

**Imperial College
London**

**Institute of
Global Health Innovation**



The Peter Sowerby Commission report

Bringing together primary and secondary
care data to improve patient care





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Foreword

Having the right information available is critical to providing good patient care. When several professionals and organisations are involved, sharing accurate information promptly is essential to integrating care for the individual patient. Analysing the data gathered while caring for patients is essential to auditing whether the best possible care is being provided, identifying how it could be improved and finding new treatments through research. It can also reveal how healthcare systems can be run more efficiently.

Many policymakers and clinicians consider better information sharing and more efficient use of the data in electronic health records (EHRs) to be important elements in providing safer and more effective healthcare that meets the twin challenges of financial constraints and increasing numbers of people with long-term illnesses due to an ageing population.

The relative absence in England of electronic patient records (EPRs) within hospitals, and the separation of hospital and general practitioner (GP) records have meant that clinicians do not always have the correct information available when treating a patient, and are therefore often unable to make relevant information readily available to clinicians in other organisations providing care. It has also limited the ability of the NHS and academic institutions to get the most from the information that is available about patients to improve their care, assess the impact of treatment or to identify how best resources can be used.

In February 2013 the Peter Sowerby Foundation, established by Dr Peter Sowerby, co-founder of EMIS, supplier of clinical information systems to GPs, hospitals and pharmacies in the UK, and his wife Ann announced a grant to the Institute of Global Health Innovation (IGHI) at Imperial College London. The purpose of the grant was to establish the Peter Sowerby Commission, with the objective of developing a strategy to bring together primary and secondary care data, and then through the Peter Sowerby Forum at IGHI to seek to ensure the proposals are implemented and to open new avenues for research to improve patient care. This report is the first output of that programme.

The Commission has found that much is going on to ensure clinicians have the right information available wherever patients are treated and to bring together the data locally, regionally, and nationally for audit and research purposes while preserving patient confidentiality. The recommendations of this report are aimed at making faster and more certain progress, raising standards of care in that process. We also need to look locally at how the NHS, universities and researchers can gather and make best use of the data to improve care now and in the future, forging ahead at a faster pace and more innovatively than can ever be achieved nationally.

We are grateful to the Peter Sowerby Foundation for making this commission possible and to the commissioners for their knowledge, advice and support.

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Terminology used in this report

In our research, we encountered a considerable degree of ambiguity regarding terms describing ways in which information about an individual's interaction with the health system can be documented and used. In this report we refer to electronic health records (EHRs) and electronic patient records (EPRs).

Electronic health records (EHRs) provide longitudinal data about a patient, extending beyond a single site of care. Their purpose is to reflect the overall health of a patient and his or her history of interaction with the healthcare system. EHRs may be made up of several individual records, which we term EPRs, below. For example, GP's records that include only information about the patient's GP-given diagnoses, appointments, prescriptions, vital signs, etc. would *not* meet our definition of an EHR because they are restrained to a single site of care. However, an EHR used or accessed in a GP's surgery which includes substantial, trustworthy information in a structured form about care given in a hospital and other care settings (diagnoses, medications, discharge summaries etc.) would meet the EHR definition. EHRs may also include patient-defined, genomic, or social care information under a broad definition of 'health'. Under this definition, there are far fewer examples of EHRs in the UK today than there are of EPRs. It is also the goal toward which the majority of this report is aimed.

Electronic patient records (EPRs) which are sometimes known as electronic medical records, are used in the course of clinical care in a single care setting, for example a hospital or GP's surgery. They are essential tools, which provide a means to input and access data about treatment provided by that institution on a single visit or multiple occasions, but do not reflect the overall health of a patient or their history of interaction with the healthcare system. Individual units in a hospital may have their own electronic records, but we have reserved EPRs to mean an accessible structured electronic record of a patient's treatment at that hospital, as a key policy aim is to integrate information from different hospital systems.

We recognise that these definitions may not be universally accepted; we have compiled them based on a number of international sources.¹⁻³ See appendix nine for a full glossary.



Summary

Electronic health records are essential to quality healthcare

Effective implementation and use of electronic health records (EHRs) can reduce errors, identify better ways of providing care, ensure coordination across care teams and give patients better care, better information and provide a better experience with regard to their health and treatment. If EHRs are safely and effectively introduced nationwide, and paper health records are replaced, the NHS in England could lead the world in the delivery of safe and effective patient-centred care. This document presents a strategy to accomplish this goal.

Developing a paperless yet safer and more effective NHS is an ambitious but achievable aim. The NHS already has several advantages: GPs in England are among the world's leaders in uptake of electronic patient records (EPRs), much of the necessary infrastructure to share relevant information between clinicians is in place, and the government is committed to the overall strategy of achieving a paperless NHS. However, health records between GPs and hospitals are separate, and few hospitals have implemented EPR systems. The challenge for the NHS is to develop EPRs in secondary care and to enable relevant clinical information to be shared electronically between clinicians in different settings by creating EHRs.

As will be shown, NHS organisations at local, regional, and national levels have made significant progress in developing technology to share information electronically and creating databases for research and auditing purposes. We examine specific examples of this progress in this report and have identified how efforts at all levels could be strengthened to pull benefits forward and minimise risks. We present five areas for action that will achieve this and suggest possible research areas that would inform and strengthen these initiatives.

**ACTION
ONE****ENSURE PATIENTS' RIGHTS AND EXPECTATIONS ARE MET**

Patients have a right to safe and effective care. To best achieve this, access to accurate information about their health is needed wherever they are treated. Patients already have the right to access their paper health record and should also have the right to access their EPR in each setting and their overall EHR, if available, and also to interact with them to check the accuracy of data, book appointments, order prescriptions, see test results, hold electronic copies, provide them to third parties if they choose, and to learn more about their own health and how to improve it.

**ACTION
TWO****ENSURE CLINICIANS HAVE IMMEDIATE ACCESS TO UP-TO-DATE INFORMATION**

Shared electronic records should be regarded as being as essential to care as the stethoscope and the thermometer. To ask clinicians to work in systems without immediate access to all the relevant information about a patient is to ask them to work in an unsafe environment.

**ACTION
THREE****DESIGN FIT-FOR-PURPOSE RESEARCH DATABASES AND USE THEM RESPONSIBLY TO IMPROVE CARE**

EHRs and EPRs allow the quality of care provided to an individual to be more easily reviewed and assured. Aggregating individuals' EHRs and EPRs into population-level databases provides a base of knowledge from which insights can be generated and improvements catalysed, improving the quality of care for everyone. Creating and using these databases heightens certain risks alongside the potential benefits. Therefore, it is imperative that databases are designed thoughtfully, used responsibly with respect for public opinion and information governance, and translated fully into improved care for public gain, which should then be publicised to demonstrate the benefits of the programme.

**ACTION
FOUR****IMPLEMENT OPEN AND INTEROPERABLE ELECTRONIC SYSTEMS**

Clinicians should have a single point of access to EHRs of patients they are treating, regardless of where the record was created. Additionally, patient data should not be inaccessible or expensive to access or at risk of loss because of commercial or financial decisions made by vendors of EPR systems.

**ACTION
FIVE****ENSURE THE IMPLEMENTATION PROGRAMME IS FIT FOR PURPOSE**

EHR implementations must be part of a collaborative exercise across health and social care systems regionally so information can be shared, helping the provision of integrated care. Changes in the structure or nature of providers and commissioners should be done in such a way as not to disrupt the flow of patient information across health and care systems or to impede progress in the implementation of shared records.

Possible topics for research and development in EPRs and EHRs

We present a programme of future research and development that would support the uptake and effective use of EPRs and EHRs. We focus on strategies to reduce patient risk, enhance patients' ability to participate in their own care and use data from EPRs and EHRs to improve clinical quality.

Introduction

The NHS in England could lead the world in the delivery of safe, effective patient-centred care through the use of shared electronic care records to reduce errors, identify better ways of providing care, ensure coordination across care teams and give patients better information about their health and treatment. This document sets out some of the key steps the NHS should take to achieve this.

It is an ambitious but achievable aim. Although we currently lag behind several countries and the best organisations in the USA, many of the building blocks are already in place. For example: NHS GPs are among the world's leaders in their use of EPRs, providing a comprehensive view of the treatment they have provided to a patient; much of the necessary infrastructure to share relevant information between clinicians is in place; and the government is committed to the overall strategy for achieving a paperless NHS.

The need for the development of shared records is recognised widely by clinicians because of the benefits it will bring. Our research, both in this country and abroad, has further demonstrated this. Having the right information available at the right time and using the most clinically effective protocols are critical to providing safe and effective care. Currently there can be information gaps because different organisations (and sometimes departments within organisations) hold different parts of a patient's record according to the treatment they have provided. Patients can also have better access to information about their care and be able to use it more easily to promote their own health and ensure their wishes and preferences are properly recorded.

Electronic health records (EHRs), and electronic patient records (EPRs) in individual institutions, are essential to good healthcare.^{4,5} They can:

- Give patients quicker and easier access to and use of their own health data, enabling them to contribute to their own care in ways that improve the quality of care and their experience of treatment.
- Reduce patient risk, for example by cutting prescribing errors and providing information promptly. Importantly, people with long-term conditions often have their care provided by several different clinicians and organisations. Sharing information is the bedrock of integrating care.⁶ As the numbers of (usually elderly) people with chronic diseases increases, so does the need for more integrated care and information sharing.
- Optimise care, making data readily available to monitor quality and identify where it can be improved in the short term, as well as supporting research into new treatments in the longer term. Linking data from different organisations is critical to finding out how well a patient has been treated in the course of their illness, whether treatments and services are having the impact desired and how they can be improved.
- Increase cost efficiency, for example by cutting the need for duplicative tests. We found a number of examples of this, although because of the difficulty of identifying costs of implementation it was not possible to assess overall savings.

EHRs are essential to quality healthcare

The advantages of EPRs in single care settings are well-documented (that is not to say that all potential benefits are realised), so we will lay out the additional evidence for EHRs here. As the Royal College of Physicians said in its 2010 report *The case and the vision for patient-focused records*:

“In recent years many national initiatives have stressed the importance of greater focus on high quality care, the needs and wishes of patients in the delivery of health services, and more patient empowerment and choice. If such requirements are to be met electronic records that are focused on the patient, rather than their disease, intervention or location will be essential. Such records must cross organisational boundaries, so that appropriate information can be recorded by both practitioners and patients, and accessed by them, in a wide variety of clinical and care contexts.”

We look at several key aspects of why EHRs matter.

EHRs can give patients more control over their own care

Patients with greater involvement in their health and greater self-management of their care are key strategic themes for all governments, who see it as a significant contributor to making health systems affordable and sustainable.

Development of EHRs can make it much easier to share information with patients. Among the potential benefits of this are: better understanding by patients of their condition; a reduction of anxiety caused by delayed communication; greater involvement of patients in decision-making and in managing their own health; better continuity of information across locations and care settings; and better quality data as a result of patients correcting errors in records.

A further benefit is that EHRs can enhance patients' ability to collaborate in and manage the organisation of their care. Other industries, such as banking and travel, have demonstrated how online self-service can dramatically cut costs for the provider while giving customers a greater sense of control. The same journey is beginning in health care, especially booking appointments, ordering prescriptions and recording health statuses. The furthest advancements today can be found in a small number of American healthcare delivery organisations and in early examples of EPRs in some GP practices in England.

One established example of patient-centred EHR comes from Chicago, where over 170,000 patients use NorthShore Connect, the patient portal that allows them to schedule appointments with NorthShore physicians, view results of medical tests, renew prescriptions, message their doctor's care team, and pay medical bills. They also have complete access to their electronic medical records, including their medical history, current medications, immunizations, allergies, past test results, and hospital visits.⁷

It is possible that EHRs could facilitate and accelerate a shift in the dynamics of healthcare delivery from the provider to the patient perspective. The European Union concluded in its study that these records can deliver more personalised 'citizen centric' healthcare, facilitating socio-economic inclusion and equality, improving quality of life, and empowering patients through greater transparency, access to services and information and the use of social media for health.⁸

EHRs can reduce patient risk and improve diagnostics and care

The most immediate benefit from EHRs is in their contribution to directly improving the quality of the care provided to patients and reducing the risk of harm. In our survey, 98 GPs (63 per cent) and 283 secondary care doctors (81 per cent) considered that sharing electronic records between professionals in different organisations would make a significant contribution to improving patient safety.

The advantages of providing information about the key aspects of a patient's medical history including their current medications and allergies, for those giving care out-of-hours or in Accident and Emergency (A&E) and in cases where the patient may be cognitively impaired, unable to speak English or have complex co-morbidities, are intuitively self-evident. In interviews, a number of respondents identified access to timely information as 'invaluable' for out-of-hours care. Our case study on page 17 gives an example of what can happen when this is not available.

Medication errors are a well-known source of avoidable harm to patients. The European Commission states that when applied effectively, eHealth (a broader term which encompasses but is not limited to EHRs, see appendix nine): ‘helps reduce errors, as well as the length of hospitalisation’.⁸ There is strong evidence of the impact of EHRs on medication errors, for example the introduction of the electronic care summary (ECS) in Scotland has resulted in a decreased risk of medication error.⁹

Staff participating in a pilot project in NHS Lanarkshire found that clinicians viewed the ECS for 75 per cent of patients and in 22 per cent of cases the ECS contained information unavailable from other sources. Overall, data from the ECS prevented harm to 23 patients by reducing missed doses of prescribed medication and preventing administration of contraindicated medications.¹⁰

But it is not only in A&E departments that sharing information electronically about patients can bring benefits. When a patient is seen in an outpatient clinic, up-to-date patient records can be unavailable or incomplete, with recent test results sometimes missing. An evaluation of the impact of missing diagnostic test data in outpatient clinics showed that in 15 per cent of appointments, clinical information was missing from the notes, and that in over 20 per cent of cases clinicians felt this posed a risk to the patient rating from a minor threat to the risk of a serious adverse event.¹¹

EHRs can improve communication

In June 2010 only one in three GPs received discharge summaries within 48 hours, according to an NHS Alliance survey. Most GPs (77 per cent) felt that patient safety had been compromised by inadequate discharge information.¹²

In our survey, the most common way for GPs to receive discharge information was through the post. The case study on page 25, gathered in the course of our research, demonstrates the weakness of current discharge arrangements.

