

## ***Grant Final Report***

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# **An Interactive Preventive Health Record (IPHR) to Promote Patient-Centered Preventive Care**

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# Abstract

**Purpose:** To test whether an *interactive preventive health record* (IPHR), a highly personalized online resource for patients, increases the delivery of recommended preventive services.

**Scope:** The IPHR is a personal health record that was created and tested with the goal of making preventive information actionable for patients. The IPHR gives patients direct access to information in their clinician's electronic record (EMR), displays tailored recommendations, provides links to online educational resources, delivers individualized self-management resources, and generates patient and clinician reminders.

**Methods:** Randomized controlled trial involving 5,500 patients invited to use the IPHR or receive usual care in eight primary care practices. Outcomes were assessed using data from the practices' EMR and patient surveys.

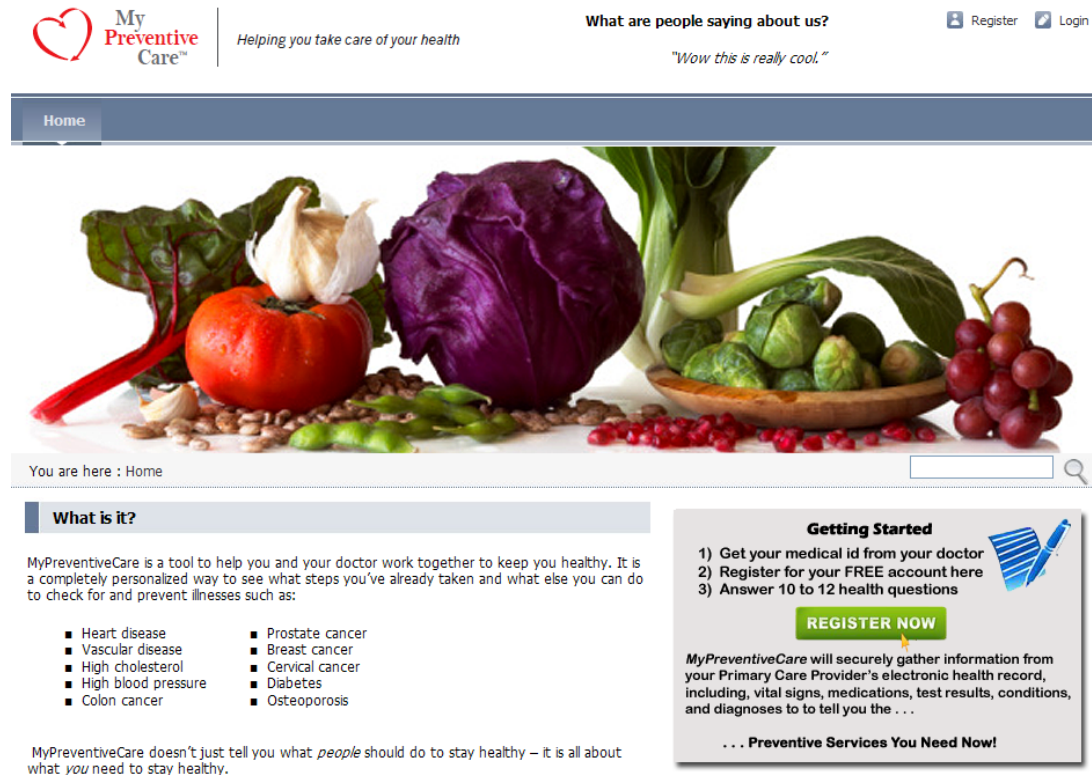
**Results:** At four and 16 months, respectively, 281 (10.2%) and 445 (16.2%) patients who were mailed an invitation, used the IPHR and received prevention recommendations. Although the intention-to-treat analysis, which compared patients who were and were not mailed invitations, revealed no significant difference in outcomes, over 4 months the timely receipt of recommended preventive services increased among intervention patients (from 62.9% to 64.4%,  $p=0.016$ ), whereas controls experienced no improvement (from 62.5% to 63.4%,  $p=0.122$ ). The largest increase was observed among intervention patients who used the IPHR (from 68.2% to 73.8%,  $p<0.001$ ). In this subgroup, receipt of colorectal, breast, and cervical cancer screening and of pneumococcal vaccination increased by 12.3-16.1%. Increased care delivery persisted 16 months after the original invitations were mailed. Similar increases were not observed in the control or non-user groups.

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

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# Final Report

Figure 1.



## Purpose

To create an interactive preventive health record (IPHR), called *MyPreventiveCare*, and test whether inviting patients to use the system would improve health habits and increase the delivery of screening tests, immunizations, and chemoprophylaxis recommended by the U.S. Preventive Services Task Forces (USPSTF). The IPHR would function as a highly personalized patient-centered health information tool.<sup>1</sup> Accordingly, it would help patients and clinicians by increasing knowledge, promoting patient-clinician communication and shared decision making, delivering self management resources, and providing reminders, all at the point of care and integrated into existing workflows. Four specific aims were evaluated. Specifically, the study evaluated whether a simple mailed invitation from a patient's primary care clinician to use the IPHR versus usual delivery of preventive care resulted in the following outcomes for adult patients:

1. Use of the IPHR;
2. Increased delivery of age and gender appropriate clinical preventive services;

3. Increased shared decision-making for preventive services; and
4. Improved clinician-patient communication about preventive needs.

## Scope

### Background

Americans receive only half of recommended preventive care,<sup>2</sup> resulting in up to 100,000 avertable deaths annually.<sup>3</sup> Patients need basic information about how to promote their health and prevent disease, tailored to their specific needs and delivered in understandable and actionable language.<sup>4</sup> Which services an individual patient should receive is dependent on a host of personal factors such as age, gender, comorbidities, prior testing, prior service delivery, family history, medication usage, and health behaviors. Easy access to comprehensive and accurate patient information is often lacking. Even if patient information is available, deciding which services a patient needs can be difficult, as some recommendations hinge on subjective values and personal preferences. Tools such as personalized decision aids are needed to foster better decisions.<sup>5-7</sup> To ensure follow-through and delivery of preventive services, patients and clinicians require logistical assistance, written plans, and reminder systems.<sup>8,9</sup>

For their part, clinicians and health systems face impediments to delivering and educating patients about recommended preventive services.<sup>10</sup> Busy clinical encounters leave little time to systematically collect patient information or provide education for patients who lack understanding of the topics.<sup>11</sup> The enthusiasm of clinicians for health promotion is often dampened by the widespread perception that reimbursement for their time is inadequate.<sup>12</sup> In busy practices, implementing shared decision-making as recommended in current guidelines is challenging because access to decision aids is limited and using them takes time and preparation.

Advances in health information technology, more specifically patient personal health records (PHRs) integrated into clinician electronic medical records (EMRs), have great potential to improve the delivery of care. Sharing with patients their health information in their clinician's EMR, and allowing patients to supplement and update their information, cultivates shared knowledge between clinicians and patients. Clinical decision support logic to assess patient's preventive needs, based on the latest evidence-based guidelines, can be added to integrated PHR-EMRs. This logic can generate personalized lists of recommended services, patient advice, evidence-based resource libraries and decision aids, relevant community resources, logistical details, and reminder systems for patients and clinicians. By automating the identification of preventive needs and initiating patient education outside of a clinical encounter, such an approach would not only leverage precious clinician-patient interaction time but elevate the patient's understanding of preventive needs prior to encounters. Collectively, such an approach could engage patients, promote collaborative care, facilitate shared decision-making, and comprehensively provide a multifaceted, integrated, systems approach to the delivery of preventive care.<sup>13-15</sup>

However, to date PHRs are much less personalized and sophisticated than described above. Only 17% to 24% of ambulatory clinicians use an EMR,<sup>16-19</sup> and less than 2.7% of Americans have an electronic PHR.<sup>20</sup> Further, many PHRs are not integrated into EMRs. The few PHRs

that are integrated into EMRs often show patients their clinical information in medical terms, failing to interpret information or use patient-centered language. The PHRs that make preventive recommendations tend to use simple age- and gender-based logic, ignoring the full range of patient information required. Given these shortcomings, there is limited evidence to demonstrate that using a PHR, in any form, improves patient outcomes.<sup>21</sup>

