Leaders need to emphasise that it is not individuals who make mistakes but systems that fail. Certainly, when misconduct has occurred individuals should be admonished or punished. But when someone reports that they have made an error or reports a risk they should be supported. In the airline industry a pilot who reports an error is immune from disciplinary action.[9] Most importantly, the person who reports the problem should see the system leap into action. Leaders in primary care need to ensure a mandatory *reacting* system, not just mandatory *reporting* system.

Tim Wilson *director, quality unit*

(twilson@rcgp.org.uk)

Mike Pringle *chair*

Royal Collage of General Practitioners, London SW7 1PU

Aziz Sheikh *NHS R&D national primary care training fellow*

Department of General Practice and Primary Health Care, Imperial College School of Medicine, London W6 8RP

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Engaging patients in medical decision making

The end is worthwhile, but the means need to be more practical

The growing consensus that patients ought to be more involved in their own care lies at the confluence of several powerful ideas. Political trends, thinking on ethics, and research on health services have all contributed. As experienced consumers, patients understand that they have rights, and they are much less inclined than they used to be to leave medical decisions entirely to the experts. Ethicists have by and large accepted the principle that autonomy (what the competent, informed patient wants) trumps beneficence (what the doctor thinks best for the patient) in all but the most extreme circumstances.[1] In addition, there is evidence that the expanding involvement of patients in care produces better health outcomes, providing an empirical rationale for what may have been an inevitable shift in power and social control.[2]

A supplement to this September's issue of *Quality in Health Care* focuses on engaging patients in medical decisions. Twelve articles, derived from a Medical Research Council conference, cover the meaning, mutability, and measurement of patients' preferences regarding treatment. The proceedings leave the clear impression that although respecting patients' preferences is a fundamental goal of medicine, these preferences are vulnerable to manipulation and bias.[3] Yet they are too important to be abandoned in a shrug of professional frustration.

Three questions dominate the debate about the role of patients in making treatment decisions. Can patients take a leading role in making decisions? Do they want to? What if doctors and public health professionals don't like their choices?

Many decisions related to health are complicated. The reasons for this complexity go beyond uncertainty in the scientific evidence and variation in how patients value different states of health. Decisions about treatment also depend on patients' attitudes to risk.[4 5] Risk involves the probability, severity, and timing of an adverse outcome. Some patients prefer a very bad outcome put off into the future to a moderately bad outcome occurring now. That is one of several reasons why patients' decisions and their behaviours are sometimes at odds with the recommendations of health providers.[6]

As if deciphering evidence and understanding patients' values were not enough, family and culture play important if poorly studied roles in decisions about health and communication between doctor and patient. Cultural beliefs can have a profound influence on decisions regarding treatment. For example, some South East Asian cultures consider surgery to result in perpetual imbalance, causing the person to be physically incomplete in the next incarnation.[7] Navajo patients and families believe that direct information about risks from a procedure or a diagnosis is harmful and that talking about death can actually hasten its arrival.[8]

These complexities explain why fully informed, shared decision making is so difficult to conduct in practice.[9] Yet communication with patients could be improved on many levels. Evidence based approaches include training doctors, coaching patients, and using aids to decision making.[10] Until these methods are more fully implemented, abandoning the shared decision making model on the grounds that patients or doctors are not up to it would be premature.

That said, not all patients want to make their own decisions. In a study of 1012 women with breast cancer, 22% wanted to select their own treatment, 44% wanted to collaborate with their doctors in the decision, and 34% wanted to delegate this responsibility to their doctors.[11] Preferences for active engagement in care vary with patients' backgrounds and the clinical situation.

BMJ 2001;323:584–5

Yet a desire for information is nearly universal. Most patients want to see the road map, including alternative routes, even if they don't want to take over the wheel.

Patients who make decisions will at times select treatments that are less effective or less cost effective than the medically recommended approach. For example, patients with mild to moderate hypertension value the benefits of drug treatment less than doctors do (particularly specialists) and are more distressed by side effects.[12] Therefore, encouraging patients to make well informed choices about treatment of mild hypertension could easily result in fewer drugs being taken, higher mean blood pressures, and more strokes and heart attacks in the population. On the other hand, an estimated 50-65% of patients with chronic conditions adhere to their treatment.[13] By not taking their drugs patients are indirectly expressing a choice. Are doctors willing to accept and encourage explicit disagreement with their recommendations? Or is the current subterfuge less painful?

Patients do want to be involved in or at least informed about healthcare decisions, and the medical profession will adapt—sooner or later. Moving towards the goal of collaborative decision making, however, requires more attention to the realities of clinical practice than is currently evident. Complex and time consuming methods of educating patients about risks and then eliciting their preferences—for example, standard gamble, time trade-off, decision analysis, repertory grid—are important for research but not realistic in a 15 minute visit to a general practitioner or even a 45 minute consultation with a specialist. We need practical tools, based on research, that help clinicians to learn from patients and help patients learn from medical experts. Asking patients how they understand their illness and how much they want to be involved in decisions regarding treatment can be a foundation for doctors seeking an informed, collaborative model of care.

Richard L Kravitz *professor and director*
Joy Melnikow *associate professor*

U C Davis Center for Health Services Research in Primary Care, Sacramento, California 95817, USA

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One fundamental guarantee that we cannot give our patients is that faults and errors in the healthcare system won't harm them. Of course, health care is by its nature risky. Not everyone undergoing surgery for an aortic aneurysm survives. Many interventions carry risks. But these risks are mostly small and usually quantifiable. Ideally, patients understand the possible risks and benefits before choosing to undergo a procedure. For some patients these are difficult decisions. Though doctors may discuss risks of treatment, they do not speak about risks of harm from the system—or even about such harm when it occurs.

Recent studies in the United States, Australia, and the United Kingdom and reports from the US Institute of Medicine and the UK Department of Health have drawn attention to the chronic "unsafeness" of health systems worldwide.[1–7] This attention is not new. What is new is that preventable, iatrogenic injuries are being quantified and openly discussed. For example, adverse drug reactions have become a national issue in the United States—studies show that adverse drug events occurred in 6.5% of hospitalisations.[8] By calling for solutions, these reports have highlighted the tensions between accountability and improvement, needs of individual patients and benefit to society, and production goals and safety.

Most causes—and solutions—lie in the systems of care and how we work. Healthcare professionals, however, focus energy on individual patients, tackling difficulties in the system as they appear—often as separate problems and not in parallel. Individual care is of course crucial. But unless attention is given to the system our patients are at risk from a faulty service. For example, inadequate handovers can mean that vital information is lost between different care givers and services. Is it that the word "system" is anathema to many doctors? Just getting health professionals to work harder or exhorting them to be safer will not help; the system of care must be redesigned. We must instil a chronic sense of unease—a constant awareness of risk in every action.[9] Such attention to risk enables crews of aircraft carriers to launch and land several planes every day on decks the size of two football fields with virtually no adverse events. All hands know that one oversight can lead to disaster.[10]

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