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Why people get involved in health and social care research: a working paper

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July 2006

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1.   Introduction

The importance of public involvement in research is increasingly acknowledged. This is further supported by the recent Department of Health policy document 'Best Research for Best Health' (1) make generous references to the benefits of public involvement in health and social care research. Given this widening commitment to involvement this working paper was commissioned by INVOLVE Evidence, Knowledge and Learning sub-group to explore what has been documented about people's **motivations** to get involved in health and social care research - the reasons or incentives that result in people getting involved in research. What makes a person enthusiastic, interested, and committed to getting involved?

We look at why people choose to get involved in research, and, in turn identify barriers that may prevent others getting involved. The paper discusses:

- What motivates people to get involved in research;
- Who gets involved and ways of involvement;
- What are the factors influencing motivation and
- How to support motivation

2. Approach: literature review and personal accounts

2.1 Scope of the paper

This paper is a mapping exercise and not a systematic literature review of the literature on this topic. Our approach included a compilation of relevant publications and reports, mainly within the UK, and a small number of personal accounts from members of the public about their reasons for getting involved in research.

The purpose of this approach was to attempt to provide an overview of what has been written about the public's motivations to get involved in health and social care research and to give a flavour of people's personal experiences on their reasons for involvement.

2.2 Literature review:

Background studies

As part of the literature review we draw on some broader based background reports exploring the general issues of public engagement though not specifically addressing motivation for involvement in health and social care research.

They include:

- a study by Paul Skidmore and John Craig for DEMOS on the pivotal role of community organisations (2).

- a report produced by the National Consumer Council (3) plus two related articles by Johnston Birchall and Richard Simmons on the importance of strengthening user participation (4, 5) and

- Jonathan Bradshaw's literature review on drivers of social exclusion for the Social Exclusion Unit (6).

These recent reports are in various ways concerned with exploring ways of engaging citizens and strengthening local democracy and accountability within the UK. They provide helpful insights in relation to the reasons why people get involved more generally in community activities.

Of more direct relevance to this paper is:

- a large-scale study carried out by Andrew Thompson, Kai Rudat, Sophie Staniszewska and others as part of the Health in Partnership Project funded by the Department of Health (7).

This study explores what citizens perceive to be the motivations and methods of influencing the NHS in relation to health care delivery, policy and planning. It refers to, but does not dwell on involvement in research when discussing the policy and planning levels of public involvement. The study does however help to pinpoint common barriers of relevance to the decisions people make about getting involved in research. One of its conclusions is that whilst most people have opinions on services and treatments there is a much smaller set of people that are motivated to get actively involved in related policy and planning activities, which would include research.

Specific studies

We also reviewed studies that included specific comments on motivational factors for public involvement in health and social care research.

These included:

three Phase 1 reports of a Scottish based study produced by a research team at the University of Stirling on the involvement of people affected by cancer in research, policy, planning and practice. One of the reports is a wide ranging literature review (8,9,10).

two Dutch studies on patient involvement, one focusing on people with spinal cord injuries and the other on people affected by asthma (11,12).

an article by Rosemary Telford and Alison Faulkner on research involvement of mental health users (13) a report by Peter Beresford funded by Joseph Rowntree Foundation (14).

And finally, a number of other published articles and reports are included that directly or indirectly discuss the various reasons for involvement in research. These articles focus mainly on particular groups of people who use health or social care services, their carers or family and friends. These individual studies cover a wide variety of groups including people with learning difficulties (15), older people (16), people with long-term conditions (17), people affected by cancer (18) and users of mental health services (19). A fuller list of references linking these studies on involvement of particular groups is provided in Section 3.4.

Appendix 1 provides more detail on the search methods used.

2.3   Personal accounts:

In response to an advertisement in an INVOLVE newsletter we received a small number (eight) of personal contributions from members of the public giving their initial reasons for getting involved in research. These do not provide a definitive account of why people get involved but they help understand the motivational factors suggested in the literature we searched. These contributions are summarised in Section 3.2.

