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BMJ Open Patients' online access to their electronic health records and linked online services: a systematic interpretative review

Simon de Lusignan,¹ Freda Mold,¹ Aziz Sheikh,² Azeem Majeed,³ Jeremy C Wyatt,⁴ Tom Quinn,⁵ Mary Cavill,⁶ Toto Anne Gronlund,⁷ Christina Franco,⁸ Umesh Chauhan,⁹ Hannah Blakey,¹⁰ Neha Kataria,¹ Fiona Barker,¹ Beverley Ellis,⁹ Phil Koczan,¹¹ Theodoros N Arvanitis,¹² Mary McCarthy,¹³ Simon Jones,¹ Imran Rafi⁶

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For numbered affiliations see end of article.

Correspondence to
Professor Simon de Lusignan;
s.lusignan@surrey.ac.uk

ABSTRACT

Objectives: To investigate the effect of providing patients online access to their electronic health record (EHR) and linked transactional services on the provision, quality and safety of healthcare. The objectives are also to identify and understand: barriers and facilitators for providing online access to their records and services for primary care workers; and their association with organisational/IT system issues.

Setting: Primary care.

Participants: A total of 143 studies were included. 17 were experimental in design and subject to risk of bias assessment, which is reported in a separate paper. Detailed inclusion and exclusion criteria have also been published elsewhere in the protocol.

Primary and secondary outcome measures: Our primary outcome measure was change in quality or safety as a result of implementation or utilisation of online records/transactional services.

Results: No studies reported changes in health outcomes; though eight detected medication errors and seven reported improved uptake of preventative care. Professional concerns over privacy were reported in 14 studies. 18 studies reported concern over potential increased workload; with some showing an increase workload in email or online messaging; telephone contact remaining unchanged, and face-to-face contact staying the same or falling. Owing to heterogeneity in reporting overall workload change was hard to predict. 10 studies reported how online access offered convenience, primarily for more advantaged patients, who were largely highly satisfied with the process when clinician responses were prompt.

Conclusions: Patient online access and services offer increased convenience and satisfaction. However, professionals were concerned about impact on workload and risk to privacy. Studies correcting medication errors may improve patient safety. There may need to be a redesign of the business process to engage health professionals in online access and of the EHR to make it friendlier and provide equity of access to a wider group of patients.

Strengths and limitations of this study

- There was a dearth of evidence from high-quality studies about the impact of online access, although the evidence around online services issues was more comprehensive.
- Many of the studies in this review originate from the USA, from large health plan-based programmes; a minority of studies originate from Europe.
- Owing to the inclusive nature of the review, we recruited a team of expert reviewers from a broad range of professional backgrounds (health, academia and policy) who volunteered to help with the RCGP initiative about online access. This group provided a rich resource in order to extract relevant data and share information, through regular teleconferences. However, this inclusivity may have resulted in some inconsistencies.
- Like all systematic reviews, evidence has been gathered from various resources from a specific time period. As such, there may be new papers recently published that have not been included in this review.

A1. Systematic review registration number:
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INTRODUCTION

Online services and applications are increasingly part of normal life. Personal computers are ubiquitous in the workplace, and many people have 24 h access through smartphones and a range of other devices.

Providing patient online record access has been described as fundamental to patient empowerment, but UK progress to date has

been limited in part by professional resistance and concerns about security and privacy,¹⁻³ legal constraints⁴ and low uptake of previous schemes to provide online resources for patients. These medicolegal concerns have been echoed in other international studies.⁵ The tensions between the growing consumer demand to access data and a healthcare system not yet ready to meet these demands have increased in recent years.⁶⁻⁷ The promise of linking personal records from multiple sources into a readily digestible single online record has not yet been realised.⁸⁻⁹ Plans to provide patients online access¹⁰ have been successfully piloted,¹¹ but not widely adopted. Patients were concerned about the relative brevity of the record and that any mistakes, though few, could be clinically significant.¹² Hybrid access involving an adult or a carer for children and young people complicates arrangements further.¹³

There have been some notable international successes in the provision of online services. Kaiser Permanente has had two-thirds of its 3.4 million members sign up for online appointment booking, test result collection and email.¹⁴ The USA Veterans Administration has also registered large numbers online with over 600 000 users making over 20 million 'visits' over the internet by 2008, the most popular service being online repeat prescription requests.¹⁵ The UK government announced in its health strategy that all patients in the English National Health Service (NHS) are to have access to their own health record by 2015.¹⁶ However, the guidance developed by pioneers of patient record access and published by the RCGP in 2010 has not been widely adopted¹⁷ and has now been superseded by updated guidance.¹⁸

Provision of online services for patients can be largely grouped into two areas.

