

An Australian Case Study of Patient Attitudes Towards the Use of Computerised Medical Records and Unique Identifiers

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Abstract

Research into patient attitudes towards the use of technology in health care needs to be given much greater attention within health informatics. Past research has often focused more on the needs of health care providers rather than the end users. This article attempts to redress this knowledge bias by reporting on a case study of the responses gained from patients in a selected Australian medical practice towards the use of computerised medical records and unique identifiers. The responses (n=138) were gained from a survey of patients over a 13 day period of practice operation. This case study serves as an example of the type of future consumer health informatics research which can be undertaken not just in Australia but also in other countries, both at local regional levels and at a national level.

Keywords

Consumer Health Informatics; Computerised Medical Records; Unique Identifiers; Patients

Introduction

A number of studies have examined the attitudes of general practitioners (GPs) to computers and computerised medical record systems in Australia and elsewhere [1, 2, 3, 4, 5]. These types of quantitative studies appear to be on the increase as more money is being spent on the uptake of information technology by GPs. Fewer studies have looked at patient reactions to doctors using computers in general practice consultations [6, 7]. This study aims to redress this information imbalance at a time when consumer rights groups are having a greater role to play in health care systems. Greater emphasis is now being placed on how computers can be used to empower not only doctors but patients as well [8]. As individuals become more aware of the use of computers in health care, their views as both patients and the consumers of health services are becoming important factors for consideration. Data about patient attitudes, particularly regarding unique patient identifiers (UPI) needs to be collected for any future understanding

and implementation of computer systems in medical practice [9].

Consumer health informatics is a manifestation of the growing power of patients' rights movements, such as the Consumers' Health Forum in Australia. Eysenbach (2000) states that "[c]onsumer health informatics is the branch of medical informatics that analyses consumers' needs for information; studies and implements methods of making information accessible to consumers; and models and integrates consumers' preferences into medical information systems." [10]. Often the focus of past health informatics research has been on the providers of health care services and not enough attention has been given to analysing the attitudes and information needs and wants of patients. This is somewhat ironic since patients are effectively sidelined from having a say about the shape of a growing technology based health care system or what is touted as electronic health care or e-healthcare. Key decisions over technology choices are made by health care administrators and experts without much regard for patient attitudes. Technology can be designed and constructed to aid in health care service provision but it must not be forgotten that technology needs to be seen from a human based focus and not the other way around, a technology based focus [11, 12].

Both public and private health care providers are finding it increasingly necessary to learn about patient experiences and their attitudes to certain developments so that services can be developed in accordance with these needs [13]. Many hospitals use patient satisfaction surveys to determine how their patients rate the care they received and then use this information to identify specific areas for improvement, such as education of patients and coordination of care [14]. Despite the widespread adoption by GPs of desktop computers there has been very little evaluation of the way in which the computer is actually used during consultations and the way in which it affects patient satisfaction. Some studies have reported that while longer consultations resulted from computer use, there was little improvement in patient satisfaction [7, 15].

Materials and Methods

One way to understand patient expectations and how well a general practice is meeting them is to use patient surveys. This technique provides patients with an opportunity to give feedback, clarify their concerns, and present their views towards health care developments.

The study focuses on the patient attitudes of one general practice within the Illawarra area, New South Wales, Australia. The Illawarra is an innovative region in Australia through its experimentation with the use of information technology in GP settings [16, 17]. The aims of the survey were primarily to investigate the attitudes of patients towards the use of: computers in the GP consultation, computerised medical records, information ownership, access, storage, unique identifiers, biometrics and the future use of smart cards.

The questionnaire comprised of 4 parts: (i) a common demographic section, (ii) a general computer and information issues section, (iii) attitudes towards the use of Medical Director (a computer package) and finally, (iv) a section on unique identifiers, smart cards and biometrics. Both open ended and closed questions were included to elicit information with space available for comments where needed. A pilot was conducted on 10 patients to identify any problems.

The questionnaire was administered to a random sample of patients at a chosen General Practice in the Illawarra region over a 13 day period in September 2000. From a possible number of 223 patients who attended the General Practice during this 13 day period, 138 chose to answer the questionnaire. This represents a sixty-two percent (62%) response rate.

Results and Discussion

Patient Demographics

An even distribution of all age brackets was recorded which meant that the opinions of all age groups were included (see Table 1).

