EUROPEAN PATIENTS' FORUM

WORK PLAN 2021

Driving Better Health for Patients in Europe

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A STRONG PATIENTS' VOICE TO DRIVE BETTER HEALTH IN EUROPE

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1. Executive Summary

The EPF work plan for 2021 reflects a swiftly changing, uncertain environment due to the COVID-19 crisis. The first year of the new European Parliament and Commission was profoundly disrupted by the impact of the pandemic, which is ongoing and will continue to influence the political and economic environment. Already it has had a transformative effect on how health is prioritised in country politics, and how the EU's health policy mandate is prioritised at the highest political level.

This work plan is guided by **EPF's new Strategic Plan for 2021–2026**, which was shaped together with our membership to reflect changes in the European health and social policy environment, new challenges, and new opportunities for EPF as an umbrella of patient organisations across the wider European region. Amidst the ongoing pandemic, patient organisations must, more than ever before, be included as partners in efforts to create high-quality, equitable, person-centred, accessible, and sustainable healthcare systems of the future.

In 2021 we will see the implementation of the new EU health and research framework programmes. The **EU4Health programme** has been allocated an unprecedented budget, despite cuts in the Council. We will monitor and contribute to the shaping of the priorities under both EU4Health and Horizon Europe programmes to ensure they reflect patients' needs and goals. In parallel, debates about the EU's health competences and the "European Health Union" will continue and EPF will add strong and united voice to these debates. In parallel and in synergy, we will engage with the WHO Regional Office for Europe as an accredited non-state actor.

The **COVID-19** pandemic will continue to have a far-reaching impact, even once the immediate situation is brought under control. The pandemic exposed 'cracks' in national health systems, revealing under-funding, under-equipment and lack of preparedness and highlighted health and wider social inequalities. EPF engaged proactively with our members, policymakers and stakeholders during 2020 as the representative voice of patients, and we will continue to do so in 2021 to ensure that learnings are taken on board and patients are included in the shaping of policy responses, and also in the wider context of health systems strengthening.

The European Commission's priority actions in 2021 will reflect the immediate needs of the pandemic response, but we need to also look collectively at where we go from here. We need to support European health systems as they adapt to the challenges of an ageing population and rising chronic diseases.

A significant proportion of illness and premature deaths could be prevented by better access to healthcare, including prevention and treatment. **Access to healthcare** remains highly inequal across the European, and gaps remain in universal health coverage. EPF will continue to actively engage our membership to bring our experiences and perspectives to the fore, building on years of work in this area.

Other priorities in 2021 will include the Commission's proposed **pharmaceutical strategy**, launched in December 2020, including its strategy on **medicine shortages**, and the shaping of the **European Health**

Data Space. We will contribute to the latter through our body of work in the area of Digital Health and Health Data and continue our involvement through a diverse portfolio of EU-funded projects and initiatives such as **Data Saves Lives**. Aware of the relevance of this area of work and building on the success of the 2019 EPF Congress, EPF will hold a **2021 Congress** focusing on digital transformation of healthcare.

Vaccination and **AMR** will continue to be high on the agenda. EPF will continue to focus particularly on vaccination, where the specific needs and vulnerabilities of patients with chronic conditions must be considered in the context of vaccines for COVID-19. Patient safety will be an ongoing priority, and we will carefully follow developments regarding the application the **EU Regulations on medical devices and clinical trials**. Our policy work is underpinned by our engagement in various **EU-funded projects**.

EPF will keep supporting its community via its **capacity building** opportunities targeting both young people (the Summer Training for Young Patients Advocates) and other patient leaders (the capacity building module on Fundraising and Engagement).

2. Introduction

The European Patients' Forum was set up in 2003 to represent the collective interests of patients in the EU, with its main focus on chronic and/or lifelong conditions, demonstrating the solidarity, commitment and unity of the patients' movement across the EU.

The Strategic Plan 2021-2026 was formally adopted at its online Extraordinary General Meeting (EGM) in October 2020 with the overall objective of defining strategic priorities to enable EPF to continue to respond effectively to the needs of Europe's patients and to ensure sustainable growth.

In 2021, EPF's work plan takes forward this strategy whilst building on the outcomes of the annual work plans from previous years. It factors in the external political environment to reflect healthcare developments, including the launch of the next EU programming period, EU4Health 2021-2027.

Our new vision and mission statements and strategic goals are central to this, reflecting also our organisational and community values.

EPF's Vision:

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

EPF'S MISSION:

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

Strategic Goals:

The 2021 annual work plan's goals identified in the Strategic Plan 2021-2026 are:

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 policy-making, 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 will, together with member organisations, help to define the future of patients' 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.

EPF's Organisational Values:

EPF's Community Values:

The work plan has been crafted with consideration of the expected impact of the COVID-19 pandemic in 2021 and beyond. In this regard, EPF's plans will be re-aligned with significant external developments throughout the year.

3. Target Groups & Partners

The primary target groups of EPF's activities in 2021 will be:

- Our member patient organisations;
- The wider patient community and the general public;
- European-level policy-makers (Members of the European Parliament, officials of the European Commission key DGs and Commissioners);
- Member States' representatives in Brussels as well as nationally, also in the context of the EU Presidencies of Germany, Portugal, and Slovenia;

- The European Medicines Agency (EMA), Fundamental Rights Agency (FRA) and European Centre for Disease Control (ECDC);
- International organisations: The OECD, WHO European Region;
- Health stakeholders, including public health NGOs, medical professionals' organisations, academia/research community, scientific/professional bodies, and the healthcare industry;
- The European Patient Academy on Therapeutic Innovation (EUPATI)
- Health media/press at EU and national levels.

4. Added Value and Impact

Patient involvement in healthcare policy adds value from a moral and principle perspective because the decisions directly impact patients' lives and well-being; but equally from a hands-on perspective, because policy and practice should focus on what matters to patients. A meaningful definition of "what matters" in healthcare is only possible with the involvement of patients.

EPF is the only European-level, non-disease specific umbrella patient organisation, and it provides a vital cross-disease perspective from a wide patient community into EU policymaking on issues that have a direct impact on patients' lives in a national and regional context. We have a unique and privileged position linking patient communities across the EU with EU-level developments. We focus on empowering patient organisations to become effective, credible civil society actors and on strengthening their capacity to partner in national health policy and practice, supporting participatory and inclusive health systems. Through our Youth Group we nurture a future generation of patient leaders, covering a wide range of chronic conditions and nationalities.

