User Involvement in the Design and Undertaking of Nursing, Midwifery and Health Visiting Research:

Supplementary literature tables

Report to the National Co-ordinating Centre for NHS Service Delivery and Organisation
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Studies directly cited in the review are shown in black text. Studies that informed the review but which were not cited in the report are shown in shaded text.

Table 1 Context issues

Full reference	Topic code	Contribution to the debate
Appleton, J.V. and King, L. 2002. Journeying from the philosophical contemplation of constructivism to the methodological pragmatics of health services research. *Journal of Advanced Nursing* 40(6): 641-8.	**Context** Philosophical issues	This paper provides background information about the philosophical origins of constructivism to consider its role as an active methodology in qualitative research. The first part of the paper summarises the philosophical background of constructivism and the five principles underpinning this paradigm as described through the works of Guba and Lincoln. The philosophical roots of constructivism are then compared with postpositivism, critical realism and participatory inquiry. The paper moves on to consider their common methodological steps, before examining how the constructivist research strategy is being adopted and adapted within the pragmatics of health service research. The paper raises questions about the philosophical underpinnings of service user involvement in research and the relationship to qualitative research methodologies.
Arnstein, S. 1969. A ladder of citizen participation. *AIP Journal* 35(4):216-224.	**Context** Philosophical issues	This seminal paper describes a ladder of citizen participation from manipulation to citizen control. This model was developed in the United States of America as a result of the 'heated controversy' over citizen participation, citizen control and involvement of the poor in federal social programmes. Arnstein believed that 'there is a critical difference between going through the empty ritual of participation and having the real power needed to affect the outcome of the process'. She identified that roadblocks to achieving 'genuine' levels of participation lie on both sides (state and citizen) including racism, paternalism and resistance to power distribution, inadequacies of socioeconomic infrastructure and knowledge base, as well as difficulties of organising representative and accountable citizen's groups.
Beresford, P. 2004. Where's the evidence? *Mental Health Today* Feb: 31-4.	**Context** Philosophical issues	Discusses origins and issues for service user involvement; particularly focussing on the issue of what experiential knowledge is and how it relates to understanding. The paper outlines testing questions for the future development of user-controlled research. Such as: do research participants feel they are treated in the same way by service user and non service user researchers; do conventional and service user interviewers get the same or different answers to their questions; what might be the differences between the outcomes of traditional and user controlled research? The paper makes important points about maintaining rigour – arguing for user involvement in research and user-controlled research is not to argue for the dilution of rigour, and second that it is not only those with experience of using services can undertake research or interpret the experience of service users.

De Certeau, M. 1984. *The Practice of Everyday life*. USA: University of California Press.	**Context** Philosophical issues	Describes concepts of social representation.
Hanucharurnkul, S. 1989. Comparative analysis of Orem's and King's theories. *Journal of Advanced Nursing* 14(5): 365-72.	**Context** Philosophical issues	Dorothea Orem and Imogene King are two nursing theorists who are contributing significantly to the development of nursing knowledge. This paper compares the similarities and differences in their strategies for theory development, their views of nursing metaparadigm concepts, and their theories of nursing system and goal attainment in terms of scope, usefulness, and their unique contribution to nursing science.
Maurin, J.T. 1990. Research utilization in the social-political arena. *Applied Nursing Research* 3(2): 48-51.	**Context** Philosophical issues (research issues)	This paper argues that many of the health problems of populations at greater risk for ill health require action at the social-political level for intervention. The experience of working with local community leaders and concerned providers to improve the resources available to meet the needs of the homeless is used to illustrate the value and problems of combining the roles of nurse researcher and change agent. Whereas the researcher must protect the integrity of the research process so that the results will be meaningful, the formation of the research questions and reporting of results also must take into account the social-political aims of the research. The paper adds to debates about the purpose of research in society.
Midgley, J., Hall, A., Hardiman, M. and Narine, D. 1986. *Community Participation, Social Development and the State*. London: Methuen & Co.	**Context** Philosophical issues	The antecedents of current conceptualisation of ‘community’ can be traced to the ‘community’-development movement in many third world countries in the 1950s and 1960s. This book examines the role of community participation in the developing world. Midgley and other contributors explore whether or not the state and community are adversaries in social development or whether they can work together. They do this by analysing the role of the state and community participation in health, education, rural development, urban development and housing, social work and finally in social policy.

Gastmans, C., Dierckx de Casterle, B. and Schotsmans, P. 1998. Nursing considered as moral practice: a philosophical-ethical interpretation of nursing. *Kennedy Institute of Ethics Journal* 8(1): 43-69.	**Context** Philosophical issues	Many ethical concepts in nursing still need to be clarified. The purpose of this paper is to develop a fundamental ethical view on nursing care considered as moral practice. Three main components are analyzed more deeply; the caring relationship, caring behaviour as the integration of virtue and expert activity, and 'good care' as the ultimate goal of nursing practice. For the development of this philosophical-ethical interpretation of nursing, the authors have mainly drawn on the pioneering work of Anne Bishop and John Scudder, Alasdair MacIntyre, Lawrence Blum, and Louis Janssens. They show that the European philosophical background offers some original ideas for this endeavour.
While, A. 1999. The unrealised potential of consumerism. *British Journal of Community Nursing* 4(10): 543.	**Context** Philosophical issues	This paper argues that there is a need to recognise the obligation and potential benefit of engaging in debates about consumerism.
Du Plat-Jones, J. 1999. Power and representation in nursing: a literature review. *Nursing Standard* 13(49):39-42.	**Context** Political issues	This paper explores concepts of power and representation and their effects for both nurses and clients. It concerns power and representation and power relationships such as patient advocacy and patient empowerment. Self-presentation and representation are key issues. The paper concludes that by working in partnership with clients, nurses can best represent their needs and redistribute power. It argues that nurses should learn to represent themselves, their interests and those of their clients more effectively to gain a greater voice within a wider political, social and health care arena.
Tee, S. 2002. Promoting patient and public involvement in primary health care: Part 2 - local case study. MCC: *Building Knowledge for Integrated Care* 10(4): 41-8.	**Context** Political issues	This literature review revealed many challenges to implementing patient involvement performance measures that would test those with responsibility for achieving a meaningful outcome for all stakeholders. The paper draws on a local study that used qualitative data from key stakeholders to examine how one Primary Care Group was responding to the involvement agenda. The findings revealed cynicism and doubt among board members about the purpose and value of involvement, despite which some progress was felt to have been made in engaging with local voluntary groups. The paper also indicates that the experience of involvement among local patients had not always been a positive one. It suggests that issues of power and organisational culture will need to be tackled through greater investment in clinical and managerial staff development.

Tee, S. 2002. Promoting patient and public involvement in primary health care: Part 1 - literature review. MCC: *Building Knowledge for Integrated Care* 10(3): 39-46.	**Context** Political issues	This literature review makes some suggestions to assist managers in achieving progress in patient and public involvement in health services, some of which may be transferable to service user involvement in research.
Tyler, S. 2002. Comparing the campaigning profile of maternity user groups in Europe - can we learn anything useful? *Health Expectations* 5(2): 136-147.	**Context** Political issues	The aim of this consultation was to compare the extent to which women in three European countries were able to exert influence over the organisation and delivery of maternity policy and the factors likely to determine their success. The design used semi-structured interviews to collect data, which was analysed in a framework that emphasised the importance of contextual environment. Representatives of 19 lay maternity user organisations in England, the Netherlands and Germany were interviewed during 1996 and 1997. Each interviewee was asked to provide details of their aims and objectives, activities and networks and perception of success. Four areas of contextual environment were used to account for variations. The main outcome measures were self-reported accounts of success in influencing policy agenda, credibility with opinion formers, campaigning activities and political networking were compared between and across countries. The results show marked differences between both the aspirations and the achievements of groups in the three countries. This paper adds to understandings about the political and cultural differences between countries in relation to user involvement and locating research within the social, political and cultural context of health-care, consumerism and citizen participation.
Jewell, S.E. 1994. Patient participation: what does it mean to nurses? *Journal of Advanced Nursing* 19(3): 433-8.	**Context** Meanings	The aim of this ethnographic study was to uncover the perceptions of primary nurses towards the notion of patient participation. It is a small explorative study that is based on one group discussion with four primary nurses working within a rehabilitation unit for elderly people. The data were subjected to a content analysis and two central themes or principles emerged. It adds to the topic of service user involvement in research as it reveals that nurses viewed participation as having a formal and informal meaning as well as a formal and informal method or practice, and secondly, it was seen to involve mutual informing or negotiation between patient and nurse. Both these principles were regarded as closely linked to the concepts of nurse-patient closeness and patient individuality.

O'Donnell, M. and Entwistle, V. 2004. Consumer involvement in decisions about what health-related research is funded. *Health Policy* Dec 70(3): 281-90.	**Context** Commissioning	The objectives of this scoping study were to consider whether, why and how research funders involve consumers in decisions about what health-related research is funded. Postal survey and semi-structured interviews were used with UK funders of health-related research. The findings show that organisations that fund research have diverse goals and remits, and perceive themselves to be accountable in different ways and to different groups. They have a variety of reasons for involving consumers in decisions about what research is funded, but also a number of concerns about doing so-particularly about the ways in which consumer input might 'distort' the research agenda. Research funders use several types of decision-making structures and processes to identify and prioritise topics in which they want to invest and to select between research proposals. They involve consumers in these structures and processes in diverse ways. Little is known about the actual effects of this involvement, but the nature and extent of consumer influence on the research agenda is likely to be moderated by a number of factors, including the types of consumers involved, the particular structures and processes in which they are involved, the timing of their input and the different ways in which they are asked to contribute in relation to others. The paper concludes by stating that a diverse range of research funding organisations are now involving consumers in the various approaches that they take to identify and prioritise research topics and to decide which proposals they will fund. The future development of their activities could usefully be informed by careful consideration not just of involvement but also of the implications of the various structures and processes that shape research agendas. The implications of the findings for user involvement in research are that the appropriateness of particular forms of consumer involvement should be considered in the broader context of the features of the whole research funding system, including the values implicit within it.
Oliver, S. 1996. The progress of lay involvement in the NHS research and development programme. *Journal of Evaluation in Clinical Practice* 2(4): 273-80.	**Context** Commissioning	This paper describes some recent examples of lay involvement in each step of the research process from setting the agenda to making use of research findings in the NHS R&D Programme. The authors claim that innovative approaches have involved lay people in identifying research need and in the subsequent commissioning process. Lay contributions have given particular emphasis to information and support, whether this is in maternity care, cancer care, HIV prevention, and participation in clinical trials or systematically reviewing evidence of effectiveness. Difficulties in identifying appropriate lay people to involve in research, their different skills, their lack of resources and support and their need for time for thought and discussion with their peers have all posed problems. The authors present suggestions for overcoming some of these obstacles, including resources, training and support, and clarification of the role, nature and potential for lay involvement.

Liberty, K.A., Laver, A. and Sabatino, D. 1999. Collaborative partnerships in evaluation and experimental rehabilitation research. *Journal of Biomechanics* 22(4): 283-90.	**Context** Commissioning	This paper argues that changes in rehabilitation and clinical practice, the recognition of the role of clients in achieving rehabilitation goals, and client participation in decision-making and administration of service delivery have contributed to the development of new methodologies for research and evaluation. In this paper, the traditional relationship between researchers and subjects in traditional rehabilitation evaluation and research is contrasted with relationships between researchers and clients-consumers in newer methodologies. The limitations and challenges to these models are discussed. Collaborative research, characterised by shared power and non-hierarchical authority between client-consumers and researchers, is described as an alternative model for experimental and evaluative research. Collaborative relationships provide a structure for building upon the knowledge and expertise of each research partner. The authors draw upon their own experience of collaborative research partnerships and models of research partnerships are described. Research developed and conducted in a collaborative partnership can include quantitative and qualitative approaches, maintain traditional scientific perspectives of objectivity, reliability and replicability, and improve participation rates, continuity of involvement for longitudinal studies and utilisation of researched methods into practice.
Allen, J., Dyas, J. and Jones, M. 2004. Building consensus in health care: a guide to using the nominal group technique. *British Journal of Community Nursing* 9(3):110-114.	**Context** Commissioning	The nominal group technique has been used in the health care sector in the development of guidelines and the identification of research priorities. The methodology suits research that includes both health professionals and consumers, since it allows for the free exchange of opinions and the generation of ideas within a structured and non-hierarchical discussion forum. This article describes the process of planning and running a nominal group and uses examples from a primary-care-based study to illustrate some of the advantages of using this method, and also the practical implications of using the technique in consensus development.

Oliver, M. 1992. Changing the social relations of research production. *Disability, Handicap and Society* 7(2): 101-114.	**Context** Commissioning	Oliver has argued over many years that disability is socially created and that interventions that are not based on this understanding are bound to become inappropriate over a period of time. He points out that most researchers have operated within the same intellectual straightjacket that attributes the social restrictions faced by disabled people to personal failings. His view is that disability cannot be abstracted from the social world, which produces it; it does not exist outside the social structure in which it is located and independent of the meanings given to it. In other words, disability is socially produced. In the past 100 years or so, industrial societies have produced disability first as a medical problem requiring medical intervention and second as a social problem requiring social provision. Research on the whole, has operated within these frameworks and sought to classify, clarify, map and measure their dimensions. These social relations are built upon a firm distinction between the researcher and researched; upon the belief that it is the researchers who have specialist knowledge and skills; and it is they who should decide what topics should be researched and be in control of the whole process of research production.
Coats, A.J. 2000. Consumer involvement in cardiovascular research: ways to combat bias and secrecy. *International Journal of Cardiology* 75(1-3): 1-3.	**Context** Commissioning	This editorial discusses the biases that exist in research; stating that, too many society decisions are shrouded in secrecy, closed-door deals and unofficial trial. The author argues that both the professional and public communities need to push for consumer involvement in developing research questions, in trial funding, in trial design and research agendas. Coats believes that greater clarity and consultation of even painful issues is needed.
Ross F., Smith E., Mackenzie A. and Masterson A. 2004 Identifying research priorities in nursing and midwifery service delivery and organisation. *International Journal of Nursing Studies*, 41(5) 547-58	**Context** Commissioning	This paper reports on a scoping study commissioned by the National Co-ordinating Centre Service Delivery and Organisation Research and Development to identify priorities for nursing and midwifery research funding in England and Wales. The study included consultation with Community Health Councils in five nationally held focus groups (32, plus six written submissions). Five priority areas for research were identified-one of which was user involvement and participation-for which exemplar research questions and issues for strategic commissioning are suggested.

Baker, M.R., Kirk, S. and Donaldson, L. 2001. *Research and Development for the NHS: Evidence, evaluation and effectiveness*. Abingdon: Radcliffe Medical Press.	**Context** Commissioning	The authors describe the NHS Research and Development programme and its influence on the provision of healthcare services. An overview of the NHS Research and Development Strategy is presented, including background information on some of the research problems experienced over the last few decades, culminating in the strategic approach to research proposed by Professor Peckham in 1991. This broad approach incorporated three core aims relating to making the NHS decision making research based, facilitating the NHS with the means to identify research related problems, and to strengthen the links between the NHS and science. It sets the background for increased attention on the principles by which research is commissioned.
Royle, J. and Oliver, S. 2001. Consumers are helping to prioritise research. *British Medical Journal* 323: 48-9.	**Context** Commissioning	In this letter the authors welcome the increasing participation of consumers in designing, conducting, and interpreting the results of randomised controlled trials. They explain the work of the National Coordinating Centre for Health Technology Assessment to recognise the importance of asking consumers to help decide which trials are needed. The organisation has developed job descriptions and person specifications and established procedures for identifying consumers and inviting and supporting their participation. When giving their views on research vignettes consumers are asked to comment on the importance of the research question, the tone and flavour of the vignette, and changes or additional information that would be useful. Consumer referees of research proposals are particularly asked to consider the choice of outcomes, patients' views about health care and needs for information and support, and patients' relevant experiences in healthcare settings and everyday life. Consumers refereeing research reports provided positive, reassuring comments and suggested changes. Some raised issues not previously mentioned and gave useful opinions on the ranking of recommendations for research. Some gave sensitive interpretations of the results from the consumer perspective, with suggestions on how the report might be made more accessible and informative. Occasionally, some were critical for example, questioning how outcomes are measured.

Tallon, D., Chard, J. and Dieppe, P. 2000. Relation between agendas of the research community and the research consumer. *Lancet* 355(9220): 2037-2040.	**Context** commissioning	This study set out to determine whether there is a discrepancy between available research evidence and the research preferences of consumers. The authors examined research on interventions for the treatment of osteoarthritis of the knee joint by searching published and unpublished studies to assess the structure of the evidence base. Focus groups and a postal survey of research consumers were then undertaken to examine their views and research priorities. Review of published and unpublished reports showed that the evidence base was dominated by studies of pharmaceutical (550, 59%) and surgical (238, 26%) interventions. 24 (36%) of 67 survey respondents ranked knee replacement as the highest priority for research, whereas 14 (21%) chose education and advice as their first choice. The authors conclude that there is a mismatch between the amount of published work on different interventions and the degree of interest of consumers. They suggest that broadening of the research agenda would be more in line with current treatment patterns and consumer views and warn that if this mismatch is not addressed, then evidence-based medicine will not represent consumer needs.
Yin, T.J.C., Hsu, N., Tsai. S.L., Wang, B.W., Shaw, F.L., Shih, F.J. et al. 2000. Priority-setting for nursing research in the Republic of China. *Journal of Advanced Nursing* 32(1): 19-27.	**Context** Commissioning	This paper describes how the question of how public funds for research should be allocated has led to participatory priority setting in prosperous democracies. The authors argue that useful criteria for research priorities are scientific merit, social benefit and feasibility.
Roberts, T., Bryan, S., Heginbotham, C. and McCallum, A. 1999. Public involvement in health care priority setting: An economic perspective. *Health Expectations* 2(4): 235-244.	**Context** Commissioning	This paper describes the approach to priority setting advocated by many health economists namely, the maximisation of quality adjusted life years (QALYs). Typically, for each health care programme, the QALY calculation takes account of four features: (1) number of patients receiving the programme, (2) survival gain, (3) gain in quality of life and (4) probability of treatment success. Only feature (3) is based upon public preferences. The authors argue that if the QALY is to be used for health care resource allocation at a societal level then it should incorporate broader societal preferences. This study used an interview-based survey of 91 members of the public to explore whether the traditional QALY maximisation model is a good predictor of public responses to health care priority setting choices. Many respondents did not choose consistently in line with QALY maximisation objective and were most influenced by quality of life concerns. There was little support for health care programmes that provided a prognostic improvement but left patients in relatively poor states of health.

Rustoen, T. and Schjolberg, T.K. 2000. Cancer *Nursing Research* priorities: a Norwegian perspective. *Cancer Nursing* 23(5): 375-81.	**Context** Commissioning	The purpose of this study was to determine research priorities among Norwegian nurses in cancer care, and to investigate implications that these priorities might have for future planning of nursing research. The nurses were asked to select the five topics they perceived as most important from a list of 80 items, and to rank them in order of research priority. The response rate was 43% (197/464), and 75 respondents were specialists in cancer nursing. Quality of life was given the highest research priority in the total sample. Patient participation in decision making was ranked highly as a priority.
Mullen, P.M. 1999. Public involvement in health care priority setting: An overview of methods for eliciting values. *Health Expectations* 2(4): 222-234.	**Context** Commissioning	This paper begins by explaining that there is increasing interest, in the UK and elsewhere, in involving the public in health care priority setting. At the same time, however, there is evidence of lack of clarity about the objectives of some priority setting projects and also about the role of public involvement. Further, some projects display an apparent ignorance of both long-standing theoretical literature and practical experience of methodologies for eliciting values in health care and related fields. After a brief examination of the context of health care priority setting and public involvement, this paper describes a range of different approaches to eliciting values. These approaches are critically examined on a number of dimensions including the type of choice allowed to respondents and the implications of aggregation of values across individuals. Factors that affect the appropriateness of the different techniques to specific applications are discussed. A checklist of questions to be asked when selecting techniques is then presented.
Glenister, D. 1994. Patient participation in psychiatric services: a literature review and proposal for a research strategy. *Journal of Advanced Nursing* 19(4): 802-11.	**Context** Professional issues	This paper examines policy and ethical issues in relation to patient participation. Studies examining immediate patient participation, for example active participation in treatments, and distant patient participation, namely participation in psychiatric service planning are reviewed. Various settings of psychiatric services are examined, including the initial interview, primary health care, hospitalisation and clinical innovation, in order to uncover common themes. These studies often fail to pay attention to the patient's experience of participation, even when clinically innovative schemes are being described, and also fail to develop hypotheses and theories about participation. The importance of a sociological perspective in future studies is indicated. The author argues that psychiatric patients want a more active role in treatments and service planning, and that psychiatric clinicians, including nurses, find more active patient participation threatening. The nurse's role in democratising psychiatric services, thus permitting greater patient participation, while fulfilling statutory obligations is a considerable challenge to nursing practice in the future. This paper concludes by discussing some current limitations of *Nursing Research* and the value of some ideas taken from critical theory, in particular reflection, dialogue and praxis, as a practical basis for social action and nursing research.

Hayward, A. 1996. Patient power or consumer confusion? *Practice Nursing* 7(7): 11-12.	**Context** Meanings	This article questions how and whether patients can be provided with information that enables them to be ‘empowered’ to make choices about health care. It argues that if patients are to increasingly be given choice, what then are the effects on the professional status of the doctors and practice nurses whose own judgment is to be continually questioned by the eager consumer? And, in practical terms, how are doctors and practice nurses to deliver ‘empowerment’?
Williamson, C. 2001. What does involving consumers in research mean? *Quarterly Journal of Medicine* 94: 661-664.	**Context** Meanings	This editorial begins by stating that consumers concerns and priorities for research are different from those of clinical researchers. That is not surprising, since consumers' and health professionals' concerns and priorities for treatment and care are also different. So creating the means for trying to reach agreement between consumers and doctors is important. Some consumer groups have long been concerned by what they see as the lack of investigation of certain topics, poorly designed or unsafe research, and a disregard of research evidence from other countries. Members of such groups have pressed research organisations to include their members or other consumers on their research committees, or they have initiated research themselves, formulating their research questions and hypotheses and inviting clinicians and researchers to join them. It discusses what the term ‘consumer’ means in relation to research and what ‘involvement’ constitutes. Different forms of involvement are described (consultation and partnership).
Pivik, J., Rode, E. and Ward, C. 2004. A consumer involvement model for health technology assessment in Canada. *Health Policy* 69(2): 253-268.	**Context** Meanings	Similar to other health policy initiatives, there is a growing movement to involve consumers in decisions affecting their treatment options. Access to treatments can be impacted by decisions made during a health technology assessment (HTA) i.e., the rigorous assessment of medical interventions such as drugs, vaccines, devices, materials, medical and surgical procedures and systems. This paper empirically assessed the interest and potential mechanisms for consumer involvement in HTA by identifying what health consumer organisations consider meaningful involvement, examining current practices internationally and developing a model for involvement based on identified priorities and needs. Canadian health consumer groups representing the largest disease or illness conditions reported a desire for involvement in HTA and provided feedback on mechanisms for facilitating their involvement. Based on the results of this national survey, health consumers believe they should have a role in determining their treatment options. By providing support and training, these organisations believe they would be capable of and are willing to devote a considerable amount of time and effort to have an influence on the assessment and evaluation of potential treatments and therapies and their availability for access. The model that is presented requires the support of the central organisation conducting HTA reviews to respect the health consumer stakeholder involvement process and provide resources for accommodating the needs of health consumer experts.

