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Identifying research priorities in nursing and midwifery service delivery and organisation: a scoping study

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Abstract

This paper reports on a scoping study commissioned by the National Co-ordinating Centre Service Delivery and Organisation (NCCSDO) Research and Development (R&D) to identify priorities for nursing and midwifery research funding in England and Wales. The study comprised three strands (i) nationally held focus groups with service user representatives (32, plus six written submissions) (ii) semi-structured telephone interviews with 64 stakeholders (nursing, midwifery, medical, social care and allied health professionals; research commissioners; policy makers; educators; managers; researchers) and (iii) literature analysis. Five priority areas for research were identified—appropriate, timely and effective interventions; individualised services; continuity of care; staff capacity and quality; user involvement and participation—from which exemplar research questions and issues for strategic commissioning are suggested.

Keywords: Research priority setting; Service delivery and organisation; Nursing and midwifery; User involvement; Scoping study

1. Introduction

The scientific knowledge base required to support the organisation and delivery of health services is potentially complex and wide ranging. The national research strategy for England and Wales clearly distinguishes between advancing knowledge to promote health of populations and research needed to support innovation and quality services (DoH, 2000a). Building the evidence base in both these areas within the field of nursing and midwifery is important as these groups comprise the largest part of the National Health Service (NHS) workforce, but have an underdeveloped research capacity (HEFCE, 2001). 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, 1999a, 2000b), and to develop research capacity (HEFCE, 2001). The National Co-ordinating Centre for Service Delivery and Organisation (NCCSDO) manages a major stream of Research and Development (R&D) funding in the NHS for England and Wales. The programme 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. In this context, identifying priorities for research funding in nursing and midwifery is an important step towards providing an evidence base for patient-centred approaches to health care.

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This paper describes a scoping study which was commissioned by the NCCSDO R&D Nursing and Midwifery Subgroup to identify priorities for research funding in the fields of 'nursing and midwifery', including health visiting. The professional groups that this work relates to are midwives, nurses, health visitors, district nurses, school nurses, practice nurses, mental health nurses, nurses for people with learning disabilities, occupational health nurses, students within these professions, agency staff, health care assistants and those working in public and private sectors.

In the UK existing work on research priority setting in nursing and midwifery service delivery and organisation is limited. The early 'Listening Exercise' carried out to inform the priorities of the SDO programme (Fulop and Allen 2000) was only intended to define overall priorities for research into service delivery and organisation, and therefore did not explore specific priorities for any professional group. Professionally led reviews of research, have gone some way to identifying priorities, notably the national exercise led by the Royal College of Nursing (Kitson et al., 1997a, b; Scott et al., 1999). Other priority setting exercises have set out to inform research strategy within a clinical setting, for example critical care (Vella et al., 2000) or to develop a multidisciplinary research agenda in a disease/patient group such as stroke rehabilitation (Legg et al., 2000) and cancer care (Daniels and Ascough, 1999). National topic reviews of R&D (DoH, 1999b) have included a nursing perspective in primary care (DoH, 1999c; Ross et al., 2002) and maternal and child health (Renfrew et al., 2002). Although most topic review groups for the National Strategy had nursing or midwifery membership, overall the opportunity to influence national policy decision-making has been limited (Rafferty et al., 2000). In general, research priority setting has been the concern of those within policy and academic communities or leaders within the professions. There are few examples of systematic consultation with service colleagues from the NHS and other sectors and most importantly with users, or potential users, of services, with the exception of Sleep and Renfrew (1995) who conducted a Delphi study that elicited views from practitioners, managers and users. From the outset, our intention was to carry out a wide reaching scoping study that would go some way to redressing this imbalance.

2. Aims and objectives

The overall aim of the scoping study was to identify priorities for research in nursing and midwifery service delivery and organisation and to make recommendations about the commissioning of research to the SDO Nursing and Midwifery Subgroup.

2.1. Objectives

1. To elicit views from a wide range of key stakeholders and service user representatives regarding priorities for research and development in relation to the organisation and delivery of nursing and midwifery services.
2. To analyse selected policy, professional literature and papers in peer-reviewed journals relating to nursing and midwifery research, focusing on the delivery and organisation of health services.

3. Methods

The scoping study was carried out over 4 months during 2002. Each of the three strands of data collection, (i) user representative focus groups (ii) stakeholder interviews, and (iii) literature analysis, are described below.

