



GIVING PATIENTS ONLINE ACCESS TO THEIR ELECTRONIC PRIMARY CARE RECORD: EXPERIENCES AND PERCEPTIONS OF PRACTICE STAFF AND SERVICE USERS

Commissioned by the UK Record Access Collaborative

Authors: Tim Shand, Claudia Pagliari, Brian Fisher

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Executive Summary

Background

The Record Access Collaborative is a voluntary network of clinicians, academics, industry representatives and policymakers interested in emerging Personal Health Record technologies and their impacts on patients and health service providers. This study was commissioned by the Collaborative to explore stakeholders' experiences with and perceptions of a system that allows patients to access their detailed primary care record online.

The specific aims of the analysis were to help understand:

- How health centres have integrated Record Access into their working practices and its acceptability to providers and recipients of the service
- How Record Access has influenced clinician behaviour, staff time or workflow, patient self-care and patient-provider relations.
- The barriers encountered during implementation and any training or support needs that should be addressed
- Features of the system, or its operational procedures, that may require modification or clarification.

Methods

The survey targeted 57 health centres that had expressed an interest, when contacted by the system suppliers, in trialling its new Record Access functionality. The survey took place shortly after the 12 month trial period had ended.

Questionnaires containing closed, open and Likert scale items were tailored to suit clinicians, administrators and patients and sent to practice managers for internal distribution. Non-respondents were followed up by email. Practices found not to have implemented the system were interviewed by telephone to determine their reasons.

Results

Of the 57 health centres originally expressing an interest in Record Access 32 were providing this service to patients at the time of the survey, of which 16 centres responded to the survey. This yielded 42 completed questionnaires from 14 practice managers, 15 clinicians and 13 patients. All patients were aged 40 or over.

Clinicians' perceptions

The majority of clinicians believed that electronic record access is well received by patients and felt that the service can be provided without creating a significant additional burden on health centres. Most had experienced no increase in consultation length or frequency, while some believed these had decreased. Most had not changed the way they write patient records as a result of providing this service although some indicated that they had become more careful.

Just over half of the clinicians believed that record access had facilitated shared decision making during consultations and had increased mutual trust between clinician and patient.

Technical and administrative challenges perceived by clinicians included the finite time and resources available to recruit patients and check their records prior to access. Concerns were also expressed about the legality of providing patients with unrestricted access to medical records and whether this contravenes the UK Data Protection Act (DPA). These reflected similar concerns expressed by the health centre managers.

Despite these caveats most clinicians said they would be willing to recommend record access to a fellow health centre.

• Managers' perceptions

Most health centre managers had heard about Record Access from a colleague, in most cases an interested clinician. A decision to offer the service was usually made following a health centre meeting. Facilitators included all-clinician support for Record Access and practices' prior experience of offering online services (all the practices surveyed already provided online appointment bookings and some also provided repeat prescriptions in this way).

Most centres had recruited patients using waiting room leaflets or posters, or opportunistically during consultations. Over half of the health centre managers indicated that patient recruitment had been easy but some identified challenges including patient concerns, lack of interest, poor understanding of potential benefits and the time required to explain the system to patients. In most cases patients obtained the service by completing a registration and consent form. Perceived challenges to patient registration included the time required to process forms and review patient notes, and technical errors. The overwhelming majority of managers stated that it had been easy to manage Record Access within their centre and that the service had not affected, or had slightly decreased, the frequency of patient requests at reception for clarification over tests, drugs and appointment times; clinical consultations and repeat prescriptions..

The concerns presented by health centre managers echoed those of the clinicians and included availability of staff time, the UK Data Protection Act and the risk of access to third party information, and technical challenges such as user (patient) errors and issues with computer and website maintenance. Health centre managers also recommended the provision of additional materials in orde to publicise the service to patients and practitioners, as well as further support and training for all staff.

• Patients' perceptions

Patients responding to the service expressed positive views about the usefulness and benefits of Record Access. Nearly all had found the system easy to set up and use, all were comfortable with the way their consent was requested and the majority had no concerns about creating a record access account.

Most patients had had access to the system for over 10 months. The majority had accessed their medical records six or more times during this period and most reported having done so within the last two weeks. Patients reported using Record Access for looking up their results, checking their condition, reading clinical letters and for supporting their hospital outpatient consultations (e.g. by checking notes beforehand).

All patients had found record access useful and all but one reported that it had improved their knowledge of their medical condition. Most also stated that record access had helped them to better self-manage their health and improved their understanding of how their condition is being managed by health professionals. Patients also reported that Record Access had improved their

satisfaction with their health centre, their confidence in sharing information or decisions during consultations, and their trust in their doctors.

Interviews with managers and clinicians from centres that had agreed to participate in the pilot, but who then did not proceed, mirrored many of the findings outlined above. Perceived barriers included concerns about the time and workload required to set up the service; a lack of clarity about the system and how it operates; a lack of support and information - particularly in relation to the UK Data Protection Act-, a lack of patient demand; the potential to distress patients; possible changes required to working practices and increases in patient contact time. Despite these concerns most respondents in these practices retained a positive attitude to record access, and planned to implement it at some point in the future, indicating the untapped potential that exists to increase the provision of record access through the provision of information, training and incentives.

Conclusions

This study found overall support amongst clinicians, practice managers and patients for online Record Access. The experience gained from practices participating in this study suggests that Record Access is easy to set up and manage and has few implications for clinical workflow. All three groups articulated benefits that this service will bring to the working practice of health centres, to the health and empowerment of patients, and to the relationships between patients and the health system. At the same time, the study pointed to a number of barriers, uncertainties and areas of improvement that should be addressed before wider deployment. Record access clearly has an important role to play in supporting a more patient focused health system and these findings provide a useful road map for the successful expansion and roll-out of these services.

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Abbreviations

BMI **Body Mass Index** DPA UK Data Protection Act (the system supplier) General Practitioners EMIS -GP

ID Identification

IT

PAERS -

Information Technology
Patient Access to Electronic Records System software
Primary Care Trust
Personal Health Records PCT -PHR -PCT

Record Access RA

Introduction

Personal Health Records (PHR) technologies are making an increasing impact on the way in which patients interact with health information and services. While patient-managed PHR are gaining currency in some parts of the world, in the UK this most commonly involves giving patients online access to their provider-held electronic health record – a practice known as Record Access. Recent guidance on Record Access has been provided by the Royal College of General Practitioners (Morris and Milne, 2010)

The Record Access Collaborative is a voluntary network of clinicians, academics and organisations involved in generating and disseminating information about best practices in Record Access. It commissioned this study to explore the experiences and perceptions of general practitioners, administrative staff and patients who had been involved in a one-year pilot of online Record Access in primary care, in order to inform the wider-scale deployment of these technologies.

The specific aims of the study were explore:

- How health centres have integrated Record Access into their working practices and its acceptability to providers and recipients of the service
- How Record Access has influenced clinician behaviour, patient self-care, patient-provider relations, and staff time or workflow.
- The barriers encountered during implementation and any training or support needs that should be addressed
- Features of the system, or its operational procedures, that may require modification or clarification.

Methods

Questionnaire development and piloting

Data were collected using questionnaires disseminated to clinicians, health centre managers and patients at health centres across the UK.

The questionnaire was developed by the research team and subjected to several iterations. Item selection was informed by the literature on Personal Health Records and themes emerging from earlier qualitative work on Record Access in UK General Practice (Fisher et al, 2011).

The questionnaire used closed-ended, open and Likert scale questions, which aimed to elicit information in the following areas:

- From clinicians: 1) Details on how record access had affected their health centre; 2) the effect of record access on the clinician's ways of working; 3) the effect of record access on consultations; 4) the support health centres received on record access; and 5) any specific barriers or challenges to operating record access and further suggestions to improve the service
- From Health Centre Managers: 1) How their health centre came to be involved; 2) Patient recruitment and registration processes; 3) How record access currently operates within their health centre; 4) The support the health centre received on record access; and 5) questions in specific to receptionists on the effect of record access on patient requests
- From patients: 1) Personal details; 2) Their experience of setting up and using record access; 3) How they use record access and suggestions for improvement; and 4) Their overall opinion about record access

Sampling frame

The researchers approached 57 health centres which were, or had previously been, providing patients with the ability to access their medical record (commonly known as record access or online record access) as part of a pilot by EMIS (the system supplier). These practices were all using the EMIS access/Patient Access to Electronic Records System (PAERS) software. This pilot involved these health centres in extending their existing EMIS access to include the provision of record access for patients. Inclusion in the survey was based solely on participation in this pilot and had no relation to the patient numbers within each health centre.

Recruitment and sample size

An email requesting participation in the study was circulated to all 57 health centres on the database provided by EMIS. Each practice was asked to complete one practice manager questionnaire, one or more clinician questionnaire and up to five patient questionnaires. The questionnaire to health centre managers also contained a specific section for receptionists, and the health centre managers were asked to consult these staff members and respond on their behalf. The health centre manager was also asked to co-ordinate completion of the survey by clinician/s and patients, and to return all surveys to the researchers.

Follow-up telephone conversations with each health centre then took place to encourage their response to the questionnaire. These initial discussions, and responses to the email request, established that out of the 57 health centres, only 32 (56.1%) were providing online record access.

¹ See eHealth Insider. EMIS seeks 100 pilot practices for patient record access. May 2007. http://www.ehi.co.uk/news/primary-care/2685

The remaining 25 health centres (43.9%) were not providing online record access; although they had originally agreed to participate in the pilot, they then pursued this no further. The database was then separated into those health centres using record access, and those that were not.

A number of further email and telephone requests were then made to the 32 health centres providing record access with the aim of encouraging their response to the questionnaire. This process was continued until the researchers believed that they had received the maximum number of possible responses.

Those 25 health centres that had not proceeded with Record Access were asked to take part in a telephone interview to establish the reasons for this decision. 15 (60%) of those practices agreed and were interviewed over the telephone. The categories of staff interviewed were as follows: 10 practice managers (66.7%), four clinicians (26.7%) and one information technology manager (6.6%).

Questionnaire response rates and breakdown

Of the 32 health centres providing record access, 16 (50%) returned questionnaires. The remaining 16 (50%) did not. These 16 practices returned a total of 42 questionnaires, which break down as follows: 14 practice manager (33.3%); 15 clinician (35.7%); and 13 patient (31%). The patient questionnaires originated from five health centres (three centres returned one patient questionnaire each, another centre returned four patient questionnaires, and another, six patient questionnaires). It was assumed that the practice managers and clinicians who completed the survey were currently using the record access system within their practice, or had been involved in using record access previously.

Each of the 14 health centre manager responses represented a different health centre. The 15 clinician questionnaires came from eight different health centres. The 13 patient questionnaires came from five different health centres. Overall, nine health centres returned only 1 questionnaire, four health centres returned between 2 - 5 questionnaires, and the remaining three health centres returned between 6-8 questionnaires.

Analysis

Questionnaire responses were entered into a database. Open questions and additional comments by respondents were coded using a simple qualitative analysis. Summary statistics were generated to provide analysis of the data.

Results

Section 1: Questionnaire on clinicians' experience

1) Clinician's perceptions of how record access has affected the work of their health centre

i. How patients view record access

A clear majority of the clinicians surveyed (12; 80%) agreed or strongly agreed with the statement that the health centre's ability to offer electronic access had been well received by patients, with only three clinicians (20%) stating that it had made no difference to patient perceptions. No clinician disagreed with this statement.

Narrative comments supported the above survey responses, but also indicated some concern about the slow uptake of RA by patients who had expressed an interest in the service.

"Record access very well received; patients enjoy the openness"

ii. Integration of record access into workflow processes

Almost half of all clinicians (7; 46.6%) either agreed or strongly agreed that record access had been easily integrated into the health centre's workflow processes. Another five clinicians (33.3%) stated that the introduction of record access had made no difference to these processes. Two clinicians (13.3%) disagreed that record access had been easily integrated and one (6.7%) strongly disagreed. See Table 1 below for a breakdown of these responses.

Narrative comments indicated that although it "takes a few minutes to set up", practices will potentially need to scrutinise every record and some financial incentive may be necessary.

"If a patient is to be offered unrestricted access, as implied by this project, then records need to be scrutinized for information to which the patient does not have a right to access"

Table 1: Clinician responses on whether record access has been easily integrated into workflow

processes		
	No	percentage
disagree strongly	1	6.7%
Disagree	2	13.3%
no difference	5	33.3%
Agree	5	33.3%
agree strongly	2	13.3%

iii. Effect of record access on frequency with which patients contact the health centre for information or clarification

Most respondents (10; 66.7%) did not perceive any effect of record access on the frequency with which patients contacted the health centre. Two clinicians (13.3%) believed that record access had made patient requests less frequent, while the same number and percentage felt that it has led patients to more frequently contact the health centre. One clinician (6.7%) did not know. See Table 2 below for a breakdown of these responses.

Additional comments included the fact that health centres had not noticed changes, and that there were "too few patients to notice any differences."

