

How patients use access to their electronic GP record—a quantitative study

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Background. Record access is likely to become an integral part of routine care in the UK. While existing research suggests that record access improves self-care and improves relationships between patients and clinicians, little is known about how patients make use of their ability to access their records or the impact that this has on health behaviour.

Aim. To explore patients' use of access to their electronic GP record and the impact of that process on their health behaviour.

Method. Self-administered postal questionnaire mailed from three general practice surgeries to patients registered to use PAERS record access system. Data were analysed using SPSS. Content analysis was used to analyse free-text responses.

Results. Two hundred and thirty-one of 610 patients responded. Frequent users of Record Access were those in poor health. Record access was used to look at test results and to read letters from those involved in health care. Forty-two per cent reported a positive impact on following medication advice and 64% a positive impact on following lifestyle advice. Just over half the sample felt accessing records prior to appointments saved time and wanted to share records with other health care providers. Approximately a third reported difficulties with understanding their records.

Conclusions. Record access appears to have a number of positive outcomes and very few negative ones, although further work is needed to confirm this. It is used by patients to help practices improve efficiency and to improve compliance. It has the potential to promote and reinforce collaborative relationships between clinicians and patients.

Keywords. Compliance, efficiency, record access, sharing records, survey of patients, use of records.

Introduction

Electronic medical records have been defined as 'an electronic application through which individuals can access, manage and share their health information ... in a private, secure and confidential environment'.¹

There are now a number of systems across the world that enable patients to view their medical health records. National Health Service (NHS) Connecting for Health's HealthSpace is in trial at the moment. Also in the UK, kiosks and online access to records, designed outside the NHS Connecting for Health programme, offer access to the full GP electronic record with linked health-related information in some surgeries.² Microsoft and Google are moving into the field. Record access may become an integral part of routine care, as it is in some health maintenance organizations in the USA.^{3,4}

We do not know how patients make use of information they access in their records nor what impact access has on their health behaviour.^{5,6} Some studies suggest

that record access improves self-care and compliance in chronic disease,^{7,8} improves relationships between patients and clinicians by breaking down barriers, providing reassurance and improving confidence and trust.^{6,9–13} However, few studies have involved actual users of record access in primary care,¹⁴ although there are studies of sharing the screen with patients in a consultation.¹⁵

Building on earlier qualitative research,¹⁶ this paper presents the findings of a survey of a large population of patients who use record access in primary care with a view to understanding who uses it, what they use it for and, from self-reported data, what impact it has on health care behaviour.

Methods

The electronic system

The Patient Access to Electronic Records System (PAERS) provides a secure log in system which

enables patients to access and navigate around their full GP electronic medical record autonomously, providing information to help patients' understanding of medical terminology. Patients can access their consultation record, their results, their letters (to and from the practice) and patient information leaflets.² Patients access the system over the Internet or via a kiosk in their general practice. A total of 40 practices were signed up for the system as at 8 April.

Survey development

Survey questions were developed from the key themes emerging from an earlier qualitative study exploring patients' experiences of using the electronic record access system and hand-held maternity record¹⁶ as well as their relevance to the research question. The record access system is described in that paper, but details can be found at www.paers.net. The questionnaire asked closed, open and Likert scale questions designed to elicit information on the following areas.

- Patients' current use of the electronic system. We asked questions about frequency and method of access, reasons for non-use and ease of use. With regard to ease of use, patients were presented with a series of statements both positive and negative and asked to indicate the extent to which they agreed or disagreed with them. For example, the record access system is easy to use, I haven't received enough help on how to use the system.
- Views about content and understanding. Patients were asked to indicate whether or not they had experienced any difficulties with understanding the content of their records. Where they indicated that they had experienced difficulties, they were provided with a list of commonly reported problems that emerged from the earlier qualitative study. These included medical words or terminology used in records, abbreviations, meaning and significance of test results, letters to and from those involved in my health care and other.
- Use of record access—patients were presented with a range of uses derived from the qualitative interviews and asked to tick those that applied to them. These included responses such as looking at test results, reading letters to and from those involved in my health care and checking what has been written about me by doctors,
- Impact of record access on health behaviour—the survey asked respondents to indicate the degree to which they agreed or disagreed with six attitudinal statements describing the impact of record access and to indicate whether or not looking their records had made any difference to any advice given about taking medications or making lifestyle changes (Tables 4, 5 and 6).