3.1. User representative focus groups

The first part of the scoping study comprised five user representative focus groups. The reason for carrying out focus groups was to find out what service users thought were the priorities for research and development in relation to the organisation and delivery of nursing and midwifery services. 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 'representative' and 'meaningful'—acknowledging that these are both relative concepts and contextually determined. We took the view that to maximise the value of the data obtained and identify priorities for research, participants needed to be able to represent the wider needs of communities of people and client groups rather than simply relaying their personal experiences. Therefore, we selected a purposive sample of user representatives from Community Health Councils (CHC). CHCs are established lay member organisations with formal links to health providers and knowledge of local issues (under government reforms CHCs will be abolished in December 2003 but at the time of the study these organisations were considered the most appropriate organisations to represent the views of service users). Of 126 CHC approached across England and Wales 32 were able to take part within the constraints of the time frame and a further six CHCs provided written submissions. Of these representatives one was a Chair of a CHC and the rest were voluntary members.

A team of five experienced researchers, who worked in pairs to lead and record the discussions, facilitated the focus groups. Two groups were conducted in London (North and South), and one each in Birmingham, Sheffield and Bristol. For consistency of approach a focus group schedule consisting of four broad questions was designed. The schedule was intended to elicit issues about nursing/midwifery organisation and delivery in general rather than specific care practices, clinical need or service configuration. Participants were asked to discuss the following:

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?
4. Thinking about these improvements, how could they be made and how could users be involved?

All of the discussions were audio taped and transcribed. The transcripts were divided into sections according to the issues or themes that were being discussed, in order to manage the large dataset. The transcripts were coded using qualitative data analysis software (Atlas.ti) and verified by an independent researcher.

3.2. Stakeholder interviews

The scoping study included interviews with key stakeholders regarding their priorities for research and development in relation to the organisation and delivery of nursing and midwifery services. Telephone interviews were used in preference to face-to-face interviews to maximise the efficient use of time and resources. For our purpose, stakeholders were selected from health and social care sectors and had a range of intra and interprofessional perspectives from policy, management, research commissioning, higher education, and included relevant disciplines such as medicine, social work, allied health professionals, general management and nursing and midwifery. We aimed to strike a balance between high profile individuals with leadership positions, for example in service provider organisations, research charities, higher education, Royal Colleges and Professional Bodies, with key players in government policy departments and workforce development and those who were unlikely to have taken part in priority setting exercises previously. As far as possible regional interests, represented crudely through geographical location, were taken into account within the sampling method, to avoid London/city centric results. Out of a total of 100 named stakeholders identified, it was possible to conduct interviews with 64 people.

A bespoke interview schedule was designed to include biographical details related to the respondents' current role and their experience of undertaking and commissioning research; open ended questions regarding their perceptions of existing nursing and midwifery services and their views on the contribution of and gaps in nursing and midwifery research. Research priorities developed from the previous SDO 'Listening Exercise' (as shown in Table 1), supplemented with broad examples for nursing and midwifery, were used as prompts. Respondents were asked to give their opinions of the appropriateness of these priorities for nursing and midwifery and to select their top five in rank order, or suggest additional research priorities. It was envisaged that the SDO framework would focus the enquiry within a policy context but also enable individual opinions, corresponding to personal/professional areas of interest, to be captured.

Table 1
Service delivery and organisation priorities (NCCSDO, 2000)

Organising health services around the needs of the patient
User involvement
Continuity of care
Co-ordinating/integration across organisations
Inter-professional working
Workforce issues/characteristics
Relationships between organisational form, function and outcomes
Implications of the communication revolution
The use of resources, e.g. de-investing in services and managing demand
The implementation of national policy initiatives

Stakeholders were provided with an E-mail or fax in advance of their interview, which gave information about the purpose of the study, method, interview content, and the research team. The semi-structured telephone interview format enabled four interviewers within the research team to probe responses fully, clarify ambiguities, and avoid misinterpretations. The interviews were recorded onto audiotape and each interviewer made detailed notes directly on to a copy of the interview schedule, which were transcribed by the interviewer directly after or within a few hours of the interview. The interview notes and E-mail responses were coded and categories formulated from recurring themes to generate the findings. This process enabled the key research priorities for the stakeholders to be identified along with additional issues related to nursing and midwifery research generally. The data were also interrogated in relation to factors such as professional background and job role of the interviewee and geographical area, to identify commonalities and differences in perspectives.

3.3. Literature analysis

The literature analysis was carried out concurrently and independently of the service user focus groups and stakeholder interviews. The purpose of the literature analysis was to identify nursing and midwifery research priorities from policy documents (Stage 1) and papers in peer-reviewed journals (Stage 2). The priority areas identified in the literature were then compared with the themes emerging from the consultation with user representatives and stakeholders, to identify areas of convergence and dissonance (as discussed later in this paper).

Stage 1: Policy documents: Policy documents written since 1997 and relevant to the government research and development strategy were the key documents for Stage 1 of the review. Databases for the Department of Health, Higher Education Funding Council, Nuffield Trust, King's Fund, Royal College of Nursing, The Wellcome Trust, Medical Research Council, and Nursing and Midwifery Council (formerly United Kingdom Central Council for Nursing, Midwifery and Health Visiting) were accessed to identify appropriate documents. Hand searching of references from key policy documents was also carried out.

