

Privacy obsesses lawyers, not patients

COMMENT: James Gillespie and Stephen Leeder | *The Australian*, October 04, 2008

JUST how worried are Australians about the privacy of their health records? This question has dogged the long and tortuous history of efforts to change to electronic health record systems. If we are to have a health service where information of relevance to the care of a patient is readily available, anywhere, any time, to those caring for them, substantial changes will be needed in the way we manage medical records.

Against this, privacy concerns are regularly adduced as the reason why progress cannot be made in using data derived from the care of individuals for improving the health service. The public, it is often said, is paranoid about the privacy of personal health records. This predominantly legal concern plays into the hands of professional and bureaucratic groups who have resisted more open scrutiny of these and other data (such as Medicare) that might reveal their own shortcomings.

Do patients trust their doctors and the broader systems to keep personal, and often sensitive, records away from unauthorised view or use? Many of the problems of our healthcare system - from unnecessary deaths from medication and hospital error to the fractured management of chronic illness - have been traced to communication problems. General practitioners, pharmacists, physiotherapists and hospital-based specialists have been unable to get easy access to a patient's medical history - their medications, allergies and past encounters with the health system. The vast majority of medical communication is untouched by advances in information technology.

Yet the power of the technological imperative, as manifest in IT, will change all of this. As new, more flexible internet technologies overcome the cost and technical obstacles that blocked information sharing, faster and more effective transfer of information has raised fears, though whether in the minds of patients is rarely proved, of new assaults on the privacy of patients' health records.

So what do Australians think about privacy and their health records? The Menzies Centre for Health Policy and The Nous Group recently surveyed a representative sample of 1200 Australians aged 18-plus on their attitudes to the health system.

One group of respondents was reminded that during a period of illness, patients are frequently treated by a series of health professionals. Should those charged with the care of the patient all have direct access to their records? Or should they rely on taking a medical history from the patient each time the patient passes from one carer to another, as happens now with astonishing frequency? There was an overwhelming consensus - 90 per cent - in favour of direct access for all treating health professionals to the patient's records: one record, available to all carers.

Another group in the Menzies-Nous survey was asked a set of more specific questions ... how willing would they be to allow their doctors, all the health professionals concerned with their

case, or a variety of others - the police, one's spouse, insurance companies - to have access to their personal medical record? For all the health professionals, the answer was the same - overwhelmingly in favour. This support varied little across age and education, and between men and women.

A third group was asked whether they felt their records were sufficiently protected by the obligations of confidentiality among professionals. Did they instead feel that any access without their explicit consent was an invasion of privacy? Given this choice, one third of these respondents opted for privacy. But a two-thirds majority was happy with a system based on assurances of confidentiality.

While Australians overwhelmingly support access to their records for health professionals, this relaxed view of privacy had firm limits. A bare majority believe the police should have access to health records. Older respondents and the more highly educated were more likely to oppose this than the younger or less well educated. There was a similar pattern in relation to access by medical insurance companies. Again, opposition increased with age. On the question of access by "spouse or de facto", many more women (52 per cent) were reluctant to allow their spouse or partner access to their medical records than were men (35 per cent).ⁱ

The Council of Australian Governments is about to furrow its brow about how to kick-start the Australia's faltering adoption of new health information technologies. This is a good time to examine the evidence that the public is "really worried about privacy".

As a consumer representative said at a day-long conference held in Canberra in the wake of the Australia Card debate in the late 1980s, "Privacy is not a consumer concern. It is a legal concern!".

This, it seems, is a widely held view with regard to privacy and medical records.

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ⁱ Note: These figures are corrected from those published in the original article.