

EUROPEAN PATIENTS' FORUM

# Annual Work Plan 2013

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## 1. EPF Strategic Plan 2007-2013

The European Patients' Forum (EPF) adopted a seven-year Strategic Plan at its Annual General Meeting (AGM) in June 2007 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 2013 takes forward this strategy and builds on the outcomes of the Annual Work Plans of the previous years, in particular 2012. It also takes on board the external political environment to reflect the likely European healthcare developments during the course of 2013 and beyond, including the new round of negotiations regarding 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 is high quality, patient-centred, equitable healthcare throughout the European Union.

Our mission is to be the collective patients' voice at EU level, manifesting the solidarity, power and unity of the EU patients' movement, and provide a strong and united patients' voice to put patients at the centre of EU health policy and programmes.

### 1.2 Strategic Goals

Our Strategic Plan identifies five strategic goals:

#### **GOAL 1: Equal Access for Patients**

To promote equal access to best quality information and healthcare for EU patients, their carers and families.

#### **GOAL 2: Patient Involvement**

To ensure meaningful patient involvement in EU health-related policy-making, programmes and projects.

#### **GOAL 3: Patient's Perspective**

To ensure a patients' perspective, including issues around human rights and quality of life, is heard in developments at the EU level on health economics and health efficacy (health, wealth and equity).

#### **GOAL 4: Sustainable Patient Organisations**

To encourage inclusive, effective and sustainable representative patient organisations.

#### **GOAL 5: Patient Unity**

To nurture and promote solidarity and unity across the EU patients' movement. No patient organisation is too small to contribute to our work.

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

- **Acting as the key interlocutor representing the European patient community to the EU institutions and to other key health-related actors at EU level.** In relation to the latter our key activities are:
  - Development of an evidence-base on patients' experience as well as identification of and monitoring the needs and expectations of patients to feed into EU health policy
  - High level presence and constructive input at major external health events
  - Building a dialogue and cooperation with Members of the European Parliament (MEPs), representatives of the European Commission and the Council through consultations, meetings, events, and campaigns
  - Close collaboration with all key health stakeholders on position papers, joint events, projects and joint actions
  - Involvement in many EU-level platforms, expert advisory groups and forums to represent the wider European patient community.
- **Providing on-going support to patient organisations across the EU.** In relation to the latter our key activities are:
  - Supporting patient communities across the EU in policy and advocacy work and sharing of good practice particularly in new EU Member States (see EPF Regional Advocacy Seminars in Lithuania 2008, Bulgaria 2009, Hungary 2010, Romania 2011 and Portugal 2012)
  - Supporting EPF members and other patient groups through the EPF Capacity Building Programme focused on organisational and advocacy capacity
  - Engaging with, supporting and promoting the establishment of national patient coalitions where not yet in place in current and candidate EU Member States.

## 2. EPF Annual Work Plan 2013

The EPF 2013 **Annual Work Plan** distinguishes between an **Operational Work Programme** consisting of all EPF's 2013 core activities which should be co-funded through the renewal of the 2012 Operating Grant under the Public Health Programme, and our portfolio of projects that will be running in parallel. 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 2013 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 (GOAL 1-5)**

### OBJECTIVE 2

**Strengthening the influence and impact of the patient perspective in health-related policy and decision-making (GOAL 1-5)**

### OBJECTIVE 3

**Feeding project' and patients' evidence into policy (GOAL 1-3)**

The Operational Work Programmes contributes mostly to Objectives 1 and 2 of the Annual Work Plan, while the projects out with the Operational Work Programme contribute primarily towards Objective 3 and indirectly towards Objective 2.

The Operational Work Programme includes, among other things, all **advocacy work** that will be carried out in 2013, including the activities of the **Policy Advisory Group**, one **Patient Evidence Workshop**, the **Annual General Meeting** and the attached **Second Strategic Planning Seminar**, the activities of the EPF **Youth Group**, and the **Sixth Regional Advocacy Seminar**.

In 2013 a lot of effort will be put into disseminating and capitalising on the outcomes of the Chain of TRUST project (ending in December 2012) on building trust and acceptance of telehealth among patients and health professionals All communications and representation work related to our core activities is also included under the Operational Work Programme.

Alongside the core programme in 2013 EPF will continue to be involved in the following projects: **EUPATI** as project coordinator, **RENEWING HeALTH**, **InterQuality**, **SUSTAINS**, the **eHealth Governance Initiative** and the **Joint Action on Patient Safety and Quality of Care** as beneficiary. Pending the outcomes of project applications submitted in early 2012, new projects may start in late 2012 – beginning 2013. These include SyMChron, a project that will investigate co-morbidities of the three major chronic non communicable diseases; AdoptHTA, aimed at strengthening hospital based HTA; and EMPATHY, consisting of a four-day event aimed at promoting the recognition of young patients' needs in EU policy-making. In 2013 the EPF **Capacity Building Programme** will be in its second year of implementation and will build on the first phase which was focused on needs' assessment and strategic planning of participating organisations. In 2013 we will further develop our work on patients and citizens' involvement culminating in a major **EU-level conference** linked to the 10<sup>th</sup> Anniversary of EPF. EPF will continue its engagement in HTA by disseminating the results of EPF HTA survey completed in 2012 and the tools developed as a result of that initiative.

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

## 2.1 OBJECTIVE 1: Reinforcing Capacity

### 2.1.1 EPF Capacity Building Programme

The resources developed through EPF Value+<sup>1</sup> and awareness gained through our Regional Advocacy Seminars and other EPF events have framed the capacity building programme that we launched in 2012. The programme is dedicated to patient organisations at national and European level and will last for three years with the long term goal of making of it a core EPF activity.

The programme has two main pillars: focus on organisational aspects for patient organisations (e.g. financial management, fundraising, organisational management, etc.); focus on policy and advocacy skills.

The first part run in 2012 focused on strategic planning and needs' assessment for the participating organisations from selected countries. 2013 will see the implementation of training modules responding to the strategic priorities and needs identified in the previous year.

### 2.1.2 Meeting and Supporting Europe's Patients

The following major EPF meetings and events will take place in 2013:

- The **Annual General Meeting (AGM)** will be held in spring 2013 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.
- A second **Strategic Planning Seminar** held in conjunction to the AGM in spring 2013 will involve EPF members in the adoption of EPF second Strategic Plan for the years 2014-2020. The outcomes of this seminar will enhance the direct involvement of our membership in the implementation of all aspects of the EPF Strategic Plan 2014-2020
- The sixth **Regional Advocacy Seminar** will take place in autumn 2013. The thematic focus of the seminar will be identified in close cooperation with our membership.
- A **major Conference focused on EPF's work on patients and citizens involvement** will take place in Dublin under the Irish EU Presidency to mark EPF's 10<sup>th</sup> Anniversary ( see 2.2.2.1)
- EPF will provide on-going support to our 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.

### 2.1.3 Involving Youth

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).

