Draft standards for good practice in public involvement in research

Summary

About:	*This resource provides an overview of recommendations about good practice in public involvement in research from a range of existing guidelines and recommendations*
What:	*29 standards regarding good practice in public involvement in research along with recommendations collated from existing guidelines along with recommendations are identified*
Who:	*For people who would like guidance on good practice in public involvement in research*
How:	*The resource provides a brief introduction to the standards. The standards are divided into sections that relate to the beginning, middle and ending of public involvement*

Background

The following draft standards have been developed as part of a research project funded by the Medical Research Council to develop the Public Involvement Impact Assessment Framework (PiiAF) to support researchers in assessing the impact of public involvement in their research. The research to develop PiiAF was carried out by researchers and members of the public attached to the Universities of Lancaster, Liverpool and Exeter.

The draft standards for good practice in public involvement in research are drawn from published recommendations and guidelines on best practice in the conduct of public involvement. The standards are intended to identify ways of maximising impacts that are perceived to be positive and to avoid adverse effects. Unlike the PiiAF and associated guidance the focus of the draft standards is on the 'doing' of public involvement rather than on assessing its impact. We anticipate that the standards will be applicable across a wide range of research contexts and approaches to public involvement.

Introduction

The growing importance of public involvement in health and social care research has seen a growth in the production of guidance advising people about how best to achieve it effectively. From an

informal review we identified 20 guidelines that offer such advice. Most of the guidelines we examined had a generic focus but some discussed the involvement of specific populations: e.g. young people with learning difficulties, carers, family members and close friends of service users, nurses. Some guidelines focused upon specific research areas such as mental health, or upon different methods of research: user-controlled, lay review, clinical research collaboration. We also collated the recommendations, guidelines, checklists developed in 6 systematic reviews (Baxter 2001, p. 102-111; Brett 2010, p. 46; Doel 2007, p. 50; Rose 2002, p. 115-117; Smith 2008, p. 147-8; Staley 2009, p. 86).

Most of the guidelines we looked at were developed by consulting people with experience of or expertise in public involvement using workshops, focus groups or interviews. A small number of guidelines were developed from audits or evaluations of public involvement activity, whilst others were derived from literature reviews. Some of the guidelines used some of these methods in combination.

These draft standards are aimed at people who are concerned with the planning, organisation and conduct of public involvement. In many cases that will be academic, clinical or professional researchers as well as public involvement facilitators but we hope these draft standards will also be of interest to those beyond the academic research community.

Principles

We identified eight principles underpinning the draft standards as part of our review of published guidelines and recommendation. The principles (below) are considered to be of equal importance:

- Commitment to high quality and meaningful public involvement
- Accessibility
- Respect and Trust
- Flexibility
- Adequate and sustainable resourcing of public involvement
- Valuing different kinds of knowledge
- Clarity
- Diversity

We are using the term 'principle' in this context to mean a general rule or belief that underpins approaches to public involvement that will maximise impacts perceived to be positive. The principles are described briefly below. On the other hand, the draft standards reported in table 1 (page 5),

represent an attempt to articulate specific actions and ways of achieving them that should be underpinned by the principles above.

Commitment to high-quality and meaningful public involvement:

Existing guidelines emphasise the importance of ensuring that good quality public involvement is undertaken so that public involvement can influence and add value to the research and avoid being tokenistic (10, 22). Quality can be defined in various ways with some authors arguing that it means creativity, listening, learning from each other and bringing about change (15). It can also mean demonstrating good practice in public involvement and effective reporting, so that others are encouraged to undertake good quality public involvement (19).

Accessibility

Meaningful and good quality public involvement is underpinned by a commitment to accessibility. This means ensuring cultural accessibility (16) as well as access to research processes, materials, meetings, information, resources etc. (11). Some members of the public might have specific physical or mental health issues that could appear to challenge existing arrangements for accessibility so research teams need to consider how they can address this (8, 22).

Respect and Trust

Mutual respect and trust are essential for effective public involvement (5, 9, 14, 21, 27).When public involvement works well it enhances relationships and increases mutual respect and trust (21). For some guidelines respect means valuing the skills, knowledge and experience that members of the public bring to a research study (23). For others it means allowing different views to be expressed and considered (11).

Flexibility

In order for public involvement to have a meaningful influence on the research, research teams should be prepared to be flexible. Flexibility should be built into research processes and structures (6, 11, 12, 15, 21, 22). Funding bodies might also think about how they can be flexible in order to allow for any changes that might occur during the research process as a result of public involvement (21).

