

Refereed papers

The patient's perspective of computerised records: a questionnaire survey in primary care

Ricardo Garcia-Sanchez MD
Medical Adviser, GlaxoSmithKline, Spain

ABSTRACT

Background The general practice consultation today has become a three-way process where patient, doctor and computer interact. Some studies have shown that the introduction of the computer has caused concern to some patients, possibly affecting their behaviour. If patients are less frank about their problems in a computer-mediated consultation this may cause concerns among doctors and become a barrier to computer use.

Objectives A questionnaire was developed to test the prevalence of worries among patients about confidentiality breaches of computer records and to identify whether those worries translated into a reduction in patients' frankness.

Results The study had a 62% response rate. Almost 48% of responders had experienced confidentiality worries during past consultations. All responders denied withholding any relevant information from their general practitioner (GP) as a result of confidentiality worries. Gender, computer literacy, knowledge of computer uses in consultation and patients' perceptions of computer record safety were selected

covariates in the multivariate logistic regression model explaining patients' worry. Thirty-three percent of patients stated they always understand what their GP is doing at the computer during consultation, 9.7% stated they did not ever know; though 64% judged it important to know what their GPs were doing.

Conclusions Patients worry about the confidentiality of their computer record and it seems that those less familiar with computers, females and those less aware of their GP's actions at the computer worry more. Patients' understanding of their GPs' actions at the computer during consultation is far from complete and they seem to place great importance on this. Those patients who place greatest importance on needing an understanding of their GP's actions are those most likely to worry about confidentiality.

Keywords: computer records, confidentiality, doctor–patient relationship

Introduction

The consultation today is a three way process where patient, doctor and computer interact. Some studies have shown that the introduction of the computer has caused concern to some patients, possibly affecting their behaviour; in particular some patients may be less frank about their problems.^{1–3} Patients' frankness with their doctors is essential to achieve the desired outcomes of a consultation and is crucial to the privileged doctor–patient relationship. In return, doctors and other healthcare professionals (HCPs) must guarantee the confidentiality and accuracy of medical records.^{4,5}

The NHS in its Code of Practice and healthcare professions' Codes of Conduct clearly state the duty of those entrusted with patient information to provide a confidential service and at the same time acknowledge the patients' trust in HCPs when disclosing information to them.⁶ Further, health care has evolved into a complex system where patients have numerous individuals involved in their care, giving rise to increased needs for information sharing which can only be met by electronic patient records (EPRs) and other computerised systems.⁷ The NHS, through its National

Programme for IT, has placed enormous resources into developing a care records service to meet information-sharing needs.⁸ If these resources are not to be wasted, sufficient safeguards for accuracy and confidentiality should be provided.⁹

Therefore, there is a need to further understand the relationships between patient trust, disclosure of information and views on EPRs. This small study provides an initial assessment of patients' worries about the confidentiality of their computer records, their frankness during consultation and finally their understanding of their GPs' actions at the computer, offering a predictive model of patients' experience of worry about confidentiality breaches of their EPR.

Method

The study was conducted in a semi-rural general practice area covering 7679 patients in North Yorkshire. A questionnaire was developed with a combination of open and closed questions divided into different sections.¹⁰ The first section consisted of general background questions (*age, gender* (gender: male=1, female=0)) and also included patient computer literacy indicators. A *computer literacy score* (CLS) was derived from questions concerning patients' use of computers, the internet and email, assigning one point to each of those items. This score could have a maximum value of three and a minimum value of zero. The second section dealt with patient understanding of the different uses of the computer during the consultation. Particularly, the *patients' reported degree of knowledge of their GP's actions at the computer* (knowledge=1, no knowledge=0) and a *quantification of the importance patients gave to having that knowledge* (importance: very important=5, unimportant=1, scale range 1–5), were measured. This section also quantified *the patient's opinion of four aspects* (safety, accuracy, reliability and information-finding difficulty) regarding EPRs and paper medical records (PMRs) (highest degree=5, lowest degree=1, scale range 1–5). The third section established a direct comparison between computer and paper records and the final section addressed patients' concerns (open lists – *worry*; experience of worries about access to medical records – *withholding of information*).

