#### Research Paper

# Disparities in Use of a Personal Health Record in a Managed Care Organization

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**Abstract Objective:** Personal health records (PHRs) can increase patient access to health care information. However, use of PHRs may be unequal by race/ethnicity.

**Design:** The authors conducted a 2-year cohort study (2005–2007) assessing differences in rates of registration with KP.org, a component of the Kaiser Permanente electronic health record (EHR).

**Measurements:** At baseline, 1,777 25–59 year old Kaiser Permanente Georgia enrollees, who had not registered with KP.org, responded to a mixed mode (written or Internet) survey. Baseline, EHR, and KP.org data were linked. Time to KP.org registration by race from 10/1/05 (with censoring for disenrollment from Kaiser Permanente) was adjusted for baseline education, comorbidity, patient activation, and completion of the baseline survey online vs. by paper using Cox proportional hazards.

**Results:** Of 1,777, 34.7% (616) registered with KP.org between Oct 2005 and Nov 2007. Median time to registering a KP.org account was 409 days. Among African Americans, 30.1% registered, compared with 41.7% of whites (p < 0.01). In the hazards model, African Americans were again less likely to register than whites (hazard ratio [HR] = 0.652, 95% CI: 0.549–0.776) despite adjustment. Those with baseline Internet access were more likely to register (HR = 1.629, 95% CI: 1.294–2.050), and a significant educational gradient was also observed (more likely registration with higher educational levels).

**Conclusions:** Differences in education, income, and Internet access did not account for the disparities in PHR registration by race. In the short-term, attempts to improve patient access to health care with PHRs may not ameliorate prevailing disparities between African Americans and whites.

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#### Introduction

In *Crossing the Quality Chasm*, the Institute of Medicine began to emphasize that care should not occur just within face-to-face visits, but that "access to care should be provided over the Internet" to foster continuous healing relationships.<sup>1</sup> Subsequent reports<sup>2–4</sup> and other groups,<sup>5</sup> including the Centers for Medicare and Medicaid Services,<sup>6</sup> have continued to support the concept of e-Health tools to increase

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patient access, activate patients in their care, and re-engineer patient-centered care. Over 70 million Americans have used the Internet to access health-related information,<sup>7</sup> and just as many may have access to a personal health record (PHR).<sup>8</sup> The online PHR is one innovation proposed to improve patients' interaction with the ambulatory health care system by providing continuous care access. As defined by the Markle Foundation report in *Connecting for Health*,<sup>2</sup> "The 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."

The PHRs overlap with, but are not the same as, electronic health records (EHRs). The EHRs do not allow patient access or patient control of access to information. The PHRs are designed for patient control and are also unique in that they can be accessed through the Internet from anywhere. The PHRs can be implemented within the context of an existing electronic health record, or can be stand-alone systems.<sup>2</sup> Integrated PHRs have the advantages of leveraging existing detailed clinical information (medication lists, etc) for access through the PHR. Although evidence for the effectiveness of PHRs for improving health outcomes is limited,<sup>9</sup> their perceived value and demand is increasing.<sup>8</sup>

The PHRs may have the potential to improve patient access and subsequently improve health outcomes. However, access to the Internet and computer literacy are not universal.

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Although some studies have assessed rates of use of PHRs, racial and ethnic minorities have rarely been included in these samples.<sup>10–13</sup> Disparities in access to technology, the "digital divide", persist along economic, education, age, and ethnic lines. Tang et al. summarized a discussion of the American College of Medical Informatics regarding potential barriers to PHRs from patient and provider perspectives.<sup>6</sup> In addition to socio-economics, computer access, and computer literacy, some patients may have concerns about time demands required to use the PHR and privacy concerns. African Americans report higher levels of distrust in health providers and systems,<sup>14,15</sup> and may be differentially affected by perceived privacy threats related to online health records. Although PHRs have potential to extend the reach of patient care, not all patients will have access to PHRs.

