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Primary Care (BCS, The Chartered Institute for IT)

# electronic care records

Alasdair Honeyman MB BS BSc MSc MRCP  
General Practitioner, Lambeth Walk Group Practice, London, UK

Benita Cox PhD  
Reader in Operational Research, Tanaka Business School, Imperial College, London, UK

Brian Fisher MBChB MSc  
General Practitioner, Wells Park Surgery, Sydenham, London, UK

### ABSTRACT

This paper examines the interest and expectations of patients having access to their electronic care records. Semi-structured prospective interviews were performed with 109 patients in a community setting in London where all records are stored digitally either as coded data, free text or scanned in from the paper original. A booth had recently been set up for patients to access their electronic records in the waiting room with secure access through fingerprint recognition technology. The interviews detailed history and levels of interest in access, impact on relationship with clinician, familiarity with digital media and issues of security and

accuracy. Patients were more interested in seeing their electronic than their paper record; they felt it would improve their relationship with their clinician; they generally trusted in the security of their records; they anticipated that there would be some mistakes; they were enthusiastic about the idea of adding to the record themselves, but were divided about having access over the internet. Patients are confident in and anticipate the value of having access to their electronic records.

**Keywords:** electronic care records system, patient access

## Introduction

Under the Data Protection Act of 1984, patients in the United Kingdom have had the legal right of access to their medical records for a number of years. Despite research that suggests that patients have a positive attitude towards accessing their notes, and that such access is an important component to breaking down barriers and improving communication with their general practitioner, few patients have sought to exercise this right.<sup>1</sup> This low uptake could be due to a general lack of interest, fears about the complexity of the information, or simply a lack of awareness of their right to do so.<sup>2,3</sup> Doctors too, as a group, have not generally encouraged patients to examine what is written about them clinically. Previous research suggests that clinicians have concerns for the potentially

negative impacts of allowing patients access to their records, fearing that patients might misinterpret the material or that it might undermine self-esteem.<sup>4</sup> Further, it might highlight the fallibility of doctors.<sup>5</sup>

In England, the National Health Service is in the process of introducing a distributed electronic health record called the 'Care Record Service', which will unify the information in community and hospital services and regard each patient as a single digital entity. It is intended that every person in England will have such a record by 2008; this record will also be available to the patient through the internet.<sup>6</sup> The question arises as to whether the advent of this electronic record will result in increased patient demand for access to their notes – the potential impact of

which remains to be well understood.<sup>3</sup> The aim of the research reported in this paper was to investigate the attitude of patients attending a London-based primary care practice to having access to their electronic records, their perception of how it would alter the sense they made about their health, the impact on the doctor–patient relationship, and patients’ interest in being permitted to add to the notes themselves.

## Setting

The research was conducted in the summer of 2003 at the Wells Park Group Practice in South London. This practice was chosen because for 18 years and up until six months before this study, patients at this practice had been handed their paper record to take into the consultation and were free to read it while they waited for their appointment.<sup>1</sup> A booth had recently been set up for patients to access their electronic records in the waiting room with secure access through fingerprint recognition technology. As patient access to their records was an established culture, the investigators felt that eliciting their attitudes towards electronic records was less likely to be confused with their attitudes towards access to records in general.

## Method

A semi-structured interview pro forma was drawn up and piloted with ten patients from the Wells Park practice and with three general practitioners, following which amendments were made. A further amendment to the pro forma was included during the process of conducting the research. This change resulted from the fact that many patients expressed an interest in accessing their electronic notes over the internet. It was therefore considered an issue that required further exploration, and an appropriate question was added to the last two interview sessions. One hundred and nine (109) patients were opportunistically selected from a total patient list of 8300 (1.31%) prior to their having access to their electronic record. Interviews were conducted over five morning clinical sessions. Two investigators collected the interview data. Patients were provided with information about the research either as they came to the front desk to book in for their appointment or while they were waiting to be seen. This information was only available in English and a consent form was attached. Interviewees were chosen according to availability. Patients were reassured that the interview would not interfere with the timing of

their consultation. Where possible, they were invited to come back after the consultation to complete the interviews. Eight interviews which were interrupted were not completed.

It should be pointed out that three of the data collection sessions for this research were conducted when there was also an antenatal clinic in progress along with a regular clinic. This may have biased the selection of interviewees to younger women. No interpreter was available, which meant a number of people were excluded.

The data collected were analysed using the Statistics Package for the Social Sciences (SPSS) version 11.5 and Microsoft Excel. The analysis consisted of descriptive statistics, bivariate correlation analysis and regression analysis. Respondents’ comments were also collated and analysed.

## Results

### Demographics

The 109 respondents were between 16 and 89 years of age with a mean age of 42 and median of 38. Over 65% were female. Ninety-eight people had their occupation recorded; 44 of these could not be classified according to socio-economic class (because they were retired or not working). Approximately one-sixth had been attending the Wells Park practice for 20 or more years, one-third for between 20 and five years, one-third for between five and one years, and one-sixth for less than one year. Data on ethnic origin were inadequate for interpretation.

