

The European Patients' Forum Work Plan 2011



Patients' Rights – Equity of Access – A Patients' Perspective

Innovation and Inclusion

Introduction by the EPF President

Dear readers,

Welcome to the EPF work-plan for 2011. A glance through this document will demonstrate how EPF is evolving and indeed changing as an organisation to respond to new and different demands from our membership and from the EU political environment.

As in previous years, our “raison d’être” will continue to be our policy influence in a European Union context, supported by our relevant projects and partnerships. But in 2011, EPF will embark on the planning of a major capacity building programme to bring EPF even closer to its members, building on the outcomes of the Value+ project. This was a clear message from the evaluation survey we undertook with our members during the latter part of 2010.

We will also engage in preparatory work to campaign for meaningful patient involvement in the next EU Programming period – 2014 - 2020, and in particular the European Public Health Programme, the 8th Framework Programme on Research and Development, and Structural Funds and Cohesion Policy.

2011 will mark the adoption of key health dossiers, in which EPF has played a critical advocacy role and we will continue to invest in these, also following adoption, when we need to work with our national members and their governments in relation to effective patient-centred transposition and implementation.

We will launch our youth strategy in 2011, developed on the basis of the outcomes of the workshop with young patient representatives at our Regional Seminar in Budapest in October 2010. We will also initiate intensive work on the needs and rights of older patients, in the framework of the European Innovation Partnership on Active and Healthy Ageing, and our own conference under the patronage of the EU Polish Presidency.

We are fully supportive of the current EU discourse on prevention and health promotion, and believe similar attention is crucial to ensure chronic disease management strategies that will put patients at the centre of systems that deliver quality, access and are sustainable. We will follow closely and input on the development of a Commission Communication on Chronic Diseases to be developed during 2011, following up on the Belgian EU Presidency Conclusions on Chronic Diseases.

Innovation from a patients’ perspective is a key driver for our work and we will engage with different parts of the European Commission in relation to the specific actions in the framework of the Innovation Union.

eHealth continues to be a core priority for EPF and we believe is absolutely central to our vision of high quality, patient-centred, equitable healthcare. We welcome strongly the significant political focus on eHealth, including the mobile segment, and eGovernment within the EU Institutions, manifested by the eHealth Governance Initiative in which we are also actively involved as a stakeholder.

‘Connectivity’ becomes increasingly crucial in all our work. Connectivity between different sectors of industry: pharmaceuticals, medical devices, Information Technology; connectivity between healthcare systems and social care systems, which for too long have run on separate tracks, rather than providing a patient-centred care model that will support the individual throughout the life

continuum and in particular older age; and connectivity between the different stakeholders, patients, health professionals, insurers, industry and the policy makers to enable data to flow more freely, more effectively and more safely. If this connectivity can be achieved then eHealth and smart technology in health can, indeed, enhance quality and access, whilst reducing costs. EPF is committed to play our role in this respect.

I hope this work plan gives you a flavour of EPF's direction in 2011. I look forward to working with all of you in order to make this a reality.

Anders Olauson

EPF President

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1. EPF's Strategic Plan

The European Patients' Forum (EPF) adopted a five-year strategic plan at its Annual General Meeting in June 2007. The EPF Work Plan for 2011 takes forward this strategy and builds on the outcomes of the 2007, 2008, 2009 and 2010 work plans. It also takes on board the external political environment and the new institutional and decision-making arrangements introduced by the entry into force of the Lisbon Treaty, to reflect the likely European healthcare developments during the course of 2011 and beyond.

Our vision is high quality, patient-centred, equitable healthcare throughout the European Union. The 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 patients' organisation is too small to contribute to our work.

2. EPF operational objectives for 2011

EPF operational objectives for 2011 are as follows:

- **Building capacity** within the governance structures, the secretariat, and through reinforcing and extending the membership, and diversifying / solidifying funding (GOAL 1-5)
- **Strengthening our policy impact** (GOAL 1-3)
- **Developing projects and patients' evidence** to feed into policy (GOAL 1-3)
- **Building powerful and effective communications and partnerships** (GOAL 1-5)

2.1 Building Capacity

2.1.1 The EPF Secretariat and Governance

In 2011, the secretariat will be composed of the equivalent of 8 full time staff including an intern and a seconded research assistant.

