

***Grant Final Report***

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**Using an Electronic Personal Health Record to Empower Patients with Hypertension**

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# Abstract

**Purpose:** Improve a personal health record (PHR) incorporating patient advice and examine its impact in patients with hypertension measured by changes in patient outcomes and changes in institutional acceptance of patient- and family-centered care (PFCC) culture.

**Scope:** The study was conducted in two ambulatory primary care clinics.

**Methods:** Qualitative input from 16 local and 5 national patients, and 4 PHR clinical experts was the basis for PHR reform. Subsequently, a cluster-randomized trial with PHR and no PHR groups was conducted (N=453). BP was the main outcome measure. Patient empowerment (Patient Activation Measure and Patient Empowerment Scale), quality of care (Clinician and Group CAHPS and Patient Assessment of Chronic Care), medical utilization (self-reported), were secondary outcomes. Institutional culture was measured using the PFCC culture survey.

**Results:** No impact of the PHR was observed on BP, patient activation, patient perceived quality, or medical utilization in the intention-to-treat analysis. Sub-analysis of those intervention patients self-identified as active PHR users (25.7% of those with available information) showed a 5.25-point reduction in diastolic BP. Younger age, greater computer skills, and more positive provider communication ratings were associated with frequency of PHR use. Institutional culture improved over time and was highly correlated with increasing use of Patient Advisors throughout the healthcare system. Simply providing a PHR has limited impact on patient blood pressure, empowerment, satisfaction with care, or use of health services. Future research describing meaningful consumer PHR use may clarify the viability of PHRs to change health outcomes.

**Key Words:** patient-centered care; personal health records; health information technology

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# Final Report

## Purpose

The purpose of this project was to examine the feasibility, acceptability, and impact of an electronic personal health record (PHR) that was modified using a patient- and family-centered approach and incorporated the experiences, perspectives, and insights of patients and family members actually using the system. Comparison of patients with the PHR intervention to a group of “care as usual” patients was performed. Blood pressure was the primary outcome measure. Patient activation and patient perception of practice behaviors in accord with the Chronic Care Model, patient/physician communication and adherence to disease management guidelines were secondary outcomes. The following Specific Aims were addressed.

### **Aim 1. To Improve the Application of Patient-and Family-Centered Care (PFCC) Elements in an Existing Electronic Personal Health Record (PHR) System**

**Hypothesis 1.** Inclusion of patients and families in the design of the PHR will increase the acceptability and amount of use by patients in the pilot samples.

1. We partnered with patient and family advisors to enhance an existing PHR.
2. The acceptability and usability of a revised system from a pilot sample of patients with hypertension was evaluated.
3. We included feedback from a national sample of physician PHR experts in the PHR reform.

### **Aim 2. To Implement and Test the Effectiveness of the Revised PHR (My HealthLink) with Patients Being Treated for Hypertension by a Team of Physicians, Mid-Level Practitioners, Nurse Clinicians, and Support Staff in Two Ambulatory Settings**

**Hypothesis 2a.** Patients in the intervention group (using the PHR) will score higher on measures of self-activation, rate their process of care as more in line with the Chronic Care Model, and experience more collaborative communication with their healthcare team than patients in the “care as usual” group.

**Hypothesis 2b.** Patients in the intervention group will have lower systolic and diastolic blood pressures, be more in compliance with recommended guidelines, and will have less emergent care and fewer hospitalization visits than patients in the comparison group.

1. We tested the intervention on 453 ambulatory patients being treated for hypertension in a family medicine and a general internal medicine clinic.
2. We compared intervention and control groups on measures of:
  - a. patient activation and patient perception of care
  - b. quantifiable biological markers, specifically blood pressure, body mass index, and lipid levels indicative of metabolic syndrome
  - c. collaborative patient—physician communication although these results were limited by procedural difficulties
  - d. congruence of treatment with guidelines and frequency of utilization of medical services.

### **Aim 3. To Monitor the Shift in Provider and Support Staff Awareness and Incorporation of PFCC Concepts as a Result of the Implementation of the PHR**

**Hypothesis 3.** Implementation of the PHR will increase physician and staff positive attitudes toward fundamental PFCC concepts and will generate increased physician requests for system-wide use of the PHR.

1. We assessed physician and staff attitudes toward the PHR and toward patient- and family-centered practice.
2. We documented additional requests for implementation of the PHR within the (GHSU/MCG) Health System.

## **Scope**

### **Background**

Recent technological advances provide an unrealized opportunity to empower patients through access to their healthcare information and to their providers. Contemporary emphasis on patient-centered care provides support for the notion that empowering patients to manage their own health leads to improved outcomes. “Early experience confirms that when patients are given the chance to bridge the information gap between themselves, their health data, and their health care providers, many people enthusiastically take a more active role”<sup>1</sup>. Patient activation should have an impact on patient safety issues brought to the foreground by the Institute of Medicine’s (IOM) report<sup>2</sup>. Ambulatory systems provide a unique perspective—one in which the patient role is even more important because most of the “care” occurs outside of the healthcare physical

environment. We tested the notion that an electronic personal health record (PHR), designed and modified by patients and families, would be effective in (a) empowering patients, (b) improving communication with healthcare providers, (c) assuring compliance with treatment guidelines, and (d) improving health outcomes in patients with hypertension.

Patient- and family-centered care (PFCC) has been defined as an “approach to healthcare which emphasizes mutually beneficial partnerships between patients, families, and healthcare providers”<sup>3</sup>. Patient-centered care involves “providing care that is respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions”<sup>2</sup>.

Audet et al.<sup>4</sup> described a vision for patient-centered primary care characterized by 7 dimensions, one of which is giving patients “the option to be informed and engaged partners in their care.” Most ambulatory care systems do not embrace this philosophy and must be redesigned to encourage patient-centered care<sup>5,6</sup>. A component of this redesigned system is free-flowing information between the patient and the provider in a “two-way interaction”<sup>1</sup>. The episodic ambulatory “visit” to a physical location gives way to a model of care that is founded on “a continuous healing relationship” sustained through effective communication, information sharing, and collaboration<sup>6,7</sup>. The Chronic Care and medical home models<sup>7-9</sup> both support the value of a patient-centered approach in the ambulatory setting.

Patients experiencing PFCC report a greater sense of power and control in managing their illness due to shared respect and dignity, information access, participation, and collaboration<sup>10</sup>. “High patient enablement” was predicated on the doctor’s interest in the effect of the problem on their lives, health promotion, and a positive approach<sup>11</sup>. “Perceived self-efficacy and related question asking are important mediators of health and healing”<sup>12,13</sup>. Older adults who perceive better relationship quality with their pharmacist have a stronger self-efficacy for medication management<sup>14</sup>. The Chronic Care Model<sup>15</sup> has stimulated significant developments nationally in the approach to chronic illness management with demonstrated improvements in the care of juvenile diabetes, where outcomes are improved when a combination of a team approach and patient-centered adjustments of food and insulin are put into play<sup>16</sup>. Stewart<sup>17</sup>, found improved outcomes where patients perceived common ground with their physician.

