# EUROPEAN PATIENTS' FORUM WORK PLAN 2019

## Driving Better Health for Patients in Europe

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A STRONG PATIENTS' VOICE TO DRIVE BETTER HEALTH IN EUROPE

# Contents

# 1. Executive Summary – a Snapshot of 2019

The European Patients' Forum (EPF) is the only European-level, non-disease specific umbrella organisation representing patients with chronic diseases. It provides a vital cross-disease perspective from a wide patient community into EU policy-making on issues that have a direct impact on patients' lives in a national and regional context.

In 2019, EPF will continue to lead patient advocacy in Europe, providing **a cross-disease perspective** from the wider patient community **and shaping the policy-making process** on issues that are important to Europe's patients.

A major focus of our work will be the continuation of our #EU4Health campaign, stressing the importance of European health collaboration post 2020, and our input in the framework of the European Parliament Elections in May 2019 to ensure we have a critical mass of MEPs supportive to the mission of EPF in the next legislature. We shall continue to argue strongly for the patients' role in EU health funded research, and that the health component of Horizon Europe reflects the real needs of patients and citizens in relation to their health. Our leadership meeting will also place particular emphasis on looking to the future – and EPF' s own strategy post 2020.

We will continue monitoring as closely as possible the implications of Brexit as we approach the crucial March 2019 deadline, cooperating closely with fellow health stakeholders to mitigate the risks for European patients.

We will also hold EPF's very first Congress in November 2019, a culmination of much work and thinking to date on a structured approach to meaningful patient involvement in health systems' and services' design and strengthening.

A revised Constitution will be presented to the Annual General Meeting (AGM) that will widen EPF 's geographic remit and create an ethics committee.

Overall, our Work Plan for 2019 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 of our advocacy work. In 2019, EPF will promote wider understanding and acceptance of the concept of meaningful **patient involvement** and move towards a framework and resources to facilitate systematic and structured patient involvement in health system and services design, strengthening and evaluation.

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

Implementing the EPF Membership Strategy, which contributed to strengthening the ownership of EPF by its membership, we will now work towards ensuring that patient organisations throughout Europe 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 the strategic direction of EPF and the patient movement in Europe post-2020.

Building on the successes of previous years, our 2019 Work Plan places emphasis on **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. We will repeat the highly successful training module on leadership and governance in 2018, comprising two face-to-face training sessions and coaching. A third **Summer Training for Young Patient Advocates** will take place and we will establish an alumni and ambassadors' programme in parallel.

The **EPF Youth Group** will continue its work to help young patients 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 and we will also start to work on the key topic of sex education for young patients with chronic diseases.

The concepts of patient involvement and patient empowerment will also be the central focus of important projects, including CHRODIS-Plus, COMPAR-EU, PREFER, the EPF-led programme EUPATI and IMI project - PARADIGM on patient engagement in the life cycle of medicines

## Sustainable health systems for all

This key objective relates to the development of a vision of what constitutes a **high-quality, safe, equitable and sustainable healthcare system from the patient perspective.**

During 2019, EPF will continue to work towards reducing health inequalities by promoting sustainable and patient-centred universal access to healthcare and non-discrimination. This objective includes policy and advocacy activities relating to access, equity, quality and patient-centeredness of healthcare.

EPF will promote recommendations set out in the EPF Roadmap to **achieving universal health coverage for all by 2030** (2017) in the context of the UN Sustainable Development Goals and the European Semester Process, holding governments and stakeholders accountable for the implementation of these and the **2030 Sustainable Agenda**. Similarly, EPF will continue to inform policy-makers and various stakeholders of unmet needs and barriers to universal access to health and related care and services. In this context, EPF will work closely with relevant stakeholders such as SDG Watch Europe, organisations representing populations that are vulnerable to health inequalities and discrimination and the multi-stakeholder **Patient Access Partnership** (PACT).

Together with relevant stakeholders, EPF will advocate for the development and implementation of policies and initiatives that **eliminate discrimination, reduce stigma and promote the inclusion** of patients with chronic diseases in healthcare, employment and society at large.

Additionally, in 2019 EPF will continue its work on Access to Medicines, disseminating widely a recently published statement, and providing a strong patient's voice in debates on this issue.

We will also pursue our work on quality of care, notably by continuing to collaborate with OECD in relation to patient relevant outcomes measures (PROMS) and WHO on follow up to work on Primary Care, and 'Walking the talk' on people-centred health care.

While contributing the patient perspective to the discourse on data protection, in 2019, EPF aims to strengthen its position on the digitalisation of healthcare and sharing of data by identifying core principles. Furthermore, EPF will continue to inform members and build capacity on the topic. We will be part of a new Health Data Platform to provide the right sort of information to patients and citizens on the value of health data and create a community to share views on EU legislation on this topic.

Project-wise, in 2019, EPF will be a part of the H2020 project DigitalHealthEurope. This project will provide comprehensive, centralised support to the digital transformation of health and care priorities of the Digital Single Market in Europe. We are also part of the EHDEN project, which will build a large-scale, federated network of data sources standardised to a common data model.

Regarding our wider 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 regulatory research and frameworks

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

We will closely monitor the developments on the negotiations on the proposal for an EU regulation on **Health Technology Assessment (HTA)**, while in parallel we will 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 its key aspects identified by patients and 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.

EPF will monitor developments and secondary legislation of the **medical devices and in-vitro diagnostics regulations**, actively contributing to the patient's perspective as and when appropriate. We will continue to inform our members on the progress made in the transitional period and its impact for the patient's community, in particular with regards to patient safety, access and information to patients. EPF will continue to engage with the medical technology industry and other relevant stakeholders via the Patient-Medtech dialogue co-led by EPF and Medtech Europe.

