



PATIENT ENGAGEMENT AND PATIENT DECISION-MAKING IN ENGLAND

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CONTENTS

About the Author	iv
Introduction	1
Context	1
Patient and Public Involvement in England.....	4
Improving Patient Engagement.....	8
Issues for Discussion.....	11
References.....	12

LIST OF FIGURES AND TABLES

Figure	6
Summary Table. Barriers to Change and Possible Solutions.....	10

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INTRODUCTION

Patient engagement and patient decision-making are of course central to clinical practice. Informed consent (or perhaps we should just say “consent” since there can be no consent if it is not informed) is the basic premise of clinical practice. And yet, despite its centrality as a concept in medicine, patient choice remains problematic within health care systems. The movement in England toward patient and public involvement in health care, which has been growing over more than a decade, is driven from the outside by dissatisfaction with service quality, more informed and expert patients, and a consumer society. From the inside, this movement may be motivated by a desire to improve health outcomes, to find new mechanisms for controlling demand, or to meet a political need to convince the public that health care is improving. Thus, patients, the public, and the managers of health care systems may have shared objectives but different reasons for pursuing them.

In light of the above, this background paper does not set about to answer the specific questions suggested by The Commonwealth Fund in preparation for this conference, although many of those questions are covered in one way or another. It is important to see the movement toward greater patient engagement from the perspective of the users of health care rather than just the providers.

CONTEXT

Modernization of the National Health Service (NHS) in England needs to be seen in the context of wider public service reform. The challenge is to deliver public services that are responsive to individual users but at the same time meet wider public needs. In the NHS this is particularly difficult. Equity of access and service often is perceived as in conflict with individual choice and quality. David Hunter, writing in the magazine *Patient Centred Care* (June 2003, p. 7) asks, “Is there a downside to all this talk of consumerism and choice. . .in a system of healthcare whose ethical underpinning from the outset has been the solidarity principle?” He goes on to assert, “Consumer choice is the very antithesis to public health.”

Such arguments seem to me to oversimplify what is being sought from patient and public involvement. Health service users are quite capable of playing different roles—patient, consumer, caregiver, citizen—depending on their particular need at the time. Nor are active consumers automatically selfish because in seeking improved service for themselves they are likely to improve service for others. It is no longer an adequate

defense of poor service for the NHS to tell patients, “Sorry, we can’t help you because we are busy helping someone else.” Organizations that pursue excellence want excellence for all, not the equality of the mediocre.

There are many barriers to a more patient-centered system, including the way in which clinicians at both the primary and secondary care levels perceive themselves and their relationship to the NHS and the way in which they are employed but not managed by the system. As a patient, it is interesting to me that the professional concern about the new consultant contract in England and to a lesser extent the new PMS contract for general practitioners (GPs) seems to be about being “managed.” We refuse to be “managed” the consultants assert, “it is an affront to our professionalism, a challenge to clinical freedom.” And yet managing patients and managing diseases is common parlance in doctorspeak. I’m not sure that in my implied contract with the NHS I have agreed to be managed either.

The absolute lack of power of patients and caregivers within the system makes patient/user-driven change very difficult. The new structural and procedural changes brought about by the NHS Modernisation Plan (see section below) will help address this imbalance in power but there remains work to be done in addressing the right to consent for people with temporary or permanent mental incapacity. In English law, there is no legal framework for advance directives or for the appointment of a health care proxy, although in Scotland the latter is now possible. The Government has announced that it will bring forward new legislation on mental incapacity in the near future.

There can be no choice without information, and information within the NHS is still carefully controlled. Patients do not routinely see or hold their own records. Patients are rarely copied into letters written about them, notes are kept at the end of the bed where they are inaccessible, and information on pharmaceuticals is censored by law. Choice is difficult when there is no surplus capacity, but even when capacity is limited, choice can be created by new ways of working and by system redesign. Further, training is key to changing behavior. Patients as teachers have a valuable role in opening up NHS staff and clinicians to new experiences. Traditional forms of training may be a barrier to change.

