QUERI

Systematic Review:

Secure Messaging between Providers and Patients, and Patients' Access to Their Own Medical Record

Evidence on Health Outcomes, Satisfaction, Efficiency and Attitudes

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PREFACE

Quality Enhancement Research Initiative's (QUERI) Evidence-based Synthesis Program (ESP) was established to provide timely and accurate syntheses of targeted healthcare topics of particular importance to Veterans Affairs (VA) managers and policymakers, as they work to improve the health and healthcare of Veterans. The ESP disseminates these reports throughout VA.

QUERI provides funding for four ESP Centers and each Center has an active VA affiliation. The ESP Centers generate evidence syntheses on important clinical practice topics, and these reports help:

- develop clinical policies informed by evidence,
- guide the implementation of effective services to improve patient outcomes and to support VA clinical practice guidelines and performance measures, and
- set the direction for future research to address gaps in clinical knowledge.

In 2009, the ESP Coordinating Center was created to expand the capacity of QUERI Central Office and the four ESP sites by developing and maintaining program processes. In addition, the Center established a Steering Committee comprised of QUERI field-based investigators, VA Patient Care Services, Office of Quality and Performance, and Veterans Integrated Service Networks (VISN) Clinical Management Officers. The Steering Committee provides program oversight, guides strategic planning, coordinates dissemination activities, and develops collaborations with VA leadership to identify new ESP topics of importance to Veterans and the VA healthcare system.

Comments on this evidence report are welcome and can be sent to Nicole Floyd, ESP Coordinating Center Program Manager, at nicole.floyd@va.gov.

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EVIDENCE REPORT

INTRODUCTION

As internet access and the use of mobile devices becomes more widely available, and as it is increasingly used by patients to access health information, many healthcare systems are capitalizing on this trend by offering patients electronic methods to communicate with providers and to learn about their health and medical problems. Some organizations or practices have developed stand-alone systems that allow for secure messaging between patients and their providers. Others, particularly those with existing electronic health record systems (EHRs), are developing companion applications specifically designed for patients that give patients access to email communication, access to their medical records and to test reports, and access to educational information on preventive care or disease-specific care. Much of this development is based on a perception that this is something that patients desire; and, that these systems will enhance patient satisfaction, improve care or make it more efficient.

As the Veterans Health Administration (VHA) expands the capabilities of its personal health record system, My Health*e*Vet (MHV), and places greater emphasis on encouraging its use, it is interested in understanding how best to prioritize different functionalities and which of them will provide the greatest benefits to Veterans. This systematic review was designed to evaluate the literature surrounding secure messaging systems and electronic applications that give patients access to their own medical records, specifically investigating the evidence that these systems improve health outcomes, patient satisfaction, healthcare utilization and efficiency, and adherence. Additionally, the review examined studies that evaluated attitudes, particularly regarding patients having online access to their own medical information; and specific patient characteristics associated with use of personal health record systems. The review distinguished between electronic systems that were "tethered" or tied to existing healthcare institution systems similar to how MHV is tethered to VHA's EHR, versus those that were "stand-alone."

METHODS

TOPIC DEVELOPMENT

This project was nominated by Kim Nazi, Veterans and Consumers Health Informatics Office/ Office of Informatics and Analytics, with input from a technical expert panel that included David Haggstrom, Tom Houston, Keith McInnes; Performance Evaluation Clinical Advisory Board Working Group.

The original key questions were listed in the following format:

Proposed Study Selection**:** Peer-reviewed articles assessing the effects of select personal health record functionalities on clinical outcomes, patient-centered outcomes, and system-level outcomes, especially among organizations most similar to the VA.

Proposed Data Extraction**:** Data on study participants (patient, health care provider or organization), study design, functionality, functionality variation (subsets), outcomes, and VA peer organizations will be extracted.

Population: include all studies in relevant peer-reviewed literature; make special note of VA peer organizations, i.e., integrated delivery systems whose experience with care delivery & online health activities may generalize best to the VA, including:

- Kaiser Permanente
- Group Health Cooperative
- Geisinger Health System

without insurance component:
- Partners HealthCare
- Palo Alto Medical Foundation

Functionalities: Note: we have listed these in order of priority

1) Secure messaging programs

Functionality variation (subsets):

(A) tethered secure messaging program vs. conventional (unsecured) e-mail

1. tethered programs are integrated with electronic health record; most similar to VA

(B) different implementation strategies (triage team (VA) model vs. other)

2) Patient access to their own medical record

Functionality variation (subsets):

(A) online tethered program vs. online stand-alone program vs. paper record (lower priority)

(B) allergy list vs. medication list vs. laboratory results vs. procedure/imaging results vs. physician notes

3) Online medication refills

4) Patient self-reported data

Functionality variation (subsets):

(A) different types of data (blood glucose, weight, blood pressure, food journal, activity journal)

5) Online preventive or chronic care reminders

Outcomes:

Clinical outcomes:

A. quality of care (performance measures, clinical processes)
B. health outcomes

Patient-centered outcomes:

C. patient satisfaction
D. provider satisfaction
E. quality of patient-provider communication
F. self-management
G. adherence
    1. medication
    2. visit

System-level outcomes:

H. efficiency
    1. telephone medicine utilization
    2. system workload
        a. provider time
    3. inappropriate use
I. privacy breaches
J. patient safety

These characteristics were then structured into the following sample Key Questions:

(1) Is secure messaging (function #1) associated with the following outcomes?

Clinical outcomes:

a. quality of care (performance measures, clinical processes)
b. health outcomes

Patient-centered outcomes:

c. patient satisfaction
d. provider satisfaction
e. quality of patient-provider communication
f. self-management

System-level outcomes:

g. efficiency (reduced use of telephone resources; reduced use of in-person visits)
h. breaches of privacy

(2) Is patient access to their own medical record (function #2) associated with the following outcomes?

> *Clinical outcomes*:
> a. quality of care (performance measures, clinical processes)
> b. health outcomes
> *Patient-centered outcomes*:
> c. patient satisfaction
> d. provider satisfaction
> e. quality of patient-provider communication
> f. self-management
> *System-level outcomes*:
> g. efficiency (reduced use of telephone resources)
> h. breaches of privacy

(3) Is patient access to online medication refills (function #3) associated with the following outcomes?

> *Clinical outcomes*:
> a. medication adherence
> b. quality of care (performance measures, clinical processes)
> c. health outcomes
> *Patient-centered outcomes*:
> d. patient satisfaction
> e. provider satisfaction
> f. quality of patient-provider communication
> g. self-management
> *System-level outcomes*:
> h. efficiency (reduced use of telephone resources)
> i. breaches of privacy

SEARCH STRATEGY

We searched PubMed for relevant literature from 01/01/1999 through 12/03/2010, using standard search terms such as electronic health record, patient, messaging, and computerized reminder (see Appendix A for complete search strategy). We limited the search to peer-reviewed articles published in the English language.

STUDY SELECTION

Two reviewers assessed for relevance the full text articles identified from the title screening of the literature searches. Each article was reviewed using a standard screener form (see Appendix B). Initial inclusion criteria were: 1) discussion of relevant functionalities, namely messaging programs, patient access to their own medical record, patient self-reported data, or online reminders; 2) study design of descriptive qualitative, descriptive quantitative, hypothesis testing, or systematic review.

After we data screened 4,607 titles to identify approximately 400 relevant articles and abstracted sufficient to classify them by study type, key question, and outcome, we then presented these data to the Performance Evaluation Workgroup on December 1, 2011; after which the workgroup determined that Key Questions #1 and #2 were the highest priority, and Key Question #3 was dropped. Furthermore, for Key Question #1 only hypothesis testing articles were of interest, and for Key Question #2, only hypothesis testing or descriptive quantitative articles were of interest. This revision narrowed our inclusion criteria to only hypothesis testing studies that assessed specific outcomes for Key Question #1, and hypothesis testing and descriptive quantitative studies assessing similar specific outcomes for Key Question #2. The specific outcomes for both Key Questions are detailed in the literature flow section of the results below.

DATA ABSTRACTION

We abstracted the following data for each included study: study design, study date, HIT intervention, setting, outcome measures, and findings.

