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ENGAGING PATIENTS THROUGH THE EHR: AN EVALUATION FRAMEWORK TO MEASURE ENGAGEMENT,
OUTCOMES AND ACCESS

BY

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An abstract of A Thesis submitted to the Faculty of the Rollins School of Public Health of Emory University in partial fulfillment of the requirements of the degree of Master of Public Health in the Career MPH program 2013.

ENGAGING PATIENTS THROUGH THE EHR: AN EVALUATION FRAMEWORK TO MEASURE ENGAGEMENT, OUTCOMES AND ACCESS

BY

Melanie Ann McLeod

Although a growing body of literature focuses on patient engagement, including some preliminary research on the EHR's capacity to increase patient engagement, there is relatively little research focused on how to evaluate patient engagement resulting from interaction with the EHR. Similarly, there is a wealth of diabetes research on methods to improve health outcomes and the important role of patient engagement. However, there is a knowledge gap regarding the role of the EHRs to increase patient engagement in this specific population. This thesis presents meta-analysis of the research around the three main topic areas (diabetes health outcomes, patient engagement and EHRs) and an evaluation framework for developing an evaluation plan. Included in the evaluation framework is an examination of possible indicators related to measuring improved health outcomes and patient engagement related to the electronic health record. The ultimate goal of the evaluation framework is to systematically identify those who could benefit from outreach and activities to increase engagement.

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Introduction:

This thesis will examine the relationship between utilization of the patient portals in electronic health records (EHRs) and patient engagement to improve health outcomes for people with Type 2 Diabetes. Specifically, the thesis will examine how access to features through a patient portal such as secure messaging, physician notes, visit summaries and patient education materials can increase patient engagement and improve health outcomes for people with diabetes. After establishing the research problem and questions, reviewing the related literature, an evaluation framework is presented to outline how these EHR features can be measured and evaluated towards the goal of increasing patient engagement and improved health outcomes. The evaluation framework will utilize findings from other research designs to present feature specific evaluation options and will incorporate appropriate clinical measures.

Although a growing body of literature focuses on patient engagement, including some preliminary research on the EHR's capacity to increase patient engagement, there is relatively little research focused on how to evaluate patient engagement resulting from interaction with the EHR. Similarly, there is a wealth of diabetes research on methods to improve health outcomes and the important role of patient engagement. However, there is a knowledge gap regarding the role of the EHRs to increase patient engagement in this specific population. Thus, although this thesis is not presenting the findings from primary research, the author believes that the evaluation framework and the meta analysis of the research around the three main topic areas (diabetes health outcomes, patient engagement and EHRs) will be a useful contribution to the growing body of literature and understanding of the applied uses of EHRs. The author anticipates that having a synthesized work around these topics will be useful to clinical providers and public health practitioners.

Research Questions:

Measuring Patient Engagement in Diabetes Care

How has patient engagement been measured in other studies? What tools have been developed to measure patient engagement? What role does patient engagement play in diabetes care and improving health outcomes? What evidence supports increased patient engagement leading to improved health outcomes for diabetes care? What are appropriate measures of patient engagement as well as clinical indicators for patients with diabetes? How can patient engagement be evaluated as it related to EHR utilization and diabetes care?

Electronic Record Utilization and Patient Engagement

How can utilization of electronic health records through a patient portal increase patient engagement? Do certain features of the electronic health record i.e. access to provider notes or after visit summaries hold greater potential for increasing patient engagement?

Electronic Record Utilization and Diabetes Health Outcomes

What is the impact of patient access to electronic health records on health outcomes for people with diabetes? Which features of the EHR have the greatest impact on health outcomes, service utilization or medication adherence for those with diabetes? How can providers leverage the EHR to improve health outcome for diabetes?

Problem Overview:

Growing Incidence of Chronic Disease and Diabetes

According to the Centers for Disease Control and Prevention, chronic diseases including heart disease, stroke, cancer, diabetes, and arthritis are the “most common, costly, and preventable of all health problems in the U.S”.(CDC, 2013) Nearly half of all adults have at least one chronic disease

which account for 70% of all deaths each year.(CDC, 2013) In 2011, nearly 26 million Americans, 8.3% of the population, had diabetes with an additional estimated 79 million U.S. adults had pre-diabetes, a condition in which blood sugar levels are higher than normal, but not high enough to be diagnosed as diabetes.(CDC, 2011)

The public health burden of diabetes is immense. Diabetes is the leading cause of kidney failure, non-traumatic lower limb amputations and new cases of blindness among adults in the United States. Diabetes is also a major cause of heart disease and stroke and remains the seventh leading cause of death in the United States. (CDC, 2011)

To successfully manage chronic conditions such as diabetes, individuals and their families must play an active role (ibid.). Because the severity of diabetes is related to individual behaviors, optimal care and disease management results when patients are actively engaged in their care. However, despite the need for coordinated care and active consumer involvement, managing chronic disease is often difficult, impacted by fragmented delivery systems and a health system geared toward acute conditions. Successful chronic disease care requires a long term, centralized approach to managing chronic disease and active patient engagement.(Bodenheimer, Lorig, Holman, & Grumbach, 2002)

The Role of Health IT to Increase Patient Engagement

Several converging forces in health care have placed patient engagement and the use of electronic health records at the top of the health care agenda. Federal initiatives such as the EHR Incentive Program require that providers use EHRs in ways that may improve patient care and health outcomes. One major force, the Medicare and Medicaid EHR Incentive Programs, provide incentive

payments to eligible providers to “adopt, implement, upgrade or demonstrate meaningful use of certified EHR technology”.(CMS, 2013)