The questionnaire did not contain any multi-item scales or repeated measurements and therefore no psychometric testing was carried out.

Sections of the questionnaire were relevant both to patients who had accessed their records and those who had registered but not used the facility.

The questionnaire was piloted with 20 patients from one practice and slight amendments were made. A copy of the questionnaire is available on request. Ethical approval was provided by the relevant NHS Trusts.

Sample selection and administration

A postal questionnaire was sent to adults >18 years registered to use the PAERS system at their GP surgery. The survey was undertaken in 3 GP surgeries who had agreed to take part in a survey from a total of 15 who had signed up at the time—2 in SE London and 1 in Manchester offering kiosk only access, online Internet access only and both methods. These practices were the only ones with substantial numbers of patients using record access at the time. Different practices had slightly different processes for registering patients to use the system. Participating practices were provided with a questionnaire pack and requested to mail them out to each person they had identified as having registered to use the PAERS system in their practice. The packs included an invitation letter, information sheet, consent forms, a questionnaire and pre-paid envelope. Reminder letters and questionnaires were sent a month later to all those who had not responded. A total of 610 people were invited to participate from the different surgeries.

We compared participating practices with the rest of the UK, using publicly available national data. They were found to be fairly typical of the UK for the percentages aged 45–64, 65–74 and 75+ years, female, in good health and with limiting long-term illness. Ethnicity is not given, for instance.

Analysis

Questionnaire responses were coded and entered into SPSS. We also created codes through a simple qualitative analysis of responses to open questions and additional comments made by respondents. The characteristics of the study population and responses to items within the questionnaire were initially described using frequency distributions and summary statistics. Comparisons were made between respondents who had accessed their records via the Internet and the kiosk. We also compared responses to some items in the questionnaire with frequency of use, age, ethnicity, health status and gender. We used Pearson's chi-square to establish associations between categorical variables, and correlation analysis to establish the strength of relationships between variables. Analysis

was performed using SPSS v.15 and 5% level of statistical significance was used throughout. We calculated 95% confidence intervals (CIs) using the Binomial Wald function. Content analysis was used to analyse the free-text responses. No adjustment for clustering is reported. The groups we compared were practice level variables; cluster analysis merely widened CIs and added no extra value to the analysis. We consider only three practices and do not attempt to generalize to other electronic GP record systems.

Results

Response rate

A total of 213 of 610 patients consented and returned the questionnaire. The overall response rate was 35%. The response rate from the practice offering online access to records only was higher than practices offering either kiosk access only or both methods at 45%, 27% and 28% respectively.

Characteristics of the study sample

Table 1 shows the characteristics of the study respondents. They had a mean age of 55 years with a range of 18–97 years, the majority between 45 and 65 years. Just over half the sample was women and 91% defined themselves as White. Self-reported health status indicated the majority of respondents: 108 (51%) had been generally well but had an ongoing condition, illness or injury requiring regular medical treatment. There were no significant differences in the demographic profile of respondents from the three different practices. We do not have the demographic profile of the non-responders as these details were not recorded on the PAERS log system.

TABLE 1 Respondent Characteristics

	Value
Age	<i>N</i> = 210
Mean	55 years
Range	18–97 years
Interquartile range	45–65 years
SD	15.086
Sex, <i>n</i> (%)	<i>N</i> = 212
Males	88 (42)
Females	124 (58)
Ethnic group, <i>n</i> (%)	<i>N</i> = 210
White	190 (91)
Other (Black, Asian, mixed)	20 (9)
Health status, <i>n</i> (%)	<i>N</i> = 210
Good health in last 12 months	22 (10)
Generally well except for odd cough, cold or minor ailment	50 (24)
Generally well except for ongoing condition requiring regular treatment	108 (51)
Not well with ongoing condition requiring a lot more treatment	30 (14)

Method and frequency of use

A total of 185 of 213 (86%) respondents had accessed their records and of these, 125 (67%) looked at their records via the Internet and 55 (30%) used the kiosk. A small minority five respondents (3%) used both methods. The majority had looked at their records three times or more (Table 2).

The most frequent users tended to have a condition, illness or injury that required regular medical treatment. Those in poorer health used records access more than those reporting good health (Spearman's $\rho = 0.232$, $P = 0.02$). We found no significant relationships between number of uses and age or ethnicity.

