



The association between patient activation and accessing online health information: Results from a national survey of US adults

Smith, SG; Pandit, A; Rush, SR; Wolf, MS; Simon, C

“The final publication is available at <http://onlinelibrary.wiley.com/doi/10.1111/hex.12316/full>”

For additional information about this publication click this link.

<http://qmro.qmul.ac.uk/xmlui/handle/123456789/12583>

Information about this research object was correct at the time of download; we occasionally make corrections to records, please therefore check the published record when citing. For more information contact scholarlycommunications@qmul.ac.uk

The association between patient activation and accessing online health information: results from a national survey of US adults

Samuel G. Smith PhD,*† Anjali Pandit MPH,‡ Steven R. Rush MA, LP,§
Michael S. Wolf PhD¶ and Carol Simon PhD**††

*Postdoctoral Fellow, ‡PhD Candidate, ¶Professor, Department of General Internal Medicine and Geriatrics, Northwestern University, Chicago, IL, USA, †Postdoctoral Fellow, Wolfson Institute of Preventive Medicine, Queen Mary University of London, London, UK, §Director Health Literacy Innovations Program, United Healthcare, Chicago, IL and **Senior Vice President and ††Director of the Optum Institute, Optum Labs, Minneapolis, MN, USA

Abstract

Correspondence

Samuel G. Smith, PhD
Department of General Internal
Medicine
Feinberg School of Medicine
Northwestern University
750 N Lake Shore Drive
Chicago
IL 60611
USA
E-mail: samuel.smith@ucl.ac.uk

Accepted for publication

12 November 2014

Keywords: consumer activation,
health information, patient activation,
personal health records

Background There are increasing opportunities for the public to access online health information, but attitudinal barriers to use are less well-known. Patient activation is associated with key health outcomes, but its relationship with using online health information is not known.

Objective We examined the relationship between patient activation and the likelihood of accessing a range of different types of online health information in a nationally representative US sample.

Design Cross-sectional nationally representative survey.

Setting and participants Data were from an online ($n = 2700$) and random digit dial telephone survey ($n = 700$) of US adults (total $n = 3400$).

Main variables studied Respondent characteristics and the Patient Activation Measure.

Main outcome measures Self-reported access of five types of online health information in the past 12 months (online medical records, cost estimation tools, quality comparison tools, health information about a specific condition, preventive health information).

Results Approximately, one-fifth of the sample had accessed their medical record (21.6%), treatment cost estimation tools (17.3%) and hospital and physician quality comparison tools (21.8%). Nearly half of the sample had accessed information about medical conditions or treatments (48.3%) or preventive health and well-being (45.9%). In multivariable analyses adjusted for participant characteristics, respondents with greater patient activation were more likely to have accessed all types of health information other than cost estimation tools.

Discussion and conclusions Activated people are more likely to make use of online health information. Increasing patient activation could improve the public's ability to participate in health care and personal health self-management by encouraging health information seeking.

Introduction

Patients are increasingly asked to manage aspects of their health and well-being. Patient activation and engagement are recognized as an important part of this process.¹ The activated patient has the motivation, knowledge, skills and confidence to make effective decisions to manage their health.² Following the development of the Patient Activation Measure (PAM),³ a growing evidence base has demonstrated associations between the PAM and outcomes such as functional health status, clinical outcomes and health-care utilization.^{4–6}

A behaviour that may partially explain the relationship between patient activation and health outcomes is engagement with health information. Accessing and evaluating health information is an important part of participating in the health-care environment, and it can facilitate shared decision making.⁷ People with higher levels of patient activation are more knowledgeable about health^{8,9} and make better decisions when using comparative health information.¹⁰ Comprehension is therefore not just a reflection of the ability to extract information, but also the effort and perseverance needed to identify it. In a US study, white collar workers with higher levels of patient activation were more likely to use health information and know where to find comparative information about hospital quality.¹¹ The use of online health information was not investigated.

Data from two national surveys indicate 3 in 4 Americans look for health information online each year.^{12,13} Approximately 40% reported that the Internet would be their primary source if they had a strong need for health information.¹⁴ This tendency to use online health information is growing,¹⁵ and personal health records (PHRs) which combine data, knowledge and software tools are more commonplace.¹⁶ Such tools offer more opportunity for patients to actively participate in their own care.¹⁷ Reflecting this, the number of people using online tools such as patient–physician e-mail has increased.¹⁵ Public attitudes towards these developments are generally positive,¹⁸

particularly in clinical subgroups such as cancer survivors.¹⁹ These new information sources can increase patient empowerment and satisfaction,^{20–22} and there is some evidence that they improve outcomes such as medication adherence and health-care utilization.²³

While it is plausible that this increasing trend of health information access is indicative of greater involvement in health care, evidence that people with high levels of patient activation are more likely to use online health information is lacking. Identifying this relationship could be a first step towards increasing patient involvement in their care¹⁰ and reducing barriers to the acceptance of new health information technologies.²⁴ This study used nationally representative data to investigate the associations between patient activation and self-reported access of online health information. We hypothesized higher levels of patient activation would be associated with an increased likelihood of accessing: online medical records; treatment cost estimation tools; hospital and physician quality comparison tools; information about conditions and treatments; and information about preventive health.

Methods

Design

Between August and September 2013, Harris Interactive undertook a mixed-mode nationally representative survey of English-speaking US adults ages 18 years and older. To ensure representation from population subgroups, random digit dial (RDD) ($n = 700$) and online sampling ($n = 2700$) was used (total $n = 3400$). Prior to dialling, the telephone sample was randomized and both landline and cell phone connections were included. The online panel was stratified by US Census parameters (education, age by gender, race/ethnicity, region and household income).²⁵ Selected individuals were sent a secure and unique URL and password by e-mail that provided access to the survey.