An application for a youth project under the EU Youth in Action Programme was submitted in early

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<sup>1</sup> <http://www.eu-patient.eu/projects/valueplus/index.php>

2012. Pending the successful outcome of the application, the project EMPATHY, agreed at the first Annual Meeting of the EPF Youth Group held in August 2011, will organise 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. If successful, the project will start in mid-2012 to continue until October 2013. The seminar is expected to be held in spring 2013.

New project applications under the Youth in Action Programme will be submitted in early 2013 to follow up on the outcomes of the EMPATHY project and support the implementation of the EPF Youth Strategy in the medium term.

As part of the implementation of the Youth Strategy (see below) we will hold the following meetings/activities:

- A **spring meeting of the EPF Youth Group** to review the implementation of the first Work Plan of the EPF Youth Strategy and plan the second Annual Congress of the Youth Group which will take place in Summer 2013. The spring meeting of the Youth Group will be attached to our 2013 AGM.
- The **Third Annual Meeting of the EPF Youth Group** will take place in summer 2013 in Bulgaria. It will focus on the shaping of the Second Work Plan implementing the EPF Youth Strategy which will cover the years 2014–2015. The meeting will include the election of the new Youth Group Board and the nomination of a youth representative for the EPF Policy Advisory Group. The Third Youth Meeting will include a workshop focused on team building and leadership skills for the members of the Youth Group.

#### 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/>

#### 2.1.4 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 mid-2012, while a board member will continue to be designated a specific 'country' to follow, in accordance with interest, geographic proximity and/or language competence.

In 2013 we will focus on Ireland, where a national patients' coalition is being established and where we will hold a major EU Conference under the Irish EU Presidency to celebrate EPF's 10<sup>th</sup> Anniversary; Portugal, building on the relationships fostered there in relation to the Regional Advocacy Seminar in Lisbon in 2012, and Italy and Greece in the context of preparatory work for their forthcoming Presidencies in 2014. Specific attention will continue to be paid to Central and Eastern European Countries, especially Romania and Hungary.

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 2013 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. These toolkits will be finalised and published in 2012 and will be used to support national patient organisations in getting involved in the transposition and/or implementation process of the above mentioned policies. The impact of these tools will be evaluated in 2013 and necessary revisions and realignment completed.

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 involvement in policy work

The **EPF Policy Advisory Group** will meet physically twice in 2013. 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.



### 2.1.5 EPF Secretariat and Governance

In 2013 EPF's secretariat will be composed of an Executive Director, a Finance and Operations Manager, an Office Manager, a Senior Policy Adviser, a Policy Officer, a Programme Manager, two Programme Officers, a Communication Officer, a Project Officer, a Research Officer, a Membership Officer, a part-time Webmaster, and a part-time Administrative Assistant .

A management team composed of the executive director, the programme manager, the senior policy advisor and the finance and operations manager was established in 2012.

An external auditor will audit the accounts for 2013 and these will be presented for adoption to the Annual General Meeting (AGM) in spring 2014, and published on the web site together with the Annual Report 2013 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 newsletter - the EPF Mailing - and the website. A membership guide updated annually facilitates communications between the secretariat and the members.

## 2.2 OBJECTIVE 2: Strengthening the influence and impact of the patient perspective

EPF's key policy areas 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.

### Our over-arching strategic goals:

- Promotion of the patients' perspective, patients' rights and responsibilities;
- Involvement of patients in all areas of EU policy, programmes and projects with an impact on health;
- Promoting equity of access and quality of life, addressing health inequalities and the sustainability of equitable healthcare systems.

Throughout 2013, EPF will continue to play a proactive role in promoting a patient-centred philosophy and agenda and be active in the follow up of the "Europe for Patients" campaign initiated by Commissioner Vassiliou and advanced by Commissioner Dalli. EPF's overall aim is to ensure that the EU2020 strategy for delivering growth in the new decade aligns "smart growth" with "inclusive growth" and takes on board a strong patients' perspective.

Our policy priorities in 2013 will address a number of broad areas that complement this vision, including future patient-centred, sustainable health systems; patient-centred innovation; addressing health inequalities and ensuring equitable access to healthcare; high-quality, safe healthcare; and supporting the implementation of key EU health-related legislation.

## 2.2.1 Specific Policy Priorities

The priority policy areas for 2013 listed below are broadly clustered under a number of themes, though many policy priorities (for example health literacy and information to patients), are in fact relevant to more than one theme.

### 2.2.1.1 *Patient-centred, sustainable and equitable health systems*

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 increasing 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 strategies for managing chronic diseases**

Having contributed actively to the Commission reflection process on chronic diseases during 2012, EPF will continue to engage its members in 2013 on the planned Commission Communication and strategy on chronic diseases. In EPF's view, tackling chronic diseases effectively requires a strategy that addresses the continuum of health promotion, primary/secondary prevention, and patient-centred management, in order to deliver high quality care which is accessible and sustainable. Patients, when appropriately supported, can not only participate actively in managing their condition, thus avoiding unnecessary complications and encouraging the best possible outcomes, but also remain in employment longer, reducing the burden on individuals, families and health and social systems. EPF will adopt policy recommendations on patients' involvement/patient-centred chronic disease management and embed these in all aspects of our work, including patient focused use of innovative technologies and services, and strategies to enable patients to contribute to the development of sustainable, equitable health systems.

#### **EU Health Strategy 2014-2020: "Health for Growth" and beyond**

In 2013 considerable energy will be directed towards contributing a patients' perspective to the policy-making process around the next EU programming period (2014-2020), particularly the new health programme, "Health for Growth"; the Eight Framework Programme for Research and Development (Horizon 2020); the new Competitiveness and Innovation Programme; the new PROGRESS programme; and the fifth reform of the Structural Funds for the years 2014-2020.

#### **Health workforce**

As European health systems increasingly implement patient-centred models for managing chronic diseases, we need a health workforce equipped with the right skills and competencies. In 2013 EPF will contribute to the debate on the future EU health workforce, including the revision of the Professional Qualifications Directive, with recommendations from the patients' perspective. We will work in partnership with health professionals' organisations at EU level to develop joint activities focusing on the key aspects of the patient-health professional relationship (e.g. adherence to therapies and concordance, effective self-care, communication, and shared decision-making).

### 2.2.1.2 *Patient-centred innovation*

Patient-centred innovation will be a priority for EPF in 2013 to ensure that patients' needs are firmly at the centre of the EU vision of innovation in healthcare, and that the Europe 2020 parallel objectives of "smart growth" and "inclusive growth" will be achieved. EPF will focus activities on the key areas listed below. In addition, (digital) health literacy will be a key factor to ensure inclusivity and build trust and confidence – this is addressed under point 2.2.1.3, "Health literacy and information to patients".

## European Innovation Partnership on Healthy and Active Ageing

Since 2011 EPF has participated at all levels in the EU Innovation Partnership on Healthy and Active Ageing and the 2012 European Year of Active Ageing, and contributed to the drafting of the Strategic Implementation Plan for the Innovation Partnership. Our focus is on the specific needs and potential contribution of older patients and the exchange of knowledge and experiences among all stakeholders to ensure older patients' empowerment and full participation in society. EPF will continue to be involved in the implementation of certain actions within the Partnership, as well as its on-going governance and monitoring.

