User Involvement in the Design and Undertaking of Nursing, Midwifery and Health Visiting Research

Report to the National Co-ordinating Centre for NHS Service Delivery and Organisation R & D (NCCSDO)

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Summary Key themes and messages

What do we mean by user involvement in nursing, midwifery and health visiting research?

'Nursing, midwifery and health visiting research' is research about the activities that nurses, midwives and health visitors undertake as part of their professional roles. It includes research about practice, education, management and policy. The broad purpose of nursing, midwifery and health visiting research is to build knowledge to inform clinical practice; promote community health; and to develop policies for the management and development of staff, services and educational practice.

Service user involvement in research might include the active involvement of service users (patients/clients, carers and the public) in the process of research, the implementation of research findings or in the commissioning of research projects, for example taking part in priority setting exercises or funding committees. It might also include involvement in the systematic development of nursing, midwifery or health visiting services as the result of research; work described as 'community development' where this has directly involved or had an impact on nursing, midwifery or health visiting services; evaluation work, such as the evaluation of service delivery initiatives or educational interventions, where service users participate in the process of the evaluation.

Service user involvement in research is not generally thought to include the involvement of service users as the subjects of research studies; the involvement of service users in their own care or the care of a relative, for example in care decisions or joint decision-making; or involvement in professional education or training programmes.

Why is it important to look at user involvement in nursing, midwifery and health visiting research?

Health and social care organisations are being encouraged to develop systems and processes that place service users at the centre of service redesign. The involvement of service users in all aspects of health services is seen as central to improving quality. Nursing, midwifery and health visiting practice, management, education and research have taken on board ideas about service user involvement. It is important to look at service user involvement in the research process because this might mean research is more appropriate to building quality health services.

The purpose of this project

The aim of this project was to find out what is known about service user involvement in nursing, midwifery and health visiting research.

The objectives of the project were:

- 1 To consult with relevant service user and carer advocacy groups, private and voluntary sector service providers and researchers from other disciplines to inform the scope of the review, support the identification of appropriate literature, reflect on the evidence and advise on outputs/dissemination.
- 2 To describe different approaches to involving service users in research, based upon a comprehensive review of the literature and a survey of current activity and practice.
- 3 To conduct a comprehensive and rigorous systematic review of the available published and grey research literature (for example doctoral studies), including relevant evidence from the UK and other countries, and from a broad range of service organisations in health and social care, on service user involvement in nursing, midwifery and health visiting research.
- 4 To present the literature on theory and evidence and analyse the strength of the relationship between the two.
- 5 To highlight gaps in the field (for example, areas that could be improved or developed) and relevant methodological issues.
- 6 To generate models of involvement and participation, which reflect different conceptual, policy and methodological approaches.

The timeframe for the project was April 2004 to March 2005.

The way the project was carried out

From the beginning of the project we took a flexible view of the topic and developed working methods to answer important questions uncovered as we gained new information.

We decided to search systematically and widely across different literature sources, but to focus on finding information that would help

User involvement in nursing, midwifery and health visiting research

to develop service user involvement in nursing, midwifery and health visiting research.

We involved service user and carer advocacy groups in the project to inform the scope of the review, support the identification of appropriate literature and ongoing work, reflect on the evidence and advise on outputs/dissemination. Our approach was to set up and support a service user reference group with 26 members specifically for the duration of the project. Members of the group connected the project with specific client/patient concerns, issues and perspectives; influenced the project by contributing to developing priorities and principles; were critical friends, challenging and stimulating; and provided advice about the best ways of disseminating findings through different networks.

We made use of information technology (for example e-mail and the Internet) and professional networks (for example at conferences) to consult with researchers and service users to find out about ongoing work in the topic area and to publicise the study.

Members of the project team kept a record of their experiences and learning about undertaking the review with service users. Members of the service user reference group were also asked to feed back their views of the experience and the way they were involved in the project.

How we used the information to produce findings

We collected information from a wide range of different sources including published evidence (over 400 papers, documents and reports) and primary data, for example, from telephone interviews with researchers. To do this we designed a Review Framework with four main themes: the context and drivers of user involvement in nursing, midwifery and health visiting research, the approaches and methods that have been taken to involve service users, the impact and outcomes of involvement and the professional and organisational factors that relate to its future development.

We used a form (a 'review tool') to extract the information from a wide range of sources. We referenced, coded and sorted the data using computer reference management software and presented it in tables in Microsoft Word.

For each finding we described whether the information we found was based on opinion, policy, research findings, or on many sources of research findings (systematic review). This helps to show where the information has come from and what the 'evidence' is.

What this project found

There is a strong tradition of community research in nursing, midwifery and health visiting research, such as in community health development. Participative research methods have been used to give patients and members of the public a more active role in a wide range of different types of research.

The use of focus groups, health diaries, and storytelling, have provided a way for service users to pass on their views and opinions to people who are doing research about nursing, midwifery or health visiting.

The meaning of, and ideas about, service user involvement in research are complicated and include many different issues to do with government policy, the views of professionals and public opinion about health services and research.

Like apple pie, user involvement in nursing, midwifery and health visiting research is widely thought to be a good thing, but there is limited evidence for this and there should be more work to explore the meaning and importance of user involvement in research in different circumstances.

Nursing, midwifery and health visiting research has contributed to the evidence base for patient communication and patient decision making in clinical care and to the development of patient centred services. User involvement is a new angle on old questions about the quality, design and delivery of professional working and health systems. Debates in the literature about expectations for user involvement in service improvement and user involvement in research have been confused.

It is difficult to define what is meant by 'nursing, midwifery and health visiting research' or 'user involvement in research' because these ideas cover many different relationships and activities. Grouping together all the issues about user involvement might overlook other important issues about different professional groups, clinical activities, research methods, or patient/client groups.

In nursing, midwifery and health visiting research we have found user involvement is based on aspirations rather than evidence. Researchers have put together different ideas (called concepts or frameworks) about user involvement. We found a few examples of nursing, midwifery or health visiting research projects that have built on these ideas. There is a need to test and evaluate different approaches to user involvement to understand what works best when.

User involvement in research can be perceived as happening in the design (planning or decision-making), undertaking (carrying out research activities) or in the evaluation of research. Different groups

User involvement in nursing, midwifery and health visiting research

of service users might be involved in one or more of these activities in any research project.

Some researchers have developed ways of showing the quality of service user involvement in research. But these do not account for differences between service users or differences between research projects.

Ideas about user involvement in research and research methods overlap and this causes confusion. Some people think that user involvement is part of the research itself and others think it is part of the methods of a research study. There are problems with linking user involvement and research methods in this way as this means people use research values such as rigour and generalisability to judge user involvement in research. These might be unrealistic or inappropriate ways to assess user involvement in research.

The literature and policy argue that user involvement in research can improve:

- the relevance and appropriateness of the research,
- the ways that research is carried out,
- benefits for service users involved.

But there are problems with using any of these ideas to measure the outcomes of user involvement in research, such as who exactly decides whether research is relevant and appropriate.

What the findings mean for policy and research

The findings of this review can be used as a framework for thinking about user involvement in nursing, midwifery and health visiting research. There are different types of issues about user involvement: the context and drivers of user involvement; the best ways of involving service users; the outcomes; and the capacity requirements of researchers to make it happen.

We have found that user involvement in research can have different outcomes or effects depending on the reasons why service users were involved and the ways in which they were involved. The findings help to show what might be appropriate criteria (measures) for assessing and evaluating user involvement in research. But it is difficult to find out whether the involvement of service users was the reason why outcomes or effects happened, or if user involvement had any impact on outcomes or change in health care practice.

Decisions about whether service users should be involved in research projects are generally made before, or at the stage of, research funding or commissioning. User involvement in research should be thought of as being different in each research project - no one size fits

User involvement in nursing, midwifery and health visiting research

all. It is for these reasons we are not recommending a single 'how to do it' model. We suggest that a better way forward is to identify triggers for decision-making to guide researchers in nursing, midwifery and health visiting in the various stages of user involvement in research.

The Report

Chapter 1 Introduction

- 1.1 Origins and context of the project
- 1.2 Aims and objectives of the project
- 1.3 Structure of the report
- 1.4 Guidance for navigating through the report

The policy drivers for the modernisation of health services are reframing the relationships between professionals and patients in terms of consumerism and participation. Fuelled by public concerns about quality and accountability, health and social care organisations are being encouraged to develop systems and processes that place the 'consumer' at the centre of service redesign. The active involvement of 'service users' (that is, patients/clients, carers and the public) in all aspects of health services is seen as central to achieving these aims (Department of Health, 2001a), which is also being addressed within nursing, midwifery and health visiting practice, management, education and research.

The drivers for user involvement in research are complex and have not always been policy-led or 'top-down' (Beresford, 2003). Claims have been made about the benefits of user involvement in a range of research disciplines and contexts such as the design of patient-focused clinical trials, service evaluation and patient satisfaction studies. There is also growing interest in showing how involving service users at a level of commissioning research can ensure that the questions research seeks to address are more appropriate to the needs of patients and communities.

Although nursing, midwifery and health visiting research is sometimes perceived as being more connected to the world of the patient and attuned to service users' perspectives when compared to other types of health research, it is not well known for its contribution to the methodological or theoretical development of service user involvement. Some would argue that the *full potential* of service user involvement in nursing, midwifery and health visiting research has scarcely been realised. Others would argue that the *full picture* of service user involvement in nursing, midwifery and health visiting research has not yet been duly recognised.

The additional costs and effort required to involve service users in research are reasons why attention has now turned to evaluating the evidence for such activities. For other people, who are committed to the ethos of user involvement, identifying and bringing together the evidence about user involvement in research is a way of reinforcing their beliefs and convincing others of the possibilities. As Beresford (2002) notes 'advocates and critics alike feel that the interest user involvement has attracted and the progress it has made, mean that it is now time to examine it systematically to explore its strengths and weaknesses, benefits, and disadvantages'. And that, 'if this is to happen it is important that such evaluation addresses the full range of approaches to user involvement in research, from the most limited and tokenistic involvement, to user controlled and emancipatory research – however they are defined – rather than seeing user involvement as monolithic and uniform'.

The complexity of circumstances and contexts in which service users have been involved in different types of research means that user involvement is not an intervention that can be easily tested or evaluated to show evidence of generalisable findings. Relatively little research has been funded to look at the process and outcomes of involving service users in research. Patient and Public Involvement in Health: The evidence for policy implementation (Department of Health, 2004a) summarised the results of the health partnership research programme. Of the 12 projects, six focused on patient and carer involvement in decisions about their own treatment and care, four addressed public involvement in service planning and delivery and two were principally concerned with education and training issues. One of the funding conditions was that projects should involve patients and the public in their design and execution. In one project service users were involved in the review of a protocol and draft report, in others users were invited to participate in steering or advisory groups. Although the report finds strong evidence that patient involvement in health care decisions improves patient satisfaction and this can be rewarding for professionals, the impact of involving users in the process of the 12 projects was not scrutinised to the same degree.

The Joseph Rowntree Foundation has recently published a review (Hanley, 2005) of the involvement of service users in the development of an evidence base for health and social care, including guidance on good practice for researchers and research funders. The report summarises a series of seminars that brought together a range of stakeholders to discuss user involvement in 'mainstream' research, user involvement in peer review, involving people from black and minority ethnic communities and emancipatory research. The report highlights barriers caused by intrinsic power differentials between researchers and service users and the methods that have been used to involve service users. There are also pressures of time and inadequate support for mentoring or training of service users.

Key questions remain about user involvement in all aspects of health research but there are also questions that relate more specifically to user involvement in nursing, midwifery and health visiting research. These are:

- How can user involvement in nursing, midwifery and health visiting research be conceptualised?
- How have nursing, midwifery and health visiting research contributed to building the theoretical and methodological development of user involvement in research?
- Should all nursing, midwifery and health visiting research involve service users?
- What are the most effective ways of involving service users in the wide-ranging contexts of nursing, midwifery and health visiting research?

1.1 Origins and context of the project

This report presents the findings of a project that was commissioned by the National Co-ordinating Centre Service Delivery and Organisation (NCCSDO) Research and Development (R&D) Nursing and Midwifery Subgroup in April 2004. The work has been carried out by members of the Nursing Research Unit at King's College London in partnership with members of other organisations.

The scope of the Service Delivery and Organisation (SDO) programme is to produce and promote the use of research evidence about how the organisation and delivery of services can be improved to increase the quality of patient care, ensure better strategic outcomes and contribute to improved health. A subgroup for the commissioning of nursing and midwifery research has a remit to support research and development in these disciplines.

In 2001 a national scoping exercise (led by Professor Fiona Ross) was commissioned to identify priorities for research in nursing and midwifery service delivery and organisation and to make suggestions about the commissioning of research to the SDO Nursing and Midwifery Subgroup. Priority areas for research were identified and proposals for research were invited on the nursing contribution to child health; and service user involvement in the design and undertaking of nursing and midwifery research. The latter is the project described in this report.

About the project

The aim of this project was to determine what is known about service user involvement in the design and undertaking of nursing, midwifery and health visiting research. For operational purposes we called the project PIN (to refer to 'patient and public involvement in nursing, midwifery and health visiting research'). The commissioners of the project stipulated that the findings should be used to show how best to involve service users in different types of nursing, midwifery and health visiting research for different purposes. A full explanation of the professions and activities we have taken to be included within the remit of the project are shown in Chapter 2. The project was a literature review that used multiple methods to gather, analyse and interpret a broad range of evidence and opinion from the published literature and people with an interest in the topic area. In examining the literature we have drawn from research undertaken in other countries and in other research disciplines to identify possible areas and ways of development in nursing, midwifery and health visiting research.

A service user reference group worked alongside the project team to inform the scope of the review and the methods used, to reflect upon the findings and plan for dissemination. Members of the group were drawn from nationally focused voluntary organisations and patient interest groups broadly representing the diversity of nursing, health visiting and midwifery activity in the full range of settings.

The project team

The project team brought together a group of people with a range of experience and backgrounds in the broad arena of participative approaches to research and service change. Professor Fiona Ross, director of the Nursing Research Unit, led the overall direction of the project. Elizabeth Smith was responsible for managing the project on a day-to-day basis. Sheila Donovan led on recruitment to the service user reference group and conducted telephone interviews with researchers. Sally Brearley chaired the meetings of the service user reference group and provided advice about consumer networks. She represents a service user organisation and has experience of policy development in patient and public involvement in the National Health Service (NHS) at national and local levels. John Sitzia is leading public and patient involvement policies at a local and national level in the context of NHS priorities and needs. He is a member of the INVOLVE committee and the NHS R&D Forum service user R&D group, which together provided wide coverage of the groups that were consulted through the course of the review. Professor Jill Manthorpe, director of the Social Care Workforce Research Unit, brought experience of involving users in sensitive or complex areas such as risk, adult protection and professional education. She contributed a social care perspective where the boundaries with nursing overlap, such as learning disability, care of older people and mental health. Peter Beresford, professor of Social Policy at Brunel University and chair of Shaping our Lives, advised on the 'involvement' element of the project. Dr Peter Griffiths (King's College London) lead researcher on a related SDO-commissioned literature review, provided advice with the methods of literature searching.

1.2 Aims and objectives of the project

This project was funded to specifically investigate service user involvement in the design and undertaking of nursing, midwifery and health visiting research. The project was a literature review that aimed to use multiple methods to gather, analyse and interpret a broad range of evidence and opinion from the published literature and from people with an interest in the topic area. The commissioners of the project stipulated that the findings should be used to show how best to involve service users in different types of nursing, midwifery and health visiting research for different purposes.

In this report we use the terms 'the review' and 'the project' to describe the work that has been undertaken. Where we use the term 'review' we mean the processes at the centre of the work for example collecting and synthesising the data. We use the term 'project' in a broader sense to discuss the relationships, partnerships or outcomes that occurred around the process of the review. We are drawing this distinction in order to describe the methods of the *review* and to convey the relationships, energy and interaction between members of the *project*.

The funded timeframe for the project was April 2004 to March 2005.

The objectives of the project were:

- 1 To consult with relevant service user and carer advocacy groups, private and voluntary sector service providers and researchers from other disciplines to inform the scope of the review, support the identification of appropriate literature, reflect on the evidence and advise on outputs/dissemination.
- 2 To describe user involvement approaches in research based upon a comprehensive review of literature and a survey of current activity and practice.
- 3 To conduct a comprehensive and rigorous systematic review of the available published and grey research literature, including relevant evidence from the United Kingdom (UK) and other countries, and from a broad range of service organisations in health and social care, on service user involvement in nursing, midwifery and health visiting research.
- 4 To present the literature on theory and evidence and analyse the strength of the relationship between the two.
- 5 To highlight gaps in the field and relevant methodological issues.
- 6 To generate models of involvement and participation, which reflect different conceptual, policy and methodological approaches.

1.3 Structure of the report

This report constructs a critical view of the evidence for methods and outcomes of user involvement in nursing, midwifery and health visiting research. The evidence is drawn from the published literature but we have also recognised experience and opinion as important sources of knowledge. **Chapter 1** provides an introduction to the report and sets the context for the project.

Chapter 2 explains how the topic of user involvement in nursing, midwifery and health visiting was conceptualised for this project.

Chapter 3, the methods section of the report describes:

- the purpose and role of the service user reference group
- systematic searches of the published literature
- searching for unpublished literature
- networking activities and researcher consultations
- development of the review framework
- methods used to analyse and interpret the data
- planning for dissemination with members of the service user reference group.

Chapter 4 presents the findings of the review. We have structured the findings around four central themes of user involvement in nursing, midwifery and health visiting research.

Part 1 of the findings looks at **the context and drivers of user involvement in nursing, midwifery and health visiting research** in which concepts and meanings of user involvement have developed. This section looks at philosophical, political and societal influences on nursing, midwifery and health visiting research. The overlap and differences of user involvement in social care research are described.

Part 2 addresses **the best ways of involving service users in nursing, midwifery and health visiting research**. This part details the methodological issues that impact on involvement of service users and carers in nursing, midwifery and health visiting research. This section begins with an overview of meanings and concepts about user involvement in nursing, midwifery and health visiting research to highlight issues about purpose and quality in involvement. We use evidence from the literature and accounts from researchers to show how different types of people have been identified and engaged in research and how working relationships have been established.

Part 3 shows what is known about **the outcomes of involving service users in nursing, midwifery and health visiting research** in relation to the different goals, or objectives, of involvement. Examples are given of the measurable outputs that can be attributed to involvement activities and the impact of involvement on different groups of people. The wider impact of involvement is discussed, including issues about evaluation, transferability and dissemination.

Part 4 of the findings is concerned with the **capacity of researchers and research organisations** to involve service users in nursing, midwifery and health visiting research. This includes the capacity of different types of organisations to involve service users in research and sustain effective involvement. Findings about the skills and training of individual researchers to facilitate user involvement activities are described.

Chapter 5 provides a discussion and reflections on the approach and our learning about the process. The chapter includes reflections from the service user reference group about their involvement. The second part of the discussion looks at the strength of the evidence in addressing the complex and diverse questions that are central to the topic of the review.

Conclusions and suggestions

The suggestions at the end of the report summarise the advice of a wide range of researchers and service users that contributed ideas and thinking to this review. Suggestions are made for future research, research commissioners, research support organisations, NHS and academic research organisations, researchers, service users and consumer organisations.

1.4 Guidance for navigating through the report

We have tried to use plain English as far as possible in this report and to explain concepts clearly. However, sometimes it has been necessary to use the language from the literature, which might be technical or abstract, to be able to engage with and discuss the issues in detail. Some of the terms we use have been used in the literature in different ways to mean different things. Our view of their meanings is shown below.

Collaboration: Interaction with an agreed purpose, bringing together different people with different expertise, knowledge and skills.

Community development: The process of involving people from a certain area, social or cultural group in the identification and reinforcement of the aspects of everyday life, culture and political activity that are conducive to health.

Consultation: In relation to involvement of service users in research, asking service users for their views, for example to inform decision-making.

Evaluation: Activities that are more than descriptions and reflections in that they present clear objectives, methods of investigation and results.

Participative research: An interactive relationship between researchers and service users with shared objectives and methods with the aim of achieving mutually beneficial outcomes.

Service user: See Chapter 2 for an operational definition.

User involvement: Different approaches to participation and involvement that operate, or are provided, at both individual and

collective levels. Including informal or structured participation, a timelimited one-off occurrence or an ongoing relationship. User involvement can be based on models of direct participation or representation.

User involvement in nursing, midwifery and health visiting research: See Chapter 2 for an operational definition.

Some sections of the report incorporate findings about the **roles** and activities that service users have taken in different aspects of research. This symbol is used to highlight sections discussing roles and activities, to emphasise the range of roles and activities that may be undertaken by service users.

Voices in the report

In the report the term 'we' is used to show the views and decisions made by the project team during the process of the research. Decisions were mostly made during face-to-face project meetings where points were discussed and documented. Our reflections are used to show our interpretation of the evidence and the reasons why we have emphasised particular findings or issues. Throughout the report we have tried to make clear the position we have taken on conceptual questions about the relevance and strength of the evidence. Our views are explicitly outlined, as they shape the analysis and synthesis of the data.

In the report we also show how other voices have been heard and contributed to the findings. The voices of researchers talking about their experiences to members of the project team during telephone interviews are shown in grey text boxes, like the one illustrated below. These real life examples and issues link to recently completed or ongoing research projects. All of these researchers gave permission for their comments to be used in this way. The identifier (R1 in the example below) refers to a specific researcher (project details are included in Appendix 5 of the report). We also highlight points made by researchers by email and by members of the service user reference group (see white boxes below).

Real life example: R1

Text boxes like this show real life examples and issues from researchers working to involve service users in their research. The boxes link to points being described in the text, providing researchers' perspectives on the issues and debates.

What researchers who responded to e-mail calls told us

The perspectives and views of researchers who responded to e-mail calls are summarised in boxes like this.

What the service user reference group thought was important

The perspectives and views of members of the service user reference group are summarised in boxes like this.

This heading is used to highlight issues or views that were made during meetings of the service user reference group. As far as possible we have used the original words and phrases of the group to avoid imprinting our interpretation over what was said. All of these points have been fed back to members of the group in newsletters after each meeting. The group did not always reach consensus on particular issues and where there were differences of opinions we have shown these.

Chapter 2 Conceptualising the topic

- 2.1 What is 'nursing, midwifery and health visiting research'?
- 2.2 What is 'service user involvement in research'?
- 2.3 Where do the boundaries lie between 'research' and other types of user involvement?

In this chapter of the report we describe the position we have taken on the important conceptual questions that have defined the scope of the methods. It is important to explicitly outline these views, as they contextualise the analysis and synthesis of the data.

We sought to formulate and clarify our views of these questions in different ways: in consultation with a wider group of researchers working in nursing, midwifery and health visiting related areas; by looking at existing definitions in the literature and through a process of clarification with different stakeholders over the course of the project.

2.1 What is 'nursing, midwifery and health visiting research'?

It was important to be clear about the definition of nursing, midwifery and health visiting we were using for the project to be clear about the professional roles and activities that the work was intending to inform.

The professional groups that these terms are associated with in the nursing literature are: midwives, nurses, health visitors, district nurses, school nurses, practice nurses, mental health nurses, nurses for people with learning disabilities, occupational health nurses, students within these professions, agency staff, health care assistants and those working in public and private sectors. The term covers a wide range of activities including: care, treatment, investigations, support, health promotion, public health and working for health in communities. However, there is a clear overlap with other professional work and areas of research and delimiting the activities of nursing, midwifery and health visiting research may be considered as contradictory to current policy trends in relation to inter-professional and collaborative research. There are also overlapping boundaries of professional work particularly at the interface of health and social care.

In April 2004 we approached all research-active staff working in one academic department of nursing and midwifery to find out their views on the meaning of nursing, midwifery and health visiting research. Given more time, this consultation would have been repeated with staff in other research organisations. The following e-mail was sent to staff asking them to send their views directly back to a member of the

project team. We used the Cochrane Library definition of nursing research as a starting point for the discussion.

Academic consultation: What do we mean by 'nursing, midwifery and health visiting research'?

1. Do you agree with the Cochrane Library definition of nursing research?

Research carried out by nurses, generally in clinical settings, in the areas of clinical practice, evaluation, nursing education, nursing administration, and methodology.

2. If no - how would you develop it?

3. Do you agree with the notion that nursing, midwifery and health visiting research is multi-dimensional? That is to say:

- research done by nurses
- research about nurses themselves (for example their working lives)
- research about the work/care interventions of nurses (for example clinical research)
- wider (health or social) research that has implications for nursing policy, organisation, education or practice.
- 4. Are there other considerations?

5. To what extent do you think the following statement covers all the domains and activities?

'Nursing, midwifery and health visiting research' relates to a wide range of activities such as care, treatment, investigations, support, health promotion, public health and working for health in communities and utilises a variety of methods. It may also encompass areas of professional overlap and links between practice, management and education, as well as research about the implementation or utilisation of research findings.

The professional groups that are within the scope of this term might include: midwives, nurses (NHS, social care and independent sectors), health visitors, district nurses, school nurses, practice nurses, mental health nurses, nurses for people with learning disabilities, occupational health nurses, specialist and consultant nurses or midwives and health care assistants. Current trends include health visiting under the term nursing, rather than as a separate profession, for example the Nursing and Midwifery Council and the SDO Nursing and Midwifery Subgroup.

> Eleven responses were received by e-mail and other views were expressed to the project team in person. The following definition of nursing, midwifery and health visiting research was developed based on these responses. There was strong feeling from health visitors that health visiting should always be referred to as a profession distinct from nursing, rather than as being encompassed by the term, we have attempted to do so in this report.

Project definition: nursing, midwifery and health visiting research

In our opinion, 'nursing, midwifery and health visiting research' is about the activities that nurses, midwives and health visitors undertake as part of their professional roles encompassing practice, education management and policy. The purpose of nursing, midwifery and health visiting research is to build generalisable knowledge to inform:

- development of practice in acute, primary, intermediate and palliative care
- promotion of community health
- evidence-based policy decision making on service innovation
- workforce interventions
- management and educational practice.

However, determining what part of these complex activities constitutes 'nursing', 'midwifery' or 'health visiting' is difficult, and some would argue counter productive. Similarly, just how much of the 'nursing', 'midwifery' or 'health visiting' element of interprofessional working can (or should) be identified as 'nursing or midwifery research' is a further limitation.

Because research is often undertaken by different professionals as part of a team it is better to classify research according to the professional activity being studied rather than who is undertaking the research. Not all nursing, midwifery and health visiting research is, or should necessarily, be carried out by nurses, midwives or health visitors. Also, these groups may be involved in research that is not about nursing, midwifery or health visiting, for example in clinical drug trials, social and policy research. Similarly, there is a distinction between sociological research that nurses, midwives or health visiting research', for example research that has no explicit connection to nursing, midwifery or health visiting activities or patient/service process/outcomes. For these reasons we are not automatically including all research that is undertaken by nurses, midwives or health visitors.

Although we are focusing on nursing, midwifery and health visiting activities, the professional groups that are within the scope of this term might include: midwives, nurses and health visitors working in the NHS, local authorities (for example social care, children's trusts) or the independent or voluntary sectors. It includes a range of grades, from newly qualified to consultant level; specialities such as mental health, learning disabilities or primary care, and members of their teams such as support workers.

If nursing, midwifery and health visiting research is multi-dimensional, it follows that the methods of investigation need also to be multi-dimensional. Nursing, midwifery and health visiting research, like education, is part of the infrastructure to support nursing, midwifery and health visiting activity; and therefore we are including research about the implementation or utilisation of research findings within the review.

2.2 What is 'service user involvement in research'?

Shortly after beginning this review we adopted the name PIN as a title for the project, to represent 'patient and public involvement in nursing, midwifery and health visiting research'. This was helpful as it was easy to communicate and it is fairly distinctive in a culture of acronyms. However this title has also has its drawbacks. Patient and public involvement (PPI) has, in the last year or so, become a term that is strongly associated with the involvement of NHS patients in the development of NHS services. Within service settings a distinction has opened up between 'PPI work' and 'research', possibly because different groups of professionals have tended to either work in research or PPI creating professional divisions.

In the project we have used the term 'service user' interchangeably with the term 'patient and public'. This is a term that is widely used in UK health policy and health service literature. The Department of Health uses the term to describe anyone that has in the past, is currently, or may in the future access NHS services. In some situations the terms 'consumer', 'lay' or 'patient' are used interchangeably with 'service user' and the term may be used to include the users of social care or independent health services. However, in the literature and everyday world 'service user' tends to be preferred over terms like 'customer', 'consumer', 'patient' or 'lay person'.

The term is problematic because it conceives of people primarily in terms of their relationship (or potential relationship) to services, which may well not be how they would define themselves (Beresford, 2003). There are also problems with defining 'service users' as a specific group of people. For example the roles of health professionals, some researchers and educators, and commissioners could be considered to be 'service providers' yet all of these groups are potentially 'service users' in their own right.

Project definition: service user

A 'service user' is any person who has, is, or may access NHS or independent sector health services in the UK. We acknowledge that some people might not see themselves as 'service users' or may never actually use or be able to access a health service for different and complex reasons.

There is no agreement about the meaning or definition of 'service user involvement'. The term has been used to describe a wide range of interactions between service users, health professionals, service managers, researchers and educators.

Project definition: User involvement in research

The term 'user involvement' encompasses different approaches to participation and involvement that operate or are provided at both individual and collective levels. It might be informal or structured participation, a time-limited one-off occurrence or an ongoing relationship. User involvement in research can be based on models of direct participation or user representation.

2.3 Where do the boundaries lie between 'research' and other types of user involvement?

The term 'research' has a broad range of meanings. Research is sometimes described as 'rigorous and systematic enquiry, conducted on a scale and using methods commensurate with the issue to be investigated, and designed to lead to generalisable contributions to knowledge' (Department of Health, 2001b).

Project definition: user involvement in research

We are including the involvement of service users in research projects, the implementation of research findings and in the commissioning of research projects, for example in priority setting exercises or on funding committees.

We are including user involvement in the systematic development of nursing, midwifery or health visiting services as the result of research, but not user involvement in other broader types of service development.

We are including work described as 'community development' where this has directly involved or had an impact on nursing, midwifery or health visiting services.

We are including evaluation work, such as the evaluation of service delivery initiatives or educational interventions, where service users participate in the process of the evaluation.

We are not including the involvement of service users in their own care or the care of a relative, for example in care decisions or joint decision-making.

We are not including the involvement of service users in educational interventions. We are including user involvement in research about the design or evaluation of nurse, midwife or health visitor education or training.

These conceptualisations of the topic were further refined in the process of developing the Review Framework (see Section 3.5).

Chapter 3 Methods

- 3.1 Setting up and working with a service user reference group
- 3.2 Systematic searching of the published literature
- 3.3 Searches for unpublished literature
- 3.4 Networking and consultation activities
- 3.5 Developing a review framework
- 3.6 Analysis and synthesis
- 3.7 Planning dissemination with service users

This chapter of the report describes the methods used in the project, as described by the section headings above.

We perceived differences from a traditional systematic review from the early stages of the review process. We did not have firm expectations about the findings or have hypotheses to be tested. We did however have a view of the principles we would follow for the methods and the outputs we expected to achieve (specifically, a final report and some form of classification or synthesis of different models of involvement we had identified).

Principles for the methods

The principles that underpinned our methodology were to:

- take a flexible approach to the topic and methods at the outset and to refine the search and steer the review towards answering questions uncovered during the process in the light of new information gained
- involve service users in the process of the review to: inform the scope, support the identification of appropriate literature and ongoing work, reflect on the evidence and advise on outputs/dissemination
- search widely across different literature sources, but to focus thinking on nursing, midwifery and health visiting research
- undertake search activities using systematic and reproducible methods
- use information technology and consultation methods to link and network with others to identify ongoing work in the topic area and publicise the study
- document our experiences and learning about the process of undertaking the review in collaboration with service users.

The findings of a study by Lilford *et al.* (2001) of researchers' and others' views on undertaking reviews about research methodology support some of these principles. For example, they recommend that investigators should not aim to chase every last reference, but should ensure that they search widely and in disparate databases and

User involvement in nursing, midwifery and health visiting research

sources. They also advocate using methods beyond the review of data including networking and collection of primary data, as well as publicising the existence of the project to bring in new ideas and short-circuit extensive search processes (this is one area where we hoped consulting with researchers and involving service users would benefit the project).

Guided by the principles of the methods, we further developed the methods over the course of the work. Figure 1 shows the main stages of the review process and the methods used at different stages. Although these are depicted in separate boxes, some flowed into each other and others were undertaken simultaneously.

- The central column of the figure represents the core activities of the search process. By this we mean actions such as selecting, retrieving, analysing and interpreting the data.
- The left hand side represents the involvement of the service user reference group at various stages of the project.
- The right hand column represents the consultations with different professional groups that served to inform and refine the core activities of the review. For example, refining our operational definitions or helping to identify existing networks or databases.

Lilford *et al.* (2001) recommend that studies of a methodological topic should include a short summary of key findings, which should include practical solutions to identified problems, to assist future researchers. This is an idea that we support and have therefore included reflections and learning about the approach in Chapter 5 of this report.



3.1 Setting up and working with a service user reference group

3.1.1 Rationale for involving service users in the project

As the purpose of the review was to draw on an extensive range of evidence and theory there was an important distinction to make in establishing which evidence was relevant. The rationale for involving consumer organisations in the project was that they would:

- connect the project with specific consumer concerns, issues and perspectives
- influence the project by contributing to developing priorities and principles
- be critical, challenging and stimulating
- provide advice about the best ways of disseminating findings through different networks.

3.1.2 Our approach to user involvement in the project

Our approach was to set up and support a service user reference group specifically for the duration of the project. This would enable collaborative and interactive working throughout the process of the review. The key features of our approach are described below.

- Consecutive meetings with the same group of people was chosen as a broad approach to working with service users. Project resources meant that a group of up to 20 participants could be funded to meet three times. We felt that three meetings over the course of the year would be workable and acceptable to members.
- We felt we should recruit members of the service user reference group as soon as possible so that they could participate with us fully in taking a real and meaningful role in informing and influencing the process of the review.
- We wanted to show some sense of national diversity within the group, and to show diversity in terms of the activities that nurses, midwives and health visitors undertake and the client groups they work with.
- We felt that the meetings should be chaired by an experienced consumer representative, who would provide a connecting role and support members to develop their own terms of reference and methods of working.
- To enable communication between the project team and the group to be interactive and responsive, we were open to using a mixture of communication methods such as: telephone conversations, e-mail, project website and newsletters.

Box 1 Overview of the service user reference group meetings

Meeting 1: June 2004

The objectives of the first meeting were for members of the group and the team to meet, to start to build relationships and share ideas, to understand different organisations and roles and to explore how the service user reference group might work. As a result of this meeting terms of reference and ways of working were developed and a detailed list of issues and topics about user involvement in research was generated (see Box 3 and Appendix 6).

Meeting 2: November 2004

At the second meeting members discussed the scope and remit of the review. A draft review framework (the final version is shown in Appendix 7) was developed from the list of issues and topics raised at the first meeting, to which further topics and issues identified through initial searches of the published literature had been added. The review framework lists the wide range of possible issues and topic areas that the review could seek to address. Members of the group identified those that they considered important and gave reasons for their decisions.

To draw on the expertise and links of members of the group, at the second meeting members were asked to undertake a mapping exercise (Appendix 9) to show the organisations they are part of/have connections with; networks they are part of/aware of and journals or websites that they use or are aware of that link to the topic area. These were grouped together and are shown in an appendix to this report (Appendix 10).

Meeting 3: February 2005

At the third meeting members were invited to contribute to planning for dissemination of the findings. A summary of the findings of the searches was presented back to the group. The group were asked to identify key messages for a range of target audiences and to think about the optimal way of conveying these (see Section 3.7).

3.1.3 Recruitment of the service user reference group

The approach to recruitment was to identify individuals who were interested in the topic area of the review and recruiting through consumer organisations, voluntary groups, participation networks and partnership groups. The recruitment process included:

- 1 **Development of a sample framework** to gain diversity of members within the service user reference group in terms of the range of nursing, midwifery and health visiting activities, different patient groups and priority clinical areas.
- 2 Identify organisations to achieve diversity of sample framework (nine weeks prior to first meeting). A specific list of

potential organisations was built up by drawing on the knowledge of the project team, project advisors and Internet based searches.

3 **Identify target individuals within organisations** (eight to three weeks prior to first meeting)

Each organisation that had been identified was contacted by telephone by a member of the project team to find the name of either the chief executive, chief officer or manager. The first contact was most often made to a general switchboard or information line and a short explanation about the review was given and that we would like to write to an appropriate member of the organisation in person.

4 **Initial contact with targeted individuals by letter** (six to three weeks prior to first meeting)

We wrote to the chief executive, chair or a known named individual within each of the identified organisations. We provided information on the aims of the review and a leaflet about joining the service user reference group, which contained a form for respondents to express their interest. The letter invited the addressee to become a member of the group or to pass the information to a suitable member of their organisation. This information was posted to individuals within four to six weeks of the first meeting.

5 **Follow up initial contact and networking** (six to three weeks prior to first meeting)

If we had not received a response to the initial contact within two weeks this was followed up with a telephone call. This part of the process took a lot of time as some people had not received the letter, had passed it to a colleague or were intending to send it out to a wider group of members to elicit interest.

6 Receipt of interest (two to three weeks before first meeting) Confirmation of receipt of interest was sent to those people who had expressed an interest in joining the group. Confirmation was sent either by e-mail or letter depending on the contact details provided to the project team. Respondents were informed that a selection process would be occurring because of limited places on the group and that they would be contacted with further information.

