

Project Title: Improving Uptake and Use of Personal Health Records
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This project was proposed to demonstrate and evaluate interventions to improve the uptake and use of personal health records (PHRs) in an ambulatory setting. Additionally, gaps existed in the literature around the factors that influence patients to adopt or reject a PHR and the role of such factors in the likelihood to use the PHR. Finally, we needed to better understand the role of PHRs in providing patient-centered care and the impact of PHR-based care on quality and coordination of care. Through this project we conducted research that addressed these three gaps in the research on PHRs.

Research Aim 1. Introduce an intervention employing multiple strategies to improve the uptake and use of PHR in an ambulatory setting.

The health IT intervention in the proposed project was the implementation of a combination of strategies to improve the uptake and use of a PHR in an ambulatory setting. The project focused on four ambulatory care practices. Of the four practices, two practices were drawn from primary care and the remaining two were drawn from a specialty area, Rheumatology. We selected specialty care as part of this intervention as adoption and use rates in specialty practices are even lower than primary care and there is little discussion in the literature on improving uptake and use of PHR at specialty practices. Within each pair of practices, one practice was designated as the intervention practice and the other practice as the control practice. The selection of the practices was based on several criteria: practices associated with low uptake and use of PHR, practices that are not using the strategies that we wish to deploy in our intervention, interest in participation from the sites, and our ability to choose control sites that remained as controls for the duration of the intervention component.

In terms of the intervention to improve the uptake of the PHR, our study employed multiple strategies to improve the uptake over a six-month intervention period. We believe that multiple strategies offer the best approach to improve the uptake of PHR given the number of different ways that patients interact with physicians and their practices. We also believe that multiple strategies are needed to reinforce messages about the availability of the PHR and to reach diverse patient audiences. We employed the following specific intervention strategies for

improving the uptake of the PHR. Since the interventions differed between the primary care and Rheumatology practices, we list these separately for each practice. The one exception to this was that at the start of the intervention period, we attended staff meetings in both practices, introduced the study, and encouraged staff to inform patients at each visit or phone conversation about the PHR and suggest that the patient enroll in the PHR if they have not already done so.

In our primary care intervention practice:

1. The check out form was revised to include a question on whether the patient had enrolled in the PHR. Three staff members – MA, PCP, and check out staff – were tasked with reviewing the question with the patient and suggesting that the patient enroll in the PHR if they had not already done so. The staff member would also note the patient's response to the question on the check out form along with their initials so that we could track which staff member completed this question. On a monthly basis over a three-month period of the six-month intervention the staff member who was associated with the highest completion rate of the question received an incentive of \$50.
2. For a second three-month period of the intervention, all staff were enrolled in a lottery for a \$100 incentive each month for their effort in encouraging patients to enroll in the PHR.
3. Several times during the six-month intervention period, research staff presented results of the ongoing intervention at both faculty meetings (attended by physicians, advanced practitioners and nurses) and meetings of the check-out staff.

In the Rheumatology intervention practice, the practice director and practice manager did not wish to implement an incentive program to improve uptake. As a result we adopted the following strategies at this practice.

1. The check out staff would ask the patient if they had enrolled in the PHR. If the patient had not enrolled in the PHR the check out staff would inform the patient about the PHR and hand an information pamphlet on the PHR to patients that also contained information on how to enroll in the PHR.
2. A computer was placed in the waiting room of the clinic for patients to self-enroll in the PHR. Both physicians and check out staff informed patients of the availability of the computer.

In terms of the intervention to improve use of the PHR, we employed two strategies in the study, both of which were applied to the two intervention groups. Our focus was on patients who had adopted the PHR but with the objective of improving or sustaining use of the PHR among these patients. The first strategy for improving use relied on a mailed approach to contacting the adopters. For this mailed approach we identified and categorized patients into two groups. First we identified patients who were using the PHR for only certain functionality such as going online to review laboratory results or viewing other components of the medical record but who were not using the PHR for functionality such as medication refills or asking their doctor a non-urgent medical question via the PHR. These patients received a letter from the Practice Director of the intervention practice (primary care or Rheumatology) pointing out the additional functionality of the PHR. In addition, we enclosed a flyer with the letter that highlighted the additional functionality. The second group was patients were frequent users of

the PHR. We defined frequent users as patients who used the PHR at least 3 times in a six-month period for functionality such as medication refill requests or asking the doctor a non-urgent medical question. These patients received a thank you letter from the Practice Director of the intervention practice for their PHR use. In addition, a pen with a logo of the practice was sent with the letter.

