

2020health – Literary and Evidence Review on Personal Health Records

This document summarises the 2020health literary evidence review undertaken in May 2012 in preparation for our report ‘Personal Health Records: putting patients in control?’, published September 2012. The content below represents our interpretation of the evidence and should not be regarded as a comprehensive academic systematic review. The material is structured as follows:

PHRs

- General
- UK – General PHRs
- UK - NHS Information Revolution
- UK – Complex / Chronic Users
- UK – various PHR suppliers
- US – General PHRs
- US – Veteran Health Affairs
- US – Kaiser Permanente
- US – Cleveland Clinic
- Canada
- EU
- Scandinavia
- Japan
- New Zealand and Australia

On-line activity

- UK

Text	Source	<u>Headline findings in the text</u>
General – entries around Personal Health Records		
Wikipedia entry on personal health records	Wikipedia page http://bit.ly/u7MQq	<p>The earliest use of the phrase ‘personal health records’ is indexed in an article published by PubMed in 1978 [‘Computerisation of personal health records’. Health Visitor 51 (6): 227. Jun 1978. PMID 248054.]</p> <p>An earlier reference, in 1956, is made to a personal health log [DRAGSTEDT, CA (1956-04-14). ‘Personal health log’. Journal of the American Medical Association 160 (15): 1320. doi:10.1001/jama.1956.02960500050013. PMID 13306552.]</p> <p>Familiar themes in an PHR:</p> <ul style="list-style-type: none"> • allergies and adverse drug reactions • chronic diseases • family history • illnesses and hospitalizations • imaging reports (e.g. X-ray) • laboratory test results • medications and dosing • surgeries and other procedures • vaccinations • and Observations of Daily Living (ODLs) <p>PHR owned by patient, EHR usually owned by provider (key difference).</p>

Text	Source	<u>Headline findings in the text</u>
		<p>The value of a personal health record, though very geared around the patient, is still unclear for healthcare organizations, according to Kaelber, David; Pan, Eric (2008). 'The Value of Personal Health Record (PHR) Systems'. <i>AMIA Annu Symp Proc 2008</i>: 343–347. PMC 2655982 PMID 18999276.</p> <p>In Rindfleisch, T.C. (1997). "Privacy, Information Technology, and Health Care." <i>Communications of the ACM</i>, 40(8) 92-100. doi:10.1145/257874.257896, we find a list of the possible concerns specifically about the PHR. They are:</p> <ul style="list-style-type: none"> • <i>Accidental disclosure</i>: A key component of PHRs is interoperability. During multiple electronic transfers of data to various entities, medical personnel can make innocent mistakes to cause disclosure of data. For example, a lab technician may see results from an acquaintance be left on the computer screen. • <i>Insider curiosity</i>: Medical personnel may misuse their access to patient information out of curiosity or for another purpose. For example, one may want to access personal medical information of friends or family, or (out of curiosity) that of celebrities. • <i>Insider subordination</i>: Medical personnel may leak out personal medical information for spite, profit, revenge and other purposes • <i>Uncontrolled secondary usage</i>: Those who are granted access to patient information solely for the purpose of supporting primary care can exploit that permission for reasons not listed in the contract, such as research • <i>Outsider intrusion</i>: Former employees, network intruders, hackers or others may access information, damage systems or disrupt operations

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<p>The Value of Personal Health Record (PHR) Systems</p>	<p>2008 Academic article by David Kaelber (Center for Information Technology Leadership (CITL), Partners HealthCare System) et al</p> <p>http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2655982/</p>	<p>“Personal health records (PHRs) are gaining attention in the US healthcare system. A large variety of provider, payer, and third-party organizations, including organizations not traditionally involved in healthcare such as Google, are discussing, developing, and in some cases bringing to market various types of PHRs.”</p> <p>They can be ‘stand-alone’ portals or ‘tethered’, providing a patient-oriented view integrated with other electronic health information.</p> <p>Markle Foundation definition: “The Personal Health Record (PHR) is an Internet-based set of tools that allows people to access and coordinate their lifelong health information and make appropriate parts of it available to those who need it.”</p>
<p>Personal Health Records: Definitions, Benefits, and Strategies for Overcoming Barriers to Adoption</p>	<p>Academic article (2006)</p> <p>By Paul Tang (Palo Alto Medical Foundation)</p> <p>http://www.ncbi.nlm.nih.gov/pubmed/16357345</p>	<p>Paul Tang et al, writing in 2006, felt more clarity was needed “to understand how PHRs might function to benefit individuals, their caregivers, and their health care providers.” The PHR, as the authors say, is managed by “the individual”, which is contrasted with the clinician’s record, managed by the clinician themselves or healthcare institution.</p> <p>PHR data can be subjective or objective. “Representative sources may include patient-entered data, home diagnostic equipment data, or data from the provider-maintained medical record. Subjective data may include symptom scores, qualitative descriptions of symptoms or medical problems, and responses to questionnaires.”</p> <p>PHRs have a “wide array of credible health information, data, and knowledge.”</p> <p>The PHR becomes a conduit for improved sharing of medical records.</p> <p>“All the advantages of PHRs for providers depend on the PHR being integrated with the provider’s EHR”.</p>

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<p><u>An update on Google Health and Google PowerMeter</u></p>	<p>Blog post http://googleblog.blogspot.co.uk/2011/06/update-on-google-health-and-google.html</p>	<p>Google Health (retiring January 1, 2012; data available for download through January 1, 2013)</p> <p>“When we launched Google Health, our goal was to create a service that would give people access to their personal health and wellness information.</p> <p>“It is not having the broad impact we’d hoped.</p> <p>“There has been adoption among certain groups of users like tech-savvy patients and their caregivers, and more recently fitness and wellness enthusiasts”</p>
<p>Personal Health Records In Action: Google Health and Microsoft HealthVault</p>	<p>Blog post http://www.justmeans.com/Personal-Health-Records-In-Action-Google-Health-Microsoft-HealthVault/46745.html</p>	<p>By Ano Lobo - an instructional designer for the newly created Master of Health Care Delivery program (mhcds.dartmouth.edu) at Dartmouth College.</p> <p>In 2008 researchers at the Military Health System launched MiCare, a one year pilot project aimed at giving service personnel greater access to their EHRs.</p> <p>The findings were fourfold:</p> <p>1 - Speed (and therefore data) Matters. Since most participants wanted all possible data to show up in their PHR, the initial default was to transfer all possible data to the PHR. Problem: the amount of data transferred was such that it slowed the system to a point that was unacceptable to many users. Solution: let patients decide what data they want to transfer to their own PHR.</p> <p>2 - Immediacy versus Perspective. Patients wanted access to information such as lab test results as soon as they were available, yet clinicians wanted a 7-day lag time between when results were ready and when they appeared in the PHR. This would give them time to interpret results and have a chance to communicate directly with the patient. Solution (sort of): test results related to sensitive issues such as sexually transmitted disease or pregnancy would be communicated by the clinician to the patient, and only appear in the PHR if the patient requested it.</p> <p>3 - Workflow matters. Providers complained that the interface between EMR and PHR was not fully automated, which necessitated an additional step for them. A tethered PHR has to automatically feed from an EMR without additional inputs</p>

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		<p>from the clinician if it expects to live a long, healthy, functional life. Another interesting point: if patients choose what information appears in their PHR, then it may be of limited utility as a communication tool for clinicians. Conversely, clinicians may not be sure exactly what information each patient has access to via the PHR. "Results of your blood panel look fine, and are available in your PHR. If you have enabled 'view my test results.'"</p> <p>4 - Giving control to patients can have unintended consequences. When patients can choose what information is shared via their PHR, it may not provide a holistic view of their health. What if you don't mention your mental health condition to your cardiologist who prescribes a drug contraindicated for patients with your condition? In addition to these possible scenarios, could giving patients ultimate power over their health information ultimately degrade provider trust and acceptance of such systems? The answer to that likely depends on who you ask.</p>
<p>Nuffield Trust – Personalised Healthcare</p> <p>October 2010</p>	<p>Report by the Nuffield Council on Bioethics</p> <p>http://www.nuffieldbioethics.org/personalised-healthcare-0</p>	<p>Types of personal health record:</p> <p>Tethered – institution offering the patient the use of the record to view their own, or parts of the own, online health records.</p> <p>Untethered – allow individuals to add and organise personal health information, as well as integrate health records from different healthcare providers, and share this with other individuals and institutions at will.</p> <p>Potential advantages</p> <ul style="list-style-type: none"> ■ Secure and useful storage; ■ convenience; ■ interactive records, e.g. alerts; ■ worldwide access; ■ benefit from research on pooled data; and ■ safeguarding function.

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		<p><i>Potential disadvantages</i></p> <ul style="list-style-type: none"> ■ Misuse of stored information; ■ advantages of centralised information may possibly be lost through separate information systems; ■ difficulties for healthcare professionals if they have to rely on inaccurate or incomplete records maintained by patients; and ■ opportunity for promotion of unnecessary or inappropriate treatments/services. <p>One study in England, which included 103 individuals and seven focus groups, found most people were not aware of “HealthSpace (see Paragraph 6.6), nor were they interested in storing or accessing their medical information via this facility. Indeed, many saw the system as “pointless”, “irrelevant” or a security risk, although “a small but important minority” saw potential benefit for those with chronic illness. (The study can be found in Greenhalgh T, Wood GW, Bratan T, Stramer K and Hinder S (2008); ‘Patients’ attitudes to the summary care record and HealthSpace: Qualitative study’ British Medical Journal 336 : 1290–5.)</p> <p>A conclusive point: <i>Public healthcare services should develop an accreditation system for online health record providers and promote it appropriately. In the UK the responsibility for developing such a system should fall on the Government Health Departments. We recommend that providers of online personal health record facilities should seek accreditation. Such an accreditation system should include requirements to include the following information prominently in lay language:</i></p> <ul style="list-style-type: none"> ■ <i>the operator of the services;</i> ■ <i>location in which the operator is based;</i> ■ <i>how information provided by users will be stored, passed on or sold;</i> ■ <i>arrangements in place to ensure the security and confidentiality of data and information if the operator went into administration or changed hands;</i>

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		<ul style="list-style-type: none"> ■ <i>the possibility that changes to terms and conditions could be made after initial sign-up and how the user will be informed; and</i> ■ <i>funding and advertising arrangements. Advertisements should also clearly be distinguishable as such.</i>
Personal electronic health records: MySpace or HealthSpace ?	BMJ Article, May 2008 http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2376005/	Michael Kidd is Professor of General Practice and Head of the Discipline of General Practice at The University of Sydney. Writing in 2008, Professor Kidd acknowledges that certain US citizens are using Microsoft’s HealthVault and Google’s Google Health, but also states that “Social networking sites, like Facebook and MySpace, offer alternative ways of storing and sharing personal information, including health details, and are being used by some people in ways that should alarm advocates of privacy.”
Use of personal child health records in the UK: findings from the millennium cohort study (2005)	Suzanne Walton, specialist registrar in public health http://www.bmj.com/content/332/7536/269.short	<p>Objectives The personal child health record (PCHR) is a record of a child's growth, development, and uptake of preventive health services, designed to enhance communication between parents and health professionals. We examined its use throughout the United Kingdom with respect to recording children's weight and measures of social disadvantage and infant health.</p> <p>Participants Mothers of 18,503 children born between 2000 and 2002, living in the UK at 9 months of age.</p> <p>Results In all, 16,917 (93%) mothers produced their child's PCHR and 15,138 (85%) mothers showed effective use of their child's PCHR. Last weight was recorded in 97% of PCHRs consulted. Effective use was less in children previously admitted to hospital, and, in association with factors reflecting social disadvantage, including residence in disadvantaged communities, young maternal age, large family size (four or more children; incidence rate ratio 0.87; 95% confidence interval 0.83 to 0.91), and lone parent status (0.88; 0.86 to 0.91).</p>
UK – General PHR materials		
Record Access collective:	Evaluation material 2007 http://www.record-access-	In the UK, kiosks designed by independents outside of the NHS Connecting for Health programme, offer full access to the GP electronic records and health-related information. Of those who have registered to use the electronic kiosk access

