

# INVOLVE



*National Institute for  
Health Research*

## **Public involvement in systematic reviews:**

Supplement to the briefing  
notes for researchers

# About this supplement

This supplement provides advice for researchers who design and carry out systematic reviews. It is a specialist supplement to support the general information on how to involve members of the public in research which can be found in the INVOLVE

**Briefing notes for researchers: public involvement in NHS, public health and social care research** and should be read alongside the Briefing notes.

(See [www.invo.org.uk/resource-centre/resource-for-researchers](http://www.invo.org.uk/resource-centre/resource-for-researchers))

INVOLVE commissioned **Claire Vale** of the Medical Research Council (MRC) Clinical Trials Unit to develop and write this supplement. She was supported by:

**Gill Gyte**, Consumer Editor with the Cochrane Pregnancy and Childbirth Group

**Bec Hanley**, Co-Director, TwoCan Associates

**Rosemary Humphreys**, Consumer with the Cochrane Skin Group

**Catherine McIlwain**, Cochrane Collaboration Consumer Coordinator

**Jennie Popay**, Professor of Sociology and Public Health at Lancaster University

**Nicolette Spera**, Volunteering Programme Manager at Macmillan Cancer Support and Patient Research Partner on a systematic review at the MRC Clinical Trials Unit

**Lesley Stewart**, Director of the Centre for Reviews and Dissemination, University of York and an NIHR Senior Investigator

**Victoria Thomas**, Associate Director of the Patient and Public Involvement Programme, National Institute for Health and Clinical Excellence (NICE).

Further information on those involved can be found on page 16

## Terms used

INVOLVE defines public involvement in research as research being carried out **'with'** or **'by'** members of the public rather than **'to'**, **'about'** or **'for'** them. This includes, for example, working with research funders to prioritise research, offering advice as members of a project steering group, commenting on and developing research materials and undertaking interviews with research participants.

When using the term 'public' we include patients, potential patients, carers and people who use health and social care services as well as people from organisations that represent people who use services. Whilst all of us are actual, former or indeed potential users of health and social care services, there is an important distinction to be made between the perspectives of the public and the perspectives of people who have a professional role in health and social care services.

In the examples the terms used reflect those used by the authors such as consumer, lay researcher partner or patient instead of public.

An explanation of some of the terms used can be found in the INVOLVE online jargon buster (see [www.invo.org.uk/resource-centre/jargon-buster](http://www.invo.org.uk/resource-centre/jargon-buster)).

This supplement is one of a series edited by Helen Hayes of the INVOLVE coordinating Centre, details of other titles are in the useful reading and resources section on page 12.

## Introduction

This supplement provides information and advice on the involvement of members of the public in systematic reviews. As for any research study, the type of involvement can be adapted to suit your specific review(s) and may also depend on those who you are seeking to involve. Systematic reviews aim to identify, appraise, select and synthesise all high quality research evidence relevant to a particular question. Some, but not all reviews will involve formal meta-analysis, in which statistical methods are used to combine the results of the studies identified as relevant to the review question. There are different types of systematic reviews, for example reviews of interventions, reviews of diagnostic studies, reviews of qualitative studies and reviews in which individual patient data are collected. Many of the methods used in systematic reviewing will be similar such as conducting literature searches, appraising the study quality and assessing study eligibility. We have therefore taken a broad approach and tried to encompass ideas for involvement in systematic reviews and other appraisals of healthcare evidence. We have drawn on examples of successful public involvement in the conduct of systematic reviews including the work of the Cochrane Collaboration which aims to involve members of the public throughout the organisation.

In this supplement we consider involvement at three distinct levels:

- 1. Involvement in individual reviews**
- 2. Involvement across a group of systematic reviews**
- 3. Involvement at a unit level.**

Advice and examples are provided for each level and we have identified some specific benefits and challenges of the different approaches, as well as covering the more general benefits and challenges that apply whichever route you take. The level of involvement you aim to develop may depend on whether you plan to establish a programme of reviews in a related field of healthcare or whether you are conducting a one-off review. It may also depend on your timescales.

## Where should I start?

Many members of the public will have no prior knowledge of systematic reviews, so you will need to provide some support or training. Individualised training and support can be resource intensive and will therefore take additional time. However, many of those who have involved patients and the public in their reviews find that the added value that involvement brings to their reviews outweighs any additional effort. You may also feel that you need support or training to help you work with members of the public.

