doi: 10.1111/j.1369-7625.2007.00450.x

Patient involvement in patient safety: what factors influence patient participation and engagement?

Rachel E. Davis MSc,* Rosamond Jacklin MRCS,† Nick Sevdalis PhD‡§ and Charles A. Vincent PhD¶

*Research Associate, Clinical Safety Research Unit, Department of Bio-Surgery and Surgical Technology, QEQM, St Mary's Hospital, London, UK, †Clinical Research Fellow, Clinical Safety Research Unit, Department of Bio-Surgery and Surgical Technology, QEQM, St Mary's Hospital, London, UK, ‡Lecturer in patient safety, Clinical Safety Research Unit, Department of Bio-Surgery and Surgical Technology, QEQM, St Mary's Hospital, London UK, §National Patient Safety Agency, 4–8 Maple St., London, UK, ¶Director of the Clinical Safety Research Unit, Department of Bio-Surgery and Surgical Technology, QEQM, St Mary's Hospital, London, UK

Correspondence
Rachel Davis
Clinical Safety Research Unit
Department of Bio-Surgery and Surgical Technology
10th floor, QEQM, St Mary's Hospital
South Wharf Road
London
W2 1NY
UK
E-mail: rachel.davis@imperial.ac.uk

Accepted for publication
4 April 2007

Keywords: patient involvement, patient participation, patient safety, treatment decision-making

Abstract

Background Patients can play an important role in improving patient safety by becoming actively involved in their health care. However, there is a paucity of empirical data on the extent to which patients take on such a role. In order to encourage patient participation in patient safety we first need to assess the full range of factors that may be implicated in such involvement.

Objective To delineate factors that could affect the participation of the patient in quality and safety issues in their health care.

Method Literature review of patient involvement in health care, drawing from direct evidence (specifically from the safety context) and indirect evidence (extrapolated from treatment decision-making research and the wider patient involvement in health care literature); synthesis and conceptual framework developed, illustrating the known and putative factors that could affect the participation of the patient in safety issues in their health care.

Main results Five categories of factors emerged that could affect patient involvement in safety: patient-related (e.g. patients' demographic characteristics), illness-related (e.g. illness severity), health-care professional-related (e.g. health care professionals' knowledge and beliefs), health care setting-related (e.g. primary or secondary care), and task-related (e.g. whether the required patient safety behaviour challenges clinicians' clinical abilities).

Conclusion The potential for engaging patients in patient safety is considerable but further research is needed to examine the influences on patient involvement, the limits and the possible dangers. Patients can act as 'safety buffers' during their care but the responsibility for their safety must remain with the health care professionals.

Introduction

Empowering patients to take an active role in their own health care has been nationally and internationally identified as a key factor in the drive to improve health services for the patient.[1,2] Patients can play an important role in the reduction of patient safety incidents (defined by the UK's National Patient Safety Agency (NPSA) as unintended or unexpected incidents which could have or did lead to harm for one or more patients receiving NHS funded care). At most stages of care there is the opportunity for the patient to contribute, for example, helping avoid medication errors and the monitoring of adverse events.[3,4] There are currently a number of national and international initiatives which support this view, which aim to facilitate patient involvement in safety.[5–8] However, the acceptability of such interventions from the patients' perspective remains unknown.

Engaging patients in the safety of the care delivered to them, however, should not be taken to mean that the patients should carry the ultimate responsibility for the safety of the care that they receive. Patients can only function as a safety 'buffer' (often, the very last one) in addition to those in the healthcare system that are already in place. In other words, patients should not feel that if they do not wish or are unable to contribute to their own safety they will, as a result, receive substandard care. Equally, the responsibility of delivering safe care remains in the hands of the health care professionals.[9]

Involving patients in safety represents a specific instance of the wider concept of patient participation in health care. Preliminary studies on patient perceptions of errors in primary care suggest that it is unlikely that patients will view safety issues in a different way to more generic concerns about the quality of health care,[10,11] though engagement in safety will carry some specific challenges. These may include the fact that some safety-related patient behaviours may be perceived by patients and clinicians alike as challenging clinicians' professionalism. In addition, while in other areas of patient involvement in health care, patient involvement has been well documented (e.g. patient involvement in TDM), patient involvement in safety is an emerging field of interest with limited evidence.

