INVOLVE

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

Exploring Impact:
Public involvement in NHS, public health and social care research

Kristina Staley | October 2009

About this report

This report has been written by Kristina Staley of TwoCan Associates with support from staff of the INVOLVE Coordinating Centre.

This report has been written for a broad audience, but with the expectation that people will have some basic understanding of research.

Where words are written in **Orange**, there are definitions available in the jargon buster at the end of the report.

Information about INVOLVE

INVOLVE is a national advisory group which promotes and supports greater public involvement in NHS, public health and social care research. We are funded by the National Institute for Health Research (NIHR).

INVOLVE works with others towards creating the research community of the future which will be broader, more inclusive and more representative of the population as a whole.

For further information on INVOLVE please visit our website **www.invo.org.uk**

Information about TwoCan

TwoCan Associates carry out research and development and provide training and support to help voluntary and statutory organisations involve people who use services in their work. For further information visit **www.twocanassociates.co.uk** or email us at **info@twocanassociates.co.uk**

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Foreword

People focused research in the NHS simply cannot be delivered without the involvement of patients and the public.

No matter how complicated the research, or how brilliant the researcher, patients and the public always offer unique, invaluable insights. Their advice when designing, implementing and evaluating research invariably makes studies more effective, more credible and often more cost efficient as well.

I have always taken the view that public involvement in research should be the rule not the exception. It is fundamental to ensure high quality research that brings real benefits for patients, the public and the NHS.

'Involvement' means an active partnership between the public and researchers in the research process, rather than using people as the 'subjects' of research. Active involvement can take the form of consultation, collaboration or user control. This would include, for example, public involvement in advising on a research project, assisting in project design, or carrying out the research.

The National Institute for Health Research aims to ensure that all our research projects have active public involvement right from the start. It is vitally important for us to document and critically assess best practice and successful outcomes, so that we can determine the best ways to involve the public.

This review by INVOLVE provides answers to many of those questions. It helps us understand how and why public involvement impacts on the various levels and stages of research, and how it influences the implementation of research findings. It also challenges us to think more about the way we record public involvement activities so that the evidence base can continue to develop.

The review itself is part of the evidence that should be seen by researchers if they need any further proof of the importance of involving patients and the public in their research.

Increasingly, research that involves patients and the public in the design and evaluation stages is carrying greater weight and greater significance in the NHS, in the pharmaceutical, biomedical and medical devices industries, and most importantly, in NHS Trusts and GPs' surgeries keen to use evidence-based treatments and clinical solutions.

Professor Dame Sally C. Davies

Director General of Research and Development
Department of Health

What difference does public involvement in research make?

Members of the public bring perspectives and skills that are not always the same as those of researchers and health and social care professionals. Their involvement helps to ensure that the entire research process is focused on what is important to people and is therefore more likely to produce results that can be used to improve health and social care services.

However, we need to better understand the best approaches to public involvement, and to learn from others the difference that it is making.

This report starts to answer the question 'what difference does public involvement in research make?' not just to the research itself but also to researchers, research participants and to the wider community.

The report provides a wealth of information about how public involvement has made a difference in practice and it includes useful case studies that illustrate the range of ways that the public are influencing research.

The findings from this review will be of value to many different audiences – motivating and inspiring people who are just starting to get involved and supporting and encouraging those who are already actively involved in research – which has the potential to change and improve our lives in the future.

Sir Nick Partridge

Chair, INVOLVE

Chief Executive, Terrence Higgins Trust

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I would like to say a big thank you to Maryrose Tarpey, Helen Hayes and Sarah Buckland for all their hard work, advice and support throughout this project.

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Kristina Staley
October 2009

Summary

Summary

Introduction

Public involvement in research is founded on the core principle that people who are affected by research have a right to have a say in what and how research is undertaken. In recent years, there has been a growth of interest in public involvement as well as increasing requirements for involvement from research funders. This has led to an understandable concern to know exactly what difference involvement makes. There has been much interest in obtaining evidence to demonstrate added value and to find out where and when involvement brings the greatest benefits. This area of enquiry has come to be framed in terms of the impact of public involvement in research.

This report summarises the findings from a literature review that aimed to increase our knowledge of the evidence of the impact of public involvement on health and social care research. The project was commissioned by INVOLVE. The work was carried out by Kristina Staley from TwoCan Associates with support from Maryrose Tarpey, Helen Hayes and Sarah Buckland at the INVOLVE Co-ordinating Centre. The work was overseen by an advisory group.

Methods used

The project involved carrying out a structured review of the literature obtained from:

- a collection of articles at the INVOLVE Coordinating Centre
- a systematic search of electronic databases
- requests for **'grey' literature** sent out to networks via INVOLVE.

Relevant articles were identified by applying inclusion and exclusion criteria at a number of stages. A total of 89 articles met all the criteria and were considered relevant for an in-depth review. This was carried out using a framework which helped with categorising the evidence of different types of impact and drawing out common themes.

Context to the findings

There is huge variation in how the evidence of the impact of public involvement has been assessed and reported. The impact of involvement is also highly context-specific. This makes it difficult to judge the quality of the evidence that is available or to draw any general conclusions.

The vast majority of the evidence of impact is based on the views of researchers and members of the public who have worked together on a research project. Most often these views have been obtained informally. Although there is not a consistent approach to assessing impact, or describing it, very similar benefits and costs are consistently reported.

Findings from the literature review

Based on the evidence from this review, public involvement in research has had a variety of impacts, including impact on the research (at all stages and levels), on the members of the public who were involved, on the researchers, on participants, on community organisations and the wider community. It has also influenced whether the results of research have been used to bring about change.

Based on their experience of public involvement in research, both researchers and the public have concluded that there are a number of factors which influence whether involvement makes a difference. These include long-term involvement, involvement throughout a project, and training and support for the people involved.

Some researchers have reflected on how to assess the impact of involvement and when and how best to involve the public in research. Their main conclusions have been that it is difficult to assess the impact of involvement or to predict where involvement would have the greatest impact. More work is needed to clarify the added value of involvement in different research contexts.

Discussion

Challenges for this review

The main challenges for this review lay in:

- identifying relevant articles, because of inconsistencies in the use of terms such as 'involvement', as well as inconsistencies in describing and reporting on impact.

- the limited amount of evidence of impact. This partly reflects the inherent problem of assessing impact and also partly reflects the lack of structure and guidance on reporting on involvement in peer-reviewed journals. The current research culture also encourages researchers to simply report the results, rather than describe the 'lessons learnt' as part of the process.

- there were a number of gaps in the evidence, the most notable being the lack of articles on the impact of public involvement on research funding and commissioning. Other gaps, for example the lack of evidence of the impact of involvement on the **analysis** of **quantitative** data, may reflect a lack of involvement, rather than a lack of evidence.

Main themes identified in the review

In spite of the limitations, some strong and consistent themes emerged from the review. Based on an assessment of where there appears to be the most evidence, some of the strongest themes were:

- public involvement was reported to increase recruitment to all types of research
- public involvement was reported to be of particular value in **qualitative** research where participants are asked to share their views and experiences
- public involvement was reported to be of particular value in **clinical trials** where it helped to improve trial design and ensured the use of relevant **outcome measures**
- public involvement was most frequently reported to benefit the people involved as well as the research participants.

Strengthening the evidence base

Based on this review the strength of the evidence base around impact of involvement could be improved by:

- producing guidance on how to report on the impact of involvement in journal articles and reports
- finding more consistent and robust ways of assessing impact
- helping researchers and the public to find the most useful ways of telling the 'story of involvement'.

1.
Introduction

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Public involvement in research is founded on the core principle that people who are affected by research have a right to have a say in what and how research is undertaken. In recent years, there has been a growth of interest in public involvement as well as increasing requirements for involvement from research funders. This has led to an understandable concern to know exactly what difference involvement makes. There has been much interest in obtaining evidence to demonstrate added value and to find out where and when involvement brings the greatest benefit. This area of enquiry has come to be framed in terms of the impact of public involvement in research.

This project was commissioned by INVOLVE. INVOLVE is a national advisory group, funded by the National Institute for Health Research (NIHR). The role of INVOLVE is to support and promote active public involvement in NHS, public health and social care research.

The work was carried out by Kristina Staley from TwoCan Associates with support from Maryrose Tarpey, Helen Hayes and Sarah Buckland at the INVOLVE Coordinating Centre, with guidance from an advisory group (see Section 2.1).

The project involved undertaking a structured literature review (see Section 1.1 below), with the aim of increasing our knowledge of research that provides information about the impact of active public involvement in health and social care research.

The objectives were to:

- build knowledge and learning on the impact of involvement to improve public involvement in research
- identify and reflect on common themes
- highlight gaps in knowledge around the impact of public involvement in research
- provide a useful ongoing resource for researchers and others to help inform their work on public involvement in research
- identify lessons learnt which could lead to practical guidelines or have implications for training.

1.1
Rationale for the approach used

The project involved carrying out a structured literature review that searched widely across different sources of published literature (further details of the methods can be found in Section 2). Whilst this was not a full systematic review, similar principles were applied to ensure a systematic and reproducible approach. Briefly these included:

- defining the scope of the review
- developing and implementing a search strategy using relevant search terms and systematically searching databases
- defining inclusion/exclusion criteria and judging the relevance of papers at each stage
- using a framework to identify consistent themes
- developing outputs for dissemination.

This structured review differed from a systematic review in that no attempt was made to judge or grade the quality of the evidence, or to assess if the results were generalisable (except where comments were made by the original authors of a report).

The reasons for taking this approach were partly due to the nature of the evidence (see Section 3.1), which makes it difficult or inappropriate to assess its quality using traditional methods. In addition the main aims of the review were to cover the breadth of literature and to identify illustrative examples of the impact of involvement. These aims therefore became a priority in making use of the limited time and resources.

1.2
Terms used[1]

The term '**public**' has been used in this report to refer to:

- patients and potential patients
- people who provide care or support on an informal (i.e. unpaid) basis
- parents/guardians
- people who use health and social care services
- disabled people
- members of the public and communities who might be targeted by health promotion, public health and social care
- groups asking for research because they believe they have been exposed to potentially harmful substances or products
- organisations that represent people who use health and social care services.

The term '**the public**' is understood to include a rich diversity of people, whether defined by age, colour, race, ethnicity or nationality, disability, gender or sexuality, who may have different needs and concerns.

The term '**involvement**' has been used to refer to an active partnership between the public and researchers in the research process, rather than the use of people as 'subjects' of research. Active involvement may take the form of consultation, collaboration or user control. Public involvement in research is often defined as doing research 'with' or 'by' the public, rather than 'to', 'about' or 'for' the public. This would include, for example, public involvement in advising on a research project, assisting in the design of a project, or in carrying out the research.

Where direct quotes have been included from articles or where case studies have described the impact of public involvement in a particular context, alternative terms have occasionally been used. These reflect the terms used by the original authors e.g. 'patient', or 'advocate' instead of 'the public' and 'participation' instead of 'involvement'.

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1   These terms have been developed by INVOLVE.

2.
Methods

2. Methods

The review involved conducting two searches for relevant literature. The first involved identifying published articles and reports held in a collection at the INVOLVE Coordinating Centre in 2007. The second involved conducting a more structured search of health and social care electronic databases and was carried out in 2008. A request for relevant **'grey' literature** was sent out to INVOLVE's networks in both years.

The project involved the following activities:

- working with advisory groups
- carrying out literature searches
- developing and refining the review framework
- disseminating the findings.

These will now be discussed in turn.

2.1
Working with the advisory groups

The two literature searches were each guided by an advisory group drawn from members of INVOLVE's Evidence, Knowledge and Learning Working Group[2] and INVOLVE Coordinating Centre staff. Both advisory groups included researchers and user researchers with extensive knowledge and expertise around public involvement in research (see Appendix 1). Members of the advisory groups helped to determine the scope of the reviews, the search terms and review framework. They also reflected on interim findings and advised on the final reports and **dissemination**.

2.2
Carrying out literature searches

The literature search in both phases involved:

- identifying articles that potentially contained evidence of the impact of public involvement in research

- scanning the selected articles to assess whether they met the inclusion criteria for this review

- carrying out an in-depth review of all the articles eligible for inclusion.

These will now be discussed in turn.

Identifying potentially relevant articles

Potentially relevant articles were identified by reading the titles and **abstracts** of published journal articles (or the summaries of reports) to see if they contained any suggestion that the full paper or report might contain evidence of impact. Articles were only included at this stage if they had been published after 1997 and had been written in English.

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2   Evidence, Knowledge and Learning is one of three working groups within INVOLVE. They meet quarterly to discuss the activities of INVOLVE.
The terms of reference of INVOLVE's Evidence, Knowledge and Learning Working Group is to create, gather, disseminate and promote the active use of evidence/knowledge on the inclusive involvement of the public in NHS, public health and social care research:
- to pursue a portfolio of evidence/knowledge building activities
- to pursue diverse strategies to gather evidence/knowledge from external sources
- to make accessible and to disseminate this evidence/knowledge base.

These articles were sourced in the following ways:

Searching the INVOLVE collection of resources

In 2007 articles/reports were identified in the collection of resources in the INVOLVE Coordinating Centre. A total of 144 potentially relevant articles including **'grey' literature** were identified through this route.

Searching electronic library bases

During 2008, a more systematic search was carried out in a number of stages as described below. The literature searches, initial review of the abstracts and identification of articles were carried out by Jon Hyslop, Maryrose Tarpey, Helen Hayes and Sarah Buckland from the INVOLVE Coordinating Centre (Stages 1 and 2). Kristina Staley (Stages 2 and 3).

Stage 1: The first stage involved searching nine health and social care electronic databases using a number of defined search terms (see Appendix 2, Tables 1 and 2). To build a sensitive search it was necessary to use a variety of search terms, to take account of the fact that there is no consistent terminology in the literature and articles are indexed in databases in several different ways.

This set of searches identified a total of 3,886 articles (after the removal of duplicates). These were reviewed to identify the articles most likely to contain evidence of impact. Initially, this involved two reviewers reading the titles of the articles, and eliminating those which did not appear to relate to the impact of public involvement in research. Where there was no consensus, the articles were put through to Stage 2, to review the abstracts.

Stage 2: The abstracts of the remaining articles (764) were read to confirm whether they were likely to be relevant to this study. Each article was classified as 'YES' (include) 'MAYBE' (uncertain – needs to be checked/discussed) or 'NO' (don't include). All articles classified as 'YES' were put through to Stage 3 to review the full papers. All the abstracts classified as 'MAYBE' or 'NO' were checked by a second person. Those thought to be potentially relevant were also put through to stage 3. This filtering exercise reduced the number to 222 articles.

Stage 3: Full papers were obtained via electronic archives, the British Library and interlibrary loans and reviewed.

Requests for 'grey' literature

Articles outlining the project and requesting 'grey' literature were placed in the INVOLVE newsletter, on the INVOLVE website and sent by email to invoNET[3] members in 2007 and 2008. Past and present INVOLVE conference abstracts and newsletters were also reviewed to identify any relevant publications.

The project and possible sources of 'grey' literature were discussed with organisations and individuals who were either known to be currently working in this area or who might be aware of networks for specific sources of information e.g. research with black and minority ethnic communities.

3   invoNET is a network of people working to build evidence, knowledge and learning about public involvement in NHS, public health and social care research. invoNET is facilitated by INVOLVE.

Few reports and articles were obtained this way. Among the articles that were submitted only a small number met our criteria for inclusion (see below).

Checking articles for eligibility

A total of 372 potentially relevant articles were identified through these search strategies: 144 through the search of the INVOLVE collection of resources in 2007; and 228 through the search of the electronic databases in 2008 and in response to requests for additional literature (222 plus 6). These 372 were read to assess whether they met the following criteria:

- the article/report contained a substantial amount of critical analysis or reflection on the impact of public involvement in research. (A 'substantial' amount was defined as a separate or distinct section within the report or article. Where an article or report only contained one or two paragraphs on the impact of user involvement as part of the conclusion/discussion, this was not considered to be substantial and the article or report was not included)
- the article/report discussed public involvement in NHS, public health and/or social care research. Some studies of public involvement in service development were included when the lessons could be generalised
- the article/report was publicly available as a journal publication, project report, book or book chapter, thesis, or as an editorial in a journal. Comments, letters and opinion pieces were not included.

At the same time, the references were checked in these articles. This led to an additional 24 potentially relevant articles being identified through citation. Full papers were obtained and subjected to the same process of assessment against the criteria.

In-depth review of the articles

A total of 89 articles met our criteria and were considered relevant for an in-depth review. This included 71 published articles and 18 from **'grey' literature** (12 from 2007 search, 6 from 2008). Of these 59 were drawn from the INVOLVE collection and 30 from the additional literature searches.

2.3
Developing and refining the review framework

The review framework was developed with the input of both advisory groups and advice from INVOLVE's Evidence, Knowledge and Learning Working Group. It was largely based on an initial scope of the literature found in the INVOLVE Coordinating Centre's collection of resources in 2007. A summary of the framework can be found in Appendix 3.

The purpose of the review framework was to provide a structure for a more in-depth review of the literature and to categorise the evidence of different types of impact. At first the framework was used to index the papers and to sort the findings. Every article was indexed by theme and the relevant information drawn out under each one. When new themes emerged during this process, these were incorporated into the framework and applied to all subsequent material.

The articles were also scanned for quotes and case studies that could illustrate the points being made under each theme. When all the articles had been indexed, a general summary was written about the points made within each theme, and linked to specific case studies reporting the same kinds of impact in more detail.

Throughout this review the main questions that were addressed were:

- what has been the impact of public involvement in health and social care research?
- how did it make a difference?

As described in Section 3 of this report it was not possible to carry out a more in-depth analysis of the different kinds of impact because of the limitations of the evidence. Nor was it possible to make judgements about the quality of the evidence, to grade the articles or to assess whether the results were generalisable. Instead, this review has highlighted issues that relate to:

- the nature of the evidence available on impact
- the challenges of reporting on the impact of public involvement and the need for more consistent reporting
- the challenges of drawing out general lessons when the impact of involvement is so context specific.

These issues are discussed in more detail in Section 5.

2.4
Disseminating the findings

This publication provides a detailed report of the findings from the review. A variety of media will be used to share the information so that it reaches a broad and diverse audience e.g. websites, mailing lists and networks, journals, conference presentations and newsletter articles.

3.

Context to the findings

3. Context to the findings

This report has only aimed to summarise the evidence of impact currently available in the literature. It has not been possible to draw out more general conclusions, because the impact of involvement is so highly context-dependent.

Many of the findings have been written up as case studies. This is because the evidence can only be properly understood with a detailed knowledge of the specific study and the nature of the public involvement.

The challenges in reporting on the findings from this review are discussed in Section 3.1 below. In spite of these limitations some strong and consistent themes have emerged from the literature. These are briefly summarised in Section 3.2 and detailed in Section 4 of this report.

3.1
Challenges

A focus on process

Most of the articles about public involvement in research report on the **process** of involvement and the results of the research, without describing what difference the involvement actually made to the research. Only a minority have reported on impact.

Different kinds of evidence

There is huge variation in the way the evidence of impact has been sought – from informal discussions at team meetings through to more formal and independent processes of evaluation. Most often articles/reports appear to contain the researchers' reflections on the impact of working with the public on a particular project. In other cases, researchers have reflected on working with

the public on a range of projects and reported more generally on the benefits and costs. Not all reports describe how the evidence of impact was obtained.

Some articles report on a very robust process of assessing the impact of involvement, for example, gathering the views of the public and academic members of research teams via interviews, pre- and post-involvement questionnaires and **focus groups**. Others have taken a much simpler approach. However, the quality of the process does not always guarantee the quality of the evidence. For example, studies which have run a **randomised controlled trial** to assess the impact of involvement, have sometimes proved inconclusive. This is because other contextual factors have limited the significance of the results. On the other hand, some of the more 'anecdotal' accounts of involvement have provided very powerful and convincing evidence of impact.

Variation in reporting

There is also variation in the way the impact of involvement is written up. Some reports focus solely on this issue and produce rich descriptions of impact. Others report on impact as an aside or as a short, separate section that is secondary to the main study.

Some of the articles that do report on impact provide only brief details of the impact that was observed. For example, researchers may report that the public helped to shape a questionnaire, but do not provide any details of the precise changes that were made. Similarly, not every article includes a consideration of all the possible types of impact. For example, they may comment on the impact on the members of the public involved, but not on the impact on the researchers or practitioners.

Where members of the public have been asked to contribute their views on impact, they are most often asked about what difference involvement has made to them personally. The researchers typically report on the impact on the research process and outcomes. In some studies, user researchers are included as co-authors of publications, but it is not always clear whose views on impact have been reported.

In the past, many of the reports of impact have been aiming to 'make the case' for involvement and to 'convince the sceptics'. For this reason, much of the focus has been on the benefits of involvement and the **potential** for involvement to improve research.

Analysis of the evidence

There has been very little critical **analysis** of public involvement in the literature. Most studies have asked simple questions about whether involvement makes a difference and what kind of difference it makes. The few studies that have attempted to address more complex questions (for example when and where does involvement have the biggest impact) have reached similar conclusions about the limitations of the evidence available. They have also highlighted the difficulty in drawing out more general conclusions when the impact of involvement is so context-specific.