A list of resources, including materials developed for patients involved in reviews, is included with this supplement. Information on training and support for researchers and members of the public is available on the INVOLVE website [www.invo.org.uk/resource-centre/training-resource](http://www.invo.org.uk/resource-centre/training-resource)

Involvement should ideally begin as early in the review process as is possible. There are examples of patients and the public being involved in helping to define the priorities of a programme of systematic reviews (Shea et al 2005). However, it is important to remember that it is (almost) never too late to involve people in a systematic review, for example public involvement can help with the dissemination of results of the review.

Consider using different approaches within the same review or group of reviews, choosing to involve people in different ways at different stages. (See Briefing note eight: Ways that people can be involved in the different stages of the research cycle [www.invo.org.uk/posttypesresource/where-and-how-to-involve-in-the-research-cycle](http://www.invo.org.uk/posttypesresource/where-and-how-to-involve-in-the-research-cycle))

For information on good practice in public involvement. (see Briefing note five: How to involve members of the public in research [www.invo.org.uk/resource-centre/resource-for-researchers/](http://www.invo.org.uk/resource-centre/resource-for-researchers/))

Ethical approval is not needed to involve people in systematic reviews (see patient and public involvement in research and research ethics committee review [www.invo.org.uk/posttypepublication/patient-and-public-involvement-in-research-and-research-ethics-committee-review](http://www.invo.org.uk/posttypepublication/patient-and-public-involvement-in-research-and-research-ethics-committee-review))

### **Potential benefits of public involvement in systematic reviews**

- Consideration and identification of the key outcomes to be assessed.
- Involvement of members of the public who know about the topic of the review and have first-hand experience of the disease and treatment.
- Researchers and members of the public learning from each other to gain a full understanding of a review and its purpose.
- Ability to deal with specific issues and questions as they arise, for example, questions about the specific illness or condition or the findings of the review.
- Adding value to the review, improving quality and relevance to patients.
- Establishing relationships between researchers and the public which may make it easier for researchers to consult people throughout all stages of their research.
- Improving ‘readability’ of scientific language and jargon.
- Contributing to wider dissemination of the review to patients and the public.

### **Potential challenges**

- Identifying people, particularly in under-researched areas where few patient groups or networks exist.
- Ensuring that people’s opinions can be heard and valued by the review team especially if it is the first review they have been involved in. You may need to offer training or support to help people with this.

- Dealing with frustration when studies included in the review do not contain the outcomes of interest to the review and those involved, for example by ensuring that the people involved understand that future research can be influenced by identifying important outcomes not considered in prior studies.
- A single review may take a long time to reach completion and so you may be asking for a long-term commitment. Alternatively, some reviews need to provide a rapid evaluation of a topic, so it may be difficult to identify people to involve and get them up to speed in time to meet a deadline.
- There may be members of the research team who have concerns about public involvement that may be difficult to deal with and overcome.

### **Advice to researchers**

#### **To help you plan public involvement in your systematic review we suggest you consider the following points:**

- Involve people as soon as possible in the development of your review, for example involve people in developing the protocol.
- Remember that in general, people are not likely to have come across the concept of systematic reviews before. You might have to find simple ways to explain the concept.
- Avoid using acronyms and research jargon. Develop a glossary of general research terms and those specific to your review.
- Be clear about the purpose of involving members of the public before you get them involved. Be clear with the people you involve about your expectations of their role and about what you want them to do. Develop a project outline and a job description on their specific role from the start.
- Ensure that members of the public have written material to refer to about the process of the review.

- Try to identify a member of the team who can be the ‘contact’ for patient and public involvement members to go to when they have queries
- Consider setting up a ‘buddy’ system, especially if people are new to systematic reviews. It might be helpful if people can discuss issues with a (possibly more experienced) fellow member of the public.
- Provide feedback to the people you involve to let them know how their contribution has helped – or be able to explain where you haven’t included their views. People feel they are often involved without seeing any change as a result.

**Further information in planning public involvement in research can be found in the Briefing notes for researchers: public involvement in NHS, public health and social care research.**

[www.invo.org.uk/resource-centre/resource-for-researchers/](http://www.invo.org.uk/resource-centre/resource-for-researchers/)

## 1. Involvement in individual reviews

This type of involvement is what many people think of when they consider involvement in a systematic review.

### Public involvement helps to:

- Ensure the question and outcomes are important for patients and the public
- Deal with specific issues and questions as they arise, for example questions about the specific illness or condition or the findings of the review.

