Annex 7

The European Patients' Forum Work Plan 2010

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

Letter from EPF's President

As we look to the future, it is with pleasure to share with you EPF's Work Plan for 2010. Our work is founded upon the principles of Patients' Rights, Equity of Access, and the Patients' Perspective. It is these concepts that motivate EPF to turn our vision, strategy, values and principles into a reality. They are inherent to the pro-active and on-going work we and our members do in shaping and influencing the EU health agenda.

What are EPF's priorities in 2010?

We will continue to move ahead in our policy work in the areas of Patients' Rights relating to Cross Border Healthcare, Patient Safety and Quality of Care, eHealth, Health Inequalities and one that is very close to EPF's heart - Health Literacy. Also a priority for us is to continue to provide input to the EU Pharmaceutical Package of proposals on Counterfeiting, Pharmacovigilance and Information to Patients. Work in the areas of Health Technology Assessment, Medical Devices and Clinical Trials will also be high on our agenda throughout 2010.

We will continue to promote our Patients' Manifesto '150 Million Reasons to Act' to the European Parliament and the new European Commission to ensure that the Patients' perspective is at the centre of EU policy developments.

Our flagship project ' Value+' on the meaningful involvement of patients in EU health projects and policies came to an end in December 2009, however we will continue to maximise on the political and practical impact of the tools that were produced as a result of the project.

2010 will be another active year for EPF with five major meetings taking place: our Annual General Meeting along with a Health Technology Assessment Seminar, a joint meeting between EPF and the European Generics Medicines Association, our Regional Advocacy Seminar in Hungary, and our conference on quality and safety under the patronage of the EU Belgian Presidency.

It is an ambitious and far reaching Work Plan that reflects the expectations and demands of our increasing membership. We look forward to working with patient leaders, patient allies and our health stakeholder partners in delivering on this Plan, and moving forward on our vision – High quality, patient –centred, equitable healthcare across the EU.

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 (AGM) in June 2007. The EPF Work Plan for 2010 takes forward this strategy and builds on the outcomes of the 2007, 2008 and 2009 work plans. It also takes on board the external political environment, with a new European Commission, a recently elected European Parliament and the coming in to force of the Lisbon Treaty, to reflect the likely European healthcare developments during the course of 2010 and beyond.

EPF agreed our strategic plan at its Annual General Meeting in June 2007. 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 careers 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 Organizations: 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.

During 2010, a midterm review of the EPF Strategic Plan will take place to update the political environment and context, and realign key action fields to ensure that the Plan has maximum relevance in preparations towards the next EU programming period (2014- 2020).

2. An Executive Summary of the EPF Work Plan 2010

EPF operational objectives for 2010 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 Project and Patients' Evidence and Expertise** to feed into policy (GOAL 1-3)
- **Building Powerful and Effective Communications** and **Partnerships** (GOAL 1-5)

2.1 Building Capacity

Meeting Europe's Patients

The following five major EPF meetings will take place in 2010:

- The EPF Annual General Meeting and Health Technology Assessment Seminar, May 2010
- A Joint Meeting between EPF and the European Generics Medicines Association, September 2010
- The EPF Regional Advocacy Seminar, Hungary, October 2010
- An EPF Conference on quality and safety under the patronage of the EU Belgian Presidency, December 2010

The board will meet four times and the elected officers will meet six times in 2010. The pilot initiative, 'The Status of Patients in the European Union' will continue.

Our campaign work will also continue on the promotion of the European Patients' Manifesto – "150 Million Reasons to Act" in the context of the new European Commission. The EPF Policy Advisory Group will meet both physically and virtually during the course of 2010 to give guidance on priority policy areas. EPF working groups and patients' evidence base workshops on specific areas identified by the membership will also take place.

In 2010, the Secretariat will be composed of the equivalent of seven full time staff including two interns.

EPF will undertake a survey with its membership in 2010, to ensure the organisation responds to the maximum to its members needs and aspirations.

Reinforcing and Growing the Membership

EPF will continue to expand its membership in 2010, also to include more representative national patient umbrellas/platforms. Our target membership for 2010 is 45 members from 42 at the end of 2009.

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.