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<p>Patient record access —the time has come!</p>	<p>collaborative.org/articles/RAC_Article_-_RCGP_Record_Access_-_The_time_has_come.pdf</p> <p>Brian Fisher</p>	<p>system, 75% have looked at their notes; the same amount who chose to look at their paper records.</p> <p>(This shows a desire to consult records and be pro-actively part of the way in which they are shared – boosting the desire for patients to own their own personal health records).</p>
<p>EPHR – Claudia Pagliari – 2007</p>	<p>Report by Nuffield Trust</p> <p>http://bit.ly/JWObVZ</p>	<p>PHR definition – (may be paper-based or electronic): “a collection of important information about your health or the health of someone you are caring for, such as a parent or child, that you actively maintain and update. The information comes from your healthcare provider, and from you.”</p> <p>The evaluation of the PHR can be seen along many dimensions which include moving from provider-dominated records to patient-dominated (or shared), passive to interactive, as well as reflecting the move from paper to electronic and web media.</p> <p>During the workshop, from which this paper has stemmed, it was agreed that further work needs to be done to ensure effective management of the dual needs for interactivity between patient and provider-held records.</p> <p>Examples of shared access include:</p> <p>USA: MyChart® software produced by Epic Systems (number of places have organised their online ePHR on this including Cleveland Clinic); PAMFOnline provides patients of the PaloAlto Medical Foundation with access to their health records and test results, along with patient-clinician email and appointment requests (www.pamfonline.org); Beth Israel Deaconess Medical Centre operates PatientSite.</p> <p>Canada: An ePHR is being developed for diabetes management in New Brunswick (National Research Council Institute for Information Technology)</p> <p>UK: NHS HealthSpace is a secure online personal health organiser developed under the auspices of NHS Connecting for Health. At the time of the workshop, HealthSpace had recently begun to offer patients the facility to develop personal medical diaries and view appointments and sources of health information (incorporating Choose& Book, Calendar & Reminders, Health Details and eLibrary). Functionality has since been extended to include personal recording and</p>

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		<p>graphing of chronic disease indicators such as blood sugar, peak flow and cholesterol, and a glossary of drugs and medicines. From 2007 patients registered with HealthSpace will be able to access their Summary Care Record via the National Care Records Service and in future may be able to edit certain fields (e.g. change of address) or contribute information about how they wish to be treated and their access needs This initiative supports other moves towards patient choice in the development of NHS integrated care records, such as the opportunity for patients to opt out or to have access to parts of their EHR restricted to specific health professionals (referred to as the ‘sealed envelope’ system). (https://www.healthspace.nhs.uk/)</p> <ul style="list-style-type: none"> - Benefits: patient empowerment; health gains; quality of care (improved relationships; flexible access; increased patient safety; reduced provider liability; ability to track patients’ hidden health behaviours and medications); burden of care (reduced waiting lists; lower costs; reduced provider liability) <p>Patient access to paper-based records has indicated a number of benefits that can crossover to the ePHR: doctor-patient communication, adherence, patient education and empowerment (found in Ross & Lin, ‘The Effects of Promoting Patient Access to Medical Records: A Review’, 2003)</p> <p>Other evidence from secondary sources that have been relayed by presentations given, during this workshop, by Brian Fisher, Don Detmer and Claudia Pagliari, on the benefits of an ePHR are:</p> <ul style="list-style-type: none"> - Improves relationships with clinicians by creating transparency, promoting informed discussions and engendering trust and a sense of involvement - Increases confidence in self-care and control - Can reduce errors by validating against patient recall and knowledge - Whilst some patients have concerns about security and confidentiality (more in the case of patients with psychiatric conditions), these do not appear to have acted as a barrier to use in trials of ePHR - Improves compliance in heart disease, hyperlipidemia and depression - Perceived as acceptable and useful by most patients, particularly people with long-term conditions. In complex ePHR, patients particularly value secure messaging, online refills, lab results, and disease management plans in addition to charts and medication lists. - Clinicians’ fear access will create misunderstanding and expose weaknesses in care, but these appear to be

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		<p>unfounded. (Physicians are generally more concerned than patients about security risks and patient safety.)</p> <ul style="list-style-type: none"> - No evidence of adverse impact on workload or safety <p>Challenges for ePHR implementation include:</p> <ul style="list-style-type: none"> - Organisation of care (such as changing the workflow of professionals and delegating off new responsibilities) - A change in culture elsewhere. The impact of patient accessible records will depend on social/contextual factors (e.g. new responsibilities of clinicians; culture of collaborative care) and further studies are needed to examine these. - Simply providing access to electronic medical records is unlikely to confer clinical and efficiency benefits. Multifaceted and interactive tools directed at promoting self-care and communication are likely to be necessary. - Little evidence is available relating to the risk of confidentiality and privacy violations, nor of the effects of records access on patient litigiousness - Most studies have looked at patient and clinician attitudes and satisfaction. Only a small number have examined actual experiences of ePHR usage by patients. Few studies have looked at clinical and safety outcomes. - Accuracy of data - Accessibility and usability (the so-called “digital divide” needs to be taken into consideration) <p>Claudia Pagliari (writing in 2007) was “optimistic about the future of NHS HealthSpace, despite its slow start and the inevitable difficulties that have been faced by the National Programme for IT in England, and supportive of planned records access in other parts of the UK.”</p>
<p>Put another record on EHI</p>	<p>Article – E-Health Insider http://bit.ly/n4GJS3</p>	<p>Many electronic record products have fallen “down the wayside” – but there are still successful products, “personal health records are working for some people with a specific use for them.” The Ki Fit unit produced by company Ki Performance is exemplified.</p> <p>“Dr Claudia Pagliari, senior lecturer in primary care at the University of Edinburgh, says ... “It’s an evolving beast – it will come with time. But it’s not going to be something that everybody has.”</p>
<p>Rapid progress or lengthy</p>	<p>Academic paper Online pub. July</p>	<p>The problem the authors find, is that there has been little attempt “to document the specific problems which might occur throughout the implementation of ePHRs in mental health.”</p> <p>“The NHS Connecting for Health system is an attempt by the UK government to coordinate all levels of care (primary,</p>

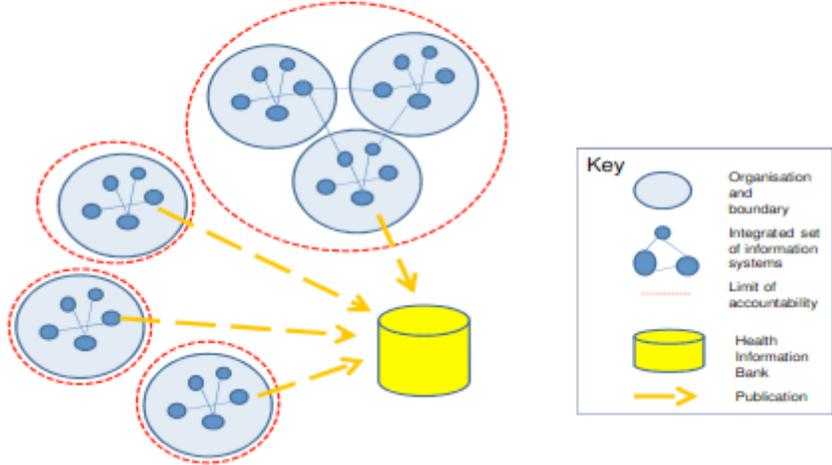
Text	Source	<u>Headline findings in the text</u>
<p>process? electronic personal health records in mental health</p>	<p>2011</p> <p>Liam Ennis, Health Services and Population Research Department, Institute of Psychiatry</p> <p>http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3163520/</p>	<p>secondary, tertiary and community) using electronic health records, begun in 2002.” They say “unsuccessful”.</p> <p>Definition: “electronic personal health records – an electronic database of an individual’s health information, accessible to and maintained by the patient”.</p> <p>Sharing of information between services – key to mental health.</p> <p>Rich source of patient data, “especially so given the recent development of search tools with the capability of pseudonymising and retrieving patient records such as the Case Register Interactive Search tool (CRIS)”.</p> <p>“The HealthSpace system consisted of two levels; a basic account, which is essentially a depository for an individual’s health information which individuals must complete themselves, and an advanced account, through which they could access their summary care records, book appointments and communicate remotely with practitioners”. Unfortunately, Greenhalgh et al found that uptake from basic account to advanced account was 0.13% rather than the 5-10% expected.</p> <p>HealthSpace, unlike Kaiser, was considered difficult to use. One problem was that it was designed by service provider, not service user.</p> <p>“Crucially, those patients with a chronic illness whom the researchers interviewed emphasised that ‘self monitoring of health data involves a complex interaction between patient and clinician and that the process of entering and accessing data cannot be meaningfully separated from the wider care relationship’.”</p> <p>One of the key debates is whether psychiatrists will be asked to defend their decisions to block patients seeing some records on the grounds that they could incur ‘serious harm’.</p> <p>Essex, Doig and Renshaw found in their evaluation of patient-held shared care records that “improved autonomy, effectiveness of shared care, and communication with clinicians” were acceptable to those with severe mental illness.</p> <p>However: “Patient distress or upset appears a common occurrence when granting patients access to health information. This is a factor not only for service users, whose upset should be minimised as much as possible, but for health care professionals, who may feel torn between pressures for transparency and a responsibility for patient protection.”</p>

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		This paper is a challenge to the assumption that “patient satisfaction, empowerment, and health status will improve as result of increased patient participation”.
NHS Oxfordshire starts rolling out summary care records	News article in HealthWire April 2012 http://bit.ly/leTRsk	(To note more localised movement towards a cultural shift of information sharing) “The local Oxfordshire Care Summary (OCS): this is ‘view only’ and will provide more detailed information than the national Summary Care Record and will only be available to local healthcare professionals involved in a patient’s treatment in Oxfordshire.” On security, a healthcare professional “must ... ask permission from the patient before accessing the patient’s record. A detailed audit trail is generated every time a patient record is viewed.”
Claudia Pagliari PhD Engaging and empowering patients and the public	PowerPoint November 2007 http://bit.ly/IAm5yA	Key messages from literary review on information sharing and personal health data: <ul style="list-style-type: none"> - Patients imagine their data are already shared and are concerned if otherwise - GPs most trusted - Uncomfortable with non-clinical staff seeing their record (receptionists) - Consent is desirable - Personal health information seen as more sensitive than other data <p>National survey of British public’s views (n=2872) on use of identifiable medical data by the National Cancer Registry. The majority <i>do not</i> consider the following an invasion into their privacy:</p> <ul style="list-style-type: none"> ▪ confidential inclusion of postcode (88%) ▪ confidential inclusion of name/address (81%) ▪ receipt of an invitation to a research study, via the doctor after inclusion in registry (87%)