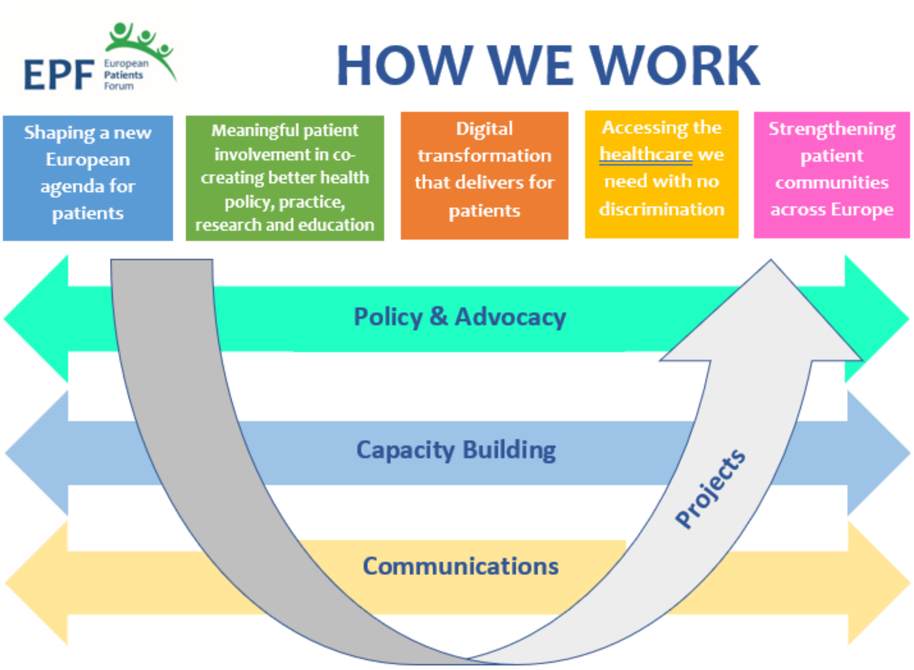
In health system performance and quality of care, measuring the right things will require a critical exploration of "what matters to patients," and how/whether that which matters most can be measured. Accurate evaluation of the added therapeutic value of new medicines, similarly, requires a meaningful patient input.

Our evidence-based advocacy helps strengthen patient involvement and recognition of patients as partners in health policy and practice, thus supporting participatory and inclusive health systems. Our work on patients' rights and responsibilities goes beyond disease- or country-specific initiatives and has the credibility of being supported by a wide cross-EU patient movement. This will support meaningful implementation of good practices in patient empowerment and involvement by practitioners as well as policymakers.

EPF also brings significant added value as a strong advocate for the value of Europe in health, and health in Europe, in our engagement with high-level strategic issues such as an EU health Union and trusted partnerships with diverse actors. We link with both EU and international bodies and can point out relevant synergies or gaps. We participate in collaborative initiatives and policy debates at European and international level, helping to define health priorities in which the patient community can contribute and reap benefit. EPF is also committed to the highest level of integrity and ethics in its interactions with all partners.

5. How We Work

EPF's work comprises three mutually reinforcing "areas": policy and advocacy; capacity-building and communications, while our extensive project work represent a platform underpinning these three areas. The illustration below shows how these methods apply to all our objectives in a cross-cutting manner. Thus, for example, our capacity-building efforts strengthen the advocacy expertise of our members and their ability to feed into our policy activities; the data collected, and good practices identified in European projects will reinforce the evidence-base of our policy work; and our policy and advocacy expertise brings added value to projects.



6. EPF's 2021 work plan

Our work plan for 2021 will focus on the five strategic goals of our new Strategic Plan 2021-2026, which are complemented by cross-cutting activities. In this section we describe the activities under each goal, although it should be kept in mind that our activities are highly complementary and often address more than one strategic goal. In addition, our 2021 work plan includes our second patient-led Congress. EPF has selected digital transformation of healthcare as the broad theme of this year's Congress, drawing on the exploration of this area in the 2019 Congress, our engagement in EU policies focusing on digital health, and the experience and key learnings of the COVID-19 pandemic.

STRATEGIC GOAL 1:

SHAPING A NEW EUROPEAN AGENDA FOR PATIENTS

- **EUROPEAN COMMISSION** EPF is a trusted interlocutor of the European Commission, working particularly closely with the directorate-general responsible for health, but also those on employment, research and innovation, and digital technology. We will work towards consolidating further our relationship with the Commission, both at high political and at operational levels.

- **EUROPEAN PARLIAMENT** EPF already has a strong profile in the European Parliament, which we continue to strengthen. In line with EPF's internal engagement strategy with the new Parliament, we will continue to raise awareness of the importance and relevance of patient involvement in the policy making process and engage in legislative activities as appropriate. As a co-founder of the Patient Access Partnership (PACT) which serves as a secretariat to the MEP interest group on Equitable Access to Healthcare, EPF will support and provide guidance to the interest group and engage in its activities.

- **EUROPEAN UNION AGENCIES** EPF has a long-standing relationship and a very strong presence at the **European Medicines Agency**. We will engage in several initiatives with EMA as detailed below. We will also work with the **European Centre for Disease Control and Prevention (ECDC)** on topics such as antibiotic resistance and vaccination and closely follow the mandate changes for ECDC, and act as needed. As a member of the Fundamental Rights Platform, EPF will continue to engage with the **EU Agency for Fundamental Rights (FRA**), through the lens of patients' rights and non-discrimination in healthcare.

- **WHO REGIONAL OFFICE FOR EUROPE** As an accredited non-state actor, EPF will contribute to WHO-led consultations and participate in events as and when appropriate.

- **EUROPEAN HEALTH NETWORKS** EPF is involved in several formal and informal bodies and networks, including the EU Health Policy Platform, EU4HEALTH Civil Society Alliance, Civil Society Europe, All Policies for a Healthy Europe, the EU Health Coalition, the European Health Parliament, the Alliance for Value-Based Healthcare, the Patient Access Partnership (PACT), the EFPIA Patient Think Tank, Dialogues with Medtech and Medicines for Europe, SDG Watch Europe and The Social Platform. 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.

- **EUROPEAN HEALTH UNION** The current health crisis has exposed the need to strengthen Europe's crisis preparedness and management of cross-border health threats. While a significant part of our focus has been on advocacy relating to the impact of the COVID-19 pandemic, we have started to also draw the first lessons from the crisis. EPF will contribute these learnings to the **European Health Union** debate. EPF will also contribute to the **Conference on the Future of Europe**, which will play a central role in determining the future of the envisioned European Health Union.

