The European Patients' Forum

Annual Work Plan

2015

EPF European Patients Forum

What we plan to do in 2015
to drive better health for patients in Europe.

Contents

1. Mission, vision statement, values and goals guiding EPF

1.1 WHO WE ARE AND WHAT WE STAND FOR

EPF was set up in 2003 to represent the collective interests of patients in the EU, with a main focus on chronic and/or lifelong conditions, demonstrating the solidarity, commitment and unity of the patients' movement across the EU. Our membership consists of 64 umbrella patient organisations (EU disease specific or national coalitions).

EPF adopted a new strategic plan 2014-2020 at our AGM 2013.

Our Vision

All patients with chronic and/ or lifelong conditions in the EU have access to high quality, patient-centred equitable health and social care.

Our Mission

Our mission is to ensure that the patient community drives policies and programmes that affect patients' lives to bring changes empowering them to be equal citizens in the EU.

1.2 EPF CORE VALUES

Patient-centred: We are driven by a rights-based, patient-centred approach to health and social care policies that affect patients and their informal carers in the EU.

Non-discrimination: We promote patients' rights for all patients regardless of health status, age, sex, ethnic origin, political belief, religious conviction, marital status, economic status, sexual orientation, gender identity or any other factor that could lead to discrimination.

Health Equity: We believe every patient should have equitable access to patient-centred high-quality health and social care, and we strive to fight the disparities existing within the EU in relation to access to and standards of care for chronic diseases and lifelong conditions.

Health in all policies: 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, including inability to work, direct and indirect costs of illness, loss of income and risk of poverty, social exclusion, discrimination and stigma.

Empowering Patients: We advance the empowerment of patients and their informal carers by fostering positive attitudes and the development of support policies and programmes that enable them to make informed choices and have their place in society as equal citizens.

Consultative: We bring a unique patients' perspective by enabling all our member organisations to contribute their distinctive expertise and wealth of knowledge to influence the programmes and policies that will impact on patients across the EU.

Independent and Transparent: We are an independent organisation, transparent in all our operations - financial, policy, communications.

Inclusive: We are an open and inclusive organisation that strives to ensure that our work reflects the needs of all patients and their informal carers including those who are under-represented.

1.3 STRATEGIC GOALS

GOAL 1: Health Literacy: To promote access for patients and their informal carers to information and education that enables them to make informed choices about their health.

GOAL 2: Healthcare Access and Quality: To contribute to improvements in health systems that enable equitable access to sustainable and high quality healthcare designed and delivered to meet patients' and informal carers' needs at all levels of care, embracing innovation in all its forms.

GOAL 3: Patient Involvement: To advance meaningful patient involvement in the development and implementation of health-related policies, programmes and projects in the EU.

GOAL 4: Patient Empowerment: To promote the development and implementation of policies, strategies and healthcare services that empower patients to be involved in the decision-making and management of their condition according to their preference, whilst raising awareness about their rights and responsibilities.

GOAL 5: Sustainable Patient Organisations: To support the development, growth and capacity building of inclusive, effective and sustainable representative patient organisations and to foster cooperation and synergies between them.

GOAL 6: Non-Discrimination: To promote the development of EU and national policies that tackle discrimination faced by patients in health and social care as well as in domains like education and employment.

1.4 GOVERNANCE

1.4.1 AGM

EPF's main governance body is the Annual General Assembly (AGM) where each member is represented by one/two delegate(s). The second delegate is a young patient (age 15-25) if the organisation concerned has nominated a representative in the EPF Youth Group. Only Full Members of the EPF are entitled to vote. The AGM makes all decisions required to implement the objectives of the EPF, according to our Constitution:

http://www.eu-patient.eu/globalassets/who-we-are/coredocuments/epf-constitution-2010.pdf

1.4.2 BOARD

The role of the EPF Board, composed of 9 members, is outlined in the EPF Constitution. The Board may form working groups to assist in the work and direct activities of EPF.

1.4.3 MEMBERSHIP

Membership: EPF has currently 64 members which are either pan-European disease-specific patient organisations or national coalitions of patient organisations representing at least 10 different disease groups. For the full list of EPF members, please see: www.eu-patient.eu/Members/The-EPF-Members/.

Full membership of EPF requires the following criteria: legitimacy, representation, democracy, consultation and transparency.

The criteria for membership are further elaborated on our website: http://www.eu-patient.eu/globalassets/membership/how-to-join.pdf.

Members pay an annual fee.

1.4.4 THE POLICY ADVISORY GROUP (PAG)

PAG harnesses input and policy expertise from our members and exchanges ideas on policy issues both in terms of strategy and of content. It complements the broader EPF membership consultation procedure on specific policies. The PAG is open to all EPF members and has 14 representatives.

1.4.5 YOUTH GROUP

The EPF Youth Group forms the backbone of the EPF Youth Strategy. It is currently made up of 11 young patient representatives with different chronic conditions nominated by EPF member organisations.

1.4.6 ACCOUNTABILITY AND CONSULTATION MECHANISMS

EPF has a clear procedure for consulting the membership in the development and endorsement of policy positions and statements. Inherent to the EPF strategic plan is a new 'thematic 'approach. This is reflected in the setting up of two working groups of our members, addressing the two overarching priorities of our work, patient empowerment and patient access, embracing the goals outlined above, and also re-organising our project, policy and communication work accordingly. Within the EPF secretariat we coordinate our work around these two themes and also set up a thematic taskforce on 'inclusive sustainable patient organisations'.

2. EPF's annual work plan for 2015

2.1 EPF'S OPERATIONAL OBJECTIVES FOR 2015

The overarching objectives for our 2015 work plan are:

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.

Their scope is both EU and Member State level:

Specific objectives in each arena of the work programme are: policy impact, communications, membership and youth strategy are outlined in the sections below, following S.M.A.R.T criteria. The evaluation section outlines the process, output and outcome indicators we are likely to draw on in our detailed evaluation plan that will be developed in more detail towards the end of 2015.

The 2015 EPF Work Plan includes all EPF advocacy work that will be carried out in 2015, including our events. All communications, dissemination and representation work related to our core activities is also included.

Alongside this, we wish to highlight that in 2015, EPF will be involved in a number of specific projects co-funded by the European Commission under different funding Programmes (Public Health, FP7and Competitiveness and Innovation Programme, Horizon 2020, Innovative Medicines Initiative) or other projects funded by unrestricted funds from sponsors/ foundations which will also enhance the overall impact of our work and achievement of our strategic goals. These are listed here http://www.eu-patient.eu/globalassets/documents/og15/project-portfolio-2015.pdf.

2.2 TARGET GROUPS OF EPF'S MAIN ACTIVITIES FOR 2015

A primary target group for EPF is our membership, 64 umbrella patient organisations, who drive and guide our work, and engage actively in all aspects of our programme. They contribute to and receive membership-specific and general communications.

Specific 'patient' target groups in 2015 are as follows:

- Patient organisations from selected regions:
    - Scandinavia – through the planning, implementation, and follow-up of the Regional Advocacy Seminar, autumn 2015.
    - National disease-specific patients' organisations in Portugal, Spain, UK, Ireland, Romania, Bulgaria, Croatia and Poland will be the target audience of a series of tailor-made regional workshops on cross-border healthcare.

- The patient community: We will continue to build on the momentum of our European Election Campaign outreach at member state level to communicate with the patient community at large, through our member organisations and policy makers and stakeholders who committed their support at national level.

- EU Health Stakeholders EPF has had a long tradition of cooperating closely with fellow health stakeholders on issues of common concern and now enjoys a constructive and trusted relationship with many leading public health and health professional groups at European Union level. In addition to regular exchange of information and dialogue, we support respective position papers where appropriate, and collaborate through projects and events.

- Members of the European Parliament: following our campaign to encourage candidates to the European elections to commit in favour of patients' rights, we will ensure on-going information and policy briefs are sent to target MEPs on an on-going basis.

- The Commission, Commissioners and their cabinets and DGs: we will target primarily the new Health Commissioner, but also other Commissioners and cabinets, as well as the civil servants of DG SANCO, DG CONNECT, DG RESEARCH, DG ECFIN, DG Employment. We also work across all DGs in the spirit of 'health in all policies'.

- Member States and Presidencies of the Council of the European Union: in 2015 we will closely work together with the Latvian and Luxembourg Presidencies as described below and in our 2015-2017 work programme.

- Media: EPF will continue to target the main EU journalists and health related publications, as well as specific national journalists from Scandinavia, Portugal, Spain, UK, Ireland, Romania, Bulgaria, Croatia and Poland in the context of our Regional Advocacy Seminar and cross- border healthcare activities

2.3 EU ADDED VALUE AND EXPECTED IMPACT OF THE ACTIVITIES PROJECTED TO TAKE PLACE IN 2015

EPF's key policy priorities are linked to our strategic goals as well as developments in the EU healthcare environment reflected in the Public Health Programme. Note: the policy priorities outlined in this draft work plan are subject to final approval by the membership.

Our priorities in 2015 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 key 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 and collective (policy) level is, in our assessment, a pre-requisite to realize equity in healthcare and advance the concept of patients as "co-producers" of health. Some of the reasons why patient participation is still absent in some key health areas, and not strong enough in others include lack of awareness; lack of resources; poor know-how on how to meaningfully involve patient groups; and a patient community with different levels of capacity across the EU.

