EUROPEAN PATIENTS' FORUM
WORK PLAN 2020

Contents

Introduction

2020 will be a transitional year for EPF as we develop a new five-year Strategic Plan for the period from 2021 to 2026. The plan will continue to reference the three key objectives in the current Strategic Plan, these being:

- **Patient Involvement and Empowerment;**
- **Sustainable Health Systems for All; and**
- **Effective and Patient Centred Research and Regulatory Frameworks**.

During 2020 we will see a refocussing of these priorities as we move towards establishing our new Strategic Plan. The evolution of our three strategic pillars set out below will enable EPF to better purpose our Work Programme based upon a reformulated organisational purpose, mission and vision, which will be developed in partnership with our Member Organisations, supporters and network.

In setting out our Work Programme within the theme of patient perspective, voice and value we aim to make our Programme to be more accessible, providing an enhanced base to demonstrate impact.

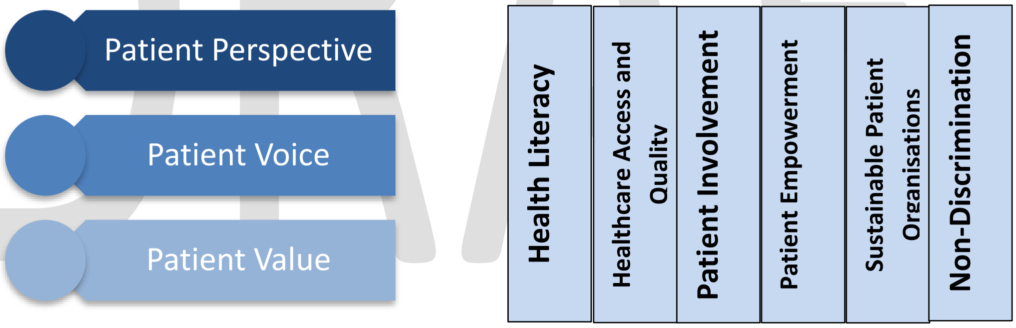

Figure One: Evolving EPF Strategic Pillars & Existing Strategic Plan Goals

Within the **Patient Perspective**, the overall aim of EPF's Policy and Advocacy work continues to bring to the European health policy arena the notion of the patient perspective and to provide such a perspective on areas of health policy and practice relevant to Europe's 500 million citizens and most particularly the 150 million with long term and enduring health conditions.

In 2020 we will continue to work on legislative and policy priorities agreed with the EPF Board and building on the outcomes of the EPF Congress, with new activity within the field of medical education.

Patient Voice refers to the training and educational activities undertaken or supported by EPF to enhance the capacity and capability of patients and patient organisations to exercise their rightful role within the healthcare arena on a local, national and European level.

In 2020 we will begin the process to scale up patient education and training on the medicines lifecycle, whilst at the same time continuing with our established organisational and youth training and development activities.

Patient Value encompasses the portfolio of projects led by or involving EPF, which aim to develop or enhance European health policy and practice. Depending on the level of maturity of areas of work and EPF positions, in such projects that are instigated by EPF or maybe externally commissioned, EPF may bring the patient perspective and/or facilitate activities to incorporate the patient voice and deliver patient driven improvement and innovation.

In 2020 we will expand the total number of projects that we are involved with, focussing on the unique elements of added value that EPF brings with regard to supporting the adoption of the patient perspective and incorporating the patient voice.

Demonstrating Value

As the only European-level, non-disease specific umbrella patient organisation, representing patients with chronic diseases, EPF 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 occupy a **unique 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.

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. It will support meaningful implementation of good practices in patient empowerment and involvement by practitioners, as well as policymakers. EPF is committed to being able to **demonstrate the impact** of the work that it undertakes and during 2020 we will continue to develop our approach, with the aim of having a fully revised approach for the new Strategic Plan in 2021.

The **EPF evaluation framework** uses standard evaluation criteria relating to the relevance of the action to EPF's overarching objectives and strategies, 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.

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.

For the 2020 work plan EPF will work on the development of **an evaluation matrix** for each operational objective, linking each activity to measurable outputs and outcomes and, wherever possible, impact indicators. The impact of certain activities, particularly policy and advocacy work not related to any specific legislative dossier, often materialises in the medium or long term, certainly longer than one year. Process indicators can help in measuring the outreach and immediate impact of our activities, as well as indicate progress made towards longer-term objectives.

EPF will use both quantitative and qualitative methods to evaluate the activities, gathering data and key information through desk reviews of documents; policy deliverables and reports; online analytics and outreach; surveys; and in-person meetings with EPF staff members and stakeholders.

Communications and Engagement

Effective communication is central to all aspects of the work undertaken by EPF. The 2020 EPF Communications Plan will be developed to support each of the three Strategic Pillars in a manner that enables effective communication and engagement.

