Comparing the perceptions of academics and members of the public about patient and public involvement in ageing research

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Abstract

Background: public and patient involvement (PPI) in clinical research is increasingly advocated by funding and regulatory bodies. However, little is known about the views of either academics or members of the public about perceptions of the practical realities of PPI, particularly in relation to ageing research.

Objective: to survey current levels of PPI in biomedical and clinical research relating to ageing at one institution. To compare and contrast the views of academics and the public about PPI relating to research about ageing.

Design: electronic survey of senior academics, postgraduate students and members of a local user group for older people.

Setting and participants: thirty-three academics (18 principal investigators and 15 PhD students) at a biomedical research institution. Fifty-four members of a local user group for older people.

Results: thirty per cent (10/33) of projects described some PPI activity. Older adults were more positive about active involvement in research about ageing than academics. The perceived benefits of and barriers to involvement in research were similar among all groups, although older members of the public were more likely than academics to acknowledge potential barriers to involvement.

Conclusion: academics and older people share some perceptions about PPI in ageing research, but members of the public are more optimistic about active involvement. Further correspondence between these groups may help to identify feasible involvement activities for older people and encourage collaborative research about ageing.

Keywords: public and patient involvement, consumer participation, biomedical research, ageing, older people

Background

The importance of public and patient involvement (PPI) in health and social care research is widely recognised throughout the developed world [1–3]. In the United Kingdom, the National Institute for Health Research (NIHR) actively encourages researchers and members of the public to come together to plan and deliver research through its advisory group INVOLVE [4]. Funders increasingly require biomedical and clinical researchers to demonstrate how members of the public have been involved in project development, and how they will continue to be involved if funding is awarded [5]. Proponents of PPI suggest that the perspectives provided by individuals who use health services provide higher quality research of greater clinical relevance [6–9].

Older people are a major user group of health services. If research is to produce findings that are more likely to improve the standard of services they use, and their quality of life, it would seem appropriate to actively explore the perspectives and values of older people in relation to healthcare research [10, 11]. It is acknowledged that older people are currently underrepresented as clinical trial participants [12]—it may be that they are similarly excluded from PPI activity.

Objectives and setting

This project aimed to investigate and compare the views of both academics and older adult members of the public with regard to involvement in current biomedical and clinical
research at an institute focusing on the topic of ageing. The setting was the UK NIHR Biomedical Research Centre (BRC) in Ageing and Chronic Disease [13]. Prior to the survey, the BRC had little formal infrastructure relating to PPI. While the university had existing resources to facilitate PPI more widely, it was not known to what extent academics and members of the public were actively collaborating in biomedical ageing research.

Methods

Survey of academics

An online questionnaire, based on the format of a pre-existing Medical Research Council questionnaire [14], was sent to two groups of academics at the BRC (Supplementary data, Appendix 1 available in Age and Ageing online). The first group comprised principal investigators (PIs) of projects funded by the BRC. The second were postgraduate (PG) students in their first or second year of PhD/MD.

Survey of members of the public

Members of an established local user group, VOICE North, comprised of older adults who have previously expressed an interest in assisting with university projects [15], were sent an initial e-mail inviting them to participate in an anonymous survey. The questionnaire for members of the public contained items matched to the topics covered in the academics’ version (Supplementary data, Appendices 1 and 2 available in Age and Ageing online). Participants were also sent an example lay summary of a current BRC project to contextualise the questions about involvement.

Data analysis and feedback

Response data from academics and members of the public were collated and categorised. An anonymised summary of results was e-mailed to PIs, and circulated to all members of the VOICE North user group in their regular newsletter, and feedback invited.

Results

Demographics and response rates

18/24 (75%) PIs at the BRC and 15/17 (88%) of postgraduate students completed the questionnaire. Project topics ranged from lab-based disciplines such as molecular biology to clinical imaging in neurodegenerative disease [13]. Fifty-four members of VOICE North completed the questionnaire. Exact response rates cannot be calculated as the contact list of the user group is dynamic, members opt in and out of the group, and not all of the email contacts are up to date. The maximum number of participants who could have received the initial email was 300.

Questionnaire items specific to academics

10/33 (30%) academics (PIs and PG students) described some level of PPI in their project. The most commonly cited motivation for PPI was to ensure relevance of the project to the target population (n = 7). Activities included modifying study design (n = 5), helping to write patient information sheets (n = 4) and identifying clinically meaningful outcome measures (n = 4).