There is only limited evidence to support the argument that patient involvement improves outcomes. This is primarily because research has not been conducted in a comprehensive or systematic way. Inaccurate, biased, directive, incomprehensible, or overcomplicated information can be harmful. It can, for example, cause increased anxiety

(Entwistle et al. 1996). On the other hand, research has shown that providing more information reduces patients' levels of anxiety (Thornton et al. 1995). In addition, the reliability of patient satisfaction ratings must be questioned. Patients may not be entirely honest when questioned about levels of satisfaction. Angela Coulter and others have argued that patient experience, that is, what happened to them rather than how satisfied they say they are, is a better measure of success.

Informed choice involves being open about information on the risk and uncertainty of the outcome of some clinical procedures (Elwyn 1999). Health professionals sometimes argue that revealing their uncertainty will undermine patient confidence, but openness promotes honesty, and a willingness to be more engaged with the patient's problem makes the doctor-patient relationship less unequal and more satisfactory to the patient (Coulter 1997; Farrell and Gilbert 1996). Patients are also more likely to follow the chosen treatment option when involved in the decision (Elwyn et al. 1999; Stewart 1995, 1999 in Towle 1999; Slowie 1999).

Some studies of patients with certain conditions have shown that better health outcomes (such as reduced blood pressure or control of hypertension (Schulman 1979, Legg-England 1992 in Kee 1996; Greenfield et al. in Slowie 1999)) resulted when the patient was given all the appropriate information and encouraged to participate in treatment decisions. Other evidence published to date on a more general level to support this claim is rather limited, however (Coulter 1997).

Informed choice is necessary to consent because there is no consent without choice. Of course informed choice is not possible in every clinical decision; for example, in an emergency there is little time for the health professional to act, much less involve the patient, or when patients are mentally incapacitated. There are many situations, however, when there are several treatment options with different possible outcomes that may be viewed differently by different patients (Kassirer 1994). In such cases, incorporating the patient's preferences and values has a stronger claim (Coulter 1997, 1999; Charles et al. 1999). The National Patient Safety Agency argues that shared understanding between clinicians and patients about what safety means and what risks might be taken reduces complications and errors.

Patients' values and preferences vary, and health professionals cannot know what is "best" for their patients or assume that their own values and priorities apply to their patients (Kee 1996). Not all patients will consider the treatment that in trials proved to be most clinically effective, particularly if the evaluation was based on a narrow set of criteria

defined by health professionals or researchers with very little understanding of what it is like to live with the condition (Entwistle et al. 1996). Additionally, individual patients have particular characteristics that may make them different from the patients selected for participation in clinical trials (Lilford et al. 1998). Patients and health professionals also differ in their assessment of the relative importance of different elements of health-related quality of life (Rothwell et al. 1997).

The public realization that there are wide variations in medical practice, demonstrated by the fact that doctors disagree among themselves about the appropriate use of particular treatments, has underlined the weaknesses of the scientific basis of much medical care and has raised the awareness that health professionals' values and beliefs play a major part in their clinical decisions. In most cases, clinical decisions are based on assumptions about what is best for the individual patient without explicitly consulting with the patient. Given that there is a frequently stated moral argument that "every human being of adult years and sound mind has the right to determine what shall be done with his own body" (Judge Benjamin Cardozo in a 1914 American court case quoted in Coulter 1997), health professionals and policymakers alike are recognizing the importance of shared decision-making on the basis of informed patient choice.

PATIENT AND PUBLIC INVOLVEMENT IN ENGLAND

A consumer/user-focused approach has been part of Department of Health and government thinking for many years. The NHS in its white paper *Working for Patients* (Department of Health 1989) introduced the internal market to the NHS, a move that separated purchasers from providers of health care. Purchasers (Health Authorities and GP fund-holders) set contracts and prices with providers (hospitals) instead of plans within budgets (Flynn 1997).