After excluding disconnected lines, 15 050 working phone numbers yielded 838 respondents

(5.6% RDD response rate). A total of 700 people met the age qualification (US resident, age 18+) for the RDD sample. A response rate for the online sample is not reported as probability sampling was not used. In accordance with polling industry standards, respondents' confidentiality was adhered to. The research company conducted this survey in accordance with the Council of American Survey Research Organization's code of ethics.

Measures

Accessing online health information

Self-reported access of online health information was assessed using the item: 'Which of the following have you done online in the past 12 months? Indicate as many as apply: accessed your medical records; accessed tools to estimate the cost of medical treatments; accessed tools to compare the quality of physicians and hospitals; accessed information about specific medical conditions and their treatments; and accessed information about preventive health and how to stay well. Responses were 'yes' and 'no'. The order of the different types of online health information was randomized for each participant to prevent the order of presentation influencing responses.

Patient activation measure

The 13-item PAM was used.³ The PAM assesses self-reported knowledge, skill and confidence for health self-management. Participants are asked to respond to statements that people sometimes make in a health context. Example statements include the following: 'I am confident I can help prevent or reduce problems associated with my health' and 'I am confident I can figure out solutions when new problems arise with my health'. Responses were recorded using a 4-point Likert scale ranging from 'strongly disagree' to 'strongly agree'. A 'not applicable' statement was available where appropriate. Scores range from 0 (low activation) to 100 (high activation), with respondents classified into four levels using pre-defined cut-offs: level 1 – may not yet

believe that the patient role is important (0–45.2); level 2 – lacks confidence and knowledge to take action (47.4–52.9); level 3 – beginning to take action (56.4–66.0); level 4 – has difficulty maintaining behaviours over time (68.5–100). The measure had good internal reliability in this sample ($\alpha = 0.90$).

Participant characteristics

Data were collected on gender, age, ethnicity (white, black, Asian or Pacific islander, other), income ($\$ < 15\ 000$, $\$ 15\ 000\text{--}34\ 999$, $\$ 35\ 000\text{--}49\ 999$, $\$ 50\ 000+$), education (high school or less, some college, college graduate, graduate school), self-rated health (poor, fair, good, very good, excellent), self-reported chronic conditions (0, 1 or 2+), region (east, midwest, south, west), Internet use [yes (1 h + per week), no] and insurance status (insured, not insured).

Statistical analysis

RDD data were weighted to US Census targets for education, age by gender, race/ethnicity, region and household income to bring them into line with the population of US adults.²⁵ The weighting algorithm also took into account landline vs. cell phone use,²⁶ and the probability of selection based on the number of available telephone lines, the number of adults in household and the recent absence of a phone connection. Online data were weighted to the same applicable parameters. The algorithm also included a propensity score which allowed adjustment for attitudinal and behavioural differences between online and offline populations, those who join online panels, and likelihood of response. The RDD and online sample data were combined into a proportioned total using Internet use information.²⁷

Weighted complex samples were performed using the following statistical tests. Chi-square analyses explored which participant characteristics were associated with patient activation. Odds ratios (ORs) and 95% confidence intervals (CIs) for the associations between patient activation, participant characteristics and accessing online health information were computed using

multivariable logistic regression. Significance was set at $P < 0.05$, and analyses were performed in spss version 22 (IBM SPSS Statistics for Windows, Version 22.0. Armonk, NY: IBM Corp).

Results

Sample characteristics

The average age of respondents was 47 years (SD = 17.41). The majority were white (77.5%), had an income $> \$50\,000$ (50.0%), had more than a high school level of education [some college (28.9%); college graduate (20.4%); graduate school (7.6%)] and had insurance (88.1%). Respondents were more likely to be female (52.8%) and from the south of the US (33.4%). Most respondents reported either good (35.9%) or very good (33.4%) health and no chronic conditions (66.5%). Most respondents (94.0%) used the Internet for at least 1 h per week. Most respondents had a working cell phone (89.0%), and slightly fewer had a working landline (68.9%).

Patient activation

The mean patient activation score placed respondents between levels 3 and 4 of the construct (M = 66.6, SD = 16.8). The majority of people were classified as being in the most activated category (level 4: 45.9%), with 29.8, 13.0 and 11.3% placed in levels 3, 2 and 1 respectively. As shown in Table 1, activation was associated with age [$\chi^2(17.41) = 95.03$, $P < 0.001$]. Younger groups achieved similar scores, while respondents aged 61–70 had the highest activation (level 4: 53.7%). Activation was lowest among those aged 71–80 (level 4, 37.4%) and 80+ (level 4, 32.0%). Higher income was also associated with higher activation levels [$\chi^2(11.40) = 69.39$, $P = 0.001$]. Over half (52.1%) of respondents with an income $> \$50\,000$ were classified as having level 4 activation. Patient activation scores increased with education [$\chi^2(8.42) = 38.69$, $P = 0.010$], with steady increases in the prevalence of level 4 activation in each education category. There was no overall

effect of ethnicity [$\chi^2(8.57) = 29.71$, $P = 0.149$]; however, Asian or Pacific islanders (31.7%) and the 'other' ethnicity category (39.0%) had notably lower levels of activation. Respondents with better health as measured by the number of chronic conditions [$\chi^2(5.89) = 26.07$, $P = 0.050$] and self-rated health [$\chi^2(11.41) = 324.62$, $P < 0.001$] had higher patient activation levels. Respondents using the Internet for more than 1 h per week were more likely to have a higher level of activation [$\chi^2(2.84) = 70.27$, $P < 0.001$]. Activation levels did not differ by gender [$\chi^2(2.95)$, $P = 6.01$, $P = 0.400$], region [$\chi^2(8.80) = 10.68$, $P = 0.804$], survey mode [$\chi^2(2.90) = 8.04$, $P = 0.317$] or insurance type [$\chi^2(2.84) = 5.61$, $P = 0.410$].

