

Developing a service-user framework to shape priorities for nursing and midwifery research



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Abstract Many people believe, and government policy recommends, that service users should be involved more in research agenda setting. This paper helps to provide a way of undertaking this, drawing on the approach used in a national research priority setting exercise for nursing and midwifery service delivery and organisation. A framework of service-user expectations for nursing and midwifery services was developed through a process of focus group discussions. Thirty-two participants were recruited from Community Health Councils (CHCs) because of their formal role in linking to health providers and as advocates of local communities. Discussions focused on the main gaps in nursing and midwifery services, priority areas for improvement and ways of involving service users in these developments. Nine broad expectations for nursing and midwifery services were identified and were used as a framework for the alignment of professional stakeholder data and literature and policy analysis. This enabled five priority areas for research to be identified that were important to all of these groups. Targeted sampling, information giving prior to

the focus groups, careful explanation of confidentiality and the purpose of the exercise and facilitation skills were important for developing a framework that covered the wide breadth of the topic area. The process also raised important questions for nursing and midwifery research. Conceptual difficulties about balancing service-user control and researcher influence, and the authenticity of the data in representing diversity, were limitations of the approach. A final report is available at www.sdo.lshtm.ac.uk/nursingandmidwifery.

Keywords user/consumer involvement, research priority, nursing research, midwifery research

Introduction

Involving service users in identifying priorities for research within the field of nursing and midwifery is important as these professional groups comprise the largest part of the NHS workforce and are key staff for the delivery of a patient-focused service (DoH, 2000a). Recent policy has highlighted the importance of strategic development and support for a research agenda to underpin necessary changes in nursing and midwifery organisation and practice (DoH, 1999; NHSE, 2000). Building 'active partnerships' with service users (Boote, 2002) in all aspects of research and development is a theme of a number of recent National Health Service (NHS) reports (NHSE, 1998; NHSE Research development Directorate, 1998; Consumers in NHS Research, 1999a).

The National Co-ordinating Centre for Service Delivery and Organisation (NCCSDO) manages a major stream of Research and Development (R&D) funding that aims 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. Previous work commissioned by the programme has identified a series of priorities for National Health Service (NHS) delivery and organisation (Fulop and Allen, 2000) but this work did not look specifically at service users' priorities, or priorities for nursing and midwifery. This paper describes the approach of involving service users in an exercise that was commissioned by the NCCSDO R&D Nursing and Midwifery Subgroup to identify priorities for research commissioning in the fields of nursing and midwifery, including: health visiting, students within these professions, agency staff, healthcare assistants and those working in public and private sectors. The timeframe for the exercise was April–September 2002.

Summary of the literature

Although user involvement in research priority setting is a rapidly developing area, existing work in nursing and midwifery service delivery and

organisation is limited. With the exception of Sleep and Renfrew (1995), who conducted a Delphi study for midwifery research, priority setting has been the concern of those within policy and academic communities or leaders within the professions (Kitson et al., 1997; Daniels and Ascough, 1999; Scott et al., 1999; Vella et al., 2000). The contribution and role of service users in the priority-setting process is a recognised priority for nursing, for example in identifying problems/issues and isolating likely dimensions and causes (Ritchie and Spencer, 1994).

The wider literature on user involvement in setting the agenda for research raises questions about: increasing conceptual clarity about purpose(s), impact and outcomes of involvement (Consumers in NHS Research, 1999b); changing and re-establishing hierarchies of power (DoH, 2000b), for example contesting professional power (Poulton, 1999); developing methods of identifying common objectives and mutually beneficial courses of action (Oliver, 1995) for the users and providers of health services (Coote, 1993); tackling issues of 'representation' (Hogg and Williamson, 2001) and 'generalisability' (Boote, 2002) whilst valuing diversity of views and perspectives (Steel, 2003); addressing additional financial costs of involvement and implications for sustainability (Beresford, 2003); and increasing capacity for user involvement, for example developing organisational infrastructure (Stevens, 2002), increasing skills and abilities of professionals to award control to service users and enabling service users to be involved (Consumers in NHS Research, 2004).

A significant amount of work has focused on research methods as a facilitator of user involvement; for example, Moran and Butler (2001) make links with ideas of accessing lay knowledge through language creation from below and finding ways to influence service development using participation research methods. This paper aims to extend understanding about the conceptual and methodological problems for researchers attempting to incorporate the user perspective in identifying priorities for research.