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3.   Findings: why people get involved in research?

3.1   Profile of involvement

Who gets involved

The studies we looked at suggest that those that are motivated to get involved do so for a combination of reasons related to their personal situation, their experiences of health and/or social care services (often negative) as well as possibly having a more general commitment to getting involved and bringing about change (11,13). Whatever the route in people want to have a strong sense that something tangible and useful will result from their involvement in research (14,15,16,17).

The background studies included in this review tended to have focused more on why people **don't** get involved. Some of the commentary has been included here as it helps us to understand some of the tipping points for involvement as well as the barriers. As a starting point these studies suggest that most of the adult population in the UK does not get actively involved in any community or other activities. They report, for example, that people view public consultations with scepticism and believe that policy or planning decisions have been made before opinions are sought, thus making the public involvement tokenistic (2,4).

The study by Thompson and others on citizen involvement in health care, reported that the people they surveyed acknowledge that they generally lack the motivation to get involved in health or social care issues (including research). They said they felt no immediate need to, either because they had no health or social care problems, were ill very rarely, or they always received good treatment (7).

This is illustrated in this study's analysis of their survey interviews with young men. They, in particular, were described as commonly ascribing to the view that although involvement in research might be a good idea in principle, they were not hopeful of its impact and were disinclined to take up any such opportunities. These young men described people who did get involved in patient panels or user groups, for example, as probably 'gullible' or 'with nothing else to do'. However this same group also predicted that their motivation for being involved might grow in direct relationship to an increased use of health and social care services as they grew older. Another group of young women described in the study wondered if the motivation of the NHS to include more people in health research was to pacify growing complaints about the state of the provision.

The Phase 1 findings of the Scottish study describe people saying they often have no wish to be involved in decision making about their own treatment, never mind a more general involvement in health care development, including research (9).

These and other studies reviewed here suggest that people's interest in involvement develops and alters over time (9,12). They propose that this applies not only between groups of people but to individuals also. It is important to recognise that at different times and for a whole host of reasons, an individual person's motivation may fluctuate from seeking active involvement in research (or other activities) through to preferring to be less active or not involved at all (7,8,11,12). A broader note of caution is sounded in a recent US study which notes that the growing expectation by Governments for public involvement in research may be viewed by many people as a 'burden of involvement' – yet another activity that the weary patient / carer / public are required to shoulder (20).

Some of these studies comment on the present lack of diversity in who gets to be involved in research and the need to include others. Giving examples of the lack of involvement of, for example, young men, people from minority ethnic communities particularly non English speakers and people from other 'hard to reach' groups, such as homeless people.

In the Scottish study on people affected by cancer, one of the Phase 1 reports found that those patients affected by cancer who did become involved were largely drawn from the majority urban-based population. The authors describe a profile of involvement of articulate middle-aged women who were relatively well-off and well-educated. Other people in the study, for example, living in rural areas or poorer urban areas tended to express more concern with issues of *access* to cancer services rather than an interest in involvement either in policy, planning or research (10).

The authors of this and other studies advise that broadening inclusion in research is likely to require a conscious effort for both commissioners and researchers, for example in terms of resources, changes to the research culture as well as promoting more innovative approaches to involvement. It is also worth noting the common focus of these studies is on the active involvement of people directly using or affected by health and social services provision - not the general public per se (11,14,18,19,21).

The ways people get involved

Most of the publications that we reviewed did not focus in any great depth on the ways people initially get involved in research. Where it is discussed there appears to be a broad concensus that usually people don't suddenly decide to actively seek involvement in research – it tends to be a more gradual process than that. A common example given is through membership of a local support group or voluntary organisation members may be invited by researchers or others to get involved in research, either locally if the opportunities arise, and/ or in national research projects (8, 22). Whether this involvement in research results from 'cold calling' by researchers on these groups or whether members have initiated the contact is not clearly documented.