Table 1: Age of respondents

Age (Years)	No. of Respondents	%
18 to 25	28	20%
26 to 35	24	17%
36 to 45	23	17%
46 to 55	25	18%
56 to 65	16	12%
Over 65	22	16%
Total	138	100%

Both genders were sufficiently represented with forty-six percent (46%) of respondents being male and fifty-four percent (54%) female. Sixty-two percent (62%) were

married and thirty percent (30%) were single. The respondents provided a wide range of occupations, with seventeen percent (17%) citing home duties, fourteen percent (14%) students, twelve percent (12%) retired and ten percent (10%) secretaries or office assistants. Through comparison with the overall patient population for this practice, it was concluded that these demographic results indicate that the patient sample was representative of the general practice patients, although it cannot be assumed that the sample was representative of the region as a whole.

Seventy-four percent (74%) of patients attended the practice a few times a year and twenty-five percent (25%) attended every month. The fact that sixty-three percent (63%) of patients had been attending the practice for more than eleven years suggests that the majority of patients surveyed have been able to appraise the changes in the practice over a considerable period of time. These patients were in a sound position to provide feedback into the possible efficiencies or improvements that computers have delivered to the practice since their introduction for administrative purposes in 1989, and for health care purposes in 1996.

Attitudes to Computerisation

Seventy-two percent (72%) of respondents were aware that the practice had incorporated computers into its operations. Ninety-three percent (93%) of respondents stated that the computer based patient record is an essential technology for health care in the future. Eighty-eight percent (88%) of respondents agreed that computers have the potential to improve the information management and efficiency at a medical practice. Furthermore, sixty-five percent (65%) of respondents agreed that computers have the potential to improve the quality of health care received at a medical practice. As seen in Table 2, twenty-seven percent (27%) were not sure of this potential which implies that although some respondents agreed with the potential of the computer to improve information management, they questioned the potential ability of computers to improve the quality of actual received health care.

Table 2: Computers have the potential to improve the quality of healthcare received at a medical practice

Response	No. of Respondents	%
Strongly disagree	1	0.7%
Disagree	9	7%
Not sure	37	27%
Agree	61	44%
Strongly agree	29	21%
No response	1	0.7%
Total	138	100%

For those who believed that computerisation would bring benefits, their most common responses were 1) easy access to accurate and useful data; 2) fast access; and 3) cross-referencing and information linking. Ninety-one percent

(91%) of respondents indicated that use of the computer by the GP did not interfere with the consultation.

Storage, Access and Ownership

Patients were asked to nominate whom they believed should own, have access to, and store their medical record. The majority of the 138 patients surveyed believe the GP should own (39%), have access to (44%) and be able to physically store the patient record (68%). However, 50% of respondents indicated that both the GP and patient should be able to access the medical record and twenty-seven percent (27%) felt that the patient should be able to physically store a copy of the record along with the GP. These figures imply that a number of patients would favour personal control over their medical information. These figures also demonstrate the responsibility and trust that the large majority of patients place in their GP.

Table 3: Storage, access and ownership of record (n=138)

Response	Ownership	Access	Storage
Patient	31%	2%	4%
GP	39%	44%	68%
Patient and GP	30%	50%	27%
Government	0	0	0
Other	0	4%	1%
Total	100%	100%	100%

Twenty-five percent (25%) of respondents had concerns for their medical information stored on paper while forty-three percent (43%) had concerns for this same information stored on computers. This illustrates a public perception that computers are somehow less secure and reliable than traditional paper based information systems. The respondents who indicated concerns about the storage, access and ownership of their records were asked to identify their top two concerns. These are presented in Table 4.

Table 4: Predominant concerns for storage methods

Response	Paper based (% of respondents, n=34)	Computer based (% of respondents, n=59)
Privacy	76%	69%
Security	67%	80%
Accuracy	30%	30%

NB: Respondents could indicate more than one response

These figures support the findings of Barber et al. [18], Morrissey et al. [19] and Wilder [20] who also identified the privacy and security of health information as predominant concerns.

The results imply that certain patients are not confident in the management of their medical information, even at a local level independent of any other medical institution. Their concerns for the privacy, security and accuracy of personal information at a general practice level could

impede their acceptance of a national UPI system where medical records can be linked and retrieved nationally using a unique identifier. However, it should be noted that the majority of patients surveyed did not have concerns for their medical information stored on paper (75%) or computers (56%).

No patient believed the government (State or Federal) should own, access or store their medical record indicating a possible scepticism or lack of trust in government organisations. These figures reinforce the prevalent concerns of privacy and security that were identified in the results.

Unique Patient Identifiers (UPI)

It was suggested earlier that a lack of confidence in general practice information management on the part of some patients might impede the acceptance of the national UPI proposal. However, while there were forty-three percent (43%) of respondents with concerns regarding computerised medical information systems, seventy-five percent (75%) either agreed or strongly agreed with the UPI proposal. However, sixty-one percent (61%) of respondents believed that there were risks associated with the UPI proposal: this suggests that patients realise the additional security implications that result from creating a national computerised health network. Seventy-one percent (71%) of respondents cited privacy and sixty-two percent (62%) listed security as one of their two major concerns for the system.

