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Service user involvement in nursing, midwifery and health visiting research: A review of evidence and practice

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Abstract

Objectives: In the UK policy recommends that service users (patients, carers and the public) should be involved in all publicly funded health and social care research. However, little is known about which approaches work best in different research contexts and why. The purpose of this paper is to explain some of the theoretical limitations to current understandings of service user involvement and to provide some suggestions for theory and methods development. This paper draws upon findings from a review of the research 'evidence' and current practice on service user involvement in the design and undertaking of nursing, midwifery and health visiting research.
Design: A multi-method review was commissioned by the NHS Service Delivery and Organisation (SDO) Research and Development Programme. The timeframe was April 2004–March 2005. The full report (Ref: SDO/69/2003) and supplementary bibliography are available from: http://www.sdo.lshtm.ac.uk.
Review methods/data: Initial searches of the health and social care literature and consultations with researchers were used to develop a broad definition of the topic area. A service user reference group (26 members) worked with the project team to refine the scope of the review, to set inclusion criteria and develop a framework for the analysis. Systematic searches of the literature were undertaken online and through library stacks (345 relevant documents were identified). Ongoing and recently completed studies that had involved service users were identified through online databases (34 studies) and through a national consultation exercise (17 studies). Selected studies were followed up using telephone interviews ($n = 11$). Members of the service user reference group worked with the research team to advise on key messages for dissemination to different audiences.
Results: Information was gained about contextual factors, drivers, concepts, approaches and outcomes of service user involvement in nursing, midwifery and health visiting research, as well as developments in other research fields. Synthesis of this information shows that there are different purposes and domains for user involvement, either as part of researcher-led or user-led research, or as part of a partnership approach. A number of issues were identified as being important for future research. These include: linking different reasons for service user involvement with different outcomes; understanding the relationship between research data and service user involvement, and developing

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conceptualisations of user involvement that are capable of accommodating complex research relationships. Suggestions for the development of practice include: consideration of diversity, communication, ethical issues, working relationships, finances, education and training.

Conclusions: Because research is undertaken for different reasons and in different contexts, it is not possible to say that involving service users will, or should, always be undertaken in the same way to achieve the same benefits. At a research project level uniqueness of purpose is a defining characteristic and strength of service user involvement.

Keywords: Service user involvement; Participative research; Systematic review

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What is already known about the topic?

- In the UK policy recommends that service users (patients, carers and the public) should be involved in all publicly funded health and social care research.
- Involving service users as active partners in research processes can help to achieve better quality research, which might lead to better quality health services. However, little is known about which approaches work best in nursing, midwifery or health visiting research contexts or under what circumstances successful outcomes can be achieved.

What this paper adds

- This paper provides an analytical account of service user involvement in the design and undertaking of nursing, midwifery and health visiting research in the UK.
- The paper suggests ways for researchers and research organisations to develop their capacity to work with service users. Important issues to consider are diversity, communication, ethics, working relationships, finances, education and training.

1. Introduction

Nursing, midwifery and health visiting research seeks to build knowledge to inform clinical, managerial and educational practice and promote community health. It looks at the activities nurses, midwives and health visitors undertake across all of these areas. There is a strong tradition of such research at community level, and this has contributed to the current evidence base on patient-centred services (Department of Health (DH), 2004, 2005). Studies have used different methods to give service users (patients, carers and the public) opportunities to share their opinions; for example using focus groups, health diaries or storytelling. However, service user involvement in research means more than people being the subjects of research. Service users can also be involved in, or take responsibility for, planning research, undertaking research or evaluating research. In the United Kingdom (UK) policy recommends involving service users in these ways to achieve better quality research (Department of Health (DH), 2001a), which might lead to better quality health services (Department of Health (DH), 2000).

Although issues of service user involvement are not specific to the UK, terminology, policy and health systems significantly influence how user involvement is constructed and perceived. There is still much to learn about the meaning and practice of user involvement internationally but this is not possible in this paper. This is not to suggest that the issues this paper raises will not be of interest or relevance to an international audience.

In the UK context, the focus on service user involvement in nursing, midwifery and health visiting research is in line with a broader policy agenda for involvement in health and social care (Department of Health (DH), 2001b). Previous reviews have brought new understanding about service user involvement in the planning and development of health care (Crawford et al., 2002), delivery and evaluation of mental health services (Simpson and House, 2002), change management (Crawford et al., 2003) and health research (Baxter et al., 2001; Boote et al., 2002). Some work has been done to review user involvement in user-focused research (Alabaster et al., 2000). There is still much to learn about what user involvement in research is, which approaches work best, when and why.

The language of ‘service user involvement’ suggests a situation in which service users are invited to participate in the research process. However there is a growing emphasis on research that is led by service users, in which they develop, take responsibility for and drive a project (Turner and Beresford, 2005). Although service user involvement should not be perceived as a wholly researcher-led activity, it is this form of user involvement that is the main concern of this paper. There are also important issues about service user involvement in research priority setting and commissioning structures, research ethics committees, and in the implementation of research findings, which are not covered here.

2. About the study

The aim of the study was to inform the NHS Service Delivery and Organisation (SDO) Research and Development Programme about the theory and evidence on service user involvement in the design and undertaking of nursing, midwifery and health visiting research. The team that undertook the work came from a range of academic and NHS research backgrounds; including nursing, mental health, social work, social policy and public involvement. Our different perspectives were helpful for making links to other research fields and involvement contexts. Team members' personal experiences of service use and caring responsibilities were also important to the study. An experienced service user representative was part of the core team and chaired a service user reference group specifically set up for the duration of the study (described below).

