



## **The European Patients' Forum Five Year Strategic Plan**

**FINAL VERSION**

**Adopted by the EPF membership June 2007**

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**A STRONG PATIENTS' VOICE TO DRIVE BETTER HEALTH IN EUROPE**

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## Foreword by the EPF President

Since its creation in 2003, the European Patients' Forum has grown significantly in recognition and influence in providing the patients' perspective in EU healthcare debates. The establishment of our secretariat in Brussels in mid- 2006 was an important milestone, and a timely opportunity also for the EPF membership to take stock, reflect on our collective achievements and challenges of previous years, and to look ahead - to our vision of future health in Europe, our ethos and core values, and the goals that EPF must pursue to ensure a truly patients' perspective in all EU healthcare developments.

Our Annual General Meeting in June 2006 agreed to a strategic planning process and my warmest thanks go to the EPF working group that invested their time and energy to leading that process, and to all our members for responding with enthusiasm and creativity.

Members are committed to this plan because they see the potential impact of EPF's work and influence for their own members - patient groups throughout the European Union. Our input on crucial areas such as patient safety, information to patients, patient mobility, and genuine patient involvement will affect all EU patients. Furthermore, the opportunities within EPF for exchange of good practice and peer support among and within patient organisations at European level will make an important difference in the future.

I am excited by the results and feel that this plan, both in its ambition and its focus, will be an important blueprint to lead us through the next five years' work. Ours is an enormous but crucial challenge. One that can only be achieved by working together in a coherent, strategic way that reflects all our basic beliefs regarding health equity and the central role of the patient. It is not a static document, however, but rather a fluid and flexible resource - the plan will be fine-tuned on an-ongoing basis in accordance with external developments and milestones and internal review and critique.

Readers who are active in EPF, I hope this plan is useful and relevant to your work. Readers new to EPF, I welcome your interest in EPF and our work and hope, helped by this document, we will develop opportunities for cooperation and synergy.

Anders Olauson  
EPF President

## Executive Summary

The EPF Strategic plan 2007- 2012 consists of 9 sections.

**Section 1: Introduction:** provides a description of EPF and its raison d'être, the prevailing health-care environment, the purpose of a five year strategic plan for EPF, and the process through which this plan was developed and will evolve during the coming 5 years.

**Section 2: Vision and mission:** outlines EPF's vision for the future and its mission

**Section 3: Core values and how we do business:** describes EPF's core values and guiding principles, which have also underpinned the strategic planning exercise and the plan itself.

**Section 4: Key Goals:** describes EPF's key goals for the coming five years

**Section 5: Key Fields of Action:** support these goals with fields of action and specific objectives

**Section 6: Areas that EPF will influence over the next five years:** describes the probable areas to be pursued over the next five years. These have been determined in accordance with members' own prioritization and the anticipated external EU healthcare environment.

**Section 7: Review and Realignment:** outlines the strategies in place for process and outcome evaluation and how the strategic plan will be refined and reshaped in accordance with on-going achievements and challenges, and the external environment.

**Section 8: Glossary and Useful Website References:** provides a glossary of terms linked to this strategic plan. It also signposts significant reference websites.

**Section 9: Acknowledgements:** lists the individuals who have played a key role in the development of the strategic plan .

**Annex I : EPF Work Plan 2007** outlines specific priorities, actions, outputs and timelines and performance indicators during 2007, the first year on implementation of the plan.

## Section 1: Introduction

### 1.1 Defining EPF

#### EPF

- Was set up in 2003 to become the collective patients' voice at EU level, manifesting the solidarity, power and unity of an emerging EU patients' movement.
- Reflects the patients' and their carers' and families' unique and direct experience and expertise in healthcare through member organisations' links with representative national, regional and local patient organisations in all 27 EU Member States.
- Adopts a holistic interpretation of healthcare, to include prevention, and the social, economic, environmental, cultural and psychological aspects of health.
- Acts as both a catalyst for positive change in EU healthcare systems and a watchdog (proactive and reactive).
- Is a credible and professional partner for cooperation, dialogue and negotiation with a broad range of EU level health stakeholders.
- Facilitates exchange of good practice and challenging of bad practice on patients' rights, equitable access to treatment and care, and health-related quality of life between patient organisations at European level and at Member State level.
- Offers a resource for member organisations on EU healthcare intelligence, information dissemination, baseline patient-rights policy responses to the EU Institutions to enable them to focus on disease specific responses.
- Is open to European patients' organisations and national umbrella organisations that fulfil criteria relating to legitimacy, representation, democracy, accountability and transparency. EPF has currently 27 member organisations.
- Is an apolitical, representative advocacy organisation with governance bodies composed of elected non-paid representatives, supported by a small secretariat of paid staff.

## 1.2 The Prevailing Healthcare Environment over the next five years

### Health and Economics

Recent years have seen important advances in the understanding of the links between health and economic development. The publication, “The contribution of health to the economy of the European Union”, for example, makes a strong case for more investment in health to nurture stronger economic growth.

Linked to this, health is an explicit part of the “Lisbon Agenda” and Europe’s ambition to become the most dynamic economy, based on knowledge and innovation. Sustainable growth is seen as dependent on investment in research, innovation and education / employment.