QUALITY ASSESSMENT

We assessed the quality of individual studies using study design (trials and observational designs of higher rigor such as controlled before-and-after studies and time series analyses being less prone to bias than pre-post studies), recruitment and retention or follow up data, the degree to which the intervention was described and the degree to which any effect could be attributed to a specific component (of a multi-component intervention), and the relevance of the outcome measured to the outcomes specified in the key questions. We assessed studies for applicability to the VA health care system.

In specific we assessed studies coming from integrated health care delivery systems, such as Kaiser and Group Health Cooperative as being more relevant to VA health care than studies coming from academic or non-academic non-VA sites. We also judged studies about chronic conditions common in VA (such as diabetes and hypertension) as more relevant than conditions rare in VA (in vitro fertilization). In addition to quality evaluation of individual studies, we evaluated the overall quality of the evidence for each key question as proposed by the GRADE Working Group.

DATA SYNTHESIS

We constructed evidence tables showing the study characteristics and results for all included studies, organized by key question, intervention, or clinical condition, as appropriate. We critically analyzed studies to compare their characteristics, methods, and findings. We compiled a summary of findings for each key question or clinical topic, and drew conclusions based on qualitative synthesis of the findings.

RATING THE BODY OF EVIDENCE

We assessed the overall quality of evidence for outcomes using a method developed by the GRADE Working Group (see Appendix C), which classified the grade of evidence across outcomes according to the following criteria:

- High = Further research is very unlikely to change our confidence on the estimate of effect.
- Moderate = Further research is likely to have an important impact on our confidence in the estimate of effect and may change the estimate.
- Low = Further research is very likely to have an important impact on our confidence in the estimate of effect and is likely to change the estimate.
- Insufficient = Any estimate of effect is very uncertain.

PEER REVIEW

A draft version of this report was reviewed by six technical experts and/or clinical leaders. Their comments and our responses are presented in Appendix D.

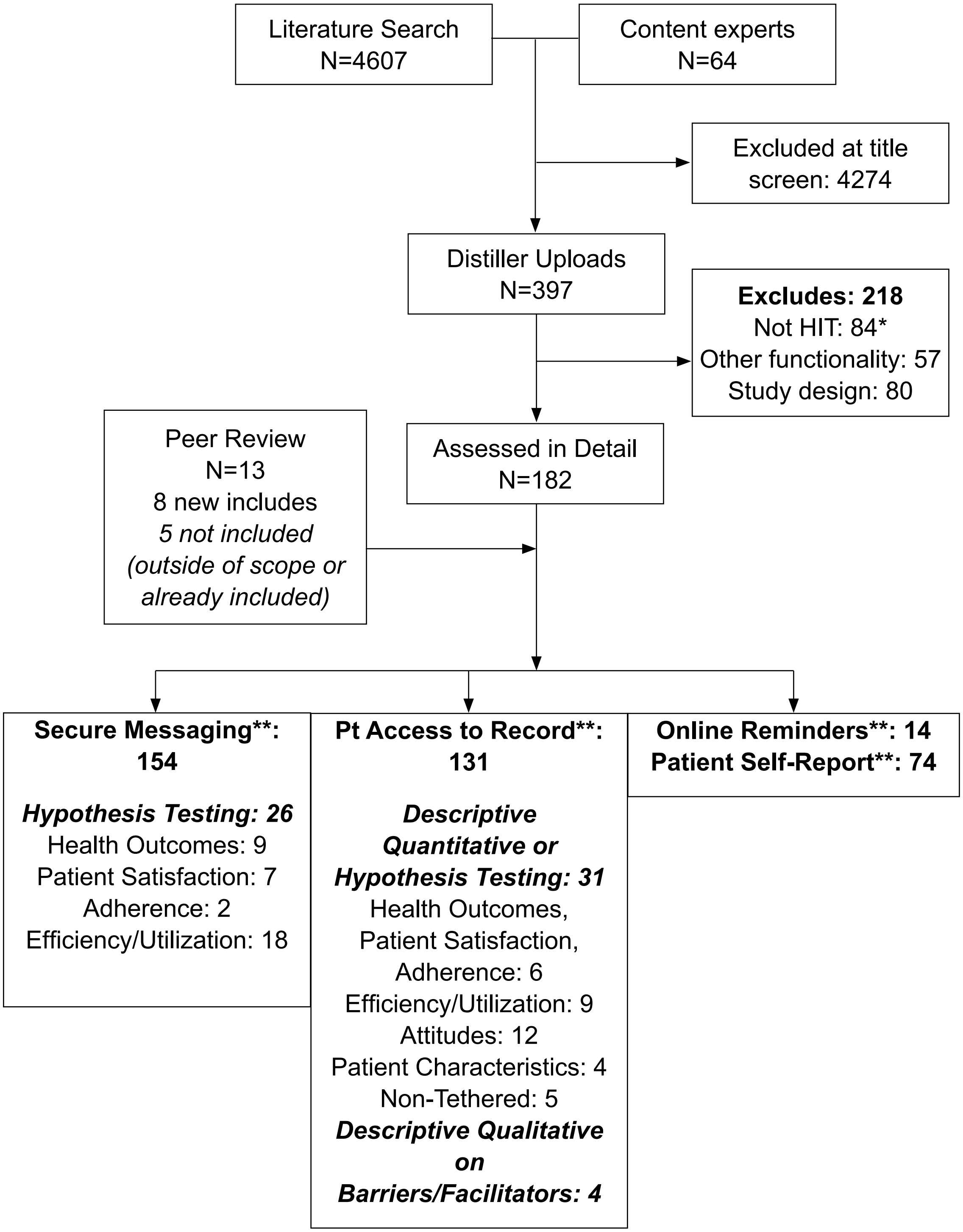
RESULTS

LITERATURE FLOW

We reviewed 4,607 titles and abstracts from the electronic search, and an additional 64 from content experts for a total of 4671 references. A title screen excluded 4,274 as unrelated to our topic, with 397 remaining for further review. After applying our screener form to the full-text articles, 218 references were excluded. Of these, there were 84 that were not relevant to consumer health information technology, another 57 did not address any of the four specified functionalities, and 80 had study designs warranting exclusion (non-systematic review, commentary or news, or other ambiguous designs). We sorted these articles based on functionality, study design, and outcomes. Inclusion based on functionality retained articles relating to two of the functionalities, patient access to medical records (N=121) and secure messaging (N=153), with articles relating to online reminders (N=14) and patient self-reported data (N=74) no longer of interest after the discussion with the Performance Evaluation Clinical Advisory Board Working Group (see Methods, p. 9). These categories were not mutually exclusive, however, so an article about secure messaging that also related to online reminders would be included, for example. Of the 13 articles identified by peer reviewers, eight met the criteria for inclusion, and were added to the appropriate categories below.

Within the included functionalities, further inclusion restrictions based on study design and outcomes were applied. Within the secure messaging functionality (N=154), the 26 articles with a hypothesis testing study design that related to health outcomes (N=9), patient satisfaction (N=7), adherence (N=2), or efficiency or utilization (N=18). The other 128 articles relating to secure messaging were excluded either because their study design was descriptive or a systematic review (N=42), or they did not address one of the desired outcomes (N=86). For patient access to medical records (N=131), descriptive quantitative studies relating to tethered medical records addressing health outcomes, patient satisfaction, and adherence (N=6); efficiency or utilization (N=9); patient characteristics (N=4); or attitudes (N=12) were included, in addition to 5 articles which addressed non-tethered record, for a total of 31 articles. Additionally, four descriptive qualitative articles addressing barriers or facilitators to patient access to medical records were also included. The other 93 articles relating to patient access to medical records were excluded either because their study design was descriptive qualitative, and did not address barriers or facilitators to use, or systematic review (N=12), or they did not address one of the desired outcomes (N=81).Figure 1 details the inclusion of articles and the number of references related to each of the key questions. The abstracted data for the included articles can be found in the evidence tables, which are organized by report section (see Appendix E).

Figure 1. Literature Flow



* Not HIT includes duplicates found during data abstraction; ** Functionality categories were not mutually exclusive.

KEY QUESTION #1. What is the association between secure messaging and health outcomes, patient satisfaction, adherence, efficiency or utilization, or automated email?