Accessing online health information and patient activation

Nearly half of the sample accessed information about medical conditions or treatments (48.3%) or about preventive health and well-being (45.9%). Approximately one-fifth of respondents reported accessing their medical record (21.6%), treatment cost estimation tools (17.3%) and hospital and physician quality comparison tools (21.8%). In univariable analyses, self-reported access generally increased across patient activation levels for the following: medical records ($P = 0.009$); hospital and physician quality comparison tools ($P < 0.001$); information about conditions and treatments ($P < 0.001$); and information about preventive health and well-being ($P < 0.001$) (Table 2). Patient activation was not related to accessing treatment cost estimation tools ($P = 0.511$).

In multivariable analyses controlling for all participant characteristics and survey mode (Table 3), compared to the least activated respondents (level 1), the most activated respondents (level 4) were more likely to have gone online to access: their medical record (OR, 2.29; 95% CI, 1.44–3.65); quality comparison tools (OR, 2.19; 95% CI, 1.36–3.52); information about a medical condition (OR, 1.76; 95% CI, 1.19–2.59); and information about preventive health and well-being (OR,

Table 1 Participant characteristics and % at highest level of activation

	<i>n</i>	%	Level 1	Level 2	Level 3	Level 4	χ^2 sig
Gender							
Male	1382	47.2	12.4	12.1	30.3	45.2	0.400
Female	2018	52.8	10.2	13.8	29.4	46.6	
Age							
18–30	585	21.9	16.4	12.3	26.2	45.0	0.000
31–40	537	16.6	7.6	11.3	34.2	47.0	
41–50	608	18.5	14.4	11.5	29.3	44.9	
51–60	649	17.3	8.9	12.2	33.5	45.4	
61–70	656	16.1	7.4	12.7	26.2	53.7	
71–80	281	7.3	12.1	19.6	30.9	37.4	
80+	84	2.4	7.1	28.9	32.1	32.0	
Ethnicity							
White	2717	77.5	10.0	12.8	30.5	46.7	0.149
Black	346	11.4	12.9	10.5	27.2	49.5	
Asian/Pacific islander	101	2.2	18.1	18.4	31.7	31.7	
Other	199	8.9	16.4	16.4	28.2	39.0	
Income							
<\$15 000	396	9.7	15.1	16.5	30.0	38.4	0.001
\$15–34 999	773	18.3	13.1	15.5	30.2	41.2	
\$35–49 999	449	12.9	14.0	14.7	31.7	39.6	
>\$50 000	1500	50.0	8.4	10.6	28.8	52.1	
Missing	282	9.2	15.1	14.7	31.8	38.4	
Education							
High school or less	884	43.2	13.9	13.9	29.8	42.3	0.010
Some college	1202	28.9	9.8	12.6	32.7	45.0	
College graduate	886	20.4	8.4	12.3	27.4	51.9	
Graduate school	411	7.6	10.2	11.1	23.9	54.8	
Region							
East	764	21.5	10.3	12.5	31.6	45.5	0.804
Midwest	833	22.4	11.3	12.4	31.8	44.5	
South	1041	33.4	10.6	12.5	29.0	47.9	
West	762	22.7	13.0	14.8	27.3	44.8	
Survey Mode							
Online	2700	77.0	10.8	12.5	29.7	47.1	0.317
Phone	700	23.0	12.9	14.7	30.3	42.1	
Self-rated health							
Poor	132	3.6	27.6	17.5	20.3	34.6	0.000
Fair	514	13.0	22.8	18.0	29.2	29.9	
Good	1324	35.9	13.0	16.5	34.7	35.8	
Very good	1042	33.4	5.4	9.4	30.4	54.7	
Excellent	388	14.1	6.2	6.9	19.3	67.5	
Chronic conditions							
0	983	33.5	7.9	11.9	32.1	48.1	0.050
1	816	24.3	11.2	13.4	30.1	45.2	
2+	1601	42.2	13.8	13.5	28.0	44.7	
Internet user							
Yes	3164	94.0	11.0	11.8	29.6	47.6	0.000
No	202	6.0	12.5	30.3	32.1	25.2	
Insurance status							
Insured	2970	88.1	11.1	13.0	29.1	46.7	0.410
Not insured	402	11.9	12.7	13.1	33.6	40.6	

n may not round to 3400 due to missing data; % are weighted.

Table 2 Self-reported access of online health information in the past 12 months by patient activation level

	Overall (%)	Level 1 (%)	Level 2 (%)	Level 3 (%)	Level 4 (%)	Chi-square (<i>P</i>)
Which of the following have you done online in the past 12 months...accessed						
Medical records	21.6	14.6	19.4	21.3	24.9	0.009
Treatment cost estimation tools	17.3	18.3	14.8	16.5	18.8	0.511
Hospital and physician quality comparison tools	21.8	16.2	22.1	17.8	26.3	<0.001
Information about conditions and treatments	48.3	42.2	42.4	46.4	54.8	<0.001
Information about preventive health	45.9	40.4	41.2	45.4	50.6	0.017

1.53; 95% CI, 1.02–2.28). No activation level group was more or less likely to have accessed treatment cost estimation tools. The level 3 activation group was more likely to have accessed their medical record online (OR, 1.85; 95% CI, 1.15–2.97), and the level 2 activation group were more likely to have accessed quality comparison tools (OR, 1.80; 95% CI, 1.05–3.10).

