

EPF Strategic Planning Seminar,
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A STRONG PATIENTS' VOICE TO DRIVE BETTER HEALTH IN EUROPE

2007-2012: The European Patients' Forum key
achievements

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EPF: 2007-2012

Strengthening Patients' Voice in the EU

2003-2007
EPF focusing
on **policy
influence in
Brussels** (e.g.
Pharma forum)

From 2008
(Value +)
EPF developing
evidence based
information
with **projects**

**Capacity
building:**
Targeted activities
for patient leaders
(regional
advocacy
seminars)

Capacity building
programme

EPF evolution from 1 to 3 pillars

strengthening policy impact

Equal access for patients

Goal 1: To promote **equal access to best quality information and healthcare** for EU patients, their informal caregivers, and families.

- Patient Empowerment: with **Respect** – EPF identified needs of children and their families & produced a model for empowerment in clinical trials
- Quality of Care: **InterQuality** projects to analyse current financing mechanisms of the healthcare system
- **Patients' right in cross border healthcare:** long and intensive involvement. Outcome: National contact points and cooperation in key areas (eHealth, HTA, rare diseases)
- **Information to patients/ Health literacy:** various member consultation + Health literacy conference. A growing priority for the European Commission

Involvement of Patients

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

- **Value + :**
 - Developing of a Model of Patient Involvement + a set of key resources
 - Model adopted in FP7 calls, used in RESPECT
 - Collaboration with DG Research + National contact point to promote patient involvement
 - Transferrable model: HTA, Structural funds
- **Pharmacovigilance:** involvement and empowerment of patients- e.g. Direct patient reporting, opening of Eudravigilance
- **Patient safety and Quality of Care:** At EU level recognition that patients need to be involved and empowered=an essential element for safety and quality of care



Patient Perspective

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

- EPF has been involved in many projects aimed at gathering patient evidence and involving patients as experts in:
 - HTA: 2010 Seminar and 3-stage survey, EUnetHTA
 - eHealth: e.g Renewing health, Chain of Trust
- To achieve patient perspective in all health related policies
 - + Gain support from EU institution:
 - EPF campaign for the manifesto 150 millions reasons to act
 - EPF is a speaker moderator or chair in more than 50 meeting/year
 - Work in specific themes e.g. Medical devices



Sustainable patient organisations & patient unity

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

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

- Implementation of four **Regional Advocacy Seminars**
 - **Youth Strategy:** launched in 2011 with the establishment of the EPF Youth Group. Step forward: EPF giving a voice to young patients and fostering their active participation in patient organisations.
 - **Rights and need of older patients:**
 - Commitment to the European Innovative
 - Partnership on Active and Healthy Ageing
- EPF Warsaw Conference 2011



Key achievements -the overall picture

- EPF joined important EU consortia delivering on EU flagship initiatives in the field of health and health ICT (RENEWING HeALTH, SUSTAINS as well as the eHealth Governance Initiative.
- As from 2007, EPF has been involved as leader in three EU projects (Value+, Chain of TRUST, and EUPATI)-
Proactive approach
- associated partner in other 9 European projects (including RESPECT, EUnetPAS, Calliope Thematic Network,, EUnetHTA, INTERQUALITY, Joint Action on Patient Safety and Quality of Care...)
- In Policy and project alike, we cooperate with an increasing number of partners: e.g. EUPATI



Key achievements - the overall picture

- Cross Border Healthcare
- Patient Safety/ Quality of Care – Commission Working group
- Pharma Package – EMA PCWP
- Health Literacy
- eHealth – eHealth Stakeholder Group
- Clinical Trials Regulation
- Personalised medicines
- Health workforce
- Medical Devices
- HTA – EUnetHTA stakeholder platform
- Research – FP7 advisory group on health research
- Ageing – Partnership steering group
- Health inequalities- Platform on access to medicines/ Fundamental Rights Platform



EPF also face big challenges

- Economic environment: difficulties to obtain funding, and in certain sensitive areas: e.g. Health inequalities
- Increased demand on EPF: In terms of quantity, quality, and technicity: prioritisation
- Engaging with an ever-growing and diverse membership: Optimising communication e.g. finding the right contacts, areas of interest knowledge base
- Capacity building follow-up: Adoption of a mainstreamed capacity building programme
- Engaging with the Council: a 'sticking point' for policy advocacy



But EPF has also acquired important ‘capital’

- Growing infrastructure: EPF has grown to become a solid and sustainable organisation in terms of both representation and impact
- The secretariat is also growing: More staff
And new areas of competence
- Dynamic and active Board key to the functioning and representation of EPF
- Growing, inclusive, active Membership: from 23 (2006) to 54 (2012) – 12 countries and growing – representativeness. Growing expertise on specific areas.





Thank you for your attention!

More information:

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