Diversifying and Solidifying Our Funding Base

Significant efforts will continue in 2010 to diversify and solidify the EPF funding base. EPF will apply for operational funding from the Public Health Programme in 2010. We will also submit proposals for funding to the European Commission for projects and activities that support its policy goals. We will cooperate closely as associate partners in relevant research projects on health, providing a patient's perspective.

In addition to building sustainable relationships with pharmaceutical companies, we will extend our work with non-pharmaceutical companies and foundations focusing on health issues in-line with our transparency policy, framework for funding support, and Code of Ethics.

2.2 Strengthening Policy Impact

EPF's policy work will be shaped by its core goals of:

- Promotion of patients' rights
- 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

Continued work will take place on legislative and non-legislative proposals on Patients Rights in Cross Border Healthcare, Patient Safety and Quality of Care, Health Literacy, ICT and Health (e-health), the Pharmaceutical Package (Counterfeiting, Pharmacovigilance, and Information to Patients) and Health Inequalities, particularly in relation to the use of EU structural funds.

Policy work started in Autumn 2009 on Health Technology Assessment, Medical Devices and Clinical trials will continue throughout 2010.

High-level meetings will take place with representatives of the Spanish and Belgian Presidencies during the course of 2010 and with the Hungarian and Polish governments in preparation for their Presidencies in 2011. We will be actively promoting a patient-centred philosophy and agenda with the new European Commission and European Parliament. We will continue to work with the European Medicines Agency (EMA), the European Union Health Policy Forum, and other health-related agencies and think-tanks.

2.3 Developing Projects and Patients' Evidence and Expertise

EPF launched its first EU funded project 'Value+' on meaningful patient involvement in 2008 and the project ended with a major conference in December 2009 to discuss outputs and next steps. Significant efforts will take place in 2010 to maximise the political and practical impact of Value+ through the range of tools produced, specific education and training initiatives and a possible future project.

In 2010, EPF will continue its role as an associate partner in the European Patient Safety Project ‘EUNETPAS’ and will be active in any extension of the project when it ends in 2010. We will also continue working on ‘RESPECT’, a project that explores the involvement of patients in clinical trials and CALLIOPE that is focused on communication between different countries’ health services and systems (interoperability) and the stakeholders’ perspective.

EPF will be involved in a new large scale project on telemedicine in 2010 called ‘RENEWING HEALTH’ and launching our own EU project ‘Chain of Trust’ on telemedicine funded under the EU Public Health Programme.

In 2010, EPF will intensify its work in promoting patient involvement in the health component of the structural funds and supporting our membership in that regard.

2.4 Building Powerful Communications and Partnerships

EPF will continue to build its relationship with the whole range of health stakeholders operating at the EU level, for example the health professionals’ organisations, and undertake selective representational work to promote the patients’ perspective.

Communications

EPF will continue to produce a mailing on a six-weekly basis for EPF members and allies, and regular communiqués to external partners. The EPF web site will continue to be developed as EPF’s flagship and central communication tool.

In 2010 EPF will explore the potential of social media in relation to ensuring the patient’s voice is heard at the EU level.

Evaluation Strategy and Performance Indicators

EPF will measure the impact of its 2010 Work Plan in accordance with a series of qualitative and quantitative performance indicators that relate back to our vision and five strategic goals.

GOAL1: EQUAL ACCESS FOR PATIENTS

GOAL2: PATIENT INVOLVEMENT
GOAL3: PATIENTS' PERSPECTIVE
GOAL4: SUSTAINABLE PATIENT ORGANISATIONS
GOAL5: PATIENT UNITY

3. A More In-Depth Look at EPF's Objectives for 2010

EPF has refined its objectives for 2010, building on the outcomes and review of previous years' work and impact.

- **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 project and patients' evidence** to feed into policy (GOAL 1-3)
- **Building powerful and effective communications** and **partnerships** (GOAL 1-5)

This Work Plan outlines in very brief terms specific actions during 2010 to achieve each of these objectives, although there is clearly some overlap.