3.2
Common themes emerging from this review

In spite of the variation in the apparent robustness of the evidence, many of the findings are the same. So although there is not a consistent approach to assessing or describing impact, very similar benefits and costs are being consistently reported.

Public involvement has been reported to have had an impact at all the various stages of the research process, from identifying research questions and priorities (see Section 4.1), through to designing and delivering research projects and disseminating the results (see Section 4.2). Early involvement at the design stage has also helped with identifying and resolving any ethical dilemmas raised by the research (see Section 4.3).

Involvement has also been reported to have had an impact on all the **stakeholders** in a project, including the members of the public involved (see Section 4.4), the researchers (see Section 4.5), the **participants** (see Section 4.6), and the wider community (see Section 4.7), including associated community organisations (see Section 4.8).

Either directly or indirectly, public involvement has also been reported to have had an influence on whether the results of research are followed up and used to bring about change (see Section 4.9).

Some researchers have reflected on which factors contribute to involvement having an impact. These relate to the quality of the involvement process and its ability to influence decision-makers (see Section 4.10). Others have commented on the challenges of assessing impact and the difficulty in predicting where involvement will have the greatest impact (see Section 4.11). Others have concluded that more work is needed to identify how public involvement brings added value in different contexts (see Section 4.11).

Summary – Context to the findings

There is huge variation in how the evidence of the impact of public involvement has been assessed and reported. The impact of involvement is also highly context-specific. This makes it difficult to judge the quality of the evidence that is available or to draw any general conclusions.

The vast majority of the evidence of impact is based on the views of researchers and members of the public who have worked together on a research project. Most often these views have been obtained via informal discussions, although some studies have undertaken a more formal evaluation. In spite of the variation in the robustness of the process, many people express similar views. So although there is not a consistent approach to assessing impact or describing it, very similar benefits and costs are being consistently reported.

Things to bear in mind when reading the remainder of this report

- The findings only describe what has been reported in the literature.

- Some issues have been raised that will require further debate. No attempt has been made to use the evidence to resolve any of these debates.

- No weight has been given to the different types of evidence of impact.

- No judgements have been made about the quality of the evidence or whether the results were generalisable (except where these have been made by the original authors of a report), nor have the articles been graded.

- There may not always be a direct link between the quality of methods used and the quality of the evidence of impact.

- What 'counts as evidence' may be subjective, depending on the individual and the context.

- There is huge variation in how impact has been assessed and how it has been reported.

- For historical reasons, there has been a stronger tendency to report on the benefits of involvement rather than the costs.

4.

Findings from the literature review

4. Findings from the literature review

The findings from the literature can be usefully grouped into the following topics:

- **'when and how'** public involvement has had an impact on the different stages of research (Sections 4.1 – 4.3)

- **'who'** was involved and the impact on these different **stakeholders** (Sections 4.4 – 4.8)

- **'what difference'** involvement made in terms of impact on implementation and change (Section 4.9)

- **'what influences impact'** in terms of the factors that increase the likelihood of benefits (Section 4.10)

- **'what have we learnt'** – from reflections on assessing the impact of involvement (Section 4.11)

4.1
Impact on the research agenda

Public involvement has been reported to influence the research agenda through its impact on:

- identifying topics for research
- shaping research questions
- initiating research projects
- making decisions about which projects to fund.

These will now be discussed in turn.

Identifying topics for research

In a number of studies, involving the public led to a wider set of topics being considered for research than if academics/health professionals had been working alone (Bryant & Beckett 2006; Hewlett et al. 2006; Lindenmeyer et al. 2007; Rhodes et al. 2002). For example, young people identified new research topics that would have been overlooked by adult researchers (McLaughlin 2006). User-controlled research in particular seems to have **'filled the gaps that have been left by other research approaches'**, (Beresford 2007 p.339).

Public involvement has also opened up new areas of research (Hewlett et al. 2006), as one researcher described, **'One thing I find very helpful about having diverse groups of advocates involved is that it can sometimes help to ... loosen up whatever the current dogma is'**, (McCormick et al. 2004 p.637).

A review of research funded in the Netherlands, found that patients' ideas on the causes or treatment of different conditions also led to the development of new research questions (Caron-Flinterman et al. 2005) (see Case Study 1).

Case Study 1: A review of practical examples of where patients have identified new topics for research (Caron-Flinterman et al. 2005).

This review found nine examples of where patients' experiential knowledge had been translated into ideas for research. They included the following:

1) A new research project was launched to find a delayed-release hydrocortisone tablet for people with Addison's disease. This followed a call for **research proposals** from the Dutch Addison and Cushing Society. The Society were aware that people with Addison's disease find it difficult to get up at night to take their medicine, although they need to take hydrocortisone every few hours. The new research project aimed to address this problem.

2) The mother of a young woman with adenocarcinoma of the vagina suggested to doctors that the fact that she had taken the drug diethylstilbestrol (DES) during her pregnancy might be related to her daughter's condition. The researchers who subsequently investigated this possibility did indeed find a link. This side-effect of DES is now well known world-wide.

3) Women with Crohn's disease found that the metronidazole they received for a vaginal infection also had a positive effect on their bowel disease. They reported their experience to their doctors, who then undertook additional research on the drug. This led to metronidazole being regularly used in the treatment of inflammatory bowel disease.

Shaping the research agenda

In some instances, public involvement has shifted the focus of research to become more in line with the public's interests and concerns. For example the involvement of women with breast cancer in research into environmental causes, shifted the focus of the whole research programme. It moved away from a biomedical model towards an environmental and political model of the disease. This much better reflected the women's interests (McCormick et al. 2004).

Researchers have also reported that public involvement added value to their work by forcing them to be clearer about why they wanted to conduct their research, and how it would be relevant to the public (Hewlett et al. 2006; Lindenmeyer et al. 2007).

On occasion, public involvement has also radically changed the way 'problems' are conceptualised (Fisher 2002). For example, disabled people involved in research into the problem of 'young carers' challenged the fundamental concept underlying the study. From a disability rights perspective, children and young people are only obliged to act as carers, because parents are denied their right to appropriate services. The disabled people therefore raised doubts about the relevance of the research. They suggested that the enquiry focus on the absence of adequate care for parents, rather than the problems faced by young carers (Fisher 2002).

Not all researchers believe this impact of involvement to be of value, as one researcher described, **'I have a negative view because… people did bring their own agendas…and I really think that's a bad thing in research, to bring your agenda to the research strategy and proposal'**, (Wyatt et al. 2008 p.160).

Initiating research projects

Some researchers have reported that public involvement simply provided the motivation and momentum they needed to get started, as one researcher described, **'without the consumers' participation it [the project] would not have got off the ground',** (Ross et al. 2005 p.273). In the case of a research programme into the environmental causes of breast cancer, the researchers and the women involved both felt that public involvement had **'pushed the science forward more quickly',** (McCormick et al. 2004 p.636).

In the field of genetics, patient organisations have become increasingly involved in biomedical and translational research (Terry et al. 2007). Their involvement has helped to initiate and accelerate this research (see Case Study 2).

Case Study 2: The work of PXE International (Terry et al. 2007).

PXE International is an organisation that initiates, funds and conducts research on the genetic disease pseudoxanthoma elasticum (PXE). Its founders, the Terry family, were personally affected by this condition. They realised there was a need to incentivise research into PXE by making best use of all the available resources.

As an important first step they established the PXE International Blood and Tissue Bank. Because they guaranteed this resource would only be used to address patients' needs, individuals who were affected by PXE generously and eagerly donated biological samples, as well as providing all the personal and medical information needed by researchers. This resource proved crucial to the discovery of the PXE gene.

At the same time as building a community of affected families, the organisation also brought together a range of researchers. This led to the formation of the PXE International Research Consortium. The researchers were also invited to meetings of the affected individuals and their families, and subsequently became more motivated to work on PXE.

By working closely with the researchers, PXE International helped to keep the research tightly focused on the needs of people with the condition. The founders also undertook some of the laboratory research that led to the identification of the relevant gene. They were therefore named as co-inventors on the patent. This has meant PXE International has been able to act as a 'caretaker' of the gene, representing the interests of the PXE community in the process of moving from gene discovery to the development of diagnostic tests and therapeutics.

This successful collaboration between patients and researchers has also resulted in plans for a **clinical trial**. This trial will test treatments for the eye defects in PXE. PXE International is raising money to support the trial. It is also helping to co-ordinate the work of the researchers and to recruit the patients.

Impact on funding decisions

Some researchers have reported that public involvement has made their research more fundable, either by adding credibility to their proposal or by improving its feasibility and overall design (Lindenmeyer et al. 2007). However, they are uncertain as to how big an influence this has been (Lindenmeyer et al. 2007). This is because there has been no clear indication from funding organisations as to whether and how much this public involvement has influenced their funding decisions.

There is potential for the public to have a more direct influence on funding decisions via their involvement in **peer review**. A number of UK research funding organisations are now involving people in this way (Staley & Hanley 2008), but the impact of this involvement has yet to be reported. One study has been carried out in the States. This study suggested involvement made little difference to decisions about which projects were funded (Andejeski et al. 2002a; Andejeski et al. 2002b) (see Case Study 3). However, this research mainly focused on the expectations, concerns and experiences of the scientific and consumer reviewers. The researchers themselves concluded that the study was limited in not addressing some of the other important questions about impact (Andejeski et al. 2002a; Andejeski et al. 2002b).

Case Study 3: An evaluation of the impact of having breast cancer survivors as review panel members for the US Department of Defense Breast Cancer Research Programme (Andejeski et al. 2002a; Andejeski et al. 2002b).

In this study, scientific and consumer reviewers took part in a survey before and after a review panel meeting, to explore their views on the process. The overall scoring of proposals was also analysed.

The researchers found there was little difference between the average consumer score and the average scientist score. The consumers' votes had minimal impact, because there were only two consumers on each panel (with 11-17 scientists), and their scores were similar to those of the scientists. It is not known whether the consumers influenced the scientists' scoring of proposals as this was not investigated.

The scientists had been worried that consumers would have a 'hidden agenda', that they would want to alter the direction of the research and that their involvement would adversely affect the scoring process. The findings of this study therefore alleviated their concerns.

Most of the scientific reviewers reported that consumers had **'added an important perspective to the review process'** (p.385). The consumer reviewers had informed the scientists about the concerns and interests of breast cancer survivors. One of the scientific reviewers also commented that **'just having consumers at the table led him to consider more carefully the potential impact of each proposed research project on breast cancer'.** (Andejeski et al. 2002a p.385)

Summary – Impact on the research agenda

Public involvement has been reported to influence the research agenda through:

Identifying topics for research

Public involvement has led to the consideration of a wider set of topics than if academics or health professionals had been working alone. It has also opened up new research areas.

Shaping the research agenda

In some instances, public involvement shifted the focus of research to be more in line with the public's interests and concerns. Researchers have concluded that involvement added value by forcing them to be clearer about why they wanted to conduct their research and how it would be relevant to the public.

Initiating research projects

Public involvement has been reported to provide the motivation and momentum necessary for researchers to initiate and conduct research. This has helped to accelerate the whole process.

Influencing funding decisions

Some researchers have reported that public involvement made their research more fundable, either by adding credibility to their proposal or by improving its feasibility and overall design. However, they are uncertain as to how big an influence this has been. There is potential for the public to have a more direct influence on funding decisions through peer review, but there has been little research into the impact of involvement.

4.2
Impact on research design and delivery

Public involvement has been reported to have had an impact at all the various stages of the research cycle. It has influenced:

- the project design
- the research tools and methods
- recruitment
- **data** collection
- the **analysis** of data
- writing and **dissemination**.

These will now be considered in turn.

Impact on the project design

Researchers have reported that involving the public right from the beginning of a project helped to reshape and clarify their research question, and also challenged their assumptions and aims (Barnard et al. 2005; Hewlett et al. 2006; Rhodes et al. 2002). Health researchers have tended to focus on 'problems' and 'health needs', whilst the public have preferred to focus on 'community strengths' (Dickson & Green 2001). As a result of these differences, public involvement has changed the way research questions have been framed and constructed and also changed the way projects have been designed (see Case Studies 4 - 7).

Case Study 4: A research project to explore the factors that affect the health and well-being of young women in Cape Town (Mosavel et al. 2005).

This study initially aimed to find out how best to develop a health promotion programme that would reduce the risks of cervical cancer in young women in Cape Town. As a direct result of involving local community members, the researchers decided to change the basic concept of their study.

The women involved in the study explained that the sexual health concerns of young, poor women in South Africa extend far beyond cervical cancer and that their health-promoting behaviour would be influenced by a very wide range of factors. These included poverty, crime, violence, and unemployment. The researchers therefore agreed that they should move away from their narrow interest in the risk factors for cervical cancer towards a broader concept of promoting 'cervical health'. This was the term suggested by the local women to better reflect their wider concerns. It also described the need to develop a number of health interventions that would address the lived experience of the target group. The researchers reported that adopting this term proved to be a vital first step in gaining the interest and trust of the local community.

Case Study 5: User involvement in a study of the effects of in-patient group medication education sessions (Trivedi & Wykes 2002; Wykes 2003).

The involvement of mental health service users in this study changed the focus of the research as well as its design and content. The original purpose of the study was to assess the effects of medication education sessions on service users' knowledge, insight and compliance. The users involved pointed out that while insight and compliance might be of major importance to clinicians, users would be more interested in their empowerment. They were concerned that the main outcome from therapy would be to **'increase the rates of swallowing medication'** which did not at all reflect the users' agenda.

After a long series of discussions, the study changed its focus. In the final project more attention was paid to the intervention itself and the way in which it was delivered. Instead of 'seeking compliance', the therapy made better use of techniques to help individuals make decisions about their treatment. The **outcomes** that were measured were also changed to better reflect the interests of service users.

Case Study 6: A systematic review of the literature on HIV health promotion (Rees and Oliver 2007 in Carr & Cohen 2007).

In this study, service users were members of an advisory group which helped to prioritise the topics for a systematic literature review. The advisory group had a major influence on the review right from the beginning. They advised against focusing on the concept of 'risky sexual behaviours' and recommended that the review instead focus on men gaining control over their own health. They believed this new focus would encourage health professionals to aim for empowerment through information and support, rather than condemning any particular behaviour. As a result of these discussions, the research team consulted the funders (the Department of Health), who agreed to revise the review in line with the advisory group's recommendations.

Case Study 7: Public involvement in breast cancer research (McCormick et al. 2004).

As a result of involving women with breast cancer in a research programme to investigate the causes of this disease, researchers considered environmental factors that would have otherwise been ignored. For example they agreed to look at radiation exposure, even though they believed residents were generally exposed to low levels. The researchers had to develop new research methods for this purpose. They also had to employ a more multidisciplinary approach so they could address the more complex research questions developed through the women's involvement. The researchers viewed this as an important factor improving the quality of the research programme.

In terms of study design, public involvement has been reported to influence what outcomes have been measured as well as **how** they have been measured (Hanley et al. 2001; Hewlett et al. 2006). As a direct result, research findings have been made more relevant and useful to the people who use them (see Case Studies 8-10).

Case Study 8: User involvement in mental health clinical trials (Wykes 2003).

The service users involved in this clinical trial complained that the outcomes being measured were not relevant to the people actually receiving the therapy. The trial was testing a new psychological therapy - cognitive remediation therapy - that aims to improve people's attention, memory and concentration. These kinds of effects are usually measured by neuropsychological tests. The service users objected to this formal assessment and asked that a more practical and relevant measure be used instead. The research team therefore agreed to use a new measure that asked people to remember items on a shopping list. This was much more useful and relevant because:

- it tested a skill that most people need
- it related to a problem service users were already experiencing
- service users would value any improvement they experienced.

Case Study 9: User involvement in a pilot study to inform the development of a clinical trial (Paterson et al. 2005).

This project involved members of the Parkinson's Disease Society in a pilot study to explore the effects of massage therapy for people with Parkinson's. The aim was to develop the **protocol** for a full-scale clinical trial and assess whether existing quality-of-life measures would be useful in this context.

The users involved not only helped to develop more relevant outcome measures but also helped with improving the design of other elements of the trial. This included:

- Making suggestions about how best to describe the intervention.
- Developing inclusion criteria – for example they recommended only including **participants** with the potential for improvement.
- Alerting the researchers to pay more attention to the time of day. This is important because people's symptoms fluctuate during the day and are affected by their medication. This had implications for the timing of the massage therapy as well as the timing of any assessment of its impact. The researchers had not previously been aware of this issue.
- Recommending that researchers help participants to complete any questionnaires. This is because people with Parkinson's have problems with their eyesight and with concentration, and because they can also find it distressing to talk about their illness.

The users also highlighted a shortcoming of the use of the quality-of-life measures. For people with Parkinson's, as with other chronic

conditions, not getting any worse may be just as important as getting any better. The users therefore suggested that the primary outcome of the trial should be about maintaining mobility in the early stages of the illness, rather than aiming to achieve a significant amount of improvement.

Case Study 10: User involvement in the design of a clinical trial for the treatment of acute stroke (Ali et al. 2006).

In this study, people affected by stroke were consulted about the design of a clinical trial that aimed to test the effects of oxygen supplementation following an acute stroke. The users were asked to comment on consent issues, the relevance and acceptability of the outcome measures and the preferred method of follow-up.

Following the consultation, one of the main changes that was made to the trial was to introduce new outcome measures. The most commonly used stroke assessment scales focus on physical health and physical recovery. However, the users pointed out that quality of life after stroke is determined more by cognitive and emotional problems than by the level of disability. They therefore wanted the trial to assess the impact of treatment on communication, mood, cognitive function, tiredness and sleep. As these are not well represented in the standard assessment tools, the researchers added their own questions to the assessment questionnaires. This helped to make the results of the study more relevant to people affected by stroke. However, the researchers were concerned that because their questionnaires had not been validated (i.e. proven to measure what they claimed to measure), the scientific rigour of their trial would be compromised.

In one study public involvement was reported to have had an adverse impact on the design of the project (Krieger et al. 2002) (see Case Study 11). In this case the public's requests for changes to the trial design meant the findings were inconclusive. This study emphasises the need to draw on the expertise and experience of both the public **and** researchers.

By way of contrast, another study reported that the use of the complementary skills of the professionals and the public improved both the project design and the relevance of the findings (Stockdale et al. 2006) (see Case Study 12). This example again illustrates the importance of recognising the knowledge and experience of all parties involved in a research partnership (Stockdale et al. 2006).

Case Study 11: Community involvement in a randomised controlled trial of an outreach/education intervention to improve the health of children with asthma (Krieger et al. 2002).

This project involved testing an outreach/education intervention designed to reduce exposure to asthma triggers in the home. Different community members were involved at all stages and a parent advisory group was set up to obtain direct input from families affected by asthma.

At the early steering group meetings, community members raised concerns about the design of the trial. They were not happy with the control group not receiving any benefit. A compromise was reached whereby one group received a high-intensity intervention and the other received a low-intensity version. However, this also compromised the results of the trial.

In the end the findings were not as convincing because of the lack of a control group. This made it harder to find funding to sustain the project activities. Therefore a new **proposal** was developed for a second study that included the proper controls.

Case Study 12: A collaborative study to investigate organisational capacity to form partnerships around mental health and substance abuse care (Stockdale et al. 2006).

This project aimed to develop a conceptual understanding as well as practical measures of 'organisational capacity' in order to help health and social care organisations develop partnerships to deliver mental health and substance abuse care. The team of academic researchers worked with local community organisations and found this collaboration to be of great benefit.

The collaboration affected the design of the project in terms of deciding which geographical areas to target and which community agencies were asked to participate. For example, the researchers were persuaded of the need to include the full range of organisations serving people with mental health and/or substance abuse disorders, not just the standard mental health and drug treatment sectors.

Most importantly it shifted the fundamental goals of the project towards issues of more relevance to the community partners. Instead of taking an academic approach, which would have looked at the barriers and facilitators to implementing a specific intervention, the researchers were encouraged to take a more holistic approach. This involved a more general assessment of the capacities of organisations as well as their individual strengths and resources.

The researchers concluded that their collaboration with community partners allowed the study to overcome the limitations of both traditional academic as well as conventional community approaches. It successfully combined researchers' knowledge with the wealth of community participants' experiential knowledge. This made the researchers more aware of some of the real-world dynamics of community partnering and ensured the study looked at the specific aspects of organisational capacity that were most relevant to the different organisations.

Impact on research tools and methods

In a number of studies, public involvement has provided researchers with background information about the people being invited to take part in their research (Burrus et al. 1998; Rhodes et al. 2002; Schulz et al. 2001). This information has proved valuable in helping researchers to adjust their research tools and methods to better suit the community concerned (Barnard et al. 2005; Burrus et al. 1998).

The overall effect of this involvement has been to make research projects more accessible, for example:

- a researcher who worked with young people found his research was made more accessible by avoiding the language used by adults (McLaughlin 2006).
- able-bodied researchers who worked with disabled people learnt the importance of using participants' own words to describe their disability (Minkler et al. 2002). This proved valuable during interviews and when recording data.