Almond, P. 2001. What is consumerism and has it had an impact on health visiting provision? A literature review. *Journal of Advanced Nursing* 35(6):893-901.	**Context** Meanings	This study analysed the concept of consumerism drawing on methods of concept analysis. It attempts to identify who the actual consumers of health visiting are, before examining whether consumerism and the consumer's voice has had an impact on health visiting provision. The study uses an integrative review of a range of literature relating to consumerism. A focused analysis of consumer views of child health clinics is used to illustrate the concept of consumerism. The findings suggest that consumerism is an outdated concept and has been replaced by other less emotive terms such as partnership and participation. The authors conclude that consumerism has had relatively little impact on improving child health clinics although high levels of consumer satisfaction with the overall service exist. The author recommends that more methodologically sound studies are needed to explore users' views of health visiting services and to implement findings to maintain or improve services.
Burton-Jones, J. 2000. Are residents' relatives consumers too? *Nursing and Residential Care* 2(12): 598-599.	**Context** Meanings	Residential homes for older people are developing customer care practices, which reflect the position of residents as consumers, but this author asks, do they see residents' friends and relatives as their customers, too? Two questions are raised in the light of discussions on customer care in homes for older people: 1. Do older people see themselves as customers of the homes in which they live? 2. To what extent are/should their relatives be seen as customers?
Cahill, J. 1998. Patient participation: a review of the literature. *Journal of Clinical Nursing* 7(2): 119-128.	**Context** Meanings	This article presents a critical review of the context of patient participation. The concept of patient participation has become widely accepted in contemporary nursing practice. It is now part of the vocabulary of professional nurses and has been heralded as a means of enhancing decision-making and human dignity and enriching quality of life. Patient participation in care is emerging as a growing movement wherein patients are assuming more responsibility for the prevention, detection and treatment of health problems in a manner that supplements or substitutes for professional services. The review concludes with some recommendations for nursing practice, education and research.
Chalmers, I., Jackson, W. and Carvel D. 1999. People are 'participants' in research. Further suggestions for other terms to describe 'participants' are needed. *British Medical Journal* 318: 1141.	**Context** Meanings	Comment on Boynton's suggestion that the word 'subject' should be banned from reports of research on humans. The term 'participants' works well for those types of research (such as controlled trials) in which active involvement of the people being studied is required, although some may prefer the word 'volunteers' to describe participants in non-therapeutic research. Choosing appropriate terms to describe people who were not actively involved in the research being reported (for example, because they were dead) presents a greater challenge. 'Patients' may be appropriate in some circumstances, but not all.

Truman, C. and Raine, P. 2002. Experience and meaning of user involvement: some explorations from a community mental health project. *Health and Social Care in the Community* 10(3): 136-43.	**Context** Meanings	This paper explores the rhetoric and realities of what user involvement entails. By drawing upon an evaluation of a community-based exercise facility for people with mental health problems, the authors explore ways in which the reality of user involvement is subject to a range of configurations within health services. The paper describes a piece of qualitative research that was undertaken within a participatory framework to explore the nature of user involvement within the facility. The data were analysed using a grounded theory approach to provide insights into the organisational context in which user involvement takes place; factors which encourage meaningful participation on the part of service users; perceived barriers to user involvement; and issues of sustainability and continuity. This research approach enabled the authors to explore the views and experiences of users, service providers and referral agencies in relation to the nature and potential for user involvement. The findings relate to the review by illustrating ways in which user involvement may take place under both flexible and formal arrangements across a variety of activities. The paper provides an account of some of the meanings and experiences of what 'successful' user participation may involve and the conditions, which underpin 'success'. The authors conclude that successful and meaningful user involvement should enable and support users to recognise their existing skills, and to develop new ones, at a pace that suits their particular circumstances and personal resources. The authors point out that this process may require adaptation not only by organisations, but also by service providers and service users that might not be involved.
Boynton, P. 1998. People should participate in, not be subjects of, research. *British Medical Journal* 317: 1521.	**Context** Meanings	This author argues that the term ‘subject’ is derogatory to service users who participate in research and criticises publications which use the term, suggesting the term ‘participant’ as an alternative.
Walmsley, J. 2004. Involving users with learning difficulties in health improvement: lessons from inclusive learning disability research. *Nursing Inquiry* 11(1): 54-64.	**Context** Meanings	In this paper the author considers the lessons to be drawn from what is termed 'inclusive' learning disability research for user involvement around health improvement. Inclusive learning disability research refers to research where people with learning difficulties (intellectual disability) are involved as active participants, as opposed to passive subjects. There is by now a considerable body of such research, developed over the past 25 years. From the review, the author draws attention to areas that can inform practice in involvement of users in a way that adds value.

Poulton, B.C. 1999. User involvement in identifying health needs and shaping and evaluating services: is it being realised? *Journal of Advanced Nursing* 30(6): 1289-1296.	**Context** Meanings (researcher skills)	This paper explores what is meant by user involvement in the context of primary care services, proposing that it exists at a series of levels ranging from information giving to true empowerment. Examples are presented from two practice development projects. The first sought to develop multidisciplinary audit in primary care, attempting to involve users in defining health needs and determining services. Although the project co-ordinators were highly committed to user involvement this was only achieved to a limited extent. It was concluded that there was a resistance to user involvement grounded in the fear that such involvement would increase user expectations and add to the pressures of overworked primary care teams. The second project used interviews with service users to assess the effectiveness of a team building initiative. Users were found to be knowledgeable about practitioner roles and how to access the care they required.
Rodwell, C.M. 1996. An analysis of the concept of empowerment. *Journal of Advanced Nursing* 23(2): 305-13.	**Context** Meanings	This paper is an analysis of the concept of empowerment and its use in nursing practice, education, research and health promotion. The paper uses concept analysis, incorporating the methods advocated by Walker & Avant and Rodgers. The concept is analysed and a theoretical definition given. Defining attributes, related concepts, antecedents and consequences of empowerment are proposed and a model case presented. The analysis demonstrates that empowerment is: a helping process; a partnership valuing self and others; mutual decision making; and freedom to make choices and accept responsibility. Implications for practice conclude the paper.
Rush, B. 2004. Mental health service user involvement in England: Lessons from history. *Journal of Psychiatric and Mental Health Nursing* 11(3): 313-318.	**Context** Meanings (working relations)	This historical analysis draws attention to differing assumptions, which promote or limit user involvement in nursing practice. The meaning of the term 'user involvement' is analyzed with reference to varying models. A continuum is offered to illustrate the relationship between assumptions about people with mental health problems and their involvement in care. It is argued that the range of views concerning recipients of mental health services, from being dangerous and irrational to being considered equal partners with health professionals, creates an unresolved tension that has existed through the ages. The authors believe that the key to resolving this tension is for all parties to acknowledge conflicts between their views and those of others and engage in meaningful dialogue about them.

Hickey, G. and Kipping, C. 1998. Exploring the concept of user involvement in mental health through a participation continuum. *Journal of Clinical Nursing* 7(1): 83-8.	**Context** Meanings	This paper identifies two approaches to user involvement in their care. The approaches are linked through a 'participation continuum', which is a framework through which the concept of user involvement can be explored, and against which practice can be assessed. The findings add to the topic of service user involvement in research in arguing that the framework must be seen within the context of constraints to user involvement. The authors suggest a more realistic assessment of the extent to which users can be involved in decisions can then be made and the risks of raising unrealistic expectations avoided.
Lanza, M.L. and Ericsson, A. 2000. Consumer contributions in developing clinical practice guidelines. *Journal of Nursing Care Quality* 14(2):33-40.	**Context** Professional issues	This paper describes a research project to develop clinical practice guidelines for a community meeting to prevent and intervene with assaultive behaviour. The research included consumer input (consultation) from psychiatric inpatients. The two-phase approach with the consumers included a focus group, followed by survey research. Results, problems, and recommendations are presented.
Cody, W.K. 2003. Paternalism in nursing and healthcare: central issues and their relation to theory. *Nursing Science Quarterly* 16(4): 288-96.	**Context** Professional issues	In this article the author examines paternalistic practices, wherein providers confer a treatment or service upon a person or persons without their consent, ostensibly by reason of their limited autonomy or diminished capacity, are widespread in healthcare and in societies around the world. In the United States, paternalism in health and human services is widespread and probably increasing with newly emergent forms. It is suggested that scientific and ethical knowing are not separate but must be united in theoretical structures that include both in unity, along with an appreciation of the infinite complexity of life as it is humanly lived. The paper adds to the topic area by suggesting that nursing's unique theory base of frameworks that honour human dignity and focus on human experience offers an opportunity for leadership in further developing theoretical frameworks that transcend paternalistic practices.

Kirkevold, M. 1994. The Contribution of *Nursing Research* - knowledge about the patient: *7th Biennial Conference of the Workgroup of European Nurse Researchers*, Oslo: Norwegian Nurses Association.	**Context** Research issues	This review study focused on articles presenting *Nursing Research* related to patient phenomena. Arguments presented in the articles focus on clinical relevance rather than its relevance within the nursing discipline; articles based on empirical research and the existence of a body of *Nursing Research* carried out within a common theoretical framework are an indication of at least an initial attempt to cumulate knowledge based on several separate studies; and although a coherent body of knowledge is evident in circumscribed topical areas, this pattern will not lead to an overall coherent body of knowledge within the discipline, because no conceptual structure(s)/philosophical perspective exist that may bind the different categories together in a unified whole. The author concludes that *Nursing Research* is making a substantial contribution to the general knowledge development about human beings and their actions and reactions in a wide range of situations.
Kearney, M.H. 2001. Focus on research methods. Levels and applications of qualitative research evidence. *Research in Nursing and Health*. 24(2): 145-53.	**Context** Research issues	This exploratory study is described as a first step toward a continued dialogue on the role of qualitative findings in improving nursing care. The paper describes concepts of complexity and discovery and modes of clinical application. The paper argues that clinicians can add qualitative research evidence to their experiential, anecdotal, quantitative, and other knowledge sources, combining relative risks with portraits of situated experience when crafting individualised patient care.
Coulter, A. 2002. After Bristol: putting patients at the centre. *Quality & Safety in Health Care* 11(2): 186-8.	**Context** Political issues	The Bristol inquiry recommended that patients must be at the centre of the NHS and must be treated as partners by health professionals as 'equals with different expertise'. Appropriateness and outcome of care can be improved by engaging patients in treatment and management decisions. Safety could be improved and complaints and litigation reduced if patients were actively involved in their own care. Regular, systematic feedback from patients is essential to improve quality of care and for public accountability.
Sculpher, M.J., Watt, I. and Gafni, A. 1999. Shared decision making in a publicly funded health care system. *British Medical Journal* 319(7212): 725-726.	**Context** Political issues	This editorial focuses on tensions between shared decision making in clinical practice and provision of services across the health system. It describes a dilemma for clinicians: should they see themselves as the agent of the patient, focusing on the effectiveness of treatments, or of the healthcare system and the population it serves, focusing on affordability. The argument is that a more promising approach to lessening the conflict between the doctor and patient is to make a clear distinction between clinical guidelines, which inform doctors (and, through them, their patients) about the health related attributes of treatments, and system guidelines, which indicate which treatments the system will fund.

McIver, S. and Brocklehurst, N. 1999. Public involvement: working for better health. *Nursing Standard* 14(1): 46-52.	**Context** Political issues	In this article, the authors explore the concept of public involvement in health service development, what it means and what techniques are being used to increase it. The aim of this article is to increase nurses' understanding of the ways in which the public can be involved in health service planning and development. In particular, it explores what public involvement means and what approaches and techniques are being used to engage the public more effectively in shaping the 'new' NHS.
Lapsley, P. 2004. Public involvement in health care. Public involvement is needed at highest level. *British Medical Journal* 328 (462).	**Context** Political issues	This letter comments on the work of Florin and Dixon to bring coherence and clarity to public involvement. It adds two further points. Firstly, the more devolved and local public involvement in *Health Policy* development becomes the more the government's national strategy and targets become givens. If governments wish to provide the sort of health care people want, public involvement in health strategy development is needed at the highest level. Secondly, a tendency prevails to see public involvement as something separate from the rest of *Health Policy* development instead of an integral part of it. An example exception to this is provided from the Action on Dermatology programme.
Anthony, P. and Crawford, P. 2000. Service user involvement in care planning: the mental health nurse's perspective. *Journal of Psychiatric and Mental Health Nursing* 7(5):425-34.	**Context** Political issues	This paper states that a dissonance between espoused values of consumerism within mental health care and the 'reality' of clinical practice has been firmly established in the literature, not least in terms of service user involvement in care planning. The main findings of this qualitative study, which uses semi-structured interviews, suggest that mental health nurses value the concept of user involvement but consider it to be problematic in certain circumstances. The study reveals that nurses hold similar views about the 'meaning' of patient involvement in care planning but limited resources, individual patient characteristics and limitations in nursing care are the main inhibiting factors. Factors perceived as promoting and increasing user involvement included: provision of accurate information, 'user-friendly' documentation, and mechanisms for gaining service user feedback, and high staff morale.
Higgins, R. 1993. Citizenship and user-involvement in health provision. *Senior Nurse* 13(4): 14-16.	**Context** Political issues	This paper explores the extent to which certain citizens and health care users formerly excluded from 'everyday activities' are not involved in service development and provision. The paper describes the development of a number of different types of advocacy; professional (individual) advocacy, self-advocacy, citizen advocacy. The project that is reported highlighted a number of challenges faced by nursing staff including scepticism about citizenship and representation and the credibility of patient stories.

Fox, J. 2003. Consumerism 1: the different perspectives within health care. *British Journal of Nursing* 12(5): 321-6.	**Context** Political issues (capacity)	This is the first of two articles by the authors which collectively consider the evolving concept of 'consumerism' within the NHS and the degree to which this can be seen as having informed pre registration nursing and midwifery education within England. The article considers the nature of consumerism in relation to the health service. It seeks to explore the place of consumerism within the NHS reforms heralded in 2000, while acknowledging that as a concept it remains problematic. The potential distinction between the individualistic and more collectively based notion of consumerism is highlighted. Finally, the article suggests that in order to adopt fully the consumer ethos in the NHS - more latterly redefined as a user- or partnership-based service - appropriate resources and education are required.
Perkins, R., Goddard, K. 2004. Reality out of the rhetoric: increasing user involvement in a mental health trust. *The Mental Health Review* 9(1): 21-24.	**Context** Political issues	This paper describes how one mental health Trust in South West London has attempted to increase user participation and involvement in planning and developing services, operation of services and care planning and delivery.
Rhoades, D.R., McFarland, K.F. and Knight, P.G. 1995. Evolution of consumerism in rehabilitation counselling: a theoretical perspective. *Journal of Rehabilitation* 61(2): 26-9.	**Context** Political issues	This article focuses on consumerism in rehabilitation counselling. It provides a historical perspective of disability in society and the ‘new paradigm’ of consumerism. The article identifies pros and cons of consumerism in the context of rehabilitation services.

Segal, L. 1998. The importance of patient empowerment in health system reform. *Health Policy* 44(1): 31-44.	**Context** Political issues	This paper explains that health system reform is on the agenda in Australia, across Europe and North America and elsewhere. Reform is being driven by attempts to meet ever-increasing health service demands in the face of cost containment pressures. There is little agreement concerning the preferred features of health funding models. A micro-economic framework is used to define universal performance characteristics for optimal health funding arrangements. Two principle requirements emerge. These are i) demand side reform to empower consumers and ii) supply side reform, to promote opportunities and incentives for a responsive service system and competition among providers. The paper argues that a focus on supply side issues only, without recognition of the fundamental importance of consumer empowerment, will fail to promote an efficient solution to the distribution of health resources.
Newman, J., Barnes, M., Sullivan, H. and Knops, A. 2004. Public participation and collaborative governance. *Journal of Social Policy* 33(2): 203-223.	**Context** Political issues	This paper draws on the findings of a study within the ESRC's Democracy and Participation Programme. It explores the processes of participation within deliberative forums – such as user panels, youth forums, area based committees – developed as a means of encouraging a more active, participating mode of citizenship and of improving welfare services by making them more responsive to users. The findings open up a number of issues about constraints on the development of ‘collaborative governance’. To understand these constraints, the authors suggest, there is need to locate participation initiatives in the context of government policy, to explore ways in which such policy is interpreted and enacted by strategic actors in local organisations and to examine the perceptions of members of deliberative forums themselves. The findings highlight the constraints on the ‘political opportunity structures’ created by the enhanced policy focus on public participation, and the consequent limits to ‘collaborative governance’. The authors discuss how governance theory and social movement theory can each contribute to the analysis, but also suggest productive points of engagement through which each of these bodies of theory might enrich the other.
Ford, R.C. and Fottler, M.D. 2000. Creating customer-focused health care organizations. *Health Care Management Review* 25(4): 18-33.	**Context** Professional issues	The authors of this article argue that most health care organisations are operating under an ‘old paradigm’ wherein the needs of physicians and third party payers drive the organisation. In the current hypercompetitive health care markets, executives need to focus more directly on their increasingly assertive and knowledgeable patient customers. This article describes practices of the best guest-services organisations that may be transferable to health services organisations. It also proposes ten principles that constitute the ‘new paradigm.’

Florin, D. and Dixon, J. 2004. Public involvement in health care. *British Medical Journal* 328(7432): 159-161.	**Context** Political issues	The authors of this article believe that the NHS needs to be clear about the aims of patient and public involvement in health care and how to achieve them. They describe government policy to allow the public to elect members of the governing boards of foundation trusts and primary care trusts. The authors identify that public involvement and other allied terms are used to mean a variety of activities or objectives. The article identifies a number of reasons why public involvement is desirable. However, the authors argue that the aims of public involvement in health care need to be more clearly thought out. If the goal is greater democratic input, more clarity is needed about the type of decisions for which public involvement is most appropriate, the methods that are most effective and cost effective, and how different initiatives complement each other. If greater responsiveness of services is the goal, greater public involvement may not be the most effective policy, at least by itself. Other approaches, such as involving individual patients more in choices about their health care decisions, may be more promising. However, the opportunity cost of achieving other desirable objectives in the NHS, such as equity and efficiency, will need to be clearly spelt out.
Maslin-Prothero, S. 2000. The rhetoric of user participation in health care. *Nurse Education Today* 20(8): 597-599.	**Context** Political issues	This editorial concerns current policy trends for collaboration and partnership in relation to improved health and social care. This incorporates user involvement in a range of relationships between those providing health care and social services and those who receive them, from simple information giving through to participation in decision-making. User involvement can range from activity in patient associations to commissioning health and social services. The author describes the need to monitor performance and the problems associated with good intentions, such as reduction of waiting lists for surgery, can distract from the prime focus of those providing services. 'Good' user participation policy will help in providing the greatest benefit to others including stakeholders, while 'bad' policy will divert the energy of staff into either negative or self-serving ends. There needs to be an acknowledgement that learning and problem solving may be more efficient using a 'bottom up' approach and effective user involvement could be one way forward. However, it cannot be assumed that activities to promote participation will always result in beneficial effects. There is a need to vigorously research and evaluate these interventions to discover the full extent of their effectiveness.

Barnes, M. and Walker, A. 1996. Consumerism versus empowerment: a principled approach to the involvement of older service users. *Policy and Politics* 24(4):375-394.	**Context** Political issues	This article critically evaluates a particular approach to user involvement and user empowerment adopted by the British Government. It argues that consumerism is a shallow model of involvement in contrast with genuine empowerment. The article contains an outline of eight key principles according to which the empowerment of service users could be realised. An example is used to show how to achieve the empowerment of frail older people. The principles developed are: 1) Empowerment should enable personal development as well as increasing influence over services. 2) Empowerment should aim to increase people's abilities to take control of their lives as a whole, not just increase their influence over services. 3) Empowerment of one person should not result in the exploitation of others: either family members or paid carers. 4) Empowerment should not be viewed as a zero sum: a partnership model should provide benefits to both parties. 5) Empowerment must be reinforced at all levels within service systems. 6) Empowerment of those who use services does not remove the responsibilities of those who produce them. 7) Empowerment is not an alternative to adequate resourcing of services. 8) Empowerment should be a collective as well as an individual process; without this people will become increasingly assertive in competition with each other.
Croft, S. and Beresford, P. 1996. The politics of participation. In: Taylor, D. (Ed.) *Critical Social Policy: A reader* (pp. 175-198). London: Sage.	**Context** Political issues	Discusses the politics of participation in Western society.
Hubbard, G., Wilkinson, H. and Petch, A. 2004. Users or Losers: Does the rhetoric of user involvement deliver? *Research Policy and Planning* 22(1): 53-56.	**Context** Political issues	This paper describes how user involvement means different things to different people. Users can be involved in both the planning of health services and in the conduct of health services research. Not all user groups have the same opportunities for involvement and little is known as to the impact that user involvement has, both on services and on the individual. Until clearer evidence is available, it remains uncertain wither users are being involved because it fits the rhetoric or because it will make a difference. The paper concludes by stating that if patient and public involvement in NHS research and development is to advance, then increasing numbers of service users, health professionals and researchers need to possess the skills and resources to make this happen. This means utilising existing guidance, expanding training and changing organisations to facilitate user involvement so that capacity is developed in ways that are sustainable. There is a need for evidence that demonstrates user involvement benefits services and patients to overcome cynicism and disillusion.

