

The European Patients' Forum

# Strategic Plan

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**2021-2026**

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## Foreword

Since its creation in 2003, the European Patients' Forum (EPF) has grown from 13 to 75 patient organisations across wider Europe, providing a strong and united patient voice in all matters relating to healthcare. We continue to lead collective patient advocacy in Europe, providing a cross-disease perspective from a wide European patient community to the policy-making process. With our members, we bring together people, knowledge and expertise working to drive profound and positive change for patients within the European healthcare landscape.

While the European healthcare environment has significantly changed since our inception, the COVID-19 crisis has exposed gaps and weaknesses in health systems that the patient community has long been aware of. It has also brought home once again the importance of strong European health policy collaboration to meet the needs of Europeans. It is crucial to turn our attention towards enhanced European policy and programmes to ensure our health systems emerge from the crisis stronger, more prepared and more person-centred.

As we approached the end of our last seven-year strategic plan (2014-2020), EPF initiated a debate with our members that led to the development of a new strategic plan. **The EPF Strategic Plan (2021-2026)** will guide our work for the next five years. It will be the basis for a renewed approach towards advocacy, research participation, fundraising, a more vibrant communication plan and an enhanced project engagement strategy. EPF will expand its project portfolio, while carefully refining criteria for involvement.

This Strategic Plan 2021-2026 reflects the latest changes in the European health and social policy environment and the new challenges and opportunities for EPF as an umbrella of patient organisations active across Europe. Overall, this plan describes who we are, what we stand for and what we want to achieve in the next five years. Amidst the ongoing COVID-19 pandemic, patients and the patient community are, more than ever before, key actors and contributors in creating equitable, person-centered, accessible, and sustainable healthcare systems in Europe.

We hope that this plan outlines our proactive role and potential impact. We also hope readers will find this document useful in understanding our organisation and cementing opportunities for working with us for the benefit of all patients and health systems across the EU.

## Executive Summary

The EPF Strategic Plan 2021-2026 consists of eight sections.

1. **Purpose and development of the Strategic Plan 2021-2026:** provides a description of the purpose of a five-year Strategic Plan for EPF, and the process through which this plan was developed and will evolve during the coming five years.

2. **Our origins and who we are now:** describes EPF’s core values and guiding principles and outlines EPF’s vision for the future and its mission. It focuses on our past and current work and details our current membership and wider Europe strategy.
3. **PEST Analysis:** describes the current trends and developments that will affect the patient community over the next five years
4. **Strategic Goals:** describes EPF’s strategic goals for the coming five years.
5. **Roadmap towards 2026:** This section of the strategic plan gives an overview of the key activities EPF will be engaged in, and their desired impact during the next 5 years, in the framework of each strategic goal.
6. **Key Indicators, Review and Realignment** describes the performance benchmarks that will be used to assess progress against strategic goals. It also outlines EPF’s approach, as a learning organisation, to process and outcome evaluation and how the Strategic Plan will be refined in accordance with on-going review of achievements and challenges, and the external environment.
7. **Acknowledgements:** lists the individuals who have played a key role in the development of the Strategic Plan.

## 1. Purpose and Development of the Strategic Plan 2021-2026

### PURPOSE OF THIS DOCUMENT

The purpose of the strategic plan is two-fold:

- It defines who we are, what we stand for and how we work
- It provides a clear blueprint on our strategic direction and aspirations over the next five years.

The EPF Strategic Plan (2021-2026) will underpin a refreshed fundraising, communication and project engagement strategy which will be developed during the coming months. EPF will expand its project portfolio, whilst carefully refining its criteria for involvement.

The EPF Strategic Plan also informs our broad human resources planning for the EPF secretariat. A work plan will be prepared on an annual basis in order to operationalise the strategy.

This document is not set in stone. It will be reviewed and realigned in accordance with internal and external developments during the next five years.

## STRATEGIC PLANNING PROCESS

As we approached the end of our original seven-year strategic plan (2014-2020) EPF initiated a debate that led to the development of a new strategic plan covering the 2021-2026 period.

The strategic planning process was participatory in nature, whereby the entire membership was involved at all stages and endorsed the final plan in October 2020.

An EPF member leadership meeting held in April 2019 represented the first step of this process. EPF members had the opportunity to review what was accomplished in recent years in relation to the strategic goals established back in 2014 and identify new challenges. The meeting launched a reflection process regarding possible future goals, strategic direction and issues around the organisation's development. The board and the secretariat then spearheaded the work.

The outcomes were consolidated in a blueprint that was revised several times based on the input provided by the following groups:

- EPF Board
- EPF Membership
- EPF Youth Group
- EPF Secretariat

Two consultations were conducted with the entire membership between May and August/September 2020. The final Strategic Plan will be endorsed at the Extraordinary Online General Meeting in October 2020.

