

Draft Annual Work Plan 2014

[Publish Date]



Contents

EPF Strategic Plan 2014-2020	3
1.1 Vision and Mission	3
1.2 Strategic Goals	3
2. EPF Annual Work Plan 2014.....	5
2.1 OBJECTIVE 1: Reinforcing the Capacity of the patient community actors to effectively contribute to the Health debate.....	6
2.1.1 EPF Capacity Building Programme in 2014	6
2.1.2 Meeting and supporting Europe’s patients	6
2.1.3 Involving Young Patients.....	7
2.1.4 Reinforcing EPF Membership.....	8
2.1.5 EPF Secretariat and Governance.....	10
2.2 OBJECTIVE 2: Strengthening evidence base, influence and impact of the patient perspective in health-related policy and decision-making	10
2.2.1 Specific Priority Areas	11
2.2.2 Policy involvement in agencies, think-tanks and advisory panels	19
2.2.3 Working with Our Partners	19
3. Communication strategy in 2014.....	21
4. Evaluation Strategy and Performance Indicators	23
4.1 Key Performance Indicators.....	23
Annex I – Main EPF and project events	28
Annex II: Summary of key policy actions in 2014	32
Annex III – Summary of main programmes and projects 2014	34
Annex IV - Concept for a series of 3 Regional one and half-day conferences on the Directive ‘Patients’ Rights in Cross Border Health Care’ during the course of 2014, modelled on EPF’s Regional Advocacy Seminars.....	35

EPF Strategic Plan 2014-2020

The European Patients' Forum (EPF) adopted a seven-year Strategic Plan at its Annual General Meeting (AGM) in May 2013 with the overall objective of defining strategic priorities for enabling EPF to grow and work effectively during the next 7 years.

The EPF Annual Work Plan for 2014 takes forward this strategy and also builds on the outcomes of the Annual Work Plans of the previous years, in particular 2013. It also takes on board the external political environment to reflect the likely European healthcare developments during the course of 2014 and beyond, including the launch of the next EU programming period 2014-2020.

Previous EPF Annual Work Plans can be accessed here:

<http://www.eu-patient.eu/Publications/Other-Material/>

1.1 VISION AND MISSION

Our vision: All patients with chronic and/or lifelong conditions in the EU exercise their rights to access high quality, equitable healthcare that is designed and delivered to meet their needs and preferences.

Our mission: To put patients at the centre of policies and programmes that affect them and to drive changes that empower them to be equal citizens in the EU.

1.2 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 equal access to sustainable healthcare designed and delivered to meet patients' and their informal carers' needs at all levels of care, embracing innovation in all its forms.

GOAL 3: Patient Involvement

To advance meaningful patient involvement in health-related development and implementation of policies, programme and projects in the EU¹.

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 patients' 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

To advance these strategic goals we operate in a number of fields of action that focus on EU level advocacy/awareness work, exchange/dissemination of good practice and building alliances/partnerships. These reflect the crucial role and responsibility of EPF in:

- reinforcing EPF's unique position as the EU umbrella organisation and respected voice of patient organisations/ and groups on cross cutting issues affecting all patients, through excellent communications and campaigning and developing the 'Patients' experience' to substantiate our policy and project work, and that of our membership.
- enhancing dialogue and impact with the EU Institutions
- establishing and sustaining key strategic partnerships and alliances
- broadening and consolidating the membership, encouraging their full involvement in EPF, EU level, transnational and national cooperation, and to foster a spirit of solidarity across the European patients' community

¹ *Meaningful Patient Involvement means that patients take an active role in activities or decisions that will have consequences for the patient community, because of their specific knowledge and relevant experience as patients.*

The Value+ Project, <http://www.eu-patient.eu/Initatives-Policy/Projects/EPF-led-EU-Projects/ValuePlus/>

1. EPF Annual Work Plan 2014

The EPF 2014 **Annual Work Plan** distinguishes between an **Operational Work Programme** consisting of all EPF's 2014 core activities which should be co-funded through the renewal of the 2012 and 2013 Operating Grant under the Public Health Programme, and our portfolio of projects. These are either projects co-funded by the European Commission under different funding Programmes (Public Health, FP7 and Competitiveness and Innovation Programme, Innovative Medicines Initiative) or other projects funded by unrestricted funds from sponsors.

The operational objectives for our 2014 Annual Work Plan are as follows and their scope is **both EU and Member State level**:

OBJECTIVE 1

Reinforcing the capacity of the patient community actors to effectively contribute to the health debate

OBJECTIVE 2

Strengthening the evidence base, recognition and impact of the patient perspective in health-related policy and decision-making

The Operational Work Programme includes all the EPF **advocacy work** that will be carried out in 2014, including the activities of the **Policy Advisory Group, two working groups on specific policy themes, the Annual General Meeting and relevant fringe meetings, three regional Conferences on Cross Border Health Care** and the activities of the EPF Youth Group.

All communications and representation work related to our core activities is also included under the Operational Work Programme.

Alongside the core programme in 2014, EPF will be involved in the following projects:

EUPATI as project coordinator, SUSTAINS, InterQuality, AdoptHTA, SmartCare, WE-CARE, the eHealth Governance Initiative, the Joint Action on Patient Safety and Quality of Care, the Joint Action on Chronic Diseases, the second Joint Action of Health Technology Assessment, and a European Commission Tender on Patient Empowerment.

The SmartCare project is closely linked to the EU Innovation Partnership on Active and Healthy Ageing where we have also been involved in an "Action" on Nutrition, and an "Action" on adherence and concordance of prescription medicines.

In 2014 the EPF **Capacity Building Programme** will be in its third year of implementation and will build on the first phases focused on organisational capacity needs' assessment, strategic planning and training of participating organisations that joined the programme in 2012.

Details on all core activities and projects are provided in the following paragraphs.

1.3 OBJECTIVE 1: REINFORCING THE CAPACITY OF THE PATIENT COMMUNITY ACTORS TO EFFECTIVELY CONTRIBUTE TO THE HEALTH DEBATE

1.3.1 EPF CAPACITY BUILDING PROGRAMME IN 2014

EPF is leading a major Capacity Building Programme with the support of its national members in the various countries participating in the programme. The Capacity Building Programme responds to needs and concerns which have been identified by EPF membership during previous activities. With this programme we aim at strengthening the impact of work undertaken by our members and their members, which should ultimately contribute to stronger more effective patient organisations at both national and European level. See <http://www.eu-patient.eu/Press/News-Archive/EPF-to-empower-its-members-capacity-and-advocacy-skills/>

2014 will be the closing year of the first phase of the programme. The focus will be on the implementation of training modules to build capacity of the participating organisations – 4 European member organisations and national members from Romania, Hungary, Bulgaria and Slovakia - on areas identified in the previous stages of the programme (2012 and 2013).

EPF will evaluate the key learning from the implementation of the programme and use this to improve the approach and the training delivery beyond 2014. The latter part of the year will be devoted to planning future relevant activities with the goal of involving more countries and make of this programme an on-going EPF core activity.