An equally influential force shaping the use of EHRs is the Meaningful Use Mandate. The goal of the Meaningful Use mandate is “to promote the spread of electronic health records to improve health care in the United States.”(HIT.gov, 2013) Anticipated benefits of Meaningful Use include access to more complete and accurate information, improved access to health information and enhanced patient empowerment. Meaningful Use is rolling out in three stages with the deadline for Stage 2, advancing clinical processes, coming in 2014. Included in Stage 2 are provisions to increase patient engagement with their health, evidenced by interaction with providers through the EHR. For instance, in Stage 2 Meaningful Use, it is a requirement that 5% of all patients send their provider a message. Stage 3 Meaningful Use is focused on improving quality, safety and efficiency that will lead to improved health outcomes.(IT.Gov, 2013)

Giving patients’ access to their health information and providing tools such as secure messaging to electronically communicate with their providers is fundamental to increasing patient engagement and making health care more patient-centered. Further, to comply with Stage 2 Meaningful Use requirements, providers must deliver EHRs with features that allow patients to electronically view, download and transmit information from the EHR as well as bidirectional information flow through secure messaging. This could include lab test results, a list of current medications, and hospital discharge instructions.(HIT.gov, 2013)

Even with the federal regulations and incentives aside, patient engagement is increasingly accepted as an essential component of quality health care and improved health outcomes. A growing body of literature demonstrates that more engaged patients have better reported outcomes, especially

with chronic disease. Since the mid 2000's, there have been several cross-sectional studies that have found patient activation to be significantly related to healthy behaviors, accessing preventive care and better managing chronic conditions.(Dixon, Hibbard, & Tusler, 2009; J. H. Hibbard & Greene, 2013; Rask et al., 2009; Remmers et al., 2009) Many of the studies related to patient engagement and health outcomes are limited, however, by reliance upon self-reported data. Further, in the body of research to date around patient engagement there has been scarce tie in to the impact of electronic health records. Anticipation that patient engagement can be leveraged through the electronic health records is strong but rigorous research to support this is lacking. As much of the research on patient engagement to date has focused on health outcomes, there has been relatively little focus on the role of electronic health records to increase patient activation.

Study Purpose

The purpose of the study is to present an evaluation framework for measuring the impact of patient engagement related to EHR interaction for people with Type 2 diabetes. The study will capture the current research surrounding patient engagement and electronic health records for patients with diabetes through a literature review and meta-analysis of the three topics. Based on the current research around patient engagement, EHR use and clinical measures for diabetes, an evaluation framework is presented that could be useful for any provider or program that provides diabetes care and has an EHR.

Chapter Two

Overview

This literature review examines the interaction between patient engagement, the EHR and improved health outcomes for individuals with Type 2 diabetes. Specifically, this review examines how the electronic health record can leverage the contribution of patient engagement contribution to improved health outcomes. Although there is a body of research on patient engagement and improved health outcomes, research that also incorporates the role of the EHR is largely absent.

Why Study Patient Engagement?

According to the World Health Organization, chronic diseases are a major cause of death and disability worldwide, responsible for 59 percent of deaths and 46 percent of the global burden of disease (WHO, 2007). Despite significant medical advances in care, optimally treating chronic disease requires an engaged patient who feels prepared to assume an active role in care. The involvement in care is especially important for individuals with diabetes because they are at a higher risk for numerous complications including “chronic kidney disease, diabetic retinopathy, coronary artery disease, peripheral vascular disease, and lower extremity amputations”, many of which can be mitigated with behavioral changes (ADA, 2008). The disease burden is not born equally across racial groups. Only one third of Hispanics and African Americans with diabetes achieve optimal glycemic control, and both groups have lower rates of blood pressure and lipid control compared with whites (Collins, 2007). Not controlling blood glucose, blood pressure, and lipids “places these individuals at higher risk for complications of diabetes such as lower extremity amputation” (Dillingham, 2011).

An individual's feelings of empowerment, confidence and self-efficacy, as described by Bandura, has long been recognized as critical to the success of an intervention. Several researchers note that patient-reported health confidence can be used to measure concepts such as patient self-care, patient self-management, patient activation, self-efficacy, productive patient-provider interaction, and engagement (Bandura, 1997; Bodenheimer et al., 2002). As presented by Hibbard and others, the term patient and consumer activation refers to the "degree to which the individual understands they must play an active role in managing their own health and health care, and the extent to which they feel able to fulfill that role" (Hibbard JH, Stockard J, Tusler M., 2005, page 1006).

Restated another way, patient activation is related to the knowledge, skill and confidence that a patient has to managing their health (Hibbard JH, Stockard J, Tusler M., 2005). A broader concept, patient engagement combines patient activation with interventions designed to increase activation and promote positive patient behavior, such as obtaining preventive care or exercising regularly. As described by the Institute for Health Improvement, employing patient engagement is a key strategy to address the "triple aim" of health care that includes the patient experience, health outcomes and lower costs (IHI.org, 2013). Other prominent entities in clinical care, such as the Center for Medicare and Medicaid Innovation announced that supporting patient activation and engagement will be a factor in scoring applications for the new Pioneer Accountable Care Organizations (ACOs). Further, incorporating standardized measures to address the patient care experience is becoming industry standard. The Consumer Assessment of Healthcare Providers and Systems (CAHPS) has instituted a measure that addresses patient engagement and clinical care through public reporting of patients' ratings of their care experience with physicians and medical practices (Giordano LA, 2010).

An expanding body of literature demonstrates the relationship between patient engagement and health outcomes (J. H. Hibbard, Stockard, Mahoney, & Tusler, 2004). In the current context of health reform and as care delivery systems are pushed to produce better health outcomes with fewer resources, patients may represent a largely untapped resource that could have enormous potential for delivery systems and to patients (Greene, 2011). A cross-sectional study of more than 25,000 patients at Fairview Health Services in Minnesota examined the relationship between patient activation and patient outcomes as documented in the electronic health record. The team found that increased patient activation improved 12 of 13 patient outcomes (Greene, 2011).

Further, as described in the evidence-based Chronic Care Model, productive interactions between patients and providers are necessary to improve health outcomes (Bodenheimer et al., 2002).

