

## EUROPEAN PATIENTS' FORUM

# Annual Work Plan 2012



europeanpatients'forum



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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 2012 takes forward this strategy and builds on the outcomes of the 2007, 2008, 2009, 2010 and 2011 Annual Work Plans. It also takes on board the external political environment to reflect the likely European healthcare developments during the course of 2012 and beyond, including the new round of negotiations over 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 networking. 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.** 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 patients and patient organisations all across the EU.** In relation to the latter our key activities are:
  - Supporting our membership through targeted activities, including capacity building activities particularly in new EU Member States (see EPF Regional Advocacy Seminars in Lithuania 2008, Bulgaria 2009, Hungary 2010, and Romania 2011) and their involvement in policy work and sharing of good practice
  - 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 2012

The EPF 2012 **Annual Work Plan** distinguishes between an **Operational Work Programme** consisting of all EPF's 2012 core activities arising from an Operating Grant under the Public Health Programme, and our basket of projects and activities 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 activities funded by unrestricted funds from sponsors.

The operational objectives for our 2012 Annual Work Plan are as follows:

### OBJECTIVE 1

**Building capacity** within the governance structures, the secretariat, and through reinforcing and extending the membership, and diversifying / solidifying funding (GOAL 1-5)

### OBJECTIVE 2

**Consolidating our policy impact** (GOAL 1-3)

### OBJECTIVE 3

**Feeding Project' and Patients' Evidence into policy** (GOAL 1-3)

### OBJECTIVE 4

**Building powerful and effective communications and partnerships** (GOAL 1-5)

The Operational Work Programmes contributes mostly to Objectives 1, 2 and 4 of the Annual Work Plan, while the activities outwith the Operational Work Programme contribute primarily towards Objective 3 and indirectly towards Objective 2 and 4.

The Operational Work Programme includes, among other things, all **advocacy work** that will be carried out in 2012, including the activities of the **Policy Advisory Group**, two **Patient Evidence Seminars**, the **Annual General Meeting** and the attached **Strategic Planning Seminar**, the activities of the EPF **Youth Group**, and the **Fifth Regional Advocacy Seminar**. All communications and representation work is also included under the Operational Work Programme.

Alongside the core programme in 2012 EPF will continue to be involved in the following projects: **Chain of TRUST** as project coordinator, **RENEWING HeALTH**, **InterQuality**, and the **eHealth Governance Initiative** as beneficiary. Three new projects started in 2012: **SUSTAINS** on patient access to Electronic Health Records (EHR), the **Joint Action on Patient Safety and Quality of Care**, and **EUPATI** to create better education/ information tools for patients on pharmaceutical research (led by EPF). We will also launch a major **Capacity Building Programme** following up on the Value+ project on meaningful patient involvement and hold a EU-level **conference on eHealth** towards the end of 2012. An EPF project on Health Technology Assessment (HTA) intended to follow up and capitalise on the series of HTA surveys carried out in 2011 is also expected to start in 2012.

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

## OBJECTIVE 1: Building Capacity

### 2.1.1 EPF secretariat and Governance

In 2012, the Secretariat will be composed of the equivalent of eleven full time staff, two part time staff.

EPF's permanent secretariat team will be composed of an executive director (Nicola Bedlington), a programme manager (Liuska Sanna), a senior policy advisor (Kaisa Immonen-Charalambous), an operations manager (being recruited), an office manager (Véronique Tarasovici), a senior programme officer (Walter Atzori), a programme officer (Giulia Evolvi), a policy officer (Laurène Souchet), a research officer (Özgün Ünver), a communications officer (Cynthia Bonsignore), a part-time webmaster (Žilvinas Gavėnas), a project officer (being recruited) and a part-time administrative assistant (being recruited).

A management team composed of the executive director, the programme manager, the senior policy advisor and the operations manager is also established.

EPF has contracted an accountancy firm to manage the book-keeping and financial accounts in accordance with Belgian and Luxembourg law. An external auditor will audit the accounts for 2012 and these will be presented for adoption to the Annual General Meeting (AGM) in spring 2013, and published on the web site together with our Annual Report 2012 within one month of this meeting in line with our policy on transparency.

The **EPF Board**, composed of 9 representatives elected by the EPF membership, will meet in Brussels four times in 2012 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 five board members.

EPF has the opportunity to meet its entire membership two-three times a year through our AGM and other conferences and seminars organised throughout the year. In between meetings on-going communications with our memberships 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 our members.

### 2.1.2 Meeting and supporting Europe's patients

The following major EPF meetings and events will take place in 2012:

- The **Annual General Meeting (AGM)** will be held on April 18-19 2012 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 the EPF, which shall include, *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 **Strategic Planning Seminar** held in conjunction to the AGM in spring 2012 will involve EPF members in the shaping of our second Strategic Plan for the years 2014-2020. The outcomes of this seminar will lead to the development of a draft EPF Strategic Plan 2014-2020 which will be circulated for further consultation with our members and allies in late 2012, with a view to adoption at our 2013 AGM.

- The fifth **Regional Advocacy Seminar** will take place in autumn 2012 in Lisbon, Portugal and will target Mediterranean EU Member States. The thematic focus of the seminar will be the involvement of patient organisations in Structural Funds.

#### EPF Regional Advocacy Seminars

Annual EPF Regional Advocacy Seminars is the approach EPF is pursuing to engage and work with national patient organisations and their national coalitions with a view to a) integrating national perspectives into the European debate to have a stronger patient voice; b) feeding policy information and policy outcomes back into national realities and contexts; c) developing and sustain the advocacy capacity of patient leaders particularly in new Member States. The value of this approach has been strongly confirmed by the success of the advocacy and capacity-building seminars for patient leaders held over the previous four years in Lithuania (November 2008), Bulgaria (September 2009), Hungary (October 2010), and Romania (October 2011).

