

Electronic Health Records



NHS England has committed to making patients' records 'largely paperless' by 2020.¹ Electronic health records will contain information about patients' histories, health and lifestyles. They will be accessible to primary, secondary and social care providers, and to patients. This POSTnote describes the plans for electronic health records and explores the associated opportunities and challenges.

Government Proposals for Health Records

The Government's target is to introduce a comprehensive system of electronic health records in England by 2020.² The intention is that each patient's electronic record will include information about his or her medical history, care preferences and lifestyle (such as diet and exercise). The records should be accessible to all health and social care providers and updated in real-time.³ Patients should be able to view and annotate a version of their health record online.³ Patients should also be able to book appointments and order repeat prescriptions online. Health policy is devolved, but Scotland, Wales and Northern Ireland have similar plans (see Box 1).

In England, electronic health record planning is managed by NHS England, the National Information Board (NIB, which develops priorities for data and technology for the Department of Health) and the Health and Social Care Information Centre (HSCIC, a non-departmental public body which manages information, data and IT systems for health and care). Together they are developing national standards for electronic health records, but local areas can choose their own systems. NHS England funds several schemes to encourage local areas to transfer their paper records to electronic databases, and to connect electronic health systems together (Box 2). A few suppliers of health record software dominate the market (see page 3). Ultimately, the

Overview

- Electronic health records are digital records of a patient's health and care.
- At present, patients may have several paper and electronic records stored in various settings. NHS England intends to connect electronic health records across primary, secondary and social care by 2020.
- This system would allow people to monitor their own health and could improve patient safety and outcomes. Electronic record keeping would also aid the collection of data for research, and inform the commissioning of health and care.
- There are a range of technological and organisational challenges to implementation, such as interoperability, staff training and maintaining the privacy of patient data.

Government expects that local initiatives will extend, join together and lead to comprehensive coverage. By April 2016, all clinical commissioning groups must submit plans to the NIB, explaining how they will introduce electronic health records by 2020.⁴ NHS England has indicated that it will distribute future technology funds based on these reports.⁵

Previous attempts to introduce comprehensive electronic health records failed.⁶ During the National Programme for IT (2002-11), the Department of Health paid four suppliers (CSC, BT, Accenture and Fujitsu) to provide electronic records.⁷ The programme was dismantled after escalating costs and delays.⁸ Criticisms included weak management and oversight of the programme and contracts that were poor value for money.⁷ The Government, NHS England and NIB argue that the programme was too centralised, and insufficiently sensitive to local circumstances.⁹

Current Use of Patients' Electronic Records

The NHS currently holds patient information in a variety of settings, both in paper form and electronically. Electronic records are stored by GPs, hospitals (notably in radiology and pathology), mental health providers and in some community care settings. There is great variation in the type and use of electronic record systems between geographical regions and even between departments within hospitals.³

Box 1. Electronic Health Records across the UK

Scotland, Wales and Northern Ireland have all made substantial progress towards enabling the sharing of electronic health records.^{10,11,12,13,14,15} Northern Ireland's Electronic Care Record (ECR) has won industry awards.¹⁶ The ECR extracts information from existing electronic records, and makes it accessible across hospitals, GPs and social care through a portal provided by the company Orion Health.¹⁵ The system was purchased by Northern Ireland's national health service, Health and Social Care (HSCNI), and will cost £9m (2013-2020).¹⁷ HSCNI conducted a pilot, analysed international sites, and engaged clinicians in designing the ECR's specifications.^{18,19}

Sharing Patient Information

At present, only a few electronic records are shared between providers. The electronic Summary Care Record (SCR) contains limited patient information (prescriptions, allergies and adverse reactions) and is shared between hospitals, GP surgeries, walk-in centres and, from 2017, with community pharmacists.²⁰ SCRs were rolled out on an 'opt-out' basis, with ~1.4% of patients opting-out.²¹ 94% of England's population had an SCR by March 2015.³ Some local areas share more detailed patient records between providers.^{3,22} Clinical commissioning groups and NHS Trusts in Bristol, Somerset and Gloucestershire have created the Connecting Care programme, which shares electronic records between primary, secondary and social care in these areas.²³

Patient Access to Information

Individuals have the legal right to access their health records except where the information may cause serious harm to the patient, or would reveal information about another person who has not consented to this disclosure.^{24,25} Since April 2014, the percentage of GP surgeries in England allowing patients to access their SCR online, book appointments and order repeat prescriptions has increased from 3% to 97%.^{3,26} However, patient take up is extremely low: only 0.4% patients have used this service.²⁷ Furthermore, only 0.1% of patients have access to their full GP record online.