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		<ul style="list-style-type: none"> ▪ all three of the above (72%) ▪ in addition, 81% of the respondents said that they would support a law making cancer registration statutory
Telehealth / Telecare	Briefing by the RCN http://www.rcn.org.uk/development/practice/e-health/telehealth_and_telecare	<p>Telehealth is the monitoring of our physiological data such as our temperature and blood pressure. This can be achieved by devices such as blood pressure monitors or weighing scales. Telehealth also covers communication facilitated through remote technologies such as telephone or videoconferencing.</p> <p>Telecare is the use of alarms, sensors and other equipment which facilitates independent living, examples of which include personal alarms, fall detectors, temperature extremes sensors, carbon monoxide detectors, flood detectors and gas detectors.</p> <p>The Whole Systems Demonstrator (WSD) programme was the largest randomised control trial of telehealth and telecare in the world, involving 6191 patients, 238 GP practices across three sites, Newham, Kent and Cornwall.</p> <p>The early indications, from late 2011, show that if used correctly telehealth can deliver a 15% reduction in A& E visits, a 20% reduction in emergency admissions, a 14% reduction in elective admissions, a 14% reduction in bed days and an 8% reduction in tariff costs. More strikingly they also demonstrate a 45% reduction in mortality rates. [http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_131689.pdf]</p>
Gordon Caldwell – Written and unwritten rules in NHS IT	Evaluation Western Sussex Hospitals NHS Trust	<p>On the law: “Non clinical staff, e.g. secretaries and ward clerks, may not have access to results of tests on CCIS, although they handle paper copies of these results and type letters containing the results all the time”.</p> <p>“Breaches of NHS IT policies are very serious and may result in criminal charges because Data Law is criminal, not civil, law, disciplinary processes, sacking, and referral to professional bodies such as the General Medical Council (GMC) or Nurses and Midwives Council (NMC).”</p>
Richard Fitton - Evolution – and international	Presentation	<p>“SNOMED CT (Systematized Nomenclature of Medicine-Clinical Terms) is considered to be the most comprehensive, multilingual clinical healthcare terminology in the world. Each year, avoidable deaths and injuries occur because of poor communication between healthcare practitioners, or because busy practitioners forget or neglect to follow their own criteria for best practices. The delivery of a standard clinical terminology for use across the world’s health information</p>

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classification of diseases (not online)		systems can therefore make a significant contribution towards improving the quality and safety of healthcare”.
Culture change	Academic paper Boaden, R., Munir S NHS Information Authority; https://www.escholar.manchester.ac.uk/uk-ac-man-scw:5b636 2001	Source of historical interest (paper pub.2001). Patient participation was recognized as a good, equitable thing in 1993, after GPs recognized large gaps in a patients’ knowledge of their healthcare and the activities of the NHS. The NHS plan (2000) dedicates a chapter to ways and means of building a patient’s knowledge, including plans to give a patient access to their health records electronically by 2004. Patient Participation Group was founded in 1994 – comprised of 12 patients Thoughts about EHRs have been on-going for years, but it wasn’t until Dec 1999 that a project encapsulated this pipe dream. There was also the NHS Electronic Record Development and Implementation Project (ERDIP). The paper discusses how patient empowerment, benefits of which are plentiful, can be facilitated through changes in organisational structures, culture and leadership.
Enabling Patients to Access Electronic Health Records RCGP	Professional guidance September 2010 http://www.rcgp.org.uk/pdf/Health_Informatics_Enabling_Patient_Access.pdf	As substantial parts of the health record are subjective, care must be taken to ensure subjective interpretations by the healthcare professional are clearly signposted – which should be explained to patients upon their record access. Professionals, then, are encouraged to write clearly, honestly and accurately. “Speculation is an important part of medical records”. (Again, where this and PHR are concerned, it should be explained to the patient on access that not everything on the record is fact, but can be speculative and require time or second opinion. This is also important when it comes to test results). “Record Access means that patients can play an important role in highlighting any errors, confirming or refuting accuracy based on their own understanding. Health professionals should amend any errors or inconsistencies as a matter of good practice” (pp.18-19) – “It will soon be possible for patients to add their own data to the record. This might include blood pressure,

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		<p>peak flow, blood sugars and oxygen saturation measurements, and lifestyle information such as diet and exercise charts. It may also be possible for patients to complete questionnaires and to write their history before arriving for a consultation.”</p> <p>Health professionals should use this to supplement, not replace, their clinical assessment [same with information from PHR]</p>
The Use of Personal Health Information in Medical Research	<p>Research report Ipsos MORI on behalf of the Medical Research Council(MRC). June 2007 http://bit.ly/JTXHEQ</p>	<p>The public tends to think medical research is private sector and thus neglects to remember that researchers also work in universities, hospitals or charities.</p> <p>There is acceptance of medical research data sharing – providing the public are informed, research is conducted by a valid body, consent is given for passing information on.</p> <p>“Many people did not see clinical records and test results, sexual history or information on mental health as sensitive in themselves – although a vocal minority, particularly in Camden, did.”</p> <p>One Female, C2, 35-44, said “Let the world know, but not my next door neighbour.”</p> <p>General feeling is that individuals should not be identified to medical researchers unless consent is given. Opt-in system most preferable.</p>
Developments in confidentiality and consent functions to support wider sharing of electronic health	<p>Technical Report by Stephen Elgar, Information Governance & Security Manager, NHS London at NHS Connecting for Health</p>	<p>Personal Health Record; [TA06], [GO10], [MI10] Personal Health Record (PHR) is a variation of the EH. Content and access to it is directly controlled by the patient. EHR is a legally mandated set of notes on the care provided by clinicians to patients as provided by an organisation. There is no legal mandate that compels a consumer or patient to store her personal health information in a PHR. Major investment is taking place by Google (Google Health) and Microsoft (HealthVault), and these suppliers currently offer use of PHR to patients without charge. Both companies have developed pilots with health service providers to feed elements of the EHR into the PHR, patients can also add information from other providers manually – see Figure 11. Consent and confidentiality functions for PHR are controlled by patients within the constraints of the provider. Should PHR usage become significant the feature that allows the patient to control and edit the record may prove problematic for clinical teams as the patient can delete or withhold information.</p>

Text	Source	Headline findings in the text								
<p>records in the UK</p>	<p>March 2011 http://www.ma.rhul.ac.uk/static/techrep/2011/RHUL-MA-2011-06.pdf</p>	<p>Figure 11 Several organisations exchanging information to Personal Health Record</p>  <p>The diagram illustrates a network of organizations, each represented by a blue oval containing a network of nodes. These organizations are connected to a central yellow cylinder representing the Health Information Bank. Yellow arrows indicate the flow of information (publication) from the organizations to the bank. Red dashed lines delineate the limits of accountability for each organization.</p>								
<p>HealthSpace Patient Survey Report - completed by HealthSpace and NHS Choices (called invitation to</p>	<p>Evaluation January 2010</p>	<p>HealthSpace Patient Survey Report – summary of analysis completed by HealthSpace and NHS Choices, January 2010.</p> <p>5,943 completed the survey. The breakdowns are:</p> <p>Gender: 68% Male / 32% Female</p> <p>Age group: 68% of responses fell within the 35-64 age bracket</p> <table border="1" data-bbox="596 1252 995 1419"> <thead> <tr> <th>Age</th> <th>% of Respondents</th> </tr> </thead> <tbody> <tr> <td>Don't know</td> <td>0.30%</td> </tr> <tr> <td>Under 16</td> <td>1.00%</td> </tr> <tr> <td>16 -24</td> <td>5.40%</td> </tr> </tbody> </table>	Age	% of Respondents	Don't know	0.30%	Under 16	1.00%	16 -24	5.40%
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<p>focus group) – from Bruce Elliot</p>		<p>25-34 - 15.20%</p> <p>35-44 - 21.60%</p> <p>45-54 - 24.80%</p> <p>55-64 - 21.10%</p> <p>65+ - 10.70%</p> <p>Long Term Conditions: 41% with a Long Term Condition / 58% without a Long Term Condition</p> <p>Carers: 19% of respondents</p> <p>Parents with children under 6: 16% of respondents</p> <p>The most useful elements of Healthspace:</p> <p>Respondents were asked to prioritise their top 5 features out of 11 features proposed and then indicate how often they would use those features. The results are indicated below:</p> <table border="1" data-bbox="611 878 1711 1396"> <tbody> <tr> <td data-bbox="611 878 678 945">1</td> <td data-bbox="678 878 789 945">75%</td> <td data-bbox="789 878 1711 945">Give me updates about relevant health issues</td> </tr> <tr> <td data-bbox="611 945 678 1011">2</td> <td data-bbox="678 945 789 1011">72%</td> <td data-bbox="789 945 1711 1011">Access to my test results online</td> </tr> <tr> <td data-bbox="611 1011 678 1078">3</td> <td data-bbox="678 1011 789 1078">65%</td> <td data-bbox="789 1011 1711 1078">Book appointments at my GP surgery</td> </tr> <tr> <td data-bbox="611 1078 678 1192">4</td> <td data-bbox="678 1078 789 1192">64%</td> <td data-bbox="789 1078 1711 1192">Record my needs so the NHS know them in advance of my appointments e.g. disabilities</td> </tr> <tr> <td data-bbox="611 1192 678 1258">5</td> <td data-bbox="678 1192 789 1258">55.%</td> <td data-bbox="789 1192 1711 1258">Access to my medical records online</td> </tr> <tr> <td data-bbox="611 1258 678 1325">6</td> <td data-bbox="678 1258 789 1325">51%</td> <td data-bbox="789 1258 1711 1325">Record how I want to be treated if I can't make my own decisions</td> </tr> <tr> <td data-bbox="611 1325 678 1396">7</td> <td data-bbox="678 1325 789 1396">26%</td> <td data-bbox="789 1325 1711 1396">Order repeat prescriptions</td> </tr> </tbody> </table>	1	75%	Give me updates about relevant health issues	2	72%	Access to my test results online	3	65%	Book appointments at my GP surgery	4	64%	Record my needs so the NHS know them in advance of my appointments e.g. disabilities	5	55.%	Access to my medical records online	6	51%	Record how I want to be treated if I can't make my own decisions	7	26%	Order repeat prescriptions
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Text	Source	<u>Headline findings in the text</u>		
		8	26%	Secure two-way email communication with my doctor or nurse
		9	18%	Add information in my medical records myself
		10	15%	Give my carers access to my health information
		11	5%	See my previous health readings online (e.g. blood pressure etc)
		<p>Overall the majority of respondents are likely to use HealthSpace at least monthly.</p> <p>“Security was cited as a key feature by respondents – patients were concerned about the confidentiality of their records being jeopardised. This suggests how critical it is to implement a secure system with a robust registration and authentication solution for patients.”</p> <p>The survey found that female patients were more likely to use Healthspace.</p> <p>“97% of respondents recognised that there are one or more benefits of using an online portal such as HealthSpace. The main benefits identified focussed around easier management of own health and improving access and communication with healthcare professionals (section 3.7).”</p> <p>Conclusions:</p> <ul style="list-style-type: none"> - Older patients will use HealthSpace more than younger - Strong appetite for young people to have red book online (96% of respondents) - 26% of responses within the open ended/ free text question indicated they were concerned about the security aspect and the confidentiality of their records being at risk 		

Text	Source	<u>Headline findings in the text</u>
<p>Patients to access online medical records by 2015</p>	<p>News article Guardian November 2011</p> <p>http://www.guardian.co.uk/healthcare-network/2011/nov/30/patients-access-medical-records</p>	<p>Plans revealed in the Chancellor of the Exchequer’s autumn spending review – Tuesday 29 November 2011.</p>
<p>Patient access to medical records will add to GP workload</p> <p>GP Magazine</p>	<p>News article GP Magazine</p> <p>http://www.gponline.com/News/article/1113203/Patient-access-medical-records-will-add-GP-workload/</p>	<p>“GPC chairman Dr Laurence Buckman ... warned that online records may not be secure enough to stop third parties from accessing sensitive patient information. ‘How do you keep the records secure so only the person who should look at it looks at it?’ he said.”</p> <p>The idea of editorial control is the thing that has stirred up criticism from the likes of GPC deputy chairman Dr Richard Vautrey and Wessex LMCs chief executive Dr Nigel Watson.</p> <p>http://www.gponline.com/News/article/1112056/radical-Future-Forum/</p>
<p>NHS IC collects info on record access</p>	<p>News Article April 2012 E-Health Insider Rebecca Todd</p> <p>http://www.ehi.co.uk/news/ehi/</p>	<p>NHS IC head of primary care strategy Dave Roberts said it had been asked to collect information about electronic patient records access [which GP practices will then be able to share with patients].</p> <p>The information provided will also include information about how many GPs have it switched on and whether patients are accessing their records.</p>