## Context

Transparency and access to information are important elements of a patient-centered system. A PHR offers the opportunity for patients to accumulate and manage their own personal health information, establish goals, track action toward those goals, manage medications, and coordinate other aspects of the therapeutic regimen. When linked to the electronic medical record, the PHR offers even greater benefits<sup>18</sup>. Although physicians may not initially perceive the empowering aspects, after use in a small study involving heart failure patients all 8 physicians involved felt that patient access to their records was empowering<sup>19</sup>. Most importantly, the public appears to want an PHR and believes that this technology will improve the quality of care<sup>20</sup>.

Several recent studies indicate that when patients have access to electronic portals, they are enthused and records are more accurate. When patients are allowed direct input into the health maintenance portion of their record, accuracy has increased in terms of who is due for screenings<sup>21</sup>. Cancer patients report that a self-monitoring system that sends notices to healthcare clinicians based on patient self report was extremely useful and highly used by patients. In fact patients rated the system as an 8 on a 10-point usefulness scale. Physicians, interestingly, rated it

as 5.6<sup>22</sup>. What is perhaps even more important, patients are increasingly computer literate and when allowed to view medical records, find it extremely useful<sup>23</sup>. Indeed, many find errors that they wish to correct. Perhaps, as suggested by Steele<sup>24</sup>, “Patients do not have the information or the confidence to manage their own care, because the health care system is more disempowering than empowering.” We proposed to use the PHR as an *empowering* strategy in patients with hypertension.

For patients with hypertension and their families, the opportunity to interact with their healthcare providers in new ways using the best features of PHRs in a patient-centered model is potentially significant. The opportunity to use an electronic system to establish goals (e.g., exercise and diet) and to manage and monitor medications and blood pressure in partnership with clinicians could offer potential new benefits.

Physician practices have demonstrated an ability to incorporate an PHR into their practices<sup>18</sup>. While there remain significant barriers to its widespread adoption, including reimbursement methods, the support for their use is growing. Physicians are dissatisfied with the current acute care model for ambulatory care and wish to restore the focus on relationships with their patients<sup>7</sup>. PHRs, as one component of a patient-centered practice, offer the opportunity for an enhanced relationship to occur.

The PHR developed during this study was the Cerner Corporation proprietary PHR system (*IQHealth*<sup>TM</sup>) deployed at GHSU/MCG Health Systems under its brand name My HealthLink. My HealthLink, facilitated patient-provider communication by including secure messaging which was triaged by a study nurse, allowed patients to schedule appointments, check for medication interactions, enter and track data, view prescribed medications, and access health education information. The product is certified and conforms to interoperability standards.

## Setting

The Georgia Health Sciences University Health System (formerly the Medical College of Georgia Health System), the site of this study, is comprised of a large tertiary-care adult medical center, a children’s hospital, an ambulatory care center with multiple outpatient clinics, and an organized multi-specialty physician practice with over 350 physicians, as well as the Georgia Health Sciences University (formerly the Medical College of Georgia), the academic arm of the health system. Patients for this study were recruited from the family medicine and internal medicine outpatient clinics.

The GHSU/MCG Health System has been committed to collaborating with patients and families since 1993, when it began planning for the construction of its Children’s Medical Center (CMC). Since the late 1990s, GHSU/MCG has worked to integrate PFCC within the infrastructure of the entire organization. PFCC values are clearly defined and included in the organization’s strategic plan. New staff are screened for attitudes and skills consistent with PFCC, and PFCC behaviors are included in the performance-review system. As of 2010 GHSU has more than 325 patient and family advisors serving in a range of efforts including: Health Partners, a patient and family advisory council for all adult clinical programs; Family Advisory Council and Children’s Advisory Council for the Childrens Medical Center; Patient and Family Advisory Council for the Multiple Sclerosis Clinic; Patient Safety Committee; Medication Reconciliation Committee; and Patient and Family Faculty. GHSU/MCG is one of two hospitals featured in the American Hospital Associations on-line Toolkit for PFCC <sup>10</sup>.

## Participants

**Aim 1.** For AIM I of this project 31 ambulatory patients with hypertension attending the family medicine clinic were recruited based on physician recommendations. In the first wave, 9 of 15 recruited patients returned for the interviews (5 females, 4 males). In the second wave, 7 of 16 recruited patients returned for the interviews (4 females, 3 males). In each wave, hypertension criteria were based on Joint National Committee (JNC) 7 guidelines and included patients with prehypertension (systolic BP 120–139 mm Hg or diastolic BP 80–89 mm Hg), stage 1 hypertension (systolic BP 140–159 mm Hg or diastolic BP 90–99 mm Hg), or stage 2 hypertension (systolic BP 160 mm Hg or above or diastolic BP 100 mm Hg or above)<sup>25</sup>. In addition 5 national patients and 4 PHR experts were recruited by the Institute for Patient- and Family Centered Care (IPFCC), project consultants, providing additional insight into the PHR revisions.

**Aim 2.** We approached 1686 patients with a documented diagnosis of hypertension with 453 (26.4%) being enrolled and included in the analyses. These patients were clustered within 13 intervention and 11 control physicians.

**Aim 3.** 13 physicians and 16 nurses and 122 patients participated in the end of study semi-structured interviews/focus groups. The PFCC Institutional Culture Survey was administered in 2005, 2008, and 2010 to GHSU faculty, staff, students, and residents. 1,637 e-mail invitations were sent in 2005 with a response rate of 26.8% (N =439). The response rate in 2008 was 23.4% (467/1,995) and in 2010 it was 29.8% (737/2475).

## Incidence and Prevalence

This study was designed to assess the feasibility, acceptability and impact of a PHR on ambulatory patients with hypertension which is one of the Ambulatory, Safety and Quality (ASQ) program's suggested study areas for PHR implementation and an Institute of Medicine priority area. Hypertension affects 65 million Americans, 24% of the US population. Of this group, estimates of those who had their blood pressure under control vary from 29% to 51.5%<sup>26-28</sup>. Thirteen southern states, including Georgia and South Carolina, have the highest prevalence of hypertension and the greatest incidence of complications compared with other regions. Stroke deaths are higher in the Southeast, earning it the designation of “stroke belt” due to the death rate exceeding the national average by 10%. Hypertension-related congestive heart failure and end-stage renal disease are also more prevalent. The Consortium of Southeastern Hypertension Control has established a goal to improve the degree of control of hypertension in the southeastern US.

Technological approaches to improve the rates of blood pressure control have largely focused on methods that make system changes, practice staff education such as academic detailing<sup>29, 30</sup> or rely on physicians to implement changes and monitor care. Rudd<sup>31</sup> reports that issues of patient compliance are a large part of the three-pronged explanation for lack of blood pressure control: behavioral, biological and pharmacological reasons. He emphasizes that solutions must be personalized, enlisting an active patient approach and recognition of patient needs and preferences. He suggests that physicians may adjust medications based on suspected rates of compliance so it may be better to let patients who know true levels of compliance be the

monitors of their own blood pressure. Personal goal setting, contingency contracting, feedback on progress and reinforcement when moving toward control are all potentially successful methods and could be implemented through a PHR strategy.

## Methods

### Study Design

To complete Aim 1, we partnered with patients and families to modify the Cerner product implemented as My HealthLink. Cerner Corporation information technology (IT) staff and our grant leadership team rank ordered the recommendations to determine which elements would be added/modified. This process included 2 iterative rotations to determine whether patients found the PHR increasingly acceptable and useful with additional patient-centered and patient-recommended modifications. Feedback was also incorporated from national samples.