Younger respondents (18–30 and 31–40 years) were more likely to have accessed online health information than the oldest group (80+ years), with particularly strong effects for accessing online quality comparison tools (18–30 years, OR, 6.70; 95% CI, 2.40–18.70; 31–40 years, OR, 4.28; 95% CI, 1.53–11.98). Compared with the lowest earners (<\$15 000), respondents with a moderate income (\$35–49 999) were more likely to have accessed quality comparison tools (OR, 1.79; 95% CI, 1.06–3.00) and information relating to a medical condition (OR, 1.56; 95% CI, 1.00–2.42). Internet users and insured respondents were more likely to have accessed all types of online health information.

Higher levels of education were also associated with a greater likelihood of accessing online health information, with the exception of cost estimation tools. For example, compared with respondents with less than a high school education, those who completed graduate school were more likely to have accessed their online medical record (OR, 1.67; 95% CI, 1.09–2.55), quality comparison tools (OR, 1.67;

95% CI, 1.09–2.57), information about a medical condition (OR, 2.13; 95% CI, 1.47–3.09) and information about prevention and well-being (OR, 1.78; 95% CI, 1.24–2.55). There were few consistent effects for self-rated health. However, compared with respondents reporting no chronic conditions, those with 1 and two or more chronic conditions were more likely to have accessed their online medical record (OR, 2.20; 95% CI, 1.56–3.10 and OR, 1.89; 95% CI, 1.36–2.64, respectively) and information about a medical condition (OR, 1.49; 95% CI, 1.13–1.98 and OR, 1.86; 95% CI, 1.41–2.45 respectively). Respondents with two chronic conditions were more likely to have accessed quality comparison tools (OR, 1.65; 95% CI, 1.18–2.32) and information about prevention and well-being (OR, 1.38; 95% CI, 1.04–1.8). No racial differences in accessing online health information were observed.

Discussion

In this nationally representative US sample, approximately one-fifth of respondents had accessed their online personal medical record and used tools to estimate medical costs and health-care quality in the past year. Nearly half of the sample reported accessing information about a specific medical treatment or how to prevent ill health. With the exception of using cost estimation tools, respondents with the highest level of patient activation were approximately twice as likely to have accessed

Table 3 Weighted multivariable logistic regression predicting 'yes' response to accessing online information