## Context

We sought to create and test whether a highly functional, prevention focused PHR, which we call an interactive preventive health record (IPHR), would improve the delivery of preventive services. An overview of the key functions of the IPHR is shown in Figure 1, *below*. The IPHR gives patients direct access to their physician's EMR, displays tailored prevention recommendations, provides individually selected links to online educational and community resources, delivers tailored self management resources, and generates patient and clinician reminders. Currently, it addresses 18 clinical preventive services and their related chronic conditions – 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. IPHR content is consistent with the U.S. Preventive Services Task Force recommendations<sup>22</sup> and supplemented by recommendations from the Joint National Committee on Prevention, Detection, Evaluation and Treatment of High Blood Pressure (JNC VII),<sup>23, 24</sup> the National Cholesterol Education Program (NCEP-ATP III),<sup>25, 26</sup> the American Diabetes Association (ADA),<sup>27</sup> the American Cancer Society,<sup>28-30</sup> the American Heart Association,<sup>31</sup> and the Advisory Committee on Immunization Practices (ACIP).<sup>32</sup>

Figure 1. IPHR overview

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| <p>The IPHR functions as a highly sophisticated integrated PHR promoting patient-centered care. It performs 7 general functions:</p> <ol style="list-style-type: none"> <li>1. <i>Link to patient's record:</i> The IPHR electronically links patients to elements of their medical record.</li> <li>2. <i>Health risk assessment (HRA):</i> The IPHR asks patients questions to update and modify clinician information and supplement information not contained in clinician records.</li> <li>3. <i>Recommendations:</i> The centerpiece of the IPHR is an individualized list of recommended preventive and chronic care needs based on risk stratification from information in #1 and #2, above.</li> <li>4. <i>Patient self management resources:</i> Patients are able to explore individually tailored resources, links, and aids to:             <ol style="list-style-type: none"> <li>a. Expand their understanding of the terminology, purpose, and content of health needs;</li> <li>b. Access decision aids to help patients prepare for difficult care decisions;</li> <li>c. Obtain advice when they are at higher risk of heart disease, cancers, or other preventable conditions; and</li> <li>d. Explore community resources to assist in health behavior change.</li> </ol> </li> <li>5. <i>Information for clinicians:</i> the IPHR sends a <i>clinician summary</i> to the patient's clinician with risk factor information, patient corrections and updates, and services alerts. The summary comes directly into the clinician's EMR and is directed and flagged for the clinician, much like a lab result.</li> <li>6. <i>Patient reminders:</i> 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.</li> <li>7. <i>Clinician reminders:</i> clinicians received reminders through their EMR as patients become due for new or repeated services.</li> </ol> |
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## Methods

### Study Design

We conducted a randomized controlled trial involving 5,500 patients randomly selected from the study practices' patient population. Intervention patients received a postal invitation to visit the IPHR, while control patients received “usual” preventive care. Outcomes assessed included the delivery of preventive care as well as specific domains of patient-centered care. Outcomes were assessed from two separate patient postal-surveys, EMR data queries, automated reports from the IPHR about system use, and patient and clinician focus groups. To limit survey length and ensure adequate response rates, we selected two separate cohorts of study participants for outcomes measurement. We mailed each cohort a different postal survey (the *Preventive Services Survey* or the *CAHPS Survey*) at baseline, 4-months, and 16-months post initial invitation to use the IPHR. For the intention-to-treat analysis, we conducted a pre-post cohort analysis of outcomes, comparing the change from baseline to 4 and 16 months for the intervention and control groups. Patient and practice perspectives about IPHR implementation were assessed by qualitative analysis of focus groups. A brief timeline is presented in Figure 2, below.

**Figure 2. Study timeline**

Year	2007		2008						2009						2010						2011	
Month	9	11	1	3	5	7	9	11	1	3	5	7	9	11	1	3	5	7	9	11	1	3
Study sample selected																						
IPHR programming																						
Invitation to visit IPHR																						
Surveys mailed																						
EMR data collected																						
Pt/MD focus groups																						
Data analysis																						
Dissemination activities																						

### Settings

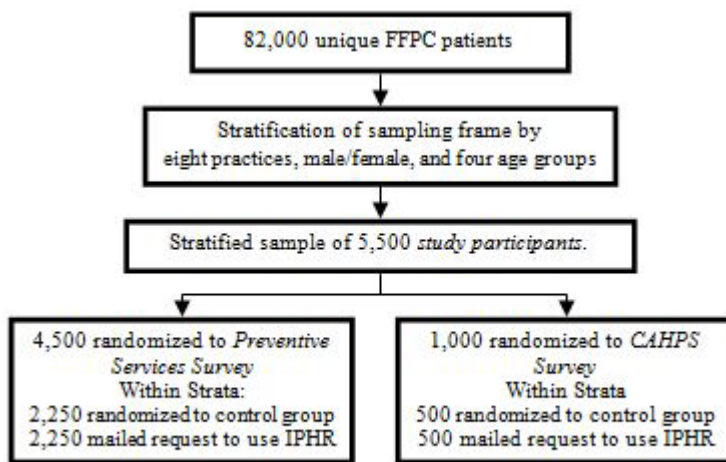
Eight primary care practices located in northern Virginia that are part of the Virginia Ambulatory Care Outcomes Research Network (ACORN) were recruited to participate in creating and testing the IPHR. The study practices shared a common EMR since 2004 (Allscripts Enterprise©), managed by a central informatics staff.<sup>33</sup> Each practice operated independently for clinical activities and had a unique practice culture. Practice size ranged from 2 to 35 clinicians (median = 7.5). Two sites had 2 clinicians; five sites had 4, 6, 9, 10, and 12 clinicians, respectively; and one site (a family medicine residency program) had 35 part-time clinicians and residents.



## Participants

Of the 82,000 active patients at the study sites, 5,500 were randomly selected for study participation (see Figure 3, *right*). Active patients were defined as all patients who had an office visit in the year prior to recruitment. Selected patients were stratified equally by practice site, gender, and age category (18-34, 35-49, 50-64, and 65-75 years). The age categories and gender stratifications were selected to ensure that the study population would require the full range of preventive services addressed by the IPHR. The sample was then randomly assigned by strata to intervention (n=2,750) and control (n=2,750) groups and substrata to receive one of two different surveys for outcomes assessment.

**Figure 3. Sampling frame, stratified sample, and randomization**



The overall characteristics of the study population were very similar to the characteristics of the patients seen by the study practices (see Table 2, *below*). Patients were predominantly college educated (65% - 68%) and white (79% - 82%). There were fewer Hispanic (126 vs. 660), African American (124 vs. 715), and Asian (193 vs. 550) patients in our study sample than we projected in our proposal based on local census data. The control and intervention groups were similar with respect to age, gender, race, ethnicity, education, comorbidities, and internet use.

## Data Sources/Collection

Three data sources were used to measure quantitative outcomes: patient-administered surveys, IPHR data, and EMR data. The IPHR data was used to measure system use. The *Preventive Services Survey* and EMR data were used to measure whether patients were up-to-date on clinical preventive services. Survey data elements included when preventive services were delivered, family history, health behaviors, height and weight, race/ethnicity, education, and household income. Survey questions were used from or modeled after the Behavioral Risk Factor Surveillance System or the National Health Interview Survey. EMR data elements included all

values and dates for age, gender, diagnoses, medications, vital signs, smoking history, immunizations, laboratory results, and radiology tests. Information that was poorly or inconsistently recorded in the EMR, such as family history, health behaviors, and race/ethnicity, was not included.

The patient *CAHPS* survey was used to measure the patient's care experience. The survey contained 35 core CAHPS Clinician & Group Survey questions, 3 shared decision-making questions, 1 health improvement question, and 6 health promotion and education questions.

Intervention and control patients were mailed the *Preventive Services* or *CAHPS* survey in March 2007 (baseline), March 2008 (4-months post-intervention), and March 2009 (16-months post-intervention). Surveys were mailed using a modified Dillman technique and included a \$1 incentive.

We conducted five, 2-hour focus groups with 28 patients – three focus groups with IPHR users (n=14) and two with non-users, defined as patients who were invited to use the IPHR but did not (n=14). A one-hour focus group was also conducted with four clinicians and three nurses from the study sites. All focus groups were guided by a list of semi-structured questions to understand experiences with and perceptions about the IPHR and the internet in general. The sessions were recorded and transcribed. Field notes were also taken during focus groups to capture participant body language and tone as well as researcher thoughts and reactions.