Our interview with Brent James of Intermountain Healthcare revealed a contrasting experience. He told us how the use of EHR systems at Intermountain to coordinate home health treatment and community teams has helped to maintain a no-readmission policy across their 22 hospitals, and that Intermountain were the only US healthcare system last year to have zero readmission penalties from Medicare. Intermountain is just one example of a number of American hospitals such as Henry Ford Health System and Banner Health who have used their advanced EHRs and analytics capabilities to reduce readmissions.¹³

Use of EHRs can lead to better care for people with chronic diseases

People with long-term conditions now account for more than 50 per cent of all general practice appointments, 65 per cent of all outpatient appointments and over 70 per cent of all inpatient bed days.¹⁴ These patients are frequently users of multiple parts of the health and social care system and account for approximately 75 per cent of the overall health and social care spend in England.¹⁵

Chronic disease management requires a high degree of information sharing between professionals, since patients receive continuous, multidisciplinary care with frequent clinical contact with different professionals, often in different organisations, to provide care and to assess changes in risk status.

Failures of coordination in care across care settings are an increasing challenge for health systems as the number of patients with multiple co-morbidities increases. There is good evidence that EHRs have the potential to remedy many of these problems. Evidence of this can be found in appendix three.

EHRs can optimise care now and in the future

EHR systems can provide data that can greatly enhance our ability to monitor the quality of healthcare and to conduct research into new ways to care for patients in the future.

There are three closely related mechanisms involved in this. Firstly, clinician decision aids can apply algorithms directly to the data held in EHRs and advise clinicians on management of patients within best practice guidelines. These can be applied by individual organisations that have provided one aspect of care through their EPR or across several organisations to get a more comprehensive view of a patient's or population's care. Secondly, data extracted from EHRs and loaded into data warehouses can be used to audit compliance with such guidelines and their impact on patient outcomes. Thirdly, the same data, once anonymised, can also be used to conduct research into the safety and efficacy of new treatments. Linking data collected from a series of separate EPRs can also have the same effect. Specific examples of these applications are given in appendix five.

CASE STUDY

Renal Patient View

Renal Patient View (RPV) is a secure internet-based system that enables kidney patients to view their live test results online and obtain information about their kidney disease. The system was designed specifically for patients' use and is available at 43 of the 52 kidney units in England. It has over 17,000 registered users. NHS Kidney Care supported the further improvement of RPV by commissioning the development of enhanced interactive capabilities, including an online discussion forum, and tools to help patients add data such as blood pressure, glucose and weight readings to their records.

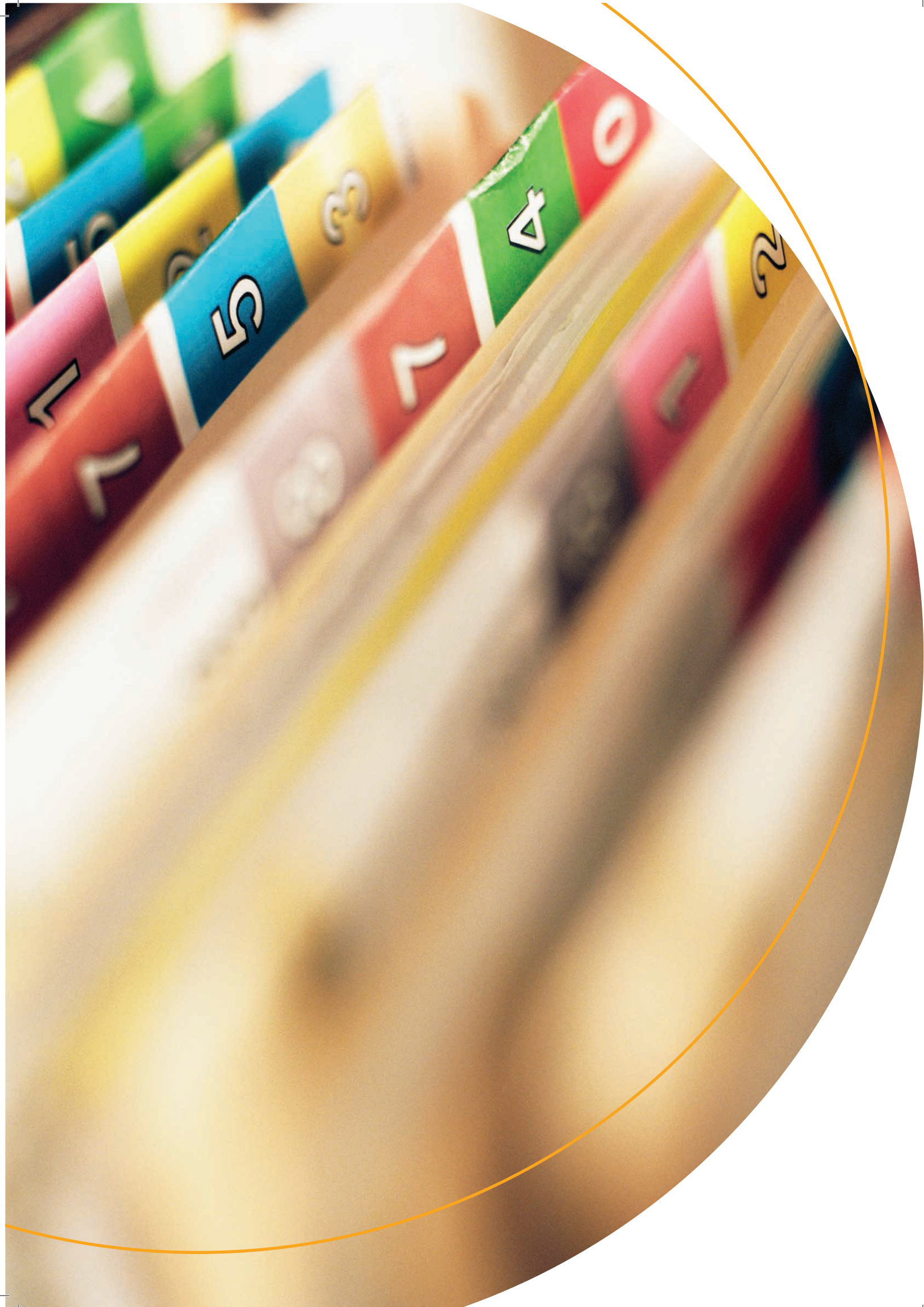
A recent evaluation found that the system improved patients' understanding of their kidney health and how factors such as diet could impact on it. It

increased their sense of control over their care and enhanced their ability to self-care; users of RPV were noted to be less reliant on professionals to make decisions and manage aspects of their care. Patients using the system felt more involved in decisions about their care and communication with professionals was improved.

This example supports the view that providing patients with continuous access to their health record could foster patient involvement in decision making about their own care, and enhance their capacity to self-care.

SOURCE: Mukoro, F. *Renal Patient View: a system which provides patients online access to their test results: final evaluation report*. NHS Kidney Care. webarchive.nationalarchives.gov.uk/20130504185629/http://kidneycare.nhs.uk/document.php?o=481 (February 2012, accessed 12 May 2014).





The state of play in England

The NHS already provides great advantages and opportunities to develop EPRs and EHRs and to use the data available for audit and research for the benefit of patient care. It has the potential to become world leading. Virtually all GP practices have EPRs that are integral to the care of patients and the management of the practice. English GPs' surgeries are among the most computerised in the world, far outstripping many other countries, as demonstrated by the 2012 Commonwealth Fund survey.¹⁶

The whole population has an NHS number, the unique identifier that is essential to the transfer and linkage of information between organisations. In addition the NHS itself offers a cohesive structure, with the organisations within it operating to a single set of rules and values enshrined through the NHS constitution.

Previous programmes have been attempted and despite some initial failures, lessons can be learned and implementation can be improved in the future. The NHS National Programme for Information Technology (NPfIT) had some successes, for example in establishing a national electronic infrastructure and a set of national information standards.

The Organisation for Economic Co-operation and Development (OECD) recently reported that the UK has the most comprehensive suite of national health databases of all 19 countries participating in their study.¹⁷

There are local and regional EHRs being developed and used to improve patient care and to engage patients more in their own care. There are also many examples of primary and secondary care data from separate record systems being linked for audit and research purposes that have led, or will lead, to better care and better use of taxpayers' money. Specific examples of these can be found in appendix six.

Despite its advantages and examples of progress, significant weaknesses remain. Overall, our research showed the NHS in England lags behind leading countries in Europe (particularly Denmark) and elsewhere and leading organisations in the USA in its use and development of EPRs in hospitals and EHRs more generally for patient care and engagement with patients. The challenge for the NHS is to provide comprehensive electronic records in secondary care organisations and to link these with the wealth of information in GPs' electronic records so that all clinicians can have access to the right information at the right time. We examine some examples of weakness in the NHS in appendix seven.

This government, like its predecessor, has committed itself to improving the availability and use of EPRs and EHRs, to achieving a paperless NHS by 2018 in its white paper *The power of information*,¹⁸ giving patients greater access to their health records, improving the availability of data and strengthening research. Key examples of policies that will be undertaken can also be found in appendix seven.

These and other policies and local initiatives will bring about significant improvement. However, our research identified a number of further steps that need to be taken to quicken the development of EPRs in hospitals and EHRs more widely, and to enable the benefits for patients to be realised. The next section discusses these in detail.

On the basis of our research both here and in leading-edge countries and organisations abroad, we consider there are five areas where further development is needed nationally and locally if more rapid and certain progress is to be made to develop EPRs and EHRs and to realise the benefits for patients. For each area, we explain the basis for our thinking, suggest two principles to help set aims and guide future action and put forward recommendations to help make those principles a reality. Our key recommendations are in bold.

The research methodology for this report involved a combination of qualitative and quantitative and primary and secondary research methods. Desk based contextual research, including a literature search, was undertaken to ensure that the research was well-grounded in an understanding of the relevant literature, policy and legislation reviewed throughout the research. Semi-structured interviews were conducted with 43 staff in NHS organisations, clinical and technical experts and national regulatory and government departments, including some from outside England. A national survey in England of 150 GPs and 350 doctors in secondary care about the value and use of EHRs was conducted in December 2013. Additional details regarding our methodology are in appendix two and a full list of participants is shown in appendix three.

ENSURE PATIENTS' RIGHTS AND EXPECTATIONS ARE MET

Benefits to patients lie at the heart of implementing EHRs. They may make clinicians' jobs easier and offer scope for greater efficiency, but, as we have seen earlier, the main reason is that they enable safer, more effective care to be provided than is achievable under current arrangements for keeping and sharing information. Evidence of this can be found in appendix six. Patient confidentiality has rightly been emphasised in connection with EPRs and EHRs, but even more important are the potential risks to patients without them. This should be the focus of attention.

Our first, overarching principle that should guide all action is therefore:

Patients' rights to safe and effective care implies that accurate information about their health and their care is available when it is needed and wherever they are treated. If their care is transferred to another clinician or organisation, they have a right to expect that the relevant information about their care can be made immediately available to the receiving clinician or organisation.

All our recommendations are geared to achieving this.

Our second principle under this theme concerns patients' rights of access to their records:

Patients currently have the right to access their paper record. They should have a similar right to access all information held about them in electronic formats, subject to existing restrictions on data protection. Patients should be able to interact with their electronic record to check the accuracy of data, book appointments, order prescriptions, see test results, hold electronic copies and provide them to third parties if they want, and to learn more about their own health and how to improve it.

Giving patients electronic access to their records will enable them to collaborate more in their care, manage their medical conditions better, achieve better coordination and encourage professionals to improve the quality of care, including the quality of record keeping and data.

The Public Inquiry into Mid-Staffordshire NHS Foundation Trust under Robert Francis QC¹⁹ recommended (Recommendation 244) that:

"Patients need to be granted user friendly, real-time and retrospective access to read their records, and a facility to enter comments. They should be enabled to have a copy of records in a form useable by them, if they wish to have one. If possible, the summary care record should be made accessible in this way."

Evidence in appendix six gives examples of patients using their records to improve their care and experience, including putting pressure on clinical professionals to improve the quality of the data. But, despite the welcome examples in England, there are significant cultural and technical barriers to be overcome. The cultural barriers are the most significant.

First, and perhaps most significantly, professionals can be reluctant to open up 'their' records. The Royal College of General Practitioners (RCGP) has taken a welcome lead. It issued guidance in 2010²⁰ on the benefits of patients' access to their record and advice on how it could be implemented, and followed this up with Patient Online: The Road Map²¹ on how patients could be supported to gain online access and engagement with their GP records. It has been supported by further guidance on safe record keeping from the Department of Health and the British Computing Society.

This attitude is not always reflected in surgeries across the country. Despite having the capability, only a small proportion of GP appointments are booked online (see appendix seven), and the comment from one interviewee who thought that online appointment booking would result in his surgery being swamped with relatively trivial concerns.

UK doctors are not alone in this. Kaiser Permanente reported to us that individual hospital departments had been allowed to choose when to open their appointment system to online booking. In one hospital, the last department had decided to take this step two-and-a-half years after the programme was introduced.

Patient read-write access to EPRs and EHRs also brings additional issues over and above access to paper records. If patients can add information to their record, what duty do clinicians have to respond to it?

We found widely differing views on this point in our interviews. Kaiser Permanente did not expect clinicians to always review and act on all patient-submitted data, citing uncertainty over the accuracy and timeliness of such input and potential issues of liability if clinicians acted on the basis of information that proved unreliable. Scotland took a similar view in respect of diabetes patients. In contrast, Intermountain had been successfully enabling patients to input data and then using that to flag alerts for clinicians (see page 22). Clear ground rules can resolve this issue, even if the results are different.

The difficulty of engaging patients should not be underestimated, and exemplified by the NHS's HealthSpace programme, which was cancelled due to lack of popularity.²² Our interviews and research showed that those systems that are furthest advanced in making health records open to patients – for example Denmark, Kaiser Permanente, Scotland, Group Health, Allina Health, and Intermountain – have found that securing patient engagement has not been easy. In Kaiser's experience, for example, there were particular difficulties getting equal uptake among black and Hispanic communities, which have lower rates of broadband internet and smartphone access.^{23, 24}

Even after records are made open and patients gain access, usability and intelligibility present further challenges. User interfaces can also be unwieldy – the PAERs system²⁵ for example is currently redesigning its user interface to address this – and medical records are not always easy to understand. Going beyond transactional activity (appointments, repeat prescriptions) so that patients can take more control over their health is likely to be demanding but worthwhile.