Adequate and sustainable resourcing of public involvement

A number of sources describe the importance of having adequate and sustainable resources (3, 13,

15, 22) for public involvement in research to be successful (5). This includes the budget, the additional time required to involve the public in research as well as making sure that research teams have applied for funding to involve the public in the research (1, 20). Responsibility for providing adequate funding also lies with project funders who should think about how they can ensure that the project is adequately resourced, so that everyone involved can be offered payment for their time and expertise, and that members of the public can be involved from the outset to the conclusion of the project (8).

Valuing different kinds of knowledge

One guideline called for lay and professional knowledge to be valued equally (31). At the very least research teams should respect the differing skills, knowledge and experience of public representatives (2, 23) and be committed to listen to the experiences of a range of people, including those whose voices are not often heard (8, 9).

Clarity

Ensuring that there is a shared understanding about the purpose and aims of the research and its public involvement has been reported to be crucial for effective public involvement (4, 8, 9, 16, 19). All stakeholders should be able to clearly define what is meant by public involvement in the research project (21).

Diversity

There are many different black and ethnic minority communities many of whom are still under-represented in research (8). Researchers should also think about diversity in terms of gender, sexuality, mental health diagnosis, physical disability (12), age and class. Whilst some research teams might deliberately focus upon involving under-represented and/or groups within communities that may have been under-represented (8), all researchers should think about whether their approach to public involvement will allow them to hear the broad range of different views and experiences (20).

The Draft Standards

Table one below contains the draft standards identified from a review of published guidelines along with some relevant recommendations. The draft standards are divided into three sections:

- Beginning involvement
- Maintaining involvement
- Ending involvement

to reflect the chronology of involvement. It is worth pointing out however that many of the guidelines agree that public involvement in practice should be an on-going process that happens through long-term relationships.

Table 1: The draft standards for good practice in public involvement in health and social care research

Beginning public involvement	
Standard	**Recommendations**
Understand the reasons for involving members of the public in the research project	- Think about why and how public involvement should happen in the project and have a clear understanding of this (3, 12) - All team members should understand the reasons for public involvement in the project (4, 19) - Members of the public should know why they want to get involved (12)
Involve members of the public as early as possible	- Think about involving members of the public as soon as possible in both planning for the project and in the project itself (4, 5, 6, 9, 10, 13, 15, 18, 20) - The earlier the involvement happens the easier it is to make changes in response to public involvement and to maximise its impact (18) - If you are not able to have public involvement at the start be clear about why not and also about what can and cannot be influenced as a result(6) - Don't be put off if public involvement does not take place at the beginning –it is never too late (10)
Ensure sufficient and dedicated budget & resources for public involvement in the research	- You need to make sure that you have sufficient and dedicated resources for public involvement (1, 3, 5, 8, 11, 13, 15 19, 20, 22, 23, 24, 25), as it is very difficult to obtain funding for public involvement if it has not been part of your original research proposal (20) - Budget for the additional costs that may be associated with public involvement in research (4), for example your budget should cover a commitment to the draft standards (below) of ensuring appropriate remuneration to members of the public for their involvement, training and support - It helps if project funders are committed to resourcing public involvement fully and over the long term, so that involvement can take place throughout the project and appropriate payment can be offered (8), although you probably have little control over this - See box 2 below for information about the kinds of things you might need to budget for
Recruit members of the public with the right skills and experiences for the project involved	- Be clear about what skills and experience the project will need from members of the public (6, 13, 18) - One size does not fit all – match public involvement to the purpose of the research for example by working with members of the public to find out about their skills and resources (5, 10, 17) - Think about how to involve members of the public who have different kinds of knowledge, experiences and skills, perhaps at different stages of the project or through different forms of involvement (6, 18)
Ensure that expectations are clearly communicated	- Make sure that you know what you expect from members of the public and what members of the public can expect from the research team (11, 17, 18, 20) - Provide information about expectations in writing (11)