## Intervention

Patients randomized to the intervention group received a mailed letter from their clinician, asking them to use the IPHR. The letter described the IPHR, related to the patient how it could improve their health, and provided a patient identification number for establishing an account. Intervention patients received up to three invitational letters until they established an IPHR account. Letters were printed on practice stationery, mailed in a practice envelope, and signed by the lead clinician from the patient's practice. In response to feedback from non-users that the invitational letter did not clearly explain the IPHR, we engaged communications experts at AHRQ to create a more effective patient informational brochure. This brochure was included in the third and final invitational mailing.

Patients randomized to the control group received "usual" preventive care. The study sites did not have a systematic approach to delivering preventive care. The clinicians and nurses were familiar with and endorsed USPSTF recommendations. However, care delivery relied entirely on the clinician to be proactive in reviewing records to determine if a patient was overdue for a service or on the patient to request a specific preventive service or a wellness examination.

## Measures

**Aim #1: Use of the IPHR.** For this intervention to be effective, patients must visit the IPHR, establish an account, and use the information in a manner that promotes patient and clinician activation. We therefore assessed the proportion of patients invited to use the IPHR (predefined sample for intention-to-treat analysis) who went on to visit the system, establish an account, and receive prevention recommendations (from the IPHR database).

**Aim #2: Delivery of Preventive Services.** Nolan and Berwick summarize three approaches to analyzing performance delivery measures: item-by-item measurement, composite



measurement, and “all-or-none” measurement.<sup>34</sup> A priori, we elected to use all three approaches. For the composite and the all-or-none variable, we selected ten preventive services that were covered by the IPHR and identified by the National Commission on Prevention Priorities (NCCP) as having the greatest potential to save quality-adjusted life years by optimizing delivery to Americans.<sup>35</sup> These included tobacco counseling, colorectal cancer screening, influenza vaccination, breast cancer screening, cervical cancer screening, *Chlamydia* screening, pneumococcal vaccination, cholesterol screening, hypertension screening, and aspirin chemoprophylaxis. Accordingly, our primary outcome measures for delivery of preventive care were the proportion of age and gender indicated preventive services (denominator) that were up-to-date (numerator) (*composite measurement*), the proportion of patients who were up-to-date on all age- and gender- appropriate preventive services (all-or-none approach), and the proportion of patients who were current for each of the individual preventive services (item-by-item approach). Our study was powered to detect differences in the first two variables, not the item-by-item approach.

EMR and survey responses were combined for each patient. In some cases, the two sources provided discrepant data on the same preventive services; these were reconciled by assuming the most recent service delivery date was correct. A preventive service with missing values was classified as not up-to-date. At baseline, 4-months, and 16-months post-intervention, we determined the percentage of all eligible patients who were up-to-date for each individual preventive service, the composite measure, and the all-or-none measure. We then calculated the incremental change between baseline and 4-months and baseline and 16-months (pre-post comparison). For the intention-to-treat analysis, we calculated the difference in the incremental changes between the control and intervention groups for the two time periods. A separate analysis was done further subdividing the intervention group into users and non-users (post hoc analysis). In all calculations, percentages were adjusted for patient age and gender, practice site, and patient response to the pre- and post-intervention survey. Practice site was not included in the adjustment for services that had a small sample size. To assess significance, we used a two-sample, one-sided McNemar test.<sup>36</sup>

**Aim #3: Shared Decision-Making.** We used the patient responses to CAHPS questions #SD1-3 to evaluate the impact of the IPHR on shared decision-making (SDM). Each question was scored as 1=“Yes” and 0=“No” and a composite score, the summed response values, was calculated. Pre-post differences in the composite scores were contrasted between intervention and control patients as well as between IPHR-users and IPHR-non-users; statistical significance was assessed using a two-sample, one-sided t-test.

**Aim #4: Clinician-Patient Communication.** We used the patient responses to CAHPS questions #14, 15, and 17-20 to evaluate the impact of the IPHR on clinician-patient communication. Each question was scored as 1=“never,” 2=“almost never,” 3=“sometimes,” 4=“usually,” 5=“almost always,” and 6=“always.” The composite score included the proportion responding never, sometimes, usually, or always. Pre-post differences in the composite scores were compared between intervention and control patients as well as between IPHR-users and non-users.

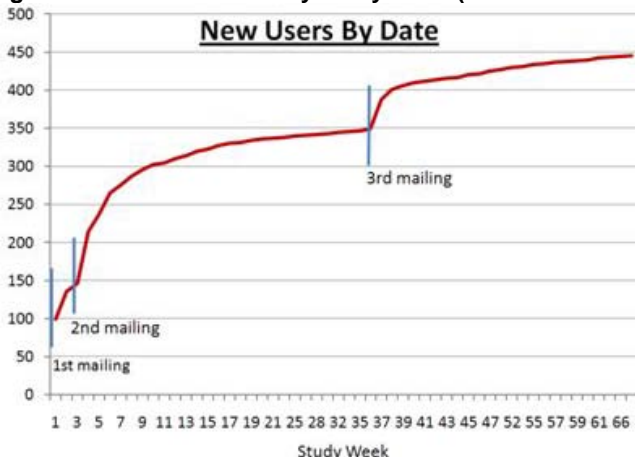
# Results

## IPHR Development

The first year of this project was devoted to creating, programming, and implementing the IPHR. We began by using the USPSTF recommendations to create the programming logic for generating patient recommendations. Three challenges quickly became apparent. First, while the focus of the IPHR was preventive care, many users would have related chronic conditions. Rather than have the IPHR fail to provide these patients with pertinent recommendations, we decided to incorporate key guidelines to address these needs as well.<sup>23-32</sup> Second, the USPSTF recommendations often lacked sufficient specificity to accommodate our need for precise heuristic logic. For example, recommendations might state that the test should be repeated “every 1 to 2 years” or “the optimal interval for screening is uncertain.” These recommendations, while evidence-based, would not allow the program to specify whether a service was or was not up-to-date. The IPHR addressed this by including messages that explained screening interval uncertainty to patients, and we referred to other guidelines when the USPSTF made ambiguous interval recommendations. We also met with AHRQ staff to discuss the issue and to encourage the USPSTF to work toward greater specificity in recommendations. Third, incorporating additional guidelines into our logic exposed discrepancies between recommendations. While we gave precedence to USPSTF recommendations, we incorporated guideline disagreements into our recommendations to inform patients of the discrepancies, and we made decision aids available on the IPHR.

We then integrated the IPHR into the study sites’ EMR (Allscripts *Enterprise*<sup>TM</sup>) to give the IPHR access to the clinical data needed to make clinical recommendations. We initially explored the possibility of using an existing patient information exchange for the EMR integration, but we quickly discovered that the exchanges available in *Enterprise* (e.g., Continuity of Care Document [CCD]) did not include all of the data elements required for measuring preventive care. Our solution was to connect the IPHR directly to the study sites’ EMR via an ODBC connection and to map the *Enterprise*<sup>TM</sup> database to identify the key patient variables the IPHR required.

**Figure 4. New IPHR users by study week (intervention cohort n=2750)**



During the IPHR development process, we identified 148 patient variables that proved essential for the program logic to generate personalized recommendations on the 18 preventive services. These variables were extracted from 167 places within the *Enterprise* EMR. We discovered that some variables were not stored in the EMR in a meaningful, reliable or adequately detailed manner, due to the EMR configuration and the inconsistencies with which the practices used the EMR. These variables included health behaviors, race and ethnicity, family history, and radiology or pathology abnormalities. We therefore chose to ask patients directly instead of relying on the EMR. We designed a 10-12 question health risk assessment that addressed these variables, completed by patients when establishing an IPHR account. The final version of the IPHR was capable of generating 573 different patient recommendations, with detailed personalized messages for each of them. The messages used modified language from the Office of Disease Prevention and Health Promotion's website, [HealthFinder.gov](http://HealthFinder.gov).<sup>37</sup> Patient comprehension and anticipated responses to content were evaluated in three phases of usability tests with 24 patients; content was modified in response to each phase of patient feedback.

## Use of the IPHR (Aim #1)

Control and intervention patient had similar demographic characteristics. Over a 66-week period after being mailed an initial invitation to visit the IPHR, 445 (16.2%) of the 2,750 intervention patients logged onto the system, established an account, and received preventive care recommendations (defined as *users*) (see Figure 4, above). Non-users were similar to the control group for all measured variables. However, compared to non-users, IPHR users were older (mean age 55.9 vs. 49.5 yrs,  $p<0.001$ ) and more likely to be male (56% vs. 49%,  $p=0.06$ ), non-Hispanic (98% vs. 94%,  $p=0.06$ ), and college educated (70% vs. 63%,  $p=0.1$ ) (Table 1, below). IPHR-users also had more comorbidities and were more likely to be daily internet users (88% vs. 72%,  $p<0.001$ ) than non-users.