Stage 2: Peer-reviewed journals: Papers in peer-reviewed journals were accessed through electronic databases (CINAHL, Medline, Social Science Citation Index, British Nursing Index, National Electronic Library for Health, Applied Social Sciences Index and Abstracts for Health, Health Management Information Consortium, King's Fund). Papers were selected for review using search terms and grading criteria determined by the quality of methods used for priority setting (Table 2). Searches were limited to documents published in the United Kingdom since 1996 (to ensure policy relevance). Two national E-mail user groups (CHAIN—Contact Help Advice Information Network and the Royal College of Nursing) circulated requests for information on priority setting initiatives recorded in grey literature. Hand searching of references from key articles or reports that identified nursing or midwifery priorities was also carried out.

4. Key findings and discussion

The scoping study provided a wealth of qualitative data covering issues relating to the provision, organisation and delivery of nursing and midwifery services as well as views on developing research capacity and the implementation and dissemination of research in practice. Each of the three strands of data were analysed independently. Themes from each strand were then scrutinised during face-to-face discussions and independent reflection by a team of researchers for patterns, consensus and divergence. Fig. 1 summarizes the methodology and analytical approach used.

Using this analytical process it has been possible to suggest areas of accord and misalignment between service user expectations, stakeholder perceptions of priorities and gaps identified by the literature in the nursing and midwifery evidence base. In the discussion of issues emerging from the consultation process and the development of an analytical framework we have taken the view that:

- The process of research priority setting is a social construction with its own technical language, which has been mostly driven by professional agendas. In

Table 2
Criteria for literature and policy inclusion in analysis

Weighting (1–5)	The extent to which the article meets the aims of the study—to identify nursing or midwifery research priorities. 1 = the least extent, 5 = the most extent.
5	Identifies nursing/midwifery research priorities generated by a systematic approach such as survey, delphi technique, nominal group technique, bibliometric assessment, meta analysis, systematic review
4a	Identifies nursing/midwifery research priorities generated by consultation, professional organisations, opinion/academic leaders, charities, but does not meet the systematic approach of 5
4b	Identifies research priorities from policy making or professional organizations that have implications for nursing or midwifery and meets the systematic approach of 5
3	Identifies nursing/midwifery research priorities generated by small interest groups (diagnostic or client groups) or small-scale studies but not meeting the criteria of 4 or 5
2	Identifies research priorities with reference to nursing/midwifery contributions to research alongside other disciplines but does not meet the criteria of 5
1	Identifies research priorities with reference to nursing/midwifery contributions to research alongside other disciplines but does not meet the criteria of 5 or 4 (opinion based)

Key search words: Research, Nursing, Midwifery, Priorities, Clinical effectiveness, Evidence-based, Utilisation, Dissemination.

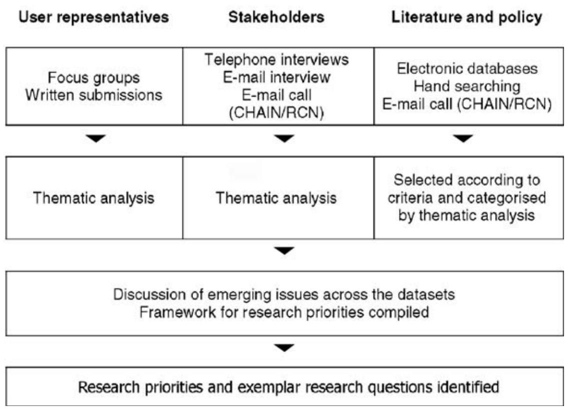


Fig. 1. Summary of data sources and process.

our analysis we have given prominence to the service user representative core expectations identified in the consultation by placing them as an independent strand of information for comparison with stakeholder views and priorities identified by the literature.

- Service user representative views on priorities have been generated from notions of gaps in service organisation and delivery, using qualitative methods, which together with data from the stakeholder interviews, raise questions for research and development that are informative but not generalisable.
- The use of purposive sampling and qualitative methods has captured diversity and depth, which enables us to raise issues and formulate questions rather than providing explanations.
- The policy and academic literature increases our understanding of the issues and provides a context for discussion of the emerging and overlapping themes between user representative core expectations and stakeholder views.