Kaiser Permanente Online, KP.org, is the Internet-based PHR component of Kaiser Permanente's EHR. In its current implementation, KP.org offers registrants a range of functions: make appointments, refill prescriptions, secure message with primary care providers, view selected laboratory test results, complete a health risk appraisal (from which selected information is entered into the patient's medical history), and obtain health information on a range of topics. The KP.org has been available to patients enrolled in Kaiser Permanente, Georgia since 2005. Information about KP.org is disseminated through patient mailings, provider recommendations, and notes in postvisit summaries which are printed and provided to patients. We conducted a longitudinal cohort study to assess whether African Americans, whites, and other racial/ethnic minorities differed in likelihood of registering to access this new PHR. Further, we evaluated whether racial/ethnic differences were moderated by differences patient characteristics including age, education, and prior Internet access. Because KP.org links patients with their providers, and because the PHR is marketed through the practice, we also sought to detect whether differences in access to KP.org could be explained by variance at the clinic-level where patients received primary care.

# **Methods**

# Study Design

Our study was a cohort study using a sample of African American, white, and other racial/ethnic minorities enrolled in Kaiser Permanent Georgia in 2005 who were followed over the next 2 years to assess whether or not these survey respondents subsequently registered with KP.org. The study protocol, including survey and survey administration, was reviewed, approved, and monitored by the KPGA and Emory University Institutional Review Board.

# Setting

Kaiser Permanente, Georgia (KPGA) is a federally qualified, group- and network-model HMO that provides comprehensive medical services to approximately 275,000 residents in the Atlanta metropolitan area. Most (88%) of membership receives care through the group-model. In 2004, the adult medicine department consisted of 16 teams located in 11 medical offices. Primary care teams ("teams") are self-managing and self-directed. A typical team consists of 4–6 practitioners and 10–15 support staff (RNs, LPNs, MAs,

receptionists). Approximately 10,000–12,000 enrollees are empanelled to an adult medicine team.

## **Study Cohort**

A survey was administered in written form, with an option to complete the survey on a Web site, from Oct through Dec 2005 to a sample of KPGA enrollees. Inclusion in the sample required: (1) enrolled with KPGA since 01/2004 and at survey time, (2) subscriber within the enrolled family, (3) employed by one of the 100 largest KPGA private or public employer groups, (4) 25–59 years of age as of 8/31/05, and (5) empanelled to one of the 16 teams as of 01/2004. Among the KPGA adults who met these criteria, the study population was further limited to 3 condition cohorts: adults with diabetes, adults with elevated lipids but no history of advanced coronary artery disease (CAD), and "low risk" adults (i.e., adults without any identifiable major morbidities). A cluster randomized design was used to collect balanced samples of respondents by condition and by primary care team. The survey sample included 5,309 enrollees: 1,668 with type 2 diabetes, 1,801 with elevated lipids, and 1,840 low risk adults. In total, 2,224 (42%) of the 5,309 targeted enrollees responded to the survey on health and lifestyle. By patient condition, the response rate was 39% for adults with diabetes, 44% for adults with elevated lipids, and 42% for low risk adults. Survey respondents and nonrespondents did not vary by ethnicity.

For this study, records of these survey respondents were linked by unique health record numbers with a KP.org database tracing access from 10/1/05-11/1/07. The final cohort included 1,777 of the 2,224 (80%) KPGA survey respondents who had not registered with KP.org at the time of the 2005 survey. We excluded 447 survey respondents who had registered with KP.org as of 10/1/05. Compared to the study cohort, these "early adopters" of KP.org were more likely to be white (64.0% of early adopters v. 41.8% of the study cohort, p < 0.01), have diabetes (32.9 vs. 28.4%, p = 0.01), have higher levels of education (e.g., 28.6% postgraduate vs. 25.5%, p < 0.01), and to respond to the 2005 survey by Internet (28.0 vs. 10.8%, p < 0.01).

# **Dependent Variable**

The principal dependent variables were: (1) whether the participant subsequently registered with KP.org between 10/1/2005 and 10/31/2007, and (2) the time (in days) from 10/1/2005 to the KP.org registration date (among those who registered). The KP.org database contained the date on which the KPGA enrollee had first registered for access to the PHR. This permitted us to measure, among those who subsequently registered, time from 10/1/2005 to date of registration with KP.org.