Numerous other studies have demonstrated that more activated patients have better care experiences including communication and comfort with their providers (Alexander, JA, 2012; Hibbard et al., 2004; Maeng D, 2012).

Measuring Patient Engagement

Patient engagement can be measured in a variety of methods including surveys and interviews with patients that may be systematic or ad hoc. A systematic method to measure engagement, the Patient Activation Measure (PAM), was developed 2004. Since its development, the PAM has been found to be a “valid and reliable measure of patient activation” (Hibbard et al., 2004). The PAM is a tool, comprised of thirteen scaled questions used to assign an “activation score” and can measure and assess an individual’s skills, knowledge and confidence to manage his or her health (Hibbard et al., 2005). The four levels of activation presented in the PAM are:

- Level 1: Patients tend to be overwhelmed and unprepared

to play an active role in their own health.

- Level 2: Patients lack knowledge and confidence for self-management.
- Level 3: Patients are beginning to take action, but lack confidence and skill to support behaviors.
- Level 4: People have adopted many of the behaviors to support their health, but may not be able to maintain them in the face of life stressors (Hibbard, et al., 2005)

Based on answers to PAM questions, individuals are categorized on the scale above to describe how passive or active a role they are likely take in their care. Specifically, those who score low on the PAM are typically passive recipients of care and do not believe in the need for an active patient role and those at higher levels on the scale are usually proactive about their health and engage in many recommended health behavior (Greene, 2011). Research has shown the individuals who score as highly activated are more likely to obtain preventive care such as health screenings and immunizations as well as to exhibit other beneficial health behaviors including maintaining a healthy diet and exercise habits as well as self-management behaviors and obtaining health information (Hibbard et al., 2007; Remmers et al., 2009).

The Role of Patient Engagement in Diabetes Care and Improving Health Outcomes

Besides being more likely to seek out preventative care, more highly activated individuals with diabetes are also more likely to better manage their conditions and may demonstrate lower HbA1c levels (Mosen D, 2007; Remmers et al., 2009). In the study noted above at Fairview Health Services in Minnesota, researchers collected data on patient activation and patient outcomes derived from the electronic health record for more than 25,000 adult patients who had a primary care visit in the

previous six months. Using the PAM as the independent variable, the researchers examined patient outcomes across multiple areas including prevention, unhealthy behaviors, clinical indicators and utilization (Greene, 2011). Using multivariate models, patient activation was positively related to 12 of 13 patient outcomes and included such having clinical indicators such as blood glucose in the normal range. This study reiterates the relationship between patient engagement and improved health outcomes (Greene, 2011; Hibbard & Greene, 2013).

A similar AARP study of patients with chronic conditions also found that low levels of patient activation made them more likely to be readmitted to the hospital and more likely to experience error prone care (Ricciardi, 2009). Interestingly, Greene found that better outcomes for more highly engaged patients were found regardless of which providers they see (Greene, 2011).

In terms of understanding how leveraging patient engagement may contribute to improved health outcomes, several longitudinal studies have demonstrated that patient activation is not only predictive of future health outcomes but that activation is a modifiable characteristic (Deen D, 2011; Hibbard, et al., 2009). Not only are more highly activated patients more likely to take better care of themselves, they are often more proactive in the care process. Greene et al found that more activated patients ensure they provide their providers with information regarding their medical background, play an active role in care coordination and getting information from the provider.

In summary, individuals with chronic illnesses who have higher PAM score are more likely to have better health outcomes than those with lower scores (M. E. Hibbard JH, Stock R, Tusler M. , 2007; Remmers et al., 2009)(Hibbard et al., 2004, 2007; Mosen et al., 2007). Especially for those with chronic conditions, it is important to examine how involvement and active participation in health care has a direct impact on outcomes. For those with diabetes, self-management and self-efficacy

skills can lead to better outcomes and lower costs (Bodenheimer et al., 2002). Further, utilizing the Institute of Medicine's Summit on Crossing the Quality Chasm as a framework, providers may want to focus on the patient experience over time that is integrated in the care delivery system; under this framework, the EHR offers numerous potential methods to increase patient engagement (Clark, 2003; Fisher et al., 2005).

EHR Background

Enacted in 2009, the Health Information Technology for Economic and Clinical Health Act (HITECH) included in the American Recovery and Reinvestment Act of 2009 implemented provisions for \$17 billion in incentive payments to eligible Medicare and Medicaid professionals and eligible hospitals on their meaningful use of certified EHR technology. Between 2011 and 2015 the core indicators will evolve to include provisions for patient engagement. (IT.Gov, 2013) Stage 2 Meaningful Use includes the requirement that providers offer access to personal health information for more than half of their patients (CAH, 2013).

EHRs replace many functions and collect information previously found on paper including scheduling, prescription order entry and notes. As such, EHRs allow providers to record information electronically and more easily share information with patients. The intended functionality of EHRs span beyond documentation only. Federal initiatives such as the EHR Incentive Program require that providers use their EHRs in ways that may improve patient care and health outcomes. The Medicare and Medicaid EHR Incentive Programs provide incentive payments to eligible providers to incorporate 'meaningful use' of certified EHR technology (CMS, 2013).

EHRs are touted to have many beneficial impacts for patients including increased access to more complete information and allowing for better care coordination where information can be shared

between care teams and with the patient. While the functionalities in the EHR are conceived as part of a larger information system package, key features in the EHR most likely to increase patient engagement are: secure messaging, access to progress notes or visit summaries, and educational materials or disease management tools including those which support patient reported outcomes (Baig, 2010; Goldzweig, 2012). Other customized disease specific modules have been found to increase engagement and improve outcomes (Darkins, 2008). Providing access to health information may help patients more fully participate in their care which is critical especially for those with diabetes and who often must coordinate across multiple providers (Ricciardi, 2009).