and addressed	• Ensure that all stakeholders understand what members of the public can and cannot do (4, 13) • Advise members of the public about the scope of the work and time commitment/ travel requirements (17) so that they can judge whether they will be able to devote the right amount of time to the project (3, 7) • Make it clear what the involvement of members of the public will contribute to the research project (13) • The approach to public involvement adopted in the study and its aims should be clearly articulated and known to all (11, 18, 19, 21)
Involve members of the public in deciding how they will be involved	• Public involvement is less likely to be tokenistic and more likely to add value to the research if members of the public have a say in how they will be involved (9, 10) • Be aware that how people want to be involved might change over time or that members of the public might not know how they want to be involved (17)
Ensure that all stakeholders have a shared understanding of the research project	• Public involvement is more likely to have a positive impact if all members of the project team have a shared understanding about the purpose of the research (8) • A shared understanding includes being clear about the aims and nature of the project (6)
Effective selection and recruitment of members of the public to be involved in the research	• Think about how you will select and recruit members of the public to be involved in the research (13) • Selection processes should be transparent (3) • A minimum of 2 members of the public should be involved (5, 17, 20) so that the pressure is removed from one person and absences including sickness or holidays can be covered
Ensure appropriate diversity	• The diversity of members of the public involved should reflect the nature of the research project itself or the population being studied (11, 12) • Researchers should take into account the diversity of the target population if building capacity among members of the public (12)
Attend to the potential ethical issues that might be associated with public involvement in research	• There are a number of ethical issues that you need to think about when involving members of the public. Although you will probably need ethics clearance for your research project, ethics clearance is not always needed for public involvement – see Box 1 below for a summary • Finding out if your project needs the approval of your local Research Ethics Committee will most likely require time and extra resources (6, 21) • If you want to involve members of the public with whom you have a pre-existing clinical relationship, consider how appropriate this is and how involvement might affect this relationship (11) • Parental consent is needed if young people under the age of 16 are involved – but you should also obtain the consent of the young person as well (13) • Make sure that members of the public know that they can stop their involvement at any time (20) • Make sure that everyone is clear about what is meant by confidentiality with reference to any data that is collected and also to discussions that take place within the project team (6)
Establish clearly defined and agreed	• Positive impacts of public involvement are more likely when all members of the project are clear about and have agreed their roles and responsibilities (1, 6, 12, 23)

upon roles	• You could think about making this information available in writing including role descriptions and terms of reference for steering groups etc. (12, 20, 27)
Assessing the impact of public involvement in research	• When planning the project consider how you will assess the impact of public involvement (19)

Maintaining public involvement	
Ensure that public involvement has an influence on the research	• How will you ensure that the views and contributions of members of the public will influence the research project? • It will be difficult for members of the public to significantly influence the research design once a project has received funding and ethics approval (18) • Building flexibility into the planning process might help to accommodate suggestions of all team members and to implement negotiated decisions (11, 18) • Involve members of the public meaningfully in as many stages of the project as possible (17) e.g. members of the public could be involved in recruitment decisions (20) • Research teams and research structures and processes should encourage diverse views to be expressed and considered (11, 18), for example members of the public should feel able to challenge processes and decisions if they are unhappy with the direction the project is taking (5) • Research teams should be willing or able to change plans and to try to resolve divergent views (11, 18) • Ensure members of the public are, and feel , listened to and know how they have influenced the research (18)
Build effective relationships with members of the public involved in the research	• Think about how you will build relationships with members of the public involved in the research • Adopt an inclusive and collaborative approach (18) • Members of the public should feel welcomed, included (2, 5) and that their skills and knowledge are valued (1) • Make sure that all members of the project team know that the perspectives of members of the public are valued (2) • Encourage mutual trust and respect (10, 12, 14, 18) but be careful not to be over-protective (18) • Members of the public should be treated as equals (2, 18) • Ensure all research team members are respectful in terms of the language they use and their general attitudes (12, 18) • Public involvement is more likely to be effective where researchers are committed to sharing power and control with members of the public (8) • Be aware of and address the different types of power held by members of the public and researchers in the research process (8)
Prepare to be flexible and responsive	• Think about how you could build flexibility into the project from the start (6, 12): it helps if structures and processes are flexible and responsive to individual needs (22) • Be flexible with regard to time and timelines, resources, support and working practices (6, 12) although external deadlines and processes mean that this might not always be possible • Prepare for the possibility that members of the public might need to spend some time away from the project (6, 12)