Aims of this review

In order to increase patient engagement in safety we must first assess the factors that may affect whether a patient would take on such an active role. Consequently, our aims in this review are threefold. Firstly, we aim to outline a conceptual framework encompassing both known and putative factors affecting patient participation in the safe provision of health care. We will draw upon the patient involvement in safety literature and where necessary the wider research on patient involvement in health care, namely patient participation in TDM. Secondly, we review the existing evidence for those factors – both direct (drawn specifically from the safety context) and indirect (i.e. extrapolated from TDM and the wider arena of patient involvement in health care). Thirdly, we discuss the practical implications of the reviewed research in terms of patient involvement in safety.

Developing a conceptual framework

We selectively reviewed the evidence on both the direct and indirect factors likely to influence patient participation in safety-related behaviours. We comprehensively examined the issues that emerged from the literature grouping them in five broad categories:

1. *Patient-related*: patients' knowledge and beliefs about safety; emotional experiences with health care delivery and relevant coping styles; and demographic characteristics.
2. *Illness-related:* stage and the severity of the patients' illness(es); symptoms; treatment plan; patients' health outcomes; and prior experience of illness (and prior experience of patient safety incidents).
3. *Health care professional (HCP)-related*: health care professionals' knowledge and beliefs about safety and patients' involvement in it; and the way in which health care professionals interact with patients.

4. *Health care setting (HCS)-related*: type of health care setting – primary, secondary or tertiary care setting; and admission process – emergency or elective.
5. *Task-related*: the specific patient actions/behaviours required for involvement in safety.

We consider these five main categories to provide a useful conceptual framework for organizing and understanding the likely determinants of patient participation in safety-related behaviours. It is likely that complex interactions exist between these factors but given that research on patient involvement in safety is in its infancy, inclusion of such interactions would render the framework cumbersome without, at the same time, providing evidence-based insights into the determinants of patient involvement. Table 1 summarises the evidence for the influence of these determinants under these five main categories.

Patient-related factors

Knowledge and beliefs

If patients perceive themselves as vulnerable to patient safety incidents, they may want to play a role in reducing their susceptibility to such occurrences. Studies looking at the public opinion found that (in the United States) 75% perceive health care as only being 'moderately' safe and would be concerned about the risk of medical errors if hospitalised.[12,13] Additional research has shown that 49% of the public felt that preventable medical errors were made 'somewhat often' or 'very often' and 59% of respondents felt that patients were 'somewhat often' or 'very often' partially responsible for errors in their own care.[14]

These generally held views are also reflected in those of the hospital inpatient population. For instance, studies have shown that patients understand that they are at risk of patient safety incidents.[15,16] Further, when errors do occur, patients are unanimous in their view that they want more information about such errors and how they can be prevented in the future.[17] With this in mind patients may want to participate in the reduction of patient safety incidents. Indeed, interventions aiming to lower prevalence rates of medication errors and hospital-acquired infections by encouraging patients to be involved in their health care and ask health care professionals questions provide some support for this view.[15,16]

Demographic characteristics

Patient involvement with the process of healthcare delivery has been found to vary according to the patient's age, sex and education and possibly also ethnicity, though this finding requires further research.[18–21] Younger patients tend to want more involvement than older patients, females prefer a more active role than males and highly educated patients opt for greater engagement than their less academic peers.[18–20] It has been suggested that some of these effects are due to differences in health literacy levels[22–24] – in general younger and more educated patients tend to have a greater capacity for obtaining, processing, and comprehending basic health information needed to make appropriate health decisions.