The High Level Pharmaceutical Forum was established by the Commission Vice President Verheugen and Commissioner Kyprianou in June 2005 to examine the competitiveness of the European-based pharmaceutical industry and related public health issues. EPF is the patient representative within the Pharmaceutical steering group and the three working groups on information to patients, pricing and reimbursement, and relative effectiveness.

### The new European Health Strategy

Consultation to date has highlighted that future health policy strategy should include a comprehensive approach to health that **mainstreams** health concerns into all Community policies; that there is a need to bridge health **inequalities** across the EU; that the EU should take a much stronger role in **global health**; that the EU should focus on health **promotion**; that it should tackle **key issues** such as mental health and cross-border matters, and that the EU, its Member States and stakeholders should work together to **deliver concrete results**. A White Paper on the European Health Strategy will be published by the end of 2007. EPF has responded to the consultation discussion document circulated in December 2006.

### The new EU Public Health Programme

The second Programme of Community action in the field of Public Health for the period 2007-2013 will be adopted during the course of 2007. The comparison with the current programme (2003-2008) reveals that some priorities remain on the agenda. In the first health strategy that was adopted (2000), the **three priorities for actions were**: the improvement of health information and knowledge (monitoring, collection of data); the quick and coordinated response to health threats (communicable diseases, effects of environmental agents); the action on health determinants (mental health, nutrition, tobacco). In the new Community programme, the first objective becomes to “improve citizen’s health security”, which can be done by protecting “citizens against health threats” and by enhancing their safety. There is a need to address cross-border threats such as avian influenza or bioterrorism and to develop vaccination policies or “European laboratories for rare or high-risk pathogens”. The coordination of responses at the European level and the provision of

support to Member States in their infrastructure capacity-building is also highlighted. Citizen's safety must also be taken into account ("frequency of avoidable incidents and infections in hospitals", "exposure to chemicals", "substances of human origin for medical use").

Regarding the second objective, promoting "health for prosperity and solidarity", it includes the health determinants of mental health, nutrition and linking with the issue of "bridging inequalities", particularly the disparities triggered by the ageing population process. The idea is to "identify the causes of health inequalities" (particularly in the new Member States), so as to foster the exchange of good practices and "cooperation between health systems on cross-border issues (mobility of patients and professionals).

Finally, the third objective (the former first one) is to "Generate and disseminate health knowledge" and it aims at reinforcing the exchange of information and expertise from different countries (for rare diseases or cross-border issues, for instance). Those active in the field of health require "comparable, reliable and up to date health information" and this an EU's remit.

### **1.3 The purpose of the EPF Strategic Plan**

During the EPF Annual General Meeting in June 2006, it was agreed that a strategic plan should be developed to enable EPF to grow and work effectively during the next 5 years. A working group composed of four EPF members, including two board members, and the EPF director was set up to spearhead this work. This group met three times during the course of autumn 2006.

This draft strategic plan documents the key ideas and thinking emerging from these meetings, and develops priorities and actions fields identified during discussions. A framework was sent out for comment by the members in autumn 2006 and was also discussed by the board during a team-building in September 2006. This plan was presented to the EPF board in January 2007 for comment and approval and then disseminated for written approval by the broader EPF membership by the end of May 2007.

The purpose of the strategic plan is two-fold:

- 1) It provides a clear blueprint for the EPF membership and newcomers on the strategic direction of the organization over the next five years in terms of policy impact and organizational development.
- 2) It will also become an important flagship for EPF for external health stakeholders to know who we are, what we are about and where opportunities exist for cooperation and collaboration.

This document is not however set in stone. It will be reviewed on an annual basis and revised in accordance with internal and external developments and achievements during the course of the next five years.

## Section 2: Vision and mission

The European Patients' vision for the future is

***Patient-centred, equitable healthcare throughout the European Union***

Our mission is

***To provide a strong and united patients' voice to put patients at the centre of EU healthcare policy and programmes***



## **Section 3:** The European Patients' Forum's core values and how we do business

This section describes EPF's core values and guiding principles, which have also underpinned the strategic planning exercise and the plan itself.

### **Patient -centred**

- The European Patient's Forum is driven by a rights-based, patient centred approach to healthcare in Europe

### **Non- discrimination**

- We combat discrimination on the grounds of illness and address health inequalities from the perspective of patients.

### **Holistic**

- We advocate a holistic approach to healthcare issues, that includes the social, economic, cultural, environmental and mental health agenda for patients, carers and their families.

### **Empowering Patients**

- We foster the empowerment of patients, carers and their families by breaking down attitudinal barriers and prejudice regarding patients' place in society as equal citizens.

### **Consultative**

- EPF consults and builds consensus within its membership to be able to address, from a uniquely patients' perspective, the multitude of EU health policy issues that will directly and indirectly impact on patients across the Member States.

### **Independent, transparent**

- We are an independent organisation, transparent in all our operations (financial, policy, communications).

### **Inclusive**

- We are an open and inclusive organisation and strive to ensure that our work also reflects the opinion of potentially marginalised and under represented patients, carers and families.

## **Gender Equity**

- Gender equity is an intrinsic part of the patients' rights agenda. EPF is committed fully to gender equality in all aspects of its work.