Benefits of Electronic Health Records

Electronic records can offer primary and secondary benefits for patients, clinicians and researchers. The HSCIC and the Academy of Medical Royal Colleges have stated that the rising demands on healthcare systems 'can only be met by the development and use of electronic health records'.²⁸

Improving Care and Patient Involvement

The NHS, NIB and clinicians agree that enabling patient data access by staff in different locations is key to providing collaborative care between health and social care.^{3,27,29,30,31} It is expected that this information will be particularly useful for the care of patients with complex needs.^{32,33} Surveys of doctors' attitudes show that most think that electronic health records will become integral to effective patient care in future, and will improve the quality of treatment decisions, reduce medical errors and improve health outcomes.^{34,35} The think-tank 2020 Health argues that patient access may enable people to monitor and influence their own

Box 2. Funding for Electronic Health Records

NHS England has several schemes to support electronic records:

- The **Integrated Digital Care Fund** awards money to NHS Trusts to facilitate the adoption of modern, safe standards of electronic record-keeping.³⁶ £43m was awarded in 2015.³⁷
- The **Nursing Technology Fund** provides grants to Trusts to buy digital services for nurses.³⁸ £35m was awarded in 2015.
- The **NHS Innovation Accelerator scheme** funds fellows who have worked with industry and the third sector to develop health technology. Seventeen were chosen in 2015.³⁹
- **Vanguard sites** are partnerships between health and care organisations that will provide new care models. 50 sites have been selected, which gain support and access to a £200m fund.⁴⁰ Many rely on the development of new technologies.⁴¹

The 2015 Comprehensive Spending Review committed an extra £1bn to technology in the NHS in the next five years.⁴² More detailed plans for precisely how and where this money will be allocated will follow.

health better (see Box 3).⁴³ Patients will no longer need to describe their health to multiple practitioners repeatedly.³³

Using Data for Research

Health data may also have secondary uses for research. Healthcare settings use data to assess standards of care, identify groups of individuals at particular risk of diseases, and for management, staffing and resource allocation.^{44,45} The analysis of data can help researchers to understand and manage illness and health, and is seen as key to the development of personalised medicine by clinicians.^{44,46,47} NHS data played a role in uncovering the mid-Staffordshire scandal, and have provided evidence to explain why cancer survival rates are lower in England than Europe.^{48,49} Health record data may also be used to create predictive algorithms, which can provide early warnings for patients at risk of adverse drug reactions or surgical complications.⁵⁰

Quantifying the Benefits

Electronic health records are being implemented across the world.⁵¹ The social and economic benefits can outweigh their costs (hardware, software, maintenance and training). In 2010, the European Commission studied 11 established electronic health record systems and found them cost-effective.⁵² The Commission predicted that a successful development would have a lifetime socio-economic return of close to 200% on investment, with an average 80% return already realised in the 11 case studies.⁵³ In all cases, benefits were not realised quickly (taking 4-9 years), but were sustainable.⁵² Key benefits were improved clinical decisions and performance.⁵² One of the most successful systems operates in Estonia (see Box 4).

Box 3. Case Study: 'Patients Know Best'

Patients Know Best is an award-winning commercial electronic health record used in 200 sites in eight countries.⁵⁴ Care facilities buy the program, and patients can register and then invite clinicians, family or friends to view their records. Reports can be shared instantly and it allows online consultations.⁵⁵ Luton and Dunstable Hospital trialled it for patients with inflammatory bowel disease. Patients received alerts about when to switch medications.⁵⁶ In Peterborough and Stamford Hospitals, the system allowed neurological patients to upload videos of seizures, allowing clinical diagnosis without visiting hospital.⁵⁷

Box 4. Estonian e-Government

Estonian citizens can view and request changes to their medical records, and restrict and monitor access by others.⁵⁸ One study found that the social and economic benefits from electronic health records, introduced in 2008, would outweigh costs by 2010. The main benefits cited were improved patient health, which would also increase tax revenue and patients' incomes.⁵⁹ Data protection is managed using encryption and a secure network called the 'X-Road'.^{58,60} While Estonia is far smaller than the UK (population of ~1.3m), the UK and Estonia Governments have agreed to share knowledge about the use of technology for public services.⁶¹

In 2012, the Department of Health estimated that over the next 10 years electronic health records would cost £1.3bn but could save £6.3bn.⁶² Key savings were patients' time and improved quality of life from earlier diagnoses, and fewer medical errors. However, estimated benefits may be disrupted by organisational change or supplier disengagement towards the end of contracts.⁸

Challenges to Implementation

A European Commission study has warned that electronic health record systems can only yield any potential benefits if they are implemented and utilised effectively.⁵² There are several challenges to implementing the Government's plans.

Interoperability of IT Systems

Electronic health record systems need to be interoperable: able to store and communicate information from different and geographically distributed databases.⁶³ There are over one hundred commercial suppliers of electronic health record software.⁶⁴ Despite this, the market is currently dominated by a few large suppliers. The majority of software for Summary Care Records and GP practices is provided by EMIS, TPP and inPractice.⁶⁵ Large suppliers of hospital software include Cerner, CSC, BT and IMS Maxims. Open Source software is also increasingly used, and has been endorsed by NHS England (Box 5). The Care Quality Commission has identified cases where IT systems from different suppliers do not communicate effectively, with staff consequently reverting to using paper records.⁶⁶ The NHS, local authorities, clinical staff and software providers have committed to ensuring that electronic health records are interoperable.^{67,68,69,70} In recognition of the need for health

Box 5. Open Source Software

Open Source software is free to use, adapt and distribute. NHS England encourages its use, citing several benefits:⁷¹

- Trusts can continuously adapt a system to their own needs
- Trusts are not 'locked in' to one provider
- healthcare professionals may have more input to adapt software
- new ideas and solutions can be shared and combined.⁷²