The intended benefits of the internal market were to improve efficiency, quality, and choice for purchasers and patients through competition and the impact of market forces on service quality (Mays et al. 2000). These benefits were seldom achieved, however, because most contracts were placed on a historical basis and because of an increase in transaction and management costs as well as other budgetary constraints. Patients also may have perceived a two-tier system of fund-holding and non-fund-holding GP practices under which patients of GP fund-holders apparently received preferential treatment over patients paid for by the Health Authority (Laing in Murley (ed) 1995; Le Grand et al. 1998). Many hospitals, particularly in more rural areas, were monopoly suppliers of health care lacking competitive incentive to make improvements (Falconer in Pyper 1996) and thus did not respond to market signals that often were constrained by

central government intervention (Le Grand et al. 1998). Evidence suggests that although choice for patients did not increase, there was a limited increase in the amount of information given to patients (Laing in Murley (ed) 1995; Le Grand et al. 1998; Mays et al. 2000). According to economic theory, markets require informed consumers if they are to operate efficiently. The information asymmetry between patients and NHS health professionals was not significantly changed, however, which made this efficiency difficult to achieve (Coulter 1997; Farrell and Gilbert 1996).

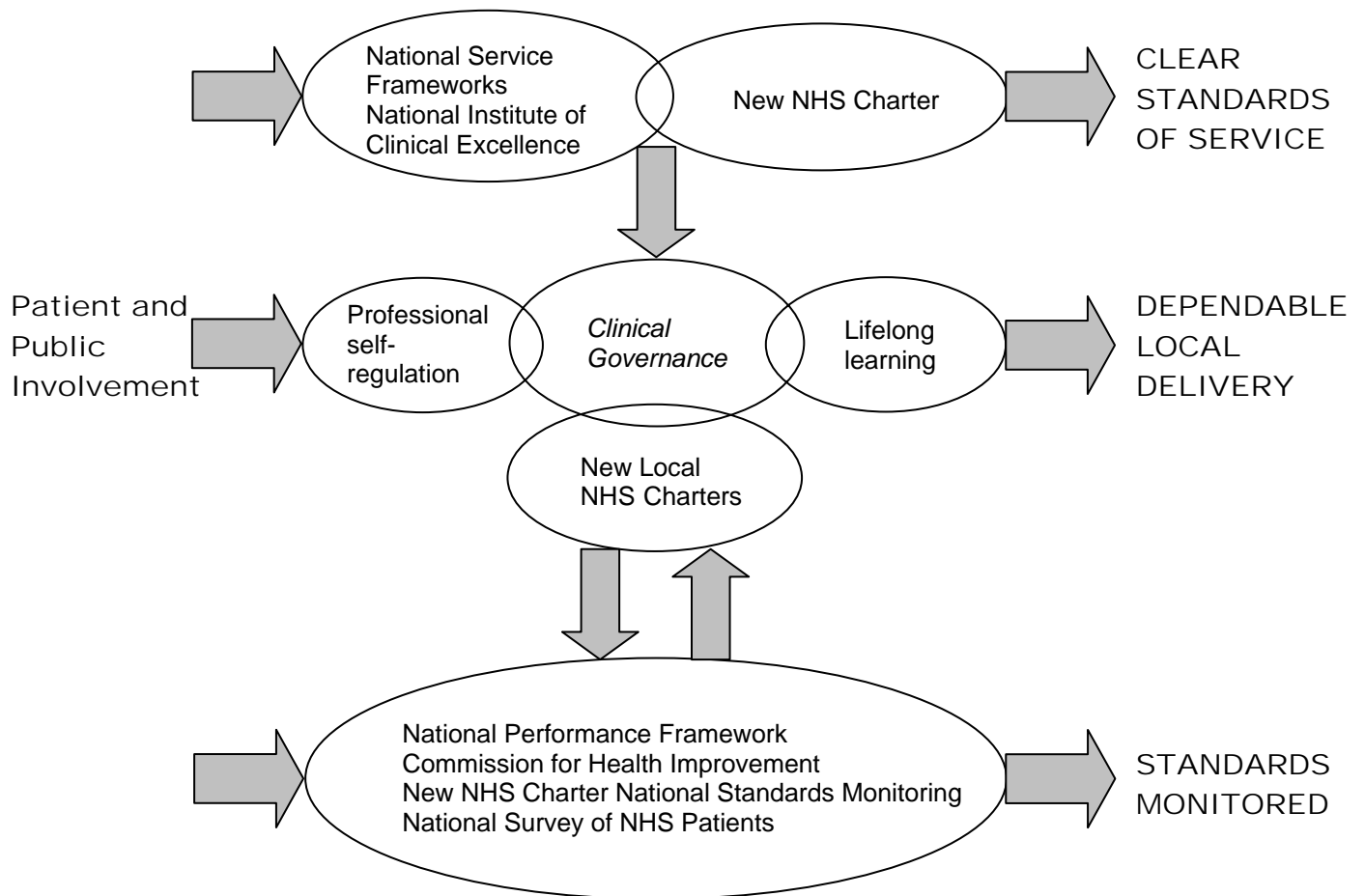
At about the same time that the internal market was being introduced, the Patient's Charter (Department of Health 1992/1995) was instituted in 1992 as part of the Citizen's Charter initiative. The Patient's Charter was intended to set out patients' rights and what patients could reasonably expect from the NHS. It has been successful at raising awareness among NHS staff of patients' needs, issues, and rights, but it also has been criticized for raising patients' expectations beyond the resources required to meet those expectations (Coulter 1999). The Patient's Charter focused on quantitative measures such as waiting times rather than on qualitative standards that were of more importance to patients, such as information and communication. Research also concluded that the charter did not place sufficient emphasis on patients' responsibilities (The King's Fund 1998). The Department of Health also published *Local Voices—The Views of Local People in Purchasing for Health* (1992). This document was intended to encourage health purchasers (health authorities and GP fund-holders) to move away from one off consultation toward ongoing involvement of local people in purchasing activities.