Table 2: Clinician responses on whether record access has affected frequency with which patients contact the health centre for information or clarification

	No	percentage
much more frequent	0	0%
more frequent	2	13.3%
the same	10	66.7%
less frequent	2	13.3%
much less frequent	0	0%
Unsure	1	6.7%

2) Effect of record access on clinician's working practices

i. Changes to the way clinicians write records after adopting record access 12 clinicians (80%) had not changed the way they write patient records as a result of providing record access. Nevertheless three clinicians (20%) stated that they had changed the way they wrote records. See Table 3 below for a breakdown of these responses.

Further light was shed on this by their narrative comments; which included:

"Clearer language, purposefully more understandable if patients have record access"

"Aware of implications when patients can look at their own notes, what I write down is now strictly medical without any comments"

Table 3: Clinician responses on whether adoption of record access has changed the way they write patient records

	No	percentage
Yes	3	20%
No	12	80%

ii. Influence of record access on clinicians confidence communicating with patients

The majority of clinicians (12; 80%) did not perceive record access to have had any effect on their confidence communicating with patients. Two clinicians (13.3%) felt that this service had made them a bit more confident, and one (6.7%) felt much more confident communicating with patients as a result of record access. No respondent stated that record access had made them less confident in communicating with patients. See Table 4 below for a breakdown of these responses.

Table 4: Clinician responses on how their confidence communicating with patients has been influenced by record access

	No	percentage
much more confident	1	6.7%
a bit more confident	2	13.3%

no different	12	80%
a bit less confident	0	0%
much less confident	0	0%

3) Effect of record access on consultations

i. Influence of record access on time required for consultations

The vast majority (13; 86.7%) of respondents stated that record access had made no difference to the time required for consultation with patients. The remaining two clinicians (13.3%) stated that it had made the consultations 'a bit shorter.' No respondents felt that record access had made the consultations longer. See table 5 below for a breakdown of the results.

ii. Influence of record access on frequency with which patients consult Ten clinicians (66.7%) felt that record access had no effect on the frequency with which patients consulted the health centre. Two (13.3%) stated that it had led to fewer consultations, with the same number stating that it had increased consultation frequency. One clinician (6.7%) did not know. See table 5 below for a breakdown of the results.

Table 5: Clinician responses on how record access has influenced time required for consultations and frequency of patients consulting

	time required	for consultations	frequency of	f patients consulting
	No	Percentage	no	percentage
much longer/ much				
more frequent	0	0%	0	0%
a bit longer/ more				
frequent	0	0%	2	13.3%
no difference	13	86.7%	10	66.7%
a bit shorter/ less				
frequent	2	13.3%	2	13.3%
much shorter/ much				
less frequent	0	0%	0	0%
don't know	-	-	1	6.7%

iii. Whether record access has facilitated information exchange during consultations
Around half of respondents (8; 53.3%) believed that record access had 'to some extent' facilitated information exchange during consultations with patients. Five clinicians (33.3%) felt that there had been no effect as a result of record access, and two (13.3%) stated that this service had significantly ('very much so') facilitated information exchange. See table 6 below.

iv. Whether record access had facilitated shared decision-making during consultations Just over half of the respondents (8; 53.3%) believed that record access had facilitated shared decision making during consultations, with six clinicians (40%) stating that it had 'to some extent' and two clinicians (13.3%) believing that it had had a significant effect. The remaining respondents (7; 46.7%) believed that record access had had no effect on facilitating shared decision-making with patients during consultations. See table 6 below. No further comments were provided on this, but it points to another potential important benefit as a result of record access.

v. Whether record access has improved mutual trust during consultations

Just over half of the respondents (8; 53.4%) believed that record access had improved trust during consultations, with four clinicians (26.7%) stating that it had 'to some extent' and the same number and percentage believing that it had had a significant effect. One of the clinicians who believed it be significant, added that record access was "particularly helpful in getting patients involved with their conditions and monitoring of it." The remaining respondents (7; 46.7%) believed that record access had had no effect on improving mutual trust during consultations. See table 6 below. Additional comments on this from clinicians highlighted that the fact that there was no effect may in part have been due to their already "always being open with patients."

Table 6: Clinician responses on changes during consultations as a result of record access

ruore or emmera	ii response	on changes a	raring consultat	ions as a resurt	or record acces	,,,
	facilitate	d information	facilitated sha	ared decision-		
		exchange		making	improve	d mutual trust
	no	percentage	no	percentage	no	percentage
not at all	5	33.3%	7	46.7%	7	46.7%
to some extent	8	53.3%	6	40%	4	26.7%
very much so	2	13.3%	2	13.3%	4	26.7%

vi. Changes to the way patients manage their health as a result of record access. The majority of clinicians (10; 66.7%) had not seen any changes to the way patients managed their health as a result of record access; for example through better medication adherence or self-care, however four clinicians (26.7%) had seen such changes. One clinician (6.7%) did not complete this item. See table 7 below.

In their narrative comments a number of clinicians indicated that their patients, particularly those with existing conditions, had become more interested in their conditions, and in looking up their own results, and were more likely to undertake online research before coming to see a clinician.

Table 7: Perceived influence of Record Access on Patient Self-Management

	no	Percentage
Yes	4	26.7%
No	10	66.7%
don't know	1	6.7%

4) Support health centres received to implement record access

i. Documentation received from EMIS

Only 5 respondents (33.3%) received a document from EMIS that set out solutions to both potential clinical and administrative issues, and also standard forms to use (such as for patient registration). One (6.7%) did not receive this information. Nine respondents (60%) could not remember. Of those who did receive the document (n=5), three (60%) found it very useful and two (40%) moderately useful. See table 8 below.

Suggestions for improving user knowledge included a "shorter idiot's guide" and "a website for patients/health centres to download such documentation."

[&]quot;Patients with existing conditions, particularly those involving secondary and primary care intervention, check their own blood test results and review consultations and discharge summaries"

Table 8: Clinician recall of guidance documents received from the software supplier

		11
	no	Percentage
Yes	5	33.3%
No	1	6.7%
don't remember	9	60%

ii. Training and support provided to health centre colleagues

Nine respondents (60%) stated that no training or support was provided to health centre colleagues. Four (26.7%) said support was provided, and two (13.3%) did not know. See table 9 below. Comments from respondents where training and support was provided highlighted that this was through a briefing meeting with admin staff, and provided at the start of the pilot.

Table 9: Clinician responses on whether training and support on record access was provided to colleagues in the health centre

	no	Percentage
Yes	4	26.7%
No	9	60%
don't know	2	13.3%

iii. Perceived usefulness of further support, information or training on record access Around a quarter (4; 26.7%) of respondents stated that it would be useful for health centres to receive further support, information or training. Six respondents (40%) did not believe it would be useful. Three (20%) did not know, and two (13.3%) left this question blank. See table 10 below.

Table 10: Clinician responses on whether further support, information or training on record access would have been useful

	No	Percentage
Yes	4	26.7%
No	6	40%
don't know	3	20%
Blank	2	13.3%

5) Barriers and facilitators to Record Access perceived by clinicians

Narrative comments indicated a number of factors that made it difficult for health centres to operate record access, as shown below.

i. Technical or administrative challenges

a) Human and financial resources

- The time required to review patient records prior to granting access was identified as a limiting factor: "If a patient is to be offered unrestricted access, as implied by this project, then records need to be scrutinized for information to which the patient does not have a right to access".
- There were also concerns about the feasibility of providing the service if all patients were to seek record access. "Currently 100+ patients have registered for this. If all 15892 registered for this it would require a full time member of staff to look after this project"

- Lack of clarity around funding sources to support this work
- It was also noted that RA may result in practices no longer receiving payments from insurance companies or solicitors for providing copies of records, as the patient could now do this without the help of the practice. "Needs financial incentive to clinicians as it removes requests for reports/extracts from records"

b) Technical factors

- Patients forgetting log on details
- EMIS website had become corrupt at one particular time.

c) Legal factors

- Concerns about the legality of providing patients with unrestricted access to medical records
- Concerns regarding contravening the Data Protection Act (DPA): "In theory I am entirely happy for patients to see their medical records. However, I am not prepared to ignore the DPA and to provide that access for patients without their notes being reviewed and information from or about third parties hidden..."
- The need for further information regarding this issue and the Data Protection Act
- Concerns that health centres being told that they can restrict patients access to only high level information or to prevent access to old information, while it appears patients had been led to expect that they could access all the information in their medical record.

These matters are explored further below.

d) Recruitment factors

• Lack of demand among patients for this service: "Uptake has been slow at 120 patients from a list of 16000"

ii. Concerns expressed to clinicians by their patients

Only one respondent (6.7%) had received expressions of concern about record access from patients. The vast majority (93.3%) had not. The former respondent highlighted login problems experienced by patients as the source of their concern.

iii. Suggestions on ways to make record access easier for health centre staff and patients to use Comments on this included the following:

a) Technical factors

- Password/username retrieval system which patients can access without recourse to the health centre
- Improving patients' ability to view attachments within the system. (This has since been resolved.)
- Tagging the records of patients who have record access in the system, to make it easier for clinicians to identify these patients
- Creating a website with specific information on record access.

b) Legal factors

- Clarity to be provided on what information can or cannot be provided to patients: "There should be a greater degree of honesty. Either the service needs to be explicit that it is ignoring the law, or it needs to be clear that it can only provide restricted access to records and why"
- Provide training on the requirements of Data Protection Act and advice on what is and is not permitted within the law

c) Information factors

- Necessary to encourage a greater number of clinicians to offer the record access service to patients
- A standard presentation on record access to make to GP registrars at their training day. Presentation to local health mgrs (PCT/Council)
- Greater support informing patients about record access

iv. Clinician willingness to recommend record access to others

Almost three quarters (11; 73.3%) of respondents said they would be willing to recommend record access to a fellow health centre. Four respondents (26.7%) stated they would not. See table 11 below.

Table 11: Clinician responses on whether they would recommend record access to other health centres

	no	Percentage
Yes	11	73.3%
No	4	26.7%

Section 2: Questionnaire to Health centre Managers

1) Details about how the health centre became involved in record access

i. How the health centre first heard about record access

Six respondents (42.9%) stated that they heard about record access through a colleague. One respondent (7.1%) said they found out about it through the clinician (GP) press. The remaining 7 respondents (50%) provided other sources, including EMIS (71.4% of the group stating other sources; 35.7% of all respondents), the local PCT (14.3% of the group stating other sources; 7.15% of all respondents) and Informing Healthcare (14.3% of the group stating other sources; 7.15% of all respondents). See table 12 below for a breakdown of those results.

Table 12: How practices first became aware of online Record Access

	no	Percentage
through a colleague	6	42.9%
through the clinician (GP) press	1	7.1%
through EMIS (other category)	5	35.7%
through the PCT (other category) through Informing HealthCare (other	1	7.15%
category)	1	7.15%

ii. Other online services which the health centre offered to patients before providing online record access

Eleven out of the fourteen health centres (78.6%) already offered some form of online service to patients prior to adopting record access (with three health centres, 21.4%, stating they did not). All of these eleven health centres provided patients with the possibility to book appointments online. Nine of those health centres (64.3% of all health centres) provided patients with the functionality to order repeat prescriptions online. Only one health centre (7.1% of all health centres) provided patients with an additional other function, which was messaging (a function that enables patients to securely send an electronic message to the health centre). See table 13 below with detailed breakdown of these results.

Table 13: Health Other online services offered by health centres before adopting record access

	no	other online						
	services		appointn	nent booking	prescripti	on reordering		other
								percentag
	no.	percentage	no.	percentage	no.	percentage	no	е
Yes	3	21.4%	11	78.6%	9	64.3%	1	7.1%
No	11	78.6%	3	21.4%	5	35.7%	13	92.9%

iii. How the health centre became involved in using Record Access

One health centre (7.1%) became involved in record access through responding to a mailshot. Five health centres (35.7%) adopted record access as a result of a member of its staff finding out about the pilot study. The remaining eight health centres (57.1%) became involved though other routes, including EMIS (50% of the group stating other sources; 28.6% of all respondents), the local PCT (37.5% of the group stating other sources; 21.4% of all respondents) and Informing Healthcare (12.5% of the group stating other sources; 7.1% of all respondents). See table below 14 for a breakdown of those results.

Table 14: How the health centre became involved in record access

	no	Percentage
responded to a mailshot	1	7.1%
colleague heard about study	5	35.7%
EMIS connection (other category)	4	28.6%
PCT influence (other category)	3	21.4%
Informing HealthCare influence (other		
category)	1	7.1%

iv. How agreement on record access was reached within the health centre A majority of respondents (9; 64.3%) stated that agreement on the adoption of record access was made following a health centre meeting. Over a quarter of respondents (5; 35.7%) said that the decision to adopt record access was through persuasion by an interested clinician. Two respondents (14.3%) also said that the decision was made through other means, including by the health centre manager and following a patient group meeting.

v. Whether all clinicians in the health centre supported the provision of record access A clear majority of respondents (12; 85.7%) stated that all clinicians in the health centre supported the provision of record access. In the remaining 2 health centres (14.3%), all clinicians did not agree. In those health centres where agreement was not reached by all clinicians, the rational for this was explained by one respondent as due to "the clinicians having reservations regarding vetting third party information on medical records (due to the Data Protection Act), and therefore the health centre agreed that one partner should trial it with selected patients."

vi. How the record access system was introduced to colleagues within the health centre In most health centres (10; 71.4%) record access was introduced to colleagues through a health centre meeting. In five health centres (35.7%) standard instructions were also circulated to colleagues. Four health centres (28.6%) used other methods in addition to the above, including one-to-one training, word of mouth, and leaflets. A breakdown of these results are in table 15 below.

