

Bilaga 2. Forskningsöversikt och litteraturanlys

Denna forskningsöversikt har tagits fram inom ramen för förstudien Din journal på nätet och medföljer som bilaga till delrapport 1.

Arbetet är utfört av doktorand Faustina Acheampoang och forskningsassistent Emma Ivarsson, under ledning av Vivian Vimarlund, professor i informatik vid Linköpings Universitet, [Institutionen för datavetenskap](#).

Huvudsakligt mål har varit att systematiskt analysera tidigare publicerat material om vad som har gjorts för att underlätta patienters tillgång till sina personliga elektroniska journaler. Artiklarna som valdes ut för denna studie utsöktes via MEDLINE- och Cochranes databaser samt via universitet i Linköpings databas.

PERSONAL HEALTH RECORDS: A LITERATURE REVIEW

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Objective

The aim of this study is to perform a systematic literature review to analyze published work that studied the facilitation of patients' access to their own health records.

INTRODUCTION

For the last few years, the healthcare industry has witnessed a surge in mainstream popularity with advanced technologies. Today in most parts of the world, there has been a gradual shift toward a more patient-centered approach to healthcare. Patients demand for specialized and quality care is ever increasing – and so is the cost of providing health care. The need to reduce the cost of healthcare while improving the quality of care is thus very imperative. Patients are currently being encouraged to take more active participation in their own care and better communication between patients and providers constitute an important component of quality healthcare. Communication between patients and care providers has traditionally occurred through in-person, telephone or paper-based encounters (Hassol, 2004). Due to the evolution of technology, this communication can be done electronically to obtain test results, schedule appointments, and renew prescriptions and so on.

The concept of patients having access to their own medical records is not new. For instance, the “Mother’s passport” for pregnant women was introduced in Germany over 45 years ago (Wackerle, 2010). As healthcare consumers, patients have the right to review and obtain copies of their medical information, the right to request amendments and corrections of information that may be erroneous, the right to know who has received copies and reviewed information and the right to complain about medical privacy practices or breach of privacy (Gerard et al.,2009; Fetter, 2009). Electronic medical records (EMR) and electronic health records (EHR) are sometimes used interchangeably to mean the same thing. However the choice of term used is more than an issue of semantics. Indeed they are as different as apples and oranges as Garets and Davis (2005) contend. They emphasize that while EMRs are computerized legal clinical records created in care delivery organizations such as hospitals and physician offices, EHRs represent the ability to easily share medical information among stakeholders and to allow it to follow the patient through various modalities of care from different care delivery organizations. In the same vein, Hayrinen et al (2008) defines HER as a repository of patient data in digital form stored and exchanged securely and accessible by multiple authorized users.

Personal health records (PHR) is any paper-based electronic health record maintained to an extent by the patient and that allows the patient to access his or her health information (Witry et al, 2010; Maloney and Wright, 2009; Roberts, 2009). The conventional paper-based medical records are now giving way to electronic records. Electronic PHRs occur in various forms or models and the distinction is drawn by who maintains and control the PHR and whether they are stand-alone PHRs or integrated with an EHR. For instance, some PHRs are components of an integrated EHR maintained by care providers and partially controlled by the patient or completely maintained and controlled by the patient (Pagliari, 2007). Examples include health kiosks located in hospitals or other convenient locations and patient portals provided by care givers. Other PHRs are in fact a self contained EHR maintained and controlled by the patient or a third party such as web service provider and this type includes Google Health, Microsoft Health Vault and health records on portable devices like USB (Malony and Wright, 2010).

The structure and content of personal health records differ but normally involves a number of features or functions including patient demographic details, health conditions, emergency contacts, immunizations, laboratory tests and results, hospitalizations, medication history (Grossman et al, 2009); self management support, links to educational and other support

sources and secure clinical email (Pagliari, 2007). Some patient portals feature online chatting with the healthcare provider. Markle (2004) suggests that an ideal electronic personal health record should have the following attributes: access controlled by patients, lifelong records, contains information from all care providers, accessible from any place at any time, private and secure, transparent and permit easy exchange of information among healthcare providers and organizations.

The benefits of electronic personal health records cannot be overemphasized enough. Research has advocated that PHRs have the ability to improve the quality of care, improve patient outcomes, enhance communication between patients and their care givers, empower patients to be actively involved in their own healthcare and help reduce the burden of care. Nevertheless, there are many challenges that obstruct the successful adoption and utilization of personal health records. Privacy and security issues remain the main barriers to PHRs aside cost, technology illiteracy, integration and accessibility. With the emergence of EHRs and a mounting emphasis on a shift towards patient-centered approaches to care delivery, it is necessary to explore previous literature and analyze what work has been done in the provision of accessible electronic health records to patients and to recommend future research areas.

