

The European Patients' Forum

Work Plan 2007

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GOAL1: EQUAL ACCESS FOR PATIENTS
GOAL2: PATIENT INVOLVEMENT
GOAL3: PATIENTS' PERSPECTIVE
GOAL4: SUSTAINABLE PATIENT ORGANISATIONS
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 7th 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
GOAL2: PATIENT INVOLVEMENT
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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

GOAL1: EQUAL ACCESS FOR PATIENTS
GOAL2: PATIENT INVOLVEMENT
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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

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| GOAL4: SUSTAINABLE PATIENT ORGANISATIONS |
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| GOAL5: PATIENT SOLIDARITY |
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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.

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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

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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).

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| 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. |