The VHA's My Health*e*Vet (MHV) application already allows for secure messaging (SM) between Veterans and their providers but because this functionality is relatively new, there is little known about the impact of SM on the health of Veterans who use SM. This was a key area of interest for the MHV team. Because of this, we focused on hypothesis testing studies of SM that evaluated its relationship to different types of outcomes, focusing more specifically on health outcomes, patient satisfaction, adherence, efficiency of care and utilization of care. This accounted for the majority of the hypothesis testing studies about SM and the results are described in the section that follows. We also found a small number of hypothesis testing studies of automated email systems, which can be distinct from SM systems that offer two-way communication between patients and providers. These automated email studies are described at the end of this section.

We identified 26 hypothesis testing articles about SM. A number of studies evaluated multiple outcomes and these studies are therefore included in each relevant section: health outcomes, patient satisfaction, adherence, and efficiency/utilization of care.

Secure Messaging and Health Outcomes

Nine hypothesis testing papers evaluated health outcomes and many focused on health conditions pertinent to VA.[1,2,3,4,5,6,7,8,9] Seven of these studies were randomized controlled trials (RCTs).[5,6,8,7,1,4,9]

Four papers focused on SM and diabetes or related conditions.[2,3,5,6] In the article by Zhou,[2] the investigators examined the relationship between SM and performance on standard HEDIS measures for diabetes and hypertension among Southern California Kaiser Permanente patients with these conditions. In regression analysis, patients with diabetes and/or hypertension who participated in SM were statistically significantly more likely to see improvements from baseline in all of the HEDIS measures (diabetes process and intermediate outcome measures and blood pressure control). Two or more emails in a two-month period (as compared to only one) were associated with better performance on some measures ("dose-response effect"). In a separate matched cohort analysis, matching patients who used SM with those who did not, email use was associated with improvement in most of the diabetes measures but not in blood pressure control in patients with hypertension.

Another study from Group Health Cooperative was a cross-sectional analysis evaluating outcomes for patients with diabetes who had completed the process of identity verification required to participate in SM, comparing those who used the service to those who did not.[3] They adjusted for a number of patient characteristics including medical comorbidity and depression severity, as well as provider characteristics such as age, sex and specialty. In terms of quality, they found that the rate of A1c<7% was 36% higher in patients with the highest rate of SM use (>= 12 threads/year); though SM was not associated with better blood pressure control and was modestly associated with better lipid control. This analysis could not ascertain whether the utilization of SM was responsible for the improved outcomes as patients who used SM more may simply have been more engaged in their health. Interestingly, primary care visit rates in this study were 32% higher in patients with high use of SM (three to four additional outpatient visits per year).

Two RCTs evaluated web-based educational programs for diabetes that included SM as a component of the system. One RCT evaluated Veteran patients with diabetes who were randomized to usual care versus web-based care management that included receipt of a notebook computer, a blood pressure monitor, a glucometer, free internet service and access to a diabetes care management website.[5] The intervention patients were able to send and receive secure messages to and from their care manager. They also had access to educational links and web-based diabetes resources. While hemoglobin A1c levels decreased over time in both groups, the intervention group demonstrated a greater decline over time (decrease of 1.6% versus 1.2% in usual care group). Blood pressure declines were also greater in the intervention patients with hypertension (-10 versus -7 mm Hg) while there were no differences in lipid levels. In the second study from the University of Washington,[6] patients were similarly randomized to usual care versus web-based and in-person care management with access to SM functionality. Hemoglobin A1c levels were 0.7% lower in the intervention group compared to usual care when evaluated nine to 12 months after the start of the study (95% CI 0.2-1.3, p=0.01). There were no differences in blood pressure or lipid control between the groups.

Another study from Group Health Cooperative evaluated the impact of managing depression care using online secure messaging available through a patient website linked to the medical record.[9] 48% of patients with new prescription for an antidepressant and who were registered for online messaging consented to participate and were randomized to usual care with their prescribing physician versus usual care augmented by three planned contacts via messaging with a mental health nurse care manager, which included structured assessments and nurse communication with the patients' providers. Intervention patients had lower depression severity at the end of the evaluation period and higher proportions experienced 50% or greater decreases in the depression scale of the Hopkins Symptom Checklist (55% v 41%, OR=1.8, 95% CI 1.0 to 3.1). Utilization rates for visits, telephone encounters and non-study online messages did not differ between the groups.

Four additional studies evaluated web-based systems that allowed patient access to medical information and SM but that were not focused solely on SM. [7,8,1,4] The two most relevant to VA included a study from Group Health and one from the University of Colorado.[7,8] The Group Health study randomized patients with hypertension to usual care versus one of two intervention groups. All participants were given access to Group Health's patient website and all were encouraged to work with their providers to improve their blood pressure control. One intervention group was given a home BP monitor and training on the use of the patient website while the other intervention group was also given access to a pharmacist care manager who initiated case management via SM and face-to-face visits.[7] Only the pharmacy case management group demonstrated significant improvements in BP control with 25% more patients with controlled BP compared to usual care (mean decrease -8.9 mm Hg) and 20% more compared to the other intervention group (mean decrease -6.0 mm Hg). The second study randomized patients with congestive heart failure (CHF) to usual care versus access to a web-based medical record system that also included an educational guide and a messaging system.[8] There were no significant differences between the intervention and usual care groups in the primary outcome of self-efficacy nor in measures of health status. General adherence to medical advice was better in the intervention group (2.3 points higher on a 0-100 scale) but there was no difference in medication adherence; and no difference overall in patient satisfaction. While there were no differences in mortality, hospitalizations or clinic visits, there was a significant increase in emergency room visits in the intervention group. In this study, email messages did not seem to replace telephone calls and particularly early in the intervention, there were more messages (phone and email combined) from intervention patients than phone messages from the control group. The other studies included one focused on Danish and Irish patients with ulcerative colitis who were randomized to a web-based educational and care management program with email and text messaging capabilities versus usual care and found improved adherence to acute care, improved knowledge and quality of life and fewer clinic visits in the intervention group;[1] a second study that randomized couples undergoing in-vitro fertilization (IVF) in the Netherlands to usual care versus access to an internet-based personal health record with email capability and found no differences in patient empowerment (e.g. self-efficacy, knowledge) or secondary outcomes such as patient satisfaction, change in anxiety or change in depression.[4]

Secure Messaging and Patient Satisfaction

Seven hypothesis testing studies evaluated patient satisfaction and SM,[10,11,8,4,12,13,14] four of which were RCTs or controlled clinical trials.[10,11,8,4] The first RCT involved an academic internal medicine clinic affiliated with the University of Colorado in Denver which was using an electronic medical record (EMR) system.[10] Six hundred and six patients with experience using an internet browser were randomized to have access to a patient portal with SM that allowed requests for appointments, medication refills, and clinical communication with the provider, or usual telephone care. Patient satisfaction was assessed at baseline and at six months and was significantly higher in the intervention group in the areas of communication with the clinic (rated better by 44% of portal group versus 11% of controls), overall rating of clinic services (rated very good or excellent by 59% of portal group versus 48% of controls), and ratings of non-urgent messaging, prescription refills, referral requests and appointment scheduling (generally 20% improvement in portal group compared to controls).

The second RCT involved physicians and patients affiliated with a Penn State faculty-based clinic.[11] Four of eight participating physicians were assigned to offer email communication to their patients. Patients of all eight physicians were asked about their home email use and those of the participating physicians who were regular home email users were offered the opportunity to participate in the study and if consented, were given access to a secure email account for a six month period. Patients of the other four physicians continued with regular telephone contact with the clinic. All patients were surveyed at baseline, three months and six months. For the 100 patients analyzed, 67 in the email group and 35 in the control (the study excluded 72 patients who did not respond to all of the questionnaires), patient satisfaction was significantly higher in the email group in the areas of convenience of communicating with their physician and the amount of time spent contacting their physician. One hundred percent of patients in the intervention group and 97% of patients in the control group felt that patients should be able to email their doctors. Providers were not as satisfied as patients though the number of physicians involved in the study (eight) was not sufficient to draw statistical conclusions. There were trends toward increased satisfaction among intervention physicians in the areas of convenience, time spent and volume of messages.

