Identifying Research Priorities for Nursing and Midwifery Service Delivery and Organisation

A study undertaken for the Nursing and Midwifery Subgroup of the National Co-ordinating Centre for NHS Service Delivery and Organisation R & D (NCCSDO)

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A full list of organisations represented in the exercise is shown in Appendix 1.

Executive Summary

This summary describes a systematic consultation exercise that was commissioned by the National Co-ordinating Centre for Service Delivery and Organisation (NCCSDO) Research and Development (R & D) Nursing and Midwifery Subgroup. The work has been carried out by members of the Faculty of Health and Social Care Sciences, Kingston University and St George's Hospital Medical School, in partnership with external consultants in health services research.

The remit of the work was to identify priorities for research funding in the fields of 'nursing and midwifery'. In brief, the professional groups that this work relates to are midwives, nurses (NHS, social care and independent sectors), health visitors, district nurses, school nurses, practice nurses, mental health nurses, nurses for people with learning disabilities, occupational health nurses, specialist/consultant nurses/midwives and health care assistants.

The exercise consisted of three strands:

- 1 focus groups with service user representatives
- semi-structured telephone interviews with a wide range of stakeholders, including nurses and midwives in the state and independent sectors, medical, social care and allied health professionals, research commissioners, policy makers, educators, managers, researchers and representatives of national service user groups
- 3 literature analysis of policy documents, selected papers in peerreviewed journals and published reports.

Altogether, 102 individuals gave interviews or participated in the focus groups. In addition, several people chose to contribute through written submissions or e-mail. Consequently, a wealth of qualitative data has been collected over a four-month period. The information has been studied and analysed by a team of researchers who have looked for key themes within each of the three sources of data. A summary of the areas of commonality and misalignment is shown in Table 1.

Five notable priority areas were identified across all three data sets. 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.

Priority Area 1 Appropriate, timely and effective interventions

Research is needed 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. Research is also needed to improve understanding of the nature of clinical interventions and to evaluate care-giving practices.

Exemplars:

- Evaluate psychosocial nursing and midwifery health interventions in relation to patient/family and community-centred outcomes.
- Evaluate comprehensive assessment tools of physical, psychological and social need linked to interventions and user/professional and organisational outcomes.

Priority Area 2 Individualised services

The evidence base for information giving, therapeutic interactions and decision making should be strengthened to develop effective communication systems and professional information-giving skills. Communication between nurses/midwives and patients/clients and carers during interventions or the 'clinical encounter' is a specific priority.

Table 1 Framework for research priorities

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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	Individualised services
Services that make use	Co-ordination/	psychosocial health interventions Organisational	-
of information, communication and	integration across organisations	factors that affect:	
technology to make sure that parts of the system	Continuity of care	(a) service delivery	Continuity of care
are informed, patients receive care faster, and patients do not have to repeat the information they give to staff	Interprofessional working		
	Implications of the communication revolution		
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 in the delivery of care, training and education of staff, standard setting and quality monitoring	User involvement Relationships between organisational form, function and outcome	User and carer 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 patients' 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

Exemplars:

- 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.

Priority Area 3 Continuity of care

Communication of patient-centred information was highlighted in relation to enhancing continuity of care. This requires the development and use of information technology (IT) and communication strategies for the transfer of information between service areas, supporting integrated pathways of care.

Exemplars:

- Examine continuity of care models for vulnerable groups, especially older people and those less likely to access services, such as 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.

Priority Area 4 Staff capacity and quality

Priorities for research relating to staff capacity and quality include; recruitment and retention; defining professional roles and clarifying optimal skill mix; quality concerns, such as establishing who are the 'right' people (professionals/volunteers/ carers) to deliver aspects of care (health interventions/essential care); and uncovering the reasons for variations in nursing and midwifery practice, with specific client groups or in areas of care perceived to be outside a person's professional remit.

Exemplars:

- Systematically review evidence on skill mix, role diversification, career pathways and working lives.
- Evaluate workforce retention strategies and employment practice.
- Generate 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.

Priority Area 5 User involvement and participation

Research is required that supports the strategic commissioning of conceptual, methodological and evaluative work into active user participation in delivery of care, training and education of staff, standard setting and quality monitoring.

Exemplars:

- Methodological development of user-centred-outcome studies that take account of the context, content and process 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.

Achieving priorities

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 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, the mode of commissioning and the need to maximise impact through joined-up initiatives were issues brought to our attention by many professional stakeholders.

Stakeholders and service users questioned whether the focus of commissioning should be on generation of evidence or implementation. Balancing generation of evidence for a practice discipline with the challenge of service development through the implementation of research findings within complex and changing health and social care organisations was also discussed. Stakeholders expressed scepticism of the existing SDO priorities in relation to nursing and midwiery research, which were seen by some as 'rhetorical', 'narrow' and perhaps likely to 'go out of fashion'. On the whole stakeholders emphasised the need for capacity building in nursing and midwifery research. Where generation of primary evidence was advocated there were concerns about separating researchable questions from managerial and policy issues.

Capacity building

Capacity in nursing and midwifery research was shown to be an important issue for stakeholders; this is reflected in the literature, as shown in Appendix 6a. Issues and concerns specifically highlighted were:

- continuity and coherence in building knowledge
- methodological development for intervention studies
- encouraging innovation and creativity through investigator-led research as well as policy-driven research
- ensuring the balance between scientific rigour and policy relevance.

Strengthening academic and service partnerships was also identified by stakeholders as important, and could be achieved through the further development of nurse consultant roles and encouraging research 'out of the ghetto of higher education'. User representatives perceived research to be carried out by academic researchers rather than nurses or midwives themselves and they therefore viewed research as being distinctly separate or remote from clinical practice.

Dissemination and implementation

Service users in all of the focus groups discussed the value of dedicated funding for the dissemination and implementation of research evidence. There is an expectation that services should enable staff to make use of research evidence in practice. Concerns were expressed that nurses and midwives might not have the power and influence within organisations to effectively implement research findings and change practice and, secondly, that systems were not in place that enabled 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 the use of research evidence in practice.

In summary, the consultation exercise revealed that, in addition to building the knowledge base in the five priority areas identified, the Nursing and Midwifery Subgroup should seek to commission a programme of research which:

- leads to the development of evidence-based, cost-efficient nursing and midwifery interventions and care-giving practices in line with service users' expectations identified in this consultation
- supports theoretical development and generalisable knowledge through coherent programmes

- produces nationally or internationally significant evidence for nursing and midwifery interventions and care-giving practice in relation to patient/carer, community, professional, organisational and economic outcomes
- informs policy and builds cost-effective models of nurse-led, usercentred services and pathways of care
- is of high scientific merit and uses appropriate methodology, or supports methodological development where necessary, including the development of outcome measures for nursing and midwifery intervention studies
- values and utilises collaborative approaches in terms of research skills, academic disciplines and with service partners, to build research capacity and capabilities in nursing and midwifery research
- involves users, where appropriate, and provides feedback to participants about their involvement
- evaluates the strategic dissemination of research findings/best practice within health and social care settings in relation to user, professional and organisational outcomes
- is cost-efficient, feasible and shows realistic objectives and deadlines
- complements research being carried out by the SDO programme as a whole.

The Report

Introduction

Context

This report describes a systematic consultation exercise that was commissioned by the Department of Health (DoH) National Co-ordinating Centre for Service Delivery and Organisation (NCCSDO) Research and Development (R & D) Nursing and Midwifery Subgroup. The work has been carried out by members of the Faculty of Health and Social Care Sciences, Kingston University and St George's Hospital Medical School, in partnership with external consultants.

The remit of the work was to identify priorities for research funding in the fields of 'nursing and midwifery'. A full explanation of the professions and activities included within this term are shown in Appendix 2. In brief, the groups that this work relates to are midwives, nurses (National Health Service (NHS), social care and independent sectors), health visitors, district nurses, school nurses, practice nurses, mental health nurses, nurses for people with learning disabilities, occupational health nurses, specialist/consultant nurses/midwives and health care assistants.

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

- understand the research priorities and needs of the health service
- enable specific interventions or specific approaches and phenomena to be evaluated
- ensure that higher education institutions are able to train researchaware professionals
- facilitate research awareness for practitioners and administrators, to support evidence-based practice and policy.
 - (Higher Education Funding Council England (HEFCE), 2001)

In 2000 NCCSDO commissioned a 'listening exercise' to inform the priorities of the SDO programme (Fulop and Allen, 2000). As this exercise was intended to define overall priorities for all research into service delivery and organisation, it did not detail specific priorities for nursing and midwifery. Professionally led reviews of research have gone some

way to identifying priorities in these service areas (Kitson *et al.*, 1997; Vella *et al.*, 2000; Ross *et al.*, 2002) and further work has been done to identify priorities for nursing and midwifery within a multidisciplinary research agenda (Legg *et al.*, 2000; Daniels and Ascough, 1999). National topic reviews of R & D (DoH, 1999; Renfrew *et al.*, 1999) have identified priorities from gaps in the evidence base and a number of policy documents have identified nursing and midwifery priorities, mainly based on the need to meet national health priorities. Generally, those within the policy and academic communities or those with a specific professional interest in nursing or midwifery have set the research agenda. To our knowledge, there are few examples of systematic consultation with service colleagues from the NHS and other sectors and most importantly the users, or potential users, of services. From the outset of this exercise our intention was to carry out a systematic consultation that would go some way to redressing this imbalance.

Aim and objectives

The overall aim of the exercise was to identify priorities for research in nursing and midwifery service delivery and organisation and to inform the commissioning of research by the SDO Nursing and Midwifery Subgroup.

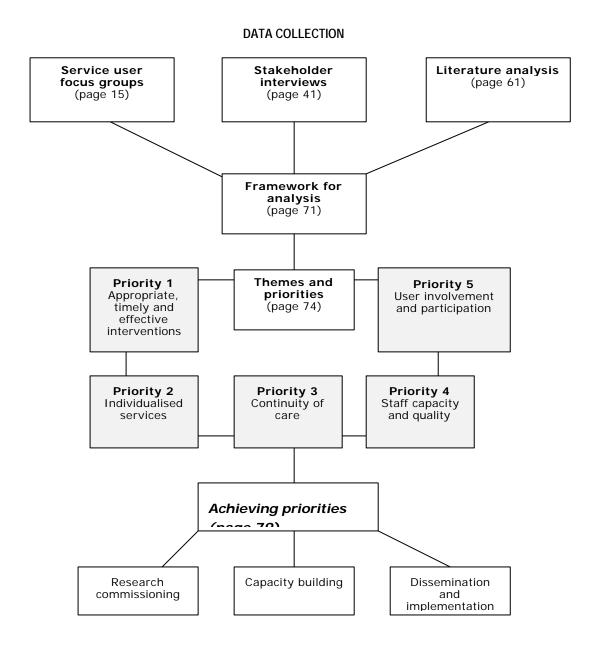
Objectives were:

- to elicit views from a wide range of key stakeholders and service user representatives regarding their 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 peerreviewed journals relating to nursing and midwifery research, specifically focusing on the delivery and organisation of services.

Document map

The structure of this report needs a few words of explanation. This document map is included as a point of reference and a guide through the report. The three large sections at the beginning of the report outline the methodological and analytical approach and findings to each strand of data collection: user representative focus groups, stakeholder interviews and literature analysis. A framework for analysis is then used to identify areas of commonality and misalignment in relation to the policy and academic literature. In the discussion, five broad priority areas for building research evidence are identified and issues relating to achieving these priorities are outlined.

Figure 1 Document map



Service user focus groups

This section describes the methodology and findings of the consultations with service user representatives. This strand of the exercise involved informed users of health care services with experience of representing views in a formal capacity.

A group of five researchers worked in pairs to facilitate five two-hour focus groups. Two groups were conducted in London (North and South), and one each in Birmingham, Sheffield and Bristol. 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. This was a complex and challenging task because of a number of methodological and sampling issues. Difficulties arose around 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. Furthermore, to maximise the value of the data obtained towards identifying priorities for research, it was important that participants were able to represent the wider needs of communities of people and client groups rather than simply relaying their personal experiences. Therefore we invited Chairs of Community Health Councils (CHCs), which are established lay member organisations with formal links to health providers and knowledge of local issues. Of 126 CHCs approached across England and Wales, 32 were directly represented in the discussions and a further six provided written submissions.

At the beginning of each session facilitators clarified the purpose and limits of the discussion and assured participants that their anonymity and that of their organisations would be protected. Written consent to participate was obtained.

For consistency of approach across the five groups, a schedule consisting of three broad questions was designed. The schedule was intended to elicit general nursing/midwifery issues rather than steering discussions towards a particular aspect of care, client group, clinical need or service configuration. Participants were asked to discuss the following:

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

All of the discussions were audiotaped and transcribed.

Analysis

To make sense of such a large amount of qualitative data, the transcripts were divided into sections according to the issues or themes that were being discussed. The coding framework used (shown in Appendix 3) was informed by Maxwell's (1984) evaluation framework. This framework was selected for the purpose of coding because it identifies values of: Equity, Effectiveness, Efficiency, Acceptability, Appropriateness and Accessibility, which are suitably broad to categorise complex data. It was necessary to modify the framework to develop categories that would accommodate the wide field of the enquiry. The transcripts were coded using qualitative data analysis software (Atlas.ti) and verified by an independent researcher.

Findings

Focus group discussions covered broad-ranging issues relating to all fields of health, as well as other topic areas. In general, participants in the focus groups showed a good understanding of issues relating to health services and were knowledgeable about the needs of a variety of client groups, medical conditions and policy/quality initiatives, such as National Service Frameworks. All of the groups were knowledgeable about nursing and midwifery roles and specialities and were able to discuss 'nursing and midwifery' in terms of the client groups that receive care, organisations/units of care delivery (including the independent sector) and specialist nursing and midwifery services.

Because participants were asked to identify gaps in services and areas for improvement their views may sometimes appear negative. This is largely an artefact of the questions posed and examples of good practice, successful pilot schemes or the implementation of research findings were frequently provided.

Core expectations

The focus groups revealed an extensive list of issues and concerns relating to nursing and midwifery services, as well as other areas. These issues were grouped under broad thematic headings, which have been interpreted as corresponding with underlying core expectations for nursing and midwifery services (Table 2). Each of these broad areas of expectation is discussed separately, with selected quotations from the transcripts being drawn upon to illustrate specific points. The focus group that each quotation came from is shown in brackets (London South, London North, Bristol, Birmingham or Sheffield) and written submissions are indicated. Communication, quality and service user involvement were identified as spanning one or more of the expectations and have been discussed in relation to each aspect they encompass.

Table 2 Core user expectations for nursing and midwifery services

- 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
- Customer-friendly services that involve patients/clients and carers in personal care decisions and provide support and information in appropriate ways for individuals irrespective of their gender, age, social background, ethnicity, or level of disability
- 3 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
- 4 Services that make use of information, communication and technology that ensure all parts of the same system are informed, patients receive care faster and do not have to repeat the information they give to staff
- 5 Services that enable staff to make use of research evidence in practice
- 6 Services that involve users meaningfully in the delivery of care, training and education of staff, standard setting and quality monitoring
- 7 Services that provide independent, confidential systems for complaint and comment for patients and staff
- 8 Services that work with communities and as close to patients' homes as possible without compromising quality
- 9 Services that are funded in ways that lead to the best outcomes for patients

Expectation 1

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

Growing public expectations for access to quality services

Participants in the focus groups perceived an escalating public demand for nursing and midwifery services flowing from mounting expectations of health care systems to provide technically advanced standards of care and equitable access. It was felt that meeting the expectations of the general public as a whole was an unattainable goal because opinions were continuously shifting and often inconsistent. Better organisation and management of services and a more efficient use of finances were considered to be areas where services could potentially be improved.

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.

(London South)

Services were described as working in isolation rather than collaboratively and there was a general consensus that the wider needs of the user and the family are not being met.

Over-reliance on family networks to support care

It was widely believed that there is an over-reliance on personal/family networks to support and assist the recipients of care. Changes to society were considered to demand a redefinition of 'community' and 'neighbourhood' in relation to nursing/midwifery services, in order that service development can keep pace with different demands and the needs of families and carers.

There isn't any longer, in the community generally, the kind of support that was around in my day, of mums, grandmothers and all the rest of it, who had experience of childbirth and supporting people afterwards.

(Bristol)

With terminally ill patients it is not always possible to provide overnight nursing care in rural areas so the dependence on family support is greater.

(Written submission)

Timely delivery of care was a recurrent issue in the categories of Appropriateness and Quality and was related to allocation of staff time according to patient need. Examples of particular groups of users not having access to care at the appropriate time were noted in emergency mental health services and in general practice, resulting in increased pressure on community nursing.

The other thing is that if you have a nervous breakdown, and that is putting it mildly, on a Sunday don't bother because apart from being admitted as an emergency there's nobody to come and sort you out at home and certainly not on the Bank Holidays.

(Bristol)

GP out-of-hours services – some practices do not have a rota system so there is a greater dependency on the ambulance service and the nurses at the local community hospitals.

(Written submission)

Having enough contact with health professionals was most frequently an issue in midwifery.

Women are complaining about infrequent visits by midwives – in parts this seems to be because, although it is recognised that fewer antenatal visits are necessary, some women do feel unsupported because of this.

(Written submission)

Perceived gaps in essential care delivery

Participants felt that essential aspects of patient care currently not being met in the acute or community setting were washing, dressing, nutritional support, appropriate communication and information giving. These activities were discussed under the terms 'basic care', 'hands-on care' and 'bedside manner'. We have described these activities as 'essential care'.