METHOD

A systematic literature review based on articles published between 2009 and 2011 was performed. The independent variable under focus was “patient access to health records” and other variables including effects, challenges, adoption, etc were dependent. The target population was adult and adolescent patients. The articles were identified using MEDLINE and Cochrane databases and others were hand searched. Initial query using individual MESH terms like electronic personal health records, mobile health records and patient access to health records yielded no results. A total of 1801 results were recorded for using the search term “electronic health records”. However from the review of abstracts available for these articles, most of them were not appropriate for the purpose of this study as they focus more on the implementation of EHRs in healthcare organizations with rare mentioning of patients access to their records. Thus the following phrases were selected as search terms: patient access to records, personal health records, personally controlled health records and patient portals. The resulting query used in MEDLINE was (“Patient access to records” [MESH] OR “Personal health records” [MESH] OR “Personally controlled health records” [MESH] OR “Patient portals” [MESH] AND (“2009” [PDAT]: “2011” [PDAT])). The query used in

Cochrane was (“Patient access to records [ALL TEXT] OR “Personal health records” [ALL TEXT] OR “Personally controlled health records” [ALL TEXT] OR “Patient portals” [ALL TEXT]) AND DATERANGE 2009-2011. The queries were made in May 2011.

To increase the sensibility of the query results, new selection criteria were introduced. Studies that gave parents or guardians access to health records of their children were excluded. Again articles in other languages besides English were excluded. Articles with no publicized authors were also excluded. Other articles which were excluded were studies that concerned access to patients’ health records for the sole purpose of patient recruitment into research.

In a further step, the methodological quality of the articles was evaluated. Due to the fact that all themes with regards to patients’ access to their records were being explored, the evaluation of the selection was not based on type of sampling, sample size, data collection techniques. In order to keep the selection as open as possible and to allow for the emergence of different themes and concepts with regards to patients’ access to health records, objective of the study and the kind of study were the criteria used for the selection. To this effect, scientific articles were rated higher than editorials, letters, comments, news and other reports. The selected articles also include systematic reviews.

RESULTS

From the 174 articles obtained in MEDLINE search queries, 95 were selected after the titles and abstracts were read and the inclusion criteria was met. A total of 1854 articles were recorded in the Cochrane search queries. Only four met the inclusion criteria and were therefore selected. Seven other articles were selected by hand searching and were included when they met the criteria for inclusion. Thus a total of 106 articles have been reviewed to write this report. Of this number, 64 are scientific articles and the remaining are mostly other journal reports including 11 letter, 1 editorial, 5 news reports and 1 comment to an article. Please find below the complete list of articles selected for this study. As previously stated, no a priori codes were established in order to explore what has been published in the area of personal health records and patients having access to their own records. This allowed for different themes to emerge from the results obtained.

Adoption and Impact of electronic personal health records

About 15 articles discussed the adoption of electronic personal health records into mainstream healthcare. Emery and McDavid (2011), Rudd and Frei (2011), Vogel L (2010) and other researchers are of the view that ePHRs have an important place in health care in the sense that they have the ability to improve communication between patients and providers, reduce medical errors, increase patient participation, and improve patient outcomes and the quality of care among others. Other articles also highlight the possibility that the rate of adoption of electronic personal health records among ethnic minority (Yamin et al, 2011; Roblin et al, 2009) and for underserved and specialized groups of patients like the elderly (Kim et al, 2009). Overall, there is huge interest for health care providers to make health records accessible to their patients and not forgetting the plethora of opportunities this creates for third parties.

Patient expectations and attitudes towards electronic personal health records

Another theme that emerged from the results regards how patients perceive the possibility of having access to their health records and what their needs of an ideal personal health records are. Nine articles placed emphasis on this important element of the provision of health records to patients. Weitzman et al (2009); Wen et al (2010); Or et al (2011); Richter et al (2010); Balas and Sanousi (2009) all contend that patients are generally willing to adopt personal health re0

ords and have access to their health records but they also have high expectations for ePHRs. Patients have a great need for continued communication with their care providers, secured access and privacy, and their data protected. In order to design personal health records that will be patronized by patients, it is important to elucidate the value of the technology, self management practices, identified information needs, practicality, customizability, flexibility and adaptability of the design (Piras et al, 2010). There is also the need for clarified meaning of information being provided. The incorporation of patient feedback on functionality is very important which Wagner et al (2010) and Walker et al (2009) emphasize.

Barriers to the adoption and use of personal health records

Many studies focus on the barriers and challenges that hinder the design, implementation and adoption of personal health records accessible by patients. Perhaps the main concern lies in the premise of ethical and security issues. Weitzman et al (2011); Gamble KH (2009); Cushman et al (2010); Wynia and Dunn (2010) assert that many patients are more worried about data protection and security, privacy and confidentiality than any other difficulty. The

ethical challenges are entrenched in medical legislation. Other problems cited include understanding medical terms and multilingualism of these terms (Zeng-Treitler et al, 2010), consumer health and technology literacy, provider workflow and decision support. A number of studies also highlighted that the inability to share information across different organizations is also a major issue. Interoperability of PHRs and other systems and the integration of PHRs into EHRs were also demonstrated to be contributing factors to the slow adoption of personal health records. Lack of technical support for consumers has also been described as a major barrier. The issue of patients' anxiety that may come with access to their health records has also been considered as a great challenge. Care providers are also very concerned about the extra work they may need to do, for instance replying to emails or chatting online with their patients and therefore normally have a relatively narrow view of PHRs (Wynia et al, 2010). This may lead to resistance to adoption of PHRs on their part.