Text	Source	<u>Headline findings in the text</u>
	7711/nhs-ic-collects-info-on-record-access	
UK - NHS Information Revolution		
DH – Information Revolution	Policy document consultation/response August 2011 http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_129580.pdf	<p>What the DH heard: There is a clear desire to enable people to be more in control of their own care, supported by greater access and use of health information, including access to the information held about them in their own care records.</p> <p>The local pharmaceutical committee thinks this would be an excellent idea as it would allow the individual to share their records with other healthcare providers</p> <p>The BMA agreed that this should start with GP practice records.</p> <p>“As a major provider of social care services Turning Point feels that our service users would benefit from access to their patient records, which will provide more control and understanding of care and allow for more informed choices and decisions around care.”</p> <p>“Access to care records for most patients over internet and web will encourage better self management of various allergies, long term illness, and even providing small information back to clinicians such as increase in blood pressure can promote better self management for various illnesses.” service user</p>
Equity and Excellence: Liberating the NHS ‘Putting patients and care first’	Policy – Government White Paper - July 2010	<p>2.6 The Government intends to bring about an NHS information revolution, to correct the imbalance in who knows what. Our aim is to give people access to comprehensive, trustworthy and easy to understand information from a range of sources on conditions, treatments, lifestyle choices and how to look after their own and their family health. The information revolution is also about new ways of delivering care, such as enabling patients to communicate with their clinicians about their health status on-line. We will provide a range of on-line services which will mean services being provided much more efficiently at a time and place that is convenient for patients and carers, and will also enable greater efficiency.</p> <p>2.11 We will enable patients to have control of their health records. This will start with access to the records held by their GP and over time this will extend to health records held by all providers. The patient will determine who else can access</p>

Text	Source	<u>Headline findings in the text</u>
		<p>their records and will easily be able to see changes when they are made to their records...Our aim is that people should be able to share their records with third parties, such as support groups for patients, who can help patients understand their records and manage their condition better. We will make it simple for a patient to download their record and pass it on to any organisation of their choice.</p>
DH favourite apps	<p>News article – Department of Health</p> <p>http://bit.ly/riyFuv</p> <p>October 2011</p>	<p>On the culture shift, Andrew Lansley notes: “So many people use apps every day to keep up with their friends, with the news, find out when the next bus will turn up or which train to catch. I want to make using apps to track blood pressure, to find the nearest source of support when you need it and to get practical help in staying healthy, the norm.”</p> <p>This move follows from the call to find the best apps which could make doctors better manage care.</p>
NHS Future Forum – Jan 2012	<p>Recommendations towards government policy on use of information</p>	<p>“...patient access to records will be a vital underpinning of a developing culture of self-care and self-management.”</p> <p>“Almost all GP practices hold electronic health records, and there are no serious technical barriers to opening them to patients. People have a right of access to their records as part of the NHS Constitution, yet such access is still the exception to the rule. Where records have been made available to patients, we have heard that this has resulted in clear benefits for patients and for practices, with patients becoming more engaged and their demands on their GP practices declining. Though patient demand for access to their health records is currently low, it is growing, in line with wider trends in society. Access to records will in future be an important contributor to maintaining and building enduring trust in an evolving NHS and, conversely, a lack of access could be harmful to trust.</p> <p>Patient organisations want patient access to records opened up, but also want the right protections and support for patients to go alongside. Patients with access to their electronic health records value it highly and use it as a platform to improve their health literacy, self-management, and engagement with their health, and to transact more conveniently with services. It has been put to the NHS Future Forum that patient access to records will be a vital underpinning of a developing culture of self-care and self-management.”</p>

Text	Source	<u>Headline findings in the text</u>
<p>Looking back, moving forward – University of Birmingham HSJ, NHS CfH – Evaluation of NPfIT</p>	<p>Evaluation by Professor Richard Lilford, University of Birmingham and Alastair McLellan, HSJ Editor</p> <p>March 2012</p> <p>http://bit.ly/Jbjr1d</p>	<p>Nick Barber, UCL School of Pharmacy: Unforeseen problems occurred with electronic prescriptions, namely non-delivery because of date-errors by the GP.</p> <p>Prof Trisha Greenhalgh: In Wales, the Individual Health Record (IHR) was created which was a “hybrid” product constructed from the best of the NHS and the best that commercial services had to bring. The intent was to have full coverage in Wales by the end of 2011, involving the following elements:</p> <ul style="list-style-type: none"> - Public sector broadband network - Email and unique id for all NHS staff (and later local government staff) - Clinical communications gateway for referrals and discharges - Individual health record - Patient portal (My Health Online) – appointment booking, repeat prescriptions, self-management
<p>Adoption, non-adoption, and abandonment of a personal electronic health record: case study of HealthSpace</p>	<p>BMJ Paper – Professor Trisha Greenhalgh</p> <p>November 2010</p> <p>http://bit.ly/boPGbf</p>	<p>Enthusiasm from patients was low. Between 2007 and October 2010, 172,950 people opened a basic HealthSpace account. 2913 (0.13% of those invited) opened an advanced account, compared with 5-10% of the population anticipated in the original business case.</p> <p>The vision of patients as active partners is for some “inherently desirable”.</p> <p>“Personal electronic health records, managed by patients and interfacing with clinician held records, are seen as having a key role in the new care model, by facilitating storage and exchange of information, promoting engagement with self-management, and supporting continuity of care.”</p> <p>Healthspace as an evolving technology: “At any time in the evaluation, multiple versions of it existed—including the version that people were actually using, the version that had been approved and was undergoing technical development and limited piloting, and one or more versions that were at the design stage.”</p> <p>“A preliminary version of HealthSpace was introduced in 2007, the main features of which were a basic account on to which patients could enter key personal data (for example, weight, blood pressure) and an advanced account through</p>

Text	Source	<u>Headline findings in the text</u>
		<p>which patients could access their summary care record.”</p> <p>Healthspace was originally conceived of as being part of the NPfIT – an addition to the SCR</p> <p>Healthspace was not a runaway success, with many saying it was neither useful nor easy to use.</p> <p>The conclusion to the paper is thus: “Unless personal electronic health records align closely with people’s attitudes, self-management practices, identified information needs, and the wider care package (including organisational routines and incentive structures for clinicians), the risk that they will be abandoned or not adopted at all is substantial”.</p>
<p>The Devil’s in the detail</p>	<p>Academic evaluation by Prof. Trisha Greenhalgh</p> <p>May 2010</p> <p>http://www.ucl.ac.uk/news/scrisesummary.pdf</p>	<p>HealthSpace: an internet-accessible personal organiser into which people may enter health data (such as blood pressure) and plan health appointments. Policy documents published in 2005-8 anticipated five main benefits of HealthSpace:</p> <ul style="list-style-type: none"> a) Personalisation of care (by supporting choice and increasing access options, HealthSpace would allow NHS care to be adapted to individual needs); b) Patient empowerment (by entering their health data onto HealthSpace, and by accessing their SCR via an advanced HealthSpace account, patients would be better able to manage their illnesses, especially long term conditions); c) Accountability, quality improvement and safety (patient input, supported by high-quality, accessible information, would drive up quality in the NHS – for example, by spotting data quality errors on their SCR) d) Reduced NHS costs (e.g. more self-management would potentially reduce the cost of managing long-term conditions); and e) Improved health literacy (the availability of HealthSpace would improve people’s ability to understand and manage their illness). <p>During the evaluation it was found that few patients were signing up to Healthspace. “The main reason for declining appeared to be that they were not actively using the technology and not interested in saying why this was.”</p> <p>“HealthSpace users interviewed found the current release of the technology of limited value; some had high hopes for future enhancements in functionality.”</p> <p>Ethnographic observation of a sample of people with diabetes and other long term conditions revealed insights about how</p>

Text	Source	<u>Headline findings in the text</u>
		<p>HealthSpace may or may not help with the lived reality of chronic illness. In particular:</p> <ul style="list-style-type: none"> a) Some people appeared to lack the health literacy or IT literacy required to use a technology-based health organiser. Others were either not motivated to reflect on the progress of their condition or felt that this was a task for their doctor or nurse; b) Some had no access to computers or saw them as serving other purposes in their lives (games, shopping, social networking); c) Some were already using or exploring other ways of documenting and monitoring their condition e.g. paper (e.g. diabetes diary), bespoke software (Excel spreadsheet), or downloads for digital personal organisers (iPhone ‘apps’) and found these more fit for purpose than HealthSpace; d) Many patients’ needs were not primarily for codified data (e.g. blood glucose levels) but for practical knowledge of how to live with their condition and for emotional support. They tended to get this from other people (e.g. relatives, local diabetes support group, Facebook); e) Some patients were constrained by poverty, an adverse physical environment (e.g. poor housing, overcrowding), major family stress, or serious disabilities related or unrelated to their condition (e.g. depression, stroke). Monitoring and managing their long term condition competed with these other problems (requiring emotional and material resources) and was rarely top of the priority list.
<p>Dr Phil Koczan</p> <p>GP in Chingford</p> <p>Clinical Lead NHS London Programme for IT</p>	<p>PowerPoint presentation</p> <p>http://tinyurl.com/8u5r2tw</p>	<p>Dr Koczan is a GP in Chingford and the Clinical Lead NHS London Programme for IT, with responsibility for the SCR rollout. He notes of the Summary Care Record:</p> <ul style="list-style-type: none"> • As of 28th May 2010 <ul style="list-style-type: none"> • 29,795,780 patients contacted nationally • 250 practices live • 1,591,845 records created • Future Plans

Text	Source	<u>Headline findings in the text</u>
		<ul style="list-style-type: none"> • Develop Health Space further • Contributions from other care settings • Enhance integration with other clinical systems
UK - Complex / Chronic Users		
King's fund – LTCs and Mental Health	Research paper February 2012 http://bit.ly/rop7sw	<p>Many people with LTCs also have mental health issues.</p> <p>Exacerbating mental illness can raise total health care costs by around 45%</p> <p>Intermountain Healthcare, Utah and Idaho, are using shared electronic health records with patients with co-morbid long term conditions, as well as a number of other interventions which are reducing total medical care costs by 48% per patient.</p> <p>The conclusion here is to recognize that the move towards self-management with long term conditions is under threat unless more is done to raise self-motivational ability of those with co-morbid emotional or mental health problems.</p> <p>The costs of co-morbid mental health problems are large, so commissioners need to work out how to strengthen the interface between patient and professional.</p>
Renal patient view	Evaluation report http://www.kidneycare.nhs.uk/Library/RPV_Final_Evaluation_Report.pdf	<p>The RPV is a secure internet based system enabling kidney patients to view their own live test results online.</p> <p>System designed specifically for patients to use and is available to 43 out of 52 kidney units in England. 17,000 registered users.</p> <p>Findings:</p> <ul style="list-style-type: none"> • Patients found having an online access point valuable and were not too concerned about privacy issues • RPV provided useful information that expanded patients' knowledge • Patients admitted that it was for test results that they had used the internet based system • Patients using RPV were empowered and very involved in their own care and very keen on knowing the status of

Text	Source	<u>Headline findings in the text</u>
		<p>their kidney function</p> <ul style="list-style-type: none"> • It reassured people about their treatment and gave them “peace of mind” • For health professionals, they were only too happy to see patients use their information and access it in such a way as RPV facilitated • The forum created a sense of community encouraged learning too • The ‘Enter My’ feature was the underused element, with only two thirds of those who used it entering at least one reading of their blood pressure, weight or glucose measures <p>Participants believe that it will become better utilized as it becomes better known. The evaluation shows the access point to increase a sense of self control, enhance self-care, facilitate decision-making and improve patient-professional communication.</p> <p><u>NHS Kidney Care’s evaluation:</u></p> <p>Results and patient info most popular; contact and help not used quite as much.</p> <p>28% said they were concerned over privacy issues when they first heard about it, 15% since using the system.</p> <p>Highest proportion of respondents said they were quite happy to share login details with family.</p>
UK - PAERS - Patient Access Electronic Record System		
PAERS - Patient Access Electronic Record System	<p>Website (information towards a case study)</p> <p>http://www.paers.net/health-information-portal.shtml</p>	<p>Background: PAERS is the result of a partnership between EMIS, which supplies the patient data and systems, and three forward-thinking doctors who invented the kiosk: Dr Brian Fisher (a GP at Wells Park Surgery, Sydenham), Dr Fraser Booth (a hospital doctor in Brighton) and Dr Lachlan Clark (now a technical manager for an IT company).</p> <p>Dr Brian Fisher : “Patients say they get a better understanding of their condition when they see their complete medical record – it helps them to put the different pieces of the jigsaw together.”</p> <p>On the PAERS information kiosks:</p> <ul style="list-style-type: none"> • 78% of patients who used the PAERS kiosk said that having access to their records had broken down barriers