Of course people who are not members of any such groups also get involved in research for example, by replying to media advertisements, websites or by being directly approached through their GP, hospital clinic or other research related links.

In a couple of studies we reviewed, for example, some people described themselves as generally not the 'type' to get involved. However despite this, their personal or related experiences of acute or chronic conditions resulted in them being motivated to get involved - primarily to get basic needs met (10,12). Other studies, including Thompson and the Phase 1 reports of the Scottish study noted a possible shift in public attitudes. People surveyed were starting to say that they would at least entertain the idea of being involved in research whereas a few years ago it is suggested by the authors that they wouldn't have (7,8,18).

A report by Joseph Rowntree Foundation on their work involving older people notes that current practice for public involvement in research still tends to remain limited to such activities as having an individual older person on a research advisory group, or a person affected by cancer sitting on a research ethics committee (21). This is supported by some of the other studies we reviewed that also report people still tending to only be involved in certain stages of the research cycle – for example as advisors to commissioning boards or reviewing research proposals (12, 23). The Scottish study noted in one of its Phase 1 reports, for example, that when people affected by cancer got involved in research it was mainly at a strategic level (ie. commissioning boards/ research planning/ consultation meetings). There were fewer examples of people acting as

advisors to individual research projects or in carrying out research (24,25,26). It is worth querying whether this is because certain types of public involvement are not reported by researchers, or whether there really is less of such involvement. This is difficult to establish given the present lack of reporting on this (27,28).

It should also be noted that public involvement will be influenced by the underlying commitment within a research area to promote active involvement. For example cancer research in the UK, has to date, a relatively stronger tradition of involving people affected by cancer in research compared to other diseases, such as diabetes. This in turn inevitably influence peoples' perceptions about the feasibility of getting involved in the subject area they are interested in and/or affected by.

3.2   Personal accounts

Background

As explained in Section 2 when we began to work on this review we put a small notice in INVOLVE's newsletter (29) asking people to email us with their reasons for getting involved in research. Eight people generously replied and gave us permission to use their contributions. Four of the eight said their involvement resulted from being members of a support group or voluntary organisation and four did not. Their interesting accounts are presented here in the text boxes. Whilst these comments are from a very small number of people, they do vividly suggest the opportune nature of not only why but how people get involved in research.

Responses

Involvement of people through membership of a group or voluntary organisation

Two contributors described themselves as members of a local support group and were both recruited locally by researchers who had approached their groups seeking involvement. The first became a member of a research advisory group and the second carried out research interviews with service users.

"I have osteoporosis and am an active member of my local osteoporosis support group. My group was contacted by the local hospital that was doing some research on preventing falls and bone fractures. They were looking for someone to join their research steering group who had osteoporosis. I thought that even if I didn't understand everything that would be said at least they would have a real live sufferer there for them all to see how terrible it can be. In fact I found I had a lot to say….and since then I've gone on to sit on other research groups with the hospital and local university" (Orla, December 2005)

" It was a chance meeting at a talk our group had organised. Over tea I got talking to the researcher who had done a presentation of the research he was planning to do in our area on dementia. He was looking for a carer interested in doing the interviews and I got the job! …. I now call myself a 'user-researcher' and am hoping to work on other projects " (Martin, December 2005)

The other two contributors said they had previously been engaged in volunteering or interested in community action. In both cases this commitment had led them to involvement in research, national as well as local, including priority setting of research, peer review, research design and the interpretation of research findings. One of these contributors had responded twice to a national newspaper advertisement for lay representatives.