For 2020 our Workplan will additionally focus on ensuring that our communication outputs are where possible provided in languages other than English to enable a greater number of our partners, stakeholders and the wider European patient population to be able to use.

In 2020 EPF will focus on continuing delivery of high-quality communications products via the channels listed above and in particular EPF will focus its communications effort in:

- Developing a new EPF website in order to better align it to the current organisational strategy as well as to improve its accessibility and readability;
- An Impact Report on 2019- 2020 activities;
- 10 monthly newsletters;
- 50 weekly insiders mailing;
- A minimum of four videos to be uploaded on our YouTube channel.

Governance

Effective governance is core to everything we do at EPF. Since our inception we have continually worked to improve the way in which we operate EPF, and are committed to **transparency** and **independence** in all aspects of our work in accordance with our Code of Ethics and Framework for working with funding partners. In keeping in line with our commitment to transparency, all financials pertaining to EPF are available on our website. EPF is also a registered NGO on the Commission's new Transparency Registry.

During 2020 we will seek to utilise, further develop and enhance the way in which we are governed and the way in which we operate. Principal areas include:

- **THE IMPLEMENTATION OF THE CONSTITUTIONAL REFORM** The EPF AGM 2019 adopted our new Constitution and we will now operationalise all the strategic implication of this change: our wider geographic remit, the creation of an ethics committee, our relationship with on-line communities and EUPATI patient alumni, and a voting representative of the Youth Group on the EPF board.
- **THE 2020 ANNUAL GENERAL MEETING** will focus on electing five board members, the ethics committee, as well as approve the next Strategic Plan (2021- 2026) and formally adopting the 2020 Work Plan.
- **CONSOLIDATION OF THE NEW EPF BOARD** investing in team development activities aimed at helping to ensure that the EPF Board and Secretariat are best able to work together.

We will operationalise the Ethics committee, having established the principle in the new Constitution and Internal Rules.

Member Organisations

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 74 in 2019. Our objective is to welcome all legitimate organisations to reinforce our collective disease and geographical representativeness. To achieve this objective, in 2020 we will undertake the following actions:

- Contacts with potential new members: EPF will constantly update the map/list of potential members, based on the 2019 EPF membership mapping;
- Implementation on the wider Europe approach: recognising that EPF's members often cover areas beyond the EU. In 2019 the EPF AGM approved the EPF new Constitution (which will be into forces as from January 2020) that opens the EPF membership to organisations that are based in geographical Europe. In 2020 EPF will revise its membership criteria and membership status for its members based on the new criteria. We will then publish updated membership materials outlining the benefits and added value of membership and reach out to new potential members;
- Supporting emerging national coalitions: national coalitions play a crucial role in monitoring, understanding and reacting to, as well as influencing national health policies. They are a vital partner in cascading messages to the grassroots. Strengthening their capacities adds value for the targeted countries and for EPF. In 2020, EPF will continue to support national coalitions through training and exchange of best practices.

EPF aims at both gaining new members and to enhance 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, Elena Balestra, 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. 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.

Work Programme

EPF has developed a Work Programme which best reflects the strategic priorities of the Board, our Member Organisations and our wider stakeholder community. In developing our programme, we have sought to complement, and not duplicate work undertaken by our Member Organisations and to align where possible to institutional themes and priorities from the European Union, European Parliament and other pan-European/international bodies such as the WHO and OECD.

2020 will be the last year of our current Strategic Plan and as we prepare for our new Plan, we will focus our efforts in the following ten areas:

1. Prioritise activities that:
    a. legitimise and facilitate the patient perspective in health policy and practice;
    b. enhance the capacity and capability of individual patients and patient organisations to exercise voice and;
    c. undertake complementary activities to make a meaningful difference to health policy and practice;
2. Review the activities that we instigate, lead and partner on with a view to increasing our overall organisational efficiency and effectiveness;
3. Consolidate on our new legal form as a Belgium registered ASBL and our extension to cover the WHO European Region by drawing in new Member Organisations and undertaking activities in new geographic areas;
4. Align with other health NGOs to further strengthen and develop its established European health policy network in order to maximise the collective impact we have on ensuring health is central in European policy making;
5. Build on our 2019 Congress by undertaking follow on activities and connecting outputs with our existing work programme to maximise long term impact;
6. Assess how we can scale our patient education and training by maximising the value of our flagship medicines research and development programmes and further develop advocacy capacity and capability at a European, national level;
7. Strengthen our project portfolio in a manner that aligns to our policy and advocacy activities and maximises overall impact for patients, carers and communities;
8. Develop a Communications Platform to make optimal use of existing and new social media forms;
9. Enhance our ability to demonstrate the impact of the activities that we undertake;
10. Develop our new five-year Strategic Plan around a reformulated purpose, vision and mission and in collaboration with our Membership and stakeholder network.