# **Independent Variables**

Our primary independent variable was self-reported race/ ethnicity as reported on the 2005 survey: non-Hispanic white, African American, and other or unknown. The survey included covariates include patient age and gender, level of education (high school [HS] or less, some college, college graduate, postgraduate), 2005 survey response by Internet or mail, and disease condition (type 2 diabetes, elevated lipids without CAD, or low risk). Response to the survey by Internet vs. mail was intended to serve as a proxy measure for an enrollee's propensity to use the Internet for interacting with a client (in this case the survey vendor) when offered alternative modes of interaction.

The survey also included a previously validated 13-item scale for patient activation (PAM-13).<sup>16</sup> Patient activation is a measure of the extent to which patients: (1) believe that their role is important, (2) have knowledge and confidence to act, (3) take action to improve health, and (4) stay the course even when under stress. The PAM-13 is scored from 0 (least activated) to 100 (most activated). The PAM-13 reliability obtained in the study sample was comparable to reliability reported by Hibbard et al.: 0.95 in the survey sample vs. 0.85 for the PAM-13.<sup>16</sup> Because a PHR is designed to increase patient access to their health information, patient activation may moderate subsequent access to a PHR.

#### **Statistical Analysis**

We tested for differences in whether or not the 2005 survey respondents registered with KP.org between 10/1/05 and 10/31/07 with race/ethnicity, and then with age group, gender, level of education, response mode (Internet v. mail), and disease condition using a  $\chi^2$  test.

We then constructed a Kaplan-Meier curve of time to registration with KP.org, comparing African Americans vs. whites. The observation period was October 2005 through October 2007. Observations were censored at the time of disenrollment if the respondent disenrolled from KPGA during this period (n = 324, 18.2% of the 1,777). A Cox proportional hazards model was then constructed using time to registration as the outcome. The primary independent variable was race/ethnicity: white, African American, other/unknown. Covariates in the model were PAM-13, age, gender, disease condition (comorbidity), level of education, Internet vs. mail mode of responding to survey. In addition to estimating a hazards model on the overall cohort, we also constructed models stratified by disease and by level of education. Our intent in these subanalyses was to evaluate whether the race/ethnicity hazard ratios differed by condition cohort or by level of education. To assess for clinic-level effects, intra-class correlation coefficients (ICCs) were estimated for clustering of registration with KP.org by primary care facility of the 1,777 adults in the study cohort, both overall and by subgroup (e.g., African American vs. white). SAS version 9.1 (SAS Institute, Cary, NC) was used for all data management and descriptive statistical tests. Stata version 10 (StataCorp, College Station, TX) was used for estimation of ICCs.

#### Results

The study cohort (n = 1,777) was diverse (Table 1) and generally representative of all respondents to the 2005 survey: 48.6% African American, 59.2% female, 20.4% with a high school education or less, and median age of 50 years. All 3 condition subgroups were included: 28.4% adults with diabetes, 35.0% adults with elevated lipids, and 36.6% low risk adults.

Overall, 34.7% of the study cohort registered with KP.org in the 2-year period between Oct 1, 2005 and Nov 1, 2007. Adults who registered with KP.org during this period (Table 1) were significantly more likely to be white than African American (41.7 vs. 30.1%) and adults with diabetes or elevated lipids than low risk adults (36.4 and 38.0%, respectively, vs. 30.1%). There was a significant educational gradi-

<i>Table 1</i> Cohort Characteristics and Percent
Registering with KP.org Between October 2005 and
Nov 2007