- ▶ Patient online access to their medical record. The ability to view, and sometimes edit or comment, on their electronic health record (EHR).
- ▶ There are also other online services linked to EHR provision. These can be grouped into those that involve a human interaction to generate a personal response to a question, largely communication with your practice, doctor or other healthcare worker by email or through a web portal, and those where the transaction is purely digital, for example booking an appointment or receiving notification of a test result.

We carried out this study to inform this important new national policy directive by identifying how access might impact on the provision, quality and safety of healthcare.

METHODS

We identified four key research questions developed from an approach used in a recent systematic review (box 1).¹⁹ This paper is an evidence synthesis that should be read in conjunction with our systematic review of 17 experimental studies; these studies were reported separately on the basis that we could assess their risk of bias.²⁰ This paper aims to bring together this research

Box 1 Aim, Objectives and Research Questions

Aim:

To assess the factors which may affect the provision of online patient access to their EHR and transactional services and the impact of such access on the quality and safety of healthcare.

Objectives

1. Identify and understand the barriers and facilitators to providing online access to records and transactional services in ambulatory care.
2. Assess the benefits and harms of online access to records and transactional services in ambulatory care and how they affect the quality and safety of healthcare.

Key research questions:

Research Question 1 (RQ1): What is the association between online patient access to their EHR and:

- ▶ Utilisation of healthcare;
- ▶ Health outcomes including patient safety;
- ▶ Patient experience and satisfaction;
- ▶ Adherence,
- ▶ Equity and
- ▶ Efficiency;

and wherever possible to identify the impact of online patient access to their EHR.

Research Question 2 (RQ2): What is the association between online patient access to transactional services provided as part of their ambulatory care EHR and:

- ▶ Utilisation of healthcare;
- ▶ Health outcomes including patient safety;
- ▶ Patient experience and satisfaction;
- ▶ Adherence,
- ▶ Equity and
- ▶ Efficiency;

and wherever possible to identify the impact of online patient access to transactional services.

Research Question 3 (RQ3): What is the association between practitioner and healthcare team being provided with:

- ▶ Education and staff training;
 - ▶ Making workload and workflow changes,
 - ▶ Achieving regulatory compliance and
 - ▶ Business process changes for ambulatory care;
- and patient uptake of online access and transactional services as part of their ambulatory care.

Research Question 4 (RQ4): What is the association between:

- ▶ IT developments which provide records access,
- ▶ Systems to enhance privacy and security,
- ▶ Usability and accessibility of transactional services, and
- ▶ Business process for technical development of EHR systems, including lead time in their development;

and patient uptake of online access and transactional services as part of their ambulatory care.

and highlights the breadth and detail of evidence emerging from each of our original research questions.

We used an established methodology, following Cochrane guidance for the review process²¹ and the Preferred Reporting Items for Systematic review and Meta Analysis (PRISMA) framework.²² The protocol for this review has already been published, including details of the key research questions and inclusion and exclusion criteria.²³⁻²⁴ The study aims were structured in a

systematic way, using the elements of a clinical research question (population, intervention, comparator and outcome/PICO).^{20 25}

Search strategies were developed and run on 10 bibliographic databases: Cumulative Index to Nursing and Allied Health Literature (CINAHL), the Cochrane database, Cochrane Effective Practice and Organisation of Care Group (EPOC), Database of Abstracts of Reviews of Effects (DARE), Embase, King's Fund, Medline, Nuffield Health and PsycINFO. Search for unpublished material was conducted using the database OpenGrey. Search strings were tailored to each database according to each source using Medical Subject Heading (MeSH) and index terms. The total number of papers identified was 9877. An example Medline search string can be viewed in our previous publication.²⁰

Screening against the inclusion criteria was carried out by SdeL, FM & MC to identify relevant papers using a framework of the types of relevant interventions and a detailed inclusion–exclusion guide.²⁰ Full text papers were sourced at this stage and apportioned to group members for review. The group members were volunteers who had expressed interest in joining Working Group 7 (and evaluation of the evidence) of a larger Royal College of General Practitioners (RCGP) exercise to define a Road Map for providing patients online access to their medical records. We recruited a purposeful sample of academics, practitioners and patient representatives with the relevant expertise. This group was given autonomy to review the evidence and has reported separately from the Road Map report.¹⁸ Evidence was subject to dual data extraction (group member and FM).