### Patients’ experience with access to records

Seventy-one out of 106 (67%) respondents stated they had been offered access to their paper medical records in the past (see Table 1). The average time of this group to be attached to the practice was 11.5 years. Of these, 53 out of 62 had taken up the opportunity and nine had not. Asked if they had ever asked for access to their paper medical records, 37 out of 55 respondents stated that they had not and 54 did not answer this question.

Of 35 respondents who had not been offered access to their records, 28 stated they had not asked for their records either. Their average time in the practice was 2.6 years. When these same respondents were asked for a reason why they had not asked for access they responded with one or more of the following – no need (12), never occurred to me (10), not aware I could (7), no time (1), or never interested (2).

**Table 1** Access to medical record

Offered access	Asked for access			Total
	No	Yes	Blank	
No	28	6	1	35
Yes	8	12	51	71
Blank	1		2	3
Total	37	18	54	109

### Patients' interest in viewing records (pre-interview)

On a nominal scale of 0 (not at all interested) to 10 (very interested) in seeing their medical record, 106 responses resulted in a mean score of 7.64. Asked how interested they were in being able to see their record in electronic form, a mean score of 8.05 was produced (paired *t*-test,  $P=0.018$ ). Eighty people gave the same answer, 22 were more interested in seeing the electronic record and six were less so. Thirty-three people provided a reason for the differences in their responses of which 15 included the word 'easy' or 'easier'. Other comments included [interested because] 'not taking up anyone's time', 'no bother for anyone', 'can just come in and sit down (at computer)', and 'while waiting'.

### Patients' interest in viewing records (post-interview)

Ninety out of the 109 respondents answered the question 'How interested are you in seeing your medical record?' both at the beginning and at the end of the questionnaire. Thirty-two of these answered 'very interested' on both occasions. The remaining 58 patients' interest levels increased but not statistically significantly (paired *t*-test,  $t=0.21$ ).

### Patients' familiarity with digital media

Seventy-four respondents out of 100 believed that gaining access to their electronic records would be 'very easy' or 'easy'. The statistical difference between those that had internet access and those that did not was significant ( $t<0.01$ ).

Ninety-seven out of 101 answered either 'yes' or 'probably yes' to feeling comfortable in asking for assistance to gain access to their electronic records. Of these 97 responses, 46 answered that they would 'not' or 'probably not' need any help, and 44 answered that they 'would' or 'probably would' need help.

### Patients' concerns with security

Eighty-one respondents out of 101 were either 'not' or 'a little concerned' about the security of their paper record, while 78 respondents out of 101 were 'not' or 'a little concerned' about the security of their electronic record.

There were 14 comments from people when asked about the security of the paper record. These included: 'I was given my friend's records...'; 'my name is often spelt wrong'; 'anyone can read them' [from someone working in reception]; 'they can be given to the wrong patient'; 'working as a CPN [community psychiatric nurse] I know security is just as much a problem with paper records'. There were 24 comments from people who had concerns about their electronic record. These included: 'there is always the ability of others to get into the system'; 'it depends on trust of people here, all systems are fallible'; 'I don't know how it works'. Some respondents expressed a lack of concern: 'at my age they can do what they like, I trust them'.

### Patients' concerns with accuracy

Asked how accurate they imagined their clinical record was, over 75% of the sample thought their record was either 'fairly' or 'completely accurate'. There was no patterning of this result either in relation to the age of the patient or whether they had previous access to their record (see Table 2).

### Patients' interest in editing their record

Asked the question: 'if you had the opportunity to add to your record yourself, how much would this interest you?', of 99 respondents, 23 answered 'very much', 17 'quite a lot', 13 'perhaps', 26 'don't think so' and 26 'not at all'. Comments that followed included: 'if there wasn't something quite accurate [I could change it]'; 'sometimes easier to write it down before or after [seeing clinician]'; 'put across feelings a bit more and

**Table 2** How accurate do you imagine your record is?

Offered access in the past	Accurate			Mistakes		Blank	Total
	Completely	Fairly	Not sure	Some	Many		
No	9	14	8	1		3	35
Yes	16	38	8	6		3	71
Blank	1	1				1	3
Total	26	53	16	7		7	109

remembering stuff after'; 'offer comments [which are] helpful to doctor'; 'it should be left for doctors'; '[it's] back to trust, [I] would have liked to give feedback after request for confidentiality not kept'; 'would it go anywhere though, would I be listened to?'; 'things that I didn't agree with, I could add an addendum'.

### Looking at the record over the internet

The last 41 people interviewed were asked how interested they would be in looking at their electronic record over the internet. On a scale of 10 (very interested) to 0 (not at all interested), 18 respondents would be very interested and 14 not at all interested. In addition, 16 comments were included: 'don't think it should happen at all'; 'there could be too much tampering'; 'compare credit card issues of security'; 'not a good idea at all'. Seven of the 16 comments specifically mentioned security issues.

### Impact on the doctor–patient relationship

Over 75% of respondents stated that having access to their notes would 'help break down barriers between them and the doctor' and 'give information which one was not sure about'. Over 70% felt it would give them more confidence in the doctor and over 65% felt it would help them to understand their condition and feel that their doctor understood them. Sixty-seven percent disagreed that it would give them less confidence in their doctor.

