EPF
European
Patients
Forum

EUROPEAN PATIENTS’ FORUM
WORK PLAN 2018

Driving Better Health for Patients in Europe

Contents

1. Executive Summary

In 2018, the European Patients' Forum (EPF) will continue to lead patient advocacy in Europe providing **a cross-disease perspective** from a wide patient community **to the policy-making process** on issues which have a direct impact on patients' lives.

Our Work Plan for 2018 will focus on **three key objectives**:

1 - Patient involvement and empowerment

2 – Sustainable health systems for all

3 – Effective and patient-centred research & regulatory frameworks

Patient involvement and empowerment

Patient involvement is a cross-cutting objective in all our advocacy work. In 2018, EPF will promote wider understanding and acceptance of the concept of meaningful **patient involvement**, embedding it in all levels of health systems, and encouraging the implementation of good practices that are "**patient approved**".

Advancing patient empowerment, we will continue our advocacy role on the importance of **health literacy for patients and also for systems**. In addition, we contribute to patients' health literacy in all our work by communicating patient friendly information on complex policy and topics, such as vaccines, nutrition and generic medicines.

Building on the work conducted under the EPF Membership Strategy which contributes to strengthening ownership of EPF by its membership, EPF will work towards ensuring that all patient organisations are recognised as essential partners in health policy-making.

Linked to the **Annual General Meeting (AGM)**, the **EPF Leadership Meeting** will provide our members' representatives the opportunity to shape strategic direction of EPF and the patient movement in Europe.

Building on the successes of previous years, our 2018 work plan places emphasis on **developing further the capacity of patient organisations,** including youth organisations, equipping them with resources and expertise to enable them to play their legitimate role in the health sector.

The **EPF Youth Group** will continue its work to help young patient develop leadership and advocacy skills, preparing the next generation of patient advocates. Non-discrimination in access to healthcare, the workplace and education will be the central focus of an awareness-raising campaign

The concepts of patient involvement and patient empowerment will also be the central focus of important projects, including CHRODIS Plus, PRO STEP, PREFER and the EPF-led programme EUPATI, and a potential new IMI project that focuses on patient engagement in the life cycle of medicines.

Sustainable health systems for all

EPF is working towards a vision and building patients' evidence of what constitutes high-quality, safe, equitable and sustainable healthcare systems from the patient perspective.

In 2018, EPF will raise awareness of the outcomes of its 2017 campaign on Universal Access to Healthcare, promoting its Roadmap on taking action to achieve universal health coverage for all by 2030 and using it as a reference document for all our activities on access to health.

We will draw on the insights from our patient survey on **quality of care** to contribute to initiatives on **health systems performance assessment**, exploring how 'what matters to patients' can be best measured as part of healthcare quality.

Digital health will constitute one of our priorities: EPF will also continue its information and advocacy role in this area with the objective of identifying core principles from the patients' perspective. To guide this work stream, we will set up a **working group on Digital Health**.

Regarding our project portfolio, the Horizon2020 project COMPAR-EU and the Joint Action EUnetHTA will work on facilitating implementation of good practices in self-management interventions and HTA processes respectively.

Effective and patient-centred research and regulatory frameworks

Under this objective, EPF will monitor, support and report on the effective implementation of key EU legislation to ensure that the patients' interests are reflected in the legislation under development and effectively implemented.

We will closely monitor the developments following the recent public consultation on **Health Technology Assessment (HTA)**, while, in parallel, continue our work to facilitate a better understanding of HTA among EPF members.

We will provide an information resource explaining the **clinical trials regulation** and key elements of particular relevance to patients. .

EPF will continue to engage actively in the **EMA Patient and Consumer Working Party (PCWP),** including as member and as co-chair, to follow and contribute to pharmaceutical legislation.

We will continue to monitor and communicate on the new legislation on **Medical Devices and in-vitro diagnostics** and its impact for the patient community.

For each major activity, in addition to the description in this Work Plan, we have a concept note and individual plan, which is available from the secretariat.

2. EPF's Key Operational Objectives for 2018

Our activities in 2018 will focus on the following objectives:

- **Objective 1: Patient involvement and empowerment;**
- **Objective 2: Sustainable healthcare systems for all;**
- **Objective 3: Effective and patient-centred research and regulatory frameworks**.

3. Problem Analysis and Evidence Base for the Activities Proposed in 2018

The main challenge facing Europe's healthcare systems – how to provide equitable access to high-quality care that meets people's changing needs – will not disappear in the near future and requires cross-country collaboration.

It is increasingly recognised that health systems must become **patient-centred**, but this is not yet the reality. The patient perspective should be integral to the development and implementation of healthcare policy and practice at European level to progress towards innovative, efficient, equitable and sustainable health systems and facilitating access to better and safer healthcare for EU citizens[1].

The emergence of **digital health** solutions and services raises economic, ethical, political and capacity questions. New technologies also offer opportunities to collect, use and share **health data** more efficiently but also set new challenges for privacy and data security. Furthermore, he availability of almost limitless information online makes it difficult for patients to assess its quality and reliability. **Health literacy, as a vital aspect of patient empowerment,** is highly pertinent for understanding the complexities around issues such as scientific evidence-base information for treatments and public health interventions, and understanding the regulatory and political processes determining access to new therapies. Health literacy is also needed to promote more rational use of antibiotics, a critical public health issue.

Disparities in **access to healthcare** have increased since the 2008 financial crisis in Europe. Access to care is affected by austerity policies, such as cuts in healthcare budgets and in insurance coverage, increased fees and co-payments, and cuts in social protection measures. Against a background of austerity measures, EPF's 2016 survey on access to healthcare among other sources demonstrate that health inequalities within and between EU countries are increasing and patients with chronic conditions are subject to specific vulnerabilities and face multiple barriers in accessing health and social care services. While universal health coverage is a well-recognised goal for all healthcare systems in the EU, this basic right is not yet a reality for all patients in the EU. All this comes at a time of even greater demand for healthcare and

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[1] OECD Ministerial Statement: The Next Generation of Health Reforms. Adopted at the OECD Health Ministerial Meeting; 17 January 2017; EC chronic disease reflection process, final report, 2013.

social support. **Access to medicines**, has become an urgent priority for the health systems and for patients. Key trends include an increase in specialty medicines; rising launch prices of new medicines; pockets of bad commercial practices; and the emergence of exceptional therapies where the usual cost-effectiveness logic no longer works.

The Council in its 2016 Conclusions asked the European Commission to conduct an analysis of the impact of existing industry incentives on medicines prices and access; the results of this study are expected in 2018 and will have important policy implications. **Generic and biosimilar medicines** are becoming increasingly available and may have a significant impact on equity of access by providing more therapeutic choices at more affordable prices.

The **quality of care** is closely linked to access, inefficiency and waste. EPF's patient survey exploring patients' perceptions of quality in healthcare confirms that persons with chronic conditions are more dependent on healthcare services than the average person; access to timely and accurate diagnosis is identified as a particular gap.

The Organisation for Economic Co-operation and Development (OECD) is currently developing a new international **benchmarking of health system performance** for "patients with complex needs", part of which will be a PREMs/PROMs[2] survey for people with chronic conditions. The aim is to support health systems to become more knowledge-based and person-centred; to achieve better governance, particularly by reducing waste; to understand and plan for complex care needs; and to understand and manage new technological developments. It is vital that the patient perspective is included in this process.

Undoubtedly, resources should be focused on providing **equitable care** that brings real benefit for patients and for society. This benefit can only be determined with the meaningful participation of patients and the integration of their experiences and preferences in the process of assessing value and value-for-money.

There is furthermore good evidence that patients, when appropriately involved in decision-making and given full information about treatment options, benefits and risks, tend to prefer less rather than more intensive treatment. However, **shared decision-making** is not embedded in patient care, patients are currently not being fully engaged and empowered, and thus the healthcare systems are missing out on a vital 'piece' of the sustainability puzzle.