CROSS CUTTING ACTIVITIES

Whilst there is both a strategic and an operational basis for dividing the work programme of EPF into three broad streams, the Secretariat operates in a manner which seeks to maximise synergies and active cooperation across all three. This is done through process of explicit prioritisation of themes as well as through ad hoc adjustments designed to maximise overall value.

For 2020 the cross-cutting themes that EPF will focus on are as follows:

- **VACCINATION** EPF has already undertaken a significant amount of activity within the realm of vaccination and, in particular, issues relating to the importance of vaccination for patients with long term conditions. EPF is currently planning to increase its Value work on vaccination with one or more projects related to increasing the take up of vaccination and lowering the population risk levels for those with long term conditions. In 2020 we will focus on making our existing information and advocacy resources available widely through translating them into EU languages, and on supporting further patient engagement at national level.
- **DIGITAL HEALTH** Issues relating to digital health including the use of patients' health data have formed a consistent element of the work programme of EPF over recent years. This will continue into 2020 with our work in the European Parliament and our leadership on the Data Saves Lives initiative. We will work with our Working group on Digital health to build a strategic vision of patients' involvement in Digital Health and Health Data, building on principles developed with our membership. Specific topics of focus for 2020 will be artificial intelligence and real-world data/evidence (RWD/RWE). EPF will also participate in the European Commission's eHealth Stakeholder Group.

In the following three sections we present areas of work which have a particular focus on either patient perspective, patient voice, or patient value.

FOCUS ON YOUTH ACTIVITIES

The EPF Board continues to support the full and active engagement of young patients in the work of EPF. Having an established position of the EPF Board and having established the EPF Youth Group as a permanent committee within the Constitution, the Board has asked the Youth Group to work with the Secretariat to develop its own programme of activities to build upon those such as the Summer Training for Young Patients Advocates youth training programme.

Patient Perspective

Traditionally termed policy and advocacy, our Patient Perspective work covers domains central to ensuring that European health policy and practice meaningfully account for the patient perspective. During 2020 we will continue with a range of existing work streams, instigate others having discontinued those which are no longer a priority or where their activities have come to a natural end. There will be a focus on building on the outputs from our EPF Congress, with an activity programme being developed during December 2019 and January 2020.

Engagement Framework

With a new European Parliament and a new European Commission, EPF will continue to build our network from which we are able to represent our Members and the wider European patient community.

- EUROPEAN COMMISSION EPF is a well-known and 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 our relationship with the new 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 and build upon, focussing in particular to involving new MEPs and developing an engagement strategy vis a vis the new Parliament.
- EUROPEAN UNION AGENCIES EPF has a very strong presence at the **European Medicines Agency**, with the appointment of Marco Greco, EPF President, to the EMA Management Board. EPF continues to engage actively in the Patient and Consumer Working Party (PCWP), as member and holding the co-chair. We will contribute as relevant to activities of other EMA working groups and task forces 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. We will also work with the **European Centres for Disease Control** on topics such as antibiotic resistance and vaccination, and with the **EU Agency for Fundamental Rights** (FRA) as member of the Fundamental Rights Platform.
- EUROPEAN HEALTH NETWORK EPF is an informal network involved in a range of bodies and networks, including the EU Health Policy Platform, All Policies for Health in Europe, EU4HEALTH, the EU Health Coalition, European Health Parliament and the Patient Access Partnership (PACT). Our activities will continue in 2020 and we will additionally seek to bring together the voice of cross cutting health NGOs operating in Brussels

European Legislative and Regulatory Activity

The EPF Secretariat follows all the relevant health related dossiers. By its nature the EPF Secretariat is required to be able to react to legislative and policy issues which may evolve over the year, but that still provides scope to set the broad parameters of our activity.

- **Health Technology Assessment (HTA)** EPF will continue to engage with the legislative proposal for an EU regulation on HTA and engage with all stakeholders and policymakers, including the successive presidencies of Croatia and Germany, in 2020. Independently of the EU proposals, we will continue to advocate for meaningful patient involvement in HTA, inter alia through our active participation in the EUNetHTA stakeholder forum and the HTAi interest group on patient and citizen involvement.
- **Clinical Trials** the EU Clinical Trials Regulation is set to become applicable in mid-2020. This means the patient community needs to be prepared, and EPF will engage in activities to inform and provide guidance on the new Regulation, how it will impact patients, and what opportunities it will provide, as well as areas where more work is needed (such as patients' representation on ethics committees nationally). We will work closely with the European Medicines Agency on information for patients and the introduction of the European clinical trials portal and database. We will conclude work within a multi-stakeholder group developing a new guidance document on lay summaries of clinical trial results, in time for the application of the EU Clinical Trials Directive in mid-2020.
- **Medical Devices** EPF will carefully monitor the implementation of the EU Regulations on medical devices and in vitro diagnostics, informing our members of developments and liaising with them to learn of any issues patients may have with the transition. EPF will also contribute as member to the work of two sub-groups of the Medical Devices Coordination Group (MDCG) – clinical investigation and evaluation, and post-market surveillance and vigilance.
- **Pharmaceutical regulation** We will participate actively in EMA activities and events and contribute to shaping discussions related to EU pharmaceutical regulation, inter alia on improving product information for patients (including digital) and including the patient perspective better in medicines evaluation through the EMA PCWP. We will follow closely the European Commission's actions following the publication of the final analysis relating to the EU pharmaceutical regulations and incentives, due at the end of 2019, and act as needed in consultation with our members.