Text	Source	<u>Headline findings in the text</u>
	<p>http://www.pae.rs.net/health-information-portal-case-studies.shtml</p> <p>Accessed April 2012</p>	<p>between themselves and their GP</p> <ul style="list-style-type: none"> • 69% of users said access had given them more confidence in their doctors • 74% said using the system had resulted in a better understanding of how their doctors think. <p>The kiosk is a groundbreaking patient communication tool that offers four optional modules:</p> <ul style="list-style-type: none"> • Medical record viewer • Online Health Information and Education • Patient Questionnaires • Blood pressure and heart rate measurement <p>‘Studies that we have conducted in the practice chime with other international studies to show that patients gain significantly from record access:</p> <ul style="list-style-type: none"> • They trust the clinician and the practice more • They feel more able to self-manage their illnesses • They feel more confident in the clinical encounter • They can correct the record and thus improve safety • There is some evidence that record access improves health outcomes, improving medication compliance in heart failure and improving smoking quit rates’
<p>Why doctors should not fear but can profit from</p>	<p>Article – Brian Fisher</p>	<p>Dr Fisher, writing in 2007: Patients’ record access is here to stay. It is available now in many countries and is gradually extending across the world. There are different systems, through smart cards, kiosks in GP waiting rooms and online.</p>

Text	Source	<u>Headline findings in the text</u>
<p>patients access – Dr Brian fisher</p>	<p>August 2007 http://bit.ly/KyZIKC</p>	<p>Access to patient records ought to include:</p> <ul style="list-style-type: none"> • Access to the full electronic record • The ability to view whenever and wherever the patient wants • The patient should be able to be reminded of key health appointments • The patient should be able to screen off information that they do not want selected professionals to see. <p>Patient access is here to stay and the benefits for patients and clinicians overlap.</p> <p>Trust in clinicians improves as a result (cites - Baldry M., Cheal C., Fisher B., Gillett M., Huet V. [1986]. ‘Giving Patients their own records in general practice: experience of patients and staff’. Br Med J [Clin Res Ed] Mar 86, 1;292[6520]:596-8)</p> <p>Improves care as it improves a patient’s safety, correcting recording errors (cites - Powell J, Fitton R, Fitton C. [2006] Sharing electronic health records: the patient view. Informatics in Primary Care 14:55-7)</p> <p>In his experience, sharing by elderly people to their carers has enabled “far better coordination and understanding”.</p> <p>The “risks to clinicians”, which can be allayed, are to do with third party information. That is: “information about the index patient given to the clinician by a non-clinician”. For instance, information given to a GP by the wife telling the clinician that the husband drinks – the wife does not want the clinician to reveal the source of the information.”</p> <p>There is no evidence to support the notion that people with serious illnesses will get upset when reading their records, therein impacting negatively upon their already existing poor health.</p>
<p>Haughton Thornley Medical Centres</p>	<p>Website/blog</p>	<p>YouTube videos for reference</p> <p>http://www.youtube.com/watch?v=thMGogHKzek</p> <p>http://www.youtube.com/watch?v=B9TEQW1cvIQ</p>

Text	Source	<u>Headline findings in the text</u>
		http://www.youtube.com/watch?v=8fk_tzcHw-A
Dr Amir Hannan – Patients need access and understanding of their EHR	Guardian article http://tinyurl.com/8vfc9ga	November 2011. “Patients, carers and the information to support them are the most under-utilised resources the NHS has available”.
ICMCC Guest post: Patient access to GP electronic health records	Blog post by Dr. Amir Hannan Accessed April 2012 http://bit.ly/p5B3ld	ICMCC: International council on medical & care compunetics. Case 1 – example of where a doctor was delayed in carrying out a pre-op assessment on the grounds that they had been waiting for the paper records – that is before the patient explains she has electronic records. How do you get access? Dr Amir Hannan explains how it works in his surgery: <ul style="list-style-type: none"> • The first stage enables patients to book appointments and order repeat prescriptions and send secure messages to the practice. They are given PIN NUMBERS (automatically generated from the clinical system). • The second stage allows patients to access the full access to the GP record. Patients are asked to go online and look at information about records access including what it is, what an example health record looks like, what the advantages and challenges are, how to keep their information safe (includes our understanding on privacy, confidentiality and the need to share information) and links to YouTube videos, articles in local newspapers, regional newspapers and the Times (an excellent read and highly recommended) as well as a radio item from the Today programme and a Radio 5 Live interview too. The purpose is to try to inform patients as much as possible on what records access is and what people are saying about it.

Text	Source	<u>Headline findings in the text</u>
<p>The Health Foundation – Helping people help themselves</p>	<p>Dr Debra de Silva</p> <p>May 2011</p> <p>http://www.health.org.uk/public/cms/75/76/313/2434/Helping%20people%20help%20themselves.pdf?realName=8mh12J.pdf</p>	<p>“Some studies argue that supporting self-management reduces the use and costs of health services. However this focus may be too simplistic. It is more likely that patterns of service use change rather than reduce overall. For example, people may engage more frequently with a practice nurse, telephone coach or with peers, but less with hospital services. The aim is not to reduce contact overall, but rather to support a different pattern of contact which may lead to fewer crises and inpatient admissions.”</p> <p>“Researchers in many parts of the world have tested using computers to provide self-management information and education. For instance, a systematic review of 22 randomised trials found that computerised patient education improved health status in people with various conditions.” Bingham, C. R., Barretto, A. I., Walton, M. A. , Bryant, C.M., Shope, J.T., Raghunathan, T.E. (2010). ‘Efficacy of a web-based, tailored, alcohol prevention/intervention program for college students: initial findings.’ Journal of American College Health 58(4): 349–56.</p> <p>Several descriptive studies suggest that computer chat rooms and online forums can be a good motivator for self-care, but the clinical effect is uncertain.</p> <p>The report cites an academic article Ross SE, Moore LA, Earnest MA et al (2004). ‘Providing a web-based online medical record with electronic communication capabilities to patients with congestive heart failure: randomized trial.’ J Med Internet Res 6(2): e12. – which points out that after one year, those who had access to their records online were more likely to adhere to treatment, but there were no differences in self-efficacy or satisfaction with care. They conclude this note by saying in their opinion the evidence is too mixed as to whether personal held records facilitate people helping themselves.</p>
<p>UK - Microsoft Health Vault</p>		
<p>South London and Maudsley</p> <p>http://www.slam.nhs.uk/media/254920/microsoft-maudsley%20faqs.pdf</p>		<p>SLaM has partnered with Microsoft to create an online resource to help get service users involved with their healthcare</p> <p>Using Healthvault, SLaM is designing a pilot online to enable people to access their own information remotely, called “MyHealthBox”.</p>

Text	Source	<u>Headline findings in the text</u>
UK - Patients Know Best		
Personal Health Records: A Guide for Clinicians Mohammad Al-Ubaydli	Book	<p>A clinician has only 1 hour with a patient on average every year, leaving some 8,700 without. For many conditions, such as asthma and diabetes for example, it is important to know what goes on during this time.</p> <p>Often the time spent with the clinician for the patient has them remembering a lot from memory, but platforms such as PatientsLikeMe demonstrate the value in symptoms diaries, which can be recorded and updated at leisure.</p> <p>Al-Ubaydli says that there are of course concerns. The expense, certainly, but there is the possibility that with the patient in control, they will have the opportunity to modify themselves and clinicians may have no idea where the modifications have taken place. This could prove beneficial, since patients can correct data, but the absence of a trail, where notes have been modified, could become problematic.</p>
UK - Others		
Individual Health Record (IHR)	Centrihealth – case study http://www.centrihealth.com/index.php?option=com_content&view=article&id=57&Itemid=62&lang=en	<p>The IHR (as referenced above in the context of Wales) has the following features:</p> <ul style="list-style-type: none"> - Obtains information from any and all health information systems such as the EHRs - Transforms all of this into a coherent account for an individual’s overall health - Creates an easily understandable record that is easy to use - Engages the user - Useful benchmark facility with health information, suitable for carers etc - Industry alerts from the likes of NICE
United States – General		
The Power and Potential of Personal	http://www.rwjf.org/pr/productions.jsp?id=49989	Research book on PHRs published Online 2010 by Robert Wood Johnson Foundation.

Text	Source	<u>Headline findings in the text</u>
Health Records		
A Research Agenda for Personal Health Records	http://tinyurl.com/9pkwqd8	Research overview, December 2008, on the use of PHRs in the US. Estimated 70M US patients have access to an EHR.
PHR webpage	Minnesota Dept of Health website http://www.health.state.mn.us/e-health/consumers/phr.html	Lists consumer benefits of PHRs <ul style="list-style-type: none"> • You have convenient and secure access to personal health information, whenever it is needed to help you make health decisions • You can ask good questions and make better healthcare decisions for your children, your elderly parent, and yourself based on personalized information • You can record your health history and set reminders to help you monitor and take responsibility for your health • You get test results quickly and can understand them • You are aware of potential drug interactions with the medications you are taking • You can use secure e-mail to ask your physician confidential health questions • You keep tabs on the health information contained in your record and provide updates when needed
PHRs: empowering consumers	HIMSS.ORG website http://www.himss.org/content/files/phr_empowering_cons.pdf	PHRs: Empowering Consumers. 2007? Originally published in <i>Journal of Healthcare Information Management</i> . Vol. 21, No.1 The report contains ‘Seven Patient and Consumer Principles’ on PHR adoption ‘within a robust national health information network that includes EHRs for clinicians and institutions, electronic data exchanges and oversight bodies.’ ‘American consumers want to have their own electronic personal health records. In the fall of 2005, 60 percent of Americans said they favoured the creation of a secure online PHR service for their own use.’ [This references data from the Markle Foundation.]

Text	Source	<u>Headline findings in the text</u>
AHIMA: The American Health Information Management Association	Website PHR pages http://www.myphr.com/StartaPHR/what_is_a_phr.aspx	<p>The PHR area of The American Health Information Management Association (AHIMA) website. Gives a detailed breakdown of the potential of a PHR.</p> <p>The privacy myth-busting page http://www.myphr.com/Privacy/common_privacy_myths.aspx</p> <p>Privacy rights page http://www.myphr.com/Privacy/your_privacy_rights.aspx</p> <p>Who Owns your Health Information?</p> <p>The Health Insurance Portability and Accountability Act (HIPAA):</p> <ul style="list-style-type: none"> • Covers medical information in any format—written, spoken, or electronic • Allows patient to view, request changes to, and obtain copies of health information documents • Provides protections <p>Your physical health record belongs to your healthcare provider, but the information in it belongs to you. Understanding what is in your health record helps you:</p> <ul style="list-style-type: none"> • Make sure it’s correct and complete • Know what is being released when you authorize disclosure of information to others • Provide an accurate health history to all healthcare providers who treat you <p>Who else has access to your health information?</p> <p>The law says that anyone can see your health record that needs it in order to provide your treatment, to facilitate payment for healthcare services, and to make sure quality care is being received.</p>
Survey Finds Americans	Markle Foundation	<u>2006</u> Survey.