- a researcher who worked with African-Americans learnt not to use the term 'key informant' to refer to interviewees. The word 'informant' has very negative connotations for this community, as it is used to refer to people who betray other community members (Stockdale et al. 2006).

Researchers have also concluded that the 'right' people must be involved, in the same way as the selection of participants is crucial (Dona 2006). This is essential when targeting a specific community. For example, in a study of the lives of children in institutions in Bangladesh, the researchers involved children who were living or working on the streets. However, these children only knew about the lives of children in similar circumstances and not about the lives of children in institutions. This bias had an impact on all aspects of the research process – the selection of participants and the questions that were asked. It made the researchers realise that there needs to be a close match between project advisors and the participants, to ensure that their advice is useful and relevant (Dona 2006).

Impact on research tools

The evidence suggests that where the public have been involved in developing research tools such as surveys, questions for interviews and focus groups, **patient information sheets** and promotional leaflets, they have improved them in a number of ways. These include (Miller et al. 2006; Minkler et al. 2002; Petrie et al. 2006):

- making sure the right language is used (Lammers & Happell 2004), so that the wording is appropriate and accessible (Faulkner 2006; Smith et al. 2008)

- improving the way questions are phrased (Miller et al. 2006; Wright et al. 2006) and ensuring they are asked in ways acceptable to the local community (Rowe 2006; Smith et al. 2008)

- providing ideas on how to obtain information from participants in a less structured, more informal way (Miller et al. 2006)

- ensuring the questions are sensitive to community concerns and issues (Burrus et al. 1998; Smith et al. 2008) as well as being culturally relevant (Krieger et al. 2002; Stiffman et al. 2005; Viswanathan et al. 2004)

- weeding out questions that would not work and replacing them with ones that would (Butcher 2005)

- bringing in subject areas for questioning and exploring nuances that would have otherwise been overlooked (Broad & Saunders 1998; Wyatt et al. 2008)

- ensuring the length of a questionnaire is appropriate (Krieger et al. 2002).

Public involvement has also changed the way that surveys have been conducted (Schulz et al. 2001). Researchers have reported that testing out draft questionnaires with the public has improved their reliability (Viswanathan et al. 2004). Involving the public in deciding **how** to collect the information has also helped to improve response rates (Smith et al. 2008). This in turn has improved the quality of the data (see below – impact on data collection).

Impact on research methods

Where the public have been consulted about research methods, they have helped to make sure that the methods are workable (Hanley et al. 2001; Smith et al. 2008) and that studies are carried out in a way that makes it easier for people to participate. For example, mental health service users involved in a study of community care identified potential problems for the users being asked to take part in focus groups (Truman & Raine 2001). They explained to the researchers that

their peers would find it difficult to work in a group and that the side-effects of medication would limit people's ability to take part in discussions. The researchers then realised that their chosen method was not appropriate for this particular group and that they needed to change their approach.

Researchers have also gained valuable feedback from public involvement during the course of a research project, as one clinical researcher described, **'They [the patients] played a pivotal role in providing "front line" intelligence on how the trial was being received during its development and execution',** (Hanley et al. 2001 p.521).

In another **qualitative** study, a service user acted as an independent observer of a number of focus groups. This person took notes and provided helpful feedback to the researchers on whether their approach had been consistent and appropriate, and whether all the participants had been given an equal opportunity to contribute (Ross et al. 2005).

Impact on recruitment

A review of community participation in research found that involvement has often had a major impact at the recruitment stage of a research project and has generally helped to increase participation rates (Viswanathan et al. 2004)

In a project where the public were involved in choosing the research topic, the relevance and importance of the research question alone was reported to have increased recruitment and retention rates (Plumb et al. 2004)

Where the public have been involved in developing and implementing recruitment strategies, or have helped to troubleshoot in projects where there was

low recruitment (Hewlett et al. 2006), they have had a major impact on the levels of participation. In particular, their involvement has:

(a) improved access to potential participants

(b) improved the information provided to potential participants

(c) ensured recruitment procedures were sensitive to the needs of the participants

(d) enhanced the credibility of the research project and researchers

(e) helped to engage seldom heard groups

(f) encouraged and motivated their peers to take part

(g) provided commitment, energy and enthusiasm

These will now be discussed in turn:

(a) improved access to potential participants

In some projects, people with insider knowledge of local communities have provided researchers with advice on the best ways to contact and access potential participants (Allen et al. 2006; Burrus et al. 1998; Rhodes et al. 2002). They have helped with negotiating access to relevant community members/community leaders (Allen et al. 2006; Hanley et al. 2001), or have simply known the best times and places to visit particular communities (Dobbs & Moore 2002).

Researchers have also reported that public involvement helped them to recruit people from specific communities because it removed both language and cultural barriers. In a number of projects, community members proved to be very good at recruiting their peers, simply because they spoke the same language (Rhodes et al. 2002).

Researchers have also found that undertaking collaborative research with voluntary organisations has accelerated recruitment, because these organisations have been able to make direct contact with large numbers of patients (Langston et al. 2005; Paterson 2003).

(b) improved the information provided to potential participants

Researchers have reported that public involvement has been of great value when developing information sheets and invitation letters for potential participants. It has helped researchers to develop **'what is basically a better sales pitch'**, (Paterson 2003 p.8). Making changes to the way information is presented, based on the views of patients, has also successfully boosted recruitment rates (see Case Study 13).

Case Study 13: Listening to patients' views improved recruitment to a prostate cancer clinical trial (Donovan et al. 2002).

This project involved carrying out qualitative research in parallel with the recruitment to a clinical trial for prostate cancer. The researchers carried out in-depth interviews with potential participants and listened to tape recordings of the recruitment appointments in order to evaluate the recruitment process.

The initial findings showed that recruiters found it difficult to explain the uncertainty about treatment and did not present the different options equally. They also unknowingly used terms that were misunderstood. For example the term 'watchful waiting' was used to describe the non-treatment arm of the trial. Potential participants interpreted this as if clinicians would **'watch while I die'** (p. 768). Changing this description to 'active monitoring' gave patients

and clinicians much more confidence. As a result of making a number of simple changes to the terms used and the order in which the different treatments were presented, recruitment rates were increased from 40% to 70%.

This study illustrates how research can benefit from a more in-depth evaluation of recruitment processes. Although there is a danger that such an approach may seem coercive, the researchers concluded that in fact the study became more ethical over time, as participants received clearer information and were thus able to make a more accurately informed decision about whether to participate. (See also Section 4.3).

(c) ensured recruitment procedures were sensitive to the needs of the participants

Some research projects have benefited from public involvement in the early stages, because the people involved helped to develop more sensitive recruitment and research procedures (Bryant & Beckett 2006). For example, a group of researchers working with Aboriginal communities at first found recruitment very difficult. Community members were often unwilling to identify themselves or to provide researchers with their contact details. This was easier to understand once the researchers had learnt more of the history of discrimination and past policies of removing Aboriginal children (Holmes et al. 2002). Working with community members helped them to address people's fears and to develop greater community trust in the project (See Case Study 29).

Researchers have also reported finding public involvement particularly important when researching sensitive topics with seldom heard groups. For example, a UK study of post-natal depression found that involving South Asian women as co-researchers was essential to

recruitment from this community, because of the cultural sensitivity around this topic (Smith et al. 2008). (See also Case Study 14).

> **Case Study 14**: A research project to study ethnic and sexual minority women's experience of domestic violence and service needs (Krieger et al. 2002).
>
> Representatives from community agencies serving different groups of ethnic and sexual minority women were involved at all the stages of this project. Their involvement proved crucial to recruiting women to discuss such a sensitive topic. Some women only participated because there were bicultural, bilingual domestic violence advocates involved, who could vouch for the researchers and the project. The researchers concluded that recruitment would have failed if they themselves had asked **'…victims of domestic violence to tell their stories to strangers'** (p. 371).
>
> The involvement of community members also ensured the safety of participants in ways that the researchers would not have otherwise considered. For example, the researchers were advised to screen out past perpetrators from the lesbian/bisexual/trans group, and were only able to do this with the use of screening tools developed by the relevant community agency. Without their help, a potentially dangerous situation could have occurred with perpetrators and victims sitting together around a focus group table.

(d) enhanced the credibility of the research project and researchers

Where the public have acted as the 'public face' of a research team, the evidence suggests they have given both the research project and the researchers greater credibility (Rhodes et al. 2002; Viswanathan et al. 2004). For example, in a research project involving Alaska Natives, community members were typically more successful in recruiting participants than the researchers (Allen et al. 2006). This was because they gave legitimacy to the claims that the project was being conducted in partnership with the community (Allen et al. 2006).

Similarly, in a study of community health in Seattle, a 77% success rate in recruitment was in part attributed to the active involvement of community agencies. The participants reported that the involvement of community members increased their confidence in the project (Krieger et al. 2002).

(e) helped to engage seldom heard groups

The public have also been reported to be particularly skilled at engaging remote parts of the community and/or speeding up recruitment from seldom heard groups (Abma 2005; Beer et al. 2005; Dobbs & Moore 2002; Plumb et al. 2004; Rhodes et al. 2002; Elliott et al. 2002). For example:

- users of forensic mental health services successfully recruited people who would not normally take part in research by publicising the project around hospital wards (Faulkner 2006)
- peer researchers involved in a study of intravenous drug-use dramatically reduced the time required to define the target population and to access and recruit participants (Coupland et al. 2005)

- involving **peer interviewers** in research into the experiences of parents who use illegal drugs enabled the researchers to interview a group of people **'who would have been difficult, if not impossible... to reach in any other way'**, (Elliott et al. 2002 p.176).

Public involvement has thus helped researchers to recruit a highly diverse sample (Minkler et al. 2002; Elliott et al. 2002). This has again enhanced the quality of the data, as more and different kinds of people have contributed to the research (see below – impact on data collection).

(f) encouraged and motivated their peers to take part

The evidence suggests that public involvement has been particularly effective in improving recruitment to research where the demands of a project are high. This is because community members know how best to motivate and encourage their peers (Abma 2005). For example, in a study of diabetes within a black community in the United States, the involvement of a well-known and respected black health educator proved crucial to developing a successful recruitment strategy. The research team believe this approach was essential to encouraging the community to take part, particularly as the survey involved giving blood samples and a follow-up medical exam (Burrus et al.1998).

(g) provided commitment, energy and enthusiasm

Community members are commonly reported as being very committed to their particular community and highly conscientious in their approach to research. Because of this, they have often been observed to make **'strenuous efforts to increase recruitment rates at every opportunity'**, (Dobbs & Moore 2002 p.167).

For example, a 50% response rate to a health promotion survey in the United States, was attributed to the work carried out by community partners to gain advance publicity for the study (Minkler et al. 2006). Similarly, an 81% response rate to a survey in a deprived community in Detroit, was attributed to the efforts of the community members hired and trained as interviewers (Schulz et al. 2001). (See also Case Study 15).

Case Study 15: A user-led study to develop a psychosocial intervention for women with breast cancer (Angell et al. 2003).

This study was initiated by breast cancer survivors living in a rural community in California. They formed a partnership with academic researchers to develop and evaluate a community-based workbook/journal to support women with breast cancer in geographically and economically isolated communities. They conducted a randomised controlled trial to assess the effectiveness of the workbook/journal.

Involving community members in recruitment to the trial resulted in an 83% recruitment rate and 98% retention. The researchers attributed this high level of success to:

- integrating the insights and experience of community partners into the recruitment process
- allowing (and budgeting for) the recruiters and potential participants to meet several times if necessary
- the skill of the community recruiters
- the endorsement of the study by the community.

The researchers concluded that it is important to be open to new ideas on how to approach and assess potential participants. This is vital for the recruitment of underserved and understudied groups, whose culture and level of trust are often different to the people who usually take part.

Negative impacts of public involvement on recruitment are rarely reported (Viswanathan et al. 2004). One researcher described how recruitment rates were reduced in their clinical trial because the patients involved felt it was unacceptable to send continued reminders to people who had not responded to earlier approaches (Hanley et al. 2001). Some researchers have also expressed concerns about:

- bias in recruitment caused by community members engaging highly motivated people who are not representative of the broader population (Viswanathan et al. 2004)
- young co-researchers potentially reducing recruitment rates if they are actively disliked by their peers (McLaughlin 2006).

Impact on data collection

Public involvement has been reported to have had an impact on both the data collection process and the quality of the data obtained. Sometimes the impact has been positive and resulted in better response rates, better quality data and more reliable information. On other occasions the impact has been negative. These different impacts will now be discussed in turn.

Better response rates

The evidence suggests that when the public have been involved at all stages of a project, their involvement has helped to create a sense of shared ownership of the research. This has increased participants' commitment to the study, which has in turn increased response rates and reduced the number of drop-outs (Viswanathan et al. 2004) (See also Case Study 16). The quality of the data has thus been improved (Warren & Cook 2005), at the same time generating more representative information on which to base decisions (Burrus et al. 1998).

Case Study 16: The involvement of the National Association for the Relief of Paget's Disease (NARPD) in the PRISM (Paget's disease: a randomised trial of intensive versus symptomatic management) clinical trial (Langston et al. 2005).

The NARPD was extensively involved in this trial from the very beginning. The Chief Executive became a member of the Trial Steering Committee and NARPD members were involved both in reviewing the trial protocol and influencing its ongoing conduct.

This involvement had a positive impact on recruitment, but the researchers concluded that the main advantage was **'the harnessing of a well-informed and interested population, who developed a sense of ownership of the trial'** (p. 83). This meant the participants were highly motivated to complete questionnaires, resulting in a 98% response rate. This greatly improved the quality of the trial data.

Better quality data through peer researchers

Involving the public as peer interviewers (or as co-facilitators of focus groups) has been reported to enhance the collection of qualitative data. This is because it generally enriches and improves the quality of any discussion (Faulkner 2006; Gillard & Stacey 2005; Johns et al. 2004) (see also Case Study 17).

Case Study 17: Involving service users and carers in prioritising topics for cancer research (Wright et al. 2006).

This study involved patients and carers as co-facilitators of focus groups with people affected by cancer. The researchers concluded that this collaboration made the groups more successful, improving the quality of the data they collected. This was because:

- the co-researchers helped to blur the distinction between researchers and patients. This made the participants feel more at ease, generating better discussion. The participants also felt more confident to discuss a range of topics, rather than focusing on what they thought would be of interest to the 'experts'.

- the co-researchers could draw upon their own experiences of cancer which helped to stimulate and guide the discussion and often prompted participants to respond.

- the co-researchers were more aware and sensitive to the needs of participants, and thus enhanced the ethical acceptability of the study.

Research projects which have involved peer interviewers have reported being able to **'reach parts which other research does not meet',** (Broad & Saunders 1998 p.11) because peer interviewers have helped to open up more subject areas for discussion.

Peer interviewers have also gained more in-depth information (Faulkner 2006), because as experts in the area under investigation, they have been able to probe more fully and to ask people the right questions (Abma 2005; Elliott et al. 2002).

Peer researchers have also succeeded in getting responses from their peer group in ways that would not have otherwise been possible (see also Section 4.6). For example:

- when children have been interviewed by child researchers, they have given different responses than when interviewed by adults (Broad & Saunders 1998; Kellett et al. 2004; Kellett 2006).

- a project that involved people with experience of intravenous drug use as peer interviewers, found the quality of the interview data to be much improved. This was because participants were more willing to disclose sensitive information to someone they perceived to be an 'insider' (Coupland et al. 2005).

- researchers working on a project that involved homeless people, concluded that the depth and richness of the information they collected was due to the involvement of peer researchers (Butcher 2005). One of the homeless people involved commented, **"For homeless people to be involved in researching homeless issues is vital… With the trust this engenders people won't mind telling you things that they might otherwise hold back",** (Butcher 2005 p.30).

- researchers working with mental health service users on an evaluation of services found that adopting the terminology and the more sensitive approach suggested by users, **'contributed significantly to the development of rapport and trust with the research participants, which ultimately influenced their willingness to share their opinions and experiences in an open and honest manner,'** (Lammers & Happell 2004 p.265).

- peer interviewers working with parents who use illegal drugs claimed that they could **'develop a rapport with interviewees, which someone who had never had problems with drug use, even as an experienced researcher, would be unable to reproduce',** (Elliott et al. 2002 p.175).

This impact of public involvement appears to have been unexpected and highly valued. Some researchers have expressed surprise at the extent and personal nature of the information that participants have been willing to share with peer researchers (Rowe 2006). They have also commented that the quality of the data they collected far exceeded their expectations (Coupland et al. 2005).

This impact of involving peer interviewers appears to be particularly important in the context of research which seeks service users' views on services. It seems to be essential to obtain more honest and reliable information. When professionals have interviewed users about services, both the interviewees and the professionals have reported feeling compromised. Service users can be afraid that any adverse comments will impact on their care (Philpot et al. 2004; Rose 2004), whilst professionals can find it hard to listen to any criticism (Coupland et al. 2005). Some professionals have reported **'trying to justify the service's position instead of listening to the views of the patients',** (Coupland et al. 2005 p.196). Involving peer researchers has been found to be an effective way of avoiding these tensions and ensuring that the research **'gets out users' real ideas'**, (Beresford 2007 p.337). (See Case Studies 18 and 19).

Case Study 18: User involvement in mental health research (Rose 2004).

In this study, user researchers and clinical academics worked together to review users' perspectives on electroconvulsive therapy (ECT). The review included articles and published testimonies from users. The academic articles reported much higher levels of satisfaction with ECT than either the user-led studies or the testimonies. The standard explanation is that the user-led research relied on biased sampling. However, based on their experience of having received ECT and having been interviewed about this treatment, the two user researchers on the team concluded that something else was going on.

The articles that reported the highest levels of satisfaction involved interviewing people as soon as the treatment ended and typically the questions were asked by the treating doctor. The user researchers concluded that under these circumstances users would not want to complain or might not tell the truth – to avoid more treatments or simply get rid of the doctor. They therefore argued that the academic papers were over-estimating user satisfaction with ECT. This led to novel conclusions being drawn from the review. Importantly the findings were fed into the National Institute of Clinical Excellence's appraisal of ECT and resulted in the criteria for treatment being made more restrictive.

Case Study 19: A comparison of two types of interviewer in an evaluation of mental health services (Clark et al. 1999).

In this study, a client satisfaction survey was first developed with client involvement. Subsequently two different methods were used to collect information on clients' satisfaction with mental health outpatient services. Clients were either interviewed by staff or by other clients.

Overall, there was little difference in satisfaction levels between the staff-interviewed and the client-interviewed groups. However, the clients did give more extremely negative responses to client interviewers than to staff interviewers. It seems that when clients are very dissatisfied with a service, they are more likely to disclose this to their peers. This is probably due to greater feelings of safety, trust and confidentiality.

The researchers concluded that involving clients in service evaluation results in more valid feedback and that client involvement should be increased at all stages.

However involving peer interviewers has sometimes been reported to have had a negative impact on data collection (Bryant & Beckett 2006; Elliott et al. 2002). In these cases, the 'shared experience' between the interviewer and interviewee seems to have limited discussion, so that certain issues have not been fully explored or recorded in the interview notes (Bryant & Beckett 2006; Elliott et al. 2002). In one project, this occurred because the peer interviewers tended to view certain topics as 'old hat' (Elliott et al. 2002 p.175). In another project, researchers concluded this had happened for the following reasons (Bryant & Beckett 2006):

- the peer interviewers had been relatively inexperienced and had not known to probe for further information or to check their understanding of what the interviewees had said
- the interviewees did not elaborate on certain points, because on the basis of their shared experience, they had assumed that the interviewer understood them
- the interviewers did not explore some points, because they had assumed they had understood the interviewee, again because of their shared experience
- the interviewer had not wanted to seem intrusive, because of an increased empathy with the interviewee, so they had not always 'pushed' the interviewee to develop a point.

The researchers have concluded that these kinds of problems could be avoided by providing appropriate support and training to improve the interviewing skills of user researchers (Bryant & Beckett 2006; Johns et al. 2004). (see also Section 4.10).

Impact on the analysis of data

Some researchers have stated that they remain unconvinced that the public has much to contribute to this stage of research (Hewlett et al. 2006). However, others have found involving the public in data analysis to be of great value, particularly when analysing qualitative data (Schulz et al. 2001).

At the most basic level, researchers who have discussed their initial interpretations of data with the public have reported that it has helped to check the validity of their conclusions (Rhodes et al. 2002). With greater levels of involvement, the public have added an extra dimension to data analysis, by contributing alternative perspectives on emerging themes and trends (Barnard et al. 2005; Beer et al. 2005; Clark et al. 2004; Johns et al. 2004; Minkler et al. 2002; Ross et al. 2005).

Public involvement has been reported to enhance the clarity and depth of the interpretation of qualitative data by:

- correcting researchers' misinterpretations (see Case Study 20)

- identifying themes that researchers would have otherwise missed (see Case Study 21)

- highlighting the findings most relevant to patients or the public (Beer et al. 2005; Ross et al. 2005)

- challenging the perceptions of researchers and changing the way in which results have been described in reports (Faulkner 2006).

