

# **Involving the public in systematic reviews: What does the evidence tell us?**

**INVOLVE Conference 2012: Putting people first in research  
13-14 November 2012 - East Midlands Conference Centre, Nottingham**

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# Papers on which the talk is based

Two recent narrative reviews on public involvement in systematic reviews

- Boote, J., Baird, W., and Sutton, A., (2012) Involving the public in systematic reviews: a narrative review of organisational approaches and eight case examples. *Journal of Comparative Effectiveness Research*, volume 1, issue 5, pages 409 – 420.  
[www.futuremedicine.com/doi/abs/10.2217/cer.12.46](http://www.futuremedicine.com/doi/abs/10.2217/cer.12.46)
- Boote, J., Baird, W., and Sutton, A., (2011) Public involvement in the systematic review process in health and social care: A narrative review of case examples. *Health Policy*, volume 102, issue 2, pages 105 – 116. [www.ncbi.nlm.nih.gov/pubmed/21641075](http://www.ncbi.nlm.nih.gov/pubmed/21641075)

The talk is focused on the involvement of the public in *individual* systematic reviews, and not their involvement in review groups or organisations that conduct reviews, such as the Cochrane Collaboration

# Why did we undertake this work?

- To examine the different methods of involving the public in systematic reviews
- To examine the extent to which the public were involved in systematic reviews at the levels/approaches of consultation, collaboration and publicly-led
- To synthesise the impacts of involving the public in systematic reviews, and to discuss the tensions and facilitating strategies that have been identified
- To make recommendations for good practice

# How did we find relevant information?

- We searched the published literature in January 2011 to try to identify all peer-reviewed journal articles published in English on public involvement in the systematic review process
  - Databases searched were: PsycINFO, MEDLINE and MEDLINE In-Process, CINAHL, EMBASE, Cochrane Methodology Register, HMIC, invoNET
- Search terms included ‘consumer’, ‘user’, ‘participant’, ‘involvement’, ‘inclusion’, ‘review’, ‘systematic review’ and ‘research’.
- We also searched a bibliography of references on public involvement to search for reports
  - Boote J. Patient and public involvement in health and social care research: a bibliography. [www.rdsyh.nihr.ac.uk/ file.ashx?id=3959](http://www.rdsyh.nihr.ac.uk/file.ashx?id=3959)

# Sifting the information collected

- 744 papers were identified in the search of databases
- All titles and abstracts were read
- We identified 3 published papers that presented accounts of public involvement in systematic reviews
- The search of the bibliography identified four further reports
- A further published account appeared in 2012
- This makes eight case examples altogether
- Of these eight examples, six published their account of the public involvement in the review process in a separate document to the review itself

# Topic areas of the identified reviews involving the public

A wide variety of topic areas were identified:

Five were 'traditional' reviews focusing on healthcare interventions

- Patients' perspectives on electroconvulsive therapy
- Teaching, learning and assessment of law in social work education
- Treatments for degenerative ataxias
- HIV health promotion for men who have sex with men
- Chemoradiotherapy for women with cervical cancer

Three focused specifically on aspects of public involvement itself:

- The conceptualization, measurement, impact and outcomes of public involvement in health research
- User involvement in nursing, midwifery and health visiting research
- Methods of consumer involvement in developing healthcare policy and research, clinical practice guidelines and patient information material

# Evidence sources (1)

Review	Main review publication	Public involvement in the review
Patients' perspectives on electroconvulsive therapy	Rose D et al Patients' perspectives on electroconvulsive therapy: systematic review. BMJ 326, 1363–1367 (2003).	Carr S, Fleischmann P. Systematic review of consumers' perspective on electroconvulsive therapy. In: Collection of Examples of Service User and Carer Participation in Systematic Reviews. Carr S, Coren E, (Eds). SCIE, London, UK (2007).
Teaching, learning and assessment of law in social work education	Braye S et al Teaching, learning and assessment of law in social work education. Institute for Excellence, London, UK (2005).	Braye S, Preston-Shoot M. Emerging out of the shadows? Service user and carer involvement in systematic reviews. Evid. Policy 1(2), 173–194 (2005).
Treatments for degenerative ataxias	Trujillo-Martín MM et al Effectiveness and safety of treatments for degenerative ataxias: a systematic review. Mov. Disord. 24(8), 1111–1124 (2009).	Serrano-Aguilar P, et al Patient involvement in health research: a contribution to a systematic review on the effectiveness of treatments for degenerative ataxias. Soc. Sci. Med. 69(6), 920–925 (2009).
HIV health promotion for men who have sex with men	Rees R, et al. HIV Health Promotion and Men Who Have Sex with Men (MSM): a Systematic Review EPPI-Centre, Social Science Research Unit, Institute of Education, University of London, London, UK (2004).	Rees R, Oliver S. An example from sexual health promotion. In: Collection of Examples of Service User and Carer Participation in Systematic Reviews. Carr S, Coren E (Eds). SCIE, London, UK (2007).

