

Universal electronic health records:

A qualitative study of lay perspectives

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ABSTRACT

Objective

To ascertain the hopes and fears of the New Zealand lay public with respect to the development and use of universal electronic health records (EHRs).

Design

In-depth, semi-structured interviews were conducted with 20 purposefully chosen members of the lay public in Dunedin and subjected to thematic analysis.

Results

Most participants could see the advantages of EHRs but all had reservations about the capture, storage and

use of their health information. Concerns emerged about privacy and confidentiality, access to records, security of the information, quality of the data entry, transparency in development, ownership of data and accountability.

Conclusions

There is a low level of awareness and many misconceptions amongst members of the lay public about e-health information and patient rights. National awareness campaigns, as recommended by the WAVE project, could go some way towards reversing this situation.

(NZFP 2004; 31:149–154)

The electronic capture, storage and sharing of data has major cultural, ethical and technological implications but there are few published studies of consumer perspectives in relation to electronic health records (EHRs).

This qualitative study of New Zealand lay people's hopes and fears with respect to the development and use of universal EHRs suggests that there is a low level of awareness and many misconceptions about e-health information and patient rights. National awareness campaigns could go some way towards reversing this situation.

Introduction

Standardisation of the capture of health information (in the form of personal electronic health records [EHRs], national databases and networks) is a key issue that has occupied health policy development internationally^{1–5} and in New Zealand^{6–9} for several years. A high level of involvement within the NZ health and disability sector workforce has been reported⁶ but there are no published NZ studies of consumer perspectives in relation to electronic health records and very few from other countries.^{10–14}

'Britain's Prime Minister, Tony Blair, has challenged its National

*Health Service (NHS) to harness the information revolution for the benefit of patients, as part of a bold modernisation strategy which includes Electronic Health Records (EHRs) for everyone in the country, round-the-clock on-line access to patient records for all NHS clinicians and genuinely seamless care for patients. In Australia, myriad federal committees have been established to examine the issues, while the individual states get on with implementation.'*⁶

US patients who were informed about general practitioner computer-based health records had positive attitudes towards them, believing that it was indicative of the

'doctor being up-to-date' and would improve the quality of care.¹¹ Others believed that their doctor did not have their complete medical information (because of changing locations, jobs and health plans) and had begun to electronically centralise their own health records at home.¹³ Ontario residents, on the other hand, were concerned about information held by their general practitioner that they did not want shared with other people.¹⁵ A UK study to determine people's attitudes towards EHRs found that most people knew that they had a right to access their EHR but that only a small proportion had done so.¹²

Other studies have shown that EHRs have the potential to encourage increased patient involvement in their health care, provided that security issues are resolved.^{13 14 16}

The electronic capture, storage and sharing of data has major cultural, ethical, logistical and technological implications, so public consultation and education are important facilitators for its introduction.¹⁷ The New Zealand Privacy Commissioner, when discussing issues in health information at the close of the twentieth century, stated that *'Patient opinion still seems to be viewed as a risk to be managed at some late stage rather than included as a key element of design... Consumer opinion does not seem to have been sought at all, let alone at an early stage'*.¹⁸ What are the hopes and fears of the lay public with respect to this new technology? Establishing the baseline of public awareness of health information and technology developments is the first step in understanding and addressing lay attitudes towards universal health care databases.

Methods

Semi-structured, audio taped interviews were conducted with 20 members of the NZ lay public, purposefully chosen to give a range of age, gender, occupation and familiarity with information technology. The aim was to ascertain the level of awareness and the diversity of people's views regarding universal electronic medical records. Participants were initially non-medical friends and contacts of members of the School of Pharmacy, University of Otago. After the interview, participants were asked to recommend someone else who was completely different from themselves. This snowballing technique provided as diverse a range of viewpoints as possible. Chart 1 gives a description of the participants in terms of age (by decade), gender, occupation (based on the NZ Standard Classification of Occupations, 1995) and self-identi-

fied familiarity with information technology (IT).

Interviews lasted from 10 to 45 minutes and were conducted either in the School of Pharmacy or at the participant's workplace or home. Open-ended, non-leading questions, such as *'Tell me what you know about computerised medical records'*, were used to guide the interview with additional questions, such as *'What makes you think that?'* arising from the participant's responses. Questions were clarified for participants where necessary, so that they were aware of the extension from medical records held on a computer by their general practitioner to centrally held records accessed by a variety of health care providers. Leading terms such as security, confidentiality, accuracy, misuse and access were avoided until the participant brought them up. Once mentioned, questions were asked to explore the participant's viewpoints on these matters. Some participants were less responsive than others and, for them, the above terms were eventually suggested by the interviewer.

The taped interviews were fully transcribed and reviewed by both researchers. Recurring and isolated themes, as mentioned by the participants, were identified and illustrative quotations extracted from the transcripts. The themes were then grouped into categories of a higher more abstract order and these were used in the analytical interpretation and the final report.

