Collection and validation of data on a large scale are expensive, and the cost of systematic reviews is considerable—an average of £30 000-£50 000 ($48 800-$81 350; €45 500-€75 800) for the Australian register. Funding is unlikely ever to be sufficient for collection of data on all procedures, and NICE will rely heavily on help from a network of specialist advisers and on its multidisciplinary advisory committee.

No other countries yet have systems in place for monitoring of new interventions. The American College of Surgeons is considering an approach but has yet to act. The Australian example and the more regulated United Kingdom plan may give other countries food for thought, but many uncertainties remain. What precisely is a new procedure? If an existing procedure is modified, how much modification makes it new? If new technology is used for an established procedure, is that new? (NICE will be explicit about its focus on procedures rather than devices.) Should doctors be restricted in undertaking new procedures? How can compliance with submission of data and guidance best be achieved? What data should be publicly available and what should be done if outcomes vary between doctors? Without clear assurances about confidentiality neither doctors nor patients will be eager to cooperate.

Finally, safety and efficacy also require a long term perspective. NICE intends to ensure that new procedures receive specific codes in the national coding system at an early stage, so that their dissemination can be monitored and any reporting of adverse events is in the context of some kind of denominator. Procedures with obvious potential for long term adverse events will need special consideration, and this will form part of the complex evolution of monitoring of safety and efficacy.

Bruce Campbell *chairman, Interventional Procedures Advisory Committee*

National Institute for Clinical Excellence, London WC2N 5HR (bruce.campbell@nice.nhs.uk)

Guy Maddern *surgical director*

Australian Safety and Efficacy Register for New Interventional Procedures—Surgical, Royal Australasian College of Surgeons, PO Box 688, North Adelaide, South Australia 5006, Australia

Competing interests: None declared.

1 Maddern GJ. Surgery and evidence based medicine—A new Australian registry promises to strengthen the push towards evidence based surgery. *Medical J Aust* 1998;169:348-9.
2 Australian Safety and Efficacy Register of New Interventional Procedures—Surgical. ASERNIP-S publications. Updated November 2002. www.surgeons.org/open/asernip-s/publications.htm (accessed 5 Nov 2002).
3 Merlin TL, Scott DF, Rao MM, Wall DR, Francis DMA, Bridgewater FHG, et al. The safety and efficacy of laparoscopic live donor nephrectomy: a systematic review. *Transplantation* 2000;70:1659-66.
4 Cooter R, Chapman A, Babidge WJ, Robinson D, Mutimer K, Wickham P, et al. Review of ultrasound-assisted lipoplasty: safety and effectiveness. *Aust NZ J Surgery* 2001;71:309-17.
5 Chapman A, Levitt M, Hewitt P, Woods R, Sheiner H, Maddern GJ. Laparoscopic-assisted resection of colorectal malignancies: A systematic review. *Ann Surg* 2001;234:590-606.
6 Australian Safety and Efficacy Register of New Interventional Procedures—Surgical. New and Emerging Techniques—Surgical (NET-S). www.surgeons.org/asernip-s_net-s/index.htm (accessed 5 Nov 2002).
7 Learning from Bristol: the report of the public inquiry into children's heart surgery at the Bristol Royal Infirmary 1984-1995. Command Paper: CM 5207. Published by the Bristol Royal Infirmary Inquiry, July 2001. Crown Copyright 2001.
8 Clinical governance. *Quality in the new NHS*. Leeds: NHS Executive, 1999. (Health Service Circular 1999/065.)

Not to be taken as directed

Putting concordance for taking medicines into practice

When the medicines that doctors prescribe fail to produce the benefit they expect, they often respond by varying the dose or selecting an alternative medicine. Thus doctors seem to behave as though non-compliance is a problem for other doctors. Although we know that about half of the medicines prescribed for patients with long term conditions are not taken as prescribed,[1] the concerns of health professionals have focused almost exclusively on improving the quality of their own prescribing choices. Similarly, attention and resources devoted by pharmaceutical companies to discovering, developing, and promoting new drugs utterly dwarf their efforts to see that medicines are taken by patients. Yet non-compliance continues to represent a serious therapeutic deficit at the core of medical practice, with consequent massive personal, societal, and economic cost.

Patients do not comply with medication for several reasons.[2] Non-compliance may be intentional or involuntary. It may relate to the quality of information given, the impact of the regimen on daily life, the physical or ental incapacity of patients, or their social isolation. Many interventions to overcome these impediments have been tried, but evidence of sustained success is scant.[1]

The difficulty for health professionals lies in acknowledging that it is the patients' agendas and not their own that determine whether patients take medicines. Patients have their own beliefs about their medicines and medicines in general. They have their own priorities and their own rational discourse in relation to health and care, risk and benefit.[3] These may differ from and sometimes contradict those of the doctors. They are, however, no less cogent, coherent, or important.[4]

By drawing on these findings and insights a new relationship between prescriber and patient was described.[5] The term concordance was introduced. While compliance describes the degree to which the patient follows the prescribed regimen of medicines, concordance describes an agreement between a patient and a healthcare professional about whether, when, and how medicines are to be taken. Concordance therefore refers to the creation of an agreement that respects the beliefs and wishes of the patient, and not to compliance—the following of instructions.

