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a survey of stakeholder experiences

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# Embedding online patient record access in UK primary care: a survey of stakeholder experiences

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## DECLARATIONS

### Competing interests

BF leads the UK Record Access Collaborative (RAC) 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

### Funding

TS received an honorarium from the RAC in order to undertake the field work.

### Ethical approval

The study was conducted under a service development remit and did not involve identifiable patient data

## Summary

**Objectives** To explore the integration of online patient Record Access within UK Primary Care, its perceived impacts on workload and service quality, and barriers to implementation.

**Design** Mixed format survey of clinicians, administrators and patients. Telephone interviews with non-users.

**Setting** Primary care centres within NHS England that had offered online record access for the preceding year.

**Participants** Of the 57 practices initially agreeing to pilot the system, 32 had adopted it and 16 of these returned questionnaires. The 42 individual respondents included 14 practice managers, 15 clinicians and 13 patients. Follow-up interviews were conducted with one participant from 15 of the 25 non-adopter practices.

**Results** Most professionals believed that the system is easy to integrate within primary care; while most patients found it easy to integrate within their daily lives. Professionals perceived no increase in the volume of patient queries or clinical consultations as a result of Record Access; indeed some believed that these had decreased. Most clinicians and patients believed that the service had improved mutual trust, communication, patients' health knowledge and health behaviour. Inhibiting factors included concerns about security, liability and resource requirements. Non-adoption was most frequently attributed to competing priorities, rather than negative beliefs about the service.

**Conclusions** Record access has an important role to play in supporting patient-focused healthcare policies in the UK and may be easily accommodated within existing services. Additional materials to facilitate patient recruitment, inform system set-up processes, and assure clinicians of their legal position are likely to encourage more widespread adoption.

**Contributorship**

BF conceived the study as part of the RAC and facilitated links to practices via the GP software supplier EMIS. CP and TS co-developed the questionnaires. TS undertook the survey, follow-up interviews and initial analysis. CP wrote the paper with input from the other authors

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None

**Reviewer**

Ray Jones

**Introduction**

The past decade has seen an increasing appreciation of the role of Information and Communications Technologies (ICT) in modernizing healthcare systems. Central to the 'eHealth' vision espoused by many governments is the promise of networked ICT (internet and mobile) to help engage citizens as partners in healthcare, chiefly through increasing the accessibility of relevant information and services.<sup>1</sup> This reflects a growing emphasis, in many Western nations, on patient-centred healthcare models and complements wider citizen-centric policy initiatives around public engagement, freedom of information and civic transparency.

Electronic Health Records (EHR) represent the central pillar of eHealth strategies worldwide, since they offer the capacity to support patient care, quality improvement, population health surveillance and research.<sup>2</sup> Until recently the topics of EHR and 'Consumer Health Informatics' tended to be considered separately; discussions of the former being mainly centred on healthcare institutions. Across North America and Europe there has been a gradual realization of the synergies between these two areas, manifested in the growing attention that is being paid to Personal Health Records (PHR) in both the scientific and policy literatures. The PHR is a complex construct and many have bemoaned the lack of consensus on its precise definition.<sup>3</sup> The central feature is a patient-accessible Electronic Health Record, although models vary in the source and controller of the information (healthcare provider or patient; single or multiple providers), the medium (e.g. web, kiosk, USB) and the additional functionalities associated with the software (e.g. education, prescription reordering, provider messaging, decision support).<sup>4,5</sup> This report is concerned with one particular aspect of the PHR concept, namely online access by patients to provider-generated information that is specific to their health history and current conditions, and held in the computer systems of primary healthcare centres. We refer to this as Record Access, in line with the language adopted in recent guidelines from the Royal College of General Practitioners,<sup>6</sup> although similar applications have also been characterised as 'tethered Personal Health Records'.<sup>7</sup>

The idea of patients accessing their own health records is not a new one.<sup>8</sup> However, the accessibility afforded by the Internet, and the capacity of emerging PHR to integrate personal health applications with provider-owned record systems, creates interesting new challenges and research questions.