In order to make sense of a large and complex dataset the key themes from each strand of enquiry are summarised using an analysis framework, as shown in Fig. 2. Five broad priority areas for nursing and midwifery service delivery and organisation emerge, illuminating questions for research and development. These are illustrated, where possible, with direct quotes (selected to best express each theme spread across data sources) from stakeholders and user representatives. The corresponding focus group locality is shown in brackets after each extract. We have attempted to illustrate how each of these priority areas are relevant and pertinent to nursing and midwifery research by providing exemplars of issues and concerns that strategic commissioning could seek to address. These exemplars have been distilled from the findings and can be applied to a variety of patient/client groups in a range of settings to inform research policy. Research capacity development is discussed separately.

4.1. Priority area 1: appropriate, timely and effective interventions

Research priorities for appropriate, timely and effective interventions flowed from service users' concerns that growing expectations for quality services are not being met and that there are perceived gaps in the provision of what we have called 'essential nursing and midwifery care'.

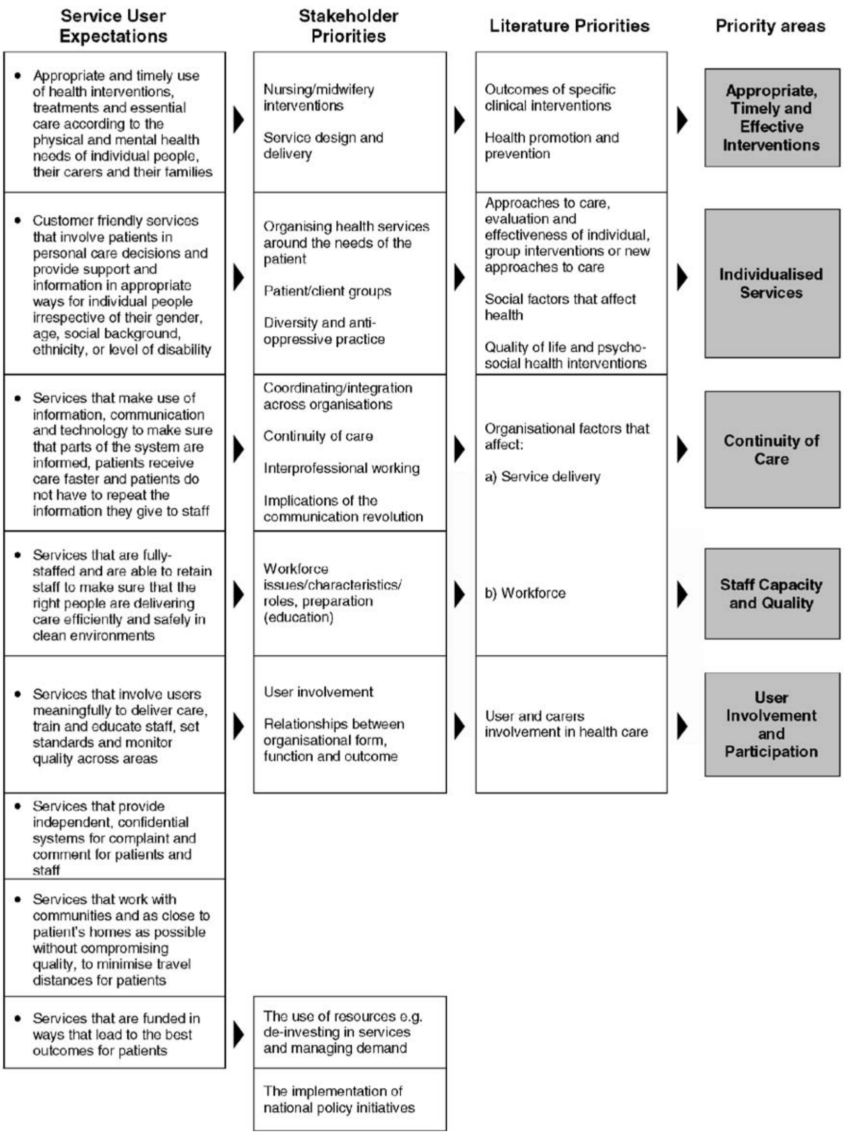
> "There is an awful lot that we assume and patients assume will happen, but because of the structure and the time constraints or resources don't or can't happen" (User representative, South London FG).

This theme also emerged from the stakeholder data, but was not as strong as workforce issues, and was articulated in terms of research priorities that develop understanding of the nursing and midwifery contribution to service delivery or as defining the component that makes a difference. The importance of comprehensive physical and mental health assessment and the corresponding provision of appropriate care were highlighted by user representatives in terms of staff failing to recognise the wider needs of the patient. One example provided was recognising the mental health needs of new mothers.

The need for research to establish what is 'appropriate care' for individuals, their carers and families, including work to evaluate public health interventions and the role of nursing and midwifery professionals in reducing inequalities in health is supported by the policy literature in national topic reviews of cancer, mental health, maternal and child health and primary care (DoH, 1999b). Research to improve the understanding of the nature and outcomes of clinical interventions and caregiving practices is highlighted for stroke rehabilitation (Legg et al., 2000), midwifery: post natal visiting patterns (McCourt and Beake, 2000) and palliative care (Daniels and Hoylett, 2002).

