Involving the public in patient safety research: benefits and challenges

- Increasingly encouraged
- Compulsory component of many grant applications
- Reviews have found that PPI involvement is tokenistic
- Limited to agenda setting and protocol development
- Few studies where lay people have been involved in execution of research

We would like to share our recent experience of PPI in data collection and analysis in a hospital-based study.
Types of PPI

- Involvement in identifying research priorities
- As joint grant holders or co-applicants
- As members of a project advisory or steering group
- Commenting and developing patient information leaflets or other research materials
- Undertaking interviews with research participants
- User and/or carer researchers carrying out the research

PPI in different types of research

Most PPI focused on clinical studies

- Health services research?

Little PPI in patient safety research

- Are there specific issues and sensitivities?

Objectives

- To highlight the benefits, challenges, barriers and facilitators to the involvement of the public in patient safety research
- To draw on shared experiences of presenters and participants in involving lay people in patient safety research
- To identify practical tips for those wishing to involve the public in this way

Outline

- Introduction (15 mins)
- Identifying the benefits, challenges, barriers and facilitators to the involvement of the public in patient safety research
  - Different groups doing these topics and then feeding back
  - Discussion (15 mins) and feedback (15 mins)
- The researcher’s perspective (10 mins)
- A lay member’s perspective (10 mins)
- Questions and summing up (10 mins)

Workshop

Identifying the benefits, challenges, barriers and facilitators to the involvement of the public in patient safety research

The researcher’s perspective

Bryony Dean Franklin and Seetal Jheeta
Example: the IMPRESS study

Our journey with patient partnership

Aim of IMPRESS

- Inpatient Medication and Patient Relationships – Electronic Systems (IMPRESS)
- The IMPRESS study aims to explore how hospital inpatients currently engage with medication safety, describe how this may differ between paper-based and electronic medication records, design an intervention to improve patient safety in this area, and explore issues related to feasibility of implementation of the intervention.

Lay member involvement

- Four lay members conducted observations on hospital wards
- Analysis of interviews
- Interviewed those involved in the observations to explore the benefits, challenges, barriers and facilitators

(Garfield et al. Patient and public involvement in data collection for health services research: a descriptive study. BMC Research Involvement and Engagement 2005; 1:8)
Registration and training of volunteers

- Ethics committee requirement that lay observers had DBS check and indemnity insurance
- Therefore lay observers were registered as hospital volunteers in order to meet these requirements
- Training included:
  - In-house standard training for all hospital volunteers
  - Specific training in data collection procedures organised by the research team

Benefits

- Enjoyable experience for lay observers
- Far more involved than previous PPI roles which had been more consultative
- Increased motivation and interest in project
- Added value to research findings - new themes identified
- Impact on study design

Benefits - quotes

- “The bottom line is, as I say, I really enjoyed it and I found it really interesting and quite eye opening. I think it’s a really valuable experience.” (Lay observer 1)
- “It has… probably contributed to how involved [the lay members] will be later in the project and discussing our findings and their findings… has meant that their involvement isn’t token. It’s probably increased their motivation and interest as well so that will be useful.” (Researcher 2)

Benefits - quotes

- “Because I am far less knowledgeable about medication and prescribing than the investigators I was working with, I concentrated much more on the human relationship between the inpatient, the patient in the bed and the [healthcare professional]… the interaction, the body language, the relationship, the physical interaction, physical location and placement [of] the healthcare professional in relation to the patient in the bed.” (Lay observer 2)
- “I felt the lay observers were picking up more about the overall conversation, about how the patient was involved, and not specific to medication related issues, it was more of a general ‘how’s the patient being involved in decision making and in the conversation’, that kind of thing. So they definitely brought a different perspective, so it was really positive, it’s a really positive thing and it almost made me reflect how I was looking at the situation as well.” (Researcher 1)

Input

- General observations on communication/relationships
- Consultation structure
- Observers’ own experiences of being inpatient

Output

- View medication specific information in wider context to enhance understanding/interpretation of medication related findings

Challenges

- Registration process
- Increased workload for researchers
- Information and research governance
- Late planning
- Recruiting a representative group of lay observers
- Conducting data collection
Challenges: quotes

- "Well, the experience at [hospital 1] was okay, a trifle lengthy. The experience at [hospital 2] I thought was absolutely appalling." (Lay observer 2, discussing registration process)
- "It seemed to me that nobody seemed to know how to do it. They didn’t fall within the typical hospital volunteer profile, because they weren’t able to commit to doing so many hours a week in the hospital shop, or whatever it is that they’re used to doing, and they were being recruited for a specific project. Nobody really knew how to deal with that, and it felt a bit like we were being passed from pillar to post, in terms of how we do it. It just took a lot of effort and time. I think both for researchers and for the patients... I think we all had to be quite motivated, otherwise it would have been very easy to just say, “You know what? This isn’t worth the aggro.” (Researcher 4, discussing registration process)

Challenges vs. Benefits

- Challenges associated with data collection:
  - Healthcare professional researchers felt responsibility for the conduct of lay observers
  - Potential for observers to deviate from project protocol or role as researchers/observers
  - There is risk associated with healthcare professional researchers’ professional representation
  - Minimal risk to affected subjects (patients or healthcare professionals)
  - Benefits associated with new perspective far outweigh any risk
  - Emphasis on ensuring lay perspective remains “lay”

The Lay Members

- Alex Taylor
- Jill Lloyd
- Fran Husson
- Charles Boucher
Lay members’ stage posts

- Joining the project
- Approvals & training
- Establishing individual roles & commitments
- Observing, recording & analysing findings
- Overview of lay member activity
- Assessing the experience

Joining the Project

- Recruitment
- Initial meeting
- Team formation

Approvals & Training

- Ethics committee approval
- CRB/DBS checks
- Volunteer training
- Indemnity insurance

Establishing Individual Roles & Commitments

- Acceptance of the additional tasks
- Further training in data collection methodology
- Agreeing availability, workload and timetables
- Costs

Observing, Recording & Analysing Findings

- Briefing
- Observing
- Recording
- Analysing Findings

Overview of Lay Member Activity

| Patients Observed | 163 |
| Wards Visited | 5 |
| Hospitals Participating | 3 |
| NHS Trusts | 2 |
| Period of Involvement | 18 Months |
Assessing the Experience

- Value of lay members to the study
- Planning deficiencies
- Diversity of the lay members
- Benefits to the lay members
- Optimism for the lay members’ contribution to have a positive impact on inpatient safety

Discussion

Lessons for the future

- PPI involvement in data collection is recommended for future patient safety research studies.
- However, the relevance to inter-professional issues that do not involve patients is unknown.
- Early planning recommended!

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