Refining the data collection forms and training the assessors

Two pilot paper-based exercises were conducted to refine the data collection tools, ensure consistency in the reviews and to inform design of online data capture forms. We also developed a data extraction form (DEF) which was used to extract the salient points from each paper. DEF training was provided to our group members in order to facilitate their review of evidence. The DEF also included a risk of bias (RoB) form for each paper, which aimed to look at limitations in study design.²⁰ The RoB form was included with the intention of applying the Grading of Recommendations Assessment, Development and Evaluation (GRADE) tool to assess the strength of evidence as a collective for each research question.^{26–28} The RoB form was grouped into six domains: sequence generation, allocation concealment, blinding, incomplete outcome data, selective reporting and other bias. Although all papers were subject to a RoB assessment, only a small number ($n=17$) were experimental in design; and these had a wide variation in their RoB. A detailed summary of these trials and RoB analysis can be seen in our previous publication.²⁰

The review forms were returned via the website ([http://www.clininf.eu/projects/patient-access/paper-](http://www.clininf.eu/projects/patient-access/paper-review-form.html)

[review-form.html](http://www.clininf.eu/projects/patient-access/paper-review-form.html)) or directly to individual team members.

Where reviewers disagreed about ratings we reached a final rating by consensus. A meta-analysis could not be undertaken, as included studies were not sufficiently homogeneous in terms of primary outcome measures to provide a meaningful summary. As such, we chose to adopt an established qualitative method to guide this synthesis.²⁹ We extracted data relating to the study setting and context, the experience and attitudes of online users and non-users, clinicians and other health-care staff, the technologies used and the impact and context of these on the organisation of primary and ambulatory care. Specific data extracted included the study aims/objectives, study design, setting, intervention and key findings. The initial analysis was undertaken by the two principal authors with input and comments from the group members/coauthors. The final synthesis of the data was undertaken at a meeting where data were presented and discussed at a group level.

Applicability

Most of the included studies were undertaken in the USA and Europe; the reviewers included those they considered applicable to countries with comprehensive primary care services.