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Take into account the increased time that public involvement takes	• Involving members of the public in a way that will increase the likelihood of positive impacts might take a longer time than you'd planned for (8, 20, 21, 23, 25, 27, 29)
	• Make sure that members of the public know the amount of time they will be expected to commit to the project (20)
	• You might need increased timelines for:
	    o Making contact with and recruiting members of the public (20)
	    o Additional training and support (20)
	    o Negotiation and discussion of roles (20)
	    o Arranging meetings at a time that is accessible to all (20)
	• Make sure you allow enough time for members of the public to engage with any relevant documents prior to a meeting (20)
	• If appropriate allow enough time between meetings for members of the public to consult with others (7)
	• Research funders should take into account the amount of extra time associated with involving members of the public in research and be flexible (21)

Ensure that the research process is accessible	• There are different ways in which you could make the research process accessible to members of the public (8, 11, 16, 18, 20) • Find out about access needs at the start of the project (12) • Think about how you could facilitate equal access to the research process (16) • Language - use plain language and avoid jargon (8, 18, 12); avoid abbreviations and/or provide a glossary of terms (11, 17) • Physical access - Make sure that meeting times are organised at suitable times and that venues are accessible (both physically and in terms of public transport) (11, 7, 18) • Make sure that members of the public have access to IT, libraries and printers etc. (11, 18) • Present materials in accessible formats (12, 18)
Think about the appropriate remuneration for public involvement and how you will achieve this	• As a minimum reimburse travel and other expenses (1, 4, 7, 17) • Ideally provide real payment (6, 15, 16, 17) • Make sure that members of the public know about what you are offering payment for and how they will be paid (7, 17) • You also need to be flexible about payment as it may not be wanted in some situations. You should be aware of any potential implications for the individual or the organisation (e.g. payment might affect benefits and tax payments) (6, 16, 20) – see box 3 below • Provide payments rapidly and appropriately (16, 17, 20) • Think about the range of non-financial incentives for being involved (6) including certificates, end of study party/event (17)
Provide appropriate training to all members of the project team	• Training should be offered (1, 3, 4, 6, 7, 8 , 12, 13, 17, 18, 20, 23, 27) and is more likely to ensure that public involvement will have a positive impact (22, 26) • Find out what training needs members of the public have (21) • Make sure members of the public know what training and support will be offered (17, 20) • Training should be offered to researchers (4, 8, 18, 20, 23) so that they have the necessary skills for public involvement (1)

	• Training should also be offered to members of the public to ensure that they can make a full contribution: e.g. to meetings; for capacity development and to minimise any potential harm associated with their involvement (2, 4, 8, 11, 17, 18, 20, 27) • Training should be flexible, carried out in comfortable surroundings, include refreshments and be adapted to the needs of individuals and to the project (6) • Introductory training should be offered (3) and include team-building, peer support and fun as well as focus on the wider context of the project and research (6) • Provide training in a way that's interesting and accessible and not long before it will be used so that it is relevant and useful(13)
Ensure appropriate levels of support are available	• Members of the public may not be used to asking for support so think about how you will find out about their support needs (11, 21) • Members of the public may need access to academic, practical, emotional, research-related or financial support (1, 2, 6, 11). Public involvement is more likely to have a positive impact with on-going support (28) • Recognise that members of the public may need to work in different ways and need different kinds of support to contribute effectively (18, 20) • Build in formal systems to provide emotional support if involvement could cause distress (18) • Involving at least two members of the public helps to avoid tokenism and provides an opportunity for mutual support (5,7)
Think about how you will communicate with members of the public	• Members of the public should be provided with information and updated on the project's progress including any problems or delays at all stages (1, 4, 15). How will you ensure this happens? • Keep everyone informed and involved by sharing information in language that everyone understands (10) • You could think about identifying a key person within the team that members of the public can contact – this should be an experienced member of the project team (4, 20). Make sure that members of the public know who the key communication contacts within the project are (17) • Plan for how you will communicate with members of the public about the project especially if they need time away from the project because of ill health (18)
Ensure good access to relevant information for members of the public	• Provide access to information that is not available to everyone (21). • Think about how you can ensure that members of the public have access to the information they need (e.g. online databases, library resources) (7, 21)
Ensure effective project management	• Good project management and leadership within a project makes effective public involvement more likely to happen (5) • Develop a strategy for public involvement that is widely owned but that is specific enough to co-ordinate action (19) • Develop a programme of work that will lead to quick wins and also to sustainable development in the long term (19) • Share your public involvement policies with members of the public involved (6) • Be patient and persevere when things are not going well (5)

