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Shared Online Health Records for Patient Safety and Care

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Abstract

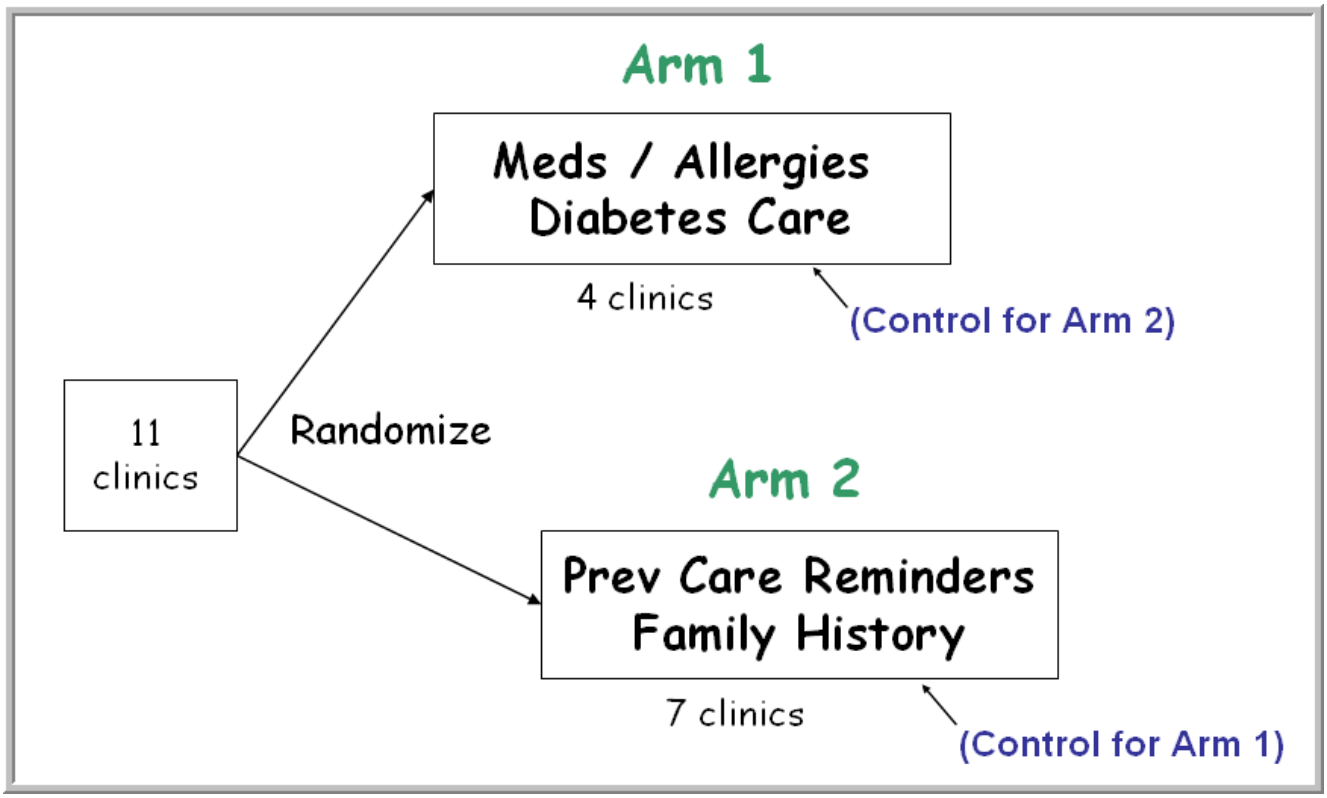
Purpose: We sought to address the following four specific aims during the project's study period. 1) To evaluate the impact of pre-visit electronic patient prompts and a shared online medication list on detection of adverse drug events (ADEs), medication list accuracy, and patient medication knowledge. 2) To evaluate the impact of pre-visit electronic patient prompts on chronic disease outcomes and adherence, in this case, for diabetes. 3) To evaluate the impact of prompted health maintenance information on patient adherence to healthcare maintenance guidelines. 4) To evaluate the impact of prompted patient family history assessment on detection of familial risk factors. 5) To identify and address technology adoption enablers and barriers to shared online health records for patients and physicians.