One clear case for patient (and in this case, carer) engagement with records can be found at the beginning of life. It is common for parents to have a paper child health record (known as a 'red book' in England), and an electronic version has proven effective at Kaiser Permanente.²⁶ An eRedbook project is underway in England and may provide an exemplar and precedent for translating familiar paper-based engagement into electronic engagement.²⁷

The government has already taken action through changes to the GP contract to require sharing of a patient's Summary Care Record (SCR) and to encourage, for example, online transactions with patients. However, this still leaves gaps in terms of access to and interaction with the full GP record, consistent with the 2012 NHS mandate; access to and interaction with secondary care EPRs (which are less well developed than those in general practice); providing access to information that is held by separate records, and encouraging greater patient engagement.

Our recommendations below are designed to address these points. We regard the first two as particularly important.

RECOMMENDATIONS

- Legal provisions should be introduced to implement patients' rights to access, interact with and, if they choose, share their electronic health record. This should be consistent with the commitment in the 2012 NHS Mandate that by 2015, everyone who wishes to will be able to get online access to their own health records held by their GP. By 2015 all patients should be able to view, interact with, download and share their GP records.
- NHS England should inform patients of their rights and encourage them to seek access to personal electronic information. It should work with patient representative organisations to examine whether there is scope and appetite for patients to share records with patient groups as a trusted third party providing (anonymised) information for research purposes and in return offer advice on care and mutual support.
- Secondary care records should be opened up in the same way as primary care records at the earliest possible point. A commitment to ensuring patients have access to all electronic information held about them, within existing data protection rights, by a fixed date should be made. Interim arrangements could be put in place whereby, as a provider reaches a specified level of digital maturity, patients are given access to its EPR systems to use and share on the same basis as in primary care.
- NHS England should investigate the market for and development of patient-held coordinated care records (i.e. a patient's own EHR) that draw on GP, hospital and social care systems and their potential use in the NHS. The technology underpinning the Hampshire Health Record provides an example of how this might be done.
- Failure to provide information to third parties in accordance with patients' wishes outside clearly delineated areas of exception should be regarded as a failure in information governance

ENSURE CLINICIANS HAVE IMMEDIATE ACCESS TO UP-TO-DATE INFORMATION

EPRs and EHRs will help to make care safer and more effective than it is now. The need for EHR systems grows as the complexity of patients' health needs increases. Increasing numbers of patients, particularly among the elderly, have a number of co-morbid conditions and require care from a variety of different clinicians and different organisations. Even if care is provided by a single organisation, there will still be different professionals in different disciplines probably located in different places delivering it. Sharing information is the only way in which integrated care can be provided.

Clinical engagement is essential to developing and implementing any EPR or EHR system. However, despite this and the recognised value and need for EPRs and EHRs, we have yet to move to a position where they are regarded as clinically essential.

Our first principle under this theme is designed to set the tone:

Shared electronic records should be regarded as being as essential to care as the stethoscope and the thermometer. To ask clinicians to work in systems without immediate access to all the relevant information about a patient is to ask them to work in an unsafe environment.

Our recommendations below are aimed at securing this.

However, providing EPRs and EHRs is not sufficient. They must also be used, which requires that access be 'user friendly' and relevant data easily shared.

If systems are poorly designed or not matched to current workflows and processes, they won't be adopted and will result in further fragmentation.^{29–30} There may even be unintended consequences including technology-induced error, creating risks to patient safety.³¹

We came across examples of carefully developed record sharing that was not used by clinicians either because there were gaps in the information provided, and/or accessing the information was time-consuming and clumsy from the user's perspective. As one respondent to our survey put it:

"To do one HIV clinic, I currently have to log in to (separately): the computer itself, (a separate system) for results, PACS for radiology, a separate programme for appointments, a separate programme for HIV drug records, a separate programme for HIV care records and finally, a separate programme for dictation. That's seven different passwords and logins to see one patient..."

CASE STUDY

A narrow escape

A frail, elderly, patient was admitted to A&E on a Friday night after seeing her GP. She was unable to provide a clear medical history and had no family or carers present to provide any collateral information. The decision was taken to phone her GP on Monday to confirm medical history.

A conversation with distant relatives the next day revealed she had kidney disease and was on permanent weekly dialysis at the hospital, had high cholesterol and hypertension and was an insulin dependent diabetic. Staff from a home care agency who provided support to the patient at home had taken the patient's medications to the hospital on the Friday evening on hearing about her admission.

However, these medications did not reach the patient.

Despite the patient attending the hospital weekly for dialysis, there was no information about this or her other conditions available in A&E at the time of admission. Without information from the patient's relatives she might not have received insulin for three days, putting her life in danger. As it was, she was kept in hospital for two weeks once the renal consultant who had been monitoring the patient's weekly dialysis became aware that she had been admitted.

If clinicians truly want to follow the first principle of 'do no harm,' they require timely access to patient's data in order to minimise the risk of everyday clinical decisions, particularly in the context of emergency care.



Our second principle addresses these points:

Features of electronic record systems that get in the way of effective clinical practice should be regarded as safety issues that need to be resolved as a priority. Failure to use such a system when it is available is a failure in professional standards.

Uncertainties and differences of interpretation of information governance requirements continue to be a barrier to sharing information for patient care. In our survey, 41 per cent of GPs and nearly half of secondary care doctors considered that EHR adoption is being slowed unnecessarily by information governance concerns. In all, 30 per cent of GPs, but less than 20 per cent of secondary care doctors, considered legitimate information governance concerns were being overruled for increasing EHR use. This illustrates the need for greater clarity on what can be done and more consistent interpretation, perhaps not surprising given the complexity and opaqueness of the legal issues that those on the ground need to navigate – the law of confidentiality, the Data Protection Act, Caldicott 2³² and article eight of the Human Rights Act.³³ We consider information governance issues in the next section, which covers audit and research.

Our recommendations are aimed at underpinning the idea that without user-friendly EPRs and EHRs, care is less safe and effective than it could be. This is both a professional and regulatory issue. As before, we consider the first two recommendations to be particularly important.

RECOMMENDATIONS

- The Royal Colleges should review their professional guidance and include reference to the importance of the use of EPR and EHR systems to manage patients. Given the importance of information sharing to providing safe and effective care, they should consider making approval of junior doctor training places conditional on having adequate EPR and EHR systems.
- Care Quality Commission standards and inspections should include a focus on the availability of electronic records. No trust should be considered ‘outstanding’ if it does not have its own comprehensive EPR and cannot at minimum demonstrate routine electronic access to and use of up-to-date summaries of GP records in A&E and on admission of patients for urgent care. They should also be delivering standardised information on diagnoses, changed medication, treatment and test results to GPs electronically upon a patient’s discharge. We recognise this is not feasible at the moment for all trusts but consider restricting the ability to classify the trust as ‘outstanding’ is reasonable given practice elsewhere. A date should be set for when a trust could no longer be considered ‘good’ without such arrangements.
- Clinicians should report any aspects of EPR and EHR systems that interfere with safe and effective clinical practice through the National Reporting and Learning Service and their employing organisations should take steps to remedy such aspects of the systems.
- The NHS Litigation Authority should review its premiums for clinical negligence so that higher premiums are incurred by those trusts without availability and extensive use of shared electronic records as set out above because of the risks to patient safety.

DESIGN FIT-FOR-PURPOSE RESEARCH DATABASES AND USE THEM RESPONSIBLY TO IMPROVE CARE

Aggregating individuals' EHRs into population-level databases provides a base of knowledge from which insights can be generated and improvements catalysed, improving the quality of care for everyone. In our survey 285 secondary care doctors (over 80 per cent) considered that EPRs and EHRs would deliver significant improvements in the data for research. Nearly two-thirds considered they would greatly improve the ability to compare current treatments with best practice. Creating and using these databases, however, heightens certain risks alongside the potential benefits.

The recent debate over NHS England's care.data initiative has elevated the public profile of this discussion and raised concerns about how and why these databases come to exist. Even this negative attention is informative, helping to highlight constraints on the responsible use of datasets. But there is a risk inherent in the specific attention, too: that care.data would become synonymous with 'using databases to improve healthcare'. This would be an unfortunate outcome, because while care.data represents one important, national-level initiative, it does not encompass all potential beneficial research activity that can be performed using population-level databases. Worries specific to that programme should not become a hindrance to other efforts.

Keeping this context in mind, this section discusses different considerations for designing fit-for-purpose research databases locally, regionally and nationally in England. Custodians of local, regional and national databases should each have a central aim which drives their research programme, makes deliberate design choices, minimises associated risks, and maximises potential benefits. In appendix eight, we provide a comparison of many well-known databases using our design framework.

Our discussion is guided by two important principles:

Data from individual EHRs provide a valuable resource for improving care delivery for everyone. These data should be responsibly organised and aggregated into fit-for-purpose databases with a specific central aim that guides design choices.

Design choices lead to risk and benefit trade-offs. Where there are significant risks, these should be identified and reasonable steps should be taken to communicate them clearly to the participants whose data are contained in the database. For national databases such as care.data, this means the national public. Where benefits are alleged, database custodians should seek to build capabilities that will translate insight into improvement, which should then be publicised to demonstrate that the benefits have been achieved.

Designing fit-for-purpose research databases

At the core of any research effort, using EHRs must be a central aim, determined by the operator of the database and focusing the effort toward a domain of potential improvements. For example, the priorities of an Academic Health Science Network (AHSN) charged with improving the overall health of a particular region will differ from a national professional body's clinical audit, which tracks improvement in a particular specialty over time. Recent legislation included in the Care Bill 2014 has circumscribed these aims for NHS data made available through the Health and Social Care Information Centre (HSCIC) – they must be directly related to the provision of health and social care or promotion of healthcare.³⁴

The central aim should serve as a guide for database design. Based on our discussions and research, we have prioritised five characteristics of population-level healthcare research databases that we consider to be the most important design considerations:

1. **SCALE** – the number of participants and the portion of their health outcomes studied
2. **INTEGRATION** – the degree of inter-linkage across sites of care
3. **VELOCITY** – the potential to make information rapidly available (including in real time)
4. **GRANULARITY** – the smallest unit of analysis
5. **EXCLUSION** – the data points or people not involved

To bring these considerations to life, we will first define the spectrum of choices for each one and provide examples of how different choices may be more appropriate for different central aims. We assess the direction of travel in healthcare research that would realise the greatest additional benefit from such databases and raise some concerns about potential risks associated with each. Last, we provide a table of several existing databases and compare them using the framework. In the following section, we will recommend ways to accelerate the impact from fit-for-purpose databases in the future by maximising potential benefits and minimising risks.

Scale

The design consideration of scale will be driven by the custodian and research focus of the database. Databases may have a local, regional, or national scope depending on the custodian's ambition and mandate. If the research project focuses on a particular health condition, instead of the entire range of health outcomes for a person, the scope will be limited, for example to study only cancer or diabetes. The largest scale databases will enable national, all-outcome research, while the smallest scale databases focus on a particular condition in a particular geography, or even a single site of care such as a hospital.

We believe the direction of travel will be toward greater scale – regional and national databases that have sufficient numbers of patients to detect and analyse epidemiological trends and compare healthcare outcomes. Pharmaceutical companies are increasingly being asked to demonstrate *in situ* results for their products, also known as 'real world outcomes', to justify regulatory approval on a national scale.³⁵ Regulators, such as the Care Quality Commission in England, embrace comparative performance measurement, which requires knowing how providers perform across the country. Lastly and simply, bigger databases are statistically more useful for performing academic research, enabling subtler and more complex phenomena to be studied.

Scale is also a major driver of actual and perceived risk. The more people whose records are located in one place, the greater the damage in the event of criminal hacking or accidental lapses in security. Similarly, risk increases with the number of health outcomes included in research and the length of time they are studied. There is also a significant element of *perceived* risk associated with the distance between national and regional databases, held by unknown bureaucrats, and the point of care.³⁶ This perceived risk requires attention and respect, to generate the requisite trust and buy-in to enable development.

Integration

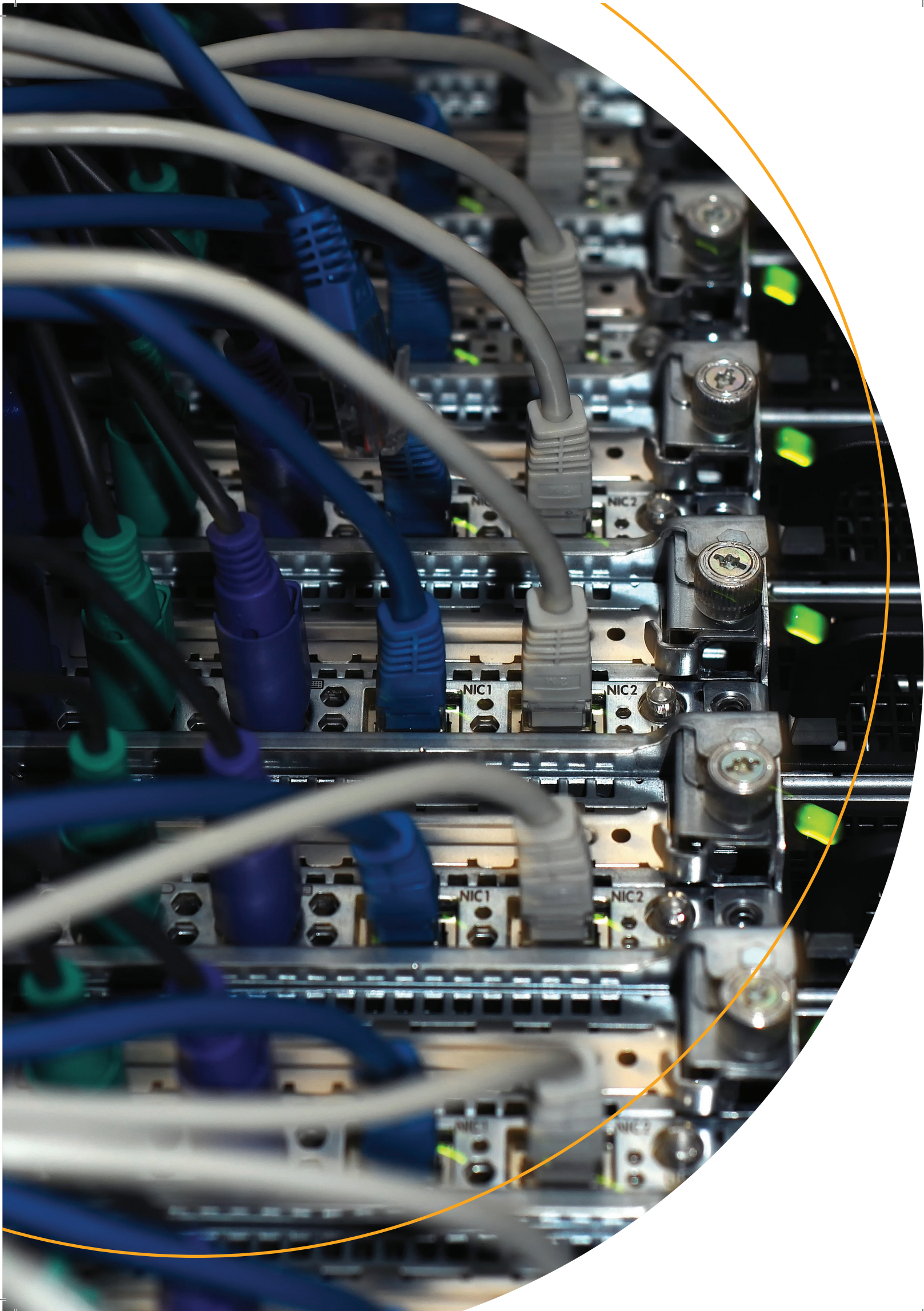
The design consideration of integration provides a 'horizontal' element to data collection alongside the 'verticals' of geography and health outcome focus. The choice here is to broaden or narrow the number of sites of care that are included to meet the central aim of the research. A person's experience with the healthcare system may include many different sites of care, in which each site keeps their own separate EHRs. There may also be relevant information contained in social care, genomic, or personal health databases.

