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A Comparison of Approaches to Providing Patients Access to Summary Care Records Across Old and New Europe: An Exploration of Facilitators and Barriers to Implementation

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Abstract

Providing online access to their medical records should empower patients. National health services in Estonia, France, and England introduced systems to provide online access to summary health data. The Estonian patient access called "Patient Portal" shares similarities with the French system "Dossier Médical Personnel" (DMP). Both are patient-controlled records. The English system "Summary Care Record" (SCR) provided access to patients through "HealthSpace,"though has now been replaced by encouraging access to GP records. Denmark and Ireland also provided access rights to patients so they could view their records. Romania, Croatia, and Greece do not have national systems. The aim of this study is to compare adoption and uptake of patient access to summary data. The Estonian record was used by 3.6% of the population, the French one by 0.5% and the English system is due for closure with only 0.01% signing up for the most comprehensive access. Few countries across Europe have adopted patient access to summary health data at a national level, and where introduced, medical records have been accessed by less than 5% of the population.

Keywords:
Records as topic; Patient care; Health records, personal.

Introduction

Online summary health data should help empower patients to interact with health systems [1], may enhance doctor-patient communication [2], and appears to be something that patients of all social groups want [3]. However, neither patients nor clinicians appear to readily utilize them [4] and clinical teams may not be pointing patients towards online tools that might enhance their medical care [5]. A review in 2003 suggested that there may be modest benefits and low risks from patient access to records [6]. We previously compared the French and English systems of providing online access [7]. This study extends this analysis to explore how systems were implemented across Europe.

Materials and Methods

We developed a sampling frame to include countries in "old" as well as "new" Europe with different types of health systems – including different levels of provisions of primary care and of free or paid access to services; varying sizes, and geographical locations. We also added, as an inclusion criterion, that there should be an active informed clinical/primary care informatics practitioner in the country we could identify to verify any findings from the literature. We identified a series of target countries: Croatia, Denmark, England, Estonia, France, Greece, Ireland, and Russia. We contacted representatives of two other countries (one in old and one in new Europe), one responded they were too busy to respond in time, and the other did not manage to provide a response by the deadline for contribution.

We carried out a focused review of the literature. We used policy documents related to providing patients access to summary information on a national scale including statements from the Ministries of Health for our sample of European countries. We included the European Commission and WHO e-Health Country briefs[1,2,3]. We reviewed authors' personal libraries of scientific papers about their countries' Health Information System. Authors' personal notes and expertise have also been used, BS is working on the DMP project at the French Ministry of Health, PR has had a leading role in the design and implementation of the Estonian Patient Portal since 2002, and SdeL is leading the evidence and evaluation working group of the new policy for the English NHS.[4] When available, on-line reports of the user statistics from the nationwide Health Information System database are reported in the study. Findings are presented using the following headings: scope and access; consent, security and privacy; uptake and costs.

Results

We report findings from each of the countries investigated: Croatia, Denmark, England, Estonia, France, Greece, Ireland, and Russia. A global table of facilitators and barriers to implementation is provided at the end of the section.

Croatia

Croatia has a computerized primary care system. This system allows e-prescription and e-referrals to be sent directly to pharmacies and labs / hospitals, as well as retrieving and up-

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[1] http://www.who.int/goe/publications/atlas/en/index.html
[2] http://www.ehealth-indicators.eu/
[3] http://www.ehealth-era.org/database/database.html
[4] http://www.crd.york.ac.uk/NIHR_PROSPERO/display_record.asp?ID=CRD42012003091

dating patient medical data. The Croatian Institute for Health Insurance and the Ministry of Health and Social Welfare pay a monthly amount to all doctors who decide to join the e-health system (i.e., on the health system network). To date some 2400 primary healthcare teams in all 20 counties and in the City of Zagreb have been networked. Whilst the insurance-based system of e-prescribing and collection of data on electronic ordering of tests and referrals means that these lists of requests could be viewed online, this is not currently routinely provided [8], and there is no comprehensive patient access to medical records. Notwithstanding the low uptake, the Croatian Academy of Medical Sciences, in its declaration on e-Health, includes the provision of access to patients.[5]

Denmark

In Denmark, the health system is joined up with technologies that enable all interactions with the health service to be available within a few hours to primary care and other medical practitioners.[6] Basic online access for patients to their records started in 1977, with a detailed history available about all "patient contacts" since 2000 and access to e-Prescription data since 2005[9], with uptake was reported as 0.4% of the population. In 2006 e-consults were added to the GP contract with substantial uptake. Implementation was welcomed as email was considered a better alternative than telephone contacts; less time-consuming for twice the pay. What appears to be a highly interoperable system is little described in the literature. Denmark is probably a world leader in meaningful reuse of data and widely using email to consult and send reminders to pa-tients. However, there does not seem any greater uptake of record access by patients.