Table 15: Health centre manager responses on how the record access system was introduced to colleagues within the health centre

			standaı	rd instructions		
	health centre meeting		circulated		othe	
	no.	percentage	no.	Percentage	no.	percentage
Yes	10	71.4%	5	35.7%	4	28.6%
No	3	21.4%	8	57.1%	9	64.3%
Blank	1	7.1%	1	7.1%	1	7.1%

2) Details about patient recruitment and registration process

i. Methods used by health centres to recruit patients

The most common methods used by health centres for recruiting patients was through waiting room leaflets or posters (used by 10 health centres; 71.4%) and opportunistic recruitment during consultations (used by 8 health centres; 57.1%). One health centre (7.1% of all health centres) also used a mail-shot to their health centre list. The same health centre (7.1% of all health centres) was the only health centre to also select patients based on their health profile, in this case their asthmatic condition. One other health centre (7.1% of all health centres) emailed out information about record access to their health centre list. In addition to those methods, five health centres (35.7%) used additional recruitment methods, including promotion through their

website, health centre newsletter, local press, patient forum, telephone messages and during patient registration. See table 16 below for breakdown of responses.

Table 16: Methods used by health centres to recruit patients

	Mails	shot to	Emai	l to	Waiti	ing	recrui	tment	Selec	tion	other	
	healtl	h centre	healtl	n centre	room		during	g	based	lon		
	list		list		leafle	ets or	consu	ltations	patie	nt		
					poste	r			profil	le		
	no.	%	no.	%	no.	%	no.	%	no.	%	no.	%
Yes	1	7.1%	1	7.1%	10	71.4%	8	57.1%	1	7.1%	5	35.7%
No	13	92.9%	13	92.9%	4	28.6%	6	42.9%	13	92.9%	9	64.3%

ii. How easy it was for health centres to recruit patients

Over half of the health centre managers found it easy to recruit patients (8; 57.1%), with one (7.1%) finding it very easy. Three respondents (21.4%) found patient recruitment difficult, and two (14.3%) left the answer blank. No respondent stated that they found patient recruitment very difficult. From these results, a clear majority of respondents (64.2%) either found recruitment easy or very easy. See table 17 below for a detailed breakdown of these results.

Table 17: How easy it was for health centres to recruit patients

	No	percentage
very easy	1	7.1%
Easy	8	57.1%
Difficult	3	21.4%
very difficult	0	0.0%
Blank	2	14.3%

The health centre managers also provided information about challenges they had faced in patient recruitment. This revealed the following issues: patient concerns about the security of their medical record, and in particular the risk of other patients or outside agencies gaining access to their medical records; patients' lack of familiarity with IT; the time required to explain how to use record access to patients; lack of patient interest or patients not seeing the benefits of record access. In a number of cases, only the clinician had recruited the patients with no involvement of the health centre manager.

"Generally many patients were interested in seeing what has been written about them, but it takes longer to show the benefit to them of using their record to monitor /self care, e.g. DM patients"

iii. Approximate number of patients recruited each week

Four respondents (28.6%) stated that their health centre recruited between 0 to 4 patients per week, two respondents (14.3%) between 5 and 10 patients per week, and three respondents (21.4%) between 10 to 15 patients. One respondent (7.1%) stated that they recruit more than 15 patients per week, while one other (7.1%) stated that it varied. One respondent (7.1%) stated that they had ceased recruitment, and two respondents (14.3%) left this question blank. See the table 18 below for a breakdown of these figures.

Table 18: Approximate number of patients recruited by health centres each week

No percentage			
			percentage

None	1	7.1%
0 to 4	4	28.6%
5 to 10	2	14.3%
10 to 15	3	21.4%
15+	1	7.1%
Varies	1	7.1%
Blank	2	14.3%

iv. Guidance and support that would have helped with patient recruitment

The Health centre Managers were asked what guidance and support would have aided the recruitment process. Their responses included:

- Further information/materials, including publicity materials and standard information of what could be expected of patients
- Additional resources/financial incentives. This would enable the health centre to have staff
 time dedicated to record access, and avoid their current adhoc approach to this service. This
 greater concentration would be used to promote the service, focus on patient recruitment and
 help patients with logging in/technical difficulties.
- Clarification on access by patients to third party information

v. Patient registration and consent processes used by health centres

The Health centre Managers were asked what patient registration and consent processes they used. A commonality across all responses was that health centres ask patients to read and sign in person a standard registration and consent form prior to gaining record access privileges. This form is available at reception. The patient is also required to provide photographic identification. One health centre manager said that they use the "standard EMIS proforma," another the "standardised forms provided by the Primary Care Trust." Patients are asked to select a password for their online record access, after which they are given the ID codes/number to access the system.

A number of health centre managers provided more details, including that the reception staff are trained on this process and given instructions to follow. One highlighted how the clinician is involved in these processes: "Patient submits form asking for access. This is given to a clinician who looks at records to see whether it is clinically appropriate for the individual [to be given access]. Conversations take place, if necessary, and patient then issued with further pin number to enable this additional element of EMIS access"

vi. Difficulties with registration process?

The Health centre Managers were asked if they faced any difficulties during the patient registration process. Their responses included:

- Technical issues, such as user errors
- Logistical challenges, such as the time required to register patients given other demands during a normal working day, the time needed for patient notes to be reviewed and the length of the form
- Standard "learning hiccoughs"

Five Health centre Managers stated that they did not face any difficulties, and two did not respond. The time for registering patients, and reviewing patient notes, appears to be the most significant difficulty faced by health centres.

vii. Induction packs given to patients

An overwhelming majority of respondents (11; 78.6%) stated that their health centres did give induction packs to patients who were provided with online record access. One health centre did not (7.1%) and two respondents did not know (14.3%).

viii. Improving the registration process

The Health centre Managers were asked for their comments on how the patient registration process could be made easier. Their responses included:

- Improved information on registration for patients, such as "better quality leaflets, and simplified leaflets"
- Adopting a universal registration policy for all practices using record access
- Technical improvements, including putting the whole registration process on line, including the consent form, so that patients were not required to come to reception. In addition, an alert should be added to the notes to alert clinicians that patients can see these notes and results.

3) Details about the current record access operation being used in the health centre

i. Ease of managing record access within the health centre

The overwhelming majority of Health centre Managers (11; 78.6%) said that it had been easy to manage record access within the health centre. Only two (14.3%) said it was difficult to manage. One response (7.1%) was left blank.

ii. Challenges/barriers to operating record access and suggested improvements

The Health centre Managers were asked if they faced any specific challenges/barriers to operating record access. Their responses included:

- User (patient) error, such as patient's forgetting passwords and having to request that they be reset
- Technical problems, such as difficulties with machines/kiosk computers in health centres and the system not being linked to the health centre domain server (to facilitate printing patient letters)
- Logistical challenges, including clinician time to check patients' notes first prior to giving access for third party information; time and extra resources needed to run the system, particularly if facing staff shortage;
- Lack of publicity and interest among patients. As one practice manager said, "It has not been properly rolled out so we have only had the odd request"

The Health centre Managers were asked if they had any specific suggestions on how to improve the record access service. Three recommendations to address perceived technical difficulties were put forward, which included: faster maintenance when the machines/kiosks were not working; patients being able to reset their passwords online; and improved interface for access to patients' details.

The availability of time and resources remains a key challenge for health centres, particularly in relation to concerns around access by patients to third party information. In addition, a number of system challenges were identified, including user errors and machine problems/maintenance.

4) Details on support health centres received on record access

i. Did health centres receive an EMIS guidance document?

Five respondents (35.7%) said they received a document from EMIS that set out solutions to both potential clinical and administrative issues, and also included standard forms for them to use. Four respondents (28.6%) were of the opinion that they did not receive this document. The remaining five respondents (35.7%) said that they were not sure. As such, only one-third definitely received this document from EMIS, while the remaining two-thirds believed they did not or could not remember.

ii. Perceived usefulness of guidance document by those that received it Of the five respondents that received the EMIS guidance document, three (60%) stated that they find it very useful. The remaining two respondents (40%) said that it was moderately useful. No respondent stated that they did not find the guidance useful.

One suggestion was provided for improving this guidance, which was to simplify the document and provide a step-by-step process for setting up and operating record access.

iii. Whether training and support was provided by EMIS

Ten respondents (71.4%) stated that training and support was provided by EMIS. One respondent (7.1%) stated that no support had been provided, and three respondents (21.4%) were unsure. The type of support provided, included "ad hoc help" as health centres were setting up the system. At the same time, however, one respondent stated that "there was very little support."

iv. Whether further support and information would have been useful Five respondents (35.7%) stated that further support and information from EMIS would have been useful. Eight respondents (57.1%) stated that it was not necessary and one (7.1%) did not respond.

Suggestions for further support included the following:

- A standard training process should be put in place to ensure that all health centre staff are aware of record access, instead of only the interested clinician. This would include information on include why record access is being implemented and how the system works, amongst other details.
- Training on governance and security issues
- A system for health centres to check records for third party information before granting access. (Most responding practices had already addressed thsis.)

In terms of information, respondents were mainly interested in receiving a general introduction on the importance of record access to all staff (which will also help to widen the net of those involved), and addressing concerns regarding patient access to third party information.

5) Feedback from receptionists

i. Whether recruiting patients was a significant challenge

Two receptionists (14.3%) stated that recruitment of patients to record access was a significant challenge. Seven receptionists (50%) stated that this recruitment was not a challenge. Five receptionists (35.7%) left the question blank.

In further information provided, those receptionists who faced significant challenges, explained that this was due to: leaflets not being very "friendly"; the time needed to explain record access to patients; the existing time restraints within a health centres' work; and the need to register

patients for different stages (e.g. recruiting them to the programme, setting them up online, etc), which takes up additional time

Three receptionists also stated that only clinicians had recruited patients to record access, and that the reception staff had not been directly involved. This lack of involvement may be as a result of the clinician targeting a specific group of patients (e.g. with high BMI) as a pilot study for record access. A specific question about recruitment was not asked in the questionnaire to clinicians.

ii. Extent to which record access influenced requests at reception in a number of areas

a. Clarification over tests, drugs, and appointment times

No respondent stated that record access has increased the number of queries at reception regarding tests, drugs and appointment times. Three respondents (21.4%) said that record access had reduced the number of queries. Eight respondents (57.1%) stated that it had made no difference. Three respondents (21.4%) did not respond. See table 19 below for a breakdown of responses.

b. Clinician consultation requests

One respondent (7.1%) stated that record access had increased the frequency of clinician consultation requests. Two respondents (14.3%) said that record access had made these requests less frequent. Eight respondents (57.1%) stated that record access had made no difference to the frequency of clinician consultation requests. Three respondents (21.4%) did not respond. See table 19 below for a breakdown of responses.

c. <u>Prescription re-ordering</u>

Three respondents (21.4%) stated that record access has increased the frequency of prescription re-ordering. Two respondents (14.3%) said that record access had reduced the frequency of such re-ordering. Six respondents (42.9%) stated that record access had made no difference to the frequency of prescription re-ordering. Three respondents (21.4%) did not respond. See table 19 below for a breakdown of responses.

These results highlight that for all three areas – clarification over tests, drugs, appointment times; clinician consultation requests; and prescription re-ordering – the majority of health centres did not experience any changes to the frequency of patient requests at reception. For clarification over tests etc and clinician consultation requests, there was a small net reduction in frequency as a result of record access.

Table 19: Health centre Manager responses on extent to which record access influenced requests at reception in a number of areas

	Clarificat tests, drug appointme	gs,	Clinician cons	sultation	Prescription reordering	
	no.	percentage	no.	percentage	no.	percentage
more						
frequent	0	0%	1	7.1%	3	21.4%
less frequent	3	21.4%	2	14.3%	2	14.3%
no difference	8	57.1%	8	57.1%	6	42.9%
Blank	3	21.4%	3	21.4%	3	21.4%

iii. Any information that would have helped receptionists discuss record access with patients

Finally, receptionists were asked if there is any information that would have helped them to discuss record access with patients. Their responses highlighted the need for more patient targeted materials, including: "friendly practical leaflets with diagrams" and an "information leaflet to give to newly registering patients."

Section 3: Questionnaire to patients

1) Background details about the patients

i. Patient age range

See table 20 below for a breakdown of the age of patients completing the questionnaire. There were no patients under 40 years old. There were two patients (15.4%) from each of the following age groups: 41-50, 51-60 and 61-70. The largest age group was 71-80 years old (6; 46.2%). One patient (7.7%) was over 80 years old.