## Discussion

The results of this research highlight important issues surrounding patients' levels of interest in accessing

their electronic health records and their confidence in asking to do so, their concerns about security and accuracy issues, and their view of the impact of such access on the doctor–patient relationship.

Six months before the start of this research, the practice had stopped handing out paper notes, but signs were clearly displayed in the waiting room indicating that these were still available on request. It is interesting to note that despite this active promotion, the majority of patients did not ask to see their notes. This finding is consistent with previous research findings in Denmark and the USA, where as few as 0.4% of patients requested permission to see their records.<sup>7,8</sup> It is unclear why this is the case. It is not through lack of interest, as evidenced in the responses to this exact question on a scale of 0 (not at all interested) to 10 (very interested) (mean score of interest = 7.64).

This finding is consistent with previous research where 75–95% of patients expressed an interest in participating in a trial to access their notes.<sup>9</sup> The question arises as to whether the deterrents to requesting access will disappear as availability and ease improves and what the potential impact of this happening is likely to be. No doubt there will be practical consequences. That 42 respondents indicate a need for assistance in accessing their records has implications for resourcing.

Despite having received a great deal of recent attention, security issues do not appear to be a significant concern – either for records stored in paper or in electronic form. These results should be interpreted with care as they may reflect the open culture of information sharing which prevails at this practice rather than a more generalisable outcome. The authors also have a concern that the respondents in this research equated the concept of 'security' with that of 'confidentiality'. It is worth noting, however, that when commenting on access via the internet, 12 out of the 19 respondents specifically raised the issue of security.

Patients were generally confident that their notes would be accurate – a perception which may need to be managed. Previous studies have found that patients discovered inaccuracies in their medical records.<sup>10,11</sup> A disparity between anticipated accuracy and the discovery of inaccuracies might not bode well for the ongoing clinical relationship.

It is important to understand the impact of patients having access to their records on the relationship between the patient and their doctor. The Wells Park practice has been unusual in inviting patients to have access to their notes for many years. In a retrospective study in 1986, changes in the relationship that occurred as a result of access were detailed.<sup>1</sup> These included breaking down barriers between doctor and patient, helping patients to understand what doctors think, and enhancing their confidence in doctors. We asked the same questions 17 years later and came up with similar results about how people anticipate or have experienced the benefits of having access to notes. If patients perceive it as so valuable to have access to their medical notes, it might be important to identify reasons why this has not been encouraged. With increasing access to information, the challenge for clinicians may be in acknowledging the shift in the balance of power towards patients, the changing nature of how patients make sense of their health, and the evolution of the role and nature of engagement by clinicians with patients.<sup>12</sup>

## Conclusion

The sharing of the digital medical record through asynchronous viewing will alter the experience of the face-to-face consultation for patient and clinician. The ways in which the record is made available will affect how easy it is for patients to choose to look at a record, which has traditionally been under the dominion of the clinician. The meaning, which is negotiated between patient and clinician, is reified and made tangible by the clinician writing in the record. How much patients understand and are either happy about what is written or confident to enquire about it, and how willing clinicians are to enter into such discussions, are a manifestation of the quality of the relationship between the two parties and their willingness to make ongoing sense of the patient's situation together.

When the arbitration of meaning surrounding a patient's health in a face-to-face consultation is straightforward and to the patient's satisfaction, there may be little wish or need for the patient to prepare beforehand or explore further. In more complex situations there could be clear benefits in preparation by

the patient to make the most use of the clinician's time and expertise.

It is to be expected that the discourse between people is going to be informed by the nature of the available artefacts and the permissions, both real and imagined, for having access to and being able to manipulate them. Given the significant issues of power and status in the transaction between doctor and patient, the issue of permission may be significant as well as the barriers, real and imagined, to having access and being able to make additions.

Agreement of the accuracy of the record between clinician and patient could play an important part in the management of risk and the prevention of litigation.<sup>13</sup>

Within a style of relating that supports a genuine engagement in both the participation and reification of the production of meaning, the nature of expertise becomes more clearly one of broker of meaning and advocate in supporting the actions of the patient within a complex healthcare system.<sup>14</sup> The consequences of an easily accessible patient record may be as much to challenge clinicians to innovate in the ways they relate with increasingly resourceful patients and to negotiate with them around the meaning of the record.<sup>12</sup>

Providing easy patient access to their medical record through digital media creates a shared artefact around which the meaning of the patient's health and their clinical care is negotiated. This research indicates that patients are interested in having access and anticipate it improving their working relationship with the clinicians they see. As a shared record they don't all expect it to be completely accurate.

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#### CONFLICTS OF INTEREST

None.

#### ADDRESS FOR CORRESPONDENCE

Dr Alasdair Honeyman  
Lambeth Walk Group Practice  
5 Lambeth Walk  
London SE11  
UK  
Email: [Alasdair@phoenixhpc.demon.co.uk](mailto:Alasdair@phoenixhpc.demon.co.uk)

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