Scope: *Patient Gateway* (PG), an internet patient portal developed at Partners HealthCare, Boston, is a web-based application available since 2002 offering secure communication between patients and their doctor's office, views of abstracted medical chart information (e.g. medications, allergies, demographic information), forms for common patient requests, and health reference information. PG messages and requests from the patient are transmitted to authorized practice staff and physicians. PG is tightly coupled to Partners' ambulatory electronic medical record system, the LMR (Longitudinal Medical Record), in use by approximately 5000 physicians as of December 2006.

In this study, we proposed to take advantage of one of the largest implementations of automated clinical information management tools for both the provider and the patient to analyze several key questions. Using the Partners Healthcare provider-oriented Longitudinal Medical Record and the consumer-oriented *Patient Gateway*, we specifically looked at the impact of these tools on medication management and patient safety, service delivery in preventive and chronic care, acquisition of patient-source data on Family History, and the barriers and enablers to use of this technology.

Methods: A randomized, prospective cohort design was employed to assess the impact of shared online health records on patient medication safety, health goal adherence and outcomes for preventive screening and diabetes, documentation and risk detection of family history, and barriers to the adoption of patient-physician communication technology.

Practices were paired using practice characteristics, and then one practice in the pair was randomized to Arm 1 or Arm 2. The other practice was placed in the opposing Arm. To provide consistency, several small practices were "grouped" with another practice prior to pairing. All patients with a Patient Gateway account in a study practice were invited to participate. Patients were included in the primary analysis if they signed a consent form to participate, whether they actually used an VBJ or not. A secondary analysis was performed for patients who actually used the journals at least once.



The study period included two phases. Phase 1 consisted of a burn-in period of at least 6 months, during which primary care practice patients received "usual care" and their physician's offices were using Patient Gateway. This allowed office staff to adjust their workflow to include electronic contact with patients for routine requests through PG along with telephone and face-to-face contact. During Phase 1, all patients using Patient Gateway received an explanation of the research study and were invited to participate in the study.

During Phase 2, the intervention phase, Arm 1 study practices offered consented patients VBJs with medication, allergy, and diabetes topics via Patient Gateway. Arm 2 practices had VBJs with

health maintenance, family history, and relevant personal history topics. Practices and patients in Arm 1 served as controls to those in Arm 2 and vice versa.

During the intervention phase, a medication use sub-study was performed in which telephone interviews were conducted with 268 patients in Arm 1 and 275 patients in Arm 2 following their office visit for which they had submitted a electronic visit-based journal (VBJ). This was designed to provide additional medication use data for detection of preventable and ameliorable adverse drug events (ADEs). The telephone survey, administered between 3 and 6 weeks after a journal visit, aimed to measure patient medication knowledge, discrepancies between the LMR medication list and each patient's self-reported medications, side effects of medications, and patient adherence to medication regimens.

Results: Based on pre-post survey analysis, over half of study patients felt that electronic visit-based journals led to their providers having more accurate information. The content of the information shared with the provider appears to impact the patient's perception of value in relation to the care experience. Among patient gateway users, intervention patients in the diabetes group were more likely to have their diabetes treatment regimens adjusted (53% vs. 15%, $p < 0.001$) and to have established medication goals with their physicians (32% vs. 2%, $p < 0.001$) compared to active controls. Over 1 year of follow up, there were no statistically significant differences in HbA1c, LDL, and blood pressure levels between study arms. Additional analysis is currently underway to evaluate the impact of the intervention on the medications, family history, and health maintenance study arms.

Key Words: Electronic health record (EHR), patient provider communication, medication management, adverse drug event, patient safety, health maintenance, family history, diabetes

A. Purpose

Our study aims were as follows:

Specific Aim 1: To evaluate the impact of pre-visit electronic patient prompts and a shared online medication list on detection of adverse drug events (ADEs), medication list accuracy, and patient medication knowledge.
Specific Aim 2: To evaluate the impact of pre-visit electronic patient prompts on chronic disease outcomes and adherence, in this case, for diabetes.
Specific Aim 3: To evaluate the impact of prompted health maintenance information on patient adherence to healthcare maintenance guidelines
Specific Aim 4: To evaluate the impact of prompted patient family history assessment on detection of familial risk factors.
Specific Aim 5: To identify and address technology adoption enablers and barriers to shared online health records for patients and physicians.

