europeanpatients'forum

The European Patients' Forum Work Plan 2009

PATIENTS' RIGHTS – EQUITY OF ACCESS – A PATIENTS' PERSPECTIVE

www.eu-patient.eu

Preface by the EPF President

It is my pleasure to introduce to you the EPF Work Plan for 2009. Fundamental to this work plan are the concepts of **Patients' Rights, Equity of Access, and the Patients' Perspective**. These underpin all that EPF strives for as an organisation, our vision, strategy, values and principles. They are inherent to the pro-active and on-going work we and our members do in shaping and influencing the EU health agenda. And given the current economic and financial landscape in Europe, this has never been more critical.

What are EPF's priorities in 2009?

Our policy priorities, framed around the Commission's own campaign 'A Europe for Patients', and the health focus of the Czech and Swedish EU Presidencies, are 'Patients Rights in Cross Border Health Care, Patient Safety, Health Literacy, Health Inequalities and E-health. We will also be inputting to the EU Pharmaceutical Package of proposals on Information to Patients, Pharmacovigilance, and Counterfeiting and advancing our work on Health Technology Assessment.

Another key pillar of our work in 2009 is our Patients' Manifesto '150 million reasons to act' in the lead up to the European Parliament elections and the new Commission in 2009.

Our flagship project 'VALUE +' on the meaningful involvement of patients enters its second and final year in 2009 and will end with a major conference under the patronage of the Swedish Presidency in Gothenburg in December 2009.

EPF will organise three other major meeting points for patients' leaders and other health stakeholders: A conference that we are co- organising with the European Commission in Brussels, in March 2009 on the outcomes of the pharmaceutical forum – delivering for patients that will look at moving forward on information to patients, pricing and reimbursement and relative effectiveness; our Annual General Meeting also in March that will review our impact and steer our direction in the coming months and years; and our regional autumn advocacy seminar that will take place in Sophia, Bulgaria in September.

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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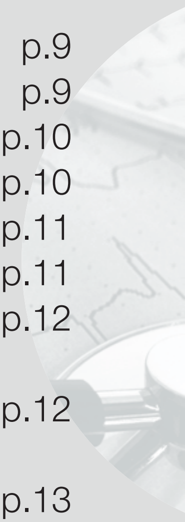

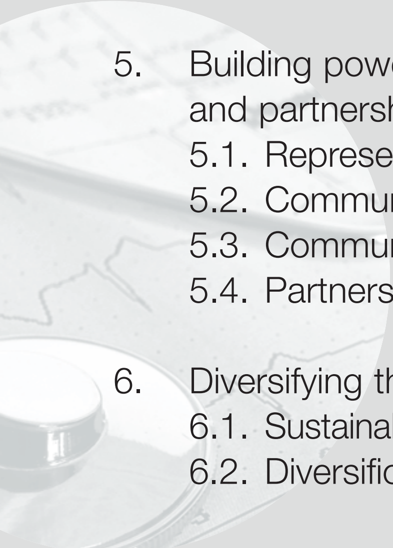

EPF Strategic Goals

EPF agreed a strategic plan at its Annual General Meeting, June 2007.

EPF's vision is high quality, patient-centred, equitable healthcare for all patients throughout the European Union.

The plan identifies five strategic goals:

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 UNITY

GOAL 5: To nurture and promote solidarity and unity across the EU patients' movement. No patients' organisation is too small to contribute to our work.

Executive Summary

EPF objectives for 2009 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)
- **Developing project and patients' evidence** to feed into policy (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** (GOAL 1 –5)

GOAL 1:
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BUILDING CAPACITY, GOVERNANCE AND SECRETARIAT

Four major EPF meetings will take place in 2009:

- Conference in cooperation with the Commission on the follow-up to the Pharmaceutical Forum, March 2009;
- The EPF Annual General Meeting, March 2009;
- Regional Advocacy Seminar, Bulgaria, September 2009;
- VALUE + Conference under the patronage of the EU Swedish Presidency, December 2009.

The board will meet 5 times.

A steering group on 'The Status of Patients in the European Union' will develop a pilot initiative linked to this project.

Campaign work will continue on the promotion of the European Patients' Manifesto – "150 million reasons to act".

A number of EPF working groups and 'patients' evidence base' workshops will also take place on specific policy areas. An EPF registry of 'patients experts' in different policy areas will also be set up.

In 2009, the secretariat will be composed of 6 staff, including a communications consultant on an ad hoc basis.

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.