The more complex and interactive models of PHR have yet to penetrate the UK market, in contrast to the US, where many healthcare management organizations are providing such services, although 'patient portals'<sup>i</sup> are beginning to feature in NHS programmes.<sup>9</sup> This may reflect differences in the organization of healthcare services. In the UK the established role of the GP as the manager and integrator of patient-specific health information removes the imperative for patients themselves to undertake this role, as can be the case in more disaggregated, multi-provider, health economies.<sup>ii</sup> Reflecting this history, the origins of the PHR movement in the UK lie with a small number of enthusiastic GPs who pioneered record sharing with patients using computer printouts and portable downloads, latterly partnering with GP systems suppliers to provide waiting-room kiosks and online portals.<sup>10</sup> This has yielded favourable user responses and positive impacts on knowledge, mutual trust and record accuracy, despite some concerns over security and confidentiality.<sup>11,12,13</sup> This ground-up approach sits in stark contrast to the top-down one used to introduce patient access to the NHS Summary Care Record via 'HealthSpace', which has so far met with limited success.<sup>14</sup>

Despite the enthusiastic response of early adopters, Record Access services remain uncommon in UK primary care and, given the caveats around privacy and liability indicated in the RCGP guidelines, more evidence is needed if they are to

<sup>i</sup>This term has been used to describe emerging systems that offer Record Access as part of a broader suite of online consumer tools for administrative tasks such as appointment booking.

<sup>ii</sup>The UK has a single National Health Service in which the GP acts as the first point of care, the conduit to specialist services and the coordinator of community-based follow-up. As a result they generally receive core documentation pertaining to their patients from other parts of the service, although more detailed records will remain with the specialist host.

become mainstream. Questions also remain about the feasibility of integrating Record Access into professional workflow in light of the potential administrative requirements. This study aimed to examine how practices had integrated record access during the course of a one year pilot, and to identify human, organizational or technical barriers warranting attention prior to wider rollout. It also sought to explore whether some of the benefits demonstrated in US studies of PHR, such as improved provider-patient relationships, patient self-care and reduced consulting time,<sup>15</sup> were also being felt in British health centres adopting record access.

## Methods

### Sample and setting

One year prior to our survey, the GP software supplier EMIS had sought expressions of interest from practices wishing to pilot its new online Record Access system. This was publicized via the email network of the UK Record Access Collaborative and local EMIS user groups.<sup>iii</sup> Fifty-seven practices had volunteered to participate and these were targeted by our survey. Record Access was available for a year prior to the survey, in order to allow the service to become embedded, although practices varied in their timescales for implementation.

### Research tools

Questionnaires contained closed, open and scaled items, tailored to user group (manager, GP, patient), covering reasons for enrollment, implementation methods, perceived benefits or drawbacks for patient care or workload, system usability and support requirements.<sup>iv</sup>

### Procedure

Questionnaires were disseminated to practice managers for self-completion (some items requiring consultation with receptionists) and relay to

one GP and at least one patient representative per practice. Managers were asked to collect and return all questionnaires. Non-respondents were followed-up by email at 4 and 6 weeks, and then by telephone. Brief telephone interviews were conducted with representatives from centres whose original agreement to participate had not translated to use of the system.

## Results

### Sample characteristics

Of the 57 centres originally enrolled in the pilot, only 32 (56.1%) had proceeded with implementation, of which 16 (50%) returned questionnaires. In total, 42 questionnaires were received from 14 practice managers; 15 clinicians; and 13 patients. All patients completing the questionnaire were aged 41 years or over with 46.2% falling between the ages of 71 and 80 years. Of these, 79.9% reported having a long-term condition and 30% indicated that they were receiving specialist care.

### Clinicians' responses

#### Impacts on workload

Overall 79.9% of clinicians felt that record access could be provided without creating a significant additional burden on the health centre. A total of 86.7% perceived no adverse effect on consultation length and 13.3% stated that it had decreased this. Furthermore, 66.7% believed that it had not affected the frequency of consultations, and 13.3% that it had reduced it.

#### Impacts on patient communication and trust

Most clinicians (80%) believed that Record Access had been well received by patients; the remainder believing it had made no difference. Just over half (53.3%) thought it had facilitated shared decision making and trust during consultations and 20% felt more confident in communicating with patients as a result. The remainder reported no change, with several citing their practice's pre-existing culture of openness with patients as the reason.

#### Impacts on patient self-management

While most clinicians (66.7%) did not perceive that record access had changed the way patients

<sup>iii</sup>eHealth Insider. EMIS seeks 100 pilot practices for patient record access. <http://www.ehi.co.uk/news/primary-care/2685>

<sup>iv</sup>Questionnaires are reproduced in our detailed report for the Record Access Collaborative, available online via the University of Edinburgh Library. <http://www.era.lib.ed.ac.uk/handle/1842/5831>

manage their health, 26.7% did (one did not complete this item). Narrative responses revealed a belief, by some, that it had increased patients' involvement in the monitoring and management of their conditions; for example, through viewing results and seeking information before coming to see a clinician.