## Section 4: Key Goals for EPF in the next 5 years

*Please note these goals are not numbered by way of priority, but rather for ease of reference*

### EQUAL ACCESS FOR PATIENTS

**GOAL 1:** To promote equal access to best quality information and healthcare for EU patients, their carers and their families

### PATIENT INVOLVEMENT

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

### PATIENTS' PERSPECTIVE

**GOAL 3:** To ensure 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).

### SUSTAINABLE PATIENT ORGANISATIONS

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

### PATIENT SOLIDARITY

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

**GOAL 1: EQUAL ACCESS FOR PATIENTS**

**GOAL 2: PATIENT INVOLVEMENT**

**GOAL 3: PATIENTS' PERSPECTIVE**

**GOAL 4: SUSTAINABLE PATIENT ORGANISATIONS**

**GOAL 5: PATIENT SOLIDARITY**

## Section 5:

**Key fields of action:** to support these goals over the next 5 years, with specific objectives

These fields of action are often related to the advancement of more than one strategic goal. They focus on EU level advocacy and campaign work, exchange and dissemination of good practice.

The fields of action are also numbered, not in priority but for ease of reference.

**Please refer also to the EPF Work Plan for 2007 (see annex I) that outlines the specific activities, outputs and timelines in 2007 to contribute towards the objectives outlined in each field of action.**

### FIELD OF ACTION 1:

<b>GOAL1: EQUAL ACCESS FOR PATIENTS</b> <b>GOAL2: PATIENT INVOLVEMENT</b> <b>GOAL3: PATIENTS' PERSPECTIVE</b>
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To reinforce EPF's unique position as the umbrella organisation and respected voice of patient organisations/ and groups at EU level by

- Developing effective, high quality and targeted communication tools
- Engaging in evidence-based surveys linked to patient centred healthcare
- Developing qualitative, anecdotal but credible evidence on patients' direct experiences
- Ensuring high level presence and constructive input at major external health events
- Developing a 'rapid response' approach, on mainstream issues/ that impact on patients
- Mapping / utilising effectively existing patient-centred materials, documentation and tools
- Working in cooperation with appropriate research networks to enhance grass-roots evidence based argumentation for campaign and policy work

### FIELD OF ACTION 2:

<b>GOAL1: EQUAL ACCESS FOR PATIENTS</b> <b>GOAL2: PATIENT INVOLVEMENT</b> <b>GOAL3: PATIENTS PERSPECTIVE</b>
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To enhance dialogue and impact with the EU Institutions by

- Developing and sustaining intelligence work and policy capacity
- Establishing champions in the European Parliament (MEPs and Secretariat staff).
- Developing relationships with European Council permanent representations' health attaches.
- Developing and implementing a long-term approach to influence the EU Council Presidencies.
- Building relationships/ profile with European Commission Directorates and relevant officials concerned with health.
- Developing and agreeing position papers and 'lines to take' on potential future EU health topics important for patients in order to ensure rapid, consolidated responses if and when needed.
- Building relationships with other mainstream Institutions that impact on EU healthcare developments, specifically Council of Europe and OECD.

### FIELD OF ACTION 3:

**GOAL1: EQUAL ACCESS FOR PATIENTS**

**GOAL2: PATIENT INVOLVEMENT**

**GOAL3: PATIENTS PERSPECTIVE**

**GOAL5: PATIENT SOLIDARITY**

To establish and sustain key strategic partnerships and alliances with

- Other umbrella health NGOs and networks (For example, the International Alliance of Patient Organisations, The European Public Health Alliance).
- EU level Health Professional Organisations.
- Health Research Organisations.
- Health Agencies and Think Tanks
- Constituency based NGOs with a interest in health (For example AGE-Europe, European Disability Forum)
- Other health related partners (health equipment and devices, health training and development, packaging, industry federations)

### FIELD OF ACTION 4:

**GOAL4: SUSTAINABLE PATIENT ORGANISATIONS**

**GOAL5: PATIENT SOLIDARITY**

To broaden and consolidate the membership and foster a spirit of solidarity across the European patients' community

- Involving members effectively in 'growing EPF' through well structured consultation, sharing contacts, specific interest areas etc (lead on

- specific policy issues, working groups)
- Sharing of good practice across different disease areas
- Engaging existing members as ambassadors and recruiters of new EPF members
- Involving significant potential new members in a joint policy initiatives or projects
- Developing an appropriate recruitment pack for new and potential members
- Recruiting highly representative organisations from specific disease areas.
- Engaging with / encourage national patient forums, or coalitions that bring together national representative patients' organisations to work strategically on EU healthcare policy and influence their respective governments.
- Bridging the work we undertake in a specifically EU context with EPF members' work and collaboration in the wider Europe

#### **FIELD OF ACTION 5:**

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

To develop a sustainable funding base by

- Striving for European Commission core funding (DG SANCO) and where appropriate project funding (DG SANCO and other relevant DGs)
- Encouraging core funding for member organisations in the medium term
- Engaging with relevant foundations and submitting projects for capacity-building and ad-hoc funding
- Continuing and reinforcing EPF's funding relationship with industry (pharma and non-pharma) in line with its policy on ethics and transparency.

## Section 6:

Probable areas of influence to be pursued over the next five years.

**6.1 These policy areas have been determined in accordance with EPF members' own prioritization and the anticipated external EU healthcare environment.**

### GOAL1: EQUAL ACCESS FOR PATIENTS

- Tackling **Health Inequalities** and Including vulnerable patients' groups

### GOAL1: EQUAL ACCESS FOR PATIENTS

- EU action in relation to **health services** and **patient mobility**, following the consultation that ended in January 2007.