Our second intervention for improving the use of the PHR adopted an electronic approach. We contacted patients via the PHR. We again identified two groups of patients. The first group of patients was those patients who did not initiate a message via the PHR in the six months prior to the start of the intervention. These patients were sent an electronic message from the Practice Director asking them to explore their PG account. They were also informed of two new functionalities in the PHR, online bill pay and the availability of the summary of office visit. The second group of patients was those patients who had used the PHR at least twice in the six month period prior to the intervention. These patients also received an electronic message from the Practice Director via the PHR thanking them for their use of the PHR and informing them of the new functionalities of online bill pay and the summary of the office visit.

Research Aim 2. Evaluate factors that influence patients to adopt or reject the PHR and the role of such factors in the likelihood to use the PHR

The conceptual framework adopted for the proposed project was the diffusion of innovation (DOI) model (Rogers 2003). Why is the DOI model a suitable fit for understanding adoption and use of PHRs? Rogers (2003:12) defined an innovation as an idea, practice, or object that is perceived as new by an individual or other unit of adoption. In this respect, a PHR which offers secure online communication is an innovation at the patient level in that it will be perceived by patients as a new idea or practice. For example, instead of calling their doctor's office for a prescription refill patients can use the PHR to request a refill. In the diffusion of innovation model, Rogers identified a set of factors called the perceived attributes of an innovation which influence attitudes toward and adoption of an innovation. The perceived attributes of an innovation are: 1. Relative Advantage, or the degree to which an innovation is perceived as being better than an idea it supersedes (Rogers 2003: 229). For example, in the case of a PHR, relative advantage would be the perceived flexibility in contacting a doctor's office via the PHR after office hours compared to calling the doctor's office during office hours. 2. Compatibility, or the degree to which an innovation is perceived as consistent with existing values and past preferences (Rogers 2003: 240). In the case of PHR, patients who prefer online communication tools and who have experience using tools such as email and Internet are more likely to adopt the PHR than patients who do not have such preference or experience. 3. Complexity is the degree to which an innovation is perceived as relatively difficult to understand and use (Rogers 2003: 257). If patients perceive the PHR to be difficult to understand and use they are unlikely to adopt it. 4. Trialability is the degree to which an innovation may be experimented with on a limited basis. The PHR allows trialability as the patient can register for an account, activate it, and use it. Trialability is positively associated with the rate of adoption. 5. Observability is the degree to which the results of an innovation are visible to others. For example, patients can observe family and friends using the PHR and decide to adopt it.

A second conceptual approach for evaluating factors influencing the adoption or rejection of PHRs adopted in this study is the evaluation of feelings that play an important role in the persuasion stage of the adoption. Our focus here is on emotions, such as good or bad, which people feel about objects with which they have interacted in some fashion. The affective component may play a particularly important role in understanding patient's behavior toward the adoption or rejection of PHR for three reasons (Slovic and Peters 2006): (1) Affective evaluations are accessed more quickly than cognitive evaluations – “feelings are first”; (2) Affective evaluations are held more confidently than cognitive evaluations; and (3) Affective evaluations may direct motivation of behavior. At the patient level, affect is likely to be a key facilitator or barrier to the adoption of PHR. If patients feel negative affect towards PHR they will likely reject the PHR; if they feel positive they will likely adopt it.