Emotional experiences and coping styles

Patients' experience of their illness(es) triggers predominantly negative-emotional reactions of vulnerability and anxiety.[25] Such negative emotions can cause patients to have an increased perception of vulnerability to negative life events,[26,27] perhaps including patient safety incidents; this may in turn increase participation in safety-related behaviours.

In addition, patients' strategies for dealing with their illness(es) or health care experience can affect involvement. Research exemplifies that active coping styles are conducive to greater involvement in medical decisions.[28] In the same way, active coping strategies could lead to greater involvement in safety.

Illness-related factors

Stage and severity of illness

Preliminary findings suggest that patients with less severe conditions may take on a more active role in their health care than patients who suffer

Table 1 Factors affecting patients' willingness to participate in improving the safety of their own health care

Factor		Evidence/relevant information
1. Patient-related	*Knowledge/beliefs*	**The public is concerned about the risk of medical errors if hospitalised,[12,13] 75% feel health care is only moderately safe[12,13] and 49% feel preventable medical errors are made 'somewhat often' or 'very often'[14]** **Patients understand the risk of medication errors and hospital acquired infections[15,16]** **59% of the public feel that patients' are 'somewhat often' or 'very often' partially responsible for errors in their own care [14]** **Patients feel they have a role in reducing their susceptibility to patient safety incidents, including medication errors[16]**
	Demographic features	Younger patients generally want more involvement than older patients[18–20] Females want more involvement than males[18] Highly educated patients opt for a more active role than their less academic peers[18–20]
	Emotions and coping style	Patients' experiences with their illness can trigger negative emotions (e.g. anxiety).[25] Negative emotions may heighten patients' perceptions of vulnerability to negative life events,[26,27] which may catalyse their participation in safety-related behaviours. Patients that use more active coping styles express greater preferences for involvement[28]
2. Illness-related	*Stage/severity of illness*	Some studies show patients with minor complaints are more likely to prefer an active role than patients with severe disease[18,29] but opposing findings show patients with serious illness/whose illness is further progressed, have higher preference for involvement[30]
	Illness symptoms, treatment plan and patients' health outcomes	Patients' preferences for involvement may change over time dependent on the symptoms of the illness[31] *Preference for involvement may be associated with illness symptoms and how these affect the functionality of the patient* *Preference for involvement may be associated with the type of treatment plan for the illness and how much opportunity for involvement this allows* *Preference for involvement may be associated with the likely impact that patient involvement will have on the patients' health outcomes*
	Prior experience • Illness	Patients' experience of illness is associated with higher preference for involvement for treatment of that illness.[32] Experience of a patient safety incident may have a similar effect in terms of an increased preference for involvement in safety-related behaviours
	• Patient safety incidents	**National and international organizations have been founded by victims of patient safety incidents** (http://www.mrsasupport.co.uk; http://www.patientsafety.org)
3. Health care professional-related	Knowledge/beliefs	**58% physicians felt that patients were either 'very often' or 'somewhat often' partially responsible for medical errors in their care.[14]**
	Interactions with patients	Clinicians generally express positive views on patient involvement [34] Positive interactions with health professionals can encourage patient participation;[35,36] Negative interactions can act as an inhibitor[37]
	HCP's professional role	**100% patients were willing to ask a nurse whether they have washed their hands, but only 35% were willing to ask a doctor[15]**

Table 1 (Continued)

Factor		Evidence/relevant information
4. Health care setting-related	Health care setting	Patients have more difficulty communicating with hospital staff than their GP,[35,38] so may be less willing to engage in safety-related behaviours which require direct communication with staff in the hospital setting. Emergency patients are typically unsure what is wrong with them so may be less willing to be involved than patients receiving ambulatory Care[39]
5. Task-related	Challenge to HCPs	*It is likely that patients will be more willing to be involved in safety-related behaviours that do not challenge the health care professionals' clinical abilities.*
	Medical knowledge required	Patients prefer to be more involved in those aspects of their health care that do not require medical knowledge.[40]