EPF's permanent secretariat team will be composed of an executive director, a senior policy advisor, a programme manager, a programme and policy officer, a communication officer, a part-time webmaster, and a part-time office manager. Our office is located in Brussels close to the EU Institutions.

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 2010 and these will be presented for adoption to the Annual General Meeting in May 2011, and published on the web site together with our Annual Report 2010 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 2011 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** will take place in April 2011 and will include an election of 3 board members.

2.1.2 Meeting Europe's Patients

The following major EPF meetings and events will take place in 2011:

- The Annual General Meeting in April will also include a capacity building programme specifically for our members focussing on Structural Funds, HTA, Animal Testing, and the 7th Framework Programme on Research and Development.

- A major conference on the rights and needs of older patients will take place in July, in Warsaw, under the auspices of the Polish Presidency.
- The EPF Policy Advisory Group (PAG) will meet physically twice in 2011. The PAG will also meet virtually by means of teleconference during the course of the year in order to provide continuous guidance on priority policy areas.
- 2 Patients' evidence workshops on specific areas identified by the membership will take place

The EPF Youth Group will meet both physically and virtually during 2011 to support in the implementation of EPF's youth strategy.

The Regional Advocacy Seminar in, September 2011 will take place in Romania targeting countries in that region, Mediterranean Member States and Croatia. The main purpose of the seminar will be to build capacity for approximately 50 patient organisations' leaders and future leaders. The seminar will focus on developing participants' communication and advocacy skills to influence policies that affect their lives and ultimately to engage in shaping the future of European society. Particular emphasis will be placed on relationships between patient organisations, and health professional organisations.

2.1.3 Reinforcing and Growing the Membership

EPF will continue to expand its membership in 2011, also to include more representative national patient umbrellas/platforms. Our target membership for 2011 is 50 members from the current 45 and to broaden the representation across the key disease areas and the Member States. 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.

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 this, each staff and board member will 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 2011 European Patients' Rights Day.

In late 2010 EPF started developing a guide for its members on how to get actively involved in the Structural Funds at design, implementation monitoring and evaluation level. This guide will be finalised and published in the first part of 2011 and will be circulated to national patient organisations across Europe. It will also support EPF advocacy activities in view of the upcoming debate on the reform of the Structural Funds' strategic priorities and Regulations for the period 2014-2020.

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 late 2010/early 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.

2.1.4 Diversifying and Solidifying Our Funding Base

Significant efforts will continue in 2011 to diversify and solidify the EPF funding base. EPF will apply for operational funding from the Public Health Programme in 2011. We will also submit proposals for funding to the European Commission outside the Public Health Programme for projects and activities that support our policy goals. In particular, we will cooperate closely as associate partners in relevant FP7 research projects on health, providing a patient's perspective.

We will contribute actively as a key stakeholder in the Commission's new Joint Actions on Health Technology Assessment and Quality of Care/Patient Safety.

We will also continue to undertake very rigorous financial planning and expenditure to ensure optimum use of the resources made available to EPF.

2.1.5 Planning a Major Capacity Building Programme in 2012

EPF intends to launch a major capacity building programme in 2012, in order to respond to our members' request for more support in knowledge building and advocacy work. This will build on the outcomes of the Value+ project and will also incorporate the employment of a membership officer who will be responsible for overseeing the capacity programme and direct and on-going liaison with the members. Significant work will take place in 2011 in relation to the planning of this programme and securing sufficient resources for its implementation over a three year period to end 2014.

2.2 Strengthening our Policy Impact

Throughout 2011 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 endorsed by Commissioner Dalli. Following the European Parliament elections of 2009 we have intensified our work with the European Parliament, using the EPF Manifesto '150 Million Reasons to Act', and work closely with MEPs involved in the legislative proposals on health.

In March 2010, the Commission issued a Communication on "EUROPE 2020 – A strategy for smart, sustainable and inclusive growth" to launch concrete discussions on the follow up to the Lisbon Agenda. During 2011 EPF will be pro-active within the framework of 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.