**Table 1. Characteristics of intervention and control patients for the preventive services cohort (n=4500)**

Characteristic	Control Population (N = 2250)	Intervention Population: Overall (N = 2250)	Intervention Population: Non-Users (N = 1877)	Intervention Population: Users (N = 373)
Age: 18-34 years	446 (20%)	444 (20%)	365 (19%)	20 (5%)
Age: 35-49 years	675 (30%)	677 (30%)	562 (30%)	87 (23%)
Age: 50-64 years	676 (30%)	676 (30%)	564 (30%)	159 (43%)
Age: 65+ years	453 (20%)	453 (20%)	386 (21%)	107 (29%)
Gender: Male	1125 (50%)	1126 (50%)	919 (49%)	207 (55.5%)
Gender: Female	1125 (50%)	1124 (50%)	958 (51%)	166 (44.5%)
Race: White	937 (82%)	905 (79%)	624 (81%)	240 (84%)
Race: African American	51 (4%)	73 (6%)	43 (6%)	16 (6%)
Race: Asian	94 (8%)	99 (9%)	67 (9%)	20 (7%)
Race: Other	43 (4%)	35 (3%)	25 (3%)	7 (2%)
Race: Unknown	23 (2%)	27 (2%)	14 (1%)	2 (1%)
Hispanic ethnicity: Hispanic	65 (6%)	61 (5%)	49 (6%)	7 (2%)
Hispanic ethnicity: Non-Hispanic	1083 (94%)	1078 (95%)	724 (94%)	278 (98%)
Education: College or higher	777 (68%)	735 (65%)	487 (63%)	200 (70%)
Education: Less than college	371 (32%)	404 (35%)	286 (37%)	85 (30%)

**Table 1. Characteristics of intervention and control patients for the preventive services cohort (n=4500) (continued)**

Characteristic	Control Population (N = 2250)	Intervention Population: Overall (N = 2250)	Intervention Population: Non-Users (N = 1877)	Intervention Population: Users (N = 373)
Comorbidities: Diabetes	208 (9%)	192 (9%)	167 (9%)	41 (11%)
Comorbidities: Cancer	68 (3%)	75 (3%)	52 (3%)	21 (6%)
Comorbidities: Coronary artery disease	96 (4%)	98 (4%)	84 (5%)	24 (6%)
Comorbidities: Hyperlipidemia	733 (33%)	696 (31%)	546 (29%)	150 (40%)
Comorbidities: Hypertension	646 (29%)	634 (28%)	557 (30%)	156 (42%)
Use internet at least once per day <sup>†</sup>	868 (76%)	839 (74%)	557 (72%)	250 (88%)

Note – Study sample included the 4,500 patients administered the preventive services survey (see Figure 2)

## Delivery of Preventive Services (Aim #2)

Tables 2 and 3, below, present data for the proportion of preventive services that were up-to-date at baseline and at 4 and 16 months after the initial mailing. All values were adjusted except those displayed in italics, which could not be adjusted due to inadequate sample sizes. Bold font represents a decrease in service delivery and underlined, an increase.

**Table 2. Percentage of up-to-date preventive services at baseline and 4 months post-intervention**

**Table 2a. Overall delivery of indicated preventive services**

	Ctrl. Pop (n= 2250)	Ctrl. Pop (n= 2250)	Ctrl. Pop (n= 2250)	Interv. Pop Overall (n= 2250)	Interv. Pop Overall (n= 2250)	Interv. Pop Overall (n= 2250)	Interv. Pop Non-Users (n= 1969)	Interv. Pop Non-Users (n= 1969)	Interv. Pop Non-Users (n= 1969)	Interv. Pop Users (n= 281)	Interv. Pop Users (n= 281)	Interv. Pop Users (n= 281)
Indicated Preventive Services	Base-Line	4 mo	p-value	Base-Line	4 mo	p-value	Base-line	4 mo	p-value	Base-line	4 mo	p-value
Percentage of up to date services (composite measure)	62.5%	63.4%	0.122	<u>62.9%</u>	<u>64.4%</u>	<u>0.016</u>	62.3%	63.2%	0.203	<u>68.2%</u>	<u>73.8%</u>	<u>&lt;0.001</u>
Patients up to date on all indicated services (all or none measure)	20.3%	20.9%	0.579	20.4%	22.4%	0.070	19.8%	21.5%	0.138	23.4%	27.0%	0.301

**Table 2b. Delivery of specific preventive services**

	Ctrl. Pop  (n=2250)	Ctrl. Pop  (n=2250)	Ctrl. Pop  (n=2250)	Interv. Pop Overall (n=2250)	Interv. Pop Overall (n=2250)	Interv. Pop Overall (n=2250)	Interv. Pop Non-Users (n=1969)	Interv. Pop Non-Users (n=1969)	Interv. Pop Non-Users (n=1969)	Interv. Pop Users (n=281)	Interv. Pop Users (n=281)	Interv. Pop Users (n=281)
Indicated Preventive Services	Base-Line	4 mo	p-value	Base-Line	4 mo	p-value	Base-line	4 mo	p-value	Base-line	4 mo	p-value
Colorectal cancer screening	36.7%	42.1%	0.036	36.2%	44.6%	0.001	38.5%	44.1%	0.054	57.4%	75.3%	0.004
Breast cancer screening	48.1%	56.2%	0.052	50.8%	55.9%	0.209	54.1%	55.7%	0.699	70.9%	88.6%	0.035
Cervical cancer screening	68.8%	73.0%	0.130	69.3%	71.3%	0.432	70.1%	70.7%	0.802	79.2%	92.8%	0.022
Prostate cancer screening	54.2%	44.0%	<0.001	51.9%	49.5%	0.473	49.6%	48.17%	0.669	72.3%	66.7%	0.416
Hypertension screening	99.9%	97.7%	<0.001	100.0%	98.2%	<0.001	100%	98.2%	<0.001	100%	99.6%	0.318
Hypercholesterolemia screening	84.1%	87.2%	0.012	80.0%	82.4%	0.102	80.7%	82.8%	0.152	90.3%	92.9%	0.382
Abd. aortic aneurysm screening	24.0%	22.7%	0.766	24.6%	23.7%	0.850	25.9%	20.1%	0.264	20.0%	35.9%	0.128
Diabetes screening	76.6%	81.4%	0.043	69.7%	79.3%	<0.001	74.6%	82.5%	0.001	75.4%	93.4%	0.036
Chlamydia screening	21.1%	10.2%	0.103	17.8%	10.0%	0.212	18.2%	11.7%	0.358	--	--	--
Osteoporosis screening	37.8%	40.0%	0.738	43.6%	49.9%	0.371	45.8%	49.0%	0.663	72.1%	92.7%	0.275
Aspirin chemoprophylaxis use	38.2%	44.7%	0.174	61.0%	56.8%	0.372	60.3%	55.2%	0.320	64.7%	65.7%	0.931
Tetanus immunization	45.7%	51.1%	0.002	47.1%	53.5%	<0.001	51.0%	56.3%	0.004	60.1%	71.3%	0.019
Influenza immunization	30.6%	28.5%	0.325	29.0%	29.5%	0.798	32.8%	32.5%	0.903	58.3%	61.3%	0.550
Pneumococcal immunization	24.0%	29.5%	0.029	20.0%	28.1%	<0.001	22.0%	29.4%	0.006	62.8%	78.3%	0.052
Smoking cessation counseling	79.4%	81.7%	0.698	67.1%	75.4%	0.323	69.4%	74.9%	0.515	70.0%	72.7%	0.897
Dietary counseling	15.5%	17.9%	0.136	15.8%	17.6%	0.258	15.9%	18.0%	0.236	14.1%	14.4%	0.927
Exercise counseling	17.0%	14.7%	0.128	19.8%	21.1%	0.457	18.2%	19.3%	0.526	20.8%	23.3%	0.551
Weight loss counseling	55.7%	57.3%	0.688	44.6%	42.0%	0.522	56.3%	52.2%	0.369	47.7%	48.0%	0.975
Body mass index < 30 kg/m2	70.5%	69.8%	0.644	73.6%	73.7%	0.979	72.8%	72.7%	0.923	71.3%	72.4%	0.758