Methods

Aims and approach

In the exercise we draw upon here, service-user views were used as building blocks for the development of a service-user framework to shape priorities for research identified in professional stakeholder interviews and a literature and policy review. The aim of involving service users was to develop a research agenda informed and shaped by service users. This aim was defined in the context of existing beliefs about user involvement — namely that this would lead to a research agenda that was more relevant

and appropriate to their needs. Three broad objectives were identified with the help of a national user-involvement organisation (INVOLVE, formerly Consumers in NHS Research) and an expert user. These were:

- To recruit a sample of individuals with suitable knowledge and experience to be able to represent the views of services users on a national basis.
- To organise and undertake five regional focus groups.
- To synthesise the service-user data and use this as a basis for the identification of research priorities in the professional stakeholder data and the literature.

In this paper, our reflections on the approach are made in the context of these objectives and are supported by process data, for example the sampling strategy, focus group transcripts or participant registration information, researcher observations and reflections.

Sample and recruitment

There were difficulties identifying a sample of service users who were sufficiently knowledgeable about nursing and midwifery services to make their involvement in the exercise 'meaningful'. Participants also needed to be able to 'represent' (Boote, 2002) the wider needs of communities of people and client groups rather than simply relaying their personal experiences. Participants were recruited through Community Health Councils (CHCs). These are established lay member organisations with formal links to health providers and knowledge of local issues. CHCs were replaced by Patient and Public Involvement Forums on 1 December 2003, but at the time were considered to be the most suitable formally recognised service-user body. We wrote to the Chair and Chief Officer of 126 CHCs in England and Wales to invite them to participate either themselves or through nominated suitable Member representative. Thirty-three CHC Members (including two Chairs and two Chief Officers) expressed their interest and all were selected to participate in the focus groups. Members of a further six CHCs provided written submissions. Those who participated were predominantly female, white and between 35–60 years of age (shown in Table 1), reflecting the wider membership of CHCs. Prior to the focus group, participants were asked to state their areas of personal interest in relation to 11 areas of nursing, midwifery and health visiting. Overall, the strongest areas of interest were acute and primary care nursing, probably due to the relative broadness of these areas. Midwifery, the care of older people and child nursing also featured strongly in participants' interests.

Table 1 Participants in the focus groups

Personal interests*	Focus group				
	1 South London 2 male 2 female	2 North London 9 female 1 male	3 Sheffield 7 female 1 male	4 Bristol 6 female 1 male	5 Birmingham 4 female 0 male
Acute	4	8	7	3	3
Mental health	1	3	2	3	1
Learning disability	1	3	1	1	1
Primary care	4	8	7	6	4
Health visiting/ district nursing	1	3	0	3	2
School nursing	2	5	3	2	0
Midwifery	1	5	5	4	2
Child	3	5	3	3	2
Adolescent	3	3	2	1	1
Adult	2	2	3	1	1
Older people	2	6	5	2	2
Other**	Men's health	Carers Critical care BME groups	–	–	–

* Participants were asked to define their personal interests in relation to nursing, midwifery and health visiting prior to the focus group.

** For each item one person stated this was a personal interest.

Design

The rationale for using focus groups was that this was considered the most practical way of capturing in-depth views of a broad topic area (Kruger, 1994) on a national basis. They were also a good way of establishing consensus between participants about priority areas and enabled us to verify emergent themes towards the end of the discussions. Project resources and time allowed for five focus groups to be undertaken. We set a high maximum number of participants in each group (up to 10 people) to maximise inclusion. Localities were chosen to be as close to participants' CHC bases as possible. A focus group topic guide comprising four broad questions was devised to enable discussions about nursing and midwifery in terms of aspects of care, client groups and service areas:

1. What are the main gaps in nursing/midwifery services?
2. What improvements would you like to see made to nursing/midwifery services?
3. What are the major priority areas and why are these important to the group?
4. Thinking about these improvements, how could they be made and how could users be involved?

The guide was sent to all participants prior to the focus group so that participants could 'come prepared' with any necessary written materials. Five experienced qualitative researchers worked in pairs to facilitate the focus groups. They aimed to keep the discussion to the discussion guide, to enable all participants to express their views and to document the characteristics of the group and the main topics covered. All of the discussions were audio-taped and transcribed. Participants were all asked to give their written consent to be involved and their consent for their views to be anonymised and used for publication. Confidentiality between participants was verbally agreed.