Despite an initial acceptance of the UPI proposal, when it was suggested that it might be possible to link an individual's medical information to other private information such as financial records without their consent, responses changed. Twenty-eight percent (28%) agreed that the risks outweigh the benefits of having a UPI system, twenty-nine percent (29%) were not sure and twenty-eight percent (28%) of respondents disagreed. These results indicate that for a national UPI system to be successfully introduced highly stringent security mechanisms will have to be incorporated to gain public confidence. This supports the claims of Dutton [21], Appavu [22] and Dorodny [23] who state that any UPI system should be accompanied by appropriate legislation, security standards, and information protection and management policies.

Respondents were asked to identify organisations or individuals from a list which they believed should have access to their medical record via the unique identifier should the system be introduced. Twelve (12%) of patients listed medical researchers as one such group while nine percent (9%) of patients included government health departments as one of their selections. The combination of medical researchers and government health departments as an exclusive category rated highest at fourteen percent (14%). This figure is slightly contradictory to the earlier results where only four percent (4%) of respondents felt that

the government should be able to have access to their medical record. It is possible that patients recognise the role government health departments will have to play should a national UPI system be implemented despite their personal attitudes towards government bodies.

It was of interest that fourteen percent (14%) of respondents felt that medical insurance companies should have access to medical records via the unique identifier. There has been recent debate over this issue after individuals had their insurance policies terminated when it was discovered that they had a genetic predisposition to certain diseases that made them high-risk members [24]. If medical insurers were granted access to patient records certain individuals could be denied insurance or have their premiums heavily increased. Perhaps those respondents who listed such organisations are in a state of good health and believe they should be rewarded with lower premiums, or perhaps they did not realise the far reaching repercussions of such a decision.

Twelve percent (12%) of patients believed that pharmaceutical companies should have access to their medical records via the UPI. This raises further ethical concerns as pharmaceutical firms could use these records to determine what diseases individuals have in order to market their products more directly [25]. Eleven percent (11%) of respondents also believed that police should be given access.

Thirty-five percent (35%) of patients surveyed believed that none of the listed groups should have access to their information, reinforcing previous concerns about privacy and security issues and the possible misuse of personal information in a growing surveillance society.

For unique identification purposes, forty-two percent (42%) of respondents preferred biometric identification, twenty-five percent (25%) nominated the use of biometric identification and smart cards together while twenty-two percent (22%) preferred smart cards alone. The idea of a unique individual number was only preferred by one respondent. Furthermore, forty-seven percent (47%) of respondents favoured the smart card as a storage medium for medical information while thirty-eight percent (38%) favoured a combination of smart card and central database recognising the need for a backup if the smart card was lost, stolen or corrupted. However, respondents would only like to store the most recent and important information on the smart card, not their whole record. This would have to be stored separately, possibly with the main GP or local public hospital.

Conclusions

The study shows that the GP still has a dominant power position within the doctor-patient relationship. However, this information gatekeeper role is gradually changing as patients wish to have greater access and control over patient

information and how it should be stored and used. Patient attitudes are also gradually changing with respect to computers and the use of biometrics and smart cards within the GP practice. Greater acceptance of such methods have resulted, possibly as a result of wider exposure to technology developments in other sectors. Nevertheless, privacy and security are still dominant concerns irrespective of the medium, paper based or computer based. This needs further consideration as patient information becomes a significant economic commodity for various healthcare actors in the supply and demand chain. Despite patient acknowledgement that a national UPI system is a good idea, patients still have concerns about the risks associated with the proposal. Interestingly there is great distrust of the Government having access to actual patient identifiable data, but ironically less so for medical researchers in combination with government health departments. Patients realise that computers will have an important role to play in the future management of medical information, both clinical and administrative, and perceive some associated improvement in the level of received health care as a result. However, this may only be perceptual rather than actual.

This study is a small step towards the development of a national patient based survey in Australia. In the next phase of this research, a number of practices in the Illawarra will be selected and surveyed using the same instrument to allow for a greater comparison of results and trends. More extensive statistical analysis of the results is needed i.e. bivariate and multivariate analyses of the data to test for the significance of key variables. It is envisioned that health policy planners and administrators can also draw upon such data in order to design health policy that also reflects the sentiments of patients and not just doctors and administrators. Researchers in other countries are welcome to follow these ideas and contribute to the overall development of consumer health informatics as a research discipline.

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