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
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.
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
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
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. Pharmcovigilance / 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