Analysis

The discussions generated a large amount of highly relevant qualitative data covering a broad range of topic areas. The data were synthesised using the Framework Approach (Richie and Spencer, 1994) to qualitative data analysis and a specialist computer package (ATLAS.ti). The themes and associations that emerged from the data were interpreted as corresponding with nine broad expectations for nursing and midwifery services. These were prioritised according to participant's views (agreed towards the end of the focus group) and the relative significance of issues that focus group participants awarded to these topic areas (Figure 1). This enabled a crude form of verification that could arguably have been improved by going back to the groups to check the interpretation, if time had permitted. Shortly after the focus groups, participants were sent a bullet point summary of the discussions but none of the participants contacted us with anything to add.

In the professional stakeholder interviews and literature analysis, two researchers independently identified priorities using thematic analysis. These were then aligned with the framework of service-user expectations for nursing and midwifery services (Figure 2).

Findings

The full findings of all three strands of data collection are available in the final project report. Here we will briefly describe some of the differences in the data. An interesting comparison with professional views was that service users awarded a greater significance to the delivery of essential care in terms of the comfort and recovery of the individual patient. A further key finding has been an understanding of the attitude and perceptions of service users towards the process of research and the view that research findings are not implemented or sustained, particularly when pilot projects show a clear advantage for patients. Differences between service user and professional views show that professional views do not

