

# National-scale clinical information exchange in the United Kingdom: lessons for the United States

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## ABSTRACT

Over the last four decades, the UK has made large investments in healthcare information technology. The authors conducted interviews and reviewed published and unpublished documents to describe national-scale clinical information exchange in England, how it was achieved, and the problems experienced that the USA might avoid. Clinical information exchange in the UK was accomplished by establishing a foundation of policy, infrastructure, and systems of care, by creating and acquiring clinical computing applications and with strong use of financial and clinical incentives. Many software and hardware vendors played a part in this effort; they participated in a national framework created by the NHS in which standards for exchange are specified and their applications designed to make clinical information exchange part of normal practice. Great potential exists for cost reduction, increased safety, and greater patient involvement as a result of clinical information exchange.

## INTRODUCTION

Over the last four decades, the UK has invested in and achieved more electronic health information exchange than the USA. Although there are substantial differences between the healthcare systems of the two countries, the USA can learn from the successes and challenges surrounding the UK NHS information systems. The purpose of this paper is to describe national-scale clinical information exchange in England, how it was achieved, and the problems experienced that the USA might avoid.

## Types and degrees of information exchange

Several scales have been proposed to classify health information exchange. Walker and colleagues<sup>1</sup> use a four-point scale (box 1), while the Semantic-HEALTH project supported by the European Commission<sup>2</sup> uses three levels. In this paper we focus on the exchange of information in a form that can be read by a person using the receiving electronic system, corresponding to level 2 or 3 in the Walker scale, and level 1 in the Semantic-HEALTH scale. Alongside the technology, we consider cultural and organizational issues—for example, the content and organization of discharge documents can be standardized with organizational and professional leadership.

## Why information exchange is important Safety

Healthcare is likely to be safer if information such as allergies and current medications are known when new treatments are ordered. Knowledge of concurrent conditions permits consideration of

those conditions in decision making; if that information, such as results of an echocardiogram showing aortic stenosis, is not available, then unsafe management decisions may occur. Diagnostic errors may occur if the full history is not known, leading to programs of evaluation or treatment that are directed at the wrong condition.

## Timeliness, convenience, and patient autonomy

Time can be saved if a consultant or emergency room physician can verify information from the primary care provider's record rather than gathering it anew. If health information is exchanged electronically, it can be made available more rapidly, and can save the inconvenience to the patient and healthcare facility of gathering records, copying them, and transmitting them to where they are needed. The difficulty of gathering health information from its dispersed locations is a commonly cited reason for interest in personal health records<sup>3</sup> along with the ability to have oversight of the health record.

## Cost—benefit optimization

An increasingly important reason for exchanging health information is the potential to reduce healthcare costs. Most clinicians knowingly or inadvertently duplicate tests because they lack access to results of studies performed elsewhere, the incentive for which may be fee-for-service payment. The Walker analysis estimated that the savings that could accrue if level 4 information exchange were broadly available in the USA is US \$77.8 billion per year.<sup>1</sup> Although this figure has been criticized as too high<sup>4</sup> or too low, there is little doubt that, with greater information exchange, substantial savings could be achieved. Political leaders point to reduction in unneeded services as one strategy for reducing US healthcare costs<sup>5</sup>; duplication of tests may be considered among those unneeded services. Indeed, Title XIII of the enabling legislation for widespread electronic health record implementation in the USA anticipates such an outcome; it is sub-labeled Health Information Technology for Economic and Clinical Health (HITECH).

## Why study the UK?

The UK has undertaken extensive initiatives in healthcare information technology<sup>6</sup> on a scale far larger than past or currently planned efforts in the USA. The most recent has been described as the largest non-military IT program in history,<sup>7</sup> with US\$32 billion appropriated in 2002. One of the goals of the most recent English health IT initiative is clinical information exchange on a national

# Box 1 Model for classifying level of clinical information exchange (from Walker *et al*<sup>1</sup>)

1. Non-electronic (mail, telephone)
2. Machine-transportable data (fax, portable document format (PDF) files)
3. Machine-organizable data (e-mail of free text, HL-7 messages)
4. Machine-interpretable data (automated exchange of coded results)

scale.<sup>8</sup> As the USA embarks on efforts to reform its healthcare system, a review of the UK experience, looking at steps that are regarded as successful, but also at those that are not, is useful. In our experience, most US providers and medical informaticians are not familiar with the UK healthcare IT experience.