To complete Aim 2, we conducted a prospective cluster-randomized controlled effectiveness trial to examine the impact of the PHR on blood pressure control, patient empowerment and patient perception of practice behaviors that are in accord with the Chronic Care Model. Additional outcomes included patient/physician communication, adherence to practice guidelines for hypertension and utilization of medical services. Qualitative interviews with intervention patients were conducted at study end to determine additional patient suggestions for subsequent improvement of the PHR.

Finally, in Aim 3, we monitored the change in provider and staff in terms of acceptance of the PHR and patient- and family-centered principles. Physicians' perception of the technology was measured via end of study semi-structured interviews. Institutional change was also measured by the PFCC Institutional Culture Survey, which was administered in 2005, 2008 and 2010 to a sample of faculty, students, residents and staff in the GHSU/MCG health and academic system.

### Data Sources/Collection

**Aim 1.** The qualitative data for Wave 1 and 2 of the PHR pilot study was collected by study researchers during semi-structured interviews.

**Aim 2.** The biological measures collected for the AIM 2 main trial study were obtained at patient study visits (4 visits 1 ½ to 3 months apart) by a trained research member. Patient empowerment, patient activation, and quality of care measures were also collected from patients at their study visit via questionnaires.

**Aim 3.** Physician and staff attitudes were measured via the Patient Empowerment Scale (PES) and by end of study semi structured interviews/focus groups. For all three distributions of the PFCC Institutional Survey, administration was conducted through an on-line survey management program (Survey Monkey)<sup>32</sup>. The survey was then exported directly from this program for data analysis.

## Interventions

**Aim 1.** Patients with a hypertension diagnosis and the national samples participated in a semi-structured interview after one to two weeks of using the PHR.

**Aim 2.** Intervention patients were asked to use the My HealthLink PHR and participated in 4 study visits.

**Aim 3.** Participating physicians were asked to complete the PES-physician version prior to the main trial intervention. Physicians and staff (nurses) were approached completed the PES-physician version and participated in semi-structured interviews/focus groups. The online PFCC Institutional Culture Survey was used to track changes over time in acceptance of PFCC values.

## Measures

**Aim 1.** The semi-structured interviews questions used for Wave 1 and 2 were based on recommendations from the American College of Medical Informatics 2005 symposium which expressed the need for PHR research to address PHR functionality, data issues, health tracking, decision support, issues concerning the patient/provider relationship, and the patient's role in their own healthcare<sup>18</sup>. Interview questions for all samples addressed ease of use, technological understanding, blood pressure tracking capability, and personal goal setting.

**Aim 2.** Demographic characteristics were collected at the time of study enrollment and, adult literacy was measured via the *Rapid Estimate of Adult Literacy in Medicine (REALM)*,<sup>33</sup> and ease of access to and familiarity with technology using the *Internet Accessibility Questionnaire*, developed for this study.

Diastolic and systolic blood pressure recording were measured at each study visit. Two seated measurements were obtained at each study visit following JNC-7 recommendations using the auscultatory method with patients sitting quietly for 5 minutes before measurement<sup>25</sup>. Additional measures of body mass index (BMI), fasting glucose, triglycerides, HDL and LDL cholesterol were tracked. Height, weight and waist circumference measurements were used to calculate BMI. Waist circumference was also used to classify patients as having metabolic syndrome. Laboratory measures were obtained from medical records as close in time to each visit as possible.

Patient empowerment was measured via the 13-item Patient Activation Measure (PAM) assessing patient knowledge, skill, and confidence in health self-management<sup>34,35</sup>. The PAM predicts self-directed behavior change, patient participation in the medical encounter, use of healthy behaviors, and use of quality data<sup>35</sup>. The Patient Empowerment Scale (PES) was also used, which assesses patient's perceived risks and benefits of having access to their EMR.<sup>19</sup>

Quality measures included the *Patient Assessment of Chronic Illness Care (PACIC)*, which is a 20-item composite measure designed to assess patient perceptions of the degree to which elements of the Chronic Care Model are incorporated into their care and the *Consumer Assessment of Healthcare Providers and Systems (CAHPS)—Clinician and Group Survey*. Developed and validated by the Agency for Healthcare Research and Quality (AHRQ) to assess "the experience of patients with their physicians and medical groups",<sup>36</sup> the Clinician and Group Survey includes 3 sub- scales: Access to Care, Provider Communication, Clerks and Receptionist

at Provider's Office and a Global Rating. Twenty-seven experimental Health Technology questions were administered at baseline and end of study.<sup>37</sup>

Utilization data included self-reported number of hospital days, emergency room visits, and outpatient visits at enrollment and study end.

End of study semi-structured interviews for intervention patients consisted of 13 questions to ascertain the acceptability, ease of use, and general usefulness of a PHR.

**Aim 3.** The Patient Empowerment Scale- Physician version was used to assess provider's perceived risks and benefits of having access to an EMR. The end of study interviews/focus groups for providers included 13 questions based on the Technology Acceptance Model (TAM) and addressed behavioral, normative, control, and other beliefs<sup>38</sup>

Culture Survey--Items on the PFCC Institutional Culture Survey (ICS) were based on the Institute for Patient- and Family-Centered Care's Hospital Self Assessment Inventory, "Strategies for Leadership"<sup>39</sup>. The 47-item instrument uses a 4-point Likert scale (strongly disagree to strongly agree) to assess 6 conceptual dimensions: personal philosophy of care, professional PFCC experience PFCC, perceptions of faculty/staff attitudes toward PFCC, perceptions of leadership attitudes towards PFCC, perceptions of system communication of PFCC standards of care, and perceptions of specific PFCC practices of care.

## Limitations

**Aim 1.** We found initial physician acceptance of the PHR to be questionable. Physicians expressed concern about increased workload and lack of time. In addition, a large number of patients screened to participate declined with 16.7% stating that lack of computer skills or internet access were the reason for not participating.

**Aim 2.** Several limitations were present suggesting that the reason for failure to find differences is not clear. We tested only one PHR with limited EMR/PHR interoperability. Significant numbers of patients declined to participate in the study limiting the sample representativeness. Some possible cross-arm contamination may have occurred as intervention patients and control patients received care in the same clinics and although physicians saw either study patients who had the PHR or study patients who did not, nursing staff saw all patients. PHR use frequency may have been greater if enrollment had been limited to patients with uncontrolled hypertension, maximizing the potential for greater BP change. Finally, we were unable to calculate individual use via PHR data extraction and relied on patient self-report to determine PHR frequency of use.