## 2. Our Origins and Who We Are Now

- **We were established** in 2003 to represent the collective interests of patients in Europe with a focus on chronic and/or lifelong conditions, demonstrating the solidarity, commitment and unity of the patient movement across Europe. Fast forward to today, and this remains our *raison d'être*.
- **We convey** the patients' and their informal carers' unique experiences and expertise through representative member organisations bringing together national, regional and local patient organisations throughout Europe.
- **We adopt** a holistic and patient-centred approach by focusing primarily on the patient experience of healthcare while building alliances with other actors to ensure that all core issues in a patient's life are addressed effectively.
- **We drive and advance** the patient agenda by acting both as a catalyst for positive change in European health systems and a watchdog.
- **We are a credible and expert partner** for cooperation and dialogue with a broad range of stakeholders in the EU and internationally.

- **We promote** the building and sharing of patient-centred good practices, through leading or partnering in projects that are at the heart of our vision and mission.
- **We engage** actively in developing the capacity of patient organisations at European and national levels to channel their expertise and knowledge in order to be effective actors in the healthcare arena.
- **We represent** the collective expertise of a large and diverse membership that builds a bridge between the EU and Member States’ policies and programmes.
- **We welcome** European and national umbrella patient organisations that fulfil criteria relating to legitimacy, representation, democracy, accountability, and transparency as our members. Our focus has now extended beyond the European Union to the Wider Europe, embracing EU neighbourhood countries.
- **We are a rights-based, apolitical, representative advocacy organisation** with governance bodies composed of elected non-paid representatives of our member organisations, supported by a professional secretariat of paid staff. We have a dedicated ethics committee and youth committee.

## VISION AND MISSION

### Our Vision is:

A Europe where patient organisations are valued partners in creating equitable, person-centered, accessible, and sustainable healthcare systems, based on patients’ unique expertise.

### Our Mission is:

To advance the interests of patients and patients’ communities by strengthening their collective impact across Europe through effective advocacy, education, empowerment, and partnership.

## EPF VALUES

We have made the distinction between values we uphold as an organisation and the way we work and wider community values which describe how we collaborate with others, but also the kind of society we aspire to live in.

**Organisational values**

Accountable  
Agile  
Committed  
Consultative  
Ethical  
Evidence-based  
Impactful  
Inclusive  
Independent  
Representative  
Transparent  
Trustworthy



## EPF COMMUNITY VALUES

Community Values
Diversity
Needs Driven
Empowerment
Health equity
Non-discrimination
Person-centredness approach
Solidarity
Universal access



## THE VOICE OF PATIENTS IN EUROPE

EPF is the collective, united, and influential **voice of patients in Europe**. We directly represent the interests and views of our members, which are umbrella patient organisations across Europe and inter alia, the interests of all patients with chronic conditions in Europe, also through cooperation with online communities.

We *indirectly* represent the interests of all patients with acute conditions, bringing our unique experience and expertise as patients living with long-term conditions to help strengthen health systems and ensure patient safety and multi-stakeholder collaboration.



The work we do on vaccines, nutrition, responsible data-sharing is all conducted **through the lenses of patients with chronic diseases**, resulting in wider societal impact. Nonetheless, citizens are not our primary target audience.

As an umbrella of umbrellas, our mandate is not to support individual patients directly, but inter alia, through our advocacy work and our deep collaboration with our European disease specific and national members to improve health outcomes for patients. We do support individual patient leaders through training and education, with the expectation that they utilise this knowledge for the benefit of their specific patient community and contribute the insights of this community to advancing EPF's mission and goals.

Patients who are leading patient organisations are also politicized in other issues that will impact on patients' lives, e.g. climate change. EPF **focuses on patients with chronic conditions** but it is our responsibility, as our organisation matures, to ensure that the specific voice of patients is being heard in wider debates, that will later impact on their lives.

Over the years, EPF has established its role as **an initiator**. A good example of this is our role in co-leading the development of the European Patient Academy on Therapeutic Innovation (EUPATI) and nurturing it to become an independent entity, while still under the chairmanship of EPF. Another example is the co-founding of the Patient Access Partnership (PACT), together with our member organisation in Bulgaria (NPO) and supporting its evolution as a multi-stakeholder partnership. EPF also plays an established role as a **convener**. An example here is our mobilisation of key partners to set up Data Saves Lives, another multi-stakeholder initiative in the field of responsible data sharing. **As a change-agent**, we have been proactive in exploring wider public health and prevention issues, such as vaccines, nutrition or more recently COVID-19, **from the perspective of patients with chronic diseases**, and then developing activities to respond to the corresponding specific needs.