EPF's policy work in 2011 will continue to be shaped by its over-arching goals:

- **Promotion of patients' rights 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**

In pursuance of these goals EPF will:

- a) Continue to work on legislative and non-legislative proposals on Patients' Rights in Cross-Border Healthcare, Patient Safety and Quality of Care, Health Literacy, eHealth, the Pharmaceutical Package (Anti-Counterfeiting, Pharmacovigilance and Information to Patients), Clinical Trials, Medical Devices, Health Technology Assessment, as well as Health Inequalities, particularly in relation to the use of EU Structural Funds during the current programming period and in the context of the post-2013 debate;
- b) Engage in the Consultation process linked to the development on a Communication on Chronic Diseases;
- c) Extend our activity to new policy strands, notably the challenges of older patients and access to healthcare for other vulnerable groups such as migrants, including undocumented, ethnic minorities, refugees and asylum seekers;
- d) Continue the policy work started in Autumn 2009 on Health Technology Assessment (HTA) through continued involvement in EUnetHTA launched in 2009 and a new Joint Action to be launched in 2011, the wide dissemination of EPF's resources on Health Technology Assessment, and the series of surveys on patient/patient organisations' involvement in HTA;
- e) Hold high-level meetings with representatives of the Hungarian and Polish Presidencies and with the Danish and Cypriot governments in preparation for their Presidencies in 2012;
- f) Continue to work with EMA, the European Union Health Policy Forum, and other health-related agencies and think-tanks;
- g) Cooperate with the Council of Europe (CoE) in the framework of the Recommendation on child-friendly healthcare to be adopted by the CoE Member States in mid 2011;

2.2.1 Specific Policy Priorities

In 2011, EPF will focus on the following policy areas:

- Quality of Care and Patient Safety
- Cross-Border Healthcare and Patients' Mobility
- eHealth (interoperability, ethics, privacy, telehealth), with a focus on patient perspective of and attitudes towards eHealth
- Health Literacy

- Patients' meaningful involvement in research
- Tackling Health Inequalities From the Patients' Perspective and non-discrimination
- Health Technology Assessment
- Medical Devices Exploratory Process and Follow-up
- Clinical Trials : Follow-up in the framework of the review of the Directive on Clinical Trials and our input in the EMA working group on Third Country Clinical Trials
- Addressing the needs and rights of older patients
- Access to healthcare for other vulnerable groups such as migrants, including undocumented, ethnic minorities, refugees and asylum seekers
- Adherence and concordance
- Personalised Medicine
- Generic Medicines and Biosimilars
- Vaccines
- Young Patients' Involvement in healthcare decision-making through the EPF Youth Strategy and Child-friendly healthcare

Please see annex 1 for an overview of these activities. Below is a snapshot of the work we will be carrying out in selected areas.

Quality of Care and Patient Safety

EPF has been actively involved in recent years with the Commission's Patient Safety Working Group, which advises the High Level Group on Health Care Services. The group brings together representatives from all 27 EU countries, EFTA countries, international organisations, and stakeholders. With the adoption of the Commission Communication and the Council Recommendation on Patient Safety, this Working Group finished and a new working group focused on quality of healthcare (the Patient Safety and Quality of Care Working Group) was set up in 2009. During 2011, EPF will continue to play an active role to represent a patients' perspective in this new Working Group that will advise the new Council Working Party on Public Health issues at senior level in developing the EU patient safety and quality agenda, and will prepare a Joint Action on Quality of Care.

Cross-Border Healthcare

The European Commission adopted a proposal for a Directive on Patients' Rights in Cross-Border Healthcare in July 2008 as part of a Social Package that also included proposals for non-discrimination legislation. EPF consulted its members and developed a clear statement on the current proposal and its strengths and weaknesses, which we used in our campaign work in the European Parliament. Many of EPF's proposed amendments were adopted by the Parliament.

However, the Council's common position, when finally adopted in September 2010, diverged significantly from the EP's approach. Negotiations were ongoing between the institutions in the second half of 2010, and in 2011 EPF will continue work with all actors involved in the legislative process, building on our High Level Round Table in December, in order to ensure that the final text and implementation process reflects patients' concerns as fully as possible.

eHealth

EPF will continue its cooperation with consortia and networks focusing on ICT and health (CONTINUA, COCIR and EUCOMED), including the wireless operators (i.e. GSMA Europe). EPF will also continue to be represented in the EU eHealth Users Stakeholder Group which will enjoy new status and responsibilities due to the Commission's introduction of an eHealth governance structure.