- EPF will engage with relevant aspects of the Commission's proposals to reinforce the EU's framework for detecting and responding to serious cross-border health threats, including the possible **new European agency for biomedical advanced research and development** with an impact assessment and legislative proposal expected towards the end of 2021, and the changing mandates of the EMA and ECDC. We will closely follow these plans, and act as needed in consultation with our members.

- **EUROPEAN HEALTH DATA SPACE (EHDS)** EPF will engage in the European Commission's plans for a European Health Data Space to harness data for better healthcare, better research, and better policy making to the benefit of patients. Meaningful patient engagement in the governance of the EHDS will be one priority topic for 2021.

- **EUROPE'S NEW PHARMACEUTICAL STRATEGY** EPF will engage actively in the shaping of the Commission's Pharmaceutical Strategy to ensure that the strategy will address access, affordability and availability of high-quality medicines and include patients as a critical stakeholder group. We will focus on specific elements, such as shortages, regulatory aspects, innovation and value, and act as needed in consultation with our members.

- **EU4HEALTH PROGRAMME** EPF will closely monitor the implementation of the EU4Health Programme and advocate for the inclusion of patients' priorities in the annual work plans implementing EU4Health.

- **EVALUATION OF THE DIRECTIVE ON THE APPLICATION ON PATIENT RIGHTS IN CROSS-BORDER HEALTHCARE** EPF will engage closely with the evaluation of the cross-border healthcare directive. We will consult our membership to guide our response, contributing to the Commission's evaluation.

- **EUROPEAN MEDICINES AGENCY** EPF will continue to actively work with the EMA in a critical period where the Agency starts to implement its new strategy on regulatory science to 2025 under the leadership of a new Executive Director. We will engage through our membership and co-chair of the **Patient and Consumer Working Party** and the **Management Board**, and our role as patient observer on the EMA's **COVID-19 Task Force (ETF)**, aiming to drive forward the principle of embedding patient engagement across regulatory assessment and linked processes, such as Health Technology Assessment. EPF will contribute to the stakeholder consultation on the EMA fee system foreseen in Q1 2021 and closely follow the mandate changes for EMA, acting as needed. We will also contribute to activities of other EMA working groups and task forces on an ad hoc basis and aim to further strengthen the flow of information from and about the EMA to patients, ensuring a good understanding of its role and encouraging wider patient involvement in its activities.

- **MEDICAL DEVICES** EPF will carefully monitor the effective and timely implementation of the EU Regulations on medical devices and *in vitro* diagnostics, informing our members of progress made. EPF will also contribute to implementation actions as and when appropriate as a stakeholder member of two sub-groups of the Medical Devices Coordination Group (MDCG) – clinical investigation and evaluation, and post-market surveillance and vigilance. Ahead of the May 2021 application date, EPF intends to co-organise with the Commission a **webinar on the Medical Devices Regulation** for patients' organisations, which will explain changes that will affect patients. Our policy work will be enriched by our involvement and contribution to a project on developing methodological approaches for improved clinical investigation and evaluation of high-risk medical devices (**CORE-MD – Coordinating Research and Evidence for Medical Devices**). As CORE-MD partner, EPF will contribute to develop a core outcome set of Patient Reported Outcomes Measures through a consensus building process, for assessing which PROMs should be included for patients with orthopaedic, trauma or cardiovascular medical devices, for both sexes and different age groups.

- **HEALTH TECHNOLOGY ASSESSMENT (HTA)** EPF will continue to engage with the legislative proposal for an EU regulation on HTA following developments in Q4 2020 under the German EU Presidency, and engage as appropriate with all stakeholders and policymakers, including the successive 2021 presidencies of Portugal and Slovenia. Independently of the EU proposals, we will continue to actively participate in the EUnetHTA stakeholder forum and the HTA Network Stakeholder Pool. To strengthen our advocacy for meaningful patient involvement in HTA and improved transparency, EPF will conduct a new consultation following on the one run in 2010/2011, to reassess the level of patient engagement in HTA across European countries. EPF will also collaborate with the HTAi interest group on patient and citizen involvement and contribute to the HTAi-ISPOR Task Force on Deliberative Processes, whose aim is to develop a consensus definition for a deliberative process from an HTA perspective and internationally recognized fit-for-purpose recommendations on the use of deliberative processes in HTA.

  CLINICAL TRIALS EPF will monitor the application of the EU Clinical Trials Regulation now planned for 2021 and engage in information and communication activities to ensure our membership is aware of the implications of the new Regulation for patients. This will inform our future areas of engagement in monitoring the implementation of the Regulation beyond 2021 and goes hand in hand with our commitment to increase meaningful patient involvement in clinical research.

STRATEGIC GOAL 2:

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

- **PATIENT INVOLVEMENT IN RESEARCH** EPF will engage with EU institutions on fostering meaningful patient organisation participation in EU-funded research projects under different funding streams and will engage with academic and other stakeholders with the aim of increasing patient involvement.

  Next year, EPF will once again contribute to the **COMPAR-EU project** that aims to identify, compare, and rank the most effective and cost-effective self-management interventions in type 2 diabetes, COPD, obesity, and heart failure. In 2021, we will continue to champion meaningful patient involvement through the project, and we will contribute to develop a patient-friendly **interactive online platform**. Https://self-management.eu/.

  Another project under the topic area of patient involvement in research is **PREFER**, which has been running patient preference studies in academic and industry settings. Patient preference studies have a potential to inform regulators' and HTA bodies' decision-making processes. In 2021 EPF will continue to contribute to the drafting of the final recommendations. https://www.imi-prefer.eu/.

  EPF will also continue to collaborate in **EATRIS Plus**, a H2020 project that aims to support the long-term sustainability of EATRIS as Europe's key research infrastructure for personalised medicine. Patient empowerment and engagement are key to strengthen EATRIS' leadership role in personalised medicine research. After setting up a Patient Advisory Committee (PAC), with the support of our member organisation EATG, EPF will contribute through the coordination PAC patient experts and multi-stakeholder outreach activities to promote and facilitate uptake of patient engagement practices among EATRIS Plus partners. https://eatris.eu/projects/eatris-plus/

  EU-PEARL (EU Patient-Centric Clinical Trial Platforms) aims to make clinical trials more efficient and patient friendly, building on the concept of platform trials. EPF manages overall patient engagement activities and will design a framework for patient engagement applicable to future platform trials, and a patient engagement platform. https://eu-pearl.eu/

  In 2021, in the H2020 project **PERMIT** (Personalised Medicines Trials), which is dedicated to improving personalised medicines research by establishing commonly agreed recommendations, EPF will join a series of collaborative workshops and trainings with all relevant stakeholders and will produce lay summary materials of key project outcomes to ensure outreach to a wider public. https://permit-eu.org/

