

Information for health - hurry slowly

In the 1998 document *Information for Health*,¹ Frank Burns, Head of Information Management and Technology for the NHS Executive, outlined an ambitious strategy for using computer technology to further the aim of 'giving the people of this country the best system of health care in the world'. Will the white heat of this revolution enable the National Health Service (NHS) to cope better with its widely recognised underfunding or will expenditure on information technology (IT) systems that fail to perform prove a further burden on inadequate health care resources? The answer will depend on the effectiveness with which the modernisation process is managed and on whether the pace of implementation takes proper account of certain major problems. Putting the machines in place and hoping the problems will get solved afterwards may not be the best approach.

Its history is not encouraging. The House of Commons Select Committee on Public Accounts recently reviewed the effectiveness of public investment in computer systems following the outsourcing or privatisation of government IT development that took place from the late 1980s onward.² The report expresses serious concern at 'the number of government IT projects that are not delivered on time or at all, are completed over-budget, and either fail to match specifications or require significant changes before they are satisfactory'. NHS computer projects have made a significant contribution to the spectacular waste of public money documented. The report makes a raft of important recommendations: that the needs of end users should be fully taken into account in the design of systems; that decisions on IT systems are business decisions in which senior management must be involved; that 'departments should consider carefully whether projects are too ambitious to undertake in one go'; that stepwise incremental introduction should be adopted wherever possible with regular milestones, each delivering an auditable business benefit; that staff training should be adequately resourced; and that expert project management is essential. The report should be read from beginning to end by anyone responsible at any level for driving forward the NHS IT agenda.

What does the NHS information strategy have to offer, and what are the problems? The idea is that there should be a lifelong electronic health record kept in a standardised form in general practice. It would be used by both primary and community health workers, accessible — at least in part — from anywhere else in the NHS at any time, and electronically transferable when patients move to another practice. Sharing of the record should be possible, under appropriate circumstances, by social service departments. Communication to and from hospitals and transmission of laboratory results would take place electronically. Appointment systems, both in hospital outpatients and in general practices, would be open to booking from other agencies, including NHS Direct. Anonymised data from patient records would permit analysis for purposes of managerial and clinical audit with selected data on the performance of provider units made public, the aim being to inform the planning and improve the quality, efficiency, and convenience of services. Appropriate information resources (protocols, guidelines, clinical evidence) would be made electronically available, both to professionals and to patients.

Most of the problems with this vision of the brave new world are recognised in *Information for Health*, but it is essential that these problems are addressed and solved if implementation of the strategy is to be a success.

The most obvious and pressing concern is confidentiality of

medical records in a system that would allow remote access to the record from anywhere in the NHS at any time. Such an arrangement must increase the opportunity for improper access to medical records, both from within and without the NHS. The strategy document recognises that 'in exceptional circumstances some patients may not wish for certain aspects of their medical history to be ... communicated to other parts of the NHS'. However, such circumstances are far from exceptional. Contraception, previous pregnancies, previous episodes of venereal disease or psychiatric illness are among the more common things that people may wish to avoid unnecessarily communicating to others. Breaches of confidentiality within families are particularly at risk of occurring with the automatic availability of even a subset of the medical record — and are a serious hazard of displaying highly legible computer summaries on big screens in consultations. Problems of this kind will render patients less ready to share confidences with doctors, and render doctors less likely to record them — both of which are detrimental to good clinical care and good record-keeping in general practice. Many existing general practice software packages have inadequate provision for restricting access to sections of the record. In my opinion it is doubtful whether the efficiency gains of remote NHS-wide access to an electronic health record outweigh the loss in confidentiality involved.

Existing computer record systems in general practice are incompatible with one another. Even with the same software, different practices and doctors structure and use their systems in different ways. Anyone who has tried to achieve consistency in computer usage in one general practice will know the difficulty of achieving any wider consensus in the structure and usage of medical records. Without basic structural consistency electronic record transfer is difficult or impossible. Computer records deteriorate on paper transfer: take a look at the large and often incomprehensible printouts received from 'paperless' practices. And yet computerisation in general practice is advanced compared to the hospital sector, where in 1998 more than 75% of acute hospitals had yet to invest in information systems capable of supporting an electronic health record. In hospitals the problem of multiple incompatible systems is worse than in primary care and the tasks in achieving a shared record structure are yet more daunting.

Direct booking of outpatient appointments just like airline tickets would need to be piloted for its impact on outpatient waiting times before any widespread introduction. Effective demand management is crucial to the NHS's ability to cope with inadequate funding, and the risk here is that convenience (for some) takes priority over clinical need in the allocation of scarce resources.

Information technology systems hit problems when they try to serve multiple agendas. The limited clinical usefulness of many NHS systems has stemmed from their having been designed to serve the needs of managers in the context of the internal market. Some of the difficulties experienced with Read codes and the Clinical Terms Project have been due to the problems of reconciling different needs in clinical coding. Enormous care will be needed in progressing the concept of the electronic health record to avoid a structure that satisfies none and frustrates most of its users.

A further risk identified by the Public Accounts Committee is that delay in implementing projects places them at risk of being overtaken by technological change. The commercially driven and

dysfunctional speed of obsolescence of computer hardware and software is a major problem, especially for a cash-strapped organisation such as the NHS. 'It is vital that project plans are sufficiently flexible to allow for the insertion of technological advances where relevant.' 'Management must be aware of the importance of halting a project that has been overtaken by events rather than continuing to spend money.'² And plenty of money will need to be spent. Expenditure on IT procurement, maintenance, and services in the NHS was £1 billion in 1998–1999.² That figure will grow rapidly if the strategy in *Information for Health* is to be effectively implemented, especially if the needs for better project management and proper staff training are recognised and adequately resourced.