Policy Activities

For 2020 we will continue our focus on certain core areas, introduce new areas and conclude or set others aside. Our programme will focus on the following policy areas:

- **Patient safety** We will re-launch our work on patient safety following the adoption of a WHO resolution on patient safety in 2018 and the establishment of an official Patient Safety Day (17 September); building on the outcomes of the EPF Congress, our work will focus on advocacy 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. 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 continue to contribute to the OECD project on PRIMs (patient reported safety incidents) survey development. EPF will also contribute for the third year of the CIOMS Working Group XI working on guidance on patient involvement in medicines development and safe use.

- **ANTIMICROBIAL RESISTANCE** Given the far-reaching implications of antimicrobial resistance for healthcare and especially for patients, EPF will continue to address AMR as part of our policy and information/communication activities, developing a fact sheet on AMR. We will aim to further develop our collaboration with the ECDC and WHO and continue as a stakeholder partner in the EU Joint Action, EU-JAMRAI.
- **QUALITY OF CARE** Building on work done to date we will continue to engage with policymakers, international organisations such as WHO and OECD, and with other stakeholders to improve quality of care. Engagement with discussions around value-based healthcare, patient-centredness, patients' priorities, and patients' involvement. We will continue to participate in OECD meetings of the HQCO working group, and the international advisory board for the PaRIS project on PROMs and PREMs.
- **SOCIAL INCLUSION AND NON-DISCRIMINATION** Building on our work on non-discrimination in healthcare, education and employment, we will consult with our membership to identify patients' priorities in this area where further advocacy is needed, e.g. in terms of social support and rights.
- **PATIENT INVOLVEMENT IN MEDICAL EDUCATION.** Building on a Congress plenary session on professional education and a new collaboration with European medical societies on CME/CPD, EPF will survey its members on their experiences of patient involvement in medical education and their views on independent medical education. We aim to further develop this initiative through a dedicated meeting in the second half of 2020, with the objective of taking concrete steps towards mainstreaming patient involvement in medical education.
- **NUTRITION** EPF will continue to engage in nutrition on a "cluster" basis, bringing together our member organisations with an interest in this area and focusing on promoting the involvement of patients in development and dissemination of clinical guidelines.
- **HEALTH LITERACY AND INFORMATION FOR PATIENTS** Health literacy is one of EPF's Strategic Goals and a core value. Health literacy and information activities are embedded in all our advocacy work as well as our projects and capacity-building. In 2020 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. EPF will also engage in awareness, information and communication activities on critical patient safety and public health issues, in particular antibiotic resistance and vaccination.

- **DATA SAVES LIVES** The work plan in 2020 has two core components. The first will be consolidating further the DataSavesLives website/portal and multi-media communications with the first wave audience, who can use an English language web site, and the second will be the community that will be building on the outcomes of the first health data community in September 2019.

Sustainable Healthcare Systems for All

Access and inclusivity will continue to be a core priority also in 2020. Priority areas will include:

- **ACCESS TO HEALTHCARE** EPF will continue to focus on access to healthcare from the patients' perspective based on our work to date, including the definition of access, and in consultation with our Working Group on Universal Access to Healthcare. We will aim to collect further patients' evidence on access barriers in collaboration with other stakeholders where relevant, and address these barriers using policy instruments such as the European Semester, the UN Sustainable Development Goals, and the European Pillar of Social Rights.
- **MEDICINES** As part of our work on access, we will continue advocacy on equitable access to medicines and their affordability, based on our updated paper on this topic published in 2019. EPF will work with our members and with other stakeholders to ensure medicines shortages are addressed by the European Commission and Member States as a priority, and as a first step hold a dedicated meeting with patient representatives in the first part of 2020. We will participate as member in the EURIPID stakeholder platform and contribute to other meetings, consultations, and fora, including via international organisations such as the WHO and OECD where appropriate. We will also consult our members to develop a consensus position on generic and biosimilar medicines, building on a policy brief.

Patient Voice

EPF offers two types of training: organisational capacity building training and individual training. The aim of these Patient Voice activities is focussed on providing education and training opportunities to patients. At the heart of this programme are the activities that we undertake to support the development of organisational capacity and capability. Organisational capacity building targets mainly EPF members and aims at strengthening patient organisations providing them knowledge and know how about strategic planning, governance, communications, fundraising, advocacy and transparency. To ensure that patient organisations are successful, impactful and resilient, such knowledge should be spread among the organisation.

