Promoting Use of an Integrated Personal Health Record for Prevention

Inclusive project dates: 06/15/10 - 05/31/12

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Abstract

Purpose: To conduct a feasibility trial to assess whether primary care practices, under usual practice conditions, can sustainably integrate a patient-centered personal health record to promote prevention into care, termed an interactive preventive healthcare record (IPHR), and to assess the impact of the integration on the delivery of preventive services..

Scope: None provided.

Methods: In eight practices, the IPHR was made available to all adult patients presenting for care. We engaged practices to create a shared vision on how to integrate the IPHR into delivery using practice champions and learning collaboratives. From the IPHR and electronic health record (EHR) databases, we applied the RE-AIM model to measure *Reach*, *Effectiveness*, *Implementation*, and *Maintenance*. We compared the *Reach* in this study to the *Reach* from a historical control when patients were mailed an invitational letter to use the system.

Results: Practices were able to get a greater proportion of patients to create an IPHR account when the IPHR was integrated into care than when it was promoted through mailed invitations (18.1% vs. 12.4%, p=0.008). Among survey respondents, 85% reported returning to use the IPHR at least once. Practices used multiple tools, staff, and points of contact in order to engage patients to use the IPHR. IPHR-users had greater increases in the delivery of preventive services than non-users. Six months after baseline, the percent of IPHR-users up-to-date with all preventive services increase from 29.0%% to 36.2%%, while the percent of non-users increased only from 23.4% to 27.7% (p<0.001 comparing the increase between users and non-users).

Key Words: primary health care; health records, personal; implementation; workflow; access to information; electronic health records; patient-centered care; primary prevention; secondary prevention; health behavior; medical informatics

Final Report

Purpose

This project sought to learn (a) whether primary care practices could encourage patients to use a patient-centered personal health record, such as the IPHR, by integrating the system into routine care, and (b) whether integrating the system into care would influence the delivery of preventive services. Three primary aims were prospectively evaluated:

Specific Aim #1

To measure the utilization of the IPHR when the IPHR is promoted to patients by primary care practices using a patient-centered approach integrated into care delivery.

Research Question #1a. Will a greater proportion of adult patients with an office visit complete the IPHR enrollment process and receive prevention recommendations (*Reach*) when the IPHR is integrated into care delivery than when the IPHR was promoted through mailed invitation letters (historical controls)?

Research Question #1b. Can the IPHR enrollment rates that practices achieve during the first six months of promoting the IPHR (*Reach* from question #1a) be sustained through the second six months (practice-level Maintenance)?

Research Question #1c. What proportion of patients return to reuse the IPHR after initially establishing an account (patient-level Maintenance)?

Specific Aim #2

To assess how practices engage patients to use the IPHR and integrate the IPHR into care as well as the IPHR's impact on the delivery rates of preventive services.

Research Question #2a. How will practices engage patients to use the IPHR and integrate the IPHR into care (*Implementation*)?

Research Question #2b. Will patients who use the IPHR be more up-to-date with age- and gender-appropriate preventive services 1, 3, and 6 months after receiving IPHR prevention recommendations compared to baseline (*Effectiveness*)?

Specific Aim #3

To explore mediators and moderators (patient, clinician, and practice characteristics) to IPHR use (aim #1) and the degree to which it impacts service delivery (aim #2).

Scope

Personal Health Records (PHRs): an Underutilized HIT Application

Health information technology (HIT) is in the national spotlight as a tool to reform healthcare, improve quality of care, coordinate care delivery, and reduce costs.[1-3] The American Recovery and Reinvestment Act placed the government in an unprecedented leadership role for directing and accelerating HIT adoption. The Act allocates $27 billion to fund clinicians and hospitals to adopt HIT, codifies and funds ($2 billion) the Office of the National Coordinator for Health Information Technology, and supports two federal advisory committees – one for HIT policy and one for HIT standards.[4-6] These committees are charged with designing a national interoperable electronic record system that permits seamless exchange of data while ensuring privacy. As a result, primary care practices have embraced the adoption of electronic health records (EHRs). In 2011, 57% of office-based physicians reported using any EHR system and 52% intended to apply for meaningful use incentives, a 26% increase from 2010.[7]

To date, the EHR has been the focus of the national HIT strategy; less attention has been given to PHRs and other tools controlled by the consumer. Incentives and penalties target clinicians and hospitals, not patients. Accordingly, a mere 2.7% of Americans have an electronic PHR, despite 79% reporting that they believe an online PHR would "provide major benefits to managing their health."[8] Yet across all transitions of health care—the primary care office, specialty office, laboratory, diagnostic center, hospital, emergency department, nursing home, and even the community—the patient is the single constant. In all of these settings, the patients, not the institutions, are the true owners of their health information. These simple facts suggest that the dissemination and use of PHRs deserves similar resource allocation and attention as EHRs have received. Such a platform not only makes design sense for creating a centralized source of information, but as a matter of ethics and informed choice, it empowers patients with information about their health, a worthy social goal.

Prevention as a Focus for PHR Development

Prevention is the ideal topic for developing PHRs and testing whether typical primary care practices and patients can use them effectively. Everyone benefits from preventive care, irrespective of age, gender, or comorbidities. Despite clear evidence that prevention markedly reduces morbidity, mortality, and health care costs,[9-12] Americans receive only half of recommended clinical preventive services.[13] According to the National Center for Health Statistics, 24% of women have not had a mammogram in the past two years, 14% of women have not had a pap smear in the past 3 years, 47% of individuals over 50 years of age have never had a colonoscopy or sigmoidoscopy, 36% of seniors have never had a pneumococcal vaccine, and 31% of seniors have not had an influenza vaccine in the past year.[14,15] Clearly, patients and clinicians need a better system for preventive care.

Through the efforts of AHRQ and the U.S. Preventive Services Task Force (USPSTF), there are well-developed, evidence-based preventive care guidelines that are amenable to clinical decision support software to prompt clinicians and interpret health information for patients.[11] The data necessary to support this logic could be used as a standard national core patient data set,

spanning demographic information, medications, immunizations, diagnoses, laboratory results, radiology results, clinician orders, and prevention procedures.

The services a person should receive depend on age, gender, and risk factors such as family history, race, and other variables. A PHR, integrated into and informed by EHR data, could provide patients the tailored advice they need.[16] Additionally, the services that a patient should receive are not straightforward and often hinge on subjective values and personal preferences. For preventive services that involve complex tradeoffs, current guidelines eschew a universal policy but recommend a process of *shared decision-making*.[17] The difficulty that both patients and providers face in implementing shared decision-making has given rise to a generation of decision aids.[18-20] A PHR could provide an easy, standardized, and automated mechanism to distribute educational material and decision aids to patients.

Beyond knowing what they should receive, patients also need logistical assistance, such as reminders. Patients benefit from reminders about the importance of healthy behaviors and the preventive services they are due to receive. They also need logistical information and assistance in knowing where to go and how to obtain such services. Health literacy and language barriers make it necessary to explain terminology and procedures in easily understood messages, and a written plan can help patients remember what they need. An integrated PHR could empower patients with greater control over information, directly providing patients with a written plan, reminders, and logistical assistance.

Interactive Preventive Healthcare Record (IPHR): a Patient-centered PHR for Prevention

With support from AHRQ (R18 HS17046-01 and RFTO #17 290-07-100113), we created an *Interactive Preventive Healthcare Record* (IPHR), which is publicly and freely available at www.mypreventivecare.org. We published the model upon which the IPHR is based in a previous *JAMA* commentary,[21] and the specifics of how the IPHR was designed and its content in a *BMC Medical Informatics and Decision Making* article.[22] An overview of how the IPHR works is also shown in Table 1, below**.**

The IPHR gives patients direct access to the personal health information stored in the electronic record of their primary care physician, displays tailored prevention recommendations, provides links to online educational resources, and generates patient and clinician reminders in a manner that is both private and secure for patients and clinicians. It addresses 18 clinical preventive services—10 screening tests: colorectal cancer, cervical cancer, breast cancer, prostate cancer, hypertension, diabetes, dyslipidemia, abdominal aortic aneurysm, Chlamydia infection, and osteoporosis; 3 immunizations: tetanus, influenza, and pneumococcal; and 5 counseling services: aspirin prophylaxis, smoking cessation, obesity, exercise, and healthy diet. All preventive services are recommended by the USPSTF, with the exception of prostate cancer screening,[11] which is included due to the high prevalence of screening and the need to promote shared decision-making tools.[23,24] Information contained within the IPHR is consistent with the USPSTF recommendations and supplemented by recommendations from the Advisory Committee on Immunization Practices (ACIP), National Cholesterol Education Program (NCEP), American Diabetes Association, and the Joint National Committee of Prevention, Detection, Evaluation, and Treatment of High Blood Pressure (JNC VII).[25-29]

Table 1. IPHR overview

The IPHR function as a highly sophisticated integrated PHR promoting patient-centered care. It performs 7 general functions:
1.   Link to patient's record: The IPHR electronically links patients to preventive elements of their medical record, showing them the status of their preventive care.
2.   Health risk assessment (HRA): The IPHR asks patients questions to update and modify clinician information and supplement information not contained in clinician records.
3.   Recommendations: The centerpiece of the IPHR is an individualized list of recommended preventive services based on risk stratification from information in #1 and #2, above.

4.   Patient education resources: From the recommendation list, patients are able to explore links and drop-down features to:
   a.   Expand their understanding of the terminology, purpose, and content of preventive health needs;
   b.   Access decision aids to help patients prepare for difficult preventive care decisions; and
   c.   Obtain advice when they are at higher risk of heart disease, cancers, or other preventable conditions.

5.   Information for clinicians: the IPHR sends a clinician summary to the patient's clinician with risk factor information, patient corrections and updates, and preventive services alerts. The summary comes directly into the clinician's EMR and is directed and flagged for the clinician, much like a lab result.
6.   Patient reminders: The IPHR sends patient e-mail reminders encouraging healthy behaviors and/or receipt of recommended services, alerting patients when they become eligible for new or repeated services, and asking patients to update their profile.
7.   Clinician reminders: clinicians received reminders through their EMR as patients become due for new or repeated services.

Entry Portal. First-time visitors to the IPHR are asked to enter their user identification number (provided by their clinician). A series of verification questions ensure that the individual establishing an account is, in fact, the patient or a patient-approved proxy user. Next, patients are asked to answer 10 (men) or 11 (women) health risk assessment questions to obtain information that is not always stored in an EHR in a consistently retrievable format (race, ethnicity, health behaviors, family history, and history of abnormal test results).

