



**IMI Scientific Committee,
1 June 2010
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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**.
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“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**
- **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



“ 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

Value + Outcomes

- 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.



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
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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**



**A STRONG PATIENTS' VOICE
TO DRIVE BETTER HEALTH
IN EUROPE**