Note – For factors/relevant information: Bold face type indicates direct evidence of effect of factor on patients' willingness to be involved in safety; Normal type indicates possible effect/indirect evidence and relevant observations drawn from TDM literature and other sources; Italic type indicates suggestive factors that could affect patients' willingness to participate in safety.

from more debilitating illnesses. For instance, patients with mild hypertension or minor upper-respiratory tract infections are more involved in their care than patients with severe diabetes, heart disease or cancer.[18] Similarly, asymptomatic HIV patients participate more than symptomatic patients.[29] However, not all the existing evidence is consistent: for example, a study on women with ovarian cancer showed that, regardless of age, those women with more serious prognosis or metastases were more involved than those with better prognoses.[30]

Illness symptoms, treatment plan and patients' health outcomes

The equivocal data on the relationship between illness severity and preference for involvement could suggest that rather than illness severity *per se* affecting patient involvement, a number of other factors which are related to illness severity may mediate patient engagement in health care. Patient involvement may be associated with: how the illness symptoms manifest themselves; how such symptoms affect functional status; the type of treatment plan for the illness and how much opportunity for involvement this allows; and the likely impact that patient involvement will have on the patients' health outcomes. For example, it is essential for chronically ill patients to participate in their care in order to successfully manage the illness and to avoid or reduce the likelihood of progression and exacerbation of symptoms. Patient participation in chronically ill patients may therefore change over time and through the course of an illness dependent on the symptoms of the illness – a view that has received some empirical support in diabetic patients.[31] On the other hand, patients who are terminally ill may view involvement in a different way; participating in decisions about their health care may be very important to them, but other forms of active engagement might seem both burdensome and irrelevant. Even if patients that are terminally ill would want to participate in their health care, the extent to which they can do this may be prevented/restricted by their illness. For instance the functionality of patients that are further progressed in their illness may be limited (e.g. they

may be bedridden, need to be fed and bathed); this may, depending on the type of safety-related behaviour required, inhibit patients' participatory levels. Furthermore, some illnesses of later life such as Alzheimer's disease will, as the illness progresses affect the patients' cognitive capacity, with the patient becoming confused and disorientated; in situations such as this it is likely that the patient would be incapable of engaging in safety-related behaviours.

Other illness-related factors: prior experience of illness and/or prior experience of patient safety incidents

Prior experience of a particular illness is associated with patient involvement. Research has shown that patients who have had a recent myocardial infarction (MI), angioplasty or coronary artery bypass graft participate more in decisions concerning acute MI than those patients that have no history of heart disease.[32] Prior experience of a patient safety incident may similarly increase involvement with safety. On an individual level, if a patient has witnessed or experienced such an incident (either first or second hand) they may participate more in safety-related behaviours in their own care in the future (e.g. checking they have been given the correct medication). On a collective level, prior experience of a patient safety incident can result in a patient becoming involved in patient safety issues for patients as a whole. Large-scale examples include national and international organizations such as MRSA Support in the United Kingdom (http://www.mrsasupport.co.uk) and Consumers Advancing Patient Safety in the United States (http://www.patientsafety.org); both of which were founded by individuals that had experienced a patient safety incident either first or second hand (i.e. personally or through members of their family).

Health care professional-related factors

Knowledge and beliefs

Fifty-eight percentage of physicians surveyed (in the United States) for a study looking at perceptions of medical errors, felt that patients were either 'very often' or 'somewhat often' partially responsible for medical errors in their care,[14] suggesting that they may consider patients have a role in reducing their own vulnerability to such occurrences. This view is important because the knowledge and beliefs of health care professionals undoubtedly have an extremely influential role in determining patient involvement. For instance, within the TDM literature, midwives' beliefs have been found to considerably affect patient involvement in antenatal HIV testing. In addition, the same study exemplified that if other information resources (e.g. leaflets) were not concordant with the midwives beliefs, the midwife may withhold the conflicting information from the patient;[33] this in turn, could reduce the patient's involvement potential.