### eHealth

In 2013 EPF will continue its involvement in eHealth issues, initiatives, and projects, addressing topics such as acceptability, patient requirements, interoperability, eHealth in cross-border settings, ethical issues, with a focus on raising awareness on patients' perspective and attitudes using the outcomes from our telehealth project "Chain of Trust" and preliminary evidence emerging from the projects "RENEWING HeALTH" (see paragraph 2.3.1) and SUSTAINS (2.3.1.3), focussing on telemedicine and patient access to Electronic Health Records respectively. On a more political level, we will continue to contribute actively to the eHealth Governance Initiative (see 2.3.1.5).

In this area EPF will continue its cooperation with consortia and networks focusing on ICT and health (CONTINUA Health Alliance, the European Health Telematics Association-EHTEL, The European Coordination Committee of the Radiological, Electromedical and Healthcare IT Industry-COCIR and EUCOMED representing the medical technology industry), including the wireless operators (i.e. GSMA Europe). EPF will also continue to be represented in the EU eHealth Users Stakeholder Group whose structure and operating mechanism was modified by the EC in 2012 in order to be a platform for stakeholders to contribute to the development of legislation or policy related to eHealth by providing reports, opinions and relevant data.

### Health Technology Assessment (HTA)

In 2013 EPF's policy work in this area will continue to focus on promoting meaningful patient involvement in HTA, drawing on our involvement in the EUnetHTA Stakeholder Forum, the recommendations from the EPF HTA seminar organised in 2010, as well as our research conducted in 2011-2012 focusing on patients' involvement in HTA processes.

The EPF research work on HTA, in particular, was developed to understand the involvement of lay patients, informal carers, and patient organisations in all the EU Member States and to contribute this knowledge to inform HTA – research, policy, and practice<sup>2</sup>. EPF will continue to disseminate the outcomes of this research initiative across HTA agencies, patient organisations and decision making bodies in the EU, but also other relevant stakeholders.

We will also continue engaging actively in the Joint Actions on HTA, supporting the implementation of the European HTA Network established by the EU Directive on cross-border healthcare, to ensure patients' have a legitimate and valued role in HTA processes.

### Personalised medicine

EPF initiated a reflection process on personalised medicine in 2011, exploring the benefits and concerns of patients; we also collaborated on several events with DG Research and academic stakeholders. Based on this preparatory work, in 2012 EPF adopted a position paper on personalised medicine, in consultation with our membership, and engaged with the DG SANCO reflection process on this theme. In 2013 EPF will continue to work with the EU-level policymakers, scientific

<sup>2</sup> See: <http://www.eu-patient.eu/Initiatives-Policy/Initiatives/>

researchers, industry stakeholders, health professionals' organisations and other stakeholders to advocate for a patient-centred, equitable EU strategy for the development of personalised medicine, and to effectively inform patients concerning new scientific and policy developments in the field, and their potential implications for patients.

### Data protection

EPF will engage in the legislative process on the Commission proposal for a Regulation on the protection of individuals with regard to the processing of personal data and on the free movement of such data, with the aim of a framework that addresses the new challenges for the privacy of patients' personal data, while ensuring safety and quality of healthcare and fostering vital health and medical research in the EU.

### Patients' Meaningful Involvement in EU Financing Programmes

In line with our goal to promote the involvement of patient organisations also in EU health-related projects, we will continue exploiting the outcomes of our Value+ project<sup>3</sup> and its resources. By taking stock of the very fruitful cooperation carried out in this area with DG Research as from 2010 (i.e. the inclusion of the "meaningful patient involvement" criterion for clinical trials under the 2011 and 2012 FP7 Health Work Programmes explicitly mentioning the Value+ project, and the participation of EPF in various national FP7 info days in 2010 and 2011) we will apply the same model of cooperation with DG SANCO and DG INFSO.

#### 2.2.1.3 Health inequalities and improving access to healthcare

Smart growth must also be inclusive growth: the reduction of health inequalities is a major pillar of the EU Health Strategy, "Together for Health" and the EU2020 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, nationality, gender, or means to pay. A major focus of EPF's work will be on implementing health literacy and patient empowerment, and on adopting a "health inequalities in all policies" approach, particularly in the context of EU Structural Funds.

#### Improving access to healthcare for all patients

In 2013 EPF will continue to bring a patients' perspective to EU-level debates and actions on health inequalities, focusing on access and quality of healthcare. We will build on the progress report on the **Commission Communication "Solidarity in health,"** and on the outcomes of a conference organised in 2012 in collaboration with our member organisation NPO in Sofia, Bulgaria, which explored health inequalities from the perspective of patients with chronic diseases and the impact of the financial crisis on patients, resulting in a Call for Action.

In 2013 EPF will also continue to engage in the *revision of the EU Transparency Directive* and its implications for patients' access to therapies. We will also draw on the outcomes of the Commission Platform on Access to Medicines in Europe and the Platform on Ethics and Transparency, part of the **"Initiative on Corporate Responsibility in the Field of Pharmaceuticals"** which concluded at the end of 2012 and where EPF represented the patients' perspective on the Steering Group and project groups, while collaborating closely with our international sister organisation, IAPO, on the Platform on Access to Medicines in Developing Countries.

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<sup>3</sup> See project website : <http://www.eu-patient.eu/Initatives-Policy/Projects/EPF-led-EU-Projects/ValuePlus/>

### Information to patients and Health Literacy

Health literacy has been a key priority for EPF since its establishment in 2003. The conclusions and recommendations flowing from a major conference on health literacy organised in 2008 continue to inform our policy work also in 2013. EPF will continue to focus on health literacy in a broad approach, as a **critical strategy for the realisation of patient-centred healthcare**, and a key contributing factor to the sustainability of future health systems, but also as a **key pillar for the reduction of health inequalities** across Europe. Furthermore, EPF believes (e)health literacy is crucial to the **realisation of the Digital Agenda** and inclusive innovation, and to ensure uptake and trust in new technologies by the users – the patients.

Information to patients is a crucial element in fostering health literacy and patient empowerment. In 2013 EPF will continue work closely with the EU Institutions on the revised Commission proposals on Information to Patients in the eventual second reading. We will continue to work with the European Medicines Agency and the European Commission to support the development of *high-quality, user-friendly EU-level information resources* for patients. We will also continue to work actively within the European Union Health Policy Forum to advance health literacy and information to patients as a common priority in the future EU Health Programme.

### Discrimination in health and the needs of marginalised patient groups

In 2013 EPF will continue work on discrimination in health, initialised in 2011, in the context of the *EU legislation on equal treatment* and its implications for patients with chronic diseases. EPF will also address the topic of *vulnerable or marginalised patient groups' access to healthcare*, having launched collaboration in 2012 with the EU Fundamental Rights Agency (FRA) and the European Social Platform, and initiated contact with the International Organisation for Migration (IOM).

### Needs and rights of older patients

EPF's work in 2013 will build on a position paper on the needs and rights of older patients with chronic diseases, developed in 2012 on the basis of EPF's response to the Commission's public consultation on healthy ageing, our work in the context of the European Innovation Partnership on Healthy and Active Ageing, and the outcomes of EPF's conference on the same theme, held in Warsaw under the Polish EU Presidency in 2011.