## The NHS and information technology

The UK NHS has been described elsewhere.<sup>9</sup> General practitioners (GPs) throughout the UK provide primary care to all citizens through agreements negotiated with the NHS and monitored using extracts from electronic medical record (EMR) systems. Emergency, outpatient and inpatient care is provided by consultants and hospitals also financed by the NHS. Most GPs are generally independent contractors, although almost exclusively state-funded rather than private practice, while hospital physicians and some 'salaried GPs' are employed by the NHS, although may have private practices as well.

There have been three large health information technology programs in the NHS over the past 20 years that have a bearing on electronic health information exchange, as shown in table 1. The accomplishments described in this paper occurred as a result of all three programs, and from other initiatives such as support for electronic records in GP offices by private industry.<sup>10 11</sup> The most recent and largest is NHS Connecting for Health (CfH), the agency commissioned to deliver the NHS National Programme for IT in 2002, formulated in *Information for Health* published in 1998,<sup>12</sup> on foundations laid by successive NHS national information systems agencies. For at least 30 years, UK primary care has been an early adopter of IT, with most practices computerizing prescribing and clinical record keeping over the past 15 years. CfH has been the subject of considerable debate in political<sup>13</sup> and academic<sup>14</sup> sectors.

## METHODS

This report is based on 1–5 h interviews with 37 individuals (listed in an online appendix) conducted between May and July 2009 by one of the authors (TP) and a review of published and unpublished documents. Interviewees were identified from published literature, by personal knowledge of their backgrounds,

**Table 1** Large NHS IT initiatives in the UK

|                                             |           |                                                                         |
|---------------------------------------------|-----------|-------------------------------------------------------------------------|
| NHS Information Management Group            | 1992–1999 | NHS Number, NHS Net, and other infrastructure, Read Codes, SNOMED CT    |
| NHS Information Authority                   | 1999–2004 | NHS Net, NHS Number for Babies, NHS Mail, IT skills training            |
| National Program for Information Technology | 2002–2010 | NHS Net 3 (N3), NHS Number adoption, Spine and local applications, PACS |

PACS, picture archiving and communication system; SNOMED CT, systematized nomenclature of medicine-clinical terms.

and by referral from people previously interviewed. In most cases, a summary of what was discussed was sent to the interviewee for review and correction. Each interviewee was also asked for published and unpublished papers and electronic documents relevant to points discussed, and many provided such information. Published literature was identified using Medline to find articles on information technology and health information exchange in the UK NHS.

## RESULTS

### Clinical information exchange in the UK

#### Requirements for clinical information exchange

We propose the following three-layer model to describe requirements for electronic clinical information exchange (figure 1). The first layer is a 'foundation': a legal, ethical, and social framework in which information exchange occurs; a secure medium for information exchange; and national standards for transmission of clinical information that are broadly adopted including the ability to identify senders and recipients and the individual whose information is communicated (table 2). The next layer is 'incentives': for providers to devote time and effort to send and receive information and for IT vendors to make it practical for information to be exchanged (table 3). The third layer is 'applications': for entry, storage, transmission, and receipt of information (table 4). The information to be exchanged must be in digital form, and there must be a place for it to be received, viewed, and stored in digital form by the recipient.

#### Foundation

##### Policy

Many UK policy initiatives have contributed to the level of clinical information exchange that occurs today. Public interest in information exchange has arisen from incidents that have received broad press coverage. The 'Victoria Climbié'<sup>15</sup> incident involved the tragic case of a child who received care from multiple providers, each unaware of the full clinical history, for what was later found to be a result of child abuse. The consequence of such cases was public interest in making a record of care available to emergency practitioners so that patterns would be more likely to become apparent. Conversely, inadvertent disclosures of private health information have heightened concern that electronic health information be carefully

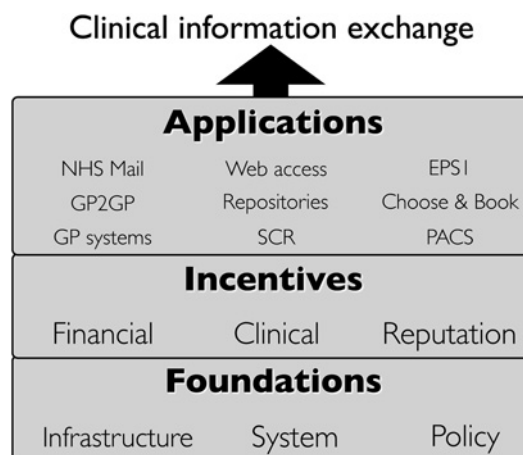


**Figure 1** The three-layer model of requirements for clinical information exchange. EPS, electronic prescribing service; GP, general practitioner; SCR, summary care record.