“The presentations and design of the materials took great care to unravel the complex world of research acronyms and concepts and explain complex ideas simply but without dumbing down. That made me feel that we were equal partners in a really important piece of work...Attending the conference with senior practitioners from all over the world was a very memorable experience for me. Understanding their priorities and their perspective on cancer treatment was very revealing and made the work with patient partners all the more essential to help build a holistic picture of people living with cancer and their needs... It’s a good feeling from a patient perspective to have contributed to a piece of work which recognises the after effects of treatment and survivorship issues.”

**Nicolette Spera,**

a patient research partner in the Medical Research Council (MRC) Clinical Trials Unit systematic review in cervical cancer

“We worried about getting it right – what we were going to be able to talk about and pitching things correctly, but we built up a relationship with the research partners that led to open and informative discussions.”

**Jayne Tierney**

Meta-analysis Group, MRC Clinical Trials Unit

### **Patient involvement in a systematic review in cervical cancer**

We conducted a systematic review and meta-analysis collecting individual patient data (IPD) from trials comparing radiotherapy-based treatments in cervical cancer. We knew that there were survivorship issues for women and were keen to learn more from patients about these key issues. Only one of the five women we recruited knew about systematic reviews, so we developed information to help them, and constantly improved and added to it from their comments and feedback.

We didn't have any prior experience of working with patients, so we were concerned initially about whether the women might be unwell. We were also unsure what their expectations were, how to meet their expectations and to ensure that the involvement was not tokenistic.

We explained at the beginning of the study that it might not be possible to answer questions about issues such as long term side effects, or sexual function because we didn't know whether the trials had collected the data. If we hadn't, it could have been disappointing because in the end, the data was not available.

An IPD review is a long process and we probably hadn't given the women enough warning up front! By the end there were only three members of the group still involved who had seen the entire project through. The group worked really well together, held together by good communications. Our efforts led to a second piece of research, related to the original work and from that a paper was published in all of our names.

**Reference:** Vale C et al, Evaluation of patient involvement in a systematic review and meta-analysis of individual patient data in cervical cancer treatment. *Systematic reviews* (2012) 1:23

[www.systematicreviewsjournal.com/content/pdf/2046-4053-1-23.pdf](http://www.systematicreviewsjournal.com/content/pdf/2046-4053-1-23.pdf)

### **Public involvement in a systematic review at the Centre for Reviews and Dissemination, University of York**

Some review topics can generate large amounts of public interest, for example because of the availability of specific treatments or services or where the evidence base is contested either clinically or politically. For these reviews, it can be important to put mechanisms in place to handle the enquiries and / or to promote the trustworthiness of the review team from the outset.

One such review about water fluoridation was conducted by the Centre for Reviews and Dissemination (CRD). It was a controversial and highly politicised issue, so researchers at CRD tried to ensure that the review process was as open and transparent as possible. They set up an advisory panel, including members of the public, to oversee the conduct of the review and to ensure that the full spectrum of views were represented.

A dedicated website ([www.york.ac.uk/inst/crd/fluorid.htm](http://www.york.ac.uk/inst/crd/fluorid.htm)) provided information about all aspects of the review. It gave interested groups and members of the public open access to the process of the review and gave them the opportunity to contact CRD to comment or provide additional information, which could be relevant to the review. Throughout the review, progress and interim findings were published on the site and a large number of enquiries and submissions of potentially relevant evidence were received.

**Social Care Institute for Excellence (SCIE) Research resource 02: Collection of examples of service user and carer participation in systematic reviews**

This resource published by SCIE outlines three examples of public involvement in different aspects of the systematic review process. In the first example service users were the lead researchers in a systematic review of consumers' perspectives on electro-convulsive therapy (ECT). In this review, service users led the systematic synthesis of the research on consumer perspectives. The project advisory group also included service users.

In the second example service user organisations were involved in the project advisory group for a systematic review concerned with HIV prevention in men who have sex with men.

The third example looked at public involvement in a piece of work to develop evidence based policy in the National Newborn Screening Programme. Public involvement was mostly concerned with the interpretation of the review findings and the development of associated guidance. [www.scie.org.uk/publications/researchresources/rr02.asp](http://www.scie.org.uk/publications/researchresources/rr02.asp)

**User involvement in the design and undertaking of nursing, midwifery and health visiting research (PIN)**

This systematic review funded by the National Institute for Health Research (NIHR) set up a service user reference group to support their work.