Because the topic area was complex and developmental we chose to use a multi-method approach to explore different aspects, perspectives and issues. The overview presented in Fig. 1 shows different stages of the methods and gives an indication of their iterative nature. For example, an initial search of the literature was undertaken to identify issues for discussion at a service user reference group meeting. This then informed the definition of inclusion criteria and key search terms for full systematic searches of the literature (summarised in Appendix A).

A consultation exercise was undertaken with professionals and research groups using a web-based questionnaire, disseminated through 30 national email networks and promoted through professional and research networks. The consultation identified 17 studies that were relevant to the review. Telephone interviews were used to gain detailed information about 11 of these. More information about the consultation methods and summaries of each study can be found in the full report (Smith et al., 2005a).

In line with the topic of the review, service users were involved to inform the scope of the review, support the identification of appropriate literature and ongoing studies, reflect on the evidence, and advise on outputs/dissemination. We brought together a service user reference group of 26 service users for this purpose, aiming for a diversity of members to reflect the broad range of activities that nurses, midwives and health visitors undertake, and the different client/patient/service user groups they work with. There is not space in this paper to provide details of the recruitment process, representation issues or dilemmas of this process. Details of these can be found in the final report.

3. The scope of the review

The project team aimed to work with members of the service user reference group to make decisions about the scope of the review and to set inclusion criteria. Before we could do this we needed to develop a broad definition of what we meant by 'service user involvement in nursing, midwifery and health visiting research'. We developed a series of working definitions (see appendix of the full report), using initial sweeps of the literature and consulting with researchers working in the area. From this broad definition of the topic area it was possible to make the following decisions about scope in discussion with members of the service user reference group.

(i) We chose to use the Department of Health definition of a 'service user': any person who has, is, or may access NHS or independent sector health services in the UK (Department of Health (DH), 1999). However, we aimed to be sensitive to different terms and concepts in policy, professional and lay discourses (for example consumer, lay person, patient; as discussed by Boote et al., 2002), and to acknowledge that, for different and complex reasons, some people might not see themselves as service users or may never actually use, or be able to access a health service (Beresford, 2005).

(ii) Although we were interested in making international comparisons it was not feasible to do this in a systematic way. The review timeframe did not allow us to explore different meanings of the topic in other cultural and health care contexts. We decided to focus on finding information relating to health, medical and social research in the UK, but not to exclude information from other countries if it provided insights that could be applied to the UK.

(iii) We defined 'nursing, midwifery and health visiting' (NM&HV) according to the professional groups that these terms are associated with in the literature. These were: 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 and temporary nursing staff, and health care assistants. We perceived NM&HV to include staff working across all grades and within all specialities; those working within the NHS and local authorities, including Care Trusts and Childrens' Trusts, and within the education, independent and voluntary sectors. We chose to broadly define 'NM&HV research' according to the professional activity being studied rather than the professional group undertaking the research. This is because not all NM&HV research is carried out by nurses, midwives or health visitors and nurse researchers may be involved in research that is not specifically about