While the core objective of strengthening patient leaders' advocacy skills was and will continue to remain the key feature of EPF's advocacy seminars, these seminars represent also an opportunity to address specific issues which we identify in close consultation with our members on the basis of needs and challenges faced by the patient community. Issues such as promoting the establishment of national coalitions of patient organisations, health literacy, the meaningful involvement of patients in EU policies and projects, the involvement of young patients in patient organisations, and cooperation between patient and health professional organisations were addressed in previous seminars.

- The **EPF Policy Advisory Group** will meet physically twice in 2012. 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. The group first met in November 2009, and holds two/three meetings a year in Brussels. In-between, it will hold teleconferences as needed, or otherwise communicate 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. Usually, the Secretariat sets the agenda for meetings in consultation of the group (focusing on the issues where the Secretariat particularly needs members' input). We then prepare a set of background briefings for the group, which will form the basis for discussion during the meeting. The PAG gives its input, approval, constructive criticism, identifies issues we haven't included but should, etc. On that basis we then prepare a final member consultation document or a formal response to an issue.

- One **patients' evidence workshop** on specific areas identified by the membership will also take place in 2012.
- A **thematic Policy Conference** focussing on the patient perspective on eHealth.

Moreover EPF will:

- Provide on-going support to our members through a dedicated membership officer who will be recruited in mid-2012. 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. The Youth Strategy, which was adopted by the 2011 Annual General Meeting, 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).

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

- 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 2012
- The **Second Annual Congress of the EPF Youth Group** will take place in summer 2012. And will focus on the shaping of the Second Work Plan implementing the EPF Youth Strategy to be adopted at the AGM in 2013. 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 Second Youth Congress will include a workshop focused on team building and leadership skills for the members of the Youth Group.

An application for a youth project under the EU Youth in Action Programme is also envisaged in early 2012. The project idea, which was agreed at the Youth Group meeting held in August 2012 is to organise a four-day seminar for young patients, experts and stakeholder actors in the fields of health, education and youth policy, including decision-makers, in order to promote a more holistic approach to addressing young patient needs in decision-making processes.

#### 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. The Youth Group will hold its official kick-off meeting in August 2011 - "I EPF Youth Congress" - when a Youth Board will be elected. It will meet physically 2-3 times per year, including at the AGM.

To implement the Youth Strategy an incremental approach will be adopted. Accordingly, the Strategy will be implemented through subsequent two-year operational work plans outlining specific operational priorities and associated activities, each contributing to at least one of the strategic goals identified for this strategy. The first operational work plan will cover the years 2012-2013 with two the key objectives:

a) establishing and consolidating the EPF Youth Group

b) implementing actions aimed at strengthening the capacity and the empowerment of the members of this group in order for them to be able to become gradually involved in EPF activities and, in the long run, in EPF governance structure.



#### 2.1.4 Reinforcing and Growing the Membership

EPF will continue to work towards expanding its membership in 2012, also to include more representative national patient umbrellas/platforms.

Our target membership for 2012 is 55 members from the current 51 and to broaden the representation across the key disease areas and the Member States (negotiations are on-going with Czech Republic and Hungary). This will be done by inviting relevant patient leaders to our events and following up on these contacts with targeted meetings in the Member States.

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 will be 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. 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 2012 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 implementation process of the above mentioned policies.

Similarly, EPF will support its members in getting involved in HTA processes through a designated HTA Guide for the EPF Membership, building on the HTA Seminar in 2010 as well as on the results of a series of targeted surveys addressed to HTA agencies, appraisal committees and patient organisations undertaken in 2011 aimed at identifying good practices of and barriers to patient involvement in HTA.

EPF will strengthen alliances with its existing active 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. We will also be supporting our members at the national level by contributing to the European health agenda, disseminating the EPF Membership Guide and translating core documents wherever possible.

#### 2.1.5 Rigorous financial planning

In 2012 we will continue to undertake very rigorous financial planning and prudent expenditure to ensure optimum use of the resources made available to EPF.

### 2.2 OBJECTIVE 2: Consolidating our Policy Impact

Throughout 2012 EPF will continue to play a pro-active role in promoting a patient-centred philosophy and agenda, notably by being active in the follow up of the "Europe for Patients" campaign initiated by Commissioner Vassilou and advanced by Commissioner Dalli.

During 2011 EPF was pro-active within the framework of the Europe 2020 policy debate in order to ensure that the European strategy for delivering growth in the new decade takes on board a strong patients' perspective. This work will continue in 2012 with a focus on the reform of major relevant

EU funding programmes aimed to support the delivery of the EU2020 Strategy, notably the 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.

EPF works on key policy areas linked to the goals and fields of actions. Our policy work is shaped by its over-arching goals:

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

Policy areas are prioritised by our membership and reflect the EU healthcare environment and include *among others*: patient safety and quality of care, health inequalities, access to therapies, clinical trials, medical devices, information to patients/health literacy, Health Technology Assessment, health innovation and eHealth.

We are extending our activity to new policy strands, notably the needs and challenges of older patients, anti-discrimination, and access to healthcare for vulnerable groups such as migrants and ethnic minorities. We are also focusing on young patient needs and child-friendly healthcare in cooperation with Council of Europe.

Targeted activities aimed at strengthening mutual understanding between young and older patients will be implemented in 2012 under the framework of the EU Year of Active and Healthy Aging and Intergenerational Solidarity.

A detailed list of our 2012 policy work is presented in the next paragraph.

## 2.2.1 Specific Policy Priorities

### 2.2.1.1 *Chronic diseases*

EPF standpoint is that that tackling chronic disease requires both effective prevention and patient-centred management strategies that deliver quality care and are accessible and sustainable. In order to achieve this in 2012 EPF will actively engage its membership in the reflection process on the planned Commission Communication on chronic diseases.

### 2.2.1.2 *Active and Healthy Ageing and the needs of older patients*

Since 2011 EPF has been participating at all levels in the EU Innovation Partnership on Healthy and Active Ageing and preparation for the 2012 theme year for Active and Healthy Ageing and Intergenerational Solidarity. Our focus is on the specific needs and potential contribution of older patients, exchange of knowledge and experiences with all stakeholders to ensure older patients’ empowerment and full participation in society. In July 2011, EPF held a conference in Warsaw under the Polish EU Presidency, focusing on the specific needs and rights of older patients. During 2012 EPF will develop a position paper on this topic, based on the outcomes of the conference and our work under the Innovation Partnership.

