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Chris N. Sciamanna  
*Thomas Jefferson University*

Melissa Clark  
*Brown University*

Joseph Diaz  
*Brown University*

Stephanie Newton  
*Providence College*

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Filling the gaps in physician communication. The role of the Internet among primary care patients.

Christopher N Sciamanna<sup>1</sup>, Melissa A Clark<sup>1</sup>, Joseph A Diaz<sup>1</sup>, Stephanie Newton<sup>2</sup>, Brown Medical School (1), Providence College (2).

Corresponding Author:

Christopher N. Sciamanna, MD, MPH  
Assistant Professor, Department of Community Health, Brown Medical School  
The Miriam Hospital, Centers for Behavioral and Preventive Medicine  
One Hoppin Street, Coro Building, Suite 500  
Providence, RI 02903  
email: csciamanna@lifespan.org

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**ABSTRACT:**

**BACKGROUND:**

Millions of people use the Internet as a source for health information yet little is understood about how the use of the Internet for health information is related to the doctor-patient relationship.

**OBJECTIVE:**

We conducted the present study to understand the association between one's interest in using the Internet for general and quality-oriented health information and attitudes about one's communications with health care provider(s).

**DESIGN:**

Cross-sectional survey.

## SETTING:

Four community-based primary care practices in Rhode Island.

## MEASUREMENTS:

A single self-administered survey included items to measure: interest in using the Internet to look for general and quality-oriented information and a patient's perceptions of the degree to which their doctors over the previous year have: 1) given them information and 2) engaged them in the decision-making process.

## RESULTS:

A total of 300 patients completed the survey. Among patients without Internet access, interest in using the Internet for health related activities was less among patients who felt that their doctor gave more information: Odds ratio 0.83 (95% CI, 0.70 to 0.98) and greater among patients who felt that their doctor engaged them more in decision making: Odds ratio 1.3 (95% CI, 1.1-1.6). Among patients with Internet access, we found no relationship between interest in using the Internet for health related activities and measures of patient-physician communication or patient-physician decision making.

## CONCLUSIONS:

Interest in using the Internet for health information is greater for those who 1) felt their doctors provided less information and 2) felt their doctors engaged them more in the decision-making process, but this is true only for those without access to the Internet.

## KEYWORDS:

Internet, Communication, Doctor-patient relationship, decision-making, information, quality

## BACKGROUND

The Internet continues to evolve as an increasingly important source of health information for millions. In March 2001 an estimated 64 million Americans used the Internet for health information, an increase from 47 million the previous year<sup>1,2</sup>. With an estimated 100,000 health related Web sites, the Internet has changed the way that Americans access health information<sup>3</sup>. Patients use the Internet to investigate many health-related topics commonly encountered by primary care providers<sup>4</sup>. Furthermore, the pace of "eHealth" development has meant that more and more types of health information are available online, including information about the quality of care of hospitals ([www.healthgrades.com](http://www.healthgrades.com))<sup>5,6</sup>.

This revolution in health care information has great potential to impact the way that patients interact with their physicians. For example, it is quite likely that 1 hour of Internet searching by an intelligent patient on a reputable website can give the patient information about his or her condition that the physician is not aware of<sup>7</sup>. Though several studies have examined the quality of medical information on the Internet and the type of medical information being searched for, little work has been done to evaluate its possible impact on the doctor-patient relationship<sup>8,9,10</sup>. We conducted the present study to understand the association between a patient's interest in

using the Internet for health-related activities and their attitudes about the relationship with their health care provider(s).

## METHODS

We recruited a convenience sample of four community-based primary care practices from Providence County, Rhode Island. Providence County has the following demographic profile from the Census Bureau: 14.6% over the age of 65, 21.6% minorities and 14.2% with a household income below the federal poverty level<sup>12</sup>. Physicians in each practice were affiliated with the Brown University teaching hospital network and had worked previously with members of the research team on other projects. One of the practices was a state-supported, suburban public health clinic serving low-income individuals, while the other three were suburban, primary care practices. The practices had an average of three full-time physicians on staff. A research assistant approached 355 consecutive adult outpatients from June 1, 2001 to August 15, 2001 to complete the self-administered survey. Subjects were paid \$20 to complete the survey. The protocol was approved by the Institutional Review Board of The Miriam Hospital.

