Impact of electronic personal health record use on engagement and intermediate health outcomes among cardiac patients: a quasi-experimental study

RECEIVED 2 March 2015 REVISED 10 September 2015 ACCEPTED 10 September 2015





Tammy Toscos^{1,2}, Carly Daley¹, Lisa Heral¹, Riddhi Doshi³, Yu-Chieh Chen⁴, George J Eckert⁵, Robert L Plant^{1,6}, Michael J Mirro^{1,6} **ABSTRACT**

Objectives To determine the impact of tethered personal health record (PHR) use on patient engagement and intermediate health outcomes among patients with coronary artery disease (CAD).

Methods Adult CAD patients (N= 200) were enrolled in this prospective, quasi-experimental observational study. Each patient received a PHR account and training on its use. PHRs were populated with information from patient electronic medical records, hosted by a Health Information Exchange. Intermediate health outcomes including blood pressure, body mass index, and hemoglobin A1c (HbA1c) were evaluated through electronic medical record review or laboratory tests. Trends in patient activation measure (PAM) were determined through three surveys conducted at baseline, 6 and 12 months. Frequency of PHR use data was collected and used to classify participants into groups for analysis: *Low, Active*, and *Super* users.

Results There was no statistically significant improvement in patient engagement as measured by PAM scores during the study period. HbA1c levels improved significantly in the *Active* and *Super* user groups at 6 months; however, no other health outcome measures improved significantly. Higher PAM scores were associated with lower body mass index and lower HbA1c, but there was no association between changes in PAM scores and changes in health outcomes. Use of the PHR health diary increased significantly following PHR education offered at the 6-month study visit and an elective group refresher course.

Conclusions The study findings show that PHR use had minimal impact on intermediate health outcomes and no significant impact on patient engagement among CAD patients.

Keywords: personal health records, patient portal, coronary artery disease, patient activation measure, health outcomes, and patient engagement.

BACKGROUND AND SIGNIFICANCE

Recent legislation, including the Affordable Care Act and the Health Information Technology for Economic and Clinical Health Act, has created a paradigm shift that has propagated technical means for patients to view and record their own personal health information as well as communicate with their health care providers through an electronic personal health record (PHR). ^{1,2} But are patients prepared and motivated to take action on the information they are provided through a PHR? Although there are promising findings that link increased patient activation and improved health outcomes with PHR use, ^{3–7} there is also evidence that suggests that this method of engaging patients has not yet made the impact originally projected. ^{1,8–14}

A PHR is an Internet-based set of tools that allows people to access and coordinate their lifelong health information and make appropriate parts of it available to those who need it. 15 PHRs can be free standing (untethered) or connected (tethered) to an electronic medical record (EMR) operated by a health system or health care provider. Use of a PHR may help patients take an active role in their health care as a result of an improved understanding of their health and related conditions. 16 The PHR is also emerging as a critical e-health tool by which legislative health information technology goals may be met, including meaningful use rules 17 and patient centered medical home criteria. 18 However, there is still a

lack of understanding about how best to leverage this tool to engage patients and to which populations targeted efforts should be directed.

A growing emphasis has been placed on increasing patient engagement as a means of enhancing self-management of chronic disease and informed medical decision-making. Patient engagement and patient activation are often used interchangeably; however, the terms have distinct meanings. Patient activation refers to an individual's ability to understand their role in managing their own health and having the knowledge, skills, and confidence to do so. ¹⁹ Patient engagement is an umbrella term that includes patient activation and the actual patient behavior that results from an intervention. In this study, we evaluate patient engagement by proxy through changes in a validated survey instrument that measures patient activation. We also measure health outcomes, which are dependent on health behaviors influenced by patient engagement (smoking cessation, weight control, diet, exercise).

OBJECTIVE

This study was designed to help understand the influence of PHRs on patient engagement and intermediate health outcomes. Our work is focused on people living with significant coronary artery disease (CAD). We selected this patient population because CAD affects over

Correspondence to Tammy Toscos PhD, Parkview Research Center, Indiana University School of Informatics and Computing, Fort Wayne, IN 46845, USA; tammy.toscos@parkview.com

© The Author 2016. Published by Oxford University Press on behalf of the American Medical Informatics Association. All rights reserved. For Permissions, please email: journals.permissions@oup.com For numbered affiliations see end of article.

15 million adults across the United States²⁰ and is the cause of almost 1 in every 6 deaths.²¹ The growing population of chronically ill CAD patients has increased the burden of health care costs on the health care system, with the total direct and indirect cost of cardiovascular diseases and stroke amounting to almost \$313 billion each year.²² Thus, the need to intensify efforts to manage patients noninvasively with lifestyle modification and medical therapy has never been greater.

Significant research has linked improvements in health outcomes for the CAD population to behaviors including proper medication management and lifestyle modification such as exercise, weight loss, and smoking cessation. ²³ Historically, physicians provide advice to patients episodically during office visits. The ability to substantially assist in lifestyle changes and medication compliance in this context is limited. PHRs offer a mechanism by which health care providers can reach out to patients in the midst of daily life through secured electronic distribution of medical information and 2-way asynchronous messaging. Enhanced communication may impact patient engagement by creating accountability, increasing health literacy, and fostering patient—provider relationships. The objective of this study was to evaluate if there is any relationship between use of the PHR in patients with significant CAD and improvements in patient engagement.

In this paper, we report the findings from a 12-month study of a tethered PHR that examined: 1) patient engagement using level of patient activation in health care pre- and post-PHR use and 2) intermediate health outcomes including body mass index (BMI), blood pressure, low-density lipoprotein (LDL), and hemoglobin A1c (HbA1c). Our work stands out from prior work that has examined the impact of PHRs on patient engagement^{3-5,24-27} in that we focused specifically on patients with significant CAD and examined the longitudinal impact on intermediate health outcomes. Another important aspect of this work was demonstrating the feasibility of populating a tethered PHR with data from a health information exchange (HIE).

METHOD

This study used a quasi-experimental design with a single group involving pre-post evaluations. The Parkview Institutional Review Board approved this study.