	Medical records OR (95% CI)	Treatment cost tools OR (95% CI)	Quality comparison tools OR (95% CI)	Information seeking – conditions OR (95% CI)	Information seeking – prevention OR (95% CI)
Gender					
Male	Ref	Ref	Ref	Ref	Ref
Female	0.94 (0.74–1.20)	0.95 (0.72–1.26)	0.99 (0.78–1.27)	1.27 (1.03–1.56)	0.98 (0.80–1.20)
Age					
18–30	2.34 (1.08–5.06)	5.10 (1.73–15.01)	6.70 (2.40–18.70)	2.39 (1.15–4.96)	3.10 (1.45–6.60)
31–40	1.53 (0.70–3.35)	4.28 (1.44–12.72)	4.28 (1.53–11.98)	2.62 (1.27–5.43)	2.43 (1.15–5.14)
41–50	0.99 (0.46–2.14)	1.75 (0.59–5.23)	2.54 (0.91–7.07)	1.65 (0.80–3.40)	1.48 (0.70–3.10)
51–60	1.16 (0.54–2.48)	1.46 (0.50–4.32)	1.98 (0.72–5.47)	1.82 (0.90–3.71)	1.79 (0.86–3.71)
61–70	1.18 (0.56–2.50)	1.08 (0.36–3.26)	1.36 (0.48–3.81)	1.51 (0.75–3.04)	1.41 (0.68–2.89)
71–80	0.73 (0.33–1.60)	0.44 (0.12–1.58)	1.17 (0.40–3.37)	1.35 (0.63–2.88)	1.08 (0.50–2.34)
80+	Ref	Ref	Ref	Ref	Ref
Ethnicity					
White	Ref	Ref	Ref	Ref	Ref
Black	1.13 (0.77–1.65)	1.32 (0.88–1.98)	1.34 (0.91–1.96)	1.17 (0.82–1.66)	1.12 (0.79–1.58)
Asian/Pacific islander	1.20 (0.64–2.26)	1.40 (0.70–2.79)	1.23 (0.65–2.34)	0.78 (0.43–1.41)	0.98 (0.52–1.86)
Other	1.08 (0.67–1.73)	0.85 (0.51–1.42)	1.05 (0.65–1.69)	0.78 (0.51–1.19)	1.29 (0.84–1.96)
Income					
\$<15 000	Ref	Ref	Ref	Ref	Ref
\$15–34 999	0.71 (0.45–1.12)	0.79 (0.48–1.30)	1.44 (0.90–2.33)	1.06 (0.71–1.56)	0.83 (0.56–1.22)
\$35–49 999	0.97 (0.59–1.59)	1.08 (0.63–1.85)	1.79 (1.06–3.00)	1.56 (1.00–2.42)	1.07 (0.70–1.63)
\$50 000+	0.88 (0.57–1.37)	1.00 (0.61–1.63)	1.55 (0.97–2.48)	1.32 (0.90–1.95)	1.08 (0.73–1.59)
Missing	0.77 (0.43–1.37)	0.82 (0.42–1.63)	1.45 (0.77–2.73)	0.91 (0.54–1.52)	0.88 (0.51–1.53)
Education					
≤High school	Ref	Ref	Ref	Ref	Ref
Some college	1.11 (0.82–1.51)	0.78 (0.55–1.11)	1.12 (0.81–1.54)	1.42 (1.10–1.84)	1.41 (1.10–1.82)
College graduate	1.21 (0.85–1.72)	0.81 (0.54–1.20)	1.31 (0.92–1.85)	1.51 (1.13–2.03)	1.34 (1.01–1.79)
Graduate school	1.67 (1.09–2.55)	0.95 (0.56–1.59)	1.67 (1.09–2.57)	2.13 (1.47–3.09)	1.78 (1.24–2.55)
Patient activation					
Level 1	Ref	Ref	Ref	Ref	Ref
Level 2	1.53 (0.90–2.60)	0.86 (0.47–1.55)	1.80 (1.05–3.10)	1.07 (0.69–1.65)	1.12 (0.72–1.76)
Level 3	1.85 (1.15–2.97)	1.00 (0.60–1.68)	1.39 (0.85–2.28)	1.26 (0.85–1.87)	1.30 (0.86–1.96)
Level 4	2.29 (1.44–3.65)	1.09 (0.66–1.82)	2.19 (1.36–3.52)	1.76 (1.19–2.59)	1.53 (1.02–2.28)
Self-rated health					
Poor	1.55 (0.76–3.13)	0.58 (0.22–1.52)	0.61 (0.27–1.34)	1.65 (0.84–3.26)	0.99 (0.52–1.89)
Fair	1.13 (0.70–1.84)	0.77 (0.44–1.32)	0.84 (0.51–1.39)	2.00 (1.30–3.06)	1.05 (0.69–1.60)
Good	1.06 (0.71–1.59)	0.67 (0.43–1.04)	0.74 (0.50–1.11)	1.23 (0.86–1.75)	0.84 (0.59–1.20)
Very good	0.76 (0.51–1.14)	0.63 (0.42–0.96)	0.55 (0.37–0.80)	1.06 (0.75–1.49)	0.85 (0.60–1.19)
Excellent	Ref	Ref	Ref	Ref	Ref
Chronic conditions					
0	Ref	Ref	Ref	Ref	Ref
1	2.20 (1.56–3.10)	1.22 (0.84–1.77)	1.34 (0.96–1.87)	1.49 (1.13–1.98)	1.23 (0.93–1.62)
2+	1.89 (1.36–2.64)	1.26 (0.87–1.81)	1.65 (1.18–2.32)	1.86 (1.41–2.45)	1.38 (1.04–1.83)
Internet user					
Yes	3.09 (1.50–6.36)	3.19 (1.11–9.13)	3.82 (1.74–8.39)	13.97 (7.21–27.10)	3.72 (1.80–7.73)
No	Ref	Ref	Ref	Ref	Ref
Insurance status					
Insured	2.57 (1.65–3.99)	1.79 (1.13–2.85)	1.70 (1.10–2.62)	2.11 (1.52–2.94)	1.82 (1.31–2.52)
Not insured	Ref	Ref	Ref	Ref	Ref

online health information as the least activated respondents. These findings were largely maintained in multivariable analyses controlling for participant characteristics and survey mode. The increased likelihood of engagement with health information may be one route through which patient activation affects health.

A national study from 2013 estimated approximately 78% of health-care providers are using an electronic health record, up from 18% in 2001.¹⁶ The likelihood of consumers using the Internet as the first source of health information is also increasing.¹⁵ As availability and use of these sources of online health information increases, the role of attitudinal barriers will become more important. Patient-reported barriers to using online health information technologies (e.g. PHRs) include a lack of perceived usefulness,²⁴ fears over privacy^{18,22,28} and poor knowledge.²⁴ Barriers to seeking information about health and medical conditions include low health literacy,^{29–31} defensive processing (e.g. informational avoidance),³² trust¹⁴ and negative experiences.³³ Our data suggest patient activation should be considered alongside these patient-reported barriers.

These data provide more support for a threshold (level 4 vs. levels 3, 2 and 1) than a gradient effect for the relationship between patient activation and online health information seeking. This is important, as the most appropriate strategy to increase patient activation can differ according to baseline levels.^{34,35} Multi-component intervention strategies may therefore be needed to raise activation to level 4 before changes to health information seeking will be observed. Future studies should continue to examine whether this threshold exists with other health-care services and health outcomes.

Our research was unable to investigate how people interacted with their online medical record. PHRs offer a multitude of functions that facilitate participation in health care and self-management. These include communicating with health-care providers, requesting medication refills and tracking clinical indicators.³⁶ Future research using more fine-grained analyses to investigate how people of different

patient activation levels navigate online health technologies is warranted.^{37–39} Similarly, we were unable to report the types of health information people were accessing and where they were searching. More activated people tend to make better decisions when offered comparative health information, but investigating the quality of information gleaned from their searches is an important next step in this area.¹⁰

These data demonstrated that nearly half of the US population was classified as being in the highest level of patient activation. This supports existing data from national research performed in 2007.⁴⁰ However, overall figures can disguise disparities that exist within population subgroups. Respondents who were older, less educated, non-users of the Internet and socio-economically disadvantaged were less activated. Higher patient activation was also associated with better self-reported health. Respondents without comorbidity were more likely to have high activation, although the strength of this association was not as strong. Surprisingly, we found no effect for racial disparities in activation, although Asian and Pacific islanders had noticeably lower levels of activation.