### GOAL1: EQUAL ACCESS FOR PATIENTS

- **Health Literacy**. Since its establishment, EPF has tried to foster support for the concept of health literacy, as an integral part of information to patients'. This will now be included as part of the EU health programme for 2007 and EPF will collaborate with selected projects that emerge from this.

### GOAL1: EQUAL ACCESS FOR PATIENTS

- Developments in relation to **eHealth** particularly in relation to the follow up of the major e-health conference 2007 under the German Presidency.

## GOAL2: PATIENT INVOLVEMENT

- Involvement of patients in all **EU funded health related projects**. EPF has highlighted this as a major goal over the next five years and will be pursuing this both in the policy arena and by submitting a project proposal in the framework of the EU Public Health Programme in 2007 that will identify good practice and key recommendations in this area.

## GOAL3: PATIENTS' PERSPECTIVE

**Health Economics and the patients' voice.** The links between achieving the Lisbon Goals on Competitiveness, Growth, and Health are now well recognised. Significant work is also taking place on the financial sustainability of health care systems. EPF will be working closely with the three EU Institutions to ensure that the patients' perspective is included in any policy developments relation to EU health economics.

## GOAL1: EQUAL ACCESS FOR PATIENTS

### GOAL2: PATIENT INVOLVEMENT

### GOAL3: PATIENTS' PERSPECTIVE

- The **Pharmaceutical Forum** and its working groups (Information to Patients; Pricing and Reimbursement; and Relative Effectiveness) that will continue their work during 2007. The next ministerial Pharmaceutical Forum in June 2007 will give some indications on the way forward.

## GOAL1: EQUAL ACCESS FOR PATIENTS

### GOAL2: PATIENT INVOLVEMENT

### GOAL3: PATIENTS' PERSPECTIVE

- The Commission's **Communication on Information to Patients** scheduled to be presented to the Parliament and the Council in April 2007 and subsequent developments in the European Parliament and the European Council. EPF will be active in presenting the patients' perspective on this Communication and its follow-up.

## GOAL2: PATIENT INVOLVEMENT

### GOAL3: PATIENTS' PERSPECTIVE

- The **EU Patient Safety Framework**. EPF is a member of the high level working group developing this and has also been approached to be involved in an EU funded project on patient safety to be launched in 2008.



**GOAL2: PATIENT INVOLVEMENT**  
**GOAL3: PATIENTS' PERSPECTIVE**

- The EU's own **Health Strategy**, to be published as a White Paper in the course of 2007. Previous consultation reveals that this should include a comprehensive approach to health that **mainstreams** health concerns into all Community policies; that there is a need to bridge health **inequalities** across the EU; that the EU should take a much stronger role in **global health**; that the EU should focus on health **promotion**; that it should tackle **key issues** such as mental health and cross-border matters, and that the EU, its Member States and stakeholders should work together to **deliver concrete results**.

**GOAL4: SUSTAINABLE PATIENT ORGANISATIONS**

**Core funding** for umbrella patients' groups to be effective consultative partners. EPF will attempt to position itself to be eligible for EU core funding from 2008 onwards and encourage similar opportunities for its members organisations.

6.2 Areas where the EPF members have identified that exchange of information and good practice would enhance our professionalism and credibility and would improve our policy impact:

- Training and development for patient advocacy (i.e. EPF annual training seminar);
- The Expert Patient ( EPF project to be launched in 2007);
- Medication management;
- Pain recognition and management;
- Patient adherence to therapies;
- Patients and clinical trials;
- Patients' rights and responsibilities;
- The patients' role in healthcare systems and delivery;
- The relationships between patients and healthcare professionals;
- Self care and self medication;
- The child patient and adolescent patient (EPF project to be launched in 2007).

## **Section 7: Review and Realignment**

The Strategic Plan review will feature as a permanent item on the agendas of the EPF Annual General Meeting and the EPF Board.

The Working Group responsible for the drafting of the plan will be invited to support the EPF review process through the development of :

- a) key indicators on an annual basis to evaluate progress,
- b) on-going consultation with the members and EPF staff working on each key goal and field of action.

The Secretariat will contribute to this through:

- a) discussions with external partners;
- b) analysis of deliverables and 'political context'.

All proposed revisions and realignment will be sent in draft to the EPF Secretariat in November to be incorporated in the following year's work-plan to be approved by the EPF Board.

## Section 8:

**Glossary and Useful References:** provides a glossary of terms linked to this strategic plan. It also signposts significant website references for information and interest

**Patients' perspective:** In line with the EPF Constitution, this also embraces the perspective of the carer, in cases where the patient is unable to represent him or herself, or would need additional support to do that on occasions.

**Rights-based approach:** In the context of EPF's work, a rights-based approach relates to access to healthcare as a basic human right, and the notion of the patient as an equal citizen.

**Health-related quality of life:** Our reference to quality of life in this document relate specifically to health, rather than other aspects of quality of life, although these of course can be linked.

**Health Literacy:** The degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions.

**Policy:** A policy is a plan of action to guide decisions and actions. The policy process includes the identification of different alternatives, such as programs or spending priorities, and choosing among them on the basis of the impact they will have. Policies can be understood as political, management, financial, and administrative mechanisms arranged to reach explicit goals.