Taunton and Somerset NHS Trust has implemented an open-source programme from IMS Maxims.⁷³ No licence fee is levied – making it cheaper than commercial alternatives – but costs are incurred for software development, implementation and maintenance. The system is used for A&E, outpatients and across 30 wards. It will be extended to prescribing, and connected to GPs and patients in 2016.⁷⁴ Commercial suppliers argue that their products are more reliable and secure than open source ones; open source users contest this.⁷⁵

Box 6. National Standards for Electronic Health Records

- **The NHS Number** should be used as a single unique identifier for patients when sharing information.⁷⁶
- **Open Application Program Interfaces** (open APIs, instructions which govern how programmes interact) should be provided by all electronic health record suppliers.⁷⁶ The interfaces can be viewed by suppliers, who can then create programmes that work together to exchange patient information.⁷⁶
- **SNOMED CT**, a common terminology, should be used by all clinicians when writing clinical terms into electronic records.⁷⁶
- **The Transfer of Care Initiative** will create common standards for how medical records are transferred when a patient is admitted, discharged or referred. The Professional Record Standards Body has also been established (endorsed by HSCIC) to develop further standards for the structure and content of electronic records.^{77,78}

systems across the UK to work together, discussions between NHS England and the Welsh Government are also in progress.⁷⁹ The HSCIC has published an 'Interoperability Handbook' to outline common specifications, frameworks and standards for medical software (see Box 6) and accredits systems which meet them.⁷⁶ NHS Trusts are advised to take this into account during procurement, but this is not a legal requirement.⁷⁶

System Installation and Staff Training

New IT systems may be introduced into hospitals in a single phase or by gradual replacement of software and hardware over several years. Moorfields Eye Hospital has taken the latter approach, enabling software to be tested, and clinicians to adapt gradually.⁸⁰ However, the HSCIC has highlighted that this makes the period of adjustment longer for clinicians.⁸¹ Cambridge University Hospitals introduced a single electronic health record system across its wards in October 2014.⁸² The system was launched overnight, with 2.1m patient records uploaded, accessible on 7,000 devices.⁸³ A Care Quality Commission inspection in Spring 2015 highlighted subsequent issues (see Box 7).⁸⁴ All staff must be trained to use new electronic systems, requiring them to gain new technical skills and change their established working patterns.^{85,86} Several factors may inhibit clinicians' adoption of electronic systems. Studies have highlighted the role of age (with junior doctors adapting to the new systems more quickly), clinicians' existing attitudes towards ICT, and the extent to which a physician identifies a system as easy to use, supported by peers and patients and demonstrating tangible results.^{86,87,88,89,90} The HSCIC and European Commission have argued that clinicians must be engaged in procuring and developing electronic health software.⁵²

Opportunities for Patient Access

At present, not all patients would be able to access electronic health records: in the first quarter of 2015, 86% of UK adults used the internet, but only 2% had had any digital interaction with the NHS.⁹¹ NHS England recognises that the groups most affected by health inequalities are also those least likely to be digitally literate or have access to online services. The not-for-profit Tinder Foundation works with community organisations to reach these groups.⁹²

Box 7. Cambridge University Hospitals

In 2015, the Care Quality Commission (CQC) reported issues with the electronic health record system at Cambridge University Hospitals:⁹³

- **Data collection** was not consistent across several wards.⁹⁴
- **Access to patient information.** Staff reported time-lags between information being recorded on handheld devices and appearing on monitors.⁹⁵ Temporary staff were unable to access records.⁹⁶
- **Loss of functionality.** Some functions were not present on the electronic system, for example individual end-of-life care plans.⁹⁷ The CQC reported problems with prescribing, especially when the system went live, when clinicians had to revert to paper records.⁹⁸
- **Hardware issues.** There were difficulties in matching new hardware ('workstations on wheels', handheld devices, and desktop PCs) to existing clinical work patterns.^{99,100}

Some staff criticised the overnight implementation of this system, the lack of testing and external governance, and the training provided.¹⁰¹ The Trust is currently analysing and sharing the lessons learnt from implementation.¹⁰² The Trust has also stated that the systems benefits are emerging. For example, handheld devices at patient's bedside record real-time observations (such as heart rate), freeing up nurses' time, and giving doctors instant access to information.¹⁰³

Consequences for the Doctor-Patient Relationship

Editorials in leading medical journals argue that electronic health records could damage the doctor-patient relationship, because electronic record keeping may leave clinicians less time for their patients.^{104,105} A recent survey of 502 doctors found that half believed that the use of healthcare IT had decreased time spent with patients.¹⁰⁶ Staff to transcribe patients' medical records can be used to free doctors' time, but this may impede the development of electronic records, as clinicians disengage with using and improving them.^{107,108} There are conflicting views about how much information patients should have access to. Surveys show that while three-quarters of adults think they should have full access to their health records, only one-third of doctors share this view.^{109,110} A more transparent flow of information may improve communication and trust between patients and doctors, but patients may not understand the information on their record, causing them unnecessary anxiety.^{59,111} The Royal College of GPs has stated that some clinicians are concerned that patient access may increase the potential for litigation, but also that there is little evidence for this.¹¹²

Data Security and Privacy

Healthcare providers have a duty of confidentiality to patients and must seek their consent before sharing their data (with some exceptions).⁴⁵ Data breaches can be accidental, resulting from a lack of knowledge about using records, or deliberate.¹¹³ Privacy campaigners have reported 7,255 cases of NHS data breaches (2011-2014), including cases where clinicians had accessed patient data inappropriately or lost hardware containing patient data.¹¹⁴ These risks can be managed in several ways:

- **Audit trails:** electronic systems record who accesses patient data. This can be used to monitor misuse and may act as a deterrent.¹¹⁵ Successful auditing can be compromised if users do not follow login procedures.¹¹⁵
- **Patient control:** some electronic record systems enable patients to restrict who may view their information.
- **Training** can improve knowledge about who can access and use patient records and in what circumstances.