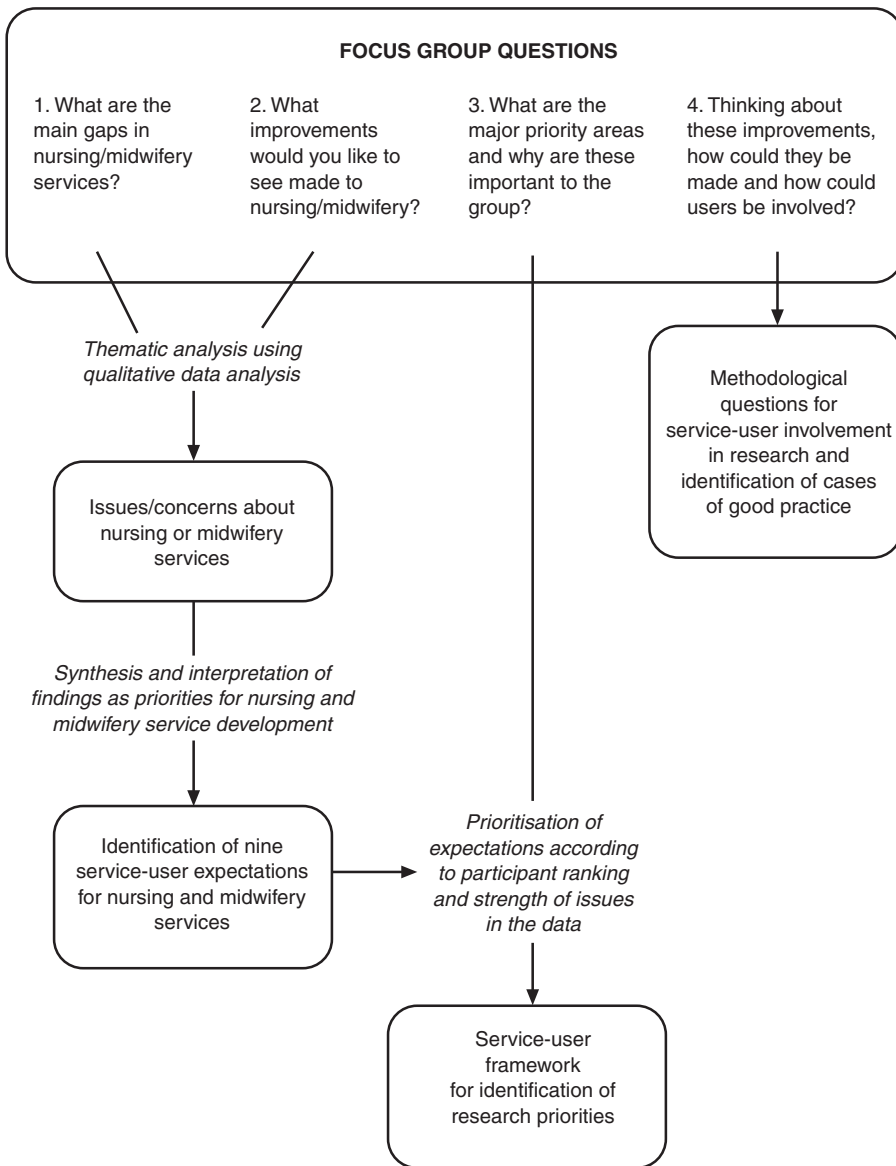
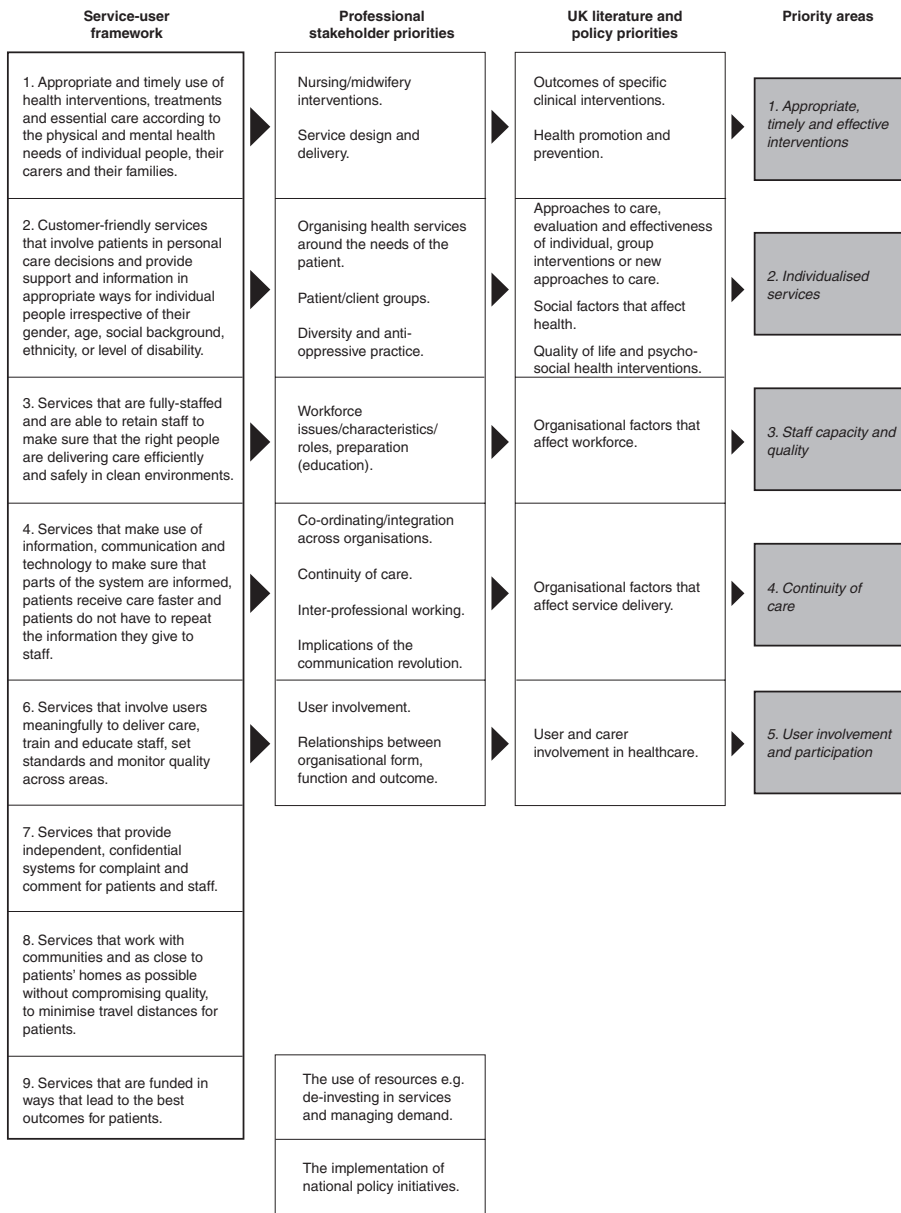


Figure 1 Flowchart to illustrate development of the service-user framework.

necessarily reflect what is important to service users. This finding supports the ‘legitimacy of the lay perspective’, as discussed by Popay and Williams (1996).