Link to Patient's Record. After completing the health risk assessment, the IPHR connects to the patient's EHR through an open database connection (ODBC) in a secure manner consistent with the Internet Engineering Task Force standards for internet information security.[30] From the EHR, 167 patient data elements that relate to preventive care – spanning demographics, vital signs, diagnoses, orders, results, management plans, medications, and immunizations – are retrieved. The IPHR shows the patient his or her information and provides an opportunity to correct or update information. Repeat IPHR users can opt at any time to "refresh" their clinical information, reestablishing an ODBC connection and updating their IPHR information from their clinician's record.

Tailored Recommendations. After reviewing their information in the clinician's EHR, the IPHR presents a list of clinical preventive services that patients should consider receiving and a list of health behaviors that they should consider changing. The list is intended to raise patient awareness about prevention and the importance of healthy behaviors. This list is generated by complex clinical decision support based on each individual user's characteristics that we programmed into the IPHR. We created the clinical decision support logic working closely with AHRQ and members of the USPSTF to ensure that the IPHR recommendations were consistent with USPSTF recommendations. Users are able to click on each recommendation and open an expanded individualized recommendation containing the sections "Your Information, "The

Basics," "The Benefits," "Your Next Steps," and "Information to Guide Your Next Steps." This content is modeled after content on the Office of Disease Prevention and Health Promotion's website www.HealthFinder.gov.[31]

Patient Education Resources. The tailored health messages include navigational features to explain medical terminology. The "Information to Guide Your Next Steps" section has hyperlinks to evidence-based web pages from federal agencies and national organizations that provide relevant patient education resources and decision aids.[18,32-41] Specific links are tailored to the individual's characteristics. All links must satisfy explicit inclusion criteria: patient-oriented, user-friendly, readable, complete, content-valid, and non-commercial.

Information for Clinicians. After a patient visits the IPHR, it sends the patient's clinician an "alert" that includes corrections and updates the patient made to the IPHR, patient's self-reported health behaviors, and a list of preventive services that appear to be overdue. This alert is intended to serve as a prompt, or reminder system, for clinicians; to reconcile inconsistencies between patients' IPHR record and the clinician's record; and to augment the encounter note and chart. All IPHR messages are sent directly into the clinician's EMR in a format similar to laboratory results, thereby ensuring a smooth actionable transfer of information.

Patient and Clinician Reminders. In addition to providing patients and clinicians immediate alerts and reminders to update overdue preventive services and improve behaviors. the IPHR provides reminders every twelve months as patients become overdue for new or repeated services.

Previous Research

Between September 2007 and March 2011, we conducted a randomized controlled trial in eight primary care practices to evaluate whether the IPHR increased the delivery of recommended preventive services to patients (R18 HS17046-01). The findings of this study were published in the *Annals of Family Medicine* and have been featured as one of AHRQ's *Success Stories*.[42,43] Of 82,000 active patients in the eight practices, 4,500 were randomly selected to receive a mailed invitation to use the IPHR or to receive usual care. We assessed the proportion of patients who were up-to-date with all indicated preventive services and the proportion of patients up-to-date with each individual preventive service using patient surveys and EHR data. Comparisons were made between invited and usual care patients and between IPHR-users and non-users among those invited to use the IPHR.

At four, 12 and 16 months, 229 (10.2%), 342 (12.4%), and 378 (16.8%) of invited patients used the IPHR. The proportion of patients up-to-date with all services increased between baseline and 16 months by 3.8% among intervention patients (from 11.4% to 15.2%, p<0.001) and by 1.5% among control patients (from 11.1% to 12.6%, p=0.07), a difference of 2.3% (p=0.05). Greater increases were observed among patients who used the IPHR. At 16 months, 25.1% of users were up-to-date with all services, double the rate among non-users. At 4 months, delivery of colorectal, breast, and cervical cancer screening increased by 19%, 15%, and 13%, respectively, among users.

This study demonstrates that patient-centered information systems such as the IPHR will increase preventive service delivery, but it remains unknown (a) whether primary care practices can adopt such systems for their entire patient population and (b) whether such systems can be disseminated to a range of primary care practices.

This study seeks to answer question (a) - whether primary care practices can adopt the IPHR for their entire practice population. It also addresses whether integrating the IPHR into care results in a greater number of patients using the IPHR then observed in the randomized control trial and whether similar benefits will be observed for the delivery of preventive services. A concurrent study (RFTO #17 290-07-100113), conducted between September 2009 and March 2012, sought to answer question (b) - whether the IPHR could be disseminated to a range of primary care practices. Collectively, the findings from the two studies were used to generate *A Handbook for Using Patient-Centered Personal Health Records to Promote Prevention.*[44]

Methods

Overview

This project was a mixed methods feasibility trial evaluating whether the eight primary care practices participating in our prior randomized controlled trial could broadly offer the IPHR to their entire patient population. Specifically, we compared whether integrating the IPHR into care enabled practices to draw more patients to use the IPHR than we achieved with a low intensity invitational mailing in the randomized controlled trial. We also examined how practices fielded the system, how patients used the system, the effect on documented preventive service delivery, factors associated with use, and maintenance of use.

A general timeline for the project is presented in Table 2, below. The first six months focused on preparing practices to field the IPHR. The next twelve months were dedicated to fielding the IPHR. The final six months were spent analyzing and beginning to disseminate our findings.

Table 2. General project timeline

Phase	Date	Study activities
Preparation	6/15/10 – 12/15/10	Updated and refined IPHR content Developed tools and resources to help practices field the IPHR Conducted 3 pre-implementation practice learning collaboratives Collected baseline EHR data Calculated baseline preventive service delivery
Fielding	12/15/10 – 12/15/2011	Practices fielded the IPHR Conducted 4 post-implementation practice learning collaboratives
Analysis	2/15/2011 – 5/31/2012	Collected post-implementation EHR and IPHR data Quantitative and qualitative analysis of outcomes Preliminary dissemination activities

Theoretical Framework for the Intervention and Analysis

We used organizational change theory to help practices create the culture change and the care delivery process change necessary to integrate the IPHR into their existing workflow through a series of learning collaboratives.[45-51] The general practice engagement process included six components: (1) establishing a sense of priority to IPHR integration into workflow, (2) forming a guiding coalition, (3) developing and communicating a shared vision, (4) empowering practices to act on their vision, (5) planning for short-term wins, and (6) consolidating improvements and institutionalizing success.[52] This approach has been successfully employed for implementing a range of practice and healthcare system changes as well as for implementing HIT in the U.S. and internationally.[52-57] In this project, the guiding coalition (step 2) was formed by establishing a learning collaborative composed of clinicians and staff from all of the practices. A staff member from the research team was trained and designated as the Learning Collaborative Coordinator to organize and lead the practices through the learning collaboratives (three leading up to go-live of the IPHR and four afterward). The Coordinator, through the learning collaboratives, catalyzed the practices to accomplish organization change components 1, 3, 4, 5, and 6, providing benchmarking, feedback, and practice facilitation. Learning collaborative details are described in greater detail below.

We used Glasgow et al.'s RE-AIM framework to evaluate our study outcomes.[58-60] The following are RE-AIM's major components. *Reach* is generally defined as the proportion and representativeness of individuals willing to participate in an intervention. *Effectiveness* is the impact of the intervention. *Adoption* is the proportion and characteristics of settings willing to initiate the intervention. *Implementation* is the extent to which the intervention is delivered as intended. *Maintenance* is the extent to which an intervention becomes institutionalized. The sampling frame for *Reach* and *Effectiveness* is the individual, for *Adoption* and *Implementation* the setting, and for *Maintenance* both the individual and setting. The details about how we used RE-AIM to define our analysis are described in greater detail below.

Setting

This study was conducted in the eight Virginia Ambulatory Care Outcomes Research Network (ACORN) practices that participated in the original randomized controlled trial.[61] The eight offices are located within a 35-mile radius of each other and care for patients in Fairfax, Loudoun, Prince William, Fauquier, and Arlington counties. The practices operate independently for clinical, staffing, and business activities but work collectively in contract negotiation, information technology assistance, human resources, and billing. Historical data exist for each practice about the IPHR enrollment rates when the system was introduced to patients by the low intensity invitational letter. All of the practices utilize a single common EHR (*Touchworks*™), stored on a central server and managed by a central information technology department. Additional HIT capabilities include electronic billing, scheduling, prescribing, secure patient messaging, and a registry with clinical reminders. The *Intuit* (previously known as *Medfusion)* patient portal provides secure messaging. It is a parallel portal to the IPHR. *CINA* is the practices' registry that prints out daily reminders of overdue care for all patients. *Intuit*, *Medfusion*, and *CINA* are all referenced in the qualitative findings of the learning collaborative.

Intervention Condition – Learning Collaboratives

Eighteen practice clinicians and staff participated in the learning collaboratives. Members included 5 clinicians, 6 nurses, 3 office managers, 2 informatics staff, and 2 front desk/reception staff. The general agenda for the seven learning collaboratives is detailed in Table 3, below.

Table 3. General Learning Collaborative (LC) timeline and agenda

Learning Collaborative	Agenda
LC #1: 4 months prior to implementation	Reviewed the function and purpose of the IPHR. Discussed the goals and role of the learning collaborative. Considered how clinicians enter data needed by the IPHR into the EHR.
LC #2: 2 months prior to implementation	Began to illustrate the practice's current workflow for preventive care and the plans for changing the workflow with the IPHR. Reviewed the practice's baseline preventive care delivery measures.
LC #3: 1 month prior to implementation	Completed the practice's workflow analysis. Developed a training program to get practice personnel prepared to implement the IPHR. Reviewed baseline data about the practice's prevention delivery.
LC #4: 1 month after implementation	Shared initial go-live experiences. Identified implementation problems and developed solutions.
LC #5: 2 months after implementation	Reviewed and discussed how well they implemented the proposed workflow revisions.
LC #6: 4 months after implementation	Shared successes and challenges with IPHR implementation. Developed strategies to overcome the challenges.
LC #7: 6 to 12 months after implementation	Developed strategies to sustain IPHR use. Decided on future directions for the IPHR and prevention delivery. Reviewed workflow and how well they implemented their proposed changes. Listed strategies for other practices to do or avoid when implementing an IPHR.

Intervention: IPHR Implementation

Once the practice sites completed their first three learning collaboratives and felt prepared to field the IPHR, the practices were asked to offer the IPHR to all of their patients ages 18-75 who present for an office visit. Throughout the IPHR fielding period (months 7-19), each practice received weekly reports about the number of new patients who had signed-up, benchmarked against the other practices. Additionally, the learning collaboratives met four times during the fielding period to review, modify, and further improve their implementation process as described in Table 3, above.

Comparison Condition

Each practice served as its own control using the historical outcomes generated from the completed randomized controlled trial when the IPHR was promoted to patients via a low-intensity invitational letter. We used historical data obtained using the same methods as this study for *Reach*, *Effectiveness*, *Implementation*, and patient-level *Maintenance*.