Our approach to study the two sets of evaluative factors – perceived attributes of an innovation and emotions – was a patient survey which we consider as our baseline survey. We created a survey that contained items capturing four perceived attributes of the innovation (relative advantage, compatibility, ease of use, and triability) and emotions such as good/bad and like/dislike. We also included other items in the survey such as computer use by patients, self-reported health status and comorbid conditions, and demographic characteristics such as income and education. Our dependent variable, likelihood to use the PHR, was also captured as a survey item. To implement the survey, we identified patients who were new adopters of the PHR, that is those who signed up for a PHR account. We identified new adopters on a weekly basis in order to survey the patients closest to the time of their adoption of the PHR. On a weekly basis we also identified a random sample of non-adopters of the PHR for our survey. The criterion for identifying the non-adopters was that they had an office visit at one of the four study practices during the weekly recruiting period. Prior to the random sampling we divided the non-adopters into two groups: patients less than 65 years, and patients 65 and older. We then selected random samples of equal number of patients from each group. The categorization by age allowed us to ensure that we included both younger and older patients in the study as some studies have reported that older patients are less likely to adopt a PHR. Our survey implementation followed Dillman's tailored design method, an approach that we employed successfully in previous studies. We sent the initial survey with a \$5 cash incentive and a stamped return envelope followed by a reminder post-card and a reminder survey with a business reply envelope. Patients could refuse participation in the study by returning a blank survey with a note on the survey or by calling a telephone number assigned to the study. We identified 582 new adopters of the Partners PHR in a sixteen-week period. Of the 582 new adopters, 372 responded to our survey for a response rate of 63.9%. In the case of non-adopters, we identified 659 patients in a seventeen-week recruiting period, of whom 281 returned the survey for a response rate of 42.6%.

Research Aim 3. Assess the role of PHRs in quality of care with a particular focus on patient-centered care

The IOM (2001) defined quality of care as comprising of six domains: safe, effective, patient-centered, timely, efficient, and equitable. In this study we focused on patient-centered care as the primary domain of interest with respect to quality of care. Patient-centered care is defined as care that is respectful and responsive to patients' preferences, needs, and values while assuring these values guide all clinical decision-making (Gerteis et al. 1993, IOM 2001). To date

most studies on PHRs have not addressed issues of patient-centered care in their evaluation of PHRs. The studies have also primarily conducted satisfaction evaluations of the use of PHRs. However, as it is now well established studies of patient satisfaction with care are inadequate to capture issues related to quality of care (Cleary and Edgman-Levitan 1997, Coulter 2005). Patients can be highly satisfied with using the PHR but the care that is received may not be of high quality. We need studies of patients' reports of their experience with care using a PHR including patients' reports of patient-centered care issues such as respect and responsiveness to patients' preferences as well as other domains of quality such as timeliness of care.

In 2012 the CAHPS ambulatory care survey was extended to include the health information technology (HIT) item set. In this study we adopted the items in the HIT item set for assessing patient reports of patient-centered care. We focused on two functionalities of the PHR: accessing laboratory results, and communicating with the doctor via the PHR. For each functionality we asked patients to report on items such as how easy it was to perform the task (e.g., ask the doctor a medical question), how easy it was to understand the information presented to them, and how often was the information available to them when they needed it. We conducted two sets of surveys related to the assessment of patient-centered care for the two functionalities. We conducted a six-month survey from baseline in which we asked patients to report on their experience with care using the PHR in the previous six months. At the end of the study, we conducted a second survey to assess patient experience with care using the PHR in the previous twelve months. This final survey included all adopters who responded to the baseline survey (369 of the 372 adopters as we did not have patient identifiers on 3 patients). In addition, this survey included items on perceived attributes of innovation that we used in our baseline survey. This allows us to compare changes in these attributes over time. We believe this will be the first study to report on such change over time in the perceived attributes of a PHR. Our implementation of the six-month and twelve-month surveys followed the Dillman tailored design approach and included the first survey with a cash incentive followed by a reminder post-card and a reminder survey.

We are in the process of preparing publications related to the different tasks we have carried out for this study. These include:

- A paper on applying the diffusion of innovation model to PHR adoption (and non-adoption)
- A paper on the impacts of the adoption and use interventions on adoption and use rates of the PHR
- A paper on six-month and twelve-month patient reports of patient experience with care overall, and specifically patient-centered care
- A paper on changes in perceived attributes of the PHR over time

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