## MEASURES:

In order to inform the instrument development, twenty subjects were recruited for 2 focus groups by emailing notices to employees of The Miriam Hospital and Rhode Island Hospital and placing posters placed in public places in both hospitals. Focus group participants were asked to identify health-related activities that they currently performed on the Internet, in addition to activities that they were aware of but had not personally used. Employees in a health care setting were recruited as they were generally felt to be more experienced in using the Internet for health information, given their experience at work. The goal of the focus groups was to create a long list of common health related activities that people were doing on the Internet. Recruiting a group of people who were more likely to be experienced with health-related activities and more likely to have Internet access made them a useful sample to recruit from for focus groups. Health-related activities that that were noted more than once, or that were felt to possibly affect the doctor-patient relationship, were added to the Internet Interest Survey described below.

Internet Interest Survey (IIS). Questionnaire items were created to measure the interest of subjects in using the Internet for each of 17 potential activities noted in the focus groups above, such as to “find information about a specific disease or medical condition” All 17 items were asked of each subject, regardless of whether or not they currently had access to the Internet.

Because our analysis was to understand the association between Internet use for general and quality of care-oriented health information and attitudes about one’s communications with health care provider(s), we limited our analysis to the eight items from the IIS that measured interest in using the Internet for activities that either 1) were typically performed by physician (e.g., “Find information about a specific disease or medical condition”) or 2) represented a form of due diligence on the part of patients (e.g., “Find information about the quality of care a doctor provides?”). The other nine items measured a patient’s interest in using the Internet for activities that were felt to be unrelated to our main research question, such as using the Internet to “buy medications from a pharmacy” and “schedule an appointment with your doctor”, and were therefore excluded from the analysis. In a preliminary factor analysis, all 8 items loaded on a

single factor with a scale reliability (Cronbach's alpha) of 0.93. The eight items included in the analysis can be found in the appendix.

In this study, we made a distinction between two types of health information available on the Internet: general and quality-oriented. General health information was categorized as information about conditions and treatments while "quality-oriented" health information was categorized as information that helps patients understand the quality of the health care they have been receiving. For example, a "general" health information Internet site would have information about heart disease (e.g., [www.webmd.com](http://www.webmd.com)), including the common tests and treatments, while a "quality-oriented" health information Internet site might list the success and complication rates of specific heart surgeons (e.g., [www.phc4.org](http://www.phc4.org)).

#### Physician Communication, Decision-Making and perceived quality of care survey items.

Previously developed and validated scales were used to measure a patient's perception of the degree to which physicians have: 1) given them all of the information they needed to know about their health and 2) encouraged them to take responsibility for their care and be involved in medical decisions<sup>13, 14</sup>. Items regarding physician communication asked patients how their doctors were at "telling you everything that you should know", "explaining treatment alternatives", "explaining the side effects of medications" and "telling you what to expect from a disease or treatment". Items were scored on a 5 point scale where 1="poor", 2="fair", 3="good", 4="very good" and 5="excellent". The sum of these items, from 4 to 20, was dichotomized into "low" and "high" categories based on a median cutpoint.

Patient's perceptions of the degree to which their doctors have encouraged them to take responsibility for their care and be involved in their medical decisions were measured with three items: 1) How often did doctors ask you to take responsibility for your treatment (1= "never", 2="rarely", 3="sometimes", 4="often", 5="very often"), 2) If there was a choice in treatments, did doctors ask you to help make decisions? (1="No, definitely not", 2="No, probably not", 3="Maybe", 4="Yes, probably", 5="Yes, definitely") and 3) How often do doctors make an effort to give you some control over treatment decisions (1= "never", 2="rarely", 3="sometimes", 4="often", 5="very often")<sup>14</sup>. The sum of these items, from 3 to 15, was dichotomized into "low" and "high" categories based on a median cutpoint.

A single item was used to measure perceived quality of care. The item was used previously in the 2000 Behavioral Risk Factor Surveillance System (BRFSS)<sup>15</sup>. The item asked patients to rate the quality of "all your health care" on a scale from 1 to 5 where 1 is the "worst health care possible" and 5 is the "best health care possible".