**Table 2** Foundations for information exchange in the UK

| Level          | Examples                                               | Comment                                                    |
|----------------|--------------------------------------------------------|------------------------------------------------------------|
| Infrastructure | NHS Number in England, CHI in Scotland                 | Uniquely identifies each UK citizen                        |
|                | Strong authentication                                  | Smartcards                                                 |
|                | NHS Net                                                | Currently 3rd version, N3                                  |
|                | National primary care computing application standards  | RFA 99 v1.1, GP System of Choice                           |
| Policy         | Coding of records                                      | Part of documentation culture. Read, SNOMED, ICD10         |
|                | Unique number for practitioners, practices, facilities | Regional reciprocal access                                 |
|                | Public discussion of privacy                           | National Information Governance board, Caldicott Guardians |
|                | National policies for protection of privacy            | Minimum datasets, etc                                      |
| System         | National service frameworks, NICE guidance             | Strong incentive to use                                    |
|                | GP coordinates care for UK citizens                    |                                                            |
|                | Largely single payer                                   |                                                            |

ICD, International Classification of Disease; RFA, requirements for accreditation; NICE, The National Institute for Health and Clinical Excellence.

protected. These concerns and others have resulted in two entities not found in the USA: Caldicott Guardians and the National Information Governance Board.

### Caldicott Guardians

A Caldicott Guardian is a senior person responsible for protecting the confidentiality of patient and service-user information and enabling appropriate information sharing,<sup>16</sup> who serves as the ‘conscience’ of an organization.<sup>17 18</sup> The Caldicott Guardian within the organization may determine what information can be disclosed and the local safeguards that need to be in place before a disclosure is made. An example of an issue in which the Caldicott Guardian may be asked to assist is when a police officer or researcher requests access to health information as part of an investigation. This role is different than the privacy officer and institutional review boards in the USA; the former typically services the entire organization in a policy development role, while the latter focuses on research. Further, while the Caldicott Guardian seeks to enable appropriate information-sharing while protecting privacy, the enabling language of health data privacy officers in the USA speaks simply to understanding of and enforcement of privacy rules.

### National Information Governance Board

The National Information Governance Board is an independent, statutory, multidisciplinary national body charged to consider ethical issues, to interpret and apply the law and policies, and to provide advice on information governance matters at a national level.<sup>19 20</sup> It reports annually to the Secretary of State for Health and is responsible for the NHS Care Record Guarantee for England. It meets monthly to consider issues referred to it concerned with how clinical information should be shared or not. After referral of an issue, it may recommend

a national policy for government or the NHS to follow, it may refer the issue to Parliament for possible legislation, or it may recommend other actions. It considers many difficult issues in the rapidly evolving area of protection of health information and also monitors access to person-specific health data for legitimate social purposes such as biomedical and public health research.

Other policies and practices include the Information Governance Toolkit, the Data Protection Act, and the Information Commissioner, and the requirement that each NHS organization develop information use policies, self-monitor and send reports to the Department of Health.

### Secure medium

‘NHS Net’ is a network used by the NHS for clinical and administrative purposes. It has developed over a decade beginning with the Information Management Group, and exists now in its third version ‘N3.’ It is for transfer of clinical information, for accessing applications used for clinical information exchange, and for clinical and administrative email (through NHS Mail). Use of the NHS Net is restricted to authorized users, including treating clinicians, many of whom possess a NHS smartcard. Connection for N3 stipulates no mixing of NHS Net and Internet outside of centrally controlled gateways.

