Viewpoint

The Primary Care Patient Record in the United Kingdom: Past, present, and future research priorities.

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Abstract
This article briefly outlines the history of the medical record and the factors contributing to the adoption of computerised records in primary care in the United Kingdom. It discusses how both paper-based and electronic health records have traditionally been used in the past and goes on to examine how enabling patients to access their own primary care records online is changing the form and function of the patient record. It looks at the evidence for the benefits of online access and discusses some of the challenges faced in this transition. Finally, some suggestions are made regarding the future of the patient record and research questions that need to be addressed to help deepen our understanding of how they can be used more beneficially by both patients and clinicians.

A brief history of the medical record
The history of medical records can be dated back as far as the Edwin Smith papyrus of 1600 B.C., which describes 48 surgical case histories and was most likely written as an Egyptian surgical manual [1]. Later examples include the case histories of Hippocrates from around 400 B.C. [2] and medieval Islamic texts from around 925 A.D., which were largely adapted from Graeco-Roman case histories [3]. Throughout the centuries, medical records were mainly used for teaching purposes [4] and the popularity of cadaveric dissection in the 17th century focussed the use of case histories for the teaching of anatomy [5]. By the 1700s, the keeping of case history books by physicians was becoming more commonplace [6] and medical centres were keeping increasingly detailed patient records towards the end of that century and into the 1800s [7][8]. In the late 1800s, attempts were made to control the content and quality of hospital records for insurance and medico-legal purposes [7], but it was common at this time for physicians to keep their own private notes separately to aid patient care [4].

In the UK, Lloyd George’s National Insurance Act of 1911 made it compulsory for employed men aged 16 -70 years to take out health insurance, and for General Practitioners providing their care to keep a written record of these patients [9]. Whilst the content and layout of the record was not stipulated, their size was determined by the tin storage boxes provided by the government at that time [10]. These metal boxes were later replaced by envelopes, but the size of the primary care record persisted after the introduction of the NHS in 1948 [10]. Early criticisms of the format of general practice records focussed on the inconvenience caused by the small size of the envelopes, and the absence of a separate problems list [10]. To overcome these problems, there were calls for GP surgeries to change to records in an A4 format in the 1960’s and 70s, but these failed to materialise
Such concerns were soon to be made redundant by the introduction of computerised records systems [9].

**The transition to electronic records**

The history of computerised records in general practice can be traced back to Exeter in 1970, when John Preece became the first GP to use a computer in the consulting room [11]. The first government sponsored electronic records system involved a small pilot by the Department of Health in Exeter in 1972 [9]. Ten years later, the government sponsored 'Micros for GPs’ involving 150 UK practices, laying the foundations for further innovations [9]. In 1987 two private companies began offering computer systems to general practices free of charge with a plan to offer anonymised data to pharmaceutical companies to recoup their initial investment [11]. These schemes were hugely popular with GPs and this, coupled with remuneration changes in 1990, resulted in an exponential growth in the number of GP practices using computerised systems [9]. While less than 5% of GP practices used electronic records in the early 80s, this rose to 80% in 1992 as government incentives continued [9] and by 1996, 96% of General Practices used computerised record systems [11].

**Evolving functions of the electronic record**

While the functions of the paper-based patient record expanded slowly over the centuries, the computerisation of medical records in primary care has opened up a wealth of additional functionality. The functions of the electronic patient record can be roughly categorised into clinical, administrative, and statistical, although there is some degree of overlap. The electronic record continues to be used primarily as a clinician’s aide memoire, enabling primary care staff to see what was discussed at previous appointments, or refer to a list of patients’ current and previous medical problems. Clinical tasks such as prescribing have become easier, safer, and more cost efficient as electronic record systems can flag allergies, contraindications, potential drug interactions, and suggest lower cost generic alternatives. Some electronic record systems link to knowledge databases such as the National Institute of health and Care Excellence Clinical Knowledge Summaries or provide handy links to patient information leaflets such as those hosted on ‘patient.info’. Computerised records make it easier to ensure patients are followed up in a timely manner through the use of a ‘recall’ function. Clinical audits can be carried out at the push of a button, enabling clinicians to ascertain how patient care can be improved, or identify patients who are slipping through the net.

Administrative tasks are now also vastly less labour intensive. Keeping an up to date list of patients containing accurate demographic and clinical information no longer requires metres of filing cabinet;
letters to patients and other specialities can be pre-populated with important information from a patients record; and patient record transfers between GP surgeries is now increasingly an electronic process. Electronic record systems are also used in the financial management of practices, for purposes such as securing reimbursement, budget planning and reducing costs. The electronic patient record system can also be used to enable secure communication between members of staff, reducing the risk of tasks being left undone and with the added benefit of an audit trail.