Electronic records may be more secure than paper records, because of audit trails. Encryption also reduces the risk of inappropriate external access to patient information.¹¹⁶

However, it is hard to compare the data safety of electronic and paper records because of the variety of systems used and the difficulty of monitoring breaches. Sanctions for data breaches are enforced by the Information Commissioner's Office (ICO), with a maximum fine of £0.5m.¹¹⁷ The ICO took action against 34 healthcare providers 2013-2015, mostly issuing warnings but also one fine (£130,000 for a pharmacy which sold customers' details) and one prosecution (a pharmacist who viewed colleagues' records was fined £1,000).^{118,119} Several stakeholders argue that criminal sanctions should apply to serious breaches.^{120,121,122,123} An independent UK review of personal health data regulation is expected in Spring 2016.¹²⁴ The European Commission's new data protection regulation (2017) is also relevant.¹²⁵

Secondary Uses of Data

The proposed secondary uses of electronic health records for research have been challenged on privacy grounds. Personal information can be removed from the health record given to researchers by using aggregation, anonymisation and pseudonymisation.⁴⁵ However, security experts have demonstrated that they can re-identify patients from data, particularly those with rare conditions.¹²⁶ Alternatively, data linkage technologies may allow data to be analysed without requiring the extraction of identifiable data.⁴⁵ However, these data may be less useful for researchers, since without identifiers they cannot link multiple records about one patient, and fully understand his or her medical history.⁴⁵

The campaign group MedConfidential argues that patients should be given the choice over how their data is used, and accurately informed about proposed secondary uses.¹²⁷ The care.data programme will extract patient data held by GPs for researchers.¹²⁸ In 2013 and 2014, leaflets were distributed to patients advising them of their right to opt out of having their data shared with the HSCIC for secondary purposes (a type 1 opt-out) or from allowing the HSCIC to share their data with other organisations for secondary purposes (a type 2 opt-out).¹²⁹ Privacy groups argued that these leaflets were not clearly written nor distributed to all houses. The care.data programme was paused in February 2014.^{130,131} After consultation the care.data trial restarted in autumn 2014 by six clinical commissioning groups.¹³² In November 2015, the ICO found that the type 2 opt-outs had not been passed from GPs to the HSCIC, and HSCIC had shared data from 700,000 patients who had opted out.¹²⁹

Patient Perspective

Surveys have shown that patients are concerned about the security of their electronic health records, but recognise the value of sharing data, both for their own care and for research.¹³³ In a 2015 survey of 2,761 patients in London, 79% reported that they worry about the security of an electronic health record, but 55% of those nonetheless supported their development.¹³⁴