Kuss, T., Proulx-Girouard, L., Lovitt, S., Katz, C.B. and Kennelly, P. 1997. A *Public Health Nursing* model. *Public Health Nursing* 14(2): 81-91.	**Context** Professional issues	This paper argues that *Public Health* nurses are in a strategic position to maintain, promote, and protect the health of populations both now and in the future. In the changing health care environment of the 1990s, defining the expanding and evolving role of *Public Health Nursing* assists in the effective utilisation of *Public Health* nurses. During a time when the health care environment is emphasising the protection and promotion of health, access to health services, and prevention of illness, it is necessary for *Public Health* nurses to be in the forefront in the changing focus to primary prevention. Therefore, a model for *Public Health Nursing* is proposed to provide a framework for defining *Public Health Nursing* roles and practice.
Watts, R.J. 1990. Democratization of health care: challenge for nursing. Advances in *Nursing Science* 12(2): 37-46.	**Context** Professional issues	This discussion paper focuses on community development as one of the key foundational principles of primary health care. It argues that the implementation of meaningful community involvement requires democratic institutions and processes within the health care system. In this context the meaning of substantive democracy and the implications of this concept for the health care system are briefly discussed. The relationship between the purpose, values, and foundational concepts of democracy and those of nursing is examined in greater detail. Based on the congruency between these, the role of nursing in generating and enhancing democratic processes within the health care system is examined and a model of nursing practice proposed.
Scott, C. and West, E. 2001. Nursing in the public sphere: *Health Policy* research in a changing world. *Journal of Advanced Nursing* 33(3): 387-395.	**Context** Research issues	The aim of this study was to identify recent trends in the academic field of *Health Policy*, setting them in the context of wider changes in the socio-political and research environments and considering their implications for nursing research. *Health Policy* is a well-established field of academic study and research in the United Kingdom. The 1990s have seen some important intellectual developments in this field, as well as some major changes in the context of health-related research. A selective review of the relevant literature shows that the Department of Health's Research & Development strategy can be understood as part of a wider trend, moving away from the traditional, university- based model of knowledge production towards a new one which involves other groups, such as employers, practitioners and patients. The authors argue that this may increase the opportunities for health care professionals in general - and nurses in particular - to influence the research agenda and to participate as researchers in the critical evaluation of *Health Policy*.

Logan, H.L. 1997. The patient and the shifting health-care paradigm. *Journal of the American College of Dentists* 64(1): 16-8.	**Context** Professional issues	The topic of this paper is the public's perception of the relationship between the health care provider and patients. The authors state that this relationship was once seen by the public as being based on trust, compassion, and good will and now is viewed as much more subject to negotiation. The public's perception of dentists and physicians is that they have been seduced by technology, money, and specialisation and that they have little time for patients' concerns, wants, and needs. Moreover, there has been a dramatic expansion of patient choice including treatment alternatives and providers. Never before have patients had access to so much information (and misinformation) about treatment, options, materials, and alternatives. The authors argue that these factors contribute to a growing discontentment among patients and practitioners.
Gatterman, M.I. 1995. A patient-centered paradigm: a model for chiropractic education and research. *Journal of Alternative and Complementary Medicine* 1(4): 371-86.	**Context** Research issues	The purpose of this study was to identify, interpret, and describe a paradigm for chiropractic education and research. The paper argues that patient-cantered research must reach beyond the randomised controlled trial, involving designs where clinicians apply their own patient-centered therapy in a 'real world' assessment. A pluralism of methods, including both qualitative and quantitative studies, needs to be designed and implemented. Patient-centered research is a process that is pragmatic, realistic, and grounded in the day-to-day experiences of both patients and clinicians.
Nolan, M., Hanson, E., Magnusson, L. and Andersson, B. 2003. The Aldre Vast Sjuharad model revisited. *Quality in Ageing* 4(2): 22-27.	**Context** Research issues	This article outlines a model for gauging the quality of a partnership approach to research that was developed for use in a Research Centre in West Sweden. The Aldre Vast Sjuharad Centre has as its main goal the promotion of partnerships between older people and their families, service providers and researchers. In pursuing these goals the Centre adopts broadly constructivist approach to undertaking research that is 'authentic' and meaningful to those who take part. In order to make judgements about the quality of its activity the Centre has adapted the quality criteria originally suggested by Guba and Lincoln (1989), so that they are more readily understood by older people, cares and service providers. These criteria can be applied at all stages of research activity, and it is suggested that they can be utilised more widely in order to make inferences about the effects of partnership working in other contexts.

Abelson, J., Forest, P., Eyles, J., Smith, P., Martin, E. and Gauvin, F.P. 2003. Deliberations about deliberative methods: issues in the design and evaluation of public participation processes. *Social Science and Medicine* 57(2): 239-51.	**Context** Research issues	A common thread weaving through the current public participation debate is the need for new approaches that emphasise two-way interaction between decision-makers and the public as well as deliberation among participants. The authors of this paper argue that increasingly, complex decision making processes require a more informed citizenry that has weighed the evidence, discussed options and arrived at a mutually agreed upon decision or at least one by which all can abide. The authors explore the recent fascination with deliberative methods for public involvement first by examining their origins within democratic theory, and then by focusing on the experiences with deliberative methods within the health sector. They answer the following questions 'What are deliberative methods and why have they become so popular? What are their potential contributions to the health sector?' The authors use this critical review of the literature as the basis for developing general principles that can be used to guide the design and evaluation of public involvement processes for the health-care sector in particular.
Boote, J., Telford, R. and Cooper, C. 2002. Consumer involvement in health research: a review and research agenda. *Health Policy* 61: 213-36.	**Context** Research issues (meanings, political issues, roles and activities)	This key paper critically reviews the state of current knowledge on consumer involvement in health research, and maps out a research agenda with the aim of stimulating systematic, empirical inquiry. It discusses definitions of 'the consumer'; considers why their involvement is believed to be important to health research; traces the development of the policy; analyses epistemological and methodological implications; discusses the various levels of consumer involvement in research; and outlines the objections that have been put forward by clinicians and researchers. Four questions were identified during the review as being in need of theoretical and empirical attention: (1) how can consumer involvement in health research be further conceptualised? (2) how and why does it influence health research? (3) how can the influence of consumers in health research be measured and evaluated? (4) what factors are associated with 'successful' consumer involvement in health research?
Rovers, R. 1986. The merging of participatory and analytical approaches to evaluation: implications for nurses in primary health care programs. *International Journal of Nursing Studies* 23(3): 211-9.	**Context** Research issues (political issues, methodology)	This paper addresses the need to make evaluation part of the nurse's expanded role within the primary health care system. It argues that in a social policy and decision-making context, the nurse is an intermediary between political authorities and community groups. This requires diverse, but complementary, evaluation skills. The author proposes a dual method of evaluation for community health programs, incorporating an objective-stance Logical Framework Analysis Model, to meet agencies' needs for program effectiveness and impact data, and a Participatory Evaluation approach, to recognise the ability of communities to judge whether health services are responsive to their needs. The nature and application of both methods within an International Primary Health Care context are explored. The paper concludes that access to a wide spectrum of evaluation data places the nursing profession in a challenging position to influence policy decisions related to health services.

Stainton, M.C., Harvey, S., McNeil, D., Emmanuel, E., Johnson, C.M. 1998. The transforming power of research on practice: involving practitioners in analysis. *International Journal of Nursing Practice* 4(4): 220-4.	**Context** Research issues	This paper reports on a phenomenological study that involved nurses in the interpretation of transcribed interviews. The nurses were invited to work with the investigators in learning and using hermeneutic methods to identify and interpret the meanings embedded in exemplars. Their expert clinical knowledge of the field of practice added rigor to the analytical process and depth to the understanding achieved. The authors report that as the analysis progressed, the nurses began to spontaneously describe transformation occurring in their practice. Involving nurses in data analysis has transformative power on practice.
Seng, J.S. 1998. Praxis as a conceptual framework for participatory research in nursing. Advances in *Nursing Science* 20(4): 37-48.	**Context** Research issues	Nursing scholars have often called upon the concept of praxis to inspire and inform their work. This article derives from praxis a conceptual framework for participatory nursing research. A praxis model cannot only guide research, but it can also provide congruent ways to assess the quality of the project and ensure that researchers are accountable to the needs of the groups they study. The intellectual history of the term provides grounding for activist, collaborative, constructive science. Along with K. Marx's and P. Freire's definitions-in-use, this article presents descriptions of components that are specific to the tasks of participatory research. A review of epistemic considerations makes the argument that it is possible to justify research based on a praxis-oriented framework.
Chappell, A.L. 2000. Emergence of participatory methodology in learning difficulty research: understanding the context. *British Journal of Learning Disabilities* 28(1): 38-43.	**Context** Research issues	This paper examines methodological debates in disability research. The author discusses the reasons why participatory methods are gaining greater acceptance than emancipatory methodology among learning difficulty researchers by examining the position of participatory research in the methodological traditions of social research into learning difficulty.

Parry, O., Gnich, W. and Platt, S. 2001. Principles in practice: reflections on a 'post-positivist' approach to evaluation research. *Health Education Research* 16(2): 215-226.	**Context** Research issues	In this study lay interviewers participate in an evaluation. The authors describe the conflicts between their perceptions of crossing between interpretive and positivist research paradigms.
Kearney, M.H. 2001. Focus on research methods. Levels and applications of qualitative research evidence. *Research in Nursing and Health*. 24(2): 145-53.	**Context** Research issues	This discussion paper describes five categories of qualitative findings, each vary in their levels of complexity and discovery: those restricted by a priori frameworks, descriptive categories, shared pathway or meaning, depiction of experiential variation, and dense explanatory description. Four modes of clinical application of qualitative evidence are proposed-insight or empathy, assessment of status or progress, anticipatory guidance, and coaching-that vary in their degree of visibility and patient involvement. The authors argue that the greater the complexity and discovery within qualitative findings, the stronger may be the potential for clinical application. This suggests that qualitative studies that make use of patient involvement may have stronger influence in clinical settings.
Larson, E. 1993. *Nursing Research* and societal needs: political, corporate, and international perspectives. *Journal of Professional Nursing* 9(2): 73-8.	**Context** Research issues (political issues)	The focus of this paper is the perceived tension between political and public pressure for fiscal constraint in health care expenditures and the scientific community urging greater allocation of research funds. The authors argue that some people contend that scientists are out of touch with the rest of society. This issue is discussed from the political, corporate, and international perspectives. The authors claim that nurse researchers need to examine their priorities and determine whether they are congruent with societal need. Increased interaction with the public, increased involvement with the federal decision making process, and the building of research consortia and collaborative endeavours are recommended.
Clarke, C. and Ramprogus, V. 2001. A new way to link research. *Nursing Times* 97(19): 37-8.	**Context** Research issues	This paper describes how partnerships between higher education and the NHS can be problematic. It contributes to the debates about the way in which research is perceived in society.

Clarke, C. and Procter, S. 1999. Practice development: ambiguity in research and practice. *Journal of Advanced Nursing* 30(4): 975-82.	**Context** Research issues (methodology)	This study based on consultation with health care researchers and practitioners explored the implications of the ambiguous position practice development activity occupies in relation to both clinical practice and research. In practice, it is seen at times as an added extra to normal work despite arguably being an inherent part of professional practice. In research, it fails to demonstrate the rigour of being generalisable because of its explicit location in a specific care environment. The results demonstrate how people manage themselves and the uncertainty that surrounds the use of research in clinical practice. The paper argues for an appreciation of reflexive forms of research, such as action and practitioner research, which do not disassociate research and practice and in which practitioners have a role in knowledge creation as well as knowledge implementation. The paper adds to arguments that participative methodologies can help to bring research closer to clinical practice.
Taylor, J.S. 1993. Resolving epistemological pluralism: a personal account of the research process. *Journal of Advanced Nursing* 18:1073-1076.	**Context** Research issues (researcher skills)	In this paper, the author seeks to address issues of personal and professional development that may occur during the research process. It argues that while research reports abound in the nursing literature, this personal aspect is often neglected. As we seek to encourage research awareness within the profession, many student and qualified nurses now produce a small research project, and this often concentrates on measurable outcomes. By examining her own perceived learning in resolving epistemological pluralism while undertaking such a project as a tutor student, the author has attempted to resolve the problem of ignoring the personal. The author claims that increased self-awareness can enhance nursing professionalism.
Chalmers, K.I. and Bramadat, I.J. 1996. Community development: theoretical and practical issues for community health nursing in Canada. *Journal of Advanced Nursing* 24(4): 719-26.	**Context** Research issues (methodology, researcher skills)	This paper provides background information on the historical origins of community development work. It draws on an extensive review of the literature. It shows that despite the importance currently given to community development as an increasingly significant role for community nurses, there is little analysis of the role in the nursing literature. Four models of community development are synthesised from literature in sociology, social psychology, education and political science - economic development, educational (both formal and informal), confrontational and empowerment models. The relevance for community health nursing practice is critiqued. Finally, issues which may arise when community health nurses attempt to practice within a community development model are discussed. Issues are examined related to the structures of organisations in which nurses work, characteristics of nurses themselves, and the communities they serve. The argument is advanced that despite the pitfalls and problems, this new role shows promise as an important mechanism for community health nurses to promote the community's health. However, much additional work will be needed to test out models for community development in actual practice. Evaluation of the role will also be important to determine the degree to which it can be implemented and the resultant health outcomes for the population.

Beresford, P. 2003. User involvement in research: exploring the challenges. *Nursing Times* Research 8(1): 36-46.	**Context** Research issues - funding, recruitment and representation Impact	This paper looks at the issue of user involvement in research and evaluation. It makes links to discussions about research governance and research ethics. The author discusses the regressive and liberatory potential of user involvement in research, together with the ideological relations of such research. Competing strands in its development and approach are identified. The paper challenges assumption that user involvement in research is a monolithic idea. A case is made for more equal access to funding for user-controlled research. The paper calls for systematic development and evaluation of user involvement in research, both to identify its strengths and weaknesses and to support its most effective development.
Gilbert, T. 2004. Involving people with learning disabilities in research: issues and possibilities. *Health and Social Care in the Community* 12(4): 298-308.	**Context** Research issues (methodology, researcher skills)	The focus of this discussion paper is the increasing inclusion of views and opinions of people with learning disabilities in research and evaluation studies. New possibilities and new challenges for researchers are described. The present paper sets out to explore some of the developments and challenges in research with people with learning disabilities. The author provides a selective overview of developments with the aim of demonstrating the richness, ingenuity and potential of research involving people with learning disabilities. The paper is divided into three broad sections that focus on: (1) the ethics and philosophy of participatory research; (2) the methodologies employed at particular points in the research process that are designed to ensure the involvement of participants in research; and (3) building capacity in participatory research as a precondition to the further development of this approach. The author argues that an investment in capacity would enable this approach to move into the mainstream of research activity involving people with learning disabilities.
Edwards, C. and Titchen, A. 2003. Research into patients' perspectives: relevance and usefulness of phenomenological sociology. *Journal of Advanced Nursing* 44(5): 450-460.	**Context** Research issues	The aim of this paper is to find a close fit between a study's research questions and a theoretical perspective with which to underpin the research. It describes the benefits of identifying a specifically relevant perspective, in this case phenomenological sociology, and discusses the potential of that particular perspective to underpin research in health care. The authors claim that the particular strengths of phenomenological sociology relevant to the investigation of patients processes of reflection are in highlighting the importance of subjectivity; its insistence on a clear link from theoretical development right back to the raw data; its wealth of evocative ideas and concepts that support the investigation of the development of interpretation; and the relatively accessible language and style of its texts.

Eckenwiler, L.A. 1999. Pursuing reform in clinical research: lessons from women's experience. *Journal of Law, Medicine & Ethics* 27: 158-70.	**Context** Research issues	This author argues that attention should turn toward the myriad social and institutional structures, relations, and processes that are embedded in and related to clinical research that can tarnish social equality and undermine persons' self-determination. Women's experiences with clinical research are ideally suited to demonstrate the importance of this because of their capacity to highlight how features of social and institutional context—norms, unquestioned assumptions, stereotypes, and economic structures—can constrain or enhance persons' capacities to lead healthy lives and to determine their actions and the conditions of their actions. The author argues that three reforms are of special importance: (1) critical attention to differences in research policy and practice; (2) democratising decision making; and (3) transforming the system for distributing research resources. Crucial to these reforms is the cultivation of conditions that enhance social equality and the self-determination of participants or, more generally, that promote social justice.
Seymour, J. and Skilbeck, J. 2002. Ethical considerations in researching user views. *European Journal of Cancer Care* 11: 215-219.	**Context** Research issues (methodology)	In this paper the authors begin by stating that current systems for treatment reflect inadequately the experiences and concerns of cancer patients. The paper examines the process of accessing user views about cancer and palliative care from an ethical perspective, drawing on a study of outcomes associated with Macmillan nursing. A moral theory framework is used to discuss some of the issues involved in trying to achieve ethically sound practice and some essentially political issues that frame the process of accessing users' views are highlighted. The paper recommends that models of research be developed for accessing user views that are congruent with the values and philosophies of supportive and palliative care. This requires striking a fine balance between the ethical duties of providing care and support, nurturing independence and autonomy, and achieving research outcomes that are rigorous while also being accessible and meaningful to users. It also requires developing an understanding of the social, political and economic context of research enquiry with users.

O'Donnell, M. and Entwistle, V. 2004. Consumer involvement in decisions about what health-related research is funded. *Health Policy* Dec 70(3): 281-90.	**Context** Commissioning	This paper considers whether, why and how research funders involve consumers in decisions about what health-related research is funded. A postal survey and semi-structured interviews were used with UK funders of health-related research. The survey showed that organisations that fund research have diverse goals and remits, and perceive themselves to be accountable in different ways and to different groups. They have a variety of reasons for involving consumers in decisions about what research is funded, but also a number of concerns about doing so-particularly about the ways in which consumer input might 'distort' the research agenda. Research funders use several types of decision-making structures and processes to identify and prioritise topics in which they want to invest and to select between research proposals. They involve consumers in these structures and processes in diverse ways. Little is known about the actual effects of this involvement, but the nature and extent of consumer influence on the research agenda is likely to be moderated by a number of factors, including the types of consumers involved, the particular structures and processes in which they are involved, the timing of their input and the different ways in which they are asked to contribute in relation to others. Diverse research funding organisations are now involving consumers in the various approaches that they take to identify and prioritise research topics and to decide which proposals they will fund. The future development of their activities could usefully be informed by careful consideration not just of consumer involvement but of the implications of the various structures and processes that shape research agendas. The appropriateness of particular forms of consumer involvement should be considered in the broader context of the features of the whole research funding system, including the values implicit within it.
Couldrick, L. 2000. Consumer involvement in research: reflections of a professional. *British Journal of Therapy & Rehabilitation* 7(7): 294-302.	**Context** Political Philosophical Meanings Roles	This paper describes a shift in health and social care research from studies about consumers to collaborative research undertaken with consumers. This view is set in the wider context of consumer involvement, political will, professional power and dominance. Different ways of involving consumers in research and its advantages and disadvantages are discussed. It refers to government policy base for user involvement in service delivery and provides a useful critique of consumer feedback via 'satisfaction surveys' identifying power as a key issue. The paper states that meaningful involvement means equal partnership at every stage of research. The paper identifies feminism as a suitable underlying philosophy and argues that feminism can bring appropriate data collection methods and collaborative working methods. A variety of issues are raised about difficulties for consumers and professionals.

Fawcett Henesy, A. 1988. Consumers and research into primary care part II. *Nursing Review* 4(4): 11-13.	**Context** Professional issues	The author of this paper is concerned that the nursing profession is under threat because other groups of people and professionals are increasingly being involved in delivering care and that consumers will increase their efforts to become independent of those parts of a health care system which itself appears uncertain about its practice. The author says that to avoid this, nurses must understand their own roles and inter-relationships at a conceptual level and avoid unnecessary duplications of practice and training. She argues that the profession needs to establish what the consumer wants, how to educate them to make that decision in an informed manner, how to generate the resources to meet those demands and most of all how to leave the consumer in the position where they are able to control and contribute to their health care.
Burke, A. 2000. The NHS Plan: stifling the patient's voice? *British Journal of Community Nursing* 5(11):528.	**Context** Professional issues	This editorial discusses chapter 10 of the NHS Plan to establish a 'package of radical reform' in the light of the abolition of Community Health Councils. It describes how fears about the future of the NHS' only patient-led watchdog brought together a coalition of groups, including patient organisations, the General Medical Council, and the Law Society.
Coulter, A. 1999. Paternalism or partnership? *British Medical Journal* 319(7212): 719-720.	**Context** Professional issues	This editorial states that paternalism is endemic in the NHS. Benign and well-intentioned it may be, but it has the effect of creating and maintaining an unhealthy dependency, which is out of step with other currents in society. The author argues that successful partnerships are non-hierarchical and partners share decision-making and responsibility. The key to successful doctor-patient partnerships is to recognise that patients are experts too. Several hurdles need to be overcome. Little is known about the readiness of patients to take on decision-making responsibility. Evidence exists that many patients do have strong treatment preferences, these are not always predictable, and that doctors often fail to understand them, but some patients may not want to have an active role thrust on them.
Patistea, E. and Siamanta, H. 1999. A literature review of patients' compared with nurses' perceptions of caring: implications for practice and research. *Journal of Professional Nursing* . 15(5): 302-12.	**Context** Professional issues	This paper describes the conceptualisation of nursing as a caring profession. Caring is a salient feature of nursing practice and has been studied extensively from the nursing perspective. Nonetheless, little has been forthcoming in relation to patients' perceptions of the meanings and processes of caring. This literature review shows that whereas nurse clinicians focus on the psychosocial aspects of caring, patients assign the highest value to technical skills and professional competence. Non-caring behaviours include physical and emotional absence, belittling and inhumane actions, and lack of recognition of a patient's uniqueness. Patients' participation in decisions regarding their care may or may not be an element of a caring interaction.

Bournes, D.A. 2000. A commitment to honoring people's choices. *Nursing Science Quarterly* 13(1): 18-23.	**Context** Professional issues	This paper is concerned with the increased emphasis on honouring personal choice, movement away from paternalism and medical models of care.
Beardwood, B., Walters, V., Eyles, J. and French, S. 1999. Complaints against nurses: a reflection of 'the new managerialism' and consumerism in health care? *Social Science & Medicine* 48(3):363-374.	**Context** Professional issues	The paper discusses the effects of restructuring on nursing as a profession through an examination of the issue of complaints in Canada. It is argued that new managerialist techniques and associated changes in the nature of work are reducing the autonomy of nurses and making it difficult for them to meet the standards of their profession. Simultaneously, the Ontario government has increased the power of the public in the disciplinary process and the College of Nurses of Ontario is encouraging patients to register their complaints. The paper argues that the growth of consumerism in health care, coupled with the disciplinary process, individualises complaints and deemphasises their relationship to restructuring. Moreover, in response to the increasing number of complaints (complaints which more often come from the public) nursing organisations have encouraged the legalisation of the disciplinary process, thus fostering the individualisation of the issues.
Lindsey, E., Stajduhar, K. and McGuinness, L. 2001. Examining the process of community development. *Journal of Advanced Nursing* 33(6): 828-35.	**Context** Professional issues	This study provides evidence of how one organisation successfully engaged the broader community on a respite care project. Using qualitative research methods and guided by the principles and practices of participatory action research, this evaluation engaged with the community in data collection, analysis, dissemination of finding, and in promoting effective change. Four themes emerged that provide insight into how one HIV/AIDS organisation successfully undertook community development. These themes include: (a) identifying a community need; (b) addressing the various components identified in the community development process; (c) highlighting the strategies used to engage in successful community development; and (d) attending to factors that influence community development. The results of this research contribute to the body of knowledge related to engaging in the process of community development.