Data Collection

We used six data sources to address the questions in our three specific aims: EHR data, IPHR data, previously collected R18 data, a patient survey, a practice survey, and learning collaborative transcripts. Table 4, below, provides an overview of data sources and analyses for each specific aim.

Table 4. Overview of data collection methods and analysis

Aim	Data source	Analysis
Aim 1: To compare IPHR *Reach* and *Maintenance*	• *IPHR database* to measure which patients use the IPHR and when they use it • *EHR database* to measure the number of potential IPHR users • *Historical R18 data* to define the *Reach* of the low-intensity promotional letter for comparison • *Patient survey* of 640 randomly selected patients to evaluate whether patients reuse the IPHR	• Difference in *Reach* between IPHR integration and invitational mailing (Wilcoxon Signed Rank test) • Difference between *Reach* (first six intervention months) and *practice-level Maintenance* (second six intervention months) (Wilcoxon Signed Rank test) • Proportion of IPHR users who reuse the IPHR (*patient-level Maintenance*)
Aim 2: To assess IPHR *Implementation* and *Effectiveness*	• *Learning collaborative transcripts* and *patient surveys* to understand the practice and patient perspective on how the IPHR was implemented • *EHR database* to measure delivery of 18 recommended preventive services	• Description of how practices engaged patients to use the IPHR and integrated the IPHR into care • Proportion of patients who are up to date with preventive care 1, 3, and 6 months after using the IPHR versus baseline (two-sided paired t-test)
Aim 3: Mediators and moderators to IPHR use and effect	• Findings from analysis of Aim 1 and 2 • *Patient survey* of 640 randomly selected patients to assess experiences with IPHR and factors that may have influenced use • *Learning collaborative observations* to detail quantitative findings and understand IPHR integration	• Patient characteristics associated with use of the IPHR (frequency statistics) • Mediators and moderators to IPHR integration (qualitative analysis of learning collaborative transcripts)

IPHR and EHR Databases. As central data sources for this study, the IPHR and EHR databases were used to assess all three specific aims (Specific Aim #1-3). In month 19, study site IT staff transferred EHR data to the research database manager for all patients age 18 to 75 years who were seen for an office visit during the intervention period. IPHR staff transferred IPHR data for all IPHR users. Throughout the data transfer process, we used a standard data transfer protocol that allowed us to link patients across all nine data sources while maximizing the patients' privacy and confidentiality. Data elements included in both databases were patient identification number, age, gender, vital signs, diagnostic codes, medication list, immunization dates, screening test dates, test results, and provider orders. Information unique to the EHR database included who the practice defined as the patient's primary clinician, the clinician's record of the patient's health behaviors, and the clinician's report of the patient's abnormal test results. Information unique to the IPHR database included who the patient considered their primary clinician as well as the patient's reported health behaviors, family history, and abnormal test results. The EHR database captured data for all patients seen in the practices, irrespective of whether they established an IPHR account, whereas the IPHR database contained information about IPHR users only.

Historical R18 Dataset. We used the data set of 5,500 patients (2,750 intervention patients mailed an invitation to use the IPHR and 2,750 receiving usual care) from the historical R18 dataset to calculate the historical *Reach* of the promotional letter (Specific Aim # 1). The data include the same EHR and IPHR database elements collected in this study.

Patient Survey. In months 9-10 (during the *Reach* phase) and 15-16 (during the *practice-level Maintenance* phase), a total of 640 patients (320 from each time period) were mailed a patient survey. The sample was drawn from patients who presented for an office visit during the respective phases and included equal proportions of IPHR users and non-users. Patients were randomly selected, stratified by age, gender, and IPHR use status, to represent the full spectrum of potential IPHR users. For each of the survey mailings, we employed several techniques to maximize the response rate including use of a modified-Dillman mailing methodology,[62,63] mailing surveys on practice stationery and in practice envelopes, and including a $1 incentive.[64] Surveys assessed whether patients were aware of the IPHR and how they learned about it, what they liked or disliked about how practices promoted and used the IPHR, to what extent they used the IPHR, the factors that influenced use, and facilitators and barriers to both using and acting on IPHR recommendations. The surveys also assessed factors that may influence health information seeking behaviors but that are not recorded in the EHR such as education, race, ethnicity, current health information use, health information seeking status (active vs. passive), health information desires, and comfort with online privacy and data security. Survey questions were derived from existing instruments on AHRQ's *Health IT Survey Compendium*.

Learning Collaborative Transcripts. Although the learning collaboratives were part of our intervention, serving as a mechanism to operationalize organizational change theory and engage practices to create an IPHR practice implementation strategy, the discussion also served as a central data source. All learning collaboratives were audiotaped and transcribed.

Outcomes and Analytic Plan

Specific Aim #1 addresses the *Reach*, *practice-level Maintenance*, and *patient-level Maintenance* of the IPHR. We defined *Reach* as the proportion of patients, age 18 to 75 years, with an office visit during the study period who signed up for the IPHR, completed the intake process, and received IPHR prevention recommendations. The numerator was measured using the IPHR database and the denominator was measured using the EHR database. The calculated *Reach* for each of the eight study sites was compared to the historical *Reach* of the low intensity promotional letter in the randomized controlled trial using the Wilcoxon Signed Rank test.

To understand *practice-level Maintenance*, we compared the *Reach* in the first to the second six months of fielding the IPHR. Patients seen during the second six months fall into three categories: those not seen during the first six months (*non-exposed*), those seen during the first six months who used the IPHR (*users*), and those seen during the first six months who did not use the IPHR (*previously exposed non-users*). For the *practice-level Maintenance* calculation, we excluded users and included both non-exposed and previously exposed non-users.

We defined *patient-level Maintenance* as the proportion of patients who established an IPHR account and reported that they re-visited the website on the patient survey.

Specific Aim #2 addresses the *Implementation* and documented *Effectiveness* of the IPHR. We defined *Implementation* as how learning collaborative members reported using the IPHR

during the learning collaboratives and how patients reported being introduced to and using the IPHR on the patient survey.

We defined overall *Effectiveness* as (a) the average percent of up-to-date age and gender appropriate recommended preventive services covered by the IPHR and (b) the percent of patients up-to-date with all indicated preventive services. For each preventive service, we defined from the EHR data the population of patients eligible to receive each service based on USPSTF recommendations.[11] We identified the patients who visited the IPHR and the date that they visited the IPHR. We then calculated, based on EHR documentation, the proportion of patients who were up-to-date with each service and with all services on the day that they used the IPHR (baseline) and 1, 3, and 6 months after initially using the IPHR. For non-users, we used the day of their initial office visit as the baseline period. The difference in the change from baseline to the three time periods was then compared between IPHR-users and non-users using a two-sided paired t-test.

Specific Aim #3 addresses how well practices integrate the IPHR into care and the mediators and moderators that influence Specific Aim #1 and #2. This information was used to understand what strategies worked or did not work for IPHR integration, which patients were more or less likely to use the IPHR, and potential improvements that could be made to the integration process. Analysis of this aim included descriptive statistics from the patient survey and qualitative findings from analysis of the learning collaboratives.

Results

Specific Aim #1: To Measure the Utilization of the IPHR

Research Question #1a. Will a greater proportion of adult patients with an office visit complete the IPHR enrollment process and receive prevention recommendations (Reach) when the IPHR is integrated into care delivery than when the IPHR was promoted through mailed invitation letters (historical controls)?

Practices were able to get a greater proportion of patients to create an IPHR account when the IPHR was integrated into care delivery than when the IPHR was promoted through mailed invitations (18.1% vs. 12.4% of patients, p=0.008). During the one year study period, the practices were able to increase the proportion of patients who used the IPHR by 5.7% by making engaging patients to use the IPHR part of the care delivery process, compared to merely mailing patients an invitation to use the IPHR unassociated with an office visit. Additionally, the practices successfully offered the IPHR to their entire practice population (all 88,538 patients seen for an office visit during the study year) versus a subset of patients selected to receive a mailed invitation (the 2,750 patients randomly selected to receive the mailed invitation). This resulted in a total of 15,999 users at the end of the study period (Table 5, below).

Table 5. Comparison of IPHR Reach with mailed invitation vs. integrated into care

Office	Mailed invitation: Patients mailed invitation	Mailed invitation: Patients who created IPHR account	Integrated into care: Patients with an office visit	Integrated into care: Patients who created IPHR account
Practice #1	550	69 (12.6%)	21,570	4,079 (18.9%)
Practice #2	50	4 (8.0%)	4,290	697 (16.3%)
Practice #3	504	75 (14.9%)	18,407	3,242 (17.6%)
Practice #4	46	5 (10.9%)	3,980	644 (16.2%)
Practice #5	500	35 (7.0%)	9,499	1,763 (18.6%)
Practice #6	100	7 (7.0%)	5,443	696 (12.8%)
Practice #7	500	70 (14.0%)	10,009	1,759 (17.6%
Practice #8	500	77 (15.4%)	16,879	3,,456 (20.5%)
Total	**2,750**	**342 (12.4%)**	**88,538**	**15,999 (18.1%)**

The number of patients who created a new IPHR account each week during the study period for each of the study sites is presented in Figure 3, below.

Nearly 50% of patients who established an IPHR account did so after 1 office visit. Although most patients created an IPHR account after a couple of office visits, a few patients created an account after as many as 11 office visits (Figure 1). The mean number of office visits before patients established an IPHR account was 2.1. Similarly, the majority of patients who created an IPHR account did so on the day of their office visit (i.e., mode number of days to create an IPHR account was 0). The median number of days after an office visit to create an IPHR account was 7 days. A few patients even created an account 500 days after an office visit (Figure 2).