Study population, setting, and recruitment

The inclusion criteria included: age 18–90, significant CAD, internet access, and ability to read and understand the English language. For the purpose of the study, significant CAD was defined as a history of 1 or more major cardiac interventions involving coronary revascularization through elective or emergency percutaneous coronary intervention with stent and/or coronary artery bypass graft. Exclusion criteria included lack of the ability to physically or cognitively carry out the tasks necessary for activating and/or utilizing the PHR.

The study setting is a large cardiology practice in Northeast Indiana, Parkview Physicians Group-Cardiology (PPG-C), which conducts about 70 000 office visits and consultations each year. Post-revascularization, patients receive care for chronic disease management in an ambulatory setting. Adult patients (age 18–90 years) with significant CAD were identified through review of the EMR. During this review, patients with known literacy issues or language barriers were excluded. Eligible patients were invited to participate in the study either by phone or in person in the office. The patient's access to the internet (self-reported) was assessed during this first contact. A trained clinical research coordinator obtained written informed consent from all participants.

Study intervention

Upon enrollment, each study participant was provided with a web-based PHR account, provided by NoMoreClipboard (NMC), with features such as personal information, medical history, prescription history, secure 2-way asynchronous messaging with health care professionals, and educational resources (Figure 1). NMC also worked with the PPG-C to incorporate a daily health diary into the tethered PHR. Patients could self-enter and transmit blood pressure, heart rate, blood glucose, weight, and BMI. Patients could also sign up for daily reminders to complete and submit their diary information. All messages were transmitted securely through the HIE.

The NMC PHR was populated with information from participant EMRs, hosted by an HIE from Medical Informatics Engineering. When new data was available in the PPG-C EMR, the practice could post that data to NMC with a single click – triggering a routing mechanism through the HIE.²⁸ The NMC PHR followed Health Insurance Portability and Accountability Act guidelines and was accessible to patients online from any computer. We refer to the NMC PHR as a tethered PHR because it had a deep level of integration with the PPG-C EMR and was branded with Parkview. However, this technology was designed to be a fully portable, interoperable PHR that can integrate with multiple data sources, making it a unique hybrid that has the strengths of both a tethered and untethered PHR.

During the activation of the PHR account, patients received one-on-one introductory training from a clinical research coordinator regarding how to access and use their PHR. This 30-min training included a printed handbook that patients took home, which included the phone number for technical support available through NMC during business hours. In addition to initial training, all participants were offered a review of basic and advanced functions in an elective "refresher course" in a group setting at PPG-C and also as an interactive online presentation. The scheduled 6-month study visit also included a brief review of how to use the PHR, particularly the health diary.

Downloaded from http://jamia.oxfordjournals.org/ by guest on January 25, 2016

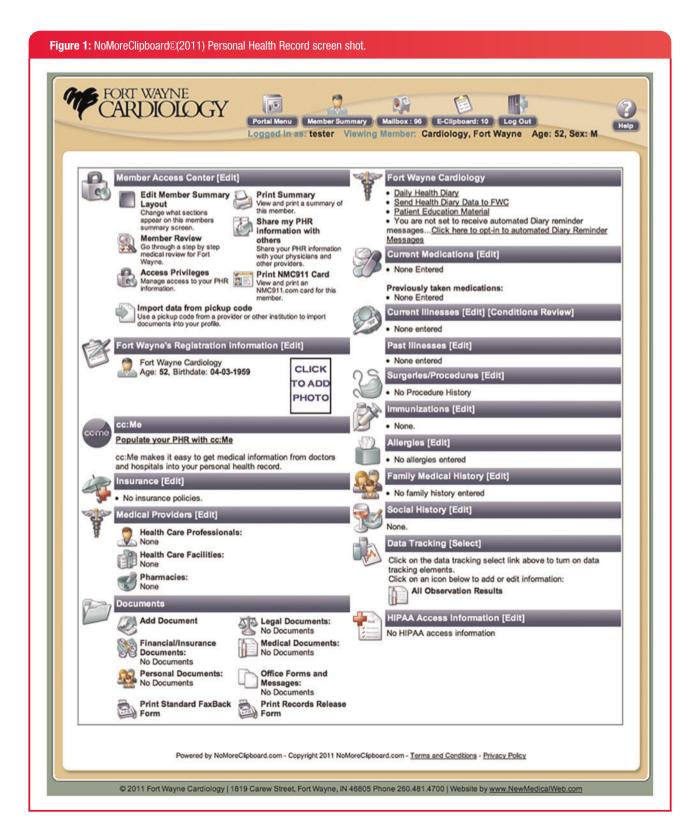
Study design and measures

Participation in the study involved 3 visits – baseline, 6 and 12 months. Health outcome data were collected at each visit, including blood pressure, BMI, LDL, and HbA1c. At baseline, patients were given laboratory orders for LDL and HbA1c if they had not been collected within the last 30 days.

Patient engagement was evaluated using the validated 13-item Patient Activation Measure (PAM®), which measures patient knowledge, skill, and confidence in self-management of health. 19,29,30 The overall PAM score corresponds to 1 of 4 activation levels that indicate an increase in activation, ranging from starting to take a role in one's own health care to maintaining healthy behaviors over time. PAM scores have been validated as a proxy measure of patient engagement. 31

Three surveys (baseline, 6-month, and 12-month) were used to collect data. The baseline survey collected sociodemographic characteristics, external factors such as computer and internet self-efficacy, perceived health status, and PAM questions. The 6- and 12-month surveys included everything in the baseline survey excluding demographic data. Surveys were made available to patients in an online form, using the Health Insurance Portability and Accountability Act-compliant SurveyMonkey[®] software, or in print form, according to patient preference. The link to the electronic survey was provided to patients via a secure message in the PHR, so patients had an option of completing it either during study visits or remotely.

PHR usage data was collected by NMC and included the number of times patients: 1) logged into the PHR and 2) sent a secure message to the clinic via the health diary.



