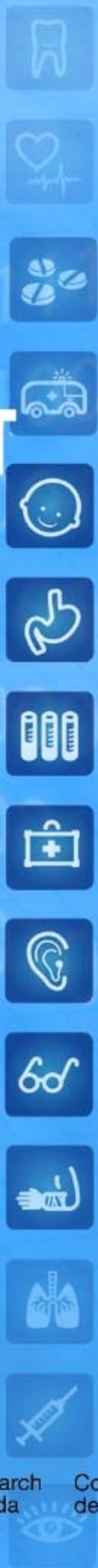

Patient Portal Technologies

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This report is for the Patient Portals for Tertiary Telerehabilitation (PPT) project, a partnership of the National Research Council Institute for Information Technology (NRC-IIT), River Valley Health (RVH) in Fredericton in New Brunswick (now called Regional Health Authority B Zone 3) and the Stan Cassidy Centre for Rehabilitation (SCCR) in New Brunswick. Please do not distribute without permission of the authors. The views expressed are those of the authors, who welcome feedback.

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1. Executive Summary

Patient portal systems enable communication and collaboration between health care professionals and patients, potentially contributing to better patient care. Patient portal technology can empower patients, enabling them to take charge of their own health care. This report defines patient portals and outlines the various types and features, technical infrastructure and security issues and outcomes.

Background

We and our partners - River Valley Health (recently renamed Regional Health Authority-B, Zone 3) and the Stan Cassidy Centre for Rehabilitation (SCCR) - conducted a comprehensive review of literature on patient portals that answered questions such as:

- What types of patient portals are already in existence?
- What features do patient portals typically contain?
- How are patient portals designed?
- What are the core components of patient portals?
- What types of security issues are patient portals vulnerable to and what solutions are employed to ensure patient privacy and confidentiality?
- What are the outcomes of patient portal use?

In our report we define *patient portal* as a secure and highly interactive website that allows people to manage health content and that provides features to foster collaboration between patients and clinicians.

Types of patient portals

Among the many different types of patient portals are: those created by IT corporations, implemented by health companies and national or regional health systems; specialty portals for specific populations; hospital-based portals; portals for specific health conditions; and telerehabilitation portals. The report includes examples for each type of patient portal.

Portal features and applications

Portals differ according to the various features they offer. These features can be customized to meet clients' needs and can include multi-media access to video and videoconferencing, messaging, medical records, medication safety tools, education, eCoaching, eJournals, eVisits, screening, self-assessments, data from monitoring devices, and mobile accessibility.

Additional applications specific to telerehabilitation that could be delivered over a portal include image-based, virtual environments, sensor-based and robotics applications. (For a full list of features, please see Chart 11.2)

Design approaches and technical infrastructure

Although the articles reviewed do not always discuss the design of portals, they describe examples of patient portals using a user-centered or participatory design process. The technologies needed to access patient portals vary to some degree; however the most basic online patient portal requires a desktop, laptop computer, or mobile device with internet access. If video or videoconferencing features are used in the portal then high-speed broadband is necessary. The components of specific portals are discussed, as are the potential security risks of patient portals and their solutions.

Outcomes of patient portals

The largest section of the report reviews the outcome of patient portal use from the perspectives of both patients and health care providers. Outcomes of patient portals, including portal uptake, depend on the demographics of those using the technology, patient and medical professional perceptions and preferences, usage rates, user satisfaction with the portal, and clinical results.

Conclusions

Our analysis of the literature reviewed found that the most successful portals had interactive information and content personalized for the individual patient. Although older people sometimes experienced barriers accessing the internet, when they had access they were more likely to use patient portals, especially if they were dealing with a chronic illness and had a portal specifically for that illness. Patient portals led to a reduction in missed appointments and greater complacence to recommended health regimes, including an increase in preventative screening appointments. Although some studies found an increase in office visits after the implementation of a patient portal, time consuming phone calls decreased due to online booking and messaging on patient portals. The main theme emerging from the literature review is that patient portals are an important supplement to patient care, can empower the patient, and can help support preventative health programs.

2. Introduction

Health care in Canada is evolving into a system that involves the patient while improving the management of costs. A variety of services and applications – such as the electronic health record, adverse drug tracking and e-prescribing – can contribute to a fully integrated system. By linking health care management and available tracking tools through a patient portal, a new health care environment is created in which patients can use the internet to manage their self-care. These systems can enable collaboration between health care professionals and patients, allowing for the exchange of patient information and contributing to better patient care (O'Brien & Duffy, 2008).

This report was written in consultation with the Project Steering Committee overseeing the New Brunswick telehealth project called Tertiary Telerehabilitation Demonstration project. Project leads are River Valley Health (recently renamed Regional Health Authority B, Zone 3), the Stan Cassidy Centre for Rehabilitation, and the Department of Health, Province of New Brunswick.

In 2008 the Tertiary Telerehabilitation Demonstration Project was selected as one of the first national projects to be funded under Canada Health Infoway's Patient Access to Quality Care (PAQC) program. The PAQC program will demonstrate patient-focused clinical management transformation and its impact on timely access to care and reduction in wait times.

The Tertiary Telerehabilitation Demonstration Project will combine the use of traditional telehealth technology (i.e. videoconferencing) and secure web based technology (i.e. patient portal). Combined, these project components will reduce wait times for patients with physical liabilities being served by the Stan Cassidy Centre for Rehabilitation, and will improve access to a range of specialty rehabilitation services in both official languages.

Within the rehabilitation field there is already a culture that fosters independent living. This culture will be further supported through this project by the investment in technologies that support patient empowerment (self-care/self management) and knowledge transfer among primary-secondary and tertiary service providers.

River Valley Health is an integrated network of hospitals and health centres along the Saint John River in New Brunswick, Canada. River Valley Health is a Canadian leader in telehealth. The Stan Cassidy Centre (SCCR) offers tertiary rehabilitation services, inpatient care, and outreach programs to residents of New Brunswick. Patients of the SSCR suffer from spinal cord and traumatic brain injuries, acquired or inherited neurological disorders, upper-extremity amputations, and developmental disorders. The majority of patients at SCCR are being treated for spinal cord and traumatic brain injuries, strokes, muscular sclerosis, progressive neurological disorders, cerebral palsy and spinal cord neoplasm (Stan Cassidy Centre, 2006).

The goal of tertiary rehabilitation is to restore as much mobility and independence as possible to the patient. Patient outcomes are dramatically improved with early intervention through a coordinated and comprehensive care program that addresses physical as well as mental (i.e., spiritual and emotional) needs. SCCR employs an interdisciplinary team of physiotherapists, psychiatrists, speech language pathologists, psychologists, nurses, and support staff (Stan Cassidy Centre, 2006).

The literature search preformed for this report updates and expands upon the information on patient portals outlined in the "Tertiary Telerehabilitation Web based Store and Forward Initiative Project Report," a prior collaboration between the National Research Council and River Valley Health (Meagher, 2006).

The literature review reported here was conducted to answer a variety of questions including:

- What types of patient portals are already in existence?
- What features do patient portals typically contain?
- How are patient portals designed?
- What are the core components of patient portals?
- What types of security issues are patient portals vulnerable to and what solutions are employed to ensure patient privacy and confidentiality?
- What are the outcomes of patient portal use? (for a full list, please see Chart 11.1)

The literature search was performed by NRC-CISTI, Canada's primary institute for scientific and technical information. Databases searched include: Scopus; Web of

Science; Medline; CINAHL; ACM Portal; INSPEC; Compendex; and IEEE Xplore. The databases were searched using a combination of subject terms and keywords including "patient portal" and "telerehabilitation." Truncation and adjacency operators were used where indicated. Terms were searched and then combined using appropriate Boolean operators. Search limits included date range (2004-2009) and language (English and French). A total of 491 unique citations were retrieved and reviewed for their relevance. The full-text of 129 of these articles was then reviewed. During our initial search we discovered that authors used a variety of terms to describe patient portals, so we broadened our search terms to include a variety of different descriptors, including portal 2.0 and PHR 2.0. Finally, article reference lists were reviewed for additional citations and a grey literature search was completed. Grey literature refers to documents that are not produced through commercial publishing (e.g., unpublished government reports, websites, etc.). In total 144 items are referenced in this report.

3. Background

As a result of Canada's aging baby boomer demographic population (i.e., the population of people born in the middle of the twentieth century), the number of people aged 55-64 in Canada rose by 28% between 2002 and 2007, contributing to an important demographic shift (Canadian Press, 2007). As Canada's baby boomer population continues to age, there will be increasing need for more health care services. To address this challenge we are conducting a series of investigations into how information and communication technologies (ICT) could be employed to improve the effectiveness and efficiency of health care delivery. In this study, we and our partners, River Valley Health and the Stan Cassidy Centre for Rehabilitation (SCCR), have conducted a comprehensive review of literature on patient portals.

Patient portal technology has the potential to empower patients by enabling them to take charge of their own health care. The use of patient portals to empower health care patients is a relatively new idea. Patient portals are defined in various ways, as indicated in the definitions section of this report.

In our report, we define a *patient portal* to be a secure and highly interactive website that allows people to manage health content and that provides features to foster collaboration between patients and clinicians. The content within the patient portal is created by both health professionals and their patients, working collaboratively. Patient portals feature a variety of interactive tools that, for example, allow patients to access their health records, schedule clinical appointments, renew prescriptions, create their own library of educational materials, and communicate with their health care professionals through secure e-mail and video.

3.1. Definitions

Patients, health care providers, and users

The term patient is traditionally used to describe a person who is in need of medical care. In this report, *patient* refers to the person who is seeking health services. In some circumstances, patients could more appropriately be called clients of health services because

they use medical services but do not require immediate care. To simplify the discussion, both clients and patients are called *patients* in this report. *Health care provider* refers to any professionals who are involved in the medical care of a patient. These could include a range of health care professionals providing medical services as well as administrative staff. *User* refers to anyone - patient or health care provider - who directly accesses the patient portal.

Portals

Portal is term with many different definitions. In its broadest and simplest definition, when delivered over the World Wide Web the term *portal* refers to "*all human-edited content aggregation that focuses on both organization and personalization of content*" (Alnamo & Marxt, 2007, p. 2). Some scholars and researchers define a portal as an all-in-one site used to access other web pages, like www.google.com or www.yahoo.com (Tatnall, 2007). This type of portal is also known as a *horizontal portal* or *megaportal* because the audience is not limited exclusively to people with specialized needs or interests (Eboueya & Uden, 2007).

Another definition for a portal is a webpage that offers a central access point to all network-accessible content and applications, including extranet and intranets as well as the Internet (Tatnall, 2007). This type of portal is known as a *vertical portal* and grants access to people with particular areas of interest; for example, portals devoted to wine connoisseurs www.wine.com (Eboueya & Uden, 2007).

A more narrow definition of portal is a site that not only acts as an access point for information but also can be customized by users and has features above and beyond the search function (Tatnall, 2007). Sites like http://sympatico.msn.ca/ are portals that display information and allow for user searches. Users can also edit what they see on the page by adding or removing content categories.

Patient portals

One important area of application for portals is in the health care sector. There are many types of health portals ranging from the broader type, which act as an entry point to health websites for the general public, to more narrow types, such as portals used for educational purposes or, even more specifically, portals intended for nurses, general practitioners, or patients (Carbone & Burgess, 2007). Currently, governments, hospitals, and private businesses are interested in how emerging *Web 2.0 technologies* can be used in patient

portals. Web 2.0 technologies such as instant messaging, e-mail, video and videoconferencing enable and facilitate collaboration, social networking and participation.

Patient portals, according the 2007 Canada Health Infoway study, "Strategies for Successful Patient Portals," are online applications that provide access to personalized health content and personal medical record information as well as tools to aid in health management and care (Canada Health Infoway, 2007). According to the Office of the National Coordinator for Health Information Technology (ONCHIT, 2006 as cited in Canada Health Infoway, 2007) patient portals can be described as *standalone*, *tethered* or *integrated*. Standalone portals depend solely on patient input – health care providers do not view or add content to standalone portals. Tethered portals allow both patients and medical providers to view health records and patient data, and integrated systems permit both patients and providers read and write access to the portal (ONCHIT, 2006 as cited in Canada Health Infoway, 2007).

Patient portals can also be characterized by their content and function, according to what data they include and which features they offer. In general, a patient portal becomes the delivery point for all clinical and business information services. People with access to a portal may be able to collaborate synchronously or asynchronously through chat and messaging, forums, threaded discussions, and/or web logs. Users can usually able to customize their own portal environment by activating different tools. Multiple systems can connect to a portal system in order to integrate functions and data. Portals may also feature a single sign-on for access to all features (Divis, Hardie & Luliano, 2007).

Electronic Health Records (EHR) and Personal Health Records (PHR)

In the patient portal literature there is some confusion over the various terms used to discuss health portals and the differences between the actual portal and the features it includes. For example, portals differ from *Electronic Health Records (EHR),* also known as *Electronic Medical Records (EMR),* and *Personal Health Records (PHR).* EHR are usually compiled by a single organization for use by clinical staff (Leonard *et al.,* 2008). Critics note that EHR or EMR systems do not incorporate patients into health care processes (Hess *et al.,* 2006) because the systems are used exclusively by organizations, and patients do not have the ability to access or annotate information in their records. Unlike EHR, PHR are tailored, designed, and sometimes created for and by patients (Leonard *et al.,* 2008). Components that are usually incorporated in a PHR include the names of health care professionals and

facilities, documented physician encounters, lab results, medications, immunizations, family medical history, allergies, health risk factors, alerts, and care plans (Greene, 2007).

EHR and PHR are not necessarily accessed through a patient portal, but patient portals *could* be a secure means for patients to view their EHR and collaborate on their PHR. However, the differences between PHR and patient portals are not clearly identified in some of the literature, so we extended the literature search to include articles related to PHRs that employed communication features. For example, Greene notes that Kaiser Permanente, a large U.S. health care organization, has a PHR that allows members to view their medical records and lab results as well as e-mail their doctor with questions (Greene, 2007). PHRs alone do not allow for secure e-mail, but PHRs delivered through a patient portal may. Although Greene does not identify this particular system as a patient portal, the description of the Kaiser Permanente PHR fits our definition of a patient portal because it allows for some level of interaction between the patient and clinician; Greene's article is, therefore, included in our study. In other articles, patient portals are described as PHR 2.0, or the combination of PHR with the social networking approaches from the Web 2.0 (Eysenbach, 2008). In this definition of PHR 2.0, as in our definition of patient portal, participation and collaboration between the patient and health care provider are key aspects.

3.2. Uses of patient portals

Portals – whether they are developed by public agencies such as governments and hospitals or by private technology service providers such as Google Health, IBM, and Microsoft HealthVault – are developed either to address the needs of the general public, specific populations, or niche markets within the health care system.

In our literature search we uncovered research on portals for the general public as well as for various niche markets, including maternity and children's hospitals. The most common type of patient portal was for patients with specific conditions like chronic illnesses, that is, illnesses or diseases that have lifelong implications such as asthma, cancer, diabetes, and heart disease (Leonard, Casselman & Wiljer, 2008). Researchers estimate that approximately 40% of the general public has a chronic condition.

The need for management of chronic conditions is a strong driver for patient portals. Portals have been created for people managing multiple sclerosis, mental illness, heart disease,

cancer, or multiple chronic conditions (Atreja *et al.*, 2005; Koivunen, Hatonen & Valimaki, 2008; Koivunen *et al*., 2007; Garrett, 2006 Cuggia *et al*., 2006; Leveille *et al*., 2007; Chan & Brudnicki, 2008). The current literature on patient portals for chronic illnesses is highly concentrated in the field of diabetes self-management, and portals specifically for patients with diabetes are heavily featured in the literature (Conley *et al.*, 2008; Grant *et al.,* 2006; Grant *et al.*, 2007; Hess, *et al.,* 2006; Hess *et al.,* 2007; Ma *et al.,* 2006; McKay *et al*., 2001; Nijland *et al.,* 2008; Nordfeld, Hanberger & Timpka, 2008; Tang *et al*., 2003).

We did not find much literature that aligns with our focus on patient portals for rehabilitation. Portals specifically related to rehabilitation are discussed in the body of this report as well as features of telerehabilitation that could be offered through a secure patient portal.

3.3. Core barriers to adoption of patient portals

This report sheds light on the four main barriers to portal adoption, identified by Canada Health Infoway as socio-cultural, economic, technical, and legal. Portals can change traditional health care relationships and roles. Socio-cultural factors, like resistance to change, can act as barriers to adoption. Economic factors surrounding the short- and long-term funding of portal development can also pose challenges. Technical issues, such as interoperability, usability, flexibility, and integration as well as legal concerns surrounding potential breaches of privacy, sub-optimal advice, and medical error, whether real or potential, could also affect portal development and implementation (Canada Health Infoway, 2007).

Some of the socio-cultural barriers are anticipatory; for example, some physicians surveyed in the literature are hesitant to adopt patient portals for fear of being overburdened by the communication aspect of portals, or being swamped with e-mail messages. Others express concerns about patient health literacy levels, potential harm to the provider and patient relationship, lack of access to computer systems and broadband, and confidentiality issues (Whitten, Buis & Love, 2007). However, patients themselves do not seem to be as concerned with these issues, especially confidentiality, even though they should be. Whitten, Buis and Love found that patients were e-mailing their physicians using traditional unsecure e-mail, unaware of privacy and confidentiality issues. As a result, some studies call for better patient education regarding the security issues related to traditional e-mail for communicating with

health professionals (Brooks & Menachemi, 2006). Brooks and Menachemi also found that clinicians who use e-mail generally do not adhere to professional guidelines when corresponding with patients. For example, they found that most physicians did not discuss security or confidentiality issues about the use of e-mail with their patients and rarely documented e-mail in the patient's record.

Recommended strategies for combating these barriers include education, leveraging the demographics of potential users in terms of their needs and involving early adopters, setting and meeting goals, improving communications, and making the portal customizable for user needs (CHI, 2007).

3.4. Benefits of patient portals

Some patients and health care providers fear that patient portals, and the more general push toward online health care, could lead to the deterioration of the health care provider and patient relationship. However, researchers state that if the potential benefits of patient portals are realized, both health care services and relationships would vastly improve (Divis, Hardie & Luliano, 2007).

Portals are convenient and it may be easier for patients to communicate over the portal than in person. Online medical records can be shared between clinics via portals, eliminating the need to transport physical records physically (Silver, 2008).

Portals provide a single secure access point for various tools, eliminating the need to sign onto multiple different systems. Information is easily accessible within a portal through search or navigation tools. Tools such as secure e-mail, bulletin boards, threaded discussion and real-time chat software can be used for communication and collaboration. Portals can, in varying degrees, be customized by the user who inputs data, and some allow users to create content and set application parameters (Eboueya & Uden, 2007). Patient portals provide patients with an inexpensive way to view their medical records privately and securely (Duncavage *et al.,* 2007).

The literature to date indicates that patient portals have the potential to improve management of care, especially for those with chronic conditions, and can lead to greater

compliance with doctors' orders, such as medication routines or diet and exercise regimes (Chan *et al*., 2008; Lindsay *et al*., 2008). Better health management can reduce absenteeism at work through the overall reduction in physician office visits (CHR, 2007). Portals can reduce the possibility of redundant medical services or loss of records, because when patients switch health care plans, hospitals or doctors, their health care information "travels" with them (CHR, 2007). Providing access to educational information about specific medical issue, as well as allowing patients an informal means of communication with their health care providers through secure e-mail are key features of patient portals (Zickmund *et al.,* 2007). Studies demonstrate that patient portals could lead to a reduction in medication interaction errors, since patients can report symptoms to their health care providers through portals (Weingart *et al*., 2008).

4. Types of Patient Portals

There are many different types of patient portals. The general public can access online patient portals such as those created by large IT corporations like Google and Microsoft. Some individual hospitals also grant their patients access to individualized portals. Specialty portals created exclusively for (for example) veterans, survivors of hurricane Katrina, or people within a specific geographic area also exist. Patient portals are popular tools for people coping with chronic illnesses like diabetes and cancer. Although patient portals are not as common for rehabilitation, a few do exist – as do many telerehabilitation applications that could be delivered over a patient portal.

4.1. Public portals created by IT corporations

Large IT corporations like Google, IBM, and Microsoft have entered into the health care field, offering access to PHRs through online portals.

On the Google Health patient portal, users can access a variety of features including a personal health profile where the individual enters demographic information plus health information including weight, height, medications, lab results, allergies, and immunizations. Medical records can be imported into Google Health from select hospitals, clinics, and pharmacies. The site also includes vaccine guidelines, the American Heart Association Heart Risk Calculator, educational health information (articles and videos) and can connect with monitoring devices. An individual enters his or her personal site by using a username and password. Google Health has a health privacy policy stating that it does not sell user information or have financial relationships with those associated with portal features; health information is, however, anonymized and aggregated to create trend statistics which are featured on the website (McCartney, 2008).

Like Google Heath, the My Health care IBM WebSphere portal is a customized site that acts as an access point for patient medical information (Erickson & Diddee, 2007). Microsoft's patient portal HealthVault also allows individual data entry and customization. External devices can be used to monitor and track exercise and health conditions, and web applications store and organize the data.

Health sites created by Microsoft and Google provide free medical storage but have limited integration of medical data; there are various sources of medical data and the sites cannot incorporate all. These systems lack the necessary tools for data that can be actioned (data which can be used for change or improvements); there is a need for not only basic access to data but also means for follow-up. In addition to permitting patients viewing access to records, patient portals need to allow patients to ask questions, schedule follow-up visits, and request prescription refills (KUHN, 2008).

4.2. Portals created by health companies and national or regional health systems

Several types of large patient portals do allow for feedback, communication, and follow-up with health care professionals. Some are meant for a specific demographic and others were created by medical foundations for their own clinics, medical professionals, and patients. Other large-scale portals cover a broad geographic area and people living within that area.

The Palo Alto Medical Foundation (PAMF) patient portal is offered to clinics and patients in the Camino Group, Palo Alto Medical Clinic, and Santa Cruz Medical Clinic. The web portal has features like office visit summaries, directed educational materials, schedules, and reminders that are important for prevention strategies and for patient motivation. The PAMFOnline system also allows patients to access lab results with annotations from doctors that interpret the results. The use of hyperlinks to definitions is another feature of the PAMF portal, as well as graphs demonstrating change (such as changing cholesterol) that serve to encourage and motivate patients (Tang, 2005).

Similarly, Kaiser Permanente (KP) offers its organization members access to the patient portal HealthConnect Online. HealthConnect facilitates secure messaging (between the patient and physicians, nurses and pharmacists), administrative requests (to update medical appointments and demographic details like addresses and phones numbers, health summaries (medications, allergies), health records (immunizations), visit-related requests (after-visit summary, referral information), and member education materials (Zhou, *et al.,* 2007).

There are also patient portals that target a specific geographic area. The geographic range could cover a broad area, like an entire country, or a smaller area, like an individual state or province. One national portal is Choose and Book – an online booking system used by

patients in the public health system, the National Health Service (NHS), in the UK. The system allows patients to choose the hospital and date and time for their medical appointments, allowing them active involvement in their health care. Patients are given the option to book either by phone or by Choose and Book (Gibbs & Alexander, 2006).

Partners Health Care in Eastern Massachusetts – a delivery network consisting of 9 hospitals and numerous community physicians – offers providers access to medical records that can be shared with patients over the patient portal Patient Gateway (PG) (Wald *et al.,* 2007). Patient Gateway allows patients access to online booking, referrals, and prescription renewals. Patients can also access educational information from the site as well as directions to clinics and hospitals. The site also offers secure communication between health professionals and patients, and a notice is sent to the patient's regular e-mail informing them when a new Patient Gateway message arrives. Studies examining the features of Patient Gateway are cited in section five, including medication safety modules and eJournal functions.

4.3. Specialty portals for specific populations

The KatrinaHealth portal was created to support the survivors of Hurricane Katrina through providing a way for their physicians and pharmacists to remotely access patient records and communicate with other health professionals in the aftermath of the natural disaster. The KatrinaHealth portal is not accessible by the individual patient. In MyHealth*e*Vet (after filling out a form to register), U.S. veterans log on with a user name and password and have access to VA entered information as well as a variety of tools designed to aid veterans in preparing for medical appointments.

Afterdeployment.org, a mental wellness resource for veterans, service members, and military families, is a fully interactive portal that provides educational information, self-assessment tools and interactive stress relieving exercises that include video demonstrations. Registration is not needed to view the port, but in order to participate in online workshops and track progress using the site's *My Data* feature, users need to register. Registration on afterdeplyment.org can be done anonymously (www.afterdeployment.org).

Healthy Texas is a website developed for people in south Texas with low health and computer literacy. It was developed by 40 health organizations, and provides directories,

regional health information and a place for health consumers to communicate with each other. The portal design uses images to welcome and guide people within the portal. The site provides three basic services: providing regional information, a directory of local health services, and perhaps the most unique feature of the site, a space for discussion where users contribute poetry, art, and stories related to health (Moore & Kaercher, 2008).

4.4. Hospital-based portals

Individual hospitals may have their own patient portals. In the literature search we found that a variety of hospitals types offer patient portals, including general hospitals, maternity hospitals, and children's hospitals.

The Beth Israel Deaconess Medical Hospital (BIDMC), a Boston teaching hospital, created the patient portal PatientSite as a secure tool for communication between health care professionals and patients. It also offers features such as allowing patients to request appointments and referrals, renew prescriptions, get educational materials, update their demographic information, and view their test results and medical records. Additional features like eCoaching, screening and medication safety modules are currently under study (see section five for more information on these features).

Several examples illustrate how portals can be used in a maternity setting. The New Mater Mother's Hospital in Brisbane uses a portal to provide teleconsultation access to patients in remote areas (Crowe *et al.,* 2007). In Canada, the Maternity Centre of Hamilton uses a personalized patient portal to educate their patients (Shaw *et al.,* 2008).

