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

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## ARTICLE INFO

## 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.
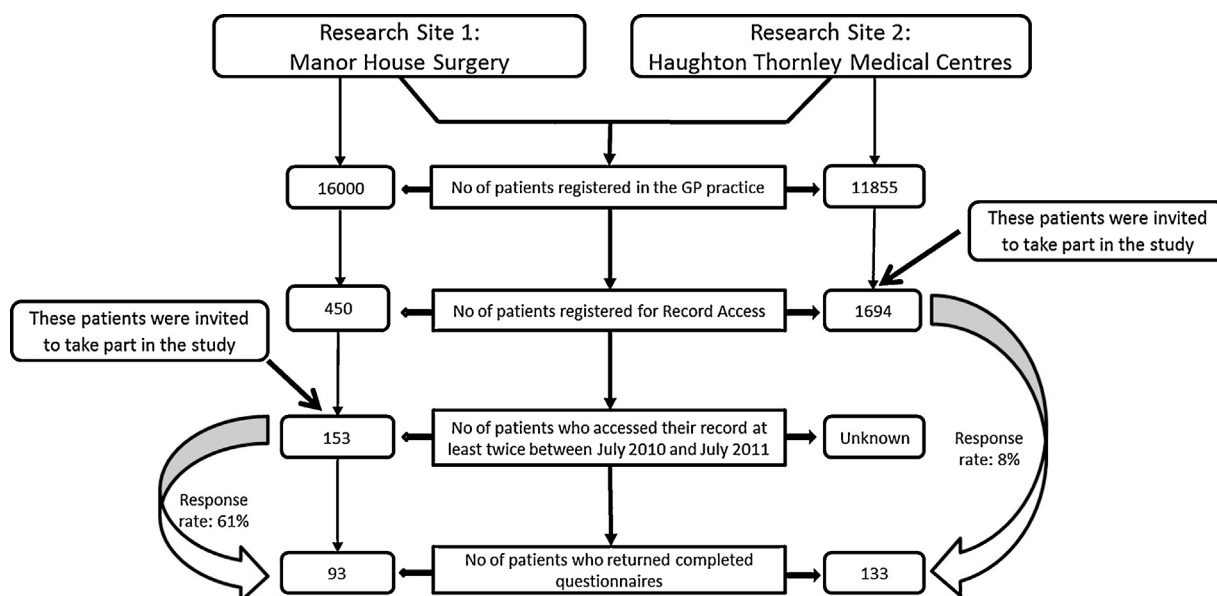
**Fig. 1 – Patient recruitment process in the two research sites.**

## 2.4. Participants

The key criterion for inclusion in the study was that patients had accessed their records at least twice in the previous 12 months. Different systems at the two surgeries necessitated a different approach being taken to identifying these patients. At the MHS, the online record access audit trail identified 153 patients who had accessed their online medical records at least twice between July 2010 and July 2011. Accessing records at least twice was the criteria for selection as we felt this was the minimal level at which we can consider that the records have been purposely accessed; a single access may be simply have been motivated by curiosity [16]. A copy of the questionnaire along with a covering letter explaining both the purpose of the survey and the procedure for returning the completed questionnaire were e-mailed to these 153 patients. Completed questionnaires were returned by 93 patients. At the HTMC, the online record access system did not allow identification of how often patients had accessed the system so copies of the questionnaire were emailed to all patients registered for record access ($n = 1694$). One hundred and thirty three patients from the HTMC who reported accessing the system at least twice returned completed questionnaires. An overview of the recruitment process is provided in Fig. 1. In total, 226 patients returned completed questionnaires: 93 from MHS and 133 from HTMC.

## 2.5. Ethics approval

These data were collected as part of the EHR access service evaluation conducted at the two surgeries and therefore ethical clearance was not required. Return of a completed questionnaire was considered indicative of the provision of consent. Participation in the study was voluntary and no data relating to patient characteristics was collected. Patients were informed that they would not be identifiable through reporting of the study findings.