It is therefore crucial that health care professionals hold positive beliefs regarding patient participation in safety so that they encourage (and not inhibit) such patient activity. However, while research is indicative that health care professionals generally express positive views on patient involvement,[34] the extent to which they would support patient participation in safety is unclear. Patients questioning health care professionals on, for example, whether they have washed their hands, or been given the correct medication, are substantial extensions of the patients' role and arguably a relinquishment of responsibility for the health care professional.

Interactions with patients

It has been reported that the way in which health care professionals' interact with patients can affect patient participation in health care. Patient participation can be increased by health care professionals who respond positively to patients' needs and views and who provide feedback to patients' concerns.[35,36] Conversely, participation can be decreased by health care professionals who are dismissive towards the patients' concerns.[37]

Health care professionals' professional role

Preliminary evidence indicates that while patients may be willing to play an active role in the reduction of patient safety incidents, patients

do not feel equally comfortable questioning the safety practices (or lack there of) of all health-care staff. For example, in an intervention aiming to involve patients in their health care in order to reduce prevalence rates of hospital acquired infections, it was found that whilst patients would ask nurses whether they had washed their hands, only about a third of them would pose the same question to doctors.[15]

Health care setting-related factors

The setting of health care delivery (i.e. primary, secondary, or tertiary) in which health care is delivered may affect patient involvement. For instance, patients experience greater difficulty communicating with hospital staff than with their GPs.[35,38] With this in mind, patients may be less involved in safety-related behaviours when they are hospitalised. This may be particularly evident in patients that are admitted as an emergency. These patients may have less opportunity for involvement (dependent on their presenting health complaint) than, for example, a patient receiving ambulatory care; emergency patients are typically unsure about what is wrong with them and thereby they are less able and knowledgeable about how to get involved with their care.[39]

Task-related factors

Type of safety-related behaviours

The nature of the required patient safety behaviour will influence patient participation in such behaviours. For example, it is easier for patients to keep a clear record of their medical history than to confront health care professionals on issues concerning the delivery of their health care, such as whether they have washed their hands. Such behaviours may be perceived as offensive to health care professionals by patients and health care professionals alike. In addition, patients are more involved in aspects of their health care that do not require medical knowledge[40] (possibly because they perceive them as less confrontational to the clinician).

Practical implications of the research findings

This overview suggests that patient participation in safety will be dependent on a complex interplay of patient-related, health care professional-related, illness-related, health care setting-related and task-related factors. We have seen that patients' and health care professionals' knowledge and beliefs will undoubtedly have an important influence on patient involvement in safety-related behaviours. Therefore, in order to achieve effective and sustainable outcomes for the active involvement of the patient in patient safety, it is important to foster a working partnership between patients and health care professionals. This requires that patient involvement in safety-related behaviours be perceived by all (i.e. hospital staff (e.g. nurses, doctors) and patients) as beneficial to the medical encounter rather than challenging the health care professionals' clinical skills and abilities.

We have also seen that patients' illness-related factors (e.g. its severity) could be an equally important predictor of patient involvement in the safety of their health care. Even if a patient possesses the requisite safety-related knowledge and beliefs on how to be involved in their care and are willing to take on such a role, they may, through no choice of their own, not be capable of participating. In some instances, such as with terminally ill patients, the impact of the patient's illness may override all other factors. Finally, we have considered the impact of a number of other factors on patient participation in safety-related behaviours, including patient demographic characteristics, the hospital admission process and others.

Our review suggests that there is a pressing need for empirical research to investigate, firstly, the relative impact/importance of each of these factors in determining patient involvement and, secondly, the interactions between them. Once these questions have been elucidated, interventions targeted to patients who have the potential to get involved can be designed, implemented, and evaluated. We believe that it is unlikely that interventions adopting a 'one size fits all' approach will be successful in facilitating patient

involvement in safety. Given the number of factors that emerged from our review, we think that interventions which are targeted carefully to specific patient groups and which employ a 'multi-modal' approach are probably more likely to engage patients successfully. For example, specific interventions could be targeted at chronic patients who have substantial knowledge both of their illness and its treatments and also of the health care system. In addition different interventions could be developed for patients of varying health literacy levels. The modalities of such interventions could include information leaflets for patients, information campaigns targeted at health care professionals, and perhaps the development of guidelines for both health care staff and for patients.