Patients' experiences of PHRs

Wäckerle et al (2010); Kahn et al (2010); Ralston et al (2009) and others reported high satisfaction rate among patients who have used a form of PHR to access their health records. The patients are of the view that the PHRs are easy to use and find them useful. The personal health records also provide them with safety and they can correct erroneous information in their records. Improved quality of life, less in-person consultations, greater knowledge, and better self-management are cited by researchers as the driving forces of patients' satisfaction with personal health records. Checking laboratory results and pharmacy-related including prescription renewals were reported to be the features frequently accessed.

Design and Implementation

Some articles focused on the different types of personal health records (Fetter, 2009) and some prototypes that have been developed (Burke et al, 2010; Cushman et al, 2010; Cushman et al, 2010). Some of these projects include Project HealthDesign (USA), MyCare card (UK project), DoctorGlobal (Australia), SUSTAINS (Sweden), NHS HealthSpace (UK) (Pagliari, 2007) are all examples of ongoing projects. One important issue discussed concerned data ownership. Integration and interoperability of PHRs with EHRs or stand-alone PHRs were also discussed in some studies.

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Selected Articles

| Author | Title | Publication type | Domain | Study Design | Findings or main issues discussed |
|----------------------------|---|--------------------|---------------------------|----------------------------|---|
| Bourgeois et al (2009) [1] | MyChildren's: Integration of a Personally Controlled Health Record with a Tethered Patient Portal for a Pediatric and Adolescent Population | Scientific article | Hospital | Multidisciplinary approach | Implementation and evaluation of PHR |
| Yamin et al (2011) [2] | The digital divide in adoption and use of a personal health record. | Scientific article | Primary care | Cross-sectional study | Ethnic minority patients adopted a PHR less frequently than white patients, and patients with the lowest annual income adopted a PHR less often than those with higher incomes. |
| Eramo LA (2011) | Patient portals and meaningful use | Journal article | | | Legislation |
| Weitzman et al (2009) [4] | Acceptability of a Personally Controlled Health Record in a Community-Based Setting: Implications for Policy Making | Scientific article | Managed care organization | Survey | Low levels of awareness/preparedness and high expectations for PCHRs exist as a potentially problematic pairing. Educational and technical assistance for lay users and providers are critical to meet challenges related to access, resistance, workflow demands, accuracy of data and privacy. |
| Gerard et al | Personal Touch | Essay | Healthcare | | Impact of personal health records |

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| (2009) | | | consumer technologies | | |
| Fetter MS (2009) | Personal health records | Journal article | Healthcare consumer technologies | | Types of personal health records |
| Tang and Lee (2009) | Your doctor's office or the Internet? Two paths to personal health records | Journal article | Healthcare consumer technologies | | Utilization of integrated and stand-alone PHRs |
| Reti et al (2009) | Governance for Personal Health Records | Scientific article | Hospital, primary care, policy makers | Survey | To improve patient-centered care, policy making for PHRs needs to include patient representation at a governance level. |
| Weitzman et al (2011) | Helping high-risk youth move through high-risk periods: personally controlled health records for improving social and health care transitions | Scientific article | Hospital | | PCHRs AND PHRs can enable supportive interventions tailored to individual patient needs to boost adherence, self-management, and monitoring. Challenges include health and technology illiteracy, privacy and security issues |
| Gamble KH (2009) | Is it registering? Patient portals , part II | Journal article | Healthcare consumer technologies | | Integration of PHRs into EMRs, privacy and security issues |
| Lawrence D. (2009) | Footing the bill: patient portals , part I. | Journal article | Healthcare consumer technologies. Primary care | | Financial management of patient portals |
| Rudd and Frei (2011) | How personal is the personal health record?: comment on "the digital divide in | Comment, journal article | Healthcare consumer technologies. Primary care | | Utilization of PHRs |

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| | adoption and use of a personal health record ". | | | | |
| Wen et al (2010) | Consumers' Perceptions about and Use of the Internet for Personal Health Records and Health Information: Analysis of the 2007 Health Information National Survey | Scientific article | Consumer health information | Survey | Consumer attitudes toward PHRs and their health care providers' use of HIE. Despite widespread positive appraisal of electronic access to PHRs as important, Internet use for tracking PHRs remains uncommon. |
| Tenforde et al (2011) [15] | The Value of Personal Health Records for Chronic Disease Management: What Do We Know? | Scientific article | Healthcare consumer technologies. Primary care etc | Systematic review | The evidence remains sparse to support the value of PHR use for chronic disease management. With the current policy focus on meaningful use of electronic and personal health records , it is crucial to investigate and learn from new PHR products so as to maximize the clinical value of this tool |
| Emery and McDavid (2011) [16] | Electronic copy versus electronic access . | Journal article | | | Adoption of PHRs and legislation |
| Cross M (2011) | BMA warns against letting patients have access to their electronic records . | News | Primary care | | BMA sounds a note of caution likely benefits, and ethical acceptability of the government's plan for NHS patients to take control of their own medical records |
| Down J.C. | Transparency makes for | Letter | Primary care | | Medico-legal vulnerability |

