community's vision of the future of healthcare for patients, with patients.

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

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

EPF CONGRESS

Need	In the current political context there are discussions at European and national level about long-term strategy for various economic, social and political areas. EPF feels there is a lack of a patient-driven definition of what **good** health care should consist of in the medium and long term.
Deliverables	Congress in Q4 2025, agenda, programme, communications materials, congress website, Congress report
Objective/ Impact	The Congress will therefore aim to bring forward best practices on various aspects of healthcare drawn from our extensive network and expertise, in order to propose a cohesive and comprehensive vision for the healthcare patients want to have.
Timeframe	Q1-Q4 2025
Region	EU, member states
Targets	Members, experts, policymakers, industry, other healthcare system stakeholders

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. Yet, health systems' resilience depends on significant, coherent investment in the coming years.
Deliverables	Report on the use of EU funding instruments to strengthen local, regional or national healthcare based on own research and case studies reported from members.

Objective/ Impact	To advocate for continued investment in the EU4Health programme and more alignment with other EU funding, to support the modernisation of health systems towards better, patient-centric healthcare
Timeframe	Q2-Q4 2025, 2026

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 2022-2024 activities including both virtual and face to face meetings, PEOF is growing and expanding geographically its network. In June 2025 a new edition of PEOF face to face event is planned in Baveno, Italy. 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 has also built a strong and steadily growing partnership with **EATRIS** (the European Infrastructure for Translation Medicine) aiming at embedding the patient perspective in translational research. EPF is also a partner in the Patient Engagement Resource Centre (**PERC**), a joint initiative from EATRIS, and the European Aids Treatment Group (EATG), funded by the Horizon 2020 funded project, EATRIS-Plus, to help academic researchers get started with meaningfully engaging patients in their research.

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 Self-Management Europe Initiative, 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). 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 view of the adoption and implementation of the pharmaceutical legislation, strengthening meaningful patient involvement in regulatory processes is a priority.
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 4) Support the nomination of patient experts as needed
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 policymakers, EU regulators

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. WHO Europe is particularly active on issues related to access to medicines, digital health, and organisation of healthcare systems. As such, there is a need to strengthen our cooperation with WHO and strengthen our involvement in relevant activities.
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; 3) Continued involvement in relevant activities (e.g. Novel Medicines Platform, Strategic Partners' Initiative for Data and Digital Health)
Objective/ Impact	Strengthen 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) continued involvement in the PaRIS initiative, focusing on dissemination of the results of the survey expected end 2024 and next steps; 3) contribution to relevant initiatives including OCED's expert group on AI in health
Objective/ 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, policy-makers

COMMUNICATIONS AND MEMBERSHIP ENGAGEMENT

BRAND UPDATE

Need	Communications and public relations are crucial tools for raising awareness of EPF's work and strengthening its position at the European level. There is a need to update EPF communications to the latest trends and future directions to promote dissemination, members reach and engagement, enhance advocacy, and engage a younger audience, but also to align the brand with the new strategic plan.
Deliverables	Conduct a comprehensive audit of the current brand. Identify strengths, weaknesses, and areas for improvement.
Objective/ Impact	**Engage Audience:** Grow and engage the community with a focus on younger audiences through tailored social media content and traditional media management. **Ensure Brand Cohesion:** Align EPF's public image with its strategic goals, ensuring consistent and compelling messaging across all platforms.

