The European Patients' Forum
Annual Work Plan
2017

Driving better health for patients in Europe

EPF European Patients Forum

Contents

1. EXECUTIVE SUMMARY

In 2017, the European Patients' Forum's (EPF) will continue to address patient empowerment as a pre-requisite to achieve equity in health and social care and advance the concept of patients as "co-producers" of health.

2017 will advance an ever more influential and proactive strategy, shaping the policy agenda based upon patients' priorities. This new impetus, inspired by our President Mr Marco Greco (EFCCA) will consolidate further our position as key interlocutor and 'go-to' partner to provide a patient perspective on cross- cutting policy and legislative discussions.

Our Work Plan for 2017 will focus on **five key objectives**:

To **listen to the needs & perspectives of our membership** and feed these into the EU health policy discourses

To promote the development and implementation of policies, strategies and services that **foster the empowerment of patients and patient organisations.**

To promote the development and implementation of policies, strategies and services that **maximise access and reduce health inequalities across the EU.**

To **reinforce the capacity of patients and patient organisations** to contribute to better health and social care for all patients in the EU, while enhancing their accountability and mutual solidarity.

To **actively engage with the wider health stakeholder community** and policy makers to advance the patient-centred agenda at both national and European level.

Patient Empowerment

EPF believes that empowered patients who have a proactive role in their health and in health policy are central to sustainable and high quality health systems.

Patient empowerment is embedded within all our work areas. Building on the outcomes of the patient empowerment **campaign**, we will continue outreach and advocacy activities in order to promote initiatives that can turn the principles of the Patient Empowerment *Charter* into concrete actions, and implement the Roadmap for Action.

In 2017, EPF will further engage in patient empowerment through active participation in many European projects, such as the **CHRODIS Joint Action**; **PRO-STEP, PISCE, PREFER and the mainstreaming of the EUPATI programme into EPF.**

Patient Access

Equitable access to health and social care is a strategic goal of EPF and remains at the core of our vision for healthcare.

In 2017 we will launch a **policy and awareness campaign on universal access to healthcare** to identify policy measures to achieve universal health coverage by 2030 in accordance with the **UN Sustainable Development Goals**. This campaign will foster discussions and actions at EU and Member States level to pave the road towards universal health coverage.

Our work on access will also tackle the topics of cross-border healthcare, health technology assessment, patient safety and quality of care, medical devices and non-discrimination.

A vibrant and reliable network

Being the only EU-level umbrella patient organisation that is non-disease-specific and acting as a "bridge" between EU developments and patient communities across the Union, EPF will continue to ensure a **clear identity** bringing **clear added value** to its membership. We will build on our vibrant network and **stimulate engagement** with various stakeholders, both at national and European level. Capacity building continues to be a central pillar of our work and EPF will extend its highly regarded programme both at national and EU level.

A key date for the EPF community is the **Annual General Meeting (AGM)** taking place in spring 2017 in Brussels. A number of internal meetings focusing on specific policy themes of interest to members will also be organised throughout the year.

EPF will also continue to work with its very energetic **Youth Group**. Made up of patient representatives between 15 and 29 years old, in 2017 it will focus on **non-discrimination**, a key issue for young patients. On the same topic, our very first Summer Training Course for Young Patients will take place in July in Vienna, offering the opportunity for young patient advocates to learn and connect with fellow patient representatives from all over Europe.

In 2017 EPF will develop its **communications strategy** with the objective to communicate to **engage**, **inform** and **persuade**. An important task will be the revamping of our communications tools and channels.

In 2017 we will undertake a mid-term review of EPF's strategic plan in order to realign for the remainder of our current plan and also start planning for the launch of a new strategic planning process for the period 2021-2028. This evaluation will be led by the EPF Board and secretariat, and assessed against our strategic goals.

On-going evaluation of the WP has been intrinsic to EPF developments over the last few years. An external evaluator will be appointed to contribute external evaluation intelligence to assessing some of the key milestones of our 2017 programme.

2. EPF'S ANNUAL WORK PLAN FOR 2017

2.1 EPF's Key Operational Objectives for 2017

- To **listen to the needs & perspectives of our membership** and feed these into the EU health policy discourses.
- To promote the development and implementation of policies, strategies and services that **foster the empowerment of patients and patient organisations.**
- To promote the development and implementation of policies, strategies and services that **maximise access and reduce health inequalities across the EU.**
- To **reinforce the capacity of patients and patient organisations** to contribute effectively to better health and social care for all patients in the EU.
- To actively **engage with the wider health stakeholder community and policy makers** to advance the patient-centred agenda.

2.2 Problem Analysis and Evidence Base for the Activities Proposed in 2017

EPF's Work Programme (WP) 2017 addresses the **continuum of care** with focus on patient-centred chronic disease management, patient empowerment, and equitable access to high quality health and social care. The WP contributes significantly to the objectives of the Third Health Programme[1] of the European Commission, in particular Obj. 3 "*supporting public health capacity building and contributing to innovative, efficient and sustainable health systems*" and Obj. 4 "*facilitating access to better and safer healthcare*".

EPF strongly believes that the proactive role adopted by empowered patients in their health as well as in shaping health policies is key to ensuring the **high quality of our future health systems** and addressing the challenges of chronic diseases, constraints on health budgets, and rapid developments in technology. The Third Health Programme recognises this by stating that "*patients need to be empowered, inter alia by enhancing health literacy, to manage their health and their healthcare more pro-actively, to prevent poor health and make informed choices.*" (Regulation (EU) No 282/2014, recital 12).

Health systems performance is part of Commissioner Andriukaitis' mandate and priorities while quality of care and integrated care were identified by Member States as priority topics in 2015-16[2]. Patient-centred care models yield many benefits: when patients are genuinely involved in healthcare decisions and their preferences are listened to and acted on, the result is better health, more engaged patients, and lower costs[3]. Despite this evidence, patient-centredness has to date not been specifically addressed or indeed defined. Continued patient advocacy is needed to ensure that patients as citizens and healthcare users are truly at the centre of these vital debates which will directly affect their lives.

Innovation and efficiency in health systems, particularly eHealth, have also been identified by the Commission as avenues to provide and safeguard sustainable and universal health coverage while tackling health inequalities. EPF focuses on patients with chronic and long term conditions which are recognised as a group vulnerable to health inequalities[4]: dependence on timely access to safe, high-quality healthcare and support services, inability to work, direct and indirect costs of illness, social discrimination, and stigma. These themes are integral to our strategic plan and EPF's 2017 WP addresses them through specific and outcome oriented activities.

The enduring economic crisis has put health systems under severe pressure while they are already facing the burden of an ageing population and increase in incidence of chronic diseases, among other issues. **Equitable access** to high-quality health and social care continues to be a core cross-cutting priority for EPF in 2017. Policies adopted in response to the economic crisis, such as cuts in healthcare budgets and in insurance coverage, have only worsened the scenario. Access to healthcare is a basic human right and a fundamental principle of health systems. Treatment should be accessible to every patient who needs it, not only to those who can pay.

The EU has committed to play a leading role in the implementation of the **UN Sustainable Development Goals**. This includes a target to achieve universal health coverage, including financial risk protection, access to quality essential healthcare services and access to safe, effective, quality and affordable essential medicines for all. However as acknowledged by several country reports as part of the European Semester (published in February 2016), there are still gaps in universal health coverage and accessibility of healthcare in various Member States. EPF sees health promotion, prevention and patient-centred chronic disease management as aspects of a holistic continuum: effective prevention can free resources to provide healthcare for patients, while investment in high-quality chronic disease management can maximise patients' quality of life, reduce the disease burden and optimise use of healthcare resources.