Patient safety is the foremost attribute of quality of care. It is both a goal – a state of being that is free from harm – and a practice, i.e., processes and structures that aim to make healthcare safer. Safety figures have not improved much over the last decade, with adverse events occurring in around one in 10 hospitalisations. Such figures undermine patients' trust in the healthcare system. To address patient safety, it is vital to build a patient safety culture, as patient safety is often linked with failures in the system.

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[2] PREMs: Patient Reported Experience Measures; PROMs: Patient Reported Outcome Measures.

The role patients and families can play in improving safety is increasingly recognised but still a hugely underused and undervalued resource. EPF's internal member survey in 2013 showed that patient representatives' awareness of the EU Council recommendation on patient safety was surprisingly low, and **patient involvement** was seen as a poorly implemented area at national level. Moreover, patient organisations did not receive much information from their national bodies.

In a project funded by the EU, the OECD is currently addressing indicators for **patient-reported safety incidents** (PRIMs). The patient perspective is crucial here, to ensure that the eventual questionnaires are designed to measure that which is most important to patients, but also to ensure that they are feasible to implement in practice.

4. Target Groups of EPF's Main Activities for 2018

The primary target groups of EPF's activities in 2018 will be:

- Our **member patient organisations**;
- The wider **patient community**; and to an extent 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, primarily in the context of the EU Presidencies of Bulgaria, Austria and Romania;
- The **European Medicines Agency** (EMA), **Fundamental Rights Agency** (FRA) and **European Centre for Disease Control** (ECDC);
- **International organisations**: OECD, WHO European Region;
- **Health stakeholders**, including public health NGOs, medical professionals' organisations, academia/research community, scientific/professional bodies, and industry primarily through trade associations;
- **Media** at EU and national levels.

5. EU Added Value and Expected Impact of the Activities Scheduled for 2018

Patient involvement in healthcare policy adds value from a moral perspective, because the decisions directly impact patients' lives and well-being; but also from a practical perspective, because policy 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 the policy-making process** on issues which have a direct impact on patients' lives. 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.

EPF is in a unique position, **connecting patient communities with EU developments**. Our work to **empower patient organisations** supports them in becoming effective, credible civil society actors. We play an important "bridging" role by supporting patients' capacity at national level, inter alia through communicating EU developments in lay-friendly ways, and by conveying information on patients' lived reality from across the EU to the European level.

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. EPF's 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 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 the future of EU health policy and partnerships with diverse actors. We link with both EU and international bodies, and can point out relevant synergies or gaps. We will participate in collaborative initiatives such as the EU Health Policy Platform and the Solidarity Corps, 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. During 2018 we will revisit our ethics framework to ensure that it remains fit for purpose.

6. Methodology

Our work will be conducted according to EPF's three mutually reinforcing pillars of work:

- Policy and advocacy;
- Projects;
- Capacity-Building.

In 2018 this methodology will be applied to all our objectives in a cross-cutting manner: our capacity-building efforts will strengthen the expertise of our members and their ability to feed in our policy and advocacy activities. Similarly, the data collected and good practices identified in European projects will reinforce the evidence-base of our policy work.

6.1 POLICY AND ADVOCACY

This pillar refers to the elaboration and drafting of the positions of EPF, and to our advocacy work. This is where the voice of the patient community is shaped, where our campaigns are born.

Key activities:

- Surveys with members and the broad patient community;
- Policy consultations with EPF membership;
- Desk research and interviews on specific topics of interest;
- Meetings with key stakeholders;
- Meetings of our working groups and bilateral exchanges;
- Drafting of position papers;
- Exchange of views with key decision-makers (representatives from the European Commission, European Parliament, Council, and at national level).
- Contribution to consultations from the European Commission;
- Participation in experts' groups;
- Representation in international conferences and fora.

6.2 PROJECTS

EPF 's participation and leadership in projects bring significant benefits:

- Being part of innovative and ground-breaking research and public health projects and accessing to first-hand information;
- Collecting data that will inform and support our policy work;
- Exchanging best practices with stakeholders and contributing to the elaboration of common understanding;
- Voicing the patients' perspective and contributing to overcoming the culture of tokenism;
- Being in contact with individual patients, therefore reinforcing our representativeness.

In 2018, EPF will continue to invest in projects and expand its project portfolio to build expertise and collect evidence on new topics (digital health, meaningful patient involvement), in coherence with its policy objectives.

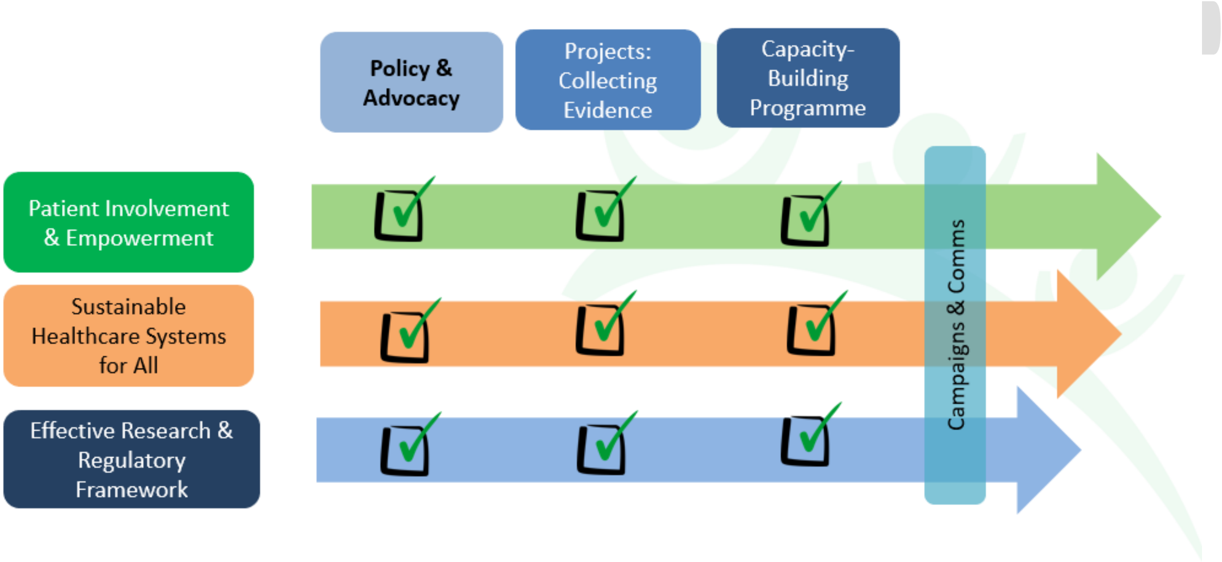
2018 will see the negotiations of the future EU funded research programme FP9. EPF will build on reflections initiated with the Value Plus project, to expand on the key messages for meaningful patient involvement in research projects. We will consult EPF members on their views and expectations on the scope and priorities of the next programme and provide feedback to the European Commission and the main stakeholders.

6.3 CAPACITY-BUILDING PROGRAMME (CBP)

The CBP is a long- term programme launched in 2012 to support the development of organisational capacities and advocacy skills of patient organisations, to enable them to be more effective in:

- achieving their objectives and aspirations
- feeding their experiences and expertise into the work of EPF and utilising the outcomes of our collective work in a national, and/ or disease specific context.

In 2018, EPF will expand its Capacity-Building Programme offer and widen its scope to include training modules on different thematic areas. Our trainings, learning materials, and patient-friendly information resources will help our member organisations and the wider patient community to grow in confidence and impact.



The three pillars of EPF's actions (policy & advocacy, projects, capacity-building) will be applied across EPF's three key thematic objectives for 2018.

7. Governance

- **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.
- **EPF's Board:** the role of the EPF Board, composed of 9 members, meets around four times a year, physically or virtually. The Board may form working groups to assist in the work and direct activities of EPF.