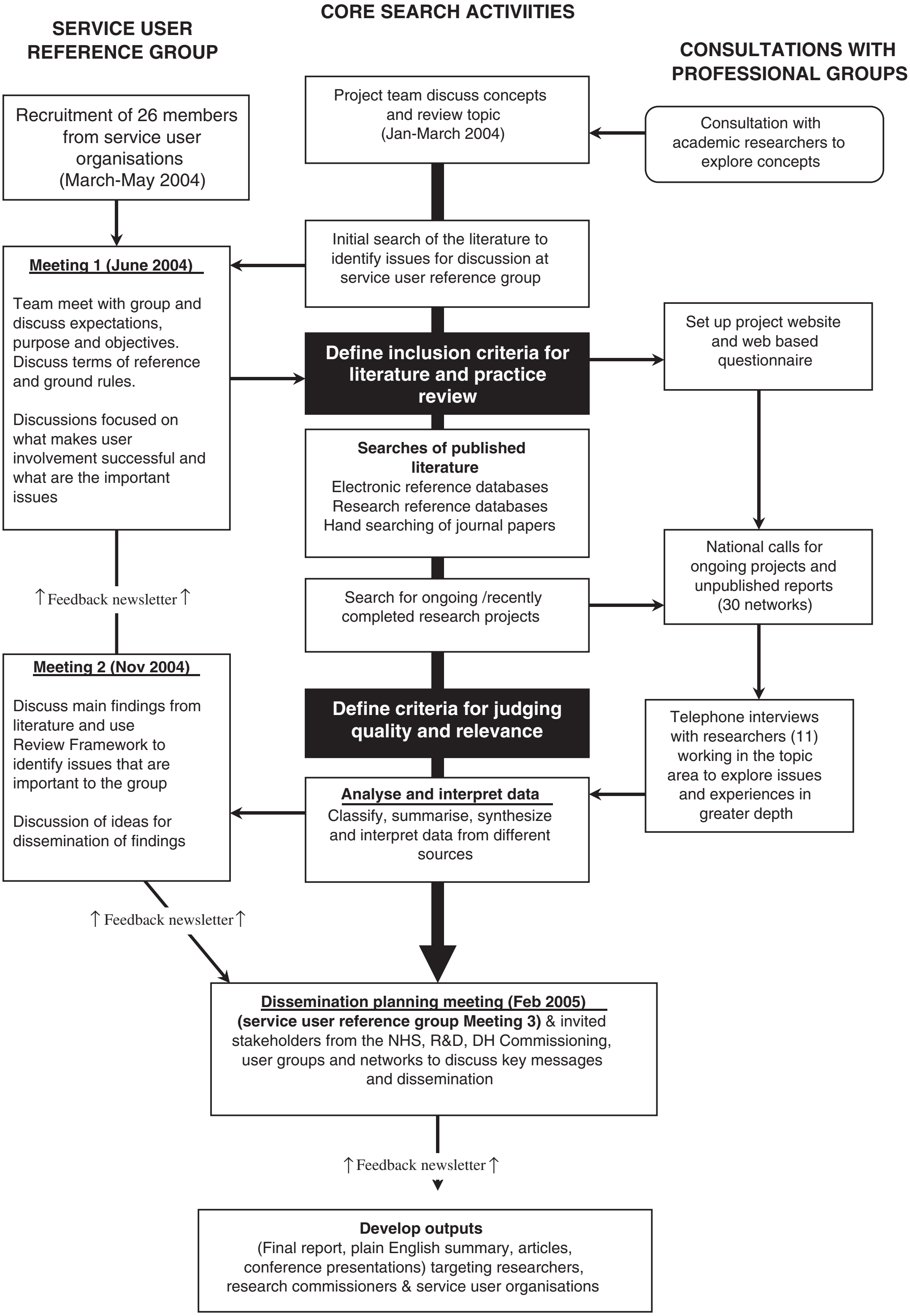

Fig. 1. Overview of the multi-method approach.

these professional groups. We perceived NM&HV activities to encompass provision of care, treatment, investigations, support, health promotion, public health and working for health in communities. We also included research about areas of joint working at the interface of health and social care.

(iv) We attempted to demarcate theoretical boundaries between service user involvement in research and other types of involvement activities, such as the involvement of service users in their own care or the delivery of care for a relative, or involvement in educational interventions. We took 'involvement in research' to include:
  - ○ funded or unfunded research projects, including programmes of work, postgraduate or doctoral research;
  - ○ time-limited one-off involvement interactions between researchers and service users as well as ongoing relationships;
  - ○ work described as 'community development' where this had directly involved or concerned nursing, midwifery or health visiting services;
  - ○ the systematic development of nursing, midwifery or health visiting services as the result of research, but not other broader types of service development;
  - ○ processes of evaluation; such as the evaluation of service delivery initiatives, research or educational interventions;
  - ○ research about the design or evaluation of nurse, midwife or health visitor education or training.

(v) We recognised that there were important related issues about service user involvement in research priority setting, research commissioning and tendering, and within ethical and scientific review bodies. However it was only possible to focus on such issues where they specifically related to service user involvement in research.

4. Synthesis and analysis

We have described our approach to using different methods to analyse and synthesise information from a wide range of sources as a multi-method review. Previously, researchers have developed different methods for synthesising information from diverse sources. We specifically looked at the work of Britten et al. (2002) and Greenhalgh et al. (2004). Although these approaches guided our thinking they did not always seem to fit the purpose of what we were trying to achieve. A review of issues in methodological research (Lilford et al., 2001) provided perspectives from researchers and commissioners that we could relate to. We did not perceive the views of the service user reference group to be data in the review. Their views informed the process, helped us to identify priority issues and provided a commentary to the findings in the final report. We would be oversimplifying the relationship between the project team and the service user reference group if we were to define it according to current conceptualisations of user involvement (discussed later in this paper).

The analysis aimed to identify the most relevant issues, points of interest, insights and ideas about the topic, with a view to informing future development of service user involvement in NM&HV research. One member of the service user reference group described this as putting a jigsaw puzzle of issues together. A Review Framework (Appendix B) was essential to this process. It was drafted from an initial trawl of the literature and refined several times as a result of discussions with the service user reference group (see full report for details, Smith et al., 2005a). We adopted a broadly structured approach to extract information from source documents (using a Review Tool which corresponded with the Review Framework, Appendix C). We wanted to pursue themes within and across different source documents, so for each document we identified key sections of the text and allocated codes to these. Three researchers independently reviewed abstracts of a sample of papers ($n = 50$) to check for consistency of judgements about inclusion and the application of code categories ($n = 6$). We used reference management software (Endnote version 9) and developed literature tables in Microsoft Word to comment on each document, note key passages, and to describe the type and source of the information (in terms of opinion, policy, research based, or systematic review findings). Because the majority of documents was discursive or comprised accounts of qualitative research it was not appropriate to apply methodological weighting criteria as is often used in the appraisal of quantitative studies.

5. The nature of the data

Searches of health and social care electronic databases (listed in Appendix A) identified 2132 publications of which 345 were judged to be relevant based on their titles/abstracts. An annotated bibliography of all documents included in the review is available online as a supplement to the full report (http://www.sdo.lshtm.ac.uk). Library searches for books and chapters revealed a further 25 documents, most of which were only partially relevant to the topic area and to the scope of the review. A search of the INVOLVE (www.invo.org.uk) online database using the terms nursing/midwifery identified 11 relevant projects. These were predominantly about service users' views of service provision, for example nurse prescribing in mental health services, residential care for people with dementia, and mental health needs of children and young people. Other projects were evaluations of professional practice (antenatal care), new specialist nursing roles (multiple sclerosis inquiry), multidisciplinary education, and drug effectiveness (Parkinson's disease). A search of the online National Research Register using the terms nursing/midwifery and user involvement identified 23 completed studies. These involved service users in the development of nurse-led services (cancer care, community mental health, children and young people with a long term illness or physical disability); developing information or guidance for professionals and service users; or establishing processes of shared-decision making, such as user directed assessments among older people. The national email calls identified a further 33 studies of which 17 were relevant to the review. Eleven of these were followed up with telephone interviews to gain information about the rationale, approach, challenges, and impact of user involvement at a project level.