It was felt that people receiving effective essential care make a faster recovery.

Nine out of ten times I tell you, the people that receive that kind of treatment (essential care) they get better quicker.

(London North)

In all five focus groups, user representatives discussed the importance of appropriate and adequate nutrition in hospital and the need for nurses to supervise, monitor and support patient nutrition. Nutritional support was also identified as a gap in service provision in the community setting, especially around the care of older people at home.

It doesn't take two minutes to walk around the ward to make sure that everyone has got the right diet. I know I've been on visits into the ward and you see some poor person, they have been given the diet that was ordered two days earlier by someone else.

(London South)

Discussions about gaps in essential care often focused on why qualified nurses and midwives were not delivering this type of care, which was attributed to gaps in competency and demarcation between the tasks that qualified and unqualified staff undertake:

This gentleman had asked for a bottle, he wanted to go to the toilet, he was bedbound, and he asked the nurse, the staff nurse who said yes she'd ask a health care assistant to get it, she went and stood behind the nursing station and stood there for three quarters of an hour, never asked anybody to do it and this gentleman wet his bed ... It might not have been her job but ... does it really hurt, when she had nothing better to do than to sit behind the nursing station, to go and get a bottle for the gentleman?

(Birmingham)

A further reason for the perceived growing gap in the delivery of essential care was deemed to be an increasing emphasis on the delivery of technically complex health interventions.

I think we have got so much equipment in hospitals and a lot of nurses feel that if they are not using that, they are not working.

(London North)

Importance of comprehensive physical and mental health assessment

Users felt qualified staff are too focused on delivering particular interventions and can fail to recognise a patient's other physical and mental health needs. Assessing a patient's total health needs was seen as a necessary prerequisite to delivering appropriate care. Recognition of mental health needs was identified specifically as a problem for women during pregnancy and following the birth of a child. A similar issue in mental health nursing was the perceived gap in physical assessment and physical care skills.

There is a big increase in the non-detection of postnatal depression and especially in our area we are finding that there are a lot more women suffering from it and the pathways are not very good to actually access the mental health services.

(Bristol)

Those who train as mental health nurses often have no concept of what is going on in that patient's body. They've got ulcers on their legs, they have things wrong with their feet, some of them have completely bunged-up systems. They were taking no notice of their bodies, they were only looking at their minds.

(London North)

User representatives felt that better assessment prior to discharge is needed so that the patient, the patient's family/carers and health professionals involved in delivering care are informed of care plans.

Several examples of unsafe or inappropriate discharge were provided (safe discharge is discussed further under Expectation 4).

Summary of Expectation 1

Appropriate and timely use of medical interventions, treatments and essential care according to the physical and mental health needs of individual people, their carers and their families

Issues/concerns:

- growing public expectations for access to quality services
- over-reliance on family networks to support care
- perceived gaps in essential care delivery
- importance of comprehensive physical and mental health assessment.

Expectation 2

Customer-friendly services that involve patients/clients and carers 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

Customer care and communication of information about care delivery

Service users felt that service delivery could be greatly improved by applying the concept of 'customer care'. Aspects of customer care were described as carrying out initial introductions (meeting and greeting) and being able to identify staff roles.

One of the common complaints that we get at the CHC is the rudeness of nurses and the staff ... What we hear 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.

(London South)

Improved communication and interpersonal relations between users and professionals were considered to be ways of maintaining users' individual identity, building confidence and reducing unease, especially where care is being delivered in unfamiliar settings. The term 'empowerment' was used to express the notion of users being able to communicate with staff and ask for assistance or advice.

The fact is, you go in there, you become anonymous, you are a patient. You are given a number, a tag is put on your wrist and then you go into the system and you get lost.

(London South)

Users wanted to see better communication of information about waiting times and delays to services, especially in Accident and Emergency

departments or at similar points of access, emphasising the importance of explanation.

You are told 'go and wait there' and you wait and you wait, other people come and go, you don't know whether you are still on the list and there is a terrible delay. In the end some of them walk out because they are so fed up and it's just a matter of saying the clinic is running 40 minutes late, 10 minutes late ...

(London South)

The communication skills of staff working in both the acute and community setting to provide information and support patients, families and carers at times of extreme vulnerability, such as loss or bereavement, were also considered important.

If you have got a patient or relative or whatever on a ward and you want to find out how they are, you have to keep asking and they say 'well I'm afraid the sister who is dealing with this isn't available, we can't tell you, your wife is all right' and perhaps she isn't. The patient's relatives do need to know how they are getting on.

(London South)

Extra support for women who have had a miscarriage, stillbirth or neonatal death who are extremely anxious during a subsequent pregnancy.

(Written submission)

Children that go home to die: there is an enormous need there in our area. We haven't got anybody who can support the family.

(Sheffield)

Communicating choices for patient care/health interventions

It was felt that better communication of health interventions could enable staff to address the complexities of different personal circumstances or individual people's perspectives rather than making assumptions about the type of care that is appropriate.

A patient chose not to breastfeed her baby and the nurse did not know that this woman had had a double mastectomy and actually reduced the woman to tears.

(London North)

Similarly if someone is admitted to A and E who's overdosed or cut their wrists or something, there is a total lack of sympathy from the nurses.

(Bristol)

There was a view that improvements would follow if more staff took time to explain and include patients in the delivery of health interventions/procedures.

Common courtesy and care: talking to somebody when you are doing something to them, talking to them, whatever you are doing, an enema or an injection or whatever else, actually talking to them while you are doing it and explaining what you are doing doesn't seem to me to be beyond the scope of anyone's imagination.

(London North)

User aspirations for empowerment were seen to be achievable through involvement in health decision-making and access to information about risks and choices.

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.

(London North)

Two groups felt that patients often needed to be provided with written information in addition to verbal advice because people find it difficult to remember information, particularly when they are under stress.

The advice being administered by either the consultant or the nursing staff, it's verbal and so the patient has to go back and they get this verbal information when they are het up, just a bit frightened, confused and then they have to relay this to either their GP or the nurse and that isn't good. I feel that any advice issued like that should be in writing.

(Bristol)

Equity through the life course, across areas and between groups

The need for interventions to be appropriate to meet expectation and demand was linked to equity of provision for different groups of users. It was felt that nurses, midwives and health visitors, often as the front line of services, are well positioned to improve knowledge and understanding of the needs of individuals and support minority groups to improve access and reduce health inequalities.

The majority of ethnic minority women do not have smear tests, they don't go, they won't have it done, because of their beliefs and I think they can't go to the male doctors without their husbands with them. They just don't have it done. Women [could] go together to say a community place where they can say go and have their smear test done, together as a group.

(Birmingham)

Services for young people/adolescents and older people were the two groups most widely discussed in terms of areas where nursing and midwifery services could take a wider role (discussed in the following section). Minority ethnic groups, people with mental illness and learning disability, chronic conditions, HIV/AIDS, cancer, Alzheimer's disease and diabetes were also identified as groups where access could be further supported.

If everyone says 'this is a cancer problem and I know nothing about cancer, I can't nurse a cancer patient', 'I'm a geriatric nurse, I can't look after young people'. There is this terrible division I think.

(London South)

One of the biggest issues we have is that people with dementia or Alzheimer's or whatever, or even people with a permanent disability and maybe in a wheelchair going into a hospital setting, nobody knows how to look after them when they go through the door into hospital, they haven't got a clue.

(London North)

The role of nursing and midwifery in delivering services in prisons and asylum centres was considered important. It was also felt that there should be more general health services for travellers and homeless people to complement specialist drug and alcohol services. User representatives also talked about aiming for equitable standards of care across geographical areas.

Specialist services for young people and older people

A general view emerged from the focus groups that there should be specialist provision for young people in the acute setting and in midwifery services.

What is wrong is sticking adolescents with diabetes, heart conditions, whatever, into an adult ward. That's the first thing we've got to sort out I think because it doesn't matter what condition it is, if you have your adolescent with 40,000 hormones running around like mad and you stick them either into a children's ward, which is also crazy, or into an adult ward it's very wrong. There must be provision made in every hospital.

(London North)

Ensuring appropriate care for teenage mothers by designating one or two midwives with a supportive attitude and necessary skills to care for them.

(Written submission)

In the community, it was felt that more work needed to be done around the general health and nutrition of young people to equip them with the skills to prevent ill health. School-based health interventions were considered one way of improving health but other models should be developed and evaluated.

I think we need to look at the area of school nursing and how they [nurses] can actually play a huge part in health improvement of children ... I think what we're tending to do with teenagers these days is wait until they go astray and then find some way of actually helping them within the health service and that's a bit topsy-turvy. I think we ought to be doing more proactively to promote healthy living and healthy diet.

(Birmingham)

All of the groups discussed care of older people and felt that nurses especially need to be more aware of the needs of the older person. An issue for community nursing, especially in rural areas, was enabling older people to stay in their own homes by increasing the nursing contribution to assessment and linking to GP practices to make sure that older people received appropriate care. This is discussed further under Expectation 8 (Services that work with communities and are as close to patients' homes as possible without compromising quality).

We used to have teams of health visitors for the elderly, with trained nurses and nursing auxiliaries who looked after the elderly in their own homes and that has been rubbed out.

(Birmingham)

Summary of Expectation 2

Customer-friendly services that involve patients/clients and carers 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

Issues/concerns:

- customer care and communication of information about care delivery
- communicating choices for patient care/health interventions
- equity through the life course, across areas and between groups
- specialist services for young people and older people.

Expectation 3

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

Career structures into and through nursing and midwifery

Service user representatives perceived a shortage in qualified midwives, health visitors, hospital nurses, school nurses and mental health nurses but also ward clerks and support staff, and attributed the closure of some units to unsafe staffing. It was felt that expanding recruitment and career pathways into and through nursing and midwifery could increase the number of qualifying nurses/midwives. Opportunities for professional development, adequate pay, car parking and public transport were also seen as influencing staff morale and retention. Enabling staff to spend more time practising their skills and working to improve relationships between professionals were seen as areas that could be built upon to improve retention and job satisfaction.

If they had a career structure for those on the academic side because that's what drives people out. They get so far up that they go out of nursing and you don't get the retention at that level.

(Sheffield)

Overseas nurses and bank/agency nurses returning to practice were specifically highlighted as potentially needing training, including induction into UK/organisational systems and the use of information technology.

It is different in other countries, the standards are different and I feel if they are coming into this country we should be giving them some sort of standard in the way that we work here.

(London South)

Some of the nurses are not well trained. There was a case recently on a cancer ward where the agency nurse couldn't even take blood pressure and had to be told by someone.

(London North)

Staff skills and competencies were considered to be generally lacking in the acute setting and nursing homes with implications for quality and

safety. Two specific areas of competency were identified as drug administration in the acute setting and resuscitation in psychiatric nursing.

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 ... In a recent report at our trust of incidents, over half were incorrect administration of drugs and blood products. When I expressed absolute horror, the Director of Nursing said to me 'it happens all the time'. And these ones are the ones that are picked up on because they have either had an effect or were actually reported. The unreported he didn't even want to put a figure on.

(London North)

We've had a big issue recently in psychiatric nursing because they're not trained in CPR and the junior doctors also are not trained in CPR, so we've had a spate of people committing suicide and being found in semi comatose positions and nobody able to give CPR.

(Birmingham)

Staff competencies and attitudes to care delivery

The appropriate staff/people delivering care was an issue that emerged under the themes of Quality and Efficacy. In terms of quality, the issue was seen to overlap with customer care and communication. In the community, the consequence of involving large numbers of professionals was perceived to be a negative impact on patient care. In terms of continuity, consistency of carer was considered to have an impact on the quality of care.

If you identify with someone I think you feel more secure; the more knowledge you have the more security you feel.

(London North)

The concept of the 'named nurse' was discussed by two of the groups but was considered an unsuccessful initiative in reality because patients often did not see their allocated nurse for long periods of time or they were not aware of who their 'named nurse' was.

A perceived lack of continuity in maternity services was highlighted around suggestions that mothers should receive care antenatally, postnatally and during labour from a midwife they know. An important aspect of continuity in midwifery was felt to be the consistency of information and advice being provided.

Providing support for breastfeeding, to ensure that all professionals, acute and community, give consistent advice and that this support is followed up in the community.

(Written submission)

In terms of efficacy, it was felt that the staff already delivering services to a particular patient should take on all aspects of care that they are capable and safe to deliver.

If a patient was in the community following a Caesarean section the midwife would be going in looking after the baby but the district nurse was going in and doing the dressing on the mother. I thought that is rubbish

because the midwife knows how to do dressings – they do them in hospital – so why was another person going in?

(London North)

Infection control

User representatives felt that the environment patients are being treated in is an important aspect of care delivery and that nurses and midwives should have the skills and facilities to monitor and enforce infection control.

One of our hospitals has gone back to having the sister in charge of the ward, in charge of cleaning, and it's so much better.

(Sheffield)

Nurses, you see them walking around the shops in their uniform and you think how many bugs are they going to take in? You've got a patient with an open wound and they [the nurse] are wearing the same clothes they've been wandering around town in.

(Birmingham)

Summary of Expectation 3

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

Issues/concerns:

- career structures into and through nursing and midwifery
- staff competencies and attitudes to care delivery
- infection control.

Expectation 4

Services that make use of information, communication and technology to ensure that all parts of the system are informed, patients receive care faster and do not have to repeat the information they give to staff

Continuing care between service areas, defined patient pathways

Participants felt that more should be done to provide defined patient pathways between units and service areas to improve continuity between services.

It's a bit like going through a demented pinball machine: you go in there and then the hammer whacks you out and you go to another section and it's 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, see how these areas can be linked up in a better manner.

(Bristol)

Particular issues were raised around handling files and inefficient transfer of patient information resulting in services being dependent on patients as the carriers of information.

... moving files around is very difficult in many cases, it doesn't arrive in the right hospital or the van has got delayed or gone to a different clinic. And then what happens, which annoys patients, is they then have to go through all their case with the doctor and they've explained it already. And the number of times that a patient has to rehearse all their complaints because the information is not there or the doctor has not read the notes or the nurse doesn't know. And it tends to make the patient more depressed and more anxious because you have told them three or four times, you've told the triage nurse then you tell the X-ray bloke and then you tell someone else and it goes all around.

(London South)

Transfer of patient information between services and sectors

It was felt that appropriate use of information technology should be considered in all aspects of service organisation and delivery but especially on communication of patient information within and between service units or departments. Inefficient information transfer between service areas was thought to contribute to long waiting times for service users at the point of access or discharge. Communication between wards and pharmacy was of particular concern in the acute setting. User representatives also felt that staff needed skills development to be able to make use of advances in technology, for example electronic patient records. There was some discussion over the need for compatible IT systems and the use of standardized clinical codes (such as READ codes). While the use of IT in the clinical area was seen as beneficial for accessing records and information systems, user representatives felt that it could compromise a patient-centred approach.

Why can't more information be sent from the hospital to the community by email? Why are they writing letters that get lost in the post – it's ridiculous.

(London South)

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.

(Bristol)

Discharge co-ordination

Three groups made suggestions for increased nurse-led discharge services and intermediate care.

We also have what are called step-down beds or community hospitals, not in all the areas but in some of the areas where they are sent from the acute hospital into this community setting, which is supervised by GPs generally, and nurses, and they are provided with a kind of step-down.

(London South)

The hotel suite is actually available for those that can't be collected or are ready for discharge but can't go home that night, or someone [who] has been in for a procedure and normally they would go home but they are not quite well enough. They don't need great nursing care but they just need a bit of care and comforting while they come round from the anaesthetic or the operation or whatever. They are put into this hotel suite where there is a nurse in charge of that and it's nice and comfortable.

(London South)

We are looking very much into intermediate care by discharging patients from acute hospitals who no longer need the acute care into community hospitals as an intermediate stage to actually give that person the chance to meet up with the social worker, set the package in order, make sure it's all there before they are then discharged home. And that's being looked at under the new nursing care regulations.

(Birmingham)

Summary of Expectation 4

Services that make use of information, communication and technology to ensure that all parts of the system are informed, patients receive care faster and do not have to repeat the information they give to staff

Issues/concerns:

- continuing care between service areas, defined patient pathways
- transfer of patient information between services and sectors
- discharge co-ordination.

Expectation 5

Services that enable staff to make use of research evidence in practice

Several groups provided examples of positive outcomes from nurses/midwives using research-based practice. The groups felt that more work needed to be done to implement the findings of research and successful pilot schemes. Reasons why research evidence is not implemented in practice were thought to be that nurses did not have the power to change practice or that pilot schemes were not maintained or rolled out because of lack of financial commitment.

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'.

[Faciliator:] So the research is undertaken but it's not evolved into practice?

Exactly: it's stopped because nurses don't have the power to actually make it happen.

(Sheffield)

A couple of years ago, we did what we called case loading and it was the midwives who were given a case load and they saw that case load from beginning to end ... and mothers absolutely thought it was fantastic and it worked brilliantly, but because it was only a pilot scheme and it was only funded for 18 months it has now died.

(Birmingham)

Summary of Expectation 5

Services that enable staff to make use of research evidence in practice Issues/concerns:

- dissemination and implementation of research findings in practice
- sustaining and rolling out successful pilot schemes.

Expectation 6

Services that involve users meaningfully in the delivery of care, training and education of staff, standard setting and quality monitoring

The value of the contribution of users/volunteers to service delivery

All of the focus groups provided examples of volunteers involved in hospitals and in the community, including: providing clerical assistance in hospital wards, meeting and greeting services, providing support at mealtimes, and respite services for carers. Fundraising and charitable work were also discussed. Some participants felt that there was potential for users to make further contributions, whereas others felt that over-reliance on voluntary effort was unsustainable in the longer term.