Our specific policy work is clustered in two very broad thematic areas 'patient empowerment' and 'patient access' that reflect our strategic vision and mission.

2.3.1 HIGH-LEVEL STRATEGIC ADVOCACY

EPF will continue to engage in the EU health-related policy and strategy at high level, in cross-cutting advocacy work promoting all 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". In collaboration with health and consumer NGOs, we will engage as relevant with the European Semester Process and the role of health therein, taking forward previous collaboration such as the Vilnius Declaration. Whilst we will not engage directly on the transatlantic trade and investment partnership (TTIP), we will support the broader health community in these debates as necessary.

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 the new EU funding programmes with a relevance to patients (PHP, HORIZON 2020, Structural and Investment Funds etc.).

We will co-organise an event under the Latvian EU Presidency in follow-up to the Vilnius Declaration on Sustainable Health Systems (2013). Under Luxembourg presidency we will use the eHealth Week in May 2015 to showcase our work on eHealth from the empowerment perspective. We will also explore the opportunity to collaborate on a political event that explores patient safety in the EU, 10 years on from the previous Luxembourg Presidency.

3. Planning and implementation of EPF annual work plan for 2015

3.1 PLANNING OF EPF'S ACTIVITIES FOR 2015

Inherent to the EPF strategic plan 2014-2020 is a new 'thematic 'approach. This is reflected in the setting up of two working groups of our members to address the overarching priorities in our work, patient empowerment and patient access, embracing the goals outlined above and also re-organising our project, policy and communication work accordingly. Within the EPF Secretariat we have also set up a thematic taskforce that focusses on 'inclusive sustainable patient organisations' which brings together all our training, toolbox, capacity-building and outreach educational efforts together and ensures maximum synergies, relevance to and engagement with our members at both European and national level.

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

3.1.1.1 Specific objective and thematic area: PATIENT EMPOWERMENT

To promote the development and implementation of policies, strategies and healthcare services that foster the effective empowerment of patients (Please see evaluation section for indicators and milestones).

Patient empowerment and the EU response to chronic disease

Ensuring the sustainability of future health systems is key to realising the Europe 2020 twin goals of smart and inclusive growth, and addressing the challenges of chronic diseases, constraints on health budgets, developments in technology, and the more proactive role adopted by well-informed, empowered patients in their health and their care. Patient-centred chronic disease management with focus on patient empowerment was identified as one of the key themes of the reflection process on chronic diseases initiated in 2010 by the European Commission, to which EPF contributed actively.

During 2015 our working group on empowerment will develop a consensus definition of patient empowerment and clarification of concepts such as patient involvement and health literacy. We will also investigate what competencies, attitudes and processes are needed from health professionals and health systems to support empowerment, identifying good practice examples inter-alia through our collaboration with the European Network on Patient Empowerment (ENOPE), and start the process of developing a toolkit for patient organisations to support empowerment, to be finalised by 2017. This will be complemented by the EPF thematic campaign on empowerment, launched with a European conference in May 2015 which will investigate key facets of empowerment – self-management, shared decision-making, and health literacy – in a patient-led approach involving key health stakeholders (out- with the operating grant).

As European health systems increasingly implement patient-centred models for managing chronic diseases, we need a health workforce equipped with the right skills and attitudes. Building on EPF's work on the review of the EU Professional Qualifications Directive, EPF will continue to develop partnerships with organisations representing different health professions to develop joint activities to promote patient-centred healthcare, with the aim to contribute to a wider understanding of the new roles and new skills needed for a sustainable, high-quality health workforce in Europe. We will continue to participate in the Working Group on health workforce to provide the patients' perspective within this area. We will also formally adopt and disseminate our 2014 draft position statement on adherence and concordance.

Our policy work will draw upon the outcomes of the EMPATHIE mapping study on patient empowerment, in which EPF was a key partner. It will be complemented by our role as an associate partner in the new EU Joint Action on chronic diseases, CHRODIS, an outcome of the chronic disease reflection process. EPF has an active role in WP6 on multi-morbidities and WP7 which will use diabetes as a case study for care of chronic conditions.

EPF will continue to participate in the European Innovation Partnership on Active and Healthy Ageing, focusing on the specific needs and potential contribution of older patients with chronic conditions and the exchange of knowledge and experiences among all stakeholders to ensure their empowerment and full participation in society. EPF will continue to be involved in the implementation of actions within the partnership under the themes "adherence to therapies", "frailty and malnutrition" and "integrated care", as well as its on-going governance and monitoring.

Health literacy and information to patients

EPF will continue to work with our members and allies to advocate for health literacy as a critical EU priority for the realisation of patient empowerment and an important pillar for the reduction of health inequalities across Europe, and a key contributing factor in the sustainability of future health systems. Our work will build on a consensus paper adopted in 2013 jointly with stakeholders, and the outcomes of the European Commission's mapping study on health literacy (forthcoming), and our own member survey on patients' health literacy needs linked to emerging innovative technologies, conducted in 2014. We will review the 2008 "core quality criteria" on information to patients to assess their continued relevance. EPF will continue to work with the European Commission and the European Medicines Agency to support the development of high-quality, user-friendly EU-level information resources for patients, in the context of implementing the EU legislation on pharmacovigilance, falsified medicines and clinical trials. We will also contribute as a partner to the European Commission tender study on self-care, an aim of which is to develop guidelines for accessible, high-quality information to support patients' capacity for self-care.

Clinical trials and patient involvement in research

In 2015 EPF will actively engage with the implementation process on the new EU Regulation on clinical trials, based on several years of work in this area. Our work will focus on realising and promoting best practice regarding patient involvement in ethics review, informed consent and information to patients, as well as transparency around clinical trials results and sharing of patient data, where we will continue to support the European Medicines Agency's efforts to increase transparency. We will explicitly link this with our previous work around EU data protection legislation and will continue our dialogue with other health stakeholders and academia to promote ethical and effective health research in Europe. We will also formally adopt and build on our position statement on patient involvement in priority-setting in research, to investigate concrete paths towards effective patient advocacy to influence the research agenda.

Technology and personalised medicine

In order to achieve the Europe 2020 objectives of smart and inclusive growth, patient-centred innovation will continue to be a priority for EPF. We will continue our engagement with personalised medicine mainly in collaboration with other stakeholders, focusing on health literacy and patient involvement, and contributing to debates around public health, ethics, equity and regulation as relevant.

EPF will also continue engaging in the areas of eHealth and mHealth through participation in a number of European projects. Drawing on evidence from projects like Renewing Health, SUSTAINS and Chain of Trust and through the involvement of our wide membership our main focus in this area in 2015 will be to ensure that eHealth policies at EU, national, and regional level encourage patient-centred design and delivery of eHealth services, and promote the empowerment of patients according to their preferences. To that end EPF will develop an evidence-based position paper on eHealth focused on what is needed from the patients' perspective to harness the potential of eHealth including mHealth, particularly in the light of the Green Paper on mHealth and the actions the European Commission will take further to the 2014 stakeholder consultation. This position paper, which will serve as a basis for our advocacy work on eHealth, will have a strong focus on ways to promote patient empowerment in a meaningful way through eHealth and recommendations for integrating ICT tools into the European patient empowerment strategy. This paper will also have a focus on quality criteria for eHealth and mHealth apps in relation to patient-centred design and delivery of eHealth services and patients' meaningful involvement therein.

EPF has been involved in the eHealth Governance Initiative (eHGI) since 2011 contributing to the work stream on trust and accessibility. A new three-year eHealth Joint Action following up on the eHGI is likely to be launched in 2015in which EPF hopes to be involved , to continue feeding a patient perspective in this important policy-oriented initiative bringing together Member States and key stakeholder representatives.

3.1.1.2 Specific Objective and Thematic area: PATIENT ACCESS

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

Health inequalities from the patient perspective

Equitable access to health and social care is a priority for EPF and is at the heart of our vision. Reducing health inequalities is also key to the success of the Europe 2020 strategy for growth, as health inequalities carry a significant economic cost. EPF's focus on access is on availability and affordability of care, on chronic disease management and access to the whole continuum of healthcare.

In 2015, our work in this area will be led by our pilot working group on patient access, which was established in 2014, to provide the structure to progress in our work on key thematic areas in accordance with our strategic plan. In 2015 the Working Group will work towards defining access to health and social care from the patients' perspective, and provide recommendations towards establishing health inequalities and access indicators that better capture the experience of patients.

EPF will also continue to support the work of the Multistakeholder Partnership on Access which we established with the National Patient Organisation of Bulgaria, comprising political decision-makers and all relevant stakeholders at EU level to develop common strategies and solutions toward ensuring access to healthcare for all EU patients.

Cross-border healthcare

In 2015 EPF will continue to monitor implementation of directive 24/2011 and contribute the patients' perspective to the Commission's first report due in October 2015. Mini workshops will be held in those countries not covered by the four regional conferences held in 2013-14.