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| (2011) | good quality health care | | | | |
| Burke et al (2010) | Transforming patient and family access to medical information: utilization patterns of a patient-accessible electronic health record | Scientific article | Hospital | Survey | A web-based Patient Accessible Electronic Health Record was designed for patients with congenital cardiac disease. The adoption rate was high, and utilization patterns suggest that the Electronic Health Record could become a useful tool for health information exchange |
| Wynia et al (2011) | Many Physicians are Willing to Use Patients' Electronic Personal Health Records, but Doctors Differ by Location, Gender and Practice | Scientific article | Primary care | Survey | Physicians broadly have concerns about the impact on patients' privacy, the accuracy of underlying data, their potential liability for tracking all of the information that might be entered into a personal health record, and the lack of payment to clinicians for using or reviewing these patient records |
| Brennan et al (2010) | Project HealthDesign: rethinking the power and potential of personal health records . | Scientific article | Consumer health information | Design -Prototyping | Separating data from the applications that used the data enhanced the innovation in the tools available for lay people engaged in self-management, and portends increased innovation and flexibility in design and application. Challenges include privacy and accessibility issues, integration of data and to generate trusted data exchange agreements between formal health care |

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| | | | | | organizations and third party data integrators like Microsoft HealthVault. |
| Wagner et al (2010) | Incorporating Patient Perspectives into the Personal Health Record: Implications for Care and Caring | Scientific article | Ambulatory care | Case study | Incorporation of patient feedback on specific utilities and functionality into an existing electronic PHR |
| Cushman et al (2010) | Ethical, legal and social issues for personal health records and applications. | Journal article | Consumer health information | Observational study | This article summarizes the issues raised by the first phase of Project HealthDesign projects, categorizing them into four topics: privacy and confidentiality, data security, decision support, and HIPAA and related legal-regulatory requirements |
| Wäckerle et al (2010) | Notes on a stick: use and acceptability of woman-held maternity notes | Scientific article | Hospital | Survey | The questionnaire confirmed that issuing women with their maternity notes on a USB stick is a major advance in patient empowerment, satisfaction and safety |
| Wiljer et al (2010) | Understanding the Support Needs of Patients Accessing Test Results Online | Scientific article | Hospital | Survey | Seven categories of technical support issues were identified: registration problems, site access , login issues, password reset, activation key issues, result access and other difficulties |
| Ko et al (2010) | Patient-held Medical Records for Patients with Chronic Disease: a Systematic Review | Scientific article | | Systematic review | There is no clear benefit of implementing a PHR, and due to medium to high risk of bias these findings should be interpreted with caution |

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| Sujansky et al (2010) | A method to implement fine-grained access control for personal health records through standard relational database queries. | Scientific article | Consumer health information | Design -Prototyping | Design and implementation of access-control mechanism for PHR repositories |
| Or et al (2011) | Factors affecting home care patients' acceptance of a web-based interactive self-management technology | Scientific article | Home care | Cross-sectional | The study demonstrates that perceived usefulness, perceived ease of use, subjective norm, and healthcare knowledge together predict most of the variance in patients' acceptance and self-reported use of the web-based self-management technology. |
| Jones et al (2010) | Characteristics of Personal Health Records: Findings of the Medical Library Association/ National Library of Medicine Joint Electronic Personal Health Record Task Force | Scientific article | Consumer health information | Review | While most PHR products have some common elements, their features can vary. PHRs can link their users with librarians and information resources. |
| Pearson et al (2011) | Potential for Electronic Health Records and Online Social Networking to Redefine Medical Research | Journal article | Consumer health information | Review | The future confluence of health information technologies will enable researchers and clinicians to reveal novel therapies and insights into treatments and disease management |
| Vogel L (2010) | "Blue button" access to medical records | News | | | Benefits of PHRs |
| Bonander and | Public health in an era | Scientific article | Public health | Survey | Benefits of PHRs on public health |

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| Gates (2010) | of personal health records : opportunities for innovation and new partnerships. | | | | |
| Vogel L (2010) | OpenNotes Project "levels the playing field" between doctors and patients | News | Consumer health information | | Adoption of electronic PHRs |
| Yaqub et al (2010) | Distributed Guidelines (DiG): A Software Framework for Extending Automated Health Decision Support to the General Population | Scientific article | Consumer health information | | Developed framework and methodology to create personal health record (PHR) systems able to transform raw health data into meaningful information |
| Oftedahl et al (2010) | The Future of Personal Health Records: A Summary of Roundtable Discussion | Journal report | Consumer health information | | Patients attitudes and expectation of PHR |
| Greenhalg et al (2010) | Adoption, non-adoption, and abandonment of a personal health record: case study of HealthSpace | Scientific article | Healthcare consumer technologies. Primary care etc | Case study | Personal electronic health record s align closely with people's attitudes, self management practices, identified information needs |
| Delbanco et al (2010) | Open Notes: Doctors and Patients Signing on | Scientific article | Hospital Primary care | Survey | The team anticipates that "open notes" will spread and suggests that over time, if drafted collaboratively and signed by both doctors and patients, they might evolve to become contracts for care |
| Page (2010) | The two paths to PHRs | Journal article | Healthcare | | Adoption of either a tethered or |