*Please note, for each major activity, (Congress, Summer Training Programme for Young Patient Advocates, Capacity Building Programme) in addition to the description in this Work Plan, we have a concept note and individual plan, which is available upon request from the secretariat.*

## 2. Problem Analysis and Evidence Base

Chronic diseases affect more than 80% of people aged over 65 in Europe, and they account for up to 80% of healthcare costs in terms of premature deaths, healthy life years lost, and lost productivity.[1] Furthermore, almost 50 million people live with *multiple* chronic diseases[2] - a figure which is likely to increase. Many chronic diseases affect young people and people of working age. The impact on patients is therefore multi-faceted and includes quality of life, social aspects, education and employment.[3]

**Emerging technologies** raise economic, ethical, political and capacity challenges. New opportunities for collecting and sharing **health data** promised to make care more effective but also pose challenges for patients' privacy and data security. Shared electronic health records and self-monitoring tools are blurring traditional distinctions between clinical and self-care.[4] The recent European Commission mid-term review of the Digital Single Market pinpointed the need for a coordinated, coherent policy vision on digital health and care innovation, followed by a Commission Communication on digital health published in April 2018.

**Health literacy** is a key element of patient empowerment and an increasingly vital "21st-century life skill" for patients, given the societal impact of technologies such as digital tools and genomics. The availability of almost limitless information can make it difficult for patients to assess quality and reliability. Health literacy is pertinent for understanding the complexities around the *scientific evidence-base* for treatments and public health interventions and the *regulatory and political processes* determining access to new therapies.[5] It is also a key element in the promotion of rational use of antibiotics to combat *antimicrobial resistance*.[6] The excessive complexity and non-transparency of health systems can affect access[7] and thus promoting "health literate" care organisations and easily navigable systems is a priority for increasing health equity.[8]

**Access to healthcare** remains an urgent priority for patients. The EU has committed itself to implementing the UN Sustainable Development Goal 3 on health (SDG3), which includes access to medicines and healthcare. EPF's previous work has shown that patients with chronic conditions face barriers in access. Over 50% of respondents to our 2016 survey reported facing *discrimination and stigma* while seeking or receiving healthcare.[9] Patients with multiple conditions are more vulnerable.[10] Stigma and discrimination may lead to worse health outcomes and contribute to persistent health

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[1] Chronic disease reflection process, Final report, 11 November 2013; OECD/EU (2016) Health at a Glance 2016, p. 19.

[2] Reflection paper on the Social Dimension in Europe (2017).

[3] J-C Suris, P-A Michaud, R Viner (2004) "The adolescent with a chronic condition. Part I: developmental issues," Arch Dis Child 2004;89:938–942.; Eurofound (2014) "Employment opportunities for people with chronic diseases," available at https://www.eurofound.europa.eu/sites/default/files/ef1459en.pdf; OECD/EU (2016), p. 20, 26-27.

[4] eHealth Action Plan 2012-2020 – Innovative healthcare for the 21st century, COM (2012)736 final, p. 9.

[5] "Communication on medicines — now and tomorrow". Report of a joint EMA workshop with patient and healthcare professional representatives about communication on medicines, European Medicines Agency, 30 May 2016, link.

[6] OECD (2017) "Tackling Wasteful Spending on Health, "10 Jan 2017; Council conclusions on the next steps under a One Health approach to combat antimicrobial resistance. 17 June 2016

[7] COM(2014) 215 final, p.8.

[8] Brach C, Keller D, Hernandez LM, et al. (2012) "Ten Attributes of Health Literate Health Care Organizations". Discussion paper. Available at https://nam.edu/perspectives-2012-ten-attributes-of-health-literate-health-care-organizations/

[9] References: European Patients' Forum, Position Statement, *Tackling discrimination in healthcare*, 19 December 2014, link. + European Patients' Forum, *Access to healthcare, EPF's survey – Final Report,* 16 December 2016, link.

[10] Reference: European Patients' Forum, *Access to healthcare, EPF's survey – Final Report,* 16 December 2016, link.

inequalities in the EU. *Access to medicines* poses a specific challenge, with many EU Member States worried about the potential impact of the cost of some new medicines on their health systems in the long run. At EU level, attention has recently been paid to incentives for the industry and their potential impact on access to medicines access.[11] On the other hand, increasing availability of *generic and biosimilar medicines* can improve equity of access by providing more therapeutic choices. Advocacy and education through relevant, evidence-based, accessible information is needed to support confidence and trust of patients.[12]

**The quality of care** is closely linked to access, inefficiency and waste. Patients with chronic conditions are more vulnerable to bad quality as they depend more on healthcare than the average person; access to timely and accurate diagnosis is a particular concern as is the patient-centredness of care. The training of health professionals in new roles including 'trainers' and advocates of patients with chronic conditions and to learn how to better engage and involve patients in care is a high priority.[13] Patient involvement in professional training, meanwhile, is an underdeveloped but promising area.[14]

Undoubtedly, limited resources should be focused on providing care that **brings real benefit for patients**. 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.[15] There is good evidence that patient participation in shared decision-making with full information about treatment options, benefits and risks leads to less rather than more intensive treatment choices,[16] but shared decision-making is still not fully embedded in care, patients are currently not being empowered, and thus the healthcare systems are missing out on a vital 'piece' of the sustainability puzzle.