## 2.6. Data analysis

Descriptive statistics were used to analyse responses to questions 1–5. This analysis is reported more fully elsewhere as part of a cost benefit analysis [17] but is briefly outlined here to provide a context for our thematic analysis of the text provided in response to the open ended questions, the responses to which were considered as comprising a single data set. This was conducted using an inductive approach. We sought to identify the most meaningful ways of classifying and grouping the comments that people had made. Two of the authors (SGSS and JB) familiarised themselves extensively with the data and cross referenced this to a developing set of themes. For illustration of the key issues raised by patients, we present some quotes from patients' comments in Section 3. The quotes are cited with an ID representing the patient number in the dataset.

## 3. Results

### 3.1. Perceived patterns of surgery contact as a result of accessing EHRs

Fig. 2 shows the percentages of patients reporting saved or extra phone calls and appointments with doctor, nurse, healthcare assistance and other professionals as well as personal time or money saved. The greatest savings as reported by patients related to calls to the practice and appointments with doctors. Thirty (13%) participants thought that they had made extra appointments with their doctor as a result of record access.
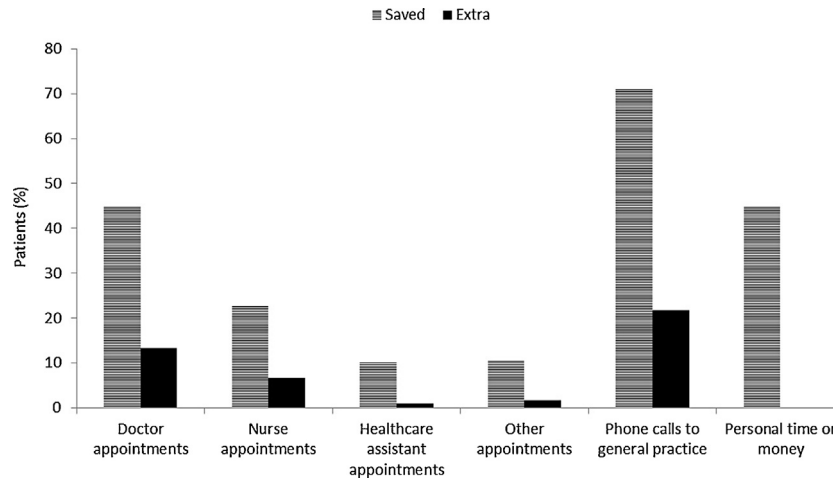
**Fig. 2 – Saved and extra appointments, phone calls and personal time and money as a result of access to electronic health records.**

| Table 1 – The presence of comments pertaining to each theme. | | |
|---|---|---|
| Theme | Number of patients commenting | As percentage of those patients that provided comments ($n = 173$) (%) |
| Making savings | 47 | 27.2 |
| Checking past activity | 58 | 33.5 |
| Preparing for future action | 39 | 22.5 |
| Setting new expectations | 15 | 8.7 |

### 3.2. Purposes and consequences of using EHRs

Of the 226 study participants, 173 (76.6%) provided comments about their EHR use. The analysis identified four main themes: making savings, checking past activity, preparing for future action, and setting new expectations. Table 1 provides an overview of the extent to which the theme was identified by those that left comments. Some patients provided comments that did not relate to these themes and the comments of others pertained to more than one theme.

#### 3.2.1. Savings
Patients associated having online access to their medical records with savings both for themselves and for their health-care providers. Patients reported saving themselves time (e.g. less need to take time off work for appointments) and money (e.g. for petrol or phone calls). There was an awareness of the possibility of possible savings for doctors' time through freed-up appointments slots.

> "For me the cost of a phone call and my petrol costs and for the practice the cost of seeing a patient to just give them a result and for no other reason so also freeing up an appointment for someone who needs to see their GP due to illness". [P#52]

Others were explicit that they had not made savings or that making savings was not an important issue rather drawing attention to having access EHRs as being indicative of better quality health care.