Figure 1. Number of office visits before IPHR users established an IPHR account
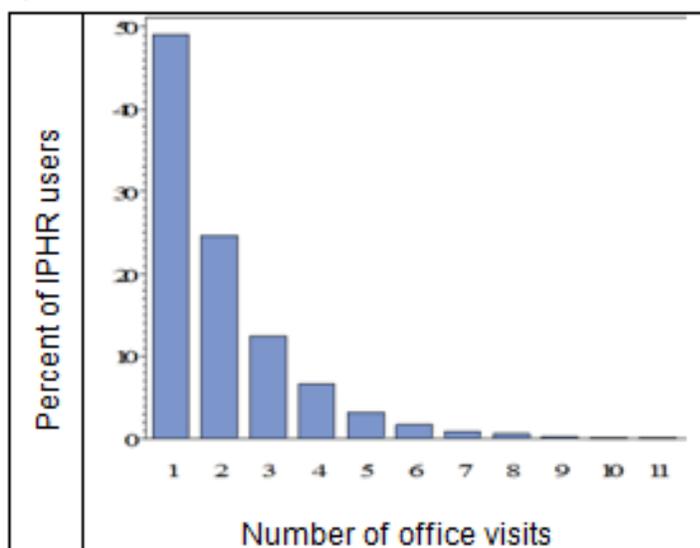
Figure 2. Number of days before an IPHR user created an account
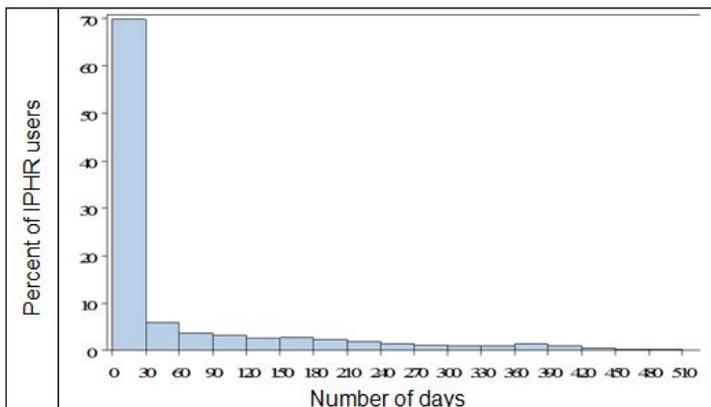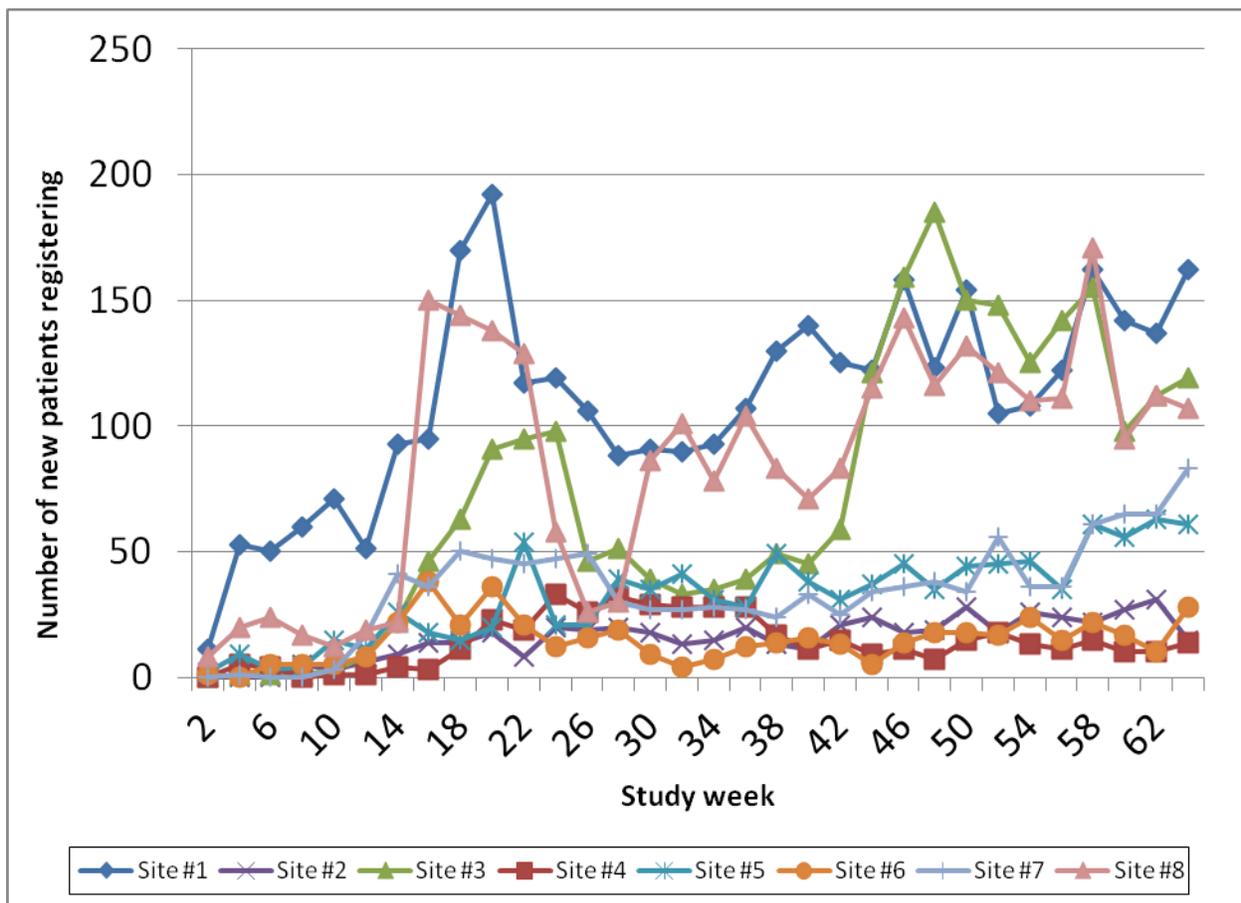

Figure 3. Number of new patients registering to use the IPHR per week per study practice

When survey respondents who did not create an IPHR account were asked the open ended question, "Please explain why you did not go to or use the IPHR," the most common answer was that they were not aware of the site (e.g., "Did not know about it." and "Never heard of the site.")

followed by a perception that the site would not be useful (e.g., "I am pretty healthy. I do not see a crisis on the horizon." and "I get information from other sources."), difficulties using the internet (e.g., "I do not own a computer." and "Poor computer skills."), and concerns about privacy online (e.g., "In general online information is misused and is hidden marketing." and "I don't want my information on the web.")

Research Question #1b. Can the IPHR enrollment rates that practices achieve during the first six months of promoting the IPHR (Reach from question #1a) be sustained through the second six months (practice-level Maintenance)?

With the exception of one, all study practices increased their Reach in the second six months of offering the IPHR. In months 1-6 of the study period, the eight study practices were able to engage 8.9% of patients seen for an office visit to create an IPHR account and use the system. In months 7-12 of the study period, overall, the eight study practices increased the Reach and engaged 11.9% of patients (who were not seen in the first six months or who had not established an IPHR account in the first six months) to create an IPHR account and use the system (Table 6, below). One practice more than doubled their Reach in the second six months (Practice #3) and only one practice had a decrease in Reach in the second six months (Practice #4).

Table 6. Comparison of IPHR Reach in the first vs. second six months of the study period

Office	Reach during months 1-6 Patients with an office visit	Reach during months 1-6 Patients who created IPHR account	Reach during months 7-12 Patients with an office visit	Reach during months 7-12 Patients who created IPHR account
Practice #1	15,035	1,536 (10.2%)	13,790	1,732 (12.6%)
Practice #2	3,009	248 (8.2%)	2,762	332 (12.0%)
Practice #3	12,950	885 (6.8%)	11,729	1,631 (13.9%)
Practice #4	2,508	259 (10.3%)	2,696	128 (4.8%)
Practice #5	6,913	503 (7.3%)	6,324	666 (10.5%)
Practice #6	3,595	224 (6.2%)	3,750	250 (6.7%)
Practice #7	7,039	605 (8.6%)	6,457	681 (10.6%
Practice #8	11,704	1,332 (11.4%)	10,601	1,443 (13.6%)
Total	**62,753**	**5,592 (8.9%)**	**58,109**	**6,863 (11.9%)**

Overall, the study sites were able to sustain patient engagement to use the IPHR and, as they learned how to better engage patients to use the system, even increased their Reach over time. Figure 4, below, depicts the "Monthly IPHR Reach" (percent of patients with an office visit who had not established an IPHR account previously and who establish an account within 90 days of the office visit) and Figure 5, below, depicts the "Cumulative IPHR Reach" (percent of patients with an office visit who either have an IPHR account established at the time of an office visit or who establish an account within 90 days of the office visit). Both the monthly and cumulative Reach increased throughout the study period.

Figure 4. Monthly IPHR Reach

Figure 5. Cumulative IPHR Reach

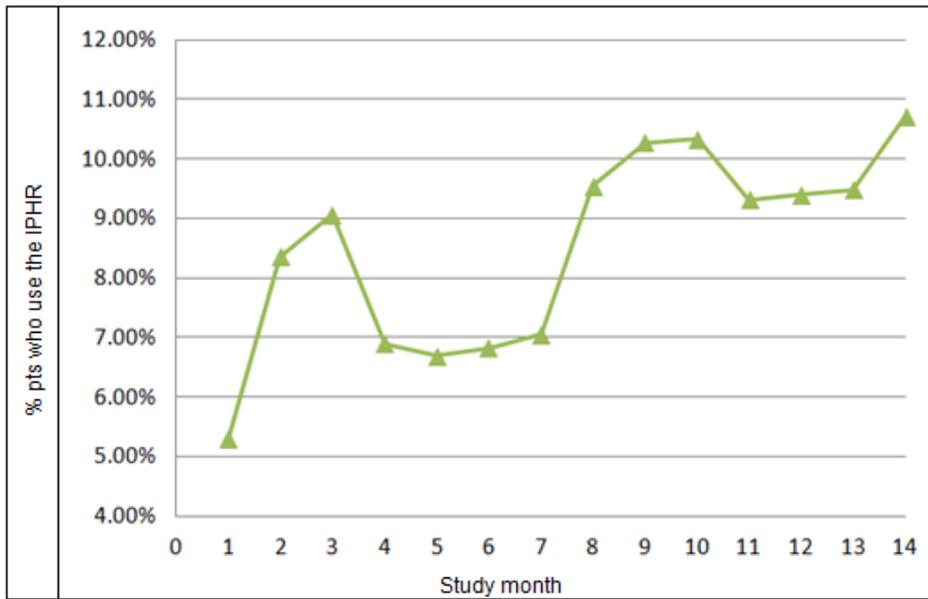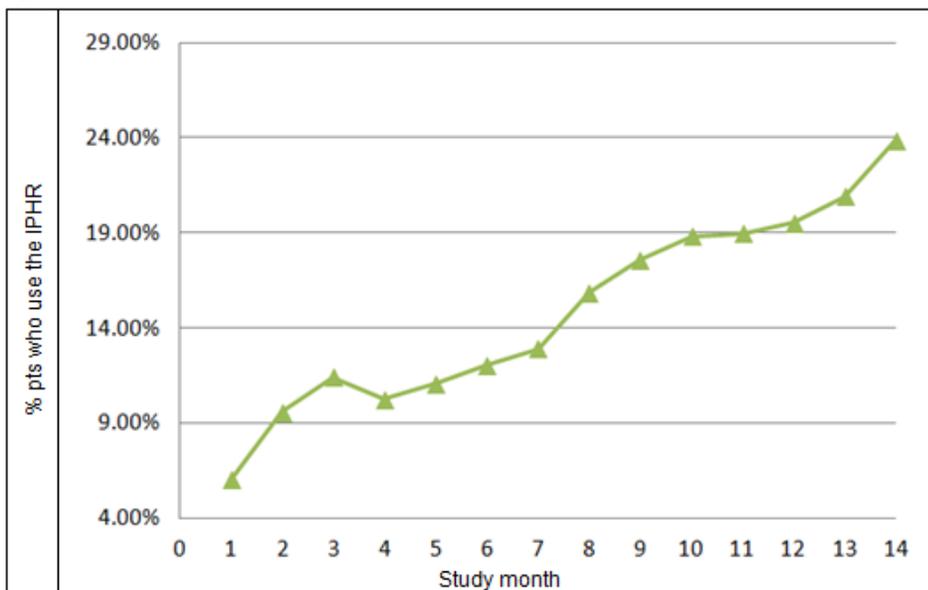**Research Question #1c.** What proportion of patients return to reuse the IPHR after initially establishing an account (patient-level Maintenance)?