7 Selecting respondents to join the group (one to three weeks prior to first meeting)

Because of cost and optimal group numbers, we were limited to a group size of 26 people. Individuals were selected to represent a balance of diversity and experience across a wide range of organisations and voluntary groups. Those who were not selected were thanked for their interest and offered a summary of the project findings.

8 **Providing information about first meeting** (two weeks prior to first meeting)

Those selected to be a member of the service user reference group were sent an outline agenda, information about access and the venue.

3.1.4 Reflections on the approach to recruitment of the service user reference group

- Some delays were experienced gaining ethical approval for recruitment of the group because the role of service users was developmental rather than being specifically defined.
- The approach placed an emphasis on organisational contacts to gain permission to participate, nominate a representative or establish a fair way of putting forward a representative of the organisation. It was difficult for multi-site organisations to nominate a single representative and help was often requested from the project team to support this selection. Some respondents expressed concerns about whether they were the best person to represent their organisation and whether they needed permission to do so.
- The flow of recruitment materials through different organisations is likely to have meant that those people who had access to email or those who had been forwarded the information directly were more likely to participate. Some organisational contacts said they did not know who to pass information to, or did not know the function of different regional offices or localities.
- Organisational e-mail networks proved to be very effective at reaching individual members of an organisation. However, the limited number of places within the service user reference group meant that the interest this generated could not always be met. A difficult but important part of recruitment was explaining to people why they had not been selected. A telephone call was felt to be the most sensitive way to say 'sorry you weren't selected to participate' and to explain that the reasons for this were not personal but were based on our aim of achieving diversity of representation within the group.
- The timing and nature of communication were important. To keep track of personal communication preferences the project team kept notes on how, when and for what purpose we had contacted individuals. However, this was a time-consuming process.
- Early responders were eager to be told more information about the first meeting as soon as possible. There was a delicate balance to be struck between providing enough information about participants' roles and enabling members of the group to develop these at their own pace.
- We took the decision to hold places within the group, in an attempt to achieve diversity. However, we were aware that we might not be able to recruit members of organisations to the vacant places. Although three places were not filled by the first

meeting, by the second meeting two organisations had put forward a representative.

 We did not include information about a fee payment for participation in recruitment information. For those who were selected to participate financial information was provided prior to them attending the first meeting as we felt they had a right to know the value of the fee (£100) they/their organisation would be receiving for their time.

3.2 Systematic searching of the published literature

A substantial part of the review comprised a search of the published literature using:

• electronic databases of papers in peer reviewed journals

• library sources. The methods for undertaking these searches are described here.

3.2.1 Search strategy

Our search strategy was to:

- undertake an initial search of the published literature using electronic databases to identify the potential breadth and nature of the topic area
- identify key terms for searching electronic reference databases by exploring each facet of the topic of 'user involvement in nursing, midwifery and health visiting research'
- undertake a first stage of sorting, using the title or abstract of references, to filter the literature and focus subsequent searches
- use the most relevant papers to identify further papers in a second stage of searching.

Facet analysis

To build a sensitive search it was necessary to explore each element, or 'facet', of the review topic and to identify all of the possible synonyms or associated terms (Figure 2). For example there are several commonly used terms in the literature that are used to mean 'service user', including 'patient', 'consumer', 'client' and 'lay'.

In the electronic searches, the OR operator was used to include all of the possible terms within each facet in the search. The search strategy for the published literature was multi-faceted and the strategy was developed iteratively and refined by adding key index terms of the most relevant papers retrieved.

For the purpose of searching electronic databases the terms identified by the facet analysis were used in the combinations shown in table 1 to produce a structured search of the literature. This created a very sensitive search that was inclusive of all the terms identified in the facet analysis. The searches were sensitive to any paper or article listed on the electronic databases that contained any combination of the terms in its title or abstract.

Figure 2 The facets of the literature search and key terms

Facet 1: Service user

user consumer patient public lay community client carer

Facet 3: Involvement

involvement participation consultation partnership collaboration

Facet 2: Nursing, midwifery, health visiting

nurse health care midwife social care health visitor

Facet 4: Research

research practice development participative research community development

The electronic databases selected for the search were those known to include research papers, those relating to health care or health care services, those specifically focusing on nursing and midwifery, as well as educational databases and sociological databases. For each of the electronic databases, index terms and key search terms were adapted appropriately to maximise sensitivity. Details of the index terms and key search terms used to search each of the databases are shown in Appendix 1.

Table 1 Summary of key index and search terms				
Words used to identify database index terms	Key search terms			
Consumer	Consumer OR User OR Client OR Patient OR Public OR Carer OR Lay			
Participation				
User involvement	ADJ3/SAME			
Patient				
	Participat\$ OR Involve\$ OR Empower\$ OR Collaborat\$ OR Consult\$			
Nurse	Nurs\$ adj3 research			
Nursing research	OR			
Research	Nurs\$ adj3 practice development			
Health	OR			
	Nurs\$ adj3 community development			

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Note: The wildcard function (\$) was used to search for multiple word endings; An adjacency operator was used to search for combinations of words with one to three words separation.

> The majority of papers were retrieved through Ovid and the Web of Knowledge interfaces. Because a large number of papers (2132) were retrieved through this initial search the title of each paper was read online to determine whether it related to the topic area and should be included. Abstracts were read if relevance could not be determined from the title. The references for papers considered relevant (n=634, see Table 2), and abstracts where available, were downloaded to reference management software (Endnote 7). Duplicate references were removed.

3.2.2 Reliability of judgements about which papers should be included

To determine whether the judgement about the inclusion of papers was appropriate, three researchers independently read all of the abstracts of papers (55). The researchers classified each abstract as 'YES' (include) or 'NO' (don't include). Two or all three of the researchers agreed that 13 papers should definitely be included and that a further four might provide background information. However, it was apparent that this yes/no classification was not sensitive enough to distinguish between papers that were highly relevant and those that would contribute to providing background information on the topic. To increase the specificity of the search we classified papers according to topical categories (shown in the left hand column of Table 2). Topical categories were selected to represent the involvement of service users in a range of different activities. This process aimed to target the most
relevant papers (those relating to user involvement in research) without disregarding partially relevant papers at this stage ('maybes' were retained on separate electronic databases). Papers cross cutting more than one category were included in each.

Category	Description	Papers
Research	Involvement in time-limited research projects Involvement in implementation of research findings Involvement in research about design or evaluation of education interventions	86
Models	Models of involvement/engagement with different groups of patients (not necessarily research methods)	70
Background	Philosophical, political, sociological debates about involvement or nursing research	38
Priority setting	Involvement in the priority setting or commissioning of research, or evaluation of research programmes	8
Service development	Involvement in service planning, development or evaluation	109
The following we	ere not included in the review:	
Community development	Collective involvement at a local level to improve opportunities for health, e.g. community development.	(72)
Care decisions	Personal or family care decisions	(167)
Expert patients	People taking responsibility for their own care or treatment	(55)
Education	Patients (or those with particular experiences) being involved in education or training of different professional groups	(29)

Table 2 Primary categorisation of included papers (Ovid and Web of
Science)

3.2.3 Second stage searching

All papers retrieved via Ovid and the Web of Science, identified as fitting within categories relevant to the review ('research', 'models', 'background', 'priority setting' and 'service development') were merged into one electronic Endnote database. Because of limited time for searching, papers in less relevant categories were excluded at this stage ('community development', 'expert patients', 'care decisions', 'education'). Full articles of papers were retrieved through electronic sources, library stacks or interlibrary loans. Additional, smaller electronic libraries were searched individually (see Appendix 2 for a list) and papers fitting the relevant categories were added to the Endnote database and a full copy of the paper was retrieved.

Journal searches: Each journal in which an included paper was found was searched electronically (through the journal website) for similar or related articles. This revealed a small number of more recently published papers that had not been retrieved through the electronic database search and several themed issues of journals with papers on a linked theme.

Reference searching: The reference lists of highly relevant and recent papers identified by the search were searched for further materials. (This, however, proved very time-consuming and was therefore only undertaken with key source documents).

A total of 345 papers about user involvement in research, research priority setting and service development, different models and background information, had been identified at the end of the second stage of searching. Of these, 311 were identified by the original search and 34 were found during the second stage searches.

The majority of papers could be retrieved in hard copy through electronic archives. A relatively small number (n=46) of papers were retrieved by interlibrary loans or from the British Library.

3.2.4 Library and policy document searches

Library searching for chapters and books was undertaken using King's College Library and King's Fund search engines. Some references were found by an element of chance, due to their proximity to other reference documents in library stacks. This revealed a small number of documents (n=25), many of which were only relevant to a small part of the topic area.

Policy documents relevant to user involvement in health services and research were targeted in the review.

Electronic databases for the Department of Health, Nuffield Trust, King's Fund, Royal College of Nursing, Research Councils and Charities; Joseph Rowntree Foundation, Nuffield Trust, King's Fund, The Wellcome Trust, Medical Research Council and the Nursing and Midwifery Council were accessed.

3.3 Searches for unpublished literature

Unpublished literature sources were searched online including:

- INVOLVE (record of research projects) <u>http://www.invo.org.uk/Database.asp</u>
- National Research Register <u>http://www.nrr.nhs.uk/search.htm</u>

We hand searched conference reports and scanned web pages about service user involvement in research. We identified research reports

that appeared to be relevant to the topic of the review and contacts to follow up during the consultation.

A search of the INVOLVE record of ongoing or completed research projects (using the index term 'nursing') revealed nine projects, of which those relevant to the topic of the study included: establishing consumer involvement in multi-disciplinary education and health care provision; cost effectiveness of classes of drugs for Parkinson's disease; evaluating the role of the Multiple Sclerosis specialist nurse; collaborative research between mental health nurses and mental health service users; mental health service users' views of nurse prescribing; the mental health needs of children and young people during the transition from primary to secondary school; and positive and negative aspects of long-term care settings as experienced by residents with dementia, their families and carers.

A search using the index term 'midwives' revealed two projects relating to: an evaluation of the impact of the supervision of midwives on professional practice; and the quality of midwifery care and women's views and experiences of antenatal care.

A search of the National Research Register (using the term 'user involvement') identified 23 completed projects. Those relating to the topic of the study included: community psychiatric nurses' empowerment of people with enduring mental disorder in the community; developing and evaluating best practice for user involvement in cancer services; development of information and advice for parents caring for ill children in a disadvantaged community; evaluation of service development in a multi-agency centre; involving children and young people with a chronic illness or physical disability in the process of local decision making about the development of health services; optimising user involvement in the planning and delivery of health care: evaluation of models used by mental health services in London; service user involvement in change management: current practice and research needs in the context of NHS modernisation; service users' evaluation of the process of providing feedback to practice co-ordinators about social work students; shared decision making in primary care; teenage parenthood and social exclusion; user-directed assessments (self assessment) to identify health and social care needs among older people: a multi-method systematic review of literature and practice.

3.4 Networking and consultation activities

3.4.1 Publicising the project

We publicised the project in a number of ways:

Regular updates about the project were placed in the INVOLVE newsletter.

- A project website was kept up to date and links were made to the site from the commissioning programme website, INVOLVE and the Health Voice Network website.
- E-mail calls for grey literature served to inform international networks about the existence of the project.
- We used professional/research networks, for example conferences and meetings to talk about the project and the topic area (one example is shown in Box 2).

Box 2 Networking with practitioners and researchers

In July 2004, at the annual conference of the Society of Academic Primary Care, three members of the project team facilitated a series of group discussions about user involvement in primary care research. The aim of the workshop was to build collective thinking about user involvement in primary care research. The format comprised progressive rounds of discussion in small groups: building from open questions to more specific identification of issues about perspectives, opportunities, challenges, and approaches to involvement.

Of the 25 people who participated, nearly all were qualified primary health care professionals and most had experience of involving patients or the public in the development of a service or in a funded research project.

Flipchart papers used in the group discussions and facilitator notes were used to produce a feedback summary for participants. We undertook a thematic analysis of the information that had emerged from the discussions. This revealed seven key topic areas, which link the project to views and concerns of researchers and practitioners working to involve service users in research.

- 1. Working towards clear meaning and purpose to 'customise' patient and public involvement to different situations and contexts.
- 2. Extensive work needs to go into raising awareness, generating interest and keeping confident and special people involved.
- 3. Challenges of redistributing power and modifying professional cultures, creating a dialogue between funders, patients, the public, providers and researchers.
- 4. Developing understanding about representation issues.
- 5. Practical issues such as money, time and training for professionals to be able to support patient and public involvement.
- 6. Developing approaches to feeding back and evaluation, to track impact and establish which methodologies are more amenable to different groups of people.
- 7. Understanding the links between involvement and the wider public understanding of science and moves towards a new user culture.

3.4.2 Calls for unpublished, ongoing or recently completed work

The field of user involvement in nursing, midwifery and health visiting research is developing rapidly, and in this context it was important to be able to access research that was in progress as well as recently completed or unpublished research. We were particularly interested in looking at a number of potentially influencing factors for individuals and their organisations; these are listed below.

- 1. Understandings about the underlying theoretical frameworks for involving service users in research.
- 2. The disciplines that have undertaken involvement activities and the primary location of the research.
- 3. Funding sources for this type of work.
- 4. Objectives and study designs.
- 5. The nature of user involvement (for example consultation, setting the agenda, data collection, interpretation, dissemination, implementation).
- 6. The type and characteristics of service organisations within which the work was undertaken.
- 7. When and for how long the work was undertaken.
- 8. Any perceived impact or evidence of impact to the process, outcomes or people involved (for example, researchers, service providers or service users).

To investigate these areas we adopted a systematic approach, using an electronically-distributed questionnaire.

3.4.3 Developing the e-mail questionnaire

There was an implicit trade off in the design of the questionnaire between capturing in-depth information of a high quality and ensuring the questionnaire was accessible. The depth of information that could be captured had to be balanced against the clarity of the questions and the time it would take to complete. Since we envisaged undertaking some follow-up interviews with leaders of selected projects it was also important to determine which aspects of user involvement were likely to serve as a trigger to identify such projects.

The final version of the questionnaire contained 13 questions designed to elicit respondent, project and user involvement information. The 'user involvement' questions focused on:

- the reasons why service users/carers were involved in the project
- how this was achieved
- which aspects of involvement led to successful outcomes.

In addition, a final open question provided respondents with an opportunity to tell us anything else that they felt was important about the topic. The questionnaire was framed by introductory and final sections which included summary information about the project (including the project funder and timescale), a brief explanation of our use of the terms 'research' and 'involvement', the contact details for the project team and a reference to the project website for further information. Respondents were asked to forward on the questionnaire to colleagues if appropriate. As an acknowledgement of their time and contribution, each respondent was offered a summary of the project findings when the project was completed.

Once finalised, the questionnaire was added to the project website. During August 2004 (five months from commencing the review) a member of the project team used a series of online distribution networks to disseminate information about where to find the questionnaire (a list of the networks is shown in Appendix 4).

3.4.4 Responses to the e-mail questionnaire

The first response was received within days of the questionnaire being disseminated via the national academic mailing list service, JISCmail. A total of 33 completed questionnaires were returned. There were a number of enquiries from potential respondents, for example, about whether their particular research was relevant or whether the PIN project was UK-specific. Each contact was acknowledged and individual queries were addressed. Most of the questions about research relevance focused on either the role of service users as partners in the research process or the interface between research and service development.

We felt a slight tension between wanting to encourage respondents to tell us about their work and not wanting to waste their time if it was apparent that their research didn't fit within the scope of the project. In these instances, our approach was to highlight what we meant by specific terms (such as 'user involvement' and 'nursing research') by reference to the working definitions on the project website and leave the decision to each individual.

Of the 33 studies brought to our attention via the e-mail call, 16 were not included in the review. Although these studies had explored users' views they did not appear to actively involve service users in the research process.

The studies we included were diverse in relation to respondent (to the questionnaire), research setting, scale and funding. Respondents included research fellows, independent researchers, PhD students, and a user researcher. Studies ranged in scale from a national survey of academic departments to locality-specific projects focused on one particular area of service delivery. In relation to funding, studies ranged from a long-term collaborative project funded by the Department of Health to self-funded research endeavours pursued in fulfilment of a higher degree. At the time of submission of the questionnaire, nine projects were ongoing and eight had completed.

Consequently, there were a range of associated outputs including published papers, conference presentations, reports and project leaflets.

The included studies spanned a range of clinical conditions and areas of service delivery including cancer, mental health, heart failure, stroke, asthma, rheumatoid arthritis, post-natal depression, learning disability, cleft lip/palate, autism, palliative care, maternity care and general hospital care. Individual projects involved people with rarer forms of cancer, younger people with stroke, South Asian women with post-natal depression and children in hospital, as well as carers.

3.4.5 Follow-up interviews with researchers

From the responses to our e-mail questionnaire, 13 projects were selected and the respondents (who had submitted the questionnaire) were invited to participate in telephone interviews. The aim of the interviews was to explore respondents' findings and experiences and to capture detailed information about how involvement works in different research contexts. Excerpts from the telephone interviews are included as real life examples throughout this report and are cross-referenced to the project details in Appendix 5.

The selected respondents were contacted via e-mail, initially to elicit their interest in participating in a telephone interview and subsequently to arrange a convenient date. Information was provided about the purpose and likely duration of the interview along with a request to tape record the discussion. When telephone contact was made at the agreed time, the researcher followed an interview checklist to: ascertain that the interviewee was happy to proceed and had given consent for the interview to be taped; explain how the questionnaire they had submitted would be used as a prompt during the interview; and discuss issues of confidentiality in relation to the collection and use of data via the telephone interview. Before the interview began interviewees were asked if they had any questions or comments.

Each interview schedule was individualised, with questions tailored to explore the responses to the e-mail questionnaire. Additional questions were asked which focused on the context within which the researcher worked (in relation to the research/project team and host institution) and where relevant, the progress in the project since the questionnaire had been completed (for example, questions about outputs).

Of the 13 researchers approached, 12 agreed to participate in a telephone interview and 11 interviews were conducted over a period of six weeks. One researcher was not interviewed as their response, which had been delayed, was received at a time when project resources were focused on analysing and synthesising the data. Interviews lasted approximately 35 minutes, and although this was

longer than the original estimation of 20-30 minutes each respondent gave permission for their interview to continue.

3.5 Developing a review framework

3.5.1 Purpose of the review framework

The project team felt that developing a review framework was a way of framing the complex issues and debates. The purpose of the framework was to:

- distinguish the boundaries of the review in the broader context of the topic area
- identify the broad range of possible issues and topic areas within the remit of the review
- produce a structure for categorising papers from the literature and other data
- identify focused areas for further investigation.

Issues identified by the service user reference group at the first meeting were used as the first building block for developing the review framework. Box 3 summarises the full range of issues that were raised.

Box 3 The contribution of the service user reference group to developing the review framework

At the first meeting of the service user reference group (June 2004) members were asked to discuss the question 'what is successful user involvement?' Key issues about user involvement in research were drawn from the discussions using various data sources: notes taken by the project team; flip charts used in the group work; post-meeting discussion by the project team; and reflections on the meeting by members of the service user reference group and the project team.



Summary of issues/themes identified by the group

The key issues (many of which are in the form of questions) were grouped into six categories, described below.

1 Definitions

- What is research? Is it restricted to work that is eligible for publication after being subjected to a process of peer review? For some, a peer-reviewed publication is regarded as the 'gold standard' (this involves academic peers validating, or giving credence to a written report of a project). We need to be aware of the 'hierarchy of evidence' and its dangers. For example, pharmaceutical companies have considerable influence over decisions about the publication of research that they have funded. In this sense, research is a political process.

- Where does research begin? Is it at the stage when the research question is decided, or at the stage when research is commissioned? This is not just a technical matter as it encompasses values about involvement of users. It is not possible to separate what the research is 'for', and its values, from the practicalities or 'doing' of it. This again highlights the political nature of research.

– What is a systematic review? In PIN we will adopt a creative approach and use criteria developed by the service user reference group to inform our review of the literature.

- Is it feasible to consider all areas of nursing, midwifery and health visiting in the review? There is huge diversity within nursing alone in relation to nursing roles and practice. We should aim to develop models of what works, although this will be challenging. We should be asking if there are any commonalities and searching for patterns and variations. It is likely that we will identify cross cutting themes and issues across different areas of nursing, midwifery and health visiting.

Our interest (in relation to the project's remit) is users' involvement in research, not their involvement in the development of services. The project's focus is on both user involvement in research (how service users work alongside researchers) and on research into user involvement (how service users experience involvement). There are definitions of user involvement in the literature.

Members of the group raised issues about the rationale for involvement and the importance of having clear expectations.

2 Rationale and expectations

- Why is nursing, midwifery and health visiting research being carried out? Is it about power and developing the careers of researchers? Research can be unethical, for example in the context of medical research where women have been subjected to unnecessary interventions.

– Why are users involved in research? For service user individuals and organisations, research must be relevant and perceived to have an impact. Service user organisations can get overwhelmed with requests to be involved in research. They have to weigh up the benefits of engaging, especially as personnel are diverted from their own work and there is often no financial recompense. In response, one organisation (represented in the service user reference group) works on the principle of engaging with research projects only if they are involved from the outset. For some organisations (and some service users) user involvement alone is insufficient, involvement must provide the opportunity for influence or change.

- What are researchers' motivations for involving users? Is it about being truly inclusive? Researchers often want a blueprint for user involvement, but it is an organic process, not a means to an end. There should be clarity about the aims and purpose of involving users. Approaches to user involvement can be tokenistic. For example, in some NHS patient and public involvement (PPI) initiatives, there is pressure to 'do' involvement but little real commitment.

Research governance and ethics. Research governance is important. Every
research ethics committee should have a lay member. There may be ethical
issues in relation to service users' priorities that lie outside of a project's remit.

3 User involvement: when, who and how?

Connected to the fundamental question of why users are involved, an examination of user involvement in research needs to consider the details of who is involved, how and when.

- When are users involved? Users should be involved from the very start of a research project. If this is not possible, there should be openness and honesty about what can and what can't be done. The recruitment of users may be delayed deliberately, for example, if energies are initially concentrated on securing funding for the research. It is important to realise when these sorts of decisions have to be made and to be clear about what's being done when and why.

– Who are users? Are there eligibility criteria for involvement? What are the 'credentials' of service users? Should service users involved in research be representative of the general population? Should they have experience / knowledge / expertise relevant to the research question?

– How are users recruited? Use creative methods to engage with 'hard to reach' groups. Research reports should describe the methods used to recruit users.

 How are users involved? Involvement must be more than consultation. Different (creative) methods should be used to enable people to contribute. These might not be recognised as valid or authentic by some people in the research community.
 Sometimes users can be the driving force in projects; without them projects might collapse.

4 Resources to support user involvement

User involvement in research needs to be resourced in a myriad of ways to make it an equal process:

- Time: Involving users takes time.

- Money: Payment for service users' time and expenses is important.

- Training: Training for users and researchers; joint training to address how to work together; user-led training.

- Relationships: Service users should be integral to the team and valued for their unique perspectives; support/mentoring systems - for users to talk through their ideas and concerns; users working together (in pairs/a group).

- Commissioning strategies: Appropriate funding for user involvement research.

- Information: Should be provided in appropriate formats and accessible language; dissemination of information via different media to meet users' needs and preferences; guidelines on user involvement, for example those produced by the National Institute for Clinical Excellence (NICE) and the cancer networks.

5 Users' perspectives of involvement

It is essential to learn about user involvement in research from the perspectives of users themselves.

- Users' feelings about the process of being involved: Users should feel safe and valued and their confidentiality should be respected.

- Is there a collective goal for users and researchers? Will we achieve 'ownership by all'?; learning together and from each other (mutual learning); building confidence of users and researchers.

6 Evaluation and follow up

Commissioners should be aware of funding issues in relation to the evaluation of service user involvement.

Impact of user involvement: Service users' feelings about their involvement are an important 'measure' of user involvement. User involvement can have a tremendous impact on individual researchers; in some cases it can irrevocably change the way they engage in research. There may be unanticipated outcomes and 'learning as a by-product' of user involvement.

Building on these themes

We summarised the issues identified by the service user reference group and expanded on this list (shown in Appendix 6) by adding further categories and issues from the initial searches and sifting of the published literature. Using issues that were important to service users and researchers as a starting point for building the review framework meant that these issues would be incorporated from an early stage.

The issues raised by the service user reference group led to our decision to incorporate the following points in the development of the review framework:

- Nursing, midwifery and health visiting research often involves children and young people. We should specifically look at the issues and difficulties associated with involving children and young people in nursing, midwifery and health visiting research. We should establish whether these issues are to do with informed consent or whether there is evidence or opinions that children and young people do not have the capacity to contribute to research.
- Nursing, midwifery and health visiting research is greatly influenced by the priorities of research programmes and the requirements of research commissioners. This is an important area that service users can, and are, contributing to. We should therefore include research priority setting and research commissioning issues in the review.
- There is no consensus about the meaning of involvement and this is particularly problematic when making judgements about whether certain activities can be classified as involvement. Published concepts of involvement identify 'levels' of involvement. It is important that we should state what we mean by 'lower levels' of involvement and how we perceive these in relation to other 'levels' of involvement (see section 4.2.1 and 4.3.2 scepticism about tokenistic involvement). The review should not exclude lower levels of service user involvement in research because different approaches to involvement have a different impact on individuals involved, broader service user groups, and the research process and research outcomes in different research contexts. It is more important to look at what works in different contexts, and why, rather than positioning one form of involvement as intrinsically better than another.
- We should be sensitive to different accounts in the literature about the involvement of carers as a distinct group of people.
- We should consider what is meant by 'public' involvement in research.

Other considerations for the process of the review

• It is important to include evidence about the process of user involvement as well as the outcomes of user involvement in

research. The process is important to researchers and service users engaging in research projects. Notions of quality in user involvement might relate to the process or the outcomes of involving service users in research.

- Service user involvement in research is an interlinking 'jigsaw' of issues. Enabling service users to be involved in research is a central theme but there is a view that researchers and professionals should be supported to achieve this, for example through education and training alongside service users.
- We should look at power relationships, the context of user involvement in nursing, midwifery and health visiting research and the position of service users in research projects.
- We should think ahead and make plans for dissemination early on in the project and identify potential audiences to disseminate findings to.

The whole range of issues and topics were synthesised to form the four broad categories of the review framework. A full copy of the review framework is shown in Appendix 7.

- External/context issues: such as: the broad philosophical or political issues associated with participation, citizenship and user involvement movements; the terminology or meanings of involvement in different contexts and between different groups of people; the involvement of service users in the commissioning of research; and conceptual issues about the nature and methods of research.
- 2 Methods issues: issues at an organisational or project level of involvement, for example the purpose or setting of involvement and methodological issues specific to involvement in that context.
- **3 Outcome issues:** including the impact of involvement and any outputs that are created such as publications or changes in practice; dissemination and the wider impact of a project or the process of service user involvement; also, issues of generalisability and quality of findings.
- 4 **Capacity issues:** including issues about organisational support, researcher capabilities, research culture, education and training, financial support and sustainability of involvement.

3.6 Analysis and synthesis

3.6.1 Approaches to multi-method reviews

We have described our approach to using different methods to analyse and synthesise information from a wide range of sources as a multimethod review. Different researchers have developed methods for undertaking work of this nature, which differ from traditional systematic review methods. For example, Campbell *et al.* (2003) describe meta-ethnography, or the combining of different types of qualitative and quantitative data sources. Greenhalgh *et al.*, (2004) have developed a technique, which they called meta-narrative review. They describe this as the unfolding 'storyline' of research drawing on seminal theoretical and overview papers and books and analysing the conceptual and theoretical models proposed by experts in the field.

Although these methods have helped to guide our thinking they did not always seem to fit the purpose of what we were trying to achieve, partly because we set out to identify evidence relating to more than one aspect of the topic and because we had taken the decision to look outside of the topic area for insights or concepts that might be of use in furthering the development of user involvement in nursing, midwifery and health visiting research.

Principles for the analysis and synthesis

A number of principles underpinned our approach to the analysis and synthesis of data.

- 1 To describe the type and source of the evidence in terms of opinion, policy, research based, or systematic review findings, rather than weighting the evidence. Weighting would be difficult because of the small amount of research-based findings in the topic area.
- 2 To retrieve from the various data sources information that relates to different themes (guided by a Review Framework), about the context and drivers of user involvement in nursing, midwifery and health visiting research, the approaches and methods that have been taken to involve service users, the impact and outcomes of involvement and the professional and organisational factors that relate to its future development.
- 3 To use a broadly structured approach to extract information (making use of a review tool) from a wide range of sources, including published evidence and primary data for example from telephone interviews with researchers.
- 4 To reference, code and sort the data using reference management software and literature tables in Microsoft Word. As each source was likely to contain information relating to more than one themed category it was not feasible to sort documents by these categories. To enable source documents to be located easily for cross-referencing, by maintaining alphabetised hard copies of journal articles and reports/policy documents.

Reflections on the approach to analysis and synthesis

It was not feasible to have clear separation between data collection, analysis and writing. For example, beginning to identify and group the issues from an early stage with the service user reference group helped to clarify the boundaries for data retrieval. And, writing

relevant sections of the report helped to clarify the process of the analysis and synthesis that we were undertaking.

The sheer volume of potentially relevant documents created difficulties in the analysis. It was not possible to give all documents equal time for scrutiny and priority of attention was awarded to: the most relevant (those making explicit reference to user involvement in research, and those relating to the UK); the most recently published documents; and documents cited most frequently by other authors, though this was based on our own judgements rather than according to citation indexes.

Some difficulties were encountered at the analysis stage determining which thematic category to code information by. We made a decision to include information in multiple categories at an initial stage and then to remove any repetition at a later one when we had a clearer view of where the information would best sit in the report. In this way the synthesis could only be partially structured, it also needed to be iterative to accommodate new information being retrieved.

The synthesis was a qualitative process of reading, assimilating and synthesising information from the themed literature tables and adding further detail by referring back to original documents or primary sources.

In synthesising the data to write the report, it was necessary to merge some of the thematic categories of the review framework (for example 'roles and activities' with the outcomes of user involvement) because the issues could not be separated in a meaningful way and this would have meant considerable duplication in the report. The process of merging categories was aided by discussing the review framework with members of the service user reference group and hearing their views on the categories that they felt should be merged (this is why the headings of some sections of the report describe more than one issue). Using cross-referencing to overlapping issues was helpful for minimising duplication.

We considered the process of drawing conclusions about the findings to involve summarising what is known about the subject and identifying where the evidence is lacking.





3.6.2 Developing the literature reviewing tool

A form for reviewing the published literature (the reviewing tool) was designed with a tick box section at the top to indicate the categories and issues covered by the paper (matching those of the Review Framework). The tick box section included an 'other' section so that any new relevant issues or themes not identified by the review framework could be subsequently added to it. The remainder of the form comprised a table with the following headings to be completed by the reviewer: category, issue, comments/reflections, page reference(s).

As a process of validating decisions about the inclusion of particular documents, three members of the project team independently reviewed three randomly selected journal papers that had been returned by the electronic searches. Each reviewer was given a hard copy of each of the three papers, a form for reviewing the literature and a copy of the review framework as an aide memoir to the categories listed on the reviewing tool. After reviewing the papers, the researchers met to discuss the process.

Each researcher had spent a different amount of time on each paper but all had taken two-and-a-half hours or more to review all three papers. The main feeling was that it was an initially cumbersome process because each reviewer had to remind themselves of the categories while reading through the paper. This meant continuously flipping between the paper, the review framework and the reviewing tool. It was difficult to remember the descriptions for each category and two of the researchers found it easier to highlight particularly interesting or informative parts of the text of a paper and then refer back to the review framework to determine which information should be identified on the review tool. The reviewers discussed each of the three papers in turn.

- The first paper described the role of academic consumer researchers in mental health research. The reviewers agreed that the paper should be included because it presented one possible model for service users to be involved in nursing, midwifery and health visiting research. However, the paper was based on opinion rather than evidence and was small in scale. The value of the paper was judged to be in 'its contribution as one model of involvement' but also in that it raised issues about academic research cultures.
- The second paper described co-operative inquiry between nurses and their patients in a project about communication in nursing. The reviewers agreed that the value of the paper in relation to the review was that it highlighted points about the difficulties of recruitment and engagement of service users' and researchers' skills.
- The third paper was on the topic of action research, which is relevant to the review but it did not relate to involving patients or

members of the public in nursing, midwifery or health visiting research and it was therefore excluded.

In deciding how each paper fits with the review the following questions were identified as being important:

- 1. Does this paper fit with the topic of the review?
- 2. What does the paper add and why?
- 3. What is missing from the paper in terms of content or quality?

3.6.3 Identifying service users' perspectives of important issues

An objective of the second meeting of the service user reference group was to identify which of the issues included in the review framework were perceived to be of most importance by members of the group. A



member of the project team outlined the purpose of the framework and described how it had been developed. Working in small groups, members were asked to consider:

- 1 Are the topics and issues covered by the review framework relevant?
- 2 Which are most important; are there any issues that are missing?
- 3 What should be the priorities and take home messages for the final report/dissemination?

General discussion points made during the feedback session included:

- Overall, it was difficult to prioritise between different issues/topics within the four categories of the review framework because they all linked together or overlapped. The issues/topics were described as fitting together like a jigsaw of inter-related priorities rather than as a hierarchy of most to least important.
- There were different messages for different audiences and some aspects should be given more importance than others in dissemination of the project findings and in the future development of service user involvement.
- Themes of access, training and funding were identified as important and were described as cross-cutting all four categories of the review framework.

A list of issues was identified as being important based on these group discussions. These issues are shown in Appendix 10 and highlighted in relevant parts of the findings (see Section 4).

3.7 Planning dissemination with service users

We discussed dissemination of the research findings at both the second meeting of the service user reference group, and at a third meeting focusing specifically on dissemination, which also included other stakeholders (see Figure 1).

The group concluded that there are a number of different groups the work should influence including commissioners, researchers, professionals and the general public. In relation to methods of dissemination, the group made a number of points:

- We should think broadly about the methods of dissemination used to convey the important messages of the project. We could make use of the media, grey literature, popular magazines, peer review journals or radio broadcasts to reach a wide range of people.
- The dissemination methods will depend on the message that is being disseminated. Bottom-up dissemination and peerdissemination are as important as dissemination from the top down in targeting messages to different groups of people.
- The methods of dissemination need to be amenable to all some methods can be more generic, such as written materials, others could be more imaginative linking in with education or communication projects. We could rouse people's interest by emphasising particularly interesting findings or by dramatising the information.

The group raised a number of points in relation to their involvement in dissemination:

 The views of the members of the service user reference group could be used to convey to other people the value of being involved as a service



user in research – for example using personal statements about the groups' views of the process and of the findings.

- Involving members of the service user reference group in conference presentations would strengthen the messages of the project and could help to inform service users about the benefits of being involved in research.
- The findings of the project could be disseminated by members of the service user reference group using presentation packs (for example suitable for using with overhead projectors) to discuss the findings with their own organisations or networks.

Next steps

- There are cost implications of disseminating to different groups in different ways.
- It is important to engage with key stakeholders for example patient and public involvement forums.
- Education and training of researchers should be alongside service users.

Chapter 4 Findings

- 4.1 The context and drivers of user involvement in nursing, midwifery and health visiting research
- 4.2 The best ways of involving service users in nursing, midwifery and health visiting research
- 4.3 The outcomes of involving service users in nursing, midwifery and health visiting research
- 4.4 The capacity of researchers and research organisations to involve service users in nursing, midwifery and health visiting research

The fourth objective of the project was to present the literature on theory and evidence and analyse the strength of the relationship between the two. Fulfilling this objective requires defining what we (the project team) mean by theory and evidence in this context; and identifying and explaining what the theoretical debates or arguments about service user involvement in nursing, midwifery and health visiting research are.

Due to the small amount of previous research on service user involvement in nursing, midwifery and health visiting research, most of what the report reflects is opinion, or untested theory, rather than evidence. This is not to say that understanding these debates is not crucial in progressing knowledge, however, the reader should not take observations/theories of how things are to be the research evidence in this area. It is important to reiterate that we chose not to make use of a methods weighting in the analysis because this may lead to a misrepresentation of what is largely theory to be evidence.

In the findings section that follows, the decision to include extracts from a particular published work was based on its ability to articulate a particular debate in a concise and authoritative way, as a starting point for those readers who want to pick up these threads. Some authors works have been selected from other research fields because they bring important debates into the health/nursing/midwifery context that otherwise would not appear. It is important for the reader to be aware that an author might not own or support such a perspective or theory even though they have written about it.

From the early stages of the project, both the project team and the service user reference group perceived there to be an overlapping and indistinct relationship between concepts of 'involvement' and 'consultation'. It is our intention to acknowledge this conceptual uncertainty without excluding useful discussions about the boundaries of such interactions, such as the relationship between the use of patient satisfaction questionnaires or complaints data and service user involvement.

The information that has been identified by this review relates to different questions about: the context and drivers of user involvement

in research (Section 4.1); the methods or process of involving service users (Section 4.2); the impact and outcomes of user involvement (Section 4.3); and the capacity of individual professionals and research organisations to involve service users in research (Section 4.4). Further details of the themes addressed in each part of the findings are provided in Figure 4. A comprehensive list of references is included in Appendix 1.