The Patient's Charter includes the right to information about conditions and treatments, including any risks involved in those treatments, clearly explained before the patient decides whether to consent. This standard, which applies to all sectors of the NHS, has been in place since 1992. Research on the Patient's Charter has shown that information and communication are particularly important to users of the service and has identified poor communication as a primary source of dissatisfaction (Audit Commission 1993). Other commentators (LeTouze 1997; Rigge 1997) have documented patients' and users' need for information and have found that such information is sometimes unavailable or difficult to get. Current research confirms the importance patients, caregivers, and NHS staff attach to good information and communication (King's Fund 1998).

In December 1997, the white paper *The New NHS—Modern and Dependable* (Department of Health 1997) was issued. This paper announced the abolition of the internal market; a new NHS charter, which would focus on the success of treatment rather than quantitative standards; and a quality framework including as one of its elements

patient/caregiver experience of the NHS. The new NHS charter became *Your Guide to the NHS*, which is principally an information booklet about the NHS setting out what patients can expect from the NHS and no longer including any reference to what information patients should receive or their involvement in decision-making. The Guide followed the issue of the NHS Plan, which is discussed below. The quality framework later developed into *A First Class Service—Quality in the New NHS* (Department of Health 1998), *Clinical Governance—Quality in the New NHS* (Department of Health 1999a) and the *Performance Assessment Framework* (Department of Health 1999c). *A First Class Service* mapped out how quality standards were to be set, first, through National Service Frameworks, which emphasize patient involvement in planning and delivery of care, choice in treatment decisions, and local implementation; second, by national monitoring via the Performance Assessment Framework and the National Survey of Patients' Experience (see Figure).

Figure



The aspects of performance focusing on patient/caregiver perceptions concerning the delivery of services in the Performance Assessment Framework include:

- Responsiveness to individual needs and preferences;
- The skill, care, and continuity of the provision of service;
- Patient involvement, information, and choice;
- Waiting time and accessibility; and
- The physical environment and the organization and responsiveness of administrative procedures.