Endnotes

- 1 [Five Year Forward View](#), NHS England October 2014
- 2 [Health Secretary outlines vision for use of technology across NHS](#), 2 September 2015, Department of Health
- 3 [Personalised Health and Care 2020: Using Data and Technology to Transform Outcomes for Patients and Citizens: A Framework for Action](#), National Information Board, November 2014
- 4 [NHS England, Local Digital Roadmaps](#)
- 5 [Beverly Bryant, 'Ten key points from eHealth Live'](#), [digitalhealth.net](#), 5 November 2015
- 6 Description of reforms from 1990 available in: [Department of Health, The power of information: Putting all of us in control of the health and care information we need - Impact Assessment](#), 16 May 2010
- 7 [House of Commons Committee of Public Accounts, 'The dismantled National Programme for IT in the NHS', Nineteenth Report of Session 2013-14](#), 15 July 2013
- 8 [National Audit Office, Review of the final benefits statement for programmes previously managed under the National Programme for IT in the NHS: Memorandum for the House of Commons Committee of Public Accounts](#), June 2013
- 9 [Jeremy Hunt, 'Jeremy Hunt challenges NHS to go paperless by 2018'](#), [gov.uk](#), 16 January 2013.; [National Information Board, Personalised Health and Care 2020: Using Data and Technology to Transform Outcomes for Patients and Citizens: A Framework for Action](#), November 2014
- 10 [Digitising the NHS: One Year On](#), [techUK](#) March 2014
- 11 [The Information Centre, SPICe Briefing: eHealth in Scotland](#), 15 February 2013
- 12 [NHS Wales, What does the IHR contain?](#)
- 13 [Welsh Government, 'E-Health and Care Strategy for Wales'](#), 16 March 2015.
- 14 [NHS Wales, Welsh Clinical Portal](#)
- 15 [Northern Ireland Direct, Northern Ireland Electronic Care Record \(NIECR\) 'HSJ Awards 2014 winners revealed'](#), [Health Service Journal](#), 19 November 2014; ['Best use of IT to support integrated healthcare services'](#), [eHealth awards](#), 2014
- 17 [Orion Health, 'Northern Ireland takes lead in deployment of nationwide Electronic Care Record'](#), 29 May 2012
- 18 [John Purvis, 'NIECR – a quiet revolution'](#), [Ulster Medical Journal](#), 2015, 84 (1), 1-2
- 19 [Gary Loughton, 'The Northern Ireland Electronic Care Record'](#), [Health and Social Care](#), June 2014
- 20 [Health & Social Care Information Centre, Summary Care Records 'SCR' at tipping point' with clinicians](#), [digitalhealth.net](#), 12 August 2015
- 22 In Bristol, the 'Connecting Care' programme is a local electronic health record that allows health and social care professionals to share a summary of medical records across Bristol, South Gloucestershire and North Somerset. See [Connecting Care](#). This programme was the overall winner of the EHI awards, for the electronic health industry, in 2015.
- 23 The Hampshire Health Record contains information from hospital, general practice, community care and social services. See [Welcome to the Hampshire Health Record'](#)
- 24 [Accessing and sharing health records and patient confidentiality](#), [House of Commons Library Briefing Paper](#), 1 October 2015
- 25 [The Conservative Party general election manifesto of 2015 committed to this principle, and to giving patients full access to their electronic health records, as well as the right to opt-out of having these records shared.](#)
- 26 [NHS England' Over 55 million patients in England can now book GP appointments, order repeat prescriptions and access summary information in their medical record online - according to latest figures'](#), 19 May 2015
- 27 [Chief Clinical Information Officer Network, 'The 'Newcastle Declaration' - Why citizens need far better information sharing across health and social care'](#), September 2015
- 28 [Health and Social Care Information Centre and Academy of Medical Royal Colleges, Standards for the clinical structure and content of patient records](#), July 2013
- 29 [Dipak Kalra and David Ingram, Electronic Health Records](#)
- 30 [Academy of Medical Royal Colleges, What the medical profession is calling for from the net Government: a compendium of views of Medical Royal Colleges and Faculties](#), April 2015, p9
- 31 [Academy of Medical Royal Colleges, i-care: Information, Communication and Technology in the NHS](#), October 2013
- 32 [NHS Scotland, Frequently Asked Questions on the Key Information Summary \(KIS\)](#), 5 April 2013, p2
- 33 [Baroness Hollins, Debate on Health and Social Care \(Safety and Quality\)](#), 12 March 2015, column 882
- 34 [Accenture, Electronic health records key to patient care quality improvement](#), 22 April 2013
- 35 [Accenture, 2015 Healthcare IT Check-Up Shows English Doctors remain positive](#)
- 36 [NHS England, Integrated Digital Care Technology Fund](#)
- 37 [NHS England, Latest round of technology funding announced](#), 27 March 2015
- 38 [Nursing Technology Fund](#)
- 39 [NHS England, NHS Innovation Accelerator](#)