If you have got a working co-operation between the nurses and the voluntary services, they will sit there and say 'are you all right, can I show you where to go?' ... Nurses are very busy – sometimes they have got emergencies; if you are very busy and you are rushing off and someone wants to stop you, you have got to have some support.

(London South)

The service is becoming more and more reliant on volunteers and the need for volunteers. If you look at the PALS [Patient Advice and Liaison] system they are not going to get enough volunteers to run the pilots. So if you can't get it somewhere like that, that is a very nice front line job, then you are not going to get them to do the nitty-gritty and they can't recruit volunteers.

(Sheffield)

Meaningful and representative user involvement in service planning and development

User representatives wanted to see the implementation of policy initiatives to involve users in service developments in meaningful ways. They felt that there needed to be more guidelines and clarity about achieving user involvement, perceiving problems around obtaining information and incorporating diverse perspectives and needs. There was a common view that 'the patient voice' should be inclusive of different groups and representative of communities.

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 are we going to do it, how are you going to live with that?'

(Sheffield)

Several models of user involvement in service development were provided. These included Community Health Councils, voluntary organisations (such as the Association of Voluntary Community Care Organisations) and representation of users on multidisciplinary working groups, Borough Safety Groups, National Service Framework advisory groups and Health and Social Care Groups. User representatives perceived difficulties in establishing representative user groups and maintaining representation in service development.

A loud voice is often the only one that is heard. Community Health Councils overcome that by listening to what the person is saying and if it's a strong enough issue then they will take it forward.

(Sheffield)

In our borough they are running out of people that are prepared to sit on those groups. They are already known as the 'usual suspects'.

(London North)

User representatives suggested methods for obtaining user views on service development. These included use of suggestion boxes, exit polls when people are discharged from services, postal questionnaires and computer-based questionnaire systems, in this case for gaining the views of young people. There were perceived benefits and drawbacks to each method of obtaining views, especially in relation to hard-to-reach groups. Pakistani and West Indian communities were specifically identified as groups currently less likely to be involved in service development or feedback.

What was done in Hounslow was to set up cybercafes and it has actually been funded by the CHC to train 500 peer leaders, young people, who are going to be able to fill the gap because young people are not actually listened to and they are the biggest gap.

(London North)

The most difficult to reach in our area, there are quite a lot of Pakistani and West Indian people and we cannot get them involved ... we try and try, we have had public meetings in their areas, we simply cannot get them to come, and there is a significant number of them with dietary requirements and nursing requirements – you know, you can only have female doctors.

(Bristol)

The focus groups revealed that user representatives would like more information fed back about service developments or initiatives in their area. They suggested that information should be explicit and appropriate and should utilise local radio or press.

I would totally support the thing of feeding back and closing that loop about people who are hard to reach. When you do make all the effort, do all the work, get their opinions and talk to them and we at the CHC scarcely get anything back or if we do it's a fat report with 300 pages or whatever which you are not going to hand back to them ... It's got to be a real serious link in terms of feeding back.

(London North)

I think it would be nice to have results published ... in an acceptable short form. not as something which is in the local library, which nobody ever looks at apart from researchers.

(Bristol)

User involvement in identifying, measuring and enhancing quality

The groups all discussed parameters for identifying and measuring quality, perceiving present systems to over-monitor service throughput, which was considered to have little relation to quality in terms of patient satisfaction. It was generally felt that quality monitoring could have a negative impact on organisations if it is not backed up with support, and individuals working within a 'poorly performing' organisation could be stressed and demoralized. It was suggested that quality monitoring should involve continuous assessment over time rather than being

dependent on the performance of an organisation on one particular day or week.

It [service evaluation] is set on throughput and it's set on quantity not quality. The corporate target is quite different from the unit target or the individual. Everyone wants to see good performance so they tick the box. For the sake of doing it, tick the boxes.

(London North)

I agree you have got to raise standards, I have no qualms about that, but if people are being beaten all the time it makes life very difficult to maintain standards. People are continuously being told they are rotten and staff are taking it home and leaving.

(Sheffield)

You have also got these people coming around monitoring the cleanliness. Our hospital, they came in and they couldn't find a thing wrong. All they are doing is ticking boxes on that day. Everybody knows they are coming on that day. We've hired plants for that day.

(Sheffield)

It was felt that more work needed to be done on sharing good practice across different regions to standardise quality.

Services can be close together, they can be adjacent health authorities and yet there is no consciousness of what is going on next door.

(Sheffield)

How nice it would be if there was a way we could know how services are provided in the different areas ... If you can do that there, why can't we? ... We can learn from somebody who is doing it really well and it works"

(Bristol)

Involving users in training and education

All of the groups discussed the involvement of users in the training and education of health care staff. It was considered important that users become more involved in conveying the patient experience and journey through care to improve professional knowledge and communication between members of staff and with service users.

I mean any chronic condition or anything, talk to the people that are actually there. When you come out of your training these are the people that you are going to have to deal with. I think that should go right the way through.

(London North)

Involving patients, you know actually, particularly observing somebody's journey, appointing somebody to be involved with them, as an advocate, to go through and actively become involved with this journey and look at where the pitfalls are in that respect.

(Birmingham)

One group talked about training for users to enable them to become involved in service planning or development.

Summary of Expectation 6

Services that involve users meaningfully in the delivery of care, training and education of staff, standard setting and quality monitoring

Issues/concerns:

- the value of the contribution of users/volunteers to service delivery
- meaningful and representative user involvement in service planning and development
- involving users in identifying, measuring and enhancing quality
- involving users in training and education.

Expectation 7

Services that provide independent, confidential systems for complaint and comment for patients and staff

Communication strategies within organisations: 'The layer of jam in the sponge cake'

User representatives felt that poor internal communication could have a negative impact on staff working in an organisation and patients accessing services. In the following quote the participant describes a perceived internal breakdown in communication between managers and staff in practice.

It's like a layer of jam through a sponge cake. The information goes so far and then it seems to vanish. So the management at the top are making all these wonderful decisions, feed it down and it just arrives on somebody's desk and they read it and if they say anything about it, it just gets absorbed in this jammy layer.

(London North)

It was suggested that communication systems should be put in place to enable staff to report concerns or make suggestions to management without fear of negative consequences.

A lot of people that I've talked to, not complainants but people just generally talking about the care in hospital, have had nurses when they are talking to them complaining about the situation they are in, the hours or whatever, which makes me think that they aren't actually getting a hearing from the management.

(London North)

They say to me on a ward round [the nurses] they don't want to say anything because they will get a black mark, 'I would be rocking the boat.' You have got to have some system where nurses can, when they see something is wrong, be able to do something about it.

(London South)

Confidential evaluation and complaints systems for staff and users

Participants provided several examples of service evaluations, invitations to comment or complaints where patients spoke directly to professionals delivering services. It was felt that evaluation of services by the same

people who deliver services was inappropriate, because patients would be reluctant to disclose any negative aspects of their care.

A patient complaining direct to the hospital feels vulnerable. If you put the advocacy service within the hospital setting or within the trust setting you've still got that barrier ... The only way you are going to get user involvement properly is by an independent body, call it what you will but unless they are independent they won't change the system.

(Sheffield)

Lots of wards have these books that people fill in; they make comments but they are usually 'I love you' books. They are afraid to put anything in those ... A number of maternity units that I have been in touch with actually do this – it isn't hugely successful. Some of them invite groups of mums to come back with their partners in tow, there's not a huge take-up with that. The trouble with it is they [the patients] are actually talking to the people who have provided the service and who may be required to provide the service again in the future and it's slightly inhibiting.

(Bristol)

One group of users suggested NHS Direct (a patient information telephone service) could be used as a confidential system for users to report concerns or evaluate services.

We know that there has been a good response over the telephone from a large cross-section of the public to things like NHS Direct and we also know that NHS Direct often call back to check on how well people feel that they have come out with whatever it was ... that kind of method, maybe by harnessing organisations that the public feel are near enough to talk to but are far enough away not damage them, like NHS Direct, might be one of the ways of trying to do that [make safe, complaint systems].

(Bristol)

Summary of Expectation 7

Services that provide independent, confidential systems for complaint and comment for patients and staff

Issues/concerns:

- communication strategies within organisations
- confidential evaluation and complaints systems for staff and users.

Expectation 8

Services that work with communities and are as close to patients' homes as possible without compromising quality

Proactive health service for young people

All five groups highlighted the role of nursing and midwifery in health promotion and the prevention of ill health. Increasing the nurse contribution to health promotion was seen as an appropriate and costeffective way of bringing services into line with public health needs. When nursing and midwifery services were discussed in terms of the optimal locality of care for specific client groups, a clear gap was identified in terms of delivering care to young people. School-based nursing services were seen as a good opportunity for providing health advice as well as delivering interventions. This perceived gap in school-based nursing interventions for young people was highlighted in all five focus groups (an issue discussed under Expectation 2: Specialist services for young people and older people).

I still think one of the most important things is education in schools and the public generally. There is a huge role for community nursing outside the hospitals. We have heard so much about schoolchildren being obese and all this sort of thing but there is no one in schools to sort them out.

(London South)

I think we need to look at the area of school nursing and how they can actually play a huge part in health improvement of children ... we ought to be doing more proactively to promote healthy living and healthy diet.

(Birmingham)

Reducing travel distances for service users and carers

The location of care delivery was considered an important factor in relation to the amount of time patients and carers are required to spend travelling to services. As well as inconvenience there was a perceived risk associated with travelling to hospital, especially for women in early labour. The distance a patient or relative has to travel to the point of service delivery was discussed in relation to the efficacy of providing specialist services. Patient choice was considered an important factor in midwifery services especially, where mothers may want their baby to be born in a particular area or hospital.

Our local maternity services have now been amalgamated with the next-door one so all those mums have to travel an extra ten miles in very heavy traffic to hospital.

(London North)

The other gap, and it's a difficult gap to fill, is the neonatal facility because you can't really staff a huge one and then find you are not using it but if it is too small you are then charging up and down the country to the nearest neonatal unit that has got a vacancy and that could be hundreds of miles.

(Bristol)

Supporting people to stay in their own homes

The appropriate location of care delivery was also related to equity through the life course, in discussions of older people's services and services for children and young people, and supporting these groups by delivering nursing care in people's own homes (a point also discussed under Expectation 2: Specialist services for young people and older people).

The paediatric outreach service sits in the acute hospital but they go out into the community and liaise. At the moment we are looking for the opposite direction because the emphasis that we want is for paediatrics to be emphasised in the community and then 'In-reach' into the hospital.

(Sheffield)

I would like to see much more done within the community nursing side to make sure that older people are more supported to stay in their own homes. And I would like to see annual checks for people of 70 to 75 seen by a nurse practitioner ... linking with GPs.

(Birmingham)

User representatives discussed the appropriateness of the location of care delivery. It was considered beneficial that nurses and midwives work in outreach services with people at home and within care homes. Appropriate location of care delivery and efficient use of services (optimal configuration) were discussed in terms of freeing up busy hospitals and reducing hospital waiting lists, especially in Accident and Emergency departments, by delivering nurse-led services in the community.

If we had much more community nursing in its various ways, surely this would be one of the great things for freeing-up hospitals from their congestion.

(London South)

Summary of Expectation 8

Services that work with communities and are as close to patients' homes as possible without compromising quality

Issues/concerns:

- proactive health services for young people
- reducing travel distances for service users and carers
- supporting people to stay in their own homes.

Expectation 9

Services that are funded in ways that lead to the best outcomes for patients

Optimal budget configuration and purchasing

Optimising the configuration of service budgets was perceived to be a way of improving the efficiency of publicly funded services. It was felt that the decommissioning of financially expensive services may not necessarily be cost-efficient over time. There was a perceived overspend on drug budgets and on the monitoring of nurse prescribing. However, there was a feeling that this overspend was justified if prescribing was effective. Some felt NHS Direct was a poor use of finances because users were not confident in the information they received. The groups also perceived financial inefficiency occurring because of duplication in health and social care services.

We've split health services from Social Services, that's the big problem and that's where the problems arise because of this demarcation. We get this in our hospital when you've got people blocking beds and they say 'It's not our fault, the trust, it's Social Services' fault', so they are blaming each other instead of working together which hopefully they will in the future.

(London South)

User representatives felt that integrated health and social care would be more cost-effective in the long term.

Having sat for a long time through the NSF for Older People which is all about keeping people out of hospital and actually stopping them becoming degenerative in their old age as much as you possibly can, not half of it is health; a lot of it is transport and leisure and things like that and you are never going to achieve change in that, and I know this is a dirty word in many areas but 'pooled budgets' between the local authority and the health authority – it doesn't happen. It happens in learning disabilities, strangely enough. It seems to be the one area where it has worked, putting the budgets together.

(Sheffield)

The relationship between private and public sectors, especially accommodating private patients in public services and vice versa, was felt to be an area of moral and political concern.

There is this enormous problem at the moment between the two sectors. I think they should be a little bit more combined or more regulated, but I think it's a big issue with the building of new hospitals because where I am there is a new hospital being built and one of the questions that came up was, 'what about consultants and their private patients, will there be any facilities for them within the hospital?'

(London South)

Long-term cost benefits of service units/health interventions

The use of finances was discussed in relation to the funding of nursing/midwifery posts. There was a view that with limited resources the cost of employing doctors or nurses on high grades was prohibitive and led to service providers employing fewer highly skilled people.

I think the government are trying very hard to get health care on the cheap by pushing a lot of stuff onto nurses.

(Bristol)

Agency nursing was seen as a drain on resources and user representatives discussed other strategies for employing nurses that would cost service providers less.

We have a flexi-time for nurses within the hospital, people who can come in a couple of days a week for one morning or afternoon or some evenings. They can be pulled in to help and that saves an awful lot of money because you don't have to have agency nurses. It's cheaper.

(London South)

Summary of Expectation 9

Services that are funded in ways that lead to the best outcomes for patients

Issues/concerns:

- optimal budget configuration and purchasing
- long-term cost benefits of service units/health interventions

User focus group summary

The focus groups elicited the views of service representatives in relation to the organisation and delivery of nursing and midwifery services. By a thematically analysing the focus group data, it has been possible to identify nine core expectations and to highlight issues and concerns under these broader headings.

Table 3 User focus group summary

_	Expectation		Issues/concerns		
1	Appropriate and timely use of health interventions, treatments and essential care	•	growing public expectations for access to quality services		
	according to the physical and mental health needs of individual people, their carers and their families		over-reliance on family networks to support care		
		•	perceived gap in essential care delivery		
		•	importance of comprehensive physical and mental health assessment		
2	Customer-friendly services that involve patients/clients and carers in personal care	•	customer care and communication of information about care delivery		
	decisions and provide support and information in appropriate ways for individual people, irrespective of their gender, age,	•	communicating choices for patient care/health interventions		
	social background, ethnicity, or level of disability	•	equity through the life course, across areas and between groups		
			specialist services for young people and older people		
3	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	•	career structures into and through nursing and midwifery		
		•	staff competencies and attitudes to care delivery		
		•	infection control		
4	Services that make use of information, communication and technology to ensure that all parts of the system are informed, patients receive care faster and do not have to repeat the information they give to staff	•	continuing care between service areas, defined patient pathways		
		•	transfer of patient information between services and sectors		
		•	discharge co-ordination		
5	Services that enable staff to make use of research evidence in practice		dissemination and implementation of research findings in practice.		
		•	sustaining and rolling out successful pilo schemes		
6	Services that involve users meaningfully in the delivery of care, training and education of staff, standard setting and quality monitoring	•	the value of the contribution of users/volunteers to service delivery		
		•	meaningful and representative user involvement in service planning and development		
			involving users in identifying, measuring and enhancing quality		
		•	involving users in training and education		
7	Services that provide independent, confidential systems for complaint and comment for patients and staff	•	communication strategies within organisations		
		•	confidential evaluation and complaints systems for staff and users		
8	Services that work with communities and are as close to patients' homes as possible without compromising quality	•	proactive health services for young people		
		•	reducing travel distances for service users and carers		
		•	supporting people to stay in their own homes		
9	Services that are funded in ways that lead to the best outcomes for patients	•	optimal budget configuration and purchasing		
		•	long-term cost benefits of service		

Three prominent and cross-cutting themes emerged.

- 1 User involvement, in
 - clinical decision making
 - service development
 - service delivery
 - education and training
 - quality monitoring.

2 Communication

- within and across service units/sectors
- between professional groups
- between service users and professionals
- utilising information technology
- accessing and transferring patient information.
- skills to enable staff to be sensitive to health problems and particular groups of users such as:
 - young people/older people
 - coping with bereavement or sexual health problems
 - communicating information to relatives or carers.
- 3 **Quality of care**, maintaining high standards of care while maximising:
 - cost-efficiency
 - resources
 - workforce capacity
 - skills.

Stakeholder interviews

The consultation included interviews with key stakeholders regarding their priorities for research and development, in relation to the organisation and delivery of nursing and midwifery services. For our purpose stakeholders were drawn from health and social care sectors and were defined as having an interest in nursing and midwifery research. Telephone interviews were used in preference to face-to-face interviews to maximise the efficient use of time and resources.

