



Innovative Medicines Initiative

Patient involvement in the PROactive project

Dr. W.I. de Boer, Netherlands Asthma Foundation



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: why? (2)



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

(Abma & Broerse, Health Expectations 13, 2010:160; Hanley et al, INVOLVE 2003; Telford et al, Br J Clin Gov 7, 2002:92; etc.)

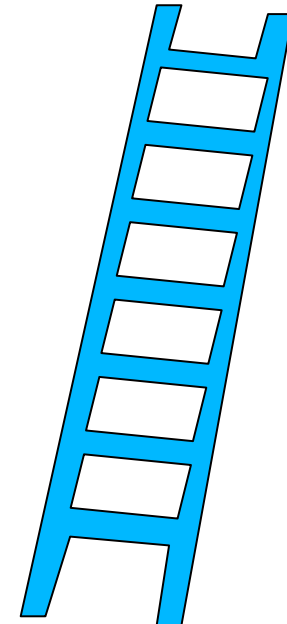


Level of patient participation

(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

(Arnstein. J Am Instit Planners 1969, 35: 216-224; Wilcox. A to Z of Participation. Joseph Rowntree Foundation, 1999)



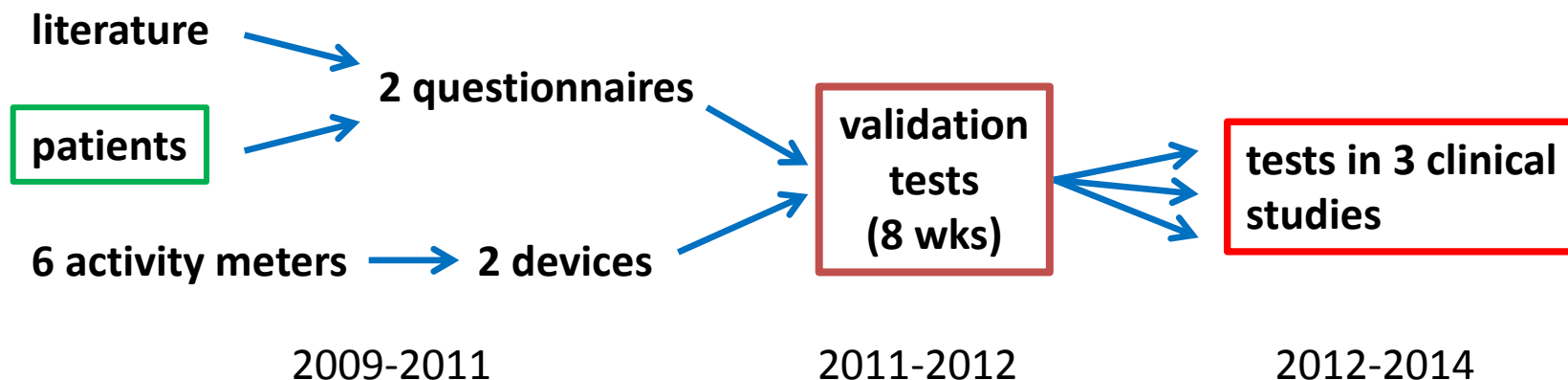
The PROactive project



Development of tools to measure physical activity status

Aim:

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



See: www.proactivecopd.com

Contribution of patients -1



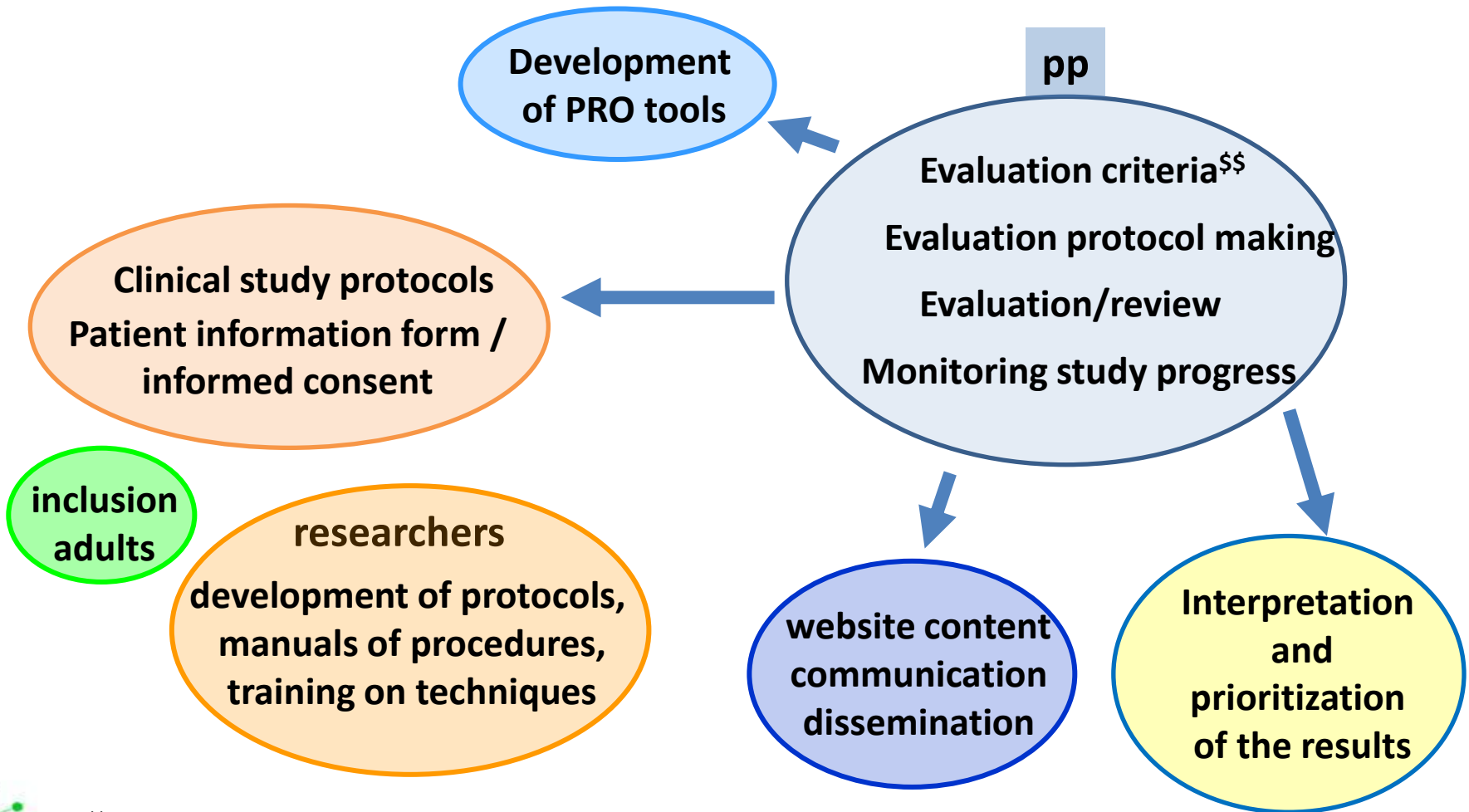
Participation in:

- ✓ 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



^{\$\$}: based on Teunissen *et al.* Health Expectations 2011: *Epub – in press*

Impression by patients



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



- Involvement
- Travel for meeting
- Language barrier
- Expectations
- Visibility
- Knowledge

(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!



Dr. W.I. (Pim) de Boer

Contact E: deboer.pim@hetnet.nl

In collaboration with:

Thierry Troosters (KU Leuven, B)

Janneke Elberse (VU University, Amsterdam, NL)

Truus Teunissen (NAF; and VUMC, Amsterdam, NL)

Damijan Erzen (Boehringer Ingelheim, D)