"I first encountered concepts of health research and evidence-based care as an elected voluntary sector member of the local Community Health Council. ... My main reason for getting involved in research sprang from membership of the Cochrane Consumer Network. Commenting on reviews and protocols made me realise how remote researchers were from consumers, speaking a completely different language. I feel strongly that consumer input at an early stage can make a real difference. Subsequently I was invited to join a research project at Liverpool University as lay rep and ended up re-writing the patient information sheet. Working with the only other lay member of the steering group for another University preparing a research bid for *SDO* (NHS Service Delivery and Organisation Programme) funding, I've just written the 'plain English' summary - 510 words down from 8,600!" (Elizabeth, November 2005)

"It's quite hard to say EXACTLY **why** I became involved in research, but 'how' is easier. I started out as a lay representative with one of the Royal Colleges. The trigger was an advertisement for volunteers in the Guardian. I was looking for any volunteering opportunity rather than a specifically health-related role, but this one seemed to gel with my experience and interests.

I can't exactly remember how I became involved in the NCRI (National Research Cancer Institute) Consumer Liaison Group. I wasn't actively looking for more involvement, but somewhere I must have read about it and applied. So twice I was prompted by a call for volunteers, which only goes to show that advertising works.
Why research? When I was being treated for breast cancer I read that people who took part in clinical trials tended to do better than those who didn't, so I promptly volunteered for everything going. (I believe that this piece of research had been superseded by others saying no difference. But I still have a feeling that there's nothing to lose by taking part). I guess this was the beginning of my interest in research.

All the reading around – especially on the internet – that I did after my diagnosis got me interested in the quality of clinical trials – I was fascinated (and still am) by the fact that the publication of an apparently high quality research study in a peer-reviewed journal like the New England Journal of Medicine or The Lancet would be followed for months by a stream of letters pointing out all the flaws and inadequacies of the study. "How did they ever get it funded or published?" was a question frequently on my lips. I taught myself to look at trials with a critical eye with the help of GMC guidelines and educational material from the internet. I was a user of survey research in my working career so knew the basics of this kind of study. So the NCRI involvement had great appeal. I understand much better now science as an iterative process. Acquiring this knowledge and understanding has been a very rewarding experience in itself.

I don't see my role in research as simply getting things such as patient information right from the participants' point of view. I believe that patients should have a much stronger voice in setting the research agenda. The way in which much research seems to be driven by individuals' career interests is deeply disturbing and in my experience results in scarce resources being frittered away on work which makes, at best, a marginal contribution to cancer knowledge" (Christine, December 2005)

Involvement of people not members of a group or organisation

Of the four contributors that did not get involved in research through pre-existing membership of a group, two initially responded to public advertisements about developing research skills. The first joined a local research training scheme, the second joined a local university based course for older people on developing research skills.

"I chose to get involved in research as a service user because I was mistreated in a couple of children's homes some years ago and, all of us (care leavers) … have a tremendous difficulties coping with life, but some of us try extremely hard to do something worth-while. NoCLoR (North Central London Research Consortium) has helped me ENORMOUSLY. Thanks to them I … can help other people from my own background…

I was taken on to the (NoCLOR) Research Scheme as a New Researcher. This means I do exactly that of a experienced researcher, but I am given training and a great mentor (a senior doctor). So far I have developed my ideas, structured the titles, carried all the research in those areas and have then written up the articles and protocol. I mainly use questionnaires, interviews, research literature at the British Library and the medical libraries and on the computer and I use my own huge amounts of knowledge and experiences" (Service User Researcher, November 2005)

"My mother in law was a widow and living on her own about three hours away by road. She had been active and independent, but now approaching her eighties was experiencing many difficulties. My wife and I were visiting on a regular basis to provide support… Eventually she was hospitalised, assessed and discharged into a private residential home. As oneself is ageing it makes you think about your own future.

At this time I had been made redundant from my employment. I saw an advertisement in the local paper for Older People to be trained in research methods and to carry out a research project on behalf of a University and a Charity that specialised in older peoples' services. ..On successful completion of the training, (I was awarded) a Certificate in Research Methods (For Older …

People). (I then worked on) an interesting research project, "Housing Decision's in Older Age" - especially after our own experience. I completed the project and thoroughly enjoyed the experience and have since gone on to carry out other projects and been involved in many workshops related to research in health and social services" (Allan, November 2005)

The other two contributors initiated their own involvement: one carried out her own research and another eventually became chair of the local research ethics committee through an initial interest in clinical trials.