**Patient safety** is at the core of quality.[17] Safety is both a goal – being free from harm – and a practice, i.e., processes and structures that aim to make healthcare safer. Improvements in safety are frustratingly slow, with adverse events occurring in around one in 10 hospitalisations, the majority of which are preventable.[18] Such figures undermine patients' trust in the healthcare system.[19] The role of patients and families in improving safety is increasingly recognised but remains underused and undervalued.[20]

**Investment in healthcare** is recognised as a pre-requisite of economic growth and social cohesion. From a patient's perspective healthcare is a fundamental right. Europe's healthcare systems will need

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[11] Council conclusions on strengthening the balance in the pharmaceutical systems in the EU and its Member States, 17 June 2016

[12] DG Grow report from biosimilars workshop 2017 or 2016

[13] EXPH Final opinion: "Future EU Agenda on quality of health care with a special emphasis on patient safety," 9 October 2014, p. 71. Link

[14] Key findings and recommendations on education and training in patient safety across Europe. Work of the education and training sub-group of the European Commission's Patient Safety and Quality of Care Expert Group, April 2014 p. 13-14. Link

[15] Facey K. et al. (2010) "Patients' perspectives in health technology assessment: A route to robust evidence and fair deliberation" *International journal of technology assessment in health care*. 26. 334-40.

[16] Stacey et al. "Decision aids for people facing health treatment or screening decisions" Cochrane review, 2014

[17] Quality of care: a process for making strategic choices in health systems. WHO, 2006. pp. 9-10

[18] RAND Europe, 2009; OECD, 2017

[19] Special Eurobarometer 327: Patient safety and quality of healthcare, April 2010

[20] Reports of the sub-groups of the European Commission's Expert Group on Patient Safety and Quality of Care, April 2014. Link; WHO Europe (2011) "Patient Engagement in Reducing Safety Risks in Health Care". Report of the meeting on patient safety and rights, Copenhagen, 31 august 2011. Link

to provide high-quality care that is equitable and meets patients' needs. Timely, equitable access to appropriate patient-centred treatment is an investment in society. EU health policy must be based on the fundamental values of universality, access to good quality care, equity and solidarity outlined in the Council conclusions of 2006. European citizens consistently identify health as a high EU priority.[21] Patients have a legitimate expectation that care should be *patient-centred*, and policymakers recognise this – but it is not yet the reality for many patients. **Meaningful, systematic and structured patient involvement** is necessary to achieve healthcare that combines innovation with efficiency, equity and sustainability health systems, both at policy level and in practice.[22]

## 3. Target Groups

The primary target groups of EPF's activities in 2019 will be:

- Our **member patient organisations**;
- The wider **patient community** and the **general public**;
- **European-level policy-makers** (Members of the European Parliament, officials of the European Commission key DGs and Commissioners);
- **Member States' representatives** in Brussels as well as nationally, also in the context of the EU Presidencies of Romania, Finland and Croatia
- The **European Medicines Agency** (EMA), **Fundamental Rights Agency** (FRA) and **European Centre for Disease Control** (ECDC);
- **International organisations**: The OECD, WHO European Region;
- **Health stakeholders**, including public health NGOs, medical professionals' organisations, academia/research community, scientific/professional bodies, and the healthcare industry;
- **Media** at EU and national levels.

## 4. Added Value and Impact

Patient involvement in healthcare policy adds value from a moral perspective because the decisions directly impact patients' lives and well-being; but equally 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, representing patients with chronic diseases. It provides a vital cross-disease perspective from a wide patient community into EU policy-making, 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.

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[21] See e.g. the recent Eurobarometer survey, 5/2017 (link).

[22] 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.

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

Our evidence-based advocacy helps strengthen patient involvement and recognition of patients as partners in health policy and practice, thus supporting participatory and inclusive health systems. Our work on patients’ rights and responsibilities goes beyond disease- or country-specific initiatives and has the credibility of being supported by a wide cross-EU patient movement. 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 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.

## 5. How We Work

Our Work Plan for 2019 will continue to focus on **three key objectives,** reflecting the EPF strategic plan 2014-2020:

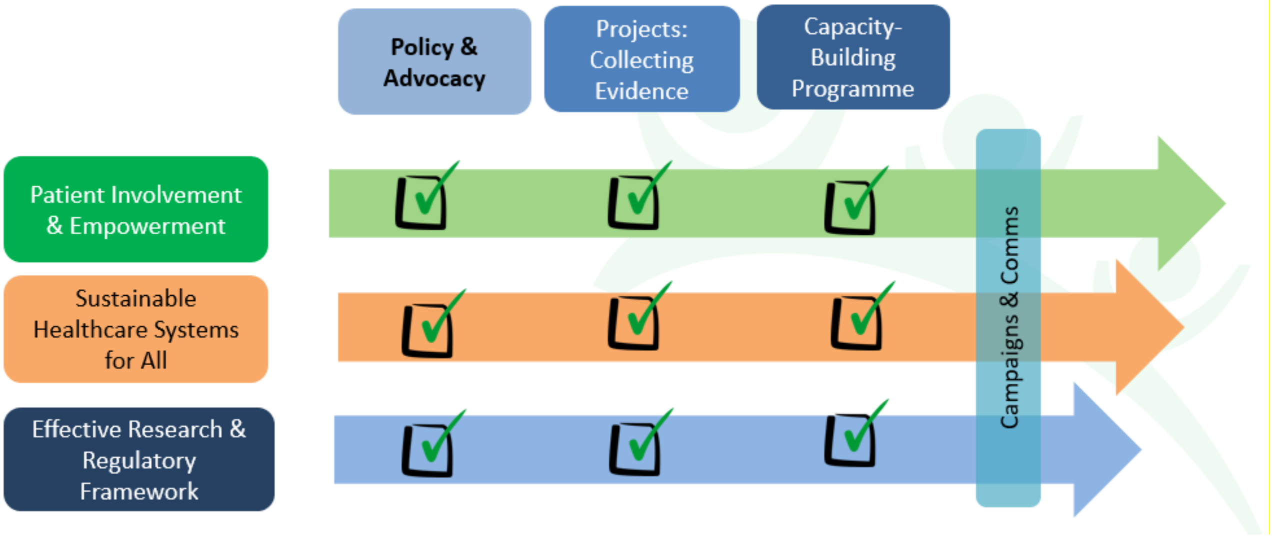
1 - Patient involvement and empowerment

2 – Sustainable health systems for all

3 – Effective and patient-centred research & regulatory frameworks

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

*The three pillars of EPF's actions (policy & advocacy, projects, capacity-building) will be applied across EPF's three key thematic objectives for 2019.*