3.1 Building Capacity

GOAL1: EQUAL ACCESS FOR PATIENTS
GOAL2: PATIENT INVOLVEMENT
GOAL3: PATIENTS' PERSPECTIVE
GOAL4: SUSTAINABLE PATIENT ORGANISATIONS
GOAL5: PATIENT UNITY

3.1.1The EPF Secretariat

EPF's Secretariat team is composed of an executive director, senior policy advisor, programme officer, communication officer, part –time webmaster, part-time office manager. We will recruit two interns for six month placements to support our policy and programme work. 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 2009 and these will be presented for adoption to the Annual General Meeting in May 2010, and published on the web site together with our Annual Report 2009 within one month of this meeting in line with our policy on transparency.

3.1.2 EPF Governance

The **EPF board**, composed of eight representatives elected by the EPF membership, will meet in Brussels four times in 2010 and will hold teleconferences as necessary in between these meetings. The elected officers will also meet on a regular basis.

The **Annual General Meeting** will take place in May 2010 where EPF members will adopt a revised Constitution that ensures associate members include patient organisations within their membership. At this meeting we will formally welcome at least five new members.

EPF will undertake a survey with its membership in 2010, to ensure the organisation responds to the maximum to its members' needs and aspirations. This will be initiated at the AGM.

3.1.3 Other Key Meetings

Four other major EPF meetings will take place in 2010:

The EPF Health Technology Assessment Seminar, May 2010 linked to the EPF Annual General Meeting.

This seminar will be an opportunity for EPF members and allies to discuss state of the art developments linked to health technology assessment and the patient's legitimate role at various levels in the health technology assessment process.

Joint Meeting between EPF and the European Generics Medicines Association, September 2010

This meeting, organised jointly by EPF and the European Generics Medicines Association will bring together the whole range of stakeholders involved in EU debates on access, affordability and availability of medicines across the European Union, to review the current state of play in light of the economic crisis, and the partnerships needed to bring about real progress for patients.

EPF Regional Advocacy Seminar, Hungary, October 2010.

The EPF Regional Training Seminar will place particular emphasis on young patients and how they interact with their healthcare environment. The main purpose of the seminar will be to build capacity for approximately 50 patients' organisations' leaders and future leaders, from Central and South-Eastern European countries. In particular, 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.

EPF Conference on quality and safety, under the patronage of the EU Belgian Presidency, December 2010.

This event will explore EU developments on quality and safety from the lens of patients' organisations and other key stakeholders. The event will identify strategies to ensure the impact of EU legislative and policy instruments at national, regional and local levels are realised.

Other Capacity Building Activities

The pilot initiative 'The Status of Patients in the European Union' exploring how patients across the EU interact with their healthcare system will continue and at the end of 2010 a report on findings will be circulated. Campaign work will continue on the promotion of the European Patients' Manifesto – "150 Million Reasons to Act" in the context of the new European Commission.

The newly set up EPF Policy Advisory Group will meet both physically and virtually during the course of 2010 to give guidance on priority policy areas.

EPF working groups and 'patients' evidence base' workshops will also take place on specific areas identified by the membership.

3.1.4 Reinforcing and Extending the Membership

It is of great importance that EPF is as representative as possible of the whole spectrum of patients at the EU level. In the last three years, EPF's membership has grown from 23 members to 42 members, with nine national patients' platforms now on board, and several membership applications in the pipeline.

The goal is to extend the EPF membership to 45 organisations by the end of 2010 and to broaden the representation across the key disease areas and the Member States.

This will be undertaken through inviting relevant patient leaders to our events and following up on these contacts with targeted meetings in the Member States.

EPF will also strengthen alliances with existing active members of EPF, 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.

Outreach Work – Supporting the Membership at National Level

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 to enable 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 European Patients' Rights Day.

Finally, we are committed to translating EPF core documents into as many languages as possible, using formal and informal translation services.

3.1.5 Diversifying and Solidifying the Funding Base

EPF’s income for 2010 will be made up of EU funding, unrestricted funding from industry and foundations, and membership fees. It is important for EPF to diversify financial sources to ensure a broad based, politically and financially sustainable funding base.

The EU Public Health Programme includes a provision for operational funding for eligible health NGOs. EPF submitted a proposal for core funding for its operational programme in 2008 and was unsuccessful because of arbitrary rules regarding percentage of industry funding received by applicants.