In 2011 EPF will also implement a pilot initiative on the patient perspective on eHealth which will consist of small piloting exercises to be carried out in three EU countries, namely Poland, Lithuania and the Netherlands, involving patients using eHealth services. The purpose is to assess patients' attitudes toward these services as well as their needs and expectations from future developments in this area. The outcomes of this initiative will support EPF in formulating more informed policy positions and making more evidence-based decisions in the area of eHealth.

Health Literacy

During 2011, EPF will continue to follow up on the Spring Conference 2008 on Health Literacy and the conclusions and recommendations emerging from that event.

There is currently renewed political momentum around health literacy, reflected among other developments, the legislative proposals on information to patients, anti-counterfeiting and pharmacovigilance. In this context, EPF continues to call for a comprehensive EU information and Health Literacy strategy. We will be working closely in the framework of the European Union Health Policy Forum to advance Health Literacy as a common priority and monitoring the implementation of the EU Health Strategy, 'Together for Health' in which Health Literacy is a key element, and we are also promoting Health Literacy as a key pillar to address Health Inequalities.

We will also explore corporate social responsibility and health literacy for patients in a work place context.

Tackling Health Inequalities from the Patients' Perspective

The Commission has stated that it will support Member States in their actions on tackling inequalities, particularly through Structural Funds monies. The Commission's published a Communication "Solidarity in health: reducing health inequalities in the EU" in 2009, and the European Parliament is currently discussing an own-initiative report on Health Inequalities, to be adopted in early 2011. EPF consulted its membership in 2009 and invited the feedback of the PAG on this issue, and we will continue to mobilise our members to ensure continuing patient involvement in these processes.

Clinical Trials

EPF will follow up on developments related to the Commission's Consultation on the Clinical Trials Directive that closed in January 2010. On the basis of this, EPF will continue to work with the EU Institutions to ensure that the review of the Directive anticipated for 2011 puts patients at the centre, and resolve some of the acknowledged loopholes and hurdles of the current text. EPF also continues to work with the European Medicines Agency on issues related to clinical trials, particularly through participation in the Working Group on Ethical Issues in Third Country Clinical Trials.

Patient Involvement in Health Technology Assessment

EPF is involved as part of the stakeholder group in the European Commission Joint Action on Health Technology Assessment (HTA) and will contribute and monitor developments within this three year project from the perspective of patients.

EPF will also be following up on the outcomes and recommendations from the EPF HTA seminar organised in 2010 and will disseminate the toolkit developed as a result of the seminar to patient organisations.

We will also engage actively in the new Joint Action on HTA to be included in the EU Public Health Work Plan 2011.

Medical Devices Exploratory Exercise

During the latter part of 2009 EPF participated in an exploratory exercise set up by the European Commission on the future of Medical Devices. This process ended in March 2010 with recommendations for future directions for Medical Devices in Europe both from a competitiveness and public health perspective. In 2011, EPF will follow up on further developments in relation to the Recast of the Medical Devices Directive from a patient's perspective.

Patients' Meaningful Involvement in Projects

One of EPF's overriding policy goals is to promote the involvement of patient organisations in EU health-related projects. We believe this will lead to stronger project outcomes that will feed ultimately more effectively into a patient-centred EU health agenda. To pursue this goal EPF will continue to work with a range of Commission Directorates, including health (Public Health Programme), research (FP7-Health), 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).

Commission Initiative on Corporate Responsibility in the Field of Pharmaceuticals

Launched officially in September 2010, the Corporate Responsibility initiative is led by DG ENTERPRISE as a follow-up activity to the Pharmaceutical Forum (2005-2008). The process will focus on non-regulatory approaches to enhance Member State cooperation in access to medicines after the granting of marketing authorisation, and on corporate social responsibility in the field of pharmaceuticals. Three platforms of discussions are to be set up under the Initiative: (1) Ethics and transparency; (2) Access to medicines in the least developed countries focusing on Africa; and (3) Access to medicines in Europe.

The Platform on Access to Medicines in Europe was the first to be launched, with a first meeting of the Steering Group taking place in Brussels on 24 September 2010. EPF was invited as a stakeholder organisation to participate in the Steering Group, which includes representatives of the EU Member States and EFTA countries, and also other stakeholder organisations such as health professionals, health managers, social insurance, consumers and the industry.

Commission high level groups, working groups and platforms

EPF will continue to be represented in 2011 on various Commission Working Groups such as 'Patient Safety and Quality of Healthcare' mentioned earlier, the 'eHealth Users Stakeholder Group' and the editorial board of the EU Health Portal. EPF will use this representation to be as pro-active as possible in ensuring a patient-centred perspective in developments of each of these areas.