### Policy and Advocacy

Advocacy refers to the development of position statements on specific EU health policy topics, and in a wider sense to the identification of priorities and formulation of views on issues of importance to patients and advocating for a strong patient perspective in relevant contexts. Key activities include:

- Surveys of our members and the broader patient community
- Consultations on key topics with EPF membership
- Desk research and interviews
- Meetings with key stakeholders
- Meetings of our working groups and bilateral exchanges with members
- Development of position papers in consultation with the membership
- Exchanges of views with key decision-makers (e.g., representatives of the European Commission, European Parliament, Council, and at national level)
- Contributions to public consultations from the European Commission and other bodies
- Participation in expert groups and working groups
- Collaborations with European and international organisations and healthcare stakeholders, e.g., healthcare professionals, academia, think tanks, industry…
- Representation of the patient perspective at international conferences and policy meetings

### Projects

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

- Being part of innovative and ground-breaking research and public health projects and having access to first-hand information;
- Collecting data that will inform and support our policy work with evidence;
- Exchanging best practices with other 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 and other patient organisations, therefore reinforcing our representativeness.

### Capacity-Building Programme

The capacity-building programme (CBP) is a 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
- understanding the importance of ethics and organisational development
- 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 2019, EPF will consolidate the CBP and widen its scope to include training on different thematic areas. Our training, learning materials, and patient-friendly information resources will help the patient community to grow in confidence and impact. CBP activities are included under the heading “Patient involvement and empowerment”.

## 6. Governance

- **Annual General Meeting (AGM):** 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.
- **Task Forces:** set up on specific topics such as nutrition
- **Strategic Planning Process:** in 2013, EPF adopted its current strategic plan for the period 2014-2020. A mid-term review of the Strategic Plan was developed and published at the end of 2017. In 2019, we shall begin our reflections on our next strategic plan that will take us in to the third decade of the 21st Century and the next EU Programming period.
- **Constitutional reform:** the EPF AGM 2019 will adopt our new Constitution and we will explore the implications of this during the remainder of 2019 regarding our wider geographic remit, the creation of an ethics committee, our relationship with on-line communities and patient alumni, and a voting representative of the youth group on the EPF board.

# 7. EPF's 2019 Work Plan

EPF's 2019 work plan is structured around the three objectives described above, which are complemented by cross-cutting activities. In this section we describe the activities under each main objective, although it should be kept in mind that our activities are highly complementary and often address more than one objective. In addition, our 2019 work plan includes a patient-led campaign around the European Parliament elections and continued strategic advocacy at high level to ensure health remains a priority in European policy post-2020.

## Strategic advocacy: the 2019 European Parliament elections and the future of European health policy

In 2019, European citizens will be voting to elect a new European Parliament. Shortly after, a new European Commission will be nominated. Patient advocacy in the European elections is crucial to drive positive change for patients. With 72 members, representing the interests of an estimated 150 million people with chronic diseases, EPF carries the voice of a high proportion of voters. EPF will again ***campaign for the patients' voice and priorities to be heard by new and re-elected Members of the Parliament***. Patients benefit from EU collaboration in health and want to see a strong European health policy also in future. We want to make health a priority for the European Union post-2020, and to position the patient community as a whole, and EPF in particular, as a key stakeholder in EU health policy.

The main objectives of the EPF Campaign will be to:

- Focus policymakers' attention on what matters to patients:
    - European patients tell their stories to illustrate evidence-based messages on why and how EU action has made a difference in their lives, giving a human face to the "facts and figures";

- Position the European patient community as a key (political) stakeholder in health policy, and EPF as the voice of patients at European level;
- Call to decision makers and MEP candidates to be ambassadors of patients in the EU:
    - Ensure MEPs' support to prioritise health and address patients' issues in the new Parliament, based on our five key priorities shaped together with our membership.

Our campaign is distinct from but highly complementary to our joint activities around ***the future of health in EU policy***. In the last years, the healthcare and policy environment in Europe have significantly changed, bringing new challenges and opportunities for patient advocacy. In 2017, the President of the European Commission, Jean-Claude Juncker, presented a white paper on the future of Europe, outlining five potential scenarios, opening the prospect of less or little meaningful EU action on health in the post-2020 era.

The negotiations on the future EU budget dominated the agenda in 2018. Together with several other public health NGOs, EPF initiated a campaign in 2017 to raise awareness on the importance of continued collaboration at EU level – #EU4HEALTH. The campaign defended the idea that EU health policies bring added value to the lives of citizens and clear return on investments to EU Member States. Our campaign in 2018 achieved the recognition of health in the EU budget proposal. As the debates stretch into 2019, we will continue as part of the NGO alliance to call for a strong health policy with appropriate priorities and budget.

The impending **withdrawal of the United Kingdom from the EU** ("Brexit") will have implications for patients in both the UK and the EU. EPF will continue working together with other health stakeholders in the sector. As was the case in 2017/18, we will ensure our active participation in the multi-stakeholder EU Health Alliance to ensure the patients' voice is heard in the negotiations on both sides of the channel. At the same time, we will continue to collaborate with EU and UK patient organisations and identify the potential threats that Brexit may bring, using as a baseline our joint position paper on Brexit.[23] Concrete actions are difficult to plan – EPF will continue to monitor the negotiations and plan targeted interventions when needed. The main date that will influence our course of action will be the 19 March 2019, when it will be decided whether or not a transition period will be in place or not.