England

The English NHS National Programme for IT (NPfIT) project was an ambitious attempt to introduce IT across the health service[10]. NPfIT included the goals of making a summary electronic patient record accessible to all physicians involved in the management of a patient and also made summary access available to patients online. Like other NHS services, it was free to patients. The “Summary Care Record” (SCR) was planned to be universally accessible to health service professionals and to patients who signed up to join “HealthSpace.” However, due to low uptake and negative evaluation findings, a decision was taken to close HealthSpace and it will go offline in 2013 [4,11]. The original plan was complex; a patient’s “local” records for direct care, the so-called “Direct Care Record” (DCR) would be "private," whereas the SCR is national and shared. Subsequent to the demise of HealthSpace, a strategic review, the “Power of Information” moved away from a central summary record. This report suggests instead that all patients should have online access to their general practice computerized record by 2015, a position then adopted in the new national information strategy.[7]

The scope of the SCR was originally planned to be: Summary of accident and emergency attendances; Inpatient discharge summaries; Outpatient attendances; Out of hours primary care encounters; Health and social care common assessments; and patients own contributions made via HealthSpace. Its scope has now been restricted to medication, allergies, and adverse reactions to drugs. The consent model for the SCR was created post development according to an “opt-out” model. To opt-out either the patient applies centrally or this is coded in primary care.

In 2010 it was reported that £96.7m has been spent on the development of the SCR as a whole, to date, and that a further £48.8m is due to be spent on the project. There was controversy in 2011 following a review carried out by the National Audit Office (NAO), which highlighted the costs of NPfIT as well as problems of security, privacy, and traceability of data within the NHS.

Estonia

Since 2009 all health providers have been obliged to send standard datasets to the Estonian Health Information System (EHIS). These are standardised HL7 documents, held on a central database. Documents contain the originator and the providers’ digital identity. Patients can access this information digitally. The technology provides different user interfaces for different users including patients, drawing on different underlying data bases. Citizens have a patient portal that they can use to view their medical data, express their own health preferences and restrict access to documents. Following a launch in 2009, and availability of e-Prescription since 2010, around 75% of people have data in their record and 3,6% of the population have accessed their records [12].To date, there are more than 8 million medical documents in the EHIS. The costs of this system for 1,3 million population have been low, around 3 million Euros, with the annual running costs around 1 million Euros. Only a small (undefined) proportion of this is spent on providing patients online access to medical records. Future plans include access to biomarkers.

France

The Dossier Médical Personnel (DMP) is the national health care tool for sharing and exchanging information about individual patients. It was established by legislation in 2004.[13] It is a secure electronic health record (EHR) accessible on the Internet with full patient control of what is contained within it and what clinicians may access. DMP account holders are also able to view records of who has accessed to their DMP (to add or read information) and can therefore verify that any access is legitimate. The system was set up to be entirely private with no secondary use of the data included within it, or at least in its first stage. The DMP has been created by the Shared Healthcare Information Systems Agency (ASIP Santé) for the Ministry of Health.

The DMP is currently a set of documents indexed by metadata using the interoperability framework developed by ASIP Santé: the patient identifier, the author of the file, the type of the file, the date of the creation of the file, the title of the document, etc. It is completed by the physicians involved in the clinical care of a patient. The DMP is only opened by a doctor (GP, specialist or hospital practitioner) with the agreement of the patient according to an “opt-in” model. It can be accessed by the patient, and all physicians involved in the management of the patient if they have been authorized by the patient. All changes to the DMP are traceable: deletions, accesses, modifications.

The DMP is on the Internet. An Internet DMP portal called “patient web access” is provided. It is essentially used for patient access. Clinicians use the DMP-compatible version of their electronic medical records system to manually uploaded or entered data. The French DMP contains a lot of different documents, from discharge summaries to biological results and imaging.

DMP was launched in April 2011. The cost of DMP is 210 million Euros for 300 000 DMP in March 2013. There are approximately 60 million French inhabitants. The Ministry of Health is considering whether this solution is viable. Studies

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[5] http://www.amzh.hr/news%20and%20events.html

[6] http://www.time.com/time/health/article/0,8599,1891209,00.html

[7] http://informationstrategy.dh.gov.uk/

are being conducted to find out how to promote the adoption of the tool.[8]

Greece

In Greece, the National Health System (ESY - Ethniko Systima Ygeias) has been established in 1983 to provide free treatment to all. However, there have been recent changes due to austerity measures being introduced including much greater use of co-payment. Only few hospitals have integrated information systems, though many are in transition.