In the **ImmUniverse** project EPF will play a supporting role to our member organisations EFCCA and EFA. The project focuses on immune-mediated diseases and aims to address current unmet needs related to the effectiveness of existing therapies. EPF will contribute to disseminate the project results. https://www.immuniverse.eu/

- **PATIENT INVOLVEMENT IN MEDICAL EDUCATION** Building on a 2019 Congress plenary session on professional education and a collaboration with European medical societies on Continuing Medical Education (CME) and Continuing Professional Development (CPD), EPF will disseminate the findings of its 2020 survey on members' experiences of their involvement in CME and CPD activities, and their views on independent medical education. We aim to further develop this initiative through a dedicated meeting in 2021 to identify follow-up actions, within the broader objective of mainstreaming patient involvement in medical education. As chair of the EUPATI board, EPF will continue to support EUPATI as an independent foundation driving patient education in medicines R&D.

- **PATIENT INVOLVEMENT IN NUTRITION** EPF will continue facilitating patient involvement in guideline development, review, and the development of lay summaries for several care areas, in collaboration with the European Society for Clinical Nutrition and Metabolism (ESPEN). As a member of the European Nutrition Health Alliance (ENHA), EPF will also continue to uphold its commitment to the alliance's Optimal Nutritional Care for All (ONCA) campaign. EPF will also contribute to ENHA's patient involvement plan, as outlined in their strategy. We will continue to communicate our recommendations on the topic of nutrition and, in particular, on the introduction of a mandatory front-of-pack labelling scheme and European harmonization in this regard.

- **PATIENT ENGAGEMENT OPEN FORUM** (PEOF) is one of the IMI project PARADIGM's key legacies. In 2021 EPF will co-design and co-host an online event with its partners, Patient Focused Medicine Development (PFMD) and the EUPATI Foundation. The purpose of PEOF is to collaborate in a multi-stakeholder context, to turn patient engagement into reality. The Forum aims to provide a holistic perspective of patient engagement, the landscape and actors, and foster collaboration and co-creation while breaking down fragmentation that are often present in patient engagement work.

STRATEGIC GOAL 3:

DIGITAL TRANSFORMATION THAT DELIVERS FOR PATIENTS

- **HEALTH DATA** Following our 2020 activities, EPF aims at further consolidating its position on health data. Through engagement with members and the EPF Digital Health Working Group in particular, EPF will work on defining a clear and updated position on health data, addressing key elements, current issues and newer trends and topics. This will support our engagement with the development of the **European Health Data Space**, in view of the European

Commission legislative proposal expected towards the end of 2021. Our work on health data will also be focused on better integrating the work of EU projects and initiatives in which EPF is engaged with our policy and advocacy work on this topic.

The **Data Saves Lives** (DSL) initiative, coordinated by EPF, will continue raising patient and public awareness and understanding about the importance of health data through effective communication and engagement with regional and national level organisations. It will also work on raising the external profile of EPF as a credible voice to shape the health data environment in Europe by equipping regional and national level organisations with practical tools to implement health data sharing initiatives locally. https://datasaveslives.eu/

EPF will also bring the patient voice to the **European Health Data Evidence Network (EHDEN)** project mission. EHDEN aims to reduce the time to provide data-backed answers to real world health challenges, and health research by creating a federated data network and an online training academy. This year, the aim of EHDEN was highlighted with the extra mission of COVID-19 data. https://www.ehden.eu/ Through its role in the **IMMUcan** project, EPF will ensure that the patient perspective is embedded throughout and that informed consent and reuse of patient data are central to the project. IMMUcan aims to investigate how the immune system and tumours interact, to understand which patients may respond better to specific therapeutic interventions. By leading on the communications work package, EPF will ensure that materials such as a website patient portal, patient information leaflet, and other online communication materials remain accessible to patient groups. https://immucan.eu/

EPF is also involved in **PharmaLedger.** The project will use block-chain technology to create a platform for the healthcare sector that integrates the supply chain, clinical trials, and health data as case studies. In 2021, EPF will keep informing the patient perspective and will contribute to the design and delivery of the Patient Collaboration Platform meant to support patient engagement activities. https://pharmaledger.eu/ . The project aims to drive the early-adoption of blockchain-based technology by working together with partners to build a complete solution for improving the quality of healthcare, and explore how blockchain technology can help us tackle real-world health challenges

- **ARTIFICIAL INTELLIGENCE** EPF will continue to engage on this topic based on our response to the European Commission White Paper on Artificial Intelligence (June 2020) and on the EPF AI Survey launched in October 2020. EPF will work on a more explicit position through increased engagement with the EPF Digital Health Working Group and our wider membership. The consolidated position will allow us to engage with upcoming EU initiatives on this topic, such as the follow-up to the European Commission's White Paper foreseen for early 2021 and participate in stakeholder dialogues and networks to convey our key messages.

- **INCLUSIVE DIGITAL TRANSFORMATION OF HEALTH AND CARE SERVICES** The COVID-19 pandemic has further accelerated the digitalisation of care and pushed for a quicker implementation of digital health solutions including telemedicine and mHealth. Through engagement with members, EPF will continue its advocacy work highlighting shortcomings and learnings from the current state of play of digital health deployment in Europe. Furthermore, EPF will build on the work of EU projects we are involved in, specifically on **DigitalHealthEurope**'s (DHE) tangible outputs (the benefits of having digitally empowered patients, the Empowerment Roadmap for better digital health uptake and the White Paper on collaboration between patients and healthcare providers) to continue its advocacy activities towards more structured and meaningful involvement of patients in digital health innovation. Finally, next year will mark the completion of the project and, EPF will focus its efforts on disseminating DHE's results including the recommendations listed in the White Paper by setting up a few virtual events. https://digitalhealtheurope.eu/

- **GRAVITATE HEALTH** While DHE is coming to an end, 2021 will see the involvement of EPF in another digital health related project, Gravitate Health, a new IMI project whose mission is to equip and empower citizens as users with digital tools that make them confident, active, and responsive in their patient journey, specifically encouraging safe use of medicines for improved adherence, better health outcomes and higher quality of life. In 2021, EPF will set up a User Advisory Group and plan training and engagement activities. https://www.gravitatehealth.eu/

- **EPF CONGRESS 2021** The success of our first Congress in 2019 highlighted the importance and impact of such an event, bringing together the key stakeholders, innovators and changemakers in the health sector, with patients at the heart of every discussion.