Researchers have found that patient portals are also an important means of communication for children's hospitals, helping to maintain connections between family physicians, pediatricians and specialists, and between regular hospitals and children's hospitals. When physicians at the Children's Hospital of Philadelphia (CHOP) expressed dissatisfaction with the referral system, an internet portal was seen as the ideal solution. Alerts were sent when children were admitted and the portal could be viewed in electronic format by physicians anywhere in hospital, which gave referring physicians access to information in a timely manner (Divis, Hardie & Luliano, 2007). The MD Portal of the Lucile Packard Children's Hospital (LPCH), Palo Alto, Calif. was created after one-third of participants in a 2004 survey of medical personnel stated that there was a need for a better follow-up system with the referring physicians (Divis, Hardie & Luliano, 2007).

Some hospital-based patient portals focus on the management and care of specific conditions. My Care Source, a portal created for the Grand River Hospital in Kitchener, Ontario, offers a variety of features for patients and their families who are coping with cancer. My Care Source offers monitoring of symptoms and side effects, treatment plan information, online appointment bookings, personal demographic and health information, a directory of care team members, educational information, a personal diary, and a discussion board. The patient can access the site from home via the internet. The Grand River Hospital also has computers available for patient use in the Cancer Centre resource room.

4.5. Portals for specific health conditions

Patient portals have most often been created for the benefit of patients with chronic illnesses and specific health conditions. A chronic condition is an illness or disease that has lifelong implications. Researchers estimate that approximately 40% of the general public has a chronic condition. Potential chronic conditions include:

- Asthma;
- Arthritis (and other joint conditions);
- Cancer (all forms);
- Diabetes;
- Heart disease;
- Inflammatory bowel disease;
- Kidney disease;
- Liver disease;
- Lung disease;
- Mental illness;
- Muscular disease; and
- Skin diseases (Leonard, Casselman & Wiljer, 2008).

The literature heavily features portal clients with the diabetes (Canada Health Infoway , 2007; Grant *et al,* 2006; Tang *et al,* 2003; McKay *et al.,* 2001; Ma *et al.,* 2006; Conley *et al.,* 2008; Kim *et al.,* 2007; Grant *et al.,* 2008; Eccles *et al.,* 2007). Patient portals built and used exclusively by patients with diabetes include: the University of Pittsburgh Medical Center (UPMC) Chronic Care Model HealthTrak – a portal for diabetes self-management

(Hess, *et al.,* 2006; Hess *et al.,* 2007); Patient Gateway (PG) – a Boston-based portal with a diabetes specific interface (Grant *et al.,* 2006); the IDEATel project for diabetes care of underserved inner-city and rural residents in the United States; the REmote Patient Education in a Telemedicine Environment (REPETE) system (Lai, Kaufman & Starren, 2006); and Diabetescoach – a self-management support program created by Medicinfo, a leading e-Health company in the Netherlands (Nijland *et al.,* 2008). Prototypes continue to be developed, as evidenced by a 2008 study investigating the feasibility of a portal for children and adolescents with type 1 diabetes (Nordfeld, Hanberger & Timpka, 2008).

Portals for people with heart conditions like congestive heart failure are common in the literature, and they often focus on preventative measures. The HeartCare2 website created by Aurora Health Care Systems in Milwaukee is currently in development. Phase one of the project focuses on developing a patient portal for patients with congestive heart failure (CHF) and their home care nurses (Brennan *et al.,* 2006). General heart health portals like "Hearts of Salford" were created in order to motivate people and act as a preventative measure as well as a common space for patients with heart disease (Lindsay *et al.,* 2008)

The University of Pittsburgh cancer center's patient portal, UPMC Care Pages, is available for cancer treatment patients and their friends and family. The site can be used while the patient is in the hospital undergoing treatment and afterwards. The CarePages site is private, free and customizable and includes progress tracking tools and features that allow people to send out updates, share photos, enter information, and communicate on a message board.

In Australia, the Charm Health patient portal was developed for cancer management in Australian clinical oncology practices. The Charm Patient Portal enables disease management and personalized support over the web. Through the portal, clients can view their treatment plans, track and monitor symptoms and side effects, create a health profile for themselves and their families, access scheduling and educational support, and communicate with health care providers (Garrett, 2006).

Curetoday.com is a United States based online website for cancer patients. Portals can demystify cancer and cancer treatment for patients and potentially improve communication

between cancer patients and their health care providers by providing quick feedback (Silver, 2008).

Some portals are dedicated to mental issues. Some mental health issues, like depression, can also be chronic illnesses. Portals related to mental illness were mentioned in our earlier study "Information and Communication Technologies for Assessing and Treating Operational Stress Injury" (Molyneaux *et al.,* 2009). In the U.S., a web-based portal was developed for staff and patients in community mental health clinics in Virginia that are run out of an in-patient psychiatric facility. The portal contained general and comprehensive information of interest to patients hospitalized for mental health conditions (Farrell *et al.,* 2004).

A team in Finland has been studying Mieli.Net (Mental.Net in English), an interactive online service for patients with schizophrenia spectrum psychosis. Miele.Net is aimed at supporting patients' independence and awareness of their own situation. Koivunen and colleagues (2007) describe the portal and indicate that it was designed for use by nurses working in psychiatric hospitals. At the basic level the portal offers educational information for patients about their treatment, information about the level of support available in Finland, and information about patients' rights. At the more advanced level, Mieli.Net includes patient-centred multimedia information (text, audio, figures, photos), a channel for peer support (discussion room, chat room, open internet diary), and an eSupport tool for counselling and support between clients and staff via a question-answer column. Nurses can use the portal to update their knowledge of the illness and treatment. The portal can be used by patients alone or with the guidance of a nurse in the hospital.

The eSchi Project, developed at the Universitat Politecnica de Catalunha in Barcelona, delivers multimedia tools over the internet for schizophrenic patients and therapists. eSchi is an eLearning tool that teaches patients basic cognitive skills (i.e., motion skills and associating stimulus), supports family members and caregivers, and complements the traditional therapeutic process. In the eSchi tool, patient response time to activities is recorded for the therapist to conduct and evaluate the session. eSchi also has a therapists' module that allows them to input patients' personal data, medications prescribed, clinical history, etc. They can also manage the records and configure activities for individual patients (i.e., change the time constraints of activities). The eSchi system was scheduled to be deployed in September 2008, and future work will involve monitoring patients and the social

and networking interactions within the eSchi system, thus researching the impact of the technologies applied to schizophrenic patients. The authors feel that eSchi can improve quality of life for those with schizophrenia while producing measurable results (Freire, Reis & Monguet, 2008).

Portals have also been developed to deal with a variety of chronic conditions. For example, the InfoWell Patient Portal was designed in Ontario to manage chronic conditions like breast cancer, diabetes, and kidney disease through education, access, and support (Chan & Brudnicki, 2008). Likewise, the NeuroBretagne Project – a Regional Health Information Network developed in Brittany (in western France) for health professionals – focuses on the treatment of chronic neurological diseases including Parkinson's disease, multiple sclerosis, and amyotrophic lateral sclerosis (Cuggia *et al.,* 2006).

National portal projects for multiple chronic conditions are currently under development. Based on surveys, approximately one million people in Singapore suffer from diabetes, hypertension, lipid disorders, or stroke. In order to address the strain on health care and to implement an Active Health Management (AHM) program, the National Health Portal (NHP) project was launched. The implementation of the portal will take place from 2008-2011 (Amin *et al.,* 2008).

4.6. Telerehabilitation portals

The main focus of this report is the use of patient portals for rehabilitation. Telerehabilitation is the use of rehabilitation services delivered remotely using technology. Telerehabilitation patients include individuals who either cannot use local services due to degree of impairment (as a result of stroke, Traumatic Brain Injury (TBI), or progressive neurological disorder) or who are in remote locations without access to rehabilitation specialists (Russell, 2007; Theodoros, Russell, 2008). While few existing articles specifically address patient portals for telerehabilitation, several describe applications that could be securely offered through a patient portal. This section of our report will discuss both portals for telerehabilitation and also types of telerehabilitation features and systems that could be offered through patient portals.

One example of a portal for rehabilitation is REHAB-Net (REHAB-NET.com: Das Internet-Portal für mehr Lebensqualität), a portal for German-speaking people seeking information

about rehabilitation services. However the site does not require a secure login or provide access to individualized information. The site features a lexicon for medical terms, a search engine for magazines and other literature related to telerehabilitation, a directory of medical aids, a listing of medical specialists, and an education and training directory (www.rehab-net.com). Another online resource, created in Slovenia, is an anonymous portal for traumatic brain injury, called "Head Up". It is an ad-hoc support group created by "Veterans," a group that meets in person once a month after rehabilitation at the Institute for Rehabilitation in Slovenia. The portal provides information about TBI and a means of communication. It is not meant to replace direct contact with specialists but rather to act as additional support to members and their families (Jenko *et al.,* 2005). Neither of these sites matches our research criteria for being considered a patient portal. REHAB-Net and "Head Up" are two examples of portals that do not allow for customizable features.

With a secure patient portal, individualized health care services can be delivered. For example, when delivered through a patient portal, stand-alone therapy software can be transformed into secure telemonitoring systems. This has been done, for instance, in CosmoBot, a system which remotely links speech therapists to children. Using CosmoBot, therapists are able to remotely monitor children with a wide range of disabilities (e.g., cerebral palsy, attention deficit hyperactivity disorder, autism, and cognitive disabilities) and provide feedback. The system uses a store-and-forward method, where the therapist reviews the child's progress after he/she finishes a session. The telemonitoring system includes an automatic data collection of all activities the child participates in during the session. The data considered useful and relevant (data from the Play and Learn sessions) is sent to the server, which can be accessed afterwards by the therapist. Therapists can tailor the child's therapy based on his/her progress. The portal – an interface for therapists, caregivers, and children – has been developed using Microsoft Sharepoint and Web Part technologies and includes sessional analysis via graphic representations of data, a private online forum for discussion between caregivers and therapists, a display of news and recent developments, and facilities for sharing educational resources such as text, video, and audio files. Future developments will involve live monitoring with videoconferencing systems to support telerehabilitation therapy and a user-centered design evaluation to gather quantitative evidence of the impact of the system on therapeutic outcomes (Parmanto, 2008).

5. Patient Portal Features and Applications

5.1. Portal features

Portals differ according to the various features they offer. Features of a patient portal site can be customized to the needs of the client. For example the HeartCare2 website for patients with congestive heart failure features a HealthTracker for patients to input daily blood pressure levels, food intake, and activity levels, as well as a WeightTracker feature that records weight (Brennan *et al.,* 2006). These features are important for heart health, but may not be needed for all portals or all patients. This section outlines the various features offered by different portals.

5.1.1. Video and videoconferencing

Videos are potential tools for patient portals; they can be used in portals for educational purposes and videoconferencing, and for communications between patients and health professionals.

Store-and -orward (asynchronous) video has been used in a portal for children with asthma. Participants were given the equipment, including a computer mounted digital video camera, to monitor their inhaler technique and peak-flow meter. The portal provides the capability for secure digital video uploads. Videos were recorded and loaded on the site to be viewed by the case managers, who scored them and sent e-mail instructions back to the children and their families. Videos were supposed to be sent twice a week for the first six weeks, then once a week thereafter. Although excellent outcomes were reported, researchers were disappointed that only a third of the anticipated videos were uploaded. The authors note that, over time, interest in the site declined steadily (but that interest in the intervention dwindled regardless of the medium) (Chan *et al.,* 2008).

The Health Technologies Knowledge Transfer Network (HT KTN) was implemented in the UK in 2006 to bring together professionals in the medical technology and health care communities through an internet-based communications portal (www.healthtechktn.com) – a site featuring customizable conferencing and information, including accessible

presentations (saved video) and a clinicians' forum designed to facilitate collaboration (Ansell, 2007).

The health portal "Hearts of Salford" is dedicated primarily to education but also contains a forum where people can discuss their experiences with food and heart disease. Participants were also asked to respond to a video advertisement from the British Heart Foundation – a video which generated a lot of discussion in the patient portal forum groups about healthy living (Lindsay *et al.,* 2008).

5.1.2. Messaging

Messaging between patients and physicians is a feature offered by a few portals. While patient acceptance is generally very high, physicians are generally hesitant to embrace this aspect of portal functionality (see perceptions section).

5.1.3. Records

Most of the portals mentioned in the literature review offer some form of patient record and are integrated to some extent with an EHR or PHR. Some portal records are entered by the patient while others are medical records uploaded from a clinic or hospital.

5.1.4. Medication safety

Using patient portals, medication lists can be made available online. However, just having the list available for patients to view does not necessarily increase accuracy and efficiency of care. Patient Gateway is a delivery network that includes four rehabilitation and long-term care facilities, five acute care hospitals, and a large network of specialty and primary care physicians. The Patient Gateway Portal has many features including a medication module, a type of journal devoted to medication regimes, side effects, refills, etc. Within the medications module, patients are asked if they are having difficulties with medication adherence. Patients are able to chose from a list of reasons for non-adherence (problems with refills, forgetting, cost), if they are having side effects (if so what type, duration), and whether or not they think the medication is working. Physicians can review a patient's journals during the patient's visit. The authors' preliminary findings indicate that a medications module could potentially improve medication safety, but patients and physicians need to first be educated about the importance of communicating medication discrepancies (Schnipper *et al.,* 2008).

Investigating the efficiency of Patient Gateway (PG) in maintaining more accurate patient medication lists, researchers compared medication lists from patients using PG to those who did not have access to the portal. Patients using the portal were able to view the list of medications they take and e-mail any changes to their physician; however by the end of the study the accuracy of the medication lists of both the intervention and control groups remained the same. Greater accuracy of medication lists was not associated with patients' ability to view their own medication lists because the e-mail system used to alert physicians of changes to medication routines (prescription and over-the-counter) was not effective. One potential solution is to have patients annotate their own medication lists, allowing physicians to view the information and click a button to update the new information (Starselsky, 2008; Schnipper, J.L., *et al.* 2008).

The MedCheck system – used over the PatientSite patient portal – sends patients a secure e-mail (notification to check secure site over traditional e-mail) 10 days after they fill or refill a prescription. The system asks if they are experiencing any medication-related problems and forwards their response to the physicians. In a random sample review study researchers found that most patients checked their message within a day of it being sent. Most patients responded over PatientSite except three who telephoned or booked appointments; clinicians and clients responded promptly and identified problems with medication & adverse drug events (ADEs). There were 21 cases of ADEs – one of which was a serious preventable case (Weingart *et al*., 2008).

The researchers discovered several outcomes of the MedCheck system intervention. There was no difference in number of calls or clinic or emergency room visits by patients who responded to the MedCheck compared to the patients who did not respond. MedCheck responders exchanged more PatientSite secure e-mails with their clinicians than non-responders. In essence, the MedCheck system maintained a continuation of the clinical experience, leading to easier and more efficient follow-up. The researchers state that automatic messages could allow for earlier detection of ADEs and timely intervention. The usefulness of this approach depends on perceived value, user friendliness of the system, and the e-literacy and enthusiasm of clients and clinicians (Weingart *et al.,* 2008).

5.1.5. Education

Many portals offer a search engine or links to educational material. Some portals personalize educational material to the individual users – for example, the Diabetes Information Profile (DIP) portal, which customizes educational material for its individual users. DIP contains information about the individual's diabetes-related situation, his or her information browsing history on the portal, the individual's information preferences, quizzing history, and agenda generation. The information services and patient responses to the quizzes are used to tailor information by filtering the information the patient needs to know (according to their specific condition and health literacy level) and prioritizing it for viewing. Patients and information items are categorized into three levels according to the patient's health knowledge (level one is basic information for patients who know little about diabetes, level three is high level information about diabetic complications). The program is implemented through a portal that also contains services for patients and providers to view and edit Electronic Health Records and computerized forms (Ma *et al.,* 2006).

5.1.6. eCoaching

eCoaching occurs when a patient has access to educational information and worksheets as well as a health care professional (usually not a physician) who monitors his or her work and provides patient coaching. PatientSite investigated a new intervention that allows patients to interact with a nurse through an e-Coach function of the PatientSite portal. Responses to the e-Coach were positive (Allen *et al.,* 2007; Allen *et al.,* 2008).

Patients taking part in this intervention tested positive for at least one of the following conditions: depressive symptoms; chronic muscular pain; and difficulty with mobility. The eCoaching component did not diagnose conditions. Initial messages from the eCoach provided some information about the condition and a link to a personalized worksheet within the portal, which patients were encouraged to fill out and bring with them for their next scheduled appointment. The eCoach inbox was monitored by two clinic nurses who responded using edited response templates (to ensure consistency in responses). The authors found that 35% of the 121 participants sent e-mails to the eCoach before their next appointment, 88% of whom requested further coaching (Allen *et al.,* 2007; Allen *et al.,* 2008).

5.1.7. eJournals

eJournals allow patients an online space to record how they are feeling (physically and mentally), what prescription and over-the-counter drugs they are taking and if they are experiencing any possible drug interactions. In Boston, patients enrolled in Partners Health care can access the Patient Gateway (PG) web portal. A subset of patients using Patient Gateway was enrolled in the Prepare for Care study, where they were able to submit online pre-visit health journals to the PG portal to track their own care. After their scheduled visit with their physician they were asked to complete an online survey to report their experience with the eJournal and their physician visit. Analysis found that 637 of 976 invited patients responded to the survey. Half of the respondents discussed the information in the journals with their health care provider and 52% noted that the journal helped improve communication with their physician; 66% of those who did discuss the journals with their physicians felt they were able to give their clinician more accurate information and they were more prepared for their visit. The study found that 67% of respondents reported interest in submitting journals for another visit, and 80% of those who discussed their journals with their clinicians reported intent to do so again. Only 54% of those who did not discuss the journal during their physician visit reported willingness to do so in the future. The authors note that patients who discussed the journals with their clinicians were more likely to see the benefit of the journal (Buckel *et al.,* 2006).

5.1.8. eVisits

eVisits occur online when a patient requires extensive consultation with a health care professional, generally a clinician or a physician. These could potentially take the form of desktop videoconference, recorded video, synchronous messaging, or e-mail. eVisits over patient portals were conducted over the patient portal Patient Online (POL) in Dartmouth-Hitchcock, a multispecialty practice in northern New England. The regular POL functions (online booking, clinical messaging, etc.) were extended to allow for eVisits - a direct e-mail based discussion with a clinician for non-emergency use, available for a fee. Through this system, the patient requests an eVisit with a provider they have seen in the past. The clinician decides over secure e-mail to accept (or not) and responds to the patient's message. When finished,the eVisit is documented, given a code, and processed (through the patient's insurance billing system). The researchers note that nine physicians in this practice have conducted eVisits and report positive experiences. The most common reasons for

eVisits include follow-up for chronic conditions (depression, diabetes, anemia, and hypertension) and for episodes of chronic conditions (sinusitis and back pain) (Walters, Barnard & Paris, 2006).

5.1.9. Screening

Patient portals are not just an efficient means of providing patients with access to their medical records and communicating with health professionals; armed with the right applications, portals can also be used to screen people for potential illness. In a 2007 survey, 981 PatientSite users participated in an online survey screening for the following chronic problems: chronic pain, mobility difficulty, and depression. Researchers found that the portal screening tool efficiently identified chronic conditions prior to their scheduled primary care visits (Leveille *et al*., 2007).

5.1.10. Self-assessment

Patient portals can be useful for patient self-monitoring and self-assessment. The IowaPHR portal, for example, contains interactive self-assessment tools as well as patient demographic information, lab and diagnostic test results, and medication and immunizations lists (Lee, Delaney and Moorhead, 2007).

Tools within CONNECT, a Norwegian patient portal, include Choice, an assessment tool for patients to self-report problems and symptoms. Choice asks questions using branching logic and generates a summary report that ranks symptoms by priorities for care. Other features include tailored self-management support where the patient's reported symptoms lead to a display of self-management activities which can be printed out or added to a care plan (Ruland *et al.,* 2008).

5.1.11. Data from monitoring devices

The Cleveland Clinic Health System's patient portal, MyChart, is being developed to include and handle data from in-home devices. Patients with congestive heart failure, diabetes, and hypertension need to take daily readings on digital devices like weight scales, glucometers, and blood pressure monitors. If the readings are within normal range the physician will review the patient's readings once a week, but if ranges are at critical levels then the patient can be seen right away. Goals of future studies include investigating the system over a longer period to chart measurable improvements in clinical outcomes (Raths, 2009).

5.1.12. Mobile access

Acknowledging the fact that wireless communication technology is ubiquitous and most adults and youth have cell phones, researchers in Korea designed a diabetic management system based on short message services (SMS) technology. They developed a knowledge matrix based on information on diet and exercise in the Korea Staged Diabetes Management Guideline. Through an automated algorithm the knowledge matrix was used to generate messages sent over cell phone SMS to the patients. The researchers also developed a dual functioning glucometer/pedometer device that automatically transmits data when connected to the patient's cellular phone. On a website, patients are also able to record their exercise and diet regime. Eighty people with type 2 diabetes were divided into intervention and control groups to study the impact of this system. Participants' blood pressure and biochemical profiles were measured at the start of the study, and again at 12 weeks into the study. Thirty-five participants in the intervention group and 36 in the control group finished the study. The intervention group participants recorded blood glucose levels more often than participants in the control group and their calorie consumption decreased significantly as did their body weight. The control group displayed no changes in body weight. The researchers found a reduction in the A1C (a test measuring the average blood glucose level over a 3-month period) in the participants in the intervention group but not in the control group. There was no difference in total cholesterol, Low Density Lipoproteins ("bad" cholesterol) and High Density Lipoproteins ("good" cholesterol) and triglyceride (a form of fat in the bloodstream) in either group (Kim *et al.,* 2007).

Some patient portals allow viewing and data entry over mobile devices. For example, there is an extension to the CONNECT portal (Care Online: Novel Networks to Enhance Communication and Treatment), which allows for mobile functioning, including database access, symptom registration, and dissemination of educational resources (Ruland *et al.,* 2008).

5.2. Telerehabilitation applications

While our literature search found few portals designed specifically for rehabilitation, there are various applications used in telerehabilitation which would be delivered securely over a

patient portal. These applications can be classified as image-based, virtual environments and sensor-based (Russell, 2007; Theodoros & Russell, 2008).

5.2.1. Image-based

Image-based telerehabilitation via videoconferencing technology is used in many applications for telehealth for assessment, therapy, and management of patients (Russell, 2007). Videoconference has been a standard technology in telemedicine since the 1960s, and was first described in telerehabilitation literature in the early 1990s (Molyneaux *et al.,* 2007). Telerehabilitation, compared to other areas of telemedicine, is just developing. Videoconferencing is widely used for telerehabilitation consultations; it has been further investigated for its use in supporting general physiotherapy, seating and wheelchair evaluations, neurological physiotherapy and the treatment of patients with spinal cord injuries. Interventions via videoconference technologies have also been evaluated in the fields of wheelchair prescription, prosthetics, foot care, gait problems, and communication disorders. More recent studies have investigated the use of videoconference for stroke rehabilitation programs. Tools to measure patient performance can also be added into videoconferencing systems. Researchers from Queensland Australia, for example, developed a PC and videoconference-based system that incorporates tools to optically measure physical performance (muscle strength, range of motion, gait) (Theodoros, Russell, 2008).

H-CAD/HELLODOC

The European Commission sponsored H-CAD project was designed for patients affected by traumatic brain injury (TBI) stroke or multiple sclerosis (MS). H-CAD allows patients to perform their rehabilitation exercises at home while monitoring their performance and transmitting data to their therapists and allowing for videoconference feedback (Zampolini *et al.* 2008).

The home care activity desk (H-CAD) system was extended into the "Health care service linking telerehabilitation to people with disabilities and clinicians" (HELLODOC) project, a 24-month European project that ran from March 2005 until February 2007. HELLODOC was created in order to extend rehabilitation supervision to the patient's home, and contained an in-hospital server and a portable unit (based on the H-CAD system) for the patient's home. The pilot study determined high overall levels of satisfaction amongst patient and therapist

groups. The system was found to be as effective as the traditional forms of care (Zampolini *et al.* 2008).

The clinical effectiveness of the home activity care desk (H-CAD) used in HELLODOC was investigated in a 2007 study. Patients with traumatic brain injury, multiple sclerosis, and stroke were recruited for the study. Eighty-one patients were recruited, of which 55 received the H-CAD intervention and 26 in the control group received regular care. For the patients in the intervention group, the intervention consisted of one month of usual care followed by four H-CAD training sessions and one month of the H-CAD intervention at home. During the H-CAD intervention, each patient averaged one 30-minute training session a day for a minimum of five days per week. The sessions featured upper-limb exercises whereby the patient would perform functional activities for grasping, reaching, holding and finger dexterity. The intervention also included a weekly scheduled videoconference meeting between the patient and therapist. The findings of the clinical trial demonstrated, through an active control equivalence study, that the intervention method featuring at-home therapy via the H-CAD system was at least as good as usual care for arm/hand functioning. Participants and users were also surveyed. Forty-five patients and 48 therapists responded and, in general, respondents were satisfied with the ease of use of the system (84.4% and 83.3%, respectively), and reported high acceptance rates (66.7% and 85.4%, respectively) and general opinion of the system (77.8% and 68.8%, respectively). Patients and therapists were less pleased with the difficulty of the tasks (57.8% and 62.5% satisfaction rates, respectively) and the aesthetic aspect of the H-CAD system (42.2% and 58.3%, respectively). The researchers concluded that the H-CAD system is a good alternative to regular care for the rehabilitation of TBI, stoke, and MS patients. Using the system, patients can receive therapy at home and increase therapy time while decreasing therapist time and effort (Hermens *et al.,* 2007).

UNB/SCCR

With the use of videoconference technologies clinicians can, from a distance, identify and address problems in their clients' homes and communities. Hughes *et al.* (2003) studied delivery of rehabilitation services using videoconference by the Institute of Biomedical Engineering (IBME) at the University of New Brunswick (UNB), the New Brunswick Easter Seals March of Dimes (NBESMOD), the Stan Cassidy Centre for Rehabilitation (SCCR), and by community-based therapists. Equipment included PCs with Microsoft NetMeeting version

3, webcams, and headsets. To ensure greater security, stand-alone computer systems were used with antivirus software. The NetMeeting software option for remote desktop sharing was disabled. Client privacy issues were complex, as video sent and received using NetMeeting software is not encrypted. Consent forms detailing the risks were produced, and clinicians learned about potential privacy risks during training. Equipment applications included video communication, remote troubleshooting for rehabilitative services, viewing rehabilitative equipment, remote assessment of clients, and remote follow-up (Hughes *et al*., 2003).