Data analysis

SAS version 9.3 was used to analyze collected study data (Copyright[©] [2011] SAS Institute, Inc., Cary, NC, USA). All analyses were conducted on a per-protocol basis. Summarized results are presented as count (percent) or mean (standard deviation) unless otherwise specified.

Changes in PHR use, PAM scores, and health outcomes were analyzed using paired *t*-tests for continuous data and Cochran-Mantel-Haenszel tests for stratified categorical data. Spearman's correlation coefficients were calculated to evaluate the associations among PAM, PHR use, and health outcomes. Multiple linear regression models were used to

evaluate predictors of PHR use, PAM scores, and changes in intermediate health outcomes – systolic (SBP) and diastolic (DBP) blood pressure, BMI, LDL, and HbA1c. No variable selection procedure was used; all variables of interest were included in the models regardless of significance. Demographics and computer/technology abilities (computer and internet self-efficacy, self-perceived health) were included in all models. The analysis of PAM also included the number of logins to determine whether patients who used the PHR more were more activated. The analyses of the health outcomes additionally included both the number of logins and the PAM score.

To determine the impact of varying usage rates among participants, the study group was categorized depending on the number of PHR logins. Patients were designated as 1 of 3 user types: Low, Active, and Super user. Patients in the Low category logged in 1–3 times over the 12-month period; patients in the Active category logged in 4–23 times; and patients in the Super user category logged in 24 or more times. These groupings were determined based on natural breaks that appeared in the login frequency data. Comparisons between the 3 groups were made using Pearson chi-square tests, Mantel-Haenszel chi-square tests, and Kruskal-Wallis tests for unordered categories, ordered categories, and continuous variables, respectively. Similar tests were used to compare subjects who attended the refresher course against those who did not attend.

RESULTS

Patients (N=360) were called or approached in the cardiology office over a time period of \sim 4 months until enrollment of 200 participants was attained. Two people with visual problems and 12 people with a diagnosis related to cognitive impairment were excluded based on chart review screening. Of the 200 patients who were enrolled and completed a baseline survey, 184 (91.5%) responded to the 6-month follow-up survey, and 173 (87%) completed the 12-month survey. Participants missing their 6-month survey were given the opportunity to complete the 12-month survey. Seven people withdrew from the study for a variety of reasons (moved, illness, etc.) and 3 participants passed away during the study period.

Characteristics of study participants

Table 1 illustrates the sociodemographic characteristics of study population according to baseline surveys. More than 70% of subjects enrolled in the study were white males older than 55 years. Approximately 75% of study participants had some college or had completed a college education. About 5% had a total family income < \$20 000, which is consistent with poverty rates for older age groups as represented in this study population. Two-thirds of the study subjects received insurance coverage through Medicare, and 4% were uninsured. At baseline, a majority of the study participants rated their abilities as "good" or "better" for the following: ability to use the computer (71%), ability to use the Internet (73%), and ability to understand online health information (84%). Almost 97% of patients perceived their health status as fair, good, or very good with very few indicating a poor health status.

PHR usage

The mean number of PHR logins declined over the study period. There were 9.43 (± 23.83) logins per patient between baseline and 6 months, which dropped to 8.58 (± 23.14) between 6 and 12 months (P= .053). The proportion of patients who used the daily health diary increased from 32 (16%) in the first half of the study to 53 (28%) in the second half (P< .0001).

At 12 months, there were 36 (18%) *Low* users, 126 (63%) *Active* users, and 38 (18%) *Super* users. *Super* users were significantly older than *Low* or *Active* users (P= .0482); 34% of Super users were age 75+ vs only 19% of Low or Active users. There were no other significant differences in characteristics (Table 1) among usage groups.

Patient activation

Patient activation over the study period was assessed at baseline (67.24 \pm 14.80), 6 months (68.13 \pm 15.21), and 12 months (68.41 \pm 14.89). Although mean PAM scores were higher at 12 months, the change was not statistically significant (P=.22). Mean scores for the entire study cohort remained at activation level 4 during the entire study period, meaning they were in the highest phase of patient activation.

The association between PHR use and patient activation was also examined. Table 2 shows the majority of participants, regardless of usage, had high activation levels of 3 and 4 during the entire the study. *Active* users had the highest percentage of participants at activation level 4 at 6 months (53%) and 12 months (54%), but there were no significant differences among the groups (P>.43). While a higher number of PHR logins throughout the study period was associated with higher PAM scores on the 12-month survey (correlation = 0.17, P=.0213), there was no significant correlation between PHR usage over the year period (logins) and change in PAM score (r=.03, P=.71).

Intermediate health outcomes

Table 3 shows the changes in health outcomes for the entire group of participants over the study period. Although mean LDL, SBP, and DBP all decreased from baseline to 12 months. the changes were not significant (P= .7211, P= .2547, P= .1011, respectively). BMI was essentially unchanged over the course of the study (P= .6582). Mean HbA1c decreased significantly from 6.25% at baseline to 6.09% at 6 months (P= .0006); however, the mean returned to baseline value at 12 months.

Downloaded from http://jamia.oxfordjournals.org/ by guest on January 25, 2016

Examining the impact of PHR usage on the initial 6-month decline in HbA1c, we found a significant improvement in HbA1c among *Active* users (-0.19, P=.005) and *Super* users (-0.19, P=.021), but no change in HbA1c for the *Low* users (Table 4). There were no other significant associations with PHR usage and health outcomes.

There was a significant association between higher SBP and the number of health diary sends at 6 and 12 months (correlation = 0.21 with P = .0057 and correlation = 0.16 with P = .0415, respectively). There were no other significant associations with health diary use and health outcomes.

Higher PAM scores were associated with lower BMI at the 6-month and 12-month surveys (r=-0.23, P=.0020 for both) and also lower HbA1c at 6 and 12 months (r=-0.22, P=.0037 and r=-0.27, P=0.0004, respectively). There were no associations between changes in PAM scores and changes in health outcomes (r<0.01, P>.21).

