

Arthritis Research UK

Primary Care Centre

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Evaluation of patient and public involvement : a case study

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Overview of presentation

1. Evaluation approach / methods
2. Background
3. Findings
4. Discussion

Evaluation approach

Mainly **formative** evaluation asking “how are we doing?” while work is in progress.

Not **summative** – waiting to evaluate or sum up at the end.

Methodology

- Case study design
- Unique analytical framework
- Driven by what we know from published evidence as well as open to surprise
- Looked for negative as well as positive impacts

Methods

Interviews with a purposive sample of Centre staff	n=17
Interviews with Research Users	n=15
Documents	n=90
Anonymous questionnaires	n=2
Field notes from observing meetings where PPI took place	n=3

Insider / outsider perspective



Organisational context

- Grant-funded programme totalling £34 million from major UK research bodies, RAE success.
- Lead on PPI for West Midlands Research Design Service

Policy context

“Patients and the public must be involved in all stages of the research process”

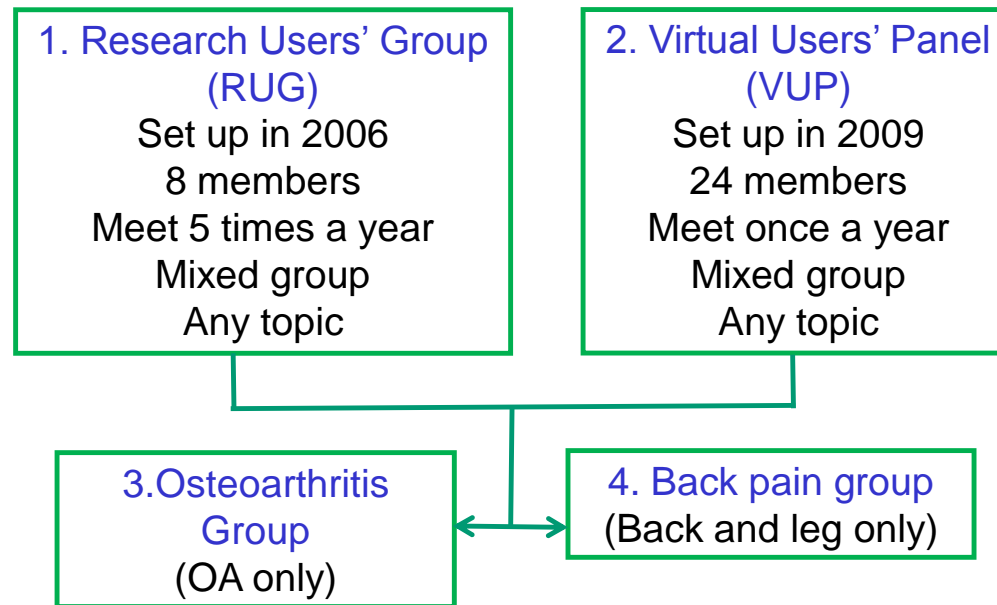
DH 2006, Best Research for Best Health p34

“Nothing about me without me”

Equity and excellence: Liberating the NHS 2010

PPI in the Centre

Centres Users' Groups



Research Questions

- Who gets involved?
- How are they supported ?
- What difference does it make ?
- What else can we learn ?

Ethics

- University ethical approval
- Informed consent
- Confidentiality / anonymity
- Use of anonymised questionnaires
- Use of loosely structured topic guide

Findings: 5 themes

1. Organisational development
2. Inclusion & exclusion
3. Roles & expectations
4. Communication
5. Positive & negative impacts

Organisational learning

- “When we started, the meetings were very ad hoc. It depended on what they were doing and if they needed us, so to speak.”
Research User
- “...big learning process I think for all of us.”
Research User
- “I think we don’t really talk a lot about the messiness of this sort of thing ...” Researcher

Arthritis Research UK site visit, 2008

“...you could certainly see the atmosphere transform when site visitors were talking to users about the contribution that they were making.... the feedback was absolutely overwhelming. ...visitors were gob smacked really about the extent to which Users were [involved].” Researcher

Prepared for involvement

“So the day before [senior researcher] and others, spent an entire afternoon talking to us about the pattern for the next day, discussing our bit. Quite seriously they stayed with us until we were comfortable.”