### 2.2.1.3 *Information to patients and Health Literacy*

Health literacy has been a key priority for EPF since its establishment back in 2003. For that reason in

2008 EPF organised a major Conference on Health Literacy;<sup>1</sup> the conclusions and recommendations from that event will continue to inform our policy work in this area also in 2012.

In a broader approach, EPF will, therefore, continue to focus on the promotion of Health Literacy as a critical tool towards patient-centred healthcare and a pillar for the reduction of health inequalities, building on the abovementioned recommendations of our Conference on Health Literacy. We will work closely within the European Union Health Policy Forum to advance Health Literacy as a common priority, and monitoring the implementation of the EU health strategy where Health Literacy is a key element.

Information to patients is crucial in fostering health literacy. Work in this area will continue to remain central to our policy agenda throughout 2012 and beyond. More specifically in 2012 EPF will work closely with the EU Institutions on the revised Commission proposals on Information to Patients to ensure they are centred on patients' needs.

#### *2.2.1.4 Health inequalities*

The reduction of health inequalities is a major pillar of the EU Health Strategy, "Together for Health". In 2012 EPF will continue to input in EU-level actions on health inequalities from the perspective of patients with chronic diseases, including the process of monitoring of the implementation of the EC Communication "Solidarity in health", focusing on health literacy as a key tool and adopting a "health inequalities in all policies" approach, particularly in the context of EU Structural Funds for the years 2014-2020.

Furthermore, in the spring of 2012 EPF will support our member organisation NPO in preparing a Summit in Sofia, Bulgaria, focusing on health inequalities from the perspective of patients with chronic diseases.

In 2012 EPF will also develop its work on discrimination in health in the context of the EU legislative proposal currently under consideration. In 2011 EPF initiated an exploratory process on discrimination in health, including access to healthcare of vulnerable patient groups. This process will continue in 2012. EPF will also launch new collaborations with relevant NGOs and bodies representing disadvantaged groups, including the European Social Platform, the International Organisation for Migration (IOM) and the EU Fundamental Rights Agency.

#### *2.2.1.5 Quality of care and patient safety*

EPF will continue to participate actively in the Commission 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. The group brings together representatives from all 27 EU countries, EFTA countries, international organisations, and stakeholders. Throughout 2012, EPF will continue to play an active role to represent a patients' perspective in this Working Group, focusing particularly on the monitoring on progress in implementing the Council Recommendation. To this end EPF will conduct a survey on the perspective of European patient groups on the implementation of the Council Recommendation. This work will be complemented by our role in the Joint Action on Patient Safety and Quality of Care, which will be launched in early 2012.

#### *2.2.1.6 Work with the European Medicines Agency (EMA)*

In 2012 EPF will continue to prioritise our close involvement with European Medicine Agency through representation in the Working Party with Patients' and Consumers' Organisations (PCWP) within the Committee for Medicinal Products for Human Use (CHMP) and the Managing Board.

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<sup>1</sup> See Conference Report:

[http://www.eu-patient.eu/Documents/Publications/ConferenceSeminarReports/EPF\\_HealthLiteracyConference\\_2008\\_Report.pdf](http://www.eu-patient.eu/Documents/Publications/ConferenceSeminarReports/EPF_HealthLiteracyConference_2008_Report.pdf)

EPF will continue to act in a coordinating role for patient involvement, disseminating information about EMA and medicines regulatory processes to patient communities across EU, and supporting EMA in further developing patient involvement. EPF will also work within several working groups, giving expert input from the patients' perspective on:

- the ethics of third country clinical trials
- implementing public access to EudraVigilance
- implementing the new EU rules on Pharmacovigilance, Falsified medicines and information to patients.

#### *2.2.1.7 Clinical trials*

In 2012 EPF will continue to engage in the process of revising the 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) on issues related to clinical trials, particularly through participation in the Working Group on Ethical Issues in Third Country Clinical Trials.

#### *2.2.1.8 Medical devices*

Having contributed to the exploratory process on medical devices in 2009, and the High Level Conference on Medical Devices, EPF will engage actively in the recast of the Medical Devices Directive from the patients' perspective. EPF has also set up a regular dialogue with the medical devices industry in order to exchange views and information from our respective perspectives. These meetings take place twice yearly in line with EPF's Code of Ethics on transparency and independence.

#### *2.2.1.9 Innovation and personalised medicine*

In 2012 EPF will continue to focus on patient-centred innovation, particularly through our role in the EIP-AHA and the "Initiative on corporate responsibility in the field of pharmaceuticals", and also by engaging with the relevant Directorates-General of the European Commission (Research, SANCO) on the development of an EU framework on personalised medicine and personalised healthcare solutions.

In consultation with our members, EPF will during 2012 develop a position paper on personalised medicine exploring its implications from the perspective of patients.

EPF will contribute to the 2012 Conference on Innovating Healthcare without borders organised by DG RESEARCH in cooperation with DG SANCO, DG ENTERPRISE and DG REGIO, and involving all key stakeholders in the innovation of healthcare chain, including the relevant industries, policy makers, researchers, patients/patients associations, and healthcare operators. The objective of the Conference is twofold: removing borders in the health supply chain assessing priorities achieved to date and areas where additional efforts are needed, and "Inequality and solidarity" exploring new challenges within EU and beyond.

#### *2.2.1.10 Improving access to medicines*

EPF is a partner in the Commission Initiative on corporate responsibility in Pharmaceuticals (2010-2012) and will continue to represent the patients' perspective in the steering group of the Platform on Access to Medicines in Europe and the Platform on Ethics and Transparency. EPF is also active in the specific project groups within each Platform, and collaborates closely with the Platform on Access to Medicines in Developing Countries through our allied organisation, IAPO. In 2012 EPF will also contribute to the revision of the EU Transparency Directive.