The second strand of our education and training programme provides independent high-quality training, which will enable patients to develop and enhance their advocacy skills so as to be able to bring the patient perspective to a range of settings. Individual training activities are targeting patient/patient advocates that want to engage in medicines R&D and want to gain objective, reliable, patient-friendly knowledge on the topic and this is the case of EUPATI. The role of these individuals and their knowledge and engagement on the matter is key to the patient movement but does not need to be spread within an organisation to be impactful. The other individual training that EPF offers is the Summer Training for Young Patient Advocates, targeting patient and patient advocates focusing on creating the future generation of patient leaders.

The European Patients Academy on Therapeutic Innovation (EUPATI)

The focus for EPF patient education and training during the period of the current Strategic Plan has centrally been on the arena of medicines research and development. The cornerstone of this work has been the EUPATI programme.

The EUPATI programme has facilitated the development of course content to support the education and training of patients, as well as providing a web portal of free-to-access training materials. As the EUPATI programmes evolves, EPF will review the manner in which its governance and organisation operates. This is likely to see a number of changes, but the central tenants of patient led, independent, high-quality education and training for regulators, industry and other stakeholders will remain.

Through our ongoing leadership of the EUPATI programme for patient education and training in the medicines R&D, EUPATI in 2020 will focus on:

- Executing the third Patient Expert Course;
- The creation of new training content for patients;
- The launch of new courses for stakeholders;
- The organisation of an ad hoc R&D engagement training (both targeting patients and industry);
- The development of a match making platform for engagement;
- Ensuring the future and sustainability of EUPATI post 2020.

Organisational Capacity and Capability

Strengthening the Capacity of the Patient Community and Building our Membership

Through our Capacity-Building Programme (CBP) activities, EPF will seek to equip patient organisations with tools and expertise to enable them to play their legitimate role in the health sector.

The EPF Leadership Meeting is a one-day event 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 post 2020. In 2020 the event will be linked to the EPF Annual General Meeting (AGM) to ensure a high level of participation.

The **Patient Advocates' Seminar (PAS),** to be organised in the second half of the year, aims at strengthening the advocacy skills of the patient community, engage members in EPF's advocacy work, and build mutual understanding and cooperation among members on a regional and European level. The meeting will follow the structure of a hackathon aiming at building on the knowledge of participants, and to be an occasion for experience-sharing and peer to peer learning. The seminar will take place over one day and a half. It will include plenary sessions and group work.

We will continue to strengthen the capacity of patient leaders at national level with a **capacity-building module dedicated to empowering leadership and positive organisational governance.** The first edition of this training was launched in 2018 and further developed in 2019. EPF decided to repeat the module thanks to its success, gathering patient organisations from all over Europe with a specific focus on organisations based in Bulgaria, Hungary, Poland, Romania, Slovakia and the Western Balkans.

Our online **Breakfast Briefings** and **webinars** will also continue in 2020, 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.

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. The YG aims at raising awareness about young patients' lives and addresses cross-cutting issues which affect their quality of life. It is composed of young patients with different chronic conditions and different nationalities across Europe.

Continuing the activities implemented in 2019, the Youth Group will continue its commitment on raising awareness on discrimination and barriers to employment for young patients, specifically on inclusion in the work force building on the results of the WAYS project (2018-2019). Furthermore, a project dedicated to sexual health/education will be a new priority for the YG in 2020.

Finally, the YG will work towards collaborating further with key stakeholders and initiatives:

- Strengthen its relationship with the EMA specifically European Network of Paediatric Research at EMA (Enpr-EMA) following recently adopted Principles for involvement of young people, to which the YG contributed. A specific topic group will continue within the EMA PCWP to prepare training and support for young patients and discuss the best ways for them to interact with the Agency.
- It will collaborate with the **European Health Parliament**, a platform of young professionals from

across Europe with diverse backgrounds who wish to shape the future of healthcare in Europe, on future innovative scenarios for health.

- It will collaborate with **Young Persons Advisory Groups** (**YPAGs**) and EPF Secretariat to create a focus group to assess the capacity building needs of European teenage patients. The focus group recommendations will inform the design of a future learning programme dedicated to European teenage patients, foreseen for 2021.

Summer Training Course for Young Patient Advocates- Leadership Programme

In line with our regular engagement with young patients, EPF will organise the fourth 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 fourth 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.

Efforts will continue in 2020 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.

Patient Value

EPF is very well positioned to build upon the solid base of projects undertaken to date. Going forward we will seek to align the project work that we undertake even more closely to the patient perspective and patient voice workstreams.

This wide range of potential areas of work requires a scanning of funding opportunities spanning from Horizon 2020 and Horizon Europe as well as IMI to the third Health Programme and its successor in ESF+ and the Rights, Equality and Citizenship Programme.