Interview schedule

A bespoke interview schedule was designed to include biographical details related to the respondent's current role and their experience of undertaking and commissioning research (as shown in Appendix 4). Openended questions were used to elicit views on existing nursing and midwifery services and the contribution of, and gaps in, nursing and midwifery research. Research priorities developed from the previous SDO 'listening exercise' (as shown in Table 4 below), supplemented with examples from nursing and midwifery, were used as prompts. Stakeholders were asked to give their opinions on the appropriateness of these priorities for nursing and midwifery and to select their top five in rank order, or suggest other/additional research priorities. It was envisaged that the SDO framework would focus the enquiry within a policy context as well as making provision for eliciting diverse opinions corresponding to personal/professional areas of interest.

Table 4 SDO Programme priorities

Organising health services around the needs of the patient

User involvement

Continuity of care

Co-ordinating/ integration across organisations

Interprofessional 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

Source: Fulop and Allen, 2000

Stakeholders were provided with an e-mail or fax in advance of their interview, which outlined the purpose of the exercise, a copy of the interview schedule and background information about the research team. The semi-structured telephone interviews enabled the interviewers to probe responses fully, clarify ambiguities, and avoid misinterpretations. Notes were taken during the interviews and, where participants agreed and circumstances permitted, the interviews were also tape-recorded.

The duration of interviews varied from 10 minutes to one hour. For several of the respondents the interview appeared to be welcomed as an opportunity to discuss their concerns about the role of research in relation to service, professional and organisational development. If participants preferred they were invited to use the interview schedule as an e-mail-based questionnaire (nine selected this option). Some of the participants also circulated information about the project and the schedule to other colleagues in their professional networks such as the Royal College of Nursing (RCN) Research Society, Senate and the Allied Health Professional Research Forum, which generated further responses. Participants were also given the opportunity to contact the interviewers at a later date to share any further insights and three participants took advantage of this option. Data from the telephone interviews and e-mail responses have been combined.

Participants

The sampling framework was drawn up to ensure consultation with a wide range of stakeholders from: medical, social care and allied health professionals; research commissioners; policy makers; educators; managers; researchers; and users (see Tables 5 and 6). Over 100 potential interviewees were identified and it was possible to arrange and carry out interviews with, or receive e-mail responses from 64 of these (or a nominated representative). The respondents represent the full range of organisations outlined in the study specification, stakeholders identified by the commissioners, and further contacts recommended by interviewees, including additional consumer groups.

Table 5 Organisations represented in the interviews

Higher Education Funding Council of England (n = 1)	Workforce Development Confederations (n = 3)	NHS managers and clinical staff (n = 13)	Health service researchers (n = 3)
Policy makers (n = 3)	Council of Deans (n = 2)	Higher education (n = 14)	Independent sector/managers (n = 3)
SDO Nursing and Midwifery Commissioning Group (n = 2)	Nursing and Midwifery Council (n=2)	Other health professions (n = 9)	Other government health-related organisations (n = 2)
Nursing and Midwifery RAE Panel (n = 3)	Professional organisations (n = 7)	Service user representatives (n = 5)	Organisations that commission and fund health-related research (n = 6)

^{*} Please note some respondents represented several categories, e.g. Professor in Higher Education, member of SDO Nursing and Midwifery Commissioning Group and Nursing and Midwifery RAE Panel Member, consequently the total number is greater than 64.

Table 6 Professional background of interviewees

Background was ascertained from the participant's own classification. Some respondents were qualified in more than one professional field but classified themselves as representing one of the professions in particular.

Analysis

The interviews were recorded onto audiotape and each interviewer made detailed notes directly on to a copy of the interview schedule, which were transcribed 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 profession, job role and geographical area to identify commonalities and differences in perspectives.

Findings

The findings of the stakeholder interviews are presented in three sections:

- Commentary on current SDO priorities
- Stakeholder views on additional priorities specific to nursing and midwifery research
- General issues relating to nursing and midwifery research.

Over half of the sample (n = 37) had experience of commissioning research and a further five regularly reviewed proposals for either the Department of Health or other funding bodies including charities. All except three had some experience of undertaking research. For a minority of these (n = 12) this had been as part of personal/professional studies. Nineteen respondents, mainly but not exclusively those from the professions outside of nursing and midwifery, had undertaken research in other fields. Where it has been possible to identify a common perspective from a particular group of respondents, such as nurse academics or NHS managers, this has been highlighted. Similarly, where appropriate the frequency of responses is noted to illustrate the recurrence of particular issues. Quotes from the interviews and e-mail responses are used throughout to illustrate the findings.

Commentary on SDO priorities

The majority of respondents suggested that the research priorities of the SDO programme as a whole were relevant and appropriate for nursing and midwifery. Indeed several of the respondents (n=17) reported difficulty in excluding any of the categories as research priorities for nursing and midwifery, as the following quote from a respondent who worked for a central government health-related organisation demonstrates:

Very comfortable with them, wouldn't question any.

However, many respondents, both from within and outside the nursing and midwifery professions, were less convinced that they were specifically issues for nursing and midwifery research:

Not sure they just relate to one professional group or another though, could be any.

Several respondents felt that many of the categories were overlapping and could be combined. For example, 'User involvement', 'Organising health services around the needs of the patient' and 'Organisational form function and outcomes'. Similarly 'Interprofessional working' and 'Workforce issues/characteristics' were considered to be interrelated. Others suggested that these broad issues should be treated as crosscutting themes, incorporated in all service delivery and organisation research rather than being identified as separate categories or topics. Some respondents held the view that the categories were too broad, which would mitigate against focused and meaningful research. For example, in relation to continuity of care, several respondents from midwifery suggested a specific focus on continuity of carer was required rather than care.

The ten SDO categories supplied with the interview schedule are discussed below in the order of the frequency with which respondents highlighted them within their 'top five' priorities. (Please note, not all respondents were prepared to acknowledge or rank the categories in this way and so the total number of responses does not equal 64).

Workforce issues/characteristics

Workforce issues/characteristics was most consistently ranked in the top five priorities by the majority of respondents (n = 39) and for those representing national organisations or based in London and the South this was frequently offered as the highest priority. Indeed, one respondent managed to recast nearly all of the priorities listed as workforce issues. 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, competence, nurse/patient dependency ratios (independent sector), appropriateness of pre- and post-registration education, and training for support staff. New role development and shifting professional boundaries were highlighted as a key priority for further work, particularly in relation to efficiency, effectiveness and impact on patient outcome. For example, one policy maker emphasised the need to investigate:

... role extension both up and down, the whole spectrum of roles and attendant tasks, specialisation and sub-specialisation. [Is it a] good thing or not? [and what] preparation/teams/supports are required?

Some challenged existing research on the workforce as being atheoretical and failing to build on knowledge such as professional power and gender. Others argued that nursing and midwifery was only one part of the health care workforce, and its preoccupation with 'presenting uniqueness' was one of its problems.

Perhaps too much attention [is placed] on role confusion, etc. because uncertainty and unpredictability is a key aspect of the modern NHS. The profession should stop worrying so much.

There was some feeling that there were broader health service workforce questions that went beyond the evaluation of roles or skill mix.

There is also a much broader question implied in the priorities: is the current division of labour in the health service workforce correct? There is a lot on shifting boundaries but perhaps we need new boxes. I am still keen to see us stand back from the [professional] boxes and question whether they are suitable or not. We need to stand back from where we are now.

(Nurse academic)

Concerns were expressed that nurses trained in universities had become neither 'fish nor fowl'.

They've been to university but they are not concentrating on basic care giving.

(Nurse academic)

This raised questions about the importance of enhancing the evidence base for nursing practice in, for example, nutritional support, and developing practice and prescribing to reduce the competency gap in the workforce. This was reinforced by other managers and the Ombudsman Office:

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)

Further issues raised in relation to Workforce issues/ characteristics

- The most effective contribution of different health care professionals to extending services, for example, nurse prescribing
- The impact of good employment practices on patients and staff
- Implementing anti-oppressive practice and training policies
- Nursing leadership, management and contribution to strategy development in health service organizations, for example, evaluation of the Nurse Executive Director/Director of Nursing role, Modern Matrons, Nurse Consultants
- Redesigning health care roles based on competencies required to meet patient need rather than traditional professional groupings
- Preparation for practice (pre- and post-registration education programmes)
- Nursing roles, access to training, skill mix and quality standards etc in the independent sector
- The impact of skill mix/division of labour on patient outcomes, particularly in relation to Health Care Assistants and social care staff
- Clinical supervision and support frameworks
- The impact of work on the health of nurses and midwives, for example, stress, physical demands of the work
- Ageing and gender in nursing and midwifery.

User involvement

Thirty-five respondents identified user involvement as one of their top five priorities. Several people suggested that user involvement should be demonstrated within all research activity.

User involvement should fall out as a set of questions that should be part of any of those other topics.

(Nurse academic)

[It is] all about the patient - it shouldn't be separated out.

(Policy maker)

Some respondents challenged the notion of 'user involvement' as tokenism and argued that research needs to evaluate models of user-led services with shared decision making through partnership.

We want user ownership of care, self-management, etc. The user example should be something like 'What is the impact of engaging users in nursing interventions?', 'How can we empower users in terms of decision making and care management?''

(Nurse academic)

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. [We] will need a different sort of health professional to deliver

that agenda. Nurses in expanded roles – 'self-management in a user-managed NHS' rather than just involvement of users.

(Nurse academic)

Some doubts were raised about how to make this involvement real and meaningful. For example, one representative from a professional organisation said:

The Benefits Agency needs to work with R & D to work out a sustainable way to pay people. The current benefit arrangements are a real barrier – [and it] needs joined-up government. A lot of the service users you would want to do this are on benefit; to ask them to do that if it threatens their benefit, you're asking them to be more altruistic than they ought to be. Without attention real user involvement will never be more than an ideal, it will be exploitation.

Other methodological challenges of investigating user-led models of care were highlighted, such as the meaning of 'representation', the importance of harnessing a diversity of views and the implications of shifting the balance of power from professionals to users, as the following quote illustrates:

We need to focus more on patient experience and outcome. We've definitely got to look at this but it's very hard to do. How can we ask patients what they think and whether they think it's better if they have never experienced the service before?

(Representative of a research-funding organisation)

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. I should think this applies across the board but we in learning disabilities have to be more creative because of the communicative difficulties of our particular client group. I think the danger is that user involvement does become consultation rather than true partnership. 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. And it's how we crack that across all levels of nursing and service users, so that users can actually influence decisions and have some real power and influence.

(Service Development Officer for Learning Disability)

Further issues raised in relation to User involvement

- Contribution of the voluntary sector and self-help groups, particularly in mental health and learning disability services
- Developing patient/client-focused outcome measures
- Professional image, public perception of nurses and nursing both in relation to specific client groups and in general.

Organising health services around the needs of the patient

Thirty-four respondents rated 'Organising health services around the needs of the patient' as a top-five priority. Services were considered to be organised around the needs of professionals and further research was needed with patients and users to identify how patients would like services organised. However, a significant number of stakeholders considered this to be an area applicable to all aspects of research. For example, one nurse academic said:

Organising health services around the needs of the patient is a pious hope rather than a researchable question and should be included in any of the others

Further issues raised in relation to Organising health services around the needs of the patient

- The best means of providing care for older people, especially those with dementia
- Importance of recognizing and understanding diversity and the need to promote and deliver culturally sensitive services, for example, implications for nurses of the Race Relations Amendment Act.

Interprofessional working

Opinions were divided among the respondents regarding the desirability or not of conducting research into interprofessional working. Thirty respondents included this category in their top five but the enthusiasm of others was muted, suggesting that the barriers to successful interprofessional work were well known and mainly structural and so investing in further research was unlikely to be a productive use of resources. Other respondents highlighted existing research gaps in our understanding of intra-professional working and would have preferred to see an emphasis on the effectiveness of teams and team working generally. As one respondent from a research funding organisation stated:

What is it that makes a successful team? What makes teams effective? (Policy analyst)

Some respondents found a paradox between the focus on interprofessional working and the notion of a dedicated funding stream for nursing and midwifery research, as the following quote from a research commissioner demonstrates:

Interprofessional working seems at odds with a unidisciplinary research agenda!

Continuity of care and co-ordination/integration across organisations

Twenty-four respondents placed 'Continuity of care' among their top five SDO categories and a further 24 selected 'Co-ordinating/integration across organisations'. However, the majority of respondents felt that these two categories overlapped so comprehensively that it was difficult to distinguish between them.

Continuity of care and co-ordination/integration across organisations are inseparable in my mind.

(Representative of a professional organisation)

There was some uncertainty as to whether or not users and patients are as concerned about continuity of care, particularly as often conceptualised by some professions in terms of continuity of carer. This is illustrated by the following quote from a representative of a professional organisation:

... How do you maintain continuity and does it matter? – big assumption that it does. When we had our first child we had the same midwife all the way through. For [the] second they changed at the end of the shift – [I] was surprised to find that it didn't actually matter to us, as long as the communication works it probably doesn't matter. Whether continuity is important or not is a big genuine question to research.

Further issues relating to the Continuity of care

- Communication between and within professions and agencies and with patients and carers
- Relationships between NHS and independent sector staff.

Relationships between organisational form function and outcome

Relationships between organisational form function and outcome was highlighted in the top five priorities by 18 respondents. Such respondents were more likely to be managers or policy makers. However, many challenging methodological issues were also highlighted, as this quote from a representative from a professional organisation illustrates:

Could you ever design a study to last long enough, and with a stable enough organisational form? Always dealing with confounding factors. [There are] so many severe methodological issues.

Respondents from the independent sector and those who had experience of voluntary services emphasised the need to research the interplay and shifting responsibilities between voluntary and independent sectors and statutory services. Changes in funding for aspects of care in relation to client groups such as older people, people with mental health problems and people with learning disabilities and the contribution of carers were also highlighted.

The use of resources, including de-investing in services and managing demand

Although 18 respondents included this category in their top five, several respondents, particularly those from the academic sector, doubted that this was in the remit of research, seeing it more as a management issue.

... de-investment [is] not in the gift of researchers. Could look at how demand could be managed but difficult to operationalise have to modify the behaviour of users and health care practitioners, not open to researchers to do that. More a policy maker task, could address theoretically but matter for economists rather than researchers.

(Nurse academic)

Implications of the communication revolution

While 13 respondents included 'Implications of the communication revolution' in their top five priorities, others suggested that the focus should be on the broader category of 'Communication', both oral and written, rather than merely the use of IT. Many respondents were also at a loss to see that there was a uniquely nursing and midwifery dimension to this area, as illustrated by the following quote from a representative of a non-nursing/midwifery professional organisation:

'Implications of the communications revolution' – on its own it is important but not sure there is anything unique about the role of nurses in this. The same issues apply to GPs and other health professionals. I would want some convincing that there was something unique about nursing.

The implementation of national policy initiatives

Respondents from national organisations, policy makers and senior managers were more likely to include 'The implementation of national policy initiatives' in their top five (n=12). However, again many of these respondents expressed considerable doubts about whether there should be a particular focus on nursing and midwifery, as the following quote from a representative of a professional organisation demonstrates:

'Implementation of national policy initiatives' – I don't see why this a nursing and midwifery issue only. One of the problems with nursing, in terms of how it's seen by the rest of the service, is the constant desire to present uniqueness. The service should be more than the sum of its parts. The 'don't forget the nurses' approach is not helpful: nursing is just part of the wider system. It's fine to research clinical governance or the implementation of the [NHS] Plan but if we just focus on nurses what are we going to learn?

A further point relating to the implementation of national policy initiatives, raised by five stakeholders, was how services and National Service Frameworks advantage or disadvantage certain groups, particularly minority groups and rural populations.

Additional priorities specific to nursing and midwifery research

In general, stakeholders considered the priorities of the SDO programme to be relevant to nursing and midwifery research. However, additional or alternative priorities were suggested by many participants. For example, one nurse academic said:

The priorities given [in the schedule] are built around the SDO programme. Are they right ones for nursing and midwifery? I am not sure I would restrict myself to this.

A summary of the additional priorities suggested is shown in Table 7. The issues raised have been paraphrased and clustered into two broad topics: 'The nursing/midwifery contribution to public health' and 'women's health'. The number of times each issue emerged is recorded in the second column. This value should not be considered an indication of ranking, as suggestions were made spontaneously during interviews and have not been the subject of wider review. Suggestions arising also tended to reflect the particular research, practice or policy interests of the individual or their organisation, although some respondents based their suggestions on the findings of previous research priority-setting exercises.

The nursing/midwifery contribution to public health

As Table 7 shows, many stakeholders identified themes or issues relating to public health, including health promotion, where nursing and midwifery research should be a priority. The role of nurses and midwives in reducing inequalities in health emerged as a significant priority not represented by current SDO priorities. Research into clinical interventions and evaluating care-giving practices or the 'value added contribution of nurses/midwifery' were also highlighted as priorities relating to nursing and midwifery. Within this, communication between nurses/midwives and patients/clients and carers during interventions, or the 'clinical encounter', was specifically highlighted as a priority area. Many of the respondents were surprised that there was little emphasis within the existing priorities on clinical issues, nursing and midwifery technologies and interventions in relation to patient/client outcomes.

Some stakeholders suggested a client group approach to identify priority areas, for example, mental health, learning disability, older people etc., particularly as such client groups are increasingly the recipients of care from multiple sectors and points of delivery. Others again suggested that a focus on particular health problems, such as cancer, or on speciality or even sub-speciality issues would be preferable. Several respondents saw the lack of focus on key issues such as ethnicity, gender, diversity, inequality, and power as a conspicuous omission from the SDO priorities.

The nursing/midwifery contribution to women's health

Priorities for both nursing and midwifery research were also identified in the areas of 'women's health', with some very focused questions emerging. A broad priority was how women's knowledge, beliefs, needs

and fears affect decisions they make about their health. Examples provided here were the influence of cultural beliefs on accessing particular health services or units and the acceptability of mixed-sex hospital wards.