Among survey respondents, 85% reported returning to use the IPHR at least once. Most commonly, respondents said that they used the site 2 times (mode use = 2.0 times and mean use = 2.7 times). One user reported using the site 12 times (Figure 6).

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Among respondents, 33% reported spending an average of 5 minutes using the IPHR and 26% reported spending an average of 10 minutes. Overall, respondents reported spending a mean of 8.9 minutes using the IPHR.

Figure 6. Number of times survey respondents reported using the IPHR
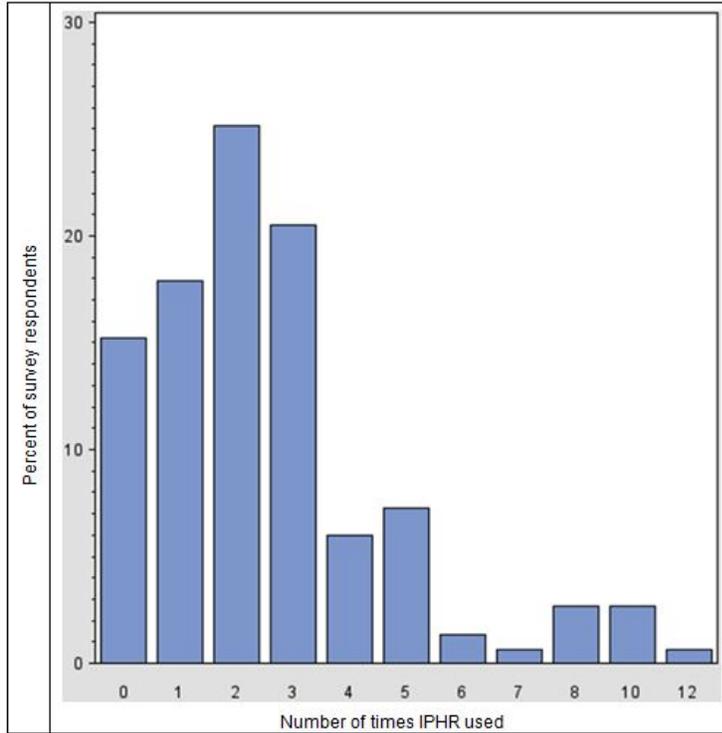
Specific Aim #2: To Assess the Implementation and Effectiveness of the IPHR on the Delivery Rate of Preventive Services

Research Question #2a. How will practices engage patients to use the IPHR and integrate the IPHR into care (Implementation)?

Practices used multiple tools, staff, and points of patient contact in order to engage patients to use the IPHR (Table 7, below). All practices used 2-4 automated tools to passively inform patients of the IPHR. All practices relied on multiple office members at multiple times to inform patients about the IPHR. Two practices had clinicians primarily inform patients of the IPHR (practices #2 and 6) and five had clinicians mainly reinforce the IPHR introduction (practices #1, 4, 5, 7, and 8). While nurses were central to engaging patients to use the IPHR in most offices, three offices did not include nurses in the workflow (practice #3, 6, 7). No practice was successful with having phone staff inform patients about the IPHR when patients called to schedule an appointment.

Table 7. How practices engaged patients to use the IPHR and integrated the IPHR into care

Table 7a. Automated tools to passively introduce the IPHR to patients

	Site 1	Site 2	Site 3	Site 4	Site 5	Site 6	Site 7	Site 8
IPHR information on practice website	AT	AT	AT	AT	AT	AT	AT	AT
IPHR information on telephone hold message	AT			AT	AT	AT	AT	AT
IPHR information on check-in kiosk	AT		AT	AT	AT			
IPHR information on waiting room posters	AT	AT	AT	AT	AT			

Table 7b. Promotional materials used to introduce the IPHR to patients

	Site 1	Site 2	Site 3	Site 4	Site 5	Site 6	Site 7	Site 8
Business cards describing the IPHR	AT	AT	AT	AT	AT	AT	AT	AT
Brochures describing the IPHR			ST					
IPHR description on health maintenance form	AT	AT	AT	AT	AT	AT	AT	AT

Table 7c. Office member charged with engaging patient to use the IPHR

	Site 1	Site 2	Site 3	Site 4	Site 5	Site 6	Site 7	Site 8
Phone staff when scheduling appointment	ST	ST		D	ST			
Front desk staff when checking-in	AT		D	AT	MT	MT	AT	AT
Nurse when rooming patient	AT		D	ST	MT			AT
Nurse when giving lab orders		ST						
Clinicians initially and/or primarily informing		AT	ST			MT		
Clinicians reinforced IPHR introduction	AT			ST	MT		ST	MT
Front desk staff when checking-out			AT					
Phlebotomists when drawing blood				AT				
Nurse when calling with results	MT	MT	AT	AT	AT	AT	AT	AT
Referral letters include IPHR material				AT	AT			

Table 7d. Office member who initially received and acted on IPHR clinical summaries

	Site 1	Site 2	Site 3	Site 4	Site 5	Site 6	Site 7	Site 8
Office unit clerks	AT				AT			AT
Designated nurse			AT	AT				
Clinician		AT				AT	AT	

Key: AT – All of the time; MT – Most of the time; ST – Some of the time, D – Discontinued after starting; N – Never started but discussed

We observed two notable increases in the number of patients creating new IPHR accounts (Appendix 1). The first increase occurred during weeks 14 - 22 and was seen mainly at practice sites #1, 3, 7, and 8. During this time period, the sites made abrupt transitions from having clinicians primarily introduce the IPHR to patients to having multiple staff members systematically introduce and reinforce the IPHR using office promotional material. The second increase occurred during weeks 42 - 50 and was seen mainly at practice sites #1, 3, 5, 6, 7, and 8. During this time period, we added new functionality to the IPHR to show patients all of their lab results, and the offices utilized the system as their primary means to inform patients of their results.

Among survey respondents who used the IPHR, the majority reported being introduced to the IPHR by their clinician, followed by the front desk staff and their clinician's nurse (Table 8, below). The importance the patients placed on the clinician promoting the IPHR is counter to our

observation that making the clinician secondary to the IPHR introduction process resulted in significant increases in new users in weeks 14 - 22. Only 22.5% of non-users reported being told about the IPHR, although 61.7% had visited the practice's website that contained a link to the IPHR, and 11.7% had even used the practice's secure email system, Intuit. When the IPHR was described to survey respondents, 67.1% reported being "very interested" or "somewhat interested" in using the system.

Table 8. How survey respondents said they heard about the IPHR

How did you hear about the IPHR	IPHR users	IPHR non-users
My clinician	57.3%	11.2%
The office's front desk	30.4%	6.1%
My clinician's nurse	20.5%	7.3%
The practice's website	11.1%	5.5%
A poster, pamphlet, or check-in card	8.2%	0%
Phone or email after a visit	2.9%	0%
Phone or email before a visit	1.8%	0%

Research Question #2b. Will patients who use the IPHR be more up-to-date with age- and gender-appropriate preventive services 1, 3, and 6 months after receiving IPHR prevention recommendations compared to baseline (Effectiveness)?

We observed increases in the average percent of up-to-date preventive services and the percent of patients up-to-date with all indicated preventive services for both the IPHR-users and the non-users. However, the IPHR-users had greater increases in the delivery of preventive services than non-users, and there was a greater increase in the number of IPHR-users who were up-to-date with all preventive services than observed in non-users at 1 month, 3 months, and 6 months (Table 9, below).

Table 9. Delivery of preventive services for IPHR-users and non-users (n=88,538)

	Avg % of up-to-date svcs.: Users	Avg % of up-to-date svcs.: Non-users	Avg % of up-to-date svcs.: Difference	Avg % of up-to-date svcs.: p value	Patients up-to-date on all indicated svcs.: Users	Patients up-to-date on all indicated svcs.: Non-users	Patients up-to-date on all indicated svcs.: Difference	Patients up-to-date on all indicated svcs.: p value
Baseline	70.6%	62.7%	N/A	N/A	29.0%	23.4%	N/A	N/A
1 Month	75.9%	65.9%	2.1%	<0.001	35.4%	26.6%	3.2%	<0.001
3 Months	76.5%	66.5%	2.0%	<0.001	35.8%	27.2%	3.8%	<0.001
6 Months	76.7%	67.1%	1.7%	<0.001	36.2%	27.7%	4.3%	<0.001

Difference = the increase from baseline of IPHR-users minus the increase from baseline of non-users [e.g., (1 month – baseline percent up-to-date services for IPHR users) – (1 month – baseline percent up-to-date services for non-users) or (75.9% – 70.6%) – (65.9% – 62.7%) = 2.1%]

While there were non-statistically significant trends in greater increases of preventive services for IPHR-users compared to non-users for all services, four services had statistically significant increases: cervical cancer screening, prostate cancer screening, cholesterol screening, and diabetes screening (Table 10, below). In our prior randomized controlled trial (R18

HS17046-01), we observed similar patterns of IPHR-users having greater overall increases in the delivery of all indicated preventive services and being more likely to be up-to-date with all services, and three individual services had greater increases for IPHR-users than non-users (colon cancer screening, breast cancer screening, and cervical cancer screening). The difference in the individual services affected in this study versus the randomized controlled trial may be a result of the difference in how the IPHR was offered to patients and integrated into care.