Access to medicines is a specific area of concern. Unacceptable disparities in patients' access to medicines persist, whilst healthcare systems are increasingly struggling to accommodate the cost of some new medicines. More effective and equitable pricing and reimbursement mechanisms for medicines are needed. At the same time, in line with the report '*Priority* *medicines for Europe and the world*' (WHO, 2013) EPF will continue to call for patient-driven valuable innovation, both in the life cycle of medicines, but also systems, process and social innovation for sustainable, high-quality, patient-centred care.

The outcome of the **EU referendum in the UK** has shaken the European political arena to a significant degree, causing an extended period of turbulence and uncertainty regarding Britain's current and future relationship with the EU. The impact of the 'Brexit' on the health sector, not just within Britain but in all other 27 countries, is of high concern to the patient community especially with regard to the consequences for health-related legislation, regulatory issues, and health research. EPF will explore with the wider EU health community, how we can best support processes that ensure that health provisions feature appropriately in the negotiations.

2.3 Target Groups of EPF's Main Activities for 2017

A primary target group is our own membership, consisting of 67 patient organisations that are either pan-European disease-specific patient organisations or national coalitions of patient organisations. Our members drive and guide our work and engage actively in all aspects of EPF's annual plan design and implementation.

Two sub-groups of members will be particularly targeted in 2017:

- We will continue to reach out to patient communities in Member States through our member organisations, policy makers, and stakeholders committed to supporting our work at **national level**.
- Existing and emerging national **patient coalitions** through the planning, implementation, and follow-up of a dedicated workshop bringing together leaders of existing and emerging patient coalitions from across the EU in spring 2017.

Other key target groups are:

- **EU Health Stakeholders**: EPF has had a long tradition of cooperating with fellow health stakeholders on issues of common concern and enjoys a constructive and trusted relationship with leading public health and professional groups at EU level.
- **Members of the European Parliament**: building on a long-standing history of collaboration, we continue to disseminate information and policy briefs to key MEPs on an on-going basis, as well as involving them in our activities.
- **The Commission**: While we will communicate with other Commissioners, our primary target is the Health & Consumer Commissioner. Officials from DG SANTE, DG CNECT, DG GROW, DG RTD, DG ECFIN, DG EMPL and DG JUST will also be on our radar, in the spirit of 'health in all policies'.

- **Council and Health Attachés**: a specific attention will be focused on the Member States holding the EU rotating presidency (Malta and Estonia).
- **Media** at national and EU levels are an important conduit for reaching out to our targeted audiences.

2.4 EU Added Value and Expected Impact of the Activities Scheduled for 2017

EPF's policy priorities for 2017 are linked to our strategic goals and key developments in the EU healthcare environment. EPF is the only EU-level umbrella patient organisation that is non-disease-specific, placing us in a **unique position** as the uniting independent voice of patients from all chronic disease areas and bridging EU developments with patient communities across the EU. We promote a '*health in all policies*' approach to ensure the multiple vulnerabilities of patients and the physical and psychological impact of their condition are properly addressed.

In addition to contributing a critical patient perspective to policies and programmes at EU level, we **build awareness and capacity** of community actors to engage in their own arenas – particularly with regard to the involvement of patient organisations in the transposition, implementation, and monitoring of EU legislation and recommendations at national level.

Our priorities in 2017 will continue to ensure that a solid **patients' perspective** is integrated into all relevant **health-related policies** at EU level, as well as supporting the implementation of EU legislation of relevance to patients. Patients living with chronic conditions are *"experts by experience"* whose perspective on disease and care is unique. Patient empowerment at both individual (disease management) and collective (policy) level is a pre-requisite to achieve equity in healthcare and advance the concept of patients as 'co-producers' of health.

Our specific policy work is clustered in two broad thematic areas – "*Patient Empowerment*" and "*Patient Access*" – that reflect our strategic vision and mission. Actions aimed at promoting more sustainable patient organisations will remain a cross-cutting theme for EPF in 2017 both within and out with our WP, e.g. our Capacity Building Programme (see below).

In 2017 EPF will continue to partake in EU health-related policy and strategy at a high level. We will engage with the future **EU strategy for the pharmaceutical sector**, outlined in the Commission's staff working document "*Pharmaceutical industry: a strategic sector for the European economy*" (2014). In collaboration with health and consumer NGOs, we will engage with the **European Semester** process and the role of health therein, taking forward previous collaboration such as the Vilnius Declaration (2013) and its follow-up event under the Latvian Presidency (2015) which resulted in the "*Riga Roadmap*" for action.

To follow up on our position statement on equal treatment of patients in the workplace and contribute to the Europe 2020 goal of an inclusive growth, we will continue to raise awareness about **patients' rights and needs in the workplace**, collaborating with the 'Fit for Work' initiative and the EU Agency for Health and Safety campaign on 'Healthy Workplaces for All Ages".

Our key role in **supporting the patient community** will continue in 2017 with a focus on strengthening the role of and enhancing cooperation among national patient coalitions. They play a key role in connecting us with the local patient community, while ensuring that decisions and recommendations taken at EU-level are effectively transposed on a national level. A dedicated workshop for national coalitions will take place in 2017 to reflect on the role and prospect of national coalitions across the EU.

In line with our goal to promote the **involvement of patient organisations in EU health-related projects**, we will continue exploiting the outcomes of our Value+ project, building on the trusted relationship with respective DGs and Agencies in relation to the many new EU funding programmes relevant to patients (PHP, HORIZON 2020, IMI 2, Structural and Investment Funds, etc.).

As in previous years, our WP will be complemented by other programmes and projects, which altogether complete our Annual Plan 2017:

- The **EPF Capacity Building Programme**, which will continue to be rolled out in Bulgaria, Hungary, Poland, Romania, Slovakia, and expanded to encompass the Western Balkan Region. We will continue to offer two European-level training modules and, for the very first time we will implement a summer school for young patient leaders.
- **Patient Academy on Therapeutic Innovation (EUPATI)**: with the 5-year IMI project coming to an end in January 2017, EUPATI will thereafter be mainstreamed as an EPF-led programme maintaining the public-private partnership model which proved highly effective and successful.
- Other projects are **PREFER** (new IMI 2 funded projects on patients' elicitation on benefit risks), the **PRO-STEP** and **PISCE** tenders on self-management, the **EUnetHTA Joint Action 3**, and the new JA on Chronic Diseases successor to **CHRODIS**. We will also closely monitor the application processes of the different consortia EPF joined in 2016 that submitted projects' proposal in Horizon2020 and the Public Health Programme.
- In 2017, EPF will develop and publish a **magazine** as a pilot initiative specifically targeted towards EU-level stakeholders and policy makers. This project will be thoroughly evaluated with a view to exploring the possibility to mainstream it in our WP as from 2018.

3. PLANNING AND IMPLEMENTATION OF THE EPF'S ANNUAL WORK PLAN FOR 2017

Inherent to the EPF strategic plan 2014-2020 is a “thematic” approach that ensures maximum synergies and complementarity between our policy-focused advocacy work and the evidence-base built up through projects. Two dedicated internal working groups address the overarching priorities of patient empowerment and patient access, aligning our project, policy and communication work accordingly.

EPF’s 2017 WP is structured around the **three thematic priorities of patient empowerment, access, and sustainable patient organisations**, which are complemented by cross-cutting activities on dissemination, management and evaluation of the WP.

PATIENT EMPOWERMENT – THEMATIC AREA 1

Ensuring the sustainability of future health systems and addressing the challenge of chronic diseases are key to realising the Europe 2020 goals of smart and inclusive growth.