We will also be actively involved in the EUnetHTA stakeholder group in the Joint Action by the EU Member States on Health Technology Assessment .

Our President will continue to sit on the high level Advisory Group on Research, chaired by the Commissioner for Research.

The Director and Senior Policy Advisor will represent EPF in the steering group of the Commission Initiative on Corporate Responsibility.

EPF will also continue to be represented in the European Union Health Policy Forum that meets biannually and be actively involved in the implementation of the EUHPF strategic plan and work plan 2011.

EPF will continue to participate in the Technical Platform on eHealth, a joint EU-level platform launched in June 2010 between DG SANCO, DG REGIO, DG Employment and the Committee of the Regions for ongoing discussions on key health issues from a regional perspective.

Building on Existing Relationships with the European Parliament

During 2010, EPF galvanised links with key MEPs already established, notably through our work on the Health Literacy Declaration and our EPF Patients' Manifesto in the context of the European Parliament elections. Over 120 MEPs have expressly committed themselves to the work of EPF in the new term of the Parliament.

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.

The EPF Manifesto Campaign '150 Million Reasons To Act'

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.

The Council of the European Union and EU Presidencies

EPF will liaise as closely as possible with Hungary and Poland who are holding the EU Presidencies in the first and second semester of 2011 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 Denmark and Cyprus who are holding the EU Presidency in 2012. Regular communication will continue with the health attaches in all permanent representations and relevant national health officials and politicians.

Policy Involvement in Agencies, Think-Tanks and Advisory Panels

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 health-related think tanks and advisory panels, including the European Federation of Pharmaceutical Industry Associations patients Think Tank, the GSK Health Advisory Board, EUROPA BIO patient's advisory group, and the Centre for Health, Ethics and Society (CHES).

EPF will use these platforms to reinforce its key policy messages on topical issues.

EPF Policy Advisory Group

The EPF Policy Advisory Group (PAG) was set up in 2009 to advise EPF's Board and Secretariat on those policy topics prioritised by EPF's AGM which, because of their complex, controversial and/or highly political nature, require a more detailed and in-depth discussion. The group is made up of elected representatives or staff of EPF members who have a particular interest in the policy areas EPF is working on.

In 2011 the PAG group will meet twice physically, and if necessary will hold teleconferences in between the meetings to discuss urgent issues. The PAG currently has 11 members, and will consider adding members to ensure representativeness across geographical and disease areas.

Patients' evidence working groups and workshops

As a result of working groups, patients' evidence workshops and on-going monitoring of policy issues, EPF will produce a number of policy papers on key topics. The nature and number will depend on the political environment and the target groups.

2.3 Developing Projects and Patients' Evidence and Expertise

The overall rationale behind these initiatives is to substantiate EPF's knowledge base and policy lines, with input from the patients' community throughout the European Union. Please see annex 2 for a list of current and speculative projects for 2011.

Following dissemination of the results and resources of the EC-funded project Value+ throughout 2010 (<http://www.eu-patient.eu/projects/valueplus/index.php>), EPF will develop a follow-up programme focused on capacity building on patient involvement targeted at various health stakeholders.

We will continue cooperation with DG Research on encouraging patient involvement in current and new health-related Calls for Proposals and providing input in the Framework Programme 8 (2014-2020).

EPF will 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.

We will continue our work in the RESPECT project on paediatric clinical trials which will be ending in 2011. We will contribute to the collection and harmonisation of different approaches and best practices in various fields of medicine and research. We will play an active role also in the dissemination of these results and the widening of the debate to encourage better informed and more collaborative European patient and research communities. We will also continue our

involvement in the eHealth Governance Joint Action/Thematic Network as a stakeholder representative.

EPF will continue our participation as associated partner in the project RENEWING HEALTH, a project implementing large-scale real-life test beds for the evaluation and subsequent validation of innovative telehealth based services and in doing so assessing whether and to what extent do these services optimise the use of resources in health provision, improve patients' quality of life, healthcare professionals' satisfaction, while enabling patient involvement and empowerment. Throughout 2011 we will play an active role in the management of the User Advisory Board RENEWING HeALTH's standing advisory committee, providing advice and on-going feed-back on the needs and requirements of users of telehealth services, monitoring the implementation of the pilots making sure that the needs and demands of telehealth user groups, including chronic patients, are effectively met to the fullest extent possible and that all the activities of the project are centered around the interest of the patient.