**Table 3. Percentage of up-to-date preventive services at baseline and 16 months post-intervention**

**Table 3a. Overall delivery of indicated preventive services**

	Ctrl. Pop  (n=2250)	Ctrl. Pop  (n=2250)	Ctrl. Pop  (n=2250)	Interv. Pop Overall (n=2250)	Interv. Pop Overall (n=2250)	Interv. Pop Overall (n=2250)	Interv. Pop Non-Users (n=1877)	Interv. Pop Non-Users (n=1877)	Interv. Pop Non-Users (n=1877)	Interv. Pop Users (n=373)	Interv. Pop Users (n=373)	Interv. Pop Users (n=373)
Indicated Preventive Services	Base-Line	16 mo	p-value	Base-Line	16 mo	p-value	Base-line	16 mo	p-value	Base-line	16 mo	p-value
Percentage of up to date services (composite measure)	62.6%	60.3%	<0.001	63%	61.9%	0.08	62.4%	60.2%	0.002	67.7%	72.2%	<0.001
Patients up to date on all indicated services (all or none measure)	20%	21.3%	0.2	20.4%	24.3%	<0.001	20.0%	22.0%	0.06	21.4%	33.8%	0.001

**Table 3b. Delivery of specific preventive services**

Indicated Preventive Services	Ctrl. Pop (n=2250) Base-Line	Ctrl. Pop (n=2250) 16 mo	Ctrl. Pop (n=2250) p-value	Interv. Pop Overall (n=2250) Base-Line	Interv. Pop Overall (n=2250) 16 mo	Interv. Pop Overall (n=2250) p-value	Interv. Pop Non-Users (n=1877) Base-line	Interv. Pop Non-Users (n=1877) 16 mo	Interv. Pop Non-Users (n=1877) p-value	Interv. Pop Users (n=373) Base-line	Interv. Pop Users (n=373) 16 mo	Interv. Pop Users (n=373) p-value
Colorectal cancer screening	39.8%	47.2%	<0.001	35.6%	45.5%	<0.001	39.6%	46.5%	0.019	56.7%	75.9%	<0.001
Breast cancer screening	44%	26.2%	<0.001	52.4%	31.8%	<0.001	53.6%	33.0%	<0.001	77.6%	63.8%	0.265
Cervical cancer screening	71.3%	72.5%	0.67	72.4%	73%	0.8	70.5%	69.9%	0.823	84.3%	95.1%	0.015
Prostate cancer screening	59.6%	51.9%	0.02	51.1%	52.4%	0.7	46.5%	51.4%	0.176	74%	63.1%	0.080
Hypertension screening	99.9%	93.5%	<0.001	99.9%	94.2%	<0.001	99.9%	93.6%	<0.001	100%	96.5%	<0.001
Hypercholesterolemia screening	83.9%	86.8%	0.03	80.4%	85.1%	0.001	79.3%	84.2%	0.001	92.6%	94.7%	0.327
Abd. aortic aneurysm screening	24%	25.3%	0.8	24.6%	25.4%	0.9	28.0%	22.2%	0.295	16%	33.3%	0.053
Diabetes screening	78.8%	83.3%	0.03	74.9%	85.1%	<0.001	77.0%	85.9%	<0.001	90.7%	97.2%	0.012
Chlamydia screening	21.1%	21.7%	0.9	17.8%	21.3%	0.6	20.4%	27.7%	0.450	--	--	--
Osteoporosis screening	46.2%	54.7%	0.2	38%	52.1%	0.06	37.9%	51.4%	0.073	77.4%	97.6%	0.388
Aspirin chemoprophylaxis use	37.9%	43.6%	0.23	61%	57.6%	0.5	62.0%	55.7%	0.229	60.0%	65.9%	0.597
Tetanus immunization	46%	50.4%	0.01	46.8%	53.7%	<0.001	51.2%	56.1%	0.010	57.7%	73.3%	0.003
Influenza immunization	33.1%	29.7%	0.1	42.7%	42.4%	0.9	37.1%	38.9%	0.4	56.6%	61.6%	0.250
Pneumococcal immunization	23.7%	32.6%	0.001	20.7%	35.6%	<0.001	23.1%	36.7%	<0.001	69.3%	86.0%	0.002
Smoking cessation counseling	79.4%	73.2%	0.3	66%	69.8%	0.6	69.0%	77.7%	0.308	71.4%	55.6%	0.4
Dietary counseling	14.2%	14%	0.9	14.4%	15.8%	0.4	15.7%	17.7%	0.269	12.5%	12.4%	0.962
Exercise counseling	17.9%	17.3%	0.7	19.5%	19%	0.8	18.2%	17.9%	0.904	20.0%	19.1%	0.790
Weight loss counseling	58%	54.8%	0.4	44.2%	40.2%	0.3	56.2%	50.0%	0.182	47.7%	47.0%	0.923
Body mass index < 30 kg/m2	70.6%	70.4%	0.9	73.2%	74.1%	0.5	72.7%	73.7%	0.499	70.8%	70.9%	0.982

Over 4 months (Table 2, above), the proportion of indicated preventive services that were received by eligible patients (composite measure) increased by 1.5% among patients in the intervention group (from 62.9% to 64.4%,  $p=0.016$ ) but changed little, by 0.9%, among controls (from 62.5% to 63.4%,  $p=0.122$ ). The 0.6% difference in the magnitude of this change – the intention-to-treat analysis, which compared patients who were and were not invited to use the IPHR – was statistically insignificant ( $p=0.524$ ). However, among patients who used the IPHR, larger and statistically significant changes were observed. Among users, the proportion of indicated preventive services received by eligible patients increased by 5.6% (from 68.2% to 73.8%,  $p<0.001$ ), whereas non-users experienced an insignificant increase (from 62.3% to 63.2%,  $p=0.203$ ), a net difference of 4.7% ( $p=0.004$ ).

Over 16 months (Table 3, above), the proportion of eligible preventive services that were up-to-date declined in both the control group (from 62.6% to 60.3%,  $p<0.001$ ) and the non-user subset of the intervention population (from 62.4% to 60.2%,  $p=0.002$ ) but increased among

IPHR users (from 67.7% to 72.2%,  $P<0.001$ ). The proportion of patients who were up-to-date with all 18 preventive services (all-or-none measure) did not change significantly over the 4 months or differ significantly between groups, in either the intention-to-treat analysis or the comparison of users and non-users. At 16 months, however, the proportion of patients who were up-to-date with all preventive services was higher among intervention patients (including both users and non-users) than among controls, but the net increase among intervention patients was demonstrably greater (10.2%,  $p<0.001$ ) among users than non-users.

Changes were observed in the proportion of patients who were up-to-date with specific preventive services at 4 and 16 months, with salutary changes observed in both the intervention and control groups (Table 2 and 3). Although the magnitude of change for any specific preventive service did not differ significantly in the intention-to-treat comparison, the net improvement in some services was striking when IPHR users were compared with non-users. For example, the proportion of women who were up-to-date with breast cancer screening over 4 months increased by 17.7% among IPHR users (from 70.9% to 88.6%,  $p=0.035$ ) but by only 1.6% (from 54.1% to 55.7%,  $p=0.699$ ) among non-users, a net difference of 16.1% ( $p=0.025$ ). The net change in rates for colorectal and cervical cancer screening differed by 12.3% between users and non-users ( $p=0.011$  and  $p=0.047$ , respectively). When baseline rates were compared with screening rates at 16 months, similar net increases were observed for colorectal (12.3%,  $p=0.008$ ) and cervical (11.4%,  $p=0.04$ ) cancer screening but the increase in breast cancer screening lacked statistical significance (6.8%,  $p=0.700$ ).

## **Impact on Delivery of Care (Aim #2)**

The primary care practices received a summary from the IPHR on all patients who used the system. The summary was transmitted electronically to the EMR task list for the patient's self identified primary provider. A chart review and content analysis of these summaries revealed that only 2.2% of users were up-to-date for all preventive and chronic care services covered by the IPHR. Among users, 49% and 56% were due for screening tests and vaccinations, respectively; 91% and 55% needed health behavior counseling and preventive medications, respectively; and 35% had inadequate control of chronic conditions. These alerts led clinicians to update the EMR records of 59% of patients to fill in missing information that patients had entered into the IPHR. With few exceptions, clinicians accepted the patient's reported updates and changes as accurate. Additionally, after receiving the summaries from the IPHR, the study practices contacted 27% of patients to schedule a wellness visit, 17% to schedule a chronic care visit, and 19% to deliver a specific service (e.g., mail a referral for a mammogram or colonoscopy, arrange a nurse visit for an immunization).