Patient Empowerment and Patient-Centred Care

Patient empowerment is embedded within all our work areas. We will pursue our work with the working group on **patient empowerment** with the production of a toolkit to support patient organisations in national advocacy. Building on the outcomes of the patient empowerment campaign, we will continue outreach and advocacy activities, developing collaborations with like-minded stakeholders, in order to promote initiatives that can turn the principles expressed in the Patient Empowerment *Charter* into concrete actions.

Integrated care constitutes an important element of patient-centred care and will be for a focus in 2017 by linking up with leading academic experts and connecting with EU developments within the health system performance assessment framework. We will also pursue our collaboration in the Integrated Care Alliance.

Health Literacy and Information to Patients

Health literacy remains a priority to **support patient empowerment and alleviate health inequalities**. We will uphold our active participation in the informal coalition of health stakeholders, that recently adopted a consensus paper. EPF will also develop a position statement on information to patients on food and nutrition, engaging with relevant public health NGOs. We will continue our close collaboration with the European Medicines Agency, disseminating information to patient communities and participating in relevant EMA activities.

Self-management is an important dimension of patient empowerment, where health literacy is of primary concern. Our advocacy work will therefore link to and build on our participation in two tender studies relating to self-care: PISCE (self-care in minor conditions) and PRO STEP (self-management in chronic diseases), the latter of which we coordinate and which will deliver key recommendations during 2017.

Clinical Trials

EPF will monitor the **implementation of the recent EU Clinical Trials Regulation**, with special attention on transparency, informed consent, data sharing and patient involvement in the assessment of trials. We will develop information resources for the patient community as needed, and engage with our members to formulate a position on sharing patient-level data. Finally, we will further disseminate and build on our position paper on informed consent.

eHealth

Patient-centred technology remains **high priority for EPF** as it is closely associated with patient empowerment and access to health services. Building on projects such as Renewing Health, SUSTAINS, and Chain of Trust which have been instrumental in gathering evidence on patients' views and expectations of eHealth, we will launch a consultation-based position paper on eHealth. Our participation in the European Commission's eHealth stakeholder group will allow us to voice the patients' perspective into eHealth, mHealth, and electronic health records. Finally, in 2017, EPF will organise a webinar to build the capacity of our membership on current developments and challenges in this area.

Personalised Medicine, Data Protection and Big Data

We will continue to follow the agenda on personalised medicine through our observer role in the European Alliance and participation in relevant events. Our focus will be on patient empowerment and information/health literacy needs, as well as ensuring **equity of access and affordability** of these new types of treatment.

We will engage our membership in discussions on **Big Data** by developing a briefing and taking this topic further with our Policy Advisory Group, ensuring the capacity of patient communities to provide meaningful input to policy discussions in this highly technical area.

Building on EPF's work on data protection since 2012, in 2017 EPF will start an internal discussion on principles for a patient-centred approach to big data to ensure that patients' needs in terms of **privacy, information and empowerment** are taken into account in related policies and strategies.

Complementary Activities and Projects

CHRODIS Joint Action and CHRODIS-PLUS

The Joint Action "*Addressing Chronic Diseases and Healthy Ageing across the Life Cycle*" (CHRODIS-JA) aims to promote and facilitate exchange and transfer of good practices between European countries and regions, addressing chronic conditions, with a specific focus on health promotion and prevention of chronic conditions, multi-morbidity, and diabetes. This project is 50% co-funded by the EU Health Programme.

As associate partner, EPF contributes the patients' perspective on care for patients with chronic diseases. We look at aspects such as integrated care, ensuring patient safety, care for patient with multi-morbidities, multidisciplinary approaches, patient empowerment, and professional training. The final aim is to share selected good practices on a platform targeted to users such as researchers and healthcare professionals but open to all, including patients. Our role is to facilitate the scalability of these recommendations to other chronic conditions.

In 2017 the Joint Action as we know it will pass on the baton to CHRODIS PLUS, the natural continuation of the initial project. The new project CHRODIS-PLUS aims to promote the implementation of new or innovative policies and practices in health promotion and primary prevention, patient empowerment, functional decline and quality of life for chronic patients, and sustainable health systems. EPF will be involved as associated partner to horizontally contribute to the implementation of several activities including multimorbidity care model, evaluation, dissemination and transferability of the diabetes care model. The project is scheduled to kick off in spring 2017, for a duration of 36 months.

http://www.chrodis.eu/

PROSTEP

In 2017, EPF will continue to lead the PRO-STEP Consortium implementing a tender project under the EU Health Programme on the promotion of self-management systems in chronic diseases in the European Union, initiated in 2016.

The tender foresees the conduction of a study (consisting of a literature review and cost-benefit analysis) and setting up of a platform of experts to explore and propose methods of promotion of self-care for chronic diseases. This is essentially a continuation of the previous tender on self-care in minor conditions (PISCE) where EPF is also involved. The consortium is led by EPF and involves other entities such as the Avedis Donabedian Research Institute (FAD), the Danish Committee for Health Education (DCHE), the Institute for Medical Technology Assessment (iMTA). The European Health Futures Forum work in close cooperation with EPF in the coordination of the project.

PISCE

PISCE is a tender project financed by the European Commission's DG SANTE. The tender aims to take action and create a platform of experts in self-care and healthcare, with the ultimate goal to put in place a framework for action to enhance self-care at EU level and develop strategies to support the broader implementation. EPF will contribute to the activities of the work packages and the platform of experts.

Led by the Danish Committee for Health Education (DCHE), the tender will end in 2017, with a final conference foreseen for March 17.

EUPATI

Funded by the Innovative Medicines Initiative (IMI), EUPATI was launched in 2012 to provide scientifically reliable, objective, comprehensive information to patients on medicines research and development.

A major change in 2017 will be the mainstreaming of the EUPATI programme into EPF annual plan. As an IMI project, EUPATI will end in January 2017 and it will continue to exist as an EPF-led programme, whilst keeping the Public Private Partnership approach in both the governance and implementation of the activities. In terms of funding, for the period 2017-2019 approximately 70% will be provided by committed private actors with the remaining 30% being in-kind contribution from public partners.

Even though we will not be able to secure the same level of funding as during the IMI project period, the core operations will be sustained:

- the exploitation of the EUPATI toolbox.
- the launch of the third Patient Expert course.
- coordination of the National Platforms.

Content will be updated to keep in line with relevant legislative and regulatory changes (especially in the area of Clinical Trials), while a dedicated working group will continue to explore opportunities for long-term sustainability of the project.

PREFER

PREFER, a 5-year project funded by the Innovative Medicines Initiative (IMI), will evaluate and test different preference elicitation methods. PREFER will provide a set of systematic methodologies and recommendations to assess, engage and include patient perspectives in medicines' development.

The PREFER project is co-led by the Uppsala University (Sweden) and Novartis. EPF is one of the four patient organisations 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.

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

PATIENT ACCESS – THEMATIC AREA 2

In 2017 EPF will continue to work towards reducing health inequalities through promoting equitable access to high quality, patient-centred healthcare, from prevention to chronic disease management.

Policy and Awareness Campaign

From EPF's perspective, universal health coverage is essential to the success of all other health and wellbeing goals developed by the UN SDGs. Building on our position statement "*Defining and Measuring Access to Healthcare: the Patients' Perspective*" and a related survey, in 2017 we will launch a **policy and awareness campaign on universal access to healthcare** to identify political measures to achieve universal health coverage by 2030 in accordance with the **UN Sustainable Development Goals**. This campaign will foster discussions and actions at EU and Member States level to pave the road towards universal health coverage.

We will organise two **roundtables** to raise awareness of universal health coverage and engage in a debate with EU decision makers and health stakeholders. Another outcome of the campaign will be a comprehensive **roadmap** which will identify key steps necessary to achieve universal health coverage for all patients.