6. What is known about service user involvement in NM&HV research

The study shows how service user involvement in nursing, midwifery and health visiting research can be conceptualised. It also shows how nursing, midwifery and health visiting research has contributed to different theories and approaches to involving service users and suggests ways of involving service users in the broad ranging contexts of nursing, midwifery and health visiting research. In this paper it is only possible to look at some of the key contextual factors, issues and challenges for the development of service user involvement in NM&HV research.

7. Contextual factors

Service user involvement in research has been influenced by a complex interplay of social and political ideas and movements. Other authors have described these factors so we will only provide a brief overview here and direct the reader to key publications.

(i) *Consumerism and participation*: From the 1980s ideas about consumerism in UK health services have been driven by attempts to meet increasing demands on health services (Segal, 1998). Consumerism has generally been interpreted as patients having more choice about how their care is provided and service providers being more responsive to these choices (Almond, 2001). Consumerism has stimulated service-wide, strategies of participation and community involvement (Croft and Beresford, 1996; Higgins, 1993). These forms of involvement have been described as being top-down and managerially led (Beresford, 2003).

(ii) *Changes in patient–professional relations*: Changes in professional working at the clinical level indicate a widespread move to involve people in decisions about their own health. Shifts in health care towards protection and promotion of health and prevention of illness further encourage self-knowledge and responsibility (Kuss et al., 1997). Concepts such as 'patient-centred care' and 'patient participation' have become commonplace in professional literature (Coulter, 1999). Nursing, midwifery and health visiting research has contributed to the evidence base for improved communication and patient decision-making in clinical care and to the development of patient-centred services (Cody, 2003).

(iii) *Growing public concern and expectations about research*: The literature also tells a story about the changing relationship between the public and research communities. It documents the work of Sir Iain Chalmers to advocate lay involvement in research (Chalmers, 1995), high profile inquiries into incidents in research and clinical practice (The Bristol Royal Infirmary Inquiry Final Report, 2001; Department of Health (DH), 2001c) and the development of the Research Governance Framework for Health and Social Care (DH, 2001a). There have also been associated movements to involve service users in processes of research commissioning and to identify priorities for research (Oliver, 1999; Oliver et al., 2001; O'Donnell and Entwistle, 2004; Smith et al., 2005b). There are also broader trends across scientific disciplines to engage public interest and build public understanding (Michael, 2002).

(iv) *Changes in the way research is undertaken*: In some fields of health research there are long traditions of user-led movements and user-controlled research (see Beresford, 2005; Mercer, 2002; Oliver, 1999). These forms of research have been important for raising questions about the social relations of research production, as discussed by Baxter et al. (2001). In NM&HV research there is a strong tradition of community-focused research, such as in community health development (Chalmers and Bramadat, 1996). 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). In these contexts participative research methods have been developed to give patients and members of the public a more active role in a wide range of community and practice development activities.

8. Conceptualisations and approaches

Service user involvement in research has been conceptualised as a hierarchy and as a continuum. The most frequently cited model in the research literature is Arnstein's (1969) ladder of citizen participation. This was developed to represent different levels of control the poor had over decision-making processes in the US. A hierarchical relationship between concepts of patient involvement, participation and partnership has also been perceived in relation to nursing practice (Cahill, 1996). In health research, hierarchical levels of consumer involvement—from consultation, through to collaboration, and consumer control—have been described by Boote et al. (2002). Within such hierarchical models, consultation has tended to be perceived as a low level of involvement. This is because the researcher/professional maintains control of the overall agenda (Rodgers, 1994). In contrast, user-led or consumer-controlled research has been perceived as being at the opposite end of an involvement continuum (Matrice and Brown, 1992).

Some researchers have interpreted an involvement hierarchy/continuum as corresponding with progressive levels of power and empowerment (for example, Barnes and Walker, 1996; Poulton, 1999). The concept of empowerment is familiar to nursing practice, nurse education and health promotion, where it has been described as a partnership in decision-making and as freedom to make choices and accept responsibility (Rodwell, 1996). In the provision of nursing services a participation continuum, has been used to relate the concepts of user involvement in decision-making to consumerist and democratic concepts of involvement (Hickey and Kipping, 1998). There is a recognised need to conceptualise involvement according to whether or not empowerment is an explicit aim of the research (Beresford, 2005). We will revisit issues about empowerment in Section 9.

Alternative classifications of involvement have positioned service users according to their possible contributions to the research process (Dixon et al., 1999) and in relation to different stages of the research process (Hanley et al., 2000).