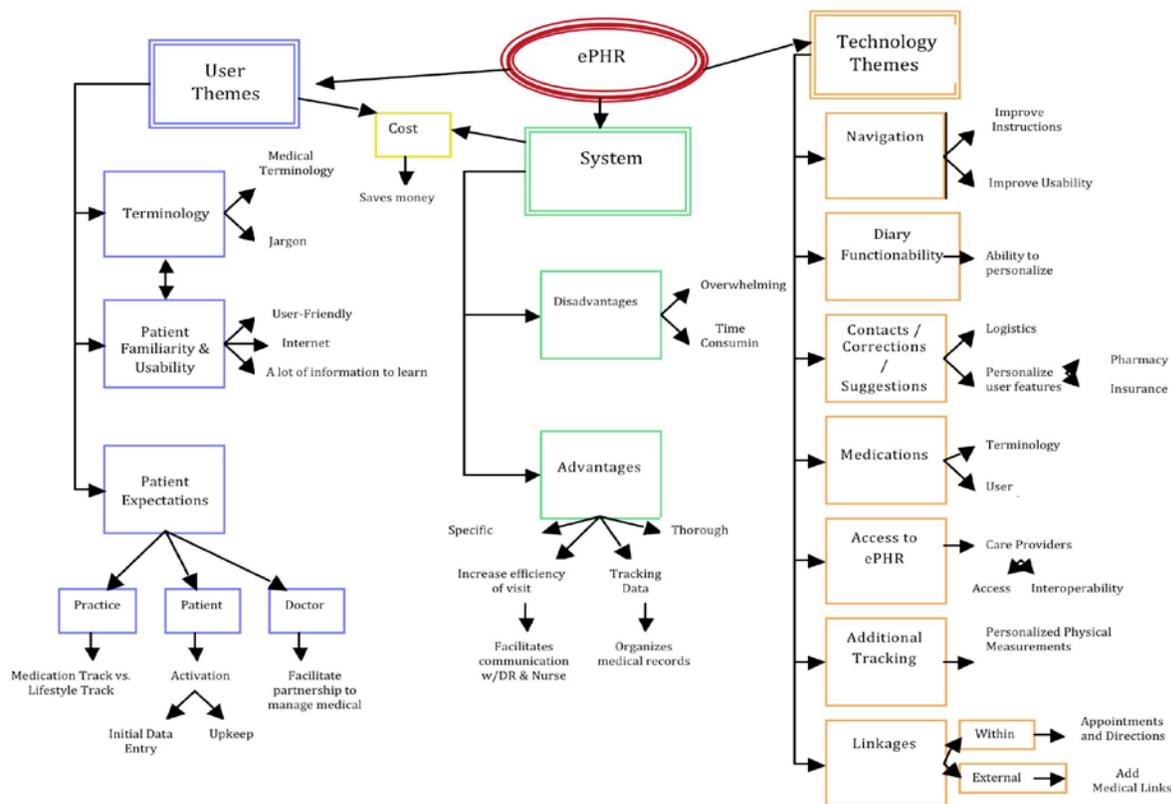
**Aim 3.** The PFCC Institutional Culture Survey was administered in 2005, 2008 and 2010 to cross-sectional sample. Thus we are not observing changes within individuals, but rather across independent samples.

# Results

## Aim 1

Incorporating patient and family feedback into design and functionality principles highlighted elements that matter to patients. Working collaboratively with patients, providers and technology experts is challenging but can result in creative innovation and improved products that are more likely to be used by the consumer. We were able to collect 58 unique patient suggestions, with 13 overall themes divided into 3 categories: User Themes, System Themes and Technology Themes were developed. Refer to Figure 1. Forty specific technology suggestions were developed and 50% were incorporated into the PHR product for the trial (80% via technology and 20% via educational strategies). The remaining 50% were ranked as not important or not technologically feasible at that time.

Figure 1. Aim 1: Patient-derived themes for PHR improvement



## Aim 2

Baseline characteristics were assessed by independent sample t-tests or by chi-square tests for group proportions as appropriate. Only 2 variables were different at baseline, gender (control

group less likely to be female) and literacy level (control group lower). Mean age was 55 years. Whites represented 50% of the sample and Blacks represented 46%. Approximately 70% of the participants had more than a high school education. 81% of the entire sample reported home Internet access. Average BMI was 34.2 and 55% were classified as having metabolic syndrome. Average systolic blood pressure (SBP) was 131.4 mm Hg and average diastolic blood pressure (DBP) was 79.0 mm Hg.

Adjusted intra-class correlation coefficients (ICC) and design effects were calculated for selected variables using baseline data. SAS PROC MIXED was used to estimate variance components for a three-level model for the selected baseline variables adjusting for Group, Gender, Race, Education, and Realm Score.

There were 24 primary care physicians (clusters). The Average cluster size was 18.4 and ranged from 3 to 37. The ICC ranged from 0.001 to 0.167 and the design effect ranged from 1.02 to 3.74. The smallest ICC (0.001) and design effect (1.02) was found for weight, suggesting that patients within primary care physician are no more similar in weight than patients within other physicians. The same holds for BMI, which had the second smallest ICC (0.002) and design effect (1.04). The largest ICC (0.167) and design effect (3.74) was found for the CAHPS HIT access-to-care scale. This suggests that patients within primary care physician were more similar to each other in how they rated access to care than patients within other primary care physicians.

A three-level GLIMM analysis of covariance (ANCOVA) was conducted to model the Visit-4 measures with the corresponding Visit-1 baseline measure (Base) as a covariate. The models for the Visit-4 outcome variables contained the following fixed factors, covariates, and interaction terms: Group, Clinic, Gender, Race, Education, Base, Age, Age\*Group, Group\*Clinic, Group\*Base, Group\*Gender, Group\*Race, and Group\*Education. We modeled the random component of Physician (nested within Clinic) using both random intercepts and random slopes. The Clinic random component was modeled using random intercepts.

The GLIMM analysis revealed some statistically significant group differences on a few of the outcomes. However, none of the raw effect sizes were of sufficient magnitude to imply clinically meaningful differences between groups.

**Table 1. Generalized linear mixed models analysis of covariance estimated least squares means**

**Table 1a. Biological measures**

Variable	Group: Intervention	Group: Control	Raw Effect Size	p-value (two-tailed)
Average SBP	129.7	129.3	0.4	0.617
Average DBP	77.3	75.6	1.7	0.287
Weight in pounds	213.0	209.3	3.7	0.023*
BMI	34.3	33.8	0.5	0.006*
Waist circumference	108.0	107.0	1.0	0.033*
HDL level	49.8	49.2	0.6	0.826
LDL level	108.4	101.0	7.4	0.116
Triglyceride level	139.2	138.3	0.9	0.336
Fasting glucose level	126.3	116.4	9.9	0.554

**Table 1b. Patient empowerment measures**

Variable	Group: Intervention	Group: Control	Raw Effect Size	p-value (two-tailed)
PAM total activation score	71.4	69.1	2.3	0.490
PES total empowerment score	41.2	40.1	1.1	0.019*
PES empowerment sub-scale score	23.9	22.6	1.3	0.134

**Table 1c. Patient perceptions of quality measures**

Variable	Group: Intervention	Group: Control	Raw Effect Size	p-value (two-tailed)
PACIC total score	70.7	72.1	-1.4	0.822
CAHPS global doctor rating	9.39	9.43	-0.04	0.001*
CAHPS Access to care composite	4.8	4.9	-0.1	0.216
CAHPS Provider communication composite	5.68	5.77	-0.09	< 0.001*
CAHPS Office staff composite	5.4	5.6	-0.2	< 0.001*
CAHPS HIT helpfulness scale	3.72	3.68	0.04	0.592
CAHPS HIT access-to-care scale	4.69	4.83	-0.1	0.133

BMI = Body Mass Index = (Weight/Height<sup>2</sup>)×703; HDL = High-Density Lipoprotein; LDL = Low-Density Lipoprotein; PAM = Patient Activation Measure; PACIC = Patient Assessment of Chronic Illness Care; PES = Patient Empowerment Scale; CAHPS = Consumer Assessment of Healthcare Providers and Systems; HIT = Health Information Technology. \* P-value < 0.05.

