
The European Patients' Forum Annual Work Plan 2016



*What we plan to do in 2016
to drive better health for patients in Europe.*

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1. EXECUTIVE SUMMARY

In 2016, the European Patients' Forum's (EPF) will continue to address patient empowerment as a pre-requisite to achieve equity in healthcare and advance the concept of patients as "co-producers" of health.

The EPF Work Plan for 2016 will focus on **two key objectives**:

- **Strengthening the patient perspective** and impact in EU health-related policy, programmes and decision-making through evidence-based, results-oriented patient advocacy
- **Reinforcing the capacity of patients and patient organisations** to contribute effectively to better health and social care for all patients in the EU and enhancing their accountability and mutual solidarity

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.

Following the successful launch in 2015 of the **Patient Empowerment Campaign**, EPF will continue to promote the development and implementation of policies, strategies and services that empower patients to be involved in the decision-making and management of their condition. The campaign will end in 2016 with a high-level event and exhibition at the European Parliament, where the "**Charter of Patient Empowerment**" and the "**Multi-stakeholder Roadmap to Patient Empowerment**" will be officially presented.

EPF will further engage in patient empowerment through active participation in many European projects, such as **EUPATI**; the **Chrodis Joint Action**; **SmartCare** and the Patient Safety and Quality of Care (**PASQ**) Joint Action. These projects all aim to promote active patient empowerment in various healthcare-related activities.

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. EPF's focus on access is on **availability, affordability, appropriateness, adequacy** and **acceptability** of healthcare throughout the whole continuum for patients with chronic and long term conditions.

In 2016 EPF will start the preparatory work for a **campaign on access to health and social care**, in order to launch in 2017. This campaign will target EU and national decision makers and health stakeholders. We will involve our membership to show the barriers that patients are facing across the European Union, and collect good practices improving access to quality healthcare. We will then produce patient-centred recommendations on actions to improve access to healthcare in the EU.

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

We will continue to invest greatly in the Patient Access Partnership, a multi-stakeholder initiative to address all aspects of patient access.

A vibrant 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 at national level and at EU level.

A key date for the EPF community is the **Annual General Meeting (AGM)** taking place in spring 2016 in Brussels. Alongside the AGM there will be a number of fringe meetings focusing on specific policy themes of interest to members.

EPF will also continue to work with its very energetic **Youth Group**. Made up of patient representatives between 15 and 29 years old, it will focus in 2016 on **transition to adult care**, a key issue for young patients. Proper coordination of responsibilities during this transition is critical and the Group will explore how this can be improved for Europe’s young patients.

In 2016 EPF will develop its **communications strategy** with the objective to communicate to **engage, inform** and **persuade**. An important milestone will be the revamping of our website, our flagship communication instrument. We will also strengthen our presence on social media via its Twitter handle, Facebook page and Youtube channel.

2. EPF'S ANNUAL WORK PLAN FOR 2016

2.1 EPF'S KEY OPERATIONAL OBJECTIVES FOR 2016

OBJECTIVE 1 - Strengthening the patient perspective and impact in EU health-related policy, programmes and decision-making through evidence-based, results-oriented patient advocacy

OBJECTIVE 2 - Reinforcing the capacity of patients and patient organisations to contribute effectively to better health and social care for all patients in the EU and enhancing their accountability and mutual solidarity

2.2 PROBLEM ANALYSIS AND EVIDENCE BASE FOR THE ACTIVITIES PROPOSED IN 2016

Empowered patients adopting a proactive role in their health and in health policy are central to ensuring high quality health systems and addressing the challenges of chronic diseases. **Patient empowerment** tackles constraints on health budgets and rapid developments in technology, whilst advancing the concept of patients as “co-producers” of health¹. The Third Health Programme from the European Commission recognises this and states 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.”²

Health systems performance is among Health Commissioner's priorities; whilst quality of care and integrated care were identified by member states as priority topics in 2015-16³. **Patient-centeredness** is recognised as a core component of quality care⁴, and patient-centred care models have been shown to be cost-effective and improve outcomes, resulting in better health, more engaged patients and lower costs⁵.

EPF will contribute to these discussions *inter alia* with our report on patients' perception on “quality” in care and by participating in the EC Expert Group on Safety and Quality.

The economic climate continues to challenge the equity and sustainability of EU health

systems. Whilst highlighting the fundamental values of universality, equity and solidarity⁶, EPF's 2016 work programme will continue to address **health inequalities** as a priority, building on the Commission's document "Investing in Health"⁷. Our focus is on access to healthcare and the impact of austerity measures from the patients' perspective, as well as reaching out to potentially vulnerable groups affected by discrimination and stigma.

The report "Priority medicines for Europe and the world"⁸ recommends developing a framework for meaningful involvement of patients in innovation. EPF will continue to call for patient-driven **innovation**, both in therapeutic advance but also to develop systems that are sustainable, equitable and offer high-quality, patient-centred care.

EPF's 2016 work plan takes forward the implementation of key **EU legislation**, including the Clinical Trials Regulation, Medical Devices Directive, In Vitro Medical Devices and Cross-border health-care.

EPF will continue to actively contribute to **EU pharmaceutical policies**, *inter alia* through our close collaboration with the European Medicines Agency.

Our long-standing commitment to strengthening the capacity of patients' organisations from all across Europe as well as empowering young patients will also continue to remain central to our 2016 Work Plan.

2.3 TARGET GROUPS OF THE EPFS' MAIN ACTIVITIES FOR 2016

A primary target group for EPF is our own membership, 65 umbrella patient organisations at EU and national levels that drive and guide our work and engage actively in all aspects of our programme.

They contribute to and receive membership-specific and general communications.