### Youth and Health

EPF's viewpoint is that needs and expectations of young patients do not necessarily match those of adult patients. For this very reason patient organisations need to do more to provide better support to young patients by for instance understanding and formulating their needs and integrating them in their mainstream activities. Therefore, in line with the goal and objectives of the Youth Strategy outlined in paragraph 2.1.3, in 2013 EPF will continue to work to ensure that the perspective of young chronic patients is effectively integrated and will take steps to mainstream youth issues in our health policy. The objective here is to make sure that the impact of future EU health policy developments on youth is properly assessed.

### Health and Structural Funds 2014-20

Over the previous years EPF has played an active role in cooperation with DG SANCO and other health stakeholders in the Cohesion Policy area, particularly in the context of the debate around the fifth reform of the Structural Funds for the 2014–2020 programming period.

2013 is a crucial year for the future of Cohesion Policy as the Member States will be finalising the new National Strategic Reference Frameworks and the new generation of operational programmes. EPF's first concern in this area is to ensure that health remains a priority for future Structural Funds'

eligible investment, but also that such investment is aligned with needs and requirements of local healthcare systems and provides an effective contribution in terms of health gains for all citizens and patients. Likewise, we will devote significant energy to ensuring that Structural Funds are used to address existing health inequalities across and within EU countries.

To achieve this objective, we will rely upon our recently established partnerships with various organisations operating in this policy area such as the Assembly of European Regions (AER), the European Association of Regional and Local Health Authorities (EUREGHA) as well as the Committee of the Regions (CoR) with which we have been working in various platforms including the Committee of the Regions, DG SANCO and DG REGIO Technical Platform on Health.

EPF will also carry out political and informative work to increase access for patient groups to Structural Funds as beneficiaries and promote their effective association as key partners in the implementation of health-related Structural Funds' programmes, particularly using the EPF Toolkit "Getting Involved in Structural Funds" and building upon the outcomes of the Fifth Regional Advocacy Seminar dedicated to Cohesion Policy.

#### *2.2.1.4 Ensuring the safety and quality of healthcare*

Creating a framework for safe, high-quality and effective health systems is a key priority of the EU Health Strategy "Together for Health", in line with the Europe 2020 goals of smart and inclusive growth. Patient safety and the quality of care have been core priority areas for EPF since our establishment, and a key component of our policy work in all areas. EPF believes 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-users' perspective.

#### **EU actions in the area of quality of care and patient safety**

Improving the safety and quality of care across the EU is key to the implementation of the **EU Directive on Cross-Border Healthcare**. EPF is a member of the Commission's *Patient Safety & Quality of Care Working Group*, which advises the Council Working Party on Public Health issues at senior level in developing the EU patient safety and quality agenda. In 2013, EPF will continue to actively represent a patients' perspective in this Working Group, focusing particularly on the implementation of the **Council Recommendation on patient safety and healthcare associated infections**, following the Commission's first progress report published in 2012, and the conclusions of EPF's own survey on the perspectives of European patient groups on the impact of the Recommendation. This work is complemented by our role as associate partner in the *Joint Action on Patient Safety and Quality of Care* (see 2.3.1.4), launched in 2012.

#### **Clinical trials**

In 2013 EPF will continue to be actively involved in the legislative proposal for the revision of the *EU Clinical Trials Directive*, channelling the patient community's views and perspectives in cooperation with other stakeholders. EPF also continues to work with the European Medicines Agency (EMA) and the European Forum on Good Clinical Practice (EFGCP) on specific issues related to clinical trials.

#### **Medical devices**

Having contributed to the exploratory process on medical devices in 2009, and the High Level Conference on Medical Devices in 2011, EPF continues to engage actively in 2013 on the legislative proposals for a *revised regulatory framework on medical devices*, to ensure patient safety and involvement. EPF set up a regular dialogue with its members and the medical devices industry, through EUCOMED in order to exchange views and information from our respective perspectives; meetings take place twice yearly in line with our Code of Ethics on transparency and independence.



### *2.2.1.5 Implementation of key EU health legislation*

In 2013 EPF will continue to monitor the transposition and implementation of key EU legislative texts on cross-border healthcare, pharmacovigilance and falsified medicines, ensuring the effective dissemination of information to patient communities across the EU, and supporting patient groups to engage proactively at national level to ensure national laws are patient-centred and effective in achieving the objectives of the EU legislation. This work complements the EPF capacity-building strategy aimed at supporting EPF members in participating as equal partners in national health debates, and strengthening the patients' voice in EU Member States.

#### **Cross-border healthcare**

EPF will monitor closely the implementation of this Directive, including working with the Commission around raising awareness in the patient communities across the EU on the new legislation, and using the EPF Toolkit and policy recommendations as an advocacy tool to support patient organisation involvement at national level. Our work with key stakeholders on the safety and quality of healthcare across and within borders feeds into this process. On the development of a European HTA Network, EPF's contribution will draw upon our activities within the framework of the Joint Actions on HTA and focus on ensuring the patient's legitimate and valued role in HTA processes.

#### **Pharmacovigilance**

EPF will continue to work closely with the Commission and the European Medicines Agency, as well as relevant stakeholders such as community pharmacists' organisations, to ensure effective, patient-centred implementation of the EU pharmacovigilance legislation, particularly the new provisions for direct patient reporting of adverse events. The EPF toolkit for patients' organisations and policy recommendations, published in 2012, will continue to serve as advocacy and dissemination tools.

#### **Falsified medicines**

Similarly, EPF will support the implementation of the Directive on falsified medicines, particularly around information and awareness-raising in the patient communities concerning medicines safety and falsified medicines.

### *2.2.1.6 EPF and the global health agenda*

In collaboration with our international sister organisation, IAPO, EPF will contribute an EU perspective on global health developments, including on pharmacovigilance, counterfeit medicines, and patient-centred healthcare.

## **2.2.2 Advancing policy and campaign outreach through building constructive partnerships**

EPF's leitmotif is partnership and trust with all stakeholders committed to improving EU health services and outcomes. For this reason, since its establishment in 2003, EPF devoted significant time to developing alliances and good working relations with a number of European organisations with which we have a common agenda. EPF will sustain and enhance this during the course of 2013.

In order to strengthen the policy impact of our advocacy work, we will continue to implement a number of additional activities and launch new ones, such as the "Thematic Policy Conference". These are briefly presented below.

### 2.2.2.1 Thematic Conference

In 2013, EPF celebrates its 10<sup>th</sup> Anniversary. EPF will hold an Anniversary Conference in Dublin, under the auspices of the Irish EU Presidency and in the framework of the Citizen's agenda and the 2013 European Year of Citizens – aiming to “raise citizens' awareness of how they can *benefit from EU rights and policies*; and *stimulate citizens' active participation in EU policy-making*. The specific issues to be addressed in the conference will be framed around the importance of EPF and our members being pro-active in shaping health policy agendas at EU and national level that really work for patients, to define the key issues and provide the evidence base to back this up, in economic, social and political terms. It will reflect the key pillars in EPF's new strategic plan and our campaign work in advance of 2014 EU Parliament elections and new Commission.