The aim of the group was to :

- connect the project with specific service user issues and perspectives
- influence the project by contributing to developing priorities and principles
- be critical, challenging and stimulating
- advise on the best ways of disseminating findings through different networks

[www.netscc.ac.uk/hsdr/projdetails.php?ref=08-1305-069](http://www.netscc.ac.uk/hsdr/projdetails.php?ref=08-1305-069)

## 2. Involvement across a group of systematic reviews

Public involvement in systematic reviews can also take place at a programme level, for example the programme of reviews undertaken through a Cochrane Review Group [www.cochrane.org/about-us/get-involved](http://www.cochrane.org/about-us/get-involved).

This can often result in reviewers becoming more aware of the breadth of expertise of those involved over time and may also increase the impact of involvement and reduce 'teething' problems that can arise in a one off situation or early on.

### Public involvement helps to:

- develop involvement across a coherent programme of systematic reviews in a given area
- draw on the experiences and expertise of people who best understand the condition/topic covered by the reviews
- ensure that the reviews address relevant outcomes and provide clear information
- ensure involvement throughout the review process
- provide opportunities for people to develop more strategic roles within the review programme as they become more experienced, for example influencing the design of new reviews or becoming co-applicants on review grants.

### Potential challenges

- Relying on the same group of members of the public who are easily accessible rather than widening involvement
- Creating a large workload or burden for individuals to take on especially if they have long term or serious health conditions
- Members of the public becoming professionalised, which some people think may make them less able to represent an 'authentic' lay view. However, people who have involved the public in this way find that these 'professionalised members of the public' provide really helpful input as while their understanding of the process of systematic reviewing grows they generally keep their valuable public perspective.



## Consumer involvement in the Cochrane Pregnancy and Childbirth Group

I was invited to set up a Consumer Panel with the Cochrane Pregnancy and Childbirth Group. We asked consumers to comment as referees on both the protocol, and then again on the full systematic review, prior to publication in The Cochrane Library. Comments from consumers were dealt with alongside those from clinicians and researchers. In the Consumer Panel model, I circulated the title and invited consumers to comment, providing them with guidelines and a checklist. Consumers only commented when they had an interest in the topic and the time to contribute. We gave them three weeks, and I then collated and summarised the comments from the consumers who contributed, so that just one feedback form was submitted from the consumer referees to the editorial office. I also sent a copy of the feedback to the consumers who contributed. I provided help and support by email, and the Cochrane Collaboration provided training in terms of workshops and further support materials. We found that this process was highly valued by both the editors and consumers.

**Gill Gyte**, Consumer Editor with the Cochrane Pregnancy and Childbirth Group and former coordinator of the Cochrane Pregnancy and Childbirth Group Consumer Panel.

“I have been enormously impressed by the quality of feedback... for example sensitising language, fuller clearer background, addressing issues of importance to women / couples ... I think the panel is doing a really, really good job.”

**Coordinating Editor,**

Cochrane Pregnancy and Childbirth Group,  
describing the input of the Consumer Panel

“One of the problems for Cochrane consumers is working in isolation, often with people in different countries. In the review I am currently working on for the Cochrane Skin Group, the lead is based in the US but has taken the trouble to telephone all members of the team personally to establish contact.”

**Rosemary Humphreys**

a Consumer in the Cochrane Skin Group  
<http://skin.cochrane.org/get-involved>

### 3. Involvement at a unit level

There are examples of public involvement within large research groups or department that specialise in conducting systematic reviews. These groups will also conduct other related research and so this type of involvement may lead to public involvement across the breadth of research activities.

#### Public involvement will help to:

- ensure a consistent or strategic approach across a unit or departments
- develop public involvement in a broad range of review activities
- coordinate the approach to involvement across reviews
- lead to public involvement at the earliest stages of reviews
- support researchers and the public involved in conducting systematic reviews – ensuring individuals are not isolated
- facilitate quick responses to specific issues – drawing on existing expertise and skills of involved people.

#### Potential challenges

- Championing public involvement at a potentially high / strategic level in a large organisation or department.
- Losing experiences of a specific disease or subject area if not also involving people in individual reviews.
- Relying upon a small group of individuals for a wide variety of reviews therefore restricting new ideas.
- Expecting a large commitment of time and input.

#### Patient and Public Involvement Programme at National Institute for Health and Clinical Excellence (NICE)

NICE is committed to involving patients, carers and the public in the development of its guidance and other products. By involving the people for whom the guidance is intended, the needs and preferences of patients and the public, and the organisations who represent their interests, are included at all levels of the organisation and at all stages of guidance development. Patients and the public have the opportunity to join the groups and committees that develop NICE guidance, to provide commentary on all draft scopes and products, and to help put the guidance into practice – [www.nice.org.uk/getinvolved/patientsandpublic](http://www.nice.org.uk/getinvolved/patientsandpublic).