Reasons for non-use

A total of 28 of 213 respondents (13%) had registered to use the system but had not accessed their records. From the free-text responses, the main reasons for not accessing records concerned technical difficulties, for example difficulty logging on, network problems and forgotten passwords. This accounted for 82% of responses. Five (18%) reported not using the system because they did not have health problems and therefore did not see the need. Further investigation is not possible with these small numbers.

Of the 185 patients who had looked at their records, 82 (44%) had experienced technical difficulties. For 29% (52) of patients, these were while logging on.

What did patients think about the information in their records?

Approximately 33% of ($n = 56/169$) patients reported difficulties with understanding the content of their medical records. The most commonly reported difficulties were understanding abbreviations, medical words and terminology and the meaning and significance of test results

A total of 178 patients (96% of 185) provided information about the quality of information in their records. Sixty-three (38%) had found errors. These included medical events or procedures not recorded and inaccurate information about allergies and health conditions. We found that 32 (48%) of the 68 patients did not take any action, often giving more than one reason for this. From the free-text responses, the most

TABLE 2 Method and Frequency of RA

Method of access, <i>n</i> (%)	<i>N</i> = 185
Internet	125 (67)
Kiosk (at GP surgery)	55 (30)
Both	5 (3)
Frequency of access, <i>n</i> (%)	<i>N</i> = 213
≥ 3 times	138 (65)
Once or twice	47 (22)
Registered but not used system	28 (13)

common reason reported was that the errors were not perceived as important enough followed by being unsure who to inform. One patient felt that it would take too much time.

What did patients use record access for?

We asked respondents to indicate from a list of options how they made use of their electronic medical records, ticking as many as relevant. One hundred and eighty-two respondents of 185 who had actually accessed their records answered this question. Overall, the mean number of responses per respondent was 7 for the whole sample. The majority of respondents indicated that they used record access to look at test results, read letters to and from those involved in health care, to check what had been written about them and to look at information concerning past treatments (Table 3).

We found a significant relationship between method of access and number of uses. Those who accessed their records online tended to make more use of records compared to those with kiosk access. The mean number of uses for online users was 8 and for the kiosk users was 5 (Spearman's $\rho = 0.294$, $P = 0.000$). There were no significant relationships between number of uses and age or ethnicity.

Just over half of the sample 112/(54% CI: 47–60%) reported that they wanted to share their records with other health care providers

What do patients feel is the effect of record access?

Respondents were asked to indicate the degree to which they agreed or disagreed with six attitudinal statements describing the impact of record access and the statements (Table 4). We had a total of 181 responses. The frequency analysis shows the following:

TABLE 3 *Uses of RA*

	<i>N</i> = 182
Look at test results	142
Satisfy curiosity	116
Read letters to and from those involved in health care	112
Check what doctors have written about me	110
Look at information about past treatments	108
Check accuracy of information in records	91
Ensure all relevant information communicated to me	91
Look at information about medication	89
Monitor my health/illness	83
Get a general picture of my health	70
Check I understood what was communicated to me during appointment	65
Help plan what to discuss with GP	45
Help me make decisions about my health	44
Help me plan what to discuss at the hospital	37
Complete a form requiring information about my health	23
Other	11

- One hundred and thirty-eight respondents, i.e. 76% (95% CI: 69–82%) felt more involved in their health care because of record access and 111 respondents, i.e. 62% (95% CI: 54–68%) felt that they understood better what had previously been discussed at appointments because of record access.
- Sixteen (9%) of respondents were more worried about their health because of record access compared with 118 (65%) who disagreed with this statement (95% CI: 58–72%). Forty-seven (26%) neither agreed nor disagreed with this statement.

Did record access have any impact on perceptions of concordance and lifestyle change?

A total of 162 of 181 respondents reported being prescribed or advised to take medications. One hundred and fifty-eight of these told us about the impact of record access on their taking of medicines, ticking as many options as relevant. Approximately 58% ($n = 91$) reported that record access made no difference to their medicine taking.

A total of 67 of 158 patients (42% (95% CI: 34–51%)) reported that record access had made a difference to their medicine taking by ticking at least one of the options given. From this group, no one thought that record access made them less likely to take medication. Most (83%, $n = 56$) thought that the record access helped them understand why they needed to take the medications. Approximately 25% ($n = 17$) felt that record access made them more likely to take their medications (Table 5).