### 2.2.2.2 Work with the EU Institutions and Agencies

#### European Parliament: Building on existing relationships

During the past few years EPF galvanised links with key MEPs already established, notably through our work on the Health Literacy Declaration and *the EPF Patients' Manifesto campaign* in the context of the last European Parliament elections. Over 120 MEPs expressly committed themselves to the work of EPF. We chose not to set up an interest group; in terms of our long-term work with the European Parliament, the aim is to secure a strong on-going relationship with highly committed MEPs from across the political groupings, to enable us to optimise our effectiveness in the European Parliament on specific health-related policy issues.

In 2013 EPF will campaign together with our pan-European membership in the run-up to the European Parliament elections, to highlight the importance of health issues to European citizens and to support our members in engaging effectively in the election process. The basis for this work will be an updated EPF Manifesto developed in 2012 in close collaboration with the EPF Membership.

#### The Council of the European Union and EU Presidencies

EPF will liaise as closely as possible with Ireland and Lithuania, which are holding the EU Presidencies in the first and second semester of 2013 respectively, by attending relevant health meetings, and ensuring input from the patients' perspective in relation to key health policy initiatives addressed by the Presidencies. Our Patients' Manifesto will continue to be an important tool in this dialogue. EPF will also establish links with Greece and Italy, which will hold the EU Presidency in 2014. Regular communication will continue with the health attachés in all permanent representations, as well as relevant national health officials and politicians. EPF will also support its national and pan-European member organisations to engage effectively at national level.

#### European Commission's Directorates-General and Agencies

As EPF's work on patient-centred healthcare becomes more mainstreamed, we will continue to work closely not only with DG SANCO, but also increasingly DG RESEARCH, INFSO, ENTER, EMPSON and REGIO. EPF will also continue to build working relations with EU health-related agencies to enhance our visibility and to encourage a stronger patient perspective in their work.

In 2013 EPF will continue to prioritise our close involvement with the European Medicine Agency (EMA) through representation in the Working Party with Patients' and Consumers' Organisations (PCWP) within the Committee for Medicinal Products for Human Use (CHMP), and the Agency's Managing Board. EPF will continue to act in a coordinating role for patient involvement, disseminating information about EMA and the medicines regulatory processes to patient communities across EU, and supporting EMA in further developing patient involvement. EPF will also work within a number of *ad hoc* working groups, giving expert input from the patients' perspective, in particular on the implementation of the new EU rules on pharmacovigilance, falsified medicines,



clinical trials, and information to patients.

In addition to the EMA, EPF will work with the Executive Agency for Health and Consumers (EAHC), the European Union Agency for Fundamental Rights (FRA), the European Observatory for Healthcare Systems and the European Centre for Disease Prevention and Control and Control.

### *2.2.2.3 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 which will hold the next Open Health Forum in 2013
- European Innovation Partnership on Active and Health Ageing
- High-Level eHealth Task Force
- 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 / EUCOMED dialogue on medical devices
- Innovative Medicine Initiative Stakeholder Group
- eHealth User Stakeholder Group
- EC Working Group on Patient Safety and Quality of Care
- EU Health Portal Editorial Group
- EuropaBio Patients-BioIndustry 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)

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

### *2.2.2.4 Working with Partners and Allies*

#### **Cooperation with other patient groups**

In 2013 we will continue to work as closely as possible with major EU and international patient groups such as the European Aids Treatment Group, European Heart Network, and our global sister organisation, the International Alliance of Patient Organizations (IAPO), with which we have a Memorandum of Understanding clarifying our geographic and political remit and supporting our joint work.

#### **Cooperation with other health stakeholders**

In 2013 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. They were also

associate partners in the EPF-led Chain of Trust telehealth project.

In 2013 we will 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 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.

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

### International organisations

EPF has developed an active relationship with the World Health Organisation (WHO) in relation to EU related matters, and the relevant health-related departments within the Council of Europe, OECD, UNICEF and the International Organisation for Migration (IOM). Our 2013 work programme will continue to build on those relationships.

## 2.3 OBJECTIVE 3: Feeding Project' and Patients' Evidence into Policy

The overall rationale behind this objective is twofold: a) to substantiate EPF's knowledge base and policy evidence, with input from the patients' community throughout the European Union and b) to feed into new projects the knowledge built through other projects and initiatives.

The list of EU projects in which EPF participates in 2013 is provided in the paragraph below. Please see Annex 2 C for a list of speculative projects that may kick-off in late 2012 early 2013.

### 2.3.1 Overview of EU Projects

#### 2.3.1.1 EUPATI



The five-year EPF-led project EUPATI, standing for "European Patients' Academy on Therapeutic Innovation" started in February 2012 with the aim of creating better education and information tools for patients on pharmaceutical research. The project is funded under the Innovative Medicines Initiative (IMI). The EUPATI academy will educate patient representatives and the lay public on personalised and predictive medicine, design and conduct of clinical trials, drug safety and risk/benefit assessment, pharmacoeconomics as well as patient involvement in drug development.

EUPATI will develop scientifically reliable, objective, comprehensive information on therapeutic innovation by:

- establishing certificate training courses to create 'expert advocates' on therapeutic innovation,
- developing a "tool kit" of educational multi-media material to be re-used by patient organisations

for educational purposes, and

- developing an Internet-based library of up-to-date, unbiased information on medicinal development for patients and the public.

The consortium, led by the European Patients' Forum, comprises of 26 leading pan-European patient organisations, academic and not-for-profit organisations as well as EFPIA member companies. As project coordinator EPF will be responsible for the management, monitoring and on-going evaluation of this project. EPF will also lead the work package dedicated to implementing the EUPATI expert, education and information programmes at European and national levels and to monitoring and evaluate on an on-going basis the quality and impact of the programmes' delivery.

### *RENEWING HeALTH*



Funded under the Competitiveness and Innovation Programme (CIP) – ICT Policy Support Programme - RENEWING HeALTH aims at implementing 19 large scale real-life pilots in nine European regions for the validation and subsequent evaluation of telemedicine services for the remote management

and monitoring of patients with diabetes, Chronic Obstructive Pulmonary Disease (COPD) and cardiovascular diseases (CVD), using a patient-centred approach and a common rigorous assessment methodology called MAST. The project was launched in early 2010 and will end in September 2013.

EPF is involved in the management of the project's User Advisory Board (UAB), the primary mission of which is to operate as a standing advisory committee for the consortium to advise and provide on-going feed-back on the needs of current and future users of the piloted telemedicine services (i.e. mainly patients and healthcare professionals, but also health authorities).

A key focus for EPF in 2013 will be to start exploiting project's results with a view to consolidating the User Requirements Document - the reference framework for the representation of user needs, requirements and expectations related to telemedicine - and formulating recommendations for future telemedicine projects on how to ensure that telemedicine services respect needs and preferences of the different user groups.

