

The role of Patients' Organisations in European Campaigns – the EPF Manifesto

Purpose of the workshop

- To look at **the important role of national patient organisations** in EPF Campaigns
- ‘Unpacking’ the example of the **EPF Manifesto** ‘150 million reasons to act’
- Brainstorm on **actions** that can be taken at national level that really make a **difference** to EU campaign work looking at the **Europe for Patients Campaign**

Rationale behind the manifesto

- Forthcoming European Parliament Elections – June 2009
- New European Commission end 2009
- Unique new opportunity to mobilise politicians and decision makers to commit to act on high quality, patient-centred, equitable healthcare throughout the European Union

Snapshot of the Manifesto

It calls for

- Equal and timely access to safe, effective diagnosis, treatments and support ;
- Better information and resources for patients to be partners in determining their care;
- A patients' voice to be heard in Brussels and throughout the European Union.

Our Manifesto is needed now

- Patients have the right to be fully informed about health issues and the responsibility to manage their health.
- Enormous and unjustifiable inequities across the EU

The fundamental Problems

- Lack of equal and timely access to treatment,
- Lack of access to quality information,
- Lack of psychological, social and environment support that help the patient during treatment and recovery.

What patients ask for

- In relation to equal and timely access to safe, effective diagnosis, treatments and support ;

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- The current EU political emphasis from purely health and wealth extended to health, wealth and equity.

What patients ask for

- Better information and resources for patients to be partners in determining their care
- “Health Literacy” as a concept must be established at both EU and national level.

What patients ask for

- A patients' voice to be heard in Brussels and throughout the European Union,
- Promote patient empowerment!
- European Patients' Rights Day 18 April
- Patients need to be involved in a formal way in EU and national health projects. With patient input, policy is more likely to respond to our vital needs.

Our manifesto developed by Patients

- Our Manifesto is based upon reports from our members.
- The proposals have been developed and endorsed by our members – leading patient organisations more than 150 million EU patients
- Achievable, make economic sense
- a significant difference to the health outcomes and quality of life of vast numbers of patients in every Member State.

Our Responsibilities

- EPF through energy and dynamism of our members commits to being a strong partner in achieving this change.
- This we can only do with our members and patient allies – i.e YOU !!!

Actions at EU level

- Major Launch in the European Parliament
Mid- September
- Highlighted at the launch of the Europe for Patients Campaign – end of September
- Discussed and disseminated at major EU health meetings
 - Eg French Presidency Conference on Patients Rights
 - European Health Policy Forum – Bad Gastein
- Health Literacy Declaration

Feedback so far at national level

- Turkey, Croatia – transform EPF manifesto into national patients’ manifestos
- Poland – specific meetings and commitment from 2 MEPs
- Lithuania – through an MEP and this seminar support for Manifesto from national parliament
- Romanian and French Translations

EPF Campaign Guide

example of contents

- Identify a coordinator
- Translation
- Standard letter
- Case studies, anecdotes, good and bad practices
- Identify Target Group
- Media and Press Relations
- Patients Rights Day

Discussion and Debate

- How would you take forward the EPF manifesto campaign in your countries – 3 actions
- Your key message ?
- What would you identify as specific themes for the Patients' Rights Day, linked to the Manifesto ?
- What help or support would you need from EPF ?
- 25 MINUTES DISCUSSION IN SMALL GROUPS

Barriers and opportunities

- EU priorities and national patient campaign priorities – how to bring them together ?
- What could be the added value of the ‘ Europe for Patients Campaign driven by the European Commission in your country
- How could we support the Commission with a ‘ roll-out ‘ programme in the countries
 - EPF ‘s role
 - national patients organisations’ role

Conclusions

- Final thought from each of participants to feed into the key take home messages for the rapporteur