## 7.1 PATIENT INVOLVEMENT AND EMPOWERMENT

As we have outlined in the previous section, in order to meet the challenges of chronic conditions, care models *must* urgently become more person-centred and co-ordinated, rather than fragmented and disease-focused. Meaningful patient involvement is an underused resource in the development of innovative, patient-centred healthcare design and delivery at all levels, and thus improving the effectiveness, efficiency and long-term sustainability of healthcare systems.

Building on our extensive work on patient empowerment – including the 2016 *Patient's Charter on Patient Empowerment* and the accompanying *Roadmap for Action*, as well as our numerous position papers – EPF aims to take patient advocacy to the next level. Our goal is to promote a wider understanding and take-up of **meaningful patient involvement**, embedding it at all levels of the health

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[23] http://www.eu-patient.eu/globalassets/library/publications/brexit--prioritising-patients---final.pdf

system and encouraging the good practices that are "patient-approved". In 2019 our main focus will be on the first European-level Congress driven by the patient community.

### The EPF Congress 2019

Patient-centredness and patient centricity are very much "in vogue". There are innumerable conferences about it, often without actual meaningful patient involvement and without moving forward policies or practices that will empower patients.

EPF has identified an opportunity to hold a different congress – driven by patients and the patient community – that can help to bring about real and lasting change. The congress will result in tangible learning outcomes, supported by educational materials and tools. It is built on the premise that the patient's own unique experiential knowledge is a hugely untapped resource in all areas of the health system, including innovation, advances in new technology, systems strengthening, and the cultural shift towards patient and citizen empowerment.

The objectives of the congress will be:

- To provide participants with insights and knowledge about how patient organisations function, thus enhancing trust and collaboration;
- To explore together the nexus between meaningful patient engagement in different areas of the health system;
- To explore opportunities and barriers for meaningful patient involvement, drawing lessons from areas where patient involvement is more established;
- To generate practical recommendations and guidance on meaningful patient involvement for policymakers and practitioners.

The audience will comprise up to 300 patient representatives across countries and disease-areas, national policymakers and public institutions/authorities, health systems experts, healthcare professionals, researchers and scientists, regulatory experts, payers/health insurance providers, and industry representatives from across the sector.

Participants will obtain a genuine understanding of how the patient community functions, evidence of the benefits of collaboration with patients, knowledge and ideas on the patient's intrinsic role in innovation in all its guises, and an understanding of how different EU regions and different areas of the health system are faring in patient engagement and involvement. The Congress will take place in November 2019 over three days in Brussels.

### Patient involvement in research

2019 is likely to see the negotiations continue around the future EU research framework programme, Horizon Europe (FP9). In line with the reflections initiated with the Value + project, our core values of meaningful patient involvement, and the results of the 2018 consultation with EPF members on their views and expectations on the scope and priorities of the next research funding programme, we will echo those messages to the European Commission, the European Parliament and the main stakeholders.

## Health Literacy

Reliable, understandable, relevant and easily accessible information is the cornerstone of individual patient empowerment and of meaningful patient involvement in health policy. In 2019 we continue our advocacy role on the importance of health literacy in all policies, and concretely contribute to patients' health literacy in all our work by communicating patient-friendly information on complex policy and topics in accessible formats, including videos and infographics. In particular, we continue to work in concert with the European Medicines Agency (EMA) regarding trusted evidence-based information for patients on medicines. We will further develop our role in the context of vaccine confidence, following up on a dedicated project in this sphere, and work with the European Centre for Disease Prevention (ECDC) to support International Antibiotic Awareness Day.

## 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 shape strategic direction of EPF and the patient movement in Europe post 2020. In 2019 the event will be linked to the EPF Annual General Meeting (AGM) to ensure a high level of participation.

We will continue to strengthen the capacity of patient leaders at national 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 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 regular online **Breakfast Briefings** and **webinars** will also continue in 2019, 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.

## Preparing the Next Generation of Patient Advocates

**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 to raise 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 2017 and 2018, in 2019, the YG will focus on non-discrimination and access to employment for young patients, specifically on inclusion in the work force; elimination of stigma and prejudice against young patients in the workplace; disclosure of chronic conditions and identification and promotion of good practices implemented by employers in hiring young patients. Building on existing EPF tools and messages, the YG will run an awareness-raising campaign on **non-discrimination with the support of EPF**, similar in concept to the "Count us in" campaign. Furthermore, sex education will be a new priority for the YG in 2019.

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.
- 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.

### Summer Training Course for Young Patient Advocates- Leadership Programme

In line with our regular engagement with young patients, EPF will organise the third 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 third edition - where an essential role will be played by the Youth Group - will look at topics that are central to the patient community as a whole and represent a key priority for the new generation of advocates. In 2019 the overarching theme will be "*Shaping the future of patient advocacy*", with a focus on advocacy at individual and community level, ethical advocacy, role of emerging actors and challenges.

Efforts will continue in 2019 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.

### Reinforcing patient organisations' legitimacy and EPF representativeness

EPF's membership has grown considerably from 13 in 2003 to 72 in 2018. Our objective is to welcome all legitimate organisations to reinforce our collective disease and geographical representativeness. To achieve this objective, we will undertake the following actions:

- *Contacts with potential new members*: EPF will constantly update the map/list of potential members, based on the 2018 EPF membership mapping.
- *Implementation on the wider Europe approach*: recognising that EPF's members often cover areas beyond the EU, in 2018 EPF board and Constitutional Reform Committee explored avenues to expand our membership. This reflection has been launched during the mid-term review of our Strategic Plan (2017) in consultation with our broader membership and the guidelines/strategy of the Constitutional Reform Committee will be presented and potentially approved at the 2019 EPF General Assembly. If the Wider Europe approach will find consensus among our broader membership 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 2019, EPF will continue to support national coalitions through training and exchange of best practices.