The User Advisory Board will meet twice in Brussels in 2013, while at least one local meeting with representatives of users involved in the RENEWING HeALTH services will be organised in one of the participating regions.

The project will hold its final conference in Brussels in September 2013.

For more information on this project: [www.renewinghealth.eu](http://www.renewinghealth.eu)

#### *2.3.1.2 InterQuality*



2013 will be the final year of the three-year "International Research Project on Financing Quality in Healthcare" – InterQuality, funded by the 7th EU Framework Programme (FP7). EPF will continue leading the implementation of the project dissemination strategy, which will culminate with a final conference in Denmark towards the end of the year.

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/>

#### 2.3.1.3 SUSTAINS



SUSTAINS - *Support Users To Access Information and Services* – is a three-year pilot study on patients' access to Electronic Health Records (EHR) co-funded under the CIP-ICT programme of the European Union. This project, which kicked-off in 2012, is gathering evidence-based information on patients' access to EHR in order to assess, among other things, whether and how patient empowerment can be effectively strengthened as a result of such access.

SUSTAINS provides a rich basket of services based on giving citizens online access to their EHR. The services proposed have been distilled from the experience of European regions which have already pioneered such access.

Although each of these services has a specific objective, all the services 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. Fostering patient empowerment through supporting the widespread deployment of patient-centered eHealth services is indeed the primary objective of SUSTAINS.

EPF plays a key role especially in two work packages (WP), notably WP3 "Evaluation and Deployment Planning" and WP 4 "User Requirements". In the context of WP4, which is led by EPF, we are leading the work on patient requirements identification through a series of focus groups organised in the various participating regions. In the context of WP3, EPF is leading the work on patient empowerment evaluation aimed at assessing the change in patient empowerment before and after using the services.

The project will hold a mid-term Workshop in Brussels in autumn 2013.

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

#### 2.3.1.4 Joint Action on Patient Safety and Quality of Care

The Joint Action on Patient Safety and Quality of Care started its work in the first half of 2012. Its overall aim is to create a permanent platform for future cooperation between EU Member States in the area of patient safety and quality of care. Three specific objectives are to:

- support the implementation of the Council Recommendation on patient safety;
- initiate Member State cooperation on quality of healthcare; and
- facilitate the sharing of good practices in patient involvement and empowerment.

EPF is actively involved in the key work packages of the Joint Action: Dissemination; Patient Safety Good Clinical Practices; Patient Safety Initiatives Implementation; Quality systems collaboration in the EU; and Network Sustainability.

#### 2.3.1.5 eHealth Governance Initiative



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.

#### *2.3.1.6 EUnetHTA Joint Action*

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 builds on the methods and tools developed by the EUnetHTA Project while also including the work done in the Working Group on Relative Effectiveness of the High Level Pharmaceutical Forum. The EUnetHTA JA activities are supported by the EUnetHTA Collaboration organisational and governance structure.

In 2013 EPF will continue participating to the second Joint Action 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.

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

### 2.3.2 Speculative EU projects

This section will be updated once information on final outcomes of the evaluation becomes available.

#### *2.3.2.1 SyMChron*

A proposal for a project called SyMChron was submitted in February 2012 under the 2012 FP7 Health call. The purpose of this project is to **apply systems biology approaches in order to strengthen the understanding of the patho- physiological mechanisms, prognoses, and diagnoses of multifactorial human diseases and their co-morbidities**. Through a patient-centered approach and multidisciplinary research crossing the borders of different disciplines, the project will investigate co-morbidities of the three major chronic non communicable diseases (CND), i.e. cardiovascular diseases, chronic respiratory diseases (COPD) and type-2 diabetes.

EPF will have an important role as co-leader of the work package on Ethics, which will supervise the good ethical conduct of the project. Moreover, we will significantly contribute to guidelines on adherence to treatment.

### *2.3.2.2 AdHopHTA*

AdHopHTA project aims to undertake a series of effective research activities to promote and improve HTA at hospital level in order to promote the introduction of valuable innovations in Europe, strengthen hospital based HTA and thereby contribute to the well-being of society. EPF will be involved as a member of the project Advisory Board.

## 2.3.3 Other projects and activities linked to this objective

### *2.3.3.1 Patients' evidence workshop*

During the course of 2013, EPF will hold one patients' evidence workshop where patient leaders from our member organisations will meet to address in depth a key policy issue for patients, either in light of EU developments in a particular area, or as a result of discussion at the Annual General Meeting in May where a specific and urgent priority area is identified in which EPF must be pro-active.

### 3. Communication strategy

2013 will be a year of **consolidation** and **proactivity** in terms of communications for EPF. Until now, we have been successful in ensuring high visibility and awareness of our activities within the membership and other stakeholders. In 2013, the role of communications is:

- To **reinforce** our already solid **foundations**: better target our representation work, fortify our identity, increase the appreciation of our role and actions;
- To **strengthen our core communications approaches and launch new ones**: make our mailing more attractive and our website more interactive, establish and implement a clear social media strategy and secure balanced media coverage;
- To **make our messages more powerful**: structure differently the way we deliver information on our website, standardize the different sources of information coming from EPF, prioritise newsworthy information.

The 2013 challenge will be to keep on going in this direction in order to consolidate EPF communications and to look into new technologies to propose proactive tools to our members and other stakeholders.

#### Proactivity: Digital First

During recent years, we have seen a big shift towards the digital world. EPF has followed this trend with the launch of a six-weekly electronic mailing, a revamped website, a new social media strategy and a revival of videos campaigns. Our **website** will continue to be our major external window. In 2012, EPF has operated significant changes in the structure to ensure the clarity of its content. The next challenge for 2013 will be to continuously and regularly update the news section, to offer clear information about the projects and policies but also to become even more interactive and proactive in relation to new technologies, website navigation, accessibility and ergonomics.

- **Video** will be much more integrated to the communication work. Video is the future of websites as it combines social communications and message transmission. Video has the triple advantage to “personalise” the speaker which allows transparency and proximity as well as to capture the interest of web users which will help us to get our messages across.
- **Social media**: EPF has embraced a new social media strategy in 2012 that will be taken forward in 2013. The aim is to increase little-by-little the involvement of our online community to encourage them to develop, share, and spread our work digitally. Doing this will reinforce EPF role as a key interlocutor on online cross-cutting issues concerning patients in the EU healthcare system and policies.

EPF is giving interactivity, easy comprehension and dynamism precedence over traditional tools to our **online PDF mailing version**. In 2012, EPF is piloting a new system of monthly e-newsletter and a revamped trimestral mailing reporting. This will enhance proactivity and innovation in the way of delivering news, always with dynamism and transparency. This work will be refined and scaled up in 2013. EPF will integrate its e-mail strategy with social media to engage even more the readers. There will always be a link to our social media properties in our e-mail campaigns to drive a conversation within social media and to give the patients' community easy ways to engage with EPF. There will also be an effort to make our e-newsletter more mobile-oriented as more and more of our audiences are navigating from mobile devices.



## Consolidation

EPF undertook some important changes in 2012 and will need a period in 2013 to solidify the new established bases.