In June 2015 we will hold a European conference bringing together patient leaders and National Contact Points from EU member states, to address the European Commission draft report to the council and steps forward to support meaningful patient involvement with the NCPs. See attached for a detailed concept note: http://www.eu-patient.eu/globalassets/documents/og15/concept-2015-events-on-cross-borderhealthcare.pdf

Health Technology Assessment

HTA has been a priority for EPF since 2010 when our first conference on HTA took place. Since then we have undertaken our own studies on patient involvement in HTA http://www.eu-patient.eu/whatwedo/Initiatives as well as being actively involved in the

European flagship project, EUnetHTA, and networks such as Health Technology Assessment International (HTAi). In 2015, we will work closely with HTAi to determine our specific contribution from a European perspective, and how we can better galvanise the work going on at global level. Specifically, we shall include discussions on the HTA provision within the EU Directive on cross-border healthcare in our national workshops and also in the context of our conference to discuss the draft report on the implementation of the Directive. We shall also examine HTA in the context of medical devices through our patient-medtech dialogue. We shall set up an informal EPF working group on HTA to facilitate our contribution to the EUnetHTA project, in which we will continue to play an active and committed role, particularly in the context of defining future strategy and our work with HTAi.

Patient safety and quality of care

Patient safety and quality of care have been core priority areas for EPF since its establishment, and form a key component of our policy work in all areas. EPF starts from the principle that patients have a fundamental right to expect safe care, and also have a legitimate role, both individually and collectively, in developing and implementing policies for patient safety and quality, and evaluating them from the end-user's perspective.

EPF is a member of the European Commission's Working Group on Patient Safety and Quality of Care, which advises the Council working party on public health issues at senior level in developing the EU patient safety and quality agenda. In 2015, EPF will continue to actively represent a patients' perspective in this working group. EPF's policy work is complemented by our role as associate partner in the Joint Action on Patient Safety and Quality of Care (PaSQ), which concludes its work in 2015. We will continue to engage actively with the successor network of PaSQ, subject to the establishment of such a network.

EPF will continue to support the implementation of the Council Recommendation on patient safety and healthcare associated infections, following the Commission's second progress report published in 2014 as part of a "patient safety package". Our work will continue to build on the EPF membership survey conducted in 2012-2013, which showed variable awareness among patient communities across the EU and low involvement at national level – a finding which was confirmed by the Commission's public consultation in 2014. In 2015 therefore we will prioritise raising awareness and dissemination of information and advocacy tools on patient safety, including patients' rights, complaints and redress, building on the outcomes of the European Commission's mapping of patients' rights in all member states (2014-15). We will also highlight antimicrobial resistance (AMR) and healthcare-associated infections (HAI) in collaboration with other organisations such as ECDC, as appropriate.

Following preparatory work done in 2014, we will pilot test and launch our membership study on quality of healthcare investigating key dimensions of quality identified in literature from a patient perspective, with the aim of developing policy recommendations on patients' perception of quality in health care. This work will take place in close collaboration with the working group on patient empowerment. With this output we will contribute to the European debate on a common definition of quality of care, and aim to prepare the ground for future development of indicators for measuring the patient-centredness of healthcare and patients' empowerment. 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 and medical devices

Medicines safety and quality is an important sub-area of patient safety, and EPF will continue to support the implementation of the EU pharmacovigilance legislation, particularly the patient reporting of suspected ADR's and updating of relevant information resources. Similarly, we will continue to engage with the EU directive on falsified medicines, focusing on information and awareness including online pharmacies and the EU logo adopted in 2014.

Having contributed to the debates on medical devices since the exploratory process on medical devices in 2009, EPF continues to engage actively in 2015 in the legislative process for the proposal for a Regulation on Medical Devices and the proposal for a Regulation on in vitro Diagnostic Medical Devices, to ensure patient safety, patient involvement and greater transparency in the system are prioritised. EPF will also develop tools to inform our members and encourage patient involvement in the development and safety of medical devices once the Regulations are adopted.

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 and work towards the adoption of a Code of Conduct for the medtech industry in 2016.

Tackling Discrimination

For patients, access also means non-discrimination. In 2015, EPF will follow up on our position on discrimination in healthcare from 2014 with decision-makers and health professionals to ensure awareness of the importance of protecting patients from discrimination and stigma in the context of healthcare services across the EU. We will also develop a position paper related to discrimination based on health status in education and the workplace, involving the EPF Youth Group in the process. The aim of this position paper is to gather evidence and raise awareness of how patients are discriminated in various areas of life and provide recommendations for decision makers to improve their situation.

EPF will continue to build its collaboration with the EU Fundamental Rights Agency and non-governmental organisations representing groups at risk of discrimination through participation as a member of the Fundamental Rights Platform.

3.1.2 POLICY INVOLVEMENT IN AGENCIES, THINK-TANKS AND ADVISORY PANELS

3.1.2.1 Health-related 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 European Health Policy Forum; European Innovation Partnership on Active and Healthy Ageing; the European Federation of Pharmaceutical Industry Associations (EFPIA) Patients' Think Tank to continue the 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, Innovative Medicine Initiative Stakeholder Group; Health Stakeholder Group; EC Working 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).

EPF will use these platforms to gather information, exchange good practice and to reinforce its key policy messages on topical issues.

3.1.2.2 Working with Our Partners

Partnership is EPF's leitmotif and in 2015 we will continue our approach of dialogue, cooperation and collaboration with other stakeholders working in our field.

3.1.2.3 Cooperation with other patient groups

In 2015 we will continue to work as closely as possible 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.

3.1.2.4 Cooperation with other health stakeholders

We will continue in 2015 as members of the European Network on Patient Empowerment (ENOPE) and involve this network in our conference and campaign on patient empowerment.
In 2015 we will continue to collaborate very closely with the European Public Health Alliance (EPHA) through the establishment of the EP Health Intergroup or similar platform and a specific initiative in the framework of the Latvian EU Presidency, following up the Vilnius Declaration.

In 2015 we will continue cooperating very closely with all major EU organisations representing health professionals, particularly the Standing Committee of European Doctors (CPME) the new patient-doctor relationship; the Pharmaceutical Group of the European Union (PGEU) on cooperation with pharmacists; and the European Federation of Nurses Associations (EFN) on the patients' role in continuing professional development of nurses. 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), 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), and the EU Health Telematics Association, and the European Forum for Primary Care, with whom we have memoranda of understanding. We will continue working with them closely in various committees, structures and projects. At global level, EPF will continue to cooperate with DIA, with a leading role at their DIA Europe meeting in Paris in spring 2015, and ISPOR, 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 European Platform of Social NGOs.

We will continue to work with major EU networks working on health issues, such as EUREGHA, the Assembly of European Regions and HealthClusterNet.

3.1.3 OBJECTIVE 2 - REINFORCING THE CAPACITY OF THE PATIENT COMMUNITY ACTORS TO EFFECTIVELY CONTRIBUTE TO THE HEATH DEBATE

3.1.3.1 Specific objective - Strengthen EPF membership and increasing members' involvement in EPF activities

Reinforcing EPF Membership

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. More precisely, the document aims at identifying the challenges to and proposes solutions for the broadening and consolidation of EPF. 2015 will be the first phase of implementation of this Membership Strategy.

The list of EPF members can be accessed here:

http://www.eu-patient.eu/globalassets/membership/2014_05_14_list_members.pdf

Objectives

1. Establishing a clear identity, clear added-value

- As a first step to clarify its membership structure, EPF will review its membership categories and processes and fill in the gaps if needed. Proposals will be made to revise the membership structure if needed and submitted to EPF's governing bodies.
- A new updated membership guide listing the benefits of EPF membership will be developed and published, spelling out the added value of EPF for members and patients' organisations.
- The "Members" section of the EPF website will undergo a makeover to integrate the changes proposed above and demonstrate our commitment to a more interactive network (see part 3.2. on communication and dissemination).

2. Creating a vibrant network

   One of the key objectives for 2015 will be to strengthen the links between the EPF Secretariat, its governing bodies and the membership base. A series of interactive tools will be developed to energise the network and facilitate cross-fertilisation of EPF members' activities and projects:

- A feasibility study on the creation of an EPF Social platform will be conducted, and, (provided the conclusions are positive) a Social platform will be launched. The EPF Social Platform will be a place for patients' organisations to exchange experiences and information;
- The "EPF Weekly Insiders" - launched as a pilot in 2013-2014, this members-only report highlights the main EPF activities, policy consultations, events and news relevant to the patient community on a weekly basis;
- "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 is has been extremely well-received by the membership so far;
- "EPF on the Spot": EPF is planning to attend a number of its members' events, in order to highlight the mutual benefit and added value of being part of the organisation, and to explore how to refine cooperation.

3. Ensuring Membership development and growth

- In terms of membership development, EPF will conduct an analysis of the situation in "white zones" (disease and geographical areas where EPF is not yet represented).
- We will also focus on extending our cooperation with patient organisations in Scandinavia and in the Balkans, two regions where to date we have had limited presence and traction.

4. Fostering strong patient organisations

- EPF will explore new formats to provide support and trainings on issues of interest to pan-European organisations (webinar, breakfast briefing). One of these new formats will run as a pilot during 2015.

5. Strengthening members' involvement in EPF's policy work

The EPF Policy Advisory Group will meet physically twice in 2015. The PAG will also meet virtually by means of teleconference during the course of the year, when needed, in order to provide continuous guidance on priority policy areas.

In 2014 EPF introduced the concept of thematic policy working groups where a cluster of our members with a particular interest in a theme will meet and work together under the leadership of a chair selected from the group and supported by the EPF secretariat.