The questionnaire was piloted with a representative sample of patients in the surgery waiting room. A cover letter, SAE and questionnaire were sent to a total sample of 100 subjects randomly selected from a subset derived from the total practice list according to predefined selection criteria. Adults from 16 to 75 years old were included. Patients that were terminally ill, mentally disordered, moderately or severely disabled, temporary residents, in residential institutions

or were on antipsychotic, cytotoxic or immunosuppressant drugs were excluded. A period of one month from mailing was established for reception of completed questionnaires. The author used Microsoft Excel to create the database and G-Stat 2.0 computer software for the handling of data and statistical analysis. A multivariate logistic regression model was used and tested for closeness of fit. *Worry* was chosen as the modelled dichotomous outcome variable. A set of potential explanatory covariates was entered into the initial model (*age, gender, safety of EPR, accuracy of EPR, reliability of EPR, information-finding difficulty of EPR, computer literacy score (CLS), knowledge and importance*). The final model was reached using a backward variable selection strategy.

Results

The total number of questionnaires received by the established deadline was 62 out of 100 sent. A total of 29 out of 50 male and 33 out of 50 female patients responded. All respondents stated that they had never withheld any information they ought to have disclosed to their doctors as a result of worrying about who might access their computer medical record. This represents the answer to one of the primary aims of this project and will be discussed later. Out of the 62 responders, 29 (47.8% ± 12.4 $P < 0.05$) had experienced worries during consultation with their GP about who might have access to their medical record, 32 (51.6% ± 12.4 $P < 0.05$) had never experienced such worries and one did not reply. The multivariate logistic regression model identified five covariates explaining patients' worries. The final model was well adjusted (χ^2 33.06, $P < 0.0001$) and attained a global predictive performance of 83.64% considering a predictive probabilities cut-off point of 50%. The final model is presented in Table 1. Being male (OR 0.16, 95% CI 0.02–1.05, $P = 0.06$), computer literate (CLS: OR 0.49, 95% CI 0.24–0.98, $P = 0.04$), aware of GP's actions at the computer (*knowledge*: OR 0.08, 95% CI 0.01–1.17, $P = 0.06$) and considering EPR safe (*EPR safety*: OR 0.15, 95% CI 0.04–0.54, $P = 0.00$) were predictors of not worrying. Considering it important to know what a GP does at the computer (*importance*: OR 4.24, 95% CI 1.56–11.53, $P = 0.00$) was a predictor of worrying. Table 2 shows a list of patients' concerns about computer records. Their main concerns were system security in general and the validity of information contained in the record. Table 3 shows individuals and groups who are the focus of patients' concerns about the confidentiality of their record. Non-clinical practice staff (mainly receptionists and secretaries) lead this table followed by insurance companies and service

Table 1 Multivariate Logistic Regression Model for worry

Explanatory variables	Regression coefficient	OR	95% CI	P-value
EPR-Safety	-1.89	0.15	0.04–0.54	0.00
Importance	1.44	4.24	1.56–11.53	0.00
CLS (computer literacy score)	-0.71	0.49	0.24–0.98	0.04
Knowledge	-2.47	0.08	0.01–1.17	0.06
Gender (m=1,f=0)	-1.85	0.16	0.02–1.05	0.06
Model constant	5.02	–	–	0.03

Table 2 Patients' concerns about computer medical records: number of responders (percentage of responders)

Concern type	Males (n=29)	Females (n=33)	Total (n=62)
Without concern	17 (58.6)	18 (54.5)	35 (56.4)
System safety	5 (17.2)	11 (33.3)	16 (25.8)
Information validity	7 (24.1)	4 (12.1)	11 (17.7)
Unauthorised external access	3 (10.3)	6 (18.2)	9 (14.5)
Database misuse	2 (6.9)	1 (3.0)	3 (4.8)
Confidentiality	1 (3.4)	2 (6.1)	3 (4.8)
Unclassified	1 (3.4)	1 (3.0)	2 (3.2)

Table 3 Groups or individuals that would worry patients if they could access their computer medical record: number of responders (percentage of responders)

Groups or individuals	Males (n=29)	Females (n=33)	Total (n=62)
Non-clinical practice staff	2 (6.9)	10 (30.3)	12 (19.3)
Insurance companies	5 (17.2)	5 (15.1)	10 (16.1)
Service industries	4 (13.8)	2 (6.1)	6 (9.7)
Employers	3 (10.3)	2 (6.1)	5 (8.1)
Government	2 (6.9)	1 (3.0)	3 (4.8)
Hackers	1 (3.4)	2 (6.1)	3 (4.8)
Strangers in general	2 (6.9)	1 (3.0)	3 (4.8)
Police	2 (6.9)	0 (0.0)	2 (3.2)
Other patients	0 (0.0)	2 (6.1)	2 (3.2)
Lawyers	1 (3.4)	0 (0.0)	1 (1.6)
None	20 (68.7)	15 (45.4)	35 (56.4)

industries. Thirty-three percent of patients stated that they always know what their GPs do at the computer during consultation, 9.7% stated that they never know and 64% judged it important to know what they were doing. Table 4 illustrates what patients believe their GPs use the computer for during consultation. Record keeping and browsing followed by prescribing were the most frequently described uses. With regard to patients' appraisal of computer and paper records, respondents made a more positive judgement on computer records in all areas (safety, reliability, accuracy and accessibility). In particular, they considered information in computer records easier for their GP to find in 53 (85%) cases and safer in 34 (55%) cases when directly compared to paper records. The non-response rate for this study was 38%.