Following high level discussions with the Commission clarifying the issue of ‘independence’ and less prohibitive rules, a new application for operational funding will be submitted in 2010 for funding in 2011 under the European Public Health Programme.

EPF will also get involved in new EU projects as an associate partner, in accordance with our criteria for joining projects.

EPF will continue to apply for funding from foundations, industry groups, and companies in line with our code of ethics and transparency practices.

Long-Term Financial Health of EPF

During the course of 2010 EPF will continue to work towards building reserves of six months of our operational budget. We will also undertake very rigorous financial planning and expenditure to ensure optimum use of the resources made available to EPF.

3.2 Strengthening Our Policy Impact and Campaign Work

GOAL1: EQUAL ACCESS FOR PATIENTS
GOAL2: PATIENT INVOLVEMENT
GOAL3: PATIENTS’ PERSPECTIVE

3.2.1 A New European Commission and European Parliament

2010 will see a new European Commission and EPF will be pro-active 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. During and following the European Parliament elections we have intensified our work with the European Parliament, using the EPF Manifesto: ‘150 Million Reasons to Act’, and will work closely with MEPs involved in the legislative proposals on health described below.

The Lisbon Treaty came into force at the end of 2009. During the early part of 2010, EPF will prepare a brief overview of the implications of the Treaty from the perspective of patients.

3.2.2 Specific Policy Priorities and Campaigns

In 2010, EPF will focus on the following policy priorities:

- The Pharmaceutical Package (Counterfeiting, Information to patients, and Pharmacovigilance)
- Quality of Health Care and Patient Safety
- Cross Border Health Care and Patients' Mobility
- eHealth (Interoperability, Ethics, privacy, telemedicine)
- Health Literacy
- Tackling Health Inequalities From the Patients' Perspective
- Health Technology Assessment
- Medical Devices Exploratory Process and Follow-up
- Clinical Trials Impact Assessment and Follow-up

In addition, EPF will monitor the follow up to the policy instruments adopted in the framework of the European Commission's campaign 'A Europe for patients'.

In 2010, EPF will continue with its own campaign to promote the EPF Manifesto, '150 Million Reasons to Act', in the framework of the new European Commission with new key contact people at all levels.

The Pharmaceutical Package (Information to patients, Pharmacovigilance and Anti- Counterfeiting)

The so-called 'Pharmaceutical Package' that brings together legislation proposals in the areas of Counterfeiting, Information to Patients, and Pharmacovigilance was adopted by the Commission in late 2008. These proposals began their legislative journey in 2009 with discussions in the European Parliament and the European Council and will continue to eventual adoption of the legislation.

This is likely to be a long and intensive process and EPF, in close consultation with its members will be ensuring that the final proposals reflect a strong patients' perspective, through our advocacy work with all three EU Institutions.

Quality of Healthcare and Patient Safety

EPF has been actively involved in recent years with the Commission's Patient Safety Working Group, (including Member States representatives and stakeholders) which has advised the High Level Group on Health Care Services. With the adoption of the Commission's patient safety legislative proposals, this Working Group (WG) finished and a new working group focused on quality of healthcare was set up in 2009.

During 2010, EPF will continue to play an active role and to represent a patients' perspective in this new Working Group on Patient Safety and Quality of Care that will advise the new Council Working Party on Public Health issues at senior level.

Cross Border Healthcare

The European Commission adopted a proposal for a Directive on Patients' Rights on 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 of its strengths and weaknesses which we used in our campaign work in the European Parliament in advance of the first reading in April 2009, and where a number of amendments proposed via EPF were adopted. The Proposal was rejected by Council in December 2009. EPF will work with all three Institutions to ensure that it remains on the agenda, highlighting the importance of a proposal that fully reflects a patients' rights approach.

Information Communication Technology and Health

Following the adoption of the European Commission's Communication on Telemedicines, EPF will develop a position paper on the document and will also be actively involved in some of the action areas, including the preparation of guidelines on optimal use of telemedicines, in close cooperation with our health professional allies.

EPF will continue its cooperation with consortia and networks focusing on ICT and health (CONTINUA, COCIR and EUCOMED). EPF will also continue to be represented in the EU eHealth user's stakeholder group which will enjoy new status and responsibilities in 2010 as the Commission introduces a e-health governance structure.