#### Covariates:

Brief screening questions for age, gender, educational attainment, health insurance status, perceived health, race and ethnicity were adapted from the year 2000 Behavioral Risk Factor Surveillance System<sup>15</sup>. Internet use was assessed using questions adapted from the Pew Internet and American Life Project<sup>2</sup>.

#### **DATA ANALYSIS:**

All data analyses were carried out using SPSS for Windows, version 10.0.5. Chi-Square tests were used to examine differences in categorical data while t-tests and analysis of variance were

used to examine differences in continuous variables. Due to the presence of some missing data, some analyses include less than 300 individuals. No variable included in our analysis was missing for more than 2% of the sample.

For the purposes of our analysis, the 8 IIS items included in our analysis were added together into a single summary measure. For use as a dependent variable in a logistic regression model, we used a median split on the IIS scale to divide the sample into “higher” and “lower” interest in using the Internet for health-related activity. Next, we stratified the sample into those with and without internet access and computed two separate multiple logistic regression models. We included variables measuring physician communication and involvement in decision making (from original hypotheses) and variables that were significantly related to the dependent variable (Internet interest) in bivariate analyses. Finally, to test whether the correlates differed by Internet access, we fit a single logistic regression model to the entire sample. We included terms for the interaction between Internet access and each of the correlates in the stratified models. Significance of the interaction terms was assessed using likelihood-ratio statistics. A significant interaction term indicated that the nature of the particular association differed by the presence or absence of Internet access.

## RESULTS

A total of 300 subjects completed the survey for a response rate of 84.5%. Approximately two-thirds (63.7%) reported having Internet access at home, work, school, family or friend’s home or at a library. The mean patient age was 45.2 years (range: 18-75 years), 83.0% (n=249) were female, 21.3% (n=64) had completed at least 4 years of college and 9.7% (n=27) had no health insurance.

Table 1 shows the bivariate associations between Internet access and background characteristics. Internet access was greater among subjects who were younger, who had more formal education and who had better self-reported health. Internet access was not related to gender, race, health insurance status, or the two physician communication variables, physician information-giving and involvement in decision-making. Table 2 shows the logistic regression, odds ratios and 95% confidence intervals for Interest in using Internet separately among those with and without Internet access. Among patients without Internet access, interest in using the Internet for health related activities was greater among patients who 1) felt that their doctor gave less information and 2) felt that their doctor engaged them more in decision making.

Among patients with Internet access, interest in using the Internet for health related activities was greater among non-white patients and those who perceived their care to be better (see Table 2). Table 2 also presents the results of the tests of interaction between Internet access and each of the covariates. We found three important interactions that confirmed the stratified analyses. First, among patients with Internet access, those who identified as non-white were more interested in using the Internet compared to those who identified as white. On the other hand, there was no association between race/ethnicity and interest in using the Internet among those without Internet access. Finally, while there was no association among patients with Internet access, among patients without Internet access, there was an association between interest in using the Internet and feeling that doctors gave less information and engaged them in more decision making. These findings were qualitatively similar using a linear regression model, with the IIS as a continuous measure.

## DISCUSSION

The Internet is changing the doctor-patient relationship because it provides patients with the potential to make better health decisions via easy access to vast amounts of health information. In the present study, we attempted to investigate the relationship between 1) patients' interest in using the Internet for general and quality-oriented health information and 2) their beliefs about their communications with their physicians. We hypothesized that patients' interest in using the Internet for general and quality-oriented health information would be greater if they believed that their health care providers either 1) did not tell them as much or 2) did not involve them as much in decisions. This paper represents one of the first studies to examine the interest of patients in using the Internet, stratified by Internet access. We considered this important because only 6 in 10 Americans has access to the Internet <sup>2</sup>.

The main findings in this study were that patients without Internet access were more interested in using the Internet for general and quality-oriented health information if they: 1) felt their doctors provided less information and 2) felt their doctors engaged them more in the decision-making process. No associations were found, however, between interest in using Internet for health information and doctor-patient communication patterns among patients with Internet access. These findings were surprising. We had anticipated finding an association between interest in using the Internet for health information and physician communication patterns among those with Internet access. We did not anticipate finding any such relationship among those without Internet access. We expected that a lack of experience with the technology would have made it difficult to characterize one's interest in using the Internet for specific tasks.

