

Lay summary: Implementing public involvement throughout the research process – experience and learning from the GPs in EDs study

This paper sets out the experience of two public contributors involved in a major study looking at GP's working in or alongside hospital emergency departments. It sets out what we did, what difference it made and what we learnt that we hope will be of use to others.

We worked closely with a member of the research team responsible for supporting PPI throughout the study, who was a large factor in making the PPI contribution so successful.

What we did

We kept a record of what we set out to do and what we actually did. As well as reporting on our own activities and experiences as public contributors, we met with the study team near the end of the project to find out how they felt about working with us.

We were involved from the very beginning of the study and set out a plan for public involvement in the funding application. We ended up doing far more than we anticipated.

As co-applicants, we

- contributed to strategic study planning and management
- took an active part in a wide range of meetings
- supported public and patient input to stakeholder discussions at key study stages.

We planned to do this from the outset but our input was more extensive than we expected.

As the study progressed we identified further opportunities to contribute. As well as the above we:

- were actively involved in data collection, analysis and dissemination
- reviewed annually what we had achieved
- assessed the study against the UK standards for public involvement and made improvements

What difference it made

The study group said public involvement exceeded their expectations. They felt our involvement made a difference to :

- patient recruitment e.g. we encouraged more participation by sending invitations on hospital headed notepaper rather than university letters and by offering incentives to patients to be interviewed
- making language clearer and appropriate for lay readers e.g.in invitation letters
- helping the other co-applicants better understand and appreciate public involvement in research
- giving the other co-applicants confidence that the study was relevant to patients
- increasing knowledge and understanding of the study more widely e.g. giving presentations to lay groups and producing lay summaries of all study publications

The study group felt the things that made public involvement work well were:

- commitment of the study lead and team to public involvement

- having a named support contact for public involvement
- building relationships and demonstrating equality;
- public contributors being confident to challenge the views of researchers
- public contributors being flexible to meet researchers' timescales and work patterns

Challenges identified were

- matching resources to roles
- concerns about the risk of over-professionalising public contributors.

Implications for practice

- Based on lessons from our experience, we make the following recommendations to support research teams to plan and undertake public involvement. These recommendations aim to ensure public contributors are a part of the team throughout the research process and their contributions are considered of equal value within all discussions and decisions
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- 1. Ensure that public involvement is embedded from the earliest stage. This allows public contributors the chance to influence the design and delivery of the project from the beginning.
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- 2. Agree a team commitment to public involvement and put this in writing in meeting documents and minutes.
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- 3. Appoint a Public Involvement Coordinator, funded by the study budget, with the skills and responsibility to lead public involvement and support public individuals in their role.
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- 4. Provide access to relevant and timely support and training so that public members have the skills and confidence to undertake their role.
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- 5. Integrate public involvement in study delivery by including public members as equal members within research management structures and processes.
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- 6. Make public involvement a standing item on meeting agendas to ensure that public contributors have an opportunity to raise issues in addition to contributing to other discussions.
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- 7. Build a relationship within the research team to establish trust for collaborative working
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- 8. Clarify structures and ways of working so that public members and researchers have clear and realistic roles and expectations.
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- 9. Review how public involvement is working during the study so that new opportunities can be identified and taken up and additional support needs can be met.
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- 10. Set up a simple system of record-keeping and keep notes throughout the study on how the public are involved and what difference they make. Report on this along with the other study outcomes so we can build the evidence base on effective public involvement

Together we have identified the good practice that made our public involvement effective. We hope people will make use of what we learnt when planning and doing research.