

The Contribution of Patients to Pharmaceutical Care Research

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What Does 'Involvement' Mean?

Not being a participant/subject



Different from 'public engagement'



What Does 'Involvement' Mean?

- Active partnership between the public and researchers
- Doing research 'with' or 'by' the public, rather than 'to', 'about' or 'for' the public
- May be **consultation, collaboration or user control**



Why Should I Involve Service Users in My Research?

- Research Governance
- Funding Body Imperatives (eg NIHR)
- Social Justice
- Better Research(?)



Some Examples of 'Involvement'

- Consulting regarding research priorities
- Advising on a study (eg design, respondent burden)
- Helping with development of study materials (eg patient information sheet)
- Participating in data collection/analysis
- Co-producing lay summaries of research
- Being a study lead or co-applicant
- Commissioning research



An Exemplar

- Burnage British Lung Foundation 'Breathe Easy' Patient Support Group
- Relationship established since 2006
- Arose from prior experience of involving users on project Steering/Advisory Groups



Role of the Group

- Selection of projects (eg relevance to users, acceptability, prioritisation, design)
- Conduct of studies (eg acceptability, respondent burden, recruitment)
- Instrument development (eg respondent burden, comprehensibility, wording)
- Lay summaries/information sheets
- Dissemination to lay audiences



Project Examples

- Family-focused health promotion in COPD
- Impact on carers of admission avoidance and early discharge in COPD
- Symptom perceptions, information needs and preferred roles in treatment decisions in COPD
- Antibiotic prescribing during exacerbations in COPD
- Development of an intervention for 'symptom clusters' in lung cancer



Ways of Working

- In for the long haul
- Guests at the party
- Reaching out and bringing in
- Give and take



Issues to Consider

- Roles and responsibilities
- Payment
- Training
- Impact on group and researchers



Benefits for Research

- Choice of projects
- Better designed studies
- More 'user friendly' instruments and materials
- Getting findings 'out there'
- Governance requirements



Weblinks

- INVOLVE main weblink

<http://www.invo.org.uk>

- People in Research

<http://www.peopleinresearch.org/>

- North West Research Design Service Public Involvement Partnerships page

<http://www.rds-nw.nihr.ac.uk/PI/PIPRNoW/index.php>

- Guys and St Thomas's NHS Foundation Trust

<http://www.guysandstthomas.nhs.uk/news/newsarchive/newsarticles/20100512user-involvement-guide.aspx>