Due to observed low uptake of PHR use among the intervention group, we performed exploratory subgroup analyses to examine possible associations with frequency of use. A four-level frequency of use variable was created based on patient self-report in the exit interview and included, no use (during training), low use (1-2 times after training), medium use (3-5 times after training, every other month, or monthly), and high use ( $\geq 2$  times per month). The use variable was dichotomized as no vs. any use for ease of interpretation in logistic regression. A logistic regression analyses was performed looking at patient and visit characteristics, utilization and biological variables, patient perceptions of and personal involvement with the healthcare system at enrollment as predictors for PHR use.

Six baseline variables were found to be significant predictors of any PHR use vs. no use ( $p < 0.05$ ): clinic, age, self-rated computer skills, number of self-reported internet use items, average DBP, and CAHPS provider communication subscale. Patients from the Family Medicine clinic were more likely to use the PHR than patients from the General Internal Medicine and as patient age increased by 4 years, PHR use decreased by 4%. It was also found that higher self-rated computer skills, greater number of self-reported internet use items, higher provider communication scores and higher average DBP were associated with greater PHR use. The number of self-reported days in the hospital also approached significance ( $p = 0.07$ ), with a greater number of inpatient days being associated with lower PHR use. In multivariable analyses, clinic, number of self-reported internet use items, hospital inpatient days, and provider communication were significantly associated with PHR use.

**Table 2. Potential predictors at enrollment of frequency of PHR use (intervention group)**

	Categories	Frequency of PHR Use <sup>†</sup> : No Use	Frequency of PHR Use <sup>†</sup> : Any Use	Logistic Regression: Crude OR	Logistic Regression: 95% CI	Logistic Regression: P-value
<i>Variable: Freq. of Use</i>	Total	43 (30.70)	97 (69.30)			
<i>Patient Characteristic: Age at enrollment (years)</i>		58.70 ± 10.65	53.99 ± 11.80	0.96	(0.93, 1.00)	0.03
<i>Patient Characteristic: Gender</i>	Male	10 (23.26)	23 (23.71)	1.00	-	0.95
<i>Patient Characteristic: Gender</i>	Female	33 (76.74)	74 (76.29)	0.98	(0.42, 2.28)	
<i>Patient Characteristic: Race<sup>‡</sup></i>	White	23 (54.76)	49 (51.58)	1.00	-	0.731
<i>Patient Characteristic: Race<sup>‡</sup></i>	Black/Other	19 (45.24)	46 (48.42)	1.14	(0.54, 2.36)	
<i>Patient Characteristic: Education<sup>§</sup></i>	HS Grad or Less	11 (25.58)	20 (20.83)	1.00	-	0.535
<i>Patient Characteristic: Education<sup>§</sup></i>	Some College +	32 (74.42)	76 (79.17)	1.31	(0.56, 3.04)	
<i>Patient Characteristic: HTN at Enrollment</i>	Uncontrolled	15 (34.88)	24 (24.74)	1.00	-	0.22
<i>Patient Characteristic: HTN at Enrollment</i>	Controlled	28 (65.12)	73 (75.26)	1.63	(0.75, 3.55)	
<i>Patient Characteristic: Clinic patient attended</i>	Internal Medicine	18 (41.86)	17 (17.53)	1.00	-	0.00
<i>Patient Characteristic: Clinic patient attended</i>	Family Medicine	25 (58.14)	80 (82.47)	3.39	(1.52, 7.55)	
<i>Patient Characteristic: IAQ: Internet Access at home</i>	No	7 (16.67)	11 (11.46)	1.00	-	0.406
<i>Patient Characteristic: IAQ: Internet Access at home</i>	Yes	35 (83.33)	85 (88.54)	1.55	(0.55, 4.31)	
<i>Patient Characteristic: IAQ: Self-rated computer skills</i>		5.15 ± 2.92	6.48 ± 2.51	1.21	(1.05, 1.39)	0.01
<i>Patient Characteristic: IAQ: Number of internet-use items</i>		3.58 ± 2.38	4.80 ± 2.43	1.24	(1.05, 1.47)	0.01
<i>Biological Measure: Average SBP</i>		126.70 ± 14.51	130.27 ± 16.61	1.02	(0.99, 1.04)	0.23
<i>Biological Measure: Average DBP</i>		73.72 ± 8.77	78.35 ± 9.81	1.06	(1.01, 1.10)	0.01
<i>Patient Perceptions of Quality Measure: CAHPS: Provider communication composite</i>		5.76 ± 0.45	5.88 ± 0.23	3.11	(1.01, 9.63)	0.05
<i>Health Care Utilization: Self-reported hospital days</i>		1.12 ± 2.14	0.49 ± 1.57	0.83	(0.69, 1.01)	0.07

<sup>†</sup> Categories of frequency of use: No Use – PHR use only during training; Any Use – PHR used outside of training. Missing on 53 patients from the intervention group.

<sup>‡</sup> For categorical variables, frequency (percent) is reported. For continuous variables, mean ± standard deviation is reported.

<sup>§</sup> Other includes Asian, Native Hawaiian/Pacific Islander, American Indian/Alaskan Native, and other races.

<sup>§</sup> High School diploma or Less includes ≤ 8<sup>th</sup> grade. Some College + includes some college, 2-year degree, 4-year degree, or > 4-year degree.

Abbreviations: PHR = personal health record; OR = odds ratio; CI = confidence interval; HS = high school; HTN = hypertension; IAQ = Internet Accessibility Questionnaire; SBP = systolic blood pressure; DBP = diastolic blood pressure; CAHPS = Consumer Assessment of Health Plans Survey.

In addition analysis of covariance models (ANCOVA) were used to examine how frequency of PHR use was associated with change modeling Visit-4 measures against the four-level (no-use, low-use, medium-use, high-use) frequency of use variable and controlling for Visit-1 measures. The univariable ANCOVA analysis of visit 4 measures, found the CAHPS HIT helpfulness and provider communication subscales to be significant. For HIT helpfulness, the high, medium and low use categories had higher adjusted averages than the no use category. Significant differences were detected between high vs. no use and low vs. no use. There was a lower adjusted average provider communication score among the high-use group compared to low and medium use groups. Waist circumference, average DBP, and CAHPS global doctor rating approached significance. The high-use group had a lower waist circumference than all other categories. Lower average DBP was found comparing high and no vs. medium use. Global doctor rating was higher in medium compared to the high use group. PHR use was also associated with fasting glucose; however, the interaction between use and baseline glucose levels was significant such that the association between use and fasting glucose at visit 4 is modified by fasting glucose at baseline.

In sum, our findings suggest that in hypertensive patients, simply providing access to a PHR (with some coaching at each of 4 visits) did not reduce blood pressure, increase patient activation or empowerment as measured via self-report instruments, improve quality of care ratings, or reduce medical utilization. More positively, in those patients who used the PHR at least twice a month, there was a reduction in SBP and DBP. Low frequency of use was associated with initially lower scores on CAHPS scores including global doctor rating, provider communication composite score, and helpfulness of HIT. CAHPS scores were collected but not yet shared with CAHPS Benchmarking Database.