Table 20: Patient age range

200 aroun	patient number	norcontago
age group	Hullibei	percentage
under 40	0	0%
41-50	2	15.4%
51-60	2	15.4%
61-70	2	15.4%
71-80	6	46.2%
80+	1	7.7%

ii. Patient sex

Seven of the patients (53.8%) were male. Six of the patients (46.2%) were female.

iii. Patient health

Patients were asked about their health in two areas: whether they had a long term condition that requires regular monitoring and medication (e.g. high blood pressure, asthma, diabetes, depression or thyroid disorder); and whether they had been undergoing any specialist treatment which might increase their need for information (e.g., in vitro fertilisation (IVF), cancer therapy or surgery)

a. Long term condition

10 respondents (76.9%) stated that they had a long term condition requiring monitoring and medication. Two respondents (15.4%) stated that they did not have such a condition. One respondent (7.7%) did not reply. See table 20 below for breakdown of results.

b. Undergoing any specialist treatment

Four respondents (30.8%) stated that they were undergoing specialist treatment. The remaining nine respondents (69.2%) stated that they were not. See table 21 below for breakdown of results.

Table 21: Patient health

	Long term condition	on requiring	Undergoing an	y specialist treatment
	monitoring and mo	edication	which may increase	need for information
	no	percentage	no	percentage
Yes	10	76.9%	4	30.8%
No	2	15.4%	9	69.2%
Blank	1	7.7%		

2) Patient experiences setting up and using record access

i. How easy patients found it to set up the record access system at home Four patients (30.8%) found setting up the record access system very easy. Eight patients (61.5%) found it quite easy. One patient (7.7%) found it quite difficult. No patients found it very difficult. See table 22 below for a breakdown of these results.

Table 22: Patient responses on how easy they found it to set up the record access system at home

	, , , ,	
	patient	
	number	percentage
very easy	4	30.8%
quite easy	8	61.5%
quite difficult	1	7.7%
very difficult	0	0%

ii. Guidance on record access received beforehand by patients

Eight patients (61.5%) received a simple leaflet about record access before they set up the system. Two patients (15.4%) received a detailed information pack. Three patients (23.1%) did not receive any guidance and no patients were given a demonstration of the system.

Patients provided suggestions on further guidance or support that would have been useful, including:

- More detailed leaflets. For example, information about what to expect in the various windows (the set-up and layout), a demonstration of how to use the system, and information about maintaining privacy and security.
- Industry standard language, e.g. "password" not "passphrase""
- Improvements in the inputting of information received from hospitals (no further details provided).

iii. Whether patients were comfortable with the way their consent was requested Every patient (100%) was comfortable with the way that consent for record access was requested. One explanation of this was given: "the consent process was clear, easy to access and confidentiality is maintained and secure."

iv. Patient concerns regarding creating a record access account

All but one patient (92.3%) stated that they did not have any concerns about creating a record access account. One patient (7.7%) did have concerns, which they explained as "security and ease of access", though did not elaborate further.

v. How user-friendly did you find record access system

Five patients (38.5%) found the record access system 'very easy to use.' Eight patients (61.5%) found the system, 'quite easy to use.' No patients found the system 'quite difficult to use' or very difficult to use.'

vi. Length of time that the patient has been using online record access

No patient had been using record access for less than one month, or between 1-3 months or 7-9 months. One patient (7.7%) stated that they had been using record access for 4-6 months, and the remainder (twelve patients, 92.3%) had been using record access for 10 or more months. See table 23 below for a breakdown of these results.

Table 23: Patient responses on length of time they have been using record access

	patient	
	number	Percentage

less than one month	0	0.0%
1-3 months	0	0.0%
4-6 months	1	7.7%
7-9 months	0	0.0%
10 or more months	12	92.3%

vii. Number of times overall patients had accessed their record since setting up system All patients had accessed their records online more than once since setting up the system. Two patients (15.4%) had accessed their records between 2-5 times, seven patients (53.8%) had accessed them between 6-10 times, one patient (7.7%) between 11-15 times, two patients (15.4%) between 16-20 times, and the remaining one patient (7.7%) more than twenty times. See table 24 below for a breakdown of these responses.

Table 24: Patient responses on number of times they have accessed records since set-up

	patient number	percentage
Never	0	0.0%
Once	0	0.0%
2-5	2	15.4%
6 – 10	7	53.8%
11 – 15	1	7.7%
16 – 20	2	15.4%
more than 20	1	7.7%

viii. Number of times patients accessed their records in the last two weeks

Two patients (15.4%) had not accessed their records in the last two weeks, with the remaining patients (84.6%) accessing their records at least one or more times during this period. Five patients (38.5%) had accessed their records at least once, four patients (30.8%) between 2 - 5 times, and one patient (7.7%) between 6 - 10 times. No patient had accessed their records in the last two weeks more than 10 times. One patient (7.7%) did not respond. See table 25 below for a breakdown of these results.

Table 25: Patient responses on number of times records accessed in last two weeks

	patient number	percentage
Never	2	15.4%
Once	5	38.5%
2-5	4	30.8%
6 – 10	1	7.7%
11 – 15	0	0.0%
16 – 20	0	0.0%
more than 20	0	0.0%
Blank	1	7.7%

3) How patients utilise record access and their suggestions for improvement

i. Ways in which patients use record access

Patients were asked to report on a range of ways in which they utilise record access. 11 patients (84.6% of total number of patients) said they use record access to look up results, six patients (46.3% of total) say they use it to prepare for a consultation, seven patients (53.8% of total) stated that they used the system to check on how there condition was going, a further seven patients

(53.8% of total) stated they used it to look at letters, six patients (46.2%) said they used it to look at consultation notes, and five patients (38.5% of total) said they used it to check what the doctor said. Two other uses were provided by the patients, which were checking Prostate Specific Antigen (PSA) levels and setting prescriptions. See table 26 below for a breakdown of these results.

Table 26: Patient responses on ways in which they are using record access

	Look up		prepa	re for a	See h	now my	look a	at	look	at	checl	k what
	resul	ts	consu	ıltation	cond	ition is	letters	S	const	ıltation	the d	octor
					going	3			notes		said	
	no.	%	no.	%	no.	%	no.	%	no.	%	no.	%
Yes	11	84.6%	6	46.2%	7	53.8%	7	53.8%	6	46.2%	5	38.5%
No	1	7.7%	6	46.2%	5	38.5%	5	38.5%	6	46.2%	7	53.8%
Blank	1	7.7%	1	7.7%	1	7.7%	1	7.7%	1	7.7%	1	7.7%

ii. Whether record access has supported hospital outpatient consultations, if applicable (no = 7) Seven of the thirteen patients (53.8%) had used record access to support hospital outpatient consultations. Of those seven, one patient (14.3% of subgroup) stated that record access had helped with printing a copy of the records in case it was needed prior to their outpatient consultation. Six patients (85.7% of subgroup) stated that record access had been useful to view before an outpatient consultation, to remind them of relevant information. One patient (14.3% of subgroup) also said that it was useful to share their record with health professionals using computer in the hospital. See table 27 below for a breakdown of these results.

Table 27: Patient responses on whether record access has supported hospital outpatient consultations

			Viewing recor	rd	Sharing record with	
			beforehand, to remind		health professionals	
	Printing copy of		patient of relevant		using computer in the	
	records in case needed		information		hospital.	
	no.	Percentage	no.	percentage	no.	percentage
Yes	1	14.3%	6	85.7%	1	14.3%
No	6	85.7%	1	14.3%	6	85.7%

iii. Whether patient has shared their record with anyone else

Two patients (15.4%) said that they had shared their record with a family member. Eight patients (61.5%) stated that they had shared their records with a spouse or partner. No one had shared their record with a friend. Three patients (23.1%) had not shared their record with anyone else. Overall, more people had shared their record with someone else (76.9%) than those that had not (23.1%). See table 28 below for a breakdown of these results.

Table 28: Patient responses on whether they have shared their records with other people

	patient number	percentage
family member	2	15.4%
spouse or partner	8	61.5%
Friend	0	0.0%
Other	0	0.0%
None	3	23.1%

iv. Usual point for patients to access records

All 13 patients (100%) stated that they had accessed their records at home. One patient has also accessed their records at work and in a public space, e.g. library. No patients stated they had accessed their records in a health centre.

v. Patient suggestions to improve the record access system

Patients provided the following suggestions to improve the record access system: use a more straightforward website address; provide an online password reset and change function; improving monitoring of patients with multiple issues, e.g. if a patient has a consultation for chest infection, but also has infected skin, both should be mentioned on the patient record.

4) Patient opinions about record access

i. Overall usefulness of record access

Five patients (38.5%) said that record access had been somewhat useful. Eight patients (61.5%) said that record access had been very useful. No patients stated that it had been not very useful or not at all useful. See table 29 below for a breakdown of responses.

Table 29: Overall useful of record access

	patient number	percentage
not at all useful	0	0.0%
not very useful	0	0.0%
somewhat useful	5	38.5%
very useful	8	61.5%

ii. Whether record access influenced patient knowledge about their health or medical conditions Six patients (46.2%) stated that record access had improved their knowledge a lot, and a further six patients (46.2%) stated that it had improved their knowledge a little. One patient (7.7%) stated that record access hadn't affected their confidence. No patient said that record access had confused them a little or confused them a lot. See table 30 below for a breakdown of responses.

Table 30: Effect of record access on knowledge about your health or medical conditions

	patient number	percentage
improved knowledge a lot	6	46.2%
improved knowledge a little	6	46.2%
hasn't affected knowledge	1	7.7%
confused me a little	0	0.0%
confused me a lot	0	0.0%

iii. Influence of record access on patient understanding regarding how their condition is being managed by clinical staff or health professionals

Four patients (30.8%) stated that record access greatly improved their understanding of how their condition was being managed. Six patients (46.1%) stated that it improved their understanding a bit. Two patients (15.4%) said that record access hadn't affected their understanding, and one patient (7.7%) said that it confused their understanding. See table 31 below for a breakdown of responses.

Table 31: Effect of record access on understanding of how your condition is being managed

	patient number	percentage
greatly improves understanding	4	30.8%

improves understanding a bit	6	46.1%
doesn't affect understanding	2	15.4%
confuses my understanding	1	7.7%
greatly confuses my understanding	0	0.0%

iv. Whether record access has helped the patient manage their health better in a number of areas Over three quarters of patients (10; 76.9%) stated that record access had helped them to manage their health in one or more areas. The remaining three patients (23.1%) said that record access has not affected their self-management of health. Of those responding positively, three patients (23.1% of total) stated that record access had encouraged them to take their medication on time. Six patients (46.2% of total) stated that it had encouraged them to follow healthy lifestyle advice. Six patients (46.2%) also stated that record access had additionally made them more aware of health and how behaviour is influencing it. See table 32 below for a breakdown of responses.

Table 32: Effect of record access on ability to manage your own health

				<u> </u>	Patie	ent more aware		
	Encouraged		Encouraged patient		of health and how		Has not affected self-	
	patient to take		to follow healthy		behaviour is		management of	
	medic	ation on time	lif	estyle advice	influencing it		health	
	no.	percentage	no.	Percentage	no.	percentage	no	percentage
Yes	3	23.1%	6	46.2%	6	46.2%	3	23.1%
No	10	76.9%	7	53.8%	7	53.8%	10	76.9%

v. How patient opinion of their health centre has changed since using record access Most patients (6; 46.2%) said there had been no change in their opinion of their health centre since using record access. One patient (7.7%) said they were slightly more satisfied with their health centre, and five patients (38.5%) said they were much more satisfied. One patient (7.7%) said they were much less satisfied. Overall there is a net increase in patient satisfaction (+38.5%) as a result of record access. See table 33 below for a breakdown of responses.

Table 33: Effect of record access on your opinion of your health centre

	patient number	percentage
much less satisfied	1	7.7%
slightly less satisfied	0	0.0%
no change	6	46.2%
slightly more satisfied	1	7.7%
much more satisfied	5	38.5%

vi. Whether record access affected patient confidence in sharing information or decisions during consultations

Five patients (38.5%) said that record access had made them more confident sharing information and decisions during consultations. Eight patients (61.5%) said that it had made no difference to their confidence. No patients said that record access has made them less confident. This shows a net increase in patient confidence (+38.5%) as a result of record access. See table 34 below for a breakdown of responses.

Table 34: Effect of record access on your confidence in sharing information or decisions during consultations

	patient number	percentage
feel more confident sharing info and decisions	5	38.5%
it has made no difference	8	61.5%

vii. Whether record access affected patient trust in their doctors or health centre
Five patients (38.5%) said that record access had increased their trust in their doctors or medical
health centre. Eight patients (61.5%) said that it had made no difference to their level of trust.
No patients said that record access had reduced their trust in their doctors or health centre. This
provides a clear net increase in trust in doctors and one's medical health centre (+38.5%) as a
result of record access. See table 35 below for a breakdown of responses.

Table 35: Effect of record access on trust in your doctors or health centres.

Tuble 33. Effect of feedla decess on trast in your decess of hearth centres.				
	patient number	percentage		
increased trust	5	38.5%		
made no difference	8	61.5%		
reduced trust	0	0.0%		

Section 4: Interviews with some eligible health centres which are not using record access

The following issues were raised by managers and clinicians of health centres that had agreed to participate in the EMIS/PAERS record access pilot, but then did not proceed.

