As research continues to identify the quality of communication as a principal shortcoming of the health service,[3] perhaps any new way of delivering information to patients should be welcomed. Yet changes in the way information for patients is presented are occurring with little evaluation of content or effectiveness.[4,5] The emphasis on clinical symptoms and description persists because medical authors assume that patients seek the same kind of knowledge that they, as doctors, value.[2] Patients' anxieties about hospital treatment may, however, relate as much to problems of managing their own personal or family obligations as to pain or anxiety about outcome.[6-9]

Basic research into patients' needs for information that remain unfulfilled by interaction with doctors and nurses is urgently needed.[10] Several forms of potentially invaluable information remain unexplored. "Insider" guides to getting the best from services and providers are one possibility. Some patients are more successful in making use of services and their providers than others. This insider knowledge that the most successful patients quickly acquire is well known to practitioners, though they would not think of codifying it as information for patients.[11] Another possibility is to encourage the use of lists. Many patients fail to get the best from their interactions with health professionals because they arrive unprepared and unequipped with the "right" questions. Historically, doctors have bemoaned patients' use of prewritten lists of questions instead of considering them seriously as aids to better communication (p 34).[12]

Leaflets—not a panacea

Despite the new high tech media the humble leaflet or fact sheet remains the most widely used medium in the health service. Yet we know that the public ignores much printed literature on health. Research by Budd and McCron has shown that, despite agencies' reliance on leaflets to give people information, the public does not use information provided in this way, nor particularly like doing so.[13] General information on health is probably least used or understood: leaflets giving information on health for consumers may not be understood by over one third of those reading them.[14] Literature that is specific to a condition probably finds a more willing readership, although its content needs to be reconsidered.[15]

How can we develop more effective information? Doctors may be more productive as advisers than as sole authors. Printed handouts produced by surgeons often display inconsistencies in how procedures are discussed, can look off putting, and do not necessarily correspond with patients' declared needs for information.[9] Some surgeons have produced fact sheets that require a signature affirming that the patient has read and understood the content, so taking advantage of the protective veneer that such literature might offer them against postoperative complaints about side effects. This increases suspicions that they may be using such literature to excuse them further from their responsibilities to communicate with their patients.

At the other extreme, it is necessary to guard against expensively produced, glossy literature that is little more than covert advertising for a particular product or an associated treatment regimen. Information given in support of oral communication must not be used to shield doctors from their patients. It should draw on the extensive efforts already made to improve the provision of information for patients and be developed independently of commercial interests.

PHILIP MEREDITH
Head
MARK EMBERTON
Research fellow
CAROL WOOD
Manager

Patient Satisfaction Audit Service,
Surgical Audit Unit,
Royal College of Surgeons of England,
London WC2A 3PN

1 Sellu DP. Computer generated information leaflets for surgical patients. *Br J Clin Pract* 1987;41:612-7.
2 Audit Commission. *What seems to be the matter: communication between hospitals and patients.* London; HMSO, 1993.
3 Meredith P. Audit and the quality of clinical care: patient satisfaction. *Ann R Coll Surg Engl* 1991;73(suppl):51-4.
4 Glasser B, Squires M, eds. *Making it happen: a guide to two-way patient information.* London: North East Thames Regional Health Authority, 1994.
5 Mclver S. *Obtaining the views of health service users about quality information.* London: King's Fund Centre, 1993.
6 Cartwright A. *Human resources and hospital care.* London: Routledge and Kegan Paul, 1964.
7 Brody D, Miller S M, Lerman CE, Smith DG, Lazaro MS, Minday J, *et al.* The relationship between patients' satisfaction with their physician and perceptions about interventions they desired and received. *Med Care* 1989;27:1027-135.
8 Fitzpatrick, R. Satisfaction with health care. In: Fitzpatrick R, Hinton J, Newman S, Scambler G, Thompson J, eds. *The experience of illness.* London Tavistock, 1984.
9 Fitzpatrick R, Hopkins A. Problems in the conceptual framework of patient satisfaction research: an empirical exploration. *Sociology of Health and Illness* 1983;5:297-311.
10 Meredith P, Emberton M, Wood C, Smith J. A comparison of patients' needs for information on prostate surgery with printed materials provided by surgeons. *Quality in Heath Care* 1995;4: 18-23.
11 Roth J. Information and the control of treatment in tuberculosis hospitals. In: Friedson E, ed. *The hospital in modern society.* Glencoe: Free Press, 1963: 295.
12 Middleton JF. *Asking patients to write lists: feasibility study. BMJ* 1995;311:34.
13 Budd J, McCron R. *The role of the mass media in health education. Centre for mass communication research.* London: Health Education Council, 1982.
14 Editorial. *Nursing Times* 1992 Jan 29:88.
15 Mayberry JF. Information booklets for patients with inflammatory bowel disease. *International disability studies* 1988;10:179-80.

NHS-wide networking and patient confidentiality

Britain seems headed for a poor solution

The NHS is spending a nine figure sum on building a nationwide computer network, with the aim of making access to administrative and health records easier. For example, if a patient from another part of the country comes into a surgery complaining of abdominal pain, states that it is a recurrence of a chronic complaint, but is unable to say what, then online access to his or her records would be convenient and might occasionally save life.