Discussion

Principal findings

This work has successfully shown, in keeping with previous research, that a significant proportion of patients (47.8%) in this semi-rural setting had experienced worries with regards to the future confidentiality of their records.^{2,3} In contrast, it appears that worry does not seem to translate into a reduction in the amount of relevant information disclosed to GPs during consultation. This finding could be in conflict with previous research and it might be the result of

bias^{1,11} although it could also tell us that doctors' initial concerns regarding a negative effect of computers on the doctor-patient relationship was unfounded.

In order to comprehend further the variables explaining patients' worries, a logistic regression model has been provided that can predict who would probably experience those worries during consultations, improving our predictive performance over mere chance by 66%. Patients' opinion on *EPR safety, knowledge of their GP's actions at the computer, CLS, importance given to knowing about their GP's actions at the personal computer (PC) and gender* seem explanatory covariates, all except *gender* amenable to modification in varying degrees over time. *Age, accuracy of EPR, reliability of EPR and information-finding difficulty of EPR* were removed from the final model as they failed to provide additional predictive value beyond that from the selected covariates.

The study could identify two major groups of concerns regarding EPRs: concerns in some way related to the computer system's safety aspects (system safety, unauthorised external access, confidentiality, database misuse) and concerns relating to the validity of the information contained in the records. It could also identify that non-clinical practice staff accessing computer medical records seemed to be of concern to patients. This is in a way to be expected as non-clinical practice staff are seen by patients to access their records (e.g. patient registration details) and they usually belong to the patient's own community.

In general, most patients had some knowledge of what their GP does when using the computer and this is also reflected in the very small number that could

Table 4 Patients' perceived computer uses during a consultation with their GP: numbers of responders (percentage of responders)

Computer uses	Males (n=29)	Females (n=33)	Total (n=62)
Medical record keeping	25 (86.2)	33 (100)	58 (93.0)
Prescribing	17 (58.6)	19 (57.0)	36 (58.1)
Access to information not on medical record	2 (6.9)	3 (9.1)	5 (8.1)
Communication	3 (10.3)	0 (0.0)	3 (4.8)
Printing PILS*	1 (3.4)	1 (3.0)	2 (3.2)
Appointments and diary alerts	2 (6.9)	0 (0.0)	2 (3.2)
Verification of patient identity	0 (0.0)	1 (3.0)	1 (1.6)
None	2 (6.9)	0 (0.0)	2 (3.2)

* Patient information leaflets (PILS)

not identify even a single use for computers within general practice (3.2%). Nevertheless, a majority of patients had either incomplete knowledge or no knowledge at all about their GP's actions at the PC during consultation and most patients judged it important or very important to have that knowledge. The model discussed above identifies these two factors as predictors of worry.

Even though patients judge computer medical records superior to paper records in various ways, this study does not establish whether patients worry more about records on computer than on paper and it might be that they simply worry about confidentiality of their medical record irrespective of the means of storage. Interestingly, patients in this study judged computer records less vulnerable (safer) to unauthorised access than paper records and as patients' rating of EPR safety is a predictor of worry, it could indirectly imply that a greater proportion of patients would worry about the confidentiality of paper records.

Implications for practice

It seems clear that there is an unmet patient need for information regarding the use of computers during consultation. Particularly, explaining the system's safety safeguards and allowing patients to access their EPR to check its information validity could help alleviate their major concerns, while offering reassurance about non-clinical practice staff's limited access to their computer record could reduce their concerns about this group of people. Both could help improve patients' rating of EPR safety. An improved *knowledge* and opinion of *EPR safety* in conjunction with the expected growth of computer literacy among patients could lead to a reduction in their experience of worry. However, the logic of the preceding reasoning could be reversed if patients were not sufficiently involved and informed when their EPRs were moved further away from the consulting room, onto a central database like the NHS Spine. GPs are unlikely to upload patients' records onto an NHS national database without their specific consent as doctors worry about confidentiality, particularly about unauthorised access by hackers and public officials outside health and social care.¹² These concerns are the same as those shown by patients with regard to their locally held EPR. It could be argued that the same level of information and involvement should apply to GPs if the circle of trust and information sharing is to be closed, as it has been shown that doctors lack sufficient information on many aspects of the UK National Programme for IT and have demanded more information, particularly in the light of recent catastrophic disclosure scandals.^{12,13}