EPF will lead the Public Health Programme Telehealth project "Chain of Trust", to be launched in early 2011 and will run for 24 months. The Chain of Trust will look 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 Chain of Trust project will kick off in January 2011.

EPF will also participate in the FP7 project "InterQuality" on financing systems' effect on quality of care which will also kick off in early 2011 and run for 36 months until late 2013

In 2011 we will continue to join consortia as associate partners in selected projects in the research, and public health field that are of particular relevance to EPF and our policy interventions. EPF will also explore funding opportunities under the Youth in Action Programme to support trans-national skill building activities for young patients and dialogue between them and policy makers in the areas of youth, health and education policy. A project idea will be developed in late 2011 and submitted to the Educational, Audiovisual & Culture Executive Agency (EACEA) in early 2012.

During the course of 2011, EPF will hold two patients' evidence workshops 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 proactive.

2.4 Building Powerful Communications and Partnerships

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.

In 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

EPF will continue to develop its comprehensive mailing list database, including the internal mailing lists comprising EPF member organisations and patient organisation allies, the external mailing lists comprising political and corporate stakeholders working on health issues, and a media mailing list.

Our media outreach work will be more proactive, 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 agree that they “market” EPF in these countries, through their own media activities.

2.4.3 Communications Products

In 2011 EPF will continue to improve the website as EPF’s flagship and major external communications tool. In 2009, we started using a content management system to facilitate more rapid uploading of news and designed a more user-friendly website that provides greater navigational capabilities and accessibility features. Both the content management system and the new website are operational since early 2010. 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 2011 is to attract a wide readership base and become the main source of information for patients and patient organisations.

EPF will continue to produce an 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 regarding the EPF mailing, EPF has expanded the mailing list of the ‘EPF Mailing’ newsletter, to make it accessible to a wider network. There will be approximately 3000 direct recipients, 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.

EPF will develop its strategy on Social Media in 2011, via the EPF young patients’ ePlatform, and YouTube.

EPF will upgrade its efforts to use existing journals, and newsletters of its members to communicate EU health developments. A one-page document will be developed four times a year to be translated by patient organisations in respective countries. EPF will also continue to produce ad hoc mailings/press releases to the external mailing list and media list highlighting more detailed information on the EPF web site.

EPF will produce its fifth annual report in early 2011, with an overview of its achievements and challenges in 2010.

EPF will translate as many key documents into French and other languages as possible.

2.4.4 Partners and Allies

In recent years, EPF has devoted 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 2011.

Specifically, with regard to patient groups, EPF will continue to work as closely as possible with the European Aids Treatment Group, the European Heart Network, and the International Alliance of Patient Organizations. EPF will work to include their views and perspectives in EU policy meetings in which we are selected as the patient representative.

EPF will also continue to develop strong relationships with the wide range of health NGOs organised at EU level, including AIM and ESIP (European Health Insurance Federations), the European Public Health Alliance (EPHA), The European Standing Committee of Doctors, (CPME), European Federation of Nurses' Associations (EFN), The Pharmaceutical Group of the European Union (PGEU) representing community pharmacists, the European Hospital and Healthcare Federation, (HOPE), European Union of Specialist Doctors (UEMS), the European Health Management Association (EHMA), the European Society for Quality in Healthcare (ESQH), and BEUC, the organisation representing consumers at EU level.

Several of these organisations are our associate partners in the "Chain of Trust" project.

In 2011 EPF will also continue to cooperate with major European networks working around health issues such as the European Network of Regional and Local Health Authorities (EUREGHA), the Assembly of European Regions (AER) and HealthClusterNet.

EPF will 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.

EPF will also develop an active relationship with the WHO Headquarters in Geneva and WHO-EUROPE based in Copenhagen, in relation to EU related matters, the health unit of the Council of Europe, based in Strasbourg, and the relevant health-related departments within OECD (Organisation for Economic Cooperation and Development) based in Paris.

3. Evaluation Strategy and Performance Indicators

On-going evaluation of our Work Plan in line with agreed measurable performance indicators and target for each core strategic goal has been intrinsic to our developments over the last three years. We are thus able to refine the EPF Strategic Plan and moreover shape our following year's work plan accordingly in line with external health policy developments.