We will be very active at the high level conference on e-Health under the Spanish Presidency where the EPF President will be a speaker. Part of this conference will explore direct patient reporting and the use of new technologies in this respect. A number of EPF members will be represented at this event.

Health Literacy

During 2010, EPF will continue to follow up on the Spring Conference 2008 on Health Literacy and the conclusions and recommendations emerging from that event. EPF will participate in the newly established EU project developing a Health Literacy Network.

EPF will be working closely in the framework of the European Union Health Policy Forum to advance on Health Literacy as a common priority and monitoring the implementation of EU Health Strategy, 'Together for Health' in which Health Literacy is a key element.

EPF will continue its political work to promote the need for a comprehensive information to patients strategy where Health Literacy is a key pillar.

Tackling Health Inequalities from the Patients' Perspective

Following the adoption of the Commission's Communication on Tackling Health Inequalities (a major pillar of the EU health strategy), EPF will be presenting the core challenges for patients in relation to health inequalities, also linking it with our work on Health Literacy. This will be the key focus of our high level meeting between the Spanish Minister of Health and the EPF leadership during the EPF presidency.

The Commission has stated that it will support Member States in their actions on tackling inequalities through structural fund monies. EPF will mobilise its membership to ensure appropriate patient involvement in these processes.

Clinical Trials Impact Assessment

EPF will consult its members in relation to the Commissions Consultation on the Clinical Trials Directive, launched in Autumn 2009 and ending at the end of January 2010. On the basis of this, EPF will continue to work with the EU Institutions to ensure that any review of the Directive puts patients at the centre, and resolves some of the acknowledged loopholes and hurdles of the current text.

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 organising its own seminar and materials to ensure that patient leaders have access to relevant information and EU policy developments to support their engagement in HTA, particularly following the adoption of the Directive of Patients Rights in Cross Border Healthcare in which HTA is a specific component.

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 will end in March 2010 and will recommend future directions for Medical Devices in Europe both from a competitiveness and public health perspective. EPF will ensure that core issues of importance to patients, linked to information, quality and safety are included in these reflections.

A New European Commission

EPF will use the EPF Manifesto '150 Million Reasons to Act' to ensure strong dialogue with the new Commission, both at college level and with new hierarchies and key players in relevant Directorates General.

Health in All Policies - Involvement of Patients

One of EPF's overriding policy goals is to promote the involvement of patients' 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 (SANCO), research, information society, regional development (structural funds), and enterprise, in the spirit of Health in all policies (health mainstreaming).

Commission high level groups, working groups and platforms

EPF will continue to be represented in 2010 on various Commission Working Groups such as “Patient Safety and Quality of Healthcare”, the ‘e-Health User Stakeholders 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.

EPF will also continue to be represented in the European Union Health Policy Forum that meets twice yearly and be actively involved in the implementation of the EUHPF strategic plan and work plan 2010.

Regarding the Seventh Framework Programme, the EPF President is a member of a high level group for health research within the seventh framework programme on research and development (FP7), set up by the Commissioner for Research. EPF will get involved as an associate partner in selected FP7 projects that contribute to the EPF strategic goals.

The European Parliament

Building on Existing Relationships

During 2009, 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 100 MEPs have expressly committed themselves to the work of EPF in the next 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 work on the EPF Manifesto campaign that was launched in the European Parliament in September 2008 in advance of the EP elections to ensure as much political support as possible from MEPs in the next term for a patients’ perspective in EU policy developments.

The EU Council and EU Presidencies

EPF will liaise as closely as possible with Spain and Belgium who are holding the EU Presidencies in 2010, by attending relevant health meetings, and ensuring input from a patient 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.

Key EPF events on health inequalities and quality of care will take place in both Member States to reinforce the visibility of patients within the respective Presidencies. EPF will also establish links with Hungary and Poland who are holding the EU Presidency in 2011 with a view in particular on promoting rights of older patients, and patient-friendly family policies. Regular communication will continue with the health attaches in all permanent representations and relevant national health officials.

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 EMEA Patients' and Consumers' Working Party and other ad hoc expert groups.

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, EUROPA BIO patient's advisory group, and the Centre for Health, Ethics and Society (CHES).