During the study period (18 months) 32 videoconference sessions took place, and 60 of the questionnaires that were given to all participants were returned (94% response rate). Video communication was used most often , followed by remote troubleshooting for rehabilitation services, and viewing of equipment. Patient and clinician responses were grouped. Reponses from the surveys indicate that the equipment was easy to use and people were comfortable using the system. Only 5 of the total 60 respondents felt that the session completely replaced a clinic or outreach visit, but only one felt that the videoconference system did not replace a visit. Most participants believed that the session partly replaced a clinic or outreach visit, indicating that the system could help assist current programs, but should not necessarily be viewed as a complete replacement for clinical visits and outreach programs (Hughes *et al*., 2003).

Using videoconference (VC) technology to view rehabilitation equipment was important – for example, in one case of remotely viewing a wheelchair, clinicians found that it needed different footrests, higher hand breaks, and a higher push bar (for parents to push the wheelchair). A troubleshooting application allowed local therapists to work with specialists remotely. The videoconferences also allowed non-verbal patients various means of communicating with clinicians via letter boards, physical expressions and gestures or verbal communication with the aid of computer-based voice output.

There were a few challenges encountered with the use of this system. Issues with the system identified in the study included problems with equipment stability – e.g., if the clinicians or patients lost the video during a conference they had to reboot the computer. Clinical assessment conducted remotely proved more challenging, as several people needed to participate at each site and the systems were best suited for one-on-one communications

(Hughes *et al.,* 2003). Videoconferencing equipment and internet connection speeds have greatly improved since Hughes' 2003 study (Molyneaux *et al.,* 2007); however desktop videoconferencing is still best suited for individuals or small groups connecting from each site.

Durfee and colleagues (2007) compared remote and co-located assessments conducted using both broadband video and audio for the following clinical evaluation instruments: Berg sit-to-stand; Berg forward reach; manual muscle test (MMT); joint range-of–motion (ROM); and timed up and go (TUG). Recruited subjects played the roles of patients, and simulated impairments to mimic the rehabilitation clinic populations. Durfee *et al.* found that the audio link was critical for communication between patients and therapists, as well as a one-way video link for therapists to monitor the actions of the patients. Videoconferencing was the main technology used in the study and the researchers note that the quality of the videoconference would be important for remote assessments done in the home, especially if the home does not have broadband access. Other technology that could be used in the assessments include measurement instruments like pressure sensors to detect the start and end of the TUG test, or a digital dynamometer to measure resistance – a element used to calculate the MMT score (Durfee, Savard & Weinstein, 2007).

5.2.2. Virtual environments

Virtual environments use computer-generated surroundings to encourage patients to complete specific motor responses. Virtual environment systems vary in range and complexity from computer-generated environments to head-mounted devices (Theodoros & Russell, 2008). More immersive virtual reality systems (VR) are possible with the use of head-mounted displays and haptic feedback units to create environments specialists can manipulate; however, the use of more immersive environments, such as VR, does not necessarily generate better outcomes. Studies on VR in telerehabilitation use small sample sizes and more work needs to be done to investigate clinical outcomes of the use of virtual environments (Molyneaux *et al.,* 2009; Simms *et al.,* 2009). As technology costs decrease VR systems may become more practical telerehabilitation options (Russell, 2007).

Virtual reality is starting to be used in rehabilitation fields including stroke rehabilitation, balance training, and training for functional activities for daily living. Research findings concerning the effectiveness of VR in these capacities include the following: people with

disabilities can learn motor skills within virtual environments; while few studies compared motor learning in virtual reality to the real world, many of the movements learned in virtual reality can be transferred to real world tasks; no occurrences of "Cybersickness" were reported. Advantages of VR-based image-based telerehab applications include online data access, flexibility and adaptability of treatment, increased patient motivation, and reduced medical costs; challenges include lack of infrastructure support, expense of equipment, lack of clinician training, and patient safety concerns (Zampolini *et al.* 2008).

The Shared Virtual Rehabilitation Room (SVRR)

Offline remote monitoring (store-and-forward and video-based systems) have been used for virtual reality environments for telerehabilitation. Utilizing internet connections, telerehabilitation can be monitored by therapists in real-time through a portal. Popescu and colleagues (2002) discuss the Shared Virtual Rehabilitation Room (SVRR), a virtual environment application where both patients and therapists can interact with shared objects. The therapist interface is a Java3D applet. Using this, the therapist can start a videoconferencing session, collect data on the patient, or start a therapy session with a variety of customizable options regarding the force level of the therapy. In this application the patient site has limited interaction capabilities, aside from the ability to start a videoconferencing session (Popescu, Burdea & Boian, 2002).

Several telerehabilitation experiments were conducted with different set-ups to examine the application of the technology for teletherapy (hand rehabilitation exercises), telediagnosis (real-time session where force, angle, and range of motion data is collected for use in diagnosis), and telemonitoring (observation of the patient's exercise in the shared environment by the therapist). In tests of the equipment, the monitoring server was located in New Brunswick, New Jersey while patient stations were in Newark, New Jersey. Advantages to this system include the flexibility offered to the therapist – any computer with internet can be used, and therapists can observe multiple patients at the same time through different windows (either switching between different windows or viewing more than one at the same time on the screen - minimized) (Popescu, Burdea & Boian, 2002).

5.2.3. Sensor-based

Sensor-based technologies employ various kinds of equipment used to measure movements, including accelerometers, gyroscopes, and tilt switches. Pilot studies of sensor-based

equipment have found the devices suitable for in-home use but due to the high costs of systems, sensor-based technologies are not integrated into conventional telerehabilitation programs (Russell, 2007). Sensor-based devices have varying levels of complexity from the SmartShirt (real-time biometrics) to the electronic pedometer. The problem is sorting and analyzing important data – the process of data mining. Two general categories of sensors include position-sensing (pedometers, goniometers, gyroscopes, accelerometers), and electromechanical switches or pressure sensors. These sensors measure orientation change, tracking the motion of limb and body positions, and human movement through space using motion sensing technologies like acoustic, mechanical, electromagnetic and electrostatic orientation trackers. Sensors can also utilize electro-optical and video tracking systems. There has been limited research on the use of sensors and the articles found in the literature search involve small sample sizes (Theodoros, Russell, 2008).

UniTherapy

While patient portals are not explicitly mentioned by Feng and Winters (2007), they discuss a consumer-centred web-based therapy for stoke survivors. The module framework they developed, UniTherapy, is designed for use in home environments and supports various types of assessment and therapy. Components of UniTherapy include: force feedback joysticks and wheels (building on Microsoft's DirectX technology); robotic "assist" and "resist" therapy with feedback for clinicians; interface standards for customization (i.e., user preferences, clinical objectives) supported by the Universal Plug and Play standard and the new ANSI INCITS 389-393:2005 suite of UI Socket/Universal Remote Console standards; and telecommunication and software platforms to support remote site assessment of client functioning and adherence to exercise protocol. Roles are assigned to different users, the therapy designer, the home client (patient), and telepractitioner, and the roles determine what the individual can do within the system. Tasks can be either be self-managed or include interaction between the client and practitioner. Feng and Winters note that their framework has the potential for use in other rehabilitation fields, such as speech therapy. Their article discussed supported devices (i.e., mouse, joysticks, wheels, and force feedback devices) and the service-oriented infrastructure. The article highlights the use of third-party games as add-ins for motivating therapy as well as the communication link between the client and the practitioner that allows for instant messaging (IM) and real-time viewing of performance data (Feng & Winters, 2007).

Morelli and colleagues (2008) describe a hand monitoring/telerehabilitation system incorporating two types of sensor devices (one for measuring finger force and hand posture, the other for measuring the force of the thumb), biofeedback software, and interactive videoconference. Their system was designed for in-home use by post-stroke patients or patients with hand injuries. Interactive software was developed to work in conjunction with force measurement equipment to allow for real time observation of biofeedback and immediate response. The patient's system included a computer, web cam, microphone, and wireless network card as well as a wireless modem – components necessary for interaction with the therapist via videoconference. Remote virtual desktop software was employed to allow the therapist access to the patient's computer and the system also allowed recorded videoconferences. The system was used for telerehabilitation follow-up for five patients recovering from hand-transplant surgery. Patients and therapists found the system effective and user-friendly (although no surveys or specific research data is mentioned) (Morelli *et al.,* 2008).

Bendixen and colleagues (2008) describe the North Florida/South Georgia Veterans Health System's Low Activities of Daily Living Monitoring Program (LAMP). LAMP is a home-based management system designed for combat-wounded veterans experiencing severe and multiple injuries. The authors discuss one case study of a veteran with complete tetraplegia and left transfemoral amputation. Through monitoring and electrical stimulation the participant was able to stay at home rather than be institutionalized.

Videoconferencing and sensors

Telerehabilitation systems allow patients to remain at home and receive treatments run by a remote therapist. Holden and colleagues' (2007) virtual environment (VE) system involved using a computer and two screens for the patient (one screen displaying the VE and the other showing the therapist via videoconference) and using Polhemus sensors to capture upper extremity motion (hand and upper arm). Participants in the study were people who were six months post-stroke and who were discharged for upper extremity therapy with some motor and sensory recovery and able to sit without back support for five minutes or more. Participants also had to pass a screening test to ensure that they did not have any visual or perceptual problems that might interfere with the outcomes of the study. Those with electronic implants, unstable seizures, severe pain, or a cerebella or bilateral cerebral

injury were excluded. Informed consent was signed by all participants (Holden, Dyar & Dayan-Cimadoro, 2007).

Patients learned by imitation – that is, they copied performed motions. The therapists controlled the session by controlling the speed of the motions and what was shown on the interface (sounds and text). VE training was delivered in one-hour sessions, five times a week (30 sessions in total). Sessions were interactive and real-time, with the therapist located at the MIT Clinical Research Center. Training was designed to improve movement control, a common issue with stroke patients, and included exercises like moving the hand away from the body, grooming and dressing movements, repeated reciprocal motion, and hand control (wrist movements and the force of the patient's grasp and release). Evaluation tests were administered in-person during screening and then during the post-test session to compare motor recovery scores based on Fugl-Meyer UE tests (FM). The authors found clinically and statistically significant findings for patient improvement (changes at the 15th session and 30th session marks were statistically significant; however the study had a small sample size, no control group, variability in the technology in the home set-up, and was limited by lack of haptic feedback). The study indicated that remote VE training could be used for neuro-telerehabilitation. Also researchers found improvements as a result of the one-hour sessions which were longer than the usual time allocated for traditional in-person sessions. This may indicate that greater improvements could occur due to longer therapy sessions), suggesting that perhaps people recovering from stroke are not being treated for long enough periods in each single session. Future developments include providing a view of force feedback to the patients (currently visual feedback of the force exerted by the patient during an exercise is only available to the therapists) (Holden, Dyar & Dayan-Cimadoro, 2007).

5.2.4. Robotics

Home-based rehabilitation for stroke survivors involves the therapist overseeing patient performance and care. Telerehabilitation can provide patients with tools for regular contact with the therapist and monitoring of therapy. Furthermore, researchers hypothesize that collaborative play is important for stroke survivors to engage and connect with others. Johnson and colleagues (2008) investigated tele-cooperation and tele-therapy using two 6DOF robot-mediated environments (a robot arm with 6 degrees of freedom in its movement) to pilot a telerehabilitation protocol. In this study Johnson *et al.* found a trend in

favour of the collaborative robot-mediated environment where patients play against each other – their survey respondents found it more interesting and engaging than telerehabilitation with just the computer program (Johnson, Loureiro & Harwin, 2008).

Eighteen healthy subjects form the University of Reading School of Systems Engineering played a game of tic-tac-toe against a computer in phase one and against a human being connected to a Haptic Master robot (a robot that records position, force, and velocities of movements while the client plays the game) across a remote connection in phase two. Each participant played three games against the computer, three against a remote player using an audio connection, and three games against a remote player supported by both an audio and visual connection to their opponent. Participants then filled out a preference survey. Most respondents (66.6%) preferred the human opponent supported by both audio and visual connection because the games were more interactive and fun – like playing a game across the table from an opponent. Eleven percent of participants noted a preference for the computer interaction because of the ability to play at any time. The final 16.9% favored audio only because they felt it was less distracting that both audio and video. About 83% of participants also noted they would be motivated to play twice as often with an actual person that a computer. Johnson *et al.* found a trend in favour of the collaborative robot-mediated environment, which their survey respondents found more interesting and engaging (Johnson, Loureiro & Harwin, 2008).

6. Design Approaches and Technical Infrastructure

6.1. Design

Although the design of portals was not always discussed in the articles reviewed, there were a few references to the use of user-centered and participatory design.

6.1.1. User-centered design

While involving the patient in participatory methods of design is important when constructing a patient portal, researchers also stated that the portal design needed to meet the needs of the medical professions. Lee and colleagues note that portal design needs to be "*driven by health behavior change theories such as the health belief model, social cognitive theory, and diffusion theory and [should] include more testing strategies, such as methods of gaining attention, tailoring message to individual knowledge and values, demonstrating observable effectiveness, and delivering feedback*" (Lee, Delaney and Moorhead, 2007, p. S313).

Gathering data from health professionals is also necessary in designing a patient portal. Patricia Brennan, Project Director of HealthDesign, noted that nurses are important in the design of portal applications because they work closely with the patients on the portals. She noted that nurses are involved in about a third of the proposals to HealthDesign (Nelson, 2007).

Brennan and Barker (2008) discuss general human factors in developing and implementing telerehabilitation systems. Human factors include the need to design uncluttered interfaces to minimize distractions, and alternative education methods to ensure patients understand informed consent issues and tasks and procedures they need to do. In a French study, the main design wish of health professionals was for the portal to have one user-friendly interface for all users (Cuggia *et al.,* 2006).

6.1.2. Participatory design

The Norwegian CONNECT system was developed using participatory design. Clients and clinicians contributed to all phases of design so the different contexts of uses and needs could be understood (Ruland *et al.,* 2008). Likewise, the designers of Patient Gateway found

that engaging patients was critical – the researchers had patients on the expert panel who were directly involved in designing several of the site's features (Wald *et al.,* 2007).

The Canadian InfoWell Patient Portal was designed using a user-centred methodology to gather feedback from patients (Chan & Brudnicki, 2008). The researchers conducted their user-centred design through ethnographic means, gathering feedback through interviews and surveys. Using a card-sorting method patients helped to improve navigation, menus, and content organization of the website. As a result, the portal was both useful (meeting the needs of the users) and easy to use (navigate). Researchers concluded that the card-sorting exercise significantly improved the content organization and that it was essential to observe the patients' interaction with the website directly (Chan & Brudnicki, 2008).

In a PatientSite survey screening for chronic pain, mobility difficulties, and depression there were some browser incompatibility issues – specifically, problems with MacIntosh computers accessing forms (although some Mac users were able to participate in the study and were able to resolve their issues). Researchers found that direct telephone availability helped ease technical difficulties and was really necessary at the start of the study (Leveille *et al.,* 2007).

The architecture of existing portals should be examined in order to learn from them and to maximize repeatability and affordability. Also designers should create interchangeable building blocks for disease-specific portals to maximize interchangeability so that the design of the portal can be utilized for different demographic groups. Portability and interoperability needs to be built into the architecture of portals (Canada Health Infoway, 2007).

Designers need to build the portals to reflect the needs of the individuals. Multidisciplinary teams should be employed during the design process because they can give the holistic perspective needed for portal development. Portals deliver real value to everyone when the consumer is empowered through improved access to care – this in turn reduces isolation while increasing autonomy and improving continuity of care.

6.2. Core components

What kinds of technologies are needed for patients to access patient portals? The answer depends on the individual portal; however the most basic online patient portal requires a desktop, laptop computer, or mobile device with internet access. If video or videoconferencing features are used in the portal then high-speed broadband is necessary (Finkelstein *et al.,* 2006).

Some systems require additional equipment. The portal VALUE (Virtual Assisted Living Umbrella for the Elderly) allows patients access to virtual homecare nurse visits (over videoconferencing), order services, self-monitoring, and general internet access. The VALUE workstation requires videoconferencing technology (two-way video and audio with the virtual nurse at the agency site and the patient at home), broadband access, and a web portal for services and monitoring. The workstation consists of: a PC platform with broadband (DSL or cable); PVX PolyCom videoconferencing software for IP videoconferencing; and monitoring devices as needed for an individual's conditions, such as oximeters, blood pressure cuffs, spirometers, scales and glucometers (Finkelstein *et al.,* 2006).

The Healthcare@home system incorporates various services for diabetes management – for education, communication, and continuous monitoring. The systems grants access to educational materials, links patients to physicians through e-mail, and also includes a wireless blood pressure cuff and glucose meters – all of these features are integrated and delivered via portal technology (Conley *et al.*, 2008).

Core components of most in-hospital systems (as a portal to communication tools, medical records, etc.) include a television, bedside remote control, wireless keyboard, and mouse or touch screen to navigate and select programs. Server PCs then send the content to the television. A pillow-side speaker and control box interfaces with the cable TV system or IP networks, a coaxial or unshielded twisted pair (UTP) network connects to transmission equipment nearby, and centralized head-end equipment is required in the facility's data center. UTP is becoming the infrastructure standard of choice because of the need to leverage existing infrastructure and design new systems able to handle the convergence of video, voice and data streams (Miller, 2007).

6.3. Security

There are many legal and regulatory issues related to patient portals; in particular, concerns over improper use by patients and security, privacy, and confidentiality are highly ranked issues. In the United States, health professionals have raised concerns that portals could violate the 1996 Health Information Portability and Accountability Act (HIPAA) that regulates the privacy of personal health information (Whitten, Buis & Love, 2007). It is important to note, however, that there are security issues with the technologies health care providers and patients currently use. It is common practice for health care workers to use the fax machine, telephone, or mail to communicate with patients and with each other. These communication options are not technically secure (Cuggia *et al.,* 2006).

Articles about patient portals indicate that patient education about security is needed (Collmann & Cooper, 2007; Zickmund *et al.,* 2007). In a 2007 study of patients using a portal for diabetes management, researchers discovered that some patients already used traditional e-mail systems to communicate and did not understand or did not care about the lack of privacy. As a result, patients did not see the increased e-mail security offered by the encrypted portal as an advantage (Zickmund *et al.,* 2007).

Concerns about patient privacy, the prevention of timely access for patients, and the accidental disclosure of information to a third party are liabilities. These problems can actually be resolved through a patient portal (Hess, *et al.,* 2006) that enables more secure access to e-mail and allows for the quick dissemination of information.

There are, however, also potential security issues involved with the use of patient portals. Common network attacks and security measures will be discussed below, as will some of the security measures currently used in patient portals.

6.3.1. Common attacks

Many common ways of attacking data can occur on the internet. Masquerading, the practice of pretending to be another entity to access privileges, can potentially compromise privacy and confidentiality. Unauthorized use of resources can also occur when people gain access to computer systems and resources on the network. Unauthorized disclosure and flow of

information can occur when the flow of stored, processed, or transferred information from a networked system is disrupted as a result of wiretapping or traffic analysis, which can result in unauthorized reading of information over a network. The unauthorized alteration of resources and information occurs in a system when people write into the memory or over networks via active wiretapping, perhaps in combination with other attacks. The unauthorized alternation of resources and information can include removing resources, and can impair integrity of data. Repudiation of actions can also be a concern. This occurs when a sender denies sending information, or a recipient denies receiving information, which could become a threat against accountability. A final common attack is an unauthorized denial of service attack, where an attacker tries to deny others' services by blocking files or network access (Win, Sussilo and Mu, 2006).

6.3.2. Security measures

User authentication through audit controls, privacy and confidentiality statements, password mechanisms, documented secure transmission, and secure messaging are common measures taken to prevent online attacks. The most common security measure is an "identifier" and a "password" – which can be read by debuggers that reverse engineer the binary program code. There is also concern related to the security of the physician's code. In clinics physicians sometimes write down their code and post it in the office, for use by other clinical staff, for example. This becomes a security risk as the code is then seen and used by others. Therefore the Personal Identification Number (PIN) and password-based authentication system is a weak security protection; a PIN is vulnerable to brute force attack and weak passwords can easily be cracked (Win, Sussilo and Mu, 2006).

HTTP protocols employed for web-based PHRs are subject to interference or eavesdropping. In secure websites, a 128-bit encryption makes interference difficult. Firewall and antivirus software can further secure the connection. Smart cards, small cards that process data through embedded integrated circuits which have an individual PIN associated with each card, can also be used to strengthen security (Win, Sussilo and Mu, 2006).

One potential security and trust issue is the lack of visual proofs in some telehealth applications. Multimedia features, like video correspondence, and biometric features, such as face recognition or smart card authentication, are possible solutions to assure patients and

providers that they are in fact corresponding with each other (Liu *et al.*, 2008; Win, Sussilo and Mu, 2006).

Other security measures include the credential system whereby only users with legitimate credentials can access the record; for example, users with credentials can perform signing or decryption to strengthen security (Win, Sussilo and Mu, 2006).

To avoid a denial of Service (DoS) attack, a client puzzle mechanism can be established. In this system a server prepares small digital puzzles for users. If the server detects a DoS attack, it sends the puzzles to the users, gaining time to allocate resources. Also, if the user cannot answer the puzzle, they will not receive the resources (Win, Sussilo and Mu, 2006).

Securing wireless devices is important, and researchers note that the current emphasis on user authentication may not be sufficient. The Advanced Encryption Standard (AES) is needed to secure wireless LAN Encryption schemes; however, this is not a perfect solution. Specific handheld devices or laptops can also be assigned cryptic keys that decrypt specific records which only the owner of the device can access (Win, Sussilo and Mu, 2006).

The next level of security is using cryptographic mechanisms in smart cards or in security modules. Public key cryptography uses a private key for each card. In this system the sender and receiver both need a common key to view or encrypt data. Websites also use a Secure Socket Layer (SSL) connection (now called Transport Layer Security Protocol) which is essentially a connection than encrypts data sent over the internet (Win, Sussilo and Mu, 2006).

Authentication security issues in basic online portals are relatively straightforward. Real time services, like telemonitoring for remote portals, complicate security issues. Real time connections may require direct connections between clients and multimedia servers, but using the multimedia server for authentication is not practical because a copy of the portal user account would need to be stored (which implies too much trust on the server). One potential solution is to set up a Kerberos realm (Lu *et al.,* 2007) – a computer network authentication protocol that allows users to prove identity over a non-secure network through secure software that is protected against eavesdropping.

Another issue is that many telehealth services involve complex processes that require multiple users to access within a variety of different roles (Liu *et al.,* 2008). Role-based Access Control (RBAC) can be used to securely grant access to multiple users. Role-based Access Control is a means to collect and distribute information to authorized users. In patient-controlled portals the patient has control over who accesses what types of information and can grant access rights to others by assigning them a role which grants them permission to access portions of information. RBAC is popular because it is simple and easy to administer; the roles only need to be defined once and can be applied to many users. Also RBAC is flexible and allows users to update permissions, changing the access granted. New roles can be created and assigned as needed, demonstrating the scalability of RBAC. RBAC is useful in a number of scenarios: when patients are moving or changing health care providers; when they are travelling and in need of medical care; to share medical information with friends or family; to grant one-time access for a limited time period; to share in an emergency; when the patient is a infant, child or youth; and to share for research purposes. In all cases users need to be informed (and continually re-informed) of the potential consequences of sharing health information (Rostad, 2008).

Storage of information on the portal is another potential privacy and security issue with patient portals. The Children's Hospital of Philadelphia (CHOP) portal administrator holds information for 90 days before purging the database in order to focus on the most recent information and to keep the database from getting too unwieldy. This particular portal is not a repository and does not replace the medical record (Divis, Hardie & Luliano, 2007).

In the case of children's hospitals, guardians need to give permission for physicians to display and retrieve information about their charges on the portal. In the CHOP portal consent has been built into the registration system (Divis, Hardie & Luliano, 2007).

6.3.3. Patient portal security: examples from the literature review

Researchers Collman and Cooper (2007) state that in order to prevent breaches in the confidentiality for synchronous messaging, health care professionals can use a synchronous collaborative platform in a secured mode. All private medical information should be accessible and shared through the web portal. Secured e-mail is accessible through portals and conventional e-mail should only be used for non-critical information exchange (e.g., education) (Cuggia *et al.,* 2006).

For the NeuroBretagne Project portal, which is used by health professionals, the e-mail solution used was CPSURE solution (edited by Enovacom™) which was approved by the French Professional Health Card – Public Interest Group. CPSURE is a secured e-mail solution that uses open-source software (IMP-HORDE) (Cuggia *et al.,* 2006).

The portal for NeuroBretagne has three access levels, the first of which contains general information and is accessible to the public. The second and third levels can only be accessed by members. The second level contains information – schedules, resources, etc. – while the third level connects to the professional web pages of individual physicians (Cuggia *et al.,* 2006).

Breaches in the integrity of health information can occur at multiple levels, including the architecture of the portal system, as well as resulting from organizational issues. In particular, researchers have examined the security breach of the Kaiser Permanente (KP) integrated health delivery system, which serves more than eight million people in the United States. In 2000, patches to the servers caused the e-mail function to fail. In order to send the outbound messages, programmers wrote a flawed script that concatenated all the messages (joined character strings end to end). Instead of receiving one message, patients and clinicians received multiple messages, causing a breach in the system. Collmann and Cooper argue that the situation began with a technical error; organizational issues, mainly the pressure to clear the e-mail messages in the outbox instead of following standard procedure, resulted in the breach (Collmann & Cooper, 2007).

In the PatientSite model, a system *developed* for secure communication, data is encrypted and password protected. Clients and clinicians need a confidential password to access the system. PatientSite sends an alert message over traditional e-mail to let people know there is a message, with a link to the site – the information in the message is not shown through the traditional e-mail (Weingart, Rind, Tofias & Sands, 2006; Silver, 2008).