EPF will invest in the follow up of the high- level Pharmaceutical Forum, and in particular political developments surrounding information to patients and health technology assessments.

Other key policy interventions will include a chronic patients' perspective on legislative and non legislative proposals on cross border healthcare, patient safety, Health Literacy, ICT and Health (e-health), the Pharmaceutical Package (Counterfeiting, Pharmacovigilance, and Information to Patients) and health inequalities.

High-level meetings will take place with representatives of the Czech and Swedish EU Presidencies during the course of 2009 and with the Spanish and Belgian Governments in preparation for their Presidencies in 2010.

EPF will be actively promoting a patient-centred philosophy and agenda with the new European Commission and European Parliament.

EPF will continue to work with EMEA, the European Union Health Policy Forum, and other health-related agencies and think-tanks.

PROJECTS AND PATIENTS' EVIDENCE AND EXPERTISE

EPF launched its first EU funded project 'VALUE +' in 2008 and the project will culminate at the end of 2009 with a major conference to discuss outputs and next steps.

EPF is also actively involved in a European Patient Safety Project 'EUNETPAS' 'RESPECT' a project that explores the involvement of patients in clinical trials and CALLIOPE that is focused on interoperability of health services and the stakeholders' perspective.

EPF has joined consortia working on FP7 project applications focused on the patient's perspective in relation to Health Technology Assessment and communicating effectively the outcomes of FP7 projects to patients and other health stakeholders. If successful, these projects will commence in Autumn 2009.

MEMBERSHIP AND PARTNERSHIPS

EPF will endeavour to extend its membership in 2009, also to include more 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

EPF will continue to be produce a Mailing on a six-weekly 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 continue in 2009 to diversify the EPF funding base. In addition to building sustainable relationships with pharmaceutical companies, EPF will extend its work with non-pharma companies and foundations focusing on health issues in line with its transparency policy, framework for funding support and Code of ethics and conduct.

EPF will submit proposals for funding to the European Commission for projects and activities that support its policy goals. EPF will cooperate closely as associate partners in relevant research projects on health, providing a patient's perspective.

EVALUATION STRATEGY AND PERFORMANCE INDICATORS

EPF will measure the impact of its 2009 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.

BACKGROUND

The European Patients' Forum adopted a five-year strategic plan at its Annual General Meeting in June 2007. The EPF Work Plan for 2009 takes forward this strategy and builds on the outcomes of the 2007 and 2008 Work Plan.

It also takes on board the external political environment, and the likely European healthcare developments during the course of 2009 and beyond.

EPF OBJECTIVES FOR 2009

EPF has identified six core objectives for 2009, that build on the outcomes and review of previous years' work and impact.

- Building capacity within the Secretariat, the governance structures and our relationship with the members (GOAL 1-5)
- Strengthening our policy impact (GOAL 1-3)
- To develop our project and patients' evidence to feed into policy (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 campaigns, communications and partnerships (GOAL 1-5)
- Diversifying the funding base (GOAL 1 –5)

This Work Plan outlines in very brief terms specific actions during 2009 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 2009 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

GOAL 1:
EQUAL ACCESS FOR PATIENTS
GOAL 2:
PATIENT INVOLVEMENT
GOAL 3:
PATIENTS' PERSPECTIVE
GOAL 4:
SUSTAINABLE PATIENT ORGANISATIONS
GOAL 5:
PATIENT UNITY

1.1. THE EPF SECRETARIAT

1.1.1. Human Resources

EPF's secretariat team is comprised of an executive director, senior policy advisor, programme officer, webmaster, office manager and stagiare. The support of external communications expertise will be sought on key campaigns and documents.

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 2008 and these will be presented to the Annual General Meeting in March 2009, and published on the website within one month of this meeting.

1.2. EPF GOVERNANCE

The EPF board, composed of 7 representatives elected by the EPF membership, will meet 5 times in 2009 in Brussels and will hold teleconferences as necessary in between these meetings.

The **Annual General Meeting** will take place in March 2009 where EPF will welcome formally at least 3 new members.

EPF set up a subsidiary organisation AISBL in 2008 to comply with Belgian law.

1.3. OTHER KEY MEETINGS

EPF will co-organise with MEP Nicodim Bulzesc meetings in the European Parliament in February 2009 on Health Literacy, linked to the EPF Manifesto Campaign.

EPF will co-organise with the European Commission a major Conference on the dissemination of the outcomes of the Pharmaceutical Forum. This will take place on 25 March 2009 and will attract approximately 120 delegates.