Results

Most interviewees could readily see advantages in having all of their medical records stored in one place, provided that concerns around security, confidentiality and access were satisfactorily addressed. Some were even *'surprised that they haven't already done it'*. The advantages mentioned revolved around issues of convenience, time-saving, efficiency and access to patient information on allergies, medications and genetic disorders in emergency situations.

'You're not having to go and say well I've had this done here, and I've had that done over there... (A database) must cut out a lot of doubling up and breakdown in communication and letter writing.' – female, 40's, associate professional.

One participant, who was strongly against the implementation of universal EHRs, thought that the emergency situation was *'the only time when different pieces of information from different health profes-*

Chart 1. Description of Participants

Details of Participant	No.
Age	
20s	9
30s	1
40s	6
50s	1
60s	1
70s	1
80s	1
Gender	
Male	9
Female	11
Occupation	
Legislators, administrators & managers	4
Professionals	2
Technicians & associate professionals	3
Clerks	0
Service & sales workers	5
Agriculture & fisheries workers	1
Trades workers	0
Plant & machine operators	1
Elementary occupations	1
Students	3
IT Familiarity	
High	1
High-middle	2
Middle	8
Middle-low	3
Low	2
Low-none at all	0
None at all	4

sionals might be needed'. Another questioned the assumption about improved efficiency and decreased workload, speculating that paper records might also be kept. Surprisingly, most of the participants were vague and unsure about how their medical records are currently stored, 'imagining' and 'guessing' that they may be 'on the computer'.

Other advantages that were mentioned included: the access to information when on holiday; not forgetting something vital during a consultation with a non-regular practitioner; and detecting abuse of the health system, such as 'people shopping around, going to different health providers to get medication'. An unexpected advantage was mentioned by one participant.

'(Creating a database) generates work and income, more information. I mean it's all product that has to be manufactured and sold and used.' – male, 40's, service worker.

In spite of acknowledging the advantages and inevitability of EHRs all participants had some reservations and often these were held strongly. The three main categories identified in the interviews, covering several inter-related themes, were:

1. Confidence in the processes,
2. Control over the data and
3. Risks to the individual.

1. Confidence in the processes

From the interviews it emerged that people need to have confidence in the processes of creation and sharing of EHRs from design through to implementation and use. Concerns were expressed about privacy and confidentiality, particularly in dealing with sensitive issues, access to records, security of information and the quality of data entry.

Privacy and confidentiality

'I just feel all uncovered.' Opinions on the sharing of health information

between health professionals ranged from 'I don't have anything to hide' to 'It's convenience at a price and I don't think it's worth it'. Most fears were expressed around the collection and use of an individual's information, a 'big brother is watching you' sort of feeling.

Some people wanted to restrict access to their records to the health professionals actually dealing with them

'The government could change the rules... they may be able to just gain access when they see fit.' – male, 30's, agriculture worker.

The mistrust or public scepticism of government and its agents was expressed in various forms by several of the participants.

Two women felt quite strongly about the handling of sensitive information.

'How would sensitive issues be dealt with, if people had had a procedure that they didn't want other people to know about, whether that would be there?' – female, 60's, professional.

'I use another doctor for feminine hygiene matters, for anything that relates to smear tests... I like those two (areas of my health) totally separate.' – female, 40's, administrator.

Access to records

'Where would you draw the line?' Concerns about access to an individual's information related to who should have access to what information and how the information might be used. Some people wanted to restrict access to their records to the health professionals actually dealing with them or to 'people who are making decisions about your health care'.

'I'm sure your dentist doesn't need to know what's going on in your uterus does he?' – female, 40's, associate professional.

'(The pharmacist) only really needs to know a specific piece of it.' – male, 30's, agriculture worker.

The fear was that the information could be made available to employers

Other people preferred restricting access to certain parts of their record, for example mental health issues or certain progressive illnesses. The fear was that the information could be made available to employers, the Accident Compensation Corporation (ACC), various government departments or insurance companies, thereby affecting other parts of the individual's life. There were also issues about access by paramedics, administrative personnel and voluntary health care workers.

'Maybe St John's (ambulance) are out at a crash site... (the information) may well determine their method of care.' – male, 40's, manager.

'I don't think receptionists need to look at the records.' – male, 20's, manager.

A few people were worried that members of the family or the general public would be able to access their files.

'I'd feel a bit better as a pleb, knowing that not everybody was able to access the information... I don't think it should be accessible by the general public.' – male, 20's, professional.

'Is it only the pharmacist that can actually draw that information up or can the technicians do it, or can anybody in the shop do it?' – male, 30's, agriculture worker.

Security of information

'We can't guarantee anything.' The security of EHRs and health databases was, for the majority of the participants, their main anxiety.