Patient Partnership: Building a Collaborative Strategy (Department of Health 1996) places considerable emphasis on the need to provide patients with the information they require to make informed choices about their treatment. A further document, *Patient and Public Involvement in the New NHS* (Department of Health 1999b) focuses primarily on involving patients and the public in the provision of service and improvements in the delivery of service. It also recognizes that there is a growing acceptance that patients can have an expert understanding of their particular condition or illness and that active patient participation in consultations and the provision of good information are significant factors in achieving a better health outcome and patient satisfaction.

In July 2000, the Secretary of State for Health issued *The NHS Plan—A Plan for Investment, A Plan for Reform*. Chapter 10 of the Plan announced radical new changes for patients and new organizational structures for patient and public involvement in health care. These may be summarized as follows:

- Increased patient access to information about health and local health services will be established.
- Letters between clinicians about an individual patient's care will be copied to the patient as of right.
- Patients will have choice of date and time for elective care.
- A fully mandatory reporting scheme for adverse health care events will be established. A National Clinical Assessment Authority will be established to assess individual doctors' performances.
- Patient Advice and Liaison Services will be set up in every trust in the country.

- Every local NHS organization will be required to publish a patient prospectus—an annual account of opinions received from patients. Each will also set out the range of local services available.
- Every NHS Trust will have a Patient’s Forum. A member of the Patient Forum will be elected as a nonexecutive director on the trust board.
- A national Commission for Patient and Public Involvement in Health will be established.
- Community Health Councils will be abolished.

These changes signaled a new set of policies for patient and public involvement in health care in England. They were further supported by the Health and Social Care Act 2001, which places a legal duty on health care organizations to make arrangements to involve and consult patients and the public and to develop an ongoing relationship rather than consultation being a one off (Department of Health 2003).

At the end of 2003 the Secretary of State for Health further strengthened the drive toward a patient-centered service by publishing *Building on the Best —Choice, Responsiveness and Equity in the NHS*, which makes patient choice central to improving responsiveness in the Health Service.

It is too soon to assess the success of these policies. The Modernisation Plan is a 10-year program. On the one hand, the messages in the policies of 1992 generally were the same as those of 2003. It could be argued that if the messages still need reinforcing after 10 years the policies could not have been that successful. On the other hand, a growing number of NHS staff strongly believe that this is the way forward in modernizing health and social care and are actively promoting this cultural shift. There is also a growing movement of patient organizations advocating and promoting change and working in partnership with those in the NHS who want change to happen.

IMPROVING PATIENT ENGAGEMENT

Patient engagement is a matter for patients rather than for professionals. Health care systems have to change to make patient engagement possible and rewarding. People who work in health care have to change their practice, their thinking, and their attitudes if real dialogue is to take place, but patients and patient organizations have to change, too. One of the real wins for public involvement may be a more realistic appraisal by health service users of what health care systems can provide and how they can be used effectively by individuals and communities. In the UK, patient and public involvement forums,

Foundation Trusts Overview and Scrutiny Committees, and the Commission for Patient and Public Involvement in Health all will help create real community engagement with local health organizations.

A subgroup of the NHS Modernisation Board, recently reviewed progress and produced a paper for discussion. In it were set out some of the possible solutions to perceived barriers to change.