The third randomized trial from the University of Colorado was discussed in the previous section as well and randomized patients with CHF to usual care versus access to a web-based medical record system that also included an educational guide and a messaging system.[8] As noted, this study did not demonstrate significant differences in patient satisfaction.

The final RCT has also been previously described and randomized couples undergoing in-vitro fertilization (IVF) in the Netherlands to usual care versus access to an internet-based personal health record with email capability and found no differences in patient satisfaction.[4]

Of the three remaining studies evaluating SM and patient satisfaction, two were cross-sectional survey studies, and one was a case-control study of implementation that included a patient survey. In the first, the investigators surveyed patients who use the internet for health information regarding their email practices with physicians.[12] Of the 1881 individuals who completed the survey, 17% reported electronic communication with their physicians or physician staff, and satisfaction was highest in those who reported that their physician always responded (OR 15.9) compared to those who reported responses less than 100% of the time. The two remaining studies evaluated a web-based SM system being implemented at a clinic affiliated with the University of California Davis Health System.[13,14] In the first paper,[14] eight providers, their patients, and their staff were surveyed about the system. Two hundred thirty eight of 645 patients with email addresses (36.9%) responded to the survey with 97% having used the system at least once (49.6% used it only once or twice). Satisfaction was related to receiving a response right away or by the next business day. The second study evaluated patient satisfaction one year later and surveyed 5971 patients from 4320 email addresses with a response rate of 40.3% (1743/4320).[13] Their findings again associated higher satisfaction with more timely responses.

Secure Messaging and Adherence

There were two papers of clinical trials that evaluated SM and adherence, both of which were randomized.[15,8] One specifically evaluated SM reminders and one evaluated an online medical record with SM as one component. In a study from Northwest Permanente in Portland, OR,[15] investigators with an established EMR randomized 2100 patients with SM accounts who were due for colorectal cancer screening to usual care or to receive a letter reminder or a secure email reminder to pick up a fecal occult blood test at the lab. The cohort was subsequently reduced to 1409 patients because of logistical issues with performing the intervention leaving 494 in the usual care group, 458 in the letter group and 457 in the SM group. The two intervention groups were significantly more likely to undergo screening than the usual care group, and at similar rates (7.8% usual care, 23.6% letter, 22.7% email). They concluded that email was as effective a prompt as a letter. The final study of an online medical record for CHF from the University of Colorado which has been previously described, assessed adherence to medications and general adherence to medical regimens and found that the latter was significantly improved in the intervention group users versus controls.[8]

Secure Messaging and Efficiency/Utilization

There were 18 studies that evaluated SM and some aspect of efficiency or healthcare utilization.[1,16,17,3,18,19,20,21,22,14,23,6,24,25,26,8,13,7] Six studies were randomized controlled trials,[1,20,6,26,8,7] ten were observational analyses,[16,17,3,19,21,22,14,23,24,13] and two were survey analyses.[18,25] Four studies evaluated provider productivity and provider attitudes,[13,22,14,26] seven studies evaluated characteristics of users of SM systems,[18,16,25,24,21,17,19] and eight studies evaluated the impact of SM on utilization of healthcare services.[24,23,3,8,6,7,20,1]

There were four papers that evaluated SM and physician productivity.[13,22,14,26] Three papers described results of the same intervention with slightly different types of analyses of physician productivity.[13,22,14] These papers evaluated a secure web-messaging system being implemented at a clinic affiliated with the University of California Davis Health System that was described in the patient satisfaction section. The first was a pre-post study that found that intervention providers had higher overall averages of visits/day for the 5- month study period compared to the same period in the previous year (increasing from 24.8 to 29.5 visits/day, p=0.02).[13] The second study compared the intervention providers with providers at a control clinic site before and after the intervention.[22] Again, intervention physicians averaged 11% more visits/day than those in the control group (25.5 vs. 22.9) and averaged 10% more RVUs/day (relative value units) than the controls, though RVUs per visit did not differ. This was viewed as a positive finding for this fee-for-service environment. The third study retrospectively compared SM and telephone volumes for the intervention clinic and a control clinic.[14] Case call volume averaged 18.2% less than control (21.6 vs. 26.4, p=0.002) and case message (phone plus web) volume averaged 13.7% less than control (phone only) (22.8 vs. 26.4, p=0.025). Patient enrollment rose rapidly during this time, presumably accounting for the decrease in contacts/1000 panel patients. The fourth paper on physician productivity evaluated the introduction of a web-based communication tool for patients in a University of Michigan academic primary care practice and found that physicians in the intervention group (whose patients were given access to the web-messaging tool) did not experience a decrease in the volume of personal email and telephone messages, which remained similar to that of the control physicians despite the addition of a modest number of web-based messages.[26]

Two studies from Group Health Cooperative evaluated the characteristics of patients who used SM.[18,16] The first compared these patients to those who had registered for access to the patient web site but had not utilized SM. SM users were more likely to be middle aged (50-65 years old), female, and with a higher overall level of morbidity.[18] They were less likely to be insured by Medicaid. As would be expected, patients treated by providers with higher levels of SM use and with a higher proportion of younger patients on their panels were also more likely to use SM. The second study focused on patients with diabetes in Group Health and evaluated predictors of initial use of SM when it became available in 2003, and then subsequent use.[16] Initial use was associated with younger age, male sex, living in a higher socioeconomic status neighborhood and greater provider level of SM use. Older patients were more likely to subsequently sign up for SM if they switched to a high-use physician. Increasing morbidity also was associated with subsequent SM use. A third study similarly evaluated characteristics of patients who used the SM application associated with "PAMFOnline," a personal health record system operated by the Palo Alto Medical Foundation.[25] Users had opted to pay an annual fee of $60 for unlimited messaging ability in addition to the general functionalities of the PHR. Compared to the general PAMF patient population, PAMFOnline messaging users were older, had more active problems, took more medications and used PAMF to conduct more office visits. In a fourth study from Kaiser Permanente Northwest that compared SM users to non-users, users were older and more likely to have diabetes.[24]

The three remaining studies in this area included one from a single surgical practice that found that email users were significantly younger than non-users but found no sex differences in use;[21] a study from Europe that identified young (<25) , higher educated and urban patients as most likely to consider the availability of email access when choosing a new doctor;[17] and a study of a Florida physician survey which found that physicians in large group practices (50 or more physicians) were more likely, and Asian-American physicians were less likely to communicate with patients via email.[19]

Data regarding healthcare utilization and SM differed among the various studies. There were two studies evaluating implementation of SM at two different Kaiser Permanente regions.[24,23] The first involved patients from KP Northwest and evaluated utilization in a pre-post fashion for a retrospective cohort of members registered for KP HealthConnect Online (the SM application) for longer than 13 months and compared utilization for a sample of this cohort to a group of non-registered patients matched for age, sex, chronic conditions and primary care physician.[24] In the pre-post cohort analysis, annual primary care office visit rates decreased significantly from 2.47 to 2.24 visits per member per year. Similarly, SM user visit rates decreased more than the visit rate for non-users (10.3% vs. 3.7%, ($p<0.003$). The second study evaluated the impact of KP HealthConnect implementation in Kaiser Permanente Hawaii and compared healthcare utilization post-implementation (2007) to that of 2004.[23] This study found significant decreases in age/sex-adjusted total office visits per member (decrease of 26.2%) and significant increases in total scheduled telephone visits per member. Total contacts including secure messages and office and telephone visits increased significantly from 5.18 contacts per member per year to 5.61. A third study from Group Health Cooperative that has been previously described compared patients with diabetes who had completed the process of identity verification required to participate in SM to those who did not.[3] Controlling for a number of variables including overall medical comorbidity and diabetes severity, primary care visit rates were statistically significantly higher in the SM users (32% higher), as were specialty visits and emergency visits. These results indicate that data is conflicting regarding whether SM results in increased or decreased visit rates and there may be unmeasured factors in these studies related to the system, the patients or the healthcare environment which contribute to the findings.