Patient Portal Access

Utilization of the EHR and clinical information systems is one of the six evidence based elements of the Chronic Care Model (CCM). The CCM aims to improve quality by building the interrelationships between elements such as proactive care, clinical information systems, decision support and self-management support. Use of clinical information systems, including patient portals, has been linked with improved quality of diabetes care (Si, 2005).

As described above, patient engagement is a fundamental pillar to quality care and the patient experience. Functionally, patient care is the product of transactions between patients and providers or delivery systems and may be facilitated by the use of a patient portal or electronic health record. In the age of the Triple Aim and the Chronic Care Model, the implication is that improving the patient experience hinges, in some part, on the ability of patients to more fully participate in their health and care, which may be supported by the use of EHRs (Greene, 2011). Despite substantial understanding of clinical guidelines to improve care for diabetic population, health outcomes for those with chronic conditions often remain sub-optimal. For the Type 2 diabetes population, well

defined strategies to increase engagement may not be widely implemented. Informatics based strategies such as use of a patient portal and electronic health records may help address low levels of patient engagement and barriers to care plan adherence.

Increasing access to information is one method to increase patient engagement. One of the largest integrated delivery networks, Kaiser Permanente, launched a mobile application for their patient portal, My Health Manager (MHM). The android application allows members (approximately 9 million at Kaiser Permanente) to access diagnostic information, e-mail physicians, obtain laboratory results, and order prescription refills through MHM (KP.org). Similarly, the Department of Veterans Affairs has launched their “Blue Button” initiative through their patient portal, MyHealthVet, that enables veterans to download health information from their EHR.(D. o. V. Affairs, 2012)

In one randomized control trial study of 422 portal users, the majority (90%) reported ease of use and 80% said that it facilitated their participation in their own care (Nagykaldi, Aspy, Chou, & Mold, 2012). The study also measured patient activation (via the thirteen question PAM and the Consumer Assessment of Healthcare Providers and Systems instrument) and that the participants perception of patient centeredness increased significantly in the portal group compared with control. Further, a greater percentage of portal users received all recommended preventive services (Nagykaldi et al., 2012)

These statistics point to the immense potential of using EHRs to increase patient engagement and the care experience (Informatics, 2013). One study examined the use of a web based wellness portal linked to another system, the Preventive Services Reminder System (PSRS) to coordinate patient centered primary care. The majority of patients using the portal reported that using the portal facilitated participation in their care. Further, patient activation (measured via the PAM) and

“perception of patient-centeredness of care (measured via the Consumer Assessment of Healthcare Providers and Systems instrument)” increased significantly in the portal group compared with control” (Nagykaldi et al., 2012).

Secure Messaging

One of the more promising features of the EHR to increase patient engagement is secure messaging. For those with diabetes, sending secure messages positively impacts glucose outcomes, patient engagement and patient satisfaction (Baer, 2011; Blumenthal, 2010; Harris, 2009; Ralston, 2009; Tenforde, 2012). In a Cleveland Clinic study of 10,000 patients, EHR patients had “better unadjusted and adjusted diabetes quality measure profiles including HbA1c levels” (Tenforde, 2012). An additional study at Group Health Cooperative also found that frequent use of secure messaging was associated with better glycemic control but also increased utilization (Harris, 2009). Additional research is recommended to examine the conflicting evidence in these studies regarding whether there is a dose-response effect for secure messaging i.e. does an increased number of messages result in better outcomes (Harris, 2009; Tenforde, 2012). Additional research is also needed to determine the role that socioeconomic demographics such as age, income and education levels play in EHR access (Tenforde, 2012). On an organizational and population level, Zhou and others found that use of secure messaging improves HEDIS measures for patients with diabetes and hypertension among Southern California Kaiser Permanente members. There dose-response effect for those sending two or more emails per month was associated with significantly better health outcomes (Zhou, 2010). Ultimately, these studies speak to the potential utility of secure messaging as an important component of a comprehensive diabetes treatment and outreach program (Baig, 2010).

Access to Medical Record/Physician Notes

There is a growing trend in the clinical community to consider giving patients access to their physician notes in an effort to increase patient engagement. Physician notes have always been available to patients through the provisions of the Privacy Rule which gives the right to review and receive a copy of medical and billing records held by health plans and health care providers (HHS, 2013). However, some providers have decided to make access more easily available in an effort to more actively involve patients in care planning.

Since people who use e-health resources report feeling better prepared for clinical encounters that may ask more questions and know more in general about their health care. Providing access to physician notes may increase patient engagement through the EHR (Feeley, 2011). A recent initiative, the Open Notes project, leveraged the EHR to increase patient engagement and improve clinical outcomes by providing patient access to their online physician notes. After having access to notes, patient in the study reporting that they felt more in control of their care and reported increased medication adherence. In the meantime, provider concerns related to increased workload and offending patients were largely unmaterialized (Leveille et al., 2012; Delbanco, T., 2012). Although this study was primarily based on patient reported outcomes, these preliminary findings highlight the potential for access to physician notes to increase patient engagement.

While patient access to physician notes may soon be an industry standard, in the future patients may require taking a more active role in creating their EHR. In a survey of patients regarding the role they would like to play in their EHR, there was general agreement that access should include the ability to make entries into the EHR, thus engaging patients as both recipients and providers of health information (Urowitz et al., 2012). Although this approach would likely result in increased

feelings of ownership of the EHR, there are multiple concerns about giving patients full access to edit their EHR including workflow challenges, liability and dealing with sensitive issues for providers.

Chapter Three

Evaluation Framework

Hypothesis/Evaluation Objectives

The hypothesis is that patient access to the EHR through a patient portal will increase patient engagement and improve health outcomes. This evaluation framework examines the indicators for patients with type two diabetes. It is essential to revisit the research questions to inform the evaluation design. The research questions directly related to this hypothesis, which form the objectives of the evaluation project, are to understand:

Evaluation Objective One: Is utilization of a patient portal associated with increased patient engagement?

Evaluation Objective Two: Which features of the electronic health record available through the patient portal i.e. access to provider notes or after visit summaries are associated with increased patient engagement?