Factors influencing PHR use

Multiple linear regression was used to predict ePHR use from baseline demographics, computer and internet self-efficacy, and self-perceived health (see Supplementary Table 1). There was no effect related to location type (P=.63); sex (P=.16); age (P=.54); income (P=.82); insurance (P=.48); education (P=.75); or self-perceptions about ability to use the computer (P=.82), use the internet (P=.55), understand internet information (P=.65), or health status (P=.34). In a separate analysis that categorized PHR use into 3 levels and left age in its original 6 levels, we found that while older patients rated their computer and internet abilities lower than younger patients (r=-0.33 and -0.36, respectively, P<.0001), older patients were

		User Type,	Refresher Course, N (%)					
	All (N = 200)	Low (N = 36)	Active (N = 126)	Super (<i>N</i> = 38)	<i>P</i> -value	Yes (N = 30)	No (<i>N</i> = 170)	<i>P</i> -value
Location Type		•						
Urban (city)	72 (36)	15 (42)	41 (33)	16 (42)	.29	13 (43)	59 (35)	.58
Suburban	75 (38)	16 (44)	48 (38)	11 (29)		11 (37)	64 (38)	
Rural Community (country)	53 (27)	5 (14)	37 (29)	11 (29)		6 (20)	47 (28)	
Sex								
Male	145 (73)	25 (69)	92 (73)	28 (74)	.90	21 (70)	124 (73)	.74
Female	55 (28)	11 (31)	34 (27)	10 (26)		9 (30)	46 (27)	
Age								
26–35	1 (1)	0 (0)	1 (1)	0 (0)	.0482	0 (0)	1 (1)	.0015
36–45	2 (1)	1 (3)	1 (1)	0 (0)		0 (0)	2 (1)	
46–55	16 (8)	5 (14)	9 (7)	2 (5)		0 (0)	16 (9)	
56–65	66 (33)	10 (28)	48 (38)	8 (21)		4 (13)	62 (36)	
66–74	71 (36)	13 (36)	43 (34)	15 (39)		16 (53)	55 (32)	
> 74	44 (22)	7 (19)	24 (19)	13 (34)		10 (33)	34 (20)	
Race	•	•	•	•	•	•	•	•
Asian	2 (1)	0 (0)	1 (1)	1 (3)	.62	0 (0)	2 (1)	.69
Black	2 (1)	0 (0)	2 (2)	0 (0)		0 (0)	2 (1)	
White	194 (98)	36 (100)	121 (98)	37 (97)		30 (100)	164 (98)	
Hispanic							•	
Yes	1 (1)	1 (3)	0 (0)	0 (0)	.09	0 (0)	1 (1)	.66
No	172 (99)	29 (97)	110 (100)	33 (100)		28 (100)	144 (99)	
Education								
Less Than High School	3 (2)	0 (0)	1 (1)	2 (5)	.39	0 (0)	3 (2)	.08
High School Graduate/GED	45 (23)	12 (33)	28 (22)	5 (14)		7 (24)	38 (22)	
Trade/Some College	69 (35)	12 (33)	45 (36)	12 (32)		7 (24)	62 (37)	
College Graduate	50 (25)	8 (22)	31 (25)	11 (30)		5 (17)	45 (27)	
PostGraduate	31 (16)	4 (11)	20 (16)	7 (19)		10 (34)	21 (12)	
Family Income			•	•				
\$0-19 999	9 (5)	0 (0)	6 (5)	3 (8)	.23	1 (4)	8 (5)	.10
\$20 000–39 999	40 (22)	9 (26)	19 (17)	12 (32)		10 (38)	30 (19)	
\$40 000–59 999	60 (33)	12 (34)	40 (36)	8 (22)		6 (23)	54 (34)	
\$60 000-79 999	18 (10)	2 (6)	10 (9)	6 (16)		4 (15)	14 (9)	
\$80 000–99 999	27 (15)	5 (14)	17 (15)	5 (14)		4 (15)	23 (15)	
Over \$100 000	30 (16)	7 (20)	20 (18)	3 (8)		1 (4)	29 (18)	
Health Insurance			1	1	1		1	
Private Health Insurance	62 (31)	14 (39)	42 (33)	6 (16)	.28	5 (17)	57 (34)	.30
Titato fioditi filodiano	0= (0.)	()	()	0 (.0)	0	0 ()	0. (0.)	

(continued)

Table 1: Continued											
		User Type, /	V (%)		Refresher Course, N (%)						
	All (N = 200)	Low (N = 36)	Active (N = 126)	Super (<i>N</i> = 38)	<i>P</i> -value	Yes (N = 30)	No (N = 170)	<i>P</i> -value			
Medicaid	4 (2)	0 (0)	3 (2)	1 (3)		0 (0)	4 (2)				
Military Health Care	1 (1)	0 (0)	1 (1)	0 (0)		0 (0)	1 (1)				
None	7 (4)	2 (6)	5 (4)	0 (0)		1 (3)	6 (4)				
Self-Rated Ability to Use Co	omputer										
Poor	10 (5)	3 (8)	5 (4)	2 (5)	.41	1 (3)	9 (5)	.84			
Fair	50 (25)	10 (28)	31 (25)	9 (24)		6 (20)	44 (26)				
Good	81 (41)	16 (44)	47 (37)	18 (47)		16 (53)	65 (38)				
Very Good	41 (21)	3 (8)	32 (25)	6 (16)		6 (20)	35 (21)				
Excellent	18 (9)	4 (11)	11 (9)	3 (8)		1 (3)	17 (10)				
Self-Rated Ability to Use In	Self-Rated Ability to Use Internet										
Poor	10 (5)	2 (6)	5 (4)	3 (8)	.60	1 (3)	9 (5)	.48			
Fair	43 (22)	9 (26)	27 (22)	7 (18)		6 (20)	37 (22)				
Good	88 (44)	17 (49)	52 (42)	19 (50)		17 (57)	71 (42)				
Very Good	41 (21)	3 (9)	32 (26)	6 (16)		6 (20)	35 (21)				
Excellent	16 (8)	4 (11)	9 (7)	3 (8)		0 (0)	16 (10)				
Self-Rated Understanding of	of Internet Health	Info									
Poor	4 (2)	1 (3)	2 (2)	1 (3)	.84	1 (3)	3 (2)	.42			
Fair	27 (14)	5 (14)	18 (14)	4 (11)		3 (10)	24 (14)				
Good	103 (52)	22 (61)	60 (48)	21 (55)		18 (60)	85 (50)				
Very Good	53 (27)	4 (11)	40 (32)	9 (24)		8 (27)	45 (27)				
Excellent	12 (6)	4 (11)	5 (4)	3 (8)		0 (0)	12 (7)				
Self-Perceived Health Statu	JS						_				
Very Poor	0 (0)	0 (0)	0 (0)	0 (0)	.38	0 (0)	0 (0)	.99			
Poor	8 (4)	0 (0)	5 (4)	3 (8)		1 (3)	7 (4)				
Fair	59 (30)	9 (25)	37 (29)	13 (34)		8 (27)	51 (30)				
Good	111 (56)	22 (61)	69 (55)	20 (53)		19 (63)	92 (54)				
Very Good	22 (11)	5 (14)	15 (12)	2 (5)		2 (7)	20 (12)				