- 40 [NHS England, New care models - vanguard sites](#)
- 41 [NHS England, Integrated primary and acute care systems vanguard sites](#)
- 42 [HM Treasury, Spending review and autumn statement 2015](#), 25 November 2015
- 43 [John Cruickshank, Carl Packman, Jon Paxman, Personal Health Records: Putting patients in control?](#), 2020 Health, September 2012
- 44 [Association of the British Pharmaceutical Industry, Big data road map, 2013](#)
- 45 [Big Data and Public Health](#), POSTnote 474, July 2014
- 46 Discussion with Health Informatics Team at the Royal College of Physicians and Professor Sir Peng Tee Khaw of Moorfields Eye Hospital, London, emphasised the potential of 'big data' for making radical improvements in human health, particularly in terms of personalised medicine.
- 47 [Volterra Partners, Sustaining Universal Healthcare in the UK: Making Better Use of Information](#), September 2014
- 48 Hospital Episode Statistics are used in the report: [Healthcare Commission, Investigation into the Mid Staffordshire NHS Foundation Trust](#), March 2009
- 49 Discussion of how hospital episode statistics are used to analyse cancer survival rates in: [L. Ellis-Brookes, S. McPhail, A. Ives, M. Greenslade, J. Shelton, S. Hiom and M. Richards, 'Routes to diagnosis for cancer - determining the patient journey using multiple routine data sets'](#), [British Journal of Cancer](#), 107, (2012), pp. 1120-1226.
- 50 See for example: R.C. Amland, K.E. Hahn-Cover, 'Clinical decision support for early recognition of sepsis', [American Journal of Medical Quality](#), November 2014; M. L. Hook, N. M. Lang, L. Joesse, L. J. Burke, E. Harper, K. Underwood, R. Amland, T. Patrick, 'Using nursing practices and health IT to reduce fall-related injuries', [AHRQ](#), June 2012; T. H. Payne et al., 'Recommendations to Improve the Usability of Drug-Drug Interaction Clinical Decision Support Alerts', [Journal of the American Medical Informatics Association](#), 2015; S. A. Choudhry, J. Li, D. Davis, C. Erdmann, R. Sikka, B. Sutariya, 'A Public-Private Partnership Develops and Externally Validates a 30-Day Hospital Readmission Risk Prediction Model', [Online Journal of Public Health Informatics](#), 2013, pp. 1947-2579; Justin Kimbrell, Tiffany Ferguson and Kelly Groth, 'Automating Readmission Prevention Workflow Improves Efficiency and Reduces Readmissions', March 2015
- 51 [Martin C. Were and Eric M. Meslin, 'Ethics of Implementing Electronic Health Records in Developing Countries: Points to Consider'](#), [AMIA Annual Symposium Proceedings](#), 2011, pp. 1488-1505; [Bradford H. Gray, Thomas Bowden, I. B. Johansen and Sabine Koch, 'Electronic Health Records: An International Perspective on "Meaningful Use"'](#), [Issues in International Health Policy](#), November 2011, pp. 1-16.
- 52 [Alexander Dobrev, Tom Jones, Veli Stroetmann, Karl Stroetmann, Yvonne Vatter and Kai Peng, Interoperable eHealth is Worth it: Securing Benefits from Electronic Health Records and ePrescribing](#), 2010. Good practice' was defined as 'a proven, real-life operational' system implemented several years before the evaluation and that enabled 'a beneficial impact on healthcare.
- 53 [Alexander Dobrev, Tom Jones, Veli Stroetmann, Karl Stroetmann, Yvonne Vatter and Kai Peng, Interoperable eHealth is Worth it: Securing Benefits from Electronic Health Records and ePrescribing](#), 2010, pp. 10, 14. The socio-economic return of the investment was calculated by analysing the ratio of discounted cumulative net benefits and cumulative costs.
- 54 [eHealth News, '2015 EU SME eHealth Competition Awards Patients Know Best \(UK\) and SOMA Analytics \(Germany\)'](#), 12 May 2015.
- 55 [Patients Know Best website](#)
- 56 [Mohammad Al-Ubaydli, 'Patient-Controlled Records Disrupting Electronic Health Records'](#), February 2015.
- 57 [Patients Know Best Blog, 'PKB partner shortlisted for HSJ award'](#), September 2015.
- 58 [Peter Herlihy, "Government as a data model": What I learned in Estonia](#), 31 October 2013
- 59 [Janek Saluse, Ain Aaviksoo, Peeter Ross, Madis Tiik, Liisa Parv, Ruth Sepper, Hanna Pohjonen, Ule Jakoblev, Kaia Enni, Assessing the Economic Impact/Net Benefits of the Estonia Electronic Health Record System: DIGIMPACT, Final Report](#), 2010
- 60 [e-estonia, X-Road'](#) (accessed 13 November 2015)
- 61 [Cabinet Office, 'UK and Estonia sign Memorandum of Understanding on digital government'](#), 28 February 2013
- 62 [Department of Health, The power of information: Putting all of us in control of the health and care information we need - Impact Assessment](#), 16 May 2010
- 63 I. Iakovidis, Towards personal health record: current situation, obstacles and trends in implementation of electronic healthcare record in Europe, [International Journal of Medical Informatics](#) (1998) (52), pp.105-15
- 64 For example, see the 100 signatories to the [techUK Interoperability Charter in health and care - techUK, techUK's Interoperability Charter](#), 29 July 2015.