Interventions demonstrating improvements to patient activation levels have been tested. For example, strategies that promote question asking,^{41,42} provide role models,⁴³ and which encourage small manageable changes in behaviour,^{35,44} have resulted in increases to patient activation. More intensive interventions such as Lorig's Chronic Disease Self-Management Program have resulted in sustained improvements in activation over time.^{45,46} Importantly, more sizeable improvements are often demonstrated in the least activated groups.^{35,42,43} A modelling study reported that meaningful reductions in health disparities could occur if activation differences were eliminated.⁴⁷

In addition to activation differences, we found evidence of a digital divide in the likelihood of accessing online health information.^{14,48} Respondents who were more educated were more likely to have accessed their online medical record and information

about preventive health and well-being. In addition, respondents reporting a moderate income were more likely to have accessed tools to compare physician and hospital quality. Both groups were more likely to have accessed information about a medical condition. Insured respondents and frequent users of the Internet were more likely to have accessed all types of information. There were no racial disparities in accessing online health information. These findings are concordant with previous studies reporting disparities in enrolment to PHRs,⁴⁹ but not in their subsequent use.^{36,50} However, there is evidence to suggest ethnic minorities are less likely to search online for general health information which was not supported by our data.¹⁴ Differences in health information use by population subgroups may exacerbate communication inequalities.^{48,51} As disparities in access to an Internet connection reduce,⁵² research should identify strategies to support underserved populations in overcoming attitudinal barriers to using online health information resources.

This study had limitations. The cross-sectional data prevent inferences of causality. It is possible that people who access online health information become more activated, and some data may support this.^{53,54} This would also have important implications, as promoting access to health information may empower patients and increase their activation for health self-management. Further research disentangling the direction of this relationship is an important next step. An equally serious limitation was that the availability of an online PHR and cost comparison tools was not assessed. It was therefore unclear for these outcomes whether 'no' responses indicated a lack of opportunity or interest. A proportion of our sample were recruited by RDD telephone survey ($n = 700$), and Internet use in this group was lower (75.4%), which may have reduced the effect of our exposure variables. Response to RDD surveys has been falling in recent years, but the rates reported within our study were particularly low in comparison with similar studies.^{55,56} This is likely to limit the generalizability of our

data. Reports of cell phone and landline telephone connections reflected national estimates^{57,58}; however, we were unable to reach people who were registered on 'no-call' lists, limiting the generalizability of our findings to these groups. Finally, the sample may not have been representative of the US population because they were more likely to be older, white and report a higher income. This may be because a large proportion of our sample ($n = 2400$) were recruited from an online panel. Response and selection biases were limited through weighting procedures, but it is still possible that this sample may have been more activated than an offline population. We may therefore have overestimated the level of patient activation in the general US sample, and associations with demographic variables may be conservative estimates.

In conclusion, in a national sample of US adults, approximately one-fifth of respondents reported accessing their online PHR and tools to assess health-care quality and cost. Reports of seeking information about specific medical conditions, treatment and prevention were higher, but nearly half of the population had not done so in the previous year. Patient activation, low income and low education were consistently associated with using online health information. Income and education disparities in patient activation were observed. Respondents with a higher income, more education and better health had higher patient activation. The role of attitudinal factors such as patient activation is likely to become more important to engagement as the opportunity for accessing online health information increases.

Conflicts of interest

The authors report no conflict of interest.

Funding source

Financial support for this study was provided by a contract with UnitedHealthcare and Optum Labs. The funding agreement ensured

the authors' independence in designing the study, interpreting the data, and writing and publishing the report. The following authors are employed by the sponsor: Carol Simon, PhD, and Steven R. Rush, MA, LP. Dr Smith is currently funded by a Cancer Research UK Postdoctoral Fellowship.

