Rapid Growth in Use of Personal Health Records in New York, 2012–2013

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BACKGROUND: Giving patients access to their own medical data may help improve communication and engage patients in healthcare. As a result, the federal electronic health record (EHR) incentive program requires providers to offer electronic data sharing with patients via personal health records (PHRs) or other technologies.

OBJECTIVE: We sought to estimate the rate of adoption of PHRs over a 2-year period.

DESIGN: Survey of 800 respondents (margin of error: 3.5 percentage points) in consecutive years of the Empire State Poll, an annual random-digit-dial telephone survey.

PARTICIPANTS: Adult New York State residents.

MAIN MEASURES: Self-reported use of a PHR.

KEY RESULTS: The rate of reported PHR use rose from 11 % in 2012 to 17 % in 2013. The proportion of these PHRs provided by doctors or healthcare organizations also increased sharply (from 50 % in 2012 to 73 % in 2013, $p<0.01$) with a corresponding decrease in the proportion provided by insurers.

CONCLUSIONS: The proportion of New York State residents using PHRs increased by more than 50 % (from 11 to 17 %) in advance of a federal incentive program requirement that healthcare organizations with EHRs must share electronic data with patients in order to receive their incentives.

KEY WORDS: personal health records; electronic health records; consumer informatics; survey research.
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INTRODUCTION

Patients who are more knowledgeable about their health, engage in disease management, and perceive their role in their own healthcare as an active one tend to have better outcomes.[1–3] One technology that is widely hoped to help support patient education and engagement is the personal health record (PHR), an emerging technology that provides access to personal medical data.[4–6] Tethered PHRs (or electronic patient portals) are web-based accounts sponsored by healthcare organizations that give patients the ability to view selected data from the electronic health record (EHR) that has been collected during their clinical care. These portals frequently also provide other functions, such as patient education, secure electronic communication with healthcare providers, and online prescription refills. By contrast, free-standing or untethered PHRs are repositories in which individuals can document their own health information as well as collect copies of their medical records from one or more sources.[7] Both have been promoted as ways to empower, educate, and engage patients in their own health and healthcare.[4,6,8–10]

To date, these technologies have been demonstrated to have only modest effects on healthcare,[11,12] although some features and programs have been associated with improved outcomes affecting health care utilization, medication adherence, patient perceptions, and medication reconciliation.[11–14] A variety of challenges have been identified that may be hindering uptake and effectiveness of these portals. Some patients have limited access to computers or to broadband Internet,[15] and the highly technical information in portals may not be easily usable by patients with limited health literacy.[16–19] Usability may be inferior to the usability of other consumer technologies.[20] Other factors, such as previous level of engagement in health care[21] and trust in the physician,[22] may also affect a patient's likelihood of using the technology.

Some of these factors may explain why surveys of the public have shown strong interest in PHRs but low rates of usage. Data from the 2007 Health Information National Trends Study found that 86 % of respondents considered electronic PHRs important, but only 9 % had used them.[23] A 2008 Markle Foundation survey found similar enthusiasm among the public for the value of PHRs, but estimated that only 2.7 % of the public had ever used them.[10] In 2009–2010, a California Healthcare Foundation survey estimated the national rate of individuals who had used a PHR at 7 %, with rates somewhat higher among those with more education, higher income, or frequent Internet use.[24]

Since these surveys were conducted, the national health information technology (IT) landscape has been transformed by the federal EHR incentive program (the so-

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called “meaningful use” program), launched in 2009 to provide financial incentives for doctors and organizations to adopt EHRs.[25,26] The proportion of acute care hospitals with at least a basic EHR has risen to 44 % in 2012 (nearly triple the proportion in 2010).[27] Among doctors, the rate rose from an estimated 26 % in 2010 to 38 % in 2012.[28]

Sharing electronic data with patients is an essential part of the meaningful use program. In Stage I, the program required that the EHR be capable of sharing data with patients.[25,26] In Stage II, which takes effect in 2014, eligible doctors and hospitals must not only give patients the ability to view, download, and transmit relevant data from the EHR, but must also document that more than 5 % of their patients have used these functions.[29]