Case Study 20: A collaborative project to research African American child health (Savage et al. 2006).

Community members worked with health nurse researchers on all stages of this project. It involved an ethnographic study of the culture of pregnancy and child care among African American women. The researchers described numerous examples of how working with community members benefited the study, including an example of how they helped with understanding the information they gathered.

During one of the interviews, a participant complained about all the "black bars" in her neighbourhood. The interviewer initially interpreted this statement as referring to African American bars selling alcohol. However, it was only through the insight provided by one of the community partners that the interviewer realised the participant was actually referring to some newly-built, black, wrought iron fences. The community partner explained that a number of these fences had been built to discourage criminal activity and that they were very unpopular with the local residents.

Case Study 21: The added value of working with disabled people on research related to disability (Fisher 2002 p. 310).

The researcher working on this social work research project found that involving a group of disabled people brought a number of benefits, including help with the analysis of data. On one occasion, while analysing interview transcripts with user researchers, the researcher reported that he **'was struck by how much attention was being given to a passage where a user described the panel [meeting] to assess his case... as a 'hearing'.**

Because there were no other similar descriptions in the rest of the transcripts, the researcher initially felt this quote should not be given that much importance. However, the user researchers then explained how **'disabled people are always having to focus on what they can NOT do... and that this passage therefore connected with a much wider sense of oppression'.**

Following his experience of involvement, the researcher concluded that **'there are...grounds to question whether researchers can ever develop the same degree of sensitivity to issues as other people who have experience of them, particularly where the issue concerns discrimination or oppression'.**

Where the public have been involved in the analysis of data, it has also had the knock-on effect of enhancing their level of commitment to a study (Ross et al. 2005). Again this has created a greater sense of ownership of the results and thus increased the likelihood of action being taken in response to the findings (see Section 4.9).

Impact on writing up and dissemination

There have been few reports of the impact of public involvement on writing research publications, which in part reflects the fact that users are rarely involved at this stage of research (Smith et al. 2008). One researcher reported that incorporating users' conclusions into their final report made it much more hard-hitting (Sutton & Weiss 2008). Another described how the advice of young co-researchers improved the 'user-friendliness' of their research publications, making them more accessible to other young people (McLaughlin 2006).

At a more general level, researchers working in the field of disability research have reported on the benefits of seeking input from the public when developing written materials (Rosenbaum 2005). They have found this to be of particular value when writing up the results of research, because it makes the information much more useful to the target audience (Rosenbaum 2005). These researchers have also found that when materials are written in plain English, they become more accessible to a broad range of audiences, not just service users and carers (Rosenbaum 2005).

There has been a greater level of public involvement in the dissemination of research results, where it has been reported to increase the likelihood of people acting on the findings. For example, in a community-based participatory research project, involving community members in reporting back the findings encouraged **'further rich dialogue'** amongst the various **stakeholders**. It also ensured continued community involvement in the development of **'plans for subsequent education and action',** (Minkler et al. 2002 p. 27).

Collaborations between researchers and the end-users of research have encouraged both the direct use of research (i.e. changing policy and practice) as well as its more conceptual use (i.e. changing awareness, knowledge and attitudes) (Walter et al. 2003). Researchers have also reported that involvement in dissemination has had practical benefits in that it has:

(a) helped to engage the target audience

In one research project, the commitment and enthusiasm that users brought to the dissemination phase proved crucial to making sure that all the relevant local agencies were made aware of the results (Rowe 2006). In other projects, service users and carers have drawn upon their own networks to inform a much wider range of people about the findings (Barnard et al. 2005).

(b) made the findings more accessible and the messages more powerful (Smith et al. 2008)

Researchers have reported this has been of particular value when presenting results at conferences or at meetings with other stakeholders. User presenters have been very persuasive because they have related the findings directly to their own experience (McLaughlin 2006) and demonstrated a sense of conviction about the research (Broad & Saunders 1998). One researcher commented that **'without doubt the participation of young people in presentations of the results to professionals brought home some of the findings and recommendations more powerfully than if they had been presented by the researcher alone',** (Petrie et al. 2006 p.44).

(c) enhanced the credibility of the findings

One research commissioner commented that **'Hearing it directly from service users improves the validity and the weight of the findings from the perspective of councillors and service managers',** (Johns et al. 2004 p. 56).

(d) helped devise novel forms of feedback

In a number of projects the public have suggested novel ways of sharing the results of the research in order to have more of an impact on the target audience (see Case Study 22). In another project which was led by people with schizophrenia, the user researchers developed and performed a theatre presentation of the results and recommendations (Schneider et al. 2004). This had a powerful impact on the health professionals who attended (see Section 4.9).

Case Study 22: Involvement of mental health service users in research (Gillard & Stacey 2005).

A group of mental health service users who were involved in a number of research projects took a novel approach to sharing their findings with professionals. They were concerned that busy people might not find time to read a report, and concluded it would be far more powerful to disseminate their findings through training. They therefore developed a mental health awareness training programme which encouraged professionals to consider the issues around relationships, power and boundaries in their daily practice.

The feedback from the professionals has almost invariably described the training as **'eye opening'** and **'a potential catalyst for change in the way they work'.** (p.30)

Summary – Impact on research design and delivery

Public involvement has been reported to have had an impact on:

Project design

In projects where the public have been involved from the earliest stages, they have helped to reshape and clarify the research question. Public involvement has also influenced what outcomes are measured, as well as how they are measured. As a direct result, research findings have been made more relevant and useful to the end-users.

Research tools

Researchers have reported that public involvement has led to improvements in the design of research tools such as questionnaires, interview schedules and questions for focus groups. Field-testing these tools with the public also improved their reliability.

Research methods

Public involvement has ensured that research methods have worked in practice and that studies have been conducted in a way that has made it easy for people to participate.

Recruitment

Public involvement has been reported to have led to increased participation rates. In particular the public have:

- improved access to potential participants
- improved the information provided to potential participants
- ensured recruitment procedures were sensitive to the needs of the participants
- enhanced the credibility of the research project and researchers
- helped to engage seldom heard groups
- encouraged and motivated people to take part
- provided commitment, energy and enthusiasm.

Negative impacts of public involvement on recruitment have rarely been reported.

Data collection

Different types of involvement have been reported to have different kinds of impact on data collection and quality. By increasing a sense of ownership of a research project, it has increased participants' response rates to questionnaires and thus enhanced the quality of the data.

Involving the public as peer interviewers (or as co-facilitators of focus groups) has been reported to enhance the collection of qualitative data and increase its relevance and reliability. This impact seems to have been unexpected and highly valued.

The evidence suggests that involving peer interviewers in research into services is especially important to obtain honest and reliable feedback on treatments and services.

However, there are also reports of some negative consequences of involving peer interviewers. In some cases, the 'shared experience' between the interviewer and interviewee has been found to limit discussion, so that certain issues have not been fully explored. These problems can be addressed by providing appropriate support and training to improve the user researchers' interviewing skills.

Analysis of data

Involving the public in the analysis of qualitative data has been reported to be of great value. Researchers have found that public involvement has helped them to:

- check the validity of their conclusions
- correct their misinterpretation of data
- identify themes that they might have otherwise missed
- identify which findings would be most relevant to patients or the public
- improve the way in which results have been described in reports.

Where the public have been involved in this stage of a project, it has also had the knock-on effect of enhancing their level of commitment to a study. This has created a greater sense of ownership of the results and thus increased the likelihood of action being taken in response to the findings.

Writing up

There have been few reports of the impact of public involvement on writing research publications. Where the public have been involved, researchers have found involvement helped to make reports more hard-hitting, accessible and useful to the target audience.

Dissemination

Public involvement in dissemination has been reported to increase the likelihood of people acting on the findings. Collaborations between researchers and the end-users of research have encouraged both the direct use of research (i.e. changing policy and practice) as well as its more conceptual use (i.e. changing awareness, knowledge and attitudes). The effects of involvement at this stage have been to:

- help engage the target audience
- make the findings more accessible and the messages more powerful
- enhance the credibility of the findings
- help devise novel forms of feedback.

4.3
Impact on research ethics

Public involvement has been reported to impact on research ethics by:

- improving the consent process
- helping researchers to develop ethically acceptable research.

These will now be discussed in turn.

Impact on the consent process

Public involvement in the development of **patient information sheets** has been reported to make the information clearer and more accessible to people considering whether to take part in research (Beer et al. 2005; Miller et al. 2006; Nilsen et al. 2006; Paterson 2003; Wright et al. 2006). Most often researchers have described how this has then had an impact on recruitment rates (see Section 4.2). However, if people are better able to understand a research project and are clearer about what taking part will involve, they are also better equipped to make an informed decision about their participation (Donovan et al. 2002).

There has been one study which has assessed the impact of involving patients in writing patient information sheets via a **randomised controlled trial**. This project found that involvement made little difference to people's level of understanding of the information (see Case Study 23). However, the researchers acknowledge that there were limitations to their research, which may limit the significance of their findings (Guarino et al. 2006).

Case Study 23: A comparison of different patient information sheets (Guarino et al. 2006).

This study compared two different patient information sheets in a **clinical trial** for Gulf War veteran illnesses. One sheet was developed by the researchers and the other was developed by the researchers and then edited by a **focus group** of Gulf War veterans. The study investigated whether this made any difference to the **participants** in the clinical trial.

The findings showed that there was very little difference between the two groups receiving the different information sheets, either in terms of participants' understanding, the overall recruitment rates, or participants' level of satisfaction and adherence to the trial. However, the researchers have identified a number of limitations to the study which may explain these results. These include:

- the researchers had considerable experience in writing patient information sheets and the focus group did not make any dramatic changes to the document
- the clinical trial was not particularly complicated and carried relatively low risk
- the study population (Gulf War veterans) are well educated and already accustomed to reading complicated documents
- the questionnaire used to measure participants' experience of the consent process had not been validated prior to the trial and may not have been very sensitive to change

The lack of a significant difference might also be explained if the conversation between participants and recruiters is a more important factor in the consent process than the actual content of the patient information sheet.

Involving the public in the recruitment process has also been reported as having an impact on the level of coercion experienced by some participants. One researcher who worked with young Aboriginal people on a research project commented:

'Aboriginal people may feel under pressure to participate when asked directly by researchers, but feel more free to decline when asked by peers. We could add that peers, probably because they are both more sensitive to subtle indications of lack of willingness and less concerned about the implications of a poor response rate, are less likely to pressure participants...', (Holmes et al. 2002 p.1273).

In another study the involvement of local community members in an advisory committee proved crucial to participants understanding the purpose of the consent process and agreeing to sign consent forms, as the researcher described:

'One part of my research was to work with people in the study sites and record my observations and informal conversations; however, before I could record anything I needed people to sign a consent form. Whilst people were happy to talk to me they were very reluctant to sign any form... At the next meeting of the advisory committee I shared this issue with the group. The African-Caribbean members of the group felt that this problem had occurred because the elders often worry that signing official-looking papers might in some way affect their benefits or rights. In order to overcome this, [some of the advisory group members] said

that they would come down to the centre and talk to people about the consent forms and explain why I needed their signatures. This proved to be very successful and, following their input, 26 people signed consent forms', (Tetley et al. 2003 p. 20).

Improving the ethical acceptability of research

In a number of studies, public involvement at an early stage of the project has helped to identify potential ethical concerns, as well as ways to improve the ethical acceptability of the research (Hanley et al. 2001; Smith et al. 2008) (see Case Studies 24 and 25).

Case Study 24: Consulting women with breast cancer about a controversial clinical trial of hormone replacement therapy (HRT) (Marsden & Bradburn 2004).

Researchers had concerns about whether it would be ethical to carry out a trial of the use of HRT in women with breast cancer, because the risks of recurrence are so high. However, many women were asking for HRT to treat the menopausal-like symptoms caused by their cancer treatment. These symptoms can have a significant, negative impact on women's quality of life. So there was also the possibility that some women might want to accept the risks, if they could be guaranteed relief from their symptoms.

To find out what women with breast cancer thought about running such a risky trial, breast cancer patients were consulted about these issues and asked to identify relevant outcomes. The aim was to develop an acceptable clinical trial protocol that would increase the likelihood of women taking part.

The consultation showed that women with breast cancer were in favour of the trial going ahead. They emphasised the importance of assessing quality of life as an outcome of the treatment. They also helped design different aspects of the protocol, for example indicating when it would be appropriate to invite women to participate (soon after starting their treatment).

The women also commented that trial participants should be provided with better information about the side-effects of cancer treatment, to help them decide whether they wanted to take part. They thought that gaining properly informed consent would therefore become quite time-consuming. However, they urged the researchers to take on board these suggestions, not as a means of speeding up recruitment, but as a way of ensuring a higher-quality process.

Case Study 25: Patient involvement in the design of a clinical trial of a new treatment for stroke (Koops & Lindley 2002).

Prior to this study, it was known that thrombolytic treatment for stroke was of benefit to a highly selected group of patients treated within three hours of the onset of their stroke. There was also some suggestion that the benefits might extend to a wider range of patients, but with a definite risk of fatal brain haemorrhage.

The researchers knew they would have to run a large clinical trial to find out the precise risks and benefits. Along with the potential serious risks, they also knew it would be difficult to obtain people's consent because patients with acute stroke are often unable to communicate. This problem was made even more difficult by the fact that the treatment had to be given within a time window of a few hours.

The researchers therefore involved patients during the design stage of the trial by running focus groups with people who had experience of a stroke as well as their carers. The groups confirmed that the trial was acceptable and also suggested solutions for some of the ethical dilemmas. These included being more specific about the potential risks and benefits, emphasising the importance of the discussion of the trial with the next of kin and (contrary to accepted best practice) suggesting that doctors have a role in a consent process if relatives are unavailable.

The researchers made many changes to their patient information leaflets as a result of this exercise. They also concluded that this involvement helped with gaining approval for the trial from a national ethics committee.

Summary – Impact on research ethics

Public involvement has been reported to impact on research ethics by:

Improving the consent process

Public involvement in the development of patient information sheets has made the information clearer and more accessible for people considering whether to take part in a research project.

Improving the ethical acceptability of research

Public involvement at an early stage of project development has helped to identify potential ethical concerns as well as solutions to these ethical problems.

4.4
Impact on the public involved

The evidence suggests that public involvement has both positive and negative impacts on the public involved. The **positive** benefits include:

a) acquiring new skills and knowledge

b) personal development

c) support and friendship

d) enjoyment and satisfaction

e) being rewarded financially.

There are fewer reports of involvement having a **negative** impact on the people involved, but in these cases, the public have had a bad experience as a result of being:

a) emotionally burdened

b) overloaded with work

c) exposed through the media

d) frustrated at the limitations involvement.

These different impacts will now be discussed in turn.

Positive impacts of being involved in research

a) New skills and knowledge

By being involved in research, many people report having gained new knowledge, in particular:

- A better appreciation of research and the processes involved (Leamy & Clough 2006; Minogue et al. 2005; Ramon 2000). For example, activists involved in the development of a breast cancer research programme described dramatic changes in their expectations of what research can discover and how long it takes (McCormick et al. 2004).

- A better understanding of current issues in their community (Cotterell et al. 2007; Lammers & Happell 2004; Meyer et al. 2003), learning more about other people's lives (Cotterell et al. 2008; Wood 2003) and becoming more aware of different opinions and viewpoints (Beer et al. 2005). For some people this has had a major impact on their beliefs and assumptions:

'...undertaking the survey enabled researchers to gain new understandings both of others and of themselves. Many of the [user] researchers had been exposed to parents whose views and priorities in relation to family life were quite different to their own. ...For some the revelation that others, within the same community, lived their lives quite differently had a significant impact on them. Being exposed to many different ways of life had mostly led them to re-evaluate their own assumptions' (Rowe 2006 p. 469).

- An in-depth understanding of research topic under investigation (Minogue et al. 2005; Ross et al. 2005).

- Practical knowledge that could directly benefit their peers (Coupland et al. 2005; Lammers & Happell 2004).

Many people have also reported learning new skills through involvement, in a similar way to receiving 'on the job training' (Bryant & Beckett 2006; Clark et al. 2004; Coupland et al. 2005; Dona 2006; Faulkner 2006; Krieger et al. 2002; Ramon 2000). For some people, these have been skills directly related to research, for example, questionnaire design, interviewing skills and **data analysis** (Beer et al. 2005; Faulkner 2004; Leamy & Clough 2006; Minkler et al. 2002; Rowe 2006). Many have also increased their research skills over time, as one researcher described: **'Co-researchers took on increasingly complex tasks [as the project progressed] and offered increasingly probing critiques regarding methodology, analyses and interpretation',** (Allen et al. 2006 p.56).

Other people have acquired more general skills that are transferable to other areas of work for example computer skills (Beer et al. 2005; Faulkner 2004), listening and communication skills (Minogue et al. 2005; Rowe 2006) and an ability to work in a team (Clark et al. 2004; Faulkner 2006). For this reason, some people concluded that their involvement experience would improve their future employment prospects (Butcher 2005; Coupland et al. 2005; Johns et al. 2004; Krieger et al. 2002).

Following involvement in research, some user researchers have enrolled in higher education (Allen et al. 2006; Wood 2003). Others have found opportunities to continue working in research (Dobbs & Moore 2002) or have successfully secured long-term employment (Wood 2003). For example:

- In a study where the public were involved in conducting baseline surveys for a regeneration project, 50% of the people involved had found further employment within three months of completing the work. In several cases they were exploring ways of acquiring additional qualifications to continue working in research or had gone on to participate in further voluntary activity linked to area-based regeneration (Dobbs & Moore 2002).

- In a project where disabled people were involved in an evaluation of local social services, one of the user researchers was so encouraged by their experience that they signed up to become a tutor for the local expert patient programme (Johns et al. 2004).

- People involved in forensic mental health research said that they had found involvement to be a valuable 'stepping stone to work' (Faulkner 2006). One of the service users reported that **'the project had given him payment, a commitment to regular hours and had made him known to the tax office. He is now self-employed and living in the community'**, (Faulkner 2006 p.14).

- Some parent researchers who were involved in an evaluation of a Sure Start Programme went on to further education, including being trained as 'Additional Learner Support Workers' at their local college. Some also used their new skills to continue working within the Programme (Rowe 2006).

- Children who have been involved in research have benefited from developing skills that are relevant to their future studies. These include skills in organising and managing their work, analysing and evaluating information as well as problem-solving and critical thinking (Kellett 2006).

b) Personal development

The public very frequently report benefiting personally from involvement, most often through a general increase in their self-confidence (Beer et al. 2005; Cotterell et al. 2008; Coupland et al. 2005; Dickson & Green 2001; Dobbs & Moore 2002; Dona 2006; Faulkner 2006; Hewlett et al. 2006; Johns et al. 2004; Kellett 2006; McLaughlin 2006; Ramon 2000; Rowe 2006; Weinstein 2006; Wood 2003). More specifically, some people have reported feeling more confident about speaking up in groups (Rhodes et al. 2002) and in giving presentations (Minogue et al. 2005).

They have also often reported an increase in their self-esteem (Bryant & Beckett 2006; Cotterell et al. 2008; Coupland et al. 2005; Dickson & Green 2001; Kellett 2006; McLaughlin 2006; Minogue et al. 2005; Weinstein 2006) and an enhanced sense of self-worth (Kellett 2006). People have come to recognise their own strengths and abilities (Dickson & Green 2001) as well as those of their team members (Faulkner 2006). They have gained self-respect from having contributed to research that they considered to be worthwhile (Dobbs & Moore 2002).

The experience of being actively involved has also been reported as being 'empowering' (Hewlett et al. 2006). People have felt better able to 'get their voices heard'. For example, after taking part in a health research project, Aboriginal women felt encouraged to '[speak] up and out on issues they felt strongly about, advocating for themselves and for the larger Aboriginal community', (Dickson & Green 2001 p. 473).

Involvement has helped the public to realise that their views do matter and are of value to others (Clark et al. 2004; McLaughlin 2006). For child researchers in particular, this has led to 'a virtuous circle of increased confidence and raised self esteem, resulting in more active participation by children in other areas of their lives', (Kellett 2006 p.13). For example, some children have become more 'politically active' as a result of being involved in research, writing to councils and corporations to express their views about issues that concerned them (Kellett et al. 2004).

Some service users have also reported that involvement has been an important step in their own personal recovery. For example, one service user researcher who took part in a study of alcohol abuse described how hearing other people's stories helped him to understand his own sobriety process. He also felt he benefited from listening and offering others support (Allen et al. 2006). Similarly Aboriginal women involved in a study of older women's health reported an increase in their well-being from 'learning other coping skills, establishing new social support systems, and reclaiming their traditional role', (Dickson & Green 2001 p. 473).