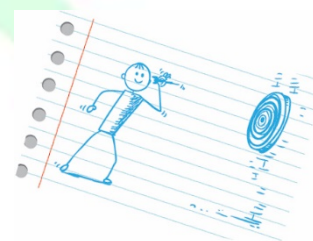
We will also specifically focus on patient organisations from selected regions and countries:

The Netherlands, Belgium, Luxembourg and Germany – through the planning, implementation and follow-up of the Regional Advocacy Seminar in spring 2016 under the Dutch Presidency. **Italian and Portuguese patient organisations**, through our national coalition building work. Thanks to its experience of local stakeholders, EPF will act as a bridge between the patient organisations and organise the discussion.

In the framework of our Capacity Building Programme we will continue to work in **Romania, Hungary, Bulgaria, and Slovakia**, and will launch the programme in **Poland**.

The patient community: In the context of our campaign on Patient Empowerment, we will continue to reach out to patient groups in member states to communicate with the patient community at large.

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. In addition to regular exchange of information and dialogue, we support position papers where appropriate, and collaborate through projects and events.

Members of the European Parliament: following our 2014 campaign around the European elections, we continue to disseminate information and policy briefs to key MEPs on an on-going basis, as well as involve them in our activities.

The Commission: the main target will be the Health Commissioner and his cabinet, whilst other Commissioners as well as civil servants of DG SANTE, DG CNECT, DG GROW, DG RTD, DG ECFIN, DG EMPL and DG JUST will also be on our radar.

2.4 EU ADDED VALUE AND EXPECTED IMPACT OF THE ACTIVITIES SCHEDULED FOR 2016

EPF's operational priorities are linked to our strategic goals and key developments in the EU healthcare environment. *Note: the policy priorities outlined in this draft work plan are subject to final approval by the membership at the annual general meeting.*

EPF is the only EU-level umbrella patient organisation that is non-disease-specific, occupying a unique position as the uniting voice of patients from all chronic disease areas and acting as a "bridge" between EU developments and patient communities across the Union.

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

Making sure a strong patients' perspective is integrated into all relevant health-related EU policies

Our priorities in 2016 will continue to ensure that a strong patients' perspective is integrated into all relevant health-related policies at EU level, as well as supporting the implementation of relevant EU legislation. Patients living with chronic conditions are "experts by experience" whose perspective on disease and care is unique. Patient empowerment at both individual and collective level is, in our assessment, a pre-requisite to realize 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.

High-level strategic advocacy

EPF will continue to engage in EU health-related policy and strategy at a high level, in cross-cutting advocacy work promoting our strategic goals. We will engage as appropriate 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*"⁹.

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. Whilst we will not engage directly on the transatlantic trade and investment partnership (TTIP), we will support the broader health community in these debates.

In 2016 we will hold a regional advocacy seminar during the Dutch Presidency to strengthen our links with the Dutch patient community, together with neighbouring countries' patients' organisations. During the Slovakian Presidency, we will plan our campaign on patient access that will culminate in a conference at the end of 2017. We will also participate very actively in the eHealth Week in May, and take forward our work on patient safety by organising a conference exploring the patient's role in patient safety during the second half of 2016.

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 and its resources, building on the trusted relationship we have built with respective DGs and Agencies in relation to all of EU funding programmes with a relevance to patients (PHP, HORIZON 2020, IMI, Structural and Investment Funds, etc).

3. PLANNING AND IMPLEMENTATION OF THE EPF'S ANNUAL WORK PLAN FOR 2016

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 working groups of our members address the overarching priorities of patient empowerment and patient access, embracing the goals outlined above and re-organising our project, policy and communication work accordingly.



Within the EPF Secretariat we have set up a thematic taskforce that focusses on 'inclusive, sustainable patient organisations', which brings together all our training, toolbox, capacity-building, and outreach efforts ensuring maximum effectiveness, relevance to and engagement with our members.





OBJECTIVE 1: STRENGTHENING THE PATIENT PERSPECTIVE AND IMPACT IN EU-HEALTH RELATED POLICY, PROGRAMMES AND DECISION-MAKING THROUGH EVIDENCE-BASED, RESULTS-ORIENTED PATIENT ADVOCACY

1A) PATIENT EMPOWERMENT

Patient empowerment and the EU response to chronic disease: Patient empowerment and patient-centred care will be at the core of our work programme in 2016. Our Working Group on empowerment will develop a consensus position on **patients' rights and responsibilities**. It will also start the development of a toolkit for patient organisations to support empowerment, to be finalised in 2017.

Our policy activities will build on the outcomes of the EMPATHIE mapping study on patient empowerment (2014), in which EPF was a work package leader, and of the Joint Action CHRODIS, in which EPF plays an active role. We will also contribute as a partner to a new European Commission tender on self-care in chronic disease, aiming at developing guidelines to promote policies and initiatives on self-management. Our advocacy work will be highly complementary with the ongoing EPF campaign on empowerment (out-with the operating grant), which concludes in June 2016.

EPF will continue to engage with the European Innovation Partnership on Active and Healthy Ageing, following the conclusion of its Action plan 2012-2015 and the preparation of a second Action Plan for 2016-2018.

Health literacy and information to patients: EPF will highlight the importance of **health literacy as a critical change agent** for the realisation of patient empowerment and reduction of health inequalities, working primarily with stakeholders in synergy with the tender on the promotion of self-care (PISCE) where EPF is a partner.  Our work will build on a joint consensus paper adopted in 2013, the outcomes  of the European mapping study on health literacy, the specific recommendations of the "Riga roadmap", and our members' feedback on patients' health literacy needs, (survey conducted in 2014).

We will continue to work with the **European Medicines Agency** to support the development of high-quality, user-friendly information resources for patients. We will also monitor the implementation of the EU legislation on clinical trials, pharmacovigilance, falsified medicines and medication safety. We will continue our review of the 2008 "core quality criteria" on information to patients to assess their pertinence 8 years on.

Clinical trials and patient involvement in research: In 2016 EPF will continue to engage with the **implementation of the EU Regulation on clinical trials**. Our work will focus on finalising the EU guidelines for development of patient-friendly, unbiased lay summaries, based on our contribution to the draft guidelines in 2015. We will contribute to patient involvement in

ethics review in synergy with EUPATI and partners such as the EFGCP; and also promote our position on meaningful informed consent and information to patients. We will continue to support greater transparency around clinical trials results and sharing of patient data, in collaboration with the European Medicines Agency.