- **Advisory Working Groups:** EPF will have two topic specific Working Groups: on Universal Access to HealthCare and Digital Health. The working groups are open to all EPF members and complement the wider EPF membership consultation process.
- **Strategic Planning Process:** in 2013, EPF adopted its current strategic plan for the period 2014-2020. A mid-term review of the Strategic Plan is currently being developed and will be published at the end of 2017.
- **Reflection on wider Europe:** recognising that EPF's members often cover areas beyond the EU, we will explore avenues to expand our membership.
- **Constitutional reform:** Over the next three years, EPF will conduct a constitutional reform to amend its statutes and ensure they enable our organisation to be as inclusive and effective as possible when working towards achieving its vision.

8. Planning and implementation of the EPF's annual work plan for 2018

EPF's 2018 Work Plan is structured around **three objectives** which are complemented by cross-cutting activities:

- **(1) Patient involvement and empowerment;**
- **(2) Sustainable healthcare systems for all;**
- **(3) Effective and patient-centred research and regulatory frameworks**.

8.1 OBJECTIVE 1 – PATIENT INVOLVEMENT AND EMPOWERMENT

In 2018, EPF aims to take one step further and encourage the implementation by the stakeholders of the public health community and beyond of two concepts which we have been working on and developing for several years: Patient involvement and patient empowerment.

Under this two-fold objective, we will work towards implementation of recommendations from our previous body of work in policy and projects, including the concept of meaningful patient involvement (Value+, 2009), the EPF Charter and Roadmap on Patient Empowerment (2015-16), and relevant position papers.

We will also look at developing further the capacity of patient organisations, including youth organisations, equipping them with tools and expertise to enable them to play their legitimate role in the health sector.

Meaningful, structured and systematic patient involvement

EPF aims to take patient advocacy to the next level to promote wider understanding and acceptance of the concept of **meaningful patient involvement**, embedding meaningful patient involvement at all levels of the health system, and encouraging the implementation of good practices that are “patient approved”. The work undertaken in 2018 will be of major importance for substantial activities and deliverables in 2019.

During 2018 we will commence preparatory work under this work stream, liaising with our networks to start mapping existing initiatives on patient involvement in different areas, such as research, Health Technology Assessment (HTA), service improvement, quality initiatives, and so on. This is also a cross-cutting objective that EPF puts into practice in all our advocacy work in different areas.

Health Literacy

Reliable, understandable, relevant and easily accessible information is the cornerstone of individual patient empowerment and of meaningful patient involvement in health policy.

Our 2018 work plan places emphasis on continuing our advocacy role on the importance of **health literacy in all policies**. In addition, we contribute to patients’ health literacy in all our work by communicating patient friendly information on complex policy and topics.

In 2018, EPF will develop a briefing on **generic medicines** to support the development of an EPF position statement in 2019. Further, we will work in concert with the European Medicines Agency (EMA) and European Commission DG Grow regarding information for patients on biosimilar medicines.

We will develop our role in the context of **vaccine confidence,** with a dedicated project in this sphere.

We will also work with the ECDC and support the International **Antibiotic Awareness Day,** and with EMA to support its role as trusted provider of evidence-based information for patients and the public.

Strengthening the Capacity of the Patient Community

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 shape strategic direction of EPF and the patient movement in Europe. In 2018 the event will be linked to EPF Annual General Meeting to ensure a high level of participation.

With the **Patient Advocates’ Seminar (PAS),** to be organised in the second half of the year, EPF will aim to inform patient organisations of EU health policy developments, engage members in EPF’s advocacy work, and build mutual understanding and cooperation among members on a regional and European level.

We will continue to strengthen the capacity of patient leaders at national level with a **capacity-building module dedicated to positive organisational governance** gathering patient organisations from Bulgaria, Hungary, Poland, Romania, Slovakia and the Western Balkans.

In addition, **national modules** will be rolled out in Bulgaria, Romania and Poland with various thematic training modules, in cooperation with the National Coalitions, our members and partners on the ground.

EPF will also propose new formats and tools specifically designed for its members. We will propose regular online **Breakfast Briefings** and **webinars**, which will respond to a double objective: increasing members' awareness and familiarity of the EU health policy stakeholders and developments and discussing potential actions for the patient community.

Building on the expertise that EPF and its members have acquired over the years, in 2018 we will map and gather learning material producing a **EPF Learning Material Mapping Report** that will be the first step for the creation of the EPF Resource Centre by 2021.

Preparing the Next Generation of Patient Advocates

The EPF Youth Group (YG) represents young patients within the EPF community. This diverse group of youngsters aims to raise awareness about young patients' lives and addresses cross-cutting issues which affect their quality of life.

Continuing the activities implemented in 2017, in 2018, the Youth Group will focus on the issues of non-discrimination and promotion of principles for protection against discrimination on grounds of chronic diseases in the EU. The YG and EPF will run a joint awareness-raising campaign on **non-discrimination in access to healthcare, the workplace and education.**

The Youth Group will also organise the second edition of its **Summer Training Course for Young Patient Advocates – Leadership Programme**, an exciting and unique opportunity offering a tailored high-quality training to young patient advocates or representatives of young patient advocates who have the motivation to learn more about the advocacy and maximise their leadership potentials in real environment.

Finally, the YG will work towards collaborating further with key stakeholders and initiatives:
- It will strengthen its **relationship with the EMA** following the 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 multi-stakeholder initiative on future innovative scenarios for health.

Reinforcing Patient Organisations' Legitimacy and EPF Representativeness

In 2018, EPF will work on increasing its representativeness in terms of diseases and geographical coverage.

To do so, EPF will **map its presence and representativeness** across Europe and in terms of diseases and produce a report, presenting all European legitimate patient organisations that are not yet part of the EPF community. Thanks to this document EPF will have a clear view of the patient movement and will reach out to new potential members to promote membership.

We will also aim at reinforcing **patient organisations' legitimacy and transparency**. We will support our members in implementing the transparency guidelines developed in 2017 by organising a webinar on transparency. In parallel, EPF will develop a membership certificate for each approved new member to foster transparency and recognition as well as a sense of community.

Social media and web 2.0 have enabled the emergence of new actors in the patient movement, such as **online communities, informal networks and key opinion leaders**. In 2018, EPF will map these new actors with the view of assessing their work and engaging with them in a constructive dialogue, identifying synergies and potential areas of collaboration.

An Empowered and Engaged Community

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.

In 2018, we will pilot two new tools: **the members' expertise database**, clustering members by policy areas they are interested in, and the **membership participation monitoring tool**. The first will enable EPF to share targeted information and tap into members' expertise when necessary. The second will allow the Secretariat to assess the level of engagement of each member and act, making sure our community continues to be as vibrant and participatory as possible.

Complementary Activities and Projects

In 2018 EPF will contribute to a wide range of projects in line with this objective such as:

CHRODIS-PLUS Joint Action

CHRODIS PLUS is a Joint Action led by the Health Institute Carlos III (ISCIII -Spain) and Vilnius University Hospital Santaros Klinikos (VULSK-Lithuania), involving 42 partners from 20 Member States. Launched in September 2017, the joint Action will run for 3 years.

Activities of CHRODIS PLUS will include policy dialogues (14 at national level, and 2 at EU level) to raise awareness and acceptance in decision-makers on improved actions to combat chronic diseases and pilot projects on health promotion & primary prevention; integrated multi-morbidity care model through ICT-based patient empowerment and employment.

EPF will play a critical role in the Joint Action, by ensuring the patient perspective in workstreams on multi-morbidity, employment, transferability of good practices to chronic conditions and dissemination, is well acknowledged.

PRO STEP

In early 2018, the **PRO STEP** pilot project coordinated by the European Health Futures Forum and EPF will come to an end. The other partners are the Avedis Donabedian Research Institute (FAD), the Danish Committee for Health Education (DCHE), the Institute for Medical Technology Assessment (iMTA) of the Netherlands.