EPF will be involved in the stakeholders groups linked to the Innovative Medicines Initiative, the Health Technology Assessment Joint Action. EPF will use these platforms to reinforce its key policy messages on topical issues.

3.3 EPF Project and Patients' Evidence to Feed Into Policy

The overall rationale behind these projects is to substantiate EPF's knowledge base, and policy lines, with input from the patients' community throughout the European Union.

During 2010, we will be following up on Value +, finalising our input in the European Union Network for Patient Safety project(EUNETPAS), RESPECT and CALLIOPE projects and launching work on new projects in the telemedicine field.

Additionally, we will be joining consortia as associate partners in selected projects in the research, and public health field and will submit a proposal for operational funding from the European Public Health Programme.

3.3.1 Value+

A major priority for EPF in 2008/2009 was the coordination of the project 'Value +' -Promoting Patients' Involvement in EU-Supported Health-Related Projects. Value+ aimed to exchange information, experiences and good practice among patients' organisations and other key stakeholders to encourage the meaningful involvement of patients' organisations in EU-supported health projects at EU and national level.

The information and knowledge on the status of patient involvement has been translated into a number of tools: (1) a Resource Kit for patient organisations to facilitate patient involvement in future projects, (2) a Handbook for project leaders and promoters, (3) Policy recommendations for policy makers, (4) a database of health projects with patient involvement.

EPF will devote much energy to ensuring these educational and training resources are translated and properly disseminated to all relevant target groups, and reflect on a possible future project focused on patient involvement. EPF will also develop a Code of Practice on patient involvement targeting various actors.

3.3.2 EUNetPaS

EPF is involved as an associate partner in EUNetPaS which aims to establish an umbrella European network to improve cooperation between EU Member States in the field of patient safety (culture, reporting and learning systems, education). The project is led by Haute Autorité de Santé in France and involves partners from all Member States and a broad range of stakeholders.

EPF will continue to promote the need to involve patients as part of patient safety education interventions, as well as the concept of "patients experts" as valuable partners in the education and training process and will contribute to drafting EUNETPAS recommendations for the Commission and Member States on education for patient safety.

EPF will also contribute to the evaluation of the project with constructive critique from a patient's perspective.

3.3.3 RESPECT Project

EPF is involved as associate partner in a research project called 'RESPECT' - Relating Expectations and Needs to the Participation and Empowerment of Children in Clinical Trials, under the Seventh Framework Programme for Research and Development. The project explores the expectations and needs of children and their families in relation to clinical trials for new drugs in Europe and how this should be translated into empowering and motivating participants in future clinical trials research.

In 2009 the project applied various approaches to collect information on positive and negative factors influencing the participation of children in clinical trials. EPF will be collecting the views of its members through a survey and focus groups.

In 2010, workshops will take place on the completion of case studies, harmonization of data and drafting a joint report and dissemination. EPF will organise the dissemination workshop in September 2010 to disseminate the results and identify pathways for future research and sustainability of project outputs.

3.3.4 CALLIOPE Project

Since 2008, EPF has been a partner in the CALLIOPE Thematic Network on cross-border eHealth Interoperability, supported by the European Commission. The aim of the project is to create a structured and open forum to support the implementation of interoperable e-Health infrastructures and services across Europe.

EPF will continue to focus its contribution towards the development of a proposal for a European e-Health Interoperability Road Map scheduled for March 2010 and of a Review Report and proposed revisions of the EC Interoperability Recommendation.

3.3.5 RENEWING HEALTH Project

Renewing health is a large scale project on good practice examples in the field of telemedicine. EPF is an associate partner to provide a patients' perspective in this work. A three year project, the kick-off meeting will take place in early 2010.

3.3.6 Chain of Trust Project

In 2009 EPF developed, in cooperation with partners from the health professional field and interested members a project called ‘Chain of Trust’ to be co-funded under the Public Health Programme. The project focuses on building confidence and acceptance of telemedicine solutions among patients and health professionals. It is hoped that the project will be launched in early 2010.

3.3.7 Patients’ Evidence Workshops

During the course of 2010, EPF will hold a series of patients’ evidence base 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 pro-active, for example concordance.