We will continue to advocate for patients' rights and empowerment in the context of the proposal for a **General Data Protection Regulation** (COM (2012)0011) in which we have engaged since 2012. Patients' health and genetic data are sensitive, requiring a high level of protection. At the same time, appropriate sharing of data is absolutely crucial for effective



healthcare services, patient safety, and for research. We will continue our collaboration with various non-profit research and public health organisations through the European Data in Health Research alliance to promote ethical and effective health research in Europe.

Technology and personalised medicine: In line with the Europe 2020 objectives of smart and inclusive growth, patient-centred innovation will be a priority for EPF. We will engage with stakeholders on personalised medicine, focusing on health literacy and patient involvement, and contributing to debates around public health, ethics, equity and regulation. We will build on the Riga Roadmap and our engagement with the Luxembourg Presidency in 2015 to take forward the debate on "value" in innovation from a patient perspective.

EPF has been involved in the eHealth Governance Initiative (eHGI) since 2011 contributing to the work stream on trust and accessibility. A three-year eHealth Network Joint Action, following up on the eHGI, was launched in 2015, to which we will bring a patient perspective through the eHealth Stakeholder Group, whose mandate was renewed in September 2015.

In 2016, EPF will finalise a position paper on eHealth and mHealth technologies. The position paper will build on evidence collected through various projects such as Renewing Health, SUSTAINS, and Chain of Trust, as well as feedback collected through the Policy Advisory Group and the Empowerment Working Group in 2015.

EPF Patient Empowerment Campaign



In 2015 EPF set up a thematic Patient Empowerment Campaign, to build the momentum for the empowerment of patients in Europe. The campaign was launched in May 2015 during the EPF Patient Empowerment Conference that gathered together over 150 patient leaders, health professionals, NGO representatives, researchers and policy-makers. With this campaign EPF aims to promote the development and implementation of policies, strategies and services that empower patients to be involved in the decision-making and management of their condition.

The first milestone was the release of the official campaign video in October 2015 (already more than 6000 views). The video was presented for the first time during the patient empowerment workshop that we organised at the European Health Forum Gastein.

By the end of 2015 EPF will release two significant documents for consultation: first, the “Charter of Patient Empowerment” which is a set of fundamental principles of patient empowerment in ten points, as defined by patients. The second document is the “Multi-stakeholder Roadmap to Patient Empowerment” which will be the basis for concrete actions that European policy-makers and healthcare stakeholders should take. These two major documents will be officially presented in 2016 at a European Parliament roundtable event that EPF will organise, to ask for the support of Members of the European Parliament to this campaign.

EPF will close the campaign on a high note in June 2016 by bringing its outcomes to the heart of European democracy with an exhibition hosted in the hall of the European Parliament. During this event, EPF will present the outcomes of the campaign as well as follow-up actions.

Projects and activities falling under the EMPOWERMENT areas

In 2016 EPF will continue to work on various EU projects that are expected to contribute to the gathering of important evidence in the field of self-care and young patients’ empowerment.

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

In 2016 this EPF-led project will enter its last year of implementation. Priorities for 2016 are the dissemination of the EUPATI Toolbox – educational material in seven European languages tailored to patient advocates– and the development of the EUPATI internet library compiling educational resources for lay patients and health-interested public at large.



Another key priority in 2016 is the delivery of the second cycle of our patient expert-level training programme involving 60 new patient advocates.

Major developments have taken place over the last few months at national level with more national platforms taking off the ground and new countries such as Romania and Slovakia having made tremendous progress setting up national teams.


With the vision, plan, and value proposition for a post 2017 EUPATI being laid out, effort is now directed towards identifying resources to continue to run the core elements of the project capitalising on the high reputation and recognition of the project.

www.patientacademy.eu

CHRODIS Joint Action

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.

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.

 In 2016 EPF will contribute to the development of common guidance and methodologies for care pathways for multi-morbid patients, and to the development of guidelines for National Diabetes Plans and recommendations to improve the quality of care of people living with diabetes. The aim for EPF is to facilitate the scalability of these recommendations to other chronic conditions. This project is 50% co-funded by the EU Health Programme.

<http://www.chrodis.eu/>.

SmartCare

The SmartCare project was launched in 2013 to promote a more integrated and effective approach to providing health and social care to older people across Europe. The project installed several pilot sites all across Europe to test integrated care pathways that are supported by Information and Communications Technology (ICT).



As a member of the project’s User Advisory Board (UAB), we took part in several site visits in 2014 and 2015 with more visits scheduled in early 2016.

Drawing on the outcomes of these visits EPF together with other members of the UAB will be working on a set of evidence-based recommendations on how to improve integrated care services in Europe from a user-perspective.

www.pilotsmartcare.eu

Patient Safety and Quality of Care Joint Action

Patient Safety and Quality of Care Joint Action

The Joint Action on Patient Safety and Quality of Care (PaSQ) in which EPF has been involved since 2012 as an associate partner, aims at contributing to Patient Safety and good Quality of Care by supporting the implementation of the Council Recommendations on Patient Safety¹⁰ through cooperation between Member States, EU stakeholders on issues related to quality of health care.

EPF has been involved in all seven work packages, bringing a significant contribution to defining the key concepts of patient involvement and empowerment in patient safety and quality of care.

We are also engaged in the building the sustainability of European Union Network for Patient Safety and Quality of Care beyond the grant period, and effective dissemination of project achievements.

<http://www.pasq.eu/>



Prospective projects

ERASMUS + Youth Project

A project proposal for our second youth project “PAEGE: Patient Access, Empowerment, and Good Practices for European Youth” will be submitted under the EU Erasmus+ project in February 2016. If successful the project is likely to start in autumn 2016.

The purpose is to promote young patients’ empowerment through “the empowered patient skill-set” which includes understanding of their own condition, self-management, peer-support guide, advocacy training, and dissemination of information on a range of chronic conditions.