- **Consistency in conveying EPF's identity** will be crucial in 2013 after the revision of EPF's logo and graphical chart in 2012. We need to emphasise it as our visual identity is the face of the organisation; it creates trust, a strong image and value.
- **Regularity in the frequency of delivered news** will be very important to keep the interest of the audience. EPF will focus on proactivity and rapid responsiveness in 2013, overall with social media, to become a main source of information regarding EU healthcare for patients.
- **Balanced media coverage** will be secured thanks to the reinforcement of key press contacts established in 2012. EPF needs to offer value to journalists with "newsworthiness" on a regular basis, as well as a comprehensive and concrete approach to help them relay information to the "wider public".

In brief, in 2013 EPF will:

- Update **regularly** its **website** with news about its policies, projects, initiatives and events
- Send **press releases** to key journalist contacts on a regular basis
- Be a dynamic presence on the **social media** and originator of debate in the area of EU healthcare systems for patients
- Release a **monthly e-newsletter** with hot topics
- **Report in a quarterly Review** about its activities in a clear, concise and attractive way
- **Produce leaflets and factsheets** to efficiently summarize important projects and policies
- **Create online videos** to concretely interact with the patients community and the stakeholders



## 4. Evaluation Strategy and Performance Indicators

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 4 years.

This approach does not involve an external evaluator, but is undertaken internally by the secretariat under the supervision of the programme manager and 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.

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.

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.

### 4.1 Key Performance Indicators

The following performance indicators will be used to measure achievements in relation to our three objectives.

#### **Objective 1 Reinforcing Capacity**

##### 1. Regional Advocacy Seminar (RAS)

Process: Regional Advocacy Seminar implemented

Output: RAS report produced, 50 participants from 4 countries representing at least 15 disease areas attended the seminar

Outcome: EPF is able to strengthen policy advocacy capacity of 30 patient organisations (assessed beyond 2013)

##### 2. EPF Capacity Building Programme

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

##### 3. Strengthening cooperation

Process: Identification of support/cooperation opportunities

Output: presence at 8 meetings of EPF members/meetings with patient groups in PT, IE, GR, IT.

Outcome: EPF is able to strengthen alliance with members and refine cooperation, participation in membership consultations in 2013 increases by 20% vis-à-vis 2011.

##### 4. Involving Youth

Process: Members of the Youth Group meet twice in 2013

Output: 18 youth members by end of 2013 (currently 11). 12 members attend the AGM, 18 the summer meeting. A Youth Strategy 2014-2020 is developed (to be adopted at 2014 AGM).

Outcome: EPF is able to integrate youth representatives in its activities and governance (15% of participants in EPF events are youth, 1 youth representative in the PAG, a member of the Youth Group is elected for the EPF Board as an observer).

## **Objective 2: Strengthening impact of patient perspective**

### 5. Policy impact

Process: 2013 Policy advocacy plan developed

Output: 8 responses to policy consultations/policy papers produced

Outcome: EPF is recognised as a key partner in determining patients' input in EU health policy measured by the inclusion of EPF comments in the EC, EP and Council's positions and initiatives envisaged in 2013.

### 6. EP elections

Process: Information and knowledge building to mobilise EPF membership and patient organisations for 2014 EP elections

Output: new EPF Manifesto.

Outcome: Expression of commitment to health issues and patients' rights from 100 MEPs

## **Objective 3**

### 7. Degree of success in feeding evidence of projects into policy

Process: integrating results in our policy documents and other stakeholders' positions.

Output: same as 5

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

### 8. Degree of success in feeding outcomes of the patient-evidence workshop into policy

Process: patient evidence workshop delivered

Output: at least 20 patient leaders attended, representing 12 different countries and 10 disease areas

Outcome: EPF is able to use workshop's outcomes to develop more evidence based policy positions

### 9. EU projects

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

## **Communication**

Process: Communication Action Plan 2013 in place

Output: EPF representatives speaks in at least 50 health events, 12 e-Newsletters + 4 Quarterly Mailings are produced and disseminated, 4 joint events with other stakeholders are organised, 4 videos produced, 8 press releases sent to target list of press.

Outcome: EPF is able to increase outreach of communication tools. Targets: total 2.500 recipients (now 2000) of our Mailing; 30.000 visits/website (now 25.000), 100 active bloggers on social media.



New cooperation with at least 3 new stakeholder organisations is established. At least 16 coverage articles produced.

An evaluation plan will be prepared in early 2013 and an evaluation report will be prepared in early 2014 to be approved at the 2014 Annual General Meeting.

## Annex I – Main EPF and project events

Month	Event (only events already scheduled are listed here)
January	SUSTAINS III Steering Committee Meeting RENEWING HeALTH VII EU-level User Advisory Board Meeting, Brussels EPF Board Meeting
February	INTERQUALITY project VI Steering Committee Meeting RENEWING HeALTH X General Assembly Meeting + Steering Committee Meeting RENEWING HeALTH III User Advisory Board local meeting with users + site visit.
March	Elected Officers' Meeting Secretariat Team Meeting Policy Advisory Group (PAG) Meeting EMPATHY Seminar, Brussels Meetings with representatives of Council Presidencies (GR and IT) Local Meetings with EPF National Coalitions
April	Annual General Meeting (AGM) Strategic Planning Workshop Involvement in the Patients' Rights Day Event Spring Youth Meeting Meetings with new potential national coalitions of patient organisations
May	EPF Anniversary Conference under the Irish EU Presidency EPF Board Meeting including Elected Officers' Meeting Secretariat Team Meeting RENEWING HeALTH XI General Assembly Meeting + Steering Committee Meeting
June	SUSTAINS IV Steering Committee Meeting Policy Advisory Group (PAG) Meeting Participation in EU and national FP7 Health Programme Info Days

July	<p>Secretariat Team Meeting</p> <p>Local Meetings with EPF National Coalitions</p>
August	<p>III EPF Youth Congress and youth workshop, Bulgaria</p> <p>Meetings with new potential national coalitions of patient organisations</p>
September	<p>EPF Board Meeting including Elected Officers' Meeting</p> <p>Secretariat Team Meeting</p> <p>Local Meetings with EPF National Coalitions</p> <p>RENEWING HeALTH VIII EU-level User Advisory Board Meeting, Brussels</p> <p>RENEWING HeALTH Final Conference</p>
October	<p>Elected Officers' Meeting</p> <p>Sixth Regional Advocacy Seminar</p> <p>INTERQUALITY project IV Steering Committee–location tbd</p>
November	<p>Secretariat Team Meeting</p> <p>SUSTAINS Mid-Term Workshop, Brussels</p> <p>Policy Advisory Group (PAG) Meeting</p> <p>Meetings with representatives of Council Presidencies (IE and LT)</p> <p>Local Meetings with EPF National Coalitions</p>
December	<p>EPF Board Meeting including Elected Officers' Meeting</p> <p>Meetings with representatives of Council Presidencies (GR and IT)</p> <p>InterQuality final conference, Copenhagen, DK</p>

