



**IMI Stakeholder Meeting,  
14, 15 June 2010  
Nicola Bedlington**

## *The presentation*

- A brief introduction to European Patients' Forum
- What patients think of IMI so far
- The rationale behind and added value of involving patients meaningfully drawing on outcomes of the Value + project
- Some reflections on moving forward IMI **with** patients



# *European Patients Forum*

- High quality, patient-centred equitable healthcare across the EU
- Strong and united voice – EU health policy
  - Umbrella body of 45 European disease specific patients' organisations *and* national coalitions
  - 150 million EU patients with chronic conditions



## ***Why is IMI important for patients***

- Fundamental purpose – to reduce **bottle-necks** in pharmaceutical innovation -**unmet** medical **needs** of patients- Pharmaceutical Forum -Leadership
- Emphasis on core **over-arching** issues of relevance to all patients – patient safety, knowledge management, education and training, risk benefit analysis + real advances in specific disease areas
- **Public- Private Partnership**
- Commitment to **consult** and involve **stakeholders**

## *The story so far ?*

- Some **positive** examples of patients involvement as partners in IMI projects – key word – “**collaboration**”  
Some **challenges**
- **BUT Low %** of involvement generally- we all recognise that more is possible
- How to tackle this ‘ **bottleneck**’ - **awareness raising** among project **promoters**- awareness raising among **patient organisations.**



## ***“Patients as real partners”***

- The **PROTECT** project  
Pharmacoepidemiological Research on Outcomes of Therapeutics by a European Consortium
- **Aim: To strengthen the monitoring of the benefit-risk** of medicines in Europe
- **Website: [www.imi-protect.eu](http://www.imi-protect.eu)**
- **29 public and private partners**
- **Patient organisation** : the International Alliance Of Patient Organizations ( IAPO) 



## **Intrinsic role – ‘ collaboration and respect’**

- Work packages : ***New methods of data collection from consumers, Benefit-risk integration and representation***

### **IAPO role:**

- Providing patient perspective on all aspects of development of the work programme
- Responsible for strategy for communicating with, recruiting and retaining research subjects and providing appropriate information



## “Understanding how we can best contribute”

### ○ U-BIOPRED


- Unbiased biomarkers in the prediction of chronic respiratory disease outcome

### ○ **European Federation of Allergies and Airways Diseases** – key role in **ethics** work package, involvement in all work packages – ‘**patients’ perspective**’





## Critical Success Factors

- Involvement right at the onset, planning the project
  - Clarity of the role of patients ' organisation in understanding impacts on the patient of severe asthma
  - Openness of coordinator
  - Use of layperson's language
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## “ Disseminating outcomes to the layperson”

### ○ PHARMA-COG

- Prediction of cognitive properties of new drug candidates for neurodegenerative diseases in early clinical development

### ○ Alzheimer Europe

- Patients' perspective
- Involvement in design of appropriate 'informed consent' forms
- Dissemination to the wider 'interested' public



## *Literature - Patient Involvement*

- **Considerable benefits of patient involvement**
- **Need for increased policy attention and investment**
- **‘Research with’** rather than ‘research on’ patients an imperative, seeing that the purpose -health research - patient benefit.’

*Source : What research means to patients, and the importance of partnership with practitioners in research’Hazel Thornton - Department of Health Sciences, University of Leicester, Leicester, UK*

## Value +

- Evidence from the **project on Value + on FP 6 and 7 highlighted that**  
*patient involvement was clearly weaker in research projects than in other projects, especially those focused on clinical trials, studies or development of technologies and devices*
- Limited patient involvement at the inception and planning stage, in the governance structures of project.

## ***Know-how in patient involvement***

- Project coordinators - clear interest in developing patient involvement
- Challenge - how to translate this in practice
- Counter attitude - patients' organisations not credible and equal partner.
- Education of patients and the public about research concepts is essential