Exemplar research questions:

- Evaluate psychosocial nursing and midwifery health interventions in relation to patient/family and community centred outcomes. For example, management of specific maternal conditions such as gestational diabetes, morning sickness and obesity or rehabilitation of older people.
- Evaluate comprehensive assessment tools of physical, psychological, social need linked to interventions and user/professional and organisational outcomes. For example, assessing the needs of people with chronic health problems.



Service User Expectations	Stakeholder Priorities	Literature Priorities	Priority areas
• Appropriate and timely use of health interventions, treatments and essential care according to the physical and mental health needs of individual people, their carers and their families	Nursing/midwifery interventions Service design and delivery	Outcomes of specific clinical interventions Health promotion and prevention	**Appropriate, Timely and Effective Interventions**
• Customer friendly services that involve patients in personal care decisions and provide support and information in appropriate ways for individual people irrespective of their gender, age, social background, ethnicity, or level of disability	Organising health services around the needs of the patient Patient/client groups Diversity and anti-oppressive practice	Approaches to care, evaluation and effectiveness of individual, group interventions or new approaches to care Social factors that affect health Quality of life and psycho-social health interventions	**Individualised Services**
• Services that make use of information, communication and technology to make sure that parts of the system are informed, patients receive care faster and patients do not have to repeat the information they give to staff	Coordinating/integration across organisations Continuity of care Interprofessional working Implications of the communication revolution	Organisational factors that affect: a) Service delivery	**Continuity of Care**
• Services that are fully-staffed and are able to retain staff to make sure that the right people are delivering care efficiently and safely in clean environments	Workforce issues/characteristics/ roles, preparation (education)	b) Workforce	**Staff Capacity and Quality**
• Services that involve users meaningfully to deliver care, train and educate staff, set standards and monitor quality across areas	User involvement Relationships between organisational form, function and outcome	User and carers involvement in health care	**User Involvement and Participation**
• Services that provide independent, confidential systems for complaint and comment for patients and staff			
• Services that work with communities and as close to patient's homes as possible without compromising quality, to minimise travel distances for patients			
• Services that are funded in ways that lead to the best outcomes for patients	The use of resources e.g. de-investing in services and managing demand		
	The implementation of national policy initiatives		

Fig. 2. Analysis framework for research priorities.

4.2. Priority area 2: individualised services

Both user representatives and stakeholder groups identified the importance of communication within the clinical encounter to improve patient-centred care delivery. This finding is supported by an expert group, which calls for more research to underpin patient-centred information giving, therapeutic interactions and decision-making (Dieppe et al., 2002). Furthermore this theme has been identified as a research priority in cancer care (emotional support and opportunities for participation) (Daniels and Ascough, 1999); stroke rehabilitation (information giving and counselling) (Legg et al., 2000); and primary care (communication) (Whitford et al., 2000). Although communication emerged as an overarching theme for both user representatives and stakeholders, not surprisingly expectations were articulated in different ways, embracing a continuum of activity from 'therapeutic interventions' to 'patient friendly' supermarket style approaches to customer care.

> "… all too often is 'what's your name—clinic's over there'. A smile doesn't do any harm—the [supermarket] approach… There is no introduction you don't know which is a nurse, which is a sister. You don't know who's who. You don't know who's responsible." (User representative, South London FG).

Stakeholders also perceived staff communication skills to be poor. However there was some feeling that communication skills training alone was inadequate for improving services, exemplified by a Trust Nursing Director who suggested "it's like putting baubles on a dead Christmas tree". Stakeholder priorities for research were the development of communication systems and skills, whereas user representatives described this in terms of information giving about treatment options and choices for care. There was a view that individuals should be supported to make informed decisions about their health irrespective of gender, age, social background, ethnicity or disability

> "A lot of nurses and midwives are working with healthy people and there is every reason to have communication and partnership and joint decision-making." (User representative, North London FG).

Stakeholders highlighted organising services around the needs of the patient as their third priority from the existing SDO priorities. There was a match here with user representatives' expectation for services that work with communities and as close to patient's homes or schools as possible without compromising quality. User representatives perceived gaps in the way that individuals and communities are involved in the design of local services and both user representatives and stakeholders felt that nurses and midwives could contribute to the development of user and carer centred systems which would improve access and health outcomes, particularly for older people, and those less likely to seek out services such as children, young people and minority groups. The policy literature also identifies approaches to care and models of care as priority areas, particularly in dementia services (DoH, 1999d), learning disability (DoH, 2001), mental health (Sainsbury Centre for Mental Health, 2001) and drug abuse (DoH, 2000c), emphasising effectiveness and efficiency. The NHS Strategic reviews highlight quality of life and psychosocial health as priorities for research in cancer (DoH, 1999f, 2000b) and stroke (DoH, 1999b).