We believe the direction of travel will be toward greater integration – databases that encompass primary and secondary care data. In health systems where capitated reimbursement for providers is being used as a commissioning tool to drive better care, these integrated databases are essential to tracking performance against quantitative indicators of population health. One aspiration for genomic and other personal health data is to combine these with traditional healthcare data to enhance predictive and preventative care. Finally, there is a growing trend toward analysing health outcomes and expenditure from a patient-centred point of view. When we focus on the individual patient experience, we see that, typically, the patient who incurs a great deal of health expenditure yet also experiences poor outcomes has multiple chronic conditions and frequently visits many sites of care. For any research into how to treat these patients more cost-effectively, such an integrated database is required to understand the full spectrum of challenges and opportunities to improve care.

We believe integration also drives increased risk, for two main reasons. First, it aggregates the most information about a single person's healthcare into one place. Linked records are more vulnerable to re-identification, one form of criminal misuse of healthcare data. Second, it combines, in many cases, two or more sets of data that may be difficult to match up technically or methodologically. The potential for error in analysis may be increased by the disparate provenance of the data, which limits its usefulness.

Velocity

We use the term 'velocity' deliberately to include both speed and direction of action. With respect to speed, databases may be made available in real time or only after a significant delay; as for direction, they may or may not retain the capability for the custodian to identify a single patient by name and contact them. There may be benefits to high-velocity, real-time monitoring at a population level when there is the possibility of clinical intervention in a short time frame. An account of how such a database is used at Intermountain Healthcare in the USA appears in the following case study. Judging from our research, few secondary care organisations in England yet have the capacity or ability to use real-time or near-real-time data to monitor the quality of care being provided, and none can assess the quality of care provided for the whole of a patient's treatment in secondary and primary care.



It is here that the distinction between ‘data used to provide direct care’ and ‘data used for quality monitoring and research’ blurs. A patient who is identified as being at increased risk through a population-level database available in real-time or near-real-time will benefit from algorithms which detect, for example, a health risk related to a chronic condition which might need attention from a clinician. However, the information in such a database is just as sensitive as a primary clinical database. Though it is ‘running in the background’, it is providing a surveillance function akin to a clinician making regular home visits.

Although a perfect categorisation may be impossible, we believe there ought to be a clear distinction between two types of databases: those that would facilitate near-term intervention for a particular patient, and those that would recommend systematic changes to care delivery. For both types of databases, the overall direction of travel here will be toward greater velocity. We believe that patient-intervention databases will be more prevalent at the local level, though less so on the regional and national level. At the same time, long delays in providing data to researchers can hamper their efforts and limit their relevance to improving care delivery. Data needs to be made available more quickly than it can be currently.

Beyond the obvious information security risks and resource requirements associated with high-velocity databases, there may also be additional risk of complacency and confusion. In our case above, the patient only benefits if someone is actively ‘watching’ the data or if the algorithms employed are able to route an alert effectively to a clinician in a position to intervene. There is a risk of overestimating the potential utility of this approach. It may also confuse the overarching message about the value of such databases by conflating the potential benefits of a high-velocity database with a low-velocity one – leading to disappointment or disillusionment when individual cases of mismanagement are not detected.

Granularity

The design consideration of granularity reflects the choice of a smallest unit of analysis, which may be as small as a single patient or larger, such as a GP’s practice or clinical commissioning group (CCG). Depending on the central aim of the database, it may not be necessary to provide individual patient-level data, even if that is how the database was originally constituted.

We believe the direction of travel will be toward more distinct levels of granularity in analysis and output but a consistent expectation for patient-level raw data to underpin those analyses. We mention the distinct levels here as a reminder that low-granularity databases can provide insight and be made available broadly, even as open data, enabling research and development activity to flourish. One example of how this approach has worked well is with GP-level prescribing data, which is available free of charge and provides data on the prescribing behaviour of every primary care practice in England, driving greater transparency and insight, for example, on the rate of generics prescribing. Nevertheless, expectations continue to grow that ‘big data’ using minute levels of granularity should inform decision-making in healthcare.

We believe there are two risks associated with a more granular approach to data collection: first, that patient-level data is stored in too many places, and second, that it is stored in too few. If patient-level data is made available to a wide variety of organisations and with too few restrictions, security is more likely to be compromised. However, local and regional organisations also need the legal and regulatory capacity to link and maintain patient level data, a status that is at present uniquely held by the HSCIC.

Exclusion

The final design consideration of exclusion reflects the explicit choice of which parts of an EHR not to include in a database, as well as which patients not to include based on the consent model (of opting in or opting out). The operative consent model for both of these questions will be responsive to ethical and political debates. Where patients have the option, they may choose to exclude some or part of their records. This will, of course, limit those designing databases. But while ethical and political considerations favour opt-out options, it will remain crucial to respect these structures. Failing to do so would be disastrous to public trust and support.

We believe the direction of travel here is uncertain. While health systems face imperatives to better understand their performance and deliver better, more cost-effective care, public sentiment may resist compulsory, comprehensive databases. The public’s increasing awareness of and scepticism toward monitoring and surveillance prevent the creation of databases that would in theory best satisfy central aims of research.

There are risks associated with more and less exclusion. With more exclusion, the instructive power of large databases is diminished and may become biased. In certain cases, stigma can be perpetuated by excluding, for example, mental health diagnoses from healthcare records. Where exclusion is not facilitated, and comprehensive coverage demanded, there will be no ‘safety valve’ for those with serious concerns to opt out and allow the scheme to continue for the majority of the population.

Real-time quality assurance at Intermountain Healthcare

Intermountain Healthcare work on the basis that, if left to memory, a physician will only execute about 50 per cent of the actions that should ideally be taken on the patient's behalf. This can be corrected if protocols are used that can be embedded in clinical systems and provide prompts and guidance to the clinician.

The design of the system is important to ensure that it does not become a burden on the physician but is instead an aid. Intermountain's clinical culture recognises that, with some exceptions, "it is impossible to generate a protocol the perfectly fits any patient". Clinicians have an explicit obligation to adapt each protocol step to the unique needs of each individual patient. Empirically, clinicians vary from Intermountain's protocols on about five to 15 per cent of protocol recommendations for each patient. This approach of 'mass customisation' (a term derived from Lean quality theory) means that Intermountain's protocols are the opposite of 'cookbook medicine'. It allows medicine's most important resource in a complex environment, the trained expert mind, to focus on a relatively narrow band of factors where it can have maximum benefit.

Variation and patient outcomes data are tracked in patient records then fed to 60 clinical teams who routinely analyse data on patient care against protocols, track variances in care, review relevant new scientific publications, and update the guidance where appropriate. Oversight teams meet monthly. As a result, most Intermountain protocols change monthly. Rates of change for a carefully developed evidence-based best practice protocol are often initially quite high, with as much as 15–30 per cent of the guideline content seeing modification. Over time the rate of change diminishes – but never disappears – unless new medical science emerges.

The revised guideline then has to be validated empirically/in real practice and amendments

fed back. This is expected and there is clear understanding that uncorrected guidelines could result in harm or substandard care.

Intermountain has partnered with Cerner to develop EPR tools to support this review and update process. That new development work sets a very demanding target: once tweaks and changes are identified, the clinical teams should need just two hours to make changes in the systems, validate them from an IT perspective and deploy them into use. New protocols, built from scratch, should be able to be implemented within two days.

EXAMPLE: elective induction

Nearly one-third (30 per cent) of pregnant women at Intermountain were having elective inductions. Analysis identified that 28 per cent were clinically inappropriate, resulting in risks of harm to the child, higher use of ICU, higher rates of maternal injury and higher rates of caesarean (c)-sections.

A protocol was developed to identify when induction was appropriate. It was implemented through the EHR system, enabling all clinicians to access it and requiring that any decision to induce an earlier birth that fell outside the protocol was questioned and if justified cleared by the most senior staff.

As a result of introducing this protocol:

- inappropriate induction fell from 28 per cent to less than one per cent
- c-section rates are 20–21 per cent compared to US national rate of 34 per cent
- 45,000 minutes taken out of labour and delivery and ICU admissions have been reduced
- 1,200–1,500 more children can be delivered using the same resources
- \$50 million has been saved as a result of fewer c-sections

SOURCE: Interview with Brent James, Intermountain Healthcare.



Using databases responsibly to improve care

Overall, we believe the direction of travel for healthcare research will be toward databases with greater scale, integration, velocity, and granularity; the issue of exclusion remains uncertain. We believe that this evolution augurs great potential benefit and also higher risk. We reiterate that not all databases need be large, integrated, high-velocity, and granular. Very effective programmes of local and regional service improvement can and should be based on databases that do not share these characteristics. Nonetheless, for databases like care.data that are heading in this direction, we have highlighted some of the potential risks alongside the benefits.

As these databases are brought into operation their custodians incur a responsibility to minimise risks and maximise the benefits from their data. Foremost among these responsibilities, regardless of the design of the database, remains information governance. While it remains imperative that national information governance rules be respected, we believe they also need to be clarified. All our interviewees recognised that patients had a right to confidentiality and that there needed to be strong rules protecting this. However, the main concerns surrounded recent interpretations, different views, doubts about who can hold what data for what purposes, uncertainty about the rules governing linking data and how to get permission for it and a negative approach that emphasised what was not possible rather than what was possible. As one interviewee put it:

“If 99 doctors favoured conducting a particular test on a patient and one did not then the test would be done. If 99 considered information governance rules allowed sharing or linking of data and one did not, then the data would not be shared or linked.”

The government recently invited Dame Fiona Caldicott to review the governance arrangements for information sharing for direct patient care, audit and research. The report (Caldicott 2³²) clearly states that health professionals involved in administering direct care can assume implied consent before sharing any information. Further guidance has been issued by the HSCIC in the light of this report. However, the reluctance to share data between organisations is deeply ingrained, fuelled in part by anxiety and fear about loss or inappropriate use of data. As one organisation stated:

“If there’s any doubt, the easier, safer and sometimes quicker route is not sharing.”

And, as a further respondent stated:

“The messages contained within this (Caldicott 2) may not be penetrating the psyche of those who are responsible for making data decisions within individual organisations.”

Once database custodians have designed a database, collected data, and assured information governance, we believe they must also look to maximise the potential benefits to patients. Many aspects of healthcare delivery run beyond the scope of this paper, but it is important to note that the insights gained from healthcare data represent the potential to save lives. Once garnered, they should not be wasted for want of clinical and managerial leadership to translate them into improvement. All the participants we spoke to regarded the lack of capacity to analyse the data as a significant barrier to progress. Concerns related both to the number of staff (or time) and to the range of skills available.

Once the improvements to healthcare or service delivery based on analysis of the data have been implemented, they should also be publicised to demonstrate that the intended benefits in creating the database have indeed been achieved.

RECOMMENDATIONS

Our recommendations show how the benefits of research databases can be maximised and their risks minimised. In these ways, we believe electronic healthcare records can be most responsibly aggregated to drive improvement.

Maximise benefits

- As the national databases continue to develop, local and regional health economies should not stand still or be held back. Trusts, CCGs, commissioning support units (CSUs), and AHSNs can each drive database development based on their mandates. It is likely that these organisations will be able to move more quickly than national programs to realise local benefits and should be empowered to do so. The Department of Health should ensure that legal and regulatory frameworks empower these organisations to link datasets and accredit them with a similar safe haven status to that the HSCIC currently holds. Last, information governance permissions should be clarified with an advice service made available under the auspices of the Caldicott 2 regulations.
- Health Education England should be tasked to develop a scheme for health data analysts to enable local and regional organisations to better use the data that they have, or will soon have, available. Similarly, training opportunities for clinicians to develop greater knowledge of the data and its possibilities should be introduced so that use of the information becomes a standard part of clinical practice, building on current expectations for clinical audit. These analysts should be given appropriate qualifications reflecting their expertise to aid in their identification by local, regional, and national organisations.