Doctors and patients may not always agree. The implication of concordance is that when this happens

BMJ 2003;326:348–9

the patient's views take precedence. This poses challenging questions about choice and responsibility. If the only treatment to which the patient will agree falls substantially short of what modern medicine can achieve the doctor may be left with a burden of responsibility that is hard to manage emotionally, ethically, and legally.

Practitioners are constantly urged to be both patient centred and evidence based. Yet these two goods can conflict. The quest is for the best health outcome, but concordance implies that we must now redefine best outcome so as to reconcile what pharmacology can theoretically achieve with what the patient desires or can bear.

Non-compliance is a multifactorial problem and requires multifactorial responses. No single blueprint for concordance exists. Nor will concordance be achieved by acquiring new communication skills alone. Intentions must also change. Concordance cannot be delivered by the imposition of top down guidelines. Doctors and patients must learn how to "do concordance" not only on the basis of established evidence but also from their own reflective experiences and from new experimental studies.

Many questions need to be answered. Few of the usual sociodemographic and biomedical variables predict non-compliance. Can we identify some that do? What does a concordant process look like in practice? What difficulties does concordance raise for patients and how can they be overcome? How can the ethical issues for doctors be addressed? What needs to change in order to implement concordance?

A change in the culture of the doctor-patient encounter is needed now. Concordance presents new challenges for patients, doctors, nurses, pharmacists, pharmaceutical companies, policy makers, and others. Crucially, as we move forward, we must learn to create robust therapeutic alliances with mutual respect for both the doctor's professional opinion and the patient's personal decisions.

In 2002 the Department of Health endorsed and adopted the principles of concordance and created the Medicines Partnership Task Force (www.medicinespartnership.org) to carry this work forward. The task force comprises representatives from the medical, nursing, and pharmacy professional bodies, patients' groups, pharmaceutical industry, and academia. Its two year remit is to look for ways to implement concordance in the NHS so as to improve health outcomes and satisfaction with care.

The *BMJ* will publish a theme issue on "people taking medicines" on 11 October 2003. We, the guest editors, invite contributions from researchers, patients, health professionals, policy makers, and other stakeholders, to reach us by 15 April 2003. Submissions should be made to www.submit.bmj.com, and the editorial contact is Giselle Jones (gjones@bmj.com). We hope to add to the store of evidence, experience, and controversial debate, and to learn more about what concordance looks and feels like in practice, how it is being taught to health professionals and patients, how barriers to it can be overcome, and to what extent we can produce evidence of clinical and other benefits for patients, practitioners, and the NHS.

Marshall Marinker *co-chair*
Joanne Shaw *director*

Medicines Partnership Task Force, Medicines Partnership, Royal Pharmaceutical Society of Great Britain, London SE1 7JN

Competing interests: MM has acted on occasions as a consultant in health policy to MSD Ltd.

1 Haynes RB, McKibbon A, Kanani R. Systematic review of randomised trials of interventions to assist patients to follow prescriptions for medications. *Lancet* 1996;348:383-6.
2 Britten N. Concordance and compliance. In: Jones R, Britten N, Culpepper L, Gass DA, Grol R, Mant D, Silagy C, eds. *Oxford textbook of primary medical care*. Oxford: Oxford University Press (in press).
3 Britten N. Patients' ideas about medicines: a qualitative study in a general practice population. *Br J Gen Pract* 1994;44:465-8.
4 Horne R. Representation of medication and treatment: advances in theory and measurement. In Petrie K, Weinman J, eds. *Perceptions of health and illness: current research and applications*. London: Harwood Academic, 1997.
5 Marinker M, Blenkinsopp A, Bond C, Briten N, Feely M, George C, et al, eds. *From compliance to concordance: achieving shared goals in medicine taking*. London: Royal Pharmaceutical Society of Great Britain, 1997.

Sudden death in the shadows of epilepsy

UK government's action plan for epilepsy needs great commitment

In a widely acclaimed BBC production, *The Lost Prince*, the short and tragic life of Prince John, son of Britain's King George V and Queen Mary, and his sudden death in the early 20th century emerged from the shadows in which he had been hidden.[1] He was hidden because of his epilepsy and learning disorder, and by the medical and social ignorance of his royal parents and advisers. Prince John has shared this fate with millions of others of all social classes and cultures before and since. In the 1920s, a few years after the death of Prince John in a seizure, the young Graham Greene received a diagnosis of epilepsy from a well known neurologist from Harley Street.[2] Initially his embarrassed parents concealed the diagnosis from him. When Greene learned of it he also concealed it for nearly 50 years until in his autobiography he eloquently described the impact of the diagnosis, which had led him to contemplate suicide. His greatest concerns were inheritance and marriage. These two lives from the past highlight two continuing anxieties for people with epilepsy and their families—stigma and sudden unexplained death.

Epilepsy is a very common disorder, as old as any medical condition and almost uniformly distributed around the world. It affects all ages, races, and social classes, including royalty and government ministers. Throughout history its strange, obscure, intermittent, and dramatic nature has elicited fear, misunderstanding, and stigma. Recent studies show that little progress has been made in public attitudes, especially in

BMJ 2003;326:349–50