Establishing the identity of, and authenticating and granting appropriate access to, users of NHS Net is accomplished using strong authentication by means of a username, password, and a token carried in a NHS smartcard typically worn around the neck by NHS staff. Without all three—username, password, and card (‘something you know and something you have’)<sup>21</sup>—authorized clinicians cannot access NHS Net or use NHS Care Records Service, Choose and Book, and the Electronic Prescriptions Service. These security provisions and others have been criticized as insufficient.<sup>22</sup>

**Table 3** Incentives for clinical information exchange in the UK

| Incentive                                                       | Who                       | Comment                                                                                    |
|-----------------------------------------------------------------|---------------------------|--------------------------------------------------------------------------------------------|
| Hospital penalized if discharge letters arrive >48 h            | Acute trusts, consultants | Introduced recently                                                                        |
| GP payments linked to Quality & Outcomes Framework <sup>1</sup> | GPs                       | Used in almost all GP practices                                                            |
| Practices appear more professional, more likely to meet targets | GPs, consultants          |                                                                                            |
| GP SoC, RFA 99, Common Assurance Process                        | Suppliers                 | Suppliers have strong incentive to comply with NHS standards                               |
| Vaccination, cervical screening and other targets               | GPs                       | Predates Quality and Outcomes Framework                                                    |
| Payment by results                                              | Hospitals                 | Requires capture of clinical activity data and central returns via Secondary Uses Service  |
| GMC and Royal College professional standards                    | All health professionals  | Encourage communication of relevant data with others to facilitate safe, high quality care |

GP, general practitioner; SoC, system of choices.

**Table 4** Current status of clinical information sharing in the UK

| Application                       | Status                                                                              |
|-----------------------------------|-------------------------------------------------------------------------------------|
| GP2GP                             | 10 22 140 uses, 23% of practice transfers.*                                         |
| Choose & Book                     | 21 million bookings; 35 000/day                                                     |
| PACS                              | 127 PACS systems, 27 Trusts                                                         |
| Discharge letters                 | Broad use, strong incentive to use                                                  |
| Summary Care Record               | Pilot, with 258 000 SCRs on Spine                                                   |
| EPSI                              | 300 million prescriptions, 83% GP practices using it                                |
| Regional repositories             | ≥2 regions                                                                          |
| NHS Mail                          | 983 152 messages are sent/received daily                                            |
| Emergency Care Summary            | National example in use for 3 years covering 5 million population of Scotland       |
| Pathology and radiology messaging | Pathology results messaging fully rolled out.<br>Pathology ordering in design phase |

Sources: <http://www.connectingforhealth.nhs.uk/newsroom/statistics/deployment> (accessed Apr 19, 2010) and other sources.

\*23% figure for GP2GP use derived by dividing number of uses by estimate of average 500 patient record transfers each year times the number of GP practices in England (<http://www.connectingforhealth.nhs.uk/systemsandservices/gpsupport/gp2gp/needed> (accessed Oct 24, 2010)).

EPS, electronic prescribing service; PACS, picture archiving and communication system; SCR, summary care record.

### National standards

Another important foundational element is the widespread use of nationally sanctioned standards within NHS computing systems. The NHS Data Dictionary, standard datasets, and standard messaging are examples of use of standards within UK health information technology. The collection of standards known as the GP System of Choice (GPSoc) includes application standards such as Requirements for Accreditation (RFA) 99 version 1.1 and more recently the Common Assurance Process for GP systems.<sup>23</sup> These standards first came into existence over a decade ago, and, coupled with incentives for use described below, assure that EMR systems have the functionality needed for electronic exchange of health information. The electronic patient records use standard clinical terminologies extensively. The UK primary care standard has been the 'Read Codes'<sup>24</sup> since the early 1990s, and SNOMED CT<sup>25</sup> is mandated to supplant this in all current deployments. The Read Codes were integrated into SNOMED CT some years ago. All shared clinical data are stored on the 'Spine' (described below) coded using SNOMED CT. The UK has also developed medication standards such as dm+d<sup>26</sup> and others including user interface standards.<sup>27</sup> The important point is that vendors who provide elements of the NHS IT framework are either contractually obligated to utilize these standards within their applications, or have strong financial incentives to do so.