Text	Source	<u>Headline findings in the text</u>
Want Electronic Personal Health Information to Improve Own Health Care	http://www.markle.org/publications/1214-survey-finds-americans-want-electronic-personal-health-information-improve-own-health	<p>Specific findings include (as on website):</p> <ul style="list-style-type: none"> • Two-thirds of the public (65%) is interested in accessing their own personal health information electronically. This interest spans demographic groups – with a majority (53%) of Americans 60 and older and high proportions of minority groups, including African-Americans and Latinos, expressing interest. • Large majorities see a number of benefits of accessing information online, which could lead to a reduction in health care costs. For example, nearly nine in 10 Americans (88%) say online records would be important in reducing the number of unnecessary or repeated tests and procedures they undergo. • Americans express strong concern that their information may be used for purposes other than their own care. Eight in 10 Americans (80%) say they are very concerned about identity theft or fraud or the possibility of their information getting into the hands of marketers (77%). • Americans believe they could gain more control over their health care by using electronic personal health records. For example, 90% say it would be personally important to track their symptoms or changes in health care online.
The Mobile Personal Health Record: Technology-enabled self-care	<p>USA: Deloitte Center for Health Solutions</p> http://www.deloitte.com/assets/Dcom-UnitedStates/Local%20Assets/Documents/Health%20Reform%20Issues%20Briefs/US_CHS_2010	<p>A 2010 report analysing findings from various US PHR providers, discussing user trends (briefly) and potential benefits now and in the future of the PHR. Considers in conjunction with (apps for) Mobile communication devices (MCDs) – cell phones, smartphones and other mobile tablet PCs.</p> <ul style="list-style-type: none"> • Only 10 % of American adults currently use a PHR [2010]; when polled, 61 % of Americans said they do not believe they need a PHR, potentially because they do not see the benefit. [NB see comment below.] • While privacy is still a concern, consumer sentiment is slowly changing. Once consumers start using a PHR, fears about privacy and confidentiality noticeably diminish. • Providers have historically voiced concern over liability and data integrity of PHRs. Today, more providers are offering pre-populated PHRs to their patients to view their medical history, access test results, email their

Text	Source	<u>Headline findings in the text</u>
	mPHR_091310.pdf	<p>physicians, refill prescriptions, schedule clinical visits and keep track of personal data such as diet, sleep and exercise. The barrier for providers lies in making the legal medical record distinct from the patient-entered data, both technically and operationally.</p> <p>[NB: First point at odds with the findings of the Markle 2006 survey (see above).]</p>
<p>Integrated Personal Health Records: Transformative Tools for Consumer-Centric Care (Oct 2008)</p>	<p>BiomedCentral article</p> <p>http://www.biomedcentral.com/1472-6947/8/45</p>	<p>A 2008 US article authored by senior representatives of AMIA, Kaiser Permanente, and Palo Alto Medical Foundation. Discusses PHR background; models; functionality, transformative potential, etc.; also consumer confidence and trust.</p> <p>Risks: ‘the widespread use of PHRs ... raises new potential areas of liability and risk for health care providers, such as the use of incomplete or inaccurate consumer-reported information, online clinician-patient communication, and privacy and security breaches.’</p> <p>2005 consumer survey, top priorities regarding the attributes of a health information exchange network:</p> <ul style="list-style-type: none"> ▪ The identity of anyone using the system would be carefully confirmed to prevent any unauthorized access or any cases of mistaken identity ▪ Individuals would be able to review who has had access to their personal health information ▪ Only with an individual’s permission could medical information be shared through a network ▪ Employers and insurance companies would not have access to secure health information exchange networks.
<p>EHR Lessons from beyond the US Borders</p>	<p>News article – EHR Institute (US) 2009</p> <p>http://bit.ly/IP2EPR</p>	<p>Despite the US wanting to be the “first and best”, particularly in areas of health and technology, it has not risen to the centre stage on use of EHRs.</p> <ul style="list-style-type: none"> - India and Australia are already using EHRs successfully - “The Journal of the American Medical Association reports that fewer than 20% of surgeries in America use Health Information Technology. But in India nearly 60 percent of the hospitals do. <p>This sub-continent is selling their technology to the U.S. and showing us how to build our technology around our healthcare needs.”</p>

Text	Source	<u>Headline findings in the text</u>
Marshfield Clinic: Health Information Technology Paves the Way for Population Health Management	Case study publication by the Commonwealth Fund, August 2009 http://bit.ly/lzKiWW	<p>Marshfield clinic has an electronic health record for information continuity, available for electronic prescribing on a portable tablet PC. It allows physicians the opportunity access patient records while patients themselves have access to their records via a web portal, which includes immunization records and prescription refill requests.</p> <p>“The Clinic is considering expanding the services the portal provides to include e-visits and electronic scheduling. Approximately 16% of patients now make use of it”.</p> <ul style="list-style-type: none"> • The record shows up when preventative and chronic care services are due and allows physicians information about when patients are not meeting treatment goals • Nurses manage telephonic care following physician-approved protocols for anticoagulation, heart failure, and cholesterol control • Nurses can also use the record to tailor advice to patients if they are staffing the 24-hour call line • Marshfield employs 800 physicians, 6400 staff, serves 377,000 individual patients at 41 ambulatory located in 33 different communities. Patients made 3.6 million visits during 2008. • EHR (CattailsMD) has been used since 1985
To err is human	Book (review) from the institute of medicine http://bit.ly/zWgUXf	<ul style="list-style-type: none"> • 1999 – in the US at least 44k people, but as many as 98k, die through medical error • ‘Among the problems that commonly occur during the course of providing health care are adverse drug events and improper transfusions, surgical injuries and wrong-site surgery, suicides, restraint-related injuries or death, falls, burns, pressure ulcers, and mistaken patient identities.’ • Types of error – diagnostic (error or delay in diagnosis, use of outdated or outmoded tests, failure to act on results of monitoring or tests); treatment (error in performance, administration of treatment, dose of drug, avoidable delay); preventative (failure to provide prophylactic treatment, inadequate follow up treatment); other (failure of communication, equipment failure, system failure). [SOURCE: Leape, Lucian; Lawthers, Ann G.; Brennan, Troyen A., et

Text	Source	<u>Headline findings in the text</u>
		<p>al. Preventing Medical Injury. Qual Rev Bull. 19(5):144–149, 1993.]</p> <ul style="list-style-type: none"> • Majority of medical errors are down to system failures not medical individuals • Improvement: leadership; voluntary reporting for practitioners; facilitating improvement through professional groups • The main lesson to the book – it may be human to err, but it is also human to find solutions, and these can be developed through creating what the Institute of Medicine call a “culture of safety”
California HealthCare Foundation	Press Release – April 2010 http://bit.ly/K1ayXg	<ul style="list-style-type: none"> • 1 in 14 Americans use a personal health record (PHR) • They know more about their health, ask more questions, and take better care of themselves • 1 in 3 PHR users take a specific action to improve their health • Most pronounced among hard to reach: multiple chronic conditions, less education, lower incomes • Usage rates of these tools are relatively low but have doubled over the last two years. <p><i>1,849 people - 15 Dec 2009 – 10 Jan 2010</i></p>
US Veteran Health Affairs		
FAQ web page	http://tinyurl.com/3shzuj7	FAQs on myhealthvet
Study to determine user experience for several popular	http://www.nesws-medical.net/news/20120106/Study-to-determine-user-	<p>A summary relating to a report published in the December 2011 issue of the <i>Journal of the American Medical Informatics Association</i>.</p> <p>‘... users found the prescription refill function to perform better than expected. More than 20 million refills have been ordered online through MyHealthVet since 2005.’</p>

Text	Source	<u>Headline findings in the text</u>
<p>functions of My HealtheVet</p>	<p>experience-for-several-popular-functions-of-My-HealtheVet.aspx</p>	<p>‘Patients indicated that they thought it important that information they uploaded into their personal health record, such as blood sugar or blood pressure levels over time, be downloadable as graphs that they could print and bring to a future doctor's visit. ‘</p>
<p>MyHealtheVet personal health record users’ characteristics, needs, and preferences</p>	<p>http://jamia.bmj.com/content/17/2/203.full.pdf+html?sid=c6fe505e-65eb-48a8-a1e2-ece3ad9ac3b2</p>	<p>Report on VA HealtheVet Kim M Nazi</p> <p>A report published 2009 that analyses user satisfaction (using the ACS Index) with My HealtheVet.</p> <p>Satisfaction is high: 8.3/10 Users are likely to return to the site: 8.6/10 Users would recommend site to others: 9.1/10 Majority of system adopters are male (91%) –although this % changes year by year; see more recent Annals of Internal Medicine study, below.</p>
<p>VA’s My HealtheVet</p>	<p>VA Website information</p> <p>https://www.myhealth.va.gov/index.html</p> <p>Accessed April 2012</p>	<p>The My HealtheVet part of the VA’s website. The system allows users to:</p> <ul style="list-style-type: none"> • Refill prescriptions online (most popular feature) • View prescription history • Store emergency medical information • View appointments • Check lab results • Send non-urgent Secure Messages to VA health team <p>A ‘blue button’ download facility allows the patient to download a pdf of their PHR to store electronically or print off. This seems to be the only way at present for a user to share information with someone outside their health system. (See next.)</p>
<p>VA’s My HealtheVet</p>	<p>Additional information on the VA’s ‘blue button’ access</p>	<p>A more comprehensive list of the VA’s PHR benefits, and what can be downloaded via the VA Blue Button. Includes self-entered information:</p> <ul style="list-style-type: none"> • Demographic information • Emergency Contact information

Text	Source	<u>Headline findings in the text</u>
	http://www.myphr.com/resources/blue_button.aspx	<ul style="list-style-type: none"> • Health Care Providers • Health Insurance • Treatment Facilities • Medical conditions and personal medical history • Medications, herbals, and supplements • Allergies and adverse reactions • Lab and test results • Immunizations • Vitals and Readings • Family Health History (Self and Relatives) • Military health history • Health data such as blood sugar, blood pressure, weight, etc. • Any other health-related information the Veteran feels a doctor or hospital might need to know <p>Veterans who are receiving medications from VA can download their VA medication history.</p> <p>VA patients who have enrolled in the enhanced (In Person Authenticated) version of My HealtheVet can also download data from their VistA Electronic Health Record including:</p> <ul style="list-style-type: none"> • VA Wellness Reminders • VA Appointments • VA Allergies • VA Chemistry and Hematology Lab Results
Patient Interest in Sharing Personal Health Record Information	Annals of Internal Medicine vol.155, 12 20 Dec 2011. A Study of VA's HealtheVet http://www.annals.org/content/	<p>'Patient Interest in Sharing Personal Health Record Information'. Online survey of 18,471 users of My HealtheVet conducted from July 7 through Oct. 4, 2010.</p> <p>'The percentage of persons in the United States who use electronic PHRs has increased from 3% to 10 since 2008'</p> <p>Naturally, given nature of the VA, most respondents were male (92%). Age range mostly 50+; 79% prepared to share their PHR with someone outside their health system – mostly with family members. 25% would share it with a non-VA provider.</p> <p>Demonstrates also the type of health information a patient might want to share with concerned parties (broken down into categories), such as medication list and lab/study results.</p>

Text	Source	<u>Headline findings in the text</u>
	155/12/805.full.pdf+html	
US - Kaiser Permanente		
Rapid progress or lengthy process? electronic personal health records in mental health	Academic paper http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3163520/ July 2011	<p>“Kaiser Permanente, a large healthcare organisation based in the US, began initiating their ePHR in 2004. The most recently published figures showed that registration had been rising steadily, and by June 2008, 27% of its 8.7 million patients had registered on their website using a variety of online facilities such as obtaining test results, refilling prescriptions and emailing doctors. The frequency of use of these online facilities has been increasing rapidly, with just over 62% of registered patients using them twice or more over a 6 month period, presumably demonstrating that individuals find the services useful once they have engaged with them. Other research on the Kaiser Permanente model showed that the online services resulted in a significant decrease in the total number of office visits per patient from 2004 to 2007. Despite this success, other systems have not met with the same enthusiasm.”</p>
KP annual report 2011	KP website download http://xnet.kp.org/newscenter/annualreport/docs/kpreport_2011.pdf	Annual report summary, including financial, operational and consumer figures. E.g. \$47.9 billion 2010 operating revenue \$1.6 billion 2010 operating income \$2.0 billion 2010 net income 8.9 million members 172,997 employees 16,658 physicians 48,033 nurses 37 Kaiser Permanente hospitals 611 Kaiser Permanente medical offices and other outpatient facilities