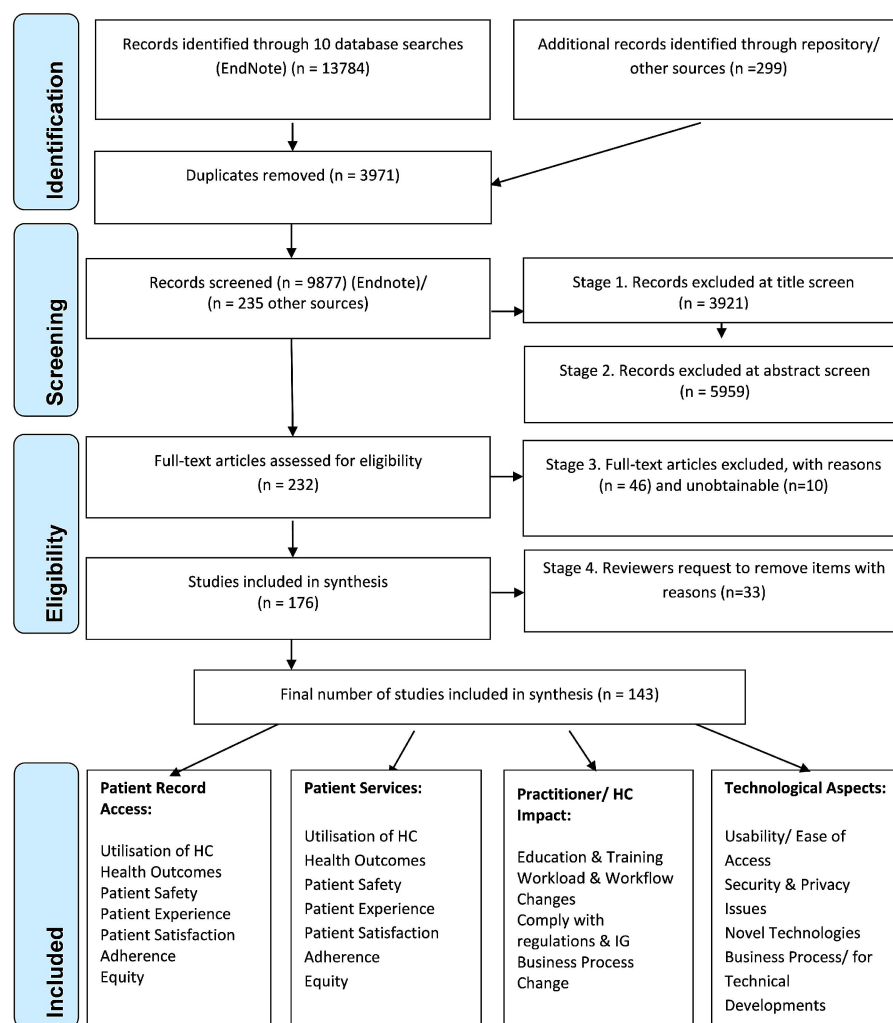
RESULTS

Excluded papers

The papers selected by the search process, but rejected by the reviewers largely comprised of studies not considered relevant to the review (see online supplementary table S1—Excluded Studies). Portals, websites, email or other online access for single conditions or diseases, such as diabetes, were excluded. The search and exclusion process is summarised in the PRISMA flowchart (figure 1). Results from these searches were stored using Endnote, and where copyright allowed, in an online repository. There were 3971 duplicate articles. After this initial filter process, 6191 papers remained.

Research Question 1: what is the association between providing patients online access to their own ambulatory care medical record and utilisation of healthcare and outcomes, including patient safety, patient experience and satisfaction, adherence, equity and efficiency?

Patient online access has a low uptake, and the effect on face-to-face utilisation of healthcare was equivocal. Female adults were the largest group of online access and online service users according to 11 papers^{30–40} (see online supplementary table S2—Research Question 1 Results). Six studies report that some were disadvantaged by lack of access to the internet.^{41–46} while others reported no such barrier.^{47 48} Seven papers stated that patients want to be able to appoint a proxy, share records with family or another healthcare professional or be able to print out segments of their records.^{30 41 49–53}

Figure 1 PRISMA Flowchart.

Two papers described the elderly's willingness to accept assistance in accessing their records^{53 54} and two further studies reported that children's advocates suggest that their guardians should have access to their records up to age 16 years.^{55 56} However, others have expressed concerns about unauthorised access,⁵⁷ as misuse or 'snooping'.⁵⁸

While online access allows patients to reflect on their records and prepare for the next consultation,^{59 60} there was no evidence of improved health outcomes.^{61 62} However, evidence from eight studies indicated that there may be an improvement in patient safety primarily through identifying errors in medication lists and adverse drug reactions.^{38 49 59 63–67} In one study about the potential to access and identify medication errors, there was significant difference between the number of discrepancies in medication with potential for severe harm in the intervention group compared with controls (0.03 intervention vs 0.08 control per patient, adjusted RR 0.31, 95% CI 0.10 to 0.92, $p=0.04$).⁵⁹ There was no evidence of harm to patients from the provision of patient online access, though there were concerns among health professionals that access to unexplained reports may cause anxiety or stress for patients. In eight

studies, health professionals were concerned that viewing notes could potentially be offensive to patients or could cause an adverse reactions and this could impact negatively on the doctor–patient relationship.^{30 41 49 68–72} Patient experience and satisfaction appears to be improved through enabling better self-care (n=13 studies)^{11 2 30 49 57 60 61 66 72–76} and patients being empowered to communicate more effectively with clinicians (n=13 studies).^{49 50 51 57 60 68 72 73 77–82}

Research Question 2: What is the association between providing patients access to online services as part of their ambulatory care and utilisation of healthcare and outcomes including patient safety, patient experience and satisfaction, adherence, equity and efficiency?