The literature review did not identify any systematic reviews specifically relating to service user involvement in nursing, midwifery or health visiting research. There are systematic reviews in related areas of user involvement:

- involving patients in the planning and development of health care (Crawford *et al.*, 2002)
- user involvement in the delivery and evaluation of mental health services (Simpson and House, 2002)
- user involvement in change management (Crawford *et al.*, 2003)
- user involvement in research and development agenda setting for the NHS (Oliver *et al.*, 2001)
- Small voices big noises. Lay involvement in health research: lessons from other fields (Baxter *et al.*, 2001).

Figure 4 The themes addressed in the four sections of the findings



4.1 The context and drivers of user involvement

This first part of the findings section looks at the context in which concepts and meanings of user involvement in nursing, midwifery and health visiting research have developed. It looks at philosophical, political and social influences on nursing, midwifery and health visiting research and what can be drawn from user involvement in social care research. The specific areas covered are:

- The political context of user involvement in research
- Professional issues that shape user involvement in nursing, midwifery and health visiting research
- The power of public opinion
- Challenges to concepts of knowledge
- Changes in research approaches
- User involvement in priority setting and commissioning of nursing, midwifery and health visiting research
- What can be drawn from user and carer involvement in social care research?

4.1.1 The political context of user involvement in research

This section describes the legislative framework for involvement, political concepts about participation, consumerism and empowerment and responses in the literature from nursing, midwifery and health visiting professionals.

The legislative framework

Under the *Research Governance Framework for Health and Social Care*, all research undertaken under the Secretary of State for Health (for example research funded through the Department of Health) is required to involve participants or their representatives wherever possible in the design, conduct, analysis and reporting of research (Department of Health, 2001b).

The Department of Health requires NHS organisations holding NHS research and development support funding to demonstrate evidence of involving consumers in their research activity (Department of Health, 2000).

In health services, involvement of service users is a requirement for all aspects of health service development. Service user involvement in research can be considered one stream of this wider policy agenda. Although it does not explicitly refer to research activities, Section 11 of the Health and Social Care Act 2001 places a duty on NHS trusts, primary care trusts and strategic health authorities to make arrangements to involve and consult with patients and the public in service planning and operation, and in the development of proposals for changes. This means consulting and involving service users in ongoing service planning and development and in decisions about service delivery. The duty to involve and consult commenced on 1 January 2003.

The legislative framework for service user involvement is influenced by the political context. The following section summarises political debates around participation, empowerment and consumerism.

Participation

The publication of the Research Governance Framework for Health and Social Care marked a political response to a growing public disquiet concerning standards of ethics, honesty and general conduct in clinical practice and research (Perkin, 1990). High profile inquiries into incidents in research and clinical practice, such as the child deaths associated with heart surgery in Bristol (Bristol Royal Infirmary Inquiry, 2001) and the retention of children's body parts for research at Alder Hey Hospital in Liverpool (Department of Health, 2001c) have led to recommendations that public interests should be embedded in all NHS organisations (Kennedy, 2001). Writing about the impact of the events at Bristol, Coulter (2002) argues that putting patients at the centre of health services has benefits for the quality and safety of health care. In the Public Interest: Developing a strategy for public participation in the NHS (Department of Health, 1998b) argued that the need for public participation in the NHS was urgent to ensure public confidence was not further eroded.

The NHS Plan (Department of Health, 2000) announced the Government's commitment to establishing new systems of health and social care delivery, which would place the patient at the centre of change. Involving Patients and the Public in Healthcare: A discussion document (Department of Health, 2001a) set out the proposals for a package of measures that required legislation for strengthening patient and public involvement in health services. The subsequent creation of new institutional mechanisms, for example patient advice and liaison services and patient forums, have shaped the form of public participation in health services. The involvement of lay representatives in clinical governance inspections has been one example of how involvement has contributed to improving the quality and safety of professional practice. However another report by the Department of Health (2004b) showed that involvement rarely changed things and that information, communication and skills in engaging with communities all needed to improve.

Beresford and Croft (1996) describe counter influences from service user organisations and movements or 'new social movements' on the concept of participation. A paper by Tyler (2002) provides a good example of new understandings about the impact of social and cultural differences on participation in maternity care internationally. Tyler compares the campaigning profile of maternity user groups in Europe to show the extent to which women in three European countries were able to exert influence over the organisation and delivery of maternity policy and the factors likely to determine their success. Representatives of 19 lay maternity user organisations in England, the Netherlands and Germany were interviewed during 1996 and 1997. The results show marked differences between both the aspirations and the achievements of groups in the three countries and the distinct nature of social, political and cultural context of health care.

Empowerment

'Empowerment' is another complex concept that is often used in relation to user involvement. Use of the term is confused by different interpretations of its meaning and its moral and political underpinnings. An explanation of the extensive literature on empowerment is beyond the remit of this review but it is important to outline meanings that have been assigned to this term in order to recognise the influence of this concept within the political context of user involvement (see section 4.2.1).

Empowerment has been expressed as being a political idea, to which the ownership of power, inequalities of power and the acquisition and redistribution of power are central. Ideas about empowerment through participation emphasise people gaining control over public services, influencing them to meet their needs and so having more control over their lives (Rodgers, 1994). The term is also used to describe personal responses to being involved in research (as well as other types of activities) and has been described as an outcome of service user involvement (see Section 4.10).

In relation to involvement in the processes of research, ideas about empowerment emerged from the 1960s onwards as researchers, predominantly from the fields of mental health and disability, challenged assumptions and social relations of research production (Oliver, 1999). Beresford (2003) defines an empowerment/democratic ideology of user involvement in research. The concept of empowerment and its use in nursing practice, education, research and health promotion is described by Rodwell (1996). Rodwell defines empowerment as 'a helping process, a partnership valuing self and others, mutual decision making and freedom to make choices and accept responsibility'.

Consumerism

From the 1980s, health system reform was on the agenda in Australia, Europe and North America. Consumerism in health services was being driven by attempts to meet ever-increasing health service demands in the face of cost containment pressures (Segal, 1998). Notions of

consumer-driven market economies based on the goal of profit maximisation through consumer purchasing were being applied to health services. Informed patient choice has been identified as the mechanism to drive new efficiency, positioning patients as citizens with consumer rights. Yet there have been problems, because the concept of the consumer does not apply precisely in the context of the health service because the patient is seldom the purchaser of care (Almond, 2001).

When applied to nursing, midwifery and health visiting research, concepts of consumerism are extremely complex. For example, government-funded research can be commissioned and funded through numerous separate programmes and in relation to disparate policy and professional agendas, which limits the capacity for resources to shift in response to consumer preferences or evidence about cost-effectiveness (Segal, 1998). Furthermore, research funds are increasingly awarded by charitable or commercial organisations which function independently of centrally funded R&D programmes. A further criticism of consumerism is that reform has focused on supply (for example which treatments should be provided), to promote opportunities and incentives for a responsive service system and competition amongst providers. Segal (1998) asserts that a focus on supply side issues only, without recognition of the fundamental importance of consumer empowerment, will fail to promote an efficient solution to the distribution of health resources, for example, overcoming difficulties for different groups in accessing health services. Segal's view of empowerment is that it is a more complex and comprehensive concept than the 'informed consumer' is a critical.

Consumerism brought with it the broad reawakening of the idea of participation and a new emphasis on the 'rights and responsibilities' of citizens (Beresford and Croft, 1996). Croft and Beresford (1996) argue that, ironically, policies of participation have arisen because of fundamental problems associated with market economies, such as gross financial and social inequalities and the concentration of political and economic power. Across a range of public service structures the focus of governance began to shift towards various forms of coproduction with other agencies and with citizens themselves through partnerships, community involvement and strategies of participation (Higgins, 1993). Newman et al. (2004) have written a thorough account of these movements in community development, drawing on examples from deliberative forums, such as user panels, youth forums and area-based committees. The findings highlight the constraints on the 'political opportunity structures' created by the enhanced policy focus on public participation, and the consequent limits to 'collaborative governance'.

In relation to health services, greater power was awarded to local governance structures, including awarding greater spending and commissioning powers to local health bodies (Department of Health, 2002), to strengthen public and private partnerships (for example *In*

the Public Interest: Developing a strategy for public participation in the NHS [1998a]; Partnership in Action [1998b]); and reduce the risk of conflict between individual needs and the needs of society. Working for Patients (Department of Health, 1989), the National Health Service and Community Care Act 1990 and the Patient's Charter (Department of Health, 1991) emphasised the need to consult with and involve service users on the level and nature of the service provided for them.

The influence of political concepts on user involvement in nursing, midwifery and health visiting research

Political ideas of participation, empowerment and consumerism connect with research in nursing, midwifery and health visiting through debates about quality and accountability. In 1995 Professor Sir Iain Chalmers wrote about a belief that 'the public might be served more effectively by research and researchers if there was greater lay involvement at all stages of the research process' (Chalmers, 1995). The establishment in late 1995 of a Department of Health R&D standing advisory group on consumer involvement, later known as 'Consumers in NHS Research' and now as 'INVOLVE', has provided guidance and support for those interested in involving service users in research.

Responses to user involvement from nursing, midwifery and health visiting professionals

A report by the Department of Health (2004b) showed that generally researchers across the health professions have received policies for user involvement in research with quiet disinterest and slow, if any, progress has been made. Patient and Public Involvement in Health: The Evidence for Policy Implementation (Department of Health, 2004a) summarises the results of the Health Partnership research programme; 12 research studies about patient and public involvement in health. The outcomes for staff, for communities and for health delivery showed that patient involvement improves patient satisfaction and is rewarding for professionals. The report emphasised the need for involvement initiatives to be a shared corporate responsibility and that planning for public involvement should encompass planning of specific initiatives and the broader cycle of learning, change and review. Beardwood et al. (1999) state that the growth of consumerism in health care has negative consequences because it de-emphasises patients' relationships to health care systems and individualises complaints. Others have described examples of professional territorialism in response to policies to award service users a greater say in health services.

There is a danger that the nursing/midwifery/health visiting response to user involvement is presumed to be similar or the same as these generalised views. The response to policies of user involvement in research from those working specifically in nursing, midwifery and health visiting research has been very variable. In the absence of evidence about professional perceptions of user involvement in nursing, midwifery and health visiting research, the following examples from professional practice provide some insight into the likely issues about policies for involvement in research.

Nearly 30 years ago Benson (1977) described the nursing response to the consumer revolution in health care in the United States of America (US). The article is an early indicator of the professional issues that would later emerge across westernised society as the consumer's right to health care translated into action at a operational level:

On the one hand, it [user involvement] provides nurses with the opportunity to create a true partnership in health with patients, making them part of the overall plan for their recovery if ill or for the continued maintenance of good health through the application of preventative measures. On the other hand, it presents nurses with very real problems in the day-to-day practice ... How far can nurses go in this newly created partnership? What are the moral and legal implications? What guidelines do nurses have for dealing with such problems?

(Benson 1977)

Although at the time Benson was describing the role of nurses working in practice, her concluding remarks have saliency today for researchers working to involve service users.

Nurses who attempt to meet the real problems in day-to-day practice that arise must be secure in their own technical competence and communication skills; have insight into their own value system; be knowledgeable about the changing social scene, especially in relation to the growing concerns of health consumers; and have an appreciation of the actions and positions of their professional organisations.

Rovers (1986) argues that in a social policy and decision-making context, the nurse is an intermediary between political authorities and community groups and that this requires diverse, but complementary skills that place the nursing profession in a position to influence policy decisions related to health services. Watts (1990) shows how democratic values have been applied to health care services in many westernised countries. Watts argues that health care is inextricably linked with power and politics and that the role of nursing is to generate and enhance democratic processes within the health care system.

If nurses are to assist communities in their development toward health through the facilitation of human potential, then they must examine these means to empower communities.

(Watts 1990)

These aspirational views of nursing as a mechanism for supporting the democratic process are not shared by all. The literature shows a tension between the political rhetoric and the reality of user involvement. Glenister (1994) undertook a literature review of patient participation in psychiatric services to examine policy and ethical issues in relation to patient participation. The review concluded that psychiatric clinicians, including nurses, found patient participation

threatening and that the nurse's role in democratising psychiatric services was perceived as a considerable challenge to nursing practice. Other research with psychiatric nurses (Lanza and Ericsson 2000) echoes these concerns.

In care planning for mental health nursing, inhibiting factors to user involvement have been identified as: limited resources (inadequate staffing, lack of time and a chaotic health care environment); individual patient characteristics and motivation; negative staff attitudes and morale; poor information provision; and conflicting responsibilities and duties (duty to care, policy obligations and a consumerist ethos) (Anthony and Crawford, 2000). Factors perceived as promoting and increasing user involvement included: provision of accurate information, 'user-friendly' documentation, and mechanisms for gaining service user feedback, and high staff morale. Perkins and Goddard (2004) substantiate this view of a divide between policies of participation and what is achievable in service settings.

In primary care practice development, Poulton (1999) presents the responses of practice nurses to user involvement in two practice development projects. Although the project co-ordinators were highly committed to user involvement this was only achieved to a limited extent. There was a resistance to user involvement grounded in the fear that such involvement would increase user expectations and add to the pressures of overworked primary care teams. Also in primary care, qualitative data from key stakeholders in one primary care group revealed cynicism and doubt among board members about the purpose and value of user involvement, although some progress was felt to have been made in engaging with local voluntary groups (Tee, 2002). The study indicated that the experience of involvement among local patients had not always been a positive one and that there needed to be greater investment in staff development.

Summary of what the literature shows

- UK health and social care policy (Section 11 of the Health and Social Care Act) states that service users should be involved in all aspects of health services. The *Research Governance Framework for Health and Social Care* identifies specific requirements for the involvement of service users in research undertaken under the Secretary of State for Health.
- Involvement of service users in research is linked to political themes of participation, empowerment and consumerism and relates to public concerns about quality and safety.
- Policies for involvement have been supported by Department of Health reports and new institutional mechanisms for participation but they tend to focus on user involvement in health services rather than research.
- Professionals' responses to user involvement in clinical practice highlight concerns about the dissonance between policy and what can be achieved in a diverse range of research and health service contexts with limited support and resources.

4.1.2 Professional issues that shape user involvement in nursing, midwifery and health visiting research

This section of the findings focuses on the professional issues that form part of the wider context in which service users are being involved in nursing, midwifery and health visiting research.

User involvement in health decision making

Ford and Fottler (2000) argue that most health care organisations are operating under an old paradigm wherein the needs of physicians and third party payers drive the organisation. They argue that managers needed to focus more directly on understanding customers in the new consumer-driven NHS, and that this means moving away from paternalistic practices towards patients having more say in their care or treatment decisions. Concepts such as 'patient-centred care' and 'patient participation' have become commonplace in professional literature (Coulter, 1999) and have influenced concepts of user involvement.

A review of the literature on patient participation in hospital care **(Cahill 1998)** found that the concept has been defined and operationalised in a variety of ways and the consequences are highly unpredictable. Cahill asserts that patient participation cannot be assumed to be an approach to care that has been universally accepted by patients and clinicians alike, but that generally, it would appear that patients prefer to participate in their care while professionals, although acknowledging the potential value of patient participation, prefer patients to be passive recipients. Cahill feels that if such approaches to care are to become the rule rather than the exception, all health care professionals need to be adequately prepared for the more facilitative roles, which are being advocated.

Bournes (2000) considers the increasing emphasis on personal choice and decision-making to be evidence for movements away from medical models of care and paternalism. A study by Brooking (1986) used questionnaire-based consultation with nurses, patient and relatives to examine current practices, opinions and attitudes towards patient and family participation in nursing (107 nurses, 114 participants and 72 relatives at two London hospitals completed questionnaires). The results show that the traditionally passive acquiescent patient role is still accepted by some patients and preferred by many nurses - though this view might now be outdated. Cody (2003) suggests that nursing's unique theory base of frameworks that honour human dignity and focus on human experience offers an opportunity for leadership in further developing theoretical frameworks that transcend paternalistic practices towards patient-centred care. These professional responses to user involvement show that professional power remains an important issue for nursing, midwifery and health visiting (Du Plat-Jones, 1999).

User involvement in the maintenance of health

Within the current health care environment there is increased emphasis on the protection and promotion of health, access to health services, and prevention of illness (Kuss et al., 1997). Nurses and midwives have been identified as being in a strategic position to maintain, promote, and protect the health of populations. The links between health promotion and community development are also increasingly being recognised. For example, a study by Lindsey et al., (2001) provides evidence of how one health care organisation successfully engaged the broader community in a HIV/AIDS respite care project. Using gualitative research methods and guided by the principles and practices of participatory action research, the evaluation engaged with the community in data collection, analysis, dissemination of findings, and in promoting effective change. Patients are also increasingly being encouraged to take more control over their own health, for example, self-management of long-term conditions and the expert patient programme in the NHS.

The relevance of research to practice

The views of NHS staff about research have been subject to limited research. There is little evidence about whether NHS staff value research and its role in generating evidence for improving practice. There is evidence for the benefits to clinical practice of involving clinical staff in the research process. This debate is beyond the remit of this project. Reported sources of dissatisfaction are most frequently about inadequate support for implementation of research findings in practice, sometimes described as the 'research-practice gap' (Rafferty and Traynor, 1999), rather than, for example, evidence for dissatisfaction with the type of research that receives funding or the way research is undertaken. (Also, see Section 4.1.5.)

Summary of what the literature shows

- Some nurses have perceived user involvement to be the democratisation of professional territory.
- There has been increased criticism of professional paternalism and increased emphasis on patient-centred care and patient-centred services.
- Across the health professions there is increasing emphasis on the promotion of health rather than focusing on curative and illness models. Patients are also being encouraged to take more control over their own health. These factors change the relationship between health care professionals and service users and have a bearing on relationships in research.
- Little is known about professionals' views of research or why research is not always implemented in practice (the research:practice gap).

4.1.3 The power of public opinion

The public's right to influence publicly-funded services

An alternative view of service user involvement in research is that service user involvement is a democratic or ethical requirement whereby those that pay for services have a right to influence how they are managed and developed. Logically, this belief must hold currency for any publicly-funded service or activity, for example the right to influence decisions about policing, education or housing services. Under the present government an increasing number of new structures have been established to involve the public. In these and other areas, there are common issues about the nature of the influence that the public *should* have, questions about the degree of influence the public *can* have, and the ability and opportunities that different people *do* have.

At an operational level, meeting the right to influence becomes a moral obligation of service providers to create opportunities for people to engage with, and seek to influence, services. For example, *Working for Patients* (Department of Health, 1989), the NHS and Community Care Act 1990 and the *Patient's Charter* (Department of Health, 1991) all emphasise the need to consult with and involve service users about the level and nature of the service provided for them. Thus, involvement of service users offers a potential mechanism for gaining public support for the NHS. To fulfil this right to influence, the processing and presentation of information as it flows through the health care system and the distribution and feedback loops that allow for shared decision-making must be made clear to service users.

Patients have been a driving force in gaining ground in their right to influence research. In the 1990s researchers with disabilities and social care service users argued that people should have more say in the agencies, organisations and institutions that provide services for them. In mental health this was fuelled by debates about the degree of exclusion from normal every day activities that certain sections of the population endured (Higgins, 1993). The women's lobby in maternity services is a further powerful vehicle of change. Campbell and Einspahr (2001) maintain that service users are demanding a more prominent voice in how research and evaluation shapes the content, character, and influence of mental health services because of the introduction of a marketplace environment into the NHS. Although this is a different angle on involvement, it supports the notion that there is an increased public interest in the efficiency and accountability of the NHS and publicly funded health research.

Public views of the NHS

Views about the NHS have been shown to be politically important to the voting public. It is therefore important to the government that the decisions about the management and funding of the NHS receive

public backing and are seen to be effective at delivering improvements for patients. Gaining public support for the NHS is pitted against meeting rising public expectations and mediating declining levels of public satisfaction with the NHS. Involving service users in health services may offer one way of gaining public support by raising awareness about the limitations of the system and involving people in decision-making about the management of limited resources.

It is known that public/patient expectations for health and service provision are rising. People's awareness of the possibilities of medical treatment, the availability of pharmaceutical drugs and health promotion for example vaccination and screening for infection or disease, are placing new demands on health services to deliver higher and more equitable standards of care to all. Consequently, in the last 20 years the NHS has witnessed a greater emphasis on involving the public in consultations about rationing, prioritisation, discontinuation or reduction of funding for services or treatments.

Public perceptions of nursing, midwifery and health visiting

As with all areas of work, roles change and responsibilities shift in response to new understanding and technological advances. Recent changes in the work of nurses, midwives and health visitors are characterised by new forms of specialist practice and greater levels of professional autonomy (Cowley, 2001). Often roles take on a research element as professionals become more specialised.

Although the benefits of these advances in terms of health outcomes are largely positive, some people fear that the public's perception of health care professionals is that they have been seduced by technology, money, and specialization and that they have little time for patients' concerns, wants, and needs (Logan *et al.*, 1997). It is generally acknowledged that the relationship between health care providers and patients was once seen by the public as being based on trust, compassion, and goodwill but it is now much more subject to negotiation.

Despite these concerns, caring remains a core concept of nursing, midwifery and health visiting practice and has been studied extensively from the nursing perspective. A literature review by Patistea and Siamanta (1999) showed that whereas nurse clinicians focus on the psychosocial aspects of caring, patients assign the highest value to technical skills and professional competence. Noncaring behaviours were found to be perceived as physical and emotional absence, belittling and inhumane actions, and lack of recognition of a patient's uniqueness. However it was not clear whether patients' participation in decisions regarding their care was considered to be an element of a caring interaction.

Public perceptions of research and user involvement in research

The position of science in society is often ambiguous and uneasy. Researchers have been criticised for being out of touch and research findings are not perceived to be taken into account in policy decisions (Maurin, 1990). Public expectations for publicly-funded research and satisfaction with research are more remote than for health services, and as far as we are aware have not been investigated nationally. It may be that the public perceive research as part of a whole system of health care. In this context, service user involvement in research may offer a mechanism for moderating public expectations and dissatisfaction with health services if service users feel they have been able to influence the NHS through the research process. It could also mean that the process of reaching major decisions is more transparent and trust and credibility are built between the public and research communities.

There is a danger of confusing or conflating debates in the literature regarding expectations for user involvement in service improvement and user involvement in research. User involvement in research has its own issues to be resolved and this is why we have set out to clarify the thinking and the links.

What the service user reference group thought was important

- Some people hold the view that there is 'too much knowledge in nursing' and that this is detrimental to care giving.
- Some people think that knowledge/research interferes with giving care. This view needs to be considered, as it impacts on service user involvement in research.
- Nurses and midwives have power in their role, this has implications for communication with service users.

Summary of what the literature shows

- Some people believe that service users have a right to influence publiclyfunded research or research about the NHS.
- Service users are pressing for a more prominent voice in how research and evaluation shapes the content, character, and influence of health services.
- Nursing, midwifery and health visiting roles are changing because of improved understanding and technological advances. There is evidence to show that the public highly value the technical skills and professional competence of nurses and midwives while nurses value the psychosocial aspects of care giving.

4.1.4 Challenges to concepts of knowledge

There is an extensive literature on the concepts of knowledge and research, which influences debates about user involvement in research. Describing this is beyond what is achievable in this review. The most relevant points are included here to contextualise debates about the drive for evidence and the nature and production of knowledge claims.

There have been few if any times in recent history when there has been such a focus as now on research in public provision. Government has emphasised the importance of 'evidence-' or 'knowledge-' based policy and practice, with research being seen as a key contributor to its achievement. 'Evidence based' has become a new construct for understanding and evaluating policy and practice.

(Beresford, 2003)

Beresford argues that when values associated with research and development of knowledge about people and how they live prioritise distance and separation major concerns are raised for the people who are the subject of such research or about whom knowledge is being sought.

Perhaps this growing interest [from users to be involved in research] represents an increased unwillingness to be deferential to research and researchers, and an increasing sense that service-users and other members of the public have a right to have a say in, and to scrutinise, research.

(Beresford, 2003)

Although service users have sought to generate or be part of the formulation of knowledge, lay knowledge or experience is generally not seen as neutral, objective or distanced from the issues. Issues around the validity of different knowledge standpoints and knowledge claims; the ownership of knowledge and its interpretation; dominant hierarchies of credibility; the nature of the relationship between knowledge and direct experience; the meaning of 'evidence-based' and what counts as evidence (Lewis, 2001) contextualise issues for user involvement in research. See Section 4.3.5 for a discussion of the development of user controlled research, which challenges the mainstream view of knowledge production

Summary of what the literature shows

• Lay knowledge or experience is generally not seen as neutral, objective or distanced from the issues this raises concerns about knowledge production and what counts as evidence.

4.1.5 Changes in research approaches

In a previous section of this report on the power of public opinion (Section 4.1.3), we showed that the position of science in society is often ambiguous and uneasy as research findings are not perceived to

be taken into account in policy decisions (Maurin, 1990). There are challenges for nursing policy research in a changing world (Scott and West, 2001). Partnerships between higher education and the NHS have also been viewed as problematic, contributing to debates about the way in which research is perceived in society (Clarke and Ramprogus, 2001). These debates have implications for how research is viewed within health care, and more specifically within nursing, midwifery and health visiting (Larson, 1993; Clarke and Ramprogus, 2001).

Grounding research methods in experience

A review of the relevant literature (Scott and West, 2001) shows that the Department of Health's R&D strategy can be understood as part of a wider trend, moving away from the traditional, university-based model of knowledge production towards research which involves other groups, such as employers, practitioners and patients. Scott and West argue that this may increase the opportunities for health care professionals in general, and nurses in particular, to influence the research agenda and to participate as researchers in the critical evaluation of health policy. Nurses and midwives have been encouraged to take a more direct and active role in research as a way of influencing change in practice, for example development of the researcher/practitioner role and changes in nurse education (see Section 4.4.2).

The gap between research and practice has been much debated (Rafferty and Traynor, 1999), but less from the point of view of how involving users may lead to change (Beresford, 2003) and more from the nursing professional perspective and utilising patient-centred research methods, for example reflexive and practitioner-orientated approaches (Clarke and Proctor, 1999, Edwards and Titchen, 2003). See Section 4.1.2 on professional issues.

Of relevance to this review, Kearney (2001) argues that clinicians can use a range of qualitative research evidence to support their experiential, anecdotal, quantitative, and other knowledge sources thus grounding research methods in the experience of patients and service users. Generally patient-centred research carried out in nursing, midwifery and health visiting, is said to involve designs that are pragmatic, realistic, grounded in the day-to-day experiences of both patients and clinicians (Gatterman, 1995) and action oriented (Stainton *et al.*, 1998).

Research as a change agent in community development and practice development

The literature on community development is beyond the scope of this project but its influence on the development of user involvement in nursing, midwifery and health visiting research should be mentioned. Evidence for the impact of research in community development has a

well-developed literature (Chalmers and Bramadat, 1996). Models of community development include: economic development models, education models, confrontational models, and empowerment models. Each has particular relevance for community health nursing practice. Linked to community development is the concept of practice development, which has been described as having an ambiguous position in relation to both clinical practice and research (Clarke and Procter, 1999), but having a potentially 'transforming power' on practice (Stainton *et al.*, 1998).

Summary of what the literature shows

- There have been movements in research away from traditional approaches towards knowledge production in partnership with other groups, such as employers, practitioners and patients.
- Patient-centred research methods have been used to ground research methods in experience and to enable evidence-based practice development or service change.
- Community development and practice development have an ambiguous relationship to user involvement in research but nursing, midwifery and health visiting have contributed to these areas.

4.1.6 User involvement in priority setting and commissioning of nursing, midwifery and health visiting research

Previous research has looked at the effect of involving service users in priority setting and commissioning and the methods that have been used to involve users. This type of user involvement has increased in recent years, mirroring requirements for researchers to show commitment to involving service users in research.

Oliver (1992) describes involvement in research commissioning as a process of changing the social relations of research production and Coats (2000) argues that involving service users in prioritising topics for research can combat bias and secrecy. Most of the literature on involving service users in setting the agenda for research is not based on research evidence (Oliver et al., 2004). Maternity services provide early examples of user involvement in research with service users being sufficiently organised to respond to consultations on prioritysetting exercises, advise on clinical trials, work towards research based health care and to call for funding, training, support and feedback to enable them to develop and evaluate their own contributions. Oliver (1996) describes some previous examples of service user involvement in the NHS R&D programme. Oliver shows that innovative approaches have involved users in identifying research priorities and in the subsequent commissioning process. Difficulties in identifying appropriate people to involve in research, the range of skills and the need for time for thought and discussion have all posed
problems. The author suggests that to overcome some of these obstacles, there needs to be dedicated resources, training and support, and clarification of the role, nature and potential for service user involvement.

When seeking research topics for a national needs-based research programme, face-to-face discussion with a consumer group was more productive than scanning consumer research reports or contacting consumer health information services (Oliver *et al.*, 2001). Service users were willing and able to play active roles as panel members in refining and prioritising topics, and in commenting on research plans and reports. Challenges to be overcome were cultural divides, language barriers and a need for skills development among service users and others. Involving service users highlighted a need for support and training for all contributors to the programme. Involvement of service users exposed processes which needed further thought and development.

More recently, O'Donnell and Entwistle (2004) undertook a scoping study, which considered whether, why and how research funders involve service users in decisions about what health-related research is funded. The findings show that organisations that fund research have diverse goals and remits, and perceive themselves to be accountable in different ways and to different groups. They have a variety of reasons for involving service users in decisions about what research is funded, but also a number of concerns about doing so, particularly in relation to the ways in which service user input might 'distort' the research agenda. Research funders use several types of decision-making structures and processes to identify and prioritise topics in which they want to invest and to select between research proposals. They involve service users in these structures and processes in diverse ways. Little is known about the actual effects of this involvement. The nature and extent of user influence on the research agenda is likely to be moderated by a number of factors, including the types of service users involved, the particular structures and processes in which they are involved, the timing of their input and the different ways in which they are asked to contribute in relation to others. The paper concludes by stating that a diverse range of research funding organisations are now involving service users in the various approaches that they take to identify and prioritise research topics and to decide which proposals they will fund. The implications of this study are that the appropriateness of particular forms of user involvement should be considered in the broader context of research funding systems, including the values implicit within it.

Researchers have looked at the methods that have been used to involve service users in identifying and agreeing priorities for research commissioning. For example, use of the nominal group technique to build consensus about research priorities (Allen *et al.*, 2004). Mullen (1999) describes a range of different approaches to eliciting values from the public about their priorities for health care. These approaches are critically examined in relation to a number of dimensions including the type of choice allowed to respondents and the implications of aggregation of values across individuals.

In the commissioning of nursing and midwifery research in England, Smith *et al.*, (2005) describe how a service user framework was developed through consultation with service user organisations to identify priority areas for research. In China, nursing research has been prioritised using the criteria of social benefit as well as scientific merit (Yin et al 2000).

Differences between professional and public priorities for health and research

Differences between professionally defined and public views of priorities for research have been used as an argument for user involvement in priority setting for health care and research. For example, in deciding priorities for health care, Roberts et al., (1999) have shown that members of the public do not choose consistently in line with professionally defined priority setting criteria (namely qualityadjusted life years: a measure based on the number of patients receiving the programme, the survival gain, the gain in quality of life and the probability of treatment success). The public are most influenced by quality of life concerns. In research priority setting, there are some accounts of mismatches between research evidence and the priorities of service users. In relation to research on osteoarthritis of the knee, Tallon et al. (2000) showed that the evidence base was dominated by studies of pharmaceutical and surgical interventions, while respondents to a survey ranked knee replacement as the highest priority for research, followed by education and advice. Research with nurses in Norway showed that quality of life and patient participation in decision making were ranked higher as a priority for research in cancer nursing (Rustoen and Schjolberg, 2000).

What the service user reference group thought was important

• Topics for research should be identified by consumers and taken forward by researchers.

Summary of what the literature shows

- There is a limited and fragmented evidence base on involvement in commissioning but studies display a range of approaches.
- Methods/approaches to service user involvement in research commissioning have not been linked to the impact on the quality of the research.

4.1.7 What can be drawn from user and carer involvement in social care research?

Nursing, midwifery and health visiting are broad areas of work and sometimes there is overlap with social care activities. Issues and ideas surrounding the involvement of service users and carers in social care research have developed within a tradition of understanding the political processes that shape care. To increase understanding of the questions for nursing, midwifery and health visiting research we have looked at approaches to user involvement in the social care research literature.

As with nursing, midwifery and health visiting research, the encouragement of service user/carer involvement in social care is advanced by the Department of Health and research funders and often led by service users themselves. A review by Pawson *et al.* (2003) notes the 'burgeoning interest' but, as yet, little evidence of impact. Many studies about service user involvement in social care cover similar topic areas to nursing, midwifery and health visiting, such as disability or family issues. Studies looking at research methods are also overlapping, particularly in qualitative research. However, there are also some notable areas of difference between these fields of research.

In social care, there is often a more direct and political emphasis on the purpose of research and the rationale for service user involvement as being to change attitudes, services and understandings. Service users who write of their commitment to this approach and report on the benefits of involvement from their perspective express such ideas. However, other studies reflect a more consumer-oriented view which is more common to nursing, midwifery and health visiting, where service improvement is the main objective of involvement.

Service user involvement in social care research has been researched to a greater extent than in health services, although there is some overlap, for example the TRUE report on training for service users in health and social care (Faulkner, 2004). Much of this work is descriptive (see Kemshall and Littlechild, 2000) but these broad accounts do offer considerable evidence of the processes and challenges of involvement.

Social care research in the UK now draws on a number of studies by service users and organisations of service users who undertake research. Some of these operate in health and social care arenas for example, organisations such as Impact, Shaping Our Lives and SURE. All of these groups have provided their own reflections on undertaking research for example Rose (2004).

Service user involvement in evaluation, audit and inspection in social care is also more prominent than in nursing, midwifery and health visiting. For example, an inspection of the impact of the white paper

on learning disability, *Valuing People*, included people with learning disabilities on the inspection team (Department of Health, 2004c).

Social care research has much to offer in its considerations of techniques to involve 'hard to reach' (now generally referred to as 'seldom heard') groups and minority populations and good practice in dissemination to groups who may not always be included and in the production of material to help people with communication difficulties, for example, including older people with dementia in research (Hubbard *et al.*, 2003, Wilkinson *et al.*, 2003). Some social care research has also argued that people who might be excluded from research studies because of difficulties in obtaining informed consent and so on may be able to participate in research if methods are tailored to their circumstances. Cooke's (2003) use of video among people with dementia is an example of such methodological initiatives.

The Research Governance Framework for Health and Social Care (Department of Health, 2001b) will bring researchers in health and social care closer together through shared systems of research governance. Researchers in both fields will need to consider the involvement of service users and carers as research informants, research participants and potential collaborators in the governance process.

Summary of what the literature shows

- Many studies about service user involvement in social care cover similar topic areas to nursing, midwifery and health visiting, such as disability or family difficulties.
- In social care, there is often a more direct and political emphasis on the purpose of research and the rationale for service user involvement as being to change attitudes, services and understandings.
- Social care research has much to offer in its considerations of techniques to involve 'seldom heard' groups and minority populations as well as good practice in involving groups that have communication difficulties.

4.1.8 Purpose and rationale

So far these findings have shown that the drivers and influences on the development of user involvement in nursing, midwifery and health visiting research are complex. They include political, professional and user-led debates that shape the discourse of user involvement. Different claims about the purpose and rationale for involving service users in research are influenced by these contextual factors but they are also shaped by the perceived or actual outcomes of user involvement in research.

Statements in the literature about the purpose of involving service users in research are difficult to locate in a systematic way and they do not necessarily relate to the subsequent outcomes or the impact user involvement had. We have chosen not to spend time recounting researchers' descriptions of the reasons they decided to involve service users, rather in Section 4.3.1 we focus on defining the wideranging outcomes of user involvement in nursing, midwifery and health visiting research as these can be linked to the evidence in the literature.

What researchers who responded to e-mail calls told us

Rationale for involving service users/carers in research:

For the research studies captured in the review via the e-mail call and subsequent telephone interviews, the rationale for involving service users often reflected the policy or commitment of the organisation. Organisational settings in which user involvement was undertaken included academic departments, a professional body and a clinical network. In many cases the commitment of individual researchers was key and informed by their own professional practice and perspectives. In some cases the drive for user involvement came from the charities that had commissioned or funded the projects.

One researcher, who was interested in exploring users' views of a service, felt an obligation to involve the service users themselves in the endeavour. In this case the service users were children and the focus was on enabling children's voices to be heard, not only in relation to their views (of hospital care) but also in other aspects of undertaking the research: issues which for this researcher were inextricably linked with children's rights. In another study, which operated in the context of a clinical (predominantly medical) international collaboration to measure outcomes for patients with rheumatoid arthritis, the researchers argued that patients' perspectives should be gained to inform the research.

4.2 The best ways of involving users in nursing, midwifery and health visiting research

The second part of the findings addresses methods issues. These are described as the issues that impact on involvement of service users and carers at an individual or project level. This section begins with an overview of the meanings and concepts about user involvement in nursing, midwifery and health visiting research to highlight issues about quality in involvement. We use evidence from the literature and accounts from researchers to show how different types of people have been identified and engaged in research and how working relationships have been established. The specific areas covered are:

- meanings and concepts
- quality in the process of user involvement in research
- recruitment and representation
- ethical issues
- diversity of service users being involved
 carers, parents and relatives

- children and young people
- older people
- groups requiring special consideration
- roles and activities of service users in research
- establishing working relationships
 - training and orientation for service users
 - strategies that we found worked in this project

4.2.1 Meanings and concepts

Different definitions and meanings of service user involvement can be found in the literature. They are summarised here.