Three studies of online medical records with SM capability also looked at utilization.[8,6,7] One study involving patients with CHF that has been previously described that randomized patients to access to the system found that intervention patients had significant increases in overall emergency department visits but no differences in mortality, hospitalizations or heart failure clinic visits.[8] Another study in patients with diabetes randomized to access to an online care management application that has also been previously described found no differences in primary care or specialty care visits or inpatient days though there was additional time spent by the care managers in the intervention group.[6] The third involved patients with hypertension randomized to usual care, access to the web-based application and access to the web-based application with pharmacy case management, and has also been previously described.[7] This study found no differences in primary care visits, inpatient or urgent care/emergency use at one year. Telephone encounters were higher in the pharmacy arm than the other two though these patients had a modest but statistically significant decrease in specialty office visits.

Finally, two European studies found that patients randomized to SM with their general practitioner had fewer office visits than those without access, though there were no differences in the number of telephone consultations between groups,[20] and patients with ulcerative colitis who had access to a web-based care management program with messaging had fewer routine visits than control patients.[1]

Summary for Key Question #1

The hypothesis testing studies that include secure messaging support the following conclusions:

- There is moderate strength evidence that secure messaging (especially as part of a web-based management system) can improve glucose outcomes in patients with diabetes. (GRADE = moderate)
- There is low strength evidence that adding a web-based pharmacist to secure messaging improves blood pressure outcomes in patients with hypertension. (GRADE = low)
- There is low strength evidence that secure messaging with a web-based management system improves ulcerative colitis symptoms. (GRADE = low)
- There is moderate strength evidence that secure messaging increases patient satisfaction. (GRADE = moderate)
- There is low strength evidence that secure messaging improves adherence to colorectal cancer screenings or heart failure management. (GRADE = low)
- There is low strength evidence that secure messaging influences either positively or negatively efficiency or utilization. (GRADE = low)

KEY QUESTION #2. What is the association between patient access to their own medical record and health outcomes, patient satisfaction, adherence, efficiency or utilization, and attitudes about access?

There were 31 articles related to patient's having electronic access to their own medical records. These articles were divided into studies that evaluated "tethered" systems, where patients accessed information through a system (usually web-based) tied to a provider-based electronic record and that included functionalities such as secure messaging; and those that evaluated non-tethered systems. The studies were further subdivided into those that were hypothesis testing, evaluating outcomes such as health outcomes, satisfaction, adherence, healthcare efficiency or healthcare utilization and attitudes; and, those that were descriptive qualitative. The latter studies were generally survey studies and generally evaluated attitudes about patient access to their own records.

Patient Access to Medical Records through Tethered Systems

Of the articles evaluating patient access to their own medical record through a system tethered to a provider-based electronic record, seven were RCTs,[8,6,27,4,7,28,29] four were observational hypothesis testing studies,[16,30,31,32] and nine were descriptive quantitative studies.[33,34,35,36,37,38,39,40,41] Only one study was a cost-benefit analysis study.[42]

The systems described in these studies included a number of functionalities as part of their intervention. These are listed in Table 1. As can be seen, almost all systems included secure messaging, access to test results and progress notes/visit summaries, and education/disease management, meaning the effects cannot be disentangled and these four functionalities represent a "core" set for patient portals.

Table 1. Tethered Personal Health Record Systems and Functionalities

Author, year	**Setting**	**Test results**	**Secure messaging**	**Progress notes/visit summaries**	**Educational materials/disease management**	**Med renewal**	**Make appts**	**Patient uploads/ diary**	**On-line reminders**
Ralson, 2007[33]	Group Health	Yes	Yes	Yes	Yes	Yes	Yes	Yes (health assessment tools)	
Green, 2008[7]	Group Health	Yes	Yes	Yes	Yes	Yes	Yes		
Weppner, 2010[16]	Group Health	Yes	Yes	Yes	Yes	Yes	Yes		
Falcao-Reis, 2010[43]	Partners	Yes	Yes		Yes	Yes	Yes	Yes (eJournal)	
Wald, 2010[44]	Partners	Yes	Yes					Yes (eJournal)	
Ralston, 2009[6]	Univ of Washington	Yes	Yes	Yes	Yes			Yes	Yes
McCarrier, 2009[28]	Univ of Washington	Yes	Yes	Yes	Yes			Yes	Yes
Hassol, 2004[34]	Geisinger	Yes	Yes			Yes	Yes		
Burke, 2010[30]	Miami Children's	Yes - imaging		Yes	Yes – discharge instructions				
Tuil, 2007[4]	Netherlands	Yes	Yes	Yes	Yes				
Ross, 2004[8]	SPPARO – Univ of Colorado	Yes	Yes	Yes					

Patient Access and Health Outcomes, Satisfaction, and Adherence

Seven articles evaluated health outcomes, health status, satisfaction or adherence with respect to a tethered record system. Six were randomized controlled trials. The first involved patients with congestive heart failure (n=107) being treated in a specialty clinic at the University of Colorado Hospital in Denver, CO, who received usual care or were given access to a secure web-based system ("SPPARO") that included access to their medical record (notes, labs and test results), an education guide and a secure messaging system (described in SM section).[8] Participants received questionnaires at baseline, 6 months and 12 months. The study found no significant difference in the primary endpoint which was a change in the self-efficacy domain of the Kansas City Cardiomyopathy Questionnaire nor in other measures of health status, though there was a trend towards improvement in the intervention group. There was also a non-statistically significant trend towards greater patient satisfaction with doctor patient-communication but not in other satisfaction domains. This study was the only one to evaluate adherence and found that general adherence to medical advice was improved in the intervention group while there was no statistically significant improvement in medication adherence. In the second study,[6] eighty three patients with diabetes from a University of Washington General Internal Medicine Clinic were randomized to usual care versus care augmented by web-based and in-person care management for a period of 12 months. Intervention patients met with the nurse care manager who introduced them to the web-based system that provided access to test results, clinical summaries of diabetes care, secure messaging, online reminders, educational materials and the ability to upload glucose readings. Intervention patients were encouraged to send weekly glucose readings and send secure messages as needed. Hemoglobin A1c levels were significantly lower in the intervention group (change -0.7%, p=0.01). More intervention patients had A1c levels <7% (33 vs. 11%, p=0.03) though there were no significant differences in blood pressure or cholesterol. A similar intervention from the same institution was evaluated in a diabetes specialty clinic.[28] In this study, 77 patients with Type I diabetes were randomized to usual care from the Diabetes Care Center or usual care plus access to a nurse practitioner case manager and the web-based disease management module. A1c values did not differ significantly after a year of follow-up. There was an increase in psychosocial self-efficacy as measured by the Diabetes Empowerment Scale in the intervention group (difference of 0.3, 95% CI 0.01 to 0.59, p=0.04).

In the fourth study from Group Health (which has been previously described),[7] investigators randomized patients with hypertension to one of three groups, all of whom had access to a tethered patient portal with secure messaging, access to test results and clinic visit summaries, ability to renew meds and make appointments, and access to educational materials. The three groups included a control group that received usual care, a second group that received a home blood pressure monitor and patient portal training, and a third group that received the above intervention together with access to pharmacist – initiated case management via SM and face-to-face visits. Only the web-based pharmacy group demonstrated significant improvements in BP control with 25% more patients with controlled BP compared to usual care (mean decrease -8.9 mm Hg) and 20% more compared to the other intervention group (mean decrease -6.0 mm Hg). There was also greater aspirin use in the web and pharmacy group compared to the others (20% more compared to web-only group and 30% more compared to usual care).

The fifth study from Partners HealthCare involved patients with diabetes who had active accounts with Partner's patient portal, Patient Gateway, which provided access to test results, secure messaging, medication renewal and appointment management, and educational materials[29]. Intervention patients (126) came from 11 practices where they were given access to a diabetes mellitus-specific personal health record that had modules for medication review, diabetes-related clinical data, and the ability to generate a "Diabetes Care Plan" to share with their primary care providers; while control patients from the remaining practices (118) had access to a system that allowed them to update their family history and review cancer screening and other non-diabetes related preventive services and submit updates or requests regarding these aspects of care. After one year of follow-up, there were no differences in A1c levels, blood pressure or LDL-C levels between groups. Fifty percent of intervention patients completed a Diabetes Care Plan and these patients were more likely to have a medication adjustment for diabetes, hypertension or hyperlipidemia than patients in the control arm who submitted a preventive care journal update or request (53% v 15%, $p<0.001$).