4. Building Powerful and Effective Communications and Partnerships

GOAL1: EQUAL ACCESS FOR PATIENTS
GOAL2: PATIENT INVOLVEMENT
GOAL3: PATIENTS’ PERSPECTIVE
GOAL4: SUSTAINABLE PATIENT ORGANISATIONS
GOAL5: PATIENT UNITY

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

4.1 Representation Work

In terms of representation, EPF will continue to have a strong presence at all major EU health events where it is vital to ensure a strong patients’ perspective. In 2009, EPF presented at, or moderated in approximately 50 such European health meetings.

In 2010, because of capacity and overriding policy priorities that require 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, gauging potential impact and added value.

4.2 Communications Outreach

EPF has a dedicated communication officer and in 2010 we hope to reinforce significantly our communications outreach, including media, corporate identity and branding of all our documentation and publications.

EPF will continue to develop its comprehensive mailings 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’ 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 they ‘market’ EPF in these countries, through their own media activities.

We will explore the use of social media in building powerful communications.

4.3 Communications Products

EPF will continue to improve and update the website as EPF’s flagship and major external communications tool. Major improvements were made in this regard in Summer 2008. In 2009, we embarked on utilising a content management system to facilitate more rapid uploading of news and designed a more user-friendly website, both of which will be ready in early 2010.

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 are now approximately 1500 direct recipients, many of whom 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 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 website.

EPF will produce its fourth annual report in early 2010, with an overview of its achievements and challenges in 2009. EPF will translate as many key documents into French and other languages as possible.

4.4 Partners and Allies

Over the last three years, EPF devoted significant time to develop 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 2010.

Specifically, with regard to patient groups, EPF will continue to work as closely as possible with the European Cancer Patient Coalition, European Aids Treatment Group, European Heart Network, and the International Alliance of Patient Organisations. 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, The European Standing Committee of Doctors, (CPME), European Federation of Nurses, The European Pharmacists Organisation, (PGEU), the European Hospitals Association, (HOPE), UEMS (European Union of Specialist Doctors) the European Health Management Association, the European Society for Quality of Care and BEUC, the organisation representing consumers at EU level.

Following the successful joint board meeting between EPF and the European Standing Committee of Doctors, CPME, both organisations agreed joint principles of cooperation at their respective AGMs. During 2010 we will be working closely with them on Health Literacy, Cross Border Healthcare and health ethics initiatives.

EPF held a joint board meeting with the European Pharmacists Organisation, PGEU in September 2008. Both groups made a commitment to regularly exchange views on EU policy developments and to work closely with EU projects they are involved in.

Specific cooperation work will also continue with the European Federation of Nurses (EFN) in relation to optimising the potential of the structural funds to drive common projects between organisations of nurses and patients at national level that support the implementation of EU policy recommendations and 'acquis'. Particular success has already been achieved in Poland in this regard.

With all three organisations, we work together in the 'Chain of Trust ' project.

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 European Medicines Agency, EMEA. 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 WHO Headquarters in Geneva, in relation to EU related matters, WHO–EUROPE, based in Copenhagen, the health unit of the Council of Europe, based in Strasburg, and the relevant health-related departments within OECD (Organisation for Economic Cooperation and Development) based in Paris. Initial contacts with all these organisations took place in 2007.

5. Evaluation Strategy and Performance Indicators for 2009

EPF is committed to ongoing monitoring and evaluation, as described in its five year strategic plan.

5.1 Evaluation Strategy

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 2010 against our five key strategic goals. These are not exhaustive, but serve to illustrate some of the benchmarks we will work towards.

EQUAL ACCESS FOR PATIENTS

GOAL 1: To promote equal access to best quality information and healthcare for EU patients.

Performance Indicator**:** *The degree to which EPF is able to influence the European Parliament and Council to support our proposals on information to patients.*

Target: *Alongside the current proposal to harness explicit support for a comprehensive information to patients strategy with a commitment to engage in three specific areas indentified in the strategy.*

Performance Indicator*: Quality of care working group:*

Performance Indicator*: The degree to which EPF is able to influence the European Commission and Member States represented in the Patient Safety and Quality of Care Working Group in ensuring a patient-centred and equitable approach in the discussions around Quality of healthcare.*

Target: *To harness support among at least five Member States and regions to develop quality strategies for their healthcare systems in which patients are involved.*

INVOLVEMENT OF PATIENTS

GOAL 2: To ensure meaningful patient involvement in EU health-related policy-making, programmes and projects.

