



Patient and Public Involvement in Clinical Research

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What is 'Involvement'?

INVOLVE definition: *research being carried out 'with' or 'by' members of the public rather than 'to', 'about' or 'for' them*

*Listening to our patients and the public, and **working with them** to ensure that our research reflects **their needs and priorities***

{in•flu•ence} v.

1. to affect the nature, development, or condition of;

Why should we let 'lay people' influence research?

- **'Equal value' reason:** 'lived' expertise has a *value* equivalent to that gained through study/profession
- **'Moral' reason:** those who pay (via taxation/donation) for and/or will be affected by the research have a right to influence its development and use
- **'Methodological/outcomes' reason:** Members of the public can improve research outcomes and reduce 'waste'
- **'Policy' reason:** Specific policy direction from government and charitable/private funding bodies (eg. Dame Sally Davis/NIHR/BHF)

Perspectives and priorities

Interest

Experience

Professional
Guidance

Training

Funding

Inertia

Something that will benefit patients



How does this compare with the **needs/wants and realities** of patients?

How can we know unless we **ask**?

Patient priorities

Research priorities: 'cure' > extend life > manage symptoms

- Outcomes that patients notice and care about
- Seeking to treat or improve symptoms as well as disease course – can we live well with this condition?
- Look for pragmatic options that understand and reflect patients' wider health and social context
- Consider the mental health burden associated with their condition (in the context of their wider social system)
- Are decided and presented in language that matches the affected population

Patient perspectives

My concern is that most participants will deviate from the diet occasionally... This is real life! It would therefore be useful to provide a diary in which to record additional food and drink....

Not the friendliest questionnaire to answer

How on earth is anyone expected to know what they weighed at 20, 40 or 2 years ago?

The questionnaire seems to have been constructed with the data inputter in mind rather than ... the patient

...the reader is informed that he/she is a member of a “high risk” group at great risk of mortality. Will this be the first time that the participant has been informed of this scary statistic?

Who to involve?

- Who will be **most directly affected** by this research?
- **More than one perspective/set** of expertise can be useful eg. public + patient/carer + charity etc
- People **outside** your sphere of experience
- Always **>1** individual!
- Don't let the 'perfect' be the enemy of the good!
- Reflect on who you *have* involved and whose voices might be missing

How? When?



- Refine research question
- Identify important outcomes
- Protocol feasibility
- Research document review
- Recruitment strategies
- Acceptability
- Funding applications

- Committee representation
- Recruitment ambassadors
- Survey delivery/lay interviews
- Co-production

- Audience mapping
- Information placement
- Narrative creation
- Accessible language
- Message identification
- Co-authorship
- Dissemination plans

Expectations and Feedback

Why they would like to be involved?

ASK!

What do they hope their contributions will achieve?

- Have clear goals about what **you** want your PPI to achieve
- Ask what feedback/contact your contributors would like
- Be clear about what can and can't be changed
- Discuss potential project outcomes
- Designate a PPI contact within your team
- Update progress, even when there is no progress!



Ethics in PPI

“You do not need to apply for ethical approval to involve the public in the planning or the design stage of research, for example helping to develop a protocol, questionnaire or information sheet, being a member of a research advisory group, or preparing an application for funding or ethical review, even when those people are approached for this role via the NHS”

INVOLVE 2016

- Balance *access vs coercion* in payments
- Consider time/location/accessibility
- Researcher/clinician relationships
- Clear about goals of activity
- Sensitive to lived experience and raw emotion
- Aware of your own (in?)experience and sensitivities
- Signpost

What does good PPI look like?

- ✓ Involves a variety of relevant voices
- ✓ Starts early and encompasses the full research process
- ✓ Uses methods appropriate to audience and research
- ✓ Clarifies expectations
- ✓ Considers and acknowledges limitations
- ✓ Is sensitive to realities and experiences
- ✓ Focuses on communication and clarification
- ✓ Acknowledges contributions
- ✓ Provides feedback about changes implemented



Thanks!



(a few members of the CUH PPI Panel)