**Table 3. Analysis of covariance of visit 4 measures by frequency of PHR use among the intervention group**

**Table 3a. Biological measures**

	Freq. of Use of PHR: No Use—V1 Mean	Freq. of Use of PHR: No Use—V4 Mean	Freq. of Use of PHR: No Use—Change	Freq. of Use of PHR: Low Use—V1 Mean	Freq. of Use of PHR: Low Use—V4 Mean	Freq. of Use of PHR: Low Use—Change	Freq. of Use of PHR: Med. Use—V1 Mean	Freq. of Use of PHR: Med. Use—V4 Mean	Freq. of Use of PHR: Med. Use—Change	Freq. of Use of PHR: High Use—V1 Mean	Freq. of Use of PHR: High Use—V4 Mean	Freq. of Use of PHR: High Use—Change	ANCOVA p-value
Waist circ (cm)	106.63	106.98	-0.35	108.09	107.66	0.44	109.86	111.00	-1.14	106.67	104.53	2.94	0.07 <sup>†</sup>
Average SBP	126.70	124.37	2.33	132.44	127.66	4.78	125.07	127.14	-2.07	132.53	128.56	3.97	0.74
Average DBP	73.72	73.19	0.53	75.19	74.03	1.16	77.66	79.07	-1.41	81.72	76.47	5.25	0.10 <sup>‡</sup>
Fasting glucose	110.20	122.37	-13.70	110.85	110.27	-6.43	114.00	124.60	-10.88	113.94	117.84	-9.54	0.003 <sup>§</sup>

**Table 3b. Patient perceptions of quality measures**

	Freq. of Use of PHR <sup>†</sup> : No Use—V1 Mean	Freq. of Use of PHR <sup>†</sup> : No Use—V4 Mean	Freq. of Use of PHR <sup>†</sup> : No Use—Change	Freq. of Use of PHR <sup>†</sup> : Low Use—V1 Mean	Freq. of Use of PHR <sup>†</sup> : Low Use—V4 Mean	Freq. of Use of PHR <sup>†</sup> : Low Use—Change	Freq. of Use of PHR <sup>†</sup> : Med. Use—V1 Mean	Freq. of Use of PHR <sup>†</sup> : Med. Use—V4 Mean	Freq. of Use of PHR <sup>†</sup> : Med. Use—Change	Freq. of Use of PHR <sup>†</sup> : High Use—V1 Mean	Freq. of Use of PHR <sup>†</sup> : High Use—V4 Mean	Freq. of Use of PHR <sup>†</sup> : High Use—Change	ANCOVA p-value
CAHPS: Global Doctor Rating	9.54	9.40	0.13	9.69	9.53	0.16	9.62	9.72	-0.10	9.77	9.32	0.45	0.07 <sup>†</sup>
CAHPS: Provider Communication composite	5.76	5.63	0.12	5.88	5.84	0.03	5.87	5.87	0.01	5.89	5.61	0.26	0.03 <sup>††</sup>
CAHPS: HIT Helpfulness	3.75	3.50	0.25	3.90	3.96	-0.07	3.78	3.79	0.06	3.86	3.80	0.04	0.02 <sup>†††</sup>

<sup>†</sup> Categories of frequency of use: No Use – PHR use only during training; Low Use – PHR used one to two times after training; Medium Use – PHR used three to five times after training, every other month, or monthly; and High Use – PHR used at least two times per month. Missing on 53 patients from the intervention group.

<sup>†</sup> Differences detected between no use vs. high use (p=0.03), and medium use vs. high use (p=0.01).

<sup>‡</sup> Differences detected between no use vs. medium use (p=0.03), and medium use vs. high use (p=0.04).

<sup>§</sup> Significant interaction between frequency of use and baseline categorical variable.

<sup>\*\*</sup> Differences detected between medium use vs. high use (p=0.01).

<sup>††</sup> Differences detected between low use vs. high use (p=0.01), and medium use vs. high use (p=0.02).

<sup>†††</sup> Differences detected between no use vs. low use (p<0.01), no use vs. high use (p=0.04).

Abbreviations: PHR = personal health record; ANCOVA = analysis of covariance; Circ = circumference; cm = centimeters; SBP = systolic blood pressure; DBP = diastolic blood pressure; CAHPS = Consumer Assessment of Health Plans Survey; HIT = Health Information Technology.

### Aim 3

**End of Study Interviews.** 122 patients who used the PHR, 13 physicians, and 16 nurses completed end of study interviews or focus groups and the Patient Empowerment Scale (PES). Providers were as likely as patients to perceive any benefits from PHR in both the PES and interviews (97% vs 91%). 87% of patients and 77% of providers viewed the PHR as empowering patients. Providers were more likely to identify concerns surrounding PHR use (97% vs 67%) with the three most common including: patient confusion about lab results (93% vs 36%); patient worry (83% vs 24%); and that patients would be offended by comments in the record (69% vs 12%). Patients’ most frequent themes about PHR usefulness were the ability to track medical data, review and update data, and medication management.

**Table 4. Comparing patients and providers for post-study patient empowerment scale scores**

**Table 4a. Score**

	<b>Patients (n=122): Median (Range)</b>	<b>Providers (n=29): Median (Range)</b>	<b>p-value Kruskal-Wallis Test</b>
PES Total Score: maximum score = 56	42 (24-55)	37 (28-49)	0.0002
PES Sub-Scale Score: maximum score = 36	27 (9-36)	26 (17-33)	0.0396

**Table 4b. Statement: expected benefits**

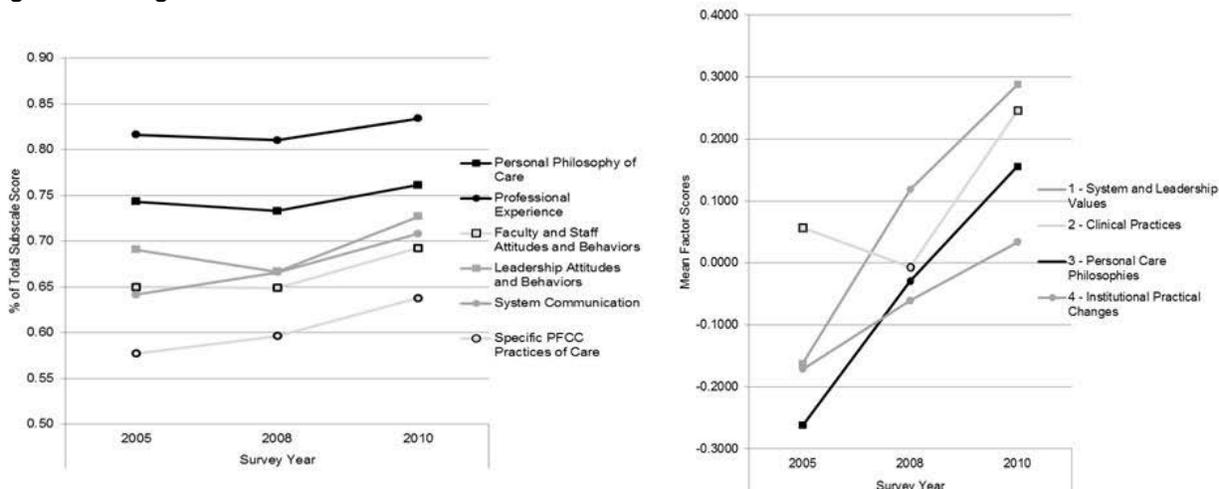
	<b>Patients (n=122): n (%) in agreement</b>	<b>Providers (n=29): n (%) in agreement</b>	<b>Providers (n=29): Chi- Square Test</b>
Patients would be prepared for visits	93 (78.2)	23 (79.3)	0.8919
Patients would have increased trust in providers	83 (69.8)	21 (72.4)	0.7782
Patients would have improved understanding of their medical condition	94 (77.7)	17 (58.6)	<b>0.0355</b>
Patients would have improved understanding of the provider's instructions	87 (71.3)	23 (79.3)	0.3840
Patients would identify errors in record	92 (76.0)	24 (82.8)	0.4372
Patients would be reassured	95 (78.5)	18 (62.1)	0.0650
Patients would have improved adherence to provider recommendations	92 (75.41)	21 (72.4)	0.7382
Patients would have an increased sense of control	99 (81.2)	25 (86.2)	0.5228
Patients would have greater satisfaction	88 (72.1)	18 (62.1)	0.2869