The project has a twofold objective: on one side it will stimulate young patients to become active citizens by promoting their rights. On the other own it aims to raise awareness among EU policy makers on young patients’ rights in access to healthcare, education and to the job market. Through the organisation of transnational seminars, the project will help further develop and extend a multi-layered network of young patients’ groups already active at European and national level.

Pilot project on the promotion of self-care systems in chronic diseases in the European Union.

In 2016, EPF will work on PRO-STEP, a tender project under the EU Health Programme on the promotion of self-management systems in chronic diseases in the European Union.

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 will work in close cooperation with EPF in the coordination of the project.

1B) PATIENT ACCESS

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

Equitable access to health and social care is central to our vision

Health inequalities: Equitable access to health and social care is central to our vision for healthcare. It is a strategic goal of EPF, and also essential to ensure the success of the Europe 2020 strategy for growth due to the economic cost of health inequalities. EPF's focus on access is on availability, affordability, appropriateness, adequacy and acceptability of healthcare throughout the whole continuum for patients with chronic and long term conditions.

Our work will be developed through EPF's working group on access established in 2014. It will work towards developing a **survey on patients' access to healthcare**. The survey will aim at gaining more knowledge on the current situation across diseases and EU countries. The survey will allow us to further develop our evidence base on health inequalities and access barriers.

The Working Group will also contribute to the development of a **campaign on access to health and social care**, preparatory work for which will take place in the second half of 2016 in order to launch in 2017. This campaign will target EU and national decision makers and health stakeholders. We will involve our membership to show concretely the barriers that patients are facing across the European Union, and collect good practices improving access to quality healthcare. We will then produce patient-centred recommendations on actions to improve access to healthcare in the EU.

We will continue to support the activities of the Patient Access Partnership, a multi-stakeholder network which we established with the National Patient Organisation of Bulgaria. The activities of the partnership aim at making access to healthcare a priority at EU

level, and seeking common solutions with all relevant stakeholders. As stated in the Communication from the Commission on effective, accessible and resilient health systems (COM (2014) 215 final) measuring access is a key challenge. The results of EPF's own survey will also feed in the Patient Access Partnership's work on indicators to ensure these reflect the patients' experience.

Cross-border healthcare: Building on the Commission's first report on the implementation of Directive 24/2011, our series of regional and local events in 2013-15, and our position paper in 2015, EPF will continue to monitor implementation and to engage our EU-wide network of patient representatives focusing on cross-border healthcare. This work will be closely linked to the development of a position on patients' rights and responsibilities, although the latter will go beyond the provisions of the directive.

Health Technology Assessment has been a priority for EPF since our first conference on this topic in 2010. We undertook our own study on patient involvement in HTA, and have been increasingly active in the HTA arena, including the HTAi sub-group on patient/citizen involvement. Within the framework of our Medtech-Patient Dialogue, we examined HTA implications in the medical devices sector. In 2016 we will continue to contribute both to the EUnetHTA Stakeholder Forum and the HTA Network. To facilitate this work, we will continue to coordinate an informal working group on HTA. Particular emphasis will be placed on defining patient organisations' input into an HTA strategy for Europe post-2020.

Patient safety and quality of care remain core priority areas for EPF. Our work in 2015 will contribute substantially towards our strategic WP 2015-17. EPF believes that patients have a fundamental right to expect safe care, and have a legitimate role, individually and collectively, in developing and implementing policies for safety and quality, and evaluating them from the end-user's perspective.

In 2016 EPF will hold a **conference on the patient's role in patient safety** and launch a task force to develop "**core competencies**" for patients and families to empower them in the area of safety. Furthermore, EPF will continue as a member of the European Commission's Expert Group, reformulated in 2015, which advises the Council working party on public health issues at senior level in developing the EU patient safety and quality agenda. Our policy work is informed by our contribution to the Joint Action on Patient Safety and Quality of Care (PaSQ). In 2016 we will engage actively in developing the permanent network for exchange and collaboration foreseen in the Council Conclusions of 2014.

We will also contribute to the debate on health systems performance assessment (HSPA), by a report on **quality of care from a patient perspective**. This work is also closely linked to our activities to support the implementation of the safety and quality dimensions of the cross-border healthcare directive. Medicines safety is an important sub-area of patient safety, and EPF will continue to work closely with the European Medicines Agency in this area.

Medical devices: EPF will continue to engage actively in the legislative process for the proposal for a Regulation on Medical Devices¹¹ and the proposal for a Regulation on in vitro Diagnostic Medical Devices¹² to ensure patient safety, patient involvement and greater

transparency are prioritised. Following adoption of the Regulations, EPF will develop **factsheets to foster awareness** and inform our membership on areas of interest to patients.

EPF will continue the twice-yearly dialogue with our members and the Medical Technology industry, in line with our code of conduct and ethics, and in accordance with our Memorandum of Understanding. The aim is to exchange views and information towards the adoption of a Code of Conduct for the MedTech industry in 2016. The Patient MedTech dialogue will continue to focus on areas of common interest such as patient centred healthcare and patient safety, and explore new areas such as HTA for medical devices.



Tackling Discrimination: To follow up on our position paper on discrimination in education and in the workplace published in 2015, EPF will work with organisations and EU decision makers in the field of education and employment, to raise awareness of barriers facing patients in those areas. This will pave the way for further actions, such as a toolkit drafted with appropriate stakeholders in 2017.

In 2016 EPF will put increased focus on working with groups potentially vulnerable to health inequalities and discrimination. We will develop a **road-map towards better inclusion of vulnerable groups' perspectives within patient organisations** which will aim at identifying and encouraging actions to support patient organisations in integrating the perspective of groups vulnerable to social exclusion and discrimination in their activities. We aim to set up a **task force with members** who have expertise or interest in this area. In addition, we will establish **stronger dialogue with relevant NGOs** to ensure our recommendations and proposed actions are realistic and achievable for our respective memberships.