- 65 [Health and Social Care Information Centre, 'Enriching SCRs with additional information'; 'TPP and EMIS announce direct data sharing', 12 March 2015](#)
- 66 [Care Quality Commission, Croydon Health Services NHS Trust: Quality Report, 7 October 2015](#)
- 67 [Chief Clinical Information Officer Network, 'The 'Newcastle Declaration' - Why citizens need far better information sharing across health and social care', September 2015](#)
- 68 The [Code4Health Forum](#) is managed by NHS England to encourage software providers and clinicians to work together to develop technology for the NHS. [techUK, techUK's Interoperability Charter, 29 July 2015](#)
- 69 ['TPP and EMIS announce direct data sharing', 12 March 2015](#)
- 70 [NHS England, The Integrated Digital Care Fund: Achieving integrated health and care records, 12 May 2014, p. 15.](#)
- 71 [NHS England, Open Source Programme.](#)
- 72 [National Health Executive, 'Taunton and Somerset Foundation Trust leads the way with open source EPR', 7 October 2015](#)
- 73 [Interview with Shane Tickell, of IMS Maxims, and Malcolm Senior, Director of Infomatics at Taunton and Somerset Foundation Trust.](#)
- 74 Arguments made by open source and commercial software suppliers are outlined in: [A. Boulanger, Open-source versus propriety: Is one more reliable than the other?, IBM Systems Journal, 44 \(2005\), pp. 239-248.](#)
- 75 [Health & Social Care Information Centre, Interoperability Handbook, 3 September 2015, p. 10.](#)
- 76 Professional Record Standards Body for Health and Social Care, Annual Report 2014/15
- 77 For the guidelines produced thus far see: [Academy of Medical Royal Colleges, Reports and Guidance](#)
- 78 [Department of Health, The UK Government's Response to the House of Commons Welsh Affairs Committee Report: Cross-border Health arrangements between England and Wales, September 2015](#)
- 79 G. W. Aylward and D. N. Parmar, 'Information technology in ophthalmology – experience with an electronic patient record', *British Journal of Ophthalmology* (1999) (83), p. 1267
- 80 [Clare Cape, Oxford University Hospitals NHS Trust: Electronic Patient Record Benefits realisation case study, 7 October 2015](#)
- 81 [Cambridge University Hospitals, 'Switch-on' for revolutionary new patient record system at CUH, 26 October 2014](#)
- 82 [Jessica Bawden, Cambridge and Peterborough Clinical Commissioning Group, 'Recent pressures in the Cambridge and South Cambridgeshire Health System: Report to the Health Committee', 20 November 2014.](#)
- 83 [Cambridge University Hospitals, Annual Report and Accounts 2014/15](#)
- 84 J. Ancker, L. Kern, Abramson, et al., 'The Triangle Model for evaluating the effect of health information technology on healthcare quality and safety', *JAMIA*, (2012) (19), pp. 61–65.
- 85 Lacey Colligan, Henry W. W. Potts, Chelsea T. Finn, Robert A. Sinkin, 'Cognitive workload changes for nurses transitioning from a legacy system with paper documentation to a commercial electronic health record', *International Journal of Medical Informatics* (2015) (84), pp. 469-476
- 86 [Marie-Pierre Gagnon, El Kebir Ghandour, Pascaline Kengne Talla, David Simonyan, Gaston Godin, Michel Labrecque, Mathieu Ouimet, Michel Rousseau, 'Electronic health record acceptance by physicians: Testing an integrated theoretical model', Journal of Biomedical Informatics, 48 \(2014\) pp. 17-27.](#)
- 87 V. Venkatesh, T. A. Sykes, Z. Xiaojun, 'Just what the doctor ordered': a revised UTAUT for EMR system adoption and use by doctors', 44th Hawaii International Conference on System Sciences (2011)
- 88 Ilie V et al. Paper versus electronic medical records: the effects of access on physicians' decisions to use complex information technologies, *Decision Sciences* (2009) (40), pp. 213–41
- 89 Aziz Sheikh, Tony Cornford, Nicholas Barber, Anthony Avery, Amirhossein Takian, Valentina Lichtner, Dimitra Petrakaki, Sarah Crowe, Kate Marsden, Ann Robertson, Zoe Morrison, Ela Klecun, Robin Prescott, Casey Quinn, Yogini Jani, Maryam Ficociello, Katerina Voutsina, James Paton, Bernard Fernando, Ann Jacklin, Kathrin Cresswell, 'Implementation and adoption of nationwide health records in secondary care in England: final qualitative results from prospective national evaluation in "early adopter" hospitals', *British Medical Journal* (2011), p. 8
- 90 Statistic that 86% of UK adults used the internet in the last three months was taken from [Office for National Statistics, Statistical Bulletin: Internet Users \(accessed 9 November 2015\)](#). Statistic that only 2% of the UK population have had any digital interaction with the NHS is taken from: ['Health Secretary outlines vision for use of technology across NHS', 2 September 2015.](#)
- 91 [Tinder Foundation, Improving Digital Health Skills in Communities: Findings from the Evaluations of Years 1 and 2 of the Widening Digital Participation Programme](#)
- 92 [Care Quality Commission, Cambridge University Hospitals NHS Foundation Trust: Addenbrooke's and the Rosie Hospitals Quality Report, 22 September 2015.](#)
- 93 [Care Quality Commission, Cambridge University Hospitals NHS Foundation Trust: Addenbrooke's and the Rosie Hospitals Quality Report, 22 September 2015, pp. 4, 15, 16, 97, 105, 106, 107, 110, 112, 113, 139, 148.](#)
- 94 [Care Quality Commission, Cambridge University Hospitals NHS Foundation Trust: Addenbrooke's and the Rosie Hospitals Quality Report, 22 September 2015, pp. 68, 70, 124, 148, 151-2.](#)
- 95 [Care Quality Commission, Cambridge University Hospitals NHS Foundation Trust: Addenbrooke's and the Rosie Hospitals Quality Report, 22 September 2015, p. 136.](#)
- 96 [Cambridge University Hospitals, Annual Report and Accounts 2014/15, p. 4.; Care Quality Commission, Cambridge University Hospitals NHS Foundation Trust: Addenbrooke's and the Rosie Hospitals Quality Report, 22 September 2015, pp. 4, 118, 119, 128.](#)
- 97 [Care Quality Commission, Cambridge University Hospitals NHS Foundation Trust: Addenbrooke's and the Rosie Hospitals Quality Report, 22 September 2015, p. 119.](#)
- 98 [Care Quality Commission, Cambridge University Hospitals NHS Foundation Trust: Addenbrooke's and the Rosie Hospitals Quality Report, 22 September 2015, p. 119, 134.](#)
- 99 [Care Quality Commission, Cambridge University Hospitals NHS Foundation Trust: Addenbrooke's and the Rosie Hospitals Quality Report, 22 September 2015, pp. 18, 114, 116, 122, 155.; Interviews conducted during a visit to Addenbrooke's Hospital.](#)
- 100 [Cambridge University Hospitals NHS Foundation Trust, Annual Report and Accounts 2014/15, p. 46; Cambridge University Hospitals, 'eHospital – a year today!', 26 October 2015](#)
- 101 [Cambridge University Hospitals, 'eHospital – a year today!', 26 October 2015.](#)
- 102 Abraham Verghese, 'Culture Shock – Patient as Icon, Icon as Patient', *New England Journal of Medicine*, (2008) (359), pp. 2748-2751.
- 103 Elizabeth Toll, 'The Cost of Technology', *Journal of the American Medical Association* (2012) (23), pp. 2407.
- 104 [Accenture, 2015 Healthcare IT Check-Up Shows English Doctors remain positive.](#)
- 105 ['iHealthBeat, 'Medical Scribes Increasingly in Demand as Providers Switch to EHRs', 13 May 2015.](#)
- 106 George A. Gellert, Ricardo Ramirez, S. Luke Webster, 'The Rise of the Medical Scribe Industry: Implications for the Advancement of Electronic Health Records', *Journal of the American Medical Association*, 313 (13) (2015), pp. 1315-1316.
- 107 [Accenture, Accenture Consumer Survey on Patient Engagement. Research Recap: England, September 2013, p. 10.](#)
- 108 [Accenture, Electronic health records key to patient care quality and improvement, April 2013.](#)
- 109 Simon de Lusignan, Freda Mold, et al., 'Patients' online access to their electronic health records and linked online services: a systematic interpretative review', *British Medical Journal Open*, 2014 (4)
- 110 [Royal College of GPs, Enabling Patients to Access Electronic Health Records: Guidance for Health Professionals, September 2010, p. 26](#)
- 111 See: [Big Brother Watch, NHS Data Breaches: A Big Brother Watch Report, November 2014, p. 7.](#) For example, a pilot programme for access to the Summary Care Record in community pharmacies found 'confusion and uncertainty' about who was able to view the records [HSCIC, Community pharmacy access to Summary Care Records, 21 September 2015, p. 7.](#)
- 112 [Big Brother Watch, NHS Data Breaches: A Big Brother Watch Report, November 2014, p. 7.](#)
- 113 See discussion in José Luis Fernández-Alemán, Inmaculada Carrión Señor, Pedro Ángel Oliver Lozoya, Ambrosio Toval, 'Security and privacy in electronic health records', *Journal of Biomedical Informatics*, 46 (2013), pp. 541-562.
- 114 [Randolph Barrows and Paul Clayton, 'Privacy, Confidentiality and Electronic Medical Records', American Medical Informatics Association, 1996, pp. 139-148](#)
- 115 [Information Commissioner's Office, How we deal with complaints and concerns: A guide for data controllers, p. 2.](#)
- 116 [Information Commissioner's Office, Enforcement \[accessed 25 November 2015\].](#)
- 117 [Information Commissioner's Office, 'Online pharmacy fined for selling customer details', 20 October 2015.](#)
- 118 House of Commons Justice Committee, [The Functions, Powers and Resources of the Information Commissioner](#), Ninth Report of Session 2012-13
- 119 House of Commons Home Affairs Select Committee, [Private Investigators, Fourth Report of Session, 2012-13](#)