### 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. The Membership Manager will be the link between the Secretariat and EPF's members. S/he will develop 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. The Membership Manager will continue to organise **weekly coffees** with EPF members and thanks to the initiative **EPF on the spot** EPF staff, and the Membership Manager in particular, will participate in members' activities, sharing EPF material and best practices with their own audiences, thus stimulating dissemination and creating a constructive feedback loop.

### Complementary Activities and Projects

In 2019 EPF will contribute to a wide range of projects that strengthen our skill-set and commitment to achieve this objective, such as:

#### *PARADIGM*

PARADIGM is an IMI project launched in March 2018, co-led by EPF and EFPIA. This project aims to co-create a framework enabling sustainable, ethical, meaningful and systematic patient engagement in medicines R&D. The strong consortium comprises 34 partners – patient organisations (members of EPF), pharmaceutical companies, NGOs, foundations, and corporate organisations. The project will end in August 2020.

EPF ensures the effective leadership and coordination of the project, also co-leading the communication track. In 2019 our focus will be on ongoing efforts to secure a smooth and efficient progress of the project, including links with important initiatives in the field such as the DIA, Patient-Focused Medicines Development (PFMD), FasterCures, Clinical Trials Transformation Initiative (CTTI), Transcelerate, and other IMI projects such as PREFER. Regarding communication, EPF will pay special attention to the online presence of PARADIGM, especially on social media (LinkedIn and Twitter).

In 2019 EPF will be responsible for the organisation of the 2nd Open Forum on Patient Engagement, together with EUPATI and PFMD. This meeting in September 2019 will gather more than 150 participants, coming from members of the consortium, EUPATI alumni and external attendees.

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

#### *EUPATI*

2019 marks the last year of the agreed 2017-2019 EUPATI bridging programme. 2018 saw the successful completion of the 3rd cohort of the Patient Expert Training course. A 4th Patient Expert Course is expected to begin in late 2019.

EUPATI will continue to strengthen the EUPATI Alumni Network and aims to provide a platform for collaboration. It will also provide the opportunity to consider continuous professional development (CPD) within the Patient Expert education stream.

With EUPATI's change of scope to focus on education in patient engagement rather than to restrict the programme to patient education, the first pilot of education for other stakeholders will be run and evaluated for its ongoing benefit and contribution to EUPATI's sustainability plans.

The second half of 2019 will see a transformation in the EUPATI programme as more sustainability models are adopted and put into daily practice to ensure the continuation of the programme in 2020 and beyond.

### *EFOEUPATI – Ensuring the Future Of EUPATI*

The IMI-EFOEUPATI project which started 1 September 2018 will begin delivering its first outputs including the beta version of the new EUPATI website – the Patient Education and Engagement Platform, and assessments of further business models for EUPATI's medium- and long-term sustainability. It will also provide the opportunity to implement some of the business models already elaborated in 2018 under the EUPATI programme and decided upon at the EUPATI Steering Group meeting at the end of September 2018. EUPATI National Platforms will be working on their own sustainability strategies on reinforcing their relationship with the EUPATI programme and the ongoing model of operation. More information at https://www.eupati.eu/

### *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 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 2019 we will work on case studies to identify patient preferences in three diseases areas: lung cancer, rheumatoid arthritis and Muscular Dystrophy. EPF will contribute to ensure the design of case studies reflects the patient perspective. More information at http://www.imi-prefer.eu/

### *COMPAR-EU*

In 2019 EPF will contribute for the second 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 2019 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/

## 7.2 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 2019, 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

In 2019, EPF will continue to promote the recommendations set out in the EPF Roadmap to achieving universal health coverage for all by 2030 in the context of the **UN Sustainable Development Goals** and the **European Semester Process**. As a member of SDG Watch Europe, EPF will aim to hold governments and stakeholders to account for the implementation of UHC and the 2030 Agenda for Sustainable Development (SDGs), contributing the patient perspective to the debate. Together with our members, we will continue to inform policy-makers and various stakeholders of unmet needs and barriers to access by encouraging national patient organisations to organise multi-stakeholder national parliamentary meetings on the topic of access on an annual basis.

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 populations that are vulnerable to health inequalities and discrimination. EPF will also continue to play a leading role within the multi-stakeholder Patient Access Partnership (PACT), supporting its work in creating a comprehensive evidence-based approach to measuring access.

In 2019, EPF will emphasise the importance of health literacy and informed decision-making in the sphere of nutrition by informing patient organisations of existing clinical nutritional guidelines and patient friendly summaries of this information. EPF will also help organisations developing clinical nutrition guidelines to better involve patients in this process and encourage them to develop lay version summaries of developed guidelines by disseminating EPF's Nutrition guideline development and lay person summaries paper (2018). EPF will also continue 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 (2018). The EPF-EGAN co-led EU patient task force on nutrition will guide this work. Similarly, EPF will continue to engage with the Optimal Nutritional Care for All Campaign (ONCA).

Regarding **access to medicines** and their affordability, EPF continues to engage with relevant initiatives and will develop a position paper on generic and biosimilar medicines, in synergy with the EMA information and in consultation with our membership, to support better understanding of these types of medicines by patients and to ensure that policymakers take into consideration patients' concerns. We will continue to collaborate with the European Commission (DG GROW) on its annual stakeholder workshop on biosimilar medicines.

### Social Inclusion and Non-Discrimination

EPF is committed to promoting **patients' rights and non-discrimination**. In 2019, 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. To advance its work in this field, EPF will organise a multi-stakeholder meeting on the integration of patients in the workplace and combatting discrimination, presenting outcomes of the CHRODIS-Plus JA Work Package on employment and chronic diseases.