	C	Cohort		
	Characteristics		Percent	
		Percent of	Registering	
	n*	Cohort	with KP. org	p Value
Overall	1,777	_	34.7%	_
Race/ethnicity				
White	743	41.8%	41.7%	< 0.01
Black	864	48.6	30.1	
Other/Unk.†	170	9.6	27.1	
Condition cohort				
Diabetes	505	28.4%	36.4%	0.01
Elevated lipids	621	35.0	38.0	
Low Risk	651	36.6	30.1	
Level of education				
HS or less	356	20.4%	24.4%	< 0.01
Some College	600	34.4	32.8	
College Grad.	343	19.7	36.7	
Postgraduate	444	25.5	44.4	
Age				
25–39	207	11.7%	30.4%	0.29
40-44	319	18.0	33.2	
45-49	402	22.6	32.8	
50-54	454	25.6	36.3	
55–59	395	22.2	38.0	
Gender				
Female	1052	59.2%	36.1%	0.12
Male	725	40.8	32.6	
2005 survey response				
By mail	1585	89.2%	33.0%	< 0.01
By Internet	192	10.8	48.4	

\*Variation in total N are due to small numbers of missing values. +Other/Unknown includes small number of Asian, Pacific Islander, and Hispanic patients. These groups were too small to assess separately.

ent. Those with postgraduate education more frequently registered with KP.org than adults with a high school education or less (44.4 vs. 24.4%). Adults who responded to the 2005 survey through the Internet option were significantly more likely to register with KP.org in the 2-year period following that survey than adults who responded using the printed form (48.4 vs. 33.0%). Mean patient activation (PAM-13) did not significantly differ between those who registered with KP.org and those who did not.

Among those who registered with KP.org, the median time to enrollment was 409 days (interquartile range: 315–592 d). Figure 1 displays the cumulative distribution by month of KP.org registrants by race/ethnicity. Differences by race/ ethnicity of the cumulative proportions of KP.org registrants were relatively small in the first several months following the 2005 survey; however, the gap between the proportion of whites who registered with KP.org compared to African Americans or other racial/ethnic groups continued to widen over the 2-year period.

African Americans and whites were each well represented among the condition cohorts, levels of education, and demographic subgroups (Table 2). Among both whites and African Americans, the percent who registered with KP.org was significantly higher among those with higher levels of 686



**Figure 1.** Cumulative Proportion by Month of KPGA Enrollees Registered with KP.org from 10/1/05.

education than those with lower levels of education. African American respondents by Internet were more likely to register than those responding by mail (the association was marginally significant among whites). African Americans with diabetes or elevated lipids were more likely to register with KP.org than low risk African Americans.

In an unadjusted Cox proportional hazards model, the KP.org registration was significantly less likely for African American adults than for whites (HR = 0.611; 95% CI: 0.518, 0.720). The significant lag in time to registration with KP.org among African American adults compared to whites remained in the adjusted hazards regression (HR = 0.652; 95% CI: 0.549, 0.776; Table 3). In addition, registration with KP.org was significantly more likely among adults with diabetes or elevated lipids (vs. low risk adults), women (vs. men), and Internet respondents to the 2005 survey (vs.

respondents using the written form). A significant educational gradient was observed. Registration with KP.org was more likely as level of education increased.

Table 4 displays adjusted hazard ratios of time to registration with KP.org for African Americans compared to whites from hazards models estimated separately by disease condition subgroup and by level of education. Within each of the condition subgroups and levels of education, KP.org registration was significantly less likely for African Americans. The lower likelihood of African Americans registering with KP.org was significant within each level of education (p values ranging from 0.04 to <0.01). Although the disparity between African Americans and whites was modestly attenuated among adults with higher levels of education (e.g., HR = 0.674 among those with postgraduate education vs. HR = 0.564 among those with a high school education or less); the differences in hazard ratios across the levels of education was not significant (for p > 0.05).

Overall, clustering of KP.org registration by primary care clinic was minimal (ICC = 0.001) and similar for African Americans (ICC = 0.001) and whites (ICC = 0.001). Similarly, ICCS were very low and indistinguishable across condition cohort and level of education (ranging from < 0.001 to 0.001).