References

- 1 Hibbard JH, Greene J. What the evidence shows about patient activation: better health outcomes and care experiences; fewer data on costs. *Health Affairs (Project Hope)*, 2013; **32**: 207–214.
- 2 Wagner EH. Chronic disease management: what will it take to improve care for chronic illness? *Effective Clinical Practice*, 1998; **1**: 2–4.
- 3 Hibbard JH, Mahoney ER, Stockard J, Tusler M. Development and testing of a short form of the Patient Activation Measure. *Health Services Research*, 2005; **40**: 1918–1930.
- 4 Smith SG, Curtis LM, Wardle J, von Wagner C, Wolf MS. Skill Set or Mind Set? Associations between health literacy, patient activation and health. *PLoS ONE*, 2013; **8**: e74373.
- 5 Mitchell SE, Gardiner PM, Sadikova E *et al.* Patient activation and 30-day post-discharge hospital utilization. *Journal of General Internal Medicine*, 2014; **29**: 349–355.
- 6 Greene J, Hibbard JH. Why Does Patient Activation Matter? An examination of the relationships between patient activation and health-related outcomes. *Journal of General Internal Medicine*, 2012; **27**: 520–526.
- 7 McCaffery KJ, Smith SK, Wolf M. The challenge of shared decision making among patients with lower literacy: a framework for research and development. *Medical Decision Making*, 2010; **30**: 35–44.
- 8 Ledford CJW, Ledford CC, Childress MA. Exploring patient activation in the clinic: measurement from three perspectives. *Health Education & Behavior*, 2013; **40**: 339–345.
- 9 Schapira MM, Fletcher KE, Hayes A *et al.* The development and validation of the hypertension evaluation of lifestyle and management knowledge scale. *Journal of Clinical Hypertension*, 2012; **14**: 461–466.
- 10 Hibbard JH, Peters E, Dixon A, Tusler M. Consumer competencies and the use of comparative quality information: it isn't just about literacy. *Medical Care Research and Review: MCRR*, 2007; **64**: 379–394.
- 11 Fowles JB, Terry P, Xi M, Hibbard J, Bloom CT, Harvey L. Measuring self-management of patients' and employees' health: further validation of the Patient Activation Measure (PAM) based on its relation to employee characteristics. *Patient Education and Counseling*, 2009; **77**: 116–122.
- 12 Duggan M. Health Online 2013 [Internet]. Pew Research Center's Internet & American Life Project. 2013. Available at: <http://www.pewinternet.org/2013/01/15/health-online-2013/>, accessed 27 November 2014.
- 13 National Cancer Institute. Health Information and National Trends Survey: In the past 12 months, have you do the following things while using the internet? Looked for health and medical information for yourself? Available at: <http://hints.cancer.gov/question-details.aspx?dataset=41&qid=757&qdid=4920>, accessed 27 November 2014.
- 14 Hesse BW, Nelson DE, Kreps GL *et al.* Trust and sources of health information: the impact of the Internet and its implications for health care providers: findings from the first Health Information National Trends Survey. *Archives of Internal Medicine*, 2005; **165**: 2618–2624.
- 15 Hesse BW, Moser RP, Rutten LJ. Surveys of physicians and electronic health information. *New England Journal of Medicine*, 2010; **362**: 859–860.
- 16 Hsiao C, Hing H. *Use and Characteristics of Electronic Health Record Systems Among Office-based Physician Practices: United States, 2001–2013*. Centers for Disease Control and Prevention and National Cancer Institute, 2014. Available at: www.cdc.gov/nchs/data/databriefs/db143.htm, accessed 27 November 2014.
- 17 Tang PC, Ash JS, Bates DW, Overhage JM, Sands DZ. Personal health records: definitions, benefits, and strategies for overcoming barriers to adoption. *Journal of the American Medical Informatics Association*, 2006; **13**: 121–126.
- 18 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. *Journal of the American Medical Informatics Association : JAMIA*, 2004; **11**: 505–513.
- 19 Beckjord EB, Rechis R, Nutt S, Shulman L, Hesse BW. What do people affected by cancer think about electronic health information exchange? Results from the 2010 LIVESTRONG Electronic Health Information Exchange Survey and the 2008 Health Information National Trends Survey. *Journal of Oncology Practice*, 2011; **7**: 237–241.
- 20 Lin C-T, Wittevrongel L, Moore L, Beaty BL, Ross SE. An internet-based patient-provider communication system: randomized controlled trial. *Journal of Medical Internet Research*, 2005; **7**: e47.
- 21 Schnipper JL, Gandhi TK, Wald JS *et al.* Design and implementation of a web-based patient portal

- linked to an electronic health record designed to improve medication safety: the Patient Gateway medications module. *Informatics in Primary Care*, 2008; **16**: 147–155.
- 22 Detmer D, Bloomrosen M, Raymond B, Tang P. Integrated personal health records: transformative tools for consumer-centric care. *BMC Medical Informatics and Decision Making*, 2008; **8**: 45.
- 23 Ammenwerth E, Schnell-Inderst P, Hoerbst A. The impact of electronic patient portals on patient care: a systematic review of controlled trials. *Journal of Medical Internet Research*, 2012; **14**: e162.
- 24 Goel MS, Brown TL, Williams A, Cooper AJ, Hasnain-Wynia R, Baker DW. Patient reported barriers to enrolling in a patient portal. *Journal of the American Medical Informatics Association*, 2011; **18**(Suppl 1): 8–12.
- 25 United States Census Bureau. Current Population Survey, March supplement. Available at: <http://www.census.gov/cps/data/>, accessed 27 November 2014.
- 26 Blumberg SJ, Luke JV. Wireless substitution: Early release of estimates from the National Health Interview Survey, January–June 2012. 2012. Available at: <http://www.cdc.gov/nchs/data/nhis/earlyrelease/wireless201212.pdf>, accessed 27 November 2014.
- 27 Pew Research Center. Health fact sheet, May 2013. Available at: <http://www.pewinternet.org/Commentary/2011/November/Pew-Internet-Health.aspx>, accessed 27 November 2014.
- 28 Simon SR, Evans JS, Benjamin A, Delano D, Bates DW. Patients' attitudes toward electronic health information exchange: qualitative study. *Journal of Medical Internet Research*, 2009; **11**: e30.
- 29 von Wagner C, Semmler C, Good A, Wardle J. Health literacy and self-efficacy for participating in colorectal cancer screening: the role of information processing. *Patient Education and Counseling*, 2009; **75**: 352–357.
- 30 von Wagner C, Steptoe A, Wolf MS, Wardle J. Health literacy and health actions: a review and a framework from health psychology. *Health Education & Behavior*, 2008; **36**: 860–877.
- 31 Greene J, Hibbard JH, Tusler M, PPI (AARP). How much do health literacy and patient activation contribute to older adults' ability to manage their health? AARP Public Policy Institute, 2005. Available at: https://assets.aarp.org/rgcenter/health/2005_05_literacy.pdf, accessed 27 November 2014.
- 32 McQueen A, Vernon SW, Swank PR. Construct definition and scale development for defensive information processing: an application to colorectal cancer screening. *Health Psychology*, 2013; **32**: 190–202.
- 33 Arora NK, Hesse BW, Rimer BK, Viswanath K, Clayman ML, Croyle RT. Frustrated and confused: the American public rates its cancer-related information-seeking experiences. *Journal of General Internal Medicine*, 2008; **23**: 223–228.
- 34 Deen D, Lu WH, Weintraub MR, Maranda MJ, Elshafey S, Gold MR. The impact of different modalities for activating patients in a community health center setting. *Patient Education and Counseling*, 2012; **89**: 178–183.
- 35 Hibbard JH, Greene J, Tusler M. Improving the outcomes of disease management by tailoring care to the patient's level of activation. *The American Journal of Managed Care*, 2009; **15**: 353–360.
- 36 Goel MS, Brown TL, Williams A, Hasnain-Wynia R, Thompson JA, Baker DW. Disparities in enrollment and use of an electronic patient portal. *Journal of General Internal Medicine*, 2011; **26**: 1112–1116.
- 37 Pyper C, Amery J, Watson M, Crook C. Patients' experiences when accessing their on-line electronic patient records in primary care. *British Journal of General Practice*, 2004; **54**: 38–43.
- 38 Eysenbach G, Kohler C. How do consumers search for and appraise health information on the world wide web? Qualitative study using focus groups, usability tests, and in-depth interviews. *BMJ*, 2002; **324**: 573–577.
- 39 Birru MS, Monaco VM, Charles L *et al.* Internet usage by low-literacy adults seeking health information: an observational analysis. *Journal of Medical Internet Research*, 2004; **6**: e25.
- 40 Hibbard JH, Cunningham PJ. How engaged are consumers in their health and health care, and why does it matter. *Research Brief*, 2008; **8**: 1–9.
- 41 Alegría M, Polo A, Gao S *et al.* Evaluation of a patient activation and empowerment intervention in mental health care. *Medical Care*, 2008; **46**: 247–256.
- 42 Deen D, Lu W-H, Rothstein D, Santana L, Gold MR. Asking questions: the effect of a brief intervention in community health centers on patient activation. *Patient Education and Counseling*, 2011; **84**: 257–260.
- 43 Frosch DL, Rincon D, Ochoa S, Mangione CM. Activating seniors to improve chronic disease care: results from a pilot intervention study. *Journal of the American Geriatrics Society*, 2010; **58**: 1496–1503.
- 44 Shively MJ, Gardetto NJ, Kodiath MF *et al.* Effect of patient activation on self-management in patients with heart failure. *Journal of Cardiovascular Nursing*, 2013; **28**: 20–34.
- 45 Lorig K, Ritter PL, Villa FJ, Armas J. Community-based peer-led diabetes self-management: a randomized trial. *The Diabetes Educator*, 2009; **35**: 641–651.
- 46 Druss BG, Zhao L, von Esenwein SA *et al.* The Health and Recovery Peer (HARP) Program: a peer-led intervention to improve medical self-