The objectives of involving service users were achieved because recruiting representatives through Community Health Councils ensured participants had suitable knowledge and experience to convey views about broad



Notes:

- Research capacity development and the implementation of research in practise were priorities identified across all three strands (service user expectation 5) but were considered separately in the analysis.

Figure 2 Framework for identification of research priorities.

aspects of nursing and midwifery on a national basis. Participants were familiar with nursing and midwifery roles and specialities and could relate these to the needs of a variety of client groups, medical conditions, current issues and policy/quality initiatives. Participant's comments about their involvement in committees and attending board meetings at the Primary Care Trust or sitting in on National Service Framework discussions showed that generally they were experienced and had good links with local health and social care providers. Time spent on information giving prior to the focus groups, careful explanation of confidentiality and the purpose of the exercise appear to have been beneficial in ensuring participants had a clear understanding of what to expect and what was expected of them.

The approach enabled the generation of five priority areas for research (shown in Figure 2) together with corresponding examples of key questions for research from the perspective of service users and professional stakeholders. Commissioning has already been taken forward in two of the identified areas — (1) User involvement in the design and delivery of nursing and midwifery services; and (2) the nursing and midwifery contribution to child health services. Because of the deficit of contextually similar exercises in the literature, it has not been possible to determine whether the findings are resonant with other knowledge of service-user's priorities for nursing and midwifery service delivery and organisation. Corroborating evidence from the literature review was used to support and refine example questions for research in the five priority areas.

Limitations of the approach

User control and researcher influence

At the outset, the aim of involving service users was to develop a research agenda informed and shaped by service users. The approach to involvement (consultation) has been criticised as being a degree of tokenism in citizen control (Arnstein, 1969) and converse to democratic empowerment because users' views are made to fit a provider defined or managerially-(professionally-) led agenda (Oliver, 1995). Others consider consultation approaches as enabling the most articulate individuals to dominate (Rodgers, 1994). Researcher influence was evident in the collection of data as we defined the focus group questions, focused the discussions and encouraged participants to explore different areas of nursing and midwifery that might not necessarily have been raised. Asking the group to prioritise issues/themes at the end of the session was a good way of verifying that these were important to the group. Service users were not involved in the analysis or interpretation of the data. Whether increased user control in these areas would have led to a research agenda

that was more relevant and appropriate to the needs of service users requires further investigation. A service-user representative on the commissioning panel did contribute to the decisions about future calls for funding.

Authenticity of the data

Although the focus group data was a good source of information for the development of a broad service-user framework, to what extent the views gained can be considered representative of the wider views of communities/different groups of people is unclear (NHSE Research Development Directorate, 1998). Community Health Councils have been criticised in the past for their membership not reflecting the diversity of the communities they represent; however, participants in the focus groups drew attention to the importance of cultural influences and the need for strategic involvement of ethnic minority groups, particularly members of Pakistani and West Indian communities, in all aspects of health service development. Similarly, the views of children/young people and older people were not directly represented but, again, participants raised issues of access and specialist services for these groups. Our experiences confirm Steel's work (2004), in that there is no singular way of prescribing how vulnerable and marginalised groups should be involved in this type of exercise and that there are difficulties with involving groups who may not have the ability or desire to convey their views. Strategies for maximising inclusion, for example the use of language translators, are an important area for future work to address.

Conclusions

It is our belief, and a policy directive, that service users should be more involved in research agenda setting. This approach to incorporating the views of service users in a national priority setting exercise was innovative because service-user views were used as a framework to which professional views and priorities in the literature were aligned. The work provides scope for wider inference as the framework could be generalised to other national nursing research studies, as this was the context in which it was developed. The findings provide evidence about the value of developing a service-user framework for research because it was possible to identify five priority areas that were also important to service users. This approach attempted to respect individuality in terms of representing diversity of need. Further work is necessary to develop theoretically based methodological approaches to service user involvement in shaping the research agenda that encompass plurality and diversity of need.

Key points

- This national research priority setting exercise for nursing and midwifery research used service user views as a framework to which professional views and priorities in the literature were aligned to identify five priority areas.
- The framework could be used in other national nursing research studies, as this was the context in which it was developed.
- There is a need to develop theoretically based methodological approaches to involving service users in identifying priorities for research.

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