Minimise risk

- In the case of care.data and other large national databases that maximise scope, integration, and granularity for national research, special investment should be made in to facilitating exclusions to respect public opinion. NHS England should establish a website allowing patients to opt out of, or back into, national data collection schemes and receive confirmation that this has happened. Similarly, patient groups should be consulted regarding sensitive data items that ought to be excluded in all cases.
- NHS England and the HSCIC should build on the existing red/amber/green data categorisation framework to more precisely identify and mitigate risks stemming from databases with greater scope, integration, velocity, or granularity. The Department of Health should ensure through legislation that only NHS or accredited academic organisations receive access to the highest-risk databases, especially care.data. These measures should together address the issue of jigsaw re-identification specifically and ensure to the greatest extent possible that no one can become identified in NHS data viewed outside the NHS.
- The NHS Litigation Authority should establish a process by which patients whose data is lost or irresponsibly used can reach a fair settlement with the health service. Further, the Care Quality Commission should promote transparency by maintaining a public database of known data breaches for which reporting is mandatory, as is required by law in the USA under the Health Insurance Portability and Accountability Act (HIPAA) regulations.
- The penalties for misusing NHS data should be made clearer and scaled with the severity of the breach of patient confidentiality. These penalties should not be made so severe as to discourage any use of data, but should deter deliberate criminal wrongdoing and could include professional disqualification as well as legal action.

IMPLEMENT OPEN AND INTEROPERABLE ELECTRONIC SYSTEMS

Individual electronic record systems that are open and interoperable can improve diagnosis and care, improve communication between care providers and result in better care for people with chronic diseases. Interoperability is essential if EPRs in individual organisations are to enable data to be shared across different organisations and so form an EHR for a patient.

While the majority of the principles highlighted in this report are not technical in their origin or solution, there are some aspects that are fundamentally technical: functionality for users, common standards across systems, ready access to the data within these systems and accessible coding standards.

Our two principles under this theme are therefore:

Clinicians should have a single point of access to electronic records about patients they are treating, regardless of where the record was created.

Patient data should not be inaccessible or expensive to access or at risk of loss because of commercial or financial decisions made by vendors of EHR systems.

Lack of common standards is a problem at every level of EHR implementation. There is not even a common understanding of what an EHR is. A 2011 report produced by the European Commission health unit³⁷ highlighted that although EHRs are present in almost every country's healthcare strategy, definitions of what constitutes an EHR vary widely and a lack of consistent nomenclatures and terminologies is a significant barrier to the uptake and use of EPRs and EHRs.

Interoperability is fundamental to enabling the sharing of data between different provider systems and to the re-use of data.³⁸ It has been a key theme in many recently published policy documents, including the *NHS Future Forum report*,³⁹ the white paper *The Power of Information*,³⁹ the *Mandate from Government to NHS England*⁴⁰ and the *NHS England Planning Guidance for 2013/14*.⁴¹ The fundamental tenet of interoperability is the ability of systems to exchange information and then use the information exchanged effectively.⁴² But, interoperability depends on low technical and proprietary barriers.

CASE STUDY

A late letter, a missed prescription

Kanthiah is 83 years old and suffers from a complex set of co-morbidities including chronic heart failure. At his last cardiology review, his medication was doubled to reduce fluid retention in his feet and ankles. The consultant's letter informing the GP to change his prescription did not arrive in the post before his next refill.

Kanthiah takes ten different medications and relies on accurate prescribing to ensure his safety. He complied with the instruction to increase his medication, but then ran out of his tablets on a Saturday morning. Since the surgery was closed, Kanthiah handed in a prescription refill request on Monday and was informed that it would be ready to collect on Wednesday. By Monday, Having missed two doses, Kanthiah was not aware of any change in his symptoms so was not unduly concerned.

On Wednesday morning, Kanthiah found walking difficult. He was breathless and both his legs were swollen up to his knees. He made an emergency GP appointment. The GP was shocked that Kanthiah had gone so long without taking any medication. The GP had also still not received the cardiologist's letter. Worried that Kanthiah might have developed a deep vein thrombosis, the GP sent him with a referral note to A&E.

Having missed five days of medication, Kanthiah spent two weeks in hospital while he was managed for the resulting complications.

All of this would have been prevented by real-time data sharing technologies. Outpatient letters should be available immediately for GPs to act upon any treatment changes and patients should be able to order urgent refills online, particularly out of hours, otherwise systematic failures in information exchange will continue to put patients at risk.



In the NHS, there are significant technical barriers to interoperability to be overcome, mainly because of the significant number of systems and suppliers in secondary care using a variety of terminology and coding structures. In the 1970s when systems were first made available there were no standards between the vendors that developed software. In early systems, even where data could be exported, the potential for inaccurate or unreliable data was high. To some extent this still occurs in secondary care where proprietary systems can make use of unique coding systems. The position is better in primary care as there are fewer suppliers who have generally (but not exclusively) adopted read codes.

Health Information Exchange (HIE), the process of electronically moving patient-level information between different organisations, is viewed as solution to fragmentation of data. But standardisation of coding structures, or at very least translation tables to allow creation of normalised data, is essential if we are not to restrict the potential of HIE.

Mapping coding structures to each other is a time-consuming exercise that can sometimes be dependent on suppliers who have little commercial interest in making this information available. Individual organisations have done this but can sometimes be reluctant to share their knowledge. For example, GP system suppliers have necessarily mapped the different coding structures, which they use in order to be able to transfer medical records between practices or to transfer data when a practice switches from one supplier to another.

Some local areas, such as Airedale, have chosen to overcome these obstacles by adopting a single vendor system for hospital, community and GPs. This is proving successful and is a course adopted by, for example, Kaiser Permanente and Intermountain in the USA, where they provide a single unified system of healthcare (unlike most of the USA). However, adoption of a single system across a region, much less across the entire NHS, would be impossible given the current differences and investment required. It would also only serve to replicate the weaknesses and failures of the National Programme for IT, only perhaps on a grander scale. Interoperability between systems will inevitably be required.

The development of the Medical Interoperability Gateway provides a technical platform for interoperability and HIE, which is already working effectively in a number of locations. However, suppliers are not obliged to be part of this, or any other system, and can put obstacles in the way of NHS organisations if they do not feel it is in their commercial interests to join.

Similarly, although the NHS draws on significant amounts of data, system suppliers can be very protective of the additional data held within their systems, making access difficult although the costs of collecting and storing the data in a logical format have already been met through fees paid by NHS organisations.

Development and implementation of common standards in NHS IT has depended on a mixture of guidance, central approval, procurement requirements and contracts. This has worked to some extent but has weaknesses, for example the non-universal use of the NHS number and the development of different coding structures. Moreover, as providers become more fragmented and less subject to central direction and funding, we think that a different approach may now be required, resting more on legislation as in some other countries with a fragmented provider system than on guidance and some large procurements.

The following recommendations address these points.

RECOMMENDATIONS

- Health information technology standards for interoperability have been both developed and recommended by national NHS bodies for many years but with only gradual and partial impact. A legislative mandate for adoption of relevant standards should be made, covering such issues as use of the NHS number and coding and messaging structures. Implementation timetables should distinguish between new procurements and existing systems.
- A condition of supply of systems to an NHS organisation should be that the data contained in them will be made available either free or at a charge that covers only the marginal cost of extraction.
- Mapping between different coding structures remains an issue. HSCIC should have responsibility for ensuring maps between different coding structures are available centrally, perhaps through a Wikipedia-type website, drawing on the information already held by vendors.
- Establishing HIEs currently depends on system vendors deciding that this is in line with their commercial interests. There is some concern that the NHS remains vulnerable to data being captured in proprietary systems and being unavailable to HIE initiatives except at significant cost. NHS England and the HSCIC should review with NHS organisations whether any barriers are in place. Where appropriate, further regulation or contractual requirements, including if necessary development of standards for clinical exchange of information, will be needed.

ENSURE THE IMPLEMENTATION PROGRAMME IS FIT FOR PURPOSE

Our review has identified issues of scale, structure and approach that need to be recognised and addressed if implementation is to be successful.

Two principles encapsulate our thinking:

EHR implementations must be part of a collaborative exercise across health and social care systems regionally. The most successful implementations have been systems that work across populations of up to 10 million people. Progress should be assessed against meaningful metrics related to clinical care.

Changes in the provision of care should be done in such a way as not to disrupt the flow of patient information across health and care systems or to impede progress in implementation of shared records.

The following paragraphs explain the rationale for them in more detail and make recommendations to resolve the issues that have emerged in our review.

Consistency over the long term

Implementation of shared records is a long-term project. It took Kaiser Permanente 11 years to develop, implement and see the full benefit of their integrated care records. This was also identified up-front in their business plan so everyone was aware of the long-term commitment required. Denmark has been working on integrated records since 1994 to reach its level of maturity. Scotland embarked on its journey to implement shared records in 2005⁴³ and has now reached the stage of sharing an emergency care record and other data but recognises that it still has some way to go to achieve their goal of full record access including social care information. In England, Liverpool began the process of sharing records in 2007/8.

Scale matters

The most successful countries so far are those that have concentrated on populations of up to five million (Denmark, Scotland and Singapore). An approach based on national coverage of 55 million people without a regional framework is unlikely to succeed. Recent developments in the USA in the use of HIEs are seeing bigger populations being encompassed within programmes (there are 17 for the whole country), but these are state-based, so there are already strong unifying factors.

Organisational fragmentation can be a barrier to success

If provider organisations are able to choose their priorities and decide whether they become fully or only partly involved, it is hard to make effective progress. In the USA, the greatest success has been achieved inside integrated systems where provider organisations can be compelled to work together. In the UK, there are little or no structures at an appropriate scale capable of coordinating implementation. For example, Basingstoke Foundation Trust has never taken part in the Hampshire Health Record, although other parts of Hampshire do.

EHRs in end-of-life care

Coordinate My Care (CMC) is an electronic care record that contains information about patients' wishes as well as their health at the end-of-life. It can be accessed by GPs, community nurses, hospital teams, out-of-hours doctors, specialist nurses, the London Ambulance Service and NHS 111. When a new record is created, the emergency services are immediately alerted.

An elderly gentleman in a nursing home created a CMC record with his nursing home manager. On his record he clearly stated that he wanted to die in a hospice.

Early one evening he fell out of bed. He was too heavy to lift back into bed, so the staff called 999, and an ambulance was dispatched. The system alerted the

London Ambulance Service that the patient had a CMC record, which they then consulted.

En route to the home, the clinical service desk phoned the hospice to check the availability of beds. A bed was available. The message was relayed to the paramedics. On arrival, the paramedics found that the patient had a large laceration to his forehead that was bleeding profusely.

With full knowledge of his CMC record, they took him to A&E where his laceration was sutured. They then transferred him to the hospice where he died. The patient's wishes were granted and an unnecessary hospital admission was avoided.

SOURCE: www.coordinatemycare.co.uk

Reconfiguration of services can stymie EHR implementation

Reorganisation, instability and reconfiguration of trusts (and now with their additional health responsibilities, local authorities) has the potential to reduce management support for projects and can undermine trust between organisations⁴⁴ as well as add an extra layer of complexity and delay. For example, merging Mile End Hospital, The London Chest Hospital, The Royal London Hospital, Newham University Hospital, St Bartholomew's Hospital and Whipps Cross University Hospital has brought in a different group of GPs to East London where there were long-standing relationships and a history of shared IT developments and required a rearrangement of priorities within the trust. As one optimistic GP put it:

"It feels as if we are two years away from achieving full interoperability with the trust, sharing records and information across East London. On the other hand it felt like that two years ago."

Change is endemic in the NHS. Although there may be no further major organisational change of the commissioning function, it is still the case that individual CCGs will find it right to merge. On the provider side, there may be more change as services are reconfigured and trusts merge to remain financially viable and improve services. Competition will also bring change as new contracts bring different providers as has happened most frequently to date in community and mental health services.

Any strategy for linking primary and secondary care information must face up to these challenges and find a way of securing a sustained implementation programme over perhaps a decade and do so on a manageable (regional) scale when providers and their accountability arrangements are fragmented and there is no regional tier.

Effective leadership and measurement of impact

Successful implementation requires strong organisational leadership and management, including lead professional or champions to bridge the gap between the technical staff and clinical staff.⁴⁵ It also requires relevant metrics to measure and challenge progress.

However, our research found:

- Benefits, costs and return on investment are not well understood or articulated, although we recognise costs and benefits for EPRs and EHRs are difficult to quantify compared with other management initiatives.⁴⁶
- The clinical case for implementation did not seem to have been strongly made and followed through. There seemed little focus on monitoring benefits through judicious use of metrics. In our interviews few if any trusts could point to a business case for EHRs or an equivalent single system that had clear metrics for clinical use and improvements in care that could be followed through.
- Aspirational national documents have been produced such as the 2012 white paper *The Power of Information*, but there is no clearly articulated strategy to underpin this. Similarly, the Secretary of State has issued a challenge to have a paperless NHS by 2018,⁴⁷ which provides a summary vision but there are no metrics beneath this that would help encapsulate the benefits for patients and clinicians. The metrics which trusts have been encouraged to use – the NHS England/EHI Clinical Digital Maturity Index⁴⁸ are limited to acute trusts and do not cover interoperability or shared records with say primary care.
- Finally, austerity and a concentration on technology implementation and funding may mean that essential training to make maximum use of new systems and shared records is squeezed. Approximately two-thirds of Kaiser Permanente's HealthConnect EHR budget went to change management.⁴⁹ This reinforces the point that business cases and metrics should emphasise use as much, or more than, technology implementation.

RECOMMENDATIONS

- Providers and commissioners investing in EPRs should be required to coordinate strategies at a regional level to make them interoperable. A condition should be placed on access to central funds that any development is in line with an agreed regional strategy and has sufficient support from partners within the community. We do not propose imposition of arbitrary geographical boundaries from the centre. However, central policy should encourage the formation of regional strategies across natural communities – usually grouped around a specific hospital or hospitals in a conurbation such as Bristol or Greater Manchester. Providers and commissioners investing in EPR programmes should ensure part of their project plans details of how the programme fits with an agreed regional strategy for interoperability. Consideration should be given to such communities forming around AHSNs, which would have the advantage of bringing deployment of the IT and analysis of the data for research and clinical purposes together.
- The aspiration of the NHS to implement EHR systems and become paperless should be underpinned by a series of metrics, which capture the use of EPRs and shared records for clinical and patient benefit. We suggest what these might be, drawing on the data that is readily available within systems rather than adding to bureaucracy. These metrics should be used nationally and locally. The metrics suggested above will mainly be process ones. Routine evaluation of outcomes, for example reductions in medication errors, would best be undertaken by commissioned studies.
- A condition of any contractual change instigated by commissioners or providers of care should be that such changes do not undermine integration of information systems across the health economy, regardless of the individual providers concerned. The providers may change but the aims of the service and its supporting infrastructure should remain constant or improve. The same test should apply to any conditions imposed on mergers and demergers by either commissioners or competition authorities.
- ‘Demonstrator sites’ that seek to bring organisations together to provide linked information for a population and showcase what can be done should cover both single integrated systems and those operating through HIEs, as this latter approach is likely to become the norm.
- All NHS providers should have a project plan for supporting implementation of EHR systems that includes details of budgets, deliverables, milestones and measurement of return on investment in terms of metrics that refer quality of care and patient experience, including any national metrics. They would be helped by development of an ‘integration maturity roadmap’ which would go beyond an individual organisation and a national template on costing and metrics, similar to that recently produced by the Institute of Medicine.⁴⁹
- As trusts in receipt of NHS England technology fund grants are expected to match the central funding, we consider there is a strong case for central funding to be identified prospectively but delivered retrospectively against achievement of aims and metrics.
- NHS England should provide support to purchaser organisations in the form of market intelligence and facilitating exchange of ideas and practice. The ‘regional’ communities we recommend above would be a starting point for such collaborative development both within the community and between ‘regions’.