"I first became interested in research while my wife was ill and looking for new drugs or any local trials. This then led me to being interested in becoming a member of our local research ethics committee. This was nearly 8 yrs ago and I have now been elected as chair of the committee, so it shows that user/carer can make a difference and show that the professionals what it is like to one of the guinea pigs" (Neil, November 2005)

"I became involved in research because I have found there is little knowledge, understanding or provision for those of us with long term unseen disabilities… (I am) unable to access some health services eg. NHS Direct, Hospitals and GP surgery because I cannot easily use a telephone, having to get another person to telephone on my behalf means deprivation of my rights to confidentiality. General medical staff are not trained to understand our problems. …We fall into a vacuum between provision for mental ill health and slow learners. Unlike RNID and RNIB there is no strong umbrella organisation to speak out for the speech impaired" (Louise, November 2005)

Comment

As previously discussed these accounts suggest that people's motivations to get involved in research develop over time. People's motivations often develop either through personal interest and/or affiliation to a support or community organisation which in turn leads to involvement in research.

3.3　Factors influencing motivation

Drawing on the previous sections (3.1 and 3.2) we have attempted to summarise the mixture of key factors, both personal and social, influencing people's motivation to get involved in research. They include the following:

Personal reasons – experiences of self or others

Personal needs:

Motivation linked to trying to meet personal needs of their own or that of their family and friends through involvement in research. This is felt to depend on how relevant the research is to their own situation and the perceived social and emotional benefits of getting involved (7,11,30).

Having a voice:

Motivation also arises from interest in having a 'say' and influence on the processes that affect people's lives (4,12). On a personal level people welcome the opportunity to find a 'voice' and to take action in a more conscious way (13,31). For example people with learning difficulties or with long-term illnesses see such involvement as challenging their social 'invisibility' (11,15,19).

Frustration:

Linked to having a voice, involvement can provide a positive channeling of the frustration and anger personally experienced by people who feel badly treated by health or social care services and research (12,13,32,33).

Personal development:

People don't necessarily know what to expect when they first get involved in research. It is important to recognise that their motivation to be involved may well be an end in itself, as well as a means to achieve various aims related to the research outcomes.

Being involved in research can increase people's confidence and understanding if well planned and resourced (30). It can provide valuable opportunities to develop a personal sense of well-being, self-esteem and empowerment and may offer practical skills and training, employment and payment (34,35). Some have argued that it is a fundamental principle of involving the public in research to offer such rewards. It acknowledges that people are being valued for what they have to contribute to the research process (36,37,38).

Social interest - political imperative to get involved

Public perspective:

Drawing on personal experiences enables people to present their perspective and that of others with similar health and social care needs. They may wish the research to take account of and benefit from their experiences and push for changes to services. It may also be linked to personal factors of frustration or anger with previous academic research (34,39).

Altruism:

People want to leave a legacy and influence research for the benefit of others. They want to put something worthwhile back. People valued the opportunity of helping others through their involvement in research. As a motivational factor it is more often given as a reason for involvement among people who are already members of a support or voluntary group (7,8,16).

Changes to research:

People believe they bring important expertise and understanding to the research based on their experience of using services or treatments – i.e. as 'experts of their own experience' (13). Among service users and their organisations awareness has grown that these experiences are a valid source of knowledge and should be considered in relation to research and service delivery (11). For example research on clinical understanding of M.E. (chronic fatigue syndrome), aphasia or improving the treatment of mental health patients. The latter have argued that research undertaken from the experiential perspective is at least as valuable and should be as influential as research from the professional perspective. It is suggested that bringing together the two perspectives, adds value in ensuring that a research investigation is meaningful and influences practice (25,33,40,41).