The tender foresees a study and the establishment of a platform of experts exploring and proposing methods of promotion of self-care for chronic diseases. PRO STEP is a tender project funded by the EU Health Programme.

EUPATI

After a successful transition period in 2017 from an IMI project to an EPF-led programme, **EUPATI** will continue its core activities in 2018 whilst keeping the spirit of a Public Private Partnership and exploring models of sustainability for the programme in the future.

These core activities include the promotion of the EUPATI Toolbox, the completion of the third Patient Expert course (including two face-to-face training events in Madrid), and support for the EUPATI National Platforms (ENPs). A second '*train-the-trainer*' capacity building event will be organised in 2018, demonstrating how to use the EUPATI Toolbox content to train advocates at national and local level.

EPF will also continue to support the EUPATI Fellows network and help facilitate speaking engagements to promote EUPATI and patient engagement. The EUPATI Team will continue to update Course and Tool box content to reflect legislative and regulatory changes. EUPATI will continue hosting webinars on a variety of topics related to patient engagement in medicines R&D.

In terms of funding for 2018, approximately 70% for EUPATI in will be provided by committed private partners with the remaining 30% coming from in-kind contribution from public partners including ISPOR and DIA.

PREFER

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 will be participating 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.

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

8.2 OBJECTIVE 2 – SUSTAINABLE HEALTHCARE SYSTEMS FOR ALL

Within this thematic area, EPF will be working towards developing a vision of what constitutes a **high-quality, safe, equitable and sustainable healthcare system from the patient perspective**. During 2018, EPF will continue to work towards reducing health inequalities by promoting sustainable and patient-centred universal access to healthcare. This objective includes policy and advocacy activities relating to access, equity, quality and patient-centeredness of healthcare.

Universal Access to Healthcare

Following EPF's 2017 Campaign on access to healthcare for all, EPF will promote its Roadmap on taking action to achieve universal health coverage for all by 2030, using it as a reference document for all our activities on access to health. Together with our members, we will continue to inform policy-makers and various stakeholders of unmet needs and barriers to access by supporting our members in organising national activities on this topic. EPF will also raise awareness of the **UN Sustainable Development Goals** and the target of achieving universal health coverage by 2030 amongst its membership.

EPF's internal **working group on Universal Access to Healthcare** will drive this stream of work. We will also engage with relevant stakeholders, notably with organisations representing groups that are vulnerable to health inequalities, and will work closely with the multi-stakeholder Patient Access Partnership (PACT), supporting its work in promoting a comprehensive evidence-based approach to measuring access and ensuring that the issue of access is high on the political agenda at both European and at national level.

EPF will work together with members to raise awareness of the role of **nutrition** in managing long-term conditions, maintaining optimal health and quality of life by disseminating our position statement on information to patients on food and nutrition (2017) and the renewed EU Patient Agenda on Nutrition (2017) and developing information materials on nutrition, translating guidelines into lay-person summaries, sharing testimonials, and developing a code of conduct for cooperation between patient groups and the (medical) nutrition .

A significant part of our work will be dedicated to **access to medicines** and their **affordability**. EPF is already engaging with relevant initiatives, having participated in the Fair Pricing Forum organised by WHO with the Dutch Health Ministry, and the OECD civil society consultation. In addition, EPF will develop a briefing for patients on generic medicines, in synergy with the EMA information on biosimilar medicines, to support better understanding of generics, and how they are regulated.

Social Inclusion and Non-Discrimination

EPF is committed to promoting **patients' rights and non-discrimination**. In 2018, we will continue to advocate for the development and implementation of policies, strategies and initiatives that eliminate discrimination, reduce stigma and promote the inclusion of patients with chronic diseases in healthcare, education, employment and society. We will develop awareness tools with the EPF Youth Group, promote EPF's recommendations on equal treatment in the workplace, education and in healthcare, and disseminate tools developed in 2017.

We will continue to cooperate with the **EU Fundamental Rights Agency**, as a participant of the Fundamental Rights Platform, working towards eliminating stigma and discrimination on the grounds of health status. Furthermore, we will strengthen alliances with NGOs representing **vulnerable groups** and support our members in implementing actions set out in our 2016 Inclusiveness Roadmap.

These activities will also contribute to the implementation of relevant principles defined in the European Pillar of Social Rights on equal opportunities, access to healthcare and protection against discrimination in employment and in healthcare. EPF will actively contribute a patient perspective to legislative initiatives required by the Pillar as and when appropriate.

A Patient Perspective on Health Systems' Performance

Our 2018 work follow up on the recommendations of the EPF 2017 Task Force on Empowerment of Patients and Families in the area of **patient safety** to advocate for the recognition of patients' contribution to safety in healthcare. Ensuring that patient-centredness is evaluated as a part of healthcare quality has been a key advocacy objective for EPF in past years. We are pleased that this has been adopted as a policy priority and we will be proactive in contributing the patients' perspective to the new OECD PARiS initiative on indicators for PROMs and PREMs.

We will draw on the insights from our work on quality (2016) and bring a critically constructive perspective by exploring how "what matters to patients" can be best measured as part of healthcare quality. A particular focus will be on patients with multi-morbidities, integrated care and self-management.

On **healthcare efficiency**, we will commence a dialogue with our member patient organisations on what patients would define as "low" or "high" value care and "waste of resources" in the context of health systems sustainability and quality of care.

We will continue to engage with WHO Europe on health systems strengthening and on person-centred, integrated health systems, inter-alia by attending relevant policy meetings and providing patient expertise.

Digital Health and Health Data

EPF's work in 2018 will relate to patient-centred digital healthcare solutions and services; access to, collection and sharing of and use/reuse of patients' health data; and electronic health records, with a focus on ethical sharing, patients' privacy and respect for patients' choices and preferences.

Following EPF's 2017 briefing on **big data in health**, in 2018, EPF's objective will be to further inform our members on the topics of digital health and health data and begin to identify core principles from the patients' perspective, also in the light of the forthcoming Commission Communication on digital health. To guide this work stream, we will set up a working group on Digital Health and Health Data, made up of EPF members and external experts and advisers, whose role will be to bring knowledge of developments in the field and to stimulate thinking.

We will develop information resources on **digital health** and **health data** with the aim to inform patient communities on this subject. Specific actions include dissemination of information to patient organisations about health data, its collection, sharing and use, to raise awareness and empower them to be active in this highly technical area.

EPF will also develop a report on the results of the patients' survey on **electronic health records and data sharing** (conducted in 2017-2018). Patient evidence generated from this survey will be used to contribute to EU and national policies, encouraging patient-centred design and delivery of digital healthcare solutions and services. In addition, we will continue to engage in multi-stakeholder efforts, including the eHealth stakeholder group and numerous other fora to ensure that the patient perspective is embedded in such initiatives.

Complementary Activities and Projects

COMPAR-EU

In 2018 EPF will contribute to the Horizon2020 project **COMPAR-EU** that aims to identify, compare, and rank the most effective and cost-effective self-management interventions. The partners are FUNDACION AVEDIS DONABEDIAN (Spain - coordinator), UOI (Greece), Nivel (The Netherlands), IR-HSCSP (Spain), iMTA (The Netherlands) and OptiMedis AG (Germany).
Ultimately, COMPAR-EU will facilitate informed decision-making and supporting implementation of best practices in different healthcare contexts.

8.3 OBJECTIVE 3 – CONTRIBUTING TO EFFECTIVE RESEARCH AND REGULATORY FRAMEWORKS

Under this objective, EPF will monitor, support and report on the effective implementation of key EU legislation to ensure that the patients' interests are reflected in the legislation under development or effectively implemented in the case of recently adopted pieces of legislation.

Health Technology Assessment (HTA)

Aware of the growing importance of HTA and of its impact on access to innovative health technologies, in 2018 EPF will continue to contribute to the evolving initiative that started in 2016 with the launch of the public consultation. We will closely follow the developments of this dossier, consult EPF membership and in cooperation with the Patient and Consumer Group of the HTA Network Stakeholder Pool, feed from the patient perspective the design of a legislative initiative on the future scenario for collaboration in HTA at EU level.