1. Reasons why health centres had signed up to the initial pilot and then did not proceed.

i. Perceived workload involved and lack of time/operational pressures/staff
 A number of health centres cited the fact that they had not had the time to take forward patient record access. The main barrier was the expected time required to set up and run the system.
 This dovetailed with current operational challenges, including staff shortages, to inhibit adoption.

Several health centres specifically expressed concern about the prohibitive nature of the time needed to go through individual patient's summary medical records to ensure they are, in the words of one clinician, "in a good state" and the time then required to maintain them.

ii. Lack of internal priorisation and/or disinterest

Some health centres stated that they simply hadn't "got around to providing it [record access]" or were "yet to press the button." These centres had a desire to initiate the process soon, although it was clear that it was not a key internal priority. The centres appeared to be at different stages of interest, with one having planned but not yet taken forward a plan to use some patients as "guinea pigs" before initiating the process, and others not knowing much about record access or what was involved. One health centre was against the provision of record access, and had simply been "putting it off for as long as possible."

Overall, most health centres were aware of the merits of record access, and open minded about it, but it had not been given sufficient priority. As a result, nothing had been taken forward.

- iii. Lack of internal agreement or information only vested in one individual
 In one health centre only one clinician was championing the provision of record access, with a
 few patients recruited directly by that clinician. It was therefore not a health centre-wide
 initiative. In two health centres the managers were keen for this service to be provided, but not
 all the clinicians agreed.
- iv. Lack of clarity about system, operating process and benefits

 Concerns were raised regarding a lack of clarity about what type of information the patient would see, and how the system would align with current working procedures. Some health centres stated that they were not clear about the set-up procedures and/or didn't fully understand the operating processes. One centre suggested that implementation may have been facilitated by circulating information about this system and about the benefits of record access within their centre. This centre felt that "we were left without support to just get on with it."
- v. Requested but not received information

Two health centres stated that they had expressed an interest in providing record access but had not received any details. As such, this service had not been taken any further forward. Another centre said they could not recall receiving any information.

vi. Unclear or hasn't been discussed

One health centre was unsure why record access had not been taken further. Another centre said that the topic of record access simply had not been discussed internally.

vii. Lack of patient demand

One health centre had previously advertised the availability record access, but no patients had requested to use the service. As a result, they stopped advertising although online record access remained available to patients, in principle. Another centre referred to the lack of demand, stating that "if more patients came forward, we would provide the facility."

viii. Security concerns

One health centre stated that it did not have full confidence in the security of the online record access system, and as such had chosen not to enable it. This centre believed more needed to be done to prevent unauthorised access to patient records. The centre was happy to provide patients with a copy of their record, if requested, but did not want to initiate electronic access.

It is important to note that all but one of these health centres did provide the facility for patients to book appointments and order repeat prescriptions online. These online services had not, however, been extended to record access.

2. Concerns about litigation and the Data Protection Act

Concerns about litigation did not appear to be a key reason why health centres had chosen not to participate in the pilot. Several centres believed that the issue had already addressed. ["This has all been covered." "EMIS had addressed this issue already."] The main reason why these health centres had no concerns about litigation and the UK Data Protection Act was the confidence they had in their data. Heath centres stated that they had "doubled checked our data", "don't put anything inappropriate in our patient records," and that their clinicians were "professional in their approach to the content of patients' records."

A further reason for the lack of concern regarding litigation appeared to be that health centres had identified processes to address this issue. As one centre manager stated, "If we did provide this service, and a patient requested record access, the file of that patient would go to a clinician to be checked. If the clinician was happy with the record access content, and believed the patient to be suitable, then we would grant the patient access. If there were concerns about this, then record access would not be granted."

However, several health centres did point to their concerns regarding the implications of providing record access within the context of the UK Data Protection Act, and that they may be in violation of this Act should patients be able to see things in their record which the Act prohibited; for example, the identity of the provider of third party information who may wish to remain anonymous. One health centre manager stated that his centre "was trying to get advice on this matter, but nobody was prepared to offer any clear guidance on how this matter should be managed."

3. Concerns about confidentiality of records

One health centre manager raised the issue of confidentiality among young people, particularly under 16s, and whether confidential information could be withheld from parents' access. This centre manager suggested that passwords could be given to under 16s, but then wondered whether this would raise issues of consent.

Another health centre also raised broader concerns around confidentiality, including how couples or families could be prevented from seeing each others' records should one contain sensitive health information they did not wish to share. Another centre expressed concerns about "patients sometimes sharing their access with partners, which they shouldn't do."

4. Concerns about content of patient records

Health centres expressed being unclear with regard to what information patients would and would not see on their record if they provided this service, and how this information will be integrated into the record. One health centre manager said she "needed to see the system from the users' point of view."

Concerns were also raised about the current content of medical records, the time required to check the content of these records, and that all clinicians in the practice would be required to do so. One clinician said that he had checked the records of his patients for accuracy, but "other clinicians in his practice [health centre] hadn't done so, so a lot of work would need to be done at once." Further concern was expressed about a perceived inability to block patients from viewing certain information on their records, and that patients would be able to see certain results on screen during consultations. No health centre expressed concerns about the possibility of scurrilous content in patient medical records, only that the records would need to be checked for accuracy to remove any mistakes, etc.

One health centre raised concerns regarding the potential for patients to view updates to their records or view information regarding their health before a clinician may have had the opportunity to see this, for example letters or results from hospital examinations. The centre expressed concern about the inability to block this recent information before a medical professional had seen it.

Other health centres were not concerned about the content of patient records. One health centre manager stated that "if there are mistakes [in the records], it is good that patients can find them" and that it will "help patients better understand medical lingo."

5. Concerns about effects on patients

A number of health centres stated that record access could lead to unnecessary concerns among patients, which could give rise to harm and distress; for example, patients uncertainty with medical terms could cause them to misunderstand something, leading to worry and distress. As one health centre put it, "there will always be types of patients where it would be destructive for them to have access to their records."

These concerns reflected another view from a health centre manager that "too much information isn't always a good thing." This person believed that it was not good practice for any patient to be given access to their record, where they may view data without it being explained properly by a clinician.

6. Concerns about changes to working practices

The health centres did not express a specific concern about the effects of any changes to working practice as a result of record access. No health centre appeared to believe that there would be a significant alteration to the way the health centre currently did its business should it adopt record access; there was no concern for example regarding clinicians having to adopt very different writing styles to complete patient records.

7. Concerns that patients will take more time

Concerns regarding the perceived extra time that patients would take related to 1) receptionists and 2) clinicians. Both of these issues are explored further below.

Receptionists

Some health centres expressed concerns about the number of queries from patients increasing at reception (in person or over the phone) as a result of record access. One centre said that they "needed to be prepared for this." It was perceived that these queries would be on issues both regarding the running of the online record access system, such as password queries, and concerns about content or related health issues. A number of health centres further stated that patients would desire to discuss not only the current content of their medical records, but may also wish to negotiate on future content.

However, many health centres were not concerned about patients taking more time at reception. Indeed some health centres felt it may save time, for example there was "no longer a need for parents calling up to know whether or not their child had had a tetanus injection."

Consultations

One health centre manager believed there would be an increase in medically irrelevant questions due to misunderstanding of the information contained in the records by patients. Making reference to prior experience when patients had requested a copy of their medical record, this person believed that patients may "think they know better than doctors" and could question why it is necessary for specific information to be included in their record or ask questions as a result of misunderstanding the information.

One clinician raised concern regarding the perception that the additional queries would be on clinical matters, so therefore could not be delegated to others (such as receptionists). As a result, there may be demand for more frequent appointments with clinicians. This clinician highlighted mental health issues as an area where further discussion between the clinician and the patient may be needed, the outcomes of which may not be helpful for the clinician or the patient.

Other health centres were not concerned about effects on consultations, such as patients taking longer/needing more time. They felt that record access had the potential to improve consultations.

8. General feeling about records access?

Many health centres said that they were not against record access in principle, but were unlikely to take it up for the reasons outlined above; for example the practicalities of the workload involved, particularly at the outset, and concerns about how patients interpret data. Indeed, one centre whose key concern was the workload, nevertheless recognized the benefits of greater sharing between the centre and patients, and that patients were requesting online record access.

In some centres there was a general feeling of disinterest towards record access as a result of other priorities or because some clinicians' views against it were "unlikely to change." In other health centres, the aforementioned lack of understanding regarding record access, or in some cases misinformation about this service, had led to a lack of interest.

Several health centres remained interested in, and positive about, record access. They noted that record access could be "very useful" and "good for strategic reasons." Comments included "giving patients more information is a good thing", it "helps to build trust in the health care system," that they would "rather have informed and empowered patients." Other health centres stated that they believed in the "spirit of openness" and that "patients should take responsibility for their own health care and education."

It is interesting to note also that a number of health centres viewed record access as a future inevitability due to it becoming a requirement on centres, and therefore something which they

would need to embrace eventually. As a consequence of this, there was an interest in preparedness, including better understanding of the system and the skills needed to support it.

9. Requested additional information and support to enable health centres to start providing record access

Several health centres were interested in receiving further information. One clinician specifically requested case study examples of what other centres have done, particularly information which could show how record access can be provided on a small scale, with small related overheads and workload

10. Follow-up and possibility of these health centres taking up records access Following discussions a number of health centres expressed an interest in initiating this system. These health centres were provided with further information.

Discussion

These results provide an overall strong case for the expansion and roll-out of electronic record access. This echoes a growing body of research highlighting the important role that information and communication technologies, particularly electronic health records, can play in improving the effectiveness of health care systems and supporting patient care (Institute of Medicine, 2001; Sheikh and Pagliari, 2011).

1. Clinician responses

The results of this study highlight that the majority of clinicians believe that electronic record access is well received by patients. This is corroborated by the results of the patient questionnaire. Indeed, those patients who liked record access were perceived by clinicians to desire more features within the system. This echoes findings from the US, where healthcare management organisations have been providing record access systems – often in more complex configurations – for some time (California Healthcare Foundation, 2010).

A key challenge in the success of record access will be the extent to which systems can be adopted by health centres with little or no impact on their current workload. The results – both in terms of integration of record access into existing workflow processes and the effect of record access on the frequency with which patients consult the health centre – would seem to strongly suggest that record access can be provided without creating a significant additional patient burden on the health centre. At the same time, challenges in relation to integration clearly exist (a matter to which this report returns below). These challenges may be partly addressed by health centres through greater use of record access systems (so that the practice becomes routinised).

These findings are supported by the results of the questions on the influence of record access on time required for consultations, and on the frequency of these consultations; in both cases, the majority of clinicians perceived there to be no effect as a result of record access. This is consistent with the theory that record access does not create a significant additional patient burden on the health centres; at worst it may be time neutral and at best may potentially confer efficiency benefits in terms of avoidance of unnecessary consultations and reduced consultation time. These results are consistent with observations elsewhere (Chen et al, 2009). However, without further research it is remains unclear whether there will be any measureable effects on cost-efficiencies in the long term.

The influence of record access on clinicians' working practices is also an important consideration. This study found that most clinicians had not changed the way they write patient records as a result of providing record access, potentially strengthening the view that adopting record access will not require significant changes to current practice. Verbal responses, however, highlight that some clinicians have changed their practices, and were clearer and more careful about what they write. This could potentially take away from the clinician's freedom to speculate about potential diagnoses or possible linkages with other aspects of the patient's health or social circumstances (which may cause upset to the patient when reading). At the same time, nevertheless, it has been argued that one of the benefits of record access is that it forces clinicians to think carefully about what they are writing in order to make sure it is reliable and avoids potentially pejorative statements. The need for training and guidance in this area is clearly essential.

Another important funding from this study is that clinicians perceive record access to have facilitated shared decision-making and improved mutual trust between the clinician and patient during consultations. Responses to both questions yielded similar results: more than half believing there to have been some improvement as a result of record access, with a smaller number perceiving this to be a significant improvement, and the majority of the remainder perceiving there to have been no effect. These results reflects benefits demonstrated in US studies on improved provider-patient relationships as a result of health records (Tang et al, 2006). These findings are reinforced by the results of the question which looks at the influence of record access on clinicians' confidence in communicating with patients, where 20% of clinicians felt more confident and none were less confident; this is consistent with other positive observations about clinician confidence and is important given that some may speculate that record access would undermine the confidence of clinicians.

These above points should, however, be mediated through the understanding that these clinicians may already have had positive relationships with their patients and the fact that clinicians are one of the most trusted people in society, and as such levels of trust and confidence are already high. Nevertheless, these results clearly point to further potential benefits of record access to improve the quality of doctor-patient interaction. In addition, they highlight the need for further research to understand the conditions within which record access has facilitated decision-making and trust.

While most clinicians had not seen any changes to the way patients managed their health as a result of record access, the fact that a quarter of respondents have seen an improvement in patient self-management of their health care should be a welcome development, and highlights the potential of greater expansion of record access. Verbal comments from clinicians highlighted that patients, particularly those with existing conditions, are more interested in, and look up, their own results – such as checking their own blood test results and reviewing consultations and discharge summaries - and that patients research more on the internet before coming to see a clinician.