Evaluation Objective Three: Are diabetes patients with online access to EHRs likely to experience better health outcomes?

These research questions will be best answered with an experimental or quasi-experimental study design rather than a descriptive study design. Descriptive study designs can provide understanding about whether a program is operating as planned and provide feedback about the services which may be useful for these questions (Walliman, 2011). However, without understanding the impact differences between those who use the EHR/patient portal and those who do not, understanding may be limited. Thus, an experimental and quasi-experimental study design is warranted to provide additional evidence of a causal or correlational relationship between access of the patient portal

and outcomes. Specifically, a simultaneous nonrandomized control study would capture the effects of patient portal access for users while also capturing a comparison population during a similar time period. Of course, changes in the intervention population could be attributable to other factors than the patient portal but this study design, coupled with controls for confounders such as age, gender or income, is preferred over a historical (pre- and post-) study design (Friedman, 2010). Experimental studies are structured to determine causality or correlation, to the extent possible by measuring change in the outcome/dependent variable/s as related to various activities or services (the independent variables). To determine if this change is caused by activity in the patient portal, the study design must compare a group who did use the patient portal as shown below and one that does not (Friedman, 2010).

Evaluation Study Population

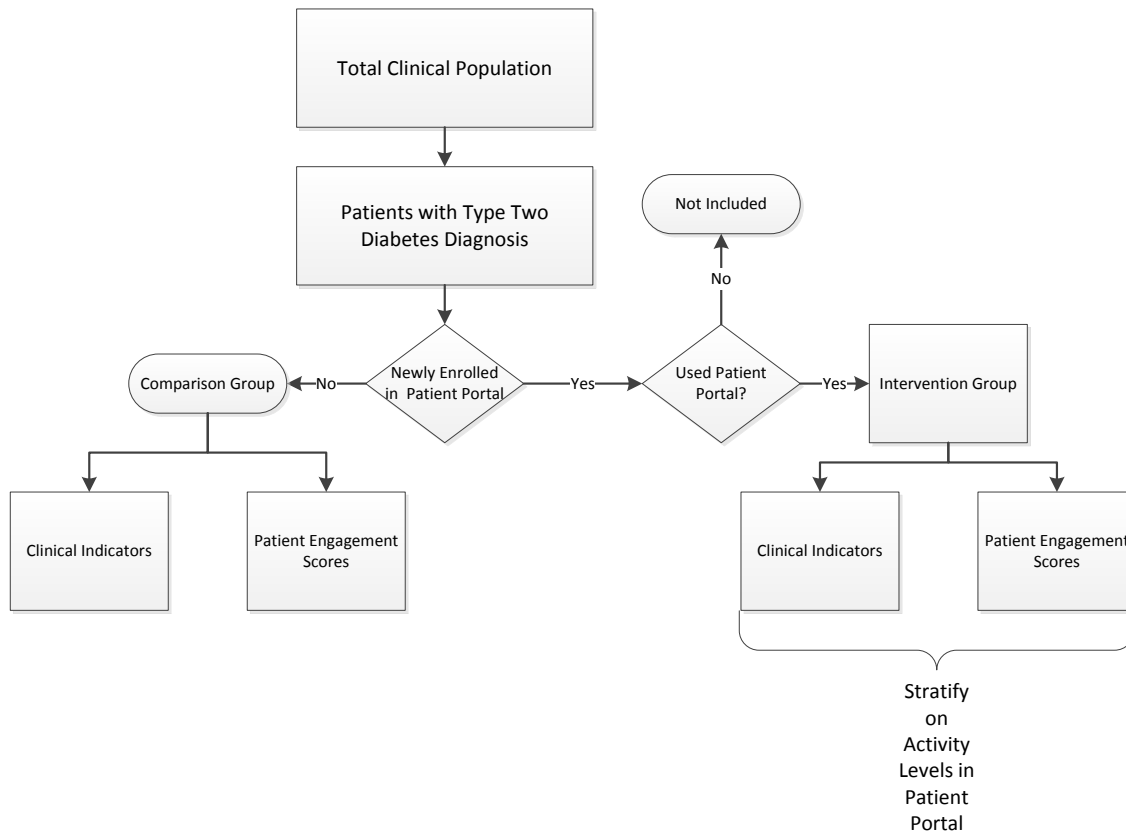
To measure the impact of the patient portal on patient engagement and health outcomes, two basic approaches may be used. Because not all organizations have similar capacity and resources to evaluate their experience with the patient portal and patient engagement, three approaches, guided by the evaluation objectives, are presented to address some of that variability. For instance, some large organizations may have dedicated research and evaluation departments and data warehousing structures to support more sophisticated approaches. Other organizations may not be able to draw on dedicated resources and may need to utilize a simpler approach. However, at minimum, all approaches do require the following capability in the organization:

Repository of clinical information and information related to patient portal usage including:

- Registration status
- Activity levels of various features in the patient portal
- Information on clinical measures including blood glucose, blood pressure, etc.

The basic study population is those patients who are newly enrolled in the patient portal over a set period of time, say for the past 12 months. Those patients who were already enrolled to use the patient portal are not included since they could have already experienced significant changes in patient engagement or health outcomes that would be associated with patient portal use. An alternative study design would be to include all patient portal users although the effect of long term portal usage should be recognized as a potential confounder.

Population Definition Diagram



The following tables outline the evaluation approaches and define the specific populations, measures, data sources, tools and proposed frequency for each of the objectives and with all three objectives merged together at the end in an evaluation logic model. The evaluation design is presented in this manner so that a provider or clinical practice can tailor an evaluation to their capacity and EHR maturity. For instance, conducting an evaluation that utilizes all the presented measures across the three objectives may not be feasible for an individual provider or even some larger practices/health organization. However, individual objectives can be addressed more easily and to also demonstrate design variations for different objectives. For example, Objective Two does not require an overall comparison group as the whole study population consists of those who have used the patient portal and comparisons are made based on specific features used.