#### Challenges to service integration

When asked if record access had been easily integrated into workflow, almost half the clinicians (46.6%) agreed, 20% disagreed and the remainder gave a neutral response. Reported challenges included the time and resources available to recruit patients and to check records for third-party references, and concerns about the legality of providing patients with access to medical records in light of the UK Data Protection Act. While 80% had not changed the way in which they write patient records as a result of providing this service, 20% reported having done so, indicating that it had motivated them to use clearer language and avoid subjective comments. Despite the challenges, three quarters of clinicians (73.3%) said they would be willing to recommend record access to another health centre.

#### Health centre managers' responses

##### Precursors to Record Access

In total, 42.0% of managers had heard about record access prior to the study, usually via a clinical colleague. Most (64.3%) reported that participation was agreed during a health centre meeting. Eleven out of the fourteen centres (78.6%) already offered some type of online service including, appointment booking (all) and repeat prescriptions (nine). Most (85.7%) indicated that all clinicians in their centre supported the provision of record access.

##### Patient Enrolment Processes

Most centres had recruited patients using waiting room leaflets or posters (71.4%), or opportunistically during consultations (57.1%). Over half (64.2%) had found this easy or very easy, and 21.4% had found it somewhat difficult (none had found it 'very difficult' and three failed to complete this item). Perceived barriers included patients' concerns about security, lack of interest, poor understanding of potential benefits and

insufficient time for receiving instruction. Patients were typically enrolled by completing a consent/registration form. Organizational challenges included the time required to complete the registration process and review patient notes.

#### Impacts on workload

Most managers (78.6%) stated that it was easy to manage record access within their centre, whilst 14.5% reported that it was difficult to manage. One response was left blank.

Around half reported no change in the frequency of requests to reception staff for clarification over drugs (57.1%), consultation booking (57.1%) or prescription reordering (42.9%), while some reported a decrease (21.4%; 14.3% 14.3% respectively). A small number reported an increase in consultation requests (7.1%) and prescription reordering (21.4%).

#### Challenges to service integration

Managers mentioned similar challenges to clinicians regarding the availability of staff time for patient registration and record checking, and uncertainties over the Data Protection Act. They also highlighted difficulties in raising patients' awareness of the service, and operational challenges such as user error (forgotten passwords), and hardware problems.

Recommendations included the provision of publicity materials for patients and further training and technical support for staff.

#### Patients' responses

##### Service integration

Most patients (92.3%) had found it easy or very easy to set up record access at home (one found it somewhat difficult) and all found the system easy or very easy to use. All were comfortable with the way in which their consent was requested, and most (92.3%) had no concerns about creating an online account. Narrative responses indicated that clear information about how security and confidentiality would be protected provided reassurance. One patient had concerns about security, despite this.

##### Lifestyle integration

All but one patient had been using record access for 10 or more months. Most (84.6%) had viewed

their record 6 or more times since registering, and 30.8% more than 10 times. Most (84.6%) had used the system once or more within the preceding fortnight. Reported uses included accessing test results (84.6% of respondents) or clinician letters (53.8%), checking condition (53.8%), and supporting hospital consultations (53.8%); for example through reviewing records beforehand or sharing records during the clinical encounter. Most had shared their record with a spouse, partner or other family member (76.9%)

#### Impacts on knowledge and self-care

All patients found record access 'somewhat useful' (38.5%) or 'very useful' (61.5%). Most believed it had improved their knowledge of their condition (92.3%) or their understanding of its clinical management (76.9%). Overall, 76.9% believed it had helped them to manage their health through encouraging them to take medication on time (23.1%), follow lifestyle advice (46.2%) or become aware of how their behavior is influencing their health (46.2%).

#### Impacts on satisfaction

A total of 46.2% of patients indicated that record access had improved their satisfaction with the health centre and 46.2% that it had made no difference. One reported a negative influence.

#### Impacts on communication and trust

38.5% of patients indicated that record access had improved their trust in the health centre and their confidence in sharing information or decisions with their doctor, while 61.5% indicated that it had not affected these factors.

#### Interviews with non-users

Representatives from 15 of the practices that had opted not to proceed with Record Access agreed to be interviewed.

Explanations included a *lack of priority* (in most cases it was regarded positively but had simply not yet been implemented), *lack of internal agreement* (e.g. only one GP advocate in the practice), *perceived workload* (e.g. time required to check records; patients seeking clarification); *uncertainty about operating procedures or likely benefits* (lack of information); *lack of patient demand* (e.g. service

offered but no take-up) and *security concerns* (privacy). None expressed concerns about *litigation*, citing confidence in the information held in their systems, although there was some uncertainty about their position if record access were to reveal third-party information. While confidentiality was a concern, inappropriate sharing by patients was felt to be potentially more problematic than a technical breach. The potential for medical records to confuse or upset some patients was also acknowledged. Overall, these non-users supported the principle of record access and regarded it as 'an inevitability', but felt that more information and support should be available to help them prepare to deliver this service.