#### 3.2.2. Checking past activity
Patients undertook a range of checking activities online either as part of, or in response to, previous interactions with health professionals. The opportunity to obtain test results on-line, rather than to ring the surgery, was welcomed. It was clear that the provision of test results on-line was a valued facility; the process was trusted and provided reassurance. There was no suggestion of double-checking online results by ringing the surgery.

It was evident that such checking was not simply about transferring offline activities to those conducted online (as was the case for test results). Record access enabled new checking activities that had not been possible before. Most notably patients were reviewing the content or outcome of a consultation that they had had with their GP, for example to remind themselves about it, to confirm that it accorded with their recollection or to ensure that any previously agreed course of action was proceeding as anticipated. In doing so, people were attuned to discrepancies between different pieces of information – a wrong address, searching for the reasons for not hearing about an appointment, and picking up on things that needed to be rectified.

> "I noticed I had missed a consultation with surgeon but didn't know I had the appointment then noticed the surgeon only had my old address so I was able to make contact and explain why I failed to attend." [P#207]

> "Once when the consultant had written a letter to the surgery about my treatment plan, the Nurses had missed part of the information. They didn't realise they had to monitor my blood pressure and weight each fortnight when my medication was changed, but I was able to refer them to the letter and it was then done." [P#125]

Other EHR checking activity was not directly related to interactions with health professionals. For example, some patients printed out information, such as letters, from their records. Doing so seemed to provide a valued physically present and tangible marker of a particular health status or event. These print outs were also carried with a view to sharing with others both in anticipated encounters, for example with a consultant or nurse as well as in anticipation of possible unplanned encounters such as with ambulance staff in case of an emergency. The value of having a physical piece of paper was not explicable in terms of lack of trust in the technology. Rather the day to day accessibility this afforded was linked to anticipated potential benefits. These ranged from providing reassurance and a point of reference in the event of doubts about the accuracy of recollection through to providing evidence that was more credible to medical professionals should such situations arise.

"If I had a hospital appointment with a consultant I used to print off my recent results which saved them time. Once it even saved me having another blood test whilst I was there. I also used to print off a list of current medications and operations and ongoing treatments to keep in my bag. This proved extremely useful when I had an asthma attack and gave it to the ambulance medics on route to A&E [Accident and Emergency]. They got all the information they required without me having to take off the mask (nebuliser). It is hard to answer questions and remember what medications you take when you are afraid and struggling for breath." [P#125]

There were also instances of records being accessed and used to provide evidence that was required in relation to other aspects of day to day living, such as insurance or benefits.

### 3.2.3.  Preparation for future action

Information in health records about a particular condition sometimes stimulated further information seeking activities, for example, to find out more about a particular condition. Sometimes this was done through a general internet search, on other occasions the link provided was used.

"I had some blood test results, which I looked up online. Some of the levels were slightly outside the normal range but I looked up information on the web link for them and was reassured." [P#116]

The proactive ways in which patients used their access to their EHRs was also evident in the way that patients prepared themselves for an interaction with the GP or another health care professional. This enabled them to be clear about the issues to be covered in the appointment and to consider what questions to ask.

"Therefore, my intention, and use, of the Medical Records Access process was, and is, not so much to make, or vary, appointments, as to better enable me to understand the cause, make-up and progress of the chronic diseases that I suffer from, and their various medicinal treatments, so that I may be better able to understand and discuss these with my GP." [P#106]

It was thus clear that record access was not an end in itself, but that patients used it to support their decision-making and to discern what action to take. One action envisaged on the basis of checking records was making an appointment or deciding that an appointment was not necessary. If there was a problem with accessing a result – due to technical problems or because the result was not there – patients would also contact the surgery for clarification.

Monitoring the course of a condition over time was clearly important to some and here EHR access provided evidence of stability or change.

"Able to monitor my own progress without bothering the practice unnecessarily. For example, online medical records provided the date when last BP [blood pressure] test was done – and therefore when next due. Similarly for routine blood and other tests. The trend and pattern of the results over time can be seen, thus obviating the need to ask for such data from practice staff." [P#60]

It was clear that the information provided was generally taken to be a reliable signal of whether further action was required or not.