In maternity services, it was considered important that research should identify outcomes which matter to women, babies, families and society in the short and long term, prioritising investigations into the physical, emotional, economic and social consequences of technical and pharmacological midwifery interventions. Further work into the physiology of normal labour and birth in non-acute settings to establish maternal and foetal risks and best practice in the use of Caesarean sections was also advocated. The aetiology and management of specific maternal conditions such as gestational diabetes, morning sickness and obesity were also identified as priority areas. Work on the cost-effectiveness of parenting programmes was also highlighted.

Table 7 Additional stakeholder priorities specific to nursing and midwifery research

The nursing/midwifery contribution to public health						
•	What should be the nursing/midwifery role in reducing inequalities in health; increasing access to services and public health? e.g. research with people with learning disabilities about their access to and experiences of health care in the community	11				
•	Health promotion, e.g. delivering national interventions in school health, pre-conception care, postnatal care, health visiting and changing health behaviours	9				
•	Effectiveness of nurse-led health interventions and nurses as first point of contact, e.g. triage, NHS Direct, nurse practitioners in general practice, walk-in clinics, asthma clinics, diabetes clinics, intermediate care, rehabilitation etc.	4				
•	Identifying where nurses can make the greatest contribution to the public health agenda or have the most impact, e.g. palliative care, chronic illness, learning disability services etc., and what stops nurses making an effective contribution	4				
•	The nature of therapeutic relationships in nursing/midwifery health interventions	2				
•	Identifying and supporting carers' needs within the public health context	2				
•	Integration of complementary and alternative medicine into nursing and midwifery practice	1				
•	Health promotion issues – dual diagnosis, e.g. needs of people with a learning disability and a mental health problem	1				
The	The nursing/midwifery contribution to women's health					
•	The links between diet and gestational diabetes, impact of gestational diabetes on the baby and nursing/midwifery support for gestational diabetes	2				
•	Replicate the Hodnett study on 'attaining and maintaining best practices in the use of Caesarean sections'	1				
•	The normal physiology of labour and birth in non-acute settings; maternal and fetal risks	1				
•	Maternity service outcomes which matter to women, babies, families and society in the short and long term	1				
•	The physical, emotional, financial and social consequences of technical and pharmacological midwifery interventions on outcomes for mother, baby, family and society	1				
•	How women's knowledge, beliefs, needs and fears affect the decisions they make about their health, e.g. cultural beliefs	1				
•	The quality and effectiveness of emotional support for women throughout labour	1				
•	Obesity post partum: how to help mothers get back to their original weight	1				
•	Aetiology and management of hyperemesis in pregnancy	1				
•	Establish the cost-effectiveness of parenting programmes	1				

General issues relating to nursing and midwifery research

The process of setting priorities

Several respondents expressed concern about the processes involved in setting priorities for research generally, and some with regard to this exercise specifically. Comments were most frequently to do with obtaining a representative sample of opinions from different professions and organisations. Many respondents from nursing, midwifery and other health and social care professions particularly stressed the importance of involving 'grass roots' staff in such exercises.

Some participants highlighted the difficulty of trying to distil priorities from a wide range of respondents without losing the essence of diverse views:

Scoping exercises are difficult if aggregating the detail leads to bland generic topic;, you need examples to sharpen up the blandness. There was an element of that in the [organisation name] scoping exercise – it lost something in the aggregation.

(Nurse academic)

Several respondents, particularly those with a higher-education background, were concerned about priorities becoming restrictive and subject to contemporary fashions and whims. There was also a difference of opinion about whether or not the research agenda should be future-focused or concentrate on present issues. The number of priorities required was also contentious, with some respondents emphasising the need to restrict priorities to two or three to enable focused work. Such respondents also tended to promote programmatic approaches to commissioning.

Top-down approaches are narrow and prescriptive – there is a time lag between policy-driven agendas and quality research.

(Nurse academic)

The value of a dedicated funding stream for nursing and midwifery research

There was a clear division between respondents who welcomed a dedicated funding stream for nursing and midwifery research and those who did not. Those who were opposed to the establishment of such a funding stream (n = 11), of whom six had a nursing or midwifery background, tended to feel that it would be contradictory to current policy trends in relation to interprofessional and multidisciplinary working. Several respondents also felt that dedicated funding would hinder the development of collaborative research and multidisciplinary teams using multiple methods. Harnessing the expertise of other disciplines such as economics, social science and medicine was generally advocated, as was the need to utilise methods used in other disciplines, such as education.

I suppose my concern is: how do we continue to justify looking at issues from a uni-professional basis?

(Policy maker, nurse)

Not sure I believe in nursing research per se – researching nursing interventions, nurses doing research and building capacity, yes, but nursing research, no. We should be building capacity so that the whole multiprofessional team is properly represented in research."

(Nurse academic)

... nurses are [only] one key part of the whole patient's journey of care. To only focus in on one domain affects the richness of understanding of that journey. It's important that the multiprofessional team shape research questions and methodology that will capture it, multiprofessional teams should be involved in undertaking research and critiquing it at the end.

(Policy maker, nurse)

Further, arguments were made that nursing and midwifery services could only be fully investigated and understood within the context of the whole service, and that a single funding stream would mitigate against the production of thematic approaches to clinical issues.

Ensuring quality through effective partnerships

Negative perceptions of existing nursing and midwifery research generally were expressed by significant numbers of those both within and outside nursing and midwifery professions. Criticism was also levelled at the national research league tables (Research Assessment Exercise). For example, one trust-based researcher stated:

[I] feel research [agendas] for nursing at a national level are very theoretical; [there is] lots of criticism about such navel-gazing and nursing is getting a bit of a hammering for it. Should perhaps distinguish between academic research and practice research. All very Research Assessment Exercise driven. The 'in practice' agenda is very different, it's genuinely about improving patient care rather than getting published in acceptable journals. Because there is that distinction, the practice-theory gap is perpetuated. Practitioners are not interested in academic research; [it's] not published in journals that practitioners read. Stronger links between universities and trusts are required.

Significant criticisms were also raised in terms of methods, quality, policy relevance, applicability and generalisability. There was strong support for using multidisciplinary research teams and perspectives to explore nursing and midwifery-specific topics and issues. There was also support, particularly from medical doctors, for the inclusion of nursing and midwifery perspectives in all health service and medical research.

Evidence generation or implementation

Diverse opinions were expressed about the suitability of investing further resources in the generation of research evidence. Seven respondents (including managers, those in practice and academics) advocated a focus on dissemination and implementation of existing research findings in practice, in order to get 'knowledge to the ends of the organisation'. Some argued for an equal emphasis in terms of funding for research and dissemination strategies but others viewed dissemination and building the capacity of the nursing and midwifery workforce to use research as urgent and a more valid use of resources. Some of the tensions are illustrated in the following quote from a midwife academic:

We already have lots of research evidence on the effectiveness of midwifery care delivery to low-risk women in small-scale units, outside of hospitals, but on the whole it's not being implemented. This creates problems for both the service and researchers. [There is] lots of research evidence there ... [it] all shows birth centres are safe, effective and cheap. Nobody would argue

with this. So on a bad day I'm not sure what research could do to bridge the gap.

Maximising impact: the need for joined-up initiatives in research commissioning

Several respondents emphasised the need to link the SDO initiative with other research investment strategies such as 'Taskforce 3' associated initiatives and the Department of Health Fellowship scheme. Possible areas of overlap in commissioning between Department of Health Policy Research Programme and charities were also identified. Indeed one existing funder of nursing and midwifery research suggested that if there were a dedicated funding stream for nursing and midwifery provided by the Department of Health, their charity might withdraw its support from this area.

Mode of commissioning

The mode of commissioning research was frequently mentioned as a key issue. Academics from all sectors often argued for thematic or programmatic approaches linked to institutions in which significant and continuing capacity could be nurtured and a robust research infrastructure developed. Inviting calls for proposals on a wide range of seemingly individual and disparate areas to the whole sector was felt to generate its own difficulties, in terms of building knowledge and capacity. Several respondents also stressed the need to develop an additional responsive funding stream for investigator-generated research ideas to nurture innovation and development.

Capacity building

Respondents were not asked specifically about capacity building. However, as this was the focus of a recent HEFCE report, and frequently emerged as an issue, as the following quotes illustrate.

The research base for nurses and midwives is currently low and so encouragement should be given to those wishing to enter a research career through fellowships and similar schemes.

(Research commissioner)

[Nursing and midwifery research has a] historically different background [there is a] need for more support now to help catch up with other professions.

(Nurse, acute trust)

Respondents emphasised the need to develop integrated roles and new career pathways for nurses, midwives and health visitors to enable them to carry out research while in practice. As one trust respondent said:

[There is a need to take] nursing research out of the ghetto of higher education and set up roles like nurse consultant or other mechanisms to give people protected time to do research.

(Nurse, acute trust)

Opinions differed regarding the desirability of building capacity through multiprofessional or uni-professional teams. For example, one respondent from a non-nursing or midwifery professional organisation said:

How to take it [nursing and midwifery research] forward; get the right people tooled up and in the right place, we need to develop groups and teams rather than just individuals. The big questions will need not just nurses but experienced health services researchers to work with nurses to make this happen.

The importance of 'researcher' role models was frequently mentioned. The need to link the lifelong learning and research agendas for all of the professions was also stressed by one respondent. Inequities in access to research funding were also highlighted by several respondents, from both higher education and practice organisations, as this quote from a higher education respondent indicates:

I recognise the difficulty in changing the [commissioning] system but there are issues around who is perceived as being pukka for research money.

Methodological approaches

Opposing views were expressed about the need and desirability for 'blue skies' research, theory building, methodological and tool development versus applied policy-relevant research. Academics were more likely to suggest the need for blue skies work than managers or practitioners. For example, one nurse academic said:

Does it have to answer a clear NHS question? Where does that leave theoretical and methodological work, e.g. basic rather than applied science? Also need anthropological and philosophical work. Not directly NHS questions but fundamental.

However, a trust-based respondent felt strongly that:

[Research] shouldn't be laboratory [or] 'blue skies' – [that is] not for the NHS to do. [It] should be someone else.

Many concerns were expressed about the types of research methods that were needed to meet the service agenda. Several respondents questioned the perceived preferences of funders for clinical trials but also criticised the preponderance of small-scale studies frequently carried out by nurses and midwives. For example, one trust respondent said:

[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.

The same respondent also highlighted some of the difficulties inherent in implementing research findings in practice, saying:

All great but real world ... Lots of things are effective but can you do them when it's only you and five agency staff? Behavioural Family Therapy is a top service priority in [place name], very laudable, good evidence base etc., but [you] can't do [it] in practice, [it] takes too much time, too lengthy. Need a better fit between what's possible in the real world.

Several respondents suggested that action research-type approaches had much to offer because they could go some way towards marrying the needs and priorities of service and research.

Further issues relating to research design, methods and implementation

- Research as innovation research itself acting as a catalyst for change
- Development of dependency tools to inform staffing levels and workload management
- What is nursing research?
- How to mainstream innovation, and implement 'best practice' and guidelines.

SDO Priorities - research, management or policy?

The schedule asked first about gaps in nursing and midwifery service delivery and then about research gaps and priorities. Some respondents objected to the terminology used, preferring instead to talk about areas for improvement or service challenges rather than gaps. Once again concerns about workforce and staffing tended to dominate. The lack of funding to support new initiatives and the implementation of National Service Framework priorities were also referred to frequently. Several respondents highlighted the challenge of separating researchable questions from managerial and policy issues, as this quote from a representative from a professional organisation explains.

[There is] a lot we don't know about the workforce and [we] know even less about the potential workforce; [there is a] real gap in knowledge of the labour market for nurses and midwives. [We] know a bit more about why they leave but need to know more, it's a whole big area that we don't understand: 'Magnet hospital' type work. It would be nice to know as an employer what works and what doesn't work. UK data is a bit dicey though according to Linda Aiken. We need to think, where does the workforce come from, why do they work in the NHS or don't, and why [do] they leave? But is this the remit of SDO [commissioning] or policy?

Some of these respondents suggested that many of the categories offered in the existing SDO priorities were well researched and that the challenge was for managers to implement the findings.

Stakeholder summary

The stakeholder interview data include views from nurses, midwives and health visitors in the state and independent sectors; medical, social care and allied health professionals; research commissioners; policy makers; educators; managers; researchers; and users, regarding their priorities for nursing and midwifery research. The list of SDO research priorities (NCCSDO, 2000) informed the development of the interview schedule and a process of content analysis was used to generate the findings.

Findings

The majority of respondents suggested that the SDO research priorities were relevant and appropriate for nursing and midwifery. The following issues, by frequency of importance, emerged:

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

Respondents also highlighted the following areas as requiring further research:

The nursing/midwifery contribution to public health, including:

- reducing inequalities in health and access to services
- health promotion, for example, delivering national interventions in school health, pre-conception care, postnatal care, health visiting and changing health behaviours
- effectiveness of nurse-led services and nurses as first point of contact, for example, triage, NHS Direct, nurse practitioners in general practice, walk-in clinics, asthma clinics, diabetes clinics, intermediate care, rehabilitation etc.
- identifying and supporting carers' needs
- · evaluation of nurse prescribing
- integration of complementary and alternative medicine into nursing and midwifery practice and dual diagnosis, for example, needs of people with a learning disability and a mental health problem.

The nursing/midwifery contribution to women's health, including:

- the links between diet and gestational diabetes, impact of gestational diabetes on the baby, and nursing/midwifery support for gestational diabetes
- attaining and maintaining best practices in the use of Caesarean sections
- the normal physiology of labour and birth in non-acute settings, maternal and foetal risks
- maternity service outcomes which matter to women, babies, families and society in the short and long term
- the physical, emotional, financial and social consequences of technical and pharmacological midwifery interventions on outcomes for mother, baby, family and communities;
- how women's knowledge, beliefs, needs and fears affect decisions they make about their health, for example, cultural beliefs

- the quality and effectiveness of psychosocial support for women throughout labour
- · reducing maternal obesity.

A series of **general issues** related to nursing and midwifery research also emerged; these were:

- the process of setting priorities and the mode of commissioning
- the value of a dedicated SDO funding stream for nursing and midwifery research
- · how to ensure quality research
- whether the focus should be on evidence generation or implementation
- the need to maximise impact through joined-up initiatives
- the mode of commissioning
- · capacity building
- methodological development
- the challenge of separating researchable questions from managerial and policy issues.

Literature analysis

The third strand of data collection, the literature analysis, was carried out concurrently with, and independently of, the stakeholder interviews and user focus groups. The purpose of the literature analysis was to specifically identify nursing research priorities in policy documents (Stage 1) and papers in peer-reviewed journals (Stage 2). Documents included in the analysis are listed in tables at the end of this report, as cited in the text. Other documents, used to inform the work but not included in the literature analysis, are shown in the references or annotated bibliography

The literature also provides the background and context for analysis, informs the discussion of the findings and the formulation of recommendations.

Stage 1 Policy documents

Policy documents written since 1997 and relevant to the government research and development strategy were the focus 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, and Medical Research Council, 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 methods used for priority setting (Table 8). Searches were limited to documents published in the United Kingdom since 1996 (we made the decision to search the literature over a six-year period to ensure policy relevance within a reasonable time period). Two national e-mail user groups were contacted: CHAIN (Contact Help Advice Information Network), an organisation with over 3000 members from trusts and health authorities, primary care, education and research organisations; and the Royal College of Nursing e-mail bulletin to identify additional grey literature. Hand searching of references from key articles or reports that identified nursing or midwifery priorities was also carried out.

Findings

The policy documents and papers from peer-reviewed journals and reports were reviewed and analysed thematically. Broad priority areas

that emerged from analysis of documents in both stages of the review are reported.

Policy documents

Only 6 policy documents included in the literature analysis explicitly identify priorities for nursing or midwifery research (Appendix 5c). Nineteen policy documents identify more general research priorities which have implications for nursing or midwifery research. Other policy documents, included in the annotated bibliography (Appendix 6), describe strategies or policy context. In addition, the National Service Frameworks make reference to research and priorities giving guidance and context to the consultation exercise; the implications of these frameworks are also summarised in Appendix 6.

Table 8 Criteria for literature and policy review

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)

- Identifies nursing/midwifery research priorities generated by a systematic approach such as survey, Delphi technique, nominal group technique, bibliometric assessment, meta-analysis, systematic review
- Identifies nursing/midwifery research priorities generated by consultation, professional organisations, opinion/academic leaders, charities, but not meeting the systematic approach of 5
- 4b Identifies research priorities from policy making or professional organizations that have implications for nursing or midwifery and meeting the systematic approach of 5
- Identifies nursing/midwifery research priorities generated by small interest groups (diagnostic or client groups) or small-scale studies not meeting the criteria of 4 or 5
- 2 Identifies research priorities with reference to nursing/midwifery contributions to research alongside other disciplines and not meeting the criteria of 5
- Identifies research priorities with reference to nursing/midwifery contributions to research alongside other disciplines but not meeting the criteria of 5 or 4 (opinion based)

Key search words

Research, Nursing, Midwifery, Priorities, Clinical effectiveness, Evidence-based, Utilisation, Dissemination

Papers in peer-reviewed journals and reports

Sixty papers were selected for review according to the criteria shown in Table 8. Journal papers were further limited according to publication in the UK, and use of systematic methods for their prioritisation. Following this exclusion process, 21 articles remained (Appendix 5a) for analysis of research priorities. These covered a range of clinical specialties: cancer nursing, stroke rehabilitation, critical care, paediatric intensive care, education, midwifery, primary health nursing and general nursing. Papers which focused on the policy context of generating research priorities or strategies for capacity building were considered separately to provide background information (Appendix 5b).