The sixth study randomized couples undergoing in-vitro fertilization (IVF) in the Netherlands to usual care versus access to an internet-based personal health record of all digital information available concerning their fertility treatments that also had secure messaging, education and discussion functionality.[4] They found no differences in patient empowerment (e.g. self-efficacy, knowledge) or secondary outcomes such as patient satisfaction, change in anxiety or change in depression between the two groups.

In a cross-sectional survey study from Group Health Cooperative in Seattle, WA,[33] investigators randomly surveyed 2002 users of their web-based patient record system (MyGroupHealth) which provided patients the potential for access to their medical record including lab results, secure messaging, medication refill services, appointment management, after-visit summaries, health information and discussion groups. There was a 46% response rate with respondents generally reporting high satisfaction with MyGroupHealth (94% satisfied or very satisfied). Patients were more satisfied with specific functionalities such as medication refills, patient-provider messaging and medical test results than they were with MyGroupHealth overall, though were not as satisfied with some of the other features.

Patient Access and Efficiency/Utilization

Nine studies evaluated tethered patient record systems and their impact on efficiency or utilization.[27,6,8,7,16,33,30,34,42] Four were randomized controlled trials.[27,6,8,7] The University of Colorado study of SPPARO for patients with CHF, previously described, found a significant increase in overall emergency department visits in the intervention group compared to the controls (20 v 8 visits, $p=0.03$) but no differences in hospitalizations.[8] The University of Washington study of patients with diabetes,[6] also previously described, found no differences among the three groups in outpatient visits, primary care provider or specialty physician visits, or inpatient days though the care manager self-reported an average of four hours per week managing the patients. The Group Health study of patients with hypertension, described above,[7] found that the mean number of secure message threads initiated by patients (includes initial message and follow-up responses), were highest in the group that included access to the web system and a pharmacist (4.2 compared to 2.7 in the web-only group and 1.8 in the usual care group), as well as higher numbers of phone encounters (mean 7.5 compared to 3.8 in the web-only group and 4.0 in the usual care group, $p<0.001$). Primary care visits, inpatient and urgent care/emergency room utilization did not differ significantly. There was a modest but significant decrease in percent of patients with visits to specialists in the web and pharmacy group compared to the other groups (numbers not provided in text). Finally, there were more antihypertensive medications used in the intervention group compared to the web-only and usual care groups (RR 2.2, $p<0.01$ for web-only and $p<0.001$ for usual care). A fourth study from Partners HealthCare surveyed patients who had been randomly assigned to two arms of a study of "eJournal" use, a component of Patient Gateway (PG), a secure EHR-connected internet patient portal that has been described above.[27] Eligible patients having a PG account and an assigned PCP from a study site either received access to medication/allergies/diabetes eJournal modules (Arm 1) or to health maintenance/family history/personal history eJournal modules (Arm 2) and were reminded prior to certain types of appointments to complete an "eJournal" and submit it to their provider prior to the visit, updating or adding to information already available in their outpatient EHR. Providers had the option of reviewing the eJournal and uploading it to the EHR. Three percent of eligible patient users (3979) agreed to enroll in the study and 59.3% of these patients completed a post-intervention survey. Of the 84 providers whose patients submitted at least one eJournal, 29 (34%) completed the post-intervention survey. Between 64 and 78% of patients opened at least one eJournal and 97% of patients edited an existing entry. There were more eJournal entries in Arm 1, but this group received more reminders because they had more eligible visits. All providers in Arm 1 reported no change in visit length, while 47% of providers in Arm 2 felt that the visits were longer ($p<0.013$).

Four studies were observational and reported data regarding use of tethered patient health record systems.[16,33,30,34] One study from Group Health Cooperative evaluated patterns of use for its "shared medical record" (SMR) system which included secure messaging, ability to request medication refills and appointments, ability to view test results, after-visit summaries, problem and allergy lists and immunizations.[16] Investigators followed 6185 enrollees with diabetes over an average of 2.8 years. About one-third of enrollees utilized the SMR with younger age, male sex, higher socioeconomic status and higher PCP use of secure messaging significantly associated with patient use. Higher morbidity was significantly associated with earlier sign-up and on-going use (rate ratio 1.3, $p<0.001$). The most frequently used features were tests result reviews, medication refill requests and secure messaging. A second study from Group Health Cooperative[33] evaluated SMR use from 2002 to 2005 and found that ID-verified enrollment increased from 3% to 25% and that registration for basic services increased from 9% to 14%. A study from Geisinger Health System conducted an online survey of active users of "MyChart," with a 33% response rate.[34] They found that 3% of users were using MyChart on behalf of a spouse or parent. Another study evaluated a web-based patient—accessible EHR for patients with congenital heart disease—that in most cases gave the patients access to history and physical reports, patient care instructions and imaging data from surgery but did not include secure messaging.[30] Of the first 270 offered access, 252 (93%) became users, with use more common while the patients (mostly infants getting cardiac surgery) were hospitalized than after discharge (median 6 v 4 logins, $P<=0.001$). There were more views of imaging data than textual data (median 8 page views v 5, $P<0.001$).

Finally, there was one study that performed a cost-benefit analysis of the "potential value to the US" of different types of personal health record systems (PHRs) comparing provider-tethered, payer-tethered, third-party (e.g. Microsoft, Google, Dossia) and interoperable systems.[42] The investigators performed a literature review to evaluate data on costs and benefits but augmented their models using expert opinion and evidence from non-PHR sources because of the paucity of quantitative evidence surrounding PHRs. Assuming a ten year roll-out period, all PHRs demonstrated an initial net negative value but eventually reached a break-even point and began to provide benefit. Interoperable PHRs had the earliest break-even point at three years followed by payer-tethered and third-party PHRs by four years. Provider tethered PHRs did not break even during the initial 10 year period.

Attitudes about Patient Access

There were twelve studies that assessed attitudes about patient access to their own medical records or related issues.[27,32,31,35,36,34,45,41,38,39,40,37] Three studies were hypothesis testing,[27,32,31] with one randomized controlled trial.[27] In this RCT from Partners HealthCare (which has been previously described), patients were provided with the opportunity to submit an eJournal using a tethered patient portal prior to specific types of visits. About 60% of participants responded to a post-intervention survey of which 34.4% reported submitting an eJournal to their doctor's office. Fifty-eight percent of patients agreed or strongly agreed that the eJournal gave their provider more accurate information and 55.9% of patients felt more prepared for their visits, but only 37.2% agreed or strongly agreed that communication with their provider improved, 37.7% of patients felt more satisfied with the visit and only 24.5% that the quality of care at the visit improved. Comparing the two different arms of the study, Arm 1 patients (access to medication/allergies/diabetes eJournal modules) were more likely than Arm 2 patients (access to health maintenance/family history/personal history eJournal modules) to feel prepared for their visit (59% v 51%, $P<0.02$) and Arm 1 physicians were more likely to feel their patients were prepared for the visit compared to Arm 2 patients (100% v 43%, $p<0.04$). A second hypothesis testing study from the University of Colorado evaluated attitudes of patients and physicians using SPPARO, an online record system for patients with CHF that has been previously described.[31] Pre-intervention, physicians were much more likely than patients to endorse concerns that patients with access to SPPARO would have more questions (71 v 37%), would worry more (71 v 5%), would find reports confusing (57 v 13%), and would find notes offensive (29 v 3%). Over the course of the trial, physician concerns in these domains decreased (though not significantly, perhaps due to the small number of physician participants). The final hypothesis testing study evaluated attitudes of Veterans with diabetes regarding their internet use and their interest in various aspects of My Health*e*Vet (MHV), VA's tethered patient web portal.[32] Surveys were mailed to eligible Veterans receiving primary care from a Durham VA outpatient clinic. Two hundred one Veterans completed the surveys for a 53% response rate. In a multivariate analyses, the investigators found that age and trust in the internet were independent predictors of interest in using MHV for diabetes management with odds of being "very interested" increasing by 1.4 for each decade younger a respondent was, and by 2.3 if the respondent had "a lot/some" trust in the internet.