Objective One: Is utilization of a patient portal associated with increased patient engagement?

This portion of the evaluation framework focuses on the impact of patient portal use on patient engagement. To establish a baseline population of PAM information, a defined period of time, six months or less, will be allotted for completion of the PAM and enrollment in the patient portal. To encourage both completion of the PAM and portal enrollment, the survey and information about registering for the portal could be included in the package of intake forms for all appointments, mailed out to existing patients and included in enrollment forms for new members/patients. The PAM must be referenced to the Unique Patient Identifier used by the practice, such as chart/medical record number, for analytics purposes.

Objective One: Is utilization of a patient portal associated with increased patient engagement?			
Overall Study Population	All patients in a care setting that have the option to enroll in a patient portal and who completed the PAM questionnaire during baseline period		
Intervention Group	Patients newly enrolled in patient portal (after questionnaire completion); used portal at least once during study period		
Comparison Group	Patients that did not enroll in patient portal		
Measures	Data Source(s)	Measurement Tool	Measurement Frequency
Changes in Patient Engagement	Scores on PAM	PAM 13 question tool	At study beginning and at least annually.
Stratification Options	Disease burden (Charlson Comorbidity Index); Diagnosis; Portal Activity Levels—to identify possibly dose response effect		

Objective One Proof of Impact: Proof of impact for objective one would be seen with greater increases in PAM scores for the intervention population as compared to the comparison population. Analysis should control for determined confounders to include, but not limited to, age, gender, disease burden, education, time with practice, etc.

Objective Two: Which features of the electronic health record available through the patient portal i.e. access to provider notes or after visit summaries are associated with increased patient engagement?

This part of the evaluation framework attempts to isolate how use of secure email, access to provider notes, online education materials and uploading patient reported outcomes in the EHR contribute to increased patient engagement. Thus, the intervention group is those who have utilized any of these features (or all) as compared to those who did not use a specific feature. This

part of the evaluation requires that the practice or organization have data reporting capability to report on activities in the EHR that can be anchored to the patient level.

Objective Two Proof of Impact: It is expected that there is a dose response effect for increased use of features in the EHR i.e. that those patients who have sent more secure messages, for instance, will have higher patient engagement scores than those with lower levels of activity. This component of the evaluation should determine which features are associated with greater increases in PAM scores for the intervention population as compared to the comparison population. Analysis should control for confounders including, but not limited to, age, gender, disease burden, education, time with practice, etc.

Objective Two: Which features of the electronic health record available through the patient portal i.e. access to provider notes or after visit summaries are associated with increased patient engagement?		
Overall Study Population	All patients in a care setting that have enrolled in a patient portal (used it at least once) and who completed the PAM questionnaire during baseline period	
Additional Evaluation Options	Stratify on activity levels to determine if there is dose response effect i.e. does engagement increase with increased activity in the EHR	
Suggested Measurement Frequency	Six to 12 months after enrollment	
Measures	Intervention Group	Comparison Group
Secure Messaging	Used secure messaging at least once	Did not use secure messaging
Access to provider notes	Viewed at least one provider note	Did not view provider notes
Combined Effect of both Features	Used both features	Did not use any features

Objective Three: Are diabetes patients with online access to EHRs likely to experience better health outcomes?

Improving diabetes care via patient engagement and the electronic health record can be measured with several clinical indicators. Quality care for people with type two diabetes can be understood as a decreased risk of developing long-term complications from diabetes as well as increasing the likelihood of better health outcomes. Because diabetes is a progressive and chronic disease, disease complications such as stroke, kidney failure, amputations, cardiovascular disease and premature death may develop over several years and necessitates regular and frequent monitoring of several clinical indicators and risk factors (Vrca-Botica, 2007).

Objective Three Proof of Impact: This component of the evaluation will measure the associated impact on health outcomes for patients with diabetes that use the patient portal. The clinical indicators should move to within the normal range and rates of process of care indicators (eye screening and nephropathy screening) should increase while lower extremity amputation rates would be expected to decrease. Analysis should control for determined confounders including, but not limited to, age, gender, disease burden, education, time with practice, etc.

Objective Three: Are diabetes patients with online access to EHRs likely to experience better health outcomes?		
Overall Study Population	All patients in a care setting that have the option to enroll in a patient portal and who completed the PAM questionnaire during baseline period	
Intervention Group	Patients newly enrolled in patient portal (after questionnaire completion); used portal at least once during study period	
Comparison Group	Patients that did not enroll in patient portal	
Measures	Intervention Group	Comparison Group
Clinical Indicators:	Most recent measure at baseline;	Most recent measure at baseline;