We will continue to work in close cooperation with the Patient Access Partnership to contribute a strong patient perspective towards identifying sustainable solutions to ensure equitable patients' access to quality healthcare.

EPF will also develop a statement on the **country specific recommendations** on healthcare from the patients' perspective to ensure that universal health coverage and the cost of health inequalities and barriers to access are acknowledged in the European Semester process.

Cross-Border Healthcare

EPF will keep its instrumental role in the area of **cross-border healthcare**, and in the following up of the implementation of Directive 24/2011. We will continue to monitor its impact through engaging our informal network of patient leaders across the EU and organising a European roundtable with patient organisations, national and European policymakers to assess progress in implementing the Directive.

Patient Safety and Quality of Care

We will pursue our work on patient safety, drawing on our involvement in the PASQ Joint Action, to foster real and lasting buy-in from Member States to accelerate their efforts to ensure patient involvement is part of the systemic and cultural change needed in this key area.

Following our 2016 conference, EPF will develop in consultation with a dedicated working group involving patient representatives and other stakeholders, recommendations for a set of '***core competencies***' for patients and families to empower them in patient safety. This will address a key gap in the implementation of the 2009 Council Recommendation on patient safety.

We will continue to contribute to the **Commission's Expert Group on safety and quality**, and engage with and comment on the Commission's studies on the costs of unsafe care and cost-effectiveness of patient safety programmes.

EPF will continue to work in close collaboration with the **European Medicines Agency**, inter alia through our role in the Patient and Consumer Working Party (PCWP) and our representation on the Pharmacovigilance Risk Assessment Committee (PRAC).

A position paper "**Quality of Care from the Patient's Perspective**" will be developed to support our engagement in the policy debates on health system performance assessment and preliminary work on indicators to measure the patient experience (**PREMs**), patient reported outcome measures (**PROMs**) and patient reported safety incidents (**PRIMs**), in collaboration with relevant agencies and organisations such as the OECD.

Medical Devices

EPF will continue to co-organise the **Patient MedTech dialogue**, according to our Memorandum of Understanding with MedTech Europe, and will particularly focus on patient access to medical devices in order to contribute to our reflection process on universal health coverage. We will continue to work with the **European Forum for Good Clinical Practice** to provide a patients' perspective during the implementation of the new Regulations on medical devices and in vitro diagnostics.

Health Technology Assessment

HTA has been a long-standing priority for EPF. Building on our numerous activities in 2016, 2017 will be a crucial year for EPF's involvement in HTA. EPF will produce a **position paper** on HTA based on consultations by the European Commission by the end of 2016. We will continue to coordinate an informal working group on HTA, with particular emphasis on defining patient organisations' input into an HTA strategy for Europe post-2020.

Non-Discrimination and Social Inclusion

EPF will continue to work on tackling discrimination in access to health and social care. We will cooperate closely with NGO's representing underserved and vulnerable groups in order to ensure their perspective is integrated in our reflection process. To follow up on the EPF 2016 roadmap on inclusion of vulnerable groups' perspective in patient organisations, we will **collect good practices** from patient organisations on their work with various groups, in order to foster scaling up of these practices and raise awareness of the importance of collaboration for universal access to healthcare.

Discrimination in the workplace and on the employment market is also close to our heart. In 2017 we will establish a task force with EPF members, that will advise the EPF secretariat via bimonthly teleconferences, and develop a **set of tools** to promote better inclusion of patients with chronic and long term conditions in the workplace. We will also dialogue with organisations promoting occupational health and safety and (re)integration of patients in the workplace. This will build on our work in the framework of the Slovak EU Presidency, in collaboration with the 'FIT to WORK' network.

Following a public consultation in 2016 to which EPF responded, the European Commission will publish legislative proposal on the European Pillar of Social Rights in 2017. EPF welcomes this initiative and will continue to provide the patient's perspective to ensure it applies across the EU and responds to the challenges faced by patients as regards their social rights.

Access to and Pricing of Medicines

Access to medicines is high on the EU agenda, having been prioritised by the Dutch presidency, and it is important that high-level discussions continue around this topic and are taken on by successive EU presidencies. Having developed a position paper "*Value and pricing of innovative medicines*" in 2016, we will continue to engage with policymakers and stakeholders on **pricing and reimbursement** where a specific focus will be the Commission's impact assessment report on pharmaceutical incentives on public health and access, during 2017.

Generic and biosimilar medicines also form an important part of access to medicines and we will continue to work together with DG GROW on promoting access and uptake, as well as providing unbiased, reliable information to patients on biosimilars.

We will continue to engage in debates around **adaptive pathways** and initiatives such as the ADAPT SMART project, in order to ensure the patient perspective is central and that patients' safety remains paramount.

Complementary Activities and Projects

ADAPT-SMART

“*Accelerated Development of Appropriate Patient Therapies: a Sustainable, Multi-Stakeholder Approach from Research to Treatment-Outcomes*” (**ADAPT-SMART**) is a coordination and support action (CSA) funded by IMI 2 and started in September 2015.

The purpose of this 30-month project is to establish a platform bringing together all relevant stakeholders for the coordination of adaptive pathways (MAPPs) related activities within IMI 2 in order to facilitate and accelerate the use of MAPPs. In particular, the project aims to identify gaps, barriers, and critical points of transition or engagement with various stakeholders, including patients, professionals, industry, payers, regulators, etc. The consortium includes 32 organisations from the public and private sectors.

The project leader is the European Medicines Agency and the project coordinator is TI Pharma.

http://adaptsmart.eu/

EUnetHTA Joint Action 3

The EUnetHTA JA3 started in March 2016. The Patients and Consumers Group is jointly represented by EPF, EURORDIS, EMSP and BEUC. The four organisations ensure an effective input to the implementation of tasks.

EUnetHTA JA3 mainly focuses on early dialogues, governance, re-use and national uptake of assessments. Special attention will be dedicated to HTA processes for medical devices. 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.