Performance Indicator: *Analysis of the impact and added value of the* Value+ *deliverables.*

Target: *To ensure in the long term that meaningful patient involvement is systematically built in to Calls for Proposals for EU funded health projects, and that EPF tools are referenced. In 2010, to ensure this is applied to two funding programmes.*

Performance Indicator: *To be recognised as a key partner, alongside health stakeholders in determining civil society's input in EU health policy.*

Target: *EPF's effectiveness in the revised European Union Health Policy Forum, measured by the inclusion of EPF comments and a patient's perspective in all EUHPF positions and initiatives.*

PATIENTS'PERSPECTIVE

GOAL 3: To ensure that a patients' perspective, including issues around human rights and quality of life is heard in developments at EU level on health economics and health efficacy (health, wealth and equity).

Performance Indicator: *The degree of uptake of the EPF Manifesto ' 150 Million Reasons To Act' in the new Commission.*

Target: *To have a core group of trusted officials in DG SANCO, RESEARCH, ENTERPRISE, and INFORMATION SOCIETY*

To have a commitment from the new Commissioner for Health and Director General of DG SANCO to take forward three elements of the Manifesto in 2010

SUSTAINABLE PATIENT ORGANISATIONS

GOAL 4: To encourage inclusive, effective and sustainable representative patient organisations.

Performance Indicator: *Perceived effectiveness of the EPF's new outreach strategy and membership guide based on independent feedback by patients leader of new EPF members.*

Target: *Direct commitment from health ministers in countries where newly formed umbrella platforms have emerged, to support their EU work.*

Performance Indicator*: To demonstrate the importance of EPF as a credible indispensable civil dialogue partner for all the EU Institutions.*

Target: *A successful application for operational funding through the EU Public Health Programme****.***

PATIENT UNITY

GOAL 5: To nurture and promote solidarity and unity across the EU patients' movement.

Performance Indicator: *The expansion of EPF's membership by the end of 2010.*

Target : *To extend representation to a total of 45 members , to include one key disease area previously underrepresented within EPF, such as cancer; and to extend direct representation, through a national platform of one major country previously underrepresented by EPF.*

Performance Indicator: *The perceived success and impact (through evaluation forms and anecdotal evidence) of the Autumn Regional Advocacy Meeting taking place in Budapest, Hungary.*

Target: *The extent of participation by 50 patients' leaders from the region in subsequent EPF work on EU health policy issues.*

6. Conclusions

EPF has set ambitious goals for 2010 which reflect on increasing external demands on our organisation. EPF's 2010 Work Plan is a strong indication of EPF's proactive work in setting new agendas in its culture and operations.

The EPF Work Plan is a guide to help us achieve our goals and objectives for 2010 but please bear in mind that it is neither exhaustive nor set in stone. The Board and Secretariat realise that unexpected events in the political or media arena can occur and we will be flexible and responsive to deal with any changes.

The work plan supports our objectives of strengthening our organisation by enhancing our capacity at the Secretariat, building trust and a stronger communication base with our members, and achieving a more sustainable financial foundation.

Most importantly, the achievements in 2010 should enhance EPF's credibility and niche as THE European Patients' voice, and move us closer towards our vision of patient centred, equitable health care throughout the European Union.

Milestones in 2010 *(this is not exhaustive, as some key dates are not yet available)*

CALENDAR

Month	**Event**
January	Officers' meeting
February	EPF Board IAPO Congress, Istanbul
March	e-Health Conference, Spanish Presidency
April	Patients Rights Day Officers meeting
May	EPF Board, AGM and Health Technology Assessment Patients' Forum, Brussels
June	EULAR meeting Patient Safety Conference, Spanish Presidency Officers meeting
July	
August	Officers Meeting
September	Funders' Briefing and Dinner, Board Meeting, Brussels EPF / EGA Conference Brussels
October	Officers Meeting EPF Regional Seminar with special emphasis on young patients, Budapest
November	Board meeting
December	Officers Meeting EPF conference on quality of care and patient safety