

Paternalism or partnership?

Patients have grown up—and there's no going back

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. Assumptions that doctor (or nurse) knows best, making decisions on behalf of patients without involving them and feeling threatened when patients have access to alternative sources of medical information—these signs of paternalism should have no place in modern health care. The articles assembled in this issue of the *BMJ* consider the scope for creating meaningful partnerships between doctors and patients and between health policymakers and local communities.

Partners work together to achieve common goals. Their relationship is based on mutual respect for each other's skills and competencies and recognition of the advantages of combining these resources to achieve beneficial outcomes. Successful partnerships are non-hierarchical and the partners share decision making and responsibility. The key to successful doctor-patient partnerships is therefore to recognise that patients are experts too.¹⁻³ The doctor is, or should be, well informed about diagnostic techniques, the causes of disease, prognosis, treatment options, and preventive strategies, but only the patient knows about his or her experience of illness, social circumstances, habits and behaviour, attitudes to risk, values, and preferences. Both types of knowledge are needed to manage illness successfully, so both parties should be prepared to share information and take decisions jointly.

The concern to equalise relationships between health professionals and lay people is gathering momentum. Consumerism was strongly promoted in the 1980s as part of the market ideology which infused health policy in many countries. The problem with consumerism was that it encouraged people to make demands but failed to emphasise reciprocal responsibilities. Growing awareness of unexplained variations in patterns of medical practice and of the gap between public expectations and the supply of services has led governments to consider ways in which demand for health care can be managed.⁴ Partnership has therefore replaced consumerism as a key plank of public policy. Official statements in the United Kingdom are peppered with the term, which is popular with politicians both because it evinces a warm glow but also because it emphasises mutual self help. The new emphasis is on shared information, shared evaluation, shared decision making, and shared responsibilities.

Patient partnership is therefore firmly on the agenda in the NHS. This year we have been promised a revised Patient's Charter; a relaunch of the patient partnership strategy; the establishment of NHS Direct Online (an online version of the telephone information and triage system); the first results from the national patient and user survey; and now, in a little noticed section of the public health white paper, a new strategy for healthy citizens.⁵ The government wants us all to be better informed about risk. It wants us to know about treatment options, outcomes, and the limitations of medical care. It is promising advice via telephone helplines, website links, health skills training programmes, and a new handbook of common ailments. Self help and informed choice is to be encouraged in the hope that it will keep costs down and ensure that demands for health care are channelled appropriately.

Will it work? 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,⁶ that these are not always predictable,⁷ and that doctors often fail to understand them,⁸ but some patients may not want to have an active role thrust on them. Younger people tend to be more critical of professional paternalism and more likely to expect active participation in decisions about their care,⁶ but some older patients and some with serious illnesses prefer to defer decision making to the doctor, perhaps because it allows them to avoid responsibility for the consequences of "wrong" decisions.⁹ It will be important to find ways of offering involvement which do not place an unwanted burden on sick people.

For doctors the trick will be to determine which patients want to be offered choice and which prefer a more passive role. The requirements for informed consent require some level of patient engagement with decision making, and the General Medical Council has laid down stringent information requirements.¹⁰ Informed consent can no longer be seen as nothing more than getting a signature on a form. But in an eight minute consultation how feasible is it to determine patients' preferences and sensitivities and provide full and unbiased information (p 753)?¹¹ There will certainly be a need for more and better training in communication skills (p 766)¹² and for better access to good quality information to support decision making (p 764).¹³ Howie et al found an association between continuity of care and patient enablement (p 738),¹⁴

but is this compatible with the demand for easier and faster access—for example, via the government's new walk-in clinics?

As O'Connor et al's systematic review of decision aids shows, patients do not necessarily make conservative choices when they are fully informed about the risks and benefits of treatment options (p 731).¹⁵ In the end the government may be disappointed if demand continues to rise despite its efforts to empower patients—but they should not be. If it increases the chance of patients being treated like grown ups, it will have been worth it.

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The increasing importance of patient surveys

Now that sound methods exist, patient surveys can facilitate improvement

People often think of “exit” and “voice” as the main ways patients can influence healthcare quality¹—that is, patients can leave providers they are not happy with or they can voice their opinions in an attempt to change care. A common strategy for eliciting patients’ “voices” is to conduct surveys. Clinicians have long been sceptical about such surveys, partly because they communicate regularly with their patients and saw no need for another method of hearing their concerns and partly because satisfaction surveys used to be flawed measures of healthcare quality. Now, however, that is beginning to change as rigorous methods have been applied to developing and evaluating patient surveys.

Despite numerous studies of patient satisfaction,² they have not resulted in the quality improvement that many expected. Previous satisfaction surveys had little impact because they often did not meet minimal standards of conceptual or methodological rigour and were not designed to facilitate quality improvement efforts. Responses to such surveys are subjective and difficult to interpret since they are a complex function of expectations that may vary greatly among patients with comparable care. Moreover, the questionnaires assessed things, such as quality of the food, that have little bearing on the quality of clinical care, and thus the results provided little direction to those responsible for improving care processes.^{3 4}

It is now widely recognised that there is a need for rigorous methods, other than clinical conversations, to elicit patients’ views on such matters as treatment decisions and the quality of care received.^{5 6} Much effort has therefore been devoted to developing and evaluating survey measures that elicit reports about specific care experiences that reflect quality of care, not amenities.^{7 8} Such questions are less subjective and less influenced by patient characteristics, are more interpret-

able, and thus may be acted on for quality improvement purposes.⁹

The Picker Institute has developed and used such instruments to evaluate the quality of hospital care in the United States⁷ and more recently, in Europe. The Consumer Assessment of Health Plans (CAHPS) project has adopted a similar approach for ambulatory care in the United States.¹⁰ These newer instruments provide qualitatively better data than many earlier surveys, and the response of patients, clinicians, and others responsible for the quality of health care has been striking. One indication of the value of such surveys is the increasing public dissemination of the resulting data. CAHPS data were available to about 90 million Americans in 1999, including 39 million Medicare beneficiaries (<http://www.medicare.gov/comparison/default.asp>), 9 million federal employees, 40 million people covered by plans reporting to the National Committee for Quality Assurance, and people in plans surveyed by other sponsors.¹¹

Regional coalitions are also increasingly coordinating data collection and dissemination. A partnership of Massachusetts healthcare, business, and government leaders recognised the need for credible, publicly available data on the quality of hospital care in the state and launched a voluntary effort to collect information using the Picker survey from 24 200 patients discharged from over 50 Massachusetts hospitals.¹² Those data were used to create a report that was distributed to the hospitals and made publicly available after an initial cycle of internal reporting (<http://www.mhqp.org/statewidesurvey.html>). A testament to the quality and focus of the project is the fact that participants agreed at the outset to use the data not to judge “winners and losers” but to educate and inform hospitals and consumers and to focus and facilitate quality improvement efforts. The news media generally

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