Patient involvement in the PROactive project

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Patient participation: why? (1)

**Chronically diseased patients:**

- Have their disease knowledge
- Have experience with their disease treatment and living

**Patient organizations**

**combined patients’ disease knowledge and experiences**
Patient participation as a means for:

- more relevance of the research
- better quality of the research
- better results and chances for societal implementation

Patient participation as a goal for:

- more patient empowerment
- higher democratic decision making level in research, its policy, budgetting

Level of patient participation
(based on: Arnstein’s and Wilcox’ ladder)

- patient is co-producer or leader
- equal partner in decision making
- consultation/advisor
- information provider
- subject in research

All levels should be achieved

Aim:

Development of Patient Reported Outcomes that measure aspects of physical activity relevant to patients and are sensitive to changes due to treatment.

- Literature
- Patients
- 6 activity meters
- 2 questionnaires
- 2 devices
- Validation tests (8 wks)
- Tests in 3 clinical studies

2009-2011
2011-2012
2012-2014

See: www.proactivecopd.com
Contribution of patients -1

Participation in:

- patient advisory board (driving force)
- Internal Ethics Board (advisory)
- Steering committee (advisory & co-decision)
- Meetings with project partners (based on equality)

(boards have European-wide representation)
Contribution of patients - 2

Evaluation criteria
- Evaluation protocol making
- Evaluation/review
- Monitoring study progress

Development of PRO tools

Clinical study protocols
Patient information form / informed consent

inclusion adults

researchers
development of protocols, manuals of procedures, training on techniques

Development of PRO tools

website content communication dissemination

Interpretation and prioritization of the results

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Impression by patients

- excellent opportunity to involve patients and
- to listen to their needs and wishes

(data from meeting together with patients from IMI U-BIOPRED study Sept. 2011)
Patient participation: profits for other projects/initiatives

- Why and how patient participation in research is useful
- Tools for evaluation, monitoring and collaboration
- Raising broader awareness on patient participation
- Opinion of patients in development of PROs also taken to regulatory agencies
- Broad collaboration between patient/- organisations, science, health care and (pharma) companies:
  - can be effectuated and
  - worthwhile in delivering societally relevant results
Why an IMI project?

- Patient participation: not yet broadly recognised as a positive contribution and need to science
- IMI JI identified reasons and defined policy for inclusion patient participation in research
- Collaboration on a European level with multidisciplinary interaction sharing knowledge

➤ Despite not having patient participation in all IMI projects: PROactive, U-BIOPRED and EUPATI prove to be good examples
Thank you!

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