Collaboration underpins the work that we do, and partnership is our leitmotif. This has enabled us to attain a strong reputation for mobilising the necessary networks towards positive change. As we move forward with our new strategic plan, however, we will need to examine very carefully our methods of engagement, **to ensure we have maximum impact for our constituency**. We will take a leadership role in carefully selected initiatives, while others we will support actively, with other organisations at the helm - be it our members or external stakeholders. With wider public health actions, we will keep a close watch and engage sporadically, when there is a clear and distinct issue for patients with chronic diseases. Our roadmap outlines in detail how we plan to do this in practice, applying **very clear and transparent criteria for involvement** in advocacy, campaign work, projects and programmes, aligned closely with our values and our goals for 2021-2026.

## MEMBERSHIP ORGANISATIONS

EPF is an umbrella of umbrellas (3<sup>rd</sup> level organisation). Patient organisations are becoming increasingly visible actors in the healthcare arena, which is an important and positive development. Nevertheless, this also brings the challenge of ensuring and preserving their organisational soundness and impact over time under the 'spotlight'. For example traditional patient organisations may be at risk, when older generations of leaders struggle to engage with younger patient leaders to ensure

institutional succession, or when online patient communities mobilise more people more swiftly than traditional organisations, but sometimes at the expense of legitimacy, recognition, transparency and/or governance. Moreover, while patient organisations are growing in numbers, they are not necessarily growing in size, which may compromise their effectiveness and impact. A further challenge may arise when organisational leaders who exchange more frequently and more intensively with several stakeholders at the same time end up feeling and/or, creating a sense of constant urgency, which may lead to difficulty in planning ahead and in advancing on their own agendas while simultaneously responding or reacting to external pressures. Political situations and particularly rapid changes in governments may also put extra pressure on patient organisations. Furthermore, a growth in visibility often does not go hand-in-hand with growth in financial and human resources, leading to small teams, of mostly volunteers and limited financial resources, who face increased challenges and growing demands from external stakeholders. Ultimately, while leaders of patient organisations are often highly committed, passionate and charismatic, they may occasionally lack the practical business/advocacy knowledge necessary to navigate the sector successfully. Thus, reputational issues can be a challenge for member organisations as they become more visible in the healthcare arena. Our roadmap outlines how EPF intends to support its members and the patient community in addressing the above-mentioned challenges.

## WIDER EUROPE

During the EPF Annual General Meeting (AGM) in 2019, EPF members voted for a new Constitution enlarging EPF's geographical mandate to the Wider Europe. It was recognised during the 2018 AGM that all our European disease-specific member organisations have a wider geographic remit and therefore that our 'enlargement' would lead to more coherence in this regard.

This took on board the implications of Brexit, our relationship with organisations in the European Economic Area (EEA), the Western Balkans, and the EU Neighbourhood Policy's East Partnership countries. It also reflects the fruitful collaboration that the new approach will bring with important EPF allies such as the World Health Organisation (WHO) and the International Alliance of Patients' Organisations (IAPO). It was acknowledged that patient organisations in many of the countries concerned were not benefiting from European or International cooperation and information.

EPF is committed to providing a platform for them to reap the benefits of our work, resources, and network.

EPF will take a stepwise approach over the next few years, investing in:

- Carefully mapping the patient movement outside EU borders and understanding national/regional needs, in part through collaborative work with our existing membership.
- Organising a high-level strategic meeting with WHO Leadership to agree on an approach to Wider Europe that also engages their national country representatives in relevant countries.
- Sharing information and resources with existing patient groups in non-EU countries.

Based on the findings and funding opportunities EPF will prepare by the mid – term of this strategic plan a full analysis and suggested approach to working with patients’ organisations in the wider Europe.

### 3. PEST Analysis

An in-depth PEST (political, economic, social, and technological) analysis took place in spring 2020 (please see attached link below).. Please note that the PEST will be updated in late autumn to reflect the final outcome of discussions around the EU4Health Programme and Horizon Europe funding. At the time of writing, the Council - following a 4-day negotiation - agreed to a Multi-Annual Financial Framework and recovery package, which reduced the budget for a proposed stand-alone health programme from EUR 9.4 billion to EUR 1.7 billion. This will be discussed further in the European Parliament. We will publish a final version of the PEST analysis alongside the strategic plan as soon as we know the final outcome of these political discussions. A penultimate version of the PEST can be found here. [here](#).

### 4. Strategic Goals

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

EPF will support strong European health cooperation in order to derive and apply key lessons from major challenges, including the COVID-19 pandemic, for future health systems that deliver [a new deal] for patients. Patients are central to identifying and shaping solutions for quality-oriented, person-centred, equitable, resilient and sustainable healthcare.