The reasons for our findings are not clear. The data suggest that individuals without access to the Internet may believe that the Internet will be able to compensate for communication deficits with their health-care provider. This is suggested by the finding that interest in using the Internet for health information was greater among patients without access who felt their doctor gave less information. To explain why this finding does not exist among patients with Internet access we hypothesize that once people get access to the Internet, they realize that it's not quite as useful as they expected. For that reason, individuals no longer believe that it can fill in the gaps in communication with their health care providers. This may be related the results by Berland and others, who noted that the quality, and usability, of health information on the Internet leaves a lot to be desired <sup>11</sup>. More recent studies suggest that the Internet users assess quality by comparing information on multiple, separate, websites, but that this approach is more common among the more experienced Internet user <sup>3, 7, 8</sup>.

This explanation is also consistent with the "assimilation gap" found in the diffusion of innovation literature. The assimilation gap refers to times when an innovation is acquired, but not fully utilized for the functions it was intended. This has been noted among businesses that, after spending large sums of money on a technology, do not fully assimilate the new technology into their processes. This assimilation gap is felt to be due, at least in part, to learning, after attempting to use the technology, that it did not meet prior expectations <sup>16 17</sup>. This is especially true of innovations that have multiple functions, where some functions are adopted faster than others. In the case of the Internet, this would be consistent with a national survey by Baker, et. al., in which 58% of people with at least one chronic condition felt that the Internet improved their understanding of possible treatments, yet only 16% agreed that the Internet affected treatments that they were using for their condition(s). <sup>18</sup>

An alternate hypothesis suggests that once people have access to the Internet, they no longer see it as filling in gaps in inadequate communications with their doctor, but as a trusted “second opinion”. This is suggested by the findings of Gupte and colleagues who noted that a significant percentage of patients find information that runs counter to what their doctor has told them<sup>19</sup>. For that reason, patients may believe that it is important to use the Internet for general and quality-oriented health information regardless of their communication patterns with their health care providers. The reasons for these findings may lie in the differences between those with and without Internet access, which may have been a source of residual confounding. Though many of the differences were adjusted for, such as age and race, other common differences, such as being disabled, employment status and attitudes such as concerns about privacy and fraud and a lack of time are noted as barriers to Internet access<sup>20</sup>.

Among those with Internet access, individuals who perceived their health care to be better (v. worse) and were non-white (v. white) were more interested in using the Internet for health information. We presume that non-white patients, who typically see white providers, have a greater interest in using the Internet for health information as the Internet is relatively race neutral. This may also be related to the finding by other investigators that non-white patients with white physicians feel that their care is not as good as non-white patients with non-white physicians<sup>21, 22</sup>. As most non-white patients see white providers in Rhode Island, it is plausible that non-white patients may be interested in using the Internet to make up for something they feel is lacking in their visits with predominately white providers. Unfortunately, all of the providers in the present study were white, so we were not able to analyze differences based on concordance of race between providers and patients.

Another finding was that non-white subjects with Internet access were more interested in using the Internet for health-related activities than whites. One hypothesis for this is that others have found that non-whites may be less satisfied with their visits and rate their providers less positively. Non-whites may be compensating for perceived problems with the doctor-patient relationship by using the Internet as a health resource<sup>22 21</sup>. This is especially true when non-whites see white providers, as was the case in this study.

Our findings have several limitations. First, the cross-sectional nature of the survey makes the direction of the relationship between interest in the Internet for general and quality-oriented health information and physician communication patterns unclear. It is possible that the relationship is actually the reverse of that hypothesized, namely that a patient’s exposure to general and quality-oriented health information on the Internet lead patients to expect more information from their health care providers, which leads them to believe that they are getting less information during the visit. Further studies, specifically cohort studies that examine the exposure of patients to health-related information on the Internet over time, are necessary to determine the direction of these relationships. Second, though our response rate was greater than 80%, our survey was only done in four primary care practices in Rhode Island, therefore may not generalize to other populations or settings.