A service user group that has frequently reported benefits from involvement are mental health service users. People with mental illness are often marginalised in society and being involved in research has helped to restore their sense of 'being normal' (Minogue et al. 2005; Ramon 2000). It has also made a tremendous contribution to people's quality of life (Schneider et al. 2004). Some people report improved mental health as a direct result of involvement (Faulkner 2004; Minogue et al. 2005) and many comment on the importance of resurrecting lost skills as well as enhancing their self esteem and self confidence (Clark et al. 2004; Ramon 2000). One researcher who worked with a group of people with schizophrenia described the impact that involvement had on the group as follows:

'There was a real transformation in group members' sense of themselves as people who could accomplish something... At the beginning of the project, they could not conceive of themselves as people who could do research. By the end of the project, they had taken on a sense of themselves as researchers... This experience increased their awareness of themselves as people with resources and strengths who could make a significant contribution to society', (Schneider et al. 2004 p.575).

c) Support and friendship

Service users have reported that they have greatly benefited from working with a team of their peers, particularly from making new friends (Hewlett et al. 2006), meeting people with different experiences and backgrounds (Broad & Saunders 1998; Faulkner 2004) and gaining additional social support (Bryant & Beckett 2006; Dickson & Green 2001; Minogue et al. 2005; Schneider et al. 2004).

For example:

- A researcher who worked with a group of people with diabetes reported that **'the opportunity to exchange information with other people with diabetes was clearly an important factor. At times, the group functioned more as a mutual support group than an advisory group. This was an important aspect of the group experience and necessary for group cohesion'**, (Rhodes et al. 2002 p.406).

- People affected by cancer have commented that involvement strongly contributed to their survival strategy by helping them to focus on things that are positive and productive, combating the isolation imposed by cancer and gaining support from other people (Cotterell et al. 2008).

- One carer described the impact of being involved for her personally as follows:

'My involvement… had filled a void left by my husband dying and I am now able to help in any way I can… I have met and become friends with some lovely people who are also members of the team. We chat and share day-to-day events and problems and we also have some laughs. We have had meetings at different venues, opening up new horizons, making life interesting again', (Tetley et al. 2003 p.22).

Bonding and working together as a group has also been reported to impact on people's capacity to engage with the research, as one researcher commented, **'Developing expertise as a group gave users the confidence to ask fundamental questions of the research'**, (Lindenmeyer et al. 2007 p.272).

d) Enjoyment and satisfaction

Many people who have been involved in research have reported that they enjoyed 'feeling useful' (Cotterell et al. 2008; Wyatt et al. 2008), having made an 'unexpected' positive contribution and having been able to 'give something back', (Beer et al. 2005; Hewlett et al. 2006; Johns et al. 2004; McLaughlin 2006; Wyatt et al. 2008).

They were pleased to find that their lived experience was of value (Clark et al. 2004; Hewlett et al. 2006; Johns et al. 2004) and gained a sense of satisfaction from turning a negative experience into something much more positive (Bryant & Beckett 2006; Butcher 2005; Clark et al. 2004; Cotterell et al. 2007; Cotterell et al. 2008; Hewlett et al. 2006; Paterson 2003; Warren & Cook 2005).

Many have also reported that they enjoyed:

- being part of a team (Bryant & Beckett 2006; Minogue et al. 2005)

- being able to concentrate on someone else and forget about themselves (Broad & Saunders 1998; Cotterell et al. 2007)

- having regular employment (Bryant & Beckett 2006)

- meeting and talking to different kinds of people (Warren & Cook 2005)

- being involved in something meaningful and personally stimulating (Cotterell et al. 2008).

They got a sense of achievement from having:

- offered a different perspective on research (Ross et al. 2005)

- contributed to the creative elements of the research (Ramon 2000)

- made a difference to a project (Cotterell et al. 2008; Dona 2006; Hewlett et al. 2006; Minogue et al. 2005)

- investigated what they regarded as an important topic (Minogue et al. 2005; Schneider et al. 2004)

- helped to produce what they hoped would be a significant and influential research report (Butcher 2005)

- been rewarded for their efforts (Hewlett et al. 2006) and recognised for their contribution (McLaughlin 2006)

- helped other people by making a positive contribution to their community (Leamy & Clough 2006; Minogue et al. 2005)

- conquered the challenge of undertaking tasks that were mentally/intellectually challenging (Beer et al. 2005; Cotterell et al. 2008).

For many people these positive benefits of involvement have helped them to overcome some of the more negative and challenging aspects of being involved, as one service user described:

'We felt that we had made a difference, no matter how small. Although many negative feelings and emotions had hit us over the past three months, we never regretted our involvement… While we have experienced many ups and downs, our hope of helping to change the lives of others has pulled us through a hard but equally enjoyable project… we have gained confidence, friends and pride (in ourselves)', (Petrie et al. 2006 p.42).

e) Financial rewards

People who have been paid for their involvement reported that they valued an opportunity to earn money (Clark et al. 2004; McLaughlin 2006; Ramon 2000) and felt it appropriate that they received a regular (and fair) payment for their contribution (Beer et al. 2005).

Negative impacts of being involved in research

a) Emotional burdens

People who have been involved as interviewers have sometimes reported that hearing about the hardships of their peers has been emotionally difficult and has caused them to relive their own painful memories (Broad & Saunders 1998; Cotterell et al. 2007; Petrie et al. 2006). As one researcher described:

'Some of the things the interviewers were told affected them, brought certain things up for them, and they found it hard just to swallow their feelings and carry on', (Broad & Saunders 1998 p.10).

Peer interviewers have also felt burdened by the confidential knowledge to which they were privy as a result of research interviews, (Broad & Saunders 1998; Meyer et al. 2003). For example, the young people involved in a study of the health needs of young adults leaving care, found it very distressing to hear some of the interviewees report having been abused in care. The peer interviewers felt ill-equipped to deal with this issue, particularly as it had not been previously discussed during training (Broad & Saunders 1998). The researchers concluded that they needed to improve the training and offer more formal support to deal with these kinds of problems more promptly (Broad & Saunders 1998).

Some **user researchers** have also found conducting interviews to be a huge responsibility (See Case Study 26). They have found it difficult to ask people about their problems and then 'just leave them'. They have felt responsible for making people upset as well as frustrated at not knowing what to say and not being able to offer help immediately (Broad & Saunders 1998; Meyer et al. 2003; Rowe 2006).

Case Study 26: Community involvement in a health needs assessment (Meyer et al. 2003).

The user researchers in this American study carried out a lengthy and detailed health survey of Hispanic women in the local community. The level of detail and range of topics covered by the survey led many of the **participants** to believe that the user researchers would be able to answer all their health-related questions. This put the user researchers under a great deal of pressure. They felt overwhelmed by people's high expectations and were also alarmed by the greater than expected levels of need. The user researchers frequently had to explain that they were unable to help and had to find a way to do this **'without jeopardizing newly gained trust or the credibility of the project'. They found that 'setting personal boundaries was an enormous challenge, especially when working within underserved communities'.** (p.829)

Expecting user researchers to cope with these kinds of emotional burdens without adequate training and support is ethically unacceptable (See Case Study 27) as individuals may consequently be put at risk of further ill-health (A User Focus Monitoring Group 2005).

Case Study 27: User involvement in mental health research (A User Focus Monitoring Group 2005).

This project involved mental health service users in a study of acute psychiatric services. However, it did not adequately prepare the users for what was involved. The user researchers were only given a half day's training prior to carrying out interviews. They were not given any advice on how to deal with difficult situations, or what to do if the interviewees were unwell. This caused a lot of distress.

Some interviewers found the interviews upsetting, as one person described:

'Some people we interviewed found it a relief to be able, at last, to talk to someone about their experiences... It was good for them to realise that they weren't on their own. These interviews initially were easy to cope with, but after interviewing a few like this, it left some interviewers distressed. Some of the interviewers had been patients at the hospital and it just brought back to them the feelings associated with their own experience of being a patient there. Some of the interviewers were shocked and numbed with the realisation that it was not the occasional patient but so many patients who had such a bad experience...' (p.44)

The system that was set up for debriefing after interviews also failed. This meant that the user researchers ended up **'downloading on each other'.** (p.44) This had an impact on some people's mental health. Some of the user researchers were taken seriously ill and even hospitalised due to the stress.

However, in spite of these very negative experiences the user researchers concluded that even with hindsight they would have still got involved. This is because they **'gained knowledge, confidence and expertise, became stronger as individuals and as a group, and learned to value themselves'.** (p.46) Very importantly for them, positive changes also took place as a result of the research. This meant they achieved their ultimate goal - ensuring that **'Life for acute patients on the ward had significantly improved'.** (p.46)

People affected by cancer have reported other emotional burdens from their involvement in health service development and/or research (Cotterell et al. 2008). Some have been upset by the loss of their fellow team members through a re-occurrence of illness (Cotterell et al. 2007). Others have found it difficult to cope with the insensitive views and opinions expressed by professionals. For example, some doctors have discussed poor prognosis in a very detached way in project meetings. Similarly some researchers have discussed the futility of drug trials for people at the end of life without apparent concern, although this has been alarming and distressing for the users and carers. People with cancer have therefore commented on the importance of preparing and equipping people before they get involved, so that they are better able to protect themselves from these kinds of emotional experiences (Cotterell et al. 2008).

b) Work overload

There has been one report of a mental health research project where the user researcher was so overloaded with work that they experienced a relapse. The academic researchers recognised they were somewhat to blame for this situation. They only recruited one user researcher and had not made arrangements for adequate support (Clark et al. 2004) (see Case Study 28). In spite of being committed to user involvement, they recognised they had failed in not following best practice.

Case Study 28: User involvement in mental health research (Clark et al. 2004)

This study involved a service user in a review of the literature on adult mental health services. The user researcher was responsible for carrying out a large amount of the reviewing but had little back-up. She had no previous experience of delivering large reports within very tight timescales, and found this very stressful. In addition, the guidance offered by an expert panel may have made the situation worse. The panel saw their job as ensuring that the work was rigorous and robust and so they sometimes asked very challenging questions. These were interpreted as criticism by the user researcher, who was not familiar with the academic culture. After four months in post the pressure of work contributed to the user researcher becoming unwell and taking time out from the study to recover.

This was very difficult for the research team. On a practical level it meant that they had to take on additional responsibilities which had not been anticipated. However (and much more importantly) on a personal level, they had to come to terms with the fact that their efforts to involve users in research had made someone

unwell and that they had not provided sufficient support. They concluded, **'For people writing about responsiveness to the needs of users, it was a major irony and an important lesson that we had become so focused on delivering the research on time that we failed to notice that a valued colleague was feeling under excessive pressure'.** (p.35)

c) Personal exposure through the media

A few user researchers have reported being personally exposed through inappropriate media coverage of the research project in which they were involved. For example:

- Following a study of teenage pregnancy, two of the user researchers received a lot of negative media attention, which was **'very unpleasant and personally distressing'**, (Petrie et al. 2006 p. 42). The results of the research were inaccurately reported which was of great concern to the user researchers, both as contributors to the project and as teenage parents. As the professional researcher commented: **'Of course, many academic researchers on a high-profile project will have concerns about possible media distortion of their findings. However, such concerns do not usually have any personal resonance'**, (Petrie et al. 2006 p.42).

- During a study of acute mental health services, a draft document was leaked to the press which 'caused a media frenzy'. One of the user researchers was inundated by visits from the press at home which made his life very difficult and caused some distress (A User Focus Monitoring Group 2005).

d) Frustration at the limitations of involvement

People have at times reported feeling frustrated with their involvement. This has been for different reasons. Sometimes they have felt frustrated at not being able to influence the research establishment. Sometimes they have felt restricted by either financial or health considerations, and sometimes they have felt anxious about how much the research costs (Paterson 2003).

Most commonly, people have felt frustrated at being powerless and unable to change the direction of research. This is usually because they have not been involved until after the **research proposal** has been written and agreed. Then there has been **'no means of altering what seems to be carved in stone'**, (Faulkner 2004 p.16). For example, in a project involving parents in a Sure Start evaluation, lack of time and resources meant that some aspects of the research **protocol** had been agreed before the parent researchers were included (Rowe 2006). This resulted in **'some stifling of the creativity offered through local involvement, frustrating the parent researchers who would have taken a completely different approach'**, (Rowe 2006 p. 472). However, the researchers in this study also commented that similar frustrations are felt by professionals when they are asked to deliver research to a pre-determined brief (Rowe 2006).

User researchers have also reported feeling frustrated at not being able to do more for the participants in a study (Cotterell et al. 2007), particularly when the ultimate goal of the research is to improve people's lives. As one researcher described:

'**The controlled linear research process of agreeing the focus of study, identifying and collecting the required data, analysing this before drawing conclusions and making recommendations based on these was too passive for some...**
For many their initial motivation [for involvement] was to support local families... and whilst the participatory... [approach] was more inclusive than many traditional models of research, it was only able to satisfy these ambitions to some extent', (Rowe 2006 p. 471).

One of the other frustrations for user researchers is that once the project comes to an end, so does their research role (Faulkner 2006). Some people have felt that their newly-developed skills have then been wasted and their experience underutilised (Warren & Cook 2005).

Summary – Impact on the public involved

Public involvement has been reported to have had both positive and negative impacts on the people involved. The **positive benefits** include:

New skills and knowledge

By being involved in research, people report that they have gained new knowledge, in particular:

- a better appreciation of research and the processes involved
- a better understanding of current issues in their community
- an in-depth understanding of the research topic under investigation
- practical knowledge that could directly benefit their peers.

Many people have also reported learning new skills through involvement. These skills might be directly related to research, or more general skills that are transferable to other areas of work. Some people expected that their experience would improve their future employment prospects. Children who have been involved in research have benefited from developing skills that are relevant to their future studies.

Personal development

The public have very frequently reported benefiting personally from involvement, most often through a general increase in their self-confidence and self-esteem. The experience of active involvement is often reported to be 'empowering'. Some service users have also found involvement to be an important step in their own personal recovery.

Support and friendship

Patients and carers have reported that they have greatly benefited from working with their peers, particularly from making new friends, meeting people with different experiences and backgrounds, and from gaining peer support.

Enjoyment and satisfaction

Many people who have been involved in research have reported that they enjoyed:

- feeling useful
- being part of a team
- being able to concentrate on someone else and forget about themselves
- having regular employment
- meeting and talking to different kinds of people
- being involved in something meaningful and personally stimulating.

Financial rewards

People who have been paid for their involvement reported that they valued an opportunity to earn money and felt it appropriate that they received a regular (and fair) payment for their contribution.

For some people these positive benefits of involvement have helped them to overcome some of the more negative and challenging aspects of being involved.

There are fewer reports of involvement having a **negative impact** on the people involved, but in these cases, the public have had a bad experience as a result of being:

Emotionally burdened

People who have been involved as interviewers have sometimes found it difficult to hear about the hardships of their peers. It has also reminded them of their own negative experiences. User researchers need training and support to deal with these issues.

Overloaded with work

Work overload has on occasion caused user researchers to become ill and leave a project. Lack of support was a critical factor.

Exposed through the media

There have been a few examples of user researchers being personally exposed through inappropriate media coverage of their research project.

Frustrated at the limitations of involvement

People have sometimes reported feeling frustrated with their involvement. The most common reason is that they have felt powerless to change the direction of research.

4.5
Impact on researchers

Public involvement has been reported to have both positive and negative impacts on researchers. The **positive** benefits include:

a) a better knowledge and understanding of the community

b) enjoyment and satisfaction

c) career benefits

d) challenges to beliefs and attitudes.

The reports of **negative** impact include:

a) an increased demand on resources and a slower pace of research

b) loss of power

c) forced changes in working practice

d) challenges to values and assumptions.

These different impacts will now be discussed in turn.

Positive impacts of public involvement on researchers

a) A better knowledge and understanding of the community

Researchers have often commented on how much they have learnt from working with the public (Minkler et al. 2002; Wyatt, et al. 2008). In the context of community based participatory research, public involvement has given researchers a much better understanding of the local area and culture from the perspective of community members (Petrie et al. 2006), as one researcher described:

'The contribution of the young people was incalculable. It would not have been possible for the researcher to understand the culture and socio-economic context of young people without the help of the Young People's Advisory Group' (Petrie et al. 2006 p. 44).

This 'insider knowledge' has also helped researchers to:

- find the most appropriate ways to be invited into communities and develop culturally acceptable research procedures (Allen et al. 2006) (see Section 4.3)
- improve the design and delivery of the research to better reflect the community's needs and interests (McLaughlin 2006; Petrie et al. 2006) (see Section 4.3)
- gain a much more informed perspective from which to interpret findings (Allen et al. 2006; Ramon 2000)
- feel less isolated from the community (Rhodes et al. 2002).

In the context of health related research, researchers have similarly benefited from a greater

understanding of a health condition and its impact on people's lives (Hewlett et al. 2006; Ross et al. 2005), as one researcher described:

'Working with a person who has a disability helps researchers to feel what it is to live with that disability. It makes them more aware of the limitations people with a disability encounter in daily life, and that will challenge them to adjust their method to these limitations', (Abma 2005 p.1325).

b) Enjoyment and satisfaction

Some researchers have found working with the public to be a rewarding (Hewlett et al. 2006) and **'satisfying, even enjoyable'** process (Faulkner 2006 p.14). They have made new friends (Hewlett et al. 2006) and even found it fun (Broad & Saunders 1998), particularly as the public have brought a lot of energy and enthusiasm to their work (Paterson 2003). Researchers have said that they have also enjoyed **'seeing the world with different eyes, being trusted, cared for, valued',** (Broad & Saunders 1998 p. 11).

c) Career benefits

Some researchers have reported that working with local communities on public health projects has had an impact on their career. This is because they have received public recognition for their community work, as well as internal recognition and validation from their university employers (Parker et al. 2003).

d) Challenges to beliefs and attitudes

Researchers have reported that their beliefs and attitudes have been challenged by public involvement (Hewlett et al. 2006). It has sometimes made them question their views of service users, as one researcher described:

'Having a service user as part of the team made other team members try to consider how users would think and feel in mental health services and when reading our report. It made us challenge our own assumptions, consider our language and to be very honest and open with ourselves about our attitudes and values,' (Clark, et al. 2004 p.34).

It has also changed researchers' attitudes to public involvement itself. The direct experience of working with the public **'often moves researchers from a position of compliance to one of enthusiasm',** (Paterson 2003 p.22).

Negative impacts of public involvement on researchers

a) Higher demands on resources and a slower pace of research

Many researchers have commented that working with the public has proved resource intensive, requiring the investment of a lot of time, energy and money (Broad & Saunders 1998; Holmes et al. 2002; McLaughlin 2006; Rhodes et al. 2002; Trivedi & Wykes 2002; Wright et al. 2006; Wyatt et al. 2008). It has required a great deal of commitment, particularly since the rewards are rarely gained within a short timeframe (Walter et al. 2003).

This has led to some frustration, as one researcher described:

'On the downside was the time-consuming nature of running the group, including numerous telephone calls and letters, and frustration when the group strayed from the immediate task in hand', (Rhodes et al. 2002 p. 408).

Researchers have found that they have had to learn to work at the pace of the people they involve. For example when working with young people, researchers have had to adapt to the **'requirement to go at the young service user's pace and... to accept that the lives of young people move to a different rhythm'**, (McLaughlin 2006 p. 1406). This becomes particularly difficult when there are competing demands, or when funders' deadlines dictate that the work must be completed within a short space of time. Sometimes this leads to frustration all round (Minkler et al. 2002), as one researcher, who worked with a group of disabled people, described:

'Competing...time demands were complicated still further by the realities of "DP" or "disabled people" time – the often inevitable delay in any life activity... due to bad weather, illness, or physical barriers (e.g. an inoperable bus lift or rapid-transit elevator). The frequent need to change scheduled meetings or begin them one hour later than the appointed time sometimes created tensions when the university or funding cycle deadlines proved difficult or impossible to meet', (Minkler et al. 2002 p. 24).

As a result of public involvement, research time frames and agendas have often had to be changed from those set out in **research proposals**. Researchers have reported having to negotiate with funders to agree changes to project milestones (Minkler et al. 2002; Ross et al. 2005).

b) Loss of power

Involving the public inevitably means researchers have to give up some of their power (Beer et al. 2005; Lindenmeyer et al. 2007). Although many researchers have recognised that this shift is essential for projects to become genuinely collaborative (Faulkner 2006), no one has reported finding it easy, as one researcher described:

'The researchers did not always enjoy the experience of being part of the group – as the patients frequently made suggestions as to what they would like to discuss...It was difficult to begin with to make the shift from researcher, to taking a more participative role, thus relinquishing the control we, as academics, had assumed over the years', (Sutton & Weiss 2008 p. 237).

c) Forced changes in working practice

Researchers have concluded that working in partnership with the public requires specific skills that are different to those required for mainstream research (McLaughlin 2006; Rowe 2006; Savage et al. 2006). These skills are often new to the researchers (Walter et al. 2003):

'...the professional researcher needs to be truly inclusive and respectful of untrained colleagues... they can be seen as acting as a facilitator, enthusiast and occasional adviser rather than a directive leader of the work', (Rowe 2006 p. 472)

Although learning new skills has been described as a benefit by some (McLaughlin 2006), more often than not, it has proved to be a difficult challenge (Walter et al. 2003). This is because researchers have found it hard to:

- find the right balance between contributing their research expertise and enabling the public to make their own contribution, as one researcher described:

  'We needed to convince [user] researchers that we were credible researchers so that they would have confidence in what we were doing. This 'expert role' needed to be balanced with an 'empowering or facilitative role' where we created an atmosphere in which [the user researchers] felt able to challenge us and propose alternative ways of doing things' (Leamy & Clough 2006 p.21)

- strike a balance between a project acting as **'a mechanism for learning... (and one therefore in which mistakes could be viewed as helpful) and a project as a piece of work requiring sound and useful findings for the commissioners',** (Rowe 2006 p. 472)

- let others set the agenda, as one researcher described:

  'At times it was tempting to step in when the patients' views did not match our own, but as we learned to step back the patients became more confident to the point where, at times, we felt superfluous to requirements', (Sutton & Weiss 2008 p. 237).

d) Challenges to researchers' values and assumptions

Researchers have reported that public involvement has on occasions caused organisations to question their traditional ways of working (McLaughlin 2006). This has been uncomfortable for some, as one researcher described:

'The process of involvement... made [the Project Leader] think more broadly about the relevance of much academic research and its usual impact on services. This was more of an uncomfortable experience, but proved to be a useful learning exercise [as it created] a desire to be able to disseminate the project findings in ways to maximise their impact', (Bryant & Beckett 2006 p.105).