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

EPF will promote meaningful, systematic and structured patient involvement in policymaking, research and in shaping healthcare practice that empower patients to be active partners in care. EPF will advance patient involvement through campaigns, advocacy, education, research, and projects.

#### 3. DIGITAL TRANSFORMATION THAT DELIVERS FOR PATIENTS

EPF will engage in the digital transformation of healthcare in Europe to support safe, high-quality, more participatory and person-centred healthcare that brings better outcomes for patients and value for society. Co-design and patient preferences must be at the heart of digital health solutions, including patients’ access to, ownership and control of their data, safe and ethical use and sharing of health data, and exploring the potential of real-world data for healthcare improvement.

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

EPF will advocate for equitable and affordable access to high-quality, state of the art, inclusive care for all and for the eradication of discrimination and stigma. EPF will advocate for the

attainment of universal health coverage in Europe, building on the EPF Roadmap and the UN Sustainable Development Goal on health.

## 5. STRENGTHENING PATIENT COMMUNITIES ACROSS EUROPE

EPF will, together with our members and partners, support European patient communities and health stakeholders with education, resources, and expertise to help them in co-designing people-centred health policies and resilient health systems.

EPF, together with member organisations, will help to define the future of patients' organisations, with the patient experience at the forefront, including the essential youth perspective.

EPF will be proactive in safeguarding the long-term sustainability of the organisation through collaborative work with its members and partners. EPF will actively support the development of its team's expertise, professional growth and well-being in line with our core values.

## 5. Roadmap Towards 2026

This section of the strategic plan describes in general terms the fields of action EPF will focus upon to work towards the strategic goals identified.

The roadmap gives an overview of the key activities EPF will be engaged in, and their desired impact during the next 5 years, in the framework of each strategic goal. It also gives a sense of the work on which EPF will lead, collaborate, support, or keep a watching brief. It is not exhaustive at this stage and will evolve over time as we review the strategic plan on an on-going basis.

The activities are generic in nature and will be defined more precisely in our Annual Work Plans.



## GOAL 1: SHAPING A NEW EUROPEAN AGENDA FOR PATIENTS

AREAS OF WORK	IMPACT	EPF SHOULD LEAD	COLLABORATION (NOT LEAD)	EPF SUPPORTS ALLIES	EPF NOT INVOLVED
<b>OVERVIEW</b>					
<ul style="list-style-type: none"> <li>• EU regulatory and legislative framework</li> <li>• Interactions with EU institutions, EMA, ECDC, FRA</li> <li>• Proactive political advocacy at European level and increase visibility of EPF Community key asks</li> <li>• EU programming on health &amp; research</li> <li>• Debates on health competence (“European Health Union”)</li> <li>• Collaboration with WHO Europe and contribute to International level initiatives</li> <li>• High-quality, person-centred, equitable, healthcare systems at national level</li> <li>• Ensuring legitimacy and representativeness of EPF</li> <li>• Ensuring communication on the role of EPF among members and partners.</li> <li>• Ensuring synergies and communications flow with members on policy/advocacy activities</li> </ul>	<ul style="list-style-type: none"> <li>• EPF is the most representative and inclusive patient voice at EU level</li> <li>• Proactive advocacy &amp; agenda setting power</li> <li>• Visible impact on EU legislation and regulations</li> <li>• Increased visibility among policymakers, members and allies.</li> <li>• Value of patient empowerment and involvement understood by all stakeholders (no tokenism)</li> <li>• Clarity on the division of roles and responsibilities among members and partners</li> <li>• Timely and best possible communication flow between members and EPF secretariat/Board</li> <li>• EPF members are more equipped to play their role as active player in the political arena and better equipped in contributing to EPF work.</li> </ul>	<ul style="list-style-type: none"> <li>• Patient perspective proactively into EU programming on health, all EU policy initiatives and legislation that matter / with potentially high impact on patients</li> <li>• Topics to be prioritised (e.g. patient safety, quality of care, vaccination, AMR)</li> <li>• Patient perspective on quality, person-centredness and how to evaluate and measure it</li> <li>• Ensuring legitimacy and representativeness of EPF</li> <li>• Ensuring communication on the role of EPF among members and partners.</li> <li>• Ensuring synergies and communications flow with EPF members on policy/advocacy initiatives</li> <li>• Increasing knowledge of members and the patient community on EU regulatory</li> </ul>	<ul style="list-style-type: none"> <li>• Broader discussion on competences, Conference on future of Europe.</li> <li>• Formal and informal discussion fora e.g. Commission expert groups, informal multi-stakeholder coalitions</li> <li>• Debates on health as an investment</li> <li>• European Health Parliament</li> <li>• Multi-stakeholder “coalitions” on health</li> <li>• OECD PaRIS</li> <li>• HSPA initiatives, value-based healthcare, International work, e.g. ISPOR, HTAi, PFMD</li> <li>• Other stakeholders like PFMD or EIT-health capacity building activities on the European agenda</li> </ul>	<ul style="list-style-type: none"> <li>• Disease-specific or national policy/ advocacy campaign by members</li> <li>• Integrity of policymaking, e.g. transparency, COIs...</li> <li>• General public health objectives, e.g. primary prevention</li> <li>• Members’ own capacity building activities on policy/advocacy</li> </ul>	<ul style="list-style-type: none"> <li>• Consumer policy</li> <li>• Environmental health</li> <li>• Food policy</li> <li>• Trade policy</li> <li>• Development policy</li> </ul>