For the PAMF portal, security required in the hospital includes an ID name, password, and physical security. When accessing the system off-campus, users need a smart card, a PIN, an ID name, and a password (Tang, 2005).

The Choose and Book system in the UK has several layers of security; access is gained through a PIN and smartcard and the booking is encrypted before it is stored at the central data facility. Upon transmission to the hospital, the data is then decoded (Gibbs & Alexander, 2006).

7. Outcomes of the Use of Patient Portals

The various outcomes of the use of portals, including portal uptake, depend on the demographics of those using the technology, patient and medical professional perceptions and preferences, usage rates, user satisfaction with the portal, and clinical results.

7.1. Portal uptake

In the United States, patients are interested in portals and hospitals and foundations are busy developing their own portals with patient-centered features. Deloitte's 2008 Survey of Health Care Consumers surveyed 3,000 Americans, finding that 60% wanted online access to medical records, test results, and appointment scheduling (Raths, 2009).

Medical institutes that are early adopters of patient portals include Kaiser Permanente, whose portal KP HealthConnect boasts almost two million members, Massachusetts General Hospital and Dana-Farber Cancer Institute's Patient Gateway (30,000 members), and Beth Israel Deaconess Medical Center's Patient Site (also based in Boston – 200 physicians, 40,000 patients) (Silver, 2008).

Portal uptake for the UK Choose and Book is also rapidly increasing, from 80,000 bookings in January 2006 to almost 2,000 bookings per day at the time the article was written in 2006. Twenty-eight percent of NHS physicians use the service along with 90% of acute-care trusts (centres for specialized care). The Choose and Book Service has led to a reduction in missed appointments (which, under the paper system, runs at 10-20%). Cultural, organizational, and local technical issues are delaying complete rollout, indicating a need for change in traditional working practices, and a redefinition of roles. Researchers note the need for strong leadership and careful planning, facilitated by a high quality project manager (Gibbs & Alexander, 2006).

Researchers studying Healthy Texas state that usage is difficult to ascertain. Conservative measures related to tracking unique visitors and visitors over time from December 2006 until November 2007 found 110,951 unique users and 25,274 unique return users. The site has not been used as often as was hoped, but the site has not been officially promoted and needs to be translated into Spanish. Other plans to develop the site (and increase users)

include getting buy-in from local health authorities and public schools as well as implementing greater promotion at regional health and community events (Moore & Kaercher, 2008).

Researchers have also studied the implementation of a patient portal at the Maternity Centre of Hamilton in Canada using a randomized trial of women presenting for prenatal care at or before 28 weeks. In this study, the researchers wanted to evaluate uptake and satisfaction with information shared between health care providers and patients. Eligible participants were divided into two groups, one with access to general health information alone, and the other with access to both the general information as well as their own antenatal health records. Both groups reported high levels of satisfaction with the portal's ease of use and relevance of information. Researchers found that the portal was used more frequently – accessed almost 6 times more often – when personal information was provided in addition to general educational information on pregnancy (Shaw *et al.,* 2008).

The uptake of portals depends on the culture of institutes and the organization and content of the portal. However, user demographics can also be an important factor in adopting portals.

7.2. Demographics

Intended users' access to the basic technology – a computer (or wireless device) and internet access - is critical to the uptake of portals. Studies have found that there are several demographic factors that may affect the use of portals, including age and gender.

7.2.1. Patient demographics

While many health portals that started in the early 1990s collapsed during the dot.com bust, Net-Doktor.at, a Danish company, survived in the Austrian market. Mate (2006) discusses the drivers for the success of the health portal: by March 2006, Net-Doktor was visited by 488,000 users – mostly a well educated population (over 50%) and mainly women (62%) – a demographic group attractive to online advertisers (Mate, 2006).

In a 2006 pilot study of 31 Medicaid beneficiaries in Durham, North Carolina, Lobach and colleagues (2006) investigated interest in internet portals and access to the internet. They found that there was considerable interest in patient portals and that most people in their

study had internet access – many having access to high-speed internet (Lobach *et al.*, 2006). The same study observed that use of a portal within this small sample size (by people without chronic conditions) would be relatively infrequent, with 3% stating they would never use a portal, 32% noting they would use it once a year, 49% of respondents anticipating using such a portal two to three times per year, and only 16% estimating using the portal more than three times per year (Willis *et al.*, 2006; Lobach *et al.,* 2006).

Alder (2006) studied the online web communication capabilities and habits of 239 medical practice patients in Arizona. About 75% of patients had web access; those with the most access to the internet (97%) were 18-29 year-olds. Those aged 70+ had the least access to the internet (56%). Students and employed patients had the highest rates of access (92% and 87%, respectively) whilst retired and disabled patients had the lowest rates of access (66% and 42%, respectively) (Alder, 2006).

Acceptance of telerehabilitation technologies, according to some researchers, is greatest among young patients, while some conditions, like stroke, involve older patients. Varying socio-economic and cultural levels also lead to varying levels of acceptance. In order to overcome low acceptance, devices need to be simplified and made usable for different types of patients, by users with different levels of computer skills, and a by wide age range of users (Zampolini *et al.* 2008).

Patients at the Geisinger Clinic Community Practice sites (41 sites) who were diagnosed with cardiovascular disease, chronic heart failure, or diabetes mellitus were surveyed in order to measure and assess their ability and confidence in managing their own health. In this study, portal users were more likely to be educated, male, and have higher incomes than those who did not use portals; portal users were also more confident in their ability to complete medical paperwork and used the internet more often for health-related activities. According to self-reported measures, medication adherence was higher in the portal user group (Shah *et al.*, 2006).

A study on the diabetes-specific interface of Patient Gateway (PG) found similar outcomes. In Grant and colleagues' (2007) 11-week study involving 115 users, the researchers found that patients consenting to use the PG site were more likely to be white, male, commercially insured, younger, and healthier than the general patient population (Grant *et al.,* 2007).

Researchers investigating the demographics of PatientSite enrollees were an average of 10 years younger than non-enrollees (although 7% of users were 65 years old and above). In general, PatientSite enrollees took fewer medications, had fewer medical problems, doctor visits and hospitalizations than non-enrollees, suggesting a digital divide based on healthy and advantaged enrollees compared to less healthy non-enrollees (Weingart *et al.,* 2006).

The demographics of users of patient portal MyGroupHealth (MyGH), a service of the Group Health Cooperative in Seattle Washington, differ from those found at the Geisinger Clinic Community Practice, Patient Gateway and PatientSite. Women were quicker adopters of the portal than men; most rapid adoption was seen in the 40-69 age group (30% growth in the 10th quarter of the implementation of the intervention); followed by the 18-39 group (22%) and 70+ group (18%). Those in the high-morbidity level and moderate morbidity level were higher adopters (34 and 32%, respectively). The low-morbidity group showed the lowest growth in adoption, at 17% growth by the 10th quarter. Adoption rates were highest in patients who were higher-morbidity, female, and middle-aged. Overall the researchers found that patient adoption varies substantially according to health status and demographics of the user population (Carrell & Ralston, 2006).

Age was not necessarily found to be a barrier to portal access in all of the studies. In a 2007 study of the KP Health Connect Online (a general health portal) users were generally older than the overall KP population. There was also a higher proportion of diabetics and people with other chronic illness in the portal user group than in the general public, suggesting the importance of a patient portal for those in need of chronic illness care (Zhou, *et al.,* 2007). Tang (2005) stated that age was not a factor in user adoption of PAMFOnline, and that older members actually were more frequent users of the system. Tang speculates that this may be because PAMFOnline offers support for the system, including telephone and e-mail assistance options (Tang, 2005).

Similarly, other portals offer telephone support for their older users and users with low computer literacy skills. One example of this is seen in the IDEATel project for diabetes care of underserved inner-city and rural residents in the United States. The REmote Patient Education in a Telemedicine Environment (REPETE) system delivers visual and audio teaching modes over low bandwidth. Telephone support is most commonly used to train

patients on telemedicine units; however it can be difficult to orient users to objects on the screen using telephone communications. The elderly in particular may have difficultly with the computer language used to describe the various elements in the user interface. The REPETE strategy recognizes the importance of being able to monitor the patient's progress visually; it even gives the trainer the ability to remotely control the patient's session. In two one-on-one training sessions both seniors felt the training was appropriate to their comfort level and abilities and that they would be able to use the skills they learned in future sessions (Lai, Kaufman & Starren, 2006).

Oone demographic group was purposely excluded from many portal studies. Currently, the use of portals by teenagers is highly contested. Portals use by minors brings up additional privacy concerns. According to a study on teen and parent reactions to portals conducted at the Palo Alto Medical Foundation, teens do not want their parents to access certain information and want secure means of asking medical professionals questions; however, parents are uncomfortable with that idea. As a result, the Palo Alto Medical Foundation's patient portal PAMFOnline is currently inaccessible to those under 18 years old (Bergman, Brown, & Wilson, 2008).

7.2.2. Health care provider demographics

The success of patient portals depends on use by both patients and medical care professionals. Responding to Weingart and colleagues 2006 article on users of the PatientSite patient portal, Podichetty and Varley (2006) state that the demographics of the physicians using the portal need to be taken into account. In particular they note that web portals are two-way communications and both types of users – physicians and patients – need examination (Podichetty & Varley, 2006). Law's 2008 study examines patterns of internet use by occupational therapists in clinical practice based on 1,382 responses to a survey mailed to Ontario occupational therapists. The majority of respondents were women working in urban areas who noted the top facilitators for internet use were accessibility of a computer at work, a work culture than enables and encourages internet use, and access to technical support. Time to access the internet and concerns about privacy issues were also mentioned. As a result of the survey, Law sees the need for technical training as well as regulatory guidelines for clinical use of e-mail (Law, 2008).

7.3. Perceptions and preferences

Several studies have been conducted asking participants which features they would like to access via patient portal technology. Other studies investigate actual preferences based on examining the usage of portal features. The findings of these studies are discussed below.

7.3.1. Patient perceptions and preferences

Statistics from the 2005 Canadian Internet Use Survey reveal that 56% of Canadians surveyed (age 18+) search for information on specific diseases on the internet. Fifty percent of those surveyed reported searching online for lifestyle information. At the same time fewer people surveyed discussed specific diseases (45%) or lifestyle information (40%) with their physicians. According to a 2008 Ipsos survey, 94% of Canadians think access to their medical history is important, however only 60% report that access to their records is easy. The same survey found that 55% of Canadians self-reported that their medical history is tracked on paper, while 30% stated their medical history is recorded electronically (Juzwishin, 2009). The majority of Canadians believed that medical errors can be prevented through better collaboration among medical professions (93%) and between caregivers and medical professionals (91%). Eighty-nine percent of the participants surveyed stated that they wanted to be more active in their own health care and the health care given to their family members (Juzwishin, 2009). Overall, personalized features were highly ranked by survey participants and portal users.

Patients were recruited from the Endocrinology Department and the Diabetes Centre of The Queen Elizabeth Hospital, South Australia, as end users of the Violet Technology (VT) web portal. In the first study of this portal, participants were asked to complete a baseline questionnaire on their perceptions and preferences of patient portals. They were then asked to enter data into the VT prototype about their own health and then were presented with educational information tailored to meet their needs. The survey was followed with an in-person interview. The majority of participants (81.81%) preferred receiving information tailored to meet their individual needs. A second study also showed strong support for information tailored to individual patients (Ma *et al.,* 2006).

In a study based on an intervention involving patients with type 2 diabetes at three primary care clinics and one practice at the University of Colorado Hospital, Ross and colleagues (2006) discuss the usage of different types of a patient portal. A control group was given communication functions and general diabetes information over a portal, while an intervention group accessed personalized content and a system to set goals and provide automated feedback. The same number of people in each group logged on at least once (83% and 84%, respectively) but, over time, the intervention group used the portal more frequently and for longer periods of time than the control group; 39% of the participants in the intervention group set health improvement goals, 42% reviewed the results of their labs, and 30% examined clinical notes. More substantial usage was seen in the intervention group, which offered personalized and interactive content (Ross *et al.,* 2006).

In surveys of non-portal users, and in studying the actual usage of existing portals, patient preferences for portal features can be measured. Alder (2006) discusses the willingness of patients in his medical practice in Arizona to pay for online services, based on survey data. The top three rated services (in order) for those with internet access were: e-mail with physicians (34%); viewing medical records (22%); and medication refills (11%) (Alder, 2006).

In a 2005 study Tang and Lansky surveyed people on their preferences for access to various portal tools; the majority of respondents demonstrated a preference for having appointment reminders and scheduling available online, direct e-mail to physicians, access to test results and electronic medical records, and the ability to send self-monitoring reports to their physician (Tang & Lansky, 2005 as cited in Canada Health Infoway, 2007). Similarly, in a 2004 study, researchers found consumer interest in viewing medical history, recording appointments and medications, viewing lab results, and self-reporting online (Angst & Agarwal, 2004 as cited in Canada Health Infoway, 2007).

PatientSite studies investigated the use of features in April 2003 and again in March 2004. In the April 2003 study, the most popular "hits" were, in order: lab and radiology results; prescription renewals; appointment requests; referrals; and clinical messaging. In the 2004 study, radiology and lab reports and e-mail messaging were the most accessed features (Weingart *et al.,* 2006).

In a pilot study of Medicaid beneficiaries in Durham County, North Carolina, researchers asked subjects about their degree of interest in various features: educational materials; visit summaries; immunizations; prescriptions; procedures; insurance benefits; doctor's notes; and test results. Participants identified office visit summaries, records of immunizations, and prescription summaries as the most important features. Participants were least interested in viewing test results (labs and other results) online. When asked what additional services they would be interested in, participants identified prescription refills, booking clinic appointments, and secure e-mail with their care providers as important services (Lobach *et al.*, 2006; Willis *et al.*, 2006).

The UPMC Healthtrak diabetes portal owners conducted a focus group where participants commented on a list of 15 features based on perceived usefulness (using a Likert scale). More than 60% of the participants listed all 15 technologies as at least "somewhat useful." Eighty-six percent rated a self-management tool for recording daily blood glucose levels as very useful. Rated second was a calculator for estimating average glucose control, followed by links to educational sites, diabetes newsletters, an electronic scheduling system, and an electronic reminder system. Sixty-one percent rated secure communication with the health care team as very useful (Hess, *et al.,* 2006).

In an examination of PHR use by low income elderly or disabled users, researchers investigated which features this demographic group uses most often. They found that the medication section of the PHR was the most often-updated feature, followed by health problems. Lab tests were the second -east used feature – perhaps because patients often neglect to obtain paper copies of results and cannot rely on their memories to populate that feature in the PHR. Immunizations were the least updated feature in the PHR (Kim *et al.,* 2007).

While the rating of features does depend on the type of portal (e.g., patients with chronic conditions like diabetes rank self-management features highly while other patient groups might not), a few generalizations can be made regarding highly-rated features. Patients ranked personalized information and portal tools highly, preferring an individualized approach. Communication tools were also highly-ranked in many of the portal studies.

7.3.2. Health care provider perceptions and preferences

Administrators

Urowitz and colleagues (2008) surveyed Chief Executive Officers (CEOs) of Canadian hospitals to assess readiness to adopt and implement EHRs in Canada. They sent 213 e-mails to CEOs with a 39% response rate. Of those responding, 54.2% reported having a hospital EHR but few hospital EHRs held electronic records predominately, and 97.6% said that the EHR was not the only method of recording patient information. Barriers identified included financial resources of the hospitals, patient computer literacy rates and clinician interest (or rather lack of interest). The CEOs stated that access to test results (25%) and diagnosis (20.2%) are functions the staff would be interested in providing to patients, while a quarter of CEOs thought the patients would want full access to their complete medical records. The survey demonstrates that administrators are still anxious about providing patients with access to their own medical records; the CEOs felt that clinicians would not want to provide patients with full access, perhaps reflecting administrative unwillingness to give up "ownership" of the medical record (Urowitz *et al.,* 2008).

Clinicians

Clinician attitudes towards patient portals are investigated by Siteman *et al.* (2006) in a survey of 72 primary care providers in Massachusetts. Over half the physicians (52%) stated that they would have more time for their patients if the patients viewed their own EHR before a visit; however, the same percentage of physicians felt that their workload would increase because of a patient portal. Overall, 51% of clinicians expected their patients' knowledge and awareness of their own health would increase as a result of a patient portal, and 57% felt that they would be able to communicate more effectively with patients as a result of a patient portal (Siteman *et al.,* 2006). This study suggests physician ambivalence towards patient portals.

Some physicians are interested in using patient portals for communicating with their patients. The University of Arkansas for Medical Sciences (UAMS) project developed from an initiative with the UAMS Center of Excellence Center on Aging to improve communications with elderly patients. A patient portal connecting the institution to its elderly patients was identified as a tool for improving communications. The UAMS department members were surveyed to identify key portal features, with implementation, patient benefits, and cost savings in mind. The top rated features included pre-registration, prescription refills,

appointment booking, medical lists, appointment viewing, and patient education information. In a list of 13 features, patient-clinic messaging was ranked number 12. Members of the department felt that the top ranked features would provide greater patient satisfaction, promote physician self-care and preventative care, reduce administration costs, and improve workflow (Editorial, 2007).

Physicians, like patients, show clear preferences for certain different types of portal features. The best-received and most widely used function on the portal for the Children's Hospital of Philadelphia (CHOPS) is the basic information section, which includes information on the physical exam and status of the child, mediation and treatment instructions, and follow-up appointments. This function lets physicians know the situation when (or even before) the child arrives and parents no longer have to convey or interpret this information for the physician (Divis, Hardie & Luliano, 2007). Other popular functions of the CHOPS site include operative summaries, deemed very important by the physicians. Operative summaries detail the type of surgery preformed, if anything was removed or repaired, and how the surgical site was closed – important information for planning recovery care (Divis, Hardie & Luliano, 2007). The idea of incorporating digitized radiology images was not greeted with enthusiasm, as the physicians who referred the patient only wanted the opinion of the specialist and did not want to see the radiology images themselves (Divis, Hardie & Luliano, 2007).

Physician perceptions of messaging

While patients show a strong preference for communication tools in the literature, medical professionals express hesitation over communication features, especially messaging systems between patients and physicians. This hesitation is due, in part, to the fact that most physicians do not currently use any type of text messaging system to communicate with their patients.

In a 2006 survey of 4,203 physicians in Florida, 689 respondents reported using e-mail to communicate with patients (16.6%) while only 120 noted that they corresponded with patients frequently over e-mail. Physicians 61 years-of-age and older and those of Asian descent were least likely to use e-mail to communicate with patients (at rates of 11.7% and 7.2%, respectively). Of the non-users, 13.4% indicated interest in using e-mail to

communicate with patients, 33.8% were undecided, and 52.8% had no interest in using e-mail in their clinical practice (Brooks & Menachemi, 2006; Silver, 2008).

Brooks and Menachemi state that the survey indicates modest advances in the use of e-mail. They also found that clinicians who use e-mail generally do not adhere to guidelines when corresponding with patients (for example, less than half of the physicians print out the e-mail correspondence and place it in the patient's chart, and only 36% of physicians informed clients about e-mail privacy issues). Other studies also reveal that physicians in general do not follow e-mail guidelines unless they are educated about the importance of these guidelines. The authors recommend educating patients and clinicians on the benefits and potential privacy issues concerning traditional e-mail correspondence (Brooks & Menachemi, 2006).

Not all physicians feel unsure about using secure messaging to communicate with patient groups. In an extended abstract, Verheij *et al.* (2008) discusses findings from data gathered in 100 GP practices participating in the Netherlands Information Network of General Practice. They found that e-mail consultations were reported in 30% of the practices involved in the study. In considering the demographic information of those patients using e-mail for consultations, they found that more men than women used e-mail consultations. People aged 25-44 were over-represented in the study. Most correspondences did not require a diagnosis, but when diagnoses were given, the most common recorded were diabetes, pregnancy, and male reproductive system complaints at a higher rate than in normal practice consultations. Less suitable conditions for e-mail consults included cardiovascular and respiratory. The researchers concluded that overall very few people use e-mail for medical consultations, and that people who visit their physicians more frequently are more likely to consult with them via e-mail (Verheij, Ton & Tates, 2008).

Internet-based technologies are employed to improve diabetes care, but have had little clinical application in pediatric diabetes clinics. A study investigated health professionals' attitudes toward a portal for youth with diabetes by interviewing health professionals after participating in a user-centred portal design process. While the professionals were positive about the portal's features, such as secure e-mail communication, they felt the portal should take on a complementary role rather than replacing in-person communication. Professionals also felt that although online peer communication was important, the social networking

functions would not be used as much. Overall they were supportive of the idea of web portals for adolescents and children with type 1 diabetes (Nordfeld, Hanberger & Timpka, 2008).

EHR

Researchers estimate that the accuracy of medication documentation could be improved by providing patients with access to their EHR before their medical visits. Siteman and colleagues (2007) conducted a pre- and post-implementation study of primary care providers at 11 practices to gauge clinician attitudes toward patient access to electronic health records on the patient portal Patient Gateway. A subset of the patient participants were asked to review their medication list and alert their primary care providers if any changes were needed. Pre-implementation, 96% of primary care providers surveyed agreed or strongly agreed that patient access to their EHRs (viewing and commenting) would ensure accuracy of medication lists; 13% felt that access to the EHR could create greater patient confusion over medications, and 46% thought physicians would be frustrated with inaccuracies in current medication lists. In the post-implementation survey, health care providers reported fewer concerns about potential negative effects. All physicians agreed or strongly agreed that the EHR ensured greater medication list accuracy, no one reported patient confusion over the EHR medication list, and only 11% reported patient frustration over EHR inaccuracies (Siteman *et al*., 2007).

A study of 922 physicians in South Dakota and Nebraska (representing 22% of ambulatory care physicians) focused on physician acceptance and usage of personal health records. The study found that 46% of physicians recalled seeing patients record their own paper version of a PHR, and estimated that approximately 18% of their patients kept a PHR in some sort of media form (PDA, website, smart card, or paper). However, a Harris Interactive Poll found that 42% of patients keep a PHR. According to the authors, physician awareness of personal health records remains low, and physicians need to be educated about the importance of patient access to health records (Fuji, Galt & Serocca, 2008).

When Patient Gateway was in the development phase, physicians were concerned that patients who were allowed to view their EHR could be worried, confused, and misread the record. Physicians also wished to avoid contact with their patients outside of the office. In order to meet their concerns, developers worked to fit the EHR into the existing workflow –

within the context of the clinic and a regular clinic visit. Patients were given restricted access to their care plan and only allowed to view it two weeks prior to a clinical visit. Physicians were only permitted to view the EHR of patients who had upcoming appointments and the physicians would then address concerns raised in the patient portal in the clinic during the appointment. For example, physicians were notified through an icon alert when patients completed the Diabetes Care Plan. They could then review and add comments and import the care plan into a physician progress note for documentation and for discussion during the patient's next appointment. During the roll-out phase of the system, researchers found that physicians needed a significant amount of time to learn how to use the system. Training was given through e-mails, a help line, online educational modules, discussions with groups, and demonstrations (Grant *et al.*, 2006).

7.4. Satisfaction rates

Another way to measure the outcome of a portal is by looking at user satisfaction rates. In the case of patient portals, both patient and health care professional satisfaction rates need to be examined.

7.4.1. Patient satisfaction rates

Patients can be motivated and empowered by patient portals. In a pilot study of UniTherapy, eight stroke patients underwent assessment for level of motor skills, played therapeutic games, and participated in teletherapy sessions. Seven of the eight patients found that the tasks represented their daily activities. The majority of patients were satisfied with the comfort and usability of the system, noting that they were motivated to engage in the therapy in order to increase their "high scores." (Feng & Winters, 2007). In a 2004 survey of PAMFOnline, 90% of both patients and health care workers reported being satisfied or very satisfied with the service, and messaging was listed as the number one feature. The most common response from the patients was that they felt empowered by the system (Tang, 2005).

Diabetescoach, a self-management support program created by Medicinfo, a leading e-Health company in the Netherlands, conducted usability tests (tracking actual use and administering a questionnaire) combined with interviews of 20 patients and five nurses. The participants' mean age was 62 years old, with an age range from 43 to 80. Eighty percent of the total group (40) used the system on a regular basis and were interested in

telemonitoring and e-mail in particular. Nurses were able to initiate e-mail contact, giving feedback on the patient's recorded information (weight, behavior, tips on healthy living, etc.) – which helped motivate patients. Researchers note that adequate training is necessary, and patients need to be well-suited to the technology (not all patients will accept it). To aid in their technological acceptance, portals need to be useful and easy to use (Nijland *et al.,* 2008).

Patient outcomes can also be measured through surveys determining patient satisfaction. MyGroupHealth is a patient website designed by the Group Health Cooperation in Washington and Idaho in 2000 that includes a shared EMR and secure electronic messaging. In a random survey of MyGroupHealth users conducted from September 2002 through December 2005, researchers found that 94% of the 921 respondents were satisfied or very satisfied with the MyGroupHealth patient portal. In particular, 81% of respondents were very satisfied with medication refills, 65% very satisfied with the secure messaging system, and 55% very satisfied with the delivery of test results over the site. Satisfaction rates were highest for features that involved accessing services and information requiring active care and client-clinician communication. Sections in the portal devoted to the transfer of archived information, like common medication lists or claims information from insurers, were of less value to patients than features that connected clients and clinicians (Ralston *et al.,* 2007). In a 2008 GroupHealth survey of 761 members, 54% found the online portal extremely valuable. Thirty-four percent of those surveyed found the portal very valuable, and only 1.8% said the online features of the portal were not important (Raths, 2009).

In a pilot study of new features of Patient Gateway, the researchers granted patients online access to lab results. Usage, patient and physician feedback (solicited and unsolicited), and surveys were used to measure the pilot's success. Patients were notified of the new feature within the portal messaging system, triggering a notification message to be sent to their regular e-mail addresses. After the feature was available for 12 weeks, a survey was administered to patients who had accessed the new feature. Users (patients and physicians) could also use the "Feedback" button to submit comments at any time (Wald *et al.,* 2007). Pilot users were 10 physicians from two practices who offered the feature to 3,583 patients (10% of notification e-mails bounced). In total, 594 patients viewed the results page. Spontaneous feedback was positive; some requested additional results, reports, graph features, and usability improvements. Survey results also indicate positive perceptions of the

ease of use of the portal (89%) and presentation (85%). About 68% of the patients surveyed would recommend the feature to others, 64% found the information very helpful, and 75% reported viewing the reference information in the portal (Wald *et al*., 2007).