Possible topics for research and development in EPRs and EHRs

The brief for this report included a request that we identify a programme of future research and development that would support the uptake and effective use of EPRs and EHRs. The following list of topics may interest a wide range of innovators, including researchers at academic institutions across the UK, entrepreneurs, patient groups and charities, and healthcare companies.

- Using EPRs/EHRs to enhance patients' ability to participate in their own care. These topics would explore issues in both the supply of patient-shared records from providers and demand to use them from patients.
 - Patient attitudes – determine the drivers of patient attitudes and behaviours toward patient-accessible care records and produce a compelling value proposition for them.
 - Clinician concerns – investigate and describe clinician concerns around sharing of records with patients. Produce a specification for a shared record that addresses these concerns.
 - Benefits for patients – detail the benefits that EHRs might be able to deliver for patients with specific disease profiles (e.g., living with multiple chronic conditions) from better access to their own records.
 - Proof of concept patient-held record – develop a prototype patient-centred record that would be patient controlled, provider authenticated and collate information from a range of care settings.
 - Integrated patient-reported outcomes – test applications of the integration of patient reported measures of health status within clinical records.
- Using EPRs/EHRs to reduce patient risk. These topics would identify barriers to implementing of EHRs and explore new approaches to improving safety through clinical led initiatives on the better use of patient data.
 - Clinician adoption – determine the drivers of clinician attitudes and behaviours toward use of EHRs in England focusing on incorporating data from other clinicians' EPRs.
 - Real-time quality monitoring – develop and validate new algorithms to identify lapses in quality of care in real time using EHR systems.
 - eHealth maturity – define the most appropriate and meaningful quantitative (process, input, and outcome) indicators of maturity in eHealth at a health system level.
 - Market performance – collect market information on e-health spending to set industry benchmarks for cost, delivery and quality of EHR systems.
- Using data from EPRs/EHRs to improve clinical quality. These topics would help improve our understanding of the potential of data to drive quality and value as well as some of the obstacles that prevent this from occurring.
 - Audit readiness – demonstrate the current feasibility and utility of using linked secondary-use data for audit purposes.
 - Information governance clarity – assess the degree of comprehension of and compliance with existing information governance regulations among clinical staff, service managers, and NHS executives.
 - Service redesign models – show how service redesign can be accomplished based on audits of secondary-use data in England. Demonstrate the use of time series analyses on live data to assess progress on implementation of new services and patterns of delivery.
 - Clinical engagement – find the barriers to and enablers of clinician-led performance improvement based on audits of secondary-use data. Explore how to maximise clinician engagement with their data including looking at the design of user interfaces for accessing longitudinal data.
 - Informatics capacity – describe the human capital needs and gaps for health informatics in England.
 - Cohort research – develop wider research into cohorts of patients with specific diseases to identify how current treatment patterns could be improved and to assess new treatments and protocols.
 - Economic modelling – develop methods to predict impact of information use on future care costs based on population-level health characteristics.

What this document means for you

Patients and the public

Information about your health can be shared between different professionals more easily when they need it to care for you, improving the quality of what they do. You should be able to access information about your health and care much more readily, including re-ordering prescriptions and viewing test results, and more easily take action to improve it if necessary. This will make your care safer and should make it easier to contact health services and arrange care when you need it. It should also help prevent miscommunication and misunderstanding between different care organisations.

For this to work effectively, patients and the public need to understand and approve of the way information is used. We encourage the public to seek access to their electronic records and to ask healthcare providers to communicate with them electronically.

We believe everyone treated by the NHS should let the NHS use information about their care anonymously to check that the care and treatments used are safe and effective. We accept that some people may wish to opt out but we hope you will agree that, ideally, everyone would do this since we all benefit from it.

Health and care professionals

Shared electronic care records should be regarded as an indispensable part of treating patients and of making sure that the care provided and the therapies used are as safe and effective as possible. Failure to have the right information available at the right time or to be able to access the record easily should be regarded as safety issues and reported accordingly.

Professional bodies

Good clinical practice requires clinicians to have information about their patients available to them at the right time. Professional guidance should reinforce this. Approval of training posts should increasingly be dependent on having proper access to shared records and the ability readily to review the appropriateness of treatments given to patients.

Providers of care

Best practice care requires that professionals in your employ have ready access to shared information about a patient. Integrating information is vital to integrating care. This document recommends ways to ensure successful implementation of shared electronic records. This will involve collaboration across a health economy so that if a patient wishes it, information you have recorded about that patient can be made available in a timely manner to other professionals outside your organisation.



Vendors of care records systems

Shared records are a vital component of health and care systems, and therefore the obligations of vendors of systems both to patients and to the broader health and care system increase. Learn from the airline industry. Interoperability between systems must become a crucial element of any development. And recognise that the fundamental role that shared electronic records have in ensuring safe and effective practice may mean increased legal and contractual obligations.

Commissioners

Integrated information is essential to integrated care. Make the ability to share information electronically across the care team at the point of care a contractual requirement for all providers. And ensure that new providers or reconfiguration changes do not hold back development of, or create a gap in, shared electronic records.

Regulators

Shared electronic care records systems are a key component of ensuring safe and effective care and failure to implement systems effectively is a regulatory issue.

NHS England

Our recommendations build on the policies you have introduced and are designed to make implementation of shared records for care, audit and research faster, more effective and more certain. They will also encourage greater patient access to and use of information held about them.

The Secretary of State for Health

You have set a goal for the NHS to go paperless. This requires information to be shared promptly and electronically across care teams and organisations. Many, but not all, the policies are in place to do this. You can help by using legislation to ensure patients have rights to their electronic data, to overcome the slow spread of common coding tools and more generally facilitate interoperability, and to ensure that vendors do not lock patient information into proprietary systems.



APPENDICES

Full list of recommendations

ACTION ONE

ENSURE PATIENTS' RIGHTS AND EXPECTATIONS ARE MET

- Legal provisions should be introduced to implement patients' rights electronically to access, interact with and, if they want, share their electronic health record. This should be consistent with the commitment in the 2012 NHS Mandate that by 2015, everyone who wishes will be able to get online access to their own health records held by their GP. By 2015 we consider all patients should be able to view, interact with, download and share their GP records.
- NHS England should inform patients of their rights and encourage them to seek access to personal electronic information. It should work with patient representative organisations to examine whether there is scope and appetite for patients to share records with patient groups as a trusted third party providing both (anonymised) information for research purposes and in return offer advice on care and mutual support.
- Secondary care records should be opened up in the same way as primary care records at the earliest possible point. A commitment to ensuring patients have access to all electronic information held about them, within existing data protection rights, by a fixed date should be made. Interim arrangements could be put in place whereby, as a provider reaches a specified level of digital maturity, patients are given access to EPR systems to use and share on the same basis as in primary care.
- NHS England should investigate the market for and development of patient-held coordinated care records (i.e. a patient's own EHR) that draw on GP, hospital and social care systems and their potential use in the NHS. The technology underpinning the Hampshire Health Record provides an example of how this might be done.
- Failure to provide information to third parties in accordance with patients' wishes outside clearly delineated areas of exception should be regarded as a failure in information governance.

ACTION TWO

ENSURE CLINICIANS HAVE IMMEDIATE ACCESS TO EFFECTIVE ELECTRONIC RECORD SYSTEMS

- The Royal Colleges should review their professional guidance and include reference to the importance of the use of EPR and EHR systems to manage patients. Given the importance of information sharing to providing safe and effective care they should consider making approval of junior doctor training places conditional on having adequate EPR and EHR systems.
- Care Quality Commission standards and inspections should include a focus on the availability of electronic records. No trust should be considered 'outstanding' if it does not have its own comprehensive electronic patient record and cannot at minimum demonstrate routine electronic access to and use of up to date summaries of GP records in A&E and on admission of patients for urgent care. They should also be delivering standardised information on diagnoses, changed medication, treatments and test results to GPs electronically on a patient's discharge. We recognise this is not feasible at the moment for all trusts but consider restricting the ability to classify the trust as 'outstanding' is reasonable given practice elsewhere. A date should be set for when a trust could no longer be considered 'good' without such arrangements.
- Clinicians should report any aspects of EPR and EHR systems that interfere with safe and effective clinical practice through the National Reporting and Learning Service and their employing organisations should take steps to remedy such aspects of the systems.
- The NHS Litigation Authority should review its premiums for clinical negligence so that higher premiums are incurred by those trusts without availability and extensive use of shared electronic records as set out above because of the risks to patient safety.

**ACTION
THREE****UTILISE ELECTRONIC HEALTH RECORDS FOR QUALITY MONITORING AND RESEARCH**

- As the national databases continue to develop, local and regional health economies should not stand still or be held back. Trusts, CCGs, commissioning support units (CSUs), and AHSNs can each drive database development based on their mandates. It is likely that these organisations will be able to move more quickly than national programs to realise local benefits and should have been empowered to do so. The Department of Health should ensure that legal and regulatory frameworks empower these organisations to link datasets and accredit them with a similar safe haven status to that the HSCIC currently holds. Last, information governance permissions should be clarified with an advice service made available under the auspices of the Caldicott 2 regulations.
- Health Education England should be tasked to develop a scheme for health data analysts to enable local and regional organisations to better use the data that they have, or will soon have, available. Similarly, training opportunities for clinicians to develop greater knowledge of the data and its possibilities should be introduced so that use of the information becomes a standard part of clinical practice, building on current expectations for clinical audit. These analysts should be given appropriate qualifications reflecting their expertise to aid in their identification by local, regional, and national organisations.
- In the case of care.data and other large national databases that maximise scope, integration, and granularity for national research, special investment should be made in to facilitating exclusions to respect public opinion. NHS England should establish a website allowing patients to opt-out or back in of national data collection schemes and receive confirmation that this has happened. Similarly, patient groups should be consulted regarding sensitive data items that ought to be excluded in all cases.
- NHS England and the HSCIC should build on the existing red/amber/green data categorisation framework to more precisely identify and mitigate risks stemming from databases with greater scope, integration, velocity, or granularity. The Department of Health should ensure through legislation that only NHS or accredited academic organisations receive access to the highest-risk databases, especially care.data. These measures should together address the issue of jigsaw re-identification specifically and ensure to the greatest extent possible that no one can become identified in NHS data viewed outside the NHS.
- The NHS Litigation Authority should establish a process by which patients whose data is lost or irresponsibly used can reach a fair settlement with the health service. Further, the Care Quality Commission should promote transparency by maintaining a public database of known data breaches for which reporting is mandatory, as is done in the USA under HIPAA regulations.
- The penalties for misusing NHS data should be made clearer and scaled with the severity of the breach of patient confidentiality. These penalties should not be made so severe as to discourage any use of data, but should deter deliberate criminal wrongdoing and could include professional disqualification as well as legal action.

**ACTION
FOUR****ENSURE ELECTRONIC RECORD SYSTEMS ARE OPEN AND INTEROPERABLE**

- Health information technology standards for interoperability have been both developed and recommended by national NHS bodies for many years but with only gradual and partial impact. A legislative mandate for adoption of relevant standards should be made, covering such issues as use of the NHS number and coding and messaging structures. Implementation timetables should distinguish between new procurements and existing systems.
- A condition of supply of systems to an NHS organisation should be that the data contained in them will be made available either free or at a charge that covers only the marginal cost of extraction.
- Mapping between different coding structures remains an issue. HSCIC should have responsibility for ensuring maps between different coding structures are available centrally, perhaps through a Wikipedia-type website, drawing on the information already held by vendors.
- Establishing HIEs currently depends on system vendors deciding that this is in line with their commercial interests. There is some concern that the NHS remains vulnerable to data being captured in proprietary systems and being unavailable to HIE initiatives except at significant cost. NHS England and the HSCIC should review with NHS organisations whether any barriers are being put in place. Where appropriate, further regulation or contractual requirements, including if necessary development of standards for clinical exchange of information, will be needed.

**ACTION
FIVE****ENSURE THE IMPLEMENTATION PROGRAMME IS FIT FOR PURPOSE**

- Providers and commissioners investing in EPRs should be required to coordinate strategies at a regional level to make them interoperable. A condition should be placed on access to central funds that any development is in line with an agreed regional strategy and has sufficient support from partners within the community. We do not propose imposition of arbitrary geographical boundaries from the centre. However, central policy should encourage the formation of regional strategies across natural communities – usually grouped around a specific hospital or hospitals in a conurbation such as Bristol or Greater Manchester. Providers and commissioners investing in EPR programmes should ensure part of their project plans details of how the programme fits with an agreed regional strategy for interoperability. Consideration should be given to such communities forming around AHSNs which would have the advantage of bringing deployment of the IT and analysis of the data for research and clinical purposes together.
- The aspiration of the NHS to implement EHR systems and become paperless should be underpinned by a series of metrics that capture the use of EPRs and shared records for clinical and patient benefit. We suggest what these might be, drawing on the data that is readily available within systems rather than adding to bureaucracy. These metrics should be used nationally and locally. The metrics suggested above will mainly be process ones. Routine evaluation of outcomes, for example reductions in medication errors would best be undertaken by commissioned studies.
- A condition of any contractual change instigated by commissioners or providers of care should be that such changes do not undermine integration of information systems across the health economy, regardless of the individual providers concerned. The providers may change but the aims of the service and its supporting infrastructure should remain constant or improve. The same test should apply to any conditions imposed on mergers and demergers by either commissioners or competition authorities.
- ‘Demonstrator sites’ that seek to bring organisations together to provide linked information for a population and showcase what can be done should cover both single integrated systems and those operating through HIEs, as this latter approach is likely to become the norm.
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- NHS England should provide support to purchaser organisations in the form of market intelligence and facilitating exchange of ideas and practice. The ‘regional’ communities we recommend above would be a starting point for such collaborative development both within the community and between ‘regions’.