However, delay in the implementation of the NHS information strategy may be vital to its success. A common record structure allowing electronic transfer of general practice records and better resolution of confidentiality concerns are necessary conditions for implementation of key elements in the strategy. These conditions have not yet been met. Delaying major new IT system investment until these problems have been resolved would concentrate the minds of the industry on helping to find solutions. There is a real risk that political pressure for rapid results may drive the NHS into another round of wasteful investment in systems that do not deliver.

And what if the standardisation of record and messaging systems necessary for the smooth functioning of an NHS intranet should prove impossible to achieve? The World Wide Web was invented in 1990 by Tim Berners-Lee at CERN to allow communication between disparate computer systems. He provided a simple set of communication protocols which allowed people to

go on using their own computers in their own way.³ This rather successful idea was conceived in response to a very similar set of problems to those facing the NHS. A lot of money is now riding on the need to achieve security and confidentiality in web transactions and good solutions may soon be found. Will an NHS intranet be necessary in five years' time? Perhaps we would do better to wait and see.

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What kind of partnership in the consultation?

The idea of partnership with patients has become not only fashionable but also part of national policy,¹ although there is evidence that not all patients necessarily welcome such partnership.² Older people may have particular problems with the concept, especially if they have been used to a different style of 'doctoring'. Patients may also reject this 'sharing' philosophy if doctors do not effectively integrate it into their consultation styles.^{3,4}

Although politically correct, this partnership may not be universally popular with doctors either. For example, doctors may hold negative stereotypes of patients who bring written lists of concerns to the consultation, perhaps because they fear the combination of excessive demands from patients and limited time in which to manage them.⁵ The workload for doctors within the consultation has also grown because of local and national initiatives and this may threaten the interaction between individual patients and their doctors in the consultation.⁶

Nevertheless, the principles of patient-doctor partnership have long been enshrined in models of the consultation.⁷⁻⁹ General practitioners may feel that they have 'been there, done that, and got the T-shirt'. Unfortunately, the finding that doctors prematurely interrupt and close down patients' accounts of their concerns is far from encouraging.¹⁰ Although attention is now being paid to the 'neglected second half of the consultation', in which information is shared and decisions made, a successful outcome is dependent on the first part of the consultation when doctors must identify and understand their patients' agendas.¹² Dysfunctional consultations often result from inappropriate

assumptions by doctors about their patients' agendas.¹² Doctors often fail to acknowledge patients' 'expertise' about their problems and how it relates to their situations,¹³ and subsequently fail to incorporate patients' beliefs and explanatory frameworks in explanation and management.¹⁴ The challenge of doing so is ever increasing as the lay expertise of patients is augmented by increasingly open access to clinical and other information; for example, medical guidelines on the Internet.¹⁵

However, partnerships may take different forms with widely varying roles within them. For example, in a professional group practice the other partners may choose to rely on the expertise of the 'administrative' partner for guidance on major strategic decisions. What is important is that the 'administrative' partner has a mandate from the others. Similarly, in the consultation, roles for the doctor and patient may need to be negotiated and mandated. Each patient's preference for partnership in the consultation is located within a multi-dimensional framework, the axes of which embrace differing desires and needs for information, assistance with its interpretation, and involvement in final decision-making. The patient's preference for 'sharing' or being directed must be determined on each axis. The abrogation of responsibility by the doctor — for example, to unload a mass of statistics about options onto a patient who has not been enabled to assimilate the information — is an impoverished model of partnership. Patients will have varying needs for information: some may have fully informed themselves about available options from the Internet¹⁵ while others will entrust the doctor to provide this information.

Patients will also have differing needs for assistance with the interpretation of such information and its application in the context of their own presentations. Finally, some patients will seek active guidance from their doctors in making the final decision while others will wish to make it themselves.

Such partnerships require doctors to understand patients' agendas; the 'first' and 'second' halves of successful consultations cannot be separated except in theory.¹⁶ In such integrated consultations, doctors can come to understand their patients' agendas — which are often complex — and patients' needs and preferences for information and assistance with its interpretation and decision-making. Doctors are then better placed to develop negotiated and agreed management plans⁷ to which patients are more likely to adhere, thus maximising the chances of successful outcomes. Unfortunately, doctors may not have been enabled to develop the required skills during their training.¹⁷ The impact of such partnership on the total time required to care for patients is unknown but it has the potential to reduce it.

Whatever our views about patient-doctor partnership, co-operation will be preferable to conflict. A perception by patients of achieving common ground with doctors is associated with lower rates of investigation and referral,¹⁸ active participation by patients with improvements in blood pressure¹⁹ and diabetic control,²⁰ and better communication with increased patient satisfaction.²⁰ Indeed, a measure of such 'patient enablement' has been found to be a useful proxy for the quality of the consultation.^{22,23} Sharing of understanding is likely to be a common factor that enables negotiation of outcomes. We have demonstrated that experienced doctors can be trained to identify more of their patients' problems and that patients can be assisted in making their agendas more explicit by completing an 'agenda form' while waiting for their consultation with their doctor.²⁴ Therefore, we believe that both patients and their doctors can be assisted to develop their partnerships.

The consultation is an invaluable opportunity for patients and their doctors to negotiate their desired outcomes and their preferred roles in achieving them. Although successful patient-doctor partnerships can yield more efficient use of health care resources it is threatened by outside pressures, time constraints, and lack of appropriate training. This partnership urgently requires investment.

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