Wald *et al.* note that test results, if provided with the necessary clinical sensitivity and privacy safeguards, are important for communication. Confidentiality is important, but when test results are not delivered efficiently to the patient there is the potential for danger (at worst) and frustration (at best). Feedback to the lab result feature was positive and half of the patients who viewed results also accessed the linked reference information (Wald *et al.,* 2007).

In a study of the messaging system in University of Colorado Hospital's patient portal My Doctor's Office, patient satisfaction was high, with 85% of patients reporting they would be more likely to use the messaging system than the telephone for non-urgent messages. One message was sent for every 250 portal patients. Staff spent about eight hours per day answering phones and five minutes a day responding to portal messages. Phone calls from the portal group were slightly less frequent than the control (but not statistically significant). Portal patients were more satisfied than the control group with their communication with the clinic and overall care (Lin *et al.,* 2008).

In a 2007 study involving 39 participants with diabetes, researchers conducted focus groups to determine patients' attitudes towards portal technology. In particular they were interested to know if the patient-provider relationship has an impact on attitudes towards portal technology. They determined that dissatisfaction with their relationship with their provider corresponded to greater interest and use of the patient portal. Patients who were satisfied with their patient-provider relationship were more disinterested in the portal. Some patients who were not interested in the portal were already contacting their providers through e-mail and other means; however, as the researchers note, traditional e-mail is not a secure method of communication, and patients need to be educated about privacy issues concerning the use of traditional e-mail (Zickmund *et al*., 2007).

7.4.2. Health care provider satisfaction rates

Nurses

The role of the nurse in the development of the PHR was explored by Lee, Delaney and Moorhead (2007) who reviewed existing literature and created IowaPHR, a patient portal with various features which were evaluated by nursing staff. Common features include patient demographic information, lab and diagnostic test results, medication lists, immunizations, access, security and privacy policy information. Nurse-specific functionalities include interactive assessment and feedback as well as a diary function. The content of the site for the nurses was created through the use of standardized nursing languages (SNLs). Nurses evaluating the usability of IowaPHR reported that the information recorded in the PHR will be useful for health care providers in the future.

Research on the Mieli.Net project in Finland evaluated information technology used for in-hospital psychiatric patient education. Researchers used a questionnaire to evaluate the reaction of nursing staff in two Finnish psychiatric hospitals to the quality and functionality of Mieli.Net. Nurses rated voice files and photos highly because they felt voice and visual components made the information more relevant for the patients (Koivunen *et al.,* 2007).

In a separate study involving the same two psychiatric hospitals in Finland, randomized controlled trials were conducted on two groups of nurses; one group used the portal for education sessions and the other used written materials. Questionnaires were administered with open-ended questions on barriers and support for usability. The nurses' IT skills and attitudes towards computers were also measured (Koivunen, Hatonen & Valimaki, 2008). The researchers noted four main categories of barriers or facilitators for in-hospital portal use, including organizational resources, nurses' individual attitudes, and patient-related and portal-related factors. Organizational resources are important; computers need to be located in an appropriate environment – an area little or no disruptions but also in a central area so nurses can transition quickly from nursing activity to patient education. The lack of equipment was also another hindrance (in these hospitals there were not enough computers with internet access). Nurses also reported that they did not have time to help patients using the portal. They noted that inadequate staff resources could shorten patient education sessions. Nurses' individual characteristics, their negative attitudes towards IT, and lack of IT skills also acted as barriers to portal implementation. Patient-related barriers include mental

status, their attitudes towards IT, and length of stay – all factors that could enable or limit use. Researchers found a need to tailor information to the individual patient, and to provide patients with easy access to computers for independent use. For successful portal implementation, support not only for patients but also for providers during transitional times is required (Koivunen, Hatonen & Valimaki, 2008).

Physicians

Although researchers report physician ambivalence to and concern with patient portal messaging, several studies found physicians reporting high satisfaction rates with portal systems. A PAMFOnline survey in 2004 found that 90% of physicians reported being satisfied or very satisfied with the service, and messaging was listed as the number one feature. Physicians noted that it was more efficient to annotate and release lab reports online for the patient to play the time-consuming game of phone tag with their patients. Physicians in general did not experience feeling overloaded by messages from patients via the portal (Tang, 2005).

In a survey recording physician reactions to the MD Portal (used in a children's hospital) physicians responded enthusiastically – especially when given the ability to immediately access the lab results of referral patients through the portal. One community pediatrician stated that "*the portal is a much more efficient way to get the information that I need … Navigation and information retrieval is simple, and it easily saves me 30 minutes or more a day on the phone. I never want to go back to the old way*" (Divis, Hardie & Luliano, 2007, 19).

Physicians who use web messaging record higher levels of patient visits per day. Researchers state this is because many patients prefer physicians that use messaging, and that messaging "counts" as a visit or patient inquiry. Higher patient visits could also be the result of increased process efficiency, as physicians who use the portal do not need to compile a separate log (as they would for telephone communications) because messaging can be a self-documenting means of communication (McGeady *et al.*, 2008).

Physician feedback to a Patient Gateway study of online access to test results was positive – one physician even wanted to be notified if the online letter was NOT opened by the patient so clinical staff could intervene if necessary. Some physicians noted that they no longer

mailed hard copy "Results Letters". They reported no increase in messages as a result of the online results and reported no extra work time needed because of the new features. Results were given after a two-business-day delay. Some physicians questioned this practice, favouring a delay to ensure that they had time to view results before the patients saw their results, and some commented that they write all the reviews of results at once ("batching" them), which can "*sometimes can take 3 weeks or longer once the results are back*" (Wald *et al.,* 2007).

7.5. Clinical results

Outcomes of the portal system Diabetes Recall And Management (DREAM) intervention in the UK included improvements in patient attendance and in adherence to four of nine areas of recommended care: recording foot examination, dietary advice, blood pressure, and smoking status. The evaluation also found improvements in patients' serum cholesterol levels. The impact on prescribing was inconclusive in this study, as both intervention and control groups showed no significant differences in drug usage (Eccles *et al*., 2007). Researchers studying a diabetes portal note that, since diabetes patients typically visit their physicians every six months, trials of diabetes portals should span a six-month period in order to observe potential changes in the patient-provider relationship (Ma *et al.,* 2006).

The health portal Hearts of Salford is designed for people with heart disease living in Salford who have heart disease. Researchers administered questionnaires to 108 men and women between 50-74 years old, all of whom received computers and a one-year broadband subscription, with only half receiving access to the portal. They gathered baseline and six-month responses from all participants on questions related to exercise, smoking, diet, and mental health. The content of discussion forums on the patient portal was also analyzed. Researchers found an increase in health visits (due to increased awareness about personal health), a slight improvement in diet, and a decrease in alcohol consumption and exposure to second-hand smoke among those in the portal group. The control group experienced significantly less social support over time and poorer mental health, poorer diet, and more health visits due to poor health (Lindsay, 2008).

In the forums of Hearts of Salford, patients were able to comment on the site's educational material. One male participant noted that the educational material acted as important

reminders for him to stay on the right track with regards to his eating and exercise habits (Lindsay, 2008). Participants were also able to respond to a video posted on the portal from the British Heart Foundation. People commented that it was well done and effective. One male participant in particular noted that "*The visual images of what goes into the popular food identified does give out a strong message. I think a lot of people will be more aware of what they are eating when they are eating the foods shown because of the visual rather than the written image*." (Lindsay, 2008, p. 325).

The U.S. Company ActiveHealth Management found overall patient compliance to physician recommended health regimes can be improved by about 20% when members are engaged in their health care. Their portal gives patient-specific information to encourage them to ask questions that pertain specifically to their care during appointments (Editorial, 2006). Results from early studies on patient portal messaging suggests that when clients and clinicians work together to support health care initiatives, patient portals achieve the highest rates of success (Ralston *et al*., 2007). However, researchers also stress the amount of resources and time needed to overcome barriers such as aiding clients in using computers. Therefore, interventions like patient portals may not see as much change over the short-term as people adjust to the technology, and changes in health may become more apparent in the longer-term study results (Lindsay, 2008).

7.6. Costs and savings

Return on investment in patient portals is not easily visible and measured because it relies on behavioral change which does not necessarily happen in the short term (Raisinghani, 2008).

Patient portals can lead to increased patient visits and increased screening as patients become more active in their own health care. For example, The Primary Care Physician Portal (PPP) – used by care teams, Mayo Clinic Primary Care physicians, and administrators – saw an increase in patients from 135,420 in 2004 when the portal was implemented to 157,837 in 2005. Visits increased from 75% to 86% (clinical, hospital, emergency); mammogram screening increased 57% to 63%; specialty utilization decreased (1,821 visits per 1000 to 1,688 per 1000); and lab use decreased during this time (6,875/1000 to 6,306/1000). By using patient portals, care providers can take responsibility for population management. Although the portal contained limited data sources, physicians still showed

interest. The changes in clinical visits, lab usage, and mammogram screening cannot be directly attributed to the use of the portal, but the authors feel that the physician portal has made a positive contribution (Rahman, 2006).

While some studies indicate patient portals may lead to increased patient visits, many studies discuss how the use of patient portals can lessen the number of patient phone calls and reduce office hours. The use of portal messaging and online appointment systems, for example, could lead to fewer telephone calls.

The extent to which messaging via a portal saves time is not clear; researchers have no clear evidence about whether messaging will increase demand for health care or substitute other forms of communication (McGeady *et al.,* 2008). Studies reviewed indicate that when comparing web messaging and control groups, the differences between the volume of telephone calls and appointments between web messagers and control groups are minor. Messaging does not seem to be more time consuming than telephone communications, and studies show that web messaging has a positive impact on patient satisfaction (McGeady *et al.,* 2008; Lin *et al.,* 2008).

Raths (2009) describes several high-profile portals, including the Seattle-based patient portal MyGroupHealth (from the Group Health Cooperative), the Duke University Health System HealthView patient portal, and Epic's MyChart EHR used by Cleveland Clinic and Kaiser Permanente. Raths highlights HealthView, where researchers found that the system reduced calls related to billing to the Health System call center.

Researchers reporting e-mail outcomes of KP's HealthConnect portal in a cohort and matched control subject study found a decrease in visit rates in both studies – by 9.7% and 10.3%, respectively. The Kaiser Permanente Network documentation procedure for telephone calls changed during the study. As a result, rates of calls increased for the entire region by 24%; however in the intervention group, telephone call rates only increased by 15.6%. Annual office visit rates by KP HealthConnect Online members decreased (by 9.7% in intervention group and 3.7% in the control group), and showed a smaller overall increase in documented telephone calls than the control group (16.2% in the study verses 29.9% in the control group) (Zhou, *et al.,* 2007).

In Hess and colleagues (2007) study of UPMC's Health Trak system – involving focus groups and tracking clinic calls and visits – they found that the use of messaging did not lead to a decrease in the number of visits to the clinic or the number of phone calls received. However, the system did reduce cases of telephone "tag," which occurs when a patient leaves a message at the clinic and when the clinic returns the call, the patient is not in. Messaging can reduce the long periods of wait time that could occur due to high volumes of phone calls or incidents of phone tag. The use of online messaging could also improve the EMR because data could be entered directly, eliminating the potential risks that could arise due to inaccurate transcriptions of phone calls or clinical visits. In the focus groups, patients said the system was useful to view lab results and communicate with their health care provider. They also found the electronic reminder messages important because of their busy schedules. Overall, the focus group participants reported feeling empowered by the Health Trak system and more involved in their own health care (Hess *et al.,* 2007).

In an analysis of time savings due to patient portals, Kuhn (2008) notes that a three to one variance occurs when comparing telephone to online services – an appointment-scheduling task taking three minutes for health care staff to accomplish on the phone can be done by the patient in one minute, creating substantial savings when multiplied according to usage. In addition, patients are given a convenient alternative to traditional means of scheduling appointments, etc. (this can be done at any time, and requests can be handled by staff at non peak hours) (Kuhn, 2008).

In previous studies, researchers stated that an early evaluation of 1,000 users of the KP HealthConnect Online System demonstrated that the messaging feature was used in 70% of online sessions, indicating the importance of secure electronic messaging. In another random sample study of 1,700 KP HealthConnect Online users, 25% of respondents stated that they would have needed to schedule appointments had it not been for the instant messaging function – in other words, the messaging system helped reduce office visits by 25% within this sample of users (Zhou, *et al.,* 2007).

In a study of 120 secure e-mail messages between patients and health providers on the PAMFOnline system, 22 of the 120 messages were classified as an eVisits warranting reimbursement, and the other messages were short inquiries or updates. Within a subset of patients with chronic illness, electronic messaging would generate approximately 1.2 eVisits

per patient annually, compared to 0.7 eVisit encounters per year for general patients. The researchers noted that sharing data through a portal (PHR, EHR) combined with communication tools that link patients and providers could be the best way to improve coordination, improve health care, and reduce costs. To lessen the number of messages (and the workload perceived by the physicians) the researchers noted that hyperlinks could be provided in patient health records, linking to information resources that explain the condition thereby answering patient questions without using e-mail. In a 2006 PAMFOnline study, 65% of patients stated that the messaging system had replaced one or more in-office visits in the past year (Tang *et al.*, 2006).

Physicians fear that portal technologies like secure e-mail will increase demand and their workloads (McGeady *et al.,* 2008). However, in a study of 67 random e-mails sent to physicians by patients in a breast surgery setting, Escallon and Fonseca (2008) found that the average length of these e-mails was very short (146 words). The average adult reads about 120 words per minute, indicating that e-mail may be a cost-effective means of communication.

There is evidence that electronic health communication can reduce office visits and lead to greater patient empowerment, greater discussion of stigmatized or embarrassing conditions, and better adherence to treatment. The use of electronic communications has been linked to higher levels of satisfaction with overall care. It is important to note that there are a handful of studies that show that e-mail is not replacing visits and phone calls but supplementing these forms of communication (Whitten, Buis & Love, 2007).

In the article "Benefits of Information Technology-Enabled Diabetes Management," the authors created a model to project the impact of IT on diabetes management in the U.S., drawing estimates of care improvements from published literature and mirroring the general diabetic population (Bu *et al.,* 2007). Their 10-year simulations predict deployment at 20% per year until full national implementation at year five. They estimate that integrated provider-patient systems could save $1,180 per enrolled person, or a total of $16.9 billion – the most modest improvements projected. Of all forms of IT-enabled diabetes management, provider-centered technologies have the greatest potential to improve process outcomes. Overall, Bu *et al.* recommend the use of IT for improved and more efficient communication

to coordinate care among medical staff and empower patients by providing tools and education.

According to researchers O'Brien and Duffy, applications that require significant investments in time (e.g. complicated systems that people need special training to use) do not appeal to all health care professionals. However, professionals who are geographically isolated are more likely to work remotely with key stakeholders using telemedicine applications than those working in urban areas (O'Brien & Duffy, 2008). Patient portals may have greater appeal to clinicians working in rural or remote areas than clinicians in urban centers.

8. Conclusions

Compared to other OECD countries, Canada's Electronic Medical Record and patient portal implementations have lagged behind. While more than 90% of physicians in Demark, the UK, and the Netherlands use technologies like electronic lab reviews and e-prescribing, only 30% of Canadian physicians use e-health technologies. Keshavjee and colleagues (2009) investigated the reasons why Canada lags behind, and point to policy issues, cost benefit analysis, and implementation. Funding and implementation services are not provided for EMR by any of the provinces, and key medical associations are not engaged. ICT infrastructures also need to be provided, including secure e-mail and secure high-speed Internet connections (Keshavjee *et al.,* 2009).

Our literature review findings highlight how patient portals can increase the engagement of patients in their health care and also engage health care professionals in innovative e-health solutions. However patient portal technologies are still in their early days and innovative approaches are only just emerging.

We can conclude that the key to successful patient portals is personalized content; patients reported higher satisfaction rates and visited the patient portals more often when the site offered personalized content. Although old age can be a barrier to accessing the internet, when older people had access they were more likely to use patient portals, especially if they were dealing with a chronic illness and the site had content specific to that illness. Patient portals led to a reduction in missed appointments and greater complacence to recommended health regimes, as well as an increase in preventative screening appointments. Although some studies found an increase in office visits after the implementation of a patient portal, time-consuming phone calls decreased due to online booking and messaging on patient portals. The main theme emerging from the literature review is that patient portals are an important supplement to patient care, can empower the patient and can help support preventative health programs.

<u>Telerehabilitation</u>

Changes will be needed at the local, national, and international levels to encourage widespread uptake of telerehabilitation technologies. National policies and guidelines would aid an institutional shift to organizations that are more portal-friendly. Changes in attitudes

might also have to be encouraged-at the level of the individual health care professional. Adoption of patient portals could be facilitated by including health care professionals in the design process of the portal system, exposing them to the possibilities of the system and educating them on e-Health concepts and principles (Theodoros & Russell, 2008).

Research on telerehabilition has been largely focused on technology and contains single or small case sizes. Researchers need to demonstrate the viability of technology use for telerehabilitation and investigate cost benefit and cost effectiveness (Russell, 2007). When judging the success of a patient portal there are many factors to consider, based not only on cost effectiveness and the needs of the government, institutions, and medical professionals, but also on patient needs. A balanced approach would avoid focusing on coast savings alone, and instead focus on determining which care models best meet the needs of patients.

9. Glossary

Chronic illness/disease--illnesses or diseases that have lifelong implications such as asthma, cancer, diabetes, and heart disease

Electronic Health Record (EHR) also known as an Electronic Medical Record (EMR) – A health record complied by a single organization for us by clinical staff.

Health care provider – Any professional involved in the medical care of a patient including health care professionals providing medical services as well as administrative staff.

Horizontal portal also known as a Megaportal – The broadest type of portal. This portal acts as an all-in-one site to access web pages. Examples of horizontal portals include Google and Yahoo.

Patient – A person who is seeking health services.

Patient Portal
In our definition a patient portal provides more than just access to test results and lab reports (more than the EHR and PHR); it also contains tools that promote learning and self-management.

Personal Health Record (PHR) – A health record that is created for, tailored by, and sometimes designed by patients.

Telerehabilitation – The use of rehabilitation services delivered remotely using technology.

User – Anyone directly accessing the patient portal.

Vertical portal – A website that acts as a central access point to all content and applications for users with particular interests.

Web 2.0 – The second generation of web design, commonly referred to as Web 2.0, focuses on the use of the internet for communication and collaboration rather than as a broadcast medium.

Web 2.0 technologies – Refers to technologies used in instant messaging, e-mail, video and videoconferencing that enable and facilitate collaboration, social networking, and participation.

10. Annotated Bibliography (143)

Adler, K. G. (2006). Web portals in primary care: An evaluation of patient readiness and willingness to ray for online services. *Journal of Medical Internet Research, 8*(4).
In this study of online web communication, 239 patients in the author's medical practice in Arizona were surveyed to establish web access. 75% of patients had web access; those with the most access (97%) were 18-29 years olds. Those age 70 and up had the least access (56%). Students and employed patients had the highest rates of access (92%, 87%), while retired and disabled patients had the lowers rates of access (66%, 42%). Researchers discuss the willingness of patients to pay for online services (47.1% of all; 60.1% of just those with access). Top three rated services (in order) for those with internet access: e-mail with physicians (34%); viewing medical record (22%); and medication refills (11%).

Al-Busaidi, A. Gray, A., Fiddian, N. (2006). Personalizing web information for patients: linking patient medical data with the web via a patient personal knowledge base. *Health Informatics Journal, 12*(1), 27-39.
The benefits, outcomes, and technical infrastructure of a web portal in South-East Wales known as "patient knowledge base (Patient KB)" are discussed in this article. The authors note that Patient KB will yield several benefits including automation and accessibility, customization, extended knowledge, patient-friendly language, privacy protection, and information control, as well as the ability to easily update information. A mediator and ontology-based approach is used for greater flexibility of the system. Patients can access an integrated view, which is stored with links to medical details and hyperlinks that provide patients with more easily-understood medical terms.

Allen, M., Iezzoni, L. I., Huang, A., Huang, L., & Leveille, S. G. (2007). Internet-based coaching to improve patient-clinician communication in primary care. *AMIA Annual Symposium proceedings AMIA Symposium*. 861.
In order to explore the use of internet tools in ambulatory settings, researchers in Boston developed an online coaching intervention delivered by nurses to communicate with patients suffering from chronic pain, depression, and impaired mobility. Participants were screened through a portal for one (or more) of the chronic conditions, and this abstract discusses their demographic information and usage of the portal.

Allen, M., Iezzoni, L.i., Huang, A., Huang, L., Leveille, S.G. (2008). Improving patient-clinician communication about chronic conditions: description of an internet-based nurse e-coach intervention. *Nursing Research, 57*(2), 107-112.
PatientSite, a Boston-based portal developed for the Beth Israel Deaconess Medical Hospital, is a secure site that enables patients to communicate with staff. In this article, the authors investigate a new intervention that allows patients to interact with a nurse through an eCoach function of the PatientSite portal. Responses to the eCoach were positive.

Alnamo, A., Marxt, C. (2007) What is a portal? *Encyclopedia of Portal Technologies and Applications.* New York: Information Science Reference.
This short encyclopedia article explains the various definitions and features of portals.

Amin, H., Tan, A., Tan, P. P., Low, S. C., & Thilagaratnam, S. (2008). *Planning the Development of the Singapore National Health Portal.* Paper presented at the Medicine 2.0, Toronto: 15-16.
Based on surveys, approximately one million people in Singapore suffer from diabetes, hypertension, lipid disorders, or have had a stroke. The National Health Portal (NHP) was developed in order to address the strain on health care and facilitate the implementation of an Active Health Management (AHM) program from 2008-2011.

Ansell, C. (2007). Fostering innovation and collaboration. *Medical Device Technology, 18*(1), 52-53.
The Health Technologies Knowledge Transfer Network (HT KTN) was implemented in 2006 to bring together those in the medical technology and health care communities through an internet-based communications portal (www.healthtechktn.com). The site features customizable conferencing and information, including accessible presentations and a Clinicians forum designed to facilitate collaboration.

Ball, M. J., Costin, M. Y., & Lehmann, C. (2008). The personal health record: consumers banking on their health. *Studies in health technology and informatics*, 35-46.
With transitions to online services in fields like banking, the health care sector is also examining online records like the PHR. Ball and colleagues describe various PHRs, most of which are administered via patient portals. They then discuss the key components of the PHR, the strategies to implement PHRs and the needs of the consumer and clinician. In particular they stress the importance of human context and interaction as well as ensuring PHR implementation is patient-centered.

Bendixen, R.M., Levy, C., Lutz, B.J., Horn, K.R., Chronister, K., Mann, W.C. (2008). A telerehabilitation model for victims of polytrauma. *Rehabilitation Nursing, 33*(5), 215-220.
Bendixen and colleagues describe the North Florida/South Georgia Veterans Health System's Low Activities of Daily Living Monitoring Program (LAMP). LAMP is a home-based management system designed for combat-wounded veterans experiencing severe and multiple injuries. The article discusses a case study of a veteran who, through monitoring and electrical stimulation, was able to stay at home rather than be institutionalized.

Bergman, D. A., Brown, N. L., & Wilson, S. (2008). Teen use of a patient portal: a qualitative study of parent and teen attitudes. *Perspect Health Inf Manag*, 5(13).
The attitudes of teens and parents towards patient portals are evaluated in this study. The researchers conducted focus groups and analyzed electronic bulletin boards with patients of the Palo Alto Medical Foundation (PAMP) in California. They found that teens were enthusiastic about the use of patient portals, but also had concerns about privacy and confidentiality.

Bodily, N. J., Carlston, D. A., & Rocha, R. A. (2007). Personal health records: key features within existing applications. *AMIA Annual Symposium proceedings AMIA Symposium*: 875.
The American Medical Informatics Association's College of Medical Informatics concluded in a 2005 symposium that PHRs are not static. Instead, they are a set of tools designed to involve patients in their own health care. The authors investigate 12 software applications from my PHR (http://www.myphr.com/resources/phr_search.asp) to identify key features of interactive PHRs.

Boye, J., & Byrne, T. (2006). Open source portals: Frustration and promise. *EContent, 29*(6), 38-42.
In this article, Boye and Byrne discuss the definition of the portal as a framework for information, applications, and processes. In particular they focus on three established open-source portals: JBoss Portal, Liferay, and Plone.

Brennan, D. M., & Barker, L. M. (2008). Human factors in the development and implementation of telerehabilitation systems. *Journal of telemedicine and telecare, 14*(2), 55-58.
Brennan and Barker discuss human factors in the design, development, and implementation of telerehabilitation systems. Human factors to consider include the need for uncluttered interfaces to minimize distraction as well as alternative education methods to ensure patients understand informed consent issues and the tasks and the procedures they need to do. The need for caregiver training is also discussed. The authors note that devices in the home need to be easy to use and reliable and that patient privacy needs to be protected.

Brennan, P. F., Burke, L., Casper, G., Sebern, M., Krause, C., Kossman, S. (2006). Creating technology-enhanced practice: A university-home care-corporate alliance. *Studies in health technology and informatics, 122*, 644-648.
This article describes the first phase of a 3-year study on the HeartCare2 website for patients with chronic heart failure (CHF) and their home care nurses in Wisconsin. In the first phase, the website was developed with a user-centered procedure involving the patients and the nurses as well as the design team. The website, with features such as a Weight Tracker and a Daily Symptoms Checklist, acts as an important means of monitoring the health of high risk patients.