## **Patient Care Experience (Aim #3 and Aim #4)**

Answers to the CAHPS questions revealed no measurable differences in patient-clinician communication or shared decision-making in either the intention-to-treat or user versus non-user comparisons. Compared to baseline, the SDM composite score was 1.4% higher for intervention patients at 4-months and 16-months than for controls, but the difference was not statistically significant ( $p=0.66$  and  $0.89$ , respectively). Similarly, there was a non-significant net difference of 3.4% ( $p=0.120$ ) between intervention and control patients reporting "almost always" or



“always” to the patient-centered composite score at baseline and 4-months. Between baseline and 16-months, the net difference remained non-significant (4.9%,  $p=0.720$ ).

## Qualitative Findings

Twenty-eight patients participated in the focus groups - 18 were women, and 26 were non-Hispanic. All participants rated their health as good or very good. The participants reported making a mean of 3.5 office visits in the preceding year, and they ranked their clinician highly (mean of 9.1) on a 10-point scale. The focus groups revealed that trust and functionality were the two major themes that influenced whether they would use a health website and the value they obtained from doing so. Trust included whether they believed (1) that the information on the website was accurate and (2) that the security and confidentiality of their personal information would be protected. Functionality included whether the patient expected a website would be useful, the anticipated benefits of using a website, and the potential challenges with using a health website. The degree to which trust and functionality (and their subthemes) mattered to patients was dependent on the relationship of their clinician to the website. For example, several participants noted that all information on the Internet is vulnerable, but they seemed willing “*to take a leap of faith*” with their personal health information and use a website if it had the imprimatur of their personal clinician.

Both users and non-users believed that the IPHR was beneficial for their care. Users viewed the IPHR as a resource for both patients and clinicians to have access to crucial health information. Users particularly liked that the offices contacted them in response to the IPHR summaries. Also useful was the personalized advice provided by the IPHR: “[*The IPHR*] talked about the number of pounds to get into the next category... That personalization, and goal, that was helpful.” Users also liked the individually tailored self management resources: “[*The IPHR*] offers sites to quickly get the information that I needed.” The majority of non-users, once shown screen shots of the IPHR, reported that they expected the IPHR to be helpful and would likely use the system; many reported not having done so because they “*just hadn’t gotten around to it.*” Non-users did not express any greater concerns about security and privacy with the IPHR than did users. Several participants felt that going to the IPHR before an office visit would be particularly helpful.

## Limitations

The key limitation of our study is that the patient population does not include a high proportion of individuals with low education or income, nor does it represent a typical American population with respect to Internet access and computer literacy. Rather, the patients from our northern Virginia study sites represent an “ideal” population for evaluating the impact and effect of the IPHR. Future studies will need to be conducted in populations with lower socioeconomic status, greater proportions of racial and ethnic minorities, and lower Internet access to establish generalizability of findings and to test content and tools designed for cultural sensitivity, language barriers, and health literacy.

## Discussion

**Conclusions.** We did not observe a benefit from the IPHR in our intention-to-treat analysis, which compared outcomes among patients who did and did not receive a mailed invitation to use the IPHR. This null result may say more about the limitations of mailed invitations in promoting the technology than about the effectiveness of the tool itself, especially given the encouraging trends we observed among patients who used the IPHR. When compared with non-users, users experienced statistically significant increases in the percent of services that were up-to-date and the percent of patients who were up-to-date with all indicated services. The large (12-16%) increases in the delivery of individual services (breast, colorectal, and cervical cancer screening; diabetes screening; and tetanus and pneumococcal immunizations) among users of the IPHR carries important public health implications. Increases were observed at 4-months and in some cases were still significant 16-months after patients received the original invitation to use the IPHR.

Attention to confounding variables is important, but a causal effect from the IPHR is suggested by observations in the control and non-user groups, where increases in the currentness of preventive services were not as consistent and of lower magnitude than with users. In fact, 16 months after being invited to use the IPHR, both control patients and non-users were less up-to-date with preventive services, while users were up-to-date on 4.5% more services. Supporting the benefit of the IPHR is the 12% to 16% increase in the delivery of some preventive services for users, which is particularly compelling given the high baseline rate of screening. Our process evaluation, including both chart reviews and focus groups, adds to our understanding of how the IPHR impacted care. As both patients and clinicians used the IPHR, we observed the dual effect of patients seeking out preventive services and clinicians proactively engaging patients to receive care outside of clinical encounters.

One explanation for the intention-to-treat analysis' null result is that the absolute number of IPHR users (n=445) provided inadequate statistical power to effect a change for the entire intervention population (n=2750). When conducting the power analysis for the study, we assumed that 50% of patients who were mailed an invitation would create an IPHR account based on pilot work that we conducted in 2004. In that project, we offered patients a prototype of the IPHR prior to a wellness visit and 78% used the system. However, in the current study, IPHR invitations were not linked to an office visit, for a wellness examination or otherwise. Furthermore, practices did not integrate the IPHR into daily clinical activities and few of the practice's patients were included in our study and invited to use the IPHR (3.4%). The study sample was composed of randomly selected "active" patients, defined as having been to the practice in the past year. In our focus groups with non-users, many participants reported that they did not think the IPHR was intended for them, because they had recently been to the office, or they planned to use the IPHR at a future date prior to an office visit. Indeed, a substantial number of participants created IPHR accounts months, or even a full year, after their initial invitation. Furthermore, several key studies suggest that our observed IPHR use rate of 16.2% was probably more realistic for a simple mailed invitation than the 50% rate we projected,<sup>38, 39</sup> but those studies were not available when we designed our study.

Motivating patients to use a PHR like the IPHR requires practices to make significant changes – changes that can only be achieved by integrating the system into daily activities for a substantial proportion of patients. To understand the value and relevance of a PHR to their care, patients need to be informed about the tool, how it works, and why it is important for them. This

is best explained over multiple contacts and reinforced by all healthcare team members. Practices need a wide range of resources and media (e.g. exam room posters, website links, informational handouts) to inform patients of the new system. To further enhance patient use of the PHR, practices need to use the system in a manner that makes it easier for patients to accomplish desired tasks such as preparing for an office visit or healthcare decision, learning about laboratory results, or accessing self management tools to improve health. These types of practice integrations can only occur through modified workflows and routine use of the PHR. Whether primary care practices can encourage patients to use the IPHR by integrating it into routine care and the influence the integration has on healthcare delivery is the subject of a future study to be conducted within our research network.

**Figure 6. A model for the functions of patient-centered health information systems**

LEVEL	FUNCTIONALITY
1	Collect patient information, such as self-reported demographic and risk factor information (health behaviors, symptoms, diagnoses, and medications)
2	Integrate patient information with clinical information through links to the electronic medical record and/or claims data
3	Interpret clinical information for the patient by translating clinical findings into lay language and delivering health information via a user-friendly interface
4	Provide individualized clinical recommendations to the patient, such as screening reminders, based on the patient's risk profile and on evidence-based guidelines
5	Facilitate informed patient action integrated with primary and specialty care through the provision of vetted health information resources, decision aids, risk calculators, personalized motivational messages, and logistical support for appointments and follow-up

**Significance.** The compelling evidence of the effectiveness of USPSTF-recommended preventive services suggests that the increased delivery we observed among IPHR-users would help prevent significant morbidity and mortality, making this technology an important tool for

public health. Among users of the IPHR, we observed increases in four preventive services that the National Commission on Prevention Priorities identified as having the greatest potential for saving quality-adjusted life years if delivery were optimized.<sup>35</sup>

The development of the IPHR helped us make technological advances in understanding the architecture of PHRs and EMRs, and the inherent challenges the health information technology movement—including industry and relevant governmental initiatives—must confront to create tools that are truly patient-centered. The project helped us clarify a new vision for patient-centered health information technology, which we described in a recent journal article.<sup>1</sup> We hope that the conceptual model we proposed (Figure 6, right) will help guide the future development of PHRs, such as the IPHR, inform practices about what is needed to effectively implement patient-centered systems, and direct policymakers in further refining Meaningful Use with the patient's needs in mind. The IPHR also bears relevance to the Patient-Centered Medical Home and current efforts to use performance monitoring and reporting to improve care quality.