Comparison with the literature

Most studies on patients' views and attitudes towards computers and computer records have shown that patients experience confidentiality concerns with regard to EPR^{1-3,11,14,15} and the present work corroborates those findings. A study looking at patients' stress levels following a computer-aided consultation found that patients with previous computer experience had more favourable attitudes towards medical computer use and that those with the most negative attitude towards computers showed the greatest degree of stress.¹⁶ Later work confirmed that patients' initial negative attitudes towards computers were associated with higher stress levels and vice versa, although patients' computer familiarity did not enter into this analysis.¹⁷ The model provided in the present work explains worry and confirms that patients' computer literacy predicts not worrying. However, there is conflicting evidence suggesting that those patients with more experience of computers were more aware of their limitations in particular with regard to possible loss of confidentiality² and that patients' familiarity with computers had a slight negative correlation with patients' satisfaction with health care when computers were used in the consultation.¹⁸

It also appears that the computer has not significantly affected the doctor-patient relationship as has been extensively reported.^{15,19} The present study in fact shows universal frankness and confirms those reports. There are, however, suggestions in earlier studies indicating some degree of deterioration of that relationship, in particular a reduction in patients' frankness in front of doctors using the computer.¹

Other papers have reported patients' demands for information on the role of the computer in consultation. Patients stating that doctors do not inform them about the role of the computer¹⁹ and patients being disturbed by not knowing²⁰ have been previously reported. This study clearly confirms that patients not only seem not to have a thorough knowledge of the computer role, but also state that it is important for them to have such knowledge.

There are extensive references in the literature of patients' favourable views on computers in the consultation and one of the most frequently recurring themes was easier access to medical records, as was also shown in this study.^{11,18} Callen reports that 80% of patients thought that using a computer facilitated the doctor's access to their medical record, while the present study reports that 85% of patients felt EPRs were more accessible than paper records.

Validity of information on the computer record has been described in this paper as of concern to patients and studies looking at patients' experience of accessing their own records suggest that patients find such

access useful and the information contained in the record accurate and complete (valid).^{14,21} These studies also report patients' concerns about confidentiality but not about information validity, suggesting that offering patients access to their records alleviates that concern.

Limitations of the study

The response rate for this study, the small number of participants and the limited number of questions were some of its weaknesses. Nevertheless, the non-responding group had a similar age and gender distribution to the responding group and it could be assumed that, had they responded, they would have given answers similar to the responding group's.¹⁰ The design of the questionnaire did not take into account the social desirability of being frank and open with your own GP and this could probably explain the failure to detect that some patients may keep some sensitive information from their GP. In other words, because the question being asked was sensitive, patients might have felt inclined to give a socially desirable response and not a true one.²² The phrasing of the question itself might have contributed to this bias. It is interesting that a pre-pilot study on doctors and practice staff revealed that 30% of participants had withheld information from their own GPs as a result of confidentiality worries. The sample population was also aware that the study was being carried out by their own general practice surgery and they might have considered a different answer would be disappointing for their doctors. These problems might have been helped by a qualitative, triangulation approach and by involving external researchers.

Call for further research

A further attempt is needed to clarify whether the well-established patients' concerns about EPR confidentiality have an impact on the doctor-patient relationship through reduced disclosure of sensitive information. Future research efforts should take into account the social desirability of patients' frank communication with their doctors and adopt an indirect way to measure the effects of worry on the patient-doctor flow of information.

Conclusions

Patients worry about the confidentiality of their computer record and it seems that those less familiar with computers, those with unfavourable opinions of

computer record safety, female patients and those with a lower level of understanding about what the GP is doing on the computer worry more. Patients' understanding of their GP's actions at the computer during consultation is far from complete and they seem to place great importance on knowing what the clinician is doing. Those patients who place greatest importance on needing an understanding of their GP's actions are those most likely to worry about confidentiality; perhaps if clinicians provided more explanation of their actions on the computer it might reassure their patients.

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CONFLICTS OF INTEREST

None.

ADDRESS FOR CORRESPONDENCE

Ricardo Garcia-Sanchez
Departamento Medico GlaxoSmithKline
Parque Tecnologico de Madrid
Calle Severo Ochoa, 2
28760 Tres Cantos
Spain
Fax: +34 918075805
Email: ricardo.rgs@telefonica.net

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