1.3.2 MEETING AND SUPPORTING EUROPE'S PATIENTS

The following major EPF meetings and events will take place in 2014:

- The Annual General Meeting (AGM) will be held in spring 2014 in Brussels. The AGM is EPF's main governance body where each member is represented by one or two delegate(s). As from 2011 the second delegate is a young patient (15-25 years old) if the organisation concerned has nominated a representative in the EPF Youth group. The AGM makes all decisions required to implement the objectives of EPF, which includes inter alia, the establishment of a budget, approval of the audited accounts and of the yearly report of the Board, appointment and discharge of the members of the organisation, the Board and an external and independent auditor, amendment of the constitution and internal rules. Alongside the AGM there will be a number of fringe meetings focusing on specific policy themes of specific interest to members.
- Considerable planning will take place for the 7th Regional Advocacy Seminar that will take place in one of the Nordic countries in 2015, in order to enhance our collaboration with the patients' community. This will include field visits by our membership officer and a high level preparatory meeting chaired by our President, who is from Sweden.
- Three Regional Conferences will take place during 2014 that will focus on cross-border healthcare. The objectives of these conferences, that will be targeted towards patient leaders in

different regions of Europe, will be to raise awareness and knowledge about the CBHC Directive and patients' rights enshrined within this legislation, to ensure understanding about the scope of the Directive and its application at national level and to agree an approach to evaluate the impact of the legislation from a patients' perspective. See Annex IV for more information.

- EPF will be a partner in the 2014 Careum Congress/2nd ENOPE Conference, "The power of patients 3.0. Patients are changing the face of health care" in March 2014.
- EPF will also be involved in the Hospital Pharmacists Summit in May 2014, to which we have been invited to send a delegation of patients to look at the role and responsibilities of hospital pharmacists.
- 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.
- EPF will play an active role in the 2014 Conference in Greece focussing on health inequalities. This is part of an on-going initiative started in 2011 to address the particular and urgent needs of patients from these countries.

1.3.3 INVOLVING YOUNG PATIENTS

In 2011 EPF launched its Youth Strategy. Adopted by the 2011 Annual General Meeting, this strategy was developed in order to enable EPF to recognise, understand, meet and effectively represent the needs and expectations of young patients through their meaningful involvement and empowerment (see box below).

In 2012-2013 much effort was put into involving the Youth Group into the EPF strategic planning process and implementing the EMPATHY project 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 focus will be on revisiting the youth strategy to align it to the new EPF Strategic Plan 2014-2020, and identifying and implementing approaches for the involvement of youth group members in EPF governing (Board), consultation (thematic policy working groups), and advisory bodies (Policy Advisory Group).

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 2014 AGM.
- The Fourth Annual Meeting of the EPF Youth Group will take place in summer 2014 in Lithuania (to be confirmed).

A new project application under the Youth in Action Programme has been submitted in late 2013 to follow up on the outcomes of the EMPATHY project and support the implementation of the EPF Youth Strategy in the medium term. If successful the new youth project is likely to start in mid-2014.

The EPF Youth Strategy and the Youth Group

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

In order to achieve this objective, EPF has identified four main strategic goals which will guide the implementation of the Youth Strategy:

- GOAL 1 Strengthening the involvement and representation of young patients in patient organisations
- GOAL 2 Promoting young patients' rights and recognition of their needs and expectations within and beyond health policy area
- GOAL 3 Promoting a better cooperation between young patient and adult patient advocates
- GOAL 4 Strengthening young patient representatives' skills

In order to be able to achieve these strategic goals EPF has established a Youth Group made up of 15 young patients between 15 and 25 years of age nominated by EPF members. The Youth Group met for the first time in April in Brussels at the 2011 EPF Annual General Meeting and held its first official kick-off meeting (First EPF Youth Meeting) in August 2011. The Youth Group meets physically 2-3 times per year, including at the AGM.

The EPF Youth Strategy is available at the following link:

<http://www.eu-patient.eu/Initatives-Policy/Initiatives/Youth-Strategy/>

1.3.4 REINFORCING EPF MEMBERSHIP

The list of EPF Full Members can be accessed here:

<http://www.eu-patient.eu/Members/The-EPF-Members/Full-Membership/>

EPF will enhance its efforts with regard to supporting the work of national patients' platforms, particularly in the newer Member States, or where a formal coalition of patient organisations does not yet exist. To achieve all this, a dedicated membership officer was recruited in early 2013, while a board member will continue to be designated a specific 'country' to follow, in accordance with interest, geographic proximity and/or language competence.

Considerable planning will take place for the 7th Regional Advocacy Seminar that will take place in one of the Nordic countries in 2015, in order to enhance our collaboration with the patients' community from that region. This will include field visits by our membership officer and a high level preparatory meeting chaired by our President, who is from Sweden.

The EPF Membership Guide published at the beginning of 2010 will help current and new members to contribute and benefit to the maximum extent from their membership to EPF. We will also encourage the EPF membership to undertake activities and engage in events linked to the 2014 European Patients' Rights Day.

In 2011 EPF started developing a series of toolkits for its members on how to get actively involved in some key policy areas such as Pharmacovigilance, Cross-border Healthcare and Structural Funds and cohesion policy. These toolkits will continue to be used to support national patient organisations in getting involved in the transposition and/or implementation process of the above mentioned policies. In 2014 EPF will prepare a new toolkit on Medical Devices, as well as update and revise our other resources as needed.

Given that 2014 marks the start of the new EU Programming Period, EPF will also be providing guidance to our members on an on-going basis with regarding to opportunities to be involved in EU funded projects through the European Public Health Programme, HORIZON 2020 and national opportunities through the new EU Structural Funds where there is particular emphasis on health.

EPF will strengthen alliances with its members, notably by attending respective Annual General Meetings to highlight the mutual benefit and added value of being part of the organisation, and to explore how to refine cooperation.

Strengthening members' involvement in EPF's policy work

The **EPF Policy Advisory Group** will meet physically twice in 2014. 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.

The EPF Policy Advisory Group

The Policy Advisory Group, or PAG, was created by the Annual General Meeting of EPF in 2009 in response to the growing “demand” on EPF in recent years – both in terms of our growing membership and in terms of the increasing complexity of health policy at EU level. The purpose of the PAG is to support the policy work of the EPF Secretariat and Board of Directors.

The group currently comprises 14 representatives from our various member organisations. Participation is open to all EPF's members. The group holds two meetings a year in Brussels. In-between, it holds teleconferences as needed, or otherwise communicates by email.

The PAG provides input from the perspective of our member organisations, and exchange of ideas around existing and emerging policy issues – both in terms of strategy and in terms of content (EPF's positions on various policies). It also complements the broader EPF membership consultation procedure on specific policies that we get involved in.

In 2014 EPF will introduce 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 will be set up 2014 as a pilot and their effectiveness will be evaluated during that year with a view to expanding this approach.

1.3.5 EPF SECRETARIAT AND GOVERNANCE

In 2014 EPF's secretariat will be composed of an Executive Director, a Finance and Operations Manager, an Office and Events Manager, a Senior Policy Adviser, a Policy Officer, a Programme Manager, one Senior Programme Officer, a Communication Officer, two Project Officers, a Membership Officer, a part-time Webmaster, a part-time Administrative Assistant.

Specifically for the EUPATI project EPF has established a small team based in Munich, composed of the EUPATI Director, Communications manager and assistant.

A management team composed of the Executive Director, the Programme Manager, the Senior Policy Advisor and the Finance and Operations manager will continue to function in 2014.