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, promoting non-discrimination and inclusivity, and encouraging our members to implement actions set out in our 2016 Inclusiveness Roadmap. We will further strengthen alliances with organisations representing populations **vulnerable to social exclusion,** whilst raising awareness of discrimination and exclusion in healthcare by developing information materials.

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

Ensuring that patient-centredness is evaluated as a part of **healthcare quality** has been a key advocacy objective for EPF in past years. Part of this exercise involves looking at what outcomes matter for patients, and how patients evaluate their care experiences.[24] In 2017-2018 we contributed to the shaping of the PaRIS initiative led by the OECD, which proposes an international survey of indicators for measuring "what matters to patients" as part of healthcare system performance. We will continue to participate in this initiative as it now takes shape following its adoption by OECD Member States in June 2018.

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 2019 will relate to patient-centred digital healthcare solutions and services; access to, 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.

Based on the work of the Digital Health Working Group, we will be taking further the results of the survey on electronic health records that was conducted during 2018. We will be developing a more concrete position on patient access to electronic healthcare records, also in line with the project Digital Health Europe. Furthermore, we will be developing principles on patient-centred digital health based on the briefing that was produced in 2018.

Alongside this, EPF will be collaborating with other stakeholders in setting up the **health data platform**, an initiative of organisations with an interest in health data. EPF is one of the leaders in this initiative and will host the platform and will support the launch of the platform in 2019.

The platform is intended to bring together different actors with common interests and build a '**health data community'**. The aim is to share views and concerns on data related issues and to discuss respective positioning regarding topics that affect all of the involved, like the GDPR and other data related legislation and policies, in a timely fashion. Ultimately, the community will agree a set of over-arching principles for the responsible use of health data.

In addition, the Platform will develop **accessible resources and a shared web platform** to provide neutral information on key issues related to health data and to sign-post patients and citizens to other useful resources. In this context, the needs of local and national communities will be kept in mind, and while the web platform will be developed in English only, the style and language used will be easily understood by non-native users, and easily translated.

In addition, we will continue to engage in multi-stakeholder efforts, including the eHealth stakeholder group, and the Stakeholder Forum of BBMRI-ERIC to ensure that the patient perspective is embedded in such initiatives.

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[24] Using patient-reported outcome measures (PROMs) and patient experience measures (PREMs), which should be also patient-defined and reflect patients' priorities.

## Complementary Activities and Projects

### *DigitalHealthEurope*

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. EPF will be in charge of engaging patients in these collaborative platforms 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.

### *Digital Twins*

The DigiTwins (DIGITAL TWINS FOR BETTER HEALTH Better diagnosis – Better care – Better life) project's vision is to revolutionise healthcare for the benefit of citizens and society. As the major (but not the only) outcome the initiative will create generic in silico reference models by integrating information on biological mechanisms and healthcare and research data of many individuals/patients, which will then be personalised into generate individual computer models: digital twins, to test all possible interventions on the model to select the individually optimal one for the individual. From its onset, the project will help citizens and patients to receive better therapy, prevention and well-being options, accelerate biomedical research and link research and clinical practice in an integrated system throughout Europe. EPF and the project consortium has entered into the last stage of drafting the project proposal and await the final decision from the EC.

### *EHDEN*

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.

### *Joint Action (JA) CHRODIS-PLUS*

**CHRODIS-PLUS** is led by the Health Institute Carlos III (ISCIII -Spain) and Vilnius University Hospital Santaros Klinikos (VULSK-Lithuania), involving 42 partners from 20 EU Member States. 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 2019, EPF will contribute to the development of 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 we will organise study visits to pilot sites in Croatia, Slovenia, Finland, Greece and Serbia. Finally, next year, EPF will keep actively communicating and disseminating project's results.

More information at http://chrodis.eu/

## 7.3 EFFECTIVE AND PATIENT-CENTRED EU REGULATORY AND RESEARCH FRAMEWORKS

Under this objective, EPF will contribute to, monitor, and report on the implementation of key EU legislation to ensure that the patients' interests are reflected in legislation under development and/or embedded in the implementation of EU laws.

### Health Technology Assessment (HTA)

Aware of the growing importance of HTA and of its impact on access to new health technologies, EPF will continue in 2019 to contribute to shaping the legislative proposal based on our formal position paper adopted last year. This complex topic entails a number of actions, from monitoring of policy developments in the EU institutions and the positions of EU and other stakeholders, to proactively promoting the EPF perspective. We will keep facilitating a better understanding of this policy dossier among EPF members through communications, training tools (already developed and in use within EUPATI). In parallel, we will continue our collaboration with Health Technology Assessment International (HTAi) and contribute as an active member of the Steering Committee of the Interest Group on Patient and Citizen Involvement in HTA.

### Clinical Trials

In 2019 EPF will continue to update patient organisations on the implementation of the EU *Clinical Trials Regulation* and its main implications for patients, including working with the EMA on the lay summaries, based on Guidelines published by the European Commission in 2017, with the aim of increasing patients' engagement in clinical research.

### Pharmaceutical Regulation and the European Medicines' Agency (EMA)

EPF continues to engage actively in the EMA Patient and Consumer Working Party (PCWP), as member and holding the co-chair. We will contribute to EMA events and task forces, taking into consideration the EMA's forthcoming relocation to Amsterdam in March 2019 and the need for continuity. We will aim to further strengthen the flow of information from and about the EMA to patients, ensuring a good understanding of its role and encouraging wider patient involvement in its activities.

### Medical Devices and In Vitro Diagnostic Devices

Two new regulations on medical devices and in vitro diagnostics entered into force in May 2017. Having engaged closely in the initial legislative process, we will monitor developments and secondary legislation and actively contribute as and when appropriate. We will continue to communicate on the progress made during this transitional period and its 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.