There is therefore no legislation yet about online data access for patients, though there are detailed legislation acts about patient data and access but this is not online-specific. The Hellenic Data Protection Authority (HDPA) states the patient whose personal data are being processed has the right to be informed about the information that is archived and about the purpose of this processing and the duration of his data processing, and also to ask for amendments or non-use of part of all his data. Greece lacks any integrated primary care system that might hold generic records [14].

Ireland

Freedom of information legislation provides patients access to their medical records. There was considerable concern about this back in the 1980s, similar to concerns being raised now in English primary care [15].

Ireland provides free primary care to the 30% who are most disadvantaged. Information technology (IT) is an increasing part of the system, but orientated towards professionals, for example the Patient Treatment System (PTS) helps identify hospital capacity/slots to treat patients waiting for operations or other treatment, the Patient Treatment Register (PTR) can be accessed electronically by health service professionals and patients to ascertain length of waiting times for different elective procedures, the Health Information and Quality Authority (HIQA) also provides data online about services and quality. National strategy includes setting up of a 24-hour National telephone and internet access, but this goal has not been realized.

Russia

There has been very little provision of online access at the national level across Russia. The health system, free at the point of contact, has undergone considerable reform [16], following a challenging period for health care in the 1990s. There are moves in Russia towards making large amounts of public information freely available online. A Federal service, the "Electronic medical card" (EMC) is under construction. No final decision has been taken concerning the types and the structure of documents to be uploaded to the storage. Documents will be uploaded into the EMC system by all public medical enterprises and, possibly by private clinics too. Rights of patients to access their data are still under discussion. It is also supposed that the system will be a hierarchy of regional systems, collecting medical data at the level of federal regions. There are 86 regions, some of them with populations of similar size to middle-sized European countries. At the same time, online appointment booking for local outpatients' clinic is rapidly developing in Russia. This service is far from direct access to personal medical data but its dissemination may train patients to use Internet and trust online services.

There is also a private free system for personal health records "med@rchive"[9] This combines two concepts. The first is the idea of the "responsible patient", i.e. the patient who is responsible for his/her health and is ready to organize and take control of his/her medical records. These records may be of various types, either entered by the patient himself, or entered or uploaded and approved by the authorized doctor, or uploaded automatically from other EMR systems. Patients are also intended to control access to these data, granting rights to other persons. The second idea is that the community of users of the proposed system will grow evolutionary. For example companies wanting to promote the health of their staff will join the system.

Whilst there are many interesting computerized medical records projects in Russia, few of them have reached maturity. Patients' access to their data has not been a major part of these developments.

Global view of barriers and facilitators to implementation

The main barriers and facilitators to the deployment of computerized medical records and online patient access are summarized in Table 1. Although it may be desirable that patients may access their medical record, this is not an absolute prerequisite for a health system. Indeed, if medical records are not implemented or supported, patients would have little opportunities to interact with these records. There is a considerable difference between clinician and patient views of an ideal online record.

Discussion

Principal findings

Whilst providing electronic access to a summary record or controlled access to a computerised record appear to be good ideas, none of the countries studied demonstrate a good uptake. Indeed where schemes existed uptake was at or below 3,6%. We need to carefully explore why this might be.

These schemes do not appear to have had sufficiently powerful benefits for patients to result in the level of uptake that their designers might have hoped for. The level of patient control varied between the systems. Most schemes appeared to allow the patient to control what could and could not be accessed by others, but this was not universal. Opt-in rather than opt-out and whether available on the Internet does not appear to make a difference to uptake. The majority of the schemes described have opt-out consent models, though there appears to be no difference between them in terms of uptake.

Where online access was provided as an extra service, it appeared to be very expensive. Where it was viewing data already available and built into the costs of wider systems, it appeared less expensive. English and French schemes were expensive and attracted criticism accordingly. The uptake of other cheaper approaches did not seem much higher, though often their true costs were unclear except Estonia where the total cost of nation-wide health information system was €7,5 per citizen.

Implications of the findings

Technologists, clinicians and policy makers need to reflect on why uptake is so poor among the population. Whilst the "activated patient", use of information systems, and provision of decision support are seen as important in chronic care, widespread uptake of online access does not appear to be part of this. Provision of access to records does not appear *per se* to meet patients' needs and may not be a wise investment.

If we accept that technology has the capability to help develop safer and more efficient health systems, we need to understand why there has not had greater uptake. We should invest in

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[8] http://www.ehealtheurope.net/Features/item.cfm?docId=194

[9] www.medarhiv.ru

more research to explore how and why this is and how this might be changed; something called for a decade ago [3,6].