B. Scope

I. Background

Healthcare delivery is in the midst of a transition. At the adolescence of the Information Age, healthcare delivery systems are faced with a variety of convergent forces that, taken together, may catalyze the metamorphosis of healthcare information management from a patchwork of heterogeneous, disparate information systems into a more seamlessly connected and continuous collaborative care system. Though Americans are taking to the internet in vast numbers, largely in pursuit of healthcare information and convenience services, providers and delivery systems are reluctantly waking to the realization that fundamental reform of healthcare delivery itself will require adoption of a variety of information technologies. Increased processing power in the PC, increased connectivity to the internet, the inexorable adoption of email and use of the web are all technology drivers for this transformation. The healthcare consumer may be

the most critical agent for innovation, in fact – increasingly empowered by the internet, experiencing less of an information disparity with the clinician, and inevitably self-interested in his or her own care. As patients are increasingly sensitized to differences in quality and/or service and to the extent they are engaged in differential reimbursement schemes (e.g. 'defined contribution') to throttle demand for high cost services, they will also be demanding better communication, better data, and better services for their healthcare dollar.

Many questions exist, however, as to how to move into this new electronically mediated world in healthcare. How do we shift from an episodic care paradigm to a continuous care paradigm? What are appropriate communications between providers or their delegates and patients? What is the impact on clinical workflow and efficiency, not to mention clinical outcomes for patients, of e-health services? What data may patients reliably provide to their health records, and how is it best obtained and validated? In light of increased awareness of the vulnerability of patients in the current healthcare delivery system, increased attention is also being given to the role of information technologies to improve provider clinical decision making. Perhaps the patient is another important target for clinical decision support and care management tools – given that he or she is the final common pathway for all healthcare decisions, interventions, and outcomes.

In this study, we proposed to take advantage of one of the largest implementations of automated clinical information management tools for both the provider and the patient to analyze several key questions. Using the Partners Healthcare provider-oriented Longitudinal Medical Record, and the consumer-oriented *Patient Gateway*, we specifically looked at the impact of these tools on medication management and patient safety, service delivery in preventive and chronic care, acquisition of patient-source data on Family History, and the barriers and enablers to use of this technology.

II. Context and Settings

The population targeted in the Prepare for Care study was all patients enrolled in Patient Gateway in 11 participating primary care practices. The study practices included both academic medical center ambulatory practices and community practices affiliated with the Massachusetts General Hospital (MGH) and the Brigham and Women's Hospital (BWH) in Boston, MA. Each study practice used LMR and PG prior to the study intervention period for at least 2 years. The Patient Gateway application was intended to serve English-literate users with an 8th grade reading level. Multilingual system development or providing patients with computer technology (and support) were beyond the resources available for this study.

III. Participants

Users of Patient Gateway (31,536) within the study practices were similar to non-users of Patient Gateway in those practices (95,016) in their mean age (45.2 vs. 45.9 years) and percent who were women (63.9% vs 62.6%) but were dissimilar for minority breakdown. Whereas PG users were 20.2% non-White (3.3% Black, 1.6% Hispanic, 3.5% Asian, 1.4% other, and 10.4% unknown), non-PG users were 35.7% non-White (7.2% Black, 8.5% Hispanic, 3.8% Asian, 2.3% other, and 13.9% unknown, $p<0.0001$).

The study sites included a total of 230 primary care physicians (PCPs) and 500 support staff. On average, a PCP panel was 750 patients (range, 368-1571), because many of the PCPs were part-time physicians or nurse practitioners with academic and other responsibilities. All participating sites cared for women, minority patients, elderly patients, and severely ill patients. Children were not included in this study.

C. Methods/Study Design

A randomized, prospective cohort design was employed to assess the impact of shared online health records on patient medication safety, health goal adherence and outcomes for preventive screening and diabetes, documentation and risk detection of family history, and

barriers to the adoption of patient-physician communication technology. This project received institutional IRB approval and is registered with ClinicalTrials.gov identifier NCT00251875. Practices were paired using practice characteristics, then one practice in the pair was randomized to Arm 1 or Arm 2. The other practice was placed in the opposing Arm. To provide consistency in number of patients, several small practices were "grouped" together prior to pairing. All patients with a Patient Gateway account in a study practice were invited to participate. Patients were included in the primary analysis if they signed a consent form to participate, whether they actually used an electronic visit-based journal (VBJ) or not. A secondary analysis was performed for patients who actually used the journals at least once.