Bensing, J. 2000. Bridging the gap: the separate worlds of evidence-based medicine and patient-centered medicine. *Patient Education and Counselling* 39(1):17-25.	**Context** Research issues	Modern medical care is influenced by two paradigms: 'evidence-based medicine' and 'patient-centred medicine', both of which have gained in popularity and influence in the last decade. However, careful analysis shows that they focus on different aspects of medical care and have, in fact, little in common. Evidence-based medicine is a rather young concept that entered the scientific literature in the early 1990s. It has basically a positivistic, biomedical perspective, offering clinicians the best evidence about the most adequate treatment for their patients, considering medicine merely as a cognitive-rational enterprise. In this approach the uniqueness of patients and their requirements are easily neglected as relevant factors. Patient-centred medicine has a humanistic, biopsychosocial perspective, combining ethical values on 'the ideal physician', with psychotherapeutic theories on facilitating patients' disclosure of real worries, and negotiation theories on decision-making. It puts a strong focus on patient participation by taking into account the patients' perspective, and tuning medical care to the patients' needs and preferences. However, in this approach the ideological base is better developed than its evidence base. In modern medicine both paradigms are highly relevant, but yet seem to belong to different worlds. The challenge for the near future is to bring these separate worlds together. The aim of this paper is to give an impulse to this integration. Developments within both paradigms can benefit from interchanging ideas and principles from which eventually medical care will benefit. In this process a key role is foreseen for communication and communication research.
Cowley, S. 2001. Health visiting. *National Association of Primary Care Annual Review* 1.	**Context** Professional issues	This paper provides information about the profession of health visiting. It explains the role and function of health visitors such as home visiting, community outreach and the role of health visiting in primary care.
Abdel-Tawab, N. and Roter, D. 2002. The relevance of client-centred communication to family planning settings in developing countries: lessons from the Egyptian experience. *Social Science and Medicine* 54: 1357-1368.	**Context** Professional issues	This paper describes changes in clinical practice and the emergence of client centred communication.

Table 2 Methods issues

Full reference	Topic code	Contribution to the debate
Sterling, Y.M. 2001. The clinical imperative in clinical nursing research. *Applied Nursing Research* 14(1): 44-47.	**Methods** Purpose	This paper relates to the design of research projects. It states that clinical nurse investigators cannot generate relevant questions to study a current phenomenon with which they are not experienced and that the nurse researcher's early involvement in the clinical world helps to design a study that has rigor and significance, but it also augments a commitment to the improvement of patient outcomes.
Birchall, M., Richardson, A. and Lee L. 2002. Eliciting views of patients with head and neck cancer and carers on professionally derived standards for care. *British Medical Journal* 324(7336): 516-519.	**Methods** Purpose	This paper examined patients' and carers views on the process of care for people with head and neck cancer; to assess whether focus groups are useful in this setting; to compare priorities and standards identified with those published by healthcare professionals; and to incorporate the expressed views into existing national standards. It draws on the findings of a multi-centre study of nine regional focus groups in an area covered by two regional health authorities. Participants were 40 patients who had had head and neck cancer and 18 carers. The main outcome measures were views of individuals and groups on standards. Opinions were expressed on waiting times, information available to patients, coordination of care, and crisis management. Professionally-derived standards were substantially improved by the incorporation of the views of patients and carers. Occasionally, participants said that the meetings were therapeutic. The paper shows that well facilitated and analysed focus groups are effective in assessing views of patients with cancer and carers on professionally derived standards for care and can be applied in settings traditionally viewed as difficult. The authors feel that views expressed by patients and carers are powerful motivators for change in the delivery of cancer care.
Fisher, B., Neve, H. and Heritage, Z. 1999. Community development, user involvement, and primary health care. *British Medical Journal* 318(7186): 749-750.	**Methods** Purpose	This article argues that the government has provided little conceptual, managerial, or financial infrastructure for public involvement, in the context of primary care trusts. Public meetings are the only mechanism for consultation mentioned in the government white paper—yet these are an inadequate means of genuinely engaging communities in the health issues that matter to them, particularly for marginalised groups. One solution is for primary care to work with community development projects, which have been tackling these issues for years. Community development recognises the social, economic, and environmental causes of ill health and links user involvement and commissioning to improve health and reduce inequalities. Community development techniques could help primary care groups develop decision-making processes that truly involve users.

Williamson, G.R. and Prosser, S. 2002. Action research: politics, ethics and participation. *Journal of Advanced Nursing* 40(5): 587-93.	**Methods** Purpose (ethics, methodology)	This paper contributes to an understanding of the political and ethical aspects of action research. The authors argue that action researchers and participants working in their own organisations should be clear about the extent to which they are engaged in a political activity, and that action research does not offer the same ethical guarantees concerning confidentiality and anonymity, informed consent, and protection from harm as other research methodologies. The authors outline three areas where action research is implicitly political, and three areas where it is ethically problematic. And, recommend that researchers and participants recognise, discuss and negotiate these problematic areas before starting their work.
Anderson, W. and Florin, D. 2000. Consulting the public about the NHS. *British Medical Journal* 320:1553-1554.	**Methods** Roles and activities	This author describes a national public consultation about how NHS funding should be spent. Twelve million leaflets with prepaid response forms were distributed through supermarkets, pharmacies, opticians, hospitals, and general practices, asking, ‘What are the top three things you think would make the NHS better for you and your family?’ ‘Census day’ was 31 May, when service providers were asked to actively encourage their users to fill in the leaflet. The public consultation process also included a website, two public forums, patient representation on the six action teams for modernisation, and meetings between patients' organisations and ministers. The author questions the lack of clarity of the aims and scope of the consultation, and says this will make it difficult to assess its impact. Meaningful consultation, especially at a national level, is complex, lengthy, and expensive. With its overly simplistic approach, the exercise may produce some useful ideas, but, at worst, it will undermine the long term partnerships which the NHS should be seeking to build with its own staff, its users, and the public.
Brooking, J. 1986. A survey of current practices and opinions concerning patient and family participation in hospital care. In Wilson-Barnett, J. and Robinson, S. (Eds). *Directions in Nursing Research*. Harrow: Scutari Press.	**Methods** Roles and activities	This study used questionnaire-based consultation with nurses, patient and relatives to examine current practices, opinions and attitudes towards patient and family participation in nursing. 107 nurses, 114 participants and 72 relatives at two London hospitals completed questionnaires. The results showed that the traditionally passive acquiescent patient role is still accepted by some patients and preferred by many nurses. However, patients' and relatives' roles are modified by factors such as social class, education, knowledge of the condition, age, anxiety and familiarity with the hospital environment.

Holloway, I. 1992. Patients as participants in research. *Senior Nurse*. 12(3): 46-7.	**Methods** Roles and activities	Discusses the concept of participation in nursing practice.
Gelling, L. 2000. Consumer involvement in research. *Nursing Standard* 15(4): 33.	**Methods** Roles and activities	This author argues that researchers need to change their attitudes towards research participants. And that, researchers must move from considering consumers as subjects to thinking of them as participatory collaborators in the search for knowledge and understanding.
Cleary, P.D. 1999. The increasing importance of patient surveys. *British Medical Journal* 319(7212): 720-721.	**Methods** Roles and activities (methodology)	Describes the growth in use of patient surveys as a method of involvement.
Griffiths, K.M., Jorm, A.F. and Christensen, H. 2003. Academic consumer researchers: A bridge between consumers and researchers. *Australian & New Zealand Journal of Psychiatry* 38(4): 191-196.	**Methods** Roles and activities (research cultures, researcher skills)	Describes the contributions that consumers, and academic consumer researchers (ACRs) in particular, can make to mental health research. Involved a literature survey and a systematic consideration of the potential advantages of consumer and ACR involvement in health research. Consumer researchers may contribute to better health outcomes, but there are significant barriers to their participation. To date, discussion has focused on the role of non-academic consumers, with little recognition of the particular contributions that consumers with formal academic qualifications and research experience can offer. ACRs offer many of the advantages associated with lay consumers, as well as some unique ones, including acceptance by other researchers as equal partners in the research process; skills in research; access to research funding; training in disseminating research findings within the scientific community; potential to influence research funding and research policy; capacity to influence the research culture; and potential to facilitate the involvement of lay consumers in the research process.
Moore, S. 2001. A need to try everything: patient participation in phase I trials. *Journal of Advanced Nursing* 33(6): 738-47.	**Methods** Roles and activities (impact)	This paper describes a study using qualitative interviews and open-stem questionnaires to begin to explore patients' own perceptions of any benefits from participating in phase I research trials. The findings suggest that for some patients, phase I trials fulfil a need to try everything in their fight against cancer. The study also suggests that being on treatment allows some patients to construct their lives meaningfully by providing a supportive structure and enabling hope.

Ghersi, D. 2002. Making it happen: Approaches to involving consumers in Cochrane reviews. *Evaluation and the Health Professions* 25(3): 270-283.	**Methods** Roles and activities	The core work of the Cochrane Collaboration is to conduct of systematic reviews on important health care questions. Its policy is to involve consumers in all stages of the review process: from refining and prioritisation of research questions through protocol design, to review conduct and ultimately dissemination of results. It has been difficult to achieve consumer involvement across all parts of the Cochrane Collaboration. Different approaches have been tried and different levels of success have been achieved. This article discusses consumer involvement in the Cochrane review process in relation to the 10 key principles that guide the work of the Cochrane Collaboration: collaboration, building on the enthusiasm of individuals, avoiding duplication, minimising bias, keeping up to date, striving for relevance, promoting access, ensuring quality, continuity, and enabling wide participation.
Jones, L., Leneman, L. and Maclean, U. 1990. *Consumer Feedback for the NHS. A literature review*. London: King's Fund Publishing Office.	**Methods** Roles and activities	Systematic review of systems and outcomes of consumer feedback across the NHS.
Wilkinson, H. 2002. *The Perspectives of People with Dementia*. London: Jessica Kingsley.	**Methods** Enablement (impact)	This book looks at different aspects of the involvement of people with dementia in research, including the ethics of involvement, consent, communication and the impact of involvement.
Cheston, R., Bender, M. and Byatt, S. 2000. Involving people who have dementia in the evaluation of services, a review. *Journal of Mental Health*. 9(5): 471-479.	**Methods** Enablement	The review explores issues of enablement of people with dementia to participate in the evaluation of health services.
Addington-Hall, J. 2002. Research sensitivities to palliative care patients. *European Journal of Cancer Care* 11(3):220-4.	**Methods** Enablement	The issues of involving patients in palliative care services.

Agrawal, M. 2003. Voluntariness in clinical research at the end of life. *Journal of Pain Symptom Management* 25(4):S25-32.	**Methods** Enablement (ethics)	This article seeks to clarify the concept of voluntariness and assess its significance in clinical research at the end of life. The terms 'vulnerability,' 'exploitation,' and 'coercion' are clarified and their relationship to voluntariness examined. The danger of using some of these terms is that they carry a lot of moral weight and labelling patients as 'vulnerable' or 'coerced' can close off conversation because they are reflexively associated with unethical research. Correctly characterised threats to voluntariness are examined and ways to ameliorate them are presented.
Kiernan, C. 1999. Participation in research by people with learning disability. *Mental Handicap* 27(2): 43-7.	**Methods** Enablement (roles and activities)	This editorial considers involvement of people with learning disability as co-researchers as new paradigm research. The authors argue that applying new paradigms to research with people with learning disability yields benefits, but there are a number of limitations, both practical and theoretical, which limit their value.
Yates, B., McEwan, C. and Eadie, D. 1997. How to involve hard to reach groups: a consumer-led project with lay carers of people with advanced HIV infection. *Public Health* 111(5): 297-303.	**Methods** Enablement	Practical account of carer-led research involving carers of people with HIV.
Karim, K. 2000. Conducting research involving palliative patients. *Nursing Standard*. 15(2): 34-6.	**Methods** Enablement	This study outlined reasons why palliative care patients are seen to be vulnerable as research participants. A literature review ascertained whether or not palliative care patients should be involved in research. The findings showed that the case for involving these patients in research is overwhelming, but that their protection must be an integral part of the research. The conclusion reached is that research design should essentially incorporate the same aims as the palliative care philosophy, that is: patient autonomy, open awareness, holism, respect and collaboration.

Crooks, D.L. 2001. Older women with breast cancer: new understandings through grounded theory research. *Health Care for Women International* 22: 99-114.	**Methods** Enablement	This study showed that older people are not necessarily a hard to reach group.
Kirby, P. 2004. A Guide to Actively *Involving Young People in Research: For researchers, research commissioners and managers*. Eastleigh: Involve. Available online (June 2006) from www.invo.org.uk/All_Publications.asp	**Methods** Enablement	These guidelines for involving young people in research were developed with a group of young people and older adults who have been involved in research. The guide contains information on the benefits of involving young people; when and how to involve young people; and the power issues of involving young researchers.
Owen, S. 2001. The practical, methodological and ethical dilemmas of conducting focus groups with vulnerable clients. *Journal of Advanced Nursing* 36(5): 652-658.	**Methods** Enablement	The importance of methodologies: conducting focus groups with vulnerable groups.

Cambridge, P. and Forrester-Jones, R. 2003. Using individualised communication for interviewing people with intellectual disability: a case study of user-centred research. *Journal of Intellectual & Developmental Disability* 28(1): 5-23.	**Methods** Enablement	A case study using individualised communication for interviewing people with intellectual disability in outcome and quality of life research is reported. The methodology and processes employed are described and lessons for the wider application of the model identified. In collaboration with Somerset Total Communication and local speech and language therapists, researchers from the Tizard Centre developed a flexible communication strategy for involving service users, drawing on core, local and individual vocabularies and using signs, graphic symbols and photographs to supplement spoken English. Individualised communication was used both to ascertain informed consent to participation in the research and to conduct the user interview. The approach was found to facilitate user participation compared with previous follow-ups, with wider lessons evident for user involvement.
Fine, P.G. 2003. Maximizing benefits and minimizing risks in palliative care research that involves patients near the end of life. *Journal of Pain & Symptom Management* 25(4): S53-62.	**Methods** Enablement (ethics, impact)	Research in end-of-life care is constrained more by pragmatic, social, cultural, and financial constraints than ethical issues that preclude the application of typical research methodologies. When normally accepted and ethically sound protections for subjects (especially for those who lack independent decision-making) are in place, exclusion of patients with far advanced disease from research is in and of itself unethical. Involvement in research may have a therapeutic, anticomiogenic effect on dying patients and their families. Institutional review boards must be educated to evaluate research protocols involving this group of vulnerable patients with an eye toward assuring that ethical safeguards are in place, conflicts of interest are transparent and minimised, and that the proposed methodology has duly considered all practical exigencies so that resources and peoples' time and emotional investments are not squandered. Investigators and research review committees must be knowledgeable about placebo effects and under what types of circumstances their use is justifiable, preferred or requisite to fulfil both ethical and scientific imperatives. The authors provide examples of investigations using various research methodologies, along with their respective ethical considerations.

Tee, S. and Lathlean, J. 2004. The ethics of conducting a co-operative inquiry with vulnerable people. *Journal of Advanced Nursing* 47(5): 536-543.	**Methods** Enablement	The aim of this paper is to consider how the ethical issues encountered when conducting participative research with vulnerable people can be addressed in the implementation of a co-operative inquiry with users of mental health services. The study was based on personal reflection and a critical review of associated literature obtained from a database search using Boolean logic. The findings, presented under the headings of the four prima facie moral principles, suggest the need for researchers using participative approaches to demonstrate the humanistic attributes required for engaging and working with people over a period of time. These include building and maintaining trusting relationships, assessing competence to participate, managing interpersonal and group dynamics and making complex collaborative decisions about participants' continued participation in a study. When using a co-operative inquiry approach involving vulnerable individuals, researchers need to demonstrate clearly how a balance between autonomy and paternalism will be achieved, how risks will be anticipated and managed and how fairness will be maintained throughout all procedures. Researchers using participative approaches need to have developed a level of personal insight and self-awareness through access to supervision, which focuses on sources of unintended manipulation and interpersonal dynamics that may arise at the inception of a study and throughout its course. Researchers and ethics committees have a shared responsibility to ensure that vulnerable people are appropriately engaged to maintain the advancement of user knowledge, which informs nursing practice.
Hancock, K., Chenoweth, L. and Chang, E. 2003. Challenges in conducting research with acutely ill hospitalized older patients. *Nursing & Health Sciences* 5(4): 253-259.	**Methods** Enablement	The focus of this study was on understanding older people's nursing needs during acute hospitalisation. The researchers faced many methodological and pragmatic factors that were related to the complexities of researching acutely ill hospitalised older patients. Potential barriers included the complexity of illness in the older person as a result of co morbidity; fatigue; normal age-related processes such as visual/hearing impairment; frequent ward transfer or early discharge; delirium or dementia; and high staff turnover resulting in difficulties in coordinating the study. This paper raises the importance of balancing the need to maximise the rigor of research and the needs of participants.

Dimond, B. 2002. Step 45: Research 5: children. *British Journal of Midwifery* 10(9): 573.	**Methods** Enablement	Outlines the rights of the young person in research.
Dixon-Woods, M., Young, B. and Heney, D. 1999. Partnerships with children. *British Medical Journal* 319: 778-780.	**Methods** Enablement	This paper reports on systematic literature searches, plus contact with professional networks, to gather and review evidence on children and young people's participation. There is a rapidly developing body of information describing and analysing innovative practices in this field. However, there is also a smaller, but substantial, amount of evidence demonstrating the limited extent of current involvement. A good deal of guidance is now available about how to promote the involvement of children and young people. However, the basis of this advice is not always clear, and more evidence about children's views and their experience of participation in public decision-making is required. Issues identified as barriers to change included adult attitudes and intransigence, lack of training for key adults, lack of clarity leading to tokenism, the nature of organisations (i.e. their formality, complexity, bureaucracy and internal politics) and the short-term nature of much funding. The evidence suggests that good practice includes a listening culture among staff, clarity, flexibility, adequate resources, skills development and training for staff and participating children and young people, inclusion of marginalised groups, feedback and evaluation. There is only limited evidence that children and young people's involvement in public decision-making leads to more appropriate services, although there is evidence that participating children and young people benefit in terms of personal development and that staff and organisations learn more about their views. The value of the participation of children and young people in public decision-making is now well accepted, and is recognised in the standards set in the Children's National Service Framework. However, there is an urgent need for internal and external evaluations of children's involvement.
Claveirole A. (2004) Listening to young voices: challenges of research with adolescent mental health service users. *Journal of Psychiatric & Mental Health Nursing*, 11 253-260.	**Methods** Enablement	Recent literature highlights a need to balance respect for the voices of young people with responsibility for their best interests. This can be achieved by paying close attention to ethical and methodological issues throughout the course of every study. This paper reviews some of the issues involved in consultation research with adolescent mental health service users, and illustrates them with examples taken from a study into the experiences of young people in three Scottish child and adolescent mental health services.

Berman, H. 2003. Getting critical with children: empowering approaches with a disempowered group. Advances in *Nursing Science* 26(2): 102-113.	**Methods** Enablement	Empowerment of young people in research.
Heller, T., Pederson, E.L. and Miller, A.B. 1996. Guidelines from the consumer: improving consumer involvement in research and training for persons with mental retardation. *Mental Retardation* 34(3): 141-148.	**Methods** Enablement (roles and activities)	In this study consumer involvement of individuals with mental health problems in research and training was assessed. Twenty-two subjects with experience in research and/or training were interviewed to determine how professionals can encourage meaningful participation of persons with mental health problems in research and training activities. Results suggest that persons with mental health problems have participated in various roles in research and training but that there are many barriers to involvement that have not been adequately addressed. Guidelines for professionals to foster meaningful consumer involvement in research and training activities are provided.
Baumann, S.L. 1996. Parse's research methodology and the nurse researcher-child process. *Nursing Science Quarterly* 9(1):27-31.	**Methods** Enablement (methodology)	The Parse research method is a human science based nursing research methodology which views young children as partners in research about universal lived experiences. To view children in this way requires a considerable revision of the view of children assumed in many traditional theories of childhood and in research with children. In the human science paradigm, persons of all ages are viewed as human beings who make choices and assign meaning. In accord with the assumptions of the Parse research method, children are considered the experts about their health and capable of contributing to nurses' understanding of the human-universe-health process. The remarkable variation of children's thoughts, feelings and actions testifies to the complex and open nature of human becoming at all ages. Children's thoughts, feelings, and imaginings are made more accessible with the aid of art, stories, and play when offered in true presence.

Chiu, L. 2004. Minority ethnic women and cervical screening: a matter of action or research? *Primary Health Care Research & Development* 5(2): 104-16.	**Methods** Enablement	Enablement of ethnic minority groups to participate in research.
Duckett, P.S. and Pratt, R. 2001. The researched opinions on research: visually impaired people and visual impairment research. *Journal of Human Movement Studies* 16(6): 815-35.	**Methods** Enablement (recruitment, purpose)	This research review paper reveals the opinions of visually impaired people on visual impairment research. The authors interviewed 37 visually impaired people across Central Region, Scotland. The findings suggest areas of need for visual impairment research, both concerning what is researched and how it is researched. The authors suggest increasing resources for recruiting participants and multimedia dissemination (e.g. audio tape, Braille, Moon). Methods may need to be refined to address difficulties in recruiting participants, and to capture the diversity of strengths and needs of visually impaired people. They make three core recommendations that identify the need for research to: respect people's individuality, be practical and action orientated, and contribute to an empowering and emancipatory research agenda.
Daly, B.J. and Rosenfeld, K. 2003. Maximizing benefits and minimizing risks in health services research near the end of life. *Journal of Pain and Symptom Management* 25(4): S33-42.	**Methods** Ethics	This article explores the ethical issues specific to health services research in palliative care, with particular attention to similarities and differences between health services research and institutional quality improvement initiatives. The authors focus on the challenges of determining what level of protection is warranted by investigations of health services and programs of care, in contrast to the traditional randomised clinical trial design, and how best to assure subject protection. A decision algorithm for formal review and informed consent is proposed as a mechanism to assure that the level of protection is commensurate with the level of risk.
Fernhoff, P. 2002. Paying for children to participate in research: A slippery slope or an enlightened stairway? *The Journal of Pediatrics* 141(2): 153-154.	**Methods** Enablement	Discusses the ethical and practical issues of paying for young people's participation in research.