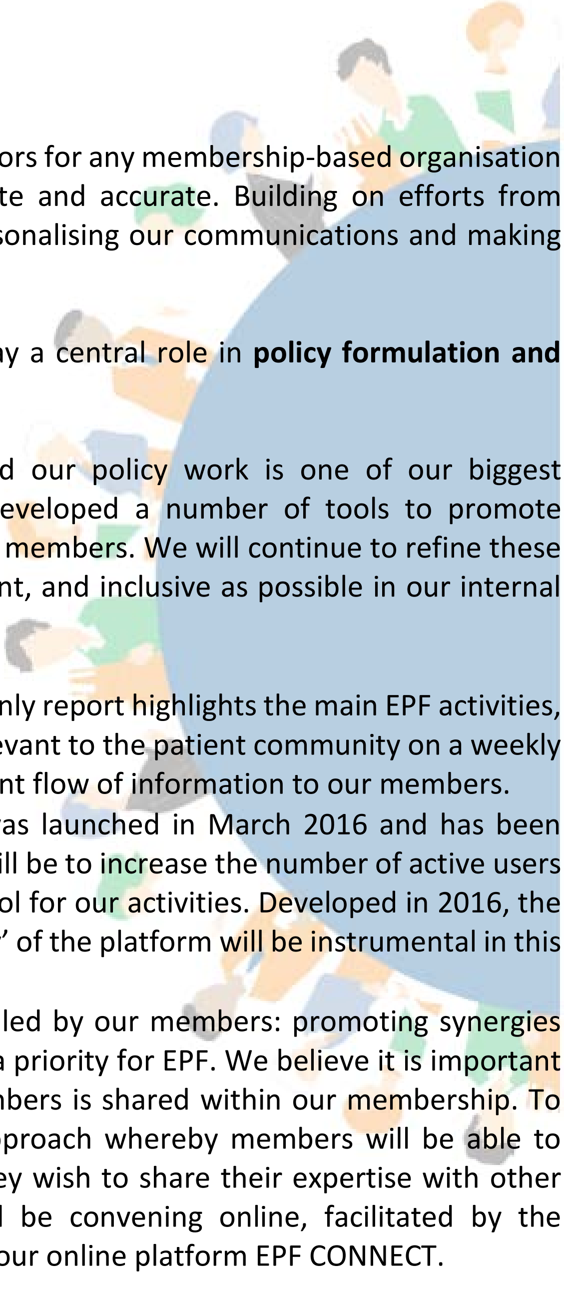
http://www.eunethta.eu/

SUSTAINABLE PATIENTS ORGANISATIONS – THEMATIC AREA 3

Reinforcing EPF membership

Adopted by our General Assembly in 2014, the Membership Strategy ensures that EPF serves the needs of its members to the maximum. 2017 will be the third year of implementation of this important milestone, which has reinforced EPF's ownership by its members. Our objective is now to go one step further and to translate this into strong strategic support around our policy and advocacy work.

Clear Identity, Clear Added Value



Our database, our wealth: one of the success factors for any membership-based organisation is the extent to which its database is up-to date and accurate. Building on efforts from previous years, we will continue to invest in personalising our communications and making sure the right message reaches the right target.

As a membership organisation, our members play a central role in **policy formulation and validation process.**

Stimulating engagement from members around our policy work is one of our biggest challenges. For the last couple of years, we developed a number of tools to promote interactions between the EPF Secretariat and EPF members. We will continue to refine these tools, with the objective of being as clear, efficient, and inclusive as possible in our internal communications:

- *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.
- *The EPF online Platform EPF CONNECT* was launched in March 2016 and has been successful so far. Our objective for 2017 will be to increase the number of active users and to make it the main online support tool for our activities. Developed in 2016, the implementation of the 'marketing strategy' of the platform will be instrumental in this regard.
- *A cluster approach* to promote the work led by our members: promoting synergies between the activities of our members is a priority for EPF. We believe it is important that the expertise developed by our members is shared within our membership. To enable this, we will propose a cluster approach whereby members will be able to create ad hoc groups on topics where they wish to share their expertise with other organisations. These ad hoc groups will be convening online, facilitated by the members themselves with the support of our online platform EPF CONNECT.

- *Policy Breakfast Briefings* – For the past two years, EPF organised "Weekly Coffees with EPF", an initiative providing a weekly opportunity for members and the Secretariat to exchange information on their current activities and priorities, on a bilateral basis. This brought EPF a lot of useful insights, delineating the needs and activities of each individual member. It is time to upgrade the format of these meetings. In 2017, we will propose regular Breakfast Briefings (online or at our premises) where EPF members will get updates on policy developments at European level and discuss potential common actions for the patient community.

Membership Development & Growth

EPF will pursue the work of the previous years and work on increasing our **representativeness** in terms of diseases and geographical coverage.

We will follow up on the contacts initiated over the past years with coalitions from Sweden, Denmark, Finland, and the Netherlands. We will also organise bilateral meetings with potential new members, notably European umbrellas with which we would like to strengthen the cooperation and explore membership.

Development of transparency guidelines: EPF has a strong and long-standing culture of **transparency**. The fulfilment of our membership criteria (legitimacy, representation, democracy, accountability and consultation, and transparency) is a precondition for patient organisations to be granted the status of members. In 2017 EPF, together with its members, will develop guidelines on transparency for members to monitor adherence to EPF membership criteria and to ensure the highest possible standards for our network.

Strong Patient Organisations

Demonstrating the added value of patient organisations – Patient organisations make a **unique contribution to the public health debate**, voicing the experience and expertise of healthcare users. This should be recognised. In 2017, we will collect evidence of the added value of patient organisations in policy-making and research and compile it in a report on the added-value of patient organisations, targeted at health stakeholders. This report will aim at promoting better understanding and recognition of the role of patient organisations and establish them as a natural policy partner at national and European level.

Meeting of the national coalitions: from the implementation of the membership strategy it appears crucial to address the needs of our two types of members separately (European disease-specific umbrellas and national coalitions). With regards to the national coalitions, our approach was to engage and work with national patient organisations and their national coalitions regionally (one geographical region per year), through annual Regional Advocacy Seminars. This has been successful, as EPF is now represented through a national coalition in 14 EU countries (as well as in FYROM). In 2017, we will organise a meeting of national coalitions of patient organisations (members and non-members of EPF) to discuss their role in the national health policy environment, and in monitoring and reporting the implementation of EU legislations.

EPF Capacity Building Programme

EPF will continue to strengthen the capacity of patient leaders through its capacity building programme and activities funded outside of the Operating Grant. The programme will continue to be rolled out in Bulgaria, Hungary, Poland, Romania, Slovakia with various thematic training modules, in cooperation with national trade associations. A possible extension of the programme to Greece, Spain and Portugal will be investigated.

We will continue to offer two European-level training modules, with one focusing on HTA in February 2017.

We will also launch a new chapter of our programme, encompassing the Western **Balkan Region** (Slovenia, Croatia, Bosnia-Herzegovina, Serbia, Kosovo, Montenegro and Albania), where systematic capacity building activities will be set up on the basis of a needs assessment and with a longer-term approach.

Involving Young Patients

The **EPF Youth Group** currently involves 12 young patients representing a wide range of chronic conditions and nationalities. After a focus on capacity development and transition to adult care, the Youth Group's 2017 core theme will be overcoming **discrimination**.

First-hand testimonials have shown that young people living with chronic conditions are frequently discriminated against in access to education, quality healthcare, and employment. The Youth Group aims to encourage debates and to sensitise civil society and policy-makers to the consequences of living as a young person with a chronic condition.

2017 will also see EPF organising its first **Summer Training Course for Young Patients Advocates – Leadership Programme**. The objective is to create a platform where young patients' advocates would share and learn from each other, by discussing and exploring common issues relevant for young patients' movement across Europe.

Following consultation of the EPF Youth Group, the first edition of the Leadership Programme will focus on non-discrimination, a crucial and common issue for young patients.

The gathering will take place in July in Vienna, with the ambition to welcome around 40 participants within the age range 18-30. Target groups include young patient advocates, but also carers or staff members of patient' organisations.

This initiative is a pilot-project for 2017, and if proven successful and meaningful for young patients, will be organised on a yearly basis.

Main actions:

- **Video** to visually communicate young patients' daily life challenges.
- **Network**: build alliances with European disease-specific youth groups and relationships with external stakeholders in the educational, employment, healthcare and disability sectors.
- Enhance **visibility** through social media networks. The Group will organise Twitter chats on specific aspects of discrimination, gathering views also from other stakeholders.
- Visibility in the **EU** context: building relationships with relevant parts of EU Institutions (youth, education, etc.).
- **Connecting** the Youth Group activities to other youth events in Europe.

In the context of the ongoing capacity development process, in 2016 a traineeship programme for young patient advocates was piloted. The programme foresees 3 to 5 month traineeships for members of the Youth Group at the EPF Secretariat. We intend to continue this approach during 2017.