Meanings of the terms 'service user' and 'consumer'

Much attention has focused on the meanings and terminology of service user involvement. In their key review paper, Boote *et al.* (2002) have shown that different definitions of 'the consumer' have been used in relation to health care research. Some of these definitions include:

- Those without professional expertise in an abstract body of knowledge that can be applied in the health care field.
- Individuals without some kind of vested interest in health care decision-making outcomes.
- Someone who uses, is affected by, or who is entitled to or compelled to use, a health-related service.
- Patients, carers, long-term users of services, organisations representing consumers' interests, members of the public who are the potential recipients of health promotion programmes and groups asking for research because they believe they have been exposed to potentially harmful circumstances, products or services.
- People whose primary interest in health care is their own health or those of their family, as past, current and potential patients, users of services or carers, and people representing these groups through community organisations, networks, or campaigning and self-help groups.

In health services, Almond (2001) has attempted to identify who the actual consumers of health visiting are and examine whether consumerism and the consumer's voice has had an impact on health visiting provision. Almond suggests that consumerism is an outdated concept that has been replaced by other less emotive terms such as partnership and participation. Further, Boynton (1998) argues that the term 'subject' is derogatory to service users who participate in research and criticises publications which use the term. In a letter written to the British Medical Journal Chalmers (1999) argued that people are 'participants' in research and that further suggestions for

other terms to describe 'participants' are needed. See Section 2.2 for the definition of 'service user' as used in this project.

Models of user involvement

The range of interactions encompassed by 'user involvement' have been expressed as working at many different levels. On one level user involvement is concerned with a patient's views, beliefs and perceptions of health care services. For patients receiving care from health professionals, user involvement might relate to joint decisionmaking or to patient-centred care (for Stewart [2001] this includes exploring the patient's concerns and reasons for the visit; seeking an integrated understanding of their world and] finding common ground on the problem and its management). These activities can be considered user involvement in service delivery, where professionals aim to involve patients in treatment or care options. Service user involvement in research links to policies for PPI in health services (for more information see Section 4.1.1).

As shown in Section 4.1.2, the concept of patient participation is widely used in contemporary nursing, midwifery and health visiting practice. It forms part of the language of professional staff and has been heralded as a means of enhancing decision-making and human dignity and enriching quality of life. The concept is revisited and reinvented through policies of participation where it has acquired new meaning and characteristics.

Jewell's (1994) ethnographic study investigated the perceptions of nurses working in primary care towards the notion of patient participation. The study reveals that nurses viewed participation as having a formal and informal meaning as well as a formal and informal method or practice, and secondly, it was perceived to involve mutual informing or negotiation between patient and nurse. However, this is a small-scale study that only involved four nurses working within a rehabilitation unit for older people. Cahill (1998) presents a more critical review of the concept of patient participation and concludes that patient participation in care is emerging as a growing movement wherein patients are assuming more responsibility for the prevention, detection and treatment of health problems in a manner that supplements or substitutes for professional services. The concept of service user involvement in nursing practice has also been observed in the context of mental health nursing.

User involvement has tended to be conceptualised as being comprised of hierarchical levels of user activities or roles. Some of these hierarchical models and classifications are included here. Perhaps the most frequently reproduced model is Arnstein's ladder of citizen participation (1969), which describes a continuum of activities from manipulation to citizen control. This model (see figure 5) was developed in the US as a result of the 'heated controversy' over citizen participation, citizen control and involvement of the poor in federal social programmes. Arnstein believed that 'there is a critical difference between going through the empty ritual of participation and having the real power needed to affect the outcome of the process'. She identified that roadblocks to achieving 'genuine' levels of participation lie on both sides (state and citizen) including racism, paternalism and resistance to power distribution, inadequacies of socio-economic infrastructure and knowledge base, as well as difficulties of organising representative and accountable citizen's groups.





In nursing practice, Cahill (1996) uses concept analysis to show a hierarchical relationship between concepts of involvement, participation and partnership.

Figure 6 Hierarchical relationship between concepts of participation (Cahill, 1996) \wedge



Hickey and Kipping (1998) relate the concepts of user involvement in decision-making to consumerist/democratic concepts of involvement. The approaches are linked through a 'participation continuum'. This arrangement challenges a hierarchical view of user involvement.

Figure 7 Hickey and Kipping's participation continuum (1999)

Democratisation



A notably different interpretation of a continuum of involvement, is Rush's (2004) continuum of the relationship between assumptions about people with mental health problems and their involvement in care. This relates more to assessments about individuals' capacity to make decisions about their care.

Other types of conceptualisations provide a framework based on the stages of research, possible involvement contributions, and ways of identifying and involving people in the research (Entwistle *et al.*, 1998). Hanley *et al.* (2000) also look at the relationships between the purpose of involvement, types, stages and processes. Dixon *et al.* (1999) provide a classification of the types and areas of involvement and suggest a scale to measure the extent of user involvement.

This review has found that papers about user involvement in nursing, midwifery or health visiting research often make reference to these models but few seek to test or contribute to the theory or concepts that they encompass.

Concepts of user involvement in research

Hierarchies of user activities as they are depicted in models of user involvement are also evident in concepts of user involvement in research. Service users are sometimes perceived as having different roles in the research that relate to levels of control in the research process for example consultation, collaboration and user-control. Involving users as the *subjects* of research might be considered a different level of involvement compared to involving users through consultation or through collaborative partnerships. Consultation with service users is sometimes described as a low level of involvement as the service provider or researcher keeps control of the overall agenda (Rodgers, 1994). Poulton (1999) proposes that user involvement exists at a series of levels ranging from information giving to 'true empowerment'. Others have perceived a connection between higher levels of involvement and the empowerment of service users through research processes. User-controlled research is often perceived as being more empowering than activities rated as lower levels of

User involvement in nursing, midwifery and health visiting research

involvement. These issues are revisited in the second part of the discussion (Chapter 5).

These conceptualisations are important because they raise issues about where decision-making power lies, the validity of different knowledge standpoints and knowledge claims and the nature of the relationship between knowledge and direct experience. Notions of 'tokenism' and 'meaningful' or 'genuine' involvement are frequently raised in the literature in relation to different levels of user involvement. Hierarchical conceptualisations of involvement tend to imply that one type of involvement is better than another and may overlook questions about the purpose of involvement in different contexts (see also Section 4.3.2).

Summary of what the literature shows

- Different definitions and meanings of the terms 'service user' and 'user involvement' can be found in the literature. There is no consensus about the meaning of user involvement and this is particularly problematic when making judgements about whether certain activities can be classified as involvement.
- Concepts of participation, empowerment and consumerism have influenced the conceptualisation of user involvement in research.
- Models of user involvement tend to define hierarchical levels representing different degrees of user control but these are not specific to the context of user involvement in research.

4.2.2 Quality in the process of user involvement in research

In the literature researchers have deliberated issues about the quality of service user involvement. In relation to nursing care, Truman and Raine (2002) provide an account of some of the meanings and experiences of what 'successful' user participation may involve and the conditions that underpin 'success'. Factors which were perceived to encourage meaningful participation included enabling and supporting users to recognise their existing skills, and to develop new ones, at a pace that suits their particular circumstances and personal resources.

Work has been undertaken by Telford *et al.* (2004) to develop principles for involvement in NHS research. A consensus study was used to identify principles and indicators of successful consumer involvement. An expert workshop, employing the nominal group technique, was used to generate potential principles and indicators and these were tested using a consensus building technique with 96 participants drawn from health, social care, universities and consumer organisations. Eight principles were developed and consensus was reached on at least one clear and valid indicator by which to measure each principle (see table 3).

Table 3 Principles of successful consumer involvement in NHS research (Telford *et al.*, 2004)

- 1 The roles of consumers are agreed between the researchers and consumers involved in the research
- 2 Researchers budget appropriately for the costs of consumer involvement in research
- 3 Researchers respect the differing skills, knowledge and experience of consumers
- 4 Consumers are offered training and personal support, to enable them to be involved in research
- 5 Researchers ensure that they have the necessary skills to involve consumers in the research process
- 6 Consumers are involved in decisions about how participants are both recruited and kept informed about the progress of the research
- 7 Consumer involvement is described in research reports
- 8 Research findings are available to consumers, in formats and in language they can easily understand

To date, principles and indicators of quality in user involvement are broad and do not relate to different research contexts or approaches. There is little evidence to show that quality criteria for the process of involving service users in research has been directly applied to, or tested in the context of, nursing, midwifery or health visiting research. Quality in relation to the diversity of service users, for example differences in ethnicity, health status or physical ability require further attention. Guidelines for involving service users in research (see Section 4.2.2) and for involving children and young people in research (See section 4.2.3) infer principles of quality.

'Involvement all the way through at every stage'

The literature shows that some people hold the view that user involvement should be all the way through, at every stage, of a research project. (This was a view held by members of the service user reference group for the project.) Our consultations with researchers showed some of the reasons why this is not always possible. The following example is from an interview with a researcher talking about the experience of involving service users in a two-stage survey of UK nursing departments. The aim of the study was to identify projects with user involvement. In this example the tensions of not being able to involve service users throughout all of the research were mediated by researchers being open with service users about what was achievable within the time and resources available.

Real life example: R1

Involving service users in as many processes as possible

We initially modified the definition of collaboration used by INVOLVE from consumers 'involved in most processes' to 'involved in all processes'. However, we've now modified our view about collaboration. We have been influenced by Alison Faulkner [see Faulkner, 2004] who argues that it's best to be up front and honest, and so we now advocate consumers being 'involved in as many processes as we can manage'.

What the service user reference group thought was important

- Optimal service user involvement in decision-making should be all the way through a project.
- Service user involvement should be direct and active in all aspects of research.

Summary of what the literature shows

- Debates about the quality of user involvement have focused on issues about involvement processes such as agreeing roles and budgeting for the costs of involvement. Guidelines, principles and indicators of quality in user involvement are broad and do not relate to different research contexts or approaches. Quality in relation to the diversity of service users, for example, differences in ethnicity and physical ability require further consideration.
- There is little evidence to show that quality criteria for the process of involving service users in research has been directly applied to, or tested in the context of nursing, midwifery or health visiting research.

4.2.3 Recruitment and representation

The personal qualities of service users recruited to be involved in research projects relate to the aims and objectives of the research. These qualities and their relationship to representation issues are discussed here.

Recruiting people with knowledge or experience of a health issue

Involving patients who have knowledge or experience of a health issue as partners in research raises similar recruitment issues as involving patients as the subjects of research (Holloway, 1992). It raises questions about how best to judge knowledge standpoints, such as the severity of a person's illness or the length of time they have lived with a condition. Often it is necessary to judge whether participants are well enough to be involved in the research. The literature shows that these issues have previously been raised by researchers involving patients as the subjects of research. Particular attention has focused on patients receiving palliative care and patients with degenerative mental health conditions (see Section 4.2.5). It was also raised during out interviews with researchers, as illustrated by the following example.

Real life example: R9

Recruiting patient research partners to a study about rheumatoid arthritis

We decided not to go down the representative route as we didn't want representatives from national organisations, professional patients as it were. We wanted somebody who had some experience of the problem we were looking at; [they] needed to be able to discuss things and articulate their opinions.

The first patient research partner was recruited at a review day held by the department to which patients involved (as subjects) in previous research studies were invited.

We just wanted to give something back and explain what our results and findings were. We took the opportunity then to ask if anyone was interested in not being a subject but being a collaborator. A few people suggested they would like to help out.

Recruiting people with views or experiences of health services

In studies about service evaluation, service users have been recruited because of their experience of accessing a particular health or social service. In service development projects that aim to improve user access to services, particular groups have been targeted because of their age or ethnic background. Again, these recruitment issues have previously been described by researchers who have recruited patients as the subjects of research studies, they are not issues that are unique to the involvement of service users in the research process.

Researchers working to engage community members in public health research have reported that people are keen to be heard in the formulation of research but that competing demands and limited resources make it difficult for community groups to allocate scarce resources to consultation (Graham *et al.*, 2001). Sometimes research issues may seem 'academic' and thus remote from the urgent priorities of the people with whom researchers wish to consult.

Real life example R3:

In a study evaluating heart failure nurse specialist services, researchers looked for certain qualities in the users/carers invited to be involved in a research advisory group

[We were looking for] anyone who was vocal enough, you have to have someone who can talk really at these meetings, they [the meetings] can be quite intimidating.

Health status and experience of the condition were important considerations in recruitment, but these changed over time.

At the time it was probably also decided to choose [name of service user] because he was quite well. There have been times he hasn't been able to come to the meetings because he's not been well. At the time he was picked because [his condition] wasn't really severe. But yet he did have severe enough heart failure to understand all the issues.

Ensuring the views of patients are represented

Involving service user representatives has been criticised in the literature for not being representative of all patients or all service users (see Boote *et al.*, 2002, for a description of the arguments). Gaining views or opinions that are representative of a group of service users can be achieved using research sampling and research methods. However these methods do not lend themselves easily to involving service users throughout decision-making processes because of the cost and time implications. Others have argued that although service users cannot be *representative* they can be *represented* (Russell *et al.*, 2002). That is, involving a service user can mean that a service user perspective is represented and this means that service users' stake in an issue is recognised.

Few studies have addressed representation of user, carer and patients' interests nationally. Jones *et al.* (2004) describe the role of consumer groups in representing the collective interests of patients, users and carers. Their survey of consumer groups showed that the majority (80% of respondents) identified influencing policy at national level as 'very important' or 'important'. From the perspective of consumer groups, key facilitators in engaging in policy processes included experiential knowledge, relationships with policy makers and working in alliances with other health consumer groups or other stakeholders. Key barriers included problems relating to the political agenda, problems with the consultation process, lack of resources and working within a context of unequal power relationships.

When service users might have a high level of expertise and training, concern has been expressed that these people do not have close enough experience of patient issues. Others are of the view that trained patient advocates can provide substantial insight into issues affecting patients and clinical practice, and they are often able to ask pertinent questions because they recognise issues that professionals might overlook (Griffiths *et al.* 2003).

What the service user reference group thought was important

 Members of the group felt strongly that their views should not be taken to be representative of all service users and that their views would not be presented as a unified opinion, unless they were. It was more important to the group that the perspectives of service users were represented and could contribute to the debates.

Involving people to improve access to particular groups

Gaining access to under researched groups is a particular challenge and requires specific planning (Berg, 1999). Techniques previously utilised by researchers include obtaining the support and endorsement of community leaders and advertising the research in community publications. Since each cultural group has unique issues and concerns, researchers have familiarised themselves with the values of their target group and emphasise these in recruitment approaches. (See Section 4.3.5 for more discussion about recruiting members of 'seldom heard' groups. Two examples from the telephone interviews are shown below.)

Real life example: R6

Recruitment criteria for co-researchers to a project about post-natal depression in South Asian women

One of the things that was very important was the confidentiality within the Asian community plus the language aspect. We didn't know at that stage what language the focus groups or interviews would be in, so we needed to recruit enough researchers where we could cover most of the Asian languages. Availability was another key criteria [for involvement].

Real life example: R10

Service user researcher compares different approaches to recruitment

A user researcher working in the field of mental health compares the two approaches to recruiting study participants in a project exploring continuity of care.

I gave a talk to a team meeting at a CMHT (community mental health team) and tried to get them to pass on recruitment packs to people. That was massively unsuccessful. There was a lot of effort went into that, I spent about 3 months trawling around these different community mental health teams. I think probably the main problem is that they're over-researched. One team said that they have a researcher coming to every single team meeting that they have, requesting participants. So, I think it was just a case of it's an exhausted route. However, at one meeting a CMHT member felt that we were going to find that there was no continuity and were going to blame staff in CMHTs for it. That was not the point of the research and it may have been that being a service user was actually a barrier to getting CMHT co-operation.

What was successful was going around to see user groups. And I think that's probably where being a user researcher is a massive advantage. Although people might have been quite sceptical at times of the types of research that we're doing, wanting to make sure that SURE also does research on alternatives to the system. Even so, people were quite interested because it was a user researcher going around I think, and that makes a difference to how you approach and involve people.

The following table generalises from the literature the qualities that researchers have looked for when recruiting service users.

Main purpose of involvement	Qualities/personal characteristics	Examples of roles
To provide personal knowledge or experience	 being diagnosed with a medical condition or having experience of a health issue 	Patient research partners
	 experience of accessing (or being a potential user of) a particular service 	
	being well enough to participate	
To provide personal knowledge or experience of caring To represent the views of a patient	 personal experience of caring time available to participate agreement from the cared-for person that the carer will represent their views on their behalf 	Carer research partners
To represent patient perspectives	 being vocal or confident to talk in a group availability (having time and being willing to participate) being well enough to participate 	Patient advocates/ representatives
To access community networks	 being able to speak a particular language having links into/with particular community groups 	Community co- researchers

Table 4 Qualities researchers have looked for when recruiting serviceusers

What researchers who responded to e-mail calls told us

Recruitment of service users/carers

For the research studies captured in the review via the e-mail call and subsequent telephone interviews, the recruitment of service users/carers was facilitated via either clinical practice (using practitioner caseloads and networks) or established service user participation and advocacy groups. There were two main criteria for recruitment. The most common criterion was that a service user/carer should have experience of a particular clinical condition or area of service provision. This was gualified further in one project by the decision not to recruit representatives from national organisations as they could be viewed as professional patients. In another project, recruitment had to be handled with particular sensitivity as it involved asking potential participants about their experiences of forensic mental health services and assessing the degree of fit with the specific project criteria. In a project in which the service user researchers were members of an established service user group, it was acknowledged that members' experience of working to see improvements in NHS services was an additional benefit. The other main criterion adopted by some projects was that service users/carers would be able to participate in discussions and express their opinions in meetings such as project advisory groups.

In relation to how these criteria were applied, the projects ranged from those that were more or less open to whomever was interested in participating, to a project in which strict criteria were combined with a formal interview to select service users/co-researchers. In one project the researcher had to modify an original set of strict criteria (related to the amount and duration of an individual's experience of a particular service) when recruitment proved persistently difficult.

Summary of what the literature shows

- Discussions about service user representation emerge in the literature, though these tend to reflect opinion rather than evidence.
- There is little research that provides evidence for what sort of representation works when and in what circumstances.

4.2.4 Ethical issues

The literature shows that many of the ethical issues for involving service users in research overlap with ethical issues for involving service users as the subjects of research. Ethical issues and guidance are described in the literature for research with particular groups, for example: involving patients receiving treatment or care (Hurst, 1985); people with mental health problems (Usher and Homes, 1997); involving children (Hallstrom, 2004); and people near the end of life (Daly and Rosenfeld, 2003). However, when involving service users as active participants in the research process, further ethical issues may arise. A number of these are described in the literature.

Williamson and Prosser (2002) explain that participative research methodologies (their example being action research) do not offer the same ethical guarantees concerning confidentiality and anonymity, informed consent, and protection from harm as other research methodologies. The authors outline three areas where it is ethically problematic and, recommend that researchers and participants recognise, discuss and negotiate these problematic areas before starting their work.

Most researchers in nursing, midwifery and health visiting work within research ethics guidelines oriented toward protecting the rights of individual research participants. In community-based, and international projects, the ethical rights of the community need to be considered and balanced with the rights of the individual (Dresden *et al.*, 2003).

What the service user reference group thought was important

 Consent was considered one of the least important issues relative to other issues about the involvement of service users in research. This was not because consent is unimportant but because gaining a service users' interest in being involved in a research project was considered to be more influenced by providing an understanding of why the research is being undertaken, the rationale for involving service users and the process of enabling their access. The group suggested there were important issues to work through around consent but that consent issues on their own were unlikely to present too great an obstacle to a person's participation and questions of purpose and enabling access should be given greater attention.

Payments for service users involved

Although the issue of payments to service users has received a lot of attention in the literature the ethical issues of providing, or not providing, payments to research participants are not well defined. Some authors have raised particular ethical issues such as the effects of financial incentives on recruitment (Erlen *et al.*, 1999) or have summarised information about the value of payments that have been made in different research projects in an attempt to establish parity. Guidelines for paying service users to participate (Department of Health, 2006). Wendler *et al.* (2002) scrutinise the ethics of paying for children's participation in research and provide a checklist of 11 items that researchers can use before deciding on payments. This list is useful but it was devised in the context of paying children as research subjects rather than as partners in the research process.

Principles about service user involvement (for example Telford *et al.*, 2004, see Section 4.2.2) can be used to guide good practice and may help researchers and service users to identify ethical issues and problems before they arise.

Summary of what the literature shows

- Many of the ethical issues for involving service users in research overlap with ethical issues for involving service users as the subjects of research: confidentiality, anonymity, informed consent and protection from harm.
- Although the practical issues of payments to service users have received a lot of attention in the literature, the ethical issues of providing, or not providing, payments to research participants are not well defined.

4.2.5 Diversity of service users being involved

Involving carers, parents and relatives in research

Like users of health services, carers are frequently the subject of nursing, midwifery and health visiting research. However, carers as a group are sometimes involved as proxy patients or their views are lost in wider public involvement activities. At one level their involvement can be as subjects of nursing research, for example, who they are, what they do, how much 'burden' they bear. Former carers such as bereaved relatives have also been the subject of nursing research (for example Beaver *et al.*, 1999) with a focus on their experiences and their reports of the experiences of the person who died.

Carers are also described in more purpose-orientated terms as 'customers' of nursing care enterprises (Burton-Jones, 2000) whose views should be sought for market research. Carers and parents often have been perceived as 'gateways' to achieving access to vulnerable populations for research. One exploration of the involvement of parents of new babies (Oberle *et al.*, 2000) in their role as providing proxy/surrogate consent on behalf of their infants indicated that parents supported the research but wished to be involved in consultation and decision-making around risk to their children.

In some studies carers are reported to have shaped the research and take a keen interest in its outcomes. Examples of carers' contributions to research methods include piloting of survey instruments (Jacoby *et al.*, 1999). Yates *et al.* (1997) set out the process of identifying HIV carers' areas of concern and their involvement in pre-testing a pilot video. In this study, particular importance was placed on the active involvement of carers or 'consumers' from the beginning of the research (although they did not appear to be involved in the initial project thinking and steering group) and the practicalities of working with individuals who may have stigmatised status.

Groups of carers

Groups of carers, sometimes referred to as relatives or caregivers, are often included in stakeholder consultations to ensure that a broad spectrum of views, for example about a particular service, can be gained. However, more often than not their views are undifferentiated from those of the people they care for (Davies and Nolan, 2003).

As members of health consumer groups, carers play roles in promoting and undertaking research (Jones *et al.*, 2004). This study found that such research could be responsive (in this example to rising caesarean rates) and used in political lobbying. There are other examples of carers who organise themselves into lobbying, self-help or support groups being powerful advocates for change and having influence over research commissioning processes.

Carers may also be involved in, or take responsibility for, determining the direction of research. For example, Melia (1996) noted that 'consumers' in the world of people with traumatic brain injury in the US were involved in deciding the action plan to evaluate the impact of a managed care programme. In this area, 'customers' such as support groups for people with traumatic brain injury were reported to be involved in encouraging a 'results-oriented' system of research and care.

Carers' experiences of involvement

From the perspective of carers themselves, few accounts emerge of their personal reasons for becoming involved in research. For carers of people with disabilities, Brereton and Dawes (2003) suggest that the reasons include: an opportunity to be listened to and to feel valued, time to reflect on problems and a desire to help future carers. Some of the negative risks of involvement are thought to include: the possibility of research evoking distress, taking up time, a concern by the disabled person that their privacy is being breached and difficulties in ending a supportive relationship with the researchers. This study focused on 'new carers' of people who have experienced a stroke and suggested that carers might appreciate information, ongoing details about the study, attention to practicalities and briefing prior to any interviews. It explains some of the benefits that carers may derive from participation but also the researcher's responsibilities around support.

Other benefits to being engaged in research studies were outlined by Fine (2003) in relation to palliative care and in cancer care (Birchall *et al.*, 2002) where carers and patients have been involved in research that has contributed to the development of standards of care. Yates *et al.*, (1997) did not anticipate the benefit to carers of people with HIV of research involvement, yet found great potential for learning, sharing and support.

Challenges for researchers

The literature reveals little about the difficulties for researchers of involving carers and families in research or of working to a research agenda set by carers. Vander Stoep *et al.* (1999) report on the tensions that emerged when parent advocates were involved in

User involvement in nursing, midwifery and health visiting research

evaluation of a US care management service model for children. At the outset, professionals doubted parents' skills and objectivity to undertake the research. The parent-led evaluation team (including siblings) designed and implemented the evaluation. Debates were held around issues of appropriate measures, standardisation, validity, relevance and dissemination. The professional researchers report that 'key ingredients' to successful partnership research with families include: flexibility, patience, time, humility, a sense of adventure and sufficient funding to explore new areas. They note that some of the parents used their experience to their benefit for gaining employment and that their involvement in research provided positive role models for other parents. Vander Stoep *et al.* (1999) conclude that 'research-savvy parents' emerged from this evaluation partnership, but also 'family-sensitive research scientists'.

Summary of what the literature shows

- The purposes of involving carers, parents and relatives in research are varied. Some conclude that this benefits the research process, others that it is empowering, and others that it provides the research findings with greater credibility.
- The best ways of involving carers or families in research are complex and sensitive. Issues of ethics, conflicts of interest and practical aspects have been raised and accounts exist of what worked well and not so well in different contexts.
- There is little evidence that the views of carers are distinguished from service users and patients, that the term 'carer' is used with precision and that issues of conflict, or that heterogeneity and difference have been fully addressed.
- Questions remain about why carers and families should be involved, how they can be involved but also how they can initiate, commission, develop and contribute to research, and the differences that their involvement might make.

Involving children and young people in research

Concerns as to whether children and young people have the intellectual capacity or understanding to be involved in research processes are at odds with the rights of the child to express their views freely in all matters affecting them (Article 12 of the *Convention on the Rights of the Child*, United Nations General Assembly, 1989). Research has focused on young people's capacity to consent to be involved in research. Increasingly children are being provided with the opportunity to be heard in legal and administrative processes affecting them, either directly, or through a representative or an appropriate body.

The Royal College of Paediatrics and Child Health Ethics Advisory Committee has produced guidelines for the ethical conduct of medical research involving children. Dimond (2002) summarises the law concerning research with children, consent, parental consent and risks to the child. Dixon-Woods *et al.* (1999) describe the debates about partnerships with children and argues that evaluation of outcomes of involvement needs encouragement from government bodies together with promotion of quality information to reassure parents that this will not lead to adverse effects. Alderson and Morrow (2004) examine the ethics issues of social research projects that involve children and young people from the planning stages through to the reporting and dissemination.

INVOLVE has published a guide to actively involving young people in research (Kirby, 2004) which gives guidance to researchers and commissioners working within the NHS, social care and public health about when and how to involve young people. The guide looks at the issues of involving young researchers and ways of supporting young people's involvement. It particularly highlights the importance of involving young people in deciding how they will be involved to ensure their participation is not tokenistic or manipulated by adults. The issue of payments for children and young people is addressed under the section on ethics (Section 4.2.4).

Clark *et al.* (2001) have looked at methods of involving different groups of young people, to different extents, in different aspects of the research process and on different issues. Kirby (1999) explores the ways in which young people can participate in the different stages of the research process. These resources detail good practice in supporting young researchers, and examine specific ethical issues. O'Quigley (2000) draws from published research about legal, administrative and mediatory processes to outline other ways of listening to children.

A study by Ward (1997) identifies key issues of concern at all stages of a project, from planning and consultancy through interviewing to dissemination, it outlines possible strategies and provides a checklist for use by all those wishing to undertake work with disabled children and young people.

France (2000) involved young people as peer researchers to identify, from young people's perspectives, the nature of transition to adulthood. In this study, young people helped to shape the way that questions were constructed and the themes that the research should explore; influence the language of the research – finding a more 'youth-friendly' way of constructing research methods; contact 'seldom heard' groups and encourage active participation of diverse youth groups in the research process. However, the project also encountered some problems. While the level of influence young people had on the research process was high, it was limited because peer researchers were engaged after the research questions had been selected. Greater influence could have been achieved if they had been

involved earlier. Young people's exit from the project was difficult because a strategy for this had not been agreed.

To date, only a limited number of projects have involved younger children (under fives) as researchers. There is some good practice in this area but more scope for development. A review by Clark et al. (2003) demonstrates that imaginative methods are being used by researchers, practitioners and consultants to listen to and to consult with young children. These include methods adapted from work with older children including interviews, questionnaires, group work and participatory games. Other techniques such as observation have been combined with the use of multi-sensory methods including the use of media, role play, drawing and puppets. There was evidence of the impact of listening to young children occurring at an individual, institutional and strategic level. At an individual level, young children experienced increased self-esteem and social competency, together with an insight into decision-making processes. Impact at an institutional level included opportunities for practitioners to reflect on practice, changes to policies and to designs of outdoor and indoor spaces. There were few examples found of the impact of young children's views on change at a strategic level.

Baumann (1996) used the Parse research method (a human sciencebased nursing research methodology) to gain views of young children as partners in research about their lived experiences. Using this method children's thoughts and feelings were made more accessible with the aid of art, stories, and play. Another example of involving young people was revealed by the telephone interviews (see R8 below).

Real life example: R8

Young people leading on dissemination

Six young people aged between 12 and 15 years were co-researchers on a project exploring the potential for children to be involved in monitoring the quality of care in hospital. They devised a leaflet citing the findings of the research and their recommendations.

'They told me what they wanted on it, one of them designed it and then I fiddled about with it – to make sure it was OK and fitted on [the paper]. They wanted it sent out. They had a list of people who they wanted me to send it to. They decided on the dissemination list. They wanted them sent to the hospitals where they'd been, the Department of Health [and to] their schools. They drew up a dissemination list, and we sent it out to people on that list.'

Summary of what the literature shows

- Involving children and young people in research processes is a relatively recent activity but it is becoming more common.
- There are some good practice guides and principles about the process of involving young people or children in research.

Involving older people in research

Assumptions are often made that involving older people in research is difficult. These hinge around concerns that health problems and cognitive capacity may intervene with participation and understanding, for example age-related or degenerative mental health problems may have implications for understanding and consent. Hancock *et al.* (2003) tackle some of these assumptions in a study that focused on understanding older people's nursing needs during acute hospitalisation. Potential barriers included the complexity of illness in the older person as a result of co-morbidity; fatigue; normal age-related processes such as visual/hearing impairment; frequent ward transfer or early discharge; delirium or dementia; and high staff turnover resulting in difficulties in co-ordinating the study. Hancock *et al.* identify the importance of balancing the need to maximise the rigour of research and the needs of participants.

There is a developing evidence base in the social research literature on the participation of older people in research (Carter *et al.*, 1991) and from the Economic and Social Research Council's Growing Older Research Programme (Walker, 2002). The Rowntree policy papers provide a helpful analysis of existing models of involvement (Carter and Beresford, 2000) that enable important links to made with older people's definitions of quality services (Quereshi and Henwood, 2000) and unmet need (Cordingley *et al.*, 2000). Research has also looked at approaches to recruitment and involvement of older people (Law and Janzon, 2004); and specifically in relation to people with sensitive and life threatening health problems (Crooks, 2001). Ross *et al.* (2005) found that contrary to expectations, attrition from a consumer panel of older people, set up to guide and support a study about falls, was not a problem.

Generally there is a good record of older people being involved in health and social care research, possibly because they have more time to participate or more interest in health and social care issues as users of these services (Carter et al., 1991; Barnes and Walker, 1996). There is a growing contribution to this field from nursing-led research, for example in service development (Bentley, 2003); using the reflective narratives of patients to improve nursing practice in an action research project to improve rehabilitation outcomes (Bridges, 2001) and in falls prevention (Ross et al., 2005). Nolan et al. (2003) drew on authenticity criteria proposed by Guba and Lincoln (1989) to develop a model designed to judge the quality of partnerships between older people and research. Reed et al., (2004) discuss partnerships with older people that take place against a background of academic research traditions and norms, which can present obstacles to collaboration. Their work is a reflection on the issues that have arisen in three projects where older people were involved in research at different levels, from providing sources of data to being independent researchers.

There is some evidence that involving older people in research has an impact on services. Glasby and Littlechild (2001) discuss the patient's role in providing information about emergency admissions to hospital. Methods for researching the rate of inappropriate admissions have several major limitations. Chief among these is the failure to consider the potential input of the individual patient. This article illustrates some of the possible benefits of patient participation by drawing on a study that involved individual older people in research about emergency hospital admissions in Birmingham.

Summary of what the literature shows

- Assumptions are often made that involving older people in research is difficult. It is important to create user involvement opportunities, which take into consideration the needs of participating service users.
- Generally there is a good record of older people being involved in health and social care research.

Other groups requiring special consideration

Although more often called 'vulnerable groups' we have called this section of the report 'groups requiring special consideration'. The danger of using the term 'vulnerable groups' is that it carries a lot of moral weight and labelling people as vulnerable can close off conversation about their involvement in research.

Patients receiving treatment or care: The process of accessing user views about cancer have been researched from an ethical perspective (Seymour and Skilbeck, 2002; Crooks, 2001). Involving patients in research requires striking a fine balance between the ethical duties of providing care and support and achieving user involvement that is accessible and meaningful to users.

Hancock *et al.* (2003) focus on the complexities of researching acutely ill hospitalised older patients. They identify potential issues as including: the complexity of illness in the older person as a result of co morbidity; fatigue; normal age-related processes such as visual/hearing impairment; frequent ward transfer or early discharge; delirium or dementia. Others have looked at the issues of involving patients receiving palliative care (Addington-Hall, 2002; Karim 2000), those with advanced HIV infection (Yates *et al.*, 1997), and people near the end of life (Agrawal, 2003). Fine (2003) argues that research in end-of-life care is constrained more by pragmatic, social, cultural, and financial constraints than ethical issues that preclude the application of typical research methodologies. Fine (2003) believes that when normally accepted and ethically sound protections for subjects are in place, exclusion of patients with far advanced disease from research is in and of itself unethical.

Women who are pregnant, in labour or breastfeeding: A charter for ethical research in maternity care produced by the Association for

Improvements in the Maternity Services and the National Childbirth Trust identifies that special consideration should be given by researchers to research on pregnant, labouring and newly delivered women. The charter provides principles for ethical working and recommends that researchers should involve women in the planning of research studies and include user representatives early in this process.

People with cognitive impairment: Researchers have looked at different aspects of the involvement of people with dementia in research and evaluation of health services, including the ethics of involvement, consent, communication and the impact of involvement (Wilkinson, 2002, Cheston *et al.*, 2000). A case study involving people with intellectual disability in outcome and quality of life research used individualised communication for interviewing (Cambridge and Forrester Jones, 2003). In collaboration with communication and speech and language therapists, researchers developed a flexible communication strategy for involving service users, drawing on core, local and individual vocabularies and using signs, graphic symbols and photographs to supplement spoken English. Individualised communication was used both to ascertain informed consent to participate in the research and to conduct the user interview.

People with learning disabilities: Kiernan (1999) considers involvement of people with learning disability as co-researchers and argues that applying new paradigms to research with people with learning disability yields benefits, but there are a number of practical and theoretical limitations that limit their value.

Burke *et al.* (2003) report on the initial setting up of a participatory research project that included adults with learning disabilities, clinicians, a researcher from a primary care trust, and support workers. The authors argue that providing people with an understanding of what would be involved was important at an initial stage.

People with a visual impairment: Methods may need to be refined to address difficulties in recruiting participants and to capture the diversity of strengths and needs of visually impaired people. A review paper by Duckett and Pratt (2001) reveals the opinions of 37 visually impaired people on visual impairment research in Scotland. The findings suggest areas of need for visual impairment research, both concerning what is researched and how it is researched. The authors suggest increasing resources for recruiting participants and multimedia dissemination (for example audio tape, Braille, Moon). They make three core recommendations that identify the need for research to: respect people's individuality, be practical and action-orientated and contribute to an empowering and emancipatory research agenda.

Research about culturally sensitive subjects: Relatively little attention has been paid to involving service users in research about culturally sensitive subjects but issues here overlap with research that involves people as the subjects of research about sensitive subjects.

Chiu (2004) has led research on enabling ethnic minority groups to participate in research about cervical screening. Issues of stigma and confidentiality are likely to be barriers to involving people in this type of research.

Black and ethnic minority groups: Involvement issues and techniques for engaging black and ethnic minority communities in health research are included in a review by (Crawford *et al.*, 2003). In most cases, black and ethnic minority groups have been involved in research as informants, rather than as commissioners or investigators (Johnson, 2002). Black and ethnic minority groups have been considered seldom heard and hard to reach groups in research (see Section 4.3.5 for more information).

4.2.6 Roles and activities of service users in research

The roles and activities of service users in research are wide-ranging and have been linked to concepts of levels of user involvement (see section 4.2.1). Some activities are perceived as relating to a low level of involvement (for example consultation) and others to a high level of involvement (for example the role of a user co-researcher). These activities are often closely linked to the context of the approach and the purpose or goals of involving service users in research.

Findings about the roles and activities that service users have taken in research are summarised in Table 5. A range of roles and activities are highlighted (using the symbol \P) to emphasise the wide range of activities service users have been involved in.

What researchers who responded to e-mail calls told us

Roles and activities of service users/carers

For the research studies captured in the review, involvement of service users/carers was demonstrated in a comprehensive range of research activities including proposing ideas and selecting topics, developing research questions, reviewing literature, collecting and analysing data, developing vignettes and influencing choice of research tools, dissemination of findings (advising on project reports, co-authorship of abstracts and papers, co-presenting at conferences) and identifying recommendations. In some projects service users/carers were involved, to varying degrees, across a significant proportion of this spectrum of activities.