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 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 work plan in question, but also in order to plan, anticipate, adapt and be as proactive and effective as possible as a fast-growing lead organisation in an increasingly dynamic EU health policy environment.

The following performance indicators will be used to measure our success in 2011 against our five key strategic goals. These are not exhaustive, but serve to illustrate some of the benchmarks we will work towards.

Performance indicators:

Objective 1. Building Capacity

- **Indicator 1:** Expansion of EPF's membership
 - Target: 50 members
 - Method: By inviting relevant patient leaders to our events and following up on these contacts with targeted meetings in the Member States
- **Indicator 2:** Perceived success and impact of the Regional Advocacy Seminar
 - Target: Increased cooperation with patient organisations at national level in the region and specific conclusions on the patient/ health professional relationship, relayed back to European Umbrella bodies
 - Method: Analysis of evaluation forms

Objective 2. Policy Impact

- **Indicator 1:** EPF is recognised as an effective key partner in the political dialogue in determining civil society's input in EU health policy
 - **Target:** Inclusion of EPF comments in the EC, EP and Council's positions and initiatives
 - **Method:** Position papers disseminated to EC, EP and Council, responding to EC consultations, meetings with EC officials, participation in EU conferences and meetings
- **Indicator 2:** Perceived success and impact of the Polish Conference (documented through evaluation forms and policy follow-up)
 - **Target:** Polish Presidency steers the outcomes of the conference on ageing into its work, to the European Year on Active Ageing and Inter-generational solidarity and the European Innovation Partnership on Active and Healthy Ageing
 - **Method:** high-level communications and meetings with Polish Presidency representatives

Objective 3. Project and Patients' Evidence and Expertise

- **Indicator 1:** Degree of success of project funding applications and of projects already running
 - **Target:** Successful programme applications for Value+ follow up and an EU operational grant successful progress/outcomes of on-going projects
 - **Method:** Approval of projects by the European Commission
- **Indicator 2:** Degree of influence on the new EU Health Programme, FP8 and Structural Funds programmes to enable better access to funds for patient organisations
 - **Target:** Inclusion of mechanisms facilitating participation of patient organisations in the strategic documents and specific Calls linked to these programmes
 - **Method:** Contact building with responsible EC officials, ...

Objective 4. Communications/Partnerships

- **Indicator 1:** Increase outreach of communication tools
 - Target: 3500 direct recipients/EPF Mailing; 70.000 visitors/website; participants social media (to be defined in line with the Youth Strategy)
 - Method: Creating of more effective dissemination strategy, upgraded mailing list and link between Mailing and Website

- **Indicator 2:** Established cooperation with the European Older People's Platform - AGE
 - Target: Participation of AGE in EU Presidency Conference on needs and rights of Older Patients and collaboration in relation to the European Year on Healthy Ageing 2012
 - Method: Close and regular dialogue with AGE on ongoing common policy issues and consultation with AGE regarding the structure and outputs of the EPF Conference

4. Calendar –MAIN EPF EVENTS

Month	Event
January	Officers meeting
February	Board Meeting, Brussels Meetings Representatives Council Presidencies
March	Meetings Representatives Council Presidencies, Brussels Patients' evidence base workshop, Brussels Meeting EPF Policy Advisory Group, Brussels Officers meeting
April	Patients' Rights Day Event Annual General Meeting and Capacity Building, Brussels and Board meeting
May	
June	Meeting EPF Policy Advisory Group Officers meeting
July	EPF Conference on 'the Rights and Needs of Older Patients' Warsaw Board Meeting
August	Officers Meeting
September	Meeting EPF Policy Advisory Group Board Meeting, Brussels Sponsors Briefing Officers meeting
October	Officers Meeting EPF Regional Seminar, Bucharest Patients' evidence base workshop
November	Officers meeting
December	Board Meeting, Brussels