On the question of whether health centres received documentation from EMIS on the record access system, only a third believed that they had done so. While a large number of clinicians could not recall whether they received this information, these results perhaps highlight the need for follow-up to be undertaken by EMIS to ensure that health centres receive such documentation. The results of the question on whether internal training and support on record access was provided by the health centre to colleagues indicates that this has also not been widespread amongst eligible health centres. This result is concerning, as it could lead to a situation where other colleagues are unaware that the system is being provided, and that the knowledge and information remains vested in one or a small group of individuals. Encouraging such training and support will be important for the future.

Comments from clinicians on technical or administrative challenges that made it difficult for health centres to operate record access highlighted the availability of time and resources as a key challenge for health centres, particularly in relation to concerns around access by patients to third party information and the need for financial incentives to support this work. This is an important point, given the fact that some practices are reviewing every patient record in advance. One other main concern was legal issues, particularly concerns regarding the legality of providing patients with unrestricted access to medical records and whether this contravenes the UK Data Protection Act. It is critical that this concern be addressed, so that health centres have confidence in the information which patients are able to view, and their ability to hide any irrelevant information from or about third parties. In addition, a number of technical challenges were identified, patients forgetting their log on details. Finally, health centres faced challenges in recruiting patients (a matter which is explored further below).

A number of useful suggestions were made by clinicians to address the above challenges, and make record access easier for health centre staff and patients to use. On technical challenges, for example, a function for patients to change their password online, and tagging the records of patients who have record access in the system (to make it easier for clinicians to identify these patients) could be useful improvements in the system. Clinicians also sought greater support informing patients about record access. With respect to legal issues, clinicians requested training on the requirements of the UK Data Protection Act (DPA) and advice on how to manage this process within the law. This latter issue highlights that the uncertainties around what is and isn't permitted under the DPA (i.e. the restrictions on what patients can see) is a barrier to roll-out of record access. Many record access systems contain safeguards to prevent breaches of the DPA, and are flexible so that practices can choose to use the system as they feel most comfortable. Nevertheless, these professional concerns mirror issues raised in other studies, and clearly merit the provision of further information and clarity on the DPA process (Wynia and Dunn, 2010).

Finally, it is noteworthy that almost three quarters of clinicians said they would be willing to recommend record access to a fellow health centre. This large proportion of clinicians displaying such faith in record access could be seen as a strong indication of its acceptability and perceived usefulness for clinicians and patients.

2. Health Centre Manager responses

The results of the Health Centre Manager survey highlight the importance that key colleagues, or record access champions within health centres, play in promoting and expanding record access. They also point to the influence of EMIS, and to a lesser but still important extent the PCT. With respect to how health centres first heard about record access, almost half of the practice managers sited that it was through a colleague. On the issue of how the health centre became involved in record access, again a key reason for centres adopting record access was due to a member of its staff finding out about the pilot study. These results reinforce the importance that individual and presumably interested members of staff play – in their own health centre and in making referrals to other health centres - in the expansion of record access. As such, working to develop and support a cadre of trained champions for record access could arguably be central to its expansion.

An important issue is how agreement on record access is reached within health centres and whether all clinicians were in support. On the former, these results clearly point to the important role that an interested clinician has in the decision making around record access, as well as the centrality of health centre meetings to decision-making. This provides further support to the need for investing resources in identifying and supporting these interested clinicians, or record access champions, and providing information which can be circulated to colleagues within health centre meetings. On the latter issue, the survey results found that a clear majority of respondents stated that all clinicians in their health centre supported the provision of record access. Where agreement was not reached by all clinicians, the verbal responses point to concerns regarding the UK DPA, and in particular the vetting of third party information on medical records as the key constraint. These results would appear to show that all clinician support is a key factor in whether health centres adopt record access. Actions to promote record access should be cognisant of this, and seek to reach out to all clinicians in health centres and provide advice on legal issues, such as operating within the DPA, as noted above.

Health centre meetings were also the most common forum for health centres to introduce colleagues to the record access system. A number of health centres were found to use other methods, such as circulating standard instructions to colleagues, and providing training. Where

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possible, it will be important to learn the lessons from these health centres, so that the widest possible number of staff are aware of this system and its utility to the health centre and patients.

A strong predisposing factor in health centres' adoption of record access was found to be whether they offered other online services to patients prior to providing record access. The majority of practices surveyed were found to offer some form of online service prior to adoption, particularly the possibility to book appointments and order repeat prescriptions online. Although one cannot discount the fact that such health centres may have been more likely to complete the questionnaire, the result highlights the importance of promoting online access together with a range of online services which practices can provide.

Developing a better understanding of methods used by health centres to recruit patients, and ease of recruitment will be central to broadening record access provision within health centres. The results of this survey highlight that most health centres recruit patients through waiting room leaflets or posters, and opportunistic recruitment during consultations. Other methods, though much less common, were used, including a mail or email-shot to their patient list, and through the health centre website, newsletter, and patient forum. These results arguably point to the need for sufficient materials to be developed and shared with health centres for display in the waiting rooms. It may also be important to learn the lessons of other health centres using a variety of recruitment methods and share this with other interested health centres, perhaps in the form of case studies. Further research would also be useful to highlight which particular methods were most effective, a question that this study was unable to address.

On the question of how easy it was for health centres to recruit patients, the results found that a clear majority of health centre managers believed it to be easy or very easy. This is an important finding, and should be built upon, highlighting that the recruitment of patients to record access can be a relatively straightforward process for health centres. Verbal responses from practice managers showed, however, that patient recruitment was not without its challenges, including patient concerns (that outside agencies could access their medical history), lack of interest, lack of understanding about the benefit to them of using their record to monitor /self care and the time required to explain the system to patients. These challenges may also explain the wide range of approximate number of patients which health centres recruited each week, the most common numbers for which were between 0 to 4 or 10-15 patients per week. However, this wide range arguably also highlights that the record access system is flexible, and that practices are making it fit to their individual needs. In order to be better prepared to respond to the above recruitment challenges, health centre managers requested more publicity and standard information for patients, as well as financial incentives. This additional information for patients, perhaps through a separate handout, should address what is expected of them, clarify concerns regarding access to third party information, provide technical trouble shooting and highlight the benefits of record access.

Once patients were recruited, health centres appeared to use a wide range of registration and consent processes. Although these methods are all familiar, particularly completing a consent/registration form, it may be useful for existing examples to be collated, and to refine and further disseminate specific EMIS forms and processes to increase standardisation across the board. On registration, the overwhelming majority of health centres also provided patients with induction packs; a practice which should continue to be supported. Health centres faced a number of registration challenges, including the time required for registering patients and reviewing patient notes (to alert clinicians that patient has record access), and technical errors. To address these challenges, health centre managers suggested better quality information, putting the whole registration process on line, and developing a universal registration policy. Providing

support in these areas, particularly continually updating the quality of information for staff and patients, and to address other challenges, will be important for the future expansion of record access.

A further important issue central to the success of record access is the ease with which health centres can manage this system. The perception of the overwhelming majority of health centre managers was that it had been easy to manage record access within their centre. Only two health centre managers (14.3%) said it was difficult to manage. This mirrors the findings in the clinician questionnaire; that the adoption of record access can be done by health centres with minimum impact on current workload. This finding mirrors increasing evidence that such systems can be cost- or time-neutral for providers (Sheikh and Pagliari, 2011). Verbal responses did, however, highlight that some heath centres faced a number of specific challenges/barriers to operating record access, including availability of staff time and resources, particularly in relation to concerns around access by patients to third party information, as well as system challenges, including user (patient) errors and machine problems/maintenance. Some specific recommendations for addressing these were provided, including faster maintenance (when kiosk not working), and patients being able to reset their password.

The response of health centre managers to the question of whether they received a guidance document from EMIS mirrored the responses from clinicians; only one-third definitely believed that they received this, while the remaining two-thirds were of the opinion that they did not or could not remember. On the question of whether health centres had received training and support, health centre managers reported a more positive result than clinicians, with most stating that this was provided to their centre by EMIS. While it is unlikely that practices could have initiated record access without reading some form of documentation, these results point to importance of systematic process to ensure that health centres not only receive this guidance and initial set-up training, but are aware of where to turn for ongoing support; this is particularly important given some of the operational challenges previously identified by health centre managers. It is noteworthy that one of the suggestions provided for improving the guidance was to simplify the documents and provide a step-by-step process for setting up and operating record access.

Although just over half of the health centre managers felt that further training or support would not have been useful – reflecting a somewhat similar response from the clinicians – the fact that over a third felt this was useful, coupled with the unevenness of support provided (as discussed above), strengthens the call for the provision of additional support and information from EMIS. Similar themes re-emerge in the main areas in which support was requested by health centre managers, particularly on a general introduction on the importance of record access to all staff, and addressing concerns regarding patient access to third party information.

The results from the responses from receptionists also provide some very useful insights into the successful integration of record access into existing health centres processes. Firstly, on the question of whether receptionists found recruiting patients to record access a significant challenge, the fact that half of those surveyed stated that this was not the case (with only two, 14.3%, stating that it was) may provide further evidence that adoption of a record access system should not necessarily pose significant administrative and procedural burdens on health centres. Verbal responses from those receptionists that did face significant challenges again pointed mainly to time constraints and the importance of specific and more detailed information to be provided for distribution to patients. Three receptionists also stated that only clinicians had recruited patients to record access, and that the reception staff had not been directly involved. This lack of involvement may be as a result of the clinician targeting a specific group of patients (e.g. with high BMI) as a pilot study for record access. A specific question about recruitment was not asked

in the questionnaire to clinicians, and it may be an interesting area for further analysis. Moving forward, to ensure the successful and broader use of record access, it will be essential that all health centre colleagues, particularly receptionists, are engaged in the process and up to speed.

The responses from the receptionists on whether they think that record access influenced requests received at reception also provide for interesting reading. In all three areas of analysis – patient clarification over tests, drugs, appointment times; clinician consultation requests by patients; and prescription re-ordering by patients – the majority of health centres did not experience any changes to the frequency of patient requests at reception after providing record access. For clarification over tests, drugs, appointment times, and on clinician consultation requests, there was a small net reduction in frequency as a result of record access. While it is clearly challenging for health centres to measure these changes, and one cannot discount the fact that these changes may be as a result of other factors than record access alone, these results do provide further evidence that the adoption of record access can have a neutral effect on, or in some cases reduce, the time needed by reception staff to deal with requests.

3. Patient responses

Overall, the results from patients were very positive regarding the perceived usefulness and benefits of record access. This is consistent with other research reporting favourable user responses, and positive impact on knowledge and trust, thus strengthening the argument for a broader roll-out of patient record access (Fisher et al, 2007; Fisher et al 2009; Bhavnani et al, 2011; Ralston et al, 2007).

In our sample a large proportion (76.9%) reported a long term condition requiring regular monitoring and medication. This may point to the fact that patients with such conditions are in need of a tool to regularly monitor their condition, and thus more likely to use record access. It could therefore be inferred from the overall positive response that patients with long term conditions are likely to find record access a very useful tool.

The overall majority of patients (92.3%) either found it very easy or quite easy to set up record access at home, which would seem to suggest that this system can be adopted by others in quite a straightforward manner. Our sample also found that a large proportion of patients had received some form of guidance regarding record access beforehand, which is clearly a positive thing. At the same time, however, around a quarter of patients were found not to have received any information, and not a single patient reported being shown how to use the system. This latter results should surely call for improvement and better standardization of information to patients from the outset; such improvement could potentially not only increase frequency of utilization of the system by those signing up for record access, but also encourage others to do so.

Ensuring that patients are comfortable with consent processes and with having a record access account, and also that they are at ease with the use of the record access system, is key to the scale-up of this service. In our sample, 100% of patients were comfortable with the way their consent was requested, and 92.3% (all but one patient) did not have any concerns about creating a record access account. All patients found the record access system either 'very easy' or 'quite easy' to use. These results, which mirror other study data (reference), could point to the fact that patients are embracing record access with far fewer concerns or anxieties than might have been expected. As a result, the case is strengthened for attempts to increase the number of patients using this facility.

On the question of length of time patients had had online record access, and their regularity of use, the results pointed to the usefulness of record access. Most patients had been using record access

for 10-12 months, or more than a year, highlighting the ongoing utility of the facility. The majority of patients (84.6%) had accessed their medical records online at least 6 or more times since setting up the system. Of this number, 53.8% accessed their records between 6-10 times, and 30.8% more than 10 times. When asked whether they had used the system in the last two weeks, most patients (84.6%) had done so at least one or more times. These results show that patients are not only using the system, but accessing it on a regular basis, arguably highlighting the fact that they find the record access system useful.

The study found that patients were using record access for a range of needs, the most common of which is looking up their results (84.6% of respondents), checking their condition (53.8% of respondents), looking at clinician letters (53.8% of respondents), and to support hospital outpatient consultations (53.8%), including viewing the record beforehand to remind the patient of relevant information and sharing the record with health professionals in the hospital. Record access is therefore being actively used by, and is a useful tool for, patients to support their health care, and may be further activating patients in this regard. The system may also be acting as a glue, that supports health centres and hospitals alike.