STRATEGIC DEVELOPMENT

Looking forward EPF is already involved in aligning to future developments in the European health research programme. In view of the shaping of the new programming period, EPF will conduct informative sessions with members to showcase emerging opportunities and consult them on the horizontal and disease-agnostic topics to be prioritised. EPF will use the results arising from the consultation to influence the design of the new programmes and inform the new Strategic Plan. Along with the three project proposals and five projects being initiated in 2020, EPF will contribute to a wide range of projects that strengthen its skillset and commitment to achieve this objective, including:

PARADIGM

Patients Active in Research and Dialogues
for an Improved Generation of Medicines

EPF ensures the effective leadership and coordination of the PARADIGM consortium, boasting 34 partners, made up of patient organisations (members of EPF), pharmaceutical companies, NGOs, foundations, and corporate organisations that aims to co-create a framework enabling sustainable, ethical, meaningful and systematic patient engagement in medicines R&D.

The project started in March 2018 and will end in August 2020. In 2020 our focus will be on ongoing efforts to secure a smooth and efficient delivery of the project and the subsequent reporting period after August. Regarding communication, EPF will pay special attention to the online presence of PARADIGM, especially on social media (LinkedIn and Twitter); with a strong outreach and engagement with ongoing initiatives in the field, working in collaboration with PARADIGM through the PARADIGM International Liaison Group.

More specifically, in 2020 EPF will be responsible for the organisation of the final Open Forum on Patient Engagement in June 2020, together with EUPATI and PFMD. This meeting is a follow up of the Open Forum on Patient Engagement 2019 that gathered 200+ participants and helped the patient engagement community to go beyond aspirations.

EPF will also coordinate the involvement of patient advocates in thematic workshops to ensure a strong patient invoice in the different workstreams. More information at www.imi-paradigm.eu

prefer.

PATIENT PREFERENCES

PREFER, a 5-year project co-led by the Uppsala University (Sweden) and Novartis, will evaluate and test different preference elicitation methods through a set of systematic methodologies and recommendations. EPF participates in the Patient Advisory Group of the project, together with the European Cancer Patients Coalition (ECPC), the International Alliance of Patients' Organizations (IAPO), and Muscular Dystrophy UK (MDUK). Our role is to ensure that the methodologies identified are consistent with the specific preferences of patients. In 2020 we will contribute to the development of recommendations on patient preferences in three diseases areas: lung cancer, rheumatoid arthritis and Muscular Dystrophy. We will join a team that will focus on communication to patients on topics including training materials, EMA/EUnetHTA methods qualification and last but not least the final recommendations package.

More information at http://www.imi-prefer.eu/

COMPAR-EU

In 2020 EPF will contribute for the third year to the H2020 five-year project **COMPAR-EU** that aims to identify, compare, and rank the most effective and cost-effective self-management interventions. In 2018 EPF conducted a Delphi Consensus Building Process that gathered patients' expectations towards preferred outcomes of self-management in the four conditions. In 2019 EPF translated into lay language some of the products that were conducted in 2018. EPF engaged in the project a few small working groups composed of patients and patient representatives in order to bring meaningful patient involvement. In 2020, we will continue to champion meaningful patient involvement through the project and will continue to support other partners in developing an interactive platform on self-management in four highly prevalent chronic conditions. Furthermore, COMPAR-EU will facilitate informed decision-making and will support the implementation of best practices in different healthcare contexts.

More information at: https://self-management.eu/ and https://self-management.eu/blog/

Digital Health Europe

This project will support large-scale deployment of digital solutions for person-centred integrated care. It aims at identifying, analysing, and facilitating the replication of highly impactful best practices, using the consortium's expertise on knowledge management and impact assessment twinning schemes, as well as mobilisation of stakeholders. Building on the unique composition of the consortium, the project will establish and manage three collaboration platforms to align all efforts of ongoing and future initiatives supporting the three Digital Transformation of Healthcare (DHTC) priorities. In 2020 EPF will continue to engage patients in these three collaborative platforms (now called multi-stakeholder communities) and by this representing the patients' perspective. The collaborative work will lead to common strategic agendas and commitments for action that will boost innovation and progress in the respective topics. In 2020 EPF will produce a roadmap for healthcare providers or larger scale healthcare ecosystems to become more successful at engaging with patients and caregivers. Furthermore, by the end of 2020, EPF together with the project consortium will develop and deliver a **White Paper** on boosting active cooperation between patients and health and care providers.

More information at https://digitalhealtheurope.eu/

EHDEN
EUROPEAN HEALTH DATA & EVIDENCE NETWORK

EPF is partner in a new IMI project to be launched in Autumn 2018. The vision for EHDEN is that it becomes the trusted observational research ecosystem to enable better health decisions, outcomes and care. The mission is to provide a new paradigm for the discovery and analysis of health data in Europe, by building a large-scale, federated network of data sources standardised to a common data model. EPF's role is to ensure a strong patient perspective is embedded at all levels of the project, and that it reflects the desires, aspirations and challenges felt by patients in the context of this topic.