#### Discussion

Although current dissemination of PHRs into clinical practice is limited, the advocacy of stakeholders groups and demand from patients may drive increased adoption of this patient-centered e-Health intervention in the future. We found that during two years of follow-up, only slightly more than one third of a stable cohort of managed care enrollees registered with an available PHR. Further, we noted important differences in use of KP.org by race/ethnicity, with

Table 2 
Percent of Whites and African Americans Registering with KP.org Between October 2005 and Nov

		Whites				African Americans				
	N	Percent of Whites	Percent with KP. org	p Value	N	Percent of African Americans	Percent with KP. org	p Value		
Overall	743	_	41.7%		864	_	30.1%	_		
Condition cohort										
Diabetes	184	24.8%	26.8%	0.16	279	32.3%	32.6%	0.02		
Elevated lipids	285	38.4	40.3		278	32.2	34.2			
Low Risk	274	36.9	32.9		307	35.5	24.1			
Level of education										
HS or less	141	19.0%	31.2%	< 0.01	186	21.8%	21.8%	0.01		
Some College	217	29.2	37.3		351	40.8	30.2			
College Grad.	139	18.7	43.9		169	19.6	31.4			
Postgraduate	246	33.1	50.4		153	17.8	38.6			
Age										
25–39	75	10.1%	29.3%	0.16	112	13.0%	33.9%	0.53		
40-44	112	15.1	41.1		180	20.8	30.0			
45-49	143	19.3	40.6		203	23.5	25.6			
50-54	202	27.2	43.1		215	24.9	32.1			
55–59	211	28.4	46.0		154	17.8	30.5			
Gender										
Female	407	54.8%	46.0%	0.01	564	65.3%	30.9%	0.51		
Male	336	45.2	36.6		300	34.7	28.7			
2005 survey response										
By mail	651	87.6%	40.6%	0.09	783	90.6%	28.6%	< 0.01		
By Internet	92	12.4	50.0		81	9.4	44.4			

	95% Confidence Interval			
	Hazard Ratio	Lower	Upper	p Value
Patient activation	0.999	0.995	1.004	0.67
(per Point)				
Race/ethnicity				
White	1.0 (reference)			
Black	0.652	0.549	0.776	< 0.01
Other/Unk.	0.707	0.503	0.993	0.05
Condition cohort				
Low Risk	1.0 (reference)			
Diabetes	1.510	1.218	1.872	< 0.01
Elevated lipids	1.439	1.177	1.760	< 0.01
Level of education				
HS or less	0.655	0.507	0.847	< 0.01
Some college	1.0 (reference)			
education	, ,			
College Grad.	1.150	0.916	1.445	0.23
Postgraduate	1.377	1.122	1.689	< 0.01
Age				
25–39	0.886	0.645	1.219	0.46
40-44	1.0 (reference)			
45-49	0.838	0.643	1.091	0.19
50-54	0.973	0.755	1.255	0.83
55–59	0.897	0.689	1.169	0.42
Gender				
Male	1.0 (reference)			
Female	1.183	1.000	1.400	0.05
2005 survey response				
By mail	1.0 (reference)			
By Internet	1.629	1.294	2.050	< 0.01

*Table 3* • Multivariate Cox Proportional Hazard Regression of Time to Registration with KP.org (n = 1,777)

whites having higher rates of use than African Americans. If our results of a digital divide for PHRs are confirmed, and if evidence of the effectiveness of PHRs in improving access, quality and safety increases, then PHRs have the potential to widen disparities in health care and health, at least in the short-term. Appropriate attention to further research on the causes of this gap in use is critical.

In a 2008 JAMIA article, a research agenda for PHRs was proposed.<sup>8</sup> The research agenda called for studies of adoption in vulnerable populations where patient (demographics) and organization adoption factors were explored.<sup>8</sup> Although research on provider-centered informatics tools such as EHRs and decision support systems is extensive, less research has been conducted on the effectiveness of e-Health interventions that include patient participation<sup>2,17-23</sup> or are designed to increase patient-centered care.24,25 Previous reports have noted high satisfaction with personal health records.<sup>20,21,26</sup> the Palo Alto Medical Foundation implemented one of the earliest PHRs in 2002. In a survey, 914 users of this PHR rated access to laboratory test results as the most valuable use of the system, and users also valued ability to request refills and access patient education materials.<sup>20</sup> Because of these previous positive reports and the national emphasis on patient-centered technology, we were somewhat surprised at the low rates of registration, 34.7%, over 2 years of follow-up. The public and providers may also be waiting for more evidence of the benefit of these systems before adoption.