Text	Source	<u>Headline findings in the text</u>
<p>More than half of Kaiser members use PHR</p>	<p>http://www.ehi.co.uk/news/EHI/6786/more-than-half-of-kaiser-members-use-phr</p> <p>April 2011</p>	<p>2011 report incorporating an interview with Anna-Lisa Silvestre, vice-president, KP online services.</p> <p>‘US healthcare provider Kaiser Permanente has achieved a 58% adoption rate for its electronic personal health record among eligible members.’</p> <p>‘Silvestre produced charts showing that between Q3 of 2007 and Q4 of 2010 secure messaging rose from 12% to 28% of contacts between members and the physician’s office, while visits to the physician’s office dropped from 72% to 58% of contacts. Telephone contacts remained steady at 16-17%.’</p>
<p>If You Build It, Will They Come? The Kaiser Permanente Model Of Online Health Care</p>	<p><i>Health Affairs</i>, 28, no.2 (2009):334-344</p> <p>http://content.healthyaffairs.org/content/28/2/334.full.html</p>	<p>2009 Report on consumers’ online health behaviour. PHR stats and findings, especially on usage demographics. Most recent collected from 2008.</p> <p>Socio-economic data: ‘half of the [surveyed KP users] reported household incomes of less than \$75,000 annually, and nearly half had not completed a college degree’.</p> <p><i>“Member registration data established that consumers spanning the age continuum are adopting online health tools.”</i></p> <p>‘The age range of site users is thirteen (the minimum age at which members may register to use the site’s secure features) to ninety-five. The mean age is forty-eight and the median, forty-seven...Our evidence demonstrates that members across the age spectrum are using online health services.’</p>
<p>The Kaiser Permanente Electronic Health Record: Transforming And Streamlining Modalities Of Care</p>	<p><i>Health Affairs</i>, 28, no.2 (2009):323-333</p> <p>http://content.healthyaffairs.org/content/28/2/323.full.pdf</p>	<p>2009 Data supportive of PHR/EHR benefits.</p> <p>Looking at the efficiencies of the EHR.</p> <ul style="list-style-type: none"> • 225,000 members surveyed. 2004-7 activity analysis showed annual age/sex-adjusted total office visit rate decreased 26.2%, the adjusted primary care office visit rate decreased 25.3%, and the adjusted specialty care office visit rate decreased 21.5%. • Scheduled telephone visits increased more than eightfold, and secure e-mail messaging, which began in late 2005, increased nearly sixfold by 2007.

Text	Source	<u>Headline findings in the text</u>
US - Cleveland Clinic		
'MyChart' – PHR access	Cleveland Clinic website http://my.clevelandclinic.org/online-services/mychart.aspx	MyChart is their electronic PHR, allowing patients to view portions of medical record, see test results, renew prescriptions, request appointments ['and more']. The patient's physician is able to send messages to the patient through MyChart, for example to detail significance of uploaded results. MyChart users can authorise a non-Cleveland Clinic doctor to access their medical information.
Determinants of Personal Health Record Use [2007]	Cleveland Clinic. http://www.himss.org/content/files/jhim/21_3/11_features_Population.pdf	Cleveland Clinic Case study from 2007. Demographic info & internet activity.
Cleveland Clinic/Microsoft Case Study Released ...	Blog report on findings at Cleveland Clinic. http://ducknetweb.blogspot.co.uk/2010/03/cleveland-clinicmicrosoft-study-case.html	Blog discusses case study: 'Disease Management with Patient/Physician Connectivity Through PHR and Wireless Devices Reporting Data.' Benefits to certain disease groups. No information on user preferences.
Canada		
Adoption and Use of Electronic Personal	eHealth 2011 Conference Slides	Canada 2011 conference scoping review of ePHRs. Presentation slides. 'People with serious chronic conditions or disabilities, parents with small children, people with a strong interest in maintaining healthy life styles, and elderly or their caregivers are more likely to adopt ePHRs.'

Text	Source	<u>Headline findings in the text</u>
Health Records in Canada	http://www.e-healthconferenc.e.com/PDFs/Presentations-2011/CS20.2.pdf	<p>‘Developers need to improve the performance of ePHRs:</p> <ul style="list-style-type: none"> • Involve potential user groups with specific health self management needs directly in requirements specification, design, and testing • Ensure that ePHRs match the cognitive and physical abilities of intended users.’ <p>The review includes a survey with 45 participants.</p>
European Union		
Security aspects in electronic personal health record: data access and preservation	<p>Briefing paper Digital Preservation Europe</p> <p>http://www.digitalpreservationeurope.eu/publications/briefs/security_aspects.pdf</p>	<p>No universally accepted definition of the PHR exists</p> <p>Models of record range vary in the extent to which “the content of the records and rights of access are controlled by the patient (simple models) or the healthcare provider (complex models), the range of tools used (i.e. telephone, electro-medical devices, Videophone, computers, wireless and internet technologies) and their interactivity.”</p>
eHealth Task Force Report European Commission	<p>Redesigning health in Europe for 2020</p> <p>Task force report May 2012</p>	<p>The first recommendation of this report (Lever for change #1: My data, my decisions) feeds into what might be achieved with Personal Health Records. For context, the recommendations are towards the five levers of change that are hoped for: 1) individuals being the owners of their own data; 2) data being liberated (ie “open” and shared on the condition that it is subject to rigorous safeguards); 3) data being “connected” (personal datasets all woven into one single datastream so as to reap benefits such as support for a continuous health treatment rather than isolated “interventions”); 4) revolutionise health with greater institutional/professional transparency and accountability (allowing patients to make more informed choices about where and how they want to be treated); and 5) total inclusion (including those in remote rural</p>

Text	Source	<u>Headline findings in the text</u>
	http://www.epractice.eu/en/library/5362646	<p>communities).</p> <p>The report calls for the creation of a legal framework and space to manage the explosion of health data. This needs to put in place the safeguards that will allow citizens to use health apps with confidence that their data is handled appropriately, and subsequently create the conditions for the integration of user-generated data with official medical data so that care can be more integrated, personalised and useful for patients.</p>
EU special eurobarometer – data protection and identity	<p>Report by Eurobarometer June 2011</p> <p>http://bit.ly/liqxee</p>	<p>74% of Europeans see disclosing personal information as an increasing part of modern life.</p> <p>Information considered as personal is, above all, financial information (75%), medical information (74%), and national identity numbers or cards and passports (73%).</p> <p>Social networking and sharing sites users are more likely to disclose their name (79%), photo (51%) and nationality (47%). Online shoppers’ actual online disclosure of personal information mainly involves their names (90%), home addresses (89%), and mobile numbers (46%).</p> <p>Almost six in ten Internet users usually read privacy statements (58%) and the majority of those who read them adapt their behaviour on the Internet (70%).</p> <p>Only one-third of Europeans are aware of the existence of a national public authority responsible for protecting their rights regarding their personal data (33%).</p> <p>A large majority of the European interviewees also see medical information, such as patient records and health information, as personal. This answer comes first in five Member States: Ireland (93%), Slovenia (90%), Sweden (89%), Belgium (84%), and France (82%). In Austria, the same number of respondents considered medical information and home address as personal (75%). The United Kingdom 83% felt their medical information was personal.</p> <p>Medical information, financial information and identity numbers are regarded as personal information by more than seven Europeans in ten. Almost eight out of ten respondents who use social networking or sharing sites, revealed their name on</p>

Text	Source	<u>Headline findings in the text</u>
		<p>the Internet (79%). Around half of them disclosed photos of themselves (51%), or their nationality (47%).</p> <p>Almost four in ten disclosed the things they do (for example hobbies, sports, places they go), their home address, and who their friends are (all three 39%). One-third shared their tastes and opinions (33%) and a quarter gave their mobile phone number (23%).</p>
RLUS and SOA Security German National Personal Health Record	Conference July 2011. http://tinyurl.com/93q3fhs	<p>A Project funded by the German Federal Ministry of Health.</p> <p>Slide presentation of: Concepts; Platform; Semantic Signifiers; Security; Trust and Communication relationships; Authentication and Authorization process.</p>
'Vendors partner on German Personal Health Records'	http://www.healthcareitnews.com/news/vendors-partner-german-personal-health-records Feb 2009 article	<p>'The second-largest public health insurance company in Germany, the DAK, has just recently joined this project. It plans to offer web-based personal health records (PHR) to its 6 million members and to link these to the Asklepios-EMR. This is by far the largest single project using web-based personal health records in Germany so far. The DAK-PHR is set up by IBM, based on the IBM-solution for the national Danish ehealth portal Sundhed.dk.' [see below]</p>
eHealth Strategies - Country Brief: Germany	http://www.ehealth-strategies.eu/database/documents/Germany_CountryBrief_eHS_12.pdf	<p>A study of eHealth in Germany. Looks at eCards, patient summary, ePrescription, standards as well as telemonitoring and telecare.</p> <p>eCard (p31...): 'For more than 15 years, German citizens who are a member of a public, statutory health insurance fund have had to carry an electronic insurance card which contains on a chip all their administrative insurance data.'</p> <p>Only briefly discusses the personal electronic health record (p.24...):</p> <p><i>Electronic Health Record:</i> 'Beyond the eCard discussed above, a basic underlying concept of the German eHealth strategy</p>

Text	Source	<u>Headline findings in the text</u>
		is a voluntary “citizen-managed, personal electronic health record” ... For access to the personal electronic health record, the eCard will be used as the citizen's tool to access and manage data in a trustworthy and secure way. This card must not be used for non-health related purposes.’
Scandinavia		
Danish eHealth Portal	Danish website, available in English https://www.sundhed.dk/service/english/about-the-ehealth-portal/background/	Every citizen has his own personal page (available upon identification), which reflects their specific situation. ‘Here, the citizen can find accurate and updated health care information, e.g. view treatments and diagnoses from his own hospital patient record, book appointments with his GP, renew prescription drugs, monitor own drug compliance, survey shortest waiting lists for operations and quality ratings of hospitals, register as organ donor, and get access to local disease management systems in out-patient clinics.’
Electronic Health Records: An International Perspective on “Meaningful Use”	Commonwealth Fund; analysing EHR in Denmark, Sweden and New Zealand http://tinyurl.com/78mdweg	<p>Report states that the USA lags behind a number of other countries in use of EHRs. It considers ‘three countries with very high levels of health information technology adoption—Denmark, New Zealand, and Sweden. ...The brief find high levels of meaningful use for EHR items and substantial information-sharing with other organizations or health authorities, although less information is shared with patients.’</p> <p>Report focuses on the nature and range of EHR systems in the three countries, especially considering communication between primary and secondary care; barely touches on patient access to the EHR and therefore the PHR perspective.</p> <p>‘...data from the Commonwealth Fund’s 2009 International Health Policy Survey of Primary Care Physicians show that almost all primary care doctors in Sweden and New Zealand reported using electronic patient records in their practices, compared with fewer than half of American primary care doctors.’</p> <p>Includes some comparison charts looking at ‘Types and functions of EHR capacities’ in the three countries.</p>
Japan		
Trends,	https://www.ntt	Short 2011 Japanese report into eHealthcare.