Patients, carers and the public have been able to offer unique insights which have supported the development of NICE guidance. These include: providing new data previously unidentified in research studies, identifying outcomes of importance to lay people, challenging professional and researcher assumptions about what people want to achieve from treatment and care, specifying patients' preferences where treatment options exist, and providing information on people's information and support needs. NICE clinical guidance is produced in versions specifically designed for patients, carers and the public - [www.nice.org.uk/patientsandpublic/index.jsp](http://www.nice.org.uk/patientsandpublic/index.jsp).

“Each person had their own personal story and motive for wanting to be on the group. This led to a sense of connectedness and commonality of purpose which I found really affirming. People's personal stories resonated with me and bridged the gap between the lay members and professionals. This made me feel comfortable about opening up and sharing my own experiences which increased my self-confidence and self esteem.”

**A lay member involved in the NICE programme**

### **Cochrane Consumer Network**

Although local Cochrane Centres support consumers and review groups by providing linguistic and geographic support, the Cochrane Consumer Network (CCNet) was also set up to strengthen local partnerships and to further support consumers in a number of ways.

For example, one Cochrane Centre worked in partnership with CCNet to provide a solution for consumers to customise the content of systematic reviews for the local population.

Another example is a recent collaboration between CCNet and the Canadian Cochrane Center (CCC). The CCC provides training for consumers and authors to better participate in the review process and improve the quality of plain language summaries of Cochrane systematic reviews. The CCC is also working with CCNet to help make evidence-based healthcare available to everyone. Working with consumers in three languages (English, French and Spanish) and three continents (North America, South America and Europe) they are developing guidance to help overcome the challenges of translating technical reviews into plain language and of reaching a multi-lingual population. <http://consumers.cochrane.org/>

“Most of the Collaboration’s authors are well aware of the benefits of patient integration in the review process. The Cochrane Consumer Network provides support to patients and review groups in order to encourage more consistent consumer involvement throughout the systematic review process.”

**Catherine McIlwain**  
of the Cochrane Collaboration

# Useful reading and resources

## Public involvement in systematic reviews

### Information from the Evaluation of patient involvement in a systematic review and meta-analysis of individual patient data in cervical cancer treatment project:

- advert from the IPDMA in cervix cancer [www.invo.org.uk/wp-content/uploads/2012/10/cancervoicesad.pdf](http://www.invo.org.uk/wp-content/uploads/2012/10/cancervoicesad.pdf)
- job description from the IPDMA in cervix cancer [www.systematicreviewsjournal.com/imedia/4539356606605075/supp1.doc](http://www.systematicreviewsjournal.com/imedia/4539356606605075/supp1.doc)
- information folder from the IPDMA in cervix cancer [www.systematicreviewsjournal.com/imedia/5981095436605075/supp2.doc](http://www.systematicreviewsjournal.com/imedia/5981095436605075/supp2.doc)

### Bandolier's 'what is' series of leaflets.

[www.medicine.ox.ac.uk](http://www.medicine.ox.ac.uk)

The leaflet on systematic reviews can be found here [www.medicine.ox.ac.uk/bandolier/painres/download/whatis/Syst-review](http://www.medicine.ox.ac.uk/bandolier/painres/download/whatis/Syst-review)

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)

Brett, J., Staniszewska, S., Mockford, C., Seers, K., Herron-Marx, S. and Bayliss, H. (2010) **The PIRICOM Study: A systematic review of the conceptualisation, measurement, impact and outcomes of patients and public involvement in health and social care research.** London: UKCRC [www.ukcrc.org/patientsandpublic/ppi/understandingppi/](http://www.ukcrc.org/patientsandpublic/ppi/understandingppi/)

Horey, D. (2010) Consumer involvement in Cochrane Collaboration

- Executive summary: [http://consumers.cochrane.org/sites/consumers.cochrane.org/files/uploads/Consumer%20Involvement%20in%20the%20Cochrane%20Collaboration%20Executive%20Summary\\_10Mar2010%20\\_final.pdf](http://consumers.cochrane.org/sites/consumers.cochrane.org/files/uploads/Consumer%20Involvement%20in%20the%20Cochrane%20Collaboration%20Executive%20Summary_10Mar2010%20_final.pdf)
- Background paper: <http://consumers.cochrane.org/sites/consumers.cochrane.org/files/uploads/Consumer%20Involvement%20in%20the%20Cochrane%20Collaboration%20Background%20paper.pdf>
- Appendices: <http://consumers.cochrane.org/sites/consumers.cochrane.org/files/uploads/Consumer%20Involvement%20in%20the%20Cochrane%20Collaboration%20Appendices.pdf>

Kreis, J., Puhan, M. A., Schünemann, H. J. and Dickersin, K. (2012), Consumer involvement in systematic reviews of comparative effectiveness research.