(Research User)

Unpredictable PPI

“So I did my workshop with [Research User] ... Then ... he said:

‘so we’ve been in this research group and we are now stagnant’ ...

so we tried to rescue this session because we hadn’t agreed it at all, ... because he’s one of those people who will go off script”

(Senior Researcher)

PPI & Clinical studies group 2009

“I thought it was brilliant, because there were
... consultants from all round the country ... er
I had this consultant from up in the North of
England and he was about 6’5” [Laughs]

Virtual Panel member

PPI & Clinical studies group 2009

“...and he was worried about catching his train back and I said ‘I’ll give you a lift’. And then I realised that I’d only got a mini [laughs] ... and he sat there with his legs up [laughs] and I took him to the station. But yes, that was a brilliant day, I really enjoyed that. It was well done, well put on and I felt I learnt something ...”

Virtual Panel member

PPI & Clinical studies group

“ it was a group of researchers together and they have to talk in research language ... but of course that made it very difficult for the users, who ... you know, they couldn't understand what was going on half the time and that their role there, as you say, wasn't properly defined, [Researcher talking about CSG](#)

[2009](#)

PPI & Clinical studies group

“ ... and probably we hadn't briefed the Chairs of each of the small groups, to tell them that there was user representation. So, I think we are learning, you know, I think we're just learning as we go along really, aren't we?”

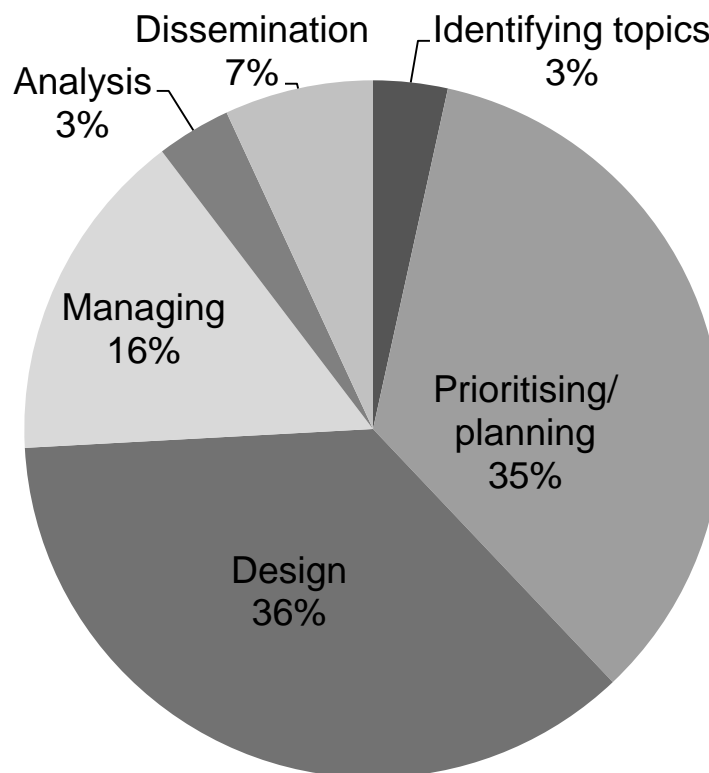
Senior Researcher talking about CSG 2009

No common understanding

Clinical Studies Group 2010

“I didn’t just want people to go, just tokenistically and ... It was never really clear why the patients were being involved and whether it was a closed clinical group or a mixed group. And so, you know, that is not my idea of meaningful involvement because there’s no common understanding...” **Researcher**

Involvement in the research cycle



Inclusion - who gets involved?

- 14 men, 23 women
- Mainly live in the local area
- Experience a range of clinical conditions
- Available for day time meetings
- Limited monitoring data on diversity
- Carers not separately identified

Who gets excluded?

“one of the sort of senior members of staff basically ... you know, sort of started talking to me and I said I'd got rheumatoid arthritis, and she said ‘oh, we don't really deal with rheumatoid arthritis’ and walked away from me, which was a bit - a bit of a strange experience. ... [Man with rheumatoid arthritis](#)

Who gets excluded?

And ... I've got plenty of other things to be doing, and at that point I thought well, you know, I'm not really too sure that there's a lot of point in me being involved with it. So I haven't come along ever since. So I just came to that one meeting.”