A total of 94 of 182 respondents had been advised to make lifestyle changes to improve health. Eighty-eight patients told us whether record access had made a difference, ticking as many options as were relevant (Table 6). A total of 36% ($n = 32$) of patients reported that record access had made no difference to following lifestyle advice.

Fifty-six of 88 patients, i.e. 64% (95% CI: 53–74%) reported that record access had made a difference to following lifestyle advice by ticking at least one of the options given. From this group, none of the patients thought that RA made them less likely to follow lifestyle changes advice. A total of 32 of 56 patients (55%) reported that the RA helped them understand why they needed to follow advice and also made them more likely to follow advice (Table 6).

Advantages and disadvantages of record access

A total of 182 of 185 people responded to statements about the advantages and disadvantages of record access. Overall, responses were positive.

- Information was seen as less likely to be lost by 119 (66% CI: 57–72%).

TABLE 4 *Impact of RA*

<i>N</i> = 181	Agreed or strongly agreed, <i>n</i> (%)	Disagreed or strongly disagreed, <i>n</i> (%)	Neither agreed nor disagreed, <i>n</i> (%)	95% confidence interval
I feel more involved in my health care	138 (76)	5 (3)	38 (21)	69–82
I am more worried about a particular aspect of my health	16 (9)	118 (65)	47 (26)	58–72
I understand better what has previously been discussed at my appointments	111 (62)	8 (4)	62 (34)	54–68
I feel more confident in my GP	97 (54)	5 (3)	79 (43)	46–61
I am confused about a particular aspect of my health	9 (5)	134 (74)	38 (21)	67–80
I have decided to seek further information about a particular aspect of my health	46 (25)	70 (39)	65 (36)	31–46

TABLE 5 *Impact of RA on medication use*

<i>N</i> = 67 (responses not mutually exclusive)	Number of responses	%
Made you more likely to take your medication/s	17	25
Made you less likely to take your medications	0	0
Helped you understand why you need to take your medication/s	56	83
Helped you understand when to take your medications	24	36
Helped you understand how to take your medications	17	25

TABLE 6 *Impact of RA on following lifestyle advice*

<i>N</i> = 58 (responses not mutually exclusive)	Number of responses	%
Made you more likely to follow that advice	32	55
Made you less likely to follow that advice	0	0
Helped you understand why you need to follow that advice	32	55
Helped you understand when to follow that advice	11	19
Helped you understand how to follow that advice	8	14

- Seventy-four respondents (41% CI: 33–48%) disagreed or strongly disagreed with the statement ‘there is more chance of inaccurate information being included in my records’. Only 32 (17%) agreed with this statement and 76 (42%) neither agreed nor disagreed.
- Just over half of respondents 99 of 182 (55% CI: 47–62%) disagreed or strongly disagreed with the statement ‘I am worried about unauthorized people having access to my electronic record’. A total of 46 (26%) respondents agreed or strongly agreed with this statement.
- One hundred and thirty-six of 182 (75% CI: 68–75%) respondents felt more confident in their GPs as a result of electronic records.
- One hundred and fourteen of 182 (63% CI: 55–69%) disagreed or strongly disagreed with the

statement ‘reading electronic records may lead to misunderstanding of information’.

- Overall, 92 (51% CI: 43–58%) felt that looking at records beforehand saved time during appointments.

The qualitative study had suggested that patients did not see the data in the record as theirs. In this survey, 129 of 209 patients (67.7%) saw the records as jointly owned by themselves and their GP. Twenty-eight thought their record was owned by the local council.

Discussion

This study has revealed a positive experience for most patients using record access. Our sample in general felt more involved in their health care, understood better what had been communicated to them during prior consultations and felt more confident in GPs as a result of record access. These findings are consistent with findings of earlier studies of patient accessible medical records.¹⁷

Overall, this study has demonstrated that record access was used frequently by patients in our sample and those with poorer health tended to use record access more frequently than healthier people for a number of purposes, the most popular being to review test results and correspondence. We know of no other study exploring these issues.