Downloaded from http://jamia.oxfordjournals.org/ by guest on January 25, 2016

Table 2: Association of PHR Use and Patient Activation Level (PAM)											
PAM	Baseline						12 months				
Activation Level	Low User	Active User	Super User	Low User	Active User	Super User	Low User	Active User	Super User		
	N=36	N=126	N=38	N = 25	N=121	N=38	N=17	N=118	N=38		
1	2 (6)	4 (3)	3 (8)	2 (8)	7 (6)	1 (3)	2 (12)	2 (2)	1 (3)		
2	2 (6)	16 (13)	5 (13)	6 (24)	12 (10)	9 (24)	1 (6)	22 (19)	6 (16)		
3	17 (47)	50 (40)	10 (26)	5 (20)	38 (31)	10 (26)	8 (47)	30 (25)	12 (31)		
4	15 (42)	56 (44)	20 (53)	12 (48)	64 (53)	18 (47)	6 (35)	64 (54)	19 (50)		

Table 3: Change in Intermediate Health Outcomes over Study Period												
Health Outcome	All Subjects: Baseline					ects with 6-1	Month Data		Subjects with 12-Month Data			
	N	Mean (SD)	Min	Max	N	Time Period	Mean (SD)	<i>P</i> -value	N	Time Period	Mean (SD)	<i>P</i> -value
BMI	198	31.17 (6.52)	18.3	59.5	178	Baseline	31.16 (6.42)		168	Baseline	31.21 (6.53)	
						6-month	31.22 (6.39)			12-month	31.15 (6.58)	
						Change	0.06 (1.28)	.5547		Change	-0.06 (1.76)	.6582
LDL	194	83.02 (34.07)	31	257	177	Baseline	82.29 (34.42)		161	Baseline	82.01 (33.35)	
						6-month	83.11 (33.03)			12-month	81.34 (32.13)	
						Change	0.82 (21.60)	.6160		Change	-0.67 (23.89)	.7211
SBP	200	129.97 (17.07)	90	182	180	Baseline	130.28 (16.91)		171	Baseline	130.03 (17.03)	
						6-month	132.55 (17.41)			12-month	128.58 (16.37)	
						Change	2.27 (17.40)	.0814		Change	-1.45 (16.60)	.2547
DBP	200	69.18 (10.86)	46	103	180	Baseline	69.09 (10.69)		171	Baseline	68.92 (10.53)	
						6-month	69.56 (11.16)			12-month	67.60 (10.33)	
						Change	0.47 (9.82)	.5244		Change	-1.33 (10.53)	.1011
HbA1c	191	6.25 (1.18)	4.8	12.2	175	Baseline	6.27 (1.20)		160	Baseline	6.25 (1.20)	
						6-month	6.10 (1.14)			12-month	6.26 (1.27)	
						Change	-0.17 (0.65)	.0006*		Change	0.01 (0.90)	.8676

bolded value is only statistically significant value change in table

Health Outcome Change		Users		Active Users				er Users		
	N	Mean (SE)	P-value for Change from Baseline	N	Mean (SE)	P-value for Change from Baseline	N	Mean (SE)	P-value for Change from Baseline	P-value for Difference Between Groups
BMI change: 6-month - baseline	25	0.13 (0.25)	.62	116	0.04 (0.12)	.74	37	0.06 (0.21)	.77	.80
SBP change: 6-month - baseline	25	5.48 (4.10)	.19	118	1.15 (1.56)	.46	37	3.68 (2.77)	.19	.68
DBP change: 6-month - baseline	25	0.24 (1.90)	.90	118	0.64 (0.89)	.48	37	0.08 (1.76)	.96	.98
LDL change: 6-month - baseline	22	2.32 (4.55)	.62	118	2.32 (2.00)	.25	37	-4.86 (3.45)	.17	.34
HbA1c change: 6-month - baseline	22	-0.02 (0.10)	.86	116	-0.19 (0.07)	0.0047*	37	-0.19 (0.08)	.0207*	.45
BMI change: 12-month - baseline	17	-0.04 (0.32)	.89	113	0.02 (0.15)	.91	38	-0.30 (0.36)	.42	.59
SBP change: 12-month - baseline	17	-2.12 (3.39)	.54	116	-1.64 (1.54)	.29	38	-0.58 (2.95)	.85	.97
DBP change: 12-month - baseline	17	-2.00 (1.56)	.22	116	-1.33 (0.96)	.17	38	-1.03 (2.03)	.62	.85
LDL change: 12-month - baseline	15	0.13 (6.36)	.98	109	0.38 (2.10)	.86	37	-4.11 (4.76)	.39	.50
HbA1c change: 12-month - baseline	15	0.16 (0.19)	.41	108	0.01 (0.09)	.91	37	-0.05 (0.12)	.71	.84

bolded value is only statistically significant value change in table

actually more likely to be *Super* users, logging in to their PHRs more frequently than younger patients in the study.