**Table 4c. Statement: expected risks**

	<b>Patients (n=122): n (%) in agreement</b>	<b>Providers (n=29): n (%) in agreement</b>	<b>Providers (n=29): Chi- Square Test</b>
Patients would be confused by provider notes	31 (25.8)	15 (51.7)	<b>0.0068</b>
Patients would be confused by test results	43 (35.5)	26 (92.9)	<b>&lt;0.0001</b>
Patients would have more questions between visits	53 (44.9)	21 (72.4)	<b>0.0080</b>
Patients would worry more	29 (24.0)	24 (82.8)	<b>&lt;0.0001</b>
Patients would be offended by some things in their record	14 (11.6)	20 (69.0)	<b>&lt;0.0001</b>

**PFCC Culture Survey.** The majority of respondents (N=1643) were female and white, non-Hispanic. Most respondents were faculty or staff, with median age of 44. Familiarity with PFCC improved over time, with 38.7% reporting being very familiar with PFCC concepts in 2005, 59.5% in 2008, and 63.1% in 2010 ( $p<0.0001$ ). A priori conceptually defined scales demonstrated solid reliability with Cronbach's alpha coefficients ranged from 0.54 to 0.96. In one-way ANOVA models, 5 of the 6 conceptual scales showed significant improvements in 2010 compared to 2005 and 2008 (Figure 2). Professional experience showed a slight, though not significant, improvement. Four factor-derived scores (explaining 53.7% of the variance) reflecting System and Leadership Values, Clinical Practices, Personal Care Philosophies, and Institutional Practice Changes also increased with time. These changes paralleled increasing use of Patient Advisors as well as incorporation of the PHR during the study time frame.

**Figure 2. Changes in PFCC cultural attitudes over time**



**Table 5. PFCC growth- patient & family advisors program**

	2007	2008	2009	2010
Total number of Patient Advisors	178	229	257	325
Committees with Patient and Family Advisors Serving	14	17	18	21
Number of hours served by Patients and Family Advisors	2192	2707	2647	2902
Patient and Family Advisors on Special Project Committees	17	21	28	44
Unit and Medical Office Based Patient Advisory Councils	18	27	34	40
Patient advisors on Quality and Safety Committees	4	6	10	8
Patient and Family Advisor "Patient as Faculty" hours	104	107	110	121

Reviewing the goals of the ASQ initiative, patients ended the study with more positive impressions of the PHR than physicians even though they still identified many potential improvements. Physicians continued to express concerns over patient confusion, worry, and the possibility of being offended by documentation. The process by which to include a PHR in the actual clinical visit remained unclear to both patients and providers. We conclude that it remains difficult to determine the global impact of PHR interventions in real-life settings due to the great range of changes occurring in all health care settings. Although we observed increasing acceptance of PFCC, implementation of other PFCC initiatives most likely contributed to change in culture as well as the snowball effect of culture changes overall.

## Outcomes

In relation to our proposed hypotheses and the principal findings discussed above we found the following.

**Hypothesis 1: Inclusion of Patients and Families in the Design of the PHR Will Increase the Acceptability and Amount of Use by Patients in the Pilot Samples.** Inclusion of patients and patient and family advisors in the development of an existing PHR did improve certain

elements of acceptability (i.e. In Wave 2 medical jargon did not appear as a theme), however PHR use still remained low overall with those enrolled in the PHR arm of the Aim 2 trial.

**Hypothesis 2a: Patients in the Intervention Group (Using the PHR) will Score Higher on Measures of Self-Activation, Rate Their Process of Care as More in Line with the Chronic Care Model, and Experience More Collaborative Communication with Their Healthcare Team Than Patients in the “Care As Usual” Group.** Overall we found minimal differences between patients in the intervention group (using the PHR) and those in the control group. Weight, BMI, waist circumference, HDL levels, PES total empowerment scores, CAHPS global doctor rating, CAHPS composite doctor communication rating, and CAHPS composite office staff rating were significant, however none of the raw effect sizes were of sufficient magnitude to imply clinically meaningful differences between groups. When looking at the rate of PHR use among the intervention patients we found that 54% used it less than twice during the study period, 20% used it 3-5 times, and 26% used it about twice a month. Only about 10% used the PHR weekly or more during the study period. Due to the low rates of use among intervention patients a sub-analysis was performed to examine potential associations with frequency of use and several predictors of use were identified.

**Hypothesis 2b: Patients in the Intervention Group Will Have Lower Systolic and Diastolic Blood Pressures, Be More in Compliance with Recommended Guidelines, and Will Have Less Emergent Care and Fewer Hospitalization Visits Than Patients in the Comparison Group.** There were no significant differences between intervention and control on either SBP or DBP in the main trial analysis, however, higher DBP was associated with greater PHR use. Among those patients who used the PHR the most frequently, we did observe a 5.25 reduction in DBP and a 3.97 reduction in SBP.

**Hypothesis 3: Implementation of the PHR Will Increase Physician and Staff Positive Attitudes toward Fundamental PFCC Concepts and Will Generate Increased Physician Requests for System-Wide Use of the PHR.** Both patients and providers reflected positively on the PHR in terms of patient empowerment, pre-visit preparation, understanding, recognizing medical errors, adherence and sense of personal control. Providers expressed concern about patient worry, confusion, and the potential for being offended by documentation comments. Results from the PFCC Institutional Survey support an increase in positive attitudes and awareness toward PFCC practices from 2005 to 2008 to 2010. These results corresponded to increasing PFCC implementation throughout the healthcare system of which the PHR was only one minor part and therefore cannot be attributed to the PHR project alone.

## **Discussion and Conclusion**

After the completion of Aim 1 (the patient-centered improvements to the PHR), two main findings were observed in the PHR trial. First, within patients provided the PHR, utilization of the PHR was quite low with only 26% using it frequently. Second, we found minimal differences between patients provided PHR access and those without PHR access in this effectiveness trial conducted in two busy primary care clinics. Contrary to optimism about PHR impact, PHR access alone failed to activate patients, improve outcomes, increase satisfaction with care or change the frequency with which patients use medical services. Simply providing patients a

method to access their health care information did not assure changes in patient outcomes. This underscores the necessity to consider the immediate health outcome potential of subsequent Stage 2 implementation plans for meaningful use criteria that require that patients are provided information access after inpatient and clinical encounters with expectations that 20% will use a portal at least once. Our results suggest Stage 2 implementation in this area may be difficult to accomplish in populations like ours (mean age 55; 50% white, 46% black; 30% high school education or less, 19% no home internet access; 55% with metabolic syndrome) without significant educational and training interventions targeting how patients and providers can use a PHR effectively. In addition, unless PHRs are used at some meaningful level, anticipated changes in patient health outcomes may not occur.