The table below lists the range of roles and activities of service users that have been identified in the literature and through researcher consultations.

Roles and activities	
Participating in public opinion surveys about health services	
Providing views about health services or the experience of being a patient	
Patient surveys/satisfaction surveys	
Developing or evaluating clinical interventions, treatment or care giving practices	
Evaluating nursing, midwifery and health visiting services	
Involvement in service development/re-design models of participation	
Developing patient-defined measures, tools or instruments	4.3.2
Public providing opinions about health issues	
Conveying the personal experience of health and illness	
Involvement in research priority setting	4.3.4
Involvement in commissioning/tendering/programme reviews	4.3.4
Planned/strategic involvement in research organisations	4.3.4
Involvement in proposal/protocol development	4.3.4
Service users as members of advisory groups	4.3.5
Service users involved in recruitment to research	4.3.5
Involvement in the development and validation of research instruments or scales	4.3.5
Service users involved in data collection	4.3.5
Service users involved in analysis or interpretation of research data	4.3.5
Service users as disseminators of research findings	4.3.5
Service users as authors of research publications	4.3.5
Service users using findings to influence commissioning or service change	4.3.5
Providing perceptions of participation in clinical/research trials	4.3.5
Providing reflections on participation in clinical/research trials	4.3.5
Involvement in the design of trials/research questions	4.3.5
Involvement in systematic reviews	
Involvement in scoping exercises	
Academic user researchers	
User-controlled research	
Service users conveying their experience of research participation	
Providing perspectives of the experience of service user involvement	

4.2.7 Establishing working relationships

There is evidence in the literature to show that strong alliances have been built between service users, nurses, midwives and health visitors through the process of research (for example Thornton, 1998).

Communication and clarification

Communication and clarification are defined in the literature as being central issues for establishing working relationships. Zielstorff *et al.* (2003) describe a disconnection between the language that service users use to express health concerns and the language used by health care professionals. The authors are of the opinion that nurses with expert training in informatics could play an important role in creating structured vocabularies comprised of lay terms, with definitions, variant spellings, and regional dialects, along with mappings to equivalent or related professional terms would help to overcome barriers to communication and participation. Interviews with researchers revealed the importance of communication for developing a shared vision.

Real life example: R4

Making decisions together

We don't ever have separate meetings. We always meet together. My colleague and I talk about things, but we take everything to the meeting. We don't actually make decisions without them [the users]. If there was anything we were thinking about changing we would meet with them to discuss it.

Real life example: R1

Lessons for next time

Values clarification [is important], to make sure the team has a shared vision. Look at roles and expectations, how to manage conflict, give each other support and challenge each other. Work with a team not as individuals. There were just two of us and that's really hard.

Training and preparation for service users

It is important for anyone involved in handling personal information or research data to have an understanding of confidentiality and responsibilities for data protection. Advanced thinking and planning around issues of confidentiality are essential to all research. However the medico-legal issues of user involvement in research and the legal responsibilities of service users in the research have not been addressed in a systematic way.

Education of children, health professionals, the public and the media has been advocated to enable the use of critical appraisal skills and good quality health information to lead to improved involvement in health-care decisions of all kinds, both individual and societal (Thornton, 2001). In research projects, some researchers have reported facilitating formal or informal learning or training to enable a service user to participate fully in the research. The text bubble below from an interview with a researcher illustrates the need for training during a project that involved service users in designing a survey.

Induction training programmes may give service users a feeling of belonging and status in the research. They may also convey the message that the researchers value involvement enough to make an investment in service users. However, this is based on opinion rather than evidence for the needs of service users. Earl-Slater (2004) suggests that researchers provide an introduction to the research, its purpose and aims, and outline any codes of conduct.

What researchers who responded to e-mail calls told us

Support for service users/carers

For the ongoing research studies captured in the review, support for service users/carers was described as including:

- communication and relationships (amongst peers and with researchers)
- the provision of specific research training
- financial reimbursement.

A valuable source of support for service users/carers was from peers at project meetings. In a project focused on the needs of younger people with stroke, it was apparent that service user members of the project advisory group were providing each other with emotional support and that there was a sense of belonging amongst the group. In another project, the role of a service user coordinator was specifically developed to support the induction of new patient research partners. For one user researcher, their own experiences of services and mental distress helped them to create a safe environment within which to discuss issues with other users of mental health services. Communication between researchers and service users/carers was also vital to the development of a supportive environment. Communication outside of scheduled meetings was an important aspect of building supportive relationships; researchers in two projects described how they maintained informal contact with service users/carers by e-mail or telephone.

Research training for service users/carers ranged from scheduling protected time for training (two projects had each provided three half-day sessions) to address specific training needs as they arose during the course of a project. The lack of a specific budget for training was a cause for concern for some researchers. In one project, the service user researcher undertook what was described as a research apprenticeship, working closely alongside one of the professional researchers. Financial support for service users/carers was provided in some projects. Arrangements included a specific hourly rate for hours worked, ad hoc honorarium payments (to meet childcare and travel costs) and employment as either full or part time user researchers. In a project working with children as co-researchers, retail store vouchers were given as a gesture of thanks for their involvement.

Real life example: R1

Preparation for partnership

The project was envisaged as a collaboration. It wasn't set out to be a training opportunity. The service user had no prior research training, was not computer literate and found the 'intellectual effort' challenging and tiring. She had what constituted a training apprenticeship, working closely alongside the researcher. Training for service users should be provided beforehand if the aim is for a true partnership.

Reflecting on working relationships

Consultation with researchers showed that much can be gained from reflecting on collaborative relationships.

Real life example: R1

Compromising on collaborative ideals: 'It's really difficult to live up to espoused values'

We [the researchers] are very clear about politics, values and ethics but actually trying to 'do' it is quite different. Our service user colleague has been fantastic but we didn't anticipate all the organisational difficulties. Also, she has not always felt listened to, or supported or included enough, which was difficult to hear. It is sometimes difficult to assure people that they're doing useful and valid work. What support is enough support? This is a dilemma in a research context, where the work isn't finished, is still ongoing. We are learning and using experiences all the time. Even though we've had all the challenges, they are the real nitty-gritty of collaborative work in mental health.

It's hard to compromise some of those collaborative ideals. But we've got lots of other really rich stuff – from the reflections, our working relationships, from debating, and arguing sometimes.

Real life example: R1

Acknowledging contributions of service users

Where possible, the researcher and service user have co-presented at conferences. On those occasions when the service user was unable to co-present, her views were 'heard', via projected PowerPoint slides entitled 'And [name of service user] says '. In relation to publications, the researchers would always publish in collaboration with the service user.

> Our experiences of involving service user organisations in the reference group for this project have helped us to learn about the best ways of involving service users in the context of secondary research. From our perspective there are a number of strategies that have been useful for developing working relationships with consumer organisations in the context of a multi-method literature review. These are summarised in Box 6.

Box 6: Our strategies for working with the service user reference group

- Communication and organisation throughout were important and we found that using plain language and pictures were very important to the group. Making a note of personal details such as the best time to contact people, access issues and special dietary requirements were small details, but were important to get right from the participants' point of view.
- Having clear objectives and a flexible agenda for each meeting allowed an open way of working but provided structure to the approach to involvement.
- Small group work and flip chart note taking were effective ways of engaging everyone in the issues during meetings.
- Acknowledging service users' contributions by paying for their expenses and time was essential.
- Informing people what impact their involvement was having was important for keeping people interested and involved.
- Feedback during meetings and in between meetings using newsletters and project letters was effective. These were not just beneficial to service users but provided a record of the development of the project.
- The project team, project partners and service users were asked to provide their reflections and experiences after each meeting by completing a reflection and feedback form that linked to the objectives of each meeting. Responses were important for planning subsequent meetings as they highlighted issues that needed further clarification or more focused attention.

Summary of what the literature shows

• Opinions of researchers in the literature state that communication and clarification, training and preparation, and feedback about progress and contributions are important for establishing working relationships with service users.

4.3 The outcomes of involving users in nursing, midwifery and health visiting research

This section shows what is known about the outcomes of service user involvement in relation to the different goals, or objectives, of involving service users in nursing, midwifery and health visiting research. Examples are given of the measurable outputs that can be attributed to involvement activities and the impact of involvement on different groups of people. The section describes:

- the wide-ranging goals of user involvement in research
- outcomes of meeting policy targets for involvement

- outcomes for the social integrity of research
- outcomes for research design and infrastructure
- outcomes for the research process at a project level
 - researcher-led models of involvement
 - pharmaceutical/clinical trial approaches to involvement
 - involvement in secondary research
 - user-led research initiatives
- improving life chances and opportunities for service users
- influencing ongoing iterative change in nursing, midwifery and health visiting research.

4.3.1 The wide-ranging goals of user involvement in research

Section 4.1 described the arguments in the literature for user involvement in research for political, quality and social reasons. In this section the evidence for outcomes of service user involvement in research are defined in the context of these wide-ranging goals of service user involvement.

A Department of Health report (1998b) argues that service user involvement has benefits for the NHS, service users, public health, and for communities and society as a whole. In the nursing, midwifery and health visiting literature, descriptions of the benefits of user involvement reveal implicit beliefs about the purpose of user involvement in research and in society.

The literature shows outcomes in relation to different purposes/goals for involving service users in research. These different categories of outcomes are addressed in the sub-sections that follow, and which are listed above.

During our consultations for this project, researchers also described the benefits of involvement and the outputs that have been produced with them. These are summarised below and examples are shown in the text.

What researchers who responded to e-mail calls told us

The impact and specific outcomes of involving service users/carers

For the research studies captured in the review via the e-mail call and subsequent telephone interviews, the impact and specific outcomes of involving service users/carers were described in relation to:

- · discrete aspects of the research process
- the overall approach and relevance of individual projects
- the identity and perspectives of service users/carers.

In addition, some researchers commented on the benefits to service users/carers and themselves.

Aspects of the research process in which service users'/carers' contributions were particularly highlighted included:

- contributing to the ethics application
- development of data collection tools
- · discussions about outcome measures
- · accessing the study population and informing the process of consent
- questioning and probing during interviews
- informing the analysis
- commenting on the findings, their significance and probable impact
- producing recommendations that reflected the concerns of service users/carers
- disseminating findings to academic and practitioner audiences and to local communities
- developing a subsequent grant application.

In some projects, service users/carers were instrumental in informing the study design, shaping or leading the research. In relation to impact, one researcher referred to the contribution of the service user's identity, in terms of how they challenged the language used and decisions that were made in the project. Another researcher described the impact of service user/carers' involvement as subtle and multi-faceted. Their involvement had enabled the research to be conducted in a culturally sensitive way and produced outputs that were relevant to service users/carers and practitioners.

In relation to benefits to service users/carers, in one project the service user researcher had since got involved in the local NHS trust promoting service user involvement. In another project with children and young people, one co-researcher had developed their own presentation of the research and used it in a key skills assessment at sixth-form college. Some researchers shared their personal reflections on involvement. One referred to the positive experience of working with service users/carers and another described it as a time of tremendous personal growth.

4.3.2 Outcomes of meeting policy targets for involvement

In the findings section on the political context of involvement (4.1.1) we showed that involving service users in research is a requirement of all research undertaken within the NHS or funded through the Department of Health R&D programmes. Research councils and other commissioning bodies are increasingly requiring researchers to identify how they will involve service users. Meeting these requirements can be considered one goal of involving service users in research. We have also shown that policy for user involvement is influenced by political concepts such as participation, empowerment and consumerism (see Section 4.1.1 for more detail).

The potential outcomes of meeting policy targets are that health service and research organisations provide a role in improving democratic practice, within which researchers become advocates of democratic processes. In theory, the focus on regulation should mean that complaints about research are reduced (Beardwood *et al.*, 1999). A description of the political, managerial and regulatory objectives of involvement can be found within Beresford's (2003) managerialist/consumerist ideology of service user involvement in research. This ideology is driven by notions of efficiency and effectiveness and relates to consumerism. It is framed in market research terms (that is, making the product better for consumers) and economic models of efficiency and productivity (see Section 4.1.1 for a counter view).

Beresford's (2001) criticism of a managerial/consumerist approach to user involvement is that it is intended to 'obtain public support for provider-led changes and legitimise the decisions of policy makers and administrators rather than devolving power'. Others are sceptical of claims that policy-directed involvement can reform the health care system and perceive this as a way of dampening down real and necessary reform. Rochefort *et al.*, (1998) take the view that:

The capacity to claim that reforms either reflect 'public values' or more often that they 'empower citizens', 'consumers' or 'communities' is valuable protection against the higher political costs of resistance and opposition to radical reforms.

Fulfilling the duty to consult

As consumers of health services, service users have played a number of roles, of which consultation activities have been important.

Participating in public opinion surveys about health services

The public has been consulted about their experiences and expectations of the NHS nationally and regionally (Anderson and Florin, 2000). Consumer feedback about the NHS has been used to evaluate services and identify areas for service development (Jones *et al.*, 1990).

Providing views about health services or the experience of being a patient

At a health service or organisational level patient experiences have been researched across the full range of nursing, midwifery and health visiting services as part of eliciting users' views of the process of health care (Nicolson *et al.*, 2000). In mental health care, Campbell and Einspahr (2001) explore the processing and presentation of information as it flows through the health care system and the distribution and feedback loops that allow for shared decision making and quality improvement using consumer satisfaction data. Other studies have looked at the importance of methodologies for researching patient experiences, for example in Pittman *et al.* (1997) a diary method is used with patients to evaluate maternity care; Frost and Cliff (2004) use narrative approaches for research in community nursing; and in lung cancer care Bell (2003) uses patient storytelling. The authors of these papers emphasise the importance of using appropriate methods for patients to provide their views.

Patient surveys/satisfaction surveys

Patient satisfaction is increasingly considered to be a principle indicator of quality of care. The use of patient surveys has increased rapidly across the NHS (Cleary, 1999), possibly as a result of the duty to consult and involve. The complex nature of individual patient expectations and experiences raises questions as to the subjective nature of the assessment of health services. Edwards and Staniszewska (2000) have reviewed the results of research in the field of patient satisfaction over the last 20 years. They summarise the main problems in the area, and suggest ways forward. Three main points emerge

- 1 the importance of developing and substantiating theory in this field to support study design
- 2 the need to exercise care if using quantitative methods and global satisfaction scores, until the process of evaluation is better understood
- 3 the need to consider how a sensitive user-led agenda can be developed.

Some researchers have tried to overcome issues of patient satisfaction surveys by using different methods of data analysis and triangulation (Hyrkas *et al.*, 2000; Hyrkas and Paunonen, 2000), others have involved patients in developing measures, tools or instruments (described later in this section).

Patient satisfaction surveys have been used to investigate patients' views of nursing developments (Pontin and Webb, 1995); satisfaction with nursing care (Bond and Thomas, 1992); and nursing services (Merkouris *et al.*, 1999). Poulton (1996) used a consultation
satisfaction questionnaire to examine patients' satisfaction with community nurses. This pilot study identified three dimensions of patient satisfaction with community nurses: professional care, depth of relationship and perceived time spent with the health professional. However, there is some evidence to show that the method of data collection can affect patients' evaluations of the quality of nursing care (Larsson 2000).

Developing or evaluating clinical interventions, treatment or care giving practices

Patient experiences have been used to improve practice through the use of storytelling (Ahlberg and Gibson, 2003) and patient stories have been used to inspire quality improvement in collaborative service development projects (Wilcock *et al.*, 2003); in clinical research (Goodare and Lockwood, 1999); and to develop clinical nursing interventions (Gamel *et al.*, 2001).

Evaluating nursing, midwifery and health visiting services

Service users with mental health problems have led monitoring and evaluation activities themselves (Hostick and McClelland, 2000).

Involvement in service development and re-designing models of participation

In Canada a model of consumer participation was used to develop services in breast cancer care (Parboosingh et al., 1997). Patient participation in service redesign has centred on the patient, rather than on any one staff group such as nurses, midwives or health visitors. For example, service users have been consulted to gain an understanding of the personal reasons for inappropriate hospital admissions (Glasby and Littlechild, 2001). In mental health services a study to explore service re-design (under the NHS modernisation agenda) showed that while there were some problems, user involvement was perceived as a strength of re-design in comparison to other modernisation programmes within the NHS. Changes and setbacks across different sites make drawing firm conclusions as to the effectiveness of the various involvement strategies problematic. The following real life example shows how users and carers have been partners in the ongoing development of cleft palate services in one London region.

Real life example: R2

Involvement in the design of a survey of cleft palate services

Ten members of the South Thames service user group were involved in all aspects of the development and administration of a survey of approximately 2000 users and carers of cleft palate services covered by the South Thames Cleft Network. An independent research consultant, who had been involved in setting up the group, advised on the methods, analysed the findings and wrote a report. In her view, this way of working with service users was effective because there was a group of very informed and very motivated people there from the start.

Starting off something from scratch, with a group of people who didn't have experience of working to see improvement with NHS service providers, would have been very difficult. What has not worked so well is trying to bring in other, new people. But it's a question of time. The effort that went into establishing a solid user group and the commitment of the chair of the board (of the South Thames Cleft Network) has really helped in creating that very solid base and creating something that could be built on in the future. Right from the start, the emphasis was on building something that was sustainable and wasn't just dependent on a few motivated individuals, so that if they left, it would all fall apart.

Developing patient defined measures, tools or instruments

The subjective nature of the service experience makes identifying and using suitable measures of evaluation a difficult task for service providers and health organisations. Patient defined outcomes have advantages for evaluating quality in health services (Davies, 1994). Patients are increasingly being involved in deciding which questions or topics questionnaire surveys should address. The design process with patients for the Healthcare Commission's national patient survey programme (see www.healthcarecommission.org.uk) are a good example of this. Parents have been involved in developing instruments, for example: to investigate parents' perceptions of research with newborn babies (Oberle et al., 2000); to develop and validate a measure of the degree to which patients perceived their needs have been met during hospitalisation (Dozier et al., 2001); and to develop patient-centred questionnaires about quality of care (Wilde et al., 1994). See Section 4.3.5 for information on the development and validation of research instruments or scales,.

Scepticism about tokenistic involvement

Beresford (2004) argues that there are growing concerns among service users that much of user involvement is tokenistic and that there is a legitimate basis for concerns that mainstream enthusiasm for user involvement in research may be short-lived and may dwindle away if and when fashions and political priorities change.

As shown in this section of the findings, policies for user involvement (particularly Section 11 of the Health and Social Care Act) have tended to be acted out through consultation activities such as patient surveys (Section 4.3.2). Views about tokenism are connected with criticisms

that consultation is a low level of user involvement (Section 4.2.1) or beliefs that consultation should not be classified as active user involvement.

Summary of what the literature shows

 Although consultation is sometimes perceived as a 'low level' of user involvement, it has been shown to be an effective way for service users to contribute their views about health services or the experience of being a patient. Consultation has been used to establish whether patients are satisfied with services and the care they have received and to inform the development of new clinical interventions, treatments or care giving practices and to evaluate nursing, midwifery and health visiting services using patient-defined measures.

4.3.3 Outcomes for the social integrity of research

Improving the relevance of research to society

Patient and Public Involvement in the NHS (Department of Health, 1999) states that involving service users in research ensures that research findings are more relevant and appropriate to patients' needs and that they have the potential to improve the effectiveness of services and the health of the public. The report argues that involving service users can improve the relevance of research to society because the topic of inquiry is important to service users, outcome measures are appropriate to patients and, the findings of research relate to what is important to service users.

Some accounts of user involvement in research make claims that involvement improved the relevance of the research to patients or community members. The 'relevance of research to society' and 'the relevance of research as perceived by members of the public' are two different things. Improving the relevance of research to the public is about understanding and addressing the issues that are important to the public. Activities which aim to better understand the views of the public about health issues are a step towards improving the relevance of research to members of the public. Yet public views may be contradictory or uncertain. The notion of improving the relevance of research to society would seem to relate more to ensuring the questions and outcomes of research are better placed to address the needs and problems of society. These issues are discussed in the second part of Chapter 5.

Public providing opinions about health issues

Public views about particular health issues have been used to inform health policy making for example public health issues such as smoking in public places.

Conveying the personal experience of health and illness

Service users have contributed to a knowledge base about the experience of health and illness for example quality of life research (Edwards and Courtney, 2003) and evidence about health choices (Glasby and Littlechild, 2001). This information helps to inform the planning and design of nursing, midwifery and health visiting research.

Summary of what the literature shows

• Improvements to the relevance of research are often cited as an outcome but there is little evidence to show that involving service users in research can improve the relevance of research outcomes.

4.3.4 Outcomes for research design and infrastructure

User involvement in research design and infrastructure is defined here as including involvement in the activities of research priority setting, commissioning, tendering for research funds, reviews of research commissioning programmes, the strategic activities that research organisations might undertake, and the involvement of service users in formulating ideas for research proposals or writing research protocols. These activities tend to involve service users in ongoing relationships rather than in time-limited activities of research projects.

Involvement in research priority setting

Nursing, midwifery and health visiting research are greatly influenced by the priorities of research programmes and the requirements of research commissioners. This is an important area that service users can, and are, contributing to (see Section 4.1.6).

Involvement in commissioning, tendering and programme reviews

Although there are increasing numbers of lay representatives on commissioning bodies, the degree to which service users are able to influence decisions about which research is funded or the questions that research seeks to address is unclear. Some researchers have claimed that commissioning decisions are more likely to be based on evidence if service users are involved in the decision (see also Section 4.1.6).

Planned/strategic involvement in research organisations

Few researchers have looked at planned or strategic models of user involvement in research. We could find little evidence of models at an organisational level. Stevens *et al.* (2003) describe a model for involving service users in research in one cancer network. Three innovations in particular are examined in detail:

 three open consumer conferences increased awareness of research among service users

- service users were recruited to sit on project steering groups and a committee that provides a strategic overview of current research
- a consumer panel for research was established where trained consumers are able to provide a considered consumer perspective in a range of settings.

It would appear from the literature that research organisations have not developed strategies or policies for involving service users in research and the decisions about user involvement rest with the leaders of individual research projects. Although Nolan *et al.* (2003) evaluate the Aldre Vast Sjuharad model for a strategic partnership approach to research based on 'authenticity criteria'. They argue that the criteria can be applied at all stages of research activity and they could be utilised more widely to support partnership working in other contexts.

Involvement in proposal and protocol development

Decisions about when and how to involve service users have tended to be made by the applicants leading the research, generally researchers. There are few examples of service users being involved in research at the design stage, for example writing a research proposal or research protocol. Some researchers have reported that the research question they proposed was replaced or amended to a more pertinent question or one with potentially greater impact because of the involvement of service users.

If service users are involved at a design stage this might mean that opportunities for involvement in a research project are recognised rather than becoming an 'add on' at a later stage. Thornton *et al.* (2003) offer 'consumer-led' reflections from a study that involved steering group members (including consumer advocates, patients' associations and patients) from pre- to post-study phases including inception, design, securing of funding and implementation of the research protocol. Difficulties can arise with involving service users at a design stage because of not wanting to raise service users' expectations that the research will be funded, or not having the time or resources to involve service users before the research has been funded. Beresford (2003) makes a case for more equal access to funding for user-controlled research. This may help to overcome these problems but it raises different issues about research commissioning processes.

Summary of what the literature shows

- Service users are increasingly being involved in research commissioning and research priority setting activities.
- There is little evidence of strategic user involvement in research organisations.
- There are problems for researchers involving service users at a research design stage because of lack of time or funds or not wanting to raise false expectations that the proposal will be successful.

4.3.5 Outcomes for the research process at a project level

This part of the research process is defined as occurring once a research project begins. Benefits for research processes at a project level need to be contextualised according to different approaches to involvement (Beresford, 2004).

These have been defined here as:

- 1 researcher-led models of involvement
- 2 pharmaceutical/clinical trial approaches to involvement
- 3 involvement in secondary research
- 4 user-led research initiatives

Researcher-led models of involvement

Service users as members of advisory groups

Researchers that have involved service users as members of advisory groups have provided their reflections in the literature about involving older people as research advisers (Tozer and Thornton, 1995), creating effective user groups in midwifery (Wray, 2003) and setting up a service users' advisory group (Rhodes *et al.*, 2001). Interviews with researchers showed that, as members of advisory groups, service users have brought unique perspectives, ideas and knowledge to research projects and have been the drivers of action. The following examples illustrate these outcomes in a range of projects.

Real life example: R3

Service users and carers brought a real life perspective to an advisory group for a project evaluating heart failure nurse specialist services

What they bring to the meeting is a real life perspective. When you get a bunch of academics and clinicians together, you can start to talk about the condition in a very abstract way. And they [the service user and carer] were a bit of a conscience. [It's] not being abstract about it and realising the condition is very real for people. And when you're confronted with someone with the condition it reminds you, it makes you talk about the research [in a way] that's understandable to everybody.

Real life example: R3

A carer helped to choose a tool to measure carer burden

The research team identified a number of carer burden scales but none were designed specifically for researching carer experiences in relation to heart failure. Researchers used the carer's expertise to inform their final decision by presenting the carer with five carer burden scales and asking her to rank the questionnaires in relation to their relevance to the experience of caring for someone with heart failure. The carer worked outside of the scheduled meetings with one of the researchers to review and rank the questionnaires. The findings were presented and discussed with other members of the research advisory group and informed the researcher team's choice of the most appropriate carer burden scale to use.

Through her involvement we probably picked a really good [tool]. But it might not have been the one I would have chosen, which was really interesting. In that sense she was really valuable. She was the best person in the group to do it. Despite all these senior clinicians and academics, she was the one ... she was the expert.

Real life example: R3

New challenges were raised by involving service users / carers in a research advisory group

It's the first time I've had a patient and a carer [on a research advisory group]. It's a real learning experience. It's a challenge. It sets up different challenges to working with colleagues. I'm a nurse. I know what it's like to be a clinician or an academic, you can share that world. I have elderly parents so I can understand them as well. But it is very different. I do find it's hard sometimes. I find myself rephrasing things all the time. It's a very positive thing but I don't think it's the easiest thing in the world to do.

Real life example: R5

Young adults who had experienced a stroke were the drivers of action

A researcher reflects on the first meeting of an advisory group for her PhD project about young adults' experiences of stroke (at which the emphasis was on getting to know each other and finding out why people wanted to get involved)

My main concern at the beginning was that the users wouldn't want to assist with the dissemination side of the research (making presentations, creating networks, sharing information etc). So that was one issue I bought up in the first meeting but in fact the opposite was true and they wanted to get active and out in the streets right away, which was a pleasant surprise! I was really taken back with how active they were prepared to be and it's because they felt so strongly about it. I really wasn't aware of the strength of feeling between them'

Service users involved in recruitment to research

There is some evidence about the benefits of service user involvement to the recruitment of participants to research studies. The use of peer interviewers with privileged access to a particular population or community group, which is difficult to reach via more conventional methods, has been acknowledged (Elliot *et al.*, 2002; France, 2000). There is evidence that peer recruitment is helpful in gaining access to hard to reach groups. In the consultations, researchers reported that connecting with community leaders, patient networks or voluntary organisations is a good method of engaging seldom heard groups in research.

Real life example: R6

Involving South Asian women as co-researchers to improve access and recruitment in a project about post-natal depression

The study population were a hard to reach group especially as the topic of depression is taboo in the South Asian community. A lot of the health visitors and midwives already knew a lot of women from the community through Sure Start. So we decided there was large enough pool of women to approach with regards to user involvement so we decided to try it.

Involvement in the development and validation of research instruments or scales

There is good evidence to show that the involvement of service users in the design of data collection instruments and tools can be very effective. Piloting of data collection tools is a research activity that service users are often involved in. Particularly in questionnaire design as this can help to validate the questionnaire in terms of the language being used, the appropriateness of the questions being asked and the method of collection and to improve response rates (Nicolson *et al.*, 2000).

Browne *et al.* (2004) have conducted 'woundcare research for appropriate products' (WRAP) which involved patients in the validation of a tool for wound care assessment. The authors took account of patients' needs in the use of *in vitro* research methods for assessing wet wounds. They use the TELER ('treatment evaluation by Le Roux') method of clinical note making to record the relationship between care given and patient-defined outcomes. Patients were involved in devising indicator codes for assessment of patient-centred treatment goals. Involvement of patients raised sensitive and challenging issues about the differences between professional and patient views of quality of care and quality of life. The involvement of patients in a systematic process of data collection enabled information and factors that were important to patients to be fed back into wound care product development.

Service users involved in data collection

It is unclear whether data collection itself is improved when service users are involved. Accounts of 'lay interviewers' show that some groups are more likely to talk to peers about their experiences. However other studies show that researchers are more effective at gaining particular types of data from participants. The influences of training (particularly ethical/confidentiality awareness), structured data collection methods and the characteristics of participants in the research are thought to be important.

A paper by Elliott *et al.* (2002) explores a number of key issues relating to the employment of peer interviewers by reflecting on a project designed to explore the views and experiences of parents who use illegal drugs. The research team recount a number of challenges. These included the need to provide on-going support for the interviewers, a sense of distance felt by the researchers from the raw data they collected, and the difficulties of gaining from the skills and experiences of peer interviewers without exploiting their labour. The paper also explores the advantages of involving peer interviewers closely in research work and reflects on the nature and boundaries of expert knowledge that can become evident in such collaborations. The authors suggest a need for a certain amount of flexibility over the roles and domains of control that lay experts and researchers traditionally inhabit, where peer interviewers can be a valuable means of enhancing knowledge and understanding of a variety of population groups who have tended to be overlooked.

A systematic review of involving service users in the delivery and evaluation of mental health services (Simpson and House, 2002) showed some evidence that clients reported being less satisfied with services when interviewed by users.

Real life example: R6

Overcoming language barriers in a study of post-natal depression in South Asian women

Service users facilitated a focus group and conducted one-to-one interviews in each of the study sites. Two of the focus groups were conducted in South Asian languages (Punjabi and Urdu).

Link workers were pivotal as they could cover all languages. The other thing we didn't know was how we could translate from the meetings etc. So it was really seat of the pants stuff in terms of language. At first we tried to translate each paragraph but this wasn't practical, so in the end we just let them speak. So we couldn't understand what was being said. Meetings were taped then the link workers would translate and I would sit there with a laptop and transcribe it, which was a very long, slow process.

Service users involved in analysis or interpretation of research data

Examples of the involvement of service users in the interpretation or analysis of research data are difficult to find in the literature. Interviews with researchers revealed that some qualitative research projects and evaluation studies have involved service users in:

- identifying questions or issues for the analysis to address
- naming or creating categories with which to analyse the data
- providing a perspective on the categories chosen for use in an analysis
- identifying issues or themes within the data
- checking a researchers application of categories to a transcript.

In some projects service users have been asked to look at interview transcripts to provide their perspective on what the participant is saying. However this might be considered the creation of new data rather the involvement of service users in the process of research.

Real life example: R6

Co-researchers provided insights during data analysis of interviews with South Asian women about post-natal depression

The independent researcher undertook the analysis but invited service users to review a sample of interview transcripts.

It was back up to give me confidence that I was going in the right direction. There were things coming up very strongly, for example the power of the mother-in-law. Now for me, because I didn't know anything about the community it was really important to me that they could explain background issues like that, why mother-inlaw has so much power etc. And because the issue has stigma and because there is very little idea of confidentiality. So a lot of them do not want Asian health professionals. So I think that is a perfect example of the great thing about doing the research and involving users.

What the service user reference group thought was important

- Service users should be involved in the interpretation of research findings and should see drafts of papers before they are finalised so that their comments can be considered.
- There is evidence to show that through involving service users in the research process researchers can learn new skills of facilitation and communication that may help to improve nursing, midwifery and health visiting research.
- Some accounts show that researchers gain new understandings of service users and their perceptions, for example of research topics.

Service users as disseminators of research findings

In participant-focused research participants may share in the products or outcomes of the research. Some research goes beyond the traditional research approach of disseminating findings to other researchers and clinicians and includes participants and community members in sharing the skills, knowledge, and resources of the study. Flaskerud and Anderson (1999) show that involving participants in dissemination can mean that research has a greater impact on changes in practice or society, for example service users presenting a paper at a conference may have greater impact, and that dissemination can be supported by the involvement of service users if they are knowledgeable of lay networks and advise on lay summaries (see Section 4.2.5 for a real life example of dissemination led by young people [R8]).

What the service user reference group thought was important

- Thinking ahead about dissemination and drawing on other previous work.
- Dissemination and feedback should be tailored for different studies and results should always be fed back to participants.

Service users as authors of research publications

Writing research publications present situations where different emphasis might be placed on particular aspects of the research or findings by different authors. McClimens (2004) asks what difference does it make who is speaking? And concludes that service user involvement in dissemination and publication raises issues about ownership and interpretation of the research findings.

Real life example: R6

The impact of involvement on a final research report

Service users reviewed the final project report. Although the researcher and health professionals had concerns about including some of the quotations from study participants, very little was amended.

So a lot more has gone into the report than we would have dared as researchers. So that's a way that their involvement has impacted on the end result.

What the service user reference group thought was important

- All research should be written up and if not published in a reputable journal should be listed and available for public scrutiny.
- Service users involved should be acknowledged on publications.
 - Service users using findings to influence commissioning or service change

We could not find evidence in the literature about service users being involved in using the findings of research to influence change. It is more likely that the outputs of a research project will be used to define the criteria for new professional posts or set up new health services.

Real life example: R6

Involvement in research informs the creation of new health care posts

As a result of the finding [about the need for Asian languages and relationships of trust] two South Asian post-natal depression advocates were appointed very early on in the study. So that was a really good impact. Synergy of money being available at the right time and the right people involved made it happen.

Summary of what the literature shows

- There are examples in the literature to show how service users have been involved in advisory groups for research projects.
- Involving service users in recruitment processes can help to access some seldom heard/hard to reach groups.
- Involving service users in the development or validation of research instruments or scales can ensure that factors that are important to patients are included in assessments of their health status or the care they receive.
- It is unclear whether data collection itself is improved when service users are involved. The evidence indicates that peer interviewers can help to inform the way research questions are asked and that this can be a valuable means of enhancing knowledge and understanding of a variety of population groups who have tended to be overlooked.
- There is little evidence in the literature about the involvement of service users in the analysis or interpretation of research findings.
- Service user involvement in dissemination and publication raises issues about ownership and interpretation of the research findings.

Pharmaceutical/clinical trial model of involvement

Providing perceptions of participation in clinical/research trials

Increasingly, researchers leading clinical trials are making use of qualitative studies to better understand the views and perceptions of potential participants. This is helping to inform future recruitment practices, particularly in groups that are traditionally less likely to participate in trials for example ethnic minority groups. Qualitative interviews have been used to establish the reasons why people agree to participate in clinical trials and what they see as the potential benefits of their involvement for them. Moore (2001) shows that participation has helped some patients with cancer to construct their lives meaningfully by providing a supportive structure and enabling hope.

Research conducted in the US by Rodeheaver *et al.* (2003) describes how information gained from patients was used to guide the planning of a clinical study using complementary therapies to reduce symptom distress and enhance quality of life during stem cell transplantation. It is their opinion that eliciting the views of patients is a necessary step in rigorous clinical trial development and that consideration of patient preferences and motivations may ensure the best fit between interventions and goals.

Service users have also been involved in the design of recruitment materials or procedures.

Providing reflections on participation in clinical/research trials

Research has been undertaken to gain an understanding of participants' experiences of being involved in a research trial. For example, Dougherty *et al.* (1999) looked at patient participation in a clinical trial of angina management, and Donovan *et al.* (2002) captured users' experiences of participating in cancer trials. This type of research is most often conducted as a follow-up study after a trial has completed, rather than during the time the person was a participant. Although this type of research can inform the design and conduct of clinical trials, it might be viewed as evaluative consultation rather than user involvement.

Qualitative studies have also been used to inform trial management practices. Cox (2000) explored patients' views and experiences using in-depth interviews and quality of life questionnaires, at the beginning of, during and after trial participation. The picture of trial participation established from this work provides insight and understanding in terms of the impact of trial involvement over time as well as details of patients' information, decision-making and support needs has significant implications for cancer clinical trial management. Cox recommends that managers of clinical trials focus on acknowledging the contribution trial participants make to cancer research, enhancing the process of preparing patients for trial participation, recognising the need for continuing care, the incorporation of patients and potential patients' views into the clinical trials system, and educating the public about clinical trials.

Involvement in the design of trials/research questions

There is less evidence to show that service users have been involved in the design of research trials at any stage or in influencing the questions the research sought to address. A national survey of user involvement in designing, conducting and interpreting randomised controlled trials (Hanley *et al.*, 2001) assessed the extent to which service users were involved in the work of 103 clinical trial coordinating centres. Responses from investigators on 48 individual trials were mostly positive, with respondents commenting that input from service users had helped refine research questions, improve the quality of patient information and make trials more relevant to the needs of patients. The authors conclude that user involvement in the design and conduct of controlled trials seems to be growing, seems to be welcomed by most researchers and seems likely to improve the relevance to users of the questions addressed and the results obtained.

Summary of what the literature shows

There is some evidence that involving trial participants in evaluation studies can support:

- recruitment to a research trial, particularly gaining participation from underrepresented groups such as Black and minority ethnic groups
- understanding about the motivation or barriers for people considering participating in a trial
- knowledge of information needs of participants
- the acceptability of the experience of being involved in a trial, thereby increasing the retention of participants over the course of the trial or in future trials
- understanding about the experience of being assigned to a particular arm of a trial.