It is, however, important to remember that patient involvement in safety is only a small part of a much bigger drive to improve the safety of modern health care systems through a variety of interventions (e.g. re-design, team training, IT solutions, etc.). Patients should only be seen as safety safeguards when they want and are able to.

Acknowledgements

This work was funded by the Health Foundation.

References

1 Department of Health. *Creating a Patient-Led NHS: Delivering the NHS Improvement Plan*. London: Department of Health, 2005a.
2 Institute of Medicine. *To Err is Human: Building a Safer Health System*. Washington D.C., United States: Institute of Medicine, 1999.
3 Koutantji M, Davis R, Vincent CA, Coulter A. The patient's role in patient safety: engaging patients, their representatives, and health professionals. *Clinical Risk*, 2005; **11:** 99–104.
4 Vincent CA, Coulter A. Patient safety: what about the patient? *Quality and Safety in Health Care*, 2002; **11:** 76–80.
5 National Patient Safety Agency. *Clean your Hands Campaign*. London: National Patient Safety Agency, 2004.
6 National Patient Safety Foundation. *Safety as you Go Home from Hospital*. North Adams, MA, United States: National Patient Safety Foundation, 2003a.
7 National Patient Safety Foundation. *Preventing Infections in the Hospital – What you can do*. North Adams, MA, United States: National Patient Safety Foundation, 2003b.
8 Agency for Healthcare Research & Quality. *Twenty Tips to Prevent Medical Errors*. Rockville, MD, United States: Agency for Healthcare Research & Quality, 2000.
9 Entwistle VA, Mello MM, Brennan TA. Advising patients about patient safety: current initiatives risk shifting responsibility. *Joint Commission Journal on Quality and Patient Safety*, 2005; **31:** 483–494.
10 Kuzel AJ, Woolf SH, Gilchrist VJ. Making the case for a qualitative study of medical errors in primary care. *Health Research*, 2003; **13:** 743–780.
11 Kuzel AJ, Woolf SH, Gilchrist VJ. Patient reports of preventable problems and harms in primary care. *Annals of Family Medicine*, 2004; **2:** 333–340.
12 National Patient Safety Foundation. *Patient Safety: Your Role in Making Healthcare Safer*. North Adams, MA, United States: National Patient Safety Foundation, 2002.
13 National Patient Safety Foundation. *National Patient Safety Foundation at the AMA: Public Opinion on Patient Safety Issues, Research Findings*. North Adams, MA, United States: National Patient Safety Foundation, 1997.
14 Blendon RJ, DesRoches CM, Brodie M *et al.* Views of practicing physicians and the public on medical errors. *New England Journal of Medicine*, 2002; **347:** 33–39.
15 McGuckin M, Waterman R, Storr J *et al.* Evaluation of a patient-empowering hand hygiene programme in the UK. *Journal of Hospital Infection*, 2001; **48:** 222–227.
16 Weingart SN, Toth M, Eneman J *et al.* Lessons from a patient partnership intervention to prevent adverse drug events. *International Journal for Quality in Health Care*, 2004; **16:** 449–507.
17 Gallagher TH, Waterman AD, Ebers AG, Faser VJ, Levinson W. Patients' and physicians' attitude regarding the disclosure of medical errors. *Journal of American Medical Association*, 2003; **289:** 1001–1007.
18 Arora NK, McHorney CA. Patient preferences for medical decision making: Who really wants to participate? *Medical Care*, 2000; **38:** 335–412.
19 Beaver K, Luker KA, Owens RG, Leinster SJ, Degner LF, Sloan JA. Treatment decision-making in women newly diagnosed with breast cancer. *Cancer Nursing*, 1996; **19:** 8–19.
20 Degner LF, Kristjanson LJ, Bowman D *et al.* Information needs and decisional preferences in women with breast cancer. *Journal of the American Medical Association*, 1997; **277:** 1485–1492.