Overall, our sample indicated that all patients found record access either 'somewhat useful' (38.5%) or 'very useful' (61.5%). This result reinforces previous responses regarding patients' frequency of use. Our study also found a net reduction (- 38.5%) in patient anxiety as a result of using record access. In addition, all but one patient (92.3%) reported that the system had improved their knowledge of their medical condition 'a lot' or 'a little,' with no patient reporting that record access had confused their existing knowledge. Over three quarters of patients (76.9%) also states that record access had helped them to better manage their own health care. Moreover, 77% of patients stated that record access had improved their understanding either greatly or a little regarding how their condition is being managed by health professionals. These results further highlight the benefits which patients perceive through having record access, and the potential for this system to inform and empower patients.

Finally, there was an overall net increase (+38.5%) in patient satisfaction with their health centre as a result of record access. The same increase was found in patient confidence in sharing information or decisions during consultations with health professionals, and in patient trust in their doctors and medical health centre, following the use of this system. These results closely mirror the responses from clinicians. It has been shown that record access does not negatively affect confidence or trust; on the contrary there is evidence of confidence building as a result of it. Engendering patient confidence and trust, and empowering patients to support their own health care, is central to creating a more patient focused health system, and clearly record access can be an important tool in supporting this process.

4. Responses from eligible health centres which are not using record access

The responses from health centre managers and clinicians from health centres who had agreed to participate in the EMIS/PAERS record access pilot, but then did not proceed, mirror many of the findings above and provide some useful lessons learned.

On the question of specifically why certain health centre signed up initially to the pilot, then failed to proceed, clear similarities emerge between their responses and the concerns expressed by those health centres providing record access, namely: the time and workload required to set up the service, including reviewing the content of individual (and potentially all) patient medical records for accuracy in advance, and implementation of the service and the lack of staff to support said workload; a lack of clarity about the system and how it operates, particularly regarding the information which would be viewed by patients at home and during consultations, and whether

patients could be blocked from viewing certain information or updates on their records before a clinician had reviewed it, all of which could lead to misunderstanding or concern; a lack of support and information, particularly on the benefits of record access; lack of patient demand; the potential for unnecessary patient harm or distress, for example patient uncertainty with medical terms causing misunderstanding and worry; and the importance of internal agreement, and that the process is not only vested in one individual within the health centre. These points reinforced the need for greater training, information and support to be provided to health centres, as well as the need to 'sell' record access to patients and potentially improve recruitment techniques. The necessity for all-round clinician support is reinforced by the example of two health centres in which the centre manager was keen for this service to be provided, but not all the clinicians agreed.

A further noteworthy similarity across the responses of those professionals within health centres that are providing record access concerned the question of the potential for record access to give rise to changes in working practices and increase the time taken by patients. As with the responses from the health centre managers, there was no overriding perception that health centres would have to significantly alter the way they did business should they adopt record access. On the question of perceived extra time that patients would take, there was a mixed response, mirroring the responses of clinicians and health centre mangers. On the one hand, some health centres perceived there would be an increase in patient queries at reception, as well as an increase in demand for more frequent consultations with clinicians as a result of patient's misunderstanding of the information contained in their records; on the other hand, other health centres felt that record access may have no effect on patient queries at reception, or may even save time, and that this service had the potential to improve consultations.

The results from these health centres on whether there were concerns about litigation and the UK Data Protection Act were interestingly mixed. Among some respondents this concern was not a key reason for their not choosing to participate in the pilot, while among others there was a belief that the health centre would be in danger of being in violation of the Data Protection Act. With regard to those who did not express concern, it is interesting to note that most of these health centres had confidence in the contents of their records; this reinforces the importance of health centres receiving advice on this matter.

Further findings which arguably warrant close attention were the concerns of one health centre on the access security of the online record access system, and whether other unauthorised individuals could access patients records. In addition, concerns were expressed regarding confidentiality, including whether confidential information about young people could be withheld from parents' access and how couples or families could be prevented from seeing each others' records should the contents include sensitive health information they did not wish to divulge. Note should also be taken of the fact that two health centres stated that they had expressed an interest in providing record access but had not received any details. Addressing such above concerns, and ensuring thorough follow-up processes, will be key to the future expansion of record access.

In conclusion, these results also point to the untapped potential to increase the provision of record access. While the concerns and lack of prioritisation among these health centres meant they were reluctant to take up the service, they were nevertheless not against it in principle and could recognise its merits and the potential benefits it could confer. Strategies may be needed to build on this broader base of acceptance by means of educating and incentivising health centres, highlighting the benefits of record access, and encouraging them to initiate the process.

This study has a number of limitations. All health centres contacted as part of this research had, at one time, expressed an interest in record access either institutionally or through one interested staff member. While many of these health centres were not providing this service, the study sample may overall have been more positive towards record access. In addition, those health centres where clinicians and practice managers were more supportive of record access may have been more likely to complete and return the questionnaire. There were also too few patients using the record access systems for firm conclusions to be drawn. Also worth noting is the fact that health centres experience a high degree of turnover; a number of health professionals who initiated the record access system within their health centre subsequently moved on. This may have led to loss of institutional memory, which may in turn have biased any given health centre's responses to the questionnaires. Finally, given the relative newness of record access, while the questions in this study specifically asked respondents about their actual experiences of the system, there is a possibility that some responses may have been influenced to a lesser or greater extent by ideas or theories rather than practical experience.

Recommendations

A number of recommendations flow from this report which have practical, policy and research implications.

Practical/health centres

- i. Information
- Refine record access guidance documents for health centres to include the following:
 - Case studies highlighting how health centres can integrate record access within their ongoing work, in particular to ensure that the system does not create a significant additional work burden on the health centres. These case studies should also include feedback from other health centres on their views on, and experiences of, record access.
 - o A step-by-step "idiots guide" for setting up and operating record access.
 - o Templates for patient registration and consent processes
 - o Overview of the benefits of record access, including potential efficiency benefits
- Guidance documents for clinicians and health centre managers should be more rigorously disseminated to health centres, with follow-up to ensure that these documents were received and passed on to the appropriate persons.
- Create a website for patients and health centres to download the above documentation and other documentation on record access
- Develop an online or CD course with a demonstration on how the user will see the record access system
- Develop a standard presentation on record access to make to GP registrars at their training day. Presentation to local health mgrs (PCT/Council)
- Disseminate information and guidance to health centres on record access and the UK Data Protection Act. This should clarify issues regarding the legality of the system, access to third party information, and steps to managing record access within the Act
- Develop publicity materials and standard information for patients regarding record access, to
 be disseminated by health centres. This would include what is expected of patients, clarify
 concerns regarding access to third party information, highlight how to use the system, provide
 technical trouble shooting and highlight the benefits of record access.
- Seek to collate examples of good practice and materials from across practices, including on areas such as patient registration and consent

ii. Other/ongoing

- Provide training to health centres on record access. This should include initial training on
 system set-up, including whether changes will be required to health practice working methods,
 good practice regarding record data on patient records, the requirements of the UK Data
 Protection Act and security issues. This training should also highlight the need for both the
 Practice Manager and clinicians, in particular, to be involved in the implementation of record
 access provision.
- Provide ongoing onsite and offsite support for clinicians and health centre managers.
- Encourage health centres providing record access to run training events for all staff on this facility, ensuring that the knowledge and information about record access is embedded through the health facility, including beyond any one interested clinician
- Examine options for financial incentives to support this work.

- Identify and encourage record access champions within practices, such as interested clinicians, to provide more details to their colleagues. This could include providing information which they can circulate to colleagues within health centre meetings.
- Create a network of record access champions that can support other health centres, including attaching these champions to neighbouring health centres interested in providing record access.
- Maintain an up-to-date database of practices providing record access including the key individuals responsible
- Provide practices with regular updates on record access, including those that are interested but have yet to sign-up for the system.
- Adopting a universal registration policy for all practices using record access

Technical

- Create a function online for patients to change, request new, or re-set their password, removing the need for recourse to the health centre
- Enable tagging of the records of patients, or an alert, within the system who have/are using online record access (to make it easier for clinicians to identify these patients)
- Improve maintenance of kiosks in health practices, and linking the system to the health centre domain server (to facilitate printing patient letters)
- Enable practices to run the patient registration and consent process on line
- Create a function for health centres to view the total number of patients that have signed up for record access
- Undertake an analysis of the security of the record access system. This could perhaps examine whether there is a need for an additional electronic key to add extra security
- Improvements in the inputting of information received from hospitals.
- Develop/provide a system for health centres to vet all requests for access to patient records to check if it contains third party information.

Policy

- Support the greater expansion of patient record access.. This should include ongoing promotion for health centres to provide patients with a broad range of online services
- Provide guidance to clarify issues regarding the provision of online record access within the context of the UK Data Protection Act, including access by patients to third party information
- Examine policy options for financial incentives to support this work.
- Develop a detailed monitoring system across the UK of current practices using record access and numbers of patients recruited

Further research

- Cost-effectiveness of record access, including whether there are longer-term cost savings and efficiencies to be gained through an effective roll-out of record access
- Understanding the conditions within which record access has facilitated decision-making and trust among patients and health professionals
- Gathering existing good practice and learning the lessons from successful practices, including
 mechanisms for introducing colleagues to the record access system, registration, consent and
 recruitment processes
- Examining the variety of recruitment methods being used by health centres and their corresponding effectiveness, to learn lessons and share this with other interested health centres.

Understanding how patients are using record access to support their own health care, such as
checking their condition, supporting outpatient consultations, and how this could be better
understood and expanded.

Please note that some of these recommendations are more relevant to EMIS/PAERS (the service provider of the record access system), and may therefore have less relevance generically.

Conclusion

This study has found that there is strong support overall amongst clinicians, practice managers and patients for online record access. All three groups have articulated clear benefits which they believe this service brings to the working practice of health centres, to the health and empowerment of patients, and to the working relationship between patients and the health system. In view of the fact that the empowerment of patients to take responsibility for their own health care is central to the creation of a more patient focused health system, it can be concluded from the stated benefits that record access is an important tool in supporting this process. At the same time cognisance must be taken of the fact that the study has highlighted a number of concerns regarding the roll out of record access, as well as areas where the current record access system leaves room for improvement.

These findings provide a clear road map for the successful expansion and roll-out of electronic record access. All health centres – those not providing record access, those interested, and those providing this service – as well as policy makers, researchers and patients, are encouraged to review and take forward the recommendations.

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Declaration of interest: BF leads the UK Record Access Collaborative and is co-director of PAERS Ltd which wrote the software that enables EMIS practices to offer online record access. He did not participate in the survey, interviews or data analysis in order to avoid influencing the results. The project was unfunded.

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Appendixes

Appendix 1: Copy of questionnaire on clinicans' experience

Part 1. This asks about how record access has affected your GP practice

1.1. In general, the practice's ability to offer electronic record access has been well received by patients

Disagree strongly	Disagree	No difference in patient	Agree	Agree Strongly
		perceptions		

If you have any other comments please write them below:

[Text box]

1.2. Record access has been integrated easily into workflow processes

Disagree strongly	Disagree	No difference	Agree	Agree Strongly

If you have any other comments please write them below:

[Text box]

1.3. Has record access influenced the frequency with which patients contact the practice for information or clarification (e.g. about medicines)?

Much more frequent	More frequent	The same	Less frequent	Much less frequent

If you have any other comments please write them below:

[Text box]

Part 2. This section asks about the effect of record access on your own ways of working

2.1. Have you changed the way that you write records since the practice has started Record Access?

YES	NO

If yes, please explain what you have changed (e.g. using different language to describe patients or avoiding certain technical terms) [Text box]

2.2. How has your confidence in communicating with patients been influenced by having record access?

	Much more confident	A bit more confident	No different	A bit less confident	Much less confident
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Please use the box below for any further comments:

[Text box]

Part 3. This section asks about the effect of record access on consultations

 ${\it 3.1. Has\ record\ access\ influenced\ the\ \it time\ required\ for\ consultations?}$

Much longer	A bit longer	No different	A bit shorter	Much shorter

If you have any other comments please write them below:

[Text box]

3.2. Has record access influenced the **frequency** with which patients consult?

Much more frequent	More frequent	The same	Less frequent	Much less frequent

If you have any other comments please write them below:

[Text box]

3.3. To what extent has record access facilitated information exchange during consultations?

Not at all	To some extent	Very much so

 $3.4.\ To\ what\ extent\ has\ record\ access\ facilitated\ shared\ decision\ making\ during\ consultations?$

