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Risk to Privacy versus Benefit of Quality Care: What Do Patients with Chronic Medical Conditions Choose

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Background:

A recent Australian NSW Health initiative was the introduction of My Health Record (MHR). The first prototype was released in December 2002 and after evaluation, a revision was issued in 2005. The rationale behind My Health Record was to have a simple practical method to encourage people to record and track all information concerning their medical condition and have it easily accessible. This would ensure continuity of care and reduce pressures on the health system by avoiding unnecessary admissions The NSW Privacy Commission and NSW Health Legal Branch were represented on the NSW Personal Health Record Steering Committee and oversaw the development of *My Health Record.*

The advantages and disadvantages of patient held portable health files have been reported in the medical literature for a number of decades. Advantages include improved continuity of care, improved patient understanding of instructions and encouraging patients to take an active role in maintaining their health. Disadvantages include practical problems such as elderly patients forgetting to bring the files to their health-care provider, losing the file, or not want the responsibility of shared-care as well as more serious ethical arguments regarding ownership, privacy and confidentiality.[1,2,3,4] In the main, loss of privacy and confidentiality is an important consideration for the young, for the employed and for those with conditions that may have peer or societal implications (sexually transmitted diseases, medical abortions or mental illness). In 1985 Stacey[5] comments that the foundations of contemporary medical ethics were laid at a time of one-to-one doctor-patient relations while in this day and age most doctors work with many other doctors as well as with other personnel. Making records openly available to patients has advantages to both the doctor and patient.

Several models of patient-accessed shared care records have been developed. Some top-down centralized electronic systems of hospital and community health information, favoured by government or by private organizations, have web-based and other up-loadable applications that allow patients to enter their own information into secure personal health records. These applications are being promoted as a means of providing patients and providers with universal access to updated medical information[6]. Some systems[7] are free and open source and claim to meet policy requirements of data encryption, secure access, authentication and authorization. However a recent review of web-based systems reported limited functionality[8].

Bottom-up solutions include patient-held paper or electronic files portable health files, carried by the patient, through which they access, manage and share their health information, and that of others for whom they are authorized, in a potentially but not of necessity private, secure, and confidential environment. Most portable health files are not designed to be the primary record of the health care system but a prospective extract of core medical information (e.g. medical conditions, medications, results of investigations and procedures and so forth). Models of portable health files include paper-based stand alone systems or systems integrated with health provider electronic medical records, portable health files carried on smart cards, on CD ROMS, and more recently on USB memory drives.

In 2005-6 we conducted a community-based trial in patients with rheumatoid arthritis, comparing an electronic personal health file carried on a USB drive, with two paper-based personal health files (NSW My Health Record and a paper-based passport sized book version of the electronic portable health file). The aim of the trial was to evaluate methods of improving health information exchange among health-care providers. During this project, using qualitative research methods, we investigated the attitudes, perceptions and opinions influencing the effective use of a patient-held portable health file by patient-consumers, with a particular focus on issues of privacy, health information security and confidentiality.

Methods:

Two qualitative semi-structured focus-groups were conducted prior to project start and another two after the tools were rolled-out. A total of 22 patients participated. All had at least one chronic medical condition and more than half were retired and/or older than 65 years. Although rheumatoid arthritis is more common in women, the gender ratio was almost 1:1 for this part of the project. The first focus group was led by a social scientist with particular expertise in focus group methodology, two latter focus groups were led by two research nurses and the final focus group by a research nurse and medical practitioner. All focus group sessions were transcribed. The project was funded by Commonwealth Department of Health and Ageing and was approved by the hospital and university Human Research Ethics Committees.

Results:

Patients recognized that patient-held paper-based health files had no security features - name, medical information etc was obtainable if the diary was lost or stolen. This was not a concern - they did not believe that this information was of any interest to anyone other than their health-care providers. Similarly, the majority of patients did not believe that an electronic health file carried on a USB drive, if lost or stolen was a significant privacy issue, even if it their medical data was posted on the internet. One patient recognized that her young son who requires employment may be concerned regarding potential loss of confidentiality and risk of discrimination with theft of medical information. However most, understood that the advantage of electronic information was that it could be password protected (like a pin number for a bank account) whereas written information could not.

Many of the patients that took part in the focus groups had many health-care providers. One patient said:

> "I've got something like eight or nine specialists … So you know, I mean it does get confused."

Regarding the issues of privacy, whether and electronic USB should be password protected:

> "Well the use of information is useless to anybody – what could they do with it? You know it's not like your Visa card or anything. You know it's meaningless to anyone else, the only thing they could get out of it would be your name and address. That can under some conditions be a bit of a worry .. It's no different – in fact it's less of a problem I think than writing it in a book. Because a book is plain for everybody to see, that little thing means nothing until you plug it in to a computer … I would much rather medical people have access – free access to my information I can't communicate myself. I'd much rather they had access to it easily than not at all .. one's life can depend on that and speed sometimes in this instance"

However another said:

> "Probably somebody with say social diseases or something won't want everybody that will hear, you know a personal problem .."

Regarding loss or theft of the USB drive whether confidentiality was a problem.

> "It's boring for anybody to read."
> "What are they going to know – that you know – that you're ill, you take pills."
> "How boring – who wants to read it. "
> "They're not going to blackmail you are they? …. I want your bottle of Prednisone."
> "I think confidentiality's gone too far."
> "If there was really personal stuff on there I wouldn't like it but you know – but if it's just in general like."

Regarding whether someone else obtained their information and posting it on the Web.

> "A lot of people wouldn't know what that was."
> "I guess what are they going to find anyway, just what's in here."
> "The only person – say if you were a famous personality."
> "But then you may not – you'd be more careful with yours.."
> "That'd be different. But for all of us.."
> "It's so boring who'd want to look at that."
> "No pictures – oh my God, we can't have that."
> "Perhaps we should say no X-rays."

Discussion:

Perhaps it is not surprising that older patient's with multiple chronic medical conditions that require the care of multiple health care providers believe that improving the quality of their health care outweighs the risk of losing health information privacy. Most patients did not think that their health information could be of any interest or of any value to anyone other than themselves, their family or their current or future health care providers. Many patients were hesitant to pass-word protect their files in case emergency treatment was needed. Furthermore, most recognized that a paper-portable file could not be password protected, although some offered suggestions on how paper-based files could be protected if needed.

These patients understood that this view would not be held by everyone. Celebrities or patients with a social disease or personal problems or who were employed with medical problems that they would not want disclosed, may not be comfortable with the security of electronic-files.

It would seem that any single approach advocated by the various stakeholders (health policy, information technology, legal profession, consumer organizations, medical profession) cannot reflect the diverse needs of the community. Risk-management is context-specific. Older patients with multiple chronic medical conditions that require the care of multiple health care providers, and that often need multiple hospital admissions, consume a greater proportion of health care resources, direct and indirect, than the young, the healthy and the employed. One argument for bottom-up patient-held portable health files is that they provide greater control for patient-consumers compared to centralized top-down electronic health-information systems with opt-in / opt-out alternatives.

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