3.1 EPF'S ACTIVITIES FOR 2017

Activity	**Deliverable**
Advocacy Work on Empowerment	- Toolkit on patient empowerment - Position statement on information to patient on food and nutrition - Position on sharing patient-level data
Working Group Empowerment Meetings	- Minutes of WG Empowerment meetings
Policy and Awareness Campaign on Access to Healthcare	- Report on roundtable on universal health coverage by 2030 - Report on final roundtable on universal health coverage by 2030 - Statement on country specific recommendations on health and long term care - Roadmap towards achieving universal health coverage by 2030
Roundtable on Cross-Border Healthcare	- Report on European Roundtable on cross-border healthcare

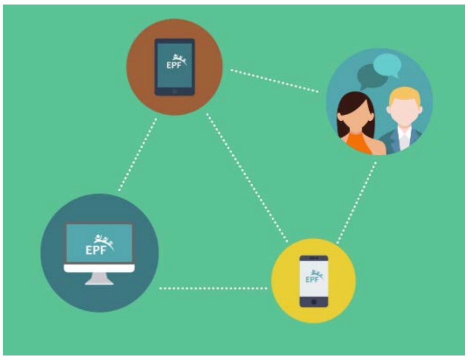
Advocacy work on access-related topics (other than campaign)	- Concept and structure for a questionnaire for patients on Directive 24/2011 - Position paper on quality of care - Set of core competencies for patients and families in patient safety - Report on Webinar on eHealth/mHealth - Position paper on HTA - Collection of good practices for cooperation with NGOs representing underserved groups - Set of tools to promote inclusion of patients in the workplace
Working Group on Access	- Minutes of WG Access
Youth Group Spring Meeting	- Report on the Spring Youth Group Meeting
Annual Youth Group Meeting	- Report on the Annual Youth Group Meeting
National Coalitions Meeting	- Report of the meeting of national coalitions
Stimulating engagement from members around our policy work	- Weekly Insiders' Mailing - Policy Breakfast Briefings
Development of transparency guidelines	- Transparency Guidelines
Demonstrating the added value of Patient organisations	- Report on the added-value of patient organisations
EPF Annual General Meeting	- AGM Minutes
Internal & External Evaluation	- Evaluation Report
Policy Advisory Group Meetings	- PAG meetings minutes
Monthly Newsletter	- Newsletter
Report of Annual activities	- Annual Report
Videos	- EPF 2017 Corporate Video - EPF Youth Group Video
Press-releases, blogs, factsheets and other communication material	- Press releases - Monthly updates on blog - Production of three thematic factsheets - Promotional Items

EPF Website	- Maintenance and Update

3.2 DISSEMINATION AND EVALUATION OF THE EPF'S WORK PROGRAMME FOR 2017

The 2015-2017 overall EPF goals that will guide our communications objectives for 2017 are Communicate to inform, to engage and to persuade. All our communication *outputs* are available to the wider public through our newsletter, website and social media. We therefore design our communication to fit the different target audiences, and to ensure the messages are clear and reliable.

Communication Tools



EPF's ***website*** is our flagship communication tool and official window displaying information on our organisation and activities. The website proposes updates aimed at diverse target groups of decision-makers, health stakeholders, lay patients, and policy makers at local, regional, and national level. Our website needs to be dynamic and easy to upgrade and maintain to embrace fast-moving web design trends. We will undertake a complete review of the website in 2017, to prepare for a full revamp in 2018, with structural renovation and layout modernisation. A reflection process will also be initiated in 2017 on how to best integrate new media formats (GIF, videos) and social media contents.

Our monthly ***Newsletter*** is extremely well received by more than 4300 subscribers. It showcases EPF's activities, projects, and events-related news and the impact of our work. A comprehensive update of the database will be completed by 2017 to maximise readership and audience-reaching. We will continue to include articles and updates from our members, strengthening our relationship with our membership.

The ***Annual Report*** is a central tool promoting our achievements to a wider public and to demonstrate how we perform against our yearly strategic objectives.

EPF's active and growing presence on ***social media*** has built a strong network of allies and solid reputation for EPF. In 2017, we will prepare interactive content on social media, such as Twitter chats and live video coverage of our events, to further maximise the outreach and interaction with our audience.

Video remains crucial to get our messages across to different target audiences. Our 2017 video will be a concise and powerful tool to convey our access campaign and our policy work.

Ancillary to the production of our corporate video, we will investigate the possibility to produce monthly video recaps of our activities.

The ***media*** scene is changing dramatically and EPF can adapt and find flexible solutions enabling us to reach out to major media players in Brussels. Our database of media contacts ensures a wider coverage at national and EU level. Expanding and updating this contact list will be an essential task for 2017. It will help us to maximise the magnitude of our press releases, updates, and invites.

EPF's ***blog*** is a strong and useful tool to demonstrate the exceptional work our members are doing for their respective patient constituency. We will provide at least one blog entry to our members per month, including a link in our newsletter. Guest external authors will also have the opportunity to write on a case by case basis.

EPF will release thematic ***factsheets*** on specific policy areas in 2017. The themes will be decided in coordination with EPF policy team and resonate the main objectives of EPF.

In 2017, EPF will develop and publish a **magazine** as a pilot initiative specifically targeted towards EU-level stakeholders and policy makers. This communication tool will be thoroughly evaluated with a view to exploring the possibility to mainstream it in our WP as from 2018

3.3 EVALUATION

On-going evaluation of the WP, in line with agreed measurable performance indicators and target for each core strategic goal, has been intrinsic to EPF developments over the last few years.

While strategic monitoring and evaluation is designed and carried out internally by the EPF Secretariat, an external evaluator will be appointed by means of an open tender to contribute external evaluation intelligence to assessing some of the key milestones of our 2017 programme. Internal evaluation will be coordinated by Director of Programmes and Operations Walter Atzori.

In order to allow for efficient use of resources available, the external evaluator will focus on selected key areas of intervention representative of EPF 2017 WP. Our plan is to involve the external evaluator in the assessment of the policy and awareness campaign on access, the national coalition workshop, and the cross-border healthcare roundtable.

A joint evaluation plan compiling internal and external monitoring and evaluation (M&E) will be agreed upon in early 2017 as soon as the external evaluator has been appointed. The plan will establish the evaluation framework in respect of each operational objective of our 2017 WP based on a logical framework matrix approach.

The evaluation 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. Evaluation 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.

The methodology for evaluation will use both quantitative and qualitative methods and will address activity-specific and cross-cutting targets. The following data gathering methods will be used: desk reviews of documents, policy deliverables and reports; online surveys and interviews with participants to EPF events and members of internal Working Groups; interviews and focus groups with EPF members and external stakeholders.

The external evaluator will be invited to attend events and will, when possible, hold focus group meetings with representatives of EPF members, Board, and Secretariat and carry out ad-hoc interviews with individual EPF member representatives and external stakeholders who play a key role in key areas of intervention.

4. MID-TERM REVIEW

EPF annual work plans disclose the yearly activities implementing the strategic lines and objectives defined in the encompassing Strategic Plan 2014 – 2020.

In 2017 we will undertake a mid-term review of EPF's strategic plan in order to begin planning for the launch of a new strategic planning process for the period 2021-2028. This crucial assessment will be led by the EPF Board and secretariat, in close consultation with members and selected stakeholders. The evaluation of progress will be assessed against our strategic goals. To that end additional specific evaluation activities involving EPF constituency and all relevant external stakeholders will be put in place and specific recommendations will be made, such as on key socio-economic and political factors or key global trends in 2017.

This mid-term review process will also help us in the preparation of our application for a new 4-year Framework Partnership Agreement operational funding with the European Commission Consumer, Health and Food Executive Agency (CHAFEA).