  For our next Congress, EPF has selected **digital transformation of healthcare** as the broad theme, drawing on the exploration of this area in the 2019 Congress, our engagement in EU policies focusing on digital health, and the experience and key learnings of the COVID-19 pandemic.

  With this Congress we aim to:

  - achieve a greater and genuine understanding of the importance and added value of patient involvement in the digital transformation of healthcare
  - look at the European Health Data Space from the patients' perspective
  - understand the patient's intrinsic role in valuable innovation and partnership
  - share the patient's experience of digital health and responsible health data sharing during the COVID-19 pandemic.

  Ultimately, we seek to create a unique patient-led congress that brings real and lasting change in patient involvement in the digitalisation of health as a pre-requisite for value based, outcome-oriented and sustainable healthcare.

  Co-produced with our patient community and high-level experts from our Advisory Board, the EPF Congress 2021 will provide the platform to bring coherence to a fragmented picture of patient involvement in digital health, promoting the uptake of person-centred and/or patient-driven digital solutions.

Due to the current public health situation, the Congress 2021 will be held virtually, over a week in October with a follow-up physical event in Brussels, in Spring 2022.

STRATEGIC GOAL 4:

ACCESSING THE HEALTHCARE WE NEED WITH NO DISCRIMINATION

- **MEDICINES** As part of our work on access, an important focus will be given to equitable access to medicines and their affordability. We will engage with the implementation of the Commission's pharmaceutical strategy, based on the EPF position paper on the pricing and value of innovative medicines, and our previous work on generic and biosimilar medicines. Potential areas of action for EPF will include a patient perspective on medicine shortages, access barriers and debates about access to, quality and affordability of medicines. EPF's advocacy at EU level will be in synergy with our contribution to the activities under the WHO's European Programme of Work (EWP) concerning access to medicines.

  We will continue to participate as member in the EURIPID stakeholder platform on medicines transparency and contribute to other meetings, consultations, and fora, where appropriate. We will also contribute to the WHO Regional Office for Europe's virtual consultations with non-state actors on access to medicines, including its resolution on improving the transparency.

  As the pandemic and containment measures continue, it is important that Europe prevents the current health and economic crisis from developing into a social one. In the context of increasing health inequalities, we will aim to collect further patients' evidence on access barriers, and address these barriers using policy instruments such as the European Pillar of Social Rights as well as the European Semester and the UN Sustainable Development Goals.

- **Employment** EPF will also highlight EPF's existing recommendations on inclusion of people with chronic conditions in the workplace in the context of the forthcoming Communication on a new occupational safety and health strategy framework.

- **The Impact of the COVID-19 Pandemic on the patient community** EPF will continue to closely monitor the situation closely, providing information and support to the patient organisation community, while conveying patients' perspectives and positions on health policy responses to the pandemic. EPF will use learnings from our 2020 **survey on the impact of COVID-19 on patients and patient organisations** in discussions around health systems post-crisis. In 2021, we will continue to survey and engage with our members on questions relating to the pandemic and its impact as the situation evolves. We will also engage in collaboration where need and opportunity arise, including with the European Commission, European Medicines Agency, or stakeholders.

The acquired knowledge will inform EPF input to **PERISCOPE** (Pan-European response to the impacts of COVID-19 and future pandemics and epidemics), an EU-funded project that will conduct multi-disciplinary research on the impacts of the COVID-19 outbreak from different viewpoints: clinic and epidemiologic; humanistic and psychologic; socio-economic and political; statistical and technological. EPF will contribute to mapping and analysing the socio-economic impact; to developing solutions and guidance for policymakers and health authorities on how to mitigate the impact of the outbreak. EPF will also co-design trainings for patients with chronic conditions to cope with the impacts of an outbreak and response measures, including to ensure adherence to medication, continuity of care and other best practices as identified in previous work plans.

- **VACCINATION** EPF has a long-standing commitment to vaccines confidence and information. In 2021, EPF will closely monitor developments relating to COVID-19 vaccines development and accessibility, with patient safety and transparency as top priorities. EPF continues to participate as a member in the stakeholder forum of the EU Joint Action on Vaccination (EU-JAV). In addition, EPF is currently leading a pilot project on increasing the uptake of and confidence in vaccination for patients with chronic conditions and their communities (VAC-PACT). The online resource supporting vaccination confidence developed by EPF and partners will be finalised and upon permission from the European Commission, published in 2021 and will incorporate information on coronavirus vaccines.

- **PATIENT SAFETY** Building on the 2019 WHO resolution on patient safety as well as the outcomes of the EPF Congress, we will continue to advocate for greater recognition of the important role of patients and family members in the area of safety and on providing information and education on patient safety topics, such as healthcare-associated infections and antibiotic resistance. We will collaborate as relevant with other stakeholders, e.g. healthcare professionals, EU agencies and international organisations such as ECDC, EMA and WHO. We will also engage in awareness-raising activities for Patient Safety Day (17 September). We also continue as stakeholder partner in the EU Joint Action on antimicrobial resistance, EU-JAMRAI and to support the European Antibiotic Awareness Day (EAAD).

- **QUALITY OF CARE** Building on work to date, we will continue to engage with policy-makers, international organisations such as WHO and OECD, and with other stakeholders to improve quality of care engaging in discussions around patient-centredness, patients' priorities, and patients' involvement as well as value-based healthcare. We will continue to participate in meetings of the OECD HQCO working group, and the international patient advisory board for the OECD PaRIS project on PROMs and PREMs.

  EPF has joined the new IMI project **H2O** (Health Outcomes Observatory) which aims to empower patients through digital tools and achieve better measurement of their health outcomes in a standardized manner in order to improve their care. EPF will contribute a strong patient perspective and in 2021 a key objective will be the setting up three patient advisory boards. EPF will identify patient advocates with expertise in diabetes, cancer and IBD disease areas and from the European and national/regional level. The coordination of these PABs will represent the cornerstone of our contribution to the project. Together with the expertise of these patients, we will ensure that there is a strong and diverse patient perspective, and that patients are consulted throughout. https://health-outcomes-observatory.eu/

- **HEALTH LITERACY** is a core value of EPF and a cornerstone of patient empowerment. Health literacy and information activities are embedded in all our advocacy work as well as our projects and capacity-building. In 2021 we will continue to work with the informal health literacy coalition involving health professionals, academia, and industry, on topics of mutual interest around mainstreaming health literacy as part of EU health policy, especially in the context of the COVID-19 pandemic. EPF will also embed health literacy priorities in our activities on critical patient safety and public health issues, in particular vaccination.