Policy involvement in agencies, think-tanks and advisory panels: EPF will continue to participate actively in a number of other health-related think tanks and advisory panels at EU level, including: The EU Health Policy Forum; the Innovation Partnership on Active and Healthy Ageing; the European Federation of Pharmaceutical Industry Associations (EFPIA) Patients' Think Tank on-going two-way transparent dialogue between patient representatives and the pharmaceutical industry; EPF-MedTech Europe Dialogue on medical devices and chair of its steering group; EGA; Innovative Medicine Initiative Stakeholder Group; Health Stakeholder Group; EC Expert Group on Patient Safety and Quality of Care; EC Medical Device Expert Group; EU Health Portal Editorial Group; EuropaBio Patients-Bio Industry Exchange Forum; Centre for Health, Ethics and Society (CHES); European Medicines Agency Patients and Consumers' Working Party (EMA PCWP); European Health Forum Gastein Steering Group; Patient Advisory Group for Medical Imaging (Chair).

Working with Our Partners: Partnership is EPF's leitmotif and in 2016 we will continue our approach of dialogue, cooperation and collaboration with other stakeholders working in our field.



Cooperation with other patient groups: we will continue to work closely with major EU and international patient groups and our global sister organisation, the International Alliance of Patient Organizations (IAPO), with which we have a Memorandum of Understanding clarifying our

geographic and political remit and supporting our joint work.

Cooperation with other health stakeholders: We will continue as members of the European Network on Patient Empowerment (ENOPE). We have established a collaboration with the European Observatory on Health Systems and Policies on the topic of empowerment. We continue to collaborate very closely with the European Public Health Alliance (EPHA), particularly in following up the Riga Roadmap. We also continue cooperating with major EU organisations representing health professionals, particularly the Standing Committee of European Doctors (CPME); the Pharmaceutical Group of the European Union (PGEU); and the European Federation of Nurses Associations (EFN). We work closely with these organisations to ensure a coherent NGO input in EU health policy debates. We will further strengthen our relationships with other key health stakeholders, such as the insurers (Association Internationale de la Mutualité, European Social Insurance Platform), informal carers (EUROCARERS) with whom we have signed a memorandum of understanding, hospitals (HOPE), medical specialists (UEMS), health managers (EHMA) as well as with major EU health platforms such as the European Society for Quality in Healthcare (ESQH), the European Forum for Good Clinical Practice (EFGCP), the EU Health Telematics Association, and the European Forum for Primary Care, with whom we have memoranda of understanding. At global level, EPF will continue to cooperate with DIA, with a leading role at their annual DIA Europe meeting, and ISPOR, through their patients' forum and in particular with their chapters in Central and Eastern Europe. We will also strengthen our cooperation with BEUC, the European consumer organisation, the European Disability Forum, AGE and the EU Youth Forum. In the light of our work on marginalised and vulnerable groups and specifically non-discrimination, we will enhance our work with the Fundamental Rights Agency and the Social Platform (the European Platform of Social NGOs), with PICUM, Doctors of the World, and ILGA Europe. We will continue to work with EU networks working such as EUREGHA, the Assembly of European Regions and HealthClusterNet, and EuroHealthNet.

Projects under the access thematic area

ADAPT-SMART

“Accelerated Development of Appropriate Multi-Stakeholder Approach from Research to SMART) is a coordination and support action September 2015. The purpose of this 30-month 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.

PROJECT

Patient Therapies: a Sustainable, Treatment-Outcomes” (ADAPT-(CSA) funded by IMI 2 and started in 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.

In 2016 EPF will lead on the organisation of a workshop on appropriate market utilisation with patients.

[EUnetHTA Joint Action 3](#)

Following negotiations between the European Commission and Member States, the EUnetHTA JA3 will kick off in March 2016.

The Patients and Consumers Group will be jointly represented by EPF, EURORDIS, EMSP and BEUC. The four organisations will ensure an effective input to the implementation of tasks.

EUnetHTA JA3 will mainly focus 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.

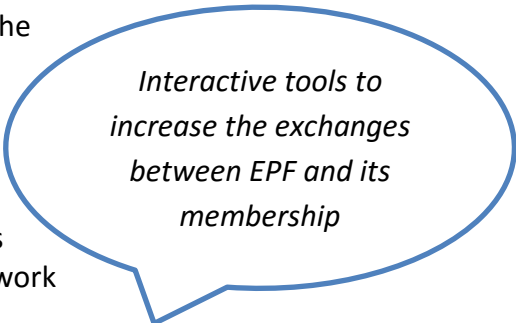
EPF will use these platforms to gather information, exchange good practice and to reinforce key policy messages on topical issues, in line with its focus on health technology assessment.

OBJECTIVE 2: REINFORCING THE CAPACITY OF THE PATIENT COMMUNITY ACTORS TO EFFECTIVELY CONTRIBUTE TO THE HEALTH DEBATE

At its Annual General Meeting 2014, EPF adopted a Membership Strategy which aims to ensure that EPF serves the needs of its members to the maximum on a daily basis. The document aims at identifying the challenges to and proposes solutions for the broadening and consolidation of EPF. 2016 will be the second year of implementation of this Membership Strategy. The work performed in 2014 and 2015 has helped defined better EPF *vis-a-vis* external stakeholders. This enables us to venture out in 2016 and to initiate a dialogue with new stakeholders (in new countries, new disease areas, or working on different topics). The list of EPF members can be accessed [here](#).

Clear Identity, clear added-value: Being clear about the added-value of EPF is a first step towards reinforcing the commitment of existing associations, and towards promoting our activities to potential new members. Our Membership Guide and our website are our two main tools to raise awareness about the benefits of EPF membership. EPF will publish a **2016 version of its Membership Guide** and make sure the **members' section of our website** is regularly updated.

A vibrant network; Stimulating engagement: after a year of implementation of the Membership Strategy, the network is visibly more energised. Developing ownership of the network



Interactive tools to increase the exchanges between EPF and its membership

remains one of the major challenges. To this aim we build on the interactive tools put in place over the past year and use them to increase the number of exchanges between the EPF Secretariat and its membership.