Priority areas

Priorities for nursing and midwifery research identified by the literature can be categorised as follows:

- A Approaches to care, evaluation and effectiveness of individual, group interventions or new approaches to care
- B Outcomes of specific clinical interventions
- C Organisational factors that affect service delivery and workforce
- D Social factors that affect health
- E Quality of life and psychosocial health interventions
- F User and carers' involvement in health care
- G Health promotion.

These categories are summarized in Table 9 together with examples drawn from policy documents, papers in peer-reviewed journals and reports. The most commonly stated priority is the evaluation and effectiveness of individual or group interventions and new approaches to care (Priority A). This priority topic is concerned with evaluating innovative practices as well as measuring the impact of practices for which there is sound evidence. The need for evaluation, particularly in primary care, of complex multidisciplinary interventions is identified in the care of older people and long-term health problems. Issues of accountability, efficacy and effectiveness are central to this research theme, which calls for conceptual development in order to unravel the intervention 'black box', define the patient, professional and interprofessional outcomes, and clarify the interplay between all components.

Outcomes of specific clinical interventions (Priority B), were well represented, with suggestions that evaluation is applied to a specific disease or client group. Organisational factors (Priority C) are mainly concerned with multidisciplinary or interprofessional working and the related topics of co-ordination within and across organisations and sectors. This has links with themes A and B as staffing issues are concerned with staff support in high-stress areas of work such as palliative and critical care nursing and with staff retention that in turn affects outcomes. Social factors that affect health (Priority D) were mainly identified in relation to reducing inequalities, which was more frequently represented by the policy documents. However, some of the journal papers interpreted this issue as specifically relating to midwifery services. Inequalities in health were an interlinking theme, for example, examining the impact of midwifery and maternity services and interventions on mothers from vulnerable or socially excluded groups. Although quality of life and psychosocial health interventions (Priority E) are not explicit in all policy documents there is some acknowledgement that psychosocial factors are linked to health status and quality of life outcomes. This emerges particularly in relation to people with long-term health problems or cancer, and their family or carers.

User and informal carers' involvement in care (Priority F) in caring practices and interventions is a wide-ranging priority that links with all others. For instance, interventions are only appropriate if they meet individual or community needs and outcomes are only useful if they measure improvements or health gain that are of importance to patients or families. Appropriate, sensitive and timely communication and personal interactions with a wide range of patients and carers are strongly advocated research topics. Communication and giving information to patients and families, as part of recovery and rehabilitation, is part of this theme. Health promotion (Priority G) is implied but not explicitly identified in many documents.

As well as noting research topics, policy documents and papers identify principles that should be used to guide research priorities. These include the suggestion that users/consumers should be involved in determining the focus of research and in the evaluation of interventions. In addition it is suggested that priorities should reflect major professional and societal issues, take account of national health policies and priorities, contribute to the resolution of individual or community health problems or represent an area where nursing or midwifery can develop a health service.

Suggestions are made for a range of methods that can be applied to nursing and midwifery research priorities, including clinical trials, observational studies, qualitative approaches, surveys and a combination of these. Strategies to improve the capacity of nursing research were the focus of 20 papers in peer-reviewed journals, raising issues about the preparation of nurses to carry out or lead research in order to enhance service delivery.

Table 9 Priorities identified in the literature

Themes	Examples from policy documents	Policy ref.	Examples from peer- reviewed journals	Doc. ref.	Comments
A Approaches to care, evaluation and effectiveness of individual, group interventions or new approaches to care	Primary health care (PHC) nursing interventions. Interventions for long-term conditions, e.g. COPD in PHC. Effectiveness of models of care for dementia, services for learning difficulty and mental illness and alcohol/drug abuse, birthing practices, cancer nursing. Care interventions for elderly people; cost-effectiveness of rehabilitation in	2, 4, 5, 6, 9, 10, 11, 12, 17, 21, 22, 23	Effectiveness of nursing interventions in PHC, stroke rehab, during second- stage labour, visiting first-time mothers, selective postnatal visiting. Practices in Caesarean section, risks for mother and fetus in labour and birth.	1, 3, 7, 12, 13, 16, 19, 21	Overlaps with Themes B and G
B Outcomes of specific clinical interventions	elderly people. Health and wellbeing after birth. Breastfeeding and infant feeding, parenting. Women's/ men's health. Symptom and pain control, diabetes, epilepsy.	2, 4, 5, 9, 10, 11, 12, 22	Symptom management in cancer and palliative nursing. Outcomes of technical and pharmacological interventions in midwifery.	6, 13, 15, 18, 21	Overlaps with Themes A and G
C Organisational factors that affect service delivery and workforce	Use of resources, multidisciplinary/ interprofessional working. Organisational coordination. Service access. Recruitment/ retention.	1, 2, 4, 6, 12, 14, 20, 23, 24	Interprofessional and team working and service delivery in critical care and maternity community care. Staff support in palliative nursing and critical care. Staffing and systems of care in midwifery. Needs of professionals in homebirth. Environmental influence on labour and birth.	5, 9, 11, 13, 15, 20, 21	
D Social factors that affect health	Reducing inequalities in health, social inequality for disadvantaged groups in older people, CHD and stroke, mental health problems, cancer.	4, 5, 6, 9, 10, 11, 12, 14, 20, 23	Antenatal practices for disadvantaged mothers.	20	Inequalities is the main theme but could be considered an overarchin g theme for all priorities.

Table 9 (continued)

Themes	Examples from policy documents	Policy ref.	Examples from peer- reviewed journals	Doc. ref.	Comments
E Quality of life and psychosocial health interventions	Emotional support in cancer care and quality of life for older people, and cancer patients.	9,10, 11, 20, 25	Mood and depression in stroke. Anxiety in pregnancy preparation, effects of emotional support in labour.	7, 15, 20	
F User and informal carers' involvement in health care	Patient-centred. Information giving, communication, planning care, decision-making, family support and a range of therapeutic and health promoting interventions.	1, 6, 9, 11, 12, 13, 23, 24, 25	Patient support, information and communication in cancer, stroke rehabilitation, primary health care. Patient involvement in paediatric intensive care. Women's views of midwifery services and outcomes.	5, 6, 7, 8, 11, 16, 20, 21	Could be considered an overarchin g theme for all research priorities.
G Health promotion	Primary and secondary promotion in adolescents, older people, and public health, CHD stroke and sexual health, mothers.	4, 9, 10, 13, 11,	Outcomes of health promotion.	1, 14, 18	Overlaps with Themes A and B

Examples from policy documents, papers in peer-reviewed journals and reports (full references are provided in Appendices 5a, 5b and 6a)

Summary of the literature analysis

This review provides a literature background to the analysis of nursing priorities from the perspectives of users and stakeholders. Out of 36 policy documents, only 6 identified specific nursing priorities but 19 identified priorities that have direct relevance to nursing in clinical areas such as cancer care, care of older people, coronary heart disease and stroke and have been produced by multidisiciplinary expert groups. These priority-setting exercises give strong guidance for research priorities that will benefit health. This focusing of research priorities is in line with the professional literature where nurse commentators note the importance of focusing on areas that can support health and that will develop nursing practice/interventions for the benefit of patient and client health.

It is evident from the policy and professional literature that the impact of nursing and midwifery research is limited because studies tend to be small-scale and time-limited. Both policy and professional literature advocate programmes of research rather than ad hoc studies, working with other disciplines, good leadership and supervision to improve research capacity.

There is a clear regard for research that measures patient or client outcomes as a result of multidisciplinary and/or nursing and midwifery interventions. In these professions this poses a challenge, because many of the interventions are complex and carried out as part of a

multidisciplinary team. It is important that nurses and midwives develop ways of assessing the benefit of interventions as well as working alongside other disciplines. Although there is some mention of developing measures for a particular patient or client group, there is little guidance on how the complexity of interventions in areas such as rehabilitation can be investigated. It is therefore considered important for nurses to be aware of the potential opportunities for research within their subject expertise and to be involved in research prioritisation and in discussing the range of research methods that are able to define the interactions and treatments that benefit patient/client health and recovery.

Involvement of clients/users and informal carers is an important theme in the literature. It is suggested that these groups contribute to identifying appropriate interventions and outcomes. Little guidance is given in the literature as to how this should be achieved but gaps in the process are noted. Indeed the literature on research priorities, with a few exceptions, does not strongly reflect published users' or carers' views of research priorities.

Research strategies and capacity building in nursing and midwifery are very evident in the professional literature; half of the papers selected focused on this subject. The importance of using appropriate research evidence in practice underpins the discussions about research strategies and prioritising. Clearly, identifying priorities for research needs to be addressed in the light of available evidence; this is a point made by the professional literature.

Limitations of the data

Service user and stakeholder consultations

There were a number of methodological issues that we needed to address in developing the consultation approach. 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 developeded for the focus groups and interviews will have influenced the type of information collected. For example, in the stakeholder interviews general SDO priorities were used as a focus for discussions, which may have constrained the responses. Secondly, asking participants for their perceptions of gaps in existing research may or may not reflect actual gaps in the evidence base. Interviewer bias may have occurred where interviewees were aware of the particular academic/professional roles of an interviewer.

Geographical distribution

Attempts were made to ensure a geographical spread of service users and stakeholders. Owing to limitations of time we limited the consultation to England and Wales (Table 10).

Table	10	Location	of	partici	nants
I GDIC		Location	U :	pai tici	parits

Region	Stakeholders (n = 64)	Service users (n = 38)	
National	42	0	
South	7	10	
London	9	15	
North	12	8	
Midlands/East	5	5	
Other	1	0	

^{*} Please note some participants represented more than one location, e.g. a national perspective in relation to their organisation/committee work and a local perspective in relation to their workplace.

Diversity of perticipants

There are over 600 000 nurses and midwives on the professional register and over 300 000 of these are employed in the NHS; consequently it is impossible to infer that the priorities and issues raised in this small, time-limited exercise reflect the views of the professions in their entirety. We deliberately aimed for a balance between high-profile individuals who already make significant contributions to the professional agenda and

those who were unlikely to have taken part in research or priority-setting exercises previously. For pragmatic reasons the sample was influenced by the availability of respondents to comment during the timescale and the ability of organisations contacted to field a suitable representative. A surprisingly high number of NHS organisations, policy making and nonnursing and midwifery professional bodies formally 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. are not readily available. The excessive demands on the time of the stakeholders we wanted to involve meant that interviews were often rescheduled several times at the participant's request or had to be cancelled altogether often at very short notice.

Participants in the service user focus groups were predominantly female, white, ex-professionals, 35–50 years of age. Although participants discussed ethnicity and minority groups in terms of access to health care services, 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 were not directly represented in the groups; however, issues were often raisedabout access to appropriate services for these groups.

Literature analysis

While a systematic approach has been 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. No additional attempt was made to critically appraise the quality of the documents or to rank them in order of importance. All were considered to be contributing to identifying priorities.

Overseas literature was identified as a result of the electronic searches but has not been analysed as part of this exercise. However, it is worth noting that a number of other countries have conducted priority-setting initiatives, namely the USA, Australia, Canada, and some South-East Asian and European countries, underlining the importance of prioritising nursing research internationally. Although this consultation exercise focuses on the UK it is acknowledged that information from the World Health Organization and European Directives are influential and important in this area.

Changes in policy influence the research agenda; indeed, the majority of policy documents which specifically mention research state that priorities must be in line with national priorities for health. This review was

therefore limited to the most recent documents, published in the last six years.

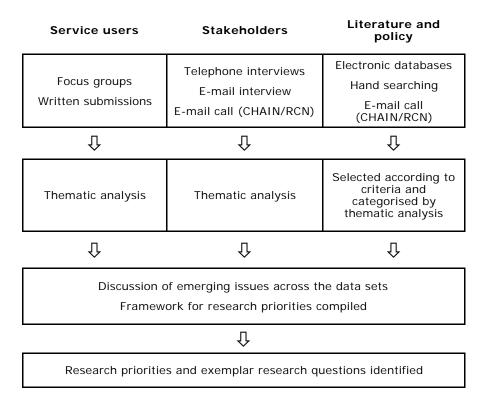
The majority of professional papers identify priorities without assessing the level of evidence already available to inform practice. We have not attempted to assess the level of evidence that might inform identification of research priorities. This would be an important next step because some professional literature, particularly in midwifery, is making a substantial contribution to the evidence base for midwifery practice, for example in breastfeeding.

Identifying the grey literature has been difficult although some attempt has been made to do this through two national e-mail calls (CHAIN and RCN). Despite responses from some key people, which have uncovered significant reports and papers, searching of grey literature has not been a major part of the literature analysis.

Discussion

Each of the three strands of data (service user focus groups, stakeholder interviews anad literature analysis) has been 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. Figure 2 summarises the methodology and analytical approach used for each strand of data.

Figure 2 Summary of data sources and process



It has been possible to suggest areas of accord and misalignment between service user expectations, stakeholder perceptions of priorities and gaps in the nursing and midwifery evidence base. In the discussion of issues emerging from the consultation process we have taken the following view.

- The process of research priority setting is a social construction with its own technical language, which has been mostly driven by professional agendas. In our analysis we have given prominence to the service user core expectations identified in the consultation – it is these expectations which provide the central spine for comparison with stakeholder views.
- Service user 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, raises questions for research and development that are tentative, 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 provide explanations.
- The policy and academic literature increases our understanding of the issues and provides a framework for discussion of the emerging and overlapping themes between service user core expectations and stakeholder views.

The discussion identifies five broad priority areas for nursing and midwifery service delivery and organisation that illuminate questions for research and development (as shown in Table 11). We have augmented each priority area with examples from the data, to indicate research questions and selected exemplars, which can be applied to a variety of patient/client groups in a range of settings.

The user expectation for services that enable staff to make use of research evidence in practice, which converges with a strong view among the stakeholders of the importance of implementation and dissemination, is discussed separately at the end of this section under 'Research capacity and development'.

Table 11 Framework for research priorities

Service user expectations	Stakeholder priorities	Literature priorities	PRIORITY AREA
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	Individualised services
		affect health	
		Quality of life and psychosocial health interventions	_
Services that make use of information,	Co-ordination/ integration across	Organisational factors that affect:	
communication and technology to make sure	organisations Continuity of care	(a) service delivery	Continuity of care
that parts of the system are informed, patients receive care faster, and patients do not have to repeat the information they give to staff	Interprofessional working		
	Implications of the communication revolution		
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 in the delivery of care, training and education of staff, standard setting and quality monitoring	User involvement Relationships between organisational form, function and outcome	User and carer 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 patients' 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

Priority Area 1 Appropriate, timely and effective interventions

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 emerged as a key expectation for users. Linked to this is the pubic perception that nurses and midwives have an important role in ensuring patient-centred services provide support and information in appropriate ways irrespective of gender, age, social background, ethnicity or disability. Users expressed strong views about the quality of essential care, for example nutrition and personal care, seeing this as a core responsibility of nurses and midwives. The need for evaluation of care-giving practices, in relation to patient and carer outcomes, emerged as a research priority for both service users and stakeholders. The evaluation of psychosocial interventions was considered a key aspect of this priority area. This priority is strongly supported by the policy and academic literature.

Above all other priorities, stakeholders most frequently prioritised research into health promotion, reducing inequalities in health, and public health. Users also identified these areas but were more likely to talk about them in terms of providing information to patients and communities, incorporating public health approaches in service delivery, the long-term economic costs to health and public services of failing to invest in health promotion activities, and in terms of patient-centred assessment approaches to identify physical, mental and health needs. In particular nutrition, exercise, smoking cessation, and young people's sexual health were emphasised.

The service user expectation for customer-friendly services that involve people – irrespective of their gender, age, social background, ethnicity, or level of disability – in personal care decisions incorporates issues of how to involve patients in clinical decision making, ways of establishing optimal dialogue between staff and individual patients, and to advise and support the needs of particular groups of users.

Exemplars

Strategic commissioning could:

- evaluate comprehensive assessment tools of physical, psychological, social need linked to interventions and outcomes
- evaluate essential care-giving practice in relation to patient, staff, organisational and cost outcomes
- evaluate psychosocial nursing and midwifery health interventions in relation to patient-centred outcomes.

Priority Area 2 Individualised services

Users and stakeholder groups identified the importance of communication within the clinical encounter to improve patient-centred care delivery. This finding is supported by the policy and academic literature, which argues that the evidence base for information giving, therapeutic interactions and decision-making needs to be strengthened. Although communication emerged as an overarching theme for both service users and stakeholders, not surprisingly expectations were articulated in different ways, embracing a continuum of activity from 'therapeutic interventions' to 'patient-friendly supermarket approaches to customer care'. Stakeholders perceived staff communication skills to be poor despite an emphasis on communication skills training, describing this as 'like putting baubles on a dead Christmas tree'. Stakeholder priorities were therefore focused on how to develop communication systems and teach effective communication skills in the busy reality of rapidly changing service delivery. Alternatively, users' priorities were to develop professional practice to improve information giving about treatment options and choices for care irrespective of gender, age, social background, ethnicity or disability; and to increase opportunities for involvement in decision making.

Stakeholders highlighted organising services around the needs of the patient as their third priority of the existing SDO priorities. This fits with the core user expectation for services that work with communities and as close to patients' homes as possible without compromising quality. Users perceived gaps in the way that individuals and communities were involved in the design of local services, and both users and stakeholders felt that nurses could contribute to the development of user- and carer-centred systems or approaches to service organisation, which may improve access and health outcomes for those less mobile (older people) or less likely to seek out services: children/young people and minority groups.