- END -

List of Annexes

Annexe 1: List of Deliverables

Annexe 2: Key Performance Indicators

Annexe 3: Events and Meetings 2017

Annexe 1 to the EPF Annual Work Plan 2017: List of Deliverables 2017 according to the Operating Grant

No	Deliverable name	Content specification	Delivery M	Dissemination
D1.1	Toolkit on patient empowerment	Toolkit to support patient organisations in their advocacy on patient empowerment in their national/regional contexts, developed with input of the Working Group.	M 12	PU
D1.2	Position statement on information to patient on food and nutrition	Position statement on information to patients on food and nutrition, building on the work of the EIP-AHA A3 action group and engaging with other public health NGOs as relevant.	M 10	PU
D1.3	Position on sharing patient-level data	Originally deliverable from 2015, response to EMA consultation, but EMA postponed such a consultation to at least 2017.	M 12	PU
D1.4	Minutes of WG Empowerment meetings	Deliverable compiling minutes of the two meetings of the Empowerment Working Group.	M12	ER
D2.1	Report on roundtable on universal health coverage by 2030	Report from the launch event of EPF reflection process on access to healthcare which will be held in February 2016.	M3	PU
D2.2	Report on final roundtable on universal health coverage by 2030	Report from the final event of EPF reflection process on access to healthcare which will be held in December 2016.	M12	PU
D2.3	Statement on country specific recommendations on health and long term care	A statement on country specific recommendations on health and long term care from the patients' perspective to ensure that universal health coverage and the cost of health inequalities and barriers to access are acknowledged in the European Semester process.	M6	PU
D2.4	Roadmap towards achieving universal health coverage by 2030	A comprehensive roadmap which will identify key steps that EU decision makers and member states need to take in order to achieve universal health coverage for all patients in the EU.	M12	PU
D2.5	Report on European Roundtable on cross-border healthcare	This deliverable will report on outcomes of the European Roundtable on cross-border healthcare and patients' rights, with the involvement of patient organisations, national and European policymakers. Second-half 2017. D22 Report of the roundtable.	M 11	PU
D2.6	Concept and structure for a questionnaire for patients on Directive 24/2011	This Deliverable outlines the concept and structure for a questionnaire to collect patient feedback on Directive 24/2011 – proposal for a tool to collect feedback from patients and the patient community, for future monitoring of the Directive and in particular the functioning of NCPs.	M 12	PU
D2.7	Position paper on quality of care	Position paper on quality of care, including recommendations on how to communicate information on quality of care to patients.	M 12	PU
D2.8	Set of core competencies for patients and families in patient safety	This deliverable outlines the set of core competencies for patients and families in patient safety to enable them to participate in improving their own safety, both individually and collectively through their patient organisations.	M 12	PU
D2.9	Report on Webinar on eHealth/mHealth	The aim of this webinar is to offer a capacity building opportunity on the topic of eHealth (including mHealth) to volunteers within our membership, in order to ensure they are up to date on the latest challenges and debates in this area as well as on the legislation and policies at EU level related to the safety and quality of eHealth services.	M5	ER

D2.10	Position paper on HTA	This deliverable will clarify patients' perspective on HTA. Based on findings gathered through an HTA training with EPF membership and online consultations led both by the EUPATI project and the European Commission, the paper will inform the HTA decision making process.	M11	PU
D2.11	Collection of good practices for cooperation with NGOs representing underserved groups	This document will summarize and provide links towards more information on the good practices collected during 2017 on cooperation between patient organisations and NGOs representing underserved groups.	M12	PU
D2.12	Set of tools to promote inclusion of patients in the workplace	EPF will develop a set of different tools (patients' testimonies, case studies recommendations aimed at employers, at decision makers), in order to promote the inclusion of patients in the workplace. A task force with volunteers from our membership will provide expert advice to develop the content and format of this toolkit.	M12	PU
D2.13	Minutes of WG Access	This deliverable will compile minutes of the two meetings of the Access WG.	M4 and M12	ER
D3.1	Report on the Spring Youth Group Meeting	Outcomes of the meeting with updates on topics such as membership, governance, planning of activities till the end of the year.	M6	CO
D3.2	Report on the Annual Youth Group Meeting	Outcomes of the meeting with updates on topics such as membership, governance, planning of activities till the end of the year.	M10	CO
D3.3	Report of the meeting of national coalitions	Report of the meeting of national coalitions of patient organisations (members and non-members of EPF). The purpose of the meeting will be to discuss national coalitions' involvement in European health policy and their specific role in monitoring and reporting the implementation of pieces of legislation adopted at European level.	M7	ER
D3.4	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. (At least 35 issues)	M1-M12	ER
D3.5	Policy Breakfast Briefings	Reports from the EPF Policy Breakfast Briefings (held online or at our premises) - updates on policy developments at European level and discussion around potential common actions for the patient community. (8 meetings)	M1-M12	ER
D3.6	Transparency Guidelines	Guidelines on transparency for members developed together with EPF members with the objective of monitoring the respect of EPF membership criteria by its members and of ensuring the highest possible standards for our network.	M11	ER
D3.7	Report on the added-value of patient organisations	Report targeted at health stakeholders with the objective to promote the recognition of the role and contribution of patient organisations to the public health debate and establish them as a natural policy partner at national and European level.	M5	PU
D4.1	AGM Minutes	Minutes of the 2017 Annual General Meeting.	M5	
D4.2	Evaluation Report	Report compiling the findings of internal and external evaluation.	M12+2	CO
D4.3	PAG meetings minutes	Minutes of the two meetings of the Policy Advisory Group.	M7 M11	ER
D5.1	Newsletter	11 publications of EPF newsletter.	M1-M12	ER
D5.2	Annual Report	Summary of achievements in past year.	M6	PU
D5.3	Video	Young patients view on discrimination.	M10	PU

D5.4	Video	Production of a video on a specific policy topic.	M12	PU
D5.5	Press Releases	Publication of 12 press releases on ad-hoc policy or EPF-related information, including 3 on the access campaign.	M1-M12	PU
D5.6	Blog	Monthly updates with focus on members' stories and guest editorials.	M1-M12	PU
D5.7	Factsheets	Production of three thematic factsheets in line with our policy priorities, including 1 related to the access campaign.	M12	PU
D5.8	Promotional Items	To promote EPF and showcase achievements.	M12	PU
D5.9	Website	Editing, updating, maintenance.	M1-M12	PU
D6	Recommendations on discrimination	To inform policy makers on discrimination in access to education, employment and health	M11	PU

Annexe 2 to EPF Annual Work Plan 2017: List of Key Performance Indicators

Specific Objective Nr./ Specific Objective	**OBJECTIVE 1 - To promote the development and implementation of policies, strategies, and services that foster the empowerment of patients and patient organisations.**
Process Indicator(s)	**Target**
The Empowerment Working Group is actively engaged across all empowerment-related policy areas	2 meetings of the empowerment work participants each
Policy and advocacy work on empowerment and patient-centred healthcare implemented	EPF actively engages in monitoring the implementation of CT Regulation
	EPF participates actively in the eHealth Stakeholder Group and eHealth Week 2017
	EPF engages actively in the area of personalised medicines and contributes our position to discussions on data protection and big data
	EPF actively engages with EMA in activities information to patients, medicines safety and transparent communication of CT.
Output Indicator(s)	**Target**
Toolkit on patient empowerment delivered	Toolkit is published
Position statement on information to patient on food and nutrition delivered	Position statement published
Position on sharing patient-level data delivered	Position published
Outcome/Impact Indicator(s)[1]	**Target**