DISCUSSION

Studies have shown that among patients with chronic conditions, those who were more engaged or activated in their care displayed better

communication with their provider and experienced fewer hospital readmissions and medical errors than those who lacked the knowledge, skills, and confidence in managing their own health care. $^{\rm 33}$ Toward this goal, our prospective quasi-experimental study made an inquiry into the effect and association of a tethered PHR with patient engagement and health outcomes among chronic CAD patients.

Patient activation

There are some studies that demonstrate a positive relationship between patient activation and PHR use. A 12-week randomized controlled trial of patients with asthma, hypertension, and diabetes (N= 201) revealed improvements in patient activation and ability to self-manage associated with use of a tethered PHR with secure messaging and targeted health education modules. In a cross-sectional observational study of 40 HIV positive patients, Crouch et al. found that those who used the PHR had significantly higher PAM scores and satisfaction with care than those who did not use the PHR. Hibbard and Greene conducted a cross-sectional analysis of 16 357 patients who had a recent primary care office visit and found that higher activated patients were more likely to use a PHR.

In our study, we found participants with higher PAM scores had a higher number of PHR logins, but found no significant relationship between PHR use and *change* in PAM scores. Our findings are comparable to results of a telephone survey done by Ancker et al., 27 which found that patients using PHRs ($N\!=\!180$) were not more highly activated when compared with nonusers, but rather more educated and more likely to use the Internet. Similarly, in a cluster-randomized effectiveness trial of a tethered PHR aimed at blood pressure management in patients ($N\!=\!466$) with hypertension, Wagner et al. 24,25 found that participants rarely used the PHR and demonstrated no increase in patient activation.

Health outcomes

According to recent systematic review, 14 PHR use has been found to be associated with improved health outcomes in a small number of studies, particularly among patients with type 2 diabetes (T2D). Tenforde et al.34 completed a retrospective chart audit of audit patients with T2D (N=10746) and found that frequency of PHR use was associated with improved diabetes quality measures, including HbA1c. A cross-sectional study of 54 patients with T2D found a significant relationship between self-reported use of secure messaging via the PHR and improved glycemic control. 35 Sakar et al. 36 found improvements in medication adherence and blood lipid levels in an observational cohort study of 8705 T2D PHR users with a 9055 matched reference group. While we found a statistically significant improvement in HbA1c in the study population at 6 months, this was not associated with changes in PAM scores. However, we did show that the patients who experienced statistically significant improvements in HbA1c were in the Active and Super user groups, while no improvements were seen in the *Low* user group during that time period. The statistically significant improvement in HbA1c as demonstrated through this short-term evaluation supports the hypothesis linking exposure to PHR and improvement in intermediate health outcomes. However, this improvement was not sustained in the second half of the study.

LDL and blood pressure declined over the 12-month study, but this was not a statistically significant change. Mean BMI of approximately 31 was essentially unchanged from baseline to 12 months, leaving patients at risk in the overweight category. Our findings seem to suggest that the simple provision of health information via a PHR may not be enough to provoke or sustain improvements in health outcomes in our study population. It is possible that the PHR design and functionality did not match the needs of the highly activated patient population in this study. A recent study³⁷ compared 10 PHRs based on 5 measures 1) Problem, Diagnosis, and Treatment Basic: encompasses related functions; 2) Self Health Monitoring: functions that help the patient manage his or her communications

with others related to health care; 4) Security and Access Control: access control and security functions; and 5) Intelligence Factors: intelligent data presentation, data export, and system alerts. NMC was average, scoring roughly in the middle of the 10 PHRs compared. The item on which the NMC PHR scored lower than the majority was Intelligence Factors. Health behavior change is a complex human process that may require a more disease-specific approach and perhaps more intelligent functionality to complement basic access to health data via PHRs.

Factors influencing PHR use

There was a dropoff in PHR logins from the first 6 months to the second half of the study. We believe this was related to the "novelty effect" because the PHR was brand new to the practice at the time of the study, likely contributing to initial excitement about using a new technology followed by a leveling off of interest. Providing participants with additional PHR training also potentially influenced usage frequency during our study. First, patients received a brief review of the health diary during the second study visit, after which a significant rise in use was seen. Second, an elective "refresher course" was offered after participants had completed 6 months of the study – 30 patients attended. There was a surge in health diary use in the second half of the study, especially in patients with high blood pressure. This finding is in contrast to prior research by Wagner et al., 24,25 who found patients with hypertension rarely used the study PHR. One plausible interpretation for this trend is that patients with high BP may have been using the health diary more frequently, perhaps to send home-monitored BP readings to their cardiologists. An alternative interpretation is that frequent use of the health diary had an adverse effect upon BP, although this seems unlikely given a similar but nonsignificant correlation between baseline SBP and the number of sends (correlation = 0.13. P= .07). It is possible that the refresher course (within the limitations of a small sample size, nonrandomization, and self-selection of subjects to the refresher) also contributed to the increase in health diary use in the 6- to 12-month period of the study. These additional training experiences may have helped to increase understanding of PHR functionality as well as promote use of the health diary.

Downloaded from http://jamia.oxfordjournals.org/ by guest on January 25, 2016

Another interesting finding was the age range of PHR *Super* users. Although older patients were more likely to be *Super* users – logging into their PHR more frequently than younger patients in the study – older patients also rated their computer and Internet abilities lower than younger patients. Ancker et al.²⁷ similarly found that older patients were less likely to be offered PHR accounts but, once offered, were more likely to activate and use them. Chrischilles et al.³⁸ also found older patients were interested in PHR for tracking medication and health information. This evidence suggests that health care providers should not hesitate to try technology-based interventions with older populations, as individuals in this group may have additional time and inclination to learn the necessary skills.