Timeframe	2025
Region	Europe
Target audiences	Patient organisations/ EPF members and potential members, European-level policy makers, and other health stakeholders (medical professionals' organisations, academia/research community, scientific/professional bodies, and the healthcare industry)

ONGOING COMMUNITY GROWTH

Need	To grow EPF's online community, thereby increasing visibility and amplifying the voice of patients across Europe.
Deliverables	12 issues of the Patient Perspective Newsletter Minimum 10 podcast episodes Increase of 2% in number of followers across all social media platforms
Objective/ Impact	Increased visibility and influence of EPF and its activities. Stronger advocacy through a united and engaged online community. Better dissemination opportunities for member organisations and EPF project involvement
Timeframe	2025
Region	Europe; North America
Target audiences	Patient organisations, European-level policy makers, and other health stakeholders (medical professionals' organisations, academia/research community, scientific/professional bodies, and the healthcare industry)

Involvement IN PROJECTS

Need

Our project portfolio underpins EPF's advocacy and communication pillars. Patient engagement is a key focus of EPF's involvement in EU projects, encompassing activities such as participating in patient advisory boards and disseminating project outcomes. Our role includes creating accessible materials in lay language to present the projects' activities and deliverables, support the general projects' promotion, and highlight the relevance of topics such as HTA (Health Technology Assessments), digital health and health literacy.

Deliverables

- Minimum 20 social media posts about EU projects
- 20 project themed articles in the Patient Perspective & Weekly Insiders
- Minimum 3 podcast episodes highlighting projects
- Minimum 3 social media campaigns following projects' activities and deliverables

Objective/ Impact	• **Promote EPF's involvement in EU projects:** To highlight how EPF's contribution to the EU projects in which we are involved advances healthcare in Europe. • **Advance projects' visibility:** To use our channels to enhance EU projects' activities and visibility on social media. • **Highlight synergies between different projects:** To highlight thematic connections between different EU projects in which EPF is involved in.
Timeframe	2025
Region	Europe
Target audiences	Patient community, projects partners, EU institutions

STRATEGIC SUPPORT

Need	Effective communication with and about our members is essential to fully support EPF's overall communication strategy. Promoting our members is one of our main goals, as it strengthens our collective impact and reinforces our commitment to their needs.
Deliverables	• An increase of 3% in the number of openings per issue for the Weekly Insiders. • Minimum 2 podcast episodes with members in the spotlight. • Minimum 6 posts per year highlighting members' activities.
Objective/ Impact	• **Strengthen the communication between EPF and its members:** To increase the regular communication with our members. • **Increase our members' visibility:** To leverage EPF's channels to enhance our members' presence.
Timeframe	2025
Region	Europe, North America
Target audiences	Patient community

POSITIONING AND REPUTATION MANAGEMENT

Need	In the last two decades, EPF has advanced patient involvement in European health policies. To maintain this position, EPF's reputation is vital in ensuring strong and transparent relationships with all health stakeholders.

Deliverables	• Minimum 15 news items on the website • 2 press releases • Annual and Impact Reports, event reports (as needed) • A video showcasing EPF's activities in the previous year (pre-read before the Partners' Roundtable) • An annual report including data from Matomo on the website traffic
Objective/ Impact	• **Enhance positive media coverage:** To increase positive mentions in the press. • **Improve media relations:** To increase the press releases picked up by journalists.
Timeframe	2025
Region	Europe, North America
Target audiences	General audience, policymakers, health stakeholders, funders, scientific community

PATIENT SAFETY

POLICY & ADVOCACY

LESSONS LEARNED FROM COVID-19

Need	As part of the Periscope Project, a large-scale European project funded under Horizon 2020 that aimed to investigate the broad socio-economic and behavioural impacts of the COVID-19 pandemic, EPF conducted a survey to assess the impacts of the COVID pandemic on the welfare of patients with chronic diseases. 5 years after the pandemic, there is a need to draw some of the lessons learned from the crisis, including the need to address barriers to access to healthcare for chronic disease patients in times of crisis and the importance of civil society engagement in crisis management to improve trust.
Deliverables	1) Report on lessons learned from the COVID-19 pandemic from a patient perspective and 2) start co-designing advocacy activities and tools with EPF members to support leveraging the report at national level
Objective/ Impact	Raise awareness of the need for patient engagement in crisis management
Timeframe	2025
Region	Europe

Targets	EPF members, patient organisations, national and EU policy-makers/institutions