The “EPF Weekly Insiders”: this members-only report highlights the main EPF activities, policy consultations, events and news relevant to the patient community on a weekly basis. We have now established a good readership.

“Weekly Coffee with EPF”: initiated in 2014, this initiative provides a weekly opportunity for members and the Secretariat to exchange information informally on their current activities and priorities, virtually or in person. It has been extremely well-received by the membership so far.

Our database, our wealth: One of the success factors of any membership-based organisation is the extent to which its database is up-to-date. Over the past two years, we have worked considerably on refreshing our database in order to further increase our impact, and we will continue to put effort in personalising our communications and making sure the right message reaches the right target.

Communication between members: the online platform currently under development aims at promoting communication between and among members and thus encouraging cross-fertilization of EPF policy work and projects. As the online platform is foreseen by the end of 2015, a fundamental task for 2016 will be to generate interest and increase the number of users (staff and members). In addition to the **daily management of the platform**, a **“marketing strategy”** should be designed to make sure all of the members can make the most of this new tool the cooperation opportunities it represents. A video will be produced to explain the platform’s objectives and its functioning.

Membership development & Growth: Thanks to the analysis on the representativeness of EPF conducted in 2015, we now have a better sense of what directions to take when it comes to membership development. We will work both on increasing our representativeness in terms of diseases and geographical coverage.

We will organise **bilateral meetings with potential new members**, especially in countries such as the Netherlands (in connection with the Regional Advocacy Seminar 2016) as well as Denmark and Sweden (following the Regional Advocacy Seminar 2015). In addition, we have identified a number of European umbrellas with which we would like to strengthen the cooperation and explore membership.

National coalition building: in some countries, the patient movement is not formally organised in a national coalition. EPF will pursue the coalition-building work initiated in 2015 to facilitate the creation of a national coalition in Italy. This work is a crucial part of EPF’s remit to share its experience in countries where the patient movement is still under development. We will explore tentatively a similar exercise in Portugal for 2016, provided that there is interest from the disease-specific patient organisations on the ground.

Meeting Europe's Patients:

A Regional Advocacy Seminar (RAS) will be organised in the Netherlands during the Dutch Presidency for countries from the Benelux and Germany. In line with EPF's commitment to



empowerment, this seminar will look at strengthening patients' organisations' advocacy capacity to become more empowered actors in national and European health policy arena. Taking on board a suggestion from our members, we will initiate a **dialogue with organisations representing vulnerable groups**, in order

to ensure that these groups' perspective is mainstreamed in our policy work.

Strengthening the patient community, promoting solidarity and young patients' involvement:

The **Annual General Meeting (AGM)** will be held in early spring 2016 in Brussels. Alongside the AGM there will be a number of fringe meetings focusing on specific policy themes of interest to members as well as meetings of our two working groups on patient empowerment and patient access.

EPF will continue to provide on-going support to the members through a dedicated Membership Officer. This will include strengthening our participation to members' Annual General Meetings and national events organised by national coalition members of EPF.

EPF online community: with the launch of the online platform in 2016, EPF members will for the first time have the chance to exchange between our physical meetings.



The EPF Capacity Building programme

The approach for the delivery of our Capacity Building Programme in 2016 and beyond focuses on:

- a) Rolling out new training modules at national and European level improving them in terms of both format and delivery drawing on lessons learnt and outcomes of the evaluation of the 2012-2014 programme
- b) Exploring opportunities to engage more patient organisations in our training modules
- c) Launching the Programme in a new country: Poland.
- d) Linking training to our policy imperatives by offering thematic training modules to build capacity among our members in areas where more patient evidence and expertise is needed to substantiate further our advocacy work

National pillar

For countries that joined the programme previously, (Romania, Hungary, Slovakia, and Bulgaria) EPF will continue to support patient organisations from across these countries developing their capacity by means of thematic training modules on areas of concerns.

Romanian, Hungarian, and Slovakian patient organisations participating in the programme will have completed the thematic training module on fundraising by the end of 2015. An evaluation meeting will take place in early 2016 in each country. At that meeting we will also agree on the topic for the 2016 training module. Bulgarian organisations are expected to complete the module on strategic communication in spring 2016. The plan is to launch the next thematic module in September 2016.

As mentioned above in 2016 we intend to launch the Capacity Building Programme in Poland. As in all other countries we should kick off with a training module on strategic planning to support our Polish Member (the Federation of Polish Patients, FPP) and up to 10 more national-level disease-specific organisations which are member of FPP in developing a strategic plan and conducting a thorough needs assessment exercise.

Our training modules last between 6 and 8 months and will continue to be offered to patient organisations as blended learning programmes combining in-person training sessions with remote and face-to-face coaching by experienced trainers. Our commitment is to strike the right balance between theoretical and practical learning to ensure that all participants are able to apply the learning and translate it into concrete strategies and actions within their respective organisations.

Overall, in 2016 with our national pillar we intend to support between 55 and 65 patient organisations from across Central and Eastern Europe.

European Pillar

Regarding the European pillar, our plan for 2016 is to offer our pan-European members and national coalitions from countries where no-national level programme is available training modules on topics identified out of needs assessment exercises carried out in previous phases of the programme.

Following up on the fundraising and strategic communications training modules offered to our members in 2014 and 2015 respectively, we will offer in 2016 two training modules. The first one will focus on transparency and good governance to train and help patient organisations and their leaders understand and comply with the highest standards of ethics and integrity, with a particular emphasis on the collaboration with private donors.

The second training module will focus on patient safety. By the end of 2016 EPF has committed to set up a working group of member representatives to take forward the work we have done so far in this area.

Our goal is to involve 10-15 participants in each of the two training modules.

Involving Young Patients

Since the Youth Strategy¹³ was launched in 2011, the EPF Youth Group has been increasingly involved in the EPF strategic planning. Through its projects and activities such as EMPATHY, the Youth Group has contributed to the EPF policies, including discrimination, empowerment and access to healthcare.