# Evidence sources (2)

Review	Main review publication	Public involvement in the review
Chemoradiotherapy for women with cervical cancer	Chemoradiotherapy for Cervical Cancer Meta-analysis Collaboration. Reducing uncertainties about the effects of chemoradiotherapy for cervical cancer: individual patient data meta-analysis. Cochrane Database Syst. Rev. 1, CD008285 (2010).	Vale C et al Evaluation of patient involvement in a systematic review and meta-analysis of individual patient data in cervical cancer treatment. Syst. Rev. 1(1), 23 (2012).
The conceptualization, measurement, impact and outcomes of public involvement in health research	Brett J, et al The PIRICOM Study: a systematic review of the conceptualization, measurement, impact and outcomes of patients and public involvement in health and social care research. UK Clinical Research Collaboration (2010).	Ibid
User involvement in nursing, midwifery and health visiting research	Smith E, et al. User Involvement in the Design and Undertaking of Nursing, Midwifery and Health Visiting Research. NCCSDO, London, UK (2005).	Smith E, et al. Getting ready for user involvement in a systematic review. Health Expect. 2, 197–208 (2009).
Consumer involvement in developing healthcare policy and research, clinical practice guidelines and patient information material	Nilsen ES, et al Methods of consumer involvement in developing healthcare policy and research, clinical practice guidelines and patient information material. Cochrane Database Syst. Rev. 3, CD004755 (2005).	Ibid



# The public who were actively involved in the reviews

As you would expect a wide variety of different ‘types’ of the public were reported to have been involved in these reviews including:

- Patients and carers, such as cancer survivors
- ‘User-researchers’
- People from voluntary and third sector organisations
  - E.g. Terrence Higgins Trust, Gay Men Fighting AIDS, Sigma Research and The National AIDS Trust in the case example on interventions for MSM
- Members of the Cochrane Consumers Network

# **‘Levels’ of public involvement**

One review was publicly-led:

- The review of patients’ perspectives on ECT led by the Service User Research Enterprise at London’s Institute of Psychiatry.

The remainder of the reviews involved the public using collaborative and consultative approaches.

Examples of collaborative methods included:

- a service user researcher being a full member of the review team
- members of the public on the review’s advisory group

Examples of consultative methods included:

- Workshops to discuss the review protocol and emergent findings
- A service user reference group consulted at key points in the review process
- A virtual forum on the web
- A Delphi process conducted through email

# Contributions of the public to the review process (1)

Five main contributions to the review process were noted:

- Refining the scope of the review (PICOS formulation choices)
  - E.g. in the review of interventions for MSM, the advisory group helped to identify the types of interventions that should be prioritized as well as the subgroups of MSM and outcomes on which the review should focus
- Suggesting & locating relevant literature
  - E.g. in the review of patients' experiences of ECT, the user group 'Communicate' located an important unpublished ECT study
- Appraising the literature
  - E.g. in the review of patients' experiences of ECT, the user-researchers were fully involved in appraising the included papers and it was reported that the critical perspective of the service user researchers revealed important methodological inadequacies in the identified studies of ECT

# Contributions of the public to the review process (2)

- Interpreting review findings
  - E.g. in the review of chemoradiotherapy for women with cervical cancer, the Patient Research Partners attended the collaborators' meeting, at which the first results of the review and meta-analysis were presented. The review team reported that the Patient Research Partners had brought,
    - *'the results of the study to life as it evidenced the experience of real people'*
- Writing up the review, as either:
  - First author (ECT example)
  - Co-author (example around user involvement in midwifery research)
  - Author of the review's foreword (example around the impact of public involvement in research)

# Tensions and barriers (1)

The case examples discussed many tensions and barriers and most of these are from the researcher perspective

- Time pressures and resourcing problems
- Researchers' concerns about involving people who are not well & discussing 'taboo' subjects
  - Expressed by the researchers involved in the chemoradiotherapy study:
    - *"We aren't medical or nursing professionals so don't have experience of working with patients. We had no idea how well or poorly the women were going to be or whether any of them were coming into it with preconceptions that would make it difficult to work with them"*
- Continuity issues due to illness
  - In the same study it was reported that one Patient Research Partner, due to the advanced nature of her illness, became too unwell to attend the advisory group meetings during the conduct of the review

# Tensions and barriers (2)

- Concerns about group dynamics
  - Sometimes in review advisory groups, it can be difficult for the public to get their views across
- Research Ethics Committee involvement
  - One review had to obtain REC permission to actively involve the public and this was questioned
- The public's perceptions on their degree of influence in reviews
  - In one review, one patient believed that the public can have less of an influence in systematic reviews compared with primary research.
    - *She stated that, “for a meta-analysis where the outcome measures have already been collected, I am not sure how much difference we have really made overall.”*

# Facilitating strategies/good practice

- Funding & payment
  - Cost payment into grant applications
- Identifying a lead or advisory group for public involvement
  - A member of the team should lead on public involvement and act as a mentor
- Recruiting the public through relevant networks
  - Use of the topic-specific and comprehensive research networks
- Training, briefing & information provision
  - Provide background reading, glossary of key terms
- Structured methods of involvement
  - Use nominal group and Delphi techniques where relevant to ensure that the public's views are incorporated into decision-making

# Summary of findings

- Only eight case examples were found detailing how the public have been involved in the systematic review process
- A wide variety of people were found to be involved including patients, carers, user-researchers and members from the voluntary/third sector
- A number of different methods of public involvement were used including consultation workshops, membership of review advisory groups, membership of the review team, email discussion lists and the Delphi process
- Examples were found of the public contributing at the consultation and collaboration approaches to public involvement. Only one publicly-led example were found
- Numerous tensions, barriers and facilitating strategies have been identified



# Recommendations

- Further guidance and good practice are needed for researchers on how best to involve the public in the review process
- INVOLVE has recently issued a supplement on systematic reviews and public involvement
- Work should be undertaken to develop quality standards for the involvement of the public in systematic reviews
  - This could use the consensus-derived principles of successful public involvement in NHS research as a starting point (Boote et al, 2006; Telford et al, 2004)
- More case examples of public involvement in systematic reviews should be published and a further synthesis undertaken in 5-10 years time
  - To ensure that these case examples are identified in any future (systematic) review on this topic, we recommend that a systematic review's abstract and main body of text should include details of the contribution(s) of the public (if any) to the review process, together

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