<ul style="list-style-type: none"> <li>Increasing knowledge of members and the patient community on EU regulatory and legislative framework and patient advocacy.</li> <li>Including young patients' perspective into the European agenda for health (via EPF youth group)</li> </ul>	<ul style="list-style-type: none"> <li>EPF increase its representativeness including young patients' perspectives</li> </ul>	<p>and legislative framework and patient advocacy.</p>			
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## GOAL 2: MEANINGFUL PATIENT INVOLVEMENT IN CO-CREATING BETTER HEALTH POLICY, PRACTICE, RESEARCH AND EDUCATION

AREAS OF WORK	IMPACT	EPF SHOULD LEAD	COLLABORATION (NOT LEAD)	EPF SUPPORTS ALLIES	EPF NOT INVOLVED
<b>OVERVIEW</b>					
<ul style="list-style-type: none"> <li>Health policy at European level</li> <li>Co-designing health innovation (systems and organisations level)</li> <li>EU-funded research projects</li> <li>Research generally, e.g. clinical trials design</li> <li>Patient-led research</li> <li>Patient centred HTA</li> <li>Health professionals' education and practice change</li> <li>Evidence-base</li> <li>Promoting the principles of meaningful patient involvement in projects, policy and health systems via capacity building activities.</li> <li>Specific focus on patient literacy and patient empowerment in Wider Europe and targeted countries.</li> <li>Promoting the concept of Patients as teachers.</li> <li>Actively ensure the participation of EPF members in project consortia.</li> <li>Promote and play a role (i.e. in research project) in promoting lay language for scientific/ technical content.</li> </ul>	<ul style="list-style-type: none"> <li>Patient Involvement (PI) at EU/ European level supported by frameworks and structures in policy, research – e.g. in governance of EU4HEALTH</li> <li>EPF priority objectives are addressed by EU initiatives and funding programmes</li> <li>Conditions and guidelines in place regarding PI in EU-funded research to ensure patient meaningful involvement in the whole project cycle.</li> <li>Compensation in place for patient experts' time and expertise.</li> <li>Members and the patient community are equipped to create change at European, National and programme/project level</li> <li>A specific patient community has a deeper knowledge on a topic and feels more empowered.</li> <li>Patients are fully recognised as expert and equal partners.</li> </ul>	<ul style="list-style-type: none"> <li>EPF as facilitator and thought leader at European level</li> <li>Advancing PI through campaigns, advocacy, education, research and projects</li> <li>Provision of advocacy and evidence-based info resources to support meaningful PI</li> <li>Patient-led learning, awareness raising and best practice sharing events</li> </ul>	<ul style="list-style-type: none"> <li>Partners (e.g. EIT-health, PFMD and EATRIS) committed to PI</li> <li>Universities &amp; academic researchers – strengthening relations with key academic partners on PI</li> <li>HCP representative organisations and learned societies</li> <li>Industry – PI innovation life cycle</li> <li>PARADIGM follow-up</li> <li>HTA at EU /international level</li> <li>European Reference networks (if extended to chronic disease broadly)</li> </ul>	<ul style="list-style-type: none"> <li>EUPATI education of other stakeholders</li> <li>Individual patient leaders</li> <li>National PI initiatives (members and others)</li> </ul>	<ul style="list-style-type: none"> <li>Disease-specific PI initiatives</li> <li>EUPATI areas of work (patient involvement in R&amp;D)</li> <li>External single company initiatives</li> </ul>