An external auditor will audit the accounts for 2014 and these will be presented for adoption to the Annual General Meeting (AGM) in spring 2015, and published on the web site together with the Annual Report 2014 within one month of this meeting in line with EPF policy on transparency.

The **EPF Board**, composed of 9 representatives elected by the EPF membership, will meet in Brussels four times and will hold teleconferences as necessary in between these meetings. The elected officers – President, Vice President and Treasurer will also meet on a regular basis. The **Annual General Meeting (AGM)** will include an election of four board members.

In-between meetings on-going communications with our membership is ensured through regular emails updates, the EPF newsletter and the website. A membership guide updated annually facilitates communications between the secretariat and the members.

1.4 OBJECTIVE 2: STRENGTHENING EVIDENCE BASE, INFLUENCE AND IMPACT OF THE PATIENT PERSPECTIVE IN HEALTH-RELATED POLICY AND DECISION-MAKING

Policy priority areas

EPF's key policy priorities are linked to our strategic goals as well as developments in the EU healthcare environment. Specific policy areas are prioritised by our membership and reflect key areas of action at EU level. **Note: the policy priorities outlined in this draft work plan are subject to approval by the membership .**

Our policy priorities in 2014 will aim to ensure that a strong patients' perspective is integrated into all relevant health-related policies at EU level. The overall theme of our policy work plan is "Patients as part of the solution to Europe's sustainable health systems." Our specific policy work is clustered in a number of broad areas that complement our strategic vision and mission:

- Patient involvement and the EU response to chronic diseases
- Patient-centred innovation
- Promoting high quality and safe healthcare
- Addressing health inequalities from the patients' perspective
- Anti-discrimination and inclusiveness

- Supporting the implementation of key EU health-related legislation.

EPF thematic campaign 2014

EPF will continue to put efforts in 2014 to advance policy outreach through our communication campaign and Manifesto entitled “*Patients + Participation = Our Vote For A Healthier Europe*” launched on 1 October 2013.

The European Parliament Elections and new Commission 2014 will offer a fresh opportunity for the European Patients’ Movement to mobilise politicians and policy makers to commit to a healthier Europe.

This time with this campaign we want to create a sense of urgency and real imperative to address the fundamental roadblocks to patients’ access to proper healthcare and to demonstrate how patients can be part of the solution to make health systems more effective and quality-oriented. In other words, a healthier Europe, as outlined in our Manifesto “*Patients + Participation = Our Vote For A Healthier Europe*”.

1.4.1 SPECIFIC PRIORITY AREAS

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. Having contributed actively to the Commission’s reflection process on chronic diseases during 2012, EPF has selected patient empowerment as a major thematic work area. This will be the focus of **one of our pilot thematic working groups**.

During 2014-2015 we will develop **policy recommendations** for patients’ involvement and patient-centred chronic disease management, which will be embedded in all aspects of our work including patient-focused use of innovative technologies and services. Further, we aim to develop a common understanding of patients’ rights using as reference points the “patient journey”, and agree a common approach to “patients’ responsibilities”. We will look into what characteristics 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 develop relevant materials for patient organisations to support empowerment.

Our policy work will be complemented by our role as an associate partner in the new **EU Joint Action on chronic diseases, CHRODIS**.

In December 2010 the Council initiated an EU Chronic Disease Reflection process in order to identify options for an optimal EU response to the challenge of demographic ageing and increase in chronic diseases which would involve the Commission, EU Member States and key stakeholders. Patient-centred chronic disease management with focus on patient empowerment was identified as one of the key themes of the reflection process. Based on discussions with Member States, a Joint Action

under the 2013 health programme was identified as the next step forward. The objectives of the Joint Action will be to map new innovative actions in chronic disease prevention and risk factors across Europe; examine the barriers for uptake of prevention, screening and treatment using diabetes as an example; and to look in more detail at how to address multi-morbidity and other complex issues in the framework of chronic diseases.

EPF will play an important role in bringing a strong patient perspective into this Joint Action. We are an associate partner and will be active in WP6 on multi-morbidities; WP7 on diabetes, through our member organization IDF Europe; WP4 on knowledge building, WP2 on dissemination, and in the sustainability dimension of the project.

We will also have a prominent role in a consortium delivering the **EC tender on patient empowerment**.

EPF will be participating in the Advisory Board of a new project started in 2013: WE-CARE Towards a Sustainable and Affordable Healthcare. The main purpose of the project is to develop a strategic plan and an R&D roadmap for cost containment in the healthcare research area gaining the commitment of EU-key players.

Patient-centred innovation

In order to achieve the Europe 2020 objectives of smart and inclusive growth, patient-centred innovation will continue to be a priority for EPF in 2014. EPF will address the health literacy, including **digital literacy and lay-friendly information**

On scientific concepts such as genomics, needed by patients for informed decision-making; and we will continue our work on **personalised medicine**, building on an updated briefing paper developed in 2013.

EPF will also build on our contribution to the European Commission's Access to Medicines in Europe platform, specifically the Working Group on Prioritisation and Innovation during 2012-2013, which updated the WHO report "Priority Medicines for Europe and the World". Based on this work, EPF will develop our position regarding **patients' involvement in identifying and setting research priorities**.

In 2014 EPF will continue to be actively engaged with the new **EU Regulation on clinical trials**, including its implementation and monitoring, based on several years of work in this area. Our work will focus on realising and promoting best practice regarding patient involvement in clinical trials assessment, ethics review, informed consent and information to patients, as well as transparency around clinical trials results. In this connection EPF will also continue to engage in the debate around **EU data protection legislation**, in dialogue with other health stakeholders and academia.

EPF will continue to participate in the **European Innovation Partnership on Healthy and Active 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.



In synergy with the areas described above, EPF will continue leading the **"European Patients' Academy on Therapeutic Innovation" (EUPATI)**, which will provide scientifically reliable, objective, comprehensive information to patients on pharmaceutical R&D. It will increase the capacity of well-informed patients to be effective advocates and advisors, e.g. in clinical trials, with regulatory authorities and in ethics committees. A consortium of 31 organisations comprises a unique combination of pan-European patient organisations, academic and not-for profit organisations expert in patient and public engagement and EFPIA member companies. It features excellence in state-of-the art, high quality and objective education to patients about therapeutic innovation.

EUPATI will make a substantial and measurable difference to patients, providing the tools and the knowledge for their meaningful involvement and empowerment in pharmaceutical innovation, safety of medicines and access to treatments. It will inform the lay and hard to reach patient community, raising public awareness of the development of new treatments.

The five year project plan constitutes three key phases. Initial educational material will become available after the first 18 months of the project during 2014.

Project Phases

The Preparation Phase (18 months) will focus on collection of information about patient needs and available information material as well as the establishment and implementation of the governance structure, the Patients' Academy Network and the IT Platform.

The Confirmation Phase (30 months) will focus on training/education/information content development and the establishment of National EUPATI Platforms.

The Sustain Phase (12 months) will focus on deployment, dissemination and future strategies (WP6, WP7), even though all WPs will be active during the whole course of the project.

For more information on the work plan and deliverables for 2014 please go to <http://www.patientsacademy.eu/index.php/en/about-eupati/7-timeplan-and-wp>

EPF will also continue engaging in the areas of eHealth and Health Technology Assessment (HTA) through participation in a number of European projects.