Patients told us that record access had a positive impact on medicine taking and the following of lifestyle change advice. Although this finding relies on self-reported data, it supports evidence linking record access with improved adherence in congestive heart failure and smoking cessation.^{7,8} It also signals the potential effect of prolonged record access on improving or reinforcing health behaviour and potentially changing health status over time.

Just over half the sample felt that accessing records prior to appointments saved time during appointments. Our earlier qualitative research found that this was

because patients were able to focus on the most important issues, as they had already seen aspects of the data, such as their results, and had understood them.

Contrary to previous research, which found a large proportion of patients expressing concerns about confidentiality and security,^{17–22} only a quarter of our sample expressed concern over the possibility of unauthorized access to records. This may be a reflection of the open culture of sharing which prevails in the practices, which took part rather than a more generalizable outcome.²⁰ This finding is, however, supported by other studies in general practice where record access has been tried.^{6,23} It also may be that when people actually use access, the concern seems to fade.

In addition, just over half of our sample reported that they wanted to share their records with other health care providers. This finding supports previous research and experience in Scotland, where record sharing between GPs and emergency services is becoming established.²⁴ Only 174 of 5 million patients have opted out of that process.²⁵

Roughly, the same small proportion of people as we found in a study in 1986 reported errors in their record to the practice.²⁶ Record access could become a trigger for improving the accuracy of the record if we can support patients in informing their practices. However, patients' reluctance to inform the practice of errors needs to be explored and tackled.

Nine per cent of respondents appeared to be more worried as a result of record access and 3% became less confident in their GP. Thirteen per cent of respondents did not use record access at all, even though they had registered. A significant minority did not understand abbreviations and some of the language they encountered. Further research is needed to examine how best to mitigate these effects.

Neither this study nor others examining patients actually using record access have demonstrated any serious harm. On the contrary, results seem in general to enhance the process of care. So far, record access appears safe.

Strengths and limitations

This is one of the first surveys to focus on actual routine users of record access in general practice, examining the practical ways record access is used by patients and the—albeit self-reported—impact. To our knowledge, previous research has provided variable or no exposure to electronic records in order to determine patient attitudes.¹⁴ Another strength of the study is that the survey instrument was designed using the findings of an earlier qualitative study with routine users of record access in general practice. It therefore sought to quantify pertinent issues and themes with a larger sample of patients.

There are a number of limitations. The first concerns the design of the survey. No psychometric

testing was carried out. Secondly, we had a low to fair response rate. It is possible that the majority of potential respondents contacted had used the system primarily to book appointments and order prescriptions rather than to access their records. Technical difficulties in using the system may have dissuaded people from replying to the questionnaire. Online users experienced less difficulty than kiosk users and we had a better response from the online group. In view of the controversial nature of record access, it is likely that those with strong views for or against the process would have come forward; non-responders may have different opinions from responders. Another limitation is that we studied self-reported behaviour rather than actual behaviour.

The majority of the sample were White and were women. Respondents therefore may not be representative of all record access users. Although our sample is representative of the population in terms of ethnicity,^{27,28} it is slightly above the UK population figures in terms of gender (58% in the sample compared to 51% in the population).²⁸ This preponderance of female respondents is common in health studies, as there is a preponderance of females who use health services. In terms of health status, as you would expect, the number of people reporting good or fairly good health decreases with age²⁹ and our study showed that the most frequent users were those who had an ongoing illness or injury that required regular medical treatment. It is likely therefore that those in poorer health will be frequent users of record access. Furthermore, it was not feasible for individual practices to provide demographic data on decliners and non-responders.

Conclusions and implications

Record access appears to be safe and well accepted, on the whole, with a number of positive outcomes and some negative ones but further research is needed to confirm this. Record access appears to fit well into the Quality, Innovation, Productivity and Prevention approach:³⁰ on the whole, it seems to improve quality and productivity and is, for the moment, innovative.

Electronic health records have the potential to promote and reinforce collaborative relationships between patients and clinicians. As record access becomes more widespread, we recommend further objective study of its impact on actual health behaviour and clinical outcomes.

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Declaration

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Ethical approval: The present study was approved by the Lewisham PCT and Tameside and Glossop ethics committee.

Conflict of interest: BF is co-director of the PAERS system, which enabled patients to see their records in this study and is also lead for the Record Access Collaborative, a post funded by EMIS. MW is the national patient lead for NHS Connecting for Health.

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