In 2015 the Youth Group focused on capacity development, with the objective of fostering a strong and sustainable community of young patients. The frequency of e-meetings increased to allow concrete improvement in the development of activities.

In line with the 2015-2017 work plan, 2016 will focus on **transition to adult care**. This is a key issue for young patients: poor coordination of responsibilities during the transition may have negative psychological effects on young patients and may result in lack of appropriate care for young adults with chronic conditions. The purpose of the Youth Group is to raise awareness on this topic through debates open to all concerned stakeholders to discuss possible ways forward.

Other specific objectives for 2016 are the recruitment of new members and strengthening relationships with youth groups in EPF's membership and with other relevant stakeholders. A spring meeting and an Annual Meeting of the group will take place. A regular flow of information and exchange of ideas will be guaranteed through conference calls and via social network tools.

In the framework of the European Youth Event 2016, the EPF Youth Group will organise a joint workshop together with the EMSP Youth Group. The workshop will focus on access to employment for young people with chronic conditions and will be a key opportunity to gain visibility and engagement from MEPs that will attend the event.

The European Youth Event is a major event co-organised by the European Parliament and the European Youth Forum. Each year it gathers around 8000 people. The next edition will take place in Strasbourg on 20 and 21 May 2016.

3.1 PLANNING OF THE EPF'S ACTIVITIES FOR 2016

| Nr./ Activity | Linked deliverable |
|---|---|
| 2. EPF working group on patient empowerment and member consultation | D1.1. Consensus position on patients' rights and responsibilities |

| | |
|---|--|
| 10. Member questionnaire on health inequalities and good practices to tackle them, from the patients' perspective | D2.2. Report on outcome of member questionnaire on patient access |
| 18. Conference on patients' role in patient safety | D1.2. Report of a multi-stakeholder conference on patient involvement in patient safety |
| Launching of a task force to develop core competencies for patients in patient safety | NA (milestone) |
| 19. EPF Survey on quality of care from the patients perspective | D2.5. Report of EPF survey |
| 21. Medical devices and in vitro diagnostic devices | D2.1. Publication of a series of tools (factsheets and briefings) on Medical Devices and in vitro diagnostic devices regulations |
| 24. Inclusiveness of patient organisations | D2.3. A road-map towards better inclusion of vulnerable groups' perspectives within patient organisations |
| 27. Spring youth group meeting | D3.1. Report on the Spring Youth Group Meeting 2016. |
| Building alliances and networking in the anti-discrimination, employment and education areas | NA |
| Position paper on eHealth | D1.6: A finalised position paper on eHealth |
| Briefing on Data Protection Regulation (new deliverable not planned in the 3 year application) | D1.7: A briefing for EPF members to explain key aspects of interest to patients in the new Data Protection Regulation |
| 28. Annual Youth Group meeting | D3.2. Report on the Annual Youth Group Meeting 2016 |
| 30. Networking and building alliances | NA |

| | |
|---|---|
| 31. Roundtable on Transition to adult care in European health systems | D1.4. Report on the outcomes of the meeting on transition to adult care D1.5. Recommendations on transition to adult care for policy makers, health managers and health professionals. |
| 33. Youth Group Internal and external communication | D3.3 blog and website updates on the Youth Group, contribution to EPF newsletter |
| 35. Making EPF added-value visible to members and to the public | D3.4. EPF Membership guide |
| 36. Stimulating engagement from members | D3.6. Weekly Insiders' Mailing; D3.7. Reports from the Weekly Coffee with EPF; |
| 37. Support the cross-fertilization of EPF's activities | D3.6. Weekly Insiders' Mailing; D3.7. Reports from the Weekly Coffee with EPF; |
| 38. Promoting Communication between members (This activity planned for March will be postponed to August: given that we have postponed the feasibility survey and subsequently the launch of the online platform, it appears to more coherent to also postpone the Marketing strategy of the online platform) | D3.5. Marketing Strategy to promote the Social platform |
| 39. Communicating to inform our audiences about our work and achievements | D5.1. Website; D5.5. 11 monthly newsletters; D5.4. 1 Annual Report; D3.9. 9 press releases |
| 40. Communicating to engage our membership and our allies | D5.2. blog articles; D3.8. 1 video |
| 41. Communicating to persuade policy-makers to put patients on their agenda | D3.9. 9 press releases; D5.3. promotional items |
| 42. Bi-weekly team and Thematic meetings | D4.1. Briefing notes |

| | |
|--|---------------------------------|
| 44. Policy Advisory Group | D4.2. Minutes of meetings |
| 45. Regional Advocacy Seminar | D3.10. Seminar report |
| 46. Access working group meetings | D2.4. Minutes of meetings |
| 47. Empowerment working group meetings | D1.3. Minutes of meetings |
| 48. Annual General Meeting (AGM) | D3.11. Minutes of meeting |
| 49. Board meetings and elected officers meetings | D4.3. Minutes of board meetings |

3.2 DISSEMINATION AND EVALUATION OF THE EPF'S WORK PROGRAMME FOR 2016

The 2015-2017 overall EPF goals will guide our communications objectives for 2016:

Communicate to inform: in 2016 EPF will outline simple and concise messages in order to inform our audiences about what we do. All communication materials will be produced with this in mind, so we will strive for concise contents further supported by background documents.

Communicate to engage: EPF will deliberately build general messages to ensure the patient community can tailor them to their unique needs (either specific to national context or disease-specific) and engage by our side.

Communicate to persuade: EPF will further their core and communicate what our to persuade them to commit to including a making, research and healthcare systems



simplify our policy messages to audiences care about as we want patients' perspective in policy-design.

The 2016 communication strategy and work plan achievements of 2015.

have been adjusted to build on the

Target audience

EPF 65 members are both the raison d'être and a main target audience of EPF internal communication.