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[1] If possible

EPF is able to engage in and influence the political dialogue in the areas falling under the thematic area of empowerment	Measured by the inclusion of EPF recommendations in EU-level legislation and initiatives concerned, as well as other stakeholders' relevant positions.
Specific Objective Nr./ Specific Objective	**OBJECTIVE 2 - To promote the development and implementation of policies, strategies, and healthcare services that maximise access and reduce health inequalities across the EU.**
Process Indicator(s)	**Target**
The Access Working Group is actively engaged across all access-related policy areas	2 meetings of the access-working group with 12 participants each.
	The WG is effectively engaged in steering the access campaign
Development of a Roadmap towards universal health coverage by 2030 as a key work-stream of the policy and awareness campaign on access.	2 roundtables held at beginning and end of the campaign with 60 participants each.
	34 EPF members undertake activities related to the campaign (dissemination of material, translation, blogs and testimonies, attendance of roundtables, comments to the roadmap)
	10 health stakeholder groups and 5 non-governmental NGOs representing groups vulnerable to health inequalities partner in the campaign.
	Meetings with 10 key MEPs to raise awareness of the campaign and discuss their perspective on universal health coverage for the development of the roadmap
EPF engages actively in monitoring the implementation of the CBHC directive	EPF is successful in engaging our informal network of patient leaders in monitoring the implementation of the directive
	A European Roundtable involving patient leaders, NCPs, and European policy makers is organised in M10
EPF engage actively with the Patient Access Partnership (PACT)	EPF attends relevant PACT meetings and contribute to the work of PACT
EPF continues to work towards addressing key gaps in the area of patient safety and quality of care	EPF participates actively in meetings of the PCWP and PRAC
Output Indicator(s)	**Target**
Roadmap towards universal health coverage by 2030 delivered	Roadmap is approved by EPF members.
Country specific recommendations on healthcare from the patients' perspective to ensure universal health	Roadmap is approved by EPF members.
Position paper "Quality of care from the patient perspective" developed	Position paper approved by EPF members
Set of core competences for patients and families in patient safety	Position paper approved by EPF members
Outcome/Impact Indicator(s)[2]	**Target**
	Pledge from 20 MEPs to work towards universal health coverage for all patients in the EU by 2030

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[2] If possible

The extent to which the campaign leads to an increased debate on universal health coverage by 2030 at European level	10 health stakeholder groups actively involved and pledging to work towards universal health coverage for all patients in the EU by 2030
The extent to which the recommendations in the roadmap are included in EU legislation, communication, reports, and initiatives in the years following the campaign (long-term outcome indicator)	As measured for example by articles in the media, MEP questions and interventions related to this, impact on the Commission's health policy and the implementation of the European Pillar of Social Rights, the European Semester process etc.
Specific Objective Nr./ Specific Objective	**OBJECTIVE 3 – To reinforce the capacity of patients and patient organisations to contribute effectively to better health and social care for all patients in the EU, while enhancing their accountability and mutual solidarity.**
Process Indicator(s)	**Target**
National Coalition Seminar implemented	50 participants from existing national coalitions, emerging coalitions and patient leaders from countries where no coalition is in place attend the meeting
Development of transparency guidelines in close cooperation with members	At least 5 members + secretariat meet twice to develop the guidelines
Development of added value of patient organisations' document	A cross cutting task force of members is involved in drafting this document
Youth group meets twice in 2017	15 participants per meeting
Output Indicator(s)	**Target**
Agreement on role of national coalitions and framework for interaction with EPF Secretariat	Consensus on the agreement is reached
Transparency guidelines are agreed upon	Adoption at the AGM 2018
Report on added value of patient organisations is agreed upon	Adoption at the AGM 2017
Reports on meetings of EPF youth group	Adopted by Youth Group
Outcome/Impact Indicator(s)[3]	**Target**
EPF is capable of strengthening the role of national coalitions and enhancing cooperation with and across national patient coalitions	National coalitions are more influential on a European and national level Improved cooperation between EPF and national coalitions, especially in working together on policy objectives
EPF capable of reinforcing commitment of members and their own members to ethics and transparency	Ethics and transparency principles outlined in the guidelines are complied with.
EPF is capable of demonstrating and promoting recognition of the role of patient organisations to the health debate	EPF is successful in engaging a dialogue with stakeholders and policy makers on the sustainability of patient organisations.
EPF is capable of raising awareness of young patient discrimination	EPF is capable of engaging dialogue on young patients' discrimination

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[3] If possible

Specific Objective Nr./ Specific Objective	**COMMUNICATIONS OBJECTIVE – Communicate to engage, persuade and inform.**
Process Indicator(s)	**Target**
2017 Communication Plan implemented	
Output Indicator(s)	**Target**
2016 Annual Report produced by M6	Distribution of 300 printed and 200 online copies
Production of 3 thematic factsheet leaflets in line with our Work Programme 2017 produced and disseminated by M12	Dissemination of 300 copies of each leaflet (900 in total)
Publication of 11 issues of the EPF Newsletter by M12	4500 active subscribers
Publication of 12 press releases on ad-hoc policy or EPF-related information, including 3 on the access campaign	25 press clippings
Live-coverage on social media of 3 events, including the 2 roundtable of the access campaign, with their dedicated hashtag.	20 re-tweets and 20 likes per event.
Regular publication of tweets and posts on EPF Twitter handle and Facebook page.	6000 likes on Facebook and 3750 followers on Twitter
Production and dissemination of two videos, including one on the access campaign.	2500 views per video
Outcome/Impact Indicator(s)[4]	**Target**
EPF is capable of increasing its audience and maximising its visibility and impact on social and traditional media.	55000 visits on the website, 6500 on the blog, and 4500 newsletters' subscribers

Annexe 3 to EPF Annual Work Plan 2017: Events and Meetings in 2017

Note this schedule is a preliminary draft.

January	
OECD policy meeting (PROMS and PREMS)	TBC
Senior Management Team meeting	
Weekly team and thematic meetings	Brussels
TC Board	
Elected officers meeting	
February	
PISCE final conference	Brussels
EFGCP annual conference	Brussels
Access working group meeting	Brussels
Access campaign round table I	Brussels
Senior Management Team meeting	Brussels

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[4] If possible

Weekly team and thematic meetings	Brussels
March	
Board meeting	Brussels
Weekly team and thematic meetings	Brussels
Senior Management Team meeting	Brussels
Patient safety working group meeting	Brussels
April	
AGM	Brussels
Senior Management Team meeting	Brussels
Weekly team and thematic meetings	Brussels
Workshop National Patient Coalitions	TBC
Spring youth group meeting	TBC
May	
Elected officers TC	
Senior Management Team meeting	Brussels
Weekly team and thematic meetings	Brussels
Empowerment working group meeting	Brussels
June	
Board meeting	Brussels
Senior Management Team meeting	Brussels
Policy Advisory meeting	Brussels
Weekly team and thematic meetings	Brussels
July	
Senior Management Team meeting	Brussels
Weekly team and thematic meetings	Brussels
August	
Senior Management Team meeting	Brussels
Weekly team and thematic meetings	Brussels
Elected officers TC	
September	
Board meeting	Brussels
Senior Management Team meeting	Brussels
Sponsors' roundtable	Brussels
Youth group meeting	TBC
Weekly team and thematic meetings	Brussels
October	
Elected officers TC	
Senior Management Team meeting	Brussels
PAG	Brussels
Patient safety working group meeting	Brussels
Roundtable on CBHC	TBC
Weekly team and thematic meetings	Brussels
November	
Board meeting	Brussels
Senior Management Team meeting	Brussels
Access working group meeting	Brussels
Access campaign round table II	Brussels
Weekly team and thematic meetings	Brussels
December	

Senior Management Team meeting	Brussels
Weekly team and thematic meetings	Brussels

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[1] http://ec.europa.eu/health/programme/policy/index_en.htm
[2] EC PSQC EG, 8 June 2015
[3] Mulley et al, 2012; Arterburn et al 2012; Veroff et al, 2013
[4] European Parliament report on reducing health inequalities in the EU (2010/2089(INI)

This document received funding under an operating grant from the European Union's Health Programme (2014-2020).