APPENDIX TWO

Methodology

The methodology for this report involved a combination of qualitative and quantitative, and primary and secondary research methods.

Desk-based contextual research was undertaken to ensure that the research was well grounded in an understanding of the relevant national and international policy and legislation. We reviewed the literature on an ongoing basis throughout the study.

A review of the academic literature was conducted using MedLine with Medical Subject Headings (MeSH) relating to eHealth. Additional literature was also identified from the Cochrane Library and a wider internet search.

The literature review focused on Australia, USA, Denmark, Singapore, New Zealand, Northern Ireland, England and Scotland – countries where they have made progress implementing eHealth and whose experience we hypothesised that the NHS could learn from.

Between September and November 2013, 43 interviews were conducted with staff in local NHS organisations, clinical and technical experts (national and international) and national regulatory and government departments. Participants were asked about their organisation's use of EHRs (as well as wider interoperability), the perceived benefits and barriers to interoperability, costs, extent of interoperability, system implementation, the use of data and analytics and plans for further eHealth roll out/implementation.

A complete list of participants is found in appendix three.

A survey of 150 GPs and 350 senior doctors in secondary care was conducted by Medconnect/Drs.Net on behalf of the Commission to benchmark the use of eHealth and data sharing in NHS organisations. Participants were asked questions on their personal use and their organisations overall use of IT including EHRs, e-prescribing, electronic communications within their organisations, barriers and benefits of IT and demographic data.

Participants were paid a nominal sum for completing the questionnaire.



Participants

England

- **Airedale NHS Foundation Trust**
Dr Andrew Catto » Medical Director/Stroke Consultant
Dr Tim Ryecroft » Head of IT and Information Governance
- **Barts Health NHS Trust**
Dr Charles Gutteridge » Chief Clinical Information Officer
Luke Readman » Director of Informatics
- **Hampshire Health Record**
Toby Cave » Project Manager
Hugh Sanderson » Clinical Lead
- **Imperial College Healthcare NHS Trust**
Dr Sanjay Gautama » Caldicott Guardian, Clinical Lead for Clinical Systems and Clinical Safety Officer for ICT
Keith Jarrold » Chief Information Officer
Dr Bob Klaber » Consultant in General Paediatrics
Dr Mando Watson » Clinical Lead, General Paediatrics
- **Imperial College London**
Professor Azeem Majeed » Professor of Primary Care and Head of Department of Primary Care and Public Health
- **Informatics Merseyside**
Kate Warriner » Deputy Director
- **NHS Cumbria CCG**
Dr William Lumb » GP and Chief Information Officer
- **North West London Integrated Care Pilot**
Dr Aumran Tahir » GP
Andrew Thorne-Marsh » ICP IT Programme Lead
- **Salford Royal NHS Foundation Trust**
Dr Bob Young » Consultant Diabetologist
- **South Commissioning Support Unit**
Catherine Dampney » Chief Information Officer
- **South London and Maudsley NHS Foundation Trust**
David Newton » Programme Manager eMPowerment Programme
- **South West Commissioning Support Unit**
Andy Kinnear » Director of Business Intelligence and Informatics
- **Tower Hamlets**
Dr Kambiz Boomla » GP

International participants

SCOTLAND

- **Scottish Care Information – Diabetes Collaboration (SCI-DC)**
Dr Scott Cunningham » Technical Consultant
Dr Alistair Emslie-Smith » GP and Lead Clinician
- **Scottish Government eHealth Unit**
Eddie Turnbull » Head of eHealth
- **University of Dundee**
Professor Andrew Morris » Professor and Dean of Medicine
Dr Claudia Pagliari » Senior Lecturer in Primary Care
Professor Frank Sullivan » Honorary Professor

USA

- **Intermountain Institute for Health Care Delivery Research, Intermountain Healthcare**
Dr Brent C. James » Chief Quality Officer, Executive Director
- **Kaiser Permanente**
Jamie Ferguson » Vice President, Health IT Strategy and Policy
- **U.S. Department of Veterans Affairs**
Gail Graham » Assistant Deputy Under Secretary for Health and Analytics

NEW ZEALAND

- **National Health IT Board**
Graeme Osbourne » Director

AUSTRALIA

- **HealthShare**
Tony Lopes » eHealth Enterprise Architect
- **The University of New South Wales**
Dr Bette Liu » Senior Lecturer

Additional individuals

- **BCS Health**
Dr Justin Whatling » Chair
- **Health and Social Care Information Centre**
Eve Roodhouse » Programme Head/Senior Responsible
Owner Data Linkage Service
- **NHS England**
Beverly Bryant » Director of Strategic Systems and
Technology
Kathy Farndon » Head of Health Information Standards
and Information Governance
Dr Geraint Lewis » Director of Open Information
Kathy Mason » Programme Director Strategic Systems
Chris Outram » Director of Intelligence
- **Oxford University Hospitals NHS Trust**
Dame Fiona Caldicott » Chairman
- **Peter Sowerby Foundation**
Dr David Stables » Trustee
- **Public Health England**
Dr Jem Rashbass » National Director of Disease
Registration
- **Royal College of General Practitioners**
Dr Arjun Dhillon » Vice Chair Health Informatics Group
Professor Simon De Lusignan » Professor of Primary
Care Informatics and Clinical Informatics and Head of
Department of Health Care Management and Policy

APPENDIX FOUR

Evidence gathered from our interviews that EHRs lead to better care for people with chronic diseases

- The Scottish Care Information – Diabetes Collaboration (SCI-DC) database is used to help manage care for 288,549 people with diabetes in Scotland as of January 2014. Evidence from our interviews and the literature showed these patients are now being monitored prospectively, resulting in local amputation rates falling by 40 per cent.⁵⁰ Eighty per cent of diabetics are now screened. There has been a 40 per cent increase in screening for diabetic retinopathy and a reduction in foot ulcers.⁵¹
- The Intermountain diabetic registry flags any patients overdue for tests and enables physician to contact the patient. Clinicians can also use the system to track complex diabetes cases – two-thirds of patients have significant co-morbidities. Since the registry was introduced, they’ve reduced mortality by three per cent and hospitalisation over a two-year period by 20 per cent.
- In Salford, alerts for diabetes patients in the EPR have led to decreased rates of ulceration, amputation and improved retinopathy screening. Through the EPR, patients are now assessed routinely for venous thromboembolism, pressure ulcers and appropriate use of antibiotics. Prior to adoption this would have been carried out sporadically with no easy, systematic monitoring.⁵²



Examples of how EHRs can optimise care now and in the future

Now

- E-prescribing data from electronic patient records used for daily monitoring of care in Birmingham University Hospital showed that between 30–40 per cent of patients received antibiotics within agreed time limits. Feeding back analysis of the data to staff resulted in over 90 per cent of patients receiving antibiotics at the correct time and decreased their length of stay in hospital.⁵³
- Intermountain Healthcare have used their single EHR system that covers all aspects of both primary and secondary care to make audit of patient care easier and so bring about improvement. They have used e-prescribing data to help identify adverse drug events. Traditional methods identify only one in 100 cases. When they automated the process they identified 570 errors in a single year. The rate has now fallen to less than 200 in a year – a 70 per cent decline in incidents, saving \$1.5 million per hospital each year.^{54,55}
- Evidence from our interview also showed that they have used their EHR to incorporate guidelines within the workflow of the clinical system. The data is then routinely audited to compare treatment against the guideline and to identify whether the guideline needs adjusting in the light of the outcomes achieved. The case study demonstrates this for one condition. There is evidence that having information from all care settings available to the clinician when treating a patient can reduce risks of poor decision-making or missed diagnoses.

In the future

The data from EHR systems are capable of greatly increasing the speed and accuracy with which research into new treatments can be conducted. Also, because of the large size of the data sets available from electronic health records, effects that might otherwise be missed can be found. So-called real world evidence (RWE) has already proved its value in identifying risks to patients from new pharmaceuticals which had not been picked up during clinical trials. Examples of how RWE can inform research into new treatments or new delivery systems are:

- An analysis of a database of 1.4 million Kaiser Permanente members, found that those who took Vioxx (a COX-2 pain reliever used by arthritis patients) were more likely to suffer a heart attack or sudden cardiac death than those who took Celebrex, Vioxx's main rival. Based on these findings, further analysis linked Vioxx to more than 27,000 heart attacks or sudden cardiac deaths nationwide from the time it came on the market in 1999 through 2003.⁵⁶ Ultimately, Vioxx was withdrawn from the market in 2004.
- An increasing number of research studies use retrospective matching methods to construct a matched control group. Though such methods may not be as good as prospective randomised studies they have the advantage that they can be applied to interventions that already exist in practice, and on a large scale to show practice in real world applications rather than in the 'artificial' context of a trial. For example a study of the impact on hospital use of a home nursing service at the end-of-life was able to look at 30,000 patients – all the people in the country who received that service within a year.⁵⁷



There was near universal recognition among our interviewees that linked anonymised data has enormous potential.

Possibilities highlighted were:

- Improved knowledge of pharmaceuticals – tracking the use and effect of drugs using existing clinical databases, rather than specially constructed studies, especially with reference to established clinical guidelines.
- Improved understanding of treatment patterns and their impact, including delayed or missed diagnoses.
- Better knowledge of the health needs and care of local populations, including identification of those people most at risk of their condition worsening and requiring more intensive care.
- Better knowledge of the costs of care and greater ability to adjust payments and financial incentives accordingly.
- Ultimately, the ability to link clinical and genomic data for a population. This is increasingly being regarded as key way of developing new treatments resulting in further development of the life science industry with consequent economic benefits for those countries that can take advantage of the opportunities offered.

Despite the very low take up of the Summary Care Record (SCR) in England, a review of the project did identify a benefit in the quality of patient consultations. A detailed review⁶² of the SCR in the NHS found evidence of improved quality in some consultations, particularly those which involved medication decisions. It also found it was particularly useful in patients unable to communicate or advocate for themselves.

Reducing medication errors

- Citizen Memorial Hospital in Missouri adopted a closed loop medication system in 2007 through use of computerised prescriptions combined with barcoding patient's record. This has contributed to a 70 per cent reduction in reported medication errors in the hospital.⁵⁹
- Greenhalgh et al.'s review⁵⁸ of the SCR in the NHS found that although there had been limited roll out/use and no direct evidence of safer care, findings were consistent with the conclusion that the SCR may reduce rare but important medication errors.

Evidence that engaging patients in their own care leads to better overall care

- Early evaluations of tailored patient portals and platforms have demonstrated small but significant improvements in some clinical outcomes as well as in patients' sense of control and empowerment.^{60–63} However, they have noted the difficulties of engaging patients and the issues around designing effective interfaces. Some studies have found a reduction in cost as a result of self-management.
- Much of the work in this area to date has focused on chronic conditions, particularly diabetes. Two recent randomised trials conducted into self-management found evidence of significant impact of personal health records and shared care on glycaemic control and self-reported efficacy.^{64, 65} The larger study (164 patients across 26 randomised primary care facilities) found a significant impact on glycaemic control but not in patient-reported symptoms of diabetes. The other (with 77 patients) found a non-significant improvement in glycaemic control and a significant improvement in a psychosocial measure of self-efficacy, the diabetes empowerment scale. This is a short form questionnaire that assesses the degree to which patients feel able to manage their own condition.
- The Scottish Care Information – Diabetes (SCI-Diabetes) portal sends patients reminders for check-ups; provides accessible, up-to-date data on test results and other patient information; and allows patients to enter home glucose monitoring data as well as other routine measurements. Although it is not possible to say that such access has itself generated improvements in care, it has had one valuable additional benefit we identified through interview. The system enables patients to report issues of data quality or completeness. One example of this led to changes in the way default values were being used in hospital with more accurate data recording as a result, an example of how patients can be effective in challenging poorly completed records or examples of poor data.⁵¹
- At Kaiser Permanente, according to our interviewee Jamie Ferguson, two-thirds of patients access their records, with those aged 59 and over being amongst the biggest users. This compares with a take-up rate of about 40 per cent two years ago. Patients mainly access their record to book appointments online, refill prescriptions and view test results immediately they are available. The system can display the same patient record information in both professional and patient terminology, depending on who is viewing it. So, for example, a patient might see the word 'miscarriage' where a professional would see 'spontaneous abortion'.
- Brent James of Intermountain told us they have enabled patients to input data and then use that data to flag alerts for clinicians. For example, if patients who have heart failure enter data that is outside normal measures, the system alerts a nurse in the heart failure clinic who would then call the patient and discuss their symptoms and assess whether the patient should go to hospital. He said the greatest impact in patient record access for Intermountain has been in childhood asthma where they have identified an associated improvement in lung function and a reduction in ER visits and admissions.
- In Scotland, the introduction of the Electronic Palliative Care Summary (ePCS) in 2010 enabled GPs to record patients' needs and wishes about end-of-life care and make this information available to those providing out-of-hours (OOH) care. The ePCS allows, with patient/carer consent, automatic twice-daily updates of information from computerized GP records to a central store, from where they will be made available to OOH services, NHS 24, acute receiving units, A&E departments and shortly to the Scottish Ambulance Service. In 2011, there were 5,097 palliative care summaries stored from 490 practices, across all 14 Boards (48 per cent of practices). Studies found that patients and carers were reassured that OOH staff were informed about their current circumstances; OOH staff considered the ePCS allowed them to be better informed in decision making and in carrying out home visits; and GPs viewed the introduction of ePCSs to have benefits for in-hours structures of care including advance care planning.⁶⁶