Brooks, R. G., & Menachemi, N. (2006). Physicians' use of email with patients: Factors influencing electronic communication and adherence to best practices. *Journal of Medical Internet Research, 8*(1).
In a 2006 survey of 4203 physicians in Florida, 689 of respondents reported using e-mail to communicate with patients (16.6%) while only 120 noted that they corresponded with patients frequently over e-mail. The survey indicates modest advances in the use of e-mail. The researchers also found that clinicians who use e-mail generally do not adhere to guidelines when corresponding with patients. The authors recommend educating patients and clinicians on the benefits and potential privacy issues concerning traditional e-mail correspondence.

Bu, D., Pan, E., Walker, J., Adler-Milstein, J., Kendrick, D., Hook, J.M., Cusack, C.M., Bates, D.W., Middleton, B. (2007). Benefits of information technology-enabled diabetes management. *Diabetes Care* 30(5), 1137-1142.
In this article, the authors report on their creation of a model to project the impact of IT on diabetes management in the U.S., drawing estimates of care improvements from published literature and by mirroring the general diabetic population. Their 10-year simulations predict deployment at 20% per year, reaching full national implementation at year 5. The most modest projections estimate that integrated provider-patient systems could save $1,180 per enrolled person, or a total of $16.9 billion. Their project demonstrates that of all forms of IT-enabled diabetes management, provider-centered technologies have the greatest potential to improve process outcomes. Overall, the authors recommend the use of IT for improved

and more efficient communication to coordinate care among medical staff, as well as for empowering patients through access to tools and education.

Buckel, L., Businger, A., Volk, L. A., Wald, J. S., Poon, E., Grant, R., et al. (2007). Patient care experience enhanced by use of online journals. *AMIA Annual Symposium proceedings AMIA Symposium*.

In Boston, patients enrolled in Partners Healthcare can access the Patient Gateway (PG) web portal. A subset of Patient Gateway's patient users were enrolled in the Prepare for Care study, where they were able to submit online pre-visit health journals to track their care. After a scheduled visit, each patient was asked to complete an online survey to report his/her experience. Half of the respondents discussed the information in the journals with their health care providers and 52% noted that the journal helped improve communication with their physicians. 66% of those who did discuss the journals with their physicians felt they were able to give their clinicians more accurate information, and felt more prepared for their visits. The authors note that patients who discussed the journals with their clinicians, as compared to those who didn't, were more likely to see the benefit of the journal.

Canada Health Infoway (2007) Strategies for successful patient portals. Health Canada. Ottawa, Ontario. 53 pages.

The 2007 Canada Health Infoway study consists of a literature review on patient portals and the results of site interviews with members of four portal initiatives and a workshop with the organizations. The four Canadian portal initiatives investigated are: MyCare Source, Grand River Hospital, Kitchener, Ontario; VIPNet Group Health Clinic, Sault Ste. Marie, Ontario; Interior Health Authority, British Columbia; and a Victorian Order of Nurses (VON) portal in the planning stages.

Canadian Press (2007) Baby Boomers Swell Ranks of Retirement-aged Canadians. CBC News http://www.cbc.ca/canada/story/2007/07/17/census-canada.html

Based on Statistics Canada reports, this article discusses demographics and the possible impact of Canada's aging baby boomer population on the health care system.

Carbone, D., & Burgess, S. (2007). Health Portals. In *Encyclopedia of Portal Technologies and Applications* (Vol. v. 1, pp. 431-436): Information Science Reference.

Authors Carbone and Burgess describe the various ways in which portals can be utilized in the health profession. In particular they discuss the use of portals for physician and nursing education, for accessing reliable health sites online, and for secure e-mail communication.

Carrell, D., & Ralston, J. D. (2006). Variation in adoption rates of a patient web portal with a shared medical record by age, gender, and morbidity level. *AMIA Annual Symposium proceedings AMIA Symposium*, 871.

The adoption rates of the patient portal MyGroupHealth (MyGH), a service of the Group Health Cooperative in Seattle Washington, are analyzed in this conference paper. MyGroupHealth integrates components of Epic MyChart software and locally-developed components (lab results, shared electronic health record, patient-provider messaging, medication refills, and Healthwise knowledge base). Portal usage by 215,998 enrollees was tracked, and indicated strong growth over a 30-month period. Women were quicker adopters than men, followed by the 18-39 and the 70+ age groups. Those in the high morbidity level and moderate morbidity level were higher adopters. Overall, the authors found that patient

adoption varies substantially according to health status and demographics of the user population.

Chan, D. S., & Brudnicki, S. (2008). *InfoWell Patient Portal: A Case of Patient-Centred Design.* Paper presented at the Medicine 2.0 conference, Toronto, 32.

The InfoWell Patient Portal was designed in the greater Toronto area to manage chronic conditions like breast cancer, diabetes, and kidney disease through education, access, and support. In this extended abstract, researchers Chan and Brudnicki discuss the user-centred design methodology used to gather feedback from patients, the benefits of this methodology, and the results.

Chan, D. S., Callahan, C. W., Hatch-Pigott, V. B., Lawless, A., Proffitt, L., Manning, N. E., et al. (2007). Internet-Based Home Monitoring and Education of Children With Asthma Is Comparable to Ideal Office-Based Care: Results of a 1-Year Asthma In-Home Monitoring Trial. *Pediatrics, 119*(3), 569-578.

In a study of two patient groups of young people whose guardians work in the military in Oahu, researchers found excellent outcomes in the group receiving online education and case management. The patients receiving virtual care achieved excellent outcomes,adhering more readily to diary submission and achieving better inhaler scores at 52 weeks than the group receiving the regular in-person clinical protocols for education and case management. The virtual group portals used store-and-forward technologies for communication, including secure e-mail and digital video uploads.

Collmann, J., & Cooper, T. (2007). Breaching the Security of the Kaiser Permanente Internet Patient Portal: the Organizational Foundations of Information Security. *Journal of the American Medical Informatics Association, 14*(2), 239-243.

Collmann and Cooper examine the security breach of the Kaiser Permanente (KP) integrated health delivery system, which serves over 8 million people in the United States. In 2000, patches to the servers caused the e-mail function to fail. In order to send the outbound messages, programmers wrote a flawed script that concatenated (or joined) all the messages, causing a breach in the system. Collmann and Cooper argue that the breach was caused by organizational issues, mainly the pressure to clear the e-mail messages in the program "Outbox" instead of following standard procedure, in addition to a technical error.

Conley, E. C., Owens, D. R., Luzio, S. L., Subramanian, M., Ali, A. S., Hardisty, A., et al. (2008). Simultaneous trend analysis for evaluating outcomes in patient-centred health monitoring services. *Health Care Management Science, 11*(2), 152-166.

Healthcare@Home (HH), a system of clinical hubs and mobile devices or home-based network computers developed in the UK, is described in this article. In the Healthcare@home system, various services for diabetes management, including a wireless blood pressure cuff and glucose meters, are integrated and delivered via portal technology for communication and continuous monitoring.

Conn, J. (2007). Upgrading to Health 2.0. *Modern Healthcare, 37*(49), 32-33.

In this article Conn describes two examples of Health 2.0 – the web portals PatientsLikeMe and Athenahealth - and compares Health 2.0 to Dale Dougherty and Tim O'Reilly's definition of Web 2.0. Health 2.0 features personally generated content and communication tools.

Covvey, H. D., & Fenton, S. (2009). *Challenges in the Realization of Effective Patient Portals*. Paper presented at the ITCH 2009 Revolutionizing Health Care with Informatics: From Research to Practice.
Active patient portals involve care providers in the development process, bridge hospital and homecare, and offer not only data to patients but also guidance and advice. Designed to engage patients and influence their behavior, active patient portals become a part of patient provider interaction by building on the EHR and PHR and bringing the content to patients and providers in a mutually-consumable form. In this article, the researchers note the challenges they came across in the design and development of an active portal for patients and caregivers coping with chronic kidney disease, and stress the need for patient involvement in the design process.

Crow, S., & Ondrusek, A. (2002). Video as a Format in Health Information. *Medical Reference Services Quarterly, 21*(3), 21-34.
Versatile and convenient, video is established as an effective means of conveying medical information. This article reviews the wide range of video technologies currently moving into the medical field, including videotapes, digital video, DVD, and online video.

Crowe, B., Maraj, A., Thatcher, M., Parrish, S., & Rogers, K. (2006). Development of a combined telemedicine and picture archiving and communication system for a tertiary hospital group. *Journal of Telemedicine and Telecare* 13(3): 35-36.
In this short article, authors Crowe and colleagues outline the coming together of a Picture Archiving and Communications System (PAC), a clinical portal system at the New Mater Mother's Hospital in Brisbane Australia that features tools for clinical administration, an electronic health record, and various clinical information systems. New features of the portal include image studies from the PAC that users can view before real-time teleconsultation through videoconference.

Cuggia, M., Herry, N., Rossille, D., Lepage, E., Edan, G., & Le-Beux, P. (2006). A model for a regional health information network sharing clinical information between professionals in Britanny. *Studies in health technology and informatics*, 449-454.
The NeuroBretagne Project in Britanny, France focuses on treating chronic neurological diseases like Parkinson's disease, multiple sclerosis and amyotrophic lateral sclerosis. Cuggia and colleagues describe a generic model of a Regional Health Information Network in this article. They emphasise the importance of adaptability and consistency for users over the interoperability of computer equipment and medical and software systems.

Dimick, C. (2008). The great PHRontier: private business stakes a claim in personal health records. *Journal of AHIMA, 79*(6), 25-28.
The journal of AHIMA staff writer Chris Dimick outlines the recent move by private companies into health care. In particular, Dimick describes products offered by Microsoft (Health Vault); Google (Google Health); Revolution Health, founded by Steve Case, co-founder of American Online; and Dossier, a non-profit organization set up by employers for employees, which is closed to the wider public. They offer PHRs delivered through web portals and are not meant for people who suffer from specific chronic illnesses. The portals offer features beyond the PHR, including health calculators and assessment tools.

Divis, K. L., Hardie, M., & Iuliano, B. B. (2007). THE UPSIDE OF PORTALS. (cover story). *Marketing Health Services, 27*(3), 14-20.

This short article examines the benefits of portals in relation to focus groups conducted with physicians at The Children's Hospital of Philadelphia (CHOP). In the focus groups, physicians expressed frustration with the existing referral system. The authors describe the implementation of an internal portal system for CHOPs and the evolution of the site's features.

Drake, M. (2007). Web-based patient empowerment. *Health Management Technology, 28*(9), 46-47.

Drake explores how the growing trend towards self-service technologies in other industries like airlines and banks might apply to the health care industry. By integrating tools like online health risk assessments, wellness suggestions, and disease management, patient portals can act as extensions of clinician care. Other compelling features of patient portals include links to electronic medical records, the development of online patient communities, and communication with health care providers, as well as mass communication on moderator-hosted blogs or health columns. Patient portals may also reduce costs by displacing many labour-intensive administrative activities (e.g. refill requests, appointment scheduling).

Duncavage, S., Mathe, J. L., Werner, J., Malin, B., Ledeczi, A., & Sztipanovits, J. (2007, Nov. 10-14, 2007). *A Modeling Environment for Patient Portals.* Paper presented at the 2007 American Medical Informatics Association Annual Symposium, Chicago.

In this article, the researchers introduce the Model-based Design Environment for Clinical Information Systems (MODECIS), a graphical design environment to assist CIS architects in formalizing systems and services. In order to evaluate MODECIS with the realities of patient care in mind, the researchers built on insights offered by the clinical operations of the Vanderbilt University Medical Center's MyHealth@Vanderbilt (MHAV) patient portal in Nashville, Tennessee.

Dunn, L. (2007). *A Knowledge Portal for the Illawarra Community Mental Health Rehabilitation Services Community of Practice.* Paper presented at the MedInfo 2007: 12th World Congress on Health (Medical) Informatics.

Dunn describes the initial stages of collaboration with the Illawarra Area Community Mental Health Rehabilitation Services (MHRS) in Australia to develop a knowledge portal for community mental health rehabilitation services. The goal of Dunn's paper is to develop a framework for mental health applications using service orientated portal architecture to provide a common standardized service and support location-based service applications.

Durfee, W. K., Savard, L., & Weinstein, S. (2007). Technical feasibility of teleassessments for rehabilitation. *IEEE transactions on neural systems and rehabilitation engineering a publication of the IEEE Engineering in Medicine and Biology Society, 15*(1), 23-29.

In this article, authors compare broadband video and audio, remote, and co-located assessments for the following clinical evaluation instruments: Berg sit-to-stand, Berg forward reach, manual muscle test (MMT), joint range-of–motion (ROM) and timed up and go (TUG). Durfee et al. found that the audio link was critical for communication between patients and therapists, as well as a one-way video link for therapists to monitor the actions of the patients. Videoconferencing was the main technology used in the study and the researchers note that the quality of the videoconference would be important for remote

assessments done in the home. Other technologies that could be used in the assessments include measurement instruments like pressure sensors to detect the start and end of the TUG test, or a digital dynamometer to measure resistance (an element used to calculate the MMT score).

Eboueya, M., & Uden, L. (2007). Benefits and Limitations of Portals. In A. Tatnall (Ed.), *Encyclopedia of Portal Technologies and Applications* (Vol. v. 1, pp. 75-81): Information Science Reference.

This short encyclopedia article defines portals before discussing portal technologies within educational settings.

Eccles, M. P., Whitty, P. M., Speed, C., Steen, I. N., Vanoli, A., Hawthorne, G. C., et al. (2007). A pragmatic cluster randomised controlled trial of a Diabetes REcall and Management system: The DREAM trial. *Implementation Science, 2*(1).

In an earlier study, researchers found that diabetes care improved with the introduction of a computerized registry in northeast England, but care then hit a plateau. In this article, the researchers present the results of a 12-month study of the portal system Diabetes Recall And Management: DREAM. The researchers found improvements in patient attendance during the study as well as improvement in adherence to 4/9 areas of recommended care including recording foot examination, dietary advice, blood pressure, and smoking status. They also found improvements in serum cholesterol levels. The impact of the intervention on prescribing was inconclusive in this study, as both groups showed no significant differences in drug usage.

Editorial. (2006). New-age PHR comes with decision-support, multiple opportunities for DM. *Disease management advisor, 12*(12), 140-142.

This short article discusses the use of PHR for disease management. In particular, the authors focus on the role of decision support in new-age PHR. New PHRs include interaction tools – not just data entered by institutions (like insurance claims and pharmacy information) but also patient-entered demographic data, information about medication, etc., serving to further engage patients in their own self-care, which leads to greater health care compliance.

Editorial. (2007) Patient portal designed for elderly patients. 15: 79-80.

This short article describes the University of Arkansas for Medical Sciences (UAMS) project that developed from an initiative with the UAMS Center of Excellence Center on Aging to improve communications between the institution and its elderly patients by using a patient portal. The UAMS department was surveyed to identify key portal features with implementation, patient benefits, and cost savings in mind.

Emelin, I. V., & Eltchiyan, R. A. (2007). Telemedicine portal and standardized clinical documents. *Medinfo, 12*(Pt 1), 267-269.

This article discusses the use of telemedicine in the Russian Federation. The authors note that certain web portals offer collaborative environments for telemedicine, like the Apollo portal in India, TempoBy in Germany, and the U.S. Military Health System portal, but these systems are not flexible or affordable enough for Russian telemedicine units (TU). The article outlines the structure of the TU portal wherein separate templates exist for different telemedicine events.

Erickson, J., & Diddee, A. (2007). *The Total Economic Impact of IBM Patient Portal Powered by WebSphere*: IBM.
The IBM Patient Portal is a customized site that acts as an access point for patient medical information. In this report, Forrester consultations examine the economic impact of the billing and account management module of the IBM Patient Portal.

Escallon, J., & Fonseca, A. (2008). *Email Communication Between Physicians and Patients.* Paper presented at the Medicine 2.0 conference, Toronto, 42.
In a study of 67 random e-mails sent to physicians by patients in a Canadian breast surgery setting, researchers Escallon and Fonseca found that the average length of these e-mails was very short – 146 words. The average adult reads about 120 words per minute, indicating that e-mail may be a cost effective means of communication.

Eysenbach, G. (2008). Medicine 2.0: Social Networking, Collaboration, Participation, Apomediation, and Openness*. Journal of Medical Internet Research,* 10(3), pp. 1-1.
Eysenbach, in this editorial, discusses the application of Web 2.0 for eHealth, specifically its value for the emergence of Personal Health Application Platforms and Personally Controlled Health Records. The theme of the Journal of Medical Internet Research for 2008 was Medicine 2.0 and Eysenbach's editorial discusses the importance of social networking tools in the creation of "second generation medicine" or Medicine 2.0 – the move towards empowering consumers. According to Eysenbach, combining PHR with social networking approaches creates new applications which he titles PHR 2.0, where participation and collaboration are key components.

Feng, X., & Winters, J. M. (2007). An interactive framework for personalized computer-assisted neurorehabilitation. *IEEE transactions on information technology in biomedicine a publication of the IEEE Engineering in Medicine and Biology Society, 11*(5), 518-526.
While patient portals are not mentioned in Feng and Winters' article, they discuss a consumer-centred web-based therapy for stroke survivors. The module framework they developed, UniTherapy, is designed for use in home environments and supports various types of assessment and therapy. In a pilot study, the motor skill levels of 8 stroke subjects were assessed as they played therapeutic games and participated in teletherapy sessions. 7 of the 8 stroke subjects found that the tasks captured their daily activities, and the majority were satisfied with the comfort and usability of the system, noting that they were motivated to engage in the therapy in order to increase their "high scores."

Finkelstein, S. M., Speedie, S. M., Xinyu, Z., Ratner, E., & Potthoff, S. (2006). *VALUE: Virtual Assisted Living Umbrella for the Elderly - user patterns.* Paper presented at the Engineering in Medicine and Biology Society, 2006. EMBS '06. 28th Annual International Conference of the IEEE.
The Virtual Assisted Living Umbrella for the Elderly (VALUE) was a randomized controlled trial of a home telehealth program in Minnesota that used broadband access for virtual visits and a patient portal for services, monitoring, and internet access. In this article, the technical infrastructure of the system and the results of focus groups with patients are discussed.

Freire, C., Reis, C., & Monguet, J. (2008). *eSchi - A Multimedia Portal for Schizophrenia Learning and Rehabilitation - Work in Progress.* Paper presented at the World Conference on E-Learning in Corporate, Government, Healthcare and Higher Education 2008, Chesapeake, VA.

The eTherapy project, designed to complement traditional learning and rehabilitation of schizophrenic patients in a psychiatric hospital in Barcelona, is described in this paper. The eSchi Project, developed at the Universitat Politecnica de Catalunha, delivers multimedia tools over the internet for schizophrenic patients and theorists. ESchi is an eLearning tool that teaches patients basic cognitive skills (i.e. motion skills and associating stimulus), supports family members and caregivers, and complements the traditional therapeutic process. The authors feel that eSchi can improve quality of life for those with schizophrenia while producing measurable results.

Fuji, K. T., Galt, K. A., & Serocca, A. B. (2008). Personal health record use by patients as perceived by ambulatory care physicians in Nebraska and South Dakota: a cross-sectional study. *Perspect Health Inf Manag*, 5, 15.

This study focuses on physician acceptance and usage of personal health records in Nebraska and South Dakota. According to the authors, physician awareness of personal health records remains low, and physicians need to be educated about the importance of patient access to health records.

Garrett, J. (2006). *Patient Portals - A powerful tool for delivering eHealth Patient Management Systems (poster abstract)*. Paper presented at the Clinical Oncological Society of Australia 33rd Annual Scientific meeting 2006. from http://www3.interscience.wiley.com/cgi-bin/fulltext/118593144/PDFSTART

The Charm Patient Portal is an application that provides disease management and support on the web for Australian oncology practices. This article abstract describes the features of the Charm portal as well as preliminary methods for evaluating the portal.

Gibbs, R., & Alexander, S. (2006). The Choose and Book service at 18 months old [patient management system]. *BJHC&IM British Journal of Healthcare Computing and Information Management, 23*(1), 18-20.

Gibbs and Alexander's article describes the Choose and Book system, an online booking system used by NHS patients in England. The system allows patients to choose the hospital and date/time for their medical appointments, allowing them to be actively involved in their health care.

Grant, R. W., Wald, J. S., Poon, E. G., Schnipper, J. L., Gandhi, T. K., Volk, L. A., et al. (2006). Design and implementation of a web-based patient portal linked to an ambulatory care electronic health record: Patient gateway for diabetes collaborative care. *Diabetes Technology & Therapeutics, 8*(5), 576-586.

The patient portal Patient Gateway in Boston is described by the authors in this article, who note that while patient portals for education, peer support and medical advice have been created, they generally do not link directly to EHRs shared between patients and physicians. As a result, these types of portals have had only a modest impact on care. When patient web portals link people with their care providers, these portals can potentially overcome many current barriers to health care.

Grant, R.W. Wald, Schnipper, J.L., Gandhi. T.K., Poon, E.G., Orav, E.J., Williams, D.H., Volk, L.A., et al. (2008). Practice-linked online personal health records for type 2 diabetes mellitus: A Randomized Control Trial. Arch Intern Med. 168(16): 1730.
The authors discuss a randomized trial of a web-based PHR directly linked to an EMR used by physicians in this Boston-based study involving 244 patients with type 2 Diabetes Mellitus. Patient demographics and outcomes of the PHR intervention are also discussed.

Grant, R. W., Wald, J. S., Volk, L. A., Williams, D. H., & Middleton, B. (2007). Adoption of an advanced diabetes patient portal in an academic primary care network. *Diabetes, 56*, A316-A316.
Grant and colleagues' abstract describes the outcome of a study on the diabetes-specific interface of Boston-based Partners Healthcare System patient portal. In their 11-week study involving 115 users, the researchers found that patients consenting to use the Patient Gateway (PG) portal were more likely to be white, male, commercially insured, younger, and healthier than the general patient population in the Partners Healthcare System.

Green, B. B., Cook, A.J., Ralston, J.D., Fishman, P.A., Catz, S.L., Carlson, J., et al. (2008). Effectiveness of Home Blood Pressure Monitoring, Web Communication, and Pharmacist Care on Hypertension Control: A Randomized Controlled Trial. *JAMA: Journal of the American Medical Association, 299*(24), 2857-2867.
A 3-group randomized trial was conducted by researchers working with Group Health, a nonprofit group serving residents of Washington State and Idaho. One group was told about their elevated blood pressure (BP) and instructed to work with their physicians to improve it. A second group was given a home BP monitor, instructions, and training about the website. A third group was given the same tools and training as the second, but was also given direct pharmacist assistance through web messaging. The findings from the follow-up indicate that patients engaged in the web-based care plus communication with pharmacists improved their BP rates the most quickly. This study supports previous research that shows that when people engage in their own health care management, health outcomes can improve.

Greene, J. (2007). The personal health record: a key to improving health care for seniors. *AHIP Coverage, 48*(5), 46-48.
Greene notes that seniors may benefit the most from maintaining personal health records; they will become more self-aware of their conditions, more likely to seek out information, and more inclined to discuss treatment with health professionals. This article discusses the importance and uses of the PHR by giving numerous examples of U.S. companies designing and implementing PHRs through web portals.

Hermens, H., Huijgen, B., Giacomozzi, C., Ilsbroukx, S., Macellari, V., Prats, E., et al. (2008). Clinical assessment of the HELLODOC tele-rehabilitation service. *Annali dell'Istituto superiore di sanita, 44*(2), 154-163.
The clinical effectiveness of the home activity care desk (H-CAD) used in the EU project "Healthcare service linking telerehabilitation to disabled people and clinicians" (HELLODOC) is investigated in this article. Recruits for the study were patients who had suffered a stroke, traumatic brain injury, or had multiple sclerosis. The findings of the clinical trial demonstrated, through an active control equivalence study, that the intervention method featuring at-home therapy via the H-CAD system was at least as good as usual care for arm/hand functioning. With this system, when patients receive therapy at home,their therapy time is increased at the same time as therapist time and effort decreases. The

researchers conclude that the H-CAD system is a good alternative to regular care for the rehabilitation of TBI, stroke, and MS patients.

Herriman, E., & Cerretani, J. (2007 (August)). Patient Non-adherence - Pervasiveness, Drivers, and Interventions [Electronic Version]. *Informed Care Spotlight*, *2*, 1-6 from http://www.northpointdomain.com/newsletters/ar/spotlight0807.pdf

While patient portals are not specifically named as an adherence intervention, Herriman and Cerretani found a growing body of literature demonstrating that internet-based adherence programs can be even more effective than traditional treatment instructions. Patients' attitudes and beliefs can be gauged on the internet and the content of the treatment support can be customized to the individual patient. Also, the internet can be a channel for interactive and dynamic programs that can engage patients in self-monitoring, educational programs, and patient/provider exchange. They conclude that internet adherence interventions may be particularly effective tools to aid in disease management, provide better patient outcomes, and lower health care costs.

Hess, R., Bryce, C. L., McTigue, K., Fitzgerald, K., Zickmund, S., Olshansky, E., et al. (2006). The diabetes patient portal: Patient perspectives on structure and delivery. *Diabetes Spectrum, 19*(2), 106-110.

In this short article, the authors describe a diabetes-specific portal, the University of Pittsburgh Medical Center (UPMC) HealthTrak portal, which is linked to an electronic medical record system. The features of the site, patient preferences, as well as future research directions are all discussed.

Hess, R., Bryce, C. L., Paone, S., Fischer, G., McTigue, K. M., Olshansky, E., et al. (2007). Exploring challenges and potentials of personal health records in diabetes self-management: Implementation and initial assessment. *Telemedicine Journal and E-Health, 13*(5), 509-517.

UPMC HealthTrak was developed by the University of Pittsburg Medical Center (UMPC). Hess and colleagues describe the challenges to implementation and patient reaction to the UPMC HealthTrak Chronic Care Module for diabetes care in this article.

Holden, M. K., Dyar, T. A., & Dayan-Cimadoro, L. (2007). Telerehabilitation using a virtual environment improves upper extremity function in patients with stroke. *IEEE transactions on neural systems and rehabilitation engineering a publication of the IEEE Engineering in Medicine and Biology Society, 15*(1), 36-42.