Summary – Impact on researchers

Public involvement has been reported to have both positive and negative impacts on researchers. The **positive benefits** include:

A better knowledge and understanding of the community

Researchers have commented on how much they have learnt from working with the public. Public involvement has helped them develop a greater understanding of a health condition, or of a particular local area or culture.

Enjoyment and satisfaction

Some researchers have found working with the public to be a rewarding process. They have made new friends and found it to be fun, particularly as the public often bring a lot of energy and enthusiasm.

Career benefits

Some researchers have reported that working with local communities on public health projects has had an impact on their career, because they have received public recognition for their community work, as well as internal recognition and validation from their employers.

Challenges to beliefs and attitudes

Researchers have reported that their beliefs and attitudes have been challenged by public involvement. It has sometimes made them rethink their views of service users and changed their attitude towards involvement itself.

There are also reports of involvement having a **negative impact** on researchers through:

Higher demands on resources and a slower pace of research

Researchers have commented that working with the public has required a lot of time, energy and money. This has led to some frustration. Researchers have also had to renegotiate timescales and deadlines with funders.

Loss of power

Researchers have commented that involving the public inevitably means giving up some power. Although many researchers have recognised that this shift is essential for projects to become genuinely collaborative, no one reported finding it easy.

Forced changes in working practice

Involving the public requires specific skills, which are often new to the researchers. Although this has been described as a benefit by some researchers, others have described it as a difficult challenge.

Challenging researchers' values and assumptions

Public involvement has on occasions caused organisations to question their traditional ways of working. This has been uncomfortable for some researchers.

4.6
Impact on research participants

Involving the public in research has been reported to benefit the people who then take part in the research. These benefits include:

- a better research process
- helping people to feel more at ease in interviews
- providing emotional support
- providing access to information and services
- offering hope and inspiration.

These will now be discussed in turn.

A better research process

Public involvement during the early stages of a project has been reported to make it easier for people to take part in research. This is because the whole approach has become more sensitive to **participants**' needs and more acceptable to the target group (Parker et al. 2003). For example, the involvement of patients has been generally reported to make **clinical trials** more user friendly (Hanley et al. 2001). More specifically, it has helped to minimise the distress and disruption of some research procedures (Paterson 2003).

However, public involvement at this stage has sometimes caused tension between the researchers and the people involved. This is because of a conflict between **'the researchers' needs to implement protocols in a timely fashion'** and the public's interest in minimising **'the burden of research activities on participants',** (Krieger et al. 2002 pp. 366-7). (see Section 4.8)

Helping people to feel more at ease in interviews

The involvement of **peer interviewers** has been reported as having a major impact on interviewees. Interviewees have reported:

- feeling a greater sense of shared experience and understanding with their interviewers (Miller et al. 2006)
- feeling more comfortable and relaxed (Bryant & Beckett 2006)
- perceiving the encounter to be less threatening and less hierarchical (McLaughlin 2006)
- being more willing to talk and raise issues they might not have done otherwise (McLaughlin 2006)
- being more honest and sharing their true experiences and views (Butcher 2005; Holmes et al. 2002; Johns et al. 2004; Schneider et al. 2004).

The evidence suggests this has been especially important for seldom heard groups of people or for people who have a distrust of being interviewed by 'officials'. For example:

- for people with mental health problems, being interviewed by a peer researcher **'offered a talking space to explore their mental health without some of the fears, barriers and constraints that characterised many of their other experiences of talking about mental health'**, (Gillard & Stacey 2005 p. 29).
- for people with disabilities, the experience of being interviewed by professionals has sometimes felt like **'a test of their ability to defend themselves against possible harmful intrusion'**, (Fisher 2002 p. 308). Where people with disabilities have conducted interviews with their peers, they have encountered less defensiveness on the part of the interviewees (Fisher 2002).

- for older women, being interviewed by another older woman made them feel more at ease because of their shared experience and greater sensitivity around the topics of discussion (Warren & Cook 2005).

Participants in **focus groups** have reported similar benefits when the groups have been run by user researchers. They have felt more at ease which has resulted in a richer discussion, as one researcher described:

'Participants have expressed relief and greater comfort when they find other patients involved in the group', (Wright et al. 2006 p.10).

However, this familiarity between user researchers and participants has not always been reported as having a positive impact on research (see also Section 4.2 – impact on **data** collection). For example, in one project there were occasions when the interviewees appeared to over-identify with the peer interviewers and 'expected' them to understand their situation. This meant they sometimes gave less than complete answers. It proved important that the interviewers had been trained to recognise this and had been taught about ways to ask for more detailed responses (Johns et al. 2004).

In some projects, the idea of using peer interviewers has not been welcomed. For example in a project researching older people's health, some of the older community members involved thought it would be inappropriate to interview their peers. They thought that **'some elders would be very wary of sharing their personal experiences with people they knew well, for fear that any personal problems or issues might become more widely known within their community',** (Tetley et al. 2003 p. 21).

Providing emotional support

For some participants, depending on the topic of the research, the process of being interviewed can be a very emotional experience. Some interviewees seem to have benefited from this 'unburdening', particularly when they have been interviewed by their peers (Rowe 2006). For example, in a project where local parents were involved in interviewing other parents in the community, simply being visited and listened to, meeting friendly local people who were interested in them and what they had to say, helped to combat participants' feelings of isolation, (Rowe 2006).

Providing access to information and services

Where the public have been involved in research, they have tended to place much greater emphasis on 'giving something back' to participants than researchers may have otherwise done. In public health related research projects, this has led to participants gaining better access to information about their health and/or relevant services (Coupland et al. 2005; Meyer et al. 2003; Rhodes et al. 2002).

Offering hope and inspiration

Peer researchers have sometimes acted as role models for interviewees (Johns et al. 2004), giving them hope and inspiring them to get more involved in shaping services (Butcher 2005). As one user researcher described:

'...it [public involvement] gave some people who lived without much hope, the opportunity to see that someone had moved on and was able to live and work in the community', (Faulkner 2006 p. 17).

Summary – Impact on research participants

Involving the public in research has also been reported to have had benefits for research participants. These include:

A better research process

Public involvement during the early stages of a project has been reported to make it easier for people to take part in research.

Helping people to feel more at ease

In projects which have involved conducting interviews or focus groups, the involvement of a peer researcher has had an impact on the participants, who have reported:

- feeling a greater sense of shared experience and understanding
- feeling more comfortable and relaxed
- perceiving the encounter to be less threatening and less hierarchical
- being more willing to talk and raise issues
- being more honest and sharing their true experiences and views.

Providing emotional support

For some research participants, the process of being interviewed can be a very emotional experience. Some people appear to have benefited from this 'unburdening', particularly when they have been interviewed by their peers.

Providing access to information and services

The public have tended to place much greater emphasis on 'giving something back' to the participants. This has led to participants gaining better access to information about their health and/or relevant services.

Offering hope and inspiration

Peer researchers have sometimes acted as role models for interviewees, giving them hope and inspiring them to get more involved in shaping services.

4.7
Impact on the wider community

Public involvement in research has also been reported to have had a positive impact on the wider community (i.e. community members beyond those actively involved in a project or those actually taking part in research) as it has helped to:

- create trust and acceptance of the research
- keep projects grounded and focused on benefits for the community
- improve relationships between the community and professionals.

These impacts will now be discussed in turn.

Creating trust and acceptance of research

Researchers have reported that in the past, some communities experienced discrimination or loss of their human rights as a result of bad practice in health-related research. As a result, these communities learnt to distrust researchers and remained reluctant to take part in any study (Schulz et al. 2001). By actively involving these communities in research projects, researchers have been able to develop new partnerships and have re-established mutual trust and respect (Mosavel et al. 2005). Public involvement has thus proved to be a valuable means of promoting local interest and support. It has also helped to dispel community concerns that research is being done solely to benefit researchers (Krieger et al. 2002).

There are numerous examples of projects where public involvement has helped to overcome such barriers to community participation in research (see Case Studies 29 and 30). For some researchers, public involvement has become a

moral and political imperative in these circumstances. It is seen as an essential way of improving current research practice and making up for past wrongdoings.

The evidence suggests that it is important that this type of community involvement continues throughout a project for this benefit to be assured. Regular contact with community members has enabled researchers to alleviate people's concerns as soon as they occur (Dobbs & Moore 2002) (see also Case Study 30).

> **Case Study 29**: A research project that involved Aboriginal young people in a study of their health and well-being (Holmes et al. 2002).
>
> The researchers in this study were aware that in the past Aboriginal people had often experienced research as another form of exploitation. For example, Aboriginal people had been researched by anthropologists who measured their body parts to draw conclusions about their 'primitive' intelligence. Subsequently, medical researchers had focused solely on the 'health problems' within the Aboriginal communities. Community members had always been passive subjects rather than active **participants**, and were never given an opportunity to correct misinterpretations of their culture. The communities who took part in research were rarely informed of the findings and their problems remained unsolved. Historically, it seemed that only the researchers benefited from the process.
>
> Therefore in this study of Aboriginal young people's health, the researchers intentionally adopted a participatory approach as a means of redressing this history of poor practice. They were also responding to current national and political goals to promote decolonisation and self-determination for indigenous people.

Because of the sensitivities around the research, the researchers set up a new ethics committee to involve community members in the review of the ethical issues. The committee monitored the conduct of the research as well as reviewing initial proposals. In addition to this involvement, Aboriginal young people took part in designing and delivering the research. They attended workshops right at the beginning to determine the scope of the study, and were later employed as **peer interviewers** to carry out a local survey.

The researchers reported that the participatory approach did shift people's attitudes and that community members became more positive about research. They also noted that they experienced very little conflict with community members, contrary to some people's expectations of a 'clash of cultures'. As they commented:

'Aboriginal organisations undertaking research have just as much interest in obtaining valid and meaningful results as the academic community. However they wish to retain the right to own the results and approve articles for publication, not in order to 'censor', but to ensure that they are aware of the information being disseminated about their community and to avoid the harmful stereotyping that has occurred in the past. The concern of Aboriginal representatives is that research results be reported with reference to the context, that confidentiality be maintained, and that Aboriginal people are not portrayed as passive victims'.
(pp. 1276-1277)

Case Study 30: A research project that involved black Americans in diabetes research (Burrus et al. 1998).

The researchers in this study were aware that some black American communities were suspicious of taking part in research, because of some well-known instances of historical abuse. They therefore adopted a participatory approach in order to eliminate these barriers to participation and to reassure community members that they could trust the researchers' intentions.

A community advisory board (CAB) was set up to develop the research tools, identify local people to become peer interviewers and promote the project to the local population. The involvement of the CAB proved crucial to the community's acceptance of the research. For example CAB members gave the project much greater legitimacy by agreeing to have their names listed on the back of the promotional leaflets.

The researchers also believe that the CAB members were vital to convincing the community of the benefits of the research, and were much more successful than the researchers would have been. For example, during the course of the study, one of the CAB members heard from another community member that the project was designed by the government to spread AIDS through the black community. Such a rumour could have been devastating since blood samples were being collected as part of the survey. The CAB member was able to correct this rumour and reassure other community members that the project would be of genuine benefit.

The fact that public involvement gives a project local credibility and legitimacy has been reported to be especially valuable when seldom heard groups are involved. Examples include a project that involved Alaska Natives in the US (Allen et al. 2006) and a project that involved South Asian communities in the UK (Rhodes et al. 2002). Participants in these studies were more accepting of the research because the 'public face' of the project was 'someone like themselves' (Rowe 2006). This type of involvement has not only helped with recruitment to studies (Allen et al. 2006; Krieger et al. 2002) (see Section 4.2 – impact on recruitment), but has also encouraged a sense of community ownership of the research which encourages people to take action (see 4.9).

Being involved in research has also increased community understanding of the value of the research. A review of a wide range of community participatory based research concluded that: **'One of the many benefits of making research partners of community members is that they begin to see the long-term gains associated with research, in comparison to the relatively short-term nuisance of data collection activities',** (Viswanathan et al. 2004 p.15).

Keeping projects grounded and focused on benefits for communities

One of the important differences that involving the public has made to research has been to keep the focus on the benefits for a community in the case of public health research, or on the wider group of service users in the case of health and social care research (Allen et al. 2006). As one researcher described:

'They certainly kept the project grounded by reminding us constantly that the patient is at the heart of healthcare and that they saw the project as their opportunity to influence healthcare policy. They…made us question what we were doing, why we were doing it and whose interest it served', (Sutton & Weiss 2008 p. 237).

The members of the public involved in research have sometimes reported seeing themselves as being directly accountable to the rest of their community, as well as feeling responsible for ensuring that any promised benefits are realised, as one researcher described:

'First and foremost, board members viewed themselves as 'guardians' of the community. At each step, they constantly questioned how the community was benefiting and at what costs. Accordingly, they reminded the research team to continuously and diligently explore options for 'giving back' to the community', (Burrus et al.1998 p. 19).

However, the inevitable differences between the interests of a community and those of the researchers/funders have sometimes been reported as a source of tension. Although some people assume that all partners in research are working towards a common goal, this is not always the case, as one researcher commented:

'The ethos of participatory research, where qualified or experienced researchers work alongside lay researchers, who are seen as partners in the research process… where both are accountable to the research funders who guide the direction of the work, assumes a common set of motivations and guiding principles. In reality, this is rarely likely to be true, as each of these tripartite partners… is likely to have at best different and at worst divergent interests in the work', (Rowe 2006 p. 471).

Researchers have reported that they have eased these tensions by ensuring that their research has genuinely delivered tangible benefits to a community. In the early stages of projects this has sometimes involved consulting community members about the direction of the research and providing people with training (Mosavel et al. 2005). In the longer term, researchers have had to redress the balance between implementing interventions and collecting data (Mosavel et al. 2005). Some researchers have therefore redesigned their projects to enable participants to gain immediately from receiving health information or access to services (see Case Studies 31 and 32). Contrary to some researchers' concerns, this has not had a harmful effect on the robustness of the research (Stiffman et al. 2005).

Case Study 31: Involving black Americans in a study of the incidence of diabetes (Burrus et al. 1998).

As a result of public involvement in the early stages of this project, the research team came to realise that local people would be more willing to take part in their survey if they saw it more as a service to meet their own needs, than as a research activity purely to meet the needs of the researchers.

The survey involved measuring people's blood glucose levels to assess the incidence of diabetes. Following discussions with community members, the researchers were persuaded to report back any non-normal measurements to individual participants, so that people would benefit from effectively being screened. The research team worked with community members to produce a list of resources to give to the people found to have health problems. In addition, the researchers also agreed to make follow up telephone calls

to make certain that these people had received the information and understood the need to seek additional care.

Although these activities were not part of the original plan, it was widely agreed to increase the value of the research to the community, with relatively little added cost. As a result, what could have been viewed as an 'intrusive' research project in fact came to be viewed as an 'in-home health fair' for selected households.

Case Study 32: Involving American Indians in research into the health needs of American Indian adolescents (Stiffman et al. 2005)

This project was designed to research the service needs and service use of young people in American Indian communities. The researchers set up a Research Implementation Team (RIT) to help develop the **research proposal**. This included tribal elders, council members, parents and representative young people. The RIT requested that the project address some controversial areas including physical and sexual abuse, HIV-risk behaviours, gay and lesbian activities, as well as drug abuse and mental health issues.

It took three years for the project to be approved for funding, by which time there were new members of the RIT. These people were concerned that the survey planned to ask questions about topics that were not normally discussed in their American Indian culture. They were worried that the young people would become disturbed. To address this concern, the researchers devised a method that allowed the participants to "skip" some of the questions if they wished.

To the researchers this represented an enormous risk because the project could have been crippled by large amounts of missing data.

They also made changes to the design of the questionnaires to make them more culturally relevant. For example, in the substance misuse sections, questions were added to clarify whether tobacco and hallucinogens were used only for traditional ceremonies. Again for the researchers this represented a serious compromise, as it involved making changes to standardised and validated research instruments.

The new RIT members also wanted to provide support to the participants who were identified as having problems. In response to this request, the researchers generated a list of available resources within the community. They gave this to all the young people who were found to be experiencing difficulties, encouraging them to read it and make appropriate calls. They found that a surprisingly high percentage of the young people (90%) had a problem that required directing them to services.

The final analysis of the data showed that the compromises made in the design did not adversely affect the research. The plan that allowed young people to skip parts of the survey was rarely used in practice and did not compromise the data integrity. The researchers concluded that **'One can learn what others' perspectives and priorities are, and find creative compromises that are compatible with each…party's priorities and provide benefits to each'** (p. iii 64) and that by balancing the demands of the community with those of the project they had **'ultimately… accelerated the end goal of all research, [i.e.] to translate research into practice or action'**. (p. iii 64)

In other projects, researchers have engaged in additional follow-up work to ensure that the findings have been used to develop successful health interventions. As a direct result of public involvement, these interventions have been much better suited to the community's needs (see also Section 4.8). For example, involving Alaska Natives in a research project to develop a health promotion intervention resulted in plans that were much more culturally grounded (Allen et al. 2006). The researchers concluded that the culture-specific elements in the plans would make a much stronger case for obtaining funding for subsequent service development.

Similarly, public involvement has resulted in research being more focused on what can be done to help a community, rather than on professionals' views as to how a community might need to change. Greater emphasis has been placed on how agencies **'should-do-more/must-do-better'** than on how communities must change their lifestyles/ behaviour (Broad & Saunders 1998 p.10).

Improving relationships between communities and professionals

As a result of working side-by-side with the public, professional researchers have often reported that their assumptions and prejudices have been challenged and overturned. For example, public involvement in a forensic mental health research project changed the views of some of the healthcare professionals involved, causing one to comment, **'they [the service user researchers] have excelled… we underestimated the people here'**, (Faulkner 2006 p. 15).

The evidence suggests that developing this mutual respect has greatly improved relationships between professionals and community members. This has subsequently had an impact on service development and service use. For example, health professionals working on a project with intravenous drug users found they had developed a much more positive attitude towards this group (Coupland et al. 2005). They came to view them as people to be learned **from**, rather than simply as clients. This experience made them recognise the importance of consulting users when developing services and increased their commitment to further service user involvement (Coupland et al. 2005). At the same time, the user researchers helped to improve relationships between the health professionals and other intravenous drug users. This created a level of trust that they hoped would increase future service use by young people (Coupland et al. 2005).

Public involvement in research has also helped to raise awareness of the capabilities of service users beyond the limits of health and social care services (Wood 2003). For example, in a research project which informed the development of the local Welfare to Work Joint Implementation Plan, the involvement of disabled people as researchers helped to raise disability awareness among local employers. It also provided a direct demonstration of the value of employing and involving disabled people (Wood 2003).

Summary – Impact on the wider community

Public involvement in research has been reported to have had a positive impact on the wider community, as it has helped to:

Create trust and acceptance of research

In the past, some communities experienced discrimination or loss of their human rights as a result of bad practice in health-related research. This made them unwilling to take part in research. By actively involving these communities in new projects, researchers have been able to re-establish mutual trust and respect, and have successfully overcome these barriers to participation.

Keep projects grounded and focused on benefits for the community

Researchers have reported that public involvement helped to keep them focused on the benefits for communities or for a wider group of service users. However, the inevitable differences between the interests of a community and those of the researchers/funders have sometimes proved to be a source of tension. Researchers have reported easing these tensions by ensuring that their projects have delivered tangible benefits.

Improve relationships between communities and professionals

The development of mutual respect through public involvement in research has greatly improved relationships between professionals and community members. This has also led to improvements in services and increased service use.

4.8
Impact on community organisations

In many community-based participatory research projects, staff and/or members of community organisations have been involved as representatives of the local community. These organisations report having benefited from this involvement because they have:

- gained credibility for the other activities they work on (Parker et al. 2003)
- gained credibility as community leaders (Meyer et al. 2003)
- increased their knowledge and understanding of a health or social condition (Parker et al. 2003)
- gained public recognition through disseminating the information to the community and participating in conferences (Parker et al. 2003)
- been able to make a positive contribution that benefits the community (Parker et al. 2003)
- become a link between the mainstream health system and people who want or need to use services (Meyer et al. 2003)
- developed new alliances which has furthered their ability to influence the research agenda (Abma 2005).