Patients' access to online services offered greater convenience particularly in time-saving when compared with other methods of interaction with their health provider.^{30 83–90} Both healthcare professionals and patients reported time-saving in terms of avoiding an in-person clinic visit^{85 86} and better efficiency in managing patient care⁹¹ (see online supplementary table S3—Research Question 2 Results).

Many disadvantaged and vulnerable people were non-users, including non-Caucasian ethnicities^{46 92} and those of lower socioeconomic status,^{44 93 94} while adult females were the most active adopters of this technology.^{32 34-40} Several studies also report disadvantages with access to online technology for other groups, such as those in poorer health and vulnerable groups.^{38 42 45 95} Evidence from four studies reported that patients wanted direct communication with their clinician⁹⁶⁻⁹⁸ while evidence from three studies suggested that clinicians preferred support staff to filter messages.^{70 90 99} Patients' satisfaction also improved if clinicians responded in a timely manner to their requests (10 studies).^{37 65 71 82 92 96 100-103}

The EHR linked services most utilised by patients were: prescriptions, viewing the test results, messaging with their clinician, arranging referrals and rescheduling appointments.^{14 30 35 52 87 89 90 96 104-109} Generally, email contacts from patients were brief, well structured and about non-urgent minor problems.^{75 82 87 89 100 110-112} Seven studies reported that patient access to online services facilitated uptake of preventative care services^{83 95 113-116} and four studies reported small improvements in adherence with medication and clinical attendance.^{30 36 49 59} Patients also felt more able to express ideas and concerns,^{82 86 89 95 112 117-119} and 16 studies reported how patient experience and satisfaction was high.^{37 59 62 75 80 81 85 89 96 97 103 106 112 116 120 121} While patients were positive about online services, a substantial minority (all from studies in the USA) would not be willing to pay for the service, and those that did put a relatively low financial value on the transaction.^{42 45 92 122 123}

Research Question 3: what is the association between patient adoption of online access and online services as part of their ambulatory care and the practitioner and healthcare team being provided with staff training, making workload and workflow changes, achieving regulatory compliance and business process changes?

Most studies identified reported levels of patient adoption of online access and services without clear reference to the impact of training (see online supplementary table S4—Research Question 3 Results). These are reported here to describe the extent of the existing evidence base. There are more reports about the effect on workload and workflow, though largely on the interrelationship between providing online access to records, email (or messaging via a portal), telephone use and face-to-face consulting.

Five studies commented on the clinicians' use of email to communicate with their patients, with only a small number of clinicians, between 3% and 17%, being regular users.^{43 109 120 124 125} Four papers described patient requests for clinical advice online^{37 39 82 110}; and many more described other EHR linked services, such as repeat prescribing and administering bookings.^{65 88 89 100 105 107 115 126} However, some clinicians

preferred sharing their mobile phone number to providing their email address.¹²⁴

Simple self-limiting problems were readily manageable by email^{36 37 45 82 83 88 100 106 108 110} but more complex problems were not.^{87 96} Overall use was judged by clinicians to be appropriate with a minority of e-consultations resulting in a subsequent face-to-face encounter (n=3 studies).^{34 85 110} After an early peak in email volume there is some evidence that the level falls back.¹²⁷ Only two papers reported that healthcare professionals felt that they lacked the skills to use these technologies^{121 128} and wanted more training.^{120 129-133} Some were concerned about the effect of providing online access and services on workload¹³⁴⁻¹³⁶; there seems to be a complex interdependency between face-to-face, online messaging or email and telephone utilisation. Seven studies reported an increase in workload^{33 43 49 97 108 132 126}; two reported a large but temporary increase that plateaued,^{71 106} and eight reported a decline.^{57 62 71 72 85 102 108 137}

Online access and services has an inconsistent effect on face-to-face consultations across studies, with some reporting a decline^{62 102 108 111 137} (n=5), an increase^{33 49 106} (n=3) or no change (n=3).^{57 101 102} Generally, email and web-messaging created new and increased volumes of contacts,^{62 81 105 106 108 126 132 137} though four studies reported no change.^{88 94 120 138} Telephone contact appeared to rise and fall back when new services were offered,^{71 106} though six studies reported no change in telephone volume,^{88 94 97 101 102 126} and three reported a rise.^{33 108 136}

Online services were perceived as fundamentally changing the business process. There was a perception that there needed to be a reorganisation of working practices.^{71 76 90 139} Clinicians felt they needed to change the way that they wrote their medical records as they were now shared with their patients rather than using them as largely private professional aide memoire.⁷² The nature of communication was felt to change in that email communication was led to a greater extent by the patient than happened in face-to-face contact; possibly, online access facilitates a subtle shift in the balance of power in the clinical consultation.^{70 98 116 127}

Research Question 4: What is the association between IT developments, and the business process for developing modified systems and patient adoption and utilisation of online access and online services provided as part of the patient's ambulatory care computerised medical record?