Computerised primary care records also provide a wealth of statistical information. The UK government has long seen the potential value of collecting such information [10] and there have been ill-fated attempts to monetise this information in the past by private companies [11]. The early GP computer enthusiasts designed computer systems to collect epidemiological data and this tradition has continued to the present day. Research using the Clinical Practice Research Datalink (CPRD), which holds data on over 11.3 million patients from 674 UK practices [12], has resulted in a multitude of improvements in patient care, and over 1,800 scientific publications [13]. There is a growing interest in using machine learning approaches to define disease phenotypes in electronic primary care health records [14] whilst others are employing statistical techniques used in astrophysics to develop predictive models of disease from the CPRD [15].

In addition to this, the patient record can now also be used by clinicians to send referrals directly to secondary care. Standardising information flow between referrer and service provider is becoming an increasingly important function of clinical systems. A 2016 audit of suspected cancer referrals in Leeds found only 48% were completed with the minimum required clinical information. This can lead to delay in investigation and/or diagnosis. By leveraging existing functionality within SystmOne, the ‘DART’ project to streamline the referrals process led to 100% of forms completed correctly within three months of introduction [16].

Projects such as this illustrate how clinical systems have the potential to both improve patient safety and free-up much needed clinical resources. However, some initiatives to improve patient outcomes by harnessing functionality within clinical systems may conversely have a detrimental impact on GP workload. The 2016 King’s Fund report aimed at “Understanding pressures in general practice”[17] cited the potential for new preventive services to negatively impact on GP workload. Preventive services (such as monitoring of chronic disease) have largely been made possible by recent advances in clinical systems. However, by linking chronic disease management functions to Quality and Outcomes Framework (QOF) targets, there is an inevitable pressure for a huge amount of
information to be manually read-coded within the record. Failure to do so can have a direct impact on practice income. Mindful of these tensions, it would seem an imperative that future initiatives to use clinical systems to improve patient outcomes must take great care not to adversely impact on a clinician’s workload.

**Enabling patients’ access to their own records**

Throughout history, the medical record has traditionally primarily served clinicians, and served patients only indirectly. The idea of enabling patients to have full access to their medical record, however, is not entirely new. For example, in 1973, Shenkin and Warner noted that “Dissatisfaction with the functioning of the medical care system has become widespread. Four serious problems are maintaining high quality of care, establishing mutually satisfactory physician-patient relations, ensuring continuity and avoiding excessive bureaucracy. We believe these problems could be alleviated, in part, if patients were given copies of all their medical records.” (p688) [18]. Early proponents of granting patients open access to their primary care record included GPs from Balsall Health Centre in Birmingham who started enabling patients to access their full primary care record in 1977 [19], and GPs from Wells Park Road Practice in London who enabled full access from 1983 [20]. Reviews of the impact of promoting such access have shown beneficial effects and minimal risks [21].

The introduction of the Data Protection Act in 1998 gave patients the legal right to access their health records [22], setting the scene for changes to come. Whilst the patient records aspect of the NHS Connecting for Health 2004/2005 business plan focussed mainly on providing a single electronic record for health professionals across hospitals, primary care and community services, it introduced a very limited degree of interactivity via the ‘chose and book’ service [23]. At the same time however, private companies were developing services which would enable patients to securely access their own electronic primary care record. In 2003 a private company started installing kiosks in GP surgeries that enabled patients to use fingerprint and pin authentication to gain access to their full GP electronic record [24]. By 2006 around 5000 patients had accessed their records in this way and it was also possible to gain online record access from home [24]. In 2007 the NHS introduced HealthSpace, an online personal electronic health record, which enabled people to enter their own health information and gain secure access to the summary care information in their GP record [25].

In 2010, the Department of Health outlined their vision of an information revolution incorporating online access, giving people more control over their healthcare and improving choice [26]. The same year, the RCGP published guidelines on enabling patients to access their electronic health records
[27], and later published a more detailed ‘Road Map’ on this topic [28]. Despite the British Medical Association’s concerns [29], the idea of online patient access was now firmly on the UK government’s agenda, and in 2014 the National Information board published a framework for action incorporating a vision stating that “In 2015, all citizens will have online access to their GP records and will be able to view copies of that data through apps and digital platforms of their choice... it is essential that citizens have access to all their data in health and care, and the ability to ‘write’ into it so that their own preferences and data from other relevant sources, like wearable devices, can be included... This framework prioritises comprehensive access – with the ability for individuals to add to their own records – by 2018.” (p21) [30]

The impact of online access to records

In 2012, to ascertain the impact of enabling patients to access their primary care record online, the Department of Health commissioned a systematic review of the evidence, supported by the RCGP [31][32]. The review identified 17 randomised controlled trials, cohort, or cluster studies and summarised both the benefits and challenges of providing patients online access to their record.