Two such working groups were set up in 2014 on empowerment and access, reflecting the thematic approach. See attached terms of reference:

http://www.eu-patient.eu/globalassets/documents/og15/Terms-of-Reference-WG-access.pdf

http://www.eu-patient.eu/globalassets/documents/og15/Terms-of-Reference-WG-Empowerment.pdf

3.1.3.2 Specific objective - Strengthen the patients' community capacity, promoting solidarity and youth involvement

Meeting and supporting Europe's patients

The following lists the opportunities for EPF members to meet and work together in 2015.

- The Annual General Meeting (AGM) will be held in spring 2015 in Brussels. Alongside the AGM there will be a number of fringe meetings focusing on specific policy themes of specific interest to members as well as meetings of our two working groups on patient empowerment and patient access.
- The Regional Advocacy Seminar (RAS) will be organised in Scandinavia in autumn 2015. 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.
- A series of national and transnational workshops on cross-border healthcare will be organised in 2015, following the success of the four Regional Conferences on Cross-border Healthcare organised by EPF 2013-2014. See attached concept note: http://www.eu-patient.eu/globalassets/documents/og15/concept-2015-events-on-cross-borderhealthcare.pdf
- A European Conference on Cross Border Healthcare on the eve of the Commission's draft report to Council on the Implementation of the Directive, bringing together patient organisations, political representatives and representatives of the National Contact Points in each EU Member State.
- A key EPF Conference on Patient Empowerment from the perspective of patients, embracing health literacy, self-care and co-decision-making, the collective patients' voice and role of patient organisations at policy level and enhancing the patient HP

relationship. This Conference will kick-start an EPF campaign on empowerment (Out-with the OG).
- EPF will 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.

Involving Young Patients

In 2011 EPF launched its Youth Strategy. The purpose was to enable EPF to recognise, understand, meet and effectively represent the needs and expectations of young patients through their meaningful involvement and empowerment. See link http://www.eu-patient.eu/globalassets/who-we-are/epfstructure/epf-youth-strategy.pdf.

In 2012-2013 much effort was put into involving the Youth Group into the EPF strategic planning process and implementing the EMPATHY project (co-financed by the Youth in Action Programme) consisting of a four-day seminar for young patients, policy-makers and stakeholder actors in the fields of health, education, social and youth policy, in order to promote a more holistic approach to addressing young patient needs in decision-making processes.

In 2014 additional efforts were invested in revisiting the Youth Strategy to align it to the new EPF Strategic Plan 2014-2020. As foreseen in the Strategy, the Youth Group has strengthened relations with the EPF Board through bilateral meetings. On the policy side the Youth Group has been increasingly involved in EPF-led events, consultations and campaigns (thematic policy working groups), and advisory bodies (Policy Advisory Group) that focus on policy domains such as discrimination, empowerment, access to healthcare and mobility-related issues (CBHC seminars).

In 2015 focus will be on capacity development for the Youth Group, with the key objective to evolve as a strong and sustainable community of young patients. The capacity development activities will respond to governance issues and will provide tools to help the Youth Group develop as a self-managed entity within EPF.

Following the EMPATHY project positive experience, EPF is investigating funding opportunities within the Erasmus + Programme in order to finance a Capacity Development Programme for the Youth Group.

Other specific objectives for 2015 are:

- Recruitment of new members,
- Building strong relationships with youth groups in EPF membership and with other relevant stakeholders from the youth, education, employment and social sectors.

As part of the implementation of the Youth Strategy we will hold the following meetings/activities:

- A spring meeting of the EPF Youth Group attached to our 2015 AGM,
- The Fifth Annual Meeting of the EPF Youth Group will take place in summer 2015,
- A regular flow of information and exchange of ideas will be guaranteed through regular conference calls and via social network tools.

3.2 DISSEMINATION AND EVALUATION OF EPF'S WORK PLAN FOR 2015

2015 will be a post-elections period which means that EPF with our members and allies will define our relationship as the key interlocutor on behalf of patients on cross-cutting health issues with newcomers to the EU policy scene and refresh our work with long-term allies. This will be underpinned by our three long-term communication objectives of communication to inform, to engage and persuade.

3.2.1 COMMUNICATION OBJECTIVES

The EPF strategic goals will guide our three communications objectives for 2015, the content of which will be framed around our 2 thematic priorities patient empowerment and patient access. (Please see evaluation section for specific indicators.)

- Communicate to inform [EPF Goals 1&2]: in 2015, EPF will develop simplified messages that will drive our communication strategy for 2015-2017, making them clearer, relevant and meaningful to the different target audiences.
- Communicate to engage [EPF Goal 2]: in 2015, EPF will define common messages to engage the patient community and health allies, demonstrating our collective strength and unity in advocacy work.
- Communicate to persuade [EPF Goal 1]: in 2015, EPF will outline clearly our specific ‘asks’ to decision-makers to put a patients’ perspective in their work for this second year of their mandate.

3.2.2 COMMUNICATION CHANNELS AND TOOLS

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

- Our website will make our messages widely accessible and updated on an ongoing basis. The policy section dedicated to patient empowerment will be updated to support the thematic campaign. We will also conduct an extensive review of our analytics in 2015 to prepare the change of the website in 2016.
- Our Newsletter will continue to provide the latest policy, projects and event developments on a monthly basis. The thematic campaign will be regularly highlighted in the different issues of the newsletter. We will use a new platform to release the newsletter in 2015 to be able to track users' needs and preferences.
- The 2014 Annual Report will be released in 2015 and will provide an overview of what was achieved in the previous parliamentary mandate including the upcoming challenges for the European Patients' Movement in addition to the report of 2014 achievements.
- EPF will continue to build a strong presence on social media by identifying key influencers and helping to build patient allies' capacity to carry on our messages. A specific hashtag on patient empowerment will be created to foster discussions on Twitter.
- EPF will develop a video defining who we are and what we expect from decision-makers to include a patients' perspective. A campaign video will also be released to support the thematic campaign.
- We will share all our key policy achievements through our press releases to our media network: News about our thematic campaign will also be released within our press contacts.
- Our blog will welcome our members as invited guests to link their own experience to our key policy positions and updates as well as to the thematic campaign.
- EPF will release three factsheet leaflets on patient-centred healthcare, patient safety, and cross-border healthcare to constitute the first part of the EPF advocacy directory. These factsheets will be easy to update in order to include the latest policy developments. An additional leaflet will be created on patient empowerment to support the thematic campaign.

The co-funding of the European Commission will continue to be mentioned on all external documents released by EPF as well as our public website, blog and newsletters.

In 2015 we will work closely with EPHA to pursue a robust cooperation with key health stakeholders in order to create a Health Intergroup in the European Parliament, or similar cross cutting 'health' platform in the EP.

3.2.3 EVALUATION STRATEGY

EPF will undertake on-going monitoring and evaluation of the 2015 Operational Plan in line with agreed measurable performance indicators and targets which are in turn derived from the long-term performance indicators set out in respect of each of the six strategic goals defined in our Strategic Plan 2014-2020.

Monitoring and evaluation will be carried out internally by the EPF Secretariat. In order, however, to ensure transparency and independence, internal evaluation will be complemented by external evaluation looking more specifically into some key processes and milestones and exploring aspects such as perception of relevance of EPF work among our constituency and external stakeholders, overall effectiveness and efficiency of EPF strategies, approaches and working methods, as well as synergy between EPF policy advocacy, programmes and projects.

EPF is committed to this approach in order to be able to demonstrate how we do business and how we deliver in the context of the Strategic Plan in question and the various Annual Work Plans implementing it, but also in order to plan, anticipate, and be as proactive and effective as possible as a lead organisation in the EU health policy environment.

The following section presents some of the key performance indicators (process, output, and outcome indicators) that will be used to assess progress against the operational objectives set out this plan. The full list of indicators and evaluation questions will be presented in the evaluation plan that will be developed in late 2014.

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

Specific Objective	**1A) Promoting the development and implementation of policies, strategies and healthcare services that foster the effective empowerment of patients**

Process Indicator(s)

- EPF is successful at launching a patient Working Group of member representatives to lead on the development and implementation of the EPF strategy on empowerment
- EPF is successful at engaging with the Latvian and Luxembourgish Presidencies in 2015 to advance work on empowerment
- EPF is successful at engaging the Policy Advisory Group to gather patient expertise to feed the development of policy positions in the empowerment thematic policy cluster
- EPF is successful at engaging in an effective way with the EMA on issues pertaining to information to patients, adherence, and transparency in clinical trials
- EPF is successful at implementing advocacy activities aimed at fostering health literacy and effective information to patients
- EPF is successful at implementing advocacy activities aimed at promoting patient-centred implementation of the EU Clinical Trial Regulation

Output Indicator(s)

- EPF is successful at developing a statement defining patient empowerment and related concepts (e.g. patient involvement, shared decision-making, health literacy) developed with the EPF working group on patient empowerment
- EPF is successful at developing an evidence-based position on eHealth and mHealth focused on what is needed from a patient perspective to harness the potential of eHealth and mHealth in terms of patient uptake by 2015
- EPF is able to deliver a review of core quality criteria for information to patients developed by the high level pharmaceutical forum to ensure they still correspond to patients’ needs
- EPF is able to produce a position paper on the implementation of the information/consent provisions of the Clinical Trials Regulation

Outcome/Impact Indicator(s)