What the service user reference group thought was important

- People consenting to participate in research trials should be informed of which parts of the trial they are involved with.
- Participants in research trials should be told at the start they can have access to a final report.

Involvement in secondary research

Service user involvement in secondary research is a growing area of interest and one to which this project can contribute.

Involvement in systematic reviews

The core work of the Cochrane Collaboration is the conduct of systematic reviews dealing with important health care questions. It is the policy of the Collaboration to involve consumers in all stages of the review process: from refining and prioritization of research questions through protocol design, to review conduct and ultimately dissemination of results. Ghersi (2002) looks at approaches to involving consumers in Cochrane reviews in relation to the ten key principles that guide the work of the Cochrane Collaboration: collaboration, building on the enthusiasm of individuals, avoiding duplication, minimising bias, keeping up to date, striving for relevance, promoting access, ensuring quality, continuity, and enabling wide participation.

An in-depth description of the experience of the Cochrane Collaboration's pregnancy and childbirth group is provided by Sakala *et al.* (2001).

Involvement in scoping exercises

Involving service users in scoping exercises, mostly consultation, has been undertaken in research priority setting (see Section 4.1.6 for more detail).

Our strategies for working with members of the service user reference group are shown in Box 6 (Section 4.2.7).

Summary of what the literature shows

- User involvement in secondary research is a growing area of research and there are few examples of user involvement in research reviews or systematic reviews.
- User involvement in scoping exercises links to priority setting for research commissioning.

User-led research initiatives

Academic user researchers

Academic user researchers are service users with formal academic qualifications and research experience. Griffiths *et al.* (2003) describe the contribution that they may make to research and the barriers to their participation. This adds a new perspective to the discussion, which has to date not recognised the particular contributions that these service users can offer. The authors described the advantages of academic consumer researchers working in academic settings as:

- acceptance of the role by other researchers
- skills in research
- access to research funding
- training in disseminating research findings within the scientific community
- potential to influence research funding and research policy
- capacity to influence the research culture
- potential to facilitate the involvement of service users in the research process.

A systematic review of involving users in the delivery and evaluation of mental health services (Simpson and House, 2002) showed that service users can be involved as employees, trainers, or researchers without detrimental effect and that involving users with severe mental disorders in the delivery and evaluation of services is feasible.

These examples are from mental health research. The review did not identify any papers about the experiences of academic service users in nursing, midwifery or health visiting research.

User-controlled research

There is a growing interest in user-controlled research as distinct from user involvement in research (Beresford, 2002). Beresford (2004) traces the origins of user controlled research back to 1962 when people with disabilities aimed to use research evidence to overcome oppressive regimes and discrimination in a home for disabled people (Miller and Gwynne, 1972). Although the report of this research, *A Life Apart*, has been perceived by many to have added to the oppressive practices that the people in the home sought to overcome, it led to disabled people developing their own approach to research that was committed to the equalisation of research relationships, the empowerment of service users and broader social change (Mercer, 2002).

User/survivor research that has subsequently been developed by mental health service users has grown from this disabled people's movement. Beresford (2004) argues that the essentially partisan and political nature of user controlled research continues to be seen by many mainstream researchers as a weakness that disqualifies it from being useful as a rigorous route to the provision of reliable knowledge. What distinguishes user-controlled research is its emphasis on experiential knowledge, that is, users control the research because they have direct experience of the issues under study. However, traditional views of research value 'objectivity' and 'neutrality' and knowledge claims generated within these value structures have always been accorded higher status than experience.

While mainstream interest in user involvement in research emphasises feeding user knowledge and experience into existing research structures and paradigms, service users and their organisations emphasise the transformation of research philosophy, production, social relations and objectives (Beresford, 2002).

In nursing, midwifery and health visiting research, user-controlled research is not easily visible in the literature.

Summary of what the literature shows

- There is very little evidence about the formal employment of user researchers within research organisations. Some examples of this type of involvement are available in the mental health literature.
- There is growing interest in user-controlled research as distinct from researcher-led research.

4.3.6 Improving life chances and opportunities for service users

Unanticipated benefits of involvement for service users

The literature provides convincing accounts of the benefits for service users of being involved in research projects or activities. The real life example below (R6) explains the personal benefits for one coresearcher involved in a project about post-natal depression). In the majority of accounts these benefits were not an explicit objective of the research but are used retrospectively to show the impact that involvement had for those service users involved. This shows a belief that improving opportunities or life chances for those involved is a positive outcome of user involvement in research. Because these benefits are unpredictable they are difficult to perceive at the outset.

The therapeutic benefits of involvement for patients and their families have been identified in palliative care and patients near the end of life (see section 4.2.5).

Although not described in the nursing research literature, several authors in other fields have raised the possibility of negative effects of involvement on users.

Real life example: R6

Personal benefits of involvement for co-researchers in a project about post-natal depression in South Asian women

Women [have gained] knowledge, research skills, confidence and a lot of them have gone on to do other things: advocacy work in a GP practice; developing a women and health group for the Asian community that is now very active; and getting involved in a stroke project.

Real life example: R1

Impact of involvement for service user researcher involved in a collaborative research project

The service user felt empowered – she talks about her work, really felt a part of the team and is proud of working for the Royal College of Nursing and doing work she feels strongly about. There have been enormous spin-offs for her, for example she is doing more work at the local trust, representing service user involvement.

Empowerment as an explicit aim of research

In some research empowerment is defined as an explicit aim of the research. For example, the emancipatory and user-controlled research developed by the disabled peoples and service users' movements and their researchers, identifies empowerment as a major goal for research (Beresford, 2005).

Barnes and Walker (1996) argue that user involvement in research has the potential to empower service users, for example:

- Mutual regard and respect is fostered between service users and professionals. Professional team working is improved. Cultures of co-operation and partnership are developed.
- Disempowered groups are enabled to participate and contribute to and gain more from society. Feedback helps service users to understand the value of their contribution.
- Involvement and feedback mean service users have a better understanding of health services or research.
- Service users have a better understanding of their disempowered status.

Barriers to empowering service users in research have recently been described by Hanley (2005) as including:

- unequal relationships between the researcher and the research participants
- limitations of the skills and knowledge of researchers
- tensions for academic researchers in meeting academic targets and involving service users
- having little influence in deciding which research is funded.

Summary of what the literature shows

- Researchers and service users have reported benefits for service users involved in research projects.
- Empowerment has been described as a goal and outcome of service user involvement in research, however, there are difficulties of interpreting what is meant by this term.

4.3.7 Influencing ongoing iterative change in nursing, midwifery and health visiting research

Making links between practice and policy

Tilley *et al.* (1999b) writes about the small stories of nurses' work and patients' or users' experiences using the work of community psychiatric nurses as an example of involving people with enduring mental health disorders. The authors say that these stories are ignored or under-valued in the literature and it is the responsibility of researchers to relate the small stories of practice and the big story of policy. Section 4.1.5 has more detail on changes in research approaches.

Generalisability - shared learning

The research principle of generalisability is sometimes applied to user involvement in research. In much the same way that qualitative research data are not gathered with the intent to generalise to all populations (Hildebrandt, 1999), service user involvement should not be perceived as an intervention that can be evaluated and generalised to other research studies. The exception to this statement is research that has been designed to specifically evaluate the outcomes of service user involvement for the research process. A good example of this is the London Primary Care Studies Programme (Barnard *et al.*, 2005). The programme specifically set out to evaluate the involvement of service users in research. Leaders of 11 different projects were regularly asked to feedback about progress with involvement activities.

Service users conveying their experience of research participation

Research that has sought to understand service users' experiences of participation in research include: clinical trials in cancer care (Donovan *et al.*, 2002), a research trial for angina management (Dougherty *et al.*, 1999), the experience of research participation for family caregivers of palliative care cancer patients (Hudson, 2003) and experience in community mental health research projects (for example Reeve *et al.*, 2002; Ramon, 2000).

Providing perspectives of the experience of service user involvement

Service users providing their reflections on the experience of service user involvement in research is a much more recent phenomena. In a report by Faulkner (2004), service users and researchers reflected on the process of being involved in a project commissioned by INVOLVE to scope the provision of training for user involvement in health and social care research in the UK (known as 'TRUE'). Themes identified included:

- project structure and resources for user involvement
- practical and emotional support
- relationships and roles
- power and inequalities.

A key recommendation was that greater flexibility should be built in to research that involves users, in relation to the need for flexible timescales and the provision of additional project support.

4.4 The capacity of researchers and research organisations to involve service users

The fourth part of the findings is concerned with the theme of capacity. This includes the capacity of different types of organisations to involve service users in research and sustain effective involvement. Findings about the skills and training of individual researchers to facilitate user involvement activities are described. The specific areas covered are:

• the role and influence of research organisations

- new ways of working for researchers in nursing, midwifery and health visiting research
- researcher skills and training

4.4.1 The role and influence of research organisations

The process of developing partnerships in research takes place against a background of academic research traditions and norms, which can present obstacles to collaboration (Reed et al., 2004). Researchers using participatory methods have found that the values and practices of mainstream academic research often conflict with those of research emphasising participation of communities under study, leading to a variety of challenges (Gray et al., 2000). These challenges are also described by Liberty et al. (1999) who compare the relationship between researchers and subjects in traditional rehabilitation evaluation and relationships between researchers and clientconsumers in newer collaborative methodologies. Shared power and non-hierarchical authority between client-consumers and researchers, is described as an alternative model for experimental and evaluative research. Liberty et al. are of the view that collaborative research can include quantitative and qualitative approaches; maintain the traditional scientific perspectives of objectivity, reliability and replicability; and improve participation rates, continuity of involvement for longitudinal studies and utilisation of research methods into practice.

Professional power in the caring professions (Hugman, 1994) is also a feature of research cultures. Challenges facing nurse, midwife or health visitor researchers are that they frequently need to combine their research role with their clinical roles and this duality can create the potential for ambiguity and conflict (Coghlan and Casey, 2001). Researchers with clinical roles need to manage the political dynamics of the employing organisation and the objectives of the research. Understanding of an organisation and an ability to manage organisational politics play an important part in the process of framing and selecting participative projects. Engaging individuals, teams, departmental heads and organisational leaders in processes of learning and change are important steps (Coghlan and Casey, 2001). When public health research is initiated by researchers (rather than by community members themselves), researchers need to be more aware of the processes of negotiation, mutuality, and respect (Oda et al., 1994).

Real life example: R10

A user researcher reflects on what has worked well in relation to achieving good outcomes for user involvement in research

The other thing is the capacity building... the department is concerned with building capacity amongst users. Because the time's ripe for user involvement, there are many opportunities around. But you're not going to be able to make the most of them if you haven't got the capacity to match them. So the research training skills courses for local users and registering researchers like me for PhDs I think is really important.

What the service user reference group thought was important

• There needs to be better understanding of power and relationships. Some form of guidance might be helpful for negotiating boundaries of responsibility and expectations in user involvement projects.

Summary of what the literature shows

- The process of developing partnerships in research takes place against a background of research traditions and norms which can present obstacles to collaboration.
- Professional power in the caring professions is also a feature of research cultures.
- Nurse, midwife and health visitor researchers frequently need to combine their research role with their clinical roles and this duality can create the potential for ambiguity and conflict.
- When public health research is initiated by researchers (rather than by community members themselves), researchers need to be even more aware of the processes of negotiation, mutuality, and respect.

4.4.2 New ways of working for researchers in nursing, midwifery and health visiting research

Resistance to user involvement might be grounded in the fear that such involvement will increase user expectations, cause marginalisation from peers (Beattie *et al.*, 1996) and add to work pressures (Poulton, 1999). Consultation with researchers shows that it can be challenging for clinical staff to overcome patient/practitioner relationships in collaborative research projects, for example see the real life example (R9) below.

Although participatory approaches to research have been heralded as ways to address issues of research relevance, community involvement and liberation, this type of research requires leadership to facilitate community participation (Lindsey and McGuinness, 1998). Gillbert (2004) argues that building capacity in participatory research is a precondition to its further development. Chalmers and Bramadat's (1996) work on the historical origins of community development shows that despite the importance currently given to community development as an increasingly significant role for community nurses, there is little analysis of the role in the nursing literature. Four models of community development are synthesised from literature in sociology, social psychology, education and political science. These include economic development models, education models both formal and informal, confrontational models and empowerment models (see Section 4.2.7 details findings on the establishment of working relationships).

Summary of what the literature shows

- The literature reveals that in service development some professionals fear that user involvement will increase user expectations and work pressures. This might mean that they are sceptical about user involvement in research.
- Participatory approaches are useful for involving service users in research but this type of work with communities requires strong research skills and leadership. This has implications for research/practitioner roles and capacity in nursing, midwifery and health visiting research.

Real life example: R9

Managing 'professional/client' and research partner relationships

The professionals found it very difficult to be working alongside a patient who's a colleague. Because however collaborative your clinical care is, and particularly in chronic illness where patients have to self manage, it's very different to a relationship where you go to a conference with someone and you go out for a meal afterwards and you go to a project meeting and you challenge what the clinician's saying who normally looks after you.

The patients said they'd found it much easier once they'd decided to compartmentalise things, they found it OK. So patients have got used to saying I'm a patient when I'm in clinic and I'm a colleague when I'm in the department. And some of them tend to call the doctor by the doctor's name in clinic but by their first name when they're in a project meeting.

I, for example, spoke to one of the patients in a project meeting, I knew she'd been unwell, she'd phoned the helpline. And I said to her 'How are you feeling? Are things any better, did the steroid injections help?' And she just looked at me and she said 'This is a project meeting I'm here as a colleague, you can talk about that tomorrow when I'm in as a patient'. You know, good for her. I was on automatic pilot you see, I'm a nurse, she's my patient, she wasn't well. So yes it hasn't been easy. It's great and we've all made good friendships from it but it hasn't always been comfortable.

4.4.3 Researcher skills and training

Nurses, midwives and health visitors learning about research and user involvement

Fox's survey of teaching organisations in the UK found that preregistration nursing and midwifery curricula include some aspects relevant to principles of user involvement for example communication and ethics (Fox, 2003). Other aspects, such as advocacy, quality assurance, and lay health beliefs, are viewed to be part of the professional role. No curriculum transparently addressed consumerism in a central and focused way, although midwifery (and to some extent mental health, learning disabilities and child branches) gave more overt attention to consumerism than adult branches. Users' views about the knowledge, skills and attributes that mental health nurses should demonstrate, have been explored to inform curriculum design (Forrest *et al.*, 2000). The issue of 'conflict' between users' views of a 'good' mental health nurse and professional views is an issue that requires further attention.

It is more common for educators to ask service users with particular conditions or health experiences to make a contribution to students' learning as a way of informing their attitudes and knowledge. There is also growing interest in user involvement in interprofessional education (Barnes et al., 2000). The nature of service users' involvement in the classroom and the quality of learning by students through this approach is increasingly being positively evaluated by educators, students and service users. Bennett and Baikie (2003) describe a model of client/nurse educator collaboration in a mental health course with undergraduate nursing students. Their paper identifies positive features of collaboration and analyses some of the challenges/issues for the nurse educator. In addition, it outlines helpful aspects of the collaborative process for both nurse educator and client, in particular, its impact on the client's personal well-being. User involvement in the evaluation of educational interventions that involve service users appears to be important to developing education models of collaboration that are beneficial for all partners in the learning process (Felton and Stickley, 2004).

In nurse education teaching about research is most often done near to the end of the student's educational experience, or through research methods courses undertaken at a post-graduate level. Many student and qualified nurses produce a small research project, and this often concentrates on achieving measurable outcomes (Taylor, 1993). Taylor seeks to address issues of personal and professional development that may occur during the research process by examining her own learning whilst undertaking such a project. Taylor claims that increased self-awareness in the research process can enhance nursing professionalism. Community-based research projects have been used as a method of teaching nursing concepts and skills to nursing students at the beginning of their course to develop skills for working in partnership with individuals, communities and other professionals (Kelley, 1995).

Meyer *et al.* (2003) explore the advantages and challenges of being trained for both researcher and health educator roles for undertaking health promotion activities. They found that combining the roles is not an easy task as it requires many skills. For example, as a researcher switching between accurately noting people's answers during

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interviews and providing people with correct health information. However, research field logs and personal reflection served to document practice and it was possible to reformulate issues into service needs.

In the US, Shaywitz *et al.* (2000) have identified a need to develop broader, more integrative approaches to understanding how biological and physiological knowledge functions in the context of the whole person and the clinical setting. The authors present and develop the rationale for a set of underlying principles for patient-oriented research that can be used to guide training. They describe a pilot program - the Harvard initiative in patient-associated science: training, education, understanding and research (known as 'PASTEUR') - that they hope will help train patient-oriented investigators and support the evolution of patient-oriented research into a fully realised academic discipline. There were no accounts in the literature of any educational research programmes of this nature in the UK. See Section 4.2.7 for a discussion of the issues of education for service users.

What the service user reference group thought was important

- Support for service users and their organisations to be involved in research and educating service users and researchers to interact with people and organisations are part of the same issue. To be successful training needs to be up-to-date, user-led and the importance of it needs to be emphasised.
- Service users and professionals should be given time to 'bounce' ideas off each other.

Summary of what the literature shows

- Some aspects of nurse/midwife education cover ideas about consumerism.
- Service users might be involved in professional education to inform students' attitudes and knowledge of different patient groups.
- Nurses and midwives receive some training about research and this can be used as a method of developing skills to work in partnership with individuals, communities and other professionals.
- There are advantages and challenges of being trained for both researcher and health care roles.

Chapter 5 Discussion

- 5.1 Strengths and limitations of the approach
- 5.2 Reflections on the approach to user involvement in the project
- 5.3 Discussion of the evidence

5.1 Strengths and limitations of the approach

From the outset, we aimed to take a flexible approach to the topic and to refine the search and steer the review towards answering questions uncovered during the process in the light of new information gained. This flexibility and responsiveness was a strength of the approach as it enabled us to identify and focus on complex and diverse questions that were central to the topic of the review.

We aimed to search widely across different literature sources, but to focus thinking on nursing, midwifery and health visiting research. This was beneficial to locating the issues for nursing, midwifery and health visiting in broader theories of participation, consumerism and empowerment. However, there were other avenues of contextual or background information that we did not have time to pursue, for example the links between user involvement and community development. Undertaking a broad search has enabled us to bring good ideas and ways forward into the domain of nursing, midwifery and health visiting research. We hope that this will connect future work with debates and evidence retrieved from other areas of health and social care research. By looking at the issues in a particular field of research, specifically nursing, midwifery and health visiting, there is a danger of reinforcing existing uncertainties about service user involvement in research, when more general understandings of involvement have not been well established. In parts of this review it has been necessary to take a broader view of the issues (for example looking at outcomes of user involvement) and in others it has been more appropriate to focus on the issues for nursing, midwifery and health visiting research (for example the best ways of involving service users). Our decision to draw on the literature from, and beyond, nursing, midwifery and research means it is likely that the findings can inform service user involvement in a range of health and social research.

We have used systematic and reproducible methods for the electronic searches of the literature. However, this was only one part of the project and other parts were less structured and more organic. These parts are not reproducible because they relate to the experiences and knowledge of people who were involved and the timing of the project. A strength of the methods was the use of information technology and consultation methods to link and network with others. This enabled us to identify ongoing work in the topic area and publicise the study nationally. We had some contact from researchers working outside of the UK (in response to the electronic questionnaire) and we did not limit searches of the literature to UK-based authors. However, the findings are set within westernised views of society and health care and prevailing research paradigms.

We aimed to involve service users in the process of the review to:

- inform the scope
- support the identification of appropriate literature and ongoing work
- reflect on the evidence
- advise on outputs/dissemination.

Reflections of the project team and members of the service user reference group shown in the next part of the discussion highlight where this process worked well and some of the reasons for problems or difficulties. Involving service users required additional time and resources but also challenged us to work in new ways and develop new skills of partnership and communication. The service user reference group and wider research team played a key role in providing critical peer review, in relating findings to policy and developing the debates about user involvement in nursing, midwifery and health visiting research.

Given further resources and time, it may have been beneficial to have also set up a practice research group as this might have helped balance some of the issues around involvement. Much of the user involvement literature included in the review was not explicitly about nursing, midwifery or health visiting research and a group of this nature may have been useful in further bringing these perspectives into play.

To make sense of the information from the various sources, we identified data relating to different themes, guided by the review framework. Using a broadly structured approach to extract information (making use of a review tool) from a wide range of sources, including published evidence and primary data for example from telephone interviews with researchers. This was beneficial for verifying the issues across different sources. Handling such a vast amount of data was supported by referencing, coding and sorting the data using reference management software and literature tables in Microsoft Word and by maintaining alphabetised hard copies of journal articles and reports/policy documents.

A limitation of the analysis was that it was not possible to give all documents equal time for scrutiny. Priority of attention was awarded to: the most relevant (those making explicit reference to user involvement in research, and those relating to the UK); the most

recently published documents; and documents cited most frequently by other authors.

We have provided a descriptive account of the type and source of the evidence in terms of opinion, policy, research based, or systematic review findings, rather than weighting the evidence. Weighting would be difficult because of the small amount of research-based findings in the topic area. We considered the process of drawing conclusions about the findings to involve summarising what is known about the subject and identifying where the evidence is lacking.

It was difficult to identify accounts of outcomes (quality or impact) of user involvement in nursing, midwifery or health visiting research, because these were often located within articles or papers with differing style and content; appearing often as a methodological aside or as a secondary consideration to the main study questions. Unclear concepts and definitions mean that relevant user involvement activities may not have recognised or reported by those who have undertaken them. The key terms of our search centred around the language of participation, involvement and consumerism. Some authors might not have recognised their work as relating to these concepts, or their work may pre-date the contemporary language of user involvement.

Nursing, midwifery and health visiting research is often undertaken using qualitative research methods and participative approaches. The findings of such studies tend to be descriptive and arguably more complex to communicate in research publications than quantitative findings, which have well-established formats for reporting. Our searches have found that information about user involvement in nursing, midwifery and health visiting research is hidden within the literature (see the first part of the discussion for details), therefore it is difficult to gain a full picture. This is a methodological issue for the topic that has partially been overcome in this project by undertaking primary data collection with researchers working in the area.

In writing this report we have faced a difficult balance between creating a document that provides useful information for nurses, midwives and health visitors embarking on user involvement in research and drawing conclusions to inform the conceptual development of the topic.

We have faced problems with language, not wanting the report to be inaccessible to those who are not fluent in the discourses of policy or research. Yet, we are fully aware that not using technical language is a risky business, as it can be interpreted as not having a full grasp of the issues at hand or being out of line with established ways of reporting research.

We have been committed to documenting our experiences and learning about the process of undertaking the review in collaboration with service users. Reflexivity became integral to the project, it helped us to work with the service user reference group and to work with one another as a project team.

5.2 Reflections on the approach to user involvement in the project

5.2.1 Project team members' reflections on the process of involvement

After each meeting with the service user reference group, the project team met to discuss how the meeting had gone. The main points of the discussions and quotes from personal reflection forms are summarised here.

 Members of the team emphasised the positive feeling of the meetings and the enthusiasm and experience of the individual service user representatives. The value of service users' contributions was often described. The team felt that group members used personal stories to develop arguments that were very powerful and that the issues they raised and debated reflected those in the literature.

I felt everyone was very enthusiastic about the questions and issues that this topic provokes.

(Member of the project team)

 Team members felt there was a conflict between welcoming and engaging people as 'partners' and fulfilling practical elements of engagement. Concerns focused on the inappropriate content and language of the consent form in relation to its use with patients and the public as collaborators or advisors in research projects.

The formalities of the research process, for example registering and consenting people, created an immediate division between the project team and those we were asking to be equal partners in the project ... It was unpleasant to focus on getting consent and financial details from participants rather then being able to spend this time welcoming people and making them feel their attendance was valued.

(Member of the project team)

• Members of the team held positive views about working with the service user reference group and what they might contribute to the project.

A 'sophisticated' group of users, which can provide high level of input – need some challenging work for them so as not to waste their time.

(Member of the project team)

 Although there were positive feelings about the diversity of the service user reference group in terms of their experience, some team members questioned the difference between representation and direct representation of service users themselves.

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I think it is very important to distinguish between people there as service users and those there from organisations that work with service users who do not identify as service users themselves ... there are big issues in taking what non-service users [i.e. representatives] say as indicative of what service users say.

(Member of the project team)

Some members of the project team expressed concern about how the work of the service user reference group could be best used in the review.

I think there is a lot of work to do to make what we have found today 'fit' with our project objectives. I am unsure what to do with the important issues that have been raised that don't sit within the limit of this review.

What happens next and how will the findings be fed back and used in a positive way? Uncertainty about roles and the future – maybe also uncertainty about how the day was going to progress.

(Members of the project team)

 Having defined objectives for the meetings and preparing approaches for different sections of the day were considered beneficial to achieving a lot in a short period of time.

The planning and team briefings was time well spent in that we were all clear what we were trying to do... Although there was a lot to get through – we managed it without feeling that things were rushed particularly.

(Member of the project team)

• The team felt that group work discussions about the review framework worked well and engaged everyone. Members of the team noted a difference in facilitation styles and suggested it was better when the group rather than the facilitator fed back about the discussion as people were then more able to explain points they had made themselves.

Discussions about the review framework produced some new ideas/perspectives and this was a really helpful process for gaining a view of the relative importance of issues/topics from a service user perspective. More time for this discussion would have been good.

(Member of the project team)

• Members of the team were concerned about the use of accessible language, particularly in relation to the review framework.

The project team should be careful about the language, acronyms and terms that are used for example not using 'nursing' as shorthand for nursing and midwifery.

(Member of the project team)

5.2.2 Members of the service user reference group's reflections on the process of involvement

Following each meeting members of the service user reference group were provided with evaluation forms to feedback their views to the project team. The following bullet points summarise some of the reflections and these are illustrated by quotes from the group.

 Some members of the group would have liked more information about the project before coming to the first meeting. Other members of the group felt it was appropriate to 'tackle the issues' at the first meeting.

The information was fine, given that the organisers are still participating in a process of deciding how to tackle the 'issue' - whatever that is!

(Member of the service user reference group)

 Not having enough time to discuss complex issues and understand the topic was a commonly expressed concern. One person suggested that this might mean it would be necessary for the team to take a more directive approach.

Sessions were interesting and enjoyable. As one would expect there wasn't enough time to cover issues in detail. I do accept the limitations of a one-day session. Perhaps the idea of being a little more directive might be considered.

(Member of service user reference group)

• Members said they preferred to work in small, facilitated groups to focus on discrete aspects of the topic and this was seen as a way of enabling everyone to participate.

..it would be helpful if more small group working could be facilitated at future meetings. It might also be useful to have different groups looking at different but related issues. This would encourage more participation.

(Member of service user reference group)

 Members were positive about receiving clear and practical information about their involvement and their expenses being paid efficiently.

Communication has been excellent with clear concise notes with an interesting layout. Clear instructions and maps to venues. Expenses paid quickly and accurately.

(Member of service user reference group)

 Some members who joined the group after the first meeting said that they found it hard to grasp the aims and objectives of the project.

I found it difficult to catch up with what the project was specifically doing. It seems to be vast if it is a systematic review of consumer involvement in nursing and midwifery research... My sense is that this project is too big for a one-year study because of the likely difficulty of accessing the information and then searching it. A difficult topic to study.

(Member of the service user reference group)

Some members could not see what the project had to do with care giving.

I can't actually see what it has got to do with nurses. Little was said about how nurses treat patients. *I* imagined this was what it was about.

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Lots of reasons for users of the health [service] to be researchers but can't imagine what will be used.

Member of the service user reference group)

In relation to the review framework, members felt that this was helpful but some were not clear of its purpose in the project or the final report.

An extremely needed framework - difficult to prioritise. Some sections had similar elements that could be closed together. Literature references will be really helpful to the framework.

(Member of the service user reference group)

This wasn't as clear as it might have been. I had difficulty putting this into context with the format of the final report.

(Member of the service user reference group)

5.3 Discussion of the evidence

In the second part of the discussion we describe the strength of the evidence to answer the key questions of the review. These are set out in Section 1.0. They are:

- 1. How can user involvement in nursing, midwifery and health visiting research be conceptualised?
- 2. How has nursing, midwifery and health visiting research contributed to building the theoretical and methodological development of user involvement in research?
- 3. Should all nursing, midwifery and health visiting research involve service users?
- 4. What are the most effective ways of involving service users in the broad ranging contexts of nursing, midwifery and health visiting research?

5.3.1 How can user involvement in nursing, midwifery and health visiting research be conceptualised?

This review has explored the meaning and conceptual origins of user involvement in research, revealing its complex and multi-dimensional nature. We have set out the cultural, political, professional and userled debates that shape the discourse of user involvement. In nursing, midwifery and health visiting research we have found user involvement to be aspirational rather than evidence based.

We have undertaken work to conceptualise 'nursing, midwifery and health visiting research' and to define 'service user involvement' within this. There are inherent difficulties with trying to define such broad ranging activities. There is a danger of over simplifying the range of professional groups, clinical activities, research methods, client groups etc. that these concepts relate to.

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Although there are existing frameworks for user involvement that are cited in the literature, for example Arnstein (1969) and Hickey and Kipping (1998), the review did not find any examples of nursing, midwifery or health visiting research that has built on these models or tested them empirically. This review seeks to address that gap, by developing a framework which was drawn from the literature and informed by the service users involved in this project. This framework provides a conceptualisation of the main domains of user involvement in nursing, midwifery and health visiting research: the context and drivers of user involvement; the best ways of involving service users; the outcomes; and the capacity requirements to make it happen.

Inevitably there are risks in setting out a framework in this way, because of the difficulty of showing the relationships between the four domains. For example if the outcomes of service user involvement in research are to be considered in a meaningful way, they need to be perceived in relation to the multiple purposes of user involvement in research. We have shown that accounts of the outcomes of user involvement are not always related to the purpose or rationale of user involvement in research. Outcomes are often unexpected or unpredictable.

This review goes some way towards establishing appropriate criteria for assessing and evaluating user involvement, by identifying the range of outcomes in different contexts. However, the impact of views and opinions of service users cannot simply be evaluated in the same way as a method or intervention because in each situation these will be different. Specifically attributing outcomes to the involvement of service users is a difficult and problematic task. We have not identified any established factors that can be used to formally evaluate outcomes of user involvement on the research process.

The review shows that the relationship between user involvement in research and research methods is central to different understandings about user involvement, yet this relationship is conceptually ill-defined and a cause of uncertainty. User involvement has been perceived as an intervention to be tested or evaluated, or as part of the methods of a research study. There are problems with linking user involvement and research methods in this way as this emphasises a focus on research values, such as methodological rigour and generalisability. When these values are applied to user involvement activities they can establish unrealistic and inappropriate goals for involvement. Intellectual thinking needs to be applied to developing measures that are appropriate for determining quality outcomes in user involvement in research. The review shows that some progress has been made towards establishing quality criteria for the processes of user involvement, such as Telford *et al.* (2004).

This is not to say that user involvement in research should not, or does not, draw on established research methods. The literature shows that where researchers have made use of research methods, particularly participative approaches, this has been beneficial for engaging service users and establishing working relationships.

Synthesis of the literature shows that user involvement can be perceived as happening in the design (planning or decision-making), undertaking (carrying out research activities) or in the evaluation of research. These are not necessarily sequential activities and different groups of service users might be involved in one or more of these activities in any research project, or not at all. Nor are these domains independent of one another, the relationship is inter-related. We have simplified it here to emphasise the multiple domains of user involvement in the research process. The domains indicated should not be viewed as discrete or unconnected. The figure does not represent user involvement in the processes of identifying, prioritising or commissioning research (but this is as a key stage for research design).

The findings show that service users are sometimes asked to evaluate the experience of being involved, which could be classified as 'user involvement in the evaluation of user involvement in research'. If service users were involved in the design of the evaluation this could be described as 'user involvement in the design of an evaluation of user involvement in research'. These subtle differences at a conceptual level represent differences of a greater magnitude in relationships between service users and researchers in actual projects.

Perceiving user involvement in this way can overcome problems about 'who is in control', that is, whether research is researcher-led or userled, or a partnership. These are important power issues, which have not been adequately conceptualised in terms of the multiple domains of user involvement in the research process.

The conceptualisation is also accommodating of variance in understandings about the purpose and outcomes (quality and impact) of user involvement. It may offer a model for investigating these different objectives. It may also mark a way forward for exploring opportunities for involvement that lie between or outside of these domains.



Figure 8 Conceptualisation of the different stages in the research process at which users may be involved

5.3.2 How has nursing, midwifery and health visiting research contributed to building the theoretical and methodological development of user involvement in research?

The literature shows that nursing, midwifery and health visiting research has contributed to the evidence base for patient communication and patient decision-making in clinical care and to the development of patient-centred services. There are overlaps between research about nursing, midwifery and health visiting; and research about social care, health issues and health services. User involvement is a new angle on longstanding questions within the nursing literature about the quality, design and delivery of professional working and health systems. That said, nursing, midwifery and health visiting research is not well-known for its contribution to the methodological or theoretical development of service user involvement. There is a danger of confusing or conflating debates about user involvement in service improvement and user involvement in research. User involvement in nursing, midwifery and health visiting research has its own issues to be resolved in order that its full potential can be realised.

5.3.3 Should all nursing, midwifery and health visiting research involve service users?

Like apple pie, user involvement is thought to be a good thing, but there is limited evidence for this and there should be more work to explore the meaning and importance of user involvement in research in different circumstances. For example, to establish when and in what context service users should be involved in decision-making (direct involvement) and when it is more appropriate for their view to be represented by others (representation). The main reasons for involving service users in nursing, midwifery and health visiting research have been shown to relate to improving the relevance of research, the quality of the research process and benefiting those service users involved.

The relevance of research

Discourses in the literature and policy argue that user involvement can improve the relevance and appropriateness of research. Most people would agree that this is a positive contribution. However, there are inherent difficulties with using relevance and appropriateness as goals for service user involvement in research. These are subjective terms that link to concepts of need, which is itself a complex concept. Exactly whose perception of relevance and appropriateness should be taken into consideration further complicates matters: the public, service providers and policymakers will all hold different perspectives on what these terms mean. 'Improving the appropriateness and relevance of research' could be to the benefit of an individual patient, a service organisation, or more broadly for the benefit of society. It is unlikely that this will mean involving service users for the same reasons or achieve the same outcomes. A good example of this is research into the role of nurses in providing childhood immunisation. Involving children and parents in research about immunisation could arguably lead to the development of more appropriate vaccination procedures to eradicate diseases in society, yet the procedures developed might not necessarily be the most appropriate for an individual child.

Research commissioners and the research community generally view members of service organisations (managers and the executive rather than NHS staff) or policy makers to be the 'users of research'. Attempts to close the research-practice gap have focused on making research more relevant and timely for these groups. Service users have not necessarily been seen as being part of this relationship.

There is no evidence in the literature to show whether service users want nursing, midwifery and health visiting research to be more appropriate or relevant for them as individuals, to health systems or to society as a whole. Judgements about the outcomes of service user involvement for the relevance and appropriateness of research are difficult to make because we cannot compare the outcomes of a chosen course of action to another that was not taken.

Quality of the research process

There is stronger evidence that user involvement can support the undertaking of research, for example in overcoming barriers to recruitment or in validating the process of interpretation of research findings. This is the context in which service users have tended to be involved in pharmaceutical or clinical research trials. However, these activities may offer limited power to service users in decision-making processes about the questions the research seeks to address or the methods that are used.

There are subtle, and often indeterminable, differences between service users being involved in the process of research and their views and experiences being used as sources of information in the research. One such area is the distinction between undertaking consultations with service users to inform a research project and service users being involved in decision-making about a research project. In the former relationship the researcher interprets (and possibly acts upon) the views and opinions of service users, in the latter service users have a responsibility for decision-making. The literature identifies 'clarifying responsibilities' as an important area for attention but this is a clear, yet significant, issue that warrants further exploration.

Benefits for service users involved

The literature shows that being involved in the process of research can have benefits for service users. The term empowerment is frequently used and encompasses ideas about the benefits for service users of being involved and the power within relationships and processes in the research. The use of empowerment as a measure of outcome of user involvement might be oversimplifying the processes involved. For example, some aspects of being involved in research might feel empowering to the service user but other aspects might feel disempowering. The difficulty with statements about empowerment is that different people interpret the concept in different ways. If a person says they *felt* empowered, this is a perception; it does not necessarily mean the person actually gained or benefited from having more power in a particular situation. Other people argue that feeling empowered is more significant than having more power (for example in decision-making). In the literature, feelings of disempowerment are less likely to be described or attributed to a research project, though challenges or barriers of the approach are often explained. It is also questionable as to whether a person can judge whether another person has been empowered. If a service user describes feeling empowered as a result of their involvement, this is likely to be an indication of a positive underlying process that warrants further explanation.
With regard to the empowerment of service users through the process of research, questions remain about:

- whether awarding service users more power in decision-making leads to service users feeling more empowered
- whether awarding power can ever be empowering if power can be withdrawn
- what professional skills and knowledge contribute to service users feeling empowered, and what skills and knowledge contribute to service users being awarded more power
- whether conflicts between involving users in research and meeting academic targets are perceived or actual barriers to service users feeling empowered
- whether service users feel empowered when they have control or decision-making power or whether service users feel empowered when their opinions are valued and used in making a decision.

Power of decisions to involve service users

At the present time decisions about whether service users should be involved in research projects are generally initiated prior to, or at the stage of, research funding or commissioning. The literature reveals a fragmented story about the influence of service users in commissioning and setting the research agenda in nursing, midwifery and health visiting research. These studies suggest that a range of approaches have been used. There has been little research that has attempted to link influence on commissioning to quality of outputs in nursing, midwifery or health visiting research.

