Patient and public involvement in research

This Evidence Spotlight, produced in collaboration with public contributors, is intended as a starting point for critically considering the evidence base around patient and public involvement in research. It includes summaries of critically appraised, selected research listed under broad subject headings. These are accompanied by CPD activities applicable to the four pillars of the RCOT *Career development framework* 2021 (Professional Practice, Facilitation of Learning, Leadership, and Evidence, Research and Development) including activities related to equity, diversity and belonging. You can use our bite-sized leaning resources (details on page 4) to capture your learning.

Introduction

Patient and public involvement (PPI) in occupational therapy research can play a vital role in improving occupational therapy services for the people who access them. PPI is an active partnership between patients, carers and members of the public (often collectively known as public contributors) and researchers, in which research is conducted with or by public contributors rather than to, about or for them (Dennington-Price et al 2022).

The *UK standards for public involvement* in health and social care research, identify that research should be informed by a diversity of public experience and insight, and researchers are encouraged to consider involving people affected by and interested in the research from the earliest stages (UK Public Involvement Standards Development Partnership 2019).

Public contributors can be involved in a variety of ways including all aspects of research from setting research priorities (James Lind Alliance 2022, Watson et al 2021), being part of a project advisory/steering group, through to co-producing research. Involvement in projects can include formulating research questions, designing and conducting the project, disseminating the findings and making recommendations for their application in practice (National Institute for Health and Care Research 2021, UK Research and Innovation 2022).

Public contributor commentary

"PPI is important to research because we bring a real-world perspective to what can be an abstract and narrowly framed academic culture. Patients and carers know what matters to them and can make a difference to their health, well-being, and quality of life. We can help identify and prioritise research questions, contribute advice on protocol feasibility and likely impact of the translation of research into the real world. We can also contribute advice on how to identify, gauge and negotiate barriers to research implementation and translation.

As a long-term mental health patient with 14 years of PPI experience (and even more years of lived patient experience), I am very much aware of the value of research and implementation science in bringing evidence-based healthcare innovation to the coalface of care. There can be so many slips between the cup and the mouth, real-world experience of patients and the wider public is crucial to ensuring that no one goes thirsty".

Sarah Markham (public contributor)

References

Dennington-Price A, Wellings A, Chambers E, Cracknell G, O'Hara M, Bortoli S (2022) *Starting out guide – why and how to get involved in research.* [s.l.]: NIHR. Available at: *https://www.nihr.ac.uk/documents/Starting-Out-Guide/30145*

James Lind Alliance (2022) *About us.* Southampton: JLA. Available at: *https://www.jla.nihr.ac.uk/about-the-james-lind-alliance/*

National Institute for Health and Care Research (2021) *Briefing notes for researchers: public involvement in NHS, health and social care research.* [s.l.]: NIHR. Available at: *https://www.nihr.ac.uk/documents/briefing-notes-for-researchers-public-involvement-in-nhs-health-and-social-care-research/27371*

UK Public Involvement Standards Development Partnership (2019) *UK standards for public involvement: better public involvement for health and social care research.* [s.l.]: NIHR Central Commissioning Facility. Available at: *https://sites.google.com/nihr.ac.uk/pi-standards/home*

UK Research and Innovation (2022) *Co-production in research.* Swindon: UKRI. Available at: *https://www.ukri.org/about-us/policies-standards-and-data/good-research-resource-hub/research-co-production/*

Watson J, Cowan K, Spring H, Mac Donnell J, Unstead-Joss R (2021) Identifying research priorities for occupational therapy in the UK: a James Lind Alliance Priority Setting Partnership. *British Journal of Occupational Therapy, 84(12),* 735–744.

Selected evidence

PPI in occupational therapy research

Røssvoll et al (2022) conducted a scoping review to explore the use and impact of PPI in occupational therapy research. Seventeen studies, 14 of which were qualitative, were included. Most studies were from the UK, Canada and Australia. The studies used PPI at various stages of the research process, but only one study reported involvement at all stages. Positive impacts on research design, ethics, public collaborators and researchers were reported anecdotally. Challenges and reflections related to PPI were also presented. The authors identify the need for greater consistency and comprehensiveness in the reporting of PPI, potentially though the use of checklists.

Reference
Røssvoll TB, Hanssen TA, Rosenvinge JH, Liabo K, Pettersen G (2022) Patient and public involvement in occupational therapy health research: a scoping review. *OTJR: Occupation, Participation and Health,* May 13. [Epub ahead of print]. doi: 10.1177/15394492221096058

Evidence, Research and Development

Reflect on potential benefits of recording the impacts of PPI. Explore how this relates to the UK Standards for Public Involvement

Consider how involvement of public contributors in identifying ways to record impact could improve the relevance of the results.

Co-design to improve service delivery

O'Donnell et al (2019) describe quality improvement initiatives from a co-design process to improve service delivery in an acute setting for frail older people. The co-design team included older people, carers, organisations advocating for older people, researchers and clinical staff. The co-design work was supported by four pillars of effective and meaningful public and patient representative (PPR) involvement: research environment and receptive contexts; expectations and role clarity; support for participation and inclusion representation; and commitment to the value of co-learning involving institutional leadership. The team identified five priority areas for improvement: collaboration along the integrated care continuum; improved mobility; access to food and hydration; continence care; and improved patient information and hospital signage. The authors identify that co-learning and recognition of mutual benefit were at the core of the co-design process, which facilitated democratic dialogue in the development of quality improvement initiatives.