21 Strull WM, Lo B, Charles G. Do patients want to participate in medical decision making? *Journal of American Medical Association*, 1984; **253:** 2990–2994.
22 Williams MV, Davis T, Parker RM, Weiss BD. The role of health literacy in patient-physician communication. *Family Medicine*, 2002; **34:** 383–389.
23 Adelman RD, Greene MG, Ory MG. Communication between older patients and their physicians. *Clinical Geriatric Medicine*, 2000; **16:** 1–24.
24 Schillinger D. Improving the quality of chronic disease management for populations with low functional health literacy: a call to action. *Disease Manage*, 2001; **4:** 103–108.
25 Department of Health. 'Now I feel Tall' What a Patient-Led NHS Feels Like. London: Department of Health, 2005b.
26 Mayer JD, Gaschke YN, Braverman DL, Evans TW. Mood congruent judgement is a general effect. *Journal of Personality and Social Psychology*, 1992; **63:** 119–132.
27 Tripp G, Tan S, Milne J. Risk perception and anxiety. *New Zealand Journal of Psychology*, 1995; **24:** 37–43.
28 Adams RJ, Smith BJ, Ruffin RE. Patient preferences for autonomy in decision making in asthma management. *Thorax*, 2001; **56:** 126–132.
29 Catalan J, Brener N, Andrews H *et al*. Whose health is it?. Views about decision-making and information-seeking from people with HIV infections and their professional carers *AIDS Care*, 1994; **6:** 349–356.
30 Stewart DE, Wong F, Cheung M *et al*. Information needs and decisional preferences among women with ovarian cancer. *Gynaecology Oncology*, 2000; **77:** 357–361.
31 Thorne SE, Paterson BL. Healthcare professional support for self-care management in chronic illness: insights from diabetes research. *Patient Education and Counselling*, 2001; **42:** 81–90.
32 Mansell D, Poses RM, Kazis L, Duefield CA. Clinical factors that influence patients' desire for participation in decisions about illness. *Archives of Internal Medicine*, 2000; **160:** 2991–2996.
33 O'Cathain A, Walters SJ, Nicholl JP, Thomas KJ, Kirkham M. Use of evidence based leaflets to promote informed choice in maternity care: randomised controlled trial in everyday practice. *British Medical Journal*, 2002; **324:** 643–646.
34 Entwistle V, Watt I, Bugge C *et al*. Exploring patient participation in decision-making. In: Farrell C (ed.) *Patient and Public Involvement in Health: The evidence for Policy Implementation-A Summary of Results of the Health in Partnership Research Programme*. London: Department of Health, 2004.
35 Preston C, Cheater F, Baker R, Hearnshaw H. Left in limbo: patients' views on care across the primary/secondary interface. *Quality in Health Care*, 1999; **8:** 16–21.
36 Little P, Dorward M, Warner G *et al*. Randomised controlled trial of effect of leaflets to empower patients in consultations in primary care. *British Medical Journal*, 2004; **328:** 441–444.
37 Saino C, Lauri S, Eriksson E. Cancer patients' views and experience of participation in care and decision making. *Nursing Ethics*, 2001; **8:** 97–113.
38 Bruster S, Jarman B, Bosanquet N. National survey of NHS patients. *British Medical Journal*, 1994; **309:** 1542–1546.
39 Harvey RM, Kazis L, Lee AF. Decision-making preferences and opportunity in VA ambulatory care patients: association with patient satisfaction. *Research Nursing Health*, 1999; **22:** 39–48.
40 Thompson SC, Pitts JS, Schwankovsky L. Preference for involvement in medical decision-making: situational and demographic influences. *Patient Education and Counselling*, 1993; **22:** 133–140.