EPF will facilitate better understanding of this policy dossier among EPF members, through posts, training tools (already developed and in use within EUPATI), and conference calls of the Informal Working Group on HTA. In parallel, we will collaborate with the HTAi and contribute as active member of the its Steering Committee of the Interest Group on Patient and Citizen Involvement in HTA.

Clinical Trials

In 2018 EPF will provide an information resource explaining the **clinical trials regulation** and its key aspects identified by patients: the lay summaries, including the Guidelines published by the European commission in August 2017, the transparency aspects of the regulation, and the provisions regarding informed consent, all of which will have significant impact on the information that will be available for patients and lay persons as well as potential for increasing patients' engagement in clinical research.

Pharmaceutical Regulation and the European Medicines' Agency (EMA)

EPF will continue to engage actively in the EMA Patient and Consumer Working Party (PCWP), including as member and as co-chair. We will contribute to EMA events and task forces as required and further strengthen our role in disseminating information from and about the EMA to patients, ensuring a good understanding of its role. Given the uncertainties around the capacity of the EMA to undertake certain planned activities due to Brexit and its foreseen relocation, we will contribute to the activities agreed under the work plan of the PCWP and engage with specific topics as relevant, such as adaptive pathways, the PRIME project, and pharmacovigilance.

Medical Devices and In Vitro Diagnostic Devices

Having engaged closely in the initial legislative process, we will monitor the implementation of the Medical Devices and In vitro Diagnostics regulations, contributing to the development of secondary legislation as and when appropriate. We will continue to communicate on the new legislation, it's implementation and impact for the patient community, in particular with regards to patient safety, access and information to patients, and support patient organisations' participation at national level.

We will continue to advocate for patient involvement in the implementation phase as member of the EUDAMED task force of the European Forum for Good Clinical Practice (EFGCP) Medical Technology Stakeholder Alliance to ensure a patients' perspective on the development of the future EU database; and our own Patient-MedTech dialogue, organising two annual workshops between EPF members and members of MedTech Europe with the aim of exchanging perspectives, promoting good practice, and agreeing on essential elements for ethical and transparent relationships between patient organisations and industry.

Complementary Activities and Projects

EUnetHTA Joint Action 3

Launched in March 2016, the **EUnetHTA** JA3 will focus on early dialogues, governance, 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.

EPF will use these platforms to gather information, exchange good practice and to reinforce key policy messages on topical issues, in line with its focus on health technology assessment. http://www.eunethta.eu/

8.4 COMMUNICATIONS AND DISSEMINATION

The 2018 EPF Dissemination plan will follow the 2018-2021 overall EPF Dissemination dual objective: (1) communicating to inform and (2) communicating to engage and convince our audience. EPF will produce clear contents (online and printed) to inform our target audiences. Short and illustrated-based messages will be used as a gateway to lead audience towards more structured and comprehensive background documents, and as a useful support for face-to-face communication or public representation.

Communicate to Inform

- EPF's **website** is our window for the outside world, displaying information and updates aimed at diverse target groups: decision-makers, health stakeholders, lay patients, at local, regional, and national level. Our website will make our messages widely accessible and updated on an ongoing basis.

- Our monthly Newsletter will continue to provide the latest policy, projects and event developments.

- Upon confirmation of its pilot phase in late 2017, the **EPF Magazine** will be produced on a regular basis in 2018 with the aim to better promote EPF policy positions, and to raise EPF profile as an influential player at the EU level. The magazine will be targeting high-level EU officials, politicians and key opinion leaders and consist of email updates and of a folder including a print out of these updates, recent policy factsheets and details about EPF.

- The **EPF Annual Report** showcases our achievements, demonstrates our performance against our objectives and shows the added-value of patients' contribution to EU policy and programmes. The 2017 Annual Report (to be published in 2018) will include cross-media and innovative digital content to promote interaction and increase visibility of EPF's activities.

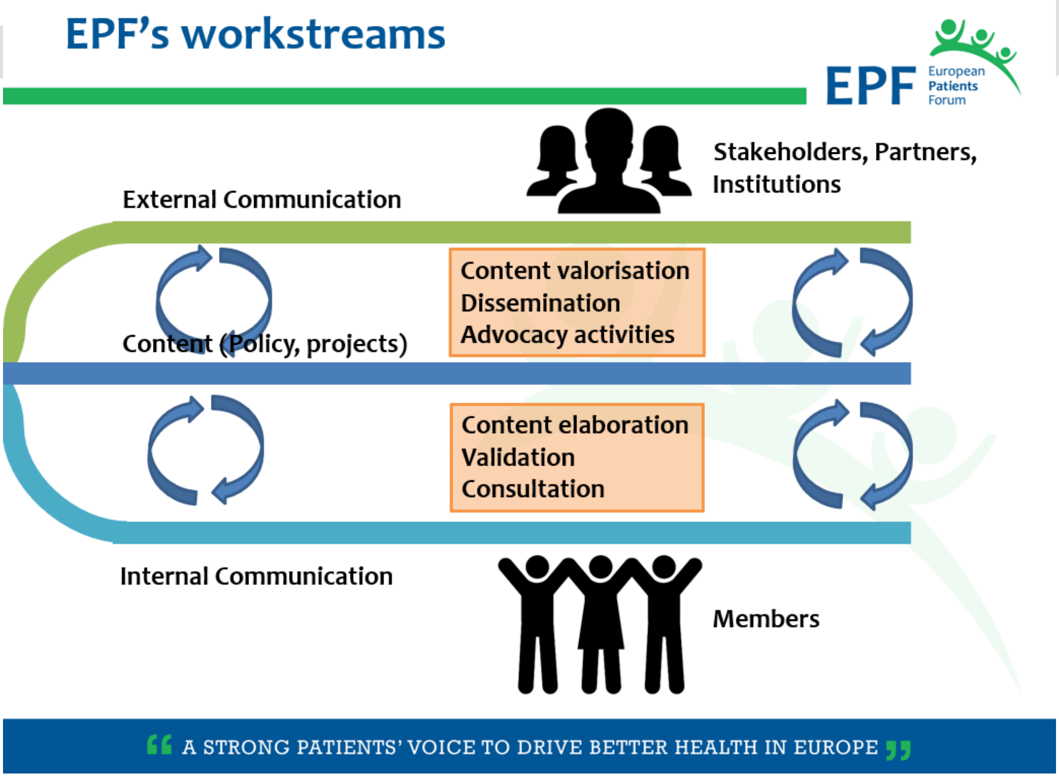
- Our **policy factsheets** will follow the same route of cross-media digitalisation, and will constitute a compelling tool supporting our advocacy work in conveying key messages in simple format for face-to-face meetings with policy makers and stakeholders. These policy factsheets also serve the purpose of informing EPF members on topics of interest to them.

- **Video** is an effective medium to relay our messages to different target audiences. In 2018, we will produce a video on a policy topic linked to our strategic objectives. We will also use **videos** to promote engagement by sharing EPF members' stories, reaching out to EU citizens and policy makers, to support our advocacy and campaign activities.

- **Weekly Insiders' Mailing** – this members-only report highlights the main EPF activities, policy consultations, events and news relevant to the patient community on a weekly basis. This is central to ensuring an excellent flow of information to our members.

Communicate to Engage & Convince

- We will develop innovative **social media content** (e.g. polls, chats, videos) to increase interactivity with and feedback from external stakeholders.
- EPF's **Blog** demonstrates the work our diverse and growing membership is doing for its patient constituency. We will provide at least one blog entry to our members per month, including a link and short summary in our newsletter.
- We will continue to promote **EPF Connect**, the online platform for EPF members to share and exchange, as well as informal meetings with our members, strengthening their capacity and the bonds in the patient community.
- An integral part of our communication strategy, targeted and extensive **speaking engagements** and human interactions are very effective for reaching target audiences and generate requests for further information and collaboration. In 2018, we will ensure maximum value from engagement by reinforcing it through key messages on social media and follow-up communications.