The study period included two phases. Phase 1 consisted of a burn-in period of at least 6 months, during which primary care practice patients received "usual care" and their physician's offices were using Patient Gateway. This allowed office staff to adjust their workflow to include electronic contact with patients for routine requests through PG along with telephone and face-to-face contact. During Phase 1 all patients using Patient Gateway received an explanation of the research study and were invited to participate in the study.

During Phase 2, the intervention phase, Arm 1 study practices offered consented patients VBJs with medication, allergy, and diabetes topics via Patient Gateway. Arm 2 practices had VBJs with health maintenance, family history, and relevant personal history topics. Practices and patients in Arm 1 served as controls to those in Arm 2 and vice versa.

During the intervention phase, a medication use sub-study was performed in which telephone interviews were conducted with 268 patients in Arm 1 and 275 patients in Arm 2 following their office visit for which they had submitted a VBJ. This was designed to provide additional medication use data for detection of preventable and ameliorable adverse drug events (ADEs). The telephone survey, administered between 3 and 6 weeks after a journal visit, aimed to measure patient medication knowledge, discrepancies between the LMR medication list and each patient's self-reported medications, side effects of medications, and patient adherence to medication regimens.

Study Outcomes

The primary clinical outcomes (Table 1) of the Prepare for Care study were to evaluate the impact of the VBJ on 1) medication safety – frequency of preventable ADEs and provider awareness of ameliorable medication side effects; 2) diabetes control – changes in HbA1c, cholesterol, blood pressure, and frequency of referrals and self-care; 3) health maintenance – changes in guideline adherence (e.g., mammogram, pap smear, etc.); and 4) family history – changes in risk factor detection and documentation.

Secondary process outcomes included a change in the completeness and correctness of physician documentation of medications, allergies, diabetes health status, health maintenance, and family history in the Longitudinal Medical Record (LMR). Additional secondary outcomes included physician and patient satisfaction with the system, and patient satisfaction with their medical care with respect to patient-provider communication, medications, allergies, diabetes, health maintenance and family history. This study also aimed to identify and address technology adoption enablers and barriers to shared online health records for patients and physicians. Finally, changes in patient knowledge about journal topics, and patient and provider usage of PG were measured.

Table 1: Study Outcomes

Clinical outcomes	EMR documentation	Patient knowledge	Satisfaction
Preventable ADE rate, duration and severity of ameliorable ADEs HbA1c, BP, lipids for diabetic patients	Medication list accuracy Documentation rates for diabetes care Documentation rates for preventive care Presence of family	Medication knowledge Diabetes knowledge Preventive care knowledge	Patient satisfaction Physician satisfaction Staff satisfaction

Clinical outcomes	EMR documentation	Patient knowledge	Satisfaction
Guideline adherence in preventive care and diabetes Family history risk detection	history risk assessment	Family history risk knowledge	

Data Collection

Data collection relied on computerized queries of electronic clinical databases, with baseline collection of patient demographic data (age, gender, race, primary language, level of education, PCP), medical chart data (number of medications, number of problems, number of allergies, and utilization data on number of visits, tests, and procedures), and characteristics of participating physicians and practices. These data were also used to check the quality of randomization by clinic. Data collection similar to baseline was conducted post intervention, with the addition of patient responses to visit-based journal questions and provider incorporation of patient responses into the LMR.

The rate of preventable and ameliorable adverse drug events (ADEs) and medication and allergy list accuracy was determined from the telephone sub-study survey of post-visit patients who had completed a VBJ. An adjudication database was constructed for blinded study investigators to assess the relationship of patient-self-reported symptoms and preventable and ameliorable ADEs identified in the survey. Assessment of VBJ usage rates by patients and technology adoption by physicians was based on software tracking of sessions and user feedback through physician focus groups.

User surveys to all patients, providers, and staff were sent to assess attitudes toward VBJs and the use of online communication tools during the pre-intervention and post-intervention periods. These, along with a short journal experience survey sent to patients 3 days after an office visit for which a journal was submitted, included items assessing usability, technology access, confidentiality, impact on workflow, satisfaction, patient knowledge, impact on care, impact on the physician-patient relationship, and impact on patient self-management of care. Survey data was used to amplify our understanding of observed patterns of use and to assess potential learning and adaptation effects.