**Health Expectations**. doi: 10.1111/j.1369-7625.2011.00722.x

[www.ncbi.nlm.nih.gov/pubmed/22390732](http://www.ncbi.nlm.nih.gov/pubmed/22390732)

Rees, R, Oliver, S. (2012) 'Stakeholder perspectives and participation in reviews', In: Gough D, Oliver S, Thomas J (eds) **An introduction to systematic reviews**, London: Sage Publications Ltd pages 17-34.

Sakala,C., Gyte, G., Henderson, S., Neilson, J., and Horey, D. (2001) Consumer-professional partnership to improve research: the experience of the Cochrane Collaboration's Pregnancy and Childbirth Group. **Birth**, volume 28, issue 2, pages 133- 137.

[www.ncbi.nlm.nih.gov/pubmed/11380386](http://www.ncbi.nlm.nih.gov/pubmed/11380386)

Shea, B., Santesso,N., Qualman, A., Heiberg, T., Leong , A., Judd, M., Robinson, V., Wells, G., Tugwell, P., and the Cochrane Musculoskeletal Consumer Group (2005). Consumer-driven health care: building partnerships in research. **Health Expectations**, volume 8, pages 352-359.

[www.ncbi.nlm.nih.gov/pubmed/16266423](http://www.ncbi.nlm.nih.gov/pubmed/16266423)

Smith, E., Ross, F., Donovan, S., Manthorpe, J., Brearley, S., Sitzia, J. and Beresford, P. (2008) Service user involvement in nursing, midwifery and health visiting research: a review of evidence and practice. **International Journal of Nursing Studies**, volume 45, issue 2, pages 298 – 315.

[www.ncbi.nlm.nih.gov/pubmed/17161402](http://www.ncbi.nlm.nih.gov/pubmed/17161402)

Smith, E., Donovan, S., Beresford, P., Manthorpe, J., Brearley, S., Sitzia, J. and Ross, F. (2009) Getting ready for user involvement in a systematic review. **Health Expectations**, volume 12, issue 2, pages 197–208.

[www.ncbi.nlm.nih.gov/pubmed/19236632](http://www.ncbi.nlm.nih.gov/pubmed/19236632)

Social Care Institute for Excellence (SCIE) Research resource 02: **Collection of examples of service user and carer participation in systematic reviews**

[www.scie.org.uk/publications/researchresources/rr02.asp](http://www.scie.org.uk/publications/researchresources/rr02.asp)

# Organisations

## The Cochrane Collaboration

[www.cochrane.org/](http://www.cochrane.org/)

## Cochrane Consumer Learning

<http://consumers.cochrane.org/cochrane-consumer-learning/>

## Understanding Evidence-based Healthcare: A Foundation for Action:

This web course has been created by the United States Cochrane Center as part of a project undertaken by Consumers United for Evidence-based Healthcare (CUE), and is designed to help consumer advocates understand the fundamentals of evidence-based healthcare concepts and skills. Registration is open and free of charge. <http://us.cochrane.org/understanding-evidence-based-healthcare-foundation-action>

## Cochrane Canada Live Webinars

<http://ccnc.cochrane.org/cochrane-canada-live-webinars>

## A selection of presentations from the Cochrane 2011 Conference:

<http://consumers.cochrane.org/presentations>

- Liabo, K. (2011). **Young People's Involvement in a Systematic Review.** Presented at the 19th Cochrane Colloquium; Madrid Spain, October 2011. <http://consumers.cochrane.org/sites/consumers.cochrane.org/files/uploads/Liabo-Young%20People%27s%20involvement%20in%20a%20systematic%20review.pdf>

- Liabo, K., Rees, R., Stewart, R., Oliver, S. (2011). **Methods for Involving Consumers in Systematic Reviews.** Presented at the 19th Cochrane Colloquium; Madrid Spain, October 2011. <http://consumers.cochrane.org/sites/consumers.cochrane.org/files/uploads/Liabo-methods%20for%20involving%20consumers%20in%20systematic%20reviews.pdf>