**Sustainability:** relating to, or being a method of harvesting or using a resource so that the resource is not depleted or permanently damaged.

**Advocacy and campaign work:** the term advocacy covers all aspects of policy work in which EPF is engaged. A campaign is linked to a single, definable policy / political goal usually with a very specific time-line.

**Directorate General :** Administrative section with the European Commission dealing with a specific policy field.

**DG SANCO :** The Directorate General, or department within the Commission dealing specifically with health.

### Useful Website References

**EPF website :** [www.eu-patient.eu](http://www.eu-patient.eu)

**Commission website:** [www.europa.eu](http://www.europa.eu)

**European Parliament:** [www.europarl.europa.eu](http://www.europarl.europa.eu)

**German EU Presidency:** [www.eu2007.de/en/](http://www.eu2007.de/en/)

## Section 9: Acknowledgements

The Board and Secretariat would like to thank the EPF strategic planning Working Group for their time and reflection in developing this Strategic Plan.

Mike O'Donovan EPF Treasurer and representative of the European Multiple Sclerosis Platform (EMSP), chair

Knud Erben, President of the European Kidney Patients' Federation,

Terry Mangan, President of the European Heart and Lung Transplant Association,

Susanna Palkonen, EPF Board member and Director European Federation for Allergy and Airways Diseases Patients Organisations (EFA).

Supported by Nicola Bedlington, EPF Director and Nick Pradalié, Assistant Policy Officer.

Special thanks are also given to all of the EPF members for their written input to the plan during the consultation process during the autumn 2006 and spring 2007
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## Annex I: EPF Work Plan 2007

# The European Patients' Forum Work Plan 2007

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**GOAL5: PATIENT SOLIDARITY**

## Executive Summary

EPF objectives for 2007 are as follows:

- Building capacity within the Secretariat, the governance structures and our relationship with the members (GOAL 1-5)
- Strengthening our policy impact (GOAL 1-3)
- Extending our membership base to ensure that EPF is a representative and as inclusive as possible (GOAL 4-5)
- Building powerful and effective communications and partnerships (GOAL 1-5)
- Diversifying the funding base (GOAL1 –5)

### *Building Capacity **Governance and Secretariat***

Three major EPF meetings will take place in 2007: the EPF spring conference in March 2007, the Annual General Meeting in June 2007 and a capacity building seminar in November. The Board will meet 5 times.

A number of EPF working groups will also take place on specific policy areas.

In 2007, the Secretariat will be composed of five staff, including a conference coordinator during the early part of the year. The Secretariat will move to new, larger premises.

### ***Strengthening Policy Impact***

EPF's policy work will be shaped by its over-arching goal of involvement of patients in all areas of EU policy, programmes and projects with an impact on health. An application will be submitted to the EU public health programme focused on this theme, and this will be a key dimension of its campaign work in the European Parliament.

EPF will continue to invest in the high- level Pharmaceutical Forum, and in particular political developments surrounding information to patients. Other key policy interventions will include a patients' perspective on the EU health services consultation, the EU Health Policy Strategy White Paper, patient safety, the 7<sup>th</sup> Framework Programme on R and D, and in the EU Health Policy Forum.

High-level meetings will take place with representatives of the German, Portuguese,

and Slovenian EU Presidencies during the course of 2007.

EPF will continue to work with EMEA, and other health related agencies and think-tanks.

EPF will engage in policy-focused project in 2007 around the child and adolescent patient, the expert patient, and enhancing our evidence base and policy lines with patients' testimonies and case studies.

### ***Membership***

EPF will endeavour to extend its membership in 2007, also to include representative national patient umbrellas/ platforms. It will also continue to build its relationship with the whole range of health stakeholders operating at EU level and undertake extensive representational work to promote the patients' perspective.

### ***Communications***

An EPF internal mailing will continue to be produced on a monthly basis for EPF members and allies, and regular communiqués to external partners. The EPF website will continue to be developed as EPF's flagship and central communication tool.

### ***Funding Base***

Significant efforts will be made in 2007 to diversify the EPF funding base. In addition to continuing to build sustainable relationships with pharmaceutical companies, EPF will extend its work with non-pharma companies, foundations in line with its transparency policy and code of ethics, and will also devote considerable energies in 2007 to obtain Commission funding for 2008. The aim is to ensure that 30% of EPF's income comes from non-pharma sources within the next 18 months.

### ***Performance Indicators***

EPF will be measuring the impact of its 2007 Work Plan in accordance with a series of qualitative and quantitative performance indicators that relate back to our vision and 5 strategic goals for the next five years.

**GOAL1: EQUAL ACCESS FOR PATIENTS**  
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## Background

The European Patients Forum adopted a Business Plan to run from June 2005 to May 2007. The organisation is also in the process of a strategic planning exercise to set EPF direction and goals over the next 5 years. It is hoped that a Strategic Plan can be adopted by the EPF membership by written procedure, by May 2007.

The EPF work plan for 2007 incorporates the reflections to date regarding EPF's strategy and priorities and the main components of the business plan. It also takes on board the external political environment, and the likely European healthcare developments during the course of 2007 and beyond.