### *2.2.1.11 eHealth and telehealth*

eHealth is central to EPF's vision of high-quality, patient-centred, equitable healthcare. In 2012 EPF will continue its involvement in eHealth, addressing topics such as interoperability, patients' data, ethics and privacy, with a focus on the users' perspective and attitudes to improve acceptance towards eHealth. EPF will continue to contribute actively to the eHealth Governance Initiative and start using the outcomes from our telehealth projects "Chain of Trust" and "RENEWING HEALTH (see paragraph 2.3.1) to inform our policy. A new project focused on patients' access to Electronic Health Records called SUSTAINS, which started at the beginning of this year, will be a key priority for EPF in 2012 and in the years to come (see EPF project section).

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 which since 2011 enjoys new status and responsibilities due to the Commission's introduction of an eHealth Governance Structure.

### *2.2.1.12 Health Technology Assessment (HTA)*

Health Technology Assessment (HTA) has come to the forefront of European health policy relatively recently, primarily as part of a strategy to contribute to the sustainability of healthcare systems, and with the purpose to enhance EU cooperation and good practice in this area of HTA. Involving patients in HTA processes is important as they are individual experts who know precisely how a disease impacts on their daily life and how specific treatments can influence quality of life and capacity to participate in a work and social environment.

In 2012 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<sup>2</sup>, as well as our research conducted in 2011 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>3</sup>. Based on the outcomes of this research initiative, EPF will publish a good practice toolkit which will be largely disseminated in 2012 mainly across HTA agencies, patient organisations and decision making bodies in the EU, but also other relevant stakeholders. A follow-up project on the HTA research work undertaken in 2011 is envisaged to be developed in mid-2012.

In 2012 we will also continue engaging actively in the new Joint Action on HTA which has been co-financed by the EU Public Health Programme Work Plan 2011.

### *2.2.1.13 Patients' Meaningful Involvement*

One of EPF's overriding policy goals is to promote the involvement of patient organisations in EU health-related projects. Our 2008-2009 Value+ project<sup>4</sup> on promoting the meaningful involvement of patients in EU projects has been very successful in raising awareness about the added-value of involving patients' organisations in projects, as well as in increasing the capacity as patients'

<sup>2</sup> See Conference Report: <http://www.eu-patient.eu/Documents/Publications/ConferenceSeminarReports/hta-seminar-2010-brussels-report.pdf>

<sup>3</sup> See: <http://www.eu-patient.eu/Initatives-Policy/Initiatives/>

<sup>4</sup> See project website : <http://www.eu-patient.eu/Initatives-Policy/Projects/EPF-led-EU-Projects/ValuePlus/>

organisations of getting involved in projects as equal partners and of applying for and managing EU supported projects. This is clearly demonstrated, for instance, by 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.

EPF standpoint is that meaningful patient involvement leads to stronger project outcomes that will feed ultimately more effectively into a patient-centred EU health agenda. To continue pursuing this goal EPF will:

- Continue to work with DG RESEARCH in order to:
  - Promote patient meaningful involvement through participation and interventions in 2012 EU and National FP7 Health Infodays
  - Participate in EU-level workshops for FP7 Health National Contact Points to provide guidance on patient involvement
  - Support project leaders and coordinators in implementing patient involvement straight from the onset of project planning
- Identify and share good practice of patient involvement in health research. Work with other Commission Directorates, including health (Public Health Programme), information society (ICT for Health), regional policy (European Regional Development Fund), employment and social opportunities (PROGRESS and the European Social Fund) and enterprise (innovation in healthcare), in the spirit of Health in all policies (health mainstreaming).

#### *2.2.1.14 Health and Structural Funds 2014-20*

Throughout 2010 and 2011 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.

2012 is a crucial year for the future of Cohesion Policy as the Commission will launch a major consultation on the new Strategic Guidelines on Cohesion to which EPF will respond while the Member States will start working on the new National Strategic Reference Framework 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. 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 preparation, implementation and monitoring of health-related Structural Funds’ programmes, particularly using the EPF Toolkit “Getting Involved in Structural Funds” currently being finalised.

As mentioned at the beginning of this document, Structural Funds will be the thematic priority of EPF fifth Regional Advocacy Seminar.

### *2.2.1.15 EU Health Strategy 2014-2020: the Public Health Programme and beyond*

In 2012 considerable energy will be directed towards the participation in the policy-making process around the next EU Programming period (2014-2020), particularly 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.

### *2.2.1.16 Health workforce*

In 2012 EPF will contribute to the revision of the Professional Qualifications Directive from a patients' perspective. We will continue to work in partnership with health professionals' organisations at EU level to develop joint activities focusing on the patient-health professional relationship in the context of the changing role of patients and patient-centred health systems (e.g. adherence to therapies, concordance, the role of self-care, communication issues, shared decision-making, etc.).

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

In collaboration with IAPO, EPF will contribute an EU perspective on global health developments.

### *2.2.1.18 Implementation of key EU health legislative texts*

In 2012 EPF will place strong emphasis on post-adoption of key EU health legislative texts by continuing to monitor the transposition and implementation of the directives on Cross-border healthcare, Pharmacovigilance and Falsified medicines, ensuring effective dissemination of information to patient communities, 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 will be part of a broader strategy aimed at supporting EPF members in participating in national health debates (including transposition and implementation of EU health-related directives) as equal partners.

### *2.2.1.19 Youth and Health*

EPF 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 2012 EPF will work on a number of youth-related policy areas to ensure that the perspective of young chronic patients is effectively integrated and will take steps to mainstream youth issues in our health policy work with a view to making sure that the impact on youth of future EU health policy developments is properly assessed.

## *2.2.2 Other Policy-related activities*

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 (e.g. a “thematic” Policy Conference). These are briefly presented below.

### *2.2.2.1 Building on Existing Relationships with the European Parliament*

During the past few years EPF galvanised links with key MEPs already established, notably through our work on the Health Literacy Declaration and our EPF Patients' Manifesto (see below) in the context of the last European Parliament elections. Over 120 MEPs have expressly committed

themselves to the work of EPF. We have chosen not to set up an interest group or an 'intergroup'. 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.