We found that few accounts of NM&HV studies specifically provided a rationale at a theoretical level about why particular individuals were being involved. The wider literature shows that many concerns have been raised about representation in user involvement. In relation to health research, particular issues have been identified by Baxter et al. (2001, p.75) to do with the under-representation of marginalised groups, people's motives for wanting to be involved, and different meanings associated with the term 'community'. Boote et al. (2002) identify further issues, including: different service users' viewpoints may not be in consensus, healthy people may not be represented, and concerns that the more an individual is involved the more they become 'professionalised' and less representative. In disability research, Beresford and Campbell (1994) argue that issues of representativeness have been used to devalue and exclude particular groups of people. Barnes (1997) provides a useful perspective of representation, making distinctions between whether participants are democratically elected individuals that represent the view of their electors, or a representative sample selected using statistical methods to represent the characteristics of a population, or individuals who are considered to be typical of others, or to have shared similar experiences.

This review found detailed accounts of different approaches to service user involvement in the NM&HV literature. These often made reference to concepts of involvement but they tended to be more focused on methodological development. Examples included setting up a service user advisory group in diabetes care (Rhodes et al., 2001), involving older people as research advisors in a project about falls (Ross et al., 2005), and creating user groups in midwifery (Wray, 2003). Other studies have focused on access or communication issues for particular groups of people in research. For example, ways of involving people with learning disabilities or intellectual disability (Kiernan, 1999; Cambridge and Forrester-Jones, 2003), people with advanced HIV infection (Yates et al., 1997), and people near the end of life (Agrawal, 2003) or receiving palliative care (Karim, 2000). Taken together these studies show that service users might be involved for different reasons at different stages and that research methods and approaches need to be tailored to suit different research questions and different groups of service users. The findings show that current conceptualisations of service user involvement as a hierarchy/continuum are limited. They do not reflect that involvement might be going on simultaneously at multiple levels of decision-making (for example, a service user is undertaking part of the research and there is also a service user advisory group), shift between levels (for example, service users have more involvement in a particular aspect of the study than in another), or graduate from one level to another (for example, service users contribute to more important decisions as the study progresses, or vice versa).

A further area of conceptual weakness is what is considered 'research data' in a study and what is 'service user involvement'. Traditionally, as the subjects of research, service users have provided views and experiences about health and illness (Entwistle et al., 1998). Through the process of research, and generally under the control of professionals, this information has been transformed to produce knowledge bases, generate indicators of health and quality of life (Edwards et al., 2003), or to predict health choices (Glasby and Littlechild, 2001). Mainstream interest in service user involvement emphasises feeding lay knowledge and experiences into existing research structures and paradigms (Beresford, 2002). We have found that at a project level service user involvement challenges established ideas about the construction of evidence. Information from NM&HV studies reveals an imprecise and undefined boundary between what can be judged to be data in a project and a decision about the research. It may be that at a project level service users broadly influence which types of knowledge are fed into the research and when. This could be perceived as an epistemological shift between service users being providers of knowledge and service users defining what knowledge is (which information is important). Researchers who perceived this difference valued the interplay between the expression of service user views through the research data and the input of service user knowledge in decision-making.

9. Outcomes of involvement

The research literature shows that involving service users in different aspects of the research process is widely thought to be valuable. Yet, without understanding the particular reasons why service users were involved it is difficult to make any judgements about the nature of the outcomes that were achieved.

We found that few published NM&HV studies had a clear rationale or objectives for involving service users. Often, reasons for involvement were described in very general terms. Previous research shows that when a rationale is presented it may not reflect researchers' actual motivations for involving service users (Alabaster et al., 2000). This could be explained in two ways: researchers believe that their actual motivations will be unacceptable; or that their motivations are difficult to articulate because they are uncertain, changing or complex.

At one level, fulfilling a policy requirement or a condition of research funding for service user involvement might be considered to be an outcome in itself. Although it may be that these requirements provide an initial stimulus for involvement, involving people for these reasons alone has been perceived as being tokenistic (Boote et al., 2002). This means that researchers are unlikely to state that service users were involved solely because policy recommended it or because it was a condition of research funding.

User involvement may be seen as a way of ensuring that research is more relevant to the groups that it intends to inform, or more appropriate to the communities it intends to serve. However, at a project level it is difficult to show whether either of these aims have been achieved because it is not possible to know what the outcomes of the research might have been without the involvement of service users.

Irrespective of whether relevance to society can be demonstrated, there is a moral argument that service users should have a voice in research which may have an impact on their health status (Boote et al., 2002). From the community development literature, there is clearer evidence that involving service users can help to ensure that research processes or methods are acceptable to participants. For example, service user involvement can enable a research project to be conducted in a way that is sensitive to different cultures or beliefs of participants (Meyer et al., 2003).

In clinical research, participants have been asked to provide information about the experience of being involved in such studies, for example in cancer care (Donovan et al., 2002; Thornton et al., 2003) and angina management (Dougherty et al., 1999). Although these activities can mean that service users help to improve the experience of participating in research, participants may have little say about the design or conduct of the research itself (Hanley et al., 2001). In other forms of research participants' experiences of being involved in the research have been used to improve research processes, for example in community mental health research projects (e.g. Reeve et al., 2002; Ramon, 2000).

Involving service users earlier, at the research design stage, can help to identify or develop approaches that suit a particular research context, and participants in the research (Gray et al., 2000). However in the interviews we conducted, researchers reported difficulties with involving service users in writing proposals because of not wanting to raise service users' expectations that the research would be funded, or not having the time or resources to do this. There is also an unresolved research governance issue about whether or not it is acceptable to involve service users before ethical approval has been obtained. Previous research findings indicate that involvement at this stage can help to identify potential ethical issues before they arise (Entwistle et al., 2002).