EPF will continue to engage with the medical technology industry and other relevant stakeholders via the Patient-Medtech dialogue co-led by EPF and MedTech Europe. In this context, we will organise 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 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 2019.

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/

## 7.4 COMMUNICATIONS

The 2019 EPF communications plan will follow our overall strategy (1) communicating to inform and (2) communicating to engage and convince our audience. EPF will produce clear content (online and printed) to inform our target audiences. Short, powerful patient messages will be used as a gateway to lead audiences 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** gives the outside world access our work, 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**, with a new layout introduced in mid-2018, will continue to provide the latest policy, projects and event developments on a monthly basis. It will also feature updates from our members and partners in the Blog section.
- The **EPF Impact Report,** based on the Annual Report, showcases in a concise publication our achievements. It demonstrates our performance against our objectives and shows the added-value of patients' contribution to EU policy and programmes, and real impact, both short and longer term.
- Our **policy factsheets and infographics** 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. In 2019, we will produce three factsheets on Digital Health, Nutrition and Generic Medicines.
- **Video** is an effective medium to relay our messages to different target audiences. In 2019, 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. In 2019, we will update the layout and introduce a fresh image that will, at the same time, improve the readers' experience.

### Communicate to Engage & Convince

- We will develop innovative **social media content** (e.g. polls, chats, videos) to increase engagement and interactivity with and feedback from external stakeholders.
- EPF's **Blog** demonstrates the work that 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 the link in our newsletter. The Blog also features the experiences of the Youth Group members, and some updates from our partners which are worth to share with our readership.
- 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 2019, we will ensure maximum value from this engagement through social media and follow-up communications.

## 7.5 EVALUATION

EPF strives for excellence and is a learning organisation committed to evaluating and improving our way of working. Ongoing evaluation of the work plan, in line with agreed measurable performance indicators and targets for each strategic goal, has been intrinsic to EPF's development over the past five years. Strategic monitoring and evaluation is designed and carried out internally by the EPF Secretariat.

EPF is committed to regularly updating its evaluation framework. We regularly organise evaluation meetings, involving all the key stakeholders, after completion of select projects / activities.

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 2019 work plan EPF has developed 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.

A list of key performance indicators is available on request from the EPF Secretariat.

# Annex 1 – List of Deliverables

| | Activities | Deliverables |
|---|---|---|
| **Patient involvement & empowerment** | EPF Congress 2019 | - Congress report and related documents/video |
| | 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 2019 | - Podcasts of the webinars |
| | EPF on the Spot | - Agendas and presentations |
| | Two meetings of the Youth Group | - Meeting reports |
| | Youth Group work on employment including meeting with employers' representatives | - Leaflet<br>- Report of meeting with employers |
| **Sustainable Healthcare Systems for All** | Monitor progress of European Semester in the context of EPF's Roadmap | - Statement on 2019 country-specific recommendations |
| | Informing patient organisations of existing clinical nutrition guidelines and raising awareness of the role of nutrition in managing chronic conditions | - Executive summary or factsheet |
| | Awareness raising on non-discrimination, including multi-stakeholder meeting on integration in the workplace | - Report of the meeting |
| | Developing a patient perspective on generic and biosimilar medicines | - EPF position statement |
| | Patient survey on electronic health records and health data sharing | - Report of the survey |
| | Information for patients and patient organisations about digital health and health data | - Information resources, format to be decided with EPF Digital Health WG |
| **EPF Operations and Communications** | Contact with potential new EPF members and emerging national patient organisations | - 2 exchanges / year with potential new members |
| | Board and Elected Officers meetings | - Minutes of the Board meetings |
| | EPF communication activities to inform and engage our members, policymakers and other stakeholders | - Weekly "Insiders" mailing (50)<br>- Up to 3 policy factsheets on priority topics<br>- Videos<br>- Website updates and maintenance<br>- 11 EPF Newsletters<br>- At least 4 Breakfast briefings, |

# Annex 2 – 2019 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** |
|---|---|
| CHRODIS + Study visit #2 | Country #2 |
| **February** | |
| CHRODIS + Study visit #3 | Country #3 |
| Board Meeting | TBC |
| DIA Europe 2019 | Vienna |
| Digital Health working group meeting | Brussels |
| **March** | |
| Universal Access to Healthcare working group meeting | Web meeting |
| Patient task force on nutrition | Brussels |
| CHRODIS + Study visit #4 | Country #4 |
| CHRODIS + General Project Meeting | TBC |
| **April** | |
| Board Meeting | Brussels |
| EPF Annual General Meeting | Brussels |
| Leadership meeting | Brussels |
| CHRODIS + Study visit #5 | Country #5 |
| **June** | |
| Board meeting | Brussels |
| Industry Roundtable | Brussels |
| Patient task force on nutrition | Brussels |
| EMA PCWP plenary meeting – 2 days | Amsterdam |
| **July** | |
| Spring Youth Group Meeting | Vienna |
| Summer Training for Young Patient Advocates | Vienna |
| **September** | |
| Board meeting | Brussels |
| Patient task force on nutrition | Brussels |
| PARADIGM 2nd Open Forum on Patient Engagement | Brussels |
| EMA PCWP workshop on vaccines | Amsterdam |
| EMA PCWP plenary meeting | Amsterdam |
| Policy Forum of Employment | Brussels |
| **October** | |
| Fall Youth Group Meeting | TBC |
| Universal Access to Healthcare working group meeting | Brussels |
| Digital Health working group meeting | Brussels |
| **November** | |
| EPF Congress | Brussels |
| **December** | |
| Board meeting | Brussels |
| Patient task force on nutrition | Brussels |
| Multi-stakeholder meeting on the integration of patients in the workplace and combatting discrimination | Brussels |