Klemm, P. and Nolan, M.T. 1998. Internet cancer support groups: legal and ethical issues for nurse researchers. *Oncology Nursing Forum* 25(4):673-6.	**Methods** Ethics (methodology)	The purpose of this study was to explore the legal and ethical issues surrounding the use of information obtained from internet cancer support groups in research. Data from published articles, news broadcasts, books, government reports were used. Internet cancer support groups are an early prototype of patient groups empowered to seek health through the use of information technology. Nurses are ideally suited to advance this new area of healthcare technology. Honouring the trust that patients have always placed in nurses is essential if this technology is to be developed further. Given the dearth of guidelines to direct researchers, legal and ethical conflicts may occur. Nurse researchers should be cognisant of the potential legal and ethical implications involved in conducting research via the Internet.
Dresden, E., McElmurry, B.J. and McCreary, L.L. 2003. Approaching ethical reasoning in *Nursing Research* through a communitarian perspective. *Journal of Professional Nursing* 19(5): 295-304.	**Methods** Ethics	Most nurse researchers work within research ethics guidelines based predominantly on the ethical principles of autonomy, beneficence, and justice. They are oriented toward protecting the rights of individual research participants. This study indicates that, in cross-cultural, community-based, and international projects, further examination is required of community rights, as an entity in and of itself, to acknowledge and protect the community's rights. The authors suggest that communitarian philosophy is a perspective for the researcher to use in examining cross-cultural and international ethical questions. To show this assertion, dilemmas in community research are examined by using case studies and existing research ethics guidelines. Specific recommendations are offered for nursing scientists in practice, educational, and research settings seeking to balance the rights of the individual with those of the community.
Hallstrom, I. 2004. Parent's and children's involvement in decision-making during hospitalisation. *Nursing Times* Research 9(4): 263-269.	**Methods** Ethics	Children’s involvement in decision making about their care.
Renfrew, M.J. 1989. Ethics and morality in midwifery research. *Midwives Chronicle* 102(1217): 198-202.	**Methods** Ethics	Discusses a wide range of moral issues about health service provision and the ethics of research.

Usher, K. and Holmes, C. 1997. Ethical aspects of phenomenological research with mentally ill people. *Nursing Ethics* 4(1): 49-56.	**Methods** Ethics	This paper outlines and discusses some of the issues associated with maintaining the balance between the aspirations of researchers and the needs and rights of patients in qualitative research. The discussion converges on the specific case of phenomenological research, which involves the invasion of participants' personal worlds, and draws attention to some of the ethical issues that arise when the participants are psychiatric patients.
Mayberry, J. 2002. The cost of questionnaire based research. *Journal of Epidemiology and Community Health* 56(12): 956-957.	**Methods** Ethics	Raises issues about the emotional cost of questionnaire based research for patients and professionals. Robust procedures need to be developed for questionnaire studies. Researchers have an ethical and legal responsibility to ensure that participants in a study are able to ask questions, comment on the quality of their care, and to receive answers. It is essential that all participants are fully aware of the mechanisms by which they can express any concerns and also of any limitations on these processes. These should be discussed with patients at the planning stage and be incorporated in any ethical submission.
Erlen, J.A., Sauder, R.J. and Mellors, M.P. 1999. Incentives in research: ethical issues. *Orthopaedic Nursing* 18(2): 84-7.	**Methods** Ethics	The authors discuss some relevant ethical questions that researchers should consider when providing payments. However the paper focuses on avoiding bias in the recruitment of ‘subjects‘, rather than the ethical reasons for payment.
Telford, R., Boote, J.D. and Cooper, C.L. 2004. What does it mean to involve consumers successfully in NHS research? A consensus study. *Health Expectations* 7(3): 209-220.	**Methods** Ethics	The objective of this consensus study was to obtain consensus on the principles and indicators of successful consumer involvement in NHS research. An expert workshop, employing the nominal group technique was used to generate potential principles and indicators. A two-round postal Delphi process was used to obtain consensus on the principles and indicators. Participants were drawn from health, social care, universities and consumer organisations. A purposive sampling strategy was used to identify people who had experience and/or knowledge of consumer involvement in NHS research. Six researchers and seven consumers participated in an expert workshop. Ninety-six people completed both rounds of the Delphi process. Eight principles were developed through an expert workshop and Delphi process, and rated as both clear and valid. Consensus was reached on at least one clear and valid indicator by which to measure each principle. Eight principles of successful consumer involvement in NHS research may help commissioners, researchers and consumers to deepen their understanding of this issue, and can be used to guide good practice.

Hurst, K. 1985. A real debate by two imaginary people... *Nursing Research* involving patient welfare. *Nursing Mirror*. 160(24): 34-5.	**Methods** Ethics	Discusses ethics in nursing and the role of nurses in patient advocacy.
Caroselli, C. and Barrett, E.A. 1998. A review of the power as knowing participation in change literature. *Nursing Science Quarterly* 11(1): 9-16.	**Methods** Methodology	This article presents a critical review of the literature on research studies using Barrett's theory of power as knowing participation in change and its accompanying measurement instrument. The authors make recommendations for further research.
Harrison, K. and Barlow, J. 1995. Focus group technique: a consumer perspective on outpatient therapeutic services. *British Journal of Therapy & Rehabilitation* 2(6): 323-327.	**Methods** Methodology	Explains the use of focus group methodology to involve patients in the development of outpatient therapeutic services.
Hyttinen, H. and Aavarinne, H. 2000. The delphi-method in *Nursing Research* - gerontological nursing as an example [Finnish]. *Hoitotiede*. 12(3): 121-8.	**Methods** Methodology	This article presents the Delphi -method and reports experiences in using it during one nursing study about the future. The study used an expert panel which included lay representatives (patients and relatives). The study proved that elderly people had difficulties in focusing their concentration on the future.

Lindsey, E., Sheilds, L. and Stajduhar, K. 1999. Creating effective nursing partnerships: relating community development to participatory action research. *Journal of Advanced Nursing*. 29(5): 1238-45.	**Methods** Methodology	The purpose of this article is to demonstrate the importance of creating effective partnerships between nurses practising community development and nurses engaged in participatory action research. An overview of the theoretical principles of community development and participatory action research is provided and the central tenets of each methodology are explored. This is followed by a discussion of the similarities and differences inherent in the methodologies, which derive from the same theoretical and philosophical foundation; that of critical social theory. Examples of two research projects highlight the relationship between community development and participatory action research and demonstrate the value of creating effective practitioner/researcher partnerships. Although this call for practitioner/researcher alliance is not new, what is new is the central role the practising nurse could take in research. Creating partnerships between practising nurses and nurse researchers advances the opportunity to actualise responsive and effective PAR and to fulfil nursing's social contract.
Meyer, J.E. 1993. New paradigm research in practice: the trials and tribulations of action research. *Journal of Advanced Nursing* 18(7): 1066-72.	**Methods** Methodology	This descriptive methodological paper reflects on the way in which nursing research has developed along similar lines to research in education. It focuses on the emergence of action research as an example of collaborative research within the practice discipline of nursing. Action research is placed in the framework of new paradigm research and questions concerning its scientific merit are addressed along with its idealistic value to nursing.
Tetley, J. and Hanson, L. 2000. Participatory research. *Nurse Researcher* 8(1): 69-88.	**Methods** Methodology	The authors discuss participatory research, emancipatory research, consumer involvement and consumer consultation.

Webb, C. and Kevern, J. 2001. Focus groups as a research method: a critique of some aspects of their use in nursing research. *Journal of Advanced Nursing* 33(6): 798-805.	**Methods** Methodology	This paper evaluates and critiques reports in the nursing literature in the period 1990–1999 of the use of focus groups as a research method. The result of the search was that very few articles were found that reported on a specific piece of research using the method. Methodological discussions were more common and these were sometimes at a somewhat superficial level without analysis or critique. The largest category of articles was concerned with service development projects. The research-based articles were found to be relatively unsophisticated in their use of the method, in particular in relation to data analysis and social interaction within focus groups. Terms such as 'content analysis' and 'grounded theory' were used in non-rigorous ways and incompatibility between the underlying research approach and implementation of the method was identified in the cases of phenomenology and grounded theory. While selection of the focus group method was often justified in terms of the benefits that participant interaction could yield, this interaction was rarely reported or discussed in the articles. One author proposed a scheme for analysing this type of interaction, and this is recommended to future researchers as a possible framework for interaction analysis. The article concludes by calling for more in-depth consideration at the research planning stages of the underlying assumptions of methodological approaches that may be used to underpin focus group research and methods to be used to analyse and report the data generated.
Ong, B.N. and Hooper, H. 2003. Involving users in low back pain research. *Health Expectations* 6: 332-41.	**Methods** Methodology	OBJECTIVE: To involve users in the design of a research project that aims at describing a 12-month course of low back pain in an adult population sample (epidemiological strand), and to determine how patient and professional perceptions of low back pain and its treatment relate to the use of health-care and to subsequent outcome (qualitative strand). DESIGN: Three focus groups were organised in the preparatory phase of the project with general practitioners, other health professionals and low back pain sufferers. Issues pertaining to the experience of living with, or treating low back pain were explored and users were asked to identify relevant research questions for consideration within the study. FINDINGS: The focus groups revealed tensions between involving users as co-researchers for design issues and their role as sufferers and health professionals who want to share their narrative accounts of low back pain. The group discussions produced a wealth of material for analysis, but no explicitly stated research topics. Three key themes and the process of user involvement in the focus groups are discussed. CONCLUSIONS: The focus group format could be restrictive in that it allows for detailed exchange between participants, but is insufficiently geared towards the production of a research agenda. We draw conclusions as to possible approaches for user involvement in health services research design.

Beaver, K., Luker, K. and Woods S. 1999. Conducting research with the terminally ill: challenges and considerations. *Homoeopath* 5(1):13-7.	**Methods** Enablement	This article explores some of the pertinent issues that arose while conducting a research study involving people with a terminal illness, their lay carers and bereaved carers. Ethical considerations are of paramount importance when carrying out research with vulnerable groups; and issues such as approaching potential participants without adding to their distress and anxiety, and obtaining consent without coercion need careful consideration. Adhering to a stringent research design, while preferable for the research agenda, is not always compatible with the ethical concepts of beneficence and non-maleficence. The potential benefits to vulnerable persons of being involved in such work may not be immediately obvious although altruism, in wanting to help others in a similar situation in the future, and the therapeutic effect of telling one's story may have indirect benefit for some. However, it may not be possible for the researcher to ever fully ascertain the actual benefit and harm incurred in carrying out such work.
Napholz, L. 1998. Enhancing research participation and retention for three ethnically diverse groups. *Journal of Cultural Diversity* 5(4): 117-9.	**Methods** Enablement	Many researchers naively assume that the methods and research approaches that are useful with European-Americans can also be used with minority populations. Little attention has been paid to the development of culturally appropriate research procedures and a discussion of the limitations of traditional research methodologies. In this article I include the experiences and suggestions for successfully conducting research with minority populations.
Burke, A., McMillan, J,. Cummins, L,, Thompson, A., Forsyth, W., McLellan, J., et al. 2003. Setting up participatory research: a discussion of the initial stages. *British Journal of Learning Disabilities* 31(2): 65-69.	**Methods** Enablement	This paper discusses the initial setting up of a participatory research project. The project included adults with learning disabilities, clinicians, a researcher from a primary care National Health Services trust, and support workers who work directly with adults with learning disabilities in various community settings. An understanding of what is involved in participatory research is important at an initial stage, and so speakers who were undertaking a similar project investigating direct payments were invited to a 1-day conference that was set up locally. At the end of the conference, volunteers were requested for the local project to investigate health. This approach enabled well-informed agreement to participate.

Carter, W., Elward, K., Malmgren, J., Martin, M. and Larson, E. 1991. Participation of older adults in health programs and research: A critical review of the literature. The Gerontologist 31(5): 584-592.	**Methods** Enablement	This collection of five papers evaluates the participation of older adults in clinical trials, health promotion/disease prevention initiatives, and health programs designed to maintain or improve the functioning of chronically ill older adults. Understanding the willingness or unwillingness of older adults to participate in these programs is critical to the development and implementation of health programs and policies for this population. In this introductory paper the authors briefly review illustrative literature to provide both an overview of the participation of older adults in health programs.
Box, V., Hepworth, M. and Harrison, J. 2003. Identifying information needs of people with multiple sclerosis. *Nursing Times* 99(49): 32-6.	**Methods** Enablement	This article reports on a survey to identify the information needs of people with multiple sclerosis (MS), both at the time of diagnosis and throughout the course of the disease. The gap between information required and received was vast. The greatest difficulties faced by people with MS were finding information on research trials; drug treatments; emotional changes; new and unusual symptoms; and balance and walking problems. The expressed a preferred for information provision through face-to-face meetings and leaflets. Although provision of information has improved greatly, there is still a long way to go before all needs are satisfied.
O'Quigley, A. 2000. *Listening to children's views. The findings and recommendations of recent research*. York: Joseph Rowntree Foundation.	**Methods** Enablement	This report was produced for a seminar for members of the Lord Chancellor's Advisory Board on Family Law on 5 July 1999. The purpose of the report was to summarise the findings of current research on the issues of listening to children and considering their best interests. This was in the context of the development of court rules in relation to section 11 of the Family Law Act (FLA). The report summarised the findings of research on: 1) the present situation regarding the representation of children's views in private law proceedings 2) the more effective representation of children's views under new arrangements; 3) children's views on how they would like to be involved.

Riesch, S.K., Tosi, C.B. and Thurston, C.A. 1999. Accessing young adolescents and their families for research. Image - the *Journal of Nursing Scholarship* 31(4): 323-6.	**Methods** Enablement	PURPOSE: To describe the strategies used to obtain and retain a sample of young adolescents and their families. METHODS: The sample was 847 families with young adolescents aged 11 to 14 years who resided in a large urban Midwestern community of the U.S. The first design strategy was becoming credible within the community. For 5 years before conducting the intervention research in the community, surveys were conducted of the needs of middle-school students as they entered adolescence, and programs were delivered to meet the assessed needs. The second design strategy was instituting developmentally appropriate recruitment and retention strategies based upon direct consultation with groups of young adolescents. The consultants recommended referring to young adolescents as young adults and holding the training sessions in sites not associated with schools. The third design strategy was setting up participation methods that were nonburdensome to schools and families. CONCLUSIONS: The successful recruitment of over 800 families and the retention of 80% of them for survey participation and 77% of them for the intervention protocol can be attributed to three major strategies: (a) community involvement; (b) adherence to principles of adolescent development; and (c) ease of participation for school personnel and families.
Davies, S. and Nolan, M. 2003. Nurturing research partnerships with older people and their carers. *Quality in Ageing* 4(4): 2-5.	**Methods** Enablement	Describes ways of establishing partnerships with older people and their carers.
Edwards, H., Courtney, M. and O'Reilly, M. 2003. Involving older people in research to examine quality of life in residential aged care. *Quality in Ageing* 4(4): 38-43.	**Methods** Enablement	Involving older people in residential aged care to examine quality of life.

Aranda, S. and Street, A. 2001. From individual to group: use of narratives in a participatory research process. *Journal of Advanced Nursing* 33(6):791-7.	**Methods** Methodology (impact)	This paper provides a theoretical understanding of narrative research and its use. It aims to expose the ways narrative research, when taken beyond the researcher's lone analysis of text, can contribute to the development of clinical knowledge. Narratives, constructed from stories of nursing practice, become texts for analysis. This is undertaken predominantly by a researcher engaged in a lone activity with little involvement of those contributing the stories. This paper is drawn from a critical praxis study of nurse-patient friendship utilising participatory research processes. The nurses involved in the study were co-researchers in an in-depth study of their relationships with patients. The paper traces the movement from naive story, through individual narratives during interviews with each nursing and demonstrates the changes in understanding about the narrative accounts that occurred during the participatory group process. The nurses involved in the study were able, through the use of narrative stories re-examined in a group context, to develop new insights and understandings about their practice. Knowledge generated in these ways remains grounded in the real life world of clinical nursing and gives voice to the complexity of those aspects of nursing practice that are taken for granted.
Barrett, E.A. and Caroselli, C. 1998. Methodological ponderings related to the power as knowing participation in change tool. *Nursing Science Quarterly* 11(1):17-22.	**Methods** Methodology	This paper describes the Power as Knowing Participation in Change Tool. The authors summarise tool development, including reliability and validity, and discuss specific methodological issues and insights. These include clarity of instructions and complexity of language used in the PKPCT along with response set, norms, and sensitivity of the instrument to detect differences between groups. Problems of linear measurement are discussed along with the appropriateness of both qualitative and quantitative methods of studying power from the view of the science of unitary human beings. Recommendations for further psychometric studies of power are proposed.
Hildebrandt, E. 1999. Focus groups and vulnerable populations. Insight into client strengths and needs in complex community health care environments. *Nursing & Health Care Perspectives* 20(5): 256-9.	**Methods** Methodology	Focus groups are a useful qualitative research technique to assist in interpreting quantitative community assessment data. Data from focus groups can provide sociological and psychological insights into the perceptions of population subgroups and suggest answers to the ‘why’ questions raised by descriptive data about such issues as teen pregnancy, poverty, immunisation or lifestyle-related morbidity and mortality. Application of these insights can lead to the better use of community strengths and the creation of community-specific responses to barriers to health care. Focus groups work well for involving hard-to-reach community members in program development, planning, and evaluation. They may be more effective than interviews and questionnaires because people often have not thought about how they feel and tend not to form opinions in isolation. The information sought through focus groups is not randomly distributed in the population. Thus, groups are not randomly selected, and data are not gathered with the intent to generalise to all populations.

Baarts, C., Tulinius, C. and Reventlow, S. 2000. Reflexivity - a strategy for a patient-centred approach in general practice. *Family Practice* 17(5):430-4.	**Methods** Methodology	The paper considers reflexivity as a strategy in general practice to implement a patient-centred approach. Reflexivity implies having a self-conscious account of the production of knowledge as it is being produced. The authors believe that GPs can gain access to additional knowledge by consciously using reflexivity as a strategy in the consultation. They discuss reflexivity in relation to the notions of empathy, personal experience and self-knowledge. By using reflexivity in order to rely on personal experience, the GP can gain access to patients' understanding of their health. Reflexivity can be a valuable concept for the GP in patient-centred medicine and can contribute to bridging the gap between the patient's perspective and the doctor's understanding of the patient's health.
Church, K. 1997. Madness in her method: creating a 'survivor frame' for mental health research. *Journal of Psychiatric & Mental Health Nursing* 4(4): 307-8.	**Methods** Methodology	This paper reflects on the legitimacy of the researcher to investigate health experience. The author describes changes in her attitudes, values and feelings for the course of a research study with mental health service users. The method of critical autobiography is advocated for acknowledging the researcher within the research.
Lindseth, A. and Norberg, A. 2004. A phenomenological hermeneutical method for researching lived experience. *Scandinavian Journal of Caring Sciences* 18(2): 145-53.	**Methods** Methodology	This study describes a phenomenological hermeneutical method for interpreting interview texts inspired by the theory of interpretation presented by Paul Ricoeur. The method enables a comprehensive understanding of a complex subject to be developed. The authors argue that the method of analysis may enable participants to better understand their way of being in the world and disclose new possibilities for change.
Packer, T., Race, K.E. and Hotch, D.F. 1994. Focus groups: a tool for consumer-based program evaluation in rehabilitation settings. *Journal of Rehabilitation* 60(3): 30-3.	**Methods** Methodology	Despite the fact that focus groups are widely used in market research, this technique has been under-utilised in rehabilitation program evaluation. This article describes a series of focus groups conducted in a vocational training and rehabilitation setting.

Griffiths, H. 2002. Participatory action research. *Nursing Bc* 34(4): 15-7.	**Methods** Methodology	Participatory action research methodology.
Bailey, P.H. and Tilley, S. 2002. Storytelling and the interpretation of meaning in qualitative research. *Journal of Advanced Nursing* 38(6):574-583.	**Methods** Methodology	This paper reviews literature on narrative analysis and illustrates the meaning-making function of stories of chronic illness through analysis and discussion of two case studies from a study of acute episodes of chronic obstructive pulmonary disease (COPD). In an ethnographic study, 10 patient-family nurse units in two Canadian general hospitals participated in interviews concerning acute episodes of COPD. Narrative analysis enabled identification of several story forms and their functions. Examples were found of a story told twice with different meanings, and of a patient's 'death story' used to communicate distrust of the nurse's ability to recognise the seriousness of distress and implications for its potential course. These examples are presented, and interpreted with respect to issues of meaning. The analysis indicates that stories told by patients in the context of nurse-client interactions inform understanding of the individual's acute exacerbation events beyond the biophysical.
Israel, B., Schulz, A., Parker, E. and Becker, A. 2001. Community-based participatory research: policy recommendations for promoting a partnership approach in health research. *Education for Health* 14(2): 182-197.	**Methods** Methodology	Overview and discussion of community based participatory research.
Kirkpatrick, S.M. 1990 Participatory nursing research: a promising methodology in Third World countries. *Western Journal of Nursing Research* 12(3): 282-92.	**Methods** Methodology	This paper argues that with nursing's long commitment to client involvement in health care, a logical component in nursing research would be the active participation of subjects throughout the research process. Although the components of the process are familiar ones to nurses, the formalisation of participatory research offers exciting new possibilities. The application of this method would be appropriate in any setting but seems to offer particular promise in developing countries.

Corcega T. 1992. Participatory research: getting the community involved in health development. *International Nursing Review*, 39 6 185-188.	**Methods** Methodology	The premise of this study is that people have the right and duty to participate individually and collectively in the planning and implementation of their health care. This means that community involvement in health development is fundamental in the battle for health. Participation in health research is necessary in the process of finding better ways and methods to provide health for all.
Lindsey, E. and McGuinness, L. 1998. Significant elements of community involvement in participatory action research: evidence from a community project. *Journal of Advanced Nursing*. 28(5): 1106-14.	**Methods** Methodology (researcher skills)	Participatory action research (PAR) has been heralded as an important research methodology to address issues of research relevance, community involvement, democracy, emancipation and liberation. This article presents the results of a study investigating the significant elements of community involvement in PAR. Through the use of qualitative research methods, five themes emerged that describe the community participation process: (a) planning for participation, (b) the structural components of community participation, (c) living the philosophy, (d) enhancing the credibility, and (e) the type of leadership required to facilitate community participation.
Rains, J.W. and Ray, D.W. 1995. Participatory action research for community health promotion. *Public Health Nursing* 12(4): 256-61.	**Methods** Methodology (roles and activities, impact)	This article describes the process and outcomes of participatory action research conducted by a Healthy City in rural Indiana and *Public Health* nurse faculty. The community was integrally involved in the process, including framing of research questions, construction and distribution of survey tools, analysis of findings, and taking action on the results. Combining local insights of the community with technical assistance from *Public Health Nursing* yielded multiple benefits. The role of participatory action research is advocated as being appropriate for *Public Health* nurses because it is consistent with the goals and characteristics of the profession.
Richardson, M. 1997. Participatory research methods: people with learning difficulties. *British Journal of Nursing* 6(19): 1114-21.	**Methods** Methodology (purpose)	The use of participatory research methods to empower disadvantaged groups or individuals has attracted increasing interest in recent years. The article critically examines the use of such methods to empower people with learning difficulties as co-researchers. Emancipatory research would, by definition, be led and processed by people with learning difficulties. However, the engagement of people with learning difficulties in truly emancipatory nursing research is currently regarded as highly problematic as it assumes empowerment as a precondition. As a step towards emancipatory research, participatory research represents a radical shift. It may potentially strengthen the voice of people with learning difficulties and enable them to express their views on nursing. The author proposes a methodology, which addresses a number of critical issues facing the nurse researcher.