### Unique patient and practitioner identifiers and inter-relationships

Several aspects of the UK healthcare system serve as a foundation for clinical information exchange. Unique identifiers for patients, practitioners, practices, and NHS sites of care are available for use in health information exchange. The NHS Number is the national identifier assigned by the Registrar of Births and is used to track health records for all patients in England. This was later combined with the NHS Number assigned by the GP during registration. The NHS Number has a long history, including the New NHS Number project, which gave new NHS Numbers to all registered patients in England. It has served as an important element for financial management and, more recently, clinical information exchange. Without some process to assure that the sender and recipient are referring to the same person, information exchange would be much more difficult, time-consuming, and potentially hazardous because of

the risk of misidentification. When combined with identifiers for practitioners and practices, the NHS Number is an important foundation for clinical information exchange and healthcare resource management. All UK citizens registered with the NHS have an NHS Number; there is no 'opt out' for assignment of a number as there is for information exchange—this reflects the importance of the NHS Number in English national administration, including links to birth and death registration and social security. In Scotland, the Community Health Index (CHI) number is more widely used. There is widespread public acceptance of the unique personal identifiers both for protection of privacy and greater data accuracy through minimized misfiling of patient records.

There also exists an explicit patient registration linkage between almost every UK citizen and a GP practice that coordinates their care and primary care medical record.

### Incentives for exchange of electronic information

Incentives are used extensively to encourage activities that directly or indirectly lead to exchange of clinical information. Two types of incentives are apparent: clinical and financial. These are applied to all involved in clinical information exchange: GPs, office staff, hospital physicians and staff, computing system vendors (referred to as suppliers), and others.

Most notable are the financial incentives; of these, the most pivotal is the support given to GPs to use computing systems. An important contribution to the broad use of EMRs in the UK is that the NHS reimburses GPs for hardware, software and maintenance (or the Trust (an NHS administrative body) is directly responsible for maintenance and insurance). This is done only if the GP selects an EMR that is certified, or accredited, to conform to NHS-established standards for electronic exchange of clinical information systems. Since the cost of these systems and their maintenance is high, this is a powerful incentive to select one that conforms to standards in the Common Assurance Program for GP systems. The standards include details on what and how data are sent through the Spine to other GP systems when a patient moves, and how data contribute to the Summary Care Record. The standards have been adopted by the systems used by the vast majority of UK GPs. In this way, the NHS has supported use of EMRs by nearly all UK GPs, and leveraging the funds used for this has brought about extremely high compliance by both vendors and GP purchasers of standards that permit clinical information exchange.

The British Medical Association lobbied for adoption of data exchange standards on behalf of its GP members, because, unless electronic exchange of information was possible, GP practice staff would need to enter by hand potentially large amounts of information about new patients moving into their practice from another practice, even if that practice held the information digitally. If they did not do this, they would need to refer to and store a paper record along with the electronic one. More recently, an additional incentive for digital storage comes from the fact that Quality and Outcome Framework scores, on which 30–50% of GP income is based,<sup>28</sup> would decline because newly arrived patients would appear in the denominator of the score as registered with the practice, but details that might count in the numerator, such as remunerated monitoring of coronary heart disease, would not appear in the numerator of this score derived from automated report transmission from practice EMRs to a national agency.

When a patient is discharged from hospital, if a discharge summary is not made available to the patient's GP within 48 h,

then the hospital will incur a financial penalty at the end of the year. The discharge summary does not have to be transmitted electronically, but if it is sent using non-electronic means it may be more difficult to achieve the 48 h requirement. When the next contract for hospital services is written, it is anticipated that this deadline will decrease from 48 h to 24 h. This achievement would be very helpful to continuity of care through handoffs between clinicians, which is fraught with risks of under- or mis-communication of important clinical information. The association between a patient and their GP makes it clear to whom the discharge summary should be sent. We have no data on adoption, or the clinical effect, of this incentive.

In recent national contracts between GPs and the NHS, out-of-hours (evenings, nights, weekends) care for primary care patients was negotiated to be given by practitioners other than the GP. Without access to the GP record, out-of-hours practitioners may not know medications, allergies, and other basic information unless the patient keeps an accurate record. The division between in-hours and out-of-hours care serves as a clinical incentive for information sharing. (Today, most out-of-hours care occurs without access to this information, although the number of communities in which this exchange occurs is growing.<sup>29</sup>)

These incentives, particularly the strong financial incentives, have been associated with substantial efforts to build on the foundation for clinical information exchange and, most importantly, to lobby for creation and use of the applications described in the next section.