Limitations:

The major limitations to this study included the fact that physician engagement was voluntary and physicians are under tremendous time constraints, making them less likely to make workflow changes needed to review and document VBJ information during the visit. Also, limitations in EHR data completeness, accuracy, coding, decision support quality, and the scope of topics covered in the VBJ reduced the amount of useful information that could be displayed in the VBJ. With VBJ content focused in several specific areas and divided among control and intervention groups, some VBJs had a paucity of information that could be used during the visit. The flow of information in this study was at high risk for interruption, because clinical data flowed a) from EHR to the patient using the VBJ, b) from patient to the provider using the LMR, and c) from provider to the EHR using documentation tools. Looking at intermediate information flows (within each segment) in addition to end-to-end flow of information is valuable.

D. <u>Results</u>

I. Principal Findings/Outcomes/Discussion

Medications module (Aim 1)

Between July 2005 and January 2007, 12,278 patients who sought primary care at one of the four medications and diabetes module intervention practices were invited to participate in the

study. Of them, 2273 (19%) completed the consent process. Of these, 1457 (64%) patients met journal eligibility criteria and were invited to complete a VBJ at least 3 weeks prior to a scheduled primary care visit. Of these, 1131 patients (78%) opened a medications journal and 1053 (72%) completed the review and updating process and submitted a journal for review. Data were reviewed electronically within the LMR for 812 (77%) of these patients.

In addition, 687 consented patients who opened their invitation to complete a medication journal prior to a visit were invited to complete a brief survey of their journal experience 3 days after their visit. Of these patients, 466 (68%) responded. Overall, 70% of these patients found the journal very easy or easy to complete. Fifty-three percent either strongly agreed or agreed that the use of the journal led their providers to have more accurate information about them, whereas 39% felt neutral about the journal's impact in this area. Similarly, 56% of respondents strongly agreed or agreed that they felt more prepared for their visit with the use of the journal, whereas 35% reported that they felt neutral about the journal's impact on feelings of preparedness.

Additional analysis is currently underway to determine the impact of the intervention on preventable ADE rates, duration and severity of ameliorable ADEs, medication list accuracy, and patient medication knowledge.

Discussion and Conclusions

Our preliminary findings demonstrate that a patient portal-linked tool to help improve medication safety has promise. Approximately two thirds of patients asked to complete a medications journal prior to an upcoming visit submitted one for review, and about 70% of these were reviewed by physicians during that subsequent visit. Patient survey data showed that the majority of patients who used a medication journal found it easy to use, felt that it led to their providers having more accurate information about them, and enabled them to feel more prepared for their upcoming visit.

The PG Medications Module represents a major effort to engage the patient directly in medication surveillance in order to decrease serious medication errors in the outpatient setting. We believe that integration of this kind of intervention into a patient portal represents a novel and potentially powerful way to reduce ADEs and medication discrepancies. The effects of this intervention on a variety of outcomes are currently being tested. It is encouraging that such a high percentage of patients were able to use the software to submit medication journals and felt better prepared by the experience. Additional improvements and enhancements to the intervention can then be designed. The reach of this type of intervention to a general patient population is an ongoing concern: overall, fewer than 8% of potentially eligible patients eventually engaged with our intervention, and major barriers exist to the widespread dissemination of tools like these. Expanding its use to a broader population will be a major focus going forward. Ongoing education of both physicians and patients regarding the prevalence and seriousness of medication discrepancies and ADEs and the importance of communication about these issues will also be needed to produce the culture change necessary to improve medication safety.

Diabetes Health Care maintenance (Aim 2)

Participant flow

Use of the parent Patient Gateway secure web-portal by patients with type 2 diabetes ranged from 7% to 14% of each practice population. Among patients with active PG accounts, the rate of consent to enroll in the advanced patient portal clinical trial was 39% in the Diabetes Portal/Medications Module intervention arm and 35% in the Family History/Health Maintenance active control arm. Practices were enrolled beginning 9/30/2005, and follow-up ascertainment completed when the study was formally closed on 3/22/2007.