In researcher-led studies, service users have been involved in developing and piloting data collection tools, designing questionnaires and deciding how data will be collected. In questionnaire design 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, leading to improved response rates (Nicolson et al., 2001). An interesting aspect of outcomes is where service users have defined which outcomes research should measure. For example, in a research project about wound care, patients were involved in developing assessment practices for patient-centred treatment goals. This highlighted differences between professional and patient views of quality of care and quality of life that were fed back into the design of assessment practices (Browne et al., 2004). There is more to learn about the potential overlaps between service user involvement and patient-defined outcomes.

Researchers may also involve service users because they have privileged access to a particular population or community group (Elliott et al., 2002; France, 2000). Several researchers who took part in the interviews said that connecting with community leaders, patient networks or voluntary organisations are good approaches to reaching seldom heard groups in research. For example, one study involved South Asian women as co-researchers to help access and recruit women who had experienced post-natal depression, which is a culturally sensitive topic in the UK context (see full report for more information). Research on peer interviewing shows that training (particularly ethical/confidentiality awareness) and structured data collection methods can positively influence the quality of the data collected (Elliott et al., 2002).

Examples of the involvement of service users in the interpretation of research data are harder to find in the published literature. Our interviews with researchers from the nursing research community 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, and checking a researcher's application of categories to an interview transcript (see full report for details of specific studies).

The literature suggests that involving service users in the dissemination of research findings, for example co-presenting a paper at a conference, can have a powerful impact and can make findings more accessible (see for example, Liberty et al., 1999; Flaskerud and Anderson, 1999). Participants in the interviews also provided us with examples of successful co-presentations of research studies. A more challenging aspect was when and how service users should be involved in writing publications. This may be because writing a publication presents a situation where different emphasis might be placed on particular aspects of the research or findings (McClimens, 2004), which raises issues about ownership and validity of different interpretations.

Policy documents and the research literature claim that there can be benefits for service users who are involved in research (for example, DH, 2004; Baxter et al., 2001; Dixon et al., 1999). Such outcomes have been described as therapeutic, and can be related to concepts of altruism (Agrawal, 2003). Accounts of research studies show that participation has helped some patients with cancer to construct their lives with greater meaning by providing a supportive structure and enabling hope (Moore, 2001).

As we have previously stated, service user involvement has been conceptualised as a form of empowerment. The idea that service users will be 'empowered' by being involved in any particular research project might be over-simplifying the processes involved. Some aspects of being involved in research might feel empowering to some service users but other aspects might feel disempowering. However, 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.

Outcomes of involving service users in research have also been described in terms of processes of change, such as changes to models of research partnerships (Liberty et al., 1999) or research strategies (Gray et al., 2000). Change might also occur to an individual person's perceptions and understandings about research or service user involvement. Changes might be ongoing or iterative, or influence others not directly involved in the research, such as clinicians, policy makers, or service users' families or friends (Hudson, 2003).

This review found very little about the disadvantages of service user involvement or the potential for less than positive outcomes. There is a particular deficit of information about what happens to service users who are involved. It has previously been suggested that the literature overlooks negative outcomes and regressive consequences of involvement (Beresford, 2003). This means there is a danger of establishing service user involvement as a wholly positive activity. More recent publications—produced since the period of this review—have sought to address this imbalance (e.g. Lowes and Hulatt, 2005). Our consultations with researchers from the nursing community revealed some negative experiences, although, these were generally described as challenges, or were couched in terms of a lack of support or interest rather than attributed to inappropriate approaches or a lack of skills. The consultations we undertook with researchers revealed some negative experiences rather than negative outcomes. Some researchers had felt pressurised by their host organisations, colleagues and service users to justify the reasons why service users were being asked to be involved. Others said they had experienced problems reconciling different agendas for the research, knowing how and when to involve service users in different parts of the research, and understanding different perspectives of ownership.

Taken together, these perspectives of outcomes show that service user involvement is about setting agreed and acceptable boundaries for research, gaining benefits for the research process, and considering the positive opportunities that research processes might offer for researchers and service users. It is difficult to predict which outcomes can be achieved in any particular project because of the unique qualities of different research contexts, different approaches to involvement and the complexity of research relationships. A previous

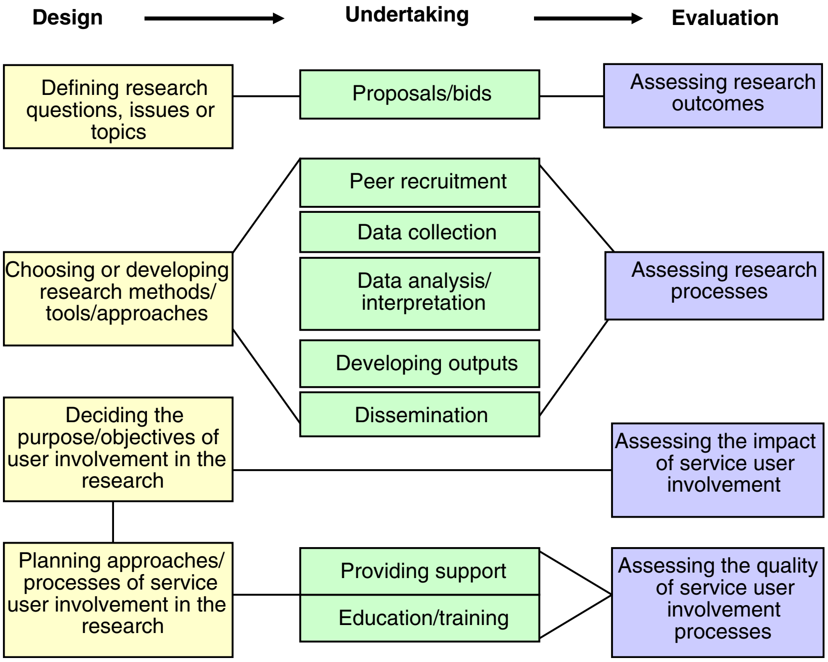

Fig. 2. Types of service user involvement in research.