## EPF Objectives for 2007

As highlighted in the business plan, EPF has identified five core objectives for 2007.

- Building capacity within the Secretariat, the governance structures and our relationship with the members (GOAL 1-5)
- Strengthening our policy impact (GOAL 1-3)
- Extending our membership base to ensure that EPF is a representative and as inclusive as possible (GOAL 4-5)
- Building powerful and effective communications and partnerships (GOAL 1-5)
- Diversifying the funding base (GOAL1 –5)

This work plan outlines in very brief terms, specific actions during 2007 to achieve each of these objectives, although there is clearly some overlap.

During EPF's formative years, much was achieved in terms of visibility, and recognition by a whole range of health stakeholders. Our work plan in 2007 will build on this and enhance our credibility through high-quality, cutting edge policy and campaign work from a uniquely patient's perspective, on behalf of our member organisations.



## 1. Building capacity

<p><b>GOAL1: EQUAL ACCESS FOR PATIENTS</b> <b>GOAL2: PATIENT INVOLVEMENT</b> <b>GOAL3: PATIENTS' PERSPECTIVE</b> <b>GOAL4: SUSTAINABLE PATIENT ORGANISATIONS</b> <b>GOAL5: PATIENT SOLIDARITY</b></p>
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### 1.1 The EPF Secretariat

A newly created full-time post of policy officer will reinforce the Secretariat from January 2007 and a conference coordinator will be engaged for a four-month period from January 2007–April 2007 to deal with the logistics of the EPF Annual Conference.

The webmaster's post will increase to 75 %: the trainee will continue to work on an 80% basis, if possible also over the summer months, and a new trainee will join us in October 2007.

The director's post will continue on an 80% basis.

Staff meetings will take place on a bi-weekly basis, and half yearly reviews and annual appraisals will take place with all staff members.

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 2006 and these will be presented to the Annual General Meeting in June 2007.

The intention is to move EPF to a larger non-serviced office by the end of 2007, to be located in the vicinity of the European Parliament and European Commission. If possible, the office will include meeting space, and a temporary office facility for member organisations visiting Brussels.

### 1.2 EPF Governance Meetings

The EPF board will meet 5 times in 2007 in Brussels and will hold teleconferences as necessary in between these meetings.

The Annual General Meeting will take place in June 2007 over a two day period, including an "Open Space" for Members to exchange policy views and good practice'.

### 1.3 Other key meetings

The EPF conference will take place in March 2007 that will convene patient

representatives and, crucially, other health stakeholders from across Europe to address patient empowerment, information to patients and the sustainability of patient organisations. This meeting is part of a rolling programme of annual conferences, and will be a major opportunity to engage more strategically with other key health care players at EU level.

An EPF annual seminar on strengthening patients' groups will take place in November 2007; this meeting will be entirely independent and funded on the basis of an unrestricted educational grant. The 'training' component and target group will be decided by the Board in early 2007.

Permanent EPF working groups will continue to meet on a regular basis to focus on conference/ seminar planning, campaign work and the implementation of the strategic plan. It is envisaged that ad hoc working groups will also be set up to address specific policy issues and the 2007 budget reflects this.

## 2. Strengthening our policy impact

**GOAL1: EQUAL ACCESS FOR PATIENTS**  
**GOAL2: PATIENT INVOLVEMENT**  
**GOAL3: PATIENTS' PERSPECTIVE**

### 2.1 Involvement of patients

One of EPF's overriding policy goals is to promote the involvement of patients 'organisations in all 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 be working with a range of Commission Directorates, including health (SANCO), research, regional development (structural funds), and enterprise.

EPF will also be submitting an application to the European Commission in the framework of the EU Public Health Programme that will focus specifically on this goal. If accepted this project would commence in 2008, however considerable preparatory work will be necessary in 2007. It is further anticipated that EPF will become an associate partner in projects around patient safety and health literacy.

### 2.2 Intelligence work on policy issues

EPF will also upgrade its 'intelligence' work with all of the EU Institutions, in terms of anticipating issues emerging at EU level, and preparing appropriate and strategic interventions in consultation with and on behalf of its membership.

### 2.3 The European Commission

The High Level Pharmaceutical Forum was established by the Commission Vice President Verheugen and Commissioner Kyprianou in June 2005 to examine the competitiveness of the European-based pharmaceutical industry and related public health issues.

The Pharmaceutical Forum will continue to dominate the EPF policy agenda, particularly in relation to one of its key areas: 'information to patients', as this is fundamental to the empowerment of patients and their contribution to patient-centred health-care.

EPF is involved in all three working groups (Relative Effectiveness, Pricing and Reimbursement, and Information to Patients), represented by EPF President and Board Members and supported by the Secretariat. An important milestone will be the next high-level Ministerial Pharmaceutical Forum scheduled to meet at the end of June 2007.

EPF will also input and monitor carefully politically developments linked to the report prepared by the Commission on information to patients, to the European Parliament and the European Council. This is due to be published in April 2007.

EPF will continue to be represented in 2007 on various Commission Working Groups such as “patient safety” and “health stakeholder involvement”.

EPF will continue to be represented in the European Health Policy Forum that meets twice yearly.

Regarding the Seventh Framework Programme, the EPF President is member of a high level group for health research within the seventh framework programme on research and development, set up by Commissioner for Research.