CHRODIS+
IMPLEMENTING GOOD PRACTICES FOR CHRONIC DISEASES

CHRODIS-PLUS is led by the Health Institute Carlos III (ISCIII -Spain) and Vilnius University Hospital Santaros Klinikos (VULSK-Lithuania), involving 42 partners representing 21 European countries. EPF plays a critical role in the JA, by ensuring the patient perspective in workstreams on multi-morbidity (WP6), employment (WP8), transferability of good practices to a wider range of chronic conditions (WP7) and dissemination (WP2). In 2020, EPF will contribute to the dissemination of the two WP 8 deliverables – a toolkit for the adaptation of the workplace and a training tool for employers and the employment sector. In the context of WP7, EPF will be a part of the final conference where results of the five study visits done in 2019 will be presented. Furthermore, towards end of 2020 – a final project conference will take place in Brussels and EPF will play a major role. Finally, next year, EPF will keep actively communicating and disseminating project's results through various channels, including events.

More information at http://chrodis.eu/

eunethta

Launched in March 2016, the **EUnetHTA** JA3 focuses on governance of HTA, early dialogues, joint production of assessments on pharmaceuticals and medical devices, re-use and national uptake of assessments. Overall the aim of this Joint Action is to establish a permanent scheme with agreed methodologies for collaboration on HTA in the EU, post 2020.

Reflecting the impact of EUnetHTA results and recommendations on the EU legislative proposal on HTA, EPF and other patient and civil society representatives in the HTA Network Stakeholder Pool, will collaborate to ensure sound patient involvement in the assessments implemented in 2020.

EPF will use these platforms to gather information, exchange good practice and to reinforce key policy messages on HTA. More information at http://www.eunethta.eu/

Next Steps

Our seven-year Strategic Plan 2014–2020 has proved an invaluable document for EPF and its stakeholders. 2020 will be the year in which we develop and validate our new Strategic Plan and we will seek to ensure that it is as robust and well-functioning as our current one.

- What should the purpose of EPF be and to what extent should it focus on patient engagement?

- Should EPF continue to focus exclusively on patients with long term conditions or should it focus on the needs of Europe's 500 million citizens.
- What should be the core business of EPF and what elements should be facilitated in a leveraged manner?
- What should be the remit of EPF's patient training and education offer?

Conclusions

EPF is very proud of our Work Plan as a document that sets out our ambition and purpose in a readily accessible form. We use it for communication with our Board, Organisational Members, supporters and stakeholder network. We also use it internally to develop our work programmes and manage and report on activities that we undertake. It is therefore a living document, which is likely to undergo revision and adaptation at an operational level throughout the year. Yet it remains the central plan that connects our Strategic Plan to our operations and then onto our evaluation and review process.

We thank you very much for taking the time to read through our Work Plan and for the contribution that you have made directly and indirectly to support its development. If you have further thoughts or reflections, then please do not hesitate to get in touch!

Annex 1 – List of Deliverables

Activities		Impact
Patient Perspective	Impactful Engagement with the new European institutions	• Engagement strategy (internal)
	Continuing engagement with external events to make visible and promote the patient voice and amplify the impact of EPF's work	• Representation in European and international conferences, ad hoc and permanent working groups, thematic events, and other fora where this brings added value and impact • Participation in activities of WHO-EURO and OECD as relevant
	Collaboration with EMA, ECDC and FRA	• Participation in 4-5 meetings and co-chairing the PCWP • Participation in themed meetings developed on the basis of the PCWP work plan, responding to EMA consultations, advisory role on patient training where relevant • Participation in and engagement with relevant activities of ECDC and FRA (e.g. EAAD)
	Developing a patient perspective on generic and biosimilar medicines	• EPF common position • Fact sheet on biosimilars and generics
	Shortages of medicines	• Policy meeting with EPF membership
	Education of healthcare professionals	• Survey of EPF membership on medical education (S1 2020) • Face to face meeting with patient organisations and medical societies on medical education and patients' involvement therein (S2 2020)
	Developing a patient perspective on digital health	• Patient perspectives on real-world data and artificial intelligence • Finalisation of principles on patient-centred digital health in consultation with EPF members • 2 (virtual) meetings of DH working group and review of priorities (internal)
	Universal, equitable access to high-quality, patient-centred healthcare	• 2 (virtual) meetings of Universal Access working group • Development of evaluation and review of priorities (internal) • Engagement with developments on cross-border healthcare as relevant • Statement on 2020 country-specific recommendations
	Quality and safety of healthcare and patients involvement in improving quality and safety	• Definition of strategic advocacy priorities following the outcomes of the EPC Congress (internal) • Contribution to the OECD PaRIS project and PROM/PREM and PRIM indicator