### Applications used to store, transmit, and receive electronic clinical information

Over the last 25 years, EMRs have been adopted in nearly all GP practices (figure 2). Along with the change in work flow from paper to electronic processes that accompanied this adoption, a wide variety of applications have been developed for clinical information exchange within the NHS.

The ‘Spine’ is one of six foundational elements of the English National Programme for IT. It includes extensions to projects preceding CfH. The Spine is a combination of national IT infrastructure, a set of transactions, and applications that use those transactions, including Choose and Book, Patient Demographic Service, Summary Care Record, GP2GP, and EPS. The

prominence of the Spine within the large CfH program reflects the importance of clinical information exchange to the objectives of CfH. It underlies and permits much of the clinical information exchange that occurs in the NHS. Although its design and architecture have changed since the beginning of CfH, today it consists in part of NHS Net, NHS Mail, shared national services such as Central (Personal) Demographics Service, as well as central security architecture and all supporting services for the applications above and for the Secondary Uses Service.<sup>30</sup> Clinicians who wish to exchange information outside the walls of their facility must authenticate using the Spine, requiring both a Smartcard placed in the keyboard and a username and password. Once this is done, the Spine makes possible the exchange of information using the applications below.

Among the most prominent applications for exchange of clinical information is ‘GP2GP’, which permits exchange of the entire GP patient record from one GP office to another, between GP EMRs from the same or different software vendors. This exchange only happens when a patient changes GP registration, because of home relocation, a change in patient choice of GP, or (rarely) expulsion of a patient by a GP. The exchange includes encoded information and narrative text accompanying the codes, the combination of which comprises the patient’s EMR. It is transmitted according to standards permitting the received information to contribute to patient data used to derive Quality and Outcomes Framework reports. The data also permit the new GP to resume the preventive or chronic care plan begun by the former GP based on that patient’s prior EMR. At present, GP2GP adoption in UK practices is not yet complete, but is rising. In a recent year, there were roughly 4.5 million UK patient record transfers between one GP practice and another; of these, over 1 million (23%) were transferred using GP2GP.<sup>31</sup>

The ‘Summary Care Record’ is intended to be available outside the GP office when the full record is not. In emergency care, after-hours care, and, more recently, end-of-life care, it gives access to information that is often required to support acute care decisions. All the GPsOC compliant systems can now export this record. The summary is also being made available within the EMR software used by out-of-hours providers. There is an intention to expand the summary to cover additional data items in the future. There was debate over whether the patient’s explicit consent should be sought to create a Summary Care Record for potential future use, or whether all citizens except those wishing not to have one (‘opt in’ vs ‘opt out’) are informed indirectly by advertising—for example, via posters in GP clinics. The result of the debate was the current policy of opt out for creating the record, but with the requirement for permission from the patient before the Summary Care Record is viewed unless an emergency exists. There is still discussion about the content and boundaries of Summary Care Records.<sup>22 32</sup> A recently published evaluation of its early use showed its benefits to be ‘more subtle and contingent than early policy documents had predicted.’<sup>33</sup>

‘Choose and Book’ is an electronic system to replace the paper and telephone process for referring a patient to a consultant or other practitioner, and for patients to request the location and sometimes provider and appointment time for consultation. It is used primarily by GPs and patients, sometimes during a clinic visit. Its purpose is to speed the referral process, to give the patient additional choice regarding who they see and when, and to attach background information to the request. Some consulting practices permit viewing of the physical location of

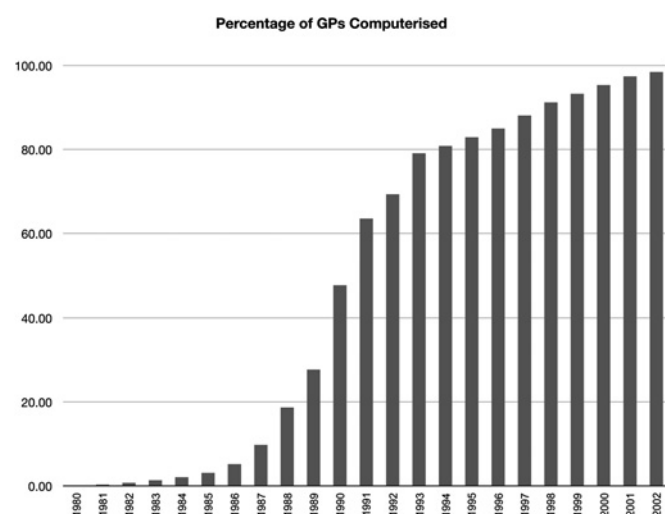


**Figure 2** Adoption of electronic medical records in UK general practices (GPs). Source: Independent Review of NHS and Social Care IT, August 2009.