Webb, C. 1990. Partners in research. *Nursing Times* 86(32): 40-44.	**Methods** Methodology (impact)	Discusses how action research benefits both researcher and the researched. Author describes how she introduced team nursing in an elderly ward at Manor Park Hospital in Bristol and how she worked alongside staff in order to gather formative, qualitative data and used senior monitor and a stress questionnaire to collect baseline measures. Discussions were held on how to divide staff and patients into teams, how to conduct drug administration, medical rounds and handover reports, how to make up the duty rotas and how to inform visitors and other staff of the system. Author says that weekly meetings for teaching and discussion were held and that problems were discussed openly. Author reports that a second stress questionnaire after six months showed small reductions in stress levels.
White, G.W., Suchowierska, M. and Campbell, M. 2004. Developing and systematically implementing participatory action research. *Archives of Physical Medicine and Rehabilitation* 85 (Supp 2): S3-12.	**Methods** Methodology	Generic description of Participative Action Research.
Funnell, C. 1997. Voices of experience: anecdotes from patient partnership. *Journal of the Royal Society of Medicine* 90(1): 40-1.	**Methods** Methodology	Discusses how patient partnership can work in practice.
Nichols, R., Meyer, J., Batehup, L. and Waterman, H. 1997. Promoting action research in healthcare settings. *Nursing Standard* 11(40): 36-8.	**Methods** Methodology	This article promotes the idea of using action research for health care exploration and change. It also introduces the work of the Healthcare Subgroup of the Collaborative Action Research Network and describes the outcomes of a research study that underpin the philosophy, process and potential benefits of the network as a means to promote practice development and change in client care.

Hays, B.J. and Mockelstrom, N.R. 1977. Consumer survey: an approach to teaching consumer participation in community health. *Journal of Nursing Education* 16(8): 30-4.	**Methods** Methodology	This consultation about community health needs was conducted by students in a family and community nursing course. The door-to-door survey was carried out by pairs of students during clinical time over a six-week period. Through a written summary of the experience and class discussion students indicated an increased awareness of the community as a dynamic reality and a heightened awareness of their caseload families' relationships to the community. Students also demonstrated an appreciation for consumer representation in health planning and for some of the strengths and weaknesses of surveying as a method for consumer involvement.
Hostick, T. and McClelland, F. 2000. 'Partnership': A co-operative inquiry between community mental health nurses and their clients. 2. The nurse-client relationship. *Journal of Psychiatric and Mental Health Nursing* 9(1): 111-117.	**Methods** Methodology (roles and activities, purpose)	Describes the output of a co-operative enquiry between community mental health nurses and their clients. Two nurses and two clients volunteered to participate as co-researchers and co-subjects with two facilitators in a co-operative inquiry group. The agreed subject of the inquiry was the relationship between the nurse and client. The description of the nurse-client relationship and its influences is extremely rich, with implications for clinical and managerial practice. Despite the study limitations study, co-operative inquiry appears to be a useful vehicle for increasing understanding of the nurse-client relationship with potential for further research and development. Unsurprisingly, when both the relationship characteristics and the health care context are appropriate there seem to be more positive outcomes for nurse and client. Within the current health policy context there are increased demands with the potential to disrupt this relationship. Nurses need to be aware of the potential effects of these so that the relationship and the client do not suffer and health service managers need to be aware of the contribution their behaviour may have on the nurse-client relationship.
Tilley, S., Pollock, L. and Tait, L. 1999. Discourses on empowerment. *Journal of Psychiatric and Mental Health Nursing* 6(1): 53-60.	**Methods** Methodology (purpose, impact)	Reports on the use of stories to understand and develop nursing practice research. Story (or narrative) and science are distinct but complementary paradigms. The authors found that a story framework can help researchers reflect on a process of social scientific investigation and consider how to 'go on'. In a study on community psychiatric nurses' empowerment of people with enduring mental disorders in the community, they encountered interesting and challenging issues related to design and use of methods. These issues are presented within a framework of story analysis, focusing on issues related to empowerment. This analysis draws on Burke's 'pentad' of story elements as a framework for narrative analysis. The authors present the elements of the 'story of the study-as-funded' and as it was carried out through the pilot stage, and outline the story of developments in the main study. 'Trouble' in a story centres on a problematic 'ratio' of story elements. The 'trouble' at this stage in the progress of the study relates to lack of fit between some parts of the instruments (the methods) and the goal (empowerment), and to the status of the community psychiatric nurses as actors or agents.

Hyrkas, K. and Paunonen M. (2000) Patient satisfaction and research-related problems, part 2: is triangulation the answer? *Journal of Nursing Management* 8 4 237-245	**Methods** Roles and activities	Overcoming issues in patient satisfaction research by using triangulation of different sources of data.
Hyrkas, K., Paunonen, M. and Laippala, P. 2000. Patient satisfaction and research-related problems, part 1: problems while using a questionnaire and the possibility to solve them by using different methods of analysis. *Journal of Nursing Management* 8(4): 227-236.	**Methods** Roles and activities	Overcoming issues with patient satisfaction research by using different methods of analysis.
Schafer, T. 2000. Towards a participatory model for the evaluation of the empowering therapeutic environment. *Mental Health and Learning Disabilities Care* 3(7): 233-237.	**Methods** Roles and activities	Involvement of service users in evaluation of the therapeutic environment.

Pontin, D.J.T. and Webb, C. 1995. Assessing patient satisfaction: 1. The research process. *Journal of Clinical Nursing* 4(6): 383-389.	**Methods** Roles and activities	The research reported in this article formed part of a project evaluating nursing developments in four demonstration wards in one health authority. The article focuses on evaluation of patient satisfaction and steps to clarify the issues involved at the planning stage of the study.
Ahlberg, K. and Gibson, F. 2003. What is the story telling us: using patient experiences to improve practice. *European Journal of Oncology Nursing* 7(3):149-150.	**Methods** Roles and activities	Methods of using patient experiences to improve practice.
Wilcock, P., Brown, G. and Bateson, J. 2003. Using patient stories to inspire quality improvement within the NHS Modernisation Agency collaborative programmes. *Journal of Clinical Nursing* 12(3): 422-430.	**Methods** Roles and activities	Methods of using patient stories to motivate change in NHS practice.

Graham, J., Broom, D. and Whittaker, A. 2001. Consulting about consulting: challenges to effective consulting about *Public Health* research. *Health Expectations* 4(4): 209-212.	**Methods** Recruitment and representation	Documentation of a failed attempt at consumer consultation supplies information on barriers to effective involvement and conditions that must prevail to improve consultation. People are keen to be heard in the formulation of health research. However, competing demands and limited resources make it difficult for community groups to allocate scarce resources to consultation. Sometimes research issues may seem 'academic' and thus remote from the urgent priorities of the people with whom researchers wish to consult. Consultation may require more time than researchers on limited budgets can afford. Despite a general *Public Health* commitment to involving consumers in research development, obstacles to consultation make it difficult to incorporate it into the research agenda. Researchers and funding bodies will need to allocate resources to consumer consultation if it is to become the rule rather than the exception in *Public Health* research.
Beattie, J., Cheek, J. and Gibson, T. 1996. The politics of collaboration as viewed through the lens of a collaborative *Nursing Research* project. *Journal of Advanced Nursing* 24:682-7.	**Methods** Working relations (decision making)	This paper explores what is meant by collaboration and the politics of collaboration. Drawing on a critical perspective, it uses Brookfield's themes of impostorship, cultural suicide and roadrunning as the theoretical framework for the analysis of a collaborative nursing study.
Zielstorff, R.D. 2003. Controlled vocabularies for consumer health. *Journal of Biomedical Informatics* 36(4-5): 326-33.	**Methods** Working relations	This paper describes a disconnection between the language consumers use to express health concerns and the language used by health care professionals. It argues that health care consumerism and the availability of vast health-related resources on the Internet have resulted in millions of people using the Internet for health-related matters daily. The mismatch in language is felt to pose a barrier to access to relevant information. It also prevents full participation in shared health records, and sometimes interferes in communication between patients and their health care providers. The authors state that nurses with expert training in informatics could play an important role in solving this dilemma. The paper suggests that structured vocabularies comprised of lay terms, with definitions, variant spellings, and regional dialects, along with mappings to equivalent or related professional terms, could make health literature much more accessible to the public. In addition, the presence of terms for which no representation currently exists in nursing terminologies could serve as a stimulus for developing new knowledge about patient phenomena not previously recognised.

Bentley J. 2003 Older people as health service consumers 4: disempowered or disinterested? *British Journal of Community Nursing*, 8 4 181-7.	**Methods** Recruitment and representation	This article discusses whether a sample of older people in a village community have a consumerist ethos in regard to health care, and whether they are prepared to act in this way. Suggestions are made for better facilitating older people's involvement in and use of services.
Berg, J.A. 1999. Gaining access to under-researched populations in women's health research. *Health Care for Women International* 20(3): 237-43.	**Methods** Recruitment and representation	Culture is an important variable in women's health research, and sample selection must include plans to recruit participants who represent the overall cultural makeup of the population. However, gaining access to under researched groups is a major challenge and requires specific planning. Salient access techniques utilised by epidemiological researchers include (a) obtaining the support and endorsement of community leaders, (b) advertising the research in community publications, and (c) utilising age, gender, and culturally matched research assistants. Although these elements were included in the planning of a study of the perimenopausal transition of Filipino American midlife women, the more powerful attractors for this particular cultural group were their pride in participating in a study that was associated with a major university and their intense community service orientation. Since each cultural group has unique issues and concerns, researchers must familiarise themselves with the values of their target group and emphasise these in recruitment approaches.
Damrosch, S.P. and Lenz, E.R. 1984. The use of client-advisory groups in research. *Nursing Research* 33(1): 47-9.	**Methods** Recruitment and representation	The use of client-advisory groups in nursing research.
Souder, J.E. 1992. The consumer approach to recruitment of elder subjects. *Nursing Research* 41(5): 314-6.	**Methods** Recruitment and representation	Recruitment issues in nursing research that involves older people.

Stanford, P.D., Monte, D.A., Briggs, F.M., Flynn, P.M., Tanney, M., Ellenberg, J.H., et al. 2003. Recruitment and retention of adolescent participants in HIV research: Findings from the REACH (Reaching for Excellence in Adolescent Care and Health) project. *Journal of Adolescent Health* 32(3): 192-203.	**Methods** Recruitment and representation	Evaluated the importance of 13 items in the recruitment and retention of HIV-positive and HIV-negative adolescent participants (aged 12-18 yrs) in a longitudinal study (REACH study). Subjects were asked to recall the importance they placed on 13 items in deciding to join the REACH study (recruitment) and to remain on study (retention). The 5 most important factors for study recruitment were identical to those chosen for retention by participants. The factors were: (a) quality medical care, (b) caring staff, (c) health education, (d) privacy/confidentiality, and (e) altruism. Items judged least important were social activities, compensation, transportation, and food/meals. Subject characteristics were not associated with statistically different mean judgment scores at recruitment and retention, although clinical site showed significant variation.
Williamson, C. 1999. The challenge of lay partnership. *British Medical Journal* 319(7212): 721-722.	**Methods** Recruitment and representation	Discuses points to consider in establishing partnerships such as in doctor-patient groups. The author argues that though both medical and lay members should have relevant expertise and links to their peers, they should be appointed for their personal contribution and not as representatives-delegates of any group. For most groups, the numbers of lay and medical members should be equal, as they are in some of the medical royal colleges' patient liaison groups. Members should not be in clinical relationships with each other. Working relationships of equality are different from clinical relationships with their complex feelings and vulnerabilities.

Jones, K., Baggott, R. and Allsop, J. 2004. Influencing the national policy process: the role of health consumer groups. *Health Expectations* 7:18-28.	**Methods** Recruitment and representation (purpose, roles and activities)	While recent research has focused on consumer involvement at local level in the UK, there have been few studies of the representation of user, carer and patients' interests nationally. This paper concentrates on the role of health consumer groups in representing the collective interests of patients, users and carers in the national policy process. The research consisted of (a) a semi-structured postal questionnaire survey of 123 health consumer groups; (b) semi-structured interviews with key informants from 39 health consumer groups; and (c) semi-structured interviews with 31 policy actors. Health consumer groups were diverse in their origins, scope and structure, and undertook a wide range of activities relating to policy and service provision. While around half the groups described their primary purpose as service provision, over four-fifths identified influencing policy at national level as 'very important' or 'important'. Health consumer groups had developed relationships with civil servants, ministers, MPs and peers to widen their policy objectives. Key facilitators in the policy process included experiential knowledge, relationships with policy makers and working in alliances with other health consumer groups or other stakeholders. Key barriers included problems relating to the political agenda, problems with the consultation process, lack of resources and working within a context of unequal power relationships. The paper concludes that health consumer groups are becoming increasingly involved in the *Health Policy* process and collectively are becoming an increasingly influential stakeholder. They have a key role to play in ensuring that the patient, user and carer voice is heard in the policy process.
Taylor, G., Brown, K., Cadwell, K., Ghazi, F., Henshaw, L. and Vernon, L. 2004. User involvement in primary care: A case study examining the work of one patient participation group attached to a primary care practice in North London. *Research Policy and Planning* 22(1): 21-29.	**Methods** Recruitment and representation	This paper details recruitment issues in the setting up of a patient participation group in a primary care setting.

Brereton, L. and Dawes, H. 2003. Building on carers' stories to enrich research. *Quality in Ageing* 4(4): 11-17.	**Methods** Recruitment and representation	Using carers stories in research.
Maslin-Prothero, S. 2003. Developing user involvement in research. *Journal of Clinical Nursing* 12(3): 412-421.	**Methods** Recruitment and representation	This paper represents work undertaken for the NHS National Cancer Research and Development Programme and NHS Executive Trent. It includes reflection on the experience of user involvement in health care research drawing on current UK *Health Policy* documents and an examination of the factors affecting recruitment to breast cancer clinical trials, and contributes to the debate on recruitment to clinical trials. It summarises key issues that nurses and midwives must consider to ensure effective user participation in research and practice.
Russell, D., Hamilton, W. and Luthra, M. 2002. Research and consumer representation. *British Journal of General Practice* 58.	**Methods** Recruitment and representation	This paper concerns issues to do with the representation of service users in research.
Thornton, H. 2001. Consumers and trials. *The Lancet* 358: 763.	**Methods** Recruitment and representation	The debate about the potential for improvement of clinical trials by involvement of consumers frequently centres on the legitimacy of advocates, and their representativeness. The author argues for a new perception and attitude that accommodates various ways in which consumers might contribute to facilitating progress with their medical collaborators.
Crist, J.D. and Escandon-Dominguez, S. 2003. Identifying and recruiting Mexican American partners and sustaining community partnerships. *Journal of Transcultural Nursing* 14(3): 266-71.	**Methods** Recruitment and representation	In this article, how community partners were identified and recruited and how community partnerships have been sustained during a current program of study designed to eliminate health and use disparities are described. The critical social paradigm, community development theories, and participatory research methods have guided a partnership with Mexican American elders and their caregivers during five research studies.

Oliver, S., Milne, R., Bradburn, J., Buchanan, P., Kerridge, L., Walley, T., et al. 2001. Involving consumers in a needs-led research programme: a pilot project. *Health Expectations* 4(1): 18-28.	**Methods** Roles and activities (commissioning, researcher skills, education)	The objectives of this study were to describe the methods used for involving consumers in a needs-led health research programme, and to discuss facilitators, barriers and goals. In a short action research pilot study, the authors involved consumers in all stages of the Health Technology Assessment (HTA) Programme: identifying and prioritising research topics; commissioning and reporting research; and communicating openly about the programme. They drew on the experience of campaigning, self-help and patients' representative groups, national charities, health information services, consumer researchers and journalists for various tasks. They explored consumer literature as a potential source for research questions, and as a route for disseminating research findings. These innovations were complemented by training, one-to-one support and discussion. A reflective approach included interviews with consumers, co-ordinating staff, CONTEXT observers and other programme contributors, document analysis and multidisciplinary discussion (including consumers) among programme contributors. The findings show that when seeking research topics, face-to-face discussion with a consumer group was more productive than scanning consumer research reports or contacting consumer health information services. Consumers were willing and able to play active roles as panel members in refining and prioritising topics, and in commenting on research plans and reports. Training programmes for consumer involvement in service planning were readily adapted for a research programme. Challenges to be overcome were cultural divides, language barriers and a need for skill development among consumers and others. Involving consumers highlighted a need for support and training for all contributors to the programme. Consumers made unique contributions to the HTA Programme. Their involvement exposed processes, which needed further thought and development. Consumer involvement benefited from the National Co-ordinating Centre for Health Technology Assessment (NCCHTA) staff being comfortable with innovation, participative development and team learning. Neither recruitment nor research capacity were insurmountable challenges, but the authors feel ongoing effort is required if consumer involvement is to be sustained.

Robert, G., Hardacre, J., Locock, L., Bate, P. and Glasby, J. 2003. Redesigning mental health services: lessons on user involvement from the Mental Health Collaborative. *Health Expectations* 6(1): 60-71.	**Methods** Roles and activities (recruitment and representation)	This study explores the involvement of mental health service users in the redesign of in-patient services in six trusts participating in a multi-regional NHS modernisation programme. Semi-structured interviews and observation of team meetings were undertaken as part of an action research study. Users, clinical, medical and managerial staff from six mental health trusts which participated in the Northern & Yorkshire and Trent regions' Mental Health Collaborative (MHC) were involved. While there were some problems, user involvement was undoubtedly a strength of the MHC in comparison to other NHS modernisation programmes. However, the particular challenges posed by the specific context of acute mental health services should not be overlooked. The initial approach taken in each of the sites was to simply invite a user or user representative to join the local project team. In the course of events, various changes were made to this initial mechanism. These changes- and setbacks in some sites- make drawing firm conclusions as to the effectiveness of the various strategies employed problematic. However, the qualitative data suggest a number of broad lessons that will assist both those leading and participating in other redesign initiatives to maximise the benefits to be gained from service user involvement.
Durand, M.A. and Jowett, S. 2001. Best value case study: commissioning research on the views of older service users. *Managing Community Care* 9(5): 25-36.	**Methods** Roles and activities	The involvement of service users in consultation about social care provision.
Gamel, C., Grypdonck, M., and Hengeveld, M. 2001. A method to develop a nursing intervention: the contribution of qualitative studies to the process. *Journal of Advanced Nursing* 33(6): 806-819.	**Methods** Roles and activities	Use of qualitative research methods as a way of incorporating patient's views in the development of clinical nursing interventions.

Ross, C. and Cornbleet, M. 2003. Attitudes of patients and staff to research in a specialist palliative care unit. *Palliative Medicine* 17(6): 491-7.	**Methods** Roles and activities	Consultation about the likelihood of patients receiving specialist palliative care to participate in hypothetical randomised trials. The patients were generally agreeable to trial participation (66% 'quite happy' or 'very happy'). The nurses were strongly in favour of research participation for the same group of patients (92% 'quite happy' or 'very happy'). The most invasive study involving venepuncture and random drug allocation had the least favourable response (46% of patients and 54% of nurses 'quite happy' or 'very happy'). A trial of reflexology attracted 77% of patients, while 62% were happy to take part in a study involving mood assessment and interview. Factors deterring willingness to participate included the need for record keeping by the patient and concern about potential emotional strain. The nurses correctly identified some of the factors deterring patients, but often their willingness for trial participation did not match that of the patient. Although there is support for research among the small number of potential trial entrants in specialist palliative care units, their limited physical and emotional reserves make careful attention to appropriate trial design essential to the success of future studies.
Rodeheaver, P.F., Taylor, A.G. and Lyon, D.E. 2003. Incorporating patients' perspectives in complementary and alternative medicine clinical trial design. *Journal of Alternative & Complementary Medicine* 9(6): 959-67.	**Methods** Roles and activities	The topic of this research undertaken by the University of Virginia Health System is the importance and process of gathering the perspectives of former patients when designing clinical studies for complementary and alternative medicine therapies and to describe how this information was used to guide the planning of a clinical study using complementary modalities to reduce symptom distress and enhance quality of life during stem cell transplantation. Structured interviews with ten former patients were undertaken to identify preferences, opinions, and other issues that may affect a clinical study in this population. In general, the 10 study participants interviewed reported that they would have been more receptive to receiving gentle Swedish massage than using guided imagery tapes during the treatment process, although neither modality would have been particularly welcome during those treatment phases with highest physical or emotional/mental stress. Personal experiences, treatment side-effects, ‘personality,’ and life situation all had an influence on not only what was considered most stressful for the patient but also why it was perceived as stressful. Eliciting the views of persons who have undergone significant medical events is a necessary step in rigorous clinical trial development. Consideration of patient preferences and motivations may ensure the best fit between interventions and the desired outcomes.

Dozier, A.M., Kitzman, H.J., Ingersoll, G.L., Holmberg, S. and Schultz, A.W. 2001. Development of an instrument to measure patient perception of the quality of nursing care. *Research in Nursing & Health* 24(6): 506-17.	**Methods** Roles and activities	The purpose of this large scale survey was to develop an instrument in consultation with patients using a new approach to assessing their perspectives about nursing care during a hospitalisation experience. Three different studies were used to develop and validate a measure of the degree to which patients perceived their needs were met during hospitalisation. In study 1, patients discharged from adult acute-care medical and surgical units in the medical centre hospital were recruited. In study 2, all patients discharged from ten adult acute care units across the five hospitals participating in the larger study were recruited. For study 3, a sample of 50 respondents was recruited from sequentially discharged medical and surgical patients in the medical centre hospital where data were collected for study 1. The 15-item instrument, Patient Perception of Hospital Experience with Nursing (PPHEN) was sent to patients' homes after discharge. With each round of studies, the instrument was revised. Findings from the comparison of hospitals over time indicated that, despite positive skewing, the 15-item PPHEN is able to detect changes in patients' perceptions of the quality of nursing care when provided in different institutions and when care delivery changes within the same institution.
Richardson, M. 2000. How we live: participatory research with six people with learning difficulties. *Journal of Advanced Nursing* 32(6): 1383-95.	**Methods** Roles and activities	Drawing on the social model of disability, six people with learning difficulties participated over 18 months in researching their own lived experiences. The method involved weekly group discussions supplemented by participant observation. The study's value stems from in-depth inquiry, which included the participants in data collection, analysis, dissemination and consequences that they found meaningful. The participants lived in nurse-managed community homes. They described how they had faced social and economic exclusion, for example concerning marriage, child rearing and decently paid employment. With the assistance of nursing staff, the participants had overcome many other social barriers and were enjoying a wide range of activities and choices. Consequently, they lived varied lives which they described as interesting and worthwhile. Contemporary models of nursing had successfully directed staff to support 'ordinary living'. However, some disabling assumptions were evident within contemporary nursing. Hence, models of nursing and service delivery were helping both to create lifestyles that the participants valued, while simultaneously contributing to their disempowerment.
Backhouse, S. and Brown, Y. 2000. Using a patient satisfaction survey to close the theory-practice gap. *Nursing Standard* 14(38):32-5.	**Methods** Roles and activities	The aim of this study was to determine whether a patient satisfaction survey could be used as a research tool to improve nursing practice. A postal questionnaire was sent to patients after discharge. Questions covered primary nursing, information, ward environment, discharge planning and social activities. The results highlighted areas where changes were needed. This resulted in a nurse-led programme of managed change, including making all experienced D and E grade nurses primary nurses, improving information provision, and involving patients in the decision-making process.