Changes to services:

One of the strongest motives for people to become involved in research is the desire to bring about change and improvements to existing services or improve the quality of care for themselves and others with the same condition. People welcome the opportunity to exercise some power and influence over the decisions that are made in health and social care, however small that might be (13,18,26).

3.4   Illustrations

To illustrate the ways motivational factors combine for people, we have noted what some of the studies say about motivations for specific groups of people involved in research:

Involvement of older people:

Motivations include: wanting to give something back; wanting stimulation; and wanting to make a difference. The emphasis is on the 'giving' domain rather than the receiving (21,42). Older people involved in research tended to already have established links with grassroots organisations, health and local authority planning groups as well as advocacy groups for specific conditions such as the National Osteoporosis Society. They expressed a particular commitment to dissemination of research (16). In one study an older person who became a user-researcher described her motivation as a way to raise her hopes and expectations. To give her a new challenge to focus her energies in retirement. She also described involvement as an opportunity to confront ageism and the stereotypical views about what older people do (43).

Involvement of people who use mental health services:

The following reasons are included: frustration with clinical academic research; promoting the value of expertise by experience; seeking change and improvements to services and treatments by research; asking different questions … and getting different answers; questioning the independence of services and professionals; challenging models of understanding and personal development of skills and empowerment (13,19,24,25,30,32,36,37).

Involvement in eleven primary care research projects:

This succinctly emphasises three main motivational factors: enthusiasm, commitment and inspiration about the proposed research (44).

Involvement of people with learning difficulties:

Tend to focus on factors related to leading to empowerment, being heard, opportunities to access skills and training, seeking changes to services and improved quality of life (15, 26).

Involvement of people with long-term conditions:

Providing avenues to have a say and raise the profile of particular research topics. For example people with spinal cord injuries involved in a study challenged the clinical researchers' focus on stem cells and recovery, prioritising instead research on quality of rehabilitation and prevention of secondary

problems such as obesity and psychosocial well-being (45). This and other studies have also reported on so called 'non-active members' who had wrongly been assumed to not be interested in involvement in research until, for example, visited at home by a user-researcher or through innovative approaches including outreach work via grassroots (11,13,17,34).

Involvement of people affected by cancer:

People want to feel their views will be taken seriously and that there is real value in getting involved. Seek to influence the research agenda to take greater account of what is researched and how (8,10,18,38).

3.5   Supporting motivation

Issues related to supporting public involvement in research have been relatively well documented (30,37,38,40,41,46,47). In relation to public involvement and motivational factors the following four issues are particularly relevant:

Diversity: Being inclusive requires researchers to focus on the issue of diversity and how barriers to reaching certain groups of people should be handled. Some of the publications reviewed suggest the need for targeted initiatives to engage those less likely to get involved including younger people (especially men), people from minority ethnic groups and so called 'non-active' members of existing groups. These studies seek to underline that just because people do not engage in research, this does not necessarily signify a lack of motivation (7,9,11,35).

Research culture: A number of the articles and reports we reviewed refer to the need to support a change in attitudes and understanding of public involvement by both commissioners and researchers. They point to the need to develop good, open communication and promote opportunities for greater public involvement in shaping research questions and approaches to research (12,23,31,39,41,46,47).

Accessibility: To help maximise involvement, issues such as the timing and location of meetings and transport to and from meetings need to be taken into account more systematically. Some studies also discuss the effectiveness of considering more innovative ways of including people motivated to be involved i.e. not just by attending meetings (8,11,17,18,19, 40).

Practical opportunities and skills training: The studies recognise the need to attend to the personal capacity and organisational structures for making involvement a reality, including information, resources and payments (38). It is acknowledged that this is likely to require considerable investment in, for example, the development of research skills and training (15,17,25,30,37).

4. Conclusions:

This paper has attempted to map information from published articles and reports as well as a small number of personal accounts to summarise some of the factors influencing the public's motivation to get involved in health and social care research. It has also tried to draw out information on possible barriers to involvement.