EPF 2018 Campaigns: Contribution to the European Parliament's Elections 2019 and the future of Europe

European Parliament Elections 2019

Every five years the European Parliament elections take place, and a new Commission is nominated.

Patient advocacy at EU level is crucial to drive positive change for patients. With 74 members, representing the interests of an estimated 150 million people with chronic diseases, EPF carries the voice of a high proportion of voters for the next EU elections.

As the 2019 European Parliament Elections approach, we will actively inform candidates to the European Parliament of what is important for the patient community and advocate for the patients' voice to be included when future MEPs set the priorities for the new legislature.

Future of Europe = Health

In 2017, EPF, together with the European Public Health Alliance (EPHA) and several other public health NGOs initiated a campaign to raise awareness on the importance of continued health collaboration at EU level. The #EU4HEALTH campaign defends the idea that EU health policies bring the EU closer to its citizens, by protecting patients and consumers against cross-border threats and improving people's health and well-being and ensuring that health is appropriately addressed in all policies.

In 2018, as the debate of the Future of Europe and the shape of its responsibilities intensifies we will build on these actions and contribute to the design of the future multi-annual work programme of the European Commission with concrete proposals on the policies and actions.

We will continue to call for a EU action on health that fosters cross-country collaboration, complements the action of Member States and supports them in addressing the unprecedented challenges the EU is facing. We will work in concert with our members and address the European Commission, Members of the European Parliament, and Member States.

8.5 EPF'S ACTIVITIES FOR 2018

Objective 1 - **Patient Involvement & Empowerment**			
	Patient involvement	**Patient Empowerment & Health Literacy**	**EPF Youth Group**
Objective pursued	Promoting wider understanding and the embedding of meaningful patient involvement in all levels of the health system	Equipping patient organisations and individual patients with tools and expertise to enable them to play their legitimate role in the health sector	Preparing the next generation of patient advocates
Policy & Advocacy Activities	- Mapping existing initiatives on **Patient involvement,** HTA, service improvement, quality initiatives, patient-centred design and delivery of digital health solutions & services	- Reinforcing patient organisations' capacity; - Reinforcing patient organisations' transparency and legitimacy - Advocating for **health literacy** in all policies	- Raising awareness about young patients' lives and addressing cross-cutting issues which affect their quality of life
Capacity-Building		- **EPF Leadership meeting;** - **EPF Patient Advocacy Seminar;** - **EPF Training module** on Organisational Positive Change for 20 organisations; - 6 Webinars; - Training for 10 organisations in Romania, Bulgaria and Poland (tentative); - Mapping of EPF learning materials: "Towards an EPF Resource Centre"	- Preparation of material for young people on the theme of discrimination; - Organising a **Summer Training for Young Patient Advocates**
Events (internal & external)		- EPF Leadership meeting; - Patient Advocacy Seminar - National Coalition Building Workshop (Austria)	**- Summer Training for Young Patient Advocates** - Youth Group meetings x2
Comms & Campaigns	EPF Magazine for decision-makers & stakeholders	- EPF Breakfast Briefings - EPF Weekly Insiders'	Youth Group campaign on discrimination
EPF Project Portfolio	- CHRODIS +; - PROSTEP; - PREFER	- EUPATI	
Relevant EU Initiatives			European Solidarity Corps
Link with Stakeholders	EC, academia, patient community	EMA, European Commission, ECDC, national patient organisations	European Health Parliament; EMA

Objective 2 - **Sustainable Healthcare Systems for All**				
	Universal Access to Care	**Social Inclusion & non-discrimination**	**Health Systems' Performance**	**Digital Health and Health Data**
Objective pursued	Working towards the reduction of health inequalities by promoting sustainable and patient-centred universal access to healthcare	Promoting patients' rights and non-discrimination	Ensuring that patient-centredness is evaluated as a part of healthcare quality	Informing patient communities on these topics, further developing patient-centred principles on digital health and data and engaging in numerous multi-stakeholder efforts and for a, ensuring the patient perspective in such initiatives
Policy & Advocacy Activities	-Promote **EPF's Roadmap 'Taking Action to achieving universal health coverage for all patients by 2030'** -Informing policy-makers and various stakeholders ofunmet needs and barriers to access and supporting our members in organising national activities on the topic **- Access to medicines & affordability**: producing a revised and strengthened position paper **- Cross-border healthcare:** consolidating EPF's network of patient advocates	- Promoting **EPF's recommendations on equal treatment** in the workplace, in education and in healthcare - Supporting EPF members to take up recommended actions of the inclusiveness Roadmap - Contributing a patient perspective to legislative initiatives required by the European Pillar of Social Rights as and when appropriate	- Contributing to initiatives on **health systems performance assessment**, including the OECD PARIs Initiative on indicator for PROMS and PREMS - Providing patient input on the survey on **patient reported safety incident measures** (PRIMs) - **Healthcare efficiency**: initiate a dialogue with patient organisations on "low" or "high" value care	- Publishing a report on the results of the patients' survey on **electronic health records and data sharing** - Engaging in dialogue with our members on these topics in order to further develop the patient-perspective and fundamental principles (planned for 2019)

Capacity-Building	- Raising awareness of the role of nutrition in managing long-term conditions, maintaining optimal health & quality of life; - Organising a **workshop on incentives** **- Briefing on generic medicines;**	- Encouraging EPF members to implement actions set out in EPF's 2016 inclusiveness Roadmap - Development of awareness tools with the Youth Group	- Initiating a reflection within the patient community on **"low"/"high" value care and waste of resources**	- Development of **information resources on health data and digital health (e.g. webinar on EHRs and sharing of health data survey results)**
Events (internal & external)	- EPF Working Group on UAC (2x) - Workshop on Incentives			- EPF Working Group on Digital Health
Comms & Campaigns	- Dissemination of information on: UN SDGs, nutrition, generic & biosimilar medicines - Information campaign on vaccination	- Dissemination of the tools on discrimination developed in 2017 - Youth Group campaign on discrimination		- Dissemination of information resources on digital health
EPF Project Portfolio			- COMPAR-EU	
Relevant EU Initiatives	EU incentives study State of Health in the EU European Semester and CSRs EC Expert Panel Opinion on benchmarking access EU Pillar of Social Rights	European Pillar of Social Rights	OECD PARiS initiative on indicators for PROMs & PREMs	European Commission's Communication on digital health
Link with Stakeholders	WHO, OECD, EMA, European Commission's DG Grow, PACT	EU Fundamental Rights Agency; NGOs representing vulnerable/ underserved groups (e.g. PICUM, FEANTSA, EDF, EPHA, ILGA Europe, Age Platform Europe)	OECD; European Commission's expert group on workforce; OECD initiative for assessing professional skills and attitutes for patient-centred care; WHO Europe	eHealth Stakeholder Group, Member States, Academics, industry, IT experts, payers, multi-stakeholder groups

	Objective 3 – **Effective Research & Regulatory Framework**	**EPF General Operations**
	HTA; Clinical trials; Medical devices & IVD	**Membership, Governance**
Objective pursued	Monitoring and supporting the implementation of EU legislation on Clinical Trials, medical devices and IVD; Contributing to the future of HTA	Ensuring good governance, the legitimacy and representativeness of the network, and fostering transparency and ethics
Policy & Advocacy Activities	- **Medical Devices & IVD:** Monitoring developments regarding secondary legislation - Contribution to the future of **HTA**	- **Representing EPF at major health events (e.g. international conferences, EU Presidency and European Commission events)**
Capacity-Building	- Production of information resource on clinical trials regulations - Developing and sharing information material on HTA	- Internal capacity-building, consolidation of HR policy, risk management, fundraising; - Conducting a mapping exercise and publishing a report on EPF's presence & representativeness (disease, geographic) - Recruitment of new members - Development of an EPF Membership Certificate - Development of Members' expertise tool and participation monitoring tool
Events (internal & external)	EPF Informal group on HTA	- Annual General Meeting - Board meetings x4 - Elected Officers meetings - EPF Weekly Team meetings
Comms & Campaigns	- Communicate on new legislation and its impact for the patient community	- #EU4HEALTH Campaign; - "The voice of patients in the 2019 elections"
EPF Project Portfolio	- EUNetHTA	
Relevant EU Initiatives	Development of the future of HTA	- Future of the EU debate; - Upcoming 2019 EU elections

8.6 EVALUATION

EPF strives for excellence and is a learning organisation committed to evaluate and always improves its way of working.