'I don't think that there is anybody who can absolutely guarantee that any information on a computer is totally secure.' – female, 40's, administrator.

Suggestions to make the idea of EHRs more comfortable included smart cards, PIN numbers and encryption of data. Fears included misuse of data by health professionals, ancillary workers and various agencies (as mentioned above) and lost data be-

cause of computer glitches. Concern about the activities of 'hackers' was mentioned by almost everyone.

'Whether (health professionals are) looking for some sort of financial gain, misusing files, falsifying files, things like that I mean people get themselves into situations that they do strange things to get out of, so that's always a concern.' – male, 40's, service worker

'You could lose all that information if it's stored in one place.' – male, 20's, manager.

'Any new system's going to be fraught with glitches and problems.' – male, 40's, service worker.

'You hear of them hacking into the likes of the US Pentagon security thing... If they can do that, I'm sure they can break a simple little password on a medical record in little old NZ.' – male, 30's, agriculture worker.

Quality of data entry

Participants questioned the type of data that would be stored, its accuracy and who would do the inputting, many of them assuming that 'doctors don't have time to do that'. One person wondered about computerised formatting resulting in the loss of quality of information.

'If they're putting things on to file there's a format that they'd have to adhere to (and doctors might leave off) short notes and things like that that no one else can read.' – male, 40's, service worker.

Another person mused about the consequences of having health professionals viewing each other's notes.

'It means that each health professional is going to be audited in an informal way, not only by his/her peers but by a raft of other health professionals, and some may not like that.' – female, 60's, professional.

Two people spoke of the effect that such records would have on the relationship between the patient

and the health professional. They felt that they would be circumspect about what they shared with their general practitioner.

'There are things that I might tell my GP that I'm not going to tell another health professional because I know I can talk with her about those things quite openly. I think there are a lot of people who would stop talking openly with their GP's if other people were going to access that information.' – female, 40's, administrator.

Concern was expressed about the use of data entry operators in terms of accuracy, confidentiality and the possibility of 'mixing up people's records'.

2. Control over the data

Participants clearly wanted to have control over their information and to know what is happening.

Transparency in development

'I'd like everything explained and laid out in a way that I could understand.' The interviewees wanted to be informed about the development and implementation of EHRs and health databases and have the right to choose whether or not to be on a database. Participants' suggestions included explanatory reviews, submissions, pamphlets and 'better communication between policy makers and the people who are going to be affected by the changes'.

'Everybody should be well aware (of) what's happening... you should be made aware who can access the information so you know what's going on, because you've got to know what's happening with your own personal information.' – male, 30's, agriculture worker.

Ownership of data

'I'd like to be consulted about it first.' It was important to participants that they have a say about what goes onto their record, who has access to all, or parts of, their information (as discussed above) and the option to view their records. Many feared 'losing control' of their information.

'The bottom line is, it's your right to decide what's public about you and what's not... for no other reason than it's your information, it's about you and you should be able to do that... I think the power has to stay with the patient to say what's OK and what's not.' – male, 20's, student.

An interesting paradox emerged in that some people wanted control over who can access what parts of their file, but they were ill-equipped to make those decisions.

'You (should) be able to say at the time that this stuff should be readily available, this stuff you should need to have consent for... (but) it's hard to say what information is relevant to what different health professionals.' – male, 20's, student.

Many participants did not know about their right to view information held about them but thought that this would be a good means of checking the accuracy of records. Other reasons for having access to one's personal record included evaluating a health professional's performance, reflecting on one's health history, monitoring a chronic condition and as a means of two-way information sharing.

'Will information be passed back... when do we get to see (the professional's) thoughts and ideas?' – male, 40's, service worker.

Most people thought that access to records should be only in the presence of their general practitioner so that technical terms could be explained.

'It's very easy to misconstrue or infer incorrectly what has been written... you could pick up on a point that is not necessarily meant to be taken that way... you just don't have

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the education, otherwise we'd all be doctors and dentists and pharmacists.' – male, 40's, service worker.

However, some said that they would prefer to access their record from their own home for reasons of convenience, monitoring of test results or because: *'communication lines can be quite difficult sometimes, and I think for me (accessing the information from home) would (be) a good way of finding out.'* – male, 20's, professional.

3. Risks to the individual

Participants were not worried about but rather resigned to the risks involved in universal EHRs. They wanted to be informed about what these risks would be and be assured that attention was being paid to minimising them.

'It's human stuff that's the risk. It's the receptionist that doesn't log off, or close her system down when she goes home at the end of the day and things like that. That's where the errors would happen. You can lock the system down very securely, but you can't make people not make mistakes.' – female, 40's, legislators, manager.

'Hackers are pretty clever yeah, so I guess that would just be a risk that we'd have to be aware of.' – female, 20's, service worker.