Exemplar research questions:

- Develop models of service users and carers' participation in clinical decision-making and the clinical encounter and evaluate in relation to organisational culture, professional approaches and service user outcomes.
- Evaluate nurse-led user centred models of care delivery in a variety of clinical and public health settings.

4.3. Priority area 3: continuity of care

Communication of patient-centred information was highlighted by user representatives in relation to enhancing continuity of care. Some powerful imagery was used to describe service users' experience of fragmentation of care:

> "It's a bit like going through a demented pin ball machine, you go in there and then the hammer whacks you out and you go to another section and its like that all the time, there's no feeling of continuity and I think somebody needs to sit down and look at it from the point of view of the patient to see how these areas can be linked up in a better manner" (User representative, Bristol FG).

User representatives identified expectations for services that make use of technology to support integrated information systems that can be responsive and avoid duplication.

> "In this age of electronic communication where you can communicate as quickly as you can talk it defeats me how it takes such a long time for information to get from one place to another." (User representative, Bristol FG).

Stakeholders also considered continuity of care as important, however this was often seen as a systems issue, going beyond nursing and midwifery, which was considered as only one part of the jigsaw of remodelling services in relation to other professional groups and agencies:

> "Continuity of care and coordinating/integration across organisations are inseparable in my mind." (Representative of a professional organisation.)

This theme of continuity of care resonates strongly with the policy and the wider literature, which calls for the development of an evidence-base to define the organisational factors that affect service delivery, continuity of care and the workforce and ultimately health outcomes. Clearly this is a concern for the health service as a whole (Fulop and Allen, 2000) and has been identified for specific client groups such as learning disability (DoH, 2001) and mental health (Sainsbury Centre for Mental Health,2001; DoH, 1999g).

Exemplar research questions:

- Examine continuity of care models for vulnerable groups (especially older people and those less likely to access services e.g. adolescents) in relation to patient/user, staff and organisational outcomes.
- Identify efficient practices and methods of transferring confidential information (including patient information) between professionals, service areas/units and agencies.

4.4. Priority area 4: staff capacity and quality

Workforce, skills, competencies, career pathways and retention were overriding issues in the stakeholder and service user data, albeit presented from different perspectives: stakeholders identifying policy issues and user representatives pragmatic considerations.

Not surprisingly workforce issues were most consistently ranked in the top five priorities by the majority of stakeholder respondents and for those representing national organisations or based in London and the South this was frequently offered as the highest priority. Within this category particular issues noted were: the absolute shortage of nurses and midwives, the ageing workforce, recruitment and retention, turnover, use of overseas and agency staff, skill mix, competencies, nurse/patient dependency ratios (independent sector) and appropriateness of pre and post registration education. New role development and shifting professional boundaries were highlighted as a particular issue by many of the respondents particularly in relation to efficiency, effectiveness and impact on patient outcomes. While some views from the policy community urged research to investigate:

> "Role extension both up and down, the whole spectrum of roles and attendant task, specialisation and sub-specialisation. (Is it a) good thing or not? (and what) preparation/teams/supports are required? (Policy Maker).

Other stakeholders challenged workforce research as being atheoretical and failing to build on knowledge such as professional power and gender. There were questions raised from managers and nurse academics about the evidence base required to close the competency gap in nursing practice, in for example nutritional support, and developing practice and prescribing:

> "Levels of care—a lot of the problems we see are really basic; nutrition, pressure area care, infection control and management of patients likely to fall" (Ombudsman Office).

User representative views were driven by quality concerns such as establishing who are the "right" people (professionals/volunteers/carers) to deliver aspects of care (health interventions/essential care) competently:

> "I know there is a basic protocol for drugs rounds but certainly in our area there have been an increasing number of incidents where something has been incorrectly administered or very nearly incorrectly administered." (User representative, North London FG).

Uncovering the reasons for variations in nursing and midwifery practice with specific client groups was also considered important. The stakeholders gave greater prominence to interprofessional approaches to care delivery and shifting professional boundaries, although mixed views emerged as to whether this reflected a management challenge or raised questions for research. In contrast the user representatives discussed team working in relation to pragmatic strategies to improve staff retention and communication of patient information to enhance continuity of care. In the literature, recruitment and retention are identified as research priorities in the care of older people (DoH, 1999e) stroke and coronary heart disease (DoH, 1999d), as is resource allocation in midwifery staffing (Renfrew et al., 2002).