The **eHealth Governance Initiative (eHGI)** is a political initiative launched in 2011 supported by two different EU financing

instruments: a Joint Action through the Public Health Programme and a Thematic Network through the CIP-ICT programme.

The eHGI aims to establish an efficient, appropriately governed and sustainable platform to enable all stakeholders to work in this political initiative. It will provide to the Member States, the European Commission, health authorities, competence centres, user groups, industry and other relevant stakeholders a European interoperability framework to facilitate involvement and usage of the work in the defined policy areas. It supports the setup of a European environment for the benefit of European patients (e.g. support and guidance for implementation, deployment and use of eHealth services throughout national health care systems, increasing patient safety and quality, better use of health care resources).

EPF is co-leader of the Work Package dedicated to Trust and Acceptability whose general objective is to provide stakeholders' representatives with the means and the opportunities to discuss and identify possible ways to enhance eHealth users' trust and acceptability and make proposals to EU Member States, representatives as well as to the European Commission, as appropriate, on how the needs of users should be best taken into account in the development of European and national eHealth strategies.

The eHGI will continue contributing significantly to the work of the EU eHealth Network.

1.4.1.1 SUSTAINS



countries.

Co-funded under the Competitiveness and Innovation Programme of the European Commission, SUSTAINS - *Support USers To Access Information and Services* – is a three-year project aiming to develop and deploy a wide range of eHealth services linked to patients' access to Electronic Health Records (EHR) in 11 regions in 9 European

SUSTAINS is one of the flagship initiatives implementing Key Action 13 of the Digital Agenda for Europe “Undertake pilot actions to equip Europeans secure online access to their medical health data by 2015”.

In doing so SUSTAINS will make a decisive contribution toward realising the full potential of participatory medical record-keeping where pure online access to the EHR is complemented with a rich basket of e-services making it possible for patients and citizens to interact with their records. These services are therefore expected to contribute to the achievement of a new paradigm in healthcare in which the citizen/patient is no longer a passive subject, but an active player in the management of his/her own health.

Since early 2012 this project has been gathering evidence-based information on benefits of patients' accessible EHR in terms of impact on healthcare systems' organisation and costs, quality of care, as well as in relation to the empowerment of patients and citizens at large.

2014 will be dedicated to assessing benefits of patient-accessible EHR-related services formulating recommendations to all other European regions on how to move forward in the development and deployment of secure online access to their medical health data.

EPF plays a key role in this project, especially in the work relating, to patient requirements' identification and the assessment of patient empowerment as a result of using the SUSTAINS services.

For more information on SUSTAINS please see:

<http://www.sustainsproject.eu>

1.4.1.2 SMARTCARE



Started in March 2013 SmartCare project's overall objective is to promote a more integrated and effective approach to providing health and social care to older people across Europe thanks to opportunities presented by state-of-the-art ICT solutions. This will effectively prevent or at least slow the otherwise inexorable progress towards the edges of health, wellness, safety and independent living.

To that end the SmartCare consortium has started piloting SmartCare services in ten European regions. These consist of ICT based support to integrating healthcare, social care and self-care for different health/living conditions, along integrated care pathways including the underlying organisational models.

As a member of the project User Advisory Board EPF will continue, throughout 2014, to ensure the project takes into consideration the interests of older patients. Drawing especially on the conclusions of our flagship Conference on the Rights and Needs of Older Patients held in Warsaw in July 2012), as well as on knowledge acquired through the Innovation Partnership on Active and Healthy Ageing and other eHealth projects such as Chain of Trust, Renewing Health, and SUSTAINS, EPF will ensure that needs and expectations of older patients are properly recognised and integrated into SmartCare service design, implementation, and assessment.

For more information on SmartCare please see: <http://www.eu-patient.eu/Initatives-Policy/Projects/Non-EPF-led-EU-projects-Associated-Partners/SmartCare/>

The **EUnetHTA Joint Action** is a response to the request by the EU Commission and EU Member States in the Work Plan 2009 of the Health Programme to continue fostering the development of HTA in Europe. The EUnetHTA JA 2 builds on the methods and tools developed by the EUnetHTA JA 1. In 2014 EPF will continue participating as member of the EUnetHTA Stakeholder Forum which is formed to ensure the transparent engagement with stakeholders and is comprised of representatives of the identified stakeholder groups with broad and balanced representation including European umbrella interest organisations, namely patient and healthcare consumer organisations, healthcare providers (professionals and hospitals), payers, industry and health related

media. We will focus particularly on the work around stakeholders' training and recommendations for a permanent European HTA Secretariat.

For further information, please consult: <http://www.eunethta.eu/>

The project **AdHopHTA - Adopting Hospital Based Health Technology Assessment (HTA) in EU** – intend to address the poor use and awareness of several hospital based HTA initiatives lately emerged in Europeit.

The project aims at strengthening the use and impact of excellent quality HTA results in hospital settings, making available pragmatic knowledge and tools to boost adoption of hospital based HTA initiatives. EPF is member of the Advisory Board.

As a secondary aim, the project will create an adequate network of the existing and upcoming hospital based HTA initiatives as well as liaison with national and regional HTA agencies.

Health literacy and information to patients

Health literacy has been a key priority for EPF since its establishment in 2003, and now forms part of our core strategic objectives. EPF will continue to **advocate for health literacy as a critical strategy** for the realisation of patient empowerment and patient-centred healthcare, a key pillar for the reduction of health inequalities across Europe, and a key contributing factor in the sustainability of future health systems. We will undertake an EPF **member survey** on patients' health literacy and information needs connected to emerging innovative technologies such as genomics and targeted therapies, preventive medicine, ICT etc.

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 and training resources for patients. We will also get involved in specific actions within the new health programme, "Health for Growth", where relevant, focusing on health literacy from the patients perspective.

Health inequalities from the patients' perspective

The reduction of health inequalities is a major element of the Europe 2020 vision. In the current economic environment, it is essential to safeguard the fundamental European values of universality, equity and access to high-quality healthcare for all patients, regardless of their background or means to pay.

EPF's work in 2014 will build notably on the outcomes of the 2 conferences held in 2012 and 2013, which explored health inequalities from the specific perspective of patients with chronic conditions, and a **survey undertaken in 2013-2014** with EPF's membership on the impact of financial austerity measures on patient access. We will also take note of the Commission's progress report on the Communication "Solidarity in Health". We will set up a second **thematic working group with our members dedicated to the theme of access and equity**. Our work will also include follow-up to the revision of the **EU Transparency Directive**, and the **European Commission's Platform on Access to Medicines in Europe**, which concluded in early 2013.

Non-discrimination and inclusiveness

In 2013 EPF members selected non-discrimination as a critical issue for patients and a core strategic goal for EPF. In 2014 we will continue our on-going work on discrimination in health, and EPF will develop a **position paper** on this topic, in the context of the EU legislation on equal treatment and its implications for patients with chronic diseases. We will build on our collaboration with the EU Fundamental Rights Agency (FRA) and the European Social Platform to **explore vulnerable or marginalised patient groups' access** to healthcare and the possibility of developing a strategy for EPF and its member patient organisations on how to reach out to excluded, under-represented and marginalised groups during 2014-2015.

We will continue to follow up our position paper finalised in 2013 on the **needs and rights of older patients** with chronic diseases, and our work will be placed broadly in the context of the European Innovation Partnership on Healthy and Active Ageing.