There has been a sustained digital divide in the national population.<sup>27</sup> Racial/Ethnic minorities, those with lower education, older, and rural patients have been found to have lower access to information technology and also have lower computer literacy. The difference by race/ethnicity in registering for KP.org was robust to adjustment by multiple factors and to stratification by education. We did not have more detailed socioeconomic information to adjust our analysis. But, the socioeconomic variation in this sample is likely less than that in the general population, because our sample is truncated to only patients enrolled in KPGA. The finding that among those with graduate degrees, African Americans were less likely to enroll (HR = 0.674) than whites suggests that factors other than education, computer literacy, and computer access are driving the difference.

<i>Table 4</i> ■ African	American (AA	<ul> <li>A) Effect from</li> </ul>	1 Multivariate	Cox Prope	ortional l	Hazard	Regression	of 7	Гime	to
Registration with	ι KP.org: Strati	fied by Cond	lition Cohort <sup>1</sup>	and Level	of Educ	ation <sup>2</sup>				

0	0	5					
	Ν	Percent AA	Hazard Ratio (HR) for AA Vs. White	Upper 95% CI	Lower 95% CI	p Value for HR = 0.00	p Value for Difference in HR*
Study population stratified by condition cohort							
Diabetes	505	55%	0.63	0.86	0.47	< 0.01	0.34
Elevated lipids	621	45%	0.72	0.96	0.55	0.02	0.19
Low Risk	651	47%	0.58	0.80	0.42	< 0.01	_
Study population stratified by level of education							
HS or less	356	53%	0.56	0.88	0.36	0.01	0.27
Some College	600	58%	0.64	0.87	0.47	< 0.01	0.44
College Graduate	343	49%	0.66	0.98	0.44	0.04	0.73
Postgraduate College	444	35%	0.67	0.93	0.49	0.02	

<sup>1</sup>Within the condition cohort models, independent variables include race/ethnicity, activation, level of education, age group, gender, and 2005 survey response (Internet vs. mail).

<sup>2</sup>Within the level of education models, independent variables include race/ethnicity, activation, condition cohort, age group, gender, and 2005 survey response (Internet vs. mail).

\*Differences in HR by condition cohort or level of education tested by t-statistic (1df).

Mode of survey administration, our marker for a digital divide, also did not attenuate our results. One might speculate other patient-level variables, cultural or psychosocial factors affecting trust in the medical system or differences in privacy concerns may be part of the racial/ethnic differences in KP.org registration. Our research was not able to address the potential mediating effect of these factors.

However, the differences in KP.org registration by race/ ethnicity could also result from differences in health system processes and provider-patient interactions. It could be that African Americans are more likely to be seen by KPGA primary care teams that are less likely to market KP.org. We did not find a strong ICC at the clinic level; but, differences among providers within a clinic in marketing the PHR are certainly possible. Our analysis cannot address variations in patient-provider interaction as a cause of the difference by race. However, further research using direct observation and qualitative methods is needed to further explore and ameliorate potential disparities in use of the PHR technology.

Interestingly, we did not find evidence of disparities in registration to KP.org by age. The age gap in the digital divide has been narrowing more rapidly than other disparities. In this study, lower propensity to access information technology by older persons may be offset by the older patients' higher number of chronic diseases. Chronic diseases seem to be driving increased access in this study. Several reports have suggested that personal health records, doctor-patient electronic messaging, and other e-Health interventions might be most valuable for those with chronic conditions.<sup>9,12,28–30</sup> In fact, there is a complex association between technology access and chronic disease. Based on national survey data from the Pew Internet and American Life project, those with chronic diseases report lower rates of technology access overall, but those with chronic disease who do attain access are more likely to seek out health information online, compared with those without a chronic condition.<sup>31</sup> This Pew survey also suggests that the information that those with chronic disease access is more likely to influence their medical decisions.