Baseline data

Patients with diabetes who enrolled in the *Prepare for Care* study were younger (56.1 vs. 60.2 years, p <0.001), and a greater proportion were White (89% vs. 67%, <0.001), commercially insured (72% vs. 47%), and at or below HbA1c goal (54% vs. 46% baseline HbA1c < 7.0, p = 0.037) compared with non-participating patients. There were no clinical differences among study participants at baseline by treatment arm.

Intention-to-Treat Analysis

Study participants had relatively good disease control at baseline with modest changes over the study period that did not differ by treatment arm. After 1 year of follow-up, mean HbA1c levels among intervention patients were 7.1 (vs. 7.2 among the controls, p = 0.45), and nearly three quarters of patients were at goal (73% vs. 68% among control patients, p = 0.53). Results were qualitatively similar for cholesterol and blood pressure control (data not shown).

On-Treatment Analyses

In contrast to the patients who submitted family history/health maintenance journals in the active control arm (n = 45), patients in the intervention arm who submitted diabetes journals (n = 74) were significantly more likely to have a medication initiation or dose adjustment for hyperglycemia, hypertension, or hyperlipidemia (53% vs. 15%, p <0.001, **Figure 2**). One half of patients (51%) who completed diabetes PHR journals prior to upcoming visits indicated that they wished to improve their blood sugar control, 32% wanted to improve blood pressure control, and 28% wanted to improve cholesterol control.

Patient Survey Results

At study conclusion, a greater proportion of survey respondents in the intervention arm expressed an increased confidence in deciding “which way of overcoming their diabetes barriers works best for them” (36% increased from baseline vs. 14% in active control arm, p = 0.012), and a greater proportion of respondents who reported not setting medication goals with their physicians at baseline had set such goals at follow-up (32% vs. 2%, p <0.001). Among intervention arm survey responders (n = 47), more than half (57%) reported that the journal helped them to “communicate with my doctor about my diabetes.”

Discussion

In this report, we present the results of a system-wide, randomized clinical trial of a web-based patient Personal Health Record linked directly to the electronic medical record used by the primary care physicians in the Partners Healthcare network. Our finding that users of the diabetes-specific PHR were markedly more likely to have their regimens changed at their next clinic visit and to report having clearer treatment goals relative to patients with diabetes who used the non-diabetes PHRs indicate that, when used, our intervention worked to improve the process of diabetes care. The lack of clinically significant impact on diabetes-related risk factor levels can be attributed to two major influences: 1) Patients who consented to enroll in the *Prepare for Care* advanced PHR study tended to have relatively good metabolic control and thus had limited room for improvement. 2) Despite the large, multi-practice population covered by the study, power to detect differences was reduced because only a small proportion of potentially eligible patients had signed up for access to the parent Patient Gateway secure web portal.

Effective translation of new innovations into improved diabetes care remains a difficult challenge for current research efforts [per Garfield]. The results of our study underscore a number of critical points for future work in this area. First – and perhaps foremost, evaluating the impact of new technologies and new strategies for care requires a rigorous study design. Our use of an active control study design eliminated “confounding by participation,” a common methodological shortcoming in which the true effect of a patient-oriented diabetes intervention is difficult to isolate from its mode of delivery. Thus, differences noted between study arms reflect the impact of the diabetes PHR on clinical care not confounded by the tendency of patients to engage in online PHR clinical interactions. In addition, because this intervention was linked to the electronic medical records used for primary care in our network, all patients with diabetes within the 11 primary care practices could theoretically have participated. Thus, our results represent a “real-world” estimate of patient participation in novel, web-based care tools.

Second, our on-treatment analysis underscores the finding that, when used, diabetes-specific patient portals linked directly to physicians’ electronic medical records can have a significant impact on diabetes care. Patients using the diabetes PHR reported greater insight into their disease management and were much more likely to have significant medication changes at the next clinical visit. This finding provides evidence that increasing patient knowledge and patient-physician communication via on-line PHRs can effectively lower clinical inertia, a critical barrier to achieving evidence-based goals of care.

Third, our findings demonstrate that the “Digital Divide” remains an important barrier to the adoption of new health information technologies. However, thought study participants were indeed younger, less likely to belong to a racial/ethnic minority group, and less likely to live in a poor neighborhood, the absolute differences in these sociodemographic factors between participants and nonparticipants was relatively small. A recent survey conducted within our network found that nearly 50% of patients with type 2 diabetes currently use the internet. Given this relatively high level of online access, the comparably low rate of participation in our study indicates that there exist important barriers to adoption of patient health portals beyond the physical availability of an internet connection.

