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
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
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
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.
Disclaimer

This report presents independent research commissioned by the National Institute for Health Research (NIHR). The views and opinions expressed therein are those of the authors and do not necessarily reflect those of the NHS, the NIHR, the SDO programme or the Department of Health.

Addendum

This document was published by the National Coordinating Centre for the Service Delivery and Organisation (NCCSDO) research programme, managed by the London School of Hygiene and Tropical Medicine.

The management of the Service Delivery and Organisation (SDO) programme has now transferred to the National Institute for Health Research Evaluations, Trials and Studies Coordinating Centre (NETSCC) based at the University of Southampton. Prior to April 2009, NETSCC had no involvement in the commissioning or production of this document and therefore we may not be able to comment on the background or technical detail of this document. Should you have any queries please contact sdo@southampton.ac.uk