Third, our instrument measured interest in using the Internet for a limited set of activities. Many other health-related activities are possible using the Internet, but were not brought up by members of our focus groups, so they were not included in the questionnaire. We assumed that they would not be used by enough individuals to allow meaningful analyses to be performed. For example, participation in health-related newsgroups (<http://groups.yahoo.com>) and disease-



specific support groups is becoming more widespread (<http://chess.chsra.wisc.edu/Chess/>)<sup>23-25</sup>, but were not included in our instrument.

Fourth, our survey relied on self-report of Internet interest. A more valid method may have been to install software on individuals' computers to record websites that were visited. This would have allowed us to use participant's actual Internet practices as a dependent variable, rather than self-reported interest. These methods were used recently in study examining ways that consumers search for and appraise the quality of health information on the Internet<sup>3</sup>. These and other methods for studying the use of the Internet for health information will likely evolve as quickly as the Internet itself and provide ample opportunity for more fully understanding how the Internet is transforming the doctor-patient relationship.

Fifth, we realize that asking people without Internet access about specific instances in which they would be interested in using it is somewhat artificial and potentially inaccurate if subjects were not aware of the fact that the Internet was a vast source of health information. At the time of the survey, in the spring of 2001, an estimated 64 million Americans had used the Internet for health information<sup>1</sup>. Given that high level of level of Internet use in American society, we believe that the majority of those without Internet access would have understood the Internet to be a source of health information. We didn't specifically ask about Internet awareness, however, so it remains a possibility that some or many people without Internet access responded incorrectly to the questions about interest in using the Internet. We felt that it was important, however, to compare the two groups, to begin to examine possible effects of access to the Internet on the doctor-patient relationship. Further studies may address this issue by providing Internet access to a group of patients without access and examining the effect of this intervention.

Finally, our definition of Internet access included access at home, school, work or at some other location, though we realize that different access locations afford different levels of privacy which may be strongly related to attitudes about using the Internet for health-related activities. In our survey, respondents were asked to answer "yes/no" to each of the locations for Internet access, which makes analyzing the data by location quite difficult, as the groups are not mutually exclusive. Furthermore, a August 2000 Pew Internet and American Life survey<sup>26</sup> found that 83% of individuals last went online from home, 14% from work, and only 3% from someplace else. The Pew survey also did not examine differences between the health-related Internet activities by location of access. This is an important area for future study, especially as employers have increased their Internet monitoring activities<sup>27</sup> and libraries are required, under the USA Patriot Act, to do likewise.

In conclusion, we found that among those without Internet access, interest in using the Internet for health information was greater for those who felt that their doctors 1) provided less information and 2) engaged them more in the decision-making process. Among those with Internet access, no significant relationships with physician communication variables existed. The implications of these findings are not clear, as the results were somewhat unexpected. We are left with the impression that the capacities of the Internet to improve health are not being fully utilized. This is consistent with a large, national survey in which half of Internet users with a chronic condition noted that the Internet helped them understand their condition better, but only a quarter noted that the Internet helped them to take responsibility and manage their condition by themselves<sup>18</sup>. These findings have implications for at least two groups. First, we believe that it is up to providers, working with Internet developers, to create useful Internet applications that help

patients to become active participants in their care, rather than simply as an online medical encyclopedia, as it largely is at this point. Second, we believe that informatics researchers have yet to understand fundamental questions about how the use of the Internet influences the doctor-patient relationship. This study is a small step in that direction.

Table 1. Background characteristics by Internet access.

	Without access (n=109)	With Access (n=191)	Pearson $\chi^2$ or F-ratio
Age (%)			
18-54	21.1	78.9	69.5, df=1 p=0.000
> 54	71.4	28.6	
Gender (%)			
Male	33.3	66.7	.24, df=1 p=0.63
Female	36.9	63.1	
Education (%)			
Less than High School	65.6	34.4	24.0, df=2 p=0.000
High School/Some College completed	38.2	61.8	
College graduate	15.6	84.4	
Race (%)			
White	37.6	62.4	.70, df=1 p=0.40
Non-white	31.3	68.8	
Health Insurance Status (%)			
Insured	35.4	64.6	1.0, df=1 p=0.32
Not Insured	44.8	55.2	
Self-reported health rating (%)			
Excellent/Very good	23.9	39.8	7.8, df=1 p=0.005
Good/Fair/Poor	76.1	60.2	
Perceived quality of care (%)			
5 (best care)	47.7	36.6	3.5, df=1 p=0.06
4/3/2/1 (less than best care)	52.3	63.4	
MD giving patient information (mean)	14.9	15.0	.14, df=1 p=0.71
MD engaging patient in decisions (mean)	10.0	10.4	1.1, df=1 p=0.28

Table 2. Final Logistic Regression Models for Interest in using Internet by Internet access: Odds Ratios and 95% Confidence Intervals.

