



**Assessment of  
Patients' Involvement  
in EU Supported  
Health-Related  
Projects**

**Preliminary findings**

# Object of Assessment

- Health-related projects 1998-2008
- Co-funded by the EC

## Sources of Information

1. Literature review
2. Questionnaires
3. Focus group with patients

# Literature Review

- Articles on experiences and research on patient involvement
- Academic journals and publications from health, academic and scientific institutions
- No chronological limitation
- **650** relevant documents analyzed

# First Findings

- Who is considered a patient?
- Patient involvement: a right?
  - Clinical trials versus other health settings
  - Trend to consider patients as a relevant stakeholder
- Three levels of involvement:
  - Advisory status
  - Institutionalized participation
  - Participation in health-related decision-making

# Barriers - Policy

- Lack of policies and legislation on patient involvement (PI)
- Lack of structural mechanisms and tools , or lack of information about them
- Lack of PI culture and little trust in political commitment to implement it
- Lack of recognition of patients as relevant opinion/pressure makers

# Barriers - Practice

- Poor PI practices partly due to lack of insight
- Lack of mechanisms for planning, implementation and evaluation
- Language/communication
- Resources
- Bureaucracy

## Factors supporting PI:

- Evidence-based knowledge
- Lobbying with health policy makers
- Working in alliances with other health patients' representative groups and relevant stakeholders
- Involvement in consultation processes
- Financial, structural and institutional support
- Working within a context of equal power relationships

# Key examples

“While the literature is growing fast on different methods of involvement, little attention has been given so far to the role which patients themselves wish to play, nor even to the conceptual meanings behind involvement or participation” (Andrew Thompson, 2007)

“More research is required to validate expressed views among the populations these stakeholders represent, and to establish effective methods for engaging patients.” (Cagliardi [et al.], 2008)

# Questionnaires

- Purpose: assess patient involvement in various project aspects
- Mix of multi-choice and open questions – facts and perceptions – pre-tested
- Sent to approx. 100 projects – project coordinator and patient/representative
- Replies from 30 projects (9 national)
- 70% replies from PCs and 18% from patients/representatives

# Findings I

- Patient involvement?
  - 83% say YES
  - 18 (60%) formal involvement–7 (23%) informal
- Project/Proposal definition:
  - 9 (30%) of projects initiated by patients/patient organisation
  - 13 (43%) involved in deciding purpose and concept
- Resources:
  - Budget for involvement? 15 YES (50%)

# Findings II

- Leadership and coordination:
  - Involved in coordinating bodies in 11 (37%)
  - Leading WPs/activities in 14 (47%)
- Policy aspects
  - Involved in advocacy/lobbying in 14
  - Patient perspective integrated into policies in 18 (60%)

# Findings III

- Gender perspective
  - Lack of understanding of the gender concept
  - Prevalence of women – implications for PI?

## **Recommendation:**

Needs to be addressed through VALUE+ deliverables

- Reasons of involvement:
  - Expertise/knowledge (essential, important, obvious)
  - For the project to be successful
  - To have better health care
  - To better influence health policy and decision-making

- **Benefits of involvement:**
  - Addressing the right issues
  - Better knowledge of issues
  - Validating good practices
  - Broader/different perspective
  - Achieving objectives - better results – legitimisation of results
  - Empowerment of patients

- **Barriers :**
  - Finding patients, patients' organisations
  - Attitudes and perceptions
  - Ethical issues
  - Health status due to disease
  - Financial
  - Representativeness
  - Self-confidence
  - Linguistic/communication

# Focus Group

**Participants:** Patients from completed projects identified

**Purpose:** getting perspective on involvement (barriers, criteria, recommendations)

**Diversity:** Type of project / Level of involvement

## Expectations

- Share ideas/learn
- Coming together to have a voice/increase influence

# Benefits

- **Practical**
  - Being involved with latest treatments/technology
  - Seeing results of work and changes
  - Being a community/patient mouthpiece ensuring needs are understood
- **Psychological**
  - Contact with other patients, sharing coping strategies
  - Being valued as an individual with abilities /expertise
- **Practical and psychological**
  - Improve people's quality of life
  - Clinicians understanding human aspect

# Barriers

- Assumption that patients are incapable of taking responsible roles
- Stigma
- Medical attitudes and resistance
- Resources and time/availability
- Language and communication
- Involvement “fatigue”

# Recommendations

- Acknowledge patients' expertise
- Consider patients as equal partners
- Provide resources/payments for involvement
- Provide training for involvement
- Share results – it enhances motivation
- Waive co-financing for patients' organisations
- Make patient involvement an eligibility criteria for project funding

# More Information?



The screenshot shows the website header with the logo and navigation menu: Home, Calendar, Membership, Policy, Publications, Core Documents, About us. A banner reads "A Strong Patients' Voice To Drive Better Health in Europe". Below the banner, there is a notice in French: "Ce site n'est disponible qu'en version anglaise. Néanmoins, pour toute information en Français, n'hésitez pas à contacter les membres francophones de notre équipe qui se feront un plaisir de vous répondre par téléphone." and "Le Forum des Patients Européens 'Mieux se faire entendre pour mieux se faire soigner'". The main content area features several sections: "EPF Spring Conference 2007 Report" with a small image and text stating the report is available for download; "Information to Patients: an EPF response" with text about the European Commission's draft report; "Highlights from EPF Annual General Meeting 9-10 June 2007" with text about the meeting in Brussels; "Information to patients - the Fundamental Right to Know" with text about the subject's momentum; and "EPF Spring Conference Outcomes : Moving forward together" with text about the March 2007 conference.

www.eu-patient.eu  
liuska.sanna@eu-patient.eu