Exemplars

Strategic commissioning could:

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

Priority Area 3 Continuity of care

Communication of patient-centred information was highlighted in relation to enhancing continuity of care. Users described lack of integration with powerful imagery of being in a 'demented pinball machine' and of experiencing services working in isolation. Thus it is not surprising that expectations were identified for services that made use of information, communication and technology to support integrated information systems, responsive care and avoid duplicating information. This required the development and use of information technology (IT) and communication strategies in the transfer of information between service areas and between professional groups supporting integrated pathways of care. Stakeholders also considered continuity of care and integration across organisations as important issues. However, these were 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.

In some cases users felt that continuity of carer was important, particularly in the areas of midwifery services and older people receiving care in their own home. Among the stakeholders (mainly from a midwifery perspective) there were a variety of views, between those who identified continuity of carer as an area for research, with others suggesting that there was an established evidence base, but that implementation in practice was problematic.

Exemplars

Strategic commissioning could:

- examine continuity of care models for vulnerable groups in relation to patient, staff and organisational outcomes
- identify efficient methods of transferring confidential information (including patient information) between professionals, service areas/units and health and social care services.

Priority Area 4 Staff capacity and quality

Workforce, skills, competencies, career pathways and retention were overriding issues for both stakeholders and users, albeit presented from different perspectives: stakeholders identifying policy issues and service users pragmatic considerations. Service users' expectations for fully-staffed services were also reflected in the stakeholder priorities for research into workforce issues and characteristics, specifically shortages, recruitment and retention. Stakeholders placed importance on reconceptualising professional roles around the needs of patients and carers and clarifying skill mix requirements. Users' views appeared to be driven by quality concerns, such as establishing who were the 'right'

people (professionals/volunteers/carers) to deliver aspects of care (health interventions/essential care) and uncovering the reasons for variations in nursing and midwifery practice with certain client groups or in areas of care thought to be outside the professional remit of a person's job.

The capacity for staff to deliver services to young people and minority groups (especially non-English-speaking people) was discussed by users in terms of defining competencies according to the needs of particular groups. Stakeholders emphasised the need for research into leadership capacity in nursing and in particular the Director of Nursing/Nurse Executive Director role, while the user perspective on role evaluation was in terms of value for money and the impact on patient care (in terms of safety and quality). For both groups the employment of overseas and agency nurses raised questions around competency.

The stakeholders awarded greater prominence to interprofessional/multidisciplinary 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. Some stakeholders criticised the status of existing work on professional roles as being atheoretical and not outcome focused. Interestingly, the service users discussed team working in relation to pragmatic strategies to improve staff retention and communication of patient information to enhance continuity of care. Not surprisingly the priorities flowing from the policy and academic literature are more closely aligned with the stakeholder views, but they specifically highlight priorities for economic evaluation of organisational and interprofessional models that have an impact on achieving effective clinical outcomes.

Exemplars

Strategic commissioning could:

- evaluate the nursing component of team interventions in chronic illness
- evaluate workforce retention strategies and employment practice
- generate success criteria for new service design, changing role boundaries, team working and reconfigured services within organisational uncertainty
- evaluate new roles providing health interventions with vulnerable/hard-to-reach groups in terms of outcomes.

Priority Area 5 User involvement and participation

User involvement emerged as a prominent and overarching issue across all three strands of the data. Some service users challenged the term 'involvement' as being ill defined, emphasising instead meaningful engagement through representation, participation and consultation. Both stakeholders and users felt achieving meaningful participation in research and service delivery, leading to improved outcomes, was an issue that should be central to all health services research. This is consistent with priorities identified in the policy and academic literature, particularly in relation to service delivery.

User representation in service development was an issue that users and stakeholders struggled to contextualise owing to the broadness of the term. Stakeholders were more likely to discuss user involvement in general or aspirational terms, whereas the expectations of users tended to articulate specific gaps and formulate questions around active participation in delivery of care, training and education of staff, standard setting and quality monitoring. For example, specific questions were raised on how best to involve users in staff training, development of skills and competencies, and designing services focused on nurse-led services to improve access.

Users provided suggestions for obtaining views on service development but were critical of existing systems that were not authentic, confidential or independent. There was an expectation that services provide independent, ethical frameworks for complaint and feedback for patients and staff, to involve users in evaluation of service delivery.

The key issues of participation and involvement reinforce the user view that expectations are not being met by nursing and midwifery interventions. Interventions therefore need to be more appropriate, targeted and timely if they are to improve user-defined health outcomes. However, the boundaries of user involvement are unclear in many health care settings and few professionals have experience of consultative approaches or partnership working. A research agenda is required that supports the strategic commissioning of conceptual, methodological and evaluative work. The exemplars below are essentially pragmatic concerns related to involving users and evaluating participation.

Exemplars

Strategic commissioning could:

- support 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.

Achieving priorities

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 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, the mode of commissioning and the need to maximise impact through joined-up initiatives were issues brought to our attention by many professionalstakeholders.

Stakeholders and service users questioned whether the focus of commissioning should be on generation of evidence or implementation. Balancing generation of evidence for a practice discipline with the challenge of service development through the implementation of research findings within complex and changing health and social care organisations was also discussed. Stakeholders expressed scepticism of the existing SDO priorities in relation to mursing and midwifery research, which were seen by some as 'rhetorical', 'narrow' and would perhaps go 'out of fashion'. On the whole stakeholders emphasised the need for capacity building in nursing and midwifery research. Where generation of primary evidence was advocated there were concerns about separating researchable questions from managerial and policy issues.

Capacity building

Capacity in nursing and midwifery research was shown to be an important issue for stakeholders; this is reflected in the literature, as shown in Appendix 6a. Issues and concerns specifically highlighted were:

- · continuity and coherence in building knowledge
- · methodological development for intervention studies
- encouraging innovation and creativity through investigator-led (blue skies) research as well as policy-driven research
- ensuring the balance between scientific rigour and policy relevance.

Strengthening academic and service partnerships was also identified by stakeholders as important, and achievable through the further development of nurse consultant roles and encouraging research 'out of the ghetto of higher education'. User representatives perceived research to be carried out by academic researchers rather than nurses or midwives themselves and theytherefore viewed research as being distinctly separate or remote from clinical practice.

Dissemination and implementation

Service users in all of the focus groups discussed the value of dedicated funding for the dissemination and implementation of research evidence. There is an expectation that services should enable staff to make use of research evidence in practice. Concerns were expressed that nurses and midwives might not have the power and influence within organisations to effectively implement research findings or to change practice and, secondly, that systems were not in place that enabled 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 the use of research findings in practice.

Summary

In summary, the consultation exercise revealed that in addition to building the knowledge base in the five priority areas identified, the Nursing and Midwifery Subgroup should seek to commission a programme of research which:

- leads to the development of evidence-based, cost-efficient nursing and midwifery interventions and care-giving practices, in line with service users' expectations identified in this consultation
- supports theoretical development and generalisable knowledge through coherent programmes
- produces nationally or internationally significant evidence for nursing and midwifery interventions and care-giving practices in relation to patient/carer, community, professional, organisational and economic outcomes
- informs policy and builds cost-effective models of nurse-led, usercentred services and pathways of care
- is of high scientific merit and uses appropriate methodology, or supports methodological development where necessary including the development of outcome measures for nursing and midwifery intervention studies
- values and utilises collaborative approaches, in terms of research skills, academic disciplines and with service partners, to build research capacity and capabilities in nursing and midwifery research
- involves users meaningfully, where appropriate, and provides feedback to participants about their involvement
- evaluates the strategic dissemination of research findings/best practice within health and social care settings in relation to user, professional and organisational outcomes
- is cost-efficient, feasible, and shows realistic objectives and deadlines

 complements research being carried out by the SDO programme as a whole.

Conclusion

This consultation has generated five priority areas for research and development that are grounded in service users' expectations for quality nursing and midwifery services. 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. The potential for research to be used as a mechanism for increasing the involvement of service users in evaluation and implementation of findings is an opportunity that could strengthen capacity and achieve change in health and social care.

Feedback to participants

It is our intention to feed back a summary of findings of the exercise to all individuals who have contributed to it. Participants in the focus groups provided with a summary of the findings in the format of a newsletter, which could then be passed to colleagues, rather than a weighty report. The Executive Summary of this report will be sent to all stakeholders who participated and to those organisations that were invited but were unable or declined to take part in the consultation.

References

- References included in the analysis of the literature are shown in Appendices 5a and 5b.
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- Ross, F., Vernon, S. and Smith, E. 2002. Mapping research in primary care nursing: Current activity and future priorities. *NT Research* 7: 46–57
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Appendices

Appendix 1 Contributors

User representative focus groups

The exercise included two Chief Officers of Community Health Councils and two Chairs; the remainder are Members.

Airedale Community Health Council

Bexley Community Health Council

Birmingham (West) Community Health Council

Brent Community Health Council

Bridgend Community Health Council

Bristol and District Community Health Council

Camden Community Health Council

Canterbury and Thanet Community Health Council

Cheshire Community Health Council

City and Hackney Community Health Council

Croydon Community Health Council*

Exeter and District Community Health Council

Gloucestershire Community Health Council

Heartlepool and South Easing Community Health Council*

Haverfordwest Community Health Council

Hillingdon Community Health Council

Hounslow Community Health Council

Lancashire (West) Community Health Council

Lancaster and Morecambe Community Health Council

Meirionnydd Community Health Council*

Merton and Sutton Community Health Council

North Yorkshire Community Health Council

Northamptonshire North Community Health Council

North-East Lincolnshire Community Health Council

North-West Herts Community Health Council

Oxford Community Health Council

Plymouth and District Community Health Council

Portsmouth and South-East Hants Community Health Council*

Redbridge Community Health Council

Rotherham Community Health Council

Shrewsbury Community Health Council

South Bedfordshire Community Health Council

Swindon and District Community Health Council

Tunbridge Wells Community Health Council

Worcestershire and District Community Health Council

Worthing Community Health Council*

York Community Health Council

provided written submission; all others participated in focus groups

Stakeholder interviews

Please note: some interviewees have more than one entry because they represent several organisations.

Anglia Polytechnic University, Department Professor of Public Health of Public and Family Health

Anglia Polytechnic University, School of Director of Research Health Care Practice

Association for Learning Disabilities Project and Service Manager

Avon, Gloucester and Wiltshire Workforce Director of Workforce Development and **Development Confederation** Design

British Association of Social Workers Professional Officer (England)

British Dietetic Association Research Committee Chair

Broxtowe and Hucknall Primary Care Practice Development Facilitator Trust

BUPA Hospitals Head of Nursing Services

Camden and Islington Mental Health and Director of Nursing and Performance Social Care Trust

Chartered Society of Physiotherapy Head of Research and Development

Chorley, South Ribble and Preston Acute Nurse Director Hospitals Trust

College of Occupational Therapists Research and Development Lead

Commission for Health Improvement Director for Nursing

Community Practitioners and Health Professional Officer Research and Visitors Association Practice Development

Council of Deans and Heads of Nursing, Midwifery and Health Visiting

Chair

Department of Health, Policy Research Principal Research Officer Programme

Foundation of Nursing Studies Deputy Director

Haringey Teaching Primary Care Trust Programme Director

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Health Service Ombudsman Nurse Advisor HEFCE Nursing and Allied Health Member Professions Task Force Hull and East Riding Primary Care Trust Service Development Officer for Learning Disability and Mental Health Independent Health Care Association Head of Operational Policy Institute for Applied Health and Social Programme Director (Mental Health) Policy, King's College, London Institute of Child Health and King's Professor of Child Health College London Institute of Health Care Management Deputy Director Professor of Midwifery and Women's King's College, London Health King's Fund Fellow in Learning Development and Health Care Policy Maternity Alliance Team Leader Health and Social Policy Medical Research Council Programme Manager for Health Services Research NHS Executive Deputy Director of Human Resources NHS Confederation Deputy Chief Executive and Policy Director North Central London Community Assistant Director R & D Research Consortium **Nuffield Hospitals** Head of Nursing Policy and Practice Nursing and Midwifery Council Professional Officer Midwifery Nursing and Midwifery Council Professional Officer Education Policy and Europe Pharmacy Practice Research Trust Director PPP Healthcare Medical Trust Head of Research Policy and Evaluation Queens Nursing Institute Director Research Assessment Exercise Nursing Members (3) Panel Research Forum for Allied Health Co-Chair **Professions** Royal College of Anaesthetists Professional Standards Advisor Royal College of General Practitioners Honorary Secretary Royal College of Nursing R & D Advisor (and 3 others) Director, Clinical Effectiveness and Royal College of Physicians **Evaluation Unit**

Therapists

Royal Pharmaceutical Society of Great

Britai

Head of Practice Research

Smith and Nephew Foundation Trustee

South Birmingham NHS Trust Deputy Director of Nursing

South Derbyshire Acute Hospitals NHS

Trust

Lead for Nursing Research

South Derbyshire Acute Hospitals Trust Lead Research Midwife

The Nuffield Trust Secretary

University of Bristol Professor of Health and Social Care

University of Central Lancashire Dean

University of Central Lancashire Unison representative, Nursing and

Midwifery Advisory Committee

University of Greenwich Head of School of Health and Social

Care and Professor of Health Care

University of Hull Reader in Community Care

University of Leeds Professor of Midwifery and Director of

the Mother and Child Research Unit

University of Manchester Dean of Nursing

University of Manchester and Christie

Hospital NHS Trust

Lecturer in Nursing and Academic Lead

for Nursing

University of North London Lecturer in Human Nutrition and

Dietetics

University of Sheffield Professor of Midwifery

University of Southampton Professor of Cancer and Palliative Care

University of Southampton Deputy Dean of the Faculty of Medicine,

Health and Biological Sciences

Wandsworth Primary Care Trust Chair

West Midlands Workforce Development

Confederation

Director of Workforce Development

Women's and Children's Services, King's

College Hospital

General Manager/Director

Appendix 2 Operational definitions

Consumer groups

Carers and voluntary groups that represent specific interests in service development and delivery, for example, National Childbirth Trust.

Nursing and midwifery services

For the purposes of the project we use the term 'nursing and midwifery services' to cover a wide range of activities such as care, treatment, investigations, support, health promotion, public health and working for health in communities. The groups that are relevant to this work are: midwives, nurses (NHS, social care and independent sectors), health visitors, district nurses, school nurses, practice nurses, mental health nurses, nurses for people with learning disabilities, occupational health nurses, specialist/consultant nurses/midwives and health care assistants. Professional overlap and links between practice, management, research and education are identified as necessary within the report. We use the term in line with current trends to include health visiting under the term nursing, rather than as a separate profession, for example the Nursing and Midwifery Council and SDO Nursing and Midwifery Subgroup.

Research

Rigorous and systematic enquiry, conducted on a scale and using methods commensurate with the issue to be investigated, and designed to lead to generalisable contributions to knowledge.

Stakeholder

For our purpose, stakeholders are defined as having an interest in nursing and midwifery research from a range of intra- and interprofessional perspectives, across health and social care sectors and from different levels including commissioning, research delivery/activity and knowledge management. Stakeholders include representatives from: service policy and management; professional associations, higher education, specialist areas of practice; doctors and allied health and social care professionals; and consumer groups.

Service user

Anyone who has in the past, is currently, or may in the future access nursing or midwifery services.

User representative

Informed users with experience of representing the views of service users in a professional or voluntary capacity.

Appendix 3 Framework for analysis of user focus groups

Modified from Maxwell (1984) Equity, Effectiveness, Efficiency, Acceptability, Appropriateness and Accessibility.

Equity for groups of users Equity through the life course Equity according to health need Staff recruitment Staff retention Use of services (optimal configuration) Efficacy Use of finances Use of information technology Use of voluntary services Use of research evidence Appropriate people delivering care Appropriate interventions for individual care needs Appropriate location for delivery of care
Equity according to health need Staff recruitment Staff retention Use of services (optimal configuration) Use of finances Use of information technology Use of voluntary services Use of research evidence Appropriate people delivering care Appropriate interventions for individual care needs
Staff recruitment Staff retention Use of services (optimal configuration) Use of finances Use of information technology Use of voluntary services Use of research evidence Appropriate people delivering care Appropriate interventions for individual care needs
Staff retention Use of services (optimal configuration) Efficacy Use of finances Use of information technology Use of voluntary services Use of research evidence Appropriate people delivering care Appropriate interventions for individual care needs
Use of services (optimal configuration) Use of finances Use of information technology Use of voluntary services Use of research evidence Appropriate people delivering care Appropriate interventions for individual care needs
Use of finances Use of information technology Use of voluntary services Use of research evidence Appropriate people delivering care Appropriate interventions for individual care needs
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Use of voluntary services Use of research evidence Appropriate people delivering care Appropriate interventions for individual care needs
Use of research evidence Appropriate people delivering care Appropriate interventions for individual care needs
Appropriate people delivering care Appropriate interventions for individual care needs
Appropriate interventions for individual care needs
Appropriateness Appropriate location for delivery of care
Appropriate care delivery to meet expectation and demand
Appropriate time and frequency of care delivery
Safe skilled staff
Customer care/communication
Compartmentalisation of care
Communication between parts of the same system
Quality Parameters for identifying and measuring quality
Valuing service users' time
Safe and clean environments of care
Safe practice
User involvement in service development
Independent and representative involvement of users
User involvement in the delivery of services
User Involvement Service feedback to users
Personal care decisions
User involvement in training and education

Appendix 4 Stakeholder interview schedule

- 1 What is your current role? (if not ascertained prior to interview)
- What is your professional background? (if not ascertained prior to interview)
- 3 Have you any experience in undertaking and/or commissioning research generally and nursing and midwifery research in particular?
- 4 What would you say are the main gaps in nursing and midwifery services currently?
- 5 How might nursing/midwifery research contribute to bridging these gaps?
- What would be your priorities for nursing and midwifery research funding?
- 7 Looking at the list of SDO priority areas below:
 - (a) How do these compare with your own priorities? (explore reasons for similarities and differences)

(b) What would your top five priorities be?