In conclusion, some of the summary points are:

Complexity: Motivations for public involvement in research are various, reflecting the contexts in which people live.

Take-up: At risk of stating the obvious, this review, including the personal accounts, suggests that no matter how motivated people might be, involvement depends on people being made aware of research opportunities.

Flexibility: Researchers need to understand the importance of timing for people and look at ways of welcoming involvement when people are interested and in ways that are appropriate.

Relevance: People want to be convinced that their efforts will not be in vain, that something worthwhile will come of the research and their involvement in it.

Support: Providing practical support and reimbursement, backed up by feedback and skills training encourage people to act on and develop their motivations for involvement in research.

Promoting diversity: Researchers need to be more proactive in engaging those that may be motivated to get involved in research but may need innovative approaches to act on their interest. This includes both those already a member of a support group or voluntary organisation and those with no such affiliations.

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6. Acknowledgements

Grateful thanks to the Evidence, Knowledge and Learning sub-group members Peter Beresford, Chris Caswill, Alison Faulkner, John Sitzia, Sophie Staniszewska, Vanessa Pinfold and Tracey Williamson for their guidance and encouragement.

Sophie Staniszewska gave invaluable advice and support particularly in the earlier stages of planning the study and suggesting key references.

Maria Grant, University of Salford gave extremely helpful instructions on methods of searching electronic databases, as well commenting on the study plan.

A special thanks to Tracey Williamson for her detailed comments and suggestions on the final draft.

And finally, Sarah Buckland and Helen Hayes (INVOLVE Support Unit) have been actively involved throughout the various stages of the review, providing on-going direction and steer of the work. They have also read and commented in detail on earlier drafts and helped shape this version of the document.

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Maryrose Tarpey
INVOLVE Support Unit
14th July 2006

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7. Appendices

Appendix 1

Approach

1.   Literature review

Library searches and key electronic databases including Allied and Complementary Medicines Database (AMED)

Applied Social Sciences Index and Absracts (ASSIA)

Caredata/ Social Care Online

Cinahl

Cochrane Library

Database of Abstracts of Reviews of Effectiveness (DARE)

INVOLVE research database

MEDLINE/PubMED

National Research Register

National electronic Library for Health (NeLH)

Psychlit

Public Health Electronic Library

ReFer

SIGLE

Sociofile

For a detailed list of search terms used contact Maryrose Tarpey at the INVOLVE Support Unit. Contact details can be found at the end of this report.

Checklist to assess whether to review papers

Review if the answers to <u>all</u> of the following criteria is **yes**

- Public's motivation to get involved in research
- Published 1995 -2005
- Health, social care, public health, (also include other public issues)
- Primary research studies, review, policy document, article or personal commentary.

Also include in review literature related to public's motivation to get involved - generic studies where the criteria are judged to be substantially similar to factors related to involvement in research.

Each relevant publication entered on a data extraction sheet listing title, author, date of publication, approach and relevant findings.

2. **Responses to the request in INVOLVE's newsletter, Autumn 2005. (see Appendix 2).**

Appendix 2

1. Request in INVOLVE's newsletter Autumn 2005:

'Can you help us?

INVOLVE is writing a short paper on why people choose to get actively involved in research. If you are someone who uses services or a carer and have been or are actively involved in research we would be really interested to hear:

What was your main reason for getting involved in research?

You can let us know by email to mtarpey@invo.org.uk. By writing to us at the Support Unit or by phoning INVOLVE – ask to speak to Maryrose Tarpey.

Many thanks for your help with this – we will let you know what we learn'.

2. Eight people responded to this request and gave permission for their contributions to be cited. These contributions are included in Section 2.3 of the report.

INVOLVE

INVOLVE is a national advisory group, funded by the National Institute for Health Research, which aims to promote and support active public involvement in NHS, public health and social care research.

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