- EPF is able to engage in and influence the political dialogue in the areas falling under the thematic cluster on empowerment as measured by the inclusion of EPF recommendations in EU-level legislation and initiatives concerned
- Through the Working Group on empowerment, our advocacy work, and complementary activities out-with the OG (empowerment conference and campaign) EPF is successful at mobilising all relevant stakeholders in fostering patient empowerment
- EPF is successful at identifying and raising awareness of remaining shortcomings in the Clinical Trial Regulation
- EPF is successful at using outcomes of eHealth projects to influence the current and future debate on eHealth and mHealth as measured by the integration of patients' perspective in eHealth policies and programmes
- EPF is successful in ensuring the Pharmaceutical Forum Core quality principles for patient information on diseases and treatment options are adopted by key stakeholders in charge of patient education and information

Specific Objective	**1B) Promoting the development and implementation of policies, strategies and healthcare services that maximise access and reduce health inequality across the EU**

Key Process Indicator(s)

- EPF is successful at setting up a patient Working Group of member representatives to lead on the development and implementation of EPF strategy on access
- EPF is successful at engaging the Policy Advisory Group to gather patient expertise to feed the development of policy positions in the access thematic policy cluster
- EPF is successful at engaging with the Latvian and Luxembourgish Presidencies in 2015 to advance work on healthcare sustainability
- EPF is successful at ensuring the sustainability of the Multi-stakeholder Partnership on Access as a co-leader of this initiative
- EPF is successful at engaging actively in 2015 in the legislative process for the proposal for a Regulation on Medical Devices and the proposal for a Regulation on in vitro Diagnostic Medical Devices
- EPF is successful at implementing a series of mini-meetings on CBHC implemented in 2015 in countries not involved in the CBHC conferences in 2013-2014
- A European Conference on CBHC involving all NCPs is held in June 2015
- EPF is successful at contributing to the Commission's Working Group on Patient Safety and Quality of Care

Key Output Indicator(s)

- EPF is successful at delivering a position statement on defining access from a patient perspective and recommendations for decision-makers on measuring access
- EPF is successful at developing a patients’ checklist and recommendations for the functioning of National Contact Points
- EPF position on implementation of Directive 24/2011 including recommendations for the European Commission draft report to the council on the patients’ experience with implementation of the directive on cross-border healthcare is developed
- Two information tools (briefing factsheets) on medical devices are produced for members and patient organisations at large provided the legislation is adopted
- EPF has published & disseminated a position paper on discrimination in healthcare, and a position paper on chronic disease by end 2015

Key Outcome/Impact Indicator(s)

- PF is able to engage in and influence the political dialogue in the areas falling under the thematic cluster on access as measured by the inclusion of EPF recommendations in EU-level legislation and initiatives concerned
- Stakeholders and decision makers are aware of the EPF position paper on access as measured by responses from decision makers and stakeholders received after sending out the position paper
- EPF is successful at promoting the active involvement of patients’ organisations in the monitoring of the implementation and functioning of the CBHC directive
- EPF is able to to raise awareness of how patients, especially youngsters, with chronic conditions can be discriminated against, e.g. at school, university, labour market, etc., as a result of their disease
- EPF is able to pave the way for the adoption of a Code of Conduct between patients and MedTech industry envisaged in 2016
- EPF is successful at promoting better understanding of medical devices and how to be involved in this area within EPF membership as measured by the extent to which they disseminate information tools & recommendations on medical devices, involvement in patient Medtech dialogue

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

Specific Objective **2A) Strengthening EPF membership and increasing members' involvement in EPF activities**

Process Indicator(s)

- Membership strategy implemented
- Annual General Meeting held in 2015
- One "light and lean training" for members implemented as a pilot in 2015

Output Indicator(s)

- 2 new members join EPF in 2015 from either diseases and geographical areas where we are currently underrepresented
- Membership Guide developed and disseminated
- EPF Social Platform for Members designed and implemented

Outcome/Impact Indicator(s)

- EPF is successful at gathering better knowledge of our membership's assets and coverage
- EPF is successful at maximising impact of EPF activities and ensure members' active involvement in the transposition and implementation and monitoring of relevant EU legislation to ensure it is as patient-patient centred as possible.
- EPF is successful at strengthening inclusiveness, representativeness, and accountability of members

Specific Objective **2B) Strengthening patients' community capacity, promoting solidarity and youth involvement**

Process Indicator(s)

- Successful running of Regional Advocacy Seminar (RAS) 2015 (50 participants from 4 countries representing at least 15 disease areas)
- EPF is successful at ensuring ongoing support to members by membership officer through ad-hoc training and ensuring effective synergy with the Capacity Building Programme
- Youth Group meet twice in 2015 and implement activities focused on discrimination and transition from paediatric to adult care to meet policy objectives identified for the youth group

Output Indicator(s)

- Toolkit for empowered young patients developed
- Report of the 2015 RAS produced

Outcome/Impact Indicator(s)

- Through the RAS EPF is able to strengthen the capacity of 50 patient leaders from the 4 countries concerned on issues tackled in the seminar as measured by RAS' participants having acquired new learning that is useful and applicable to their work as patient advocates
- EPF is perceived as a resourceful and representative umbrella organisation by patient organisations involved in the RAS
- EPF is able to integrate youth representatives in its activities and strengthen the capacity and sustainability of the Youth Group

3.2.3.3 Specific indicators for Communication

Specific Objectives	**Communications to inform, to engage and persuade our respective target groups**
Process Indicator(s)	
• Communication Plan 2015 implemented	
Output Indicator(s)	
• Annual report 2014 produced • 3 factsheet leaflets on EPF Work Programme 2015 produced and disseminated • 11 e-Newsletters produced and disseminated • 2 videos produced • 10 press releases sent to target press lists • 2 events live-tweeted; regular tweets/retweets and Facebook update/shared status per month • 1 article per month posted on EPF blog	
Outcome/Impact Indicator(s)	
• EPF is able to increase its outreach through communication tools. Targets: 700 annual reports disseminated per year, 1,500 factsheet leaflets; 3,500 recipients of the EPF newsletter; 1,000 views per video; 42,000 visits of the website; 1,500 visits of the blog; 3,500 likes on Facebook; 1,500 followers on Twitter.	

4. Overview of EPF projects and Capacity Building Programme

This brief document provides an overview of projects EPF is currently involved in as either coordinator or associate partner.

The last part of this document describes the objectives, structure, and current status of implementation of the EPF Capacity Building Programme.

4.1 RUNNING PROJECTS

4.1.1 EUPATI

EUPATI stands for the "European Patients' Academy on Therapeutic Innovation". It is a five-year EPF-led project funded by the Innovative Medicines Initiative (IMI).

As part of our ongoing commitment to empowering and improving the quality of life of people living with chronic diseases, since 2012 EPF has been leading a consortium involving several pan-European patient organisations, academic institutions, to create a training platform designed to provide patient experts, patient organisations, and the health-interested lay public with reliable, objective, and relevant information on the medicine research and development process.

Priorities for 2015 are: continuing to run the first Expert Level Training Course, and launch of the second Course in September, adaptation of educational material to the patient advocate level, further establishment and consolidation of EUPATI National Platforms and development of a project sustainability plan for the post 2017 period.

To manage this project EPF set up a dedicated secretariat in Munich consisting of a Project Director, a part-time Project Officer and a part-time Communication Officer. The project is set to finish in early 2017.

4.1.2 PASQ JOINT ACTION

PASQ stands for the Joint Action on Patient Safety and Quality of Care (PaSQ) in which EPF has been involved since 2012 as an associate partner. The goal of this JA is to strengthen cooperation between EU MS, international organisations and EU stakeholders on issues related to quality of health care, including patient safety. This project is funded by the European Union, in the framework of the Public Health Programme.

EPF's role is at the core of the Joint Action as one of the objectives of the project is to address patients' empowerment and patient involvement in patient safety and healthcare quality.

Our main tasks have been to lead on the identification of existing and proven good practices in patient safety and quality of care focusing on patient empowerment and involvement, and identification of strategies for improving quality of healthcare through patient empowerment and involvement. We are also involved in building network sustainability and effective dissemination.

EPF participated also in the research concerning the involvement of patients in the implementation of selected safe clinical practices in 18 countries across Europe. This research opens the opportunity to promote patients' participation to the safety and quality in various healthcare settings, based on the lessons learned and the data collected.

The results reached in three years of project implementation were presented at the 5th Coordination Meeting developed in Brussels from 12 to 13 March 2015.

This JA is 60% co-funded by the EU Health Programme and will end in spring 2016.

For a detailed presentation of the project, see: http://www.pasq.eu/.

4.1.3 CHRODIS JOINT ACTION

This Joint Action "Addressing Chronic Diseases and Healthy Ageing across the Life Cycle" (CHRODIS-JA) started in early 2014 with the overall objective of promoting and facilitating a process of 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.

EPF is an associate partner in this JA. Our role involves contributing the patients' perspective on care for patients with chronic diseases. We will be looking at aspects such as integrated care, ensuring patient safety, care for patient with multi-morbidities multidisciplinary approaches, patient empowerment, and professional training.

More specifically we are involved in the development of common guidance and methodologies for care pathways for multi-morbid patients. EPF's priorities for 2015 include a consultation building process on the definition of criteria for good practices on patients driven interventions.

The final aim is to share the selected good practices on a platform for exchange knowledge targeted to users such as researchers and healthcare professionals but open to all including patients.