Table 1 - Global barriers and facilitators to online patient access to their medical records

	Facilitators	Barriers
General	• Clear governance of National e-health strategy • Legal clarity (necessary requirements to the patient, health service provider, document standards, opt-in/opt-out data collection, access rights, etc. are defined by the legislation) • Mature ecosystem for e-services provided by the state • Use of internationally acknowledged document and data exchange standards. • Clear recognition that patients' access to medical data is not obligatory [Russia]	• Data integrity (physicians and hospitals may not forward required data to the central repository or fulfil this task partly) • Technical problems (users could not log in as their ID-card software or certificates had not been updated)
Doctors	• Instant access to patient data produced by other health care institutions [Estonia] • Almost 100% penetration of electronic medical records among GPs [Estonia, Croatia], and hospital doctors [Estonia] • E-prescription service [Estonia, Croatia] • Inclusion of medical informatics in Medical Schools Curricula [Croatia] • Improving medical knowledge through e-education	• Poor acceptance of hospital personnel to share medical data with patients [Estonia] • Poor acceptance of physicians to share "their" medical data with other physicians and patients [France] • Concerns about security and electronic authentication [Estonia, France] • Lack of familiarity with health information technology tools (average age of clinicians is high) [Estonia, France] • Computerized primary care and hospitals are not connected [Croatia] • Technical problems (current versions of medical health records systems are not DMP-compatible) [France]
Patients	• Wide range of e-services provided by the state including e-health applications such as e-prescription [Estonia] • Trusted security and authentication measures [Estonia, Croatia] • Confidence in the benefits of storing data on the Internet to improve availability of patient data at the point of care. • Control of the quality and completeness of data recorded in their medical records [France] • Patient empowerment and actor of their health (sharing decision with physicians, checking their treatment with similar patients on forums and social networks, etc.) [France]	• Available data are incomplete [Estonia] • Not enough transactional services, e.g. appointment booking and health declaration form are not provided [Estonia] • Concerns about the confidentiality of medical data • Poor awareness about advantages of e-health

It has been suggested that patients are interested in record access but unsure about access over the Internet. However, with increasing use of Internet banking and other transactions, this may not be plausible. And, whilst recent reviews of stakeholders report optimistically about their acceptance of this concept, this has not been taken up widely in the area surveyed.

Comparison with the literature

Projects supporting patient access to shared health care records showed to have low uptake in the studied countries. However, in Scotland there is widespread use of the Emergency Care Summary [17]. Kaiser Permanente has had two-thirds of its 9 million members[10] sign up for online services; with online booking of appointments, collecting test results and e-mail the most used [18]. The principal interaction has been doctor-patient interaction via email, with 7,000 Californian physicians receiving six million secure messages, resulting in fewer attendances and improved primary care quality. The United States Veterans Administration has also managed to register large numbers online with over 600,000 users making over 20 million "visits" over the Internet by 2008. The most popular service is online repeat prescription requests. However, incorporation of reimbursement into the electronic process may also be important in overcoming clinician resistance and get services established.

Limitations of the method

The data were taken from a limited range of countries in a single continent. Lessons from other nations excluded from our study may have added to the findings. The lack of literature and publication lead times may mean that we have underreported the level of uptake of technology in a rapidly moving field.

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[10] http://xnet.kp.org/newscenter/aboutkp/fastfacts.html

Conclusions

None of the models of access to online summaries or full medical records has been effective in the countries studied. This is despite generous investment in both English and French programmes. However, on line transactional services – repeat prescription requests, test results, and email enquiries – have been much more successful. Though, these have not been successful until reimbursement and the place within clinical workflow of these transactions have been established in the business process.

We make the following recommendations:

- Ensure that this is part of the business process – i.e., ensuring appropriate reimbursement is in place according to the norm for the health system.
- Focus on transactional services – appointment booking and repeat (refill) prescriptions – appear a good place to start.
- Next, add services which provide results and reminders. This will start the process of communication with patients – and support the learning process for patients and staff.
- Research carefully, and especially the patient safety issues and support systems need to provide safe on-line asynchronous communication (email) between clinicians and patients. Concerns about volume, missed messages, and other aspects of clinical risk.
- Near misses and critical incidents around use of online access to records need to be recorded as case studies; as part of an on-going confidential enquiry into risks. We need to differentiate between hypothecated risk and actual harm done. Risk is a function of "hazard" and likelihood. Patients and practitioners need to understand whether risk outweighs any benefits.
- Confidential reporting should also include whether there has been any exploitative access to others records.
- Research is needed to elicit areas of their records patients might find most useful, and how that data might best be presented.

Much like computerised medical record systems themselves, patient online access is readily technically feasible. Modest benefits are described, harm is hypothecated but not widely reported. Patient involvement in shared decision making is desirable, transactional services may be a better starting point than investment in online records access.

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