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Accessing personal medical records online: A means to what ends?

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ABSTRACT

Background: Initiatives in the UK to enable patients to access their electronic health records (EHRs) are gathering momentum. All citizens of the European Union should have access to their records by 2015, a target that the UK has endorsed.
Objectives: To identify the ways in which patients used their access to their EHRs, what they sought to achieve, and the extent to which EHR access was related to the concept of making savings.
Methods: An audit of patients' online access to medical records was conducted in July–August 2011 using a survey questionnaire. Two hundred and twenty six patients who were registered with two general practices in the National Health Service (NHS) located in the UK and who had accessed their personal EHRs at least twice in the preceding 12 months i.e. from July 2010 to July 2011, completed the questionnaire.

Data analysis A thematic analysis of the comments that patients gave in response to the open ended questions on the questionnaire.
Results: Overall, evaluations of record access were positive. Four main themes relating to the ways in which patients accessed their records were identified: making savings, checking past activity, preparation for future action, and setting new expectations.
Conclusions: Quite apart from any benefits of savings in healthcare resources, this study has provided qualitative evidence of the active ways in which patients may make use of access to their EHRs, many of which are in line with proportionate health management strategies. Access to personal EHRs may contribute to the development of new expectations among patients.

1. Introduction

Patients' access to their own medical records is an important element of patient centred healthcare [1]. Initiatives in the UK

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to enable patients to access and understand their electronic health records (EHRs) are gathering momentum. All citizens of the European Union should have access to their records by 2015, a target that the UK has endorsed. [2]. In England, patients' access to their health records is guaranteed under the National Health Service (NHS) constitution for England [3] with 2015 having been set as the year by which patients should enjoy online access to their EHRs held by general practitioners (GPs) in the NHS [4].

The direction and intended speed of adoption of EHRs was set out in the information strategy for NHS in England [5]. Aimed at putting citizens in control of the health and care information that they need, this strategy sets out the path to making heath information accessible and transparent. The needs of patients, carers and citizens are to drive local innovation enabling and encouraging access to personalised information. From this perspective, the individual health record is the cornerstone of the EHR system, starting with transactions such as booking online appointments and ordering repeat prescriptions. In the longer term, patients can expect access to letters, test results and personal care plans, promoting patients' participation in decision-making, enabling good choices for their health and care, and thus leading to improved outcomes [6]. Record access has been endorsed by a number of professional organisations of healthcare providers including GPs [7] although reservations have also been expressed [8].

The potential for UK primary care practices to provide patients with access to EHRs is increasingly widespread [9], but in practice actual provision is limited. The Royal College of General Practitioners reports that only 25% of practices allow patients to book and cancel appointments on line though 73% have the systems to enable this [10]. Similarly, 53% could provide access to records and letters, but less than 1% actually do [10].

Earlier work in the context of the National Programme for Information Technology focused on Summary Care Records – the part of the record that was intended to be accessible to patients [11]. In theory, patients were positive about them although attitudes were strongly related to previous experience [12]. Other research on record access has identified concerns – in principle at least – about data sharing and confidentiality and revealed a range of perspectives held by patients and clinical staff on expanding EHR access [13].

Thus far, there has been limited research in the UK evaluating the success of locally based record access. An early study with patients who first viewed their EHRs revealed reservations about confidentiality and data accuracy, but found that people generally considered it useful [14]. Recent work in primary care has noted that record access is well received by regular users [1,15,16], who see it as beneficial, for instance, by enabling them to prepare for the consultation more effectively. Patients appreciated the opportunity to compare their recollection of the consultation with the GP's record of it and generally felt reassured that nothing was being hidden from them [15]. They reported that record access had improved their knowledge of their health state and its clinical management. Finally, the potential of record access to enable efficiency gains and cost savings has also been noted [17].

Given the focus on information sharing in the NHS strategy – both in terms of patient benefits and of greater efficiencies – this study seeks to extend and update the previous research conducted in the context of NHS general practice [15,16]. Using qualitative audit data gathered in two general practices in the north of England we have characterised the engagement of patients with their EHRs.

The study had two objectives: to identify the ways in which patients used their EHRs and to determine what they sought to achieve in doing so.

2. Methods

2.1. Design

This was a cross sectional audit of the online record access service for patients that involved self-completion of a survey questionnaire by patients in two NHS general practices. Data were collected between 22nd July 2011 and 14th August 2011.

2.2. Practice settings

Manor House Surgery (MHS) in Glossop, and Haughton Thornley Medical Centres (HTMC) in Hyde, both located in Tameside and Glossop Primary Care Trust in North England were the practice research sites of this study. Using the Patient Access to Electronic Records System (PAERS) via a secure log in, access could be gained to a record of consultations, results, letters to and from the practice and information leaflets. In MHS, 450 (2.81%) of the mostly white 16,000 patients had had record access for 18 months. In HTMC, 1694 (14.28%) out of 11,855 largely Asian patient had access since this facility had been offered for over 6 years (1, 17). Patients had been informed about the possibilities of record access through information on and off line, meetings with doctors after surgery, and through YouTube videos. There had also been extensive local media coverage of the initiative.

2.3. Survey questionnaire

The questionnaire used in the audit was developed by one of the authors (RF) and comprised five closed questions each followed by an open question. The closed questions asked patients whether access to personal EHR in the last 12 months had: ever saved them from telephoning the GP surgery (Q1); led them make extra telephone calls to the GP surgery (Q2); saved them from making an appointment with the doctor, nurse, health care assistant or other professional (Q3); led them make an extra appointment with the doctor, nurse, HCA or other professional (Q4); or ever saved time or money for themselves (Q5). For each question, patients were required to answer 'yes' or 'no' and, if 'yes', to estimate the number of times this had been the case. Importantly for the purposes of this paper each of the 5 questions above was followed by an open question asking patients to provide examples of how they had used record access and, if desired, to make any further observations. It is these data that are the focus of the present analysis. It is worth mentioning that we did not collect demographic data of participants.