#### *2.2.2.2 The EPF Manifesto Campaign '150 Million Reasons To Act'*

In 2012 EPF will continue to promote the EPF Manifesto amongst patient organisations as an advocacy tool to be used in their work at national and European levels<sup>5</sup>.

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

EPF will liaise as closely as possible with Denmark and Cyprus, who are holding the EU Presidencies in the first and second semester of 2012 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 Ireland and Lithuania, which are holding the EU Presidency in 2013. Regular communication will continue with the health attaches in all permanent representations and relevant national health officials and politicians.

#### *2.2.2.4 Policy Involvement in Agencies, Think-Tanks and Advisory Panels*

As briefly mentioned in 2.2.1.6 EPF will continue to provide input in the European Medicines Agency (EMA) inter alia through the patient representative on the EMA Board, and direct involvement of an EPF representative in the EMA Patients' and Consumers' Working Party and other ad hoc expert groups, including the Working Group on Third Country Clinical Trials, and working group on public access to the Eudravigilance database.

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

- the European Health Policy Forum
- European Innovation Partnership on Active and Health Ageing, in which EPF has been involved at many levels, including as a member of the Steering Group in charge of mapping the specific objectives and drafting the Strategic Implementation Plan
- 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 health systems and services
- EC Working Group on Patient Safety and Quality of Care
- Platform on Access to Medicines in Europe

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<sup>5</sup> For more information on the EPF Manifesto "150 Million Reasons to Act", see: <http://www.eu-patient.eu/Initatives-Policy/Policy/EPF-Manifesto-150-Million-Reasons-to-Act/>



- EU Health Portal Editorial Group
- EUROPA BIO patient's advisory group,
- the 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.

#### 2.2.2.5 Thematic Conference

EPF will hold a major thematic conference in December 2012 on eHealth which will be attached to the Final Conference of the Chain of TRUST project. This joint event is a key opportunity for EPF to influence proactively the EU agenda, rather than be reactive to the legislative and policy environment. In order to prepare this Conference, a scientific advisory group will be established to develop a reflection document that will inter alia, outline the issue at hand, the rationale and structure behind the Conference, and will also implement the outcomes of the Conference with the three key EU Institutions.

#### 2.2.2.6 2012 Conference on Gender and Health through Life

In line with EPF's commitment to equitable healthcare, EPF will be a partner in the Copenhagen Conference 2012 on Gender and Health through Life, with the support and participation of the Danish EU Presidency. This will take place in mid June 2012. The Conference is organised by the European Men's Health Forum, the European Institute for Women's health and the Danish Society for men's health, and EPF and will be supported by the Danish Ministry of Equality.

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

The overall rationale behind this objective is to substantiate EPF's knowledge base and policy lines, with input from the patients' community throughout the European Union. Since 2007 EPF has participated in different EU-funded projects, as either leader or associate partner in accordance with specific criteria for participating in EU projects agreed by the EPF Board in 2008.

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

### 2.3.1 Overview of EU Projects

#### 2.3.1.1 Chain of Trust



In 2012 EPF will continue to lead the Public Health Programme-supported Telehealth project "Chain of Trust", launched in early 2011 and running for 24 months. The Chain of Trust project looks at assessing the

perspective of the main end users of telehealth services across the EU with the purpose of seeing if and how views have evolved since the initial deployment of telehealth and what barriers still exist to enhancing users' confidence in and acceptance of this innovative type of services.

The project has two specific objectives:

- Objective 1 Knowledge gathering

To improve available knowledge of the specific views – needs, perceptions on the added value and concerns - among patients and health professionals with regard to telehealth services.

- Objective 2 Raising awareness and understanding

To increase awareness and understanding of users' perspective on telehealth amongst patients' and health professionals' organisations and health authorities at European and Member State level.

While in 2011 the project largely focused on gathering knowledge of users' perspective through undertaking a literature review, conducting an online survey and implementing six national workshops in different European countries, namely Greece, Latvia, the Netherlands, Norway, Poland and Portugal, the main focus in 2012 will be on delivering on the second objective, i.e. Raising awareness and understanding. Among other things, in 2012 the project will implement four European focus groups one for each user group identified for this project, i.e. patients, doctors, nurses and pharmacists, and six national roundtables with policy makers in the countries selected for the national workshops. A final conference will be organised in Brussels in December.

More information on the Chain of Trust project:

[www.chainoftrust.eu](http://www.chainoftrust.eu)

### 2.3.1.2 RENEWING HeALTH



Funded under the Competitiveness and Innovation Programme (CIP) – ICT Policy Support Programme - RENEWING HeALTH aims at implementing 26 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 development and 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).

For more information on the Chain of Trust project: [www.renewinghealth.eu](http://www.renewinghealth.eu)

### 2.3.1.3 InterQuality



2012 will be the second year of the three year “International Research Project on Financing Quality in Healthcare” – InterQuality. This project officially started in December 2010 and is funded by the 7th EU Framework Programme (FP7). It is led by the Medical University of Warsaw and is implemented by a consortium of eight partners in addition to the coordinator. EPF is involved as an associate partner and is leading the work related to dissemination of project progress and results.

InterQuality has the following objectives:

1. Investigate 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. Develop 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 the Chain of Trust project: <http://interqualityproject.eu/>

#### 2.3.1.4 SUSTAINS



SUSTAINS - *Support USers To Access INformation and Services* – is a three-year pilot study on patient access to Electronic Health Records (EHR) co-funded under the CIP-ICT programme of the European Union. This project, which kicked-off in January 2012, represents an excellent opportunity to explore and gather evidence-based information on patients' access to EHR and assess whether and how patient empowerment can be effectively strengthened as a result of such access.

To this end SUSTAINS will provide 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 will play a key role in this project, 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, EPF will lead the work on patient requirements identification which will inform the use cases specification of the piloted services. In the context of WP3, EPF will lead the work on patient empowerment evaluation aimed at assessing the change in patient empowerment before and after using the services.