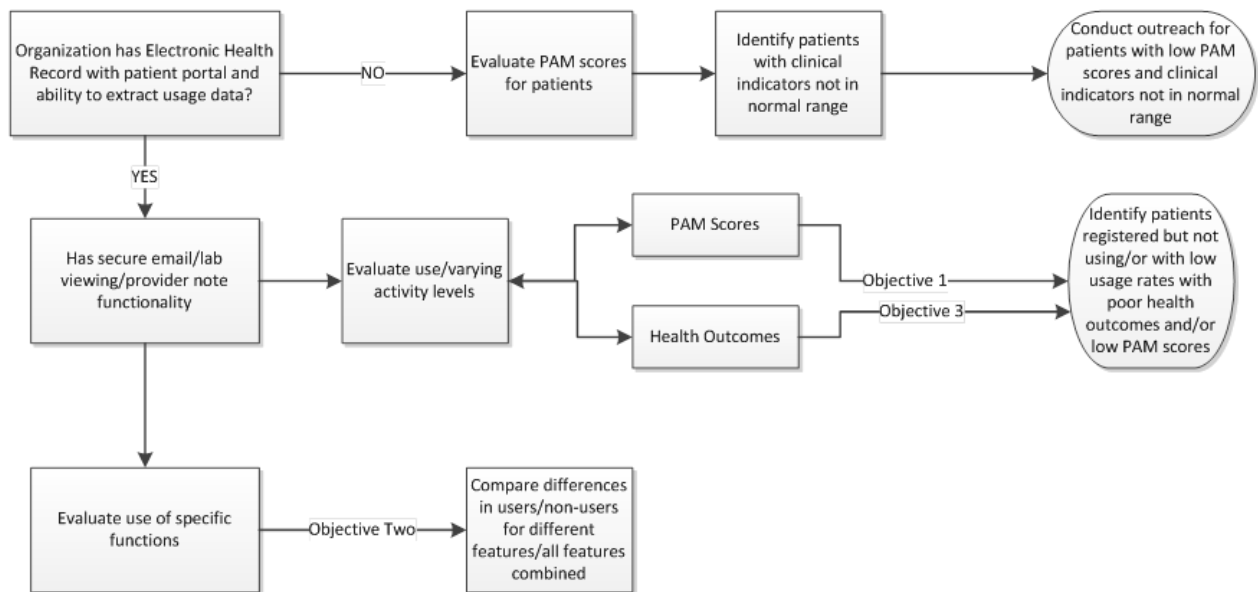
(Glycated hemoglobin (HbA1c), LDL cholesterol, Fasting plasma glucose (FPG), Postprandial plasma glucose (PPG), Body mass index (BMI), Blood pressure)	every six months	every six months
Process of Care Indicators: Annual screening for nephropathy, Annual eye exam, Lower extremity amputation rates	Most recent measure at baseline; every six months	Most recent measure at baseline; every six months

Evaluation Framework Summary

This evaluation framework has presented three evaluation objectives and proposed measures and activities. The ultimate contribution this thesis would make to the literature is to examine all three objectives together to understand how the components interact. This synthesis of all three activities is presented below in an evaluation logic model that captures the potential for evaluating these activities. Not all practices or providers will have access to all the data needed for this type of evaluation, however, and the framework will need to be tailored for the capacity of an individual provider or practice.

Developing Comprehensive Indicators

Focus Areas/Evaluation Objectives	Evaluation Questions	Indicators	Technical Assistance Needed
To understand whether patient engagement is associated with use of patient portal (Objective One)	Do patient portal users have higher PAM scores than non-users? Is there a dose-response affect to increased patient engagement through the patient portal?	<ul style="list-style-type: none"> • Registration information to determine users, non-users • Frequency data • PAM Scores 	<p>Ability to track registration, log in activity</p> <p>Investment to administer the PAM at least twice (baseline and again at follow up)</p>
To understand whether certain features of the patient portal are associated with increased/decreased patient engagement	Are certain features of the patient portal more associated with increased patient engagement?	<ul style="list-style-type: none"> • #/ activity levels of those using the following features: • Secure Messaging • Access to provider notes • Combined Effect of both Features • PAM Scores 	<p>Ability to track activity data</p> <p>Ideally stratify on age, gender, other chronic conditions, etc.</p> <p>Investment to administer the PAM at least twice</p>
To understand how utilization of the patient portal impacts health outcomes	Is utilization of the patient portal associated with better health?	<ul style="list-style-type: none"> • #/ activity levels of those using the patient portal • Clinical Indicators: (Glycated hemoglobin (HbA1c), LDL cholesterol, Fasting plasma glucose (FPG), Postprandial plasma glucose (PPG), Body mass index (BMI), Blood pressure) • Process of Care Indicators: Annual screening for nephropathy, Annual eye exam, Lower extremity amputation rates 	<p>Access to lab results and capture of process of care indicators in the EHR</p>



Inputs	Activities	Outputs	Outcomes	Impact
<p>Access to:</p> <ul style="list-style-type: none"> • Patient Portal • Electronic Health Record • Clinical Data • PAM Survey Instrument\ <p>Collect and analyze PAM Scores for patients—correlate these to feature use and clinical measures</p> <p>Collect data on feature utilization</p> <ul style="list-style-type: none"> • Stratify on activity levels, condition, age and gender • Conduct T-tests to compare means for users versus non users <p>Collect and analyze clinical data for patients</p> <p>Conduct T-tests to compare means for users and non-users</p>	<p>For particular patient population, identify the following :</p> <ul style="list-style-type: none"> • Association of features with clinical measures and PAM scores • Identification of patient populations with low PAM scores and poor health outcomes, clinical measures • Identification of patient population who are currently non-users to conduct outreach 	<p>Strategy developed to convert current non-users with low PAM scores and poor clinical outcomes to patient portal users</p> <p>Strategy developed to engage population with low PAM scores and target interventions to improve clinical measures</p> <p>For instance, work to increase patient activation through use of the patient portal (encourage uptake, increased frequency of use)</p>	<p>Improved patient activation as evidenced by improved PAM scores across the practice and on an individual level</p> <p>Improved health outcomes as evidenced by improved clinical and process of care measures</p>	<p>Improved population health</p> <p>Spread of understanding related to association between patient engagement, clinical measures and health outcomes</p>

Summary

In conclusion, this chapter presents a framework to evaluate the impact of patient portal access to the EHR on patient engagement and health outcomes for patients with type two diabetes. Each facet of the evaluation is presented separately to allow a practice or provider to choose which component is most important and feasible. Although an integrated approach is recommended, this

may not be feasible for all providers and a flow chart helps delineate the process for specific capabilities in the organization. Depending on the data infrastructure and aims of the practice the evaluation framework can be adapted to meet the specific needs and objectives.

As providers look to the infrastructure of electronic health records and patient portals to improve population health, understanding how interaction with the tools impact care is critical. Evaluation of the associations between features in the EHR and impact on health outcomes and patient engagement are an essential input to understanding how to leverage use of features and increase engagement. The following chapter will address some areas for discussion and limitations of the evaluation framework.