Promoting safe and high-quality 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 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 2014, EPF will continue to actively represent a patients' perspective in this working group, focusing particularly on reporting and learning systems and patients' role in them, and embedding patient safety and healthcare professionals' education, and using patient experiences as a learning tool.

EPF will continue to **support the implementation of the Council Recommendation** on patient safety and healthcare associated infections, following the Commission's first progress report published in 2012 which identified a specific gap in the area of patient and citizen empowerment. Our work will continue to build on the EPF membership survey conducted in 2012-2013 on the patient communities' awareness of the Council Recommendation and their involvement at national level. This policy work is complemented by our role as associate partner in the **Joint Action on Patient Safety and Quality of Care (PaSQ)**, and our continuing collaboration with WHO EURO following the publication of the report on patient involvement in patient safety in 2013.

EPF will initiate a **member study** on what quality of healthcare looks like from the patient's perspective, including exploring concepts such as "choice" and patient-centredness, with the aim of developing policy recommendations on key elements of quality in health care.

Having contributed to the debates on **medical devices** since 2009 with the exploratory process on medical devices, EPF continues to engage actively in 2014 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 continue the regular twice-yearly dialogue with our members and the medical devices industry, in line with our code of conduct and ethics, to exchange views and information and work towards the adoption of a Code of Conduct.

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 our participation in the “**International Research Project on Financing Quality in Healthcare**” – **InterQuality**, funded by the 7th EU Framework Programme (FP7) where we lead the implementation of the dissemination strategy, which will culminate with a final conference in Brussels.

By that time the project will have achieved its objectives of:

1. Investigating ways of funding and incentive systems affecting the quality, effectiveness and equity of access to health care in four areas, i.e. Pharmaceutical Care, Hospital care, Ambulatory care, integrated health care;
2. Developing practical integrated models of health care financing;
3. Determining the feasibility and effectiveness of the developed models for the determinants of the health systems in the countries of the project partners.

For more information on this project: <http://interqualityproject.eu/>

Finally EPF will continue to be closely involved with the **European Medicines Agency** at many levels, including as member of the Patients and Consumers' Working Party (PCWP), having a patient representative on the Pharmacovigilance Risk Assessment Working Party (PRAC), and participating in ad hoc working groups on specific topics as relevant.

Implementation of key EU health legislation – supporting patient organisations' capacity to engage at national level

EPF will continue to monitor and support the implementation of the **Cross-Border Healthcare Directive**, including the organisation of 3 regional conferences to support patient communities' awareness.(see annex IV) . We will also continue to work closely with the Commission and the European Medicines Agency, as well as relevant stakeholders, to ensure a patient-centred implementation of the **pharmacovigilance rules**, particularly patient reporting. The EPF toolkits published in 2012 will be updated as relevant and continue to serve as an advocacy tools.

Similarly, EPF will continue to support the implementation of the **Directive on falsified medicines**, in the wider context of medicines safety, and the implementation of the future regulations on medical devices and clinical trials, through the production of toolkits and advocacy resources targeted at patient organisations.

Patient Involvement in EU Programmes

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+ project² 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 Funds etc).

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

EPF will continue to participate actively in a number of other health-related think tanks and advisory panels at EU level, including:

- The European Health Policy Forum
- European Innovation Partnership on Active and Health Ageing
- the European Federation of Pharmaceutical Industry Associations (EFPIA) Patients' Think Tank to continue the on-going two-way dialogue between patient representatives and the pharmaceutical industry, promote increasing understanding within the industry of patients' perspectives and needs, and within patients' organisations of the industry's perspective and debate the respective positions of patients and EFPIA, on EU policy, EU strategies and EU goals. EPF is also a member of the steering group.
- EPF / EUCOMED Dialogue on medical devices and chair of its steering group
- Innovative Medicine Initiative Stakeholder Group
- eHealth Stakeholder Group
- EC Working Group on Patient Safety and Quality of Care
- EU Health Portal Editorial Group
- EuropaBio Patients-Bio Industry Exchange Forum This platform aims to promote exchange of views and expertise between patient organisations and biotech industry on issues of common concern related to healthcare biotechnology, including non-product specific information around scientific, regulatory and policy questions.
- Centre for Health, Ethics and Society (CHES)
- European Medicines Agency Patients and Consumers' Working Party (EMA PCWP)
- Gastein Steering Group.

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

1.4.3 WORKING WITH OUR PARTNERS

Partnership is EPF's leitmotif and in 2014 we will continue our approach of dialogue, cooperation, collaboration with other stakeholders working in our field.

Cooperation with other patient groups

In 2014 we will continue to work as closely as possible with major EU and international patient groups such as the European Heart Network, and our global sister organisation, the International

² See project website : <http://www.eu-patient.eu/Initatives-Policy/Projects/EPF-led-EU-Projects/ValuePlus/>

Alliance of Patient Organizations (IAPO), with which we have a Memorandum of Understanding clarifying our geographic and political remit and supporting our joint work.

Cooperation with other health stakeholders

Having initiated the collaboration in 2013, we will continue in 2014 as members of the European Network on Patient Empowerment (ENOPE).

In 2014 we will continue cooperating very closely with all major EU organisations representing health professionals, particularly the Standing Committee of European Doctors (CPME) around various issues relating to 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.

In 2014 we will strengthen further 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 Public Health Alliance (EPHA), the European Forum for Good Clinical Practice (EFGCP), and the EU Health Telematics Association. We will continue working with them closely in various committees, structures and projects.

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 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.

2. Communication strategy in 2014

2014 will mark a turning point for EPF communications as we enter a new era with the new strategic plan. The new vision and mission statements will forge the new communication messages and the new goals will help to build the communication objectives, to target audiences, to choose vehicles for dissemination and to define the tone come across these new messages.

Communication objectives

The priority goals of the Communication Officer for 2014, and to a large extent for the 2014-2020 periods, are:

- Objective 1- Providing best quality information: we want to offer an equal access to information to our audience. It is important to disseminate qualitative as well as clear, transparent and structured information regarding our shared achievements with our members and allies, our involvement in policy, our project involvement to build evidence, our representation work and our membership base. The tone we will use will be more assertive to follow the strategic plan ambitions, but with the humanity and responsiveness required for communications with our audiences.
- Objective 2 - Change attitude for a united patients' movement: we would like our members and the patient community at large to bring a united and influential patient voice to healthcare debates. Our key asset to help us achieving this goal is our members; they are our priority target to help us scale the movement up elsewhere. This can only be achieved through increasing even more our visibility and forging cooperation with allies to create a united patients' movement throughout Europe. Besides to reach the objective of knowledge, we will need to link our efforts with the patient's perspective which is only possible thanks to this networks of European patients.
- Objective 3 - Change behaviour to encourage patient-centred health-related policies: we want to encourage new and re-elected EU decision-makers to support our Manifesto and show their commitment to our work towards a healthier Europe for all citizens..

Communication vehicles

Our **website** will continue to be our major external window. The content and the general layout have been improved and updated over the recent years to enable our audience to access the best quality information on this support. In 2014 writing, designing, publishing and sharing will help content keep its crown, while responsive design will enhance the delivery of information on different mobile supports.

Video will continue to be much more integrated to the communication work. This vehicle is ideal for our communications as it combines social communications bringing a human face on EPF and the patients' community with message transmission as it captures attention and facilitates retention of information.