#### 2.3.1.5 EUPATI



The EPF-led project EUPATI, standing for "European Patients' Academy on Therapeutic Innovation" will kick off 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), a public-private partnership between the European Commission and EFPIA, the umbrella organisation of pharmaceutical industry and associations operating in Europe.

From 2012, 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, pharmaco-economics as well as patient involvement in drug development.

To improve the availability of both patient-centric information as well as educated patient experts, 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. It features excellence across disease areas in state-of-the art, high quality, objective education to patients about therapeutic innovation.

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.

#### *2.3.1.6 Joint Action on Patient Safety and Quality of Care*

The Joint Action on Patient Safety and Quality of Care will start work in early 2012 with the overall aim of creating a permanent platform for future cooperation between 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
- Facilitate the sharing of good practices in patient involvement and empowerment

#### *2.3.1.7 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.

#### *2.3.1.8 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.

The overarching objective of the EUnetHTA Joint Action (JA) is to put into practice an effective and sustainable HTA collaboration in Europe that brings added value at the European, national and regional level. The Collaboration's vision is to contribute to the generation of HTAs to inform policy and healthcare decision-making in European countries so that new health technologies can be adopted and obsolete technologies abandoned in a well-informed and robust manner, hence bringing about high quality, safe, accessible, sustainable, ethical and efficient health care for citizens across Europe.

Uniting government-appointed organisations from EU Member States, EEA and EFTA countries and a large number of relevant regional agencies and non-for-profit organisations that produce or contribute to HTA, the EUnetHTA Collaboration focuses on HTA in Europe to facilitate efficient use of resources available for HTA, to create a sustainable system of HTA knowledge sharing, and to promote good practice in HTA methods and processes.

EPF is a 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

Other project applications submitted in 2011 include (*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 early October 2011 under 2012 FP7 Health. 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.

The application was successful in the first stage and a full project proposal comprehensive of detailed budget will be submitted in early February.

### 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.

This project is subject to a two-stage application process. Since the application was successful in the first stage, a full project proposal will be submitted in February 2012 and EPF needs to nominate a representative for the project Advisory Board.

### 2.3.3 Other projects and activities linked to this objective

#### 2.3.3.1 EPF Capacity Building Programme

Following dissemination of the results and resources of the EC-funded project Value+ throughout 2010 and 2011 (<http://www.eu-patient.eu/projects/valueplus/index.php>), in 2012 EPF will launch a major follow-up project focused on capacity building among patient organisations at national, and European level.

As far as patient organisations are concerned the EPF Capacity Building Programme will have two main pillars: focus on organisational aspects for patient organisations (e.g. financial management, fundraising, organisational management, etc.); focus on policy and, advocacy skills.

A different approach will be followed depending on whether organisations are national or pan-European patient organisations. Hence, whereas national organisations will be supported through targeted activities tailored to the specific national contexts and priorities, EU-level organisations will also benefit from specific activities aimed to help them better support their national members.

#### 2.3.3.2 Patients' evidence workshop

During the course of 2012, 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.

#### 2.3.3.3 HTA project

As mentioned earlier a follow up- project on HTA is envisaged to be developed during the course of 2011 building on the outcomes of the survey work undertaken in 2011.

#### 2.3.3.4 New projects

In 2012 we will continue to join consortia according to our policy on participating in EU projects as associate partners in selected projects in the research, and public health field that are of particular relevance to EPF and our policy interventions. In line with our Youth Strategy, EPF will also explore funding opportunities under the Youth in Action Programme to promote dialogue between the large young patient community and policy makers in the areas of youth, health, employment, and education policy.

## 2.4 Communication and partnership

In 2012 EPF will continue to build powerful and effective communications and partnerships, using the external communication strategy adopted by the board in December 2007.

### 2.4.1 Representation Work

EPF will continue to have a strong presence at all major EU health events where it is vital to ensure patients' perspective. In 2010, EPF presented at, or moderated in approximately 50 such European health meetings. A non-exhaustive list of major events we participated as either speakers or moderators can be found on page 29-30 of the 2010 Annual Report which is sent together with this 2012 Annual Work Plan.

Since 2011, because of capacity and overriding policy priorities that require an on-going presence in the EU Institutions, strict criteria have been agreed by the board to decide whether participation is

appropriate in specific events, to which we are invited. This will mainly be done by gauging their potential impact and added value.

## 2.4.2 Communication Outreach

### 2.4.2.1 Communications and dissemination Capacity

Thanks to our ever growing membership EPF is in a privileged position to give high visibility to its activities while ensuring that impact is shared with grassroots patients. Thanks to the solid partnership with EU level health stakeholders, including the EU institutions, EPF is in the position to ensure high visibility and awareness of our activities to the other stakeholders, i.e. informal carers, health professionals, health and regional authorities, industry, EU policy-makers and think-tanks. A full-time communication officer will coordinate the communications and dissemination work of EPF in 2012.

### 2.4.2.2 Communication Products

- Our **website** will continue to be our major external communications tool. In 2009 we designed a more user-friendly website with greater navigational capabilities and accessibility features. The website will be regularly updated with new information on policy initiatives, project updates and news. As a central communication tool for EPF, our aim for 2012 is to attract a wide readership base and become the main source of information for patients and their organisations. To that end we will make our website more interactive and, thus, a more 'complete' dissemination tool.
- In 2012 EPF will continue to produce the **EPF Mailing** to members and those working closely with us, with EU news, information and issues with a potential impact on patients. Based on the very positive feedback received so far, we have expanded the distribution list to make it accessible to a wider network. There will be approx. 3000 direct recipients in 2012, many of whom will pass it on to their respective networks. The EPF Mailing includes strategic contacts in all the EU Institutions, industry and in the Member States. See: <http://www.eu-patient.eu/Publications/EPF-Mailing/>
- Up to 2011 **Social Media** were explored mainly in relation to the Youth Strategy although videos of EPF events are already being updated on our YouTube channel. In 2012 we will launch a broader social media strategy to further expand our outreach capacity
- **EU-level press and media.** Over the last years EPF has developed relations with a number of EU-level press and media. In 2012 our media outreach work will be more proactive, thanks to the recruitment of a dedicated communication officer, and will be linked to our external activities and our presence at key health events. We will also continue to cultivate contacts with selected health journalists and EU journalists. EPF will work in close cooperation with national umbrella patient organisations in countries where there is a strong media outreach (e.g. Spain, Poland and Romania) and agree that they "market" EPF in these countries, through their own media activities.
- **Other tools:** In 2012 we will:
  - continue to produce ad hoc press releases to the external mailing and media lists
  - produce our **VI Annual Report** with an overview of its achievements in 2011
  - translate as many key documents into French and other languages as possible