Text	Source	<u>Headline findings in the text</u>
Standardization, and Interoperability of Healthcare Information	<p>http://www.na-hit.org/review.jp/archives/ntttechnical.php?contents=nt201104gls.pdf&mode=show_pdf</p> <p>April 2011</p>	<p>Seeks specific definition of the EMR, EHR, and PHR, with reference to USA’s National Alliance for Health Information Technology (NAHIT).</p> <p>The report also considers: International EHR and PHR trends; Japan’s domestic trends for EHRs and PHRs; standardization and interoperability; future directions.</p> <p>‘...in June 2010, the Japanese government’s IT Strategic Headquarters published the “New Information Communications Technology Strategy Schedule”, which describes the initiative called “My Hospital Everywhere (Japanese Personal Health Record)” and seamless regional healthcare enterprises, which are closely linked to the use of EHRs and PHRs.</p>
New Zealand & Australia		
New Zealanders’ attitudes towards access to their electronic health records	<p>New Zealand</p> <p>http://jhi.sagepub.com/content/15/3/212</p> <p>Pub. September 2009</p>	<p>‘New Zealanders’ attitudes towards access to their electronic health records: Preliminary results from a national study using vignettes.’</p> <p>[As of 2009 NZ were not doing much with ePHRs, in spite of having a well integrated EMR system.]</p>
Placing the Next Pieces in New Zealand’s EHR Jigsaw Puzzle	<p>New Zealand</p> <p>http://www.hinz.org.nz/uploads/file/2010conference/P29_Jacobson.pdf</p> <p>2010</p>	<p><i>“Today, in mid 2010, the New Zealand health system is in the enviable position of having 100% of general practices using a highly functional electronic medical record system (EMR).”</i></p> <p><i>“The journey to create a personally controlled electronic record system has now begun.”</i></p> <p><i>“ Compared with six other nations—The US, Australia, Canada, Germany, the Netherlands, and the United Kingdom— New Zealand has the most advanced healthcare IT systems.”</i></p> <p><i>“A growing number of patients access information from their own electronic personal health record which is attached to their GP’s electronic medical record (EMR) system.”</i></p>

Text	Source	<u>Headline findings in the text</u>
Australian PHR Mandate Demonstrates Significance of MMRGlobal	Bloomberg http://www.bloomberg.com/article/2012-05-10/aZp0519DLJbk.html	Financial article: 'In the 2012-13 financial year, the Australian Government projects approximately 500,000 Australians to take up the Personally Controlled Electronic Health Record (PCEHR) service, with 1.5 million in the following year, 2.2 million in the year after and 2.6 million in three years, according to figures released by the Australian Government. Also reported, doctors will be required to participate in the electronic health records system due to launch on July 1 [2012] or lose an existing incentives package worth up to \$50,000 a year per practice.'
General views on on-line activity		
Internet users' perceptions of 'privacy concerns' and 'privacy actions'	Academic report, 2007 http://bit.ly/lgg4eN	<ul style="list-style-type: none"> • Overwhelming finding is that users of the internet in general do worry about their privacy. • when doing the grocery shopping online, users may be concerned about whether a retailer stores information about their purchases, and whether this information may be sold to third parties who will then send them unwanted mail • a PC world survey (2003) of 1500 Internet users found that 88% were concerned about websites sharing their e-mail address, and 91% were concerned about being tracked while using the web • Common reasons for concern (399 respondents): viruses 16.1%; Spam 10.5%; Spyware 9.9%; Hackers 8%; access to personal information 6.8%; security 5.6%; Id theft 3.7%; Trojan 3.1%; Deception/honesty 1.2% • Common reasons for not having concerns: IT experience 23.1%; Not caring 17.4%; Nothing to hide 15.7%; not knowing 11.6%; Asking 'Why? Should I?' 4.1%; Had no problems before 3.3%
Next Generation Users: The Internet in Britain –	Academic report, 2011 http://bit.ly/IIHAjC	'...an authoritative source of information about Internet access, use and attitudes—and the difference this makes for everyday life—in Britain.'

Text	Source	<u>Headline findings in the text</u>
Oxford Internet survey		
Facebook privacy settings: who cares?	Academic report by Danah Boyd and Eszter Hargittai http://www.uic.edu/htbin/cgiwrap/bin/ojs/index.php/fm/article/view/3086/2589	(Boyd is a Researcher at Microsoft Research and a Research Associate at Harvard’s Berkman Center for Internet & Society) <ul style="list-style-type: none"> • This paper aims to challenge the view, of for example David Kirkpatrick, that “The older you are, the more likely you are to find Facebook’s exposure of personal information intrusive and excessive”. • Based on data collected in early Fall 2009, [Pew Internet & American Life Project] found that 71% of the 18–29-year-old social network site users they surveyed reported changing their privacy settings while only 62% of those 30–49 and 55% of those between the ages of 50–64 had. • Teen girls were especially concerned, which is not surprising given that the narrative of fear was targeted specifically at them (Cassell and Cramer, 2007).
Facebook, YouTube and MySpace: The people, the hype and the deals behind the giants of WEB 2.0 – Sarah Lacy	Book, 2008 http://www.amazon.co.uk/The-Stories-Facebook-YouTube-MySpace/dp/1854584537	Lacy notes the “dark side” of social networking websites, namely how they can facilitate damaging a person's reputation. In March 2007 the Washington Post reported that Yale law students were posting slanderous messages about other students that were impacting negatively upon their job prospects. As Lacy says, “In many ways, that's worse than identity theft. It's certainly more emotionally devastating”.
'Friending': London-	Academic	- Interview is with 16 undergraduates who all joined Facebook soon after it was created in 2005

Text	Source	<u>Headline findings in the text</u>
based undergradu ates' experience of Facebook	report http://eprints.lse.ac.uk/26623/	<ul style="list-style-type: none"> - In September 2006, it was opened up to anyone over the age of 13 with a valid email address and by December 2007, more than half of Facebook users were outside universities (Facebook, 2007b). [...] In October 2006 Facebook had just 448,000 users in the UK (Kiss, 2007a) and by April 2009, 200 million active users (Facebook,2009); the UK was the third largest country in terms of users after the USA and Canada (Burcher, 2009). - Little research is available on the size of people’s networks, but of the few estimates of the exact number of people known, it has been suggested that approximately 290 people are known to a random individual (Killworth et al., 2006).
Multi- dimensional role of trust in Internet banking adoption – Cardiff University	Academic report http://orca.cf.ac.uk/19602/	<ul style="list-style-type: none"> - Majority of customers were once reluctant to adopt internet banking on the grounds of privacy and trust - Many other scholars have reinforced that only after security and privacy have been addressed, consumers will consider other web features to determine the extent to which they can trust and feel safe in transacting with the web vendor (e.g. Benassi, 1999; Dayal et al., 1999). - They also find that trust has to do with how much control an individual has with the content they are dealing with (ability to control the actions of the web vendor – P. Benassi – Truste – an online privacy seal program / Dayal – how to build trust online [marketing management]) - The report's findings are: the higher the level of the trust is contingent on the lower level of risk – in the words of Gefen (Gefen, D., Rao, V., & Tractinsky, N. (2003). Conceptualisation of trust, risk and their relationship in electronic commerce: the need for clarifications; perceived risk mediates between trust and behaviour. What then do people want to perceive? They want to know that nothing untoward is likely to happen with their details. - Even if online security in every transaction was measurable objectively, it would never be enough to settle our subjective fears about online security, that is to say “it is unclear whether this measurement would readily correspond to the consumers’ perceptions of security.” - Privacy as defined by Goodwin is having control over the presence of other people in a given transaction and the dissemination of provided information (Goodwin, C. (1991). Privacy: Recognition of a consumer right. Journal of Public Policy Marketing,10(1), 106–119.)

Text	Source	<u>Headline findings in the text</u>
		<ul style="list-style-type: none"> - 441 internet banking users from Halifax – after 2000 questionnaires were sent out. - The results, from the data, show that uncertainty reduction and knowledge about 'intention' is a key component of trust in internet banking – and trust is based on three things: reliability of the bank, perceived security in safeguards such as firewalls and encrypted pages, and perceived privacy and knowledge that the information given will not be sold to third parties without consent. - Other traits may come into play – such as disposition to trust and belief in humanity (McKnight, D., Cummings, L., & Chervany, N. (1998). Initial trust formation in new organizational relationships. Academy of Management Review, 23(3), 472–490.)
The Filter Bubble	Book http://www.thefilterbubble.com/	<ul style="list-style-type: none"> - 900,000 blog posts, 50m tweets, 60m fb updates, 210bn emails every day ... Eric Schmidt says we create 5bn gig every two days (pp.10-11) - trying to find ways of uncovering your id even if using highest privacy settings (p.111)
Online privacy as legal safeguard – USA	Academic report http://bit.ly/InpxNN	<ul style="list-style-type: none"> - Overwhelmingly consumers want to see more legal safeguards and are happy to see companies detail their policies on privacy. - Despite privacy as a right is enormously important (“to those in the West”) there are discernible holes in our right to privacy online. - As the authors say “Given the profitable trade in personal data, the lack of codified legal protections for this information is anachronistic and provides opportunity for misuse.” And yet, our online behaviour does not match up to this. - We prefer (86%) opt-in policies for use of our personal data. - “only 10% of internet users modify browser settings to reject cookies; 5% employ anonymising software to conceal

Text	Source	<u>Headline findings in the text</u>
		<p>their computer identity; and 24% provide false personal data to avoid revealing true information.”</p> <ul style="list-style-type: none"> - “In contrast [to the UK], European Union member countries follow strict regulations that protect consumer privacy, specified by the Directive on Data Protection of 1998.” - “Graber in 2002 [Graber, M.A., D.M. D’Alessandro and J. Johnson-West (2002) ‘Reading Level of Privacy Policies on Internet Health Websites’, Journal of Family Practice 31(7): 642–5] found that a third of the health websites he studied did not have a privacy statement.” - Private information can now be regarded as a commodity and a currency
<p>Privacy and Trust: The role of situational and dispositional variables in online disclosure – The Open University</p>	<p>Academic report http://bit.ly/lzq1zz</p>	<ul style="list-style-type: none"> - for marketing purposes or for personalisation - that's why we give it up - ‘Westin privacy segmentation’: a) privacy fundamentalists; b) privacy pragmatists (acknowledge use to society, but are generally of the opinion that privacy is important); c) privacy unconcerned. - 87%, according to Westin, are concerned about privacy online. - “people are often willing to disclose personal information to strangers on a train because the ramifications of such revealed vulnerability are lessened”
<p>Privacy policies of air travel web sites: a survey and analysis – USA</p>	<p>Academic report http://bit.ly/ICfBNW</p>	<p>“An analysis of the studies suggests that the single most important concern that consumers share about the online transaction process is related to privacy of personal information”.</p>

Text	Source	<u>Headline findings in the text</u>
Measuring Use of Social Networking Sites (Oxford University)	Blog post http://bit.ly/zgNR3D	<ul style="list-style-type: none"> - “[Do you] use any of the following: a. Facebook; b. LinkedIn; c. Twitter; d. An online dating site like eHarmony, Match.com or Zoosk; e. Another social networking site?” (QC35). Any respondent answered “yes” to any of those five items was coded as a SNS user. Using this approach, 66% of Internet users reported using social networking sites.
Young people and the digital divide: data from the Oxford Internet Surveys	Blog post http://bit.ly/GSMR4g	<ul style="list-style-type: none"> - In Britain as a whole, 17% of young people did not have access to the Internet in 2009: these people [Grant Black – Oxford University] call[s] 'non-users'. - more young people (about 83%) are online than older people (about 70%). - 64% of young non-users (aged 16-24) are not employed as opposed to 15% of users are not employed
Online Gambling and Trust (Oxford University)	Blog post http://bit.ly/HaJSAw	<ul style="list-style-type: none"> - 17% of respondents at the extreme trust end, “Total trust”, report [having recreationally partaken in] gambling compared to 11% of those who have “No trust at all” [based on use of the so-called Likert scale for measuring trust]. Findings based on a survey of gamblers and non-gamblers on the internet, the vast majority of whom, 87%, have never gambled.