evaluation of service user involvement in primary care research suggests that criteria for judging impact must take into consideration differences between groups of people, the experiences they have, the ways they are involved and the services they are trying to improve (London Primary Care Studies Programme, 2005). The influence of service users' contributions to the research cannot be easily identified and it is difficult to attribute any change or impact directly to their involvement. It may also take many years for any detectable outcomes to emerge from any particular study.

The literature and our analysis of ongoing studies reveals a need to understand how different approaches to involvement can best be devised or developed to suit particular research contexts. Fig. 2 conceptualises different stages at which service users might be involved in research. It illustrates the multiple domains for involvement, either as part of researcher- or user-led research, or indeed as part of a partnership approach. This conceptualisation may offer a model for investigating different objectives and outcomes for involvement. However, there are significant challenges for expanding and connecting learning beyond individual studies. Service user involvement is undoubtedly complex, dynamic and changing. Furthermore, involvement activities are interconnected and link to related processes of prioritising, commissioning or regulating research. Realising possibilities for service user involvement in research also requires the research community to reflect upon and understand the influence of different epistemiological positions, methods and practices.

10. Practical challenges for developing service user involvement in research

10.1. Capacity to develop research relationships

A range of social, cultural and economic resources is required to support research relationships effectively. Those who fund, lead or otherwise contribute to nursing, midwifery and health visiting research can plan for and address these in a number of ways.

10.1.1. Strategic planning

We have found that in NM&HV research, decisions about whether to involve service users are generally made by lead researchers or principal investigators at proposal stage. Service user involvement is often perceived to be a specialist area, or to only be appropriate to particular types of research. Researchers might have to negotiate and defend their decisions to involve service users in relation to the organisational priorities and objectives of their employer or research-funding source. The process of developing research relationships tends to take place against a backdrop of research traditions and norms, which might present obstacles to collaboration but can offer opportunities for innovation (Reed et al., 2004). Research organisations can strategically address issues of service user involvement in relation to their work (see Stevens et al., 2003; Ghersi, 2002). This might enable researchers and service users to explore how their work links to a wider set of organisational values (Gray et al., 2000) and new forms of research relationships to emerge (Liberty et al., 1999). One such example is the contribution that service users with formal academic qualifications and research experience can offer. In mental health research, academic consumer researchers have helped to improve the relevance of mental health research and bridge the gap between the academic and consumer communities and have contributed to the process of de-stigmatising mental health problems (Griffiths et al., 2003).

Involving service users requires building greater flexibility into projects, particularly in relation to timescales and the provision of additional support (Faulkner, 2004). Little is known about how organisational factors such as patterns of working and job pressures influence whether service users are involved in research. Research organisations need to consider the economic implications of service user involvement when costing research proposals and managing research budgets.

10.1.2. *Working in new ways*

Redefining roles and responsibilities is complex because professional power will always be a feature of both the caring professions and research cultures (Hugman, 1994). Clinical relationships introduce a particular dimension to research relationships with service users. Nurse, midwife or health visitor researchers often need to combine their research role with their clinical roles and this duality is a potential cause of ambiguity and conflict (Coghlan and Casey, 2001). Researchers need to be aware of processes of negotiation, mutuality and respect in their work with service users. Existing principles about the process of service user involvement (for example Telford et al., 2004) can be used to develop acceptable working practices.

10.1.3. *Education and training*

Working in new ways can present education and training needs for researchers (Hanley, 2005). Nurses, midwives and health visitors may receive some training about research and this could incorporate skills development in relation to working in partnership with individuals, communities and other professionals (Fox, 2003; Kelley, 1995). At the moment however, there is limited evidence about what kind of training best supports relationships with service users. New courses in service user involvement in research may flow from a growing interest in patient participation in interprofessional education (Barnes, 2000), collaborative student/patient projects (Bennett and Baikie, 2003) or patient involvement in educational assessment (Felton and Stickley, 2004). Above all, the findings suggest there is a need for researchers to gain greater insight into their own understandings and motivations for research and user involvement.

10.2. *Ethical issues*

The review found that new forms of partnerships with service users in research raise new and different ethical issues in relation to confidentiality, anonymity, informed consent and protection from harm. Where service users are involved as co-researchers or active members of project teams there is a need to consider ethical issues both on the part of service users and to protect other participants in the research. As previously discussed in the section on Outcomes (Section 9), the literature reveals little of the negative consequences of involvement, which means it can be difficult to foresee ethical implications for researchers and service users. User involvement studies may help to show when and why some ethical principles become ethical issues.

The ethical issues of providing, or not providing, payments to research participants can be complex. Some authors have raised particular issues such as the effects of financial incentives on recruitment (Erlen et al., 1999). The issue of reimbursement has received much attention in the literature, and national guidance on the principles and practice of recognising and rewarding service users' contributions has been produced (Department of Health (DH), 2006).