Holden and colleagues describe the design of a virtual environment designed for telerehabilition as well as the results of a study of 11 stroke recovery patients. Using the system, patients can receive therapist-run treatment while remaining at home. The authors find clinically and statistically significant findings for patient improvement indicating that remote VE training could be used for neuro-telerehabilitation. The authors also note that greater gains are seen after longer sessions and suggest that perhaps people recovering from stroke are not being treated long enough.

Hughes, G., Hudgins, B., Hooper, J. E., & Wallace, B. (2003). User satisfaction with rehabilitation services delivered using Internet video. *Journal of telemedicine and telecare, 9*(3), 180-183.

The case study for this article examines rehabilitation services delivered by the Institute of Biomedical Engineering (IBME) at UNB, the New Brunswick Easter Seal March of Dimes (NBESMOD), the Stan Cassidy Centre for Rehabilitation (SCCR), and community-based

therapists through videoconference. Hughes and colleagues conclude that the use of videoconference technologies can help clinicians identify and address problems within their clients' homes and communities.

Jenko, M., Pustisek, M., Bester, J., & Marincek, C. (2005). Web Portal for Traumatic Brain Injury Rehabilitation Support. In A. Pruski & H. Knops (Eds.), *Assistive Technology: From Virtuality to Reality*: IOS Press, 86-90.

In this article, the structure and organization of an anonymous portal for traumatic brain injury (TBI) for people in Slovenia is discussed. The portal, called "Head up" is an "ad hoc" support group. It is created by the group "Veterans" that meets in person once a month after rehabilitation at the Institute for Rehabilitation in Slovenia. The portal provides information about TBI and acts as a means of communication. It is meant not to replace direct contact with specialists, but to act as additional support for members and their families.

Johnson, M., Loureiro, R. C. V., & Harwin, W. (2008). Collaborative Tele-rehabilitation and Robot-mediated therapy for Stroke Rehabilitation at Home or Clinic. *Intelligent Service Robotics, v. 1*(2), 109-121.

Home-based rehabilitation for stroke survivors involves the therapist overseeing patient performance and care, and telerehabilitation can be used to provide regular contact. Furthermore, the authors hypothesize that collaborative play is important for stroke survivors to engage and connect with others. In this paper, Johnson and colleagues investigate tele-cooperation and tele-therapy using two 6DOF robot-mediated environments to pilot a tele-rehabilitation protocol. In this study, Johnson et al. found a trend in favour of the collaborative robot-mediated environment because respondents found it more interesting and engaging to play against each other using the robot than to use just the computer program and telerehabilitation.

Juzwishin, D. (2009). *Health 2.0, Medicine 2.0 and Web 2.0: Enabling technologies for practice, policy and systems*. Paper presented at the ITCH 2009 Plenary - Revolutionizing Health Care with Informatics: From Research to Practice.

In his presentation, Jurwishin discusses the need for change in the health care system and suggests that the critical condition needed for change is the power and the will of patients, providers, and governments to improve the system through collaboration. In order to achieve change, Jurwishin states we need to culturally reform the structure and the processes of the system rather than attempt to impose e-health onto the existing system.

Katzenbeisser, S., & Petkovic, M. (2008). *Privacy-Preserving Recommendation Systems for Consumer Healthcare Services.* Paper presented at the Availability, Reliability and Security, 2008. ARES 08. Third International Conference on Availability, Reliability and Security. 889-895.

Cryptographic privacy protocols for protecting consumer eHealth services are discussed in this article. The researchers describe different scenarios in which cryptographic privacy can be applied to the use of PHRs.

Keshavjee, K., Manji, A., Singh, B., & Pairaudeau, N. (2009). *Failure of Electronic Medical Records in Canada: A Failure of Policy or a Failure of Technology?* Paper presented at the ITCH 2009. Revolutionizing Health Care with Informatics: From Research to Practice.

Compared to other OECD countries, Canada's EMR implementations have lagged behind. Keshavjee and colleagues investigate the reasons why, and point to policy issues, cost benefit analysis, and implementation challenges.

Kim, C., Park, J., Kim, H., Noh, T., Nam, J., Ahn, C., et al. (2006). Internet diabetic patient management system using short messaging service automatically produced by knowledge matrix system.. *Diabetes Care* 30(11): 2857- 2858.

Acknowledging that wireless communication technology is ubiquitous and most adults and youth have cell phones, the researchers designed a diabetic management system that uses short message services. A knowledge matrix was developed based on diet and exercise information in the Korea Staged Diabetes Management Guideline. The researchers also developed a dual functioning glucometer / pedometer device that automatically transmits data when connected to the patient's cellular phone. The authors state the need for long-term studies to see if other health measures are affected and suggest that an internet diabetic management system may be more effective than conventional management.

Kim, E. H., Stolyar, A., Lober, W. B., Herbaugh, A. L., Shinstrom, S. E., Zierler, B. K., et al. (2007). Usage patterns of a personal health record by elderly and disabled users. *AMIA Annual Symposium proceedings AMIA Symposium*, 409-413.

In an examination of PHR use by low income elderly and/or disabled users in federally-funded housing near Seattle Washington, researchers investigate what features this demographic uses most often. They found that the medication section of the PHR was the most frequently updated category, followed by health problems. Lab tests were the second least-used field – perhaps because patients often neglect to option paper copies of results and cannot rely on their memories to populate that field in the PHR. Immunizations was the most infrequently updated category in the PHR.

Koivunen, M., Hatonen, H., Valimaki, M. (2008). Barriers and facilitators influencing the implementation of an interactive internet portal - application for patient education in psychiatric hospitals. *Patient Education and Counseling*, 70(3), 412-419.

This study was conducted as part of the Finnish Mieli.Net project which evaluates information technology used for in-hospital psychiatric patient education. Random trials were conducted on two groups of nurses: one using the portal for education sessions, the other using written materials. Questionnaires were administered with open ended questions on barriers and support for usability. The nurses' IT skills and attitudes towards computers were also measured.

Koivunen, M., Valimaki, M., Pitkanen, A., & Kuosmanen, L. (2007). A preliminary usability evaluation of Web-based portal application for patients with schizophrenia. *Journal of Psychiatric and Mental Health Nursing, 14*(5), 462-469.

Researchers evaluated the reaction of nursing staff to the quality and functionality of Mieli.Net – a Finnish portal used for educating in-hospital psychiatric patients. Nurses rated voice files and photos highly because they felt voice and visual elements made the information more relevant for the patients.

Koonce, T. Y., Giuse, D. A., Beauregard, J. M., & Giuse, N. B. (2007). Toward a more informed patient: bridging health care information through an interactive communication portal. *Journal of the Medical Library Association, 95*(1), 77-81.
This paper reports on the collaboration among Eskind Biomedical Library (EBL) and the informatics and clinical teams on the MyHealthatVanderbilt (MHAV) portal. The role of the EBL was to select for the portal the best online consumer sources containing disease topics relevant to the patient. Future plans include adding to the 25 current health topics and getting feedback via focus groups in order to increase usage.

Krohn, R. (2007). The consumer-centric personal health record--it's time. *Journal of healthcare information management JHIM, 21*(1), 20-23.
Krohn notes that there is no uniform definition of the personal health record and describes various types of PHR, from stand-alone models populated only by the patient to the PHR health plan, as well as patient portals that allow input for multiple sources, alerts, and messaging.

Kuhn, P. (2008). Patient portals. *Health management technology, 29*(10), 44.
Kuhn notes that over 70% of participants in a 2008 Deloitte Survey of Health Care Consumers wanted their hospital to provide access to their medical information online; however, connecting to EMRs is challenging. Various EMR solutions are used by physicians, making it likely that in a single community, a hospital portal might have to interface with many distinct EMRs. Motivating factors include consumer demand for improving value and tracking costs. In terms of time savings, Kuhn notes that there is a 3 to 1 variance comparing telephone to online services, where a task taking 3 minutes for hospital/clinical staff to accomplish on the phone can be done by the patient in 1 minute, saving substantial time when multiplied according to usage. Patients are also given a convenient alternative to traditional means of scheduling appointments, etc. (i.e. can be done at any time, and requests can be handled by staff at non-peak hours).

Lai, A. M., Kaufman, D. R., & Starren, J. (2006). Training digital divide seniors to use a telehealth system: a remote training approach. *AMIA Annual Symposium proceedings AMIA Symposium*, 459-463.
While telehealth is important for patients in rural and remote areas, training can sometimes be an issue (in-person training is costly and time consuming). One solution is to remotely educate patients about their home telemedicine unit (HTU) – in this case, by instituting the IDEATel project for diabetes care of underserved inner-city and rural residents in the United States. The Remote Patient Education in a Telemedicine Environment (REPETE) system, delivering visual and audio teaching modes over low bandwidth, is discussed in this proof-of-concept article.

Law, V. (2008). *Internet Use Among Occupational Therapists in Their Clinical Practice.* Paper presented at the Medicine 2.0 conference, Toronto, 44.
Law's study examines patterns of internet use by occupational therapists in clinical practice. In this abstract, she reports the findings of 1382 surveys completed by Ontario occupational therapists. The majority of respondents were women working in urban areas who noted that the top facilitators for internet use were accessibility to a computer at work, a work culture that enables and encourages internet use, and access to technical support. Time to access the internet and concerns about privacy issues were also mentioned. As a result of the survey Law sees the need for technical training as well as regulatory guidelines for clinical use of e-mail.

Lee, M., Delaney, C., & Moorhead, S. (2007). Building a personal health record from a nursing perspective. *International Journal of Medical Informatics, 76*(s2), S308-S316.

The role of nursing is essential to health care, but is not often explored in PHRs. The authors in this article explore the role of the nurse in the development of the PHR by reviewing existing literature and creating IowaPHR, a patient portal with various features that are evaluated by nursing staff.

Leese, G. P., Boyle, D. I. R., & Morris, A. D. (2006). The Tayside Diabetes Network. *Diabetes Research and Clinical Practice, 74*(SUPPL. 2): S197-S199.

The Tayside Diabetes Network is a portal used in Scotland by medical professionals. This short article describes the research applications of the portal as well as the clinical system that links health care providers.

Leonard, K. J., Casselman, M., & Wiljer, D. (2008). Who will demand access to their personal health record? A focus on the users of health services and what they want. *Healthcare Quarterly, 11*(1), 92-96.

In this article the authors focus on people with chronic conditions – illnesses that affect 40% of the population and account for 70% of health care spending. By offering electronic delivery of some regular services to patients, like routine test results, Canada's health care system could save approximately $5 billion dollars a year. The authors advocate an electronic delivery system – a website or e-mail system – so that patients have access to their Personal Health Records.

Leveille, S. G., Huang, A., Tsai, S. B., Weingart, S. N., & Iezzoni, L. I. (2008). Screening for chronic conditions using a patient internet portal: Recruitment for an internet-based primary care intervention. *Journal of General Internal Medicine, 23*(4), 472-475.

Patient portals are an efficient means of providing patients from Boston's Beth Israel Deaconess Medical Center (BIDMC) with access to their medical records as well as a means of communicating with health professionals. Portals can also be used to screen people for potential illness. In a 2007 survey, 981 PatientSite users participated in an online survey screening for the following chronic problems: chronic pain, mobility difficulty, and depression. Researchers found that the portal screening tool efficiently identified chronic conditions.

Lin, C. T., Wittevrongel, L., Moore, L., Beaty, B. L., & Ross, S. E. (2005). An internet-based patient-provider communication system: Randomized controlled trial. *Journal of Medical Internet Research, 7*(4).

This article is a randomized controlled study of online messaging over the University of Colorado Hospital's patient portal "My Doctor's Office." Patient satisfaction with the portal was high, with the majority of patients reporting they would be more likely to use the messaging system than the telephone for non-urgent messages (85%). One message was sent per day for every 250 portal patients involved in the study. Staff spent about 8 hours/day answering phones and 5 minutes a day responding to portal messages. Phone calls from the portal group were slightly less frequent than those from the control, but the difference was not statistically significant. Portal patients were more satisfied than the control group with their communication with the clinic and overall care.

Lindsay, S., Bellaby, P., Smith, S., & Baker, R. (2008). Enabling healthy choices: is ICT the highway to health improvement? *Health, 12*(3), 313-331.

The health portal Hearts of Salford is designed for people living in Salford who have heart disease. Researchers administered questionnaires to 108 men and women between 50-74 years old, all of whom received computers and a 1-year broadband subscription, with only half receiving access to the portal. They gathered baseline and 6-month responses from all participants on questions related to exercise, smoking, diet, and mental health. The content of discussion forums on the patient portal was also analyzed. Researchers found an increase in the number of health visits, a slight improvement in diet, and a decrease in alcohol consumption and exposure to second hand smoke in the portal group. The control group experienced significantly less social support over time and poorer mental health, poorer diet, and more frequent health visits.

Liu, Q., Lu, S., Hong, Y., Wang, L., & Dssouli, R. (2008). *Securing telehealth applications in a Web-based e-health portal.* Paper presented at the ARES 2008 - 3rd International Conference on Availability, Security, and Reliability, Proceedings, Barcelona, 3-9.

Telehealth applications are important tools for delivering of medical services to rural and remote locations; however, these applications have to deal with issues of trust. In the article, the authors study two security issues: the lack of visual proofs and the complexity of telehealth applications. They suggest a public key infrastructure using biometric-based authentication to establish trust as well as an access control method for work-flow using a module already established in the portal system.

Lobach, D. F., Willis, J. M., Macri, J. M., Simo, J., & Anstrom, K. J. (2006). Perceptions of Medicaid beneficiaries regarding the usefulness of accessing personal health information and services through a patient Internet portal. *AMIA Annual Symposium proceedings AMIA Symposium,* 509-513.

In this pilot study of 31 Medicaid beneficiaries in Durham, North Carolina, the authors investigate interest in internet portals and access to the internet. They found that there was considerable interest in a patient portal and that most people in their study had internet access.

Lu, S., Hong, Y., Liu, Q., Wang, L., & Dssouli, R. (2008). *Access control in e-health portal systems.* Paper presented at the Innovations'07: 4th International Conference on Innovations in Information Technology, IIT, Dubai, 88-92.

eHealth portal systems can be created using special-purpose architectures or off-the-shelf software. This article examines the security insufficiencies of off-the-shelf components and proposes a 2-tier system for secure access control of a general e-Health portal.

Ma, C., Warren, J., Phillips, P., & Stanek, J. (2006). Empowering patients with essential information and communication support in the context of diabetes. *International journal of medical informatics, 75*(8), 577-596.

Violet Technology (VT), the collective implementation of a Diabetes Information Profile (DIP), is described and evaluated in this paper. Twelve participants were recruited from the Endocrinology Department and the Diabetes Center of the Queen Elizabeth Hospital, Adelaide, South Australia. VT was implemented through a portal that also contains services for patients and providers to view and edit EMRs and computerized forms.

Mandl, K. D., Simons, W. W., Crawford, W. C., & Abbett, J. M. (2007). Indivo: a personally controlled health record for health information exchange and communication. *BMC Medical Informatics and Decision Making,* 7(25).
This article describes the INDIVO system – a personally controlled health record deployed in 2007 at the Children's Hospital in Boston. Patients have control over sharing, annotating, and customizing their records, within certain limits.

Maté, C. (2006). *Austrian E-Health Experience: Economic Framework for Consumer Health Portals*. Paper presented at the 1st World Congress of Teledermatology, 1012.
While many health portals begun in the early 1990s collapsed during the dot.com bust, the Danish company Net-Doktor.at survived in the Austrian market. Mate discusses its success in this paper.

Mathe, J. L., Duncavage, S., Werner, J., Ledeczi, A., Sztipanovits, J., & Malin, B. (2007). Towards the security and privacy analysis of patient portals. *ACM SIGBED Review, 4*(2), 5-9.
This article discusses the technical infrastructure behind the Nashville-based patient portal MyHealth@Vanderbilt, in particular a graphical design environment called the Model-based Design Environment for Clinical Information Systems (MODECIS). MODECIS models information technology was applied to clinical processes or Clinical Information Systems (CIS) on an abstract level in order to meet CIS security, utility, and policy requirements. The authors note that MODECIS is still a work in progress.

McCartney, P. R. (2008). The new networking. The electronic personal health record. *MCN: The American Journal of Maternal Child Nursing, 33*(6), 390-390.
Nurses are active participants in promoting self-care; this article explains personal health records to nurses. Portals discussed include Google Health and Microsoft. McCartney urges nurses to investigate the portal to learn about its features, resources, policies, and health IT terms, and to discuss these issues with their colleagues.

McGeady, D., Kujala, J., & Ilvonen, K. (2008). The impact of patient-physician web messaging on healthcare service provision. *International Journal of Medical Informatics, 77*(1), 17-23.
Web messaging is currently one of the portal functions most widely accepted by patients; however, physician uptake of the technology has been slow. This article reviews the body of literature surrounding patient-physician web messaging and discusses the fears, costs, and potential benefits of online messaging between patients and physicians.

Meagher, R. (2006). Tertiary telerehabilitation web based store and forward initiative project report. River Valley Health, Fredericton, N.B. 269 pages.
Meagher's report discusses a collaborative project between the National Research Council and River Valley Health, initiated to investigate the current utilization of telerehabilitation technologies. Emphasis was placed on patient portals and store-and-forward technologies.

Miller, C., & Larmore, N. (2007). Vision of the future. Patient portals advance the environment of care. *Health facilities management, 20*(7), 23-26.
This short article discussed the infrastructure, uses, and benefits of patient portals used in U.S. hospital for entertainment, education, and health care information. In particular, Millar stresses the importance of using videoconference to the future of health care.

Molyneaux, H., Gibson, K., Simms, D., O'Donnell, S., Oakley, P., Kondratova, I., McIver, W., Lumsden, J., Fournier, H., and Hagerman, V. (2009). Information and Communication Technologies for Assessing and Treating Operational Stress Injury (OSI). Fredericton: National Research Council. 114 pages. ERB-1159. NRC 50740
Operational stress injury (OSI) and posttraumatic stress disorder (PTSD) are health issues faced by many Canadian veterans of military operations in the previous century and more recently in Afghanistan. Assessing and treating OSI and PTSD is complex and costly. This report reviews current and recent research on how information and communication technologies (ICT) can be used effectively for this purpose.

Moore, M., & Kaercher, D. (2008). Healthy Texas: The Eight-Year Odyssey of a Community Health Web Portal. *Journal of Consumer Health on the Internet, 12*(2), 95-104.
Healthy Texas is a South Texan website developed by 40 health organizations for lower health and computer literate audiences to provide directories, regional health information, and a place for health consumers to communicate with each other. Moore and Kaercher describe the creation and design of the portal.

Morelli, S., Maccioni, G., Lanzetta, M., Macellari, V., & Giansanti, D. Morelli, S. (2008). A home-care system for the telemonitoring and telerehabilitation of the hand incorporating interactive biofeedback. *Journal of Telemedicine and Telecare, 14*(7), 372-376.
Authors Morelli and colleagues describe a hand monitoring/Telerehabilitation system that incorporates two sensors (one to measure finger force and hand posture; the other for measuring the force of the thumb), biofeedback software, and interactive videoconference. Their system, designed for in-home use by post-stroke patients or patients with hand injuries, was used for telerehabilitation follow-up for five patients recovering from hand-transplant surgery. Patients and therapists found the system effective and user-friendly.

Nazi, K. M., & Woods, S. S. (2008). MyHealtheVet PHR: A Description of Users and Patient Portal Use. *AMIA Annual Symposium proceedings AMIA Symposium,* 1182.
Nazi's investigation of the MyHealth*e*Vet health record randomly sampled visitors via an online survey. In this paper, Nazi describes the demographic responses of those surveyed as well as their use of the various features on the site.

Nelson, R. (2007). The Personal Health Record: Digital Information is Easy to Access, But is it Secure? *American Journal of Nursing, 107*(9), 27-28.
Nelson's short article on Personal Health Records discusses the need for standardization and reviews several PHR and EHR, some of which are available via web portals.

Nijland, N., Van Gemert-Pijnen, L., Kelders, S., Brandenburg, B., & Seydel, E. (2008). *Evaluation of the Use of an Interactive Web-Based Support Program for Optimizing the Management of Diabetes Mellitus.* Paper presented at the Medicine 2.0 conference, Toronto, 37.

In this extended abstract, the authors discuss the results of the usability tests of Diabetescoach, a self-management support program created by Medicinfo, a leading e-Health company in the Netherlands.

Nordfeldt, S., Hanberger, L., Timpka, T. (2008) *Health professionals' attitude toward using an internet portal for child and adolescent diabetes care.* Paper presented at the Medicine 2.0. conference, Toronto, 45.

Internet-based technologies have been employed to improve diabetes care, but have had little clinical application in pediatric diabetes clinics. This study investigates health professionals' attitudes about a portal for youth with diabetes through interviews conducted after they have participated in a user-centred portal design process.

O'Brien, J., & Duffy, J. (2008). *Primary Healthcare in Canada: Technology Adoption, Drivers, and Investment*: IDC.

Health care in Canada is changing into a fully integrated system that involves the patient while improving the management of costs. A variety of services and applications such as the electronic health record, adverse drug tracking, and e-prescribing can help. O'Brien and Duffy's study investigates developments in IT and Health care in Canada and discusses adoption, application sourcing (specifically health care applications), and future needs.

Parmanto, B., Saptono, A., Murthi, R., Safos, C., & Lathan, C. (2008). Secure Telemonitoring system for Delivering Telerehabilitation Therapy to Enhance Children's Communication Function to Home. *Telemedicine and e-Health, 14*(9), 905-911.

In this article, the authors discuss the transformation of the stand-alone speech therapy software system CosmoBot into a secure telemonitoring system that links speech therapists to children remotely. Future developments will involve live monitoring by videoconference to support telerehabilitation therapy, and a user-centered design evaluation to gather quantitative evidence of the impact of the system on therapeutic outcomes.

Podichetty, V. K., & Varley, E. (2006). e-Talking to Patients: Connecting with the Health Care Consumer, *Journal of the American Medical Informatics Association* 13(5), 579-579.

Responding to Weingart et al.'s 2006 article on users of the patient portal The PatientSite, Podichetty and Varley state that the demographics of the physicians using the portal need to be taken into account. In particular they note that web portals are two-way communication tools and both types of users – physicians and patients – need to be examined in order to develop successful patient portals.

Popescu, G. V., Burdea, G., & Boian, R. (2002). Shared virtual environments for telerehabilitation. *Studies in health technology and informatics*, 362-368.

Offline remote monitoring (store-and-forward and video-based systems) were used for virtual reality environments in telerehabilitation. With the use of internet connections, telerehabilitation, like remote therapy, can be monitored by therapists in real-time through a

portal. In this article, Popescu and colleagues discuss the therapist interface of a virtual environment shared by the patient and the therapist.

Rahman, A. S., Naessens, J. M., Cabanela, R. L., & Anderson, S. S. (2006). Primary care physician portal--delivering practice information at the finger tip. *AMIA Annual Symposium proceedings AMIA Symposium, 1069*.
The authors describe the Primary Care Physician Portal (PPP), a portal used by care teams, Mayo Clinic Primary Care physicians, and administrators. Through the PPP, care teams can remind patients about preventive care services and can track utilization patterns, measure the quality of care given to patients, and assist in making strategic health care decisions.

Raisinghani, M. S., & Young, E. (2008). Personal health records: key adoption issues and implications for management. *International Journal of Electronic Healthcare, 4*(1), 67-77.
In order to explore why personal health records have not been universally adopted, Raisinghani and Young define the different types of personal health records and explore financial, technical, and cultural impediments.

Ralston, J. D., Carrell, D., Reid, R., Anderson, M., Moran, M., & Hereford, J. (2007). Patient Web Services Integrated with a Shared Medical Record: Patient Use and Satisfaction. *Journal of the American Medical Informatics Association, 14*(6), 798-806.
This research reports on the results of a random sample of MyHealthGroup users in Washington and Idaho who were administered surveys by mail. The survey results demonstrated high levels of overall satisfaction with the site in general, and users responded extremely favorably to features that enabled greater client-clinician communication.

Raths, D. (2009). CIOs Know that Empowering Patients Goes a Long Way Toward Improving Care, and Building Loyalty. *Healthcare Informatics*, 45-46, 49.
Raths describes several high-profile portals in this article, including the Seattle-based patient portal MyGroupHealth (from the Group Health Cooperative), the Duke University Health System HealthView patient portal, and Epic's MyChart EHR used by Cleveland Clinic and Kaiser Permanente.

Ridley, G., & Young, J. (2006). Towards evaluating health information portals: a Tasmanian E-health case study. *Int J Electron Health, 2*(1), 79-91.
Various criteria are used to evaluate health information portals. In their literature review, Ridley and Young identify many key success factors including access, accuracy, audience, timelines, authority, content, and privacy. Ridley and Young's case study concerns the Health Access for Rural Tasmanians (HART) portal and its implementation and use by residents in Lilydale, a small rural community in north-east Tasmania, Australia. A range of Australian portals were identified, but no niche competitors were found.

Rosenthal, E. T. (2007). The Evolution of Revolution: New Health Web Portal [Electronic Version]. *Emergency Medicine News*, 29(7), 28. Retrieved Dec. 3, 2008 from http://www.em-news.com/pt/re/emmednews/pdfhandler.00132981-200707000-00033.pdf;jsessionid=JQWJs0pfP6ddrFqZ6zSnnPt2Cyps02RkbysGYQBKfpvQMSrKzjTP!-269263472!181195628!8091!-1.

The patient portal Revolution Health, created by AOL co-founder Steve Case, was created to empower people and offers a customizable home page and various online tools, resources, health care information and links to an online community.

Ross, S. E., Haverhals, L. M., Main, D. S., Bull, S. S., Pratte, K., & Lin, C. T. (2006). Adoption and use of an online patient portal for diabetes (Diabetes-STAR). *AMIA Annual Symposium proceedings AMIA Symposium,* 1080.

The authors discuss an intervention involving patients with type 2 diabetes at 3 primary care clinics and 1 practice at the University of Colorado Hospital. The control group was given communication functions and general diabetes information over a portal, while the intervention group accessed personalized content and a system to set goals and provide automated feedback. More substantial usage was seen in the intervention group.