Man with rheumatoid arthritis

Beyond the usual suspects?

“But the people ... Who sit on the [CLRN] board, are, they advertise for those folks in the Guardian didn't they? So they were looking for, sort of, professional people, business-type people.”

Senior Manager

Recruitment methods used for PPI in the Centre

- Referral by GP
- Referral by existing member
- Referral by a member of staff
- Referral by a research nurse
- Invited in their capacity as Chair of a local patient group
- Heard about PPI via local radio

How are Research Users supported ?

- PPI Co-ordinator = “User”
- Finances
- Physical access
- Glossary of terms
- Training
- Mentoring / support
- Organisational framework

Roles & expectations

“You never know whether you're just being erm meddler and shouting too much or whether you're doing...just being self-assertive or just enjoying the meeting.”

(Research User)

Virtual panel

The other ladies introduced themselves as members of the err, the Virtual Patients Panel, you know, and of course when it was my [turn] I said I'm not a member of anything [laughs]. Somebody said 'you are now!' [laughter]." (Virtual panel member)

Metaphors for PPI roles

- At a project meeting PPI input was described as “cage rattling”
- In interview a Research User used the term “Devil’s Advocate” to describe their role
- Another RUG member described themselves as a “patient representative”

Communication

- “Ideally partners have a critical though constructive and proactive attitude. “
- “‘Critical’ means to be able to ‘interrupt a professor in full flow’, or to question the validity of statements irrespective of their author” [deWit et al \(p.724\)](#)

Talking as equals?

“And also for me as well what I got out of that was I found I could talk to anybody, you know, whether they’re a professor or a – they’re still a person aren’t they?”

Research User, female

Non Verbal Communication

“and I don’t remember if he was like a medical doctor or a professor, the chair wasn’t he? I don’t know but he gave me a couple dirty looks and I thought you’d better shut up now” [laughs].

(Research User)

Translation

“Well I just think of it it’s like, if you put me in a room of people talking French how, how can I contribute? But if you give me some terms then I could tell you what I wanted to eat or what I wanted to drink. And that’s the same with the users isn’t it? They don’t need to know everything.”

PPI Co-ordinator

Glossaries help researchers

“physios and different people ask ‘Can we have copy of the glossary ‘cause we don’t actually understand that study, we only understand our bit.’”

“Not just a problem for users”

“I think some of the terminology , is, I think some groups go into their own language which I think’s unfair for everyone, **not just a problem for users**, And I just think some groups just do that, they like to think that they have, er, a theoretical body that everyone should adhere to and it becomes a [problem].”

Senior researcher

Positive & negative impacts

	positive	negative
Research users	<ul style="list-style-type: none"> • Learning new skills • Keeping active in retirement • Increased self-confidence • Social support 	<ul style="list-style-type: none"> • Fatigue • Asked to do too much • “Dys-empowerment” • Stress / worry
Researchers	<ul style="list-style-type: none"> • Personal satisfaction • Encouragement • Fun • Learning new skills 	<ul style="list-style-type: none"> • Threat to professionalism • Less time for academic interests / career development • Unpredictability
Research	<ul style="list-style-type: none"> • Improved communication • Improved questionnaires • Feasibility checks for study designs 	<ul style="list-style-type: none"> • Need for extra time & money

Senior Researcher

“Everything becomes better I think as a result of a patient being in the room, or a patient representative being in the room.”

What difference does PPI make?

“It wouldn’t be true to say that we changed our plans at [project] because we had someone like [Research User] on the project management team. But it changes the way people communicate, it changes the language that’s used, and for the better I think”

Senior Researcher

Discussion

Gauvin et al:

“... what is often assumed to be a consensual concept is actually a contentious one characterized by divergent views about who should be involved, in what domain, and to what level.” (p.1523).

Gauvin et al (2010) “It all depends”: Conceptualizing public involvement in the context of health technology assessment agencies” *Social Science & Medicine* 70 (2010) 1518-1526

Recommendations

- Develop a PPI induction pack
- Review terms of reference
- Contribute to PPI evidence base
- Document impact using INVOLVE forms
- Consider the needs of lay people on steering committees
- Clarify PPI in Clinical Studies Group etc.

References

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NHS

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