STRATEGIC GOAL 5:

STRENGTHENING PATIENT COMMUNITIES ACROSS EUROPE

- **CAPACITY-BUILDING PROGRAMME** (CBP) Our capacity-building activities, will seek to strengthen patient organisations offering them tools and expertise to enable them to play their legitimate role in the health sector.

  The EPF Leadership Meeting will take place as a one-day event or a webinar series aimed at empowering EPF members' leadership through high-level discussions and exchanges. The event will provide EPF members with the opportunity to further shape strategic direction of EPF and the patient movement in Europe on Artificial Intelligence and its application in healthcare. In 2021 the event will be linked to the EPF Annual General Meeting (AGM) to ensure a high level of participation.

  We will continue to strengthen the capacity of patient leaders at national and European level with **a capacity-building module dedicated to supporting patients' organisations to improve their fundraising and engagement strategy in the light of the current health and financial crisis**. The module will be open to patient organisations from all over Europe with a specific focus on organisations based in Bulgaria, Hungary, Poland, Romania, Slovakia, and the Western Balkans. Given the current scenario the training will happen fully online providing a balanced mixed of online learning circles and content-based webinars.

  Our **online webinars and online informal gatherings** will also continue in 2021, responding to a double objective: 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.

EPF is undergoing preparatory work to create an **International Master's Degree Programme on Patient Advocacy** in partnership with Cattolica University, Milan, and will launch the first ever recognised international master on patient advocacy. The Master will attract mainly patient advocates and other key stakeholders who would like to get a deeper understanding of international patient advocacy. The master will be a mix of state of the art academic and practical knowledge as well as group and individual work.

The EPF Youth Group (YG) represents young patients within the EPF community. The objective of the YG is to recognise, understand, meet, and effectively represent the needs and expectations of young patients through their meaningful involvement and empowerment. In 2021, the YG will conduct research on youth participation and activities in patient organisations in Europe, to evaluate their participation, advantages, opportunities, and possible barriers. The YG will also start the research phase of an exciting new project on sexual health and wellbeing of young European patients, where they will gather material, opinions, patients' stories, and key asks of the young European patients on the matter. Finally, the YG will organise monthly calls to ensure the engagement of the group and the advancements of projects, meet twice a year for a two-day strategic meeting, participate in several events representing the youth perspective, contribute to EPF policy work and participate in learning opportunities to strengthen their knowledge and capacity. Via the EPF YG social media channels they represent and amplify the young patients voice, via the EPF communication channels (mainly social media and newsletter) the YG contributes greatly to the vibrancy of EPF. Finally, as per the new EPF Constitution, one youth group representative is elected as EPF board member, therefore the YG is also involved in ensuring the good governance of EPF.

In line with our regular engagement with young patients, EPF will organise the fifth edition of the **Summer Training Course for Young Patient Advocates – Leadership Programme**, an exciting and unique opportunity offering a tailored high-quality training to young patient advocates. The fifth edition, where an essential role will be played by the Youth Group, will look at topics that are central to the patient community as a whole and represent a key priority for the new generation of advocates. In 2021 the overarching theme will be, "Be the future of patient advocacy", with a focus on the role that young patient advocates can play in the aftermath of the COVID-19 health and economic crisis for patient advocacy at individual and community level, ethical advocacy, role of emerging actors and challenges. Given the current scenario the training will happen fully online providing a balanced mixed of online learning circles and content-based webinars. After an initial phase, participants will be split into teams and their progress will be monitored. Efforts will continue in 2021 to establish an EPF Young Patients' Alumni and Ambassador Programme, creating a powerful network of 'graduates' from the Summer Training Programme, able to collaborate and champion EPF and its work with young people.

EPF will also provide **ad hoc support and training** to its members on a variety of topics depending on member's needs (from advocacy to organisational development).

6.1 COMMUNICATIONS, ENGAGEMENT AND MEMBERSHIP

The importance of effective, agile and high-quality communication was endorsed in 2020 when there was a need to inform all stakeholders on the expected impact and effects of the COVID-19 pandemic.

Communication is central to all aspects of the work undertaken by EPF and the new Vision and Mission statements will forge the new communication messages and the new Goals and Values will support the communication and engagement objectives.

EPF's website was refreshed and redesigned in 2020 and will continue to be the first point of contact for members, and stakeholders. Accessibility guidelines were utilised to ensure all citizens would be able to use it without problems.

The **COVID-19 Resource Point** was launched in March 2020 to combat the 'infodemic' surrounding COVID-19 and leverage our relationships with the European Medicines Agency, particularly Prof. Jean-Michel Dogne, to provide our members and key stakeholders with relevant and credible facts, figures and updates surrounding the virus. The resource point is updated weekly with any relevant news surrounding the development of therapeutics and vaccines, research from the field and patient perspectives. Adjacent to the resource point, members can find all the work we have done concerning COVID-19, including statements, letters as well as the consolidation of our members' work. All this information is promoted through our social networks and our weekly newsletter to members.

For 2021, the work plan will additionally focus on ensuring that our communication outputs are, where possible, provided in languages other than English to enable a greater number of EPF's partners, stakeholders, and the wider European patient population to be able to use.

Particular attention will also be brought to a customised format and presentation for each of EPF's policy and advocacy outputs, which will be systematically accompanied by an effective and tailored dissemination strategy.

In 2021, EPF will focus on continuing delivery of high-quality communications products via the channels listed above and EPF will focus its communications effort in producing:

- An Impact Report on 2020-2021 activities;
- An Annual Report on 2020 activities;
- 12 monthly newsletters (The Patient Perspective);
- 50 Weekly Insiders newsletter;

- A minimum of four videos to be uploaded on our YouTube channel.

The EU Patients' Podcast

To adapt to the "new normal" and working from home procedures, EPF will launch a Podcast "**The EU Patients' Podcast**" to 1) increase members' and stakeholder awareness of the EU health policy developments; 2) provide members a platform to amplify their voice and perspective; 3) promote all EPF activities to a wider audience; and 4) provide a personal touch to EPF communications. The podcast will be available in audio and video format and published on EPF channels. The goal is to produce 30 episodes within the first year.

EPF will continue to segment its voice and audience using its **social media** channels of Facebook, Twitter, and LinkedIn. Facebook will be used to promote EPF and member activities, using a lay language voice. Twitter will use a hybrid of such and be the main platform when attending or hosting events. LinkedIn will be used on a more formal basis, promoting only EPF activities concerning policy and project initiatives as well as promoting vacancies and important announcements. This will help to provide brand coherence while ensuring proper growth within the three channels.