### GOAL 3: DIGITAL TRANSFORMATION THAT DELIVERS FOR PATIENTS

AREAS OF WORK	IMPACT	EPF SHOULD LEAD	COLLABORATION (NOT LEAD)	EPF SUPPORTS ALLIES	EPF NOT INVOLVED
<b>OVERVIEW</b>					
<ul style="list-style-type: none"> <li>• EU policy and knowledge building activities regarding digital health – EU data strategy, RWD, Electronic Health Records, Artificial Intelligence, European Health Data Space, telemedicine/telehealth, mHealth</li> <li>• WHO European programme of work</li> <li>• Co-production of innovation in digital health – patient-centred digital health solutions</li> <li>• Actively ensure the participation of EPF members and patient representatives in project consortia on digital health.</li> <li>• Connecting members and knowledge -sharing on digital health</li> </ul>	<ul style="list-style-type: none"> <li>• European Health Data Space and relevant policies and initiatives are “truly” patient-centred</li> <li>• Digital policies are co-developed with patients</li> <li>• Patients have free and portable access to all their health data in one place; patients’ rights are respected</li> <li>• Tangible progress towards interoperable Electronic Health Records</li> <li>• EU &amp; national action on (digital) health literacy</li> <li>• Equal access to digital health solutions</li> <li>• Increase in PI in developing digital health solutions codes and guidelines in place at EU level</li> <li>• Members and the patient community are equipped to contribute to a fast-moving environment at European, National and programme/project level</li> </ul>	<p>Advocacy and policy work:</p> <ul style="list-style-type: none"> <li>• Robust patient perspective on key issues – ethics, privacy, protection, safe and ethical use and sharing of patient data, use of telemedicine, Artificial Intelligence</li> <li>• Patients’ ownership, control and access of their data.</li> <li>• Access issues relating to digitalisation including co-design, usability...</li> <li>• Organise and lead major events to advance the patient perspective on digital health (EPF Congress 2021)</li> <li>• Advocate for prioritisation of (digital) health literacy</li> <li>• Coordinating activities of (digital) health literacy</li> <li>• Capacity building/internal communication activity to increase patient knowledge and access to information on digital health.</li> <li>• Continued leadership of Data Saves Lives</li> </ul>	<p>Practical applications:</p> <ul style="list-style-type: none"> <li>• mHealth, telemedicine, RWE in healthcare improvement and therapeutic research</li> <li>• Technical projects/capacity building activities</li> </ul>	<ul style="list-style-type: none"> <li>• Members’ initiatives on digital health</li> <li>• Stakeholders initiatives with a focus on patients</li> </ul>	<ul style="list-style-type: none"> <li>• Cybersecurity</li> <li>• Block chain, interoperability &amp; other very technical issues</li> <li>• Disease specific digital health projects/solutions</li> </ul>

## GOAL 4: ACCESSING THE HEALTHCARE WE NEED WITH NO DISCRIMINATION

AREAS OF WORK	IMPACT	EPF SHOULD LEAD	COLLABORATION (NOT LEAD)	EPF SUPPORTS ALLIES	EPF NOT INVOLVED
<b>OVERVIEW</b>					
<ul style="list-style-type: none"> <li>• Access to healthcare (5As principles)</li> <li>• Access to medicines including pricing and reimbursement</li> <li>• HTA</li> <li>• Tackling health inequalities<sup>1</sup></li> <li>• UN SDG Framework, European Semester</li> <li>• Non-discrimination and stigma (e.g. via the youth group and other capacity building activities)</li> <li>• Social/ psychosocial aspects of illness</li> <li>• Patient safety and quality of care</li> <li>• WHO European programme of work</li> <li>• Vaccination for patients with chronic conditions</li> <li>• Identify projects/proposals focusing on access/non-discrimination and ensure patient participants via EPF members.</li> <li>• strong collaboration with members on communication about access barriers in Europe.</li> </ul>	<ul style="list-style-type: none"> <li>• In-depth solid evidence to capture patients' access barriers plus solutions to address them</li> <li>• EU puts in place better data and indicators to measure access (with PI)</li> <li>• Implementation of EPF's recommendations on access to innovative medicines</li> <li>• Members and the patient community are more knowledgeable on HTA and access related matters</li> <li>• through EPF, higher emphasis is placed on ensuring equal access/ non-discrimination across health projects.</li> </ul>	<ul style="list-style-type: none"> <li>• Present the patient perspective in relevant EU policies, e.g. pharma strategy, medicine shortages, health inequalities &amp; access to care and digital health)</li> <li>• Patient safety &amp; quality of care</li> <li>• Patient perspective on social aspects e.g. stigma, discrimination</li> <li>• Building patient evidence on access</li> <li>• Calling for patient-centred data and indicators on access</li> <li>• Liaison with WHO on access issues</li> <li>• Vaccination for patients with chronic conditions (awareness and access)</li> <li>• Leveraging the insights from our smaller members, including them in projects</li> </ul>	<ul style="list-style-type: none"> <li>• SDGs monitoring</li> <li>• Research on access / building the evidence-base</li> <li>• Biosimilar and generic medicines</li> <li>• Relationship with EMA</li> <li>• AMR advocacy</li> <li>• OECD PRIMs</li> <li>• PACT</li> <li>• SDGs monitoring</li> <li>• Research on access / building the evidence-base</li> </ul>	<ul style="list-style-type: none"> <li>• Member organisations and other health NGOs if common positioning found</li> <li>• Social care and public health as relevant</li> <li>• Issues relating to specific diseases (members), specific groups e.g. older people, women, men... (members, other NGOs where appropriate)</li> <li>• PACT</li> </ul>	<ul style="list-style-type: none"> <li>• Health economics</li> <li>• Specific products or treatments</li> <li>• Orphan Regulation / orphan medicines</li> <li>• Paediatric Regulation</li> <li>• Complementary medicine (CAM)</li> </ul>