## Annex III: Summary of key policy actions in 2013

Action	Objective	Strategic Goal(s)
Chronic Diseases	<p>Continue engagement of our membership in the process related to the Commission Communication on chronic diseases.</p> <p>Development of policy recommendations on patient involvement in chronic diseases management.</p>	2 and 3
Active and Healthy Ageing and the needs of older patients	<p>Continue to participate at all levels in the EU Innovation Partnership on Healthy and Active Ageing.</p>	ALL
Information to patients and Health Literacy	<p>Continue to promote Health Literacy as a critical tool towards patient-centred healthcare and a pillar for the reduction of health inequalities.</p> <p>Work closely with the EU Institutions on the next steps related to the Commission proposal on Information to Patients to ensure it is centred on patients' needs.</p>	ALL
Health Inequalities	<p>Follow up to the Commission Communication on Health Inequalities and EP Resolution (January 2011), tackling health inequalities through health literacy strategies.</p> <p>Input in EU-level actions on health inequalities including EC Communication Solidarity in health.</p> <p>Work on discrimination in health including access to healthcare of vulnerable patient groups in partnership with relevant NGOs/bodies.</p>	ALL
Quality of care and patient safety	<p>Continue to participate in the Commission Patient Safety &amp; Quality of Care Working Group.</p> <p>Monitoring on progress in implementing the Council Recommendation from the patients' perspective.</p> <p>Participating in the Joint Action on Patient Safety and Quality of Care launched in 2012.</p>	1, 2 and 3
Work with the European Medicine Agency	<p>Representation in the CHMP/PCWP and Managing Board.</p> <p>Coordinating role for patient involvement; disseminating information on medicines regulatory processes to patients.</p>	ALL
Clinical Trials	<p>Monitor and influence developments linked to the revision of the Clinical Trial Directive.</p> <p>Continue work in European Medicine Agency working group on Third Country Clinical Trials.</p>	2 and 3
Medical Devices	<p>Engage actively in the recast of the Medical Devices Directive from the patients' perspective.</p> <p>Continue regular transparent dialogue with the medical devices industry in order to exchange views and information from our respective perspectives.</p>	1,2 and 3
Innovation and personalised medicine	<p>Fostering patient-centred health innovation in the EU.</p> <p>Continue involvement in EIP-AHA and the "Initiative on corporate</p>	1, 2 and 3

	<p>responsibility in the field of pharmaceuticals”.</p> <p>Engaging with the relevant Directorates-General of the European Commission (Research, SANCO).</p>	
Access to medicines	<p>Continue to represent the patients’ perspective in the steering group and project groups within the “Access to medicines in Europe” and “Ethics and deontology”.</p> <p>Contribute to the revision of the EU Transparency Directive.</p>	1, 2 and 4
Patient meaningful involvement in EU financing programmes	<p>Continue close collaboration with DG Research and the Innovative Medicines Initiative:</p> <ul style="list-style-type: none"> <li>-to strengthen patient meaningful involvement including through direct involvement in 2013 EU and National FP7 Health Infodays</li> <li>-Support to project leaders and coordinators in implementing patient involvement straight from the onset of project planning</li> <li>-Identifying and sharing good practice of patient involvement in health research and share it with stakeholders.</li> </ul> <p>Work with other EC Directorates to foster patient involvement in the spirit of Health in all policies (health mainstreaming).</p>	ALL
Structural Funds	<p>Continue advocacy work with DG REGIO and SANCO to ensure health is central and that the patient’s perspective is included in the next Programming period 2014 -2020.</p> <p>Disseminate EPF’s Toolkit on Structural Funds among members.</p>	1, 2 and 3
HTA	<p>Contribute actively to the EUnetHTA project and stakeholder forum.</p> <p>Disseminate EPF Research on patient involvement in HTA.</p>	1,2 and 3
ICT and eHealth	<p>Develop EPF’s position on eHealth, continue strong presence in EC eHealth User Group, continue participation in the eHGI, develop transparent relationship with IT industry.</p> <p>Continue to work on RENEWING HEALTH on Telemedicine.</p>	1,2 and 3
EU Health Strategy 2014-2020	<p>Participating in the policy-making process around the next EU Programming period (2014-2020), particularly Third Public Health Programme, the Eight Framework Programme for Research and Development (FP8), the new Competitiveness and Innovation Programme, the new PROGRESS programme and the fifth reform of the Structural Funds for the years 2014-2020 to ensure strong focus on patient-centred health and patient involvement.</p>	ALL
Youth Strategy	<p>Continue to implement the EPF Youth Strategy and develop the Second Operational Work Plan 2013-2014.</p> <p>Cooperation with other youth organisations and youth groups.</p> <p>Watching brief of Commission’s work on youth and health.</p>	ALL
Health Workforce	<p>Contribute to the revision of the Professional Qualifications Directive in partnership with health professionals’ organisations at EU level.</p>	1,2,3 and 4
Implementation of key EU health legislative texts	<p>Continuing to monitor the transposition and implementation of the directives on Cross-border healthcare, Pharmacovigilance and Falsified medicines.</p> <p>Ensuring effective dissemination of information to patient communities.</p>	ALL

	Supporting patient groups to engage proactively at national level to ensure national laws are patient-centred and effective in achieving the objectives of the EU legislation.	
EPF and the global health agenda	In collaboration with IAPO, contribute to an EU perspective on global health developments.	1, 2 and 3
Strong patient perspective in the EU Presidencies	Influence to the maximum degree possible the governments holding the EU Presidencies in 2013 and starting a dialogue with those holding the EU Presidency in 2014. Regular communication with the health attaches in all permanent representations and relevant national health officials and politicians.	ALL
Campaign for the elections of the European Parliament and the European Commission	To secure a strong on-going relationship with highly committed MEPs from across the political groupings to enable us to optimise our effectiveness in the European Parliament on specific health-related policy issues. Disseminate EPF updated Manifesto.	ALL
Policy Involvement in Agencies, Think-Tanks and Advisory Panels	Continue to work with EU agencies and participate actively in a number of other health-related think tanks and advisory panels to gather information, exchange good practice and to reinforce its key policy messages on topical issues.	ALL



## Annex II – Summary of main programmes and projects 2013

Action	Objective	Strategic Goal(s)
eHealth Governance Initiative	Participate actively in this Initiative as one of the key stakeholders	1, 2 and 3
RENEWING HeALTH	Pilot telemedicine – Co-managing the User Advisory Board Project implementation: year 3 Continue active contribution as an associate partner to ensure the integration of patient perspective	1, 2 and 3
EMPATHY	Youth involvement in policy making 4-day seminar with youth and policy makers	1, 2 and 3
InterQuality	Quality and Sustainability of healthcare systems Last year of implementation – Final conference Continue active contribution as an associate partner	1, 2 and 3
SUSTAINS	Collecting user requirements for the piloted services Developing a model for patient empowerment assessment	1,2 and 3
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	1, 2 and 3
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.	1,2 and 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	1,2 and 3
Capacity Building Programme	Organisational and advocacy capacity building of patient groups	2 and 4
Patients' evidence workshop	To address in depth a key policy issue for patients, either in light of EU developments in a particular area, or as a result of discussion at the Annual General Meeting.	1,2 and 3