Patient organisations and the patient community: through our members, EPF addresses and cooperates with national disease-specific patient groups. We need them to rally to our cause and to become the bridge between the national and European level and respective players.

Members of the European Parliament (MEPs): we target them across the political parties to ensure that all policies reflect patients' real life needs, capabilities and preferences.

Commission, the cabinets and DGs: we target primarily DG Santé, DG CNECT, DG RESEARCH, DG ECFIN, DG EMPL and we also work across all DGs to remind them that citizens' access to health is everyone's business.

Council and Health Attachés: we focus on high profile champions that will speak out for health and a patient's perspective.

Health stakeholders: much of EPF's work is by nature linked to health therefore we can best serve our purpose through close cooperation with key partners of other health related organisations such as other NGOs, industry, academics, research organisations, etc.

Media at national and EU levels are an important conduit and channel for reaching all the target audiences therefore we must continue to inform these 'influencers'.

EPF plays a bridge role between the patient community and the EU institutions. We also place strong emphasis on forging alliances with European organisations, with whom we have a common agenda, to act upon the maxim 'we are stronger together' and create a strong network within the health community.

All our communication outputs are available to the wider public through our newsletter and website. We therefore design our communication to fit the different target audiences, such as e.g. lay patients, and to ensure the messages are clear.

Communication Channels and Tools.

EPF has a well-established set of communication channels and tools to serve our core audiences:

EPF's **website** is an important communication tool for everyone who wants to know more about the organisation and understand what we do. We have diverse target groups of decision-makers and health stakeholders at EU level, lay patients and policy makers at local, regional and national level. Our website needs to be dynamic, easy to upgrade and maintain to embrace fast-moving website trends. This is currently not possible despite some changes that we implemented in 2014. We conducted a review of our analytics to prepare the change of the website to an open source Content Management System. Building a new website and going live is one of the main communication activities in 2016.

Our **Newsletter** system initiated in 2012 will continue to provide the latest policy, projects and event news on a monthly basis. The new platform developed in late 2015 enables us to better track user's needs and preferences. We will continue to strive for maximum impact as a major information source for EPF's external audiences.

The **Annual Report** is vital for us to show to the wider public the tangible results of how we perform against our strategic objectives each year.

EPF's active presence on **social media** has helped to create a strong network of allies. EPF will continue to offer training to EPF members, Secretariat and Board Members on how to use social media to make the most of it and give a human face to EPF.

Video has always been integrated in EPF communication work as a crucial tool to get our messages across to different target audiences. Our 2016 video will be a short and powerful tool to explain the new internal platform to our members to support its use – the release will depend on the platform's feasibility survey.

Our **media relations** will evolve in parallel with the evolution of the Brussels-based media landscape. We updated our media list in 2015, including national contacts, to ensure a wider media coverage at national level in 2016. We will continue to send traditional press releases to media who are interested in our policy issues for their specific audience; we will also aim to publish more op-eds to inform and stimulate public debate and attract journalists also at national level.

We will build on the 2015 results of our **blog** and continue to invite members and allies as guest authors to bring testimonials and wider views to our work and to further improve the outreach of this important tool.

EPF will release 3 thematic **factsheets / leaflets** on our main policy areas by 2017. The themes will follow the policy agenda and will add to the pool of information resources for our members at European and also crucially at national level.

3.3 EVALUATION

On-going evaluation of the Work Programme in line with 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 2016 programme. EUR 7.500 has been earmarked for external evaluation.

On-going evaluation is essential to EPF's development

In order to allow for efficient use of resources the external evaluator will focus on selected key areas of intervention that altogether are representative of EPF 2016 WP. Our plan is to involve the external evaluator in the assessment of our work on patient safety and quality of care (including the Conference), with a focus on impact assessment by means of a longitudinal approach, the Regional Advocacy Seminar, and the activities envisaged in the field of access and health inequalities.

Internal evaluation will be coordinated by EPF Senior Programme Officer Walter Atzori involving other team members in the assessment of activities under their respective areas of responsibility

A joint evaluation plan compiling internal and external M&E, emphasising remit of and synergies between the two as well as the overall methodology and evaluation methods, will be agreed upon in early 2016 as soon as the external evaluator has been appointed. The evaluation plan will establish the evaluation framework in respect of each operational objective of our 2016 Work Plan based on a logical framework matrix approach.

The evaluation will use the standard evaluation criteria, namely: relevance of the action to overarching objectives and strategies, effectiveness of specific actions, efficiency in use of resources, social/organisational sustainability that may have been determined by the action, 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. It will also help to identify new strategies and demonstrate EPF accountability to its members, patient organisations at large, and donors.

The methodology for evaluation will use both quantitative and qualitative methods and will address both 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, where possible hold focus group meeting 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.

List of Annexes

Annexe 1: List of Deliverables

Annexe 2: Key Performance Indicators

Annexe 3: Events and Meetings 2016

¹ The Health Foundation [2013](#), Mulley et al., [2012](#); Reflection Process on Chronic Diseases, [Final Report](#), 8 October 2013

² [Regulation \(EU\) No 282/2014](#), recital 12

³ European Commission Patient Safety and Quality of Care Expert Group, [Meeting of 8 June 2015](#)

⁴ [Expert Panel on Effective Ways to Invest in Health](#), 2014

⁵ Mulley et al, [2012](#); Arterburn et al [2012](#); Veroff et al, [2013](#)

⁶ Council conclusions on [Common Values and Principles of Health, 2006](#)

⁷ European Commission Staff Working Document, [Investing in Health, February 2013](#)

⁸ [WHO Report on Priority Medicines, 2013](#)

⁹ [Pharmaceutical Industry: a Strategic Sector for the European Economy, 2014](#)

¹⁰ [Council Recommendations on Patient Safety, 2009](#)

¹¹ [COM \(2012\) 542 final](#)

¹² [COM \(2012\) 541 final](#)

¹³ The purpose of the Youth Strategy was to enable EPF to recognise, understand, meet and effectively represent the needs and expectations of young patients through their meaningful involvement and empowerment.