		projects • Specific engagement on antibiotic resistance through appropriate channels and fora, incl. ECDC • Contribution to CIOMS working group XI on patient involvement in medicines development and safe use
	Vaccination for patients with chronic conditions	• Translation of EPF's educational resources into further languages, promotion and dissemination of the tools • Engagement with EU policy initiatives relating to vaccination
	Nutrition and diet in chronic conditions	• Engagement through EPF cluster working on nutrition • Participation in events e.g. ONCA Conference
	Social and inclusivity aspects of chronic illness	• Consultation with EPF members on future priorities in the area of employment social rights and non-discrimination • Continuing advocacy for inclusivity inter alia through partnerships with other health NGOs
	Data Saves Lives Initiative	• Web portal in accordance with specifications outlined by the first Health Data Community meeting. • 3 podcasts and 2 webinars on "hot" topics identified by the first Health Data Community meeting. • A Health Data Community Workshop concept note, agenda, pre-reads and report • Health Data Community "summit' concept note, agenda, pre- reads and report (September 2020) • Meeting reports of the core group, advisory group and editorial board • Funding Concept note • Evaluation Grid 2020 with process and outcome indicators to measure immediate impact
Patient Voice	Focus Group with YPAGs	• Set of recommendations
	Leadership Meeting	• Meeting agenda, presentations
	Summer Training for Young Patient Advocates	• Report of the training
	EPF Capacity Building Module on Empowering Leadership and Positive Organisational Governance	• Report of the course
	4 webinars on topics related to EPF work in 2020	• Podcasts of the webinars
	2 Breakfast Briefings	• Video recording available on our YouTube channel
	EPF on the Spot	• Agendas and presentations
	Supporting Emerging National Coalitions	• 2 exchanges a year either virtually or physical meetings/presentations

	Two meetings of the Youth Group	• Meeting reports
	Youth Group work on employment including meeting with employers' representatives	• Leaflet • Report of meeting with employers
	Patient Advocates' Seminar	• Meeting agenda, presentations
	Contact with potential new EPF members and emerging national patient organisations	• 2 exchanges / year with potential new members
	Organisation of the 2020 EPF AGM Universal Access to healthcare working group	• Minutes of the meeting • 2 virtual meetings
	Contact with potential new EPF members and emerging national patient organisations	• 2 exchanges / year with potential new members
EPF Operations, Governance & Communications	Operationalisation of EPF new Constitution and Internal Rules	• Youth Board member elected and creation of Ethics Committee
	Board and Elected Officers meetings (4 meetings a year)	• Minutes of the Board meetings
	EPF communication activities to inform and engage our members, policymakers and other stakeholders	• Weekly "Insiders" mailing (50) • Up to 3 policy factsheets on priority topics • Videos • Impact Report • Website updates and maintenance • 11 EPF Newsletters • At least 4 Breakfast briefings, • Extensive speaking engagements • Youth Board member elected and creation of Ethics Committee • Annual Report

Annex 2 – 2020 Key Events (co-) organised by EPF

Please note this schedule is tentative and does not include all events organised or attended by EPF in 2019.

January	**Place**
Launch application Summer Training for Young Patients' Advocates	Online
February	
Launch applications CB Module on Empowering Leadership & Positive Governance	Online
Board Meeting	TBC
Digital Health working group meeting	web meeting
Launch of consultation process with members on topic prioritisation for Horizon Europe and other upcoming programmes	Web meeting

March	
Universal Access to Healthcare working group meeting	Web meeting
EMA PCWP meeting	Amsterdam
EPF members’ meeting on medicines shortages	Date TBC
April	
Board Meeting	Brussels
EPF Annual General Meeting	Brussels
Leadership meeting	Brussels
OECD HCQO meeting	Paris
May	
Chrodis+ WP7 Final Conference	TBC
Spring Youth Group Meeting	TBC
CIOMS WG XI meeting	TBC
June	
Board meeting	Brussels
Industry Roundtable	Brussels
PARADIGM 3rd Open Forum on Patient Engagement	Brussels
EMA PCWP meeting	Amsterdam
July	
Focus Group with YPAGs	Brussels
Summer Training for Young Patient Advocates	Vienna
September	
Board meeting	Brussels
EMA PCWP meeting	Amsterdam
EPF-BioMed Alliance meeting on medical education (tbc)	Brussels
October	
Fall Youth Group Meeting	TBC
Universal Access to Healthcare working group meeting	Brussels/virtual
Digital Health working group meeting	Brussels/virtual
OECD HCQO meeting	Paris
CIOMS WG XI meeting	TBC
November	
EPF Patient Advocates’ Seminar	Brussels
EMA PCWP meeting	Amsterdam
December	
Board meeting	Brussels