the requested consultation; others do not show appointment availability for individual practitioners, but, in response to pressure from the British Medical Association and GPs, named practitioners are increasingly available for booking.

One of the most enthusiastically embraced national health IT systems is the network of 'picture archiving and communication systems' (PACS) now used in all Trusts in England (Peter Singleton, personal communication, 2010). Regional PACS repositories permit authorized clinicians, typically consultants, to view images and radiologist's interpretations for studies performed in that region.

'NHS Mail' is an email system devoted to NHS employees, authorized by professional societies for clinical use. It uses encryption for all direct communications and prevents spoofing of email sender identity, so it can be used for administrative and clinical communication with reduced risk of disclosure, which might occur using other email systems.<sup>34</sup>

Prescriptions are partially transmitted electronically, using a barcoded paper form given to the patient and used by some pharmacists. Around 30%, and rising, of the nearly one million prescriptions entered in the UK each day are processed electronically. The process is as follows. Most community-based prescriptions are written by GPs, since they manage all prescriptions other than a limited supply of discharge medications after hospitalization. A printed prescription is generated in the GP office and given to the patient, and the details of the prescription are transmitted to a central server on the Spine, tied to the GP prescription using a key. On the right border of the paper form is a barcode containing this key. When the patient delivers the paper prescription to the pharmacy, the pharmacy software reads the barcode to retrieve the Spine data, and then generates the prescription label, patient information, and data for internal pharmacy purposes. This process is referred to as 'Electronic Prescription Service 1' (EPS1) and represents a large volume of clinical information transfer within the UK. The second version of this process, EPS2, does not require a paper prescription, but instead will electronically transfer the electronically entered prescription to the pharmacy designated by the patient.

Some NHS agencies and regions have developed repositories to collect information from several facilities to permit viewing of data across multiple care settings. Examples include the Salford Integrated Record<sup>35</sup> and the Scottish Diabetes System, SCI-DC.<sup>36</sup> Although not available nationally in England, they permit authorized practitioners to have a consistent view of the EMR from multiple settings and systems, and for longitudinal summaries and outcome models to be created to support the management of long-term conditions. These repositories are not part of the English national IT programs, but add value to its infrastructure. SCI-DC is a project of the Scottish eHealth Strategy Board.

Applications to permit citizens to view their own health information include the NHS HealthSpace, some vendor EMRs, and regional initiatives.<sup>37</sup>

### Protecting the privacy of health information

Because of the growth in electronic health information and plans voiced by national leaders to increase exchange of information, an active, public discussion of protection of private health information has occurred. It is a breach of policy and a disciplinary offense to view records of patients for which the individual has no responsibility, which can be detected using audit trails. There is opportunity for those who are not deterred by such sanctions to view, copy, and disseminate electronic health information.

Much of this privacy debate has focused on the choice between opt-in and opt-out models for consent, as mentioned above, but wider concerns about protection of personal health information continue in the UK and elsewhere.<sup>22</sup> Despite coverage in the press,<sup>38</sup> on the web, and in hearings, at the moment the collection and exchange of electronic health information continues, as does the debate.

### DISCUSSION

Over several decades, the UK has created a foundation of policies and infrastructure, on which it has built strong financial, clinical and other incentives, to nurture an ecosystem of applications, which together have resulted in national-scale clinical information exchange. The three layers described in this paper have each been essential. For example, standards for data exchange alone are unlikely to have resulted in the achievements of the UK without policies, privacy protection, and incentives to exchange information. Creating one of the three layers alone is unlikely to have resulted in success; the presence of all three, on the other hand, has been associated with remarkable achievement. An estimate of the volume of clinical information exchange is given in table 4.