Of the remaining studies, only four evaluated existing systems.[35,36,34,45] In a study from Geisinger Health System,[34] investigators conducted an online survey of registered users of "MyChart," a tethered personal health record system. Of 4282 users invited to participate, 33% completed the survey (60% of whom were female). Patients reported high rates of understanding of medical information and test results, with higher rates of understanding for more highly educated respondents. Only approximately 30% of respondents had concerns about confidentiality and security. In a study from Partners HealthCare,[35] investigators surveyed a random sample of 2000 patients who held an account with Patient Gateway (PG), a secure patient web portal. There was a 23% response rate. The most highly rated features were the administrative functions such as the ability to renew prescriptions, ask administrative questions or obtain referral approvals. 38% felt that PG improved communication with the provider practice while 30% disagreed and 32% were unsure. Another study from Partners evaluated patient attitudes about a new module within Patient Gateway to improve medication safety.[45] The module allowed patients to review their medication and allergy lists and make comments about its accuracy, about their compliance, and about problems with compliance or side effects. Of 12,278 patients invited to participate, only 7% 812) were eligible for the study and completed a medications journal within Patient Gateway. A smaller number completed a survey (687). 70% found the journal very easy or easy to complete while 53% thought it gave providers more accurate information (39% were neutral). 56% felt more prepared for their visit; 35% were neutral on this issue. In the final study from Sweden,[36] investigators piloted a system called "SUSTAINS" that allowed patients access to the hospital information system and laboratories, the general practitioner's EHR and secure messaging. They surveyed 100 users of the system but did not report a response rate. 82% of "users" had no worries about security while 15% expressed "some concern; and only 2% were very concerned about the security risks of "full scale service."

The remaining studies were surveys of attitudes regarding potential systems and all but one were from Europe or Canada. In one study from Intermountain HealthCare/University of Utah,[37] investigators surveyed physicians prior to giving patients web access to their electronic medical record. Ninety-one of 150 email-using physicians responded to the survey. Providers approved of giving patients access to medication lists, normal lab studies, prescription refills, appointments and referrals ($P<0.05$) but were less likely to approve of giving patients access to abnormal lab studies, progress notes or care over the internet. A study from England assessed attitudes about a test system that was available via a booth at a London group practice.[38] Investigators surveyed patients on their interest in viewing their records before and after seeing the system, their concerns about security and accuracy, their interest in editing their record and the impact on the doctor-patient relationship. Patients had high rates of interest in viewing their records and most felt that having access to a record would break down barriers with their providers. Small numbers were concerned about security or accuracy. A study from Canada surveyed 30 patients with lung transplants given access to a personal health record simulation environment and found that 60% of patients felt that having access to information about their medical care would help them manage their care at home.[39] Another study from England gave 100 patients access to view their physician-held electronic medical records and found that most had little difficulty navigating or understanding most sections with the exception of referrals.[40] Forty-eight percent were worried about security before seeing the record while 61% were confident of the security in use after seeing the record. Another study from Canada surveyed men with prostate cancer regarding their attitudes towards web-based personalized electronic health record information systems.[41] The study included a convenience sample of 41 men and 18 spouses/significant others and found that 80% would be willing to try a web-based system. Between 36 and 55% of men had some concerns about accuracy, security and confidentiality of information.

Patient Access and Patient Characteristics

There were four studies that evaluated the characteristics associated with use of patient portals. In one study from Group Health Cooperative, diabetes patients were surveyed regarding their use or non-use of a patient portal tethered to Group Health's electronic health records system.[46] Of 873 patients eligible for inclusion, 718 or 79% agreed to participate. 53% of participants had used the patient website, and in unadjusted analyses, Whites (compared to Blacks, Asians or other), younger patients, and those with higher education and income were more likely to be users of the patient portal. In a model adjusted for age, sex, health need, education, income, and provider factors, Blacks were 82% less likely and Asians 60% less likely to use the patient portal. When restricting to those who used the internet, Blacks were still 75% less likely to use the portal.

In a second study from Kaiser Permanente Georgia,[47] investigators surveyed a cohort of racially diverse enrollees and subsequently evaluated registration rates for Kaiser's tethered personal health record, KP.org. Of the 1777 patients included in the evaluation, 35% registered with KP.org during the study period and these patients were significantly more likely to be white than African American (42 v 30%, $p<0.01$), to have diabetes or elevated lipids compared to low risk adults (36 and 38% v 30%, $p=0.01$), and to have a higher level of education (greater than high school). Differences in registration rates between whites and African Americans persisted when adjusting for different variables.

Another study from Kaiser Permanente in Northern California evaluated patients with diabetes and their use of KP.org, focusing specifically on health literacy.[48] 14,102 patients who had completed a survey as part of a larger study evaluating ethnic and educational disparities in diabetes-related behaviors, processes of care and health outcomes, were included in the analysis. Only 40% registered for KP.org and 27% signed on one or more times. African Americans, Latinos and Filipinos were more than twice as likely to not sign on to KP.org compared to Whites. Those with lower self-reported health literacy were 1.7 times less likely to sign on to KP.org. Among those with computer access, the racial/ethnic differences persisted as did the effect of limited health literacy.

A fourth study from Partners HealthCare compared primary care patients who had activated their account giving them access to an online tethered personal health record (Patient Gateway) with those who had not as of September 2009.[49] Of 75,056 included in the analysis, 43% were "adopter" – having registered for the portal. Rates of adoption were lower among all racial/ethnic minorities with blacks 50% less likely to be adopters compared to whites. Patients with selected comorbidities (asthma, CHF, diabetes, hypertension) were more likely to be adopters while patients with more visits were less likely to be adopters.

Qualitative Studies on Patient Access – Barriers and Facilitators

There were four papers that utilized qualitative research methodology to evaluate personal health records and that identified specific barriers or facilitators to their success. In one paper from a University of Washington general internal medicine clinic, patients with Type 2 diabetes mellitus had access to a patient portal that allowed them to view their record, upload glucose readings, send secure messages with a case manager and provided disease-specific information.[50]

Qualitative interviews with nine participants identified that for many, the portal provided a means for patients to discuss non-urgent matters related to their health but that frustrations with the system (e.g. technical, lack of timely response) could result in the patient feeling devalued. Two papers described results from a University of Pittsburgh evaluation of a diabetes-focused patient portal (UPMC Health Trak) that included secure messaging, preventive healthcare reminders and disease-specific tools and information.[51,52] Focus groups of 39 patients identified forgotten passcodes, lack of knowledge about all aspects of the system, and an inability to view all records of interest as potential barriers. Facilitators included an enhanced sense of patient empowerment and ability to communicate regarding appointments as well as with providers between scheduled appointments. Focus group discussions also revealed that patient use and interest in the portal was associated with dissatisfaction with the existing patient-provider relationship – particularly related to communication with and responsiveness of the provider or office, and access to information. Patients with greater satisfaction with their existing patient-provider relationship were less interested in using the portal. Lastly, an assessment of variations in adoption at four primary care practices affiliated with Partners HealthCare found differences between high and low adoption practices in leadership and marketing practices.[44] The addition of an incentive for patient enrollment was associated with 3-6 fold increases in adoption.

Summary for Key Question #2 – Tethered Systems

The evidence reviewed regarding patient access to their own medical records, when this is tethered to an electronic health record, supports the following conclusions:

- There is low strength evidence that patients' access to their own medical record improves health outcomes for chronic diseases such as diabetes, hypertension, or heart failure (GRADE = low).
- There is low strength of evidence that patient access to their own records, combined with the ability to submit an electronic care plan can improve medication decisions at a subsequent visit for patients with diabetes (GRADE = low).
- There is insufficient evidence to reach conclusions regarding the potential effect of patients' access to their own medical record on efficiency (GRADE = insufficient).
- There is low strength evidence that patients' access to their own medical record influences utilization (GRADE = low).
- There is insufficient evidence to reach conclusions regarding the potential effect on patients' access to their own medical record on patient attitudes.
- There is moderate strength evidence that use of patient portals is lower among certain racial or ethnic groups, in particular African Americans (GRADE = moderate).
- There is moderate strength of evidence that use of patient portals is lower in persons with lower literacy or education level (GRADE = moderate).