CROSS-CUTTING ACTIVITIES

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) Further development and dissemination of a communication toolkit including key messages on AMR from the patient perspective; 3) Continue populating the AMR Info Point on EPF website; 4) Organisation of capacity-building training for patient advocates to build knowledge and awareness of the issue; 5) Tailored support to members wanting to engage in AMR policy at national level; 6) continued engagement with key stakeholders to foster collaboration
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
Timeframe	Ongoing
Region	Europe
Targets	EPF members, EU and international policy makers

ADVOCACY AND CAPACITY BUILDING ACTIVITIES ON MEDICAL DEVICES AND COMBINATION PRODUCTS

Need	7 years after the adoption of the medical devices and in-vitro diagnostic medical devices regulations, the full implementation of the new framework is considerably delayed. Ensuring that the regulations fulfil their objective to improve the quality and safety of devices on the EU market remains a priority. In addition, education of patient organisations on the regulations and relevant provisions to improve patient information (such as EUDAMED) is key 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.

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) and combination products; 4) Initiation of work towards a concept note including activities to foster more systematic patient engagement in medical devices R&D
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 2025
Region	Europe
Targets	EPF members, patient organisations

PROJECTS

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, leading to inconsistencies and gaps in clinical evidence generation before market entry.
Deliverables	The project will deliver a harmonised EFS methodological framework, an ad hoc database for recording and monitoring EFS, improved clinical evidence quality, and increased patient involvement in medical device development.
Objective/Impact	The project aims to standardize 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 organizations, health technology developers, 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 2025)
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.

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, involving 12 countries across the EU.
Targets	Citizens, healthcare professionals, policymakers, and patient organisations, with a focus on enhancing engagement and capacity in personalised prevention practices.

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 starting in 2025 (Grant Agreement to be signed).
Region	Europe, involving organizations and research centres from multiple EU and associated countries.
Targets	Expand clinical and laboratory networks, support trial logistics and methodology, develop preparedness tools, engage social scientists, and empower European citizens in health matters.

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 2025)

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.

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 starting in 2024 (Grant Agreement to be signed).
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.

ENKORE

Need	The vision of ENKORE is to enable accelerated innovation through an ecoDesign framework (circular, safe & sustainable by design), inspired by the Safe & Sustainable by Design (SSbD) framework that supports the development of safe and environmentally responsible patient solutions, minimising the environmental impact, reducing the carbon footprint, and maximising the use and preservation of resources while promoting industries' prosperity. The framework considers a holistic and complete view of the product lifecycle (from materials and products' design to end of life). This approach aims to shape future producers, design and develop effective circular packaging and single-use devices while continuing to meet patient safety requirements.
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.
Objective/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 2029)
Region	Europe
Targets	Patients, healthcare professionals, hospitals, manufacturers, decision makers

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. This review must be seen in conjunction with other important EU regulatory developments, including the implementation of the Clinical Trials Regulation (CTR). Addressing the barriers to patients' access to clinical trials and continuously improving patient involvement in clinical research are priorities in this context.
Deliverables	1) Continued advocacy activities and engagement with policy-makers/relevant stakeholders on relevant legislation; 2) Continued dissemination of toolkit for EPF membership to engage with decision-makers at national level
Objective/ Impact	Support a patient-centred regulatory framework for medicines and improved patient access to 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) Development and dissemination of an updated version of the 2016 survey on access to healthcare; 3) Analysis of EC report on implementation of the CBHC Directive and start reflection on plans for targeted awareness activities (depending on timing of EC publication).
Objective/ Impact	1) Identify the barriers to healthcare access and propose policy solutions that reflect the needs of patients, carers, and communities. 2) Monitor implementation of the CBHC and remaining barriers to cross-border access to care for patients.
Timeframe	2025
Region	EU
Targets	EPF members, EU policymakers

CAPACITY BUILDING & MEMBERSHIP

CAPACITY BUILDING AND TOOLS TO SUPPORT PATIENT INVOLVEMENT IN THE EU'S HTA AGENDA

Need Foster meaningful involvement of patients in the HTA agenda

Deliverables:

- Landing page on the EPF website to ensure higher visibility of training materials and templates on HTA (EUCAPA, HTA4PAtients, HTAi)
- Translations of the EUCAPA materials in 5 languages
- Organise at least one online and one F2F capacity building sessions potentially including consensus building exercises and Patient Involvement Simulation workshops
- Leaflet about Patient Involvement in EUHTA

Objective/ Impact Raise awareness about the relevance of the HTA Regulation with EPF members and non EPF member patient organisations

Timeframe	Throughout 2025
Region	Europe
Targets	EPF members, Patient organisations

PROJECTS

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 September 2025)
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.

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.

EUROPEAN CAPACITY BUILDING FOR PATIENTS (EUCAPA)

Need	EUCAPA addresses the need for patient and patient organizations to gain essential knowledge and skills for effective involvement in the Health Technology Assessment (HTA) process, as mandated by the HTA Regulation (EU) 2021/2282.
Deliverables	The project provides training programs to equip patient experts with the necessary skills and knowledge for meaningful participation in HTAs, and raises public awareness about the HTA Regulation.
Objective/Impact	The objective is to build patient advocates' capacity for HTA participation, ensuring that patient perspectives are integrated from the start of HTA processes in 2025, thereby improving the relevance and quality of health technology assessments.
Timeframe	24 months (1 March 2023 – 28 February 2025)
Region	The project operates across Europe, involving patient organizations and stakeholders from multiple countries.
Targets	The project targets patient advocates, patient organizations, and HTA bodies.

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

POLICY & ADVOCACY

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. Following political agreement on the EHDS and AI legislation in 2024, member states and EU institutions are expected to focus on implementation moving forward. It will be crucial to ensure that patients are involved in these discussions.
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) Continued dissemination of the results of the AI survey and preparations for survey update (planned in 2026)
Objective/ Impact	Ensure patient-centered 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

CAPACITY BUILDING & MEMBERSHIP

DATA SAVES LIVES

Need	As the European Health Data Space (EHDS) is being implemented, patient organisations require support to understand the framework, its potential impacts and benefits for patients and healthcare systems, and patient organisations' role in its implementation. The same applies to regulation and roll-out of AI technologies in healthcare. Since 2019, the Data Saves Lives initiative has aimed to raise patient and public awareness and understanding of the importance of health data. Moving forward, the DSL tools and framework can be adapted to support digital health literacy in the context of the implementation of the EHDS.
Deliverables	1) Finalisation and dissemination of the toolkits for patients and patient organisations (DSL toolkit 4.0); 2) 3-5 presentations of DSL at national level and additional DSL awareness raising activities (participation in events etc.); 3) translations of the DSL toolkit in 5 European languages
Objective/ Impact	Establish a trusted environment for multi-stakeholder dialogue about responsible use of health data and good practices across Europe
Timeframe	2025
Region	EU/European region
Targets	EPF members and patient organisations; collaboration with national decision-makers as needed

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 – 31 October 2025)
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.

COMMUNITY

CROSS-CUTTING

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.
Deliverables	1) Finalisation of the Barometer on patient involvement and engagement in health policies at national level, including dissemination of survey and drafting of report – target launch in November 2024; 2) development of the concept and methodology 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 as needed

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 they will focus on digital health.
Deliverables	F2F training, Virtual courses and STYPA report
Objectives/ Impact	Training future patient leaders
Timeframe	February - November 2025
Region	Europe
Targets	Patient advocates aged 18-30

MASTER'S PROGRAMME ON INTERNATIONAL PATIENT ADVOCACY

Need	Offer the European Patient community the possibility to join an accredited master's degree on international patient advocacy, hosted by Cattolica University of Rome.
Deliverables	Master Curriculum
Objectives /Impact	Professionalise the leaders and future leaders of European patients' organisations
Timeframe	2nd edition February 2024-December 2024, 3rd edition February 2025-December 2025
Region	Europe