Exemplar research questions:

- Systematically review evidence on skill mix, role diversification, career pathways and working lives.
- Evaluate workforce recruitment and retention strategies and employment practice.
- Generate and evaluate success criteria for new service design, changing role boundaries, team working and reconfigured services within organisational uncertainty.
- Evaluate health interventions with vulnerable/hard to reach groups.

4.5. Priority area 5: user involvement and participation

User involvement emerged as a prominent and overarching issue across all three strands of the data, although stakeholders were more likely to discuss it in aspirational terms, whereas the expectations of user representatives tended to articulate specific gaps and formulate questions around active participation. Thirty-five of the stakeholder respondents identified user involvement as one of their top five priorities and the point was made that user involvement should be demonstrated across all research activity:

> "It is all about the patient—it shouldn't be separated out" (Policy maker)
>
> "I would like to see money spent on the implications of a user-led NHS. Probably users will want to do a lot for themselves and be much more in command. This will need a different sort of health professional to deliver that agenda" (Nurse academic.)

Some user representatives challenged the term involvement as being ill defined, emphasising instead meaningful engagement through representation, participation and consultation:

> "Everything that comes down from the department these days will say public and patient involvement. They do not tell you how you are going to get it. Or do they care if you do?… . It's the difference in the

> word consultation. Some people think consultation means 'I got an input into the way the service is going to be developed' Certain services take the word consultation to mean "this is how we are going to do it. How are you going to live with that?" (User representative, Sheffield FG).

Both stakeholders and user representatives felt that achieving meaningful participation in research and service delivery leading to improved outcomes was an issue that should be central to all health services research. However, the boundaries of user involvement are unclear in many health care settings and it was pointed out that few professionals have experience of consultative approaches or partnership working:

> "We often struggle with getting the views or representing the diversity of views of our clients, to meet their needs. We want to meet their needs as partners rather than on a consultancy basis... If you are just using their knowledge to develop a baseline of views then you are not actually sharing power with them in terms of decision-making." (Service Development Officer for Learning Disability.)

The lack of a conceptual map and methodological approaches for user involvement is mirrored in professionally led research agendas with the exception of midwifery research (Renfrew et al., 2002) and in some areas of social policy/disability research (Beresford, 2003). Therefore research is required that supports the strategic commissioning of conceptual, methodological and evaluative work into active user participation in the delivery of care, training and education of staff and quality monitoring.

Exemplar research questions:

- Methodological development of user centred outcome studies that take account of the context, process and content of the intervention.
- Evaluate nursing and midwifery interventions in relation to identified outcomes across psychosocial and health domains.
- Develop capacity and skills to strengthen user participation in nursing and midwifery research and evaluate the impact in terms of changes in practice at individual, family or community levels.

5. Achieving priorities

5.1. Research commissioning

Stakeholders expressed views about the status of research activity in nursing and midwifery and the process of setting priorities. There was some concern as to the value of having a dedicated funding stream for nursing and midwifery research, especially as this could be perceived as discordant with policy initiatives to enhance multiprofessional working. Similarly, many stakeholders raised issues about the mode of research commissioning and the need to maximise impact through joined up initiatives.

Stakeholders and user representatives entered into debates as to whether the focus of commissioning should be on the generation of evidence or research utilisation. Both are a challenge within complex and changing health and social care organisations. Some stakeholders expressed scepticism about the existing SDO Programme priorities, which were seen as 'rhetorical', 'narrow' and would perhaps go 'out of fashion'.

5.2. Capacity building

Although capacity building was not a primary focus of this scoping study it emerged as an issue in the interviews and in both the policy and professional literature. Key points are summarised here. The stakeholders particularly identified capacity problems in nursing and midwifery research, reflecting views of recent commentators (Rafferty and Traynor, 1999; Wilson-Barnett, 2001) and an influential policy review and statement (HEFCE, 2001). Issues and concerns specifically highlighted were the need for:

- Continuity and coherence in building knowledge by conducting substantial research investigations rather than multiple small-scale studies.
- Methodological development for intervention studies.
- Encouraging innovation and creativity through investigator-led, as well as policy driven research.
- Ensuring a balance between scientific rigour and policy relevance.

Strengthening academic and service partnerships was also identified by stakeholders as important, which it was felt could be achieved through the further development of nurse consultant roles and as one stakeholder commented encouraging research "out of the ghetto of higher education". Service user representatives perceived research to be carried out by academics and therefore viewed it as separate from clinical practice.

5.3. Dissemination and implementation

User representatives in all focus groups discussed the value of dedicated funding for the dissemination and implementation of research evidence. There was an expectation that services should enable staff to make use of research evidence in practice. However, there was a perception among some that nurses and midwives may not have the power and influence within organisations to effectively implement research findings and change practice:

> "Research is going on with the University all the time and they come up with wonderful conclusions and we all say 'that's lovely' put that away in the filing cabinet and nothing happens... nurses don't have the power to actually make it happen" (User representative Sheffield FG).