In spite of these achievements, the results of the most recent large-scale initiative, CfH, have fallen short of what political leaders expected. The complete health record is not transmitted from one city to the next at the time of need during an emergency as envisioned. Much of the success in information exchange has been on the local level and has resulted from local initiatives. The small but critical portion of the Summary Care Record that can be transmitted currently covers only a small part of the UK population and thus far has had limited clinical benefit.<sup>39</sup> In the case of elective clinical information exchange when a patient moves from one GP practice to another, a nearly complete<sup>40</sup> transfer of the record occurs, but only on roughly one-fifth of the occasions when such a transfer of care occurs. Use of GP2GP and Summary Care Record is growing, but not quickly enough to satisfy many. In one sector of health information transfer—imaging—the intended goal of national-scale exchange is closer to being achieved. There are financial incentives for transmission of discharge letters from hospitals to GP practices. Image transfer is also very common, and digital content of transfer of letters is growing.

Little work has been published on how clinical information exchange has benefited the UK clinically or financially.<sup>41</sup>

Yet despite the shortcomings of clinical information exchange in the UK, it is occurring on a much larger scale than in the USA. Discussions in the USA focus on the need for improvements in data exchange standards and the availability of EMRs to healthcare providers. The other layers described here receive less emphasis. The closest to a national 'Spine' in the USA is the NHIN, which has inconsistent participation across providers—not an issue in the UK with one NHS.

### Limitations

This analysis has several important limitations. It is based on interviews with 37 individuals over 2 months and review of materials available from them and from the publicly accessible literature. This topic is complex, the programs described here have developed over decades, and these complexities are unlikely to be fully apparent in such a brief exposure. It is likely that those with whom we spoke have different perspectives from those who were not accessible to interview, and so an acquisition or volunteer bias is likely. In a rapidly evolving

area such as healthcare IT, what may have been true when interviews were conducted or materials were written may no longer be the case, even if accurate at the time of interview. Also, some of the experiences described are those of demonstrator or early-adopter sites, which may be more optimistic than the majority. Finally, most of the interviews were with individuals in England, yet Scotland and Wales have had different experiences, successes, and failures than England. This paper mostly describes the experience in England rather than in the entire UK.

We have reviewed the strengths and some of the limitations of UK healthcare IT initiatives, including the largest one, CfH. The National Programme for IT is described by some as a failing project, and by others very positively. It is not our intention to judge whether timelines were met, budgeted funds were used optimally, or expenses were justified by accomplishments. Deeper analyses collectively may come closer to these goals. We have not focused on problems associated with health IT programs in the UK.<sup>42 43</sup>

### Lessons for the USA

The UK's remarkable achievements in national-scale clinical information exchange are the result of establishing a foundation of policy, infrastructure, and systems of care, by creating and acquiring clinical computing applications developed over decades, and with strong use of financial, clinical, and reputational incentives. Many software and hardware vendors play a part in this effort; they participate in a national framework created by the NHS in which standards for exchange are specified and their applications are designed to make clinical information exchange part of normal practice. The UK has thus made enormous progress toward enabling clinical information exchange while also assuring policies to both protect data and allow regulated access for desirable social good including research.

Features of the UK efforts that stand out are the use of strong financial incentives, RFA and GPSoc programs, envisioning and working to create the Spine, the broad use of EMRs in primary care, PACS implementations, and the national scope of UK healthcare IT programs.

Great potential exists for cost reduction, increased safety, and greater patient involvement.

Successive UK healthcare IT initiatives have encountered substantial obstacles over 30 years. The consensus among those interviewed is that efforts should be concentrated on local and regional exchange of clinical information more than the widely cited, but less common, scenario where an accident befalls a citizen in a distant city. Rather than use a single suite of applications within one large region, there is preference for more flexibility to choose applications that meet local requirements while complying with national standards—a major departure from the 2003–2004 philosophy of the NHS National Programme for IT. Working to achieve engagement of clinicians in all of these initiatives is critical to success, since the IT programs in the complex domain of healthcare benefit from the expertise of clinicians who practice within it. The UK course has been difficult, open, and creative.

As the USA renews efforts to improve the quality and control costs of healthcare, development of a framework, incentives, and applications for clinical information exchange is likely to be among the national goals. Studying the experience of a nation farther along the road may help.

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