This rapid national transformation will increase the proportion of patients who are offered access to PHRs and portals. In addition, it is likely to affect patient experience and attitudes toward health IT. For example, we recently found that consumers who had a doctor using an EHR were more likely to endorse the belief that EHRs and electronic health information exchange (HIE) would improve the quality of their healthcare.[30]

We therefore surveyed consumers about their experience with PHRs in two consecutive years of an annual statewide telephone survey, conducted during a time when many physicians and hospitals were implementing EHRs in response to the meaningful use incentive program.

METHODS

Survey Development and Administration. The Empire State Poll is a telephone survey of adult residents of New York State conducted annually by Cornell University’s Survey Research Institute (SRI). Questions that are repeated annually include queries about sociodemographics, political ideology, and attitudes toward a number of statewide community, government, and workplace issues. Each year, Cornell investigators may submit additional questions on topics of research interest. In 2012 and 2013, our research group developed and submitted questions pertaining to health IT including a question pertaining to PHRs (Text Box 1). The concept of PHR adoption could be defined in different ways, and in fact differences have been found between individuals who receive access to a portal, those who activate their account and use it once, and those who use the portal repeatedly.[17] For simplicity and to ensure broad understanding of the question, we simply asked patients whether they had “ever used” a portal. (A slightly different list of questions that did not include the PHR questions was included in the 2011 poll.[31]) The 2012 and 2013 polls were administered in February through April of the calendar year. In 2012, interviewers contacted 1,193 eligible individuals by telephone to achieve the desired sample size of 800 (67.1 %). In 2013, 1,208 eligible individuals were contacted to achieve the 800 sample size (66.2 %). In both years, the interview length was about 25 min.

TEXT BOX 1. Health information technology questions in 2012 and 2013 Empire State Poll

1. Some hospitals, doctor’s offices, health plans, and different organizations are offering websites where you can get, keep, and update your health information online. This information could be lab test results, medicines, doctors’ visits, or other information. You would get a user name and password so that only you could see your information on this website. These websites are sometimes called personal health records (PHRs) or patient portals. Have you ever used one of these websites where you can get, keep, or update your health information? (*yes/no/do not know*)
2. (if yes) Is this website sponsored by: (*your doctor or health care provider/your health insurance plan/your employer/another organization/do not know*)?
3. An electronic medical record is a computer-based version of your paper medical records and charts. It is used to store your medical information on the computer. Do any of your doctors use an electronic medical record? (We are specifically interested in whether a computer is used for your medical information, not for insurance information or scheduling.) (*yes/no/do not know/do not have a doctor*)
4. How do you think keeping your personal medical information in a computer could affect the privacy and security of your medical information? (*greatly improve/slightly improve/no effect/slightly worsen/greatly worsen*)

Sampling. Cornell SRI draws the sample from random-digit-dial lists including cell and land lines. To ensure that each adult in a sampled household had an equal chance of being selected, interviewers applied the “most recent birthday” method.[32] Census districts with large proportions of minority residents were oversampled. Sample weights were applied to permit generalization to the entire state. The sample size of 800 produces a margin of error of ± 3.5 percentage points.

Analysis. For the current analysis, the primary outcome was use of a PHR in each of the 2 years, and the secondary outcome was provider of the PHR (doctor or healthcare provider, insurance company, etc.). In a more detailed analysis of the 2013 data, sociodemographic and attitude characteristics were tested for association with the primary outcome, along with two other health IT-oriented questions that we added to the poll: personal experience with a doctor who used an EHR, and perceived effects of EHRs on privacy and security. Missing responses to questions (including refusal to answer) were infrequent and were dropped for most variables. However, for the question about whether the individual’s doctor had an electronic health record, “do not know” responses were grouped with “no” responses for the analyses. Bivariate associations were tested with chi-squared tests. Variables significant at

$p<0.05$ were added to a multivariate logistic model. Data were analyzed with SAS v9.3.