EPF will co-organise with Active Citizenship Network a key event on 18th April to celebrate the European Patients‘ Rights Day.

An EPF Regional Advocacy Seminar on strengthening patients' groups will take place in September 2009 in Sophia, Bulgaria.

A EPF Flagship Conference on VALUE + and Patients Involvement under the patronage of the Swedish Presidency will take place in December 2009

An EPF working group will monitor and support the campaign linked to the Patients' Manifesto '150 million reasons to act'.

A further working group will be set up to advance work on 'The Status of Patients in the European Union', to undertake a mapping exercise regarding existing literature and research in the area, and to identify the structure of the project, and a number of key indicators for a pilot survey and report.

Ad hoc working groups and patients' evidence base workshops will also be set up to address specific policy priorities and the 2009 budget reflects this.

A EPF registry of 'patient experts' in different policy areas will also be set up at the beginning of 2009 to support EPF's policy work.

2. Strengthening our policy impact and campaign work

2.1. SPECIFIC POLICY PRIORITIES AND CAMPAIGNS

In 2009, EPF will focus on the following policy priorities

- Follow –up to the Pharmaceutical Forum Process
- The Pharmaceutical Package (Counterfeiting, Information to patients, and Pharmacovigilance)
- Quality of Health Care and Patient Safety
- Cross Border Health Care and patients' mobility
- ICT and Health
- Health Literacy
- Tackling Health Inequalities from the patients' perspective
- Health Technology Assessment

A number of disease specific initiatives will take place in 2009, in the framework of the Commission's work programme, on cancer, Alzheimer's disease and rare diseases. These will be taken forward by the relevant EPF member organisations and allies and EPF will endeavour to support their efforts from a broader patients' perspective in the spirit of solidarity. EPF will monitor EU policy development on organ donation and transplantation.

EPF will be active in 2 specific campaigns in 2009: the EPF's own campaign to promote the EPF Manifesto, '150 million reasons to act', and the Commission –led campaign 'A Europe for Patients'. These campaigns are highly complementary and help to frame the major policy initiatives outlined above, for patients and citizens throughout Europe.

2.1.1. Follow- Up to the High Level Pharmaceutical Forum Process

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 ended formally in October 2008, with a substantive report and a number of key deliverables. EPF will continue to invest in the necessary follow up in relation to the three key areas: 'information to patients', relative effectiveness, and pricing and reimbursement, notably through its role in the co-organisation of a Conference on the outcomes of the Pharmaceutical Forum in March 2009.

2.1.2. Quality of health care and patient safety

EPF has been actively involved in recent years in 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 forthcoming adoption of the Commission's patient safety legislative proposals, this Working Group (WG) will have finished its mandate will no longer in its current form. A new WG focussed on quality of health care will be set up in 2009.

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 at Senior Level.

2.1.3. 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 will commence their legislative journey in 2009 with discussions in the European Parliament and the European Council and eventually adoption through a co-decision-making process by these Institutions. 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.

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2.1.4. 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 has consulted its members and developed a clear statement on the current proposal and its strengths and weaknesses and will be working closely with lead MEPs in the European Parliament and the Council Presidencies regarding to ensure the final proposal reflects fully a patients' rights approach.

2.1.5. Information Communication Technology and Health

Following the adoption by the European Commission of a Communication on Telemedicines, EPF will develop a position paper on the document and will also be actively involved is 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 also continue our cooperation with consortia and networks focusing on ICT and health (CONTINUA, COCIR and EUCOMED)

2.1.6. Health Literacy

During 2009, EPF will follow up on the Spring Conference 2009 on Health Literacy and the Conclusions and Recommendations emerging from that event.

Specifically we will be active in the European Parliament to promote support for a Health Literacy Declaration, co-organising a Public Hearing in February 2009.

We will participate in the newly established EU project developing a Health Literacy Network.

We will be also 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.

2.1.7. Tackling Health Inequalities from the patients' perspective

One of the Commission's priorities is 2009 is a Communication on Tackling Health In-equalities which is 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.

2.2. 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 mainstreaming.

2.3. INTELLIGENCE WORK ON POLICY ISSUES

EPF will 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.

2.4. THE EUROPEAN COMMISSION

2.4.1. Tackling Health Inequalities

Regarding the specific items in the European Commission work plan 2009, EPF will focus in particular on the Commission's proposed Communication on 'Solidarity in health: Reducing health inequalities'.
The Commission has stated that it will support Member States in their actions on tackling in-equalities through structural fund monies. EPF will mobilise its membership to ensure appropriate patient involvement in these processes.