### 2.4.3 Working with Partners and Allies

EPF's *leitmotif* is partnership and trust with all other stakeholders committed to improving EU health services and outcomes. For this reasons since its establishment in 2003, EPF has been devoting significant time to developing alliances and good working relations with a number of European organisations with which we have a common agenda, and EPF will sustain and enhance this during the course of 2012.

#### 2.4.3.1 Cooperation with other patient groups

As to patient groups, we collaborate at all levels with organisations that have yet to join EPF, and encourage the establishment of national coalitions where not yet in place and exchange of good practice among patient organisations.

In 2012 we will continue to work as closely as possible with major EU and international patient groups such as the EU Aids Treatment Group, European Heart Network, and our global sister organisation, the International Alliance of Patient Organisations (IAPO) with which we have a Memorandum of Understanding clarifying our geographic and political remit and supporting our joint work.

#### 2.4.3.2 Cooperation with other health stakeholders

In 2012 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, Pharmaceutical Group of the European Union (PGEU) on cooperation with pharmacists, the European Federation of Nurses Association (EFN) on the patients' role in continuing professional development of nurses. We work closely with these NGOs to ensure a coherent NGO input in EU health policy debate. These organisations are also associate partners in the EPF-led Chain of Trust telehealth project.

In 2012 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), specialists (UEMS), health managers (EHMA) as well as with major EU health platforms such as the European Society for Quality in Healthcare, the European Public Health Alliance 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 consumer organisations, 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.

#### 2.4.3.3 European Commission's DGs 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, EMPSOC and REGIO. EPF will also continue to build working relations with EU health agencies to enhance our visibility and to encourage a stronger patient perspective in their work. In addition to EAHC (European Agency for Health and Consumers) and EMA (European Medicines Agency), EPF will also work with the European Observatory for Healthcare Systems and the European Centre for Disease Prevention and Control and Control.

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 Council of Europe, OECD and UNICEF.





## 3. 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 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.

### 3.1 Key Performance Indicators

The following performance indicators will be used to measure our success in 2012 against defined objectives.

#### Objective 1: Building Capacity

- **Indicator 1: EPF is able to broaden its membership**

Target: 55 members-at least 2 are national coalitions (currently 50).

- **Indicator 2: Perceived success of Regional Advocacy Seminar** (evaluation forms)

Target: Increased cooperation with patient orgs in Mediterranean Member States through their contribution to EPF's positions and statements.

- **Indicator 3: EPF is able to integrate youth representatives in its activities and governance**

Target: 15% of participants in EPF events are youth, 1 youth representative is nominated for the Policy Advisory Group, and preparation for the election of a Youth Board member in 2013.

#### Objective 2: Consolidating EPF Policy Impact

- **Indicator 4: EPF is recognised as a key partner in determining civil society's input in EU health policy**

Target: EPF's effectiveness in the political dialogue measured by the inclusion of EPF comments in the European Commission, European Parliament and Council's positions and initiatives envisaged in 2012.

- **Indicator 5: EPF is able to support national patient organisations in engaging in transposition of EU directives having an impact on patients**

Target: patient organisations are involved in the transposition process of key EU directives

- **Indicator 6: Degree of influence on the 3rd Public Health Programme, FP8 Health, ICT and Structural Funds 2014-2020 programmes to enable better focus on key health issues and participation of patient organisations in projects**

Target 1: key health issues and health inequalities with clearly defined indicators (health in all policies) are addressed in EU programmes.

Target 2: inclusion of mechanisms facilitating participation of patient organisations in the strategic documents and specific Calls linked to these programmes.

Target 3: participation of national patient coalitions in the preparation of Cohesion Policy documents 2014-2020

### **Objective 3: Feeding Project' and Patients' Evidence into policy**

- **Indicator 7: Degree of success in feeding project evidence into policy**

Target 1: feeding outcomes of current projects into policy

Target 2: developing a clear evidence-based patient position on eHealth and HTA

- **Indicator 8: Degree of success in feeding outcomes of the patient-evidence workshop into policy**

Target: EPF is able to use workshop's outcomes to develop more evidence based policy positions and consensus across the membership

### **Objective 4 Communications/Partnership**

- **Indicator 9: Increase outreach of communication tools**

Target: 3000 recipients/EPF Mailing (now 2500); 50.000 visitors/website (now 35000); 1.000 participants/social media

- **Indicator 10: Enhanced Cooperation with new stakeholders, AGE, EU Youth Forum, AER Youth Group, European Social Platform, IOM and the EU Fundamental Rights Agency**

Target: Joint events/projects, participation at each other's events, meetings of youth groups.