Reference
O'Donnell D, Ní Shé É, McCarthy M, Thornton S, Doran T, Smith F, O'Brien B….Cooney Marie T (2019) Enabling public, patient and practitioner involvement in co-designing frailty pathways in the acute care setting. *BMC Health Services Research, 9(797),* 1–11. doi: 10.1186/s12913-019-4626-8

Evidence, Research and Development

Professional Practice

Explore how occupational therapists could become involved in co-designed quality improvement initiatives in your area of practice. Identify ways you could get involved.

Review methods of communication in your area of practice (such as leaflets, posters, online information) with public contributors and consider whether there are ways in which inclusivity could be improved.

Co-design to support self-management

Salmon et al (2019) worked with health care professionals (including occupational therapists) and patients to co-design an intervention to support self-management of rheumatoid arthritis fatigue through modifying physical activity. The research involved: establishing the existing evidence base; identifying preferences of patients and health care professionals; and use of a theoretical framework to develop intervention components. Participants emphasised the importance of choice and patient-led decision making in facilitating motivation and behaviour change. These factors informed intervention design. The authors identify that consultation and collaboration with people accessing/delivering an intervention enhances the likelihood of acceptability and implementation.

Reference
Salmon VE, Hewlett S, Walsh NE, Kirwan JR, Morris M, Urban M, Cramp F (2019) Developing a group intervention to manage fatigue in rheumatoid arthritis through modifying physical activity. *BMC Musculoskeletal Disorders, 20(194),* 1–13. doi: 10.1186/s12891-019-2558-4

Examining use of co-design in research

Slattery et al (2020) conducted a rapid overview of reviews to examine co-design in the planning phase of research. Findings included that there was variation regarding definition of co-design, as well as contexts, scope and theoretical focus. It was also found that the effectiveness of research co-design has rarely been evaluated empirically or experimentally, but qualitative evaluations have reported positive and negative outcomes associated with co-design. The authors suggest that realising the potential of co-design may involve development of clearer and more consistent terminology, improved reporting of the activities involved, and better evaluation.

Reference
Slattery P, Saeri AK & Bragge P (2020) Research co-design in health: a rapid overview of reviews. *Health Research Policy Systems, 18(17),* 1–13. doi: 10.1186/s12961-020-0528-9

Exploring patient involvement in research

Skovlund et al (2020) used a single case study to explore ways of embracing patients' perspectives in a research process, as well as challenges and impact on patients, researchers and the research outcomes. The case focused on the involvement of five patient research partners (PRPs) with metastatic melanoma in a Danish clinical controlled intervention trial and nested intervention study. The PRPs were involved in designing, undertaking and disseminating the trial, which tested the effect of using patient-reported outcome measures as a dialogue tool in patient-physician consultation. Findings included that patients contributed a new vocabulary and perspective on the dialogue, and validated the results. Challenges included emotional, administrative, and intellectual factors.

Reference
Skovlund PC, Nielsen BK, Thaysen HV, Schmidt H, Finset A, Ahm Hansen K, Lomborg K (2020) The impact of patient involvement in research: a case study of the planning, conduct and dissemination of a clinical, controlled trial. *Research Involvement and Engagement, 6(43),* 1–16. doi: 10.1186/s40900-020-00214-5

Leadership
Professional Practice

Reflect on decision making within your own practice. Could it be altered to facilitate a more shared approach with the people who access your service? Consider how a collaborative approach could benefit people who access services and practitioners.

Consider how you could promote inclusion of public contributors from minoritised or seldom heard groups.

Evidence, Research and Development

Review the UK Standards for Public Involvement

Consider the benefits of public contributors being involved in the planning phase of research and identify how a lack of involvement at this stage could adversely affect the outcomes and relevance of the research.

Evidence, Research and Development
Facilitation of Learning

Carry out further reading on co-production, for example on the UK Research and Innovation website.

Appraise a co-produced research paper in a journal club.

Further reading

Benjamin-Thomas TE, Rudman DL (2018) A critical interpretive synthesis: use of the occupational justice framework in research. *Australian Occupational Therapy Journal. 65(1)*, 3–14.

Harries P, Barron D, Ballinger C (2020) Developments in public involvement and co-production in research: embracing our values and those of our service users and carers. *British Journal of Occupational Therapy. 83(1)*, 3–5.

UK Standards for Public Involvement: https://sites.google.com/nihr.ac.uk/pi-standards/standards

Access to journal articles

RCOT members can access the full text of the articles via the RCOT e-journals collection, by searching CINAHL and Medline or, in the case of open access articles, via the link/DOI provided in the reference.

Access the RCOT e-journals collection at: https://www.rcot.co.uk/practice-resources/library-resources/journals-and-e-journals

Search CINAHL and Medline: https://www.rcot.co.uk/practice-resources/library-resources/search-cinahl-and-medline

Resources

Top 10 priorities in occupational therapy research in the UK - https://www.rcot.co.uk/top-10

RCOT information on public contributors - https://www.rcot.co.uk/public-contributors

Career Development Framework

The *Career development framework: guiding principles for occupational therapy*, 2nd edition (RCOT 2021) is an over-arching set of guiding principles for occupational therapy and offers a structured process to guide careers, learning and development within our profession. It contains four interacting pillars of practice (each with nine career levels):

- Professional practice
- Facilitation of learning
- Leadership
- Evidence, research, and development

Access the framework at: https://www.rcot.co.uk/cpd-rcot

Bite-sized learning

Use RCOT CPD resources to capture your learning from the CPD activities: https://www.rcot.co.uk/bite-sized-learning

Evidence Spotlight

Royal College of Occupational Therapists