On-going evaluation of the Work Programme, in line with agreed measurable performance indicators and target for each strategic goal, has been intrinsic to EPF developments over the past five years.

Strategic monitoring and evaluation will be designed and carried out internally by the EPF Secretariat.

EPF has developed for the 2018 work plan an evaluation framework in respect of each operational objective based on a logical framework matrix linking each activity to measurable outputs and outcomes and when possible impact indicators.

EPF commits itself to regularly update the evaluation matrix and to organise evaluation meetings, involving all the key stakeholders, after completion of each project/activity.

The evaluation matrix will use the standard evaluation criteria: relevance of the action to overarching objectives and strategies, effectiveness of specific actions, efficiency in use of resources, social/organisational sustainability, and insofar as possible, impact of the specific action.

The evaluation matrix is also expected to identify successful strategies for extension/expansion/replication/adaptation of current activities, to identify new strategies, and to demonstrate EPF accountability to EPF members, patient organisations at large, and donors.

To evaluate EPF 2018 work plan, EPF Secretariat will use both quantitative and qualitative methods. EPF Secretariat will gather data and key information thanks to desk reviews of documents, policy deliverables and reports, online analytics (or online outreach) surveys and in person meetings with EPF staff members.

9. List of Annexes

Annex 1: List of Deliverables

Annex 2: Key Performance Indicators

Annex 3: Events and Meetings 2018

Annex 1 – EPF WP 2018
List of Deliverables

Objectives	Activities	Deliverables
Objective 1 - Patient Involvement & Empowerment	Status Report on Patient Involvement (internal)	- Review of the status of preparatory work in liaison with our networks on mapping existing patient involvement initiatives, practices and tools
	Leadership Meeting	- Leadership meeting agenda, participants list, presentations
	Patient Advocates' Seminar (PAS)	- PAS agenda, participants' list, presentations
	Summer Training for Young Patient Advocates	- Report of the Training
	6 webinars	- Podcasts of the webinars (6) - Recording of the webinars and ppt presentation;
	Mapping of EPF learning material and development of new learning materials	- EPF Learning material mapping report - Presentation, infographic
	Meetings of the Youth Group	- Meeting reports
	Youth Group-led campaign on non-discrimination	- Non-discrimination Campaign Toolkit
	National Coalition-building workshop (Austria)	- Report of the meeting
Objective 2 - Sustainable Healthcare Systems for All	Information to patients on UN SDG Health	- Factsheet on UN Sustainable Development Goal on Health
	Raising awareness of the role of nutrition and diet in managing long-term conditions	- Information materials on nutrition

	Development of information on generic medicines, including biosimilars	- Series of information resources/tools (Fact-sheet on generic medicines)
	Contribution to Commission DG Grow and EMA activities on biosimilar medicines	- Co-organisation of stakeholder session with DG Grow and participation in drafting EMA task group recommendation
	Patient survey on electronic health records and health data sharing	- Report of EPF survey on electronic health records and sharing of health data
	Information to patient organisations about digital health and health data	- Information resources on health data and digital health technology
	Contribution to OECD PROM/PREM/PRIM initiative including input to HCQI expert group meetings (2/year) at least until 2019	- Participation in OECD HCQI EG meetings, M5 and M11
	Lay-friendly information on patient safety (e.g. articles, podcast, factsheet…) and guidance for patients	- Lay-friendly information for patients on key safety topics (e.g. articles, infographics, podcasts including on antibiotics, vaccinations)
	Work with members to raise awareness of high/low-value care, commenting on OECD, WHO and other relevant initiatives	- Briefing for patient organisations on waste of resources in health systems and high/low-value care including commentary on evidence
	Further work with EPF Members on patients' rights and responsibilities	- Consensus paper on Patient's rights and responsibilities, building on previous work and in consultation with EPF members
	Participation in EMA activities, including PCWP, ad hoc initiatives and task forces; survey of EPF members on the impact of EU Pharmacovigilance legislation	- Participation at 4 meetings of PCWP as well as additional topical events where requested by the EMA or otherwise necessary
Objective 3 – **Effective**	Informing patients on EU Clinical Trials Regulation, including lay summaries,	- Lay-friendly and relevant information for patients on the EU Clinical Trials Regulation and its implications,

Research & Regulatory Framework	transparency, informed consent	including the lay summaries, e.g. factsheet, infographic, article, podcast
	Work with the Informal Working Group on HTA, monitoring and contributing to HTA legislative initiative	- Position paper on patient involvement in future HTA Strategy
EPF General Operations (Membership, Governance)	Annual General Meeting	- Annual General Meeting minutes
	Mapping update of EPF potential new members	- Mapping report on potential new members
	Contact with potential new EPF members & emerging national patient organisations	- 2 exchanges/year with potential new members
	Mapping of emerging actors	- Report on emerging networks and stakeholders in the patient community
	Board meetings and Elected Officers meetings	- Minutes of the Board meetings
	Development of a EPF Membership Certificate	- EPF Membership certificate template
	Development of Members' expertise tool and participation monitoring tool	- EPF membership engagement tool - EPF membership expertise tool
Comms & Dissemination	Production of information materials, infographics, videos, new website, weekly and monthly newsletters, electronic and in-print 'magazine'	- Weekly Insiders' mailing - Policy Factsheets - Videos - Website updates and maintenance - EPF Newsletters
	Weekly mailing to members, Production of videos, Breakfast Briefings (5/year)	- Breakfast Briefings - Weekly Insiders' mailing - Videos

Annex 1 – EPF Work Plan 2018
Key Performance Indicators

OBJECTIVE	OBJECTIVE 1 – Patient Involvement and Empowerment
Process Indicator(s)	**Target**
EPF consults members and stakeholders on available patient involvement initiatives and tools	Implementation of a Call for expressions of interest/submission of available good practices, resources, tools
EPF raises awareness on the added value of patient involvement among external stakeholders and policy-makers	5 speaking engagements at external events, incl. conferences, roundtables, workshops
Successful implementation of the capacity building strategy on leadership and advocacy skills	The three following meetings are successfully implemented with at least 20 participants from at least 5 different countries for each: - Training module on Organisational Positive Governance - Leadership meeting - Patient Advocacy Seminar
Successful implementation of the EPF Summer Training for Young Patient Advocates	The STYPA is successfully implemented with at least 35 participants from at least 10 different countries.
Successful implementation of the milestones to create an EPF Resource Centre	Delivery of the mapping report on EPF learning material
Implementation of the Youth Group Strategy with a specific focus on non-discrimination	2 Youth Group's F2F meetings held with 75% of the group members participating to at least one event a year
The EPF Youth Group develops a youth campaign on non-discrimination	Campaign material available by December 2018
Output Indicator(s)	**Target**
Training resources for EPF members are developed in 2018	Successful creation of 3 new learning materials in 2018
Power points and learning material developed for the Patient Advocacy Seminar, Leadership Meeting 2018 and	60% of EPF members and selected organisations participating at the PAS, Leadership Meetings and Module on Organisational Positive Governance in 2018