ANNEX I – Summary of key policy actions in 2011

ACTION	OBJECTIVE	Strategic goal
Central Campaign Core Funding	Core funding from the Commission for patients groups – Diversification and balance with corporate Income	ALL
Cross Border HealthCare Directive	Ensure a patients' perspective in Directive as it follows its legislative pathway in 2011 (Second Reading in EP January 2011)	3
Pharma Package	Follow legislative pathway – Information to patients and anti-counterfeiting, influence according to our position. Examine implications of the transposition of new legislation on pharmacovigilance and, contribute to European Medicines Agency working group on Eudravigilance	1,2,3
Health Inequalities	Follow up to the Commission Communication on Health Inequalities and EP Resolution (January 2011), tackling health inequalities through health literacy strategies. Follow-up consultation of EPF membership in 2011.	ALL
Cohesion Policy and Structural Funds	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 To disseminate EPF's Guide to Structural Funds among members	1,2,3
Patient involvement in Research	Continue close collaboration with DG Research and the Innovative Medicines Initiative to encourage more PO involvement in health research projects Prepare a campaign to ensure that patients involvement is a key pillar in the health component of FP8	2
Clinical Trials	To monitor and influence developments linked to the revision of the Clinical Trial Directive following up our position of Jan 2010. Continue work in European Medicine Agency working group on Third Country Clinical Trials	2,3
Post Pharma Forum Initiative	To represent patients in the Commission's Corporate Responsibility Initiative, including Platform on Access to medicines in Europe	1,2,3
Medical Devices	To monitor Commission's follow up the Exploratory Exercise on Medical Devices in which we were involved in Dec 2009	1,2,3

Health Technology Assessment (HTA)	To contribute actively to the EUNETHTA project and stakeholder group Finalise and disseminate EPF Advocacy Resource on HTA	1,2,3
Adherence to Medicines	To participate in PGEU/ EFPIA initiative to raise awareness on adherence/concordance	1,4,5
Needs of Older Patients	To develop a policy paper based on the outcomes of a major EPF conference under the patronage of the Polish Presidency To contribute as appropriate to an Innovation Partnership on Active and Healthy Ageing	All
Personalised Medicine	To monitor Commission developments in this area and agree an EPF position as put forward by the PAG; contribute to Commission conference in May 2011.	1,2,3
EPF and the global health agenda	In collaboration with IAPO, contribute an EU perspective on global health developments	1,2,3
ICT and eHealth	Develop EPF's position on eHealth, continue strong presence in eHealth User Group, respond to relative consultations on eHealth, develop relationship with IT industry	1,2,3
Next Public Health Programme 2014	Devise a campaign strategy to ensure strong patient component in public health programme (health literacy), core funding for patient groups and a sufficient funding for the programme	ALL
EPF Youth Strategy	Implement recommendations from Budapest Regional Seminar Watching brief of Commission's work on youth and health	ALL
Generic Medicines	To hold a meeting with the European Generic Medicines Association's board to discuss access, affordability and availability	1,3
Vaccines	To monitor development with the European Vaccines Manufacturers re the setting up of a European Immunisation Coalition	1
Strong patient perspective in the EU Presidencies	Continue work initiated by Tomasz Szelagowski to really profile the patients ' perspective in the Polish Presidency priorities Influence to the maximum degree possible the Hungarian Government's Presidency priorities	ALL
Non Discrimination	To examine and influence the scope of the new framework directive on non-discrimination to ensure optimum relevance for patients in the areas of treatment, insurance, workplace	1,2,3

ANNEX II – Summary of main programmes and projects 2011

ACTION	OBJECTIVE	STRATEGIC GOAL(S)
Core Funding	Submit a proposal for EPF core funding 2012	ALL
eHealth Governance and Thematic Network	Participate actively in this Initiative as one of the key stakeholders	1,2,3
Renewing Health	Pilot telemedicine – user perspective Continue active contribution as an associate partner	1,2,3
Chain of Trust	Confidence and Trust in Telehealth Project launch and year 1 implementation EPF Coordinator role	1,2,3
Inter-quality	Quality and Sustainability of healthcare systems Continue active contribution as an associate partner	1,2,3
Value+	Develop follow-up capacity building programme using Public Health Programme and other funding	2
Quality of care and Patient Safety	Participate as partner in the Joint Action focussing on patient involvement and empowerment	1,2,3
Young Patients Media Network	Implement the recommendations from the Budapest Regional Seminar	
IMI Project	IMI project on enhancing awareness – pharmaceutical research Develop project as a co-leader of Consortium	ALL
FP7 project	FP7 project on increasing knowledge among patient community on health research	ALL
RESPECT	Young patients' involvement in Clinical Trials Continue involvement of EPF as an associate partner in final stage of project (end May 2011) Dissemination of deliverables	2,3