10.3. *Diversity*

It is a fundamental but often overlooked fact that service users have diverse perspectives, experiences, expectations and interests. Working with any particular group does not provide a definitive service user view. Which service users are involved needs to be considered in relation to the purpose, aims and context of any proposed research. Such decisions should be explored, where possible with service users themselves. The literature provides valuable information about ways of approaching different service users, raising awareness, generating interest and keeping people involved (see full report for exemplars).

10.4. *Communicating with service users before and during the research process*

Service users need support and information about getting involved, for example, guidance on what will be expected of them and what their contribution to the research process might be. Related to this, Boote et al.

(2002, p. 227) have shown that some professionals are concerned that service users will not understand the complexities and rigour of research, or have the necessary skills to be involved. There are a range of research training programmes for service users (Faulkner, 2004), however during the review researchers and service users told us it was essential to be open about discussing expectations as early on in the process as possible and to use feedback mechanisms throughout the process, such as reflective notes and suggestion sheets. Enabling two way communication takes time, which suggests that these activities should be built into the process from the start.

11. Conclusions

The review brought together disparate information about user involvement in nursing, midwifery and health visiting research using systematic and reproducible methods. Undertaking the national consultation and interviews with project leads was highly beneficial for identifying and interpreting key issues, ideas, suggestions and ways forward. Although these elements of the review were dependant on the experiences and knowledge of members of NM&HV research communities at the time, the information is a useful supplement to the literature. Working with members of the service user reference group connected the project with specific concerns, issues and perspectives that might not otherwise have been gained. Service users influenced the project by identifying issues and priority areas for future development. They were critical friends, challenging and stimulating us to reflect on our own understandings of the issues, and they provided advice about the best ways of disseminating findings through lay networks.

Nursing, midwifery and health visiting research is undertaken for different purposes and in different contexts. It is not possible to say that involving service users could, or should, always be undertaken in the same way to achieve the same benefits. Future development relies on understanding: links between different reasons for service user involvement and outcomes; the relationship between research data and service user involvement; and developing conceptualisations of user involvement that are capable of accommodating complex research relationships. The NM&HV research community can develop capacity to work with service users by considering issues of diversity, communication, ethical issues, working relationships, finances, education and training. However, future development should not compromise the uniqueness of purpose that seems to be a defining characteristic and strength of service user involvement in research.

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Contributorship: All of the authors contributed to conception and design, analysis and interpretation of data through team discussions and writing. FR had overall responsibility for the project. ES undertook the literature searches, led the analysis and drafted the paper. Other authors critically revised it and gave approval for publication.

Appendix A. Key search terms and index terms

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

Notes: Different electronic databases use different index terms to categorise publications. Key words were used to identify index terms and then these categories were individually searched.

The wildcard function ($) was used to search for multiple word endings. An adjacency operator was used to search for combinations of words with 1–3 words separation.

Electronic databases searched included: AMED (Allied and Complementary Medicine) 1985–July 2004 (313 papers), British Nursing Index 1985–July 2004 (136 papers), CINAHL (Cumulative Index to Nursing & Allide Health Literature) 1982–July Week 4 2004 (79 papers), EMBASE 1980–2004 (111 papers), MEDLINE 1966–July Week 4 2004 (1078 papers), PsychINFO 1985–July Week 4 2004 (114 papers), Health Management Information Consortium (HMIC) (96 papers), ISI Web of Science 1990–2004 (187 papers). Additional database searches of AgeInfo, Applied Social Sciences Index and Abstracts for Health, British Education Index, Care Data (via Electronic Library for Social Care), Cochrane Library, ERIC (Educational Database), Health Promis (UK Health Promotion), IBSS (Social Science), Internurse.com, National Electronic Library for Health, Social Service Abstracts, revealed a further papers.

Appendix B. Review framework

Context/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, e.g. funding streams/programmes. The involvement of service users in commissioning, e.g. identifying priorities for research. Commissioning strategies that enable service user involvement.
Research issues:	When does research begin? The difference between service development/research and evaluation. What is nursing, midwifery and health visiting research? The difference between user involvement in research and research on user involvement.
Funding:	Funding of involvement an organisational level, e.g. 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, e.g. clinical area, client group, service setting, etc.
Setting:	Issues about the organisation or setting in which the research is taking place, e.g. 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, e.g. advisory group, individual representative on board Responsibilities of different roles.
Activities:	What are service users doing? The activities service users are involved in, e.g. design, data collection, analysis, publication, etc. Involvement in recording or evaluating the process, e.g. user diaries, reflection.
Recruitment:	'Representation' issues. Determining who is/should be involved. Ways of approaching different groups/individuals, e.g. 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 relations:	Professional/lay 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, e.g. 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 e.g. commissioners/clinicians/wider public, e.g. public understanding of science.
Outputs:	The products of research, e.g. 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:	The use of the findings of user involvement projects in other research projects or contexts.

Transferability:	Issues about the implications of findings to other contexts.
Capacity issues	
Organisation:	Factors associated with the organisation(s) that are conducting the research, e.g. 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 C. literature Review Tool

Author(s) of paper: (*for Reference*) ________________

Which of the following topics does the paper cover? (*Indicate ALL that are covered*)

Context/background

- ☐ 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 issues

- ☐ 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.

Topic(s)	Issue identified/described	Comments/reflections	Page(s)

(Please add further rows to this table as necessary).

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