RESULTS

In 2013, 17 % of respondents had ever used a PHR, a sharp increase from 11 % in 2012 ($p<0.01$). The proportion of these PHRs provided by doctors or healthcare organizations also sharply increased, from 50 % in 2012 to 73 % in 2013 ($p<0.01$). The proportion provided by insurers decreased from 39 % in 2012 to 21 % in 2013 ($p=0.002$).

In bivariate analyses of the 2013 data, PHR use was associated with race, education, income, Internet use, prescription medication use, and privacy concerns (Table 1).

In multivariate analyses, PHR use remained significantly less common among those who were widowed (AOR 0.22; 95 % CI 0.08–0.67) or single (AOR 0.55; 95 % CI 0.32–0.92) than those who were married; more common among college-educated respondents (AOR 1.84; 95 % CI 1.02–3.30); more common among those who used the Internet daily (AOR 2.97; 95 % CI 1.49–5.94); and more common among those who used prescription medications in the past year (AOR 1.88; 95 % CI 1.09–3.26). It also remained slightly less common among those with privacy concerns about electronic medical data, but the effect missed statistical significance (AOR 0.69, 95 % CI: 0.45–1.05; $p=0.08$). Race was not significant in the multivariate analysis, possibly because of its correlation with education.

A similar analysis on the 2012 data produced associations in the same direction and of similar magnitude as the associations in the 2013 data (data not shown).

DISCUSSION

The percentage of New Yorkers reporting use of personal health records increased by more than 50 % (from 11 to 17 %) in a 12-month period between 2012 and 2013, the time when physicians and hospitals were also rapidly implementing electronic systems. There was also a large and significant change in the sponsorship of personal health records, with most users in 2013 using products sponsored by their physicians or healthcare organizations, rather than products sponsored by their insurance company or a commercial vendor.

Although adoption rose across the board, use of PHRs was more commonly reported by certain subgroups: those who were married; used prescription medications; had more education; or used the Internet/email daily. Reasons for these findings are likely varied. There is some evidence that married individuals make more use of preventive health services such as cancer screening and vaccinations, which might give them more reason to use a PHR.[33,34] In addition, married individuals may have health management responsibilities for family members as well as themselves; our survey asked only about being a caregiver for an individual with a serious illness, without asking more broadly about helping to provide or manage health care for family members. The use of prescription medications is likely to indicate having a regular relationship with a physician, as well as at least some need for healthcare services and potentially a greater need to view laboratory test results, which are all likely to increase interest in PHRs. The association with education and Internet or email use is consistent with other surveys by ourselves and others finding that these characteristics are associated with greater interest in and more positive attitudes about health information technology in general.[24,31,35–37] Single-institution studies of actual use of portals have also identified socioeconomic disparities in use along the lines of race, ethnicity, and insurance status.[17,38]

These continued findings of socioeconomic disparities in adoption of patient portals suggest that although the use of this new technology is rapidly increasing, it is not disseminating with equal rapidity to all patients. Continued development is needed to translate the medical data in portals into information that is understandable and actionable by patients with a wide range of literacy and numeracy levels. Additional work is needed to improve user interfaces, particularly for smartphone access, because Internet access via smartphone is more common than via computers for minority populations.[39] Individualized training, in person with a medical assistant or librarian or online via video, may help some patients.

Limitations. These findings should be interpreted in light of the well-recognized limitations of telephone polls in terms of potential nonresponse bias. Nevertheless, this particular survey used a dual-frame sampling method to ensure inclusion of cell-phone-only respondents and was weighted by geographical region. The weighting was designed to be reflective of New York State demographics, not necessarily those of the nation. The survey was conducted as consecutive cross-sectional studies, limiting ability to draw inferences about causality. Finally, the questions did not distinguish between electronic patient portals and PHRs, as our pilot testing indicated that respondents were unlikely to clearly understand the difference without extensive explanations.