- management for persons with serious mental illness. *Schizophrenia Research*, 2010; **118**: 264–270.
- 47 Hibbard JH, Greene J, Becker ER *et al.* Racial/ethnic disparities and consumer activation in health. *Health Affairs (Project Hope)*, 2008; **27**: 1442–1453.
- 48 Viswanath K. The communications revolution and cancer control. *Nature Reviews Cancer*, 2005; **5**: 828–835.
- 49 Roblin DW, Houston TK II, Allison JJ, Joski PJ, Becker ER. Disparities in use of a personal health record in a managed care organization. *Journal of the American Medical Informatics Association*, 2009; **16**: 683–689.
- 50 Yamin CK, Emani S, Williams DH *et al.* The digital divide in adoption and use of a personal health record. *Archives of Internal Medicine*, 2011; **171**: 568–574.
- 51 Viswanath K, Nagler RH, Bigman-Galimore CA, McCauley MP, Jung M, Ramanadhan S. The communications revolution and health inequalities in the 21st Century: implications for cancer control. *Cancer Epidemiology, Biomarkers & Prevention*, 2012; **21**: 1701–1708.
- 52 Zickuhr K, Smith A. Home Broadband 2013. Pew Research Center's Internet & American Life Project. 2013. Available at: <http://www.pewinternet.org/2013/08/26/home-broadband-2013/>, accessed 27 November 2014.
- 53 Nagykaldi Z, Aspy CB, Chou A, Mold JW. Impact of a wellness portal on the delivery of patient-centered preventive care. *Journal of the American Board of Family Medicine*, 2012; **25**: 158–167.
- 54 Solomon M, Wagner SL, Goes J. Effects of a web-based intervention for adults with chronic conditions on patient activation: online randomized controlled trial. *Journal of Medical Internet Research*, 2012; **14**: e32.
- 55 Cantor D, Coa K, Crystal-Mansour S, Davis T, Dipko S, Sigman R. Health Information National Trends Survey (HINTS) 2007 final report. 2009. Available at: <http://hints.cancer.gov/docs/HINTS2007FinalReport.pdf>, accessed 27 November 2014.
- 56 Cantor D, Covell J, Davis T, Park I, Rizzo L. Health Information National Trends Survey (HINTS) 2005 final report. 2007. Available at: http://hints.cancer.gov/docs/HINTS_2005_Final_Report.pdf, accessed 27 November 2014.
- 57 Blumberg SG, Luke JV. Wireless substitution: Early release of estimates from the National Health Interview Survey, January–June 2013. National Center for Health Statistics. 2012. Available at: <http://www.cdc.gov/nchs/data/nhis/earlyrelease/wireless201312.pdf>, accessed 27 November 2014.
- 58 Pew Research. Internet Project, device ownership over time. Available at: <http://www.pewresearch.org/fact-tank/2013/06/06/cell-phone-ownership-hits-91-of-adults/>, accessed 27 November 2014.