Of the 23 academics that had not included PPI activity, the most commonly cited reason was a belief that early stages of biomedical research did not warrant public involvement (n = 7). Other reasons included a lack of understanding of pathways to facilitate public involvement (n = 3), and a belief that the rigidity or complexity of research protocols precluded public involvement (n = 3). Example verbatim responses are shown in Figure 1. No academics expressed specific concerns about involving older people in comparison to younger people.

Comparative questionnaire items

In relation to perceived feasibility of future PPI activity in relation to BRC projects, older adults were more likely than academics to believe that members of the public could play an active role in biomedical research. Three PIs felt that older members of the public had no feasible future role in their own particular project.

Benefits of and barriers to PPI

Academics and older adults expressed similar perceptions as to the potential benefits of PPI (Supplementary data, Figure 3 available in Age and Ageing online). However, older adults were more likely than academics to believe that PPI could improve the knowledge and skills of the research team. Older adults were more likely to perceive there to be barriers to PPI than academics, particularly in terms of translating.
Discussion

This survey is unique in seeking the views of older members of the public about PPI in biomedical projects relating to ageing and directly comparing public perceptions with those of academics. Encouragingly, academics and older adults shared views about the potential benefits of PPI and agreed that ensuring relevance was the most likely benefit. The survey found that members of the VOICE North group believed that they could contribute to an ongoing range of activities related to BRC projects, further corroborating a potential role for older people in biomedical and clinical research [10, 11]. Interestingly, although both groups recognised a range of barriers to PPI in biomedical research, older adults were more likely to acknowledge barriers than academics, particularly in relation to the difficulty of translating scientific to lay language.

Our finding that only 30% (10/33) of BRC projects described some level of PPI is in keeping with previous surveys of Medical Research Council trial units (31%) [14], the National Research Ethics Service (37%) [16] and projects on the National Research Register (17%) [17]. It appears that in biomedical research environments, PPI activity remains the exception rather than the norm. Comments made by academics completing our survey reiterate concerns reported elsewhere that there may be an enduring resistance to PPI for a number of reasons, including a belief that PPI is not relevant or is simply too difficult to organise [16, 18].

In response to our survey, we subsequently organised a joint educational meeting for PG students and older adults to discuss findings and implications. The meeting generated lively discussion and positive feedback from students and volunteers, suggesting that there is willingness for correspondence and co-operation. Students expressed a view that the interaction with older adults helped them to keep their own research aims in perspective. Currently, guidelines for conducting education and training sessions about PPI are available [19], but there is an absence of robust evidence as to the long-term impact on academic staff and their subsequent commitment to PPI. The success of this educational meeting has prompted extension of PPI training for BRC staff, increasing the number of opportunities for researchers to recognise the mutual benefits of PPI throughout the research process.

This survey has a number of limitations. Firstly, it was undertaken in a single research centre that is likely to have its own idiosyncrasies, curbing generalisability of the results. However, shared findings with other surveys as cited above suggest challenges common to many academic centres. The relatively small sample size of academics was countered to some extent by a high response rate, giving a comprehensive snapshot of this particular environment. Sample sizes precluded tests of significance between groups, and multiple comparisons were made, raising the possibility of identifying apparent differences by chance. Our findings are exploratory—larger sample sizes would be required to demonstrate statistically significant differences of opinion between academics and older people. Further, as per many patient and public groups, VOICE North is not necessarily representative of the population at large, with underrepresented groups such as ethnic minorities and people with cognitive impairment.

Conclusion

This exploratory study has highlighted examples of both convergent and divergent perceptions of academics and older people about PPI in research, and what their ongoing contribution to the overall research endeavour of research institutions such as Newcastle NIHR BRC might be. Prompted by the results of this survey, PPI in the BRC has subsequently become more visible with a defined administrative structure,
single point of contact and dedication of resources including formal education and training.

Key points

• PPI is expected by funders as an integral part of each stage of the clinical research process.
• Little is known about the views of either academics or members of the public with regard to the practical realities of PPI in relation to ageing research.
• One-third of the research projects relating to ageing at a single institution described some level of PPI activity.
• This survey demonstrated that older people were more positive about active involvement in research about ageing than academics.
• Collaborative education for academics and older people may help to identify feasible involvement activities for older people.

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Conflicts of interest

None declared.

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Ethical approval

Approval was obtained via the university ethics review process. Questionnaire administration and data collection were password protected. Data collected from members of the public were anonymous and data collated from academics were anonymised.

Supplementary data

Supplementary data mentioned in the text are available to subscribers in Age and Ageing online.

References