Finally, the current generation informatics tools appear to have only a limited impact on improving diabetes care. The diabetes patient portal we developed included an innovative patient interface that presented key clinical information and individualized patient decision support, grouped results and current medications within each risk factor domain (hyperglycemia, hypertension, hyperlipidemia), and facilitated the development of a Care Plan that was automatically shared with the PCP as a patient-authored note in the medical record. We believe that this organizational format created a necessary first step toward the ideal patient diabetes portal. Missing from this intervention, however, were methods to 1) easily upload clinical information from home (e.g., blood sugars, blood pressure, weight and exercise activities from wireless monitors) and 2) effectively integrate these data with the clinical workflow. Because of the novel and potentially disruptive impact on usual care of providing online and interactive patient access to their medical record, in this initial study, we sought to minimize the amount of additional work required of PCPs. Prior surveys had documented physician concerns and resistance to any interventions that increased demands on their already limited time. Thus, we did not undertake any formal training of patients and physicians with regard to creating and acting on the Care Plans, and we did not seek to significantly change the ways in which PCPs currently practiced. The limited impact of our intervention, however, suggests that a more radical “re-design” of current practice may be necessary to effectively integrate new patient-oriented informatics tools into existing patterns of care delivery.

In summary, we took advantage of an advanced clinical informatics system that included a password-protected patient portal to conduct a rigorous, population-level controlled trial of a novel, "first-generation" DM tool designed to engage and activate patients toward achieving goals of care. Our findings suggest that the close link between the PHR and the patients’ physicians’ electronic medical records may have facilitated the process of medication initiation and dose

adjustment. However, despite enrolling 11 primary care practices, our study was limited by a "ceiling effect" among participants and ultimately underpowered to show differences between study consenters in the intervention vs. control study arms. Realizing the promise of web-based patient-centered care will require finding ways to more effectively engage both practicing physicians and patients in collaborative, non-visit-based care.

Health Maintenance and Chronic Disease Outcomes (Aim 3)

Between July 2005 and November 2006, patients who sought primary care at one of the seven study practices were invited to participate in the study. Of them, 2779 completed the consenting process, which included a baseline attitude survey. Of the 2779 patients who consented, 63% were women. Their mean age was 47.4 at the time of consent.

Of these 2779 patients who completed the consent process, 2361 (85%) reviewed their HM records. In addition, 970 of 2779 (35%) patients had a routine visit scheduled at least 3 weeks in advance and therefore were invited to update their HM record and state their preference for taking care of overdue HM care items. Of these 970 patients, 696 (72%) completed the review and updating process and submitted the information for their clinicians to review. Clinicians reviewed the data electronically within the electronic medical record for 460 (66%) of these patients.

Between July and November 2006, 437 patients who opened their invitation to update their HM record prior to a visit were invited to respond to an online survey to assess their experience with the HM module. Overall, 179 patients (response rate = 41%) responded, and 81% of the respondents found the journal very easy or easy to complete; 51% of respondents either strongly agreed or agreed that the use of the journal led their providers to have more accurate information, with another 37% feeling neutral about whether the use of the journal had an impact in this area. Forty-eight percent of respondents agreed that they felt more prepared for the visit, with another 41% feeling neutral.

Although patients' responses to the HM module were largely positive, review of the qualitative comments from the survey revealed that not all clinicians were aware of their ability to review HM data submitted by the patient. Some patients felt that their clinician did not review data submitted by them. Others reported that their physicians asked them to fill out another paper survey in the waiting room that largely duplicated their interaction with the HM module. Certain patients desired the ability to enter information in free form to the physician, such as reason for the visit or other active concerns.

Additional analysis is currently underway to determine the impact of the intervention on patient adherence patient knowledge of preventive care guidelines as well as provider documentation rates for preventive care.

Discussion and Conclusions

Our preliminary findings demonstrate that sharing the medical record and decision support tools between patients and their providers is a promising approach for improving quality of care. Not all eligible patients and clinicians used this new set of tools when offered the opportunity, but those who did generally found the toolset easy to use, and many thought that it made them feel more prepared for the visit and allowed their clinicians to have more up-to-date information.