Two other major policy initiatives on the part of the EU Commission will require considerable attention by EPF during the course of 2007: specifically developments in relation to the EU health services consultation; and the EU health policy strategy, that will be presented as a White Paper during the latter part of 2007. EPF will be liaising closely with the Commission officials involved to ensure proposals reflect a strong patients' perspective, and will be following their course through the European Parliament and Council.

## **2.4 The European Parliament**

During 2007, EPF will galvanise some of the links with key MEPs already established, notably through our liaison work with MEPs in the lead up to the EPF – EFPIA seminar in 2006.

An EPF campaign event will take place in the European Parliament in April 2007, to launch our campaign work, in collaboration with other health NGOs, on ‘information to patients’, raising the annual budget for the new EU health programme during its launch year (2008), and to reinforce our work regarding the importance of involving representative patient organisations in all EU funded health projects. In terms of our longer-term relationship with the European Parliament, the aim is to secure a core group of highly committed MEPs from across the political groupings to enable us to optimise our effectiveness in the European Parliament on health-related policy issues.

## **2.5 The EU Council and Presidency**

EPF will liaise as closely as possible with Germany and Portugal, holding the EU Presidencies in 2007, by attending relevant health meetings, and ensuring input from a patient perspective in relation to key health policy initiatives addressed by the Presidencies. A high-level meeting will be organised to this effect, in February 2007 with both German and Portuguese Health Representatives.

In the latter part of 2007, EPF will also establish links with Slovenia and France, holding the EU Presidencies in 2008.

Efforts will be made to kick-start work to ensure that the Swedish Presidency in 2009 will have a specific focus on the role of patients in the European healthcare agenda, spearheaded by an EPF conference under the auspices of the Presidency.

Regular communication will continue with the health attaches in all permanent representations.

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

EPF will continue to 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' working party.

EPF will continue to participate actively in a number of health related think tanks and advisory panels.

The purpose of such meetings is information exchange, but increasingly EPF will use these platforms to reinforce its key policy messages on topical issues.

## **2.7 Policy-focused projects**

EPF intends to launch three small policy-focused projects during the course of 2007, specifically relating to improving our consultation processes, patient case studies and personal testimonies, and baseline positions on potential future policy areas; exploring concepts around the expert patient, and enhancing understanding of the child and adolescent patient. The overall rationale behind these projects is to substantiate EPF's knowledge base, and policy lines, with meaningful input from the patients' community throughout the European Union.

## **3. Reinforcing the membership base and cooperation with the members**

<b>GOAL4: SUSTAINABLE PATIENT ORGANISATIONS</b> <b>GOAL5: PATIENT SOLIDARITY</b>
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It is of great importance that EPF is as representative as possible of the whole spectrum of patients at EU level. Currently EPF has 23 members that are European NGOs and 5 organisations are at the stage of proposing EPF membership to their respective boards.

EPF will undertake a project during 2007 with specific emphasis on extending EPF's membership to European Patient Organisations that have not yet joined EPF but have expressed an interest in being involved, and national patient coalitions and platforms.

In the framework of this project, EPF will develop a membership guide to support new and existing members in contributing and benefiting to the maximum from the work of EPF.

The goal is to extend the EPF membership to 30 organisations by the end of 2007 and to broaden the representation across the key disease areas.

EPF is a collaborating partner in a EU funded project organised by the European Multiple Sclerosis Platform, and will communicate on-going developments in this project to the broader EPF membership.

## **4. Building powerful and effective communications and partnerships.**

<p><b>GOAL1: EQUAL ACCESS FOR PATIENTS</b> <b>GOAL2: PATIENT INVOLVEMENT</b> <b>GOAL3: PATIENTS' PERSPECTIVE</b> <b>GOAL4: SUSTAINABLE PATIENT ORGANISATIONS</b> <b>GOAL5: PATIENT SOLIDARITY</b></p>
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EPF will continue the work commenced in 2006 in relation to building powerful and effective communications and partnerships.

### **4.1 Representation work**

In terms of representation, EPF will continue to ensure a strong presence at all major EU health events, where it is vital to ensure a strong patients perspective. Criteria will be developed to decide whether participation is appropriate in specific events, and gauge potential impact. Where it is judged that EPF is unable to be present in an event, a written contribution will be sent.

### **4.2 Communications outreach**

Our communications approach in 2007 will include the reinforcement of EPF's corporate identity and house style (statements, policy papers, publications)

EPF will continue to develop its comprehensive mailings lists, 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.

### **4.3 Communications products**

EPF will also continue to produce a monthly internal mailing to members and those working closely with us, with EU news, information and issues with a potential impact of patients. EPF will take on board the outcome of the membership survey in late 2006 on improving the relevance and quality of the mailing.

The new EPF website was launched in September 2006. EPF will continue to improve and update the website as EPF's flagship and major external communications tool.

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 first annual report in early 2007, with a resume of its first years of operation and an overview of developments since the setting up of the EPF secretariat in Brussels in mid- 2006.

EPF will also develop and test an EPF intranet system for members

#### **4.4 Partners and allies**

During 2006, 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 2007.

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

EPF will also continue to develop strong relationships with the wide range of the health NGOs organised at EU level, including the European Public Health Alliance, The European Standing Committee of Doctors, European Federation of Nurses, The European Pharmacists Organisation, PGEU, the European Hospitals Association, HOPE etc. EPF will explore the idea of a regular joint meeting with the Presidents and Directors of these organisations on the eve of key external health events.