	• Ensure that there is transparency in the project especially where politics are involved or if the project's resources need to be reduced (5, 14)
Champion Public Involvement • Within the project team • Beyond the project team	• People associated with the project should act as public involvement champions (5) • Demonstrate and model good practice in PI and disseminate your good practice (19) • Make the value and benefits of public involvement clear to all team members (2) • Ensure PI activity is visible and adds value to other activities (19)
Address organisational issues that might affect public involvement	• Sometimes you might need to work with others within your organisation who have little experience of public involvement (e.g. HR and finance departments) • Ensure you have senior level commitment to public involvement (19) • Build strategic alliances around public involvement within your organisation(19) • Try to prepare other stakeholders in your organisation so that their policy and practice is supportive of public involvement e.g. HR/Finance departments (18) • Develop positive strategies to challenge sceptics, for example demonstrate how public involvement can help organisations achieve their goals (19) • Clarify organisational responsibilities (20)
Ending public involvement	
Ensure that research findings are accessible	• The research findings should be available and accessible (1, 8) to all, but especially to the members of the public involved in the research (17)
Obtain feedback about how public involvement has happened within the project	• Obtain feedback from members of the public about their experiences of being involved so you can improve the involvement process in the future (4)
Acknowledge public involvement both to: • Members of the public involved in the research • The wider audience for the research	• Think about how you will document and record the public involvement in the research (20) • The involvement of members of the public should be acknowledged in reports, presentations and other published works (1,17) • Acknowledge the input from members of the public and provide feedback to them how their involvement has made a difference to the research (4, 18)
Think about members of the publics' involvement	• Members of the public might have developed skills they want to go on to use (17) when the research has finished • Plan for what will happen on completion of the study during the study (17) • Ask members of the public if they would like to continue being involved if the

after the study	opportunity arises (4)

Box 1: Issues associated with ethical clearance and public involvement in research

Finding out if your project needs to have the approval of your local Research Ethics Committee will require extra time and resources to negotiate (6, 21).

Some of the ethical issues concerning members of the public acting as subjects or participants of research (e.g. confidentiality and the right to withdraw) might also apply to when they are actively involved in the research process (24). But the issue of whether ethical clearance from an ethics committee is required for public involvement (as opposed to research participation) is less clear-cut. Guidance, produced jointly in the UK in 2009 by the National Research Ethics Survey and Involve provides some clarity on this issue. [1]

This guidance distinguishes between active public involvement on the one hand and participation in research as a subject or participant on the other. Ethical approval from an ethics committee might be required for the research study as a whole. But ethical approval is not required for the 'active involvement element' [30:p.1] where that active element has **'no direct contact'** [30: p.2] with participants. So if the public involvement in your project consists of, for example members of the public developing research tools, being members of advisory groups or analysing data then you do not need to obtain ethical approval.

If, on the other hand your public involvement will lead to members of the public having direct contact with research participants for example through facilitating focus groups or interviewing, then this will need to be considered by an ethics committee. The ethics committee will want to know that the member of the public carrying out research has received appropriate training and will be supported and supervised (30). Please read the guidance for more details

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[1] NRES. Patient and public involvement in research and research ethics committee review. London: National Research Ethics Service and INVOLVE; 2009; http://www.invo.org.uk/posttypepublication/patient-and-public-involvement-in-research-and-research-ethics-committee-review/

Box 2: Checklist of items to consider when drawing up a budget for public involvement (adapted from: 26, 25 and 11)

❑ How many people will be involved?

❑ What distances will they travel regularly?

❑ Do members of the public involved in the project have any childcare or carer support to pay for?

❑ What support will you pay for?

    ❑ Support worker

    ❑ Translator

    ❑ Interpretation costs

❑ How many meetings do you want to hold?

    ❑ Face to face, teleconference or videoconference meetings?

    ❑ Accessible venue hire

    ❑ Refreshments

    ❑ Travel expenses

    ❑ Thank you payment for expertise and time

    ❑ Overnight accommodation

    ❑ Subsistence or meal allowances

    ❑ Stationery costs (e.g. printing and posting documents prior to the meeting)

    ❑ Do you need an external facilitator to lead the meeting?

❑ What will the costs of training related to public involvement for members of the public, academic researchers and other members of the project team be?

❑ What costs associated with dissemination of the project will there be?