Module on Organisational Positive Governance	
Publication on EPF website of the reports of the Youth Group meetings	- 1000 page views by the end of 2018 from 10 different countries - Engagement strategy for the Campaign available by December 2018
Outcome/Impact Indicator(s)	**Target**
Through the events and learning opportunities offered by EPF, the capacity of patient organisations is strengthened on the topics discussed in the events or presented in the learning material	70% of the participants found that the event – material useful/ or that the event met their needs evidenced by a concrete example of how they could improve and advance their work after six months of the participation to the event.
Young patients and young people have a greater awareness of discrimination on the grounds of health status and are engaged in devising strategies to fight it	At least 100 young people engaged in the campaign by the end of 2018

Specific Objective	OBJECTIVE 2 - Sustainable Healthcare for All
Process Indicator(s)	**Target**
EPF raises awareness about access to healthcare, in particular universal health coverage and EPF's Roadmap, amongst its membership and other stakeholders	2 meetings held with patient organisations and stakeholders
EPF promotes non-discrimination and social inclusion in healthcare and employment	2 meetings held with stakeholders
EPF contributes the patient perspective to stakeholder meetings on quality of care	EPF speaking or otherwise substantially contributing to at least 3 meetings during the year
EPF contributes the patient perspective to stakeholders' meetings on digital health	EPF speaking or presenting at at least 2 meetings
Output Indicator(s)	**Target**

Publication of a Factsheet on UN SDG Health	300 factsheets produced and disseminated
EPF produces policy brief on high/low value care	
Outcome/Impact Indicator(s)	**Target**
EPF Members are able to cascade EPF's work on access at national level;	EPF members hold at least 1 meeting per year on access at national level
Take-up of the patient perspective on quality of care in OECD policy	The patient perspective is included in OECD documents/ outputs related to PROMs, PREMs, PRIMs
Building awareness and capacity of patient communities on universal health coverage, in order to be involved in and provide meaningful input to policy discussions in this area.	

Specific Objective	OBJECTIVE 3. CONTRIBUTING TO EFFECTIVE RESEARCH AND REGULATORY FRAMEWORKS
Output Indicator(s)	**Target**
EPF produces a series of information resources on digital health and data	Information resources on digital health and health data (e.g. webinar on survey results, factsheet)
Information for patients on the Clinical Trials Regulation	Lay-friendly, accessible information published on the implications of the "lay summaries", transparency provisions and informed consent provisions in the Regulation.
Outcome/Impact Indicator(s)	**Target**
Building awareness and capacity of patient communities on digital health, in order to be involved in and provide meaningful input to policy discussions on this highly technical area.	

Specific Objective	**EPF General Operations: Good Governance and Membership**
Process Indicator(s)	**Target**
- EPF's representativeness & growth strategy implemented (2018-2021); - Dissemination of the transparency and ethics guidelines - Implementation of the collaboration strategy with emerging network and stakeholders	2 exchanges in 2018 with potential members or emerging national coalitions. Successful organisation of one webinar on transparency guidelines in 2018 with at least 10 organisations participating or watching the recording. Production of a mapping report on emerging network and stakeholders

- Membership engagement strategy implemented;	70% of EPF members participate at minimum 2 key activities in 2018
Output Indicator(s)	**Target**
- Update of the mapping of EPF's potential outreach; 2 exchanges a year with emerging national coalitions or with prospective members focusing on a disease or geographical area where EPF is under represented; - Production of a podcast of the webinar on transparency and ethics; - Production of a report mapping emerging network and stakeholders;	- 100% clarity on the areas where EPF can still increase its representativeness and on the strategy to achieve potential growth; - 50 unique views of the recording of the webinar on transparency - 100% clarity on emerging networks and stakeholders and on potential next steps for EPF collaboration strategy
- Development of an EPF members' expertise tool; - Set up of an EPF Membership Participation tool;	- Identification of 5 areas of expertise of our members - 2 "inactive" organisations become active in 2018
Outcome/Impact Indicator(s)	**Target**
- EPF is successful in reinforcing its representativeness (in terms of diseases and geographical areas covered); - EPF is successful in disseminating transparency and ethics guidelines;	- 2 exchanges with non EPF members in 2018 - 100% of the organisations that join EPF 2018 sign the EPF code of conduct
EPF is successful at empowering its members and engaging them, the network is visibly more vibrant.	- 70% members active in the EPF community, with active meaning participating at least 2 key activities in 2018.

Specific Objective	Communication: Ensuring effective and targeted communications to inform and engage
Process Indicator(s)	**Target**
- Communications Plan 2018 implemented	Communication materials are developed according to plan, EPF events and activities are promoted and advertised to increase their outreach and impact.

Output Indicator(s)	**Target**
- Annual report produced and disseminated; - 3 Factsheets produced - 1 video produced - 5 Breakfast Briefings and 4 podcasts are produced - Weekly Insiders' (at least 25/year) - EPF Magazine (10 editions of the electronic updates, 5 editions of the print-out) – should this project be confirmed following the pilot edition (end of 2017).	
Outcome/Impact Indicator(s)	**Target**
- EPF is perceived as a reliable and high-profile partner; - EPF is perceived as a trusted relay of quality EU information for its members - EPF is perceived as the main source of information on patients' perspective on health-related issues for the stakeholders;	- 5 articles written about EPF and EPF's activities per year by media or external stakeholders. - EPF becomes more visible is able to increase the visibility of its members and of the patients' voice. o Facebook likes: 5% increase (2018: 8400) o Twitter followers: 10% increase (2018:4500) o Website unique visitors: 5% increase (2018: 60,000) o 5 bilateral meetings with policy-makers per year (Commission's officials and civil servants, Members of the European Parliament and their assistants)

Annex 3
EPF 2018 Events and Meetings

Please note this schedule is a preliminary draft

Last updated: 08 November 2017

DAY	January	Place
	EPF Webinar (topic to be determined)	Online
	Senior Management Team meeting	Brussels
	Weekly team meetings	Brussels
	February	
	Workshop on Incentives	Brussels
	Senior Management Team meeting	Brussels
	Weekly team meetings	Brussels
	March	
	CHRODIS+ Conference	Brussels
	Senior Management Team meeting	Brussels
	Weekly team meetings	Brussels
	April	
15	Board Meeting	Brussels
16	EPF Annual General Meeting	Brussels
17	Leadership meeting	Brussels
	Spring Youth Group Meeting	Brussels
	Webinar	
	Digital Health Working Group	Brussels
	Senior Management Team meeting	Brussels
	Weekly team meetings	Brussels
	May	
	Good Governance Face-to-face meeting I	Bratislava (TBC)
	Access Working Group Meeting	Brussels
	Senior Management Team meeting	Brussels
	Weekly team meetings	Brussels
	June	
	Senior Management Team meeting	Brussels
	Weekly team meetings	Brussels
	July	
	Summer Training for Young Patients Advocates	Vienna (TBC)
	Board meeting	TBC
	EPF Webinar (topic to be determined)	
	Senior Management Team meeting	Brussels
	Weekly team meetings	Brussels
	August	

	Senior Management Team meeting	Brussels
	Weekly team meetings	Brussels
	September	
	Board meeting	Brussels
	EPF Webinar (topic to be determined)	
	Industry roundtable	Brussels
	Youth Group Meeting	TBC
	Senior Management Team meeting	Brussels
	Weekly team meetings	Brussels
	October	
	European Health Forum Gastein	Gastein (A)
	Patient Advocates’ Seminar	Brussels
	Digital Health Working Group	Brussels
	Senior Management Team meeting	Brussels
	Weekly team meetings	Brussels
	November	
	Good Governance Face-to-face meeting II	TBT
	Access Working Group Meeting	Brussels
	Senior Management Team meeting	Brussels
	Weekly team meetings	Brussels
	December	
	Board meeting	Brussels
	EPF Webinar (topic to be determined)	
	Senior Management Team meeting	Brussels
	Weekly team meetings	Brussels