Eight studies reported formalised systems to ensure governance and compliance with other relevant regulations,^{53 90 100 106 115 120 124 126 140} but there was a lack of knowledge about what made an appropriate framework^{76 140-142}; and other studies reported a need for future guideline development^{58 72 90 96 143-145} (see online supplementary table S5—Research Question 4 Results).

Several studies (n=16) also highlighted clinicians' concerns about privacy and confidentiality.^{43 51 58 67 77 82–84 98 105 111 121 138 146–148}

Patients in one study expressed willingness to trade-off security for ease of access.¹¹⁵ Clinicians reported in three papers that they preferred controlled access via a portal, authenticating users and ensuring privacy.^{67 130 142} Incorporating a fee for service appears to be highly effective in promoting clinician uptake of online services; some organisations have experimented with incorporating a fee, but this practice is not widespread, especially among large organisations having the most experience (such as Kaiser, VHA and most health systems in the USA and in Europe).^{86 149}

Seven studies outlined a number of novel technologies that had been introduced including providing links to X-ray and scan images^{34 70 98}; automated test result tracking;⁸⁰ text messaging question and answer service¹²⁵; portals that use a code number or pictures of medications to avoid medication names being displayed⁴¹; and web-based triage.³⁶ Many of the portals were carefully designed to deliver full or partial online access^{87 96} and some required complex technical development linking different systems, for example to provide access to pathology results and X-ray reports or images.^{70 98} Despite the level of technical innovation, 10 studies report often lower than anticipated levels of patient uptake.^{35 36 53 74 99 105 109 114 150 151}

DISCUSSION

Statement of principal findings

Patients generally report benefits of greater access; however, there was a lack of evidence of improvement in health outcomes. However, clinicians in several studies (n=8) feared access to records, or reports without a clinician available to interpret them may cause patients worry. Further research is needed to report whether any harm or privacy breaches occur as a consequence of online access.

Providing online access generally lowers the threshold for patient–clinician contact and can change the nature of their interaction. The medical record changes from being an aide memoire for clinicians to an opportunity for patients to learn about their condition and reflect on the questions they might wish to ask at their next consultation. This creates opportunities for preventive care and for patients to take the lead in clinical consultations, though this is limited by much of the record being written in a way that is inaccessible to patients.

Technical and contractual developments of business processes are needed to facilitate patient online access; they are important and necessary for success. The technical developments include the development of portals, which provide privacy, and allow monitoring and thereby ensure that messages and responses are recorded and not lost; they also measure workload to facilitate billing or other forms of reimbursement. Contractual processes include ensuring that there is the

necessary training and other mechanisms in place to ensure that the service is provided and to a defined standard.

Comparison with the literature

Berwick *et al*¹⁵² described the triple aims of health systems: how to improve the experience of healthcare, reduce per capita cost and improve the health of populations. Online access may improve the experience of healthcare and improve patient satisfaction; it may also be more cost effective if cheap online contacts substituted for more expensive ones, but the change in thresholds of access makes this hard to determine. We do not know the impact on business processes and costs in primary care. Other than correcting medication errors it is yet to be demonstrated how it improves health outcomes and that of the population.