This project is 50% co-funded by the EU Health Programme. See http://www.chrodis.eu/.

4.1.4 SMARTCARE

The overarching objective of the SmartCare project, which started in mid-2013, is to promote a more integrated and effective approach to providing health and social care to older people across Europe.

To this end, the project set out to define and pilot a comprehensive set integrated health and social care services to overcome a range of threats to independent living commonly faced by older people. The project will incorporate interoperable components to enable cooperative delivery of healthcare, social care and independence-enhancing support by healthcare and social care organisations, family and informal carers, as well as voluntary sector personnel. The project is piloting two care pathways: short term after hospital discharge following an acute event and long term pathways for chronic patients in need of long term care.

See http://pilotsmartcare.eu/home/.

EPF role in this project is to ensure the project takes into consideration the interests of older patients. Priorities for 2015 are to complete the round of UAB site visits to gather evidence of users' perception of the integrated care services piloted in the various European regions involved in the project. As a result of these visits the UAB will produce a report and a set of recommendations from a user perspective.

4.1.5 WE CARE

We Care is a two-year project funded under the former FP7 Programme coordinating the development of a R&D Roadmap to deliver high-quality, affordable Healthcare to all EU-citizens. The R&D Roadmap focuses on pathways to respond to the urgent need to keep EU countries' healthcare budgets under control while guaranteeing a maintained or even improved quality of care for all EU citizens. The assumption is that an effective response to growing healthcare budgets does not come from simple cuts, but from important investments on both health research and innovation (both technical, methodological and institutional).

See http://www.we-do-care.eu/.

EPF is involved as associate partner and plays a core advisory role in every aspect of the project to ensure a strong and strategic patient perspective. EPF contributes to the overall discussions with a special focus on quality, affordability and accessibility aspects. The main activities foreseen in 2015 include the development and validation of the new Strategic plan and the R&D roadmap.

4.1.6 PISCE

The Pilot Project on the Promotion of Self-Care Systems in the European Union (PISCE) is a tender project for the European Commission running from September 2014 to February 2016. PISCE is run by a consortium of project partners, including EPF and many of our partners from the EMPATHIE tender study. The lead of the project is in the hands of the Dutch Institute for Healthcare Improvement (CBO).

The goal of this project is to put in place a framework for action to enhance self-care at EU level, and to develop strategies to support implementation. PISCE will focus on five minor conditions selected for the project on the basis of a cost-benefit study; but the consortium will also address wider issues regarding self-care, which will be relevant to many patients: these include health literacy, access to information, health inequalities and access to health services.

The main deliverables are split between three work packages:

1. Guideline on the promotion of self-care in Europe;
2. Guideline for creating and using communication tools on self-care;
3. Recommendations for policy actions on self-care at EU level.

EPF is actively involved in all three work packages as well as the Platform of Experts. PISCE will hold a final conference in early 2016.

4.1.7 EUNETHTA JA2

The EUNetHTA Joint Action 2 (JA2) brings the cooperation among Member States and stakeholder on HTA established under the first EUNetHTA JA (2009-2012) to a higher level to provide the European Commission and MS ways to establish a sustainable structure for HTA in the EU. EUNetHTA JA2 is developing a general strategy, principles, and an implementation proposal for a strong collaboration in the framework of the Cross-Border Healthcare Directive.

The Joint Action 2 is connecting public national/regional HTA agencies, research institutions and health ministries, enabling an effective exchange of information and support to policy decisions of the Member States. 2015 is the concluding year of the JA2 and is dedicated to the fine-tuning of outputs and implementation and adaptation of results at the national level.

EPF is part of the Stakeholder Forum created as part of the governance structure of the EUnetHTA Joint Actions. It consists of organisations representing four stakeholder groups – patients/consumers, industry, payers, and healthcare providers – to allow having a permanent structure for involvement of stakeholders.

See http://www.eunethta.eu/activities.

EPF receives no funds from the European Commission under this action.

4.1.8 ADHOPHTA (FP7)

The project AdHopHTA - Adopting Hospital Based Health Technology Assessment (HTA) in EU – addresses the problem that several hospital based HTA initiatives have lately emerged in Europe but there is a poor use and awareness of it. EPF is member of the Advisory Board. By participating in this project, EPF has the opportunity to:

- Ensure patients perspective is considered and strengthened during the project lifecycle,

- Make policy recommendations to guarantee a patient-based approach in transferring lessons learnt and best practices to other hospitals,
- To access accurate knowledge on how decision making for adopting innovation is specifically done at hospital level and use for its development in HTA research.

EPF receives no funds from the European Commission under this project.

4.2 PROSPECTIVE PROJECTS

4.2.1 NEW JOINT ACTION ON EHEALTH

A new joint action on eHealth is to be launched by the European Commission in 2015 to follow up on the eHealth Governance Initiative (2011-2014). Further to changes regarding the process of granting Joint Actions under the Public Health Programme, the extent of stakeholder involvement remains unclear. EPF holds close dialogue with other key healthcare stakeholders (doctors, nurses, pharmacists, dentists, and hospital) to explore opportunities for meaningful stakeholder engagement in this project. Provided positive outcomes of the negotiation with the EC and the coordinator (Austrian Ministry of Health) participation in this project should start in mid-2015.

4.2.2 ADAPT-SMART

Accelerated Development of Appropriate Patient Therapies:
A Sustainable, Multi-stakeholder Approach from Research to Treatment-outcomes.

EPF is involved as an associate partner in a new coordination project within the framework of IMI. It has been selected to go to the second phase, and will comment in June 2015.

Progress in the life sciences and related technologies offer the potential to bring a wide range of beneficial therapies to patients over the coming years. There will be more personalised or stratified medicines, combinations, borderline products, and advanced therapies that will require new ways of evaluation and new ways of managing utilisation in clinical practice. Several initiatives are exploring new pathways to market, collectively referred to as Medicines Adaptive Pathways to Patients (MAPPs). This represents a flexible development and access pathway within the current regulatory framework that maximizes the positive impact of new medicines on public health by balancing timely access for patients with the need to provide evolving information on benefits and risks.

ADAPT-SMART, coordinated by the European Medicines Agency, is aligning a limited number of major stakeholders, including EPF eager to progress towards MAPPs implementation. In addition to engaging a dialogue with relevant stakeholders, the ADAPT-SMART consortium will contribute to align understanding of the impact of MAPPs, to share learnings between all stakeholders, and to allow the field to actively work towards MAPPs implementation. This will increase the probability of successful innovation and accelerate access to crucial therapies for patients.

4.2.3 PATIENT- SMART

A Sustainable Multi-stakeholder Approach from Research to Treatment (SMART):
A Structured Patient Engagement Knowledge Platform (PEKH) for Improved Outcomes".

EPF is co-leading, with EURORDIS, an expression of interest to Call 3 of the Innovative Medicines Initiative, which will, if accepted, be part of the sustainability strategy for the European Patient Academy on Therapeutic Innovation.

The field of medicine development is rapidly evolving and challenges societies faced with health budgetary pressures but opportunities for innovation are still growing. One key area of change is the engagement of patients along the whole life cycle of a product. The expertise of patients who experience living with a disease and new methods to identify patients’ preferences enrich development and assessment pathways towards better patient health outcomes. Currently, there is little consensus-based guidance on how to conduct patient engagement across international, European and national levels.

This project aims to create a knowledge repository of good practices, enabling sharing of information/ capabilities by all stakeholders to provide non-binding standardised guidance to engage patients at the relevant moment. The main focus of the project is on enabling and structuring systematic patient engagement during product development and assessment.

Based on a gap analysis on the conceptualisation of a smarter patient engagement, its implementation during an evaluated pilot phase, and on the standardisation and production of a Manual of Good Practices, the project will create long-term services to be used by all stakeholders.

The repository will be the go-to platform to engage with patients at every stage. Its use will provide meaningful information and concrete guidance on patient engagement, mitigation of conflicts of interest and improve professionalization of patient organisations. It will enhance the quality of product development and favour convergence between the requirements of regulators.

Overall, this uniform approach to patient engagement and good practices piloted in real-life will enable immediate use by early adopters and a scaled-up for a wider use, both for the development and the assessment of medicines. It will also provide a framework to improve perception between society and stakeholders involved in medicines development.

4.2.4 PRIME CHOICE

(Principles, Requirements, Information, Management and Ethical framework for Citizen/Carer-centric Holistic Optimised Integrated Care in Europe) is a proposal that responds to the call Horizon 2020 PHC-25-2015 with the purpose to address emerging societal challenges in the health systems and identify holistic integrated solutions of care supported by ICT tools. Prime Choice targets older patients with multiple chronic conditions and seeks to combine their needs and preferences with more integrated, respectful and cost-effective services delivered in a modern ICT-enabled society. EPF will be involved in the identification of patients' needs, validation of solutions and definition of recommendations for policy makers.

4.2.5 MIDATA

MIDATA is a proposal for "Health Data Cooperatives - Implementation of personalised medicine by adding citizens' control over their personal (health) data to existing healthcare systems". MIDATA.COOP (Call PHC24-2015) aims to change EU citizens from passive recipients of care into central actors by enabling them to control their personal medical and health data. It will build national citizen-owned and citizen-controlled Health Data Cooperatives (HDC) in which citizens and patients can securely store, manage and share their data.