❑ Think about budgetting for project team members to attend conferences, events or workshops

In collaboration with the Mental Health Research Network, Involve have produced guidance on budgeting for the active involvement of members of the public in research [2]. In addition, Involve have produced an on-line Involvement Cost Calculator which will help you identify the different kinds of things you need to think about when drawing up a budget for public involvement. The Involvement Cost Calculator can be accessed here:

http://www.invo.org.uk/resource-centre/involvement-cost-calculator/

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[2] Mental Health Research Network and INVOLVE (2013) Budgeting for involvement: Practical advice on budgeting for actively involving the public in research studies, Mental Health Research Network, London and INVOLVE, Eastleigh

Box 3 Guidelines providing advice on payment for Public Involvement

Involve Internal Payment rates:

http://www.invo.org.uk/wp-content/uploads/2012/01/INVOLVE-internal-payment-policy-FINAL-
       Jan2012.pdf.

INVOLVE (2010) Payment for involvement: a guide to making payment to members of the public
actively involved in NHS, public health and social care research. http://www.invo.org.uk/wp-
content/uploads/2011/11/PaymentGuideWEB240510.pdf.

National Institute for Health Research (2008), Payment rates for public involvement.
http://www.invo.org.uk/posttypepublication/national-institute-for-health-research-payment-rates-
for-public-involvement/

Scott J (2008), Payment for involvement in research: helpful benefit rules and systems for avoiding
benefit problems. INVOLVE; www.nice.org.uk/media/B46/01/BenefitRulesPayment.pdf

Department of Health (2006) Reward and recognition: the principles and practice of service user
payment and reimbursement in health and social care (second edition);
http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/D
H_4138523

In May 2013 Involve produced an update on the implications of current changes to welfare benefit
regulations, including the introduction of Universal Credit, for payment for involvement;
http://www.invo.org.uk/wp-content/uploads/2013/05/Benefit-regulations-update-May-2013.pdf

Reference Number	Reference
1	Telford, R., Boote, J. & Cooper, C. (2004). What does it mean to involve consumers successfully in NHS research? A consensus study. *Health Expectations, 7* (3), 209-220.
2	TwoCan Associates for the UKCRC and NCRI (2010)*Patient and public involvement (PPI) in research groups – Guidance for Chairs.* Available from: www.twocanassociates.co.uk/perch/resources/files/GuidanceForChairs2.doc
3	Association of Medical Research Charities (AMRC) (2006), *Briefing Paper: Using lay reviewers in the peer review process*. London: AMRC. Available from: http://www.amrc.org.uk/research-resources_guidance
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5	Cartwright, J. and Crowe, S. (2011) *Patient and public involvement toolkit.* Chichester, BMJ Books ISBN 978-1-4051-9910-0
6	Faulkner A (2004), *The Ethics of Survivor Research. Guidelines for the ethical conduct of research carried out by mental health service users and survivors*. Bristol: The Policy Press. Available from: http://www.jrf.org.uk/publications/ethics-survivor-research-guidelines-ethical-conduct-research-carried-out-mental-health-.
7	Hanley, B., Bradburn, J., Barnes, M., Evans, C., Goodare, H., Kelson, M., Kent, A., Oliver,S., Thomas, S. & Wallcraft, J. (2nd Edition) Edited by Steel, R. (2004*) Involving the public in NHS, public health, and social care research: Briefing notes for researchers*. Eastleigh: INVOLVE.
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9	Kirby P. (2004) '*A Guide to Actively Involving Young People in Research: For researchers, research commissioners, and managers'*. INVOLVE. Available from: http://www.invo.org.uk/posttypepublication/a-guide-to-actively-involving-young-people-in-research/
10	McKenzie A and Hanley B. (2009) *Consumer and Community Participation in Health and Medical Research. A practical guide for health and medical research organisations*. The University of Western Australia and The Telethon Institute for Child Health Research: Australia. Available from: http://www.involvingpeopleinresearch.org/index.php/resources/green-book
11	Repper, J, Simpson, A. , Grimshaw, G. (2012) *Good practice guidance for involving carers, family members and close friends of service users in research.* NIHR, London, Available from: http://www.mhrn.info/data/files/MHRN_PUBLICATIONS/REPORTS/Carer_good_practice_guidance_-_complete.pdf
12	UK Mental Health Research Network Service User Research Group England (2005) *Guidance for Good Practice Service User Involvement in the UK Mental Health Research Network.* Available from: http://www.mhrn.info/pages/guidance-and-policy-publications.html
13	National Children's Bureau (2010), *Young People in Research: How to involve us Guidance for researchers from the PEAR young people's public health group.* Avaialbe from: www.ncb.org.uk/media/111093/pear_guidelines.pdf
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