Social media use will turn into a campaign mode as it will serve as the platform to enable the change of attitude (objective 2) and the change of behaviour (objective3). The aim is to increase little-by-little the involvement of our online community to encourage them to develop, share, and spread the patients' voice digitally. This will be done partly through our Campaign for the 2014 EU elections. As many health stakeholders and decision-makers are also present on social networks, it will help to increase our visibility and make EPF viewed as a key interlocutor on online cross-cutting issues concerning patients in the EU healthcare system and policies.

Our **newsletter** will continue to provide the latest policy, projects and events developments on a monthly basis. We will embed proactivity and assertiveness in the way of delivering news, always with a focus on quality, dynamism and transparency.

We need to reinforce our key **press contacts** to allow for balanced media coverage to share our achievements and increase our visibility. EPF needs focus its content regarding newsworthiness to offer value to journalists to encourage them to write stories but also the "grand public" to become more familiar with what EPF does and is about.

Our **annual report** and **leaflet** will also contribute to disseminating our best achievements in an effective way. We will put our efforts on delivering qualitative as well as clear, transparent and structured information regarding our shared achievements with our members and allies, our involvement in policy, our project involvement to build evidence, our representation work and our membership base.

The co-funding of EC will be highlighted in 2014 in materials produced in the same way it has in 2012 and 2013.

3. Evaluation Strategy and Performance Indicators

Evaluation approach

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

In 2012 the evaluation of our Annual Work Plan was further strengthened in an attempt to improve the way we measure the impact of our activities and inform the preparation of future ones.

Evaluation of our Work Plan is undertaken internally by the secretariat under the supervision of the Director and involves the EPF board on an on-going basis and the entire EPF membership at the Annual General Meeting where the Annual Report for the previous year and the Annual Work Plan is discussed, evaluated and approved. As from 2013, internal evaluation is complemented by an external evaluator looking more specifically into some key processes and milestones within our work programme.

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 Annual Work Plan in question, but also in order to plan, anticipate and be as proactive and effective as possible as a fast-growing lead organisation in the EU health policy environment.

3.1 KEY PERFORMANCE INDICATORS

The following performance indicators will be used to measure achievements in relation to our three objectives. A comprehensive evaluation plan will be prepared in early 2014 and an evaluation report will be prepared in early 2014 to be approved at the 2014 Annual General Meeting.

1. Annual General Meeting

Process: Annual General Meeting implemented in spring 2014.

Outputs: At least 75% of EPF Members participate to the 2014 Annual General Meeting; 2013 Annual Report and Accounts approved. 2014 annual Work Plan and Budget approved. Evaluation Plan and Methodology approved; Minutes of the AGM produced.

Outcomes of EPF activities implemented in 2013 are received positively by the AGM and perceived as relevant and beneficial to the patient community. 2014 Annual Work Plan's objectives, priorities and activities are perceived as relevant to EU patients by EPF members.

2. Regional Conferences on Cross-Border Healthcare

Process: Three regional conferences on cross-border healthcare implemented

Output: 3 conference reports produced; 1 toolbox for patient organisations produced. Globally 150 participants (50 in each of the three conferences from all targeted countries representing at least 15 disease areas) attend the conferences.

Outcome: EPF is able to raise awareness and knowledge about the CBHC Directive and patients' rights enshrined within this legislation, to ensure understanding about the scope of the Directive and its application at national level and to agree an approach to evaluate the impact of the legislation from a patients' perspective, on a longitudinal basis, and create an informal network of patient leaders interested and committed in CBHC to monitor developments over the coming years.

3. EPF Capacity Building Programme

The EPF Capacity Building Programme has a specific evaluation strategy and plan in place.

4. Strengthening cooperation

Process: Identification of support/cooperation opportunities

Outputs: presence at 5 meetings of EPF members/meetings with patient groups.

Outcome: EPF is able to strengthen alliance with members and refine cooperation.

5. Involving Youth

Process: Youth Strategy implemented in 2014.

Outputs: Spring Meeting of the Youth Group implemented; IV Annual Youth Meeting Implemented in summer 2014. Reports produced.

Outcome: EPF is able to integrate youth representatives in its activities and advisory/consultation bodies, 1 youth representative is involved in the PAG, and in the two policy working groups. EPF is successful at launching a second youth project to follow up on EMPATHY.

6. Policy Advisory Group

Process: Policy Advisory Group Consulted

Outputs: PAG meets twice in 2014; 2 PAG reports produced; positive feedback from PAG members on PAG's involvement in EPF policy advocacy work.

Outcome: outcomes of PAG meetings used to inform EPF advocacy work on selected policy areas as shown by integration of PAG input into EPF's policy advocacy strategies, position papers, and responses to policy consultations.

Objective 2

7. EPF Thematic Campaign

Process: Communication campaign implemented.

Output: 100 candidate MEPs targeted from all Member States, 50 European Stakeholder organisations targeted.

Outcome: EPF is successful in raising awareness about who EPF is and encourage decision-makers to meaningfully include the patients' perspective in healthcare decision-making processes. Expression of commitment to health issues and patients' rights from 50 MEPs

8. Policy impact

This is an overview of policy-related process, output, and outcome indicators. Specific indicators for each policy area will be developed in the Evaluation Plan.

Process: Policy advocacy work implemented in the following areas: Patient involvement and the EU response to chronic disease; Patient-centred innovation; Promoting high quality and safe healthcare; Addressing health inequalities from the patients' perspective; Anti-discrimination and inclusiveness; Supporting the implementation of key EU health-related legislation.

Output: Policy recommendations on patients' involvement/patient-centred chronic disease management; Position paper on patient-centred healthcare; Briefing paper on complementary therapies; Contribution to EIP action on adherence; Position paper on patient adherence/concordance; eHealth position paper; Position paper on stigma and discrimination; Recommendations for EU health literacy strategy.

Outcome: EPF is successful in influencing EU-level policy making processes as shown by integration of EPF advocacy priorities

With specific reference to the assessment of EPF policy advocacy work, it is important to remark that outcome evaluation of policy advocacy requires a longitudinal approach to understand the extent to which advocacy efforts have contributed to the achievement of policy priorities set out at the beginning of the process.

Although a thorough assessment of the effectiveness of advocacy efforts can only be made once the legislative process at stake has been completed, EPF regularly conducts interim evaluation of the various legislative processes we have engaged in with a view to assessing whether our advocacy priorities have been taken on board at different stages of such processes and if so to what extent.

In 2013 EPF has subcontracted the outcome evaluation of two key policy dossiers, namely the Cross-border Healthcare Directive and Clinical Trials Regulation to a team of external evaluators. The rationale there is to have advocacy efforts made in relation to these policies thoroughly assessed "from the outside" in such a way as to be able to conclusively assess how successful we have been,

but also, and perhaps more importantly, to draw lessons that will help inform future advocacy strategies.

In 2014 our plan is to select two more policy dossiers which will undergo thorough external evaluation. Similarly, in respect to other policy dossiers intermediate assessment will continue to be conducted internally by the EPF Secretariat with a view to understanding how effective our advocacy strategies have been as well as how successful we have been at involving our wide membership in such processes.

9. Feeding evidence of projects into policy

Process: Evidence gathered from projects completed between 2013 and mid-2014 is used to inform policy advocacy work.