EPF will continue to enlarge its **database** to expand its reach concerning statements, press releases and updates. As a result of our work on COVID-19, our online database, regarding social media, newsletters, and emails have increased substantially. We will continue on this path in 2021, to ensure the patient perspective and voice are seen in worthwhile publications and platforms for our members in an accessible and lay-friendly manner.

EPF members are at the core of everything we do. They are the legitimacy of EPF, and they shape the strategy and the priority of our organisation. EPF's membership has grown considerably from 13 in 2003 to 75 in 2020. Our objective is to welcome warmly all eligible organisations to reinforce our collective disease and geographical representativeness. To achieve this objective, we will undertake the following actions in 2021:

- **Increase contact** with potential new members: EPF will constantly update the map/list of potential members, based on the 2020 EPF membership mapping;
- Continue with the **implementation on the wider Europe approach**: recognising that EPF's members often cover areas beyond the EU, the EPF AGM 2019 approved the EPF new Constitution (which entered into force as from January 2020) opening the EPF membership to organisations that are based in geographical Europe. In 2021 EPF will continue to reach out to new potential members and build connections with existing patient organisations in Europe.

In 2021 EPF will work on a **mapping report on Western Balkans patient organisations** to better understand the patient movement landscape in the region and start building bridges with national coalitions and patients organisations active in the region;

- **Support emerging national coalitions**: national coalitions play a crucial role in monitoring, understanding, and reacting to, as well as influencing national health policies and they are a vital partner in cascading messages to the grassroots. Strengthening their capacities adds value for the targeted countries and for EPF. In 2021, EPF will continue to support national coalitions through training and exchange of best practices.

EPF aims at both gaining new members and to continue the engagement of existing ones. We will continue to improve our tools to promote interactions between the EPF Secretariat and EPF members, with the objective of being as clear, efficient, and inclusive as possible in our internal communications. The Membership and Capacity-Building Manager is the link between the Secretariat and EPF's members. She has regular and personalised contact with members (e.g., through the Weekly Insider's, a weekly update, tailored emails, field visits) ensuring that members make the most of EPF membership. Virtual weekly coffees with EPF members will continue to take place and thanks to the initiative "EPF on the spot" Elena and the EPF staff, will participate in members' activities, sharing EPF material and best practices with their own audiences, thus stimulating dissemination and creating a constructive feedback loop. In 2021 EPF will pilot a new format **Members' Online Circle.** In 2021 we will organise 3 online informal gatherings for our members to share best practices and current challenges that they are facing.

7. Governance

Effective and transparent governance is core to everything we do at EPF. EPF has several governing bodies that meet regularly during the calendar year:

- **ANNUAL GENERAL MEETING** EPF's highest governance body is the Annual General Assembly where each member is represented by one delegate. The AGM meets once a year and makes all decisions required to implement the objectives of the EPF, according to our Constitution. The AGM will happen either as a virtual event or as a face-to-face event depending on the status of COVID-19 pandemic in Europe.

- **EXTRAORDINARY GENERAL MEETING** EPF will organise an online (prior approval of all EPF Full members) Extraordinary General Meeting to vote a change to the EPF Constitution to include Online General Meeting as an option.

- **EPF'S BOARD** EPF is administered by Board Members, who are elected by the Annual General Meeting for a term of two years. The Board meets around four times a year, physically or virtually to provide political leadership, ensure the good running of the Secretariat and oversee the implementation of the annual work plan. The Board is composed of 9 members. Since April 2020 EPF has an elected Board representative coming from the Youth group.

- **SECRETARIAT** The EPF Secretariat executes the annual work plan based on the EPF Strategic Plan and works to support and inform the members.

- **ADVISORY WORKING GROUPS** EPF has two topic specific Advisory Working Groups to guide and support two of its priority areas of work: one on Universal Access to Healthcare and the other on Digital Health.

- **ETHICS COMMITTEE** The EPF Ethics Committee is a key part of the organisation's mission. The first EPF Ethics committee was elected during the 2020 EPF Annual General Meeting. The role of the Ethics Committee members include issuing opinions or advice upon written request from the Board; recommending appropriate handling of conflict of interests, and providing general advise on wider ethical issues that EPF needs to address, in the context of legislation or practice. It is comprised of five members, who are nominated by an EPF member and voted by the AGM Members of the organisation. These representatives hold a 3-year term, during which their duties align in order to ensure a balanced check mechanism for the organisation.

- **EPF'S OPERATING GRANT TASK FORCE** Set up in 2020, this task force is made up of EPF members and the EPF Secretariat. The main objective of the task force is to agree on a common position and approach on the sustainable financing of patients' organisations through public funds such as the EU Health Programme, as well as joint advocacy activities. The task force also aims to raise awareness and recognition of the role and contribution of patients' organisations and civil society in policy-making. The task force will continue this work in 2021, beyond the EU4Health programme, while reflecting on a long-term sustainable funding strategy for patients' organisations and civil society.

- **YOUTH GROUP** The EPF Youth Group (YG) is made up of young patient representatives between 15-29 years old. They all have different chronic conditions and they come from all over the EU. The aim of the YG is to become the reference group of the young patient community and its role is to communicate the needs and expectations of young patients to EPF and its members.

8. Transparency and Independence

Since our inception we have continually worked to improve the way in which we operate EPF and we are committed to **transparency** and **independence** in all aspects of our work in accordance with our Code of Conduct as well as our Constitution and Internal Rules. Adopted by the EPF Annual General Assembly in March 2009 and updated in 2018, our 'Framework for Cooperation' outlines how EPF works with partners who provide unrestricted sustainable funding to contribute to EPF's strategic plan and annual work plan, and why this is important. This partnership is not solely financial and focuses also on open and transparent dialogue and the exchange of independent views and positions between

EPF and these partners. This framework document also describes how this is undertaken in practice, without comprising either party.

In line with our commitment to transparency, all financial information related to EPF's activities is available on our website. Our Annual Report outlines the source of our funding and the amount received. EPF is also a registered NGO on the Commission's new Transparency Registry.

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. It is expected that EPF will apply for an Operating Grant in 2021 for the period 2022-2025 with the dual aim to balance the funding from public and private funding whilst protecting its independence and embedding the desired financial sustainability.