Our study has limitations, including that the study is limited only to patients in Kaiser Permanente and accessing a single PHR. Thus, these results may not be strictly generalizable to other PHRs. As noted, although enrollment in Kaiser is a limitation, it in some ways truncates the diversity of the sample and makes the variations by ethnicity even more stunning. Conducting this study in Georgia provided access to a larger number of African Americans than other samples with PHR access. Another important limitation is the potential for unmeasured confounding common to all cohort studies. This cohort study is limited to the covariates included in the past survey. The KPGA health survey was designed and conducted in 2005, and does not include important covariates such as computer literacy or Internet access, although we have used preference for completing the baseline survey online as a proxy. Also, we were not able to analyze other ethnic minorities as separate groups because of small numbers. Evaluation of variations in access by Hispanics and other minorities is equally important.

### Conclusions

The PHRs have considerable promise in improving care delivery and the patient-centeredness of medical care. But, an unanticipated consequence of these tools may be a resulting widening of disparities due to unequal access and use. Health disparities research typically follows a two-step process. First, identifying a disparity and then defining the cause of the disparity. Our study clearly only addresses the first step. Although we identified an adoption gap by race/ethnicity, the factors moderating this difference remain under-explained. That we do not know the cause does not remove the disparity. Further research is needed so we can determine the cause and ameliorate this disparity. E-Health researchers should further investigate cultural issues related to trust, privacy, economic status, and literacy that may sustain the PHR adoption gap. PHR developers should consider ways to create adaptive interfaces that allow for variations in computer literacy, and potentially provide access to PHR information through systems more available to minorities, such as mobile phones. Clinical groups deploying these systems should consider ways to increase equity in access at the time of implementation with marketing strategies or other innovations. Providers should avoid prior assumptions that certain patient subgroups may not have Internet access or may not use the Internet for seeking health care information, and market the PHR equally to all. Much work needs to be done to understand and reduce ethnic disparities in access to potentially valuable extensions to clinical services such as PHRs and other e-Health interventions.

#### References

- Committee on Quality of Health Care in America IoM. Crossing the Quality Chasm, Washington, DC: National Academy Press, 2001.
- 2. Personal Health Working Group. Connecting for health, New York, NY: Markle Foundation. Available at: http://www.connectingforhealth.org; Accessed:
- 3. Pagliari C, Detmer D, Singleton P. Potential of electronic personal health records. BMJ 2007 Aug 18;335(7615):330–3.
- Computer Science and Telecommunications Board. National Research Council, ed. Networking Health: Prescriptions for the Internet, Wash, DC, United States: National Academy Press; 2000.
- 5. The value of personal health records. A joint position statement for consumers of healthcare by the American Health Information Management Association and the American Medical Informatics Association. J Ahima 2007 Apr;78(4):22, 4.
- Tang PC, Ash JS, Bates DW, Overhage JM, Sands DZ. Personal health records: Definitions, benefits, and strategies for overcoming barriers to adoption. J Am Med Inform Assoc 2006 Mar– Apr;13(2):121–6.
- Anderson JG, Rainey MR, Eysenbach G. The impact of Cyber-Healthcare on the physician–patient relationship. J Med Syst 2003 Febr;27(1):67–84.
- Kaelber DC, Jha AK, Johnston D, Middleton B, Bates DW. A research agenda for personal health records (PHRs). J Am Med Inform Assoc 2008 Nov–Dec;15(6):729–36.
- Ross SE, Moore LA, Earnest MA, Wittevrongel L, Lin CT. Providing a web-based online medical record with electronic communication capabilities to patients with congestive heart failure: Randomized trial. J Med Internet Res 2004 May 14;6(2):e12.
- 10. Hess R, Bryce CL, Paone S, et al. Exploring challenges and potentials of personal health records in diabetes self-manage-

ment: Implementation and initial assessment. Telemed J E Health 2007 Oct;13(5):509–17.