However, they have also reported downsides to their involvement, in particular from bearing the costs of the work. The expenses associated with involving people in the early stages of proposal development often occur before any funding is secured. In many cases, these costs have been borne by the patients and/or the patient organisations (Paterson 2003).

On occasion, community organisations have been put in a difficult position when research has led to an increased demand for a service that cannot be met within the limits of the project. For example, some organisations have been 'blamed' for restricting access to much-needed services, because funding has not been available to expand or continue successful pilot programmes (Plumb et al. 2004).

Summary – Impact on community organisations

Staff and/or members of community organisations have been involved in some research projects as representatives of the local community. These organisations have reported benefiting from involvement through gaining knowledge, a higher profile, making links with other community members and making a positive contribution.

However, their involvement has had some disadvantages, including some financial costs. Community organisations have also been put in a difficult position when research has led to an increased demand for a service that is impossible to deliver.

4.9
Impact on implementation/change

Public involvement has been reported to make a major difference to the way research findings are used to bring about change, particularly in developing new services or improving existing ones. This has often involved directly influencing organisations or changing professional practice. On other occasions the impact has been more indirect. It has involved developing the capacity of individuals or establishing partnerships to take further action. These impacts will be discussed in turn.

New and improved services

The evidence suggests that public involvement in health service research has ensured that the community's real needs have been identified and understood. This has led to the development of new types of service and much needed improvements. For example, the involvement of service users in a study of intravenous drug use helped to identify the need for an outreach service in one of the research sites (Coupland et al. 2005). Users also helped to develop this new service. Similarly in a study of Aboriginal health needs, the involvement of young people led to the development of a new clinic (see Case Study 33).

Case Study 33: A research project that involved Aboriginal young people in a study of their health and well-being (Holmes et al. 2002).

Aboriginal young people were involved in designing and delivering this project and were later employed as **peer interviewers** to carry out a local survey.

The study brought about a number of changes to services. The young people involved suggested a separate clinic for their peers.

The researchers therefore collaborated with a local youth group to provide a new clinic at a meeting place for young people one evening a week. This proved to be highly successful.

It also resulted in the introduction of a new model of clinical consultation. In the informal atmosphere of the meeting place, young women often asked whether they could be seen by the doctor with two or three of their friends - each of them bringing their own health question or concern. They seemed to feel more confident in discussing their problems this way than if they had seen the doctor on their own.

In another example, the involvement of mental health service users in a range of research projects within a mental health trust helped to improve the information given to people using those services (Minogue et al. 2005). It also resulted in the continuation of a service which might otherwise have been closed down (Minogue et al. 2005).

Changes in practice

Public involvement in research has also led to changes in the way services are delivered (see Case Study 33 above). In another example people with schizophrenia were involved in a project which investigated the doctor-patient relationship. This led to a change in healthcare practice, by influencing the way psychiatrists and other professionals communicated with their patients (Schneider et al. 2004). The users involved in this study presented their findings in a series of drama performances. At one of these performances, **'a psychiatry resident raised his hand to tell us that as a result of hearing group members speak about their experiences…, he had changed how he interacts with his patients',** (Schneider et al. 2004 p. 576).

Developing the capacity of individuals to bring about change

Researchers have reported that public involvement has often increased people's capacity for further advocacy work by enabling them to form new relationships with key policymakers and local agencies (Holmes et al. 2002). This in turn has enabled the people involved to use their newly acquired skills and confidence (see Section 4.4) to continue to affect community action and change, for example:

- Aboriginal women involved in a project researching older Aboriginal women's health, were given a voice through the project and **'connecting them with others to create alliances'.** (Dickson & Green 2001 p. 480). As the project became more widely discussed in the community the women came to be **'in high demand, to receive visitors and sit on committees, to give their voice and wisdom on many issues',** (Dickson & Green 2001 p. 475).

- in a project that involved older people in research on falls, the researcher reported:

  'There were significant ways in which the consumer panel acted as a 'cohort of advocates' and realised their aspirations to contribute to ongoing local policy development on falls prevention. One example was their participation in key Primary Care Trust (PCT) decision-making groups... the panel soon began to operate as independent participants, attending the PCT falls meetings even when the research nurse was unable to do so... the research team [also] facilitated links between the consumer panel and wider local authority initiatives, such as the Home Safety Project', (Ross et al. 2005 p. 274).

- users involved in an evaluation of a mental health service decided to take action themselves to address one of the perceived gaps in the service identified through the research (Truman & Raine 2001). The same users also established a new group to undertake all further evaluations:

  'A feedback session was organised with users to discuss the early findings... During the feedback session, we discussed how these findings might be used as the basis to develop an evaluation tool... A user's evaluation group was born... Users determined the content of the evaluation tool (a structured questionnaire) and used their own experiences to devise a research strategy oriented around the needs and constraints of other users', (Truman & Raine 2001 p. 224).

- users involved in a study of asthma in Seattle, went on to join the local asthma coalition, helping to develop new Vietnamese and African-American asthma support groups and organising asthma community meetings (Krieger et al. 2002).

Some people who have been involved in research have also become local experts in public involvement. For example in a study involving older people, some of the advisory panel members were subsequently involved in developing strategies for public involvement across local health and social care services (Ross et al. 2005).

Establishing partnerships with capacity to take action

The evidence suggests that public involvement in research has often helped to establish long-term partnerships. This is because working on a research project has helped to break down the barriers between the different **stakeholder** groups involved. Community relationships have thus been strengthened and improved (Burrus et al. 1998; Schulz et al. 2001), as one researcher described:

'Initially, the members of the partnership came from three distinct viewpoints – researcher, stakeholder, or community member. As the partnership progressed, these distinctions became less obvious, especially during the data analysis phase. The formation of the partnership helped to build a [long-term] working relationship... they built trust with each other', (Savage et al. 2006 p. 476).

Researchers have also reported that the processes surrounding public involvement provide **'a catalyst to enhance partnership working more generally',** (Dobbs & Moore 2002 p. 168), as one researcher described:

'The steering committee provided a mechanism to creatively reach mutually agreeable solutions. Such a process can strengthen partnerships by openly addressing differences rather than sweeping them under the carpet', (Krieger et al. 2002 p. 365).

Public involvement has also generated new partnerships with an interest in continuing to work together (Krieger et al. 2002), described by one researcher as **'a strong community coalition interested in confronting the community's problems,** (Burrus et al. 1998 p. 24). Although such partnerships have sometimes taken many years to develop (Schulz et al. 2001), they have

had a major impact in terms of increasing the community's capacity to further progress and change (see Case Study 34). As one researcher commented:

'Once a degree of transparency has been achieved, agencies seemed more willing to share capacity and control, and partners that had previously been marginalised in the decision-making process were more likely to play a central role', (Dobbs & Moore 2002 p.168).

Case Study 34: A research project that involved the local community in developing health promotion activities (Minkler et al. 2006).

This project was one of ten selected for an in-depth evaluation of the impact of community-based participatory research on public health policy in the United States. It was chosen because follow-up activity had continued for over a decade after the original project had been completed. It demonstrates how public involvement in research can bring about sustainable change.

Community members from the town of New Castle, Indiana, were involved in the project via membership of a Healthy Cities Committee (HCC). They helped shape the study and then developed and collected data for a household survey. Crucially they were also involved in analysing the **data**.

The survey data was discussed in **focus groups** and in a multi-stakeholder workshop. This enabled the community to compare its own health status with national norms. They thus came to their own conclusions about their collective heath problems and identified priorities for change.

This seemed to galvanise the HCC and the broader community to move into the action phase of the project. A major outcome of the public involvement in the research was the widespread acceptance of the concept of healthy communities and the community's increased concern about health.

A number of different activities were undertaken following the survey including efforts to get a smoking ban in all City buildings, to build a playground and to develop a land use policy that would promote physical fitness and a healthy environment. These were highly successful. Much of this success was credited to community members and in particular their efforts in:

- holding formal meetings with government officials
- raising awareness through the press
- informal networking
- developing plans and strategies
- getting government support and funding for **proposals**.

The community involvement in this project thus created a strong and dynamic community partnership that was willing to continue to work for change long after the formal research partnership had ended.

At the same time as establishing partnerships, public involvement has also helped to create a sense of shared ownership amongst the various stakeholders. This has made them more willing to act on the findings (see Case Study 35), as one researcher described:

'...statutory agencies, voluntary and community organisations and local people alike generally felt that their views and perspectives had been included in the research, and there was a general sense of agreement that the results were representative of the community. Building a culture of inclusivity ensured that groups and individuals were likely to embrace the results and to move forward on collectively agreed recommendations. This benefit was noticeable in cases where stakeholders had previously been in open conflict and disagreement about service planning... Because all stakeholders recognised the validity of the findings there was agreement on the way forward...' (Dobbs & Moore 2002 p.168).

Case Study 35: A comparison of two approaches to service evaluation, a traditional approach and a user-led approach (Weinstein 2006).

This study compared two approaches to the assessment of a mental health service. These were carried out at different times. The first assessment took the form of a traditional top-down inspection event. Whilst it showed that the service met the required standards, it had much less ownership from service users and staff.

The second assessment was undertaken collaboratively with a user-led agenda. It therefore focused on different priorities. It used a new approach to seeking users' views and achieved a higher response rate. Because users and staff were both involved in the second review, they were more willing to work together afterwards to develop an action plan to make improvements. The project also contributed to a change in the organisation's culture, promoting further user involvement in service development and governance.

Creating broad ownership of research through public involvement seems to be particularly important in projects that aim to increase people's knowledge and awareness and/or change their attitudes and behaviour. For example, a study of different approaches to developing health promotion programmes, showed that these projects are more likely to lead to change if the public are involved in the development, implementation and evaluation stages (Niba & Green 2005).

Summary – Impact on implementation/change

Public involvement has been reported to make a difference to the way research findings are used to bring about change. The changes include:

New and improved services

Public involvement in health service research has helped to ensure that the community's real needs have been identified and understood. This can lead led to the development of new and improved services.

Changes in practice

Public involvement in research can also lead to changes in the way services are delivered.

Developing the capacity of individuals to bring about change

The individuals involved in research have on occasion formed new relationships with key policymakers and local agencies. They have then been able to use their new skills and confidence to continue to affect community action and change.

Establishing partnerships with capacity to take action

Public involvement in research has helped establish long-term partnerships. Although such partnerships may take many years to develop, they have had a major impact in terms of increasing the community's capacity to further progress and change. At the same time public involvement has helped to create a sense of shared ownership. This has made the various stakeholders more willing to act on the findings.

4.10
Factors that influence the impact of involvement

Based on their experience of public involvement in research, both researchers and the public have concluded that there are a number of factors which influence whether involvement makes a difference. The factors which appear to maximise its impact include:

- involvement throughout a research project
- long-term involvement
- training and support for the people involved
- linking involvement to decision-making.

These will now be discussed in turn.

Involvement throughout a research project

The evidence suggests that public involvement has had the greatest impact when people have been involved throughout an entire research project, rather than just at discrete stages (Minogue et al. 2005; Wyatt et al. 2008). This is because the public have been more involved by being able to input from the start. They have also developed a greater sense of ownership of the research as well as a greater feeling of commitment (Faulkner 2006).

One study suggested that limiting involvement to one aspect of a project could at times be detrimental to research (see Case Study 36). Similarly researchers who experienced some initial difficulties with recruitment to their project concluded that **'Many of the problems we encountered might have been avoided if users had participated as fully at the beginning of the research as they did**

at the end', and that **'the quality and validity of our research improved as user participation increased'**, (Truman & Raine 2001 p. 225).

> **Case Study 36**: Involving older people in evaluation of services (Miller et al. 2006).
>
> This study involved older people in designing and conducting interviews with users of services provided by health and social services partnerships. The user researchers had a considerable influence on the research questions used in the interviews, both in terms of their form and content.
>
> Later in the project, some of the user researchers expressed an interest in being involved in the **data analysis**. They were therefore given some additional training by their academic partners. This training made a big difference as it significantly improved the users' understanding of the purpose of the project. More importantly it also improved their interview skills. They were subsequently better able to ask for relevant information from the interviewees. An analysis of the transcripts showed that prior to the training, the user researchers had not asked the key questions as often, and had been unaware of new themes coming up in the discussions.
>
> The academic researchers therefore concluded that involving user researchers at all stages of the research process improves the quality of peer interviews, and that participation in only one part of a project could limit the effectiveness of involvement.

Another study which investigated the impact of involvement on the **dissemination** and the uptake of research findings, concluded that research partnerships are most effective when the people who will use the research are involved in all stages of the research process (Walter et al. 2003). It seems that involvement is less effective when people are just co-opted for the dissemination stage. The researchers concluded that this is because:

'To have an impact, research frequently needs to be translated within local contexts…research is [also] more likely to be taken up where users have had the opportunity to discuss its implications with researchers. Building deep and enduring partnerships facilitates both these processes', (Walter et al. 2003 p. 60).

Long-term involvement

An evaluation of a long-established research panel of users found that a major contributor to its success was the fact that it had been in place for a long time (Lindenmeyer et al. 2007). This meant that:

- users had gained more insight into research
- users and researchers had developed more constructive working relationships and had maintained ongoing interactions
- a general ethos of 'learning from each other' had been established

Another study concluded that ensuring continuity in the membership of a research advisory group helps to maximise its impact by **'aiding cohesion of the group and facilitating a deeper knowledge of, and contribution to the research process'**, (Rhodes et al. 2002 p. 408).

Training and support for the people involved

The evidence suggests that public involvement is more likely to have a positive impact if users first receive appropriate training and then subsequently receive continued support (McLaughlin 2006). This issue has been highlighted in the context of:

Peer interviewing

Conducting an interview can be a complex task and some user interviewers have reported finding the process quite difficult. More specifically, they have found it difficult to keep the interview tightly focused on the research topic and to be certain that a particular discussion is relevant to the project (Leamy & Clough 2006). It is therefore essential for peer interviewers to be properly trained in interviewing skills. Time also needs to be invested in developing a relationship of trust between researchers and **peer interviewers** (Elliott et al. 2002).

Based on their experience of problems with peer interviews, one researcher has concluded that it may be best to have pairs of service user and professional researchers working together (Bryant & Beckett 2006). This would help to maximise the use of the skills and experience of both parties. Another researcher has suggested making more effort to match each individual's level of involvement with their level of skill and experience (Miller et al. 2006). They believe this would help to **'maximise the potential added value'** of their contribution (Miller et al. 2006 p. 203).

Disseminating results

One researcher has commented on the importance of training service users in presentation skills, if they are to be involved in presenting research findings. If this training is not provided, the researcher believes, **'There is a greater danger that the research messages will be lost through poor delivery, insufficient preparation and inadequate presentation. If this does happen, it may not only prevent the research messages being heard but undermine the credibility of the whole research process'**, (McLaughlin 2006 p. 1405).

Linking involvement to decision-making

Some research projects have established advisory groups to provide advice and guidance at all stages. One researcher commented that integrating this group into the management structure of the project, **'ensured the continued visibility and authority of the group and highlighted the value of members' contributions'**, (Rhodes et al. 2002 p. 408).

Summary – Factors that influence the impact of involvement

Based on their experience of public involvement in research, both researchers and the public have concluded that there are a number of factors which influence whether involvement makes a difference. These include:

Involvement throughout a research project

The evidence suggests that public involvement has had the greatest impact when people have been involved throughout an entire research project, rather than just at discrete stages.

Long-term involvement

Over a longer term, involvement is reported to have more impact because:

- members of the public gain more insight into research
- members of the public and researchers develop more constructive, ongoing dialogue
- a general ethos of learning from each other is established.

Training and support for the people involved

Public involvement is reported to be more likely to have a positive impact if members of the public receive appropriate training and continued support.

Linking involvement to decision-making

Some research projects have established advisory groups. Integrating these groups into the management structure of a project can ensure the public's views actually influence decisions.

4.11
Reflections from the literature on assessing the impact of public involvement

Based on their direct experience of public involvement in research, a number of researchers have reflected on the issues around assessing the impact of involvement and predicting where best to involve the public to ensure the greatest 'added value'. The main conclusions have been:

- it is difficult to assess the impact of involvement
- it is difficult to predict where involvement would have the greatest impact
- more work is needed to clarify the added value of involvement in different research contexts

These issues will now be discussed in turn.

Assessing the impact of involvement

Some researchers have tried to assess whether involvement has made any difference to the end results of research and found it challenging (Rhodes et al. 2002). This is because:

- It is often too difficult or too costly to set up a comparison project **without** involvement, to establish the links between involvement and outcomes (Burrus et al. 1998; Smith et al. 2008; Wyatt et al. 2008).
- The most valuable contributions from the public often come from personal interactions with researchers, for example helping to focus researchers' minds on the issues that are most relevant to service users. These kinds of interactions are hard to evaluate or capture

through any form of process evaluation (Lindenmeyer et al. 2007). They are best captured simply by asking for personal reflections on involvement (Bryant & Beckett 2006).

- The public are often involved in research within the context of a committee or steering group. The complexity of decision-making processes in most groups, makes it very difficult to assess the impact of **any** individual on the group's decision, let alone whether the views of the public have had an influence (Caron-Flinterman et al. 2005).
- Involvement activities are interconnected and link to several stages of the research process including prioritising, commissioning or regulating research (Smith et al. 2008). This makes it difficult to pinpoint the precise impact of any particular aspect of the involvement.
- It may also take many years for any detectable outcomes to emerge from any particular study (Smith et al. 2008).

These challenges in assessing the impact of involvement also make it difficult to describe involvement within the typical structure and format of a journal article, as one researcher who carried out a review of participatory research commented, 'Authors of interventional studies often must publish their findings and study methodology in separate articles. The nature of community based participatory research (CBPR) further compounds this fragmentation when years of partnership development and collaboration must be distilled to a few words in a small number of journals willing to publish this more descriptive science. This may be why information regarding the implementation of CBPR... was often missing', (Viswanathan et al. 2004 p. 5).

Predicting where involvement would have the greatest impact

Public involvement in research is a complex, social process that is undertaken for many different reasons and in many different contexts. Some researchers have therefore concluded that, **'It is not possible to say that involving service users will, or should, always be undertaken in the same way to achieve the same benefits'**, (Smith et al. 2008 p. 309). It seems that there is no single approach that will guarantee the benefits of involvement, but rather that by taking an approach that ensures high-quality involvement (see Section 4.10) the likelihood of a positive impact is increased.

Similarly, reflecting on the benefits and costs of involvement, one researcher who works with young people, concluded, **'It is not possible to add these benefits and costs as an arithmetic equation to decide whether or how young service users would benefit a particular research proposal. This decision is as much a political and ethical one as it is a practical and resource driven one'**, (McLaughlin 2006 p. 1407).

Clarifying the added value of involvement in different research contexts

Professionals and the public bring different types of knowledge and skill to the process of partnership working in research. One researcher has concluded that these contributions need to be more fully explored to be clear about where public involvement brings added value (Dewar 2005):

'Is it true that everyone can do research? If so why do we spend money and effort preparing academics to learn and gain extensive experience in this activity? What does doing research with users actually mean? Is everyone doing the same thing?... When users [are involved] in data collection, analysis and writing up, does this mean that people are asking users to play a research assistant role, doing similar tasks that they might do themselves if they had the time. In other words are we asking users to do the same as us or is there something about their role that is equal but distinctly different? There is little guidance in the literature on what constitutes this equal but different contribution to partnership working,' (Dewar 2005 p. 51).

'A brief review of educational courses that helped to prepare people for a role of partnership working in research... found that few courses existed and those that did tended to focus on learning tasks that were the same as those deemed appropriate for students embarking on a research methods training course... more work needs to be carried out in exploring appropriate education that prepares... people to be equal but different partners', (Dewar 2005 p. 51).

Maximising the impact of involvement therefore requires providing the best and most appropriate support to enable members of the public to make their unique and most valuable contributions.

Summary – Assessing the impact of involvement

Based on their experience of public involvement in research, some researchers have reflected on how to assess the impact of involvement and when and how best to involve the public to ensure the greatest 'added value'. Their main conclusions are:

It is difficult to assess the impact of involvement

This is because:

- it is often too difficult or too costly to set up a comparison project without involvement, to assess the links between involvement and outcomes.
- the most valuable contributions from the public often come from personal interactions with researchers. These are hard to capture and evaluate.
- the public are often involved within the context of a committee or steering group. The complexity of decision-making processes in most committees makes it very difficult to assess the impact of any individual on the group's decision.
- involvement activities are interconnected and link to several stages of the research process. This makes it difficult to pinpoint the precise impact of any particular aspect of the involvement.
- it may take many years for any detectable outcomes to emerge from a study.

It is difficult to predict where involvement would have the greatest impact

Public involvement in research is a complex, social process that is undertaken for many different reasons and in many different contexts. Some researchers have therefore concluded that it is not possible to say that public involvement should always be undertaken in the same way to achieve the same benefits.