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| | | | consumer technologies. | | untethered PHR |
| Fonda et al (2010) | Combining iGoogle and personal health records to create a prototype personal health application for diabetes self-management | Scientific article | Healthcare consumer technologies | Design –Prototyping | Creation of a prototype for a personal health application (PHA) for patients. This PHA can provide the backbone for a decision support system that can bring together the cornerstones of diabetes self-management |
| Johnson (2010) | Project HealthDesign: advancing the vision of consumer-clinician-computer collaborations | Editorial | Healthcare consumer technologies. Primary care etc | | Adoption and barriers to PHRs |
| Webster PC (2010) | Albertans to gain electronic access to personal health files | News | Healthcare consumer technologies. Primary care etc | | Adoption and acceptance f PHRs |
| Horan et al (2010) | A Multidimensional View of Personal Health Systems for Underserved Populations | Scientific article | Healthcare consumer technologies. Primary care etc | Grounded theory methodology | The conclusion notes that heightened national attention toward health information technology and reform provides a significant opportunity for initiatives whose goal is to increase widespread access to PHRs |
| Wynia and Dunn (2010) | Dreams and nightmares: practical and ethical issues for patients and physicians using personal health | Journal article | Healthcare consumer technologies. Primary care etc | | Usage , barriers and ethical issues concerning PHRs |

| | records | | | | |
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| Reti et al (2010) | Improving Personal Health Records for Patient-centered Care | Scientific article | Hospital, primary care, ambulatory care, policy making | Survey | Most organizations enable many patient -centered functions such as data access for proxies and minors. No organization allows patient views of clinical progress notes, and turnaround times for PHR reporting of normal laboratory results can be up to 7 days |
| Kahn et al (2010) | Personal Health Records in a Public Hospital: Experience at the HIV/AIDS Clinic at San Francisco General Hospital | Scientific article | Primary care | Survey | Laboratory results were the most commonly accessed feature. Patients were satisfied with the PHR and more than 80% of users agreed that the PHR helped them manage their medical problems; however, some users were concerned that their health information was not accurate or secure. Patients in a safety net setting will access and use an online PHR. |
| Johnson et al (2010) | Patient Access to Radiology Reports: What Do Physicians Think? | Scientific article | Hospital | survey | Regarding direct patient online access to results, both radiologists and RPs were concerned that patients would not understand report contents and that such access would lead to greater patient anxiety and demands on RPs' time. Referring physicians were also concerned that direct patient access to results would cause RPs to lose some control in the patient- |

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| | | | | | physician relationship |
| Fisher et al (2009) | How Patients Use Access to their Full Health Records: a Qualitative Study of Patients in General Practice | Scientific article | Primary care | Survey | This study suggests that record access improves shared management, with patients using their records to improve interactions with healthcare providers, make decisions about their health and improve the quality of the care they receive. These findings also suggest a possible long-term potential for record access to improve health outcomes. |
| Nazi et al (2010) | Embracing a Health Services Research Perspective on Personal Health Records: Lessons Learned from the VA My HealtheVet System | Scientific article | Healthcare consumer technologies | Survey | The need to address PHR data ownership and consent, and the promotion of effective PHR research collaborations. User experiences |
| Nazi (2010) | Veterans' Voices: Use of the American Customer Satisfaction Index (ACSI) Survey to Identify My HealtheVet Personal Health Record Users' Characteristics, needs and Preferences | Scientific article | Healthcare consumer technologies | Survey | Satisfaction with My HealtheVet is high and users are highly likely to return to the site and recommend the site to other veterans. Most veterans currently visit the site to utilize pharmacy-related features |
| Peregrin (2009) | Personal and electronic | Journal article | Healthcare | Case study | Interoperability and incorporation |

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| | health records: sharing nutrition information across the health care community | | consumer technologies | | of PHR in nutritional assessments |
| Maloney and Wright (2010) | USB-based Personal Health Records: An Analysis of Features and Functionality | Scientific article | Healthcare consumer technologies | survey | While PHRs are very important in the health care field, at the present time, USB-based PHRs currently on the market appear to have deficiencies. Tethered or web-based PHRs may be a better option for consumers at present. |
| Hannan (2010) | Providing patients online access to their primary care computerized medical records: a case study of sharing and caring | Scientific article | Primary care | Case study | This case study provides a model of how to set up patient access to electronic records |
| Hargreaves (2010) | Will electronic personal health records benefit providers and patients in rural America? | Scientific article | Healthcare consumer technologies. Primary care etc | Literature search | Electronic PHRs hold great promise to enhance access and improve the quality of care provided to patients in rural America. Government, vendors, and insurers should create incentives for providers and patients to implement PHRs. |
| Marshall (2009) | Keeping tabs. How personal health records are changing the face of healthcare | Journal article | Consumer health information | | Stakeholders perspective of PHR adoption |
| Witry et al (2010) | Family Physician Perceptions of Personal Health Records | Scientific article | Primary care | Focus groups | While physicians identified numerous patient groups that could benefit from using PHRs, they also |