## Annex I – Main EPF and project events

Month	Event (only events already scheduled are listed here)
January	Chain of Trust project III Steering Committee meeting–Oslo, NO SUSTAINS project Kick-off Meeting, Uppsala, SE EPF Board Meeting
February	INTERQUALITY project III Steering Committee–Hamburg, DE RENEWING HeALTH project VII Steering Committee meeting–Treviso, IT RENEWING HeALTH local meeting with users
March	Elected Officers' Meeting Secretariat Team Meeting Policy Advisory Group (PAG) Meeting Meetings with representatives of Council Presidencies (DK and CY) 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 Conference on Innovation in Healthcare without borders
May	EPF Board Meeting including Elected Officers' Meeting Secretariat Team Meeting RENEWING HeALTH, VI User Advisory Board Meeting Health Inequality Summit, Sofia, BG
June	Policy Advisory Group (PAG) Meeting Participation in EU and national FP7 Health 2013 Programme Info Days RENEWING HeALTH VIII PSC Meeting – location Odense DK Conference on Gender and Health through Life, Copenhagen, DK
July	Secretariat Team Meeting Local Meetings with EPF National Coalitions
August	II EPF Youth Congress and youth workshop, Brussels, BE Meetings with new potential national coalitions of patient organisations

September	<p>EPF Board Meeting including Elected Officers' Meeting</p> <p>Secretariat Team Meeting</p> <p>Local Meetings with EPF National Coalitions</p> <p>Chain of Trust project IV Steering Committee meeting – Brussels, BE</p> <p>RENEWING HeALTH IX PSC Meeting, Lulea, SE</p>
October	<p>Elected Officers' Meeting</p> <p>Fifth Regional Advocacy Seminar – Lisbon, Portugal</p> <p>INTERQUALITY project IV Steering Committee–location tbd</p>
November	<p>Secretariat Team Meeting</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> <p>RENEWING HeALTH, VII User Advisory Board Meeting, Brussels</p>
December	<p>EPF Board Meeting including Elected Officers' Meeting</p> <p>Meetings with representatives of Council Presidencies (IE and LT)</p> <p>Chain of Trust Final Conference, Brussels, BE</p> <p>EPF Policy Conference on eHealth, Brussels</p>

## Annex III: Summary of key policy actions in 2012

Action	Objective	Strategic Goal(s)
Chronic Diseases	Actively engage our membership in the reflection process on the planned Commission Communication on chronic diseases to ensure that both effective prevention and patient-centred management strategies that deliver quality care are accessible and sustainable.	2 and 3
Active and Healthy Ageing and the needs of older patients	Continue to participate at all levels in the EU Innovation Partnership on Healthy and Active Ageing. Targeted activities in the framework of the 2012 theme year for Active and Healthy Ageing and Intergenerational Solidarity.	ALL
Information to patients and Health Literacy	Continue to promote Health Literacy as a critical tool towards patient-centred healthcare and a pillar for the reduction of health inequalities, building on the abovementioned recommendations of our 2008 Conference on Health Literacy. Work closely with the EU Institutions on the second reading of the Commission proposal on Information to Patients to ensure it is centred on patients' needs.	ALL
Health Inequalities	Follow up to the Commission Communication on Health Inequalities and EP Resolution (January 2011), tackling health inequalities through health literacy strategies Input in EU-level actions on health inequalities including EC Communication Solidarity in health. Work on discrimination in health including access to healthcare of vulnerable patient groups in partnership with relevant NGOs/bodies.	ALL
Quality of care and patient safety	Continue to participate in the Commission Patient Safety & Quality of Care Working Group. Monitoring on progress in implementing the Council Recommendation from the patients' perspective. Participating in the Joint Action on Patient Safety and Quality of Care to be launched in early 2012. Collaboration with WHO Europe on an initiative exploring patient safety and patients' rights.	1, 2 and 3
Work with the European Medicine Agency	Representation in the CHMP/PCWP and Managing Board. Coordinating role for patient involvement; disseminating information on medicines regulatory processes to patients.	ALL
Clinical Trials	To monitor and influence developments linked to the revision of the Clinical Trial Directive. Continue work in European Medicine Agency working group on Third Country Clinical Trials.	2 and 3
Medical Devices	Engage actively in the recast of the Medical Devices Directive from the patients' perspective. Continue regular transparent dialogue with the medical devices industry in order to exchange views and information from our respective	1,2 and 3

	perspectives.	
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 responsibility in the field of pharmaceuticals".</p> <p>Engaging with the relevant Directorates-General of the European Commission (Research, SANCO).</p>	1, 2 and 3
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 projects	<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 2012 EU and National FP7 Health Infodays</li> <li>-Participate in EU-level workshops for FP7 Health National Contact Points to provide guidance on patient involvement</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> <p>Developing a Value+ follow-up capacity building programme.</p>	ALL
Structural Funds	<p>Continue advocacy work with DG REGIO and SANCO to ensure health is central and that the patients perspective is included in the next Programming period 2014 -2020.</p> <p>To disseminate EPF's Toolkit on Structural Funds among members.</p>	1, 2 and 3
HTA	<p>To contribute actively to the EUnetHTA project and stakeholder group.</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 eHealth User Group, respond to relative consultations on eHealth, develop transparent relationship with IT industry.</p> <p>Continue to work on Chain of Trust project on Telehealth and RENEWING HeALTH on Telemedicine.</p> <p>Starting new projects in Health ICT area pending successful outcome of the evaluation.</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>	ALL

	<p>Cooperation with other youth organisations and youth groups.</p> <p>Watching brief of Commission's work on youth and health.</p>	
Health Workforce	<p>Contribute to the revision of the Professional Qualifications Directive and the upcoming Green Paper from a patients' perspective 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> <p>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.</p>	ALL
EPF and the global health agenda	<p>In collaboration with IAPO, contribute to an EU perspective on global health developments.</p>	1, 2 and 3
Strong patient perspective in the EU Presidencies	<p>Influence to the maximum degree possible the Danish and Cypriot governments who are holding the EU Presidencies in 2012 and Irish and Lithuanian who are holding the EU Presidency in 2013.</p> <p>Regular communication with the health attaches in all permanent representations and relevant national health officials and politicians.</p>	ALL
Building on Existing Relationships with the European Parliament	<p>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.</p>	ALL
Policy Involvement in Agencies, Think-Tanks and Advisory Panels	<p>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.</p>	ALL
eHealth Conference	<p>Influence future eHealth policy developments in Europe through evidence based patient perspective</p>	ALL



## Annex II – Summary of main programmes and projects 2012

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
Chain of Trust	Foster confidence and Trust in Telehealth Year 2 implementation, EPF Coordinator role	1, 2 and 3
InterQuality	Quality and Sustainability of healthcare systems 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	Develop follow-up capacity building programme using Public Health Programme and other funding	2 and 4