Examples of progress, weaknesses and new policies within England

Progress

- From a slow start there are now 31 million summary care records (SCRs) drawn from GP records available for view in secondary care. Each SCR includes information about patient prescriptions, allergies and previous adverse reactions.
- Airedale NHS Foundation Trust is part way through implementing a single system (SystemOne) that will combine with the same one used by GPs to produce a shared record. The first steps include e-prescribing and e-discharge along with a patient administration system. Salford has developed its own shared e-health record covering primary and secondary care.
- In Liverpool, key elements of GP records are now widely shared across different care settings including GP out-of-hours, community services, A&E and urgent care admissions in hospitals. The amount shared varies according to the service, from medications and allergies to the full record. Similar developments are taking place in Cumbria, East London and elsewhere.
- Renal Patient View (RPV) is a UK system that allows patients with kidney disease to view their records. Patients and health professionals felt that using RPV makes patients feel more in control of their medical care as well as giving them a better understanding of their kidney disease. Professionals observed that patients who use RPV are more informed about their kidney disease, and are much more involved in decisions about their treatment. RPV enhances patients' awareness and ability to self-care. Users of RPV were noted to be less reliant on professionals to make decisions and manage aspects of their care. RPV users understood how changes in lifestyle could impact on their health. In addition, being able to see their results enables patients to make adjustments to their lifestyle, especially their diet, where necessary.⁶⁷
- Patient access to electronic record systems (PAERS) Ltd is a small independent company set up by doctors in 2003. It provides patients registered with EMIS practices with a secure view of their record either via the Internet or a kiosk at their general practice. It is a self-contained system, which allows patients to access and navigate around their GP electronic medical record autonomously, and which provides them with the information that they need to understand the medical terminology. It does not provide access to narrative text, but provides all details on past medical history, access to referral letters, medications and allergies. The system also allows patients to book appointments and request repeat prescriptions. They can also correct inaccuracies in their data.
- The Royal Marsden Hospital in London has introduced Coordinate My Care (CMC) – an electronic personalised urgent care record that contains information about patients' wishes and preferences as well as an escalation treatment plan. It can be accessed 24/7 by GPs, community nurses, hospital teams, out-of-hours doctors, specialist nurses, the London Ambulance Service and NHS 111. When a new record is created, the emergency services are immediately alerted. By the end of 2014, CMC plans to give patients and carers access to their CMC record. Research data on the effect of the record yet to be published shows that it has succeeded in decreasing A&E attendance and hospital admissions. Furthermore, more than three quarters of the people who have died while on the CMC programme have died where they have wanted to.⁶⁸
- Patients of South London and the Maudsley NHS Foundation Trust have begun to use a new system to give them greater access to their data. Every two weeks, data from GPs is linked with that from secondary care records in 'myhealthlocker'. Patients can add information, for example they can 'rate their day', add observations or complete a wellbeing survey. Data from the survey that gives information about patient outcomes is fed into the trust's main clinical data repository and used for research, once anonymised.
- In England, one exemplar of progress in this area can be found in Houghton Vale, in Greater Manchester, where Dr Amir Hannan and colleagues have been providing access to patients to view their own records for several years. As Dr Hannan has said, "The practice has also saved a lot of time and money. For example, patients are now going online to see test results, rather than coming in to the surgery. This has freed up appointments and reduced call volumes."⁶⁹
- Linked data from national and local databases has been used for many different audit and research projects. The outputs vary from 'risk-stratification' systems which identify patients most at risk of requiring emergency hospital admission and who therefore might most benefit from enhanced community support;^{70,71} identifying in North East London how diagnosis and treatment of COPD could be improved in primary care to prevent exacerbations requiring hospital treatment and improve overall outcomes for patients; and assessing the effectiveness of new telehealth and telecare technology.⁷²
- Creation and take up of SCRs is growing but from a low base. By November 2013 there were 31 million SCRs covering 55 per cent of the population and 12,000 views per week.⁷³ Among the reasons put forward for the slow growth have been non-availability of records – if on too many occasions no record is available, people stop using the system. Another issue has been technical problems such as bugs and system incompatibility. Lack of training and information governance problems such as lost smart cards and passwords and staff fear of surveillance have also been identified as problems.⁷⁴

Weakness

- The Future Forum, an expert inquiry in the reform in the NHS in England found that the inability to share data effectively due to poor interoperability between health and social care providers is a major barrier to ensuring that patients receive a safe, high quality and integrated service.³⁹
- EPRs are much less developed outside general practice and sharing standardised information electronically is very variable. In our survey, secondary care doctors often had no access to a patient's record outside their hospital, and in a quarter of cases said they had no electronic access to data about prior admissions to their own hospital. The most common way for GPs to receive discharge information was by post. In June 2010 only a third of GPs received discharge summaries within 48 hours, according to an NHS Alliance survey. Most GPs (77 per cent) considered patient safety had been compromised by inadequate discharge information.¹²
- Information to gauge take-up of NICE guidance is poor. Extensive prescribing data is available nationally for primary care but this does not link the medicine to the patient's condition. Data on prescribing in hospital is based on volumes dispensed in pharmacies. Clinical data is available only in so far as there are national audits.
- There is extensive national data on hospital activity but this does not contain detailed clinical information (for example on prescribing). Extensive clinical data is available from GP EPRs but this has not been collected nationally or linked to hospital information.
- In our survey, just over half of GPs would not use IT to communicate with patients about their care, possibly saving face-to-face consultation time.
- Most GP information systems have the capability to give patients access to their records (and to undertake transactional tasks such as booking appointments) but this has rarely been made available or taken up. On a Monday in June in 2013, some 750,000 appointments were logged by practices using EMIS systems, the GP practice software used by about half the practices in the country. Although this software has the functionality to allow online booking, only 7,000 were booked in this way.⁷⁵ Use of online booking remains low despite enthusiasm from patients. 31 per cent of patients in the 2013 GP survey said they would prefer to book appointments online.⁷⁶

New policies

- Establishment of a £1 billion Safer Hospitals Safer Wards fund in September 2013 to develop paperless hospitals, improve e-prescribing and increase interoperability across organisations. £500 million will come from central funds, the remainder to be provided locally in matched funding.
- Changing the GP contract to encourage greater online appointment booking and use of electronic communication with patients and to enable patients to access their SCR. The 2012 NHS mandate requires that patients be given electronic access to their full GP record by 2015.⁴⁰
- Encouraging greater sharing of information electronically to support integrated care as part of the requirements of the £3.8 billion Better Care Fund that will form a pooled budget between Clinical Commissioning Groups and Social Services Authorities in 2015/16.⁷⁷
- Development of 'care.data' which will from spring 2014 extract clinical data from GP systems and link it to Hospital Episode Statistics (HES) to provide an anonymised national database of patient's primary and secondary care records for research and service planning purposes, so adding to the linked data that is already available using HES and the minimum mental health data set and from Office of National Statistics (ONS) mortality information. The intention is gradually to add hospital clinical data and information from community services and social care.
- Investing through the Medical Research Council in four centres for e-health research across the UK. Also, each of the Academic Health Science Centres and Networks has information and use of data as key elements for development and impact.

Comparison of research database designs

This table gives a high-level summary of various database designs currently used for healthcare research. It is not an exhaustive list.

| care.data (care episode statistics) | |
|--|--|
| SCALE | national (England); all treatments and diagnoses |
| INTEGRATION | primary and secondary care data |
| VELOCITY | low-velocity: several month lag |
| GRANULARITY | patient-level |
| EXCLUSION | opt-out |
| Hospital Episode Statistics (HES) | |
| SCALE | national (England); all treatments and diagnoses |
| INTEGRATION | secondary care only; additional datasets as available including cancer registry and mortality data |
| VELOCITY | low-velocity: several month lag |
| GRANULARITY | patient-level |
| EXCLUSION | no exclusions |
| Clinical Practice Research Datalink (CPRD) | |
| SCALE | selection of GP practices across England (<10%) |
| INTEGRATION | primary and secondary care data; additional datasets as available including cancer registry and mortality data |
| VELOCITY | low-velocity: several month lag |
| GRANULARITY | patient-level |
| EXCLUSION | opt-in by GP practices |
| Intermountain Healthcare | |
| SCALE | regional (Utah and Idaho, USA) |
| INTEGRATION | primary and secondary care |
| VELOCITY | high-velocity: real-time monitoring and intervention |
| GRANULARITY | patient-level |
| EXCLUSION | no exclusions |
| Hampshire Health Record analytics (HHRa) | |
| SCALE | regional |
| INTEGRATION | primary and secondary care; mental health; social care: GP records plus diagnostic/outpatient/discharge information from hospitals; additional condition-specific datasets |
| VELOCITY | low-velocity: pseudonymised for research (separate HHR system enables clinical intervention) |
| GRANULARITY | patient-level |
| EXCLUSION | opt-out |
| National Cancer Data Repository | |
| SCALE | national (England): cancer cases only |
| INTEGRATION | secondary care only; linkage possible to CPRD, ONS, HES |
| VELOCITY | low-velocity: no patient intervention |
| GRANULARITY | patient-level |
| EXCLUSION | no exclusions |
| NHS GP prescribing data | |
| SCALE | national (England): prescribing data only |
| INTEGRATION | primary care only |
| VELOCITY | low-velocity: no patient intervention |
| GRANULARITY | GP-level |
| EXCLUSION | no exclusions |

Quality and Outcomes Framework (QOF)

| | |
|-------------|--|
| SCALE | national (England) |
| INTEGRATION | primary care only |
| VELOCITY | low-velocity: no patient intervention |
| GRANULARITY | GP-level |
| EXCLUSION | no exclusions; in GP contract tied to incentives |

QResearch

| | |
|-------------|--|
| SCALE | national (selection of GP practices with EMIS) |
| INTEGRATION | primary care only |
| VELOCITY | low-velocity: de-identified |
| GRANULARITY | patient-level |
| EXCLUSION | opt-out |

ResearchOne

| | |
|-------------|---|
| SCALE | national (selection of GP practices with TPP) |
| INTEGRATION | primary and some secondary care |
| VELOCITY | low-velocity: de-identified |
| GRANULARITY | patient-level |
| EXCLUSION | opt-out |

Scottish Care Information – Diabetes Collaboration (SCI-DC)

| | |
|-------------|---|
| SCALE | national (Scotland): diabetes care only (~300,000 people) |
| INTEGRATION | primary and secondary care |
| VELOCITY | high-velocity: real-time monitoring and intervention |
| GRANULARITY | patient-level |
| EXCLUSION | opt-out |

Systemic Anti-Cancer Therapy dataset (SACT)

| | |
|-------------|---|
| SCALE | national (England): cancer patients receiving chemotherapy only (~130,000 people) |
| INTEGRATION | secondary care only |
| VELOCITY | low-velocity: no patient intervention |
| GRANULARITY | hospital trust level |
| EXCLUSION | no exclusions |

The Healthcare Improvement Network (THIN)

| | |
|-------------|---|
| SCALE | national (selection of GP practices with INPS/CSD) |
| INTEGRATION | primary care only; linkage possible to HES for some practices |
| VELOCITY | low-velocity: no patient intervention |
| GRANULARITY | patient level |
| EXCLUSION | no exclusions |

Glossary

There is a lack of consistency in terms so for clarity we have used the terms throughout this report in the following ways:

Audit data: this term refers to information held about patient care by clinicians or provider organisations for the primary purpose of monitoring care standards rather than to inform the decisions about individual patients.

Administrative data/routine data: information held about patient care by provider organisations with the primary intention of helping with the administration of the organisation rather than to inform clinical decisions about individual patients.

Clinical data: information held about patient care by provider organisations with the primary intention of informing clinical decisions about individual patients.

eHealth: eHealth has many definitions, as described in a systematic review by Oh et al., which noted, among other findings, that eHealth typically describes the way computer-based or internet-based tools can be applied to the process of delivering healthcare.⁷⁸ It is thus less focused on the contents of records themselves and more on an attitude or expectation that technology be used to enable care. For this reason, we have found it helpful to describe trends in health system strategy and investment – based upon a common philosophy that the judicious application of technology can deliver improved care – which can be translated into a number of activities, the development of EHRs included.

Medical records: this refers to the official medical records as defined in the UK. Medical records in the UK are held on paper.

Summary care record (SCR): A summary care record is a shortened form of an EHR designed to be shared among clinicians for specific treatment purposes. For example, in the UK, the SCR is intended for use primarily to provide key details in the event of a patient needing emergency treatment outside their normal site of care.⁷⁹

Electronic health records (EHRs) provide longitudinal data about a patient extending beyond a single site of care. Their purpose is to reflect the overall health of a patient and his or her history of interaction with the healthcare system. EHRs may be made up of several individual records, which we term electronic patient records or EPRs, below. For example, GP records that include only information about the patient's GP-given diagnoses, appointments, prescriptions, vital signs, etc. would *not* meet our definition of an EHR because they are restrained to a single site of care. However, an EHR used or accessed in a GP's surgery that includes substantial, trustworthy information in a structured form about care given in a hospital and other care settings (diagnoses, medications, discharge summaries etc.) would meet the EHR definition. EHRs may also include patient-defined, genomic, or social care information under a broad definition of 'health'. Under this definition, there are much fewer examples of EHRs in the UK today than there are of EPRs. It is also the goal toward which the majority of this report is aimed.

Electronic patient records (EPRs) which are sometimes known as electronic medical records, are used in the course of clinical care in a single care setting for example a hospital or GP's surgery. They are essential tools that provide a means to input and access data about treatment provided on a single occasion or multiple occasions by that institution and do not reflect the overall health of a patient and history of interaction with the healthcare system for a particular patient. Individual units in a hospital may have their own electronic record, but we have reserved EPR to mean an accessible structured electronic record of a patient's treatment at that hospital, as a key policy aim is to integrate information from different hospital systems.

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The Peter Sowerby Foundation was established in 2011 with a multi-million pound endowment from Dr Peter Sowerby, a North Yorkshire GP and medical entrepreneur. Dr Sowerby was the co-founder of Egton Medical Information Systems (EMIS), the clinical management system, now used by over half of the country's GP practices, as well as many other healthcare providers.

The Foundation's principal aim is to have a lasting impact through supporting well-researched initiatives that can make positive changes in aspects of primary healthcare. Through the provision of long-term targeted grant-making, the Foundation is developing partnerships with some of the country's leading healthcare institutions, working together to improve patient outcomes by, for example, re-evaluating the use of data across the healthcare sector and raising standards in palliative and end-of-life care.

The Foundation also invests in Peter and his late wife Ann's other personal charitable interests around education, enhancement of the natural world and improving the quality of life for people living in his locale of rural North Yorkshire.

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The Institute of Global Health Innovation (IGHI) works to improve people's health through innovation. By working with others and harnessing Imperial's expertise across medicine, science, business and engineering, we are able to find sustainable solutions to the greatest global health challenges.

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