Patient and public involvement is vital to many studies and funding applications, so researchers must know which processes to undertake and why they are important.

Valuing patient and public involvement in research

In this article...

- What is meant by patient and public involvement (PPI)
- What to do and what to avoid when conducting PPI

Author: Kath Maguire is associate research fellow, National Institute for Health Research Collaboration for Leadership in Applied Health Research and Care (NIHR CLAHRC) for the South West Peninsula, University of Exeter Medical School; Emma Jones is doctoral research fellow, University of Leicester; Barbara Williams-Yesson is clinical research manager, Yeovil District Hospital Foundation Trust; Shirley Stevens is patient/public representative, NIHR CLAHRC for the South West Peninsula Public Involvement Group.


Patient and public involvement is now mandatory in funding applications for most health sciences, and clinicians and academics are expected to embed PPI throughout the lifespan of their projects. PPI in health sciences is defined as "conducting research with, or by, patients or the public; it is not research undertaken on or about them." (INVOLVE, 2014).

Gaining views

In March 2014 a conference about PPI was held by Yeovil District Hospital Foundation Trust, attended by 99 delegates, including 51 academics/NHS staff and 48 patients/members of the public representing 31 organisations.

A cohort of 41 self-selected delegates took part in a workshop entitled Active vs Re-active, which explored experiences of PPI in research. Patient representatives spanned several clinical specialties – such as diabetes – as well as a range of contexts, including, for example, National Institute for Health Research networks. Participants were split into discussion groups of four or five, comprising patients, the public, clinical and non-clinical staff, and academics. The groups produced worksheets on:

- Insights into drivers for conducting PPI in research;
- Successes and failures;
- Mechanisms for support.

Drivers for conducting PPI

Participants identified the relevance of research to the needs of the population as a key theme. Within this, strong views were voiced on patients’ rights to be involved: "Research is pointless if it fails to answer questions the public want answered.”

Public responsibility to retain relevancy also featured strongly: "It’s public money – we need to rebalance the power.”

Sharing information was seen as important so clinicians understand how the condition their research focuses on affects patients. This sharing is about ensuring the quality and validity of research so the study does investigate the intended topic. In addition, information sharing was seen as important for patient understanding so that when research participants are approached for a trial they understand what is proposed and why it is important.

Another central theme was beneficence, or patients feeling that they had a duty to do good:
"We are so fortunate to have a health..."
BOX 2. RECOMMENDATIONS FOR DEVELOPING MORE MEANINGFUL PATIENT AND PUBLIC INVOLVEMENT

- Create joined-up working and better communication across and within organisations. This can help create a “soft” interface between organisational requirements and the complex life issues of patient and public participants.
- Set up a database of relevant contacts and invite communications regularly.
- Use both electronic and traditional media to disseminate messages among the research team and to the public about the research that is taking place.
- Give participants an opportunity to provide feedback; it is important for organisations to listen to what is going wrong as well as what works well.
- Create systems that enable feedback in both directions between patients/public and staff, to assure a reciprocal relationship that involves give and take. This means being aware of the different goals people bring to research.
- Explicitly recognise the range of expertise that patients and the public have, including lived experience of medical conditions, service use, experiences as research participants and understandings of different social and cultural issues.
- Be clear about what contributions are required and recognise that there can be unexpected benefits from including people with different perspectives.

...service and we must have an interest in it and help in any way we can.”

This was also linked to feeling “empowered” to encourage and help improve the future care of patients.

Successes and failures

A version of the game “consequences” triggered small group discussions about what people understood to be the point of involving patients and the public in health research, and what were the priorities. Identifying what works and why was felt to be important, but “knowing” whether an element is working was seen as difficult to pin down. Mechanisms identified for achieving this included:

- Observing a cause and effect between patients’ and the public’s contributions, along with a change in the conduct of the project – “I know involvement works when I see PPI input acted upon”;
- Compliance and growth – “I know involvement works when a lot of people want to take part”;
- Understanding and feedback – “I know involvement works when I hear the patient explain (accurately) what is going on” and “I know involvement works when (patient) feedback is positive, when I am formally thanked for my involvement”;
- Measurement using patient satisfaction or experience scores for PPI representatives and from patients in trials – “the patient experience”;
- Reduced drop-out or withdrawal rates from the PPI representatives – “Keeping people engaged”.

In the group discussions, participants identified what they saw as enabling good involvement processes. The issues seen as most important concerned the quality of relationships and communication (Box 1).

Poor communication was seen as a threat to trust, leading people to withdraw from involvement. This was described by patients/members of the public as organisations “talking at us, not with us”. It was strongly argued that research priorities, and the communication of these, have been skewed by commercial and policy interests when a patients, clinicians and researchers partnership would be better.

For some, face-to-face communication was important for building effective relationships; staff changes and short-term contracts were seen as disruptive, requiring new relationships to be built. Others felt the need for a range of ways to involve people – including increased use of electronic tools like Skype and FaceTime – to include people who would struggle to attend meetings and events. Electronic media was also seen as a way to leave feedback about processes, without people feeling they were challenging individual researchers or clinicians. The traditional newsletter was also seen as valuable for maintaining relationships.

Mechanisms for support

“Friendly” and “open” environments were deemed important when conducting PPI.

Procedural and organisational mechanisms were also highlighted, including ensuring consistency and consensus in an approach to engagement processes across (and within) organisations. This included, for example, providing job descriptions for patients and the public so “everyone understands what/why they are involved”.

It was felt that “knowing what you are doing, what are your barriers, boundaries, who are your relevant contacts” was important to participants. But it was suggested there also needs to be space for people to raise issues “related to the patient experience”, with “no-holds-barred approach” that values the “innocent question”.

This alludes to several processes included in patient and public involvement. Staley (2013) suggests involvement is a complex of different activities that need to be selected, managed and supported in ways appropriate for participants and research processes. PPI activities may change over time because an appropriate method to involve patients in the identification of a research question may not be ideal for managing a research process or disseminating results. PPI throughout research processes means thinking about using different techniques and tools; it also means communicating this to participants effectively.

Managing complex, individual patient support needs within hospital or university systems was also highlighted as an issue. This can lead to difficulties ensuring patients’ personal circumstances are taken into account, for example, planning meetings, catering or considering access issues.

An important contribution made by this workshop was that it enabled a space within the conference for patients, clinicians and researchers to talk about PPI and the values they bring to it. Study costing was raised as an important requirement for sustainable PPI. In particular, effective administrative support was highlighted to manage the practical support some people require. The importance of a truly multidisciplinary team was suggested as a key way to redress the power balance so patients and lay participants are seen as “equal experts”.

Conclusion

We feel strongly that recommendations (Box 2) should be practical and achievable, to ensure a tangible change that makes PPI in research more effective and useful. They are intended to create effective partnerships between patients, clinicians, non-clinical staff, academics, and researchers to support improvements in healthcare.

References

INVOLVE (2014) What is Public Involvement in Research? tinyurl.com/INVOLVEPublicInvolvement

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Bit.ly/NTPlacementFeedback