More work is needed to clarify the added value of involvement in different research contexts

Professionals and the public bring different knowledge and skills to the process of partnership working in research. These contributions need to be explored in more depth to be clear about where public involvement brings added value.

5.
Discussion

Discussion

5.1
Challenges in undertaking the review

Identifying relevant literature

The main challenges to identifying relevant articles for this review were the inconsistencies in the use of terms such as 'involvement', as well as inconsistencies in describing and reporting on impact.

A common problem was the different uses of the term 'participatory research'. Some researchers used this term to refer to projects where the public had simply been asked for their views, for example, on health services. Although this marked a significant change, in that previously service users had not been consulted at all, these studies did not meet the criteria for inclusion. This meant that large numbers of articles were identified through the use of 'participatory' as a search term, but most were found to be irrelevant.

Some researchers also use the term 'participatory' to describe a process by which research **participants** shape the direction of their own participation in a project. This approach is often used in research interviews with children. Children are usually given the freedom to decide what they want to discuss and how they want to communicate their ideas. For example they may choose to talk about an issue or draw a picture to explain what they think and feel. Similarly some researchers have reported on a process whereby **focus group** participants have directed their own involvement. For example they have chosen to get involved in analysing the **data** from the group's discussions or have decided to take the group in new directions following on from the research.

These examples of individual involvement were not included in the review. The **active** involvement of the public was understood to only include processes whereby the public help to shape the direction and delivery of a research project in a way which impacts on **all** participants.

There were also many inconsistencies in the reporting of the impact of involvement. For example, some **abstracts** suggested there would be discussion of impact, when very little information was actually included in the main paper. Other abstracts did not mention impact when the paper included a significant amount of relevant evidence. This meant that a considerable number of articles were included in the 'maybe' category during the initial screen (see Section 2). All these papers had to be read in full to make sure all the relevant articles were included. However, it also means some relevant articles may have been missed in the initial screening process.

Assessing and reporting impact

Public involvement in research is by its nature a complex, social process. It involves a wide range of people influencing other people's beliefs, attitudes and awareness, in a variety of arenas and at different points in time. This makes it difficult to capture the impact of involvement (see Section 4.11). In a recent Delphi study that involved a wide range of **stakeholders** with considerable experience of involvement, the participants concluded that there were many situations where it was simply not feasible to evaluate the impact of involvement (Barber 2008). The limited evidence in the literature therefore partly reflects this inherent problem.

There are also difficulties in reporting public involvement in peer-reviewed journals. The current format for journal articles does not provide a clear structure for describing involvement at the same time as reporting the results of research. This makes it difficult to report on the **process** of involvement, let alone to describe the methods and findings of any evaluation of its impact.

Similarly, the academic research culture as well as the traditional style of reporting results, both tend to encourage researchers to report solely on the positive findings from a study, rather than to reflect on the 'mistakes made' and 'lessons learnt' along the way. This also sets constraints on publishing any evidence of impact, since public involvement often leads to important changes during the early stages of design and development of a project.

Gaps in the evidence

There were a number of gaps in the evidence of the impact of involvement. One notable gap is the lack of published articles on the impact of public involvement on research funding and commissioning. Many UK **clinical research** funders are beginning to involve the public in **peer review** and other processes around making funding decisions. Several organisations are also interested in seeking the public's views on research priorities (Staley & Hanley 2008). However, as yet there is very little published information on whether this involvement is influencing the funding or commissioning of research.

There were other apparent gaps in the evidence, for example, there was no evidence of the impact of involvement on the **analysis** of **quantitative data**. However, such 'gaps' may reflect a lack of involvement, rather than a lack of evidence of any impact. This is because the added value of involvement in these areas is still being debated. Therefore some people may not perceive these as 'gaps in the evidence', but rather as reflecting the expected limits of involvement. However, others may perceive these as important areas of missing evidence that will need to be obtained via further research.

5.2
Main themes identified in the review

In spite of the limitations of the evidence, some strong and consistent themes have emerged from this review. These are based on an assessment of where there appears to be the most evidence. However, it is not clear whether this reflects what has actually been observed or what has been selectively reported.

Some of the strongest themes are:

- Public involvement was reported to have increased recruitment to all types of research. This has been the result of improving information provided to **participants**, providing legitimacy to a project/researchers, or helping to develop a recruitment strategy. It has also been the more direct result of actually involving the public in the recruitment process 'knocking on doors' and talking to people. It seems that the public are particularly skilled in recruiting their peers.

- Public involvement has been reported to be of particular value in **qualitative research** where participants are asked to share their views and experiences. This involvement has had a positive impact at all stages: designing research tools, carrying out interviews/ **focus groups**, analysing the **data** and communicating the findings to others. The evidence suggests this type of involvement improves the quality and robustness of the data, thus providing a stronger evidence base from which to inform both policy and practice. It also helps to strengthen the power and persuasiveness of the results, making it more likely that other people will take action.

- Public involvement is reported to benefit **clinical research**, particularly in ensuring the ethical acceptability of **clinical trials** and improving trial design. It has also helped to ensure that the researchers use **outcome measures** that are most relevant and meaningful to patients.

- Public involvement is frequently reported to benefit the people who get involved as well as the research participants. Much less has been said about the impacts on researchers, and most of these reports highlight the challenges and difficulties they have faced in involving people.

It is not possible draw conclusions about which findings are the most significant or the most convincing. This is because the evidence is very wide ranging and will be relevant to a broad range of **stakeholders**. It is likely that different people will draw different conclusions based on their particular interest, experience and expectations.

5.3
Strengthening the evidence base

Based on this review, there appear to be a number of steps that could be taken to greatly increase the strength of the evidence base around the impact of involvement.

In the first instance, it would be valuable to produce some guidance on how to report the impact of public involvement in journal articles and reports. This would help to ensure all the different elements were described (for example impact on all the different stages of a project). It would also ensure that sufficient information was provided about evaluation methods to make some judgement about the nature and quality of the evidence. This would also have implications for researchers, in providing some guidance on what aspects could be most usefully assessed.

However, the complex, social nature of public involvement makes evaluation of its impact inherently difficult (see Section 4.11). Further work is needed to develop more robust and rigorous methods.

At the same time, this review has shown that very powerful and convincing evidence can come from simply telling the story of involvement. Strengthening the evidence base may therefore not only be about finding the most robust and rigorous ways of assessing impact, but also about helping researchers and the public to find the most useful and consistent way of telling their stories.

Summary – Discussion

Challenges for this review

One of the main challenges for this review lay in identifying relevant articles, because of inconsistencies in the use of terms such as 'involvement', as well as inconsistencies in describing and reporting on impact.

The other main challenge lay in the limited amount of evidence of impact. This partly reflects the inherent problem of assessing impact and also partly reflects the lack of structure and guidance on reporting on involvement in peer-reviewed journals.

There were also a number of gaps in the evidence, the most notable being the lack of articles on the impact of public involvement on research funding and commissioning. Other gaps, for example the lack of evidence of the impact of involvement on the **analysis** of **quantitative data**, may reflect a lack of involvement, rather than a lack of evidence.

Main themes identified in the review

In spite of the limitations in the evidence, some strong and consistent themes emerged from the review. Some of the strongest themes were that:

- public involvement was reported to have increased recruitment to all types of research
- public involvement was reported to be of particular value in **qualitative research** where participants are asked to share their views and experiences
- public involvement was reported to be of particular value in **clinical trials** where it helped to improve trial design and ensured the use of relevant **outcome measures**
- public involvement has been most frequently reported to benefit the people involved as well as the research participants.

Strengthening the evidence base

Based on this review the strength of the evidence base around impact of involvement in research could be improved by:

- producing guidance on how to report on the impact of involvement in journal articles and reports
- finding more consistent and robust ways of assessing impact
- helping researchers and the public to find the most useful ways of telling the 'story of involvement'.

Jargon Buster

Jargon Buster

Abstract

This is a brief summary of a research study and its results. It should tell you why the study was done, how the researchers went about it and what they found.

Analysis

Data analysis involves examining and processing research data, in order to answer the questions that the project is trying to address. It involves identifying patterns and drawing out the main themes, and is often done with specialist computer software.

Clinical research

Clinical research aims to find out the causes of human illness and how it can be treated or prevented. This type of research is based on examining and observing people with different conditions and sometimes comparing them with healthy people. It can also involve research on samples of blood or other tissues, or tests such as scans or X-rays. Clinical researchers will also sometimes analyse the information in patient records, or the data from health and lifestyle surveys.

Clinical trial

Clinical trials are research studies involving people who use services, which compare a new or different type of treatment with the best treatment currently available. They test whether the new or different treatment is safe, effective and any better than what already exists. No matter how promising a new treatment may appear during tests in a laboratory, it must go through clinical trials before its benefits and risks can really be known.

Data

Data is the information collected through research. It can include written information, numbers, sounds and pictures. It is usually stored on computer, so that it can be analysed, interpreted and then communicated to others e.g. in reports, graphs or diagrams.

Dissemination

Dissemination involves communicating the findings of a research project to a wide range of people who might find it useful. This can be done through:

- producing reports (often these are made available on the Internet)
- publishing articles in journals or newsletters
- issuing press releases
- giving talks at conferences.

It is also important to feedback the findings of research to research participants.

Focus group

A focus group is a small group of people brought together to talk. The purpose is to listen and gather information. It is a good way to find out how people feel or think about an issue, or to come up with possible solutions to problems.

'Grey' literature

Grey literature is material that is less formal than an article in a peer review journal or a chapter in a book – so it's not easily tracked down. It includes internal reports, committee minutes, conference papers, factsheets, newsletters and campaigning material. However, 'grey literature' may be made available on request and is increasingly available on the Internet.

Outcome measures

Outcome measures are measurements of the effects of a treatment or service. They might include physical measurements - for example measuring blood pressure, or psychological measurements - for example measuring people's sense of well-being. So if someone takes part in research, they may be asked questions, or may be asked to have extra tests to assess how well the treatment or service has worked.

Participant

A participant is someone who takes part in a research project. Sometimes research participants are referred to as research 'subjects'.

Patient information sheet

Researchers must provide a patient information leaflet to everyone they invite to take part in a research study, to ensure people can make an informed decision about this. The leaflet explains what taking part will involve and should include details about:

- why the research is being done, how long it will last, and what methods will be used.
- the possible risks and benefits
- what taking part will practically involve e.g. extra visits to a hospital or a researcher coming to interview someone at home
- what interventions are being tested, or what topics an interview will cover
- how the researchers will keep participants' information confidential
- what compensation is available to people if they are harmed as a result of taking part in the research
- who to contact for further information
- how the results will be shared with others.

Peer interviewers

In peer interviews the participants are interviewed by people who have a similar experience to them – their peers. For example, in a project to find out about children's experiences of after school care, children with experience of using after school care may act as peer interviewers, asking other children for their views.

Peer review

Peer reviewing is where a research proposal or a report of research is read and commented on by people with similar interests and expertise to those who wrote the proposal or report. Peer reviewers might be members of the public, researchers, or other professionals. Peer review helps to check the quality of a report or research proposal.

Members of the public who act as peer reviewers may choose to comment on:

- whether the research addresses an important and relevant question
- the methods used by researchers
- the quality of public involvement in the research.

Placebo

A placebo is a fake or dummy treatment that is designed to be harmless and to have no effect. It allows researchers to test for the 'placebo effect'. The placebo effect is a psychological response where people feel better because they have received a treatment, and not because the treatment has a specific effect on their condition. By comparing people's responses to the placebo and to the treatment being tested, researchers can tell whether the treatment is having any real benefit.

Proposal – see **– Research proposal**

Protocol

A protocol is the plan for a piece of research. It usually includes information about:

- what question the research is asking and its importance/relevance
- the background and context of the research, including what other research has been done before
- how many people will be involved
- who can take part
- the research method
- what will happen to the results and how they will be publicised.

A protocol describes in great detail what the researchers will do during the research. Usually, it cannot be changed without going back to a research ethics committee for approval.

Qualitative research

Qualitative research is used to explore and understand people's beliefs, experiences, attitudes or behaviours. It asks questions about how and why. Qualitative research might ask questions about why people want to stop smoking. It won't ask how many people have tried to stop smoking. It does not collect data in the form of numbers.

Qualitative researchers use methods like focus groups and interviews (telephone and face-to-face interviews).

Quantitative research

In quantitative research, researchers collect data in the form of numbers. So they measure things or count things. Quantitative research might ask a question like how many people visit their GP each year, or what proportion of children have had an MMR vaccine, or whether a new drug lowers blood pressure more than the drugs that are usually used.

Quantitative researchers use methods like surveys and clinical trials.

Randomised controlled trial

A controlled trial compares two groups of people: an experimental group who receive the new treatment and a control group, who receive the usual treatment or a placebo. The control group allows the researchers to see whether the treatment they are testing is any more or less effective than the usual or standard treatment.

In a **randomised** controlled trial, the decision about which group a person joins is random (ie based on chance). A computer will decide rather than the researcher or the participant. Randomisation ensures that the two groups are as similar as possible, except for the treatment they receive. This is important because it means that the researcher can be sure that any differences between the groups are only due to the treatment.

Research proposal

This is usually an application form or set of papers that researchers have to complete to say what research they want to do and how they want to do it. It will also cover the aim of the research, what the research questions are, who will be involved (both as participants and in carrying out the research), the timescale and the cost.

Stakeholder

A stakeholder is anyone who has an interest in a research project. It includes the people and organisations who are actively involved, as well as the people who might be affected by the outcomes.

Systematic review

Systematic reviews aim to bring together the results of all studies addressing a particular research question that have been carried out around the world. They provide a comprehensive and unbiased summary of the research.

For example, one clinical trial may not give a clear answer about the effectiveness of a treatment. This might be because the difference between the treatments being tested was very small, or because only a small number of people took part in the trial. So systematic reviews are used to bring the results of a number of similar trials together, to piece together and assess the quality of all of the evidence. Combining the results from a number of trials may give a clearer picture.

User researcher

A user researcher is someone who uses or has used health and/or social care services because of illness or disability, who is also a researcher. Not all researchers who use health or social care services call themselves user researchers. Calling yourself a user researcher is making a statement about your identity as a service user as well as a researcher.

Appendix 1 – Advisory Group members

Terms of Reference

The role of the Project Advisory Group is to provide advice, support and guidance to the researcher and the Support Unit.

It will include:

- reviewing progress in the project
- reflecting on learning within the project
- drawing on the knowledge of members of the advisory group
- ensuring that necessary expertise including equality and policy perspectives are incorporated into the project
- discussing and recommending follow up action from findings throughout the project
- suggesting ways emerging findings of phase 1 can be developed in phase 2
- commenting on draft documents or draft final documents
- proposing and supporting dissemination of the project findings.

Membership of the Advisory Groups

Advisory Group 2007

Alison Faulkner, John Sitzia, Tracey Williamson
INVOLVE Evidence, Knowledge and Learning Working Group

Vivienne Brown
Worthing and Southland Hospitals NHS Trust

Helen Hayes and Sarah Buckland
INVOLVE Coordinating Centre

Advisory Group 2008-9

Peter Beresford (Chair), Alison Faulkner, Sophie Staniszewska
INVOLVE Evidence, Knowledge and Learning Working Group

Laura Serrant-Green
INVOLVE Strategic Alliances Working Group

Helen Hayes, Maryrose Tarpey and Sarah Buckland
INVOLVE Coordinating Centre

Appendix 2 – Searches of health and social care electronic databases

The structured search of health and social care electronic databases involved using the search terms listed in Table 1 to search 9 databases (listed in Table 2).
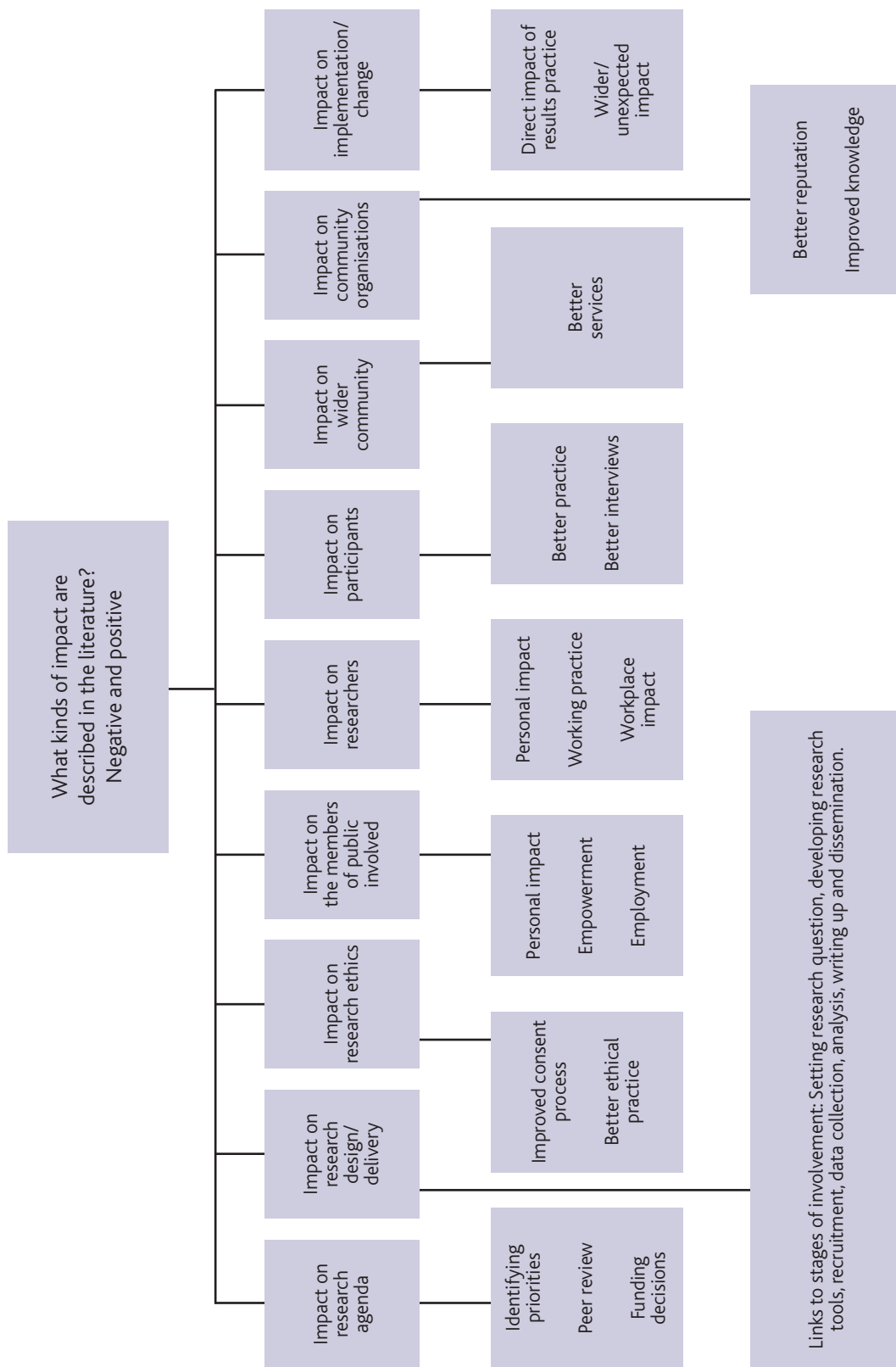
Table 1: Search terms used to search the electronic databases

1: Public and Patient	2: Health, Public Health and Social Care
• user	• health
• service user	• health care
• lay	• social care
• consumer	• public health
• community	
• patient	
• client	
• public	
• carer	
• citizen	
3: Involvement	**4: Research**
• involvement	• research
• partnership	• practice development
• participation	• participative research
• collaboration	• participatory research
• consultation	• participatory action research
• emancipation	• community development
• engagement	• evaluation
• empowerment	

Table 2: Electronic databases searched

	Primary Topic Area
ASSIA	Social Sciences
CINAHL	Professions Allied to Health
EMBASE	Medicine
HMIC~	Health
MEDLINE	Medicine
PsychINFO	Psychiatry
SCOPUS	General
Social Care Online~	Social Care
Social Science Abstracts	Social Sciences

Appendix 3 – Analytical framework

What kinds of impact are described in the literature? Negative and positive

Impact on research agenda
- Identifying priorities
- Peer review
- Funding decisions

Impact on research design/delivery
- Improved consent process
- Better ethical practice

Impact on research ethics

Impact on the members of public involved
- Personal impact
- Empowerment
- Employment

Impact on researchers
- Personal impact
- Working practice
- Workplace impact

Impact on participants
- Better practice
- Better interviews

Impact on wider community
- Better services

Impact on community organisations
- Better reputation
- Improved knowledge

Impact on implementation/change
- Direct impact of results practice
- Wider/unexpected impact

Links to stages of involvement: Setting research question, developing research tools, recruitment, data collection, analysis, writing up and dissemination.

When analysing the findings under each of these themes, consideration will be given to:

- both positive and negative impacts
- tensions that develop from involvement
- key issues that might be relevant to the different stakeholders already identified – users, researchers, funders/commissioners, policymakers.

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