2.4.2. A Europe for Patients Campaign

EPF has been an active supporter of the Commission's Campaign 'A Europe for Patients' launched in September 2008 and will liaise closely with the Commission services responsible to cooperate in the roll-out of the Campaign in different Member States in 2009 and ensuring appropriate links with the EPF's own campaign around the EPF Manifesto '150 million reasons to act'.

2.4.3. A new European Commission

2009 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 to the Commission's recent Conference on 'Delivering for Tomorrow's European Consumers' that took place on 29-30 October 2008 and the discussion document Future Challenges for EU Health and Consumers Policies.

2.4.4. Commission high level groups, working groups and platforms

EPF will continue to be represented in 2009 on various Commission Working Groups such as "patient safety and quality of healthcare", the 'e-health stakeholders group' and the editorial board of the EU Health Portal. EPF will use this representation to be a pro-active as possible in ensuring a patient-centred perspective in developments in each of these areas.

EPF will 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 2009.

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 (FP7), set up by Commissioner for Research.

EPF will get involved as an associate partner in selected FP7 projects that contribute to the EPF Strategic Plan.

2.5. THE EUROPEAN PARLIAMENT

2.5.1. Building on existing relationships

During 2008, EPF galvanised links with key MEPs already established, notably through liaison work with MEPs for our Advocacy Seminars. Over 80 MEPs have expressly committed themselves to the work of EPF.

We have chosen not to set up an interest group or an 'intergroup' In terms of our longer-term work with the European Parliament, the aim is to secure a strong on-going relationship with highly committed MEPs from across the political groupings to enable us to optimise our effectiveness in the European Parliament on specific health-related policy issues.

2.5.2. The EPF Manifesto Campaign '150 million reasons to act' and the European Parliament Elections in June 2009

EPF will continue to work on the EPF Manifesto Campaign that was launched in the European Parliament in September 2008 and ensure as much political support as possible from current and future MEPs for a patients' perspective in EU policy developments, particularly in the framework of the European Parliament elections in June 2009.

2.5.3. Patients' Rights and the European Parliament

EPF will cooperate closely with the Active Citizens Network and its work in the EP on patients' rights. The aim is to share ownership of these initiatives with patients' and citizens organisations. Key events will take place across the EU Member States on 'Patients' Rights Day on 18th April 2009 and a European event in the European Parliament in Strasbourg soon afterwards.

2.6. THE EU COUNCIL AND PRESIDENCY

EPF will liaise as closely as possible with the Czech Republic and Sweden holding the EU Presidencies in 2009, 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 be an important tool in this dialogue.

In the framework of VALUE +, close work has taken place with the Swedish Government 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 patronage of the Swedish Presidency.

In the latter part of 2009, EPF will also establish links with Spain and Belgium holding the EU Presidency in 2010.

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

2.7. POLICY INVOLVEMENT IN AGENCIES, THINK- TANKS AND ADVISORY PANELS

EPF will continue to input in the European Medicines Agency (EMEA) inter alia through the patient representative on the EMEA Board, and direct involvement of an EPF representative in the EMEA Patients' and Consumers' Working Party.

EPF will continue to participate actively in a number of health-related think tanks and advisory panels, including the EFPIA patients Think Tank, and the Centre for Health, Ethics and Society (CHES)

EPF will be involved in the stakeholders group linked to the Innovative Medicines Initiative.

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

3. Our 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 meaningful input from the patients' community throughout the European Union.

VALUE +

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

In 2009 the project is at its second year of implementation and the focus will be on developing a set of specific targeted resources. The information and knowledge on the status of patient involvement acquired in 2008 and part of 2009 will be 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.

These resources will be developed and reviewed by and with patients and will be presented in their final form at a final conference under the patronage of the Swedish Presidency.

EUNETPAS

EPF is involved as an associate partner in EUNetPaS (European Union Network for Patient Safety) 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 critiqe from a patient's perspective.

RESPECT

EPF is also 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 will explore 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 will make use of 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.

CALLIOPE

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 eHealth infrastructures and services across Europe.

EPF will focus its contribution towards the development of a proposal for a European eHealth Interoperability Road Map and of a Review Report and proposed revisions of the EC Interoperability Recommendation.