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| | | | | | perceived several unique barriers, including the potential of PHRs to facilitate narcotic abuse, low levels of patient computer and health literacy, low levels of patient motivation, and difficulties with PHR and electronic medical record interoperability. Physicians' relatively narrow view of PHR functions and benefits and perception of barriers to using PHRs may restrict widespread support of PHR use. |
| Schoevers et al (2009) | Patient-held Records for Undocumented Immigrants: a Bind Spot. A Systematic Review of Patient-held Records | Scientific article | Primary care | Systematic review | A PHR for undocumented immigrants seems to be appropriate because in most cases there is no other record available |
| Osborn et al (2010) | Patient Web Portals To Improve Diabetes Outcomes: A systematic Review | Scientific article | Primary care | Systematic review | A summary of 26 articles revealed the positive impact patient web portals have on patient outcomes, patient -provider communication, disease management, and access to and patient satisfaction with health care. Innovative and useful approaches included the evaluation of specific components of the PWPs, assessing the impact of PWPs on mediators of health behaviors, such as patient distress, identification of barriers to use, and |

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| | | | | | patient willingness to pay for access. |
| Fetter (2009) | Personal Health Records: Protecting Behavioural Health Consumers' Rights | Journal article | Healthcare consumer technologies. Primary care etc | | Privacy issues concerning use of PHRs |
| Ralston et al (2011) | Group Health Cooperative's Transformation Toward Patient-Centered Access | Scientific article | Healthcare consumer technologies. Primary care | Survey | Patients reported high satisfaction with Group Health which includes access to health records |
| Pringle and Lippitt (2009) | Interoperability of electronic health records and personal health records : key interoperability issues associated with information exchange | Journal article (essay) | Healthcare consumer technologies. Primary care | | Interoperability between EHR and PHR |
| Richter et al (2010) | Changing attitudes towards online electronic health records and online patient documentation in rheumatology outpatients | Scientific article | Hospital | Survey | Attitudes of patients with rheumatic disorders (Internet users and non-users) towards online EHRs have improved |
| Roblin et al (2009) | Disparities in Use of a Personal Health Record in a Managed Care Organization | Scientific article | Healthcare consumer technologies. Primary care | Cohort study | Differences in education, income, and Internet access did not account for the disparities in PHR registration by race. In the short-term, attempts to improve patient access to health care with PHRs |

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| | | | | | may not ameliorate prevailing disparities between African Americans and whites. |
| Chen (2010) | The role of patients in transiting personal health information: a field study | Scientific article | Hospital Primary care | Ethnographic study | The self-managed records provide patients with a strong sense of ownership and control over their own health information. This study indicates that patients can be effective contributors to their own health and suggest the design of health information systems to rethink the role of patients in the healthcare process and shift the responsibility of healthcare to the patients' side |
| Kim et al (2009) | Challenges to Using an Electronic Personal Health Record by a Low-income Elderly Population | Scientific article | Healthcare consumer technologies | Survey | Use was also highly correlated with the availability of in-person assistance. Residents' ability to use the PHR system was limited by poor computer and Internet skills, technophobia, low health literacy, and limited physical/cognitive abilities. Our findings suggest that those who can benefit the most from a PHR system may be the least able to use it. Disparities in access to and use of computers, the Internet, and PHRs may exacerbate health care inequality in the future. |
| DeTora and Linkon (2009) | The New Age of Healthcare Communications | Journal article | Healthcare consumer technologies | | Use, development and resistance to patient portals |

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| Wiljer et al (2010) | The anxious wait: assessing the impact of patient accessible EHRs for breast cancer patients | Scientific article | Healthcare consumer technologies. Primary care | Quasi-experiment | Participants generally found the portal easy to use; however, the perceived value of improved participation was not detected in the self-efficacy scores. Having access to personal health information did not increase anxiety levels. These results suggest that the use of this PHR may be of benefit for informing patients. |
| Roberts (2009) | Personal Electronic Health Records: from Biomedical Research to people's health | Conference report | Healthcare consumer technologies | | The key messages of the conference were: PEHR have the potential to ensure equity, continuity and healthcare quality. Ethical dilemmas are already emerging from the use of PEHRs - largely stemming from our experiences within the UK |
| Miller et al (2011) | Web-based Self-Management for Patients with Multiple Sclerosis: a Practical, Randomized Trial | Scientific article | Hospital Primary care | Randomized controlled trial | We established the feasibility of conducting a randomized, controlled trial using e-PHRs for patient self-management. We did not find that e-PHR-enabled self-management augmented multidisciplinary MS center-based care, possibly because the differences between interventions were not great enough. |
| Frampton et al (2009) | Open Medical Records | Journal article | Healthcare consumer technologies. | | Implementation and users' perception of open medical records |