Potential benefits of online access

Providing patients with online access to their record has been shown to benefit both patients and clinicians. Online access enables patients to book appointments online; request repeat prescriptions; and view test results, letters, problems lists, and free text GP entries [33], although there are wide variations in degree of access provided by GP surgeries [34]. Patients who use online access report higher levels of satisfaction [35] and improved communication with healthcare professionals [31]. Benefits to patients include being able to use the online record as an aide memoir and to help them prepare for their next appointment [36] [34]. Patients like the convenience of online access, stating that it saves time and money, and reduces the number of telephone calls and appointments required [31][34]. Online access can also be empowering and increase patients feelings of autonomy, with one study noting that 77-87% of patients with online access feel more in control of their care [37]. Other benefits include enabling patients to share their records with family members or other healthcare providers, or to appoint a proxy to access their record [32]. Online access benefits both patients and clinicians in other ways, such as improving self-care, increasing uptake of preventive services, and enabling patients to spot medication errors and have them corrected [31]. One study found that 70% of clinicians reported online access improved trust, strengthened relationships, and enhanced decision making [37], whilst another found it reduced the annual number of visits and telephone calls [38].
**Challenges and potential negative consequences**

Despite the many benefits of enabling patients to access their record online, there are also a number of associated challenges. Clinicians have been especially resistant to opening up patient records for online access due to concerns that it will lead to an increased workload, cause unnecessary anxiety amongst patients, increase the likelihood of litigation, or challenge the current primary care business model [32]. Other concerns relate to security and confidentiality, equality issues (e.g. literacy, internet access), risk of coercion, and IT system compatibility [28]. The evidence regarding the impact of online access on clinician workload is currently mixed, but there is inevitably an increase in workload in the early transitional stage including activities such as staff training [31]. The patient record was not initially designed to be viewed by patients, and so the manner in which clinicians write in the notes will have to change if there are to be easily understood by a lay audience. One study, for example noted that up to 36% of clinicians changed record content to allow for online access, and up to 21% reported spending more time writing notes [37]. Despite clinician concerns regarding online access causing anxiety amongst patients, leading to an increased risk of litigation, or data security breaches, a review of the studies to date has found little evidence these concerns are realised [32]. There is some evidence however that online access could potentially lead to increases in health inequalities as those using online access are more likely to be white, female, and middle class [31]. Although one might expect online access to increase patient activation and thus improve health outcomes, less activated patients may be less likely to take advantage of online access [39] thus potentially exacerbating health inequalities. Disappointingly, reviews of the literature to date reveal a lack of evidence for the impact of online access on health outcomes [31][32], although an up to date systematic review is underway [40].

**Future directions**

We are still some way from realising the National Information Board’s vision of all UK citizens having read and write access to their full primary care record through a variety of digital platforms that enable them to upload data from wearable devices. The majority of GP practices offering online access do so in a limited way, and although there are some notable exceptions [41], most do not allow access to the clinicians free-text entries [42]. As De Lusignan et al. note, there is a need for further research to determine “how the medical record might be redesigned to guide and teach patients in a way that promotes self-management and ultimately improves health” [32] (p7). Such research should be multidisciplinary, drawing upon expertise from fields beyond medicine such as health psychology and human computer interaction. We need to engage with health economists to
ascertain the full economic potential of online access and the impact it may have on the primary care business model. Although some studies using self-report measures exist [34] [36] [43], further research is also needed to examine how patients actually interact with their online record and the functionality they would like to see. The impact of online access on the patient-clinician relationship and the power dynamic is also worthy of further investigation, especially with regards to the impact of enabling access to the full free-text record. All of these issues underlie what must be our prime concern, and something for which the evidence is still limited, i.e. how we can harness the potential of online access to improve health outcomes. Patient expectations regarding access to their health information are changing, and the newly introduced General Data Protection Regulations [44] will undoubtedly shift the conversation further towards full unrestricted online access. Clinicians will need to change how they view the patient record and learn to work with systems providers and patients to help instigate changes that will lead to improved health outcomes and increased savings for the NHS.

References


29. Cross M. BMA warns against letting patients have access to their electronic records. Br Med J 2011; 342: d206. PMID:21228010


35. Matheny ME, Gandhi TK, Orav EJ, Ladak-Merchant Z, Bates DW, Kuperman GJ, Poon EG. Impact of an automated test results management system on patients’ satisfaction about test
result communication. Arch Intern Med 2007; 167(20): 2233–2239. PMID:17998497