Output: eHealth position developed out of results from Chain of Trust, Renewing Health, and eHealth Governance Initiative. Results of EMPATHY project on young patient perspective integrated in relevant EPF policy positions. Outcomes of INTERQUALITY project used to inform work on healthcare financing.

Outcome: EPF is able to use projects' outcomes to develop more evidence based policy positions.

10. Feeding outcomes of the thematic working groups into policy

Process: Four thematic working group meetings delivered (two each)

Output: to be defined.

Outcome: EPF is able to use working groups' outputs to develop more evidence-based policy position(s) on selected topic(s)

11. EU projects

Evaluation of individual EU projects in which EPF participates is carried out separately within the framework of those projects.

Cooperation with stakeholders

Process: Cooperation with other stakeholders continued.

Output 3 joint events with other stakeholders are organised; EPF participates as a speaker, chair or facilitator in at least 40 health-related events by M12 Relevant stakeholders and policy makers regularly participates at events organised by EPF in which participation of those actors is envisaged.

Outcomes: EPF is able to strengthen relations with EU-level health stakeholders and policy makers.

Communication

This is an overview of communication-related process, output, and outcome indicators. Specific indicators for each communication activity will be developed in the Evaluation Plan.

Process: Communication Plan 2014 implemented

Outputs: Annual report 2013 produced in M3; Leaflet on EPF Work Programme 2014 produced in M4, 12 e-Newsletters (one per month) are produced and disseminated, 2 videos produced, 8 press releases sent to target list of press; 3 events tweeted. 8 tweets and Facebook update status per month, EPF Blog with 1 post a month and average of 10 active bloggers following the story.

Outcomes: EPF is able to increase its outreach through communication tools. Targets: 20% more website visits in 2014 vis-à-vis 2012; total 2.500 recipients (now 2000) of EPF eNewsletter; 30.000 visits/ website (now 25.000). Facebook page with 150 “likes” more than December 2013 by M12.

Annex I – Main EPF and project events

Month	Event (only events already scheduled are listed here)	Output	Outcome
January			
February	<p>EPF Board meeting including Elected Officers' Meeting</p> <p>Meeting with National Coalition not yet EPF member</p>	<p>Board agenda, documents and summary minutes</p> <p>Meeting Agenda and summary report</p>	<p>Key governance decisions</p> <p>Exploration of potential membership and strong networking and alliance building</p>
March	<p>Elected Officers' Meeting</p> <p>Regional conference on CBHC</p> <p>Support Partners in the ENOPE Conference on Patient Empowerment</p>	<p>As per February meeting</p> <p>Input on patient involvement in research targeting researchers, patient organisations and DG Research representatives and National Contact Points: case studies; principles; cooperation opportunities; participation to meetings.</p> <p>Contribution throughout</p>	<p>Understanding of principles and opportunities for patient involvement in research amongst the different players.</p>

European Patients' Forum • Rue du Commerce 31 • 1000 Brussels • Belgium
 Office Phone number: +32 (2) 280 23 34 • Email: info@eu-patient.eu • www.eu-patient.eu

		the programme; support for patient representatives to attend conference	Patient perspective integrated throughout the Conference.
April	Annual General meeting and fringe meetings including inaugural meeting of working group # 1 on specific policy themes	Terms of reference, membership, roles and responsibilities; work plan for the next year agreed. Report to membership	Engagement of membership in EPF's policy work, initiation of a member-led working group model, robust policy with enhanced representativeness, consensus-building
	InterQuality final conference	Project Guidelines and Policy Recommendations	Key project event enabling dissemination of the project outcomes among decision-makers and the wide public
	Spring Youth Meeting (fringe meeting of the AGM)	Input into the new youth project, consultation on relevant policy dossiers	Engagement of youth group in EPF activities.
May	Elected Officers' Meeting	See Feb	
	Local Meetings with EPF National Coalition	Agenda and report Contribution to the	Stronger allegiance and understanding between EPF national member and

	EPF at the European summit on hospital pharmacy	programme, funding of patient representatives to attend	EPF Understanding of the patient's perspective and needs by hospital pharmacists, fostering collaboration
June	Meeting with National Coalition not EPF members	As per March event	As per March event
	Regional conference on CBHC	As per March event	As per March event
July	Local Meeting with EPF National Coalition	As per May event	As per May event
August	IV EPF Youth Congress and youth workshop	Input into the new youth project, consultation on relevant policy dossiers.	Engagement of youth group in EPF activities.
	Meeting with National Coalition not EPF members		
September	EPF Board Meeting including Elected Officers' Meeting	As per Feb meeting	As per Feb meeting
	Policy Advisory Group (PAG) meeting	Updates on key policy developments, PAG feedback, contribution to finalisation of EPF positions on the topics discussed.	Engagement of membership in EPF's policy work, robust policy with enhanced representativeness, consensus-building

October	<p>Elected Officers' Meeting</p> <p>Working group meeting on specific policy themes #2</p> <p>Meeting with National Coalition not EPF member</p>	<p>As per Feb meeting</p> <p>Review of the work of the two groups, addressing issues that arise, discussion of EPF positions, finalisation of policy papers if applicable. Reports to the membership.</p> <p>As per Feb event</p>	<p>As per Feb meeting</p> <p>Engagement of membership in EPF's policy work, robust policy with enhanced representativeness, consensus-building.</p> <p>As per Feb event</p>
November	<p>SUSTAINS Steering Committee Meeting Final Workshop, Brussels</p> <p>Regional conference on CBHC</p>	<p>As per March event</p>	<p>As per March event</p>
December	<p>EPF Board Meeting including Elected Officers' Meeting</p> <p>SUSTAINS Final conference</p> <p>Meeting with a National Coalition not EPF member</p>	<p>As per Feb meeting</p> <p>Presentation of project's findings</p> <p>As per Feb event</p>	<p>As per Feb meeting</p> <p>Key project event enabling dissemination of the project outcomes among decision-makers and the wide public</p>

Annex II: Summary of key policy actions in 2014

Action	Objective	Strategic Goal(s)
EPF thematic campaign	Policy outreach through communication campaign focusing on key theme endorsed by the membership Raising awareness and s about EPF's role, patients involvement in healthcare policy processes, and the links between EU and MS levels in health policy	All
Chronic disease and patient empowerment	Contribution to EU Joint Action on chronic disease Policy recommendations for patient involvement and patient-centred CD management Initiating EPF working group model to develop concept of patients' rights and responsibilities, actions needed to support patients empowerment Contribution to EC tender on patient empowerment	2, 3, 5
Patient-centred innovation	Continued work on personalised medicine Developing position on patients involvement in research priority-setting Promoting patient perspective in the context of the EU Regulation on Clinical Trials Promoting patient's perspective in data protection, in context of the new EU Regulation Continued participation in European Innovation Partnership on Healthy and Active Ageing –action groups on adherence, frailty and integrated care, as well as governance and monitoring	2, 3, 5
Health literacy and information to patients	EPF survey on health literacy needs connected to emerging technologies and scientific concepts Promoting health literacy as key strategy for a patient empowerment and key pillar for a reduction of health inequalities Work with European Commission and EMA on supporting the development of high-quality and user-friendly EU-level information and training resources for patients	1, 2, 3, 5
Health inequalities	Continued focus on health inequalities specifically from the patients perspective, building on the outcomes of 2012 and 2013 conferences and EPF's 2013-2014 survey on impact of austerity measures on access to healthcare Setting up EPF working group on Access and Equity Follow-up on Commission's progress report on the communication "Solidarity in Health" Follow-up on the revision of the EU Transparency Directive Follow up on the European Commission's Platform on Access to Medicines in Europe	2, 3
Non-discrimination and inclusiveness	Position paper on non-discrimination from the perspective of patients with chronic diseases Continuing collaboration with other bodies to explore vulnerable or marginalised patient groups' access to healthcare	3, 4, 5, 6