The observed infrequent use of PHRs is a finding similar to others<sup>40-44</sup>. Utilization was infrequent—54% using it less than twice in 9-12 months, 20% using it 3-5 times, and 26% using it about twice monthly. Only about 10% used the PHR weekly or more. Additionally, only 26% of patients approached to participate in the study volunteered, suggesting that PHR utilization by the general population of our patients may actually be much less. What level of PHR use is likely to produce changes remains unknown.

Even though we had worked with patients to improve the PHR functionality, many patient expectations were not met. We recognize that PHRs operate at increasingly useful levels<sup>45</sup> and ours was limited, storing information, providing some linkages and allowing limited tracking and appointment scheduling. Of note, we did not find that ease of entry of BP data via a USB port produced any additional effect on PHR use or outcomes.

We do retain some optimism about PHR potential. Patients who were the most frequent PHR users evidenced a reduction in DBP of 5.25 points and 3.97 in SBP. Although, it is not clear this reduction can be attributed to PHR use, greater motivation to change in general, or other unexamined constructs, we consider 5 factors related to frequency of use that may clarify practical directions for future research that will produce changed health outcomes.

**Access and Technology Skills.** Considering PHR use as a “health practice,” self-efficacy theory suggests that patients need to *view themselves as capable of successfully using the PHR*<sup>46</sup>. Age, self-rated computer skills, number of ways the Internet is used, and baseline perceptions of the utility of HIT predicted PHR use, and all are indicative of higher computer self-efficacy. 83% of infrequent users possessed a home computer compared to 91% of frequent users.

**Salient Clinical Need.** Evidenced in our frequent users as high initial BP, increased need may encourage use. Seventy percent of our patients demonstrated controlled hypertension and may not have perceived a need to document or track BP, thus perceptually limiting immediate need for a PHR. Patients perceiving pronounced need, such as those receiving a new critical diagnosis or those challenged to manage conditions such as abnormal BP, may maximize PHR use.

**Activation.** Patients with the lowest PHR use had the lowest baseline activation scores and patients with the highest PHR use had the highest scores suggesting that *activation* may be a PHR use mediator. However, our high user group demonstrated reduced activation by Visit-4. Our study team is challenged to explain the degradation. For some patients, readiness to engage the health care system may involve “surrendering” decision-making involvement while for

others, readiness may reflect active decision-making preferences. Patients “taking care of [their] health problems” may influence PHR use in contrasting ways.<sup>47</sup>

**Patient-Provider Relationship.** Considering the context of the patient-physician relationship, we found that higher scores on the CAHPS provider communication subscale were associated with greater use of the PHR. Others have found that use of a PHR is most likely when the invitation and interaction of the provider encourages such use.<sup>48-50</sup> Thus before we can expect PHRs to change clinical outcomes, we need to understand how both patient and provider engage the PHR and use the information contained with the PHR in the context of collaborative care. Great variability occurred in our study from both patient- and physician-directed conversations about the PHR and health data contained therein.

**System History.** Examining system level variables, the Family Medicine clinic reported greater PHR use. Discussions with clinic stakeholders suggest patient continuity is highly embedded in their care process, and Family Medicine care teams have used an EMR for 13 years. Both provider and patient comfort with technology and established long-term relationships between patients and providers appear to have stimulated adoption and use of the additional technology of a PHR.

Health informatics trials are ‘complex interventions,’ used with great variability by the patient and provider and uniquely implemented within each health care system.<sup>51</sup> We found infrequent use of a PHR, no increase in patient activation with PHR access or use, and little change in outcomes except in limited areas among those using the PHR frequently. Although clinical outcomes such as BP are typically considered the prime objective, process adaptation and intermediary measures are arguably critical to understand PHR use. Expectations of the outcomes produced by patient access to a PHR may need to be tempered until we understand which patients choose to use PHRs and how they use them. It is critical to understand how providers and systems can best incorporate PHRs into the practice settings and individual clinical encounters where the physician and patient join together to use the increased health information. Meaningful use criteria will support the provision of and access to web portals and PHRs. However, additional steps will be necessary to conclude that such access will improve patient health outcomes.

## Significance

Although our study did not produce significant change in the measured outcomes, it does help set direction for future research in PHR. We posit that next steps examine methods of teaching patients about health information within the context of technology applications. Understanding of individual patient needs and questions would allow for individualized implementation of the PHR to best satisfy their questions. We also posit that implementation needs occur differently for different contexts and that some patients will not immediately benefit from access to their health information. Patients who have immediate need, are active in their own care already, have access to technology and have skills therein, will most immediately benefit. In addition, on the provider front, the partnership between patients and providers remains critical. We must study how to best incorporate patient use of data within the context of the clinical setting instead of simply expecting patients to use their health information independently. Finally, health care systems must be ready to have a different kind of patient, one expecting care

that addresses their individual needs and values; a patient expecting to have impact on the health care system; a system that incorporates patient-centered care.

As we address safety and quality in the ambulatory setting, part of the work is building relationships among patients, providers, and the systems in which they interact. Patient-centered health technology initiatives need to be formulated on the premise that each patient needs unique health information to understand and make better personal health care decisions. Can we create PHRs that assist a patient in understanding their own specific health assets, weaknesses, beliefs and values? And if we can understand their unique perspective, can we frame their health information in a way that builds on the context of the individual's personal values, beliefs and health care questions? We will need to identify the information gaps with which patients struggle, and find technological ways to make answers easy to find. Further, we need to study the process by which we incorporate PHRs into busy practice settings augmenting technological interventions with the strength of the patient-provider relationship to maximize potential for health outcomes impact.

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## List of Publications & Products

Wagner, PJ Bentley, DR, Howard, SM,Seol,YH, Sodomka, PK. "Incorporating Patient Perspectives into the Personal Health Record: Implications for Care and Caring" *Perspectives in Health Information Management*, Fall 2010.

Wagner, PJ, Dias, J, Howard, S, Kintziger, K, Hudson, M, Seol, Y, Sodomka, P. "Personal Health Records and Hypertension Control: A Randomized Trial" *Journal of the American Medical Informatics Association*, in press.

Wagner, PJ, Howard, S, Kintziger, K, Dias, J, Sodomka, P. "Measuring Institutional Culture Change about Patient-and Family-Centered Care" *Journal of the American Board of Family Medicine*, under review.

Wagner, PJ, Howard, S, Kintziger, K, O'Meara, C, Sodomka, P. "Personal Health Records and Patient Empowerment: Patient and Provider Perceptions" in preparation.

Wagner, PJ, Howard, S, Kintziger, K. "Impact of Personal Health Records on Adherence to Guidelines for Hypertension Care," in preparation.

Seol, YH, Wagner, PJ, Howard, S. Assessing Patients' Perceptions and Experiences in Using the Personal Health Record: An analysis of the exit interview," in preparation.

Seol, YH, Wagner, PJ, Howard, S. "Assessing the Usability of a Personal Health Record," in preparation.