Technical feasibility of using HIE data

This study also demonstrated the ability to make HIE data available to patients with a PHR in a clinical setting, overcoming some of the technical barriers identified in prior research.³⁹ NMC was able to rapidly develop and test solutions that enabled patients to access, manage, and benefit from HIE data. This project demonstrated the feasibility of 1) making HIE data available and easily accessible to patients using established interoperability standards; 2) ensuring appropriate patient identification and authentication for secure data transmission from an HIE; and 3) enabling secure messaging between patients and clinicians using an HIE as a routing service.²⁸

Study limitations

One limitation to generalizing these findings is the study population, which was mainly white males over 55 years of age who were educated, insured, not living with income below poverty level, of fair health or better, had a mean patient activation level of 4, and were confident using a computer and the Internet. While the age-structure of the study population is representative of the significant CAD population, ²⁰ the education rates and race diversity are not representative of the United States population. 40 Our results were also confounded by the fact that participants were required to come to the office at 6 and 12 months for lab and survey data, despite the fact that these meetings coincided with routine follow-up care and matched the standard of care typically used for general CAD patients. Regardless, these meetings may have created an additional sense of awareness in participants that their PHR activity was being observed, and some may have logged in more frequently as a result of Hawthorne effect. Another limitation in the interpretation of our results is the lack of a control group, which would have led to more valid findings. Because this study was conducted in an authentic clinical practice and the standard of care was that patients were being messaged data regarding CAD care in a nonstandardized fashion, a true control group would not have been possible. The introduction of the PHR to PPG-C was a new concept at the time of the study, and part of our study focus was simply to demonstrate the feasibility of using the technology in the cardiology practice environment. The goal was not only to improve patient engagement, but also to prepare for compliance with phase 2 of meaningful use.²⁸ In addition, quasi-experimental single group, pre-post study designs are well accepted in the scientific community. The findings are also limited by the fact that we did not formally evaluate the usability of the NMC PHR when compared with other vendors.

CONCLUSION

The management of chronic disease such as CAD is influenced by patient engagement - patient activation (an individual's ability to understand their role in managing their own health and having the knowledge, skills, and confidence to do so) and change in health behavior.²³ The evolution of Internet tools, specifically PHRs, has created an opportunity to provide additional resources to patients, which can result in increased patient engagement and improved health outcomes. The lack of sustained improvement in patient activation and health outcomes observed in this study may have been related to the population we studied, who rated themselves as highly activated at the beginning of the study and thus had no room to improve. The null findings could have also resulted from our study design, which lacked a control group. In addition, the PHR was not designed specifically for CAD patients. Applying a user-centered design approach to create a PHR that is purposefully focused on the unique needs of this patient population may improve outcomes. Designing an intervention aimed at health behavior change is complex and as we, and others, ³⁹ found, can be complicated by a variety of sociotechnical factors that are difficult to control for in a study. In keeping with meaningful use rules for the use of EMRs, 1,17 it is imperative to conduct further research into the long-term relationship between patients' use of a PHR linked to EMRs and intermediate health outcomes.

ACKNOWLEDGEMENTS

This project was supported through a grant from the Office of National Coordinator for Health Information Technology. We are grateful for the panel of reviewers from *JAMIA* whose feedback significantly improved the presentation of our work.

FUNDING

This work was supported by the Office of National Coordinator for Health Information Technology, grant number EP-HIT-10-002.

COMPETING

The authors have no competing interests to declare.

CONTRIBUTORS

C.D., L.H., R.D., G.E., R.P., and M.M. were involved with the conception of the research and study protocol design. C.D. and L.H. executed the study and collected the data. M.M. recruited patients and provided clinical research oversight as Pl. T.T., C.D., L.H., R.D., G.E., and Y.C. were involved with analysis and interpretation of data from the work. G.E. conducted all of the statistical analysis. T.T., supported by C.D., L.H., R.D., G.E., and Y.C., wrote the first draft of the manuscript. All authors critically commented on and revised the manuscript at all stages of development. All authors have read and approved the final version of the paper. This research was conducted while R.D. was employed at Parkview and M.M. was employed at Parkview Physicians Group - Cardiology.

SUPPLEMENTARY MATERIAL

Supplementary material is available online at http://jamia.oxfordjournals.org/.

REFERENCES

- The Health Information Technology Resource Center. The value of personal health records and web portals to engage consumers and improve quality. Robert Wood Johnson Foundation. 2012;1–9. Available at: http://force-s4quality.org/af4q/download-document/5596/Resource-value_of_personal health records and web portals 12-000-for rwif review.pdf.
- United States Congress. Patient Protection and Affordable Care Act. Pub. L. No. 111-148, §2702, 124 Stat. 2010; 119, 318-319.
- Hibbard JH, Greene J. Who are we reaching through the patient portal: enqaging the already engaged?. Int J Pers Cent Med. 2011;1(4):788–793.
- Nagykaldi Z, Aspy CB, Chou A, et al. Impact of a Wellness Portal on the delivery of patient-centered preventive care. J Am Board Fam Med. 2012;25(2):158–167.
- Solomon M, Wagner SL, Goes J. Effects of a Web-based intervention for adults with chronic conditions on patient activation: online randomized controlled trial. J Med Internet Res. 2012;14(1):e32.
- Hibbard JH, Greene J. Who are we reaching through the patient portal: engaging the already engaged?. Int J Person Centered Med. 2011;1(4):788–793.
- Crouch PCB, Rose CD, Johnson M, Janson SL. A pilot study to evaluate the magnitude of association of the use of electronic personal health records with patient activation and empowerment in HIV-infected veterans. *PeerJ.* 2011;3:e852.
- Tang PC, Ash JS, Bates DW, et al. Personal health records: definitions, benefits, and strategies for overcoming barriers to adoption. JAMIA. 2006;13(2):121–126.
- Nazi KM. Veterans' voices: use of the American customer satisfaction index (ACSI) survey to identify my HealtheVet personal health record users' characteristics, needs, and preferences. *JAMIA*. 2006;17(2):203–211.
- Haggstrom DA, Saleem JJ, Russ AL, et al. Lessons learned from usability testing of VA's personal health record. JAMIA. 2011;18:i13-i17.
- Tsai J, Rosenheck RA. Use of the internet and an online personal health record systems by US Veterans Affairs mental health service users and other veterans nationally. *JAMIA*. 2012;19:1089–1094.
- 12. Goel MS, Brown TL, Williams A, et al. Patient reported barriers to enrolling in a patient portal. *JAMIA*. 2011;18:i18–i112.
- Ammenwerth E, Schnell-Inderst P, Hoerbst A. The impact of electronic patient portals on patient care: a systematic review of controlled trials. *J Med Internet Res.* 2012;14(6). Available at: http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3510722/.
- Price M, Bellwood P, Kitson N, Davies I, Weber J, Lau F. Conditions potentially sensitive to a Personal Health Record (PHR) intervention, a systematic review. BMC Med Inform Decis Mak. 2015;15(1):32.