Summary Table. Barriers to Change and Possible Solutions

Culture Change Barrier	Possible Solution
Contradictory messages and conflicting values. Increased activity and financial balance are presented as being the key deliverables rather than improving patient experience.	Shared values and consistent messages. Create a balanced approach involving activity targets, health outcomes, and improved patient experience.
Lack of understanding of patient experience in policy development and health care delivery.	Clarity of message. Sustained communications effort about patient experience and the desired NHS cultures. The NHS is the patient journey rather than a collection of NHS organizations and professional groups. Increase capacity for patient representation within the NHS and through patient organizations.
Confusion about the roles and interrelationships of the new organizations.	Better clarity concerning the roles and responsibilities of each organization. Communications effort.
Centralized power—power still at the top of the system.	At an organizational level, <i>shift the balance of power</i> from structures to people. Department of Health and NHS to develop strategic relationships with patient and voluntary sectors. Integration of health and social care to increase local democratization and public accountability. At an individual level, embark on a devolution program to give power to patients (copying letters to patients, patient-held records, better patient information, choice at time of booking appointments).
Disempowered frontline staff.	Enable frontline staff to support patients. Promote a change of management focus. Help middle managers to lead locally.
Poor use and dissemination of patient feedback.	Rapid analysis and distribution of national survey program results. Encourage systematic collection and use of customer data. Patient Experience Collaborative to develop a systematic way of measuring performance and support the implementation of change resulting from the surveys.
Professional demarcations on the patient journey in training and professional cultures.	Eliminate professional segregation. When possible, train all staff involved in patient journey together. If possible, locate health and social care professionals on common patient journeys together. Promote teamwork and move away from hierarchies.
Possible conflicts between evidence-based medicine and patient experience.	Ensure recognition of patient experience in evidence-based medicine and by regulators such as National Institute of Clinical Excellence.
Difficulties in accessing sufficient and valid information for patients to support choice.	Develop a strategy to provide information to patients and promote joint decision-making between patients and health professionals.

(Unpublished paper 2003)

ISSUES FOR DISCUSSION

There is still much to debate concerning the role of patient and public engagement in improving quality in health care systems. Below are some questions participants may want to consider:

- What is the purpose of patient and public involvement?
 - Improving health outcomes?
 - Improving health service delivery?
 - Improving patient experience?
 - All of the above or none of the above?
- What are the differences in patient focus between publicly funded systems and insurance-based health care providers?
- Why are health care systems so resistant to becoming patient-centered?
- Why do people working in health care think patient and public involvement is a political fad or a distraction from their “real” work, which is treating and caring for patients?
- Why do doctors and nurses (in England, at least) think they are victims of the health service, while patients think doctors and nurses are its masters?
- Why are knowledge and compassion, the true virtues of health care professions, no longer enough to satisfy patients?
- Should patients have responsibilities without having rights?
- Are we seeking patient compliance with what health care systems need or health care systems that comply with what patients need?
- Are we engaged in a radical rethinking of the relationship between health care providers and the people who pay for them or are we just trying to use patient compliance to manage the system better?
- How do we put the public into public health?
- Is choice the antithesis of public health or a new opportunity to improve public health?

REFERENCES

- Audit Commission. 1993. *What Seems to Be the Matter?* London Audit Commission.
- Charles, C., T. Whelan, and A. Gafni. 1999. "What Do We Mean by Partnership in Making Decisions About Treatment?" *British Medical Journal* 319 (September 18): 780–82.
- Coulter, A. 1997. "Partnerships with Patients: The Pros and Cons of Shared Clinical Decision-Making." *Journal of Health Services Research and Policy* 2 (April 1997): 112–21.
- Coulter, A., V. Entwistle, and D. Gilbert. 1999. "Sharing Decisions with Patients: Is the Information Good Enough?" *British Medical Journal* 318 (January 30): 318–22.
- Department of Health. 1989. *Working for Patients*. Her Majesty's Stationery Office.
- Department of Health. 1992. *Local Voices—The Views of Local People in Purchasing for Health*. Her Majesty's Stationery Office.
- Department of Health. 1992/1995. *The Patient's Charter*. Her Majesty's Stationery Office.
- Department of Health. 1996. *Patient Partnership: Building a Collaborative Strategy*. Her Majesty's Stationery Office Leeds.
- Department of Health. 1997. *The New NHS—Modern and Dependable*. Her Majesty's Stationery Office.
- Department of Health. 1997. *Your Guide to the NHS*. Her Majesty's Stationery Office.
- Department of Health. 1998. *A First Class Service—Quality in the New NHS*. Her Majesty's Stationery Office.
- Department of Health. 1999a. *Clinical Governance: Quality in the New NHS*. Her Majesty's Stationery Office.
- Department of Health. 1999b. *Patient and Public Involvement in the New NHS*. Her Majesty's Stationery Office.
- Department of Health. 1999c. *Performance Assessment Framework*. Her Majesty's Stationery Office.
- Department of Health. 2003. *Strengthening Accountability—Involving Patients and the Public*. Her Majesty's Stationery Office.
- Department of Health. 2003. *Building on the Best—Choice, Responsiveness and Equity in the NHS*. Her Majesty's Stationery Office.
- Elwyn, G., A. Edwards, R. Gwyn, and R. Grol. 1999. "Towards a Feasible Model for Shared Decision-Making: Focus Group Study with General Practice Registrars." *British Medical Journal* 319 (September 18): 753–56.
- Entwistle, V., T. Sheldon, J. Sowden, and I. Watt. 1996. "Supporting Consumer Involvement in Decision-Making: What Constitutes Quality in Consumer Health Information?" *International Journal for Quality in Health Care* 8 (October): 425–37.
- Farrell, C., and H. Gilbert. 1996. *Health Care Partnerships*. King's Fund.