SDO Priority	Examples	
Organising health services around the needs of the patient	 Exploring the contribution of nursing and midwifery to improving patient/client access to services/information 	
User involvement	 Investigating how nurses and midwives can increase public/lay/service user participation in service planning/service delivery/research 	
Continuity of care	 Researching assessment and care delivery processes and their impact on continuity of care 	
Co-ordinating/ integration across organisations	 Exploring the effectiveness of referral/communication across professional services, care sectors (health and social care/ primary and secondary care), and with voluntary sector/carers 	
Interprofessional working	 Researching team effectiveness; integration across disciplines/sectors; and effectiveness of shared learning 	
Workforce issues/ characteristics	 Exploring the impact of new role developments; shifting professional boundaries; skill/grade mix, recruitment/retention/work and family balance; career pathways; value for money of the workforce 	
Relationships between organisational form function and outcomes	 Evaluating changes to service design/delivery on the quality of nursing/midwifery services and health outcomes. Identifying what makes nursing/midwifery services good 	
Implications of the communication revolution	Exploring the contribution of nursing and midwifery to the use of the internet in patient information; tele health care, electronic patient records, e-learning etc.	
The use of resources, e.g. de-investing in services and managing demand	 Assessing the effectiveness of nursing and midwifery interventions with particular client groups and in particular services Deciding how nursing/midwifery resources are used 	
The implementation of national policy initiatives	 The impact and contribution of nurses and midwives to the National Service Frameworks, clinical governance, managed networks, modernisation agenda etc. 	

- 8 Are there any other issues/questions/topics that you feel are important?
- 9 Is there anyone else in your organisation or externally you feel it would be important for us to talk to?

Following this interview, should you have any further thoughts or issues you would like us to note, please feel free to contact us.

Appendix 5a Literature analysis: policy documents

Policy documents used to identify nursing and midwifery research priorities or of reference to nursing or midwifery practice.

Note: References here are cited in Table 9, under the policy number.

Policy	Reference
1	National Co-ordinating Centre for NHS Service Delivery and Organisation R&D (NCCSDO). 2000. National Listening Exercise: Report of Findings
2	Contracted Report to Task Group 3 of HEFC. 2001. Promoting Research in Nursing and the Allied Health Professions. CPNS, RCN, RFAHP, ACU.
3	Research, Evidence and Knowledge in Health Conference Proceedings: CHAIN. Sunningdale Park, London 18–19 February 2002. Available at: www.nelh.nhs.uk/knowledge_management/chain.asp
4	Department of Health 1999. NHS R&D Strategic Review. Primary Care. Report of Topic Working Group. London: HMSO
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Appendix 5b Literature analysis: papers in peer-reviewed journals

Selected papers (peer-reviewed journals and reports) that identify research priorities for nursing and midwifery.

Note: References here are cited in Table 9, under the document number.

Document	Reference
1	Ross, F., Vernon, S. and Smith, E. 2002. Mapping research in primary care nursing: Current activity and future priorities. <i>NT Research</i> 7: 46–57
2	Hale, C., Crofts, L. and Stokoe, L. 1999. Managed care, case management, multidisciplinary pathways of care: A selective review for the RCN R&D priority-setting exercise. <i>NT Research</i> 4(5): 366–77
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7	Legg, L., Pollock A., Langhorne, P. and Sellars, C. 2000. A multidisciplinary research agenda for stroke rehabilitation. <i>British Journal of Therapy and Rehabilitation</i> 7(7): 319–24
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14	Hagen, S. and Hunt, J. 1998. Assessing nurses' views of research priorities: a pilot study. <i>Managing Clinical Nursing</i> 2: 49–53
15	Soanes, L., Gibson, F., Bayliss, J. and Hannan, J. 2000. Establishing nursing research priorities on a paediatric haematology, oncology, immunology, and infectious diseases unit: A Delphi survey. <i>European Journal of Oncology Nursing</i> 4(2): 108–17
16	Adams, T. 1996. Informal family care giving to older people with dementia: research priorities for community psychiatric nursing. <i>Journal of Advanced Nursing</i> 24(4): 703–10
17	Fyffe, T. and Hanley, J. 2002. Scoping the nursing and midwifery research and development capacity in Scotland to inform the development of a future strategy.

NT Research 7(4): 255-62

- Nursing Initiative for Scotland (NRIS). 1998. Results of the Research Matrix questionnaire survey. *NRIS Newsletter* 6 (July)
- 19 Clement, S. Undated (?2000). A Study to Identify the Research Priorities of Community Midwives. Report of project
- McCourt, C. and Beake, B. 2000. Establishing research priorities in maternity and Primary Care research. Primary Care Studies programme report of project. Centre for Midwifery Practice, DH Regional Office
- 21 Newborn, M., National Childbirth Trust. 2002. Response to e-mail

Appendix 6a Literature on capacity building

- Selected papers (peer-reviewed journals) that provide background information or discuss strategies for capacity building in nursing and midwifery research.
- Bagnall, P. and Dilloway, M. 1996. In a different light. School nurses and their role in meeting the needs of school-age children. London: DoH and QNI
- Brocklehurst, N., and Allen, H. 1998. The health environment: A definition and conceptual framework for research and practice. *NT Research* 3(3): 214–25
- Campbell, S., Roland, M. and Bentley, E. 1999. Research capacity in UK primary care. *British Journal of General Practice* 49(449): _967–70
- Davidson, P., Merritt-Gray, M., Buchanan, J. and Noel, J. 1997. Voices from practice mental health nurses identify Research Priorities. *Archives of Psychiatric Nursing* X1(6): 340–5.
- Hicks, C. 1998. Evidence-based care in nursing: Reforms versus research rhetoric versus reality. *Health Services Management Research* 11(4): 246–54
- Hirschfield, M.J. 1998. WHO Priorities for a common nursing research agenda. *The Journal of Nursing Scholarship* 30(2): 114
- Hunt, J. 2001. Research into Practice: The Foundation for Evidence-Based Care. *Cancer Nursing* 24(2): 78–87
- International Nursing Review. 1998. ICN advises WHO's research body on nursing priorities (News report), Staff. International Nursing Review 45(1): 5
- Jenkins-Clarke, S. 1999. Does nursing need 'the dismal science'? The case for economic evaluations in nursing. *Nursing Times* 4(6): 448–56
- Mulhall, A., Alexander, C. and Le May, A. 1998. Appraising the evidence for practice: what do nurses need? *Journal of Clinical Effectiveness* 3(2): 54–8
- Nursing Management 2000. Prioritising research and development, report of workshop. Nursing Management 7(7): 7
- Rafferty, A.M. and Trayner, M. 1999. The research–practice gap in nursing: Lessons from the research policy debate. *NT Research* 4(6): 458–65
- Rafferty, A.M. and Traynor, M. 1997. On the state of play in nursing research. *Journal of Interprofessional Care* 11(1): 43–8
- Rafferty, A.M., Bond, S. and Traynor, M. 2000. Does nursing, midwifery and health visiting need a research council? *NT Research* 5(5): 325–34
- Rafferty, A.M., Newell, R. and Traynor, M. 2002. Nursing and midwifery research in England: Working towards establishing a dedicated fund. *NT Research* 7(4): 243–54

- Thompson, C., McCaughan, D., Cullum, N., Sheldon, T.A., Mulhall, A. and Thompson, D.R. 2001. The accessibility of research-based knowledge for nurses in United Kingdom acute care settings. *Journal of Advanced Nursing* 36(1): 11–22
- Tierney, A. 1998. The leading edge in nursing research. *NT Research* 3(4): 303–14
- Tierney, A.J. 1998. Nursing Research in Europe. *International Nursing Review*, 45(1): 15–18
- Traynor, M. and Rafferty, A.M. 1999. Nursing and the Research Assessment Exercise: past, present, future. *Journal of Advanced Nursing* 30(1): 186–92
- Wilson-Barnett, J. 2001. Research capacity in nursing, editorial. International Journal Nursing Studies 38, 241–2

Appendix 6b Annotated bibliography

For the purposes of the consultation exercise the following documents (as well as others not listed here) were used as background information to provide contextual data and to inform our thinking. Although these documents have implications for nursing and midwifery research they do not explicitly identify research priorities.

Department of Health. 2002. Shifting the Balance. London: HMSO

Describes the policy for shifting the balance of power to patients and staff in NHS by organisational and culture change and devolving from the centre to primary care trusts. Notes for directors of R&D, cancer, mental health, primary care, capacity building.

National Co-ordinating Centre for NHS Service Delivery and Organisation R&D. 2001. SDO News 2 November

Gives useful information on SDO activities. Notes commissioned projects – continuity of care, mental health and carers, methods to implement research findings.

Department of Health. 2001. *Putting NHS Research on the Map. An analysis of scientific publications in England 1990-97.* London: NHSE Executive and The Wellcome Trust

Maps research outputs in the NHS in England to provide information source for policy makers, demonstrate the usefulness of bibliometric indicators in R&D evaluation, develop a standard set of indicators for future evaluations of research outputs, support decision making in funding allocations. It notes that nursing research is one of the fastest-growing areas in terms of papers produced. Multinational and collaborative (agency or professions) research has greater impact than lone science research. Bibliometric analysis (the number and impact of scientific papers in peer-reviewed literature) is one indicator of a centre of excellence; patient-oriented, clinical research is another indicator and collaboration across institutions and professions. Other indicators are listed on page 10 for evaluating funded research. Also linked to the payback model page 12 refers to priority-setting exercises in mental health, cardiovascular disease and stroke, physical and complex disabilities, primary and secondary care interface, cancer, mother and child health, primary dental care, asthma management, methods of implementing research findings, forensic mental health for commissioning. This has implications for nursing research, which fits into some of these areas.

Department of Health. 2001. Research and Development for a First Class Service: next steps. London: HMSO

Describes the timetable for R & D, changed from previous review (2000).

Smith, L. 2001. A Position paper: Nursing research in Europe (unpublished paper). The Working Group of European Researchers (WENR)

Provides background and wider context of nursing research in Europe. Recommends nursing research should take into account: clinical outcomes that reflect burden of disease, multidisciplinary working, evidence-based nursing practice.

Department of Health. 2001. *National Service Framework for Older People*. London: HMSO

The single multidisciplinary assessment process, health promotion, falls prevention, and the promotion of an active healthy lifestyle are core to the NSF for Older People. Communication to support patient-centred care is also highlighted (Standard Two, page 23). 'The communication should be two way – seeking views about how services can be improved and providing information about the action under way' (page 25) providing information and support for those with long-term illness or disability to develop expertise in their own care, and to become partners in managing their continuing needs for healthcare (page 25). Rehabilitation and support as health declines to ensure that quality of life and independence are maximised (page 26).

Department of Health. 2001. *National Service Framework for Diabetes: Standards*. London: HMSO

The NSF for Diabetes: Standards identifies health interventions where nursing and midwifery could contribute to delivering services and building an evidence base, including; the detection and management of long-term complications (page 40), management of diabetic emergencies (page 31), care of people with diabetes during admission to hospital (page 34) and key interventions for diabetes during pregnancy (page 36). The framework identifies health promotion as a key development and considers the implications for service planning 'The NHS and partner organisations will need to review their local strategies for improving diet and nutrition, increasing physical activity, reducing overweight and obesity, and helping people to maintain weight loss, to ensure that they are targeting subgroups of the population at increased risk of developing diabetes, particularly people from minority ethnic groups. Strategies will need to consider people of all ages, particularly children, and to link with existing work based in schools and the wider community.' (page 17). The NSF implies further nursing contributions to increasing public awareness of diabetes through health promotion, testing of individuals known to be at increased risk, opportunistic screening, and empowering people with diabetes. For example, conducting small group interventions with children that address practical diabetes management issues and provide a forum for support and guidance to lead to improvements in knowledge of diabetes management, self-care and blood glucose control. A Research Advisory Committee was established jointly with the Medical Research Council with the involvement of Diabetes UK to produce a topic review of research on diabetes.

Department of Health. 2000. The NHS Plan: a plan for investment, a plan for reform. London: HMSO

Identifies areas of government priority. Improvements in services are identified for cancer, heart disease and mental health. Also mentioned are older people and inequalities. Organisation of services could lead to integration, better rehabilitation, shorter waiting lists; improved services will result in better screening and response to acute conditions such as heart disease. Nurses' roles will be expanded, particularly in primary health care (page 19).

NHS Centre for Reviews and Dissemination. 2000. *Promoting the Initiation of Breastfeeding*, Vol. 6 (July) No. 2

Notes gaps in evidence and gives comprehensive background to the evidence for this topic. Gaps in evidence – cost-effectiveness of health services and public/social interventions to initiate breastfeeding, information about the acceptability of interventions, effects of policy on maternity leave, effects of supportive environments.

Department of Health. 2000. *National Service Framework for Coronary Heart Disease*. London: HMSO

Within the NSF for Coronary Heart Disease effective interventions and policies are discussed as 'the evidence suggests that when care is not provided systematically many people are not offered all the care that would be appropriate and that would be of benefit to them.' (page 5). Health improvement, reducing smoking, promoting healthy eating, promoting physical activity, reducing overweight and obesity (page 4) are all key aspects of the framework which nurses/midwives/health visitors could contribute to service development and strengthening the evidence base. The NSF also states that special considerations should be made for adolescent health promotion and minority ethnic groups as some groups are at higher than average risk of heart disease. Health visitors are specifically identified as having an important role in community development to include the assessment of the needs of individuals, families and communities. (page 8).

Department of Health. 1999. Saving Lives: Our Healthier Nation London: HMSO

Identifies government targets for improving health and notes where improvements can be made. This will imply where research efforts can be focused. Four major areas are Cancer, CHD and Stroke, Accidents, Mental Illness related to suicide and undetermined illness. Suggests increasing nursing roles in public health for Health Visitors, School Nurses, Occupational Health Nurses and prevention, screening health promotion with regard to school health education, smoking cessation, alcohol reduction, parenting, stress reduction, asthma, long-term care and reducing inequalities.

Department of Health. 1999. *Making a Difference, Strengthening the nursing, midwifery and health visiting contribution to health and healthcare*. London: HMSO

Describes the past and future nursing roles in the NHS and the government's strategic intentions for nursing. Has implications for research in the evaluation of new roles and ways of working that are proposed and described. Mentions clinical governance and research evidence and increasing research capacity briefly. Provides background to the increased autonomy and accountability of nurses.

Dargie, C. 2000. *Analysing Issues for Health in 2015*, Part 2: Implications for health care. Nuffield Trust. Available at: www.nuffieldtrust.org.uk

Looks at current trends and implications for policy and service provision. Rising public expectations, ageing population, new technologies, IT, workforce education, system performance and quality. Suggests research in ageing should prioritise the diseases that are associated with ageing and the causes and prevention of chronic disease, disability and maintenance of health. Suggests develop additional indicators that are meaningful to older people. Notes move to evidence-based performance and outcomes and increasing use of IT.

Department of Health. 1999. *National Service Framework for Mental Health*. London: HMSO

The NSF for mental health states that nurses in primary care teams have an important role to play in assessment of mental health and working to remove stigma associated with mental health. This could involve work around mental health promotion: emotional resilience, citizenship, community development and anti-stigma campaigns, in the areas of postnatal depression, eating disorders and preventing suicide among individuals in contact with health and social services. Mental health in schools should seek to discover what concerns young people, such as bullying, examinations, helping to care for an older relative and loss of, or worry about a family member. Occupational Health Nursing can contribute to managing stress in the workplace and to improving the mental health of the NHS workforce itself. (page 22). The NSF suggests that research

priorities are likely to include investigating ways to enhance staff morale, retention, recruitment and performance, and thereby improve service user engagement and outcomes, developing and evaluating a range of occupational activities to maximise social participation, enhance self-esteem and improve clinical outcomes and developing research tools with service users to assess their view on how services can best meet their needs (page 115).

Department of Health. 1998. *Towards an evidence-base for health services, public health and social care: An information pack.* London: HMSO

An information document that details the NHS programme, the Department's policy research programme and wider research issues. Details priorities and commissioned research by the NHS Central Research and Development Committee (CRDC) which has led to establishment of national programmes of R & D in Mental Health and Learning Disabilities, Cardiovascular Disease and Stroke, Physical and Complex Disabilities, Primary and Secondary Interface, Cancer, Mother and Child Health, Primary Dental care, Asthma Management, Methods of Implementing Research Findings. Priorities and commissioned projects are listed under each programme. Majority are relevant to nursing practice. Notes the establishment of the SDO and New and Emerging Technologies programmes.

Paediatric Intensive Care Framework. 1996. Report from the National Co-ordinating Group on Paediatric Intensive Care to The Chief Executive of the NHS Executive

The Paediatric Intensive Care Framework focuses on specialist nurse training, to improve nurse staffing in paediatric intensive care services, and to advise and provide guidance on staffing, training and development of staff. Other priorities for service development are communication/networks, and organisation of services. Priorities for research include risk assessment, costing methods, needs assessment and specific interventions.

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Addendum

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