	<p>Follow-up on EPF position paper on the needs and rights of older patients</p> <p>EPF Youth Strategy</p>	
Safe and high-quality healthcare	<p>Within EC working group PS&QC, contribute a patient perspective inter alia on reporting and learning systems and health professionals' education</p> <p>Initiation of EPF member survey on quality of healthcare</p> <p>Continued follow-up on the implementation of the Council Recommendation on patient safety, focusing on patients and citizens' empowerment and involvement</p> <p>Continuing collaboration with WHO Europe on patient involvement in patient safety</p> <p>Continued engagement with EU Regulation on Medical Devices and In Vitro Medical Devices, including production of a advocacy Toolkit for the implementation phase</p> <p>Continued involvement with the European Medicines Agency, including in the PCWP, specific thematic events, and PRAC.</p>	1, 2, 3, 5
Health workforce	<p>Continued partnership with health professionals' organisations at EU level to develop joint activities on patient-centred healthcare, and understanding of the roles and skills needed from health professionals realise patient-centred, safe and high-quality care</p>	2, 3, 5
Supporting implementation of EU legislation	<p>Monitoring the implementation of key legislation including Cross-Border Healthcare Directive, pharmacovigilance patient reporting, falsified medicines, and others to be implemented in 2014</p> <p>Production of an advocacy toolkit on medical devices.</p>	All

Annex III – Summary of main programmes and projects 2014

Action	Objective	Strategic Goal(s)
eHealth Governance Initiative	Participate actively in this Initiative as one of the key stakeholders	2, 3, 4
InterQuality	Quality and Sustainability of healthcare systems Last year of implementation – Final conference Continue active contribution as an associate partner	2, 3
SUSTAINS	Collecting user requirements for the piloted services Developing a model for patient empowerment assessment	1, 2, 3, 4
EUnetHTA Collaboration	Continue active involvement in the Stakeholder Forum Ensure that sustainable system of HTA, knowledge sharing, good practice in HTA methods and processes produced by the EUnetHTA Collaboration includes	2, 3, 4
Joint Action on Patient Safety and Quality of Care	The overall aim of the Joint Action is to create a permanent platform for future cooperation between Member States in the area of patient safety and quality of care. EPF will be associate partner.	2, 3
EUPATI – IMI project	Major 5 year project in which EPF leads a consortium of patient groups, academia, specialised networks and industry to foster awareness among patients regarding pharmaceutical research	2, 3
Capacity Building Programme	Organisational and advocacy capacity building of patient groups	All
EMPATHY+ (speculative project)	The purpose of EMPATHY+ is to develop strategies for the establishment of cross-disease young patient groups based on the EPF Youth Group model in 8 EU countries in order to strengthen young patients' meaningful involvement within national-level patient organisations.	3,4,5,6
Joint Action on Chronic Diseases	This action addresses the challenge of the increased burden that chronic conditions and diseases place on the health systems and individuals in Europe, with a specific focus on multi-morbidity	2, 3
WE-CARE	Developing an R&D roadmap towards cost containment EPF is member of the Advisory Board	2
EMPATHIE	The general objective of this proposal is to help understand the concept of patient empowerment - meaning a principle of patients making informed choices as a prerequisite to exercise patient rights.	1, 2, 3, 4

Annex IV - Concept for a series of 3 Regional one and half-day conferences on the Directive ‘Patients’ Rights in Cross Border Health Care’ during the course of 2014, modelled on EPF’s Regional Advocacy Seminars.

Objectives of the Conferences

- To raise awareness and knowledge about the CPHC Directive and patients’ rights enshrined within this legislation
- To ensure understanding about the scope of the Directive and its application at national level
- To ‘unpack’ various aspects of the Directive which have wider policy and systems implications of interest to patients (eHealth provision, HTA provision, general provisions on Quality of Care and Patient Safety, specific provisions linked to Rare Diseases etc)
- To facilitate greater understanding regarding the role on National Contact Points in each country and how patient groups could support their effectiveness
- To agree an approach to evaluate the impact of the legislation from a patients’ perspective, on a longitudinal basis.
- To create an informal network of patient leaders interested and committed in CBHC to monitor developments over the coming years

Target Group

Patient leaders from different countries with the capacity to transfer learning and knowledge from the conferences to peers within their organisation and networks (board representatives, directors and communication specialists within the organisations). Strict criteria will be applied regarding interest and commitment to work on this theme and ability to work in either English or the language of the respective host country.

Each event will attract between 50 -60 patient leaders from the countries listed below. This will enable high quality interactive, break-out work that will facilitate more meaningful understanding of the topic, and its relevance and applicability

Locations

A 2013 event will take place in Brussels, BELGIUM, and will include participants from FRANCE, GERMANY, LUXEMBOURG AND THE NETHERLANDS. This will be a ‘pilot’ and the learning/ evaluation from this event will help to shape the 3 regional conferences in 2014. Specific dates to be decided but early spring, early summer and early autumn would be envisaged.

Possible host cities and the geographical remit for their audiences (to be confirmed in cooperation with our member organisations)

Ljubljana, SLOVENIA – AUSTRIA, CZECH REPUBLIC, HUNGARY, SLOVAKIA

Athens, GREECE- MALTA, CYPRUS, ITALY

Tallinn -ESTONIA - FINLAND, LATVIA, LITHUANIA, SWEDEN, DENMARK

It is envisaged that conferences could take place in 2015 in the countries not covered in the 2013 2014 events

Romania, Bulgaria, Poland, Spain, Portugal, UK, Ireland. EPF has either direct membership, or strong contacts in each of these countries and the tool box envisaged as the output will be circulated in 2014 as an interim step prior to further conferences in 2015.

Languages

The conferences will be conducted in English and the language of the host country and materials will also be produced in those languages

Outputs

- Preparatory documents to enable attendees to prepare properly for the conference (criterion for participation)
- Tool kit to enable participants to refer to core material afterwards and pass it on to peers (criterion for participation)
- Press Kit and Press Release to optimise opportunity to raise broader public awareness regarding the event. Where possible, a press conference will be convened on the eve of the event

Outcomes

- At least 10 patient leaders per country with a strong knowledge base on CBHC and with the capacity
 - o to interact with government representatives and other stakeholders on the issue
 - o to explain to fellow patient leaders in their country facts about CBHC and how it works in practice
 - o to be a potential resource to National Contact Points to ensure information that is produced is fit for purpose from a patient's perspective
 - o to be part of an informal EPF patient network on CBHC to monitor the implementation of the Directive from the perspective of patients and provide feedback to EPF and inter alia the European Commission

Evaluation

The conferences will be evaluated in accordance with key indicators linked to the objectives of the meeting and developed in the context of the Ghent Conference. EPF will also circulate evaluation

questionnaires to the participants one year after the respective conference to evaluate long term impact.