- Flynn, N. 1997. *Public Sector Management*. Prentice Hall.
- Hunter, D. 2003. "Patient Centred Policies Ignore our Public Duties as Citizens." *Patient Centered Care* (June 2003): page 7
- Kassirer, J. P. 1994. "Incorporating Patients' Preferences into Medical Decisions." *New England Journal of Medicine* 330 (June 30): 1895–96.
- Kee, F. 1996. "Patients' Prerogatives and Perceptions of Benefit." *British Medical Journal* 312 (April 13): 958–60.
- King's Fund. 1998. *The Patient's Charter: Past and Future*. King's Fund.
- Le Grand, J., N. Mays, and J. Mulligan. 1998. *Learning from the NHS Internal Market*. King's Fund.
- LeTouze, S. 1996. *Patients' Views of Hospital Care*. Centre for Health Service Studies, University of Kent.
- Lilford, R., and G. Royston. 1998. "Decision Analysis in the Selection, Design and Application of Clinical and Health Services Research." *Journal of Health Services Research and Policy* 3 (1998): 159–66.
- Mays, N., J. Mulligan, and N. Goodwin. 2000. "The British Quasi-Market in Health Care: A Balance Sheet of the Evidence." *Journal of Health Services Research and Policy* 5 (January): 49–58.
- Murley, R. (ed). 1995. *Patients or Customers: Are the NHS Reforms Working?* Institute of Economic Affairs. London.
- Pyper, R. 1996. *Aspects of Accountability in the British System of Government*. Tudor.
- Rigge, M. 1997. "Dr. Who?" *Health Service Journal* 11 (September): 24–26.
- Rothwell, P. M., Z. McDowell, C. K. Wong, and P. J. Dorman. 1997. "Doctors and Patients Don't Agree: Cross Sectional Study of Patients' and Doctors' Perceptions and Assessment of Disability in Multiple Sclerosis." *British Medical Journal* 314 (May 31): 1580–83.
- Secretary of State for Health. 2000. *The NHS Plan—A Plan for Investment, A Plan for Reform*. Her Majesty's Stationery Office.
- Slowie, D. F. 1999. "Doctors Should Help Patients to Communicate Better with Them." *British Medical Journal* 319 (September 18): 784.
- Thornton, J. G., J. Hewison, R. J. Lilford, and A. Vail. 1995. "A Randomised Trial of Three Methods of Giving Information About Prenatal Testing." *British Medical Journal* 311 (October 28):1127–30.
- Towle, A., and W. Godolphin. 1999. "Framework for Teaching and Learning Informed Shared Decision Making." *British Medical Journal* 319 (September 18): 766–71.