In conclusion, two consecutive years of a statewide survey found a rapid increase in proportion of residents who reported using personal health records, as well as an increase in the proportion of PHRs in use that are offered by doctors or hospitals. This increase comes in the context of the rapid change created by the federal “meaningful use” program, which has led to year-by-year increases in the numbers of physicians and hospitals using EHRs. Since its inception in 2009, the meaningful use program has promoted sharing electronic data with patients, and the new stage of the program that takes effect in 2014 sets even more ambitious goals, requiring doctors and hospitals to demonstrate that more than 5 % of their patients have accessed their medical

Table 1. Respondent Characteristics and Association with Use of PHRs in 2013

Characteristic	Mean (95 % CI) or weighted *n* (%)	OR (95 % CI)	Adjusted OR (95 % CI)
Age	47.2 (46.0–48.5)	1.00 (0.99–1.01)	–
Female	407 (51)	1.08 (0.74–1.59)	–
Race (not mutually exclusive)			
White	556 (71)	2.64 (1.55–4.53)	1.48 (0.48–4.62)
Black	178 (23)	0.33 (0.17–0.62)	0.58 (0.19–1.79)
Other	119 (15)	0.57 (0.29–1.11)	0.82 (0.29–2.31)
Hispanic/Latino	118 (15)	0.82 (0.45–1.52)	–
Urban resident	747 (93)	1.62 (0.79–3.36)	–
Marital status			
Married	381 (48)	Ref	Ref
Divorced/separated	87 (11)	0.78 (0.41–1.49)	1.00 (0.52–1.91)
Widowed	51 (6)	0.19 (0.06–0.53)	0.22 (0.08–0.67)
Single	275 (34)	0.42 (0.26–0.68)	0.55 (0.32–0.92)
At least 1 household resident ≥ 65	224 (28)	0.68 (0.43–1.08)	–
At least 1 household resident < 18	321 (40)	0.98 (0.66–1.45)	–
Education			
Up to vocational school	209 (26)	Ref	Ref
Some college	202 (25)	1.86 (1.01–3.41)	1.54 (0.83–2.88)
College or postgraduate	386 (48)	2.91 (1.70–4.96)	1.84 (1.02–3.30)
Employment			
Employed	487 (61)	Ref	–
Not employed	146 (18)	0.86 (0.49–1.49)	–
Retired	109 (14)	1.08 (0.62–1.86)	–
Disabled or unable to work	58 (7)	1.01 (0.47–2.17)	–
Income			
< $100,000	566 (72)	Ref	Ref
≥ $100 K	223 (28)	2.42 (1.62–3.63)	1.39 (0.89–2.17)
Internet or e-mail at least once a day	647 (81)	3.46 (1.79–6.68)	2.97 (1.49–5.94)
Self-rated health			
Good to excellent	687 (86)	Ref	–
Fair	90 (11)	0.83 (0.44–1.68)	–
Poor	23 (3)	0.85 (0.23–3.09)	–
Took Rx medications in previous year	581 (73)	2.17 (1.29–3.64)	1.88 (1.09–3.26)
Caregiver for somebody with illness	100 (12)	1.26 (0.74–2.21)	–
Has a doctor who uses an EHR	637 (80)	1.60 (0.85–2.99)	–
Believes computerized medical data will worsen privacy/security	364 (46)	0.64 (0.43–0.96)	0.69 (0.45–1.05)
Has used a PHR	(136) 17	NA	NA
Among PHR users, type of PHR used		NA	NA
Sponsored by healthcare provider	(97) 73		
Sponsored by health insurance plan	(27) 21		
Other	(9) 7		

Marital status does not total 100 % as two individuals had other marital status. Totals may not sum to 100 % because of missing data. Race categories are not mutually exclusive and therefore total more than 100 %

data. The findings of the current survey may reflect the early impact of this program on patients, and may indicate a larger future role for these technologies to influence patient health and patient engagement.

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