There was also concern that systems are not in place that enable sharing and dissemination of good practice across care settings and sectors. This was again highlighted by stakeholders who discussed the importance of using research to create 'a momentum for change' through action research approaches, leadership development and prioritising implementation of research findings to change practice:

> "[We] need a different approach to research in the health service, traditional forms of research have too big lead in times and this makes the findings obsolete." (Acute Trust Representative.)

6. Limitations of the data

6.1. User representative and stakeholder consultations

There were a number of requirements that needed to be addressed in designing the scoping study. These included: the limited time available to access views and the need to enable novel ideas to emerge but give participants some structure to work from. The data collection tools utilized for the focus groups and interviews will have influenced the type of information received. For example, the SDO research priorities developed by Fulop and Allen (2000) were used to focus discussion in the stakeholder interviews (see Fig. 1), which may have constrained the responses. Also, it is not clear to what extent asking participants for their perceptions of gaps in existing research, reflects actual gaps in the evidence base. Interviewer bias may have occurred where interviewees were aware of the particular academic/professional roles of the interviewer. Attempts were also made to achieve a geographical spread of user representatives and stakeholders.

As previously discussed, managing the tension between seeking representation and interpreting diversity was a feature of both strands of the consultation with stakeholders and user representatives. For pragmatic reasons the sample was to an extent determined by the availability of respondents to comment during the timescale and the ability of organisations contacted to field a suitable person. In the stakeholder sample some NHS organisations, policy makers and non-nursing and midwifery professional bodies declined to comment either because they felt their involvement would be inappropriate or because they could not see the relevance of their particular perspectives to the questions being addressed, or because they were too busy and 'research' was not a priority for them. Accessing databases of relevant contact details for many of the stakeholders was extremely difficult. Penetrating newer organisations (particularly Primary Care Trusts and Workforce Development Confederations) was also challenging because many of the telephone numbers, E-mail addresses, etc. were not readily available at the time. Excessive workload demands on stakeholders we wanted to involve, meant that interviews were often rescheduled several times at the participant's request or had to be cancelled altogether.

In contrast to the stakeholder sample the user representative sample was more homogenous, being predominantly female, white, ex-professionals, 35–50 years of age. Although participants discussed diversity, ethnicity and minority groups in terms of access to health care services, we acknowledge that specific issues relating to cultural background or ethnicity may not have been identified because of the composition of the sample. Similarly, children, young people and older people (over 70 years of age) were not directly represented although issues about access to appropriate services for these groups was raised by all of the groups.

6.2. Literature analysis

While a systematic approach was used to review the literature it has necessarily been selective. Criteria were applied to select literature that identified nursing and midwifery research priorities or that had relevance for these priorities. All are seen as contributing to identifying priorities. Overseas literature was identified by electronic searches but has not been analysed as part of this exercise. It is worth noting that a number of priority setting initiatives have been carried out in the USA, Australia, Canada, South East Asia and Europe, underlining the importance of prioritising nursing research internationally. Although this consultation exercise focuses on England and Wales it is acknowledged that information from the World Health Organisation and European Directives are influential and important. Changes in policy influence the research agenda, indeed the majority of policy documents that specifically mention research state that priorities must be in line with national priorities for health. The literature review therefore focused on the most recent documents, published in the last 6 years.

The majority of professional papers identify priorities without assessing the level of evidence already available to inform practice. No attempt has been made to assess the level of evidence that might inform identification of research priorities. This would be an important next step as some professional literature, particularly in midwifery, is making a substantial contribution to evidence for care giving practices, for example in the field of breastfeeding.

7. Conclusion

This scoping study generated five priority areas for research and development that are grounded in user representative's expectations for quality nursing and midwifery services and informed by priorities identified in the policy and peer reviewed literature. These emphasise that research is needed to ensure services are appropriate to meet individual patient and carer needs within the context of a complex system that is facing rapid change, uncertainty and capacity problems. All the priority areas are concerned with either the delivery or the organisation of health services or both. In practical terms the issues overlap and are linked, for instance effective interventions or treatments are reliant on competent staff who are sensitive to the needs of the patient or client and on continuity of care.

Given that nurses are the main group of professionals who have intimate and continuous contact with patients or clients they are key to influencing the quality of what service users consider 'essential nursing and midwifery care'. An important conclusion is that more information is needed about nursing and midwifery interventions and interactions with patients and clients and the resulting outcomes. The assessment of patient and client needs and measurement of outcomes that are sensitive to nursing interventions and authentic methods of service user involvement are important aspects of the ongoing research agenda.

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