- Markle Foundation. The personal health working group final report. 2003. http://www.providersedge.com/ehdocs/ehr_articles/The_Personal_Health_ Working_Group_Final_Report.pdf. Accessed February 24, 2015.
- Ball MJ, Smith C, Bakalar RS. Personal health records: empowering consumers. J Healthc Inf Manag. 2007;21(1):76–86.
- Ahern DK, Woods SS, Lightowler MC, et al. Promise of and potential for patient-facing technologies to enable meaningful use. Am J Prevent Med. 2011;40(5):S162–S172.
- National Center for Quality Assurance (NCQA). NCQA's Patient-Centered Medical Home (PCMH) 2011 Standards. 2011. http://www.ncqa.org. Accessed February 24, 2015.
- Hibbard JH, Mahoney ER, Stockard J, et al. Development and testing of a short form of the patient activation measure. Health Serv Res. 2005;40(6p1):1918–1930.
- Go AS, Mozaffarian D, Roger VL, et al. Heart disease and stroke statistics— 2013 Update: a report from the American Heart Association. *Circulation*. 2013;127(1):e6—e245.
- Wonder C. Compressed Mortality File. Secondary Compressed Mortality File. http://wonder.cdc.gov/mortSQL.html. Accessed February 24, 2015.
- Medical Expenditure Panel Survey (MEPS) of the Agency for Healthcare Research and Quality (AHRQ). United States; 2008.
- National Institutes of Health. How To Prevent and Control Coronary Heart Disease Risk Factors. http://www.nhlbi.nih.gov/health/health-topics/topics/hd/prevent. Accessed February 25, 2014.
- Wagner PJ, Sodomka P, Dias J, et al. Using an Electronic Personal Health Record to Empower Patients with Hypertension. Rockville (MD): Agency for Healthcare Research and Quality; 2011. http://healthit.ahrq.gov/sites/de-fault/files/docs/publication/R18HS017234WagnerFinalReport2011.pdf. Accessed February 24, 2015.
- Wagner PJ, Dias J, Howard S, Kintziger KW, et al. Personal health records and hypertension control: a randomized trial. JAMIA. 2012;19(4):626–634.
- Ryvicker M, Feldman PH, Chiu YL, et al. The role of patient activation in improving blood pressure outcomes in black patients receiving home care. Med Care Res Rev. 2013;70(6):636–652.
- Ancker JS, Osorio SN, Cheriff A, et al. Patient activation and use of an electronic patient portal. *Inform Health Social Care*. 2014;40(3):1–13.
- NoMoreClipboard. An HIE-populated personal health record for cardiac revascularization patients. https://www.nomoreclipboard.com/wiki/ONC_Ch

- allenge_Grant_%E2%80%93_Consumer-Mediated_Information_Exchange. Accessed April 25, 2015.
- Novak M, Costantini L, Schneider S, et al. Approaches to self-management in chronic illness. Semin Dialysis. 2013;26(2):188–194.
- Stellefson M, Chaney B, Barry EA, et al. Web 2.0 chronic disease self-management for older adults: a systematic review. J Med Internet Res. 2013;15(2):e35. http://www.jmir.org/2013/2/e35/. Accessed February 24, 2015
- Hibbard, JH, Mahoney ER, Stock R, et al. Do increases in patient activation result in improved self-management behaviors? Health Services Res. 2007;42(4):1443–1463.
- STATS Indiana. http://www.stats.indiana.edu/poverty/index.html. Accessed February 24, 2015.
- Ricciardi L, Mostashari F, Murphy J, et al. A National action plan to support consumer engagement via e-Health. Health Aff. 2013;32(2): 376–384.
- Tenforde M, Nowacki A, Jain A, Hickner J. The association between personal health record use and diabetes quality measures. *J Gen Int Med.* 2012;27(4):420–424.
- Wade-Vuturo AE, Mayberry LS, Osborn CY. Secure messaging and diabetes management: experiences and perspectives of patient portal users. *JAMIA*. 2013;20(3):519–525.
- Sarkar U, Lyles CR, Parker MM, et al. Use of the refill function through an online patient portal is associated with improved adherence to statins in an integrated health system. Med Care. 2014;52(3):194–201.
- Genitsaridi I, Kondylakis H, Koumakis L, Marias K, Tsiknakis M. Evaluation of personal health record systems through the lenses of EC research projects. Comp Biol Med. 2013;59:175–185.
- Chrischilles EA, Hourcade JP, Doucette W, et al. Personal health records: a randomized trail of effects on elder medication safety. JAMIA. 2014;21:679–686.
- Ancker JS, Miller MC, Patel V, Kaushal R. Sociotechnical challenges to developing technologies for patient access to health information exchange data. *JAMIA*. 2014;21(4):664–670.

Downloaded from http://jamia.oxfordjournals.org/ by guest on January 25, 2016

 United States Census Bureau. http://quickfacts.census.gov/qfd/states/ 00000.html. Accessed February 25, 2015.

AUTHOR AFFILIATIONS

¹Parkview Research Center, Parkview Health, Fort Wayne, Indiana, USA

²Indiana University School of Informatics and Computing, Indianapolis, Indiana,

³Department of Community Medicine, University of Connecticut, Hartford, Connecticut, USA

⁴College of Pharmacy, Manchester University, Fort Wayne, Indiana, USA

⁵Department of Biostatistics, Indiana University School of Medicine, Indianapolis, Indiana, USA

⁶Indiana University School of Medicine, Fort Wayne, Indiana, USA

This submission is for the Special Issue on Interactive Systems for Patient-Centered Care to Enhance Patient Engagement