Some commissioners may not perceive user involvement to have benefits for research because of limited access to evidence about the benefits of involvement in particular research contexts. Commissioners might not be in an informed position to recommend or challenge proposed objectives or approaches to involvement in particular research proposals.

Although funding applications generally require information about how service users will be involved in the research, scrutinising these decisions more closely might encourage applicants to question their objectives for involving service users and how they could evaluate whether these are met. It will also give researchers the opportunity to argue that the involvement of service users might not be an objective of the research. These findings support previous recommendations for procedures and mechanisms to be put in place by funders and sponsors of research to ensure that commitment to user involvement is turned into a reality (Baxter *et al.*, 2001). However, it is problematic for research commissioners to require applicants to provide detail about rationale, objectives and approach to user involvement, or to describe how involvement will be evaluated, before these elements are negotiated with service users themselves during the course of the research.

It is not currently within the role of research ethics committees to scrutinise the moral implications for involving, or not involving, service users in the research, their remit is to look at the ethical issues of the research (generally for the protection or safety of research participants). The guidance available to ethics committees is the same as that provided to researchers – namely the *Research Governance Framework for Health and Social Care* (Department of Health, 2001b). It would be very difficult for an ethics committee to require that a particular research study involved service users on ethical grounds alone.

Another issue is follow up from research commissioners to find out whether, how and to what effect service users actually were involved in the research. However, it is important to draw attention to concerns about the implications of the regulation of user involvement in health services research. As Beresford (2002) points out there is a difference between following up research and regulation.

5.3.4 What are the most effective ways of involving service users in the wide-ranging contexts of nursing, midwifery and health visiting research?

A continuous theme in our analysis of the literature is that user involvement is complex and multi-faceted. It is about relationships and is therefore dynamic and changing. It is our view that compartmentalising user involvement carries risks of oversimplification. No one size fits all. It is for these reasons we are not advocating a single 'how to do it' model. We suggest that a more appropriate way forward is to identify triggers for decision-making to guide nurses, midwives and health visitors in the various stages of user involvement in research – a decision-making aid (see Box 4). This has been informed by the evidence from the literature about context, purpose, methods and possible outcomes of involving service users in research. The decision-making aid was devised in the context of researcher-led involvement and the outcomes for the research process. In time, there is significant potential for this aid to be further developed to encompass decisions about when, why and how service users will be involved.

Box 4 A decision-making aid for user involvement in nursing, midwifery and health visiting research

In the context of researcher-led involvement and outcomes for the research process

- 1 Gain an understanding the context of user involvement in research
- Look at policies for service user involvement in research and how they apply to the research (for example the *Research Governance Framework for Health and Social Care*, Section 11 of the Health and Social Care Act 2001).
- Identify requirements of commissioners/funders for service user involvement.
- Be aware of the range of professional perceptions and issues of user involvement in research.
- Be aware of the range of opinions the public hold about research and user involvement.
- 2 Consider the domains of user involvement in the research project
- a) Could service users be involved in any or all of the following activities:

Design of the research, for example:

- the design of the research questions that the research seeks to address
- the design of the research methods
- designing the purpose (objectives) of user involvement
- designing the process of user involvement, that is, the way that service users will be involved.

Undertaking of the research, for example:

- recruitment
- data collection
- analysis or interpretation of the findings
- creating research outputs
- supporting other service users to be involved in the process of the research.

Evaluation of the research or user involvement, for example:

- evaluating research outcomes
- evaluating the research process
- evaluating the impact of user involvement
- evaluating the quality of the user involvement process.

- b) What might service users bring to each of these activities.
- personal knowledge or experience of health service provision etc.
- personal knowledge or experience of caring
- an understanding of the views of a patient or family member
- · knowledge of groups of people or patient perspectives
- knowledge of community networks or groups targeted by the research.

3 Recognise capacity issues to undertake the work

a) How might you best support service users to make these contributions?

b) What are the challenges for you as a researcher? How can your skills and training support these activities? Try to recognise where further support or guidance might be needed. Use the following areas as a guide:

- recruitment of service users to be involved in the research process
- ensuring quality in the process of involvement (making use of existing guidance for example Telford, 2004)
- enabling diverse groups of service users to be involved
- ethical issues specifically relating to user involvement in the research process
- training and orientation needs of service users
- methods or strategies that enable working relationships to be established.

4 Think ahead to likely outcomes for the research process and evaluation

What types of outputs might be achieved by involving service users in the way you have identified?

5 Planning for dissemination

How might service users support the dissemination of findings? Things to think about include:

- Designing dissemination collaboratively: identifying who the target audiences are, what the key messages might be and how best they can be delivered.
- Planning who will undertake dissemination activities and how service users might want to be involved.
- Discussing issues of ownership of the findings with service users who have been involved in the research.

Chapter 6 Conclusions and suggestions

- 6.1 Conclusions
- 6.2 Future research
- 6.3 Suggestions

This section of the report draws conclusions from the review and makes suggestions for future research, and for the consideration of research commissioners, research support organisations, NHS and academic research organisations, researchers, service users and consumer organisations.

6.1 Conclusions

The evidence in the literature shows that service user involvement in nursing, midwifery or health visiting research has not previously been addressed in a systematic way. The evidence relates to different questions about: the context and drivers of user involvement in research; the methods or process of involving service users; the impact and outcomes of user involvement; and the capacity of individual professionals and research organisations to involve service users in research.

The literature shows that user involvement is a complex notion that relates to concepts of consumerism, partnership and empowerment. Although there are existing frameworks for user involvement in the literature, we did not find any examples of nursing, midwifery or health visiting research that have built on these models or tested them empirically.

The reasons why service users have been involved in research – for example skills, experiences, views, knowledge or opinions – were shown to be as diverse as the opportunities that user involvement offers.

User involvement in research was found to have different domains. In the design of research, involvement might be in the design of the research questions that the research seeks to address; the design of the research methods; in designing the purpose (objectives) of user involvement; or in designing the process of user involvement (the way that service users will be involved). In the undertaking of research, service users have been involved in: recruitment, data collection, analysis or interpretation of the findings, and in creating research outputs. In evaluation of the research or user involvement service users might be involved in: evaluating research outcomes, evaluating the research process, evaluating the impact of user involvement, or evaluating the quality of the user involvement process. The diversity of service users was a strong theme of the literature and researcher consultations, particularly in relation to enabling different groups to be involved. The language of 'user involvement' positions service users as the group who are being asked to participate, they are the group being brought into the world of research. Yet service users may commission, lead, take responsibility, drive, or evaluate research. Growing interest in user-controlled research as distinct from researcher-led involvement is also challenging these notions.

Some work has been undertaken to establish principles for quality in the process of user involvement. To date, principles and indicators of quality are broad and do not relate to different research contexts or approaches. Quality in relation to the diversity of service users, for example differences in ethnicity and physical ability have received little consideration.

There is relatively little published literature on the evidence of outcomes of service user involvement in nursing, midwifery and health visiting research. The benefits of involving service users in research were identified in relation to meeting policy targets, for improving the social integrity of the research, for research design and infrastructure, for the research process, and for improving life chances and opportunities for service users. However, there are difficulties with using any of these outcomes as evaluative measures because they are directly related to the context in which user involvement is undertaken, the purpose of involvement and the different approaches that might be used.

6.2 Future research

The following suggestions for future research are the areas judged to be most pertinent to the future development of service user involvement in nursing, midwifery and health visiting research. The review revealed many other issues that would benefit from future research but it is important to focus development in key areas that are important to researchers and service users alike. These areas have not been adequately addressed by the literature and consequently little guidance or evidence is available at the present time.

Future research should seek to:

- Clarify the rationale for service user involvement by further investigating the benefits for the research processes, the outcomes for social integrity of the research and the opportunities and benefits for service users involved.
- Understand professionals' anxieties about user involvement and explore ways of overcoming these.
- Build the evidence base for the benefits of involving service users in research in relation to different opinions about the goals of user involvement.

- Develop approaches to involvement that recognise service users may have different or opposing views; to better understand potential differences in perspectives of service users and carers.
- Understand the barriers for service users to becoming involved, such as negative perceptions of research or researchers, and the reasons behind the view that researchers are not ready to involve service users.
- Investigate the impact of involvement in relation to new interpretations of research rigour and ethical research practices.
- Promote further understanding of the concepts of 'tokenism' and 'meaningful' involvement from service users' and researchers' perspectives.
- Build links between involvement in health service design and delivery and in the research process by establishing areas of overlap, commonality and potential shared learning.

6.3 Suggestions

The suggestions that follow are draw from the evidence in the literature and the advice of a wide range of researchers and service users that contributed ideas and thinking to this project. It should be noted that these are based on consensus of opinion rather than evidence, where it is lacking in the literature. Because of the wide range of constituencies that user involvement in research relates to, suggestions are made for a wide range of audiences including research commissioners, research support organisations, NHS and academic research organisations, researchers, service users and consumer organisations. Areas of overlap between suggestions for different audiences are intended to support shared goals for the development of service user involvement in research.

6.3.1 Suggestions for research commissioners

Nursing, midwifery and health visiting research are greatly influenced by the priorities and the requirements of commissioners. Issues to do with research priority setting and research commissioning emerged as being central to the review. Commissioning of research is an important area that service users can and are contributing to.

There is some overlap between the suggestions made here and those made for research support organisations and research organisations. This reflects the importance of different stakeholders supporting shared goals for the development of service user involvement in research. This review has included extensive national consultation with service user organisations and researchers working in the topic area. The suggestions for future research that have been made are supported by the views of both service users and researchers.

- 1. Research commissioners should seek to fund exploratory and empirical research in the areas outlined in Section 6.2.
- 2 Although this review did not set out to look at the evidence for involving service users in research commissioning, it became an important part of the findings and evidence was found for the benefits of involvement at a commissioning level. Research commissioners should involve service users and service user organisations as representatives on commissioning panels to ensure that service users' perspectives are taken into account.
- 3 This review found that the questions research seeks to address are often set, before service users are involved in the research. Research commissioners should consider ways to involve service users and service user organisations in identifying and shaping research questions.
- 4 Different researchers have different understandings about the meaning and value of involving service users in research. Research commissioners should guide researchers by asking that they outline their intentions for involvement at proposal stage; including describing the objectives of involvement, who will be involved, how they will be supported and how feedback will be provided. The importance of having clear objectives/reasons for involvement should be emphasised.
- 5 Service user involvement in research needs extra time and resources. Research commissioners should be willing to provide these resources to projects that involve service users. They should ask researchers to specifically outline the costs of involving service users, fees and payments at proposal stage.
- 6 Service users deserve recognition for the time and expertise they bring to the research. Research commissioners should support appropriate payments of service users for their time and expenses (including carer costs). Increasing flexibility of payment options should be a priority, including developing systems to make direct payments to service user organisations.
- 7 Researchers should be encouraged to develop plain English summaries (as well as traditional executive summaries) for dissemination to appropriate voluntary and consumer organisations. Research commissioners should support the production and dissemination of plain English summaries that use at least 14-point size font, clear layouts and plain language. These should be suitable for photocopying and electronic dissemination for example using e-mail or web-based.
- 8 Researchers should feedback to all stakeholders in the research, including service users, by providing accessible written materials that explain the impact that their involvement is having and to outline any results or findings as they emerge. Research commissioners should encourage researchers to feedback (for example using project newsletters) to all stakeholders in the research about the impact of their involvement on the research.

6.3.2 Suggestions for research support organisations and networks

The following suggestions are intended for research support organisations and networks. We are including research ethics committees and research and development departments with a responsibility for research governance in this grouping. The project revealed that service user involvement raises new ethical issues for research. Research ethics committees have an important role to play in supporting researchers to develop ethical practices for involving service users in research.

It is suggested that research organisations develop policies for involving service users in research and guidance for staff about providing information, feedback and plain English summaries for service users. Support organisations should provide advice to research organisations and researchers about these activities.

Members of research support organisations and networks may also like to consider the suggestions made in Sections 6.3.3 and 6.3.4 for research organisations and researchers.

- Service users perceive the ethics of research to be problematic. Research support organisations and networks should support researchers to talk through ethical issues with those who are involved in the research process. Consent, data protection, freedom of information, ground rules, rights to anonymity and confidentiality are important considerations even though service users involved in the research process are not 'subjects' of the research. Given the developments in research commissioning that require service user involvement in a wide range of research roles that span consultation, advice and participation in the process, it may be timely for ethics committees to review consent processes to support this type of work.
- 2 Researchers should feedback to all stakeholders in the research, including service users, by providing accessible written materials that explain the impact that their involvement is having and to outline any results or findings as they emerge. Research Support Organisations and Networks should support researchers to develop ways to design feedback to all stakeholders in the research about the impact of their involvement on the research.
- 3 Researchers should be encouraged to develop plain English summaries (as well as traditional executive summaries) for dissemination to appropriate voluntary and consumer organisations. Research support organisations and networks should support the production and dissemination of plain English summaries that use at least 14-point size font, clear layouts and plain language. These should be suitable for photocopying and electronic dissemination for example using e-mail or web based.

4. There is a need for research organisations to think strategically about involving service users. Support organisations can help to advise on principles for involvement (see Section 6.3.3).

6.3.3 Suggestions for research organisations

The following suggestions are intended for organisations active in research in the academic sector, the NHS or the private sector. The review specifically set out to inform service user involvement in nursing, midwifery and health visiting research. The following suggestions apply to research organisations working within these disciplines but they are also relevant for organisations undertaking research in a broader range of research fields.

- Involving service users in research is increasingly a requirement of gaining research funding and there is evidence to show that user involvement can make research better in a range of ways. Research organisations should emphasise to staff that involving service users in research should be a supportive and positive process.
- 2 Researchers need to know how their work with service users relates to the organisation that they work for. Research organisations should be clear about their strategy for involving service users in research by clearly defining a position or principles for service user involvement in research. This should be determined in consultation with research staff and should consider relevant policy documents such as the *Research Governance Framework for Health and Social Care* (Department of Health, 2001b) and previously published principles (for example Telford *et al.*, 2004) for involving service users in research.
- 3 Researchers are likely to have a broad range of views about involving service users in research. It is likely that different people will have mixed views, different levels of enthusiasm and anxieties. Researcher Organisations should aim to establish their research staff's understandings of involvement policy, knowledge of the benefits of involving service users and knowledge of the methods that might be appropriate for the type of research they are undertaking.
- 4 Researchers may receive training for specific research methods, for example interview techniques or questionnaire design, but there is a big gap in relation to training for working with service users. Research organisations should consider who or what influences researcher skill and knowledge and the training needs of different groups of researchers in relation to working with service users in the design or undertaking of research.
- 5 Formal training for researchers might be one way of supporting the involvement of service users in research – but it is difficult to generalise the skills that are necessary for researchers to have and the best setting for these to be gained – in some cases it

might be better for researchers to learn about involving service users 'on the job', or by working alongside a colleague. Research organisations should work with research staff to identify the most appropriate ways for them to learn and develop their skills for working with service users.

- 6 There are added costs of service user involvement in research that sometimes will be borne out by research organisations but there are also benefits for the research organisation. Research organisations should recognise that investing time and resources in involvement activities can have benefits to the research organisation. These should be shown and acknowledged appropriately.
- 7 Service users are diverse. They have diverse needs, understandings, experiences, expectations and interests. Involvement of a group of service users should not be considered as a way of gaining a 'definitive user view'. If a different group of service users were involved this would lead to different ways of working and outcomes. Research organisations should encourage research staff to consider involving any particular group of service users in relation to the purpose, aims and context of the research that is being proposed. Decisions about who are the most appropriate people to involve should be explored with groups of service users themselves. For research that involves people, there are benefits to involving service users at every stage.
- 8 Service users, as well as researchers, require support and information about service user involvement in research. Research organisations should provide guidance to research staff about the type of information service users should be provided with before becoming involved in a research project, for example what is expected of them and what their contribution to the research process might be.
- 9 Service users involved in research deserve to know what difference their involvement has made. Research organisations should provide guidance to research staff about how to feedback to service users that have been involved. For example using newsletters, project updates or a website.
- 10 Service users involved in research should be given the opportunity to comment on any publications, presentations or outputs from the research they were involved in. Research organisations should provide guidance to research staff about how to involve service users in producing outputs and disseminating the findings of research.

6.3.4 Suggestions for researchers

This review specifically set out to inform service user involvement in nursing, midwifery and health visiting research. The following suggestions apply to researchers working in these disciplines but they are also relevant for researchers undertaking research in a broader range of research fields, particularly research about public sector services.

The suggestions made here are for general guidance to researchers.

- 1 Involving service users in research is increasingly a requirement of gaining research funding and there is evidence to show that user involvement can make research better in a range of ways. Researchers should view involving service users in research as a supportive and positive process that can have a range of benefits for the research process.
- 2 Researchers have a broad range of views about involving service users in research. Different researchers will have mixed views, different levels of enthusiasm and anxieties. Researchers should develop their understandings of involvement policy, knowledge of the benefits of involving service users and knowledge of methods that might be appropriate for the type of research they are undertaking. They should consider relevant policy documents such as the *Research Governance Framework for Health and Social Care* (Department of Health, 2001b) and previously published principles for involving service users in research (for example Telford *et al.*, 2004).
- 3 Training for researchers might be one way of supporting the involvement of service users in research but it is difficult to generalise the skills that are necessary for researchers to have and the best setting for these to be gained in some cases it might be better for researchers to learn about involving service users 'on the job', or by working alongside a colleague. Researchers should consider their existing skills and knowledge and the training needs they might have in relation to working with service users in the design or undertaking of research. Support for training in these areas should be sought from their research organisation to identify the most appropriate ways for them to learn and develop their skills for working with service users.
- 4 Service users all have different personalities, needs, understandings, experiences, expectations and interests. Involvement of a group of service users should not be considered as a way of gaining a 'definitive user view'. If a different group of service users were involved this would lead to different ways of working and outcomes. Researchers wishing to involve any particular group of service users should consider involvement in relation to the purpose, aims and context of the research that is being proposed. Decisions about who are the most appropriate people to involve should be explored with groups of service users themselves. For research that is about patients, there are benefits to involving service users at every stage.

- 5 Service users, as well as researchers, require support and information about service user involvement in research. Researchers should seek information and guidance from their colleagues and research organisation about involving service users in research.
- 6 Researchers should provide information to service users prior to them becoming involved in a research project, so that they have a good understanding about what is expected of them and what their contribution to the research process might be. Service users should be involved in research on their own terms. Researchers should be clear about their objectives for working with service users but develop 'terms of reference' (ways of working) with service users and be flexible within these limits.
- 7 Service users should feel that their contribution to the research has been acknowledged and is valued. Service users should be paid expenses for their involvement in a research project. It may not always be possible or appropriate to pay a fee for service users' time but service users should always be acknowledged for their contribution to the research.
- 8 Researchers might feel that they need to tell service users what they want them to do because there is a lot to do in a short time. Researchers should be willing to listen to service users' suggestions about different ideas or approaches and assess whether this is likely to be better for them and the research.
- 9 Communication and organisation are vital to building good working relationships. Researchers should not under estimate the importance of paying attention to personal details, access issues, comfort issues and dietary requirements. In written materials, researchers should always use plain language, clear layouts and at least 14-point font size.
- 10 Informing people what impact their involvement is having is important for keeping people interested and involved. Service users involved in research deserve to know what difference their involvement has made. Researchers should provide feedback to service users who have been involved, for example, using newsletters, project updates or a website.
- 11 Service users involved in research should be given the opportunity to comment on any publications, presentations or outputs from the research they were involved in. Researchers should involve service users in producing outputs and disseminating the findings of research.
- 12 Reflections and experiences are an important part of planning for subsequent involvement activities and they also reveal aspects of involvement that need clarification or more focused attention. Researchers should aim to gain reflections and experiences from all stakeholders, including themselves, to reflect on the process and identify ways of improving involvement.

See Section 4.3.5 for findings on working with particular client groups (for example children and young people, older people or groups requiring special consideration) and Section 4.4.5 for findings on researcher-led models of involvement.

6.3.5 Suggestions for service users and consumer organisations

The following suggestions for service users and consumer organisations are based on researchers' and service users' opinions about what works well and what service users should expect from involvement.

- 1 For involvement to work well it is important that service users are involved in research on their own terms. Service users should ask to be involved in writing 'terms of reference' for projects they get involved with. This means deciding when, why and how to be involved.
- 2 Sometimes researchers feel that they need to tell service users what they want them to do because there is a lot to do in a short time. Service users should be willing to suggest a different idea or approach if they think that it will be better for them or the research.
- 3 Service users should feel that their contribution to the research has been acknowledged and is valued. Service users should expect to be paid expenses for their involvement in a research project. It may not always be possible or appropriate to pay a fee for service users' time but service users should expect to be acknowledged for their contribution to the research.
- 4 There is no one right way to involve service users in research and different researchers will have different levels of experience and confidence. Service users should feed back their views about their involvement to researchers in a supportive way so that they can identify and make positive changes.
- 5 Talking about involvement experiences is a very powerful way of showing that involvement can have benefits for the people that are involved. Service users should talk to other people about their experiences of involvement to encourage others to voice their opinions and share their experiences when there are opportunities to do so.
- 6 Some service users who have been involved in a research project might be involved in writing an article, attending a meeting about the research or presenting at a conference. These are some ways of sharing the findings of a research project (dissemination). Service users should expect to be invited to be involved in sharing the findings of the research with other people.

See Chapter 5 for the reflections of the service user reference group about their involvement in this project and Section 4.4.5 for findings on user-led models of involvement.

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Appendices

Appendix 1 Electronic search histories

	AMED (Allied and Complementary Medicine) 1985 to July 2004				
1.	(consumer adj3 (participat\$ or involve\$ or empower\$ or collaborat\$ or consult\$)).mp. [mp=abstract, heading words, title]				
2.	(user adj3 (participat\$ or involve\$ or empower\$ or collaborat\$ or consult\$)).mp. [mp=abstract, heading words, title]				
3.	(client adj3 (participat\$ or involve\$ or empower\$ or collaborat\$ or consult\$)).mp. [mp=abstract, heading words, title]				
4.	(patient adj3 (participat\$ or involve\$ or empower\$ or collaborat\$ or consult\$)).mp. [mp=abstract, heading words, title]				
5.	(public adj3 (participat\$ or involve\$ or empower\$ or collaborat\$ or consult\$)).mp. [mp=abstract, heading words, title]				
6.	(carer adj3 (participat\$ or involve\$ or empower\$ or collaborat\$ or consult\$)).mp. [mp=abstract, heading words, title]				
7.	(lay adj3 (participat\$ or involve\$ or empower\$ or collaborat\$ or consult\$)).mp. [mp=abstract, heading words, title]	133			
8.	Patient satisfaction/ or Consumer satisfaction/ or Patient participation/	papers			
9.	Or/1-8				
10	Nursing care/				
11	Models theoretical/ or research design/				
12	(research methodology adj3 nurs\$).mp. [mp=abstract, heading words, title]				
13	(practice development adj3 nurs\$).mp. [mp=abstract, heading words, title]				
14	(community development adj3 nurs\$).mp. [mp=abstract, heading words, title]				
15	nurses/ or nursing staff/				
16	or/10-15				
17	9 and 16				

Bri	tish Nursing Index 1985 to July 2004	Papers
1.	(consumer adj3 (participat\$ or involve\$ or empower\$ or collaborat\$ or consult\$)).mp. [mp=title, abstract, subject headings, drug trade name, original title, device manufacturer, drug manufacturer name]	
2.	(user adj3 (participat\$ or involve\$ or empower\$ or collaborat\$ or consult\$)).mp. [mp=title, abstract, subject headings, drug trade name, original title, device manufacturer, drug manufacturer name]	
3.	(client adj3 (participat\$ or involve\$ or empower\$ or collaborat\$ or consult\$)).mp. [mp=title, abstract, subject headings, drug trade name, original title, device manufacturer, drug manufacturer name]	
4.	(patient adj3 (participat\$ or involve\$ or empower\$ or collaborat\$ or consult\$)).mp. [mp=title, abstract, subject headings, drug trade name, original title, device manufacturer, drug manufacturer name]	
5.	(public adj3 (participat\$ or involve\$ or empower\$ or collaborat\$ or consult\$)).mp. [mp=title, abstract, subject headings, drug trade name, original title, device manufacturer, drug manufacturer name]	
6.	(lay adj3 (participat\$ or involve\$ or empower\$ or collaborat\$ or consult\$)).mp. [mp=title, abstract, subject headings, drug trade name, original title, device manufacturer, drug manufacturer name]	
7.	(carer adj3 (participat\$ or involve\$ or empower\$ or collaborat\$ or consult\$)).mp. [mp=title, abstract, subject headings, drug trade name, original title, device manufacturer, drug manufacturer name]	136
8.	CONSUMER SATISFACTION/	papers
9.	Patients- Empowerment.sh.	
10.	"Patients- Attitudes and Perceptions".sh.	
11.	or/1-10	
12.	Nursing Research.sh.	
13.	(Nursing Management or "Management- Education and Training").sh.	
14.	Research Methods/	
15.	(research methods adj3 nurs\$).mp. [mp=title, abstract, subject headings, drug trade name, original title, device manufacturer, drug manufacturer name]	
16.	(practice development adj3 nurs\$).mp. [mp=title, abstract, subject headings, drug trade name, original title, device manufacturer, drug manufacturer name]	
17.	(community development adj3 nurs\$).mp. [mp=title, abstract, subject headings, drug trade name, original title, device manufacturer, drug manufacturer name]	
18.	or/12-17	
19.	11 and 18	

	CINAHL (Cumulative Index to Nursing & Allied Health Literature) 1982 to July Week 4 2004					
1.	(consumer adj3 (participat\$ or involve\$ or empower\$ or collaborat\$ or consult\$)).mp. [mp=title, cinahl subject headings, abstract, instrumentation]					
2.	(user adj3 (participat\$ or involve\$ or empower\$ or collaborat\$ or consult\$)).mp. [mp=title, cinahl subject headings, abstract, instrumentation]					
3.	(client adj3 (participat\$ or involve\$ or empower\$ or collaborat\$ or consult\$)).mp. [mp=title, cinahl subject headings, abstract, instrumentation]					
4.	(patient adj3 (participat\$ or involve\$ or empower\$ or collaborat\$ or consult\$)).mp. [mp=title, cinahl subject headings, abstract, instrumentation]					
5.	(public adj3 (participat\$ or involve\$ or empower\$ or collaborat\$ or consult\$)).mp. [mp=title, cinahl subject headings, abstract, instrumentation]					
6.	(lay adj3 (participat\$ or involve\$ or empower\$ or collaborat\$ or consult\$)).mp. [mp=title, cinahl subject headings, abstract, instrumentation]					
7.	(carer adj3 (participat\$ or involve\$ or empower\$ or collaborat\$ or consult\$)).mp. [mp=title, cinahl subject headings, abstract, instrumentation]	79 papers				
8.	Consumer participation/					
9.	or/1-8					
10.	Research, Nursing/					
11.	Clinical Nursing Research/					
12.	Nurse Researchers/					
13.	Nursing Administration Research/					
14.	"Quality of Care Research"/					
15.	(research methodology adj3 nurs\$).mp. [mp=title, cinahl subject headings, abstract, instrumentation]					
16.	(practice development adj3 nurs\$).mp. [mp=title, cinahl subject headings, abstract, instrumentation]					
17.	(community development adj3 nurs\$).mp. [mp=title, cinahl subject headings, abstract, instrumentation]					
18.	or/10-17					
19.	9 and 18					

ΕN	BASE 1980 to 2004 Week 31	Papers
1.	(consumer adj3 (participat\$ or involve\$ or empower\$ or collaborat\$ or consult\$)).mp. [mp=title, abstract, subject headings, drug trade name, original title, device manufacturer, drug manufacturer name]	
2.	(user adj3 (participat\$ or involve\$ or empower\$ or collaborat\$ or consult\$)).mp. [mp=title, abstract, subject headings, drug trade name, original title, device manufacturer, drug manufacturer name]	
3.	(client adj3 (participat\$ or involve\$ or empower\$ or collaborat\$ or consult\$)).mp. [mp=title, abstract, subject headings, drug trade name, original title, device manufacturer, drug manufacturer name]	
4.	(patient adj3 (participat\$ or involve\$ or empower\$ or collaborat\$ or consult\$)).mp. [mp=title, abstract, subject headings, drug trade name, original title, device manufacturer, drug manufacturer name]	
5.	(public adj3 (participat\$ or involve\$ or empower\$ or collaborat\$ or consult\$)).mp. [mp=title, abstract, subject headings, drug trade name, original title, device manufacturer, drug manufacturer name]	
6.	(lay adj3 (participat\$ or involve\$ or empower\$ or collaborat\$ or consult\$)).mp. [mp=title, abstract, subject headings, drug trade name, original title, device manufacturer, drug manufacturer name]	111
7.	(carer adj3 (participat\$ or involve\$ or empower\$ or collaborat\$ or consult\$)).mp. [mp=title, abstract, subject headings, drug trade name, original title, device manufacturer, drug manufacturer name]	papers
8.	CONSUMER/	
9.	or/1-8	
10.	Nursing/	
11.	(research methodology adj3 nurs\$).mp. [mp=title, abstract, subject headings, drug trade name, original title, device manufacturer, drug manufacturer name]	
12.	(practice development adj3 nurs\$).mp. [mp=title, abstract, subject headings, drug trade name, original title, device manufacturer, drug manufacturer name]	
13.	(community development adj3 nurs\$).mp. [mp=title, abstract, subject headings, drug trade name, original title, device manufacturer, drug manufacturer name]	
14.	or/10-13	
15	9 and 14	

ME	DLINE 1966 to July Week 4 2004	Papers
1.	(consumer adj3 (participat\$ or involve\$ or empower\$ or collaborat\$ or consult\$)).mp. [mp=title, original title, abstract, name of substance, mesh subject heading]	
2.	(user adj3 (participat\$ or involve\$ or empower\$ or collaborat\$ or consult\$)).mp. [mp=title, original title, abstract, name of substance, mesh subject heading]	
3.	(client adj3 (participat\$ or involve\$ or empower\$ or collaborat\$ or consult\$)).mp. [mp=title, original title, abstract, name of substance, mesh subject heading]	
4.	(patient adj3 (participat\$ or involve\$ or empower\$ or collaborat\$ or consult\$)).mp. [mp=title, original title, abstract, name of substance, mesh subject heading]	
5.	(public adj3 (participat\$ or involve\$ or empower\$ or collaborat\$ or consult\$)).mp. [mp=title, original title, abstract, name of substance, mesh subject heading]	
6.	(lay adj3 (participat\$ or involve\$ or empower\$ or collaborat\$ or consult\$)).mp. [mp=title, original title, abstract, name of substance, mesh subject heading]	
7.	CONSUMER ADVOCACY/ or CONSUMER PARTICIPATION/	1078
8.	Patient Participation/	papers
9.	or/1-8	
10.	NURSING RESEARCH/ or NURSING EDUCATION RESEARCH/ or NURSING ADMINISTRATION RESEARCH/ or COMMUNITY HEALTH NURSING/ or NURSING EVALUATION RESEARCH/ or NURSING/ or CLINICAL NURSING RESEARCH/ or NURSING METHODOLOGY RESEARCH/	
11.	Patient-Centered Care/	
12.	(research methodology adj3 nurs\$).mp. [mp=title, original title, abstract, name of substance, mesh subject heading]	
13.	(practice development adj3 nurs\$).mp. [mp=title, original title, abstract, name of substance, mesh subject heading]	
14.	(community development adj3 nurs\$).mp. [mp=title, original title, abstract, name of substance, mesh subject heading]	
15	or/10-14	

16. 9 and 15

Ps	ychINFO 1985 to July Week 4 2004	Papers
1.	(consumer adj3 (participat\$ or involve\$ or empower\$ or collaborat\$ or consult\$)).mp. [mp=title, abstract, heading word, table of contents, key concepts]	
2.	(user adj3 (participat\$ or involve\$ or empower\$ or collaborat\$ or consult\$)).mp. [mp=title, abstract, heading word, table of contents, key concepts]	
3.	(client adj3 (participat\$ or involve\$ or empower\$ or collaborat\$ or consult\$)).mp. [mp=title, abstract, heading word, table of contents, key concepts]	
4.	(patient adj3 (participat\$ or involve\$ or empower\$ or collaborat\$ or consult\$)).mp. [mp=title, abstract, heading word, table of contents, key concepts]	
5.	(public adj3 (participat\$ or involve\$ or empower\$ or collaborat\$ or consult\$)).mp. [mp=title, abstract, heading word, table of contents, key concepts]	
6.	(lay adj3 (participat\$ or involve\$ or empower\$ or collaborat\$ or consult\$)).mp. [mp=title, abstract, heading word, table of contents, key concepts]	
7.	(carer adj3 (participat\$ or involve\$ or empower\$ or collaborat\$ or consult\$)).mp. [mp=title, abstract, heading word, table of contents, key concepts]	144 papers
8.	exp CONSUMER SURVEYS/ or exp CONSUMER RESEARCH/ or exp CONSUMER SATISFACTION/	
9.	exp CLIENT PARTICIPATION/ or exp PARTICIPATION/	
10.	involvement/	
11.	or/1-10	
12.	nursing/	
13.	exp "Quality of Care"/	
14.	(research method\$ adj3 nurs\$).mp. [mp=title, abstract, heading word, table of contents, key concepts]	
15.	(practice development adj3 nurs\$).mp. [mp=title, abstract, heading word, table of contents, key concepts]	
16.	(community development adj3 nurs\$).mp. [mp=title, abstract, heading word, table of contents, key concepts]	
17.	or/12-16	
18.	11 and 17	

He	ealth Management Information Consortium (HMIC)	Papers
1.	(consumer adj3 (participat\$ or involve\$ or empower\$ or collaborat\$ or consult\$)).mp. [mp=title, other title, abstract, heading words]	
2.	(user adj3 (participat\$ or involve\$ or empower\$ or collaborat\$ or consult\$)).mp. [mp=title, other title, abstract, heading words]	
3.	(client adj3 (participat\$ or involve\$ or empower\$ or collaborat\$ or consult\$)).mp. [mp=title, other title, abstract, heading words]	
4.	(patient adj3 (participat\$ or involve\$ or empower\$ or collaborat\$ or consult\$)).mp. [mp=title, other title, abstract, heading words]	
5.	(public adj3 (participat\$ or involve\$ or empower\$ or collaborat\$ or consult\$)).mp. [mp=title, other title, abstract, heading words]	
6.	(carer adj3 (participat\$ or involve\$ or empower\$ or collaborat\$ or consult\$)).mp. [mp=title, other title, abstract, heading words]	
7.	(lay adj3 (participat\$ or involve\$ or empower\$ or collaborat\$ or consult\$)).mp. [mp=title, other title, abstract, heading words]	
8.	exp CONSUMERS/	96 papers
9.	exp PUBLIC PARTICIPATION/ or exp PATIENT PARTICIPATION/ or exp COMMUNITY PARTICIPATION/ or exp PARTICIPATION/ or exp CLIENT PARTICIPATION/ or exp GROUP PARTICIPATION/	
10	or/1-9	
11.	exp NURSING RESEARCH/	
12	(research method\$ adj3 nurs\$).mp. [mp=title, other title, abstract, heading words]	
13	(practice development adj3 nurs\$).mp. [mp=title, other title, abstract, heading words]	
14	(community development adj3 nurs\$).mp. [mp=title, other title, abstract, heading words]	
15	or/11-14	
16	10 and 15	

si w	/eb of Science 1990-2004	Papers
#1	DocType=All document types; Language=All languages; Database(s)=SSCI; Timespan=1990-2004	1023
	TS=(consumer* same (participat* or collabor* or involve* or consult* or empower*))	1023
#2	TS=(user* same (participat* or collabor* or involve* or consult* or empower*))	1562
#3	TS=(client* same (participat* or collabor* or involve* or consult* or empower*))	1491
#4	TS=(public* same (participat* or collabor* or involve* or consult* or empower*))	4122
#5	TS=(patient* same (participat* or collabor* or involve* or consult* or empower*))	8536
#6	TS=(lay* same (participat* or collabor* or involve* or consult* or empower*))	309
#7	TS=(carer* same (participat* or collabor* or involve* or consult* or empower*))	179
#8	TS=(research* same (nurs* or idwife* or health visit*))	3718
#9	TS=(community develop* same (nurs* or idwife* or health visit*))	18
#10	TS=(practice develop* same (nurs* or idwife* or health visit*))	33
#11	#1 or #2 or #3 or #4 or #5 or #6 or #7	16427
#12	#8 or #9 or #10	3755
#13	#11 and #12	187

Other databases	Key search terms
AgeInfo	Involvement, Participation Research, Consumer
Applied Social Sciences Index and Abstracts for Health	Involvement, Research
British Education Index	Health, Research, Involvement
Care Data (via Electronic Library for Social Care	Involvement, Participation
Cochrane Library	Consumer (next) Involvement
ERIC (Educational Research Information Centre)	Involvement, Participation
Health Promis (UK health promotion)	Involvement, Participation
IBSS (social science)	Involvement, Participation
Internurse.com	Involvement, Participation, Consumer
National Electronic Library for Health	Involvement

Appendix 2 Electronic databases included in the searches

Electronic databases searched

Ovid Databases Allied and Complementary Medicine Database (AMED) British Nursing Index

CINAHL

EMBASE

Health Management Information Consortium (HMIC)

MEDLINE

PsychINFO

Web of Knowledge

Social Science Citation index

Other databases

AgeInfo http://www.cpa.org.uk/ageinfo/ageinfo2.html

Applied Social Sciences Index and Abstracts for Health

British Education Index http://www2.dialogatsite.com/atsiteext.dll

Care Data (via Electronic Library for Social Care http://www.elsc.org.uk/)

Cochrane Library http://www.nelh.nhs.uk/cochrane.asp

ERIC (educational database)

Health Promis (UK health promotion)

IBSS (social science)

Internurse.com http://www.internurse.com

National Electronic Library for Health http://www.nelh.nhs.uk/

Social Service Abstracts

Appendix 3 E-mail questionnaire

Patient and public involvement in nursing, midwifery and health visiting research (PIN Project): Recently completed or ongoing projects questionnaire

We would like to know about your work with service users / carers:

The Nursing Research Unit has been funded by the Department of Health to find out what is known about patient and public involvement in nursing, midwifery and health visiting research. This work is known as the PIN Project.