- McIlwain, C. (2011). **Involving Consumers in Systematic Reviews.** Presented at the Annual UK and Ireland-based Contributors Meeting, March 2011. <http://consumers.cochrane.org/presentations>

## The Evidence for Policy and Practice Information and Co-ordinating Centre (EPPI Centre)

<http://eppi.ioe.ac.uk/cms/Default.aspx?tabid=169&language=en-US>

## National Institute for Health Research (NIHR) Systematic review programmes

[www.nihr.ac.uk/research/Pages/Systematic\\_Reviews.aspx](http://www.nihr.ac.uk/research/Pages/Systematic_Reviews.aspx)

# Public involvement in research resources

## **INVOLVE Briefing notes for researchers: public involvement in NHS, public health and social care research. INVOLVE 2012**

[www.invo.org.uk/resource-centre/resource-for-researchers](http://www.invo.org.uk/resource-centre/resource-for-researchers)

## **Public involvement in clinical trials: Supplement to the briefing notes for researchers INVOLVE 2012**

[www.invo.org.uk/resource-centre/resource-for-researchers/browse/?content=Supplement](http://www.invo.org.uk/resource-centre/resource-for-researchers/browse/?content=Supplement)

Other titles in the series of supplements to the briefing notes:

- different ways of involving members of the public in research
- how to find people to involve in research
- strategies for diversity and inclusion

## **Staley, K., (2009) Exploring Impact: Public involvement in NHS, public health and social care research, INVOLVE, Eastleigh**

[www.invo.org.uk/posttypepublication/exploring-impact-public-involvement-in-nhs-public-health-and-social-care-research](http://www.invo.org.uk/posttypepublication/exploring-impact-public-involvement-in-nhs-public-health-and-social-care-research)

## **Patient and public involvement in research and research ethics review. Joint INVOLVE and National Research Ethics Service (NRES) statement 2009**

[www.invo.org.uk/resource-centre/publications-by-involve](http://www.invo.org.uk/resource-centre/publications-by-involve)

## **INVOLVE Evidence library – an online database of references on the impact, nature and extent of public involvement in research**

[www.invo.org.uk/resource-centre/evidence-library](http://www.invo.org.uk/resource-centre/evidence-library)

## **INVOLVE Putting it into Practice database – an online database of references of reports and articles on guidance and the practice of public involvement in research**

[www.invo.org.uk/resource-centre/putting-it-into-practice-database](http://www.invo.org.uk/resource-centre/putting-it-into-practice-database)

## **Involving Users in the Research process – leaflet produced by Guy's and St. Thomas' and King's College London Biomedical Research Centre**

[www.involvinglondon.co.uk/RDSPPI/media/PPI-PDFs/A-how-to-guide-for-researchers.pdf](http://www.involvinglondon.co.uk/RDSPPI/media/PPI-PDFs/A-how-to-guide-for-researchers.pdf)

## **People in Research – resource to help members of the public find opportunities to get involved in research and for research organisations / researchers to advertise involvement opportunities.**

[www.peopleinresearch.org](http://www.peopleinresearch.org)

For further information and resources on public involvement in research please visit the resource centre on the INVOLVE website  
(see [www.invo.org.uk/resource-centre](http://www.invo.org.uk/resource-centre))

## The following people were involved in the development of this publication:

**Gill Gyte** has been the Consumer Panel Coordinator for the Cochrane Pregnancy and Childbirth Group since 1997 bringing women's views to the Cochrane reviews in that group. She has also worked with the Cochrane Infectious Diseases Group and Consumer Network and was also a member of the Cochrane Collaboration Steering Committee. She has been a consumer representative on two National Institute for Health and Clinical Excellence (NICE) guidelines and one World Health Organisation (WHO) guideline. Gill is currently the Consumer Editor with the Cochrane Pregnancy and Childbirth Group.

**Bec Hanley** has worked for 15 years to promote and support patient and public involvement (PPI) in research. She has a particular interest in clinical trials, and works as an adviser to the Medical Research Council (MRC) Clinical Trials Unit on PPI. She is Co-Director of TwoCan Associates, which helps voluntary and statutory organisations involve people who use services in their work, through which she has have carried out a wide range of projects, including: Development of guidance for PPI for the Research for Patient Benefit Programme; evaluations of PPI for the UK Clinical Research Collaboration and providing training and support for PPI for the National Institute for Health Research (NIHR) Clinical Research Network Coordinating Centre (CRNCC) and INVOLVE.