Entwistle, V., Tritter, J. and Calnan, M. 2002. Researching experiences of cancer: the importance of methodology. *European Journal of Cancer Care* 11(3): 232-237.	**Methods** Roles and activities	The paper highlights concepts of patient experience and methods of data collection. Explains the issues of using concepts from other fields.
Glasby, J. and Littlechild, R. 2001. Inappropriate hospital admissions: patient participation in research. *British Journal of Nursing* 10(11): 738-41.	**Methods** Roles and activities (impact)	Discuses the patient's role in providing information about emergency admissions to hospital. Although political interest in reducing the number of inappropriate hospital admissions is mounting, methods for researching the rate of inappropriate admissions have several major limitations. Whereas traditional studies have tended to be predominantly subjective, more recent studies using clinical review instruments also have a number of limitations. Chief among these is the failure to consider the potential input of the individual patient. To illustrate some of the possible benefits of patient participation, this article cites findings from a study in Birmingham, which sought to involve individual older people in a research study into emergency hospital admissions.
Donovan, J., Brindle, L. and Mills, N. 2002. Capturing users' experiences of participating in cancer trials. *European Journal of Cancer Care* 11(3): 210-4.	**Methods** Roles and activities	Patients experiences of participating in cancer trials.

Thornton, H., Edwards, A. and Elwyn, G. 2003. Evolving the multiple roles of 'patients' in health-care research: reflections after involvement in a trial of shared decision-making. *Health Expectations* 6(3):189-97.	**Methods** Roles and activities	This paper offers 'consumer-led' reflections by steering group members of a patient-centred research study involving consumer advocates, patients' associations and patients, throughout the whole study, from pre- to post-study phases. The study: 'Shared decision making and risk communication in general practice' incorporated systematic reviews, psychometric evaluation of outcome measures, and quantitative, qualitative and health economic analyses of a cluster randomised trial of professional skill development, all informed by consumer and patient engagement. The work was produced by a wide collaboration led by researchers from the Department of General Practice, University of Wales College of Medicine, Cardiff, including a consumers' advisory group and a patients' association. The study participants were 20 general practitioners from Gwent, their practice staff, and almost 800 patients at these practices. Consumers and patients contributed to several stages of the research from inception and design, securing of funding, implementation of the protocol, and interpretation and dissemination of the findings. 'Patient involvement' research initiatives that include an equally wide variety of 'user' participants as 'health-professional' participants, accountable to a 'Health in Partnership' funded project, require a user-led viewpoint to be presented and disseminated.
Edwards, C. and Staniszewska, S. 2000. Accessing the users' perspective. *Health and Social Care in the Community* 8(6): 417-24.	**Methods** Roles and activities	This paper aims to assist individual service providers in planning their strategy of user involvement and evaluation, based on an awareness of the current state of knowledge in this area. It reviews the results of research in the field of patient satisfaction over the last 20 years; summarises the main problems in the area, and suggests ways forward. Three main points emerge: the importance of developing and substantiating theory in this field to support study design; the need to exercise care if using quantitative methods and global satisfaction scores, until the process of evaluation is better understood, and the need to consider how a sensitive user-led agenda can be developed. The paper calls for a pause for reflection on the reason for our inquiry into user opinion, and for careful consideration of how we might best design studies to obtain information to fulfil this inquiry.
Merkouris, A., Ifantopoulos, J. and Lanara, V. 1999. Patient satisfaction: a key concept for evaluating and improving nursing services. *Journal of Nursing Management* 7(1): 19-28.	**Methods** Roles and activities	Discusses the concept of patient satisfaction.

Simpson, E.L. and House, A.O. 2002. Involving users in the delivery and evaluation of mental health services: systematic review. *British Medical Journal* 325: 1265.	**Methods** Roles and activities (impact)	The objectives of this systematic review were to identify evidence from comparative studies on the effects of involving users in the delivery and evaluation of mental health services. Five randomised controlled trials and seven other comparative studies were identified. Half of the studies considered involving users in managing cases. Involving users as employees of mental health services led to clients having greater satisfaction with personal circumstances and less hospitalisation. Providers of services who had been trained by users had more positive attitudes toward users. Clients reported being less satisfied with services when interviewed by users. The review concludes that users can be involved as employees, trainers, or researchers without detrimental effect. Involving users with severe mental disorders in the delivery and evaluation of services is feasible.
Elliott, E., Watson, A.J. and Harries, U. 2002. Harnessing expertise: Involving peer interviewers in qualitative research with hard-to-reach populations. *Health Expectations* 5(2): 172-178.	**Methods** Roles and activities	The use of peer interviewers with privileged access to a particular population group, which is difficult to reach via more conventional methods, has been acknowledged in recent research. This paper explores a number of key issues relating to the employment of peer interviewers by reflecting on a project designed to explore the views and experiences of parents who use illegal drugs. The project presented the research team with a number of challenges. These included the need to provide on-going support for the interviewers, a sense of distance felt by the researchers from the raw data they collected, and the difficulties of gaining from the skills and experiences of peer interviewers without exploiting their labour. The paper also explores the advantages of involving peer interviewers closely in research work and reflects on the nature and boundaries of expert knowledge that can become evident in such collaborations. The need for a certain amount of flexibility over the roles and domains of control that lay experts and researchers traditionally inhabit is suggested. In conclusion, it is argued that the involvement of peer interviewers in research can be a valuable means of enhancing our knowledge and understanding of a variety of population groups who tend to live beyond the gaze of more orthodox researchers.
Rhodes, T., Nocon, A., Wright, J. and Harrison, S. 2001. Involving patients in research. Setting up a service users' advisory group. *Journal of Management in Medicine* 15(2): 167-171.	**Methods** Roles and activities	An account of the process of setting up a service users' advisory group for a research project.

Northway, R. 2000. The relevance of participatory research in developing Nursing Research and practice. *Nurse Researcher* 7(4): 40-52.	**Methods** Roles and activities	Links between nursing research and participatory methods.
Coggan, C., Disley, B. and Patterson, P. 1998. Community based intervention on adolescent risk taking: using research for community action. *Injury Prevention* 4: 58-61.	**Methods** Roles and activities (impact)	The purpose of this New Zealand study was to use research on adolescent risk taking behaviour as an impetus for a community to develop locally based injury prevention strategies. School-aged adolescents and the safety policies and practices of community organisations involved with adolescents participated. Evaluation six months after intervention identified increased community awareness of the adverse effects of adolescent risk taking and some changes in policies and practice related to adolescent safety. Providing a community with local information that has high relevance for its members may act as a stimulus for the development of injury prevention initiatives. While this case study illustrated that a comprehensive approach focusing on adolescent risk taking behaviour, rather than on isolated injury problems, may be an appropriate way to highlight escalating adolescent injury rates, it also demonstrates the limitations of a short time frame for a community development project.
Earl-Slater, A. 2002. The superiority of action research? *British Journal of Clinical Governance* 7(2): 132-135.	**Methods** Roles and activities	Looks at where action research has been used in health care in the UK and suggests lessons can be learned by looking at action research taking place in other fields, such as education, policing and social services.
Parboosingh, J., Stachenko, S. and Inhaber, S. 1997. A model of consumer participation: the Canadian breast cancer initiative. *Canadian Journal of Aging/Canadian Public Policy Supplement:* 177-186.	**Methods** Roles and activities	The development of user involvement in practice and research in breast cancer in Canada.

Bridges, J. 2001. Action research in rehabilitation care for older people. *British Journal of Therapy & Rehabilitation* 97(5):37-8.	**Methods** Roles and activities	Issues and benefits of undertaking action research methodology with older people to improve rehabilitation services.
Dougherty, C.M., Nichol, W.P., Dewhurst, T.A. and Spertus, J.A. 1999. Patient perspectives on participation in a clinical trial of angina management. Applied *Nursing Research* 12(2): 107-11.	**Methods** Roles and activities	Patient's views of their involvement in clinical trials.
Cox, K. 2000. Enhancing cancer clinical trial management: recommendations from a qualitative study of trial participants' experiences. *Psycho-Oncology* 9(4): 314-22.	**Methods** Roles and activities	Using a qualitative approach, a total of 55 adult patients with advanced cancer were interviewed to examine their perceptions of participating in early phase anti-cancer drug trials. Patients' views and experiences were explored, primarily through the use of in-depth interviews, with additional information accessed through two widely-used quality of life questionnaires, at the beginning of, during and after trial participation. The picture of trial participation established from this work suggests that it is a dynamic process, that has a different meaning and impact according to the stage of trial involvement the patient is experiencing. The findings identify how patients perceived the offer of the trial, dealt with the trial treatment, and came to terms with trial conclusion. The insight and understanding that this work provides in terms of the impact of trial involvement over time as well as details of patients' information, decision-making and support needs has significant implications for cancer clinical trial management. The recommendations put forward by the authors focus on acknowledging the contribution trial participants make to cancer research, enhancing the process of preparing patients for trial participation, recognising the need for continuing care, the incorporation of patients and potential patients' views into the clinical trials system, and educating the public about clinical trials.

Thornton, H. 2002. Patient perspectives on involvement in cancer research in the UK. *European Journal of Cancer Care* 11(3): 205-9.	**Methods** Roles and activities	Involvement in clinical trials. Three types of involvement are classified.
Bell, N. 2003. Using patient stories to improve lung cancer care. *Cancer Nursing Practice* 2(3):21-24.	**Methods** Roles and activities	The use of patient stories to develop services in lung cancer care.
Frost, D. and Cliff, D. 2004. Narrative approaches for research in community nursing. *British Journal of Community Nursing* 9(4): 172-178.	**Methods** Roles and activities	Narrative methods for research in community nursing.
Jacoby, A., Lecouturier, J., Bradshaw, C., Lovel, T. and Eccles, M. 1999. Feasibility of using postal questionnaires to examine carer satisfaction with palliative care: a methodological assessment. *Palliative Medicine* 13(4): 285-98.	**Methods** Roles and activities	This paper reports on the methodological findings from a project which examined the feasibility of using a postal questionnaire to assess lay carer satisfaction with palliative care. The focus of this paper is the process of questionnaire development and its psychometric evaluation. The questionnaire was derived from an interview schedule used in previous national surveys of care for the dying, and was refined through qualitative work with recently bereaved lay carers. It was then tested in a postal survey of 355 lay carers identified from death registration certificates. Postal approaches appear to represent an acceptable means of assessing user satisfaction with palliative care, compared with more resource-intensive methods.

Lecouturier, J., Jacoby, A., Bradshaw, C., Lovel, T. and Eccles, M. 1999. Lay carers' satisfaction with community palliative care: results of a postal survey. *Palliative Medicine* 13(4): 275-83.	**Methods** Roles and activities	This paper reports the findings of a study that examined the feasibility of using postal questionnaires to assess the satisfaction of lay caregivers with the care received in the community by those dying of cancer. The focus of the analysis was the quality of information provided by health professionals, health services used in the final year of the dying person's life and the lay carer's views about the quality of these services. A comparison of the findings from this postal study with those reported in earlier retrospective interview surveys of lay carers suggests that the use of the postal questionnaire is a valid and cost-effective approach for assessing quality of care.
Sakala, C., Gyte, G., Henderson, J., Neilson, J.P. and Horey, D. 2001. A consumer viewpoint. Consumer-professional partnership to improve research: the experience of the Cochrane Collaboration's Pregnancy and Childbirth Group. *Birth* 28(2): 133-7.	**Methods** Roles and activities	Partnership working in the Cochrane Collaboration's Pregnancy and Childbirth Group.
Goodare, H. and Lockwood, S. 1999. Involving patients in clinical research. *British Medical Journal* 319(7212): 724-725.	**Methods** Roles and activities	Issues for involving patients in clinical research.

Hanley, B., Truesdale, A., King, A., Elbourne, D. and Chalmers, I. 2001. Involving consumers in designing, conducting, and interpreting randomised controlled trials: questionnaire survey. *British Medical Journal* 322: 519-23.	**Methods** Roles and activities (impact)	The purpose of the study was to assess the extent to which consumers are involved in the work of clinical trial coordinating centres in the United Kingdom and the nature of consumers' involvement in randomised trials coordinated by these centres. National surveys using structured questionnaires with some open ended sections were used. The study included 103 clinical trial coordinating centres in the United Kingdom identified through a database assembled in 1997 by the NHS clinical trials adviser. Named contacts at 62 coordinating centres and investigators in 60 trials that were identified as involving consumers. Of the 62 eligible centres, 23 reported that consumers had already been involved in their work, and most respondents were positive about this involvement. 17 centres planned to involve consumers. 15 centres had no plans to involve consumers, but only four of these considered such involvement irrelevant. Responses from investigators about the 48 individual trials were mostly positive, with respondents commenting that input from consumers had helped refine research questions, improve the quality of patient information, and make the trial more relevant to the needs of patients. Consumer involvement in the design and conduct of controlled trials seems to be growing and seems to be welcomed by most researchers. Such involvement seems likely to improve the relevance to consumers of the questions addressed and the results obtained in controlled trials.
Duff, L. and Lamping, D. 2000. Different ways to measure satisfaction. *British Journal of Midwifery* 8(7): 422-428.	**Methods** Roles and activities	Measuring satisfaction.
Gotlieb, J.B. 2002. Understanding the effects of nurses on the process by which patients develop hospital satisfaction. *Holistic Nursing Practice* 16(5): 49-60.	**Methods** Roles and activities	An understanding of the process by which hospital patients evaluate their nurses could be very useful. However, no theory-based model exists in the nursing literature to explain the relationship among patients' hospital rooms, locus of causality, patients' evaluation of nurses, and hospital satisfaction. This article proposes a model to help fill this void. It also presents empirical evidence supporting the model--a study finding that patients' evaluation of their hospital rooms and their perception of locus of causality affected their evaluations of nurses. The results suggest patients' evaluation of their nurses and rooms are two key variables that affect their overall hospital satisfaction. However, patients' evaluation of nurses appears to have a much greater influence on hospital satisfaction than does patients' evaluation of their rooms.

Roberts, P. 1999. Testing user satisfaction tools. *Nurse Researcher* 6(3): 67-76.	**Methods** Roles and activities	Satisfaction surveys.
Poulton, B.C. 1996. Use of the consultation satisfaction questionnaire to examine patients' satisfaction with general practitioners and community nurses: reliability, replicability and discriminant validity. *British Journal of General Practice* 46(402): 26-31.	**Methods** Roles and activities	Consumer feedback on primary health care services relates mainly to doctor-patient relationships, which fails to reflect the multidisciplinary nature of primary health care. A pilot study aimed to examine the feasibility of using a patient satisfaction questionnaire designed for use with general practitioner consultations as an instrument for measuring patient satisfaction with community nurses. A total of 1575 patients in three practices consulting general practitioners or community nurses were invited to complete a questionnaire. Three dimensions of patient satisfaction were identified: professional care, depth of relationship and perceived time spent with the health professional. The pilot study showed that it is possible to use the consultation satisfaction questionnaire for both general practitioners and community nurses.
Bisset, A. and Chesson, R. 2000. Is this satisfaction survey satisfactory? Some points to consider in their planning and assessment. *Health Bulletin* 58(1): 45-52.	**Methods** Roles and activities	Satisfaction surveys.
Bond, S. and Thomas, L.H. 1992. Measuring patients' satisfaction with nursing care. *Journal of Advanced Nursing* 17(1): 52-63.	**Methods** Roles and activities	The kinds of study in which patient satisfaction has been used as an outcome are considered and show the range of conceptualisations and the general lack of rigour in its measurement. It is argued that research methods are often flawed by using inappropriate measures and greater care is warranted in their selection. Where appropriate measures do not exist, only then is the costly process of developing new assessments warranted. Some of the necessary steps in arriving at reliable and valid measures of patient satisfaction are discussed in the context of asking particular research questions.

Wray, J. 2003. Powerful sharing? Creating effective user groups. *Practising Midwife* 6(8): 18-9.	**Methods** Roles and activities	Advisory groups.
Browne, N., Grocott, P., Cowley, S., Cameron, J., Dealey, C., Keogh, A., et al. 2004. Woundcare research for appropriate products (WRAP): validation of the TELER method involving users. *International Journal of Nursing Studies* 41(5): 559-71.	**Methods** Roles and activities (impact)	Woundcare Research for Appropriate Products (WRAP) is a novel collaboration between industry and clinicians, funded by the Engineering and Physical Research Sciences Council. WRAP objectives included the development and testing of methodologies to identify patients' and clinicians' needs with respect to wound dressings for exudate management. The management of exudate was the focus because it was demonstrated to be the pivotal problem for patients and clinicians in a study of malignant wounds, and is a recurring problem in other wound types. A clinical note-making system (Treatment Evaluation by Le Roux's method-TELER) was validated as a method of collecting observational data of dressing performance in the context of total patient care, thereby involving the users of dressing products. The validation process was a form of consensus where multiple sources of data were used to define patient problems, within the TELER indicators, to measure a change or lack of change in the problems during a period of treatment and care and to draw conclusions about dressing performance and patient experiences.
Campbell, J. and Einspahr, K. 2001. Building partnerships in accountability: consumer satisfaction. In Dickey, B., Sederer, L.I. (Eds) *Improving Mental Health Care: Commitment to Quality* (pp.101-113). Washington, DC: American Psychiatric Publishing, Inc.	**Methods** Roles and activities	Consumer satisfaction of health care services is the focus of this chapter. As public mental health systems become privatised and enter a marketplace environment, mental health services consumers are demanding a more prominent voice in how research and evaluation shapes the content, character, and influence of mental health services. Therefore, the processing and presentation of information as it flows through the health care system and the distribution and feedback loops that allow for shared decision making must support quality improvement in policy, management, and clinical practice. If the voices of service recipients are welcomed as partners, the knowledge gained from satisfaction assessments can become a major value-added force in mental health service delivery.

Davies, A.R. 1994. Patient defined outcomes. *Quality in Health Care* 3(Suppl): 6-9.	**Methods** Roles and activities	Patient defined outcomes of care.
Thornton, H. 2002. Patient perspectives on involvement in cancer research in the UK. *European Journal of Cancer Care* 11(3): 205-9.	**Methods** Roles and activities	Patients perspectives about involvement in cancer research.
Geanellos, R. 2002. Exploring the therapeutic potential of friendliness and friendship in nurse-client relationships. *Contemporary Nurse* 12(3): 235-45.	**Methods** Working relations	Friendliness and friendship, within the nurse-client relationship, are explored. Friendliness is superficial and includes nurses' smiling, joking, a warm tone of voice and interest in clients, while friendship is a deeper more affective involvement between client and nurse. The therapeutic outcomes of friendliness and friendship are significant. When nurses are friendly, client feelings of disease, strangeness and alienation are replaced by feelings of comfort, belonging and involvement.
Thornton, H. 1998. Alliance between medical profession and consumers already exists in breast cancer. *British Medical Journal* 316: 148-149.	**Methods** Working relations	Experiences of partnership in breast cancer care.

Vander Stoep, A., Williams, M., Jones, R., Green, L. and Trupin, E. 1999. Families as full research partners: what's in it for us? *Journal of Behavioral Health Services and Research* 26(3): 329-44.	**Methods** Working relations	This article describes a children's managed mental health care program that incorporates both a family participation service model and a family-initiated evaluation model. The authors begin by tracing the evolution of the family support and the participatory research movements leading to current developments in children's mental health services research. In the King County Blended Funding Project, three service systems pool funds that are spent flexibly by child and family teams. Family advocates have led efforts to design and implement the project evaluation. During this process, many tensions have arisen between meeting the demands of both scientific rigor and multiple community stakeholders. Examples are given of the issues raised by family advocates and research scientists as together they established a theory of change, identified meaningful outcomes, selected measurement tools, and implemented the evaluation protocol. Guidelines are given for how services research partnerships can be successfully built to better address community needs.

Table 3 Outcomes issues

Full reference	Topic code	Contribution to the debate
Lynn, M.R. 1987. Toward more credibility in nursing research: researcher-subject collaboration. *Journal of Pediatric Nursing* 2(3): 205-7.	**Outcomes** Impact	Social credibility of research conducted with service users.
Hudson, P. 2003. The experience of research participation for family caregivers of palliative care cancer patients. *International Journal of Palliative Nursing* 9(3): 120-123.	**Outcomes** Impact	The experience of research participation for family caregivers of palliative care cancer patients.
Koch, T., Selim, P. and Kralik, D. 2002. Enhancing lives through the development of a community-based participatory action research programme. *Journal of Clinical Nursing* 11(1): 109-17.	**Outcomes** Impact	A community-based participatory action research (PAR) programme that has spanned 5 years is discussed in this article. A primary healthcare philosophy requires research in this practice setting and supports the way healthcare is ideally organised within an integrated team and supported by a community network that includes not only the healthcare workers and service providers but also the community as partners. The authors conclude that the cyclical processes inherent in PAR promote reflection and reconstruction of experiences that can lead to the enhancement of people's lives, either at an individual or community level, or both.