But wider access brings with it a problem that the NHS has ignored—the threat of aggregation. At present, hospitals make do with relatively little security; after all, not many people will walk into a ward and steal a file from the note trolley. But once the records are aggregated into a database covering tens of millions of patients, that database will be a major target for data thieves, blackmailers, and others with less than altruistic motives. Evidence for this comes from the military, the banking industry, and the American health care system.

Firstly, soldiers know that if you gather a lot of information together then the collection may be much more sensitive than the individual items. Thus the Pentagon may occasionally release a satellite photograph to make a point, but it would never publish its whole collection as this would show its technical capabilities and the history of its intelligence priorities.

Secondly, the banking industry discovered the threat of aggregation the hard way. Thirty years ago bankers kept their records on paper, and customers' financial affairs remained private. But now that every teller can access every customer's account through a computer network the privacy is gone: when thousands of people have access to information some of them will always be prepared to sell it for cash. Last year, newspapers showed how banking records could be bought for a few hundred pounds[1]; even cabinet ministers and the head of MI5 were successfully targeted.[2]

Thirdly, the United States has gone much further in building health care networks than the NHS, and the problems are starting to become apparent to doctors and patients there. For example, a banker who sat on a state health commission accessed a list of people who had been diagnosed as having cancer and promptly called in their loans.[3] The records of sports and political personalities are regularly accessed by the curious, and a Harris poll in 1993 found that a quarter of all respondents had experienced improper disclosure of their medical information.[4]

On the level of institutionalised abuse, prescription records are being used extensively for marketing purposes; 40% of American insurers now disclose medical records to third parties, such as employers; and fully half of the largest 500 companies admit to using medical records in hiring decisions, under the excuse of managing the costs of healthcare.[4] In fact, the largest medical information network under construction in the United States is being built by Equifax, a credit reference agency.

Wide and slippery slope

The NHS is rushing headlong down this wide and slippery slope. It proposes to grant network access to the "extended NHS community"—officialese for social workers, insurance companies, and the police. The proposed control is that they will sign a "code of connection," a declaration that they will behave themselves; but this is backed neither by a credible security policy nor by the prospect of punishment for transgressors.

So we could shortly find ourselves sharing the Americans' problems. In fact, we could be even worse off, because of Britain's combination of a centralised health service, privatised data centres, and the fact that selling private records is not a criminal offence here (as it is in Germany).

It is not inevitable that computers will destroy privacy in medicine. While Germany tackled the problem with legislation, other states are using technical measures: Quebec has developed a record that patients carry around with them in a smartcard. This has five different zones—identity, emergency, vaccinations, drug treatment, and the full medical history—and each health care profession can access only the zones it needs. This project has been judged a success and of special benefit to elderly people and of those who are chronically ill.[5] In another approach a European Commission project has developed encryption software that enables records to be transmitted safely over insecure networks[6] and encryption software (that codes data to prevent unauthorised access) is now available for free.[7]

The NHS has a long way to go to catch up. It has conceded that databases on patients with AIDS should not be connected to the network, but HIV status is not the only sensitive medical fact; contraceptive status is another, and the mere suggestion of a psychiatric problem may render a person uninsurable.[8] No easy way exists, however, to predict what is sensitive: adherents of some religions might consider even a blood transfusion to be profoundly shameful.

Once medical records become endowed with the power to cause great harm there will be strong incentives to alter them. Not only will patients try to gloss over unpleasant facts but we may even see companies offering to sanitise medical files—just as there are companies which "repair" credit ratings. The reliability of records will become suspect, with obvious consequences.

One way or another, the proposed network falls far short of reasonable standards; its security would not be acceptable in other government departments or, for that matter, in industry. No doubt a carefully designed network could save costs and improve patients' care; but the profession should not be rushed into installing a poorly designed system with considerable potential to do harm instead.

ROSS ANDERSON
Senior research associate

Computer Security Group,
Computer Laboratory,
University of Cambridge,
Cambridge CB2 3QG

1 Luck N, Burns J. Your secrets for sale. *Daily Express* 1994 Feb 16:32-3.
2 Rufford N, Leppard D, Chittenden M. How £200 can buy bank account details. *Sunday Times* 1992 Nov 29:1, 3.
3 Bartlett ED. RMS need to safeguard computerised patient records to protect hospitals. *Hospital risk management* 1993;15:129-33.
4 Who's reading your medical records? *Consumer Reports* 1994 Oct:628-32.
5 Quebec healthcard evaluation almost finished. *Card World Independent* 1995 May: 4-5.
6 Bleumer G. Security for decentralized health information systems. *International Journal of Bio-Medical Computing* 1994;35(suppl):139-45.
7 Schneier B. *E-Mail security—how to keep your electronic messages private*. New York: John Wiley, 1994.
8 Bass A. Insurers spurn anyone in therapy. *Boston Globe* 1995 Apr 3:25.