The key objectives of MIDATA are to:

- establish health data cooperatives in selected countries,
- implement an IT platform,
- implement pilot field labs to demonstrate the added value of this approach in disease prevention, rare diseases, and common chronic conditions. It includes an evaluation of the health, economic and social values involving all relevant stakeholders.

4.3 THE EPF CAPACITY BUILDING PROGRAMME

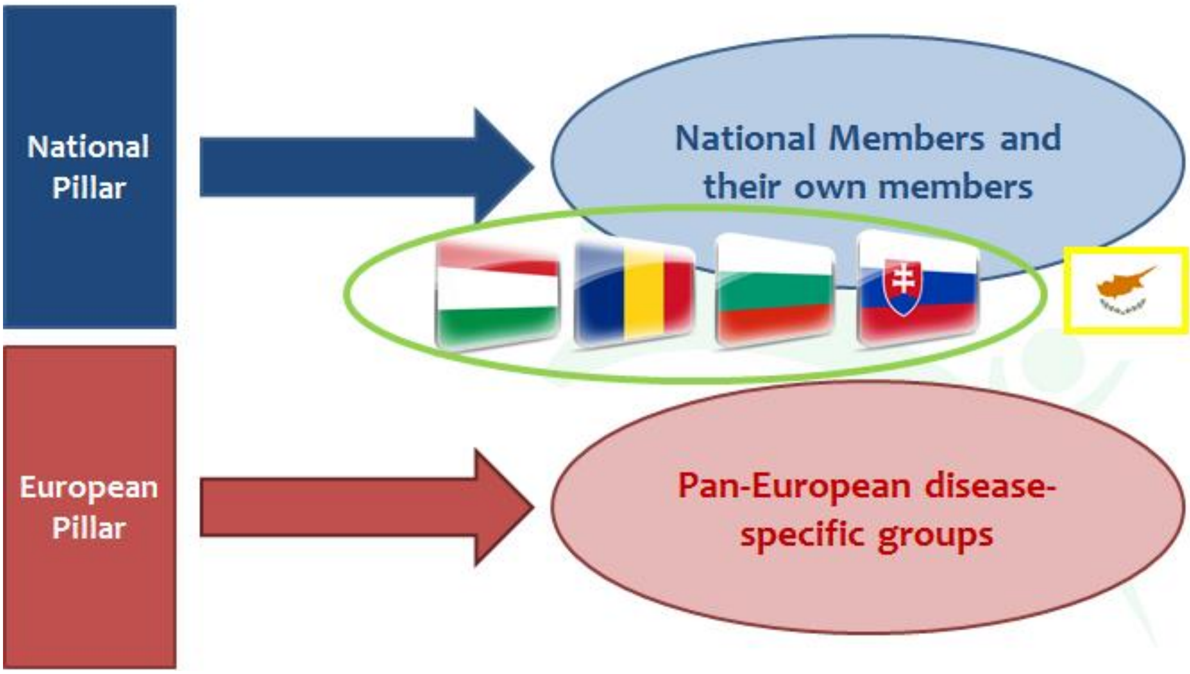
The Capacity Building Programme (CBP) was launched in 2012 to respond to needs and concerns which have been identified by our membership during previous activities of EPF. The CBP has been rolled out as a pilot programme over the three year period 2012-2014. An in-depth evaluation of this pilot is currently underway.

The overall objective of the programme is to strengthen the capacity of both national and European level Patient Organisations to enable them to be more effective in:

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

The programme consists of two main strands:

1. Capacity Building Programme for National Patient Organisations (national coalitions member of EPF and their own members),
2. Capacity Building Programme for pan-European Disease-Specific patient organisations.



Post 2014 strategy and activities are being adapted drawing upon the outcomes of the evaluation in close consultation with the organisations involved and the EPF members who have expressed an interest in joining/benefiting from the programme.

While the evaluation process is still ongoing, our plan for the 2015+ period is to consolidate the programme by means of: a) designing and delivering new training modules at national and European level exploring opportunities to engage more organisations; b) rolling out the programme in new countries providing more resources become available.

More precisely our strategy for the delivery of the programme in 2015 revolves around the consolidation of the programme by means of:

a) designing and delivering new training modules at national and European level exploring opportunities to engage more organisations,
b) rolling out the programme in new countries providing more resources become available.

4.3.1 NATIONAL PILLAR

While the evaluation process is still ongoing, there is already good evidence from mid-term evaluation in Romania and Hungary (2013) which is quite indicative of the need to continue to invest in strengthening the capacity of patient organisations especially in Central and Eastern Europe.

As far as the countries that joined the programme during the pilot phase are concerned, our plan is to continue to provide support in developing the capacity of the organisations by means of thematic training modules on areas of primary concerns as identified during the needs assessment exercise carried out as part of phase 1 (strategic planning).

The strategy and concrete steps in each country as well as in respect of the European programme will be worked out based on evaluation findings in close consultation with the participating organisations.

In Romania where, the evaluation has been completed in late 2014, a consultation workshop was held in December 2014 with all 10 organisations to gather needs and expectations for the next phase of the programme which is set to kick off already in spring this year with a first thematic training on fundraising and financial management.

Meetings with local organisations will take place in March in Bulgaria, Hungary, and Slovakia to gather qualitative insight to inform the evaluation process and gather needs and expectations on the next phase of the programme.

In Hungary, where a new coalition BEMOSZ was set up in 2014 - also thanks to the CBP, the next phase of the programme will be jointly coordinated by EPF and the coalition themselves, who joins the programme as the ninth organisation. The fact that a large number of people who sit on the board of the coalition have been participating in the programme in 2012-2014 on behalf of their own organisations is a distinctive advantage that will ensure optimal cross-fertilisation of learning within and across the coalition.

As far as Cyprus is concerned, priority is to complete the needs assessment process with the Federation by April 2015. It has already been agreed that EPF will continue to support the Federation in developing their 2016 operational plan in close consultation with the full membership.

Regarding involvement of new countries, there is an ongoing dialogue with our Polish member the Federation of Polish Patients who had expressed an interest in joining the programme already in 2013. The ongoing evaluation of the 2012-2014 programme offers a new window of opportunity to roll out the programme in Poland. As the FPP general assembly recently appointed a new leadership a meeting with FPP is scheduled in March this year to assess the feasibility of launching the programme in the country already in 2015. Should that be the case additional resources will have to be identified. It is likely that the same approach followed in Cyprus will apply to Poland as well as to any new country joining the programme in the future. This approach, which is largely backed up by emerging evidence from the evaluation, calls for consolidating capacity within the national coalition in the first place with a view to then putting in place effective mechanisms to ensure knowledge and learning is optimally passed on to the all members.

4.3.2 EUROPEAN PILLAR

Regarding the European pillar, our plan is to offer our European member shorter training modules on a more frequent basis (twice a year). This is based on emerging evidence from evaluation and feedback received from the various organisations involved as well as challenges faced in delivering the first training module on fundraising, where the coaching phase proved quite demanding for patient leaders, given their on-going heavy workloads.

Further to consultation with our European members the focus in 2015 will be on strengthening the capacity of 10 EPF European Full Members in Communication and Advocacy.

Annex I: List of EPF Activities for 2015

Nr./ Activity	2015												Linked deliverable(s)
	M 1	M 2	M 3	M 4	M 5	M 6	M 7	M 8	M 9	M 10	M 11	M 12	
1. EPF working group patient empowerment					x								D1 Consensus definition
2. Information to patients – Review of core quality criteria									x				D2 Report/position
3. Contribution to the EMA transparency policy on clinical trial data			x										D3 Consultation response
4. Clinical trials regulation			x										D4 Position on the implementation of the information/consent provisions
5. EPF Working group access												x	D5 Position statement on defining and measuring access
6. Cross-border healthcare					x								D6 Patients' checklist and recommendations for the functioning of NCPs
7. Cross-border healthcare						x							D7 EPF feedback on implementation of directive
8. Mini workshop on CBHC	x	x	x	x	x								D37 Workshop report
9. EU conference on CBHC						x							D44 Conference report
10. EPF patient/NCP conference on cross-border healthcare						x							D8 Conference report

11. Patient safety – dissemination of information on patient safety & rights, including AMR and HAIs		x		x				x		x			D9 EPF newsletter special articles, blogs
12. Quality of care – pilot test and launch EPF survey							x						D10 Final questionnaire
13. Tackling discrimination										x			D11 Position paper on discrimination in education and workplace
14. mHealth /eHealth						x							D12 Position paper
15. Spring youth group meeting				x									D14 Report on the Spring Youth Group Meeting 2015
16. Annual Youth Group meeting									x				D15 Report on the Annual Youth Group Meeting
17. Capacity development training for the Youth Group				x					x				D17 Toolkit for sustainable Youth Groups
18. Youth Group Internal and external communication		x		x	x		x		x		x	x	D16 Youth Group leaflet D34 blog articles on the Youth Group D31 Website updates on the Youth Group D30 contribution to EPF newsletter
19. Towards a clearer EPF identity, and a more visible added-value		x				x							D19 EPF membership guide D18 EPF membership flowchart D20 Improved Members’ section on the website