### 3.2.4.  Setting new expectations

For some, the process of accessing EHRs created a new set of expectations around what was possible in managing their own health and some frustrations were expressed when these were thwarted. Some of these frustrations related to technical issues around accessing the system or with information being temporarily unavailable. Other frustrations related to perceived limitations in the content (e.g. wanting to know more about test results or more details of interactions between the GP and the hospital) or the timeliness with which content became available. There was also evidence of instances where more information was required in order to interpret and make sense of the information that was there. This ranged from needing to know what medical abbreviations stood for, through to understanding the significance of a changed test result. There was certainly an expectation that information should be available more quickly on line than it would be via more traditional routes, such as a letter in the post.

A lack of usability in the portal through which EHRs were accessed was highlighted by some patients. For some this led them to contact the surgery, whilst others, when faced with this, were inclined not to use the system further.

"Login procedure a bit protracted. Why can't practice number be incorporated into user ID? Why 2 levels of security with 2 passwords?" [P#76]

For some the extent of information that was available was considered to be rather superficial and was not in line with what they imagined this to be.

"I was quite surprised about how little of my past medical history was available to me to view. I am unsure whether this is because what I have been allowed to view has been restricted or if it is because my records are not up to date yet having relatively recently joined the practice. If it is the former, I think it is pointless being able to access my medical records when what I want to know is so restricted."[P#28]

## 4.    Discussion

The results of qualitative analysis of information collected in an audit of those using online access to EHRs in two GP practices has provided evidence that patients actively used online access to HRs in order to make sense of their health status and the health care processes within which this was managed. Although patients appreciated that access to their records could save them time and money and provide increased efficiencies for healthcare providers, it is noteworthy that within the context of an audit that focused on assessing savings, there was considerable evidence of other benefits [5,18,19]. This chimes with the observations of Kranzberg [20] that the social consequences of technical developments can go beyond their immediate and intended purposes. EHRs were actively used for a range of purposes: monitoring and tracking previous health states, comparing a changing profile of test results, establishing what is normal, and adjudging acceptable degrees of variation in test results. In addition, access to personal medical records provided patients with the opportunity to identify and communicate errors and omissions in the records and in line with Olola et al. [21] this served as a source of indirect quality control.

There was evidence that participants equipped themselves through EHR access, taking the information into the consultation [15] and using it as a springboard for further clarification and prioritisation of discussion points [22]. It was also evident that people used EHRs in a proportionate and measured way and that this enabled them to feel more efficacious in managing their health [1,22].

The use of EHRs can be seen as linked to a range of health information seeking practices that people may conduct either prior to or following face to face consultations with health professionals [23]. The Web is the most widely used resource for health information and this is a growing trend: of those that use the internet, 71% used it at least once to find health information in 2011, compared to 37% in 2005 [24]. This practice may not always be welcomed by health professionals [25,26] but it is one manifestation of patients seeking to have a role in managing their health [27]. It is possible for EHRs to capitalise on this by providing links to relevant credible and authoritative sources and thus contribute to increasing health literacy [28,29]. Indeed, the record access system used in this study has links from the Read Codes, which are standardised codes of clinical terms used in IT systems in primary and secondary healthcare and social care in the UK [30] to patient information leaflets, and voluntary agencies associated with those health conditions (personal communication from BF).

The audit was understandably framed in terms of seeking to characterise the increased or diminished patterns of contact with the GP surgery that resulted from EHR use. Patients reported savings for themselves and clearly anticipated that EHRs could have a role in streamlining patient access to GPs. In line with previous research there was no evidence of access to EHRs generating excessive queries or seeking additional contact with health professionals [1]. Clearly, patients did have expectations about EHRs and expressed varying degrees of disaffection when these were thwarted. Arguably, high standards of online access to information have been set in a variety of commercial domains and patients may well use these as a reference point in generating expectations of how EHR access will function. There was some evidence that problems with access could lead to discontinuing use of EHRs. Once access is gained, the quality of the experience can be further enhanced by simple tools that can help make sense of results, for example explaining any abbreviations used.