THE YOUNG PATIENT

During the course of 2008, EPF completed a preliminary project on young patients and the way in which they perceive their healthcare environments – identifying some of positive aspects of how they are treated, and the challenges. On the basis of the report from a series of workshops in Sweden, EPF will set up a European internet Forum for young patients, to be able to feed their views into key health development at EU level, and also to exchange experience and good practice. The aim of this virtual network is to become a sounding board for EPF's policies to ensure that a young patients' perspective is also included. EPF will seek the advice of the European Youth Forum on this issue.

PATIENTS' EVIDENCE WORKSHOPS

During the course of 2009, 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 the light of EU developments in a particular area, or as a result of discussion at the AGM in March where a specific and urgent priority area is identified in which EPF must be pro-active, for example concordance.

PATIENT EXPERTS

In early 2009, EPF will set up a registry of patient experts in different policy areas who will be able to contribute towards EPF's policy work on an ongoing basis.

4. Reinforcing the membership base and cooperation with the members

It is of great importance that EPF is as representative as possible of the whole spectrum of patients at EU level. In the last two years, EPF's membership has grown from 23 members to 38 members at the end of 2008, with 6 national patients' platforms now on board, and several membership applications in the pipeline.

The goal is to extend the EPF membership to 42 organisations by the end of 2009 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 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 also 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.

An EPF Membership Guide will also be produced that will help to enable current and new members to contribute and benefit to the maximum extent from their membership to EPF.

GOAL 4:
SUSTAINABLE PATIENT ORGANISATIONS

GOAL 5:
PATIENT UNITY

5. Building powerful and effective communications and partnerships.

GOAL 1:
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EPF will continue to build powerful and effective communications and partnerships, using the external communication strategy adopted by the board in December 2007.

5.1. 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 2008, EPF presented at, or moderated in approximately 50 such European Health meetings.

Criteria have been agreed by the board 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.

5.2. COMMUNICATIONS OUTREACH

Our communications approach in 2009 will again include the reinforcement of EPF's corporate identity and branding. (Position statements, policy papers, 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.

EPF will also work in close cooperation with National umbrella patient organisations in countries where there is a strong media outreach (e.g Spain, France) and agree they 'market' EPF in these countries, through their own media activities.

During 2008, we developed a clear policy on our members and members' members using our logo and making a link to the EPF website.

We will also continue to cultivate contacts with selected 'health' journalists and EU journalists.

5.3. COMMUNICATIONS PRODUCTS

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. Major improvements were made in this regard in Summer 2008. In 2009 we will embark on a content management system to facilitate more rapid uploading of news.

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 enlarged the mailing list of the 'EPF Mailing' newsletter, to make it accessible to a wider network. There are now approximately 1000 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 third annual report in early 2009, with an overview of its achievements and challenges in 2008.

EPF will attempt, depending on budget, to translate key documents into French.

5.4. PARTNERSHIPS 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 2009.

Specifically, with regard to patient groups, EPF will continue to work as closely as possible with the European Cancer Coalition, European Aids Treatment Group, 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 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, (CPME), European Federation of Nurses, The European Pharmacists Organisation, (PGEU), the European Health Management Association (EHMA), the European Hospitals Association, (HOPE), UEMS (European Union of Specialist Doctors) etc.

Following the successful joint board meeting between EPF and CPME, the European Standing Committee of Doctors, both organisations agreed joint principles of cooperation at their respective AGMs. During 2009 we will be working closely with them on health literacy, cross border healthcare and ehealth ethics.

EPF held a joint board meeting with PGEU, the European Organisation representing Pharmacists in September 2008. A very fruitful discussion took place and a commitment to regular exchange views on EU policy developments and work closely in the EU projects in which both organisations are involved.

Specific cooperation work will also continue with the European Federation of Nurses 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.

In 2009, 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 EMEA (see above) EPF will also work with the European Health Observatory, and the European Centre for Disease Prevention and Control.

In 2009, EPF will also develop our active relationship with 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.

6. Diversifying the funding base

GOAL 1:
EQUAL ACCESS FOR PATIENTS

GOAL 2:
PATIENT INVOLVEMENT

GOAL 3:
PATIENTS' PERSPECTIVE

GOAL 4:
SUSTAINABLE PATIENT ORGANISATIONS

GOAL 5:
PATIENT UNITY

EPF's income in 2009 is made up of unrestricted funding from the industry, EU funding and Membership fees.

EPF will be receiving funding in 2009 for the second year of a two year project in the framework of the EU Public Health Programme, VALUE + and participating as an associate partner in several other projects that meet our criteria for involvement.

6.1. SUSTAINABLE PARTNERSHIPS WITH PHARMACEUTICAL COMPANIES

We are currently in partnership with 12 different pharmaceutical or health-care companies or federations.