Rostad, L. (2008). *An Initial Model and a Discussion of Access Control in Patient Controlled Health Records.* Paper presented at the Availability, Reliability and Security, 2008. ARES 08. Third International Conference on Availability, Reliability and Security, 935-942.

Patient Controlled Health Records (PCHR) are currently used to collect and distribute health information. In this article, Norwegian researchers investigate the use of Role-Baser Access Control (RBAC) for health care systems, especially for use in PCHR where the patient assigns roles to users so that others (family members, physicians) can access portions of the health record.

Ruland, C. M., Brynhi, H., Andersen, R., & Bryhni, T. (2008). *Developing a shared electronic health record for patients and clinicians.* Paper presented at the Studies in Health Technology and Informatics, 57-62.

Ruland and colleagues discuss the development of CONNECT (Care Online: Novel Networks to Enhance Communication and Treatment), a Norwegian patient portal with communication tools and a shared electronic health record.

Russell, T. G. (2007). Physical rehabilitation using telemedicine. *Journal of telemedicine and telecare, 13*(5), 217-220.

Russell's article defines and provides a literature review of telerehabilition and the various technologies used for telemedicine, including image-based, sensor-based, and virtual environments. He concludes that research on telerehabilition has been largely focused on technology and contains single or small case sizes. Researchers need to demonstrate the viability of technology use for telerehabilitation and investigate the cost benefits and effectiveness.

Sajedi, M., & Kushniurk, A. W. (2009). *"Physicians' Adoption Score" - Physicians are not a Homogeneous Group*. Paper presented at the ITCH 2009. Revolutionizing Health Care with Informatics: From Research to Practice.

Physicians are not all the same, and adoption rates of patient portals differ among physicians according to a variety of factors. In this article, Sajedi and Kushniruk propose a physician adoption scoring method. The validation of their method is currently in its testing

phase. In their scoring methodology, various factors including age, geographic location, area of specialty, and patient/provider ratios are taken into consideration when estimating physician adaption rates.

Schnipper, J. L., Gandhi, T. K., Wald, J. S., Grant, R. W., Poon, E. G., Volk, L. A., et al. (2008). Design and implementation of a web-based patient portal linked to an electronic health record designed to improve medication safety: The Patient Gateway medications module. *Informatics in Primary Care, 16*(2), 147-155.

The researchers in this article investigate the Patient Gateway Medication module on the Patient Gateway portal. Patient Gateway is a delivery network that includes 4 rehabilitation and long-term care facilities, 5 acute care hospitals, and a large network of specialty and primary care physicians in Massachusetts. The medication module is a type of journal devoted to medication regimes, side effects, refills, etc. The preliminary findings of authors indicate that a medications module could potentially improve medication safety, but patients and physicians need to be educated about the importance of communicating medication discrepancies.

Shah, N. R., Jones, J. B., Daar, Z., & Stewart, W. F. (2006). Are early adopters of a web-based patient portal more activated than matched controls? *Journal of General Internal Medicine, 21*, 14-14.

The researchers conducted phone interviews and sent questionnaires to patients of Geisinger Clinic Community Practice sites who were diagnosed with cardiovascular disease, chronic heart failure, or diabetes mellitus. Patients were asked questions that would measure and assess their ability and confidence in managing their own health. Portal users were compared to non-portal users. The demographics of early adopters of portals are reported.

Shaw, E., Howard, M., Chan, D., Waters, H., Kaczorowski, J., Price, D., et al. (2008). Access to web-based personalized antenatal health records for pregnant women: a randomized controlled trial. *Current Medical Literature: Gynecology & Obstetrics, 13*(3), 38-43.

In this study of a patient portal designed for pregnant women, researchers evaluate uptake and satisfaction with information shared between health care providers and patients at the Maternity Centre in Hamilton, Ontario. They found that the portal was used more frequently when personal information rather than just general educational information on pregnancy was provided.

Silver, M. (2007). Portal Authority. *Cure* (Summer 2007).

Curetoday.com is an online website for cancer patients. In this article, Silver describes patient portals, noting they are especially beneficial for patients with chronic illnesses like cancer.

Siteman, E., Businger, A., Gandhi, T., Grant, R., Poon, E., Schnipper, J., et al. (2006). Clinicians recognize value of patient review of their electronic health record data. *AMIA.Annual Symposium proceedings / AMIA Symposium. AMIA Symposium*, 1101.

Clinician attitudes towards patient portals are investigated in this conference paper abstract. Authors Siteman et al surveyed 72 providers in Massachusetts. While 52% of clinicians believe their workload would increase as a result of a patient portal, 51% stated their

patients' knowledge and awareness of their own health would increase and 57% felt their communication with patients would improve.

Siteman, E., Businger, A., Gandhi, T., Grant, R., Poon, E., Schnipper, J., et al. (2007). Physicians value patient review of their electronic health record data as a means to improve accuracy of medication list documentation. *AMIA Annual Symposium proceedings AMIA Symposium,* 1116.

The authors conducted a pre- and post-implementation study of primary care providers at 11 practices in Massachusetts to gauge clinician attitudes about patient access to electronic health records on the patient portal Patient Gateway (PG). A subset of the patients were asked to review their medication list and alert their primary care providers if any changes were needed. In the post-implementation survey, health care providers reported fewer concerns about potential negative effects.

Simms, D., O'Donnell, S., and Molyneaux, H. The Use of Virtual Reality in the Treatment of Posttraumatic Stress Disorder (PTSD). 2009 International Conference on Human-Computer Interaction (HCI International). San Diego, CA, USA. July 19-24, 2009.

Interest in the treatment of PTSD is increasing with concerns about the psychological effects of war on troops. The authors performed a comprehensive literature review on virtual reality (VR) for treating combat-related PTSD. Canada's primary institute for scientific and technical information (NRC-CISTI) performed the initial literature search in 2008. Of 296 items which met inclusion criteria, 20 pertained to VR in the treatment of mental health. An additional 20 more recent items were added in 2009, making a total of 40 items reviewed. Of those, 6 empirical studies involved patients with PTSD. VR exposure therapy (VRET) has been successfully used to treat anxiety and phobia disorders including PTSD. VRET may be particularly suitable for clients with combat-related PTSD as it aids in exposure treatments for these clients who are often unable to engage in traditional therapy. Future research should include randomized, controlled studies employing large samples.

Slamanig, D., & Stingl, C. (2008). Privacy aspects of eHealth. *2008 3rd International Conference on Availability, Reliability and Security ARES '08*, 1226-1233.

Portals are accessed via the internet, which raises issues of security and privacy. Slamanig and Stingl discuss various threats, for example disclosure attack, and suggest pseudonymization of medical data, identity management, anonymous authentication, and obfuscation of metadata for protection.

Smith, S. P., & Barefield, A. C. (2007). Patients Meet Technology: The Newest in Patient-Centered Care Initiatives. *Health Care Manager, 26*(4), 354-362.

Smith and Barefield discuss a variety of health care technologies currently available in the U.S. that could potentially empower health care consumers. They identify various technological devices and services, including e-registration in emergency rooms, radio frequency identification to track patients, smart beds that alert health care professionals, patient portals, and personal health records.

Staroselsky, M., Volk, L. A., Tsurikova, R., Newmark, L. P., Lippincott, M., Litvak, I., et al. (2008). An effort to improve electronic health record medication list accuracy between visits: Patients' and physicians' response. *International Journal of Medical Informatics, 77*(3), 153-160.
Investigating the efficiency of the patient portal Patient Gateway (PG) in Eastern Massachusetts in promoting more accurate medication lists, researchers compared the accounts of patients using PG to those of patients who did not have access to the portal. Both groups of patients had similar rates of accuracy. Greater accuracy in the list was not associated with the patients' ability to view their medication lists because the e-mail system used to alert physicians of changes to medication routines (prescription and over-the-counter) was ineffective. One proposed solution was to allow patients to annotate their own medication lists so physicians could view the information and update with new information at the click of a button.

Tang, Paul (2005). At the Quality Crossroads: Integrating Electronic Health Record Systems and Patient Portals.
http://clinicalinformatics.stanford.edu/scci_seminars/03_11_05.html
Both the California-based portal PAMFOnline and the need for tailored health information and communication are discussed in this presentation. Tang states that web portals enable features – like office visit summaries, directed educational materials, schedules, and reminders – that are important for prevention strategies and patient motivation.

Tang, P. C., Black, W., & Young, C. Y. (2006). Proposed criteria for reimbursing eVisits: content analysis of secure patient messages in a personal health record system. *AMIA Annual Symposium proceedings AMIA Symposium,* 764-768.
Tang *et al.*, analyze 120 messages from the California-based PAMFOnline system, organizing the messages into the categories of eVisit (requiring physician reimbursement), medication request, simple question, or message that doesn't require an answer. Based on the analysis, the researchers propose modified Evaluation and Management (eVisit E&M) criteria to determine physician reimbursement.

Tatnall, A. (2007). Preface. *Encyclopedia of Portal Technologies and Applications.* New York: Information Science Reference.
The overview of the *Encyclopedia of Portal Technologies and Applications* discusses the importance of portals as well as the various definitions of the term.

Theodoros, D., & Russell, T. (2008). Telerehabilitation: current perspectives. *Studies in health technology and informatics*, 191-209.
In this review article of telerehabilitation technologies, Theodoros and Russell discuss various applications for telerehabilitation, classified as image-based, sensor based, or virtual environments. The authors state that much of the existing research has focused on designing new technologies, and research on telerehabilitation has consisted of single or small sized case studies.

Urowitz, S., Wiljer, D., Apatu, E., Eysenbach, G., Delenardo, C., Harth, T., et al. (2008). Is Canada ready for patient accessible electronic health records? A national scan. *BMC medical informatics and decision making*, 8(33).
Many Canadians are unable to access health information through EHRs. To assess readiness to adopt and implement EHRs in Canada, Urowitz and colleagues surveyed Chief Executive Officers (CEOs) of Canadian hospitals.

Verheij, R., Ton, C., Tates, K. (2008). *Hesitative Introduction of E-mail Consultations in General Practice.* Paper presented at the Medicine 2.0 conference, Toronto, 9.
In this extended abstract the researchers discuss the findings from data gathered in 100 GP practices participating in the Netherlands Information Network of General Practice. They found that e-mail consultations occurred in 30% of the practices involved in the study. Researchers discuss the demographic information of those patients using e-mail for consultations.

Wald, J. S., Burk, K., Gardner, K., Feygin, R., Nelson, E., Epstein, M., et al. (2007). Sharing electronic laboratory results in a patient portal--a feasibility pilot. *Medinfo. MEDINFO, 12*(Pt 1), 18-22.
Partners HealthCare in Eastern Massachusetts, a delivery network consisting of 9 hospitals and numerous community physicians, offers providers access to medical records that can be shared with patients over the patient portal Patient Gateway (PG). In this pilot study, the researchers granted patients online access to lab results. Usage, patient and physician feedback (solicited and unsolicited), and surveys were used to measure pilot success. Feedback was positive, and half of the patients who viewed results also accessed the linked reference information.

Walters, B., Barnard, D., & Paris, S. (2006). "Patient portals" and "E-visits". *Journal of Ambulatory Care Management,* 29(3), 222-224.
Patient portals and E-visits conducted in Dartmouth-Hitchcock, a multispecialty practice in northern New England are described in this article. Their patient portal Patient Online (POL) was deployed to focus on administrative features (booking appointments, medication renewals, etc.), and then extended to allow for e-Visits. The researchers note that 9 physicians in this practice have conducted e-Visits and report positive experiences. The most common reasons for e-Visits were to follow-up on some chronic conditions (depression, diabetes, anemia and hypertension) and handle discrete episodes of other chronic conditions such as sinusitis and back pain.

Weingart, S. N., Hamrick, H. E., Tutkus, S., Carbo, A., Sands, D. Z., Tess, A., et al. (2008). Medication safety messages for patients via the web portal: The MedCheck intervention. *International Journal of Medical Informatics (formerly International Journal of Bio-Medical Computing), 77*(3), 161-168.
In a random sample review study there were 21 cases of adverse drug events – one of which was a serious preventable case. To address that danger, the MedCheck system is used over the PatientSite patient portal; it sends patients an e-mail 10 days after they receive a new or refill prescription, asking if they filled the prescription and whether they are experiencing any medication-related problems. Their responses are forwarded to their physicians. The authors conclude that automatic messages could allow for earlier detection of ADE and timely intervention.

Weingart, S. N., Rind, D., Tofias, Z., & Sands, D. Z. (2006). Who uses the patient Internet portal? The PatientSite experience. *Journal of the American Medical Informatics Association, 13*(1), 91-95.
PatientSite was developed and introduced in 2000 by the Beth Israel Deaconess Medical Center (BIDMC), a Boston teaching hospital, as a means for secure internet communication and added patient-centered features. This 2006 study examines PatientSite user preferences and presents a demographic profile of PatientSite users.

Werner, J., Mathe, J. L., Duncavage, S., Malin, B., Ledeczi, A., Jirjis, J. N., et al. (2007). *Platform-based design for clinical information systems.* Paper presented at the IEEE International Conference on Industrial Informatics (INDIN), Vienna, 749-754.

Clinical Information Systems (CIS) have complex and conflicting requirements. Werner and colleagues' article discusses an approach to the design of CIS based on the tools and principles of Model-Integrated Computing (MIC), Platform-Based Design (PBD), and Service Orientated Architectures (SOA). The authors discuss the Model-Integrated Clinical Systems (MICIS) design environment, a formal approach to CIS design that uses complex design methodologies. MICIS was modeled in the Vanderbilt University Medical Center patient portal, MyHealth@Vanderbilt, based in Nashville, Tennessee, and will scale to a variety of portal functions.

Whitten, P., Buis, L., & Love, B. (2007). Physician-patient e-visit programs: Implementation and appropriateness. *Disease Management and Health Outcomes, 15*(4), 207-214.

e-Visits refer to the online exchange of information between patients and providers. In this article, Whitten and colleagues discuss the use of the MyHealth, PatientSite, and Kaiser Permanente portals for patient-provider communications. The barriers and potential implications of patient portals are also discussed. The authors stress that even though there are barriers to the adoption of portals, consumers are driving the push for health care communication through web portals.

Willis, J. M., Macri, J. M., Simo, J., Anstrom, K. J., & Lobach, D. F. (2006). Perceptions about use of a patient Internet portal among Medicaid beneficiaries. *AMIA Annual Symposium proceedings AMIA Symposium,* 1145.

Willis and colleagues' conference paper abstract outlines the methods and results of a study on the attitudes of Medicaid beneficiaries from Durham North Carolina towards adopting a patient portal. While the 31 participants showed interest in numerous features, their estimated use of the portal over the next year was relatively low.

Win, K. T., Susilo, W., & Mu, Y. (2006). Personal health record systems and their security protection. *Journal of Medical Systems, 30*(4), 309-315.

Win, Sussilo and Mu investigate different PHR systems in this article, including personal and web-based records to health kiosks. They note possible security functions and issues with PHR, as current systems remain inadequate from a security protection standpoint. In this article, the authors present some security mechanisms to alleviate this problem.

Wright, A., & Sittig, D. F. (2007). Encryption Characteristics of Two USB-based Personal Health Record Devices. *Journal of the American Medical Informatics Association, 14*(4), 397-399.

In a study of the security risks of two USB-based personal health record devices, Personal HealthKey and the E-Health-Key, researchers identified three critical flaws in the systems. These flaws were attributed to the methods used to encrypt the database, and the authors recommend guidelines for improving security of non-internet based personal health records.

Zampolini, M., Todeschini, E., Bernabeu-Guitart, M., Hermens, H., Ilsbroukx, S., Macellari, V., et al. (2008). Tele-rehabilitation: present and future. *Annali dell'Istituto superiore di sanita, 44*(2), 125-134.

Zampolini *et al.*'s article reviews telerehabilitation with a particular focus on upper limb telerehabilitation. Preliminary applications of the H-CAD (home care activity desk) and

HELLODOC (Health care service linking telerehabilitation to disabled people and clinicians) systems are also discussed.

Zhou, Y. Y., Garrido, T., Chin, H. L., Wiesenthal, A. M., & Liang, L. L. (2007). Patient access to an electronic health record with secure messaging: impact on primary care utilization. *American Journal of Managed Care, 13*(7), 418-424.

While messaging is heralded as a technology that could improve the efficiency and quality of health care services, the authors note that studies on patient/physician e-mail communication present conflicting results. This study investigates the messaging and telephone contact rates in the Kaiser Permanente Northwest (KPNW) operating region of Oregon and southwest Washington.

Zickmund, S. L., Hess, R., Bryce, C. L., McTigue, K., Olshansky, E., Fitzgerald, K., et al. (2008). Interest in the use of computerized patient portals: Role of the provider-patient relationship. *Journal of General Internal Medicine, 23*(1 SUPPL.), 20-26.

Authors conducted a focus group with 39 patients diagnosed with diabetes. In the focus groups, a moderator asked several questions about their current sources of information on diabetes, their relationships with their care providers, and their attitudes towards the UPMC HealthTrak portal. The researchers found that the patients' attitudes about the portal depended on how they felt about the provider-patient relationship. People dissatisfied with that relationship were more likely to use the portal, while patients who had good relationships with their health care providers were less interested in the portal. Several patients who were satisfied with the provider-patient relationship used their traditional e-mail accounts to keep in contact with their providers. The authors note that patients need to be educated about the privacy concerns of using traditional e-mail communication in order to see the encrypted e-mail services in the portal as advantageous.

11. Charts

11.1. Chart: Full list of research questions

- What is an accepted definition of patient portal? Of telerehabilitation?
- Who will be able to access the patient portals – what are the statistics on the number of NB households with Internet connections, the type/speed, the number of NB clinicians that have frequent access to an Internet connection (many seem to still share a terminal)? This information may also guide the type/format and length of educational materials for the portal.
- Who are the "movers and shakers" in the patient portal arena in terms of who is publishing their results and outcomes in peer-reviewed literature?
- What are the benefits of patient portals?
- What are the constraints and barriers patients may encounter when using a patient portal?
- What enablers facilitate the use of patient portals?
- What are some examples of patient portals in the literature and how frequently do patients visit these patient portals?
- What are the opportunities for delivering some patient portal services via:
  a) mobile devices? (eg. SMS appointment reminders, patient's journal, etc.)
  b) online video (eg. videos generated by patients or clinicians with rich visual information)
  c) multi-modal applications (particularly speech-based applications)
  d) archived telehealth (videoconference) content
- How long does it take to orient users to the patient portal?
- Is it necessary to design the portal to work with special assistive devices?
- What patient populations are patient portals most suited to?
- Has anyone monitored the progress of patients in completing their assignments on the patient portal? What "compliance" requirements for telerehabilitation using portals are in place for ensuring patients are using them to help them on their roads to recovery?
- Is there any evidence that patient portals reduce wait time for service, and if so, are there specific portal features or applications that contribute to this impact?
- Which interface usability features for patient portals are recommended for ensuring optimum usability by patients with disabilities?

- What are examples of specialized treatment software being used in the rehabilitation field from 2006 -present (asynchronous and synchronous applications) that could be featured on a patient portal?

- What methods are recommended to develop the content of patient portals, i.e. focus groups with patients?

- How are patient portals used by caregivers and extended family members?

- What portal applications are most valued by patients? Which applications are least used or valued and why?

- How have portal providers dealt with issues related to privacy, security, and authentication, such as transborder flow of patient data?

- What, if anything, would prevent care providers from communicating with their patients and sharing results over a portal?

11.2. Chart: Types of patient portals

Portal	Affiliation	Website	Target Audience	Features
MyHealth@Vanderbilt (MHAV) patient portal	Vanderbilt	https ://www.myhealthatvanderbilt.com/myhealth-portal/app	Patients	• See lab test results • Secure messages with Doctor • Personal medical information
University of Pittsburgh Medical Center (UPMC) UPMC HealthTrack	University of Pittsburgh Medical Center	http://clinicaltrials.gov/ct2/show/NCT00409786?spons=%22U.S.+Air+Force+Office+of+the+Surgeon+General%22&spons_ex=Y&rank=2 https://myupmc.upmc.com/default.asp?mode=stdfile&option=faq#EQ_what	Patients with Diabetes	• View medical record information • Self management tools
University of Pittsburgh Medical Center (UPMC) UPMC Care Pages	University of Pittsburgh Medical Center	http://www.upmccancercenters.com/ptCare/carepages.html	Cancer treatment patients	• Free, private websites that can be personalized (e.g., photos) • Track progress • Update multiple people simultaneously
Patient Gateway	Partners Health Care, Eastern Massachusetts	https://www.patientgateway.org/scripts/phsweb.mwl?APP=PTGW&OPT=START	Providers and patients of Partners Health Care	• Online appointment booking • Medication renewal • Educational materials
Indivo (Personally controlled health record – PCHR)	Children's Hospital Boston, Dossia Consortium	http://www.indivohealth.org/	Patients	• Patient owned and controlled medical info • Customizable site
My Care Source	Grand River Hospital, Kitchener, Ontario	http://www.grhf.org/_grrcc/new_site/pub/patientsVisitors/myCareSource.asp	Patients with Cancer or Chronic Kidney Disease	• Treatment plan information • Symptom monitoring • Appointment information • Personal health profile and diary • Patient education
VIPNet, Group Health Clinic	Sault Ste Marie, Ontario		Patients of the clinic	• Self management • Goal setting • Monitoring

				• Targeted education
Interior Health Authority, British Columbia	The interior of British Columbia		Patients with diabetes and cardiovascular difficulties	• Patient medical information (e.g., lab results) • Education • Decision support
Victorian Order of Nurses (VON)	Ontario branch		Caregiver support	• Patient medical information • Education • Patient workflow support • Multi-cultural capabilities
Healthcare@home (HH)	Beth Israel Deaconess Medical Hospital (BIDMC) – Boston teaching hospital		Patients	• Messaging system (non-urgent care) • Appointment / referral request • Prescription renewals • Medical information
PAMFOnline	California: The Camino Group, Palo Alta Medical Clinic and Santa Cruz Medical Clinic	https://mychart.sutterhealth.org/pamf/	Clinicians and patients in The Camino Group, Palo Alto Medical Clinic and Santa Cruz Medical Clinic	• Electronic communication with nurses and physicians
CharmHealth	Australia	http://charmhealth.build9.com.au/default.asp	Patients with cancer	• Communication with doctors • Appointment scheduling • Lab results • Treatment effects
Horizon Portal	McKesson, Horizon	http://www.mckesson.com/static_files/McKesson.com/MPT/Documents/VIP2007_UniversityHealthNetwork_PRT292.pdf	General Use	• Appointment scheduling and reminders • Pay hospital bills • Interactive reference guide • Patient symptom monitoring • Daily journal
My Healthcare	IBM WebSphere	http://www.demos.ibm.com/on_demand/Demo/IBM_Demo_WebSphere_Portal_My Healthcare_Patient_Portal-May08.html	General Use	• Bill payment • Prescription ordering • Appointment scheduling • Podcasts • Web articles • Messaging with

				physicians • Scheduling reminders • Chat service with nurses
REHAB-NET	Germany	www.rehab-net.com	General Use	• Medical dictionary • Search engine for rehabilitation literature and support groups • Directory of medical specialists • Education and training directory
Bolton Mental Health	Bolton, UK	http://www.boltonmentalhealth.org.uk	People with mental health issues, their families and caregivers	• Online counselling • Rehabilitation
Connects: The Mental Health and Learning Disabilities Portal	UK Mental Health Foundation	http://www.mentalhealth.org.uk/information/connects	People with mental health issues and learning disabilities	• Reasoning and Rehabilitation course offered
Health Connect	KAISER Permanente	https://www.kaiserpermanente.org	Kaiser Permanente members (health care providers and patients)	• Links to local rehabilitation centers
Hellodoc	European Health Portal	http://ec.europa.eu/information_society/activities/eten/cf/opdb/cf/project/index.cfm?mode=detail&project_ref=ETEN-517508#pastnavigation	Rehabilitation patients	• Rehabilitation
MHA Portal	Mental Health America	http://affiliateportal.mentalhealthamerica.net/Home/tabid/36/ctl/Login/Default.aspx?returnurl=%2fHome%2ftabid%2f36%2fctl%2fPrivacy%2fDefault.aspx	People with mental health issues	• Links to mental health affiliates that include rehabilitation
My *HealtheVet*	U.S. Department of Veteran Affairs	https://www.myhealth.va.gov/mhv-portal-web/anonymous.portal?_nfpb=true&_nfto=false&_pageLabel=mhvHome	Veterans and families	• Readjustment counselling and rehabilitative care

NMFA Mental Health Portal	National Military Family Association	http://www.nmfa.org/site/PageServer?pagename=mental_health_deployment_and_stress	Veterans and families	• Post deployment mental health care
Rehab-Net.com	Cominfo	http://www.rehab-net.com/	Patients with disabilities	• Resources for rehab professionals and people with disabilities
Mental Health Counselling Portal	U.S. Army	https://www.fbo.gov/index?s=opportunity&mode=form&id=4e4ee759b8967262affdd445a77e5ad5&tab=core&_cview=0	Veterans and families	• Web counselling and resources for members of the U.S. Army
Mental Health Portal	Victoria, Australia Military	http://www.nextgov.com/nextgov/ng_20080805_4104.php	Veterans and families	• Anonymous behavioural health web portal • Assessments • Checklists
Missouri Telemedicine Network	University of Missouri	http://www.telerehab.net/who.htm	Clinicians	• Telerehab training site
Veterans' PTSD Portal	MySpace.com	http://profile.myspace.com/index.cfm?fuseaction=user.viewprofile&friendID=361121905	Veterans and families	• Resource plus communication tool
Online Mental Health Portal	Dublin, Ireland	https://www.cs.tcd.ie/TMH/project/online-mental-health-portal	Patients with mental health issues	• E-mail counselling • Contact information for support services
Veterans PTSD Portal	Facebook.com	http://www.facebook.com/people/Veterans-Ptsd-Portal/1576410357	Veterans and families	• Communication tool for rehabilitation
Afterdeployment.com	Input from the United States Department of Defense and the Veterans Administration	http://www.afterdeployment.org/	Veterans and families	• Educational resources • Self-assessment tools • Interactive exercises