There are several potential limitations to this approach to improve the quality of routine HM care. First, this approach does not benefit patients who do not have internet access or who do not have sufficient computer literacy to use our system. However, this concern is partially mitigated by the fact that internet access in the US is rapidly increasing (11). In addition, we have taken every effort through usability testing to ensure that our system is easy to use. Second, in our current implementation, only patients who are scheduled to have a visit are invited to update their HM records, and those without upcoming visits do not benefit from this

aspect of the HM module. Also, patients are only invited to update their records in focused and structured ways and cannot express their thoughts and concerns in free form using the VBJ. We would have liked to provide these features, but physician practices were concerned early during the project that allowing patients to submit updates to their HM record without an upcoming scheduled visit or providing free-form entry might impose undue workflow and liability burden on the practices. Additional research is needed to examine these issues that arise from the deployment of EHR-connected PHRs. In addition, if our long-term evaluation demonstrates a clinical benefit to the use of the HM module, then it may be possible to articulate the business case for the broader deployment of this approach. Finally, successful deployment of this approach requires the full support of local clinical leaders and extensive training. Though we invested significant resources in these areas, our efforts did not reach all clinicians, as evidenced by the fact that some clinicians were not aware that they could review HM data submitted by patients. Optimal ways for deploying this technology at various types of institutions deserve more investigation.

We have implemented a novel approach to improve the quality of routine HM care by allowing patients and their providers to share the medical record and decision support tools. Our preliminary results indicate that this approach is accepted by patients and their providers. Additional analysis will determine the short-term impact of this tool. More research will be needed to determine the long-term impact and sustainability of this approach.

Significance (AIM 4 and overall):

Policy Implications

The adoption of an online visit-based journal for patients through a secure patient web portal with review by providers using an EHR would likely have several policy implications, including those relating to liability, data sharing, and interoperability.

Liability. There will need to be policies addressing the potential for increased liability for providers. For example, whereas sharing EHR medication lists or laboratory results with the patient could help the patient update their medications or avoid a missed test result, leading to better EHR data accuracy, there is also the risk that it might identify a provider who appeared to have missed a medication or failed to report on a test result, perhaps implying the use of inaccurate data for care decisions. Similarly, sharing EHR decision support advice with the patient could improve patient knowledge and adherence to care recommendations but might surface differences between system recommendations and a provider's recommendations. This could be common, especially if patient-supplied data were rejected by a provider or if a provider overrode a system recommendation based on clinical judgment. Another concern is urgent communication about a clinically important symptom, such as fever in an immunocompromised patient or a symptom of medication toxicity. If the online patient journal shares clinically important information with a provider but does not facilitate a rapid provider response when appropriate, liability could increase.

Data Sharing and Interoperability. Information sharing between patient-controlled systems and provider-controlled systems requires clear policies that identify how permissions to release information to another entity for a given purpose are managed. Providers must understand how and under what circumstances EHR data will be released to patients, and patients must understand how their online journal entries are to be shared with providers. Policies are also needed to promote data adherence to existing or emerging standards to promote interoperability so that data captured in one system can be used coherently in another.

In summary, the Prepare for Care study is designed to evaluate a new tool for patient-provided data and provider review, the visit-based journal, which displays patient medical chart information and EHR decision support reminders directly to the patient and summarizes patient-provided medical history information to the provider for visit-based care using clinical systems in

daily use at Partners Healthcare, including the Longitudinal Medical Record and the Patient Gateway. We anticipate that investigations of collaboration tools used by patients and providers for communication and information sharing will grow with time and anticipate that results of this intervention will help inform the value of these tools in improving patient care.

E. List of Publications

The following publications and presentations are products of this grant.

Publications:

Wald JS, Middleton B, Bloom A, Walmsley D, Gleason M, Nelson E, Li Q, Epstein M, Volk L, Bates DW. A patient-controlled journal for an electronic medical record: issues and challenges. Medinfo, 2004; 1166-70.

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- Medications Conceptual Framework (submitted pending review)
- Medications Outcomes Results

- Diabetes Outcomes Results (submitted pending review)
- Family History Outcomes Results
- Patient-Provider PHR Adoption