SURVEY FOR THE STRATEGIC PLAN ON CAPACITY BUILDING NEEDS

Need	To build and inform the creation of the next EPF Strategic Plan we need to survey EPF members to understand their needs regarding among other things capacity building
Deliverables	Survey report (internal use only)
Objective/ Impact	Increase the sense of community and membership engagement
Timeframe	June 2025

Region	Europe
Targets	EPF Members

YOUTH GROUP

- ### EPF Youth Group Spring and Fall meetings

Need	EPF YG members need to meet in person to discuss current project work and future strategic plans for the group.
Deliverables	Events agenda and minutes.
Objective/ Impact	Increased young patient involvement in the patient advocacy arena on both national and European level
Timeframe	Spring and Fall 2025
Region	Europe

- ### Communicating the EPF youth group projects

Need	Increase the dissemination reach of the youth group work and provide them opportunities to engage with diverse audience.
Deliverables	EPF YG invited to speak to 3 national and/or international relevant events in 2025
Objective/ Impact	Ensure great outreach and dissemination of EPF Youth group work
Timeframe	Throughout 2025
Region	Europe

- ### Self-learning course, free of charge, online course on youth involvement in patient organisations

Need	Provide tools and opportunities for patient organisations to learn how to involve and engage young people in their work.
Deliverables	Course curriculum
Objective/ Impact	Increase interest by Patient organisations in Europe in involving young patients into patients' organisations and creating a tailored youth strategy
Timeframe	End of 2025
Region	Europe

101 COURSE – A FREE OF CHARGE, ONLINE ADVOCACY COURSE FOR YOUNG PATIENTS

Need	Easily accessible and flexible training for young patients on the basics of advocacy
Deliverables	Report and 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.
Timeframe	Throughout 2025
Region	Europe as main target but the course is available worldwide

THEMATIC WEBINARS

Need	Information on important topics for our members
Deliverables	3 webinars on HTA, AMR and Medical Devices
Objective/ Impact	To meet the needs of our members, and to increase capacity and knowledge on various topics
Timeframe	Throughout 2025
Region	Europe
Targets	EPF Members

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 2025
Region	Europe
Targets	EPF Members and other patient advocates/organisations

EPF LEADERSHIP MEETING

Need	Ensure co-design of EPF Members in the layout of the EPF Strategic Plan 2027-2032
Deliverables	Agenda
Objective/ Impact	Increase the sense of community and membership engagement in the preparation of the EPF Strategic Plan
Timeframe	May 2025
Region	Europe
Targets	EPF Members

STRENGTHEN EPF MEMBERSHIP NETWORK

Need	Reach all legitimate patient organisations in Europe that want to and can join EPF
Deliverables	Internal report on potential members exchanges and mapping
Objective/ Impact	Reinforce EPF collective disease and geographical representativeness
Timeframe	Throughout 2025
Region	Europe
Targets	EPF Members

INCREASE INVOLVEMENT OF EPF MEMBER ORGANISATIONS IN EU FUNDED AND OTHER INTERNATIONAL PROJECTS

Need	Members want to be more involved in EU and internationally funded projects
Deliverables	Inform EPF members about EU funded and other international projects opportunities to support their diversification of funding and presence at EU level via email exchange on 1:1 meetings.
Objective/ Impact	Increase involvement of EPF member organisations in EU funded and other international projects

Timeframe	Throughout 2025
Region	Europe
Targets	EPF Members

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 78 in 2025. 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 2025:

1. **Increase contact with potential new members**: EPF will constantly update the map/list of potential members, based on the 2024 EPF membership.
2. **Wider Europe approach**: In 2025, 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 2025, EPF will continue to support national coalitions through training and exchange of best practices.

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. The AGM will take place along with EPF's Leadership Meeting on the strategic plan in May 2025.

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 23, 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.