Not at all			
	To some extent	Very much so	
3.5. To what extent l	as record access improved	mutual trust during consultations	9
Not at all	To some extent	Very much so	
If you have further c [Text box]	omments on any of the abov	ve please write them below:	
3.6. Have you notice self-care)?	d any changes in the way po	ntients manage their health as a re	sult of record access (e.g. medication adherenc
YES	NO		
If the answer was ye [Text box]	s, please explain the change	s in the box below:	
Part 4. This asks al	oout the support your prac	tice received on record access	
4.1. Did you receive included standard fo		t set out solutions to both potentia	l clinical and administrative issues, and also
YES	NO	Don't remember	
42 If was the quide	nce documentation which w	as provided for you was:	
4.2. If yes, the guida	nce documentation which w	us provided for you was.	
Very useful	Moderately useful	Not useful	Did not receive any documentation
[Text box] 4.3. Was training an	d support provided to practi	ice colleagues?	
YES	NO		
If yes, please give m	ore details:		
[Text box]			
	een useful for your practice	to have received any further supp	ort, information or training on record access?
	een useful for your practice	to have received any further supp	ort, information or training on record access?
4.4. Would it have b			ort, information or training on record access?
4.4. Would it have b YES If you answered yes. [Text box]	NO please use the box to provide		
4.4. Would it have b YES If you answered yes. [Text box] Part 5. This asks al	NO please use the box to provide bout any specific barriers of	de more details: or challenges operating record a	
4.4. Would it have b YES If you answered yes [Text box] Part 5. This asks al 5.1. Have there been your practice? [Text box]	NO please use the box to provide pout any specific barriers of any specific technical or act	de more details: or challenges operating record a	ccess and further suggestions we made it difficult to operate record access wit
4.4. Would it have b YES If you answered yes [Text box] Part 5. This asks al 5.1. Have there been your practice? [Text box]	NO please use the box to provide pout any specific barriers of any specific technical or act	de more details: or challenges operating record a dministrative challenges which ha	ccess and further suggestions we made it difficult to operate record access wit
4.4. Would it have b YES If you answered yes. [Text box] Part 5. This asks al 5.1. Have there been your practice? [Text box] 5.2. Have your pater	NO please use the box to provide the providence of the providence	de more details: or challenges operating record a dministrative challenges which ha	ccess and further suggestions we made it difficult to operate record access wit
4.4. Would it have b YES If you answered yes. [Text box] Part 5. This asks al 5.1. Have there been your practice? [Text box] 5.2. Have your patent YES If YES, please give (Text box]	NO please use the box to provide the providence of the providence	de more details: or challenges operating record a dministrative challenges which ha about the record access service to	ccess and further suggestions we made it difficult to operate record access wit
4.4. Would it have b YES If you answered yes. [Text box] Part 5. This asks al 5.1. Have there been your practice? [Text box] 5.2. Have your pater YES If YES, please give of [Text box] 5.3. Please use the b patients to use. [Text box]	NO please use the box to provide the providence of the providence	de more details: or challenges operating record a dministrative challenges which ha about the record access service to	ccess and further suggestions ve made it difficult to operate record access wit you?
4.4. Would it have b YES If you answered yes. [Text box] Part 5. This asks al 5.1. Have there been your practice? [Text box] 5.2. Have your pater YES If YES, please give of [Text box] 5.3. Please use the b patients to use. [Text box]	NO please use the box to provide the providence of the providence	de more details: or challenges operating record a dministrative challenges which ha about the record access service to	ccess and further suggestions ve made it difficult to operate record access wit you?

Part 1. This asks about how your practice came to be involved

	ı personally first		ving patients online ac	cess to their GP records?	
GP press		Colleague		Other (please specify below):	
1.2 Before you dec		Record Access system, wh	at other online service	s, if any, did your practice offer to	patients? (please
☐ Appointment bo☐ Prescription rec		☐ Other, plea	ase specify:		
1.3 How did your	practice hecome	involved in record acces	· c 2		
Responded to a ma		Colleague heard ab		Other (please specify below):	
	ement reached w	rithin the practice to offer	r record access?		
Practice meeting		Persuasion by inter	rested GP	Other (please specify below):	
1.5. Did all clinicit YES	ans within the pro	actice support the provisi	ion of record access?		
If you answered no [Text box]	o, please explain	why:			
	ıctice, how were o	colleagues introduced to	the system itself?		
Practice meeting		Standard instruction	ons circulated	Other (please specify below):	
Part 2. This asks	about your patie	ent recruitment and reg	istration processes		
2.1. How did your	practice go abou	at recruiting patients?			
Mailshot to practice list	Email to practice list	Waiting room leaflets or poster	Opportunistic recruitment during consultations	Selection based on patient profile (e.g. long-term condition)	Other (specify below
2.2. How easy was	it to recruit patie	ents?			
Very easy	E	Easy	Difficult	Very difficul	t
2.3. Are there any [Text box]	specific challeng	es you encountered when	a trying to recruit patie	nts?	
2.4. Approximately	y how many patie	nts does your practice re	ecruit per week?		
2.5. What types of [Text box]	support or guida	nce would have helped yo	our practice improve it	s recruitment processes?	
2.6. What patient r [Text box]	registration and c	consent processes did you	ı implement?		
2.7. Did you encou [Text box]	ınter any specific	difficulties with the regis	stration process?		
2.8. Were register	ed patients given	an induction pack or set	of guidance notes?		
YES			NO		
2.9. Do you have a [Text box]	iny comments on	ways to make the registro	ation process easier?		
Part 3. This asks	about how recor	rd access currently oper	rates in your practice		
3.1. How easy has	it been to manag	e Record Access within y	our practice?		
Easy to manage			Difficult to m	anage	

3.2. Have there been any s [Text box]	pecific challenges or barrie	ers which have made it dif	ficult to operate record access within your practice?
3.3. Please use the box be patients to use. [Text box]	low to make any suggestion.	s about ways in which the	service could be made easier for practice staff or
2. Have patients expressed	l views about record access	to you?	
YES	NO	7	
Part 4. This asks about t	the support your practice	received on record acces	<u>s</u>
4.1. Did you receive a doc included standard forms fo		ut solutions to both poten	tial clinical and administrative issues, and also
YES		NO	
4.2. If yes, the guidance do	ocumentation which was pro	ovided for you_was:	
Very useful	Moderately useful	Not useful	Did not receive any documentation
Do you have any suggestic [Text box]	ons on how the documentati	on could be improved?	
4.3. Was training and supp	port provided by EMIS to pr	actice colleagues?	
YES		NO	
If you answered yes, pleas [Text box]	e give more details:		
4.4. Would it have been us	eful for your practice to hav	ve received any further su	pport, information or training on record access?
YES		NO	
If you answered yes, pleas [Text box]	e use the box to provide mo	ore details:	
4.5. Please use this space [Text box]	to provide any other comme	ents you have on record ac	ccess:
Part 5. Questions in this	section are aimed at recep	tionists, who we would a	sk you to consult prior to completion
5.1 Did you find recruiti	ng patients a significant cha	allenge (if applicable):	
YES	NO		
If you answered yes, pleas [Text box]	e use the box below to expl	ain the reasons why:	
5.2. To what extent do you things:	think that Record Access h	as influenced the number	of requests received at reception for the following
a) Clarification over tests,	drugs or appointment times		
More frequent	Less freque	nt	No detectable difference
b) Requests for GP consul	tations or phone calls		
More frequent	Less freque	nt	No detectable difference
a) Decomintion and the			
c) Prescription reordering	Lace fragua	nt	No detectable difference

5.3. Please use the space below to suggest items of information that would have helped you discuss record access with patients: [Text box]

Part 1. About you. This will help give us a better idea of the types of patients for whom Record Access may be most helpful.

11	Your age	(nlease	circle'	١
1.1.	Tour age	Unicase	CITCIE	,

Under 20	21-30	31-40	41-50	51-60	61-70	71-80	80 +

1.2. Your sex

M	ale	Female

1.3. Your health

a) Do you have a long term condition that requires regular monitoring and medication? (For example, high blood pressure, asthma, diabetes, depression or thyroid disorder)

Yes	No

b) Have you been undergoing any specialist treatment which might raise your need for information? (For example, IVF, cancer therapy or surgery)

Yes	No

Part 2. This asks about your experiences setting up and using record access

2.1. <u>Setting up</u> the record access system at home was:

Very easy Quite easy	Quite difficult	Very difficult
----------------------	-----------------	----------------

2.2. What guidance did you receive beforehand?

A simple leaflet	A demonstration	A detailed information pack	I did not receive any
		containing instructions for using the	guidance
		system and information about	
		security, etc.	

What additional support or information would you have found useful? [Text box]

2.3. Are you comfortable with the way your <u>consent</u> was requested?

I	Yes	No

Please use the box below for any further comments: [Text box]

2.4. Did you have any concerns about creating a record access account?

Vec	No	

Please use the box below for any further comments: [Text box]

2.5. How <u>user-friendly</u> have you find the record access system to be?

Very easy to use	Quite easy to use	Quite difficult to use	Very difficult to use

If you have any specific comments on the system's usability, please write them below: [Text box]

2.6. Approximately how long have you had online access to your GP record?

Less than one	1-3 months	4-6 months	7-9 months	10-12 months	More than a year
month					-

2.7. Roughly how many times, overall, have you accessed your record since getting access?

Never	Once	2-5	6-10	11-15	16-20	More than 20

2.8. How many times you have accessed your record in the last two weeks?

Never	Once	2-5	6-10	11-15	16-20	More than 20
110101	Office	2 3	0 10	11 15	10 20	Triore didni 20

Part 3. This asks about how you actually use record access and for your suggestions on how the system could be improved

3.1. I use Record Access to (please tick as many as apply to you):

Look up results Prepare for a consultation See how my condition is going Look at letters Look at consultation notes Check what the doctor said

Please use the box below to describe any other things that you use record access for: [Text box]

3.2. If you have attended hospital outpatient consultations, has record access helped you in any of these ways? (Please tick all that apply to you)

Printing a copy of my records in case they are needed.	Viewing the record beforehand, to remind myself of relevant information	Sharing my record with health professionals using a computer in the hospital.	Other. Please specify below:
--	---	---	------------------------------

3.3. Have you shared your record with anyone else that you know? (Circle all that apply)

Family member	Spouse or partner	Friend	Other (e.g. work colleague)
---------------	-------------------	--------	-----------------------------

3.4. Where do you usually access your records?

At home	At work	In a health centre	In a public space, such as a
			library

3.5. Please use the box below to suggest any ways in which the record access system could be improved: [Text box]

Part 4. This section seeks your opinions about record access

4.1. How useful has record access been for you?

Not at all useful	Not very useful	Somewhat useful	Very useful

4.2. How has record access affected your confidence about your health?

It has made me more anxious	It hasn't affected my	It has reduced my anxiety
	confidence	

4.3. Has record access influenced your knowledge about your health or medical conditions?

Improved my	Improved my knowledge a	Hasn't affected my	Confused me a little	Confused me a lot
knowledge a lot	little	knowledge		

4.4. Has record access influenced your <u>understanding</u> of the way in which your condition is being managed by GP staff and other health professionals?

Greatly improves my	Improves my understanding a	Does not affect my	Confuses my	Greatly confuses my
understanding	bit	understanding	understanding	understanding

 $4.5.\ Has\ record\ access\ helped\ you\ to\ manage\ your\ health\ better\ in\ any\ of\ the\ following\ ways?\ (Circle\ all\ that\ apply)$

Encouraged me to take my	Encouraged me to follow lifestyle	Generally I am more aware of	It has not affected the
medications, when I am	advice, such as eating healthily,	my health and how my	way I manage my
supposed to	exercising or quitting smoking.	behaviour is influencing it	health

4.6. Has your opinion of your GP practice changed since you received record access?

35 11 10 1				1
Much less satisfied	Slightly less satisfied now	No change	Slightly more satisfied	Very much more
	<i>5</i> ,	ε	8 3	antinfied
now				satisfied

4.7. Has record access affected your <u>confidence in sharing information or decisions</u> during consultations?

I now feel more confident about sharing	It has made no difference	I am now less confident about sharing information
information and decisions		or decisions with health professionals

 $4.8. \textit{Has record access affected the } \underline{\textit{trust}} \textit{ you have in your doctors or GP practice?}$

Increased my trust in my doctor/	Made no difference to the amount of trust	Reduced my trust in my doctor/practice
practice	I have	

Appendix 4: Questions asked to eligible health centres which are not using record access

We understand that you signed up for the EMIS/PAERS records access process (linked to EMIS Access) about 18m or more ago. Is that correct?

If they really cannot recall anything about this, there may not be any point in pursuing the conversation. If they do recollect that, continue:

It looks as though you signed up to the initial pilot and then did not proceed. Why was that?

Did you have concerns about litigation? If so, how might record access make that more likely?

Are you concerned that patients would see things in the record that the Data Protection Act says they should not see? For instance, the identity of the provider of the information who has given 3rd party information when they want to remain anonymous. Or that patients would see things that would lead to serious harm to them or someone else.

Are you concerned about the content of the practice records?

- Scurrilous content?
- Accuracy?
- · Bad typing?
- Anything else?

Are you concerned that the clinicians would have to write the records differently? If so, why?

Are you concerned that patients will take more time by:

- Attending more often?
- Taking longer in the consultation?
- Asking questions that are medically irrelevant?
- Taking up reception time
 - o Talking over problems
 - Setting up passwords etc

Are you concerned that it involves too much alteration in the way the practice does its business that the benefits were outweighed by the risks? If so, what alterations do you think would be needed?

What is the general feeling about records access?

- A benign feeling?
- Fear?
- Ignorance?
- An in principle agreement, but a concern about risk for the practice overall?

What would make you change your mind about starting record access?

Any other thoughts?

Would you now like to take up records access? If so, how can EMIS/PAERS/Rec Acc Collab help?