<sup>1</sup> Tackling health inequalities example: Gathering evidence on barriers plus solutions on addressing them

## GOAL 5: STRENGTHENING THE PATIENT COMMUNITY ACROSS EUROPE

AREAS OF WORK	IMPACT	EPF SHOULD LEAD	COLLABORATION (NOT LEAD)	EPF SUPPORTS ALLIES	EPF NOT INVOLVED
<b>OVERVIEW</b>					
<ul style="list-style-type: none"> <li>• Sustainability of patient organisations (e.g. fundraising, legitimacy, representativeness, transparency).</li> <li>• EPF alone or in collaboration with third parties to support the creation of learning opportunities for patients that will help them define the future of patient organisations.</li> <li>• Support creation / strengthening of patient organisations at national and European level (including Wider Europe).</li> <li>• Strengthen and support new generations of European patient advocates</li> <li>• Increase EPF role in ensuring properly resourced meaningful patient involvement in projects as a way of strengthening and resourcing the European patient movement.</li> </ul>	<ul style="list-style-type: none"> <li>• A stronger, more visible patient community – especially in “wider Europe”</li> <li>• Perceptions of patient organisations shift -&gt; positive, valued, trusted.</li> <li>• Sustainable funding framework in place at EU level</li> <li>• Large network of patient advocates EPF can rely on to multiply our work</li> <li>• An engaged membership that actively contributes to EPF’s work (legitimacy, representativeness)</li> <li>• A large, active Youth Group well connected to other youth groups and the young patient community.</li> </ul>	<ul style="list-style-type: none"> <li>• Young patient advocacy</li> <li>• Connecting patient organisations horizontally</li> <li>• Provide learning opportunities for future and patient advocates and for patient advocates that would like to improve certain skills</li> <li>• Advocating for added value and sustainable funding of POs at EU level</li> <li>• Organisation of major learning and awareness raising event on key EPF and patient community topic to advance on the future the patient movement.</li> </ul>	<ul style="list-style-type: none"> <li>• Support to member organisations in their advocacy efforts</li> <li>• Collaboration with Academia and other key stakeholders (EUPATI) to design and deliver core capacity building activities to members/patient community</li> </ul>	<ul style="list-style-type: none"> <li>• Patient education in therapeutic R&amp;D (aimed at individual patients) – EUPATI</li> <li>• Support to members’ events and activities as needed &amp; relevant</li> </ul>	<ul style="list-style-type: none"> <li>• Global capacity-building or networking initiatives could be supported via collaboration with or support to international PO allies but only where clear added value</li> <li>• Company-led capacity-building activities (or by other private entities)</li> </ul>

## 6. Key Indicators, Review and Realignment

EPF strives for excellence and is a learning organisation committed to evaluating and improving its way of working on an on-going basis. EPF will undertake monitoring and evaluation of the Strategic Plan in line with agreed measurable performance indicators and targets for each core strategic goal. Evaluation of the 2021-2026 Strategic Plan will be an integral part of the EPF Annual Work Plans during this period.

The strategic plan's overall evaluation will draw on indicators against specific annual operational objectives. Key processes and milestones stretching over several years (e.g. advocacy work, EU projects, EPF capacity building programme, communication strategy etc.) will be followed through from inception to final delivery and beyond to measure their short, medium, and long term impact and inform our work and direction accordingly.

Monitoring and evaluation will be carried out internally by the EPF Secretariat using standard evaluation criteria relating to the contribution of the actions to EPF's overarching goals as outlined in our Strategic Plan; the effectiveness of specific actions; efficiency in the use of resources; social/organisational sustainability; and, insofar as possible, the impact of the specific action. The evaluation is also expected to identify successful strategies for extension, expansion, replication, and/or adaptation of current activities, to identify new strategies, and to demonstrate EPF's accountability to its members, patient organisations at large, and donors.

The EPF Board will be involved regularly in reviewing and appraising evaluation findings to ensure that these are acted upon in a prompt manner.

The strategic plan evaluation will also involve the EPF constituency at large, i.e. EPF members as well as lay patients and informal carers, external stakeholders, i.e. health professional associations, industry players, academia as well as media and policy makers.