In 2007, EPF will also initiate working relations with EU health agencies to enhance our visibility and to encourage a stronger patient perspective in their work. In addition to EMEA (see above) EPF will also work with the European Health Observatory, European Centre for Disease Prevention and Control, WHO –Europe, etc



## 5. Diversifying the funding base

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

EPF's income in 2007 is made up primarily of unrestricted funding from the pharmaceutical industry. We are currently in partnership with 9 different pharmaceutical or health-care companies.

### 5.1 Sustainable partnerships with pharmaceutical companies

EPF will continue to build sustainable partnerships with representatives of industry in accordance with our frameworks on transparency and ethics, also through relevant industry organisations such as the European Federation of Pharmaceutical Industry Associations, EFPIA, the Pharmaceutical Research and Manufacturers of America PhRMA, AESPG (the European Association of self medication industries) and GIRP (the European Association of Pharmaceutical Wholesalers). In order to rationalise communication, it is envisaged to organise a single high-level meeting with all pharmaceutical partners in September 2007 to discuss perspectives beyond 2008.

A major goal for EPF is to diversify financial sources to ensure a broad based, politically and financially sustainable funding base.

### 5.2 Diversification

Our strategy in 2007 will be to submit a proposal to the European Commission in the framework of the European Union Public Health Programme, on the involvement of patients in EU project (see above), to obtain project funding, and campaign with vigour for core funding from the European Commission from 2008 onwards.

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

Our aim is to work towards by 2008, 30 % of our funding comes from non-pharma sources.

## 6. Performance indicators 2007

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

The following performance indicators will be used to measure our success in 2007 against our 5 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:** Evidence of EPF's influence on the Information to Patients Report to be submitted to the European Parliament in April 2007, as reflected in the text and subsequent debate/ policy development. One measurement of this will be the number of EPF proposed amendments and proposals regarding the report that are incorporated in the final version.

**Performance indicator:** Active participation and input in all aspects of the Pharmaceutical Forum reflected by a strong patients' perspective in agreed texts and outcomes in 2007

**Performance indicator:** Evidence that patients' organisations, and the concept of patient empowerment is an integral part of the European Health Strategy. This will be measured by the degree to which EPF's response to the discussion paper and proposals therein, have been incorporated into the Health Strategy.

### PATIENT INVOLVEMENT

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

**Performance indicator:** The submission and approval of a EU project on involvement of patients under the Public Health Programme Call 2007.  
**Performance indicator:** EPF representation in all the major EU level health Forums, Consultative Committees and Working Groups.

### 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 endorsement at the EPF Spring Conference of Action Points to move forward on empowerment, information and sustainability, and

effective follow-up by EPF.

**Performance indicator:** the drafting of and consensus among the membership for 5 key policy positions/ responses during the course of 2007.

Performance indicator: Production of 4 external mailings during the course of 2007.

## SUSTAINABLE PATIENT ORGANISATIONS

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

**Performance indicator:** 30% of EPF's funding to come from non-pharma sources by the end of 2008

**Performance indicator:** The perceived success and impact (through evaluation forms and anecdote) of the EPF training seminar in November 2007

## PATIENT SOLIDARITY

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

**Performance indicator:** The enlargement of the EPF membership to 30 members by the end of 2007, and to extend representation in one key disease area previously unrepresented within EPF.

**Performance indicator:** The perceived success and impact (through evaluation forms and anecdote) of the EPF Annual General Meeting in June 2007.

## Conclusions

EPF's exciting and ambitious work plan for 2007 reflects the increasing external demands on the organisation, and also a shift towards EPF becoming more proactive and agenda-setting in its culture and its operations.

The work –plan is not exhaustive nor set in stone and it should be borne in mind that the Board and the Secretariat will need to be flexible enough to respond effectively and rapidly to unanticipated media or political events during the course of 2007.

The work plan includes also scope to consolidate the organisation in terms of enhancing the Secretariat capacity, building communication and trust with and between the members, and achieving a more sustainable financial base.

Most importantly, the achievements in 2007 should enhance EPF's credibility and niche as the European Patients' voice, and move closer towards its vision of patient centred, equitable health care throughout the EU.

**Milestones in 2007 (this is not exhaustive, as some key dates are not yet available including Pharmaceutical Forum working group meetings and major external conferences).**

January	Board meeting, policy officer in post, conference coordinator in post
February	Call for proposals for EU public health programme funding, Joint meeting with the German and Portuguese Presidency EFPIA Think Tank
March	European Voice Conference on Healthcare Launch of European Patients' Directory EPF Spring Conference
April	Board Meeting Campaign event in the European Parliament European Health Policy Forum EFPIA Think Tank
May	Submission of proposal to Public Health Programme
June	Board Meeting EPF Annual General Meeting Pharmaceutical Forum EFPIA Think Tank
July	Mid year review with staff
August	
September	High Level Meeting With Sustainable Funding Partners Board Meeting EFPIA Think Tank
October	Bad Gastein Health Forum
November	EPF Seminar European Health Policy Forum EPF Board Meeting EFPIA Think Tank
December	Opening of EPF's own office from serviced offices Staff Appraisals.