Table 10. Percent of IPHR users vs. non-users up-to-date with preventive services

Preventive Service	IPHR users (n= 15,999): Start	IPHR users (n= 15,999): Mo 1	IPHR users (n= 15,999): Mo 3	IPHR users (n= 15,999): Mo 6	IPHR non-users (n= 72,539): Start	IPHR non-users (n= 72,539): Mo 1	IPHR non-users (n= 72,539): Mo 3	IPHR non-users (n= 72,539): Mo 6	p value
Colon cancer screening	63.1%	67.3%	69.0%	70.0%	47.5%	50.2%	51.2%	53.6%	0.21
Cervical cancer screening*	43.9%	54.0%	54.8%	55.2%	32.9%	38.7%	39.6%	40.5%	<0.001
Breast cancer screening	66.4%	69.7%	71.6%	72.3%	51.3%	54.2%	56.2%	57.9%	0.87
Prostate cancer screening*	42.0%	72.6%	72.2%	68.3%	33.9%	52.9%	53.1%	52.2%	<0.001
Hypertension screening	99.8%	99.6%	99.8%	99.9%	99.7%	99.7%	99.7%	99.8%	N/A
Cholesterol screening*	74.6%	89.7%	90.2%	90.6%	61.0%	70.1%	71.3%	72.1%	<0.001
AAA screening	8.3%	10.9%	12.0%	10.9%	16.8%	16.9%	20.1%	21.3%	N/A
Diabetes screening*	79.8%	93.9%	94.6%	95.1%	69.1%	78.1%	79.2%	80.0%	<0.001
Osteoporosis screening	50.7%	56.8%	58.7%	59.7%	38.4%	41.3%	43.3%	59.7%	0.67
Tetanus vaccine	69.7%	70.2%	70.7%	71.0%	54.7%	55.4%	56.1%	56.9%	0.68
Influenza vaccine	31.0%	30.1%	30.1%	29.3%	20.9%	20.8%	20.7%	19.8%	0.88
Pneumonia vaccine	59.9%	60.3%	60.4%	61.0%	51.1%	51.5%	51.9%	52.4%	0.99

Specific Aim #3: To Explore Mediators and Moderators (Patient, Clinician, and Practice Characteristics) to IPHR Use (Aim #1) and the Degree to Which It Impacts Service Delivery (Aim #2)

Patients with an office visit during the study period who established an IPHR account were older and more likely to have chronic conditions than non-users (Table 11, below).

Table 11. Demographic distribution of patients seen for an office visit

	Users	Non-Users	p value
Total number of patients	15,999	72,539	N/A
Mean age (years)*	44.3	40.1	<0.001
Gender: female	55.9%	55.5%	0.43
Comorbidities: Diabetes*	7.4%	5.3%	<0.001
Comorbidities : Cancer*	3.0%	2.0%	<0.001
Comorbidities: Coronary artery disease*	2.0%	1.5%	<0.001
Comorbidities: Hyperlipidemia*	38.7%	25.1%	<0.001
Comorbidities: Hypertension*	26.4%	18.1%	<0.001

Of the 640 patients mailed a survey (320 IPHR-users, 320 non-users), 335 (52.3%) returned the completed survey. Respondents were older than non-respondents (mean age 51.2 vs 44.0 years, p<0.001) and had higher rates of cancer (6.3% vs 2.0% had colon, breast, cervical, lung, or prostate cancer, p=0.007). Gender distribution and frequency of other comorbidities were similar between respondents and non-respondents.

Among survey respondents, IPHR-users were more likely than non-users to be non-Hispanic or Asian (Table 12, below). There were no statistically significant differences between IPHR-users and non-users in age, gender, overall health, education, income, or co-morbidities. The fact that there were no differences in age or comorbidities between IPHR-users and non-users, unlike what we observed in the general patient population (Table 11, above), may have been due to the selection of our survey sample (we surveyed equal numbers of 21-39, 40-49, 50-64, and 65-75 year olds) and insufficient power. In general, survey respondents tended to be well educated and affluent, similar to the population of the region. The survey respondents also had higher rates of hyperlipidemia and hypertension than we observed in the general patient population (Table 11, above). This may have been an artifact of our sampling strategy.

Table 12. Demographic distribution of all survey respondents (n=335)

	Users	**Non-Users**	**p value**
Survey response rate	53.4%	51.3%	0.63
Mean age (years)	53.0	51.2	0.63
Gender: female	56.4%	43.6%	0.95
Ethnicity: Hispanic*	**3.0%**	**8.8%**	**0.03**
Race: White	74.9%	81.7%	0.13
Race: Black	5.3%	5.5%	0.92
Race Asian*	**14.0%**	**6.7%**	**0.03**
Rate health "excellent" or "very good"	58.8%	59.6%	0.88
Education: high school or less	7.2%	10.98%	0.23
Income: less than $60,000	16.3%	15.68%	0.89
Comorbidities: Diabetes	14.6%	6.7%	0.19
Comorbidities: Cancer	8.2%	4.3%	0.14
Comorbidities: Coronary artery disease	4.1%	3.7%	0.84
Comorbidities: Hyperlipidemia	50.9%	47.0%	0.47
Comorbidities: Hypertension	34.5%	35.4%	0.87

Overall, survey respondents commonly had health goals (most frequently improving health behaviors and staying healthy) and felt activated, confident, and comfortable with their ability to make health changes (Table 13, below). IPHR-users were more likely to express a health goal of making sure they get needed tests; using the internet for information in the past; being more interested in using the internet to make sure their information is correct, look at lab and test results, seeing clinician's instructions, emailing their clinician; and being less concerned about the cost of using technology. Other than these seven differences, IPHR-users and non-users had similar responses (Table 13, below).

Table 13. Survey responses to factors that may influence use of the IPHR (n=335)

		Users	Non-Users	p value
Health goals	Has a current health goal of: Managing a chronic illness	22.3%	17.7%	0.30
Health goals	Has a current health goal of: Making sure I take my medications	32.2%	29.9%	0.65
Health goals	**Has a current health goal of: Making sure I get the tests I need***	**36.9%**	**25%**	**0.02**
Health goals	Has a current health goal of: Eating healthier	59.7%	61.0%	0.80
Health goals	Has a current health goal of: Losing weight	56.7%	61.0%	0.42
Health goals	Has a current health goal of: Quitting smoking	3.5%	4.3%	0.72
Health goals	Has a current health goal of: Exercising more	67.3%	66.5%	0.88
Health goals	Has a current health goal of: Staying healthy	80.7%	76.2%	0.31
Activation	Plans in the next 6 months to take actions to improve your health	81.0%	79.5%	0.97
Confidence	"Very" or "somewhat" confident in managing my health	92.9%	91.4%	0.60
Comfort	"Strongly agree" or "somewhat agree" that: I know what I want to learn about health	92.2%	92.6%	0.36
Comfort	"Strongly agree" or "somewhat agree" that: I know where to get health information	90.5%	94.5%	0.70
Comfort	"Strongly agree" or "somewhat agree" that: I am satisfied with how I get information	91.1%	88.9%	0.95
Comfort	"Strongly agree" or "somewhat agree" that: I am in control of what I learn about	89.3%	90.1%	0.90
Past information seeking activities	Got "a lot" of health information in the past year from: TV	10.6%	14.8%	0.41
Past information seeking activities	Got "a lot" of health information in the past year from: Family and friends	13.0%	21.3%	0.12
Past information seeking activities	Got "a lot" of health information in the past year from: Community of church organization	1.9%	1.4%	0.93
Past information seeking activities	Got "a lot" of health information in the past year from: Newspapers or magazines	18.0%	14.5%	0.97
Past information seeking activities	Got "a lot" of health information in the past year from: Books	18.2%	10.7%	0.11
Past information seeking activities	**Got "a lot" of health information in the past year from: Internet***	**53.9%**	**46.2%**	**0.04**
Interest in using IT	Interested in using a website to: Track a chronic disease	24.0%	26.2%	0.64
Interest in using IT	Interested in using a website to: **Remind me to take prescriptions***	**7.0%**	**16.5%**	**0.007**
Interest in using IT	Interested in using a website to: Remind me when I need tests	53.2%	54.9%	0.76
Interest in using IT	Interested in using a website to: Track my diet and calories	33.9%	39.0%	0.33
Interest in using IT	Interested in using a website to: Track my exercise	33.3%	39.0%	0.28
Interest in using IT	Interested in using a website to: Stay healthy	49.7%	48.8%	0.87
Interest in using IT	**Interested in using a website to: Make sure my information is correct***	**73.9%**	**62.8%**	**0.03**
Interest in using IT	Interested in using a website to: Manage my health information	73.1%	67.7%	0.28
Interest in using IT	**Interested in using a website to: Look at lab and test results***	**83.6%**	**70.7%**	**0.005**
Interest in using IT	**Interested in using a website to: See doctor's instructions***	**69.6%**	**59.2%**	**0.05**
Interest in using IT	Interested in using a website to: Get reminders when I need care	73.1%	66.5%	0.19
Interest in using IT	Interested in using a website to: Renew a prescription	68.4%	66.5%	0.70
Interest in using IT	Interested in using a website to: Schedule a visit	73.1%	72.0%	0.81
Interest in using IT	**Interested in using a website to: Email my doctor or nurse***	**74.3%**	**64.0%**	**0.04**
Interest in using IT	Interested in using a website to: Share information with my family	25.6%	30.4%	0.32
Barriers to using IT	"Strongly agree" or "somewhat agree" with my health information being online: I worry about privacy	77.4%	82.4%	0.28
Barriers to using IT	"Strongly agree" or "somewhat agree" with my health information being online: I don't need this to manage my health	43.5%	55.5%	0.14
Barriers to using IT	"Strongly agree" or "somewhat agree" with my health information being online: I don't like using computers	8.1%	12.9%	0.19
Barriers to using IT	"Strongly agree" or "somewhat agree" with my health information being online: It would take too much time	18.2%	23.5%	0.24
Barriers to using IT	**"Strongly agree" or "somewhat agree" with my health information being online: It might cost too much***	**16.8%**	**38.0%**	**0.003**

We identified several common themes about using the IPHR from the leaning collaborative transcripts (Tables 14 and 15, below). We considered themes as "common" if a theme (1) was expressed by multiple learning collaborative participants on multiple occasions, (2) was supported by the quantitative data and site observations, and (3) was not refuted by other learning collaborative statements, quantitative data, or site observations. For some themes, learning collaborative participants made both positive and negative statements. Quotes counter to the primary themes are highlighted in bold red text.

Table 14 presents the qualitative themes we observed as practices prepared to implement the IPHR (during the pre-implementation learning collaboratives) or as practices modified their existing IPHR implementation (during the post-implementation learning collaboratives). We grouped the themes into the domains of anticipated value, concerns, and training. These domains and themes present the learning collaborative members' beliefs, fears, and preparations that explain why they wanted to use the IPHR and how they planned to use it successfully. Concerns with the system, particularly about the work involved, were a focus of all three pre-implementation learning collaboratives. In general, nurses expressed more concerns about work involved with using the IPHR, while clinicians were more likely to discuss the perceived values of the system.