**Implications.** Our findings have implications for the future research agenda of patient-centered health information technology, such as the IPHR, to promote the appropriate delivery of preventive care. For technologies like the IPHR that appear effective, strategies to promote more rapid uptake by patients and practices are emerging as an important focus for translational research and implementation science. We believe that greater use and utility of PHRs can be obtained by better integrating systems like the IPHR into daily clinical activities, such as targeting patients who are preparing for an office visit or having physicians and nurses direct patients to resources on the site to support their self-management of health conditions. Additionally, our study sites' homogenous patient population, skewed toward highly literate and internet-savvy patients, necessitates evaluation of the IPHR and similar patient-centered systems among more diverse patient populations and a range of primary care settings.

*Personal health record* is a legacy term – more is needed than mere “records” for patients. Technology has sufficiently advanced to support the creation of truly patient-centered health information systems that can emerge as action tools that improve health. Practices will need support in adopting and implementing such patient-centered systems, and patients will need encouragement and direction on how to take full advantage these new resources – representing substantial workflow and cultural changes from current care.

## References

1. Krist AH, Woolf SH. A vision for patient-centered health information systems. *Jama*. Jan 19 2010;305(3):300-301.
2. McGlynn EA, Asch SM, Adams J, et al. The quality of health care delivered to adults in the United States. *N Engl J Med*. Jun 26 2003;348(26):2635-2645.
3. Farley TA, Dalal MA, Mostashari F, Frieden TR. Deaths preventable in the U.S. by improvements in use of clinical preventive services. *Am J Prev Med*. Jun 2010;38(6):600-609.
4. 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.
5. McNutt RA. Shared medical decision making: problems, process, progress. *JAMA*. Nov 24 2004;292(20):2516-2518.
6. O'Connor AM, Stacey D, Entwistle V, et al. Decision aids for people facing health treatment or screening decisions. *Cochrane Database Syst Rev*. 2003(2):CD001431.

7. O'Connor AM, Legare F, Stacey D. Risk communication in practice: the contribution of decision aids. *BMJ*. Sep 27 2003;327(7417):736-740.
8. Stone EG, Morton SC, Hulscher ME, et al. Interventions that increase use of adult immunization and cancer screening services: a meta-analysis. *Ann Intern Med*. May 7 2002;136(9):641-651.
9. Ramsay CR, Eccles M, Grimshaw JM, Steen N. Assessing the long-term effect of educational reminder messages on primary care radiology referrals. *Clin Radiol*. Apr 2003;58(4):319-321.
10. Stange KC, Zyzanski SJ, Jaen CR, et al. Illuminating the 'black box'. A description of 4454 patient visits to 138 family physicians. *J Fam Pract*. May 1998;46(5):377-389.
11. Stange KC, Flocke SA, Goodwin MA, Kelly RB, Zyzanski SJ. Direct observation of rates of preventive service delivery in community family practice. *Prev Med*. Aug 2000;31(2 Pt 1):167-176.
12. Lesser LI, Bazemore AW. Improving the delivery of preventive services to Medicare beneficiaries. *Jama*. Dec 23 2009;302(24):2699-2700.
13. Wagner EH, Glasgow RE, Davis C, et al. Quality improvement in chronic illness care: a collaborative approach. *Jt Comm J Qual Improv*. Feb 2001;27(2):63-80.
14. Glasgow RE, Orleans CT, Wagner EH. Does the chronic care model serve also as a template for improving prevention? *Milbank Q*. 2001;79(4):579-612, iv-v.
15. Solberg LI, Brekke ML, Fazio CJ, et al. Lessons from experienced guideline implementers: attend to many factors and use multiple strategies. *Jt Comm J Qual Improv*. Apr 2000;26(4):171-188.
16. Jha AK, Ferris TG, Donelan K, et al. How Common Are Electronic Health Records In The United States? A Summary Of The Evidence. *Health Aff (Millwood)*. Oct 11 2006.
17. Blumenthal D. The federal role in promoting health information technology. New York: The Commonwealth Fund Perspectives on Health Reform, January 2009. Available at: <http://www.commonwealthfund.org/content/publications/perspectives-on-health-reform-briefs/2009/jan/the-federal-role-in-promoting-health-information-technology.aspx>. Accessed May, 2009.
18. Hing ES, Burt CW, Woodwell DA. Electronic medical record use by office-based physicians and their practices: United States, 2006. *Adv Data*. Oct 26 2007(393):1-7.
19. Audet AM, Doty MM, Peugh J, Shamasdin J, Zapert K, Schoenbaum S. Information technologies: when will they make it into physicians' black bags? *MedGenMed*. Dec 6 2004;6(4):2.
20. Connecting for Health: Americans overwhelmingly believe electronic personal health records could improve their health. *Markle Foundation*. Available at: <http://www.connectingforhealth.com/resources/ResearchBrief-200806.pdf>. Accessed May, 2009.
21. Chaudhry B, Wang J, Wu S, et al. 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.
22. Preventive Services. U.S. Preventive Services Task Force. Available at: <http://www.ahrq.gov/clinic/uspstfix.htm>. Accessed January, 2011.
23. 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.
24. Chobanian AV, Bakris GL, Black HR, et al. The Seventh Report of the Joint National Committee on Prevention, Detection, Evaluation, and Treatment of High Blood Pressure: the JNC 7 report. *Jama*. May 21 2003;289(19):2560-2572.
25. Grundy SM, Cleeman JJ, Merz CN, et al. Implications of recent clinical trials for the National Cholesterol Education Program Adult Treatment Panel III guidelines. *Circulation*. Jul 13 2004;110(2):227-239.
26. 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.
27. 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.
28. Levin B, Lieberman DA, McFarland B, et al. Screening and Surveillance for the Early Detection of Colorectal Cancer and Adenomatous Polyps, 2008: A Joint Guideline From the American Cancer Society, the US Multi-Society Task Force on Colorectal Cancer, and the American College of Radiology. *Gastroenterology*. Feb 8 2008.

29. Smith RA, Cokkinides V, Eyre HJ. American Cancer Society guidelines for the early detection of cancer, 2006. *CA Cancer J Clin.* Jan-Feb 2006;56(1):11-25; quiz 49-50.
30. Smith RA, Cokkinides V, Brawley OW. Cancer screening in the United States, 2009: a review of current American Cancer Society guidelines and issues in cancer screening. *CA Cancer J Clin.* Jan-Feb 2009;59(1):27-41.
31. Scientific Statements and Practice Guidelines for 2009-2010. *American Heart Association.* Available at: <http://www.americanheart.org/presenter.jhtml?identifier=9181>. Accessed July, 2010.
32. Recommendation and Guidelines: Advisory Committee on Immunization Practices (ACIP). Department of Health and Human Services. Centers for Disease Control and Prevention. Available at: <http://www.cdc.gov/vaccines/recs/ACIP/default.htm>. Accessed January, 2010.
33. Welcome to Fairfax Family Practice Centers. *Fairfax Family Practice Centers.* Available at: <http://fairfaxfamilypracticecenters.com/>. Accessed July, 2010.
34. Nolan T, Berwick DM. All-or-none measurement raises the bar on performance. *Jama.* Mar 8 2006;295(10):1168-1170.
35. Maciosek MV, Coffield AB, Edwards NM, Flottemesch TJ, Goodman MJ, Solberg LI. Priorities among effective clinical preventive services: results of a systematic review and analysis. *Am J Prev Med.* Jul 2006;31(1):52-61.
36. Feuer EJ, Kessler LG. Test statistic and sample size for a two-sample McNemar test. *Biometrics.* 1989;45:629-636.
37. HealthFinder.gov. *U.S. Department of Health and Human Services. Office of Disease Prevention and Health Promotion. (ODPHP).* Available at: <http://healthfinder.gov/>. Accessed January, 2010.
38. Ralston JD, Coleman K, Reid RJ, Handley MR, Larson EB. Patient experience should be part of meaningful-use criteria. *Health Aff (Millwood).* Apr 2010;29(4):607-613.
39. Silvestre AL, Sue VM, Allen JY. If you build it, will they come? The Kaiser Permanente model of online health care. *Health Aff (Millwood).* Mar-Apr 2009;28(2):334-344.

## List of Publications and Products

### Publications

Krist AH, Woolf SH. A Vision for Patient-Centered Information Systems. *JAMA* 2011; 305(3): 300-301.

