

Patient and Public Involvement in systematic reviews: Why bother? What's the way forward?

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WHAT do systematic reviews do?

Systematic reviews use clear methods to identify and summarise what is known about a health or social care topic.

They can be about topics as wide apart as the effectiveness of a drug, people's experiences of care, or the best way to organise care in the community.

There are well-established methods for doing systematic reviews. The Cochrane Collaboration publishes a comprehensive handbook detailing these methods.

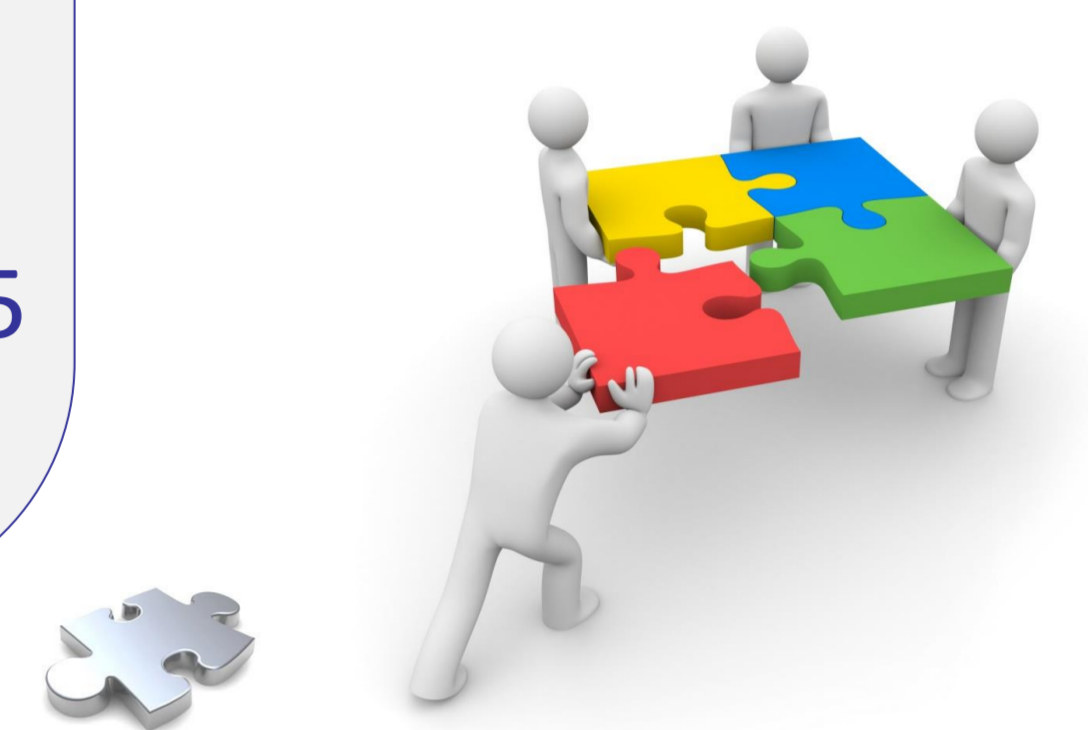
AN example of PPI in a systematic review

This systematic review* was part of a larger project about peer support for parents of disabled children.

The idea for the project came from a member of the PenCRU Family Faculty.

The project was led by a stakeholder group that included 8 parents of disabled children (including 5 from the Face2Face peer support service).

"I hope we gave it an edge of realism; grounding the researcher's practices in our living situations more"



HOW were parents involved?

Parents were involved at key stages of the review:

- Suggesting the topic and development of the research question
- Helping to determine the appropriate inclusion and exclusion criteria and identifying relevant outcomes
- peer reviewing an academic paper and leading the production of the plain language summary (available at www.pencru.org)

For example, parents suggested that we should expand the population to include parents of children with conditions such as diabetes and arthritis but that it would not be appropriate to include parents of babies in NICU or bereaved parents.

They also felt that the outcomes included in the review should include family function and long term impact of peer support.

WHAT can PPI add to systematic reviews?

Some examples of how PPI has influenced systematic reviews include:

- suggesting and locating relevant literature e.g. unpublished research and reports
- contributing to appraising the literature e.g. appraising literature on patient experiences
- interpreting the findings e.g. in a workshop where preliminary findings are discussed with members of a PPI group
- helping write up the findings



WHAT could we have done differently?

Parents were involved in the systematic review mostly at the beginning and at the end.

We think we missed opportunities for involvement in the conduct of the review itself e.g.

- The screening of articles and decisions about which should be included in the review
- Developing the thematic framework for the synthesis of the qualitative literature

This needs to be balanced against:

- the additional time commitment for parents and researchers
- the ability of the researcher to facilitate these activities well

Overall PPI had a very positive impact on this systematic review. However, in order to realise the full potential of PPI, this work needs to be planned and fully costed into bids with someone responsible for leading the PPI activities.

"being a parent carer is like being catapulted into a life that you did not expectyou end up being deskilled... involvement gives you a direction out of that fog; some empowerment and a chance to skill up again."



*Shilling V. et al. (2013) Peer support for parents of children with chronic disabling conditions: a systematic review of quantitative and qualitative studies. *Developmental Medicine & Child Neurology*, 55: 602–609.

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