The sociotechnical school describes the implementation of a technology as a journey of mutual transformation of that technology and its users.^{153 154} The mutual transformation required may have three intertwined themes. First, providing patients with easier online access needs to be done in such a way that it improves convenience, but does not result in multiple interactions about self-limiting conditions (unless getting patients to engage in this way is seen as a goal of the health system). It is plausible that online access might not actually improve health, but reduce efficiency. Second, the nature of the medical record needs to change so that it informs the patient, possibly linked to relevant educational material that might provide greater self-management support. Third, there may be a subtle shift in the balance of authority in the clinical consultation; patients and the technology itself (through reminders and links to information) may increasingly take the lead in the clinical consultation, reinforcing the trend away from clinician-led consultations.¹⁵⁵

The chronic care model suggests that a range of components including creating activated patients who improved their self-management support might have better health outcomes¹⁵⁶; though there is a suggestion that the most effect is seen in complex cases.¹⁵⁷ Implementing self-management support has demonstrated improved health outcomes in specific diseases, for example diabetes¹⁵⁸; and computerised self-management support, has also shown benefits.¹⁵⁹ Such computerised support might be readily linked to EHRs. However, there is currently no evidence of improved health outcomes from implementing generic self-management support processes^{160–162}; though further trials of self-management support are currently underway.

Implications for research, policy and practice

Quality in healthcare includes improving convenience, satisfaction and patient safety^{163 164}; and online access can contribute to these. However, there is a risk that highly qualified clinicians become less efficient through

answering multiple emails and electronic contacts about minor and self-limiting conditions. The business requirements of systems where users pay may be different from the ones where the state or social insurance wants to focus on improved population health outcomes.

There were no reports of harm caused by breaches of privacy; however, there were concerns and calls for further guideline development. The policy of the English NHS to provide online access via computerised medical record systems vendors seems appropriate. However, there may be scope for development of a common specification that might be more usable by patients with more similar functionality provided across the different brands of computer systems.

Call for further research

Research, including well-designed trials, is needed to determine whether and how online services might improve health outcomes. In particular, how the medical record might be redesigned to guide and teach patients in a way that promotes self-management and ultimately improves health. There is also a need for further research concentrating on the impact of online access by patients with specific long-term conditions, such as diabetes, where it is potentially easier to define health outcomes.

Health services need to learn if it is possible to provide ready access without being overwhelmed by requests and questions about potentially self-limiting conditions. Studies are needed to explore whether patient online access to reports and traditional medical records induces anxiety and fosters dependence or reassures, and if so, what needs to be done to mitigate this.

Trials comparing the potential impact of patient online access in more complex cases compared with lower risk cases, possibly including tools to improve self-management support, might provide some insight into where patient access and technology might add most value.

CONCLUSIONS

Online access offers patients more convenience, a vehicle for engaging with their healthcare information, and *may* improve patient safety. These services are currently not widely taken up by patients, nor met with widespread enthusiasm by healthcare professionals, and there is no evidence-base that they improve health outcomes. This review suggests that online access and services are perceived as fundamentally changing the business process of primary care, and with careful development, may be successfully incorporated into clinical workflows. Patient online access is to stay and set to grow, albeit slowly. Health systems may find that, in the short-term, online access reduces efficiency. Record systems may need to change to become more patient-friendly; in the long term this may enable patients to

more effectively self-manage and take the lead in consultations about their healthcare.

Author affiliations

¹Department of Health Care Management and Policy, University of Surrey, Guildford, UK

²Centre for Population Health Sciences, University of Edinburgh, Medical School, Edinburgh, UK

³Department of Primary Care & Public Health, Faculty of Medicine, Imperial College London, London, UK

⁴Leeds Institute of Health Sciences, University of Leeds, Leeds, UK

⁵Faculty of Health and Medical Sciences, University of Surrey, Guildford, UK

⁶The Clinical Innovation & Research Centre (CIRC), Royal College of General Practitioners, London, UK

⁷Health and Social Care Information Centre (HSCIC), Leeds, UK

⁸University of Dundee, Dundee, UK

⁹School of Health, University of Central Lancashire, Preston, Lancashire, UK

¹⁰St George's—University of London, London, UK

¹¹UCL Partners, London, UK

¹²WMG, Institute of Digital Healthcare, University of Warwick, Coventry, UK

¹³Belvidere Medical Practice, Shrewsbury, Shropshire, UK

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Patients' online access to their electronic health records and linked online services: a systematic interpretative review

Simon de Lusignan, Freda Mold, Aziz Sheikh, Azeem Majeed, Jeremy C Wyatt, Tom Quinn, Mary Cavill, Toto Anne Gronlund, Christina Franco, Umesh Chauhan, Hannah Blakey, Neha Kataria, Fiona Barker, Beverley Ellis, Phil Koczan, Theodoros N Arvanitis, Mary McCarthy, Simon Jones and Imran Rafi

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