'I think that they shouldn't create a database unless they can (put things in place to improve security)... there (should) definitely be something in place to protect the information... But I mean I guess none of it is fool-proof, completely watertight... it's about what risks am I being placed under.' – female, 20's, student.

Information for research purposes

'Many people have a basic altruistic side to them.' Attitudes towards the

use of health databases for research purposes were positive, provided that attention is paid to issues such as consultation, anonymity and consent.

'You can lock the system down very securely, but you can't make people not make mistakes.'

'I like the idea of being able to assist where I can, and I guess knowledge is growth.' – male, 20's, professional.

Accountability

'The buck would have to stop at my doctor, my surgeon, my anaesthetist, my physio.'

Two people mentioned the important issue of accountability.

'(Accountability should lie with) both the patient and the process or the (health care) providers... People have to accept a level of responsibility for their own decision making and for their own lifestyle.' – female, 60's, professional.

Opting Out

Although mentioned by only one person the issue of opting out is also an important one. Are there consequences of not authorising your health information for inclusion in an EHR or on a particular database? What are your responsibilities as a consumer of state-funded health care?

'I wondered about how non-conformists would be treated, those who would refuse to have information stored on a database... could people have the right to refuse or to opt-out... how would people be treated if they didn't fit within the norm.' – female, 60's, professional.

Discussion

Many participants had very little idea of how their medical records are currently stored. None had any aware-

ness that several national databases already exist,¹⁹ or are being planned and trialled,²⁰⁻²² or of the existence of the WAVE (Working to Add Value to E-information) project to better organise health information.⁶

This study found that participants generally had a low level of awareness and knowledge about universal EHRs. Attitudes towards the collection, storage and use of personal health information, ranged from those who *'had nothing to hide'* and thought it a good idea with several advantages to those who were vehemently opposed to *'having everything on a computer file'*. The views of this last group, comprising a fifth of those interviewed, cannot be ignored, since their co-operation relies upon the trust that is gained when people understand the motivation of others. In general, though, the participants were mostly positive about electronic medical records. Perhaps, their low level of knowledge translated into a lack of concern and anxiety. These findings are in agreement with those from the UK National Health Service electronic record development and implementation programme (ERDIP) which found that public awareness and interest were at a low level and concluded that a *'significant education process may be needed'*.¹⁷

However, what fears the participants did have were held strongly and there were many misconceptions that could be dispelled. The security

of a health database emerged as a key issue that may stand in the way of public support. All interviewees sought reassurance that measures are being built into the system to maintain confidentiality and to protect their privacy. Computer *'hackers'* were seen as a major threat to the integrity of any database. Several au-

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* The NZ Ministry of Health's mandate to collect health information is set out in legislation, in particular, in section 22 of the Health Act 1956, section 139A of the Hospitals Act 1957, and the Cancer Registry Act 1993. The collection, storage and use of health information is also governed by the Privacy Act 1993, the Health Information Privacy Code 1994, the Health (Retention of Health Information) Regulations 1996, the Accident Insurance Act 1998 and the Electronic Transactions Act 2002. (see NZHIS website for more detail)

thors, both national and international, have also highlighted security issues as a major concern.^{13 14 20 23 24}

There was a high level of ignorance about what data would be collected, who would have access to it and what their rights are as patients, even amongst those familiar with information technology. These details have been discussed within the NZ health sector,^{20 21} and many of them are covered by law* but, judging from participant's understandings, the particulars have not adequately made their way into the public arena. Of particular concern was the misuse of the information and its disclosure to people other than health professionals, fears also previously recognised and addressed.^{15 20 21}

In line with another study,¹¹ several participants identified the risk that EHRs may affect the patient-practitioner relationship, in that they would censor what they said to their general practitioner knowing that

their information could be accessed by other people. The implications of EHRs on the patient-practitioner relationship needs further research.

In summary, the participants were positive about the advantages of EHRs but had concerns about being informed about developments, knowing the risks and giving consent for data capture, storage and use. Finally, they wanted the right to choose, without consequence, whether or not to have their medical records held electronically in a universal database.

In 2001, the WAVE project '*recommendations centred around ensuring that consumers... are made aware of their... rights in regard to personal health information capture, storage and disclosure*'.⁶ Specifically, recommendations were made for national awareness campaigns for patients about the purpose and use of health information including the NHI (National Health Index) system and how the attached data is used. Although

the WAVE project reports that it conducted three consumer focus groups and received submissions from consumer organisations, the results of this study suggest that the general public are still not well informed about e-health information, and actually hold many misconceptions about its use. Because this was a small study conducted in one locality, further work, in the form of a quantitative survey of consumer knowledge and attitudes, could be conducted to confirm these findings. Either way, this study indicates that the national awareness campaigns identified by the WAVE project are clearly overdue.

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