We are undertaking a review of the published literature but would also like to include work that is UNPUBLISHED, ONGOING or RECENTLY COMPLETED. For example, unpublished research projects, MSc or PhD project work, research undertaken in practice or action orientated projects.

If your research has involved working in partnership with service users or carers we would like to hear about it. We would be grateful if you would complete the QUESTIONNAIRE below and return it to us. We are offering to send each person who completes the questionnaire a summary of our findings.

- We will be collecting information on this type of research until the end of January 2005.
- We are only collecting information about the involvement of service users / carers in RESEARCH projects.
- By INVOLVEMENT in research we mean an active partnership between service users / carers in the research process, rather than involvement as the 'subjects' of research.
- We are not including involvement of service users / carers in other activities such as seminars, commissioning groups or meetings.
- We are interested in research with a nursing, midwifery or health visiting focus that has involved service users / carers. The research might relate to the promotion of community health, evaluation of service provision and workforce, evaluation of specialist and new roles, chronic and palliative care, symptom assessment and management, education and competence or the interface with social care, or any other aspect of nursing, midwifery or health visiting practice. We are including research that has involved any age groups (children or adults).

The questionnaire focuses on the reasons why service users / carers were involved in the project, how this was achieved and what aspects of involvement led to successful outcomes.

The information we collect will help to develop an understanding of the complex and rapidly expanding area of patient and public involvement in research. We will also invite some projects to be included as 'case studies' in our final report, to show how involvement can work in different contexts.

If you are unsure whether a project is within our remit or if you have any comments or queries about the PIN Project please e-mail: [email contact]

Further information about the PIN Project can be found at: http://www.kcl.ac.uk/nursing/nru/pin.html

Please take some time to tell us about your work by answering the following questions:

- If you have been involved in more than one research project please complete a separate questionnaire for each
- If you know of a colleague whose research has involved working with service users or carers as partners, please forward this questionnaire to them
- 1. What was your role in the research project? (for example lead researcher, user researcher, research partner)
- 2. Please let us know your contact details so that we can contact you for further information about the project if necessary (name, position, organisation, address, e-mail address and telephone number)
- 3. Please give a brief description of the project (title, aims, methods, funding source, start and completion dates)
- 4. What aspects of nursing, midwifery or health visiting does the project relate to?
- 5. Please explain why service users/carers were involved in the project.
- 6. How many service users/carers were involved and how did you recruit them?
- 7. Please describe how service users/carers were involved (their roles and activities)
- 8. How were service users/carers supported during the project?
- 9. Overall, what impact did their involvement have?
- 10. What were the specific outcomes of involving service users / carers?
- 11. What worked well? (factors that helped achieve good outcomes)
- 12. What was less successful? (barriers / difficulties)
- 13. Were there any ways in which service users' / carers' views or reflections of being involved were captured?
- 14. Any other comments?

Thank you very much for your time

I would like to receive a summary of the findings of the PIN Project? YES/NO

Appendix 4 Dissemination networks for the e-mail questionnaire

The following online distribution networks were used to disseminate the electronic questionnaire to researchers.

CHAIN I (research and development / evidence-based practice) <u>http://www.nhsu.nhs.uk/webportal/chain/</u>

CHAIN (contact, help, advice and information networks) are online networks for people working in health and social care. They are based around specific areas of interest, and give people a simple and informal way of contacting each other to exchange ideas and share knowledge. CHAIN I focuses on evidence-based practice. It was established in 1997 as part of the NHS R&D Programme. It has more than 3000 members, drawn from a wide range of professions and organisations.

JISCmail (national academic mailing list ervice)

http://www.jiscmail.ac.uk

JISCmail is an electronic mailing list service specifically for the higher and further education and research communities. It is a free service, funded by the JISC (joint information systems committee). It uses the World Wide Web and e-mail to enable groups of academics and support staff to talk to each other and to share information. Twenty-six JISCmail lists were targeted, all of which related to nursing, midwifery or health visiting professions.

Health Voice Network

http://www.healthvoice-uk.net

Health Voice Network was set up to 'enable more people to have more of a say in planning and improving services that affect their health'. The network is a member of the 'communities for health' initiative that brings together a number of organisations and projects that are supporting people to play active roles in planning and implementing.

Royal College of Nursing R&D Co-ordinating Centre

http://www.man.ac.uk/rcn/

The centre provides advice and information, research and consultancy services on R&D in nursing. Each week a newsletter is e-mailed to thousands of stakeholders: nurses working in all areas of clinical practice, research, education and management; healthcare providers and higher education institutions; funders of both research and/or development. The newsletter can also be accessed via the 'What's New' link on the website.

NHS R&D Forum UK (user and carer involvement working group)

http://www.rdforum.nhs.uk/

The NHS R&D Forum UK is a network for research and development management in health and social care. The aims of the user and carer involvement working group are to 1) facilitate and empower service users and carers involvement in NHS R&D through the research process and 2) to synthesise existing evidence of user involvement in research and development nationally and internationally, providing extrapolated information to determine current practice.

Appendix 5 Details of example projects (interviews with researchers)

Notes:

- The tables in this Appendix are reproduced from the questionnaire responses for each participant. We have only included details of the projects followed up by telephone interviews. They relate to the real life examples provided in the report (i.e. R1 – R11).
- Interviewee R1 did not complete a questionnaire. Project details are summarised below from information provided during the telephone interview.

Project details for respondent [R1]

Project title: The Collaborative Research Project - Service Users and Mental Health Nurse Researchers Working Together

Funder: Royal College of Nursing: Mental Health Programme

Project aims:

- 1 To explore the nature and topic of research being conducted by mental health nurses and service users together and investigate the extent of 'collaboration' and 'involvement'.
- 2 To examine and critically reflect upon our own experiences of working collaboratively.

Method: Two-stage survey of UK nursing departments with follow-up telephone interviews (case studies)

Respondent code and research dates	Area of nursing/HV/midwifery	Focus of research	Location	Funder
[R2] Independent research consultant Start: March 04	Organisation and delivery of services for children born with a cleft lip and/or palate.	Survey to examine carer / service user views of cleft services and gather views about reconfiguration of services.		
Rationale for user involvement	Roles and activities of users	Recruitment of users	Support for users	Overall impact of user involvement
	Service users / carers were involved in: design and piloting of survey form; collating responses; responding to queries raised in responses; consideration of a report of a preliminary analysis of the findings and development of the subsequent detailed analytical approach; identifying recommendations based on an analysis of the responses.	Ten service users were actively involved in all aspects of the development and administration of the survey.	Regular meetings of the service user group provided a support base for the service users involved in the project. The lead researcher provided methodological advice, analysed responses to the survey, presented these to the user group and wrote the report based on their recommendations.	 Service users had a significant impact on: the design of the data collection form the way the data collection form was distributed to service users/carers the analytical approach the recommendations made to the Network Board.

R2 continued

Outcomes of	Factors that helped	Factors that hindered	Users' views of	Respondent's additional comments
user involvement	user involvement	user involvement	being involved	
 Design of a highly user friendly data collection form. Rapid and sympathetic Response to queries raised by carers / service users when responding to the survey. Analytical approach that reflected the concerns of the service users / carers. Recommendations that reflected the concerns of the service users / carers. 	Including a mechanism that enabled service users / carers to obtain rapid feedback to concerns they had about services. Regular forums of service users / carers (i.e. user groups) at which the user survey was discussed as part of the agenda. The very high level of commitment of a small number of core members of the service user group who were very actively involved in all stages of the questionnaire design, administration, analysis and report.		Not as yet	

Respondent code and research dates	Area of nursing/HV/midwifery	Focus of research	Location	Funder
[R3] Acting principal investigator March 04 to February 07	Community-based specialist nursing care; interprofessional and inter-agency working.	A study of the development and impact of community-based heart failure specialist nurse services.	England	
		A multiple case (embedded) design using a mixed methodology of audit quality of life outcome measures and qualitative data.		
Rationale for user involvement	Roles and activities of users	Recruitment of users	Support for users	Overall impact of user involvement
A service user and carer (patient with heart failure and their informal carer) were asked to participate in this study to help with design and to advise on progress.	User and carer participate in a research advisory group (meets twice a year). Patient and carer consulted regarding quality of life outcome measures being used in study, and contribute to discussions about progress.	One user and one carer. Contacted through heart failure specialist nurse who participated in the pilot study.	User and carer provided with information from the INVOLVE website. R3 has contact with them outside of the advisory group meetings to ensure they have felt able to participate. At times they have commented that meetings are difficult for them where meetings concentrate on methodological issues or statistics.	They significantly contributed to discussions about outcome measures – how many were acceptable and which to use (particularly in relation to satisfaction and carer burden).

R3 continued

Outcomes of user involvement	Factors that helped user involvement	Factors that hindered user involvement	Users' views of being involved	Respondent's additional comments
To inform discussions related to outcome measures.	 Good working relationship with user and carer. Good facilitation of the 	At times having user and carer in a discussion with professionals (such as	Not formally captured but R3 has contact with user and carer outside meetings to ensure they	Thus far, their participation has been very important and R3 believes they will continue to
To offer insight into recruitment issues.	meetings to include user and carer.	cardiologists, specialist nurses) and researchers has excluded them from participating.	are happy to participate and to deal with any concerns or anxieties.	participate through comments and questions about the research as the project progresses.
• To comment on patient and carer information sheets and the process of consent.	 Choice of user and carer who felt able to voice their opinions in a group. 			
 To comment on findings, dissemination of findings and reports. 				

Respondent code and research dates	Area of nursing/HV/midwifery	Focus of research	Location	Funder
[R4] Lead researcher Sept 04 to Sept 05	Supportive and palliative care for patients living with cancer.	Ongoing needs of patients with rarer cancer.	[not specified]	
Sept 04 to Sept 05	Aims: Explore needs of patients diagnosed with rarer cancer either living with but not dying from rarer cancer or with no clinical disease; explore services accessed by these patients; explore patients' coping strategies.			
Rationale for user involvement	Roles and activities of users	Recruitment of users	Support for users	Overall impact of user involvement
	Selecting the topic for research, developing the question, methods, membership of steering group. Involvement in the entire research process.	Six users. Recruited via patient and user participation group.	Supported financially by Macmillan.	Project is ongoing. Very positive experience. Very helpful in shaping the research.
Outcomes of user involvement	Factors that helped user involvement	Factors that hindered user involvement	Users' views of being involved	Respondent's additional comments
Ease of access to sample, help with ethics application, positive benefits to users themselves.	Involvement from the very beginning. Very equal relationship.	How representative are they? They have their own agenda and needs/biases.	This is planned.	

Respondent code and research dates	Area of nursing/HV/midwifery	Focus of research	Location	Funder
[R5] PhD research student	Any nurse / HV / midwife	Appropriate patient-centred	[Not specified]	Chief Scientist Office, Scottish
November 03 to October 06	working with a young adult who has had a stroke (acute care;	outcomes for young adults post stroke and their families.		Executive
	rehabilitation; primary care).	Aims: identify what tools /		
		measures for patient centred		
		outcomes are already available		
		for young people post stroke;		
		discover what issues are		
		important to young adults and		
		their families post-stroke;		
		determine whether or not these		
		issues change over time; and		
		determine if the issues		
		identified in the research can be		
		addressed by the current		
		service provision of health,		
		social care and voluntary		
		organisations.		

R5 continued

Rationale for user involvement	Roles and activities of users	Recruitment of users	Support for users	Overall impact of user involvement
As study participants; also in the process of establishing an advisory group (comprised of service users, carers and occupational therapists) to provide feed back on various aspects of the study.	As study participants (qualitative interviews). Advisory group – still to have first meeting and determine its function – possibly to include feedback; analysis; advice; motivation for the project.	Participants: up to eight service users plus members of their family; recruited through stroke nurses and other stroke health professionals. Advisory group: up to seven members (four are/were service users and one spouse); recruited through stroke nurses and by word of mouth.	Study participants: access to peer support from Different Strokes. Advisory group: peer support & access to peer support from Different Strokes.	Data collection and advisory group both about to start at the time of writing (September 04).
Outcomes of user involvement	Factors that helped user involvement	Factors that hindered user involvement	Users' views of being involved	Respondent′s additional comments
Project not concluded.	Project not concluded.	Project not concluded.	Not yet considered but plans to do so.	

Respondent code and research dates	Area of nursing/HV/midwifery	Focus of research	Location	Funder
[R6] Independent researcher January 03 to December 04	Midwifery and health visiting – post-natal depression.	Local health visitors felt that the <i>Edinburgh Post-Natal</i> <i>Depression Scale</i> was not suitable for the South Asian population. The aim of the project has been to explore the experience of post-natal depression amongst local South Asian women, in particular looking at how South Asian women describe post-natal depression and what they feel would help them.	East Lancashire	 Blackburn with Darwen Sure Start Hyndburn and Ribble Valley Sure Start Burnley, Pendle and Rossendale Sure Start.
Rationale for user involvement	Roles and activities of users	Recruitment of users	Support for users	Overall impact of user involvement
Study population are a 'hard to reach' group especially as the topic of depression is taboo in the South Asian community. We felt that having South Asian women service users as researchers would inform the research design, provide the languages necessary and improve access to South Asian women who had experienced post-natal depression.	Service user researchers attended project meetings and advised on research design. They facilitated a focus group in their area and then conducted up to five one-to-one interviews in their area. They also advised on the analysis of the qualitative data and reports from the project.	A total of nine service users were recruited, three for each Sure Start area. Adverts were placed in Sure Start amenities and some women were approached directly by health visitors and midwives. We had strict criteria for recruitment and candidates were interviewed by the project lead, and health visitors and midwives who were project members.	Service users were given three half-day training sessions covering post-natal depression, data protection and confidentiality, focus group facilitation and interview technique. They were given <i>ad hoc</i> honorarium payments to cover childcare and travel expenses.	The overall impact was multi- faceted and often subtle. The service users in-depth understanding of the community meant that health professionals were sure the research was being conducted in a culturally sensitive way. They also provided advice on appropriate venues. In focus groups and interviews they were fully confident in questioning and probing in a way that non-Asian researchers would not have been.

They could speak several South
Asian languages and so the team
were confident they could involve
non-English speakers in the study
population. They also advised on
the significance of the findings and
their probable impact within the
South Asian community. They are
advising on dissemination of the
findings in the local area, especially
amongst the male South Asian
community. They also disseminate
the findings themselves through
talking to local community groups.

Outcomes of	Factors that helped user involvement	Factors that hindered	Users' views of	Respondent's
user involvement		user involvement	being involved	additional comments
A research project that has been completed successfully and in which we have a great deal of confidence in the findings and their applicability to the local community. Their presence has kept the research project focused on the needs of the service users and outputs that are relevant to both service users and practitioners.	Working on a problem that was important to both the health professionals and the service users provided a well defined focus for the project, from research design to outputs from the project, and implementation. Project meetings were very informal - almost social events. All got on very well. Most of the service user researchers were known to the health visitors and midwives.	Over the project timescale some service users moved on to other things and stopped attending. However, there were sufficient service user researchers on the project to maintain the service user input.	In practising interview technique the researchers talked about their involvement in the research project in the early stages. This has not yet been analysed. We intend to hold a focus group of the service user researchers at the end of the project to assess the impact on the women of being involved.	Outputs from the project so far: employment of two post-natal depression advocates for the South Asian community in Blackburn; four booklets for service users and health professionals containing quotations from women about post- natal depression; an innovative training course for health professionals aimed at understanding post-natal depression in the South Asian community.

Respondent code and research dates	Area of nursing/HV/midwifery	Focus of research	Location	Funder
[R7] Research fellow June 2004 to June 2005	Mental health nursing	'Engaging service users in the evaluation and development of forensic mental health care services.'	London	Forensic Mental Health R&D, Department of Health
		Aims: To support service users in developing research questions and undertake research.		
		Methods: Inviting people who have been in forensic mental health services to attend weekly meeting where research is developed.		
Rationale for user involvement	Roles and activities of users	Recruitment of users	Support for users	Overall impact of user involvement
To get their perspective.	Attended meetings, proposed ideas, discussed their experiences and worked at getting their bank accounts in order so that they can be paid for the work they are doing	Aiming at ten. There are five regular participants who have received mental health care in prisons, secure units and special hospitals. Researchers have spoken to over 20 possible participants and have recruited through community psychiatric nurses and advertising in local trusts and advocacy newsletters.	They are paid £6.38 per hour. Researchers write to them with minutes and agendas to keep them informed, and ring them to encourage them to attend.	Too early to say. But viewed as a good learning experience so far.
Outcomes of user involvement	Factors that helped user involvement	Factors that hindered user involvement	Users' views of being involved	Respondent's additional comments
Not known yet. Researchers hope it will affect the agenda of their research.	Developing regular contact enables things to move forward.	Not known yet.	The service users helped design a poster for a conference. Their style and emphasis was different from the initial draft.	Researchers are enjoying working with service users and hope that the project will be successful.

Respondent code and research dates	Area of nursing/HV/midwifery	Focus of research	Location	Funder
[R8] Lead researcher Study completed July 2003	Children's nursing. Quality of care/clinical audit.	Whose quality is it? Participatory research with young people to explore if and how children can be involved in monitoring the quality of care in hospital.	APU Institute of Health & Social Care, Chelmsford	Self-funded as part of PhD
Rationale for user involvement	Roles and activities of users	Recruitment of users	Support for users	Overall impact of user involvement
It was the children and young people's voices that needed to be heard.	Group of six were involved as co-researchers. They helped to set the research agenda, collected data, analysed the data and then contributed to the dissemination of the findings.	9 young people were interviewed. Then six agreed to become co-researchers and formed the research group. Data was collected from a further 129 children and young people.	Group met on a weekly basis. They were trained in aspects of research as they arose.	Their involvement led to the findings being specifically from children and young people. Their report was published in <i>Paediatric Nursing</i> and brought responses from nurses across the UK.
Outcomes of user involvement	Factors that helped user involvement	Factors that hindered user involvement	Users' views of being involved	Respondent's additional comments
The young people devised a leaflet citing the findings of the research and their recommendations. They also drafted the report which R8 edited and published.	Data collection by the young people worked well. Group sessions ran very well. Analysis of data was good.	Constrained by time, lack of resources.	Evaluation forms were filled in by some of the young people.	

Respondent code and research dates	Area of nursing/HV/midwifery	Focus of research	Location	Funder
[R9] Lead researcher	Rheumatoid arthritis (RA)	RA projects:	[Not specified]	[Not specified]
[Dates not specified]	 patient support for coping with long-term conditions outcome measures major outcome in which nursing potentially can intervene outcome measures. 	 nurse clinics to support newly diagnosed RA patients (qualitative and quantitative methods) important outcomes in RA (qualitative and quantitative methods) fatigue in RA (qualitative research) sensitivity to change of the RA self-efficacy scale. 		
Rationale for user involvement	Roles and activities of users	Recruitment of users	Support for users	Overall impact of user involvement
Ensure relevance and patient perspective to study design, data interpretation.	On steering committee for each project, attend each meeting; fully included in all discussions; co-	One per project, recruited through routine clinical practice.	One to one meeting with lead researcher first, to look at protocol.	Worked with nurse researcher to conduct letter analysis; reviewed focus group analysis, changed
	authors on abstracts and papers; presentation on study days for the multi-centre study; co-applicant on new projects arising from these		One half day and one full day training session, one half day review session.	outcome labels after factor analysis; changed study design by simple comments on the nature of RA fatigue; comments led to
	projects.		Volunteer co-ordinator (an experienced patient research partner).	development of further grant application and project.

R9 continued

Outcomes of user involvement	Factors that helped user involvement	Factors that hindered user involvement	Users' views of being involved	Respondent's additional comments
Have submitted a paper on approach to making this work; jointly presented with a patient to the MRC in London.	Support, time, encouraging users to voice opinions, positive feedback and thanks. Obtaining honorary university	Both sides had to work out how to move from being patient and clinician, to being equal research colleagues.		
Have made joint conference presentations on collaborative research partnerships.	status for research partners.	Patient research partners on disability benefits cannot receive payment for their work.		
		Patients have difficulty raising funds to get to medical conferences.		

Respondent code and research dates	Area of nursing/HV/midwifery	Focus of research	Location	Funder
[R10] User researcher Started in April 2002; part of a five- year project.	Mental health nursing has been touched upon where it is relevant to an understanding of continuity of care, or where users or carers have raised it as important to them in some way.	Aim: to explore users' and families' experiences (in mental health) and perceptions of continuity of care and to produce two questionnaires, one for users and one for families, to attempt to measure experiences, satisfaction and attitude towards continuity.	[Not specified]	SDO
		PhD development: project is the basis for R10's thesis: conducting indepth analysis of focus groups with the main aim of exploring experiences unique to being a user or a family member of a user.		
Rationale for user involvement	Roles and activities of users	Recruitment of users	Support for users	Overall impact of user involvement
R10 has experience of mental distress and is employed by the Service User Research Enterprise (SURE). This is phase one of a five- year collaborative project, designed to capture users' and families' views of continuity in a measurable way, to be taken forward in further research. An initial SDO scoping study showed gap in understanding users' / families' perspectives of continuity.	R10 has experience of using services, as does project supervisor. This phase of the project was designed largely by supervisor. Users and families were involved in the project in terms of participation in focus groups and subsequent expert panels to make decisions about the developing questionnaires.	Approximately 50 in focus groups and expert panels. Recruited via local user and carer groups – the CMHT route to recruitment was tried but largely failed, despite three months' hard work.	SURE believes it is essential to pay people for their involvement, and also to meet with people at times and places that suit them and are not threatening. As users themselves, the facilitators were better able to create a safe environment within which to discuss issues.	Without the involvement of other users and family members the questionnaires would have been developed without an exploration of what continuity meant to people.

R10 continued

Outcomes of	Factors that helped	Factors that hindered	Users' views of	Additional
user involvement	user involvement	user involvement	being involved	comments
Specifically, the production of measures of experienced continuity.	 The research team sharing the experiences of the participants. Spending time building relationships with people before they attended groups. This meant being available on the phone, maintaining contact with letters and so on. Going through a lengthy process of setting up groups to suit the majority – this led to a near perfect attendance rate. After the groups, contact has been maintained through thank you cards, Christmas cards, project updates and invitations to participate in SURE in other ways for example conferences, open meetings, advisory group etc. R10 is intending to present research results to all participants both to check their validity, to present them in an accessible form and to achieve closure for people. 	 The project was conducted in what felt like a very short time span. Researcher would have preferred to have involved people directly in the analysis, rather than presenting the results of analysis for verification. Time prevented this. There have been periods of illness, which have impacted on the project's progress. Despite sharing an identity with the participants (that of user and/or family member) it seems that coming from the Institute of Psychiatry as an academic can be a barrier. 	Most participants had the opportunity to give feedback on specific groups and is an area for further consideration.	

Respondent code and research dates	Area of nursing/HV/midwifery	Focus of research	Location	Funder
[R11] Research fellow 2001-2002	Midwifery	Qualitative study of women's experience of giving birth in Camden and Islington aiming to involving hard to reach women from ethnic minorities low income groups teenage mothers.	Camden & Islington	Community Health Council (CHC), Camden & Islington
Rationale for user involvement	Roles and activities of users	Recruitment of users	Support for users	Overall impact of user involvement
'Hard to reach' women; i.e. those on low income, teenage mothers, Bengali women those in need of additional support.	Involved in discussions re the research planning through CHC meetings. (Also as participants in focus groups.)	35 recruited through various community organisations Homestart; Parents and Co; Bengali women's group; post- natal support group run in a health centre.	By involvement in planning meetings and dissemination of research findings.	Ensuring appropriate questions were asked.
Outcomes of user involvement	Factors that helped user involvement	Factors that hindered user involvement	Users' views of being involved	Respondent's additional comments
The research involved hard to reach groups.	Focus groups produces really valuable data the research is interesting but in parts quite shocking to read.	Keeping users involved and producing action when research completed.	The whole research was of users' views but not of their involvement in the design.	Team is enjoying working with service users and hopes that the project will be successful.

Appendix 6 Service user reference group issues that informed development of the review framework

Summary of issues/themes from the first service user reference group meeting

1 Definitions

- What is research? (Hierarchy of evidence)
- Where does research begin? (Values underpinning research)
- Diversity within nursing, midwifery and health visiting (in PIN we aim to develop a model of what works)
- User involvement in research (users as active partners / their experiences)

2 Rationale and expectations

- Why is research being carried out? (Career development / ethics)
- What are researchers' motivations for involving users?
- For service users, involvement must be a positive influence for change

3 User involvement in research: when / who / how?

- When are users involved? (Ideally from the start; importance of honesty)
- Who are 'users'? (Eligibility criteria / 'credentials')
- How are users involved? (Not just consultation; creative methods)

4 Resources to support user involvement

- Time / money / training / relationships / commissioning / information

5 Users' perspectives of involvement

- Users' feelings about the process (safety; confidentiality; feeling valued)
- What are the benefits of being involved?
- Is there a collective goal for users and researchers? (Learning together)

6 Evaluation and follow-up

- Impact of user involvement on service users' and on researchers
- Unanticipated outcomes / 'learning as a by-product' of user involvement

Appendix 7 Review framework

Content/background

-			
Philosophical issues:	Philosophical reasoning, ideologies and beliefs that underlie theories of user involvement. This might include concepts of society, democracy, governance, rights, efficacy, empowerment, inclusion etc.		
Political issues:	Implications of policy developments.		
	Links between user involvement and political drives towards a consumer-citizen culture.		
Meanings:	The use of terminology or concepts associated with user involvement, for example distinctions between 'providers' and 'service users'.		
Commissioning:	Issues relating to the way research is commissioned for example funding streams/programmes.		
	The involvement of service users in commissioning for example identifying priorities for research.		
	Commissioning strategies that enable service user involvement.		
Research	When does research begin?		
issues:	What is the difference between service development/research and evaluation?		
	What is nursing, midwifery and health visiting research?		
	What is the difference between user involvement in research and research on user involvement?		
Funding:	Funding of involvement an organisational level, for example creating new roles, project grants.		
Methods issues			
Purpose:	The rationale or reasons given for involving service users within a specific project. These might not be based on known outcomes and could include to improve quality of process or to produce research outcomes that are more relevant to people's lives.		
Topic of inquiry:	The topic of the research for example clinical area, client group, service setting etc.		
Setting:	Issues about the organisation or setting in which the research is taking place for example service setting, community setting, partnerships.		
Ethics:	Anonymity, data protection, safety, duty of care, ownership of data/knowledge. Gaining ethical approval. Research governance.		
	Organisational responsibility and accountability. Use of guiding principles.		

Consent:	Informed consent, consent to participate/consent to use information, appropriateness of consent. When to breech consent. Capacity to consent.		
Roles:	The stage at which service users are involved.		
	The nature of involvement for example advisory group, individual representative on board.		
	Responsibilities.		
Activities:	What are service users doing? The activities service users are involved in for example design, data collection, analysis, publication etc.		
	Involvement in recording or evaluating the process for example user diaries, reflection.		
Recruitment:	'Representation' issues. Determining who is/should be involved.		
	Ways of approaching different groups/individuals for example recruitment through networks/ organisations.		
	Raising awareness, generating interest. Providing information prior to involvement.		
	Maintaining interest and keeping people involved.		
Enablement:	Concepts of diversity and inclusion.		
	The use of methods/ways of project working that allow service users to be involved. Strategies for involving people from hard to reach groups.		
	Barriers for particular groups of service users.		
Payments:	Funding service users for their time and participation.		
Training/support :	Training and support issues for service users to enable people to be involved.		
Working	Professional/lay relations.		
relations:	Communication issues.		
	Explaining why users are (invited to be) involved.		
	Explaining why the research is being done.		
	Clarity about boundaries.		
	Honesty about what is possible		
	Acknowledging different values.		
Decision-making:	Identifying common objectives. Deciding courses of action. Identifying priorities for action/investigation.		
Feedback:	Issues about methods of feeding back to participants about their involvement.		
	Developing approaches to evaluation, to track impact and establish which methodologies are more amenable to different groups of people.		

Outcomes		
Impact:	The impact of involvement on research process.	
	Unanticipated outcomes. Learning as a product of research.	
	The impact of involvement on service users involved for example perceptions of the significance of their involvement.	
	The impact of involvement on researchers, including emotional impact.	
	The impact of involvement on others not directly involved fo example commissioners/clinicians/wider public for example public understanding of science.	
Outputs:	The products of research for example publications, changes in policy/practice/ research.	
Quality:	Transferability, generalisability, validity etc.	
	Multiple perspectives – validity of interpretation.	
Dissemination:	Issues relating to dissemination of research findings or dissemination of learning about research processes/involvement.	
Generalisability:	ability: The use of the findings of user involvement projects in oth research projects or contexts.	
Transferability:	Issues about the implications of findings to other contexts.	

capacity			
Organisation:	Factors associated with the organisation(s) that are conducting the research for example patterns of working, job role pressures.		
Researcher skills:	Researcher support, skills, training etc.		
Research culture:	Issues about professional identity/roles. Power. Academic priorities/perspectives.		
	Redistributing power and modifying professional cultures.		
	Creating a dialogue between funders, patients, the public, providers and researchers.		
Education:	The development and design of educational packages to support researchers.		
Financial:	Issues about the financial implications of involving service users, added costs.		
Sustainability:	Issues associated with maintaining involvement.		

Appendix 8 Literature reviewing tool

Author(s) of paper:

Which of the following TOPIC does the paper cover?

EXTERNAL issues

- Philosophical issues
- Political issues
- □ Meanings
- Commissioning
- Research issues
- □ Funding

METHODS issues

- Purpose
- Ethics
- Setting
- Consent
- Roles
- Activities
- Recruitment
- Enablement
- Payments
- Training/support
- Working relations
- Decision-making
- Feedback

OUTCOMES

- Impact
- Outputs
- Quality
- Dissemination
- □ Generalisability
- □ Transferability

CAPACITY

- Organisation
- Researcher skills
- Research culture
- Education
- Financial
- Sustainability

Other(s)

Please summarise each of these issues below, making reference to particular paragraphs or pages in the paper that highlight these.

Торіс	Issue	Comments/reflections	Page(s)
(Please add further rows to this table as necessary)			

Appendix 9 Service user reference group networks

Network mapping exercise

At the second meeting of the group, members wrote their connections, networks and interests on post-it notes. These were put on the wall and members of the project team and the group arranged them into different categories, as shown below.

Commissioners

Department of Health

 England, Wales, Scotland, Ireland, Northern Ireland - Service Delivery and Organisation

Joseph Rowntree Foundation

Consumer focused organisations

Age Concern, England APEC (Association for pre-eclampsia) APPGC (All Party Parliamentary Group for Children) Association for Improvements in the Maternity Services (AIMS) BACUP Bedford Advocacy Alliance Bedford Council of Faith **Bedford Creative Arts** Bedford Diversity Forum – Gujarati group BLISS – The premature baby charity British Council of Disabled People Cancer Voices - organises training users of the cancer services to be involved/participate - keeping journals CEMACH (Confidential Enquiry into Maternal and Child Health) CEMOV (Council for Ethnic Minority Voluntary Organisations) CERES Clifford Beers Foundation (mental health promotion) Contact a Family Croydon Voices, London Voices (mental health) Diabetes UK – national and local - North West Surrey Local Diabetes Advisory Group - Voluntary Groups Advisory Council – Diabetes NSF implementation **Disability Alliance** Friends of the Elderly FSID (Foundation for the Study of Infant Deaths) Hear Us Intercamhs

Macmillan Cancer Relief Maternity Alliance Mental Health Foundation - National Service Framework Mental Health Mentality MIND National Centre of Independent Housing (disability) National Childbirth Trust National Children's Bureau NIMH NPFU Ovacome - National support group for ovarian cancer - links to other similar organisations People First - nationwide Perceptions SANDS SANE Shaping our Lives Survivors UK – mental health **TENOVUS** The Foundation for Learning Disabilities **UK Youth Parliament** Values into Action Voice UK Your Voice

Patient/service user reference groups

Ashford and St. Peters Patient Panel Consumer groups - National Cancer Research Institute – Tony Stevens Health Space - project board (computer aided health research) Patient Partnership Panels - Cancer Networks Public Reference Group Service user reference group – PIN project Patient and Public Involvement Forum - Royal College of General Practice

Support/ organisations

Citizen Advocacy: Information and Training Health and Social Care Advisory Service INVOLVE MIDRIS – Information and research service TUC (Trades Union Congress) Valuing people support team

Regulatory bodies

Ethics committees – Local Research Ethics Committees National Institute for Clinical Excellence

Health and social care organisations

Cancer Networks Cancer Services Collaborative Department of Health – Harry Cayton Director for Patient and Public Involvement National Centre for Independent Surgery NHS acute Trusts - Chief Executives, Directors of Nursing, Directors of Midwifery – Guy's and St. Thomas's NHS Trust NHS Research and Development Division Patient and Public Involvement Forums Primary Care Trusts – North West Surrey, Woking, Redbridge

Institutes/professional organisations/societies

American Society Clinical Oncology Association of Retired Personnel British Association of Perinatal Medicine British Institute for Leaning Disability British Society of Gerontology Community Practitioners and Health Visitors Association European Society of Medical Oncology National Family and Parenting Institute Neonatal Nurses Association Paediatric Association Royal College of General Practice – Patient and Public Involvement Forum Royal College of Nursing Royal College of Paediatrics and Child Health

Research Centres

Association of Research Centres in Social Research National Cancer Research Institute Norah Fry Research Centre (Bristol) Nursing Research Unit, King's College London Social Care Institute for Excellence

Education

Board of Governors – Robert Bruce School Department of Education and Training Higher education - King's College London National Association of Head Teachers Media Aspire Magazine Balance Magazine BBC News Children Now Magazine Good Times Magazine

Journals

Birth

British Journal of Cancer Nursing British Journal of General Practice British Journal of Midwifery British Medical Journal Care and Health Children and Society Journal Community Practitioners and Health Visitors Association Journal **Disability and Society** Health Expectations Health Informatics (e-mail) Health Service Journal Infancy International Conferences of Community Nursing Research International Journal of Mental Health Promotion Journal of Community Care Journal of Education in Primary Care Journal of Interprofessional Care Journal of Medical Education Journal of Neonatal Nursing MIDIRS (Midwives Information and Resource Service) Midwifery Matters Nursing Standard **Nursing Times PPI** Monitor **Practicing Midwife** Royal College of Medicine Journal The New Generalist

Databases/Websites

Cochrane Database Dipex – web based database of patient experiences INVOLVE – research projects database Shaping our Lives Website Social Care Electronic library – Social Care Institute for Excellence

Appendix 10 Service user reference group views about priority topics

The following issues were identified as being important based on group discussions of the review framework. These issues are highlighted in the findings section of the report.

External/context issues

- Improving access for service users to be involved in research.
- Understanding the impact involvement has.
- Issues about service users leading research.
- Some people think that there is 'too much knowledge in nursing'.
- Some people think that knowledge/research interferes with giving care.
- The public are cynical about politics and policy decisions are not seen as research based.
- The public are not aware or interested in research but there is interest in ethical debates such as animal testing and euthanasia.
- Professionals have power and there are communication issues between service users and service providers.

Methods issues

- Placing service users at the beginning and centre of research as the driving force and part of decisions all the way through. This links closely with the topic of the research and it should be considered in consultation with service users to ensure its value and worth to service users.
- Feedback to participants should be integral to research and not just an added extra.
- Enablement to participate/contribute is linked to issues about recruitment, training and payments.
- Thinking ahead about dissemination and drawing on other previous work.

Outcomes issues

- All research should be written up and if not published in a reputable journal should be listed and available for public scrutiny.
- Research Ethics Committees should be required to submit to a national database a list of all projects that have received approval.

- Service users should be involved in the interpretation of research findings and should see drafts of papers before they are finalised so that their comments can be considered.
- There is a need to gather evidence that consumer involvement improves the research. Long-term follow-up should be specified at the beginning of research projects.
- Dissemination and feedback should be tailored for different studies and results should always be fed back to participants.
- People consenting to participate in research trials should be informed of which parts of the trial they are involved with and they should be told at the start they can have access to a final report.
- Topics for research should be identified by consumers and taken forward by researchers.
- Service users involved should be acknowledged on publications.

Capacity issues

- Service users should be supported to be involved in research and researcher training. To be successful training needs to be up-todate, user-led and the importance of it needs to be emphasised. Service users and professionals should have time to 'bounce ideas' off each other.
- There needs to better understanding of relationships and where power lies.
- Researchers knowing who service users are, networks and communities.
- Involvement should be about opening new doors to employment or other activities to support personal interests and development.

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Addendum

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