***'The Value and Challenges of Participatory Research: Strengthening Its Practice'***

*Margaret Cargo and Shawna L. Mercer*

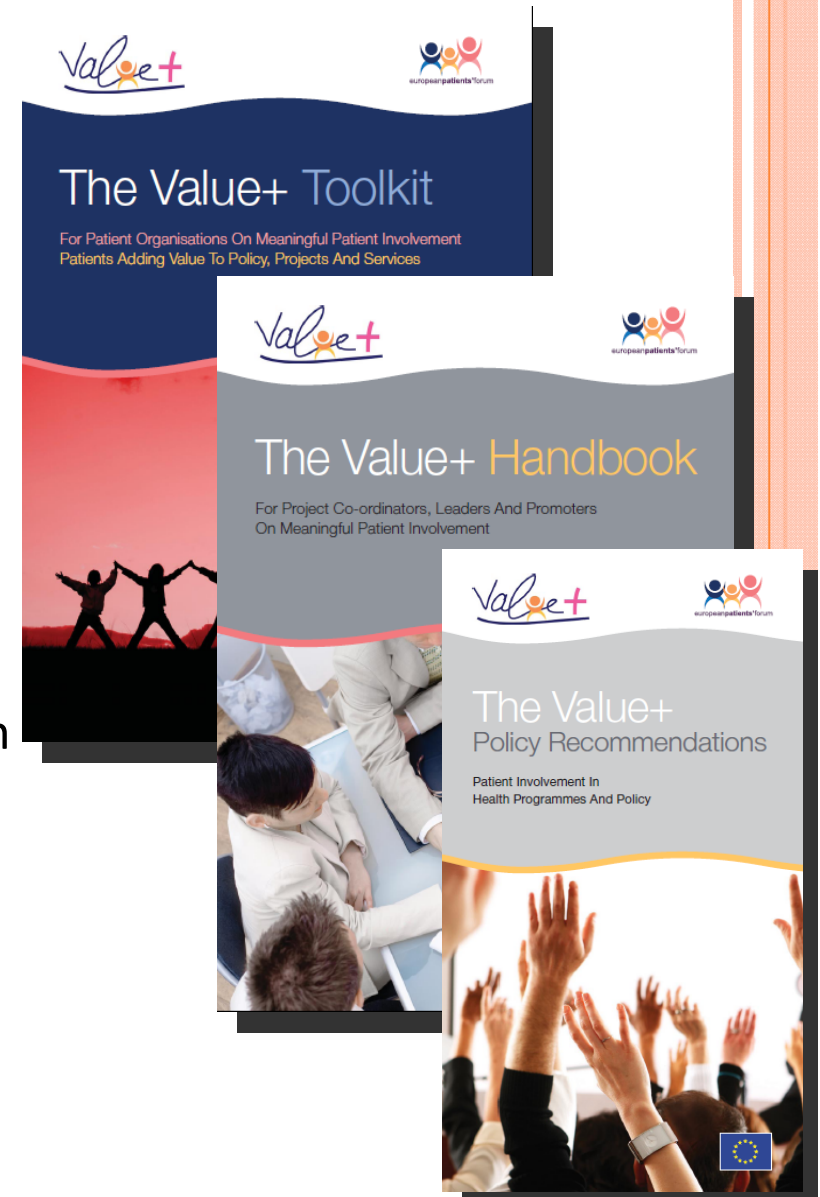
## *Strengths of Patient Involvement*

- When patients engaged from the onset - more committed to applying research in real life settings
- A key strength -integration of researchers' theory expertise with patients' real-world knowledge and experiences
- Balance scientific excellence with social and cultural relevance



## Series of tools:

- ❑ to enable patients to become more involved in EU funded projects including research projects
- ❑ for project promoters and coordinator to acquire more skills to enable them to facilitate in practice
- ❑ a series of policy recommendations look at linking research project outcomes with patient – centred policy development
- ❑ Comprehensive Directory of Patient Organisations in every EU member state



## ***Value + Handbook***

- **Why**
- Two-fold purpose: raising awareness and providing know-how
  
- **What**
- Value+ Model of Meaningful Patient Involvement
- Involvement at each project stage
- Knowing patients and patient organization to facilitate working with them



## *Reflection*

- **Importance of patient involvement**
- Capacity to **translate** the outcomes of projects into the **policy domain** – e.g Pharmacovigilance / patients safety
- **Knowledge management** – dissemination of the outcomes in a more **accessible and inclusive** way
- **Power balance** between different partners involved – industry, academia, patients organisations
- At what stage should patient groups be involved – Expression of interest stage or once a consortium has been agreed : **PREQUISITE ??**

## *Reflection*

- 3rd Call – A **chance** to move forward together to **promote patient involvement – powerful awareness raising strategies**
- “ Patient reported outcomes”
- Ensuring the **right role** for patients’ organisations in highly technical /scientific projects
- **Inter-sector collaboration** – Pharma/ Medical Devices/ Information Communication Technology
- Creating an **eHealth** dimension of IMI Knowledge Management –EHR

## *Reflection*

- Links with the **post Pharmaceutical Forum** process  
Corporate Responsibility Task Force DG Enterprise
- **Correlation** with IMI projects with likely developments within **European Medicine Agency** and **HTA processes**
- **Global Perspective**
- Process evaluation on IMI – **patient involvement a core indicator**
- Looking to the future ... **IMI 2.....the patient's vision**

[www.eu-patient.eu](http://www.eu-patient.eu)

[info \[AT\] eu-patient.eu](mailto:info[at]eu-patient.eu)



The screenshot shows the homepage of the European Patients' Forum website. At the top left is the logo and the text "europeanpatients' forum". To the right of the logo is a search bar and a "Search" button. Below the logo is a navigation menu with the following items: MEMBERSHIP, INITIATIVES & POLICY, PUBLICATIONS, PRESS, ABOUT EPF, and CONTACT US. The main content area features a large banner with the text "A strong patients' voice to drive better health in Europe" and an image of a man holding a child. Below the banner are three featured articles: "HTA Seminar and AGM 2010", "Autumn Advocacy Seminar '09", and "EPF's Patients' Manifesto". To the right of the main content is a sidebar with a "News" section containing several headlines and a "More all the news" link. At the bottom of the main content area, there are two more articles: "LATEST NEWS" and "Membership Guide".