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| | | | Primary care | | |
| Tuil et al(2009) | Dynamics of Internet Usage During the Stages of in vitro Fertilization | Scientific article | Healthcare consumer technologies. Primary care | Survey | This reflects the patients' need for continued communication and support during the last stages of treatment, a service that IVF clinics traditionally cannot or do not provide. |
| Horan et al (2009) | The Prospective Role of Personal Health Records in Streamlining and Accelerating the Disability Determination Process | Scientific article | Healthcare consumer technologies. Primary care | Literature search | Our research suggests that system wide improvements such as the Nationwide Health Information Network and other such health information technology initiatives could be used to bring benefits to the disability community. |
| Frisse (2010) | Health Inforamtion Exchange in Memphis: Impact on the Physician-Patient Relationship | Journal article | Healthcare consumer technologies. Primary care | | Early evidence suggests a positive impact on patient care and a change in the way providers interact with their patients and on another. Personal health records , consolidated EHR systems, and other alternative models promise to have similar impacts on the way in which providers and patients interact with one another |
| Dixon et al (2009) | Assessing HIE Stakeholder Readiness for Consumer Access: Lessons Learned from the NHIN Trial Implementations | Scientific article | Healthcare consumer technologies | Survey | The conversations identified important concerns that need to be addressed. These challenges include provider workflow, authentication of consumer access , impact on provider- patient communication and consumer health literacy. Developers, |

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| | | | | | <p>policymakers, providers and patients should work together to confront and find solutions to these challenges to achieve the full potential of PHRs in the healthcare system.</p> |
| Goedert (2009) | Keeping Personal Health Records | Journal article | Healthcare consumer technologies | | Confidentiality issues concerning PHRs |
| Groll et al (2009) [112] | Electronic Surveillance of Testicular Cancer: Understanding Patient Perspective on Access to Electronic Medical Records | Scientific article | Healthcare consumer technologies Primary care | Survey | <p>Practicality, meaning of information, patient-physician relationship, risk of recurrence, and role of technology were identified as interrelated factors that frame how patients regard potential surveillance technology. The influence of each factor hinged on its relationship with reassurance—the central predominant factor. Additionally, time since start of surveillance seemed to affect the relative importance of all other factors.</p> |
| Grossman et al (2009) | Information Gap: Can Health Insurer Personal Health Records Meet Patients' and Physicians' Needs? | Scientific article | Healthcare consumer technologies Primary care Insurance claims | Case study | <p>Physicians question (1) the validity of claims data in making treatment decisions and (2) whether accessing these PHRs is worth the disruptions to their workflow</p> |
| Vishwanath (2009) | Using Frames to Influence Consumer Willingness to Pay for | Scientific article | Healthcare consumer technologies | survey | <p>The findings demonstrate the need to carefully communicate the value of a technology to adopters and</p> |

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| | the Patient Health Record: a Randomized Experiment | | Primary care | | suggest the possibility of using frames to spur the diffusion of PHRs. |
| Lahteenmaki et al (2009) | Interoperability of personal health records | Scientific article | Healthcare consumer technologies | Design-prototype | Interoperability, requirements related to exchanging non-clinical PHR information between services |
| Jenkins et al (2009) [119] | Integration of self-management tools in personal and provider e-health records | Journal article | Healthcare consumer technologies Primary care | | Challenges in basic issues such as user characteristics, practice traditions of data ownership and workflow, and financing are discussed. |
| Zeng-Treitler et al (2010) [129] | Can multilingual machine translation help make medical record content more comprehensible to patients? | Scientific article | Healthcare consumer technologies | Case study | Multilingualism of medical terms in PHRs |
| Fernandes-Luque et al (2010) | Personalized Health Applications in the Web 2.0: the Emergence of a new approach | Review | Healthcare consumer technologies | | We reviewed the health applications integrated in Google Health , Microsoft HealthVault and Facebook. We studied the goals of the applications and also the personalized feedback they provided. |
| Wald et al (2010) | Implementing practice-linked pre-visit electronic journals in primary care: patient and physician use and satisfaction. | Scientific article | | Randomized controlled trial, survey | Surveyed patients reported they felt more prepared for the visits and more accurate information about them. More arm 1 versus arm 2 providers reported that ejournals are helpful to patients in visit |

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| | | | | | preparation and would recommend them to colleagues.. eJournal integration into practice warrants further study |
| Simborg (2009) | The Limits of Free Speech | Journal article | Healthcare consumer technologies Primary care | | Integration issues regarding PHRs |
| Walker et al (2009) | Insights for internists: “I want the computer to know who I am” | Scientific article | Healthcare consumer technologies Primary care | Survey | Focus group participants have dynamic ideas about how information and related technologies could improve personal health management. Their perspectives, largely absent from the medical literature, provide insights that health professionals may lack |
| Neupert and Mundie (2009) | Personal Health Management Systems: Applying the Full Power of Software to Improve the Quality and Efficiency of Care | Scientific article | Healthcare consumer technologies Primary care | Review | Integration and interoperability |
| Jones (2009) | The Role of Health Kiosks in 2009: Literature and Informant Review | Journal article | Healthcare consumer technologies Primary care | | A role remains for: (a) integrated kiosks as part of patient 'flow', (b) opportunistic kiosks to catch people's attention. Both require clear 'ownership' to succeed. |
| Balas and Sanousi (2009) | Interoperable Electronic Patient Records for Health | Journal article | Healthcare consumer technologies | | Expectations for PHRs. Interoperability |