	Without access (n=109)	With Access (n=191)	Test of Internet access Interaction $\chi^2$ or <i>F</i> statistic
Age (%) 18-54 > 54	1.3 (0.52-3.2) Reference	1.2 (0.50-3.1) Reference	0.00, df=1 <i>p</i> =.96
Gender (%) Male Female	1.8 (0.49-6.6) Reference	0.53 (0.24-1.2) Reference	2.41, df=1 <i>p</i> =.12
Education (%) Less than High School High School completed Some college or college grad	0.32 (0.05-2.0) 0.87 (0.2-3.9) Reference	0.42 (0.10-1.7) 1.0 (0.49-2.0) Reference	0.06, df=1, <i>p</i> =.97
Race (%) White Non-white	1.7 (0.41-6.8) Reference	0.38 (0.15-1.0) Reference	2.96, df=1, <i>p</i> =.09
Health Insurance Status (%) Insured Not Insured	0.25 (0.04-1.44) Reference	0.42 (0.13-1.4) Reference	0.51, df=1 <i>p</i> =.48
Self-reported health rating (%) Excellent/Very good Good/Fair/Poor	1.2 (0.41-3.5) Reference	1.1 (0.56-2.1) Reference	0.02, df=2 <i>p</i> =.88
Perceived quality of care (%) 5 (best care) 4/3/2/1 (less than best care)	1.8 (0.61-5.2) Reference	0.99 (0.48-2.0) Reference	0.78, df=1 <i>p</i> =.38
MD information giving	0.82 (0.70-0.97)*	0.95 (0.86-1.0)	3.47, df=1, <i>p</i> =.06
MD decision sharing	1.3 (1.1-1.6)*	0.95 (0.82-1.1)	6.40, df=1, <i>p</i> =.01

## APPENDIX

### Internet Interest Survey (IIS) Items.

Please answer the following questions based on a scale of 1 to 5 where 1 is “not at all interested” and 5 is “extremely interested”. How interested are you to use the Internet to...

#### (QUALITY)

1. Find information about the quality of care a doctor provides?
2. Find information about the quality of care a hospital provides?
3. Find out how the quality of care your doctor provides compares to other doctors?
4. Find out if your health care provider is giving you all of the tests and treatments that you are due to have?

#### (INFORMATION)

5. Find information about a specific disease or medical condition?
6. Look for information about a medication?
7. Find out what questions you should ask your doctors when you see them?
8. Find out what tests and treatments you are due to have when you see your doctor?

### Physician Communication and Decision-Making Items.

#### (COMMUNICATION)

In your experience, how have doctors that you have seen been at...

1. ...telling you everything that you should know
2. ...explaining treatment alternatives
3. ...explaining side effects of medications
4. ...telling you what to expect from a disease or treatment  
(poor / fair / good / very good / excellent)

#### (DECISION-MAKING)

In the last 12 months...

1. How often did doctors ask you to take some responsibility for your treatment?  
(never / rarely / sometimes / often / very often)
2. If there was a choice in treatments, did doctors ask you to help make decisions?  
(no, definitely not / no, probably not / maybe / yes, probably / yes, definitely)
3. How often did doctors make an effort to give you some control over treatment decisions?  
(never / rarely / sometimes / often / very often)

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**GENERAL AND SPECIFIC CONTRIBUTIONS BY EACH AUTHOR:**

Study concept and design: Sciamanna

Analysis and interpretation of data: Sciamanna, Clark, Diaz

Critical revision of the manuscript for important intellectual content: Sciamanna, Clark, Diaz

Statistical expertise: Clark

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