Patient Access to Medical Records: Non-Tethered Systems

There were five papers focusing on patient access to their own medical records using systems that were not necessarily tethered to a provider-based EHR.[53,54,55,56,57] All were survey studies and four were from Europe or Canada. The one US study from the University of Washington evaluated the use of a web-based personal health record by disadvantaged people living at a low-income housing facility.[56] The study utilized nursing students to help residents utilize the system and found that utilization was much higher on the days that the students were available or on the day after. 12 of 24 registered users completed a survey. Only two were able to complete the health record entry on their own, though 92% were satisfied with the system and most felt the system helped them manage their health information. A Swedish study evaluated patient attitudes towards a national pharmacy register using a web survey.[53] Of 7860 unique site visitors, 22% completed the survey. Respondents generally rated the system highly and felt that it would help with medication safety and healthcare, particularly that given by the pharmacist. A study from Switzerland evaluated the attitudes of patients given "CardioCard," a small CD-ROM containing cardiac medical information including study reports and reports of clinical examinations.[55] Seventy three percent of 536 patients who received a CardioCard responded to the survey. Seventy three percent found it very useful or useful and 78% were willing to pay for it. Most (73%) did not access the card themselves and 88% did not have their physicians access the card. Only 5% were worried about data security.

The final two studies surveyed patients on their attitudes regarding having access to online health information.[57,54] One from England invited 1050 patients to participate in a survey with a 60% response rate (629 responses).[57] Analyses were conducted for patients aged 21 and older. Most felt they should have access to their health records (83%) and 79% thought it was a good idea to make them electronic. 35% preferred print-outs of records and 50% had concerns about the security of their records held on computers. A study from Canada surveyed Chief Executive Officers of Canadian public and acute care hospitals to understand organizational readiness for patient accessible records.[54] Eighty-three of 213 CEOs responded (39% response rate). Fifty-four percent of hospitals had some sort of EHR. 87% of respondents identified hospital financial resources as the most important barrier to providing patient access to the EHR.

Data for the non-tethered systems confirms the generally positive attitudes from other survey studies of patients regarding their interest in having access to their medical records. The one study in a low income and elderly population identifies potential barriers related to computer and internet skills.

SUMMARY AND DISCUSSION

SUMMARY OF EVIDENCE BY KEY QUESTION

A summary of the conclusions and strength of evidence is presented in Table 2.

Table 2. Conclusions and Strength of Evidence by Key Question and Outcome

Conclusion	GRADE Classification
KEY QUESTION #1. What is the association between secure messaging and health outcomes, patient satisfaction, adherence, efficiency or utilization, or automated email?	
Health Outcomes	
Secure messaging (especially as part of a web-based management system) can improve glucose outcomes in patients with diabetes.	moderate
Adding a web-based pharmacist to secure messaging improves blood pressure outcomes in patients with hypertension.	low
Secure messaging with a web-based management system improves ulcerative colitis symptoms.	low
Patient Satisfaction	
Secure messaging increases patient satisfaction.	moderate
Adherence	
Secure messaging improves adherence to colorectal cancer screenings or heart failure management.	low
Efficiency/Utilization	
Secure messaging influences either positively or negatively efficiency or utilization.	low
KEY QUESTION #2. What is the association between patient access to their own medical record and health outcomes, patient satisfaction, adherence, efficiency or utilization, and attitudes about access?	
Health Outcomes, Satisfaction, and Adherence	
Patients' access to their own medical record improves health outcomes for chronic diseases such as diabetes, hypertension, or heart failure.	low
Patient access to their own records, combined with the ability to submit an electronic care plan can improve medication decisions at a subsequent visit for patients with diabetes.	low
Efficiency/Utilization	
There is insufficient evidence to reach conclusions regarding the potential effect of patients' access to their own medical record on efficiency	insufficient
Patients' access to their own medical record influences utilization.	low
Attitudes	
There is insufficient evidence to reach conclusions regarding the potential effect on patients' access to their own medical record on patient attitudes.	insufficient
Patient Characteristics	
Use of patient portals is lower among certain racial or ethnic groups, in particular African Americans.	moderate
Use of patient portals is lower in persons with lower literacy or education level.	moderate

LIMITATIONS

The primary limitation of this systematic review is the quantity and quality of the original studies. Evidence was sparse for all but two of the outcomes assessed (the effect of SM on diabetes outcomes and patient satisfaction), and studies frequently had methodological problems including the use of study designs with greater risk of bias (pre/post studies), poor response rate or poor follow-up rate for surveys and cohort studies, and little explanation of the implementation process for the IT functionality, which has two consequences: it makes it challenging to distinguish between failure of the intervention and failure of the implementation in studies reporting no effect; and for studies that do report beneficial effects it leaves providers and policymakers at other institutions unclear about how to replicate the success. The above limitations are common to almost all systematic reviews of health information technology. An additional limitation of this review is that the functionalities of interest, secure messaging and patient access to their own records, were often part of a bundle of interventions, making attribution of any beneficial effect to any one functionality difficult. In practice, attributing the independent effect of individual functionalities may not be necessary or even meaningful, since many champions consider these two functionalities (plus others) as interdependent. Many champions consider the package of functionalities – secure messaging, patient access to renew medications and appointments, and online disease management tools to be core elements of a tethered personal health record. Additionally, there may be a "ceiling effect" present, meaning that patients practicing greater health engagement with providers and in terms of self-management may be more likely to adopt new technology sooner, making it harder to demonstrate strong improvement. Lastly, much of the evidence comes from non-VA settings – e.g., studies from academic tertiary care medical centers working in a fee-for-service or similar reimbursement environment – although several observational studies from Kaiser and from Group Health Cooperative tend to support the findings from the academic medical centers. The relevance of these settings to VA is a judgment for VA policymakers.

DISCUSSION

The literature surrounding secure messaging and patient access to their own records is evolving as the systems themselves become more complex. In some respects, evaluating the individual components of patient portals may no longer be relevant since most of the functionalities are not conceptualized as independent features, but rather as part of an overall package that is intended to facilitate information exchange with patients as well as patient communication with providers and healthcare institutions. Our review identifies a few core elements consistently described in most of the published evaluations that comprise the basic patient portal: secure messaging, access to test results, access to progress notes or visit summaries, and educational materials or disease management tools.

The evaluation of the impact of these portals is further complicated when one considers that they are also being designed to align with a larger patient management system that includes case management, remote health care delivery and non-face-to-face care. Attributing outcomes to any one component becomes more and more difficult as these layers are added one to the other; yet it appears that utilizing patient portals as part of a broader effort to improve care, particularly one that involves case management, may in fact yield beneficial results.

These patient portals are also being created as part of a movement to make patients more active participants in their care, as opposed to passive receivers of information. Early consumer health systems provided educational materials to patients. Robust patient portals offer patients the ability to drive and direct their care. Yet our review has identified some potential key barriers to achieving more uniform access to these systems. Successful and widespread implementation will require attention to these disparities in use as well as tailored approaches to engage certain populations that are not readily embracing personal health record systems.

RECOMMENDATIONS FOR FUTURE RESEARCH

Any research within VA is going to be pragmatic by design, since VA is already implementing secure messaging and patient access to their own record (meaning that any kind of randomized study where this is withheld is not practical). Nevertheless, a time series study of the implementation of secure messaging across institutions would be feasible and could provide reasonable, hypothesis-testing data to assess the effect of increasing SM use on quality (via EPRP), productivity, and patient satisfaction. Such a study would need to use both within-institution and across-institution comparisons to deal with the possibility of secular trends in quality, productivity and satisfaction as well as the "institution effect".

CONCLUSIONS

Data are sparse, but support that the use of secure messaging can improve glucose outcomes in patients with diabetes and increase patient satisfaction. Data from other studies suggest that secure messaging as part of a web-based management program is more effective than secure messaging alone. This finding supports the conclusions from other studies of health information technology that HIT is a tool, and if implemented by itself may have modest or even no measurable effect, but HIT can enable the implementation of more comprehensive programs (e.g., the web-based management system, in this case) that have meaningful effects on quality of care.

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