Table 14. Common themes observed as practices prepared to implement the IPHR

Table 14a. Domain: anticipated value of the IPHR

Themes	Quotes
Will help staff to function at a higher level.	*"It is quite a pat on the back… I trust you to send this information to the patient"* [Nurse]
Will engage patients in their care better.	*"I think it's an easier way for providers and nurses to educate patients."* [Clinician] *"It's all about patient accountability and patient responsibility"* [Nurse]
Will improve the quality of care.	*"I have some patients who I see every 3-6 months for chronic stuff and you never thing about it [prevention]… This may be a way to get it all at once."* [Clinician]
Will support other organizational activities.	*"This just follows right into this medical home stuff."* [Office Manager]

Table 14b. Domain: concerns about the IPHR

Themes	Quotes
May create extra work.	*"The concern is that it's going to be something else I have to do."* [Nurse] *"That's all they're hearing, that it's extra work."* [Nurse Manager] **"We've been handling this information anyway. It's just a different way to handle it. It's not additional work." [Clinician]***
Patients may not like using the Internet	*"… some patients may be turned off by that. They may not want to be told to go to MyPreventiveCare to read about it."* [Nurse] *"We have patients who have a lot of trouble and are IT challenged."* [Clinician] **"Because there are so may people that are on computers now, it just makes sense." [Clinician]***
Patient provided information may not be accurate.	*"If you don't have a record of what it actually was, then you have no idea except a date that the patient told you."* [Clinician]
Increased medicolegal risk.	*"Does that become a liability for us then? Say they had an abnormal colonoscopy and never follow-up on it."* [Clinician] *"Do you think that perhaps the privacy issue comes into play?"* [Nurse]
Resources may be needed for IT support.	*"…We have had patients who have a lot of trouble and are IT challenged or computer challenged. Did we decide how we are going to handle that?"* [Clinician] *"Nobody screamed louder than my phone staff about Medfusion [a prior email system]. They saw the number of people calling for support."* [Office Manager]

Table 14c. Domain: training to prepare offices for the IPHR

Themes	Quotes
Hands on training with clinicians and staff.	*"I like the idea of going to the logon and seeing what it does for you. Then it allows you to WOW this does this for me. Then they can talk to patients."* [Office manager]
Reinforced desired behaviors.	*"And they constantly remind us. There are constant reminders."* [Nurse] *"We want to go back and spy on them and say, did they do it? You know, a way to double check and push it."* [Office Manager]
Sought buy-in from clinicians and staff.	*"It will definitely be helpful getting people to participate and how it fits into their workflow from their perspective, versus top-down."* [Clinician] *"I think we need to get more of the providers involved and the nurses involved."* [Office Manager]

Table 15, below, presents the qualitative themes we observed *after* practices implemented the IPHR. We grouped the themes into the domains of facilitators to effectively use the IPHR, barriers to effectively use the IPHR, and the impact of the IPHR on practices, clinicians, patients, and care. During the learning collaboratives, members generally agreed on the factors that facilitated or hindered use of the IPHR. As evidenced by each practice's workflow and overall Reach, some practices were more able to overcome barriers and capitalize on facilitators than others. Learning collaborative members agreed that the IPHR increased patient engagement in care, helped to advance staff roles, reduced practice workload overall, and improved documentation and delivery of preventive care. These impacts were counter to many of the concerns that learning collaborative members expressed in the pre-implementation period.

Table 15. Common themes observed after practices implement the IPHR

Table 15a. Domain: facilitators

Themes	Quotes
Practice culture amenable to change.	*"You know this is a change organization. We are constantly changing workflows and bringing out new things and ideas.*" [Clinician]
Obtained clinician buy-in and participation.	*"I really like this and I think it has a lot to offer my patients."* [Clinician] *"Provider participation makes a huge difference."* [Nurse] *"I saw a lot of physicians actively asking patients to sign in and I've seen a huge jump and that's because of that."* [Nurse]
Systematically embedded into workflow and care.	*"The front desk was doing a very good job at handing out the cards and then when the nurses were taking the patients back, they were also reminding patients."* [Office manager]

Table 15b. Domain: barriers

Themes	Quotes
Competing demands.	*"We've got a lot of staffing issues and stuff."* [Nurse] *"If they remember, because it's kind of hard with our front desk and answering phones"* [Nurse Manager]
Gun shy from prior bad IT experiences.	*"I mean, for example, Medfusion, you know everybody was promoting it. Hurray, hurray this is an awesome thing and then it fails. So the trust isn't there."* [Nurse] *"I think a lot of people stepped away from it [CINA] because they didn't want to go off of it if there were so many errors."* [Nurse]
Difficulties rethinking workflow.	*"I have a provider out there that probably, I'm not sure how they'll respond, because it kind of crimps into the way they do things and they don't want to change."* [Office Manager] *"The main thing that, even myself, I'm cautious about is the workflow itself."* [Clinician]
Inadequate training and engaging clinicians and staff.	*"So they're just not on board. So it's an educational thing and it's a training thing."* [Nurse]

Table 15c. Domain: impact

Themes	Quotes
Patient engagement increased	*"Patients are going to the website to get answers."* [Clinician] *"It's amazing the kind of questions that come from the patients. The kind of stuff that patients ask. And we're getting phone calls – so when is my mammogram due?"* [Nurse]
Staff roles changed.	*"That way, even before I get to go the room, the nurse can say oh you need a flu shot today, boom, we got that."* [Nurse] *"I would put this information right to my unit clerk and let them begin to decipher. It's not a task that needs to go to the doctor."* [Nurse]
Practice workload was reduced.	*"Patients are going to the website to get answers. Well that means they don't have to call and the front desk doesn't have to answer."* [Nurse] *"We just cut a huge chunk of workflow every day."* [Office Manager]
Improved documentation.	*"They'll actually enter the colonoscopy and the mammogram and stuff in the EMR."* [Nurse] *"This just gets better and better with how we document."* [Clinician]
Improved preventive care.	*"When the patient ends up leaving the office, a lot of time we have difficulty tracking them in terms of their glucose, their weights. We really can't keep tabs on them, but if they are using MyPreventiveCare, it will send them information."* [Nurse] *"Instead of at the end of the visit, oh yeah you need a flu shot, pneumovax, colonoscopy; it's already done kind of before, and it's all organized in one place."* [Clinician]

References

1. Chaudhry B, Wang J, Wu S, Maglione M, Mojica W, Roth E, Morton SC, Shekelle PG. Systematic review: impact of health information technology on quality, efficiency, and costs of medical care. *Ann Intern Med.* May 16 2006;144(10):742-752.

2. Shekelle PG, Morton SC, Keeler EB. Costs and benefits of health information technology. *Evid Rep Technol Assess (Full Rep).* Apr 2006(132):1-71.

3. Goldzweig CL, Towfigh A, Maglione M, Shekelle PG. Costs and benefits of health information technology: new trends from the literature. *Health Aff (Millwood).* Mar-Apr 2009;28(2):w282-293.

4. The American Recovery and Reinvestment Act of 2009. 2009; http://thomas.loc.gov/cgi-bin/query/z?c111:H.R.1:. Accessed Apr, 2012.

5. Steinbrook R. Health care and the American Recovery and Reinvestment Act. *N Engl J Med.* Mar 12 2009;360(11):1057-1060.

6. Recovery.gov. 2009; http://www.recovery.gov/. Accessed May, 2009.

7. Hsiao C-J, National Center for Health Statistics (U.S.). *Electronic health record systems and intent to apply for meaningful use incentives among office-based physician practices : United States, 2001-2011.* Hyattsville, MD: U.S. Dept. of Health and Human Services, Centers for Disease Control and Prevention, National Center for Health Statistics; 2011.

8. Connecting for Health: Americans overwhelmingly believe electronic personal health records could improve their health. 2008; http://www.connectingforhealth.com/resources/ResearchBrief-200806.pdf. Accessed May, 2009.

9. New recommendations from the United States Government on breast cancer screening. *Rev Panam Salud Publica.* Mar 2002;11(3):205-209.

10. Screening for colorectal cancer: recommendation and rationale. *Ann Intern Med.* Jul 16 2002;137(2):129-131.

11. Preventive Services. 2009; http://www.ahrq.gov/clinic/uspstfix.htm. Accessed May, 2009.

12. Dear K, Holden J, Andrews R, Tatham D. Vaccines for preventing pneumococcal infection in adults. *Cochrane Database Syst Rev.* 2003(4):CD000422.

13. McGlynn EA, Asch SM, Adams J, Keesey J, Hicks J, DeCristofaro A, Kerr EA. The quality of health care delivered to adults in the United States. *N Engl J Med.* Jun 26 2003;348(26):2635-2645.

14. Influenza and pneumococcal vaccination coverage among persons aged > or =65 years and persons aged 18-64 years with diabetes or asthma--United States, 2003. *MMWR Morb Mortal Wkly Rep.* Nov 5 2004;53(43):1007-1012.

15. BRFSS - CDC's behavioral risk factor surveillance system. 2007; www.cdc.gov/brfss. Accessed January, 2009.

16. Goldstein MG, Whitlock EP, DePue J. Multiple behavioral risk factor interventions in primary care. Summary of research evidence. *Am J Prev Med.* Aug 2004;27(2 Suppl):61-79.

17. McNutt RA. Shared medical decision making: problems, process, progress. *JAMA.* Nov 24 2004;292(20):2516-2518.

18. O'Connor AM, Stacey D, Entwistle V, Llewellyn-Thomas H, Rovner D, Holmes-Rovner M, Tait V, Tetroe J, Fiset V, Barry M, Jones J. Decision aids for people facing health treatment or screening decisions. *Cochrane Database Syst Rev.* 2003(2):CD001431.

19. O'Connor AM, Legare F, Stacey D. Risk communication in practice: the contribution of decision aids. *BMJ.* Sep 27 2003;327(7417):736-740.

20. Medline Plus: Trusted Health Information for You. 2009; http://www.nlm.nih.gov/medlineplus/. Accessed May, 2009.

21. Krist AH, Woolf SH. A vision for patient-centered health information systems. *JAMA.* 2011;305(3):300-301.

22. Krist AH, Peele E, Woolf SH, Rothemich SF, Loomis JF, Longo DR, Kuzel AJ. Designing a patient-centered personal health record to promote preventive care. *BMC Med Inform Decis Mak.* 2011;11:73.

23. Sirovich BE, Schwartz LM, Woloshin S. Screening men for prostate and colorectal cancer in the United States: does practice reflect the evidence? *Jama.* Mar 19 2003;289(11):1414-1420.

24. Woolf SH, Krist AH. The liability of giving patients choice: shared decision-making and prostate cancer. *American Family Physician; publication pending.* 2005.

25. Recommendation and Guidelines: Advisory Committee on Immunization Practices (ACIP). 2009; http://www.cdc.gov/vaccines/recs/ACIP/default.htm. Accessed May, 2009.