**Rosemary Humphreys** has had long-term involvement with the National Eczema Society and the Cochrane Skin Group, where she has peer-reviewed protocols and reviews and been a consumer member of review teams. She was a member of Folk.us, a user involvement organisation in Devon. In 2003, she joined the Royal College of GPs Patient Partnership Group and represented it on the College's research committees. From 2007 -2010 she was a Patient/Public member of the South East Coast Research for Patient Benefit (RfPB) regional funding committee.

**Catherine McIlwain** is the Cochrane Consumer Coordinator, responsible for supporting consumers and promoting consumer involvement in The Cochrane Collaboration. She has a Masters Degree in Public Health from Tulane University, New Orleans, and spent many years conducting consumer research in behavioural health. Catherine is now working with the Cochrane Consumer Network and Cochrane review groups to integrate consumer participation into the review process.

**Jennie Popay** is Professor of Sociology and Public Health at Lancaster University where she does research on health inequalities. She is also the Director of Health R&D North West. She has a particular interest in developing the role of qualitative research in public health and has developed methods for the review of qualitative research and mixed method studies. She was founding convenor of the Cochrane Collaboration Qualitative Research Methods Group. She is currently producing guidance on approaches to assessing the impact of public involvement in research.

**Nicolette Spera** is the Volunteering Programme Manager at Macmillan Cancer Support. Since 2004, she has been involved as a Patient Research Partner in a systematic review of treatments for cervical cancer, working with a team at the MRC Clinical Trials Unit.



**Lesley Stewart** is the Director of the Centre for Reviews and Dissemination, University of York and an National Institute for Health Research (NIHR) Senior Investigator. Lesley has been involved in evidence synthesis in healthcare since the late 1980's, previously running the Medical Research Council (MRC) Clinical Trials Unit meta-analysis research programme. Together with colleagues in Cambridge and Oxford, she helped establish the methodology and framework for individual patient data (IPD) reviews and was a founding member of the Cochrane Collaboration. She is a member of the NIHR Reviews Infrastructure Advisory Group and is also Co-Editor in Chief of the journal Systematic Reviews.

**Victoria Thomas** is the Associate Director of the Patient and Public Involvement Programme at the National Institute for Health and Clinical Excellence (NICE). Victoria has worked for NICE since 2001 and has a long-standing interest in patient involvement in healthcare quality improvement activities.

**Claire Vale** is a Senior Research Scientist in the Meta-analysis Group at the Medical Research Council (MRC) Clinical Trials Unit where she has been involved in systematic reviews and meta-analyses in cancer treatments for the last 10 years. She has recently led a project involving a group of women in a systematic review of treatment for cervical cancer. Claire currently chairs the Consumer Involvement Group at the MRC Clinical Trials Unit, where she has been involved in developing advice and guidance on involving consumers in trials.

**This supplement should be referenced as:** INVOLVE (2012) Public involvement in systematic reviews: Supplement to the briefing notes for researchers. INVOLVE, Eastleigh

© **INVOLVE October 2012**

This publication is the copyright of INVOLVE. We are happy for our materials to be downloaded, printed out, copied, used or distributed free of charge for non-commercial purposes. Where our materials are copied, used or distributed, the source of the material must be identified and the copyright status acknowledged. No alteration or adaptation of any of the materials may be made without obtaining the permission of INVOLVE. Reproduction or distribution of materials either in whole or in part for a commercial purpose is prohibited without the prior written permission of INVOLVE.

Supporting public involvement  
in NHS, public health and  
social care research



# INVOLVE

INVOLVE is a national advisory body that is funded by the National Institute for Health Research to support public involvement in NHS, public health and social care research and development.

If you would like to know more about what we do, please contact us:

## INVOLVE

Wessex House  
Upper Market Street  
Eastleigh  
Hampshire  
SO50 9FD

Web: [www.invo.org.uk](http://www.invo.org.uk)  
Email: [admin@invo.org.uk](mailto:admin@invo.org.uk)  
Telephone: 02380 651088  
Textphone: 02380 626239

If you need a copy of this publication in another format please contact us at INVOLVE.

Email: [admin@invo.org.uk](mailto:admin@invo.org.uk)  
Telephone: **02380 651088**  
Textphone: **02380 626239**

This publication is also  
available to download from:

**[www.invo.org.uk](http://www.invo.org.uk)**