## Discussion

### Statement of principal findings

The generally favourable attitudes revealed by all three stakeholder groups in this survey reflect a common finding in the research literature on record access and personal health records; namely that where these are available, such systems are well liked by patients and accepted by most professionals.<sup>16-19</sup> The results also support previous studies that have identified professional concerns around security, privacy and liability, for which technical, educational and regulatory steps may be warranted.<sup>20</sup> Only one patient in our sample expressed concern about having their detailed GP record available online (possibly as a result of the experience) and all felt comfortable with the way in which consent had been requested. Moreover the majority had shared their record with a partner or family member, indicating that patients and clinicians may have rather different views of the costs and benefits of data transparency, an observation also made in the recent evaluation of the Summary Care Record in England.<sup>21</sup>

Despite some concerns about operational resourcing, the relative ease with which record access appears to have been integrated into work practices and its lack of impact (or its positive impact) on administrative time and clinical workflow bode well for more widespread use. It is noteworthy that practices which had yet to implement the service remained positive about it and intended to do so in the future.

Both patients and clinicians' believed that record access had facilitated shared decision making, health knowledge and self-management, suggesting greater patient empowerment. Our survey also gives early signals to the potential efficiency gains that may come from record access once it has become more widely embedded. For example, some clinicians felt that it had reduced the frequency and length of consultations, and some patients reported having used it to help make more effective use of hospital appointments.

### Strengths and weaknesses of the study

This is the largest UK survey of primary care centres offering online access to a detailed electronic health record. By including administrative staff, in addition to patients and clinicians, it has usefully highlighted operational considerations for general practices wishing to deliver these systems as well as possible outcomes for patient health, satisfaction, empowerment and practice efficiency.

However, the number of respondents within each sub-group is too small to generate definitive conclusions about impact. The study also relies on users' perceptions and will have been influenced both by *experiences* of using record access and *expectations* about its potential to deliver benefits, which are hard to disentangle.

Recruitment to the pilot targeted clients of one system supplier, who coordinated the request in conjunction with the UK Record Access Collaborative<sup>v</sup>. Those agreeing to participate and then proceeding to implement the service and complete our survey may conceivably be more patient-centred, more technologically literate or have more patients with long term illnesses, than the others. Little is known about how the practices recruited patients to complete the questionnaire, and their decisions may have been influenced by knowledge of individuals' health characteristics or involvement in relevant groups. In this respect the high proportion of over 40s with long-term conditions is noteworthy. Nevertheless, such factors may, paradoxically, increase the ecological validity of this study, since these technologies are

<sup>v</sup>An informal community of interest including representatives from general practice, patient groups, academia, policy and industry. <http://www.record-accesscollaborative.org/>

most likely to be adopted by those for whom the potential benefits are greatest and who are most interested.<sup>22</sup>

### Meaning of the study: possible mechanisms and implications for clinicians or policymakers

Mindful of these caveats, our results indicate that online record access offers great potential to address patient and citizen-centred agendas in the UK.

Some of our findings are consistent with American research indicating that such portals can increase efficiencies by changing the way in which patients seek professional interaction, such as via telephone rather than in-person consultations.<sup>15</sup>

While not all patients are likely to use this type of Personal Health Record, it may be a useful resource for some and should be provided as an option alongside other online services. The UK primary care sector is in an excellent position to integrate these services at relatively low cost, given the universal use of electronic health record systems, state-mandated interoperability requirements and competition between suppliers for the lucrative general practice systems market, in which patient-facing services are likely to offer an advantage.

### Unanswered questions and future research

Quantitative studies of use and impacts are required to verify these observations, although the positive responses revealed in this study suggest that it may be appropriate to conduct such research in tandem with implementation, so as to avoid delaying a useful service. Vigilance will nevertheless be required in order to monitor unintended consequences, particularly given the sensitivity of personal health data. Research to explore patient characteristics associated with the use of record access would be useful,<sup>23</sup> as would studies examining the mediating influence of clinician characteristics.<sup>24</sup> Poor public awareness of Personal Health Record technologies has been cited as a barrier to their adoption<sup>25</sup> and is among the inhibiting factors noted in this study. Given the apparently low impact of the NHS

information campaign around HealthSpace, research exploring how best to bring these systems to the attention of potential users may be warranted.

The effort involved in masking third party references remains a practical challenge to scaling this service and evaluating alternative methods for achieving this would be worthwhile.

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