9. List of deliverables

Strategic Goal	Activity/Output	Deliverables
Shaping a new European agenda for patients	Participation in high-level policy debates on the future of EU health policy, including the European Health Union, health competences and the eventual Conference on the Future of Europe	• Contribution of the patient perspective through various channels and in various formats, e.g. by participating in policy debates, issuing statements and reactions, disseminating information to the EPF membership network and consultations with members • Contribute as co-leading organisation to the EU4Health CSA 2021 workplan, including targeted activities on the EU Health Union
	Bringing a patient perspective on the responses to the COVID-19 pandemic at different levels	• Survey to patients and patient organisations, 2nd edition • Engagement with EMA through membership of the COVID-19 Task Force • Participation in / co-development of ad hoc stakeholder meetings on vaccines and therapeutics
	Monitoring of implementation of key pieces of EU legislation	• Information to EPF members on the implementation of the Medical Devices Regulations • Contributing to the implementation of the Medical Devices Regulations through participation in meetings of the MDCG sub-groups on clinical studies and post-market vigilance • Information to EPF members on implementation of the EU Clinical Trials Directive
	Further engagement on patient involvement in research and professional education, building on previous work done	• Meeting with medical societies to discuss results of EPF survey on PI in CME/CPD and identify priority actions • Dialogue with academic stakeholders on PI in research

Meaningful patient involvement in co-creating better health policy, practice, research, and education	EU-PEARL	EU-PEARL Stakeholder meeting report (including section on patient engagement)
	Patient Engagement Open Forum	Presentations and summary notes of the discussions of various sessions of the PEOF
Digital transformation that delivers for patients	DSL campaign	Increase the interest in understanding health data at regional/national patient orgs
	DSL survey - Understand the gaps and expectations of EPF members	Outcomes to be shared with the Health Data Community (multi-stakeholder)
	Virtual workshops, webinars, social media discussions	Build a DSL toolkit for DSL survey that support practical implementation of health data sharing initiatives locally/regionally
	EHDEN	A solid sustainability plan for EHDEN that also benefits patients/patient orgs
	EPF Congress 2021	• EPF Congress website (epfcongress.eu) • Congress 2021 newsletter (monthly issues) • 3-4 Press Releases • Invitations • 6-10 Q&As/Podcasts with speakers/Advisory Board
	Digital Health Europe (DHE)	White paper on boosting active cooperation between patients and health and care providers (DHE) -Report
	H2O	Leaflets explaining PROs in lay terms

	Contribution to the debates on digitalisation of health and Commission’s proposals for a European Health Data Space and on Artificial Intelligence	• Definition of a Position statement on AI based on previous work in 2020 • Two meetings of the EPF Working Group on Digital Health and definition of new work plan for the WG • Consolidate EPF position on health data through dedicated activities in response to the EHDS debate.
Accessing the Healthcare we need with no discrimination	VAC- PACT	• Toolkit for patients, HCPs, communities • Virtual workshops to test and disseminate the Toolkit • Final report and policy recommendations
	Access to healthcare, including medicines; patient safety and quality of care	• Engagement with EU proposals for the European pharmaceutical strategy in appropriate format, e.g. statements, consultation responses, participation in high-level policy meetings • Participation in WHO Euro consultation on access to medicines • Consultation with EPF membership concerning the Commission’s evaluation of the cross-border healthcare directive • Further dissemination of EPF’s Patient Guide to Vaccination and other related information resources • Participation in OECD PaRIS survey international advisory panel • Two meetings of the EPF Working Group on Universal Access to Healthcare and definition of new work plan for the WG

Strengthening patient's communities across Europe	Summer Training for Young Patients Advocates	Final report, training concept note
	Leadership webinars series or face to face event	Meeting agenda/ webinars agenda, participants list. In case of webinars 5 outputs.
	EPF Youth group Monthly call (10 per year)	Upon request meeting minutes.
	EPF Youth group Spring and Fall Meeting	Meeting Agenda/ participants list
	Capacity Building Module on Fundraising and Engagement	Final report, training concept note
	International Master on Patient Advocacy	Master curriculum
Operations, Governance & Communications	EPF activities to inform and engage our members, policy-makers and other stakeholders	• The Patient Perspective monthly newsletter (12 editions) • EPF Weekly Insiders newsletter (50 editions) • COVID-19 Resource Point weekly updates • The EU Patients Podcast (30 episodes in video and audio format) • Impact Report 2020-21 (June 2021) • Annual Report 2020 (April 2021) • Website • Social Media (daily updates on Twitter, Facebook and Linkedin) • Video (minimum of 4 to promote EPF events and webinars) • Leaflets and brochures (for key policy and advocacy campaigns)
	Mapping report on Patient Organisations in Western Balkans	• Report
	Members' online circle	• 3 episodes agenda
	Board Meetings	• Meeting minutes

	EGM	- EGM Agenda, participants’ list
	AGM	- AGM Agenda, participants’ list

10. Key Events 2021

Please note that the schedule is tentative and at this stage includes a cross section of events organised by EPF in 2021. An update with specific dates will be made available in January 2021.

January	Target Group	No. of Participants
-	-	-
February		
Board Meeting	The Board	9
DSL Webinar	EPF Members and other Data Community members	60-70
EGM	EPF Members	70+
March		
DSL Tweet chat	EPF Members and other Data Community members	20-30
Capacity Building Module on Fundraising and Engagement	Capacity Building Module Participants	30
April		
Board Meeting	The Board	9
DSL Webinar	EPF Members and other Data Community members	60-70
AGM	EPF Membership	70
Leadership Meeting (or kick-off webinar series)	EPF Membership	70 or 20/25 per session
May		
Launch of STYPA 2021		30/50
June		
Board Meeting	The Board	9
Industry Roundtable	Industry partners	40-50
DSL Tweet chat	EPF Members and other Data Community members	20-30
STYPA	STYPA participants	40-50
DSL toolkit launch	EPF Members	60-70
H2O Training on PROMs	H2O Patient Advisory Board Members	24-30
July		
STYPA	STYPA participants	40-50
August		

DSL Webinar	EPF Members and other Data Community members	60-70
September		
Board Meeting	The Board	9
DSL Tweet chat	EPF Members and other Data Community members	20-30
Capacity Building Module on Fundraising and Engagement	Capacity Building Module participants	30
October		
DSL Webinar	EPF Members and other Data Community members	60-70
STYPA closing event	STYPA participants	40-50
EPF Congress 2021	All stakeholders	300+
DSL Virtual summit at EPF Congress	EPF Members and other Data Community members	
Gravitate Health Training	Patients/ citizens/HCPs	20-30
November		
-	-	-
December		
Board Meeting	The Board	9
DSL Tweet chat	EPF Members and other Data Community members	20-30
Patient Engagement Open Forum	EPF members, larger patient community, regulators, HTA, industry, academia	TBD