26. Complete Report: the Seventh Report of the Joint National Committee of Prevention, Detection, Evaluation, and Treatment of High Blood Pressure. Vol NIH Pub. No. 04-5239. Bethesda, MD: National Heart, Lung, and Blood Institute; 2004.

27. National Cholesterol Education Program. Third report of the expert panel on detection, evaluation, and treatment of high blood cholesterol in adults. Vol NIH Pub. No. 02-5215. Bethesda, MD: National Heart, Lung, and Blood Institute; 2002.

28. Grundy SM, Cleeman JI, Merz CN, Brewer HB, Jr., Clark LT, Hunninghake DB, Pasternak RC, Smith SC, Jr., Stone NJ. Implications of recent clinical trials for the National Cholesterol Education Program Adult Treatment Panel III guidelines. *Circulation.* Jul 13 2004;110(2):227-239.

29. American Diabetes Association (ADA). Standards of medical care in diabetes. II. Testing for pre-diabetes and diabetes in asymptomatic patients. *Diabetes care.* Jan 2008;31(Suppl 1):S13-14.

30. The Internet Engineering Task Force. 2007; http://www.ietf.org/. Accessed January, 2007.

31. HealthFinder.gov. 2009; http://healthfinder.gov/. Accessed May, 2009.

32. O'Connor AM, Stacey D, Rovner D, Holmes-Rovner M, Tetroe J, Llewellyn-Thomas H, Entwistle V, Rostom A, Fiset V, Barry M, Jones J. Decision aids for people facing health treatment or screening decisions. *Cochrane Database Syst Rev.* 2001(3):CD001431.

33. Patient Decision Aids. [Website]. 1996-2004; http://204.187.39.28/cochsearch.php?orderby=Top_descr+ASC&all=on. Accessed May, 2004.

34. Krist AH, Woolf SH. Should You Get a PSA Test? A Patient-Doctor Decision. 2002; http://www.acorn.fap.vcu.edu/psa/. Accessed March, 2005.

35. Medline Plus: Trusted Health Information for You. 2004; http://www.nlm.nih.gov/medlineplus/. Accessed May 2004, 2004.

36. Cancer Home. 2005; http://www.cdc.gov/cancer/index.htm. Accessed March 2005, 2005.

37. Health Information. 2005; http://www.nia.nih.gov/HealthInformation/. Accessed March 2005, 2005.

38. Cancer Topics. 2005; http://www.nci.nih.gov/cancertopics. Accessed March 2005, 2005.

39. NIH Senior Health. 2005; http://nihseniorhealth.gov/. Accessed March 2005, 2005.

40. Learn About Cancer. 2005; http://www.cancer.org/docroot/LRN/LRN_0.asp. Accessed March 2005, 2005.

41. Healthy Lifestyle. 2005; http://www.americanheart.org/presenter.jhtml?identifier=1200009. Accessed March 2005, 2005.

42. Krist AH, Woolf SH, Rothemich SF, Johnson RE, Peele JE, Cunningham TD, Longo DR, Bello GA, Matzke GR. Interactive preventive health record to enhance delivery of recommended care: a randomized trial. *Ann Fam Med.* Jul 2012;10(4):312-319.

43. Krist AH. Success stories from the AHRQ-funded health IT portfolio (2010). Patients take a bite of prevention apple with web-based interactive personal health records. 2011; http://healthit.ahrq.gov/portal/server.pt/document/955335/krist_success_story_final_7_29_2011_pdf. Accessed July, 2012.

44. Department of Family Medicine. Virginia Commonwealth University. A How-To Guide for Using Patient-Centered Personal Health Records to Promote Prevention. 2012; http://healthit.ahrq.gov/KRIST-IPHR-Guide-0612.pdf Accessed June, 2012.

45. Glanz K, Lewis FM, Rimer B. *Health Behavior and Health Education*. 2nd ed. San Francisco: Jossey-Bass; 1997.

46. Glanz K, Rimer BK. Theory at a Glance. A Guide for Health Promotion Practice. 2005; 2nd:http://www.cancer.gov/PDF/481f5d53-63df-41bc-bfaf-5aa48ee1da4d/TAAG3.pdf. Accessed May, 2009.

47. Porras JI, Robertson PJ. Organization Development Theory: A Typology and Evaluation. In: Woodman RW, Passmore WA, eds. *Research in Organizational Change and Development*. Greenwich, CN: JAI Press; 1987.

48. Fischer LR, Solberg LI, Kottke TE. Quality improvement in primary care clinics. *Jt Comm J Qual Improv.* Jul 1998;24(7):361-370.

49. Solberg LI. Improving medical practice: a conceptual framework. *Ann Fam Med.* May-Jun 2007;5(3):251-256.

50. Koeck C. Time for organisational development in healthcare organisations. Improving quality for patients means changing the organisation. *Bmj.* Nov 7 1998;317(7168):1267-1268.

51. Senge PM. *The Fifth Discipline: The Art & Practice of the Learning Organization*. New York, NY: Currency Doubleday; 1990.

52. Kotter J. Winning at change. Leader to Leader, 10, 27-33. 1999; http://leadertoleader.org/leaderbooks/L2L/fall98/kotter.html. Accessed May, 2009.

53. Feifer C, Ornstein SM, Jenkins RG, Wessell A, Corley ST, Nemeth LS, Roylance L, Nietert PJ, Liszka H. The logic behind a multimethod intervention to improve adherence to clinical practice guidelines in a nationwide network of primary care practices. *Eval Health Prof.* Mar 2006;29(1):65-88.

54. Ovretveit J, Scott T, Rundall TG, Shortell SM, Brommels M. Implementation of electronic medical records in hospitals: two case studies. *Health Policy.* Dec 2007;84(2-3):181-190.

55. Borkan JM. Mixed methods studies: a foundation for primary care research. *Ann Fam Med.* Jan-Feb 2004;2(1):4-6.

56. Creswell JW, Fetters MD, Ivankova NV. Designing a mixed methods study in primary care. *Ann Fam Med.* Jan-Feb 2004;2(1):7-12.

57. Scott JT, Rundall TG, Vogt TM, Hsu J. Kaiser Permanente's experience of implementing an electronic medical record: a qualitative study. *Bmj.* Dec 3 2005;331(7528):1313-1316.

58. Glasgow RE, Vogt TM, Boles SM. Evaluating the public health impact of health promotion interventions: the RE-AIM framework. *Am J Public Health.* Sep 1999;89(9):1322-1327.

59. Glasgow RE, Bull SS, Gillette C, Klesges LM, Dzewaltowski DA. Behavior change intervention research in healthcare settings: a review of recent reports with emphasis on external validity. *Am J Prev Med.* Jul 2002;23(1):62-69.

60. Reach Effectiveness Adoption Implementation Maintenance (RE-AIM). 2012; http://re-aim.org/. Accessed August, 2012.

61. Virginia Ambulatory Outcomes Research Network. www.acorn.fap.vcu.edu. Accessed Dec, 2006.

62. Dillman D. *Mail and Internet Surveys: The Total Design Method*. 2nd ed. Hoboken NJ: John Wiley and Sons; 1999.

63. Dillman DA. *Mail and Internet Surveys: The Tailored Design Method*. 2nd ed. Hoboken NJ: John Wiley Company; 1999.

64. Edwards P, Roberts I, Clarke M, DiGuiseppi C, Pratap S, Wentz R, Kwan I. Increasing response rates to postal questionnaires: systematic review. *BMJ.* May 18 2002;324(7347):1183.

List of Publications and Products

Publications: Reporting the Findings from this Study (5R21HS018811-02)

There are currently no publications focused on the findings from this study. We are working on a key publication to report what we learned about factors that influence the Reach of PHRs such as the IPHR.

Combined Publications: Reporting Aggregate Information from Three Studies Involving the IPHR (5R21 HS018811-02, RFTO #17 290-07-100113, and R18HS17046-03)[21,22]

Krist AH, Woolf SH. A vision for patient-centered health information systems. *JAMA*. 2011;305(3):300-301.

Krist AH, Peele E, Woolf SH, Rothemich SF, Loomis JF, Longo DR, Kuzel AJ. Designing a patient-centered personal health record to promote preventive care. *BMC Med Inform Decis Mak.* 2011;11:73.

Presentations: Reporting the Findings from this Study (5R21HS018811-02)

Krist AH, Woolf SH, Longo DR, Rothemich SF, Kuzel A, Johnson RE, Peele JE, Kerns JW. Integrating a Preventive Personal Health Record into Primary Care Practice Workflow. 39th *Annual Meeting of the North American Primary Research Group*. Banff, Alberta, Canada. Nov 15, 2011.

Combined Presentations: Reporting Aggregate Information from Three Studies Involving the IPHR (5R21HS018811-02, RFTO #17 290-07-100113, and R18HS17046-03)

Krist AH. Patient Centered Health Information Technology to Promote Prevention. *OCHIN Executive Strategic Oversight Council*. Portland OR. May 2, 2012.

Krist AH, Estabrooks P, Glasgow R, Hesse B. Identifying, Assessing, and Acting Upon Common Behavioral and Psychosocial Data Elements within Electronic Records. *33rd Annual Meeting and Scientific Sessions.* Society of Behavioral Medicine. New Orleans LA. April 12, 2012.

Krist AH. Patient-centered health information technology to promote prevention. *Public Health Seminar.* Virginia Commonwealth University. Richmond, VA. March 8, 2012.

Krist AH, Nemeth L. Patient-centered HIT to promote prevention. *Preventive Medicine 2012*. American College of Preventive Medicine. Orlando FL. February 25, 2012.

Krist AH, Rothemich S, Kashiri P, Longo D, Mitchell S, Johnson RE, Peele E, Loomis J. Facilitators and barriers to integrating a personal health record for prevention into primary care practices. *AHRQ National Research PBRN Conference*. Agency for Healthcare Research and Quality. Bethesda MD. June 22, 2011.

Krist AH. Patient centered health information technology to promote prevention. *Grand Rounds.* Georgetown University. Washington DC. June 3, 2011.

Awards and Recognition

1) The IPHR was selected as a finalist for the *2012 Health Information Technology Innovation Award* from the Virginia Chamber of Commerce, http://www.virginiahealthcareinnovators.org.

2) We were asked to present the IPHR and participate in a two-day workshop, *Advancing Prevention: Knowledge Gaps and New Partnerships*, at the National Institute of Health, sponsored by the Office of Behavioral and Social Sciences Research on June 28-29, 2012. The purpose of the meeting was to bring together key federal agencies to define a future agenda for funding prevention research.

3) From 2010-2012, the IPHR has been a recognized *Physician Quality Reporting System* (PQRS) *registry* for the Centers for Medicare and Medicaid Services (CMS). The IPHR is one of the only four reporting registries that collect data from multiple EHRs.