A mid-term review of progress made against strategic goals will be undertaken in 2023.

The following KPIs will be used to assess progress against strategic goals.

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

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*EPF will support strong European health cooperation in order to derive and apply key lessons from major challenges, including the COVID-19 pandemic, for future health systems that deliver [a new deal] for patients. Patients are central to identifying and shaping solutions for quality-oriented, person-centred, equitable, resilient and sustainable healthcare.*

Key performance indicators:

- EPF is effective in influencing the design and, where possible, the implementation, of EU-level health related programmes
- EPF is effective in understanding and gathering the experiences and positions of its members for the benefit of evidence-based policy making
- EPF and its members are successfully engaging as partners in project consortia on projects that are (co-) designed to reflect our priorities
- EPF is successful in driving stronger involvement of patients in health professionals' education
- EPF is successful in engaging in collaborations with relevant stakeholders (e.g. health professionals, healthcare quality bodies, patient safety societies) on driving implementation of high-quality, person-centred care practices
- EPF is effective in profiling the impact of COVID-19 on patients with chronic conditions and patient organisations and the importance of engaging with them to understand their experience in the context of the crisis, for better policy-making, preparedness and resilience in the future.

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

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*EPF will promote meaningful, systematic and structured patient involvement in policymaking, research and in shaping healthcare practice that empower patients to be active partners in care. EPF will advance patient involvement through campaigns, advocacy, education, research and projects.*

Key performance indicators:

- EPF is successful in raising greater awareness of best practice patient involvement in policymaking
- EPF is successful in gathering evidence of increased uptake of best practices
- EPF is successful in advancing meaningful involvement of patient organisations in EU projects
- EPF is effective in promoting healthcare practices that empower patients to be active partners in care;

- EPF is successful in promoting the implementation of the PARADIGM project outputs on meaningful patient engagement in innovation;
- EPF is successful in driving appropriate compensation measures for patient experts engaged in policy work.

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### 3. DIGITAL TRANSFORMATION THAT DELIVERS FOR PATIENTS

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*EPF will engage in the digital transformation of healthcare in Europe to support safe, high-quality, more participatory and person-centred healthcare that brings better outcomes for patients and value for society. Co-design and patient preferences must be at the heart of digital health solutions, including patients' access to, ownership and control of their data, safe and ethical use and sharing of health data, and exploring the potential of real-world data for healthcare improvement.*

Key performance indicators:

- EPF is successful in influencing digital health policies so they have at their heart patient preferences;
- EPF is successful in promoting patient access to, ownership and control of their data as a policy priority at European level, and responsible data sharing;
- EPF (and its members) are successful in promoting and sharing person-centred solutions in digital health through project-related activities;
- EPF is successful in promoting the importance of patients' empowerment, co-design, digital health literacy and skills as a key element of the digital transformation of health.

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

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*EPF will advocate for equitable and affordable access to high-quality, state of the art, inclusive care for all and for the eradication of discrimination and stigma. EPF will advocate for the attainment of universal health coverage in Europe, building on the EPF Roadmap and the UN Sustainable Development Goal on health.*

Key performance indicators:

- EPF is successful in gathering and presenting patient evidence on access to inform policy making and result-orientated policy solutions
- EPF is effective in promoting an improved EU monitoring system to measure access barriers experienced by patients, collection of comparable data and its public reporting, for result-oriented policy solutions
- EPF is successful in influencing relevant EU policies and strategies

- EPF is effective in promoting universal health coverage for all by 2030, while raising awareness of health inequalities, healthcare exclusion, gaps in the accessibility of health care and a lack of data
- EPF is effective in promoting inclusive, non-discriminatory healthcare practices.

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## 5. STRENGTHENING PATIENT COMMUNITIES ACROSS EUROPE

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*EPF will, together with our members and partners, support European patient communities and health stakeholders with education, resources, and expertise to help them in co-designing people-centred health policies and resilient health systems.*

*EPF will, together with member organisations, help to define the future of patient organisations, with the patient experience at the forefront, including the essential young patients' perspective. EPF will be pro-active in safeguarding the long-term sustainability of the organisation through collaborative work with its members and partners. EPF will actively support the development of its team expertise, professional growth and well-being in line with our core values.*

Key performance indicators:

- EPF is successful in supporting the future generations of patient advocates
- EPF is successful in providing innovative and tailored learning opportunities to strengthen patient organisations in Europe;
- EPF is successful in contributing to a perception of patient organisations as equal, transparent, representative and reliable partners in healthcare throughout Europe;
- EPF is effective in advocating for sustainable public funding for patient organisations both at European and national levels

## 7. Acknowledgements

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