20. Making EPF a more vibrant netWork	X	x	x	x	x	x	x	x	x	x	x	x	D21 Feasibility study on the creation of an EPF Social Platform D22 EPF Social Platform D23 Weekly Insiders' Mailing D24 Reports from the "Weekly (virtual) Coffees with EPF"
21. Membership Development & Growth					x								D25 Report on analysis of the situation in "white zones"
22. Towards sustainable patient organisations											x	x	D26 Report of the Regional Advocacy Seminar (RAS)D27 Concept for "lighter training" pilot
23. Communicating to inform	X	x	x	x	x	x		x	x	x	x	x	D31 Website; D30 11 monthly newsletters; D28 1 Annual Reports; D33 9 press releases
24. Communicating to engage	X	x	x	x	x	x			x	x	x	x	D34 blog articles; D29 3 factsheet leaflets; D32 1 video
25. Communicating to persuade	X	x	x	x	x	x			x	x	x	x	D29 factsheets leaflets; D33 9 press releases; D32 1 video; D42 promotional items
26. Bi-weekly team and Thematic meetings	X	x	x	x	x	x	x	x	x	x	x	x	D35 Briefing notes
27. Policy Advisory Group						x					x		D36 Minutes
28. Regional Advocacy Seminar										x			D26 Seminar report
29. Access working group meetings				x					x				D38 Minutes

30. Empowerment working group meetings				x					x				D39 Minutes
31. Annual General Meeting (AGM)				x									D40 Minutes
32. Board meetings and elected officers meetings		x		x					x	x			D41Minutes

Annex II: List of EPF Deliverables for 2015

No.	Deliverable Name	Content specification	Delivery month
1.	Consensus definition patient empowerment	Statement defining patient empowerment and related concepts (e.g. patient involvement, shared decision-making health literacy) developed with the EPF working group on patient empowerment	M5
2.	Position quality criteria for information to patients	Review of core quality criteria for information to patients developed by the high level pharmaceutical forum to ensure they still correspond to patients' needs	M9
3.	Consultation response to EMA transparency policy	Response to consultation on sharing of patient-level data based on previous work in clinical trials, data protection and members' input	M3
4.	Position on information/informed consent provisions of the Clinical Trials Regulation	Position paper on the implementation of the information/consent provisions of the Clinical Trials Regulation	M3
5.	Position statement on defining and measuring access	Statement defining access to health and social care from the patients' perspective, and provide recommendations towards establishing health inequalities and access indicators that better capture the experience of patients, developed with EPF working group on Access	M12
6.	Patients' checklist and recommendations for National Contact Points	Based on input of workshops on cross border healthcare with patient organisations we will prepare a "patients' checklist" and recommendations for the functioning of National Contact Points	M5
7.	EPF position on implementation of Directive 24/2011	Recommendations for the European Commission draft report to the Council on the patients' experience with implementation of the directive on cross-border healthcare	M6
8.	Conference report	Report of conference EPF patient/NCP conference on cross-border healthcare	M6

9.	EPF newsletter special articles, blogs on patient safety	Dissemination of information and advocacy tools on patient safety, including HAIs, AMR, patients' rights, complaints and redress, to raise awareness and support the patient communities capacity to advocate for patient safety in member states	M 2,4,8,10
10.	Final questionnaire on quality of care	Launch of pilot-tested questionnaire for an EPF member study on quality of healthcare from the patient's perspective	M6
11.	Position paper discrimination in education and the workplace	A position paper to raise awareness of how patients are discriminated in various areas of life and provide recommendations for decision makers to improve their situation.	M9
12.	Position paper on eHealth	An evidence-based position paper on eHealth focused on what is needed from the patients' perspective to harness the potential of eHealth including mHealth, especially in the light of the Green Paper on mHealth and the actions the European Commission will take further to the 2014 stakeholder consultation	M12
14.	Report on the Spring Youth Group Meeting 2015	Outcomes of the meeting with updates on topics such as membership, governance, planning of activities till the end of the year	M6
15.	Report on the Annual Youth Group Meeting 2015	Outcomes of the meeting on topics such as membership, governance, strategic planning of activities for the following year	M10
16.	Youth Group leaflet	Short description of the Youth Group	M4
17.	Toolkit for sustainable Youth Groups	Manual with useful tools for YG members on governance, membership, communication	M11
18.	EPF membership Flowchart	The membership flowchart will present the outcomes of the membership structure's review, outlining the different membership categories and the subscription process.	M6
19.	EPF membership guide	The objective of the membership guide is to help members maximise the benefit of their membership in EPF. It will include an overview of the support we offer and inform potential new members about EPF and the	M2

		advantages of joining us.	
20.	Improved members' section on EPF website	Following the upgrade of the website, the members' section will be re-organised in a clearer and friendlier way, integrating the EPF membership flowchart and the EPF membership guide, and offering more visibility for our members.	M11
21.	Feasibility study on the creation of a Social Platform	A survey will be conducted among EPF members and members of the staff to measure their interest in the development of an online forum and list their needs and expectations. These needs will be translated into a list of features and technical requirements that should help us to choose the most adequate tool and provider. The feasibility study should also include a simple budget plan linked to the development of the online forum.	M6
22.	EPF Social Platform	The EPF Social Platform will be an online forum for EPF members to exchange experiences and information. The production of this deliverable is subject to the outcomes of the feasibility study to be conducted in the first semester of 2015.	M9
23.	Weekly Insiders' Mailing	The Weekly Insiders' is a members-only report which highlights the main EPF activities, policy consultations, events and news relevant to the patient community on a weekly basis	M1-M12
24.	Reports from the "Weekly (virtual) Coffees with EPF"	This initiative provides a weekly opportunity for members and the Secretariat to exchange informally about their current activities and priorities, virtually or in person.	M1-12
25.	Report on analysis of the situation in "white zones"	EPF will conduct an analysis of the situation in "white zones" (diseases and geographical areas where EPF is not yet represented).	M5
26.	Report of the Regional Advocacy Seminar (RAS)	In line with EPF's commitment to empowerment, this seminar will look at strengthening patients' organisations' advocacy capacity to become a more	M 11

		empowered actor in national and European health policy arena. The RAS will take place in Scandinavia.	
27.	Concept for “lighter training” pilot	EPF will explore new formats to provide support ant trainings on issues of interest to its members. One of these new format will be run as a pilot.	M12
28.	EPF 2014 Annual Report	The 2014 Annual Report will describe EPF activities and achievements of 2014 and will be distributed at health events and in bilateral meetings with key policy-makers of the European Commission and the European Parliament.	M5
29.	Factsheet leaflets	The factsheet leaflets will provide a concise and simple summary of one theme following the policy agenda to constitute the EPF advocacy directory.	M3-M6-M9
30.	EPF Monthly newsletters	The newsletter reaches a large number of stakeholders to provide them with latest information about our activities within EU policy developments and projects, as well as reports of events that we have attended or organised.	M1 to M12
31.	Website	Our website remains a vital element of our communication’s strategy and will be constantly updated.	M1 to M12
32.	Video	We will release one video to define who we are and what we expect from decision-makers.	M3
33.	Press Releases	We will issue press releases to share our key policy achievements in 2015.	M1 to M12
34.	Blog	Regular posts to add more depth to our work with contextual information and new angles to a specific theme.	M1 to M12
35.	Briefing notes of bi-weekly team and Thematic meetings	Bi-weekly the staff will be held a meeting to coordinate activities. Briefing notes will be produced for each meeting.	M1 to M12
36.	Minutes of the meeting of the Policy Advisory Group (PAG)	The Policy Advisory Group will advise on EPF’s policy input from both a strategic and content perspective, in order to support EPF’s broader membership, Board and the Secretariat in this work. The group will also serve as a platform of information exchange on current work between EPF member organisations. Twice a year the PAG will meet. Minutes of the	M6 and M11

		meetings will be produced and disseminate to the group.	
37.	Report of mini workshop on CBHC	In 2015 we will organise 6 mini workshops on the Cross Border Directive in Europe. Reports will produces for each workshop.	M1, M2, M3, M4, M5
38.	Minutes of the meetings of the working group on Access	The working group will inform EPF's policy development on access, from both a strategic and content perspective, in order to support EPF's broader membership, Board and the Secretariat in this work. The group will also take a lead on specific activities as defined by its members in the work plan. The working group will meet physically twice a year in Brussels. In addition, regular webinars and/or teleconferences will be organised. Minutes of the meetings will be produced	M4 and M9
39.	Minutes of the meetings of the working group on Empowerment.	The working group will inform EPF's policy development on empowerment from both a strategic and content perspective, in order to support The working group will meet physically twice a year in Brussels. In addition, regular webinars and/or teleconferences will be organised. The group will communicate mainly by email. Minutes of the meetings will be produced.	M4 and M9
40.	Minutes of General Annual (AGM) meeting	The AGM is the higher level governance body. The EPF Members meet once a year. The decisions and discussions are reported in the minutes.	M4
41.	Minutes of Board meetings and elected officers meetings	Decisions and discussions reported in the minutes of the meetings.	M1, M4, M9, M11
42.	Promotional items	To raise awareness about EPF.	M3
43.	EPF blog posts and website updates on the Youth Group, contribution to EPF newsletter	Articles, blog posts and information about the Youth Group members and activities	M2-M4-M5-M7-M9-M11-M12 2015

44.	Conference report	EPF will organise a conference to European conference bringing together patient leaders and National Contact Points from EU member states, to address the European Commission draft report to the council and steps forward to support meaningful patient involvement with the NCPs. A report will be produced	M6