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| | Care Improvement | | | | |
| Kahn et al (2009) | What it takes: Characteristics of the Ideal Personal Health Record | Journal article | Healthcare consumer technologies Primary care | | Current barriers to PHR adoption among patients include cost, concerns that information is not protected or private, inconvenience, design shortcomings, and the inability to share information across organizations |
| Ralston et al (2009) | Web-Based Collaborative Care for Type 2 Diabetes | Scientific article | Hospital | Randomized controlled trial | Care management delivered through secure patient Web communications improved glycemic control in type 2 diabetes. Adoption of PHRs |
| Randeree (2009) | EE Exploring Technology Impacts of Healthcare 2.0 Initiatives | Journal article | Healthcare consumer technologies | Review | Technical challenges of adoption of PHRs |
| Brennan et al (2009) | Project HealthDesign: Rethinking the Power and Potential of Personal Health Records | Scientific article | Healthcare consumer technologies | Design-prototype | The project advanced PHR development in two key ways: intensive user-centered design and a development architecture that separates applications of PHRs from the infrastructure that supports them. The initiative also allowed systematic investigation of significant ethical, legal and social issues, including how privacy considerations are changed when information technology innovations are used |
| Sorenson (2009) [161] | Patient portals: survey of nursing | Scientific article | Healthcare consumer | Literature review | It is evident that there is no standard of the scope of functions |

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| | informaticists | | technologies Primary care | | that are essential in the Patient Portals and to date most are only accessible in English. If we are truly moving towards a patient centered focus in health care in a diverse society, we need to design patient portals that tailor these resources to the needs of this diverse population |
| Raths (2009) | Is the bar still too high? | Journal article | Healthcare consumer technologies | | Portal offerings from EHR vendors may be convenient but they could also limit your ability to add features or get data from other systems. Although the ROI on the clinical side is likely to be more qualitative than quantitative, administrative efficiencies should be easier to demonstrate. |
| Henderson and Laughame (2011) | User-held Personalised Information for Routine Care of People with Severe Mental Illness | Scientific article | Healthcare consumer technologies Primary care | Systematic review | There is a gap in the evidence regarding patient-held, personalised, accessible clinical information for people with psychotic illnesses. It cannot be assumed that patient-held information is beneficial or cost-effective without evidence from well planned, conducted and reported randomised trials |
| Brown and Smith (2011) | Giving Women their Own Case Notes to Carry During Pregnancy | Scientific article | Primary care | Systematic review | All the trials reported that more women in the case notes group would prefer to hold their antenatal records in another pregnancy, but |

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| | | | | | there was not enough evidence to determine the effect of women carrying their own case notes on health behaviours such as smoking and breastfeeding and clinical outcomes. |
| Miller et al (2011) | Web-based Self-Management for Patients with Multiple Sclerosis: a Practical, Randomized Trial | Scientific article | Healthcare consumer technologies Primary care | Systematic review | Self-management support is an emerging aspect of chronic care management. We established the feasibility of conducting a randomized, controlled trial using e-PHRs for patient self-management. We did not find that e-PHR-enabled self-management augmented multidisciplinary MS center-based care, possibly because the differences between interventions were not great enough |
| Emont (2011) | Measuring the Impact of Patient Portals: What the Literature Tells Us | Scientific article | Healthcare consumer technologies Primary care | Systematic literature review | Many research initiatives document patient-level measures such as use of patient portals features, user demographics, and overall satisfaction with the portal. A limited number of studies bridge the gap between patient-level measures and long-term outcome measures, including health care quality indicators and operational efficiency. Factors that point to future acceleration of patient portal use and impact measurement include: (1) the need to meet |

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| | | | | | meaningful use requirements; (2) a greater focus on patient- and family-centered care; and (3) increased patient demand for health information technology. |
| Piras et al (2010) | Prototyping a Personal Health Record Taking Social and Usability Perspectives into Account | Scientific article | Healthcare consumer technologies | Design -protyping | We identified three distinct document management strategies (zero effort, erratic, networking) and ‘translated’ them into three design characteristics: flexibility, adaptability and customizability. We argue that the key to such PHR success is its capability to support the existing activities carried out by laypeople in managing their health record. |
| Hoerbst et al (2010) | Attitudes and Behaviours Related to the Introduction of Electronic Health Records among Austrian and German Citizens | Scientific article | Primary care | Survey | Majority of respondents were supportive of the idea of an electronic health record exchange of health-related data between healthcare providers as core functionality of an HER. However many respondents formulated concerns with regard to data protection and data security within an EHR. |
| Heinze and Bergh (2009) | Establishing a Personal Electronic Health Record in the Rhine-Neckar Region | Scientific article | Healthcare consumer technologies | Design-prototype | Vision for the system, technical aspect, status and experience |