Chapter Four

Summary of Findings

Patient engagement and utilization of the patient portal are each individually associated with improved health outcomes. There is a lack of literature that examines the impact of patient portal use on patient engagement and health outcomes. This thesis presents a framework that can be used to evaluate use of features in the EHR patient portal, patient engagement and health outcomes for those with diabetes. The evaluation purpose is to identify opportunity for targeting health IT interventions such as increasing enrollment in the patient portal or encouraging use of secure email for those who may benefit. As such, the goal of this thesis is to provide the framework for action oriented research. The ultimate purpose of this evaluation framework is to inform efforts to improve the quality of care provided by an organization or provider (Walliman, 2010).

Research Limitations

Perhaps the largest limitation in the research is the inability to develop a framework which is useful to all provider types and practice sizes. Given the wide variation in organization size, services provided and analytic capability, it is difficult to develop a framework that is feasible across all care settings. However, it is anticipated that any provider who services a diabetic population will find at least one component of the current framework useful for evaluation purposes. For instance, even if a provider does not have a patient portal, at a minimum, the practice could implement the PAM and target those patients who have low scores to encourage use of EHR or other activities to increase engagement. Ideally, however, a provider will have a patient portal and the capability to capture some of the proposed metrics. Further, the proposed methodology, a quasi-experimental study design, which includes both intervention and comparison groups, may not be feasible for all

providers. This type of study requires dedicated resources to implement, manage and report on the evaluation.

Selection bias is also an issue with this study since the intervention group is not selected randomly and because participants are self-selected into the study by their enrollment in the patient portal. Other studies have also found that portal users may differ from non-portal users in other ways that may introduce additional bias. Tenforde, et al found that compared to non-users, PHR users were younger, had higher incomes and educational attainment, were more likely to identify as Caucasian, and had better unadjusted and adjusted diabetes quality measure profiles (Tenforde, 2012). These differences may have the potential to skew some of the evaluation results although this can be mitigated some by controlling for these variables in analysis.

Public Health Implications & Areas of Future Research

As a growing number of providers transition to electronic health records, understanding the impact of these public health informatics systems is critical. Research that identifies how to increase patient engagement through the EHR may have substantial benefit for public health practitioners. By understanding the relationships between use of the patient portal features available in the EHR and how these play a role increasing patient engagement and health outcomes, practitioners can provide better quality services.

While the main focus of this thesis is the role of technology and the patient to increase engagement and improve health outcomes, additional research should also identify the role that providers play in patient use of the portal. Zickmund found that diabetes patients were more likely to use the portal if their providers were high utilizers of secure messaging (greater than 20% of encounters) (Zickmund, 2007). As several studies have found, provider behaviors help patients to “monitor their

condition, set goals, and/or set up an exercise program,” thereby increasing patient engagement (Glasgow, 2005; Parchman, 2010).

As briefly mentioned above, further research is also needed to better understand the role that race/ethnicity and other socioeconomic demographics plays in utilization of the patient portal. Specifically, public health practitioners should understand how disparities in access may impact health outcomes and patient engagement. While multiple studies have documented significantly lower portal use among racial/ethnic minority groups, few have been able to examine potential factors driving these differences beyond the influences of socioeconomic status. Efforts should be made to understand the underlying factors that impact patient portal utilization (Lyes, 2012; Urmimala, 2011). Increasing patient engagement through the use of EHRs may be a powerful tool for improving health outcomes and reducing disparities in sub-populations. A recent national survey showed that “low-income, chronically ill people who used personal health records reported a greater sense of connection with their providers and more positive behavior changes than members of other demographic groups (CHCF, 2010).

Another future area of research is developing condition specific modules for those with diabetes and other chronic conditions. At Partners Health System in Boston, MA, a diabetes specific module was developed as part of the patient portal that allowed patients to upload glucose results, receive feedback on those results, access educational materials and participate in an online diary to enter information on diet and exercise

A specific diabetes interface was designed to maximize patient engagement by importing the patient’s current clinical data in an educational format, providing patient-tailored decision support, and enabling the patient to author a “Diabetes Care Plan” that may point to the future direction of efforts to increase patient engagement through an EHR’s patient portal (Grant et al., 2006).

The evidence on the association between reduced utilization and EHR use is mixed and is another area of future research. Several studies have documented the association between frequent use of electronic messaging and increased service utilization (Harris, 2009; Palen, 2012). Both of these studies used one measure, accessing the EHR once for a study population as independent variable, and future efforts could employ advanced analytic techniques such as data mining to better understand the interactions between features and patients.

Because EHRs are maintained by providers for patients in their practices, patients often have medical information charted in multiple EHRs. Despite the initiatives to increase use of EHRs, they not always interoperable and not suitable for cross-enterprise care (Blechman). In the coming years, successful health care reform requires an information system and information sharing “paradigm shift” to address the current deficiencies in the system resulting from dispersed patient care and fragmented record keeping (Goel, 2011). In the interim period, prior to the establishment and usage of statewide or national health information exchanges, some individuals may benefit from access to a personal health record (PHR). PHRs can address some of the dispersed and fragmented care particularly burdensome to chronic disease populations (Blechman). Research which can contextualize the use of patient portals and the EHR is needed.

Lastly, further research should examine the use of the PAM as an effective predictor of poor health outcomes. In a study of the relationship between the PAM and future health outcomes for those with diabetes, Remmers found that higher PAM scores predicted “hemoglobin A1c (HgA1c) testing levels (Remmers et al., 2009). The PAM may be utilized as an effective predictor to identify those patients most at risk and could be leveraged for use in public health.

Conclusion

A growing body of literature confirms the value of EHRs to improve patient care. Several studies have documented the ability of EHRs to improve patient safety, care coordination and documentation. The link between the patient portal, patient engagement and health outcomes is currently inadequate in public health research. An evaluation framework, presented in this thesis, may help to focus efforts on increased understanding of the dynamics and interplay between these factors.

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