### Presentations

Kerns JW, Krist AH, Longo DR, Kuzel A, Johnson RE. Trust and Functionality: Key Themes for a Personalized Patient Portal for Prevention. 36th Annual Meeting of the North American Primary Research Group. Seattle WA. Nov 14, 2010.

Krist AH. MyPreventiveCare – A Personalized Portal to Promote Patient-Centered Preventive Care. VCU Massey 2010 Research Retreat, Richmond, VA. October 29, 2010.

Krist AH, Jack B, Lapane K. Improving Care Through AHRQ Health IT Tools. AHRQ 2010 Annual Conference, Agency for Healthcare Research and Quality. Bethesda, MD. September, 2010.

Kerns JW, Krist AH, Longo DR, Kuzel A, Johnson RE. Trust and Functionality: Key Themes for a Personalized Patient Portal for Prevention. Qualitative Health Research. Montreal. June 14, 2010.

Krist AH, Atlas S, McTigue K. Using Health IT for Preventive Care Services. Annual Health Information Technology Grantee and Contractor Conference, Agency for Healthcare Research and Quality. Bethesda, MD. June 3, 2010.

Krist AH, Woolf SH, Longo DR, Rothemich SF, Johnson RE, Peele JE, Kerns JW, Kuzel A. Impact of a Personalized Portal on the Delivery of Recommended Services – MyPreventiveCare. Annual Health Information Technology Grantee and Contractor Conference, Agency for Healthcare Research and Quality. June 3, 2010.

Sinsky C, Krist AH, Ritchie C. Leveraging Health Information Technology for Patient Empowerment. AHRQ National Resource Center for Health Information Technology Webinar, Agency for Healthcare Research and Quality. April 8, 2010. Available at [http://healthit.ahrq.gov/portal/server.pt/gateway/PTARG\\_S\\_0\\_3882\\_911575\\_0\\_0\\_18/Patient%20Empowerment%2003%2031%2010v4%20FINAL.pdf](http://healthit.ahrq.gov/portal/server.pt/gateway/PTARG_S_0_3882_911575_0_0_18/Patient%20Empowerment%2003%2031%2010v4%20FINAL.pdf).

Krist AH, Woolf SH, Longo DR, Rothemich SF, Johnson RE, Peele JE, Kerns JW, Matzke G. An Interactive Preventive Healthcare Record to Promote Patient-Centered Preventive Care. 35th Annual Meeting of the North American Primary Research Group. Montreal. Nov 15, 2009.

Krist AH, Woolf SH, Longo DR, Rothemich SF, Johnson RE, Peele JE, Kerns JW, Kuzel A, Matzke G. An Interactive Preventive Healthcare Record (IPHR) to Promote Delivery of Patient-Centered Preventive Care. AHRQ Annual Conference. Bethesda, MD. Sept 15, 2009.

Krist AH, Woolf SH, Longo DR, Rothemich SF, Johnson RE, Peele JE, Loomis JF, Kuzel A, Kerns JW, Matzke G. An Interactive Preventive Healthcare Record to Promote Delivery of Patient-Centered Preventive Care. Annual Research Meeting, Academy Healthy. Chicago, IL. June 14, 2009.

Krist AH, Woolf SH, Longo DR, Rothemich SF, Johnson RE, Peele JE, Loomis JF, Kuzel A, Kerns JW, Matzke G. An Interactive Preventive Healthcare Record (IPHR) to Promote Delivery of Patient-Centered Preventive Care. AHRQ National PBRN Research Conference. Bethesda, MD. June 24, 2009.

Krist AH, Woolf SH, Longo DR, Rothemich SF, Johnson RE, Peele JE, Kerns JW, Matzke G. An Interactive Preventive Healthcare Record to Promote Patient-Centered Preventive Care. 34th Annual Meeting of the North American Primary Research Group. Puerto Rico. Nov 17, 2008.

## Press Releases

We have had multiple press releases regarding this project. A few examples include:

VCU Gets Grant to Study Whether Linking Patient Health Information to Physician Electronic Records Will Improve Outcomes. *VCU News Center*. Available at: [http://www.news.vcu.edu/news/VCU\\_Gets\\_12\\_Million\\_Grant\\_to\\_Study\\_Whether\\_Linking\\_Patient\\_Health](http://www.news.vcu.edu/news/VCU_Gets_12_Million_Grant_to_Study_Whether_Linking_Patient_Health), October 23, 2007.

An associated press article describing doctor shortages featured the IPHR as a new innovation to improve care. The article was widely disseminated but one example is: Primary Care Doctor Shortage to Get Worse. *Associated Press*. Available at: <http://www.cbsnews.com/stories/2010/03/29/health/main6343148.shtml>, March 29, 2010.

Dean's Discovery Report. *Virginia Commonwealth University*. Available at: <http://www.medschool.vcu.edu/giving/publications/index.html#ddr>, Spring 2011.

Advance Newsletter. *Massey Cancer Center, Virginia Commonwealth University*. Available at: <http://www.massey.vcu.edu/news/?pid=1923>, Spring 2011.

JAMA Commentary Encourages Design of Patient-Centered Health Information Systems. *AHRQ News and Numbers*; January 28, 2011.

Author Interview: A Vision for Patient-Centered Health Information Systems. *JAMA*. Available at: [http://jama.ama-assn.org/site/audio/authorinterviews/author\\_interview\\_index.xhtml](http://jama.ama-assn.org/site/audio/authorinterviews/author_interview_index.xhtml), January 19, 2011.

EXPERT ADVISORY: Making Health Information Technology More Patient-Centered. *VCU News Center*. Available at: [http://www.news.vcu.edu/news/EXPERT\\_ADVISORY\\_Making\\_Health\\_Information\\_Technology\\_More\\_PatientCentered](http://www.news.vcu.edu/news/EXPERT_ADVISORY_Making_Health_Information_Technology_More_PatientCentered), January 19, 2011.



## Products

Six key products were created in the process of completing the research for this grant:

1. Our primary product is the *IPHR clinical website*. The website remains freely available on the web at [www.MyPreventiveCare.org](http://www.MyPreventiveCare.org). Through this grant and other AHRQ support, the IPHR is integrated into three EMRs (Enterprise or Touchworks, Professional or A4, and Epic) and is being used in 15 primary care practices that care for over 500,000 patients throughout the state of Virginia. During this project, we programmed the IPHR to be sustainable and generalizable to other clinical databases, primary care settings, and patient populations. We hope to continue to broadly disseminate this resource nationally.
2. Additionally, during this project, we configured the IPHR to serve as a *translational research platform* for future work. One of the key benefits of the IPHR is that it was a shared space for patients and clinicians that integrated into their normal workflow (web for patients and EMR for clinicians). Accordingly, the IPHR can serve as an efficient means to deliver future interventions for preventive and chronic care to patients and clinicians using the system at the point of care.
3. In 2010, we obtained recognition from the Centers for Medicare and Medicaid Services (CMS) for the IPHR as a *PQRI reporting registry*. This allows us to submit performance measures and e-prescribing measures to CMS for clinicians to receive incentive payments. Furthermore, our future vision is that the IPHR could serve as a platform to not only measure performance measures, but also to directly and efficiently act on the performance measures – reaching out to populations of patients in need of care through the IPHR interface.
4. In conjunction with our JAMA article describing the model for patient-centered health information technology that guided our creation of the IPHR, JAMA arranged for us to create a *podcast describing patient-centered personal health records* for the lay audience. The podcast is available at <http://jama.ama-assn.org/content/suppl/2011/01/18/305.3.300.DC1/krist011911.mp3>.
5. In 2008, with assistance from communications experts at AHRQ, we developed a patient-centered informational brochure to describe the IPHR and motivate patients to use the system. This brochure has been the basis for much of our communications strategy for subsequent projects involving the IPHR.
6. To measure the delivery and process of care delivery for our outcomes, we created a series of *preventive care, chronic care, and knowledge surveys* (available upon request).

## **Recognition**

The IPHR and the research conducted through this grant have received three key recognitions:

1. Annual Research Meeting abstract received Distinguished Abstract recognition by Academy Health, June 14, 2009.
2. This study was presented at the Massey Cancer Center's Annual Research Retreat to demonstrate the exemplary work Virginia Commonwealth University is doing in the area of cancer control and prevention, Oct 29, 2010.
3. The IPHR was highlighted in the Dean's Discovery Report at Virginia Commonwealth University, March 15, 2011.