DeMarco, R. and Johnsen, C. 2003. Taking action in communities: women living with HIV/AIDS lead the way. *Journal of Community Health Nursing* 20(1) 51-62.	**Outcomes** Impact	A successful collaboration of a medical centre, a community-based HIV/AIDS service organisation, a university school of nursing, and women living with HIV/AIDS in an inner city community resulted in a series of educational programs for women living with HIV/AIDS, their family, friends and caregivers. These programs were intended to provide inner-city women who were living with HIV/AIDS with knowledge and new insights from the voices of their peers. Topics focused on their self-care and empowerment so that they could take control of their wellness and their health care while remaining in their community. The efforts made in launching the collaborative educational series created trusting relationships between academic, clinical, and community service agencies, professional caregivers, and the recipients of their care. The most significant contribution belonged to the women living with HIV/AIDS themselves: After the programming they turned their health and life experiences into 'action' by planning a research project that will test the efficacy of an intergenerational HIV prevention program for adolescent women of colour in their community in the future.
Crighton, M.H., Goldberg, A.N. and Kagan, S.H. 2002. Reciprocity for patients with head and neck cancer participating in an instrument development project. *Oncology Nursing Forum Online* 29(10): E127-31.	**Outcomes** Impact	This qualitative study aimed to examine reciprocity (i.e., a mutual exchange of benefit) in study participation via a thematic analysis of field notes on study participation from a parent psychometric study. Seven patients with head and neck cancer were recruited to participate in an instrument development project. A notion of reciprocity in research participation was apparent. The role of the study nurse is an important element in the process of reciprocity. This role should be explored to enhance study participation. Implications, particularly for clinical trial nurses, include recasting the benefits of participating in research, better addressing preparation for patients scheduled to receive treatment for head and neck cancer, and exploring and enhancing the role of the study nurse.
Flaskerud, J.H. and Anderson, N. 1999. Disseminating the results of participant-focused research. *Journal of Transcultural Nursing* 10(4): 340-9.	**Outcomes** Impact (dissemination)	Participant-focused research (PFR) includes ‘subjects’ as full partners. As such, they share in the research products or outcomes. PFR goes beyond the traditional approach of disseminating findings to other scientists and clinicians and includes participants and community residents in sharing the skills, knowledge, and resources of the study with the aim of empowering them. This article demonstrates the use of PFR in disseminating outcomes to participants through two examples of long-term research projects conducted in Los Angeles. The first is a community-based study of HIV prevention with low-income Latina women. The second is an ethnographic study of health concerns and risks among adolescents in juvenile detention. These examples provide two approaches to dissemination of research findings and benefits to the participants and the community.

Beresford, P. 2002. User involvement in research and evaluation: liberation or regulation? *Social Policy & Society* 1(2): 95-105.	**Outcomes** Impact	Discusses the potentially regressive as well as the progressive impact of involvement.
Trivedi, P. and Wykes, T. 2002. From passive subjects to equal partners: qualitative review of user involvement in research. *British Journal of Psychiatry* 181: 468-472.	**Outcomes** Impact	This study aimed to illustrate the challenges in joint research projects with mental health service users. The involvement of the user-researcher changed the focus of the study and its design and content. More attention was paid to the intervention itself and the way in which it was delivered. This process increased the amount of time taken to carry out and write up the project as well as incurring financial costs for user consultation payments and dissemination. This experience has clarified the contribution that users can make, for example by raising new research questions, by ensuring interventions are kept 'user friendly', and the selection of outcome measures.
Craig, A. 2004. Public involvement in health care. Every voice counts not just that of patients. *British Medical Journal* 328: 462.	**Outcomes** Impact	‘Public’ involvement in health care.
Meyer, M.C., Torres, S., Cermeno, N., MacLean, L. and Monzon, R. 2003. Immigrant women implementing participatory research in health promotion. *Western Journal of Nursing Research* 25(7): 815-34.	**Outcomes** Impact	Few studies on women's health include immigrant women, and fewer are conducted by immigrant women themselves. Here the authors present a model that allowed their full participation as researchers and authors. They describe their experiences using participatory research methods with Hispanic women in multiple ways to reach out to isolated women, collect data about community needs and provide health education. They explore the advantages and challenges of being trained for both researcher and health educator roles, describe opportunities to use this approach to assess service needs, and discuss the potential for personal empowerment. They also report on the time commitment that a bilingual project requires. They conclude that health promotion and participatory research complement each other, and that combining participatory research with health promotion activities has promise to contribute toward increased empowerment of immigrant communities.

Crawford, M.J., Rutter, D., Manley, C., Weaver, T., Bhui, K., Fulop, N., *et al.* 2002. Systematic review of involving patients in the planning and development of health care. *British Medical Journal* 325(7375): 1263-5.	**Outcomes** Impact	Systematic review of involving patients in the planning and development of health care
McClimens, A. 2004. What difference does it make who is speaking? Audience ownership and authority in learning disability research. *Journal of Learning Disabilities* 8(1):71-88.	**Outcomes** Dissemination	The argument for and impact of service users being involved in writing publications.
Wilson, R. 2002. Research notes: Pros and cons of consumer involvement in research. *Nursing Standard* 16(49): 21.	**Outcomes** Impact	Discusses the pros and cons of consumer involvement in research.
Tilley, S., Pollock, L. and Tait, L. 1999. Discourses on empowerment. *Journal of Psychiatric and Mental Health Nursing* 6(1): 53-60.	**Outcomes** Generalisability	The discourse of the 'big stories' of service policy and planning are clearly articulated in journals, but the 'little stories' of nurses' work and users' experiences may be ignored or under-valued. This paper illustrates how the 'big story' of a central policy theme - empowerment - is articulated in the realm of research funding and design, and how it is articulated by practitioners. It focuses attention on the responsibilities faced by researchers, in relating the 'little stories' of practice and the 'big story' of policy. It reports tentative early findings from a study of community psychiatric nurses' empowerment of people with enduring mental disorders. It suggests ways in which strategies for qualitative analysis of interview data with community practice nurses may be informed by ideas from the field of discourse analysis; reflexively examining how researchers' discourses relate to those of policy makers and mental health nurses.

Table 4 Capacity issues

Full reference	Topic code	Contribution to the debate
Barnes, D., Carpenter, J. and Bailey, D. 2000. Partnerships with service users in interprofessional education for community mental health: a case study. *Journal of Interprofessional Care* 14 (2):189-200.	**Capacity** Researcher skills	Looks at the topic of user involvement in interprofessional education.
Boyd, C.O. 1993. Toward a nursing practice research method. *Advances in Nursing Science*. 16(2): 9-25.	**Capacity** Researcher skills	This article promotes a structure for Nursing Research in which the primary feature is the nurse researcher-as-clinician in a collaborative relationship with the client-as-subject. A nursing practice research method is conceptualised not as merely a technical activity with a focus on narrative data, but also as an explicit recognition of research as practice with an emphasis on intersubjectivity and dialogue in the research process as constitutive of reality. Research and knowledge development are thus envisioned as taking place from within the nursing situation and contingent on the quality of the nurse-client relationship. Both nurse and patient have the potential for positive growth and change when these unique perspectives of nurse and client are joined.
Telford, R., Beverly, C. and Cooper, C. 2002. Consumer involvement in health research: fact or fiction? *British Journal of Clinical Governance* 7(2): 92-103.	**Capacity** Researcher skills	This study identified the range and diversity of current NHS research projects involving consumers within an NHS region, to investigate the extent to which the policy is being implemented. Trust R&D directors and managers were surveyed and the National Research Register scrutinised. Researchers were found to be involving consumers in research in less than a third of trusts in the region. Difficulties were encountered in categorising research activities and the level of consumer involvement, suggesting that more precision in describing consumer involvement in the research process is necessary. Researchers had concerns about the practicalities of involving consumers and expressed a need for more direction and resources. This paper makes recommendations for trust management to facilitate more active involvement of consumers in research.

Gray, R.E., Fitch, M., Davis, C. and Phillips, C. 2000. Challenges of participatory research: reflections on a study with breast cancer self-help groups. *Health Expectations* 3(4): 243-52.	**Capacity** Research culture	The objective of this paper is to review and discuss issues related to participatory research, as they apply within the arena of cancer control. A participatory research study with Canadian breast cancer self-help groups is referred to for description and discussion purposes. The study employed primarily individual and group interviews to assess benefits and limitations of self-help groups. Four breast cancer self-help groups in Ontario communities provided the core involvement in the participatory research project. The researchers found that the values and practices of mainstream academic research often conflict with those of research emphasising participation and control of communities under study, leading to a variety of challenges. Practical constraints faced by many community groups have important implications for participatory research approaches. The authors conclude that a balance needs to be found for participatory research within cancer control, one that ensures that the core aims of participatory research are maintained, while simultaneously acknowledging the various challenges that make a fully participatory project unrealistic.
Stevens, T., Wilde, D., Hunt, J., Ahmedzai, S.H. 2003. Overcoming the challenges to consumer involvement in cancer research. *Health Expectations* 6(1): 81-88.	**Capacity** Strategic (roles and activities, research culture)	Within the last decade, there have been many government initiatives to promote consumer involvement in research, especially in cancer. At the same time, the number and influence of consumer groups themselves have expanded. However, the organisational infrastructure necessary to facilitate consumer involvement has not been developed. Consequently, consumer involvement has tended to remain essentially localised and project driven, with no strategic or regional lead. Opportunities for involvement and identification of consumers: The opportunities for consumers to influence the research process at each stage of the research process are identified. The different types of consumer involvement are also examined. Novel ways of identifying and recruiting consumers that have been adopted by one cancer network are discussed. The strategies used in one cancer network: An organisational model designed by one cancer network for involving consumers in research is illustrated. Three innovations are examined in detail. First, how three open consumer conferences have increased awareness of research among service users. Second, the recruitment of consumers to sit on project steering groups and a committee that provides a strategic overview of current research. Third, the establishment of a Consumer Panel for Research where reimbursed, trained consumers are able to provide a considered consumer perspective in a range of settings. The paper concludes that cancer networks need to take the lead in the development of an organisational infrastructure to facilitate consumer involvement.

Bennett, L. and Baikie, K. 2003. The client as educator: learning about mental illness through the eyes of the expert. *Nurse Education Today* 23:104-11.	**Capacity** Education	Increasingly, educators are asking clients who have a mental illness to make a contribution to nursing students' learning as a way of informing their attitudes towards persons experiencing mental illness and thus enhancing care delivery. The nature of clients' involvement in the classroom and the quality of learning by students through this approach has rarely been questioned. This paper discusses a model of client/nurse educator collaboration in a mental health course with undergraduate nursing students. It draws on the nursing education experiences of the first author, and the personal views of the second author, a user of mental health services. Specifically, it addresses positive features of collaboration as perceived by students, client, and nurse educator and analyzes some of the challenges/issues for the nurse educator. In addition, it outlines helpful aspects of the collaborative process for both nurse educator and client, in particular, its impact on the client's personal well being. This kind of analysis is essential if we are to develop education models of such collaboration that are beneficial for all partners in the learning process.
Kelley, B.R. 1995. Community-based research: a tool for community empowerment and student learning. *Journal of Nursing Education* 34(8): 384-6.	**Capacity** Education	Teaching nursing research is most often done close to the end of the student's educational experience. This article describes Northeastern University College of Nursing's experience using community-based research projects as a method of teaching nursing concepts and skills to beginning nursing students. By using Paulo Freire's model of Community Empowerment, a group of inner-city teens developed a drug awareness manual that is used to teach elementary school students about drugs and drug use. Through this model, students also learn that healthcare is a partnership among individuals, communities and professionals.
Manthorpe J., Alaszewski A., Gates B., Ayer S. and Motherby E. (2003) Learning disability nursing: User and carer perceptions *Journal of Learning Disabilities* (London). Vol. 7(2)(pp 119-135), 2003.	**Capacity** Education	It is frequently asserted that the views of patients or service users should inform the structure and delivery of health and social care services. In the UK, patient participation, the expertise of service users and user involvement in the design and outcomes of research have been repeatedly emphasised as producing services which are more responsive, better coordinated and less stigmatising. The NHS has highlighted the importance of involving service users in education and training. This article reports on user and carer views about learning disability nursing.

Shaywitz, D.A., Martin, J.B. and Ausiello, D.A. 2000. Patient-oriented research: principles and new approaches to training. *American Journal of Medicine* 109(2): 136-40.	**Capacity** Education	The authors of this essay explain that a challenge for physicians and physician-scientists is ensuring that advances in medical technology find expression in clinical practice. They identify a need to develop broader, more integrative approaches to understanding how biological and physiological knowledge function in the context of the whole person. Although there appears to be a consensus about the need to pursue such integrative, patient-oriented research, a mechanism for training future investigators in this discipline is less well established. The authors present and develop the rationale for a set of underlying principles for patient-oriented research that can be used to guide appropriate training in this field. They also describe briefly a recently established prototype program-the Harvard initiative in Patient-Associated Science: Training, Education, Understanding, and Research (PASTEUR)-that they hope will help train patient-oriented investigators and support the evolution of patient-oriented research into a fully realised academic discipline.
Thornton, H. 2001. Information and involvement. *Health Expectations* 4:71-4.	**Capacity** Education	This article discusses the beliefs that provision of good quality information is the key to (a) successful and satisfying involvement of patients in their own decision-making and (b) involvement of lay people in the research process, in debate and other involvement in wider health issues. Education of children, health professionals, the public and the media is advocated, enabling critical appraisal skills and good quality health information to lead to improved involvement of citizens in health-care decisions of all kinds, both individual and societal. Examples of individual, group and specific group involvement through research projects, debates about screening; Citizens' Juries, etc. are used to illustrate benefits to patients and to health provision in general.
Felton, A. and Stickley, T. Pedagogy, power and service user involvement. *Journal of Psychiatric & Mental Health Nursing* 11(1): 89-98.	**Capacity** Education (recruitment and retention)	This paper explores mental health nurse educators' perceptions of the involvement of service users in pre registration nurse education. The concepts of 'role' and power relationships are used to explore the reasons for ineffective involvement of service users in education.

Fox, J. 2003. Consumerism 2: pre registration nursing and midwifery curricula. *British Journal of Nursing* 12(6): 378-86.	**Capacity** Education	This article presents findings from a four-stage study exploring the extent to which consumerism and its related aspects have been incorporated into the pre-registration nursing and midwifery curriculum. The study involved use of a Delphi panel, postal questionnaire, review of curriculum documentation, and timetables, together with a small focused group discussion. Findings indicate some aspects relevant to consumerism in health care, e.g. communication and ethical principles were included in the curriculum. Other aspects, such as advocacy, quality assurance, and lay health beliefs, were viewed logically from the perspective of the professional role. In essence, no curriculum transparently addressed consumerism in a central and focused way, although midwifery - and to some extent mental health, learning disabilities, and child branches -gave more overt attention to consumerism than adult branches.
Forrest, S., Risk, I., Masters, H. and Brown, N. 2000. Mental health service user involvement in nurse education: exploring the issues. *Journal of Psychiatric and Mental Health Nursing.* 7(1): 51-7.	**Capacity** Education	This paper reports on findings and issues arising from a study designed to promote mental health service users' involvement in a pre registration nursing curriculum. Users' views about the knowledge, skills and attributes required by mental health nurses were explored to inform the curriculum design. Strategies that would facilitate long term, active user involvement in the design and delivery of the curriculum were also explored. Findings are presented with concurrent discussion of issues arising from the research process in relation to user involvement in education. The issue of 'conflict' explores findings relating to users' views of a 'good' mental health nurse and inherent conflicts between user and professional views are highlighted. The representativeness of the research participants is explored and debated in relation to service user involvement in nurse education. Finally, the concepts of 'involvement' and 'tokenism' are discussed and recommendations made about how active user involvement in nurse education can be achieved.
Kavanagh, K., Absalom, K., Beil, W. Jr. and Schliessmann, L. 1999. Connecting and becoming culturally competent: a Lakota example. *Advances in Nursing Science* 21(3): 9-31.	**Capacity** Education	Addressing how nurses become culturally competent is essential for knowledge development beyond why sociocultural understandings are important. This article reports participatory research conducted during intercultural immersion learning experiences of non-native nurses on an Indian reservation. Emphasising collaborative relationships within unfamiliar social, political, and economic circumstances, and using Diekelmann's ‘concernful practices’ as an organising scheme, prompted participants to explicate practices that promote intercultural connecting. Suggesting integral shifts in value orientations with changes in cultural competence, the findings argue for attending to associations between those dynamics and potential for developing co-responsibility (with consumer groups) for advocating improved health and health care.

Morrell-Bellai, T. and Boydell, K. 1994. The experience of mental health consumers as researchers. *Canadian Journal of Community Mental Health* 13(1): 97-110.	**Capacity** Researcher skills	Experiences of consumer researchers.
Reeve, P., Cornell, S., D'Costa, B., Janzen, R. and Ochocka, J. 2002. From our perspective: consumer researchers speak about their experience in community mental health research project. *Psychiatric Rehabilitation Journal* 25(4): 403-408.	**Capacity** Researcher skills	Experiences of consumer researchers.
Canter, R. 2001. Patients and medical power. *British Medical Journal* 323(7310): 414.	**Capacity** Research culture	Power within caring professions.
Hugman, R. 1994. *Power in Caring Professions*. London: Macmillan Press.	**Capacity** Research culture	Professional power.

Liberty, K.A., Laver, A. and Sabatino, D. 1999. Collaborative partnerships in evaluation and experimental rehabilitation research. *Journal of Biomechanics* 22(4): 283-90.	**Capacity** Research culture	This paper contrasts the relationship between researchers and subjects in traditional rehabilitation evaluation and research with relationships between researchers and clients-consumers in newer methodologies. The limitations and challenges to these models are discussed. Collaborative research, characterised by shared power and non-hierarchical authority between client-consumers and researchers, is described as an alternative model for experimental and evaluative research. Collaborative relationships provide a structure for building upon the knowledge and expertise of each research partner. The authors draw upon their own experience of collaborative research partnerships and models of research partnerships are described. Research developed and conducted in a collaborative partnership can include quantitative and qualitative approaches, maintain traditional scientific perspectives of objectivity, reliability and replicability, and improve participation rates, continuity of involvement for longitudinal studies and utilisation of researched methods into practice.
Tallon, D., Chard, J. and Dieppe, P. 2000. Relation between agendas of the research community and the research consumer. *Lancet* 355(9220): 2037-2040.	**Capacity** Research culture	This study set out to determine whether there is a discrepancy between available research evidence and the research preferences of consumers. The authors examined research on interventions for the treatment of osteoarthritis of the knee joint by searching published and unpublished studies to assess the structure of the evidence base. Focus groups and a postal survey of research consumers were then undertaken to examine their views and research priorities. The review of published and unpublished reports showed that the evidence base was dominated by studies of pharmaceutical (550, 59%) and surgical (238, 26%) interventions. 24 (36%) of 67 survey respondents ranked knee replacement as the highest priority for research, whereas 14 (21%) chose education and advice. The authors conclude that there is a mismatch between the amount of published work on different interventions and the degree of consumer interest. They suggest that broadening the research agenda would be more in line with current treatment patterns and consumer views and warn that if this mismatch is not addressed, then evidence-based medicine will not represent consumer needs.
Reed, J., Weiner, R. and Cook, G. 2004. Partnership research with older people - moving towards making the rhetoric a reality. *Journal of Clinical Nursing*. 13 (3a): 3-10.	**Capacity** Research culture	As nursing develops closer partnerships with older people in delivering care, it also needs to develop partnerships in order to create the knowledge base for practice in a way that challenges professional hegemony and empowers older people. However, the process of developing partnerships in research takes place against a background of academic research traditions and norms, which can present obstacles to collaboration. This paper is a reflection on the issues that have arisen in three projects where older people were involved in research at different levels, from sources of data to independent researchers. It points to some of the areas that need further exploration and development.

Cody, W.K. 2003. Paternalism in nursing and healthcare: central issues and their relation to theory. *Nursing Science Quarterly* 16(4): 288-96.	**Capacity** Research culture	Paternalistic practices, wherein providers confer a treatment or service upon a person or persons without their consent, ostensibly by reason of their limited autonomy or diminished capacity, are widespread in healthcare and in societies around the world. In the United States, paternalism in health and human services is widespread and probably increasing with newly emergent forms. Numerous issues surround paternalistic practices. In this column, the author examines these issues in relation to theory development in healthcare and nursing as well as theory as a guide to practice. It is suggested that scientific and ethical knowing are not separate but must be united in theoretical structures that include both in unity, along with an appreciation of the infinite complexity of life as it is humanly lived. It is also suggested that nursing's unique theory base of frameworks that honour human dignity and focus on human experience offers an opportunity for leadership in further developing theoretical frameworks that transcend paternalistic practices.
Coghlan, D. and Casey, M. 2001. Action research from the inside: issues and challenges in doing action research in your own hospital. *Journal of Advanced Nursing.* 35(5): 674-82.	**Capacity** Research culture	There is a paucity of literature on the challenges that face nurse action researchers on doing action research in their own hospital. The aim of this article is to address this paucity by exploring the nature of the challenges, which face nurse action researchers. Challenges facing such nurse-researchers are that they frequently need to combine their action research role with their regular organisational roles and this role duality can create the potential for role ambiguity and conflict. They need to manage the political dynamics which involve balancing the hospital's formal justification of what it wants in the project with their own tactical personal justification for the project. Nurse-researchers' pre-understanding, organisational role and ability to manage hospital politics play an important role in the political process of framing and selecting their action research project. In order that the action research project contribute to the organisation's learning, nurse action researchers engages in interlevel processes engaging individuals, teams, the interdepartmental group and the organisation in processes of learning and change. Consideration of these challenges enables nurse-action researchers to grasp the opportunities such research projects afford for personal learning, organisational learning and contribution to knowledge.
Chambers, R. 2000. User involvement should be integral to research and everyday practice. *Physiotherapy Singapore* 5(4): 189-91.	**Capacity** Researcher skills	Argues that user involvement should be integral to everyday working rather than being seen as an add on or particular set of activities.

Britten, N. 2003. Clinicians' and patients' roles in patient involvement. *Quality & Safety in Health Care* 12(2): 87.	**Capacity** Researcher skills	Places an onus on professionals to change practice to involve patients in clinical decision making.
Meyer, M.C., Torres, S., Cermeno, N., MacLean, L. and Monzon, R. 2003. Immigrant women implementing participatory research in health promotion. *Western Journal of Nursing Research* 25(7): 815-34.	**Capacity** Researcher skills	Few studies on women's health include immigrant women as participants, and fewer are conducted by immigrant women themselves. In this article, the authors present a model that allowed their full participation as researchers and authors. They describe their experiences using participatory research methods with Hispanic women in multiple ways to reach out to isolated women, collect data about community needs, and provide health education. They explore the advantages and challenges of being trained for both researcher and health educator roles, describe opportunities to use this approach to assess service needs, and discuss the potential for personal empowerment. They also report on the time commitment that such a bilingual project requires. In the process of interviewing marginalised women, they realised how much health promotion and participatory research complement each other. The authors conclude that combining participatory research with health promotion activities has promise to contribute toward increased empowerment of immigrant communities.
Oda, D.S., Ogrady, R.S. and Strauss, J.A. 1994. Collaboration in investigator initiated public-health *Nursing Research* - university and agency considerations. *Public Health Nursing* 11(5): 285-290.	**Capacity** Research culture	There is a significant difference in the collaborative process between whether a *Public Health Nursing* research project is requested (of the researchers) by the agency or if it is conceived by an outside investigator. This article discusses the underlying concepts of negotiation, mutuality, and respect and the important components within the planning, development, implementation, and completion phases of project working.

Law, S. and Janzon, K. 2004. Engaging older people in reviewing the influence of service users on the quality and delivery of social care services. *Research Policy and Planning* 22(2): 59-64.	**Capacity** Strategic	Engaging older people in reviewing the influence of service users on the quality and delivery of social care services.