It was noteworthy that the trust that is regularly accorded to GPs seemed to have extended to include the on-line manifestation of that relationship. The veracity of the information provided in the EHR was accepted and in many cases was taken to provide reassurance. It is also notable, though perhaps not surprising considering that those who took part in the study were those that had used EHR, that there were almost no mentions of the concerns about security and confidentiality which have been reported in other studies [31]. The reason for this is unclear. It might well be that it is those who have few issues with security and have a more trusting stance that go on to be early adopters of EHR access [32]. It may be that initial concerns are quickly outweighed by the benefits. Further research to understand this process more clearly is warranted and may assist with promoting confident EHR use more widely.

Increasingly, in line with the benefits that are associated with patients taking greater responsibility for their care, there are calls for patient and citizen involvement in the design of systems of an EHR [33,34]. If the aim of meaningful use is to be achieved more empirical work is required that attends to the context of EHR use and that takes account of the systems within which EMRs are embedded as well as the design of the technology itself [35]. We remain some way from the scenario where continuity of care is enabled not only through access to personal health records but where these records reflect contain information about self-monitoring activities related to wellness as well as illness [36].

Overall, and in line with the previous literature, it was found that patients generally evaluated access to EHRs positively: as convenient, useful, usable, and flexible. However, not all evaluations were positive – some were indifferent or negative. Negativity was generally associated with reports of EHR access as being limited. This was linked either to an assessment that there was little to access in them or in some instances being unable to access more frequently due to technical problems.

In terms of the weaknesses of the study we acknowledge that having the two different methods of recruiting patients to the study, though unavoidable, is not ideal. In particular, the reliance on patient self-report to ensure that they meet the criterion of having accessed their records twice brings a potential source of bias to the study that is not present in the case where the EHR record system itself indicated that the patient had met the access criterion for inclusion in the study. Moreover, it is not possible to discern whether the reported frequencies of subsequent contact with healthcare services are valid as we do not know how discrete and memorable EHR was for these patients. These factors are important in determining whether behaviour might be under or over reported [37], thus the results of the present study should be considered within the framework of the constraints the self-reports often pose. Finally we should reiterate that the results of this study were

**Summary points**

What was already known on the topic

- Patient access to EHR is currently limited in primary healthcare settings in the UK.
- Security, integration of diverse data, and costs are some of the main challenges in patients' access to EHRs.
- There is a resolve among healthcare regulators and policy makers to provide patients access to EHRs by 2015.
- Healthcare providers' bodies in principle support patients access to EHRs albeit with some reservations.

What this study added to our knowledge

- Patients actively use GP EHRs for a range of personal health management activities.
- Patients trusted the information provided in their EHRs as a basis for action and decision making.
- The process of accessing the EHRs may create a new set of expectations in relation to healthcare management.

obtained, and should be interpreted, in the context of a focus on the costs and benefits of EHR.

## 5.    Conclusion

The results of this study illustrate that access to EHRs provides patients with a means to a range of ends, which extend above and beyond savings. Most notably access and utilisation of EHRs enabled people to have an enhanced role in managing their personal health. There was no evidence that trust in health care communications had been eroded by online provision although clear patient expectations around both the content of EHRs and the reliability of provision and providers was also evident.

## Authors' contributions

SGSS analysed data and prepared the manuscript. RF, AH and BF conducted the audit. TY reviewed the manuscript. JB supervised data analysis and manuscript preparation and critically reviewed and revised the manuscript.

## Conflicts of interest

BF is a co-director of PAERS Ltd., the software company that makes the record access described in the paper possible. AH is a board member of a board member of Tameside & Glossop CCG and has talked at meetings sponsored by Pfizer, Kings Fund, BT Health and the DH.

## Acknowledgements

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