- Hassol A, Walker JM, Kidder D, et al. Patient experiences and attitudes about access to a patient electronic health care record and linked web messaging. J Am Med Inform Assoc 2004 Nov–Dec;11(6):505–13.
- 12. Grant RW, Wald JS, Poon EG, et al. Design and implementation of a web-based patient portal linked to an ambulatory care electronic health record: Patient gateway for diabetes collaborative care. Diab Technol Ther 2006 Oct;8(5):576–86.
- Denton IC. Will patients use electronic personal health records? Responses from a real-life experience. J Healthc Inf Manag 2001 Fall;15(3):251–9.
- 14. Jacobs EA, Rolle I, Ferrans CE, Whitaker EE, Warnecke RB. Understanding African Americans' views of the trustworthiness of physicians. J Gen Intern Med 2006 Jun;21(6):642–7.
- Benkert R, Peters RM, Clark R, Keves-Foster K. Effects of perceived racism, cultural mistrust and trust in providers on satisfaction with care. J Natl Med Assoc 2006 September;98(9):1532–40.
- Hibbard JH, Mahoney ER, Stockard J, Tusler M. Development and testing of a short form of the patient activation measure. Health Serv Res 2005 Dec;40(6 Pt 1):1918–30.
- 17. Committee on Enhancing. The Internet for Health Applications: Technical Requirements and Implementation Strategies-Computer Science and Telecommunications Board—National Research Council. Networking Health: Prescriptions for the Internet, Washington, D.C.: National Academy Press, 2000.
- Katz SJ, Moyer CA. The emerging role of online communication between patients and their providers. J Gen Intern Med 2004 September;19(9):978–83.
- Katz SJ, Nissan N, Moyer CA. Crossing the digital divide: Evaluating online communication between patients and their providers. Am J Manag Care 2004 September;10(9):593–8.
- 20. Tang PC, Black W, Buchanan J, et al. PAMFOnline: Integrating EHealth with an electronic medical record system. AMIA Annu Symp Proc 2003:644–8.

- Tang PC, Lansky D. The missing link: Bridging the patientprovider health information gap. Health Aff Millwood 2005 September–Oct;24(5):1290–5.
- Lorig KR, Ritter PL, Laurent DD, Plant K. Internet-based chronic disease self-management: A randomized trial. Med Care 2006 Nov;44(11):964–71.
- Wantland DJ, Portillo CJ, Holzemer WL, Slaughter R, McGhee EM. The effectiveness of web-based vs. non-web-based interventions: A meta-analysis of behavioral change outcomes. J Med Internet Res 2004 Nov 10;6(4):e40.
- 24. Glasgow RE, Nutting PA, King DK, et al. Randomized effectiveness trial of a computer-assisted intervention to improve diabetes care. Diab Care 2005 Jan;28(1):33–9.
- Wu RC, Delgado D, Costigan J, Maciver J, Ross H. Pilot study of an internet patient–physician communication tool for heart failure disease management. J Med Internet Res 2005;7(1):e8.
- Wald JS, Middleton B, Bloom A, et al. A patient-controlled journal for an electronic medical record: Issues and challenges. Medinfo 2004;11(2):1166–70.
- Chang BL, Bakken S, Brown SS, et al. Bridging the digital divide: Reaching vulnerable populations. J Am Med Inform Assoc 2004 Nov–Dec;11(6):448–57.
- Houston TK, Sands DZ, Jenckes MW, Ford DE. Experiences of patients who were early adopters of electronic communication with their physician: Satisfaction, benefits, and concerns. Am J Manag Care 2004 September;10(9):601–8.
- Patt MR, Houston TK, Jenckes MW, Sands DZ, Ford DE. Doctors who are using e-mail with their patients: A qualitative exploration. J Med Internet Res 2003 Apr–Jun;5(2):e9.
- Houston TK, Allison JJ. Users of internet health information: Differences by health status. J Med Internet Res 2002 Apr–Nov; 4(2):E7.
- Fox S. E-patients with a disability or chronic disease. Available at: http://www.pewinternet.org/PPF/r/222/report\_display. asp. Accessed Oct 1, 2008.