-
- ¹²² [Joint Committee on the Draft Communications Data Bill, Final Report, Section 5, Paragraph 226](#)
- ¹²³ [Big Brother Watch, NHS Data Breaches: A Big Brother Watch Report, November 2014, p. 7.](#)
- ¹²⁴ [Department of Health and National Data Guardian, Consultation: The role of the National Data Guardian for health and social care, 17 September 2015.](#)
- ¹²⁵ [European Commission, Reform of the data protection framework in the EU](#)
- ¹²⁶ [Paul Ohm, 'Broken Promises of Privacy: Responding to the Surprising Failure of Anonymization', UCLA Law Review, \(2010\).](#)
- ¹²⁷ See [medConfidential website](#).
- ¹²⁸ For recent discussion of care.data see: [Accessing and sharing health records and patient confidentiality, House of Commons Library Briefing Paper, 1 October 2015, pp. 6-7.](#) For background information see: [care.data, House of Commons Library Briefing, 22 October 2014](#)
- ¹²⁹ [Letter from Dawn Monaghan, Information Commissioner's Office to Kingsley Manning, Health and Social Care Information Centre, 74-6](#)
- ¹³⁰ [Lizzie Presser, Maia Hruskova, Helen Rowbottom and Jesse Kancir, 'care.data and access to UK health records: patient privacy and public trust', Technology Science, 2015](#)
- ¹³¹ [Sigrid Sterckx et al. "'You hope we would sleep walk into accepting the collection of our data": controversies surrounding the UK care.data scheme and wider relevance for biomedical research', Medicine, Health Care and Philosophy, 2015](#)
- ¹³² [Tim Kelsey, 'Together we can get care.data absolutely right', NHS England, 2 May 2014.](#) Before care.data restarted, the Information Governance Oversight Panel produced a report raising key issues for the pilot stage: [The Independent Information Governance Oversight Panel's Report to the care.data Programme Board on the care.data Pathfinder Stage, December 2014.](#)
- ¹³³ [Accenture, UK Patients with Chronic Conditions Believe the Ability to Access Electronic Medical Records Outweighs Concern of Privacy Invasion.](#)
- ¹³⁴ C. Papoutsis, J. E. Reed, C. Marston, R. Lewis, A. Majeed, D. Bell, 'Patient and public views about the security and privacy of Electronic Health Records (EHRs) in the UK: results from a mixed methods study', *BMC Medical Informatics & Decision Making*, 2015, 15 (1).