EPF will continue to build sustainable partnerships with representatives of industry in accordance with code 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), GIRP (the European Association of Pharmaceutical Wholesalers) and the Health Compliance Packaging Council. EPF is involved in the steering group of the Innovative Medicines Initiative.

6.2. DIVERSIFICATION

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

The EU Public Health Programme includes a provision for core funding for eligible health NGOs. EPF submitted a proposal for core funding for its operational programme in 2008 and was unsuccessful.

Following high level discussions with the Commission clarifying the issue of 'independence', new applications will be submitted under the European Public Health Programme.

EPF will also continue to get involved in new EU projects as an associate partner in accordance with EPF's own strategic plan, criteria for joining projects and human resource availability within the secretariat.

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.

Longer term financial health of EPF

EPF during the course of 2009 will continue to work towards building reserves of 6 months of our operational budget. We also undertake very rigorous financial planning and expenditure to ensure optimum use of the resources made available to EPF.

7. Evaluation strategy and Performance indicators 2009

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

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 pro-active and effective as possible as a fast-growing lead organization in increasingly dynamic EU health policy environment.

The following performance indicators will be used to measure our success in 2009 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:
The degree to which EPF is able to influence the European Parliament and Council to support the Cross Border Healthcare Directive and introduce key changes.

Target:
To introduce a rethink on upfront payments and involve patient organisations in the national information points, make the proposal as inclusive,patient-centred and workable as possible.

Performance indicator:
The adoption of the Health Literacy Declaration in the European Parliament.

Target:
To achieve the required number of signatures and to secure political engagement in the Council and Commission to follow up the Declaration.

INVOLVEMENT OF PATIENTS

GOAL 2: TO ENSURE MEANINGFUL PATIENT INVOLVEMENT IN EU HEALTH-RELATED POLICY-MAKING, PROGRAMMES AND PROJECTS.

Performance indicator:
Direct feedback through the evaluation forms and analysis of the impact and added value of the VALUE + conference under the patronage of the Swedish Presidency, including the utility and applicability of the three 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.

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

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

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'.

Target:
To have a reference group of 80 new MEP allies ready to work actively with EPF on the issues raised in the Manifesto in the next Parliament.

Performance indicator:
Evidence in the final text of EPF's contribution to the forthcoming EU Communication on Tackling health inequalities.

Target:
Specific reference to potentially margnialised patients in the Communication and strategies to overcome this.



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 based on independent feedback by patients leaders in the countries concerned.

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

Performance indicator:
A successful application for funding through the EU Public Health Programme.

Target:
To engage key stakeholders to work with patient groups in project focussed around health literacy and patient empowerment.

PATIENT UNITY

GOAL 5: TO NURTURE AND PROMOTE SOLIDARITY AND UNITY ACROSS THE EU PATIENTS' MOVEMENT.

Performance indicator:
The enlargement of the EPF membership to 42 members by the end of 2009.

Target:
To extend representation in one key disease area previously unrepresented within EPF, such as cancer; and to extend direct representation, through a national platform of one major country previously under-represented by EPF.

Performance indicator:
The perceived success and impact (through evaluation forms and anecdote) of the Autumn Regional Advocacy Meeting taking place in Sophia, Bulgaria.

Target:
The extent of participation by a wide range of patients' leaders from the Region in subsequent EPF work on EU health policy issues.

8. Conclusions

EPF's exciting and ambitious work plan for 2009 reflects the increasing external demands on the organisation, and also a continuing shift towards EPF becoming more pro-active 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 2009.

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 2009 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 2009 (this is not exhaustive, as some key dates are not yet available)

January	EPF Mailing Board meeting
February	EFPIA Think Tank Public Hearing in the European Parliament on Health Literacy
March	Board meeting EPF Annual General Meeting Conference on the outcomes of the pharmaceutical forum EPF Mailing
April	European Patients Rights Day
May	Application for core funding from the European Commission submitted European Health Policy Forum EPF Mailing
June	Board Meeting EFPIA Think Tank
July	EPF Mailing Mid year review with staff
August	
September	EPF Mailing Board Meeting EPF Autumn Seminar Bulgaria High Level Meeting With Sustainable Funding Partners EFPIA Think Tank
October	Bad Gastein Health Forum
November	EPF Mailing European Health Policy Forum EPF Board Meeting EFPIA Think Tank
December	EPF VALUE + Conference Sweden EPF Mailing Staff Appraisals.

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